

# REPORT OF THE CHILDREN AND YOUNG PEOPLE'S HEALTH OUTCOMES FORUM 2013/14

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## Foreword

We are delighted to be publishing the first Annual Report of the Children and Young People's Health Outcomes Forum. For the past two years, the Forum, as an independent advisory group of professionals and representatives from across the children's sector, has worked together to provide expertise, constructive challenge and evidence based advice to improve children and young people's health outcomes and to drive up standards of care.

Over the past two years we have seen immense change across the health system as it reforms following the implementation of the Health and Social Care Act 2012. When our original recommendations were published in July 2012 many organisations were undergoing transformation, with some yet to be fully established.

This Annual Report provides an opportunity to take stock of progress, acknowledging the unprecedented focus on children and young people's healthcare and the need for it to continue as the new health system settles down. Undertaking system change during a period of austerity has been challenging for everyone involved. However, it has highlighted the need to take a life course approach and the importance of getting services right for children and young people. If we get services right for them, in terms of prevention, early intervention, and better health outcomes, then this has not only the potential to improve the life chances of many individuals, but also to reduce their reliance on the NHS in the future and thus is a very effective investment.

One of the most significant challenges in compiling this report has been to extract the information and evidence on how the Forum's recommendations for improvement have progressed within the system. While this can partly be explained by the range and scope of response and positive activity, it underlines a central challenge of accountability. It is not the Forum's role as an independent body to hold the ring on accountability; however, it is problematic to see who else does. We have found it difficult to maintain an overview of what is happening at local and national level and how performance management is being undertaken. It is clear that the system has come a long way in a short time in putting in place changes that should lead to improved health outcomes. However, we also recognise that there is a lot more to do to implement the remaining changes that we identified in our initial report. In this report we highlight those areas where we feel that progress has been too slow or has stalled, and we challenge the system to respond. The real test of the Forum's work will be whether in the next few years there is evidence of improved health and healthcare outcomes and children and young people say that services have improved.

We have been delighted in the interest and support for the Forum's work shown by Dr Dan Poulter MP (Minister responsible for child health), the Chief Medical Officer

(CMO), Professor Dame Sally Davies, and the senior leadership of the organisations that make up the new health system.

The Minister has provided clear leadership by launching, at the time of the system wide response to the Forum's recommendations, the *Better health outcomes for children and young people* pledge. Through this pledge many organisations across the system entered into a joint commitment to 'improve the health outcomes of our children and young people so that they become amongst the best in the world'. The pledge explains why action is needed to improve children and young people's health outcomes and our shared ambitions for doing so, examples of what joint commitment and effort could achieve, and how momentum on this issue is being built.

We were delighted that the Chief Medical Officer's 2012 Annual Report, published in October 2013, focussed on improving children's health and wellbeing. Her recommendations, falling broadly into three areas, (a) the voice of children and young people, (b) building services and joining services, and (c) the economic case for a shift to prevention, are in line with our previous recommendations and have our full support. In her Report, the CMO made a formal recommendation that the Forum's Annual Summit should provide an opportunity for the review of health outcomes that are relevant to children, and to examine regional variation. We welcome this recommendation and agree that this focus would be entirely appropriate for the Forum's future Annual Summits. CMO's Report also recommended a National Children's Week, which would aim to identify where we stand with respect to children's health and wellbeing outcomes and the wider determinants of health. We support this recommendation, and would ensure that the Forum and its members played a full role.

The Forum's first two day Annual Summit in September 2013 heard from senior leaders of a range of health system organisations. We are grateful for the positive way that they have engaged with the Forum and that they understand the Forum's role of constructive challenge and evidence based advice to improve children and young people's health outcomes. We recognise the pressures on their organisations to deliver at a time of financial restraint.

We are extremely grateful to Forum members for giving their time and sharing their expertise. Their enthusiasm and commitment has made the task of co-chairing the Forum and agreeing the content of this Annual Report a relatively painless process.

The Forum is fortunate to be able to draw upon the wide knowledge and wise advice of Dr Catherine Calderwood (National Clinical Director, Maternity and Women's Health, NHS England), Dr Jackie Cornish (National Clinical Director, Children, Young People and Transition to Adulthood, NHS England), Dr Ann Hoskins (Director, Children, Young People and Families, Public Health England) and Ann Gross

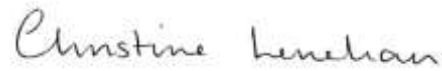
(Director, Foundation Years and Special Needs Group, Department for Education)  
who attend Forum meetings as observers.

We know that there is a hard-working and dedicated children's health workforce that want to be involved in improving services for children and young people. We are keen to hear your views on what you think we should be focussing on or to hear of examples of innovative practice. We have a webpage [here](#) where you can keep up to date with what the Forum is doing, access the Forum's reports and contact the Forum.



Ian Lewis

April 2014



Christine Lenehan

## Introduction

This report is for those who have an interest and contribution to make towards improving children and young people's health outcomes. This includes national and local Government, and those leading and working in the health, healthcare, social care and education system and wider children's sector.

## Background

In January 2012, the then Secretary of State for Health, Andrew Lansley, established the Children and Young People's Health Outcomes Forum to develop a strategy that would help deliver health and healthcare outcomes for children and young people that would rank amongst the best in the world. Specifically, the Forum was asked to:

- identify the health outcomes that matter most for children and young people;
- consider how well these were supported by the NHS and Public Health Outcomes Frameworks and make recommendations; and
- set out the contribution that each part of the new health system needed to make in order that these health outcomes are achieved.

In July 2012 we published the *Report of the Children and Young People's Health Outcomes Forum* which outlined the health outcomes that we had found matter most to children and young people and our recommendations for the new health system.

