

# REPORT OF THE CHILDREN AND YOUNG PEOPLE'S HEALTH OUTCOMES FORUM 2014/15

Forum Co-Chairs:

Professor Ian Lewis

Christine Lenehan, Director, Council for Disabled Children

Dr Sheila Shribman [interim co-chair]

## SUMMARY

The Children and Young People's Health Outcomes Forum was established by Ministers in January 2012 as an independent expert advisory group of professionals and representatives from across the children's sector. The Forum provides expertise, constructive challenge and evidence based advice to improve children and young people's health outcomes and healthcare and to drive up standards of care.

The Forum has actively engaged with children and young people. Young people attend and contribute to discussions at Forum meetings, their views are collected in regular surveys, and young people have read and commented on this report.

There is good evidence that the Forum has raised the profile of children and young people's health within the health system and has been influential in putting in place structures that will lead to improved outcomes over time.

However, despite some 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.

This is perhaps most starkly illustrated by comparing 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 lost each year in the UK, the majority of which would be as healthy adults contributing to the country's social and economic strength.

In line with a wide range of stakeholders in the children's sector the Forum believes that the next Government should develop and implement a Children's Health Strategy, closely working with stakeholders, including children and young people. In the Position Statement in this report we set out some of the key issues that we think should be included in the Strategy.

The Forum believes that, as an independent expert advisory group with a record of making an impact, it is well placed to play a role over the next few years in providing advice, support and challenge to improve the outcomes of our children and young people so that they become amongst the best in the world.

## INTRODUCTION FROM CO-CHAIRS

We are delighted to be publishing the second Annual Report of the Children and Young People's Health Outcomes Forum. This Report builds on and extends the recommendations in the Forum's initial report, published in July 2012, and the Forum's first Annual Report published in April 2014. Since the Forum's previous Annual Report it has held a two day Annual Summit in June and meetings in September and December 2014 and February 2015 as part of its work to improve children and young people's health outcomes.

### The Forum's Impact and the Future

This document looks at the impact of the Forum since its establishment in January 2012 and, as it is published just before a General Election, looks ahead to what we think the next Government should do to improve children and young people's health outcomes.

### This Report's structure

The report is set out as follows -

- Position Statement – The need for a Children and Young People's Health Strategy.
- Impact of the Forum.
- Theme Groups – with links to reports being published alongside this Report.

### Thanks and Contact Us

We would like to give special thanks to the young people that have attended Forum meetings and those that have commented during the drafting of this Annual Report. Your views, based on your experience of the NHS, have been essential in focussing the Forum on what really matters to children and young people.

We have continued to value the support and interest of Dr Dan Poulter MP (Minister responsible for children's health) in the Forum's work. He came to our Annual Summit to speak and take part in a Q&A session and has made time available to discuss the emerging findings from our Theme Groups.

Dame Sally Davies, the Chief Medical Officer, has also shown a keen interest in the Forum's work and we are grateful for her support and commitment to the cause of improving children and young people's health outcomes.

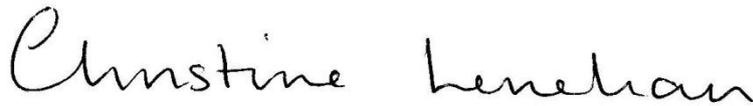
We are very grateful to all Forum members for making time to contribute to Forum meetings and the Theme Groups. Working with you has meant that the Forum's discussions have been informed by practical experience of how the health service operates on a day to day basis. Dr Catherine Calderwood, Dr Jackie Cornish (both NHS England), Ann Gross (Department for Education) and Dr Ann Hoskins (Public Health England) have attended Forum meetings as observers and have provided helpful contributions.

Finally we would like to place on record our continuing thanks to the team headed by Megan Bidder at the Department of Health that provide the secretariat to the Forum.

We are always interested to hear from anyone wanting to know more about the Forum's work. You can email the Forum [here](#)



Professor Ian Lewis



Christine Lenehan



Dr Shelia Shribman

March 2015

## POSITION STATEMENT - THE NEED FOR A CHILDREN AND YOUNG PEOPLE'S HEALTH STRATEGY

The main focus of the debate on health and social care policy has been on meeting the needs of an ageing population. There has been less attention paid to children and young people's health outcomes which, contrary to popular belief, are worse than in comparable countries.

