

# Annual Report of the Chief Medical Officer 2012

## Our Children Deserve Better: Prevention Pays



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Prevention Pays**

October 2013



*Deau Reader*

I come from a generation that believed the future would be better than the past; we expected and, in the main, have enjoyed longer, healthier, easier, richer, more comfortable and happier lives compared with our own parents and grandparents. However, our children and grandchildren face a more uncertain future, with a challenging economic outlook and increasingly disproportionate social disadvantage.

We have seen great success in some areas of health, but if we look at our key healthcare outcomes – mortality and morbidity – we see a worrying picture when we look back historically, when we look across the regions of our country and when we compare ourselves with other similar nations. This is particularly true for long-term conditions. And this, despite the enormous efforts of front-line staff in social care, healthcare and education, intense focus by our politicians and increased financial investment.

Yet the science runs ahead and is increasingly clear. There is a growing knowledge of the complex interplay between psychosocial events and biological factors, and we now understand that events that occur as a fetus and in early life play a fundamental part in later life, and indeed in the lives of future generations. This inevitably leads us to the conclusion that early interventions and preventive measures such as immunisation, health checks and education do make a difference to outcomes. If we act early we can prevent harm. To address these issues, we need to take a population health perspective – to think about what benefits the most. Key principles of public health are also fundamental. This means ‘proportionate universalism’ – improving the lives of all, with proportionately greater resources targeted at the more disadvantaged groups.

The challenge for us as a society is how to harness this evidence and momentum and turn it into improved outcomes for our current and future generations of children and young people. This is not just a moral responsibility but also an economic imperative. For failure to invest in health leads to poorer educational attainment and affects the nation’s future productivity.

My report seeks to provide the up-to-date evidence to help to answer these key questions. It lays out the scientific evidence and, crucially, alongside this examines the economic benefits and financial savings from improved health in children and young people. It also identifies that improving health and wellbeing in early life benefits us all – not just through improved health gains but also economically. We need to stop thinking of spend on healthcare for children and young people and instead think of investing in the health of children and young people as a route to improving the economic health of our nation. We need to understand that health plays a powerful role in allowing children and young

people to meet their academic potential, and that academic achievement helps to improve health.

We also need to listen to our children and young people if we are to develop effective strategies to deal with the increasing cost of healthcare. Youth is key to many of these diseases, such as diabetes; either because the diseases begin in adolescence, or because key habits of self-management develop during this crucial phase. Without efforts to engage young people in both disease prevention and management, we will not succeed in reducing their future burden of disease. We have seen considerable improvements over recent years in the numbers of young people smoking or using drugs, but we have yet to see similar gains in the prevalence of healthy behaviours such as meeting physical exercise guidance.

Reducing disease is fundamental but so too is ensuring that our young people are capable of meeting the changing requirements of life. We need to ensure that they are resilient and primed to succeed.

This report lays out a series of recommendations that are grounded in the evidence base. My concern for our current state is such that I am proposing a National Children's Week to focus attention on the health of children and young people. Whilst, there are international precedents for such events in countries with better health outcomes, I am proposing "we look to develop" a National to date there is no evidence of correlation, I believe it is appropriate to undertake this approach in England and evaluate the impact.

As individuals, whether we are parents, grandparents or siblings, we need to ask ourselves about our responsibility to the future for improving our children's health and wellbeing. As policy makers, we need to ask ourselves whether we are shaping our actions to ensure that we allow the next and future generations to be the best they can be. As individuals working within health or beyond, we need to reflect deeply on current practice and identify how we can improve if we are to tackle the problems that we face, such as improving outcomes for long-term conditions. As a society, we need to ask ourselves how we want to spend our resources to deliver the most for our nation's future.

If we want our legacy to be a productive, effective, healthy country, we need to take heed of the evidence base laid out in this report. I commend it to you. And I ask all political parties to take this evidence into consideration as they prepare their manifestos for the next election.

*Yours ever*



Prof Dame Sally C Davies



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This report could not have been produced without the generous input of the following people and their teams.

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# Contents

A single PDF download of this report is available via [www.gov.uk](http://www.gov.uk)

All of the sections of this report are also available as discrete downloads. For this reason, every section is numbered separately. For example Chapter 1, the Chief Medical Officer's summary of the report is numbered "Chapter 1 page 1", "Chapter 1 page 2".

## Foreword

## Editors and authors

## Contents

**Chapter 1** Chief Medical Officer's summary

**Chapter 2** Overview

**Chapter 3** The economic case for a shift to prevention

**Chapter 4** The voices of children and young people

**Chapter 5** Life stage: Pre-conception and pregnancy

**Chapter 6** Life stage: Early years

**Chapter 7** Life stage: School years

**Chapter 8** Life Stage: Adolescence

**Chapter 9** Children with neurodevelopmental disabilities

**Chapter 10** Mental health problems in children and young people

**Chapter 11** Looked-after children and young people

**Chapter 12** Youth justice

**Chapter 13** Future challenges

**Annex 1** Recommendations

**Annex 2** Acknowledgements

**Annex 3** Summary for Children and Young People

**Annex 4** Summary for Clinical Commissioning Groups

**Annex 5** Summary for Families

**Annex 6** Summary for Health and Care Professionals

**Annex 7** Summary for Head Teachers

**Annex 8** Summary for Local Authorities

**Annex 9** Atlas of Variation in Healthcare for Children and Young People

## Chapter 1

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# Chief Medical Officer's summary

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## Introduction

My annual report must fulfil two functions: to provide **an assessment of the state of the public's health and to advise government on where action is required. To achieve this, as with my 2011 report, I am continuing with two volumes.** The first volume is a compendium of the data and information used to describe the health of the population. The narrative of this second volume (hereafter called 'this report') fulfills the independent advocacy role of the Chief Medical Officer.

Volume one of the 2012 report will be available shortly and contains data and trend analyses of many of the health issues mentioned in this report. The 2011 annual report (volumes one and two) is available at [www.gov.uk](http://www.gov.uk).

### The purpose of this report

This report sets out my response as Chief Medical Officer to **the challenges to the health and wellbeing of our children and young people.** To produce this report **I have drawn on the expertise of a broad range of experts, academics, clinicians and service providers who have set out the evidence about the challenges faced** by policy makers, researchers and front-line professionals such as teachers and clinicians. Crucially, though, **I have also listened to and drawn on evidence from children and young people themselves as well as those who care for them.**

### The choice of focusing on the health and wellbeing of children and young people

I have chosen to focus on children and young people, and in particular on whether we are giving them a good start and building their resilience, for a number of reasons:

- **The evidence base for the life course approach is strong.** What happens early in life affects health and wellbeing in later life. There is increasing evidence that, in England, we are not doing as well as we should to achieve good health and wellbeing outcomes for our children and young people – when we compare both historically and within and between countries for mortality, morbidity, wellbeing, social determinants and key indicators of health service provision.
- **The variation we see within our country shows us what 'good' looks like** and what is possible: we know we can do better.
- While our economic future may be challenging, there is a growing business case for improving the lives of children and young people. Improving health has the potential to **benefit our nation economically.**

Throughout this report I refer to children and young people using the United Nations definition of young people,<sup>1</sup> which includes all those under the age of 25. I have chosen to extend the age cut-off for this report to under 25 (rather than

stopping at adolescents at age 16–18) because I have listened to the evidence of experts who make two clear arguments for the extended definition. First, that **key elements of development, particularly emotional development, continue until the early 20s.** Second, many services end for young people at 16 or 18, yet adult services may not always start at this point. It is thus important to ensure that service provision fits with the evolving scientific evidence base.

### The intended audience for this report

This first chapter is my response to the evidence base underpinning **the challenges facing children and young people today, and is therefore aimed at policy makers and politicians.** This report shines a light on those issues that require specific focus by politicians and makes recommendations aimed at policy makers, health and social care commissioners, police and crime commissioners, and providers of health, social care, education, housing and beyond.

In addition to making recommendations for action by specific bodies, I am also publishing, for the first time, **short summaries for key organisations and individuals to enable them to quickly identify what they can do to improve the health and wellbeing of the children and young people they support, educate and care for.**

The remainder of this report consists of chapters written by internationally recognised experts who were asked to provide an assessment of the key issues facing the health and wellbeing of children and young people in England today. These chapters were written to inform me, as Chief Medical Officer, of the areas I need to champion for action. The chapters were written by the authors and represent their views rather than mine, but they provide the evidence base on which my calls for action are made. Accompanying this report is the Atlas of Variation in Healthcare for Children and Young People 2013, published as an annex to this report, which has been updated and expanded and provides data that have helped shape my thinking.

I have chosen to look at the evidence using a life course approach. Additionally, I have examined four other groups of children and young people, the business case for investing in the health of children and young people, and the views of young people and their families. I have chosen these four groups because they exemplify the challenges that we face. By looking at two disease areas, mental health and neurodevelopmental disabilities, key themes emerge around **the importance of data, service provision and prevention.** Focusing on looked-after children and youth justice reveals themes around **the importance of early life determinants such as parenting and the inequalities that exist in child health.**

This report is not aimed at the general public but, as it addresses issues that affect all of us, it will be useful to those with an interest in this area.

## Recommendations

### Introduction

In the next section I lay out my recommendations. I have grouped these recommendations under themes; ensuring that early action happens, proportionate universalism, engaging with children and young people and building resilience. In the Annex, I have tabulated the recommendations for easy reference. **These recommendations broadly fall into three types; the voice of children and young people, building services and joining services, the economic case for a shift to prevention.** The recommendations I have developed are grounded in the data. While developing this report I have sieved and cogitated on the evidence, and this has led me to believe that we, as a nation, need to strengthen our efforts and develop more co-ordinated approaches to child health and wellbeing if we are to improve outcomes.

The review of the evidence by experts clearly identifies that children and young people in England are not doing as well as they could; with high mortality, morbidity and inequality. In the UK the equivalent of 132,874 excess person years of life are lost per year in the UK, when our mortality is compared to the best performer – Sweden.<sup>2</sup> As an example of morbidity: fewer of those under 25 years old with Type 1 diabetes in England and Wales have good diabetes control compared to their peers in other countries; only 16% achieve HbA1C's under 7.5%. In the equivalent audit in Germany and Austria, 34% of young people achieved this standard.<sup>3</sup> One example of inequality in health is that there would be a 59% potential reduction in psychological and behavioural problems, in children and young people with conduct disorders if all children had the same risk as the most socially advantaged.<sup>4</sup>

Perhaps the most challenging question is why we fare worse than other similar countries. The causes are complex and multifactorial. From listening to many passionate advocates and experts during the course of developing this report it is clear that there is great depth and breadth of enthusiasm, but this does not come together in a fully co-ordinated manner. I welcome the attention that this topic generates, but I believe that the messages need to be clearer and more co-ordinated to allow strong policy responses. I understand that some believe that the best way to achieve this is through altering government structures or processes; others look to the creation of umbrella groupings. **I hope that my report will provide a unifying call around the need, the evidence and achievable actions.**

I am therefore proposing as my first recommendation that England should consider adopting a National Children's Week. While there are international precedents for such events in countries with better health outcomes, to date there is no evidence of correlation. I believe, though, that it is appropriate to undertake this approach in England and evaluate the impact.

A National Children's Week, supported by the Cabinet Office, Public Health England (PHE) and the Children's Commissioner could provide a focal point for all those who are committed to working for improved outcomes for children and young people. Such a week would be the annual opportunity to identify where we stand with respect to children's health and wellbeing outcomes and the wider determinants of health. This week would also build on PHE's and the Department of Health's development work on Start4Life and the Information Service for Parents.

The week could also be an opportunity to highlight how to improve wellbeing. This builds upon evidence that a mechanism to ensure wellbeing amongst young people is to allow them the opportunity to give back to society.<sup>5,6</sup> I welcome recent efforts to encourage community engagement, social cohesion and the transition to adulthood through programmes such as National Citizen Service.<sup>7</sup> Thus this week would showcase young people's achievements, the benefits of youth volunteering and opportunities such as National Citizen Service and the Campaign for Youth Social Action. By focusing attention on young people, this week would also be a lightning rod for the public to better understand the complexity of issues and proposals for improvements.

This would provide an opportunity for synergy between third sector organisations, private institutions and public institutions involved with children and young people. It would showcase to the wider public the efforts of young people, so that we could become a nation that celebrates children and young people more and recognises the positive contributions they make.

**Recommendation 1:**  
**Cabinet Office supported by Public Health England, and the Children's Commissioner, should consider initiating an annual National Children's Week.**

### Ensuring that early action happens

The evidence base clearly identifies that **events that occur in early life (indeed in fetal life) affect health and wellbeing in later life.** Whether this is through changes in genetic expression, how the brain is formed or emotional development, we increasingly understand that what happens in these years lays down the building blocks for the future. **This is particularly the case at times of rapid brain growth in the early years (i.e. from birth to 2 years) and adolescence. Increasing investment in research in recent years is helping to explain the complicated links between psychology, sociology and biology.** This understanding underpins the concept of the life course, that each stage of life affects the next. Therefore, to try to impact on the diseases of adult life that make up the greatest burden of disease, **it makes sense to intervene early.**

This report draws together both the evidence for early action and, supports this with the economic argument for why this is important. **We know that in straitened financial times it is challenging to identify resources to allocate**

**upstream**, that is before problems have developed. It is hard to balance the need to respond to the pressures of the here and now with the evidence that we should be investing in the future: children and young people. **The evidence base increasingly suggests that failure to invest does not make economic sense.** Our analysis for this report identifies that:

- **the annual cost to the public sector in England associated with children born preterm until age 18 is around £1.24 billion** – total societal costs (including parental costs and lost productivity) are around £2.48 billion in total
- the potential annual long-term cost to UK society of one major kind of injury, severe traumatic brain injuries, is estimated at between £640 million and £2.24 billion in healthcare, social care and social security costs and productivity losses
- **the long-term costs of obesity in England are £588–686 million per annum**
- for mental health disorders the annual short-term costs of **emotional, conduct and hyperkinetic disorders among children aged 5–15 in the UK are estimated to be £1.58 billion and the long-term costs £2.35 billion.**

**Acting early is underpinned by sound science and sound finance.** There are increasingly good data on the return on investment and future cost savings from prevention and early intervention, **for example a 6–10% annual rate of return on investment for spend on intervention in the early years.**<sup>8</sup>

This report also identifies that young people are disproportionately disadvantaged: **26.9% of children and young people (age 0–19) are in or at risk of poverty or social exclusion, compared with the overall population rate of 22.6%.** These figures compare poorly with the best performing country – the Netherlands, with 15.7% in or at risk of poverty.<sup>9</sup> Therefore, **the very group in our population on which science suggests we should be focusing investment is the group that we disadvantage the most.**

I believe that acting early matters. I am therefore recommending that PHE in collaboration with the Early Intervention Foundation examine the extent of early action in health spending, alongside that of other government departments and continue to monitor this over time, building on the work of the National Audit Office. It is also why I strongly support the work of the Big Lottery Fund's A Better Start programme, which aims to improve the life chances of children in their first years by investing £165 million for up to 10 years.<sup>10</sup> Acting early does not mean just acting in early life therefore I am further encouraged that the Big Lottery Fund will shortly announce a new investment to increase the resilience of young adolescents and prevent the onset of mental disorders. Both of these long-term schemes will be evaluated in a robust and timely manner.

## Recommendation 2:

**Public Health England in collaboration with the Early Intervention Foundation should assess the progress on early intervention and prevention, continue to develop and disseminate the evidence base for why this matters and build advice on how health agencies can be part of local efforts to move from a reactive to a proactive approach.**

## Recommendation 3:

**Public Health England, working with Directors of Public Health and Health and Wellbeing Boards, should support the work of the Big Lottery Fund programmes and ensure that the lessons learnt are disseminated.**

## Proportionate universalism

If the argument that early action is important is accepted, as it should be, the question then becomes – how to act? **Proportionate universalism – improving the lives of all, with proportionately greater resources targeted at the more disadvantaged** identifies that a combination of approaches are needed; those that target and those that are more universal. Universal approaches tend to be the most upstream i.e. those based around primary prevention through encouraging the adoption of healthy lifestyles and reducing risks e.g. vaccination programmes. Targeted approaches can be both preventative e.g. seeking to reduce risk, for example current Vitamin D supplementation to specific high risk groups, or secondary prevention, also known as early intervention – seeking to act once early signs are seen, e.g. speech and language interventions.

**I strongly support programmes such as the Healthy Child Programme**, which underpin the public health efforts directed towards children and young people, and seek to include both universal and targeted approaches. The Healthy Child Programme is an evidence-based approach to ensure that children have the best start in life, underpinned by key health professionals, particularly health visitors. **I welcome the current drive to increase health visitor numbers** and the approach taken to transform their profession which clearly articulates the proportionate universalism approach, with a range of services from universal to universal plus and beyond.<sup>11</sup> This work, alongside similar work by school nurses, is critical, as are the commendable efforts of the Department of Health and the Department for Education to meld programmes of school readiness assessment with developmental health checks, culminating in a combined assessment at 2–2½ years. It is, however, fundamental, as changes in health, public health and social care commissioning responsibilities roll out, to ensure that the progress made to date is maintained and built on.

Straitened times potentially force those delivering the Healthy Child Programme to make difficult choices, to cherry pick parts of the programme and only focus on statutory elements or to limit investment just to the most needy. **I am therefore pleased to see the linkage of public health efforts, including the Healthy Child Programme, to public**

## health outcomes indicators<sup>12</sup> by PHE and the Child and Maternal Health Intelligence Network.<sup>13</sup>

To ensure that the Healthy Child Programme continues to be up to date I am asking PHE in association with the National Institute for Health and Care Excellence (NICE) to update the evidence base for the Healthy Child Programme, beginning with pregnancy and the first five years. This work will support the transition of commissioning responsibilities from NHS England to local authorities, overseen by PHE on behalf of the Department of Health.

### A further universal approach is to encourage exercise.

I welcome efforts to encourage more people into physical exercise – a key preventative approach, for example Join In.<sup>14</sup> The recent report by the four UK Chief Medical Officers identifying how much physical exercise should be taken clearly set out the evidence base.<sup>15,16</sup> This report shows that **children and young people are failing to meet this guidance**. I note the efforts by the Welsh Government with respect to improving access to swimming for children; I know too that many attempts have been made to open access further within England.<sup>17</sup> Some local authorities have developed innovative partnerships to utilise facilities out of regular hours. With this in mind, I am recommending that local authorities and schools **develop innovative approaches to widening access to their sports facilities in order to allow children and young people to exercise more easily**.

The area of nutrition exemplifies the challenge for identifying how to promote good health. The growing concern over the prevalence of disease related to Vitamin D deficiency suggests to me that we should re-examine whether the Healthy Start vitamin programme should become a universal offering. There is a growing body of evidence to suggest that providing free vitamins to targeted groups has not led to high enough levels of uptake. This in turn has therefore not impacted on reducing the morbidity associated with vitamin deficiency.<sup>18</sup> I am therefore recommending that NICE examines the cost-effectiveness of the Healthy Start vitamin programme becoming universal.

The Scientific Advisory Committee on Nutrition (SACN) has already recommended mandatory fortification of flour with folic acid to reduce the risk of pregnancies affected by neural tube defects such as spina bifida.<sup>19</sup> SACN subsequently reviewed the potential relationship between high folate status and bowel cancer, concluding that there was no substantial basis for changing their recommendation on folic acid fortification.<sup>20</sup>

I commend the ongoing work of SACN on the impact of current access to iodine intake and health,<sup>21</sup> and look forward to their findings.

**I welcome too the expansion of successful targeted programmes such as the Family Nurse Partnership, and the hugely important work of the Social Mobility and Child Poverty Commission** and their decision to explore the inter-relationships with health for those most in need.<sup>22</sup>

I recognise the important role that programmes such as the Troubled Families Programme can have in turning the lives of families around, helping adults into work, and supporting children to do well at school and build opportunities for their future. The health of carers and children is a crucial foundation upon which to base an effective programme and I know that health organisations play a central role. I am therefore recommending that PHE should work with key health organisations as the Troubled Families Programme grows to ensure this.

### Recommendation 4:

**Public Health England should undertake a Healthy Child Programme evidence refresh, starting with the early years.**

### Recommendation 5:

**Public Health England should work with local authorities, schools and relevant agencies to build on current efforts to increase participation in physical activity and promote evidence based innovative solutions that lead to improved access to existing sports facilities.**

### Recommendation 6: Nutrition

- **CMO recommends that NICE examines the cost-effectiveness of moving the Healthy Start vitamin programme from a targeted to a universal offering**
- **Department of Health to set out next steps in the light of evidence from the Scientific Advisory Committee on Nutrition (SACN) about folic acid**
- **Action is taken if required on iodine following recommendations by SACN**

### Recommendation 7:

**The Social Mobility and Child Poverty Commission and Public Health England should work together to ensure that efforts to narrow attainment gaps in education complement efforts being made to narrow health inequalities.**

### Recommendation 8:

**Public Health England should work with NHS England, the Department for Communities and Local Government and the Department of Health to identify how the health needs of families are met through the Troubled Families Programme.**

## Engaging with children and young people

This report clearly identifies the **all-too-common mismatch between the expectations of children and young people and their families and the reality of healthcare delivery**. I am pleased to see:

- the work of NHS England to develop a Friends and Family Test for children and young people
- the ongoing work on the trial health and wellbeing local level survey for children and young people



- the recent development of a forum of young people which will work with, and guide the work of, NHS England around children and young people.

To me it is clear, through the voices of the children and young people who contributed to this report, that they want us to go further. The Government's pledge to improve children and young people's health outcomes identifies the importance of responding to their needs; the first priority: 'Children, young people and their families will be at the heart of decision-making.'<sup>23</sup> The Department of Health has previously focused on this through the You're Welcome initiative.<sup>24</sup> This allows organisations to self-identify how young person centric they are.

I am therefore recommending that the Department of Health, NHS England and PHE build on the work of You're Welcome and the suggestions in the Children and Young People's Manifesto for Health and Wellbeing in Chapter 4 and **develop a 'health deal' for children and young people**. This would clearly identify what is expected of health organisations that serve them and how they can best engage with healthcare. Central to the development of this work is the engagement of children and young people in the process at national and local levels, as well as leading children and young people's organisations such as the National Children's Bureau and the Association for Young People's Health. I would expect this to also fully consider the needs and views of those groups of children and young people who experience additional disadvantage, including looked-after children, young people in the justice system, disabled young people, black and ethnic minorities and those who are victims of neglect and abuse. Developing a compact between young people and health providers which stresses responsibility on the part of young people with promises of more young people friendly care is crucial to re-engineering professional relationships that can address the challenge of the current burden of disease such as long-term conditions.

**A fundamental principle is that the workforce that cares for children and young people must be properly trained to deliver age-appropriate care.** This is why I am recommending that Health Education England (HEE) ensure that such training is commissioned. Part of the challenge for children and young people identified in this report is navigating our complex health and care system. I warmly welcome the earlier work by the NHS Institute for Innovation and Improvement, to develop lesson plans which teach all children and young people, in an age-appropriate manner, how and where to find necessary support and care in the NHS.<sup>25</sup> I also therefore recommend that HEE ensures that training develops a workforce that is able to assist children and young people in identifying where to go for care and when.

Furthermore **I am keen to see that the extension of GP training includes as part of the core component training on paediatrics and child health.** Following the Secretary of State for Health's announcement that older people would benefit from a named GP to provide continuity of care, I believe that **there are certain groups of children**

**who would benefit similarly, in particular those with long-term conditions such as diabetes and mental health disorders.**

### **Recommendation 9:**

**The Department of Health, NHS England and Public Health England, alongside representatives of children and young people, should build on the You're Welcome programme and the vision outlined in the recent pledge for better health outcomes for children and young people to create a 'health deal' which outlines the compact between children and young people and health providers, and creates a mechanism for assessing the implementation of this.**

### **Recommendation 10:**

**Children with long-term conditions, as vulnerable people, should have a named GP who co-ordinates their disease management.**

### **Recommendation 11:**

**As plans are made to extend GP training, paediatrics and child health should be part of the core component of extended training.**

### **Recommendation 12:**

**Health Education England should commission education to ensure that the workforce is trained to deliver care that is appropriate for children and young people, in the same manner as is being currently carried out for age-appropriate care for older people.**

### **Recommendation 13:**

**Health Education England, the Department of Health and Public Health England should work to ensure that commissioned education of health professionals stresses the important role of school nurses.**

## **Building resilience**

The seminal work of researchers such as Sir Michael Rutter clearly identifies the importance of ensuring that young people are equipped with the skills and knowledge to navigate the complexities of life. **Rutter uses a powerful metaphor to explain the importance of this approach. We vaccinate our children against infection** by using modified strains or parts of the infective organism that we are aiming to protect against (e.g. measles). This means that, while we cannot fully eliminate the risk to young people of exposure to the pathogen, they are equipped later when challenged to mount a successful immune response. **Similarly, we need to develop strategies to enable young people to be able to mount successful responses against life's challenges, and to do this we need to inoculate them and thus develop resilience.** By exposing young people to low doses of challenges, in safe and supported environments, we strengthen their ability to act effectively later in life. This report identifies many of the key factors that are needed to ensure that such exposure is safe. In particular there is **increasing evidence that schools and local authorities can successfully step in.** I am

therefore very pleased to see the recent publication by NICE of a local government public health briefing entitled *Social and emotional wellbeing for children and young people*,<sup>26</sup> which should provide those involved in commissioning and delivering services for children and young people with the information to adopt an approach that increases resilience and wellbeing.

I am recommending that PHE works with leading organisations in school health improvement, such as the Education Endowment Foundation, to develop and disseminate the evidence base, attempt to identify a marker of resilience and nurture implementation strategies to support organisations such as schools and colleges that wish to use this approach.

Just as schools and other organisations can play an important role in resilience, so too can they play an important role in wellbeing. **There is a strong association between school connectedness or sense of belonging and wellbeing.**

To date, there has been considerable success in addressing behaviours that can increase harm to health, for example smoking. **These behaviours are often called 'risky behaviours'; however, in this report they will be grouped as 'exploratory behaviours' in order to be fair and destigmatised. Evidence suggests that resilience and feeling connected have a positive effect in reducing participation in exploratory behaviours. So too does having strong communication between parents and young people.** My report identifies that there is increasing evidence of the interactions between different exploratory behaviours. I therefore support the work of PHE to develop an adolescent health framework and recommend that the framework addresses exploratory behaviours as a group rather than as individual topics, and pays special heed to how families and organisations can facilitate this. Furthermore, **I support PHE's planned youth social marketing programme Rise Above, which will engage young people on issues around exploratory behaviours through multiple platforms.**

Just as important as addressing exploratory behaviours is improving healthy behaviours. I acknowledge the efforts of school nurses in health promotion and coordinating health and wellbeing services in school. I support and welcome the agenda developed in the School Food Plan<sup>27</sup> to improve the eating habits of young people and the quality of food provided. There is a similar need to encourage increased exercise, with recent evidence showing that only half of children and barely a third of girls meet the recommended standard. I am very pleased to see the effect of the London 2012 Olympics legacy supporting efforts by the Department for Education, the Department for Culture, Media and Sport, schools and the voluntary sector to encourage school exercise programmes, for example Change4Life Sports Clubs and the £300 million investment in primary school sport.<sup>28</sup> These both engender better health and create the sense of connectedness that is so important to wellbeing.

Listening to the voices of children and young people it is clear that they value education and knowledge about health. Evidence also identifies the benefit that good education about health can have on health behaviours. I believe that **successful schools are increasingly showing how improved educational results are achieved by looking holistically at children and young people. The recent School Food Plan and the offer of extended free school meals are examples of how practice has been changed because of the potential benefits to educational attainment and wellbeing.** I therefore recommend that PHE and the PSHE Association work to develop models of good practice to show how these schools have demonstrated success in educational attainment, in part through activities beyond didactic education, thereby allowing others to embrace such steps. Areas that could be explored would be personal, social, health and economic (PSHE) education, a subject that forms a bridge between health and education by building resilience and wellbeing.

**Recommendation 14:**  
**PHE should develop and enact a youth social marketing programme, "Rise Above" to engage young people around exploratory behaviours through multiple platforms.**

**Recommendation 15:**  
**Public Health England and other leading organisations working in the field should work together to strengthen the evidence base for programmes that develop resilience in young people.**

**Recommendation 16:**  
**Public Health England should develop an adolescent health and wellbeing framework which includes the inter-relationships of exploratory behaviours. As part of their public-facing work, Public Health England should model engagement with young people on multiple health and wellbeing issues through a variety of platforms.**

**Recommendation 17:**  
**Public Health England, the PSHE Association and other leading organisations in the field should review the evidence linking health and wellbeing with educational attainment, and from that promote models of good practice for educational establishments to use.**

## Oversight

The new landscape of the NHS and the focus on integration (vertical and horizontal) are of fundamental importance to children and young people. However, current health and social care utilisation by children and young people is different from adults. Thus it is fundamental that children and young people's needs are fully addressed and not lost in the bigger picture of health and social care reform.

**I welcome the enthusiasm and energy of the Maternity and Children's Services Strategic Clinical Networks and the efforts that they are making, led by NHS England,**



to deliver change and improvement in local systems. I am also very **pleased to see the evolution of the Child and Maternal Health Intelligence Network** which will provide strong data support for changes in healthcare for children and young people at a national and local level. One example of the important data now becoming available is that of the Child and Maternity Dataset – allowing us for the first time to map influences in pregnancy and their effects at scale. **I also welcome the new NHS England Maternity and Perinatal National Clinical Audit, supported by the Healthcare Quality Improvement Partnership**, which will provide invaluable information with evidence-based questions and outcomes-focused data to describe trends in outcomes, morbidity and mortality.<sup>29</sup> It will be complementary to Mothers and Babies: Reducing Risk through Audits and Confidential Enquires across the UK (MBRRACE-UK).<sup>30</sup> I believe that the collection of such data is fundamental: locally this allows the provision of key evidence to underpin health and wellbeing boards' joint strategic needs assessments, and nationally it permits transparent sharing and examination of the data, looking at variation and questioning causation.

**I believe that the work of the Children and Young People's Health Outcomes Forum has been invaluable in identifying the key indicators for child health and wellbeing.** I therefore suggest that the Children and Young People's Health Outcomes Forum highlights the progress towards this and other key health indicators at their annual summit, thereby shedding light on this fundamental information. Having an annual opportunity to examine how well we are doing, led by experts, is an important mechanism to ensure progress.

As strong regulatory frameworks develop, it is fundamental that they oversee the relevant interactions to ensure that children and young people, particularly those with additional needs whether due to disability, safeguarding or other issues, do not fall between the gaps. **I therefore welcome the reviews by the Care Quality Commission (CQC) to enhance healthcare services for children and young people in care and recent care leavers and those in need of safeguarding**<sup>31</sup> as well as the review looking into children and young people with complex health needs transitioning to adult services.<sup>32</sup> I believe that the development of case-tracking methodology will help to highlight the issues faced by families, in particular as the pathways of care cross regulatory boundaries. I am therefore recommending that Ofsted and the CQC work together to develop inspection methods and regulatory questions that probe the interconnectedness of health and other services.

**I also welcome the creation of Healthwatch**<sup>33</sup> and the involvement in this of organisations and individuals who are focused on the needs of children and young people, which will enable users of services to maintain a voice in the improvements to the services that they receive.

**Recommendation 18:**  
**The Children and Young People's Health Outcomes Forum annual summit should provide an opportunity**

**for the review of health outcomes that are relevant to children, and to examine regional variation.**

**Recommendation 19:**  
**Regulators, including the Care Quality Commission and Ofsted, should annually review the effectiveness of inspection frameworks and the extent to which they evaluate the contribution of all partners to services for children and young people. This includes the contribution of statutory partners, local safeguarding boards and health and wellbeing boards to the health and protection needs of children and young people.**

### Professional responsibility

**All health care professionals have a responsibility to safeguard children and young people in their care.** Health care regulators such as the General Medical Council and Nursing and Midwifery Council have guidance in place in respect of the responsibilities of their professional members. Indeed recent General Medical Council guidance particularly stresses that safeguarding is part of the role of all doctors and thereby marks an important evolution in our attempts to protect the most vulnerable in society.<sup>34</sup> I believe that one of the key strengths of the UK health system is our family-orientated approach to care. The role of GPs is fundamental in providing holistic care which joins up the needs of the whole family. However, **just as safeguarding is everyone's business, so too should be thinking about the whole family.** I therefore recommend that the Royal Colleges use the opportunity of the review of the *Safeguarding Children and Young people: roles and competences for health care staff – intercollegiate document* to embed the whole family as integral to the professional responsibility of all healthcare professionals. I would additionally **urge the professional colleges/bodies of other health care professions, including for nursing and allied health professionals (AHPs), to review their guidance and documentation to ensure that family health is central to multi-professional practice.** I know that this work seeks to embed learning at all stages of career development. I am especially keen that this should be built into continuing professional development via a variety of means, including e-learning and further emphasis within the RCGP safeguarding toolkit.

**Recommendation 20:**  
**The review of 'Safeguarding Children and Young people: roles and competences for health care staff – intercollegiate document' should embed the professional responsibility to the whole family, and professional bodies should develop the necessary innovative tools to support this.**

### Mental health

The recent extension of Improving Access to Psychological Therapies (IAPT) to children and young people and the soon-to-be-reached figure of 60% geographical coverage are to be applauded, as is the focus on this area by the National Clinical Director for Children, Young People and Transition to Adulthood. I also **welcome the creation of the national**

**Child and Adolescent Mental Health Services (CAMHS) data set** which will allow valuable insight into care provision to be addressed. However, **CAMHS services face pressure and cuts** as the part of their budget that is supported by local authorities comes under budgetary constraints. To ensure that provision meets demand it is therefore imperative that data are collected on the prevalence and incidence of mental health conditions and an annual audit of services and expenditure in the area undertaken.

**I welcome the development of the trial health and wellbeing local level survey for children and young people.**<sup>35</sup> This builds on the national work of Office for National Statistics (ONS) in this area, supplementing local data and widening the ages included. This will provide key information to underpin the work of cross government and beyond working. **As 75% of adult mental health problems begin before age 18 it is imperative that the burden of disease is monitored regularly.**<sup>36</sup> I therefore recommend that the Mental Health of Children and Young People in Great Britain, 2004 survey is repeated, and is extended to include those with underlying neurodevelopmental issues, those aged under 5, ethnic minorities and those in the youth justice system. These data will therefore form a core part of local authority joint strategic needs assessments, commissioning and balancing finite resources.

#### Recommendation 21:

- **The Department of Health should work with Office for National Statistics, Public Health England and relevant third sector organisations to investigate opportunities to commission a regular survey to identify the current prevalence of mental health problems among children and young people, with particular reference to those with underlying neurodevelopmental issues, those aged under 5, ethnic minorities and those in the youth justice system.**
- **This data collection should include international comparisons and be linked to the Child and Adolescent Mental Health Services data set, providing key data for developing local services to meet clinical need.**
- **An annual audit of services and expenditure in the area should be undertaken.**

#### Research call

As the burden of disease continues to shift towards long-term conditions, there has been considerable focus on how to meet this challenge in adults. **The data on mortality for children and young people dying from non-communicable disease in the UK, and the variation shown in long-term condition management by the Atlas of Variation in the Health of Children and Young People 2013, attest to how much further effort is required for children and young people.** The National Institute for Health Research will support a programme of evaluative research that increases the knowledge base. This will also help to build research capacity in the area.

I am absolutely committed to supporting the work of the Royal College of Paediatrics and Child Health Child Mortality Taskforce. I commend the recent work of the Clinical Outcome Review Programme: Child Health Reviews to better understand the causes of death in young people. I fully support the collaborative efforts of the Department for Education and the Department of Health to reposition the Child Death Overview Panels within the remit of the Department of Health in order to facilitate improved insight from these deaths for healthcare. Furthermore, I am keen to build on the work carried out in Northern Ireland by the Chief Medical Officer, Dr Michael McBride, and others such as the Child Accident Prevention Trust (CAPT) to better understand and reduce deaths from blind cords. **Pooling data on patterns of child deaths allows key trends such as these to be identified.**

#### Recommendation 22:

**The National Institute for Health Research should develop a research call to provide the evidence base to improve health outcomes for long-term conditions in childhood, to match the best worldwide.**

#### Recommendation 23:

**The National Institute for Health Research (NIHR) Clinical Research Network, including the NIHR Medicines for Children Network, should work with children and young people to input to the design of clinical studies in order to facilitate increased participation of children and young people in drug and other trials.**

#### Recommendation 24:

**The four UK Chief Medical Officers have agreed that the Chief Medical Officer in Northern Ireland, Dr Michael McBride, will lead a group with the four public health agencies and The Royal Society for the Prevention of Accidents (RoSPA) to develop strategies to combat blind cord deaths.**

#### Conclusion

As Chief Medical Officer, my role is to collate, evaluate and articulate the evidence on key topics such as child health and wellbeing. My recommendations seek to catalyse change based on the evidence provided in this report. However, as I said in the Foreword, I do not underestimate the enormity of effort required to bring about real change in this area, for the **health and wellbeing of children and young people is a complicated mixture of genetics, sociology and psychology. Committed collaborative efforts are required.** Perhaps more than the effect of any one single recommendation, I believe that the benefit of this report will be to remind us all of how much the health and wellbeing of children matters to us all. Despite the continued efforts of many across many fields, **the evidence still points to room for improvement. We need everyone in the public services to 'think family and children and young people' at every interaction.** Increasingly, the wider benefits of such action are being honed into clear numerical

statements. We cannot waste the lives of children, we need to ensure we have a healthy population able to ensure our continued economic viability; we need to make sure our children start school ready and able to learn, and leave school fit for work. Such strong evidence should never be ignored: **rarely in health are there such opportunities to improve lives as well as show economic benefit** – surely addressing this means acting not just because our hearts tell us to do so, but because, with increasingly clear evidence, our heads should also encourage us.

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## Chapter 2

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# Overview

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## Key statistics

- Death rates for injury and poisoning have fallen for all social groups except the poorest: these children are 13 times more likely to die.<sup>1</sup>
- The UK ranks 24th out of 27 European countries in a composite measure of pressure on families.<sup>2</sup>
- The UK has the highest proportion of children living in a family where no adult is employed compared with other European countries.<sup>2</sup>
- Disproportionate social disadvantage is borne by the young: 26.9% of children and young people (aged 0–19) are living in or at risk of poverty or social exclusion, compared with the overall population rate of 22.6%. These figures compare poorly with the best performing country – the Netherlands, with a rate of 15.7% in or at risk.<sup>3</sup>
- Social disadvantage shows a particularly strong ‘hereditary’ component in the UK, being 1.5 times stronger than in countries such as Sweden, Germany and Canada.<sup>4</sup>
- The average cost of raising a child from birth to 21 in 2013 has risen to £222,458 from £140,389 in 2003.<sup>5</sup>
- The weight of children on leaving primary school is increasing, despite lower weights on entering.<sup>6</sup>
- There is a developing gender gap for exploratory and healthy behaviours among teenagers, with girls appearing to have worse behaviours.<sup>7</sup>
- One extra year in education increases life expectancy in the USA by 1.7 years. Where poor school attendance and poor achievement are present, the risk of ill health is 4.5 times higher in adulthood.<sup>8</sup>
- The last decade has seen high levels of utilisation of both primary care and secondary care. There has been a 28% increase in admissions for those under 15 years old. During the same time period hospital admissions for less than one day have doubled.<sup>9</sup>
- The average number of visits to the GP by preschool children is 6; during school age this falls to 2–3. Around 1 in 11 children utilise hospital outpatients and 1 in 10–15 are admitted overall. Around half of under 1 year olds visit an Accident & Emergency department, leading to 1 in 3 being admitted.<sup>10,11</sup>
- Key adverse health outcomes would be reduced by 18–59% if all children were as healthy as the most socially advantaged.<sup>12</sup>
- Young men living in the poorest 10% of postcodes are almost five times more likely to attend an Accident and Emergency department as those in the richest 10%.<sup>13</sup>



## Introduction

This chapter explores the rationale for this report's focus on the health of children and young people in England, and provides the context for Chapter 3, which lays out the financial rationale for investing in their health and wellbeing.

We start with a brief overview of recent policy initiatives for children and young people, which have attempted and often succeeded in addressing the challenges they face.

Next, we provide evidence for why this work needs to be sustained and built on further. Firstly, we consider the evolving evidence of the importance of the life course approach (i.e. how early events affect later disease patterns) and the biological underpinning of this. Secondly, drawing on the updated *NHS Atlas of Variation in Healthcare for Children and Young People 2013* and other sources, we identify the variation in patterns of healthcare utilisation in England, which signal that there is still great potential for improvement in children's outcomes. The Atlas allows comparisons between different geographic regions. Throughout this report, where variation is seen this is described as a comparison between the highest region and the lowest, e.g. three-fold variation would mean that occurrence was three times higher in one region than in the lowest.

The following section examines the range of ways to think about the drivers of health, with a focus on social determinants, risk and protective factors and exploratory behaviours. This section explores the common themes behind each of the report's later chapters: those following the life course and those focusing on mental health, neurodevelopment problems, looked-after children, and children and young people in the youth justice system.

The final part of the chapter examines the key policy approaches that run through much of this report: early intervention and prevention.

### Recent focus on children and young people

Over the last five years there has been a wealth of reports to government seeking to address the many challenges of improving the lives of children and young people.<sup>14–19</sup> These reports put forward a number of recommendations. Many of these focused on early intervention in the early years, either developing new resources or, for example, in the case of early years education, enhancing the quality of provision and widening access. Equally, these reports stress the need to enhance the evidence base. The reports also advocate new approaches to these problems, for example using behavioural economics to examine promoting good parenting.

This has led to a number of government initiatives which have sought to modify these complex determinants for children and young people. This work has involved many central government departments and more independent voices such as that of the Children's Commissioner (see Box 2.1).

### Box 2.1 Timeline of children and young people related policy initiatives

|      |                                                                                                                                                                                                       |
|------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1998 | National Childcare Strategy                                                                                                                                                                           |
| 1999 | Pledge to eradicate child poverty in a generation                                                                                                                                                     |
| 1999 | Sure Start Local Programme                                                                                                                                                                            |
| 2004 | National Service Framework set standards                                                                                                                                                              |
| 2004 | Sure Start development                                                                                                                                                                                |
| 2004 | <i>Every Child Matters</i> – framework for a collaborative approach, focused on five domains: being healthy, staying safe, enjoying and achieving, making a positive contribution, economic wellbeing |
| 2004 | Children Act                                                                                                                                                                                          |
| 2007 | Children's Plan                                                                                                                                                                                       |
| 2008 | Healthy Child Programme                                                                                                                                                                               |
| 2009 | <i>Healthy Lives, Brighter Futures: the strategy for children and young people's health</i>                                                                                                           |
| 2009 | Laming Report                                                                                                                                                                                         |
| 2010 | Child Poverty Act                                                                                                                                                                                     |

### Life course

There is an increasing **understanding of the long-term effects of early life events**.<sup>20</sup> Barker et al. started to identify in the late 1980s that the nutritional status of the late fetus had long-term effects, specifically that 'under-nutrition' creates changes in the fetus that in later life can lead to increased rates of coronary heart disease.<sup>21</sup> This was revolutionary thinking. Barker was among the first to postulate that events which happen early in the life course, for example in fetal life, contributed independently to these disease types. Today it is widely accepted that 'programming', i.e. intrauterine events, affects the development of coronary heart disease, non-insulin dependent diabetes, hypertension, chronic obstructive pulmonary disease, some cancers and stroke.<sup>22</sup>

### The effect of external factors does not stop at birth.

Recently published data identify the prevalence of adverse childhood events in England.<sup>23</sup> This builds on **work from the USA that has identified a key set of events which, when they occur, have profound effects on the life course of the child**. Events include growing up in a household with a family member who is depressed or who suffers from mental health problems, or exposure to domestic violence. Long-term studies have associated these events with poorer outcomes, such as poorer educational attainment, increased risk of imprisonment, more substance abuse, increased mental health problems, higher levels of obesity, heart disease, cancer and unemployment, and increased involvement in violence. Of particular note, the presence of adverse childhood events is cumulative, i.e. the greater the number of adverse events experienced, the higher the likelihood of experiencing more adverse outcomes.<sup>23,24</sup>

## Box 2.2 Examples of children and young people policy initiatives from May 2011

- Pupil premium.
- Early Intervention Grant.
- Community based budgets.
- Troubled Families Programme.
- Increased support and evaluation of the Family Nurse Partnership programme.
- Changes to childcare provision and maternity/paternity leave flexibility.
- Increased numbers of health visitors to support the Healthy Child Programme.
- Reinforcing the Early Years Foundation Stage and re-emphasising the importance of communication with parents.
- Creating the Early Intervention Foundation.
- Setting up the Social Mobility and Child Poverty Commission.
- The creation of a Social Mobility Index to be housed at the Department for Business, Innovation and Skills: e.g. the percentage of children achieving basic measures in GCSEs, and how well schools with the lowest percentage of free school meals do vs. those with a high percentage.
- The government mandate to NHS England included a focus on pregnancy, listening to the voice of children and young people through Healthwatch, continuing to join up resources around safeguarding, a focus on transition, continued support for Improving Access to Psychological Therapies, and an emphasis on special educational needs.
- Ministerial pledge in response to the Children and Young People's Health Outcomes Forum Report and recommendations.
- *The NHS Outcome Framework 2013/14* included a life years lost measure and a cancer survival measure with data to be available in five-year age bands. There were also placeholders for indicators of children and young people's experience of care and integrated care.
- UK Chief Medical Officers' guidance on physical activity.
- Support for school games and Change4Life Sports Clubs.
- Setting up of specialist clinical network for children by NHS England.
- Report of the Children and Young People's Outcomes Forum
- Catalysing work on medicine usage in children.
- Increased emphasis on child health workforce planning through Health Education England, the Centre for Workforce Intelligence and the Royal College of General Practitioners.
- *Improving Children and Young People's Health Outcomes: a system wide response.*
- Ministerial pledge on better outcomes for child health.

## Box 2.3 Adverse Childhood Experiences (ACE) and their impacts in the UK<sup>23</sup>

Compared with those with no ACE, those with four or more had:

- 3.96 times greater risk of smoking
- 3.72 times greater risk of drinking
- 8.83 times greater risk of incarceration
- 3.02 times greater risk of obesity

These children and young people are more likely to:

- have poor educational outcomes/poor unemployment opportunities
- have low mental wellbeing and life satisfaction
- have had more recent inpatient hospital care and chronic conditions
- have been pregnant unintentionally before age 18

In summary, while there has clearly been considerable effort focused on children and young people, the next section outlines the need to build further on this and previous work.

### Biological underpinning

Recent research has also started to identify how these complex interactions play out at a biological level. We have begun to understand that **developing executive functionality and self-regulatory skills are linked to the development of the pre-frontal cortex, and that this begins in infancy and continues until adulthood.**<sup>25</sup> Emotional insults during this key stage can disrupt this functionality (working memory, attention and inhibitory control mechanisms). Equally, being supported and nurtured leaves a young person more able to manage challenges in life.

Resilience is an important dimension of this. **Normative stress is part of normal development and helps to develop coping mechanisms.** Children can cope better with stress if they have effective buffers, such as a positive attachment with an adult. Toxic stress is an insult that occurs without such a protective factor and is able to damage the wiring of the child's brain and, with it, future function. It is not just the extent of the insult that has an effect: the time period over which the stress happens matters as well as the exact moment. For example, excess alcohol in pregnancy can cause fetal alcohol syndrome.<sup>25</sup>

As Jack Shonkoff has argued, as our 'knowledge base grows, it will be increasingly difficult to defend the absence of an explicit 'brain protection' strategy that focuses on both primary prevention and 'physiological healing' for young children whose life circumstances increase the risk of debilitating sequelae from toxic stress'.<sup>25</sup>

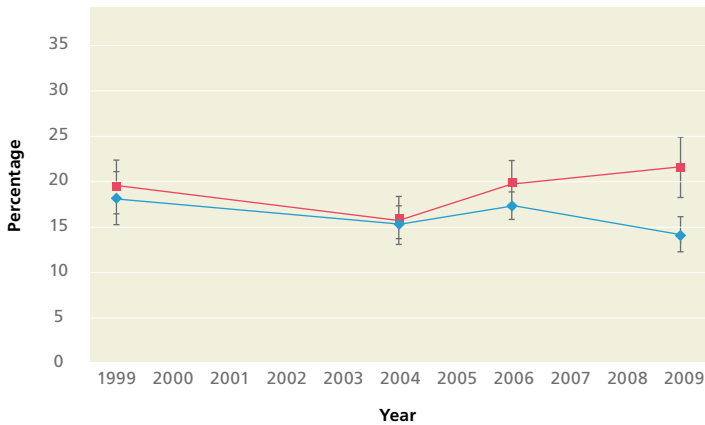
Variation

Looking across England, it is clear that there are great variations in the health of our children and young people. This is not a recent observation; the Court Report in 1976 clearly identified this as a major issue facing child health, and many reports since then have further stressed this.<sup>22,26</sup> Variation in health measures is complex; however, as a society we have become increasingly concerned by those variations that seem preventable.<sup>27</sup>

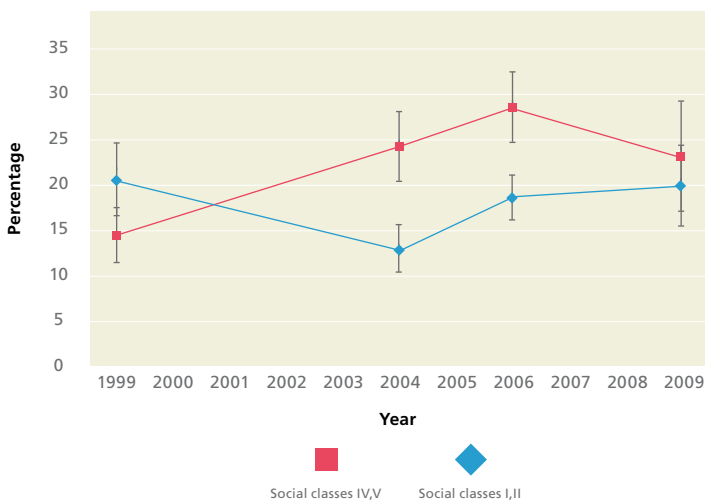
**We refer to this preventable variation as health inequality.** Health inequality does not just affect those in the top or bottom 10%, as there is a gradient across the population from better to worse health; this was clearly demonstrated by the Whitehall Study.<sup>28</sup> Perhaps the most profound inequality is in healthy life expectancy.<sup>20</sup> Furthermore it is increasingly clear that health inequality is bad not just for individuals and families, but also for wider society.<sup>29</sup>

**Figure 2.1 – Prevalence trends of poor health/health risk by age group, England, 1999-2009 (%)**<sup>31</sup>

Long-standing illness 0–12



Long-standing illness 13–24



The importance of health inequality has been recognised by successive governments, with a Health Inequalities Strategy running from 1997 to 2009 and a legal duty to tackle health inequalities introduced in the Health and Social Care Act 2012. However, the contribution of early inequality to lifelong health has only been fully appreciated more recently.

Trends in variation

Using the *Atlas of Variation in Healthcare for Children and Young People 2013* (see Annex of this report), we can start to see themes emerging with respect to geographic variation. The Atlas has been updated and amended since it was first published in March 2012. The data are now broken down by local authority rather than primary care trust areas. In the section below we look at three key groups of indicators: mortality, health promotion and healthcare utilisation. While the Atlas does not cover all aspects of child health, the indices chosen are those that cover a broad range of issues and those where data is available; thus they give the best snapshot of children’s health and variation currently available. As Marmot and others have shown, these social gradients are manifest across a very wide range of outcomes.<sup>20</sup>

Mortality

The Atlas identifies a number of important trends in mortality:

- **Mortality** for children aged 1–17 **varies more than three-fold between regions, with a range of 7–23 deaths per 100,000 children.**
- **Infant mortality** shows similar variation, **with ranges of 2.2–8 deaths per thousand live births.**
- **Perinatal mortality** shows similar variation, with a **range of 4.2–12.2 deaths per thousand live births.**

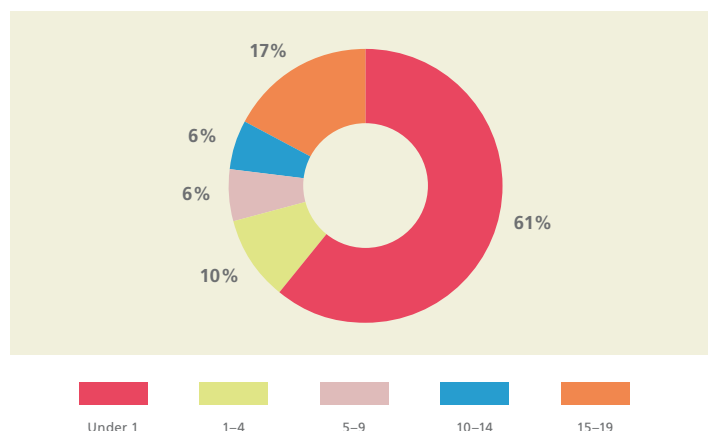
Of these, only **perinatal mortality** was captured in the 2012 version of the Atlas, and at that time the variation was two-fold. The most recent data therefore **show increased variation.**

**Recent work by Wolfe et al. (2013) has shown that 20 years ago our mortality, in children under 19, was similar to other countries in Europe – now we are among the highest in Europe.** Specifically, if we compare ourselves with the country with the lowest mortality for children and young people, Sweden (after controlling for population size among other variables), we find that **every day five extra children under the age of 14 die, which equates to 132,874 excess person years of life being lost per year in the UK.**<sup>31</sup>

While international comparisons should be interpreted with caution, the increase in variation coupled with the international data is a concern. Further analysis of the data around deaths identifies that **the majority of deaths in childhood are in the under 1 year olds; in fact, 70% of infant deaths (deaths under 1 year) in England and Wales in 2011 were due to neonatal deaths – deaths at**

**less than 28 days.**<sup>32</sup> The most common cause of death, in children as a whole group, is now being related to perinatal problems and congenital abnormalities.

**Figure 2.2 – Age distribution of deaths among 0-19 year olds, UK, 2012**



Data source: "Deaths by single year of age tables, England and Wales, 2012" ONS <http://www.ons.gov.uk/ons/rel/vsob1/death-reg-sum-tables/2012/rft-deaths-syoa-tables--2012.xls>

Earlier work on infant mortality showed that the Child Poverty Strategy aims – meeting targets for obesity, smoking, sudden unexpected death in infancy, overcrowding and teenage pregnancy – could go a long way to ameliorating this.<sup>33</sup>

Deaths shortly after birth, though, are not the whole story. We also know that deaths in later childhood, particularly adolescence, are of concern. The data show that more children die in adolescence than in any period other than infancy.<sup>34</sup>

The World Health Organization (WHO) classifies deaths into communicable disease and non-communicable disease (NCD). Deaths due to communicable disease are very low, but the latest data available on **NCD deaths in the UK show that for all ages, except 20–24 year olds, the UK does worse than its comparators.**<sup>35</sup> Indeed, the UK has poorer mortality than the USA for this group. We also see that up to 74% of deaths in the UK occur in children with co-morbidities, i.e. a long-term condition, of which the most common was a neurological or sensory condition affecting 44% in England.<sup>36</sup>

However, the story is not all bad. The UK does well when compared with the EU 15+ countries for injuries,<sup>35</sup> although we see variability for 10–18 year olds when looking across the four devolved UK administrations, with England performing better than its neighbours, and this disparity has increased since 1980. Researchers estimate that if the UK as a whole had the same mortality rate as England, then there would be 52 fewer deaths per year in 10–18 year olds. **The Atlas data show considerable variation, with the rate of deaths from non-accidental injury showing more than a five-fold variation and that from accidental injury showing a seven-fold variation across the regions.** Deaths from road-related injury show a more than 10-fold variation. Furthermore, we see that the rate of deaths from intentional injury (e.g. assault and self-harm) has not changed over three decades. Boys are particularly likely to experience harm. If

## Case study

### The HOPE groups: involving mothers of children at most risk of infant death in decision making about maternity care – Bradford and Leeds

The Social Networks and Infant Mortality research study has established HOPE Bradford and HOPE Leeds project development groups, made up of bereaved Pakistani, African and teenage mothers who have experienced an infant death. The groups have been supported to identify priority areas for service development, based on findings from the study, along with ideas for how identified barriers to support might be addressed. The groups provide a mechanism for women from populations at most risk of infant mortality to feed into decision making about the care they and other women like them receive.

A number of initiatives are being developed, including:

- a pathway for women from Pakistani and African Caribbean backgrounds based on models already developed for teenage mothers
- a joint training event for health visitors and midwives on accessible/appropriate bereavement support
- representation of group members at the Maternity Services Liaison Committee and at a neonatal services users' support group they initiated
- group members will receive Sands (Stillbirth and Neonatal Death Society) bereavement support training and have fed into the organisation's work on improving access for minority ethnic parents
- support for a group member in relation to safeguarding has involved raising issues highlighted by her case with commissioners, care providers and advocates
- training/capacity development for group members has included sessions on communication/media skills and involvement in local and national dissemination activity. A member of HOPE Leeds appeared on Radio 4's 'Woman's Hour' and members of both groups will contribute to local developmental workshops and a national Sands conference.

we look to other data sources, we also see that the **most deprived are 13 times more likely to die from injury and poisoning.**<sup>1</sup>

In summary, more children seem to die in the UK compared with other similar countries. Crucially, this high mortality seems to be due in large part to neonatal deaths. Adolescent deaths give further cause for concern as well as deaths from non-communicable diseases. Furthermore, the data show that the variation in mortality rates (particularly perinatal mortality rates) has increased. Perhaps most concerning of all is that while mortality from injury is an area in which England is performing well, there is profound variation across the country. Thus as a country we have little to be complacent about.



## Case study

### Blind cord Education At Registration (BEAR) Project – Eastern Group Environmental Health Committee, Northern Ireland

Since 2010, there have been 13 deaths in the UK of children under the age of 3 as a result of becoming entangled in the loop of a blind cord. Most deaths have occurred where cots or beds have been close to the windows, but any window with a blind cord is a risk. A safety check of almost 2,700 homes in Northern Ireland with children under 5 years old revealed that, where blind cords were present, they posed a risk in 76% of living rooms, 68% of children's bedrooms and 62% of other rooms.

This project raises awareness of blind cord risks with parents/grandparents/carers at the registration of a birth and encourages preventive action to protect the life of their newborn.

When births are being registered at council offices, there is a short wait while birth certificates are being printed. Registrars use these few moments to raise awareness of home safety and to draw new parents' attention to the British Blind and Shutter Association leaflet 'Make it Safe!', which warns of the dangers of blind cords and is supported by the Royal Society for the Prevention of Accidents.

This intervention at registration of birth means that parents become aware of the issue at a very early stage and so can use this information to choose a more suitable window covering and site the cot (and future bed) away from the window. If they already have blind cords in their home, they are given cleats along with the leaflet so that they can make their blind cords safe.

In one year more than 3,331 families registering births have been provided with the information and, where relevant, equipment to ensure that the risk of blind cord strangulation in the home is minimised. They are also encouraged to share this message with grandparents, childminders, family and friends to make other homes safe.

The innovative nature of this intervention lies in its timing which coincides with birth registration – probably the optimal time to get the safety message across to parents. The fact that there is also one-to-one advice to back up the printed material is also important in encouraging the parent to take the recommended precautionary action.

This is a low-cost intervention (leaflets cost £52 for 1,500 and cleats can be purchased for 15p or less) that makes contact with **every** new parent.

Mary Heaslip, Registrar, Castlereagh Borough Council – *'In the Registration Service in Castlereagh we have been engaging with parents on the blind cord safety issue for the past year... we register approximately 1,300 births every year. The leaflet is on display on our desks and I have also given it to couples giving notice of marriage and to other clients. This is usually at their request because the leaflet has caught their attention and this has instigated a discussion. Blind cord accidents involving infants touch everyone and the issue brings out our overriding desire to protect babies and children.'*

*'Handing the leaflet out only takes one minute at the end of the registration, and I and my staff have no hesitation in continuing to highlight it. If just one life can be saved from thousands of leaflets handed out then it is worthwhile.'*

**A father of three said 'It's good to be aware of the dangers'**, pointing out that children develop at different rates and it is better to be prepared in advance of each development stage.

**A new mum also thought the advice at registration was provided at a good time** *'never too early to know about home safety'*.

## Health promotion

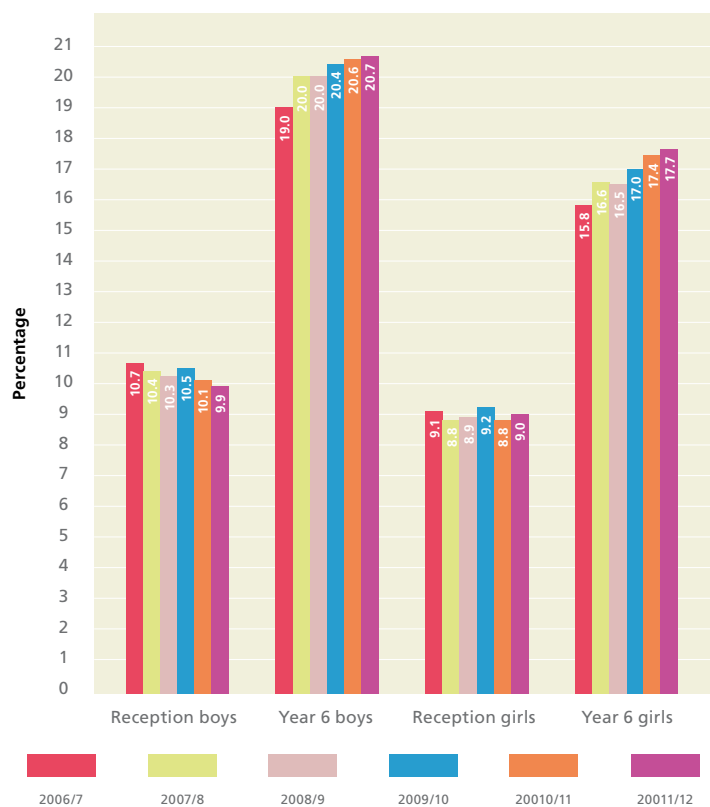
Over the past two years, cases of measles in England and Wales reached their highest figures for two decades, with 1,168 confirmed cases in January–May 2013.<sup>37</sup> These outbreaks demonstrate that vaccination coverage across the population is not high enough. We know that for the measles, mumps and rubella vaccine in particular, the rates of uptake range from 69.7% to 95.3%. Similar figures exist for other vaccination programmes, with the widest variation being seen in human papilloma virus vaccination (from 2.8% to 27.7%, a 13-fold variation). Successful vaccination strategies are important to consider at this juncture, with the recent extension of the programme to include rotavirus, among others.

Three worrying trends emerge with respect to very early life. Firstly, we know that breastfeeding is very important in promoting child health and is linked with fewer hospital admissions of infants for diarrhoea, vomiting and respiratory infections; less risk of sudden unexpected death in infancy; improved cognitive attainment; and a lower lifetime risk of obesity and diabetes. Additionally, there are benefits for the mother, such as improved breast and ovarian cancer survival. Breastfeeding promotion is cost-effective for both the families themselves and society.<sup>38</sup> Despite this knowledge, **there are local authorities where the breastfeeding initiation rate is as low as 42% and those where it is as high as 94%**. For breastfeeding at 6–8 weeks the range is 20%–83% (a four-fold variation). The most recent data available are for the first quarter of 2012, which show that there has been a small decrease in mothers initiating breastfeeding and infants being breastfed at 6–8 weeks.

When compared with Europe, we do badly for breastfeeding; for example, 90% of babies in Norway are breastfed.<sup>22</sup> Socio-economic factors play a role; however, rates of breastfeeding are influenced by many other factors, such as the provision of support mechanisms to encourage and assist mothers to breastfeed. Indeed, women suggest that their key reasons for not breastfeeding are: other people's attitudes; lack of knowledge and support; poor experience; and concern over baby's weight gain.<sup>39</sup> While many attempts have been made to improve this, there are two particularly important areas for further effort: increasing involvement with WHO and UNICEF's Baby Friendly Initiative; and monitoring and examining the effects of allowing formula milk to advertise health claims.<sup>22</sup>

The second worrying trend is the rate of smoking at delivery. The Atlas identifies that **there is a 10-fold variation in mothers self-reporting smoking at delivery across local authorities**. Given the earlier insight into the effect of early life events, this is an important marker.

**Figure 2.3 – Prevalence of obesity by year of measurement, school year, and sex**



*NB: In this analysis 'children are classified as obese where their BMI is greater than or equal to the 95th centile of the British 1990 (UK90) growth reference*  
*Data source: Public Health England*

A third and particularly worrying trend is emerging in relation to obesity. **While, year on year, children are entering reception classes weighing less, children are leaving primary school weighing more.** The Atlas demonstrates that at both ages there is a nearly two-fold variation in children classified as overweight or obese across the country.<sup>40</sup>

If trends in behaviours adopted by children and young people themselves are examined, two groupings can be seen: exploratory behaviours and healthy behaviours – where exploratory behaviours are those that have the potential to lead to harm, e.g. alcohol use. This terminology captures the fact that many of the so-called 'risky behaviours' are those that most adults engage in safely, e.g. sex.

**Overall there has been a significant reduction in the prevalence of exploratory behaviours in the past decade.<sup>7</sup>**

The number of young people drinking regularly has fallen dramatically. In 2002, 52% of 15-year-old boys and 48% of 15-year-old girls reported drinking weekly; by 2010 this was down to 32% of boys and 23% of girls. However, within this story there is huge variation: **hospital admissions for alcohol-specific conditions, in 0–17 year olds show an eight-fold variation (16.9 per 100,000 to 138.3 per 100,000)**. Similarly, there has been a decline in physical fighting.

The overall story, however, hides some areas of concern: that the declines are less marked for girls, and indeed with some behaviours there has been a rise. For example, in England while cannabis use at age 15 fell for boys between 2006 and 2010, there was a rise for girls. This compares poorly against smoking as a whole, where the proportion of young people who reported smoking (at least occasionally) was 7% of boys and 10% of girls, which was a fall for both sexes (in 2002, 15% of boys and 21% of girls reported smoking).<sup>7</sup>

Where the picture is more mixed in England is with sexual health, although the number of 15 year olds reporting having had sexual intercourse early has fallen, for boys from 17% in 2002 to 10% in 2010 and for girls from 9% to 4%. **More worrying is the fall in condom use since 2006.<sup>7</sup>** Huge variation exists in the rate of conceptions across England in women aged under 16 (9.4%–58.1%, more than a six-fold variation), and even greater variation in the percentage of delivery episodes where the mother is aged <18 years ranges from 0.3% to 2.8% (nine-fold variation). Given the data on mortality and the known correlation between the age of the mother and outcomes for the baby, this continues to be a disturbing statistic.<sup>41</sup> Rates of chlamydia infection also show considerable variation (nine-fold).

With respect to healthy behaviours, the story is less rosy. There has been no dramatic improvement over the last decade; indeed there has been some falling back, including eating fruit daily, eating breakfast and physical activity. Eating breakfast and physical activity also show a marked gender skew, with girls missing breakfast more. The gender differences are also marked with respect to body image – 22% of boys and 45% of girls think they are fat; and 9% of boys and 26% of girls report engaging in weight loss behaviour at age 15.<sup>7</sup> **England now has the highest rate of sugary drinks consumption in Europe.<sup>7,42</sup>**

*'Eating healthy makes you excited, 'cos it makes you happy, tasting and enjoying the food while being healthy.'*

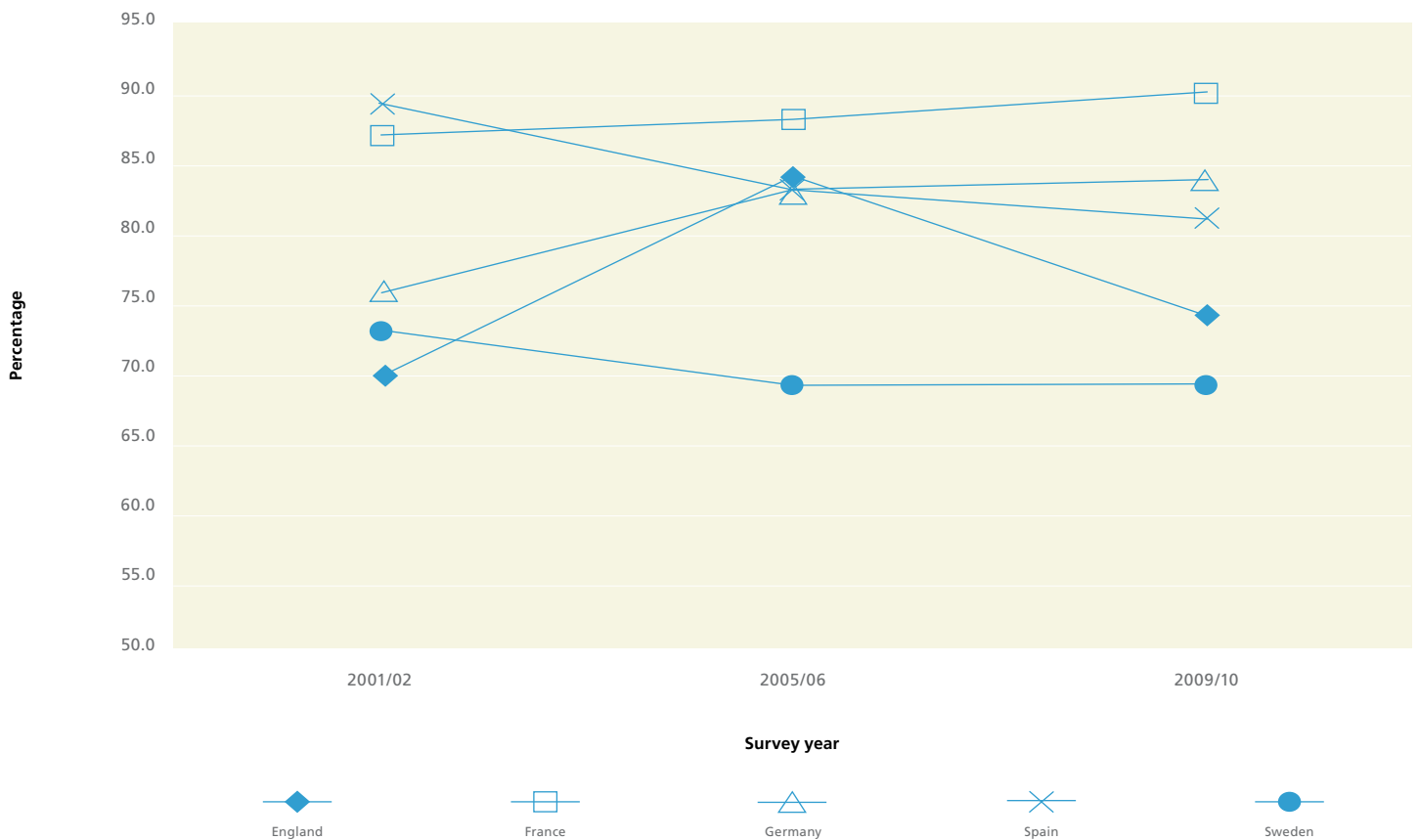


**Figure 2.4a – 15-year-old girls who used a condom at last sexual intercourse<sup>7</sup>**



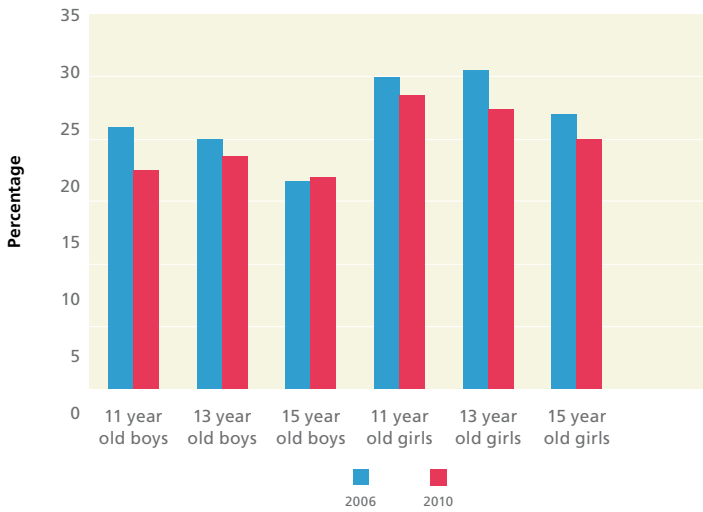
Source: Health behaviour in school-aged children international reports from the 2001/02, 2005/06 and 2009/10 surveys

**Figure 2.4b – 15-year-old boys who used a condom at last sexual intercourse<sup>7</sup>**

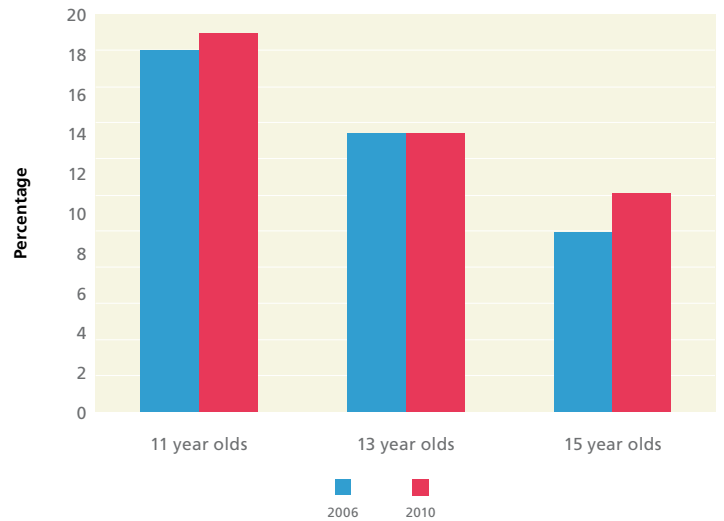


Source: Health behaviour in school-aged children international reports from the 2001/02, 2005/06 and 2009/10 surveys

**Figure 2.5 – Percentages of young people who report eating fruit every day 2006-2010**



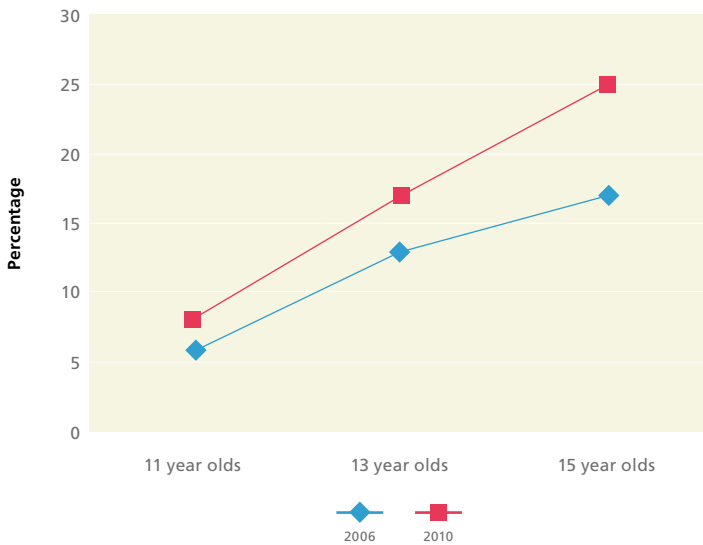
**Figure 2.7b – Percentages of girls who meet recommended physical activity levels**



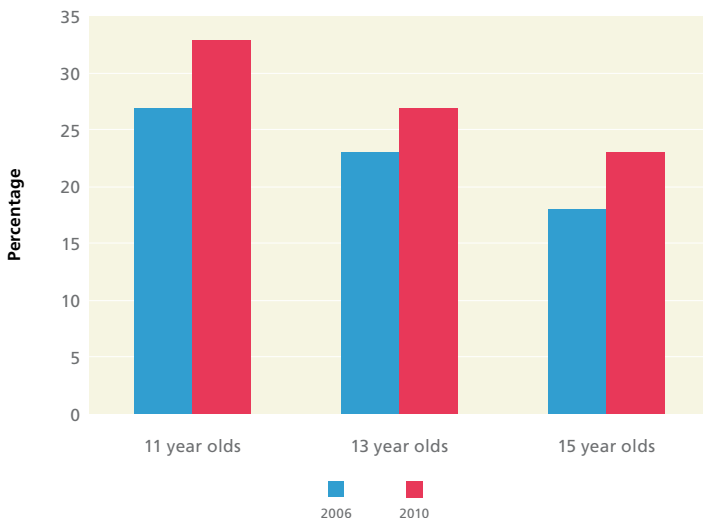
*'Running, jogging, sleeping and eating carrots makes me feel good.'*

*'Fruits and vegetables are healthy. I have salad at home once a month. My mum likes salad and lemon.'*

**Figure 2.6 – Percentages of young people who said they never eat breakfast on weekdays**



**Figure 2.7a – Percentages of boys who meet recommended physical activity levels**



**An electric apple, created by primary-aged children to show how exciting fruit and vegetables can be.**

Source: Kids Company

The trends in health promotion seem to suggest that, while improvements have been seen in exploratory behaviours, healthy behaviours have lagged. Furthermore, areas such as breastfeeding are showing worrying early signs of falling off.

### Healthcare utilisation

Drawing on data from the Atlas and beyond, it is possible to see trends in conditions and usage of healthcare:

- The average number of visits to the GP per year by preschool children is six during the school-age years.<sup>11</sup>
- **Around 1 in 11 children utilise outpatients each year.<sup>11</sup>**
- **Around 1 in 10–15 children are admitted overall each year.<sup>11</sup>**

- For children less than 1 year old, 50% visit an Accident & Emergency department and 1 in 3 are admitted each year.<sup>10,11</sup>
- 67% of the admissions for children are short stay; 39% are for minor infections.<sup>11</sup>
- **There has been a 28% increase in admissions of children aged under 15 over the last decade and admissions for less than one day have doubled.**<sup>9,10,11</sup>

The data from the Atlas show a nine-fold variation for emergency attendances for children under four and an eight-fold variation for emergency admission length of stay. Some improvement can be seen in bronchiolitis variation between the 2012 Atlas and the current one, although there is still considerable variation; previously six-fold after excluding outliers (the highest five and lowest five values) and now greater than four-fold.

Long-term conditions also show variation. As an example, emergency admissions for asthma are still showing a nearly seven-fold variation and those for epilepsy show a 13-fold variation.

A further trend is that **between 1999 and 2009 the health gap between social classes increased for hospital admissions in children under 5.** This was despite a national strategy to reduce health inequalities and a significant reduction in child poverty rates over this period.<sup>30</sup> Increasing demand for healthcare seems to be coupled with increasing disparity in access to healthcare, despite investment to reduce inequalities.

## Summary

The health of children and young people matters for its own sake. This section has demonstrated that focusing on this area of health is important for a further reason: variation. Clear trends in mortality, health promotion and healthcare utilisation are apparent. There is an urgent need to improve access in England and to eliminate regional poor performance, as illustrated by variation.

*'I like running around 'cos I'm fast. Young people run around and get energy – they can go to the Olympics. It is good to have energy. You can't be lazy – don't be lazy, be energetic. Exercise is actually good.'*

## The drivers of health

Health is driven by a wide range of factors operating at different levels, ultimately mediated by a complex interaction of genes and environment. One approach is to focus on the social determinants of health: to recognise that a range of interweaving elements such as poverty influence eventual health outcomes, and that these elements are reciprocally affected by health. Another is to think about eventual health as the sum of risk and protective factors, including resilience. These approaches are not mutually exclusive; rather, by

using both approaches to examine the issues better, our understanding can be improved.

This report follows the life course but also has four areas of particular focus: mental health, neurodevelopmental disorders, looked-after children and those in the youth justice system. This section is important because it helps to explain how children and young people may develop problems within these categories and how these issues may be aggravated – for example, the factors that are associated with increased risk of a child being placed into the social care system: parental socio-economic status; receipt of benefits; single parenthood; parental mental illness; neurodisability in the child; and many more. Many of these are similar to the factors that would be found when looking for those associated with a child developing mental health problems or entering the youth justice system. This section therefore explores these common determinants.

## Case study

### Connecting care for children's health

The London Boroughs of Hammersmith and Fulham, Westminster, and Kensington and Chelsea have high rates of paediatric unscheduled care use. Many of these children could have been seen in a GP or community setting, and a similar trend characterises paediatric outpatient referrals: up to 50% of cases could have been managed within a primary care setting.

Work has been undertaken locally to understand the drivers behind this and three factors have been identified:

- **Access** to same-day GP appointments or urgent consultation.
- **Parental capability** to 'self-care' with the right support.
- **Parental confidence** in GP paediatric expertise.

The model aims to strengthen networking between primary and secondary care; build links with local authority services (e.g. schools); and facilitate better contact between children, families and primary care, to improve communication, information exchange, diagnosis and education. Its core elements are: paediatric outreach (joint clinics and multidisciplinary team meetings); developing community capacity through practice champions; and open telephone access (patient to GP and GP to paediatrician). Pilot projects have tested the key elements of the model. These have been developed collaboratively with local children, parents and professionals.

Children, families and professionals have all benefited through working in a more trusting network of professionals and patients, moving care out of the hospital to primary care, schools, children's centres and the home. Professionals in both primary and secondary care benefit from the discussion, joint diagnosis and management of conditions. Families have valued the open contact with their GP, even more when that GP is supported by a hospital specialist.

The long-term benefit will be to strengthen primary care's role in children's health, linking primary care practitioners to paediatric expertise and building strong community networks in order to reduce hospital activity for families, and shaping the way children and young people learn how to use the health service. The project is innovative in addressing the core issue of parental and professional confidence and expertise. The proposed model for commissioning these services has the potential to support integration and reduce the perverse incentives in the current contracting model, as well as driving the development of meaningful patient outcomes for children and young people. The project has been evaluated through quantitative and qualitative methods and has shown significant impact:

- 74% of parents said that they would be more likely to see their GP for child health related issues. 98% of parents would recommend the outreach clinics to their friends.
- 2% Did Not Attend rate.
- Increased confidence in diagnosis in primary care, reduced referrals.
- Sustained decrease in admissions for asthma in the period 2011–13.
- Reduced hospital admissions for paediatric diabetes and improved HbA1c (glycosylated haemoglobin) levels.
- Development of an information app for children and young people with sickle cell.

**Mother of a child with diabetes** – *'Our son, aged 8, was diagnosed with type 1 diabetes in January 2009 at the age of 4 and we first met Mae as part of the team at St Mary's. However, diabetes is an illness that is notoriously difficult to manage and understanding how to count carbohydrates and to juggle that with exercise, the weather and general wellbeing as the child grows is increasingly tricky. This autumn we were offered the opportunity to have Mae come to our house on two occasions to help monitor our son's progress. We had been finding it difficult to regulate his blood sugar levels and Mae's help was invaluable. Before that we may have seen Mae perhaps once a year under the more stressful conditions of a hospital clinic, which our son always hated as he didn't like missing school or seeing doctors in a hospital. Is it cost-effective? He had two bad hypos in early September and he was quite ill on both occasions. With Mae's help we have been able to avoid any further hypos and, what's more, the possibility of any extremely costly hospital admissions.'*

**GP involved in outreach clinic** – *'I don't think I have done a general paed referral since the clinic started.'*

**Paediatric trainee** – *'I learned how much parental anxiety GPs have to hold and manage', and 'I appreciated the context in which primary care sees families.'*

## The social determinant approach

In 1980, Sir Douglas Black published his seminal *Report of the Working Group on Inequalities in Health*, highlighting how position in society affects disease. Indeed, Black did not just identify the problems, he proposed radical solutions to government: that improvements in health required improvements in healthcare and in the domains of social policy, for example housing,<sup>43</sup> a clarion call repeated by many since.<sup>22</sup>

This built on the work of Illich,<sup>44</sup> who identified that the previously accepted biomedical paradigm was not the only way to look at health and ill health. Black's work was also an evolution of Urie Bronfenbrenner's Ecological Model, which forms the basis of our understanding of how individuals are shaped by a very broad range of factors: family, community and society.<sup>22</sup>

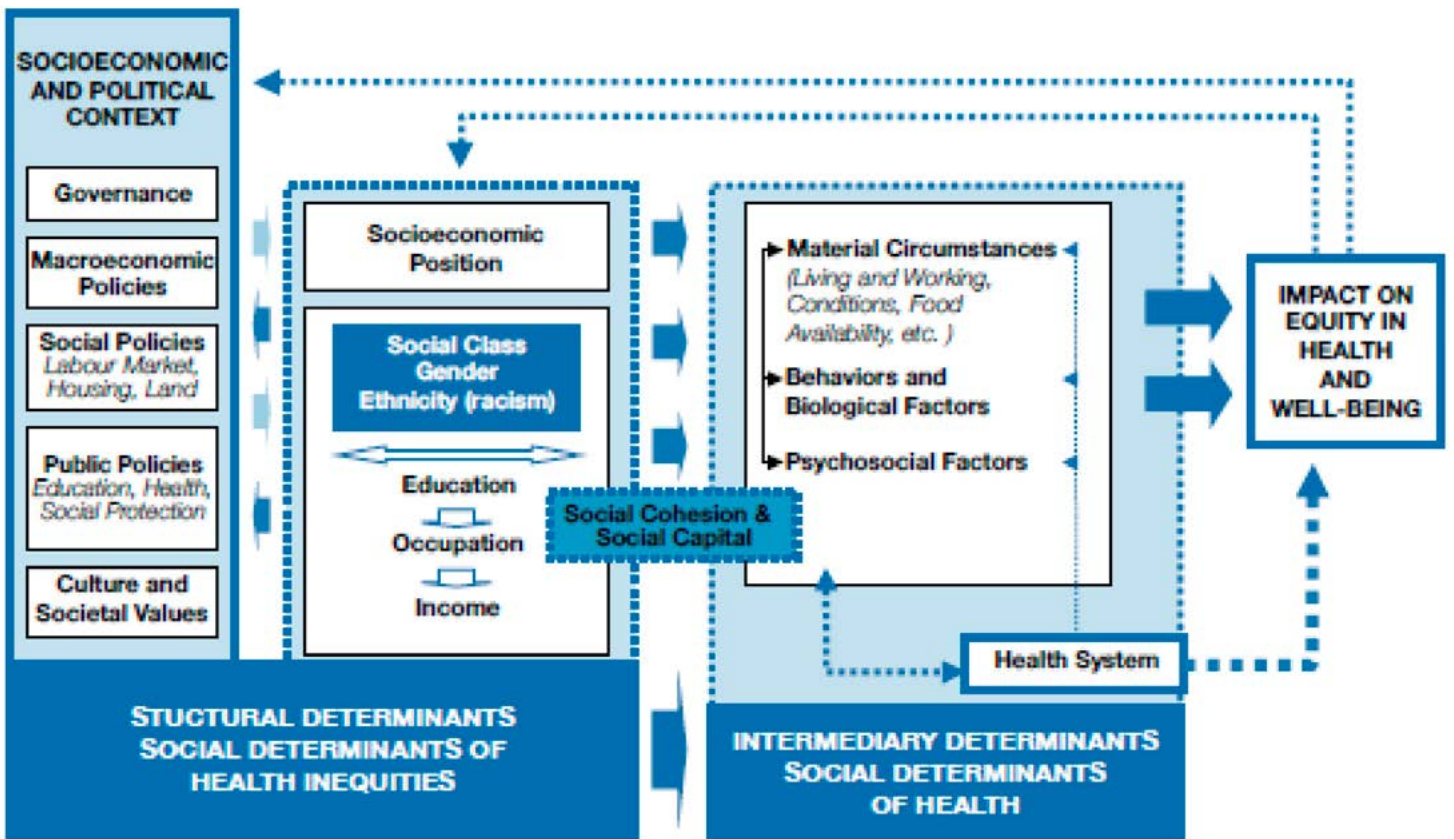
Since the Black Report, the public health community has embraced the concept of the underlying social determinants of disease. If Barker's hypothesis of programming made a crucial connection, then the social determinant approach adds the understanding of how these life-altering events occur and interact, i.e. why these exposures happen and why the consequences of these exposures are different in different people.

WHO defines the social determinants of health as 'the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels.'<sup>45</sup>

The WHO Commission on Social Determinants of Health reconceptualised thinking about how the health of an individual is affected by individual factors, the wider community and indeed national policies and practices. In this framework it is possible to see how the complicated tapestry of factors interrelates to affect the health of individuals and, importantly, the health of individuals relative to others in that society. The model includes **two concepts, social cohesion and social capital, relatively new to our understanding, as important links between the underlying determinants of health such as education and occupation, and how these interact with the intermediary determinants such as the psychosocial profile of the individual.** Thus this model emphasises the glue that binds individuals into wider groups – the sense of community.<sup>45</sup>

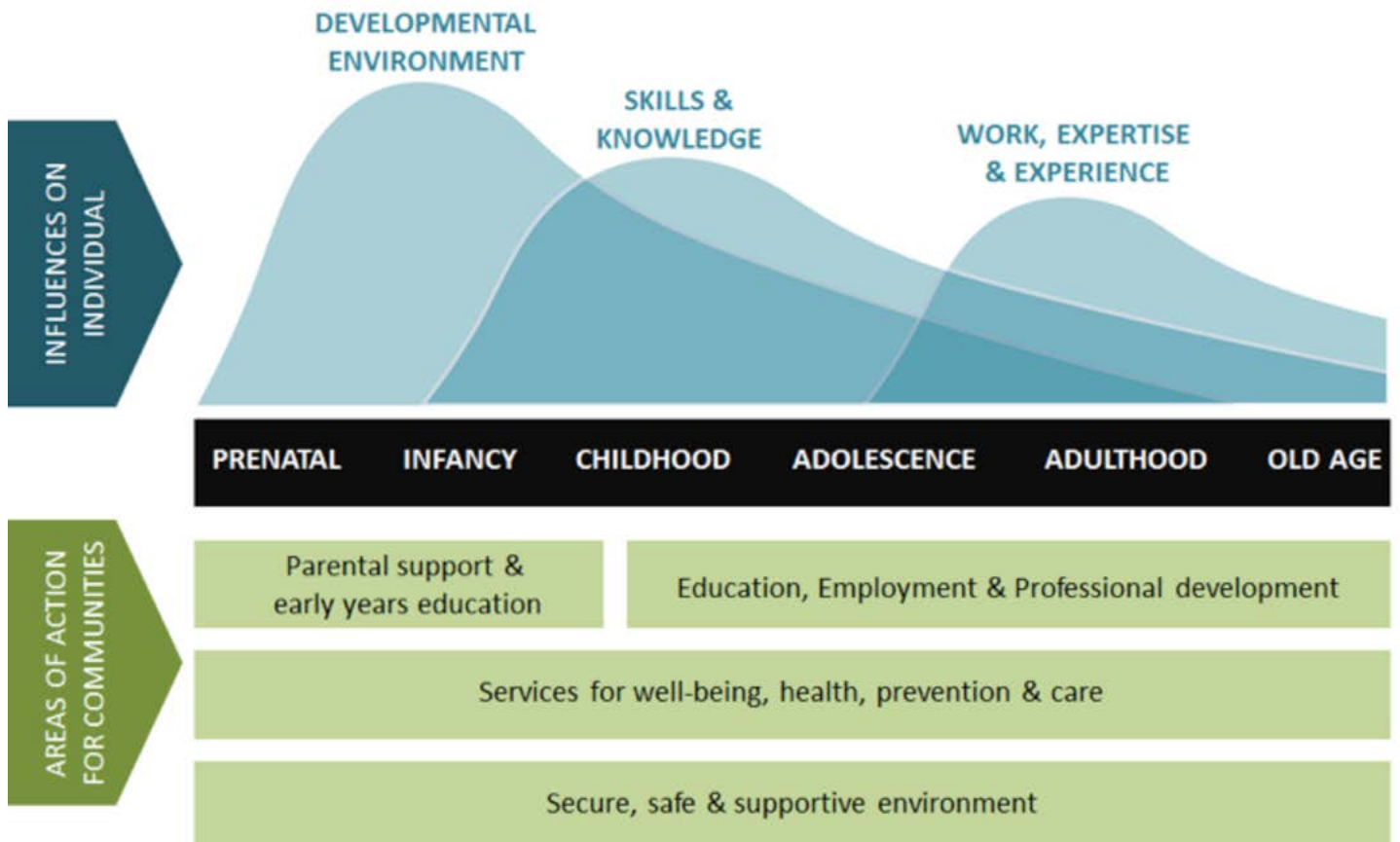


Figure 2.8 WHO Commission on Social Determinants of Health



Source: WHO A Conceptual Framework for Action on the Social Determinants of Health WHO 2010

Figure 2.9 Influences and actions along the life course



Source: Annual Report of the Chief Medical Officer, Volume One 2011 On the State of the Public's Health

Looking at Figure 2.9, it can be seen that there are potential areas of action relating to both the **individual** and the **community**. This model maintains the emphasis on the accumulation of effects on health and wellbeing starting before birth seen in the Marmot Review life course model.<sup>20</sup>

The top section of the diagram depicts areas of activity experienced by an **individual** that influence his or her development along the life course. The curves represent the **significance** on health and wellbeing of each individual activity, exerting the greatest influence in earlier years and tapering off in later life. These influences are as follows:

- **Developmental environment** – includes the environment into which a child is born, socio-economic conditions, pre- and postnatal nutrition, imprinting and epigenetic influences, and the psychosocial and developmental support received, all of which influence a child's life course.
- **Skills and knowledge** – includes all life skills, from social skills and resilience, to vocational skills and knowledge gained through all forms of direct and indirect education.
- **Work, expertise and experience** – indicates the acquisition of expertise and experience through all forms of paid and unpaid work and work-related activity.

The lower section of the diagram depicts areas of action at the **community** level, i.e. where action needs to be taken at a group rather than an individual level and often focused towards specific communities. These will (in part) determine the societal influences on individuals, and action here is essential for the healthy development of society. These areas of action are as follows:

- **Parental support and early years education** – includes family building in a more holistic sense, such as interaction with parents and/or caregivers, as well as targeted education on the importance of parenting, and nutritional and developmental support.
- **Education, employment and professional development** – includes the need for policy action in providing opportunities for continuous education and development at work.
- **Services for wellbeing, health, prevention and care** – includes basic physical, mental, emotional and preventive health measures delivered by and provided for communities, including the need for policy action in providing services for early diagnosis and treatment. 'Care' includes all aspects of health and social care across the life stage from a policy perspective but, equally, empowering families and communities to create caregiving environments.
- **Secure, safe and supportive environment** – not only alludes to the idea of creating supportive and caregiving environments, but also to taking policy action to ensure the safety and security of communities as a basic requirement.



*Happy dancing bear, created in a workshop with primary-aged children to represent how Christmas at Kids Company feels.*

Source: Kids Company

### Social determinants and children and young people

Recent work by Sheffield University<sup>46</sup> has attempted to identify which of the social determinants have the most effect in putting children and young people at social, emotional and cognitive risk. Taking into account prevalence and risk size, **the most important factors they identified are: lone parenthood; low income; social housing; living in areas of deprivation; young motherhood; maternal education; and health.**<sup>47</sup> Frank Field, in his report *The Foundation Years*, placed these and other factors within the life course, which helps to identify when key factors come into play.<sup>17</sup>

Rather than addressing each of these social determinants, this next section focuses on a number of factors that are of particular importance to children and young people.

The relationship between health and education is increasingly an area of significant focus, and exemplifies the reciprocal interaction between determinants. While understanding of these links goes back at least to Abraham Maslow's work in the 1940s, unpicking this is challenging. There is, however, **increasing evidence that improving health improves educational attainment.** Some is focused on the micro level, for example work on understanding the role of iron deficiency in cognitive development.<sup>22</sup> Some is focused on much broader interactions; indeed, there is a growing body of evidence about the benefit of school-based activities on educational attainment. The best evidence is around asthma, mental health, nutrition, social and behavioural and focused interventions.<sup>48,49</sup>

Figure 2.10 The key drivers of life change throughout childhood



Source: HM Government (2010). *The Foundation Years: preventing children becoming poor adults, the Report of the Independent Review on Poverty and Life Chances*

There is also evidence on how **improved education helps health**: one extra year in education increases life expectancy in the USA by 1.7 years. Equally, if poor attendance and poor achievement are present, the risk of ill health is 4.5 times higher in adulthood. Some 12% of decrease in birth weight and 20% of decrease in prematurity risk are attributed to improved maternal education in the UK. Similarly, improved cancer survival occurs in those who are better educated, perhaps due to participation in screening in adulthood. More educated people abstain from alcohol and drink to excess less.<sup>8</sup>

There is also limited evidence from comparing schools that the school environment has an effect on health.<sup>8,50</sup>

Heated recent debate has focused on one particular set of social determinants: those addressing financial inequality and, in particular, poverty. This is a complex area, where definitions are key and highly controversial. No single indicator captures the full extent of the meaning and experience of poverty; is it about relative income standards across society, is it in relation to a threshold of need, or is it about ability to afford particular goods?<sup>22</sup> In his review of poverty and life chances, Frank Field suggested that, alongside longstanding indicators of child poverty, there should be a range of life chances indicators: cognitive, behavioural, social, physical and emotional development; the home learning environment; positive parenting; maternal mental health (although paternal mental health is of importance too); age of mother's first child; maternal education; and the quality of nursery care.<sup>17</sup> The Government laid out how they would respond to this through developing indicators in *A New Approach to Child Poverty*.<sup>51</sup>

This Chief Medical Officer's report recognises that different comparisons will be appropriate for different contexts. What is clear is that however poverty is defined the effects on the life course are profound. It is also important to note that poverty is increasing at present.

Source: UNICEF

As with many of the social determinants the effects span generations. The effect of parental income in the UK is one of the the strongest in OECD countries – it has 1.5 times the impact in Britain compared with Sweden, Germany or Canada.<sup>18</sup> Also important is how quickly socio-economic factors have an effect. Using cohort data, it is possible to predict from tests carried out with 5 year olds (such as the ability to copy shapes) the success of children at age 10 in terms of their reading and maths, and later at age 30 as measured by the highest educational attainment they have managed. Children of families from low socio-economic status with high scores at age 5 did not achieve the same success as those children from higher socio-economic backgrounds with similar test scores. Therefore the effect of family background is starting to override innate skills before children reach their second decade.<sup>8</sup>

Equally clear is that **the UK fares badly when compared with its neighbours**. Overall, 22.6% of the population are in or at risk of poverty or social exclusion, compared with the best performer, the Netherlands with 15.7%. **Most worrying is that 26.9% of children and young people (aged 0–19) are in or at risk of poverty or social exclusion; thus young people are disproportionately disadvantaged.**<sup>3</sup>

As Figure 2.8 (WHO Commission on Social Determinants of Health) identifies, effects of poverty are mitigated through other elements, for example parental education. Thus it is not just poverty that matters, but also how parents interact with their children, such as how they develop their communication skills.

The *NHS Atlas of Variation in Healthcare for Children and Young People 2013* has identified that **there is a six-fold variation in the percentage of children living below the official poverty line and a 74-fold variation in family homelessness across England** (defined as homeless households per thousand households with children).



## Box 2.4 Effects of poverty<sup>1</sup>

**Pregnancy** – Mothers are more likely to be in poor health, have more psychological problems in pregnancy, gain less weight, smoke more and have more genital infections, and their babies to weigh less and be born early, with increased risk of infant mortality.

**Infancy** – Those in the lowest social economic group are nine times more at risk of sudden unexpected death in infancy. Death rates from injury and poisoning have fallen in all groups except this one and are now 13 times higher than those for more privileged children.

**Children** – Poorer children are more likely to be admitted to hospital and to be smaller.

**Mental health** – There is evidence of more attention deficit hyperactivity disorder, bed wetting, suicide and deliberate self-harm among younger children.

## Box 2.5 Poor housing and fuel poverty<sup>52,53</sup>

- 1.4 million children (one in seven) live in bad housing.
- Poor housing increases ill health by 25%, causes three to four times the level of mental health problems and results in more school absence; children are more likely to suffer respiratory disease and there is a soft link with increased mortality.<sup>63</sup>
- Children in overcrowded homes being 10 times more likely to contract meningitis and to have poor growth.<sup>63</sup>
- Homelessness increases the likelihood of hospital admissions and worse access to care.
- Associated with this is fuel poverty, defined as having to spend 10% of net family income to heat the home to adequate levels of warmth (defined by WHO as 21°C for living rooms and 18°C for bedrooms for at least 9 hours per day). Fuel poverty is the effect of three variables: the efficiency of the home, the cost of fuel and income. It is notable that because of how poorer families buy their energy, they often pay higher unit prices than their wealthier neighbours and are less likely to switch their tariffs to find better deals. The impact of fuel poverty is profound:
  - ❑ More than one in four adolescents living in cold homes are at risk of mental health problems.
  - ❑ They are less likely to have a good diet.
  - ❑ Infants show poorer weight gain.
  - ❑ Children and young people have increased hospital admissions.
  - ❑ More are at risk of accidents in the home.
  - ❑ The effects do not just occur in health – cold homes are related to decreased educational attainment, emotional wellbeing and resilience.

## Case study

### Rotherham Warm Homes Healthy People Project – Rotherham Metropolitan Borough Council (MBC)

Some 18.2% of householders in Rotherham live in fuel poverty. The failure to tackle this issue will result in an increased strain and burden on the NHS and social care. Families living in fuel poverty and a cold home are also at increased risk of social isolation, and poor mental health and educational attainment.

Funding was received from the Department of Health's Warm Homes Healthy People (WHHP) Fund in 2012/13 to develop work aiming to reduce death and illness caused by cold housing during the winter and meet the aims of the 2012 Cold Weather Plan. The funding has enabled partner organisations to offer support to the most vulnerable members of the Rotherham community, including older people, families, deprived communities, people living in poor housing stock and those with long-term conditions, including mental ill health. Project outputs include:

- 2,000 warm packs distributed to adults and children across Rotherham with a focus on vulnerable households
- more than 140 households supported by handy person services
- more than £40,000 of extra benefits identified
- energy best deal and energy efficiency training for front-line staff
- energy and health, and Green Deal awareness raising for the public and the local workforce.

**Rotherham MBC Parenting Team** – The Slovakian Roma population is increasing in Rotherham. Historically this group has been difficult to engage with and subsequently offer support to. The WHHP funding has enabled the Parenting Team to offer cooking sessions to 33 families. The Rotherham branch of Jamie Oliver's 'Ministry of Food' was commissioned to run sessions to support the families to create 'winter warmers on a budget'. A translator was required in order to run the sessions, which were held at a local children's centre.

*'The cooking sessions and warm packs have proved to be a great way for my team to engage with families from ethnic populations we have not worked with before. There have been many wider benefits from the cooking sessions that we may not have been able to achieve without the WHHP funding.'*

**GROW, Women Making Informed Choices** – A single mother with two children has previously been involved in a violent domestic relationship which has impacted on her mental health and had detrimental effects on her children. She has struggled to maintain a secure tenancy and has recently moved into private accommodation which is two



bus rides away from her children's schools. She finds it difficult to manage her finances and budget accordingly and has needed additional support with this. Recently she had her benefits suspended due to failure to attend her Jobseeker's Allowance appointment; this was because she had no funds to get to her appointment and now needs to make a new claim. This has left her and her children in an extremely vulnerable situation and resulted in the family being left in crisis. She has no close family or friends that she can turn to for support; her dad, who is the only close relative she has any contact with, has terminal cancer, which adds additional pressure and stress.

On two occasions GROW has provided the woman with funds for fuel as the family were in their home without any fuel supply or means of obtaining any for a number of days. This funding for help in emergencies was secured from Rotherham MBC.

## Case study

### Warm Homes Healthy People Suffolk County Council Adult and Community Services

This project aimed:

- to reduce the impact of fuel poverty and improve energy efficiency of homes so as to maintain health and wellbeing during the winter months; households with young children were a key target group for this intervention
- to reduce the incidence of cold-related illness and improve quality of life and attainment; this relates to Suffolk County Council's Raising the Bar education outcomes strategy.

It identified health and social care professionals in primary care, children's and family centres, social care, community teams and hospital discharge teams and, through direct training and support, enabled them to identify, inform and, with consent, directly refer vulnerable individuals and families whose health, financial or housing circumstances could be improved by this programme.

Vulnerable households received an energy survey and, where appropriate, free supply and installation of insulation, energy-saving products and smoke alarms.

Free emergency boiler repairs were undertaken, with temporary heating supplied until the heating system was repaired. Finance/benefit checks, money management and fuel tariff advice were provided. Fuel payments were made depending on families' housing and health circumstances.

The project demonstrates effective partnership working across tiers of local government, the health sector, and voluntary and social enterprise organisations.

A key innovation was the training and support provided to front-line health and social care providers via the health liaison officers, raising awareness and dramatically

increasing the quantity and appropriateness of referrals across the spectrum of need, particularly in households with young children.

The following are direct quotes from grateful families, via their support worker:

**Family with two boys aged under 5** – *'Nobody ever helps us as my husband works but just on a low income. I'm so pleased I came today even if you had to persuade me. They are going to help put £75 on both the gas and electric meters, which will mean I can have the heating on more and try and dry out our damp flat which should reduce condensation and mould. I hope then that the boys' asthma will improve.'*

**Single mother with three children aged under 6, privately owned property** – *'Oh my God, I can't believe somebody is going to help me financially with my heating costs, it will make all the difference with being able to buy food or just have sandwiches for tea. It was so simple and they might be able to help with my boiler too. They are sending somebody round to check the house to see if they can make it more energy efficient. I still just can't believe it, I feel shaky and like I'm going to cry any minute. Thank you all so much again.'*

**Single mother with four children aged under 10** – *'Thank you so much for yesterday, I can't believe it; that will make such a difference as to what I can do with my boys as opposed to worrying about heating the house and how I can manage to pay for it.'*

**Single mother with two children, one with a severe disability** – *'Whoop, Whoop, just left and they gave me £250 worth of credit on gas and electric. Thank you so, so much. I still can't believe it and it was so simple.'*

**Support worker** – *'Thank you once again for what you offered all our families on the assessment for 'Surviving Winter' day.'*

In summary, as WHO's seminal commission identifies, social determinants are complex interacting factors. It is clear that these determinants have a profound effect on health.

## Risk and protective factors

A complementary approach to thinking about disease causation is that of risk and protective factors. In this approach, disease development depends on the exact interplay of the two types of factors. Thus two children subjected to the same negative risk may not have the same outcome because one may be protected by, for example, a strong attachment to an adult.

There is increasing recognition, including financial modelling, that promoting wellbeing (sense of happiness, lack of worry as perceived by both parent and child) and developing good mental health improves health behaviours and health outcomes throughout life. Wellbeing is strongly linked to the

environment that children grow up in, both directly, i.e. in the family, and in the wider community/local geography. The relationship of factors is increasingly clear, such as screen time (negative to wellbeing), physical activity (positive), healthy eating (positive), having lots of friends (positive) and maternal wellbeing (positive).<sup>54</sup>

In particular, developing good parenting or surrogates for parenting (such as Multisystemic Therapy, Functional Family Therapy or Multidimensional Treatment Foster Care) has a positive effect. Similarly, enhancing school readiness through programmes that focus on preschool provision, enhancing the home learning environment and good primary school education are needed to improve educational attainment for the less well off. The evidence base for supporting mental health in schools is also considered promising. There is weaker evidence for the beneficial effect of nature and green space. This is particularly important because there is evidence that the mental health of children and young people is deteriorating. Key risk factors include parental mental health and parental substance misuse. Other factors which can work as both risk or protective factors are parenting skills, support groups, school support and wider community support.<sup>55</sup>

## Case study

### Resilient practice with families and children – BoingBoing social enterprise, University of Brighton

The dominant paradigm on how to build resilience emphasises resilience as residing solely in individuals, rather than arising from person–environment interactions. This risks resilience-based approaches ignoring system improvement dimensions.

The social enterprise BoingBoing has been jointly established by academics and community collaborators ([www.boingboing.org.uk](http://www.boingboing.org.uk)). A series of Resilient Therapy (RT) research and development projects emerging from the joint enterprise have generated new knowledge about context-specific resilience building in a range of circumstances. What's more, the work has highlighted the importance of working with parents, practitioners and young people themselves to enable this.

Community and academic collaborators have implemented and adapted RT and its Resilience Framework across many practice arenas both nationally and internationally, including adoption, fostering, mental health, learning disabilities, youth offending, and practitioner resilience in social care and health fields.

The RT approaches have been embedded in 10 local authority children's workforce training programmes and 12 university courses, in addition to community sector organisations such as Sussex Central YMCA, local Brighton charity Amaze, national charity YoungMinds and Newport Mind. Internationally, RT has been taken up by children's services in Greece, Italy and Sweden.

**M** – At 14, M turned to self-harming to cope with the tough times she was facing. M first encountered RT when volunteering with a community art group for young people with mental health issues which works collaboratively with the University of Brighton. More and more she started to replace self-harm with art as she occupied herself with her voluntary work and applied the Resilience Framework to her own life. M has worked as part of BoingBoing, collaborating with university academics on several RT projects and, together with other young volunteers, has written RT practice guides and talked about RT to a range of audiences. M is passionate about art and helped write a guide for working with young people with complex needs through community arts practice following a resilience-building project exploring the RT approach in this context.

**T** – T is a young person who participated in the Visual Arts Practice for Resilience study with the University of Brighton: *'It's built my confidence up, like I can travel on the bus without getting nervous. And when I go home I feel all good about myself, I get on better with my family 'cos if I'm doing art and I'm expressing my feelings about things like college and stuff, and then when I go home and see my family, well my foster family, I feel really cuddly and really happy.'*

M and her community group friends also wrote a Mental Health and Resilient Therapy Toolkit using examples of their own experiences. The book helps parents and carers understand how they can support their children using the RT approach when they are facing mental health challenges. She said: *'RT has not only given me new ideas on how to be more resilient in my everyday life, but taught me to acknowledge how resilient I am and have been in the past. Before my involvement in RT I looked at things in a more negative way and didn't fully appreciate the power of the positive steps I was taking. I feel a great sense of purpose and am hopeful that I have drawn something positive from my own negative experiences by helping other people going through similar difficulties by creating resources with Brighton University using RT.'*

At BoingBoing, resilience research is more than just taking part in projects; parents, practitioners, young people and academics have formed a community around the work, allowing knowledge, ideas, skills and development to cross boundaries and challenge traditional hierarchies.

*'I feel good when I get to do stuff that I want to do, like swimming.'*

Resilience is the term used to describe the relative resistance that can be shown by the brain to psychosocial risk experiences.<sup>56</sup> It is one mechanism of encapsulating this risk/protection profile. Put simply, 'it is the capacity to resist or bounce back from adversity'.<sup>56,57</sup> It is the ability to overcome stressful insults or to experience a relatively good outcome despite exposure to situations or insults that create negative effects in others.

As the earlier section on the biological underpinnings notes, the developing brain can benefit from controlled exposure to stress. Thus it is not necessarily true that avoidance of stress is beneficial to healthy brain development. Indeed, Sir Michael Rutter, a leading researcher in this field, has clearly articulated the parallels with immunisation. We seek to protect our children from infectious disease, not only by avoidance or eradication of that disease, but by boosting the individual's reactions to that disease, i.e. inoculation with a low dose of the infectious agent. Thus exposure to a small dose of the harm produces a lifelong ability to respond better to that harm.

Resilience is similar: **exposure to low-level stressors leads to changes in the developing brain that are protective for later life events.** As with immunisation, dose matters and there is an important cumulative effect. A single vaccine, however, does not protect against all infectious diseases; thus children may show resilience to some situations or exposure and not to others. Also important is that acute stressors are generally less deleterious than chronic ones.<sup>56,57</sup>

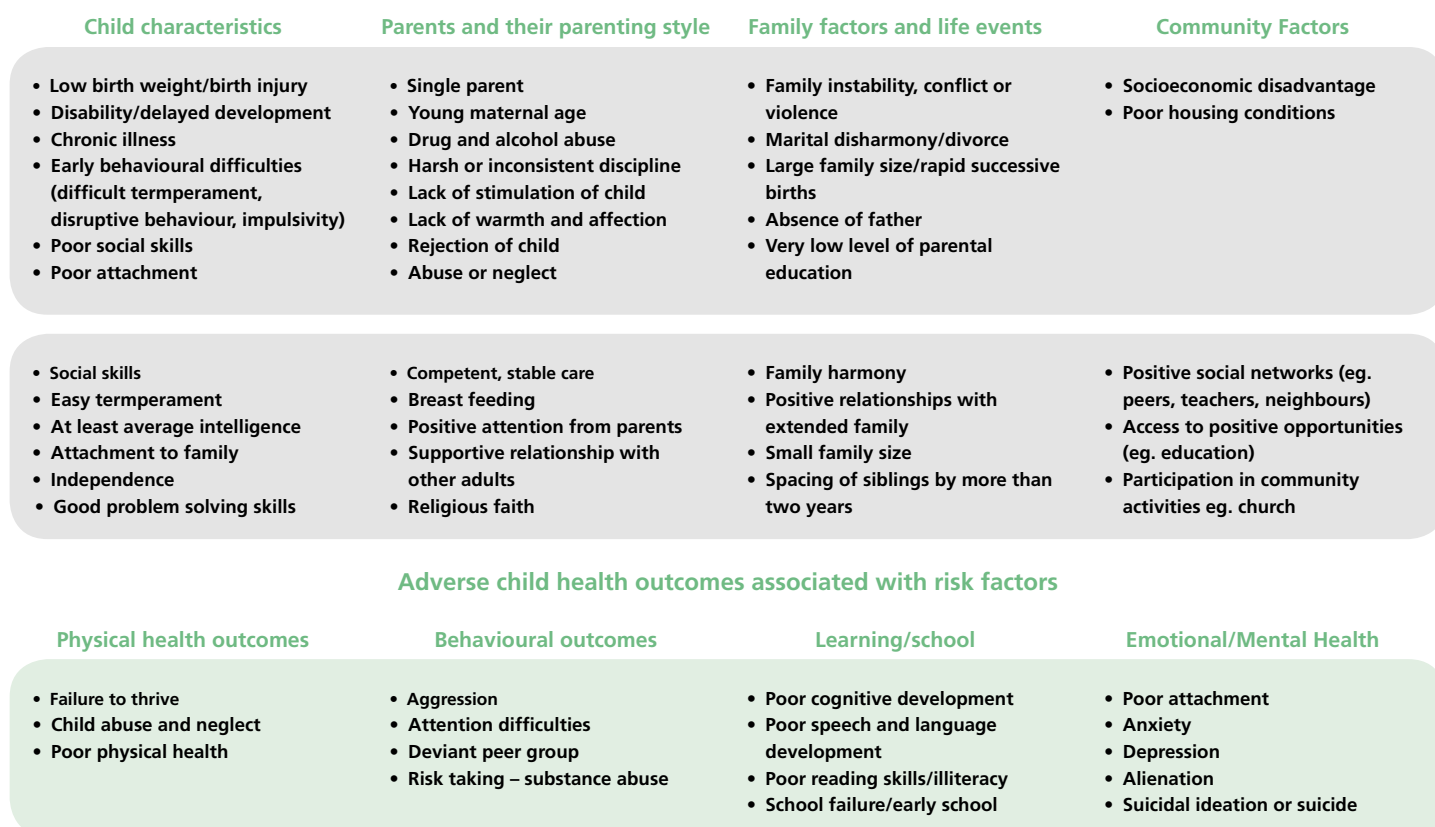
Crucially, as with immunisation, the exact response of children to the stressor varies. Individuals mount immune responses that vary in strength, due to a range of factors. In the case of resilience, factors which influence the response include the presence of other risk and protective factors. Examples of this include the genetic make-up of the child and the local environment, such as family experiences.

Importantly, while positive experiences matter, it seems that they do not have a strong protective effect; rather, they help to balance some of the effect of risk factors. Equally, parental oversight to limit risks is important. An important mitigating factor is that **processing the adverse effect helps to support the development of resilience rather than acute harm.**

Perhaps this concept is best encapsulated in the case of children from troubled homes fostered in an institutional setting. Those most likely to have positive outcomes are the young people who have a good relationship with one parent or positive experiences from school, perhaps because this connection constrains the negative exposure and allows time for the cognitive or emotional processing that helps the young people develop mechanisms to cope with the stressor. These young people have higher social functioning in later life, through increased ability to self-manage, and higher self-esteem. It is interesting to note, though, that there is a saturation effect; if there was a positive experience in the home setting, additional positive school experiences had a limited additional effect.<sup>56</sup>

To conclude, the unique combination of protective and risk factors that a child experiences plays a fundamental role in determining the life chances for that child. Resilience is a concept that encompasses many of the protective factors.

**Figure 2.12 Risk and resilience factors affecting health outcomes**



*Adapted from a table created by Centre for Mental Health*

## Summary

There is a role for health services in addition to the family unit, schools, social services and broader communities. This section explored ways of thinking about the drivers of health: the social determinant approach and that of risk and protective factors. Understanding both approaches allows insight into different approaches to improvement.

## How can policy make a difference?

The evidence presented to date clearly articulates that the life course matters. In particular, events in the early period of life have a profound effect on future health and wellbeing of children and young people. Furthermore, it is clear that the social circumstances into which children are born and grow up, interacting with and through the biological underpinnings, matter. This final section looks at two fundamental responses to these challenges: the prevention approach and that of early intervention, which the following chapters explore in more detail.



**'What don't break you makes you stronger' – This sculpture uses the wardrobe as a metaphor to explore feelings about family, home and identity.**

Source: Kids Company

## Box 2.6 Developing areas for building resilience based on Barnardo's work<sup>57</sup>

In the antenatal period:

- Optimising maternal health through nutrition, avoidance of maternal passive smoking, maternal alcohol consumption and nurturing maternal mental health.
- Social support to mothers from partners, family and external networks.
- Good access to antenatal care.
- Interventions to prevent domestic violence.

During infancy:

- Breastfeeding to at least 3 months.
- Continuous home-based input from health and social care services, lay or professional, for those at risk, e.g. Family Nurse Partnership.
- Social support for mothers with moderate perinatal stress.
- Good-quality housing.
- Parent education.
- Safe play areas and provision of learning materials.
- Support from male partners.

During the preschool period:

- High-quality preschool day care.
- Availability of alternative caregivers.
- Food supplements.
- Links with other parents, local community networks and faith groups.

Effective strategies for middle childhood (ages 5 to 13):

- Creation and maintenance of home-school links for at-risk children and their families, which can promote parental confidence and engagement.
- Positive school experiences: academic, sporting or friendship-related.
- Good and mutually trusting relationships with teachers.
- Provision of breakfast and after-school clubs.
- Development of skills, opportunities for independence and mastery of tasks.
- Structured routines, and a perception by the child that praise and sanctions are being administered fairly.
- In abusive home settings, the opportunity to maintain or develop attachments to the non-abusive parent, other family member or, otherwise, a reliable unrelated adult; maintenance of family routines and rituals.
- Manageable contributions to the household that promote competencies, self-esteem and problem-focused coping.
- In situations of marital discord, attachment to one parent, moderation of parental disharmony and opportunities to play a positive role in the family.
- Help with resolving minor but chronic stresses as well as acute adversities.



Effective strategies for adolescence and early adulthood (ages 13 to 19):

- Participation in a range of extracurricular activities.
- Positive school experiences.
- Strong social support networks.
- The presence of a least one unconditionally supportive parent or parent substitute.
- A committed mentor or other person from outside the family.
- A sense of mastery and a belief that one's own efforts can make a difference.
- The capacity to re-frame adversities so that the beneficial as well as the damaging effects are recognised.
- The ability – or opportunity – to 'make a difference' by helping others or through part-time work.
- Not to be excessively sheltered from challenging situations.

## Approaches to public health

Geoffrey Rose identified the seemingly paradoxical concept that the majority of disease is to be found in low- or medium-risk groups, and that relatively less occurs among those with higher risks. Thus, **to maximise impact, the efforts to prevent disease should be focused on reducing risk across the population – shifting the curve**, not just focusing on the tails, i.e. the outliers. The importance of this approach can sometimes seem counter-intuitive. While many would argue that it is obviously better to target potential teenagers at risk of becoming teenage mothers, the evidence actually suggests otherwise, i.e. the most benefit can be obtained from a universal approach.<sup>58</sup> The same is true for approaches to other lifestyle factors.<sup>59</sup> Recently attempts have begun to address safeguarding using such a population-level approach, rather than just a targeted one.<sup>22</sup>

This demonstrates the importance of taking a population approach. However, we should acknowledge and act on the reality that a targeted approach for those at greatest risk can also deliver benefits. While universal approaches have their challenges, targeted programmes have particular problems, as illustrated by Healthy Start. Despite seven years of effort, a variety of problems such as supply and access issues have meant that less than 10% of those for whom this approach was intended are receiving their supplements.<sup>60</sup>

A further example is the mental health of women in the periods before and after birth. We know that 10% of women will suffer pregnancy-related mental health problems, yet many of these women will previously have been well. Thus supporting mental health is important, but so too is screening for disease or disease risk factors and concentrating efforts on those affected, for example improving the number of midwives who are trained in these areas (73% of services do not have a specialist midwife in mental health) and addressing the shortage of mother and baby units.<sup>61</sup>

Since both targeted and universal approaches have their advantages and disadvantages, using a careful combination

of the two approaches – proportional universalism – is likely to produce the best results of all.

## Box 2.7 Definition of troubled families

- Not in work
- Overcrowded/poor housing
- No qualifications
- Maternal mental health issues
- One parent with longstanding illness/disability
- Low income
- Not able to afford food/clothing.

Outcome of interest: improved-school attendance, decreased criminal behaviour, parents obtain work, decreased cost.

## Early intervention and prevention

The launch of the Early Intervention Foundation saw the coming to fruition of the efforts of many to focus attention on the need to change how we address problems earlier in society. Early intervention identifies that **we have sufficient knowledge in many areas to implement policies further upstream to prevent sequelae**. This is true of any life course stage, but clearly the higher upstream the intervention, potentially the more consequences that can be avoided. Thus much of the focus of early intervention is on the early years.<sup>63</sup> **The case for early intervention is increasingly clear**. Graham Allen's review found 19 interventions for which there was a solid evidence base in the area on which he focused. Our societal challenge is how to fund the intervention when the return on investment will come many years down the line. Before this benefit can be realised, money must continue to be spent on the consequences of previous lack of investment, that is, dealing with the reactive, rather than being ably proactive.<sup>16</sup> **The recent National Audit Office report identified that few areas of government were currently using early intervention.**<sup>64</sup>

Public health approaches tend to use terminology such as primary, secondary and tertiary prevention, where primary prevention is about stopping the disease occurring, secondary prevention is about minimising harm of the disease and tertiary prevention is about mitigating the functional impact. Clearly the concept of early intervention has similarities to that of the prevention approach, but whereas the public health approach tends to focus on the population level, for example screening for diseases, the early intervention approach tends to be more targeted, as with the Family Nurse Partnership.<sup>62</sup>

Outlined in this section are two approaches to improving health: taking a universal approach (at a population level) and targeting high-need groups, and the concept of early intervention (working as close to the root of the problem as possible). Prevention and early intervention, while not mutually exclusive, are relevant for different situations.

### **Box 2.8 The prevalence and long-term impact of speech, language and communication needs – Royal College of Speech and Language Therapists**

- 7% of children age 5 have speech, language and communication needs.
- 88% of long-term unemployed men have speech, language and communication needs.
- 60% of young offenders have speech, language and communication needs.
- Every £1 spent on enhanced speech and language therapy generates £6.43 through increased lifetime earnings.

### **Conclusion**

This chapter has outlined the case for why it is important to focus on children and young people's health. Events in childhood affect the rest of the life course, and there is profound variation in child health and the wider determinants that affect it across England. This means there is significant potential for improvement.

The chapter then used two lenses – social determinants, and risk and protective factors – for looking at why health problems occur, and started to explore the commonality behind the later chapters in the report.

The final section explored how to address these challenges in particular through the approaches of prevention and early intervention. Successful policy needs to select the right approach for the right problem, combining both population-level and targeted approaches.

The next chapter underpins this argument by demonstrating the financial case for focusing on children and young people. It highlights the cost of ill health and how the tools identified in this chapter can help to ameliorate these issues, by addressing the relevant social determinants, boosting protective factors and mitigating risk factors.

### Key messages for policy

- The foundations of lifelong obesity, smoking and other substance misuse, sexual health and mental health are all established in childhood and adolescence. Local and national strategies to address these problems must include age-appropriate interventions for children and young people, not consider them an optional extra.
- Social determinants matter. Recent evidence from studies such as the UK Adverse Childhood Experiences (ACE) study and improved understanding of the biological underpinnings identify that effecting health improvement requires a broad approach.<sup>23</sup>
- Much of the data that underpin evidence around the life course are based on cohort studies such as the Whitehall Study. More recent studies, such as the 1970 Cohort Study and the Millennium Cohort Study, continue to play a crucial role.
- For optimal outcomes, early intervention during phases of rapid brain growth (the early years and adolescence) is increasingly understood to be fundamental.
- Developing resilience is an important adjunct to navigating the life course.
- Population health approaches are crucial to reducing the burden of disease and such an approach should be applied to safeguarding.
- Where population level approaches are already in place, such as the Healthy Child Programme,<sup>76</sup> attention needs to be focused on sustaining this approach through austerity.
- Delivering programmes that benefit the whole population should be used in combination with targeted approaches, for example Healthy Start.
- Interventions must be evidence based and new services should be evaluated.
- Educating those involved in childcare around practices such as healthy eating should be integrated with efforts to improve the quality of education.
- Breastfeeding requires further encouragement, for example through the extension of WHO and UNICEF's Baby Friendly Initiative.<sup>76</sup>
- The community focus needs to be on healthy behaviour improvement as well as exploratory behaviour reduction. Exploratory behaviours should be looked at as groups, rather than individual issues, with special emphasis paid to girls.
- Further work should be carried out on understanding better the relationship between mortality and underlying long-term conditions.

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## Chapter 3

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# The economic case for a shift to prevention

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## Key statistics

- **£4 trillion** – The approximate cost of a range of preventable health and social outcomes faced by children and young people over a 20-year period, according to research by Action for Children and the New Economics Foundation.<sup>8</sup>
- **6–10%** – The annual expected rate of return on investment to be achieved by investing in interventions early in life.<sup>122</sup>
- **6%** – The National Audit Office estimate of current government spending on early action, which it estimates has remained relatively static. The report concludes that ‘a concerted shift away from reactive spending towards early action has the potential to result in better outcomes, reduce public spending over the long term and achieve greater value for money’.<sup>8</sup>
- **4%** – The percentage of health spending in England in 2006/07 on preventive measures according to Health England research.<sup>8</sup>
- **£149,240** – The cost of a year’s placement for a child in a local authority children’s residential home.<sup>123</sup>

Our analysis focuses on the costs of certain health issues that may be preventable to improve outcomes in later life. We look at preterm birth, unintentional injury, child obesity and certain child mental health problems.

- Our analysis estimates the public sector annual costs of preterm birth to age 18 at £1.24 billion and total societal costs at £2.48 billion (including parental costs and lost productivity).
- Based on our analysis, the potential annual long-term cost to society of one major type of injury, severe traumatic brain injury, may be between £640 million and £2.24 billion in healthcare, social care, social security costs and productivity losses.
- Our analysis estimates the long-term costs of child obesity to be £588–686 million.
- Our analysis estimates the annual short-term costs of emotional, conduct and hyperkinetic disorders among children aged 5–15 to be £1.58 billion and the long-term costs to be £2.35 billion.
- A range of strongly evidence-based interventions, already recommended in National Institute for Health and Care Excellence (NICE) guidance, if implemented effectively and at scale could have a dramatic impact, improving children’s lives while saving costs to the system.

## Introduction

If, as a society, we invest adequately in our children and young people's health and development, we will reap the rewards. If energy and resources are focused on interventions that help to avoid or address challenges early in life – that is, implementing an effective preventive agenda – not only will we improve the lives of children and families, but we will also start to save resources quite quickly. Taking steps to prevent problems before they occur or deteriorate, as the Early Action Taskforce has argued, offers a 'triple dividend – thriving lives, costing less, contributing more'.<sup>1</sup>

It is widely understood that preventing debilitating or catastrophic life events has a profoundly positive effect on people's lives: they live better as well as longer. Despite a wealth of evidence, the challenge has been to translate this logic into action. Tackling preventable physical and mental health problems more effectively would reduce healthcare costs, reduce caring costs borne both formally and informally, and have an impact on working lives with important economic effects. Most public investment is spent on dealing with pressing, acute needs. Of course such needs require immediate action, but their call on society's collective attention may go beyond this. The image of a life or limb saved by state-of-the-art surgery is a powerful one; it speaks to the immensity of our scientific progress, the skill of practitioners and the ability to overcome potential tragedy. By contrast, an incident prevented is more abstract; it is the life path altered, the accident avoided, the potential tragedy averted. We know only about the absence of incidents from statistical charts, not from life stories.

At any time there is a responsibility to invest scarce public resources where they will have the greatest effect. In the current climate of fiscal retrenchment and rising need, particularly in the areas of health and social care, this responsibility has become a necessity. An effective social justice agenda cannot be pursued without taking a step change in society's approach to early action and prevention.

Early action may mean preventing or tackling problems early in life, or it may mean catching an emerging problem early enough to minimise potentially damaging effects. The possible benefits of early action exist in many aspects of public services: the falls clinic that prevents a hip fracture; the smoking cessation service that slows the progression of chronic lung disease; the strategies to support employee mental health that enable people to remain in work. In many fields there is room for more preventive work, for considering even small steps 'upstream' in the way services are delivered.

Public health typically talks about three approaches to prevention:

- primary – universal approaches which tackle the causes of ill health
- secondary – early intervention with those identified as at risk

- tertiary – treatment aimed at avoiding the most damaging consequences of a disease or condition.

The case for early action is particularly compelling for children and young people. As analyses of the life course have shown repeatedly, the seeds of the future are sown early in life,<sup>2</sup> and the way they are nourished will have important implications for their future growth in terms of health, education, employment and many other areas.

In this chapter we make two main arguments:

- Spending on the early years of life should, as the Organisation for Economic Co-operation and Development (OECD) has argued, be seen as an investment which will yield returns in future. Giving children the right platform of physical and emotional health, and cognitive, social and linguistic skills from which to thrive will enhance their lives, help to avoid the human and economic costs associated with adverse childhood and adult experiences (See Table 3.1) and provide a skilled, capable adult population to support a future economy. (See for example the case as made by Greater Manchester in the case study below.)
- In many areas of child health, small shifts in focus towards prevention would have a profound impact on children's lives while also saving money. These financial gains are major in the long term, but even in the short term they represent significant health improvements and cashable savings. There is a wide range of evidence-based practice set out, for example in NICE guidance, which if properly implemented would make a real difference.

### Case study

#### Making the economic case for early investment – the Greater Manchester Strategy 2013–2020

The Greater Manchester Economic Strategy takes an explicit life-course approach, connecting early-years investment and outcomes with future economic growth in the conurbation. The strategy states that:

*'40% of children in GM [Greater Manchester] were not 'school ready' when they were assessed towards the end of reception class in 2012. They may well start their school journey on a negative trajectory, with poor social, communication, emotional and behavioural skills meaning they are likely to fall behind from the outset. Without the right support, by the time they are teenagers, these children are more likely to engage in antisocial behaviour, and leave school with poor qualifications, contributing to GM's low levels of economic activity and weak skills base.'*<sup>3</sup>

Building on Total Place pilots and reconfiguration of services, Manchester is committed to providing a combined universal-targeted early-years offer to increase the potential of its population.

**Table 3.1 Could some of these costs be saved? The estimated costs of dealing with a range of health and social problems**

|                                                                           | Costs                                   |
|---------------------------------------------------------------------------|-----------------------------------------|
| <b>Youth unemployment</b>                                                 | £133 million per week <sup>4</sup>      |
| <b>Youth crime</b>                                                        | £1.2 billion per year <sup>4</sup>      |
| <b>Educational underachievement</b>                                       | £22 billion per generation <sup>4</sup> |
| <b>One year in a children's residential home</b>                          | £149,240 <sup>5</sup>                   |
| <b>One year in foster care</b>                                            | £35,152 <sup>5</sup>                    |
| <b>Admission to inpatient child and adolescent mental health services</b> | £24,482 (median) <sup>120</sup>         |

As well as the range of reports published in recent years, we draw in particular on a fresh analysis of four major child health challenges: preterm birth, accidental injury, child obesity, and child and adolescent mental health problems, to highlight the potential benefits of a shift to prevention.

## From Wanless to Allen: the new canon of evidence for prevention

Whether the focus is on setting children up for co-dependent, supportive, contributory adult lives or ensuring that during their childhood they thrive, the potential benefits of early action are clear. We have reached a tipping point in the policy debate about early action in the last few years; a new canon has emerged, drawing together a wealth of evidence and making this case powerfully (see Table 3.2). The growing evidence base alongside this strong discourse, evident in reports such as those of Derek Wanless, Michael Marmot and Graham Allen, is driving new policy and practice development across different sectors.



