REPORT OF THE CHILDREN AND YOUNG PEOPLE'S HEALTH OUTCOMES FORUM 2014/15 – Health Outcomes Theme Group

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HEALTH OUTCOMES

Key questions/challenges

The Health Outcomes Theme Group compiled a paper, attached at Annex A, for the Chief Medical Officer reviewing children and young people's health outcomes and examine regional variations. We think this is a valuable exercise which needs to be undertaken annually from now on so that all those involved and interested in children and young people's health issues, in England, Scotland, N.Ireland and Wales, can see whether or not progress is being made.

There are currently NHS, Public Health and Adult Social Care Outcomes Frameworks. The glaring omission is the lack of a Children and Young People's Social Care Outcomes Framework. Whilst we appreciate that children's social care comes under the responsibility of the Department for Education (DfE) rather than the Department of Health that is not a valid reason for excluding and disadvantaging children. Introducing a Children and Young People's Social Care Outcomes Framework would produce a comprehensive set of Outcomes Frameworks. Following that there would be a need to ensure that they all tied in together.

Key areas for the development of new indicators include –

- **Time to diagnosis**
  We are pleased that the Department of Health has commissioned the Policy Research Unit in the Health of Children, Young People and Families (CPRU) at the UCL Institute of Child Health to produce a think piece on how an indicator on time to diagnosis could be developed.

- **Children and young people's experience**
  NHS England and CQC have developed with Picker Institute Europe a National Children's Inpatient and Day Case Survey. There are three aligned surveys, covering 0-7 year olds, 8-11 year olds and 12-15 year olds. This is the only nationally mandated survey of children's experience of health services and presents an opportunity to construct a children's experience indicator for the NHS Outcomes Framework (currently a placeholder). The Forum will be submitting comments to the Department of Health on the key questions to be included as part of the indicator.

- **Transition to adult services**
  Indicator could be developed using the framework published by London South Bank University (Faith Gibson).

- **Outcome – confident to manage own care?**
  Forum member Russell Viner has been leading research looking at routine data collections, Hospital Episode Statistics (HES) and national audits, to see whether transition can be tracked through them. We note that the Adult Social Care Outcomes Framework includes an indicator on experience of transition. It may be possible to make progress on this issue through including questions on experience of transition in surveys involving the relevant age group.

- **Experience of mental health services**
  We are pleased that the mental health prevalence survey for children and young people is being commissioned. Additionally, data on Child and Adolescent Mental Health Services (CAMHS) from the Children and Maternity Dataset will begin to flow next year.

- **Age appropriate settings**
  The importance of young people being managed in age-appropriate settings arose at the NHS Outcomes Framework refresh stakeholder event. The NHS Outcomes Framework Team at the Department of Health said that they would welcome the Forum's thoughts on how an indicator could be developed.

- I**ntegration**
  The Children's Health and Wellbeing Partnership, which brings together key organisations in children's health and wellbeing from different sectors, including the NHS and local government, convened a Task and Finish Group, including a Forum member, to explore the development of an indicator on the integration of care for children and young people. This has led to a draft paper *Integrated services for children and young people: Developing effective indicators* providing guidance for local commissioners and providers on approaches to assessing integration through evidence-based indicators. The Forum will look to work closely with the NHSOF Team to develop such an indicator.

<u>Key areas for action and research</u>, deriving from the review of health outcomes and regional variations are:

- Reducing mortality from non-communicable diseases; and

- Reducing geographical variation, and health inequalities among socioeconomic groups – special needs, disability, demographics.

Additionally,.we want to see the nationally based independent and comprehensive database and review process of all deaths in children and young people, currently being developed by NHS England, fully funded and implemented.

The National Child and Maternal Health Intelligence Network, hosted and facilitated by PHE, has been important in providing a methodology and framework to continue to explore outcomes. The Network plays a vital role which we wish to see continue.

The Forum also recommends that a transparent regularly updated surveillance of trends, outcomes and variation in performance be published. This should include benchmarking against international outcomes where possible and appropriate. We recommend PHE take responsibility for this and it be included in their Children and Young People Benchmarking Tool. There needs to be investment in the development of robust exploration of variations between countries in children and young people's health outcomes so that we can identify and learn from the best performers.