Investing in children and young people's physical and mental health makes sense and will not only benefit the population, but reduce pressure on the NHS in the long term. The consequences of inaction on improving children and young people's health outcomes are both serious and costly.

The Forum, established as an independent expert advisory group in January 2012, has welcomed progress made in implementing *some* of its recommendations, but we have yet to see the step changes really required to improve the track record of the health system in relation to children and young people. Recent concern on access to mental health services for children and young people is a lightning conductor for wider children and young people's health.

Improving children and young people's health outcomes must be a central focus for the health system of the future and an urgent priority for action by an incoming Government.

### Making it happen

**A new Government must develop and implement a national Children and Young People's Health Strategy, including mental health.**

We need a coordinated, system-wide approach to improving children and young people's health. We think that some of the key elements of the Strategy should be as follows:

*'It is our NHS too'*

#### **Children and young people's involvement and engagement**

- Involve children and young people fully in their own health and wellbeing and in improving the services they use.
- Ensure children and young people are always asked about their experience of services. This should become a key part of regulatory inspections.

### Financial incentives for a healthy population

- Ensure that financial incentives in the health system are evolved to encourage innovation and development that delivers the type of services that children and young people need and want – integrated local services in their communities together with expert specialist services when required.

### Health outcomes and strengthening international comparisons

- Develop outcomes measures that join up NHS, public health, social care and education for children and young people.
- Fully fund and implement a nationally based independent and comprehensive database and review process of all deaths in children and young people, currently being developed by NHS England.
- Use international evidence to explore variations between countries in children and young people's health outcomes so that we can identify and learn from the best performers.

*'If we count, count us too'*

### Information sharing and data linkage

- Drive improvement through the transparency of good data. Current outcomes frameworks still do not cover many of the most important outcomes that matter to children and young people. New data collections are welcome, but need sustained investment.
- Improve information sharing within and across services through use of the NHS Number as an identifier to ensure system compatibility.

*'Will I get lost between services?'*

### Integration

- Ensure that children and young people benefit from an integrated approach as they grow up. A range of agencies and professionals provide support for children and young people at different stages of their development. Recent developments to drive integrated care across the NHS and adult social care are **not** mirrored for children, such as mechanisms to drive pooling of resources, or the use of the NHS number as a common identifier.
- Develop new models of care for children and young people, as signalled in the *Five Year Forward View*, to reflect the way they want to live their lives.

**Mental health**

- Proactively support the mental health and wellbeing needs of infants, children and young people.
- Build on the work of the Children and Young People's Mental Health and Well-Being Taskforce and see its recommendations implemented.

*Will the people who care for me be expert enough?*

**Workforce and sustainability**

- Develop and deliver a workforce across the entire children's sector so that children and young people are treated at the right time, in the right place, by people with the right skills.
- New technology and medical advances mean that children and young people are presenting with different health needs and expecting different ways of communication, treatment and support – this needs to be reflected in workforce planning.

## Maintaining momentum

The Forum's initial report demonstrated that children and young people's health outcomes were falling behind those in comparable countries and needed to improve. The Forum has helped raised the profile of children and young people's health within the health system and its recommendations have been instrumental in putting in place structures that will lead to improved health outcomes over time. However, there is still a long way to go if we are to achieve the ambition that children and young people's health outcomes in this country should be amongst the best in the world.

Background on the Forum, including membership details, and copies of its publications are available [here](#)

Further information on this position statement can be obtained by contacting the Forum Co-Chairs Christine Lenehan and Professor Ian Lewis via the Forum's email address [here](#)

## THE NEED FOR A CHILDREN AND YOUNG PEOPLE'S HEALTH STRATEGY

### Key Background Information

There are over 15 million under 20s in England, accounting for nearly 25% of the population. Of these –

- 6% have a disability;
- 14% have a long-standing illness;
- over 10% have asthma;
- 66,000 have autism;
- 60,000 have epilepsy;
- 23,000 have diabetes;
- 68,840 are looked after children (at 31 March 2014); and
- 48,300 are children subject to child protection plans (at 31 March 2014).