**Table 3.2 A selection of recent major reports focused on early intervention, early action and prevention, and the costs of intervening later**

| Year | Report                                                                                                                                 | Key messages                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|------|----------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2004 | <i>Securing Good Health for the Whole Population</i> , Derek Wanless                                                                   | Without a greater focus on prevention, the NHS as a publicly funded system as we know it will be unsustainable given the range of pressures over the medium term.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| 2009 | <i>Backing the Future: why investing in children is good for us all</i> , New Economics Foundation/Action for Children                 | Of 16 European countries, the UK has the highest estimated 20-year costs of a range of health and social problems, including: productivity losses from 16–19 year olds not in education, employment, or training (NEETs); NHS costs from obesity; costs of crime to the state and wider economy; welfare and health costs of teenage births; welfare and health costs of substance misuse; costs of mental health problems to the state and wider economy; costs of family breakdown to the state; and NHS costs from dealing with the consequence of violence experienced by children.<br><br>Through a combination of targeted and universal interventions the payback would start to be realised within five years. After 10 years the cumulative return on investment would be £259 billion. |
| 2009 | <i>Public Health and Prevention Expenditure in England</i> , Health England Report No. 4                                               | In 2006/07 the NHS in England spent an estimated £3.78 billion (4% of total NHS health expenditure) on prevention.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 2010 | <i>Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010</i> ,                                     | Comparing the current situation with one in which the whole population had the same health outcomes as the most affluent 10%, the economic consequences of existing health inequalities are estimated to be more than £30 billion in productivity losses and £20–32 billion in lost taxes and higher social security costs. The costs to the NHS of acute illness, mental illness and prescriptions are estimated to be at least £5.5 billion.                                                                                                                                                                                                                                                                                                                                                   |
| 2010 | <i>Grasping the Nettle: Early intervention for children, families and communities</i> , Centre for Excellence in Outcomes for Children | A 'how to' guide for effective early intervention drawing on a wide range of practitioner expertise. Focus is on early childhood, language development, working with parents, more effective services through better commissioning, partnership working and smarter use of data.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 2011 | <i>Early Intervention: The next steps</i> . An Independent Report to Her Majesty's Government, Graham Allen                            | Concentrating on social-emotional development, the cost of inaction is high. Well-evidenced interventions can make a difference. Significantly, the Allen Reports have helped to catalyse action on innovative models of investment in early years.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| 2011 | <i>Early Intervention: Smart investment, massive savings</i> . The Second Independent Report to Her Majesty's Government, Graham Allen |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 2011 | <i>Early Years Interventions to Address Health Inequalities in London – the economic case</i> , Greater London Authority Economics     | Highlighted the mismatch between current patterns of investment and potential returns, with minimal amounts spent in the early years compared with later expenditure. Modelled the cost benefit of a range of early childhood interventions.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 2011 | <i>The Triple Dividend: Thriving lives. Costing less. Contributing more</i> , The Early Action Taskforce                               | Ten-year funding cycles, early action transition plans, better data on current costs and early action champions in government would strengthen delivery of effective early action across government.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| 2013 | <i>Early Action: Landscape review</i> , National Audit Office                                                                          | Estimated that 6% of government spending funds activity which could be called 'early action'. There is a range of remaining barriers to more widespread early action.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |

This agenda crosses party political lines; it is not ideologically driven beyond the view that, through the effective implementation of appropriate evidence, we can achieve better outcomes for people and as a consequence deliver better financial outcomes for HM Treasury and the broader economy. The cross-party support for Graham Allen's work and the new All-Party Parliamentary Group for Conception to Age Two – The First 1001 Days are signs of this consensus.<sup>6</sup>

This consensus extends beyond the political sphere. To mark the NHS at 65, PricewaterhouseCoopers published a report on how the NHS could get itself into a 'healthy state' over the next decade. They concluded that there were six major drivers, the first of which was that 'prevention needs to become a reality'.<sup>7</sup>

Policy makers have talked about prevention for many years. The 2000s saw many initiatives which developed the social and physical infrastructure for early intervention, such as the opening of 3,500 children's centres. More recently, a new wave of innovation has focused on developing tools to tackle financial and other systemic barriers to prevention work. These innovations include Total Place, Community Budgets, the Commissioning for Quality and Innovation (CQUIN) payment framework, Payment by Results and social finance models.

### **Action, inaction and barriers to progress**

Despite this swell of activity, early action is far from becoming mainstreamed. A review by the National Audit Office in 2013 found that over recent years only 6% of government activity could be called 'early action'. The review also highlighted a range of remaining barriers to more widespread early action.<sup>8</sup>

Austerity in national and local government and in the health and care system is frequently portrayed as both a threat to and an opportunity for the prevention agenda. The threat is clear. At a time of rising acute need and falling levels of funding, finding new resources to invest in upstream prevention activities is hard. In fact prevention initiatives may be precisely those which may be at greatest risk of losing their funding. For example, a recent survey suggested that two-thirds of councils had cut their funding for child and adolescent mental health services,<sup>9</sup> and the National Children's Bureau estimated that the children's voluntary sector faces cuts of £405 million by 2016.<sup>10</sup>

The opportunity provided by austerity is less straightforward. The extreme asymmetry of resources and needs means 'business as usual' is not a straightforward option and many policy makers, commissioners and providers are considering radical solutions. However, while resource constraints necessarily catalyse action, a range of barriers still exist to implementing prevention approaches effectively. These barriers have been mentioned frequently in the reports highlighted in Table 3.2 and include:

- the perceived time lag between investment and benefit, which means that any savings are not likely to be realised in any given financial or political cycle
- the reality that investments from one budget, department, institution or commissioner may be required to bring benefits to another, limiting budget holders' willingness to take action
- lack of sufficiently compelling evidence that interventions will lead to promised outcomes, and therefore difficulty in passing a 'business case' test
- lack of incentives for different parts of the system to grapple properly with the challenges of shared goals, let alone pooling or aligning budgets
- absence of sufficient data to understand fully the costs of existing approaches and therefore the real costs of inaction
- lack of resources to invest in up-front prevention while acute need is ongoing
- lack of a workforce that understands the benefits of evidence-based practice, has the tools to implement it, and is sufficiently settled and secure to deliver ambitious change
- the many challenges of disinvestment – it is difficult to stop doing those things which may not be working effectively but are part of the accepted local landscape in order to reinvest
- lack of encouraging examples of prevention delivered at population scale which have successfully reduced demand for 'late intervention' services (see case study below for an example).

### **Case study**

#### **Reducing demand for late intervention at scale – Triple P in South Carolina**

A major trial of a population-based strategy to reduce child harm was published in 2009, showing the benefits of delivering an evidenced-based programme at scale. The Triple P Positive Parenting Program has five tiers, including universal communication and media strategies designed to normalise and de-stigmatise parenting and family support alongside intensive support for families with severely troubled children. The trial targeted 85,000 families with a child aged under 8 in the catchment area and compared outcomes with nine other counties. This involved training a large number of professionals working in family support services, social services, preschool and childcare settings, elementary schools, non-governmental organisations, private sector practitioners, health centres and other community entities having direct contact with parents and families.

The results were equivalent to 688 fewer cases of child maltreatment, 240 fewer out-of-home placements and 60 fewer children with injuries requiring hospitalisation or emergency room treatment in a population of 100,000 children aged under 8.<sup>11</sup>

## A new analysis of the benefits of prevention

Despite the wide recognition of the benefits of a shift to prevention, the barriers outlined above remain. In this chapter we consider four areas of child health on which we have carried out a new analysis of the benefits of prevention. We look at:

- preterm birth
- unintentional injury
- child obesity
- child and adolescent mental illness.

These were chosen because they form a major burden of disease in children and young people and they also offer variety both in the types of health problem they represent and in their place across the child's life course. However, it is worth noting that, while helpful conclusions can be drawn about activity within these specific areas, we also intend for this approach to be indicative, highlighting the benefits of a prevention approach which might be applicable to other areas.

The analysis focuses on both the short and long-term costs associated with these health challenges. Long-term costs matter and should influence decision making, but we know that often they do not, with budgets shaping shorter-term horizons. By including short-term costs our intention is to draw policy makers', commissioners' and providers' attention to the benefits which could be accrued even over a relatively short time span such as an electoral or budget cycle, where the economic as well as the health and social benefits will be seen.

## Method

The analyses comprised five main steps:

- **A review of the published literature**, considering academic studies and governmental and non-governmental reports in the four areas of child health. We identified these through systematic searches of bibliographic databases (PubMed, EconLit) and targeted searches of websites of governmental and non-governmental organisations nationally and internationally, including guidance by NICE.
- **Development of a conceptual framework** for each area under review, building on the identified evidence (see Figures 3.2–3.5). The frameworks show the pathways followed by each child health area, including the points for early intervention along the pathway, alongside potential outcomes and costs.
- **Further refinement of the literature review** guided by the frameworks (see Tables 3.1–3.4).
- **Analysis of evidence** considered eligible for inclusion. We used the conceptual frameworks to drive the search strategy in each area. Papers were considered for inclusion if they reported findings from a high-income country, were in English and, in the case of interventions, reported outcomes quantitatively. Studies were then assessed as to

whether they were high quality, based on a well-defined research question, robust methods and clear findings. An assessment was made about the appropriateness of transferring findings from other countries to the context of England. For example, many of the costs and interventions reported around preterm birth in the USA were difficult to transfer given the differences in healthcare system and specific populations that interventions targeted.

- **Cost calculation** – All costs are given in 2012 current prices (GBP) (see Supporting information tables 3.1–3.4). Public sector costs refer to calculated direct public spending, including health, education, social care and social security costs. Societal costs include estimates associated with lost productivity in adulthood, either through reduced income from employment (both duration and wages) or caring responsibilities, as well as public sector costs.

The availability of data in the different areas of our analysis resulted in differences in the geographies analysed. For preterm birth we look at England and Wales, for unintentional injury, the UK, for child obesity, England and for mental health, Great Britain. The approach we took to considering costs did not address two important factors:

- The implications for individual and family wellbeing. These are difficult to monetise, particularly in a study which does not consider Quality Adjusted Life Years and Disability Adjusted Life Years.
- Mortality: some of the health issues considered have important mortality dimensions. For example, recent statistics show that in 2011 in England and Wales there were:
  - 1,386 infant deaths caused by immaturity-related conditions<sup>12</sup>
  - 205 deaths among children aged 28 days to 15 years from external causes<sup>13</sup>
  - 141 suicides among 15–19 year olds.<sup>14</sup>

Our findings are shown in Table 3.3. The analysis follows, with data tables and details of studies found in the supporting information at the end of this chapter.

**Table 3.3 Estimated annual costs associated with preterm birth, accidental injury, child obesity and certain child mental health problems**

| Condition                           | Costs                      | Definition                                                                                                                            |
|-------------------------------------|----------------------------|---------------------------------------------------------------------------------------------------------------------------------------|
| <b>Overall costs</b>                |                            |                                                                                                                                       |
| <b>Preterm birth</b>                | £1.24 billion              | Additional public sector costs for children aged 0–18                                                                                 |
|                                     | £2.48 billion              | Total additional societal costs                                                                                                       |
| <b>Unintentional Injury</b>         | £15.5–87 million           | Short-term hospital costs of severe unintentional injuries to children                                                                |
|                                     | £640 million–£2.24 billion | Potential long-term societal cost of childhood traumatic brain injury                                                                 |
| <b>Obesity</b>                      | £51 million                | Short-term costs of treating child obesity                                                                                            |
|                                     | £588–686 million           | Long-term health and societal costs                                                                                                   |
| <b>Child mental health problems</b> | £1.58 billion              | Short-term health, social care and education costs of childhood conduct, emotional and hyperkinetic disorders                         |
|                                     | £2.35 billion              | Long-term health, earnings, benefits, education and criminal justice costs of childhood conduct, emotional and hyperkinetic disorders |
| <b>Costs per child</b>              |                            |                                                                                                                                       |
| <b>Preterm birth</b>                | £25,920                    | Additional public sector costs per preterm birth (for children aged 0-18)                                                             |
|                                     | £51,656                    | Additional societal costs per preterm birth (up to 18 years of age)                                                                   |
| <b>Unintentional injury</b>         | £2,494–14,000              | Short-term health costs of treating severe injury                                                                                     |
|                                     | £1.43–4.95 million         | Potential long-term societal costs of a childhood traumatic brain injury                                                              |
| <b>Obesity</b>                      | £35                        | Short-term costs of treating child obesity per obese child                                                                            |
|                                     | £585–683                   | Long-term health costs per obese child growing up to be an obese adult                                                                |
| <b>Child mental health problems</b> | £2,220                     | Short-term health, social care and education costs per child with mental health problems                                              |
|                                     | £3,310                     | Long-term societal costs per child with mental health problems                                                                        |

## Preterm births

A preterm birth is defined as a birth at less than 37 weeks gestation. The consequences of being born preterm can be substantial, and can include a wide range of physical, neurodevelopmental, and behavioural sequelae. In 2010/11, more than 7% of live babies were born at less than 37 weeks gestation in England.<sup>15</sup>

Compared with infants born at term, preterm infants tend to have more health problems, which may include higher rates of temperature instability, respiratory distress, apnoea (cessation of breathing), seizures, jaundice and feeding difficulties.<sup>16</sup> They are also more likely to require readmission to hospital. The degree of prematurity is important, with greater prematurity associated with higher risk of hospitalisation, long periods in neonatal intensive care units or special care baby units, serious long-term complications and mortality. Periods of hospital treatment early in life can in themselves give rise to further health problems. However, even those of moderate and late levels of prematurity (32–36 weeks gestation) are at higher risk of short and long-term poor health outcomes or disability. A number of

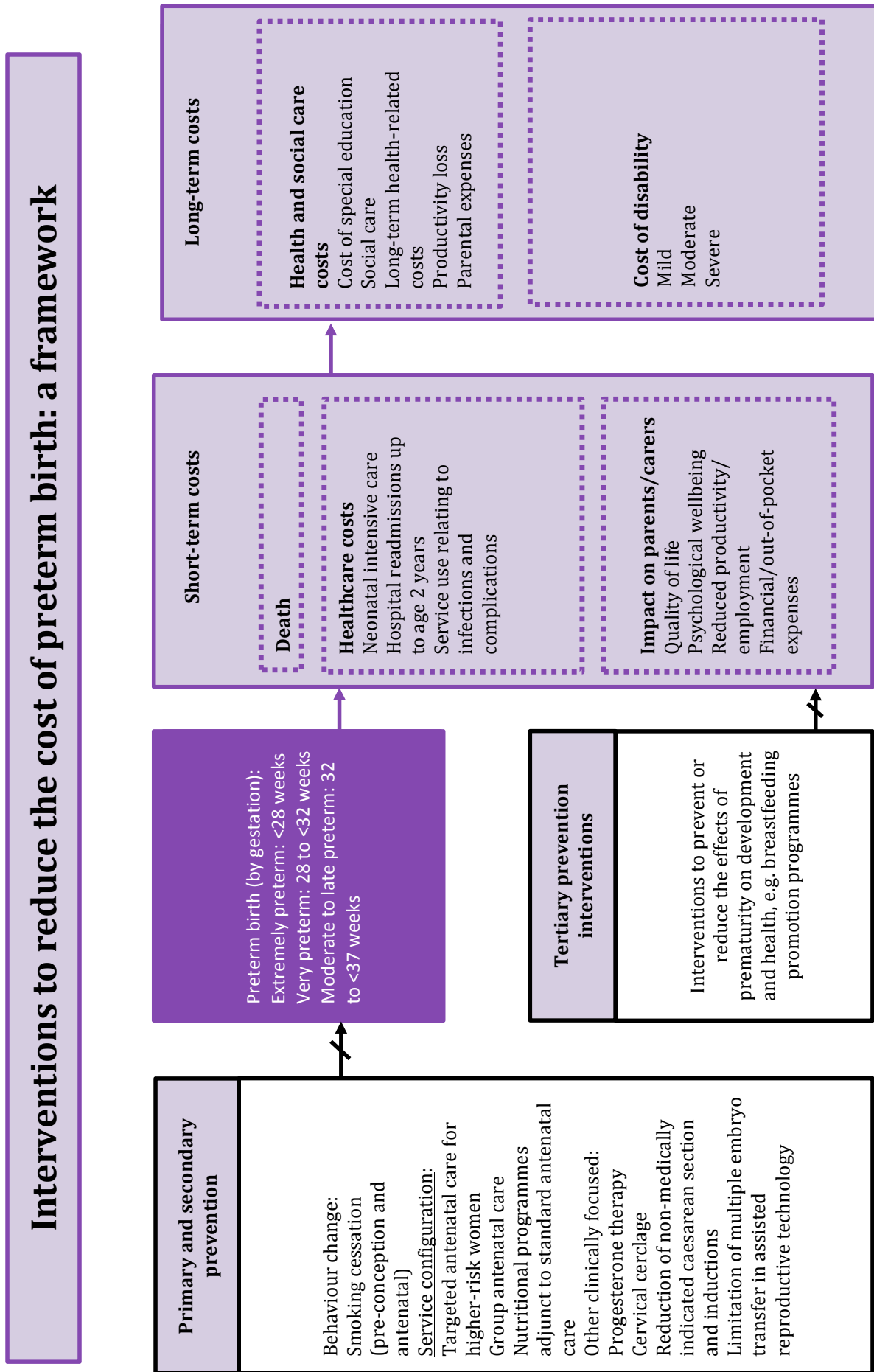
neurodevelopmental and behavioural problems have been associated with being born prematurely, including cerebral palsy, sensory impairments and overall developmental issues, including in areas such as attention, visual processing and academic progress.<sup>16</sup>

Estimates of the proportion of preterm infants who have long-term problems vary. A model used by Mangham et al. predicted that 4.2% of all preterm (i.e. <37 weeks gestation) survivors in England and Wales would have a severe disability at age 18. This rises to 7.9% for those born at less than 28 weeks gestation.<sup>17</sup> Saigal and Doyle reported that 25% of the most premature infant survivors may have substantial neurological morbidity.<sup>16</sup> A study by Platt et al., published in 2007, examined data from 16 European countries and found that the prevalence of cerebral palsy may be decreasing for preterm infants but, in the absence of more recent data, it is unknown whether this trend has continued.<sup>18</sup>

### Costs associated with preterm birth

In the study mentioned above, Mangham et al. estimated the costs of preterm birth throughout childhood in England and Wales. They modelled the various stages that could

Figure 3.1 Preterm birth: a framework for costs and prevention





follow a preterm birth, including death, discharge or admission to neonatal care, which was used as a proxy for neonatal complications. Similarly, for those surviving to age 2, pathways included different stages from no disability to severe disability. The costs were discounted by 3.5% after the first year of life. Using a similar model, Petrou and Khan (2012) estimated the wider societal costs of preterm birth, including health and social care, education, parental expenses and lost productivity.<sup>19</sup> We used these two studies as the principal sources for estimating costs.

Based on Mangham et al.'s study, we estimate the additional public sector cost associated with preterm birth up to age 18 at £1.24 billion.<sup>17</sup> The vast majority of this cost, some £1.22 billion, is accumulated in the early years of childhood, from birth to age 2, with 92% of the cost accrued during the neonatal period (first 28 days of life).

Healthcare costs associated with preterm birth during the first two years of life are largely attributable to initial infant hospitalisation. The mean additional cost for preterm survivors' neonatal period has been estimated at approximately £24,000 per infant compared with an infant born at term. By comparison, the mean additional cost for delivery for a preterm infant compared with a term infant is £360, and £1,000 for the period between discharge and age 2.<sup>17</sup>

The long-term costs (up to age 18) associated with preterm birth include those related to healthcare, but also to social care, education, income and productivity losses incurred by parents and wider society. Together, these can be referred to as societal costs. Petrou and Khan found that in all categories of prematurity, societal costs are higher for preterm infants compared with babies born at term, with the greatest mean cost per preterm survivor among the most premature infants ( $\leq 27$  weeks).<sup>19</sup> Drawing on their study, we estimate the mean societal costs of care for the most premature infants ( $<27$  weeks) at £172,156, which is almost three times that attributable to a child born at term (£58,521) and twice that for a child born between 32 and 36 weeks' gestation (£75,484). Overall, the incremental societal cost per preterm child (gestational age  $<37$  weeks) surviving to age 18 is estimated to be £51,656. Based on these costs, we estimate the total incremental societal costs associated with preterm birth to be £2.48 billion in England and Wales. As this is inclusive of costs beyond public sector costs, it is higher than the estimate above of £1.24 billion for public sector costs. The estimates used to derive the societal and the total public sector costs reported here draw on similar data sources, and the societal costs are likely to be inclusive of public sector costs, although costs are measured in different ways in the two papers.

In considering disability as a specific longer-term outcome of preterm birth, severe disability among preterm children (affecting approximately 4.2% of surviving preterm infants) aged 2 to 18 accounts for around 10% of the total public sector costs of severe disability among children. This equates to approximately £60.5 million per year. Mild disability affects

a larger proportion, 18.5% of surviving preterm infants, and is associated with a total cost of £91.6 million.

## Preventing premature births and improving outcomes for premature babies

Interventions can either target prevention of preterm birth or seek to improve life-long outcomes following preterm birth. Interventions are both clinically and behaviourally focused, including encouraging mothers' smoking cessation and breastfeeding. The most recent high-quality study on interventions to prevent preterm birth in developed countries identified the top five interventions as: smoking cessation, progesterone therapy, cervical cerclage, reduction of non-medically indicated caesarean delivery and induction, and limitation of multiple embryo transfer in assisted reproductive technology.<sup>20</sup> The study estimated that full implementation of all five interventions could lead to a reduction in preterm birth of 2% annually in the UK.

We consider here two important public health interventions: breastfeeding, which can reduce the risk of infection associated with prematurity, and smoking cessation, which can reduce the risk of prematurity. These interventions confer a much broader range of benefits to children and mothers, beyond addressing prematurity or its consequences, though we do not consider these here.

For preterm infants, the benefit of breastfeeding is most often associated with reducing the risk and severity of necrotising enterocolitis (NEC), an infection predominantly affecting preterm infants which can cause sepsis and death.<sup>21</sup> For example, in England, from 2007 to 2009, 27% of preterm infants admitted to neonatal units who were born at  $<28$  weeks gestational age were estimated to have been treated for NEC. Of these, 67% died.<sup>22</sup> A systematic review of breastfeeding promotion interventions in neonatal care units examined the effectiveness of an intervention which involved increasing staff contact to encourage breastfeeding to reduce treatment costs of NEC and sepsis.<sup>23</sup> Based on US data, the review suggested an incremental total cost of about £670 for infants whose mothers did not receive the intervention; this applied to very small infants (500–999 g, which is typical of infants born at  $<28$  weeks gestational age). The intervention group incurred a substantially lower cost (mainly attributable to lowered NEC and sepsis). Costs considered included that of the intervention (at £138 per infant), treatment of NEC and sepsis, length of inpatient stay in level I, II or III neonatal units and lifetime cost of disability.

Smoking cessation during pregnancy has been associated with reducing the risk of preterm birth. A recent systematic review suggested that interventions to reduce smoking by pregnant women could result in approximately 6% fewer women continuing to smoke.<sup>24</sup> Furthermore, among all women receiving a smoking cessation intervention, there could be a reduction of about 15% in preterm birth and low birth weight.<sup>24</sup> (If only high-quality studies were considered, the reduction in preterm births was only 3%.)



In the UK around 26% of mothers smoked in the 12 months before and/or during pregnancy.<sup>25</sup> Using the prevalence rate of preterm birth in England of 7.6%, and an estimated incremental annual cost to the public sector of £26,058 per preterm infant (derived from Mangham et al. (2009)) we estimate potential savings from smoking cessation interventions of up to £3.1 million. The costs of implementing and running this intervention were not available.

There are limited data on the effectiveness of interventions other than breastfeeding or smoking cessation, such as improved nutrition or antenatal care.<sup>26,27</sup> However, it is important to set this lack of evidence against some of the context within which interventions are being implemented. For example, women who are at higher risk of preterm birth are frequently also least likely to receive routine antenatal care. Also, while the overall evidence of effect of, for example, targeted antenatal programmes may not be sufficient, some interventions may be more promising than others. These include group antenatal care, prevention programmes targeting women with clinical risk factors for preterm birth, and nutritional programmes as an adjunct to standard antenatal care.<sup>28</sup>

## Unintentional severe injury in childhood and early adolescence

Injury constitutes a major cause of death and disability for children in England. We focus on the large majority of childhood injuries which are unintentional, defined by NICE as 'predictable and preventable'.<sup>29</sup>

In England, in 2011/12 unintentional injury resulted in approximately 135,000 admissions to hospital among children and adolescents aged 0–14,<sup>30</sup> and about 6,000 children were hospitalised for at least three days because of severe injury (estimates from Hospital Episode Statistics (HES)<sup>31</sup> and Office for National Statistics (ONS)<sup>32</sup>).

The causes of injury are diverse and risks vary with age: the main causes of unintentional injury are road traffic injury (RTI) (pedestrian injury in particular), drowning, poisoning, falls and burns.<sup>33</sup> RTIs increase with age, while burns and scald injury are more prominent among the youngest children.<sup>33</sup> In addition to age, children from deprived backgrounds or living in urban areas, and boys are more likely to suffer injury than children from more affluent backgrounds or living in rural areas, and girls.<sup>34</sup> Severe injuries are associated with a range of health and psychosocial problems in both the short term and long term. These problems include post-traumatic stress,<sup>35</sup> physical disability,<sup>36</sup> cognitive or social impairment,<sup>37</sup> and lower educational attainment and employment prospects.<sup>37</sup> Severe paediatric injury may also place a significant psychological burden on families and carers.<sup>38</sup>

## Costs associated with childhood injury

There have been few estimates of the economic costs associated with unintentional childhood injury. The cost estimates used below are not specific to children, but represent the average cost of injury per case.

The estimates in this section are based on children under 15 years old, due to available data. Extending the analysis to 16–24 year olds would show even greater significance, particularly in relation to RTIs. Estimates have then been multiplied by injury prevalence rates among 0–14 year olds. Prevalence rates for 2012 were derived from HES data<sup>31</sup> and ONS population estimates.<sup>32</sup>

We focus on severe injury only, because the costs associated with this kind of injury are better documented than those for mild and moderate injury. Although definitions may vary across studies, severe injuries are systematically associated with at least one contact with the hospital. We therefore do not include the costs associated with minor or moderate injury treated in primary care, or by general practitioners, physical therapists or pharmacists.

All cost studies are based on British data, with the exception of two studies.<sup>39,40</sup>

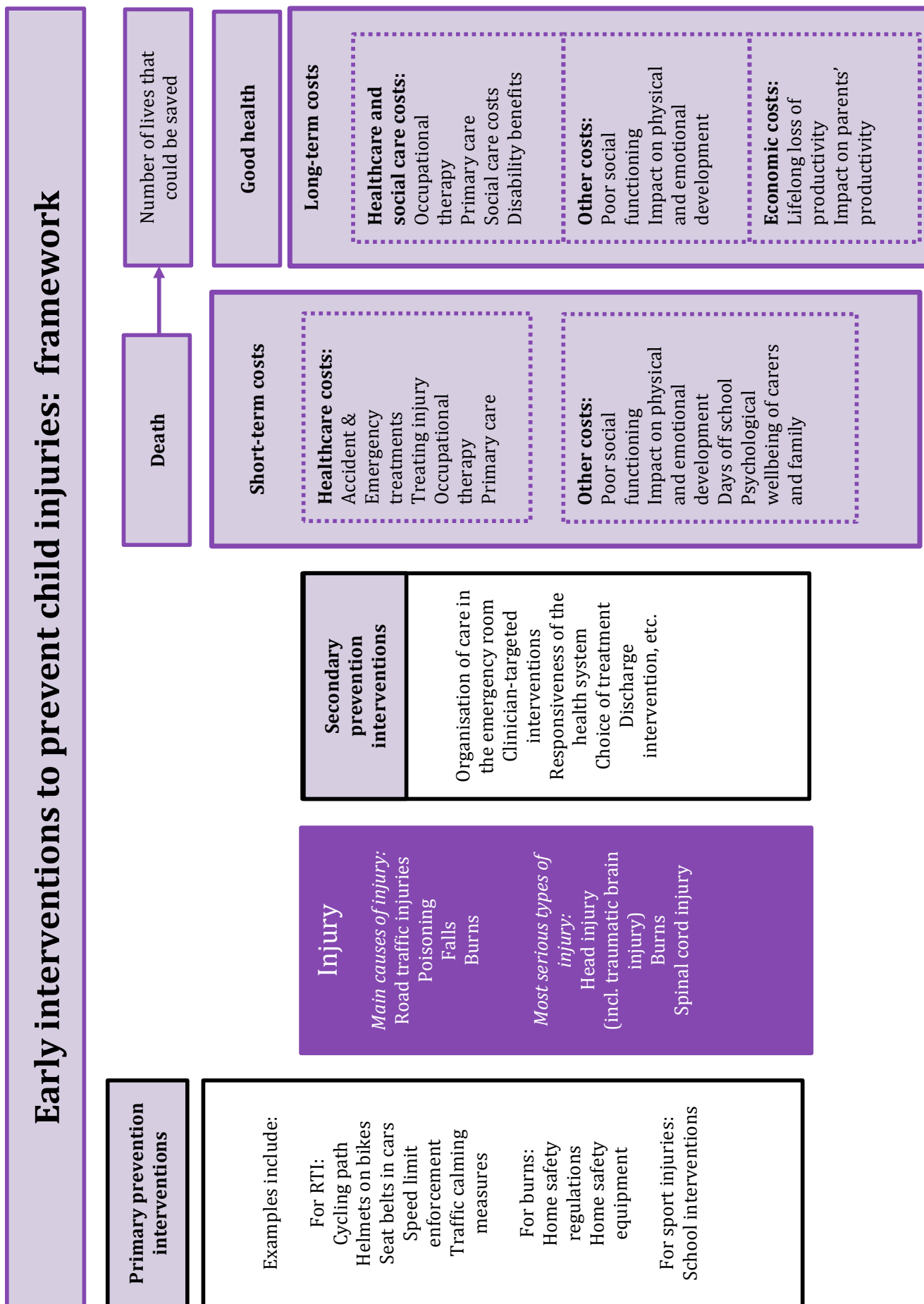
### Short-term cost estimates

The average cost for Accident & Emergency treatments leading to admission is £146 per patient, and £66 for minor injury services leading to an admission. This would correspond to a minimum total Accident & Emergency cost of about £9 million for unintentional child injury per year in England.

In addition, we estimate the total hospital costs for treating severe childhood injuries requiring inpatient stay at between £16 million and £87 million (estimates of average injury cost range from £2,494 per case for an average injury (all types)<sup>41</sup> to £14,000 per case for an RTI injury<sup>42</sup>). RTIs alone were estimated to cost about £31 million in short-term medical costs in 2012.

Short-term healthcare costs incurred by injuries depend on the type and severity. For example, in a small study based in the South West Regional Paediatric Burns Service in Bristol, the average cost of inpatient treatment for a major third degree burn (covering 30–40% of the body), including high dependency unit care, has been estimated at about £65,800.<sup>43</sup> These costs include theatre time, bed time, medications and fluids, dressings, invasive procedures, therapy services and investigations from admission to discharge. In a study evaluating the impact on healthcare cost of mild traumatic brain injury (TBI) in the USA, Rockhill et al. found a 75% increase in mean total healthcare costs compared with a matching cohort of young people and adolescents who were not victims of such an injury.<sup>44</sup>

Figure 3.2 Unintentional injury: a framework for csts and prevention



## Long-term cost estimates

Selected severe injuries are associated with long-term healthcare costs. For example, costs for traumatic brain injury incurred in childhood have been estimated at £268,000 per patient over the lifetime.<sup>45</sup>

Other long-term consequences of sustaining severe injuries in childhood can involve lost productivity and reduced lifetime earnings because of fewer employment opportunities. For example, one Australian study<sup>39</sup> modelled the cost of a severe TBI over a lifetime, and estimated that the costs to society are about £1.43 million per patient, including healthcare costs, social care costs, productivity costs, carer costs, social security costs and lost taxes. Despite the fact that those costs are specific to the Australian system and do not focus on children, they give an indication of the financial burden of severe injury. Similarly, calculations by Wright et al. and adapted by the Child Accident Prevention Trust show that the lifetime cost of a severe paediatric TBI can add up to as much as £4.9 million, including medical costs, educational costs, government benefits and missed employment opportunity. There were about 450 cases of paediatric TBI resulting from unintentional injuries in the UK in 2003.<sup>46</sup> This potentially amounts to total societal costs of £640 million–£2.24 billion. Focusing on a less common type of injury, paediatric spinal cord injury, Anderson and Vogel found, in one study of 195 adults in the USA who sustained a spinal cord injury at age 18 or younger, that they were less likely to be in employment compared with the general population of the same age (at 50% and 80% employment respectively).<sup>47</sup>

## Preventing childhood injuries

Home and road safety are two of the priorities defined by NICE public health guidance to prevent unintentional injuries in childhood.<sup>48,49</sup>

### Road safety

The use of cycling helmets has been associated with a 63–88% reduction in the risk of head, brain and severe brain injury for all ages of cyclists involved in accidents.<sup>50</sup> The facts that only 17.6% of children were wearing helmets in 2008 in Great Britain,<sup>51</sup> and that about 10% of severe TBIs in children aged 0–14 are attributable to cycling injuries,<sup>49</sup> suggest that interventions promoting the use of helmets have the potential to reduce the number of severe TBIs in children.

The introduction of speed cameras has been linked to a reduction in car crashes of between 8% and 49%, and a reduction in RTIs and deaths of between 11% and 44%.<sup>52</sup> Although the review from which these data were drawn was about the impact of speed cameras on injuries in the general population, it is reasonable to assume that children would be likely to benefit from such interventions. These studies did not estimate economic costs.

### Home safety

A systematic review of the impact of home safety interventions found such interventions to be effective in

increasing the proportion of families with home safety equipment.<sup>53</sup> Families who received the interventions were as a result 1.4 times more likely to have safe hot water temperatures and were better equipped against fire (1.8 times more likely to have functional smoke alarms and twice as likely to have a fire escape plan). Participating families also tended to store dangerous products in a safer place (about 1.5 times more likely to store medicines and cleaning products safely) and were 2.7 times more likely to have safer electrical sockets. These interventions have the potential to reduce injuries among children. Little is known about the cost-effectiveness of the various home interventions, and only a few studies conducted an economic evaluation of injury prevention initiatives. Among them, King et al.<sup>40</sup> evaluated the cost-effectiveness of home safety assessments and provision of injury prevention information packs in Canada. The intervention group reported an injury rate 25% lower than the control group. They estimated a cost of £303 per injury prevented (cost of the intervention minus direct healthcare costs). In the UK, Phillips et al.<sup>54</sup> evaluated the cost-effectiveness of introducing bath thermostatic mixer valves in social housing to prevent bath scalds. On the basis of this evaluation they reported that every £1 spent on thermostatic mixers would save £1.41 in healthcare costs.

## Child obesity

Obesity is defined as excess body fat accumulation that may impair health.<sup>55</sup> It is measured by means of body mass index (BMI), an index of weight-for-height ( $\text{kg}/\text{m}^2$ ), with an adult with a BMI greater than or equal to 30 classified as obese. This classification is not easily transferable to children, however, because children's BMI changes as they grow.<sup>56</sup> In the UK, the classification of a child as obese is determined on the basis of a growth chart and defined as a BMI greater than or equal to the 95th percentile for age.<sup>57</sup>

The prevalence of child obesity in England rose steadily until the mid-2000s, with some stabilisation of rates thereafter. In 2011, prevalence among boys aged 2–15 was 16.6%, up from 11.1% in 1995; among girls of the same age obesity prevalence in 2011 was 15.9% (12.2% in 1995).<sup>58</sup> However, although there is an indication, overall, of child and adolescent obesity levelling off, this has varied by population groups, and there is evidence that obesity levels among children and adolescents of low socio-economic status have continued to rise.<sup>59</sup>

Child obesity has been associated with a wide range of health and psychosocial problems in childhood.<sup>60</sup> These include respiratory disorders, high blood pressure, sleep apnoea (interrupted breathing during sleep) and musculoskeletal disorders,<sup>61</sup> with evidence also pointing to an elevated risk of developing type 1 or type 2 diabetes.<sup>63,62</sup> Obese children are also more likely than non-obese children to experience psychological or psychiatric problems, including low self-esteem, depression, conduct disorders, and reduced school performance and social functioning,<sup>63,64,65</sup> and it is plausible that these associations operate in both directions.<sup>64</sup>

A recent analysis of hospital admissions for obesity-related diagnoses among 5–19 year olds in England found these to have more than quadrupled since 2000, from 93 per million children to 414 per million in 2009.<sup>66</sup> The majority of admissions were for conditions where obesity was mentioned as co-morbidity, that is, hospital care was directed at addressing associated conditions rather than obesity itself; the most common reasons for admission included sleep apnoea, asthma and complications of pregnancy.

Child obesity is also linked to poorer health outcomes in adulthood.<sup>67</sup> Thus, between 50% and 75% of those who are obese as children or adolescents are likely to grow into obese adults.<sup>63,68,69</sup> Also, co-morbidities developed in obese children, such as type 2 diabetes, are likely to progress more rapidly and to lead to earlier presentation of adult-life complications such as cardiovascular disease.<sup>61</sup> There is evidence that childhood BMI is associated with type 2 diabetes, hypertension and coronary heart disease in adulthood;<sup>70</sup> however, it remains uncertain whether child obesity increases adult morbidity and mortality independently of adult BMI.<sup>71</sup>

## Costs associated with child obesity

Compared with adult obesity, work that has sought to assess the economic costs associated with child obesity is still emerging.<sup>72</sup> A review of nine recent studies of the economic burden of child obesity in different countries reported that most, but not all, found elevated or excess healthcare costs for obese children.<sup>75</sup> Importantly, studies vary in design and approach to estimating costs and it is therefore difficult to generalise findings across countries.<sup>73</sup>

Analyses presented here build on work undertaken in the UK, specifically the 2011 report by the Greater London Authority (GLA) on child obesity in London.<sup>74</sup> That report drew on an earlier report by the 2004 House of Commons Select Committee on Health.<sup>75</sup> Costs considered by the 2004 report include:

- the direct costs of treating obesity, namely GP consultations, hospital admissions and day cases, outpatient attendance and prescription drugs
- the direct costs of treating the consequences of obesity, using the same range of cost items for a range of diseases and complications that are most often linked to obesity such as type 2 diabetes, hypertension, myocardial infarction, stroke, selected cancers and osteoarthritis, among others
- the indirect costs as a result of loss of earnings attributable to premature mortality, incapacity and sickness.<sup>78</sup>

Neither of the reports produced estimates specific to child obesity; the GLA therefore estimated those by apportioning the costs for adults to children aged 2–15.<sup>74</sup>

Here we use estimates from these reports to estimate the short- and long-term healthcare costs as well as the long-term non-healthcare costs that can be attributed to child obesity in England.<sup>74,75</sup>

## Short-term cost estimates

Based on estimates provided by the GLA,<sup>77</sup> and assuming that one obese child in London will incur the same costs as one obese child in the rest of England (at £34.50 per annum in 2012), and that healthcare costs remain constant over time, we estimate the total current cost of publicly funded treatment of child obesity and its associated consequences in England at £51 million per year.\*

## Long-term cost estimates

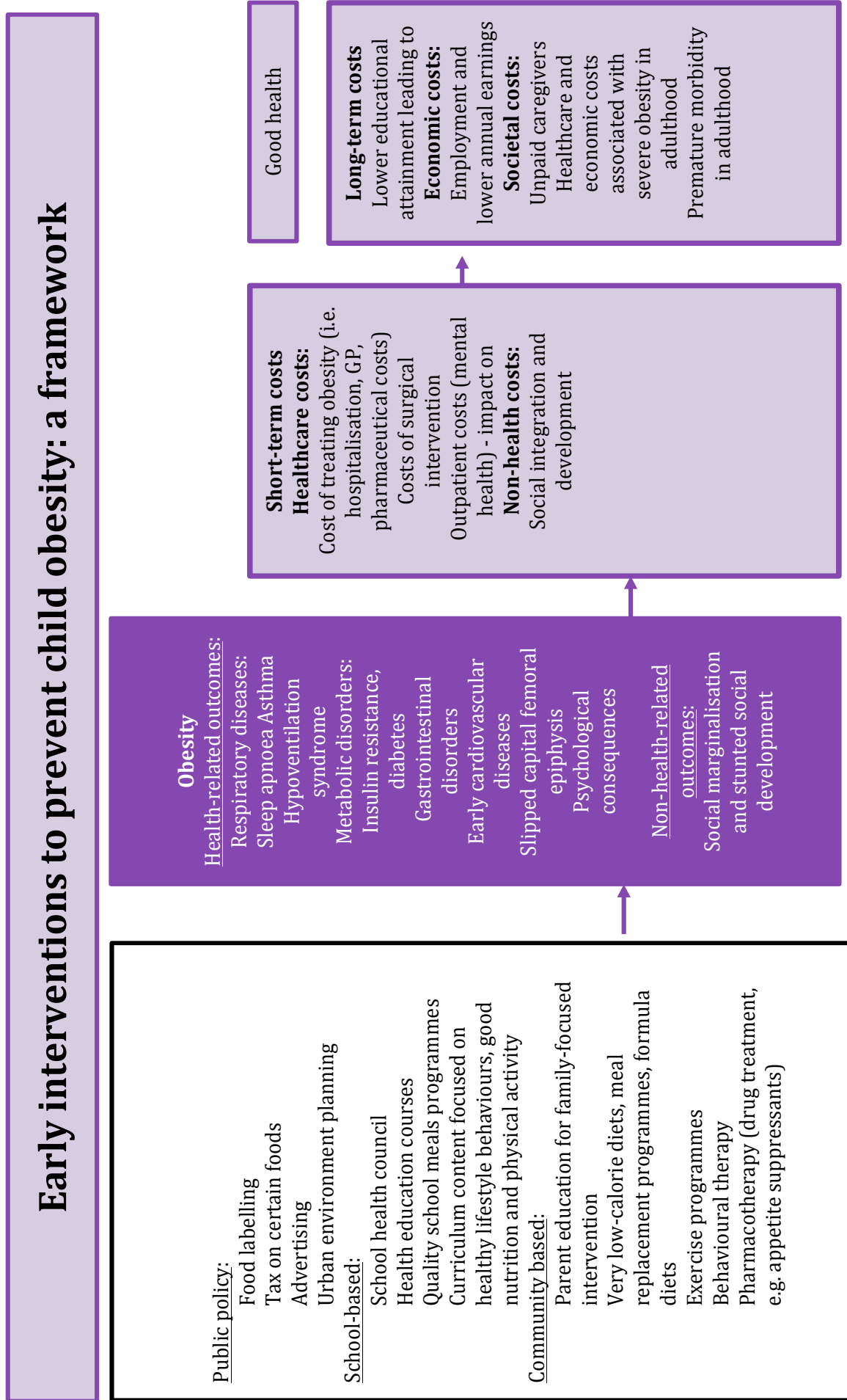
The long-term healthcare costs that can be attributed to child obesity in England are estimated to range between £172 million and £206 million. The lower figure draws on the healthcare costs of treating adult obesity and its associated consequences as estimated by the 2004 House of Commons report,<sup>75</sup> which translates<sup>68</sup> into a cost of £179 per obese adult. The higher figure is derived from the current average medical treatment cost of one obese adult in London estimated by the 2011 GLA report (£205).<sup>74</sup> For both estimates we assume that 68% of the obese child population aged 2–15 in 2012 will grow into obese adults,<sup>71,76</sup> and that treatment costs remain constant over time.

The long-term non-healthcare costs that can be attributed to child obesity in England are estimated to range between £416 million and £480 million. The lower figure draws on the long-term non-healthcare costs for obese adults as estimated by the 2004 House of Commons report,<sup>75</sup> which translates into a cost of £414 per obese child. The higher figure builds on the GLA report, which assumed that the long-term non-healthcare costs of an obese adult constitute about 2.3 times the direct treatment costs, equating to £479 per obese adult. As above, for both estimates we assume that 68% of the obese child population aged 2–15 in 2012 will grow into obese adults.

Our estimates update those derived in earlier analyses of child and adult obesity in England and therefore are subject to the same limitations as described in some detail by the GLA and House of Commons reports.<sup>74,75</sup> Ideally, estimates would have taken account of actual health service utilisation patterns of obese children, differentiating those related directly to treatment of obesity and those related to the consequences of obesity, and data on lost earnings and productivity because of incapacity or sickness absence that can be more directly attributed to child obesity rather than inferred from adult obesity. A recent analysis of current trends of adult obesity in the UK projected the medical costs associated with treating obesity-related diseases to be £648 million annually in 2020, but rising to £1.9–2 billion per year in 2030.<sup>77</sup>

\* It is important to note that these figures might already present an upper range of current healthcare costs of child obesity in England, as underlying estimates draw on direct costs of treating obesity and the consequences of obesity (such as type 2 diabetes) among adults. Alternatively they may underestimate, as they do not reflect the large number of child health problems for which obesity may be an underlying cause.

Figure 3.3 Child obesity: a framework for costs and prevention





## Preventing child obesity and its consequences

Given the multifaceted and complex nature of the causes of obesity that interact at different levels, there is no single best intervention to address child obesity. Programmes to prevent obesity in children are mainly aimed at modifying behaviours related to diet and exercise, and the evidence that is available has identified school-based interventions as being among the most promising approaches.<sup>78,79</sup> Increasing evidence also points to the possible impact of interventions targeting early life, such as *in utero* and infancy, including breastfeeding,<sup>80</sup> although better understanding is still needed about the aetiology of obesity to target intervention efforts more effectively.<sup>81</sup>

We focus here on findings from two recent evidence reviews of the effectiveness of interventions for preventing obesity in children. A systematic review by Waters et al. considered interventions targeting diet and nutrition or exercise and physical activity, and found that programmes were effective at reducing fat levels, although not all individual interventions were effective and studies varied greatly.<sup>79</sup> The best estimate of effect on BMI was of a reduction of 0.15, kg/m<sup>2</sup> and the evidence was strongest for programmes targeted at children aged 6–12. For example, for a preschool child aged 3.7 years with a BMI of 16.3, programme effect would equate to a reduction in average BMI of 1.6%; whereas for a child aged 14 with a BMI of 16.3, the effect would correspond to reducing average BMI by 0.4%. The authors noted that while effect sizes might appear small overall, they would lead to important reductions at population level if sustained over several years. Of interventions considered, those combining dietary and physical exercise components were found to be more effective than isolated programmes.

The authors cautioned that, because of the wide range of interventions considered by studies, it is not possible to distinguish which specific components contributed most to the beneficial effects observed. They identified a range of most promising strategies, typically based in the educational or school setting. The review did consider costs, but the authors were unable, based on available cost data, to assess the level by which interventions were affordable and cost-effective.

The conclusions by Waters et al. were confirmed in a more recent comparative effectiveness review of child obesity prevention programmes.<sup>78</sup> Of a total of 124 included intervention studies, 84% were school based, although frequently with components implemented in other settings such as the community. The review found strong evidence that school-based combined diet and physical activity interventions with a home (e.g. involving parents) or community component prevent obesity or overweight. This conclusion was based on four randomised controlled trials and four non-randomised controlled trials. Evidence was moderate that school-based interventions alone contribute to obesity prevention while the evidence for non-school interventions was insufficient or scarce.<sup>82</sup> There is a lack of high-quality studies that test environment- or policy-based

interventions, such as regulations on food retailing and distribution.<sup>83</sup>

There is evidence of the cost-effectiveness of selected interventions,<sup>72</sup> and a number of studies have projected the potential savings that might be achieved by implementing prevention programmes. For example, Ma and Frick (2011) modelled the costs and possible savings resulting from child obesity interventions.<sup>68</sup> They projected that, in the USA, interventions that result in a 1 percentage point reduction in the prevalence of obesity among children and adolescents aged under 18 could lead to healthcare cost savings of between US\$1.4 billion and \$1.7 billion. The GBP equivalent in 2012 would be £865 million–1.05 billion. They also studied interventions specifically targeted at obese children, finding that those would likely yield higher cost savings than population-based interventions for young children aged 0–6, while population-based interventions would result in higher cost savings for adolescents aged 13–18. This is because obesity in adolescence is more strongly associated than obesity in young children with adult obesity and its lifetime costs.

Also using the US population, Wang et al. estimated that a 1% reduction in overweight and obese adolescents aged 16–17 could reduce the future number of obese adults by more than 50,000.<sup>84</sup> They further estimated that this reduction could be associated with a decrease in the lifetime medical costs after 40 years of about US\$580 million, although the magnitude of savings would vary depending on the assumptions of progression of obesity-related adverse health outcomes. The GBP equivalent in 2012 would be £323 million. While these estimates provide useful pointers for the possible savings that may be accrued from population-based child obesity interventions, studies assume an effectiveness of existing interventions that has yet to be demonstrated. There is a need for strengthened study and evaluation designs, and for better reporting to capture process and implementation factors, longer-term outcomes and potential harms, alongside better understanding and assessment of direct and indirect costs to inform intervention design and implementation.<sup>72,79</sup>

## Mental health: emotional, conduct and hyperkinetic disorders

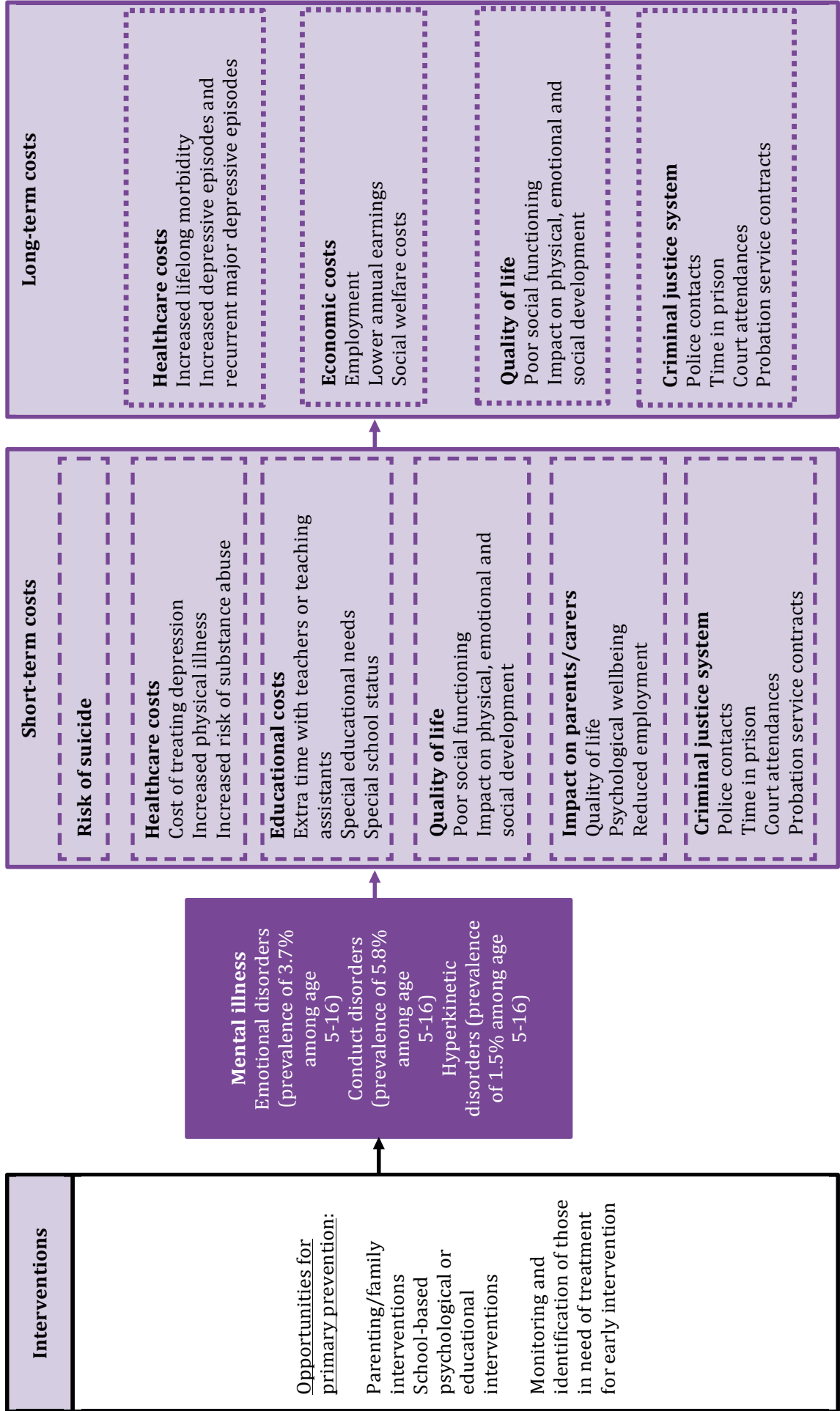
The final area of child health addressed in this study is mental health. The World Health Organization (WHO) defines mental health as 'a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community'.<sup>85</sup> Mental health in childhood and adolescence is the foundation of healthy development, and mental health problems at this life stage can have adverse and long-lasting effects.

The most recent evidence on the prevalence of mental disorders among young people in England is from the 2004



Figure 3.4 Adolescent mental health: a framework for costs and prevention

# Early interventions to prevent adolescent mental illness: a framework



ONS survey of the mental health of children and young people living in private households in Great Britain.<sup>86</sup> This survey reported that in 2004 9.6% of all children aged 5–16 in Great Britain experienced a mental disorder. The report set out the three most common kinds of mental disorders found in children and adolescents aged 5–16: emotional disorders (3.7% of all children in this age group), conduct disorders (5.8%) and hyperkinetic disorders (1.5%). Other less common disorders include autistic spectrum disorders, tic disorders, eating disorders and mutism.<sup>86</sup>

We focus primarily on the three most common types of mental disorders among young people: emotional disorders (e.g. anxiety), conduct disorders and hyperkinetic disorders (e.g. attention deficit hyperactivity disorder). Onset of mental health disorders frequently occurs during childhood and adolescence.<sup>87</sup> In the Dunedin Multidisciplinary Health and Development Study cohort, half of the adults with psychiatric disorder at age 26 had a psychiatric disorder before age 15, and three-quarters by age 18.<sup>88</sup>

## Short-term costs

Our short-term cost estimates are based on estimates derived by Snell et al.<sup>89</sup> This study presents data on health, education and social care service utilisation of children aged 5–15 with psychiatric disorders over three years, and estimated mean annual costs per child. Costs for a comparator group not experiencing mental disorders are not provided. We have modelled based on 2012 population estimates<sup>90</sup> and prevalence data from the 2004 ONS survey.<sup>86</sup>

Mean annual healthcare cost per child is estimated to be £141, which includes primary care costs, paediatric and child health service costs, and mental health service costs. The largest healthcare costs in terms of mean cost per user, according to Snell et al.,<sup>89</sup> are those incurred by speech therapy, psychiatric inpatient services and child psychiatric services. Healthcare costs vary by type of disorder, with hyperkinetic disorders the most costly at £291, followed by conduct disorders at £138 and emotional disorders at £96. Total annual healthcare costs for mental disorder across the England population currently aged 5–16 are calculated at £118 million.

Mean annual education cost per child is £1,733, which includes costs of front-line education and special education. Education costs were largest for children with hyperkinetic disorders, at £2,946, followed by conduct disorders at £1,764 and emotional disorders at £1,133. Total annual education costs for mental disorder across the population of England currently aged 5–16 are calculated at £1,390 million.

Mean annual social care cost per child is £75, but with wide variation between different types of disorder: hyperkinetic disorders £123, conduct disorders £104 and emotional disorders £31. Total annual social care costs for mental disorder across the population in England currently aged 5–16 are calculated at £67 million.

Across the health, education and social care sectors, the total additional short-term cost is £1.58 billion.

Other short-term costs of mental disorder will include costs of the police and youth justice services. However, there is limited cost information available for these.

## Long-term healthcare costs

The Maudsley long-term follow-up of child and adolescent depression estimates the long-term effects of adolescent depression in adulthood, both in terms of healthcare and wider costs.<sup>91</sup> The mean annual costs of health and social care services (in 1996/97 prices), based on service use between the age of 17 and time of interview (average age 35), were £801 per individual (including primary, secondary, mental health care, social workers and day care). This is translated into an annual cost per child of £1,100. If we assume that this cost is the same across all emotional disorders, the total annual cost will be £301 million for the population with emotional disorders who are currently aged 5–16.

Studies suggest that those with a conduct disorder as children are likely to suffer further mental disorders as adults. Colman et al. found that children with severe externalising behaviour (behaviours such as non-compliance, aggression and antisocial behaviour) in adolescence (aged 13–15) have higher odds of depression/anxiety and self-reported history of 'nervous trouble'.<sup>92</sup> Scott et al. applied costs to data which followed 142 children from age 10 to age 28.<sup>93</sup> Data were compared between three groups: children with a conduct disorder, with conduct problems but no disorder, and with no problems at age 10. Total cost of health services per individual with a conduct disorder from age 10 to age 28 (in 1998 prices) was £2,178, compared with £247 among those with no conduct problems. This equates to an annual cost of £145 per individual, or £62 million for the population with conduct disorders who are currently aged 5–16.

## Wider long-term costs

Colman et al. showed that adolescents with severe externalising behaviour were more likely than other adolescents to leave school with no qualifications.<sup>92</sup> In Scott et al.'s analysis, the total costs of education services per individual from age 10 to age 28 (in 1998 prices) were: conduct disorders £12,478, conduct problems £7,524, and no problems £1,508,<sup>93</sup> giving an increased annual cost of £609 per individual with a conduct disorder compared with those with no problems. In 2012 prices, this equates to an annual cost of £820 per individual, or £351 million for the population with conduct disorders who are currently aged 5–16.

In terms of employment, average total social security costs per individual from age 10 to age 28 (in 1998 prices) were £2,832 in those with conduct disorders compared with £1,710 in those with no conduct problems, giving an increased annual cost of £62 per individual with a conduct disorder compared with those with no problems.<sup>93</sup> In 2012 prices, this equates to an annual cost of £84 per individual,

or £36 million for the population with conduct disorders who are currently aged 5–16.

Knapp et al. used British Cohort Study data to look at the relationship between a range of mental health problems at age 10 and outcomes at age 30.<sup>94</sup> Attention deficit problems at age 10 were associated with lower employment rates, worse jobs, lower earnings if employed, and lower expected earnings overall, for both males and females. The differences between the 25th and 90th percentiles in average expected earnings per year were £1,878 for males and £3,183 for females (in 2000 prices).<sup>94</sup> In 2012 prices, if we assume that these costings are applicable across all children with hyperkinetic disorders, this equates to an annual cost of £2,460 for males and £4,170 for females, per individual, or £302 million for the population with hyperkinetic disorders who are currently aged 5–16.

Those who had experienced anxiety problems at age 10 had lower expected earnings than those with no problems. The differences between the 25th and 90th percentiles in average expected earnings per year were £1,304 for males and £1,513 for females (in 2000 prices).<sup>94</sup> If we assume that costs are similar for all emotional disorders, this equates to an annual cost of £1,710 for males and £1,980 for females, per individual, or £508 million for the population with emotional disorders who are currently aged 5–16.

For men who had exhibited antisocial conduct at age 10 there was an unexpected finding. While males with antisocial conduct at age 10 showed a higher probability of being unemployed at age 30, those who were employed at age 30 had higher earnings than those without such behaviour (again after adjusting for other factors).<sup>97,†</sup> When probability of employment and predicted earnings are combined, the annual expected earnings of males at the 95th percentile for the antisocial conduct measure are £1,618 higher (in 2000 prices) than those at the 25th percentile.<sup>94</sup> For females there was no significant difference in annual expected earnings. In 2012 prices, this equates to an annual monetary benefit of £2,120 per individual, or £602 million for the population with conduct disorders who are currently aged 5–16. By contrast, a smaller UK longitudinal study<sup>95</sup> modelled the adult labour market implications of different antisocial developmental pathways. The study followed 411 boys living in South London to age 32. They found that boys (girls were not included in the study) with antisocial behaviour at age 8–10 and who were convicted between age 10 and 16 were less likely to be in employment, and had lower average earnings than boys who were not identified as troublesome at age 8–10 and were without convictions between age 10 and 16. Colman et al. also found that unemployment was higher among those who had had a conduct disorder than others,

but not significantly.<sup>92</sup> This study did not include a costing element.

Scott et al. found that average crime costs (criminal justice system costs only) per individual from age 10 to age 28 (in 1998 prices) were £44,821 for those who suffered from a conduct disorder as a child compared with £2,541 for those with no conduct problems.<sup>93</sup> In 2012 prices, this equates to an annual cost of £3,160 per individual, or £1,360 million for the population with conduct disorders who are currently aged 5–16. McCrone et al. found that costs among those with major depression as adolescents, followed up for an average of 20 years,<sup>91</sup> included a mean annual criminal justice cost of £89 (1996/97 prices), including police contacts, time in prison, court attendances and probation service contracts. In 2012 prices, if we assume that the costs for depression are applicable across all emotional disorders, this is equivalent to £33 million for the population with conduct disorders who are currently aged 5–16.

The total long-term costs across all disorders and conditions studied were £2.3 billion.

## Preventing childhood mental health problems

We consider two interventions that have been shown to be effective in addressing common types of mental disorders among young people.

### Parenting programmes to prevent conduct disorders

NICE guidance recommends the use of evidence-based parenting programmes as a secondary prevention measure for parents of children who have been identified as at high risk of developing oppositional defiant disorder or conduct disorders, or who already have these disorders.<sup>96</sup>

Costs of group parenting programme delivery have been estimated to range between £670 and £4,100.<sup>97,98</sup> Bonin et al. modelled the likely long-term savings to society of implementing an evidence-based parenting programme for the prevention of persistent conduct disorders, estimating that this could result in savings of about £17,500 per family (2012 prices) over 25 years (compared with a cost of £1,016–£2,218).<sup>99</sup>

### Psychological or educational programmes to prevent child and adolescent depression

A recent Cochrane systematic review of psychological or educational prevention programmes for young people aged 5–19 found some evidence of effectiveness of interventions in reducing the risk of having a depressive disorder.<sup>100</sup> The evidence of sustained effect beyond 12 months was weak, and the quality of studies considered in the review varied greatly. The review did not examine the cost of the intervention. On this basis it is difficult to quantify the likely long-term savings that may accrue from implementing universal depression prevention programmes. However, on the basis of the effect at month 12 post-intervention, such programmes for those aged 5–16 with depressive disorders might result in an annual saving of £5 million in short-term health, education and social care costs (multiplying the

† The authors of this study acknowledge that this finding is unexpected and has not been previously reported. However, they report that this finding was robust to a range of exploratory analyses. One suggestion given by the authors is that some characteristics of antisocial individuals may lend themselves to occupations that are well remunerated in early adulthood, for example jobs that involve physical activity, risk taking, or where more aggressive behaviour is rewarded.

reduction in risk by our calculations of the annual short-term cost of depression).

## Discussion

Identifying the costs associated with these major health problems is challenging. The nature of the evidence means that our estimates are indicative. Differences in definitions, limited data on costs, variety in the ages for which there is evidence and the challenges in generalising from one context to another with different health and wider social welfare systems are among the most significant hurdles. Pinpointing the savings from particular interventions is even harder as the data uncertainties are multiplied.

However, this analysis does show the very high costs associated with major childhood health problems, some of which are preventable.

Our estimates were conservative. The analyses are limited by the age groups considered, and the limitations of these typically will underestimate costs. For example, the estimated costs of mental illness include costs only for children up to age 15, long-term costs for preterm birth are only calculated to age 18 and mental health costs to fairly early adulthood. Moreover, we only included the limited number of costs where there have been previous studies.

As each of the four frameworks shows, these are health problems in which many of the causes are in the environment, where the immediate costs lie with the health service but where the long-term costs are picked up right across society. Of course, the biggest cost is for individuals themselves but if we need further evidence to invest in prevention, the economics of these preventable childhood health problems should provoke action.

## Conclusion

England is in an era of change in the way we think about and deliver public services. Since the inception of the Welfare State there has been recognition that we should be achieving better outcomes. However, the response of policy makers has often been to identify holes in provision and fill them. In the current financial climate this is rarely an option. For example, Birmingham City Council is budgeting to cut expenditure by £615 million by 2017.<sup>121</sup>

Whether as a society we can find significant extra resources for children, recognising this as an investment in society's health and wealth over the long term, is a political question.

But how we respond to the current resource challenge is a question for all policy makers and practitioners from the national to the local level, councillors, commissioners and service providers. We have evidence of policies and interventions that make a difference, yet they are not routinely implemented. Many effective interventions are already recommended in NICE guidance and quality

standards, both clinical and public health, and proper implementation at scale could have a dramatic positive impact. The 'what works' centres such as NICE and the Early Intervention Foundation should increase accessibility to the evidence base and help with the translation of that evidence into everyday practice.

Despite the groundswell of voices calling for a greater focus on prevention and early action, including the many reports highlighted earlier in this chapter, a systemic response is not inevitable. It remains easier to slice budgets ever more thinly, tightening thresholds for access, and cutting those services and interventions that some may not notice are missing immediately, but whose absence will create problems further down the line.

The Local Government Association has put forward the following statement in relation to safeguarding children; it also succinctly summarises the broader challenge:

*'The argument that resources should be re-focused on early intervention and prevention, to improve outcomes and reduce demand on safeguarding services in the longer term commands widespread support. However, there is a real challenge to make this a reality against a backdrop of increasing demand on statutory services; less money and reduced local discretion over it; political and budgetary cycles that are shorter than the period in which the benefits of early intervention are realised; costs and benefits falling to different agencies; and incomplete evidence to inform decisions.'*<sup>102</sup>

Rethinking approaches, while meeting acute need at a time of fiscal constraint, is much harder. It requires leadership to have foresight, place trust in the scientific evidence and be brave enough to follow through on delivering different approaches. It requires individuals thinking across professional boundaries at a time when people naturally feel defensive, protecting their corner. How can the system support the leadership and collaboration required to shift the balance more towards prevention?

As the National Audit Office's landscape review on early action stated, short termism is a major barrier to prevention initiatives which take time to take root and for the benefits to be realised. A narrow perspective on financial value is one part of this. As the NAO asserted:

*'there is some evidence that departments have identified some early action investment as areas that could be reduced because of their flexibility compared to acute service spending. While this may be sensible in some cases in current fiscal circumstances, it may also reflect the finding that departments and the Treasury lacked good information to properly compare the value from different resource allocation options and inform spending prioritisation when budget-setting.'*<sup>103</sup>

The Big Lottery Fund's 'Fulfilling Lives: A Better Start' programme investing £165 million over 8–10 years in a small number of areas is an important example of a longer-term



investment. The same funding approach could be hugely valuable, for example, in relation to child and adolescent mental health. The Early Action Taskforce called for 10-year funding commitments and the LGA is calling for fixed-term funding agreements for the life of a Parliament. That such propositions seem radical only demonstrates that we do not currently see spending on children as an investment. Government regularly invests in long-term projects, from the £9 billion on the London 2012 Olympic and Paralympic Games to more than £40 billion for the North–South High Speed Rail project. Another approach is what Little and Sodha refer to as ‘1 per cent for prevention’.<sup>104</sup> They recommend that local authorities making substantial cuts add an extra 1% to their cuts programme but reinvest this amount in prevention activities.

As David Robinson has identified, the world of pooled budgets has existed at the margins of best practice for several years now and its move to the mainstream is overdue.<sup>105,106</sup> What are the levers we could use to make this change happen, to ensure that those allocating public funds move this agenda forward, ensuring that budgets are pooled, objectives aligned and data shared? What contractual mechanisms are available that would allow partners to share the benefits of effective collaboration on prevention? One such mechanism may be for a local area to set major goals that can galvanise actors across multiple sectors. For example, a goal to reduce the number of children referred with safeguarding concerns, young adults in the prison system or children requiring significant psychiatric support would require collective action from health, education, children’s services and criminal justice, and each sector would benefit. Such meaningful shared goals should capture the imagination of local politicians and could also inspire local people. Local areas could ensure collective action by setting these kinds of major long-term goals through health and wellbeing boards; indeed, unless health and wellbeing boards take on these kinds of challenges they are unlikely to gain the kind of buy-in that represents real collaboration.

The quality of data routinely available on children’s health and wellbeing is poor, as the Kennedy Report highlighted.<sup>107</sup> At a local level there is often insufficient system-wide understanding of the health challenges children face. There is rarely sufficient insight into what is spent on preventable health challenges, and therefore uncertainty remains as to the true costs of inaction and the respective level of spending on prevention activities which could inform strategic approaches. Addressing this gap could transform the conversation between health and children’s services leaders, and political decision makers.<sup>108</sup>

For many the concept of evidence-based practice remains relatively new. The translation of evidence into practice requires commitment to a trained, stable workforce able to deliver and committed to doing so.<sup>109</sup> Moving to a system based on evidence-based practice requires cultural change across the spectrum, from political leaders through to those working at the front line; flexibility among those managing finances; and support for ambitious change. New tools, such

as the Dartington Social Research Unit’s Investing in Children project, may transform access to the quality of information required; however, it will require long-term cultural transformation and skills to implement effectively at scale.

The vast majority of public sector service spending is on the acute services end and will remain there. The pipe from which acute need flows cannot simply be turned off, allowing the world to be reconfigured to a place of early intervention with all its benefits. How can prevention approaches inform how acute services are delivered? Could prevention become part of all appropriate pathways, and providers expected to consider what they could contribute? For example, could ‘Think Family’ principles be more widely embedded in children’s and adult services?<sup>110</sup> Could health and social care providers be more attuned to mental health problems, housing and finance difficulties, and drug and alcohol misuse, referring people where appropriate? Can pre-conception health be taken seriously so the health of young men and women before they become parents is on the agenda? Commissioners could use incentives to ensure that evidence-based prevention options are maximised. It is worth considering whether inspectorates could judge services based on answers to the following questions: ‘What steps have you taken to shift towards prevention and how can you evidence it?’, and ‘How have you collaborated with major partners [i.e. children’s services and health] to meet shared goals?’

Reflecting on the findings of the analysis in this chapter and the wider discussion on making steps forward around prevention, early action and early intervention, we set out our conclusions for policy and practice below.



## Key messages for policy

- There should be a strong commitment to implementing NICE guidance in the following areas:
  - Support for breastfeeding (PH11 *Maternal and child nutrition*).
  - Promoting smoking cessation for pregnant women and preconception (PH26 *Quitting smoking in pregnancy and following childbirth*).
  - Developing and implementing accident prevention strategies targeting home safety and road traffic injuries (PH29, 30, 31 on prevention of unintentional injuries in under-15s).
  - Taking steps to tackle the obesogenic environments faced by many children and young people, and in particular using schools as a central place to promote healthy living (e.g. PH8 *Physical activity and the environment*).
  - Providing proportionate universal parenting support that ensures adequate evidence-based provision which does not stigmatise, and school-based approaches to wellbeing (e.g. CG158 *Antisocial behaviour and conduct disorders in children and young people* and NICE briefing on social and emotional wellbeing).
- There is a need for longer-term funding commitments and support for service transformation. Those handing funds down from HM Treasury to local authorities, clinical commissioning groups or third sector organisations should make longer-term commitments to their recipients, enabling them to invest to save.
- The setting of major long-term transformative goals at a local level could drive effective collaboration, realised through pooled or aligned budgets; shared incentives; and public engagement which both involves and enthuses local people and holds public bodies to account.
- Investing in data in a way that gives a comprehensive understanding of local need, a realistic assessment of the costs of ongoing intervention and the potential benefits of preventive action could transform the strategic capability of places.
- A commitment to implementing evidence-based practice would ensure that precious resources are invested in the most effective ways. This requires a nurturing of the conditions on which evidence-based practice thrives: a settled, committed workforce and the creation of learning organisations.
- While the overwhelming allocation of public resources remains in acute spending, prevention needs to be a greater part of most service commissioners' and providers' remit.

Supporting information 3.1 Table of cost derivations – preterm birth (page 1 of 2)

| Cost                                                | Value updated to 2012 prices | Base value/s  | Incidence/prevalence population base                                                       | Unit                                                                                                                                                                                 | Source                                                                                                                                                                                |
|-----------------------------------------------------|------------------------------|---------------|--------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Societal costs</b>                               | £2.4 billion                 | £2.18 billion | 7.6% preterm<br>94.5% survival<br>rate 668,195 live<br>births<br>Cost £51,656 per<br>child | Incremental societal costs for all preterms (<37 weeks) from delivery to age 18                                                                                                      | Petrou and Khan (2012) <sup>19</sup>                                                                                                                                                  |
| <b>Short-term costs</b>                             | £1.22 billion                | £1.07 billion | 7.6% preterm<br>94.5% survival<br>rate 668,195<br>live births Cost<br>£25,372 per child    | Incremental short-term cost of care for all preterms, inclusive of delivery, neonatal and discharge to age 2                                                                         | Mangham et al. (2009) <sup>17</sup><br>NHS Maternity Statistics (2011). <sup>15</sup><br>Assumes survival rate at age 18 is approximately the same as at age 2 (may be underestimate) |
| <b>Long-term costs (up to age 18)</b>               | £1.24 billion                | £1.09 billion | 7.6% preterm<br>94.5% survival<br>rate 668,195<br>live births Cost<br>£25,920 per child    | Incremental long-term cost of care for all preterms (<37 weeks) through childhood to age 18                                                                                          | Mangham et al. (2009) <sup>17</sup><br>NHS Maternity Statistics (2011). <sup>15</sup>                                                                                                 |
| <b>Cost of disability</b>                           | £10,314                      | £9,058        | N/A                                                                                        | Sum of mean costs of mild disability per preterm (<37 weeks) survivor across childhood (costs at 2–4, 5–10 and 11–18 years)                                                          | Mangham et al. (2009) <sup>17</sup>                                                                                                                                                   |
| <b>Health and social care costs – preterm child</b> | £70,916                      | £62,279       | N/A                                                                                        | Mean health and social care costs per surviving preterm child (cost varies by gestational age ≤27, 28–31, 32–36 weeks) compared with child carried to term (≥37 weeks), up to age 18 | Petrou and Khan (2012) <sup>19</sup>                                                                                                                                                  |
| <b>Health and social care costs – term child</b>    | £8,833                       | £7,757        | N/A                                                                                        |                                                                                                                                                                                      |                                                                                                                                                                                       |
| <b>Societal costs – extremely preterm child</b>     | £172,156                     | £151,189      | N/A                                                                                        | Mean societal costs of care over childhood for surviving preterm children (<28 weeks)                                                                                                | Petrou and Khan (2012) <sup>19</sup>                                                                                                                                                  |
| <b>Societal costs – term child</b>                  | £58,521                      | £51,394       | N/A                                                                                        | Mean societal costs of care over childhood for surviving term (≥37 weeks) children                                                                                                   | Petrou and Khan (2012) <sup>19</sup>                                                                                                                                                  |

Supporting information 3.1 Table of cost derivations – preterm birth (page 2 of 2)

| Cost                                                 | Value updated to 2012 prices | Base value/s | Incidence/prevalence population base                                                                                           | Unit                                                                                                                               | Source                                                                               |
|------------------------------------------------------|------------------------------|--------------|--------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| <b>Cost of neonatal period</b>                       | £23,987                      | £21,066      | N/A                                                                                                                            | Incremental cost per preterm (<37 weeks) survivor in neonatal period                                                               | Mangham et al. (2009) <sup>17</sup>                                                  |
| <b>Public sector cost per preterm child</b>          | £26,059                      | £22,885      | N/A                                                                                                                            | Incremental public sector cost per preterm (<37 weeks) survivor up to 18 years                                                     | Mangham et al. (2009) <sup>17</sup>                                                  |
| <b>Cost of severe disability – preterm children*</b> | £61 million                  | £53 million  | 4.2% incidence of disability among preterm survivors at age 2<br>48,035 preterm survivors<br>Cost of severe disability £30,000 | Sum of the mean standard costs of long-term severe disability (£30,001 from age 2–18) preterm (<37 weeks) infant across childhood  | Mangham et al. (2009) <sup>17</sup><br>NHS Maternity Statistics (2011) <sup>15</sup> |
| <b>Cost of severe disability – term children*</b>    | £685 million                 | £60 million  | 3.7% incidence of disability among term survivors at age 2<br>616,811 term survivors                                           | Sum of the mean standard costs of long-term severe disability (£30,001 from age 2–18) for term (≥37 weeks) infant across childhood | Mangham et al. (2009) <sup>17</sup><br>NHS Maternity Statistics (2011) <sup>18</sup> |

\* Assumes those with severe disability remain severely disabled (might be overestimation of costs).

Supporting information 3.2 Table of cost derivations – unintentional injury (page 1 of 2)

| Cost                                                         | Value updated to 2012 prices | Base values      | Incidence (if applicable)                                                                                      | Population base                                                                                                                                                                                         | Unit                                                                                      | Sources                                       |
|--------------------------------------------------------------|------------------------------|------------------|----------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|-----------------------------------------------|
| Average cost for A&E treatments leading to admissions        | £146 per patient             | £146 per patient | N/A                                                                                                            | Number of cases: 135,131 (HES 2012)                                                                                                                                                                     | Average cost for the UK (all types, all ages)                                             | Curtis (2012) <sup>5</sup>                    |
| Average cost for minor injury services leading to admissions | £66 per patient              | £66 per patient  | N/A                                                                                                            | Number of cases: 135,131 (HES 2012 <sup>30</sup> )                                                                                                                                                      | Average cost for the UK (all types, all ages)                                             | Curtis (2012) <sup>5</sup>                    |
| Short-term costs, healthcare, RTI                            | £14,000                      | £13,500          | 0–4 year old: 82.5/100,000 (HES 2011 <sup>31</sup> )<br>5–14 year old: 55.75/100,000 (HES 2011 <sup>31</sup> ) | Population estimates:<br>0–4 year olds: 3,393,400 (ONS 2012 <sup>90</sup> )<br>5–14 year olds: 6,091,500 (ONS 2012 <sup>90</sup> )<br>Total seriously injured (at least three-day hospital stay): 6,196 | Average cost of a serious RTI (all ages)                                                  | Department for Transport (2011) <sup>42</sup> |
| Short-term costs, healthcare, RTI                            | £14,000                      | £13,500          | N/A                                                                                                            | 2,272 seriously injured or killed on the road (Department for Transport (2013). Reported Road Casualties in Great Britain: Main results 2012, London) minus about 40 killed (HES 2010) = 2,232          | Average cost of a serious RTI (all ages)                                                  | Department for Transport (2011) <sup>42</sup> |
| Short-term costs, healthcare                                 | £2,494                       | €2,769           | 0–4 year old: 82.5/100,000 (HES 2011 <sup>31</sup> )<br>5–14 year old: 55.75/100,000 (HES 2011 <sup>31</sup> ) | Population estimates:<br>0–4 year olds: 3,393,400 (ONS 2012 <sup>90</sup> )<br>5–14 year olds: 6,091,500 (ONS 2012 <sup>90</sup> )<br>Total seriously injured (at least three-day hospital stay): 6,196 | Average cost of an injury (all types, all ages)                                           | Polinder et al. (2008) <sup>41</sup>          |
| Cost of a serious burn, short-term, healthcare               | £65,788                      | £63,157          | N/A                                                                                                            | N/A                                                                                                                                                                                                     | Average cost of inpatient treatment for a major burn, including high dependency unit care | Pellatt et al. (2010) <sup>43</sup>           |

Supporting information 3.2 Table of cost derivations – unintentional injury (page 2 of 2)

| Cost                                                                  | Value updated to 2012 prices | Base values       | Incidence (if applicable)                        | Population base                                                            | Unit                                                                                                                                                     | Sources                                                                         |
|-----------------------------------------------------------------------|------------------------------|-------------------|--------------------------------------------------|----------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------|
| <b>Lifetime cost of a paediatric TBI (medical costs)</b>              | £271,805                     | £268,000          | 5.6 (Source: Parslow et al. 2005 <sup>46</sup> ) | 448 (2003; Source: Parslow et al. 2005 <sup>46</sup> )                     | <b>Indication of</b> the lifelong medical cost for a child who suffers a severe TBI at age 3                                                             | Adapted from Wright (2011) by the Child Accident Prevention Trust <sup>45</sup> |
| <b>Lifetime cost of a paediatric TBI (all costs)</b>                  | £4.95 million                | £4.89 million     | 5.6 (Source: Parslow et al. 2005 <sup>46</sup> ) | 448 (2003; Source: Parslow et al. 2005 <sup>46</sup> )                     | <b>Indication of</b> the lifelong medical cost, educational cost, productivity loss, benefits and tax loss for a child who suffers a severe TBI at age 3 | Adapted from Wright (2011) by the Child Accident Prevention Trust <sup>45</sup> |
| <b>Short and long-term costs of TBI healthcare and non-healthcare</b> | £1.43 million                | \$AUS 2.1 million | 5.6 (Source: Parslow et al. 2005 <sup>46</sup> ) | 448 (n=47 for cyclists) (2003; Source: Parslow et al. 2005 <sup>46</sup> ) | Lifetime average cost of TBI (all ages), including all healthcare costs, plus social care costs, productivity loss, carer costs, etc.                    | Access Economics Pty Limited (2009) <sup>39</sup>                               |

A&E Accident & Emergency  
HES Hospital Episode Statistics  
ONS Office for National Statistics  
RTI Road traffic accident  
TBI Traumatic brain injury



Supporting information 3.3 Table of cost derivations – childhood obesity (page 1 of 2)

| Cost                                              | Value updated to 2012 prices* | Base value/s                                                          | Incidence/prevalence                                                         | Population base                                                                                                                                                            | Unit                                                                                                                  | Source                                                                                                                                                                                                                                                                                                                                                                     |
|---------------------------------------------------|-------------------------------|-----------------------------------------------------------------------|------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Short-term healthcare costs</b>                |                               |                                                                       |                                                                              |                                                                                                                                                                            |                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Short-term healthcare cost per obese child</b> | £34.50                        | £31.00 per obese child in London, 2007                                | London: boys 21%, girls: 16% (England: boys 17%, girls 17%) ages 2–15, 2007  | London: 1,236,800 (England: 8,427,900), 2007<br>⇒ London: 229,383 obese children (England: 1,391,618)                                                                      | Current cost of publicly funded treatment of childhood obesity and its associated consequences                        | Cost: GLA (2011) <sup>74</sup>                                                                                                                                                                                                                                                                                                                                             |
| <b>Total short-term healthcare cost</b>           | £50,979,270                   |                                                                       | Boys: 16.6%, girls: 15.9%, ages 2–15, 2011                                   | 9,234,000 (2–15 years, 2012)<br>⇒ 1,477,660 obese children (boys: 761,047; girls: 716,613)                                                                                 | Current cost of publicly funded treatment of childhood obesity and its associated consequences                        | Prevalence: Mandalia (2012) <sup>58</sup><br>Population: ONS**                                                                                                                                                                                                                                                                                                             |
| <b>Long-term healthcare costs</b>                 |                               |                                                                       |                                                                              |                                                                                                                                                                            |                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Long-term healthcare costs (1)</b>             | £171,822,305                  | £135 per obese adult in England, 2002 (£171 per adult in 2012 prices) | Adult obesity: 20% (based on report 'Tackling Obesity in England', NAO 2001) | Total 2002 adult population (age 16+): 39,810,900<br>⇒ 7,962,180 obese adults<br>9,234,000 (ages 2–15, 2012)<br>⇒ 1,477,660 obese children (boys: 761,047; girls: 716,613) | Cost of treating the consequences of obesity per obese adult (total cost 2002: £1,075 million ⇒ £135 per obese adult) | Prevalence and cost: House of Commons (2004) <sup>75</sup> (using 2001 NAO report prevalence data)<br>Population: ONS (2002) <sup>***</sup><br><br>Note:<br>Assumption: 68% of current obese child population aged 2–15 grow into obese adults (1,004,809 obese children in 2012) (Department of Health 2008, <sup>76</sup> Ma and Frick 2011 <sup>68</sup> ) <sup>†</sup> |
| <b>Long-term healthcare costs (2)</b>             | £205,985,804                  | £184 per obese adult in London, 2007 (£205 in 2012 prices)            | Boys 16.6%, girls 15.9%, ages 2–15, 2011                                     | 9,234,000 (ages 2–15, 2012)<br>⇒ 1,477,660 obese children (boys: 761,047; girls: 716,613)                                                                                  | Average medical treatment cost of one obese adult in London                                                           | Cost: GLA (2011) <sup>74</sup><br>Prevalence: Mandalia (2012) <sup>58</sup><br>Population: ONS**<br><br>Note:<br>Assumption: 68% of current obese child population aged 2–15 grow into obese adults (1,004,809 obese children in 2012) (Department of Health 2008, <sup>76</sup> Ma and Frick 2011 <sup>68</sup> ) <sup>†</sup>                                            |

Supporting information 3.3 Table of cost derivations – childhood obesity (page 2 of 2)

| Cost                                      | Value updated to 2012 prices* | Base value/s                                                  | Incidence/prevalence                     | Population base                                                                              | Unit                                                                                                                     | Source                                                                                                                                                                                                                                                                                                                                         |
|-------------------------------------------|-------------------------------|---------------------------------------------------------------|------------------------------------------|----------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Long-term non-healthcare costs</b>     |                               |                                                               |                                          |                                                                                              |                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                |
| <b>Long-term non-healthcare costs (1)</b> | £415,990,926                  | £327 per obese adult in England in 2002 (£414 in 2012 prices) | Boys 16.6%, girls 15.9%, ages 2–15, 2011 | 9,234,000 (ages 2–15, 2012)<br>⇒ 1,477,660 obese children<br>(boys: 761,047; girls: 716,613) | Costs incurred from loss of earnings because of incapacity, sickness and premature mortality as a consequence of obesity | Cost: House of Commons (2004) <sup>75</sup><br>Prevalence: Mandalia (2012) <sup>61</sup><br>Population: ONS**<br><br><i>Note:</i><br>Assumption: 68% of current obese child population aged 2–15 years grow into obese adults (1,004,809 obese children in 2012) (Department of Health 2008 <sup>76</sup> ; Ma and Frick 2011 <sup>68</sup> )† |
| <b>Long-term non-healthcare costs (2)</b> | £480,298,702                  | £429 per obese adult in London (£478 in 2012 prices)          | Boys 16.6%, girls 15.9%, ages 2–15, 2011 | 9,234,000 (ages 2–15, 2012)<br>⇒ 1,477,660 obese children<br>(boys: 761,047; girls: 716,613) | Costs incurred from loss of earnings because of incapacity, sickness and premature mortality as a consequence of obesity | Cost: House of Commons (2004) <sup>75</sup><br>Prevalence: Mandalia (2012)<br>Population: ONS**<br><br><i>Note:</i><br>Assumption: 68% of current obese child population aged 2–15 years grow into obese adults (1,004,809 obese children in 2012) (Department of Health 2008 <sup>76</sup> ; Ma and Frick 2011 <sup>68</sup> )†               |

GLA Greater London Authority  
NAO National Audit Office  
ONS Office for National Statistics

\* Conversion US\$ into £ derived from HM Revenue & Customs. Foreign exchange rates: USA. Unit of currency: US Dollar. [www.hmrc.gov.uk/exrate/usa.htm](http://www.hmrc.gov.uk/exrate/usa.htm) (accessed August 2013).

\*\* Office for National Statistics. Population Estimates for England and Wales, Mid-2012. [www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-310118](http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-310118) (accessed August 2013).

\*\*\* Office for National Statistics. Population Estimates for England and Wales, Mid-2002. [www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-england-and-wales/mid-2002-to-mid-2010-revised-subnational/rft---mid-1971-to-current-year-timeseries-tables-including-revisions.zip](http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-england-and-wales/mid-2002-to-mid-2010-revised-subnational/rft---mid-1971-to-current-year-timeseries-tables-including-revisions.zip) (accessed August 2013).

† Estimates for the persistence of obesity from childhood into adulthood vary by age with the likelihood of an obese child growing into an obese adult increasing as the baseline age rises (Ma and Frick 2011<sup>68</sup>). The Department of Health, in its 2008 report *Healthy Weight, Healthy Lives*,<sup>76</sup> assumes persistence at 55% for 6–9 year olds and 79% for 10–14 year olds. The GLA (2011)<sup>74</sup> used 79% as the upper level in all its calculations but this does not take account of lower persistence levels at younger ages. We weighted the child obesity figures according to the proportion of 6–9 year olds and 10–14 year olds using the 2012 child population in England, so arriving at an average persistence of 68% for the obese child population aged 2–15.

Supporting information 3.4 Table of cost derivations – child mental health (page 1 of 4)

| Mental health condition                       | Population cost updated to 2012 prices (£ millions) | Annual cost in 2012 prices, per child or adolescent/£ (Note 1) | Prevalence age 5–16 (2012) (Note 2) | Population base, age 5–16, males and females unless otherwise indicated (2012) | Unit                                                                                                                                                       | Cost source                       |
|-----------------------------------------------|-----------------------------------------------------|----------------------------------------------------------------|-------------------------------------|--------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| <b>Total short-term costs</b>                 | £1,580                                              | £2,220                                                         | 0.096                               | 7,383,200                                                                      | The cost per child was derived by dividing total population cost by number of children with any mental disorder (prevalence multiplied by population base) | N/A                               |
| <b>Hyperkinetic healthcare cost</b>           | £32.2                                               | £291 (from £269 in 2008 prices)                                | 0.015                               | 7,383,200                                                                      | Healthcare costs, including primary care, paediatric and child health services, mental health services                                                     | Snell et al. (2013) <sup>89</sup> |
| <b>Conduct disorder healthcare cost</b>       | £59.3                                               | £139 (from £128 in 2008 prices)                                | 0.058                               | 7,383,200                                                                      |                                                                                                                                                            |                                   |
| <b>Emotional disorder healthcare cost</b>     | £6.39                                               | £96 (from £89 in 2008 prices)                                  | 0.037                               | 7,383,200                                                                      |                                                                                                                                                            |                                   |
| <b>Hyperkinetic disorder education cost</b>   | £326                                                | £2,950 (from £2,730 in 2008 prices)                            | 0.015                               | 7,383,200                                                                      | Education costs, including front-line education additional resource costs and special education resource costs                                             | Snell et al. (2013) <sup>89</sup> |
| <b>Conduct disorder education cost</b>        | £756                                                | £1,760 (from £1,630 in 2008 prices)                            | 0.058                               | 7,383,200                                                                      |                                                                                                                                                            |                                   |
| <b>Emotional disorder education cost</b>      | £75.3                                               | £1,130 (from £1,050 in 2008 prices)                            | 0.037                               | 7,383,200                                                                      |                                                                                                                                                            |                                   |
| <b>Hyperkinetic disorder social care cost</b> | £13.7                                               | £123 (from £114 in 2008 prices)                                | 0.015                               | 7,383,200                                                                      | Social care service costs                                                                                                                                  | Snell et al. (2013) <sup>89</sup> |
| <b>Conduct disorder social care cost</b>      | £44.6                                               | £104 (from £96 in 2008 prices)                                 | 0.058                               | 7,383,200                                                                      |                                                                                                                                                            |                                   |
| <b>Emotional disorder social care cost</b>    | £2.03                                               | £31 (from £28 in 2008 prices)                                  | 0.037                               | 7,383,200                                                                      |                                                                                                                                                            |                                   |
| <b>Total long-term costs</b>                  | £2,346                                              | £3,310                                                         | 0.096                               | 7,383,200                                                                      | The cost per child was derived by dividing total population cost by number of children with any mental disorder (prevalence multiplied by population base) | N/A                               |

Supporting information 3.4 Table of cost derivations – child mental health (page 2 of 4)

| Mental health condition                      | Population cost updated to 2012 prices (£ millions) |                  | Annual cost in 2012 prices, per child or adolescent/£ (Note 1)               |                                                                              | Prevalence age 5–16 (2012) (Note 2)                                             |                                                                                                                                                                                          | Population base, age 5–16, males and females unless otherwise indicated (2012)                                                                                        |                          | Unit                                                                                       |                           | Cost source |                                                                                                                                                          |
|----------------------------------------------|-----------------------------------------------------|------------------|------------------------------------------------------------------------------|------------------------------------------------------------------------------|---------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------------------------------------------------------------------------|---------------------------|-------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                              | Unable to identify                                  | robust estimates | £2,460 lower annual expected earnings at age 30 (from £1,880 in 2000 prices) | £4,170 lower annual expected earnings at age 30 (from £3,180 in 2000 prices) | £145 per individual with conduct disorder as a child (from £107 in 1998 prices) | £2,120 higher annual expected earnings at age 30 for those scored at the 95th percentile compared with the 25th percentile for antisocial conduct at age 10 (from £1,620 in 2000 prices) | £0 difference in higher annual expected earnings at age 30 for those scored at the 95th percentile compared with the 25th percentile for antisocial conduct at age 10 | £242                     | £60.1                                                                                      | £61.9                     | —£602       | 0                                                                                                                                                        |
| <b>Hyperkinetic disorder long-term costs</b> |                                                     |                  |                                                                              |                                                                              |                                                                                 |                                                                                                                                                                                          |                                                                                                                                                                       | 3,782,000 (males only)   | Crime and Healthcare                                                                       |                           |             | Knapp et al. (2011) <sup>94</sup><br>The study compares those at the 95th percentile and the 25th percentile as scored for severity of attention deficit |
|                                              |                                                     |                  |                                                                              |                                                                              |                                                                                 |                                                                                                                                                                                          |                                                                                                                                                                       | 3,601,100 (females only) | Expected earnings (men)                                                                    | Expected earnings (women) |             |                                                                                                                                                          |
| <b>Conduct disorder long-term costs</b>      |                                                     |                  |                                                                              |                                                                              |                                                                                 |                                                                                                                                                                                          |                                                                                                                                                                       | 7,383,200                | Healthcare costs, including hospital inpatient, psychiatric and abortion/miscarriage costs |                           |             | Scott et al. (2001) <sup>93</sup><br>Compares cost incurred by those diagnosed with conduct disorder vs. those without                                   |
|                                              |                                                     |                  |                                                                              |                                                                              |                                                                                 |                                                                                                                                                                                          |                                                                                                                                                                       | 3,782,000 (males only)   | Expected earnings (men)                                                                    | Expected earnings (women) |             |                                                                                                                                                          |

Supporting information 3.4 Table of cost derivations – child mental health (page 3 of 4)

| Mental health condition                             | Population cost updated to 2012 prices (£ millions) | Annual cost in 2012 prices, per child or adolescent/£ (Note 1)                                              | Prevalence age 5–16 (2012) (Note 2)   | Population base, age 5–16, males and females unless otherwise indicated (2012) | Unit                                                                                                            | Cost source                                                                                                                                                                                                                                                |
|-----------------------------------------------------|-----------------------------------------------------|-------------------------------------------------------------------------------------------------------------|---------------------------------------|--------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Conduct disorder long-term costs (continued)</b> | £351                                                | £820 per individual with conduct disorder as a child vs. no conduct disorder (from £609 in 1998 prices)     | Prevalence among boys and girls 0.058 | 7,383,200                                                                      | Education costs, including remedial health at school, exclusion, social worker costs and adult literacy classes | Scott et al. (2001) <sup>93</sup><br>Compares cost incurred by those diagnosed with conduct disorder vs. those without<br>Scott et al. (2001) <sup>93</sup>                                                                                                |
|                                                     | £35.8                                               | £84 per individual with conduct disorder as a child vs. no conduct disorder (from £62 in 1998 prices)       | Prevalence among boys and girls 0.058 | 7,383,200                                                                      | Benefit costs, including unemployment and single parent benefits                                                |                                                                                                                                                                                                                                                            |
|                                                     | £1,360                                              | £3,160 per individual with conduct disorder as a child vs. no conduct disorder (from £2,349 in 1998 prices) | Prevalence among boys and girls 0.058 | 7,383,200                                                                      | Crime costs, including conviction and prison costs                                                              |                                                                                                                                                                                                                                                            |
| <b>Emotional disorder long-term costs</b>           | £301                                                | £1,100 per individual suffering from depression as a child (from £801 in 1997 prices)                       | Prevalence among boys and girls 0.037 | 7,383,200                                                                      | Healthcare costs, including primary, secondary and social care                                                  | McCrone et al. (2005) <sup>91</sup><br>Assumes long-term costs for other emotional disorders are similar to those for depression                                                                                                                           |
|                                                     | £200                                                | £1,710 per individual suffering from anxiety as a child (from £1,300 in 2000 prices)                        | Prevalence among boys 0.031           | 3,782,000 (males only)                                                         | Expected earnings (men)                                                                                         | Knapp et al. (2011) <sup>94</sup><br>The study compares those at the 95th percentile and the 25th percentile as scored for anxiety problems<br>Calculations assume that costs are similar for all emotional disorders<br>Knapp et al. (2011) <sup>94</sup> |
|                                                     | £307                                                | £1,980 per individual suffering from anxiety as a child (from £1,510 in 2000 prices)                        | Prevalence among girls 0.043          | 3,601,100 (females only)                                                       | Expected earnings (women)                                                                                       |                                                                                                                                                                                                                                                            |



Supporting information 3.4 Table of cost derivations – child mental health (page 4 of 4)

| Mental health condition                               | Population cost updated to 2012 prices (£ millions) | Annual cost in 2012 prices, per child or adolescent/£ (Note 1)                           | Prevalence age 5–16 (2012) (Note 2)   | Population base, age 5–16, males and females unless otherwise indicated (2012) | Unit                   | Cost source                                                                                                   |
|-------------------------------------------------------|-----------------------------------------------------|------------------------------------------------------------------------------------------|---------------------------------------|--------------------------------------------------------------------------------|------------------------|---------------------------------------------------------------------------------------------------------------|
| <b>Emotional disorder long-term costs (continued)</b> | £33.4                                               | £122 per individual diagnosed with major depression as a child (from £89 in 1997 prices) | Prevalence among boys and girls 0.037 | 7,383,200                                                                      | Criminal justice costs | McCrone et al. (2005) <sup>91</sup><br>Calculations assume that costs are similar for all emotional disorders |

Notes:

- (1) Costs are rounded to the nearest £ and to 3 significant figures for larger values.
- (2) 2012 population estimates and prevalence data from the 2004 ONS survey.<sup>86</sup>

Supporting information 3.5 Table of costing studies – preterm birth

| Study                                       | Type of study                                              | Country, year                                    | Data                                                                                                                                                                                                                                        | Costs considered                                                                                                                                                                                                                                                                                                                                           | Summary of cost estimates                                                                                                                                                                                                   |
|---------------------------------------------|------------------------------------------------------------|--------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Petrou and Khan (2012)</b> <sup>19</sup> | Modelling                                                  | UK                                               | Studies derived from literature search covering Jan 1980–Sept 2011                                                                                                                                                                          | <ul style="list-style-type: none"> <li>Costs of initial hospitalisation</li> <li>Costs following initial discharge</li> <li>Societal costs of care over childhood, including health and social care, education, parental expenses, lost productivity</li> </ul>                                                                                            | <p>Mean societal costs per survivor (2006 prices):</p> <ul style="list-style-type: none"> <li>=&lt;27 weeks £151,189</li> <li>28–31 weeks £113,160</li> <li>32–36 weeks, £66,291,</li> <li>=&gt;37 weeks £51,394</li> </ul> |
| <b>Mangham et al. (2009)</b> <sup>17</sup>  | Modelling                                                  | UK                                               | EPIcure study; Department of Health; Schroeder EA, Petrou S, et al. The economic costs of Group B Streptococcus (GBS) disease: prospective cohort study of infants with GBS disease in England. <i>Eur J Health Econ.</i> 2009;10(3):275-85 | <ul style="list-style-type: none"> <li>Childhood costs</li> <li>Costs to the public sector</li> <li>Hospital, community health and social care, education costs</li> <li>Cost of disability states ranging from no disability to severe disability</li> <li>Costs per period of life, type of expenditure, gestational age, level of disability</li> </ul> | <p>Incremental cost per preterm survivor over childhood £22,764 (2006 value) to public sector is £22,855 (2006 value), and over neonatal period is £21,066 (2006 value)</p>                                                 |
| <b>Renfrew et al. (2009)</b> <sup>23</sup>  | Health Technology Assessment/ cost-effectiveness modelling | UK                                               | NHS Reference Costs; other sources derived from literature                                                                                                                                                                                  | <ul style="list-style-type: none"> <li>Cost of breastfeeding intervention</li> <li>Cost of necrotising enterocolitis treatment</li> <li>Cost of long-term disability</li> <li>Cost of formula and donor supplements</li> </ul>                                                                                                                             | <p>Incremental costs ranging from £–328 to £586 for those without intervention depending on birth weight group and formula versus donor supplements</p>                                                                     |
| <b>Chang et al. (2013)</b> <sup>20</sup>    |                                                            | Countries with very high human development index | Global Alliance to Prevent Prematurity and Stillbirth Review Group; Institute of Medicine (US) Committee on Understanding Premature Birth and Assuring Healthy Outcomes                                                                     | <ul style="list-style-type: none"> <li>Cost savings if five high-coverage interventions fully implemented: smoking cessation, reducing multiple embryo transfers during assisted reproductive technologies, cervical cerclage, progesterone supplementation, and reduction of non-medically indicated labour induction or caesarean delivery</li> </ul>    | <p>Approximately 58,000 preterm births averted and total annual economic cost savings of about US\$3 billion (based on 2005 US data)</p>                                                                                    |

Supporting information 3.6 Table of costing studies – unintentional injury

| Study                                                                                        | Type of study                                            | Country, year      | Data                                                                                                                                                                                                                                                           | Costs considered                                                                                                                                                                                                                                                                                                                                                                   | Summary of cost estimates                                                                                |
|----------------------------------------------------------------------------------------------|----------------------------------------------------------|--------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| <b>Curtis (2012)<sup>5</sup></b>                                                             | Cost unit review                                         | UK                 | NHS trusts and primary care trusts combined                                                                                                                                                                                                                    | <ul style="list-style-type: none"> <li>■ Average cost for A&amp;E treatments leading to admissions</li> <li>■ Average cost for minor injury services leading to admissions</li> </ul>                                                                                                                                                                                              | £146 and £66 per patient respectively                                                                    |
| <b>Polinder et al. (2008)<sup>41</sup></b>                                                   | Modelling                                                | Europe (incl. UK)  | Emergency department data systems and hospital discharge register systems                                                                                                                                                                                      | Hospital costs for injury patients (A&E visits, inpatient days in hospital and readmissions)                                                                                                                                                                                                                                                                                       | Average short-term healthcare cost per patient in the UK: €2,769                                         |
| <b>Department for Transport (2011)<sup>42</sup></b>                                          | Modelling                                                | UK (Great Britain) | 2011 prices and values of prevention for accidents and casualties, including the National Transport Survey                                                                                                                                                     | <ul style="list-style-type: none"> <li>■ Ambulance cost</li> <li>■ Short-term healthcare cost</li> </ul>                                                                                                                                                                                                                                                                           | Average short-term healthcare cost of a serious road traffic injury (all ages): £13,500                  |
| <b>Access Economics Pty Limited (2009)<sup>39</sup></b>                                      | Modelling (incidence-based costing approach)             | Australia          | Data from compensation claim (Victoria State) and governmental sources                                                                                                                                                                                         | <ul style="list-style-type: none"> <li>■ Healthcare</li> <li>■ Social care</li> <li>■ Productivity (carer)</li> <li>■ Taxation, revenue forgone and welfare transfers</li> </ul>                                                                                                                                                                                                   | Average lifelong cost of severe traumatic brain injury: \$AUS 2.1 million per case                       |
| <b>Pellatt et al. (2010)<sup>43</sup></b>                                                    | Case study                                               | UK (Bristol)       | Analysis of the cost for three cases                                                                                                                                                                                                                           | Three major paediatric burns of 30–40% total body surface area admitted to Burns Service in Bristol; the acute costs per patient from the initial inpatient stay, from admission to the burns service, to first discharge                                                                                                                                                          | Mean cost per patient of £63,157.22 (range £55,354.79–£74,494.24)                                        |
| <b>Adapted from Wright et al. (2011) by the Child Accident Prevention Trust<sup>45</sup></b> | Scenario development from combination of different cases | UK                 | Adaptation of cost calculated by Wright et al. (2011), <sup>45</sup> based on cost of different healthcare services provided by the NHS Reference Costs 2008–09 (NHS trusts and primary care trusts combined) and other governmental sources for various costs | <ul style="list-style-type: none"> <li>■ Medical costs</li> <li>■ Education</li> <li>■ Direct social care costs</li> <li>■ Missed employment (carer)</li> <li>■ Cost to government in lost tax revenue for mother and child</li> <li>■ Cost to government in benefits (transfer payments including Disability Living Allowance, Carer's Allowance and Child Tax Credit)</li> </ul> | Approximate total lifelong costs: £4.89 million<br>Approximate total lifelong healthcare costs: £268,000 |

Supporting information 3.7 Table of costing studies – childhood obesity (table adapted from John et al.<sup>111</sup>) (page 1 of 2)

| Author/s                                        | Country        | Time frame | Population                                                      | Data sources                                                                                                                                                                                                                                                   | Definition of overweight/obesity                                              | Cost considered                                                                                                                                                                                           | Main findings                                                                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------------------------|----------------|------------|-----------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Breitfelder et al. (2011)</b> <sup>112</sup> | Germany        | 2007       | 3,647 9–<12 years                                               | Birth cohorts of healthy full-term neonates born between 1995 and 1999 in four cities in Germany (German Infant Nutritional Intervention study; Influence of lifestyle factors on the development of the immune system and allergies in East and West Germany) | BMI (measured)                                                                | Direct medical costs: physician visits, (physical) therapies, hospitalisation, inpatient rehabilitation<br>Indirect costs: parental work absence (cost estimated from parental-reported utilisation data) | <ul style="list-style-type: none"> <li>Mean annual direct and indirect costs higher for obese children compared with normal-weight children in all cost categories</li> <li>Total direct medical costs for obese children €680 (443,975) vs. normal-weight children €402 (328,646)</li> <li>Indirect costs for obese children 118 (59,187) vs. normal-weight children 100 (90,110)</li> </ul> |
| <b>Hampel et al. (2007)</b> <sup>113</sup>      | USA Midwest    | 2002/03    | 8,404 5–18 years                                                | Claims data of children presenting at a paediatric integrated delivery system                                                                                                                                                                                  | BMI: measured in clinic 21.9% obese (42.9% had clinical diagnosis of obesity) | Number of visits to primary care, emergency room, inpatient, outpatient primary care, same-day surgery, lab use, observation unit stays                                                                   | Mean healthcare charges for those with diagnosed obesity US\$172 higher than those with normal weight (\$617 (SD 533) vs. \$445 (SD 450)); undiagnosed obesity: \$481 (SD 439; mean difference to normal weight: 39) (2003 prices)                                                                                                                                                            |
| <b>Hering et al. 2009</b> <sup>114</sup>        | Israel         | 2003/04    | 363 obese children matched with 382 control children 4–18 years | Clalit Health Care database                                                                                                                                                                                                                                    | BMI: measured in child care centre                                            | Cost: medication<br>Utilisation: paediatrician primary care, emergency department, medication                                                                                                             | Spend on medication over two years significantly higher among obese children (US\$115,760 vs. \$60,269); utilisation (clinic visits, number and length of hospitalisation) also significantly higher among obese children; e.g. no. of admissions: 67 vs. 34; no. of hospital days: 207 vs. 79                                                                                                |
| <b>Janssen et al. (2009)</b> <sup>115</sup>     | Canada Ontario | 2002/03    | 2,440 12–17 years                                               | 2000/01 Canadian Community Health Survey<br>Cost: Ontario Health Insurance Plan 2002/03                                                                                                                                                                        | BMI (based on self-reported height and weight)                                | Physician costs                                                                                                                                                                                           | Adjusted overall mean physician costs in normal-weight adolescents (US\$233 per year; 95% CI: 194, 264) not different from those for overweight/ obese adolescents (\$233 per year; 95% CI 196, 274)                                                                                                                                                                                          |

Supporting information 3.7 Table of costing studies – childhood obesity (table adapted from John et al.<sup>111</sup>) (page 2 of 2)

| Author/s                                               | Country        | Time frame | Population                                                            | Data sources                                                                            | Definition of overweight/obesity                              | Cost considered                                                                                                                                     | Main findings                                                                                                                                                                                                                                                                                                      |
|--------------------------------------------------------|----------------|------------|-----------------------------------------------------------------------|-----------------------------------------------------------------------------------------|---------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Janicke et al. (2010)</b> <sup>116</sup>            | USA<br>Florida | 2007       | 200<br>7–15 years<br>(recruited from paediatric primary care clinics) | Florida Medicaid claims database                                                        | BMI<br>(measured)                                             | Outpatient and medical/physician use, pharmacy, acute care                                                                                          | Adjusted mean annual expenditure higher among obese children at US\$3,042 compared with \$2,578 among normal-weight children although not uniformly across cost components (outpatient: \$1,813 vs. \$1,176; acute care: \$212 vs. \$132; pharmacy: \$1,017 vs. \$1,270) (Total cost overweight children: \$2,907) |
| <b>Ma and Frick (2011)</b> <sup>68</sup>               | USA            | 2006       | 4,148<br>6–17 years                                                   | National Health and Nutrition Examination Survey Cost: Medical Expenditure Panel Survey | Not stated                                                    | Annual medical expenditure including insurance and out-of-pocket payments                                                                           | Obese children spent US\$264 per capita more than normal-weight children (2006)                                                                                                                                                                                                                                    |
| <b>Trasande &amp; Chatterjee (2009)</b> <sup>117</sup> | USA            | 2002–05    | 19,613<br>6–19 years                                                  | Medical Expenditure Panel Survey                                                        | BMI<br>(based on parental or self-reported height and weight) | Emergency room, outpatient attendance, prescription drugs                                                                                           | Obese children US\$194 higher outpatient visit expenditures, \$114 higher prescription drug expenditures and \$12 higher emergency room expenditures compared with normal/underweight                                                                                                                              |
| <b>Wenig et al. (2011)</b> <sup>118</sup>              | Germany        | 2006       | 14,836<br>3–17                                                        | German Interview and Examination Survey for Children and Adolescents (KiGGS)            | BMI<br>(measured)                                             | Prescription drugs                                                                                                                                  | Mean pharmaceutical costs per year in obese children were 24% higher compared with normal-weight children €211 vs. €170                                                                                                                                                                                            |
| <b>Wenig (2012)</b> <sup>119</sup>                     | Germany        | 2006       | 14,836<br>3–17                                                        | German Interview and Examination Survey for Children and Adolescents (KiGGS)            | BMI<br>(measured)                                             | Physician (GP and specialists outside hospital), allied health services, hospital (cost estimated from parental-reported utilisation data in KiGGS) | Total healthcare cost per child per year did not differ: normal weight €438 (392,492), obese €443 (417,688) (NB overweight but not obese: €540 (417,688)). Cost of physician visits significantly higher for obese children €136 (123,150) compared with normal weight €111 (109,114)                              |

CI Confidence interval  
SD Standard deviation



Supporting information 3.8 Table of costing studies – mental health (page 1 of 2)

| Study                                      | Country, time frame | Data and sample                                                                                       | Age definition                                                                                              | Costs considered                                                                                                                                                                                                                                                                                   | Cost estimate                                                                                                                                                                                                                                                                                                                                                             |
|--------------------------------------------|---------------------|-------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Snell et al. (2013)</b> <sup>89</sup>   | UK, 1999–2002       | Nationally representative sample of 5–15 year olds in Britain, 2,461 children                         | 5–15<br>Assessment of psychiatric disorder using the Development and Well-being Assessment                  | <ul style="list-style-type: none"> <li>■ Primary care</li> <li>■ Paediatric/children's health services</li> <li>■ Mental health services</li> <li>■ Front-line education (extra resources required)</li> <li>■ Special education</li> <li>■ Social care</li> </ul>                                 | <p>Mean annual cost of disorder per child:</p> <ul style="list-style-type: none"> <li>■ Hyperkinetic disorders £3,108.03</li> <li>■ Conduct disorders £1,856.44</li> <li>■ Emotional disorders £1,165.23</li> </ul> <p>Cost for each disorder subdivided further based on service type</p>                                                                                |
| <b>McCrone et al. (2005)</b> <sup>91</sup> | UK, 1970–1998       | Adults who had as children attended the Maudsley Hospital in South London, 149 subjects               | Any children attending the Child and Adolescent Psychiatric Department for depression between 1970 and 1983 | <ul style="list-style-type: none"> <li>■ General hospital</li> <li>■ Psychiatric hospital</li> <li>■ Criminal justice</li> <li>■ Primary healthcare</li> <li>■ Psychiatrist</li> <li>■ Social worker</li> <li>■ Community mental health nurse</li> <li>■ Counsellor</li> <li>■ Day care</li> </ul> | <p>Mean annual cost per user:</p> <ul style="list-style-type: none"> <li>■ General hospital £248</li> <li>■ Psychiatric hospital £343</li> <li>■ Criminal justice £89</li> <li>■ Primary healthcare £56</li> <li>■ Psychiatrist £14</li> <li>■ Social worker £67</li> <li>■ Community mental health nurse £7</li> <li>■ Counsellor £17</li> <li>■ Day care £51</li> </ul> |
| <b>Colman et al. (2009)</b> <sup>92</sup>  | UK, 1946–1999       | Cohort (3,652 subjects) whose behaviour was assessed at ages 13 and 15, (2,297 followed up at age 53) | Teacher rating questionnaire at ages 13 and 15<br>Survey data at ages 36, 43 and 53                         | <p>No costing. Data on the following outcomes:</p> <ul style="list-style-type: none"> <li>■ Mental health in adulthood</li> <li>■ Family life in adulthood</li> <li>■ Employment and educational outcomes in adulthood</li> <li>■ Global life adversity</li> </ul>                                 | N/A                                                                                                                                                                                                                                                                                                                                                                       |

Supporting information 3.8 Table of costing studies – mental health (page 2 of 2)

| Study                                     | Country, time frame | Data and sample                                                                                                            | Age definition                                                                                               | Costs considered                                                                                                                                                                                                                                                | Cost estimate                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-------------------------------------------|---------------------|----------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Scott et al. (2001)</b> <sup>93</sup>  | UK, 1970–1988       | Children age 10 from a disadvantaged London borough (inner London longitudinal survey) followed up at age 28, 142 subjects | Children screened at age 10 using the Rutter Children Behaviour Questionnaire for teachers                   | <ul style="list-style-type: none"> <li>■ Foster and residential care in childhood</li> <li>■ Special educational provision</li> <li>■ State benefits received in adulthood</li> <li>■ Breakdown of a relationship</li> <li>■ Health</li> <li>■ Crime</li> </ul> | <p>Cost of services per individual from age 10 to age 28 (in 1998 prices):</p> <ul style="list-style-type: none"> <li>■ Health services cost: Conduct disorder £2,178, No problems £247</li> <li>■ Education cost: Conduct disorder £12,478, No problems £1,508</li> <li>■ Foster and residential care: Conduct disorder £7,647, No problems £1,320</li> <li>■ Relationships: Conduct disorder £63, No problems £97</li> <li>■ Benefits: Conduct disorder £2,832, No problems £1,710</li> <li>■ Crime: Conduct disorder £44,821, No problems £2,541</li> </ul> <p>Total cost, including healthcare: Conduct disorder £70,019, No problems £7,423</p>               |
| <b>Knapp et al. (2011)</b> <sup>94</sup>  | UK, 1970–2000       | Children from the British Cohort study, 11,261 subjects                                                                    | Children were retrospectively assessed at age 10 for antisocial conduct, attention deficit problems, anxiety | Unemployment and earnings at age 30                                                                                                                                                                                                                             | <p>Conduct disorder:</p> <p>Annual expected earnings of males at the 95th percentile for the antisocial conduct measure are £1,617.50 higher (in 2000 prices) than those at the 25th percentile. For females there was no significant difference in annual expected earnings.</p> <p>Attention deficit:</p> <p>The differences between the 25th and 90th percentiles in average expected earnings per year were —£1,878 for males and —£3,183 for females (in 2000 prices)</p> <p>Anxiety:</p> <p>The differences between the 25th and 90th percentiles in average expected earnings per year were —£1,304 for males and —£1,513 for females (in 2000 prices).</p> |
| <b>Healey et al. (2004)</b> <sup>95</sup> | UK, 1961–86         | UK Cambridge Study in Delinquent Development) of 411 boys living in South London                                           | Interviews of cohort members at age 30 obtained occupational and earnings data                               | <p>No costing. Data on:</p> <ul style="list-style-type: none"> <li>■ Extended unemployment</li> <li>■ Employment in manual/unskilled jobs</li> <li>■ Earnings at age 32</li> </ul>                                                                              | N/A                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |

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## Chapter 4

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# The voices of children and young people

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*'We're the next generation: if we're supported to do well and we become healthy adults physically and emotionally, we can do good and look after the future generations.'* – 19-year-old female from the YoungMinds focus group

## Overview

The aim of this chapter is to gather the voices of children and young people and to incorporate their views into the recommendations for this report. We start by understanding why the opinions of children and young people are so important to include in the development and implementation of health and social care policy. After a discussion of the methods used to gather their voices, we explore what children and young people have said about health, healthcare and wellbeing, including their views on specific themes that have arisen in other chapters of this report. We then examine particular areas of concern voiced by the four populations of children that this report focuses on: children with neurodisability, mental health problems, looked-after children, and those within the youth justice system. We also consider the views of representative parents. All the evidence from this chapter is ultimately brought together in the conclusion to produce a Children and Young People's Manifesto for Health and Wellbeing; and by doing so, we propose the children and young people's recommendations for this report.

### The participation of children and young people in health policy

Patients working in partnership with clinicians and carers in decisions about their healthcare is one of the guiding principles set out in the NHS Constitution<sup>1</sup> (see Box 4.1). There is also an expectation that patients, service users and the public participate nationally and locally in the development, implementation and accountability processes of health and social care policy and services. The Health and Social Care Act 2012<sup>2</sup> set duties for the NHS Commissioning Board, clinical commissioning groups, Monitor, and health and wellbeing boards with regard to involvement of patients, carers and the public. Commissioning groups have to consult the public on their annual commissioning plans and involve them in changes that affect patient services. The Act also established Healthwatch England as a national body representing the views of users of health and social care services, other members of the public and local Healthwatch organisations. It advises and provides information to the Secretary of State, NHS England, Monitor, English local authorities and the Care Quality Commission on the views of users of health and social care services and their experience of such services. In addition, local Healthwatch organisations, based in and funded by local authorities, help to ensure that the views and feedback from

patients and carers are an integral part of local commissioning across health and social care.

#### Box 4.1 The NHS Constitution for England, 26 March 2013

The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be co-ordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services.

This expectation for patient and public participation has no age limit. Children and young people (CYP), so far as they are able (and when appropriate with the support of their parents or carers), should be encouraged and facilitated to participate in decisions about their own care and, more broadly, about the health and social care services and policies that affect them. This principle is set out in the United Nations Convention on the Rights of the Child (1989)<sup>3</sup> and the Children Acts of 1989 and 2004,<sup>4,5</sup> and has been policy for successive governments,<sup>6–8</sup> including in response to the Children and Young People's Health Outcomes Forum recommendations, *Improving Children and Young People's Health Outcomes: a system wide response*.<sup>9</sup>

The practice of engaging with children and young people on health policy has developed a great deal over the last 15 years,<sup>10–14</sup> with more investment in resources and new dedicated staff employed in many organisations for this purpose.<sup>14</sup> There is ample evidence that demonstrates that young people value their role in participation<sup>12,13,15–21</sup> and the clear benefits that can be realised through consulting with them.<sup>10,22</sup> In 2005, the National Institute for Health Research created the Medicines for Children Research Network to speed up the process of studies for medicines for children and young people. More recently, organisations across the new health and care system are developing their processes to increase the role of young people in decision making. The Care Quality Commission is involving children and young people in their inspection activities, and Healthwatch England has appointed a children's advocate to its board. Local Healthwatch bodies are being supported by the National Children's Bureau to include children and young people.<sup>23</sup> In line with these changes, NHS England is introducing three new initiatives involving children and young people. Firstly, the expansion of the Friends and Family Test will be rolled out for children's services to all areas by March 2015 so that children and young people can participate in giving their views as part of normal patient feedback processes. Secondly, a strategic voice for children will be formalised through an NHS youth forum, to be established with the British Youth Council, that will hold NHS England to account. Finally, in

2014, new children's experience measures will be developed for the NHS.

There is, however, still a long way to go; as the Children's Commissioner recently highlighted, 'children's participation has not been sufficiently embedded into everyday practice and largely relies on the commitment of key individuals'.<sup>13</sup> Young people participating in focus groups commissioned specifically for this report echoed these views. One young person said:

*'More of an active step is needed to take on board the views of children and young people; there are lots of focus groups but these are often targeted at parents, and young people will have very meaningful things to contribute. It would be good to have more opportunity for participation across more NHS services.'*

Crucially, patient feedback surveys, as a mechanism for children's participation, are nearly non-existent. A review of national surveys undertaken between 2001 and 2011 showed that fewer than 3% included the views of under-16s.<sup>24</sup> Although this issue is being partially addressed by some of the initiatives from NHS England, further steps should be taken to include the voices of children and young people in all relevant NHS surveys as recommended by the Children and Young People's Health Outcomes Forum in 2012.<sup>25</sup> Steps are also needed to involve groups that are often excluded from participation, such as very young children, asylum seekers and the groups highlighted in Chapters 9–12.<sup>11,12,26–31</sup> The views of children and young people are particularly under-represented in areas such as health treatment services,<sup>28</sup> developing ideas, setting the agenda, commissioning, delivery and evaluation,<sup>13</sup> so that children and young people are mainly involved in the tokenistic 'sounding out' of ideas. There is also a need for more evaluation and more rigorous evidence of outcomes<sup>27,29,32</sup> to demonstrate whether or not the feedback from young people is acted on and the quality of the decisions made in response to their views.<sup>10,28,33</sup>

There is, however, a mood for a change. At a recent conference attended by more than 100 young people and health workers, 'Embedding Children and Young People's Participation in Health and Social Care Services', one of the speakers highlighted that 'we're at the tipping point of engaging children and young people in health and social care'. Part of this process of engagement is 'closing the loop of recommendations'; we need to get better at listening to young people's recommendations and then feeding back to them the changes that have been made as a result of their suggestions. If 'our children deserve better', we therefore need to hear what they have to say and then act on it. That is what we have aimed to do here; this chapter is a celebration of the voices and recommendations of children and young people, which concludes with their Manifesto for Health and Wellbeing.

## Methods

### Literature review

A literature review was carried out using a search of electronic databases, including Social Policy and Practice, Embase and Web of Science.

The terms for the search were:

- those relating to young people and their views (young people\* or young person\* or teenage\* or teen or adolescent\* or child\* or youth\*) adjacent by three words to (represent\* or voice\* or participa\* or opinion\* or feedback\* or view\* or perspective\* or satisfac\*) **and**
- those relating to health (welfare\* or NHS\* or hospital\* or doctor\* or nurse\*) **and**
- those relating to the types of young person participation (focus group\* or webinar\* or workshop\* or interview\* or review\* or survey\*) **and**
- those relating to England (England\* or English\* or NHS\* or United Kingdom\* or UK\* or brit\*).

Criteria for inclusion were sources written in English since 2004<sup>12</sup> and only relating to the UK, principally England. These yielded 206 results in Social Policy and Practice, 657 results in Embase and 342 results in Web of Science on 16 July 2013. Conference abstracts were discarded.

Other material was identified through the references of relevant papers and following recommendations from key individuals. The websites of significant bodies such as the National Children's Bureau, YoungMinds and the Children's Commissioner were also searched for relevant material. We achieved saturation of topics, suggesting that our research had been sufficient.

### Participation of young people

Four focus groups/workshops were commissioned specifically for this report. The young people were chosen to be representative of wider groups of views and we used these groups to triangulate issues from the literature review. Two focus groups included children aged between 13 and 22 affiliated with the Royal College of Paediatrics and Child Health's (RCPCH's) Youth Advisory Panel; there were five children in one focus group and eight in the other, with some overlap of attendees. The third focus group involved seven young people aged between 17 and 23 affiliated with YoungMinds. Many of those from YoungMinds suffer from mental health problems, and some are involved with the looked-after care system. During these three focus groups the young people were given the opportunity to reflect on an early draft of this annual report and highlight key areas that they wanted the Chief Medical Officer to address. Quotes from these focus groups are included throughout this chapter. The fourth workshop involved eight young children aged between 5 and 13 from Kids Company. They took part in a workshop on the theme of 'Healthy living', during which they

produced some of the artwork for this report and discussed their views of health, health services and being healthy. Some of the quotes from the Kids Company workshop are included throughout this report.

## The voices of parents

We also consulted five parents, including parents of children with neurodisability, mental health problems and chronic conditions. These telephone interviews were conducted during August and September 2013, using an interview guide. Most of the parents we spoke to are involved with patient groups and act as parent representatives for a number of organisations. As with the young people, the parents were chosen to be representative of a wider group of views and we used the interviews to triangulate issues from the literature review. Parents were recruited through the Children and Young People's Health Outcomes Forum or through introduction via parents who had been interviewed. As with the young people's focus groups, parents were given the opportunity to reflect on an early draft of this annual report and highlight key areas that they wanted the Chief Medical Officer to address. Quotes from these interviews are also included throughout this chapter.

## What children and young people say – findings from the literature review and focus groups

In this section we explore five key areas identified as being important for children and young people (CYP) for health and wellbeing. They are:

- being informed and having a say in decisions about their care
- child-friendly, personalised care
- access to age-appropriate services as they grow, and support through the transition to adult services
- understanding their rights and responsibilities
- the role of school.

*'I don't know if it exists but something as simple as an online list of all the services that can be accessed in your area would help.'* – Young person from an RCPCH focus group

### Being informed and having a say in decisions about their care

Two of the main themes highlighted in the literature and our focus groups were that **young people receive insufficient information about their health and health services, and they want more say in decisions about their own care.** In particular:

- **Where to go** – CYP want better information about where to go locally for help and trustworthy health advice,<sup>20,34–36</sup> including the availability of child-friendly services, the locations and costs involved.<sup>34</sup> They have said that not knowing what services are available can result in their not seeking urgently needed help.<sup>37,38</sup> On some occasions, health professionals were not able to direct them to appropriate child-friendly services and they suggested that to overcome this they could work with professionals to **create a local directory of child-friendly services for users and health workers.**<sup>17</sup> Young people in our focus groups suggested having simple flow charts or information available at GPs and at their schools to show them how to access health services.
- **Information about consultations** – CYP would like more information about symptoms, prognosis, treatment and signposting to sources of further advice.<sup>34</sup> They talked about the **usefulness of a printout or email from the doctor after their appointments with a summary of such information.**<sup>34</sup> They were not always told why they were being referred if a referral was made<sup>11,39</sup> or what would happen at their next appointments,<sup>26</sup> and they wanted this to be addressed.

*'It would be very helpful to know what is going to happen, even when you are going to speak to a GP or counsellor. You wouldn't want to see someone if you didn't know what the outcome would be; the more you know the more comfortable you will feel.'* – Young person from an RCPCH focus group

- **Presentation** – CYP want information to be presented in a clear, concise, accessible and child-friendly way, with pictures and diagrams if applicable.<sup>11,13,21,34,37</sup> Young people in our focus groups and some of the parents we interviewed agreed with the need for appropriate and impactful presentation.

*'Young people are so energised, motivated, full of passion and energy; and we educate them using only dry ways... We need to think creatively about how we communicate with this group – and the best group to show you how to do this are the young people themselves, whether it is memes, social media and whatever gadgets that they are able to get hold of.'* – Parent

A number of channels for delivering health and health service information have been suggested in the literature, including posters, leaflets, television, websites, health apps and social networks that can be accessed easily, confidentially and at no cost, in a number of settings, including schools.<sup>13,17,21,34</sup> **CYP also value hearing and learning from the past experiences of other young people.**<sup>13,34</sup>



The internet is increasingly the preferred source of information for young people. **In a recent study looking at preferences for sources of sex and relationship education (note that answers were not mutually exclusive), 45% of 13-14 year olds said they preferred websites as a source of further information**, about 30% preferred each of magazines, phone lines and school, only about 20% favoured each of drop-in centres or their homes and less than 10% preferred each of youth clubs and leisure centres.<sup>40</sup> Young people were reassured by the NHS logo on apps but were concerned that an SMS message could be spam.<sup>34</sup> In our focus groups young people said that internet sites and social media provide an effective method for reaching young people about health issues and should be better utilised for this purpose.

- **Involvement in their own care – In general, young people were unhappy with their role in making decisions about their own care.**<sup>11,24,26,28,38</sup> **They value being involved in these decisions**<sup>11,20,21,25,41,42</sup> and want to take the lead if appropriate,<sup>25</sup> although they know that is not always possible.<sup>11</sup> For example, **they wanted to give consent for procedures carried out on them.**<sup>12</sup> CYP using specialist health services perceive themselves as experts on their own conditions and health status, and want those with non-specialist knowledge to acknowledge this expertise and specialists to recognise them as partners in their care.<sup>20,38</sup> Benefits of involving young people include empowerment for the young person, helping professionals to fully understand their illness and how it affects them, equipping young people with the skills for making decisions about their health in adulthood,<sup>11</sup> and helping them to 'feel prepared and less anxious about undergoing operations and treatment'.<sup>42</sup> One study highlighted how it can avoid diagnostic delay and poorer psychological outcomes.<sup>43</sup>

The evidence suggests various ways of involving children and young people in their own care,<sup>11,42</sup> which to some extent is affected by the age, maturity and communication skills of the individual.<sup>41</sup> It has been suggested that health workers should alter a child's level of involvement in consultations as he or she matures.<sup>44</sup>

## Child-friendly, personalised care

Young people want child-friendly services, including good interaction with health professionals and easy access to services where they feel welcome and not belittled. Some did not feel that health professionals took them seriously enough.<sup>31,45</sup> They highlighted **the need for good communication by health professionals, particularly listening and treating them with respect.**<sup>26,38,46</sup> They do not like jargon, an inappropriate level of language or explanations that they cannot understand.<sup>11,12,15,28,34,38</sup> They want health workers to be trained to communicate effectively with them,<sup>11,15,25</sup> and to talk directly to them and not just their parents.<sup>11,12,15,28,38</sup>

*'I've experienced this myself: a physician will look at me, and ask me a question about my child, and I ask my child, and she replies and the clinician waits for me to reply, and it is so rude and disrespectful... having the ability to communicate well with children and young people and the intention to do it should be the aim of your care.'* – Parent

**Good relationships with health professionals who are familiar and can be trusted is valued by young people,**<sup>20,35,37</sup> and they particularly appreciated having relationships with people who had known them for a long time and were empathetic to their needs.<sup>13,37</sup> In a 2012 survey of more than 93,000 young people in the UK by the Schools and Students Health Education Unit, up to 23% of the 12–15-year-old females surveyed reported feeling 'quite uneasy' or 'very uneasy' on their last visit to the doctor.<sup>47</sup> The importance of professional expertise and competence was also highlighted,<sup>20,37,48,49</sup> as were accessibility and availability.<sup>37</sup>

Young people have repeatedly commented that they want **improved co-ordination, communication and integration** between health workers so they do not have to keep repeating their experiences to different professionals.<sup>11,20,31,35,38,50–53</sup> They also want improved continuity of care, with one person nominated as their care co-ordinator.<sup>46</sup> Some agreed that **an advocate to help navigate the system and fight on their behalf would be helpful.**<sup>20,54</sup> This was particularly the case for looked-after children, children with neurodisability and those with long-term conditions, who felt that seeing one person helped develop trust, confidence and independence. They were concerned that receiving care from different health professionals who did not know the nuances of their condition or their individual background meant that their progress could not be monitored effectively or encouraged.<sup>31,46</sup>

**Better access to health services for CYP** was thought to be a priority by those taking part in our focus groups. They identified several difficulties with access that can result from the following:

- **Disability** – *'I have a wheelchair, and for those who have a condition like me, getting to places is hard. Some services don't have ambulances or offer transport. Black cabs or buses are not helpful and private taxis are too expensive. Young people should have help to access their services... it can cost £70 for me to get to an appointment.'*
- **Living in remote areas** – *'I live in a rural area in the North of England, in the middle of nowhere. I couldn't access help until I could drive, I couldn't get a bus, and my mental health deteriorated; within two weeks I was sectioned. If I could have got help earlier I would have avoided it.'*

## ■ Not being able to consult medical care

**independently** – *‘There are lots of issues that young people might not want to ask their parents about, and they can’t go to the GP without their parents’ help, either in getting them there during school hours or without a car. They need another route to find the answers they need without needing to utilise their parents.’*

**In general, young people want their services to be easy to access at convenient, non-stigmatising locations, close to home.**<sup>20,52,55</sup> **They want flexible opening times, including weekends, late afternoons and early evenings.**<sup>20,38,56</sup> The need for late afternoon clinics was echoed by young people in our focus groups:

*‘They should have clinics from 5 to 8pm so as not to disrupt school or your working life, especially for those with complex conditions. You can become disadvantaged if you have to keep leaving school; it affects your education and why should it?’ – Young person from an RCPCH focus group*

There was some support for a ‘drop-in centre’ format, especially for sexual health clinics;<sup>20,52</sup> however, some young people reported waiting for long periods at such services, where they were bored, nervous and no one checked on them while they waited.<sup>38</sup>

## **The role of GPs in child-friendly services**

There is evidence that, in general, many young people are not satisfied with GP services and are less satisfied with GP care than adults are.<sup>57</sup> Often they and their families attend Accident & Emergency services unnecessarily as they are unwilling or unable to access their GP.<sup>58</sup> In a recent survey of 11–19 year olds, over a quarter of those taking part said that they were not comfortable visiting their GP, either because they felt embarrassed, felt judged, found it hard to explain their problem or did not understand what the GP was saying to them.<sup>36</sup> In another survey, over a third of young people asked rated their last contact with their GP as being average or poor.<sup>59</sup> In one study, young people diagnosed with cancer reported that the possibility of early diagnosis and their chances of being taken seriously were affected by ‘not having access to a regular GP’.<sup>53</sup>

*‘GP training is geared towards adults, they treat children as small adults and they need more guidance. 15-16 year olds are not children but they are not adults either’. – Young Person from a RCPCH focus group*

A recent report by the National Children’s Bureau<sup>57</sup> examined how general practice is working for CYP and found that poor communication, lack of involvement in making decisions about their own care, the GP waiting room environment,

access to services, and lack of paediatric or specialist training were all problematic issues for CYP and their families. The report made various recommendations that resonate with comments from our focus groups. The young people we talked with also thought that GPs should all have specialist training in paediatrics, including learning how to communicate with different age groups.

