

CHILDREN AND YOUNG PEOPLE'S  
HEALTH OUTCOMES STRATEGY

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



Forum Co-Chairs:

Professor Ian Lewis, Medical Director, Alder Hey Children's NHS Foundation Trust

Christine Lenehan, Director, Council for Disabled Children

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# Forum membership

Dr Janice Allister	GP/RCGP Clinical Champion for Child Health
Dr Maggie Atkinson	Children's Commissioner for England
Gillian Baird OBE	Paediatrician, Guy's Hospital London
Dr Amit Bhargava	Chair, Crawley Commissioning Consortium
Professor Debra Bick	Professor of Evidence Based Midwifery Practice, Kings College London
Professor Dr Mitch Blair	Consultant and Reader in Paediatrics & Child Health, Imperial College London
Simon Blake OBE	Chief Executive, Brook
Sarah Brennan	Chief Executive, Young Minds
Sir Cyril Chantler	Chairman, UCL Partners
Dr Ronny Cheung	Specialist Registrar in General Paediatrics, Evelina Children's Hospital, London.
Lisa Christensen	Director of Children's Services, Norfolk County Council
Dr Dick Churchill	Associate Clinical Professor in Primary Care, University of Nottingham Medical School
Tracey Cogan	Deputy Regional Director for Child Health & Well Being, Midlands & East – East of England Office
Andy Cole	Chief Executive, BLISS
Professor Sir Alan Craft	Head of Child Health, University of Newcastle upon Tyne
Jacqui Double	Parent/National Diabetes Care
Dr Helen Duncan	Programme Director, Child & Maternal Health Observatory [ChiMat]
Naomi Eisenstadt CBE	Research Fellow, University of Oxford
Carol Ewing	Consultant Paediatrician, Royal Manchester Children's Hospital
Dame Elizabeth Fradd DBE	Independent Health Service Adviser
Barbara Gelb	Chief Executive, Together for Short Lives
Anna Gill OBE	Parent – Disability/Palliative Care
Colin Green	Director Children, Learning & Young People, Coventry City Council
Jean Gross CBE	Former Communication Champion for Children
Dougal Hargreaves	Paediatric Registrar, London
Barbara Hearn OBE	Deputy Chief Executive, National Children's Bureau
Nicholas Hicks	Director of Public Health, NHS Milton Keynes
Dr Ann Hoskins	Interim Regional Director of Public Health/Director of CYP and Maternity

Dr Eric Kelly	GP/Chair Doncaster Clinical Commissioning Group
Sir Ron Kerr	Chief Executive, Guys and St Thomas'
Dr Claire Lemer	Paediatrician Registrar, North London
<b>Christine Lenehan OBE</b>	Forum Co-Chair, Director, Council for Disabled Children
Simon Lenton	Chair, British Association for Community Child Health
<b>Professor Ian Lewis</b>	Forum Co-Chair, Medical Director, Alder Hey Children's NHS Foundation Trust
Anthony May	Corporate Director for Children, Families & Cultural Services, Nottinghamshire County Council
Sue Morgan MBE	Teenage Cancer Trust Nurse Consultant, Leeds General Infirmary
Michelle Morris	Consultant Speech & Language Therapist, Salford Royal NHS FT
Margaret Murphy	Child Psychiatrist
Christine Outram	Managing Director, Medical Education England/SRO Health Education England
Ruth Owen OBE	Chief Executive, Whizz-Kidz
David Pugh	Leader of the Council, Isle of Wight Council
David Richmond	Vice President, RCOG
Professor Stephen Scott	Consultant Child & Adolescent Psychiatrist, Kings College
Sonia Sharp	Executive Director of CYP and Families Portfolio, Sheffield City Council
Fiona Smith	Adviser in Children and Young People's Nursing, Royal College of Nursing
Roly Squire	Consultant Paediatric Surgeon, Leeds Teaching Hospitals NHS Trust
Professor Terence Stephenson	Nuffield Professor of Child Health, Institute of Child Health, UCL
Sue Sylvester	Youth Justice Health Lead, NHS South of England
Professor Russell Viner	Professor of Adolescent Health, UCL Institute of Child Health
Dr Miranda Wolpert	Director, CAMHS Evidence Based Practice Unit

# Foreword

In December 2011 we were asked by the Secretary of State to co-chair a Children and Young People's Health Outcomes Forum and Strategy. Both of us have spent the majority of our professional lives working with children, young people and their families yet had never met before January of this year. We quickly discovered that even from our very different perspectives, we had similar opinions about the current state of services for children and young people and shared views about how to approach the task. In our everyday jobs we see lots of people completely committed to serving children and young people within healthcare, education, social care and the youth justice system. Many dedicate their lives for this purpose and are clearly doing an excellent job. Yet it is becoming increasingly evident that health outcomes for children and young people in our country are poor. This is not what most people to believe. There is a general sense that healthcare is good, that we care about our children and that the outcomes are at least comparable with other countries. The system and country appears to be both sentimental and complacent.

We have seen a number of well-intentioned initiatives over many years aimed at improving care and services for children and young people, and we have made personal contributions to some of them. Whilst there have been improvements these have mainly been in specific areas and have not led to comprehensive or system wide changes that could have resulted in the step changes that are really required to improve outcomes.

It is against this background that we wish to express our appreciation to the Secretary of State for the challenge to lead this exciting work and to have the potential to influence the new system as it develops. We recognise his personal commitment to the healthcare of children and young people and the opportunity to put them at the heart of the new system.

Secretary of State's letter to us asked the Forum to use this opportunity to respond to the challenges set out in Sir Ian Kennedy's report published in 2010 '**Getting it right for children and young people**'. In his report, Sir Ian concluded that the health system has a poor track record in relation to children and has not seen it as a central concern. The Forum members are fully in agreement with Sir Ian's analysis and have used a number of his points as benchmarks with which to set the tone for this strategy.

This strategy is the result of a highly collaborative piece of work undertaken by the Forum within the very demanding timescale of 6 months. The Forum remains absolutely committed to the rejoinder 'No decision about me without me' and has put the voice of children, young people and their families at the very heart of its work. The recommendations for the outcomes frameworks are centred on the issues identified by them as being most important. One of the key questions that the Forum has asked throughout its work is 'How will children, young people and their families have confidence that the system will deliver for them?'

The Forum believes that there is a huge opportunity for a system that has to change and shares the vision of a health system where patient voice and clinical expertise work together. This report contains a number of recommendations for different bodies. We urge each of these bodies to accept them and use them to work towards improving outcomes for children and young people.

We wish to acknowledge and thank the very many people who have contributed to this work.

Firstly we want to thank all the hundreds of children, young people and their families who participated in this work, whether through the National Children's Bureau survey, at engagement meetings, via the webchats or website responses – they have all been immensely valuable and have really shaped this report.

We have had a tremendous input from many organisations within the voluntary sector who have given us major insights from their very special perspectives. Similarly we have had constructive contributions from a wide range of professional organisations and individuals. Both the voluntary and professional spheres clearly shared the desire that this report makes a difference to the whole system.

We met many individuals and organisations within government, the NHS, and throughout the new system who gave us advice and who also listened to us thoughtfully and with enthusiasm. It has become clear to us that there is a deep wish within the system to try and get it right and improve many of the longstanding shortcomings for children and young people.

We want to offer our warm thanks to all the members of the Forum, each of whom has made a considerable personal impact, bringing enormous expertise together with a passion for improving the experience and outcomes for children and young people. Perhaps equally notable has been how collaboratively the Forum has worked as a body. This has been challenging, exciting and fun, supplemented by the enthusiasm with which each of the theme groups has approached their tasks. We can't mention all the members here but we do particularly wish to thank the theme group chairs for their marvellous contributions – Barbara Hearn and Ann Hoskins (Public Health); Lisa Christensen and Margaret Murphy (Mental Health); Gillian Baird and Colin Green (Long Term Conditions, Disability and Palliative Care); Carol Ewing and Eric Kelly (Acute illness). Their commitment, insights and skills have been invaluable.

Both of us want to thank our 'home' organisations – Alder Hey Children's NHS Foundation Trust and the Council for Disabled Children – for allowing us to undertake this work in addition to our day jobs and for supporting us so unreservedly.

Lastly but by no means least we wish to thank all the policy leads and their supporting teams from the Department of Health and the Department for Education. We have been enthused by their engagement, contributions and willingness to think anew. They have absolutely made this report happen but in a way that has preserved it as the independent work of the Forum.

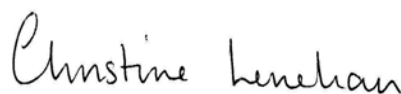
There are 4 people at the DH who have formed our core team and whose assistance, guidance, humour, and dogged hard work has been so crucial that it would be completely invidious not to name them. Denise Snow has organised our work and the work of the Forum without fault. Tommy Denning with his unfailing humour and clear advice has been at the absolute core of our work. They are both marvels. We owe so much to Sheila Shribman and Karen Turner. Sheila, the National Clinical Director has been a continual source of challenge, wisdom and inspiration. Her knowledge is expansive and her enthusiasm boundless. Karen, our lead within DH, has guided us and been beside us from the moment we started this work. She has fulfilled her task unreservedly, wholeheartedly and with complete respect for the independence of our position and of the Forum. We can't envisage having a more dedicated or helpful colleague.

We join with the Forum and all of those who supported this work in the expectation that this report gains traction and can initiate the change that will improve the health and lives of children and young people.



Ian Lewis

26 July 2012



Christine Lenehan

# Executive Summary

In January 2012, the Secretary of State for Health launched the development of a Children and Young People's Health Outcomes Strategy by establishing a Forum composed of individuals with a wide range of expertise and a shared commitment to improving health care for children and young people.

The Forum was asked 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 Frameworks, 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.

This is the report of the Forum's work. It is the result of a conversation with some two thousand people – children, young people and their families and those working in the wider health and social care system. Their messages are the building blocks of our recommendations.