Introduction

The central role of the Forum is to improve children and young people's health outcomes. It is therefore imperative for the Forum to –

- ensure that system levers are being used effectively to stimulate improved performance and that they sufficiently cover children and young people;
- use available data to assess whether health outcomes are improving and whether regional variations are diminishing; and
- contribute to the improvement of indicators and data systems for assessing and improving outcomes for children and young people.

The Health Outcomes Theme Group has taken forward work on all three of the above points.

System Levers

In its initial report the Forum made wide ranging recommendations to strengthen existing indicators and develop new indicators for the NHS and Public Health Outcomes Frameworks. Some of the recommendations were relatively easy to implement, such as presenting all data in 5 year age bands up to 25. Others, particularly the development of new indicators, are ongoing.

The publication of the stakeholder engagement document for the NHS Outcomes Framework (NHSOF) 2015-16 refresh was awaited with interest by the Forum. We were highly disappointed at the lack of ambition reflected in the proposals. Forum members attended the engagement events and have followed up in meetings with

the NHSOF Team at the Department. It has transpired that our disappointment, shared with other stakeholders, was largely due to the lack of transparency in the document about the reason for proposed changes and the lack of information provided on the development of new indicators.

At our meetings with the NHSOF Team we have –

- made the case for all indicators to apply to children and young people except where they are specifically for another age band (e.g. elderly) or where numbers of children and young people involved would be too small to make an indicator useful;

- made the case for Forum priorities for the development of new indicators; and

- linked in with ongoing work by the Department to develop new indicators in line with previous recommendations by the Forum (e.g. around indicators for integrated care, transition and children's experiences of care).

The Forum has been assured by the NHSOF Team at the Department that in the future there will be:

- more transparency about the reasons for proposed changes to the Framework;

- a closer working relationship with the Forum so that we will be able to input our view on priorities and advice on developing new indicators; and

- a commitment from the NHSOF Team to keep the Forum updated on the development of new indicators.

The Department has also initiated a project intended to drive improvements across all the Outcomes Frameworks (NHS, Public Health and Social Care). Members of the Forum have been invited to contribute to this project. Initial recommendations from the Forum include:

- Improving the integration across these Frameworks, to reflect the way in which children and young people live their lives, rather than being limited by the boundaries of individual organisations or government departments;

- Introducing a Framework and/or indicators for children's social care;

- Follow a life-course approach to demonstrate the benefits of preventative policy and early intervention on overall health outcomes and life chances; and

- Maintain all these outputs on one platform in order to improve ease of access and read across the different domains.

It should also be noted that all existing indicators which relate to children and young people from the various Outcomes Frameworks have been published in one place, under the guidance of the Forum, in order to improve accessibility and transparency. These are published using PHE's Fingertips toolkit as the CYP Health Benchmarking Tool. Click here

Current Performance and Trends

In the Chief Medical Officer's (CMO) 2012 Annual Report *Our Children Deserve Better: Prevention Pays*, published in October 2013, she recommended that "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 variations." The Health Outcomes Theme Group took forward the task of putting together a short paper for the CMO after reviewing progress for children and young people's indicators at the Forum Annual Summit in 2014. The paper is attached at **Annex A** with a table showing an overview of progress at **Annex B** to this document.

The paper concluded that –

- Progress on child and adolescent mortality has been on a downward trajectory in the past 40 years relative to comparable countries, including those in the European Union;

- With regard to other indicators of child health and healthcare, while there has been progress in some areas since the Forum's inception, these are accompanied by worrying negative trends in others;

- Geographical variation, and disparities among different socioeconomic groups, persist, and in some cases, are worsening; and

- Key priority areas for improvement include:
    - Mortality from non-communicable diseases.
    - Geographical variation, and health inequalities among socioeconomic groups.
    - Rising use of urgent/emergency healthcare among all age groups, in particular those with long term conditions.

We need to keep the focus on improving children and young people's health outcomes by stressing the importance of doing so because of the –

- Impact on their health and wellbeing in later life;
- Impact on their life chances (educational attainment, employment opportunities);
- Experience and engagement with the NHS during youth will influence their future use of the NHS (e.g. use of A&E), so there is a need to engage children on public health messages such as resilience and self-care; and the
- Future cost to NHS of not improving health outcomes.