Some suggested having specialist paediatric GPs just for children and young people in primary care. They didn’t always like having a family doctor:

The also said that they wanted to be able to access their GP outside of school hours, between 4 and 8pm. They suggested that GPs could work more closely with schools to teach students about health issues and how to navigate the health system. They also wanted GPs to play a greater role during the transition to adult services. The young people suggested that GPs should be more proactive in including them in their decision making for services, and they wanted to have more of a participatory role in the new clinical commissioning groups.

*‘I don’t want the same doctor as my family, where the doctor can tell my parents that they have just seen me about something. I want my own doctor or a separate doctor that is just for children and young people.’ – Young person from an RCPCH focus group*

## **Access to age-appropriate services as they grow, and support through the transition to adult services**

*‘This is hugely important, not just for teenagers, but also for paediatric patients. My daughter’s hospital has created separate waiting areas; for those in secondary school and above, and for those below. The children’s area has toys, and is big enough for them to run about and be sticky. The teens have a games table, and some computer games and posters on subjects that might be beginning to affect them like drinking and driving that you can’t put in the paediatrics area. This works really well for both sides.’ – Parent*

## **One area repeatedly addressed in both the literature and our focus groups was the lack of age-appropriate services, especially for teenagers.**<sup>11,16,20,51</sup>

Young people have said that staff are unable to communicate appropriately with their age group and that they are often placed on paediatric wards, with babies and pictures of ‘giraffes’,<sup>11,15,20,25,46,50</sup> which they view as inappropriate for their needs. Alternatively they are placed on adult wards,<sup>52</sup>

which they find daunting, boring or isolating, where they receive little educational support or information, where too much independence is demanded of them and where they are exposed to inappropriate risks, including serious physical and sexual abuse on adult psychiatric wards.<sup>11,60</sup>

**Research demonstrates that the quality of care and the experience of teenagers are best when they are cared for on wards specifically for their age group.<sup>25,61</sup>**



Source: Kids Company

Children and young people want welcoming, friendly spaces with age-appropriate entertainment such as magazines, games, books and toys on the wards and to keep them occupied while they wait for appointments.<sup>11,26,34,38,46</sup> They also suggested phones and computers to contact family and friends<sup>38</sup> and flexible visiting times for inpatient wards.<sup>15</sup> Play specialists were valued.<sup>11,46</sup> Cleanliness and safety of the environment were seen as a high priority.<sup>15,46,51</sup> They complained about the food quality, lack of choice and the noisiness of wards at night.<sup>38</sup>

**Managing the transition from children's to adult services has also been consistently identified as a problem for young people, in particular for some vulnerable groups such as those with long-term disabilities and mental health problems.<sup>11,16,21,38,45,60,62</sup>**

Young people in our focus groups felt passionately about this issue and wanted a complete overhaul of the transition process across specialties.

Problems highlighted include:

- lack of an integrated structured transition process<sup>11</sup>
- lack of support during transition<sup>11,63</sup>
- lack of clarity about how to navigate adult services, young people describing themselves as lost or in limbo at the time of transition<sup>60</sup>
- difficulty in adjusting to the differences between adult and children's services in a short space of time, such as having to stay in hospital alone and suddenly needing to take on all responsibility of their own care<sup>11</sup>
- health professionals in adult services lacking understanding of being a teenager and being able to communicate effectively with them<sup>62</sup>

- the loss of relationships with trusted professionals and the loss of continuity of support.<sup>11,63</sup>

*'Leaving Child and Adolescent Mental Health Services (CAHMS) felt like I was falling off a cliff; I lost the support and fell through the gaps... Once you are 18 they treat you like you are responsible, but overnight that doesn't change, we still need that support.'* – Young person from YoungMinds focus group

*'Moving from child services to adult services, I have felt the pivotal services I require fall away and am left helpless and almost stranded.'* – Young person from an RCPCH focus group

**Young people have said that these problems can lead to disengagement with the health service, often at a critical time.<sup>38,51,60</sup>**

Solutions identified by young people include services developing a more co-ordinated transition process<sup>62</sup> with more information about the process and increased support,<sup>46</sup> and for the process to begin earlier and develop at a slower pace according to individual needs through consultation with them and their families. The need for a slower, more staggered period of transition that starts earlier was also highlighted by some young people in our focus groups who pointed out that 'you don't change overnight'.

Those taking part in our focus groups suggested that there should be national guidelines for transition to ensure consistency across services. They wanted a specific transition care plan with more information, introductions, pre-warning, support and signposting. They also suggested that **at the time of transition there should be joint clinics between paediatric and adult services, where a young person can get used to adult services and key information can be shared so that the experience of transition from one service to another becomes seamless.**

*'I want my paediatric clinician to introduce me to my adult one and I want the three of us to meet and discuss what's happening next so I feel secure in moving on.'* – Young person from an RCPCH focus group

### **Changing the boundaries of children's services**

One of the discussions arising from this report was the possibility of extending children's services to age 24, in line with the UNICEF definition of a youth. Young people from the focus groups thought that this would be very beneficial so that there was more time to manage transition. Many did not feel ready to enter adult services at age 18.



*'Eighteen is a crucial part of someone's life, you might be leaving for university or going on to employment. You need more support at that time in your life and 18 is not exactly the easiest time, it would be better if you could delay this transition, even if up to 24.'* – Young person from an RCPCH focus group

CYP thought that there could be a specialist service for 16–24 year olds that included transition preparation. Those in the RCPCH focus group wanted healthcare at university to be part of the paediatric healthcare journey.

*'They certainly should not be transitioned to adult care at 15-16 years old, my daughter has diabetes and I am dreading her being in a waiting room with adults who have lost toes, limbs and legs; it is not what they want to see, and it is not appropriate for them to be there with them'* – Parent

## Understanding their rights and responsibilities

**CYP want to know their legal rights and the health policies applicable to them.**<sup>21,50</sup> They want policies to be **presented in child-friendly formats**, possibly using images, film and social media with child-friendly versions of documents.<sup>34</sup> They suggested that health policy could be taught at school or that health organisations could raise awareness and improve understanding about the work they do with <sup>11,13,50</sup>

**Privacy and confidentiality were particularly highlighted as an issue for young people, both in the literature and in our focus groups.**<sup>11,15,20,35,37,46,64–66</sup> In one study, one in four young people asked felt that they were not given enough privacy when being treated or examined.<sup>11,26</sup> Children did not like staff to talk about them and their condition in front of other people on the ward.<sup>38,67</sup> There were concerns about whether their disclosures would be treated confidentially by all staff, including GPs and reception staff, and they wanted information to be shared only on a 'need to know' basis.<sup>20,51</sup> Confidentiality was a particular concern for those living in rural areas,<sup>38</sup> for looked-after children<sup>64</sup> and with regard to mental<sup>38</sup> and sexual health, where in some cases concerns of confidentiality and privacy prevented young people from using services.<sup>38,55,56,68,69</sup> They voiced that they were uncertain about their confidentiality rights,<sup>66</sup> and this was highlighted repeatedly in our focus groups where young people said they wanted a simple explanation of these rights to increase their understanding and therefore their confidence in using health services. Young people in our focus groups were also worried about their families finding out about their confidential information. Our focus groups highlighted that even when young people go to the GP with a family member they might still want to keep

things confidential from them, and they wanted health practitioners to recognise this.

*'We need to know when things are confidential. When you see a doctor who is your entire family's GP you feel insecure and ask 'Will they tell my parents?' You wonder who else will find out.'* – Young person from an RCPCH focus group

*'It should be common practice to ask children if they want to be seen alone without their parents... if it becomes normal policy to ask, it will help a lot. Sexual health clinics do that a lot.'* – Young person from an RCPCH focus group

Parents largely agreed with the need for increased confidentiality and knowledge of confidentiality rights for, some of their children having had experience of poor practice in this area. However, one parent pointed out some of the difficulties from a different perspective:

*'I have a daughter with mental health issues, and I could not get any useful information out of them [health services], as my daughter didn't want me to know anything, but I felt she was not in a mental state to make that decision... I found it hard to know what to do, and as a mum it was pretty awful not to know anything about what was going on.'*

**The right to complain** – CYP have highlighted that they are not sure how and where to register complaints in the NHS. Indeed, a recent report suggests that **access to and use of complaints processes for CYP is under-developed.**<sup>59</sup> Young people say that they are not provided with information about their rights to complain, nor do they know how to do so, and that the system can be so complicated that often they do not bother. Furthermore, they say that when complaints are made through formal channels, often staff are not trained to receive and act on complaints by young people.<sup>59</sup> They want increased awareness of complaint services, which they say should be fully inclusive of their needs, including training staff to relate to them.<sup>70,71</sup>



**'The right...': The Children's Rights Manifesto – what our young people believe are the innate rights of children.** Source: Kids Company

### The role of school

CYP thought that school should play **an important role in health and wellbeing, not only in terms of educating them on health issues**, but also as a setting for health professionals, including school nurses or other services such as sexual health drop-in clinics.<sup>68</sup> The literature review demonstrated that want access to specialised staff in schools for individual guidance and support for wellbeing,<sup>11,72</sup> the type of support depending on the individual. In one evaluation of extended school services, children from black and minority ethnic backgrounds wanted help with health and wellbeing; those from deprived backgrounds wanted support for bullying; and girls were more likely to want support with matters relating to bullying, sexual health and examination stress.<sup>20</sup> CYP also consider school to be **a centre to encourage healthy behaviours, including healthy eating**,<sup>72,73</sup> through, for example, 'cook and eat' sessions to increase their confidence in experimenting with a variety of foods.<sup>11,74</sup>

Young people in our focus groups said that 'schools have a responsibility to teach life skills' as that is where young people spend most of their time, and that school was a good place

to access large numbers of young people who usually do not need to see health professionals and so may miss access to key health messages. They highlighted that some young people, such as looked-after children or those from single-parent families, might not get full parental support at home so school provides 'a chance for health and equality to be levelled out'. They also reflected that school would be a good forum for feedback and participation in decision making on health topics from a range of young people who might not normally get involved in participation activities.

Young people in our focus groups wanted teachers to be more understanding about school absence for health issues. They stressed that they may not want teachers or fellow students to know all the details of an absence, especially if it involved accessing emotional support.

*'If you walk into class half way through the day, the teacher always asks 'Where have you been?' in front of the whole class! So then all the students want to know and it is hard to keep it from them as they pester you to find out why you weren't there; school teachers are no different.'* – Young person from an RCPCH focus group

**School plays a wider role for children with chronic disease or disability, for example in supporting them through their disease**, which was valued by young people and their families.<sup>20,75</sup> Young people are more likely to feel that their needs are being met in schools with a full-time appointed member of staff to support them for this purpose;<sup>20,38</sup> **however, one in three CYP have said they did not have a person at school that they could turn to with concerns**.<sup>20,76</sup> Those with more complex conditions say that they want to feel confident that their schools can meet their requirements.<sup>20,54</sup>

*'I think schools should have a care plan, setting out what to achieve for a year, for long-term conditions and have staff training for life-threatening conditions or some specialised training. Now most schools are dependent on families to come in and help... There should be an Ofsted category of how well the school is caring for the physical and mental health of the children.'* – Parent

**CYP with chronic conditions also highlighted the need for school support in helping them catch up with work that they miss while in hospital.** They wanted education in hospital to give them something to do and to prevent them falling behind, and for this to be integrated with education in their locality.<sup>38,51</sup>



*'I was ill over my GCSEs and the teachers kept saying where is she? But when I came back they never offered me any help and I missed over 50% of all my lessons. They didn't give me any work or help with my exams, eventually they even stopped asking where I was.'* – Young Person from a RCPCH focus group

School is also a setting where CYP with long-term conditions take medication. One study showed that for those taking regular medicine, accessing and storage of medication was not problematic; however, for 'as required' medication, there were barriers to access, including a lack of privacy.<sup>75</sup> Children with disability have said that they want support to access extracurricular activities at school as well as areas within the syllabus.<sup>20,77</sup>

## **Personal, social, health and economic education**

Young people want **the quality of personal, social, health and economic (PSHE) education to be improved**,<sup>17</sup> including suggesting that Ofsted inspect PSHE more effectively.<sup>78</sup> This was consistent with the views expressed by young people in the RCPCH and YoungMinds focus groups, who felt strongly that the structure of these lessons should be changed completely. They wanted PSHE to be taken more seriously; to be given more prominence in the curriculum, with lessons to be made mandatory, properly planned and structured; and for the content to be regulated. They suggested that lessons should include topics such as mental health, depression, preparation for employment, sexual health and healthy eating. The quality of PSHE lessons experienced by those in our focus groups was extremely varied, ranging from very successful programmes where students could choose from a range of interactive weekly sessions with external speakers, to those who were given the slot as 'a free period once a week'.

Some young people preferred specialist or external speakers rather than teachers to tackle all topic areas in PSHE<sup>78–80</sup> because of the sensitive nature of some topics and concerns about confidentiality. For example, in one study students appreciated being taught sexual health education by sexual health workers.<sup>40</sup> The young people from our focus groups also felt that health professionals would be beneficial or that peer educators, medical students, recovering drug addicts, teenage parents or volunteer groups could give valuable insights.

*'Music teachers should not be teaching PSHE; there should be a special teacher who does just this, or why not get a sexual health or mental health worker to come in?'* – Young person from YoungMinds focus group

The young people pointed out that they did not want to talk about sex or personal issues in front of their teachers whom they see every day. They felt that if teachers do run the sessions, they wanted them to be better informed, equipped and trained to deal with the topics. One of the parents interviewed had been a teacher who had taught PSHE in the past and said that:

*'It made for some uncomfortable moments, where students shared more than they might want to with me as they wanted to know more about sexual education.'*

Sex education was one area of PSHE particularly addressed by young people as so many were unhappy with the amount and quality taught in schools.<sup>38,81</sup> In a 2006/07 survey by the UK Youth Parliament, 40% of young people surveyed thought that their school sex education was either poor or very poor.<sup>78</sup> **Young women wanted sex education to be taught in single-gender groups with time for confidential individual sessions.**<sup>38</sup> CYP in our focus groups and in the literature were concerned that they were not getting the whole story about sexual education in schools; they wanted it taught earlier and for it to have a greater priority in the curriculum, with more issues covered, including detail about contraception, teenage pregnancy, sexually transmitted diseases, how to access their local sexual health clinic, gender crises and emphasis on relationships.<sup>38,81</sup>

*'Lots of people come in to talk about embarrassing things a girl can get, very few talk about embarrassing things that a boy can get! There needs to be more advice for boys.'* – Teenage boy from YoungMinds focus group

There was also some concern in our focus groups that many young people in religious schools around the country were not being taught sexual education at all and the young people agreed that: 'Even if they wouldn't give you the information in school they should tell you how to find it out.'

## **School nurses**

**Young people want their school nurse to be more visible<sup>82</sup> and to have more contact with them so that they become someone who knows you and whom you 'know and can trust'.**<sup>83</sup> Many young people reported that they rarely saw or knew their school nurse<sup>82</sup> and felt that they could not discuss issues such as sex and relationships with them.<sup>40</sup> CYP in the literature and in our focus groups suggested that assemblies, presentations and introductory sessions should be developed for all students on starting at a new school, to introduce the school nurse and their role, the service offered and how to access them.<sup>82</sup>

*'They should do health promotion, and be encouraged to lead assemblies, to teach the PSHE curriculum and be able to articulate or explain things we don't understand.'* – Young person in an RCPCH focus group

**CYP wanted a guarantee that their school nursing service is confidential,**<sup>82,83</sup> possibly even independent from the school, so that information would not be shared with teachers. They wanted easy access to the school nurse and waiting rooms where staff and other students could not see them, with the possibility of being able to contact the nurse directly by text, phone or email, without the need to tell their teachers.<sup>82,83</sup>

Some young people suggested being able to access the nurse outside school, for example at a youth centre, shopping centre or a local GP, to ensure anonymity, or for the nurse to be accessible outside of school hours.<sup>17,82</sup> The top five services that CYP have reported that they want their school nurse to provide advice on are: drugs; contraception; sexually transmitted infections; smoking cessation; and how to access other health services.<sup>82</sup> Other services CYP young people thought that nurses should provide included alcohol advice, mental health and wellbeing, confidence building, body image workshops and general health check-ups.<sup>83</sup>

Young people and the parents whom we spoke to valued the concept of a school nurse, particularly with regard to ease of access, confidentiality and not missing out on school time to access this form of healthcare, they also found the school nurse to be less intimidating than other health professionals. When asked to choose between funding for a school nurse or free school meals for all, as part of a priority-setting activity in our focus group, most of the young people said that a school nurse was more important.

## The views of specific groups of young people

In this section we explore the views on health and wellbeing of the four groups focused on in this report: children with neurodisability, mental health issues, looked-after children, and children in the youth justice system.

Issues important to these groups echo some of the general themes described above, including: lack of information about services and wanting more involvement in decisions about their own healthcare; ensuring that the health workforce is adequately trained to work and communicate with them; good relationships with health professionals; wanting to be taken seriously; the aspiration for integrated and co-ordinated care; and the need for good-quality transition services. It should also be noted that these are not discrete groups of children; for example, many looked-after children, and those in the youth justice system,<sup>65</sup> may also have a neurodisability or mental health problem.

## Children with neurodisability

There is much evidence in the literature on what CYP with neurodisability would like from their relationship with health professionals however, much of this is covered in the general section 'Child-friendly, personalised care' above. A predominant issue relevant to this group throughout the literature was the **lack of appropriate communication skills of health professionals**, for purposes of either consultation or participation.<sup>31,98</sup> They want clearer, child-friendly explanations and communication that is appropriate for their needs and disability.<sup>31</sup> As with CYP generally, **young people with learning disabilities do not like it when professionals use language they cannot understand or address their parents rather than them.**<sup>31</sup> They also want more involvement and explanation about procedures, including understanding why particular procedures are being done.<sup>31</sup> Overall, CYP with neurodisability want more training for staff on how to communicate effectively with young people with disability.<sup>31,45,77,98</sup>

CYP also want more support from health services to support them in being 'able to communicate to the best of their ability, encompassing a wide range of communication techniques and assistive technology to enable them to take part in the decision-making process'.<sup>99</sup> Parents of children with neurodisability and the young people themselves think that communication is an important aspect so that they can indicate their choices, be involved in decision making and controlling the management of their disease, and exert some independence, where 'not being able to communicate was a source of anxiety';<sup>99</sup> for example, they liked being able to manage their own medication.<sup>31</sup> They think that having someone to support them during their appointments, who they can ask questions of afterwards, or as an advocate would be helpful as they reach transition or move towards independence.<sup>31</sup> However, there was a fine balance with receiving too much support, which they felt could be disempowering.<sup>31</sup>

One approach that young people thought could increase their independence is having a health passport (hand-held records including information about them and their condition, and how they want to be supported to prevent them having to repeat themselves); another is enabling them to go to appointments independently.<sup>31</sup>

Many CYP with neurodisability and their families reported that **health services are not well integrated.** They are **not always given clear information** about how services interact, or how health services differed from each other in what they provide. They also feel frustrated about how they need to be persistent or have to 'fight' to get the services they need.<sup>45</sup> Another important issue is the time taken for diagnosis, which ranged from 3 months up to 15 years in one study. The need for continuation of care after leaving school to help them with further studies or a career was also highlighted.<sup>20,77</sup>

**Access to local health services can be a problem, especially for those in wheelchairs.**<sup>46</sup> A mother we

interviewed, who sits on many representative groups, said that access for referrals through primary care could be improved. Based on discussions with other families in parent groups, she recommended further training for GPs in the needs of their children with disabilities and in listening to parents' concerns. She said that it can be very difficult for parents of children with neurodisability to be taken seriously by health professionals as the symptoms begin to manifest themselves, and that 'jumping through the hoops for access' increases the anxiety for families. She highlighted the three key issues consistently mentioned by parents of children with neurodisability: 'the difficulty of getting into the healthcare system at the start, the need for good, integrated, co-ordinated care when you are in the system and the need for better transitional care'. She also talked about the support needed for parents of young people with neurodisability, especially the need for good sleep and exercise.

*'Family resilience is cropping up a lot in the disability world, the need to create resilient families as opposed to dependent ones.'* – Parent

### Children with mental health problems

CYP want mental health to have more prominence and to be a greater priority. They argue that mental health services should form a central part of all mainstream services for them, they want **'mental health to be taken as seriously as physical health'**<sup>51</sup> and for health and non-health professionals to be as confident in talking about mental health as physical health.

**Stigma was highlighted as a key issue for young people with mental health problems,**<sup>38,51,52,84</sup> **mainly as a barrier to their accessing services and support.**<sup>51,52,65</sup> Some young people are put off attending services because the word 'mental' is included in the title.<sup>51</sup> Young people were also concerned about the public perception of mental health issues. CYP who had never used mental health services before suggested that they were for people who were 'mad' or 'mental'.<sup>85</sup> **They want more health promotion campaigns and teaching in schools to counter the stigma associated with mental illness.**<sup>11,51</sup>

*'Stigma is bred into society from early experiences, children call someone a name because they are different; we need to educate people and normalise mental health issues.'* – Young person from the YoungMinds focus group

The literature shows that **who use mental health services want a confidential, accessible mental health service, when and where needed.**<sup>38,52</sup> This was echoed in our focus groups, especially the YoungMinds focus group. They want to be listened to, to know about different treatments, to be able

to give their consent to treatment<sup>38</sup> and for services to be age appropriate, with flexible opening hours at times that suited them.<sup>16,38,51,86</sup> Preferred referral methods include self-referral and drop-in services<sup>51</sup> available through the internet, mobile phones, text or email. A number of venues were mentioned, including at home, in clinics, in coffee shops, outside conventional mainstream health and welfare centres, or having a multiagency, multidisciplinary service to reduce the stigma associated with accessing mental health services, and to reduce the expense and time of accessing different services at different sites.<sup>11,16,51</sup> With regard to inpatient facilities, young people want interesting activities, education provision and support on discharge, as well as clean facilities with good food.<sup>38</sup>



**A happy boy (from a Kids Company workshop)**  
Source: Kids Company

Young people seeking mental health care want access to holistic services to improve all aspects of their lives and access to a range of help and support options,<sup>51</sup> including alternative treatments to medication. Many young people said that they felt 'fobbed off if they were only given medication, and weren't offered someone to talk to'.<sup>51</sup> This was reflected in our focus groups, where young people also said that



cognitive behavioural therapy, which is usually offered as standard, does not work for everyone.

*'The mental health system is very reactive, rather than proactive. It is more likely to respond to people in distress rather than respond to them before they get to that point; it feels like young people have to do something drastic in order to be heard and that shouldn't happen.'* – Young person from the YoungMinds focus group

Young people have said that they often feel as if they are not taken seriously when they talk about issues surrounding mental health and that professionals do not respond to them appropriately until they are very unwell or in crisis.<sup>11,51</sup> Young people have said in particular that they are often not given enough support at first presentation<sup>51</sup> and that **they often wait a long time to get support.<sup>85</sup> They want more support at first presentation, quicker access to help during an emergency, and better out-of-hours and crisis services, with inpatient units that are easier to access.<sup>51</sup>**

The quality of relationships with health professionals has been addressed as one of the most important aspects of care for CYP with mental health issues. Trust is a key issue.<sup>51</sup> Young people felt that they needed to trust the practitioner and build a relationship with them before they could talk openly about their problems; however, trust takes time to build and staff turnover, leave, shift patterns and being passed around services often obstructed this.<sup>11,51,85</sup> They want time to get to know staff and establish relationships.<sup>38,87</sup> **They want staff who are approachable, available and skilled in engaging and listening to young people.<sup>38</sup> Children and young people valued continuity, confidentiality and support, particularly at transition.<sup>86</sup>** Flexibility and accommodation of health workers to the young person's needs were seen as positive attributes.<sup>39</sup> Young people also want choice about their therapists, with the option to change practitioner if they want to.<sup>51</sup> They think that peer mentoring may be appropriate if support is given and it is managed well.<sup>85</sup>

For young people using mental health services, **lack of adequate information is a repeatedly highlighted problem.<sup>20,38,51,52,88</sup>** They say that the quality of information given to them about Child and Adolescent Mental Health Services (CAMHS), the illness and the treatment can be inadequate. Some young people report that they have been referred to specialist CAMHS without being given any information. Others have said that, although they were given all the information at the time, they could not take it all in as they were in too much turmoil.<sup>11,51,89</sup>

Young people from the YoungMinds focus group thought that teachers should be given more support to report any mental health concerns that they have for their students,

particularly very young children. They also wanted closer liaison between mental health services and schools, so that there could be mental health workers in schools or more collaboration of staff with CAMHS. **Many young people want access to counselling services within their school,** but others had reservations due to the stigma associated with going to a counsellor. It was suggested that a universal service such as the school nurse, where people did not know your reasons for attending, might be better.<sup>51</sup>

## Looked-after children

*'I have been through 56 foster places... sometimes when you are in looked-after care, the odds are stacked up against you, and then you add mental health problems to this as well.'* – 19-year-old female from the YoungMinds focus group

A key issue for looked-after children is the potential for frequent moves leading to discontinuity, and a lack of permanence and sense of belonging; looked-after children say that this can affect their sense of identity.<sup>64,90</sup> Children in care therefore particularly value stability of their placements and having continuity of care with one social worker and one key health worker with whom to build a trusting relationship.<sup>20,52,91-93</sup> Love, affection and a sense of belonging were desired but often lacking in the lives of looked-after children.<sup>90</sup> It should be noted, however, that the looked-after system can be very effective. In one recent study most children (97%) were happy and relieved to be with kinship carers. When asked where they would choose to live, 73% said with their kinship carer.<sup>94</sup>

CYP without parental support feel that they receive less information and advice on issues relating to health and health service access, particularly relating to: relationships; healthy lifestyle; sexual health; how to navigate the health system; how to register with a doctor or dentist; and entitlements such as free prescriptions.<sup>11,13,95</sup> **They also said that people did not always explain the details of their medical assessments so that they could not always understand why they were having them.<sup>20,96</sup>**

Some looked-after children face difficulties in using GP services and the literature shows evidence that care leavers can be very critical of their GPs, including feeling that they were not being listened to or that they could not discuss mental health issues with them.<sup>57</sup> They want social workers and other professionals not to make assumptions about the ease with which they could address sensitive topics.<sup>38,96</sup> They also think it is important that their teachers and youth workers understand key health issues to help them navigate the system and to explain things that they did not understand.<sup>25</sup> They particularly value speaking to older peers or health workers who have had personal experience of being in care.<sup>64</sup>

Looked-after children and young people in the literature **identified stigma and prejudice as being significant in their lives**.<sup>64,94</sup> They reported negative attitudes, curiosity and pity, and being singled out to feel different.<sup>90</sup> Those who had experienced stigma said it would 'affect their willingness to confide in friends at school or outside the care setting'.<sup>64</sup> Young people feel that there needs to be more widespread understanding of what it means to be a 'looked-after young person'. Participants say they are tired of telling peers that they are 'not like Tracy Beaker', a character from children's books and television, who young people feel is the only representation of children in care that others know about. They want some normalising of the concept of looked-after children, including the range of settings of care, to increase knowledge and alleviate some of the stigma attached.<sup>9</sup> A number of studies stress that children and young people in care want to be treated like other people and not singled out.<sup>20,91</sup>

Many young people in care were not asked their opinions on important matters or involved with decision making about their own care or health issues, leading to an 'overwhelming helplessness'.<sup>12</sup> Children in care want choice and control regarding their treatments, counselling or disclosure.<sup>64</sup> They want to be involved in the small decisions as well as the big ones, such as greater involvement in organising appointments and 'engaging meaningfully in their therapy'.<sup>18,20</sup>

**Young people in care also want more involvement in the review system.** Children in care did not like that they did not always know who would be attending their review and reported finding teachers attending when they could not see the relevance of this.<sup>12</sup> They have reported that they find it difficult to 'express themselves in review meetings and in court and want support with this, and they **value having independent advocates who can help them express their views and ensure they are heard**'.<sup>20,93,97</sup>

**Children in care say that they want adequate preparation for discharge from services.**<sup>20</sup> Where it was not done well, young people felt isolated,<sup>20,92</sup> and the transition from care 'triggered additional health problems or difficulties in maintaining their health... Some found this traumatic and were psychologically unprepared practically and emotionally for the transition'.<sup>90</sup> Looked-after children who had been through the process identified areas for improvement, including the need for more advice on how to manage their own healthcare, particularly at the time of leaving the care system,<sup>11,13</sup> and to not be required to move on until they were ready to do so.<sup>93</sup>

## Children in the youth justice system

In one study most young people entering custody said that they had very good access to healthcare on admission;<sup>100</sup> however, in a regular survey of young people's perceptions and conditions in custody, only 52% of young males and 60% of young females said it was easy to see a doctor, and only 32% of young males and 39% of young females

said it was easy to see a dentist.<sup>11,88</sup> Overall, girls rated the healthcare in their establishments lower than boys did.<sup>38,101</sup>

**Over a third of young people in custody interviewed for a study expressed feeling unsafe in their establishments at some point.**<sup>38,101</sup> A quarter of them said they had not received a visit from a friend or family member.<sup>38</sup> CYP said that being in custody would give them the opportunity to improve their health by eating well, stopping drugs and alcohol and by exercising, and they wanted support from their establishments for this.<sup>11,102</sup>

## Discussions with parents

Most of the comments from the parents have been included in the specific sections of this chapter. The key themes drawn from the interviews include:

- help for young people to gain independence in managing their own care
- services to be more child oriented
- more co-ordination, integration and consistency of care for individuals and across localities
- improved transition to adult services and for this to occur later (around age 24)
- schools to be more supportive of young people with long-term conditions.

*'One problem I see is that 18 year olds can't use GP services. It is hard for them to register on campus at university even though it is not complicated, as they don't feel engaged with the GP; it is something their parents have always had control over.'* – Parent

Parents also highlighted that it can be difficult to get their child into the correct health services and to be taken seriously initially by health professionals, although things become considerably better once they are in the system.

Parents were concerned about sending the right health promotion messages to the public. For example, two mothers who had daughters with type 1 diabetes said that people kept blaming their children for not having a healthy diet or exercising, but type 1 diabetes, unlike type 2 diabetes, is an autoimmune disease. There was also feedback that health promotion campaigns for young people should focus on the short-term effects as young people do not respond to warnings relating to long-term effects.

*'It is surprising that in this modern era hospitals are so behind in providing information to patients on their own websites... there is very little information about what they offer.'* – Parent



Some parents felt that there was insufficient support for new parents in the first weeks after birth and they were concerned that vulnerable families could 'fall through the cracks'. They also wanted greater support and more consistent messages from health visitors and for more information to be in the Personal Child Health Record (known as the 'Red Book'), including common medical conditions or conditions relating to mental health. One parent talked about the value of antenatal care that prepared you for life with the baby and not just for birth. One mother said that supporting families to build their own resilience would be important and wanted support to be offered earlier, as often families 'have to reach crisis point before interventions are put into place'. She also pointed out that building early relationships with parents during the antenatal period means that they are already involved with the healthcare system, and have already built up relationships with health professionals for when a child is ill or if more complex care might be needed.

One parent pointed out that, although it is good that the voices of children are being increasingly heard, these children are not in isolation and it is important to also 'speak to carers and the whole family as we are the ones that have to bear the brunt of the decision making'. She said that this was particularly the case for families with children with neurodisability, where some children cannot always vocalise their needs or make informed choices.

## Conclusion

In this chapter we have explored some of the key messages highlighted by children and young people in the literature and in our focus groups as being important to them. We asked all the young people in our focus groups what were the most essential aspects to include for this report. The main topics mentioned – which reflect much of what has been written in this chapter – were:

- need for better transition from children's to adult services
- improving the role of GPs for the health of children and young people
- better access to health services, particularly mental health services
- an improvement of PSHE education, especially sex education
- greater knowledge and practice of their confidentiality rights
- making health services more CYP friendly
- greater co-ordination and integration of healthcare
- increasing participation of CYP in health decision making
- the need for increased information about health services, including what to expect and how to access different services.

Children and young people clearly want to be involved in decision making on health and wellbeing issues, both on a national level and in relation to their own care, and many

of the ideas explored in this chapter are perceptive and insightful; there is clearly much we can learn from them. We therefore conclude this chapter with a **Children and Young People's Manifesto for Health and Wellbeing** – their requests and recommendations summarised from their voices throughout this chapter.

## A Children and Young People's Manifesto for Health and Wellbeing

### To improve their health and wellbeing, children and young people want:

- **to be informed and have a say in decisions about their care**, for example by:
  - services providing child-friendly health information in places where children and young people can find it easily, such as in schools, clubs and on the internet
  - having a directory of child- and young people-friendly services that they can consult and which can be used by health workers to signpost to relevant services
  - receiving a printout or email from the doctor after their appointments with a summary of the key information discussed
  - health professionals taking time to ensure that children and young people can give informed consent, including for procedures carried out on them when appropriate
  - including young people in more national surveys about health, particularly hard-to-reach groups and children with disabilities
- **to have personalised, child-friendly care from people they know and trust and who treat them with respect**, for example by:
  - health professionals, service providers and commissioners communicating and working together to ensure that services are co-ordinated and integrated, so that children and young people are not 'passed around different systems' and do not have to keep 'repeating their story' to each new health worker they meet
  - having an advocate (e.g. the GP) to help them navigate the system and negotiate on their behalf
  - having the opportunity to hear and learn from the past experiences of other young people
  - health professionals, service providers and commissioners being seen to take mental health as seriously as physical health
  - particularly for young people with mental health issues, more support at first presentation, shorter referral times, quicker access to help during an emergency, and better out-of-hours and crisis services, with inpatient units that are easier to access
- **to have access to age-appropriate services where and when they need them**, for example by:
  - health professionals, service providers and commissioners listening seriously to and learning from the past experiences of other young people
  - providing services in convenient, non-stigmatising locations, close to home and with flexible opening times, including weekends and early evenings
  - having hospital wards specifically for teenagers and young adults
- **to be supported through the transition to adult health and social care services**, for example by:
  - GPs and other health professionals working in partnership with the young person and their families or carers, where appropriate, to manage the transition process over a period of time and at a pace that is appropriate for the individual, with information, continuity of care and a clear handover to adult services
  - health and social care professionals ensuring that looked-after children have the preparation they need for discharge from services
  - supporting looked-after children to be more involved with their case reviews
- **to understand their rights and responsibilities**, for example by:
  - policy makers ensuring that they provide information about the health policies applicable to CYP in child-friendly formats and in places where it can be found easily, such as through social media
  - policy makers, health professionals and teachers helping children and young people to understand their rights to confidentiality
  - healthcare and social care professionals and teachers showing due regard for children and young people's rights to privacy and confidentiality
  - service providers and commissioners ensuring that children and young people are told how to make complaints about their care and are supported through the process
- **for schools to play a greater role in health and wellbeing**, for example by:
  - schools supporting children and young people to help them catch up on missed work if they are absent for long periods of time due to a health condition
  - schools playing a role in health promotion campaigns and encouraging healthy behaviours, including healthy eating health promotion campaigns
  - improving the quality of personal, social, health and economic (PSHE) education, especially sex education, and including a wider variety of topics taught by health and social care professionals as well as teachers (e.g. to counter the stigma associated with mental illness).

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## Chapter 5

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# Life stage: Pre-conception and pregnancy

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### Key statistics

- In 2011, the number of infants dying before their first birthday (i.e. the infant mortality rate) in England and Wales was 4.2 per thousand live births: an all-time low. For comparison, the rate was 11.1 per thousand in 1981.<sup>1</sup> Immaturity due to preterm birth remains the commonest cause of death in the first year.
- Infant deaths, however, are not evenly distributed across society. The 2011 rate was 2.5 per thousand in children born to fathers in higher professional occupations and 4.9 per thousand in children born to fathers in semi-routine occupations.<sup>1</sup>
- In 2010 in England and Wales, 7.1% of births were preterm: 5.5% of these occurred between 32 and 36 weeks' gestation and 1.2% before 32 weeks.<sup>2</sup>
- In 2010 in England, the proportion of babies breastfed at birth was 84% and a third were still breastfed at 6 months of age. The highest rates were in babies from minority ethnic groups and the lowest rates were in babies whose mothers are from lower socio-economic groups.<sup>3</sup>
- In 2010 in the UK, around a quarter of women smoked during pregnancy. However, the figure was 57% among those aged below 20.<sup>3</sup>
- Around 6% of women in the UK have a body mass index of 35 (obese) or over during pregnancy.<sup>4</sup>
- In 2010, about 40% of women drank alcohol during pregnancy. Alcohol consumption is more likely in mothers aged 35 or over (52%) and in mothers from managerial and professional occupations (51%).<sup>3</sup>
- In 2010 in the UK, 37% of women reported taking folic acid before they were pregnant and 79% reported taking it during the first three months of pregnancy.<sup>3</sup>
- In 2010, the rate of stillbirths in England and Wales (at or after 28 weeks of gestation) was 3.8 per thousand live births. This rate is relatively high compared with other European countries (almost double the rate for Iceland and the Czech Republic, for example).<sup>5</sup>
- Extremes of maternal age are associated with poorer outcomes for babies including increased risks of stillbirth and neonatal death. England has a relatively high proportion of teenage mothers (around 5%) and mothers aged 35 or older (around 20%) compared with other European countries.<sup>5</sup>

## Overview

### The central importance of pregnancy for future child health

Helping women make healthy choices during pregnancy is a central policy objective.<sup>6</sup> National and local policy makers in health, public health and beyond have important roles to play. *Fair Society, Healthy Lives* (2010) stated as its Policy Objective A 'Give every child the best start in life'.<sup>7</sup> To achieve this, the report highlighted the need to prioritise pre and postnatal interventions that reduce adverse outcomes of pregnancy and infancy. During pregnancy most women want to do 'the best for baby' and this heightened motivation can provide leverage for tackling unhealthy lifestyle choices and promoting healthy ones; for example, helping women to stop smoking when pregnant and encouraging them to breastfeed following the birth.

However, a woman's social circumstances can constrain her from making healthy choices which may in turn be reflected in poorer outcomes of pregnancy and subsequent child development. Policy makers and service providers must therefore also address women's choices during pregnancy in their social context. Fundamental to achieving healthy pregnancies is the role of the midwife. Health promotion programmes through which health and care professionals engage with young pregnant women from poor backgrounds, such as the Nurse-Family Partnership<sup>8</sup> pioneered in the USA (and evaluated as the Family Nurse Partnership model in England<sup>9</sup>), have demonstrated the effectiveness of promoting healthy choices and enhancing access to care during pregnancy on future child development. More broadly, the effects of the Nurse-Family Partnership on improving mothers' return to employment and reducing future offending behaviour in their children point to the potential for inter-sectorial gains beyond health for maternal health policies. Conversely, the influence of maternity leave entitlement policy on maternal health points to the importance of policy initiatives beyond health in improving pregnancy outcomes.<sup>10</sup>

**The effect of a mother's mental health on the subsequent health of her child is equally important as her physical health**, and we are only now beginning to properly investigate this influence on child development (see Table 5.1). At the extremes, we sometimes refer to 'maternal mental illness' or 'maternal stress', but these terms fail to capture **the complex picture of the accumulated influences of being brought up in poverty, sometimes living hand to mouth, having low self-esteem and associated feelings of being socially excluded and hopeless about the future. Evidence is emerging that these influences affect mental health and are**

**also associated with biological changes which can be transmitted to the fetus and can adversely affect future child health and development.** This is referred to as 'fetal programming'. It is central to understanding future child development and is a main strand of the scientific foundation justifying Marmot's approach to tackling inequality from conception.



***Funky Pineapple: Created by primary-aged children to show how exciting fruit and vegetables can be.***

*Source: Kids Company*

# What science tells us: risks, interventions, context and mechanisms

## Main modifiable risk factors during pregnancy for future child health

Certain behaviours, circumstances and events, if they occur during pregnancy, increase the risk of poor outcomes for either the pregnancy or future child health or both. These risk factors, such as smoking or obesity, are also known as 'exposures'. 'Prevalence' of an exposure is defined as the proportion of a population (e.g. pregnant women in England during 2012) who are exposed to a given risk factor (e.g. smoking). Some risk factors cannot be prevented or altered, but those which can are called 'modifiable'. However, demonstrating that a risk factor is truly a 'cause' of a poor outcome rather than incidentally linked is a difficult task. As for some factors it is not yet entirely clear whether the identified causal factor may not actually be casual rather than linked to other factors (e.g. social deprivation) which are causal.

Table 5.1 lists the main modifiable risk factors during pregnancy, citing evidence of their effects in humans. The effects of physical illness on pregnancy outcomes, although important, and non-modifiable risk factors are not included here.<sup>11</sup>

## Intervening to improve future child health

Many of the risk factors appearing in Table 5.1 'cluster together' in certain groups of women. For example, the opiate user is more likely than not to smoke, have poor nutrition, and be mentally ill, poor and stressed. This suggests that targeting risk factors individually is unlikely to be the best approach. Generally, a multifaceted approach (such as the Nurse-Family Partnership) which permits simultaneous engagement with a number of risk factors embedded in the social context is likely to be more appropriate than offering non-integrated interventions for each risk factor separately. In Table 5.2, the evidence for interventions targeting specific risk factors and for multifaceted interventions is summarised.

## Case study

### Perinatal Support Project – Family Action

Family Action's Perinatal Support Project (PSP) is an innovative low-cost, high-impact service. It trains and supports volunteer befrienders to work with women at risk of ante and postnatal depression, providing a vital service for women who are not eligible for acute perinatal depression support services. With significant referral numbers coming from health visitors and midwives, the PSP works alongside local agencies to ensure a joined-up, integrated approach to the referral and provision for mothers-to-be, new mothers, their partners and children.

The PSP:

- helps mothers with moderate mental health difficulties to overcome social isolation and depression
- assists mothers in developing a stronger bond with their babies
- safeguards the development of vulnerable babies.

The PSP was piloted in Southwark in London and subsequently extended to four additional sites – all achieving outstanding outputs and outcomes and with a well-received national evaluation undertaken by Warwick University which highlighted significant improvements in anxiety and depression, social support and self-esteem. There was also a significant improvement in the mother's relationship with the baby in terms of warmth, but not invasiveness.

The PSP has exceeded expectations – particularly when service users have progressed to become volunteers within Children's Centres and volunteer befrienders have begun further training or employment in health and social care.



Table 5.1 Main modifiable risk factors during pregnancy and their effects in humans

| Risk factor                      | Evidence                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|----------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Tobacco</b>                   | Of all the harmful exposures in pregnancy, it is arguably smoking which causes the greatest harm. Not only does it cause impaired fetal growth, low birth weight and preterm birth, it is also associated with an increased risk of miscarriage, stillbirth, neonatal death and sudden infant death syndrome (SIDS). <sup>12</sup> Furthermore, smoking prevalence during pregnancy remains unacceptably high in the UK. Evidence of causal effects on neurodevelopment remains unclear. <sup>13</sup>                                                                                                                                                                                                                                                                                                                                                            |
| <b>Alcohol</b>                   | Heavy alcohol consumption during pregnancy causes a birth defect called fetal alcohol syndrome. <sup>14</sup> It may also damage the fetal brain without affecting other organs or tissues. <sup>15</sup> Evidence that drinking at low-to-moderate levels causes harm during pregnancy is equivocal. <sup>16</sup>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Obesity</b>                   | Apart from increased risks to the mother's health (e.g. through gestational diabetes) obesity is also associated with large-sized babies (macrosomia). <sup>17</sup> Children of obese mothers are at an increased risk of later obesity themselves. <sup>18</sup> The relative contributions of genetic factors, the effect of the obesity on the fetal environment <sup>19</sup> (fetal programming) and of poor eating habits/nutrition in childhood remain unclear but all are likely to be important.                                                                                                                                                                                                                                                                                                                                                        |
| <b>Diet</b>                      | Maternal under-nutrition in pregnancy is associated with the development of heart disease in the adult offspring. <sup>20</sup> There may even be effects transmitted to future generations. <sup>21</sup> This finding (another example of fetal programming) is a very active area of research at the moment.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Illicit drugs</b>             | Particular concerns have been expressed about the effects of illicit drugs such as heroin, cocaine, cannabis and ecstasy on the fetus. <sup>22</sup> Use of illicit drugs is associated with problems in child development. Where the mother is a regular drug user there will often be other complex social factors involved and it is therefore difficult to tease apart the toxic effects of the drugs from the effects of being brought up in the frequently chaotic life circumstances of a drug-using mother (and possibly her partner) and the effects caused by the mother's often poor physical and mental health. Studies in humans have shown that, when adjusted to take account of other risk factors, many of the effects seem more related to the environment the child is brought up in rather than direct toxicity from the drugs. <sup>23</sup> |
| <b>Mental illness</b>            | <p>Although the role and relative contributions of mental illness during pregnancy, drug treatment and the effects of postnatal continuation of mental illness remain unclear, a substantial body of research documents the adverse impact of maternal depression during pregnancy on birth outcomes,<sup>24</sup> on continuing depression in the postnatal period<sup>25</sup> and on infant development and later child outcomes.<sup>26</sup></p> <p>In addition to depression other less commonly occurring mental illnesses can have an impact on pregnancy and birth outcomes.<sup>27</sup></p>                                                                                                                                                                                                                                                            |
| <b>Low socio-economic status</b> | Low socio-economic status is associated with poorer outcomes in children: data from the UK Millennium Cohort Study indicate that a significant socio-economic gradient in children's development is already evident by 3 years of age. <sup>28</sup> Several adverse pregnancy outcomes including preterm birth <sup>29</sup> and stillbirth are linked to lower socio-economic status. <sup>30</sup> Preterm birth in particular is responsible for a high proportion of later neurodisability. <sup>31</sup> A sizeable proportion of the effects of low socio-economic status on birth outcomes may be due to a greater smoking prevalence in poorer populations. <sup>32</sup>                                                                                                                                                                                |
| <b>Psychosocial stress</b>       | One area which has been of particular interest for child development is how maternal psychosocial stress could operate during pregnancy to influence pregnancy outcomes, the child's development and later risk of disease. <sup>33</sup> Although a compelling idea with some supportive evidence from studies in humans, <sup>34</sup> there seems to be a low correlation in some studies between reported stress symptoms and the assumed biological processes involved. <sup>35</sup> Furthermore, there is no substantial evidence base yet on how or in what ways stress could be modified in this population of pregnant women. Further research on interventions is needed.                                                                                                                                                                              |

**Table 5.2 Interventions for modifiable risk factors**

| Intervention                                                            | Evidence                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Smoking cessation</b>                                                | Behavioural interventions can increase smoking cessation rates during pregnancy and reduce low birth weight and preterm birth. <sup>36</sup> However, the evidence for the effectiveness of nicotine replacement therapy in pregnancy has been equivocal with better quality studies showing little or no effect on fetal outcomes. <sup>37,38</sup> There is a need for interventions that can penetrate the so-called 'hard-to-reach' groups where smoking prevalence remains high and standard interventions may not work as well. Although somewhat controversial, the case for using financial and other incentives to promote smoking cessation in pregnancy has been proposed. <sup>39</sup> Using the technology favoured by teenage smokers, such as mobile phones and social media, may be a user-friendly way to promote cessation, as well as using social marketing, e.g. the Stoptober campaign. <sup>40</sup>                                                                             |
| <b>Interventions for reducing alcohol consumption in pregnant women</b> | A Cochrane review in 2009 found limited evidence to support the effectiveness of interventions for reducing alcohol consumption in pregnant women. <sup>41</sup> It remains unclear which type of intervention to recommend. Further trials are needed.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Interventions to reduce gestational weight gain</b>                  | There have been no trials to evaluate the effectiveness or safety of trying to reduce weight in obese pregnant women. <sup>42</sup> Interventions in pregnancy to manage weight gain can result in reduced weight gain during pregnancy <sup>43,44</sup> but may not affect the risk of macrosomia in the baby. Evidence of the effects of interventions on long-term child outcomes is lacking.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Improving maternal nutrition</b>                                     | Folate supplementation given around the time of conception and continued through early pregnancy has been shown to reduce the risk of birth defects such as spina bifida. It is recommended that women take 400 micrograms of folic acid each day during this time. The Scientific Advisory Committee on Nutrition is also considering the role of iodine, having looked at fortification of flour with folic acid.<br><br>Vitamin D supplementation in pregnancy is officially recommended: interim advice is that pregnant and breastfeeding women should take a daily supplement containing 10 micrograms of vitamin D. However, the evidence of effects on bone health remains equivocal <sup>45,46</sup> and little is known about the effects on other outcomes related to pregnancy. More research is needed on the effects of vitamin D supplementation in pregnancy: <sup>47</sup> an independent advisory committee is reviewing current recommendations on vitamin D and will report in 2014. |
| <b>Managing the use of illicit drugs</b>                                | Guidance on the best management of women who continue to use illicit drugs during pregnancy is provided by the National Institute for Health and Care Excellence (NICE). <sup>48</sup> A systematic review of psychosocial interventions for pregnant women in outpatient illicit drug treatment programmes found weak evidence of effect on retention in treatment but more evidence is required. <sup>49</sup>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Perinatal mental illness and psychosocial stress</b>                 | Since stress may be a manifestation of an underlying psychiatric disorder such as depression or anxiety, pregnant women complaining of symptoms of stress and women with other symptoms of psychiatric illness should be evaluated in accordance with the NICE guideline on antenatal and postnatal mental health. <sup>50</sup> For stress which is not related to an underlying disorder then relaxation, exercise or counselling may be beneficial but there has been no clear evidence on how best to intervene. Hence this is another area where intervention evaluation is needed.                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Promoting breastfeeding</b>                                          | Breastfeeding has been shown to have important effects on child health including neurodevelopment. <sup>51</sup> The World Health Organization recommends that infants should be exclusively breastfed until 6 months of age. Yet breastfeeding initiation is low in more disadvantaged groups of women. Interventions to promote initiation of breastfeeding are effective <sup>52</sup> as are interventions to prolong the duration of time for which a woman breastfeeds. <sup>53</sup>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

| Intervention                      | Evidence                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Multifaceted interventions</b> | Work in the USA identified the importance of starting an early childhood programme during pregnancy in order to give a child the best start in life. The Nurse-Family Partnership programme specifically aims to improve pregnancy outcomes by helping pregnant women to engage with prenatal care, improve their diets, and reduce smoking, alcohol and illicit drug use. Forty years on, the programme's effects have been evaluated in three randomised controlled trials and substantial benefits across multiple domains for both mothers and children have been demonstrated. <sup>8</sup> A more recent innovation in the USA has been group prenatal care where women receive their care in groups rather than individually. Evidence suggests that women receiving group care have equivalent or improved pregnancy outcomes compared with traditional prenatal care. <sup>54</sup> Some sites in the UK are implementing group antenatal care and evidence is due. These models may also be effective in ensuring continuity of care and developing peer support during pregnancy. |
| <b>Pre-conception care</b>        | Pre-conception care is very important for women with established medical or psychiatric disorders. For women who are otherwise well it provides an opportunity to encourage healthy choices and establish folate supplementation. <sup>55</sup>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

### The importance of context: why interventions may fail or be less effective

Holistic approaches to health emphasise the importance of working with pregnant women to assess their psychological, physical and social needs as well as capitalising on their assets and empowering them to make the health and care choices they desire. However, this approach does not always fit well with health service delivery models and may be part of the reason why some apparently effective interventions seem to work less effectively with certain social groups and hence worsen health inequalities – so-called ‘intervention-generated inequalities’.<sup>56</sup> The apparently intractable problem of the continuing high prevalence of smoking in pregnant teenagers provides an illustration. Hilary Graham<sup>57</sup> has pointed out

how the emphasis on changing behaviour combined with stigmatisation of smokers has led to an impasse and that viewing tobacco control policy through a social class and social inequalities lens is likely to be more helpful. One implication of the context-specific nature of effectiveness is the importance of carrying out effectiveness trials in disadvantaged groups or making sure that trials aimed at the general population can be analysed to show effects in disadvantaged sub-groups of the population.

Another area where context has been important is in trying to tackle the higher infant mortality rate and prevalence of some birth defects seen in certain minority ethnic groups in England. Periodic emotive calls to ban cousin marriages have caused alarm and concern among these communities. Instead, there is a need to commission enhanced antenatal, paediatric and genetic services for these communities both to improve awareness of risk and to help to care for the increased number of children with birth defects.<sup>58</sup>



***This sculpture uses the wardrobe as a metaphor to explore feelings about family, home and identity.***

Source: Kids Company



**Child's drawing from Kids Company's gallery**

Source: Kids Company

### Mechanisms: what basic science tells us

Plausible mechanisms exist to explain the effects of a number of risk factors on the developing fetus and on the fetal brain in particular. For example, the effects of toxins in cigarette smoke, illicit street drugs and alcoholic drinks on organs, tissues and cells have been studied extensively in animal models and, to a limited extent, in humans. Full consideration of the basic science is beyond the scope of this report but the following important principles have been established:

- Both nature and nurture are important: the complex interplay of both genetic and environmental factors<sup>59</sup> is fundamental in determining exposure to risk, susceptibility to risk and future outcomes. In particular, some pregnant women will be much more susceptible to the effects of certain risk factors than others.

- Certain risk factors during pregnancy (e.g. starvation, obesity, smoking and alcohol consumption) can change the expression of certain genes during development resulting in longer-term effects on child and adult health.<sup>60</sup> This is now generally referred to as **fetal programming**.<sup>61</sup>

**This mechanism can help to explain why some risks during pregnancy (e.g. under-nutrition) can be transmitted to the following generation.**

### What we still need to find out

There is still a lot we do not understand about brain development and, although the scientific basis of fetal programming is becoming clearer, there is still no evidence that interventions are able to alter the process. While pregnancy is undeniably an important period in development, so are later periods in childhood and adolescence. Furthermore, even the best constructed of the multifaceted interventions do not protect against the experience of being brought up in poverty.

There is much that we still need to find out including:

- The relative importance of fetal programming to later problems such as neurodevelopmental problems or childhood obesity and whether it can be altered to improve outcomes.
- How the relationship between humans and the microorganisms (principally bacteria) which live in or on them<sup>62</sup> can become perturbed during pregnancy<sup>63</sup> potentially causing disease, and how the development of healthy gut microorganisms early in a child's life can be affected by breastfeeding and potentially by dietary supplements of bacteria (probiotics).<sup>64,65</sup>
- In developing countries severe iodine deficiency in pregnancy is associated with neurodevelopmental health problems in the offspring.<sup>66</sup> Recent evidence suggests that, in the general population of UK women, even mild deficiency of iodine during pregnancy may be an important determinant of changes in child cognition.<sup>67</sup> These findings reinforce the need for a balanced diet in pregnancy but also support iodine supplementation during pregnancy.<sup>68</sup> Further work in this area is required.
- While the cause of preterm birth can be established in some cases, in most the cause is not fully understood. This may be part of the reason why interventions to date have had limited success. Therefore, further work is needed to investigate the causes of preterm birth and how to prevent it.
- Despite promising work in the new science of epigenetics,\* we still do not understand exactly how poverty 'gets under the skin' to cause problems during pregnancy and in later child development. In particular, the extent to which some of the problem might be mediated by psychosocial stress as opposed to material deprivation needs to be elucidated.<sup>69</sup>
- How we can better engage with disadvantaged groups of women both pre-conceptionally and during pregnancy to support them to make healthy choices. To what extent do we need to target health services to certain groups in order to improve outcomes and which services would be better provided universally?

\* Epigenetics is the understanding of how chemical modification of DNA or the histone protein cover of DNA affects the switching on or off of genes. This allows effects to be passed along generations – work done on nicotine exposure in pregnant rats showed that not only do their offspring develop asthma, so do future generations.

- What interventions are helpful for women to improve and optimise mental health during pregnancy? New mindfulness group-based stress reduction programmes appear promising but need further evaluation in this context.

Some of this will require more work on the basic science and possibly new and more robust research methods<sup>70</sup> in humans. The long period between pregnancy and the development of adult disease makes large intervention trials such as those done by Olds a very challenging and expensive option.<sup>8</sup> Animals such as rodents have much shorter life spans and we can control aspects of the environment as well as genetic variation to create models of the human situation. However, the extent to which findings from these models can be translated to humans remains open to debate. The large birth cohort studies conducted in the UK such as the Avon Longitudinal Study of Parents and Children,<sup>2</sup> the Millennium Cohort Study<sup>71</sup> and the newly established Life Study<sup>72</sup> will continue to be extremely valuable resources allowing researchers to follow up children from birth and through childhood to adult life. In the meantime, it is important to make sure that we implement what we already know works and to ensure that it works in an equitable manner in all groups of the population.



### Key messages for policy

- In order to achieve giving 'every child the best start in life', policy makers need to prioritise interventions that reduce adverse outcomes of pregnancy. This will require a greater investment in research and expansion of services for pregnancy and the early years. This needs to address the quality of both universal care and support and of services which provide a more targeted approach, and not one at the expense of the other.
- Pregnancy is the very start of child development and a time when women are often more motivated to make healthy choices. Most women are in contact with services and hence there is the potential to intervene and make a difference.
- The science of fetal programming demonstrates that exposure during pregnancy to poor nutrition, obesity, smoking, alcohol and stress can adversely affect later health as a child and adult. Some of these effects are likely to be transmitted to subsequent generations.
- Optimising maternal mental health during pregnancy needs to be given equal prominence to optimising maternal physical health in policy as it is a major influence on future child development and outcomes. Linking the pregnancy and public mental health policy agendas would be an excellent first step. This should be done at all levels – from local Health and Wellbeing Boards through to Public Health England and the Department of Health. Furthermore, implementation of guidance in terms of identification, referral support, appropriate treatments and further education and training for those who work with pregnant women and new mothers is fundamental.
- Social factors including poverty may constrain a woman's ability to make healthy choices and result in inequalities in pregnancy outcomes. Tackling social disadvantage early in pregnancy can lead to major improvements in child health outcomes.
- Health interventions during pregnancy may have benefits for other sectors beyond health. It is important to consider the costs to education, justice and social services which can be averted by increased investment in the antenatal period.
- Disadvantaged groups of pregnant women may better engage with less stigmatising approaches to health promotion, for example smoking cessation. There is an opportunity for innovative approaches to reduce this health inequality through the newly established local authority public health departments working with their partners in health.
- Multifaceted intervention programmes such as the Nurse-Family Partnership which help disadvantaged mothers to engage with multiple health behaviours at the same time hold great promise.
- Preterm birth causes a considerable amount of neurodisability; we still do not know the cause or how to prevent it in most cases.
- Policy makers should continue to ensure that care for mothers is holistic and integrated both vertically and horizontally.

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## Chapter 6

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# Life stage: Early years

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### Key statistics

- Around 12.5% of toddlers are obese<sup>1</sup> and, although the number of obese children entering school has fallen, the percentage is still high at around 9–10%.<sup>2</sup>
- Around 90% of toddlers consume energy-dense snacks daily and 70% consume sugar-sweetened beverages.<sup>3</sup>
- One in eight toddlers are anaemic, with around 35% among minority ethnic children and white children from impoverished inner-city areas.<sup>4</sup>
- Vitamin D deficiency has a prevalence of around 12% with as many as 40% of young children having levels below the accepted optimal threshold despite early interventions such as Healthy Start.<sup>5</sup>
- Around one in four children have missed all or part of their MMR vaccination and are not therefore protected against measles, mumps and rubella.<sup>6</sup>
- Only two-thirds of young children are securely attached to at least one caregiver,<sup>7</sup> and around 80% of children who are abused have a 'disorganised' attachment.<sup>8</sup>
- By 3 years of age, children from poor families have heard 200,000 discouragements and 75,000 encouragements, while children from professional families have heard 80,000 discouragements and 500,000 encouragements.<sup>9</sup>
- Over half of the nursery-age children living in areas of disadvantage have language delay,<sup>10</sup> with evidence of as many as 70% of children experiencing such problems in some cities.<sup>11</sup>
- For every £1 spent on early years education, £7 has to be spent to have the same impact in adolescence.<sup>12</sup>
- The benefits of early intervention are significantly higher than the costs, with rates of return on investment significantly higher than those obtained from many other sources of public and private investment.<sup>13</sup>
- Just under half (42%) of children with a Child Protection Plan are under 4 years of age.<sup>14</sup>
- Over two-thirds of children killed at the hands of another person in England and Wales are aged under 5 years, with the parent being the principal cause of death in two-thirds of these cases.<sup>15</sup>
- Under-5 mortality in the UK is higher than other comparable Western countries with many of these deaths being in infants, and many also being preventable.<sup>16</sup>

## Overview

The preschool years, including both infancy (birth through to age 1 year) and toddlerhood (1 to 3 years), involve children undertaking a number of important developmental tasks relating to their physical development (e.g. establishing healthy patterns of eating and activity), social and emotional development (e.g. establishing a capacity for self-regulation via their attachment relationship to the primary caregiver) and language and cognitive development (e.g. early acquisition of both expressive and receptive language skills, and wider learning). *Fair Society, Healthy Lives*<sup>17</sup> suggested that in order to reduce future social and health inequalities we need to give every child the best start in life, and this reflects the view that **the origins of much adult disease lie in the 'developmental and biological disruptions occurring during the early years of life'**<sup>18</sup> and more specifically what has recently been referred to as **'the biological embedding of adversities during sensitive developmental periods'**.<sup>17</sup>

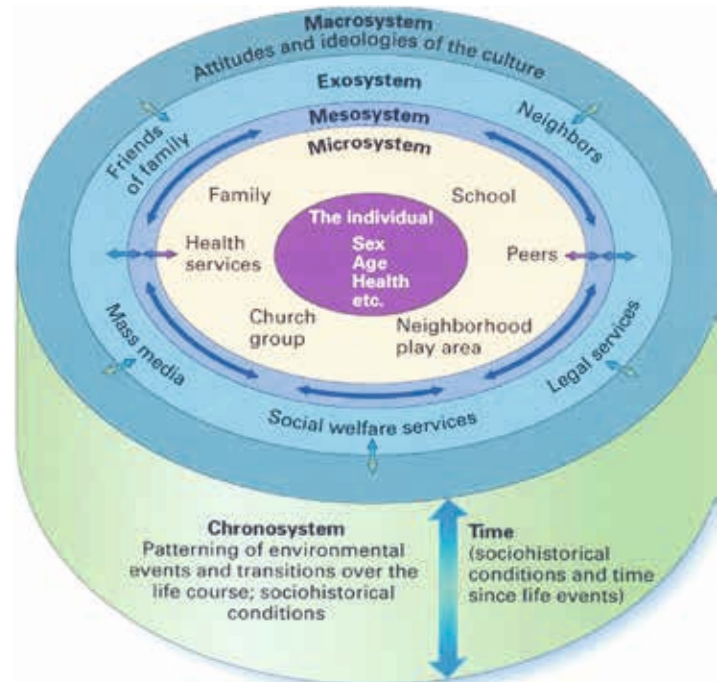
This chapter examines the evidence about the key aspects of development during the early years alongside the nature and prevalence of problems that can arise at this time, and the association between these problems and later child outcomes. The chapter also examines the key drivers of outcomes across the above three developmental domains, focusing in particular on factors at the level of the child, parent and wider ecological context, and what works to build resilience during the preschool years. Bronfenbrenner's Ecological Model<sup>19</sup> is a particularly useful frame of reference for this age group.

Bronfenbrenner's Ecological Model indicates the many aspects of the environment that can have an impact on the child, ranging from his/her immediate family, siblings, peers and school (Micro/Mesosystems) through to the wider environment including the neighbourhood, parents' work environment, extended family and mass media (Exosystem), and the wider environment beyond that including the socio-economic and political, cultural and legal contexts (Macrosystem). These factors can interact with each other (see Figure 6.1) and are also influenced by the Chronosystem which includes a range of sociohistorical patternings and conditions.

### Physical development

The early years are important in terms of building children's physical resilience. **Optimal nutritional intake (e.g. in terms of iron and vitamin D) alongside the development of healthy eating and activity patterns have been identified as key to building resilience and protecting against later chronic diseases.** Breastfeeding, for example, protects children from a range of later problems including reducing the risk of ear (otitis media) and lung infections, asthma, obesity and diabetes, sudden infant death syndrome (SIDS), dermatitis, gastrointestinal disorders (coeliac and inflammatory bowel disease) and leukaemia,<sup>20</sup> and may also have an impact on neurodevelopmental outcomes including intelligence.<sup>21</sup>

Figure 6.1 Bronfenbrenner's Ecological Model



However, iron deficiency anaemia may be one of the consequences of prolonged breastfeeding alongside an excessive intake of cow's milk and limited diet; around 30–40% of preschool children have iron deficiency anaemia.<sup>22</sup> In infancy and the early years, this is associated with a range of later problems including impaired psychomotor and/or mental development<sup>23</sup> and social emotional development.<sup>24</sup> Vitamin D deficiency may be another consequence in addition to the reduced levels of exposure to sunlight that many children experience as a result of the increased time spent indoors; it has a prevalence of around 12% with as many as 40% of young children having levels below the accepted optimal threshold.<sup>25</sup> Vitamin D deficiency impacts on children's physical development, and is associated with adverse outcomes such as rickets, hypocalcaemic convulsions and motor delay.<sup>26</sup> This has occurred despite the implementation of a targeted approach to supplementation (e.g. Healthy Start vitamins), and suggests the need for a universal approach.<sup>27</sup>



**Food Queue: A section from a sculpture by a young person representing her journey from the streets to Kids Company.**

Source Kids Company

Recent research also shows that many children consume inappropriate foods during the preschool years, many of which are introduced during infancy, and which are in excess of their energy requirements.<sup>28</sup> While the number of overweight children entering Reception classes at age 4 years appears to be levelling off,<sup>2</sup> the overall prevalence remains high at around one in ten children.

It is also of concern that children are less physically active than previously at a time when there is excessive energy intake. Scottish children as young as 3 years, for example, have been found to display a predominantly sedentary lifestyle<sup>29</sup> which is well below the recommended level.<sup>30</sup> A recent study of Dutch families showed that one in ten 2–4 year olds had a television in their bedrooms, and one-fifth of parents reported having little time to go out with their child.<sup>31</sup>

The neighbourhood environment in terms of safe play areas and traffic control as well as provision of appropriate sports and leisure facilities are examples of the exosystem influences on physical development. At the macrosystem level, there is also a growing recognition that marketing of foods high in sugar, fat and salt to very small children needs to be appropriately monitored and controlled.<sup>32</sup>

### Injury

Unintentional injuries are one of the major causes of both morbidity and mortality during the early years, with a significant proportion (around 14.5%) of attendance at Accident and Emergency departments being children under 10 years of age,<sup>33</sup> with a 6% increase between 2007/08 and 2009/10.<sup>34</sup> Hazard surveillance and home safety schemes have been shown to have a significant impact on injury reduction in young children,<sup>35</sup> and local authorities have an important role to play in ensuring that public housing allocated for families with young children is fitted with appropriate safety equipment, and that injury hazards are minimised.

Intentional injury in the UK has increased over the past 5 years<sup>6</sup> and is linked with levels of violence in society as a whole. When levels of stress are high due to inter-parental conflict, lack of basic resources or unemployment, for example, this lowers the threshold for abuse (see the section on 'toxic stress' below).

### Protection from infectious disease

Immunisation is one of the most effective public health interventions. High rates of immunisation are necessary to protect individuals and the community from the diseases against which vaccination has been developed. Public confidence in the system was undermined in the 1970s, and again in the late 1980s, when concern was raised about the potential harms of whooping cough and MMR immunisations respectively. This led to excessive cases of both pertussis and measles, and a number of deaths.

One of the key issues in terms of increasing protection from infectious disease is to ensure that the most socially vulnerable are fully immunised<sup>36</sup> (e.g. looked-after children

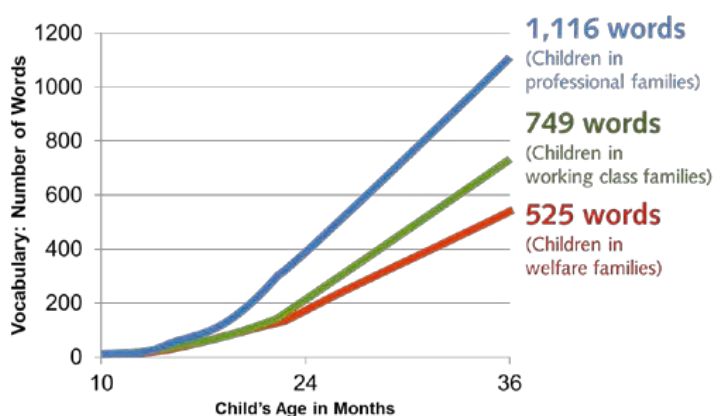
and young people have substantially lower immunisation rates<sup>37</sup>), and public confidence remains high.

### Language and cognitive development

The brain is highly sensitive during the early years in terms of the development of a range of skills including language and cognition. The preschool years are as such an optimal time for the development of early receptive and expressive language skills, and recent research suggests that **the age of functional language acquisition impacts on not only later reading and language behaviour, but also the 'corresponding neurocircuitry that supports linguistic function into the school-age years'**.<sup>38</sup>

Figure 6.2 shows the wide disparity in children's exposure to words across socio-economic groups during the first three years of life that was identified in one study. Early exposure to language-rich environments and reading schemes at home and in early years settings have been shown to enhance language development.<sup>39</sup>

**Figure 6.2 Word exposure at 3 years by socio-economic group (adapted from Hart and Risley)**



A number of longitudinal studies have also shown that early cognitive ability influences later educational outcomes, with evidence to suggest that assessments of ability at 22 and 42 months predict educational outcomes at age 26 years.<sup>40</sup>

### Socio-emotional development

One of the developmental tasks of the early years is the capacity for emotional regulation, and this lays the necessary foundation to enable children to negotiate later developmental tasks. **Attachment is a significant bio-behavioural feedback mechanism that evolves during the first and second years of life in response to early parenting, and plays a key role in the development of emotional regulation both during the early years<sup>41</sup> and across the life span.**<sup>42</sup> Evidence from a number of longitudinal studies has demonstrated that securely attached children function better across a range of domains including emotional, social and behavioural adjustment, as well as peer-rated social status and school achievement,<sup>43</sup> in addition to having better physical outcomes.<sup>44</sup> More recently,

disorganised attachment has been found to be a strong predictor of later psychopathology.<sup>45</sup>

**Toxic stress, which is characterised by the infant or toddler's prolonged exposure to severe stress that is not modulated by the primary caregiver, who may be experiencing a range of problems (e.g. poverty, mental health problems, domestic violence and substance/alcohol dependency), has been identified as having a significant impact on the young child's rapidly developing nervous system, development, health and wellbeing across the life span.**<sup>46</sup>

This form of stress leads to atypical parent–child interaction, which can represent a significant form of early emotional abuse and neglect.<sup>47</sup> **Recent research suggests that decision making in terms of the need for the removal of children is not currently being undertaken in accordance with children's developmental needs.**<sup>48</sup>

The exo and macrosystems are also important in relation to children's social and emotional development. For example, the schools and neighbourhoods in which children grow up have been identified as playing a significant role in children's later development, with evidence to suggest that factors such as chronic noise, poor quality housing, lack of access to natural environments, and traffic density and flow can all have an impact on the wellbeing of young children.<sup>49</sup>

### The caregiving environment

Evidence from diverse disciplines has shown that the early caregiving environment, and in particular parenting, mediates around 50% of the impact of many of the contextual factors (e.g. poverty) that influence children's early development,<sup>50</sup> in addition to having direct effects on children's wellbeing.

In terms of children's physical development, parental feeding practices affect children's food preferences and their



**Vegetable Monster: Created by children at a Summer Holiday Healthy Living Workshop to learn about, and conquer fears over, vegetables.**

Source: Kids Company

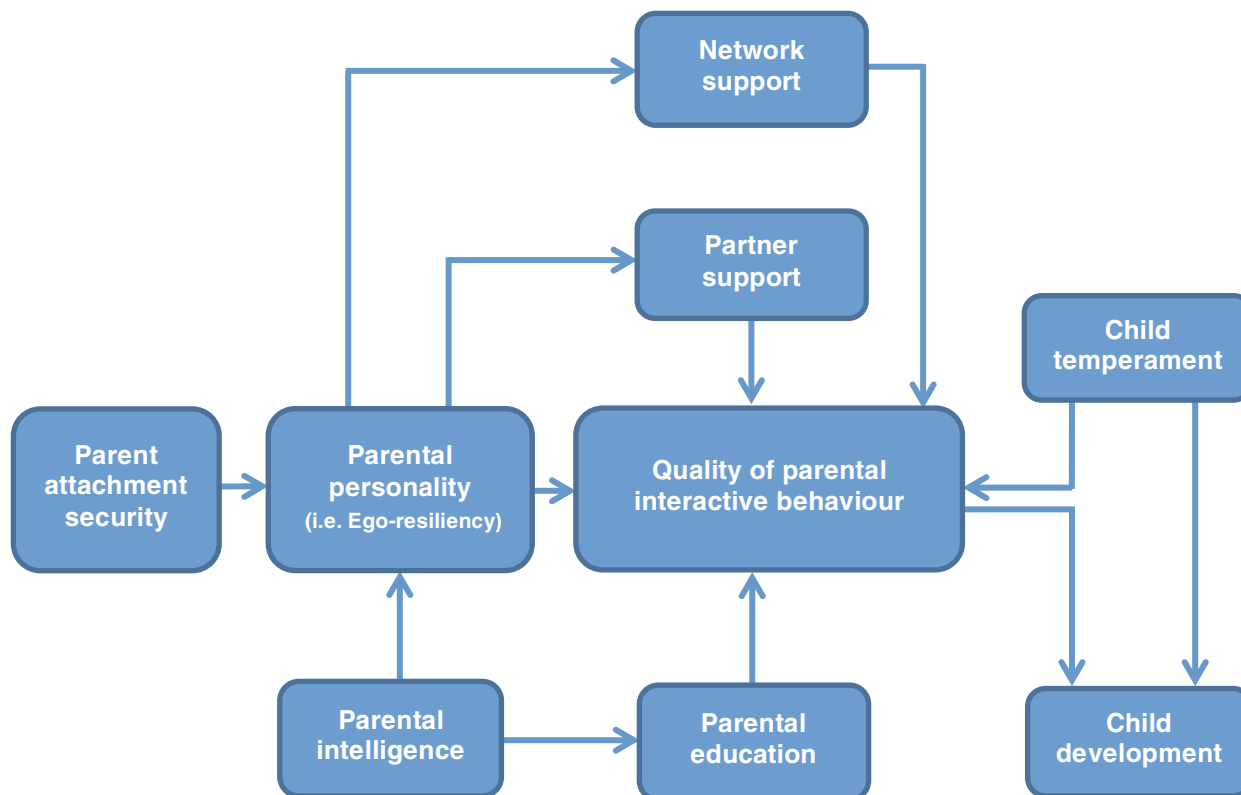
regulation of energy intake,<sup>51</sup> and early dietary patterns that are established during weaning may persist into the second year of life and beyond. Parenting styles and feeding practices such as family eating patterns (shared or separate meals), parental control of overeating (pressure, restriction and monitoring), emotional feeding (excessive feeding to calm a child) and instrumental feeding (use of food as a reward) are all associated with childhood obesity.<sup>52</sup> Likewise, parental activity levels and sedentary behaviours have also been shown to predict activity levels in children.<sup>53</sup>

Parenting is also one of the key factors influencing children's early socio-emotional development. For example, **parental sensitivity<sup>54</sup> and parental mind-mindedness<sup>55</sup> are significant predictors of infant attachment security.** Research has also demonstrated a clear link between later parenting practices (e.g. characterised by harsh, inconsistent discipline, little positive parental involvement with the child, and poor monitoring and supervision) and child antisocial behaviour.<sup>56</sup> **Positive, proactive parenting (e.g. involving praise, encouragement and affection) is strongly associated with high child self-esteem and social and academic competence, and is protective against later disruptive behaviour and substance misuse.**<sup>57,58</sup>

Parental sensitivity, engagement and verbal stimulation in interaction have also been shown to be important in terms of early speech, language and learning, with such sensitivity and engagement being more likely to be compromised in parents who are poor, less educated and know less about parenting.<sup>59</sup> Aspects of early language development such as word learning are also improved where parents engage in joint attention activities with their children,<sup>60</sup> and where the caregiver is responsive in terms of the attention and vocalisation of the child.<sup>61</sup> **Recent research has also found that indicators of household chaos and in particular household disorganisation accounted for significant variance in expressive and receptive language at 36 months** (after controlling for 13 covariates including maternal education and poverty).<sup>62</sup>



**Figure 6.3** Pattern of relations among parental, contextual and child characteristics; quality of parental behaviour; and child development. Adapted from Hedwig et al 2002<sup>63</sup>



## Factors that moderate the impact of parenting

A range of factors have been identified as influencing parents' capacity to parent. In addition to the cultural and socio-economic factors referred to earlier in this chapter (e.g. poverty and parental education), a number of aspects of the parent's environment (e.g. social support and partner support) and internal functioning have been identified as also playing a role. These are captured in Figure 6.3 which depicts the pattern of relations among parental, contextual and child characteristics, quality of parental behaviour and child development.

At a socio-political level, poverty is one of a number of factors (including young maternal age, family size and low maternal education) that can have both a direct influence on children's wellbeing via the physical environment (e.g. housing), but also an indirect impact in terms of its influence on the parenting that children receive. **Poverty has significant consequences in terms of both the physical health of preschool children<sup>64</sup> and their wider functioning (e.g. language development).**<sup>65</sup> One study, for example, showed that by 3 years of age, children from poor families had received 200,000 discouragements and 75,000 encouragements, while children from professional families had received 80,000 discouragements and 500,000 encouragements.<sup>66</sup>

In terms of the internal functioning of the parent, their own attachment status predicts the infant's likelihood of being securely attached,<sup>67</sup> and the parent's ability in relation to affect

regulation (i.e. their ability to manage stress, anger, anxiety and depression) also has a significant impact in terms of the development of mental health problems and psychopathology in the early years.<sup>68</sup> More generally, **factors such as severe mental illness,<sup>69</sup> substance dependency<sup>70</sup> and domestic violence<sup>71</sup> have all been identified as having a significant impact on parenting during this period.**

A number of factors at the level of the child have also been identified as moderating the impact of the early caregiving environment, and Figure 6.4 demonstrates the potential interaction of competencies and vulnerabilities at the level of the parent and the child in terms of later outcomes, with the poorest outcomes occurring where vulnerable children are parented by vulnerable adults.

**Figure 6.4** Predicted infant/preschool child outcomes without intervention. Adapted from Weatherston and Tableman (2002. p. 5)<sup>72</sup>

| Parent     | Infant/preschool child |            |
|------------|------------------------|------------|
|            | Competent              | Vulnerable |
| Competent  | Optimal                | Poor       |
| Vulnerable | Poor                   | Very poor  |



A further area in which there has been considerable interest is children's temperament, with some evidence about the role of early temperamental difficulties (e.g. infants/toddlers who are highly negative and reactive or behaviourally inhibited) in modifying the impact of the environment (e.g. parenting).<sup>73</sup>

However, overall the direction of causality remains inconclusive with some evidence to suggest that infants with more extreme temperamental characteristics (e.g. very low on irritability) may be less affected by the environmental input than infants with more moderate levels of such qualities.<sup>74</sup>

**More recent research has supported the concept of 'differential susceptibility', which suggests that children's genotypes interact with their caregiving environment to influence the impact of the latter.** For example, gene–environment studies show that children with a short *5-HTTLPR* allele have very unfavourable outcomes when parenting is compromised, but that these children also have significantly better outcomes than usual when parenting is better than average.<sup>75</sup>

### Effective support for optimising health and development during the early years



**Smiling Table: A mood table to show what children love to do.**

Source: Kids Company

The Healthy Child Programme – Pregnancy and the First Five Years of Life<sup>76</sup> recommends a range of evidence-based interventions that are aimed at building resilience in early childhood across all developmental domains. The delivery of the programme is based on a proportionate universal approach that involves adapting interventions according to risk factors present in the community, with the aim of achieving equitable outcomes for all children.

### Physical

While the evidence concerning the causes of childhood obesity is mixed, there is increasing consensus that primary interventions that address feeding styles and activity levels in early life are important for later weight status and health outcomes, and that parental practices have a central role in reducing children's exposure to obesogenic environments.

**The importance of intervening in infancy and toddlerhood to prevent obesity has been highlighted by recent research,** which suggests the potential benefit of multi-component behavioural interventions in preventing the development of obesity in infants and toddlers.<sup>77</sup> Health visitors and early years education workers have a key role in the delivery of such interventions, particularly in terms of supporting parents to provide the optimal nutritional intake during the preschool years (e.g. highlighting the need for dietary supplements during breastfeeding and early childhood). Enhancing physical activity and maintaining progress on immunisations, as described in other chapters, are also fundamental.

### Language

Evidence about the importance of the quality of the home learning environment and early preschool education,<sup>78</sup> particularly for children living in socio-economically deprived circumstances, has identified the need for intensive early intervention. Possibly one of the most successful early intervention programmes targeting disadvantaged children is the HighScope Perry Preschool Program, which involves 'active participatory learning' aimed at helping children to excel in language and cognitive learning and promoting independence, curiosity, decision making, co-operation, persistence, creativity and problem solving.<sup>79</sup> A longitudinal study found that this way of working with children resulted in them having higher earnings at age 40, and being more likely to keep a job, less likely to commit a crime and more likely to have graduated from high school than adults who did not receive this preschool programme.<sup>80</sup> A range of UK-based programmes aimed at improving the early home learning environment (e.g. Bookstart; Campaign for Learning; Home Start's Listening and Learning with Young Children; I CAN; Newpin's Family Play Programme; One Plus One's Brief Encounters; PAFT; PEAL; PEEP; PICL; SHARE; and Thurrock Community Mothers) were evaluated as part of the Early Learning Partnership Project. These programmes were found to be beneficial in terms of improving the parent's relationship with the child and opportunities for children to learn from day-to-day activities.<sup>81</sup>

### Case study

#### Stoke Speaks Out – Stoke-on-Trent City Council

Speech and language delay has a direct impact on children's development and educational outcomes, health and wellbeing.

Stoke Speaks Out is tackling the high incidence of language delay identified in young children across Stoke-on-Trent through a preventive, multi-agency approach. In 2002 local studies identified that 64% of children were entering nursery with significantly delayed language skills. By 2010 this was reduced to 39% of children.

A multi-agency training framework ensures joined-up messages and thinking, and shared knowledge focusing on early attachment, the role of the carer, child development and strategies to support development. The training has reached over 4,500 practitioners working with children and families. They in turn have adapted their practice to ensure that the needs of families and children are met.

In the long term this will support children to reach their full educational potential and will benefit their mental health, career prospects and their own parenting skills.

### Socio-emotional

A range of methods of working have been identified that promote children's early resilience by helping parents to provide parenting that supports the development of optimal socio-emotional regulation. The Healthy Child Programme recommends the provision of methods of supporting early parenting (e.g. skin-to-skin care and infant carriers)<sup>82</sup> within the context of universal services (e.g. midwifery and health visiting), and the use of such universal-level services to identify families who are in need of additional support, using techniques such as ante and postnatal promotional interviews.<sup>83</sup> It also recommends the use of a range of targeted methods of working to promote early attachment and positive parenting methods more generally. 'Attachment-based' interventions include methods of working that focus directly on changing parental behaviours (e.g. using techniques such as video-interaction guidance),<sup>84</sup> or that operate indirectly in terms of changing parental behaviours by intervening to change parental capacity for affect regulation (e.g. mindfulness-based programmes such as Parents Under Pressure)<sup>85</sup> or parental internal working models (e.g. parent-child psychotherapy).<sup>86</sup> A review of attachment-based interventions showed that they are effective in improving parental sensitivity and infant attachment security.<sup>87</sup> There is also consistently strong evidence to support the use of interventions such as home visiting programmes (e.g. Family Nurse Partnership) during the perinatal period.<sup>88</sup>

Brief, group-based parenting programmes that are focused primarily on enabling parents to support their children's growing independence using positive methods of discipline and good supervision have been shown to be effective in the short term in improving both parental psychosocial functioning<sup>89</sup> and the emotional and behavioural adjustment of young children.<sup>90</sup>

### What we still need to find out

There has been rapid progress in our knowledge about the importance of the preschool years in terms of building early resilience, but there is still more that we need to know about a number of issues:

- Research is needed that involves the application of a Common Practice Elements Framework<sup>91</sup> to identify some of the common elements of the different programmes that are currently used to target a range of outcomes during the early years. For example, many programmes that target both early language and attachment focus on improving parental sensitivity and interaction with the child.
- Although we now recognise the importance of toxic stress<sup>46</sup> for young children and the various components that contribute to such stress, further work is needed in terms of practical ways of monitoring the levels of toxic stress to which children are exposed in the UK.
- Further UK-based research is needed to identify effective methods of preventing obesity in infants and toddlers.
- More research is needed to increase our understanding about the concept of differential susceptibility<sup>75</sup> and what other factors in addition to genotype make some children more resilient to early adversity.
- Our knowledge about 'what works' in preventing abuse during the preschool years is still insufficient,<sup>92</sup> and there is a need for further research about effective methods of working and supporting high-risk pregnant women and vulnerable mothers of babies and toddlers.

## Key messages for policy

- The early years lay the foundations for later resilience in terms of key aspects of children's development, and investment during this period therefore has considerable potential cost benefits.
- Investment should be made in both universal and targeted services as recommended by the Healthy Child Programme, which should be commissioned *in full*. Where targeting has not made an impact (e.g. vitamin D supplementation), universal approaches should be considered if such an approach is also cost-effective.
- Universal services such as midwifery and health visiting provide key opportunities to identify families in need of additional input.
- Improved training and competence of the early years workforce in evidence-based child health and development interventions are needed to increase the life chances of disadvantaged children.
- Early years services should focus on reducing the toxic stress experienced by many disadvantaged children.
- There is a need for an increased focus on improving the attachment security of all children, and improved decision making is required to identify children about whom there are child protection concerns to prevent disorganised attachment.
- The primary prevention of obesity should begin in infancy with the delivery of interventions aimed at improving the eating and activity patterns of young children.
- The early learning and language of disadvantaged children should be targeted using intensive, high-quality home and centre-based interventions.
- Improvement is needed in information sharing across key groups of practitioners (e.g. midwives, health visitors and early years workers) and support should be provided for continued and rapid development of child health information systems.
- Continued integration is needed between the Department for Education and the Department of Health on the Healthy Child Programme and Early Years Foundation Stage across the early life course, combining them at key points, as with two-year assessment.
- Sure Start centres should focus on bringing together as many aspects of early years provision as possible, e.g. antenatal care. Centres should increasingly focus on improving Ofsted scores where these are poor.

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## Chapter 7

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# Life stage: School years

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### Key statistics

- Currently there are around 8.2 million pupils in all schools in England. Some 4.3 million pupils are in state-funded primary schools and 3.2 million pupils in state-funded secondary schools.<sup>1</sup>
- Eligibility for free school meals is a marker of social deprivation. Pupils known to be eligible for and claiming free school meals account for 19.2% of pupils in maintained nursery and state-funded primary schools and 16.3% of state secondary school pupils. Among pupils in special schools the figure claiming free school meals is much higher (38.3%) and even higher for pupils attending referral units and alternative provision academies and free schools (40.1% of pupils).<sup>1</sup>
- 31% of school pupils in 2012 aged 11–15 who reported having a long-term illness, disability or medical condition felt it impacted negatively on their ability to participate in education.<sup>2</sup>
- The National Child Measurement Programme reported that in 2011/2 over a fifth (22.6%) of the children measured in Reception were either overweight or obese. In Year 6, this proportion was one in three (33.9%). The percentage of Year 6 (19.2%) who were obese was over double that of Reception year children (9.5%).<sup>3</sup>
- Studies consistently identify that only a minority of young people meet the Chief Medical Officer's guideline for physical activity. The proportion meeting the guideline declines with age, most notably among girls.<sup>2,4</sup>
- In 2012, boys aged 11–18 years, on average, consumed 3.1 portions of fruit and vegetables per day and 13% met the 'five a day' recommendation. Girls in the same age group consumed 2.7 portions per day and 7% met the recommendation.<sup>5</sup>
- 12% of boys and 17% of girls aged 11–15 in 2012 reported never eating breakfast on weekdays.<sup>2</sup>
- The majority of young people in 2012 (88%) reported feeling well supported by their parents and 95% reported that they were encouraged by their parents to do well at school.<sup>2</sup>
- In 2012, there were 1,174 whole-time equivalent qualified school nurses to meet the needs of the school-aged population,<sup>6</sup> which equates to one nurse per 6,985 children.
- In 2013, Ofsted reported that in 40% of schools in England the quality of personal, social, health and economic education required improvement or was inadequate.<sup>7</sup>
- Among 5–9 year olds the most common causes of death are malignant neoplasms and leukaemia, followed by cerebral palsy and traffic accidents among boys and influenza among girls. Unintentional injuries and accidents are the leading cause of mortality among all secondary school children (10–19 years).

## Overview: resilience and the school-aged population

The middle years of childhood and early adolescence are sometimes assumed to constitute a period of good health often characterised as a time unburdened by adult stressors. While it is true that the health of children has improved over the past decade, a number of national and international reports have highlighted that the reality of childhood is very different, with marked and persisting inequalities in the area of child wellbeing in the UK.<sup>8,9,10</sup> Major life events such as illness and family breakdown, as well as economic and material hardship, are realities for many children and younger adolescents that impact on their development and ability to reach their full potential. Having a long-term condition or disability in childhood can also have a marked effect on educational accomplishment and the attainment of life goals, as well as restricting social and emotional development.<sup>11</sup> The current generation are growing up in very different environments from their parents and grandparents and are subject to new and emerging health determinants.

Strategies to improve child wellbeing have often focused on disease prevention or risk reduction. Targeting a single risk factor has limited evidence of effectiveness<sup>12</sup> and may even have unwanted negative effects. More importantly, better outcomes may result from equipping children to deal

with general life stressors.<sup>13,14</sup> *Fair Society, Healthy Lives*, published in 2010, specifically called not only for continued commitment to children and young people during the education years but also for policies to maximise capabilities in order to sustain reductions in inequalities achieved by early years interventions.

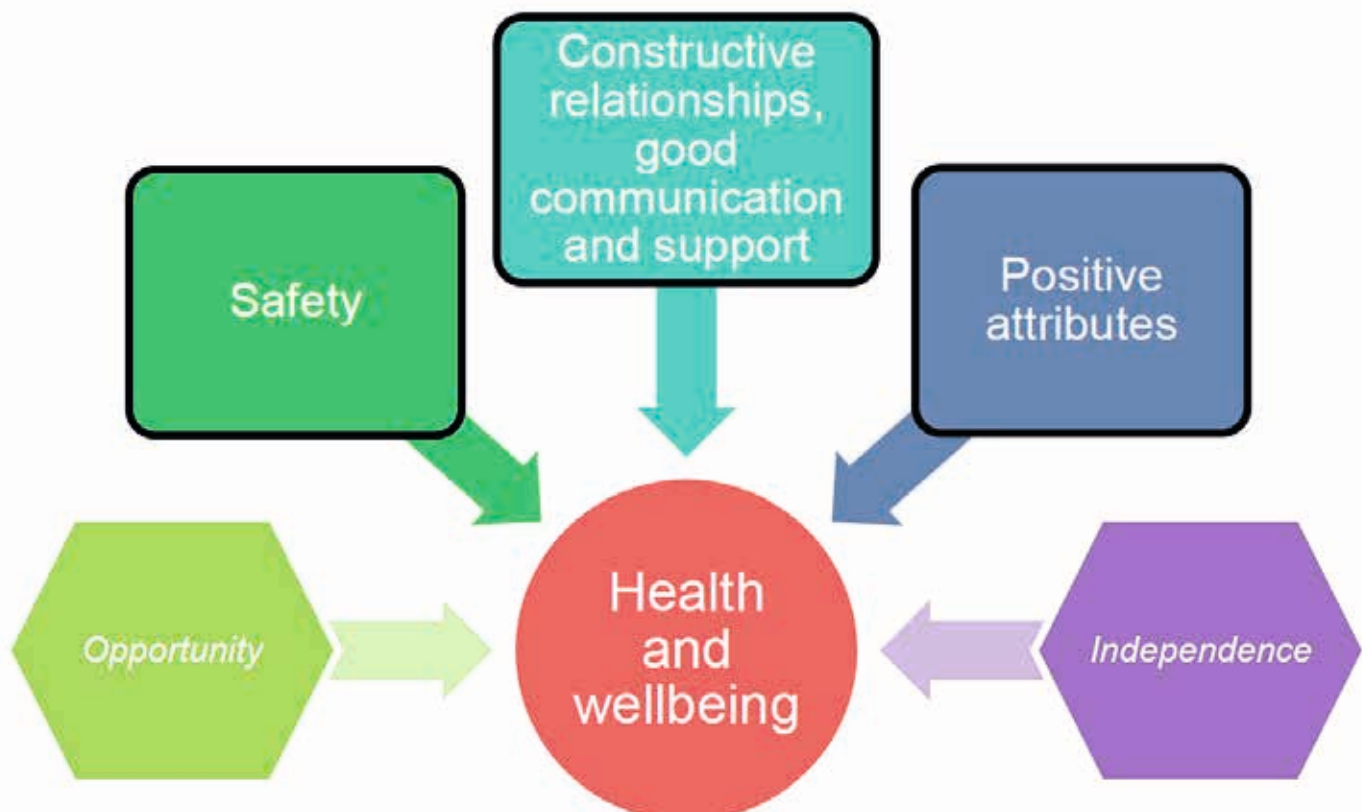
There is evidence that approaches focusing on the building of young people's social and emotional skills have greater long-term impacts than deficit-based programmes.<sup>15</sup>

**Strengthening protective factors or health assets in schools, in the home and in local communities can make an important contribution to reducing risk for those who are vulnerable and in so doing promote their chances of leading healthy and successful lives.**<sup>16,17,18</sup>

### Chapter structure

This chapter examines the protective health factors or assets that operate as key drivers for the school-aged population to enhance and sustain health and wellbeing. These **assets illustrate how promoting physical and mental health simultaneously can form a virtuous circle that reinforces overall health, wellbeing and achievement for children.** These key drivers can be conceptualised into three main areas, outlined in Figure 7.1.<sup>19</sup>

**Figure 7.1 Assets model to shape health promotion with young people**



Source: Fenton, C. 2013. *An assets based approach to health promotion with young people in England: Doctoral Thesis*. Hatfield: University of Hertfordshire.



**Constructive relationships** represent a core determinant for building resilience during childhood, a keystone asset, from which children can develop and marshal other resources that are protective of their health and wellbeing.

**Positive attributes** or a positive sense of self, encompasses concepts related to resilience such as self-esteem, self-efficacy and a problem-solving approach.<sup>20,21</sup> The facility to act autonomously, identify opportunities and pursue these to meet goals could be considered internal assets.<sup>22</sup> There are similarities between such attributes and the concept of being socially competent.<sup>23</sup>

**Safety** is a broad heading encompassing both physical and emotional safety that links to the acquisition of social and practical competencies. This encompasses notions of school and neighbourhood support and physical safety, as well as being able to set boundaries.<sup>22,24,25</sup>

This chapter will commence with a focus on the relationship between resilience and wellbeing in the core domains or environments of the child; these include the family, the school and the social networks and wider community of the child. The chapter will then consider in detail health-promoting behaviours, notably physical activity and healthy weight and diet. Throughout the chapter evidence that links to mental health status and the importance of improved emotional wellbeing are highlighted.

### Limited data

There are important gaps in the evidence base relating to childhood and the key factors that impact on development and the promotion of resilience.<sup>26</sup> For example, a recent report by the Organisation for Economic Co-operation and Development (OECD) for the European Commission highlighted that policy makers need to have better access to accurate information from surveys of children on family structure and to improved indicators on parenting practices.<sup>27</sup>

### Families and parenting

Throughout childhood and adolescence the family dynamically impacts on the child's life chances and the nature of his or her external relationships. Consideration of how parenting influences child development has often focused on the early years. More recently the importance of families in maintaining emotional wellbeing and health behaviours during middle childhood and early adolescence has been highlighted,<sup>28</sup> for example, stability and sense of belonging within a family have been linked with youth life satisfaction.<sup>24</sup>

Material disadvantage clearly plays a significant role in the ability of families to maintain their children's health and wellbeing and intersects with issues relating to both family structure and quality of interaction. The UNICEF report in 2010 which looked at the most disadvantaged children in OECD countries found that a significant dimension of child poverty and social exclusion was the quality of parental engagement and the differing levels of support offered by parents.<sup>8</sup> **The relative ability of parents to provide**

**their children with important social, educational and developmental opportunities, such as engaging leisure activities, has been termed the 'socialisation gap'. This appears to have widened over the past 30 years,** with profound implications for the maintenance of children's health and wellbeing and overall life chances of children in the poorest families.<sup>29</sup>

### Family structure

Over the past three decades the composition and structures of families in England have radically altered with significant implications for children and adolescents. Stress and conflict within families including poor experiences of family break-up can have profoundly negative impacts on child wellbeing.<sup>30</sup> One study<sup>31</sup> looked at the impact of changed family structures on life satisfaction and found that children living with both biological parents reported higher levels of life satisfaction than children living with a lone parent or with a parent and step-parent. Those who reported the lowest levels of life satisfaction were those not living with their mother. **In the Millennium Cohort Study of 15,500 children, poverty and parental mental health status have been identified as key factors that interact with family structure to produce poorer outcomes for children.**<sup>32</sup> Some protective health assets may mediate the effect of family structure on child health and wellbeing; for example, adolescents from lone parent families who participated in activities outside school were much less likely (1.8 times) to engage in substance misuse.<sup>33,34</sup>

**Key domains of parental engagement that act as protective health assets are:**

#### Communication

**A mutually interactive style, non-judgemental listening by the parent and the child believing the parent to be trustworthy, all appear to be dimensions of parental communication that contribute to child wellbeing.**<sup>35,36</sup>

The quality of parental communication can be influential for the development of pro-social values and provide children with an important resource for the management of stressful situations,<sup>13,24</sup> as well as helping them navigate adverse influences including health risk behaviours such as smoking, substance use and aggressive behaviours.<sup>37,38</sup> **For example, open family communication on sexual issues corresponds to less high-risk sexual behaviours in adolescents.**<sup>39</sup> Young people during late childhood to mid-adolescence who report good communication with their parents or guardians have higher overall life satisfaction and report fewer physical or psychological complaints.<sup>40</sup> For example, girls who find it easy to talk to their fathers report higher life satisfaction and a more positive body image than comparable peers.<sup>41</sup>

#### Parental monitoring

**How parents set age-appropriate boundaries, create rules and regulate the degree of autonomy that children exercise are key elements of parenting that contribute to children's emotional safety and security.**<sup>21</sup>

**Table 7.1 Percentage of children undertaking activities with their families**

| Activity                                                | 11 year olds |      | 13 year olds |      | 15 year olds |      |
|---------------------------------------------------------|--------------|------|--------------|------|--------------|------|
|                                                         | Girls        | Boys | Girls        | Boys | Girls        | Boys |
| <b>Watch a TV programme or DVD together once a week</b> | 79           | 78   | 74           | 78   | 72           | 73   |
| <b>Eat a meal together every day</b>                    | 58           | 55   | 54           | 55   | 46           | 46   |
| <b>Play sports together once a week</b>                 | 40           | 51   | 29           | 34   | 15           | 29   |
| <b>Talk about things together once a week</b>           | 75           | 73   | 64           | 65   | 62           | 56   |

Source: (HBSC England data) Brooks, F., J. Magnusson, E. Klemmer, N. Spencer & A. Morgan. 2011. *HBSC England National Report: World Health Organization Collaborative Cross National Study*. Hatfield: CRIPACC.

Monitoring is a core aspect of the familial environment that helps to develop self-control and decision-making skills in the child. For example, parental regulation of autonomy that involves negotiated decision making about what children do in their spare time has been associated with a reduced likelihood of participation in multiple health risk behaviours.<sup>33</sup>

### **Parental support**

Support from parents and a strong family bond are linked to positive emotional wellbeing and reduced prevalence of health risk behaviours.<sup>42</sup> Data from the Health Behaviours of School-aged Children (HBSC) study suggest that the majority of children in early to mid adolescence feel their parents are interested and engaged with them, although parental engagement and support were significantly related to family affluence.<sup>2</sup>

How families spend time together offers opportunities for positive interaction that builds and reinforces resilient capacities and health-promoting behaviours.<sup>43</sup> Longitudinal studies have identified that parental support in terms of a good relationship, and time spent in family meals and support for extra-curricular activities have been associated with both positive mental health and educational attainment.<sup>21,22,44</sup> **Family support also appears to have a significant impact on behaviour change in terms of the adoption and maintenance of healthy lifestyles by adolescents, especially physical activity.**<sup>24</sup> The HBSC study in England considered the range of activities families undertake together to give a picture of family interaction (see Table 7.1). Encouragingly, most families do find time to talk and undertake some form of leisure activity together and about half eat together every day as a family. Notably, family interaction declines with age and girls are much less likely than boys to be engaged in sport activities with their families.



**Dinner (from an educational workshop in a school)**

Source: Kids Company

### **Parenting vulnerable children and young people**

**Quality of communication with a supportive parent figure appears to be a key component in the development of resilient and coping mechanisms among vulnerable or marginalised children.** For example, a longitudinal study of primary school children found that the prevalence of emotional and behavioural problems among victims of bullying was significantly reduced if their families, parents and siblings provided warm, empathetic relationships and the home environment was calm and well structured.<sup>45</sup> In another example a recent qualitative study of very vulnerable black and minority ethnic teenage mothers who had been looked after by the care system reported that having a supportive relationship with a carer (foster parent or social worker) promoted the development of improved self-worth and reinforced a sense of self-directedness.<sup>46</sup>

Overall, studies of family communication and parenting highlight a component critical to the establishment of resilience in childhood, that of having access to at least one supportive, caring adult.

# Actions for resilience in families

## Parenting programmes

There is evidence, including National Institute for Health and Care Excellence (NICE) guidance, **that structured parenting programmes can assist parents in providing a supportive and caring relationship** and a structured home environment;<sup>47</sup> for example, The Incredible Years group programme or the Triple P stepped approach, both based on social learning theory, aim to improve child–parent interaction.<sup>48</sup> Triple P Parenting also includes levels designed to support parents with mental health problems.<sup>49</sup> Parenting programmes are widely, but not universally, available and almost exclusively targeted at families with children under 12 years.

## School

School can be an important driver of resilience in children – a protective health asset that provides children with the learning opportunities and competencies to develop a positive identity and healthy behaviours, as well as the skills that enable successful negotiation of life challenges; for example, children feeling safe in school has been associated with greater levels of social competence.<sup>22</sup>

School can also function as a risk to children’s health and wellbeing. Factors such as the experience of bullying and poor educational attainment can impact negatively on children’s mental health status, generating disconnection from school. In England and Wales, the school system is associated with two of the most significant transitions during childhood (that of starting school at age 4–5 and transferring to secondary school for the majority at age 11). **Children with long-term conditions or disabilities can find it difficult to maintain attendance and access the resources that schools offer.** For example, of school students aged 11–15 years with a long-term condition or disability, just under a third (31%) felt it impacted negatively on their participation in school.<sup>2</sup>

**There appears to be a strong association between a sense of belonging to school and wellbeing.**<sup>20,25,50</sup>

A number of studies have found that feeling connected to school (having a sense of belonging in a school) and/or teacher connectedness (having a teacher who is interested in you as a person) operate as important assets.<sup>51</sup> Longitudinal studies from the USA found that school connectedness was the only single school-related variable that was protective against participation in health risk behaviours (including violence, substance and alcohol misuse and early sexual initiation).<sup>52</sup> Liking school is also a significant predictor of attainment.<sup>53</sup> **School connectedness appears to be generated in schools through extra-curricular activities, positive classroom management and tolerant disciplinary policies.**<sup>54</sup>



**Running: A young person representing how he keeps healthy.**

Source: Kids Company

## Personal, social, health and economic education and emotional learning in school

The contribution of schools to developing resilience and enhancing wellbeing as a component of the curriculum is grounded in an extensive evidence base, for example the establishment and development of healthy relationships was identified as a teachable core competency by the Collaborative for Academic, Social and Emotional Learning (CASEL).<sup>54</sup> The Healthy Schools programme along with SEAL (Social and Emotional Aspects of Learning) for primary schools are whole-school initiatives designed to develop emotional wellbeing and healthy positive behaviours among school students.

**‘School should teach you to be healthy and make you learn to eat well.’**

## Case study

### Penn Resilience Programme in English schools

The Penn Resilience Programme (PRP) was developed by the University of Pennsylvania. The 18-lesson programme is aimed at 11–13 year olds and enables young people to develop skills that empower them to deal with setbacks and focus and thrive in intense times both in and out of school.

The PRP was implemented in 22 schools in Hertfordshire, Manchester and South Tyneside as part of a three-year research study. Some 4,000 young people participated. Since the initial research project a further 60+ schools now teach the PRP as part of the core curriculum. The lessons feel different to other lessons – they are more conversational and led by student input.

The lessons build to enable students to develop a more sophisticated understanding about their thinking style and how this impacts both on how they feel and on what they do. Students are able to think more accurately and flexibly about different or difficult situations and so are more likely to solve problems effectively, keep things in perspective, not give up and enhance their optimism and confidence.

The PRP has a strong evidence base. The findings of a three-year study led by the London School of Economics show a significant improvement in pupils' depression symptom scores, school attendance rates, academic attainment in English, anxiety scores, and maths attainment concentrated in a few groups of pupils.

The impacts varied by pupil characteristics with larger impacts for pupils entitled to free school meals, who had not attained the national targets at Key Stage 2 and who had worse initial symptoms of depression or anxiety.

Gary Lewis, Head of Kings Langley School in Hertfordshire, views the benefits of the PRP as follows:

*'Students have become more proactive in their learning, attend school readily and manage themselves (homework issues; equipment for e.g. sports lessons) more effectively. Students have increased self-efficacy leading to the setting of realistic but challenging academic targets and aspirations. UKPRP has contributed to our improved school attendance figures. Students are actively encouraged to put the skills learned in Resilience lessons into practice at home and in school. We have heard via CAMHS [Child and Adolescent Mental Health Services] that local GPs report that the PRP is having an impact.'*

## Case study

### Healthy Schools London – Greater London Authority

Healthy Schools London is a voluntary awards programme that recognises schools' achievements in improving pupil health and wellbeing across four areas: healthy eating; physical activity; personal, social, health and economic education; and emotional health and wellbeing. It provides information and support to all London schools via a website and local and pan-London training, and through a network of local leads. It builds on the success of the National Healthy Schools Programme (NHSP). Since the demise of the NHSP, not all London schools have had access to support and recognition for their work on pupil health and wellbeing. Healthy Schools London fills this gap.

Since the Healthy Schools London launch on 25 April 2013, 224 schools have registered and 66 schools have achieved a Bronze Award. Examples of work that is being undertaken across London schools include:

- increasing active travel to school
- increasing physical activity during lunch and playtimes through playground markings and playground peer monitors
- changing the dining room environment to more family-style dining

#### St Peter's London Docks Primary School, Tower Hamlets

Headteacher Liz Dickson was determined to improve the lunchtime experience for her 238 pupils.

Nearly half the children get free meals, 46% compared with the 16% national average. The school transformed their dining room experience into a family-style environment with children seated at tables served by their peers.

*'We abolished queuing because it was noisy and time consuming,'* Liz Dickson explains. *'It was an awful system where they ate on trays – we got rid of the trays and put plates and bowls on the tables with tablecloths.'*

Children have a salad bowl and dish-of-the-day at each table, served by the pupils who take turns and also set up and clear the tables themselves, taking responsibility for their own mealtimes.

St Peter's has its own vegetable garden. Waitrose, nearby in St Katharine Docks, gave the school seeds to plant and promised that the children can sell their produce outside the store when it has been harvested.



Personal, social, health and economic education (PSHE) aims to equip young people with the knowledge, understanding, attitudes and practical skills to live healthily, safely, productively and responsibly. **Children and young people appear to value PSHE and feel that it provides relevant and useful information, although older teenagers are less likely to be positive about the quality of PSHE that they receive.**<sup>2</sup> There is evidence that specialist teachers trained in PSHE deliver the most effective health-related teaching, especially in relation to the topics that children are reported to be most likely to want information about, including health exploratory behaviours and sexual health.<sup>55</sup>

PSHE also offers an opportunity for young people to access advice and guidance relating to new and emerging health risks. Children and young people are part of a digital, online generation. It is estimated that the majority of children under 1 will have a 'digital shadow'\* and the majority will have some experience of the internet by age 2. Children and young people in England are among the highest users in Europe of video games and communicate with peers via electronic media more than children in the majority of countries.<sup>2</sup> While new technologies can offer numerous educational and some pro-social advantages, it is important to enable children to reduce the potentially harmful effects of the internet and electronic media, including exposure to violent and pornographic content.<sup>56</sup>

The quality of PSHE input and teaching experienced by children and young people appears to be highly variable across the country. A recent Ofsted report<sup>7</sup> identified that, although in 60% of schools PSHE was good, in 40% of schools the quality of PSHE required improvement or was inadequate. Notably, the report identified gaps in the way in which PSHE provision provided children and young people with personal and social skills and abilities to manage their personal safety. Moreover, in relation to sex and relationship education, in a third of schools children were left *'unprepared for the physical and emotional changes they will experience during puberty, and later when they grow up and form adult relationships'*. Addressing the gaps and weaknesses in PSHE provision, especially in relation to personal and social skills, is likely to be vital for the engagement of children in education; for example, studies are now indicating the link between the development of emotional intelligence in children and young people and academic success.<sup>57</sup>

## Health-promoting behaviours

### Play and physical activity

Regular participation in physical activity offers children and young people an array of positive health and social benefits, impacting not only on physiological health and development,<sup>58</sup> but also on psychological and social wellbeing;<sup>59</sup> for example, participation in sporting activities has been associated with reductions in social anxiety among primary school children.<sup>60</sup> **Despite the positive benefits of physical activity, over the last decade studies have consistently identified that few children and young people achieve the Chief Medical Officer's guideline for physical activity of one hour of moderate-to-vigorous physical activity every day.**<sup>61</sup> The HBSC study reported in 2010 that 28% of boys and only 15% of girls aged 11–15 years were meeting the recommended levels.<sup>2</sup> Physical activity levels also decline with age and across all ages girls are much less active than their male peers. The lower rates of participation by girls in physical activity compared with their male peers have a complex range of causes: girls have a limited range of provision specifically designed for them, and this, coupled with negative, often subtle, gender stereotyping from peers and families, may all serve to reinforce young women's sedentary behaviours (see Table 7.1).

Evidence is accumulating on the types of physical activity and the programmes that deliver an increase in physical activity rates along with associated positive health and psychosocial benefits, including offering intrinsic motivation for children to sustain their physical activity levels into adolescence. **Physical activity programmes in schools can have positive influences on cognitive performance, with demonstrable positive results in academic attainment, concentration, memory and classroom behaviour.**<sup>62</sup> **Participation in physical activity also appears to be an important component in creating school satisfaction and school connectedness,** factors that have been associated with lower levels of participation in health-risk behaviours.<sup>51</sup> Successful school-based physical activity programmes appear to have a number of common elements: notably, they tend to create a positive culture concerning physical activity, provide long-term interventions, employ specialist PE teachers, link to the community, and avoid stigmatising those who have been inactive and instead emphasise enjoyment combined with a focus on skills development.<sup>63,64</sup> They also take into account the elements that children and young people value, providing students with choice over the range of activities and sports; encouraging young people's leadership through being able to enhance the skills of other students may also increase commitment to physical activity.

\* A digital shadow is a trail of visibility that can be found within the internet and other digital records.



One teenager who had participated in a junior sports leadership programme spoke about the benefits of such programmes from a personal development point of view.<sup>65</sup>

*'You have to get inside the little ones' heads and think 'how do I explain this to them?', it makes you realise how to pass on a skill, the knowledge. It feels really good.'* (girl aged 14)



**Footballer (from an educational workshop in a school)**

Source: Kids Company

For children of primary school age, time spent in active, free play outside school (running around and playing games) can contribute a significant amount of time to their physical activity rates.<sup>66</sup> **For the current generation of children in England a number of factors can be seen as contributing to a decline in free play.** These include parental as well as children's own concerns over safety and a lack of appropriate green or urban spaces to play in combined with a reduced general tolerance towards children playing on the streets. If, however, parents feel that an area is safe they are more likely to let their children play outside, which also may bring a range of physical and emotional benefits.<sup>67</sup> For both younger children and adolescents, physical activity undertaken as part of leisure time outside school can enable children and adolescents to widen their friendship groups and participate in their local communities, thereby providing opportunities to develop social skills that help to build positive personal attributes such as self-esteem and self-confidence.<sup>60</sup>

## Case study

### Exploring nature play – Play England

Children's access to nature has declined dramatically – fewer than 25% of children use their local 'patch of nature' compared with over 50% of their parents. As children, 70% of adults enjoyed most of their adventures in natural outdoor environments compared with only 29% of children today.

Play England, with £500,000 from Natural England's Access to Nature programme, is working with three adventure playgrounds and local children's centres and schools to test what works in engaging children with nature through their play.

As a result, 3,000 children in deprived areas in London, North Tyneside and Torbay regularly engage with nature. Eating habits have changed as a result of growing and cooking healthy food outdoors – 'from yuck to yummy', as one child said.

Shiremoor children's centre in North Tyneside now has a presumption in favour of their children being outdoors in all weathers. Local schools say that children are readier to learn, more confident with increased levels of challenge, and have more imaginative conversations and improved writing and descriptive skills. Children attending the nature play days take four times as many steps per day as in normal school days as measured by pedometers.

A child, aged 7, from Waterville Primary School said:

*'Our trips to Shiremoor Adventure Playground every half term are fun because we get to play for the whole day and I always get very mucky. I wear warm clothes and I am usually covered in mud but I don't care. My mam knows I have fun if I'm muddy.'*

*When it was the 'Wet and Wild' day, I liked doing skids on the water slide. There was also loads of water in the sandy area and I got soaking wet. It was really fun. I always need to take spare clothes.'*

*Some of us have used pedometers at Shiremoor Adventure Playground to find out how many steps we take on a play day and at school. I knew there would be loads more steps when I am at Shiremoor because I am out and moving about all day.'*

## Case study

### An economic evaluation of play provision – Play England

An adventure playground provides a good quality play space for children to take risks, explore and experiment. The type of play an adventure playground encourages promotes the healthy development of children – physically, emotionally, mentally, socially and creatively.

In the short run an adventure playground promotes children’s physical activity and social play. It has been estimated that in the long term these short-term effects will lead to improved health and educational outcomes. Increased physical activity in childhood has been associated with higher levels of physical activity in adulthood, which in turn decreases the chances of experiencing a number of diseases including coronary heart disease, stroke, type 2 diabetes and colon cancer.

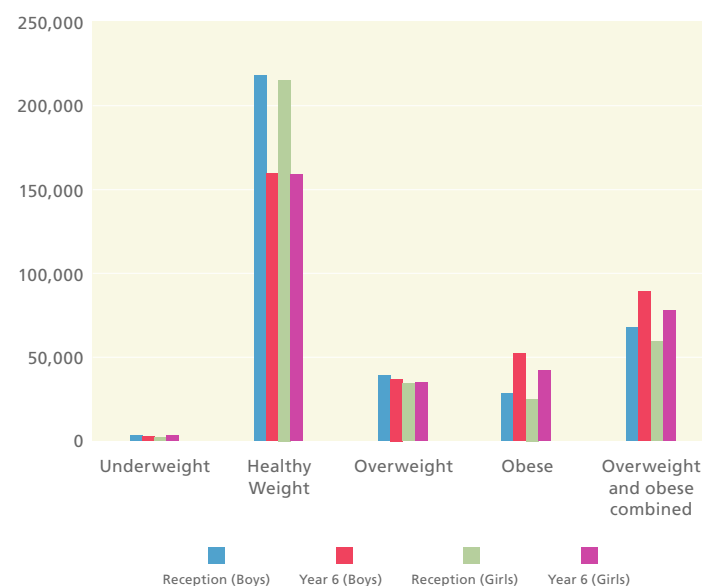
- The benefits generated by an adventure playground compared with no playground exceed the costs by £0.67 million.
- Every £1 invested in an adventure playground generates £1.32 in social benefits.
- The total cost of an adventure playground over 20 years is estimated at £2.13 million.
- The estimated present value of the long-term benefits of improved physical activity for all children attending an adventure playground is £0.31 million.
- The estimated present value of the long-term benefits of increased social play and associated improvement in educational outcomes for all children attending an adventure playground is £2.49 million.

## Screen time

Evidence suggests that extended screen time per day has an effect on health which is independent of the sedentary aspect:

- There is a link between screen time and type 2 diabetes, hypertension, obesity and attention deficit hyperactivity disorder (ADHD).
- Adolescent boys who have more than 2 hours a day of screen time have two times higher levels of insulin, suggesting relative resistance
- Other potential mechanisms through which this effect is mediated are food cuing, food intake via advertising and interaction with the dopamine pathway.
- Mechanisms to reduce this effect include age-specific maximum times set by parents.<sup>68</sup>

**Figure 7.2 – Prevalence of underweight, healthy weight, overweight, obese and combined overweight and obese children by year and sex, England, 2011/12**



Source: Mandalia, D. 2012. Child Obesity. In *Health Survey for England – 2011, Health, social care and lifestyles*, ed. Health Survey For England. The Health and Social Care Information Centre.

## Healthy eating, healthy weight

In October 2011, the Government published *Healthy Lives, Healthy People: A call for action on obesity in England*.<sup>69</sup> This outlined detailed national ambitions to address overweight and obesity through a ‘life course’ approach. For children, the national priority is to achieve ‘a sustained downward trend in the level of excess weight by 2020’.<sup>69</sup> The National Child Measurement Programme reported that in 2011/2 over a fifth (22.6%) of the children measured in Reception were either overweight or obese. In Year 6, this proportion was one in three (33.9%). The percentage of Year 6 (19.2%) who were obese was over double that of Reception year children (9.5%),<sup>3</sup> with older children more likely to be obese than younger children (see Figure 7.2). Although there is some indication that the trend may be flattening, a downward trend is not yet in evidence.<sup>70</sup>

**‘Grown ups should get children to get more active, eat lots of fruit and vegetables, and get outside more. I get out lots and lots. I’ve got lots of energy and like the trampoline and swings.’**

Obesity and overweight also have implications for the immediate wellbeing of children and young people; for example, the HBSC 2010 study found that the highest average life satisfaction was among those who say that their body size is ‘about right’, followed (in rank order) by those who think they are ‘a bit too thin’, ‘a bit too fat’, ‘much too thin’ and ‘much too fat’. The same pattern is found for both genders.<sup>2</sup> When the diets of children are examined, healthy

## Case study

### Street play – Playing Out

Playing Out is part of a national project with Play England, London Play and the University of Bristol, funded by the Department of Health, to support local residents who are keen to make their street a safe place to play and work with local authorities and others to create the conditions that will enable children to play out more on the streets where they live.

In 2010, grassroots organisation Playing Out supported residents to pilot a model of short, after-school temporary road closures on six streets in Bristol, allowing children to play freely and safely near their own front door. In response to this project, Bristol City Council launched a trial Temporary Play Street Order (TPSO) from September 2011 to September 2012, enabling residents to close their street to through traffic for up to 3 hours a week, with stewarded car access for residents.

During the trial year, with support from Playing Out, 16 streets organised regular weekly or monthly sessions, directly involving approximately 500 children and 200 adults. Children of all ages engaged in a wide variety of freely chosen activities and play types including vigorous play such as cycling, scooting and running, relishing the opportunity to use the space directly outside their homes, forming friendships and gaining a sense of belonging in their local environment. Adults, including older residents, benefitted from the increased interaction with neighbours.

Since the trial, Bristol has rolled out the TPSO and several other councils have adopted similar policies. The project has sparked national discussion about the importance and benefits of street play and demonstrates the use of residential streets as shared public space.

This simple, low-cost, resident-led intervention has immediate and long-term benefits for children and the wider community. With widespread uptake, there is potential to change the culture towards outdoor neighbourhood play being a normal part of everyday life for children across the UK.

*'It's great to see relaxed parents and energetic children in a street environment, not something we get to see every day.'* – Resident, Bristol

*'All in all a very positive community-building activity, led by residents, and focused on children who are to be the future community.'* – Retired resident, Bristol

*'As time has gone on, it's become almost a self-contained thing, with very little organisation needed as people pass the responsibility for stewarding around.'* – Resident organiser, Bristol

*'The weather wasn't always kind in April, May and June but it had to be really pelting down for the children to give up and go indoors.'* – Resident organiser, Bristol

*'I look at my kids and their friends running, skipping and playing and I know it's doing them so much good – not just the exercise but the fun and the chance to feel part of where they are growing up.'* – H, Bristol.

eating appears to feature in the lifestyle of only a minority. For example, **only about a quarter of children are likely to eat the recommended five portions of fruit and vegetables a day, and their diets tend to contain high levels of energy-dense foods and sugar.**<sup>4</sup>

In response to the obesity epidemic there have been a plethora of interventions designed to improve the eating patterns of children. The majority over the past decade have consistently called for integrated approaches that involve schools, parents and children in actions to promote healthy eating and physical activity.<sup>71,72,73,74</sup> Multi-domain and multifactorial approaches towards tackling obesity represent a significant opportunity to enable children to benefit from the health protective elements of a healthy diet with positive actions in schools providing a link to the home and community.

### **A multifactorial whole-school approach to healthy eating has been associated with having a positive impact on improving the diet of children in schools.**

For example, the overall number of different actions that secondary schools have in place to promote healthy eating has been associated with increasing the proportion of healthy food choices made by students.<sup>73,75</sup> Another study also found that engaging primary school children and their school in wider issues about food production and sustainability when combined with experiential food education impacted positively on fruit and vegetable consumption.<sup>74</sup> An overview of the types of positive assets-based actions that may enable children to adopt and sustain healthy eating is outlined in Table 7.2.<sup>75</sup>

## School nursing

**The school nursing service is ideally located to deliver an assets-based public health agenda.** The potential of the school nurse to adopt a leadership role in the promotion of health and wellbeing among the school-aged population has recently been reasserted, with new policy guidance on school nursing.<sup>76</sup> Identified as key public health professionals, school nurses are intended to lead, co-ordinate and provide services to deliver the Healthy Child Programme to the 5–19 years population and ensure a smooth transition from the health visiting service for the school-aged population.

Relative to the 8.2 million school children, England can be deemed to have a small school nursing workforce. In 2012, there were 1,174 whole-time equivalent qualified school nurses to meet the needs of the school-aged population.<sup>77</sup> In most areas school nurses are supported by school staff nurses, and in some cases community nursery nurses and healthcare assistants. Overall, the entire workforce is likely to be approximately 5,000 individuals including part-time staff. The Centre for Workforce Intelligence also recently highlighted that, despite the increasing demand for skilled school nurses, the workforce is ageing and there are planned reductions in commissions for school nurses.<sup>78</sup>

Often negatively associated in the past with very task-focused services such as immunisation, school nurses in fact can and

**Table 7.2 Examples of healthy weight and diet initiatives (school based)**

| Area for change                                                 | Examples of strategies                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-----------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Promoting healthy food in schools</b>                        | <ul style="list-style-type: none"> <li>■ Regular taster sessions to promote the taste and texture of different foods</li> <li>■ Involve young people in the development and promotion of menus and snacks</li> <li>■ Promote benefits other than generic health benefits, e.g. foods give a natural energy boost, good for nails/hair etc.</li> <li>■ Develop sustainable food policies/agenda and encourage young people to become active consumers</li> </ul> |
| <b>Food/eating culture</b>                                      | <ul style="list-style-type: none"> <li>■ Develop 'buddy systems' to encourage children to support each other to try new foods</li> <li>■ Boost the social aspects of eating through addressing the dining environment</li> <li>■ Consider giving young people more choice about where to eat, e.g. healthy food van</li> </ul>                                                                                                                                  |
| <b>Positive culture of body acceptance and health promotion</b> | <ul style="list-style-type: none"> <li>■ Deliver training for school staff so that mixed messages about weight are not given to children and young people</li> <li>■ Invite parents and communities into schools to discuss their own experiences of weight, diet and physical activity</li> </ul>                                                                                                                                                              |

Source: *The Health and Social Care Information Centre, LifestylE Statistics 2012*

do undertake a variety of public health roles. For example, school nurses have been seen as critical in supporting the care of children with complex needs, long-term conditions and disability in schools; enhancing health-promoting behaviours including healthy eating and healthy weight initiatives; and enabling schools to enhance the mental health and emotional wellbeing of their students. School nurses can also have a significant expert role to play in the delivery of PSHE, with some evidence suggesting that they are perceived by young people as offering authoritative and credible information.<sup>79</sup> However, the evidence base relating to the impact of school nurses on the health of the school-aged population is small and relatively weak. Models for the assessment of the impact of school nursing on health outcomes and determinants of health require development.

## Conclusion

The middle years of childhood represent a key part of the life course. As the child moves through the education system their early years experiences provide a foundation from which they begin to navigate their expanding environment. During childhood, school and community settings offer further opportunities to accumulate and strengthen the assets that are protective of health and wellbeing.

The evidence presented in this chapter has illuminated how the core domains of the child, family, school and community can operate to provide constructive relationships, safety and security and opportunities that build resilience and positive personal attributes for all children. Protective health factors or assets within these domains operate as key drivers for the school-aged population to enhance and sustain health and wellbeing.

Targeted single-issue interventions aimed at reducing health risk behaviours have often characterised responses to child and adolescent health. The evidence presented in this chapter highlights how multi-domain and multifactorial approaches

to promoting health-enhancing behaviours represent the greatest opportunities to build resilience in childhood. The promotion of physical and mental health simultaneously can offer great benefits for children, working dynamically to create a **virtuous circle** that keeps reinforcing overall health, wellbeing and achievement. It is vitally important that all children and young people have access to good quality PSHE in schools that supports their developmental goals and enables them to successfully negotiate health risk behaviours and develop positive personal attributes.

The most disadvantaged and vulnerable children have fewer opportunities to access social, educational and developmental opportunities that build self-esteem and positive personal attributes. Schools and communities can play a fundamental role in addressing the socialisation gap and providing children and families with important social, educational and developmental opportunities.

In core areas relating to the development of resilience in childhood there is a need for an improved evidence base concerning how to develop and sustain health-promoting behaviours among the school-aged population. This improved evidence base is vital if successes from early years interventions are to be sustained and in order to prepare children to manage the challenges and developmental goals of late adolescence and early adulthood.

## What we still need to find out

Good prevalence data relating to health behaviours exist in relation to children and young people. There are, however, notable gaps in our understanding of the key factors that impact on the development of resilience and wellbeing. If the capabilities of children are to be enhanced across the inequalities gradient, an important part of such a strategy is a public health research agenda that identifies the best forms of multifactorial and multifaceted interventions to enhance resilience. Most notably, we need to be able to distinguish



what protective factors **work for who** and **in what context**.

In terms of assets-based research we still need to understand what assets operate as keystone assets, in terms of being essential for both wellbeing and the development of resilience as well as enabling children to martial other capabilities and assets.

In core areas relating to the development of resilience in childhood there is a need for an improved evidence base that identifies how to develop and sustain health- promoting behaviours among the school-aged population, in particular:

- This requires evidence across the environments of the child, including educational interventions but also attention as to how community or neighbourhood initiatives may impact positively on health and wellbeing for children.
- Too little attention has been given to gender as a key determinant of resilience and wellbeing for children; for example, there is a need to understand how to improve the psychological wellbeing of girls and how to enhance health- promoting behaviours for girls.

This chapter has highlighted the central importance of family life and parenting for the wellbeing of children of school age. However, relatively little attention has been given to understanding how to enhance health-promoting dimensions of family life; for example, relatively little attention has been given to parenting programmes for older children. Evidence is needed relating to effective interventions that address persistent inequalities in children's health and wellbeing created by the cycle of inter-generational poverty and the socialisation gap. International comparative policy analysis relating to family policies is also likely to be a valuable source of information and intelligence in this area. A recent report by the OECD for the European Commission highlighted that policy makers need to have better access to accurate information from surveys of children on family structure and importantly to improved indicators on parenting practices.<sup>27</sup>



***A Hunger Monster: Children who had experienced hunger, missed meals or came from a background of poverty created Hunger Monsters to represent how it feels to go without regular food.***

*Source: Kids Company*



### Key messages for policy

- Strategies that focus on the acquisition of protective health factors or assets have the ability to promote resilience and positive capacities in children and young people. The promotion of skills, capacities and protective health assets in relation to confidence building and self-esteem offers significant associated benefits across a range of social, emotional and educational outcomes. They specifically equip children and young people to navigate exploratory behaviours.
- Positive parenting throughout childhood and adolescence provides children with the necessary emotional repertoires and social skills to successfully navigate childhood and adolescence.
- The socialisation gap (ability to provide access to social events) represents an increasing inequality that determines the ability of parents to maintain and enhance children's health and wellbeing and reinforces social exclusion.
- Communication within families is an important protective health asset and a factor in enabling children and young people to become resilient.
- School and teacher connectedness can operate as an important driver of resilience for children.
- Children with disabilities or long-term conditions may find it difficult to access educational opportunities, including participation in programmes that build resilience.
- PSHE at school is an important part of the way in which schools can contribute to improving resilience and health among children.
- Physical activity undertaken as part of leisure time provides opportunities for children to build positive personal attributes such as self-esteem and self-confidence.
- Participation in physical activity also appears to be an important component in creating school satisfaction and school connectedness, factors that have been associated with lower levels of participation in health risk behaviours and academic performance.
- Multi-domain and multifactorial approaches towards tackling obesity represent a significant opportunity to enable children to benefit from the health-protective elements of a healthy diet.

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## Chapter 8

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# Life stage: Adolescence

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### Key statistics

- There are now as many young people in the second decade of life (10–19 years) in the UK as children in the first (0–9 years); adolescents from 10 to 19 years make up 12% of the population.<sup>1</sup>
- The gap between puberty and adult social and financial independence has widened from around six years in the 1950s to 15 years or longer for most young people today.<sup>2</sup>
- All-cause mortality among adolescents (10–19 years) is now higher than for other periods of childhood except the newborn period. Injuries are the main cause of adolescent mortality.<sup>3</sup>
- Morbidity due to disability and long-term conditions is higher among adolescents than children and long-term conditions rise from early adolescence.<sup>4</sup>
- Five of the 'top 10' risk factors for the total burden of disease in adults are initiated or shaped in adolescence.<sup>5</sup>
- Some 75% of lifetime mental health disorders have their onset before 18 years of age, with the peak onset of most conditions being from 8 to 15 years. Approximately 10% of adolescents suffer from a mental health problem at any one time.<sup>6</sup>
- Health service use is higher in adolescence than in childhood after age 3 years. It rises during adolescence, yet there are few dedicated services for young people.<sup>7</sup>
  - Long-term condition outcomes are poorer in adolescents than in adults.
  - Some 70% of childhood type 1 diabetes occurs in adolescence, yet adolescents have poorer diabetes control and more emergency hospital admissions than children or adults.<sup>8</sup>
- Adolescents have seen the least improvement in cancer survival compared with children and adults.<sup>9</sup>
- Age-appropriate services for adolescents have been shown to increase the quality of care.<sup>10</sup>

## Why does adolescence matter?

Young people aged 10–19 years, defined by the World Health Organization (WHO) as adolescents, have experienced the least improvement in health status of any age group in the British population over the last 50 years.