This is a summary of the most important messages for the Secretary of State for Health:

Too many health outcomes for children and young people are poor, and for many this is involved with failures in care. Despite important improvements – for example, reductions in the number of young people smoking<sup>1</sup> and of teenage pregnancies – and in some areas of specialist healthcare, more children and young people under 14 years of age are dying in this country than in other countries in northern and western Europe. There is enormous and unexplained variation in many aspects of children's healthcare,<sup>2</sup> and the UK is worse than other countries in Europe for many outcomes that could be improved through better healthcare and preventative interventions.<sup>3</sup> This alone makes a compelling case for change. The work the Secretary of State asked the Forum to do can lead to the changes that are necessary. We have identified key areas where improvements are urgent.

Outcomes for children and young people will be improved if the wider health system pays more attention to inequality. Infant mortality, obesity, childhood accidents and teenage pregnancy all affect more children and young people from disadvantaged backgrounds.<sup>4</sup> Children who have a disability, who are looked after or are in the criminal justice system face even poorer health outcomes. It is not just their health that is affected – it is their social and economic potential.

Children, young people and their families really struggle to get their voices heard and to be involved in decisions about their own health. This makes it difficult for them to take responsibility for their treatment and care. They know what needs to be done to improve the services they use. Their voices must be heard throughout the health system.

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1 Fuller E. Smoking, drinking and drug use among young people in England in 2010. 2011. NHS Information Centre for Health and Social Care.

2 Cheung R (Ed). NHS Atlas of Variation in Healthcare for Children and Young People. 2012. NHS Right Care.

3 Wolfe I, Cass H, Thompson MJ, Craft A, Peile E, Wieggersma PA, et al. Improving child health services in the UK: insights from Europe and their implications for the NHS reforms. *BMJ* 2011;342:d1277.

4 Marmot M. Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England post 2010. The Marmot Review, 2010. <http://www.instituteofhealthequity.org/>(accessed 20.6.12).



Many clinical staff have inadequate training in paediatrics and child health.<sup>5</sup> Some have training only in adult healthcare, while others do not have sufficient training in physical and mental health to be able to undertake their work with children and young people safely and well. This is one of the most important reasons why children and young people's health outcomes are poor in so many areas. Improving education and training would deliver real improvements in their health outcomes.

Those who work with children outside the healthcare system, such as teachers and youth workers, have an important contribution to make to improving health outcomes – but again their training in physical and mental health is too often minimal or non-existent.

The NHS and social care have been designed around the system, rather than the individual. To children, young people and their families, that system feels fragmented and often means they have to tell their story repeatedly, striving unsuccessfully to be heard and get the properly joined up care they need. Designing and planning health and healthcare round the needs of the individual child or young person, taking account of their changing needs over time, will improve their experience of the service and their health outcomes – not just at a point in time, but for the longer term – and improve their lives enormously.

## Health outcomes that matter most for children, young people and their families

The Forum's starting point for identifying the outcomes and indicators that matter most for children and young people was the existing NHS and Public Health Outcomes Frameworks.<sup>6,7</sup> We have reviewed those outcomes and indicators already included in the Frameworks and have made a number of recommendations that would strengthen them and make them more relevant. These are set out in **chapter 3** of the report.

The Forum concluded that, if we were to make meaningful recommendations to improve outcomes for children and young people, we needed to propose a limited number of new indicators. In developing these proposals, we used both a patient pathway and a broader life course approach, whilst drawing strongly upon the views that we received from children and families through our public engagement process.

One of our key recommendations is that, **with immediate effect, all data about children and young people should be presented in 5 year age bands through childhood and the teenage years.** This will allow relevant international comparisons of key outcomes as well as national or local comparisons of outcomes at significant transition points, such as joining secondary school and transition to adult life.

The Forum recommends four new outcome indicators for inclusion within the ***NHS Outcomes Framework***. These are:

- **time from first NHS presentation to diagnosis or start of treatment;**
- **integrated care – developing a new composite measure;**
- **effective transition from children's to adult services; and**

5 Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. 2010. London DH.

6 Department of Health. The NHS Outcomes Framework. 2012–13.

7 Department of Health. Healthy Lives, Healthy People. Improving outcomes and supporting transparency 2012. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_132358](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358)

■ **age-appropriate services – with particular reference to teenagers.**

The Forum also makes recommendations about strengthening patient experience measures. **By 2013–14, DH and the NHS Commissioning Board (NHS CB) should incorporate the views of children and young people into existing national patient surveys in all care settings.**

We also make a recommendation about the future need to develop specific outcome measures and indicators for the very wide variety of illnesses and conditions of children and young people

Within the ***Public Health Outcomes Framework***, the Forum recommends a number of new indicators in each of the domains. For example, we recommend an indicator measuring the proportion of mothers with mental health problems, including postnatal depression. To strengthen an existing indicator, we propose that the indicator on the proportion of women smoking in pregnancy is extended to look at the proportion of those who *stop* smoking during pregnancy.

In order to support these recommendations for improving public health outcomes, the Forum recommends the development of two new surveys:

- **a population-based survey of children and young people to look at trends in health and wellbeing; and**
- **a survey to support measurement of outcomes for children with mental health problems.**

We believe that the proposed new indicators, together with the recommendations we have set out in our report, will improve the health outcomes that matter most for children, young people and their families.

## **The Forum's recommendations**

There are of course, examples of outstanding health care resulting in good health outcomes for children and young people. It is upon these examples that we have built our evidence for change, from which our recommendations come. They are set out under the key themes that need addressing:

- putting children, young people and their families at the heart of what happens;
- acting early and intervening at the right time;
- integration and partnership;
- safe and sustainable services;
- workforce, education and training;
- knowledge and evidence;
- leadership, accountability and assurance; and
- incentives.

## **Putting children, young people and their families at the heart of what happens (chapter 2)**

The Forum heard from hundreds of children and young people directly and very many more, and their families, indirectly. They told us that where health outcomes are better it is because children, young people and their families are involved in decisions about their care, having received relevant and age-appropriate information, and that care is provided in environments appropriate for their age.

Their voices need to be heard and responded to consistently, and there are both new and existing mechanisms for doing this. Our recommendations therefore are:

**All health organisations must demonstrate how they have listened to the voice of children and young people, and how this will improve their health outcomes.**

**The revised NHS Constitution is drafted in such a way as to be applicable to all children, young people and their families.**

**The Department of Health (DH) should bring together all relevant partners to co-produce a children's health charter based on the principles of the UN Convention on the Rights of the Child, and aligned with the NHS Constitution. The application of these principles should be audited through the regulators.**

**Healthwatch England gives appropriate consideration to the importance of all children and young people's voices to inform its work programme, and is able to demonstrate this through its annual report. Local Healthwatch includes children and young people's voices as core to their work and demonstrates this through their reporting mechanisms.**

### **Acting early and intervening at the right time (chapter 4)**

The focus on children and young people is not only an emotionally driven one. It is also based on economic reality: children and young people are crucial to the future well-being and prosperity of our nation. This is why a focus on the health of the pregnant mother, infancy and the early years and tackling disadvantage quickly is so critical. Poor mental health in pregnancy is associated with low birth weight and increased rates of mental and physical ill health in children. However, the current system does not recognise this. The Forum's recommendations are designed to address these issues:

**All organisations in the new health system should take a life-course approach, coherently addressing the different stages in life and the key transitions instead of tackling individual risk factors in isolation.**

**Directors of Public Health and their local clinical commissioning groups (CCGs) should work together with maternity and child health services to identify and meet the needs of their local population.**

**In 2013 DH should explore the development of a new outcomes measure on perinatal mental health, and implement it as soon as possible.**

In this chapter we have also focused on inequality and disadvantage. The Forum welcomes the new duty on the Secretary of State for Health and CCGs which should increase action to address health inequalities. Whilst there are many groups facing disadvantage, the Forum has focused in particular on the very poor health outcomes of the 65,000 children and young people who are looked after by the State, as many of these poor outcomes are avoidable. To address this disadvantage we recommend:

**Directors of Public Health, through their health and wellbeing board, should ensure that they include comprehensive data for all children and young people within their Joint Strategic Needs Assessment – including those requiring tailored provision, such as those who are looked after, those with disabilities and long term conditions and those in contact with the criminal justice system.**

**CCGs with their local authority partners need to ensure sufficient clinical expertise and leadership for looked after children, including a designated doctor and nurse.**

**Directors of Children's Services should be responsible for overseeing the overall quality and delivery of health and wellbeing for looked after children.**

**Social care staff and others dealing with looked after children should have responsibility for ensuring they are registered with a GP and that the GP is kept informed of the details of their care.**

**CCGs and local authorities should specifically recognise care leavers in early adulthood (18–25), as well as looked after children, in their commissioning, including requiring children in care health teams to include a focus on this group.**

## **Integration and partnership (chapter 5)**

One of the Forum members, a parent, said that for her integration means 'not having to repeat myself thirty times to every different person or part of the system'. The varied needs of many children and young people can only be met by different organisations. However, only by putting the child or young person and their family's needs first, and using sensible systems for sharing information, is it possible to move from fragmentation to proper integration. The Forum's recommendations here, therefore, are for better systems for information, as well as for the new and existing health, social care and education systems:

**The NHS Number should be used as the unique identifier to bring together health, education and social care data for all children and young people.** The intention is not to create an enormous 'big brother' database, but rather to have a simple way of linking information, on health interventions and their impact as well as to understand the impact of long term medical conditions, disability or disadvantage (such as being looked after) or educational attainment. Schools, colleges and youth settings are important contributors to good health outcomes. Schools and colleges with the right culture and ethos are vital in supporting children and young people's well-being. The Forum therefore recommend that the National Curriculum Review include the provision of health and wellbeing within the 'statutory aims' of the revised national curriculum.

**The NHS CB and Monitor should prioritise and promote the issue of integrated care provision in their regulatory and performance roles within the NHS, and work with the Care Quality Commission (CQC) and Ofsted in developing a framework across non-health providers.**

**DH should work with other government departments and partners to achieve better integration of health with education, social care and other local authority led services.**

**DH and partners should select some sentinel conditions and pathways which reflect needs along the life course in order to monitor significant risk of gaps in services, including prevention, and provide focus on improving integration of care.**

## **Safe and sustainable services (chapter 6)**

We all share the ambition to provide world class services and outcomes, delivered using the best available evidence. The Forum does not believe this is achievable with the current pattern of services and the lack of adequate training in paediatrics and child health. This chapter sets out the components

of good, safe and sustainable services which, if implemented, should meet the needs for care to be as close as possible to the individual child and family's home, whilst being high quality and safe.