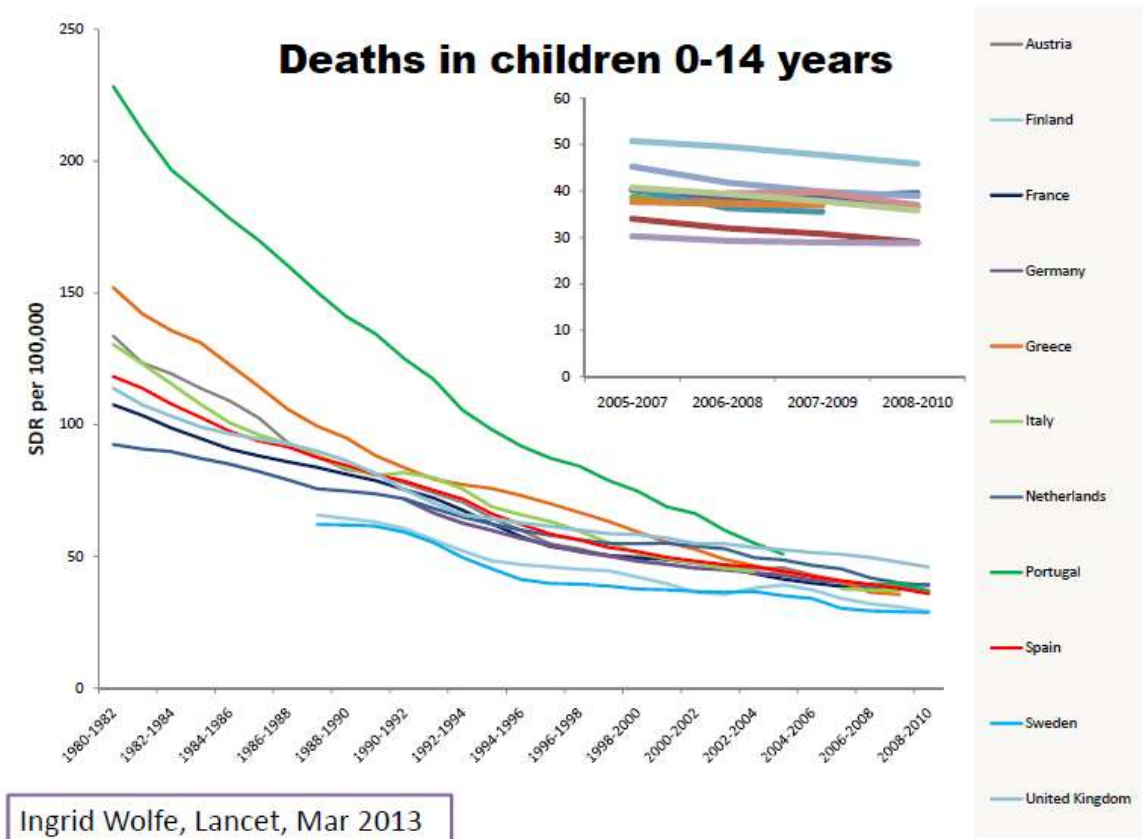
In February 2013 *Improving Children and Young People's Health Outcomes: a system wide response* was published setting out a series of completed and proposed actions to address the Forum's recommendations. As part of the Government response the Forum was invited to re-form with a refreshed membership in order to continue to advise on the next stage of work to improve children and young people's health outcomes.

Details of the Forum's membership, Pathway Group membership, meeting dates and agendas are in Annexes 2, 3 and 4 (separate documents).

## Why we need to improve children and young people's health outcomes

Whilst there have been some notable improvements in measured outcomes for children and young people over recent years, the evidence is still telling us that this is at a slower rate in the UK and that they are poor in many areas when compared to other countries in northern and western Europe.

The most telling of these is mortality data for children and young people. Our first report used a report from 2010 which showed that the all-cause mortality rate for children aged 0–14 years, despite a slow improvement, has moved from the average to amongst the worst in Europe. This information was updated in 2013 and shows a similar finding (see table below).



As a consequence, 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 in the UK every day five children under the age of 14 die who would not die in Sweden. This equates to the alarming figure of 132,874 person years of life being lost each year in the UK, the majority of which would be as healthy adults contributing to the country’s social and economic strength (*Our Children Deserve Better: Prevention Pays – Annual Report of the Chief Medical Officer 2012*).

Within England there are major unexplained and unacceptable variations in a number of key measurements. The updated *Atlas of Variation in Healthcare for Children and Young People*, published as an Annex to the *Annual Report of the Chief Medical Officer 2012* shows continuing wide and unwarranted variations around the country in service provision, care and outcomes.

These include:

- a 3 fold variation in admission of term babies into neonatal units;
- a 4 fold variation in admissions to hospital for bronchiolitis or asthma;
- a 3 fold variation in tonsillectomy rates;
- the rate of deaths from non-accidental injury showing a 3-fold variation after outliers;
- deaths from accidental injury showing a 3-fold variation across the regions after exclusions; and
- measles, mumps and rubella vaccine rates of uptake range from 69.7% to 95.3% and human papilloma virus vaccination rates in girls vary from 62.3% to 97.2% by local authority.

There are serious consequences for inaction on improving children and young people's health outcomes. Five of the 'top 10' risk factors for the total burden of disease in adults are initiated or shaped in adolescence. Although there has been a significant reduction over the past decade in the number of young people drinking regularly or starting to smoke there is still much to be achieved as:

- more than half of 15–16 year olds had consumed more than five alcoholic drinks in the previous month;
- hospital admissions for alcohol-specific conditions in 0–17 year olds show an eight-fold variation around the country;
- more than 8 out of 10 adults who have ever smoked regularly, started before age 19;
- 8 out of 10 obese teenagers go on to be obese adults;
- 50% of life-time mental illness (excluding dementia) starts before age 15 and 75% by the mid-20s although there is evidence from longitudinal data that much of the risk may be accumulated by age 18; and
- approximately 10% of adolescents suffer from a mental health problem at any one time, although estimates of prevalence are based on the ONS surveys which are now 10 years old and there have been important societal and demographic changes which may affect rates of disorder.

There are some important indicators which demonstrate real inequality in health, particularly in infant mortality, obesity and childhood accidents as well as particular groups such as looked after children, those from black and minority ethnic groups and those with disabilities.

In future we expect our annual reports to increasingly focus on specific outcomes and the success or otherwise of the methodologies being employed to improve them.



## **Specific work during the year**

We have undertaken several pieces of work in response to invitations from Health Ministers. We have provided commentary and recommendations for the Government's response to the Mid Staffordshire Foundation Trust Public Inquiry, and the refresh of the Mandates for NHS England and Health Education England respectively. We have also been asked to contribute to the Winterbourne View response and review aspects of the Chief Medical Officer's Annual Report.

Details of the recommendations we made are available through links on the Forum's webpage (see final web-link in the appendix to this document).

## **How this report is structured**

In the following pages the Forum's challenges to the system are set out and then, under the headings used in the Forum's initial report, we highlight some of the progress made and the Forum's continuing concerns. There is an additional heading, culture, which results from the importance of this area highlighted by the Francis Report.

We then set out the Forum's work plan for 2014 which is, of course, linked to our challenges to the system. Finally we include web links to the documents mentioned in this report.

## Chapter 1: The Forum's challenges to the system

In its initial report the Forum made 78 far reaching recommendations to a wide range of health system organisations. Subsequently we have made recommendations in respect of children and young people's aspects of the Francis Report and the NHS and HEE Mandate refreshes. Many of our recommendations have been taken on board by the new health system. Others require a sustained focus and action over time to achieve system wide change.