**Adolescents have been assumed to be low users of health services and adolescence understood as the healthiest period of life. These assumptions have not been true since the 1960s, yet their persistence makes young people nearly invisible** in a health service that focuses on the middle-aged and elderly and on young children.

Six key issues underpin the case for a greater focus on adolescents in our health services and across government. These are population changes, the shift of disease burden out of childhood into adolescence, the widespread initiation of health and self-management behaviours in adolescence, the rise of long-term conditions and injuries during adolescence, shifts in health service use, and **the huge potential for change brought about by dramatic brain and psychosocial development in adolescence.**

## Shifts in population towards adolescence

**There are now the same numbers of young people in Britain in the second decade of life, 10–19 years of age, as there are children in the first decade.** Each group made up 12% of the UK population in 2012.

Worldwide there are now 1.2 billion young people aged 10–19 years, the largest youth cohort in history, who form 20% of the global population.<sup>11</sup> Adolescence is rapidly becoming a major priority for governments and health systems across the world. **The World Bank has identified youth as a key driver of economic productivity, providing a potential ‘demographic dividend’.**<sup>12</sup> In its 2011 report on the state of the world’s children, *Adolescence: An age of opportunity*, UNICEF identified adolescence as a key time of opportunity for preserving life-long health.<sup>13</sup> Britain today has more adolescents than at any time in its history, with its own ‘youth bulge’ of the children of migrants over the past four decades. **This population of young people has unparalleled potential to influence the future of Britain over the next 50 years.**

## Rapid development presents opportunities

Adolescence is often seen as a risky and turbulent period of life, with young people ‘at risk’ from a range of new health problems. However, it is important to recognise the beneficial potential of changes during adolescence, understanding that young people can become positive levers for change in society.

Adolescence is a key period of rapid and extensive psychological and biological growth, second only to early childhood in the rate and breadth of developmental change. Changes in the brain and all organ systems during puberty and adolescence interact with social development to set up



**Toilet roll puppets – making something fun and beautiful out of rubbish**

Source: Kids Company

a range of new behaviours that can be both positive and potentially negative. Brain and body development also set up a number of transitions that are important for an individual to function as a productive adult.<sup>2</sup>

## Biological, psychological and social development

Puberty is one of the central biological dramas of human life, a period of major bodily change that has dramatic effects on the psychological and social aspects of young people’s lives. **During puberty, the body achieves its maximum potential in terms of fitness, physical strength and reproductive capacity.** Puberty for most British young people starts around 10–13 years of age, and is largely over by 14–16 years.

Human puberty is unique, in that we are the only animals that have major brain development at the same time as puberty. One of the great discoveries of neuroscience in the past 20 years has been the recognition that **there is a surge of brain development during early adolescence, and that brain development continues into the early 20s if not beyond. Waves of ‘synaptic pruning’ travel across the brain between 10–12 and 20 years of age, cutting away unused connections between brain cells to increase cognitive capacity and speed.** Particular areas that develop rapidly are those dealing with social relationships, with taking risks and with controlling feelings and emotions. While it is still too early to translate neuroscience into policy interventions, **we are beginning to understand why adolescents are particularly vulnerable to peer**

### **influences and why there appears to be a 'window of vulnerability' to risky behaviours around ages 14 to 17 years, particularly in the presence of peers.<sup>14</sup>**

Rapid brain development and the acquisition of new cognitive abilities, such as complex abstract thinking, drive a series of changes in young people's lives in terms of identity and relationships with families, peers and schools. This dynamic interaction between body changes, changing identity and changing social groups during adolescence gives rise to both great potential and significant risk in young people's lives.

### **Transitions**

This rapid development drives transitions in nearly all parts of young people's lives, not just within health. The World Bank identified the key adolescent transitions as being from dependent child to autonomous adult, from primary to secondary and later education, from education into the workforce, transition into responsible and productive citizenship and transitions in health from dependent recipients of children's healthcare to adults responsible for their own healthcare.<sup>12</sup> Successful negotiation of these transitions is necessary for young people to become economically productive members of society and to have the best chances for good health and wellbeing across the life course.

### **Widening gap between puberty and adulthood**

Adolescence has increased in prominence as a life period because the timing of puberty is increasingly out of kilter with young people's social development in the modern world.<sup>2</sup>

The average age of starting puberty fell dramatically in the early 20th century, but timings have been largely stable in the UK and most developed countries since the 1960s. Yet over the last 40 years we have seen a major divergence between the timing of puberty and the achievement of 'adult' social and financial independence. In the 1960s, for most young women, marriage and childbirth followed within five to six years of the start of their periods. Today, the average gap between puberty and moving out of the family home (mean age 25 years) is around 12 years, with the gap between puberty and having children (mean age around 29 years) around 16 years.

This widening gap between physical and sexual maturity (i.e. at the end of puberty) and attaining adult social and financial independence has been postulated to explain growing mental health, behavioural and substance use issues among adolescents and young adults.<sup>2</sup>

### **Shifts in burden of disease: childhood to adolescence**

Conventionally, adolescence has been seen as the healthiest time of life – a time when nature prepares us to take on the adult roles of work, reproduction and family life. However, this is no longer true.

In all high-income countries globally, mortality among adolescents is now greater than in 1–9 year olds, a reversal of traditional mortality patterns dominant for millennia.<sup>3</sup> This shift has been driven by the 'health' transition from infectious diseases to injuries and non-communicable diseases. The health transition has particularly benefitted younger children, but left adolescents vulnerable to the largely preventable morbidity and mortality related to injuries, mental health and non-communicable diseases such as asthma, cancer, diabetes and obesity.<sup>3,15</sup>

Among children and adolescents, burden of disease has largely coalesced into two poles, namely infants (<1 year) and adolescents, and middle childhood has replaced adolescence as the healthiest period of life.

### **Initiation of health behaviours and disease during adolescence**

The shift of burden into adolescence relates to the development of new health-related behaviours and to new problems appearing during adolescence.

### **Health behaviours**

Adolescence is the most significant period in the life course for the initiation of a wide range of health behaviours that are associated with the largest health burdens in adult life. Smoking in the UK leaps up from a population prevalence of 1% at age 11 years to around 20% at 15 years. In fact, nearly 90% of lifetime smoking is initiated between the ages of 10 and 20 years in the UK. Similarly, approximately 80% of lifetime alcohol or cannabis use is initiated <20 years, with the proportions initiating other illicit drugs in adolescence closer to 50%. Once initiated, these behaviours track strongly into adult life, highlighting the importance of intervention in adolescence to prevent health burden.<sup>16</sup>

Initiation is far more common than sustained substance use, and five of the 10 key risk factors for adult disease burden identified in the WHO Global Burden of Disease Study (tobacco, physical activity, overweight, unsafe sex and alcohol use) are problems that are usually initiated or heavily shaped (e.g. physical activity) in adolescence. Adolescent health and development are therefore key to the prevention of adult non-communicable diseases.<sup>17,18</sup>

Health risk behaviours and mental and physical health problems co-occur in adolescence to a greater degree than in adulthood: **common factors such as deprivation, poor parental connection, low self-esteem and poor mental health are responsible for a range of exploratory behaviours.**<sup>19</sup> As outlined in the following table taken from the US Institute of Medicine, interventions addressing common risk factors have the potential to prevent multiple problems.

**Table 8.1 Table from the Institute of Medicine (IOM) report On the Science of Adolescent Risk Taking 2011**

| Risk factors                                                              | Substance abuse | Delinquency | Teen pregnancy | School dropout | Violence | Depression and anxiety |
|---------------------------------------------------------------------------|-----------------|-------------|----------------|----------------|----------|------------------------|
| <b>Community</b>                                                          |                 |             |                |                |          |                        |
| Availability of drugs                                                     | ✓               |             |                |                | ✓        |                        |
| Availability of firearms                                                  |                 | ✓           |                |                | ✓        |                        |
| Community laws and norms favourable towards drug use, firearms, and crime | ✓               | ✓           |                |                | ✓        |                        |
| Media portrayals of violence                                              |                 |             |                |                | ✓        |                        |
| Transitions and mobility                                                  | ✓               | ✓           |                | ✓              |          | ✓                      |
| Low neighbourhood attachment and community disorganisation                | ✓               | ✓           |                |                | ✓        |                        |
| Extreme economic deprivation                                              | ✓               | ✓           | ✓              | ✓              | ✓        |                        |
| <b>Family</b>                                                             |                 |             |                |                |          |                        |
| Family history of the problem behaviour                                   | ✓               | ✓           | ✓              | ✓              | ✓        | ✓                      |
| Family management problems                                                | ✓               | ✓           | ✓              | ✓              | ✓        |                        |
| Family conflict                                                           | ✓               | ✓           | ✓              | ✓              | ✓        | ✓                      |
| Favourable parental attitudes and involvement in the problem behaviour    | ✓               | ✓           |                |                | ✓        |                        |
| <b>School</b>                                                             |                 |             |                |                |          |                        |
| Academic failure beginning in late elementary school                      | ✓               | ✓           | ✓              | ✓              | ✓        | ✓                      |
| Lack of commitment to school                                              | ✓               | ✓           | ✓              | ✓              | ✓        |                        |
| <b>Individual/Peer</b>                                                    |                 |             |                |                |          |                        |
| Early and persistent antisocial behaviour                                 | ✓               | ✓           | ✓              | ✓              | ✓        | ✓                      |
| Alienation and rebelliousness                                             | ✓               | ✓           |                | ✓              |          |                        |
| Friends who engage in the problem behaviour                               | ✓               | ✓           | ✓              | ✓              | ✓        |                        |
| Favourable attitude toward the problem behaviour                          | ✓               | ✓           | ✓              | ✓              |          |                        |
| Early initiation of the problem behaviour                                 | ✓               | ✓           | ✓              | ✓              | ✓        |                        |
| Constitutional factors                                                    | ✓               | ✓           |                |                | ✓        | ✓                      |

Source: Hawkins and Monahan presentation (data from Brooke-Weiss et al, 2008).

## Self-management behaviours for long-standing conditions

Long-term self-management behaviours for diabetes, asthma, epilepsy and other chronic conditions are also largely initiated in adolescence. It is in early and mid-adolescence that individuals take over the management of their chronic conditions from their parents, and **there is strong evidence that the self-management behaviours initiated in adolescence remain with them throughout life.**<sup>20</sup> Adolescence therefore provides an important window of opportunity to influence the trajectories of non-communicable diseases throughout later life.

## Adolescent development precipitates an avalanche of new-onset diseases

Rapid changes in the brain and across all organ systems in adolescence result in a host of new mental and physical health disorders appearing at this time. **Approximately 75% of lifetime mental health disorders (excluding dementia) have their onset before 24 years of age, with the peak onset of most conditions from 8 to 15 years.**<sup>21</sup>

Type 1 diabetes and many other auto-immune conditions have their peak incidence in early adolescence, and adolescence sees the development of new types of rheumatological conditions, epilepsy and respiratory conditions.<sup>2</sup> Indeed, some 'paediatric' diseases such as type 1 diabetes are predominantly diseases of adolescence: the National Paediatric Diabetes Audit showed that 70% of the childhood diabetes population is aged 12–19 and that

the great majority of emergency hospital admissions for diabetes are in this age group.<sup>8</sup>

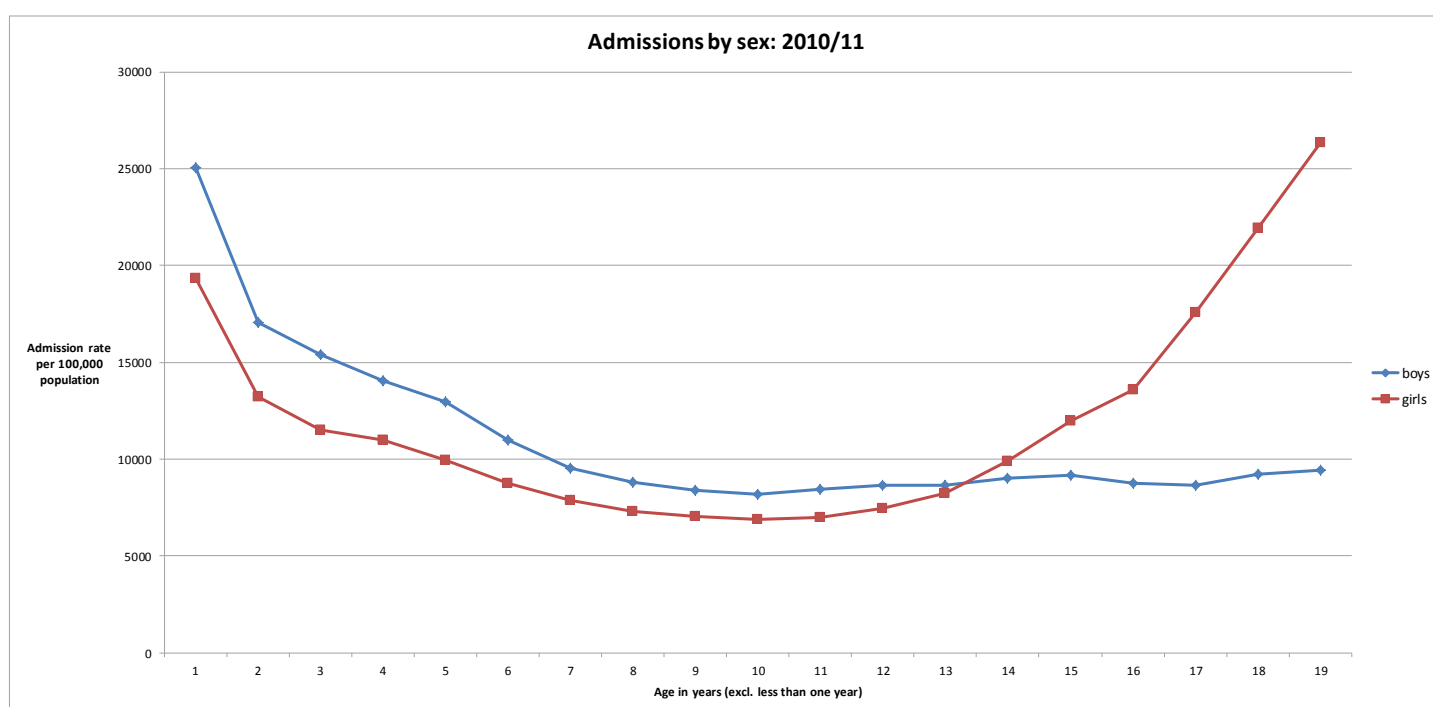
Cancer in adolescence has a distinct biology and behaviour to that in either children or adults, and cancer survival in adolescents has failed to match the dramatic improvements seen in child or adult cancer over the past 20 years.<sup>9</sup> This may in part reflect poor participation in research by young people, as there is good evidence that the poor progress in adolescent cancer is related to very low participation in clinical trials compared with the participation rates of children or adults.<sup>22,23</sup>

**Behaviourally related conditions such as sexually transmitted infections and HIV begin to appear in early adolescence and escalate rapidly:** 16–24 year olds have the highest incidence and prevalence of the majority of sexually transmitted infections in both sexes in the UK.<sup>24</sup> Globally, 45% of new HIV infections occur in 15–24 year olds.<sup>25</sup>

## Long-term condition outcomes are poorer in adolescence than in childhood

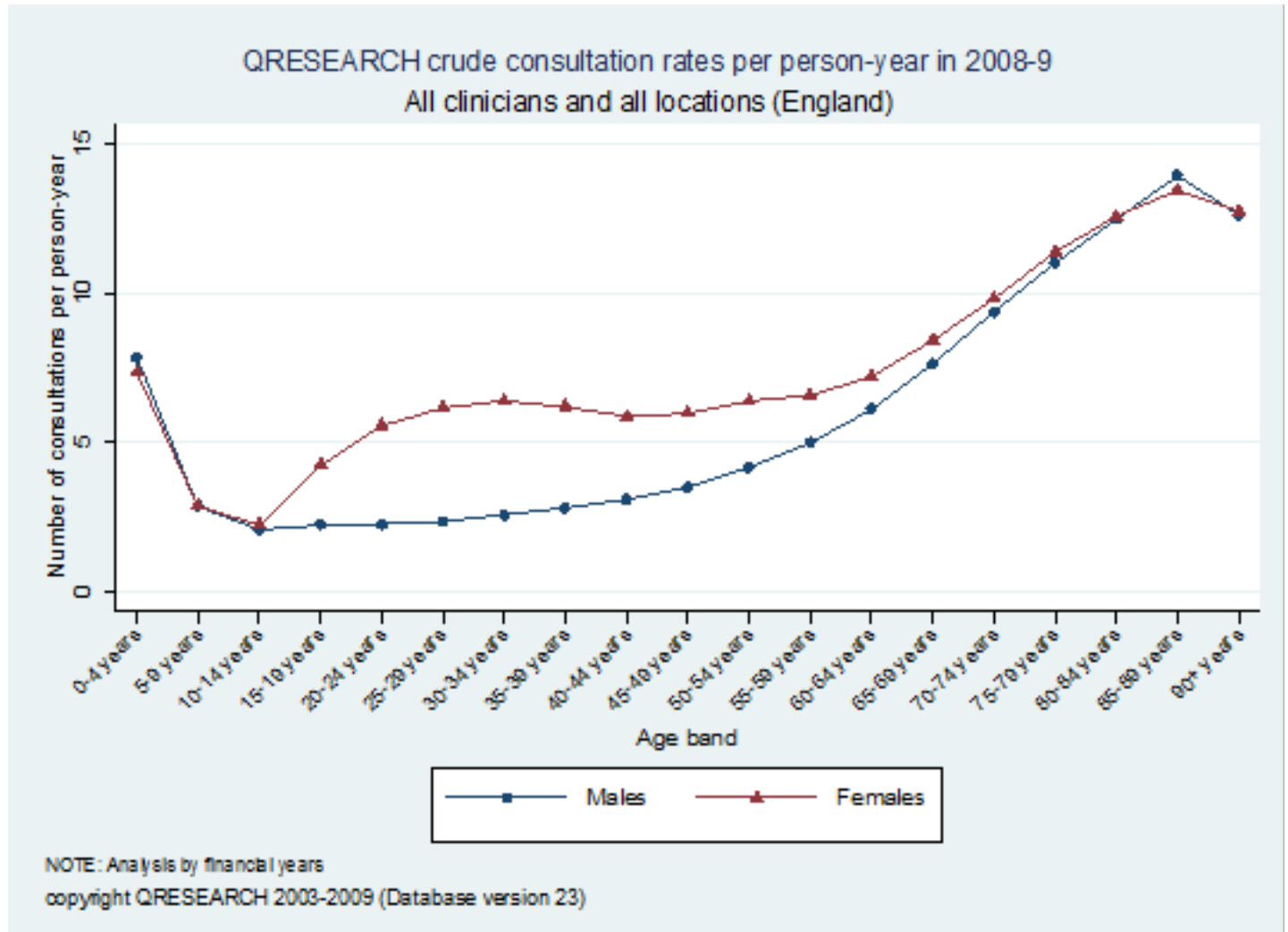
Outcomes for many long-term conditions are poorer in adolescents than in children or adults. For example, markers of diabetes control such as the HbA1c level are worse in adolescence than in childhood or adulthood in type 1 diabetes.<sup>8</sup> **Given poorer outcomes for diabetes in Britain than in other European countries, this places British adolescents at the bottom of the outcome leagues.**<sup>8</sup> Similarly, asthma and epilepsy control are poorer in adolescents than in children. As noted above,

**Figure 8.1 Hospital admission rate by age for <20 year olds in 2010/11**



Source: Child and Maternal Health Intelligence Network, Public Health England



Figure 8.2 Primary care consultation rates by age Source: NHS Information Centre<sup>26</sup>

adolescents have seen the least improvement in cancer survival compared with children and adults.

These poorer outcomes in adolescence reflect both biological factors and psychosocial issues related to regimen adherence and self-management.

### Increasing health service use in adolescence compared with childhood

The myth that adolescents are low users of health services dissipates with even a cursory glance at health service use in the UK. **Data from Hospital Episode Statistics (HES) show that inpatient, outpatient and Accident and Emergency department use are higher in adolescence than in childhood after 3 years of age.** Inpatient length of stay is higher in adolescence than in childhood after infancy. **Primary care use is higher in adolescence than in mid-childhood, with most young people seeing their GP more than yearly.**<sup>26</sup>

### Schools and peers emerge as new social determinants of adolescent health

Policy actions relating to the social determinants of health by the WHO and in the UK have focused on interventions

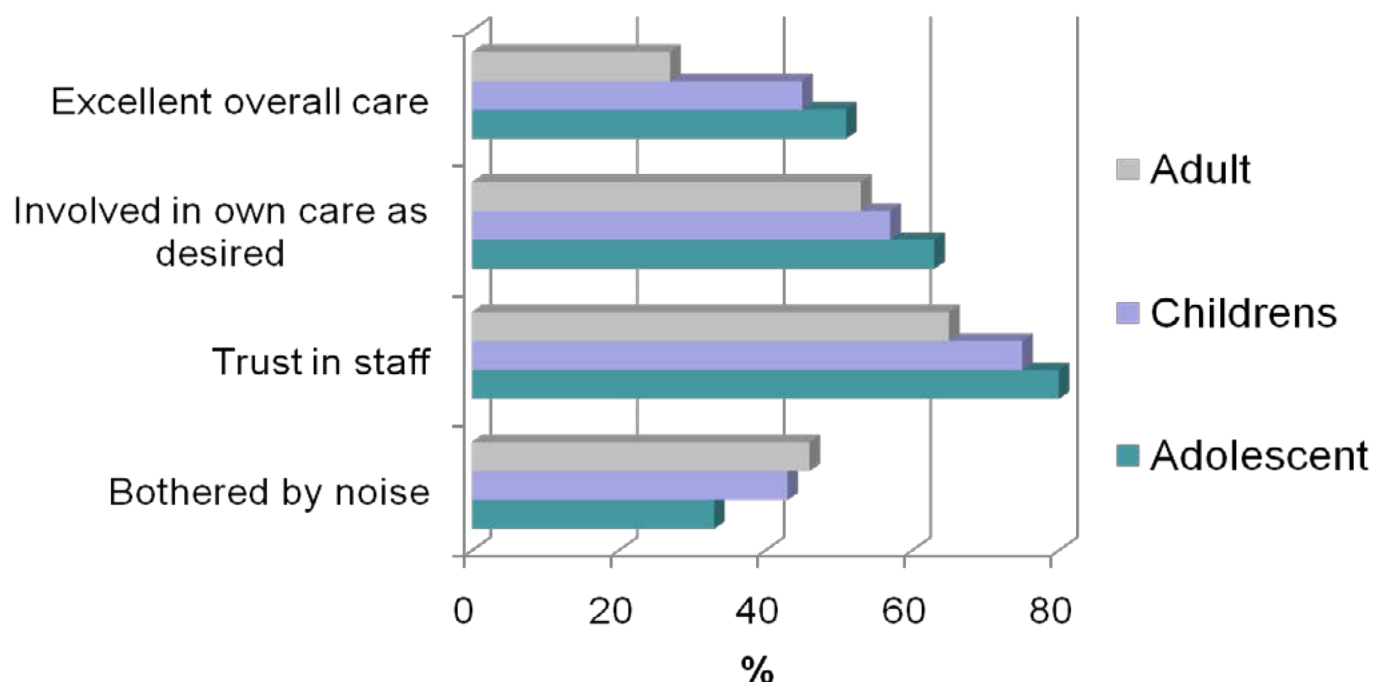
with young children as a strategic way of improving health across the life course. Yet the **major transitions and developmental changes occurring during adolescence make the teenage years a time of immense potential for preventive interventions and building resilience in young people.**

While parenting and family factors, so crucial in early childhood, remain key protective determinants in adolescence, new social determinants arise in adolescence that influence the transition from childhood into adult life.

Peers begin to exert influences that can be both pro-social and anti-social and begin to attenuate the influence of family on young people.

**Schools begin to exert new influences, with connection with school (sense of belonging) becoming a key protective factor in addition to attainments.** Further, health in adolescence is strongly predictive of educational outcomes including attainments and employment. Promotion of health by schools should be an essential part of their 'core business' of increasing attainments and enhancing later life chances.

**Figure 8.3 Adolescent inpatient wards improve quality of care**



Source: National Young Patient Survey, England, 2004<sup>10</sup>

**Neighbourhood environment begins to exert strong effects** not seen in earlier childhood, particularly in later adolescence as young people begin to explore life outside the family. Young people also have their own experiences of unequal chances related to gender, ethnicity, education, employment and socio-economic status – determinants that impacted upon child health only through their parents.<sup>27</sup>

In addition, **it is likely that latent determinants such as puberty and brain development recapitulate the biological embedding of social determinants seen in very early life.**

### Adolescence as a second opportunity for intervention

Adolescence is a second opportunity for intervention after very early childhood. A rational early intervention approach targets critical periods of rapid development, i.e. adolescence as well as very early childhood.<sup>27</sup>

Given that health and health behaviours track strongly from adolescence into adult life, the way that health is promoted and protected during adolescence is key to the health of the whole population and the economic development of the nation.

### New approaches to adolescent health are required

so that young people stop being the neglected minority in adult public health areas, for example the tobacco, alcohol, and sexual health strategies. Given evidence that health risk behaviours co-occur in adolescence and that common factors underlie all such health behaviours in adolescence, horizontal approaches focusing on these common factors have great potential to prevent multiple problems.

### Age-appropriate services across all areas of the health service

Despite the large proportion of young people in the population, their higher mortality and morbidity rates than most of childhood, and their poorer long-term condition outcomes than in childhood, **there are few specific age-appropriate services for young people in the UK. Services are organised around professional groupings (child health versus adult health professionals) and on historical grounds.**

Adolescence needs to be thought of as a discrete period within the life course in which preventive services and clinical services need to be targeted and age-appropriate.

There is currently sufficient adolescent usage of inpatient healthcare (12–19 years) to form an 18-bed ward in most district general hospitals serving a population of around 250,000, with greater activity than this in regional and teaching hospitals.<sup>28</sup>

### There is evidence that age-appropriate adolescent services improve outcomes by improving attendance and retention of young people in clinical services.<sup>10</sup>

There are few data on the health economic consequences of developing adolescent age-appropriate services and this is a key research need.

### Transition

The focus of child health services on the under-5s, and the focus of adult health on the elderly, have meant that young people with ongoing needs for healthcare have often faced barriers to accessing quality care.<sup>29</sup> Concepts of transition (i.e. the purposeful planning of moving from child to adult health

systems) have been around for many decades, yet many young people still face poor transitions.

There is good evidence that poorly planned transition may be linked with increased risk of non-adherence to treatment and loss to follow-up for young people.<sup>30</sup> Outcomes can be disastrous, for example in solid organ transplants, and problems with transition have been identified as among the major causes of graft loss.<sup>31</sup> However, there is also good evidence that well-planned transition can improve outcomes, for example dramatically reducing graft loss after renal transplantation and improving disease control in diabetes.<sup>32</sup>

Effective and timely transition planning should be a routine part of all long-term condition management for children and young people. It may also be useful to provide young adult services together with adolescent services, as AYA (adolescent and young adult) services, such as are now commissioned in all cancer services in England. This appears to be improving patient-related outcomes for young people, although it is too early to examine the effects on disease outcomes.

## Conclusion

Young people must no longer be the ‘forgotten tribe’ of the health service. In the modern world, adolescence is a time of increasing health burden and a time of great potential for preventing the accelerating burden of non-communicable diseases in later life. The provision of age-appropriate care and effective transition from child health to adult health systems improve outcomes for young people, but caring for young people is everyone’s business.

## What we still need to find out

There is still a great deal we need to find out about the best way to help young people live healthy and satisfying lives. This includes:

- **The relative impacts and benefits of intervening in adolescence compared with in early life.** There has been considerable work done on the economic case for intervention in early life, yet very little is known about the benefits of intervening in adolescence.
- **How puberty, nutrition, deprivation and stress during adolescence affect brain development, and how these affect health throughout life.** There is promising research on such questions in early childhood, examining how poverty ‘gets under the skin’, but the same questions need to be examined in adolescence.
- **How health services are best provided for young people, and how this might be done without further fragmenting healthcare.** Current health services have poor aim and reach for young people, yet there is a risk that developing specific age-appropriate services may further fragment healthcare.
- **How to increase the participation of young people in research.** While there has been a marked increase in the participation of children and young people in research in the last 10 years, particularly relating to medicines, it is believed that poor progress on some adolescent outcomes (e.g. cancer) relates directly to low levels of participation in clinical trials.
- **How to best preserve young people’s wellbeing and emotional health given rapid social change.**
- **How to best engage schools in the business of preserving and promoting young people’s health.** There is clear evidence that health and educational attainments affect each other, yet the evidence base for improving health through schools is poor.

### Key messages for policy

- Caring for young people is everyone's business.
- A rational early intervention approach targets critical periods of rapid development; therefore it should target adolescence as well as very early childhood. Public health and intervention strategies must have twin foci on early childhood and on adolescence.
- A discrete adolescent public health strategy is needed. This must be horizontal across substance use, sexual health, mental health and long-term conditions rather than young people being the neglected minority within each adult public health silo.
- Common intervention strategies should be used to prevent or reduce substance use, improve sexual health, reduce injuries and improve mental health, focusing on common risk factors across behaviours/problems.
- Schools are a central factor for young people's health during adolescence. Promotion of health by schools helps schools achieve their 'core business' of increasing educational attainment and enhancing later life chances. A refocusing of school health services is needed.
- Outcomes for almost all long-term conditions are poorer among adolescents than children. Given poorer outcomes in Britain than in other European countries, this places British adolescents at the bottom of the outcome leagues. Successful strands from the adult long-term conditions strategy should be deployed specifically for adolescents.
- Age-appropriate facilities for adolescents should be provided across a range of outpatient and inpatient physical and mental health services, as there is evidence that they improve outcomes.
- High-quality transition from child-centred to adult-centred care should be a standard part of any long-term condition pathway.
- Improved participation of young people in clinical trials may help to improve survival from cancer and other long-term conditions in adolescence.

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## Chapter 9

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# Children with neurodevelopmental disabilities

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## Key statistics

- There are 0.8 million disabled children and young people aged 0–18 in the UK, 6% of all children.<sup>1</sup>
- Children with neurodevelopmental impairments and conditions are the largest group of disabled children and young people. The estimated prevalence of neurodevelopmental impairments and conditions is around 3–4% of children in England.<sup>2</sup>
- Attention deficit hyperactivity disorder (ADHD) is the most common neurodevelopmental condition in the UK and is estimated to affect 1–2% of children and young people, if the narrower criteria of International Classification of Diseases-10 are used.<sup>3</sup>
- Autism is thought to occur in at least 1% of children and young people in the UK.<sup>4</sup>
- The most common functional limitations reported for disabled children and young people concern mobility (18%), communication (22%) and memory, concentration or learning (24%).<sup>1</sup>
- The household income for a household with a disabled child has been shown to be around 13% lower than for those with non-disabled children.<sup>5</sup>
- Children in socio-economically disadvantaged households in early childhood are twice as likely than the least disadvantaged children to develop a disabling condition in later childhood.<sup>6</sup>
- Some 32% of disabled children and young people live with a lone parent compared with 22% of their non-disabled peers.<sup>5</sup>
- Almost half of disabled children and young people, as compared with a fifth of non-disabled children and young people, live with a parent who is also disabled.<sup>5</sup>
- Some 28% of disabled children and young people experience barriers to education, leisure or play. Barriers include unsuitable environments, lack of money and the attitudes of others.<sup>7</sup>

## Overview

Childhood disability continues to be a significant public health issue in England and across the world. **While disabled children and young people can lead full and fulfilling lives, for many, disability is associated with limited development and social participation, and with poor educational, health and employment outcomes.**<sup>8</sup> It can create difficulties and sometimes pain for the children and young people concerned and, indeed, for their families. This chapter focuses particularly on children and young children with neurodevelopmental disorders, sometimes referred to as neurodisabilities. This group of conditions (which includes autism, intellectual and developmental conditions) is of particular importance because the children and young people affected frequently have other conditions and complex medical and support needs.

The chapter begins by discussing how we understand childhood disability generally. It then examines the percentage of disabled children with specific impairments/conditions and functional difficulties before outlining the broad range of risk factors associated with neurodevelopmental disability. After a brief discussion of how disability can impact on the daily lives of children and families, it examines key approaches to improving outcomes for children and young people with neurodevelopmental health problems.

### What is childhood disability?

The ways we define and measure disability determine how we understand the nature and causes of any difficulties disabled children and young people face and what we regard as effective interventions aimed at enabling them to lead as fulfilling lives as their peers who do not live with disability.

The past three decades have seen substantial changes in ways of understanding and defining disability. Crucially there has been a challenge to the notion that a child's impairment or medical condition is primarily responsible for any restrictions that they face and a much greater emphasis has been placed on the disabling role of contextual factors. It is now widely accepted that disability results from the interaction of individuals' impairments and conditions with the context in which they live.<sup>9</sup> This way of understanding childhood disability is reflected in international human rights conventions<sup>10</sup> and the World Health Organization's approach to classifying health and disability.<sup>11</sup> One implication of this approach is that any attempt to improve the situation for disabled children and their families through service provision and other means needs to be based on an understanding of children's individual conditions, the environment in which they live and on the dynamic relationship between the two.

### How many disabled children and young people are there?

Information on the prevalence of and trends in childhood disability is important for the development of effective

policies and interventions to reduce it and improve disabled children's outcomes. There is a variety of sources of information on the numbers of disabled children that measure disability in different ways for various purposes. Robust quantitative sources of information on child disability, however, are more limited than those on adults and, as yet, do not reflect the understandings of disability discussed above.<sup>8</sup>

According to the UK Equality Act 2010, a person is disabled if they have a physical or mental impairment that has a substantial and long-term effect on their ability to carry out normal day-to-day activities. **In total there are 0.8 million disabled children and young people, aged 0–18 (6%) in the UK.**<sup>1</sup> The estimated percentage has remained relatively stable over the past decade.<sup>1</sup> The population estimates for all-cause childhood disability in the UK fall in the middle of the range of estimates for other high-income countries (1.5 to 10%).<sup>13</sup>

A wide range of impairments and conditions is associated with child disability, with neurodevelopmental conditions forming the largest group. Unlike the USA, the UK does not have a single survey or administrative source that can provide data on the number of children and young children with specific neurodevelopmental impairments/conditions across the 0–18 age range. A range of sources has been used here, therefore, to provide prevalence estimates (see Table 9.1). The estimated prevalence of neurodevelopmental disorders in England is around 3–4% of children.<sup>2</sup> ADHD, impairments affecting speech, language and communication, and specific and moderate learning difficulties are the most commonly reported primary disorders or diagnoses. **Many children and young people with neurodevelopmental conditions, however, experience a number of impairments and co-morbidities which, in conjunction with restrictions and barriers to participation, result in complex medical, educational and social support needs.**

Prevalence estimates for some impairments and conditions associated with childhood disability appear to be rising. Information on trends for specific conditions, however, is limited. **ADHD, the most common behaviour disorder in the UK, is one such condition.** Estimates of prevalence appear to have risen over time, although this increase is, at least in part, associated with increased recognition and diagnostic practices.<sup>14</sup> Estimates of prevalence also vary depending on the diagnostic criteria used. **Using the broader Diagnostic and Statistical Manual of Mental Disorders IV diagnostic criteria, it is estimated to affect 3–9% of school-aged children and young people. The narrower criteria of ICD-10 suggest a prevalence of 1–2%.**<sup>15</sup>

Autism is another condition for which prevalence appears to have increased over the last two decades. Although it is thought to have a genetic component, little is known about risk factors for autism. It occurs in at least 1% of children.<sup>3</sup> Some of the reported increase, however, is likely to be attributable to increased awareness, new administrative

classifications and diagnostic practices.<sup>4</sup> Increased identification of some conditions has resulted in increasing demand for diagnostic and support services, and welfare benefits for children, young people and their families. For example, **the number of children in receipt of Disability Living Allowance diagnosed with autism, ADHD or learning disabilities has increased from around 50,000 in 1995 to around 210,000 in 2012.**<sup>16</sup>

**Table 9.1 Percentage of children and young people with specific neurodevelopmental impairments, conditions or needs**

| Impairment/condition                                   | Disabled children % |
|--------------------------------------------------------|---------------------|
| Any neurodevelopmental disorder <sup>2</sup>           | 3.0–4.0             |
| ADHD: <sup>17</sup>                                    |                     |
| <i>DSM IV</i>                                          | 3.0–9.0             |
| <i>ICD10</i>                                           | 1.0–2.0             |
| Cerebral palsy <sup>18</sup>                           | 0.2                 |
| Epilepsy <sup>19</sup>                                 | 0.3                 |
| Autism:                                                |                     |
| <i>All children</i> <sup>3</sup>                       | 1.0                 |
| <i>School-aged children</i> <sup>20</sup>              | 0.9                 |
| Specific learning difficulties <sup>20</sup>           | 1.0                 |
| Moderate learning difficulties <sup>20</sup>           | 2.0                 |
| Severe learning difficulties <sup>20</sup>             | 0.4                 |
| Profound learning difficulties <sup>20</sup>           | 0.1                 |
| Speech, language and communication needs <sup>20</sup> | 1.7                 |
| Hearing impairment <sup>20</sup>                       | 0.2                 |
| Visual impairment <sup>20</sup>                        | 0.1                 |
| Multi-sensory impairment <sup>20</sup>                 | 0.01                |
| Physical disability <sup>20</sup>                      | 0.4                 |
| Other (unspecified) <sup>20</sup>                      | 0.4                 |

In addition to information on children's impairments and conditions, information on functional difficulties is also important. **The most commonly reported functional difficulties are with memory/concentration/learning, communication, mobility and physical co-ordination** (see Table 9.2).

**Table 9.2 Functional impairments experienced by disabled children and young people aged 0–18 years**

| Functional impairment type    | All disabled children % | Boys % | Girls % |
|-------------------------------|-------------------------|--------|---------|
| Mobility                      | 18                      | 17     | 20      |
| Lifting, carrying             | 8                       | 7      | 9       |
| Manual dexterity              | 10                      | 11     | 8       |
| Continence                    | 12                      | 12     | 12      |
| Communication                 | 22                      | 25     | 19      |
| Memory/concentration/learning | 24                      | 29     | 17      |
| Recognising when in danger    | 18                      | 22     | 13      |
| Physical co-ordination        | 15                      | 17     | 12      |
| Other                         | 28                      | 29     | 27      |

Source: Family Resources Survey 2010/11

## Factors associated with neurodevelopmental disability

The causes of childhood disability are not always clear, but **many conditions result from social and genetic factors coming together in complex ways, often across generations.**<sup>21</sup> Impairments/conditions resulting from purely genetic or purely social/environmental factors are rare.<sup>6</sup> Common factors include birth weight, age, sex, ethnicity, socio-economic status, parental behaviours, communicable diseases and unintentional injuries.

## Pregnancy outcomes

**Birth weight, influenced by both genetic and social factors, is associated with a number of impairments/conditions, including cerebral palsy, reduced cognitive function and epilepsy.**<sup>22–25</sup> Using cerebral palsy as an example, a child's risk of cerebral palsy decreases with increasing birth weight up to a weight of 4.5 kilograms, before rising slightly among babies with birth weights above 4.5 kilograms.<sup>23</sup>

**In England and Wales in 2010, 7.1% of babies were born prematurely. Children born extremely prematurely are at greater risk of poor health outcomes and developing neurodevelopmental disabilities than those born at term.**<sup>26</sup> Improvements to neonatal care in England between 1995 and 2006 appear to be associated with increased survival rates for preterm births. The EPICure 2 study of children born very preterm in

2006 suggests that more children are surviving disability-free; however, there does not appear to have been any reduction in the proportion of children at age 3 years with moderate or severe impairments/conditions.<sup>27</sup> **The EPICure 1 study of children born very preterm in 1995 showed that at age 11 years more than half of premature birth children have no or only minor impairments or health problems; however, this means approximately 45% have a moderate or severe impairment or condition by the time they reach this age.**<sup>28</sup>

## Sex

The prevalence of all-cause childhood disability is higher among boys than girls in the early years, although by late teens the prevalence rate among girls is similar to that of boys.<sup>29</sup> Neurodevelopmental conditions appear to be more common among boys than girls. Understandings of why this is the case, however, are incomplete but may be associated with genetic differences between sexes, or under-identification in females due to diagnostic criteria based on male characteristics.<sup>30</sup>

## Ethnicity

Limited evidence suggests there may be an association between some impairments/conditions and ethnicity. Studies that have taken account of the association between deprivation and ethnicity have found an increased risk of all-cause disability among children and young children of mixed ethnicity and black African/Caribbean origin only.<sup>31</sup> For intellectual and developmental disabilities, the pattern is complex. Emerson<sup>2</sup> reported that among children and young people aged 7–15 years in England, rates of identification were lower in children from minority ethnic groups overall. Notable exceptions were higher rates of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage, and more severe forms of intellectual disability among children of Pakistani and Bangladeshi heritage.

## Socio-economic disadvantage

The prevalence of child disability increases as socio-economic status decreases.<sup>29</sup> **Intellectual and developmental disabilities are strongly associated with socio-economic disadvantage.**<sup>6,18</sup> A systematic review<sup>31</sup> indicated that for children and young people in low socio-economic status households, the odds of being reported to have any intellectual disability or a mild, moderate/severe intellectual disability were over two times greater when compared with others. Exposure to socio-economic disadvantage in early childhood has been shown to be a predisposing factor for the onset of disabling conditions in later childhood: **for children in the most socio-economically disadvantaged households, the odds of developing such conditions are twice those for children in the least disadvantaged households.**<sup>32</sup>

The likely explanations for this association include the fact that children and young people in socially disadvantaged

households are frequently more exposed to social and environmental risk factors in the prenatal and early childhood periods that may result in the later onset of activity-limiting conditions.<sup>6,33</sup> These include poverty, poor nutrition, unsafe housing, environmental pollutants and hazards, infections, unintentional injuries, and some negative parental behaviours.

## Parental behaviours

Some impairments/conditions may be associated with some parental behaviours. Parental **smoking**, particularly maternal smoking, is associated with low birth weight and preterm birth, and is thought to play a role in the development of a number of neurodevelopmental disorders including autism.<sup>6</sup> Various child health outcomes, including growth before and after birth, preterm birth and fetal alcohol syndrome have been associated with mothers' alcohol intake.<sup>34</sup> **Unsupportive and unstimulating parenting** has been linked with some intellectual **disabilities and conduct disorders.**<sup>33</sup> Many parental behaviours associated with poor health outcomes, however, are more common in socio-economically disadvantaged households and linked to poor personal and household resources.

## Communicable diseases

Communicable diseases such as German measles (rubella) and other infections acquired during pregnancy can lead to disabling conditions in childhood. Although relatively rare, complications of communicable diseases such as measles and mumps acquired later can also lead to child disability. Some groups of children and young people, for example those not registered with a GP, those from some minority ethnic groups or non-English-speaking families, and looked-after children, are at greater risk of contracting preventable communicable diseases because they are less likely to be fully immunised.<sup>35</sup>

## Unintentional injuries

**These become increasingly important causes of disability as children get older.** Infants and toddlers are most at risk of injuries in the home while road traffic accidents dominate as children get older. At all ages, children and young people in poorer households and neighbourhoods are at greater risk of injury. This partly results from living in accommodation near busy roads and in poor quality housing.<sup>36</sup>

## The circumstances of disabled children and their families

As in any other group, disabled children's circumstances vary. The evidence, however, indicates that, in general, **children and young people with neurodevelopmental and other conditions are at greater risk of adversity than others.**

## Household composition

The majority of disabled children and young people are brought up in their families of origin. Disabled children are more likely than non-disabled children to live in lone-parent



households (32% compared with 22%).<sup>5</sup> They are also more likely than their non-disabled peers to live with other disabled adults (47% compared with 21%) and one or more siblings who are also disabled.<sup>5</sup> While further research is needed to explain this, it is crucial to recognise the additional needs and difficulties that may arise when parents and children in the same household are disabled.

### Household living standards

**Households with disabled children and young people are more likely to have poverty-level incomes than those with non-disabled children.** The household income for a household with a disabled child has been shown to be around 13% lower than for those with non-disabled children.<sup>5</sup> The lowest incomes are to be found among lone parents, black and minority ethnic families and those with disabled parents and disabled children in the same household.<sup>5</sup> **At the same time, such families incur higher rates of expenditure associated with disability.**<sup>37</sup> Caring for a disabled child appears to have a negative effect on



**Wipe that Smile... (from an installation by a young person expressing her past)**

Source: Kids Company

parental employment. The strongest impact is on mothers, particularly lone mothers.<sup>52</sup>

Households with disabled children and young people are more likely than those with non-disabled children to report one or more debts and not being able to afford items and activities generally seen as important for all children and young people, and those caring for them.<sup>5</sup> **Many also live in poor or unsuitable housing which is more likely to be rented and have fewer rooms than the households of non-disabled peers.**<sup>35,37</sup>

### Social participation

Disabled children and young people are more likely to experience barriers to social participation than their peers. These include barriers to participation in sport, education, leisure and using public transport, and in personal relationships.<sup>7,39</sup> Commonly reported barriers are lack of money, unsuitable physical environments and the attitudes of others.<sup>16</sup> The type and severity of impairment can also be associated with levels of participation, with those experiencing pain and more severely impaired mobility, fine motor skills, communication and intellectual abilities experiencing lower levels of participation.<sup>7</sup>

### Violence and abuse

**Children with neurodevelopmental impairments/conditions appear to be at higher risk than their non-disabled peers of all forms of violence, including abuse and neglect by parents/carers, peers and others.**<sup>41,42</sup>

There is limited information on prevalence rates of violence and abuse of disabled children in England and little is known about the effectiveness of safeguarding services for this important group. In addition, concern has been raised about professional responses to violence and abuse in relation to disabled children.<sup>42</sup>

### Accessing key services and support

Many disabled children, young people and their families experience considerable difficulties accessing appropriate health, education and social care services.<sup>43–45</sup> **Of particular concern is the absence of essential co-ordination of provision within and between services.**<sup>43</sup> There is evidence of geographical variation in support provided to children and their carers, and inequitable provision, for example, of short-term breaks and direct payments.<sup>46,47</sup> Young people with learning disabilities are at an increased risk of mental health or behavioural problems. However, it is widely recognised that there is a serious lack of appropriate mental health provision to meet these needs.<sup>48</sup>

### Improving outcomes for disabled children

Improving outcomes for disabled children requires a range of approaches: primary prevention, early identification and interventions to maximise disabled children's and young people's life chances.

## Primary prevention

Reducing the incidence of preventable impairments/conditions is important because, for children and young people, these may be associated with pain and restriction. While gene markers and gene therapies may offer a way forward for a small number of conditions, for most common childhood conditions, in most cases, primary prevention is likely to be best achieved through public policies to reduce exposure to social and environmental hazards.<sup>6</sup> See Box 9.1 for key elements of a primary preventive approach.

### Box 9.1 Key elements of a primary preventive approach

Strategic interventions at national and local level to:

- **Reduce socio-economic disadvantage** across the life course through 'living wages' and employment, and adequate welfare benefits.
- **Improve material environments** such as safe and healthy housing, schools and workplaces.
- **Reduce exposure to environmental hazards** including air pollutants, and environmental and industrial pollutants, especially lead.
- **Reduce exposure to parental and other sources of environmental tobacco smoke** in utero, infancy and childhood.
- **Promote safe alcohol consumption** in pregnancy.
- **Ensure adequate dietary intake of key nutrients, including folic acid and other vitamins and minerals**, among women of childbearing age, to protect against neural tube conditions and other consequences of vitamin deficiencies. Vulnerable groups may require supplementation around the time of conception.
- **Achieve population coverage of immunisation against common communicable diseases**, notably rubella, sufficient to ensure herd immunity to protect both the fetus from pregnancy-acquired infection and children from complications of these diseases.

### Box 9.2 Nationally approved population screening programmes recommended by Public Health England

#### Antenatal and newborn

- NHS Fetal Anomaly Screening Programme
- NHS Infectious Diseases in Pregnancy Screening Programme (hepatitis B, HIV, syphilis, susceptibility to rubella)
- NHS Linked Antenatal and Newborn Sickle Cell and Thalassaemia Screening Programme
- NHS Newborn and Infant Physical Examination Screening Programme (developmental dysplasia of the hip, eye disease and congenital heart disease)
- NHS Newborn Blood Spot Screening Programme (phenylketonuria, congenital hypothyroidism, medium-chain acyl-CoA dehydrogenase deficiency)
- NHS Newborn Hearing Screening Programme

#### Childhood

- Vision screening for 4–5 year olds
- NHS Diabetic Eye Screening Programme (age 12 years+)

## Early identification

Early identification of impairments and conditions may allow children to receive specialist care services at an early stage, improving outcomes and preventing severe disability and sometimes death.<sup>49</sup> Box 9.2 lists approved systematic population screening programmes in pregnancy and early childhood of direct relevance to early detection of impairments/conditions associated with disability. Screening can raise complex questions for parents; thus it is important they receive adequate, unbiased information and support to make choices about taking up screening opportunities and accessing appropriate services. In addition to screening, impairments and conditions may also be identified early through the parents coming into contact with well-trained healthcare practitioners when services are accessible.

## Case study

### Breathe Magic: magic in rehabilitation

A research programme developed by Dr Dido Green, Oxford Brookes University, and the team at Breathe Arts Health Research, explored the feasibility of using a magical theme in intensive bimanual occupational therapy programmes for children. Specially scaled and adapted magic tricks and theatrical skills, using a group therapy model, were incorporated into a 2-week summer day camp to address children's motor and psychosocial difficulties. For the camp finale, the children put on a magic show in a professional theatre, reflecting both their new magical abilities and bimanual developments.

Research evidence shows significant motor skills gains and increased positiveness and self-esteem for children with mild to severe movement restrictions (Green et al., 2013; Green, 2013; Weinstein et al., 2013). Furthermore, parents report a reduction in the hours needed to support their children from an average of 8 to 4 hours per day, corresponding with the child's increased independence in daily skills (Green, 2013). Costs compare favourably with those of current procedures, such as botulinum toxin A injections, but achieve more functional skills for the child. This research has been translated into an evidence-based clinical service run by Breathe Arts Health Research and funded as a clinical commission from Lambeth Clinical Commissioning Group.

This innovative therapy programme delivered gains for the children and their families. It showed that a fun, engaging, effective and efficient means to provide intensive, task focused therapy for children could be developed.

Occupational therapists, working collaboratively with researchers, artists and social entrepreneurs, achieved this and evaluated the methodology.

*'This is the first time I am going back to school and can show my friends something they can't do, it is always the other way around'* – Breathe Magic camp attendee.

*'It has helped our whole family. We have seen huge improvements in T – he can do things now he could never do before, such as eating independently, and because of that his self-esteem has improved dramatically. He has even been moved up two reading groups in school, as he now believes that he is capable of more. Breathe Magic has helped him across all areas of his life and we are eternally grateful. The summer camp model has also allowed us to spend some much needed time with his brother, who usually gets significantly less of our time due to T's disability'* – mother of Breathe Magic camp attendee.

## Meeting the needs of disabled children, young people and their families

The aim of services for children and young people with neurodevelopmental disabilities and their families should be to enable them to maximise their health, wellbeing and life chances and to promote opportunities for social participation. Some of this may be achieved by ensuring that universal services, environments and facilities are designed to include them and safeguard their interests – an approach enshrined in both domestic law and international conventions.<sup>50</sup> A substantial amount of legislation and good practice guidance also governs assessment and service provision for individual disabled children and those close to them to support them to achieve their fullest potential.<sup>50</sup>

As the new legislation comes into place shortly, it will be important to ensure that the needs of those no longer covered by the definition of disability are being adequately managed, as there is a risk that targeting might mean that the very children who could benefit the most will miss out.

It is considered important that:

- children, young people and their families should have **personal** health, education and social care planning with provision that matches their individual needs and reflects **their preferences**<sup>51,52</sup>
- services develop care pathways with children, young people and their families that reflect the above principles and apply them in timely and consistent ways
- while children's, young people's and their carers' needs are intimately connected, the **needs of each** are addressed in their own right
- children, young people and their carers should have **timely and accessible information** about the services to which they are entitled<sup>52</sup>
- service providers recognise that children with neurodevelopmental disabilities may have complex needs and co-morbidities which all require skilled attention and may need innovative practice approaches; for example, the lack of appropriate mental health services for children and young people with learning disabilities has given rise to concern<sup>48</sup>
- there are robust measures in place to ensure that **services are joined up**
- the particular needs of households with both **disabled children and disabled adults** are recognised and that there is a co-ordinated approach to service provision
- **periods of transition from children's to adults' services** require particular attention as they have been shown to be hazardous for young people and their carers<sup>13</sup>
- **poverty and the substantial additional costs** to families are recognised and reduced

## Case study

### Aiming High for Disabled Children – Sunderland Adaptive Snowsports

Of approximately 11 million disabled individuals in the UK, less than 20% take part in sport. In Sunderland, a pilot site for the national Aiming High for Disabled Children project, an inter-agency project board was established including the health, education and social care services, the voluntary sector and parent carers. Parent carers' and children's and young people's participation officers were appointed.

Consultation work with disabled children and young people revealed that they wanted to go on ski trips like their friends, but were unable to do so because their disabilities were a barrier to participation.

Using Aiming High for Disabled Children money to get it going, Sunderland Adaptive Snowsports was established, led by Mike Stansfield, head of the specialist support team from Sunderland Education, and Karen Parry, project officer for Aiming High for Disabled Children Sunderland, supported by the project board.

An appropriate venue in the South of France was risk assessed and Sunderland Adaptive Snowsports instructors were recruited. Young people were identified from the Aiming High for Disabled Children's inter-agency database, most of whom had never previously been away from home or the care of their parents because of their disabilities. Activities were planned around the specific needs of each individual.

Three highly successful annual ski trips have now taken place, benefitting the children and young people enormously. The young people themselves, their families and the team of professionals who worked with them describe the experience as life changing, improving independence and enhancing confidence, drive, caring and nurturing of others as well as providing a social experience.

One young person with unilateral cerebral palsy feared a life of unemployment. His experience with Sunderland Adaptive Snowsports has inspired him to train as a ski instructor himself.

Another young person is working towards training with the Paralympic junior development squad. Parent's remarks include;

*'Before she became involved with the Snowsports group, my daughter, who is a wheelchair user with cerebral palsy, talked unconfidently about eventually leaving home, now she talks confidently about when she is going to leave the country!'*

*'Being away with kids of all disabilities made him appreciate his limitations and not see them as a bad thing or restrictive. It made him almost happy to NOT be 'normal'. He is so much happier and coping better. It has changed his outlook on life.'*

- service commissioners have access to **robust data** about the population of disabled children and young people in order to plan and commission appropriate services; this includes data on technology-dependent children and children experiencing violence and abuse and the effectiveness of support and safeguarding services
- the **attitudinal, social, environmental and financial barriers** that impede the development and participation of children and young people with neurodevelopmental conditions and other disabilities are reduced
- children with neurodevelopmental and other disabilities are provided with the resources to enable them to live an **ordinary life** (see, for example, the case study on the variation in aspects of healthcare for children and young people with cerebral palsies living in northern England).

## Conclusion

In considering the situation of disabled children and their families, there needs to be two basic approaches. Many would accept that reducing the prevalence of preventable disabling conditions is desirable in order to limit the number of children whose health and wellbeing are likely to be adversely affected. This requires a multidimensional strategy that addresses the factors associated with rates of impairment, discussed earlier. At the same time, for the existing population of disabled children and their families, there needs to be a range of measures to reduce barriers to participation and to ensure that individual needs are met.



## Case study

### Variation in aspects of healthcare for children and young people with cerebral palsies living in northern England

Mortality rates for children and young people in the UK are among the worst in Europe. One potential contributor to this is the quality of health services they receive. There is a dearth of literature about this, especially for disabled children and young people, as population-based data are not routinely collected. A well-established population-based register, the North of England Collaborative Cerebral Palsy Survey (NECCPS), was used to underpin an audit of evidence-based aspects of healthcare for children and young people with cerebral palsies to explore any local variations in healthcare.

A facilitated consultation event involving children and young people with cerebral palsies and their families and key stakeholders across agencies and the voluntary sector, including national and international experts in the field, considered the existing care pathway for children and young people with cerebral palsies and an aspirational care pathway.

A retrospective medical record review was undertaken of 389 children and young people with cerebral palsies registered on the NECCPS, born between 1 January 1995 and 31 December 2002, with subsequent data validation by paediatricians and physiotherapists. Data were collected on magnetic resonance brain imaging as a marker of aetiological assessment, hip and spine status, pain and its management, feeding and nutritional status. The Townsend deprivation index, derived from maternal residential postcode and divided into quintiles, was used as a proxy for socio-economic status.

The audit confirmed that there is variation in aspects of healthcare between districts in the north of England, for children and young people with cerebral palsy. A new care pathway has been agreed across the north of England with funding from the Health Quality Improvement Programme, and the main NECCPS database has been extended to capture the new indicators to facilitate ongoing quality assurance. These data will assist with working towards more equitable healthcare and thus more equal opportunities for the best health outcomes. The new care pathway has been incorporated into the care pathway for children and young people with cerebral palsies that has been published by the British Academy of Childhood Disability ([www.bacdis.org.uk/policy/guidelines.htm](http://www.bacdis.org.uk/policy/guidelines.htm)).

## What we still need to find out

While there is a growing body of research, there is still a great deal we do not know and need to understand about the causes of neurodevelopmental disability in children and the most effective way of meeting their needs. We need to know more about the following.

- **The trends in the prevalence of specific neurodevelopmental conditions across the whole of the 0–18 age range** (such as is available in the USA), particularly those conditions where prevalence appears to be increasing. Research will be needed to investigate and design the most appropriate ways of collecting such data. Currently, there is a lack of sufficiently detailed nationally representative data on prevalence and trends.
- **The ways of improving the nature and quality of data on the numbers, characteristics, needs and circumstances of disabled children and their families at the local level.** This needs to be done in consultation with service users and providers. Only limited data are available to local service commissioners.
- **The causes of and risk factors for neurodevelopmental conditions**, as these are not always clear. More research is needed to investigate how a range of genetic and social/environmental factors interacts across the life course to increase the risk of neurodevelopmental conditions.
- **How to meet the needs of particular groups of children and young people for whom provision has been very unsatisfactory.** This includes children and young people who have learning disabilities and mental health issues, including challenging behaviour. A programme of research is urgently required, **designed with children, young people and their families**, to identify effective provision that would meet these needs.



## Key messages for policy

- As there continues to be a lack of robust data, particularly at local health service and local authority level, on the numbers, characteristics and circumstances of disabled children, there is an urgent need to improve the quality of data available to service commissioners.
- The lack of sufficiently detailed nationally representative data sources to provide information on the trends in prevalence of **specific conditions** across the whole 0–18 age range should be addressed.
- Environmental risk factors and hazards, including airborne and other pollutants and environments unsafe for children, need to be tackled at a public health level.
- As many neurodevelopmental disabilities are associated with socio-economic disadvantage, it is important to target preventive efforts to reduce socio-economic disadvantage in order to improve maternal health and wellbeing, as well as that of children and young people across the life course.
- Because of the evidence of increased poverty among households with disabled children and the impact this has on their social participation and life chances, it is important that they have adequate incomes, whether through wages or welfare benefits, that offset the additional costs of disabled living.
- There should be evidenced-based programmes to support parents to change behaviours associated with increased risk of disability.
- At local and national levels, there need to be action plans to address the specific attitudinal and environmental barriers to full participation and life chances identified in the recent cross-government report, *Fulfilling potential. Building a deeper understanding of disability in the UK today*.<sup>1</sup>
- Services at national, local and individual levels should be shaped by the needs, wishes and aspirations of both children and their families.
- All services for disabled children should be underpinned by their legal rights and aim to maximise their health, wellbeing and life chances. Services should promote opportunities for social participation and the chance to lead an ordinary life.
- The recommendations of the Care Quality Commission on practical ways to improve local healthcare services for disabled children should be implemented.
- There should be robust measures in place to ensure co-ordination within and between services for children and their families.
- As transition from children's to adults' services too frequently causes disruption and stress, and results in unmet needs, appropriate transition arrangements should be a priority for all services.
- Careful attention needs to be paid to the effect of the new Children and Families Bill and how the redefinition of disability affects outcomes.
- Care providers should extend the use of rehabilitation prescriptions more widely to all children with neurodisabilities, to ensure that children and young people are helped to reach their best possible function and quality of life.

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## Chapter 10

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# Mental health problems in children and young people

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## Key statistics

- The British Child and Adolescent Mental Health Surveys in 1999 and 2004 found that 1 in 10 children and young people under the age of 16 had a diagnosable mental disorder. Among the 5 to 10 year olds, 10% of boys and 5% of girls had a mental health problem while among the 11 to 16 year olds the prevalence was 13% for boys and 10% for girls.<sup>2,3</sup>
- The most common problems are conduct disorders, attention deficit hyperactivity disorder (ADHD), emotional disorders (anxiety and depression) and autism spectrum disorders.<sup>2,3</sup>
- Rates of mental health problems in children and young people in the UK rose over the period from 1974 to 1999, particularly conduct and emotional disorders.<sup>9</sup> In the absence of more recent data, it is unknown whether this trend has continued.
- Mental health problems in children and young people cause distress and can have wide-ranging effects, including impacts on educational attainment and social relationships, as well as affecting life chances and physical health.<sup>13,14</sup>
- Mental health problems in children and young people can be long-lasting. It is known that 50% of mental illness in adult life (excluding dementia) starts before age 15 and 75% by age 18.<sup>20</sup> In addition, there are well-identified increased physical health problems associated with mental health.<sup>15-18</sup>
- There are strong links between mental health problems in children and young people and social disadvantage, with children and young people in the poorest households three times more likely to have a mental health problem than those growing up in better-off homes.<sup>3</sup>
- Parental mental illness is associated with increased rates of mental health problems in children and young people, with an estimated one-third to two-thirds of children and young people whose parents have a mental health problem experiencing difficulties themselves.<sup>24,25,57</sup>
- Mental health problems in children and young people are associated with excess costs estimated as being between £11,030 and £59,130 annually per child.<sup>21</sup> These costs fall to a variety of agencies (e.g. education, social services and youth justice) and also include the direct costs to the family of the child's illness.
- There are clinically proven and cost-effective interventions. Taking conduct disorder as an example, potential life-long savings from each case prevented through early intervention have been estimated at £150,000 for severe conduct problems and £75,000 for moderate conduct problems.<sup>22</sup>



## Overview

### Mental health problems in children and young people are common and account for a significant proportion of the burden of ill health in this age range.

The World Health Organization (WHO) defines mental health as not simply the absence of disorder but 'a state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community'.<sup>1</sup> This broader definition is particularly appropriate in childhood and adolescence, as mental health is the foundation of healthy development and mental health problems at this life stage can have adverse and long-lasting effects. In this chapter we will focus mainly on mental disorders, the most severe end of the spectrum of problems. The use of the term 'mental disorder' should not be taken as an indication that the problem is entirely within the child as mental disorders can develop for a variety of reasons including a reaction to or interaction with external circumstances.

### Rates and profile of mental health problems among children and young people

The most recent British surveys carried out by the Office for National Statistics of children and young people aged 5–15 years in 1999 and 2004<sup>2,3</sup> (referred to as the British Child and Adolescent Mental Health Surveys or B-CAMHS) found that **10% had a clinically diagnosable mental disorder** (i.e. a mental health problem associated with significant impairment). Among the 5 to 10 year olds, 10% of boys and 5% of girls had a mental disorder while among the 11 to 16 year olds the prevalence was 13% for boys and 10% for girls. In these two surveys the prevalence of anxiety disorders was 2–3%, depression 0.9%, conduct disorder 4.5–5%, hyperkinetic disorder (severe ADHD) 1.5% and autism spectrum disorders 0.9%. Rarer disorders including selective mutism, eating disorders and tics disorders occurred in 0.4% of children. Conduct disorders, hyperkinetic disorder and autism spectrum disorders were more common in boys, and emotional disorders were more common in girls.

Young people aged 16 and over are included in the Office for National Statistics surveys of adult psychiatric morbidity. As these surveys used different assessment methods and categories to the surveys of under-16s, direct comparison is more difficult. In the 2007 survey of adults in England,<sup>4</sup> **in the 16–24-year-old age group 2.2% experienced a depressive episode, 4.7% screened positive for post-traumatic stress disorder, 16.4% experienced anxiety disorder, 0.2% had a psychotic illness and 1.9% had a diagnosable personality disorder.**

**Self-harm among young people is a major concern.** In the 2004 B-CAMHS survey,<sup>3</sup> the rate of self-harm in 5–10 year olds was 0.8% in those with no disorder, rising to 6.2% in those with an anxiety disorder and 7.5% among the group of children with hyperkinetic disorder, conduct disorder

or one of the less common disorders. **The prevalence increased dramatically in adolescence with rates of 1.2% in those with no disorder, rising to 9.4% in those with an anxiety disorder and 18.8% in those with depression.** In a 2007 survey of young adults,<sup>4</sup> 6.2% of 16–24 year olds had attempted suicide and 8.9% had self-harmed in their lifetime. Suicide is the leading cause of death in young people. The suicide rate among 10–19 year olds is 2.20 per 100,000; it is higher in males (3.14 compared with 1.30 for females) and in older adolescents (4.04 among 15–19 year olds compared with 0.34 among 10–14 year olds).<sup>5</sup> Recent research has shown a significant fall in the rates among young men in the period 2001–2010.

Despite the increasing recognition of the importance of the early years as a focus for early intervention, there has been less research on the profile and rates of problems in the under-5s and they were not included in the B-CAMHS surveys. One study showed that the prevalence of problems for 3-year-old children was 10%, with 66% of parents sampled having one or more concerns about their child.<sup>6</sup> A further study showed that 7% of children aged 3–4 years exhibited serious behaviour problems.<sup>7</sup> Differentiating normal from abnormal behaviour in younger children can be difficult and a substantial proportion of children will 'grow out of' early childhood problems, particularly among the under-3s. However, longitudinal studies suggest that 50–60% of children showing high levels of disruptive behaviour at 3–4 years will continue to show these problems at school age.<sup>8</sup> Moreover, neurodevelopmental problems including language delay, ADHD and autism spectrum disorders are first manifest in the pre-school years.

### Are mental health problems among children and young people becoming more common?

There is a popular perception that children and young people today are more troubled and badly behaved than previous generations. Research looking over a 25-year period from 1974 to 1999 found increases in conduct problems in young people, affecting males and females, all social classes and all family types.<sup>9</sup> There is also evidence for a rise in emotional problems, but mixed evidence in relation to rates of hyperactivity. There were no differences in rates between the 1999 and 2004 B-CAMHS surveys.

However, evidence for a recent rise in levels of psychological distress is provided by data from the West of Scotland Twenty-07 study<sup>10</sup> in which marked increases in GHQ 12 'caseness' (a scoring system for mental health) were found in females between 1987 and 1999 and among both males and females between 1999 and 2006. In addition, **self-harm rates have increased sharply over the past decade, as evidenced by rates of hospital admission<sup>11</sup> and calls to helplines,<sup>12</sup>** providing further indications of a possible rise in mental health problems among young people. However, in the absence of up to date epidemiological data, it is uncertain whether there has been a rise in the rates of mental health problems and whether the profile of problems has changed.

## The impact of mental health problems

Mental health problems not only cause distress but can also be associated with significant problems in other aspects of life and affect life chances. In the B-CAMHS surveys cited earlier<sup>2,3</sup> all forms of mental disorder were associated with an increased risk of disruption to education and school absence. Research on the longer-term consequences of mental health problems in childhood and adolescence have found associations with poorer educational attainment<sup>13,14</sup> and poorer employment prospects,<sup>13,14</sup> including the probability of 'not being in education, employment or training' (NEET).<sup>13,14</sup> The mechanisms by which mental health problems in childhood and adolescence affect educational attainment and life chances are complex, but it is likely that at least some of the risk is attributable to the direct effects of the disorder itself.<sup>13</sup> Social relationships can be affected both in childhood and adolescence and in adult life.<sup>13</sup> Other increased risks include drug and alcohol use, particularly for young people with conduct disorder, ADHD and emotional disorder.<sup>13</sup> Conduct disorder and ADHD are also both associated with an increased risk of offending<sup>13</sup> and conduct disorder in girls is associated with an increased risk of teenage pregnancy.<sup>13</sup>

The risks are not confined to psychosocial problems. There are also associations between mental health problems in childhood and adolescence and poorer physical health as well as the possibility of developing at-risk health behaviours. In the B-CAMHS surveys,<sup>2,3</sup> parents of children and young people with mental health problems were more likely to report that their child's general health was poor. There are particular risks associated with some mental health problems, for example psychosis, which is associated with premature mortality in adult life,<sup>15</sup> and anorexia nervosa,<sup>16</sup> which can be life-threatening and lead to longer-term health problems. Adversity in childhood – including abuse and neglect, parental mental illness, parental drug and alcohol abuse, and domestic violence – has been shown to be associated with an increased risk of the major morbidities of mid-life, including heart disease and some cancers.<sup>17,18</sup> It is thought that the development of mental health problems and at-risk health behaviours act as mediating factors in the link between early adversity and later-life problems. For example, it is known that young people with histories of conduct problems, depression and suicidality are 4–6 times more likely to smoke<sup>13</sup> and 2–4 times more likely to use alcohol regularly.

**Mental health problems in children and young people are often persistent;** this is particularly true for conduct disorder, hyperkinetic disorder and autism spectrum disorders.<sup>19</sup> Although emotional disorders have a better prognosis, they are not always benign, and again may persist.<sup>19</sup> The persistence of child and adolescent-onset disorders into adult life is of particular concern. **The Dunedin study,<sup>20</sup> which followed up a large cohort of children through to adulthood, found that half of the adults in the study who had a psychiatric disorder at age 26 had first had problems prior to age 15, and three-quarters had problems before age 18;** these rates were even higher among adults in contact with mental health services.

As well as the impact on the individual child and family, mental health problems in children and young people also result in an increased cost to the public purse. **Mental health problems during childhood and adolescence in the UK result in increased costs of between £11,030 and £59,130 annually per child.**<sup>21</sup> Taking conduct disorder as an example, lifetime costs of a one-year cohort of children with conduct disorder (6% of the child population) have been estimated at £5.2 billion, with each affected individual being associated with costs around 10 times that of children without the disorder.<sup>22</sup> Costs falling on the public sector are distributed across many agencies. The cost of crime attributable to adults who had conduct problems in childhood is estimated at £60 billion a year in England and Wales, of which £22.5 billion a year is attributable to conduct disorder and £37.5 billion a year to sub-threshold conduct disorder.<sup>23</sup>

## Risk factors and associations

Research from around the world has found that **the risk of developing a mental health problem is strongly increased by social disadvantage and adversity.**

In the 2004 B-CAMHS survey,<sup>3</sup> the prevalence of mental disorder was higher in children and young people:

- in lone-parent (16%) compared with two-parent families (8%)
- in reconstituted families (14%) compared with families containing no stepchildren (9%)
- whose interviewed parent had no educational qualifications (17%) compared with those who had a degree-level qualification (4%)
- in families with neither parent working (20%) compared with those in which both parents worked (8%)
- in families with a gross weekly household income of less than £100 (16%) compared with those with an income of £600 or more (5%)
- in families where the household reference person was in a routine occupational group (15%) compared with those with a reference person in the higher professional group (4%)
- living in areas classed as 'hard pressed' (15%) compared with areas classed as 'wealthy achievers' or 'urban prosperity' (6% and 7% respectively).

Parental mental illness is known to be associated with a higher rate of mental health problems in children and young people,<sup>24,25</sup> as are parental substance misuse<sup>26</sup> and parental criminality.<sup>27,28</sup> Violence between parents also increases the risk of children and young people developing mental health problems, as well as increasing the risk that the children may experience abuse and neglect.<sup>29,30</sup>

Children and young people who have experienced severe adversity such as abuse and neglect are at particularly high risk of developing a mental health problem, as are looked-after children and young people in contact with the criminal

justice system (see Chapters 11 and 12 of this report). Severe bullying and experiences of discrimination can also act as risk factors for the development of mental health problems.

Physical illness, disability and developmental co-morbidities also act as risk factors for mental health problems. Living with long-term physical illness or disability raises the risk of developing a mental health problem. Young people living with a long-term physical illness are twice as likely to suffer from emotional or conduct disorders.<sup>31</sup> Children and young people with learning disabilities and children and young people with ASD are at greatly increased risk of developing a co-morbid mental health problem.

Research has shown that being among the youngest in the school year is associated with educational disadvantage and in the 1999 B-CAMHS survey being among the youngest in the school year group was found to be associated with a slightly greater risk of mental disorder.<sup>58</sup>

## Ethnicity and mental health

The 1999 and 2004 B-CAMHS surveys<sup>2,3</sup> found differences in the rates of mental disorder across different ethnic groups. However, as there were only a small number of ethnic minority children and young people in the studies and the information gathered from non-English speaking informants was more limited than that obtained from English speaking informants, interpreting the results was difficult. With this caveat in mind, in the 2004 B-CAMHS survey the rates of disorder were found to vary by ethnic group – children and young people categorised as Indian had a rate of approximately 3%; children and young people in the Pakistani/Bangladeshi group a rate of just under 8%; children and young people in the black group a rate of around 9%; with the highest rate in the white group at approximately 10%. The low rate of problems in young people of Indian heritage has been replicated in a more recent study.<sup>59</sup>

To date, there has been relatively little research on the relationship between ethnicity and child mental health.<sup>60</sup> The most recent census of England and Wales in 2011 found an increase in ethnic diversity. There is a need for better research evidence on the prevalence of child mental health problems in minority ethnic groups as well as looking at service utilisation and whether particular groups experience barriers to receiving a service, in addition to understanding why some groups and communities may be more resilient.

## Strategies for intervention and prevention

Risk factors for developing a mental health problem can operate at a societal level, at a community level and at the level of the individual and their family. Similarly, strategies to improve the mental health of children and young people can be employed at multiple levels. In this chapter we concentrate primarily on interventions targeted at the individual child or young person and their family. This is not to deny the importance of developing strategies to tackle the social determinants of poor health. Government policy and actions should effectively address inequalities to

promote population mental health as well as prevent mental ill health and promote recovery when problems develop.<sup>32</sup> In focusing primarily on what might be thought of as ‘clinical interventions’, we are not intending to overlook the important role that school and community play in the lives of children and young people and the potential for intervention through these domains.<sup>33</sup>

The past two decades have seen major developments in research evaluating the effectiveness of treatments for the mental health problems of childhood and adolescence<sup>34,35</sup> as well as an increasing interest in strategies for prevention.

### Case study

#### PreVenture – school-based programme to reduce teenage substance misuse in London

PreVenture is a school-based drug and alcohol prevention programme that helps teenagers to learn coping skills in order to better manage personality traits associated with risk for addiction. The programme uses psycho-educational manuals within interactive group sessions with students aged 13–16 years. The group sessions focus on motivational factors for risky behaviours and provide students with coping skills to aid their decision making in situations involving anxiety and depression, thrill seeking, aggressive and risky behaviour (e.g. theft, vandalism and bullying), drugs and alcohol misuse. Students identified as being at elevated risk of engaging in risky behaviours are given a two-session intervention workshop and followed up every 6 months for 2 years. School-based facilitators included teachers, school counsellors and pastoral staff.

Studies to evaluate the effectiveness of the programme in more than 20 London schools (located in densely populated, low-income areas of London as well as suburban areas) demonstrated that brief school-based targeted interventions can prolong survival as a non-drug user over a 2-year period. The success of this programme is likely to be due to its selective nature in that only high-risk youth with known personality risk factors for early-onset substance use were targeted. This selective approach allowed delivery of interventions that were brief and personally relevant, and focused on risk factors directly related to the individual’s risk for substance use.

These studies are the first to demonstrate that teacher-delivered and personality-targeted brief coping skills interventions can reduce substance use over a 2-year period, not only in those being treated but also spreading to the rest of the school. Although designed to prevent substance misuse, analyses have shown that the interventions concurrently reduce or prevent common emotional and behavioural problems in adolescents.<sup>61,62,63,64</sup>

*‘I have learned that I don’t have to go with whatever I first think of and that I should try to do more stuff to help me with what I want to do when I am older.’*



## Effective 0 to 5 early years intervention programmes and outcomes

As outlined in the chapter on preconception and pregnancy (see Chapter 5), there is particular interest in this period of the life span as a focus for prevention.

The Evidence2Success project<sup>36</sup> for the National Institute for Health and Care Excellence (NICE) Public Health Intervention Advisory Committee on the social and emotional wellbeing of vulnerable children aged 0–5 years looked at programmes that target one or more key developmental outcomes in infancy (0–2 years) and early childhood (3–5 years), aiming to achieve positive relationships (reduce risk of maltreatment) and behaviour (increase in pro-social behaviour), emotional wellbeing (self-regulation and free from depression and anxiety) and educational skills and attainment, particularly readiness for school.

**Of the 100 programmes identified, 25 yielded relevant positive outcomes and 11 of these were found to be based on strong, reliable evidence.** The benefit-to-cost ratio was based on the calculations provided by the Washington State Institute for Public Policy.<sup>37</sup> These programmes are currently implemented in the UK primarily through children's centres, Child and Adolescent Mental Health Services (CAMHS) or other specialist units. They fall into the following five categories:

- **pre-school curricula to enhance children's readiness for school**, in particular skills in language and literacy (e.g. Early Literacy and Learning Model with a benefit-to-cost ratio\* of \$3.60)
- **parenting group programmes to improve children's behaviour** (e.g. Incredible Years BASIC with a benefit-to-cost ratio of \$4.20)
- **parent and child therapy programmes to improve children's relationships with their parents/carers** (e.g. parent-child interaction therapy with a benefit-to-cost ratio of \$7.37)
- **home-visiting programmes to improve children's relationships with their parents/carers** (e.g. Nurse-Family Partnership with a benefit-to-cost ratio of \$3.23)
- **intensive child and family support programmes to improve behaviour and children's relationships with their parents/carers** (e.g. multidimensional treatment foster care with a benefit-to-cost ratio of \$5.20).

There are several additional programmes without adequate cost-effectiveness studies but with **strong evidence of efficacy**. These include:

- the **detection and treatment of postnatal depression** (e.g. group cognitive behavioural therapy and individual counselling for depression of perinatally identified cases)<sup>38</sup>
- **improving relationship quality in the first year of life** (e.g. video feedback interactive programmes)<sup>39–41</sup>

\* Benefit-to-cost ratios are calculated from the ratio of the monetary gain that follows from an intervention against the costs of setting up and providing the intervention.

- **specific child maltreatment prevention programmes** based on family therapy and social learning principles which achieve increased maternal educational attainment and parent involvement in school as well as decreased family problems.<sup>42</sup>

## Treatments for mental health problems of childhood and adolescence

The upsurge of research evaluating the effectiveness of treatments for mental health problems of childhood and adolescence has allowed the potential to introduce evidence-based practice (EBP) in CAMHS across the country.<sup>43</sup>

EBP in mental health, as in other medical specialties, involves three components:

- taking account of the best available research into the intervention
- patient preference
- the individual patient's context (which in mental health is complex and includes the family system, school, any co-occurring physical illness, any safeguarding concerns, history of abuse or neglect, and any history of substance misuse or involvement with the criminal justice system).

Although the intervention offered is important, the therapeutic alliance between the clinician and the child/young person and family is also a potent determinant of outcomes in mental health.<sup>44</sup> **There is evidence that EBP is statistically superior to usual care.**<sup>45</sup> Experimental work also demonstrates that the major benefit from EBP to child mental health services is in **value**, conceived of as the ratio of the outcome that matters to patients to the cost of delivering that outcome.<sup>46</sup> **Using EBP has been shown to reduce costs by up to 35%<sup>47</sup> and duration of treatment by up to 43%.<sup>48</sup>**

Intervening early in the course of disorder can reduce the risk of later disorder and has the potential to generate savings for services and society. For example, **recent neurobiological research has shown that depression leaves its mark on the developing brain, and undiagnosed or untreated depression in young people creates a more treatment-resistant form of the illness.**<sup>49</sup> The case for prevention is even clearer for conduct disorder. Potential savings (including intangibles) from each case prevented through early intervention have been estimated at £150,000 for severe conduct problems and £75,000 for moderate conduct problems.<sup>22</sup>

Below we provide a broad-brush summary of the literature on evidence-based treatments for two of the most common mental health problems as illustrative examples.

## Evidence-based treatments for conduct disorders

**Psychosocial therapies are the mainstay of treatment for conduct disorders** and are both clinically and cost-effective. Up to the age of 11, conduct disorders are best

treated through modification of parenting practices. There are numerous programmes with dozens of studies. **Parent training delivered in group formats is highly cost-effective.** In more severe cases of conduct disorder, parent-child interaction therapy, which helps parents to modify their behaviour with their child in real time, appears to be quite efficacious. The key factor is improving positive parenting. The maintenance of these gains is less clear and the programmes make substantial demands on families, creating a significant problem in relation to dropout, particularly among high-risk groups. Social and cognitive problem-solving interventions with the child may be helpful in increasing self-control and maintaining gains.

In young people aged 12 and older, interventions tend to be less effective. However, with this group even small effect sizes can imply relatively large social and economic benefits. Paradoxically, the highest-risk adolescents show greatest improvement. In this context perhaps more than any other, rigorous adherence to treatment protocols appears to be particularly important. **All effective treatments for conduct disorder involve the family.** Multisystemic therapy, brief strategic family therapy and functional family therapy appear effective for moderate-to-severe cases. Multidimensional treatment foster care is an approach practised in the USA and now being trialled in the UK for the most severely affected young people who are already in care. Cognitive behavioural therapy, although most commonly practised, has a limited evidence base. Social and problem-solving skills training, also commonly used, lacks evidence of generalisation of improvements. Anger management, frequently used with some optimism, has had some positive trials but its value across contexts is questionable. In the USA, medication is increasingly used in the treatment of conduct disorder and, in particular, risperidone is used in the management of aggression. NICE has recently included this in the guideline on treatment for conduct disorder for use in the management of explosive aggression as a short-term (up to 6 weeks) adjunct in combination with other approaches.<sup>50</sup>

## Evidence-based treatments for depression

There are effective treatments for depression in children and young people.<sup>34</sup> Cognitive behavioural therapy for depression has been shown to be effective in both individual and group settings, but is most likely to be helpful in the acute phase of the disorder and in individuals who are motivated. Using cognitive behavioural therapy principles in general case management (e.g. careful monitoring of problems and lifestyle, providing practical suggestions about sleep, hygiene and diet) appears to achieve good results. Interpersonal psychotherapy and family therapy are also effective, and attachment-based family therapy has been shown to be helpful for quite severe suicidal ideation.

Medication in the form of selective serotonin reuptake inhibitors (SSRIs), especially fluoxetine, is effective in the treatment of depression, and maintenance doses may be able to reduce the likelihood of recurrence. However, controversy surrounds their use because some SSRIs appear

to increase the risk of suicide in this population. Therefore, NICE recommends that they should be administered with care by child and adolescent psychiatrists<sup>51</sup> and reserved for moderate-to-severe depression. There is evidence supporting the use of adjunctive psychosocial treatments, which may speed up response to treatment and decrease suicidality.

## State of services

**Despite the existence of an evidence base**, now formalised by NICE in a suite of guidelines that are relevant to children and young people's mental health, **there are problems in access to evidence-based treatments.**

The final report of the National CAMHS Review in 2008<sup>52</sup> found that, although there had been considerable investment in services since 2004, there was variation in access to services and in implementation of evidence-based interventions. **More recently, however, there has been disinvestment in CAMHS, particularly in local authority expenditure.**<sup>53</sup> There are also frequent anecdotal reports of services having long waiting lists and of thresholds being too high in terms of referrals of children and young people with less severe problems not being accepted. The multi-agency nature of services and complex commissioning arrangements allow the potential for a lack of co-ordination or integration between agencies which, particularly at a time of shrinking budgets, may mean that children and young people fall through the net. **There may also be reluctance for agencies to invest in interventions when they themselves may not benefit from any savings accrued, for example by providing early intervention.**

There is room for some optimism in that there has been some investment in the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme,<sup>54</sup> which is attempting to address some of the shortfalls in access to evidence-based treatments, particularly in relation to cognitive behavioural therapy and parenting programmes, and which by the end of year 3, in 2015, should reach 60% geographical coverage. However, as noted, this is against a backdrop of austerity.



## Case study

### Specialist day service for young people with complex mental health needs – Greater Manchester West Mental Health NHS Foundation Trust

This nurse-led service provides a variety of treatment options and consultation to colleagues in 'specialist' CAMHS teams, young people aged 14–18 and their families/carers. Operating for almost 3 years, the service offers an alternative to specialist inpatient admission and supports early transition from hospital to home, ensuring that young people are treated in the least restrictive environment.

Other members are co-opted into the project as required to provide, for example, sessional input from a dietician and art therapist. It provides a day service for six young people and an extensive outpatient and outreach facility, and conducts individual, group and multi-family group sessions depending on client need.

Most of the young people present with enduring mental health problems such as psychosis, eating disordered behaviour and self-harm. In some instances, inpatient admission can be counter-therapeutic and using day and outpatient provision can reduce issues of dependency and contagion.

## What is an acceptable child and adolescent mental health service?

An adequate service must be able to offer comprehensive assessment by clinicians who are skilled in engaging children and young people and who have a good understanding of how mental health problems manifest at different developmental stages and ages. Intervention should be based on careful formulation of evidence and practice and be collaborative between families and practitioners, and the effects should be systematically monitored using appropriate outcomes measures, with intervention being modified on the basis of the outcomes. Services should be able to report treatment outcome in at least 50% of cases on the basis of a standardised patient or carer-rated measure.<sup>55</sup>

The service must be able to offer a range of evidence-based treatments for the most common child and adolescent mental health problems including:

- treatment for ADHD including medication and psychosocial treatments
- interventions for suicidality and self-harm
- cognitive behavioural therapy and other evidence-based treatments for anxiety (including obsessive compulsive disorder and social phobia) by clinicians trained to at least CYP IAPT practitioner criteria
- parent training groups for oppositional and conduct disorders

- family therapy including evidence-based approaches for conduct problems
- cognitive behavioural therapy and interpersonal therapy for depression and medication where appropriate.

Services should also have arrangements in place to ensure provision of specialist interventions/services for less common problems where there may not be a sufficient critical mass of patients presenting to an individual team to warrant provision. The 'commissioning footprint' in terms of population mass required to support such interventions/services may be larger than that of a single clinical commissioning group (CCG) and require collaboration across CCGs and, in some cases, local authorities. Examples of such interventions/services include psychodynamic psychotherapy; specialist eating disorder teams who are able to offer a range of interventions including eating disorder-focused family therapy for anorexia nervosa; dialectical behaviour therapy or other evidence-based treatment for young people who repeatedly self-harm; and treatments for young people with psychoses. As self-harm and anorexia are both common reasons for admission to hospital, the provision of such services also has the potential to reduce the need for hospital admission as well as improving outcomes. In addition, there should be access to what are sometimes called crisis/home-treatment services providing intervention aimed at reducing the need for hospital admission.

Services must take active steps to increase access, including multiple access points, telephone advice and psycho-education, and carry out ethnic monitoring to show accessibility to diverse communities. Services should offer web-based interventions for parents to ensure immediate help, adequate signposting and low-intensity evidence-based interventions. School-based services should be available, but these also must be evidence based. They must, in addition, be alert to the possibility of these children and young people being stigmatised and must take steps to protect them from this.

There should be joint agency protocols across health (including adult mental health services), education and social care in relation to joint working, referrals between agencies and the management of risk, including safeguarding concerns. Where possible, interventions for adults in the family and those for the child should be integrated, as families with complex needs have the poorest outcomes. Parents contribute to the delivery of therapy for their child, but deserve to have their own needs attended to in turn. Above all, all those attending CAMHS have a right to feel listened to and appropriately responded to, not solely according to the diagnosis but in terms of their personal need.

## Conclusion

Mental health problems in children and young people are common, can be long-lasting and affect life chances as well as being costly for the individual and society. In order to improve the mental health of England's children and young people, action is needed on multiple levels – from societal to the level of the individual – both to build resilience and to

effectively intervene when problems develop. Fortunately, there are effective measures and interventions. **The challenge is ensuring implementation.**

## What we still need to find out

Since the start of the 21st century there has been a considerable increase in the quantity and quality of outcomes research in child and adolescent mental health, but despite this there remain many areas where research knowledge is insufficient to guide practice. Future efforts in research and practice will need to address the following issues if we are to meet the ideal of reaching and treating all children and young people with mental health problems:

- For some mental health disorders of children and young people there is still a lack of clarity about diagnostic criteria. This makes it difficult to conduct research and to interpret it in order to determine which treatments have the best evidence for effectiveness and cost-effectiveness, which ultimately has implications for services 'in the field'.
- It is known that modifying the child's family environment can yield substantial positive outcomes, and behavioural genetic studies have shown that social and environmental influences play a key role in triggering genetic vulnerabilities (increasing the likelihood of disorder developing) or, conversely, protecting against genetic predispositions. Future research will need to make sophisticated assessments of environmental influence to help us to better understand how the social environment may counteract genetic risk – which may lead to the development of better preventive and therapeutic interventions – and whether vulnerability to environmental influence can indicate whether a given psychosocial intervention may be suitable or unsuitable for a given child.
- Too many studies on which our current evidence base rests have significant methodological flaws, such as small sample sizes, failures of replication, or differences in outcome between research and clinical settings. This means that it is often difficult or impossible to generalise findings from research into everyday practice. These problems need to be tackled if we are to truly understand which interventions are most effective for the mental health problems of children and young people.
- We also need to carry out studies with longer follow-up periods, to help us to assess, for example, how long pharmacological treatments for ADHD or depression should be continued once remission has been achieved, or the relative benefits of short-term and extended psychological interventions.
- As mentioned above, we need to collect data on both what services are offered to children in mental health services and what the outcomes of these interventions are. We are currently lacking a way of integrating information nationally as well as locally across services. For example, we have no way of relating the outcomes of health service interventions to educational or often even social service interventions, yet where children present with mental health problems is more likely to be the consequence of circumstance rather than the characteristics of their presenting problem.
- At present, many children and young people do not respond adequately to even the best-evidenced treatments. We need to find out more about sub-groups who do not respond to treatment, and to explore whether better results could be achieved by alternative means – in terms of both different treatments and different settings in which treatment is provided (as outlined below). This could help us to develop care pathways for children and adolescents who present with different mental health problems, starting with simpler interventions and moving on to more complex interventions (or combinations of interventions) if the initial ones do not achieve a good outcome.
- At present, some interventions are being offered that have not been adequately evaluated (for example, systemic therapies). We need to evaluate these treatments more fully and to identify the effective elements that they contain, as it is possible that they may help the 'poor responders' to existing evidence-based treatments.
- We also need more information (from both research and practice) about the adverse outcomes of treatments. In the case of pharmacological treatments, it is already accepted that such adverse effects must be monitored and reported, and these reports help to guide marketing authorisations and prescribing decisions. The possibility of adverse outcomes from psychological therapies needs to be investigated and reported with the same diligence.
- We need to understand more about alternative settings in which treatments may be implemented, especially for those children and young people who are not currently reached by existing services. This should include not just physical locations such as schools and community centres, but also social contexts, for example involving community leaders, peers and near-peers (that is, young people who are slightly older than the young service users).
- As unmet need is so high, we need to develop innovative methods of service delivery (e.g. the internet, the media and improving mental health literacy in the wider community) in the contexts of prevention and intervention.

## Key messages for policy

- Improving the mental health outcomes of England's children and young people requires action at multiple levels from the societal to the individual.
- The B-CAMHS surveys should be repeated to provide more up-to-date information in order to aid planning of healthcare services. In view of the recognition of the importance of the early years as a focus for intervention, the survey should be extended to the under-5s. The new survey should also address the need for better evidence on the mental health of children and young people from ethnic minorities.
- The investment in and focus on children and young people's mental health should be proportionate to the associated health burden.
- Government policy and actions should effectively address inequalities to promote population mental health, prevent mental ill health and promote recovery.
- Policy to support parents as well as strengthening parenting skills has the potential to yield benefits in relation to physical and mental health. Measures can range from indirect (e.g. alleviating aspects of family adversity which may negatively affect parenting) to direct (e.g. delivery of parenting interventions).
- Services should ensure that where parents have a mental illness both services and interventions are available which take account of their needs and role as a parent.
- Service design should recognise the role and importance of schools in relation to children and young people's health in terms of both the potential of schools to foster the development of resilience and providing opportunities for the delivery of interventions aimed at improving mental health.
- Healthcare needs to support developing better mental health informatics to support evidence-based commissioning by understanding patterns of prevalence and need as well as aiding the monitoring of outcomes.
- Healthcare systems need to ensure integration across all parts of the system so that the mental health needs of children and young people can be met in the most effective and efficient way and that children and young people do not fall through the net.
- Healthcare professionals need to ensure implementation of evidence-based and outcome-based approaches to intervention is encouraged in all parts of the system.
- Efforts need to be made to support the delivery of effective CAMHS by addressing workforce and training issues and shortfalls in resources.

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## Chapter 11

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# Looked-after children and young people

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## Key statistics

- In England, there were 67,050 looked-after children (0.6% of the childhood population) on 31 March 2012. Of these, 28,220 started to be looked after during the year 1 April 2011–31 March 2012.<sup>1</sup>
- Some 56% of the children who started to be looked after during the year became so because of abuse or neglect.<sup>1</sup>
- Following a significant fall in the number of children in care over the past 30 years, numbers rose in the UK between 2008 and 2012, from 81,315 to 91,667.<sup>1</sup>
- Around 13% of children remain in the care system for more than five years.<sup>1</sup>
- An analysis of serious case reviews in England shows that 10% (2003–2005) and 13% (2005–2007) related to a child in care.<sup>1</sup>
- There have been 33 child deaths in youth custody since 1990.<sup>1</sup>
- Looked-after children and care leavers are between four and five times more likely to self-harm in adulthood. They are also at five-fold increased risk of all childhood mental, emotional and behavioural problems, and six to seven times more likely to have conduct disorders.<sup>2</sup>
- Looked-after teenage girls are 2.5 times more likely to become pregnant than other teenagers.<sup>3</sup> ChildLine counselled 3,196 children and young people in 2009–2010 about problems related to being looked after – this is 1 in 26 of all looked-after children in the UK.<sup>1</sup>
- The cost of a foster care placement is £676, and the cost of living in a children's home is £2,639 per week (2010).<sup>4</sup>

## Overview

Looked-after children and young people in care are a vulnerable group; their issues feature prominently in the United Nations Convention on the Rights of the Child (UNCRC).<sup>5</sup> Article 9 of the convention emphasises the importance of family life, except when this is not in the best interests of a child; article 20 lays out the responsibilities of the state to children who enter public care; article 21 describes the place of adoption; and article 22 summarises governmental responsibilities to asylum-seeking and refugee children. Article 25 outlines the need for regular reviews of a child's plan while in care, which is called a statutory review in England (see Box 11.1). This operational statement is remarkable in a global document such as the UNCRC and reflects real concern for the wellbeing of these children. This chapter will summarise the evidence for why looked-after children are a vulnerable group and look at what we can do to build their resilience.



**'If someone hurts you it can break your heart'.**

Source: Kids Company

### Box 11.1 Relevant articles from the UNCRC for looked-after children

- **Article 9** – *States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child.*
- **Article 20** – *A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State... Such care could include, inter alia, foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background.*
- **Article 21** – *States Parties that recognize and/or permit the system of adoption shall ensure that the best interests of the child shall be the paramount consideration.*
- **Article 22** – *States Parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, whether unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present Convention and in other international human rights or humanitarian instruments to which the said States are Parties... In cases where no parents or other members of the family can be found, the child shall be accorded the same protection as any other child permanently or temporarily deprived of his or her family environment for any reason, as set forth in the present Convention.*
- **Article 25** – *States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.*

### Epidemiology of children in care

The term 'looked after' was introduced by the Children Act 1989<sup>6</sup> and refers to children and young people under the age of 18 who live away from their parents or family and are supervised by a social worker from the local council children's services department. A 'looked-after child' may either be accommodated (which means that the council is looking after them with the agreement, at the request or in the absence, of their parents) or subject to an order made by the family courts.<sup>6,7</sup>

**On 31 March 2012, there were 67,050 children in care in England, more than 1 in 200 of the total child population, and over a 12-month period more than 95,000 children will have an episode in public care, almost 1 in 100 of the total child population.**<sup>8</sup> Spending some time in care is relatively common; even more common are referrals to social care, which have remained relatively static over the last 10 years: 4.9% of all children in 2001 and 5.6% in 2011. The percentage placed on a plan has stayed at 0.3–0.4% of all children.<sup>9</sup> While each child in care has a unique story with a different set of circumstances leading to the care episode, there are recognisable patterns which mean that children can usually be placed in groups that share characteristics. Some children enter care for a short time period and then return home. Other young children enter care and, if the assessment of the birth parents is unfavourable and a search for extended family members does not identify suitable carers, a plan for permanency by adoption is usually made. If children enter care at an older age and with a strong relationship with their parents who are unable to care for them (because of issues which often include mental illness, drug or alcohol misuse or learning difficulties), a plan for long-term fostering and contact with parents may be appropriate. Some young people, usually from conflict zones around the world, come as unaccompanied asylum seekers and are accommodated by the local authority. Children with disabilities are another distinct group of children in public care.



**'They took my mummy away from me'.**

Source: Kids Company

## Current outcomes of care

Research on the 1970 birth cohort, which enrolled 16,567 infants born between 5 and 11 April 1970, provides **evidence of the adverse outcomes experienced by people who spent time as looked-after children.** Viner and Taylor reported the adult outcomes for the cohort population who spent time in public care (n=343) compared with the rest of the cohort (n=9,214). After controlling for socio-economic status, men with experience of care were significantly more likely to have been homeless (odds ratio (OR) 2.0; 95% confidence interval (CI) 1.1–3.8), have a conviction (OR 2.3; 95% CI 1.5–3.4), have psychological morbidity (OR 1.8; 95% CI 1.1–3.0) and be in poor general health (OR 1.6; 95% CI 1.1–2.6). They were less likely to

attain high social class (OR 0.6; 95% CI 0.4–0.9). Similar associations were identified for women. Men, but not women, with a history of care were more likely to be unemployed (OR 2.6; 95% CI 1.4–5.0) and less likely to attain a higher degree (OR 0.4; 95% CI 0.2–0.7).<sup>10</sup> It is possible that the real outcomes for people who spent time in care as children are worse than this study suggests, as only people with data collected at all the time points were included in this study, and people with a history of care are often mobile and would be over-represented in the group excluded from the study population because of missing data. Clearly the people in this study were children in the 1970s and 1980s and the care system has changed a great deal since then, but nonetheless the findings are important and similar outcomes have been reported from the USA,<sup>11–13</sup> Sweden<sup>14</sup> and Spain.<sup>15</sup>

The Department for Education collects data on educational outcomes for looked-after children compared with other children at Key Stage 2 and GCSE. While the recent cohorts taking examinations do show improving outcomes, the gap remains very wide and **the educational attainment of children in care lags well behind that of their peers.**<sup>16</sup>

Another key concern is the mental health and wellbeing of children and young people in public care. In 2003, a major study by Meltzer et al. used versions of the Strengths and Difficulties Questionnaire (SDQ) tailored for carers, teachers and young people followed up by an interview with a mental health practitioner to validate the SDQ scores.<sup>17,18</sup> Mental health issues were described as emotional, hyperkinetic or conduct disorders. The research team had used the same methodology to evaluate the mental health of children and young people living at home two years earlier and so a comparison group was available. Children in care have significantly higher rates of mental health problems than the general child population and this rate did not fall quickly with longer time in care.<sup>17</sup> There is also evidence of an increased prevalence of mental illness rates for children in care in the USA,<sup>19,20</sup> Australia<sup>21</sup> and Denmark.<sup>22</sup> The risk of suicide for care leavers in Sweden is more than twice the general population risk<sup>23</sup> and other Scandinavian population studies have found excess mortality risks for care leavers.<sup>24,25</sup>

Children and young people in care also have high levels of risk-taking behaviours such as smoking, and alcohol and drug misuse.<sup>17,26–29</sup> In Sweden, research has investigated the prevalence of teenage parenthood and it is clear that populations with social welfare interventions show high teenage parenthood prevalence figures and highly elevated odds ratios in some sub-groups, but there is also significant variation.<sup>30</sup> A follow-up study looking at teenagers placed in public care found that every third girl placed in a secure residential unit and every fourth girl placed in other residential homes because of behavioural problems became mothers as teenagers.<sup>14</sup>

**Children and young people in care are also at increased risk of sexual exploitation, as recent high-profile media cases have identified.**<sup>31</sup>



Sometimes the care system can add to distress, with looked-after children moving placements too frequently and at short notice. Some 23% of those changing were informed on the day of the move, and 55% were given less than one week's notice.<sup>32</sup>

## Case study

### Happy Hands – Central London Community Healthcare NHS Trust

The looked-after children nursing service provided by Central London Community Healthcare is aimed at improving the health outcomes of looked-after children. Service users are some of the most vulnerable children in the community, with a range of profiles, including safeguarding backgrounds, mental health and behavioural issues, and drugs and substance misuse.

Due to their specific needs, this group of children and young people can be particularly challenging and resistant to care. However, the looked-after children service truly puts the children and young people at the heart of everything it does, embedding engagement within its everyday practice in innovative and creative ways to ensure that the service is completely shaped by service users.

Some examples of how the service puts the individual at the centre of everything it does include:

- meeting for health assessments at times and sites chosen by the service user
- communicating with the service user by their chosen method (for example, email or text) and in ways that are flexible/accessible
- making changes to language used and using cultural references specific to the user group
- limiting note-taking during health assessment discussions to retain personal connection, with assessments written up directly after the discussion.

Creative arts are used to elicit feedback from children using the service; children are asked to draw around their hand and then write on the hand shape their feedback about their nurse. This feedback informs ongoing service delivery. Specific changes have been made in response to feedback; for example, staff now wear jeans and more casual clothing to be more approachable.

## Risk factors associated with entering care and outcomes

Key risk factors of children entering care have emerged from research in England,<sup>33,34</sup> Scandinavia<sup>35–37</sup> and the USA.<sup>38,39</sup>

A recent systematic review of the risk factors associated with children entering care found, for mothers, evidence of association with socio-economic status, benefit receipt, single parenthood, ethnicity, age, disability, smoking in pregnancy, mental illness, alcohol misuse and learning difficulties. For children, there was evidence of association with low birth weight and prematurity, disability, injuries and attendance

at Accident & Emergency departments. None of these risk factors were very specific, and research using longitudinal data sets is needed to identify more specific risk factors associated with children entering care and to combine risk factors in a cumulative risk model.<sup>40</sup>

In 2010, the National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) published guidance on promoting the quality of life of looked-after children and young people.<sup>41</sup> A review of correlates commissioned by the Topic Expert Group explored the interventions and factors associated with outcomes for children and young people in public care. Ninety-two studies were included in the review and the key factors were the number of placements, behavioural problems and age at first placement. Placement stability was a key mediator.<sup>42</sup> A different approach to caring for children and young people in care called social pedagogy, which emphasises holistic education and care, has been developed in countries such as Denmark, Germany, Holland and Hungary. **With the growth of more integrated children's services in Britain, there has been an interest in social pedagogy as a means of making sense of the professional development of staff, as it embraces the activities of youth workers, residential or day care workers (with children or adults), work with offenders, and play and occupational therapists.** Pedagogues are trained to master's degree level and provide ongoing support to children and young people in small residential units. There has been one pilot study of social pedagogy in England which did not demonstrate an effect but recognised the link between social pedagogy, the society in which it is located and wider social policy. The authors concluded that for social pedagogy to develop in England it is likely that wider changes would also be required to the role and status of children's residential care.<sup>43</sup>

### Box 11.2 The experiences, views and preferences of looked-after children and young people<sup>44</sup>

**Love** – Looked-after children and young people say that:

- love and affection are desired but are often lacking in their lives
- love, or the lack of it, has a significant impact on their emotional wellbeing, in particular their self-esteem
- for some, the training and payment for foster carers undermines the sense that they are wanted or loved
- an unmet need for love and affection is perceived by some to have a profound and lasting impact on their future outcomes.

**A sense of belonging** – Looked-after children and young people feel that:

- a sense of belonging is desirable, yet often lacking in their lives
- their sense of identity is compromised by a lack of sense of belonging

- frequent moves and lack of permanence are a characteristic of being looked after that undermines any sense of belonging and therefore has a negative emotional impact for them
- a potential barrier to achieving the desired state of belonging is the conflict that arises from being part of two families simultaneously, their birth family and their carers' family
- achieving a sense of belonging and identity is compromised further when they are placed with carers from different ethnic and cultural backgrounds.

**Being supported** – Looked-after children and young people say that:

- they need to feel that there is someone to support them
- emotional support is an important need
- encouragement to achieve in education and other aspects of their life is also needed
- practical support, such as help with homework and provision of materials, is key for achieving success in their lives.

**Having someone to talk to** – Looked-after children and young people report that:

- opportunities to talk to someone about their concerns were often not available, but they appreciated them when they were
- they were often mistrustful of talking to professionals as they could not be sure that what they said would be kept confidential.

### Contact with birth parents

- Many children and young people in public care have a strong desire to maintain contact with their birth families.
- Maintaining contact with birth families is important for supporting their self-identity.
- Children and young people in public care felt that social workers and care providers can obstruct their efforts to maintain contact with their families, and were resentful of this.
- A lack of contact causes significant emotional upset for children and young people in public care.
- Contact with birth families is a complex issue: although an overwhelming majority of children and young people in public care saw it as positive, not all felt the same.

**Stigma and prejudice** – Looked-after children and young people reported that:

- negative attitudes towards them are common
- curiosity and pity are also attitudes commonly experienced and disliked
- a common and unwelcome experience was being singled out and made to feel different because of their looked-after status when what they particularly wanted was to feel 'normal'.

**Education** – Important issues for looked-after children and young people were that:

- encouragement to attend and do well at school is lacking for many, yet those who have achieved success in education feel it is a key factor in their success
- the provision of practical support and resources is felt to be another key facilitator of success, yet is frequently lacking, particularly in residential care
- another source of support often felt to be pivotal in educational success was education-specific support, in the form of educational advice
- emotional support during education, particularly higher education, was noted as a need
- stereotyping and stigma on the part of others, including teachers, was seen as a common barrier to educational success
- a lack of continuity in placements and schooling is a further barrier to the educational success of looked-after children and young people
- being placed in residential care was seen as particularly disadvantaging educationally.

Looked-after children and young people who had achieved success in education cited their self-reliance as the key factor which helped them overcome the barriers mentioned above.

raise the following concerns:

- the issue of continuity in their relationships with professionals
- the negative impact of a lack of continuity
- a desire to form a personal relationship with professionals

**Professionals** – Looked-after children and young people the need to have professionals who listen, are accessible, can be relied upon to be there for children and young people and have the ability to get things done.

**Preparation and support for leaving care** – In order to improve the process of leaving care, looked-after young people would like:

- improved and more timely preparation for independent living prior to leaving care
- a network of support to provide ongoing practical help and emotional support after leaving care
- greater and more appropriate information and advice about entitlements to help make better use of services available to them on leaving care
- a higher level of financial support and more advice for managing finances to prevent serious financial problems for care leavers
- access to better-quality and more appropriate housing.

### Box 11.3 NICE quality standard for the health and wellbeing of looked-after children and young people

**Statement 1:** Looked-after children and young people experience warm, nurturing care.

**Statement 2:** Looked-after children and young people receive care from services and professionals that work collaboratively.

**Statement 3:** Looked-after children and young people live in stable placements that take account of their needs and preferences.

**Statement 4:** Looked-after children and young people have ongoing opportunities to explore and make sense of their identity and relationships.

**Statement 5:** Looked-after children and young people receive specialist and dedicated services within agreed timescales.

**Statement 6:** Looked-after children and young people who move across local authority or health boundaries continue to receive the services they need.

**Statement 7:** Looked-after children and young people are supported to fulfil their potential.

**Statement 8:** Care leavers move to independence at their own pace.

### Improving outcomes for children and young people in care

In 2000, at the start of the Quality Protects programme,<sup>46</sup> Professor Leon Polnay wrote on how to improve outcomes for children and young people in public care: 'What is needed is much earlier intervention with the aim to avoid children developing major social, educational and behavioural problems, combined with innovative, skilled and consistent care for those where early intervention has not been available or successful.'<sup>47</sup> Children and young people in care and care leavers continue to experience significant disadvantages and do require a comprehensive approach to reducing the impact of adverse early life experiences; this strategy could be thought of as primary prevention, early identification and intervention with families in need, and specialist expertise to address the issues of children and young people in care.

In this context a primary prevention approach includes the policy objectives recommended in the report *Fair Society, Healthy Lives* to reduce social disadvantage. This review contains policy recommendations to '**Give every child the best start in life**' and '**Enable all children... to maximise their capabilities and have control over their lives**'.<sup>48</sup> Sure Start Children's centres are a key foundation of this strategy and, once children are safe and their basic health needs met, children's centres should focus on children's health and development, parenting and parents' lives.<sup>49</sup>

### What young people tell us about the care system and how to build resilience

Another document underpinning the NICE/SCIE guidance on looked-after children was *What outcomes matter to looked-after children and young people and their families and carers? A systematic review of their experiences, views and preferences*.<sup>41,44</sup> This research eloquently communicates what looked-after children and young people see as the important issues impacting on their health and wellbeing and therefore what could improve their resilience (see Box 11.2).<sup>44</sup>

The brief of one of the first social care quality standards developed by the new National Institute for Health and Care Excellence was promoting the health and wellbeing of looked-after children and young people.<sup>45</sup> This took the 2010 NICE/SCIE guidance,<sup>41</sup> including the systematic review<sup>44</sup> described above, and created eight statements<sup>45</sup> (see Box 11.3) to describe high-quality care.

#### Early identification

A secondary prevention approach is **embodied in the proportionate universalism of the Healthy Child Programme** with targeting of resources at families in need. Children in need and looked-after children are identified as vulnerable groups within the Healthy Child Programme.<sup>50,51</sup> Attachment to primary care givers is often disturbed and these experiences underpin the relational difficulties that some children have with foster carers and residential staff. Access to evidence-based parenting interventions to promote healthy attachments is needed.

#### Meeting the needs of children and young people in care

A tertiary prevention strategy **starts with the comprehensive implementation of the Statutory Guidance on Promoting Health and Wellbeing of Looked-After Children<sup>52</sup> by the health service and its partners**, but is more fully embodied by the social care quality standards described in Box 11.3.<sup>45</sup> Young people tell us that they want to have continuity of professional contact, and services that are joined up and co-ordinated. They are particularly concerned about transition to adulthood and access to adult health and care services.

Leon Polnay and Harriet Ward expressed the challenge for those working with and for looked-after children and young people: 'bringing about better outcomes... will also require exceptionally high levels of commitment and a culture change. **There needs to be both a continuity of policy and a continuity of relationships between looked-after young people and their health and social service professionals.**'<sup>53</sup>



**'Love'**

Source: Kids Company

## Conclusion

Looked-after children are a vulnerable group highlighted by the UNCRC. Compared with their peers they have significantly more educational and mental health problems and care leavers have worse adult outcomes. There are socio-economic, parental and child-based risk factors associated with children entering public care. Looked-after young people have clearly stated what they feel is lacking in their lives and what could help them overcome their difficult earlier experiences, and a primary, secondary and tertiary prevention approach is needed. Warm, nurturing care in a stable placement is a key component of this strategy.

## What we still need to find out

- What interventions improve outcomes for children with disorganised attachment?
- Are combinations of child, parental and socio-economic risk factors able to predict which children enter care?
- What interventions improve parenting in vulnerable families and reduce the risk of children entering care?
- What interventions improve educational outcomes for children in care?
- What interventions improve adult outcomes for care leavers?
- What interventions improve transition for young people in care, particularly around mental health and wellbeing?
- What interventions reduce risk-taking behaviours in looked-after children and young people, particularly early sexual activity, sexual exploitation, smoking, and alcohol and drug use?
- Does a public health approach to health, embodied in *Fair Society, Healthy Lives*, reduce the number of children entering care?
- What interventions promote wellbeing for looked-after children and young people?

## Case study

### Siblings Together

The charity Siblings Together champions, builds and strengthens relationships between brothers and sisters, aged 7–18 years, separated by the care system. It uses creative activities and skilled adult support to help the young people it works with in rebuilding their sibling relationships, supporting their broader social welfare and emotional wellbeing. Its role is to provide the guidance, structure, consistency and opportunities that children and young people should receive within a family but often lose when in care.

It has a lively annual programme of opportunities for siblings. The residential summer camps, which have been the cornerstone of Siblings Together's work since its conception, have gone from strength to strength as it continues to implement and develop its tried and tested camp model and to expand the number of camps available to siblings.

In addition to camps, Siblings Together has developed a range of other initiatives to encourage sustained positive contact between siblings. It has piloted and developed a monthly activity day programme which provides an opportunity for regular sibling contact. This programme provides a model for supporting siblings that can be applied throughout the country. It also organises a range of other 'one-off' educational and creative activities, such as a theatre project with the Roundhouse Theatre and the Arvon writers' camp, which encourage positive sibling contact in the context of learning new creative and educational skills.



## Key messages for policy

- Implementing the United Nations Convention on the Rights of the Child in full is a priority.
- Addressing socio-economic determinants is a primary prevention strategy that may reduce the number of children entering public care.
- Implementing the proportionate universalism inherent in the Healthy Child Programme may limit children developing major social, educational and behavioural problems.
- Primary care and adult mental health workers should assess and support the parenting capacity of patients with mental illness, alcohol and drug misuse issues or learning disability. Implementing evidence-based interventions to promote secure attachment may limit children developing major social, educational and behavioural problems.
- Promoting resilience is a focus of the eight social care quality standards for the health and wellbeing of looked-after children and young people. This includes warm, nurturing care, a sense of belonging and emotional support.
- Further evidence is needed on effective interventions across a primary, secondary and tertiary prevention strategy.
- Action plans are needed to address the barriers to full participation in life and promoting wellbeing for looked-after children and young people.
- All parties must address the obstacles preventing access to Child and Adolescent Mental Health Services for looked-after children and young people.
- Ensure that staff in contact with looked-after children are trained to identify signs of sexual exploitation.
- Ensure that care leavers move to independence at their own pace, with a network of support to provide ongoing practical help and emotional support after leaving care



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## Chapter 12

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# Youth justice

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## Key statistics

- The number of children and young people in custody has fallen by just over 50% in the last five years.<sup>1</sup>
- The rate of suicide in boys aged 15–17 who have been sentenced and remanded in custody in England and Wales may be as much as 18 times higher than the rate of suicide in boys aged 15–17 in the general population.<sup>2</sup>
- Some 18% of 13–18 year olds in custody have depression, 10% have anxiety, 9% have post-traumatic stress disorder and 5% have psychotic symptoms.<sup>3</sup>
- Of children and young people on community orders, 43% have emotional and mental health needs.<sup>4</sup>
- Over a quarter of children and young people in the youth justice system have a learning disability.<sup>5</sup> Some 60% of boys in custody have specific difficulties in relation to speech, language or communication.<sup>6</sup>
- Looked-after children make up 30% of boys and 44% of girls in custody.<sup>7</sup>
- One in 10 girls in custody have been paid for sex.<sup>8</sup>
- Around 39% of children and young people in custody have been on the child protection register or experienced neglect or abuse.<sup>9</sup>
- One in eight children and young people in custody have experienced the death of a parent or sibling.<sup>9</sup>
- Some 40% of children and young people in custody have previously been homeless.<sup>10</sup>
- Over half of children and young people who offend have themselves been victims of crime.<sup>11</sup>

## Overview

Children and young people in contact with the youth justice system are more likely to have mental health problems than those who are not, and to have more than one mental health problem alongside a range of other challenges. Many of their health and social care needs go unrecognised and unmet.

Yet the **costs of failing to respond are high: the lifetime costs of crime amount to around £1.5 million for each prolific offender.**

The last decade has seen a reduction in the number of children and young people entering the youth justice system, but this reduction is not uniform and there is **evidence of growing levels of multiple, complex and damaging health and social needs among those who come into contact with the youth justice system.**

**Children face a stepping-stone pattern of risk, where risks during infancy increase the chances of antisocial behaviour during childhood, which in turn amplify the likelihood of convictions during adolescence.**

To counter these risks, **it is important to take a life course approach and to strengthen the protective factors in children themselves and their surrounding environment.** Many opportunities exist to change the trajectories of children's lives. These start before birth, providing high-risk expectant mothers with support to reduce stress and foster healthy attachment styles.

Early child development and school readiness checks provide opportunities to track not just physical development milestones but also communication, neurodevelopmental, behavioural and emotional health. Children communicate distress, frustration or developmental difficulties through their behaviour. Behavioural problems also represent one of our most common childhood mental health problems.

High-quality parenting programmes and school-based interventions can prevent or mitigate behavioural problems among children who are at risk.

For those who have not benefitted from early intervention, **Youth Offending Teams offer an opportunity to turn around the lives of children with multiple and complex needs.** Effective screening and assessment should be followed by the provision of effective interventions such as multidimensional treatment foster care, functional family therapy and multisystemic therapy.

### Current trends and prevalence

The youth justice system in England and Wales is different and largely separate from that for adults, with much more emphasis on preventing offending and re-offending and a wider range of ways of dealing with those who offend. The Children Act 1989 allocated duties to local authorities, police, courts, parents and other agencies in the UK to ensure that children are safeguarded and their welfare is promoted.

The last decade has seen a significant reduction in the number of children and young people (aged 10–18) in contact with all parts of the youth justice system. Since 2000–2001, arrests have fallen by 34%; the number of first-time entrants into the youth justice system by 59%; offences committed by young people on the youth offending team caseload by 47%; and the population in custody by 30%.<sup>12</sup>

There are a number of factors that may have contributed to this trend, including the removal of the offences brought to justice target (a performance measure for the police), work by Youth Offending Teams and other partners to divert young people into alternatives, such as Youth Restorative Disposals, triage, liaison and diversion screening for health, and the introduction of the Youth Rehabilitation Order; but it is not possible to attribute direct causality to any of these factors or to quantify the size of the effect from each.<sup>13</sup>

Reductions, however, have not been uniform across all groups of children and young people. The greatest reductions have been seen for younger children (under-15s), girls and first-time entrants into the youth justice system. Smaller reductions have been seen for older boys and black and minority ethnic children. For example, from 2007–2008 to 2010–2011, the percentage fall in the numbers of black and minority ethnic children in custody was 16%, compared with 37% for white children.<sup>13</sup>

More recent changes also have the potential to reduce the custody population further. The Legal Aid, Sentencing and Punishment of Offenders Act 2012 aims to simplify the remand framework so that all children and young people (aged 12–17) are subject to the same remand provisions. The status of 'looked-after child' will be applied to all children and young people on remand and the costs of keeping a young person in custody on remand will be transferred to local authorities in order to provide an incentive to use remand more sparingly and to develop more robust community-based alternative/bail support packages. These community-based alternatives need to be evidence based.

Although the Youth Offending Team caseload and custody population have reduced year-on-year, children and young people in contact with the youth justice system have very high levels of multiple health and social inequalities (see Key statistics and Box 12.1), and their level of complexity (e.g. offence history and health needs) may have actually increased. UK data on the prevalence of psychiatric morbidity in children and young people in the youth justice system are out of date and do not reflect recent significant changes in the youth justice population; equally, other studies focusing on the broader health and social care needs of those within the wider youth justice system are smaller in scale or suffer methodological problems. **There is, therefore, a real need for robust representative prevalence data on the health and social care needs of children and young people in all sectors of the youth justice system.**

Also, despite the declining custodial population, there are ongoing concerns that England and Wales are failing to use



custody as a 'last resort', in line with the United Nations Convention on the Rights of the Child. Questions also remain about the appropriateness and effectiveness of custodial regimes as a response to children and young people with multiple vulnerabilities. Further work is required to establish an evidence base for effective alternatives to custody.

**Despite improvements by custodial establishments and the Youth Justice Board, reports (such as the recent inspection report of HMP Young Offenders Institution Feltham<sup>14</sup>) continue to highlight custodial regimes characterised by excessive levels of violence and where children and young people often report feeling unsafe.<sup>15</sup>**



**Faces watching a fight showing a lack of reaction to violence**

Source: Kids Company

Children and young people in contact with the youth justice system are more likely to have mental health problems than those who are not.<sup>23</sup> They are also more likely to have more than one mental health problem, to have neurodevelopmental and learning disabilities/difficulties, to have problematic drug and alcohol misuse and to have experienced a range of other challenges, such as exclusion from school, homelessness, bereavement, trauma and being in care. Many of these health and social care needs go unrecognised and unmet. There is, therefore, a need for comprehensive screening and assessment throughout the youth justice system. Unmet needs persist into late adolescence/adulthood and can lead to a wide range of adverse outcomes, such as continuing/worsening mental health problems, unemployment, teenage parenthood, marital problems, suicide and self-harm and further criminal activity. The costs to society are also immense. For example, the lifetime cost of crime committed by a single prolific offender is around £1.5 million.<sup>24</sup>

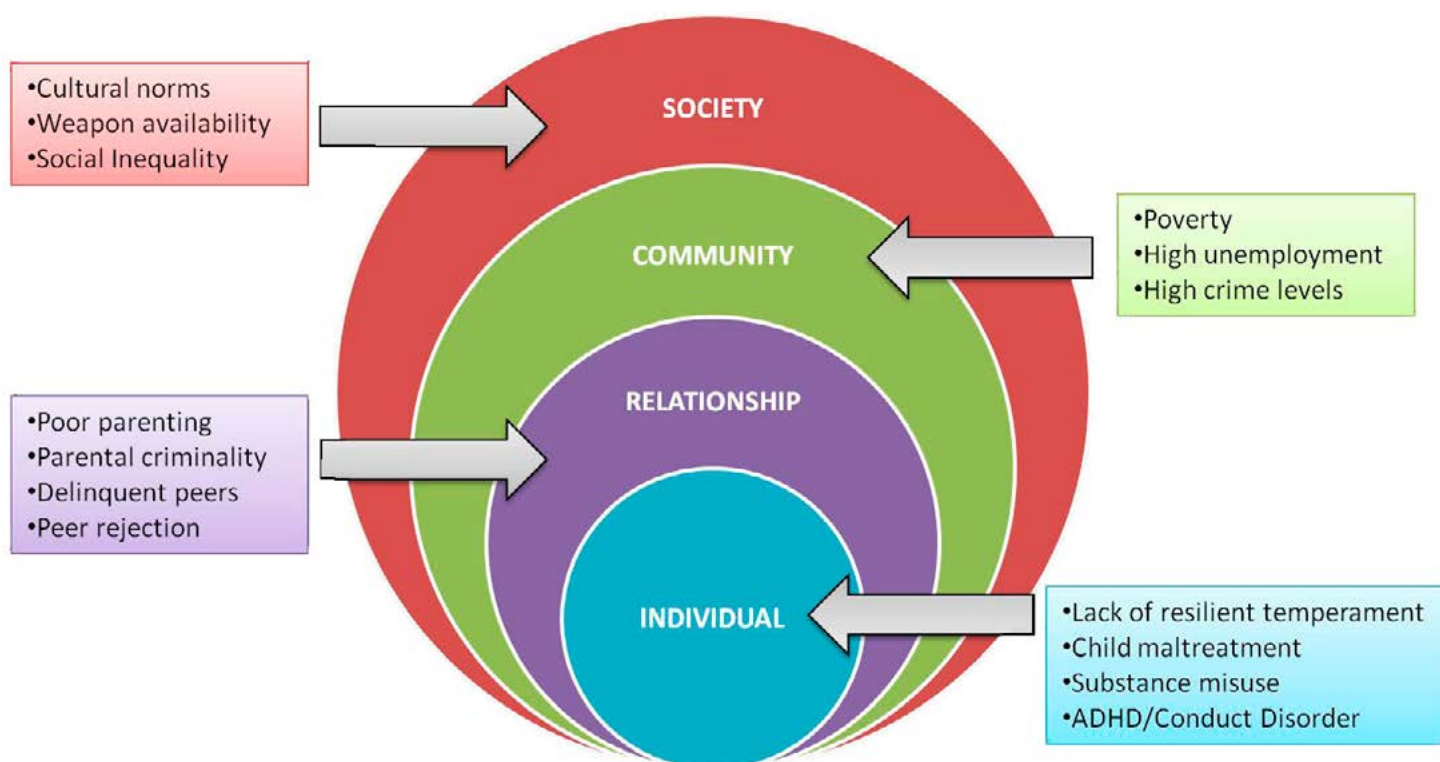
## Risk and protective factors affecting involvement in the youth justice system

Life course studies, tracking children's development and circumstances over time, identify many factors which increase the likelihood of poor outcomes (see Figure 12.1) as well as those associated with a reduced chance of children experiencing negative outcomes (see Table 12.1).

### Box 12.1 Additional evidence for health and social inequalities for children and young people in the youth justice system

- Young black and minority ethnic people, and girls, were most likely to present with post-traumatic stress disorder.<sup>3</sup>
- In 2011–2012 there were three deaths of young people in custody.<sup>12</sup>
- In 2011, there were 20 deaths in the community involving young people under Youth Offending Team supervision who died either through murder, suicide or accidental death.<sup>12</sup>
- There were 1,725 reported incidents of self-harm in the secure estate in 2011–2012, up 21% on 2010–2011.<sup>12</sup>
- There are around 200,000 children of adult prisoners in the UK, with a point prevalence of 90,000.<sup>16</sup> Children who have a parent in prison are three times more likely to have mental health problems<sup>17</sup> and 65% of boys with a convicted father go on to offend.<sup>18</sup> There is no official agency catering to the needs of prisoners' families and children and no support is routinely offered to them.
- Eight out of 10 children and young people disclosed problematic or risky substance misuse before entering custody. Three-quarters had used cannabis, around a third had used ecstasy or cocaine, 9% had used crack and 1% heroin. Poly-drug misuse was also high.<sup>19,20</sup>
- Prior to custody, 67% of young offenders got drunk at least once a week, and 16% were getting drunk every day.<sup>19</sup>
- Some 26% of young women in custody reported having three or more male sexual partners in the last year and only 15% stated that they always used a condom. Almost a quarter (23%) had at some time been diagnosed with a sexually transmitted
- The educational background of children and young people in custody is poor: 86% of boys and 82% of girls said they had been excluded from school and 42% said they were 14 years or younger when they were last in education.<sup>21</sup>
- Around 72% of incarcerated male young offenders reported suffering at least one traumatic brain injury of any severity, 41% reported experiencing a loss of consciousness and 46% reported suffering more than one injury.<sup>22</sup>
- The educational background of children and young people in custody is poor: 86% of boys and 82% of girls said they had been excluded from school and 42% said they were 14 years or younger when they were last in education.<sup>21</sup>
- Around 72% of incarcerated male young offenders reported suffering at least one traumatic brain injury of any severity, 41% reported experiencing a loss of consciousness and 46% reported suffering more than one injury.<sup>22</sup>

**Figure 12.1** Examples of risk factors in childhood associated with prevention of offending and other adverse outcomes



Source: produced for this report by Lorraine Khan and Charlotte Lennox (2013)

**Table 12.1** Protective factors in childhood associated with prevention of offending and other adverse outcomes

| Individual characteristics           | Parents and their parenting style                   | Family factors and life events              | Community factors                                                 |
|--------------------------------------|-----------------------------------------------------|---------------------------------------------|-------------------------------------------------------------------|
| <b>Social skills</b>                 | Competent, stable care                              | Family harmony                              | Positive bond with peers, teachers, neighbours and neighbourhood. |
| <b>Easy temperament</b>              | Breastfeeding                                       | Positive relationships with extended family | Teachers who encourage aspiration                                 |
| <b>At least average intelligence</b> | Healthy attachment                                  | Small family size                           | Access to positive opportunities (e.g. education)                 |
| <b>Attachment to family</b>          | Positive (non-harsh) parenting style                | Spacing of siblings by more than two years  | Pro-social peers and community values                             |
| <b>Independence</b>                  | Religious faith                                     |                                             | Participation in community activities                             |
| <b>Good problem-solving skills</b>   | Effective supervision of child during teenage years |                                             | Safe neighbourhood                                                |
|                                      | Supportive relationships with other adults          | Supportive relationships with other adults  | Supportive relationships with other adults                        |
|                                      | Clear boundaries and expectations                   | Clear boundaries and expectations           | Clear boundaries and expectations                                 |

Source: produced for this report by Lorraine Khan and Charlotte Lennox (2013)

The more risks that children accumulate, the greater the probability of:

- offending
- persistent offending
- poor mental health, poor educational and employment performance, violence, lower life expectancy and poor physical health.<sup>25,26</sup>

A stepping-stone pattern of risk is commonly observed; risks during infancy increase the chance of antisocial behaviour and health and social inequalities during mid-childhood which in turn amplify the likelihood of convictions during adolescence.<sup>27</sup>

However, some children and young people exposed to risk never offend; or if they do they eventually desist. **Protective factors (see Table 12.1) moderate the detrimental effects of risk factors; either preventing them from developing in the first place or interacting with risk factors to block adverse effects.**

## Individual or temperament-based factors

**Research suggests that risk is associated with individual child characteristics;** for example, being female protects against offending. Research also suggests that children with resilient temperaments, good problem-solving skills, an ability to plan ahead, a positive outgoing disposition and higher intelligence are protected against the risks of adverse circumstances.<sup>28-31</sup> It is also likely that resilient children who are temperamentally outgoing and likeable are generally easier to raise than those who are unsure of themselves, pessimistic or socially awkward. Attachment bonds with parents are therefore more likely to be reinforced and positive experiences at school will increase their sense of self-esteem and self-efficacy.

Temperamental differences can be associated with antenatal exposure to risk and/or to subtle genetic and neurodevelopmental differences. Temperament alone does not predict poor outcomes; **future life chances are heavily influenced by a complex interplay between biological, caretaking and environmental factors with outcomes for 'at-risk' children considerably improved with the right protective environment, care and support.**<sup>32,33</sup>

Individual difficulties such as persistently challenging, hyperactive or aggressive behaviours during early childhood are key risk factors for a range of adverse life chances.

## Family-based factors

Family-based influences also play an important part in protecting or predisposing children towards early behavioural problems and later crime. A strong attachment with one or both parents/caregivers, characterised by a stable, warm, affectionate relationship, has been shown to protect children from offending.

On the other hand, risks for antisocial behaviour and crime include:

- exposure in the womb to antenatal maternal stress
- being a child of a teenage parent
- parental mental illness, substance use and/or offending
- attachment issues – particularly insecure, ambivalent (linked to anxiety and poor relationship-forming skills) and disorganised attachments (characterised by impulsivity, emotional volatility, disruptive behaviour, aggression and poor concentration)
- poor parenting
- maltreatment, neglect and exposure to violence/conflict in the home.<sup>34-43</sup>

## School-based factors

Some children start school already disadvantaged by a range of individual and family-based risk factors which compromise achievement and amplify disadvantage. Poor emotional wellbeing and mental health (particularly early attentional and behavioural problems) are linked with poor educational attainment.<sup>44</sup> Poor family support for academic success and aspiration along with income inequality contribute further to a widening gap in achievement,<sup>45</sup> increasing chances of poor motivation, dropout and exclusion. **School exclusion rates are particularly high for Afro-Caribbean boys.**<sup>46</sup>

On the other hand, a positive social attitude/commitment to school can help to protect young people. Encouraging all pupils to fulfil their potential, setting clear rules and applying them consistently reduce disruptive behaviour.<sup>47</sup>

## Peer-related factors

Bullying others, peer rejection and having antisocial peers are associated with a higher risk of offending,<sup>48</sup> whereas having a non-delinquent peer group with pro-social attitudes can be a strong protective force for young people's prospects.<sup>49</sup> Poor relationships and experiences of victimisation seem to have a particular impact on young women's pathway into criminality.<sup>50</sup>

## Neighbourhood and community

Children and young people living in deprived neighbourhoods are more than twice as likely to have serious behavioural problems as children living in less deprived areas. High levels of community deprivation have been noted as a particular feature of some black and minority ethnic children and young people's developmental experiences. **Strengthening attachments in communities and reducing social inequalities are particularly important mechanisms for preventing violence and offending.**<sup>51</sup>





**A young person's description of their past: 'This is my past. I have lived a cold life and I saw a lot of blood. People stabbed you in the back'**

Source: Kids Company

### Opportunities for changing children's life course

Understanding risk factors helps to identify children and young people at risk of experiencing poor life chances; however, building resilience and strengthening protective factors are critical. **Children and young people exposed to multiple risk factors face the worst prospects but can be protected by mobilising strengths in families, schools or communities providing critical 'turning points'.**

**There is increasing evidence that early fetal and infant experiences are important shapers of robust child mental health and life chances.** Many multi-agency opportunities exist to change the trajectories of children's lives and their risk of offending. These start before birth, providing high-risk expectant mothers with engaging support to:

- improve healthy lifestyle choices
- reduce the impact of stress and toxic stress on children's development
- develop good quality early communication between mothers and babies to 'jump-start' electrical activity in the brain
- foster healthy attachment styles.<sup>52-54</sup>

Early childhood behavioural problems are often a manifestation of unmet needs (e.g. speech and communication needs and abuse) and can cause professionals to focus on the symptoms rather than the underlying cause.