The development of networks and partnerships at all levels of the system is essential. Our main recommendations here are designed to achieve this and reduce fragmentation between different services:

**The NHS CB must ensure there is a nationally designated, strategic managed network for children and young people. This should include maternity and neo-natal care. The network should incorporate:**

- all children and young people's services within the Specialised Services Definition Set; and
- all parts of relevant pathways, from specialist centres through district general hospitals to community service provision and primary care. The NHS CB must ensure explicit links between the specialist elements of the pathway commissioned by them, and those areas of the pathway commissioned by CCGs.

**CCGs need to develop local networks and partnerships with providers to address and deliver the sustainable provision of local acute, surgical, mental health and community children's services and to ensure both care closer to home and no gaps in provision.**

**The NHS CB, with CCGs, should address service configuration to meet the needs of children and young people on a sustainable, safe and high quality basis.**

In addressing safety, we looked closely at medicines – at both medication errors and the licensing and testing of medicines. No one knows exactly how many medication errors there are, nor how much harm those errors cause, as staff are not obliged to report errors, but from those that are reported we know the numbers are significant. Errors can be very serious and result in avoidable mortality. The Forum believes action can be taken to address this, and quickly:

**DH should adapt the existing indicator in Domain 5 of the NHS Outcomes Framework to measure all drug errors that reach patients.**

**The Medicines and Healthcare products Regulatory Agency (MHRA), with immediate effect, should prioritise pharmacovigilance of children's medicines, including medication errors and off-label use, in line with the new EU legislation effective in July 2012.**

**From April 2013, the reporting of medication errors to the National Reporting and Learning System should become mandatory as part of the reporting for the NHS Outcomes Framework, and should become part of the regulatory framework for CQC and Monitor.**

**With immediate effect, the Royal Pharmaceutical Society should work with the Colleges and the NHS Institute for Innovation and Improvement to develop a bundle of interventions in order to eliminate or reduce drug errors.**

The majority of medicines prescribed to children and young people are not licensed and have not been tested for use in them.<sup>8</sup> This is true for newborn right through to older children. We believe this is unacceptable.

<sup>8</sup> Van't Hoff W, Tomlin S. The use of unlicensed medicines or licensed medicines for unlicensed applications in paediatric practice. 2009 RCPCH/NPPG Standing Committee on Medicines.

**DH should commission a study, in 2013, to quantify the harm to children and the costs that arise due to errors from unlicensed and off-label prescribing and through lack of age-appropriate formulations. Using the findings, DH should work with the industry and academia to develop properly the use of all medicines, whether old or new, starting with those producing the most harm.**

## **Workforce, education and training (chapter 7)**

All those working with children and young people should have the right knowledge and skills to meet their specific needs. Too often they do not. This is not just within the NHS, but in schools and youth services, whose staff can make an important contribution to children and young people's health outcomes.

The new health system, Health Education England (HEE) and the local Education and Training Boards (LETBs) provide the ideal opportunity to take stock of the children's health workforce needs for the whole country. We recommend:

**HEE should prioritise children and young people, providing early strategic direction for workforce planning, education and training for the core and specialist children's health workforce.**

**HEE should identify a lead LETB to co-ordinate education, training and workforce development to reduce variability and maintain national standards.**

The Forum considered many issues facing the wider health workforce – the desire for care closer to home, the training and staffing requirements of the different care settings and the difficulty of recruiting to some professions. These need proper consideration:

**As a matter of priority, the Centre for Workforce Intelligence, in conjunction with key professional bodies whose members provide services to children and young people, should undertake a scoping project to identify and address the issues of providing a safe and sustainable children and young people's healthcare workforce.**

The wider workforce such as teachers, social workers and youth workers have an important role in improving health outcomes, and the theme groups have addressed the role of schools particularly in their individual reports. As well as understanding their physical health needs, children and young people need those working with them to understand the importance of good support for emotional health and well-being. This is of the utmost importance. We therefore support the DH-led consortium of organisations producing a mental health e-portal, which we hope will form part of many professions' initial training and continuing professional development (CPD) from 2014.

General practice, and GPs in particular, have a critical role to play in children and young people's health as they are often the first point of contact when a health problem arises, and their response to the child's problem can determine the outcome. The next group of recommendations therefore relate to GPs and general practice staff training:

**The Royal College of General Practitioners proposal to extend GP training to allow for adequate training in paediatrics and physical and mental child health is supported.**

**All GPs who care for children and young people should have appropriately validated CPD reflecting the proportion of their time spent with children and young people.**

**All the relevant Royal Colleges should work together to agree skills and competencies in child health.**

**All general practices that see children and young people should have a named medical and nursing lead.**

**All general practice staff should be adequately trained to deal with children and young people.**

## **Knowledge and evidence (chapter 8)**

Collecting information and turning it into knowledge and evidence, and putting that alongside research is central to the drive for better health outcomes. The Forum has made many suggestions in this area including, at its most basic, the interpretation of data – the need to present data in relevant age bands (see the recommendation in chapter 3).

As part of the drive to involve children, young people and their families in their care, the Forum looked at access to health records and good personal health information, and also at the need for new data sources.

The systems and data currently in use require significant development to meet future needs. In this chapter we make a number of detailed recommendations designed to start to put that right. Some of the main ones are:

**The NHS CB, with support from Health and Social Care Information Centre (HSCIC), should establish electronic child health records, accessible for both patients and professionals.**

**The NHS CB, with support from the HSCIC, should improve the quality of routinely collected data, collecting them once and using them for multiple purposes, as well as making secondary uses data readily available to and useable by clinical professionals.**

**Once established, the coverage of the new maternity and child health dataset should be extended, in particular to enable tracking of:**

- **child development outcomes at age 2–2½ years, as included in the Public Health Outcomes Framework;**
- **care and outcomes associated with the Improving Access to Psychological Therapies (IAPT) initiative; and**
- **care and outcomes for children with disabilities and complex conditions.**

**The Chief Medical Officer should consider how an intelligence network for children and young people's healthcare, which crosses all settings, can be established by 2013, to drive up standards and effective use of data, information and intelligence in decision making.**

Key to delivering improved health outcomes is high quality evidence, to inform the setting of standards for treatment and services. There were too few Quality Standards relevant to children and young people, but the Forum is pleased to note that an increased range of topics is now planned. This will go some way to addressing the gap, but much more needs to be done, and we recommend that **the National Institute for Health and Clinical Excellence (NICE) and the NHS CB work with the professional bodies to expand and prioritise the Quality Standards work programme as it applies to children and young people.**

Children and young people's healthcare research has had some significant successes in recent years, most notably the development of the Medicines for Children Research Network (MCRN).<sup>9</sup> However, this has been against a more general background of paediatric research struggling to find a clear identity within universities.

The data in this report on children's outcomes raise three major research questions that need to be addressed as a matter of urgency:

1. Is it true that children and young people's health outcomes in many areas are as poor in comparison to other countries as the data suggest?
2. If so, why?
3. What action or interventions need to be taken to improve these outcomes?

The Forum is clear that this area needs more focus. **The Chief Medical Officer should use her role as head of research and development to stimulate the development of academic child health, both physical and mental, and the evidence base for practice and improving outcomes.**

### **Leadership, accountability and assurance (chapter 9)**

New organisations in the system are setting up their structures and ways of working so that they can deliver their responsibilities. The Forum believes that leadership and accountability for improving health outcomes across the whole lifecourse must be embedded and demonstrated throughout the system – within both new organisations and those already established.

**All organisations leading the new system – DH, Public Health England (PHE), the NHS CB, Monitor, local authorities and CCGs – should clearly set out their responsibilities for children, young people and their families and how accountability will be exercised at every level in the system, and should be transparent about the funds they spend on child health.**

Clinical leadership – an important feature of the new health system – must be visible at every level.

**DH, the NHS CB and PHE should identify national clinical leadership on children and young people, for example through a deputy reporting to the Chief Medical Officer in DH and a National Clinical Director reporting to the Medical Director within the NHS CB.**

**Local commissioners, including CCGs and local authorities, should identify a senior clinical lead for children and young people.**

The system regulators have a key role in quality assurance. The Forum believes that Monitor, CQC and Ofsted, working together, could drive improvements in child health. Our recommendations are designed to help them do so:

**CQC should make maximum use of thematic reviews to examine aspects of the new health system from a children and families' perspective.**

**Monitor, CQC and Ofsted should collectively produce a clear joint statement which demonstrates how they will work together to foster integration of key services and partnership across sectors.**

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<sup>9</sup> <http://www.mcrn.org.uk/>



Safeguarding children and young people and identifying abuse early are core responsibilities of the health system. This is such an important area that we have made a number of recommendations to help ensure that focus is not lost in the transition to the new landscape. These include:

**DH and the NHS CB should publish a full accountability framework for safeguarding children in the wider health system as soon as possible.**

**As part of the new multi-agency inspections, CQC should consider how all parts of the health system, including relevant adult services, contribute to effective local safeguarding.**

**Further work should be undertaken on indicators that would drive improvement to protect and promote the welfare of children and young people. This should include a focus on measuring the effectiveness of early help/early intervention.**

**NICE should be commissioned to develop a Quality Standard for safeguarding children.**

### **Incentives for driving service improvement (chapter 10)**

The changes to the health system will result in changes in funding flows, most notably from the NHS to local authority public health services. Child health services cross these new boundaries and this brings a risk. It is important that, with new commissioning roles, these funding flows do not become a barrier to good service provision.

**DH, in its system oversight role, should maintain a focus on the pattern of funding flows across the NHS, local authorities, public health and, where relevant, wider care or wellbeing, to ensure that perverse incentives are not adversely affecting patient care or service provision.**

There is a range of incentives available to drive improvements across the NHS. For children's services, these have largely focused on specialist services. Child and Adolescent Mental Health Services (CAMHS) and community service incentives are starting to evolve but gaps remain, particularly in areas where the integration of different services is required. Incentives in general practice are almost entirely focused on adult health. The Forum's recommendations address these issues:

**The NHS CB and Monitor should prioritise and promote the issue of integrated care provision in their funding, regulatory and performance roles within the NHS, and DH should address this issue across government for those services that fall within the remit of local authorities, education, or other government departments.**

**The Forum recommends that the NHS CB prioritise the development of an appropriate range of incentives within the Quality and Outcomes Framework [QoF] for general practice to provide high quality care reflecting the needs of children and young people.** The current QoF for general practice is a completely inadequate reflection of the workload of general practice and the potential quality gains that could be achieved.