Our focus here is not to add to our recommendations but to challenge the system where more progress needs to be made. These challenges are grouped around a small number of themes and aimed at organisations that can directly influence improved health outcomes. Running through all these themes is getting the culture right post the Francis Report.

### Ensuring effective engagement with children and young people so that their views are sought and acted upon

The Challenge to all organisations is that -

- they should be able to evidence how engagement with children and young people is embedded (including at Board level), is responded to and improves outcomes;\*
- all staff involved in engaging with children and young people are properly trained to do so;
- there should be an assumption that all patient experience surveys apply to children and young people as well as adults. All experience measures should include children and young people as standard unless there is a very good reason why this is not appropriate – which we expect to be articulated and explained; and
- system leaders ensure that the principles and values in the NHS Constitution are adopted and supported and applied to children and young people.

\* Via their annual reports/at Forum's Annual Summit.

### Ensuring that the children and young people's workforce across the professions is fit for purpose

The Challenge to organisations that are responsible for recruiting and training relevant staff\* is that –

- all those working with children and young people are appropriately trained, possess common core skills, attitudes and behaviours and have a shared understanding/language facilitating joint working and integration;

- the Government's forthcoming mandate to HEE sets out a wide range of objectives that aim to improve the skills and knowledge of the children's workforce. We don't underestimate the level of the challenge to HEE and its partners and it will take a concerted effort across the system, at a time where there is pressure on financial and staffing resources, to meet these objectives.

\*Health is everyone's business across the whole children and young people's workforce and skilling up the whole workforce including social workers, youth workers, teachers, GPs etc. is a vital plank in prevention work.

### **Ensuring that the incentives for service development incentivise prevention, early intervention, and safe and sustainable services**

The Challenge to all organisations, and in particular Monitor, NHS England and the NHS Trust Development Authority, is that they engage with the Forum so that –

- there is a shared understanding of how funding flows are impacting on patient care and service provision;
- future development of Payment by Results currencies and tariffs for child health related areas incentivise safe and sustainable services; and
- models of funding are developed to encompass whole pathway provision and incentivise preventative and early intervention strategies alongside safe and sustainable services.

### **Ensuring that the appropriate children and young people's health outcome indicators are in place and that progress against the indicators, including regional variations, is reviewed**

The Challenge is that -

- the Department of Health and NHS England prioritises the development of outcome indicators on transition, integration and age appropriate care;
- NHS England funds a children and young people's mental health prevalence survey and also one that includes perinatal mental health; and
- relevant organisations attend the Forum's Annual Summit so that the Forum can review progress against the indicators including regional variations.

### **Data sharing and integration – there is a lack of coherent data and a system that links outcomes of children and enables them to be tracked**

We are concerned that children and young people are too often an afterthought in national and local efforts to improve integrated care. For example, the Government established the £3.8bn Better Care Fund to better integrate health and social care. However, the focus has been upon integration of services for adults and we are disappointed that few of the integrated care pioneers include any focus upon children and young people's services.

- The Challenge to the Department of Health, the Department for Education and local agencies (such as the Association of Directors of Children's Services, the Local Government Association and SOLACE) is that they make progress on the use of the NHS Number as an identifier in health, education and social care;
- The Challenge to the Government is to learn from the experience of improving integrated care for adults and to develop a coherent approach for extending this to children and young people; and
- The Challenge to the Children's Health and Wellbeing Partnership, which has already identified the integration of children's services as an important issue, is to ensure that integration remains high on its agenda and that initiatives to better integrate adult services are replicated for children and young people's services.

**Ensuring that children and young people's services are accountable at a national and local level and knowing this is working on the ground.**

The Challenge to the System

- Commissioning – Ensuring that there are incentives for local authorities, primary care and secondary care to improve outcomes and that gaps in service provision are addressed and not exacerbated e.g. the lack of integration between specialised services directly commissioned by NHS England and those services commissioned by Clinical Commissioning Groups, the absence of a clear mechanism to ensure collaboration between commissioners where this is required, for example, where services need to be commissioned over a geographical area which is larger than the footprint for a single Clinical Commissioning Group, and where joint commissioning with local authorities is required;
- That the Forum receives a clear explanation about the accountability structures for Clinical Commissioning Groups – and how local concerns are identified and addressed. In mental health; the lack of joined up services and disinvestment in early help services is leading to an increasing gap in parity between physical and mental health services. A strategy leading on children's mental health services is now urgently required.

## Chapter 2: Culture

In March 2013, the Secretary of State for Health accepted the Forum's offer of assistance in addressing the broad issues, particularly of culture change, raised in the Francis Report. We additionally considered the subsequent associated reports by Professor Don Berwick, on patient safety, and Sir Bruce Keogh, on the quality of care and treatment in fourteen hospital trusts.

We sent the Forum's response to the Francis Report to Dr Dan Poulter in October. It was informed by the views of children and young people, including those gathered on our behalf over the summer by the National Children's Bureau. We focused on a number of key themes to address the particular needs of children and young people:

- a culture that supports a child and young person focused approach, with the involvement of children and young people in their own care;
- leadership at all levels in all organisations which commission, regulate or provide services for children and young people to advocate for, and support, the needs of children and young people;
- workforce capacity and competence; and
- specific issues of patient safety that are most relevant to children and young people.

We concluded that, although Francis focuses primarily on NHS hospitals, the core messages are applicable to all staff and organisations working across the health and care system, whatever the setting. We called for a universal children and young people friendly culture, and proposed a number of ways in which to build on the Forum's initial report and the shared ambitions articulated in the Pledge.

The Forum's response helped inform the Government's response to the Mid Staffordshire NHS Foundation Trust Public Inquiry, *Hard Truths: The Journey to Putting Patients First*, published in November 2013.

We have been asked to work with Department of Health officials responsible for bringing together action to implement Francis. In particular, they want to work with us on culture, which will be a key focus for the Forum for the next year. A series of engagement events are being planned and the Forum will help to arrange an event to explore issues of particular relevance to children and young people.

The Forum needs to better understand what getting the right culture means in children and young people's services. How do you quantify it and how do you make it happen? We think that recruiting the right people with the right values, for example nurses qualified in adult and paediatric health, will be key in improving services, helping transition and getting the right culture in place.

The recognition of the needs of young carers, by the amendment made during the Parliamentary progress of what became the Children and Families Act 2014, shows the type of values that the system should be striving to put in place - improving support for young carers through local services working together across the statutory and voluntary sectors to consider the whole family's needs.