**Reducing child neglect and maltreatment is critical to reducing childhood behavioural problems. All sectors should be alert to signs with clear systems in place to access early, engaging and evidence-based support;** without early intervention, there is a risk that children are left to accumulate risks, later moving into more expensive crisis-orientated services. Examples of promising prevention initiatives in this area include Triple P, which helps parents pick

up positive parenting techniques. In one US state, systematic availability of Triple P parenting programmes led to significant reductions in child protection registrations as well as out-of-home placements.<sup>55</sup>

### Early intervention

Early child development and school readiness checks provide opportunities to track not just physical child developmental milestones but also communication skills, and neurodevelopmental, behavioural and emotional health and wellbeing. There are particular advantages in responding early to the very first signs of poor child mental health/early behavioural problems,<sup>56,57</sup> helping affected families to link up with well-implemented and engaging positive parenting programmes such as The Incredible Years<sup>58</sup> and Triple P.<sup>59-61</sup> However, there is also a need for larger, more robust independent evaluations of such parenting programmes with a particular focus on following up children's behavioural outcomes in the longer term.<sup>62,63</sup>

Targeted pre-school programmes (such as the HighScope Perry Preschool Program targeted towards low-income 3-4 year olds) using active participatory learning approaches demonstrate positive effects on a range of child outcomes (including criminality), improving broader prospects as well as generating significant savings.<sup>64</sup>

Educational settings have the potential to mobilise a range of compensatory support to help children to attain and prevent criminality. According to the World Health Organization, a health-promoting school draws together a spectrum of support, including proven universal evidence-based programmes, in-house support and strong relationships with community resources to support children's development and wellbeing.<sup>47</sup> Particular attention is required for those at risk of exclusion; these children need prompt and full holistic assessment to identify and address hidden disabilities (such as learning disabilities, traumatic brain injury or speech and communication problems) affecting their progress.

### Youth justice opportunities

Some children may miss opportunities for early identification and intervention or may need additional support over the years. Effective health screening and assessment are critical to ensure that children and young people entering the youth justice system get the help they need. A newly introduced youth justice system health needs assessment tool (called the Comprehensive Health Assessment Tool<sup>65</sup>) provides a vital opportunity for the holistic assessment of children and young people's health needs. In addition, the recent publication of the Healthcare Standards for Children and Young People in Secure Settings<sup>66</sup> provides an excellent opportunity to identify and make real improvements. For gains to be sustained, these assessments will need to be combined with robust commissioning in local areas to meet the multiplicity of needs faced by these children as they return home.

International legislation<sup>67</sup> places a duty on governments to use the formal youth justice system and custody as a last resort for children – with evidence suggesting that processing

## Case study

### Youth liaison and diversion schemes

Liaison and diversion services are intended to improve health and justice outcomes for children and young people who come into contact with the youth justice system, where a range of complex needs are identified as factors in their offending. Liaison and diversion is not itself a treatment service, but an identification, assessment and referral service. It uses assessments to make appropriate referrals for treatment and support, and ensures that youth justice practitioners and other relevant agencies are notified of specific health requirements and vulnerabilities which can be taken into account when decisions about charging and sentencing are made. Liaison and diversion services are particularly useful for earlier identification of children and young people with mental health, safeguarding and other vulnerabilities. Subject to approval of a business case, liaison and diversion services will be trialled over the next two years and evaluated with a view to rolling out across the country from 2015.

'J' is a 13-year-old boy. He was referred by the police to a point of arrest health liaison and diversion project for an alleged offence of shoplifting. The health worker visited J and his family at home, completing an initial screen for problems requiring fuller assessment.

J lived at home with his mother and younger brother; his father had recently separated from the family following a history of domestic violence. J's mother described increasing problems managing her son's behaviour on her own. J struggled with schooling and was now a regular non-attender. J and his mother disclosed long-term problems with behaviour, staying focused and expressing emotions. During discussions, J also talked of problems with cannabis use, alcohol and anger (talking of being scared about what would happen if he really 'lost it'). He said that cannabis stopped his mind racing and helped him relax and calm down.

This assessment led to a referral to local Child and Adolescent Mental Health Services for suspected attention deficit hyperactivity disorder (ADHD). He was successfully diagnosed and a package of support was put in place involving medication, support from the school special educational needs team and parenting support for his mother. While awaiting assessment, J was also linked up with substance misuse support locally to explore his cannabis use (children with ADHD have a higher risk of reliance on substances). He was also referred to youth offending prevention workers to address offending risks.

children through the youth justice system is not only detrimental to children's wellbeing but also increases their chance of future re-offending.<sup>68</sup> **Reducing the numbers of children and young people entering the youth justice system is now a key public health outcome.** For this reason, Youth Offending Team triage and health liaison and diversion screening initiatives are often located at the gateway to the youth justice system, working with the police and courts to assess early risk/needs and diverting young

## Case study

### A promising approach to supporting young people with Asperger syndrome at HMP Young Offenders Institution Feltham – Barnet, Enfield and Haringey NHS Trust

Young people need effective communication skills to cope in custodial establishments, to complete rehabilitation programmes and to gain and maintain employment. Stable employment can help prevent re-offending and effective communication skills are highly valued by employers.

The speech and language therapist at HMP Young Offenders Institution Feltham works directly with young people with speech, language and communication needs. The therapist also works with prison staff to raise awareness of speech and communication needs and how behaviour can often mask underlying needs.

'S' was referred to the speech and language therapist. He appeared to be isolating himself from others on the unit. He was also prone to violent outbursts and staff generally struggled to manage his behaviour. An initial speech, language and communication assessment identified some deficits in social communication and recommended a more detailed assessment. This identified a diagnosis of Asperger syndrome.

The speech and language therapist and the psychologist within HMP Young Offenders Institution Feltham worked jointly with the young man to address both speech, language and communication needs and emotional/behavioural needs. They also provided support to the wider staff team. During this work the young man was able to improve his understanding of his behaviour and why he felt the way he did. As a result, he became easier to manage and was able to develop more appropriate coping strategies. There were no further episodes of violence and destructive behaviour in custody and as a result the young man was considered for early release.

At the release meeting, in recognition of this progress, he was initially offered a reduced period on Home Detention Curfew (or 'tag'). However, to his credit, he was able to recognise that he needed an additional period of monitoring to help him embed and maintain a more socially acceptable and productive routine and avoid going back to his old ways. He therefore argued, in front of a group of professionals, for an extended period of curfew to support his progress.

people towards resources best placed to prevent further offending. Many police forces also aim to resolve youth crime and reduce risks through talking to the victim and the young person and brokering a solution to make recompense for their crime (known as Youth Restorative Disposals/Community Resolution). **This type of restorative justice/mediation, if well implemented, has a good record of reducing crime.**



A number of other interventions (often working closely with the family and strengthening support systems around the young person) have been identified as effective in reducing youth offending.<sup>60,63</sup> These include the following:

**Multidimensional treatment foster care:** young people with high safeguarding needs or conduct problems are placed with intensively trained foster parents, providing a structured environment and promoting social and emotional skills. Programme staff work closely with foster parents, teachers, Youth Offending Team workers and employers to ensure consistency of approach and reinforcement of pro-social values. The Legal Aid, Sentencing and Punishment of Offenders Act 2012 provides an important opportunity to commission and make more use of options such as multidimensional treatment foster care which have a better record of success than standard custodial remands.

**Functional family therapy:** teenage behavioural problems are addressed through a collaborative, problem-solving approach, working weekly with the family and child to build communication, negotiation and other skills over three to six months.

**Multisystemic therapy:** professional therapists (supervised by clinical psychologists or psychiatrists) have small caseloads and provide an outreach service to families with 24/7 availability for four to six months. Plans are developed collaboratively with the child and family and interventions are pragmatic and tailored to address specific needs, often including work with school staff, peers, neighbours and community organisations. Multisystemic therapy also has a promising record of supporting improvements in progress in drug and alcohol misuse.

**Aggression replacement therapy:** this targets adolescents with entrenched patterns of aggression using cognitive behavioural and social skills approaches. **It is highly cost-effective with proven reductions in crime, anger and aggression.** However, most violence prevention programmes are designed for and tested with young males; evidence suggests that young females need more gender-sensitive and specific responses acknowledging the importance of experiences of victimisation, positive relationships and improved self-esteem as an exit from crime and violence.

**ADHD in Youth Offending Teams:** many children remain unidentified with ADHD in Youth Offending Teams or receive a medication-only approach to help manage their needs; these children often require a multidisciplinary approach backed by National Institute for Health and Care Excellence (NICE) guidance to sustain progress.<sup>69</sup> For those still in education, closer working is required between Youth Offending Teams and special educational needs support teams to improve children's outcomes.

Plans are currently in progress to transform regimes in custodial settings for children and young people by placing greater emphasis on strengthening educational attainment.<sup>70</sup> Many children and young people entering custody have

high levels of learning disability and speech, language or communication difficulties. In addition, many have very poor records of school engagement and attainment in schools; for example, in a 2011 Inspectorate of Prisons/Youth Justice Board survey, 86% of young men and 82% of young women surveyed said they had been excluded from school<sup>71</sup>, and 42% of young men surveyed said they were 14 years or younger when they were last in education.<sup>71</sup> Under-attainment is often the result of entrenched unidentified health and social care needs with **poor mental health and emotional wellbeing being particularly associated with poor achievement in school.** There is currently no robust evidence that increasing educational attainment in secure settings will lead to decreases in offending. Furthermore, focusing solely on education, using a mainstream school approach, is unlikely to be sufficient to support progress in these children and young people. A special educational needs approach, based upon theoretical models used in residential schools for those with emotional and behavioural difficulties, is more likely to promote sustainable progress. Any changes to regimes should be carefully monitored and evaluated using high-quality research methods to ensure that findings not only support community safety concerns but also the broader life chances and safeguarding needs of a vulnerable group of children and young people with long-standing unmet needs.

## Service models

Priority should be placed on developing and resourcing more robust pathways to a range of engaging specialist services. Children and young people in the youth justice system often have sizeable and multiple health needs but poor records of engaging with largely clinic-based community health services. **Traditional service models are not designed to meet their multiplicity of need; nor are funding streams which create gaps during critical transition points during the teenage years.** Youth Offending Teams could provide an opportunity to improve outcomes for a concentration of young people with high health and social inequalities who impose a significant burden on a range of budgets over time. Earlier intervention and closer links with an array of local health and social services and smarter commissioning are required to ensure that service models and funding streams better match the pronounced needs of these young people.

Young people with mild-to-moderate needs may not meet the threshold for support from specialist services. Therefore, effective interventions need to be able to be delivered by non-specialist services (but with support available via training and consultancy from local networks of specialist practitioners). Engaging voluntary sector services offering wraparound support can provide important support to help young people make progress towards healthy adult lives, but these must be evidence based.

## Case study

### Multisystemic therapy – the Brandon Centre, London

Multisystemic therapy is an intensive home-based, goal-oriented and time-limited therapy (usually delivered over three to five months) shown to reduce offending, antisocial behaviour and the chances of being placed in care. Multisystemic therapy empowers caregivers to regain control and promote sustainable behaviour change in a young person, reducing reliance on formal systems. Therapy is closely supervised, ensuring that it is delivered in a way which maximises the likelihood of promised results.

'C' was 15 and lived with his mother, and siblings. His parents were separated. His father had been in an alcohol rehabilitation unit and his mother suffered from depression and anxiety. C was attending the Child and Adolescent Mental Health Service for cannabis-triggered anxiety and psychosis, as well as the Youth Offending Team, following a number of offences. He was also involved with a gang. He was excluded from school and was sporadically attending a pupil referral unit where his behaviour was poor. A referral was successfully made to the Brandon Centre multisystemic therapy team in London to help C address mounting difficulties.

The therapist engaged C's mother, setting treatment goals based on C's behaviour. They identified multiple risk factors fuelling his behaviour but also many untapped strengths within the family. The therapist held a professionals' meeting to secure whole-system alignment and to set goals for treatment. The therapist worked with C's mother to help her improve her supervision of his behaviour, introducing a contract of rewards and boundaries.

Negative peer influences were identified and addressed through liaison with parents and through the help of the neighbourhood police who acted quickly to find C at key addresses when he absconded. The therapist worked closely with staff in the pupil referral unit to implement and review a plan supporting behavioural improvements. C was also eventually found an alternative placement in a college where he could foster more positive peer contacts. His uncle also found him work in a local gym. He earned a 'wage' that was held in a bank account he could only access when he had completed a month of clean drug tests. Although initially resistant, he slowly began to engage with the system of rewards offered for clean drug tests and began to reflect on his drug use. By the end of treatment he had eight weeks of clean tests.

The therapist noted that C's mother found it a struggle to remain warm in her relationship with her son, particularly when he misbehaved. This fuelled his negative behaviour. Through role play and observation, the therapist helped his mother to develop more positive communication skills and strategies and also completed a six-week cognitive behavioural therapy programme with her to help her depression. The therapist worked with both parents together, to enable C's father to remain supportive to his mother.

After five months C was no longer using drugs or involved in a gang. He had not committed an offence for four months and was engaging in college with no unauthorised absences. He was also no longer having hallucinations and had bonded with pro-social peers. His relationship with his mother, father and uncle had also improved.

C's mother said:

*'Thank you for all your hard work with us, no one has fought so hard to help us [...] you've helped me to be a calmer, more understanding mother and I'll always be grateful.'*

## Conclusion

Children and young people in the youth justice system can accumulate severe and multiple risks across their life course. By the time they enter the youth justice system, their life chances are compromised, they significantly impact on the wellbeing of their communities, risk factors are embedded and attempts to mobilise and build compensatory protective factors are more complex and costly. There is a need for integrated commitment, funding mechanisms, and action from all sectors to identify and intervene at the earliest possible point with these children to change costly and damaging life trajectories. There is also a need for service models and approaches which reach out to children and families in their communities, which are evidence based and which recognise and respond better to multiplicity and longevity of need.

## What we still need to find out

There is still a lot we do not understand about why certain children and young people end up in the youth justice system and the complex interplay of risk and protective factors that affect their life trajectories. We particularly need better quality longitudinal information to help crystallise the protective factors which can reduce the chances of children and young people entering the youth justice system. Measuring behaviour change resulting from health and social interventions is critical to evaluating their usefulness. There is currently a dearth of high-quality evaluations of interventions for children and young people in the youth justice system. Evaluations need to be independent, with robust and sensitive outcome measures, and with both short and long-term follow-ups comparing intervention outcomes with those receiving standard support.

Specifically, we need the following:

- **Up-to-date and robust representative prevalence data on the health and social care needs of children and young people at all stages of the youth justice system.** A previous national prevalence study was narrow in focus (i.e. psychiatric morbidity and custody) and there is an urgent need to capture the significant changes in the youth justice system population over recent years.
- Continued investment in high-quality UK research concerning what interventions work for children and young

people in the youth justice system and at what point in their lives these are most effective. For example:

- ❑ **There is a particular need to improve the quality of research available on gender-specific and black and minority ethnic-specific protective factors and interventions; most research into prevalence and interventions has so far been focused on white British males.**
- ❑ We know that many young men in custody show signs of acquired and traumatic brain injury. However, there is a lack of clarity concerning effective interventions to improve prospects. We also have poor information concerning the prevalence of this condition among young people on community Youth Offending Team caseloads or among young women and black and minority ethnic young people.
- ❑ The same is true for children and young people with speech and language difficulties, mild-to-moderate learning disabilities and attachment disorders. We are increasingly aware that relatively large proportions of the youth justice population face these challenges; however, there is less high-quality research pinpointing what works to support improvements, reduce offending and improve broader life chances.
- ❑ We need to continue to develop a higher quality evidence base for what works for children with substance misuse, conduct difficulties and multiple needs.
- ❑ We also need more research focused on how effective interventions such as multisystemic therapy, multidimensional treatment foster care and functional family therapy can be more systematically and effectively integrated into standard Youth Offending Team practice.
- ❑ We need continuing analysis of both the effectiveness and cost-effectiveness of interventions in the youth justice system with follow-up of the long-term outcomes of interventions.
- ❑ We are developing a better awareness of neuroscientific changes taking place in the adolescent brain, but we also need a better understanding of the extent to which these changes provide a critical opportunity for intervention during a young person's development.
- Children and young people should only enter custody for grave offences and as a last resort. There is currently a lack of high-quality evidence driving the design of custodial regimes for those who must enter secure units. There is an urgent need for high-quality international research investigating which regimes (e.g. size of unit, theoretical approach underpinning the regime, adaptations to better support black and minority ethnic-specific and gender-specific needs and experiences, and units closely linked to local communities vs geographically distant units) have the best chance of improving outcomes for this vulnerable group.

### Key messages for policy

- Good evidence exists that high-quality programmes focused on strengthening support systems around children and young people (particularly parenting) in combination with developing children and young people's internal resilience have the best chance of improving multiple outcomes.
- Behavioural problems in children and young people often mask underlying unmet needs (e.g. maltreatment, trauma, bereavement, skills deficits and learning disabilities).
- Children and young people in contact with the youth justice system are more likely to have multiple health problems, yet many of their needs go unrecognised and unmet, thus undermining their life chances and placing a significant burden on the public purse.
- While the numbers of children and young people entering the youth justice system are falling, the health and social needs of those in the youth justice system are increasingly complex.
- Children and young people face a stepping-stone pattern of risk where early risks lead to antisocial behaviour during childhood and increased likelihood of convictions as a teenager.
- Early multi-agency, multi-sector action to strengthen protective factors is key to breaking this pattern.
- Life course action plans are required for children and young people with behavioural problems, integrating early multi-sector action and co-ordinated funding but also recognising that it is never too late to intervene.
- Youth offending prevention activity and Youth Offending Teams provide an important moment to assess need and support resilience with effective evidence-based interventions.
- A priority should be placed on developing and resourcing more robust pathways to engaging a range of specialist services with the capacity to strengthen the assets of these young people.
- Children and young people in the youth justice system need outreaching, engaging and youth-shaped models of support to maximise the chances of supporting change.
- Custody should be used as a last resort and high-quality research is required to establish an evidence base as to the size and type of regime best placed to support the high needs of these vulnerable children and young people and improve community safety.

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## Chapter 13

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# Future challenges

### **Chapter author**

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This chapter seeks to draw together some of the overarching themes from this report. We identify certain areas that are likely to provide an ongoing challenge to our ambitions to ensure the very best health for children.

## Burden of disease

### Child obesity

While many aspects of the burden of childhood disease show long-term improvements, obesity is an area providing a relatively new and evolving challenge. Although it is covered extensively elsewhere in this report, it would be remiss not to mention obesity. Chapter 3 of this report analyses our current understanding of the cost of obesity and presents an estimate of the long-term societal costs of child obesity as £596–686 million a year in England. As the chapter identifies, there is evidence that childhood obesity continues to rise steadily, and there are worrying trends, particularly that obesity is persisting most strongly among those of low socio-economic status. Chapter 3 outlines the known factors associated with obesity and the complications of obesity both in childhood and in later life. As the chapter identifies, there are effective strategies – taking a universal approach and combining multiple place-based interventions; and targeted approaches;<sup>1,2,3,4,5,6,7</sup> national-level policy around food and drink will also be important.

The data are therefore increasingly clear about the prevalence of obesity, the consequences in health and financial terms, and the nature of successful interventions. The challenge for the next period is to take this evidence and ensure that it is implemented at scale in order to harvest the benefit of the interventions. Perhaps the greatest effort needed is to halt a potentially widening social divide in obesity.

### Mental Health

A further area highlighted in this report that is likely to remain of considerable importance is that of mental health, and indeed more generally, wellbeing in children and young people.

It is increasingly clear how the foundations of good mental health are formed in childhood and adolescence and there are interventions to maintain wellbeing and reduce the risk of mental health problems; however, the challenge is doing so at scale in an economical manner. And where prevention fails, mental health services need to step in, and ensuring that these are adequately resourced is a continuing challenge.

### Infection/immunisation

The Annual Report of the Chief Medical Officer Volume Two, 2011 focused on infection and antimicrobial resistance. A number of areas gave cause for concern in childhood: developing antimicrobial resistance, tuberculosis, hepatitis B and C, invasive group A streptococcal infections, strains of *Staphylococcus aureus* producing Panton-Valentine leukocidin toxin, and meningococcal and pneumococcal disease. In adolescence, concern shifted to sexually transmitted diseases.

Additionally, uptake of immunisations was noted to be critical to prevention of disease.

The year 2013 sees the expansion of childhood vaccination programmes to incorporate rotavirus and influenza. Rotavirus is thought to cause around half of all gastroenteritis in children under 5 and is the most common cause of gastroenteritis leading to hospital admission in children. Influenza, although a common upper respiratory illness, can cause severe problems in children, particularly those under 6 months. It is hoped that the introduction of vaccination for children aged between 2 and 17, in a phased manner, will substantially reduce influenza-related illness, GP consultations, hospital admissions and deaths. 2013 also sees 2 and 3 year olds being offered a nasal influenza vaccination for the first time. Alongside these novel introductions are alterations to the current vaccination schedule to account for new information, for example changes to the timing of meningococcal immunisation.<sup>8</sup>

As diseases are countered with new or improved vaccination, perhaps the area of challenge facing healthcare professionals is two-fold. First, how to ensure that strong messages about the advantages of vaccination reach those who need to hear them, and second, how to ensure that the health and care system responds to altered delivery needs. The changes required to ensure that amendments to the childhood vaccination programme occur are considerable and I appreciate the burden that this places on healthcare professionals. The impact of success will be profound and, indeed, may well lead to altered service needs as some diseases wane and others take their place.

### Rare diseases

Rare diseases, when considered as a group, are not uncommon; more than 3.5 million people in the UK have a “rare” disease. More than 50% of those with a rare disease are children and young people. 30% of those with a rare disease will die before they reach the age of 5. Improved testing and genetic knowledge continue to expand our understanding of these diseases, but crucially policy and healthcare delivery need to keep up with the evolving science. The imminent publication of a UK Strategy for Rare Diseases is an important step. The Strategy highlights the importance of rare diseases as a healthcare issue and the need to promote collaborative working between patients, healthcare professionals, researchers and industry. This collaboration needs to happen at all levels; locally, nationally and internationally. The work will be supported by initiatives such as the creation of the Rare Diseases Advisory Group which will help to steer NHS England policy in this area.

Perhaps the biggest challenge here is ensuring speedier diagnosis for those suffering. Nearly half of those with a rare condition report waiting more than one year for a final diagnosis, and a similar figure had an incorrect diagnosis before the correct one was made. Healthcare needs to ensure those working within the system are sufficiently trained, and supported with technology, both to identify such disease and to assist families in navigating the system.

Another important aspect in the approach to rare diseases is the world-leading work, being led by Genomics England Limited, to sequence 100,000 whole genomes. The inclusion of rare diseases, as one of the first phase key priorities, is a considerable step forward for rare diseases research and treatment development. Analysis of data from whole genome sequencing will increase our understanding of rare diseases, especially in those cases where a diagnosis has been hard to define. When linked to other NHS clinical and patient data, this has the potential to provide yet more detailed insight into the causes of rare diseases, and to progress possible therapies for rare diseases.

## Transition

Chapter 7 of this report focuses on adolescence. A core challenge is the transition from childhood to young adulthood i.e. moving from paediatric to adult services, and for many, moving away from home. In addition, many significant personal changes may be occurring at this stage in the life course. As the chapter identifies, poor transitions can have a deleterious effect on health outcomes. Given how much disease of adulthood starts in adolescence (for example, 75% of adult mental health problems begin before 18), transitions are very significant for many young people.

There are models of good practice. For example, some cancer services have chosen to manage transitions by amalgamating young adult and adult services, while other specialties run transition clinics. Further evidence is required to identify what works best, and in which particular situation.

## Technology

Many of the chapters in this report have noted the potential for new technology to enhance the ability of the healthcare system to manage disease, whether through improved data records such as those developing within hospitals, or patient- or family-held patient records, such as the current Electronic Red Book Pilot. Concerns over the protection of these data have rightly been examined as the programmes develop. Improved data herald an exciting era for the NHS, one where communication between professionals is dramatically better, and where population-level research becomes possible. The development of more transparent data sets will mean real changes in the information that is available to the public and researchers e.g. the imminent release of care.data, the Clinical Practice Research Datalink and information about individual healthcare performance.

Alongside the data security challenge comes the challenge of how to ensure that new systems do not increase the burden on healthcare professionals. Similarly, data without interpretation are unlikely to be of benefit to the public.

These technologies are very much healthcare system orientated, but the exponential rise of 'apps' and healthcare devices is creating the potential for an entirely different type of participation in healthcare by patients and their families. Whether it be through home monitoring of long-term diseases or remote assessment of vital signs, the creation

of high-technology but increasingly low-cost solutions is a monumental opportunity which healthcare is embracing. One such example is SXT Health; this search tool is run by clinicians and allows individuals to anonymously identify their nearest sexual health clinic, thus increasing access.<sup>9</sup> Future developments may include remote access to testing and counselling, potentially widening access still further.

A further new technology is e-cigarettes. A recent MHRA review identified that there were concerns about their safety and efficacy.<sup>10</sup> Internationally there are anxieties about these products potentially being marketed to children and young people, a worry heightened by the addition of flavours such as bubble gum to these products. This unease is supported by evidence from the US Centers for Disease Control and Prevention, which shows that ecigarette use in teenagers in the USA doubled between 2011 and 2012. In addition, 1 in 5 middle school students who reported ever using e-cigarettes said that they had never tried conventional cigarettes.<sup>11,12,13</sup> This raises concern that there may be young people for whom e-cigarettes could be an entry point to use of conventional tobacco products, including cigarettes.

## Cyber-bullying/pornography

It is sad to note that teenagers have committed suicide, apparently due to negative experiences of social media or internet use. There is concern among professionals working with children that there is increased access of pornography by children, and indeed that children and young people may be increasingly involved in pornography. This report has extensively examined the importance of wellbeing and good mental health in young people. Clearly, an important future challenge will be how to balance the potential of social media for enhancing connectedness and wellbeing with the risk of exploitation of particularly vulnerable young people. Part of the solution lies, as with other areas of building resilience, in ensuring that young people develop protective skills. Some of these come from family-based communication, some from peer-to-peer support systems, but the role of the health and social care system and schools needs to be enhanced. This is a fast changing area and one where careful monitoring is important, combining our responsibilities to protect children with an acknowledgement of new and evolving ways in which our children communicate.

## Workforce

### Meeting standards

A considerable challenge for child health services has been laid out by the recent identification of core standards for healthcare organisations providing paediatric services by the Royal College of Paediatrics and Child Health (RCPCH), and by the accompanying audit of whether organisations are meeting these standards. The headlines from these data show that just under a quarter of children admitted to hospital do not see a paediatrician above or at the middle grade level within 4 hours of admission. Similarly, only 88% of children and young people see a consultant paediatrician within 24 hours of admission. Low levels of consultant



presence at peak times underpin these omissions, due to shortfalls of staffing. These findings led the RCPC to call for reconfiguration of children's services, which I support.<sup>14</sup> This work should also be examined in the light of the findings of the Atlas of Variation in Healthcare for Children and Young People (see Annex of this report), i.e. considerable variation in both process and outcome data. These findings occurred against the recent background of judicial reviews and stoppages for reconfigurations. The future for the creation of safe healthcare environments that meet professional standards and maintain public support is an area that is likely to become more relevant as resources become even tighter in the NHS. Strategic clinical networks, working alongside professional bodies, commissioners, patient groups and public representatives, will be key to finding local solutions.

Alongside reconfiguring services will be the need to deliver services differently. The current rigid lines between primary and secondary care are increasingly being tested in attempts to better provide the right care to children and young people when it is needed. This may be hospital-based specialists working alongside GPs, or in alternative settings such as schools. Similarly, as general practice evolves it may be that the concept of GP specialists – those who either lead on domains for practices (or groups of practices) or who have sub-interests – becomes more common. Changing parts of these systems requires large-scale evaluations in varied settings. The case study "Connecting care for children's health" in Chapter 2 of this report is just such an example.

### An adequately trained workforce

Underpinning the changes to service delivery laid out in the previous section is a need to ensure that the workforce continues to provide healthcare which is robust and evidence based. In a world where new evidence is accruing with great alacrity, this presents a considerable challenge. Bringing together training through Health Education England and local outposts provides opportunities to address this. So too there is need to ensure that during primary training the importance of life-long learning is stressed, and then underpinned through career-long assessment of professional competencies.

### Determinants of disease

Chapter 2 of this report outlines clearly the role that social determinants beyond health play in shaping the health of individuals – these are perhaps the greatest challenges facing the improvement of child health, because they are not within the domain of health at all but rather within broader public policy. Hence not losing sight of what is happening to inequalities, child poverty and the most vulnerable in our society will remain paramount to our goal of promoting health for all children.

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Annex 1

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# Recommendations

## Recommendations

### Where

|        |                                                                   |
|--------|-------------------------------------------------------------------|
| CQC    | Care Quality Commission                                           |
| CYP    | Children and young people                                         |
| CYPOF  | Children and Young People's Health Outcomes Forum                 |
| DCLG   | Department for Communities and local Government                   |
| DH     | Department of Health                                              |
| DsPH   | Directors of Public Health                                        |
| GP     | General Practitioners                                             |
| HEE    | Health Education England                                          |
| HWBB   | Health and Wellbeing Boards                                       |
| NI CMO | Chief Medical Officer (Northern Ireland)                          |
| NICE   | National Institute for Health and Care Excellence                 |
| NIHR   | National Institute for Health Research                            |
| Ofsted | Office for Standards in Education, Children's Services and Skills |
| ONS    | Office for National Statistics                                    |
| PHSE   | Personal Social Health and Economic Education                     |
| PHE    | Public Health England                                             |
| RCGP   | Royal College of General Practitioners                            |
| RoSPA  | Royal Society for the Prevention of Accidents                     |

| Recommendation |                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Type  | Organisation                                     |
|----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|--------------------------------------------------|
| 1              | Cabinet Office supported by Public Health England, and the Children's Commissioner, should consider initiating an annual National Children's Week.                                                                                                                                                                                                                                                                                                                 | Join  | PHE<br>Cabinet Office<br>Children's Commissioner |
| 2              | Public Health England in collaboration with the Early Intervention Foundation should assess the progress on early intervention and prevention, continue to develop and disseminate the evidence base for why this matters and build advice on how health agencies can be part of local efforts to move from a reactive to a proactive approach.                                                                                                                    | Build | PHE<br>Early Intervention Foundation             |
| 3              | Public Health England, working with Directors of Public Health and Health and Wellbeing Boards, should support the work of the Big Lottery Fund programmes and ensure that the lessons learnt are disseminated.                                                                                                                                                                                                                                                    | Build | DsPH<br>HWBB                                     |
| 4              | Public Health England should undertake a Healthy Child Programme evidence refresh, starting with the early years.                                                                                                                                                                                                                                                                                                                                                  | Build | PHE                                              |
| 5              | Public Health England should work with local authorities, schools and relevant agencies to build on current efforts to increase participation in physical activity and promote evidence based innovative solutions that lead to improved access to existing sports facilities.                                                                                                                                                                                     | Build | PHE<br>Local Government                          |
| 6              | <p>Nutrition</p> <ul style="list-style-type: none"> <li>■ CMO recommends that NICE examines the cost-effectiveness of moving the Healthy Start vitamin programme from a targeted to a universal offering,</li> <li>■ Department of Health to set out next steps in the light of evidence from the Scientific Advisory Committee on Nutrition (SACN) about folic acid</li> <li>■ Action is taken if required on iodine following recommendations by SACN</li> </ul> | Build | NICE<br>DH                                       |

| Recommendation |                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Type         | Organisation                          |
|----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|---------------------------------------|
| 7              | The Social Mobility and Child Poverty Commission and Public Health England should work together to ensure that efforts to narrow attainment gaps in education complement efforts being made to narrow health inequalities.                                                                                                                                                                                                                             | Build        | PHE<br>Commission for Social Mobility |
| 8              | Public Health England should work with NHS England, the Department for Communities and Local Government and the Department of Health to identify how the health needs of families are met through the Troubled Families Programme.                                                                                                                                                                                                                     | Join         | PHE<br>NHS England<br>DCLG            |
| 9              | Department of Health, NHS England and Public Health England, alongside representatives of children and young people, should build on the You're Welcome programme and the vision outlined in the recent pledge for better health outcomes for children and young people to create a 'health deal' which outlines the compact between children and young people and health providers, and creates a mechanism for assessing the implementation of this. | Voice of CYP | DH<br>NHS England<br>PHE              |
| 10             | Children with long-term conditions, as vulnerable people, should have a named GP who co-ordinates their disease management.                                                                                                                                                                                                                                                                                                                            | Build        | RCGP                                  |
| 11             | As plans are made to extend GP training, paediatrics and child health should be part of the core component of extended training.                                                                                                                                                                                                                                                                                                                       | Build        | DH<br>HEE<br>RCGP                     |
| 12             | Health Education England should commission education to ensure that the workforce is trained to deliver care that is appropriate for children and young people, in the same manner as is being currently carried out for age-appropriate care for older people.                                                                                                                                                                                        | Build        | HEE                                   |
| 13             | Health Education England, the Department of Health and Public Health England should work to ensure that commissioned education of health professionals stresses the important role of school nurses.                                                                                                                                                                                                                                                   | Join         | HEE<br>DH<br>PHE                      |
| 14             | PHE should develop and enact a youth social marketing programme, "Rise Above" to engage young people around exploratory behaviours through multiple platforms.                                                                                                                                                                                                                                                                                         | Build        | PHE                                   |
| 15             | Public Health England and other leading organisations working in the field should work together to strengthen the evidence base for programmes that develop resilience in young people.                                                                                                                                                                                                                                                                | Build        | PHE                                   |
| 16             | Public Health England should develop an adolescent health and wellbeing framework which includes the inter-relationships of exploratory behaviours. As part of their public-facing work, Public Health England should model engagement with young people on multiple health and wellbeing issues through a variety of platforms.                                                                                                                       | Build        | PHE                                   |
| 17             | Public Health England, the PSHE Association and other leading organisations in the field should review the evidence linking health and wellbeing with educational attainment, and from that promote models of good practice for educational establishments to use.                                                                                                                                                                                     | Join         | PHE<br>PSHE Association               |
| 18             | The Children and Young People's Health Outcomes Forum annual summit should provide an opportunity for the review of health outcomes that are relevant to children, and to examine regional variation.                                                                                                                                                                                                                                                  | Join         | CYPOF                                 |

## Recommendations

| Recommendation                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Type         | Organisation                                  |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|-----------------------------------------------|
| <p>19 Regulators, including the Care Quality Commission and Ofsted, should annually review the effectiveness of inspection frameworks and the extent to which they evaluate the contribution of all partners to services for children and young people. This includes the contribution of statutory partners, local safeguarding boards and health and wellbeing boards to the health and protection needs of children and young people.</p>                                                                                                                                                                                                                                                                                                                                                                                                | Join         | CQC<br>Ofsted                                 |
| <p>20 The review of 'Safeguarding Children and Young people: roles and competences for health care staff – intercollegiate document' should embed the professional responsibility to the whole family, and professional bodies should develop the necessary innovative tools to support this.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Join         | Professional organisations                    |
| <p>21</p> <ul style="list-style-type: none"> <li>■ Department of Health should work with Office for National Statistics, Public Health England and relevant third sector organisations to investigate opportunities to commission a regular survey to identify the current prevalence of mental health problems among children and young people, with particular reference to those with underlying neurodevelopmental issues, those aged under 5, ethnic minorities and those in the youth justice system.</li> <li>■ This data collection should include international comparisons and be linked to the Child and Adolescent Mental Health Services data set, providing key data for developing local services to meet clinical need.</li> <li>■ An annual audit of services and expenditure in the area should be undertaken.</li> </ul> | Join         | Local Government<br>PHE<br>NHS England<br>ONS |
| <p>22 The National Institute for Health Research should develop a research call to provide the evidence base to improve health outcomes for long-term conditions in childhood, to match the best worldwide.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Build        | NIHR                                          |
| <p>23 The National Institute for Health Research (NIHR) Clinical Research Network, including the NIHR Medicines for Children Network, should work with children and young people to review the design of clinical studies in order to facilitate increased participation of children and young people in drug and other trials.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Voice of CYP | NIHR                                          |
| <p>24 The four UK Chief Medical Officers have agreed that the Chief Medical Officer in Northern Ireland, Dr Michael McBride, will lead a group with the four public health agencies and The Royal Society for the Prevention of Accidents (RoSPA) to develop strategies to combat blind cord deaths.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Join         | NI CMO<br>RoSPA                               |



Annex 2

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# Acknowledgements

# Acknowledgements

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Annex 3

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# Summary for Children and Young People

## What is the Chief Medical Officer's Annual Report?

Professor Dame Sally Davies is the Chief Medical Officer. She advises the Government on health issues.

Every year, Professor Davies chooses an important topic to look at closely. She writes a report for the Government and suggests how to improve things. This year, she decided to look at how healthy children and young people are and whether they can get help easily if they need it.



## What does the report say?

- Spending money to help people early isn't just a good thing to do, it's sensible too. Sometimes a little help early on can make a huge difference to a person's life. It's a really good idea to make sure that children and young people can get help and information as soon as they need it.
- England should hold a National Children's Week every year. During the week, people can ask if things have changed, plan together to make improvements and celebrate just how great our children and young people are.
- People who work with children and young people should be trained to listen and behave in a way that makes sense to you. They shouldn't use complicated or confusing words.
- Schools and local councils should try to find a way to make sports facilities and swimming pools easier for everyone to use. This will encourage us to use them, and exercise helps to keep us healthy.

## Who helped the Chief Medical Officer?

Professor Davies asked lots of experts to collect information and to put the pieces together. She wanted to hear the voices of families and kids so she held workshops to talk about things like food and exercise. Professor Davies thanks all the children and young people who helped to make the report with their stories, quotes and art.



*Sally*

The full report can be found at [www.gov.uk](http://www.gov.uk)

(Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays)

### You told us what you wanted from a better healthcare system:

- personalised, child-friendly care from people who treat you with respect
- to be informed and have a greater involvement in decisions about your care
- access to age-appropriate services where and when you need them
- greater support through the transition to adult health and social care services
- to understand your rights and responsibilities regarding healthcare
- for schools to play a greater role in your health and wellbeing
- for mental health to be taken as seriously as physical health

Annex 4

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# Summary for Clinical Commissioning Groups



## Key points for Clinical Commissioning Groups

### Key Findings

1. England has poor outcomes for children and young people with respect to mortality, morbidity and inequality.
2. We need to raise the profile of children and young people and encourage the public sector and other institutions to work together more closely. The Chief Medical Officer (CMO) is therefore asking the Cabinet Office supported by Public Health England, and the Children's Commissioner, to consider initiating an annual National Children's Week.
3. Early action matters: the economic case is increasingly clear and we need to move from reactive to proactive care. CMO is asking for regular assessment of progress.
4. We need to ensure that efforts to improve outcomes are underpinned by proportionate universalism: improving the lives of all, with more resources targeted at the more disadvantaged. With this in mind CMO is asking for a refresh of the Healthy Child Programme evidence base to ensure that budgetary constraints do not compromise enactment of the programme. CMO is also asking Public Health England and local authorities and schools to identify innovative ways to make their sports facilities more available. Nutritional guidance is also to be re-examined. CMO is mindful of current targeted work and for example, supports Public Health England in ensuring that the Troubled Families Programme meets the health needs of families.
5. CMO has noted the evidence on the value of the views of children and young people and seeks to harness this through the development of a "health deal", building on the recent government pledge on health outcomes and pre-existing engagement work. This will allow young people to have access to services that they feel comfortable with. CMO has recommended that Health Education England ensure that the workforce receive necessary training on age appropriate care.
6. CMO seeks to develop further the evidence base for how to nurture resilience in young people, and how this can assist in educational attainment.
7. CMO seeks to mirror the recent announcement by Secretary of State, such that all young people with a long term condition have a named GP to coordinate their care. Similarly CMO believes that responsibility to the whole family should be a professional responsibility.
8. To aid commissioning CMO seeks to develop better data around health and wellbeing in children and young people and in particular mental health problem prevalence.

### Background

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In her report, the CMO makes recommendations on how to improve the health of children and young people and why this is important to do.

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Annex 5

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# Summary for Families

# Key points for Families

### What can you do?

- Make healthy choices and encourage your family to be healthy.
- If you find parenting hard – seek help – we are getting better at knowing how to help and support parents.
- Communicating with your family really matters – where there is open communication we know that young people are less likely to try smoking and other unhealthy choices.
- Praising your children helps – we know that where this happens young people have higher self-esteem, do better academically and make fewer unhealthy choices.

### Key Findings

1. England has poor outcomes for children and young people with respect to how long they live, how healthy they are and how rich children do compared to poorer ones. The Chief Medical Officer (CMO) is therefore encouraging more research about how to improve this and how to involve more young people in clinical trials. CMO wants to make sure that experts have an opportunity every year to look at how much this has changed and to suggest to government how to make further improvements.
2. We need to encourage the public sector and other institutions to work together more closely to support children and young people. CMO is therefore asking for the Cabinet Office supported by Public Health England, and the Children's Commissioner, to consider initiating an annual National Children's Week.
3. Early action matters: the economic case is increasingly clear that investing money in our young people is wise and CMO is asking commissioners to move towards a focus on early action.
4. We need to ensure that efforts to improve outcomes are underpinned by improving the lives of all, with more resources targeted at the more disadvantaged. With this in mind, CMO is asking for a refresh of the current guidance on what we expect from local services about how to keep children healthy: the Healthy Child Programme. CMO is also asking local councils, Public Health England and local authorities and schools to identify innovative ways to make their sports facilities more available. Nutritional guidance is also to be re-examined.
5. CMO has noted the evidence on the value of the views of children and young people and seeks to harness this through the development of a "health deal", building on the recent government pledge on health outcomes and pre-existing work. CMO has also recommended that Health Education England ensure that the workforce receive necessary training on age appropriate care.

6. CMO seeks to develop further the evidence base for how to nurture resilience in young people, and how this can assist in educational attainment.
7. CMO seeks to mirror the recent announcement by Secretary of State, such that all young people with a long term condition have a named GP to coordinate their care. Similarly CMO believes that responsibility to the whole family should be a professional responsibility.
8. CMO is also asking those that regulate places that care for looked-after children, like Ofsted and the health equivalent (CQC), to check every year that they are doing the best they can for this vulnerable group.
9. To aid commissioning CMO seeks to develop better data around health and wellbeing in children and young people and in particular mental health problem prevalence.

### Background

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In her report, the CMO makes recommendations on how to improve the health of children and young people and why this is important to do.

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Annex 6

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# Summary for Health and Care Professionals

# Key points for Health and Care Professionals

### Key Findings

1. England has poor outcomes for children and young people with respect to mortality, morbidity and inequality.
2. We need to raise the profile of children and young people and encourage the public sector and other institutions to work together more closely. The Chief Medical Officer (CMO) is therefore asking the Cabinet Office supported by Public Health England, and the Children's Commissioner, to consider initiating an annual National Children's Week.
3. Early action matters: the economic case is increasingly clear and thus we need to move from reactive to proactive care, therefore CMO is asking for regular assessment of progress on this.
4. We need to ensure that efforts to improve outcomes are underpinned by proportionate universalism: improving the lives of all, with more resources targeted at the more disadvantaged. With this in mind CMO is asking for a refresh of the Healthy Child Programme evidence base to ensure that budgetary constraints do not compromise enactment of the programme. CMO is also asking Public Health England and local authorities and schools to identify innovative ways to make their sports facilities more available. Nutritional guidance is also to be re-examined. CMO is mindful of the current targeted work and for example, supports Public Health England ensuring that the Troubled Families Programme meets the health needs of families.
5. CMO has noted the evidence on the views of children and young people and seeks to harness this through the development of a "health deal", building on the recent government pledge on health outcomes and pre-existing engagement work. This will allow young people to have access to services that they feel comfortable with. CMO has also recommended that Health Education England ensure that the workforce receive necessary training on age appropriate care.
6. CMO seeks to develop further the evidence base for how to nurture resilience in young people, and how this can assist in educational attainment..
7. CMO seeks to mirror the recent announcement by Secretary of State, such that all young people with a long term condition have a named GP to coordinate their care. Similarly CMO believes that responsibility to the whole family should be a professional responsibility.
8. CMO believes that thinking about the family, not just the child or young person in front of you, should be a professional norm – like safeguarding – and has asked regulators and professional bodies to develop how to do this.
9. CMO has asked for more research into improving our outcomes for long term conditions, and how to improve participation of adolescents in clinical trials.
10. To aid commissioning, CMO seeks to develop better data around health and wellbeing in children and young people and in particular mental health problem prevalence.

### Background

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Annex 7

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# Summary for Head Teachers

# Key points for Head Teachers

### Key Findings

1. England has poor outcomes for children and young people with respect to mortality, morbidity and inequality.
2. We need to raise the profile of children and young people and encourage the public sector and other institutions to work together more closely. The Chief Medical Officer (CMO) is therefore asking the Cabinet Office supported by Public Health England, and the Children's Commissioner to consider initiating an annual National Children's Week.
3. Early action matters: the economic case is increasingly clear and thus we need to move from reactive to proactive care, therefore CMO is asking for regular assessment of progress on this.
4. Schools matter: there is a strong association between school connectedness or sense of belonging and well-being. School connectedness appears to be generated in schools through extra-curricular activities, positive classroom management and tolerant disciplinary policies. School based action as part of a multi-site program is one of the most promising approaches to prevent obesity.
5. CMO seeks to develop further the evidence base for how to nurture resilience in young people, and the link between health and wellbeing with educational attainment. CMO is also asking that PHE, PSHE Association and other leading organisations promote models of good practice in this area for educational establishments to use.
6. We need to ensure that efforts to improve outcomes are underpinned by improving the lives of all, with more resources targeted at the more disadvantaged. With this in mind CMO is asking for a refresh of the Healthy Child Programme evidence base to ensure that budgetary constraints do not compromise enactment of the programme. CMO is also asking Public Health England and local authorities and schools to identify innovative ways to make their sports facilities more available. Nutritional guidance is also to be re-examined. CMO is mindful of the current targeted work and for example, supports Public Health England ensuring that the Troubled Families Programme meets the health needs of families.
7. CMO has noted the evidence on the views of children and young people and seeks to harness this through the development of a "health deal", building on the recent government pledge on health outcomes and pre-existing engagement work. This will allow young people to have access to services that they feel comfortable with. CMO has also recommended that Health Education England ensure that the workforce will receive necessary training on age appropriate care and skills to help them guide young people better around the healthcare system, including understanding the role of school nurses.
8. CMO seeks to mirror the recent announcement by Secretary of State, such that all young people with a long term condition have a named GP to coordinate their care. Similarly CMO believes that responsibility to the whole family should be a professional responsibility.
9. CMO believes that thinking about the family, not just the child or young person in front of you, should be a professional norm – like safeguarding – and has asked regulators and professional bodies to develop how to do this.
10. CMO has asked for more research into improving our outcomes for long term conditions, and how to improve participation of adolescents in clinical trials.
11. To aid commissioning CMO seeks to develop better data around health and wellbeing in children and young people and in particular mental health problem prevalence.

### Background

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In her report, the CMO makes recommendations on how to improve the health of children and young people and why this is important to do.

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Annex 8

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# Summary for Local Authorities

## Key points for Local Authorities

### Key Findings

1. England has poor outcomes for children and young people with respect to mortality, morbidity and inequality.
2. We need to raise the profile of children and young people and encourage the public sector and other institutions to work together more closely. The Chief Medical Officer (CMO) is therefore asking the Cabinet Office supported by Public Health England, and the Children's Commissioner, to consider initiating an annual National Children's Week.
3. Early action matters: the economic case is increasingly clear and thus we need to move from reactive to proactive care, therefore CMO is asking for regular assessment of progress on this.
4. Schools matter: there is a strong association between school connectedness or sense of belonging and well-being. School connectedness appears to be generated in schools through extra-curricular activities, positive classroom management and tolerant disciplinary policies. School based action as part of a multi-site program is one of the most promising approaches to prevent obesity.
5. CMO seeks to develop further the evidence base for how to nurture resilience in young people, and the link between health and wellbeing with educational attainment. CMO is also asking that PHE, PSHE Association and other leading organisations promote models of good practice in this area for educational establishments to use.
6. We need to ensure that efforts to improve outcomes are underpinned by improving the lives of all, with more resources targeted at the more disadvantaged. With this in mind CMO is asking for a refresh of the Healthy Child Programme evidence base. Strengthening the evidence is designed to add weight to the case for enactment of more than just the statutory elements of the programme. CMO is also asking Public Health England and local authorities and schools to identify innovative ways to make their sports facilities more available. Nutritional guidance is also to be re-examined. CMO is mindful of the current targeted work and for example, supports Public Health England ensuring that the Troubled Families Programme meets the health needs of families.
7. CMO has noted the evidence on the views of children and young people and seeks to harness this through the development of a "health deal", building on the recent government pledge on health outcomes and pre-existing engagement work. This will provide an opportunity for organisations to show how young people focused they are. CMO has also recommended that Health Education England ensure that the workforce will receive necessary training on age appropriate care and skills to help them guide young people better around the healthcare system, including understanding the role of school nurses.
8. CMO seeks to mirror the recent announcement by Secretary of State, such that all young people with a long

term condition have a named GP to coordinate their care. Similarly CMO believes that responsibility to the whole family should be a professional responsibility.

9. CMO believes that thinking about the family not just the child or young person in front of you should be a professional norm – like safeguarding and has asked regulators and professional bodies to develop how to do this.
10. CMO has asked for more research into improving our outcomes for long term conditions, and how to improve participation of adolescents in clinical trials.
11. To aid commissioning CMO seeks to develop better data around health and wellbeing in children and young people and in particular mental health problem prevalence.

### TOP 5 Questions for Local Councillors to ask of their health systems, with respect to children and young people's health:

1. How does local mortality, morbidity and inequality data compare to comparable areas?
2. How focused are we on early action?
3. How are local schools engaging with the health agenda e.g. creating school connectedness, building resilience, supporting health and wellbeing and encouraging physical exercise?
4. Are we enacting the Healthy Child Programme in full and are we prepared for the change in commissioning of this programme that is due shortly?
5. How do we know that our health and care organisations meet the needs of children and young people? Are we using 'Your'e Welcome'?

### Background

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In her report, the CMO makes recommendations on how to improve the health of children and young people and why this is important to do.

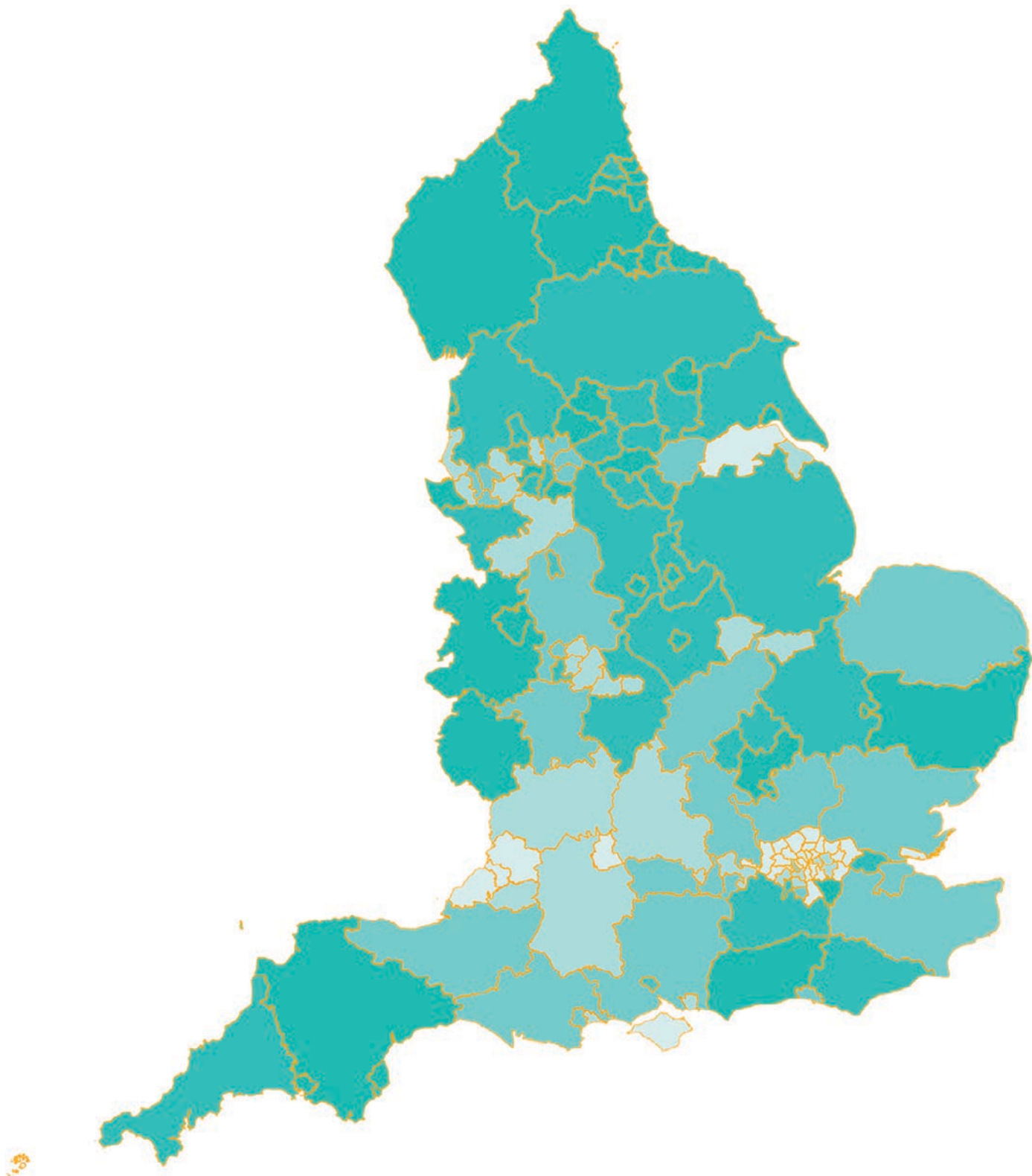
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Annex 9

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# Atlas of Variation in Healthcare for Children and Young People





## **Atlas of Variation in Healthcare for Children and Young People**

Annex of the Annual Report of the Chief Medical Officer 2012,  
Our Children Deserve Better: Prevention Pays

Reducing unwarranted variation to increase value and improve quality  
(October 2013)

|                                          |     |
|------------------------------------------|-----|
| Introduction.....                        | 08  |
| Maps and chart presentation methods..... | 10  |
| Glossary of essential terms.....         | 115 |
| Acknowledgements.....                    | 119 |

## Section 1: Determinants of child health ..... 13

### A: Poverty and homelessness

|                                                                                                                                                                                                                                        |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 1 Child poverty: Percentage of children aged under 16 years living in families in receipt of out-of-work benefits or tax credits where their reported income is less than 60% of the median income, by local authority, 2010 ..... | 14 |
| Map 2 Family homelessness: Rate of households accepted as unintentionally homeless and eligible for assistance per 1,000 households, by local authority, 2011–2012 .....                                                               | 15 |

### B: Vulnerable Children

|                                                                                                                                                                                                                 |    |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 3 Children in the child protection system: Rate of children aged 0–17 years who were the subject of a child protection plan, per 10,000 children aged 0–17 years, by local authority, at 31 March 2012..... | 18 |
| Map 4 Healthcare (medical) for looked-after children: Percentage of looked-after children (in care for at least 12 months) who had their annual health assessment, by local authority, 2011–2012.....           | 19 |
| Map 5 Healthcare (dental) for looked-after children: Percentage of looked-after children (in care for at least 12 months) who had their teeth checked by a dentist, by local authority, 2011–2012 .....         | 20 |

### C: Education

|                                                                                                                                                                                                       |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 6 School readiness: Percentage of children at the end of foundation stage (at age 5) who are assessed as having achieved a 'good level of development', by local authority, at January 2012 ..... | 23 |
| Map 7 Special educational needs (SEN): Percentage of children in state-funded schools with a statement of SEN, by local authority, at January 2012 .....                                              | 24 |

### D: Crime & Youth Justice

|                                                                                                                                                                                                          |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 8 Crime and youth justice: Rate of young people aged 10–17 years receiving their first reprimand, warning or conviction, per 100,000 population aged 10–17 years, by local authority 2011–2012 ..... | 27 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## Section 2: Health promotion .....29

### A: Mortality

|                                                                                                                                                                          |    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 9 Perinatal mortality: Perinatal mortality rate per 1,000 births, by local authority, 2009–2011 .....                                                                | 30 |
| Map 10 Infant mortality: Infant mortality rate per 1,000 live births, by local authority, 2009–2011 .....                                                                | 31 |
| Map 11 Childhood mortality: Directly standardised mortality rate for children aged 1–17 years, per 100,000 children aged 1–17 years, by local authority, 2009–2011 ..... | 32 |

### B: Injury

|                                                                                                                                                                                                                                                            |    |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 12 Hospital admissions due to injury: Rate of hospital admissions due to injury in children aged 0–17 years, per 10,000 children aged 0–17 years, by local authority, 2011–2012 .....                                                                  | 35 |
| Map 13 Injuries from road traffic accidents: Rate of children aged 0–15 years killed or seriously injured in road traffic accidents, per 100,000 children aged 0–15 years, by local authority, 2009–2011 .....                                             | 36 |
| Map 14 Mortality from accidental injury: Directly standardised rate of death in children and young people aged 0–24 years due to all accidental injury, per 100,000 children and young people aged 0–24 years, by local authority, 2002–2011 .....         | 37 |
| Map 15 Mortality from non-accidental injury: Directly standardised rate of death in children and young people aged 0–24 years due to all non-accidental injury, per 100,000 children and young people aged 0–24 years, by local authority, 2002–2011 ..... | 38 |

### C: Weight

|                                                                                                                                                        |    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 16 Weight in 4–5-year-old children: Percentage of pupils in Reception class classified as overweight or obese, by local authority, 2011–2012 ..... | 41 |
| Map 17 Weight in 10–11-year-old children: Percentage of pupils in Year 6 classified as overweight or obese, by local authority, 2011–2012 .....        | 42 |

### D: Alcohol, smoking and substance misuse

|                                                                                                                                                                                                                         |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 18 Alcohol-related hospital admissions: Hospital admission rate for people aged 0–17 years due to alcohol-specific conditions, per 100,000 people aged 0–17 years, by local authority, 2008–2009 to 2010–2011 ..... | 45 |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## E: Dental health

|                                                                                                                                                                      |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 19 Dental health: Hospital admission rate for dental caries in children aged 1–4 years, per 100,000 children aged 1–4 years, by local authority, 2009–2012 ..... | 48 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## F: Immunisations

|                                                                                                                                                                                                                                                                |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 20 Diphtheria, tetanus, polio, pertussis and Haemophilus influenzae type b (DTaP/IPV/Hib) vaccine coverage at 2 years: Percentage of immunisation completion for routine vaccinations against DTaP/IPV/Hib at 2 years, by local authority, 2011–2012 ..... | 50 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                                                                              |    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 21 Pneumococcal conjugate vaccine (PCV) coverage at 2 years: Percentage of immunisation completion for routine vaccinations against pneumococcal disease at 2 years, by local authority, 2011–2012 ..... | 51 |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                                                               |    |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 22 Measles, mumps and rubella (MMR) vaccine coverage at 5 years: Percentage of immunisation coverage for routine vaccinations against MMR at 5 years, by local authority, 2011–2012 ..... | 52 |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                                                                          |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 23 Human papillomavirus (HPV) vaccine coverage at 13 years: Percentage of immunisation coverage for routine vaccinations against HPV for girls aged 12–13 years, by local authority, 2011–2012 ..... | 53 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## G: Sexually Transmitted Infection

|                                                                                                                                                                            |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 24 Chlamydia: Rate of diagnoses of genital Chlamydia trachomatis in young people aged 15–24 years, per 100,000 people aged 15–24 years, by local authority, 2012 ..... | 56 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## Section 3: Child health in the perinatal period .....59

### A: Teenage pregnancy

|                                                                                                                                       |    |
|---------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 25 Teenage conceptions: Conceptions in females aged <18 years, per 1,000 females aged 15–17 years, by local authority, 2011 ..... | 60 |
|---------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                              |    |
|------------------------------------------------------------------------------------------------------------------------------|----|
| Map 26 Teenage births: Percentage of delivery episodes where the mother is aged <18 years, by local authority, 2011/12 ..... | 61 |
|------------------------------------------------------------------------------------------------------------------------------|----|

### B: Antenatal health

|                                                                                                                                   |    |
|-----------------------------------------------------------------------------------------------------------------------------------|----|
| Map 27 Low birth weight: Percentage of live and stillborn infants who have a birth weight <2,500g, by local authority, 2011 ..... | 64 |
|-----------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                   |    |
|-----------------------------------------------------------------------------------------------------------------------------------|----|
| Map 28 Smoking in pregnancy: Percentage of women who currently smoke at the time of delivery, by local authority, 2011–2012 ..... | 65 |
|-----------------------------------------------------------------------------------------------------------------------------------|----|

## C: Breastfeeding

|                                                                                                                                                  |    |
|--------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 29 Breastfeeding initiation: Percentage of infants who are given breastmilk within 48 hours of delivery, by local authority, 2011–2012 ..... | 68 |
|--------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                       |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 30 Breastfeeding at 6–8 weeks: Percentage of infants who are totally or partially breastfeeding at 6–8 weeks, by local authority, 2011–2012 ..... | 69 |
|-------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## D: Postnatal Health

|                                                                                                                                                                    |    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 31 Postnatal health: Rate of emergency admissions to hospital of babies within 14 days of being born per 1,000 deliveries, by local authority, 2011–2012 ..... | 72 |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## E: Preterm birth

|                                                                                                                                                                                                                       |    |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 32 Neonatal mortality: Percentage of infants born at <30 weeks' gestation and admitted to neonatal units, who died ≤28 days, by neonatal network of booking, directly standardised by gestational age, 2012 ..... | 74 |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                                                                                                                                                                       |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 33 Breastfeeding at discharge: Percentage of infants born at <30 weeks' gestation and admitted to neonatal units who were receiving any mother's milk at discharge from neonatal care, by neonatal network of discharge, directly standardised by Index of Multiple Deprivation (IMD), 2012 ..... | 75 |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                                                                                                                          |    |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 34 Survival free of any impairment at age 2 years: Percentage of infants born at <30 weeks' gestation and admitted to neonatal units who survived to 2 years of age free of any impairment (mild, moderate or severe), by region, born in 2010 ..... | 76 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## Section 4: Healthcare for children and young people ....79

### A: Accident & Emergency Attendances

|                                                                                                                                                                                                       |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 35 Emergency attendance: Rate of attendance to Accident and Emergency departments in persons aged 4 years and under, per 1,000 population aged 4 years and under, by local authority, 2010–2011 . | 80 |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

### B: Unplanned Hospital Admissions

|                                                                                                                                                                              |    |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 36 Duration of non-elective hospital admissions: Mean length of stay (days) for non-elective admissions in children aged 0–17 years, by local authority, 2011–2012 ..... | 82 |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|                                                                                                                                                                                     |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 37 Zero-day admissions: Percentage of hospital admissions in children aged 0–17 years where the duration of stay was shorter than 24 hours, by local authority, 2011–2012 ..... | 83 |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|        |                                                                                                                                                                                                                    |    |
|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 38 | Emergency readmissions: Percentage of emergency admissions in children aged 0–15 years occurring within 28 days of the last, previous discharge from hospital after admission, by local authority, 2010–2011 ..... | 84 |
|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## Section 5: Healthcare for acutely ill children.....87

### A: Bronchiolitis

|        |                                                                                                                                                                                                                            |    |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 39 | Bronchiolitis: Hospital admission rate: Directly standardised rate of emergency admissions with bronchiolitis in children aged under 2 years, per 100,000 children aged under 2 years, by local authority, 2011–2012 ..... | 88 |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|        |                                                                                                                                                            |    |
|--------|------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 40 | Bronchiolitis: Duration of hospital stay: Mean length of stay (days) for bronchiolitis in children aged under 2 years, by local authority, 2011–2012 ..... | 89 |
|--------|------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

### B: Lower Respiratory Tract Infections (LRTIs)

|        |                                                                                                                                                                                                                    |    |
|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 41 | LRTIs: Hospital admission rate: Directly standardised rate of emergency admissions with LRTIs in children aged 4 years and under, per 100,000 children aged 4 years and under, by local authority, 2011–2012 ..... | 92 |
|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|        |                                                                                                                                                |    |
|--------|------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 42 | LRTIs: Duration of hospital stay: Mean length of stay (days) for LRTIs in children aged 4 years and under, by local authority, 2011–2012 ..... | 93 |
|--------|------------------------------------------------------------------------------------------------------------------------------------------------|----|

### C: Ear, Nose and Throat Surgery

|        |                                                                                                                                                                            |    |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 43 | Tonsillectomy: Directly standardised rate of elective tonsillectomy in children aged 0–17 years, per 100,000 children aged 0–17 years, by local authority, 2011–2012 ..... | 95 |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

|        |                                                                                                                                                                                                                   |    |
|--------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Map 44 | Aural ventilation tube insertion: Directly standardised rate of aural ventilation tube (grommet) insertion in children aged 0–17 years, per 100,000 children aged 0–17 years, by local authority, 2011–2012 ..... | 96 |
|--------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|

## Section 6: Children with long term conditions.....99

### A: Asthma

|        |                                                                                                                                              |     |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Map 45 | Asthma: Crude emergency admission rate for children with asthma, per 100,000 population aged 0–18 years, by local authority, 2011–2012 ..... | 100 |
|--------|----------------------------------------------------------------------------------------------------------------------------------------------|-----|

### B: Epilepsy

|        |                                                                                                                                                  |     |
|--------|--------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Map 46 | Epilepsy: Crude emergency admission rate for children with epilepsy, per 100,000 population aged 0–18 years, by local authority, 2011–2012 ..... | 102 |
|--------|--------------------------------------------------------------------------------------------------------------------------------------------------|-----|

|        |                                                                                                                                                                     |     |
|--------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Map 47 | Epilepsy: Duration of hospital stay: Mean length of emergency inpatient stay (days) for children with epilepsy aged 0–18 years, by local authority, 2011–2012 ..... | 103 |
|--------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|

### C: Diabetes

|        |                                                                                                                                                                                                                           |     |
|--------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Map 48 | Diabetes: Percentage of children and young people aged 0–24 years with diabetes cared for in a Paediatric Diabetes Unit (PDU) whose most recent HbA1c measurement was less than 58 mmol/mol (7.5%), by PDU, 2010/11 ..... | 106 |
|--------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|

## Section 7: Mental health.....109

### A: Prevalence and outcomes

|              |                                                                                                                                                                                                                       |     |
|--------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Indicator 49 | Mental health: prevalence of problems: Variation in community prevalence of mental health disorders for 11–13 year olds in secondary schools, by local authority, 2009–2011 (controlling for known risk factors)..... | 110 |
|--------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|

|              |                                                                                                                                                                                                                                                        |     |
|--------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Indicator 50 | Mental health: specialist service outcomes: Variation in change in mental health disorders following contact with Specialist Services for 11–18 year olds accessing Child and Adolescent Mental Health Services (CAMHS), by CAMHS units, 2008–12 ..... | 110 |
|--------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|

This section of the Annual Report of the Chief Medical Officer 2012, *Our Children Deserve Better; Prevention Pays* illustrates the current state of child health in England by highlighting existing variation in healthcare and health outcomes for children and young people. It builds on the work of Right Care's NHS Atlas of Variation in Healthcare for Children and Young People, published in March 2012<sup>1</sup>, and expands on the analysis of healthcare indicators by using a broader range of measures of child health.

## Unwarranted variation

Variation occurs because healthcare exists as part of a complex system. That variation exists is beyond debate – the stories which clinicians, commissioners and, most importantly, children, young people and their families could tell about how health services vary would fill the pages of this report several times over. It is useful to separate out the aspects of variation which are inevitable or desirable, and explore and tackle unwarranted variation – 'variation that cannot be explained by patient illness or preference'.<sup>2</sup>

There are many legitimate reasons why variation occurs. There may be differences in population demography or socio-economic status, and variation may even be desirable if it is the result of local innovation and excellence. Unwarranted variation, however, describes that which cannot be explained either by patient choice or by the nature of their illness.

Policy debate around reducing variation often focuses on reducing healthcare inefficiency and providing value to the NHS. However, examining variation can highlight inequity and inequality in:

- quality of care
- access and appropriateness of healthcare
- health outcomes.

There are many possible reasons for unwarranted variation:

- Where the evidence for preventive or therapeutic interventions is inconclusive, variations in interpretation and practice may lead to variable outcomes.
- Where evidence is clear, it may be that there are limitations to systems that prevent high-quality care from being delivered.
- Supply of resources may directly influence healthcare utilisation, magnifying variation with no demonstrable improvement in outcome.

To understand the causes of unwarranted variation in child health, we must also look beyond healthcare. Variation in how policies and guidance are applied, and variable access to proven interventions, are not problems which belong exclusively to healthcare. They exist in educational and social care services, which may have a significant impact on health outcomes in children.

## Child health atlas project

The first NHS Atlas of Variation in Healthcare for Children and Young People (2012) gave clinicians, commissioners and the public information about how healthcare services for children and young people differ between regions in terms of quality, activity, expenditure and outcome. It sought to move beyond the headlines of 'postcode lottery' and into interpretations of variation, identifying causes and practical suggestions for improvement to healthcare services.

It was used extensively, and was well received by, commissioners, policy makers, clinicians and service users. Public Health England has committed to continuing to produce this resource<sup>3</sup> in order to continue to:

- highlight variations
- illustrate healthcare on a population basis
- drive accountability and transparency in commissioning and delivering healthcare.

The indicators included in section one of this Atlas illustrate variation not only in healthcare, but also in child public health and its broader determinants. It demonstrates the value of viewing child health in a broader context, in tandem with the Annual Report of the Chief Medical Officer 2012 (Special Report – *Our Children Deserve Better; Prevention Pays*).

## Policy implications

Highlighting unwarranted variation in health services and outcomes is of little consequence unless we start to unravel the causes. Indicators in this report are accompanied by commentaries which describe the evident variation and explore the underlying reasons. Commentaries include suggestions for possible actions to tackle variation, many of them focused on local options for commissioners and clinicians.

Populations that are similar, but in which health outcomes vary significantly, provide an especially rich source of learning. Showing clinicians and commissioners the outcomes that are possible in comparable populations can help to shed the perception that variation is inevitable, and exclusively related to patient factors. Instead, it should provide motivation to explore approaches and interventions to improve health and healthcare for the children and young people.

Reliable and timely data, presented meaningfully are key to understanding, planning and evaluating child health and healthcare services well. Many indicators were suggested for this Atlas but could not be included as data were not available or complete. Others indicators could not be included due to lack of standardisation or linkage between data systems, either within health services or among related agencies such as educational and social care services. Some issues transcend regional boundaries or individual conditions and pathways.

1 [www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/](http://www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/)

2 Wennberg JE. (2010). *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

3 Department of Health (2013). *Improving children and young people's health outcomes: a system wide response*. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/214928/9328-TSO-2900598-DH-SystemWideResponse.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214928/9328-TSO-2900598-DH-SystemWideResponse.pdf)



Efforts are under way to improve the quality of, and access to, data for research and service improvement; the leadership provided by the newly established Child and Maternal Health Intelligence Network and the Children and Young People's Health Outcomes Board will be vital in developing data systems to help better understand and improve the health of children and young people. Strategic clinical networks for children and young people will work to improve integrated pathways of care. The advent of these networks will also provide an opportunity for data sharing.

Research into variation analysis is a relatively young science. Investigating the causes of unwarranted variation, and supporting related innovations to drive improvement in healthcare, may improve outcomes for children and young people's health; sustaining research has the potential to pay dividends.

## Acknowledgments

This version of the Atlas would not be possible without the foundations laid by Muir Gray, Philip DaSilva and Erica Ison at NHS Right Care in their pioneering Atlas series. The Child and Maternal Health Intelligence Network and child health colleagues within Public Health England have been, and continue to be, vital to the production of the majority of the indicators included in this Atlas. Most of all, I am thankful for the many contributing clinicians, experts and researchers who have contributed data and expertise to this Atlas.

## Selection of indicators

Experts in clinical child health and health data analysis in public health observatories and Department of Health policy teams were consulted about the selection and development of indicators for the NHS Atlas of Variation in Healthcare for Children and Young People (2012). Topics were selected to include as wide a range of child health services as possible, and indicators relating to those topics were chosen because they were deemed of particular interest with respect to unwarranted variations in healthcare.

For this iteration of the Atlas, the Editor has chosen to widen the range of indicators beyond healthcare to include public health indicators. Many of the new indicators have been chosen to reflect the recommendations of the Children and Young People's Health Outcomes Forum report (2012).<sup>1</sup> The Editor has also chosen to update 14 indicators from the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

Limitations of data quality and availability have precluded the inclusion of some topics that would benefit from variation analysis. This Atlas should be viewed as a stimulus to encourage commissioners and clinicians to investigate health outcomes in local populations.

Public Health England welcomes suggestions for potential new indicators for inclusion in their online range of indicators <http://atlas.chimat.org.uk/IAS/dataviews/> or <http://datagateway.phe.org.uk/>.

## Data sources

Data for most of the indicators have been extracted by colleagues at Public Health England from existing national datasets, including:

- Health and Social Care Information Centre Indicator Portal
- Department for Education statistics
- Health Protection Agency Centre for Infections
- Hospital Episode Statistics
- Office for National Statistics
- Integrated Performance Measure Return.<sup>2</sup>

For the remaining indicators, data from research institutions and national audits have been used to generate the maps; provenance of these datasets is given in the relevant commentaries.

The metadata, including details of data provenance, will be made available online at the Child and Maternal Health Intelligence Network, Public Health England ([www.chimat.org.uk/CMO2012](http://www.chimat.org.uk/CMO2012) or <http://datagateway.phe.org.uk>) and at [data.gov.uk](http://data.gov.uk).

## Classification

Data have been mapped by several geographies: by local authorities, provider units and clinical networks. The choice of geography has been made based on appropriateness – what is termed 'data attribution'. However, for some indicators, data may not be available in a suitable format for mapping with the optimal geography and instead a pragmatic choice has been made. In particular, it has not yet been possible to map some healthcare indicators by clinical commissioning group (CCG), and they have instead been presented by local authority. These indicators will be presented by CCG in Public Health England's online data atlas in the near future, where possible.

Data for each of the indicators included in the Child Health Atlas are displayed as both a chart and map to show variation in terms of magnitude and geographical location within England. London is shown as a page inset on all maps in order to keep detail that otherwise might be lost.

The charts and maps for all indicators are colour-classified into thematic displays, which group the areas (e.g. local authorities) into categories and allow the reader to view and compare areas on the map without having to refer to individual values. A simple method of classification using equal counts of areas was used to display all indicators, regardless of distribution of data within indicators. Five equal counts of areas or 'quintiles' were classified for all indicator data where possible. However, as most of the indicators include a total number of areas that are not divisible by five, in most cases the classifications do not include exactly the same number of areas. The method used to create the classification was to rank order the areas from highest to lowest values, then divide the ranks into five equal categories. However, in some cases, indicators included tied ranks (i.e. where some area values were exactly the same) and no areas were split into different categories where the rank was equal; this meant that an equal split was not possible in these cases. For the few indicators where there were many tied ranks of equal data, the split between categories was adjusted to ensure a 'best fit' of equal numbers, without splitting areas with the same values.

The disadvantage of using quintiles and equal counts of data is that this method does not take into account the distribution of the data, and categories can be created with very different ranges of variation between the highest and lowest values. This should be taken into consideration when comparing areas in different categories within indicators.

The classification is shaded from light green (lowest value) to dark green (highest value) on both the charts and maps. The ranges and their shading do not indicate whether a high or low value for an area represents either good or poor performance.

The charts have been originally produced in Microsoft Excel 2010 and the maps originally created using InstantAtlas.

1 <http://webarchive.nationalarchives.gov.uk/20130805112926/http://www.dh.gov.uk/health/files/2012/07/CYP-report.pdf>

2 Previously known as Vital Signs Monitoring Return.

## Standardisation

Standardisation allows like to be compared with like, by making sure that differences in the number of events (e.g. deaths or infections) observed in two or more populations are not due to differences in the age and sex profile between the different populations (e.g. suppose population A has a higher death rate than population B; however, if population A also has a higher proportion of older people, then we would expect there to be more deaths and it would be misleading to infer that people are dying at a faster rate in population A than population B). The two main methods of standardisation are directly standardised rates and indirectly standardised rates.

Directly standardised rates adjust for differences in age and sex distribution by applying the observed rates (e.g. of death or infection) for each age-band in the study population to a standard population structure in order to obtain a weighted average rate.

Indirectly standardised rates adjust for differences in age and sex distribution by applying the observed rates (e.g. of death or infection) for each age-band in a standard population (e.g. England) to the population of the same age bands in the study area.

The directly standardised rate is the method that has been used to standardise data in the Child Health Atlas, and the data have been standardised by age alone.

For certain indicators, it has been possible to investigate correlations between the data and socio-economic deprivation; these are presented as separate visualisations in the accompanying commentaries. Values from the Index of Multiple Deprivation (IMD) 2010 have been used. The IMD is a composite rating of seven markers of social deprivation: income, employment, health and disability, education and skills, housing and services, living environment and crime.

## Confidence intervals

The indicators have error terms associated with them to give an indication of the level of uncertainty of the calculation, referred to as confidence intervals. Statistical uncertainties usually arise because the indicators are based on a random sample of finite size from a population of interest. Confidence intervals are used to assess what would happen if we were to repeat the same study, over and over, using different samples each time. The precise statistical definition of a 95% confidence interval states that, on repeated sampling, 95 times out of 100 the true population value would be within the calculated confidence interval range and for 5 times out of 100 the true value would be either higher or lower than the range. Where these confidence intervals have been calculated for indicators in the Atlas, they are displayed on the bar graphs of the indicator as a banded line.

The smaller the confidence interval, the more stable the indicator; a larger number of events leads to a smaller interval.

## Exclusions

For each of the indicators mapped to an upper-tier local authority geography or provider unit, the calculation of the full range of variation is given in the accompanying commentaries; in addition, the range has then been calculated from which the highest five values and the lowest five values have been excluded. This is because 'outliers' could be the result of errors in data management (e.g. some data may not have been returned or events may have been recorded twice). This exclusion was originally suggested by Professor Sir Mike Richards for Atlas 1.0, and Right Care has continued to use the 'Richards heuristic' in subsequent Atlases.

For some indicators, where a local indicator value is created from less than five events, then these values are removed from the map and associated chart (e.g. where the indicator value is the rate of elective admissions to hospital per population, the events are the number of admissions to hospital). The indicator values are removed for two reasons:

- They are not considered sufficiently reliable, where chance could have too much influence over the value.
- They are considered potentially disclosive of individuals in the local area.

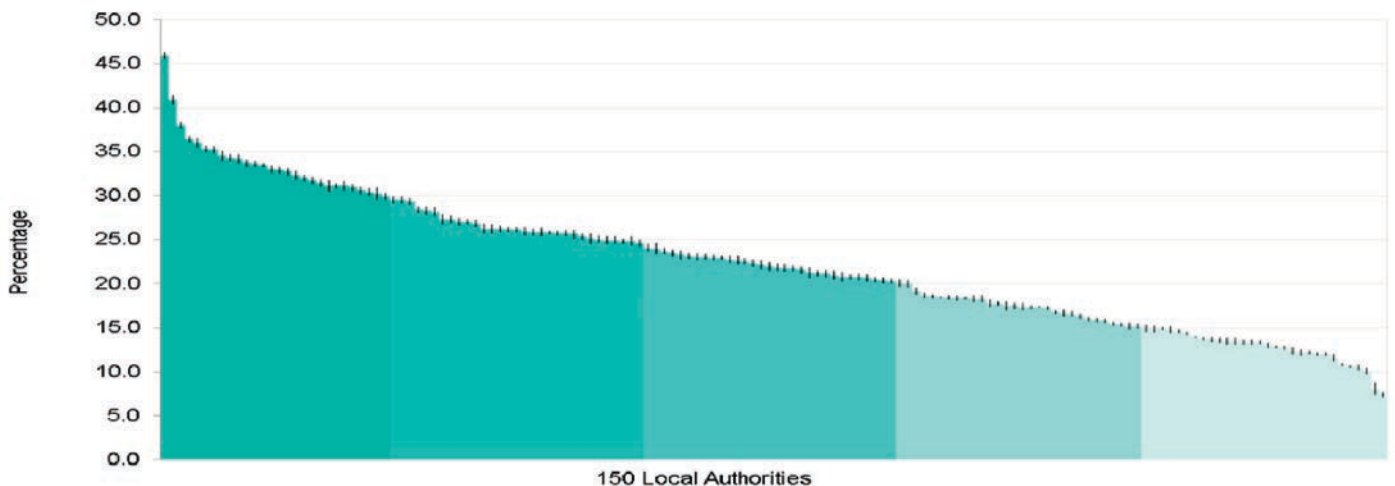
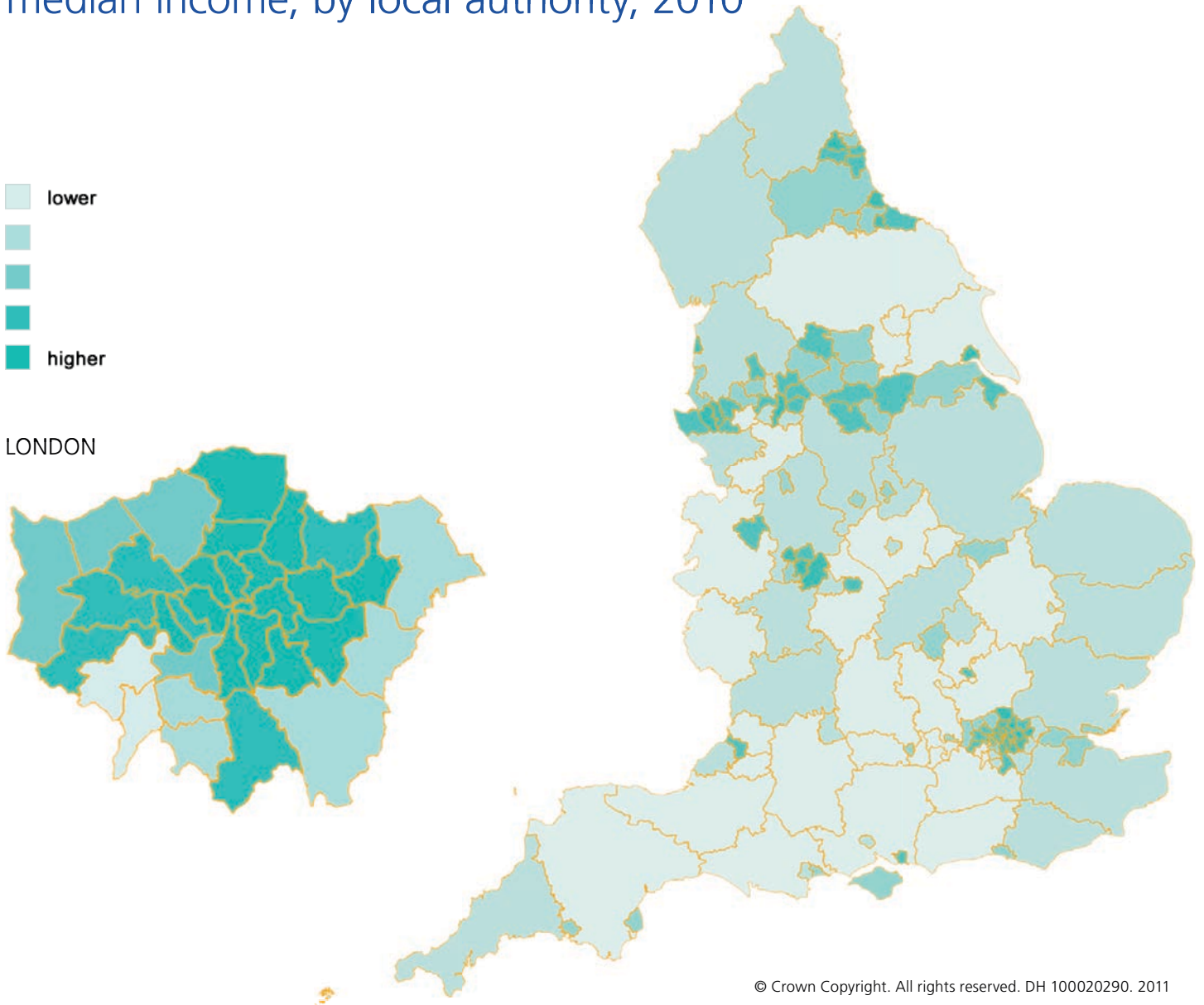
Section 1:

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# Determinants of child health

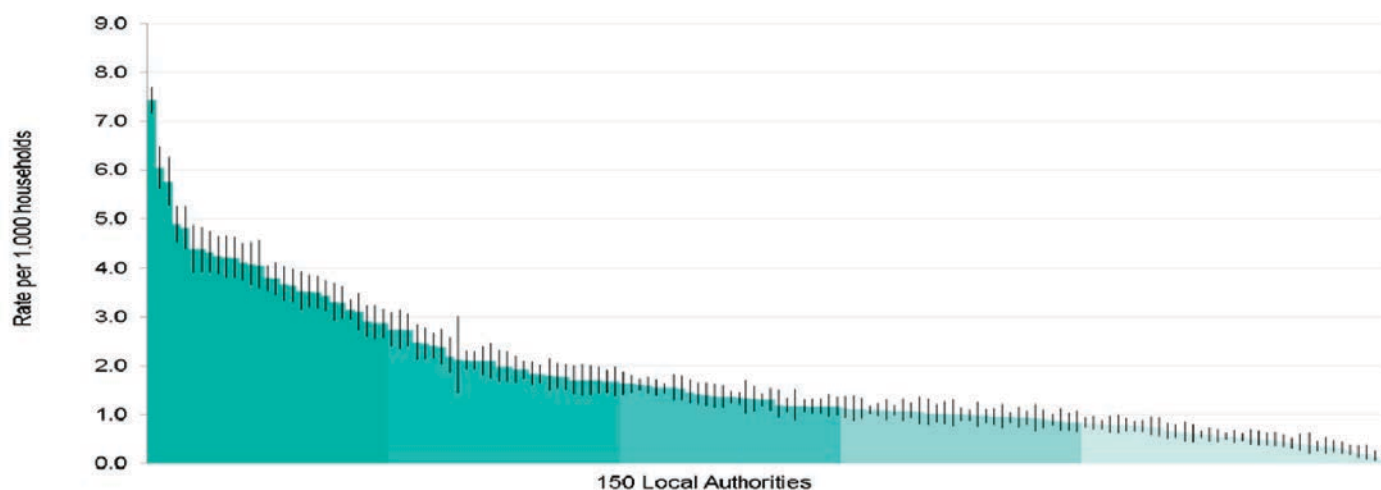
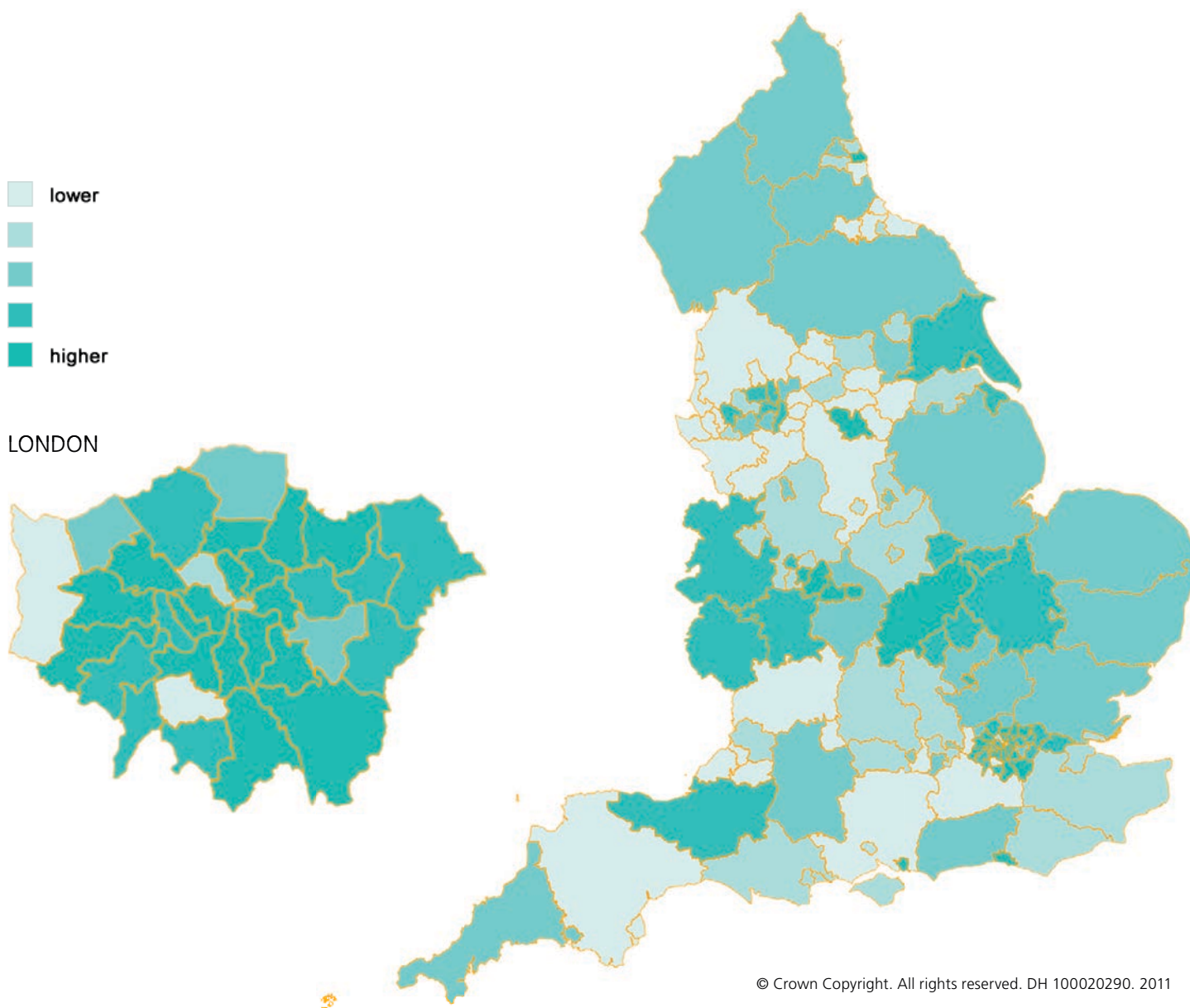
A: Poverty and homelessness

**Map 1** Child poverty: Percentage of children aged under 16 years living in families in receipt of out-of-work benefits or tax credits where their reported income is less than 60% of the median income, by local authority, 2010





**Map 2** Family homelessness: Rate of households accepted as unintentionally homeless and eligible for assistance per 1,000 households, by local authority, 2011–2012



## Context

Social and material disadvantage is now well established as a predictor of poor health, social and educational outcomes in children.<sup>1</sup> Although there is debate over the definitions of how to measure poverty, whether relative or absolute inequality is more important, and the impact of other mitigating factors on future development, there is little argument that the effect of this disadvantage has a lasting impact on the life course.

An inadequate living environment has lasting effects on a child's health, and is a risk factor for the development of poor health in future. Homelessness is only the extreme end of the spectrum of poor living conditions – many children and families are living in poor-quality, overcrowded housing, or in food or fuel poverty.<sup>2,3</sup>

The Child Poverty Act 2010 made law the Government's aspiration to reduce child poverty in the UK to below 1 in 10 of all children by 2020.<sup>4</sup> 'Children in poverty' is included as an outcome measure in the Public Health Outcomes Framework 2013–16. The Children and Young People's Health Outcomes Forum report 2012 recommended 'Number of children and young people living in decent housing' for inclusion as a national outcome measure.

## Magnitude of variation

### Map 1: Child poverty

For local authorities in England, the percentage of children aged under 16 years living in families in receipt of out-of-work benefits or tax credits, where their reported income is less than 60% of the median income, ranges from 7.4% to 45.9% (i.e. a six-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 10.8% to 35.3%, and the variation is over three-fold.

### Map 2: Family homelessness

For local authorities in England, the rate of households accepted as unintentionally homeless and eligible for assistance, per 1,000 households, ranges from 0.1 to 7.4 (a 74-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 0.3 to 4.4, and the variation is nearly 15-fold.

Child poverty is, unsurprisingly, correlated with living in a deprived neighbourhood. What is more surprising is that rates of family homelessness are only weakly associated with living in a deprived area (see Figure 1A.1), which suggests that there are alternative reasons for unwarranted variation.

## Options for action

Although the causes of poverty and homelessness are complex and multifactorial, their effects on the future health and wellbeing of affected children may be mitigated by targeted early interventions on:

- perinatal factors (such as antenatal health and nutrition, and healthy behaviours)
- support for at-risk parents and families, such as Family Nurse Partnerships
- community services to support early years education and child development, including health visitors and Sure Start programmes.

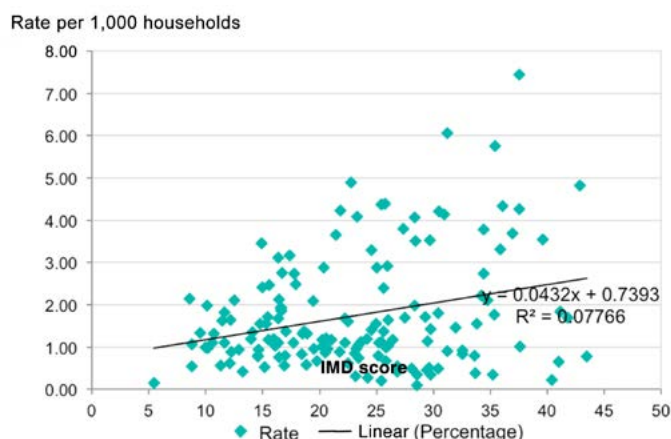
Commissioners can reduce variation by ensuring that these evidence-based, targeted interventions are appropriately resourced.

Measures of poverty and homelessness are not the only indicators to assess the impact of material and social disadvantage. Commissioners and local authorities can better identify at-risk populations by also evaluating other indicators of disadvantage for their population.

Housing stock and quality have tangible public health consequences. Health and Wellbeing Boards may wish to consider prioritising this issue.

1 Marmot M et al. (2010). Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England Post-2010. Marmot Review; London.  
 2 BMA Board of Science (2013). Growing up in the UK: Ensuring a healthy future for our children. BMA; London.  
 3 National Children's Bureau (2013). Greater Expectations: Raising aspirations for our children. Available from: [www.ncb.org.uk/12976](http://www.ncb.org.uk/12976).  
 4 Department for Education (2010). Child Poverty Act. Available from: [www.education.gov.uk/childrenandyoungpeople/families/childpoverty/a0066302/the-child-poverty-act](http://www.education.gov.uk/childrenandyoungpeople/families/childpoverty/a0066302/the-child-poverty-act).

**Figure 1A.1 Correlation between deprivation and rate of family homelessness, by local authority, 2011–2012 (High IMD score indicates more deprived area)**



## Resources

For more on the Government's strategy and accountability for tackling child poverty, see:

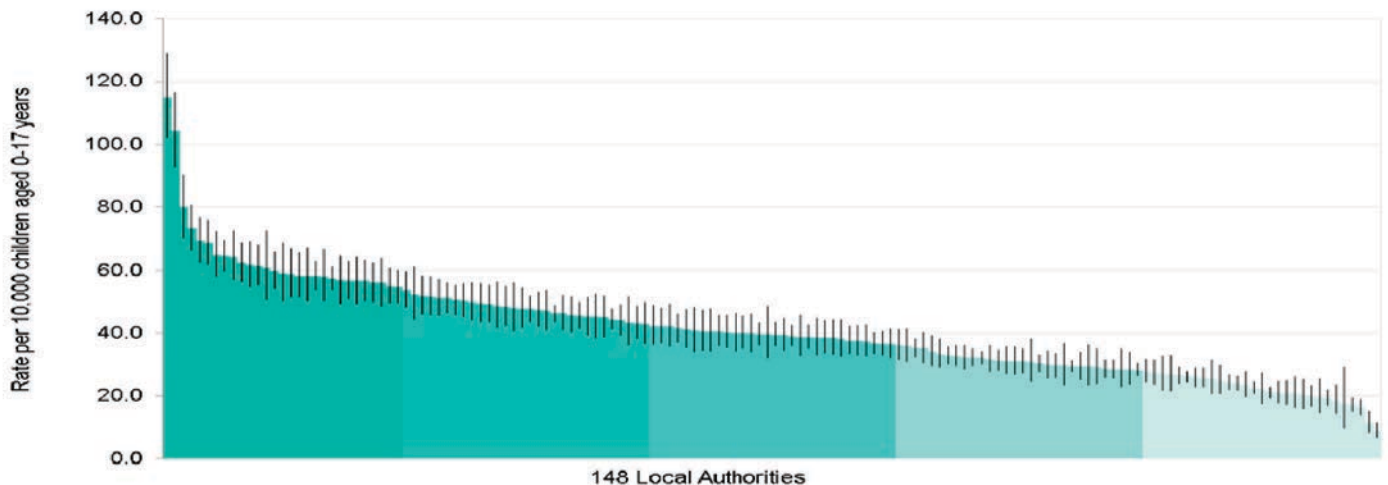
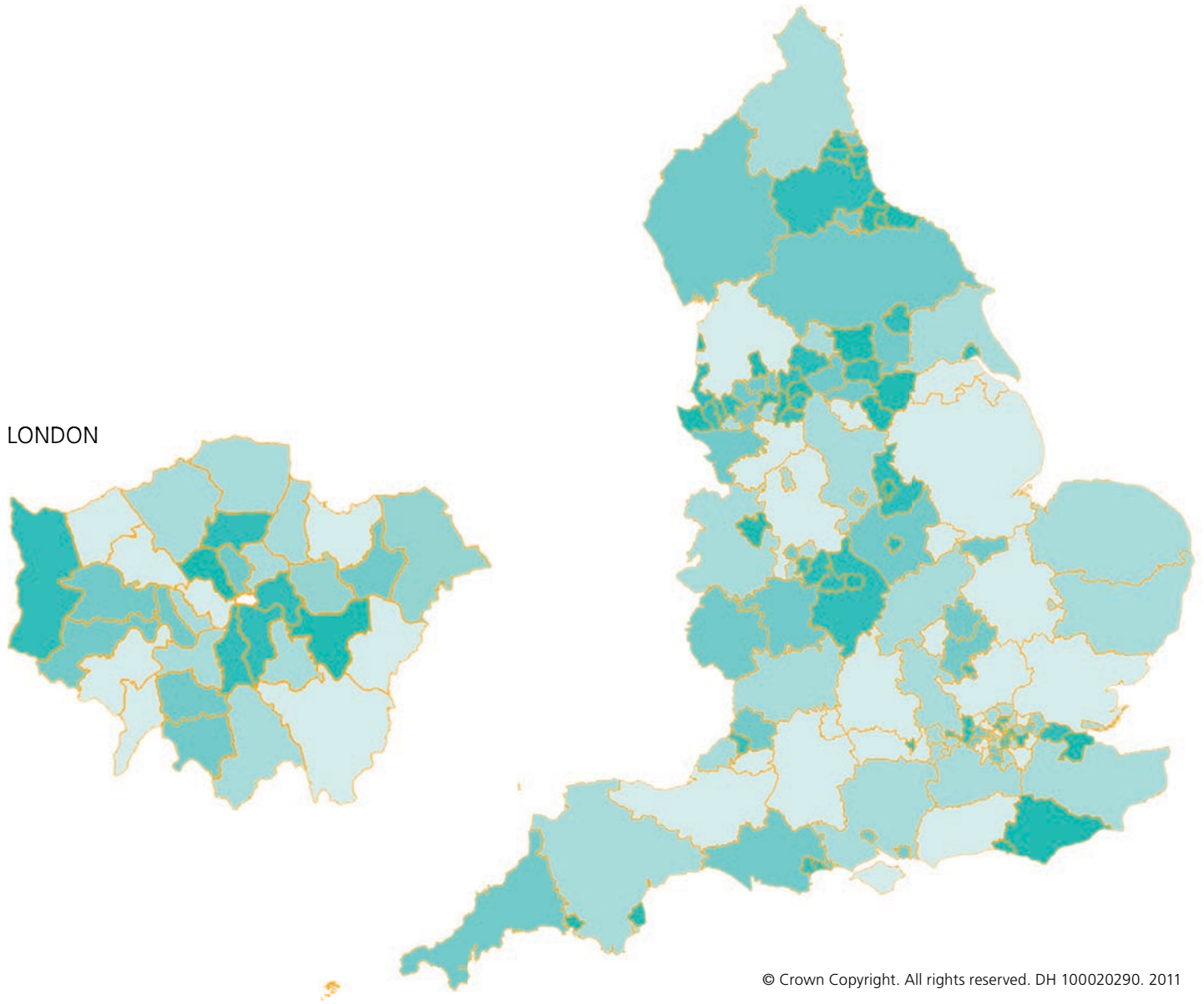
- Child Poverty Act (2010)  
([www.education.gov.uk/childrenandyoungpeople/families/childpoverty/a0066302/the-child-poverty-act](http://www.education.gov.uk/childrenandyoungpeople/families/childpoverty/a0066302/the-child-poverty-act))
- A New Approach to Child Poverty: Tackling the Causes of Disadvantage and Transforming Families' Lives  
([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/177031/CM-8061.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/177031/CM-8061.pdf))

Also see:

- UNICEF report card 10: Child poverty across industrialised nations:  
Adamson P (2012). Measuring child poverty: New league tables of child poverty in the world's rich countries  
([www.unicef-irc.org/publications/660](http://www.unicef-irc.org/publications/660))
- End Child Poverty's 'Child Poverty Map of the UK 2013'  
([www.endchildpoverty.org.uk/images/ecp/130212%20ECP%20local%20report%20final\(2\).pdf](http://www.endchildpoverty.org.uk/images/ecp/130212%20ECP%20local%20report%20final(2).pdf))
- National Children's Bureau (2013). Greater Expectations  
([www.ncb.org.uk/12976](http://www.ncb.org.uk/12976)).

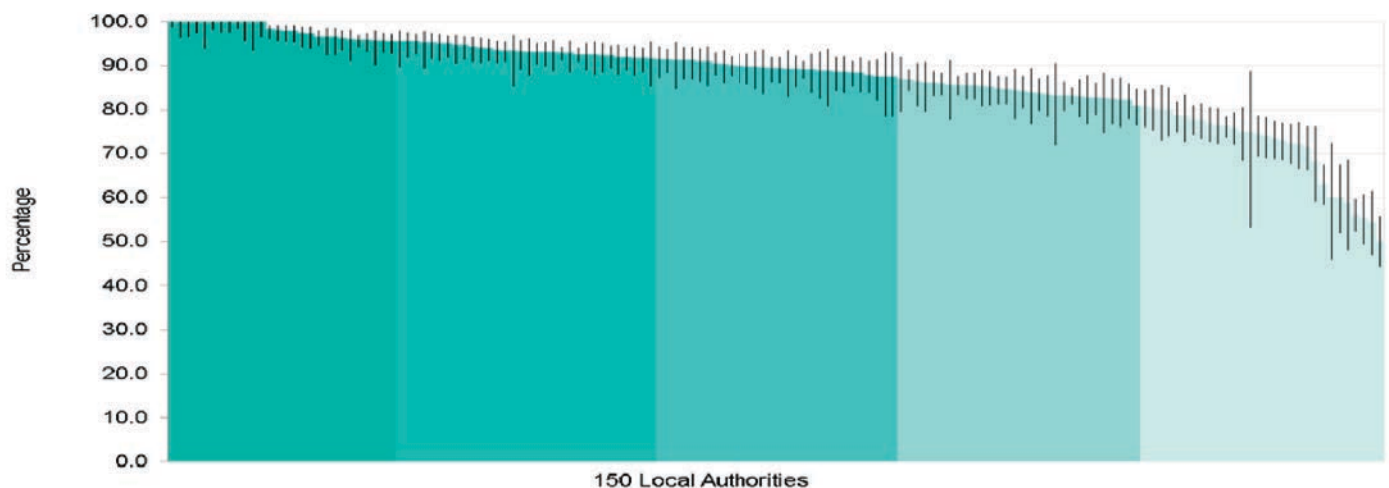
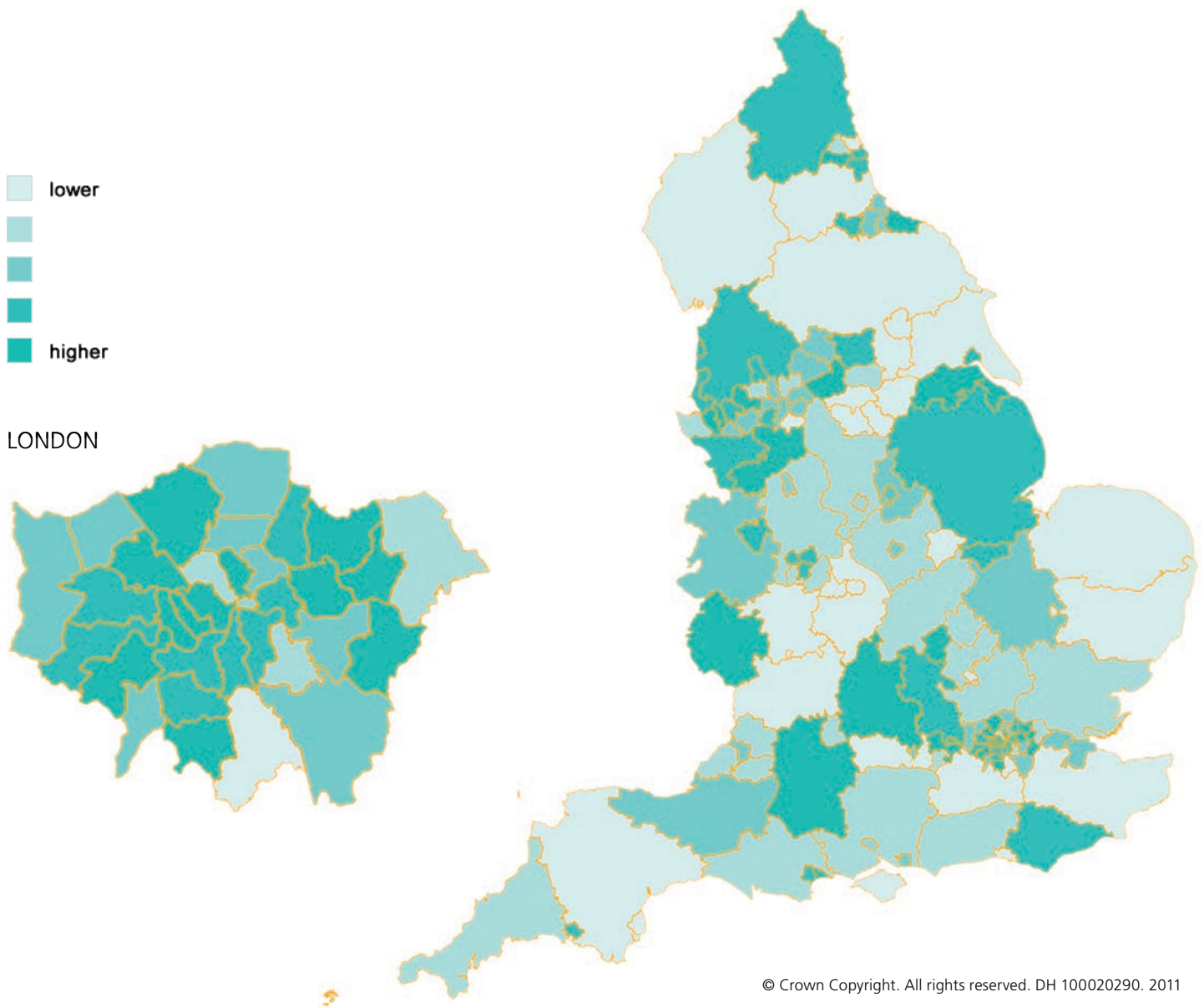
B: Vulnerable children

**Map 3** Children in the child protection system: Rate of children aged 0–17 years who were the subject of a child protection plan, per 10,000 children aged 0–17 years, by local authority, at 31 March 2012



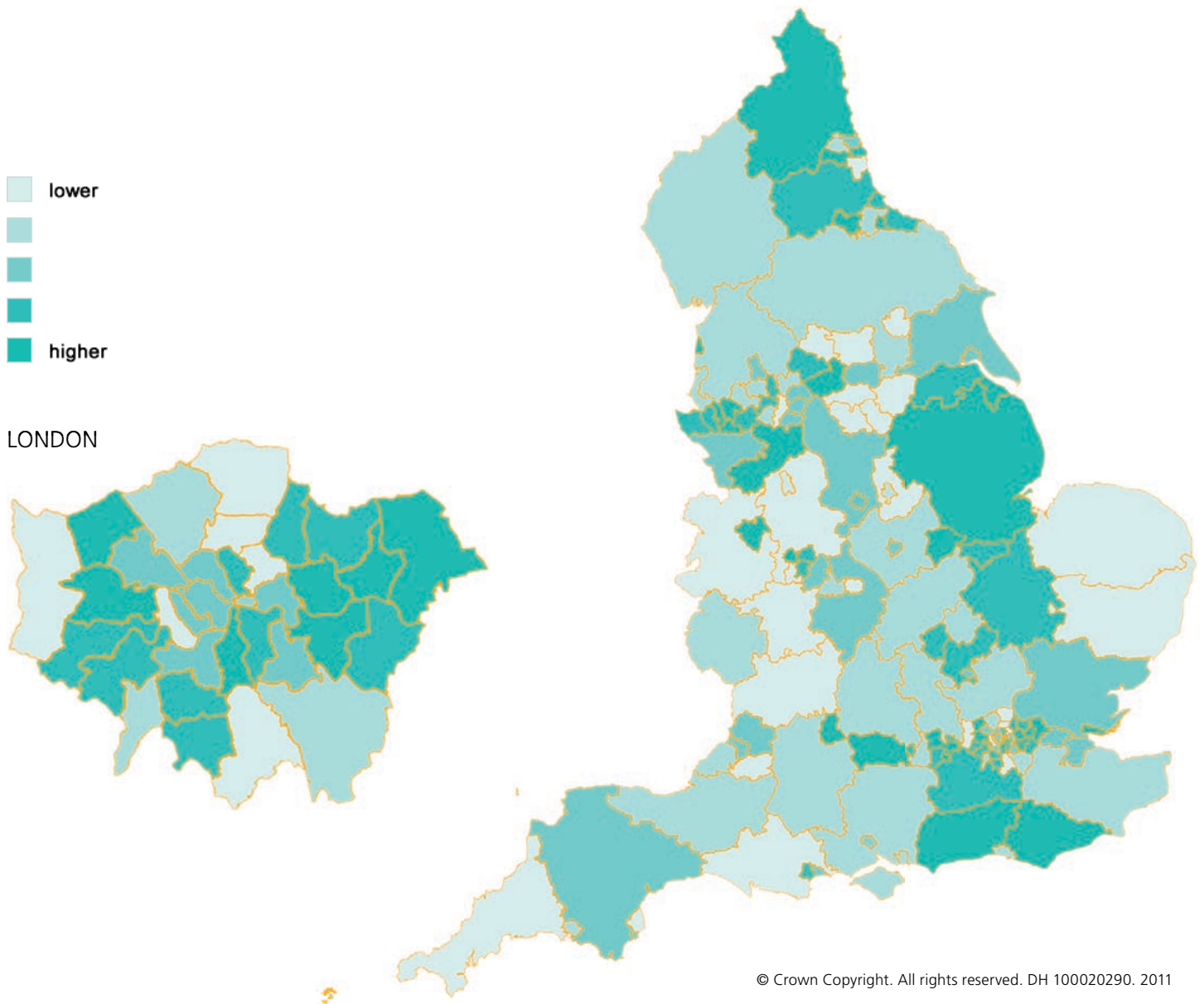


**Map 4** Healthcare (medical) for looked-after children: Percentage of looked-after children (in care for at least 12 months) who had their annual health assessment, by local authority, 2011–2012

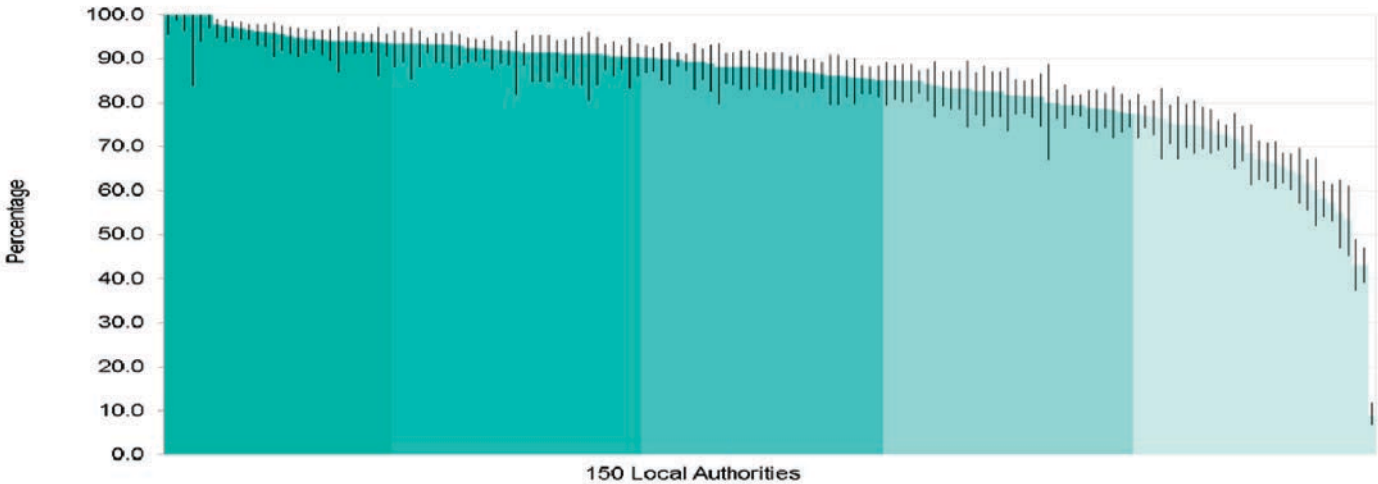




**Map 5** Healthcare (dental) for looked-after children: Percentage of looked-after children (in care for at least 12 months) who had their teeth checked by a dentist, by local authority, 2011–2012



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## Context

Child maltreatment has a prevalence of between 1 in 10 and 1 in 25 children.<sup>1</sup> The self-reported figures for maltreatment are higher, with reported rates of maltreatment of 5.9% in children aged under 11 years, 18.6% of 11–17 year olds, and 25.3% of 18–24 year olds.<sup>2</sup>

In England, children who are identified as being at serious risk of maltreatment are placed under a child protection plan. The number of children who are placed under a child protection plan is a crude indicator for child maltreatment – it reports only those children who are deemed to require intervention, without information on the thresholds for intervention. Increasing rates of children placed under a child protection plan may represent higher prevalence of maltreatment, more cases being identified or changes in the threshold for intervention.

The overall rates for child maltreatment do not appear to have changed significantly over the past 30 years.<sup>3</sup> However, the number of children (both absolute and as a proportion of all children) being placed under a child protection plan in England has increased by 63% over the past decade.<sup>4</sup>

‘Looked-after children’ refers to children who are placed in the care of the state, away from their parents or family and under the supervision of a social worker. On 31 March 2012, more than 1 in 200 children in England were in care, with over half being due to maltreatment (including neglect). Other reasons include physical disability, parental absence or incapacity. While many children benefit from the secure environment provided by being placed in care, looked-after children tend to display poorer health, educational and social outcomes.<sup>5</sup>

There is a statutory requirement for looked-after children to undergo a health assessment and dental review on entry to care and at least annually thereafter. These assessments are designed to identify otherwise unrecognised health needs, and should lead to a health plan which forms part of the overall care plan. Although evidence for these assessments as a health screening tool is limited, they demonstrate benefits for health promotion and ensure inter-agency communication between health and social care.<sup>6</sup>

The two indicators involving looked-after children exclude

children who have been in care for less than 12 months – while statutory data are collected for all children in care, the data are only reported for children who have been in care for more than a year.

## Magnitude of variation

### Map 3: Children in the child protection system

For local authorities in England, the rate of children aged 0–17 years who were the subject of a child protection plan, per 10,000 children aged 0–17 years, ranges from 8.9 to 114.9 (just under a 13-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 18.5 to 68.6, and the variation is 3.7-fold.

### Map 4: Healthcare (medical) for looked-after children

For local authorities in England, the percentage of looked-after children (in care for at least 12 months) who had their annual health assessment ranges from 50% to 100% (a two-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 60% to 100%, and the variation is 1.7-fold.

### Map 5: Healthcare (dental) for looked-after children

For local authorities in England, the percentage of looked-after children (in care for at least 12 months) who had their teeth checked by a dentist ranges from 9% to 100% (an 11-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 57.3% to 100%, and the variation is 1.7-fold.

The rate of children placed under a child protection plan is positively associated with area deprivation. Although this correlates with the literature on inequalities in the distribution of child maltreatment, these data relate only to those children who come to the attention of social services and are deemed to require safeguarding measures.

Variation in the numbers of children placed under child protection plans may reflect capacity of services as much as the genuine extent of the maltreatment problem in the local population. This may be due to:

- variation in expertise in identifying, assessing and flagging child protection concerns to appropriate services
- capacity-driven variation in thresholds for placing children under a plan, and subsequently removing them from such a plan at the appropriate time.

For variation among local authorities in the provision of annual health and dental assessments for looked-after children, it is clear that any variation from 100% is inadequate. There is no association between the area deprivation scores and compliance with either of these statutory assessments.

1 Woodman J, Gilbert R. (2013). Child maltreatment: moving towards a public health approach. In BMA Board of Science. Growing up in the UK: Ensuring a healthy future for our children. BMA: London.

2 Radford L, Corral S, Bradley C et al. (2011). Child Abuse and neglect in the UK today. NSPCC. Available from: [www.nspcc.org.uk/inform/research/findings/child\\_abuse\\_neglect\\_research\\_PDF\\_wdf84181.pdf](http://www.nspcc.org.uk/inform/research/findings/child_abuse_neglect_research_PDF_wdf84181.pdf).

3 Gilbert R, Fluke J, O'Donnell M et al. (2012). Child maltreatment: variation in trends and policies in six developed countries. *Lancet* 379: 758–72.

4 Harker L et al. (2013). How safe are our children? NSPCC. Available from: [www.nspcc.org.uk/inform/research/findings/how-safe/how-safe-2013-report\\_wdf95435.pdf](http://www.nspcc.org.uk/inform/research/findings/how-safe/how-safe-2013-report_wdf95435.pdf).

5 Viner R, Taylor B. (2005). Adult health and social outcomes of children who have been in public care: population-based study. *Pediatrics* 115(4): 894–9.

6 Hill CM, Watkins J. (2003). Statutory health assessments for looked-after children: what do they achieve? *Child Care Health Dev.* 29(1): 3–13.

### Options for action

Where maltreatment is identified, children are not necessarily assessed to be at high enough risk to reach the threshold for a child protection plan.<sup>1</sup> Simply measuring the rate of investigation, recognition and monitoring of maltreatment may significantly underestimate the true prevalence of maltreatment. Commissioners and local authorities can investigate a range of indicators when assessing the adequacy of their child safeguarding processes and outcomes, including measuring the rate and impact of interventions to tackle maltreatment.

Commissioners and local authorities may want to note there is evidence to support a population-based, preventive approach to child maltreatment, involving investment in community-based, family-oriented services to support parenting.<sup>2</sup>

It is plausible that resourcing levels in health and social care services may account for some of the variation in these indicators. Commissioners and Health and Wellbeing Boards can use these data as a starting point to consider whether their services are appropriately resourced to address the scale of the local problem.

Local child safeguarding processes could be improved by:

- sharing information on performance
- collaborating in order to standardise the assessment process where possible.

The new Child Protection Information Sharing project (see 'Resources' later in this section) should improve information sharing from local authorities to urgent and emergency healthcare settings for looked-after children and those children placed under a child protection plan.

There is variation in access to the minimum standard of healthcare for looked-after children (statutory health assessment). It requires co-ordinated effort from a range of local professionals (NHS England, CCGs, local authorities and social care) to ensure that:

- routine healthcare assessments are arranged, and that they are carried out
- services are commissioned to adequately deliver assessments and other healthcare needs which arise
- access to healthcare, both routine and as needed, is regularly assessed and reported, and the appropriate service is held accountable for failures in access or provision.

### Resources

World Health Organization Regional Office for Europe (2013) European report on preventing child maltreatment ([www.who.int/violence\\_injury\\_prevention/publications/child\\_injuries/en/index.html](http://www.who.int/violence_injury_prevention/publications/child_injuries/en/index.html)).

The National Institute for Health and Care Excellence has produced the following relevant documents:

- Clinical guidance, When to suspect child maltreatment (2009) ([www.nice.org.uk/cg89](http://www.nice.org.uk/cg89)) – with further guidance expected to be produced by 2016.
- Quality standards for the health and wellbeing of looked-after children and young people (2013) (<http://guidance.nice.org.uk/QS31>).
- Public health guidance, Promoting the quality of life of looked-after children and young people ([www.nice.org.uk/ph28](http://www.nice.org.uk/ph28)).

Department for Children, School and Families and Department of Health (2009). Statutory Guidance on Promoting the Health and Wellbeing of Looked-after Children (<http://media.education.gov.uk/assets/files/pdf/s/promotinghealth.pdf>).

Department for Education (2013). Working Together to Safeguard Children – A guide to inter-agency working to safeguard and promote the welfare of children (<http://media.education.gov.uk/assets/files/pdf/w/working%20together.pdf>).

Department for Education (2012). The Children's Safeguarding Performance Information Framework ([www.education.gov.uk/childrenandyoungpeople/safeguardingchildren/protection/b00209694/perf-info](http://www.education.gov.uk/childrenandyoungpeople/safeguardingchildren/protection/b00209694/perf-info)).

Child Protection Information Sharing project (CP-IS) ([www.gov.uk/government/news/child-protection-information-sharing-project](http://www.gov.uk/government/news/child-protection-information-sharing-project)).

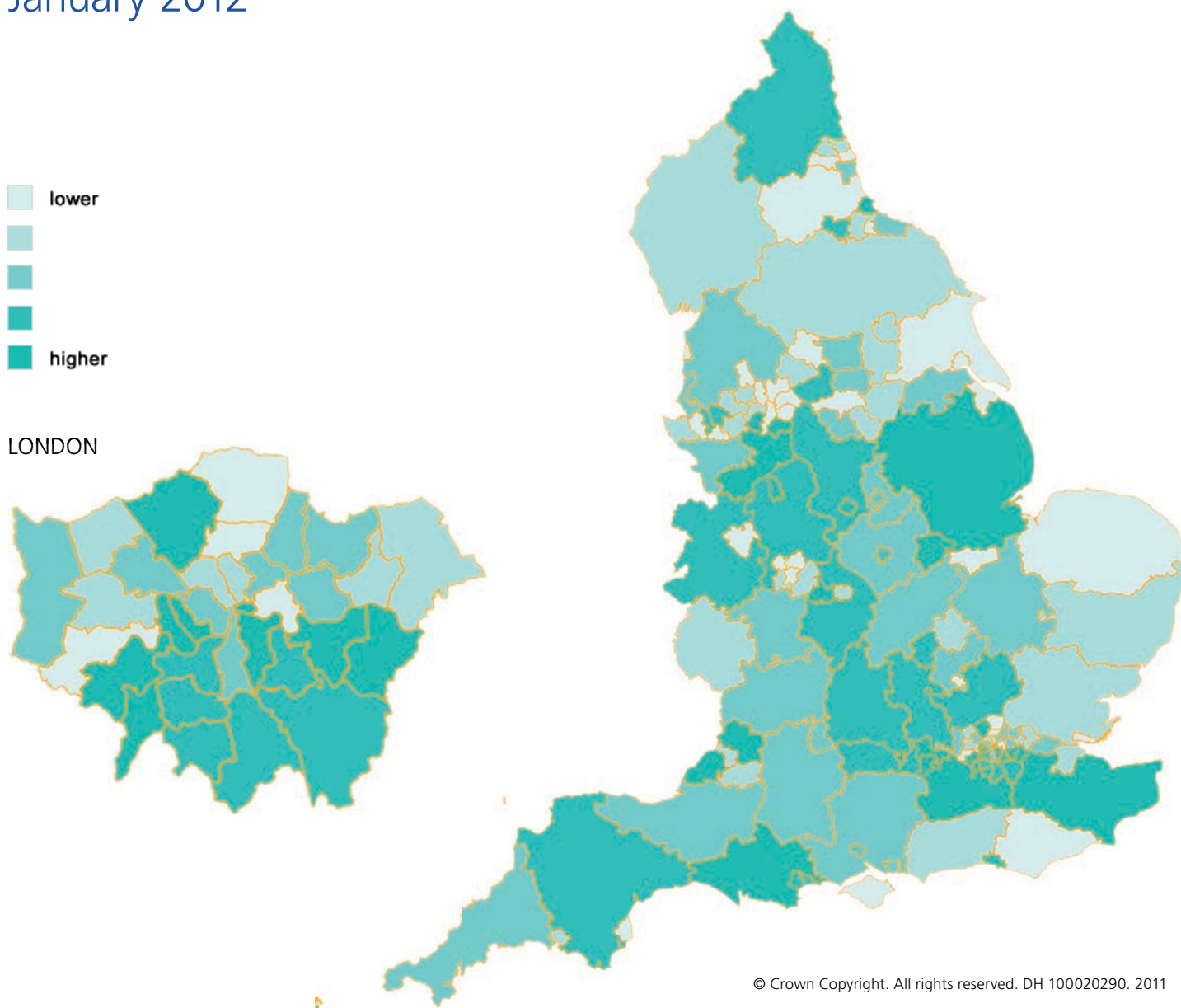
Harker L et al. (2013). How safe are our children? NSPCC ([www.nspcc.org.uk/Inform/research/findings/how-safe/how-safe-2013-report\\_wdf95435.pdf](http://www.nspcc.org.uk/Inform/research/findings/how-safe/how-safe-2013-report_wdf95435.pdf)).

1 Gilbert R, Kemp A, Thoburn J et al. (2009). Recognising and responding to child maltreatment. *Lancet* 373; 167-80.

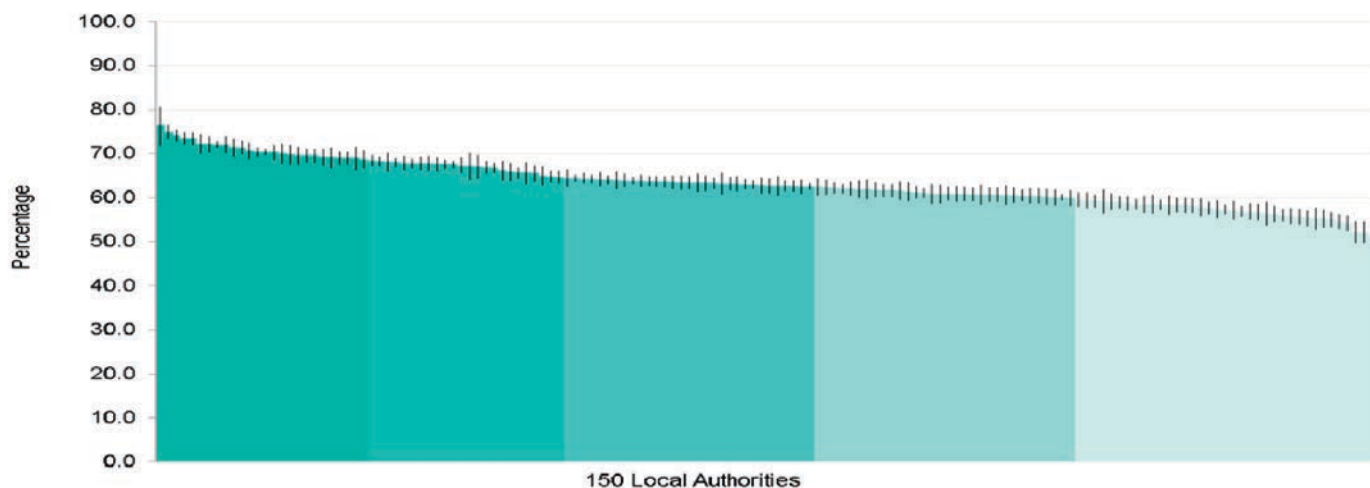
2 Woodman J, Gilbert R. (2013). Child maltreatment: moving towards a public health approach. In BMA Board of Science. Growing up in the UK: Ensuring a healthy future for our children. BMA, London.