Making progress on improving children and young people's health outcomes relies on a wide range of factors, in addition to ensuring that data from indicators and sources more widely is used to improve local health outcomes, including –

- Ensuring that children and young people's views are heard and taken into account when designing/providing services;
- Making financial incentives within the system fit with policy of correct diagnosis/acknowledgement of need, early intervention, treatment at a time and place that suits the individual; and
- Delivering effective data linkage – at population level and an individual level.

ANNEX A

CHILDREN & YOUNG PEOPLE'S HEALTH OUTCOMES FORUM

Date: **13 January 2015**

To: **Professor Dame Sally Davies, Chief Medical Officer**

From: **Ronny Cheung, Helen Duncan & Russell Viner (on behalf of the Forum's Health Outcomes Theme Group)**

Subject: **Review of recent trends in health outcomes for children and young people and regional variation**

1. **Summary:**

1.1. Within the relatively short timescale since the inception of the Children and Young People's Health Outcomes Forum (CYPHOF), trends in health outcomes for children and young people (CYP) have shown variable progress. There has been some improvement in certain indicators, but there are caveats as to how the data can be interpreted, and the difficulties with time lags (both for data availability on a national level, as well as the long lead time from policy and public health interventions to achieving measurable outcomes).

1.2. However, all the data, including those with cause for optimism, still mask inequalities and often do not compare favourably to other nations and health systems.

1.3. Key areas to prioritise for policy and research include:

- Mortality from non-communicable diseases;
- Geographical variation, and health inequalities among socioeconomic groups; and
- Rising use of urgent/emergency healthcare among all age groups, in particular those with long term conditions.

2. **Purpose**

2.1. This paper is a response to Recommendation 19 in CMO's 2012 Annual Report: "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 variations."

2.2. This paper will be divided into sections on:

- Overview of child mortality, and
- Trends in key outcome measures divided into those which have shown improvement, those which have stayed the same, and those which have deteriorated.

2.3. Mortality indicators aside, this paper will concentrate on trends since the inception of CYPHOF (i.e. c.2012 onwards).

3. Notes on interpretation of outcomes and trends

3.1. The data that are presented come with the various caveats that accompany many outcomes, particularly with regard to public health:

- that interventions may have significant lag time until they translate into improvements in health outcomes, and
- that it is difficult to robustly attribute causality to interventions which precede or coincide with improvements in outcomes.

3.2. Changes in commissioning geographies have coincided with the inception of the CYPHOF, such that direct comparisons with regard to variation are difficult to make. But where comparable data are available for an indicator, any changes in the degree of variation are displayed by comparing the coefficient of variation (a measure of sample variance which is adjusted for range, so that two samples can be compared: the smaller the coefficient, the less variation).