However, we were disappointed that the refresh of *The NHS Constitution* in 2013 did not result in a document that is drafted in such a way that it is applicable to all children, young people and their families. In a document which includes in its title "the NHS belongs to us all" there is no specific reference to children, with only cursory references to children in the accompanying *Handbook*. The NHS Constitution is an important document, setting out the principles and values of the NHS in England. If children and young people learn at an early age that entitlement to high quality care comes with responsibilities, such as the need to turn up on time to appointments, which can only be good for the future running of the NHS.

We are concerned about the following issues –

- ensuring that children and young people are treated in age appropriate settings;
- ensuring that standards applied to other vulnerable groups, such as the elderly, are applied to children and young people; and
- embedding a culture of continuous quality improvement.

## Chapter 3: Putting children, young people and their families at the heart of what happens

We set out in our initial report the importance of engaging with children and young people. We recognise that effective engagement is not easy. By engagement we mean (a) individual engagement in clinical decisions and (b) participation to inform strategy and service improvement. In the former case engagement should also include parents and carers, not only in relation to the very young, but any young person facing difficult decisions. In the latter case engagement needs to cover the whole population, not just those who are easy to engage with.

Not listening to families and thus not providing the right sort of services can have huge consequences. For example, children with long term conditions who are not effectively treated may miss school thus limiting their future career opportunities and their parents may need to stay at home thus prohibiting them from taking on full time jobs. GPs may be well placed to understand the needs of the whole family, sometimes in a way that a specialist clinician or team may not be.

We are aware of a range of senior appointments across the health system on patient engagement and specifically on ensuring that children and young people's voices are sought and taken into account at the highest level when planning, delivering and inspecting services. An example is the Care Quality Commission's (CQC) appointment of Dr Sheila Shribman as a lead advisor on the design of the inspection regime for children and young people's services. We remain committed in our belief that children and young people should be involved in CQC inspections.

We welcome the work being done at a national level to engage with children and young people. To make progress in measuring children and young people's experience of healthcare, NHS England intend to roll out the Friends and Family test to all areas, including children and young people, by 2015. NHS England and the Care Quality Commission are also planning to measure the experience of young people in inpatient settings from 2014. This survey will cover a number of areas identified as key gaps by the Forum, such as staying on an age-appropriate ward, feeling safe, and the provision of information about their condition in a way that the child or young person understands. There is a need to extend this survey programme to cover outpatient and community settings, where transition, communication and integration are key issues. These surveys could usefully find out whether children and young people have been in contact with Local Healthwatch or have been asked to act as children and young people's ambassadors.

The children and young people's inpatient survey should include a means by which they can provide feedback on the survey itself. Most organisations still don't routinely engage with or understand children and young people. The healthcare workforce needs to receive training to support effective engagement with children and young people. The principle of engaging with and surveying children and young people's views and their experiences of care should be embedded throughout the services they need.

The Forum is not well sighted on how organisations are demonstrating that they are engaging effectively with children and young people, particularly strategic planning at a local level by Clinical Commissioning Groups, Health and Wellbeing Boards, Local Healthwatch and Local Authorities. Other national organisations that we would particularly welcome evidence of engagement with children and young people are the NHS Trust Development Authority and Monitor. It is important that engagement with children and young people is not tokenistic and therefore the Forum wants to see evidence that engagement with children and young people is informing policy and service delivery. There would be benefit in having an approach to share best practice and extend knowledge on the difference it makes listening to their views.



## Chapter 4: Health outcomes that matter to children and their families

Annex 7 includes a table setting out the progress made on outcomes indicators recommended by the Forum for inclusion in the NHS and Public Health Outcomes Frameworks.

In the introduction we draw attention to the mortality data for children and young people which exemplifies the need to improve the UK's health outcomes. Forum members have been engaged with the Healthcare Quality Improvement Programme's (HQIP) Child Health Programme, a national programme of work to examine the incidence and associated features of mortality and serious morbidity in 1-18 year olds which is delivered by the RCPCH in collaboration with the MRC Centre of Epidemiology for Child Health, University College London Institute of Child Health. The Programme's reports *Overview of child deaths in the four UK countries* and *Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies*, both published in September 2013, allow policy makers and clinicians to identify variations and to learn from the past.

In order to make it easier for those concerned with children and young people's healthcare the Child and Maternal Health Intelligence Network have developed a benchmarking tool which brings together all relevant indicators within the Public Health Outcomes Framework and the NHS Outcomes Framework, new indicators which are in development for these frameworks and other important indicators relating to outcomes. This facility supports geographic mapping of variation in performance, the monitoring of trends over time and benchmarking of statistically significant variation from the England average performance. Data is available at both the England level and the local level. This will be a very important future resource for the Forum and wider community. It can be found [here](#)

We welcome the progress that has been made to date, particularly that in developing a range of integration indicators for children and young people. This is a key indicator as without integration individuals will experience disjointed and thus poor treatment.

The Maternity and Children's Dataset (MCDS) is a key element that will inform outcome measures. It has been delayed but we are now looking forward to its full implementation by the end of 2014. The Dataset is key to delivering better outcomes and further delays would not be acceptable.

We recognise the potential of the recently piloted e-Redbook, a new digital version of the current Personal Child Health Record (also known as the 'Red Book') which will enable parents to manage their child's personal health records online. We expect to see NHS England fund the roll out of the e-Redbook through the technology fund.

With outcomes indicators having been developed and others in development it is fair to ask whether we are confident that the data that is available, related to the Outcomes Frameworks and more generally, will be used effectively to commission and deliver the services which are required at a local level. There is a need for transparency on how NHS England will hold Clinical Commissioning Groups to account against outcome measures. NHS England's performance assessment of Clinical Commissioning Groups should include assessment against a common framework of agreed outcomes for children and young people. Although this holds true for every group in society, this is particularly relevant for children and young people where there is little health outcomes evidence. Commissioning undertaken by Clinical Commissioning Groups, including strategy and contracting, should be driven by outcomes, rather than inputs. NHS England should facilitate standard contracts which include outcomes as Key Performance Indicators, rather than targets.

The Forum will of course maintain a close watch on progress on outcomes indicators, and remains acutely concerned about the lack of progress on the indicators on emergency readmissions within 24 hours, quality of life for children and young people, and age appropriate care. The Forum also needs to keep track of regulators' concerns with outcomes data. The Forum itself wants to look at overall progress on the development of the outcome indicators and to prioritise and work out a long term plan for their development.

## Chapter 5: Prevention, acting early and intervening at the right time

The evidence base for prevention and early intervention is strong. Chapter 3 (The economic case for a shift to prevention) of *Our Children Deserve Better: Prevention Pays – Annual Report of the Chief Medical Officer 2012* sets it out in detail. Two of the key statistics alone in CMO's Annual Report make the case for investment. Research by Action for Children and the New Economics Foundation estimated the cost of preventable health and social outcomes faced by children and young people over a 20 year period as £4 trillion. Other research has estimated an annual expected rate of return of 6-10% on investment in interventions early in life. We welcome the support being provided to families with young children through the increased focus upon health visiting and the Family Nurse Partnership. The Forum intends to keep pushing for investment in prevention and early intervention throughout the life course.