C: Education

**Map 6** School readiness: Percentage of children at the end of foundation stage (at age 5) who are assessed as having achieved a 'good level of development', by local authority, at January 2012

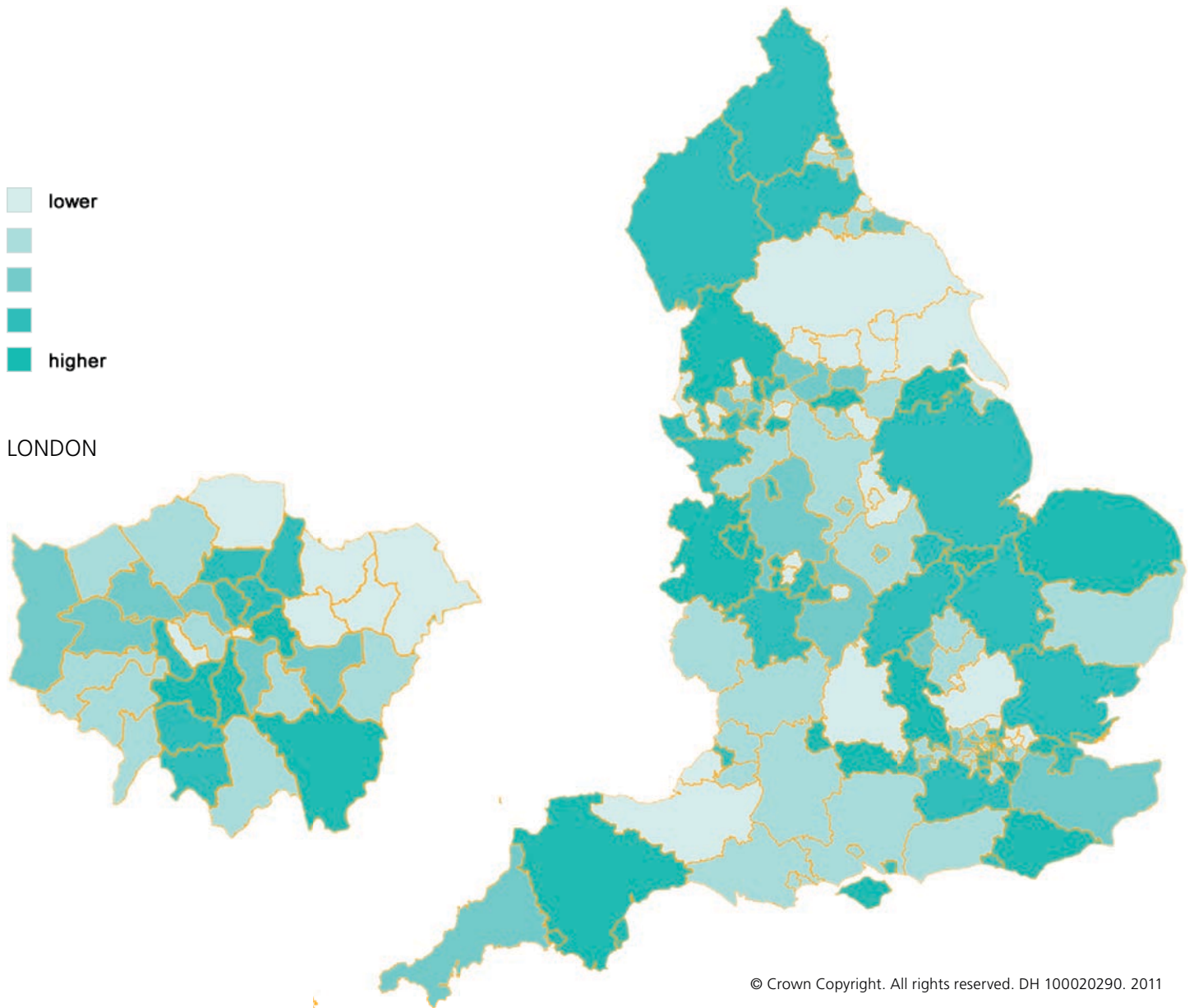


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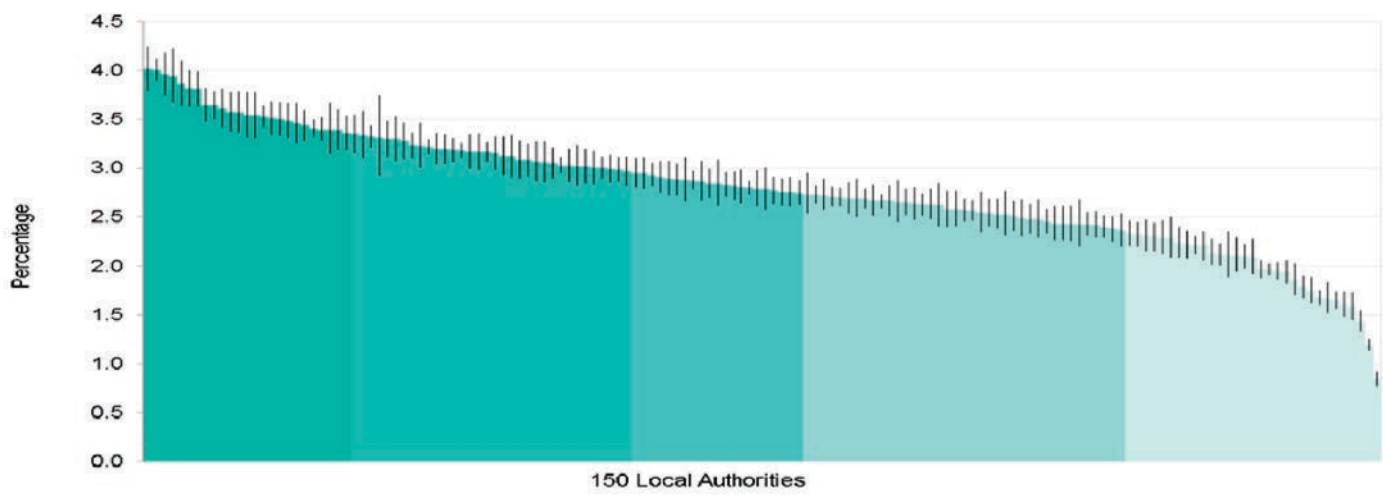




**Map 7** Special educational needs (SEN): Percentage of children in state-funded schools with a statement of SEN, by local authority, at January 2012



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## Context

The preschool period of the life course is strongly correlated with long-term health outcomes and educational attainment.

'School readiness' – i.e. having achieved appropriate development in the early years in social, emotional, communication, language and literacy domains – is a key predictor of educational attainment. At a population level, low rates of school readiness may be due to factors such as deprivation or prevalence of child disability. However, it may also reflect variation in early detection of developmental problems.

Children with SEN have a learning difficulty that requires special educational provision. A learning difficulty means that the child has:

- significantly greater difficulty learning compared with the majority of children in the same age-group
- a disability preventing or hindering them from using general educational facilities provided in the local authority for children of the same age-group.

There are currently four levels of special educational provision: usual support, School Action, School Action Plus, and a statement of SEN. Children with a statement of SEN are either not making progress under School Action or School Action Plus or they require considerable additional support due to severe and complex needs. The local authority reviews the statement at least once a year. All children in special schools have a statement of SEN.

The Children and Families Bill<sup>1</sup> will replace statements of SEN with an Education, Health and Care Plan, which is designed to allow better integration of services for children, to extend age of coverage to 25 years of age and to allow families to take control of their child's personal budget if they so wish.

'School readiness' is included as a placeholder in the Public Health Outcomes Framework 2013–16.

For Map 7, a similar indicator relating only to primary schools – 'Percentage of primary school children in state-funded schools with a statement of SEN' – was included in the Atlas of Variation in Healthcare for Children and Young People (2012).

## Magnitude of variation

### Map 6: School readiness

For local authorities in England, the percentage of children at the end of foundation stage (at age 5) who are assessed as having achieved a 'good level of development' ranges from 51.5% to 76.5% (1.5-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 55% to 72.2%, and the variation is 1.3-fold.

### Map 7: SEN

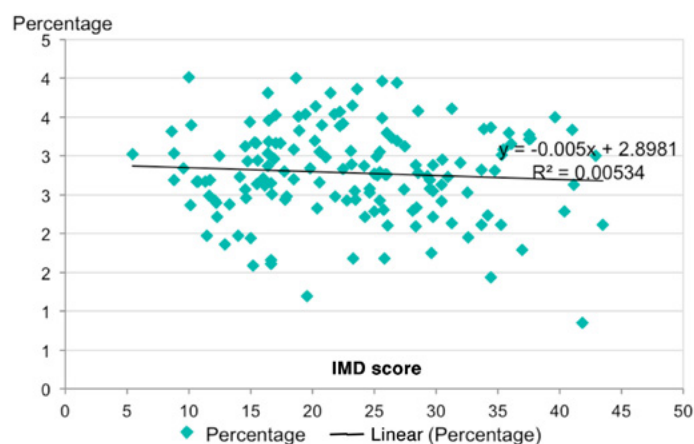
For local authorities in England, the percentage of children in state-funded schools with a statement of SEN ranges from 0.8% to 4.0% (five-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 1.7% to 3.8%, and the variation is over two-fold.

Possible reasons for variation are differences in:

- prevalence of complex medical conditions, although it is unlikely to account for the degree observed
- deprivation levels in different areas
- resource allocation for child health, including health visiting, school health and community child health services
- criteria used to decide whether existing resources in each school are sufficient to support children with SEN, without the need for statements.

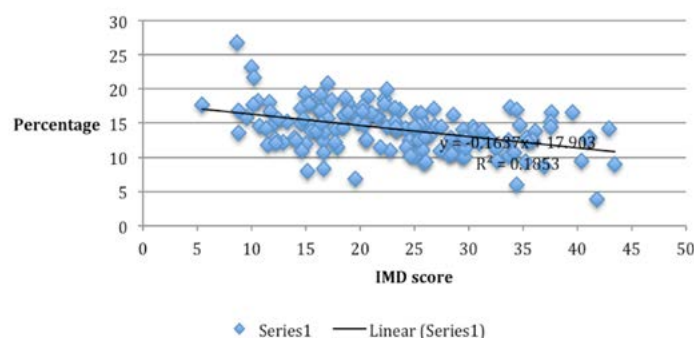
While school readiness is strongly correlated with deprivation, the relationship between SEN and deprivation is more complex. Our data show no association between an area's level of deprivation and the proportion of schoolchildren who have a statement of SEN (see Figure 1C.1). However, there is a negative association between an area's level of deprivation

**Figure 1C.1 Correlation between deprivation and percentage of all school pupils with a statement of SEN, by local authority, 2012 (High IMD score indicates more deprived area)**



**Figure 1C.2 Correlation between deprivation and percentage of pupils identified as having SEN who have a statement of SEN, by local authority, 2011–2012 (High IMD score indicates more deprived area)**

### Percentage of children identified as needing SEN who have an SEN statement



1 <http://services.parliament.uk/bills/2012-13/childrenandfamilies.html>

## Section 1: Determinants of child health

and the proportion of children with identified SEN who have received a formal statement of SEN (see Figure 1C.2). This suggests inequity in the provision of educational support in England: children with SEN living in more deprived areas are less likely to receive a statement than their peers in less deprived areas, though the reasons for this difference are unclear.

### Options for action

The data show inequality in both level of intervention (in statements of SEN and the support that entails) and in outcomes (school readiness and prevalence of SEN in general). Early-years development is strongly correlated with long-term health outcomes. Local commissioners may want to note that The Annual Report of the Chief Medical Officer 2012 (Special Report – Our Children Deserve Better; Prevention Pays) discusses the importance of early investment in great detail in Chapter 3 ‘The economic case for a shift to prevention’.

Local authorities and commissioners can analyse child health service spending, availability of nursery places and availability of staff, such as speech therapists. By doing this, they can identify how to better support all levels of identified educational need in school, and improve efforts to meet the proposed measures of early development in the Tickell Report (see ‘Resources’ later in this section), and measures in the Early Years Foundation Stage Profile (statutory assessment requirement for children reaching the end of the Foundation Stage).

Commissioners and health and education professionals in agencies caring for children with additional needs can improve performance by:

- sharing information on performance
- collaborating to standardise the assessment process
- using evidence-based modelling of future workload to inform workforce planning
- redeploying resources to prevention/early intervention through better and earlier identification of at-risk children.

### Resources

Department for Education (2013). Children and Families Bill (<http://services.parliament.uk/bills/2012-13/childrenandfamilies.html>)

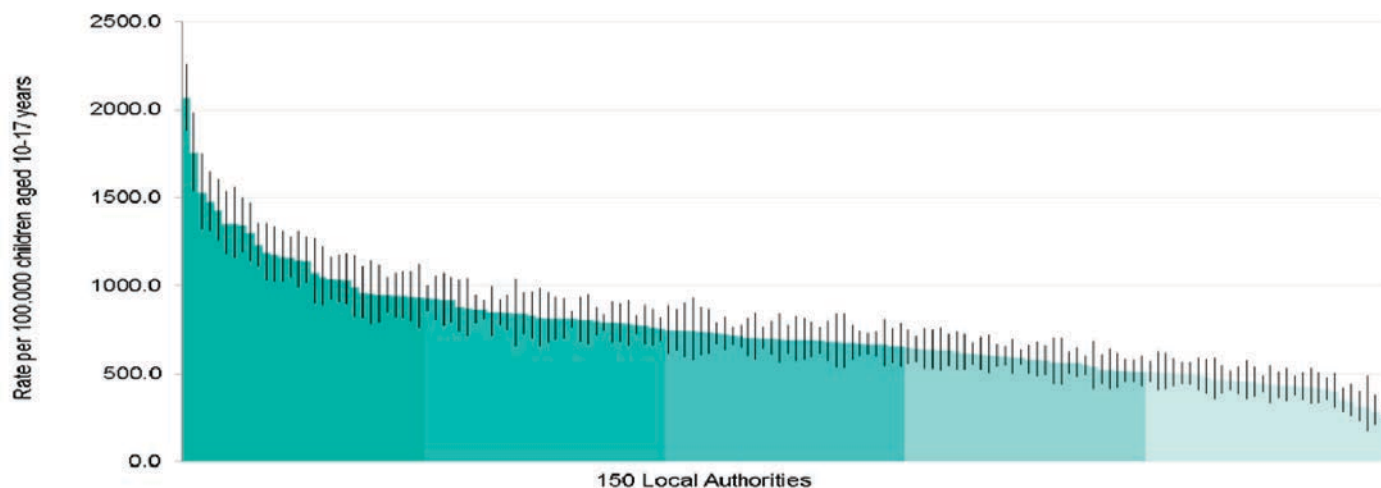
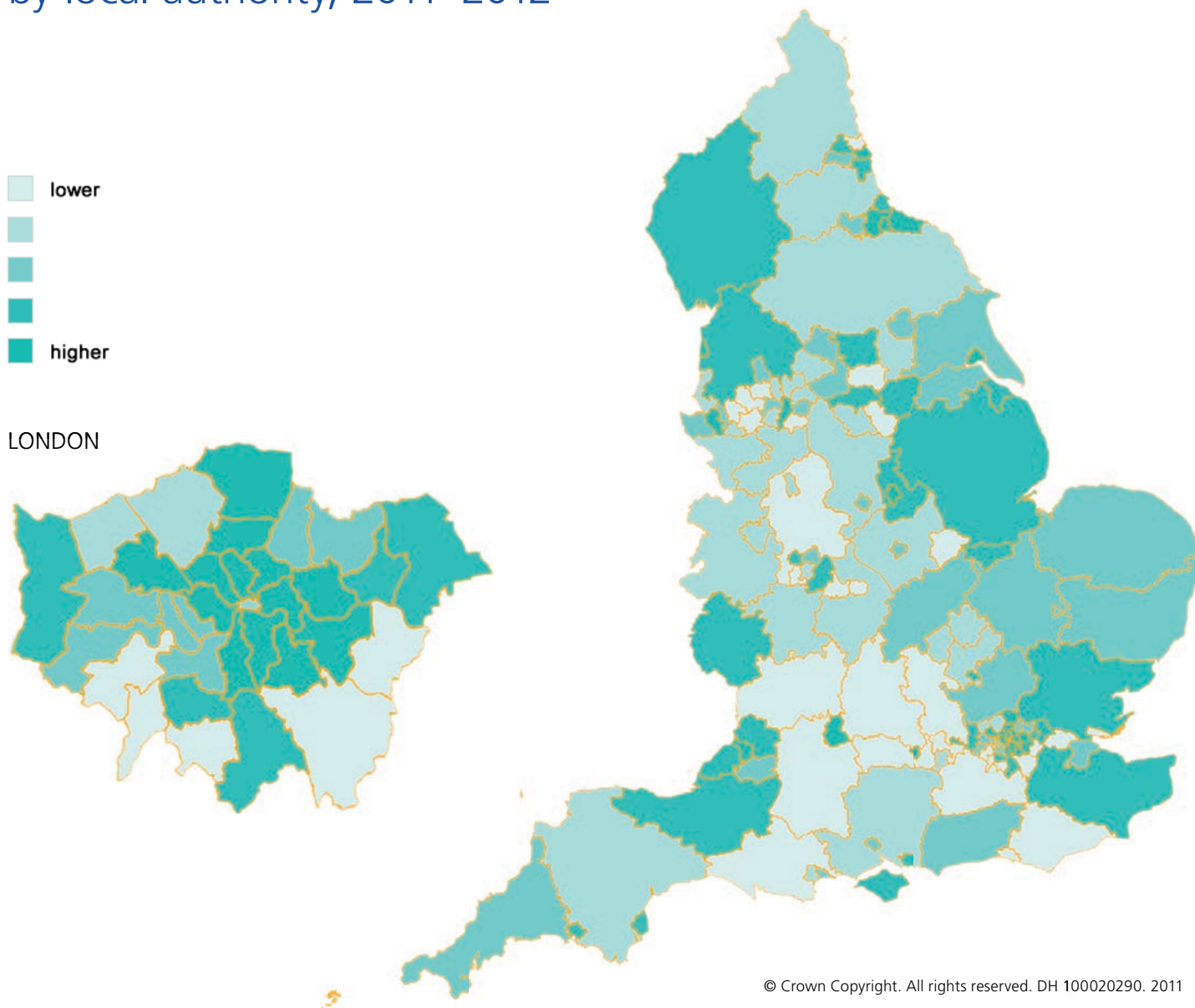
Tickell C (2011). The Early Years: Foundations for life, health and learning. An Independent Report on the Early Years Foundation Stage to Her Majesty’s Government (<http://media.education.gov.uk/MediaFiles/B/1/5/%7BB15EFF0D-A4DF-4294-93A1-1E1B88C13F68%7DTickell%20review.pdf>).

Early Years Foundation Stage Profile Data (<http://data.gov.uk/dataset/early-years-foundation-stage-profile-results-england-2010>).

Early Years Foundation Stage Profile – assessment scales reference sheet (<https://orderline.education.gov.uk/bookstore.asp?FO=1307426&Action=PDFDownload&ProductID=9781445907512>)

D: Crime and youth justice

**Map 8** Crime and youth justice: Rate of young people aged 10–17 years receiving their first reprimand, warning or conviction, per 100,000 population aged 10–17 years old, by local authority, 2011–2012



# Section 1: Determinants of child health

## Context

At a population level, contact with the youth justice system is strongly associated with multiple risk factors that start with the perinatal period and include early parental attachment, child development and social and behavioural risk factors in childhood and adolescence.

The number of first-time offences committed by 10–17 year olds is falling, as is the number of children and young people in custody. Fewer children and young people are reoffending, but the overall reoffending rate is rising, which suggests that there is a smaller group of children and young people who are becoming more entrenched in criminal and antisocial behaviour.<sup>1</sup>

This indicator is included in the Public Health Outcomes Framework 2013–16.

## Magnitude of variation

**Map 8:** For local authorities in England, the rate of young people aged 10–17 years receiving their first reprimand, warning or conviction, per 100,000 population aged 10–17 years old, ranges from 267 to 2,066 (nearly eight-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 349 to 1,352, and the variation is nearly four-fold.

The link between deprivation and rates of first offending is well recognised, and these data confirm this correlation.

## Options for action

Options for primary and secondary prevention could take a life-course approach in order to improve resilience and pro-social behaviours and interactions in early childhood.

Local authorities could target variation by ensuring that evidence-based, youth crime prevention strategies are resourced appropriately. Options include approaches which have been shown to be beneficial in the reduction of youth offending, such as school-based initiatives; family and multi-systemic therapy; youth work, including mentoring; and restorative justice programmes.<sup>2</sup>

## Resources

Public Health England has produced web resources to aid planning of health and wellbeing needs assessments related to children and young people in the youth justice system. The Child and Maternal Health Intelligence Network, Public Health England.

Ministry of Justice and Youth Justice Board. Developing the secure estate for children and young people in England and Wales – Plans until 2015 (<http://yjbpublications.justice.gov.uk/en-gb/scripts/prodView.asp?idproduct=502&eP=>).

Centre for Mental Health (2009). Chance of a lifetime: Preventing early conduct problems and reducing crime ([www.centreformentalhealth.org.uk/publications/chance\\_of\\_a\\_lifetime.aspx?ID=604](http://www.centreformentalhealth.org.uk/publications/chance_of_a_lifetime.aspx?ID=604)).

Young Minds and Prison Reform Trust (2013). Turning young lives around: How health and justice services can respond to children with mental health problems and learning disabilities who offend ([www.prisonreformtrust.org.uk/Portals/0/Documents/turningyounglivesaroundFINAL.pdf](http://www.prisonreformtrust.org.uk/Portals/0/Documents/turningyounglivesaroundFINAL.pdf)).

1 Youth Justice statistics 2011/12. Available from: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/218552/yjb-stats-2011-12.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/218552/yjb-stats-2011-12.pdf)

2 Stevens A, Kessler I, Gladstone B. (2006). Review of Good Practices in Preventing Juvenile Crime in the European Union. Available at: [www.eucpn.org/pubdocs/A%20review%20of%20good%20practice%20in%20preventing%20juvenile%20crime%20in%20the%20EU.pdf](http://www.eucpn.org/pubdocs/A%20review%20of%20good%20practice%20in%20preventing%20juvenile%20crime%20in%20the%20EU.pdf).

Section 2:

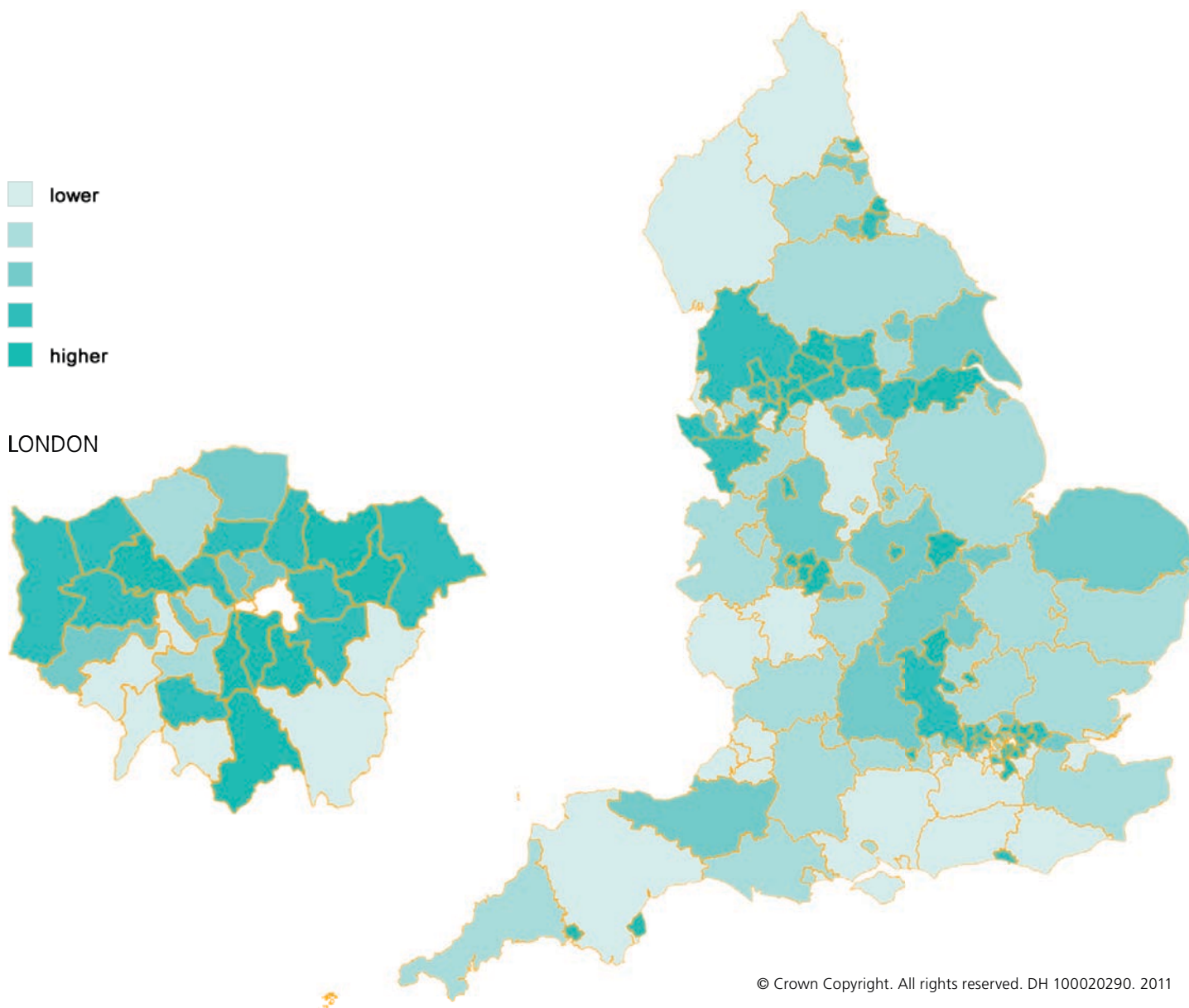
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# Child health promotion

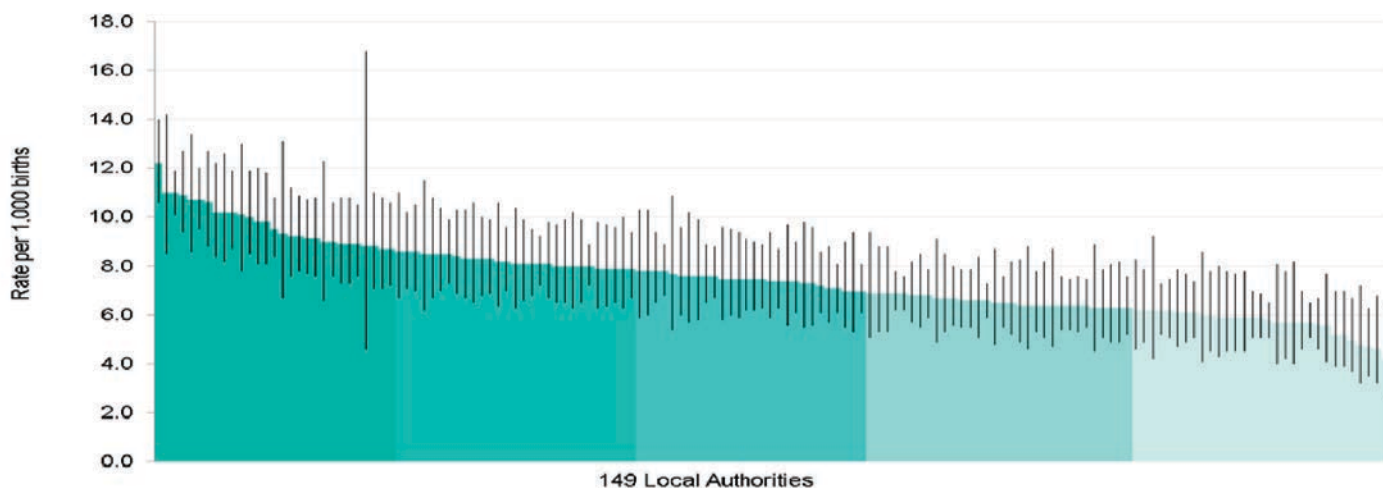


### A: Mortality

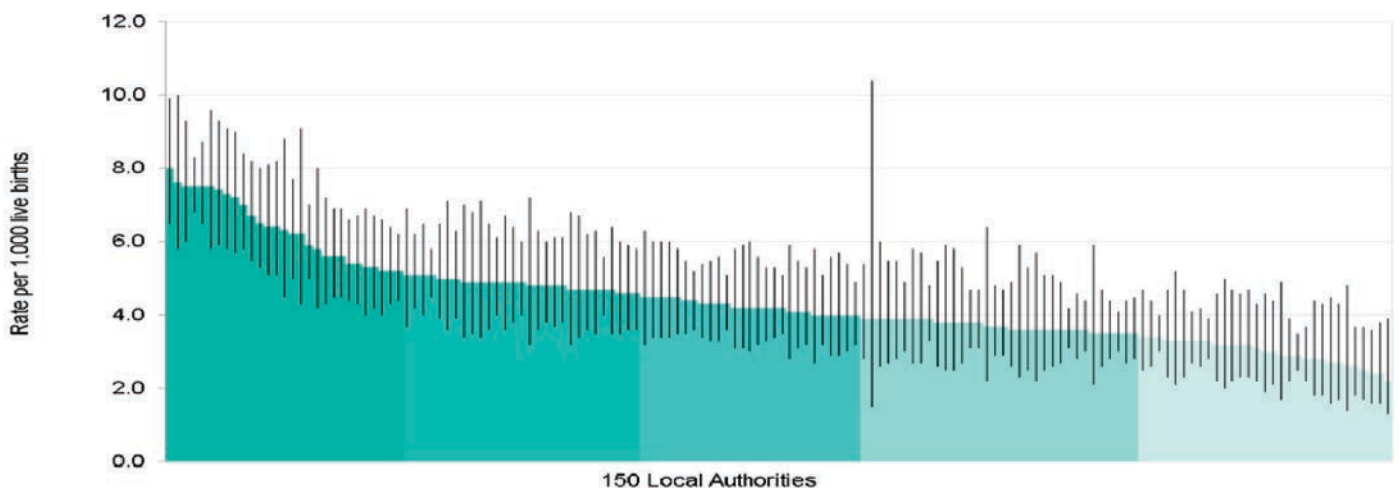
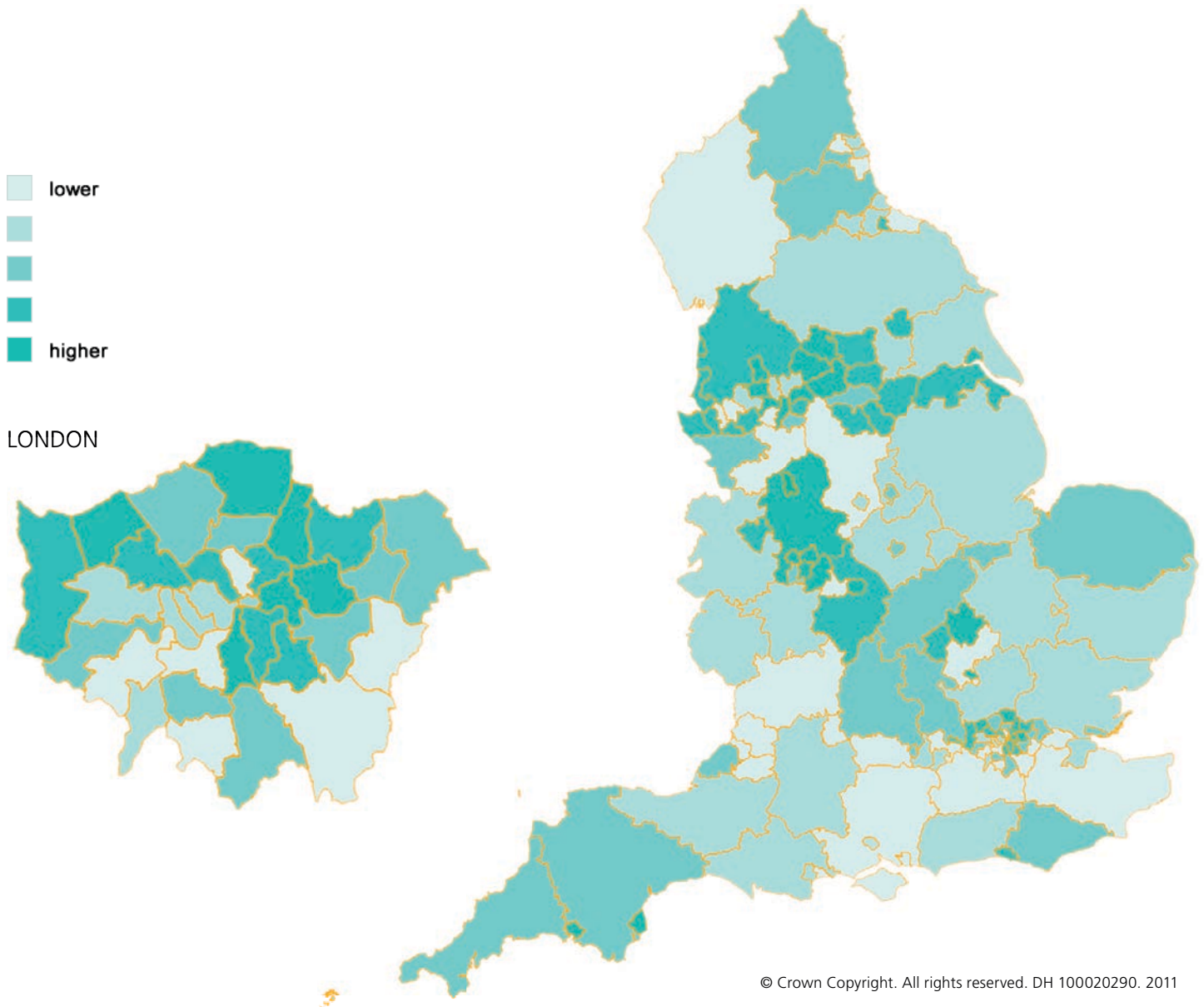
**Map 9** Perinatal mortality: Perinatal mortality rate per 1,000 births, by local authority, 2009–2011



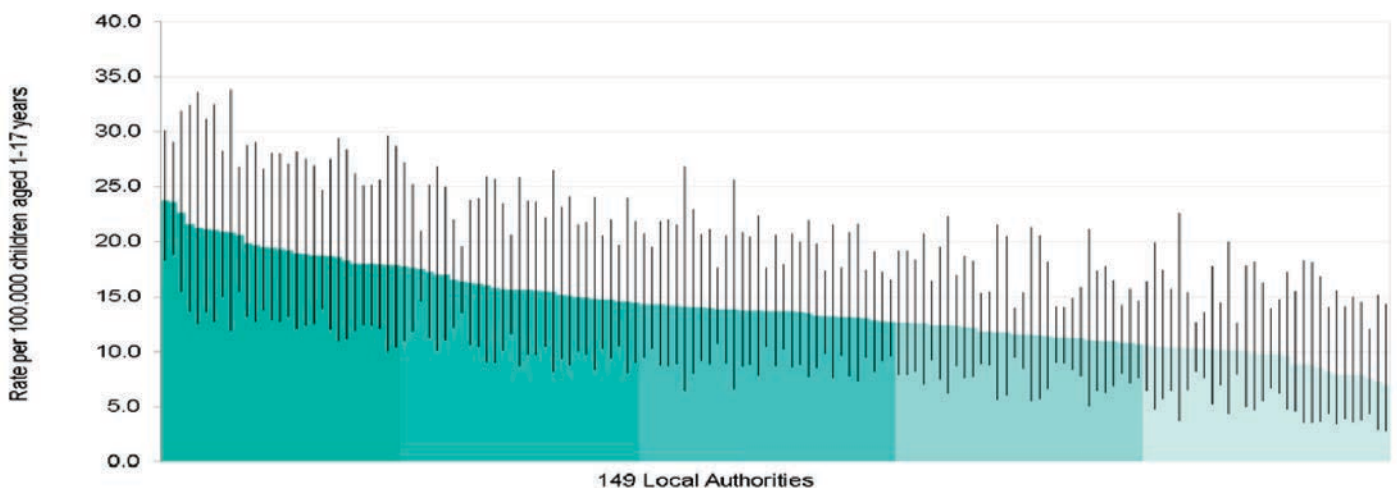
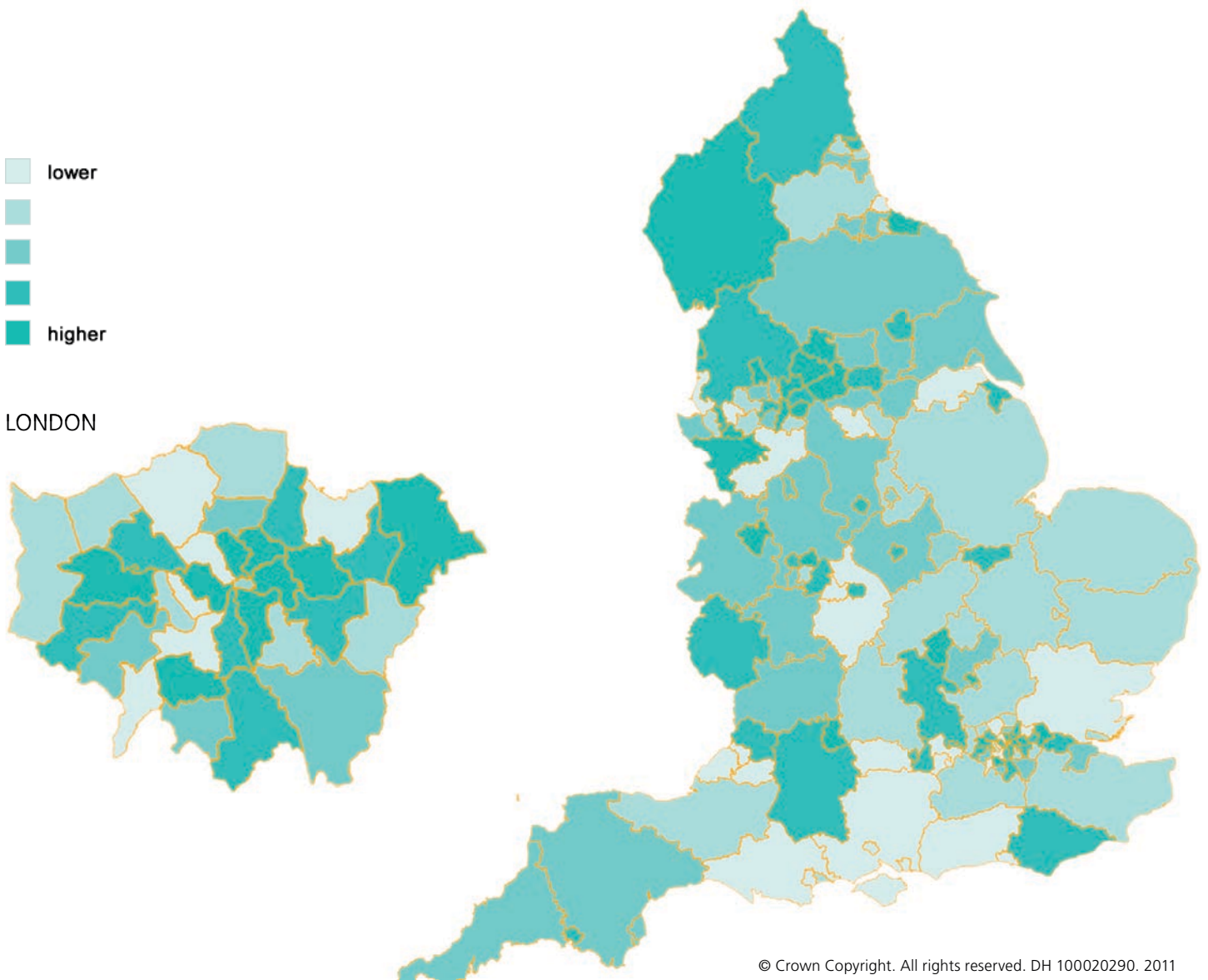
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**Map 10** Infant mortality: Infant mortality rate per 1,000 live births, by local authority, 2009–2011



**Map 11** Childhood mortality: Directly standardised mortality rate for children aged 1–17 years, per 100,000 children aged 1–17 years, by local authority, 2009–2011



## Context

Mortality is an important indicator of population health. However, it is a fairly crude measure, especially for children in developed countries such as England, where deaths are relatively rare. All three measures used here are known to correlate with levels of deprivation, with the association being particularly strong in perinatal and infant mortality.

Perinatal mortality comprises all stillbirths (babies born dead after 24 weeks' gestation) and early neonatal deaths (babies born alive who die within 7 days of birth), expressed as a rate per 1,000 of all births. Perinatal mortality is an indicator that highlights the state of maternal health and nutrition, as well as healthcare in the antenatal, obstetric and neonatal period.

Infant mortality measures all deaths in children who die before their first birthday as a rate per 1,000 live births. Low birth weight and prematurity are particularly strong risk factors for infant mortality – and both are strongly associated with deprivation. Unsurprisingly, infant mortality is itself strongly correlated with deprivation and, as an outcome measure, it is considered to be related more to wider determinants of health than directly to healthcare.

Mortality in childhood in England, beyond the first year, is most likely to be due to injuries. Although the death rate from injury in England is much lower than in many other comparable countries, it is strongly associated with deprivation.

Perinatal mortality was included in the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

Infant mortality is included in the Public Health Outcomes Framework 2013–16. 'Childhood mortality' and 'Potential years of life lost from causes considered amenable to healthcare' were recommended for inclusion as national outcome measures in the report of the Children and Young People's Health Outcomes Forum (2012).

## Magnitude of variation

### Map 9: Perinatal mortality

For local authorities in England, the perinatal mortality rate per 1,000 births for 2009–2011 ranges from 4.2 to 12.2 (nearly three-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 5.2 to 10.7, and the variation is two-fold. By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2009) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 5.0 to 11.0, and the variation was greater than two-fold.

### Map 10: Infant mortality

For local authorities in England, the infant mortality rate per 1,000 live births for 2009–2011 ranges from 2.2 to 8.0 (3.6-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 2.6 to 7.5, and the variation is nearly three-fold.

### Map 11: Child mortality

For local authorities in England, the directly standardised mortality rate for children aged 1–17 years (per 100,000 children aged 1–17 years) for 2009–2011 ranges from 6.9 to 23.7 (3.4-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 7.9 to 21.1, and the variation is 2.7-fold.

These data support the association between all three mortality markers and socio-economic deprivation. Many public health and social risk factors, such as obesity, smoking, ethnic background and teenage pregnancy, can influence the rates of stillbirth and preterm birth; some preterm babies will die before 7 days of age. However, variation in the quality and access to antenatal and perinatal healthcare may account for unwarranted variations in perinatal mortality.

## Options for action

Commissioners and local authorities can analyse the patterns of child, infant and perinatal mortality in their populations, especially in comparison with populations with similar demographic and socio-economic characteristics.

Infant mortality is amenable to improvement. Action in key areas such as teenage pregnancy and parenthood, antenatal health, maternal smoking and housing can have a significant impact upon reducing infant mortality.<sup>1</sup> To better understand opportunities for improvement, commissioners and local authorities can analyse the patterns of child, infant and perinatal mortality in their populations, especially in comparison with populations with similar characteristics.

Commissioners may be able to improve the quality of their local pre-pregnancy, antenatal, intrapartum and neonatal care by:

- studying local variations in perinatal mortality in order to identify whether variations in outcomes are warranted or unwarranted
- ensuring that there is adequate capacity and training of community-based and hospital-based health professionals in order to deliver a high-quality antenatal and perinatal service for mothers and babies, including nutritional and other preventive health advice.

<sup>1</sup> Department of Health (2010). Tackling health inequalities in infant and maternal health outcomes: report of the infant mortality national support team. Available from: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215869/dh\\_122844.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215869/dh_122844.pdf).



### Resources

Office for National Statistics: Full report on Child, Infant and Perinatal Mortality (data available up to 2011) ([www.ons.gov.uk/ons/rel/vsob1/child-mortality-statistics--childhood--infant-and-perinatal/2011/stb-cms-2011.html#tab-Child-mortality-rates](http://www.ons.gov.uk/ons/rel/vsob1/child-mortality-statistics--childhood--infant-and-perinatal/2011/stb-cms-2011.html#tab-Child-mortality-rates)).

The National Institute for Health and Care Excellence (NICE) has produced a suite of guidelines for:

- maternal and child nutrition (<http://guidance.nice.org.uk/PH11>)
- management of pregnancy and birth (<http://guidance.nice.org.uk/Topic/GynaecologyPregnancyBirth>)
- routine postnatal care ([www.nice.org.uk/CG037](http://www.nice.org.uk/CG037)).

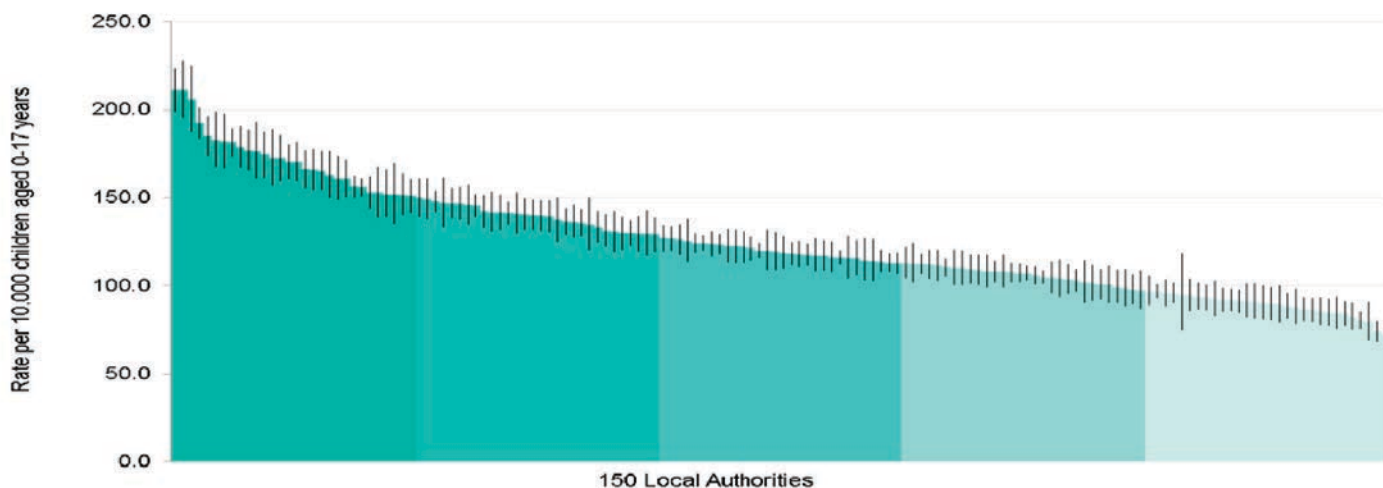
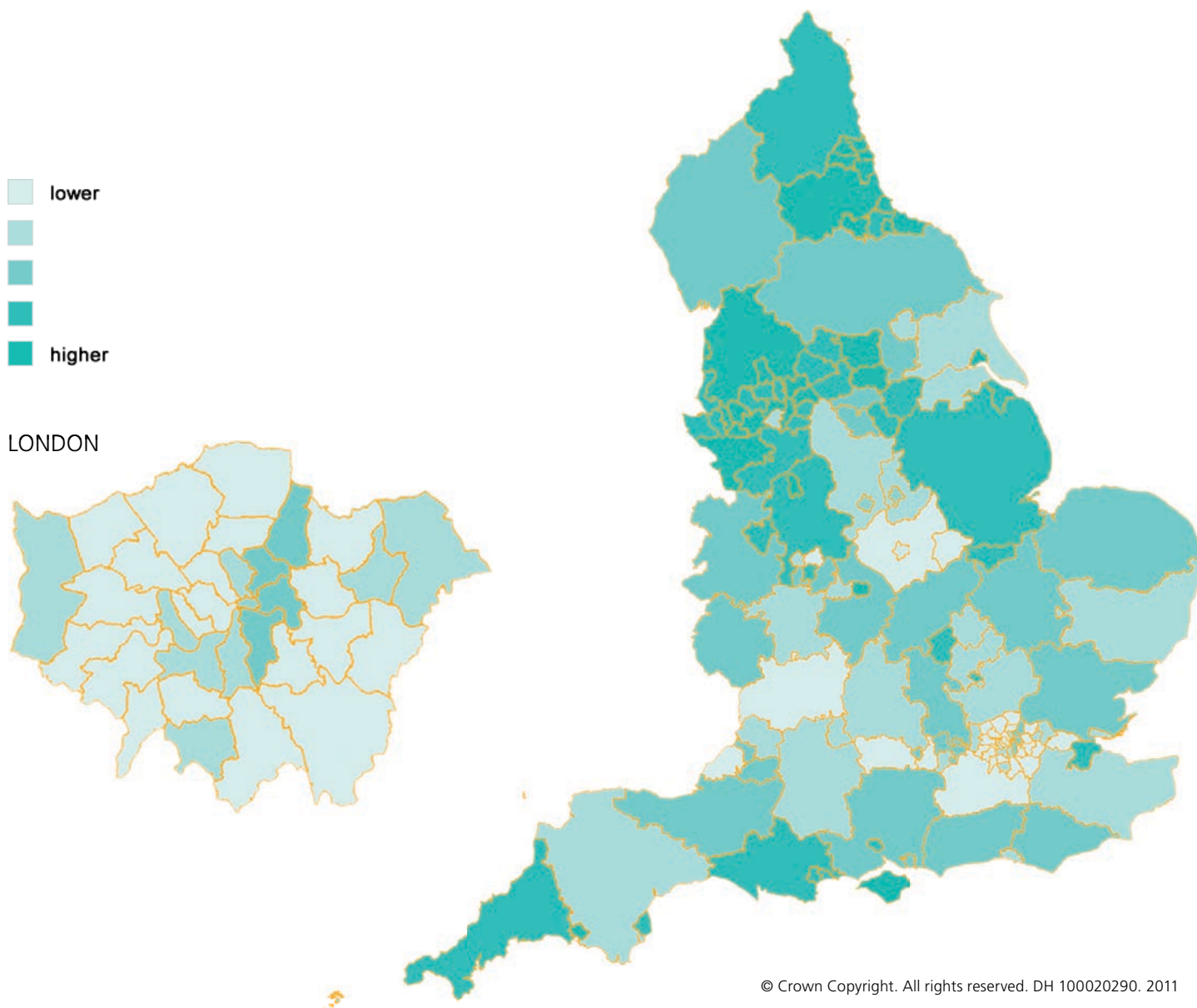
There is also a NICE quality standard for specialist neonatal care, which describes best practice and recommends measures to assess the quality of the service ([www.nice.org.uk/guidance/qualitystandards/specialistneonatalcare/specialistneonatalcarequalitystandard.jsp](http://www.nice.org.uk/guidance/qualitystandards/specialistneonatalcare/specialistneonatalcarequalitystandard.jsp)).

Department of Health (2010). Tackling health inequalities in infant and maternal health outcomes: report of the infant mortality national support team ([www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215869/dh\\_122844.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215869/dh_122844.pdf)).

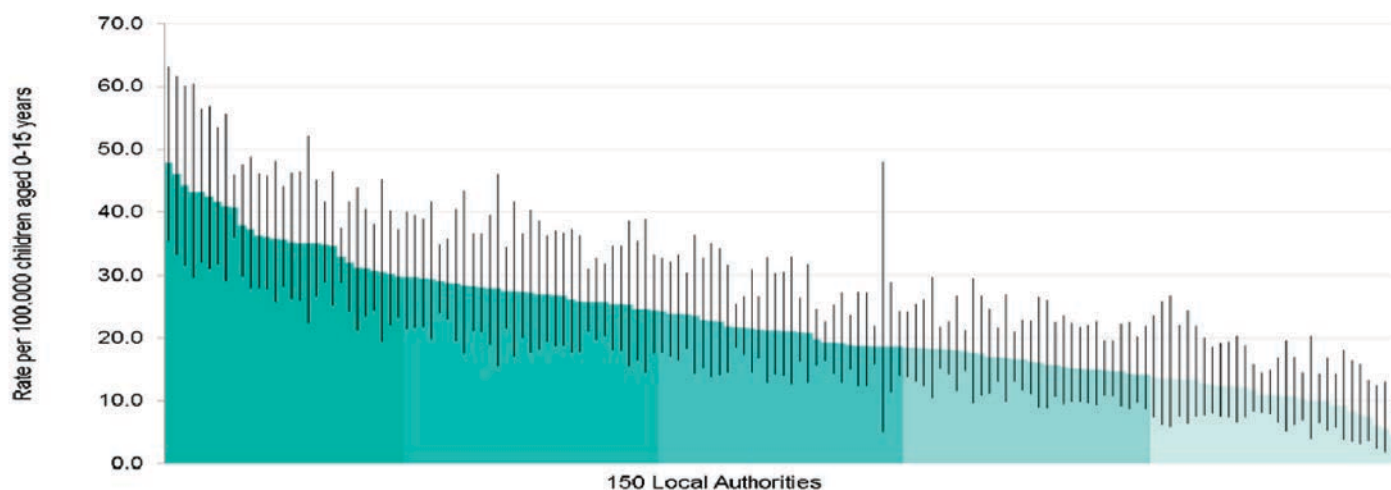
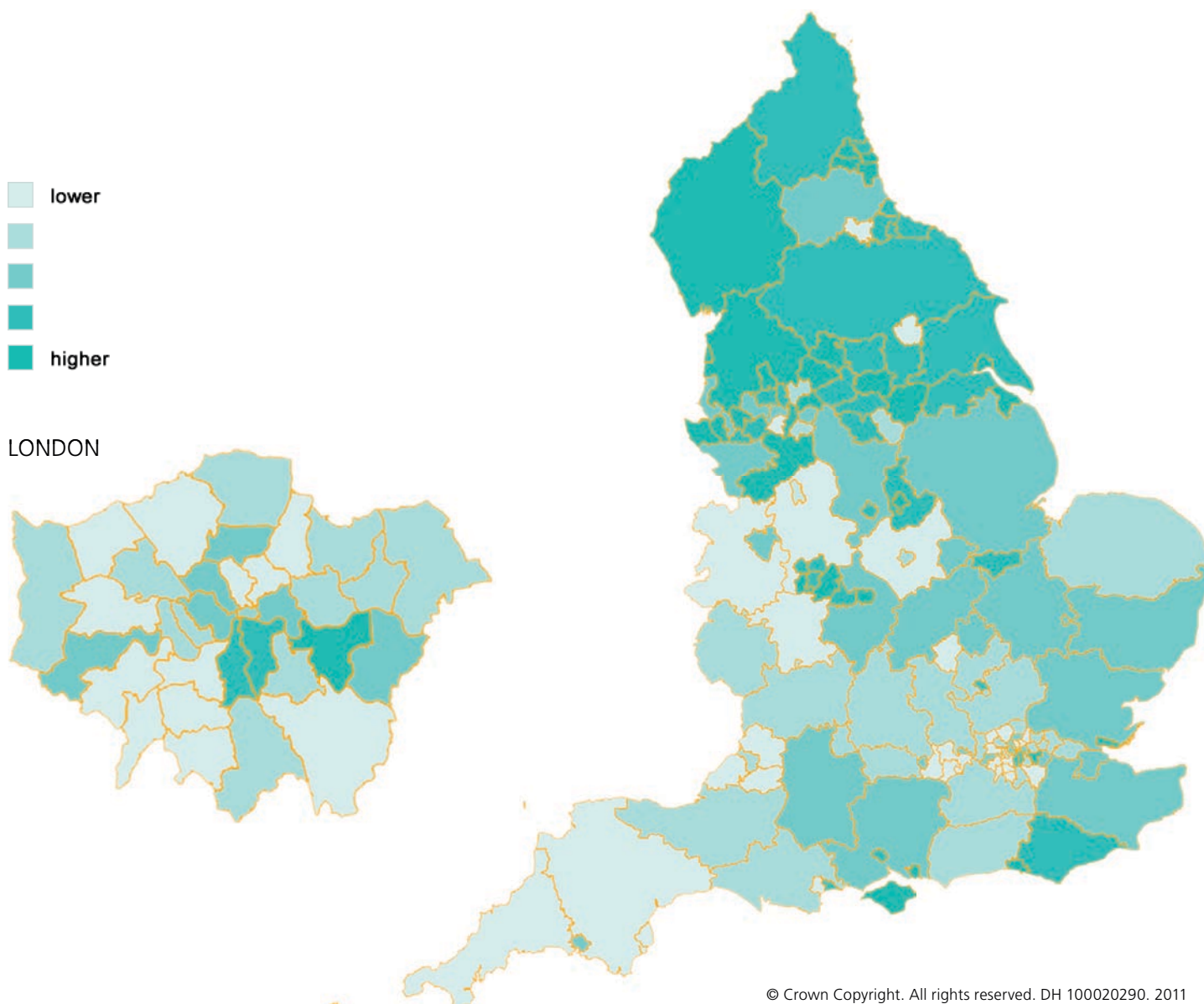


B: Injury

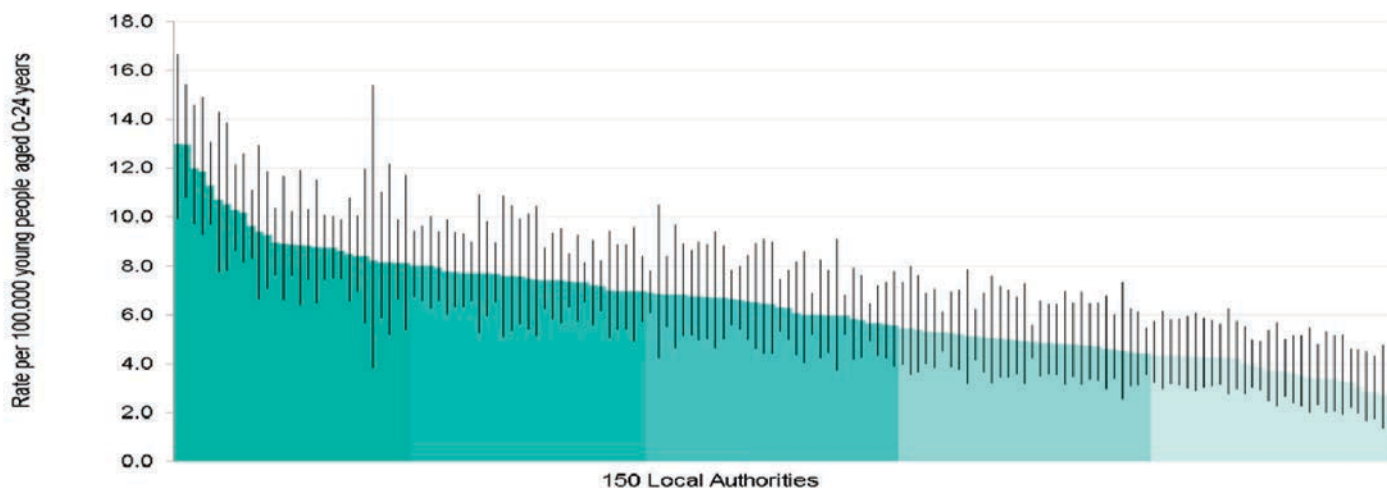
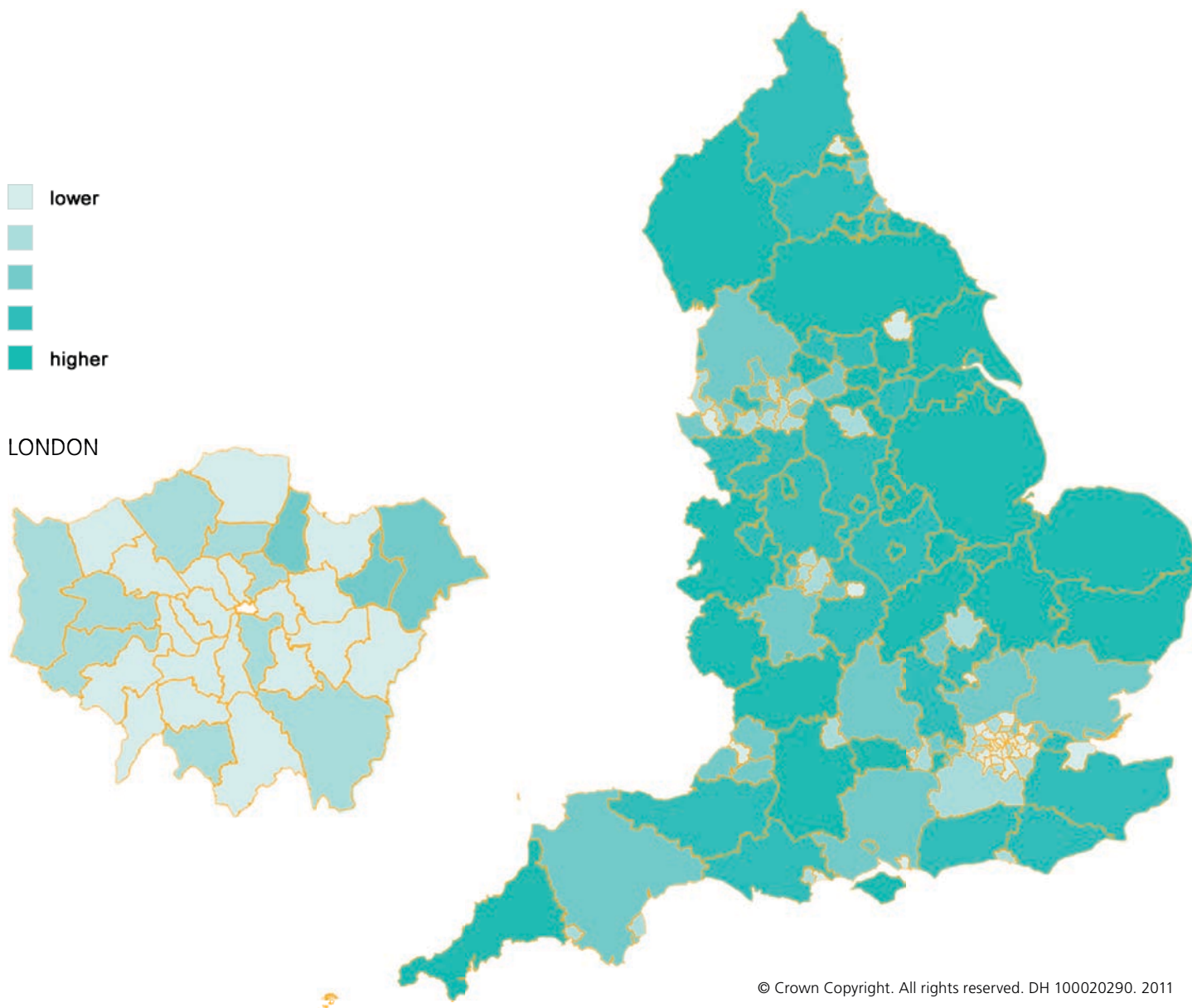
**Map 12** Hospital admissions due to injury: Rate of hospital admissions due to injury in children aged 0–17 years, per 10,000 children aged 0–17 years, by local authority, 2011–2012



**Map 13** Injuries from road traffic accidents: Rate of children aged 0–15 years killed or seriously injured in road traffic accidents, per 100,000 children aged 0–15 years, by local authority, 2009–2011

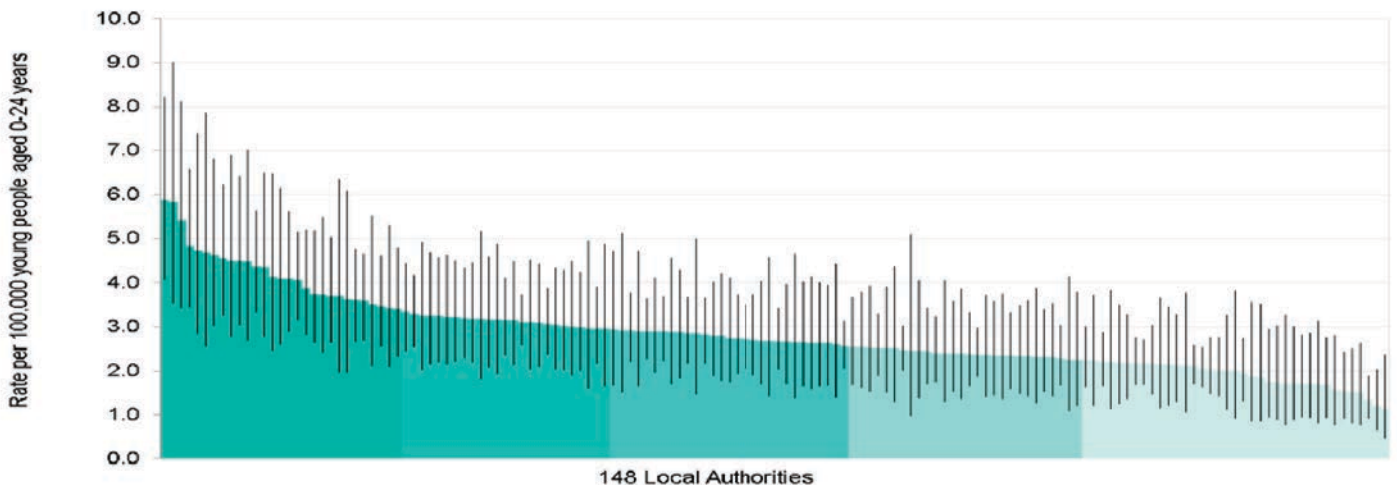
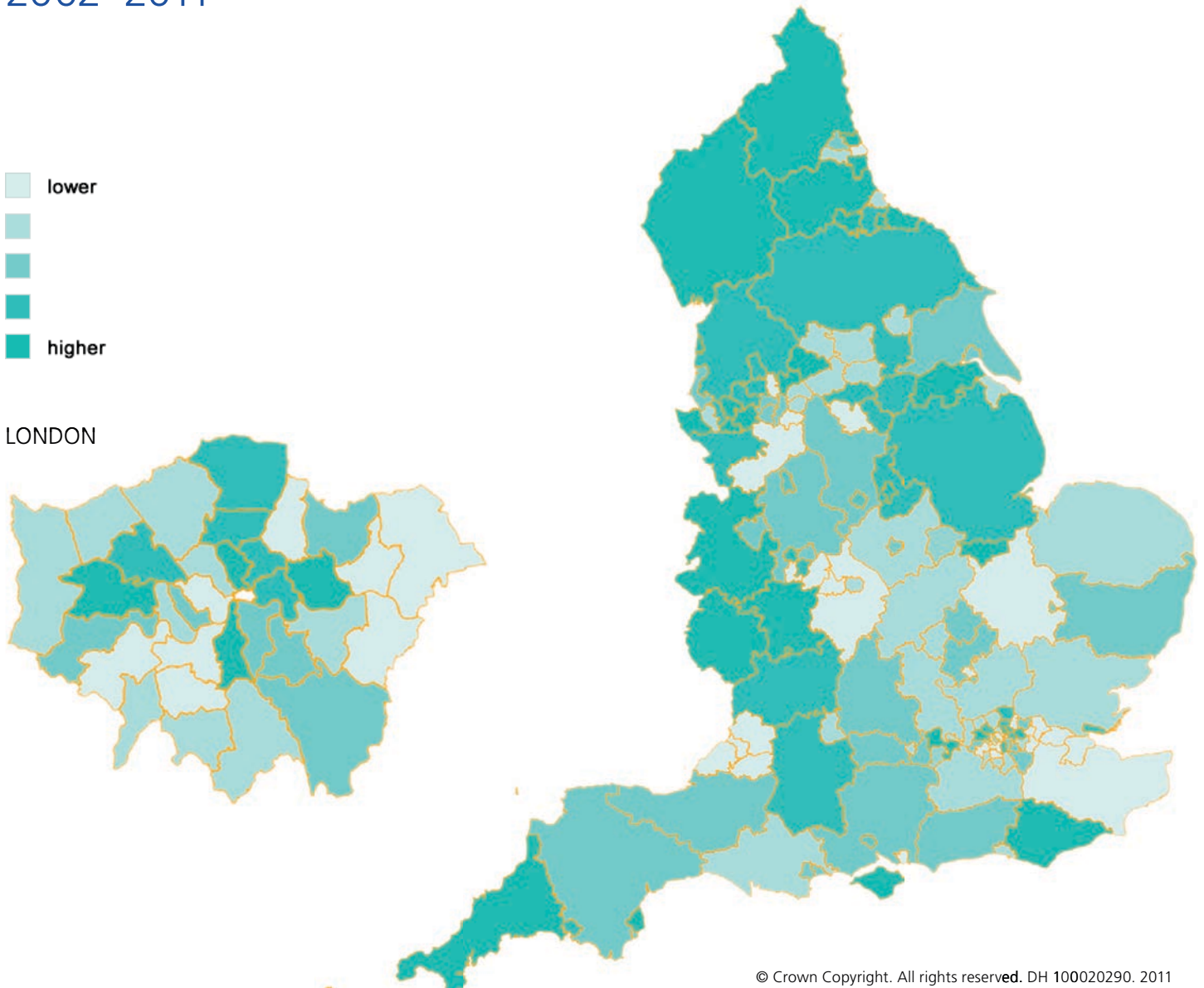


**Map 14** Mortality from accidental injury: Directly standardised rate of death in children and young people aged 0–24 years due to all accidental injury, per 100,000 children and young people aged 0–24 years, by local authority, 2002–2011





**Map 15** Mortality from non-accidental injury: Directly standardised rate of death in children and young people aged 0–24 years due to all non-accidental injury, per 100,000 children and young people aged 0–24 years, by local authority, 2002–2011



## Context

Injuries are a leading cause of hospitalisation, morbidity and premature mortality in children and young people. Hospitalisation from injury is much more common in children aged under 5 years, with 143 admissions for injury per 10,000 children in 2010–2011 compared with 116 for children aged 5–17 years.<sup>1</sup> Healthcare services face a significant burden when the volume of relatively minor injuries is considered in conjunction with the long-term burden some serious injuries effect.

Non-accidental injuries consist primarily of assault and self-harm, and show two peaks: one in the pre-school age range as a result of maltreatment, and another in adolescence from violence. Accidental injuries in England are most likely to be caused by road traffic accidents in older children, while in younger children accidents in the home such as drowning, poisoning, falls and burns predominate.<sup>2</sup>

Despite being one of the commonest causes of death, mortality from injury, both accidental and non-accidental, has steadily declined over the past 30 years in England and is still rare in absolute terms.<sup>3</sup> The mortality data presented here are therefore aggregated over a 10-year period, and presented for children and young people up to 24 years of age.

The indicator 'Killed or seriously injured casualties on England's roads' is included in the Public Health Outcomes Framework 2013–16.

## Magnitude of variation

### Map 12: Hospital admissions due to injury

For local authorities in England, the rate of hospital admissions due to injury in children aged 0–17 years, per 10,000 children aged 0–17 years, ranges from 72.4 to 211.1 (nearly three-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 84.3 to 182.7, and the variation is two-fold.

### Map 13: Injuries from road traffic accidents

For local authorities in England, the rate of children aged 0–15 years killed or seriously injured in road traffic accidents, per 100,000 children aged 0–15 years, ranges from 4.4 to 47.9 (nearly 11-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 8.4 to 42.5, and the variation is five-fold.

### Map 14: Mortality from accidental injury

For local authorities in England, the directly standardised rate of death in children and young people aged 0–24 years

due to all accidental injury, per 100,000 children and young people aged 0–24 years, ranges from 2 to 13 (6.5-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 3.3 to 10.7, and the variation is greater than three-fold.

### Map 15: Mortality from non-accidental injury

For local authorities in England, the directly standardised rate of death in children and young people aged 0–24 years due to all non-accidental injury, per 100,000 children and young people aged 0–24 years, ranges from 1.1 to 5.9 (more than five-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 1.6 to 4.7, and the variation is threefold.

## Options for action

Prevention of non-accidental injury is increasingly acknowledged as requiring a population-based approach. A system approach, involving professionals from commissioning groups, local authorities, public health, education and health visiting, can aid early detection and mitigate the impact of risk factors for self-harm and child maltreatment.

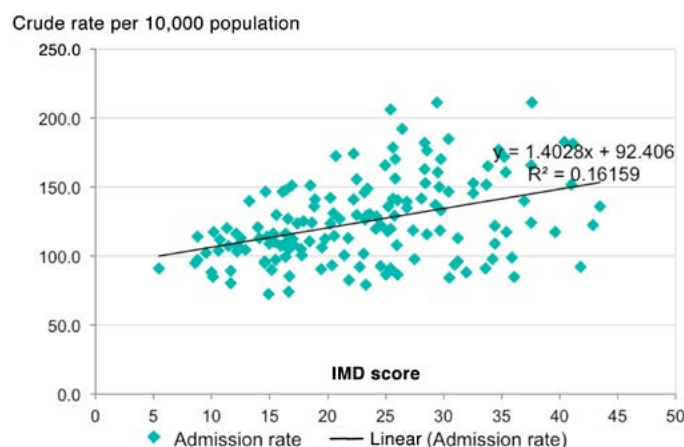
For unintentional injuries, interventions aimed at the riskiest environments – road safety and injuries in the home – are likely to have the greatest impact.<sup>4</sup>

1 Public Health England Injury Profiles data. Available from: [www.apho.org.uk/default.aspx?QN=INJURY\\_PAGE02](http://www.apho.org.uk/default.aspx?QN=INJURY_PAGE02).

2 Fauth R, Ellis A, editors (2010). Reducing unintentional injuries in childhood. London.

3 Hardelid P, Davey J, Dattani N, Gilbert R. (2013). Child deaths due to injury in the four UK countries: a time trends study from 1980 to 2010. PLoS One. 8(7): e68323

**Figure 2B.1 Correlation between deprivation and hospital admission rate for injuries in children aged 0–15 years, by local authority, 2011–2012 (High IMD score indicates more deprived area)**



4 Annual Report of the Chief Medical Officer 2012 (Special Report – Our Children Deserve Better; Prevention Pays)



### Resources

The National Institute for Health and Care Excellence has published a range of public health guidance for the prevention of injury:

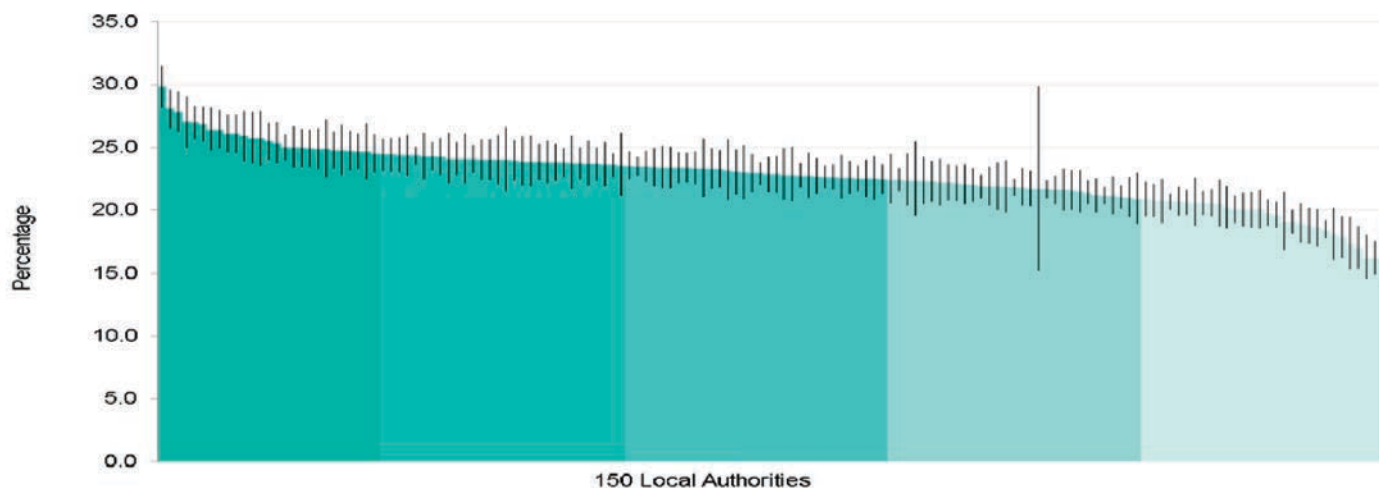
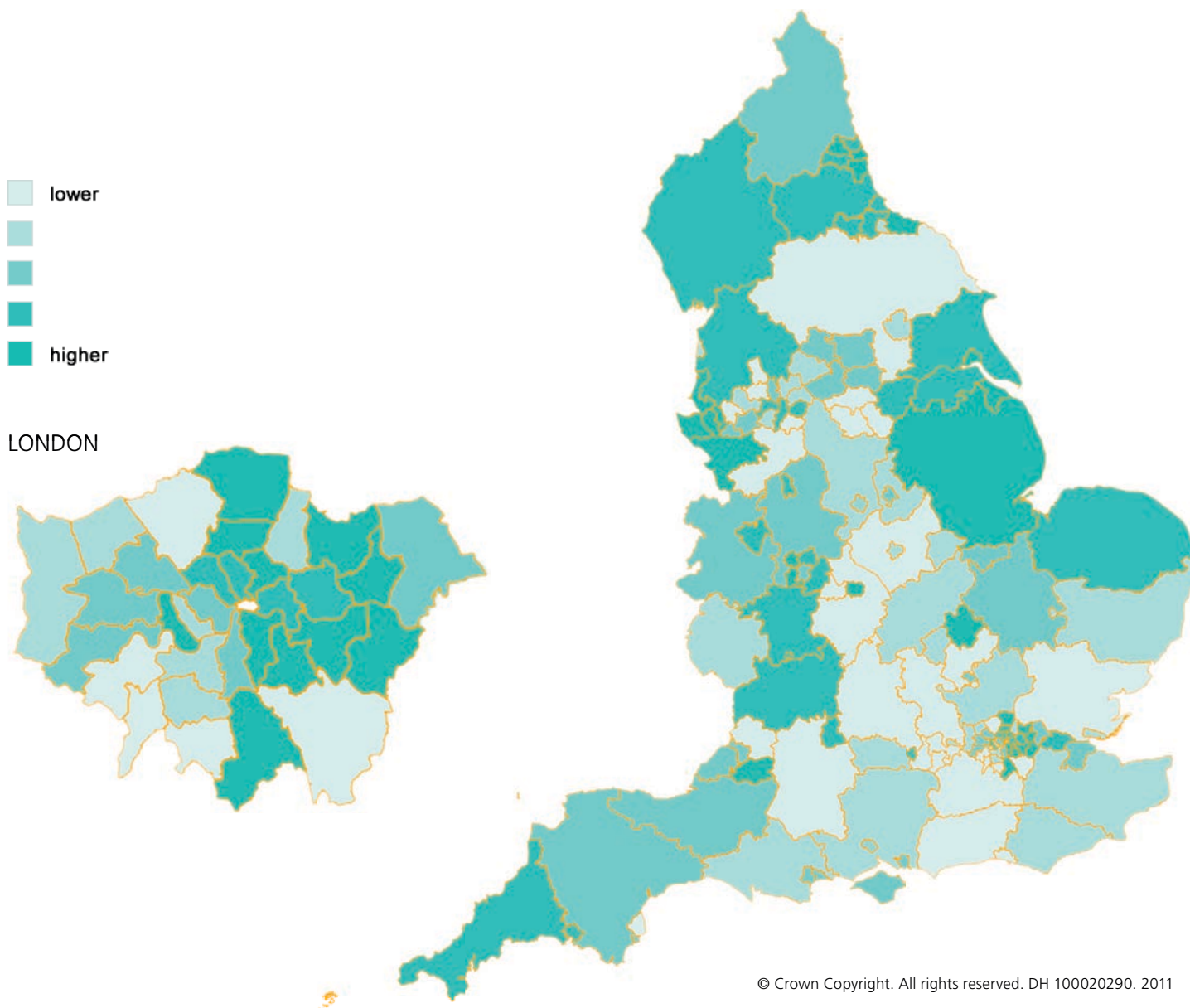
- Strategies to prevent unintentional injuries among the under-15s (2010) ([www.nice.org.uk/PH29](http://www.nice.org.uk/PH29)).
- Preventing unintentional injuries among the under-15s in the home (2010) ([www.nice.org.uk/PH30](http://www.nice.org.uk/PH30)).
- Preventing unintentional road injuries among under-15s (2010) ([www.nice.org.uk/PH31](http://www.nice.org.uk/PH31)).

Public Health England produces Injury Profiles for local authorities to assess and highlight variations among local authorities for a multitude of indicators for injury ([www.apho.org.uk/default.aspx?QN=INJURY\\_DEFAULT](http://www.apho.org.uk/default.aspx?QN=INJURY_DEFAULT)).

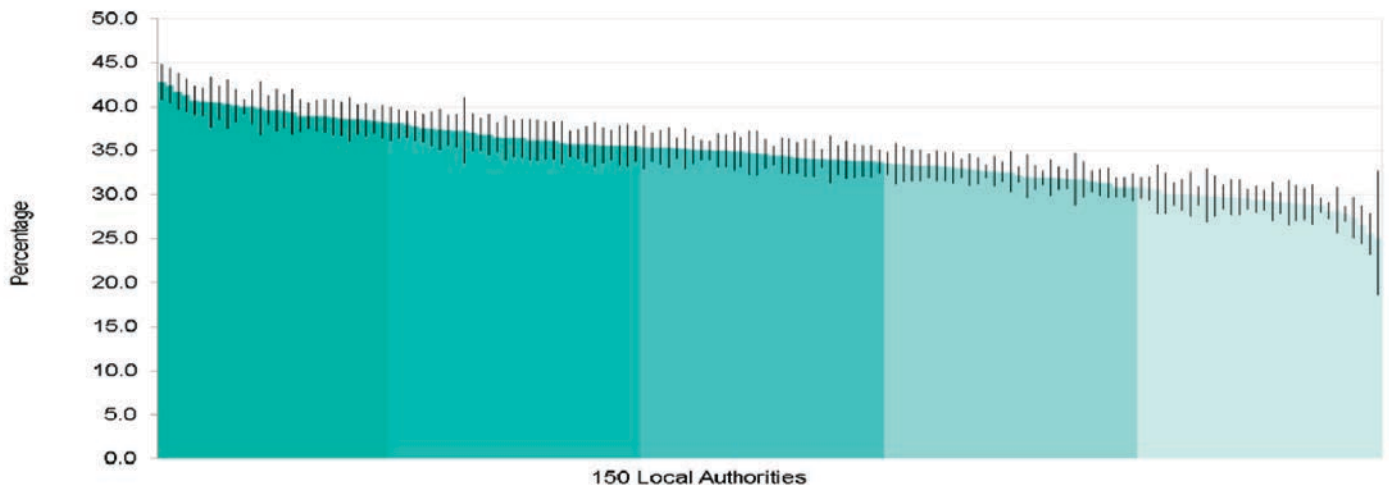
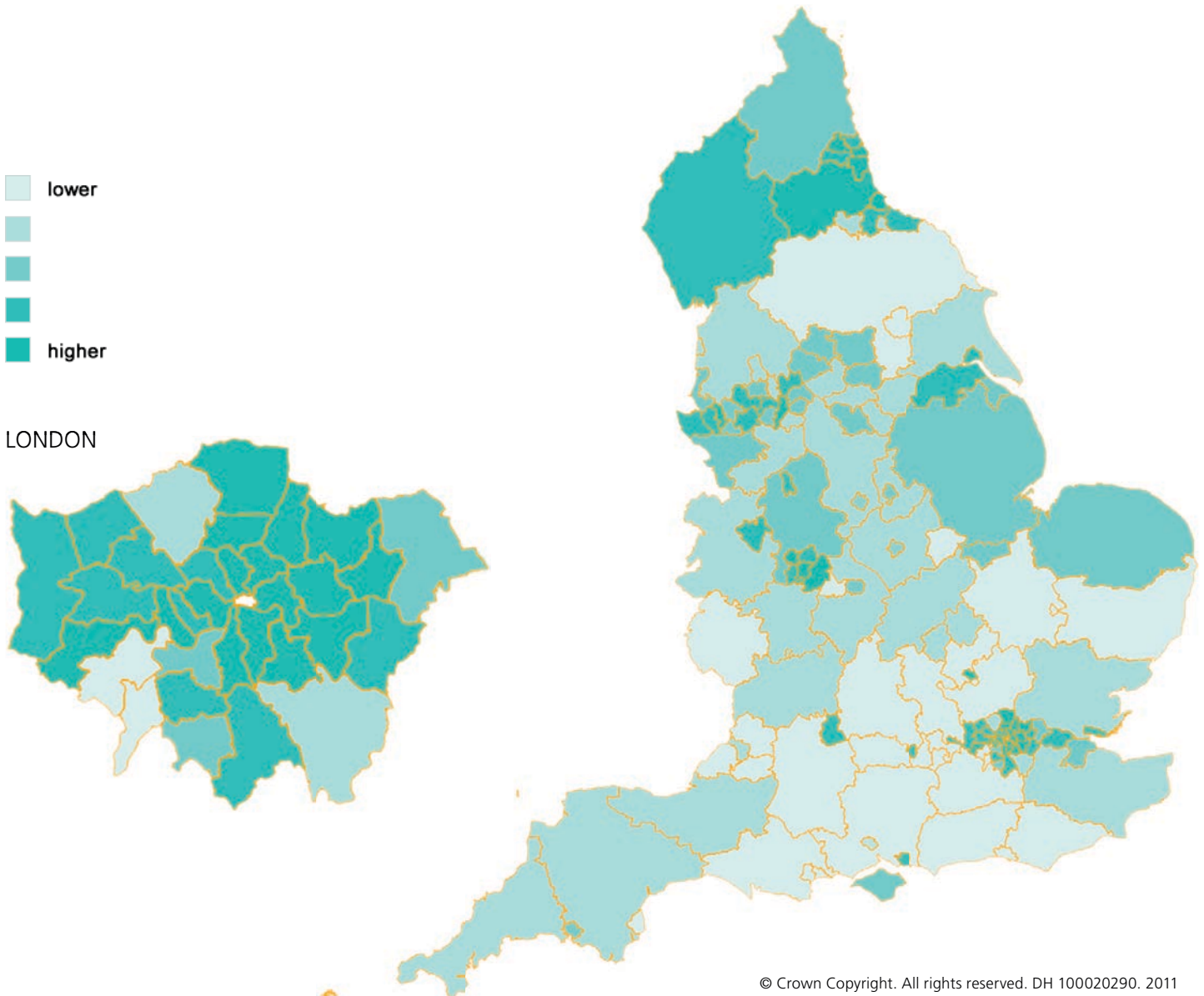
Child Health Reviews – UK, a project backed by the Royal College of Paediatrics and Child Health, is (at time of writing, October 2014) conducting an all-cause analysis of mortality, and is due to report in 2015. ([www.rcpch.ac.uk/chr-uk](http://www.rcpch.ac.uk/chr-uk)).

C: Weight

**Map 16** Weight in 4–5-year-old children: Percentage of pupils in Reception class classified as overweight or obese, by local authority, 2011–2012



**Map 17** Weight in 10–11-year-old children: Percentage of pupils in Year 6 classified as overweight or obese, by local authority, 2011–2012



**Map 16** Weight in 4–5-year-old children: Percentage of pupils in Reception class classified as overweight or obese, by local authority, 2011–2012

**Map 17** Weight in 10–11-year-old children: Percentage of pupils in Year 6 classified as overweight or obese, by local authority, 2011–2012

## Context

Obesity is a significant public health problem in England. Childhood obesity rates have been steadily rising for the past decade (data from pupils in Year 6 continue to show annual increases in obesity prevalence by 0.32% per year),<sup>1</sup> although there is some evidence to suggest that rates may now be plateauing. Obesity in childhood is associated with an increased risk of being overweight or obese in adulthood.

Obesity is associated with poor physical health and emotional wellbeing, including:

- type 2 diabetes mellitus
- non-alcoholic liver disease (which, as a result, is the most common chronic disease of the liver in children and young people in the developed world)
- lower self-reported physical and psychosocial wellbeing
- increased lifetime risk of cardiovascular disease and of certain cancers.

At a population level, the causes of obesity are complex and multifactorial. There is significant variation in rates of obesity among age groups, gender, geographical distribution and socio-economic status.

'Excess weight in 4–5 and 10–11 year olds' is included in the Public Health Outcomes Framework 2013–16.

## Magnitude of variation

### Map 16: Weight in 4–5-year-old children

For local authorities in England, the percentage of pupils in Reception class (aged 4–5 years) classified as overweight or obese ranged from 16.1 to 29.8 (nearly two-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 17.8 to 26.8, and the variation is 1.5-fold.

### Map 17: Weight in 10–11-year-old children

For local authorities in England, the percentage of pupils in Year 6 (aged 10–11 years) classified as overweight or obese ranged from 25.0 to 42.8 (nearly two-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 28.1 to 40.6, and the variation is 1.4-fold.

There is a clear association between being obese and living in an area of deprivation (see Figure 2C.1 for Year 6 pupils).

However, there is no clear association between being overweight (rather than obese) and living in an area of deprivation, either in Reception or Year 6. This may suggest that progression from overweight to obesity is more common in children living in an area of deprivation.

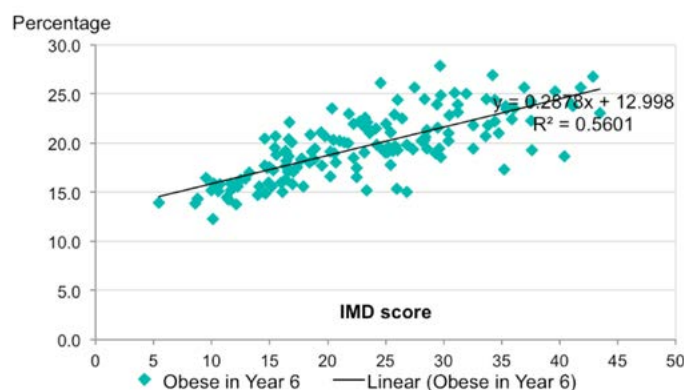
## Options for action

Commissioners can begin to analyse whether local variations are warranted or unwarranted by assessing the proportion of overweight and obese children and young people in their populations in comparison with demographically similar regions.

Commissioners can move towards delivering evidence-based, integrated interventions for healthy eating and physical activity by working with local government, education and social care to adopt a co-ordinated approach, and considering adequate capacity and training of relevant community- and school-based professionals.

Treatment of obesity in children and young people is complicated by the fact that simply reducing calorie intake may interfere with growth and development. However, there is evidence that a co-ordinated and multicomponent approach involving both healthy eating and physical activity can be effective, particularly if implemented as part of a school- or family-based initiative.

**Figure 2C.1** Correlation between deprivation and percentage of Year 6 pupils classified as obese, by local authority, 2011–2012 (High IMD score indicates more deprived area)



<sup>1</sup> National Obesity Observatory, [www.noo.org.uk](http://www.noo.org.uk).

### Resources

A detailed overview of social and biological aspects of obesity, as well as evidence on interventions and policy, is available in the Foresight report:

- Foresight Report: Tackling Obesities – Future Choices (2007) HMSO ([www.bis.gov.uk/assets/foresight/docs/obesity/17.pdf](http://www.bis.gov.uk/assets/foresight/docs/obesity/17.pdf)).

More current analysis from the National Obesity Observatory:

- Ridler C, Dinsdale H, Rutter H. (2013). National Child Measurement Programme: Changes in children's body mass index between 2006/07 and 2011/12. National Obesity Observatory, Oxford ([www.noo.org.uk/uploads/doc/vid\\_17929\\_NCMP\\_Changes\\_children.pdf](http://www.noo.org.uk/uploads/doc/vid_17929_NCMP_Changes_children.pdf)).

National strategy for tackling obesity:

- Department of Health (2011). Healthy Lives, Healthy People: A call to action on obesity in England. London ([www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/134840/dh\\_130487.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/134840/dh_130487.pdf)).

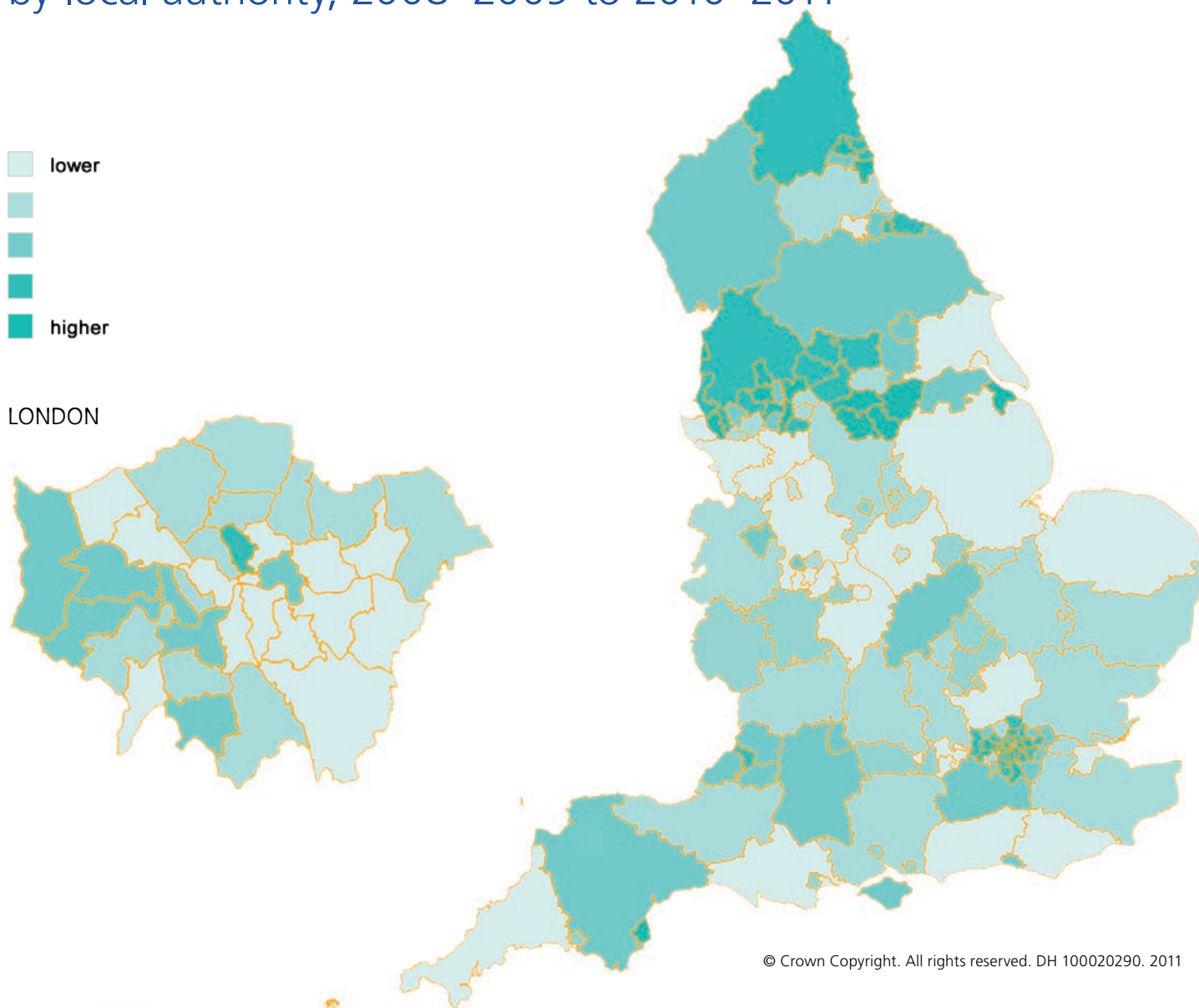
The National Institute for Health and Care Excellence has produced evidence-based guidance on a life-course, pathway approach to prevention and interventions for obesity:

- NICE Clinical Guideline CG43 (2006). Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children ([www.nice.org.uk/cg043](http://www.nice.org.uk/cg043)).

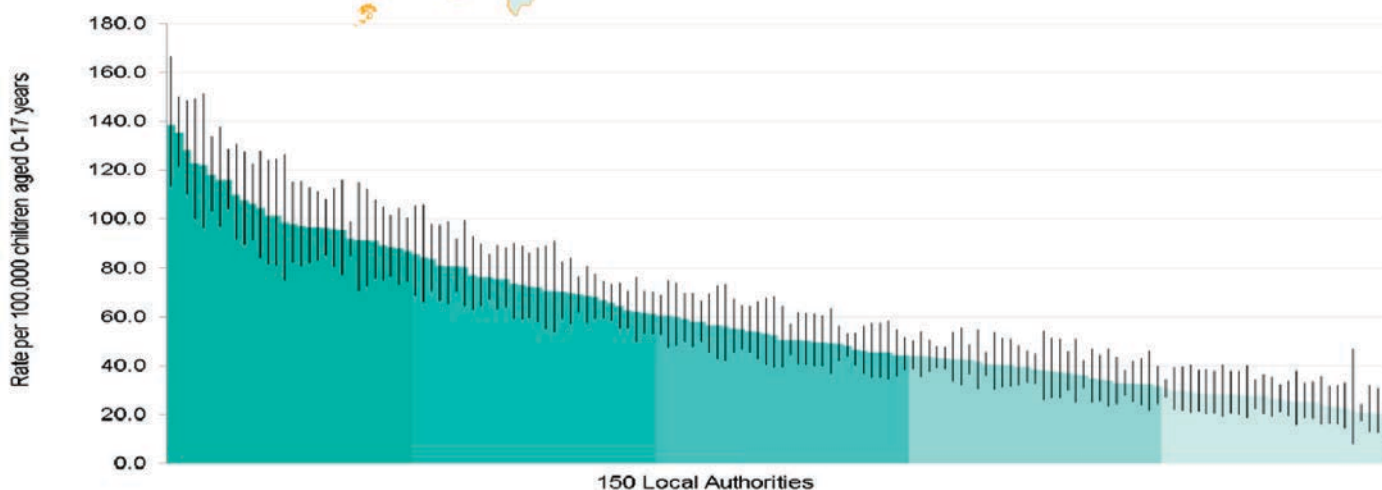


D: Alcohol, smoking and substance misuse

**Map 18** Alcohol-related hospital admissions: Hospital admission rate for people aged 0–17 years due to alcohol-specific conditions, per 100,000 people aged 0–17 years, by local authority, 2008–2009 to 2010–2011



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## Section 2: Child health promotion

### Context

Alcohol misuse in children and young people, along with smoking and substance misuse, remains a concern for public health, despite impressive reductions in prevalence of all three behaviours in children and young people. In 2012, 43% of 11–15 year olds had already consumed alcohol at least once. Some 25% of 15 year olds had drunk alcohol within the last week. Children who had a drink within the last week consumed, on average, 12.5 units.<sup>1</sup>

In England, approximately:

- 120,000 children aged 11–15 years smoke regularly
- 200,000 had taken drugs in the past month
- 320,000 had drunk alcohol in the past week.<sup>1</sup>

UK adolescents are, on average, more likely than their European counterparts to report frequent intoxication and heavy drinking – as well as more positive expectations of being drunk.<sup>2</sup>

Early age of drinking onset is associated with an increased risk of developing alcohol dependence in adulthood. Similarly, most current smokers report having started smoking in adolescence and early adulthood.

Alcohol-related hospital admissions and attendances place a considerable burden on healthcare services. Alcohol abuse and dependence are strongly associated with a range of physical and mental health problems, including an increased risk of:

- other risk-taking behaviours and their consequences, such as injuries, violence, and risky sexual behaviours
- self-harm, suicide and other mental health problems
- longer-term complications such as alcoholic liver disease and certain cancers.

‘Alcohol-related admissions to hospital’ is included as a placeholder in the Public Health Outcomes Framework 2013–16.

### Magnitude of variation

#### Map 18: Alcohol-related admissions

For local authorities in England, the rate of hospital admissions in people aged 0–17 years for alcohol-specific conditions, per 100,000 people aged 0–17 years, ranged from 16.9 to 138.3 (an eight-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 22.5 to 117.9, and the variation is greater than five-fold.

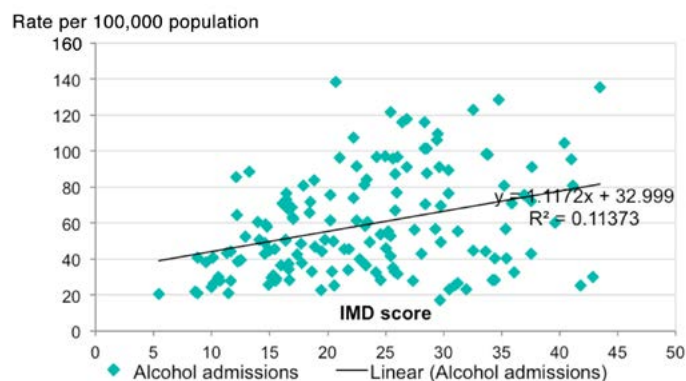
1 Health and Social Care Information Centre (2012). Smoking, drinking and drug use among young people in England, 2012. Available from: [www.hscic.gov.uk/catalogue/PUB11334](http://www.hscic.gov.uk/catalogue/PUB11334).

2 The 2011 European School Survey Project on Alcohol and Other Drugs (ESPAD) Report (2012). Available from: [www.espad.org/en/Reports--Documents/ESPAD-Reports/](http://www.espad.org/en/Reports--Documents/ESPAD-Reports/).

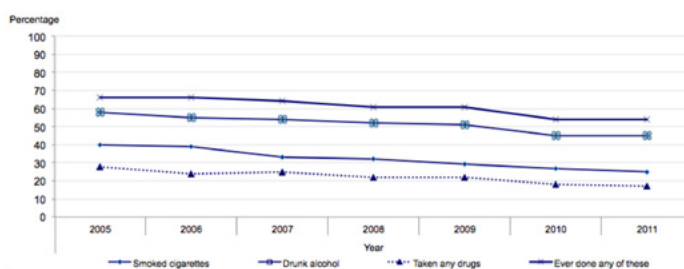
Alcohol misuse, like smoking and substance misuse, is associated with deprivation and this finding is corroborated to some degree by our data. However, the correlation seen in Figure 2D.1, is unlikely to be strong enough to fully explain the variation.

Alcohol consumption, smoking and substance misuse comprise a set of risk-taking behaviours which cluster together, with shared risk factors and shared consequences for ill health. Those who undertake one of these behaviours are at higher risk of also undertaking the others. In 2012, 17% of all 15 year olds in England reported taking drugs at least once, and 23% reported having smoked at least once.<sup>1</sup> Although there has been a downward trend over the past few years in self-reported rates for all three behaviours, the overall rates are still unacceptably high (see Figure 2D.2).

**Figure 2D.1 Correlation between deprivation and hospital admission rates for alcohol-related conditions, by local authority, 2008–2009 to 2010–2011 (High IMD score indicates more deprived area)**



**Figure 2D.2 Percentage of school pupils aged 10–15 years who reported having ever smoked, drunk alcohol and/or taken drugs, 2011**



## Options for action

Hospital attendance for alcohol-related reasons represents only the extreme end of the spectrum of alcohol-related health problems in children and young people. However, hospital attendance presents opportunities for intervention and secondary prevention. These include:

- referral to alcohol and youth services
- broader, more integrated health interventions such as family services
- safeguarding
- broader health promotion.

Commissioners can analyse rates of smoking, alcohol and substance misuse in children and young people in their populations and, through comparison with demographically similar local authorities, decide whether local variations are warranted or unwarranted.

Adolescence is a key period for intervention to change behaviours which may otherwise become entrenched well into adulthood.

School health and youth services are key resources in the prevention, detection and treatment of smoking, alcohol and substance misuse.

Commissioners can move towards delivering evidence-based, integrated interventions for prevention and treatment of alcohol and substance misuse, and for smoking cessation, by working with local government, education and social care to adopt a co-ordinated approach, and considering adequate capacity and training of relevant community- and school-based professionals.

Commissioners can consider how they ensure their populations can access suitable, multiprofessional addiction services (services for children and young people which are young people friendly and accessible).

## Resources

Alcohol Concern has a series of helpful briefing documents on background, policy, interventions and commissioning guidance:

- Reducing underage alcohol harm in Accident and Emergency settings (2011) ([www.alcoholconcern.org.uk/publications/other-publications/reducing-underage-alcohol-harm](http://www.alcoholconcern.org.uk/publications/other-publications/reducing-underage-alcohol-harm)).
- Investing in alcohol treatment (2010) ([www.alcoholconcern.org.uk/publications/other-publications/investing-in-alcohol-treatment-reducing-costs-and-improving-lives.-alcohol-concerns-learning-from-10-years-of-consultancy-and-training](http://www.alcoholconcern.org.uk/publications/other-publications/investing-in-alcohol-treatment-reducing-costs-and-improving-lives.-alcohol-concerns-learning-from-10-years-of-consultancy-and-training)).
- Lessons learnt from alcohol harm reduction initiatives across England: HubCAPP briefing (2010) ([www.alcoholconcern.org.uk/publications/other-publications/lessons-learnt-from-alcohol-harm-reduction-initiatives-across-england-hubcapp-briefing](http://www.alcoholconcern.org.uk/publications/other-publications/lessons-learnt-from-alcohol-harm-reduction-initiatives-across-england-hubcapp-briefing)).

- Guidance for user-led commissioning: how to involve alcohol service users in commissioning (2008) ([www.alcoholconcern.org.uk/publications/other-publications/user-led-commissioning](http://www.alcoholconcern.org.uk/publications/other-publications/user-led-commissioning)).

The Home Office published a national alcohol strategy in 2012:

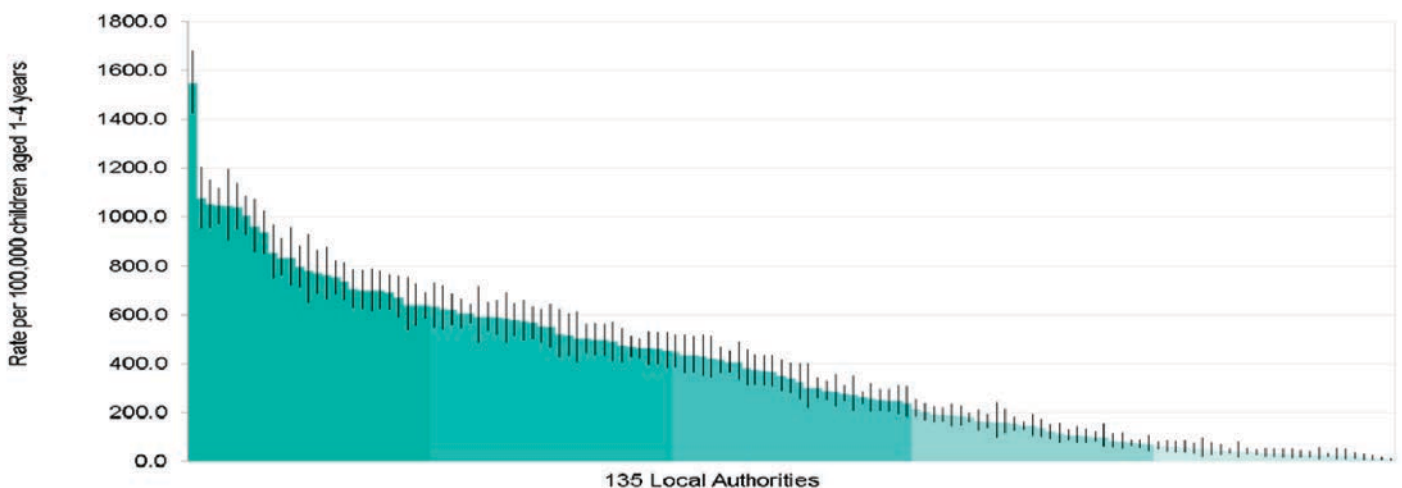
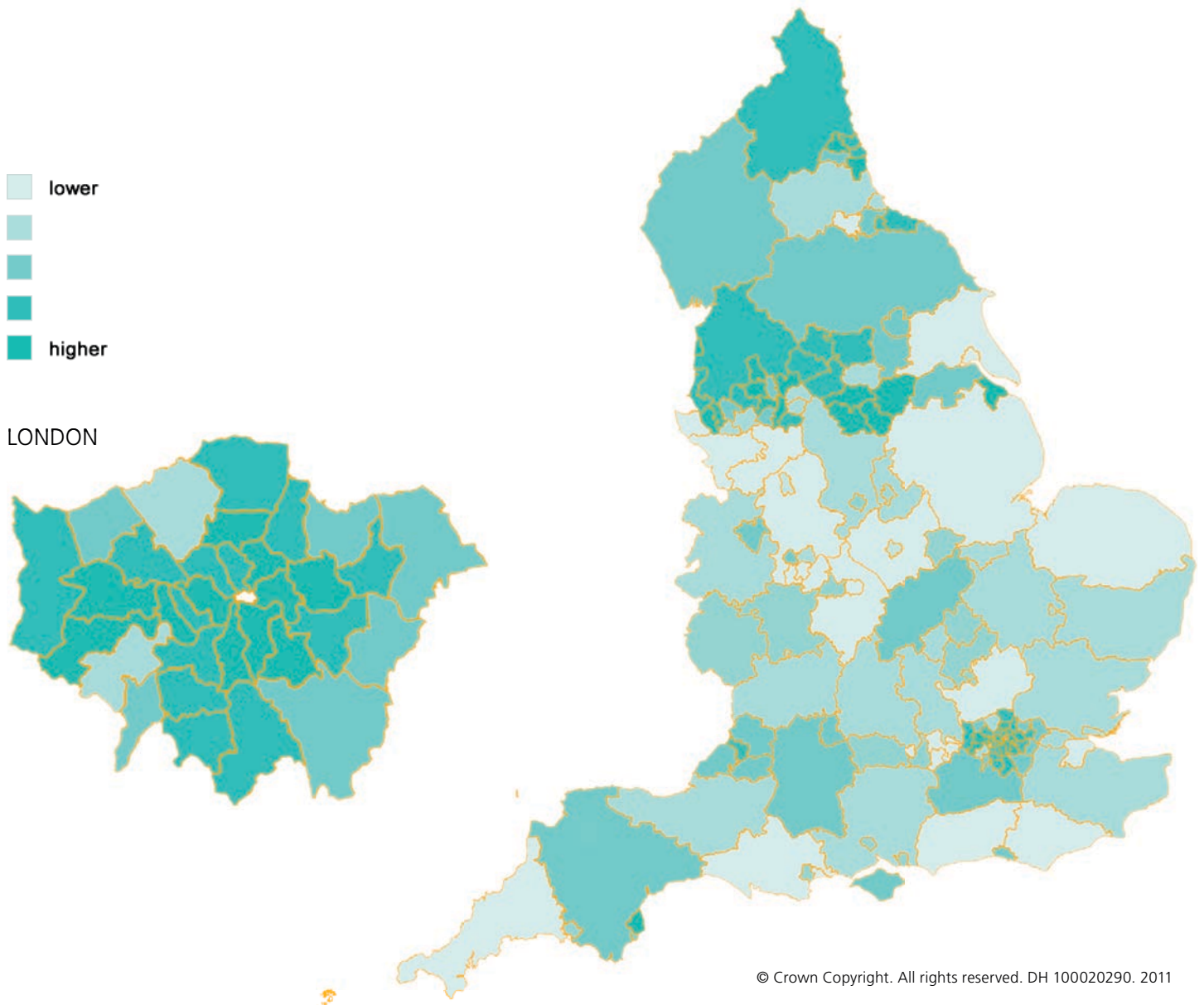
- The Government's Alcohol Strategy (2012). HMSO, London ([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/224075/alcohol-strategy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224075/alcohol-strategy.pdf))

The National Institute for Health and Care Excellence has produced evidence-based guidance on prevention, diagnosis and treatment of alcohol dependence:

- NICE Clinical Guideline CG115 (2011). Alcohol use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. NICE ([www.nice.org.uk/CG115](http://www.nice.org.uk/CG115)).

E: Dental health

**Map 19** Dental health: Hospital admission rate for dental caries in children aged 1–4 years, per 100,000 children aged 1–4 years, by local authority, 2009–2012





## Context

Tooth decay in childhood is common and preventable. Early childhood caries can have significant impacts on the health and wellbeing of preschool children, and constitute a considerable burden on healthcare services in the form of emergency hospital and dental attendances, hospitalisation and operative intervention.

Early childhood caries is a public health problem which is multifactorial in origin. It is associated with socio-economic deprivation, but has specific risk factors which include a diet rich in fermentable carbohydrates, oral hygiene practices and the acquisition of specific cariogenic bacteria.<sup>1</sup>

Dental health in England has improved significantly over the past 50 years as a result of public health interventions such as oral health education, dietary changes and access to dental services. However, it remains a significant problem, particularly among the most deprived populations.

A similar indicator, 'Tooth decay in children aged 5', is included in the NHS Public Health Outcomes Framework 2013–16.

## Magnitude of variation

**Map 19:** For local authorities in England, the hospital admission rate for dental caries in children aged 1–4 years, per 100,000 children aged 1–4 years, ranges from 7 to 1,550.3 (over 200-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 25.9 to 1,041, and the variation is 40-fold.

The rate of admission for dental caries is correlated with deprivation. However, there is considerable variation which may be affected by:

- preventive and public health interventions in the population
- early recognition of children at risk of developing dental caries
- access to dental care
- assessment of dental emergencies and criteria for admission and operative intervention.

## Options for action

Hospital admission rate is only one indicator for dental health among children and young people, and will significantly underestimate the population prevalence of disease. Commissioners and local authorities can look to broader indicators to closely monitor the dental health of their populations, including prevalence and incidence data.

Oral health shows marked inequalities, which are related to both increased risk of developing caries as well as poorer access to dental care. Evidence-based preventive interventions (including water fluoridation) and early treatment to at-risk groups, in particular to areas of high deprivation, can be an effective way for commissioners and local authorities to tackle variation.

## Resources

Scottish Intercollegiate Guidelines Network guidance: Preventing dental caries in children at high caries risk (2000) ([www.sign.ac.uk/pdf/sign47.pdf](http://www.sign.ac.uk/pdf/sign47.pdf)).

National Institute for Health and Care Excellence guidance:

- Oral health promotion: A guide to effective working in pre-school settings (1999) ([www.nice.org.uk/niceMedia/documents/ohp\\_preschool.pdf](http://www.nice.org.uk/niceMedia/documents/ohp_preschool.pdf)).
- Oral health: local authority strategies to improve oral health particularly among vulnerable groups. In progress (<http://guidance.nice.org.uk/PHG/61>).

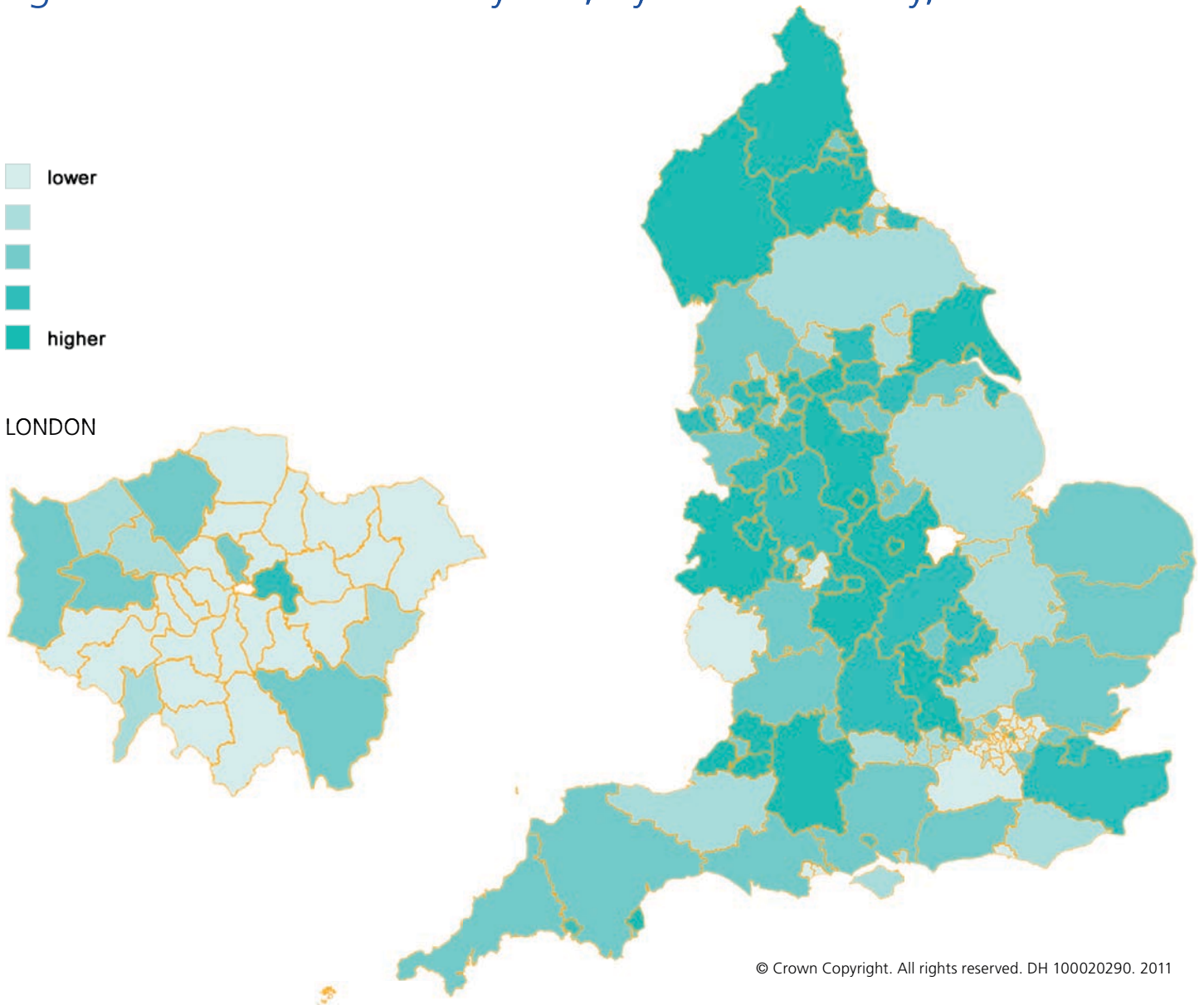
European Academy of Paediatric Dentistry (2008). Guidelines on prevention of early dental caries ([www.eapd.eu/dat/1722F50D/file.pdf](http://www.eapd.eu/dat/1722F50D/file.pdf)).

<sup>1</sup> Harris R, Nicoll AD, Adair PM, Pine CM (2004). Risk factors for dental caries in young children: a systematic review of the literature. *Community Dental Health* 21:71–85.

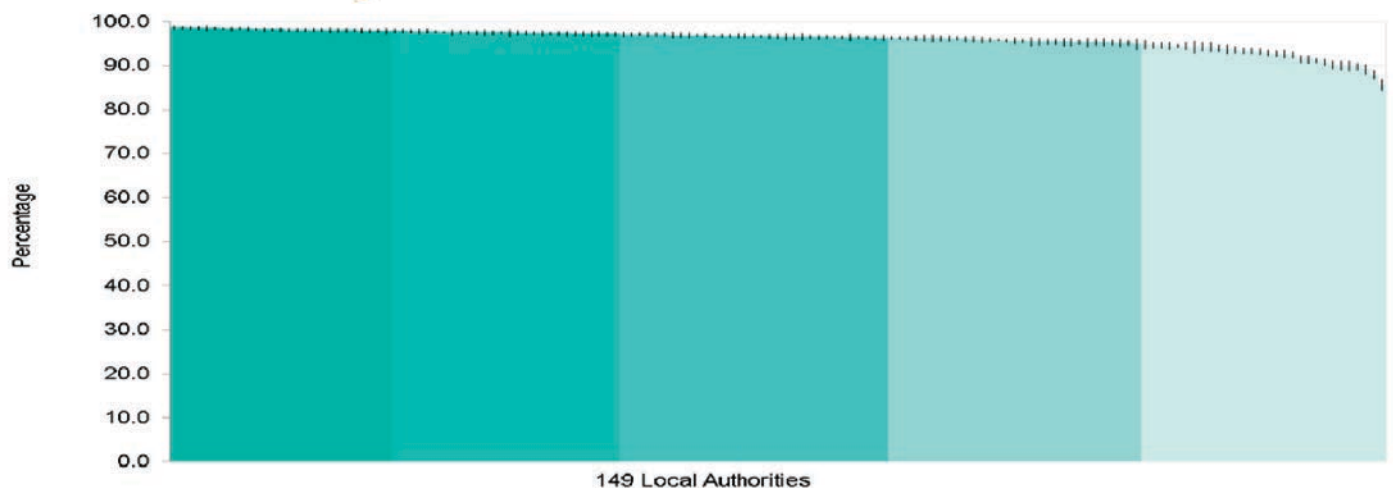


F: Immunisations

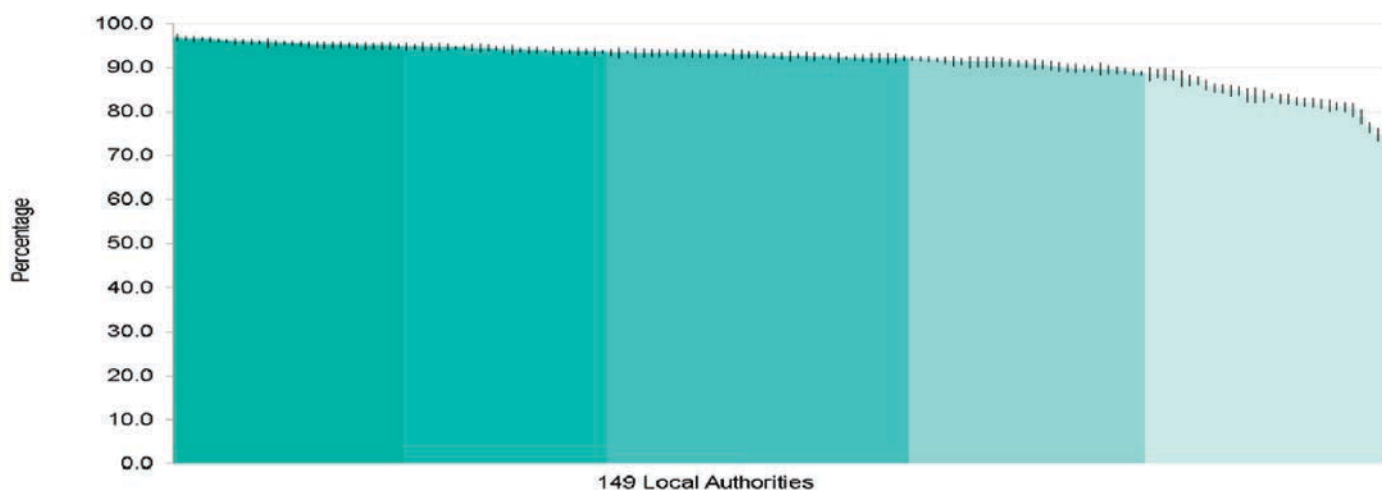
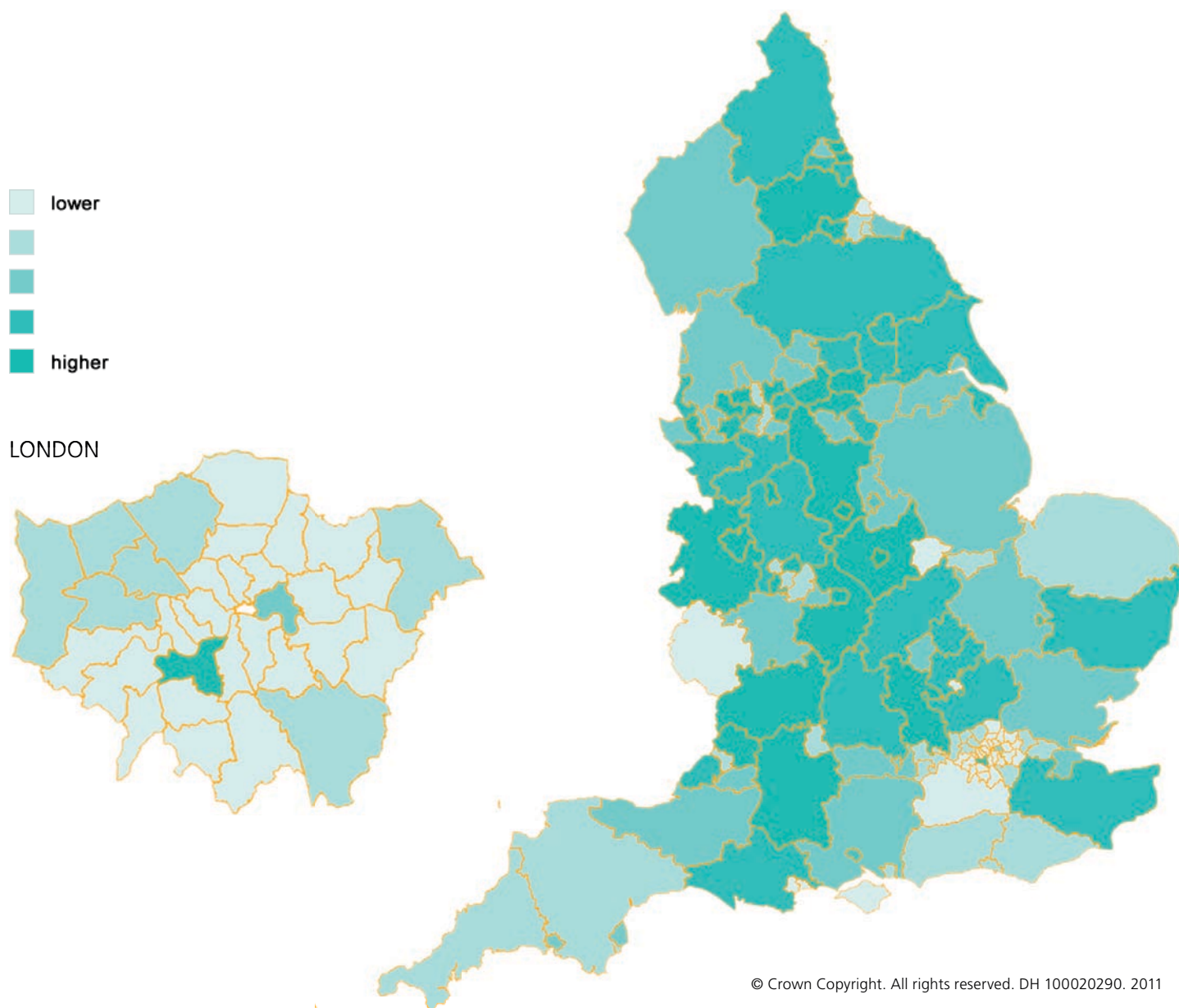
**Map 20** Diphtheria, tetanus, polio, pertussis and *Haemophilus influenzae* type b (DTaP/IPV/Hib) vaccine coverage at 2 years: Percentage of immunisation completion for routine vaccinations against DTaP/IPV/Hib at 2 years, by local authority, 2011–2012



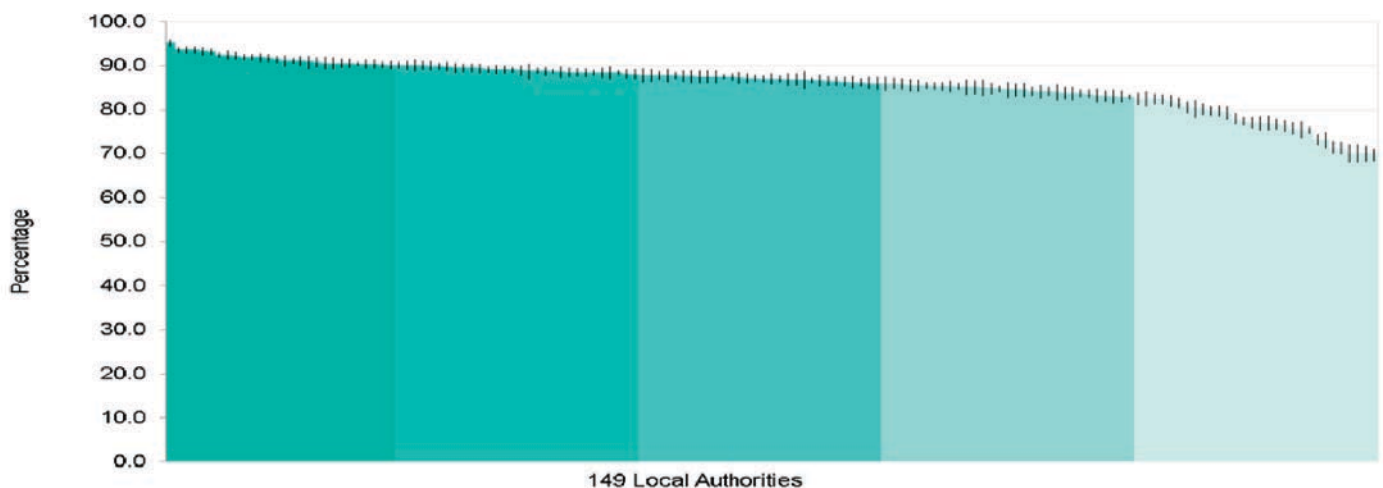
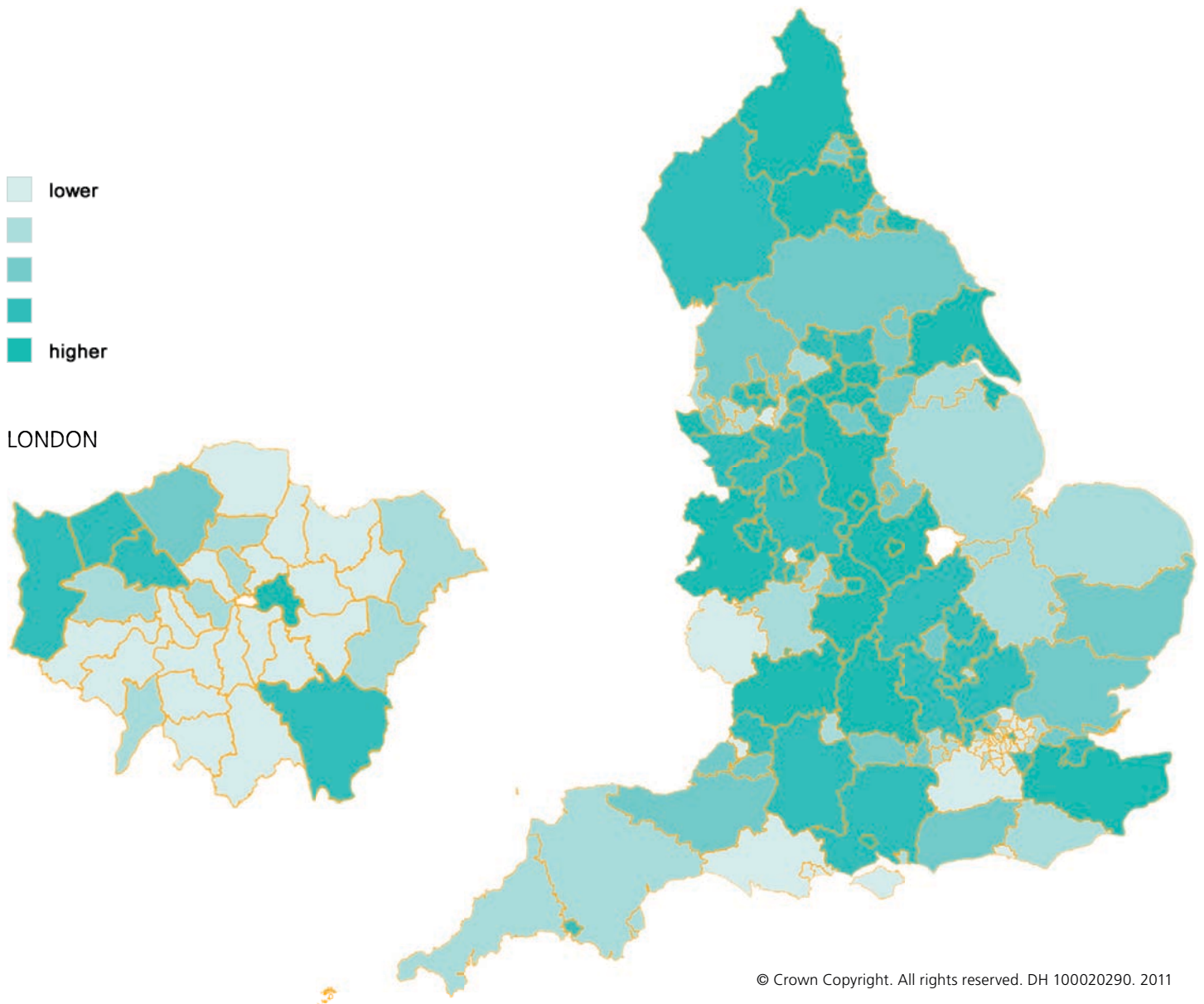
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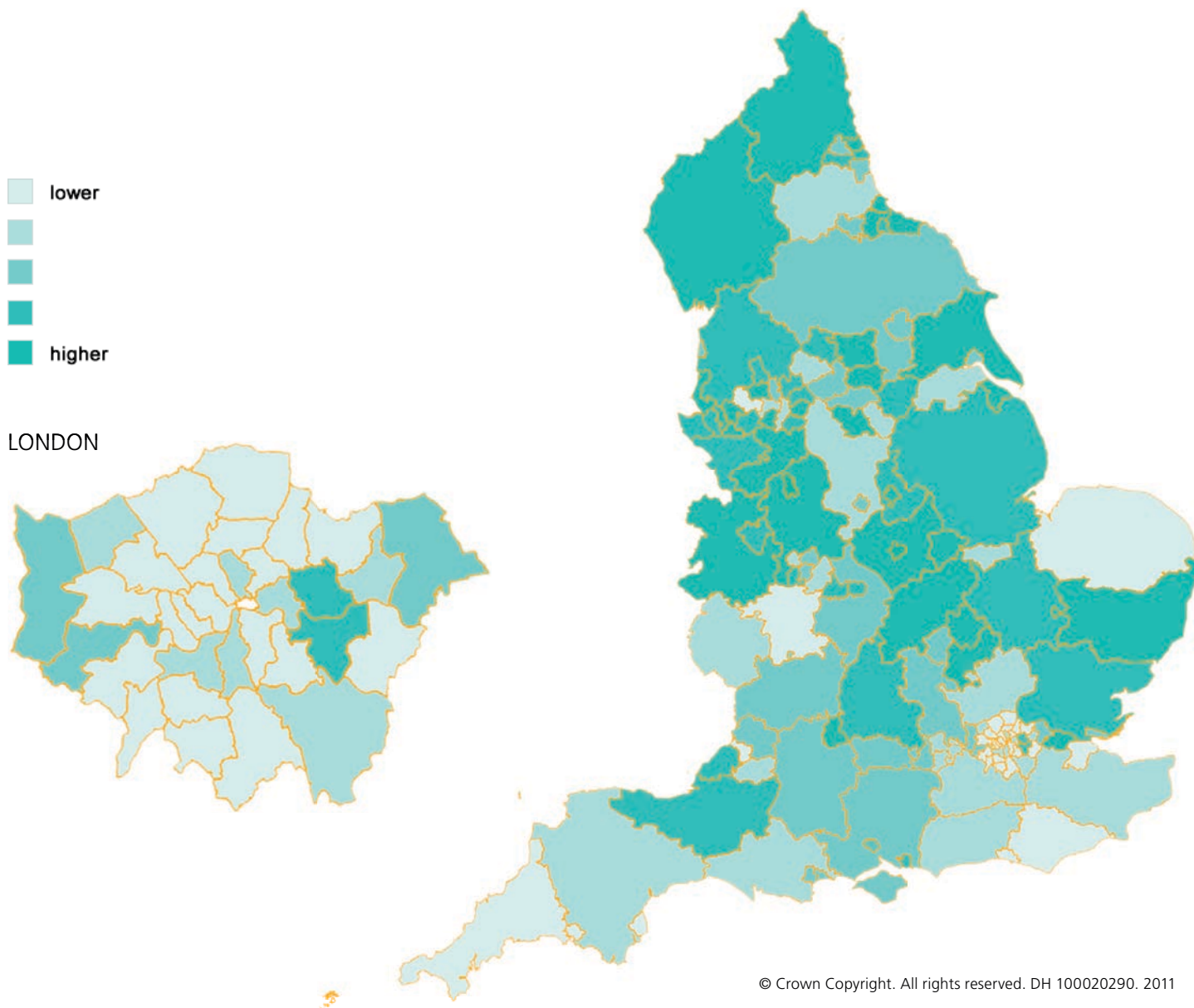
**Map 21** Pneumococcal conjugate vaccine (PCV) coverage at 2 years: Percentage of immunisation completion for routine vaccinations against pneumococcal disease at 2 years, by local authority, 2011–2012



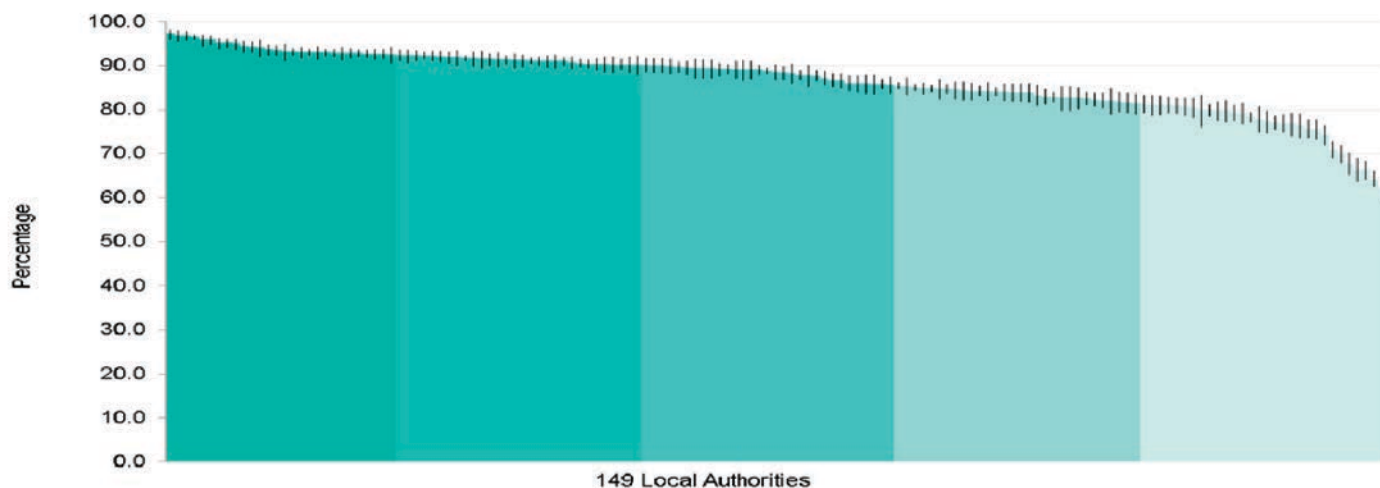
**Map 22** Measles, mumps and rubella (MMR) vaccine coverage at 5 years: Percentage of immunisation coverage for routine vaccinations against MMR at 5 years, by local authority, 2011–2012



**Map 23** Human papillomavirus (HPV) vaccine coverage at 13 years: Percentage of immunisation coverage for routine vaccinations against HPV for girls aged 12–13 years, by local authority, 2011–2012



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### Context

Childhood immunisations have transformed the health of children worldwide. For individuals, they may:

- prevent infection
- reduce deaths and morbidity from common, and often serious, infections
- reduce rates of related illnesses, such as certain cancers or secondary infections.