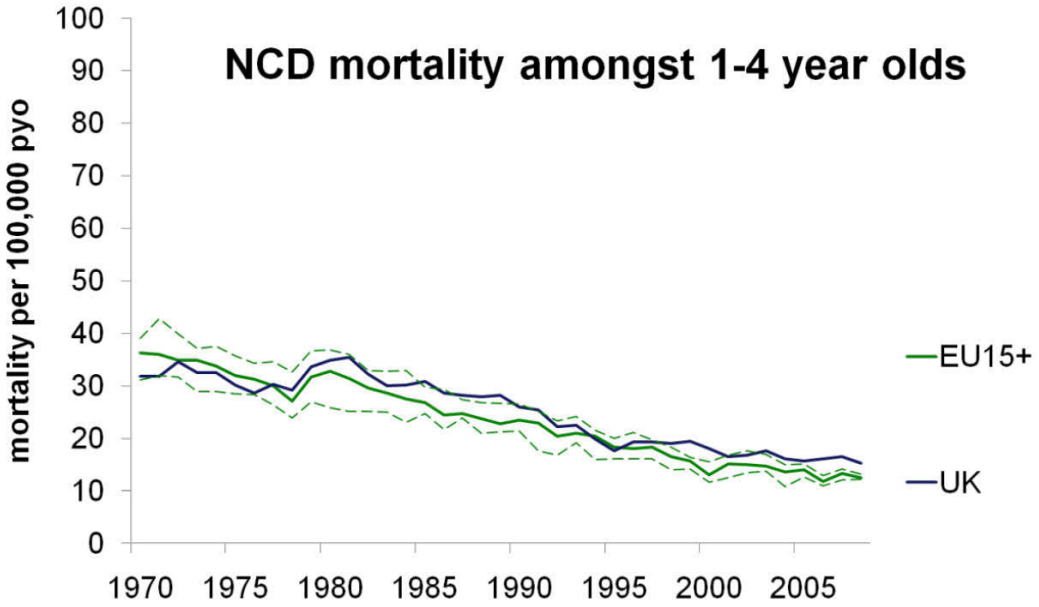
4. Child and Adolescent Mortality

4.1. Total mortality for UK CYP has fallen behind that of other comparable wealthy countries (EU15 plus Canada, Australia and Norway) since 1970. The UK was in the best quartile for mortality in every age group from birth to 24 years in 1970; by 2010 we were worst quartile for infants and 1-4 years with 5-9, 10-14, 15-19 and 20-24 in the middle quartiles. The speed of reduction in the UK was significantly poorer in every age group than the EU15+.

4.2. The UK had excellent injury mortality across all age groups.

4.3. However it is only excellent injury mortality that makes our older child, adolescent and young adult total mortality average i.e. the UK has very poor performance on non-communicable diseases mortality in the past 20 years: now in worst quartile in every age group compared with the EU15+. (See Figure 1).

Figure 1: Non-communicable disease mortality: aged 1-4 years



4.4. Poor performance is seen across all long-term conditions, particularly neurological and psychiatric causes.

5. Other Health Outcomes

5.1. The following section is divided into sections detailing selected indicators which show improving trends; those where there are equivocal or fluctuating trends; and those where outcomes appear to have deteriorated.

5.2. Improving trends

5.2.1. Road Traffic Accidents: The rate of children (aged <16 years) killed and seriously injured in road traffic accidents has fallen from 24/1,000 in 2008, to under 20/1,000 in 2012. There is an ongoing collaboration between Public Health England (PHE) and the Royal Society for the Prevention of Accidents to continue this encouraging trend.

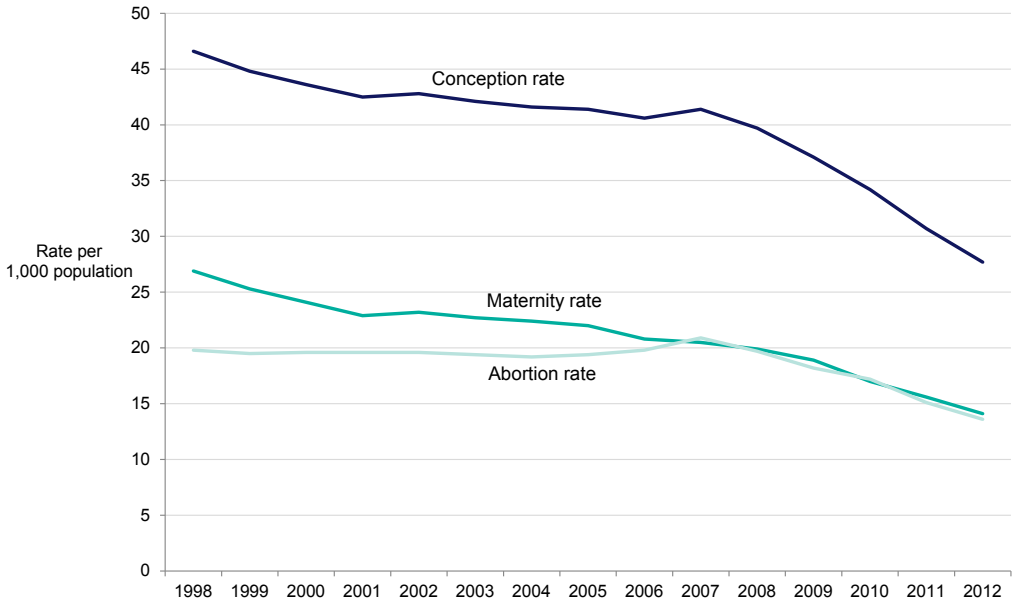
5.2.2. Smoking in pregnancy: There has been a sustained fall in rates of women smoking during pregnancy over the past 5-10 years, from 15.1% in 2006/7 to 12.7% in 2012/13. However, the ambition is to reduce maternal smoking prevalence to 11% or less by the end of 2015 – which, if current trends continue, will not be met.