Getting in early, on a multi-agency basis, in the lives of children and young people is crucial if we are going to tackle the gap between our children and young people's health outcomes (for both mental and physical health) and those in other nations. We need to get better at tackling issues upstream, preventing health problems and not waiting until illness becomes a feature in the life of a child or young person. By investing in prevention and early intervention we can in the longer term reduce the pressure on the health service, through reduced demand for accident and emergency departments etc.

However, there is a lack of equivalent support, to that provided to the 0-5s, for those aged 10-19/25 years when we know habits around alcohol, smoking, diet, and exercise take root and are difficult to shift in later life. Early intervention needs to address 0-10-25 year olds rather than just be associated with early years (0-5) as it commonly is at present.

Universal support stops problems happening e.g. intervening in early stages of post natal depression could prevent attachment problems, also the universal assessment will identify problems. Another example is sexual health services where problems can be prevented through advice and condom distribution and, of course, early intervention when treatment is needed. We know from the report that the National Children's Bureau undertook for the Forum, before the Forum's initial report, that children and young people want information on health to inform their behaviour.

There needs to be a raised profile of the role of schools in prevention and early intervention. There should be a common purpose between the education sector and the health service. This goes much wider than simply prevention and early

intervention. Children and young people educated in what they can do to achieve and maintain good health reduce the burden on the NHS. Similarly children and young people who receive good healthcare are more likely to be able to attend school and concentrate on achieving good academic results. Schools play a vital role in educating children and young people through (a) a whole school ethos that promotes mental and physical wellbeing, (b) a curriculum to build knowledge about health through Personal, Social and Health Education, and (c) the provision of onsite confidential health advice and counselling and signposting to community and online services for young people.

There are examples where progress is being made, such as the joint education, health and care plans to be introduced by the Children and Families Act 2014 for children with special educational needs. However, the reality is that too often there is a disconnect between the education sector and the health service. This can result in individuals, such as those with long term medical conditions, not receiving the relevant support at school because information is not shared by the NHS or because that information is not used by the school.

We welcome the duty placed on schools by Section 100 of the Children and Families Act 2014 to make arrangements for supporting pupils at school with medical conditions. Both the NHS and the education sector need to work on improving co-ordination at a local level and we think that there is a role for organisations at national and local level to encourage positive relationships between schools and the health service.

The importance of preventable ill health in babies and children is key in the development of service models that fit with contemporary midwifery practice. There is a critical public health contribution that midwifery care can make to the future of health outcomes of babies where midwives are accessible for very early antenatal booking. In partnership with health visitors more public health pathways need to be developed which will have a significant impact on health outcomes for babies and children.

Parental attachment is of key importance to enabling the best start in life. Attachment relationships are internalised and carried forward to influence expectations for other important relationships. Thus a history of consistent and sensitive care with the parent is expected to lead to the child developing a model of self and others as loveable and loving/helpful (*Parenting and outcomes*, Joseph Rowntree Foundation, 2007). We would have hoped to have seen progress on developing an outcome measure on parental attachment as this is a key indicator in the early years. However, we recognise that parental attachment is difficult to measure and we are keen to work with others to understand how an outcome measure could be developed and used to support parents and children/young people.

One area in which early intervention is particularly important is children and young people's emotional wellbeing and mental health. We welcome the raised profile of this area.

*No health without mental health: A cross-government mental health outcomes strategy for people of all ages* (Department of Health, 2011) set out the need to take a life course approach when tackling mental health issues. With one in ten children and young people aged between 5 and 16 years having a clinically diagnosable mental health problem and half of those with lifetime mental illness (excluding dementia) first experiencing symptoms by the age of 14 it is essential that early identification, appropriate support and referral to relevant services takes place.

In support of the strategy the Department of Health published *Closing the gap: priorities for essential change in mental health* in January 2014 which sets out 25 priorities for change. These include –

- There will be improved access to psychological therapies for children and young people across the whole of England;
- We will use the Friends and Family Test to allow all patients to comment on their experience of mental health services – including children's mental health services;
- We will change the way frontline health services respond to self-harm;
- Schools will be supported to identify mental health problems sooner; and
- We will end the cliff-edge of lost support as children and young people with mental health needs reach the age of 18.

There needs to be adequate focus upon lower level emotional wellbeing and mental health problems. Local Authorities and Clinical Commissioning Groups need to continue to invest in early help, tackling mental health issues from the start of life, from maternal and paternal mental health problems, problems during infancy, childhood, adolescence and then transition to adulthood. Young people need to be supported and empowered to have the confidence to access services. Schools have a major role to play in identifying individuals with mental health problems and referring them to appropriate services but also working alongside services to support the individual child or young person.

In March 2014 the Health Select Committee announced an inquiry into children's and adolescent mental health and CAMHS (Child and Adolescent Mental Health Services). The Forum's Mental Health Sub Group has submitted written evidence to the Committee.

PHE are developing a framework for public health to improve young people's health and wellbeing. This will be a valuable aid to inform local prevention activity, including commissioning.

PHE, NHS England and the Department of Health are collectively working on the recommendation in CMO's Annual Report 2012 that, alongside representatives of children and young people, they should build on the *You're Welcome* programme and the vision outlined in *the Better health outcomes for children and young people* pledge 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. We understand that an initial meeting is to take place in early May with key stakeholders and young people's groups will be involved in this work.

## Chapter 6: Integration and partnership

We want to get to a situation where it is the norm that children and young people (and others) receive care and treatment as part of a life course approach, receive patient centred care in age appropriate settings, where transitions and transfers are planned and supported, and where data is shared appropriately. This requires integrated teams, integrated working, and integrated / joint commissioning. We need to be clear that when we are talking about integration we mean integration around the needs of the child and family and not integration between layers within the system.

Major issues in providing integrated services often arise at transitions. This does not simply mean the transition from children's services to adult services, but the many transitions across the life course such as starting school, moving to secondary school, leaving school etc. Each transition is very important to the individual concerned and they can be vulnerable if appropriate support is not provided.

The importance of health professionals, particularly in general practice, taking a whole family approach is pivotal. Children and young people who are not supported by appropriate networks and joined up thinking, especially where the GP is not closely involved in care, perform poorly against many of the domains of care. If GPs are bypassed there can be a problem when the child transitions to adult services and they are suddenly left without a clear support network or advocate.