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).*

Giving every child the best start in life is crucial for securing health and reducing health inequalities across the life course. The foundations for virtually every aspect of human development – physical, intellectual and emotional – are laid in early childhood. What happens during these early years, starting in the womb, has life-long effects on many aspects of health and well being – from obesity, heart disease and mental health, to educational attainment and economic status.

*(Fair Society, Healthy Lives, 2010 – the Marmot review of health inequalities in England)*

Events that occur in early life affect health and wellbeing in later life. Acting early is underpinned by sound science and sound finance. There is a 6-10% annual rate of return on investment for spend on intervention in the early years.

*(Our Children Deserve Better: Prevention Pays – Annual Report of the Chief Medical Officer 2012).*

- More than one in three 11-15 year olds in England are obese or overweight.
- Only 14% of boys and 8% of girls aged 13-15 meet recommended physical activity levels.
- Almost two-thirds of adult smokers begin before they are 18.
- 10% of 5-16 year olds have a diagnosable mental health disorder.
- Half of all mental health illnesses (excluding dementia) start by age 14, three quarters by age 24.

*(Improving young people's health and wellbeing – A framework for public health, PHE/AYPH, 2015)*

Long-term chronic conditions and disability affect a significant minority of the adolescent population. These conditions include asthma, diabetes, allergies, epilepsy, cancer and physical and mental impairment. Results for England from the Health Behaviour in School Aged Children study (HBSC) in 2010 found that one in seven young people (15%) aged 11-15 reported having been diagnosed with a longterm medical illness or disability.

*(Key Data on Adolescence 2013, PHE/AYPH)*

It is not unusual for a preschool child to visit a GP around 6 times a year.

*(RCGP Child Health Strategy 2010-2015)*

Under 20s account for over 4.9 million (26.5%) A&E attendances each year. This compares to 3.6 million (19.4%) A&E attendances by those aged over 65.

(Hospital Episode Statistics – Accident and Emergency Attendances in England – 2012/13)

The Forum has conducted a recent review of children and young people's health outcomes for the Chief Medical Officer, in response to a recommendation from her, which found:

- Improvement in child and adolescent mortality has been less in the past 40 years than in comparable developed countries which puts us towards the bottom of countries in the European Union;
- There are worrying negative trends e.g. emergency department attendances among children and young people have risen by 40% over recent years and hospital admissions for common childhood conditions such as infant feeding difficulties, for bronchiolitis and self-harm have also risen significantly; and
- Whilst there have been some improvements in areas such as teenage pregnancy conception rates, smoking during pregnancy and deaths of young people due to road traffic accidents, the top line outcome data still masks inequalities within our country and often do not compare favourably to other nations and health systems.

(Forum's health outcomes paper for CMO, 2015)

## IMPACT OF THE FORUM

The Forum was initially asked in early 2012 to:

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

The Forum published a report in July 2012, which took into account the views of some 2,000 people – children, young people, their families and those working in the health and care system, making 78 recommendations to health system organisations to improve children and young people's health outcomes. In February 2013, a System-Wide Response was published by the Government to the Forum's 2012 report. The Forum published its first Annual Report in April 2014 which took stock of progress and set out a series of challenges to the health system.

In assessing the Forum's impact we first need to look at the response to the Forum's initial recommendations.

We are pleased that there has been progress in that many of the recommendations have been implemented or work is ongoing to implement them. For example –

- New indicators in the NHS and Public Health Outcomes Framework, leading to a greater breadth of indicators for children and young people. The indicators are used to provide a national overview of how well the NHS and other organisations involved in improving children and young people's health outcomes are performing and to drive up quality by providing a transparent impetus that focusses on health outcomes;
- All data about children and young people now presented in 5 year age bands through childhood and the teenage years;
- New survey (What about YOUth? Study) which asks around 300,000 15/16 year olds in England about a range of important subjects including alcohol, smoking, exercise and bullying;
- Commitment by the Government to fund a new prevalence survey for children and young people with mental health problems;
- Launch of the National Child and Maternal Health Intelligence Network; and
- Getting key organisations, such as NHS England, Public Health England and Health Education England, to identify the need for and appoint national clinical leaders on children and young people.