5.2.3. School achievement: The percentage of children achieving five or more good GCSEs continues to rise, with 2012/13 being the first year that more than 60% of children achieved this. It will be crucial to build on the close working with Department for Education and with schools, to emphasise the co-dependent nature of health and education outcomes.

5.2.4. Teenage Conception: Rates of teenage conception have fallen in the past decade, from 46.6 conceptions per 1,000 population in 1998 to 27.7 in 2012 –particularly marked

since 2006/7. The maternity and abortion rates have also fallen in that time, but teenage conception rates have fallen at a proportionately greater rate. (See Figure 2)

Figure 2: Teenage conceptions and maternity/abortion rate: 1998-2012

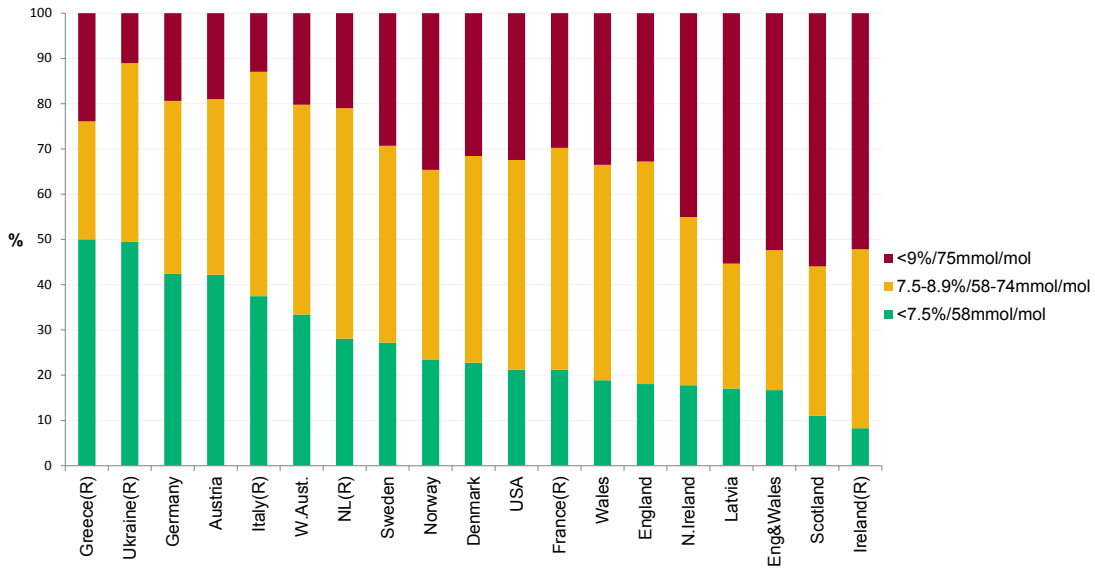


- However, the overall positive trend masks inequalities and variation, with 6-fold difference between Local Authorities, and a strong correlation with deprivation.
- Moreover, it is worth noting that a large proportion of young adults who fall pregnant possess no pre-existing risk factors for teenage pregnancy. Therefore interventions targeted at high-risk groups will have only limited benefit, and a universal approach to prevention is still required. PHE's recent publication of whole system commissioning guidance for sexual, reproductive health and HIV will build on the advances that have been made.

5.2.5. Diabetes outcomes: Using the latest available data (from 2012/13), the median HbA1c (a measure of diabetic control) has fallen for the third consecutive year.