**Monitor and the NHS CB should ensure that they continue with the outcome-orientated development of Payment by Results currencies and tariffs for child health related areas.**

The Forum strongly supports the move to provide care for children and young people closer to home, at home or in community settings. Managed properly, this will improve health outcomes. To achieve this, a mixture of specialist services, 24 hour acute services and local community services is needed, but current funding arrangements do not necessarily incentivise care to be provided in the best place

for individual children. This will have significant consequences: services will need to be redesigned, and some will close.

**The NHS CB and CCGs must be mindful of the potential consequences to providers of general and specialist services and consider how they will adopt a risk sharing approach between different provider organisations in developing their commissioning plans for delivering care closer to home.**

## Conclusion

The Forum has set out recommendations for the new health system which, if accepted and put in place, will start to address the key obstacles to improving children and young people's health outcomes that exist now.

The implementation of these recommendations is crucial. The Forum is clear that without consistent attention and further development of the strategy this report could go the way of many of its predecessors and fail to secure the benefits that our children and families need and the country requires.

So this work should be seen as the first phase in the new Children and Young People's Health Outcomes Strategy. This is a real opportunity for improvement and the Forum therefore urges government and all organisations in the health system to accept these recommendations and act now.

# 1. Introduction

'I know what I want, you need to listen to me'

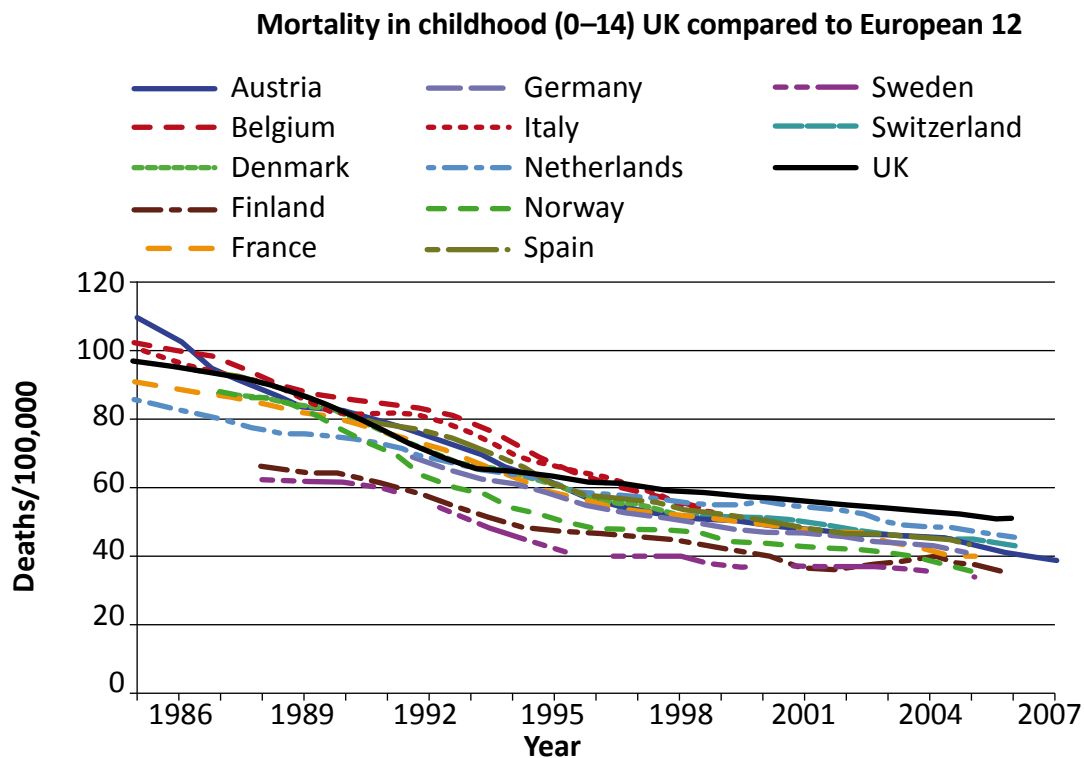
## Who is this report for?

This report is for everyone who has an interest in and responsibility for improving health outcomes for children and young people. This includes those working in the new as well as established organisations within the health system, professionals and practitioners and of course children, young people and their families.

## Why have a Children and Young People's Health Outcomes Strategy in 2012?

Whilst there have been some notable improvements in measured outcomes for children and young people over recent years, the evidence is telling us that this is at a slower rate in the UK than in comparable countries in northern and western Europe. Some of the most important health outcomes for children and young people in this country are worse than in many of these countries.<sup>10</sup>

Perhaps most telling, 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.



<sup>10</sup> Wolfe I, Cass H, Thompson MJ, Craft A, Peile E, Wieggersma PA, et al. Improving child health services in the UK: insights from Europe and their implications for the NHS reforms. *BMJ* 2011;342:d1277.

Additional outcome indicators of note include:

- death rates for illnesses that rely heavily on primary care services (eg asthma, meningococcal disease, pneumonia) are higher in the UK;
- survival rates for childhood cancer are lower;
- diabetic control markers in children are significantly worse than in other countries with comparable information; and
- more than 1 in 5 children are overweight or obese by age 3.

There are some costly failures of care:

- 26% of deaths showed 'identifiable failure in the child's direct care';
- for 43% of deaths there were 'potentially avoidable factors' [(CEMACH 2008)];
- half of children subsequently found to have meningococcal infection are sent home from the first primary care consultation;
- approximately 75% of hospital admissions of children with asthma could have been prevented with better primary care;
- more than a third of short stay admissions in infants are for minor illnesses that could have been managed in the community.

There are serious consequences for inaction:

- more than half of 15–16 year olds had consumed more than five alcoholic drinks in the previous month;
- half of life time mental illness starts by the age of 14;<sup>11</sup>
- more than 8 out of 10 adults who have ever smoked regularly started before 19;<sup>12</sup> and
- 8 out of 10 obese teenagers go on to be obese adults.<sup>13</sup>

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.

There are wide and unwarranted variations around the country in service provision and care.<sup>14</sup>

These include:

- a 3 fold variation in admission of term babies into neonatal units;
- a more than 4 fold variation in numbers of children attending emergency departments from equivalent general practices;
- a 4–6 fold variation in admissions to hospital for bronchiolitis or asthma;
- an 8 fold variation in expenditure on community children's services; and
- a 3 fold variation in tonsillectomy rates.

When we asked children and young people their views of the healthcare they received, they offered an extensive list of areas where improvements could be made – some of them simple, some more

11 Kessler RC, Angermeyer M, Anthony JC, DE GR, Demyttenaere K, Gasquet I, et al. Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry* 2007 Oct;6(3):168–76.

12 Robinson S and Bugler C. Smoking and drinking among adults, 2008. *General Lifestyle Survey 2008*. ONS, 2010.

13 Donaldson L. Under their skins:Tackling the health of the teenage nation. *Chief Medical Officer's Annual Report 2007*. 2008. London, DH.

14 Cheung R (Ed.). *NHS Atlas of Variation in Healthcare for Children and Young People*. 2012. NHS Right Care.

complex and costly. But mostly they wanted to be listened to when decisions were being made about their own health, and to receive treatment in an environment appropriate for their age.

In 2010, Professor Sir Ian Kennedy produced a report, *'Getting it right for children and young people'*, in which he highlighted poor health outcomes and the lack of priority given to children and young people within the health system. He identified a number of specific issues which would need to be addressed if improvements needed in healthcare for children and young people were to be achieved. These included:

- GPs having little or no formal paediatric training;
- caring for children and young people being low on most GPs' priorities;
- wide variations in care;
- a lack of co-ordination, and services not working together;
- the configuration of services, and the importance of networks;
- a need to promote positive help;
- a need for improved data and information;
- a need to improve workforce competence; and
- a need to improve leadership throughout children's services.

## The Children and Young People's Health Outcomes Forum

In January 2012, the Secretary of State for Health announced the development of a Children and Young People's Health Outcomes Strategy, the first of its kind in the context of the new health system brought in through the Health and Social Care Act 2012. He established an independent Children and Young People's Health Outcomes Forum to develop the Strategy, which brought together individuals with a wide range of expertise and a shared commitment to improving health care for children and young people.

At the heart of the health reforms is an ambition to deliver outcomes that are amongst the best in the world, through the creation of an outcome based health and social care system. The Secretary of State confirmed that he accepted Sir Ian's analysis of the current situation, and was very clear that this new Strategy needed to be set in the context of the challenges set out in Sir Ian's report.

The Secretary of State asked the Forum to undertake three key tasks:

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

## Questions the Forum addressed

The current NHS and Public Health Outcomes Frameworks include a number of outcomes and indicators specific to children and young people, and others that are relevant and important. The Forum has therefore had to consider where these could and should be strengthened, and what gaps there are which need to be filled.

This was the major focus of the Forum's work.

With regard to the new health system, there were specific questions that concerned Forum members – and these questions are not new:

- Will the system reinforce the fragmentation of services for children and young people? How can that be avoided?
- How will parts of the system work together to meet the full range of children and young people's needs?
- How will the system listen to their voice?
- There are levers and opportunities within the system to improve health care – how can we ensure they are used to improve children and young people's health outcomes?
- This report looks in detail at the points made by children and young people themselves about their health and healthcare, as well as those raised by others. The proposed outcome measures and recommendations that follow are the results of a conversation with several thousand people.

The Forum was organised, on the basis of members' expertise, into four theme groups:

- Public Health;
- long term conditions, disability and palliative care;
- mental health; and
- acute illness.

The output of these themed groups underpins the findings within this report. Their papers accompany the report. Additional groups covered other important areas, which are also reflected and referred to throughout this report.