There is a need to build the evidence on the impact of integration and transition, to ensure that integrated approaches to commissioning and provision are evidence-based.

Children and young people with complex health and care needs, including those with life limited/life threatened and palliative care needs and disabled children, are often dealing with a number of health issues and therefore rely on there being an integrated, multi-agency approach to support them.

One area where progress is being made is through the Children and Families Act 2014 introducing a statutory framework for joint commissioning by local authorities and Clinical Commissioning Groups of education, health and care services for disabled children and those with special educational needs. A number of local authority pathfinders are currently piloting new collaborative approaches to inform national implementation from September 2014. The framework potentially provides an exemplar of collaboration across health, education and other services.

There is similarly a new statutory duty in the Children and Families Act 2014 on local authorities to ensure all schools make arrangements to support pupils with complex or significant medical conditions, backed by statutory guidance, which will provide a basis for bridging the significant gap between health and education.

The linking of health, education and social care data through use of the NHS Number has the potential to assist the provision of better integrated services. For example, it could really benefit children and young people with complex health needs through tracking their progress and identifying what works best and what doesn't work so well.

Progress has been slow. In March 2014 the Department of Health brought together representatives from a wide range of organisations to discuss the use of the NHS Number in children's social care.

With Local authorities (LAs) upgrading their IT systems to incorporate the NHS Number in their adult social care records database there is the opportunity to also upgrade them to include children's social care at marginal cost. In order to move things forward the Forum will seek to work with the Association of Directors of Children's Services (ADCS), the Local Government Association (LGA) and the Society of Local Authority Chief Executives (SOLACE) to encourage LAs to upgrade their IT systems for children's social care at the same time as they upgrade their IT systems for adult social care to incorporate the use of the NHS Number. We still think that there is a strong case for the education sector to also use the NHS Number and think that extending the use of the NHS Number to children's social care will strengthen the case for doing so.

Whilst we still support our original recommendation we acknowledge that there have been genuine barriers to its swift implementation. These include a lack of buy in from some of those that would need to be involved in using the NHS Number, resource implications and a lack of clarity on what benefits using the NHS Number would bring. Getting services to use the NHS Number enables them to share basic information but needs to be accompanied by appropriate information governance arrangements.

In addition Public Health England (PHE) and the Health and Social Care Information Centre (HSCIC) are looking at technical issues around sharing anonymised population level data.

We welcome the Children's Health and Wellbeing Partnership's (CHWP) work to develop an outcome measure of integrated care for children and young people, but are aware that the integration outcome measure for adults is further advanced.



Forum members will participate in the CHWP's thematic seminar on integrated care and support for children and young people. More information on the CHWP is in the section on Leadership, accountability and assurance.

We welcome the work of the National Clinical Director for Children and Transition to Adulthood, Dr Jacqueline Cornish, to push forward work on developing a generic framework for a consistent approach to transition to adult services and measurable outcome indicators to inform commissioning.

There needs to be national and local effort to really address transition for all children with long term conditions. We note that *Closing the gap: priorities for essential change in mental health* includes a commitment to end the cliff-edge of lost support as young people with mental health needs reach the age of 18 as one of the 25 priorities for change. The system and organisations need to help to children become more confident in themselves in engaging with healthcare providers.

It is important that there is an outcome measure for transition (for both physical and mental health). This should be linked with work on the integration outcome measure. We are aware that data sources are needed to develop this indicator, and reiterate our call for surveys of children and young people.

We urge NHS England and Monitor to develop financial and other incentive schemes for integrated commissioning and provision. Currently the system works against an integrated approach. There needs to be a payment system for integrated care working to standards which are then audited.

## Chapter 7: Safe and sustainable services

The safe and sustainable section in our initial report had a major focus on improving patient safety, especially medicines. We recognise that the sub-committee on medicines, co-chaired by the Chief Pharmaceutical Officer and the President of the Royal College of Paediatrics and Child Health (RCPCH), of the CMO's Children and Young People's Health Board is addressing these issues, but want to reiterate our belief that this needs to be an on-going priority and resourced appropriately. We are particularly keen to see recommendations emerging soon for interventions that will improve medicines safety in children and young people.

Our other main focus was on the establishment of a Strategic Clinical Network for Maternity, Children and Young People. This has been established by NHS England and is supported and funded through network support teams covering 12 defined geographical areas, with support teams hosted by NHS England. Whilst recognising that these Strategic Clinical Networks are still in an early phase of development we would like to emphasise the importance they should play in addressing many of the poor outcomes highlighted in our initial report. We would recommend that there needs to be some agreed prioritisation for improvement programmes across all of the geographical areas if we are going to see national benefit in terms of improved outcomes and that this should be led by the National Clinical Directors. This included programmes for the key patient safety risk areas for children.

In the Forum's response to the Francis Report we highlighted the importance of reducing avoidable mortality as a key improvement aim. We recommended that providers develop an agreed methodology for reviewing each individual death in childhood and that NHS England support the development of a standardised mortality assessment that is relevant for assessing children's services. We would like to see early progress with these so that there is rapid development of a programme to reduce avoidable mortality in children. This equally applies to the importance of reducing stillbirths and perinatal mortality.

Some of the other areas that in the Forum's view would benefit from a nationally led focus within the Strategic Clinical Networks under the direction of National Clinical Directors include transition from children's to adult services; acceleration of improvement programmes for diabetes, asthma and epilepsy, the common long term conditions of childhood; improved management of anxiety and depression probably through further rollout of the Children and Young People's IAPT (Improving Access to Psychological Therapies) programme; and the development of clear networks for surgery in children.

## Chapter 8: Workforce, education and training

The Forum's initial report drew the link between an inadequately trained workforce and poor health outcomes for children and young people. All those working with children and young people should have the right knowledge and skills to meet their specific needs – wherever they are in the health system and beyond.

Health Education England (HEE), which took over responsibility from April 2013 for ensuring that the health workforce has the right skills, behaviours and training and is available in the right numbers, has a major role to play. In addition those organisations responsible for training individuals that work with children and young people, such as teachers and youth workers, need to ensure that their training enables staff to support individuals with health issues.

We have provided recommendations for the refresh of the mandate from the Government to HEE. We understand that the mandate is to be published soon. We have been assured that the mandate will include a focus on ensuring that healthcare staff working with children and young people have the right knowledge and skills to meet their specific needs. We look forward to seeing the published mandate and the Forum is keen to work with HEE on identifying key training issues to improve the care of young people with physical or mental illness from childhood to adolescence.

We welcome the recent and on-going discussions between HEE, the Department of Health, RCPCH, RCN, NHS England and members of the Children's Health and Wellbeing Partnership to develop a strategic approach to workforce planning and commissioning for children and young people. We are pleased that RCPCH and RCGP have agreed to work collaboratively to develop the right models of care for children and young people.