- However, the proportion of children achieving the target HbA1c level (<58mmol/l) is low at 15.8%, and furthermore has reduced in the past year from a three-year high of 17.4% in 2011/12.
- Over a quarter of children still have unacceptably high HbA1c values (>80mmol/l).
- Less than 10% of variation in these outcomes can be attributed to case mix and socioeconomic deprivation, meaning the majority is related to service resource and delivery.
- Recent evidence continues to underline that England (along with Wales, Scotland and Ireland) fall far behind comparable European countries in these outcomes. (See Figure 3)

Figure 3: Diabetes control in young people aged 25 years (2010/11)



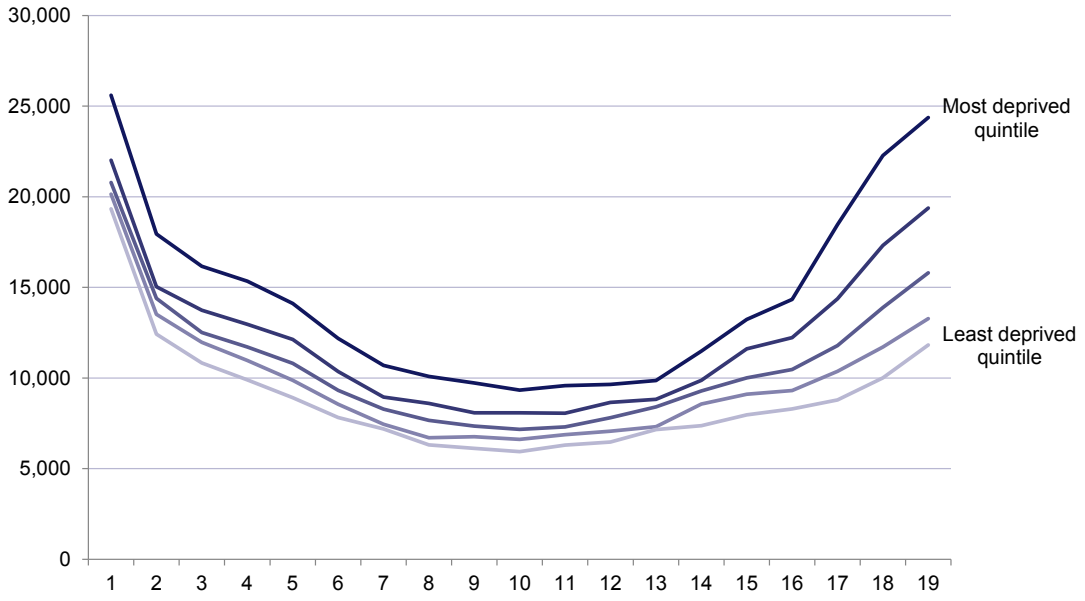
5.3. **Equivocal indicators**

5.3.1. Proportion of babies born at low birthweight: Although there is a downward trend nationally in those born at low birthweight, both in babies born at term and at all gestations, this is gradual and not statistically significant. PHE and NHS England continue to work on broader factors affecting this, including maternal health, smoking cessation, maternal nutrition, and detection and prevention of intrapartum infections. For term babies low birthweight varies across the country from 1.5 % to 5%. For all babies it varies across the country from 4.2% to 10.2 %.

5.3.2. Emergency hospital admissions: Emergency admissions from all causes in CYP (aged 0 - 19 years) rose until 2010/11, and the rate has fluctuated in recent years with no clear trend. Preschool and late teenage groups remain the most likely to be admitted.

- However, specific subgroups of hospital admissions are rising. For example, admissions for respiratory infections in those aged under 5 years (the commonest reason for admission, among the age group most likely to be admitted) continues to rise. Although this is due to a combination of public health factors and community care, the mean duration of hospital admission within a region seems to be inversely correlated with regional admission rates, which supports the role of health care factors rather than determinants of health as an explanation.
- The "deprivation gap" for overall hospital admissions widens during adolescence: the most deprived quintile of adolescents are twice as likely to be admitted than the least deprived, which is a much larger deprivation gap than for any other age group. (See Figure 4)