The Forum's full report and supporting information includes:

- Listening to Children's views on health provision – a rapid review of the evidence, National Children's Bureau, 2012
- Long Term Conditions, Disability and Palliative Care Group Report
- Public Health Group Report
- Mental Health Group Report
- Acute Illness Group Report
- RCPCH Facing the Future: a review of paediatric services 2011
- Confidential Enquiry into Maternal and Child Health 2008
- Atlas of Child Variation [www.chimat.org.uk/variation](http://www.chimat.org.uk/variation)
- Getting it Right for Children and Young People – Sir Ian Kennedy (2010) [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_119445](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445)

## 2. Putting children, young people and their families at the heart of what happens

'I want to be listened to and have a say about my own health'

'I want to be treated in child friendly places'

Children and young people need to be in control of their own health and well-being. Where they are too young, or have special needs which limit their ability to speak for themselves, their parents or carers must be given an opportunity to express their views and opinions on their behalf. It is essential that the voice of families and carers is heard, as well as (but not instead of) that of their children.

The benefits of involving children and young people when designing quality health services are already evidenced through the *You're Welcome* quality standards developed by the Department of Health (DH) and through the Young Inspectors used by some local health providers and developed as part of the Department for Education's (DfE) *Positive for Youth* initiative. Other public services that involve and listen to children and young people find the result to be better services, better informed consumers and overall, better value for the investment.

It is therefore extraordinary that, in so many parts of the NHS and wider health system, adults fail to take account of children and young people's views or to measure their health outcomes. We found too many examples where only adults' views or health outcomes were measured.

### What children and young people told us matters most to them

We undertook a survey of over 350 young people about the relevance of the NHS and Public Health Outcomes Frameworks to their lives. We also heard from over forty looked after children and care leavers of their particular experiences. More than 1000 responses were submitted to the Forum website on line.

We also completed a rapid review of literature on children and young people's views and opinions about improving their health and health systems published over the past five years.<sup>15</sup>

**Children and young people told us** that the existing outcomes and indicators are important, to varying degrees. The public health and NHS indicators to which they gave the highest number of positive scores were on:

- premature mortality;
- deaths of babies and young children;
- quality of life for those with long-term conditions; and

<sup>15</sup> La Valle I, Payne L. Children's experiences and views of health provision: a rapid review of the evidence. 2012. National Children's Bureau. [www.ncb.org.uk](http://www.ncb.org.uk) (accessed 31.5.12).

- domestic violence.

Those that received the lowest number of positive scores were:

- reduced time in hospital for those with long-term conditions; and
- improved access to dental services.

Children and young people also told us they want:

- to have a say and to be listened to in decisions about their health, and to take a lead where able;
- information to be presented in a child friendly way;
- care by professionals who have had training in working with children and young people;
- care in environments appropriate to their age and needs; and
- appropriate and efficient systems for transfer from children's to adults services.

The **on-line responses** told us some of the concerns of children and their families:

- a lack of join up around health, social care and education;
- poor and delayed diagnosis of conditions impacting on outcomes;
- general practice, the key and most frequent point of contact, is not meeting the needs of children and young people;
- outcomes need to take a whole family approach, because the health and wellbeing of families (carers) directly impacts on children and young people and affects their resilience;
- outcomes need to be measured for different ages along the life cycle; and
- transition to adult services is often very disjointed, and planning needs to involve the young person and their family.

From the **rapid review** we found that, generally, children and young people want:

- good, child friendly information about what is available and how they can access it;
- to be able to receive information directly from health staff, as well as from parents who are important providers and translators of information;
- knowledge of health issues to extend beyond health professionals – for example to teachers and youth workers – particularly so that they can support those who do not have parents to help them to access and translate health information and advice;
- to give their own views about their health needs and the care they receive; and
- health staff to show respect and recognition of their right to be involved in decisions about their health and care.

With regard to both their physical and their mental health, children and young people want:

- care to be delivered by competent professionals who communicate well with them;
- to be involved in decisions with regard to their care and make informed choices;
- information about them to be kept confidential;
- care to be in environments which are appropriate to their age and needs; and
- appropriate and efficient systems for the transfer from child to adult services.

With specific regard to mental health, children and young people want:

- to have a voice in the development and delivery of mental health services; and
- to have the stigma surrounding mental illness to be tackled, as a block to seeking help.



With regard to health promotion, children and young people:

- understand that peer pressure and advertising can work against healthy choices;
- need better information and advice about healthy lifestyles;
- believe that too many public health campaigns are aimed at adults;
- connect being healthy with 'things to do' in their area and access to public transport and sports facilities;
- want involvement in the design, development and evaluation of child friendly campaigns and services;
- recognise and value the role of the school in encouraging healthy behaviour; and
- recognise there is a place for social media.

With regard to health services, children and young people:

- believe they should have a say and be listened to in decisions about their health, and take a lead where able;
- value the support and advice of parents and carers but have their own opinions; and
- expect environments to be child and young person friendly.

To ensure the NHS addresses the points that children and young people have made about their experience, the Forum is recommending a new outcome measure. This is detailed in the next chapter.

## Healthwatch

Healthwatch, an important new player in the health and social care system, is designed to be a 'consumer champion' for everyone and will operate at a national and local level. Nationally, from October 2012 Healthwatch England will be established as a statutory committee within the Care Quality Commission (CQC). Healthwatch England will present people's views and experiences to influence at the national level; it will also provide leadership and support for local Healthwatch.

From April 2013, there will be a local Healthwatch in every local authority area, and they will be a member of the Health and Wellbeing board (see chapter 9). Healthwatch will gather local views to inform the local Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies.

Healthwatch's role in relation to children and young people will be important. The intention is that local Healthwatch builds on activities currently carried out by LINKs (Local Improvement Networks). However, most LINKs have focused on adults and not addressed issues to do with children and young people.

We believe that both Healthwatch England and local Healthwatch provide welcome opportunities for children and young people's voices to be heard – in some areas for the first time. To ensure that this happens, **the Forum recommends:**

- **that Healthwatch England, as the national champion for health and social care, gives appropriate consideration to the importance of the voice of all children and young people in informing its work programme, and is able to demonstrate this through its annual report; and**
- **local Healthwatch includes children and young peoples voices are core to that work and demonstrates this through their reporting mechanisms.**

## Children and young people's voices across the system

Taking account of all the points children and young people told us, **the Forum recommends that all health organisations demonstrate**

- **how they have listened to the voice of children and young people,<sup>16</sup> and**
- **how this will improve their health outcomes.**

## Children and young people's rights

### *The NHS Constitution*

The NHS Commissioning Board (NHS CB) has a duty to act in a way that enables patients to make choices about health services. DH plans to publish a Choice Framework alongside the Secretary of State's mandate to the NHS CB. It is essential that the development of choice in healthcare includes exploration about how choice can be extended to children and young people. This may be more complex than for adults, as it requires relevant information to be presented in ways appropriate to the level of development and capacity of the child or young person.

We identified the rights and entitlements set out in the NHS Constitution as a powerful driver that could be used to effect significant improvements in health outcomes for children and young people.

For the first time in the history of the NHS, the Constitution<sup>17</sup> brings together in one place details of what public, patients and staff can expect from the NHS. It also explains what individuals can do to help support the NHS, help it work effectively and help ensure that its resources are used responsibly. The Constitution sets out the individual's rights as an NHS patient. These rights cover how patients access health services, the quality of care they will receive, the treatments and programmes available, confidentiality, information and a right to complain if things go wrong.

The NHS Constitution is currently being reviewed and this is an opportunity to set out clearly the rights and responsibilities of children, young people and their families.

**The Forum recommends that the revised NHS Constitution is drafted in such a way as to be applicable to all children, young people and their families.**

### *UK international commitments*

The UK is a signatory to the Council of Europe Declaration on child friendly health care.<sup>18</sup> This Declaration is based on a model of service delivery identified within the UN Convention on the Rights of the Child (UNCRC).<sup>19</sup> The aim of the declaration is for Europe to adopt and adapt this approach to create effective, integrated services.

The UNCRC spells out the basic human rights of all children under 18 years of age. It includes a specific article about expressing their views (Article 12) and it says children have the right to good quality

16 This is a statutory duty for most of these organisations but the Forum recommends it as good practice for ALL and that just public engagement is not sufficient without demonstrating children and young people and not just adults voices' have been heard.

17 Department of Health. The NHS constitution for England. 2012. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_132961](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961)

18 9th Council of Europe Conference of Health Ministers. Child-friendly Healthcare: Building a Health Future for and with Children. 2011 Lisbon. <http://www.coe.int/t/dg3/health/Final%20Declaration%20Lisbon%2030%209%2011%20E.pdf>

19 UNCRC. Article 12, United Nations Convention on the Rights of the Child. 1990. <http://www2.ohchr.org/english/law/crc.htm#art12>

health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy (Article 24). The Forum believes that adoption and implementation of these principles would be a significant driver to improving health outcomes for children and young people.

**The Forum recommends that DH should bring together all relevant partners to co-produce a children's health charter based on the principles of the UNCRC Article 12 Principles, and align these with the NHS Constitution. The application of these principles should be audited through the regulators.**

### Healthcare provision through a child friendly lens

Although the NHS has responsibilities for people from conception to death, the reality is that the health system has been largely designed by adults for adults, and has persistently been informed by the interests of adults rather than those of children and young people. Facilities within the NHS often pay lip service or no attention to the needs of children, teenagers or nursing mothers. Many members of the workforce have received little or no training in the needs of children and young people.

The benefit of adopting a child friendly health care approach will be to maximise the opportunities for improving outcomes. Looking through a child friendly lens will promote and create alignment and synergy between all the various stakeholders involved in providing services. This includes children and families themselves, providers, commissioners, those in policy and planning roles as well as regulators.

Clearly this approach needs to include promotion, protection and prevention at each stage and encourage child and family participation in individual decision-making, service improvement and policy priority setting.

This section has described what children and young people themselves considered important. The rest of this report is the result of the deliberations of the Forum, but it all has a strong resonance with what the children and young people said themselves.

The Forum's full report on these areas and supporting information includes:

- Listening to Children's view on health provision – a rapid review of the evidence, National Children's Bureau, 2012.
- UNCRC Articles 12 and 24.
- National Children's Bureau Report on LINKs [www.ncb.org.uk](http://www.ncb.org.uk).