High levels of population immunity to some infectious diseases may protect those who are not immunised, known as 'herd immunity'.

Vaccines are cost-effective. The Health Protection Agency has demonstrated the economic benefits of vaccines currently included in the routine childhood immunisation schedule.<sup>1</sup>

Despite efforts to promote uptake, opportunities for immunisation are missed.<sup>2,3</sup> Investment (e.g. in Sure Start programmes) does not guarantee:

- improvement in overall rates<sup>4</sup>
- reduction of socio-economic inequalities in uptake.<sup>5</sup>

While most infants undergo routine immunisations, a small but significant minority of children remain unimmunised. In older children and adolescents, vaccination coverage is patchier. Recent outbreaks of vaccine-preventable diseases such as pertussis and measles have attracted media coverage but encouraging vaccination uptake remains essential.

In the UK:

- infants at 2 years of age should have received doses of vaccination against DTaP/IPV/Hib, meningococcal meningitis type c, rotavirus, pneumococcus and MMR
- by age 5, all children should have received further doses to maintain their immunity
- at 12–13 years, all girls are routinely offered the HPV vaccination, which helps to prevent future development of cervical cancer<sup>6</sup>
- by age 15, all vaccination programmes should be complete.

1 Health Protection Agency (2005). *Protecting the health of the Nation's children: the benefit of vaccines: 2005*. Available from: [www.hpa.org.uk/Publications/InfectiousDiseases/InfectionControl/0505Childrenhealthvaccinereport/](http://www.hpa.org.uk/Publications/InfectiousDiseases/InfectionControl/0505Childrenhealthvaccinereport/).

2 Conway SP (1999). Opportunistic immunisation in hospital. *Archives of Diseases in Childhood* 81:422 doi:10.1136/adc.81.5.422

3 Walton S, Elliman D and Bedford H (2007). Missed opportunities to vaccinate children admitted to a paediatric tertiary hospital. *Archives of Diseases in Childhood* 92:620 doi:10.1136/adc.2006.104778

4 Melhuish E, Belsky J, Leyland AH et al. (2008). Effects of fully-established Sure Start Local Programmes on 3-year-old children and their families living in England: a quasi-experimental observational study. *Lancet* 372:1641.

5 Reading R, Colver A, Openshaw S et al. (1994). Do interventions that improve immunisation uptake also reduce social inequalities in uptake? *British Medical Journal* 308:1142.

6 Department of Health (2013). *Immunisation against infectious disease: the green book*. Available from: [www.gov.uk/government/organisations/public-health-england/series/immunisation-against-infectious-disease-the-green-book#publications](http://www.gov.uk/government/organisations/public-health-england/series/immunisation-against-infectious-disease-the-green-book#publications).

The immunisation programme is constantly reviewed and new vaccines added as they become effective, available and affordable.

Four vaccinations have been selected for visualisation:

- At age 2 years: combined five-in-one vaccine for DTaP/IPV/Hib.
- At age 2 years: PCV.
- At age 5 years: MMR vaccination.
- Girls at age 12–13 years: HPV vaccination.

The first two indicators were included in the Atlas of Variation in Healthcare for Children and Young People (2012).

'Population vaccination coverage' is included in the NHS Public Health Outcomes Framework 2013–16.

### Magnitude of variation

#### Map 20: DTaP/IPV/Hib coverage at 2 years

For local authorities in England, the percentage of immunisation completion for routine vaccinations against DTaP/IPV/Hib at 2 years ranged from 85.7% to 98.8%. When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 90% to 98.6%.

However, this means that the percentage of children who did not receive the full course of DTaP/IPV/Hib vaccination ranged from 1.2% to 14.3% (nearly twelve-fold variation), and when the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 1.4% to 10% and the variation is seven-fold.

By comparison, after removing outliers in a similar way, the range (for 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 1.5% to 12.4%, and the variation was eight-fold.

#### Map 21: PCV coverage at 2 years

For local authorities in England, the percentage of immunisation completion for routine vaccinations against pneumococcal disease at 2 years ranged from 74.7% to 97% (range for percentage **not** having received the vaccine being 3% to 25.3% – an 8.4-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 81.1% to 96.3%, the range for percentage **not** having received the vaccine therefore being 3.7% to 18.9% – a five-fold variation.

By comparison, after removing outliers in a similar way, the range (for 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 5% to 28.5%, and the variation was nearly six-fold.

#### Map 22: MMR coverage at 5 years

For local authorities in England, the percentage of immunisation completion for routine vaccinations against MMR at 5 years ranged from 69.7% to 95.3% (range for



percentage **not** having received the vaccine being 4.7% to 30.3% – a 6.4-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 71.4% to 93.3%, the range for percentage **not** having received the vaccine therefore being 6.7% to 28.6% – a four-fold variation.

## Map 23: HPV coverage at 13 years:

For local authorities in England, the percentage of immunisation coverage for routine vaccinations against HPV for girls aged 12–13 years ranged from 62.3% to 97.2% (range for percentage **not** having received the vaccine being 2.8% to 27.7% – a thirteen-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 69.9% to 96%, the range for percentage **not** having received the vaccine therefore being 4% to 30.1% – a seven-fold variation.

In comparison with 2009–2010 data, DTaP/IPV/Hib coverage at 2 years has remained relatively static, while PCV coverage at 2 years is showing reduced range of variation through improved coverage in previously poorer performing areas. These improvements in uptake may reflect the fact that PCV is a relatively recent addition to the immunisation schedule: there is further scope for improvement.

## Options for action

Clinical leadership among public health, primary care and secondary care health professionals is key to maximising immunisation rates. Effective joint working between organisations and professionals may improve immunisation rates, especially in light of recent changes in commissioning and public health mechanisms. Child public health is currently the least well represented specialist function of community paediatric teams,<sup>7</sup> and plays an important role in the promotion of immunisation.

The National Institute for Health and Care Excellence recommends that commissioners ensure that their information and data collection systems can identify children who have missed immunisations, and offer them the opportunity to receive them in a timely manner.

The improvements shown in the population coverage for certain vaccines may not reflect a uniform improvement across all population subgroups. Further improvements may occur through targeting at-risk groups for improvement in immunisation rates, particularly among children who:

- have missed previous immunisations
- are not registered with a GP
- are from certain ethnic minority groups or non-English-speaking families

- are vulnerable, such as children with disabilities or a chronic illness, looked-after children, children who are homeless and children who are asylum seekers.

The reasons for partial immunisation may be different from the reasons given by people who refuse immunisation for their children; this should be taken into account when working to increase uptake rates.<sup>8</sup>

## Resources

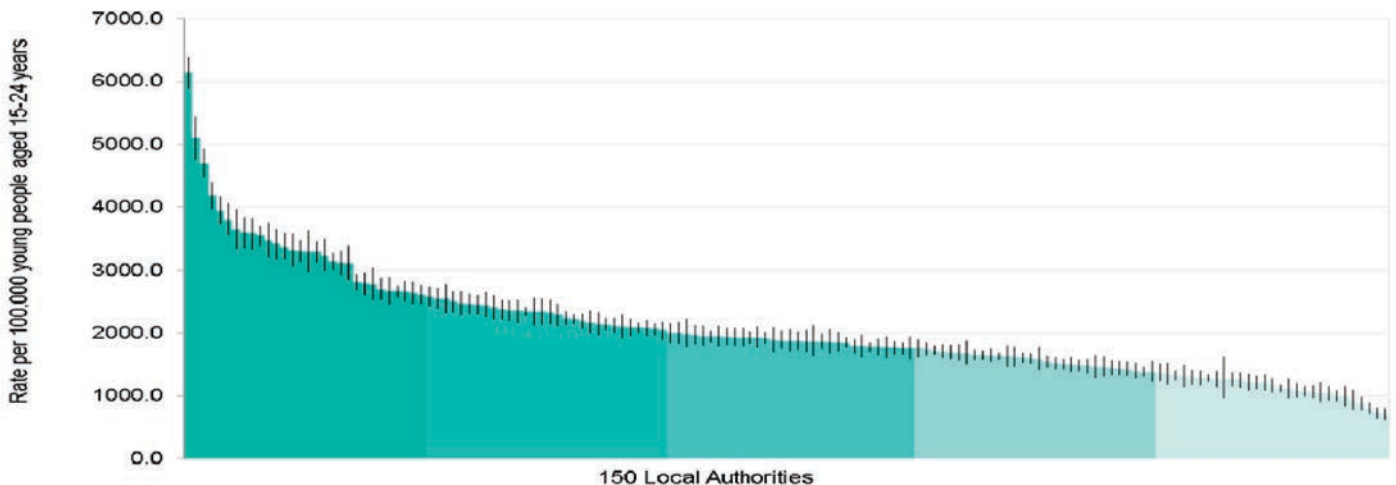
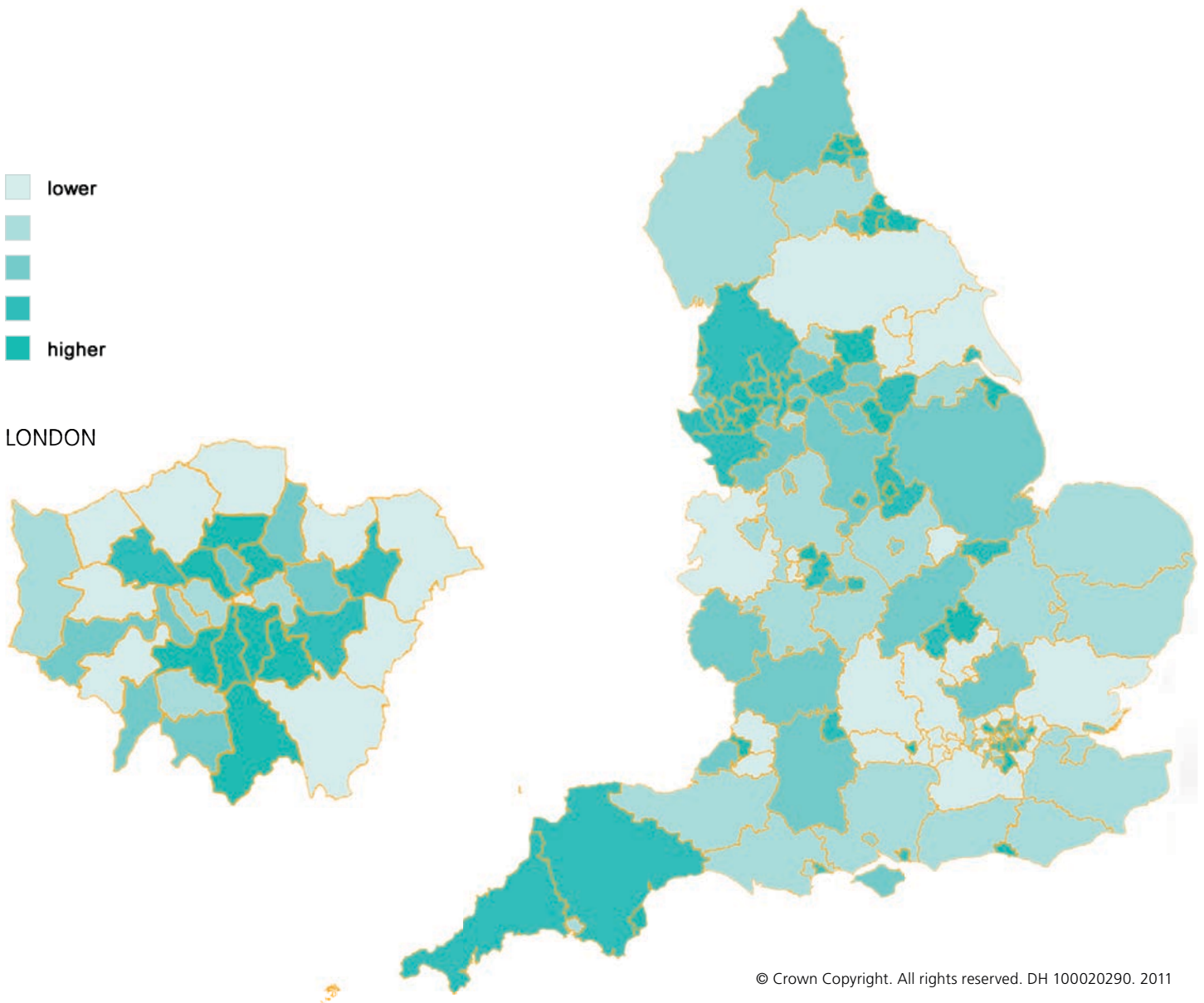
- NICE Guidance (2009). Guidance on differences in the uptake of immunisations (including targeted vaccines) in people younger than 19 years. Public health guidance, PH21 ([www.nice.org.uk/PH21](http://www.nice.org.uk/PH21)).

7 Royal College of Paediatrics and Child Health (2013). Medical Workforce Census 2011. RCPCH, London. Available at: [www.rcpch.ac.uk/system/files/protected/page/RCPCH%20census%20FINAL\\_0.pdf](http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20census%20FINAL_0.pdf).

8 Samad L, Tate AR, Dezateux C et al. (2006). Differences in risk factors for partial and no immunisation in the first year of life: prospective cohort study. *British Medical Journal* 332:1312.

G: Sexually transmitted infections

**Map 24** Chlamydia: Rate of diagnoses of genital *Chlamydia trachomatis* in young people aged 15–24 years, per 100,000 people aged 15–24 years, by local authority, 2012



## Context

Sexually transmitted infections (STIs) refer to infections which are transmitted through sexual contact. Commonest among these are chlamydia, gonorrhoea, syphilis, hepatitis B and C, and human immunodeficiency virus (HIV). Rates of STIs are highest in those aged under 25 years.<sup>1</sup>

Chlamydia (genital infection by *Chlamydia trachomatis*) is among the commonest bacterial STIs in England, particularly prevalent in young sexually active adults. Because it is often asymptomatic, many infections remain undetected, and can go on to cause long-term health problems such as pelvic inflammatory disease, ectopic pregnancy and subfertility. Once diagnosed, it can be treated with a course of antibiotics.

The National Chlamydia Screening Programme (NCSP) has been implementing chlamydia screening for sexually active young adults since 2003.

Any increase in the rate of diagnosis of chlamydia is more likely to reflect better detection, rather than being an indication of true increase in prevalence – although earlier and better diagnosis can lead to reduction in prevalence and future complications.

This indicator is included in the Public Health Outcomes Framework 2013–16.

## Magnitude of variation

**Map 24:** For local authorities in England, the rate of chlamydia diagnoses in young people aged 15–24 years, per 100,000 people aged 15–24 years, ranges from 702.8 to 6,131.9 (nearly nine-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 988.3 to 3,798.5, and the variation is nearly four-fold.

The NCSP recommends that local areas aim towards a diagnosis rate of over 2,300 per 100,000 population – a figure that only 47 out of 149 local authorities have been able to achieve.

The rate of chlamydia diagnosis is correlated with deprivation (see Figure 2G.1). This relationship, which mirrors the relationship that also exists between teenage pregnancy and deprivation, suggests that a targeted approach towards sexual health literacy and other related interventions in socio-economically deprived areas might be an effective means of reducing variation for local authorities.

## Options for action

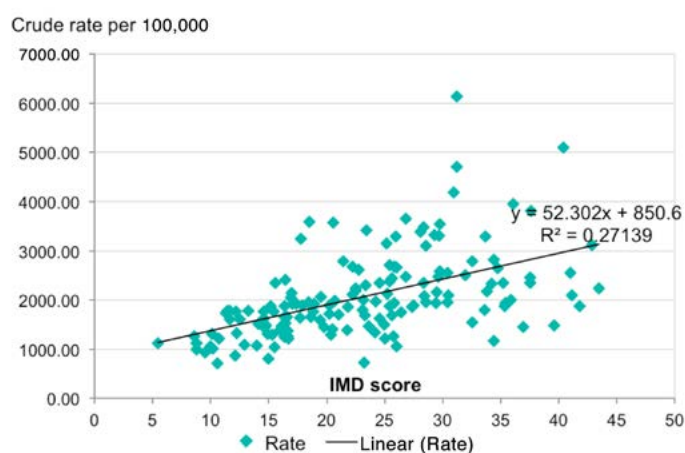
Chlamydia diagnosis rate is only one indicator of the sexual health of children and young people. Other STIs, in particular gonorrhoea, are becoming increasingly problematic in the context of antimicrobial resistance.<sup>2</sup> Commissioners and health and wellbeing boards are accountable for the sexual health of their populations based on a broad range of indicators. An example is the Sexual Health Balanced Scorecard (see 'Resources' later in this section).

Commissioners may maximise value by commissioning appropriate STI screening services through opportunistic health contacts such as general practice, sexual health services, abortion services, pharmacies and existing resources.

Adequate support and resource for public health messaging around sex education, sexual health services and proactive contraceptive advice is key. School- and community-based interventions have been shown previously to be particularly effective. Youth work, school nurses and pharmacy services, if appropriately resourced, can all play a significant role in this process.

It is important in sexual health services to take into account the needs of young people; following the You're Welcome criteria for young-people friendly health services will help to achieve this.<sup>3</sup>

**Figure 2G.1 Correlation between deprivation and rate of chlamydia diagnosis per 100,000 population, by local authority, 2012 (High IMD score indicates more deprived area)**



- Public Health England (2013). Sexually transmitted infections and chlamydia screening in England, 2012. Health Protection Report 7(23), 2013. Available from: [www.hpa.org.uk/hpr/archives/2013/hpr2313.pdf](http://www.hpa.org.uk/hpr/archives/2013/hpr2313.pdf).
- Department of Health (2007). You're Welcome - making health services young people friendly. Available from: <http://media.education.gov.uk/assets/files/pdf/y/youre%20welcome%20quality%20criteria%20making%20health%20services%20young%20people%20friendly.pdf>

1 Public Health England (2013). Sexually transmitted infections and chlamydia screening in England, 2012. Health Protection Report 7(23), 2013. Available from: [www.hpa.org.uk/hpr/archives/2013/hpr2313.pdf](http://www.hpa.org.uk/hpr/archives/2013/hpr2313.pdf).

### Resources

Department of Health (2013). A Framework for Sexual Health Improvement ([www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW\\_ACCESSIBLE.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW_ACCESSIBLE.pdf)).

The National Institute for Health and Care Excellence has produced national guidance related to one-to-one interventions in sexual health and for prevention of pregnancy in teenagers:

- Prevention of sexually transmitted infections and under 18 conceptions: guidance (2007) (<http://guidance.nice.org.uk/PH3/Guidance/pdf/English>).

Public Health England has a suite of tools to help commissioners and clinicians to understand local performance and variation in sexual health in their area:

- Sexual health tools and resources for commissioners ([www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/STIs/SexualHealthToolsResourcesForCommissioners/](http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/STIs/SexualHealthToolsResourcesForCommissioners/)).
- Sexual Health Balanced Scorecard ([www.apho.org.uk/sexualhealthbalancedscorecard](http://www.apho.org.uk/sexualhealthbalancedscorecard)).

NCSP ([www.chlamydiaSCREENING.nhs.uk/](http://www.chlamydiaSCREENING.nhs.uk/)).

- Commissioning guidance on integration of screening into core services ([www.chlamydiaSCREENING.nhs.uk/ps//resources/guidelines/NCSP-Commissioner-Integration-Guidance-Feb2012.pdf](http://www.chlamydiaSCREENING.nhs.uk/ps//resources/guidelines/NCSP-Commissioner-Integration-Guidance-Feb2012.pdf)).

Section 3:

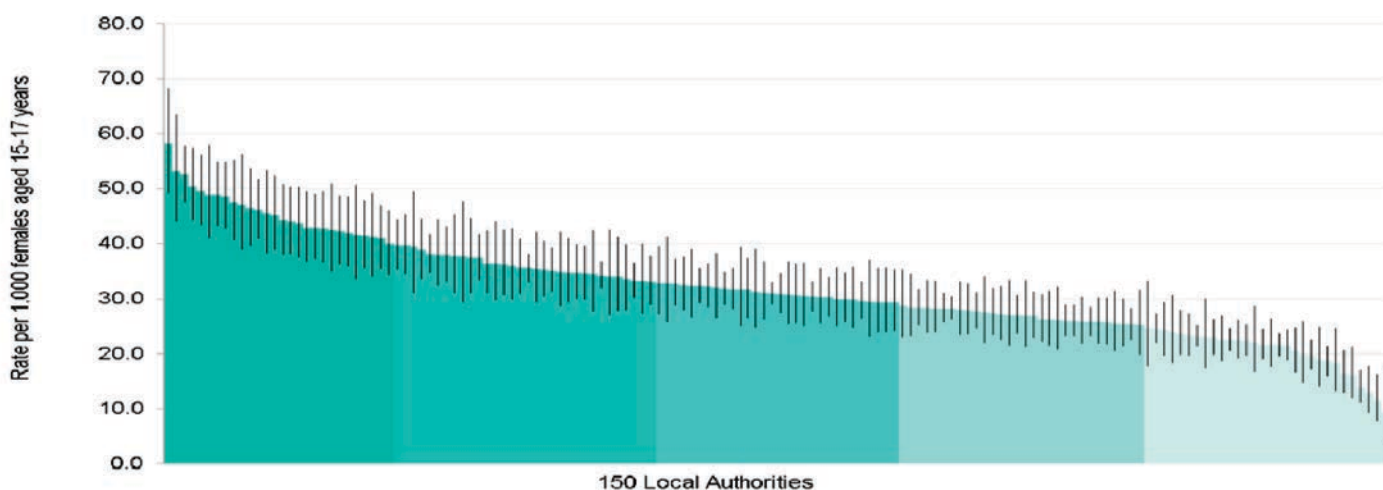
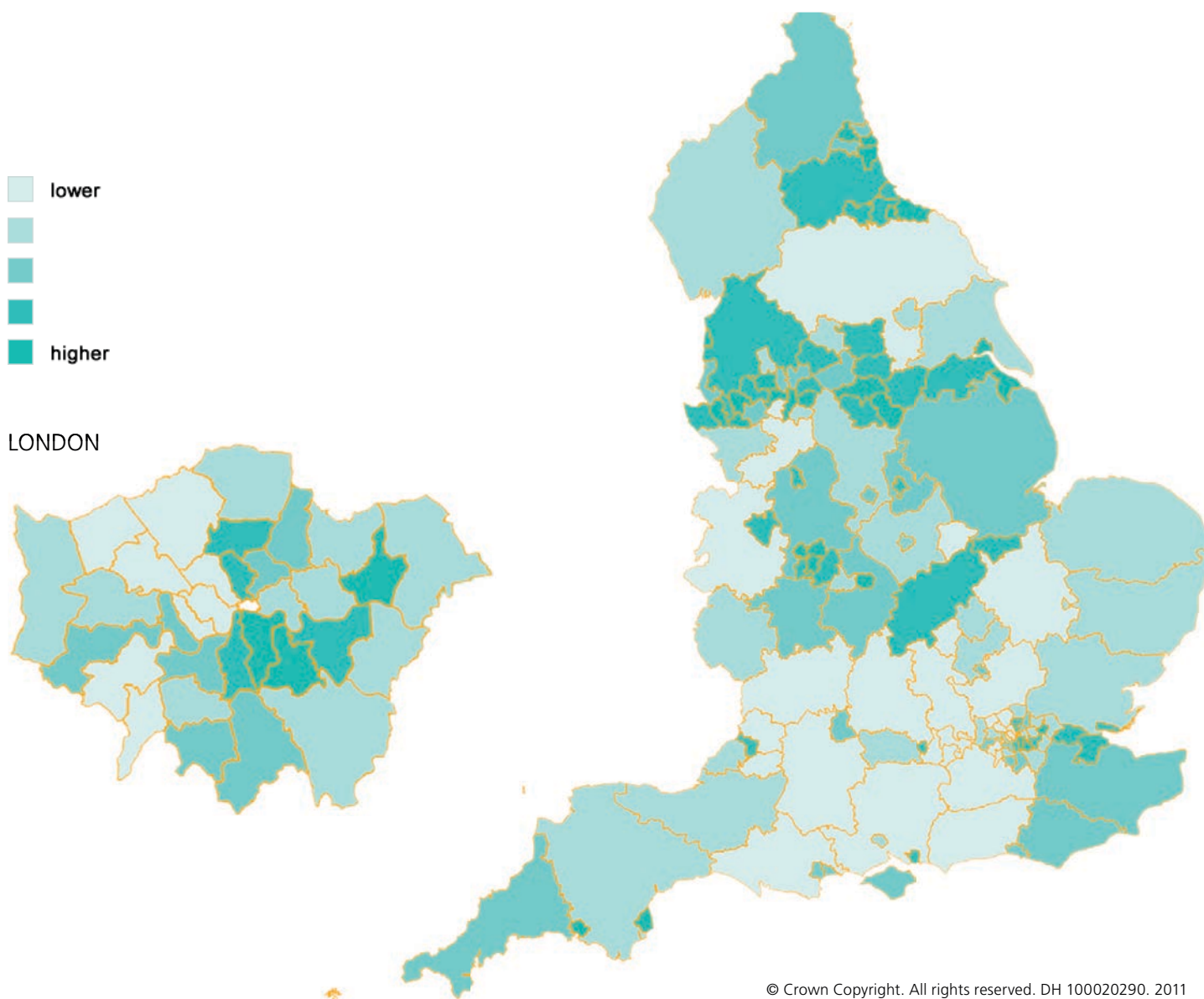
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# Child health in the perinatal period

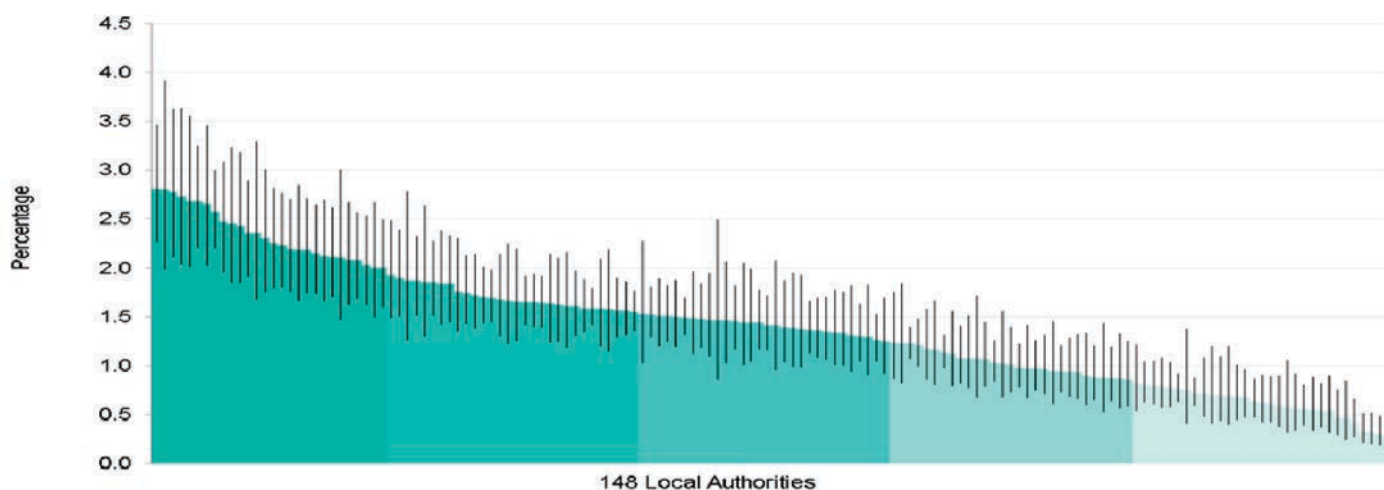
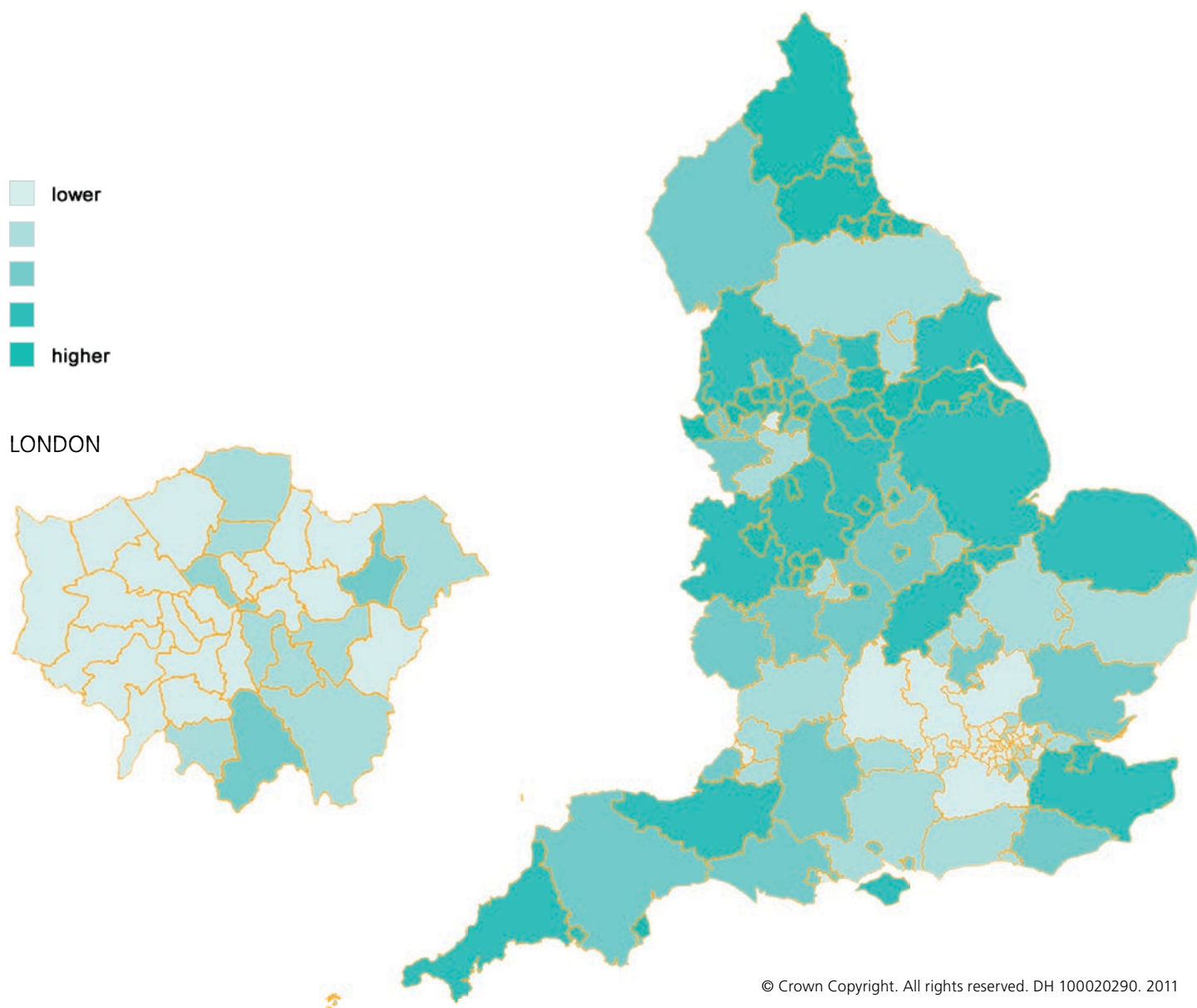


## A: Teenage pregnancy

**Map 25** Teenage conceptions: Conceptions in females aged <18 years, per 1,000 females aged 15–17 years, by local authority, 2011



**Map 26** Teenage births: Percentage of delivery episodes where the mother is aged <18 years, by local authority, 2011



## Context

Rates of teenage pregnancy in the UK have declined steadily since 1969. However, rates are still among the highest in Western Europe, and preventing teenage pregnancy is identified by government as a priority area in sexual health improvement.<sup>1</sup>

Rates of teenage pregnancy and motherhood are strongly related to wider determinants of health, and the effects on mother and child may be partly explained by these relationships. For the teenager herself, teenage pregnancy and motherhood is associated with lower socio-economic status and poorer educational outcomes, although the relationship is not necessarily causal. For the infant, the effect on life course is more significant. Infants of teenage mothers are at higher risk of:

- premature birth
- having a lower birth weight
- higher infant mortality
- poorer educational attainment
- becoming teenage mothers themselves.<sup>2</sup>

These indicators were recommended for inclusion as national outcome measures in the report of the Children and Young People's Health Outcomes Forum (2012). 'Teenage conceptions' is also included in the Public Health Outcomes Framework 2013–16.

## Magnitude of variation

### Map 25: Teenage conceptions

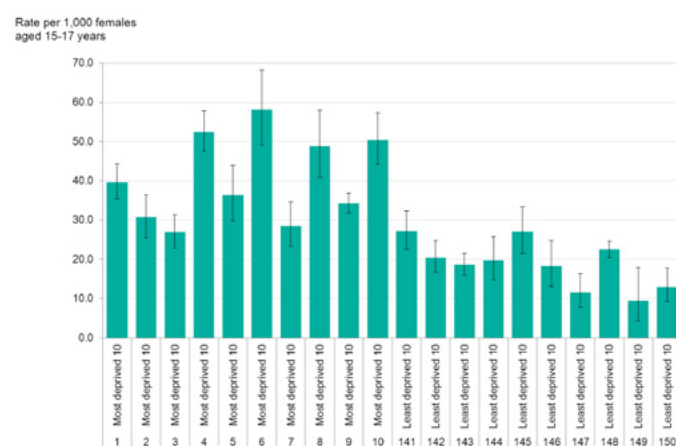
For local authorities in England, the rate of conceptions in females aged <18 years, per 1,000 females aged 15–17 years, ranges from 9.4 to 58.1 (over six-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 16.5 to 48.9, and the variation is three-fold.

### Map 26: Teenage births

For local authorities in England, the percentage of delivery episodes where the mother is aged <18 years ranges from 0.3% to 2.8% (nine-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 0.5% to 2.7%, and the variation is over five-fold.

Rates of teenage conception and delivery are strongly linked with deprivation. However, deprivation alone is unlikely to be the sole factor. Figure 3A.1 shows a two-fold variation in teenage conception rates among the 10 most deprived local authorities,

**Figure 3A.1 Teenage conception rate by local authority, in 10 most deprived and 10 least deprived local authorities, 2011**



and similar magnitude of variation among the 10 least deprived. This would suggest that unwarranted variation exists.

## Options for action

Public health messaging around sex education, sexual health services and proactive contraceptive advice are crucial. School and community-based interventions have been shown to be particularly effective. Youth work, school nurses and pharmacy services all play a role in this process and resourcing levels could be considered.

Commissioners and health professionals can work together to:

- assess whether performance locally compares favourably with that in localities which have a similar population profile
- share good practice, particularly among localities that have a similar socio-economic and age profile
- identify whether there are any unwarranted variations among social, ethnic or other groups in the local population, in order to target any relevant interventions.

Particularly where rates of teenage births are high, commissioners can investigate, working jointly with health and social care to resource and deliver community services that support teenage mothers leading to improved outcomes for mothers and infants.

It is important that antenatal and maternity services for teenage mothers are age-appropriate and that they take the needs of young mothers and their families into account, following the You're Welcome criteria for young people friendly health services.<sup>3</sup> Commissioning guidance is available (see 'Resources' later in this section).

1 A Framework for Sexual Health Improvement (2013). Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW\\_ACCESSIBLE.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW_ACCESSIBLE.pdf).

2 Swann C, Bowe K, McCormick G, Kosmin M. (2003). Teenage pregnancy and parenthood: a review of reviews. Health Development Agency, London. Available at: [www.nice.org.uk/niceMedia/documents/teenpreg\\_evidence\\_briefing\\_summary.pdf](http://www.nice.org.uk/niceMedia/documents/teenpreg_evidence_briefing_summary.pdf).

3 Department of Health (2007). You're Welcome – making health services young people friendly, 2007. Available from: <http://media.education.gov.uk/assets/files/pdf/y/youre%20welcome%20quality%20criteria%20making%20health%20services%20young%20people%20friendly.pdf>.

## Resources

Review of progress, evidence and case studies of interventions to reduce teenage pregnancy in England over the past decade:

- Department for Education (2010). Teenage pregnancy strategy: Beyond 2010 ([www.education.gov.uk/childrenandyoungpeople/healthandwellbeing/teenagepregnancy/a0066808/teenage-pregnancy-guidance](http://www.education.gov.uk/childrenandyoungpeople/healthandwellbeing/teenagepregnancy/a0066808/teenage-pregnancy-guidance))

Up-to-date government policy on this area is laid out here:

- A Framework for Sexual Health Improvement (2013) ([www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW\\_ACCESSIBLE.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW_ACCESSIBLE.pdf)).

The Department for Education and Department of Health have jointly produced several planning and commissioning guides to develop maternity services for young parents:

- Getting maternity services right for pregnant teenagers and young fathers (2010) ([www.swpho.nhs.uk/resource/item.aspx?RID=41060](http://www.swpho.nhs.uk/resource/item.aspx?RID=41060))
- Teenage parents: Who cares? A guide to commissioning and delivering maternity services for young parents (2008). ([www.swpho.nhs.uk/resource/item.aspx?RID=41058](http://www.swpho.nhs.uk/resource/item.aspx?RID=41058))

Local government and health and wellbeing boards will have a co-ordinating role in setting strategy for implementing services to reduce rates of teenage pregnancy:

- Local Government Association (2013). Tackling teenage pregnancy: Local government's new public health role ([www.local.gov.uk/publications/-/journal\\_content/56/10180/3964823/PUBLICATION](http://www.local.gov.uk/publications/-/journal_content/56/10180/3964823/PUBLICATION))

The National Institute for Health and Care Excellence (NICE) has produced national guidance related to one-to-one interventions in sexual health and for prevention of pregnancy in teenagers:

- Prevention of sexually transmitted infections and under 18 conceptions: guidance (2007) (<http://guidance.nice.org.uk/PH3/Guidance/pdf/English>).

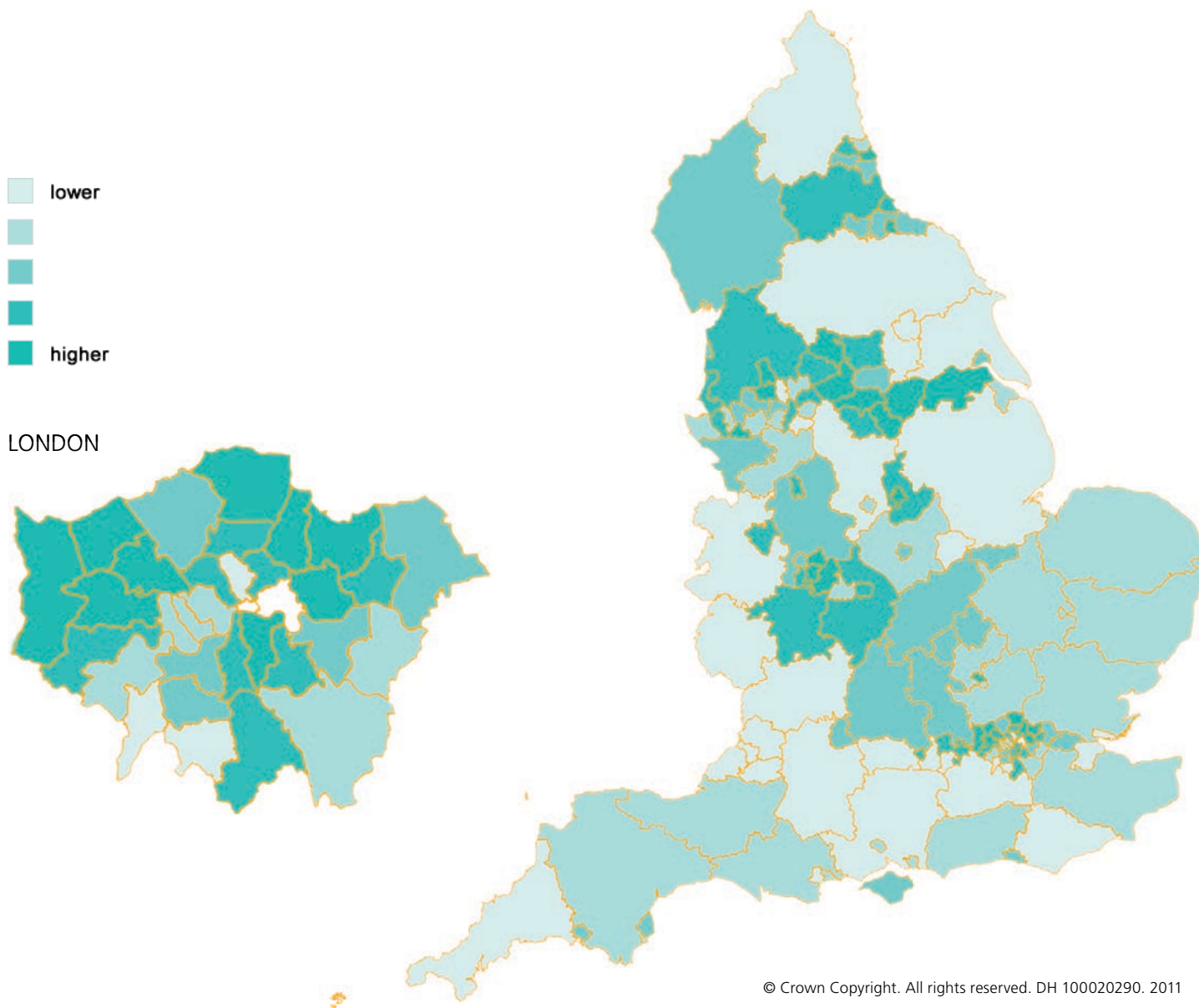
In addition, NICE has produced a review of systematic reviews which outlines the evidence for public health interventions both to reduce teenage pregnancy rates and to support teenage parents:

- Trivedi D et al. for NICE (2007). Update on review of reviews on teenage pregnancy and parenthood ([www.nice.org.uk/nicemedia/pdf/TeenagePregnancyUpdateReviewFeb08.pdf](http://www.nice.org.uk/nicemedia/pdf/TeenagePregnancyUpdateReviewFeb08.pdf)).

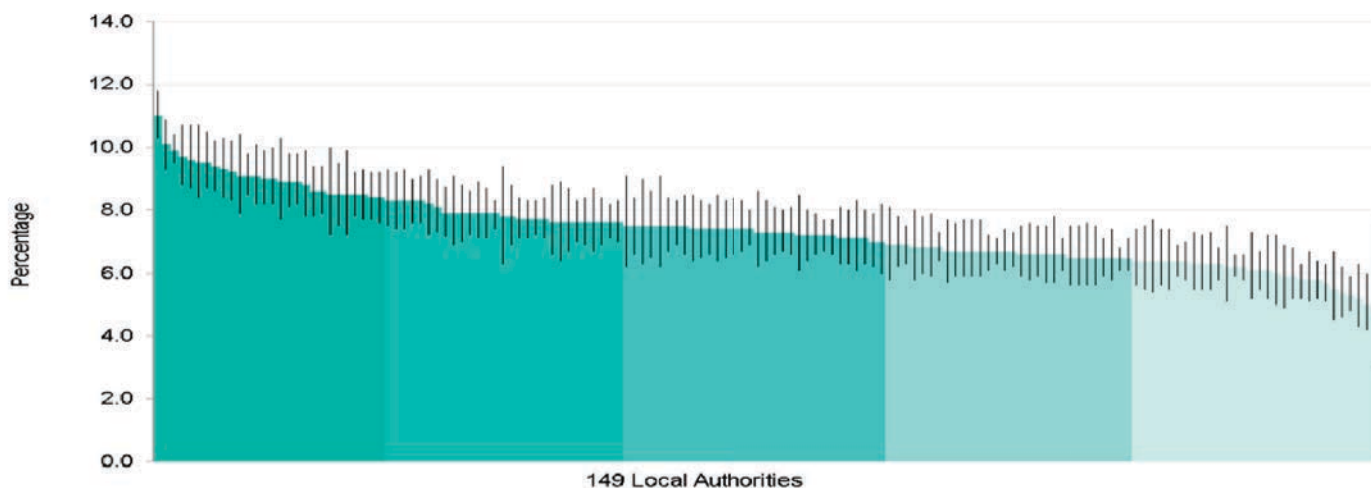


## B: Antenatal health

**Map 27** Low birth weight: Percentage of live and stillborn infants who have a birth weight <2,500g, by local authority, 2011

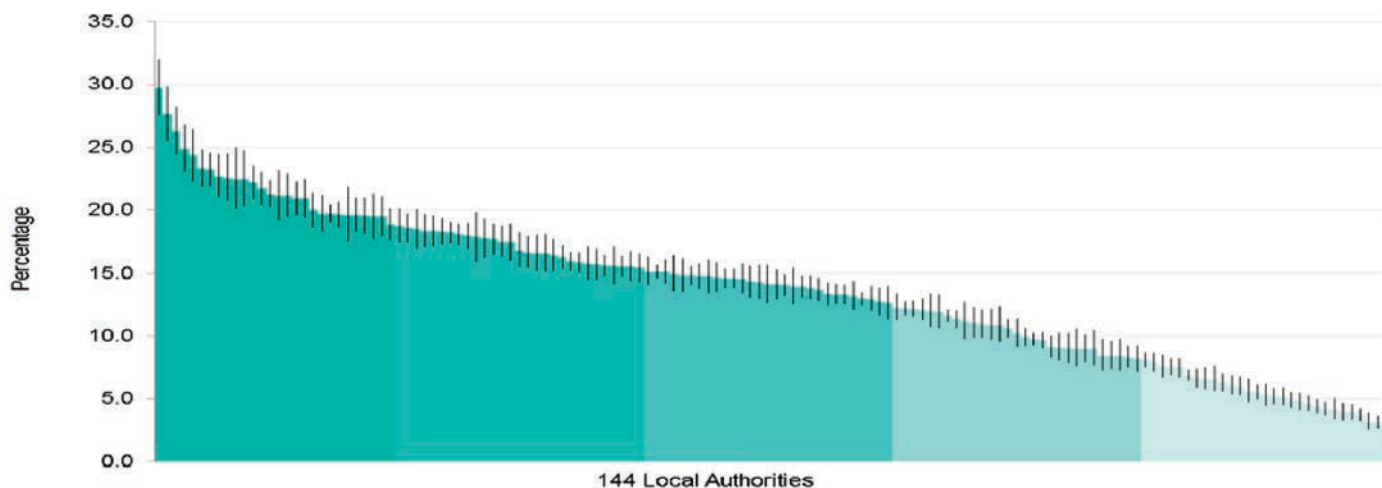
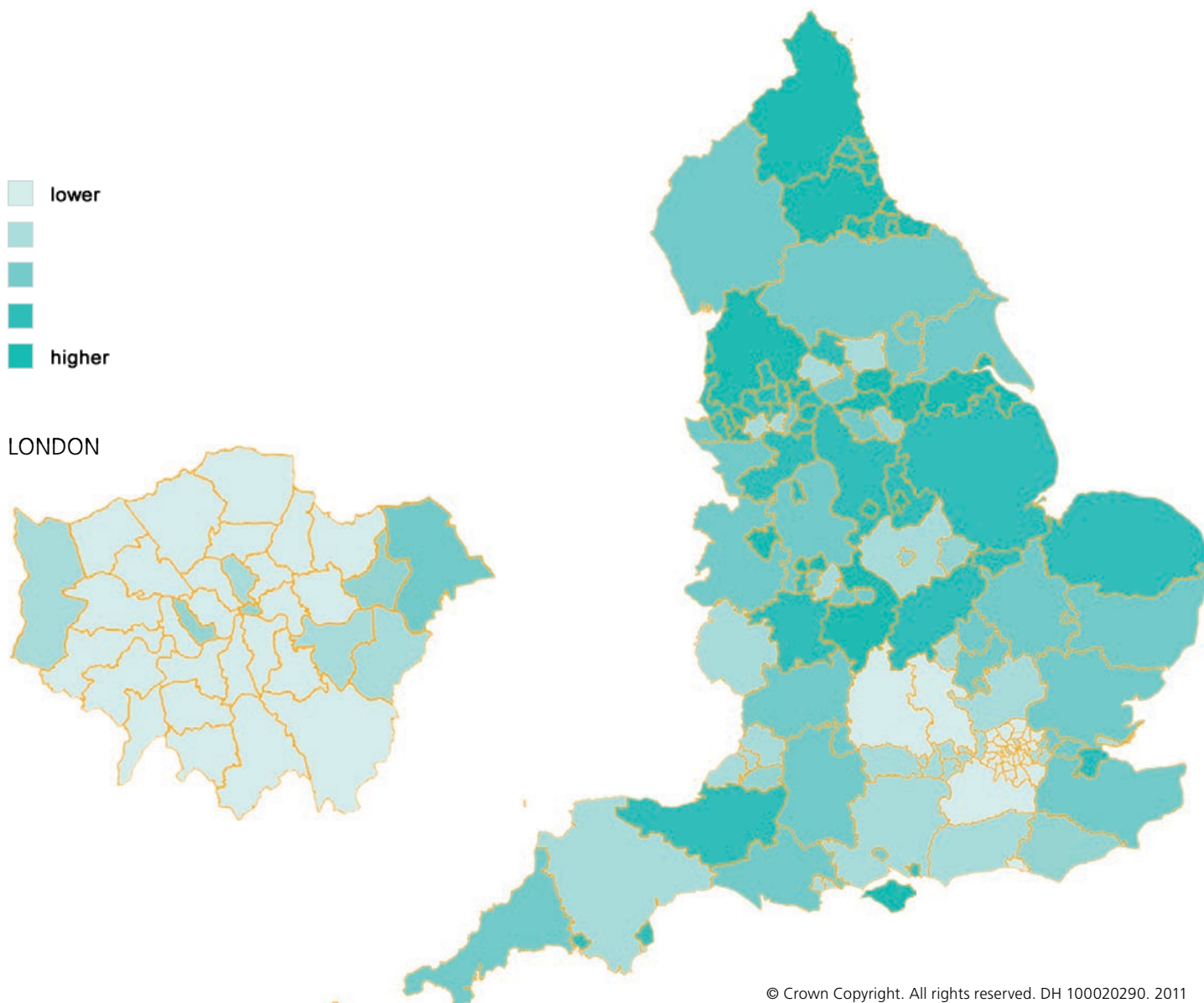


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**Map 28** Smoking in pregnancy: Percentage of women who currently smoke at the time of delivery, by local authority, 2011–2012



## Section 3: Child health in the perinatal period

### Context

The state of maternal health in the antenatal period has profound implications for the future health of the infant. Smoking and low birth weight are two selected indicators among many which highlight the state of maternal health and nutrition, as well as the quality of antenatal healthcare.

Smoking in pregnancy is known to cause deleterious effects on the health of the infant, both in infancy and in the future. These include increasing the risk of low birth weight babies.

Low birth weight may simply be constitutional, but is more often the result of other factors such as poor maternal nutrition, maternal hypertension, smoking, substance misuse or congenital infection. In those circumstances, low birth weight is associated with higher perinatal mortality, lower educational attainment and increased risk of cardiovascular disease and diabetes.<sup>1</sup> At a population level, the rate of infants born with a low birth weight may be a marker of poor maternal health in the antenatal period.

'Low birthweight of term babies' and 'Smoking status at time of delivery' are included in the Public Health Outcomes Framework 2013–16.

'Proportion of women who stop smoking during pregnancy' has also been recommended as a national outcome measure in the report of the Children and Young People's Health Outcomes Forum (2012); this data should be available through the new Maternity Services Secondary Uses Data Set.<sup>2</sup>

### Magnitude of variation

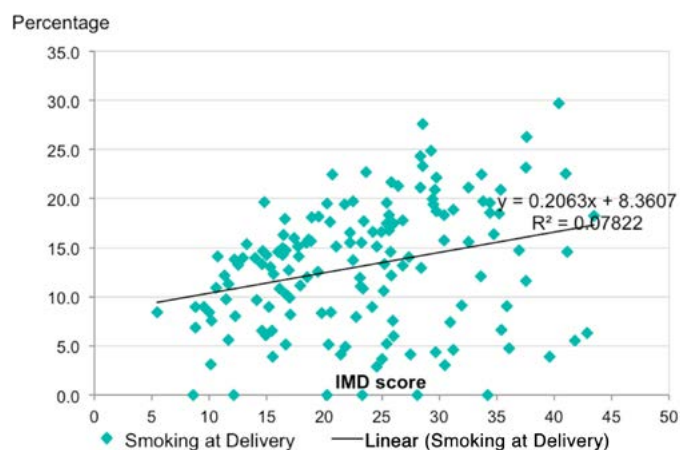
#### Map 27: Low birth weight

For local authorities in England, the percentage of live and stillborn infants who have a birth weight <2,500g ranged from 4.7% to 11% (2.3-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 5.5% to 9.5%, and the variation is 1.7-fold.

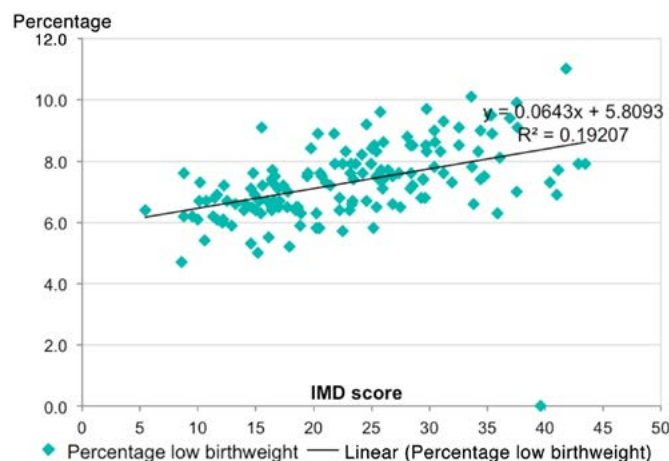
#### Map 28: Smoking in pregnancy

For local authorities in England, the percentage of women who currently smoke at the time of delivery ranged from 2.9% to 29.7% (over 10-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 4% to 23.3%, and the variation is nearly six-fold.

**Figure 3B.1 Correlation between maternal smoking at delivery and deprivation, by local authority, 2011 (High IMD score indicates more deprived area)**



**Figure 3B.2 Correlation between low birth weight and deprivation, by local authority, 2011 (High IMD score indicates more deprived area)**



Rates of low birth weight babies may be clouded by the inclusion of premature babies in the data. However, since risk and incidence profiles for both low birth weight and premature deliveries are known to be similar, this is unlikely to be able to fully account for the observed variation, but is more likely to reflect a common causal pathway related to antenatal health.

Socio-economic deprivation is known to be associated with both maternal smoking rates and incidence of low birth weight.<sup>3</sup> However, Figure 3B.1 and Figure 3B.2 demonstrate that the correlations shown in our data are relatively modest, meaning that deprivation cannot be the sole reason for the variation observed at local authority level.

Many other factors, such as ethnic background or maternal age, can also influence outcomes related to antenatal health. However, variation in the quality and access to antenatal and perinatal healthcare may account for unwarranted variations in perinatal mortality.

1 Kramer, M. S., Séguin, L., Lydon, J. and Goulet, L. (2000). Socio-economic disparities in pregnancy outcome: why do the poor fare so poorly? *Paediatric and Perinatal Epidemiology* 14: 194–210.

2 [www.hscic.gov.uk/maternityandchildren/maternity](http://www.hscic.gov.uk/maternityandchildren/maternity).

3 Oakley L et al. (2013). Factors associated with breastfeeding in England: an analysis by primary care trust. *BMJ Open* 2013; 3:e002765.

## Options for action

Commissioners can act to ensure the quality of pre-conception and antenatal care by:

- studying local variations in outcomes related to antenatal healthcare, in order to identify whether these variations are warranted or unwarranted
- ensuring that there is adequate capacity and training of community and hospital-based health professionals to deliver a high-quality antenatal and perinatal service for mothers and babies, including nutritional and other preventive health advice
- applying the evidence for the long-term benefits to infants and mothers of improvements in the health of women in the pre-conception period.

## Resources

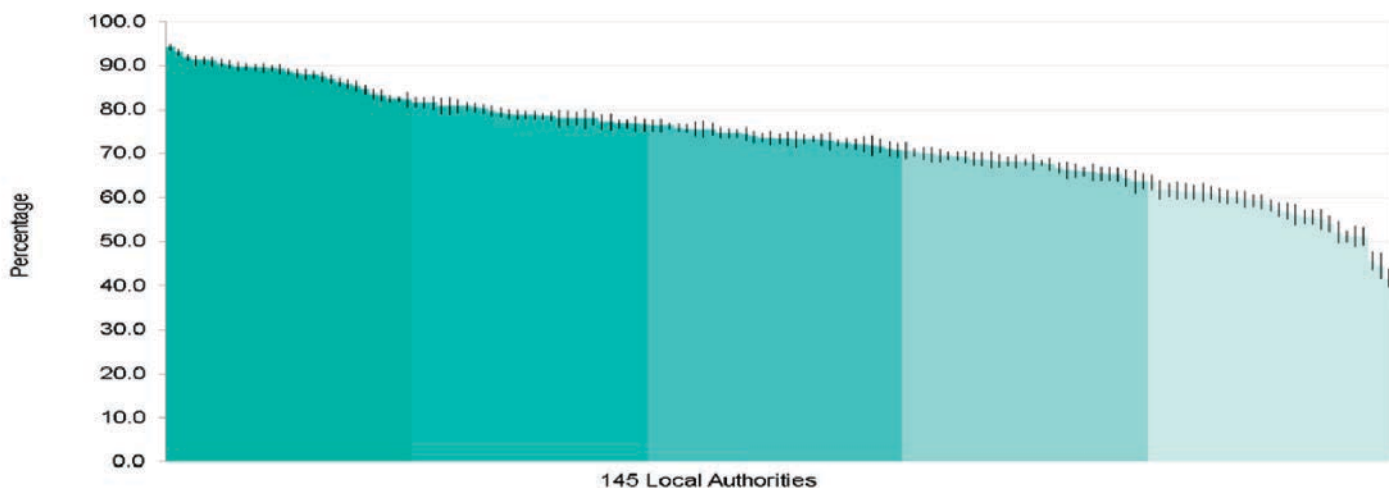
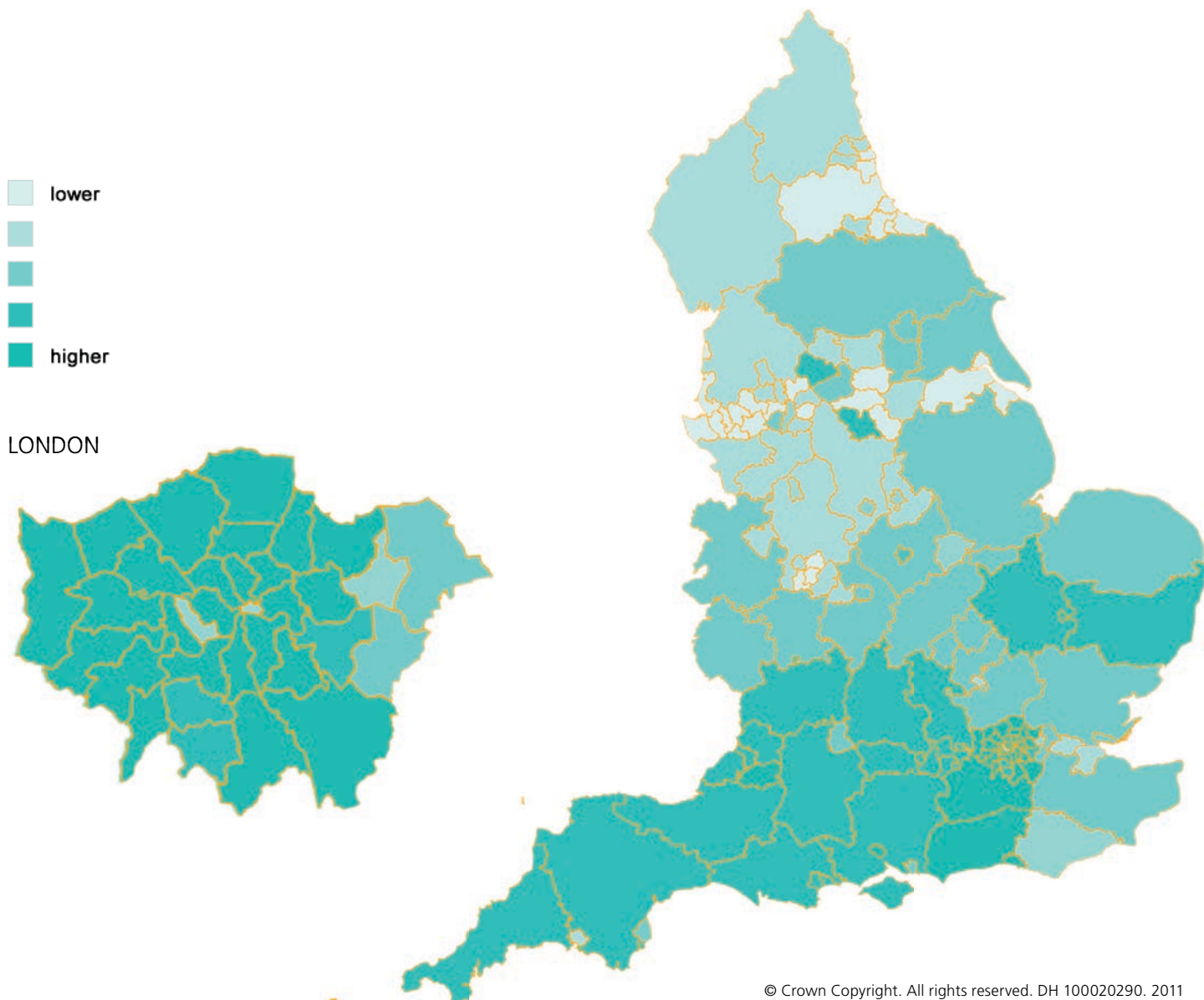
The National Institute for Health and Care Excellence has produced a suite of guidelines for:

- maternal and child nutrition (<http://guidance.nice.org.uk/PH11>)
- management of pregnancy and birth (<http://guidance.nice.org.uk/Topic/GynaecologyPregnancyBirth>).

Royal College of Obstetrics and Gynaecology, Faculty of Sexual and Reproductive Healthcare. Commissioning Women's Health Services: advice for clinical commissioning groups and NHS England. ([www.rcog.org.uk/files/rcog-corp/CommissioningWomen'sHealthServices\\_standards.xls](http://www.rcog.org.uk/files/rcog-corp/CommissioningWomen'sHealthServices_standards.xls)).

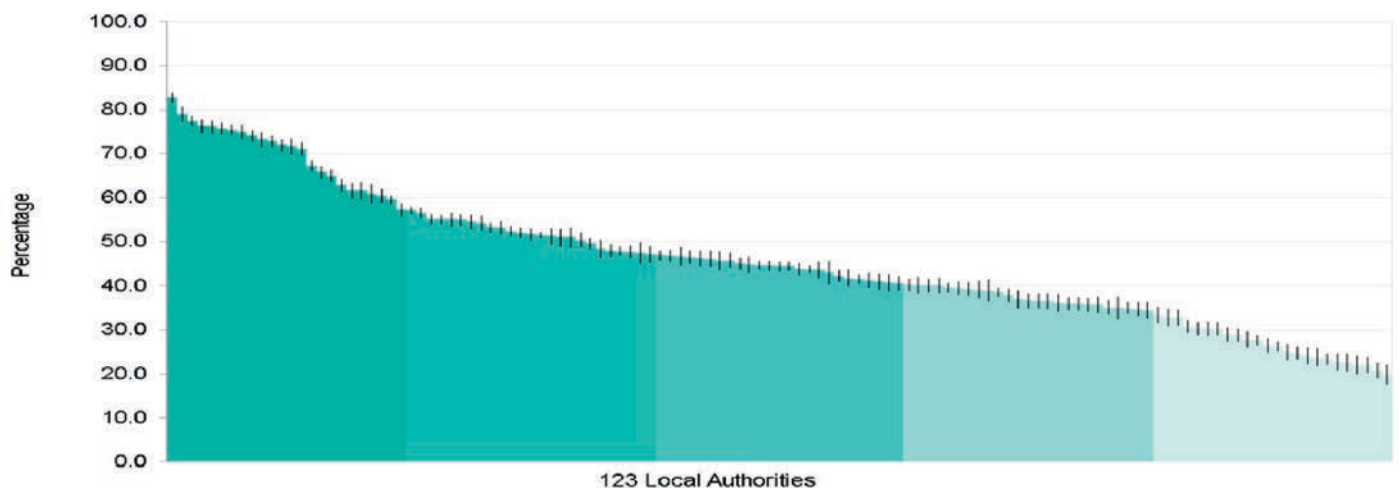
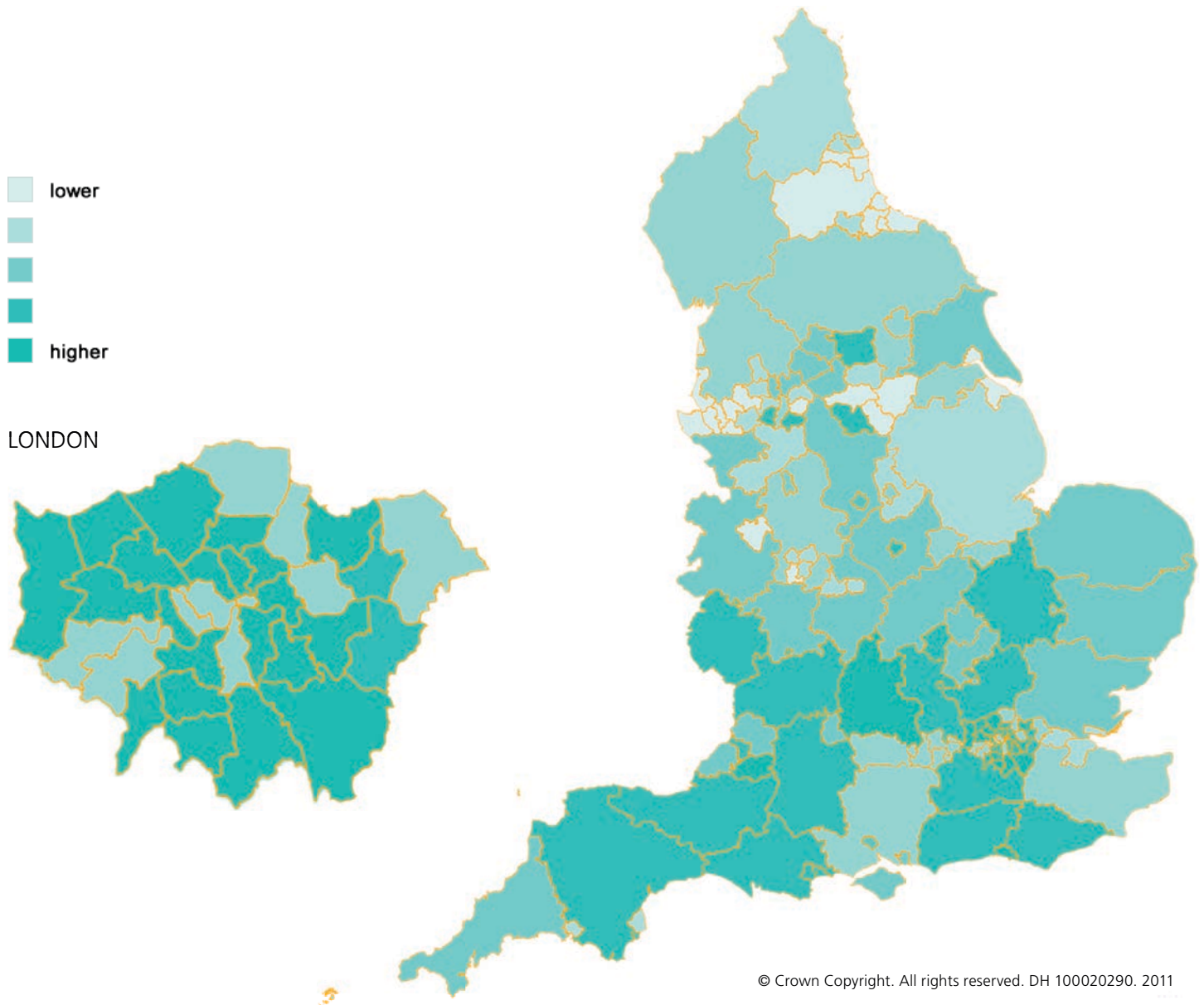
C: Breastfeeding

**Map 29** Breastfeeding initiation: Percentage of infants who are given breastmilk within 48 hours of delivery, by local authority, 2011–2012





**Map 30** Breastfeeding at 6–8 weeks: Percentage of infants who are totally or partially breastfeeding at 6–8 weeks, by local authority, 2011–2012





### Context

The World Health Organization and the Department of Health recommend exclusive breastfeeding of infants up to the age of 6 months. Although a minority of babies cannot be breastfed due to maternal health or other reasons, the benefits of breastfeeding are well established:

- Reduced hospital admissions of infants for diarrhoea and vomiting, and respiratory infections.
- Reduced risk of sudden infant death.
- Reduced lifetime risk of obesity and diabetes.<sup>1</sup>

In addition, women who breastfeed have a reduced risk of ovarian and breast cancers.

In economic studies, increasing rates of breastfeeding in infants have been found to have an overall cost benefit for families, health services and wider society.<sup>2</sup>

These indicators were recommended for inclusion as national outcome measures in the report of the Children and Young People's Health Outcomes Forum (2012).

Breastfeeding is included in the Public Health Outcomes Framework 2013–16.

### Magnitude of variation

#### Map 29: Breastfeeding initiation

For local authorities in England, the percentage of infants who were given breastmilk within 48 hours of delivery ranges from 41.8% to 94.3% (greater than two-fold variation).

When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 51.2% to 91.0%, and the variation is 1.8-fold.

#### Map 30: Breastfeeding at 6–8 weeks

For local authorities in England, the percentage of infants who are totally or partially breastfeeding by the 6–8 week infant examination ranges from 19.7% to 82.8% (four-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 22.7% to 75.7%, and the variation is over three-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2010/11) demonstrated in the NHS Atlas of Variation in Healthcare for Children and Young People (2012) was 23.1% to 74.6%, and the variation was also over three-fold.

The proportion of children being breastfed is heavily influenced by socio-economic factors, with deprivation

being associated with lower levels of breastfeeding.<sup>3</sup> Our data corroborate this association, although the correlation with deprivation is not marked (see Figure 3C.1). Although breastfeeding is a complex issue for which deprivation is only one influencing factor, this finding suggests that considerable unwarranted variation exists.

New mothers vary in the degree of support they need to initiate and sustain breastfeeding. Variation in the provision of local community midwifery, health visitor and perinatal care will significantly impact on rates of breastfeeding among local authorities.

### Options for action

Commissioners and clinicians can review the proportion of infants being breastfed in the local population and share good practice, particularly among localities that have a similar socio-economic and ethnic profile.

Commissioners and health professionals can improve the service they provide by:

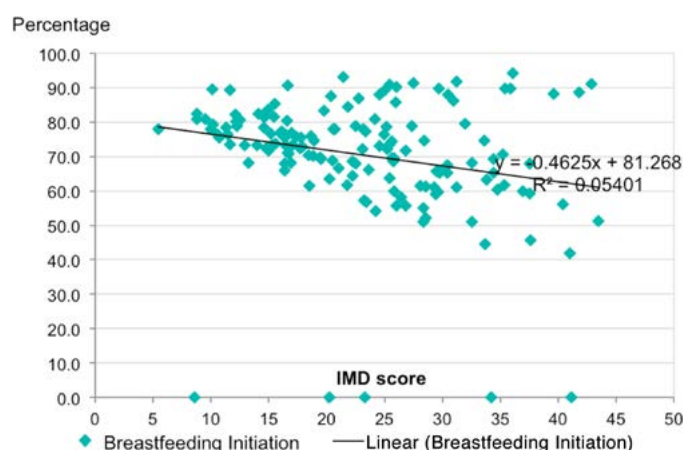
- assessing whether local performance compares favourably with that in localities which have a similar population profile
- identifying whether there are any unwarranted variations among social, ethnic or other groups in the local population, to understand the reasons for low rates in order to target relevant interventions.

Commissioners can help to ensure that there is adequate support for mothers and families, not only to establish breastfeeding, but also to prolong its duration. Actions could include:

- improving education (both antenatal and postnatal)
- dissemination of public health messages.

In particular, these actions should be aimed at groups where rates are found to be especially low.

**Figure 3C.1 Relationship between deprivation and breastfeeding initiation, by local authority, 2011–2012 (High IMD score indicates more deprived area)**



1 Horta BL, Victora CG (2013). Long-term of breastfeeding: a systematic review. World Health Organization. Available at: [http://apps.who.int/iris/bitstream/10665/79198/1/9789241505307\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/79198/1/9789241505307_eng.pdf).

2 Renfrew MJ et al. (2012). Preventing disease and saving resources: the potential contribution of increasing breastfeeding rates in the UK. UNICEF UK. Available at: [www.unicef.org.uk/Documents/Baby\\_Friendly/Research/Preventing\\_disease\\_saving\\_resources.pdf](http://www.unicef.org.uk/Documents/Baby_Friendly/Research/Preventing_disease_saving_resources.pdf).

3 L Oakley et al. (2013). Factors associated with breastfeeding in England: an analysis by primary care trust. *BMJ Open* 3:e002765

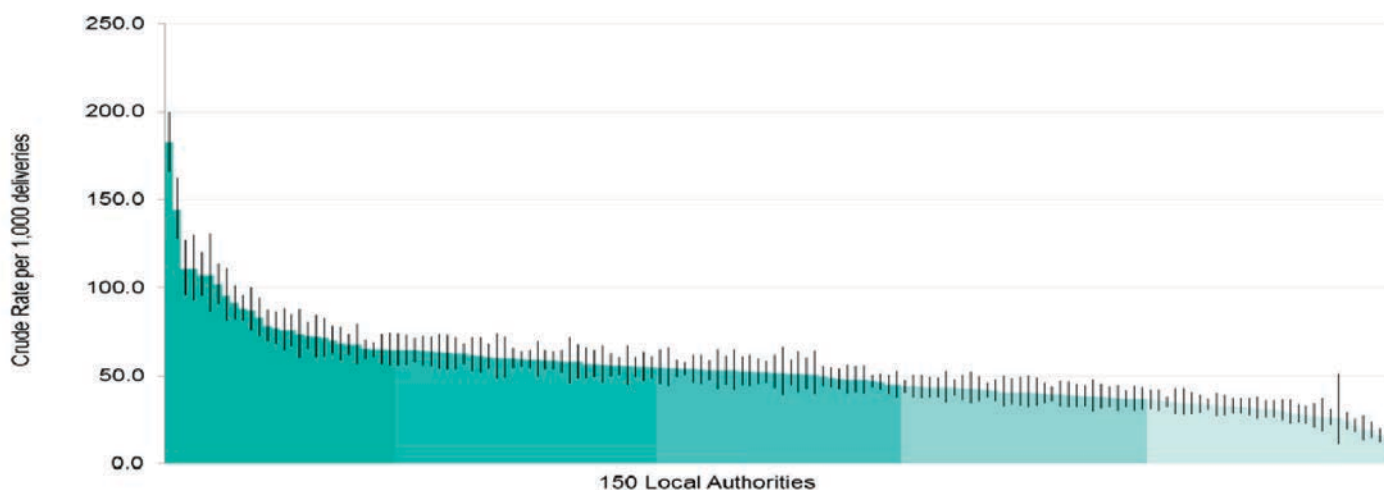
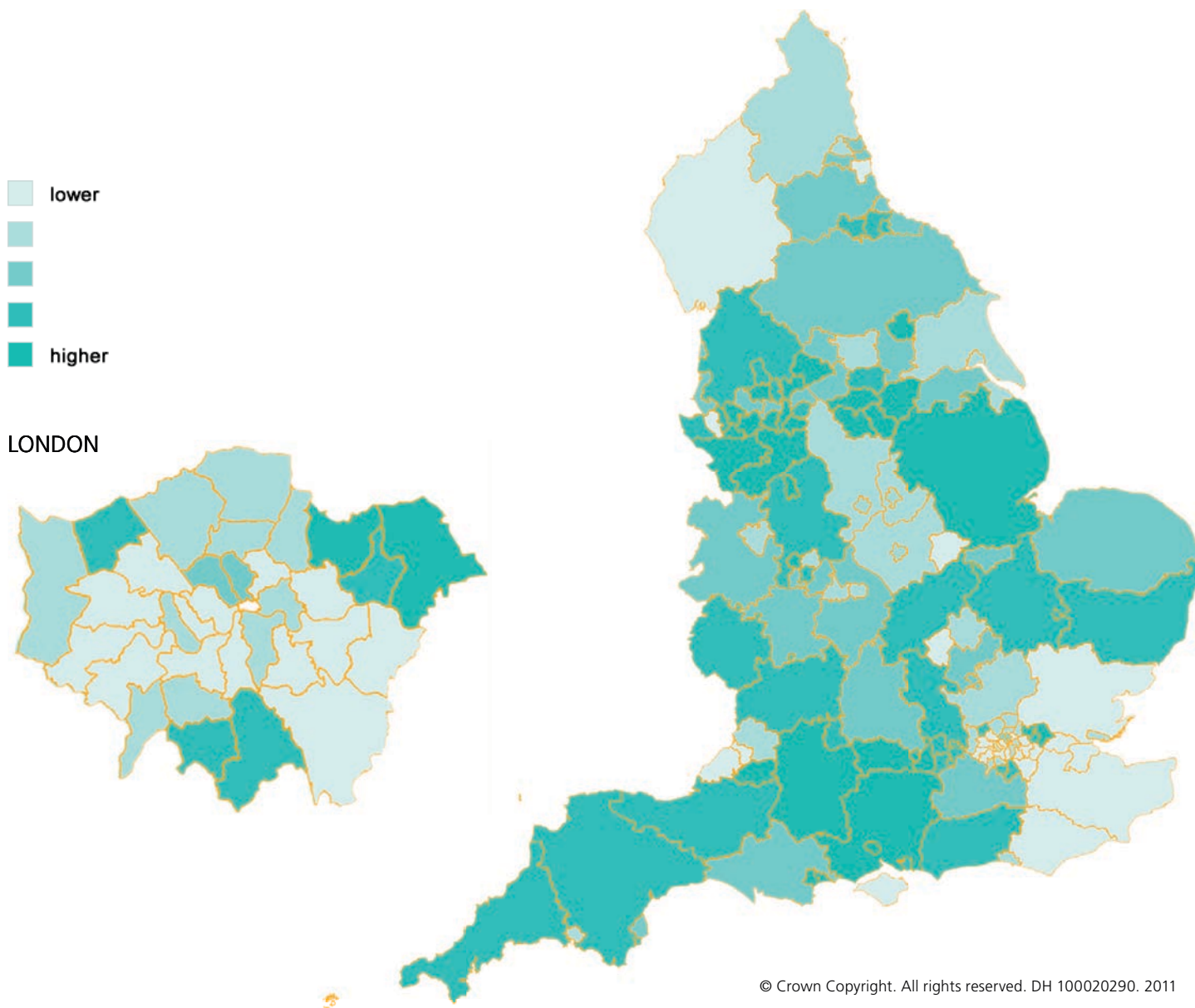
## Resources

The National Institute for Health and Care Excellence has produced a suite of guidance for promoting breastfeeding:

- A briefing on evidence-based actions for breastfeeding promotion – ‘Promotion of breastfeeding initiation and duration: Evidence into practice’ (2006) ([www.nice.org.uk/niceMedia/pdf/EAB\\_Breastfeeding\\_final\\_version.pdf](http://www.nice.org.uk/niceMedia/pdf/EAB_Breastfeeding_final_version.pdf)).
- A commissioning guide to implement a peer support programme for women who breastfeed ([www.nice.org.uk/usingguidance/commissioningguides/breastfeed/breastfeed.jsp](http://www.nice.org.uk/usingguidance/commissioningguides/breastfeed/breastfeed.jsp)).
- Best practice guidelines for routine postnatal care ([www.nice.org.uk/CG037](http://www.nice.org.uk/CG037)) and maternal and child nutrition (<http://guidance.nice.org.uk/PH11>).

D: Postnatal health

**Map 31** Postnatal health: Rate of emergency admissions to hospital of babies within 14 days of being born per 1,000 deliveries, by local authority, 2011–2012



## Context

The Healthcare Commission report 'Towards better births: a review of maternity services in England' drew attention to the problem of re-admission of mothers and babies:

*'High levels of re-admissions of either mother or babies can suggest problems with either the timing or quality of health assessments before the initial transfer or with the postnatal care once the mother is home. Dehydration and jaundice are two common reasons for re-admission of babies and are often linked to problems with feeding. Half of the trusts had an admission rate of 8 per 1,000 babies or greater for these conditions two or more days after birth.'*<sup>1</sup>

Postnatal care provision crosses acute and primary healthcare sectors, with the majority of care taking place in the woman's home. Care is likely to include:

- routine clinical examination and observation of the woman and her baby
- routine infant screening to detect potential disorders
- support for infant feeding
- ongoing provision of information and support.

Helping mothers to know what signs and symptoms indicate something serious and what is normal gives them reassurance and confidence.

Giving babies the best start in life through good-quality postnatal care means that they are less likely to have health problems during childhood and into adulthood.

A similar indicator – 'Emergency admissions of home births and re-admissions to hospital of babies within 14 days of being born per all live births' – was included in the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

'Admission of full-term babies to neonatal care' is included in the NHS Outcomes Framework 2013/14.

## Magnitude of variation

**Map 31:** For local authorities in England, the rate of emergency admissions to hospital of babies within 14 days of being born per 1,000 deliveries ranges from 14.6 to 182.3 (greater than twelve-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 24.3 to 107.1, and the variation is 4.5-fold.

## Options for action

Commissioners and providers can work together to improve the antenatal education and information provided to parents. At each postnatal contact, parents could be offered information and advice to enable them to:

- assess their baby's general condition
- identify signs and symptoms of common health problems in babies
- contact a healthcare professional or emergency service if required.

Commissioners can work with providers to ensure that National Institute for Health and Care Excellence (NICE) guidelines on postnatal care are implemented (see 'Resources', below), and in particular that:

- examination of the newborn is undertaken by suitably qualified healthcare professionals
- each woman has her own personalised care plan which takes into account not only her needs but also her baby's.
- Evaluating babies who develop jaundice within the first 24 hours
- For babies aged  $\geq 24$  hours, monitoring and systematically recording the intensity of the jaundice together with the baby's overall wellbeing, with particular regard to hydration and alertness.

As a minimum standard, all maternity care providers could implement an externally evaluated structured programme that encourages breastfeeding, such as the Baby Friendly Initiative (see "Resources" later in this section).

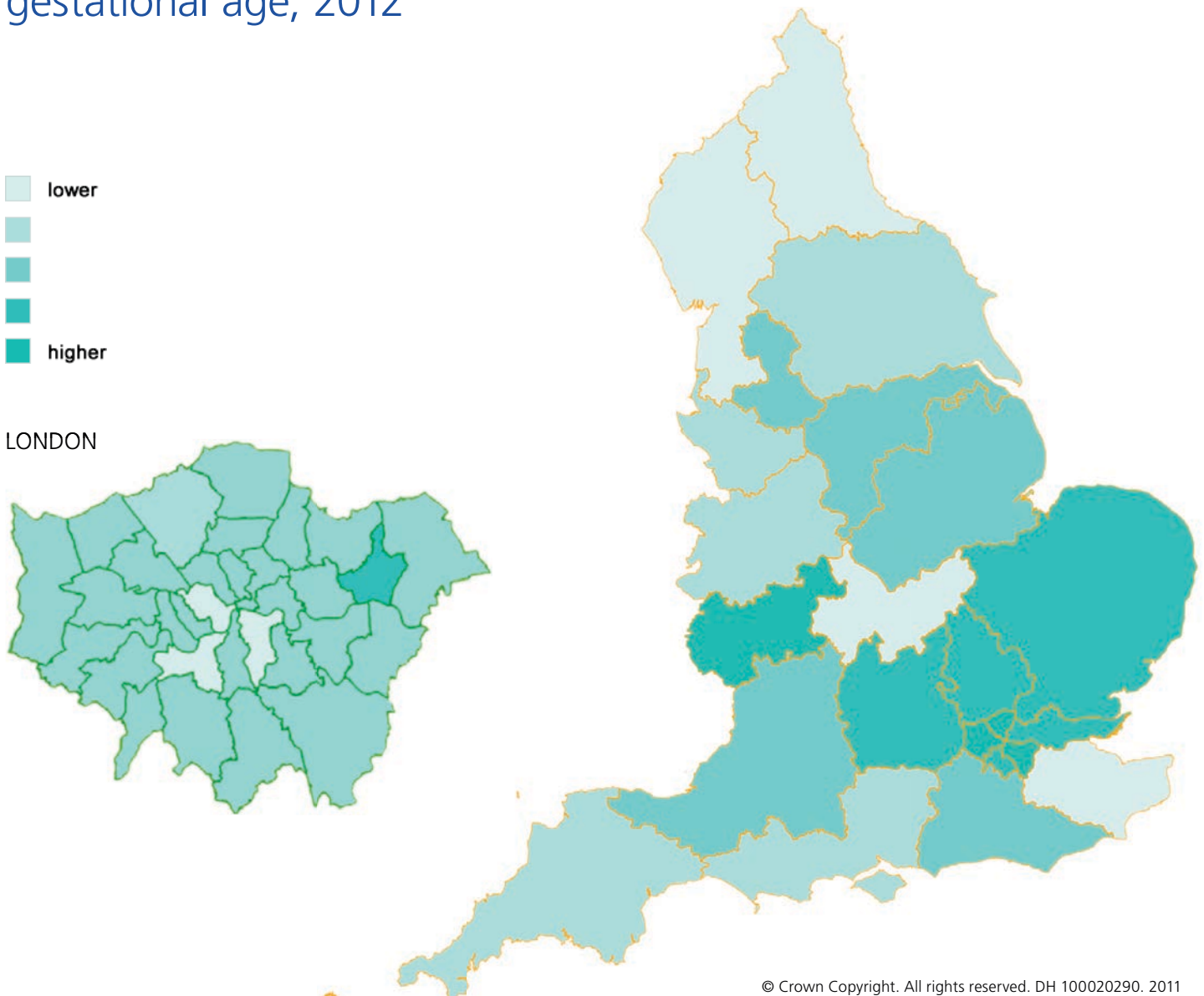
## Resources

- NICE Guidance (2006). Postnatal care: Routine postnatal care of women and their babies. Clinical guidelines, CG37 ([www.nice.org.uk/CG037](http://www.nice.org.uk/CG037)).
- Baby Friendly Initiative ([www.babyfriendly.org.uk](http://www.babyfriendly.org.uk)).
- Royal College of Obstetricians and Gynaecologists (2008). Standards for Maternity Care ([www.rcog.org.uk/womens-health/clinical-guidance/standards-maternity-care](http://www.rcog.org.uk/womens-health/clinical-guidance/standards-maternity-care)).

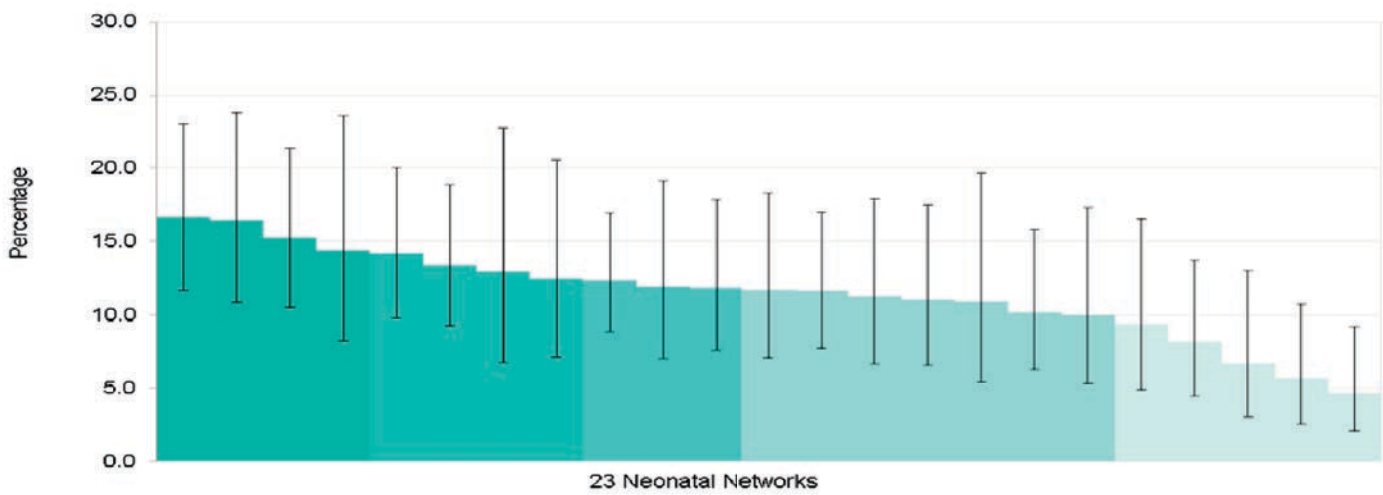
<sup>1</sup> Healthcare Commission (2008). *Towards better births: A review of maternity services in England*. Available at: [http://webarchive.nationalarchives.gov.uk/20101014074803/http://www.cqc.org.uk/\\_db/\\_documents/Towards\\_better\\_births\\_200807221338.pdf](http://webarchive.nationalarchives.gov.uk/20101014074803/http://www.cqc.org.uk/_db/_documents/Towards_better_births_200807221338.pdf).

E: Preterm birth

**Map 32** Neonatal mortality: Percentage of infants born at <30 weeks' gestation and admitted to neonatal units, who died ≤28 days, by neonatal network of booking, directly standardised by gestational age, 2012

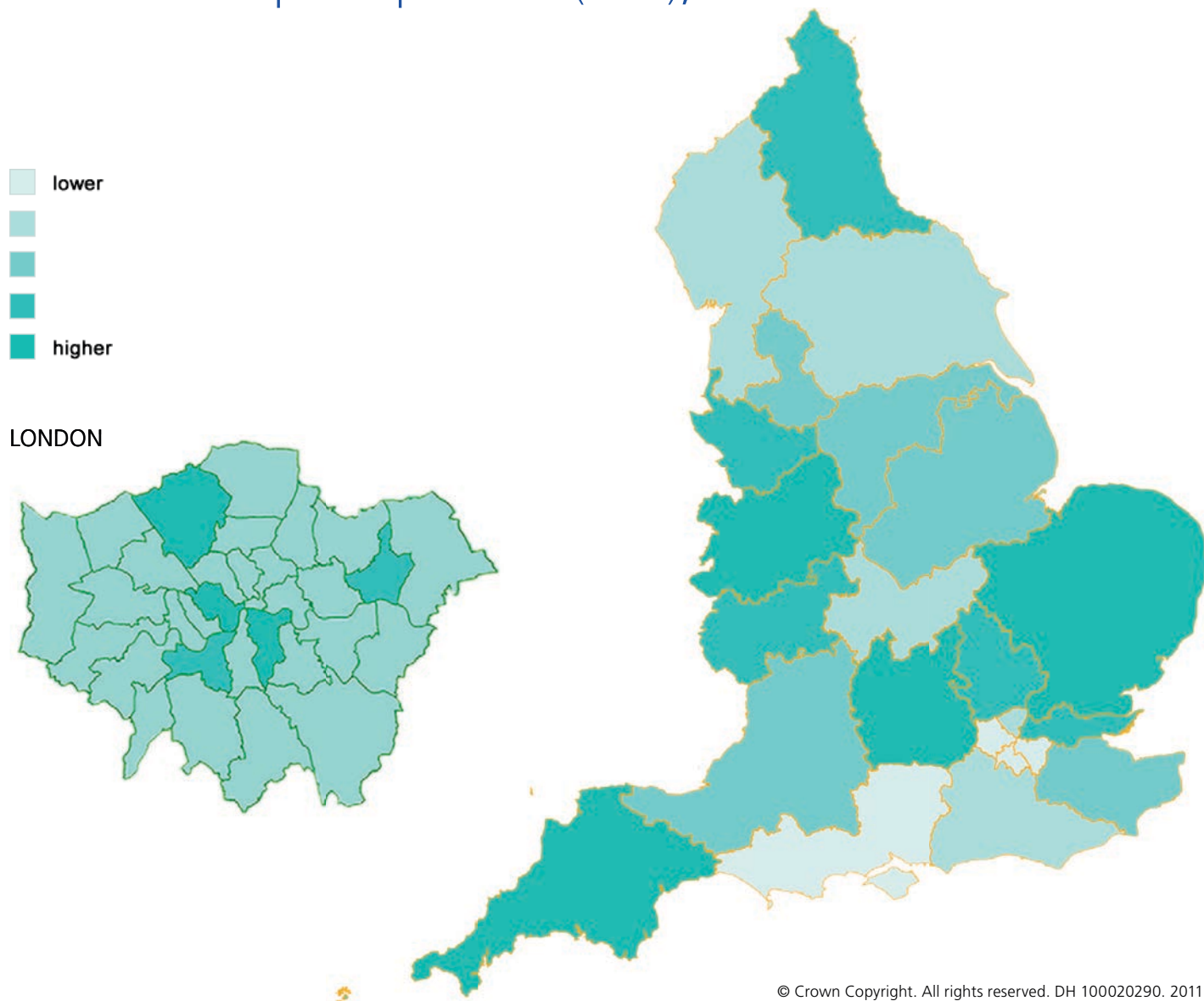


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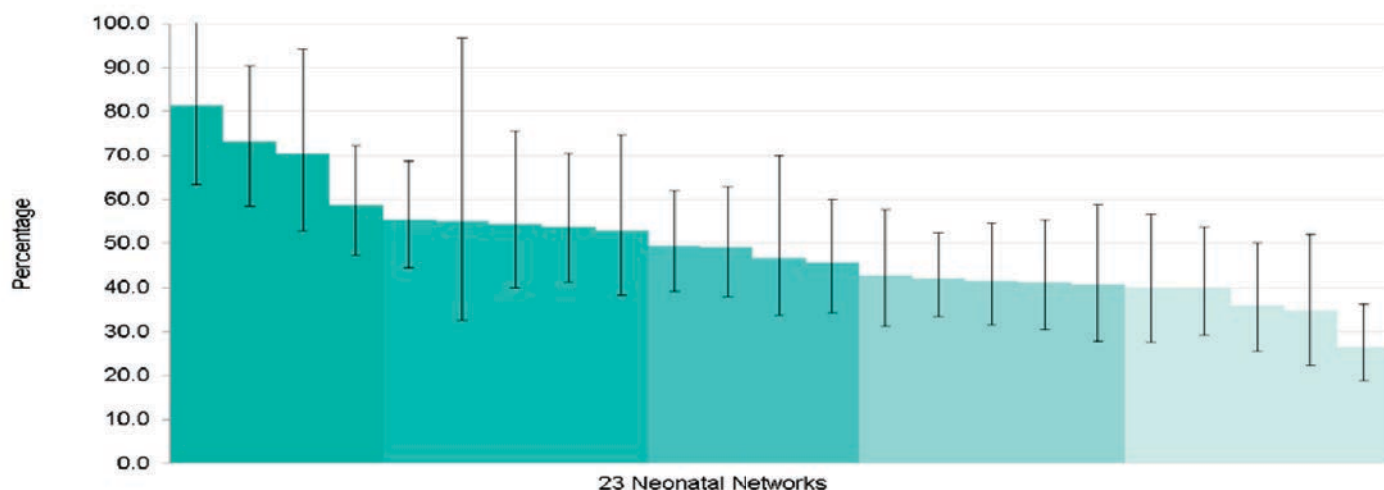




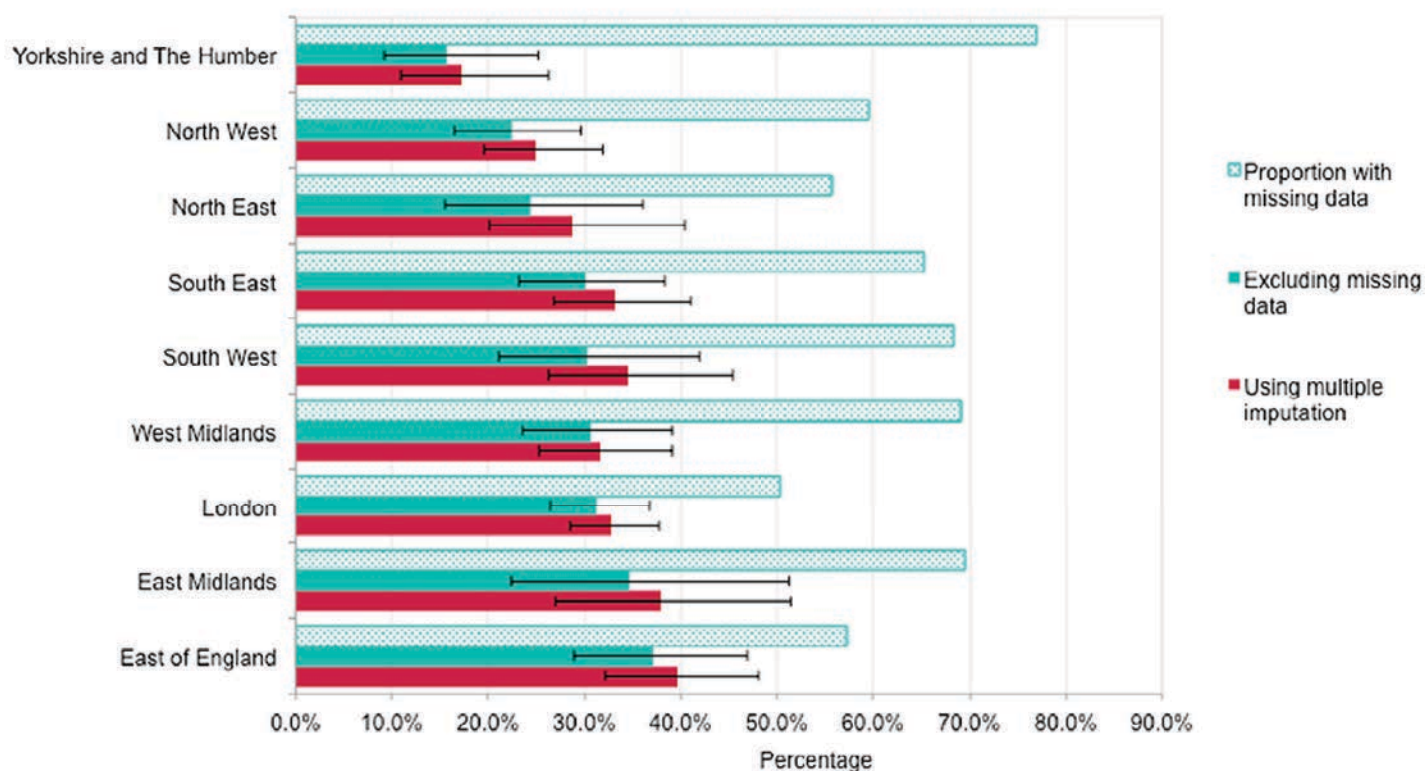
**Map 33** Breastfeeding at discharge: Percentage of infants born at <30 weeks' gestation and admitted to neonatal units who were receiving any mother's milk at discharge from neonatal care, by neonatal network of discharge, directly standardised by Index of Multiple Deprivation (IMD), 2012



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**Map 34** Survival free of any impairment at age 2 years: Percentage of infants born at <30 weeks' gestation and admitted to neonatal units who survived to 2 years of age free of any impairment (mild, moderate or severe), by region, born in 2010



## Context

Approximately 1 in 10 infants are born preterm. This equates to around 70,000 preterm births in England each year. These infants, particularly the most immature, require skilled care provided by neonatal specialised care services, which are delivered through clinical networks.

Each network includes around 6–8 neonatal units that together provide a full range of neonatal services. Infants requiring the highest level of support are transferred to a neonatal intensive care unit, and then transferred back to the hospital closest to home once this level of support is no longer required.

Neonatal networks do not have distinct geographical boundaries; approximate maps of neonatal networks were created based on previously known primary care trust (PCT) boundaries. Each PCT was allocated to one neonatal network based on where mothers in that PCT were most likely to book their deliveries in 2011. The geographical area of each neonatal network was then defined along the boundaries of the allocated PCTs.

The three indicators mapped here represent key clinical outcomes for very preterm infants, live-born <30 weeks' gestation (i.e. more than 10 weeks early). They describe neonatal mortality and, for those discharged from neonatal care, two additional indicators of life-long health:

- Breastfeeding: a practice associated with many benefits including reduced risk of infection and improved neurocognitive outcome.
- Survival free of impairment at two years: a global index of the long-term consequences of preterm birth.

Data were obtained from the National Neonatal Research Database, a national resource held at the Neonatal Data Analysis Unit (NDAU) at Imperial College London and Chelsea and Westminster NHS Foundation Trust. The UK Neonatal Collaborative comprises all neonatal units in England and Wales that provide agreement for data from neonatal Electronic Patient Records to be extracted and transmitted to the NDAU.

## Magnitude of variation

### Map 32: Neonatal mortality

For neonatal networks in England, the percentage of infants born at <30 weeks' gestation and admitted to neonatal units who died  $\leq 28$  days in 2012 ranges from 4.7% to 16.6%, a greater than three-fold variation. When the three neonatal networks with the highest rates and the three networks with the lowest rates are excluded, the range is 8.2% to 14.4%, and the variation is nearly two-fold.

Infants were assigned to the neonatal network of booking to reflect variation by residence, and because attributing deaths to network of discharge might distort the level of variation due to cross-network referrals for the most unwell infants.

As numbers are small, confidence intervals are wide. However, mortality data from 2011 show a statistically significant correlation with 2012 data, which suggests that the pattern of variation is consistent across years.

### Map 33: Breastfeeding at discharge

For neonatal networks in England, the percentage of infants born at <30 weeks' gestation and admitted to neonatal units that were receiving any mother's milk at discharge standardised by IMD ranges from 26.5% to 81.4%, representing a three-fold variation. When the three neonatal networks with the highest percentages and the three networks with the lowest percentages are excluded, the range is 39.9% to 58.7%, and the variation is 1.5-fold.

Standardising the data for deprivation did not greatly alter the pattern of variation initially seen in the unadjusted data, which suggests that variation in preterm breastfeeding is much less heavily influenced by maternal socio-economic status than among the general population.

### Map 34: Impairment-free survival at age 2 years

For regions in England, the percentage of infants born at <30 weeks' gestation and admitted to neonatal units that survived to 2 years free of any impairment ranges from 15.7% to 37.1%, a 2.4-fold variation; 2-year health status data were only available for 40% of eligible infants. An infant was classified as impaired based on criteria developed by the National Perinatal Epidemiology Unit and the former Oxford Regional Health Authority; mild, moderate and severe impairment are included.<sup>1</sup>

There are a variety of possible reasons for missing data, for example:

- infants may not be brought for follow-up appointments if they are considered well, or alternatively if they are too sick
- families may have moved away or lost contact
- follow-up may have taken place but data were not entered into the neonatal Electronic Patient Record.

If the infants with missing data have different outcomes from infants with complete data, excluding the missing data will give a biased result. We used a technique known as multiple imputation to estimate the missing data based on the known neonatal characteristics of the infants (gestational age, birth weight z-score, sex and region). The impairment-free survival rates and standard errors are estimated for each imputed dataset, and these are combined to produce a revised estimate of the impairment-free survival rate and corresponding 95% confidence interval. The revised estimates range from 17.3% (95% confidence interval 10.9% to 26.2%) to 39.6% (32.2% to 37.8%), which still shows a 2.3-fold variation.

<sup>1</sup> Johnson A. (1994). Disability and perinatal care: measurement of health status at two years. A report of two working groups convened by the National Perinatal Epidemiology Unit (NPEU) and Oxford Regional Health Authority. NPEU, Oxford.

## Section 3: Child health in the perinatal period

This revised estimate reduces some of the bias and uncertainty due to the missing data. However, it is based on the assumption that for infants with similar neonatal characteristics and from the same region, the probability of surviving to 2 years free of impairment is the same whether the outcome is known or missing. As we cannot know whether or not this assumption is true, the results must be interpreted with caution.

### Options for action

There is considerable variation in neonatal mortality and breastfeeding following preterm birth. While this may be due to a number of factors, the magnitude of variation remains largely unaltered following standardisation for major potential confounders, suggesting that local factors are likely to be important. Learning from the highest performing networks, coupled with strong clinical leadership, is likely to improve outcomes nationally with minimal requirement for additional resources.

Health professional teams may consider these results in the light of their own performance and discuss areas for improvement with commissioners. More detailed comparison of network populations and identification of unwarranted variation in outcomes could be achieved through more detailed analyses of the National Neonatal Research Database. Commissioners can work together with providers to ensure that adequate support is made available and relevant action taken to address unwarranted variation.

### Resources

- The Royal College of Paediatrics and Child Health's National Neonatal Audit Programme audits breastfeeding at discharge and 2-year outcomes for infants admitted to neonatal units across England and Wales ([www.rcpch.ac.uk/nnap](http://www.rcpch.ac.uk/nnap)).
- An extended set of analyses, including neonatal mortality attributed to alternative neonatal care locations, exclusive breastfeeding at discharge and sensitivity analyses for the 2-year health status data, are available at the NDAU website, along with methodological details ([www.imperial.ac.uk/ndau](http://www.imperial.ac.uk/ndau)).

Section 4:

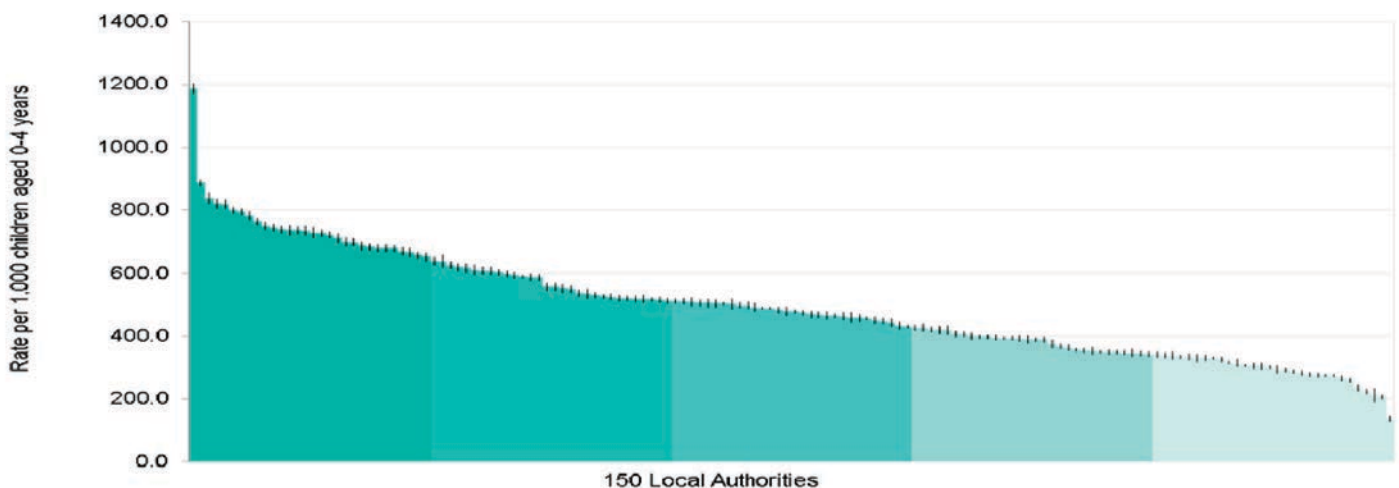
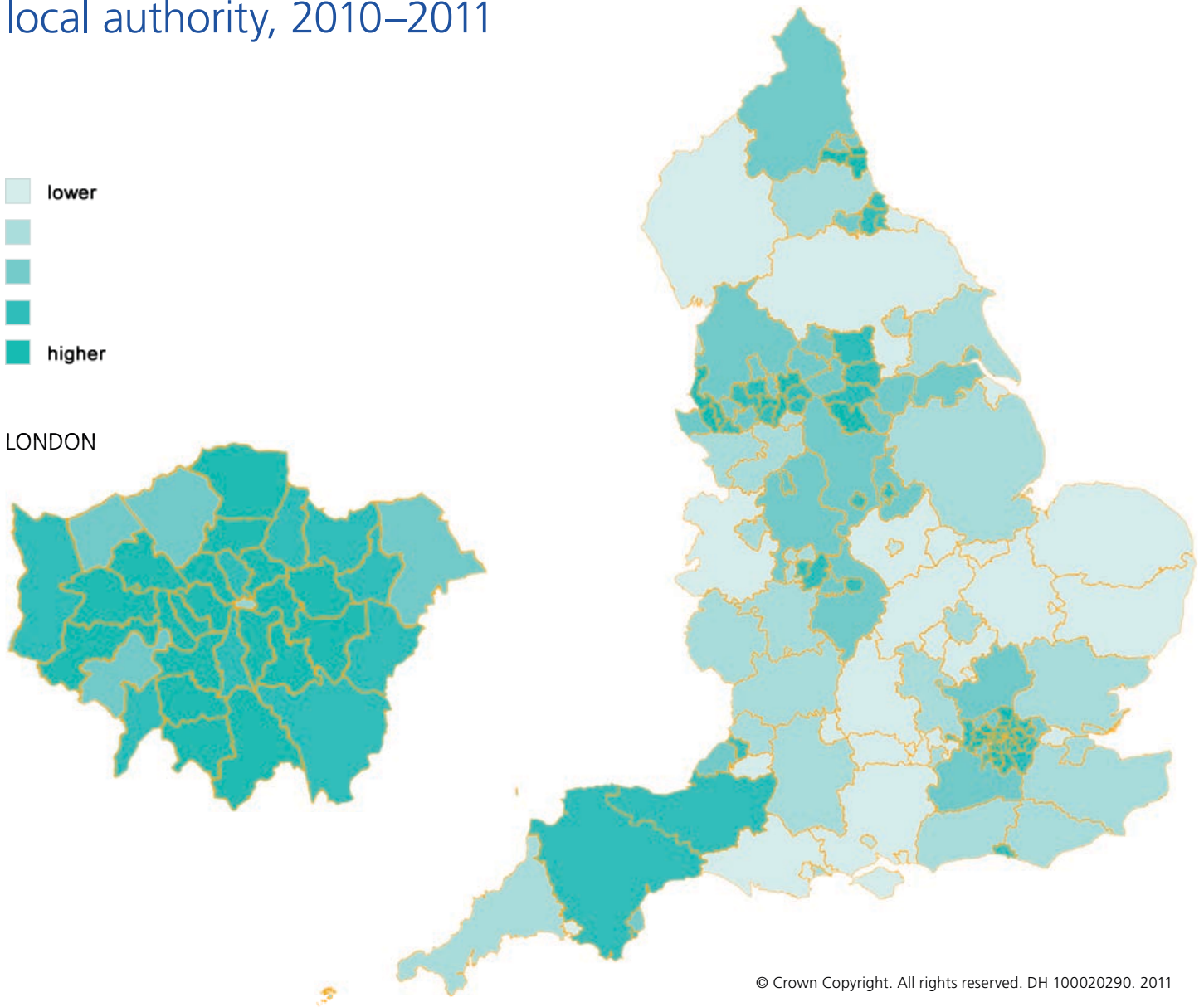
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# Healthcare for children and young people



A: Accident and Emergency department attendances

**Map 35** Emergency attendance: Rate of attendance to Accident and Emergency departments in persons aged 4 years and under, per 1,000 population aged 4 years and under, by local authority, 2010–2011



## Context

In 2010–2011, there were 16.2 million recorded attendances to Accident and Emergency departments in England, an increase of 4.3% from the previous year. More than one-quarter (27.8%) of attendances were made by children and young people (0–19 years).<sup>1</sup>

The recent NHS England Urgent and Emergency Care Review has found that the capacity of primary care to manage the healthcare needs of children and young people is more stretched than it has ever been, and out-of-hours access is a particular issue.<sup>2</sup>

Emergency department attendance for accidental injury occurs most commonly in children aged under 5 years. The same age group also accounts for nearly 70% of self-referrals to Accident and Emergency departments for medical problems in children, such as respiratory problems or feverish illnesses.<sup>3</sup> Targeting a reduction in the variation in Accident and Emergency department attendance for the under-5 age group is likely to realise considerable financial savings and reduce pressure on overstretched Accident and Emergency department services.

This indicator was included in the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

## Magnitude of variation

**Map 35:** For local authorities in England, the rate of attendance to Accident and Emergency departments in persons aged 4 years and under, per 1,000 population aged 4 years and under, ranged from 136.3 to 1,187.4 (nearly nine-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 259.1 to 795.3, and the variation is greater than three-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust (PCT) in 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 231.1 to 805.4, and the variation was 3.5-fold.

These data confirm that emergency attendance rates have increased across England since 2009–2010, although the magnitude of variation has not. However, caution should be exercised when comparing magnitudes of variation since the geographical and population units of analysis have changed from PCTs to local authorities.

While public health measures such as accident prevention or family education on appropriate use of health services are important, the provision of local primary and community care

(particularly out-of-hours urgent care) is likely to account for much of the ongoing variation in demand for emergency care for young children.

## Options for action

Commissioners can use the specific pattern of demand for emergency services in their local area in order to commission services that reflect local needs. Studying local variation in presentation to emergency departments can help to identify the causes of unwarranted variation and to ensure that the right balance of community and hospital-based services is provided.

Although injury and accident prevention is a public health issue, it is also the responsibility of local health services to support education on prevention of injury.

Commissioners can ensure that children have the appropriate level of access in relation to their healthcare needs by safeguarding the quality of local primary and community-based care.

Primary care professionals and local hospital paediatricians can reduce variation by agreeing and implementing standards and guidelines for the management of common conditions. For instance, ensuring that National Institute for Health and Care Excellence guidance on the recognition and management of a young (under 5 years of age) feverish child (see 'Resources' later in this section) is widely disseminated and followed.

## Resources

NHS England Urgent and Emergency Care Review ([www.england.nhs.uk/ourwork/pe/uec-england/](http://www.england.nhs.uk/ourwork/pe/uec-england/)).

NICE (2007). Feverish illness: assessment and initial management in children younger than 5 years ([www.nice.org.uk/CG047](http://www.nice.org.uk/CG047)).

NHS Institute for Innovation and Improvement (2011). A whole system approach to emergency and urgent care for children and young people: A practical step by step guide and resource pack ([www.rcpch.ac.uk/system/files/protected/page/Final%20NHSi%20CYP\\_for%20web.pdf](http://www.rcpch.ac.uk/system/files/protected/page/Final%20NHSi%20CYP_for%20web.pdf)).

Fernandes A for Royal College of General Practitioners (2011). Guidance for commissioning integrated urgent and emergency care: a whole system approach ([www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~/\\_media/Files/CfC/CfC-Urgent-Emergency-Care.ashx](http://www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~/_media/Files/CfC/CfC-Urgent-Emergency-Care.ashx)).

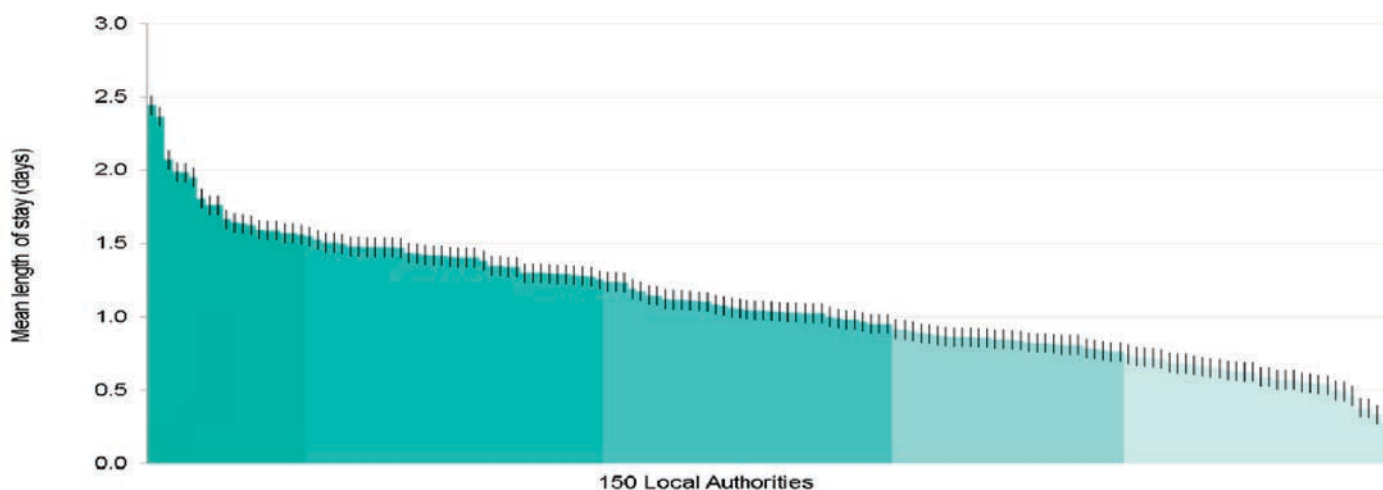
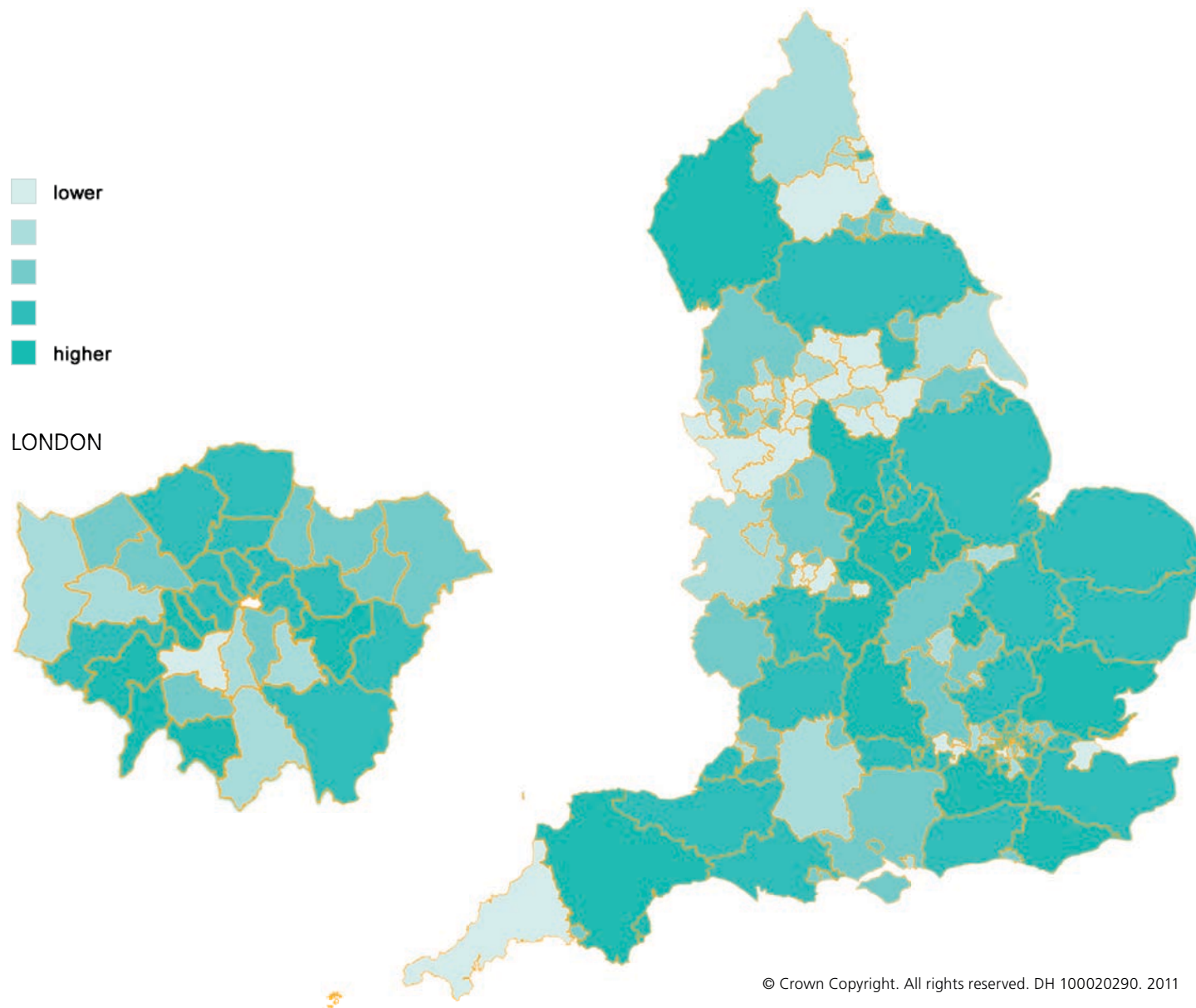
1 Health and Social Care Information Centre. Available at: <https://catalogue.ic.nhs.uk/publications/hospital/AandE/acci-emer-atte-eng-2011-2012/acci-emer-atte-eng-2011-12-rep.pdf>.

2 [www.england.nhs.uk/wp-content/uploads/2013/06/urg-emerg-care-ev-bse.pdf](http://www.england.nhs.uk/wp-content/uploads/2013/06/urg-emerg-care-ev-bse.pdf).

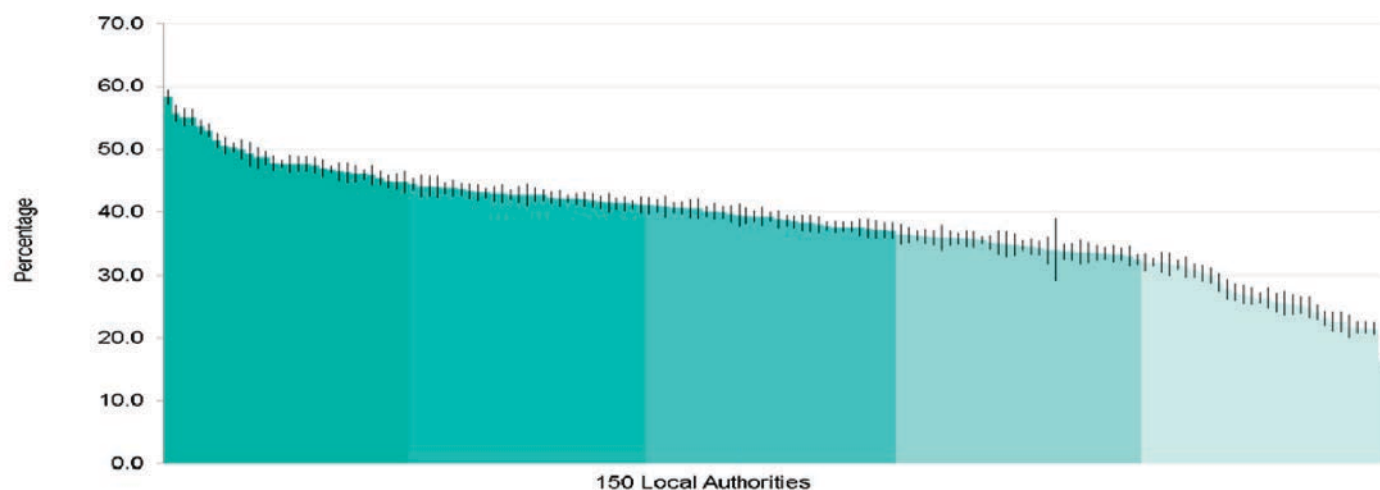
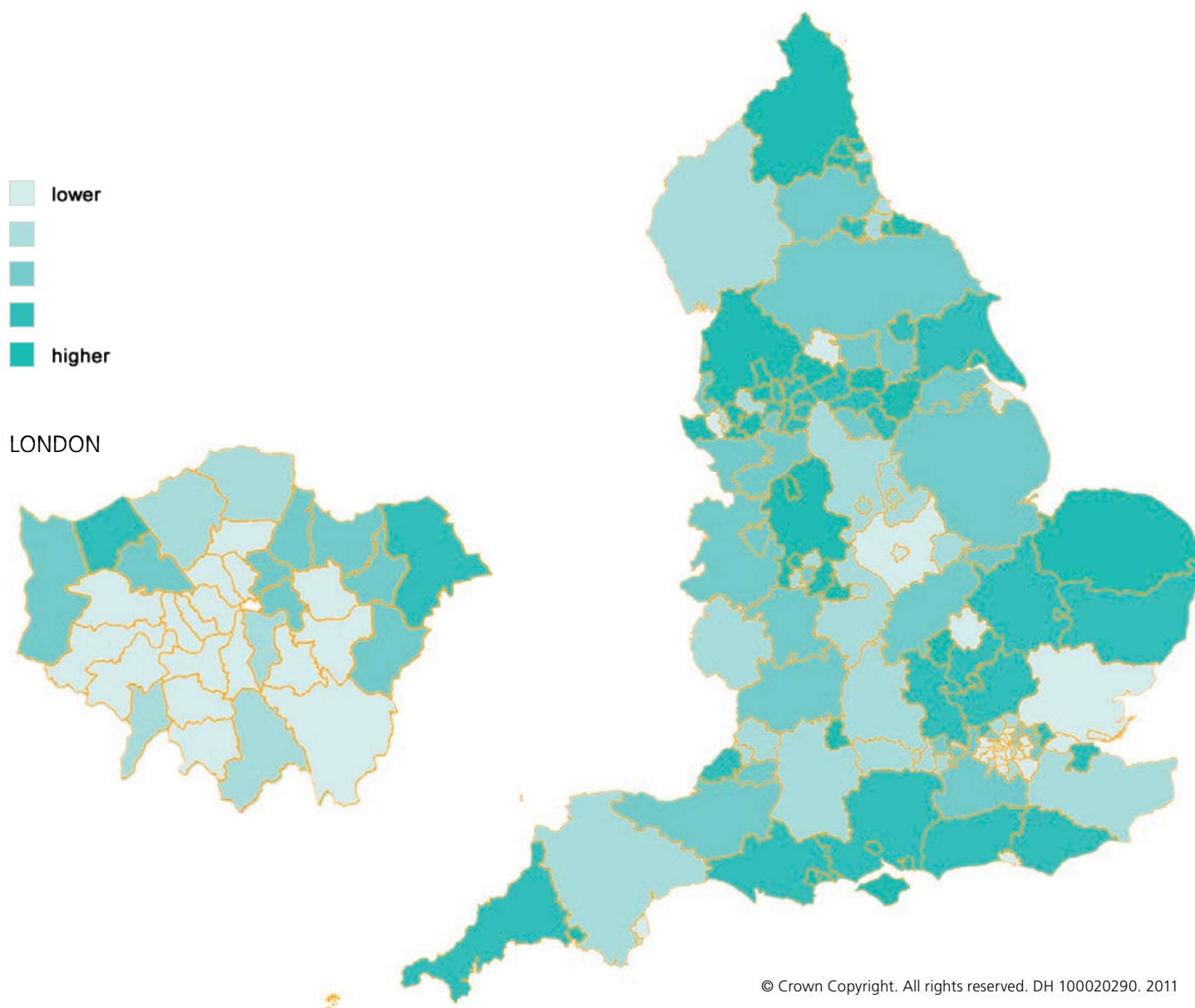
3 Sands R et al. (2011). Medical problems presenting to paediatric emergency departments: 10 years on. *Emergency Medicine Journal*.