Figure 4: Hospital admissions of CYP aged under 20 years, 2010/11

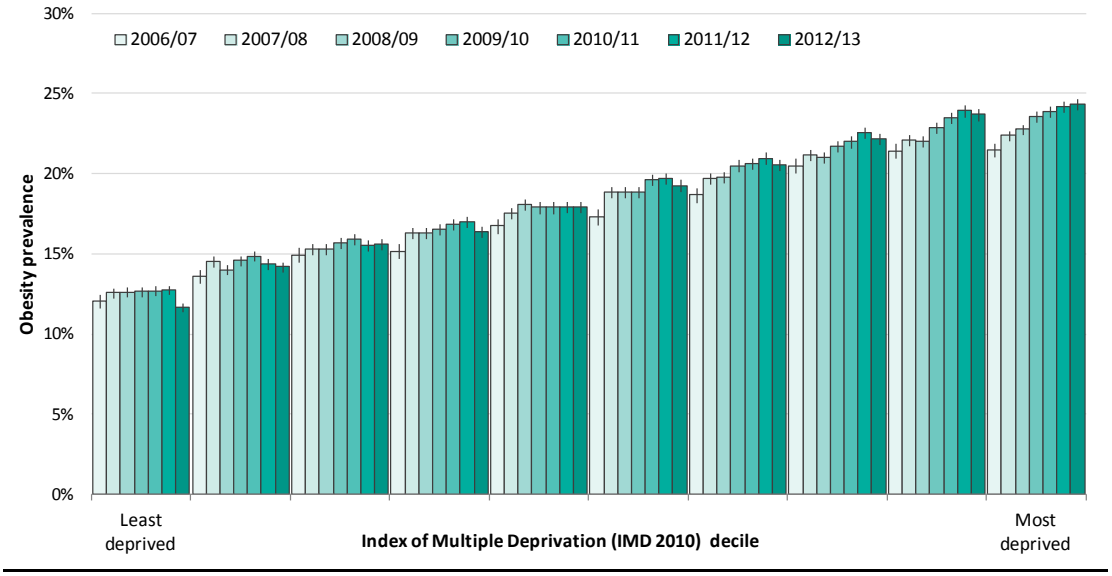


5.3.3. Obesity:

Since it began in 2006/7, there has been a mixed trend in outcomes from the National Child Measurement Programme (NCMP).

- In reception year (aged 5 yrs) the proportion of obese children in 2012/13 is lower than in 2011/12, and lower than in 2006/7.
- For children in Year 6 (aged 10-11yrs), the proportion of obese children has risen year-on-year. 2011/12 to 2012/13 marks the first time since the NCMP began that there has been a year-on-year reduction, which is encouraging but cannot be seen as a robust trend.
- However, obesity is strongly correlated with deprivation, and the inequalities gap appears to be widening. Prevalence of obesity shows a pattern of increases over time (from 2006/7-2012/13) among the most deprived Year 6 children whereas for the least deprived children prevalence has remained relatively stable. (See Figure 5)

Figure 5: Obesity prevalence by deprivation decile and year of measurement: Children in Year 6 (aged 10-11 years)



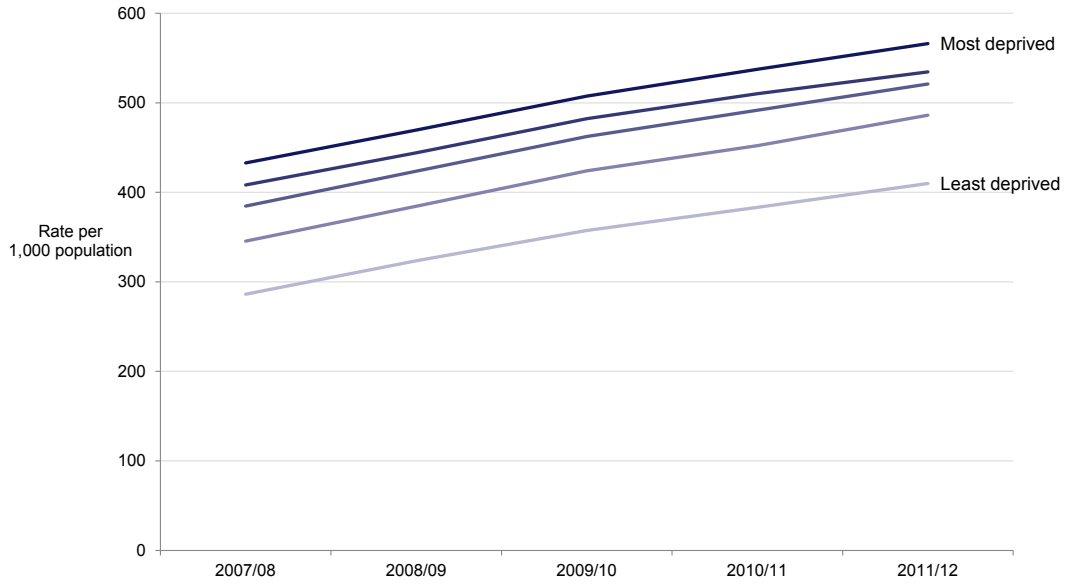
- A similar disparity is seen in Reception year children, with reducing levels of obesity since 2006/7 in the least deprived groups, and no change in the more deprived areas.