### 3. Health outcomes that matter for children, young people and their families

Children believe that overall, having a health system that puts prevention, quality, experience and safety high on the agenda matters. Preventing poor health and particularly premature mortality – including tackling the wider determinants of health, such as domestic violence – is very important to children and young people.

In physical and mental health, children and young people want:

- Care to be delivered by competent professionals who communicate well with them.
- To be involved in decisions about their health and care and make informed choices.
- To be treated with dignity and respect.
- Care to be in environments which are appropriate to their age and needs.
- An appropriate and efficient system for the transfer from child to adult services.
- Access to timely and effective care.

#### Developing outcomes

In line with the Secretary of State's commission, our starting point for detailing the outcomes and indicators that matter most to children and young people was the existing NHS and Public Health Outcomes Frameworks. Conscious of the limited scope available to expand the top-level Outcomes Frameworks, we have been careful to recommend new indicators and amendments only where there was the strongest evidence and the largest impact for children, young people and their families.

We also considered the role of the Commissioning Outcomes Framework, recognising that, as it is currently under development, we are not yet able to assess fully how it might play its part in improving health outcomes.

In developing our recommended outcomes and indicators, we used both a patient pathway approach, which sets out questions that those using health services may ask for each pathway step, and a broader life course approach, which helps identify indicators important at particular life stage(s). The indicators were chosen for important areas where we need to make progress and improve outcomes for all children and young people, including those with limited engagement with health services.

In making our recommendations, we have sought to strengthen existing indicators, extending a number of them to reflect that different stages of the life course and life cycle require a different emphasis; from conception through pregnancy to birth, the early years, mid-childhood, to teenagers and young adults, and that using a single measure for 0–19 year olds is inappropriate.

**The Forum therefore recommends that, with immediate effect, all data about children and young people are presented in 5 year age bands through childhood and the teenage years. This will allow relevant international comparisons of key outcomes as well as national or local comparisons of outcomes at significant transition points, such as joining secondary school and transition to adult life.**

**The Forum also recommends that incremental improvements are made to data collection, to allow data to be analysed by gender and socio-economic status at population level, in order to ensure equity for health outcomes is addressed.**

## **NHS Outcomes Framework**

The NHS Outcomes Framework has a number of outcome measures relevant to children and young people. However, we do not believe that they adequately reflect the range of health issues that need to be improved. Nevertheless, we decided that it is perfectly feasible to adapt or extend many of the existing indicators to make them more relevant and improve their impact. For example, we recommend the inclusion of indicators on childhood mortality at all ages and cancer survival rates for children and young people. We recommend extension of the indicators on employment rate to consider an equivalent for children – namely, pupil absence from school.

However, even after doing this, we identified four areas that are particularly important to children and young people – principally, but not exclusively, those with long-term conditions, disability or complex needs – which need to be addressed if we are to see improvements in healthcare outcomes. These are:

- time to diagnosis and initiation of treatment;
- integrated care;
- transition to adult services; and
- access to age-appropriate care.

### ***Time to diagnosis/start of treatment***

A key element of good quality care for children and young people is early diagnosis and initiation of effective interventions. Evidence suggests that delayed time to diagnosis and starting treatment leads to poor outcomes and increased mortality, particularly for vulnerable groups and those with meningococcal disease or cancer. In our engagement with the public and voluntary sector, we received very strong messages to include this crucial outcome that impacts on children and families.

**The Forum therefore recommends the inclusion of a new indicator that reports the time to definitive diagnosis/start of treatment from first symptomatic presentation or contact with NHS services. Initially we recommend this for a set of exemplar conditions including cancer, diabetes, meningococcal disease and epilepsy.**

This outcome indicator should be extended to other areas in due course, such as autistic spectrum disorders and mental health problems in children and young people.

### *Integrated care*

The Forum has received considerable evidence about this area. We consider that one major priority is that the system should feel integrated from the patient and family perspective so that children, young people and their families are not left to negotiate gaps between services. Integrated care, whilst recognised as essential, is not easily measured or assessed by a single measure.

**The Forum therefore recommends that a composite indicator be developed to look at the provision of integrated care for children and young people with a long-term condition, disability or complex needs.**

Essential elements of this indicator have been identified in our recommendations for the Commissioning Outcomes Framework – namely, that each child or young person with a long term condition, disability or special educational needs, and each looked after child or young person or care leaver, has a coordinated package of care, including a quality assessment, access to key working and appropriate equipment; and that the individual's and their family's experience of the service is measured.

### *Effective transition from child to adult health services*

This is simply the maintenance of high quality care across child health services into adult care. When performed well between adult and paediatric teams that are both committed to working effectively with young people, transition can be a very positive experience that nurtures confidence and leads to excellent relationships in adult care. Yet the transfer between child health services and adult services is often fragmented. Young people frequently fail to engage with adult services. Poor transition can lead to frankly disastrous health outcomes for both physical and mental health. For example, in diabetes and asthma, disease control is often lost for extended periods, and renal transplant recipients may lose donor kidneys.<sup>20,21</sup> At its worst, poor transition leads to drop-out from medical care for those with a long-term condition, and deterioration in those with disabilities – both leading to unnecessary, costly hospital admissions. This was also one of the issues most frequently raised during our public engagement.

**The Forum therefore recommends that DH includes a new outcome in the NHS Outcomes Framework to ensure that effective and healthy transitions take place between child-centred and adult-centred health care.**

We propose an outcome using Hospital Episode Statistics (HES) data in sentinel conditions (such as diabetes, inflammatory bowel disease and complex disabilities) to monitor whether children and young people continue to receive the care they need following transfer from paediatric services.

An approach combining both a pull (from adult care) as well as a push (from paediatrics) needs to be adopted. To achieve this, **the Forum recommends that the Royal College of Physicians works with the Royal College of Paediatrics and Child Health (RCPCH) and other Colleges to develop a plan, by 2014, to ensure that health outcomes and the experience for transition are improved.**

**The Forum also recommends that NICE produce a Quality Standard for age and developmentally appropriate care of teenagers and young adults, including through transition.**

20 Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child* 2011 Jun;96(6):548–53.

21 Harden PN, Walsh G, Bandler N, Bradley S, Lonsdale D, Taylor J, et al. Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. *BMJ* 2012;344:e3718.

### Age-appropriate health care

Teenagers tell us repeatedly that they often have poor experience of health care and that they are marginalised, whether they are in GP surgeries, community clinics or hospital wards – in both children's wards (average age 3 years) and adult wards (average age over 70 years). While few children under 14 years are now cared for in adult wards across the UK, many 14–17 year olds are nursed with elderly adults and often exposed to inappropriate risks. Research shows that clinical quality and experience is best for young people in dedicated teenage wards, with children's wards being next best and adult wards poorest.<sup>22</sup>

The World Health Organization (WHO) has developed the concept of *youth friendly services*, emphasising that services that provide young people with good experiences are more likely to be effective and used. Based upon this, clear quality criteria for adolescent-friendly health services were developed, validated and published by the DH in 2007 – *You're Welcome*.<sup>23,24</sup>

Local authority commissioned drug, alcohol and sexual health services also need to be youth friendly and sensitive to the needs of both young men and women. This means being confidential, in the right place, open at accessible times and well publicised to reduce the stigma of asking for help and encourage young people to seek early advice. Involving young people in the JSNA (such as through Healthwatch, chapter 2) will help local authorities design services around how young people in their areas live their lives, rather than around professional boundaries, and provide a more coordinated approach to prevention and support. The duty on local authorities to provide services and activities to improve young people's well-being provides another opportunity to integrate health advice into youth settings and other services young people trust.

**The Forum recommends that the NHS CB, all clinical commissioning groups and LA commissioners of public health services, commission services in a way that ensures that teenagers are managed in age-appropriate services – either in paediatrics, adult services or dedicated young people's services – and that a measure of this is included in the NHS Outcomes Framework. All services for teenagers should be commissioned using the quality criteria outlined in *You're Welcome*.**

### Children and young people's experience of their care

In chapter 2, we set out what children and young people told us matters most to them, and many of the points they raised concerned their experiences of their care.

**The Forum therefore recommends that, by 2013–14, DH and the NHS CB incorporate the views of children and young people into existing national patient surveys in all care settings – primary care, community health care, acute/in-patients, neonatal units and outpatients. This should include the following:**

- provision of information about their care;
- involvement in decisions about their care;

22 Viner RM. Do adolescent inpatient wards make a difference? Findings from a national young patient survey. *Pediatrics* 2007 Oct;120(4):749–55.

23 Department of Health (England). *You're Welcome* quality criteria: Making health services young people friendly. 2007. London, DH.

24 Hargreaves DS, McDonagh JE, Viner RM. Validation of *You're Welcome* quality criteria for adolescent health services using data from 2 national inpatient surveys in England. *J Adol Health*. [Epub ahead of print 8 June 2012.] DOI: 10.1016/j.jadohealth.2012.04.005

- timely access to primary care;
- children's experience of transition into adult services;
- pain management;
- accommodation for families during care where appropriate;
- parent experience of neonatal care; and
- stigma and discrimination experienced by children in healthcare settings.<sup>25</sup>

## Generic and condition-specific indicators

The outcome indicators in this report are predominantly generic and, apart from a few examples, we have not identified specific indicators for the very large number of separately identifiable conditions of pregnancy, childhood or the teenage years. This needs to happen if we are to see the improvements required in health outcomes. Children, young people and their families also need to be able to assess the quality of care and service as measured by outcomes for these conditions. As an example, identifying poor outcomes for children's congenital cardiac conditions has led to wide public knowledge of and engagement in the issues, and a national review which has agreed standards and service reconfiguration in order to provide safe and sustainable cardiac services in the future.<sup>26</sup>

**The Forum recommends that Colleges and specialist societies develop robust and evidence based outcome measures and indicators for the key conditions within their remit, and that these are transparently reported by service provider organisations for the information of children, young people and their families, as well as for commissioners and regulators.**

## Public Health Outcomes Framework

Key NHS staff such as GPs, health visitors and school nurses are critically connected to the delivery of good public health. It is with this in mind that we reviewed the Public Health Outcomes Framework, whilst also recognising this important contribution within the NHS Outcomes Framework. We acknowledge that the Public Health Outcomes Framework already includes a significant proportion of indicators for children and young people, as well as indicators that, with minor modification – such as extending the age range – could be used from infancy to childhood and through the teenage years. In our thinking about the Public Health Outcomes Framework, we have applied the life course approach as a way to reinforce the importance of specific interventions for the different age bands, ie pregnancy and the early years, children and young people.