The Forum has also contributed over the past 3 years by assisting Health Ministers on a range of issues including:

- The Government's response to the Mid Staffordshire Foundation Trust Public Inquiry (Francis Report) and working with the Department of Health's team on the children and young people's issues raised;
- The refresh of the Mandates for NHS England and Health Education England respectively;
- The Winterbourne View response;
- Reviewing aspects of the Chief Medical Officer's Annual Report;
- The establishment of the Children and Young People's Mental Health and Well-being Taskforce. Several Forum members have been involved in the Taskforce itself in an independent capacity; and
- The NHS Outcomes Framework refresh.

We then need to consider whether, with these changes in place, children and young people's health outcomes have actually improved. From the outset we recognised that it would take several years to demonstrate consistent improvement.

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.

The paper, which is being published as part of the Health Outcomes Theme Group report, concluded that:

- Improvement of child and adolescent mortality has been less over the past 40 years than comparable countries, including those in the European Union;
- There has been progress in some areas of child health and healthcare since the Forum's inception e.g. there has been a fall in the rate of children killed or seriously injured in road traffic accidents, there has been a fall in the number of women smoking in pregnancy, and there has been a fall in the teenage conception rate;
- In other areas there are worrying negative trends e.g. emergency department attendance among children and young people (particularly those with long term conditions) and for hospital admissions for infant feeding difficulties, for bronchiolitis among infants and for self-harm; and

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

Key priority areas for improvement 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.

In addition, we know that progress is being made on some public health issues with self-reported rates of smoking, alcohol and drug use among young people falling. The need to keep focussed on public health issues is well set out in *Improving young people's health and wellbeing: A framework for public health* (PHE and AYPH, 2015)

So a mixed picture on trends. However, there is good evidence that the Forum has raised the profile of children and young people's health within the health system and has been influential in putting in place structures that will lead to improved health outcomes over time.

So what about the future? The Forum's view is that despite this promising beginning we have a long way to go to achieve or improve on the level of children and young people's health outcomes in comparable countries.

There is a range of action being taken across the health system but currently this action is unco-ordinated and unfocussed. The case for early intervention and investment in children and young people's health and the long term benefits of such an approach is very strong – it has a direct and major impact on their future life, particularly their educational attendance, attainment and future employment prospects.

In line with a wide range of stakeholders in the children's sector the Forum believes that the next Government should develop and implement a Children and Young People's Health Strategy, closely working with stakeholders, including children and young people. In the Position Statement we set out some of the key issues that we think should be included in the Strategy.

We do not believe that putting together a Children and Young People's Health Strategy will be a difficult task. Ensuring that it is implemented over the next Government's five year term is much harder. The Strategy will need Ministerial backing across Government and there will need to be regular reports on progress.

## ACCOMPANYING THEME GROUP REPORTS

Much of the Forum's work has been taken forward outside Forum meetings by Theme Groups, covering the key challenges that we identified in our first Annual Report. The Theme Groups have put together short reports which we are publishing alongside this Annual Report.

### Accountability

- Sets out a series of questions that the Forum suggests organisations should be asking themselves on accountability.
- Annex - AYPH survey on *Young People's Views on Involvement and Feedback in Healthcare*, undertaken for the Forum.

### Culture, Engagement and Voice

- Sets out key questions and challenges for the system.
- Separate summary of children and young people's rights in healthcare.

### Financial Incentives

- Sets out the importance of financial incentives in delivering the type of services that meet the needs of children and young people and concerns that currently there is a need for much improvement.
- Sets out the Forum's intention to work with clinicians, commissioners and financial regulatory bodies to improve the methodology used in financial incentives.

### Health Outcomes

- Sets out key questions/challenges.
- Annex - Paper sent to Chief Medical Officer reviewing recent trends in health outcomes for children and young people and regional variation.

### Information sharing

- Sets out what needs to happen to improve outcomes by ensuring effective information sharing.
- Provides case studies on use of the NHS Number as a link identifier.
- Separate paper on why health, education, and social care should use the NHS Number as the link identifier for children and young people.

### Workforce, Education and Training

- Sets out recommendations on encouraging ownership and oversight, developing standards and training, monitoring performance, supporting integrated working and effective pathways of care and encouraging cultural change.
- Annex includes examples of good practice.

The Theme Group reports can be found [here](#)