5.4. Health outcomes which appear to be worsening

5.4.1. Hospital admissions for infant feeding difficulties: This indicator continues to show an increase, from 44.9/1,000 births in 2006/7, to 57.9/1,000 in 2010/11. This may reflect factors including early (unsupported) postnatal hospital discharge; quality of community support for feeding and maternal health; or late recognition of problems with feeding. Rates vary geographically, which may reflect variations in admission criteria among different hospitals, in addition to the factors outlined above. In 2011/12 these rates varies across the country from 14.6/1,000 births to 182.3/1,000 births, a 12.5 fold variation.

5.4.2. Emergency department attendance among CYP: Attendance rates in England have risen year-on-year and are 40% higher in 2011/12 than in 2007/8. The deprivation gap in attendances is preserved over the past 5 years, reflecting a universal increase in use of A&E services. (See Figure 6)

Figure 6: Emergency department attendance of children aged under 5 years



5.4.3. Hospital admission for bronchiolitis among infants: Hospital admissions have increased by more than 40% since 2006/7. Regional geographical variation has increased in the last 3 years, which implicates differences in hospital admission criteria and treatment rather than underlying sociodemographic factors (which are unlikely to have changed in such a short space of time). For 2012/13 in the under-fives, hospital admissions for lower respiratory tract infection ranged from 38.7/100,000 population to 239.0/100,000 population, a 6 fold variation.

5.4.4. Hospital admissions for self-harm: Although rates in older teenagers (15-19 years) seem to be stable, those in adolescent and young people age range on the whole (10-24 years) have risen significantly, from 329.5/100,000 population (2007-10) to 352.3/100,000 (2010-13).

6. Conclusion

6.1. Progress on child and adolescent mortality has been on a downward trajectory in the past 40 years relative to comparable countries, including those in the European Union.

6.2. With regard to other indicators of child health and healthcare, while there has been progress in some areas since the inception of the CYPHOF, these are accompanied by worrying negative trends in others.

6.3. Furthermore, geographical variation, and disparities among different socioeconomic groups, persist, and in some cases, are worsening.

6.4. The CYPHOF will continue to highlight priority areas for improvement, and continue to communicate this to key policymakers including CMO, NHS England, PHE and DH.

6.5. Key priority areas include:

- Mortality from non-communicable diseases;
- Geographical variation, and health inequalities among socioeconomic groups; and
- Rising use of urgent/emergency healthcare among all age groups, in particular those with long term conditions.

Annex B

Public Health England

Overview of progress

	Progress since 2010
Road traffic accidents	↓
Low birth weight	–
Smoking in pregnancy	↓
Obesity	–
Teenage conceptions	↓
Teenage mothers	↓
GCSEs	↑
A&E attendances	↑
Emergency admissions from all causes	–
Injury admissions	↓
LRTIs (under 5 years) and bronchiolitis (under 2 years)	↑
Asthma admissions	–
Self-harm admissions	–

16 Children and Young Peoples Health Outcomes: progress

Upward trend, performance deteriorating

Downward trend, performance, improving

Upward trend, performance improving

Level trend, performance stable

Level trend, performance stable/Mixed trend, performance varies by age