There were three important areas that we felt were missing from the indicators:

- the mental health of mothers during pregnancy and the first few years after delivery;
- those which measure emotional health and resilience; and
- those which cross the key lifestyle areas such as physical activity, and drink and drug use.

We have demonstrated poor outcomes in these areas, yet there are little or no data available in local areas to drive improvements for these key parts of the life course.

We have sought both to fill these gaps and to strengthen and adapt existing indicators to be more effective for children and young people. We have suggested that all indicators should be broken

<sup>25</sup> See outcomes marked as (2) in the tables that follow for indicators that could be derived from this survey.

<sup>26</sup> [http://www.specialisedservices.nhs.uk/safe\\_sustainable/childrens-congenital-cardiac-services](http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-congenital-cardiac-services).



down by age bands to allow local and national comparison. Additionally, to ensure we monitor health inequalities, we suggest that the indicators, where appropriate, should be able to be analysed by specific risk factors, or by vulnerable groups – such as deprivation, looked after children, children and young people with disabilities or young offenders.

We therefore recommend a number of new indicators under each of the domains. For example, as a new outcome, we recommend development of a measure looking at the proportion of mothers with mental health problems, including postnatal depression. This supports the strong evidence on the importance of early years for good long term outcomes for children, and the impact of maternal mental health. To strengthen an existing indicator, we are proposing that the indicator on the proportion of women smoking at the time of delivery is extended to look at the proportion of women who stop smoking during pregnancy.

**The Forum recommends that DH, with partners, develop a population-based survey of children and young people to look at trends in health and wellbeing.**

Such a survey should provide local level information to inform the JSNA and the Joint Health and Wellbeing Strategy with regard to a number of the proposed indicators, including:

- children and young people having access to age-appropriate health information to support them to lead healthy lives;
- self-reported wellbeing;
- lifestyle areas such as smoking prevalence, alcohol and drug use, physical activity, nutrition and diet;
- percentage of children and young people with mental health problems who experience stigma and discrimination;
- percentage of children and young people who experience bullying; and
- percentage of young people who experience gender based, homophobic and sexual violence.

Effective delivery of public health services requires the commitment of staff and organisations which are outside the direct control of the health system but are core partners to it. The new health and wellbeing boards bring tremendous potential – to connect schools, the environment, housing and safeguarding services for example, all to improve health outcomes.

## Commissioning Outcomes Framework

We recognise the role of the Commissioning Outcomes Framework in allowing the NHS CB to identify the clinical commissioning group's contribution to achieving priorities for health improvement in the NHS Outcomes Framework. The developing Commissioning Outcomes Framework has much scope for additional areas that focus on important outcomes for children, young people and their families – and this is reflected in the number of indicators being proposed for inclusion. For example, we have identified a number of indicators which will help to improve outcomes for those with mental health problems.

**The Forum recommends that, in addition to the recommendations for the existing NHS and Public Health Outcomes Frameworks, the NHS CB uses the Forum's report as a starting point for positioning children and young people within the final Commissioning Outcomes Framework.**

## Information needs to implement and measure outcomes in all the frameworks

We recognise that for a number of our proposals there are not currently sufficiently robust and comprehensive data to implement them immediately. We are very clear this must be addressed as an early priority: there is, for example, a worrying lack of data on children and young people with poor physical and mental health or disability and the impact of this on their education.

**The Forum therefore recommends:**

- **the addition of identifiers into the pupil database and the child health information systems so that they allow subdivision of information by children with long term conditions and long-term mental health problems, disability, special educational needs and looked after children.** This will allow measurement for children in need and comparability with the general population. A similar process should be used for justice data;
- **the addition of a marker in the existing Pupil Level Annual Census to identify previously unidentified/unknown conditions at school entry.** This would enable quality assurance of the key objectives of the Healthy Child Programme from pregnancy to 5 years; and
- **the use of the NHS Number as the unique identifier bringing together health, education, social care and criminal justice records for children and young people.**

Currently, locally available data on school absence does not include information on why the child was absent from school. The Forum recommends that the pupil database be adapted to identify if an absence is associated with the child's illness or disability. This will provide a powerful set of information around the impact of a child's health on their educational experience.

## Mental health

In view of the paucity of data in this area on the scale and nature of poor mental health, **the Forum recommends a new survey to support measurement of outcomes for children with mental health problems.**

In particular, we recommend a survey on a three-yearly basis to look at prevalence of mental health problems in children and young people. This could build on the work of the survey, 'Mental health of children and young people in Great Britain, 2004', published by the NHS Information Centre in 2005.<sup>27</sup>

<sup>27</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_4118332](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4118332)

## Key to tables of outcomes and indicators

Over the accompanying tables, we have set out our recommended outcomes and indicators for each of the three Outcomes Frameworks. A key to the classification of these changes is below.

1	No change to existing Outcomes Framework indicator
2	Extension of existing indicator reflect the life course
3	Adaptation of indicator to make more relevant to children
4	New indicator or area to be included in framework

## Assessment of indicator readiness:

Red	New data source required (or adaptation to existing data source)
Amber	Data available, definition needs development
Green	Indicator readily available
Blue	Indicator in, or being developed for, existing outcomes framework

**Table 1 – Outcomes for children and young people in the NHS Outcomes Framework**

Domain	Indicator/Outcome	Recommended change	Indicator status	Proposed data source
Domain 1 – Preventing people from dying prematurely	<b>Overarching indicator</b>			
	1a Potential Years of Life Lost from causes considered amenable to healthcare	2	Amber	ONS
	<b>Reducing premature mortality from the major causes of death</b>			
	1.4.viii Cancer survival rates for children and young people	2	Green	ONS
	<b>Reducing premature death in babies, children and young people</b>			
	1.6.i Infant mortality	1	Blue	ONS
	1.6.ii Neonatal mortality and stillbirths	1	Blue	ONS
	1.6.iii Mortality in childhood and young people	2	Amber	ONS
	<b>Reducing the time taken to receive a diagnosis</b>			
	Time from presentation at NHS setting to i) definitive diagnosis: ii) initiation of treatment: for set of exemplar conditions	4	Red	<i>New data source</i>
Domain 2 – Enhancing quality of life for people with long-term conditions	<b>Overarching indicator</b>			
	2b Quality of life for children and young people with long-term conditions (including long term mental health problems) and disabilities	2	Red	<i>New data source</i>
	<b>Ensuring people feel supported to manage their condition</b>			
	2.1.ii Children and young people and their families feel supported to manage their condition	2	Red	<i>New data source</i>
	2.1.iii <i>Healthcare for children and young people is integrated (composite) (placeholder)</i>	4	Red	<i>New data source</i>
	<b>Improving functional ability in people with long term conditions</b>			
	2.2.ii Pupil absence in children and young people with long-term conditions and disabilities	3	Red	DfE pupil database
	<b>Reducing time spend in hospital by people with long term conditions</b>			
	2.3.ii Unplanned hospitalisation for children and young people with asthma, diabetes and epilepsy	1	Blue	HES
	<b>Enhancing quality of life for carers</b>			
2.4.i Health related quality of life for carers – extend to measure carers of children separately	2	Red	GPPS	
2.4.ii Family Functioning Index for families where children and young people are carers	3	Red	<i>New data source</i>	
<b>Enhancing quality of life for people with mental illness</b>				
2.5.ii Pupil absence in children and young people with mental health problems	3	Red	DfE pupil database	

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Domain	Indicator/Outcome	Recommended change	Indicator status	Proposed data source
Domain 3 – Helping people to recover from episodes of ill health or following injury	<b>Overarching indicator</b>			
	3a Emergency admissions for acute conditions that should not usually require hospital admission	2	Amber	HES
	3b Emergency readmissions within 48 hours of discharge from hospital for children and young people	3	Amber	HES
	<b>Improving outcomes from planned procedures and treatment</b>			
	3.1v PROM to measure outcomes from planned procedures for children and young people	3	Red	New data source
	3.1vi PROMs for children and young people with mental health problems	3	Amber	CAMHS dataset
	<b>Preventing lower respiratory tract infections in children and young people from becoming serious</b>			
	3.2 Emergency admissions for children and young people with LRTI	1		HES
	<b>Improving recovery from injuries and trauma</b>			
	3.3 Measure of functional recovery 1 year after injury for children and young people with severe traumatic brain injury	3	Red	TARNLET
Domain 4 – Ensuring that people have a positive experience of care	<b>Improving women and their families' experience of maternity services</b>			
	4.5 Women's experience of maternity services	1		CQC
	<b>Improving the experience of care for people at the end of their lives</b>			
	4.6.ii Improving the experience of care for children and young people at the end of their lives	2	Red	New data source
	<b>Children and young people's experience of physical and mental healthcare</b>			
	4.8 Children and young people's experience of healthcare in all settings	1	Red	Experience survey of C&YP (2)
Domain 5 – Treating and caring for people in a safe environment and protecting them from avoidable harm	<b>Children and young people's experience of transition to adult services</b>			
	4.9 Children and young people continue to receive the care they need following transfer from paediatric services (placeholder)	4	Amber	HES
	<b>Reducing the incidence of avoidable harm</b>			
	5.2 Incidence of hospital acquired infection i.MRSA ii.C.Difficile iii. Late onset BSIs in children	2	Amber	HPA
	5.4ii Incidence of medication errors for children and young people that reach the patient	3	Amber	HPA
	<b>Improving the safety of maternity services</b>			
	5.5 Admission of full-term babies to neonatal care	1		Neonatal audit
<b>Delivering safe care to children and young people in acute settings</b>				
5.6 Incidence of harm to children and young people due to 'failure to monitor'	1		NRLS	
5.7 Rates of admission to age inappropriate environments for children and young people	4	Red	New data source	