B: Unplanned hospital admissions

**Map 36** Duration of non-elective hospital admissions: Mean length of stay (days) for non-elective admissions in children aged 0–17 years, by local authority, 2011–2012

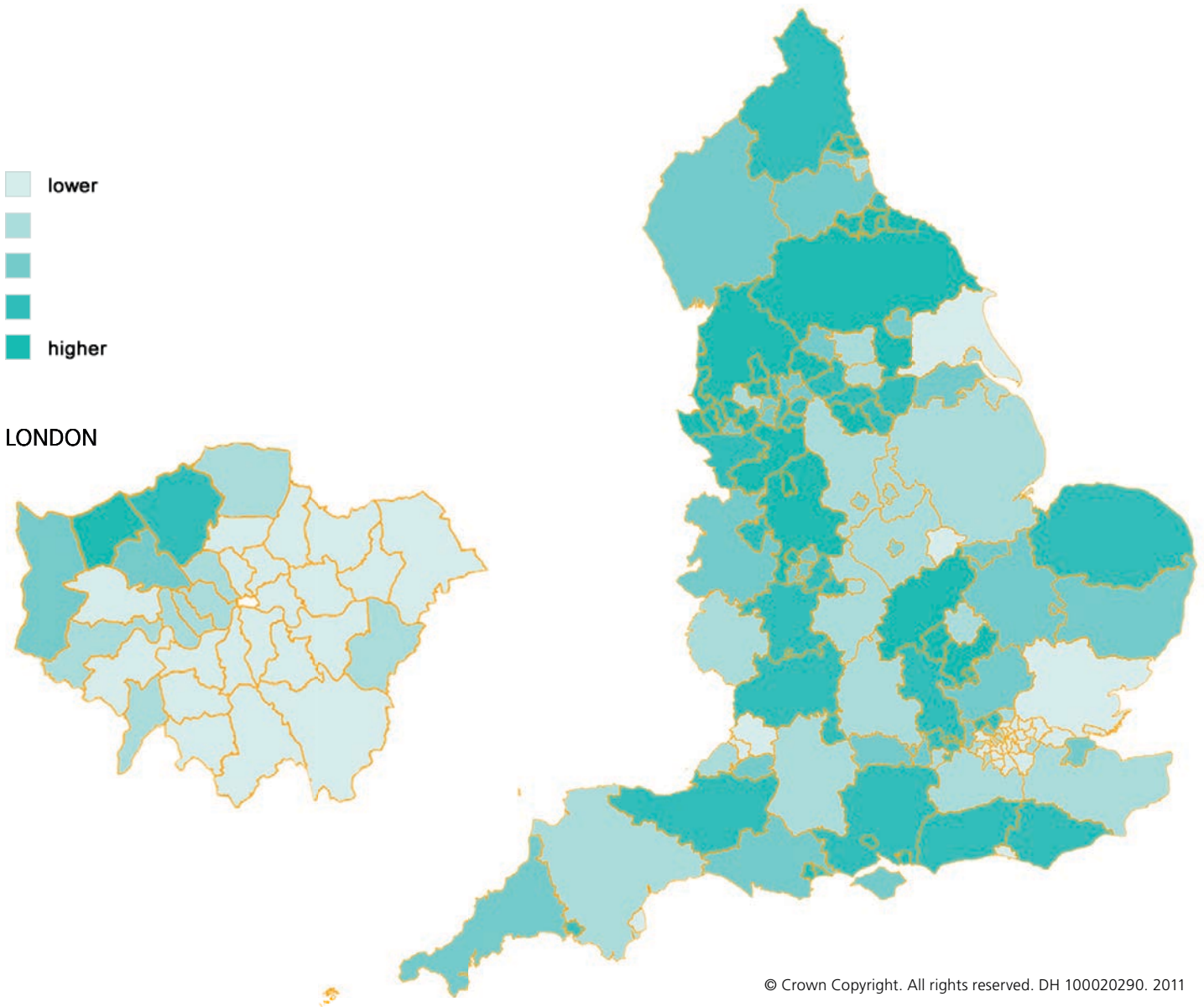


**Map 37** Zero-day admissions: Percentage of hospital admissions in children aged 0–17 years where the duration of stay was shorter than 24 hours, by local authority, 2011–2012

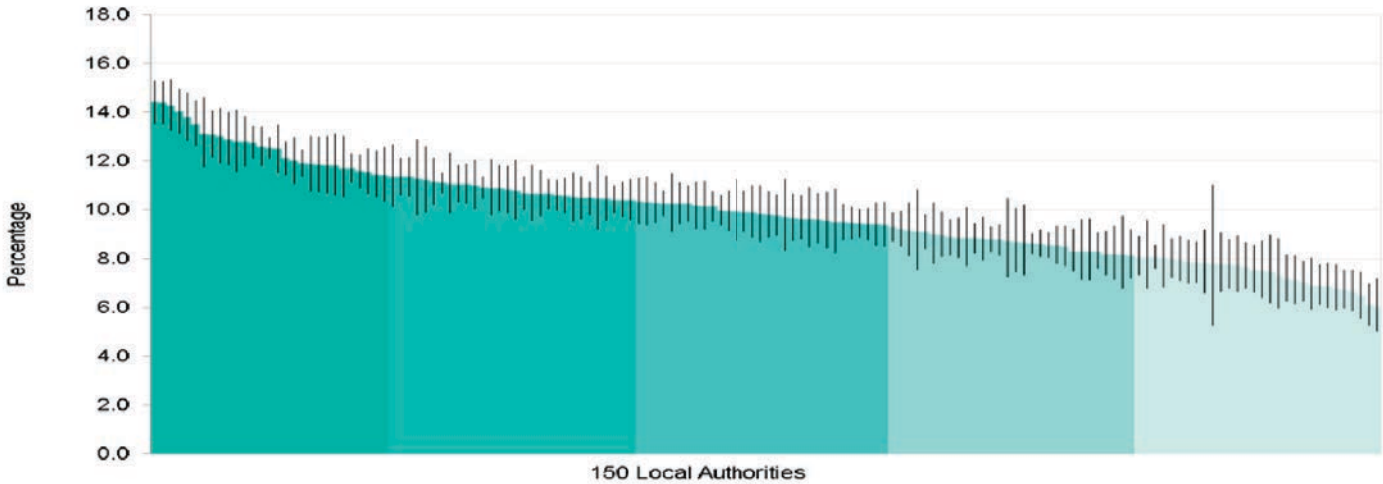




**Map 38** Emergency readmissions: Percentage of emergency admissions in children aged 0–15 years occurring within 28 days of the last, previous discharge from hospital after admission, by local authority, 2010–2011



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## Context

Emergency admissions for children and young people have been rising steadily over the past decade and increased by 28% between 1999 and 2010. Of these, hospital admissions of fewer than 24 hours' duration, so called 'zero-day admissions', have doubled during the same period.<sup>1</sup> The increase in Short Stay Paediatric Assessment Units in England – where children who may not require overnight admission are admitted, treated and observed for a short length of time before being discharged home – may account for much of this increase.<sup>2</sup> High zero-day admission rates may also reflect:

- systems failure in emergency departments where admission to hospital becomes a default or preferred option
- reduced capacity of primary care to manage patients with ambulatory care-sensitive conditions which would not otherwise require admission to hospital.<sup>1,3</sup>

Emergency readmissions may be the result of a legitimate planned discharge strategy, reflecting the natural history of disease, and may reflect good safety netting and high-quality care. However, variation may also be due to differences in:

- quality of management of the initial admission episode, including thresholds for discharge
- quality of community and primary care post-discharge
- thresholds for admissions from subsequent attendances at emergency departments.

Rate of emergency readmission to hospital is increasingly seen as a quality of care indicator, and has been included in the NHS Outcomes Framework since its inception, at least for adult services.

Excess admissions are a source of waste for health services. More importantly, unnecessary, or unnecessarily prolonged, admission to hospital is distressing to the child and family, causes great disruption to family life and has a financial and emotional cost. Reducing variation in duration of stay and unplanned readmissions will reduce this unnecessary burden for both families and health services. However, there is currently little high-quality evidence for any individual intervention which reduces emergency admissions in children.<sup>4</sup>

- 1 Gill PJ, Goldacre M, Mant D et al. (2013). Increase in emergency admissions to hospital for children aged under 15 in England, 1999–2010: national database analysis. *Arch Dis Child*. 98:328–334.
- 2 RCPCH (2013). Back to facing the future. London. Available from: [www.rcpch.ac.uk/system/files/protected/news/Back%20to%20Facing%20the%20Future%20FINAL\\_1.pdf](http://www.rcpch.ac.uk/system/files/protected/news/Back%20to%20Facing%20the%20Future%20FINAL_1.pdf).
- 3 Saxena S, Bottle A, Gilbert R et al. (2009). Increasing short-stay unplanned hospital admissions among children in England: Time Trends Analysis '97–'06. *PLoS One* 4:e7484.
- 4 Thompson Coon J, Martin A, Abdul-Rahman AK et al. (2012). Interventions to reduce acute paediatric hospital admissions: a systematic review. *Arch Dis Child* 97:304–11.

## Magnitude of variation

### Map 36: Duration of non-elective hospital admissions

For local authorities in England, the mean length of stay for non-elective admissions in children aged 0–17 years ranged from 0.3 to 2.4 days (eight-fold variation). When the five local authorities with the highest length of stay and the five local authorities with the lowest length of stay are excluded, the range is 0.5 to 2.0 days, and the variation is four-fold.

### Map 37: Zero-day admissions

For local authorities in England, the percentage of hospital admissions in children aged 0–17 years where the duration of stay was shorter than 24 hours ranged from 16.3% to 58.4% (3.6-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 22.6% to 53.1%, and the variation is greater than two-fold.

### Map 38: Emergency readmissions

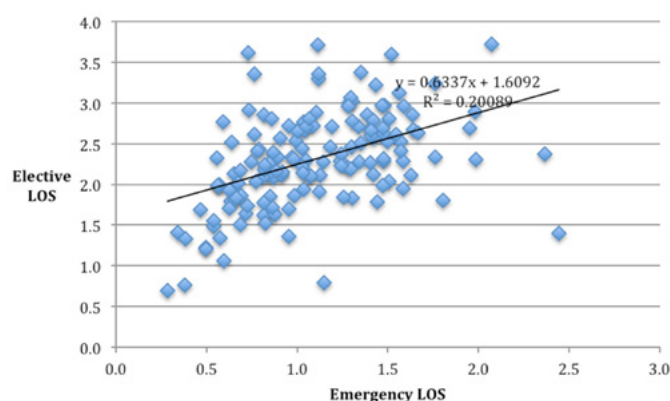
For local authorities in England, the percentage of emergency admissions in children aged 0–15 years occurring within 28 days of the last, previous discharge from hospital after admission ranged from 6.1% to 14.4% (2.4-fold variation). When the five local authorities with the highest percentages and the five local authorities with the lowest percentages are excluded, the range is 6.8% to 13.5%, and the variation is two-fold.

Variation in the duration of stay for non-elective admissions may reflect differences in disease severity at the time of admission. However, it may also reflect variation in healthcare system performance, including differences in:

- hospital discharge processes
- adequacy of community support and services.

If variation in length of stay were the result of system failures such as these, we would expect both elective and non-elective patients to be similarly affected. Indeed, Figure 4B.1 confirms just such a strong correlation, which suggests that the variation is unwarranted.

**Figure 4B.1 Correlation between duration of stay in elective and non-elective admissions, by local authority, 2011–2012**



## Section 4: Healthcare for children and young people

Duration of stay has an impact on readmission rates: discharging patients prematurely from hospital is likely to result in a higher rate of failed discharge and emergency readmission. These data do show such a negative correlation between length of stay and percentage of emergency readmissions (see Figure 4B.2). A careful balance needs to be sought to ensure that patients are discharged at the appropriate time in order to optimise patient safety and use of healthcare resources.

There is little evidence to suggest what an 'appropriate' readmission rate may be, but data from the USA show an average readmission rate of around 6.5%.<sup>1</sup> The rates seen here are significantly higher – however, this is more likely to reflect the differences in our healthcare system rather than differences in clinical practice, and should be interpreted with that in mind.

Zero-day admission rates should not be studied in isolation either. Clearly, there will be a relationship with mean duration of stay. More interestingly, it shows a strong positive correlation with emergency readmission rates (see Figure 4B.3). This may represent the same relationship described

above (in Figure 4B.2), where shorter mean lengths of stay lead to higher readmission rates due to premature discharge from hospital.

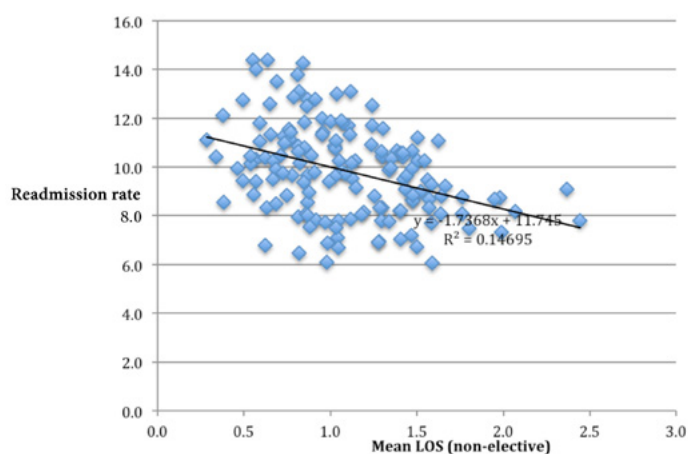
### Options for action

There is a complex interplay between these three indicators, and they should be reviewed together to ensure that their services provide an optimal balance for the healthcare needs of the population.

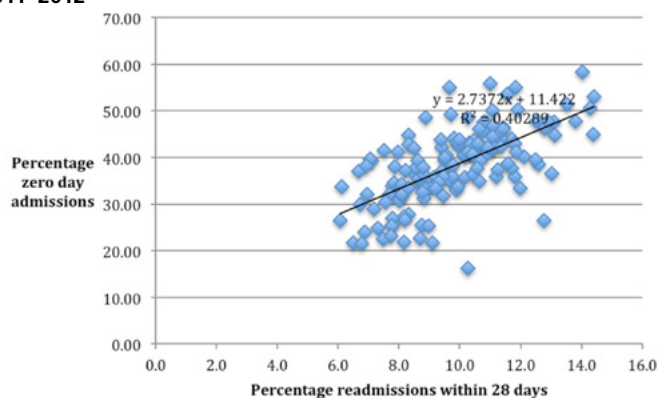
Although these are indicators of emergency department and hospital utilisation, they are also heavily influenced by the quality and capacity of primary care and community services. Commissioners can use these indicators to understand the capacity and quality of the local healthcare system for acutely ill children and young people.

There is increasing consensus that high-quality, sustainable care for acutely ill children and young people will involve consultant-led healthcare delivered in fewer specialist centres, alongside an expansion in primary care expertise and capacity to manage children and young people outside hospital.<sup>2</sup> This is a challenge for commissioners, local authorities and policymakers to address with some urgency.

**Figure 4B.2 Correlation between percentage of emergency readmissions and duration of stay in emergency admissions, by local authority, 2011–2012**



**Figure 4B.3 Correlation between percentage of zero-day admissions and percentage of emergency readmissions, by local authority, 2011–2012**



### Resources

NHS England Urgent and Emergency Care Review ([www.england.nhs.uk/ourwork/pe/uec-england/](http://www.england.nhs.uk/ourwork/pe/uec-england/)).

Royal College of Paediatrics and Child Health (2013). Back to facing the future ([www.rcpch.ac.uk/system/files/protected/news/Back%20to%20Facing%20the%20Future%20FINAL\\_1.pdf](http://www.rcpch.ac.uk/system/files/protected/news/Back%20to%20Facing%20the%20Future%20FINAL_1.pdf)).

NHS Institute for Innovation and Improvement (2011). A whole system approach to emergency and urgent care for children and young people: A practical step by step guide and resource pack ([www.rcpch.ac.uk/system/files/protected/page/Final%20NHSi%20CYP\\_for%20web.pdf](http://www.rcpch.ac.uk/system/files/protected/page/Final%20NHSi%20CYP_for%20web.pdf)).

Fernandes A for Royal College of General Practitioners (2011). Guidance for commissioning integrated urgent and emergency care: a 'whole system' approach ([www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~media/Files/CfC/CfC-Urgent-Emergency-Care.ashx](http://www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~media/Files/CfC/CfC-Urgent-Emergency-Care.ashx)).

1 Berry JG, Toomey SL, Zaslavsky AM et al. (2013). Pediatric readmission prevalence and variability across hospitals. *JAMA* 309(4):372–380.

2 Royal College of Paediatrics and Child Health (2013). Back to facing the future. Available from: [www.rcpch.ac.uk/system/files/protected/news/Back%20to%20Facing%20the%20Future%20FINAL\\_1.pdf](http://www.rcpch.ac.uk/system/files/protected/news/Back%20to%20Facing%20the%20Future%20FINAL_1.pdf).

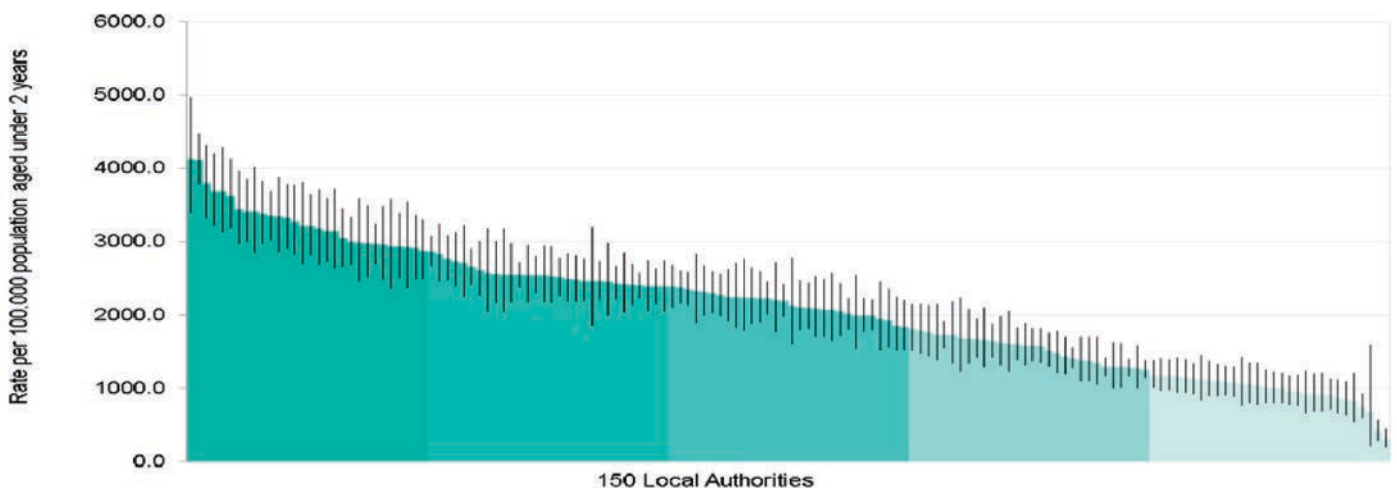
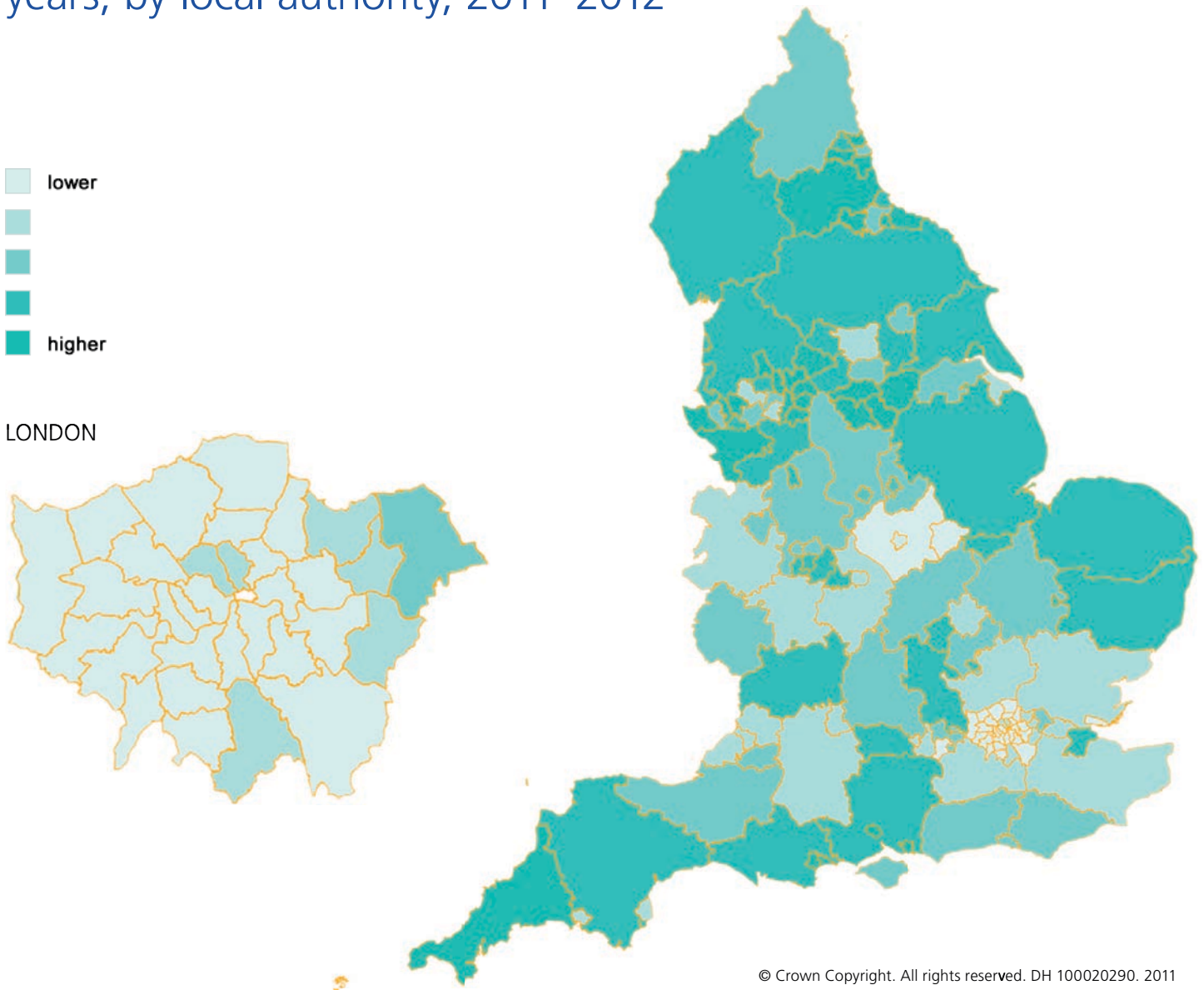
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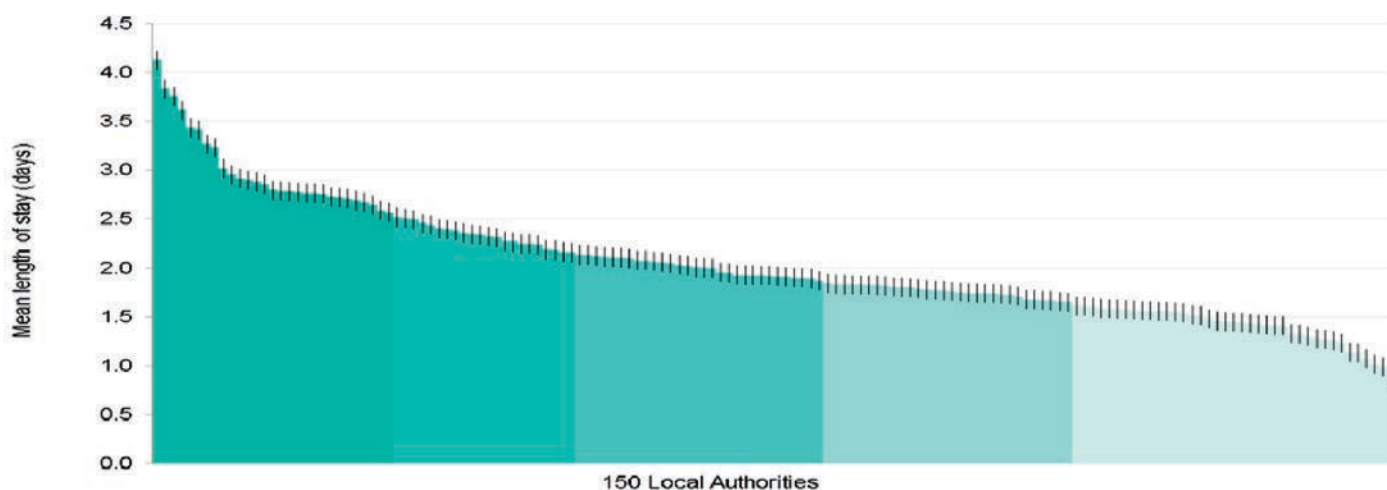
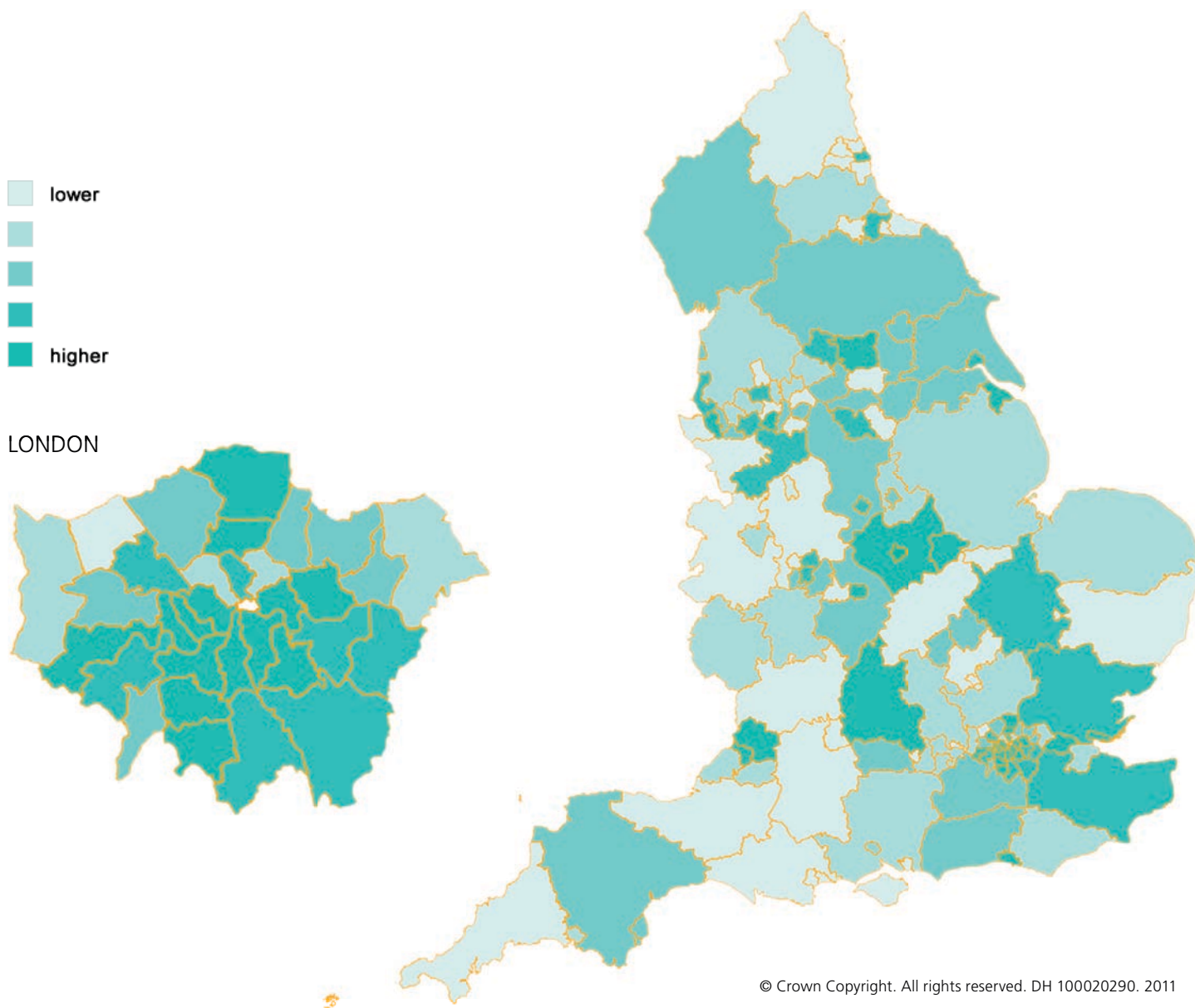
# Healthcare for acutely ill children

A: Bronchiolitis

**Map 39** Bronchiolitis: Hospital admission rate: Directly standardised rate of emergency admissions with bronchiolitis in children aged under 2 years, per 100,000 children aged under 2 years, by local authority, 2011–2012



**Map 40** Bronchiolitis: Duration of hospital stay: Mean length of stay (days) for bronchiolitis in children aged under 2 years, by local authority, 2011–2012





## Context

Bronchiolitis is a viral respiratory infection of the lower airways, predominantly affecting infants under the age of 1 year but occasionally infants up to the age of 2 years. In industrialised countries, 1% to 3% of all infants are admitted to hospital as a result of bronchiolitis.<sup>1</sup> Human respiratory syncytial virus (RSV) is the most common cause of bronchiolitis in infants and RSV is the single most common cause of hospital admissions in infancy.<sup>2</sup> Globally, RSV is the most common cause of childhood acute and severe lower respiratory tract infections and a cause of substantial mortality.<sup>3</sup> There is currently no available human vaccine against RSV but, due to the burden of the disease, its development is a priority for the World Health Organization.<sup>4</sup>

Although the majority of children with bronchiolitis do not require admission to hospital, those that do will often require feeding therapy and/or supplemental oxygen therapy. Prolonged hospital admission of young children disrupts family life and affects the wellbeing of the child and their family, including the financial impact of time off work.

The incidence of bronchiolitis tends to be seasonal: most cases in England occur in the winter, with a typical epidemic peak that places an additional stress on resources at a time of year when hospital services already experience high levels of demand. Unnecessarily prolonged inpatient stays squander this resource.

Both of these indicators were included in the Atlas of Variation in Healthcare for Children and Young People (2012).

## Magnitude of variation

### Map 39: Bronchiolitis – Hospital admission rate

For local authorities in England, the rate of emergency admissions in persons aged under 2 years with bronchiolitis, per 100,000 children aged 2 years and under, ranged from 306.9 to 4,124.7 (greater than 13-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 843.3 to 3,627.2 and the variation is greater than four-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2008 to 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 689 to 3,826, and the variation was six-fold.

1 Leader S, Kohlase K (2002). Respiratory syncytial virus-coded pediatric hospitalizations, 1997 to 1999. *Pediatric Infectious Disease Journal* 21: 629–632.

2 Deshpande SA, Northern V (2003). The clinical and health economic burden of respiratory syncytial virus disease among children under 2 years of age in a defined geographical area. *Archives of Diseases in Childhood* 88:1065–1069.

3 Nair H et al. (2010). Global burden of acute lower respiratory infections due to respiratory syncytial virus in young children: a systematic review and meta-analysis *Lancet* 375:1545–1555.

4 [www.who.int/vaccine\\_research/IVR\\_AC\\_Web\\_2011.pdf](http://www.who.int/vaccine_research/IVR_AC_Web_2011.pdf).

### Map 40: Bronchiolitis – Duration of hospital stay

For local authorities in England, the mean length of stay for bronchiolitis in children aged under 2 years ranged from 0.8 to 4.1 days (five-fold variation). When the five local authorities with the highest lengths of stay and the five local authorities with the lowest lengths of stay are excluded, the range is 1.1 to 3.4 days and the variation is three-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2008 to 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 1.3 to 3.3 days, and the variation was 2.6-fold.

Variations in admissions for children with bronchiolitis may reflect epidemiological factors including:

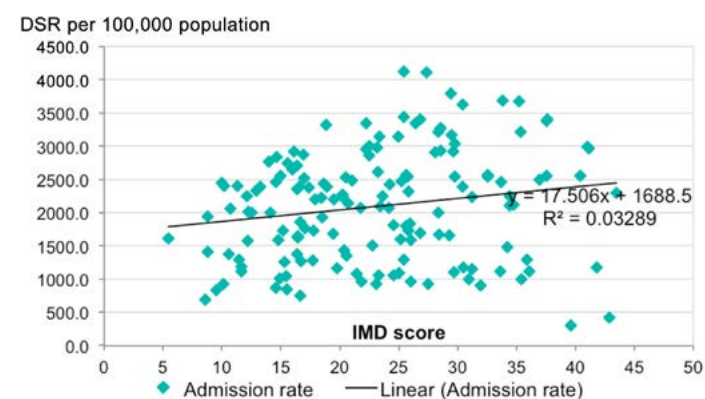
- socio-economic deprivation
- maternal tobacco smoking during pregnancy
- household tobacco-smoking status.<sup>5</sup>

There is a positive correlation between the number of admissions for bronchiolitis and socio-economic deprivation, but the relationship in these data is weak (Figure 5A.1). There is no simple relationship between deprivation and duration of stay either, an observation supported by findings in the published literature with respect to socio-economic deprivation, severity of illness and duration of admission.<sup>5</sup>

The degree of variation observed cannot be attributed purely to variation in socio-economic deprivation. Admission rate and duration of admission is partly a function of the severity of illness; it could also be related to local differences in:

- the management and assessment of children with bronchiolitis in the emergency department
- thresholds for admission and discharge from hospital
- quality of primary, community and social care support available to families during the infant's recovery period.

**Figure 5A.1 Correlation between rate of admission for bronchiolitis and deprivation, by local authority, 2011–2012 (High IMD score indicates more deprived area)**



5 Semple MG, Taylor-Robinson DC, Lane S, Smyth RL (2011). Household Tobacco Smoke and Admission Weight Predict Severe Bronchiolitis in Infants Independent of Deprivation: Prospective Cohort Study. *PLoS ONE* 2011; 6(7): e22425. doi:10.1371/journal.pone.0022425.

Hospital admission rates should not be assessed in isolation.<sup>6</sup> Areas which have higher admission rates are likely to have shorter mean duration of stay, and vice versa, because a cautious approach to admission criteria setting is likely to result in greater numbers of admissions of less severely affected infants, who will be less likely to require a prolonged admission. This negative correlation is borne out by our data (see Figure 5A.2).

Therapies for bronchiolitis are mainly supportive, involving:

- nasogastric tube feeding
- supplemental oxygen
- in severe cases, mechanical ventilator support.

Despite evidence-based national guidance,<sup>7</sup> there are differences in the use of these treatments, particularly the criteria for starting and stopping supplemental oxygen, as well as variation in the clinical criteria for discharge for children with bronchiolitis.<sup>8</sup> Differences in discharge could also reflect:

- general discharge processes for all children in the local department, hospital or provider unit
- level of support available in the local community.

A family's capacity to care for a recovering infant at home may influence a clinician's decision whether to discharge a child with bronchiolitis. The level of support available locally from the extended family, community health and social services may account for some of the variation observed. For selected patients, brief admission to short-stay observation units in combination with home oxygen therapy can be a

safe means to reduce the burden to families and services of prolonged hospitalisation.<sup>9</sup>

## Options for action

Local clinicians, in particular, emergency department practitioners and paediatricians can act to reduce variation by applying:

- evidence-based guidance for the assessment of children with respiratory illness
- clear admission criteria for children presenting with bronchiolitis, based on national evidence-based guidelines supplemented by frequent reviews of the most recent literature.

To identify factors responsible for variations in the duration of admission for bronchiolitis in the local population, commissioners and providers can investigate differences in:

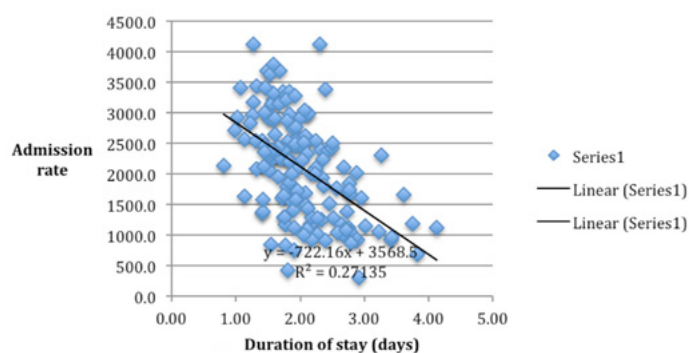
- clinical management of bronchiolitis
- wider hospital processes and patient flows.

Introduction of a clinical care pathway has been shown to reduce variation in treatment of bronchiolitis and to significantly reduce duration of admission.<sup>10</sup>

Commissioners can act to ensure that vulnerable children and families have access to adequate community-based support regarding recovery after discharge.

Clinicians, supported by commissioners, can target at-risk children (such as those with pre-existing lung disease or significant congenital heart disease) to ensure they receive seasonal prophylaxis with monthly injections of monoclonal antibody against RSV in accordance with Department of Health guidance (see 'Resources' later in this section). Mechanisms are required not only to deliver treatment to those who present themselves to healthcare services, but to identify and contact pro-actively the families of at-risk children to ensure that the children are protected.

**Figure 5A.2 Correlation between rate of admission for bronchiolitis in children aged under 2 years and duration of stay, by local authority, 2011–2012**



6 Shahnaz A, Parker RA, Wills S, Ross Rossell RI. (2013). Assessing efficient patient care – should length of stay be calculated independently of local admission rates? *Arch Dis Child*. In press.

7 Scottish Intercollegiate Guidelines Network (SIGN) (2006). Bronchiolitis in children. A national clinical guideline. Available from: <http://www.sign.ac.uk/pdf/sign91.pdf>.

8 Cunningham S, McMurray A (2011). Observational study of two oxygen saturation targets for discharge in bronchiolitis. *Archives of Diseases in Childhood* (2011). doi:10.1136/adc.2010.

## Resources

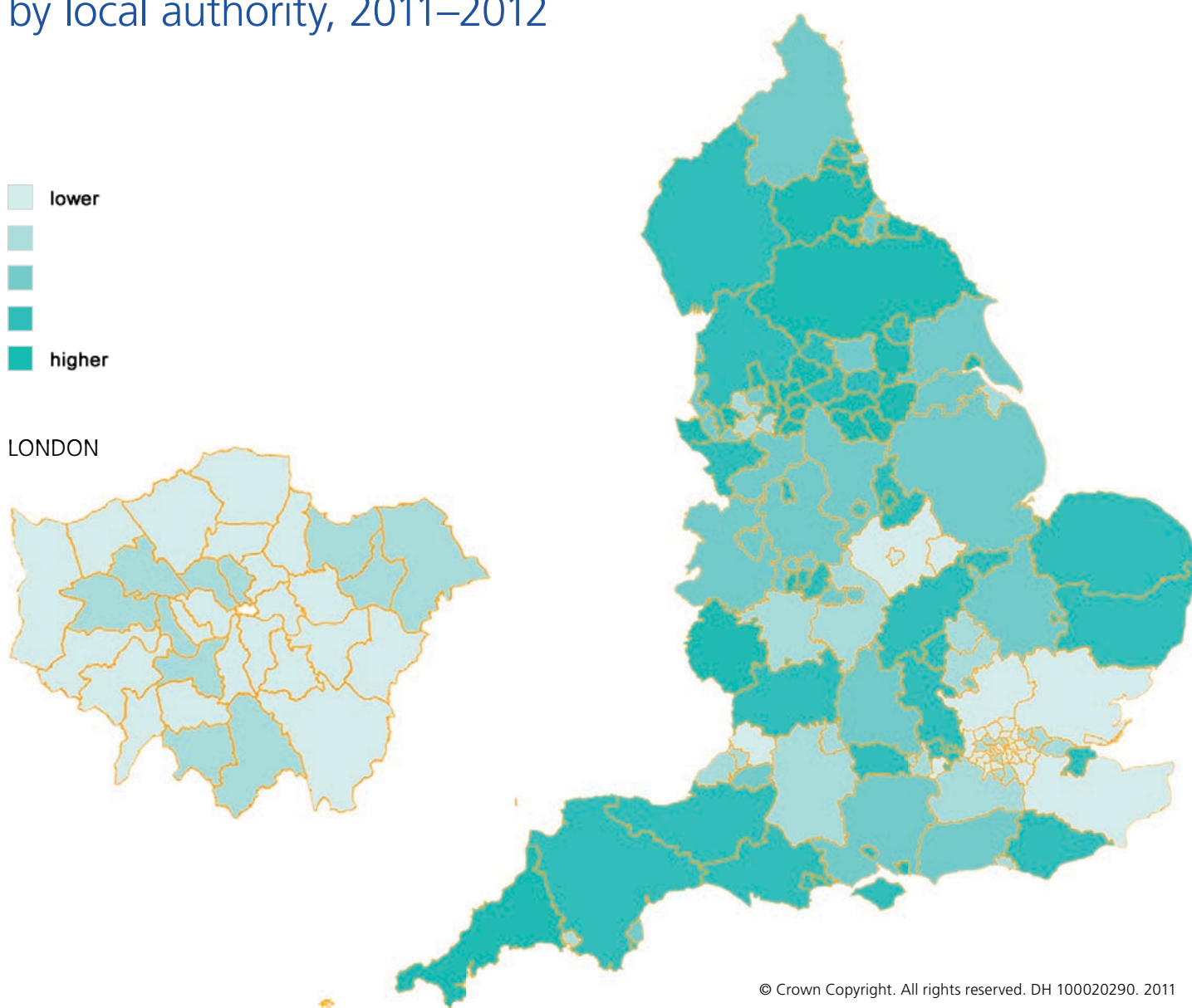
- Scottish Intercollegiate Guidelines Network (SIGN) (2006). Bronchiolitis in children. A national clinical guideline ([www.sign.ac.uk/pdf/sign91.pdf](http://www.sign.ac.uk/pdf/sign91.pdf)).
- The Joint Committee on Vaccines and Immunisations statement on prophylaxis against RSV ([www.dh.gov.uk/ab/JCVI/DH\\_094744](http://www.dh.gov.uk/ab/JCVI/DH_094744)).
- Department of Health (2006; updated 2011). Immunisations against infectious diseases ('Green Book'). Chapter 27a – Respiratory Syncytial Virus.

9 Sandweiss DR, Mundorff MB, Hill T et al. (2013). Decreasing Hospital Length of Stay for Bronchiolitis by Using an Observation Unit and Home Oxygen Therapy. *JAMA Pediatr*. 167(5): 422–428.

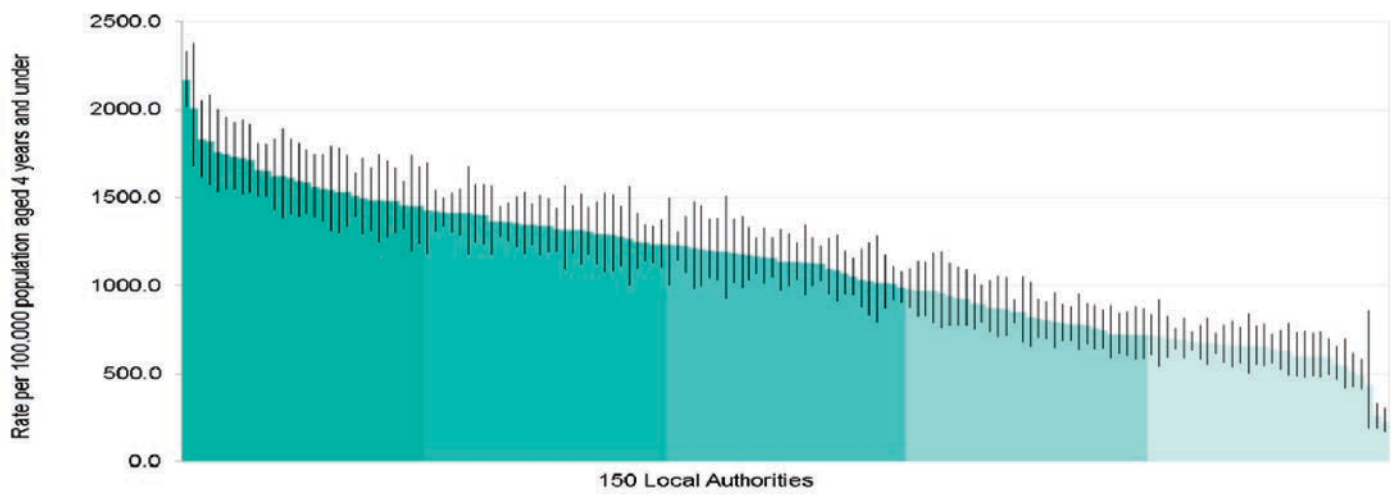
10 Walker C, Danby S, Turner S (2011). Impact of a bronchiolitis clinical care pathway on treatment and hospital stay. *Eur J Paed* doi: 10.1007/s00431-011-1653-9.

## B: Lower respiratory tract infections (LRTIs)

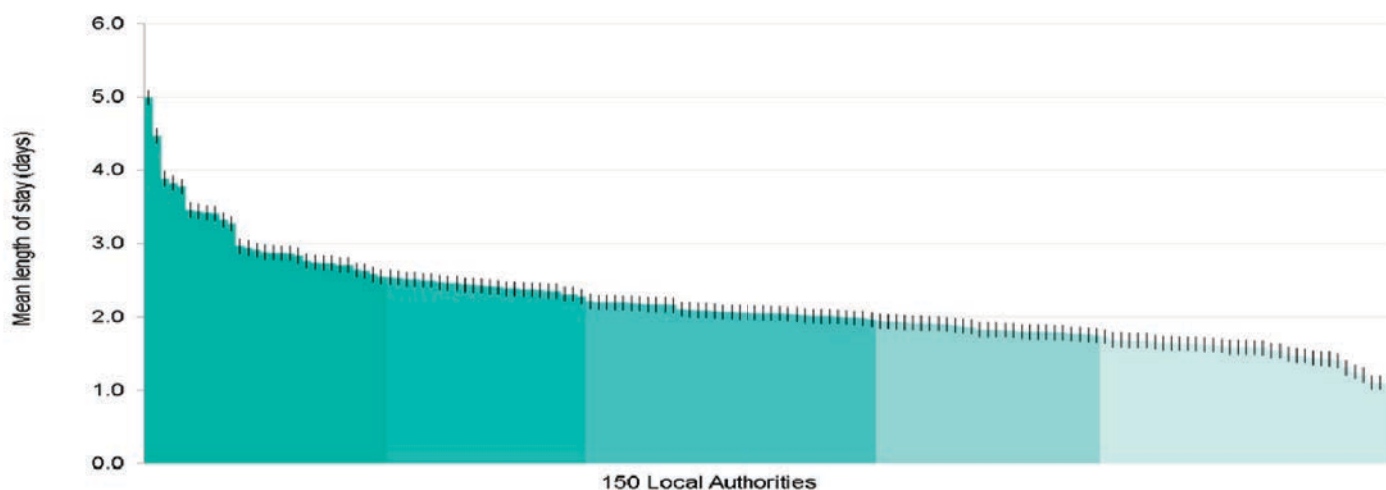
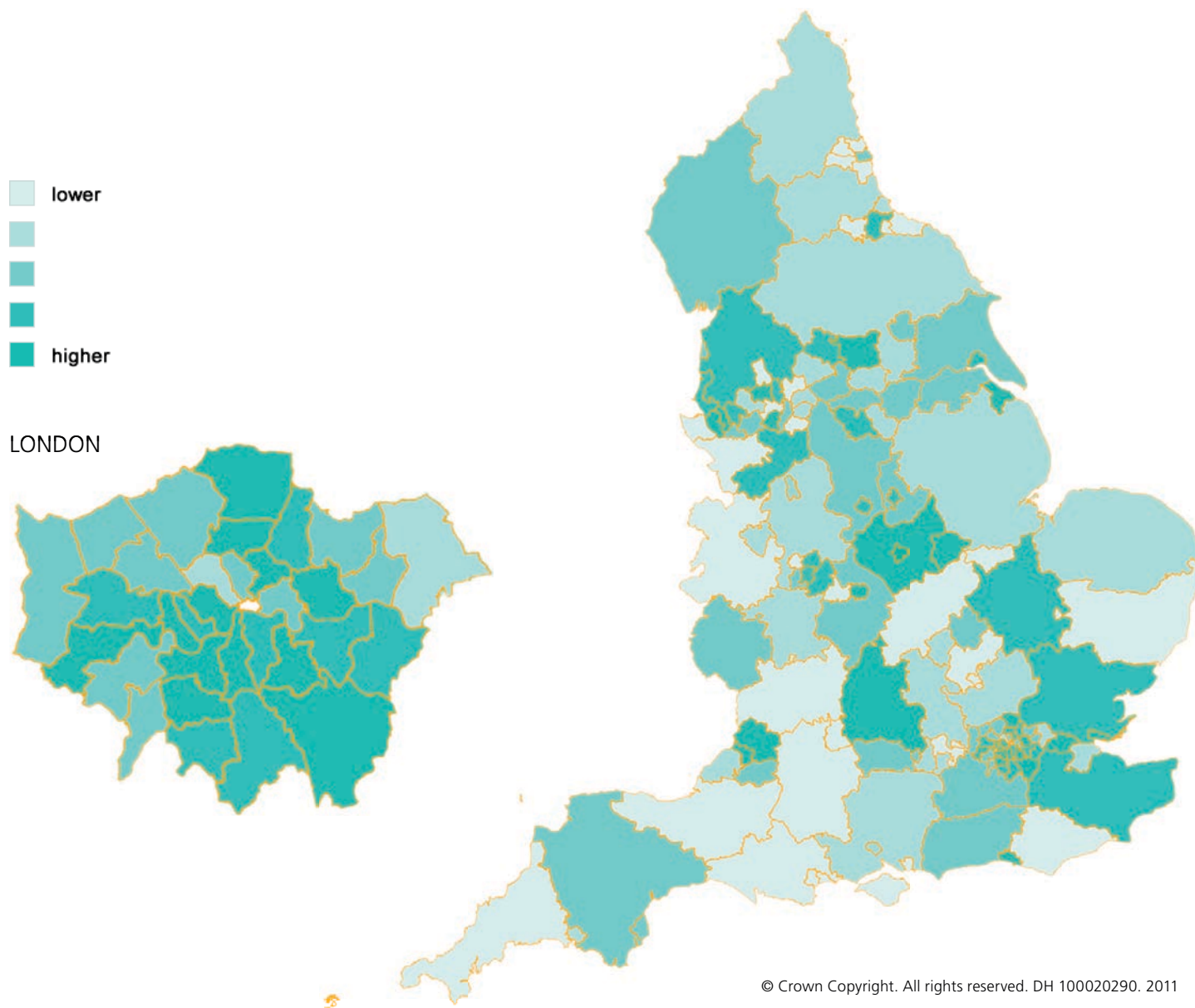
**Map 41** LRTIs: Hospital admission rate: Directly standardised rate of emergency admissions with LRTIs in children aged 4 years and under, per 100,000 children aged 4 years and under, by local authority, 2011–2012



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**Map 42** LRTIs: Duration of hospital stay: Mean length of stay (days) for LRTIs in children aged 4 years and under, by local authority, 2011–2012





### Context

LRTIs are a very common cause for admission to hospital in children, particularly in infancy and early childhood. They include bronchiolitis in infants, bronchopneumonia and pneumonia, of both viral and bacterial origin.

Rates of emergency admission for LRTIs reflect a number of factors, such as socio-economic deprivation and pre-existing health status. Breastfeeding is known to be protective, while tobacco smoke exposure increases the risk.

For acutely ill children, admission rate should be analysed alongside duration of stay. An inappropriate reduction in admission rate may manifest itself as a longer than expected duration of stay (as children who stay are more unwell), and vice versa.

'Emergency admissions for children with LRTIs' is included in the NHS Outcomes Framework 2013/14.

### Magnitude of variation

#### Map 41: LRTIs – Hospital admission rate

For local authorities in England, the rate of emergency admissions in persons aged 4 years and under with LRTIs, per 100,000 children aged 4 years and under, ranged from 230.6 to 2,168.7 (9.4-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 546.5 to 1,741.9, and the variation is greater than three-fold.

#### Map 42: LRTIs – Duration of hospital stay

For local authorities in England, the mean length of stay for LRTIs in children aged 4 years and under ranged from 1.1 to 5.0 days (4.5-fold variation). When the five local authorities with the highest lengths of stay and the five local authorities with the lowest lengths of stay are excluded, the range is 1.3 to 3.5 days and the variation is 2.6-fold.

In these data, there is no simple correlation between LRTI admission rate and socio-economic deprivation. Other factors may influence the early course of an LRTI, which subsequently changes the risk of admission, for instance:

- differences in health-seeking behaviours for children with LRTIs or their families
- early, accurate diagnosis
- timely, appropriate and effective treatment in the community
- differences in clinical practice, including threshold for intervention and choice of therapy
- timely and appropriate referral to secondary care.

It may also reflect differences in secondary care, in terms of treatment threshold, choice of therapy and in admission thresholds.

### Options for action

Commissioners can work together with clinicians in primary and secondary care to improve the early treatment and recognition of LRTIs in primary care. By reducing unplanned admissions to hospital, this will reduce the burden on unplanned secondary care services, as well as improving health outcomes and wellbeing for children and families.

Hospital clinicians, in particular emergency department practitioners and paediatricians, can act to reduce variations by applying

- evidence-based guidance for the assessment of children with respiratory illness and
- clear admission criteria for children presenting with LRTIs, based on national evidence-based guidelines supplemented by frequent reviews of the most recent literature.

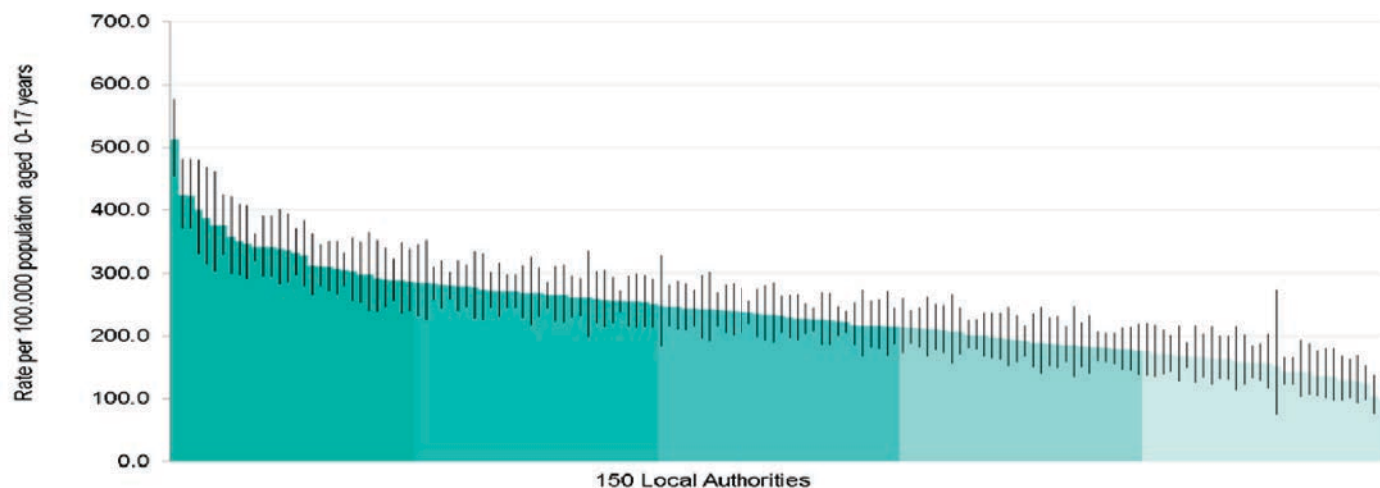
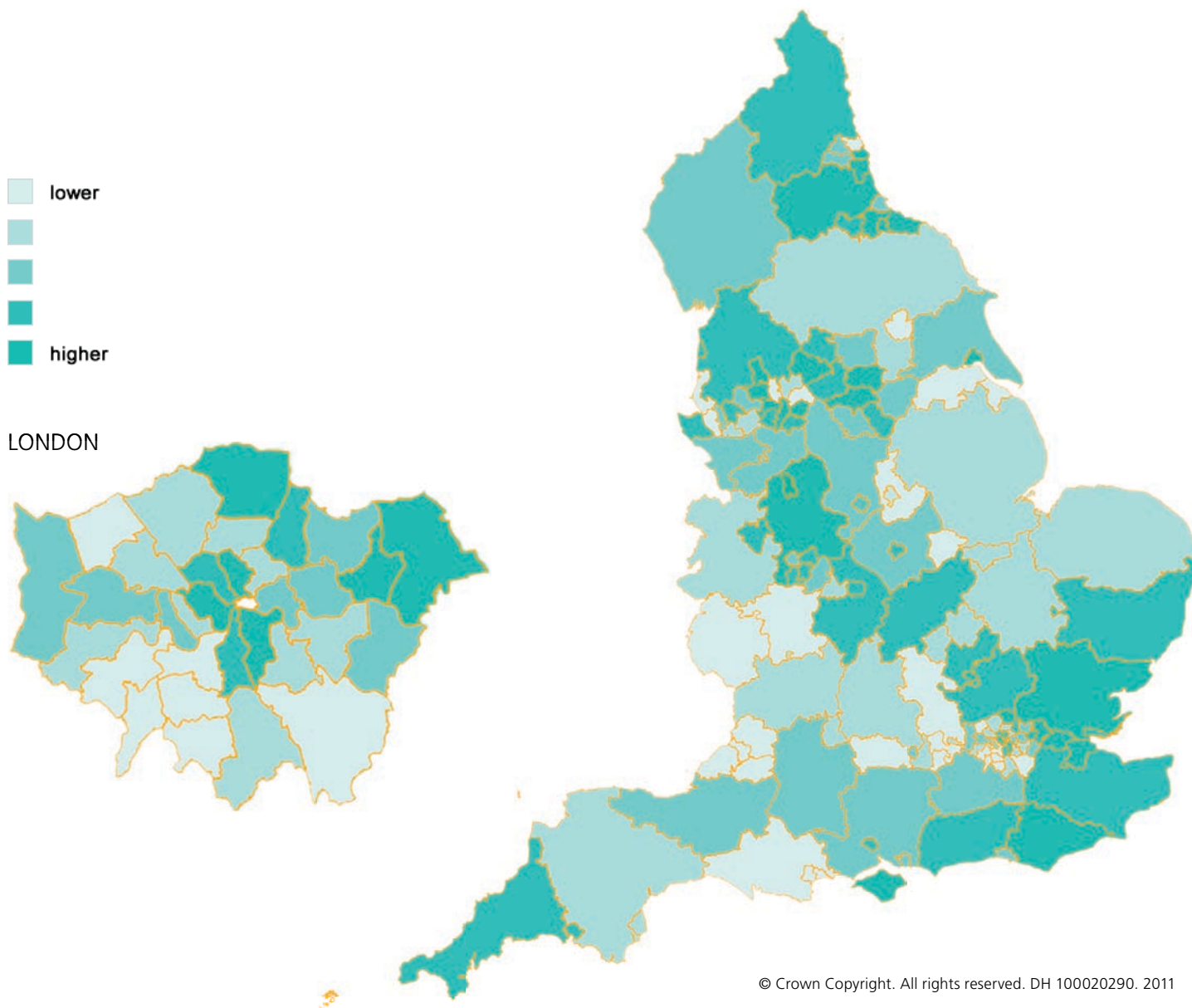
### Resources

- British Thoracic Society (2011). Guidelines for the management of community acquired pneumonia in children: update 2011 ([www.brit-thoracic.org.uk/Portals/0/Guidelines/Pneumonia/CAP%20children%20October%202011.pdf](http://www.brit-thoracic.org.uk/Portals/0/Guidelines/Pneumonia/CAP%20children%20October%202011.pdf)).
- NICE guideline CG69 (2008). Respiratory tract infections – antibiotic prescribing: Prescribing of antibiotics for self-limiting respiratory tract infections in adults and children in primary care (<http://guidance.nice.org.uk/CG69/>).

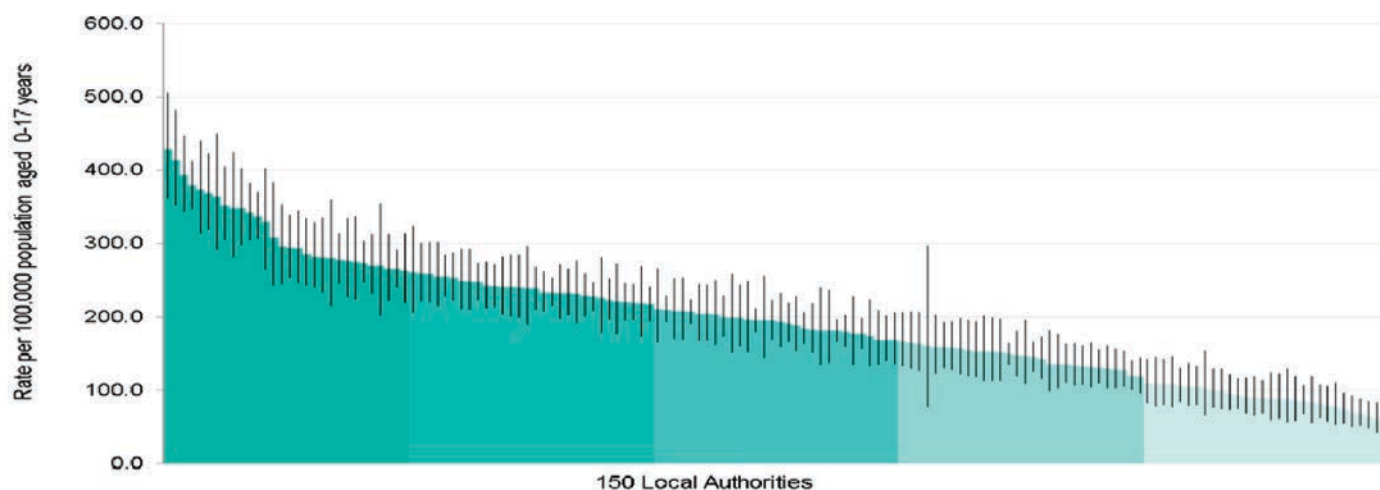
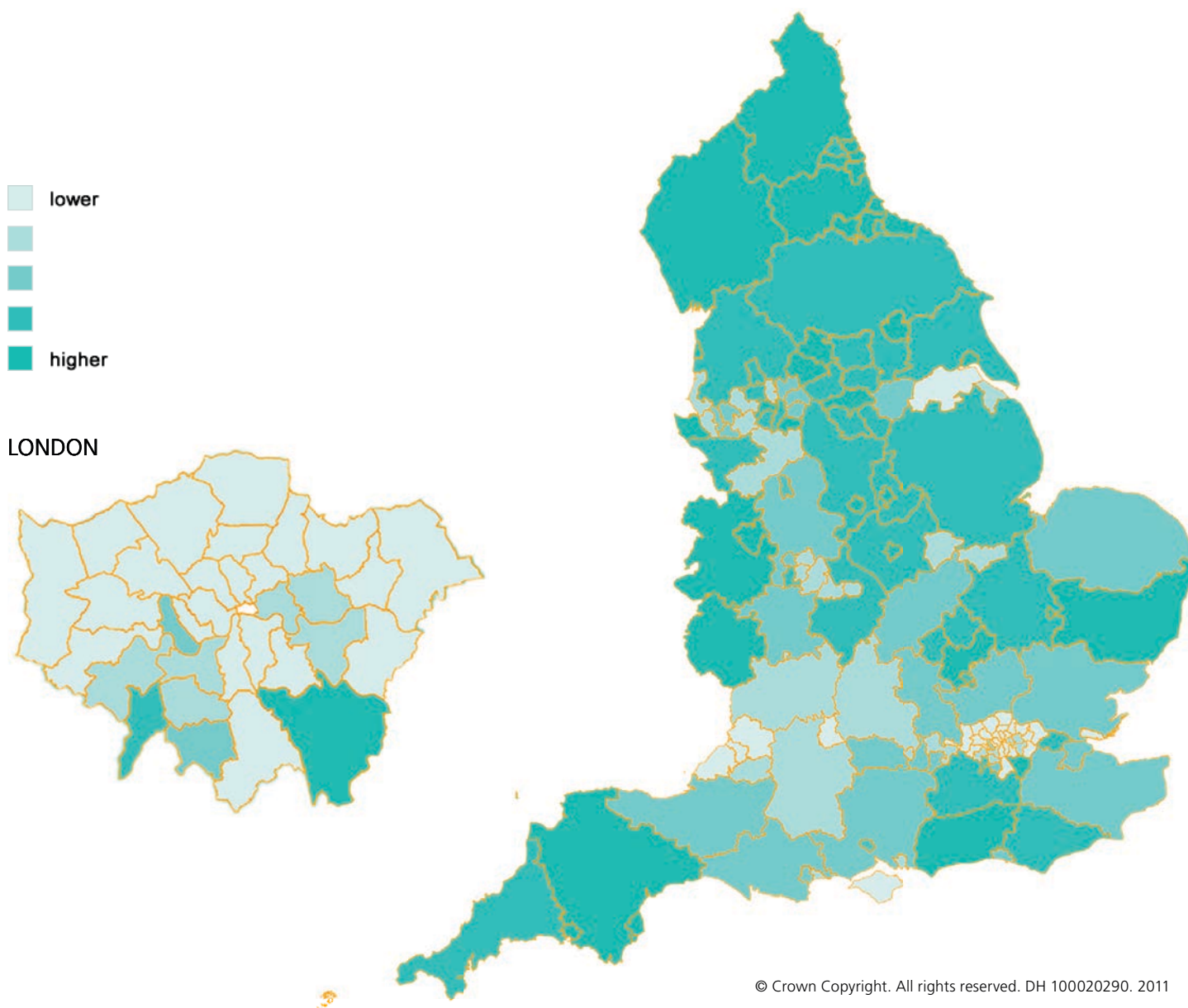


C: Ear, nose and throat surgery

**Map 43** Tonsillectomy: Directly standardised rate of elective tonsillectomy in children aged 0–17 years, per 100,000 children aged 0–17 years, by local authority, 2011–2012



**Map 44** Aural ventilation tube insertion: Directly standardised rate of aural ventilation tube (grommet) insertion in children aged 0–17 years, per 100,000 children aged 0–17 years, by local authority, 2011–2012



## Context

The commonest indications for childhood tonsillectomy are recurrent tonsillitis and sleep-related breathing disorders (SRBD), including obstructive sleep apnoea (OSA).

While there is national evidence-based guidance for tonsillectomy for the treatment of recurrent tonsillitis (see 'Resources' later in this section), no such guidance exists for the appropriate threshold for surgical intervention for SRBD. SRBD and OSA form a spectrum of conditions where upper airway obstruction during sleep produces poor sleep quality, daytime fatigue, poor school performance and, in severe cases, serious disorders of cardiopulmonary function. Treatment for SRBD currently accounts for about 25% of tonsillectomies (combined with adenoidectomy) for children in England.

Over-use of tonsillectomy places increased demand on limited resources and can lead to unnecessary complications for those children in whom active monitoring might be a more appropriate strategy. However, failure to intervene for children who fulfill the treatment criteria may be just as harmful, affecting the quality of life of the child and their family, as well as incurring increased costs from repeat attendances, antibiotic prescriptions and hospital admissions, as well as loss of parental income.

Aural ventilation tubes are predominantly used to treat otitis media with effusion (OME), which is a build-up of fluid in the middle ear resulting in hearing loss. Approximately 80% of children suffer an episode before the age of 5 years. The majority of cases are self-limiting, with recovery of hearing loss. No treatment other than active monitoring has proved effective during the early stages of the condition.

For children with bilateral OME in whom there is no resolution over a three-month period, with a specified level of hearing impairment, surgical treatment by inserting an aural ventilation tube (grommet) is effective, and recommended by National Institute for Health and Care Excellence guidelines.

Both of these indicators were included in the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

## Magnitude of variation

### Map 43: Tonsillectomy

For local authorities in England, the directly standardised rate of elective tonsillectomy in children aged 0–17 years, per 100,000 children aged 0–17 years, ranged from 98.5 to 512.2 (greater than five-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 129.7 to 376.1, and the variation is 2.9-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2008 to 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 145.1 to 423.7, and the variation was also 2.9-fold.

### Map 44: Aural ventilation tube insertion

For local authorities in England, the directly standardised rate of aural ventilation tube (grommet) insertion in children aged 0–17 years, per 100,000 children aged 0–17 years, ranged from 50.3 to 429.2 (8.5-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 73.9 to 368.1 and the variation is five-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2008 to 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 92 to 424, and the variation was 4.6-fold.

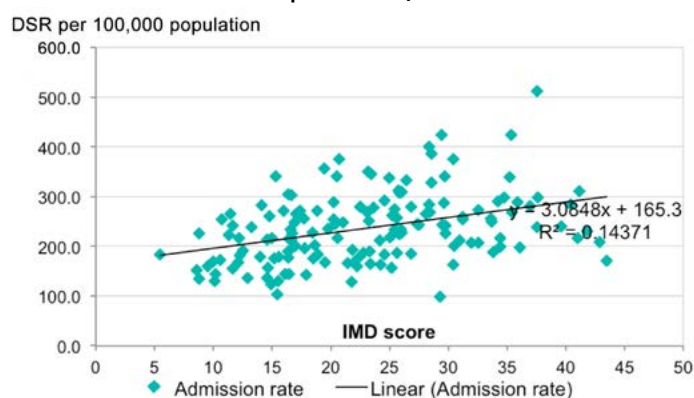
In contrast to the historical view that childhood tonsillectomy is an operation undertaken on children of higher socio-economic status, area deprivation appears to be associated with higher rates of tonsillectomy (Figure 5C.1).

In comparison with 2007–2008 to 2009–2010 data, current rates of tonsillectomy appear to show a reduction in rates of tonsillectomy for each area, without a change in the degree of variation among areas. Of course, it would be unwise to directly compare previous rates aggregated by primary care trusts with these local authority rates. However, as an overall distribution, the results should be broadly comparable on a nationwide level.

The historical overuse of tonsillectomy in children has had a high profile and remains problematic in selected areas and populations. Some variation may be due to differences in thresholds for OSA and SRBD, for which evidence-based clinical and functional thresholds for surgical intervention are still lacking.

Conversely, there is also a danger that, in some areas, children who may benefit from the procedure are now unable to obtain access to it. There are clinically proven benefits for selected children and, barring exceptional individual cases, it would be equally inappropriate to withhold treatment as it is to provide it unnecessarily. The data here appear to show a shift of the curve towards lower rates of tonsillectomy nationally. Although it remains impossible to say with any certainty what the 'optimal rate' for tonsillectomy in children

**Figure 5C.1 Correlation between elective admission rate for tonsillectomy and deprivation, by local authority, 2011–2012 (High IMD score indicates more deprived area)**



## Section 5: Healthcare for acutely ill children

might be, this overall reduction should trigger commissioners to investigate whether this reflects a reduction only in unwarranted variation in tonsillectomy rates.

The data for aural ventilation tube insertion show a similar shift in the overall distribution towards lower rates of surgery, with the degree of variation across the country being also largely unchanged. Over the past decade, emphasis has been placed on the clinical and financial sequelae of unnecessary surgical intervention for OME, often justifiably so. However, the consequences of failing to intervene in a child with persistent OME are:

- prolonged hearing impairment
- social, developmental and language delays
- harmful effects on educational progress.

The degree of variation observed shows much work still needs to be done to ensure that quality and value are maximised for this intervention.

### Options for action

Commissioners can use national guidelines (see 'Resources' later in this section) when commissioning services to ensure equity of access for clinically justified interventions, while reducing unnecessary interventions that divert resource from those who fulfill clinical criteria.

As no national evidence-based clinical guidance currently exists for the thresholds for tonsillectomy for SRBD, commissioners and clinicians can use jointly agreed local criteria, which should be:

- based on best available evidence
- outcome as well as process based
- benchmarked against the agreements made with other local commissioning bodies to ensure equity of access and high-quality outcomes.

There is an urgent need to define evidence-based clinical and functional thresholds for surgical intervention in OSA based on high-quality research. In the interim, commissioners can investigate what proportion of the activity in local rates of tonsillectomy is attributable to recurrent tonsillitis and OSA in order to identify whether there is inappropriate over or under-activity for each of the indications, and thereby enable interventions to be targeted accordingly.

Commissioners and clinicians can jointly investigate the reduction in rates of tonsillectomy and aural ventilation tube insertion in order to ensure that this reduction is warranted (due to reducing unnecessary and low-value interventions), rather than under-provision that will result in unmet need and, in the long term, poor outcomes for children.

### Resources

Scottish Intercollegiate Guidelines Network (2010). Management of sore throat and indications for tonsillectomy. A national clinical guideline ([www.sign.ac.uk/guidelines/fulltext/117/index.html](http://www.sign.ac.uk/guidelines/fulltext/117/index.html)).

NICE Guidance (2008). Surgical management of children with otitis media with effusion (OME). Clinical guidelines, CG60 (<http://guidance.nice.org.uk/CG60>).

NHS Right Care, in conjunction with the Royal College of Surgeons and ENT-UK, has produced:

- a value-based commissioning guide for tonsillectomy ([www.rcseng.ac.uk/providers-commissioners/docs/rcseng-ent-uk-commissioning-guide-tonsillectomy-out-for-consultation-17-may-14-june-2013](http://www.rcseng.ac.uk/providers-commissioners/docs/rcseng-ent-uk-commissioning-guide-tonsillectomy-out-for-consultation-17-may-14-june-2013))
- the Procedures Explorer Tool, a supporting commissioning tool for clinical commissioning groups which highlights local and regional variation for each surgical procedure ([www.rcseng.ac.uk/providers-commissioners/nscc/data-tools](http://www.rcseng.ac.uk/providers-commissioners/nscc/data-tools)).

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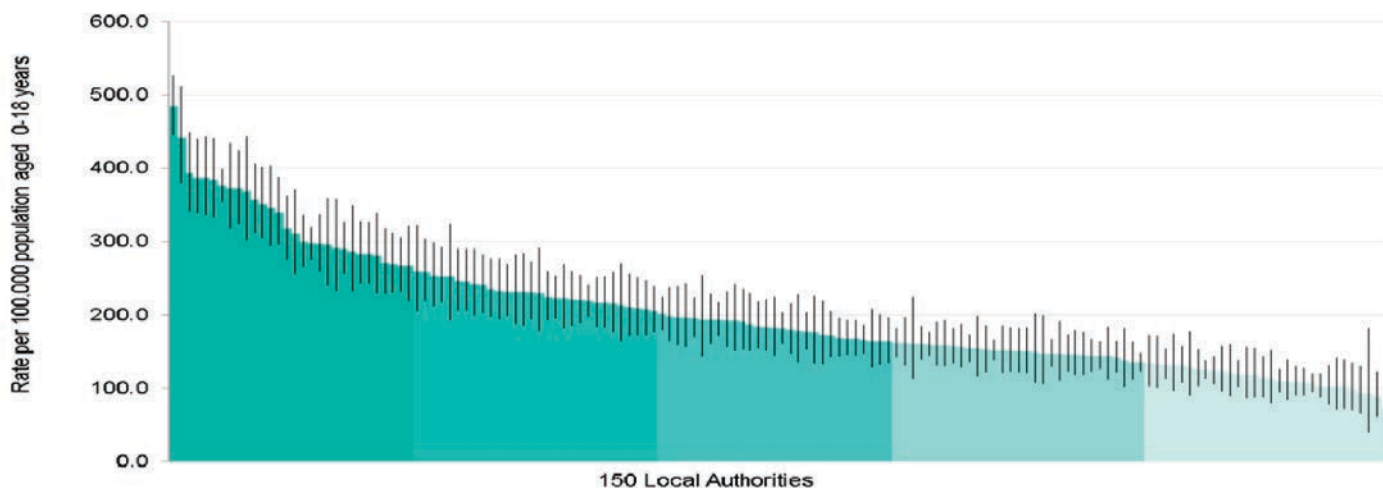
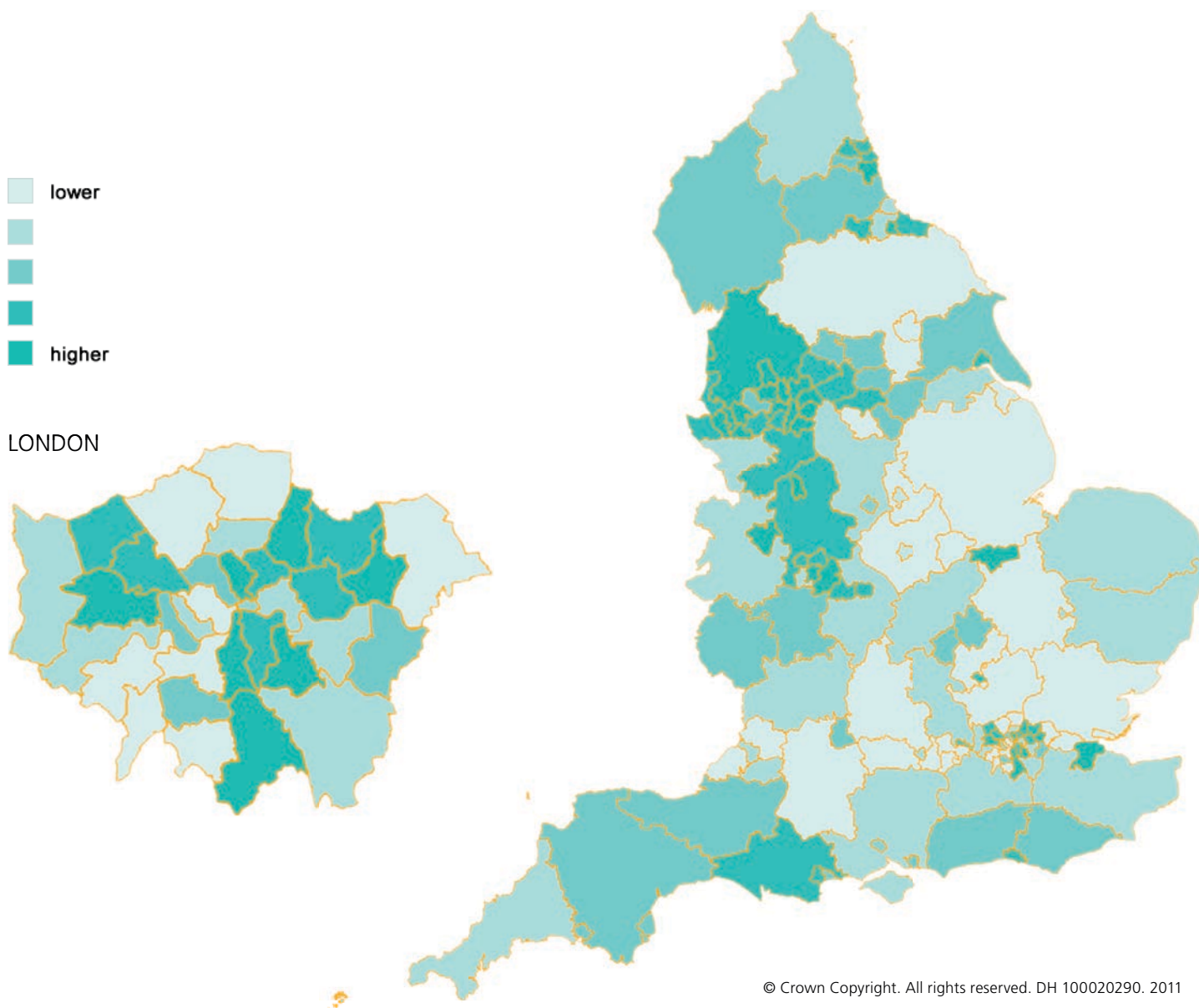
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# Children with long-term conditions



A: Asthma

**Map 45** Asthma: Directly standardised emergency admission rate for children with asthma, per 100,000 population aged 0–18 years, by local authority, 2011–2012



## Context

Asthma is the commonest long-term medical condition in childhood. Emergency admissions should be avoided whenever possible.

'Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s' is included in the NHS Outcomes Framework 2013/14.

This indicator was included in the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

## Magnitude of variation

**Map 45:** For local authorities in England, the emergency admission rate for children with asthma, per 100,000 population aged 0–18 years, ranged from 73.4 to 484.4 (6.6-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 102.2 to 384.1, and the variation is almost four-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2009–2010) demonstrated in the NHS Atlas of Variation in Healthcare for Children and Young People (2012) was 97.6 to 468.5, and the variation was nearly five-fold. For 2008–2009, after exclusions, the variation was almost four-fold.<sup>1</sup>

Variation in the rate of emergency admission may be due to a variety of reasons:

- suboptimal symptom management and secondary prevention in the community
- suboptimal emergency care in the accident and emergency department
- differences in admission criteria among paediatric clinicians.

The reduction in the magnitude of variation compared to previous years is to be welcomed, reflecting greater equity in asthma services. However, one cannot draw firm conclusions based on these data as the geographical and population units of analysis have changed from primary care trusts to local authorities. Moreover, any apparent reduction in variation does not appear to be accompanied by an overall reduction in admission rates.

## Options for action

Commissioners can use the Disease Management Information Toolkit (see 'Resources' later in this section) to identify unwarranted variation in the local management of long-term conditions such as asthma.

A management pathway for asthma would help to reduce unwarranted variation.

The British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) guideline on management of asthma (see 'Resources' later in this section) suggests that every child with asthma should have an Asthma Care Plan.

Commissioners and clinicians could consider ensuring that the BTS/SIGN guideline forms the basis of local clinical asthma pathways for which they are responsible, and to support implementation of up-to-date evidence on best practice, such as omalizumab for severe persistent allergic asthma.<sup>2</sup>

As the causes of asthma are multifactorial, action to reduce emergency admission requires a whole pathway approach, including public health, primary and secondary care. Parental education and school medication management are also vital aspects of the overall care of the child with asthma.

## Resources

Disease Management Information Toolkit (<http://atlas.chimat.org.uk/IAS/dmit> or <http://datagateway.phe.org.uk/>).

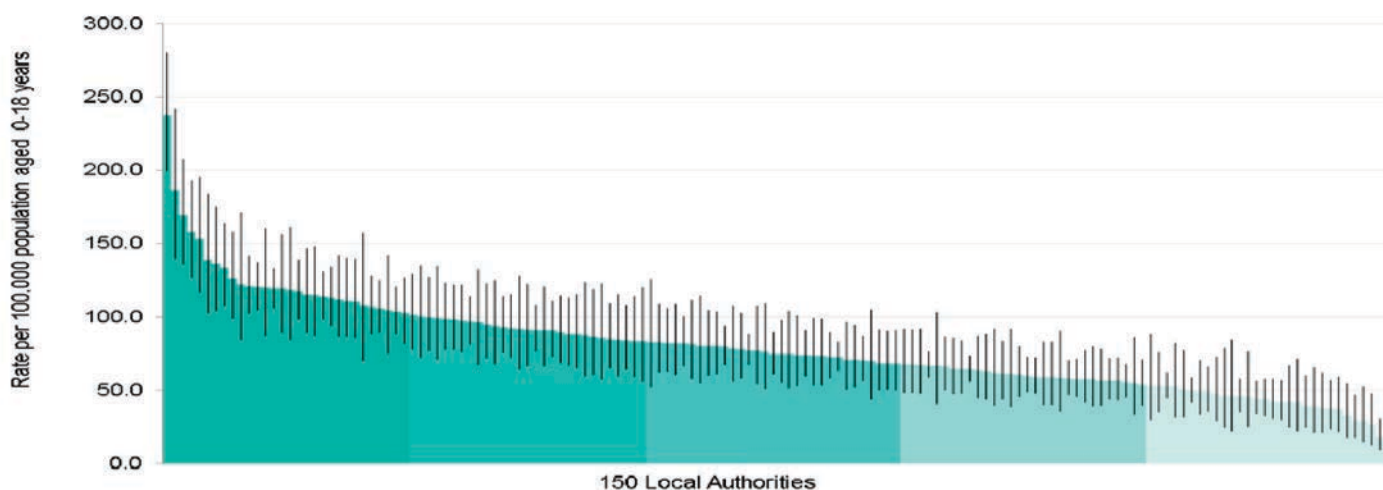
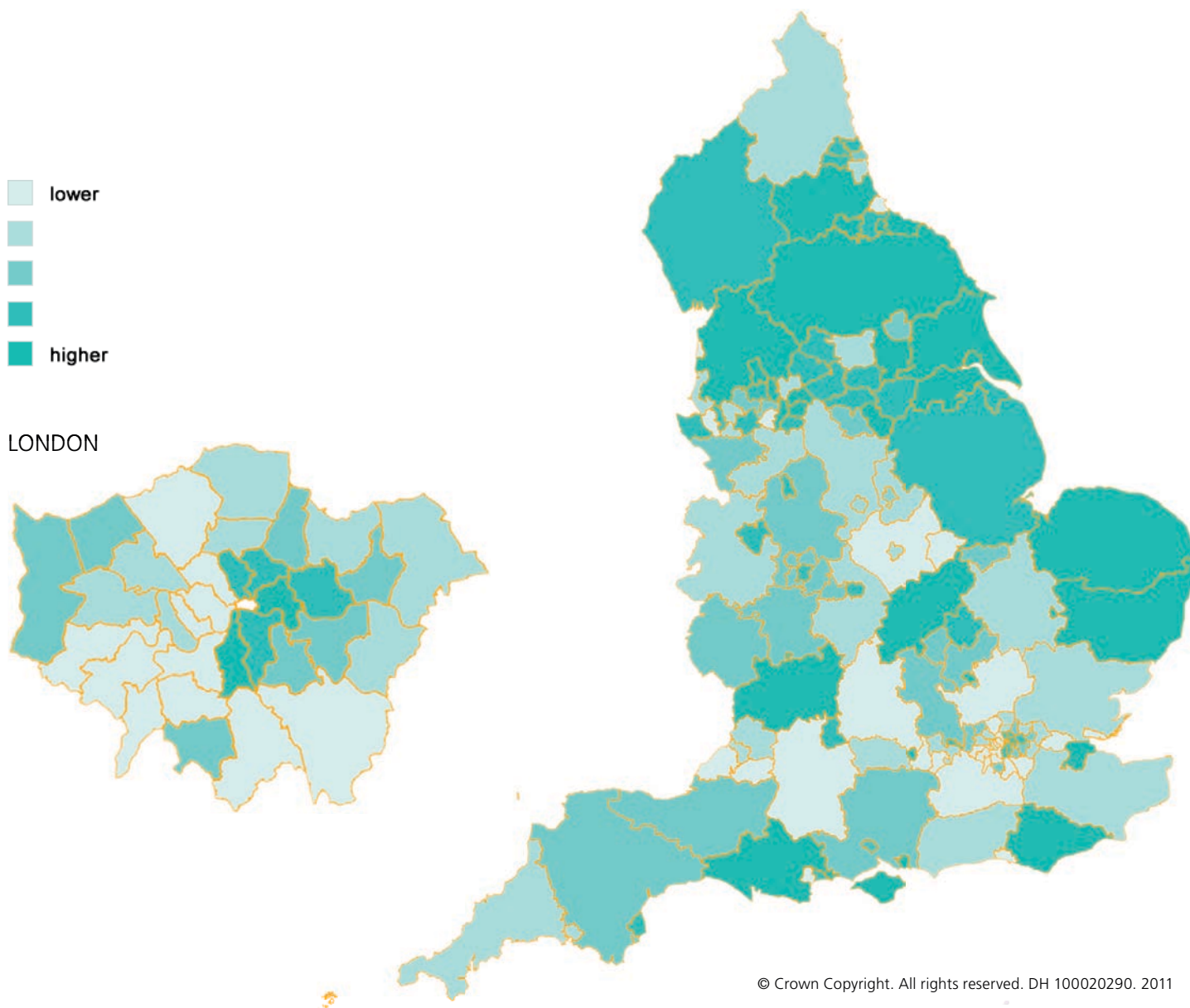
BTS/SIGN (2011). British Guideline on the Management of Asthma. May 2008; revised May 2011 ([www.brit-thoracic.org.uk/guidelines/asthma-guidelines.aspx](http://www.brit-thoracic.org.uk/guidelines/asthma-guidelines.aspx)).

1 NHS Atlas of Variation in Healthcare 2010. Map 17. Available at: [www.rightcare.nhs.uk/index.php/atlas/atlas-of-variation-2010/](http://www.rightcare.nhs.uk/index.php/atlas/atlas-of-variation-2010/).

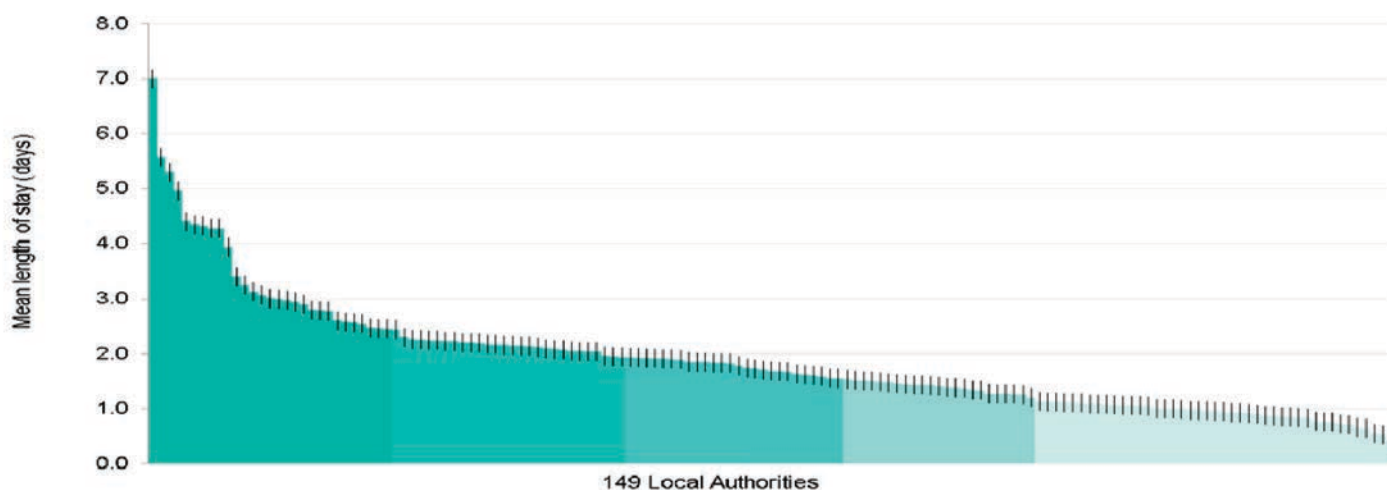
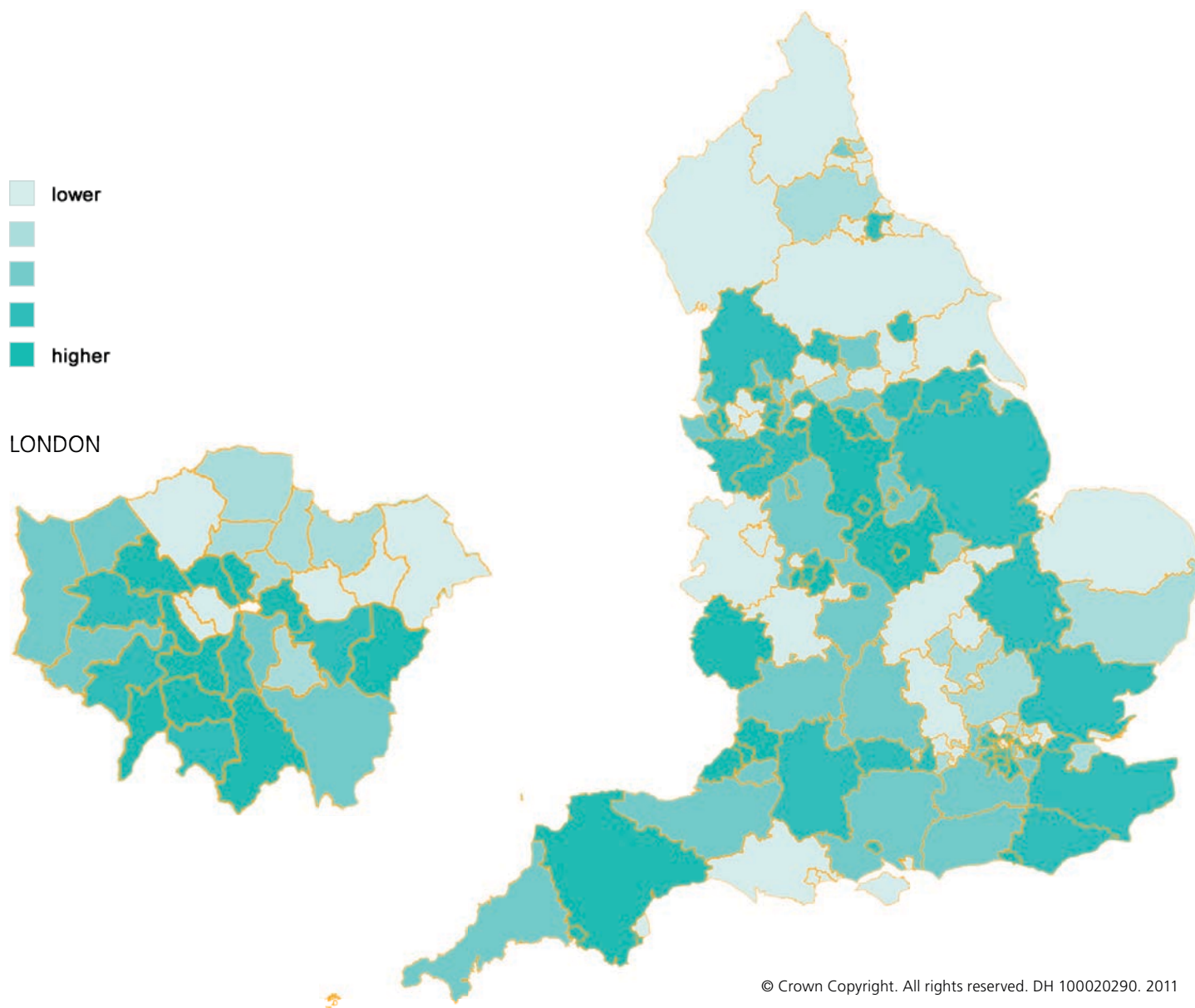
2 NICE Technology Appraisal 278: Omalizumab for treating severe persistent allergic asthma. 2013. Available from: <http://publications.nice.org.uk/omalizumab-for-treating-severe-persistent-allergic-asthma-review-of-technology-appraisal-guidance-ta278>.

## B: Epilepsy

**Map 46** Epilepsy: Emergency admission rate: Directly standardised rate of emergency admissions for children with epilepsy, per aged 0–17 years, by local authority, 2011–2012



**Map 47** Epilepsy: Duration of hospital stay: Mean length of emergency inpatient stay (days) for children with epilepsy aged 0–18 years, by local authority, 2011–2012





### Context

Epilepsy is common in children, affecting approximately 48,000 in England. Epilepsy is not a single diagnosis; it is, more accurately, the epilepsies – encompassing a range of disorders of varying complexity and diagnostic difficulty. Complex co-morbidities are also more common in childhood than in adult epilepsy.

Frequent or prolonged hospital admissions for children with epilepsy disrupt their education and family life, thereby affecting their wellbeing and that of their families.

In a review of health economic analyses of the cost of care in childhood epilepsy, unnecessary hospital admission was one of the most expensive aspects of epilepsy care.<sup>1</sup> The cost of caring for children in whom the control of epilepsy is poor is greater than twice that involved in caring for children in whom seizure control is good. The increased expenditure is due to greater costs of both medication and hospital admissions.

From 2013–2014, the Department of Health will implement a best practice tariff for secondary paediatric epilepsy via the Payment by Results system. Criteria for a high-quality service that attracts the tariff will include:

- named lead paediatrician for epilepsy
- access to local epilepsy specialist nurse
- planned network-based pathways for children requiring tertiary support
- epilepsy care plans for affected children, including planned transition pathways for young people with epilepsy
- participation in national audit (via the 'Epilepsy 12' audit – see 'Resources' later in this section).

Both of the above indicators were included in the NHS Atlas of Variation in Healthcare for Children and Young People (2012).

'Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s' is included in the NHS Outcomes Framework 2013/14.

### Magnitude of variation

#### Map 46: Epilepsy – Emergency admission rate

For local authorities in England, the directly standardised rate of emergency admissions for children with epilepsy, per population aged 0–18 years, ranged from 18 to 237.4 (greater than 13-fold variation). When the five local authorities with the highest rates and the five local authorities with the lowest rates are excluded, the range is 37.2 to 139.1 and the variation is 3.7-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2008 to 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 30.8 to 133.7, and the variation was over four-fold.

#### Map 47: Epilepsy – Duration of hospital stay

For local authorities in England, the mean length of emergency inpatient stay (days) for children with epilepsy aged 0–18 years ranged from 0.4 to 7.0 days (greater than 17-fold variation). When the five local authorities with the greatest lengths of stay and the five local authorities with the lowest lengths of stay are excluded, the range is 0.7 to 4.3 days, and the variation is greater than six-fold.

By comparison, after removing outliers in a similar way, the range (by primary care trust in 2007–2008 to 2009–2010) demonstrated in the Atlas of Variation in Healthcare for Children and Young People (2012) was 0.8 to 2.8 days, and the variation was 3.5-fold.

Epilepsy is more common in deprived populations. However, as the higher prevalence rate in socio-economically deprived populations is only about one-quarter greater than the mean rate, deprivation alone cannot explain this degree of variation.

Variations in emergency admission rates for children with epilepsy can reflect:

- effectiveness of ongoing seizure control
- emergency management of acute seizures
- differences in the admission criteria of local departments.

The occurrence of seizures in childhood epilepsy can be unpredictable. For a few children, long-term seizure control can be very difficult. These children, who may also have other neurodevelopmental problems and physical disability, could influence the number and duration of emergency admissions in certain local authorities. However, as the numbers are small, it is unlikely to account for the degree of variation observed.

Variation is also seen in the prevalence of epilepsy and the proportion of children diagnosed with epilepsy who do not have the disease. Epilepsy can be difficult to diagnose in children. In the absence of referral guidance and specialist expertise within a managed network setting, children with equivocal clinical presentations can be misdiagnosed.<sup>2</sup>

While admission rates for epilepsy appear relatively stable over time, the increasing variation in duration of stay in 2011–2012 compared with previous years is of concern, particularly as it appears to reflect a shift towards greater overall lengths of stay.

The reasons for unwarranted variation could be generic to hospital patient-flow processes and experienced in common with many other conditions, for example:

1 Beghi E et al. (2005). A review of the costs of managing childhood epilepsy. *Pharmacoeconomics* 23: 27–45.

2 Uldall P, Alving J, Hansen LK, Kibæk, Buchholt J (2006). The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events. *Archives of Disease in Childhood* 91: 219–221.



- differences in criteria for admission
- delays in investigations
- availability of health professionals for inpatient consultations
- sub-optimal discharge processes.

Differences in the level of community-based support may also contribute to a delay in discharge, affecting the confidence of both families and clinicians to discharge the child at an appropriate time.

## Options for action

Commissioners may want to consider the benefits of commissioning the following interventions for children with epilepsy:

- First-seizure services to streamline investigation and diagnosis where possible.
- Integrated care pathways, including the development of personal management plans for children and their families.
- Specialist nurses in the epilepsy service, whose roles could include co-ordination of care pathway, family support, population education and liaison with primary care and education services.
- Enhanced links with social care and education, including medication policies in schools.
- Specific services to aid the transition of children with epilepsy from paediatric to adult epilepsy services.

A managed network model of delivering epilepsy care can help to improve seizure control in many children with epilepsy and rationalise clinical decision making about the need for admission.

## Resources

The National Institute for Health and Care Excellence (NICE) has produced both clinical guidance and quality standards for the management of epilepsy in children:

- Quality Standards: NICE (2013). The epilepsies in children and young people. Quality Standard QS27 (<http://guidance.nice.org.uk/QS27>).
- Guidance: NICE (2012). The epilepsies. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. Clinical guidelines, CG137 (<http://guidance.nice.org.uk/CG137>).
- Commissioning guide (2013). Diagnosis and management of the epilepsies in adults, children and young people. (<http://www.nice.org.uk/guidance/CMG47>).

Epilepsy Best Practice Tariff  
([www.isb.nhs.uk/documents/isb-0028/amd-17-2012/0028172012guid.](http://www.isb.nhs.uk/documents/isb-0028/amd-17-2012/0028172012guid.))

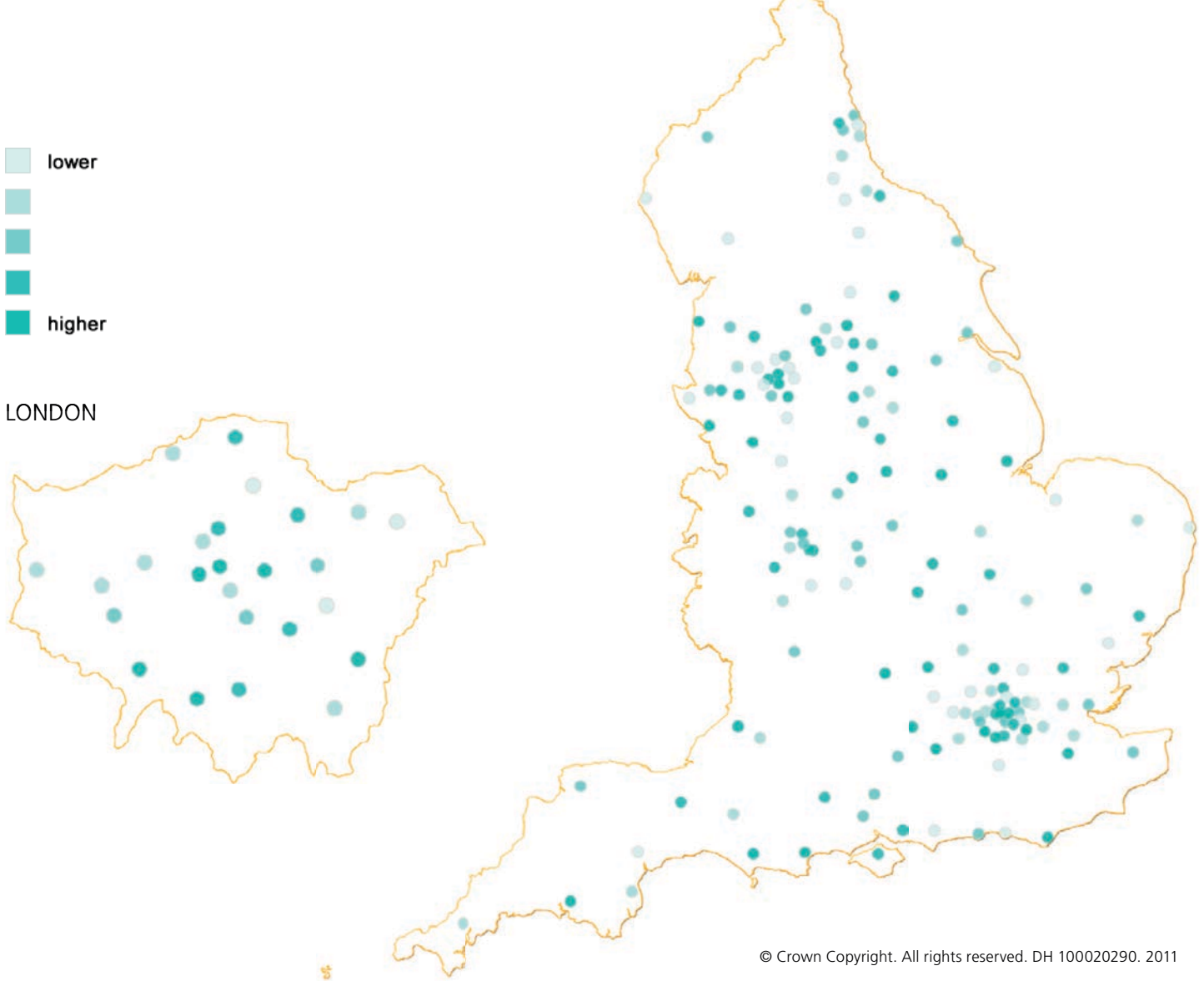
Epilepsy 12 is a national audit of childhood epilepsy, monitoring performance of units against 12 key quality standards: 99% of eligible units have signed up. National and individual provider reports from Round 1 are available here: [www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/epilepsy12-national-audit/results](http://www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/epilepsy12-national-audit/results).

The British Paediatric Neurology Association runs courses in the UK for health professionals involved in the management of children with epilepsy. These courses help to ensure a consistent clinical approach to the diagnosis and management of epilepsy in children ([www.bpna.org.uk/pet/](http://www.bpna.org.uk/pet/)).

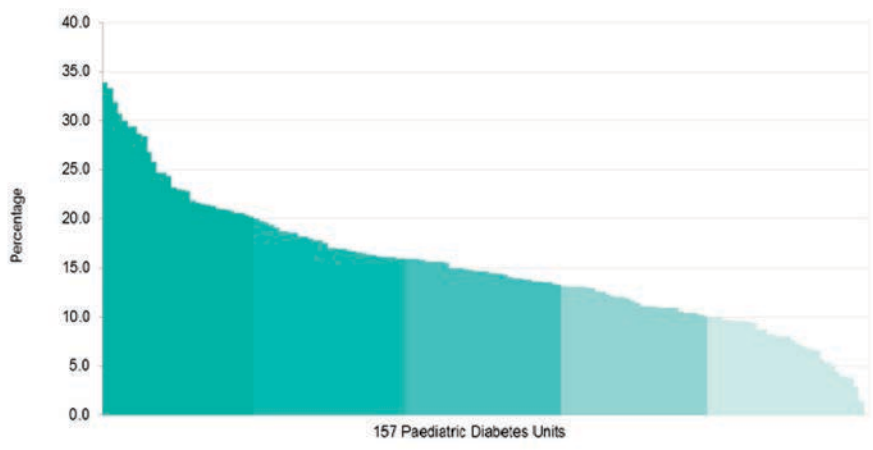
Patient education and support is available from national and local services ([www.epilepsy.org.uk/info](http://www.epilepsy.org.uk/info)).

C: Diabetes

**Map 48** Diabetes: Percentage of children and young people aged 0-24 years with diabetes cared for in a Paediatric Diabetes Unit (PDU) whose most recent HbA1c measurement was less than 58 mmol/mol (7.5%), 2010/11, by PDU



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## Context

Ongoing good blood glucose control in children and young people with diabetes reduces the risk of developing complications in the longer term. Glycated haemoglobin (HbA1c) is an indicator of average blood glucose control over the previous 10-12 weeks. In national and international guidance, an HbA1c of less than 58 mmol/mol (7.5%) is recommended for children with diabetes.<sup>1,2</sup>

The data presented here are taken from the National Paediatric Diabetes Audit (NPDA).<sup>3</sup> Specialist Paediatric Diabetes Units (PDUs) in England and Wales have been submitting process and outcome data to the NPDA since 2003/4. In 2010/11, 97% of PDUs in England and Wales submitted data to the NPDA. This gave data on approximately 24,000 children and young people who were under the care of a Consultant Paediatrician at the time of the data collection. The majority had Type 1 diabetes (97%), with the greatest numbers in the 10-14 year age group.

In 2010/11, only 5.8% of children and young people with diabetes in England and Wales received all eight NICE-recommended care processes.<sup>3</sup> Since April 2012, paediatric diabetes care in England has been subject to a Best Practice Tariff, whereby providers receive the maximum tariff for managing children and young people with diabetes only if they are compliant with 13 best practice standards – of which submission of audit data to NPDA is one. (See “Resources”)

A related indicator on paediatric diabetes – “Percentage of children aged 0-15 years with Type 1 diabetes whose most recent HbA1c measurement was 10.0% (86 mmol/mol) or less” was included in the Atlas of Variation in Health Care for Children and Young People 2012.

## Magnitude of variation

**Map 48:** For PDUs in England, the percentage of children and young people aged 0-24 years with Type 1 diabetes whose most recent HbA1c measurement was less than 58 mmol/mol (7.5%) ranged from 0% – 33.8% (over 33-fold variation). When the five PDUs with the highest percentages and the five PDUs with the lowest percentages are excluded, the range is 3.9% - 29.4% and the variation is 7.5-fold.

Overall, only 15.7% of all children and young people with diabetes in the NPDA (England and Wales) had an HbA1c value below the recommended target level of 58 mmol/mol.<sup>3</sup> In Germany and Austria, the equivalent statistic is 34% of children and young people.<sup>4</sup>

## Options for action

Every commissioned diabetes service could provide a continuum of care from hospital to the community for children and young people with diabetes including those in transition to young adult services. This care could be delivered by a specialist paediatric multidisciplinary team (MDT), including consultant paediatricians with expertise in children and young people with diabetes, paediatric diabetes specialist nurses and educators, paediatric diabetes dietitians, psychologists with an interest in diabetes, social workers, pharmacists and play therapists.

Providers can ensure that services are staffed by adequate numbers of skilled, experienced paediatric multidisciplinary teams, under clear clinical leadership, facilitated by managed clinical networks.

Commissioners can consider reviewing minimum service specifications to ensure they are in line with current Best Practice Tariff Guidance, NICE guidance and Department of Health policy on service configuration.<sup>5</sup> Local, regional and national peer review of diabetes services can promote best practice, and help to assess performance and improve outcomes.

Commissioners and providers could collaborate to deliver age-appropriate and validated self-management education programmes, individually tailored for each child and young person, their family and school. Standardised, accredited specialist training could be provided for all healthcare professionals involved in the care of children and young people with diabetes.

## Resources

- NICE Guidance (2004) Diagnosis and management of type 1 diabetes in children, young people and adults (CG15). [Update ongoing] <http://guidance.nice.org.uk/CG15>
- NICE pathway for managing diabetes (including in children and young people) <http://pathways.nice.org.uk/pathways/diabetes>
- Paediatric Diabetes Best Practice Tariff. More information, including service standards, available here: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/214902/PbR-Guidance-2013-14.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214902/PbR-Guidance-2013-14.pdf)
- RCPCH National Paediatric Diabetes Audit [www.rcpch.ac.uk/national-paediatric-diabetes-audit-npda](http://www.rcpch.ac.uk/national-paediatric-diabetes-audit-npda)
- SWEET project e.V. ([www.sweet-project.eu](http://www.sweet-project.eu)): an international collaboration of paediatric diabetes services working to improve care through benchmarking clinical outcomes, comparing services and best practice, and sharing standards, guidance, models of education and research.
- International Society for Pediatric and Adolescent Diabetes (ISPAD) (2009) ISPAD clinical practice consensus guidelines. [www.ispad.org/FileCenter.html?CategoryID=5](http://www.ispad.org/FileCenter.html?CategoryID=5)

1 NICE (2004) Diagnosis and management of type 1 diabetes in children, young people and adults (CG15). <http://guidance.nice.org.uk/CG15>

2 ISPAD (2009) ISPAD Clinical Practice Consensus Guidelines. *Pediatric Diabetes* 10: Suppl 12. [www.ispad.org/FileCenter.html?CategoryID=5](http://www.ispad.org/FileCenter.html?CategoryID=5)

3 Royal College of Paediatrics and Child Health (2012). National Paediatric Diabetes Audit Report 2010-11. [www.rcpch.ac.uk/system/files/protected/page/NPDA%20Annual%20Report\\_25%2009%2012%20for%20web.pdf](http://www.rcpch.ac.uk/system/files/protected/page/NPDA%20Annual%20Report_25%2009%2012%20for%20web.pdf)

4 [www.hqip.org.uk/national-paediatric-diabetes-auditreport-2012](http://www.hqip.org.uk/national-paediatric-diabetes-auditreport-2012)

5 Department of Health (2007) Making every young person with diabetes matter. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_073674](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674)

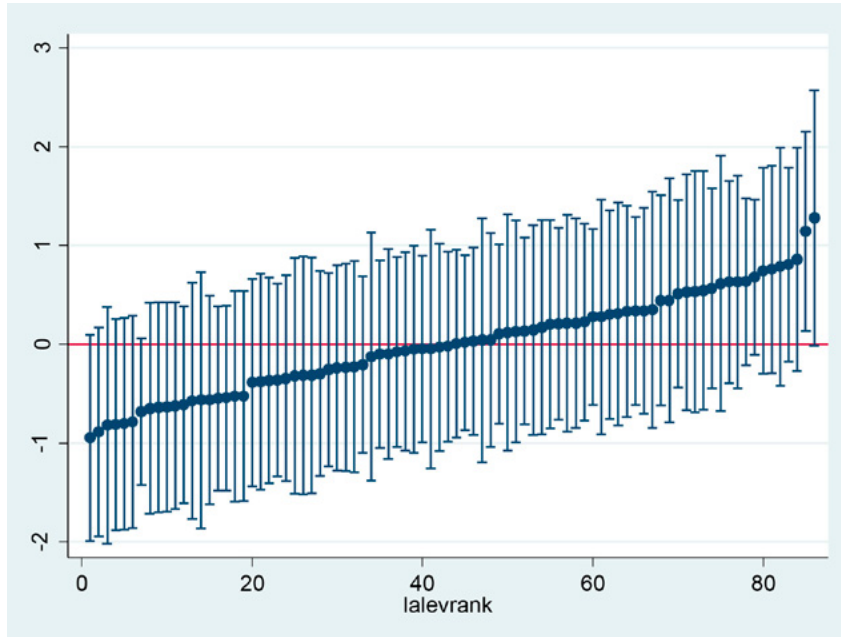
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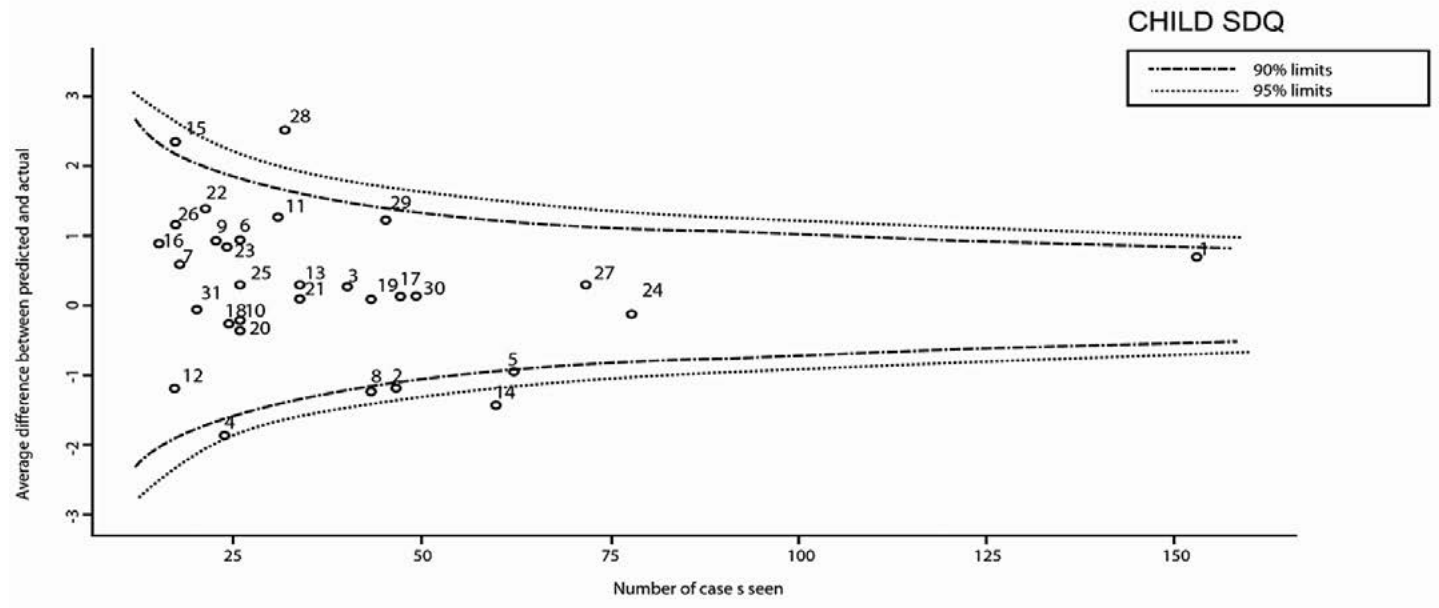
# Child mental health

A: Mental health problems – prevalence and outcomes

**Indicator 49** Mental health – prevalence of problems: Variation in community prevalence of mental health disorders for 11–13 year olds in secondary schools, by local authority, 2009–2011 (controlling for known risk factors)



**Indicator 50** Mental health – specialist service outcomes: Variation in change in mental health disorders following contact with Specialist Services for 11–18 year olds accessing Child and Adolescent Mental Health Services (CAMHS), by CAMHS units, 2008–12





## Context

In the UK, 10% of 5–16 year olds have a diagnosable mental problem.<sup>1</sup> There are higher rates of disorder among adolescents compared with children and 40% of young people experience at least one mental disorder by the age of 16.<sup>2</sup>

The prevalence of mental health problems is associated with key risk factors including poverty, special educational needs, poor housing and trauma.<sup>3</sup> Thus variation in prevalence is correlated with indices of deprivation, vulnerability and adverse life circumstances (as illustrated in Table 7A.1), leading to variation in mental health disorders across the country following patterns of deprivation.

**Table 7A.1 Prevalence of mental health disorders in children from higher-risk groups (adapted and reproduced with permission)<sup>4</sup>**

| Group                                                                                                                           | Expected prevalence of mental disorders                                                    |
|---------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|
| Looked-after children                                                                                                           | 45%                                                                                        |
| Children with special educational needs requiring statutory assessment                                                          | 44%                                                                                        |
| Children with learning disability                                                                                               | 36%                                                                                        |
| Children absent from school more than 15 days in previous term                                                                  | 17% with emotional disorder<br>14% with conduct disorder<br>11% with hyperkinetic disorder |
| Children from households with no working parent                                                                                 | 20%                                                                                        |
| Children from families receiving disability benefits                                                                            | 24%                                                                                        |
| Children from families where the household reference person is in routine occupational group (such as unskilled manual workers) | 15%                                                                                        |
| Children of parents with no educational qualifications                                                                          | 17%                                                                                        |
| Children living in 'hard-pressed' areas                                                                                         | 15%                                                                                        |
| Children from household with weekly income <£100                                                                                | 16%                                                                                        |
| 11–16 year olds from household with weekly income <£200                                                                         | 20%                                                                                        |
| Children in stepfamilies                                                                                                        | 14%                                                                                        |
| Children from lone parent families                                                                                              | 16%                                                                                        |

The long-term consequences of mental health disorders in childhood, if not effectively treated, can include poorer academic achievement, unemployment, premature morbidity and long-term physical and mental problems in adulthood.<sup>5</sup> Up to 50% of lifetime mental illness (excluding dementia) arises by age 14, and 75% by the mid-20s.<sup>6</sup>

1 Green H et al. (2005). *Mental health of children and young people in Great Britain*, 2004. Basingstoke: Palgrave Macmillan.

2 Jaffee SR et al. (2005). Cumulative prevalence of psychiatric disorder in youths. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(5), 406–407. doi: S0890-8567(09)61499-4 [pii] 10.1097/01.chi.0000155317.38265.61.

3 Rutter M, Stevenson J (2008). Using Epidemiology to Plan Services: A Conceptual Approach. In M. Rutter et al. (Eds.), *Rutter's Child and Adolescent Psychiatry* (5th ed., pp. 71–80). Malden, Oxford and Carlton: Blackwell.

4 Joint Commissioning Panel for Mental Health (2013). *Guidance for commissioning public mental health services*. Updated July 2013. Available from: [www.jcpmh.info/resource/guidance-for-commissioning-public-mental-health-services/](http://www.jcpmh.info/resource/guidance-for-commissioning-public-mental-health-services/).

5 Belfer ML (2008). Child and adolescent mental disorders: the magnitude of the problem across the globe. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 49(3), 226–236. doi: 10.1111/j.1469-7610.2007.01855.x JCPP1855 [pii].

6 Kessler RC et al. (2007). Age of onset of mental disorders: a review of recent literature. *Current Opinion in Psychiatry*, 20(4), 359–364. doi: 10.1097/YCO.0b013e32816ebc8c; 00001504-200707000-00010 [pii].

## Section 7: Child mental health

The estimated annual cost to the UK economy of mental disorders is £105 billion, in contrast with obesity (£16 billion a year) and cardiovascular disease (£31 billion).

Only around 25% of children with clinical mental health disorders receive help from specialist CAMHS within 3 years in the UK.<sup>1</sup> Access may be most limited for the most deprived and needy groups.<sup>2</sup>

In this section we consider variation across England in child mental health problems in the community and change after receiving specialist help, in terms of self-reported emotional and behavioural difficulties. We focus here on child self-reporting only. However, it should be noted that there are differences in parent, child and clinician reporting, and ideally a combination of all three should be used when considering variation in populations.<sup>3</sup>

Development of a new survey to support measurement of outcomes for children with mental health problems was recommended in the report of the Children and Young People's Health Outcomes Forum (2012).

### Magnitude of variation

#### **Indicator 49: Mental health – prevalence of problems: Variation in community prevalence of mental health disorders for 11–13 year olds in secondary schools, by local authority, 2009–2011 (controlling for known risk factors)**

No nationally collected returns are routinely aggregated for community level prevalence of diagnosable mental health disorders. Though there are important national surveys, these have not set out to consider regional variance.<sup>4</sup>

Research suggests that, once known factors as outlined above are controlled for, there appears to be little variation across areas. In community settings, school-level variation in mental health difficulties – controlling for known risk factors – has been found to be below 5%.<sup>5</sup>

Below, we present prevalence data collected in 2009 from a large study of mental health of children in schools<sup>6</sup> to consider levels of variation across local authorities, controlling for known risk factors. These data were collected from 22,730 adolescents from 86 local authorities. The measure used is the child self-report Strengths and Difficulties Questionnaire (SDQ).<sup>7</sup> The SDQ is a widely used measure of symptomology, distress and impact, and has been validated in general community as well as clinical populations.

Prior to accounting for known socio-demographic risk factors and variation accounted for by schools, local authorities account for 3% of the variation in mental health scores. After taking into account gender, socio-economic status and school level variation, 1.5% of the variation is accounted for by local authorities.

Indicator 49 illustrates the spread of residual variance scores across local authorities (i.e. the variability in scores not explained by gender, socio-economic status or school at the local authority level) with their confidence intervals.

Although the spread of scores seems large, all the confidence intervals (but one) are in contact with the horizontal line, which indicates that they are not significantly different from one another and that the variations seen are most likely to be due to chance.

1 Ford T, Hamilton H, Meltzer H, & Goodman R. (2007). Child Mental Health is Everybody's Business: The Prevalence of Contact with Public Sector Services by Type of Disorder Among British School Children in a Three-Year Period. *Child and Adolescent Mental Health*, 12(1), 13–20.

2 Champion J, Bhugra D, Bailey S, Marmot M. (2013). Inequality and mental disorder: opportunities for action. *Lancet* 382: 183–4.

3 Verhulst FC, Van der Ende J. (2008). Using rating scales in a clinical context. In M. Rutter, D. Bishop, D. S. Pine et al. (Eds.), *Rutter's Child and Adolescent Psychiatry* (5th ed., pp. 289–298). Malden, Oxford and Carlton: Blackwell.

4 Green H et al. (2004). Mental health of children and young people in Great Britain. Available from: [www.esds.ac.uk/doc/5269/mrdoc/pdf/5269technicalreport.pdf](http://www.esds.ac.uk/doc/5269/mrdoc/pdf/5269technicalreport.pdf).

5 Hale D et al. (2013). School-level variation in health outcomes in adolescence: analysis of three longitudinal studies in England. *Prevention Science*. doi: 10.1007/s11121-013-0414-6.

6 Wolpert M et al. (2011). Me and My school: Findings from the National Evaluation of Targeted Mental Health in Schools 2008-2011. Research Report DFE-RR177. London: Department for Education.

7 Goodman R. (1997). The Strengths and Difficulties Questionnaire: a research note. *J Child Psychol Psychiatry*, 38(5), 581–586.

**Indicator 50: Mental health – specialist service outcomes: Variation in change in mental health disorders following contact with Specialist Services for 11–18 year olds accessing CAMHS, by CAMHS units, 2008–12**

There is as yet no mandated return of data related to outcomes of treatment offered in all CAMHS, though a number of national initiatives are in train (e.g. CYP IAPT – see: [www.iapt.nhs.uk/cyp-iapt/](http://www.iapt.nhs.uk/cyp-iapt/)). For some years now, however, services across the UK have voluntarily come together as part of a learning collaboration to collect outcome data, particularly from the perspective of service users, as part of the CAMHS Outcomes Research Consortium (CORC) – see: [www.corc.uk.net](http://www.corc.uk.net).<sup>8</sup>

CORC is a practice-research network of around half of all CAMHS teams, primarily outpatient teams seeing children with moderate to severe difficulties, including both statutory and voluntary providers. CORC aggregates outcome data and allows members of the collaboration to consider variation between their service outcomes and those of others.

Risk-adjusted outcome data (with clinical risk score based on clinician-rated severity of symptoms at outset) from 194 cases aged 9–18 years from 31 CAMHS units (collected 2008–2012) from the CORC database are presented, as a funnel plot. It shows risk-adjusted change in child mental disorder scores aggregated over a unit. For each mental health unit, the difference between predicted and observed outcomes (y-axis) is plotted against the number of cases seen (x-axis). Plots such as these are recommended for use across healthcare to identify teams outside of the confidence intervals as warranting a closer investigation of potential reasons for differences in service performance.<sup>9</sup> Figure 7A.2 suggests that no more units fall outside the 95% confidence interval than might occur by chance based on child self-report data.

## Options for action

### Early intervention to improve life chances:

Early intervention and commissioning of mental health provision in schools and clinics, which have been shown in some studies to improve outcomes and life chances for children and young people into adulthood, may be an opportunity for commissioners to prevent and reduce mental health disorders in adulthood.

### Funding for data collection to consider unwarranted variation:

Greater support for services to collect routine data will allow appropriate analysis and meaningful interpretation of variance in outcomes in collaboration with commissioners, in particular to ensure adequate IT. It is estimated that at least 3–5% of a commissioning budget should be allocated to support data collection and handling.<sup>10</sup>

### Data quality and adjustment:

Unadjusted variation between areas or services in relation to child mental health disorders is likely to be the result of known correlation with risk factors and/or chance variation in data rather than substantive differences in practice. For commissioners, unadjusted variation data can be useful to inform service planning and resource allocation. However, for analysing performance and outcomes of services, we would encourage using risk-adjusted funnel plots, followed by triangulation of data with other sources. This should reduce the risk of over-interpretation of difference on the one hand, and the tendency to explain away differences as due to measurement error on the other.<sup>15</sup>

### Collaboration between commissioners to promote child mental health:

Health and wellbeing boards bring a real opportunity for collaborative commissioning across agencies (in particular health, education and social care) to address all aspects that contribute to and maintain mental health disorders in children, with a particular focus on those groups most in need.

8 Wolpert M et al. (2012). Patient-reported outcomes in child and adolescent mental health services (CAMHS): use of idiographic and standardized measures. *Journal of Mental Health*, 21(2), 165–173. doi: 10.3109/09638237.2012.664304.

9 Spiegelhalter DJ (2005). Funnel plots for comparing institutional performance. *Stat Med*, 24(8), 1185–1202. doi: 10.1002/sim.1970.

10 Wolpert M et al. (2008). *Review and recommendations for national policy for England for the use of mental health outcome measures with children and young people*. London: Department for Children, Schools and Families.

# Glossary of essential terms

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## Introduction

Much of the disagreement that occurs during the commissioning or management of services arises because different people use the same term but have a different understanding of its meaning. This glossary is provided in order to help develop a shared or common language. If there is a clear, short and memorable definition from the literature, this has been cited and presented in italics; where definitions in the literature are overly long, Right Care has composed and provided a short definition.

## Appropriate

*A procedure is termed appropriate if its benefits sufficiently outweigh its risks to make it worth performing.*

**Source:** Kahan JP et al. (1994). Measuring the necessity of medical procedures. *Medical Care* 32: 352–365.

## Confidence intervals

*Confidence intervals give the range within which the true size of a treatment effect (which is never precisely known) lies, with a given degree of certainty (usually 95% or 99%).*

**Source:** Evans I, Thornton H, Chalmers I (2006). Testing Treatments. *Better Research for Better Healthcare*. The British Library.

## Costs

Costs are not only financial. Costs may be measured as the time used, the carbon produced or the benefit that would be obtained if the resources were used for another group of patients (i.e. the opportunity cost).

## Effective care

*The extent to which an intervention, procedure regimen or service produces a beneficial outcome under ideal circumstances (e.g. in a randomised controlled trial)*

**Source:** Canadian Agency for Drugs and Technologies in Health (2009). *Optimal Therapy Report: Cost effectiveness of blood glucose test strips in the management of adult patients with diabetes mellitus*. Volume 3, Issue 3.

## Efficiency

See also Productivity

*Efficiency can be defined as maximising wellbeing at the least cost to society.*

**Source:** Mitton C, Donaldson C (2004). *Priority setting toolkit. A guide to the use of economics in healthcare decision making*. BMJ Publishing Group.

## Equity

Equity is a subjective judgement of unfairness.

## Health

*Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.*

**Source:** Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 1946. The definition has not been amended since 1948 ([www.who.int/suggestions/faq/en/index.html](http://www.who.int/suggestions/faq/en/index.html)).

## Inequality

Inequality is defined as objectively measured differences in health status, healthcare access and outcome.

## Input, output and outcome

Input is a term used by economists to define the resources used, such as the number of hospital beds, to produce the output, such as the number of patients admitted per bed per year.

The economists' terminology is different from the language utilised in quality assurance, in which the terms structure, process and outcome are used. Input equates to structure and process, i.e. the number of beds and the number of admissions per bed, respectively. However, the outcome is distinct from the output. Outcome includes some measure of the effect that the process has had on the patients, for example, the number of patients who were discharged to their own home.

## Integrated care

*Clinical integration, where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions such as through use of shared guidelines and protocols.*

**Source:** Kodner DL, Spreeuwenberg C (2002). Integrated care: meaning, logic, applications and implications – a discussion paper. *International Journal of Integrated Care* 2: 1–6.

## Mean (average)

The mean is the sum of values (e.g. size of populations) divided by the number of values (e.g. number of populations in the sample).

## Network

If a system is a set of activities with a common set of objectives, the network is the set of organisations and individuals that deliver the systems.

## Outcome, see Input

## Output, see Input

## Population medicine

Population medicine is a style of clinical practice in which the clinician is focused not only on the individual patients referred but also on the whole population in need.

## Preference-sensitive care

*'Elective', or 'preference-sensitive' care, interventions for which there is more than one option and where the outcomes will differ according to the option used because patients delegate decision making to doctors, physician opinion rather than patient preference often determines which treatment patients receive. I argue that this can result in a serious but commonly overlooked medical error: operating on the wrong patients – on those who, were they fully informed, would not have wanted the operation they received.*



**Source:** Wennberg JE (2010). *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

## Preference-sensitive treatment decisions

*Preference-sensitive treatment decisions involve making value trade-offs between benefits and harms that should depend on informed patient choice.*

**Source:** O'Connor AM et al (2007) Toward the 'Tipping Point': Decision aids and informed patient choice. *Health Affairs* 26: 716–725.

## Productivity

See also Efficiency

Productivity is the relationship between inputs and outputs, such as the number of operations per theatre per year; efficiency is the relationship between outcomes and inputs, such as the number of successful operations per theatre per year.

## Quality

*The degree to which a service meets pre-set standards of goodness.*

**Source:** Donabedian A, personal communication.

## Range

The range is the difference between the highest and lowest value in the sample. The range provides a crude measure of the spread of the data.

## Safety

*Patient safety can, at its simplest, be defined as: The avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare ... the reduction of harm should be the primary aim of patient safety, not the elimination of error.*

**Source:** Vincent C (2006). *Patient Safety*. Churchill Livingstone.

## Shared decision-making

*In a shared decision, a healthcare provider communicates to the patient personalised information about the options, outcomes, probabilities and scientific uncertainties of available treatment options, and the patient communicates his or her values and the relative importance he or she places on benefits and harms.*

**Source:** Wennberg JE (2010). *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

## Standard deviation

See also Variance

The standard deviation is a measure of spread and is the square root of the variance.

## Supply-sensitive care

*It differs in fundamental ways from both effective care and preference-sensitive care. Supply-sensitive care is not about a specific treatment per se; rather, it is about the frequency with which everyday medical care is used in treating patients with acute and chronic illnesses. Remedying variation in*

*supply-sensitive care requires coming to terms with the 'more care is better' assumption. Are physician services and hospitals in high-cost, high-use regions overused?*

**Source:** Wennberg JE (2010). *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

## System

A set of activities with a common set of objectives, with an annual report.

## Unwarranted variation

*Variation in the utilisation of healthcare services that cannot be explained by variation in patient illness or patient preferences.*

**Source:** Wennberg JE (2010). *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

## Value

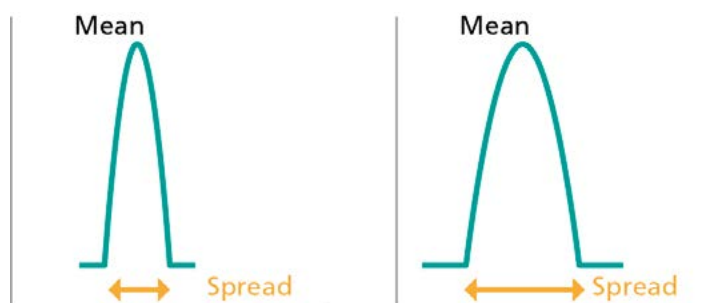
*... value is expressed as what we gain relative to what we give up – the benefit relative to the cost.*

**Source:** Institute of Medicine of the National Academies (2008). *Learning Healthcare System Concepts v. 2008. The Roundtable on Evidence-Based Medicine, Institute of Medicine. Annual Report.*

## Variance

See also Range

The variance is another measure of spread, which describes how far the values in the sample lie away from the mean value. It is the average of the squared differences from the mean and is a better measure of spread than the range.



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