Improvement on a number of vital outcome indicators will not be easy to achieve without significant progress on workforce, education and training issues. There is work for the Forum here on investigating whether the children's workforce is right in terms of numbers, skills and culture and we are keen to work with HEE on these issues. The Forum encourages HEE to look at all involved in the children's workforce and to undertake work with organisations across children's health.

The Forum's initial report particularly drew attention to general practices being the most frequent point of contact with the health service for children and young people but families too often report that their needs are not met. The Kennedy Report identified that many GPs had little or no formal paediatric training. We appreciate the cost and other implications of extending GP training to allow for adequate training in

paediatric and physical and mental child health (a recommendation in our initial report) but this issue does need urgently addressing.

## Chapter 9: Knowledge and evidence

The Forum's initial report stated that turning information into knowledge and evidence, together with research, is central to the drive for better outcomes.

A Health Intelligence Network for Child and Maternal Health has been established. The infrastructure for this is hosted and facilitated by PHE, which builds on the previous work of the Child and Maternal Health Observatory, ChiMat. Led by Forum Co-Chair Ian Lewis the Network pulls together stakeholders from across the system, including PHE, NHS England, the Health and Social Care Information Centre (HSCIC), Royal Colleges, academia and the voluntary sector, to focus on the creation and utilisation of the best possible data, information and intelligence. The Network has a key role to play and we look forward to it developing into a catalyst for service improvement.

We are concerned that mental health services, and specifically those for children and young people, are under considerable pressure at a local level. We are aware that Joint Strategic Needs Assessments (JSNA) often fail to adequately identify the number of children and young people in the local level who, for example, are likely to require support from services because of their mental health needs or disabilities. The consequence is that there has been disinvestment in early help services leading to increased pressure on specialist who are also experiencing disinvestment. We are concerned that many children and young people are not receiving the quick and effective access to relevant services that they need and that child safety is thus being compromised. Services need to be commissioned in a way that enables integration between tiers - across universal, targeted and specialised services and education etc.

We are hopeful that the provisions in the Children and Families Act 2014 on joint commissioning will address some of these concerns, but we feel there needs to be a specific focus on mental health and that this should be addressed by providing funding for a follow up to the *Mental Health of Children and Young People in Great Britain, 2004* (ONS) prevalence survey. Not only is it important that local commissioners have access to reliable up to date figures of the likely prevalence of mental health issues but policy makers and academics would find the survey useful for tracking and responding to changes in prevalence. There should also be a prevalence survey on perinatal mental health.

We recognise and welcome the CAMHS dataset coming on line. Early analysis of this data will assist in assessing the current workload of services. The Forum will also continue to keep in close focus on progress on the parity of esteem agenda and to contribute to the CMO's Annual Report on mental health.

Two key issues appear earlier in this Report. The delays to the roll out of the Maternity and Children's Dataset (MCDS) and our concerns about progress on getting the use of the NHS Number extended are covered in the Health outcomes that matter for children, young people and their families and the Integration and partnership sections respectively.

We were pleased to see that the National Institute for Health Research (NIHR) recently issued a call for evaluative research for long-term conditions in children and young people. The aim of the research will be to provide the evidence base to improve the health outcomes for children and young people that result from long-term conditions. We hope that NIHR will be able to provide more support for research on children's health, particularly acutely ill children, not only in the quantity of research but in the number of researchers in children and young people's health.

We shall seek assurances from NHS England that they will monitor and act upon good quality research, not just the latest research, for children and young people e.g. spacers not nebulisers for asthma and fewer antibiotics for upper respiratory tract are not new research but they still need acting upon.

## Chapter 10: Leadership, accountability and assurance

The Department of Health, as the steward of the new health system, plays a pivotal leadership role. We will continue to press the Department to use Mandates to ensure the NHS maintains a focus on children's health, particularly the acutely ill and those with long term conditions, and support the embedding of a culture of learning throughout all networks.

The Children's Health and Wellbeing Partnership (CHWP), co-chaired by the Department of Health and SOLACE (Society of Local Authority Chief Executives), was established in 2013 to bring together key national organisations to lead and commission work which requires a multi-agency approach to improve children and young people's health and wellbeing.

The CHWP have agreed a common principle of retaining a clear focus on the recommendations of the Forum to deliver its core objectives, which are as follows:

- champion and network: bringing together the national and local system and working through networks for children and young people's health and wellbeing to provide a common narrative;
- work across Government: to link with wider Government agendas, clearly articulating connections;
- maximise resources through identifying efficiencies and ensuring cost effectiveness;
- collectively share information, knowledge and learning; and
- champion preventive policies and approaches.

Dr Catherine Calderwood (National Clinical Director for Maternity and Women's Health, NHS England) and Dr Jacqueline Cornish (National Clinical Director for Children and Young People and Transition to Adulthood, NHS England) attend Forum meetings as observers. Their leadership has been crucial in pushing children and young people's healthcare issues up the agenda of health system organisations. However, we are concerned that they do not have sufficient programme support for their leadership role and to influence change. Dr Ann Hoskins (Director, Children, Young People and Families, Public Health England) is also an observer at Forum meetings and her system leadership role, particularly in relation to the public health and prevention agenda is pivotal.

The new health system represented a major shift away from central control. Whilst this has many advantages, with local areas best placed to assess, commission and

provide for their local population's needs, it has highlighted the need for clarity on local accountability. There needs to be assurance that the unacceptable variations in health outcomes across the country are reduced through a general improvement in outcomes and that local areas which are struggling are identified and receive appropriate support.



## Chapter 11: Incentives for driving service improvement

Our initial report made no reference to the contribution made by the voluntary and community sector. This was because the Forum's remit at that stage was to comment on the NHS and Public Health Outcomes Frameworks and to ensure that the new health system was set up in a way that ensured that children and young people's healthcare issues were given sufficient priority.

The Forum includes representatives from the voluntary and community sector. We know that engagement with the voluntary and community sector at national and local level is essential for achieving integrated and co-ordinated services. For example, the Health and Care Voluntary Sector Strategic Partners Programme, jointly managed by DH, NHS England and PHE, is designed to build capacity and capability across the voluntary sector and use their knowledge and expertise to inform and shape national policy and provide input into the NHS, social care and public health.

The Health and Social Care Act 2012 gives Monitor and NHS England responsibility for designing and implementing the payment system for NHS health care services for the financial year 2014/15 onwards. This includes setting the national prices for certain health care services as well as setting the rules for local pricing negotiations between providers of health care services and commissioners.

Monitor recently published the *2014/15 National Tariff Payment Scheme* with the content agreed jointly between NHS England and Monitor. Amongst the limited number of changes was the introduction of a new mandatory price for health assessments of looked after children.

We do, of course, support the intentions behind Payment by Results (PbR). It is designed to support healthcare policy and the strategic aims of the NHS - that money will follow the patient to promote high quality care, drive efficiency and support choice with providers paid according to outcomes, not just activity, and providing an incentive for better quality care. There are recent examples of PbR tariff that do incentivise out of hospital care and early intervention such as the 'Best Practice Tariff for Diabetes in Children'.

However, we are concerned that in many areas funding flows may still be drawing resources away from community services, precisely the opposite of the desired policy direction. At a time of financial pressure, services commissioned through block contracts appear to be more vulnerable than services covered by payment by results. In order to achieve safe and sustainable services, it is essential that there are no perverse incentives adversely affecting patient care. The vast majority of elderly care occurs in the community and this should be the same for children and

young people. Additionally the future development for payment by results in maternity services needs to improve. This is important in relation to the current system where providers of care need to recoup costs for women who give birth outside the local provider and where healthcare boundaries crossover. The payment system is a complex area but one that the Forum needs to understand better to influence change.

The Forum would welcome much greater engagement with Monitor, to understand how funding flows are impacting on patient care or service provision and work with all system organisations, and in particular Monitor and NHS England, to ensure future development of Payment by Results currencies and tariffs for child health related areas incentivise whole pathway care including prevention and early intervention strategies, and safe and sustainable services as close to home as appropriate.

Other Forum concerns around driving service improvement are as follows -

- The Department of Health to recognise the positive impact of the outcomes frameworks and the fact that the full benefits of this approach will only become fully evident in the longer term;
- Ofsted and CQC agree with their joint outcomes for children and ensure inspectors have an appropriate skill base; and
- When there are incidents (of poor care etc.) the Department of Health should look at what has been learnt and how this learning has been disseminated and embedded.

## Chapter 12: The Forum's work plan for 2014

The Forum's work plan for 2014 is designed to link with the Forum's challenges to the system.

Ensuring effective engagement with children and young people so that their views are sought and acted upon

- Work with Department of Health's Francis Implementation Team, particularly on getting the right culture for children and young people in the health service;
- Ensure that the Forum itself has children's voices at the heart of everything it does.

Ensuring that the children and young people's workforce across the professions is fit for purpose

- Work with HEE and other relevant organisations to ensure that the children and young people's workforce is right in terms of numbers, skills and culture, and that opportunities for improving the children and young people's workforce are identified and taken;

Ensuring that the incentives for service development incentivise prevention, early intervention and safe and sustainable services

- Work with all system organisations to understand how funding flows are impacting on patient care or service provision and work with them to ensure future development of Payment by Results currencies and tariffs for child health related areas incentivise safe and sustainable services.

Ensuring that the appropriate children and young people's health outcome indicators are in place and that progress against the indicators, including regional variations, is reviewed

- Use the Forum's Annual Summit to review progress (a) against the outcome indicators for children and young people including regional variations, and (b) on the development of outcome indicators for children and young people previously recommended by the Forum;
- Invite senior representatives from health system organisations, and others that have a role to play in improving health outcomes, to Forum meetings so that we can better understand progress made on children and young people's issues, their plans for the future and how the Forum can assist them;
- Work with key gaps in indicators e.g. undertake a review of sexual health.

Data sharing and integration – there is a lack of coherent data and a system that links outcomes of children and enables them to be tracked

- Work with the Department of Health, Department for Education and local agencies (such as the Association of Directors of Children's Services, the Local Government Association and SOLACE) to make progress on the Forum's recommendation for using the NHS Number as an identifier in health, education and social care;
- Contribute to Children's Health and Wellbeing Partnership's work on integrated care and support for children and young people;
- Contribute to Chief Medical Officer's next Annual Report on mental health.

Ensuring that children and young people's services are accountable at a national and local level and knowing this is working on the ground

- Work with key system players to fully understand accountability in the new system and how this is understood by all elements including, crucially, children, young people and families.

## APPENDIX

### Links to documents mentioned in this Report

*Our Children Deserve Better: Protection Pays - Annual Report of the Chief Medical Officer 2012* (Department of Health, October 2103)

<https://www.gov.uk/government/news/chief-medical-officer-prevention-pays-our-children-deserve-better>

*Report of the Children and Young People's Health Outcomes Forum* (July 2012)

<https://www.gov.uk/government/policy-advisory-groups/children-and-young-peoples-health-outcomes-forum>

*Improving Children and Young People's Health Outcomes: a system wide response* (February 2013)

<https://www.gov.uk/government/policy-advisory-groups/children-and-young-peoples-health-outcomes-forum>

*Overview of child deaths in the four UK countries* (RCPCH and MRC Centre of Epidemiology in Child Health, University College London Institute of Child Health, September 2013)

*Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies* (RCPCH and MRC Centre of Epidemiology in Child Health, University College London Institute of Child Health, September 2013)

<http://www.hqip.org.uk/royal-college-of-paediatrics-and-child-health/>

Children and Young People's Health Benchmarking Tool

<http://www.chimat.org.uk/cyphof>

Children and Families Act 2014

<http://www.legislation.gov.uk/>

Child and Maternal Health Intelligence Network

<http://www.chimat.org.uk/>

*2014/15 National Tariff Payment Scheme* (Monitor and NHS England, December 2013)

<http://www.monitor.gov.uk/nt>

*No health without mental health: A cross-government mental health outcomes strategy for people of all ages* (Department of Health, July 2011)

<https://www.gov.uk/government/news/no-health-without-mental-health>

*Closing the gap: priorities for essential change in mental health* (Department of Health, January 2014)

<https://www.gov.uk/government/publications/mental-health-priorities-for-change>

*Mental Health of Children and Young People in Great Britain, 2004* (ONS)

<http://www.esds.ac.uk/doc/5269/mrdoc/pdf/5269technicalreport.pdf>

*Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (chaired by Robert Francis QC) (February 2013)

<http://www.midstaffpublicinquiry.com/report>

*Hard Truths: The Journey to Putting Patients First* (Department of Health, November 2013)

<https://www.gov.uk/government/publications/mid-staffordshire-nhs-ft-public-inquiry-government-response>

*The NHS Constitution for England* (Department of Health, March 2013) and *Handbook to the NHS Constitution* (Department of Health, March 2013)

<https://www.gov.uk/government/publications/the-nhs-constitution-for-england>

Forum's webpage

<https://www.gov.uk/government/policy-advisory-groups/children-and-young-peoples-health-outcomes-forum>