**Table 2 – Outcomes for children and young people in the Public Health Outcomes Framework**

Domain	Indicator/Outcome	Change	Indicator status	Proposed data source
<b>Domain 1 – Improving the wider determinants of health</b>	Children and young people in poverty	1		DWP
	Number of children and young people living in decent housing	4	Red	DCLG
	Statutory homelessness	2	Amber	DCLG
	School readiness	1		DfE
	Pupil absence – for all children and young people those with LTCs, disabilities, LAC, and mental health problems	3	Red	DfE
	Educational attainment and progress for all children, children and young people with LTCs – including long term mental health problems – and disabilities, mental health issues, disaggregated by social deprivation	4	Red	DfE
	First time entrants to the youth justice system	1		MoJ
	16–18 year olds not in education, employment or training	1		CCIS
	Killed or seriously injured casualties on England's roads	1		DfT
	Domestic abuse	2	Amber	Home Office
	Violent crime and sexual violence	1		Home Office
	Utilisation of green space for exercise/health reasons	2		MENE survey
	Proportion of children who experience bullying	4	Red	New survey of C&YP (1)
	Proportion of children and young people with mental health problems who experience stigma and discrimination	4	Red	New survey of C&YP (1)
Social connectedness	2		tbc	
<b>Domain 2 – Health improvement</b>	Low birth weight of term babies	1		ONS
	Breastfeeding	1		DH
	Prevalence of exclusive breastfeeding at 4 months	2	Red	New data source
	Smoking status at time of delivery – Percentage of women stopping smoking during pregnancy	3	Amber	Maternity dataset
	Percentage of women abusing alcohol or non-prescription drugs at the time of booking with maternity services	3	Amber	Maternity dataset
	Under 18 conceptions	1		ONS
	Number of births to under 18s	3	Green	ONS
	Child development at 2–2.5 years	1		tbc
	Healthy weight in 4–5 and 10–11 year olds	1		NCMP
	Healthy weight in young people	2	Red	New survey of C&YP (1)
	Hospital admissions and A&E attendances for accidental and unintended injuries; and non-accidental injuries, neglect and maltreatment in children and young people	3	Amber	HES
	Self-reported well-being (all children and young people, LAC, and those with LTCs and disabilities) <sup>28</sup>	3	Red	New survey of C&YP (1)
	Smoking prevalence – 15 year olds	1		IC
	Hospital admissions as a result of self-harm	1		HES
	Diet – Percentage of children and young people who eat at least 5 portions of fruit and vegetables a day; mean number of portions of fruit and veg eaten per day	2	Red	New survey of C&YP (1)
	Physical activity – Physical activity in 5–9, 10–14 and 15–19 year olds	2	Red	New survey of C&YP (1)
	Alcohol related A&E attendances and hospital admissions	2	Amber	HES
	Access to non-cancer screening programmes	1		Maternity dataset
	Percentage of women presenting as a healthy weight at the time of booking with maternity services i) in their first pregnancy; ii) in their second or subsequent pregnancy	2	Amber	Maternity dataset
	Prevalence of drinking and substance misuse in children and young people	3	Amber	IC
Proportion of children and young people who play games on a computer 2+ hours on weekdays	4	Green	HBSC	
Proportion of mothers with mental health problems, including postnatal depression	4	Red	New data source	
Proportion of parents where parent child interaction promotes secure attachment in children age 0–2	4	Red	New data source	
Proportion of parents with appropriate levels of self-efficacy	4	Red	New data source	
Children, young people and families have access to age-appropriate health information to support them to lead healthy lives	4	Red	New survey of C&YP (1)	
<b>Domain 3 – Health protection</b>	Number of young people aged 15–19 presenting with HIV at a late stage of infection	1		HPA
	Chlamydia diagnoses (15–24 year olds)	1		HPA
	Treatment completion for TB	1		HPA
	Population vaccination coverage – Vaccination coverage of preventable notifiable diseases	1		HPA
<b>Domain 4 – Healthcare, public health and preventing premature mortality</b>	Infant mortality	1		ONS
	Mortality in childhood and young people ( <i>link to NHS Outcomes Framework Domain 1</i> )	2	Green	ONS
	Tooth decay in children and young people aged 5	1		NW PHO
	Suicide	2	Green	ONS
Emergency admissions within 30 days of discharge from hospital ( <i>and within 48 hours to link with NHS OF</i> )	3	Amber	HES	

28 Emotional well-being of Looked After Children is currently included in the Public Health Outcomes Framework. We recommend extending this to other groups. ONS are currently developing a measure of well-being for children.

**Table 3 – Outcomes for children and young people in the Commissioning Outcomes Framework**

Domain	Indicator/Outcome	Change	Indicator status	Proposed data source
Domain 1 – Preventing people from dying prematurely	<b>Generic</b>			
	Childhood mortality for specific conditions (meningococcal, septicaemia; asthma; LRTIs, diabetes and epilepsy)	4	Amber	ONS, Child Health Reviews
	<b>Maternity</b>			
	1.25 Antenatal assessments < 13 weeks	1	Blue	DH
	Percentage of women presenting as a healthy weight at the time of booking with maternity services i) in their first pregnancy; ii) in their second or subsequent pregnancy	4	Amber	Maternity dataset
	1.26 Maternal smoking in pregnancy	1	Blue	DH
	1.27 Maternal smoking in delivery	1	Blue	DH
	1.28 Breastfeeding initiation	1	Blue	DH
	1.29 Breastfeeding prevalence at 6–8 weeks	1	Blue	DH
	Prevalence of exclusive breastfeeding at 4 months	4	Red	New data source
Percentage of babies on exclusive breastmilk at discharge from neonatal units	4	Green	Neonatal audit	
Domain 2 – Enhancing quality of life for people with long-term conditions	<b>Generic</b>			
	Each child or young person with an LTC, disability, special educational needs, looked after or a care leaver, has a coordinated package of care, including a quality assessment, access to key working approach and appropriate equipment	4	Red	New data source
	Any CYP in transition from paediatric to adult care should have a defined and agreed plan for handover of care with access to a key worker.	4	Red	New data source
	A&E attendance rates and unplanned rates of hospitalisation for constipation and urinary tract infections	4	Amber	HES
	Numbers of children and young people with multi-disciplinary care plans	4	Red	New data source
	Pupil absence for children with LTCs, disabilities and long term mental health problems	4	Red	DfE
	Number of children and young people with a disability	4	Red	New data source
	<b>Diabetes</b>			
	Proof of HbA1C audit with % of HbA1c above the agreed standards	4	Green	Diabetes audit
	Percentage of patients diagnosed with diabetes, who are later admitted due to Diabetic Ketoacidosis (DKA).	4	Green	Diabetes audit
	Pupil absence for children with diabetes	4	Red	DfE and health data
	% of patients with diabetes being discussed at a local MDT in the past year.	4	Amber	Diabetes audit
	% of patients with Type 1 diabetes screened for secondary conditions on a timescale in accordance with NICE guidelines.	4	Amber	Diabetes audit
	<b>Mental health</b>			
	Progress against child or young person and family's goals – as for example in the IAPT protocol	4	Amber	CAMHS dataset
	Repeat hospital admissions for children and young people with mental health problems	4	Amber	HES
	Patient reported outcome measures, and clinician reported outcome measures for children and young people in CAMHS – as for example in the IAPT protocol	4	Amber	CAMHS dataset
Domain 3 – Helping people to recover from episodes of ill health or following injury	<b>Generic</b>			
	Percentage of admitted children and young people with a length of stay of less than 24 hours	4	Green	HES
	Average length of stay in hospital for children and young people	4	Green	HES
	Day case rates (for certain procedures – to be determined)	4	Amber	HES
	<b>Maternity</b>			
	Disability-free survival at 2 years of age for babies born at <30 weeks of gestation	4	Amber	Neonatal audit, NDAU
	<b>Trauma</b>			
	Time from decision made to transfer a child from Trauma unit to major treatment centre	4	Amber	TARNlet
	Incidence of moderate/major trauma as measured by index severity score >=9	4	Amber	TARNlet
	Time from arrival in Emergency Department to receive CT scan for infants, children and young people with serious head injury	4	Amber	TARNlet
	<b>Mental health</b>			
	Women with postnatal depression who receive successful treatment	4	Red	New data source
	Time to appropriate treatment for children and young people using mental health services	4	Red	New data source
<b>Urgent and emergency care</b>				
Emergency department attendances for children and young people defined per age	4	Amber	HES	
Domain 4 – Ensuring that people have a positive experience of care	<b>Generic</b>			
	% of children and young people who report that their pain was managed	4	Red	Experience survey (2)
	<b>End of life care</b>			
	Numbers of children and young people with end of life plans who die in the place of their choice	4	Red	New data source
	<b>Mental health</b>			
Rates of admission to age inappropriate environments for children and young people with mental health problems	4	Green	DH	
Children, young people and families experience of CAMHS	3	Amber	CAMHS dataset	

Domain	Indicator/Outcome	Change	Indicator status	Proposed data source
<b>Domain 5 – Treating and caring for people in a safe environment and protecting them from avoidable harm</b>	Rate of catheter-associated and catheter-related bloodstream infections (CABSIs and CREBSIs)	4	Red	<i>New data source, NDAU</i>
	Number of unexpected cardiac arrests for children and young people in hospital	4	Red	<i>New data source</i>
	Paediatric Early Warning System in place and being acted on for children and young people	4	Red	<i>New data source</i>
	Number of SUIs reported (physical and mental health)	4	Amber	NRLS
	Emergency admissions of home births and re-admissions to hospital of babies within 14 days of being born, per 1000 live births	4	Green	HES
	<b>Mental health</b>			
	Rate of partially and fully upheld complaints for CAMHS patients	4	Red	<i>New data source</i>

For the full Forum report on this section see:

- The patient pathway.
- Reports for the Public Health, Long Term Conditions, Disability and Palliative Care, Mental Health and Acute Illness groups.

## 4. Acting early and intervening at the right time

How do I stay healthy?

How do I get the most out of my life?

### Why it matters

*'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 achievement and economic status'<sup>29</sup>*

*Fair Society, Healthy Lives* (2010) – the Marmot review of health inequalities in England, p. 94

### A life course approach

Disadvantage starts before birth and accumulates through life, as shown in the figure below. A life course approach, which helps focus on the key transitions which so often fail children and young people, will help break the link between early disadvantage and poor outcomes.<sup>30</sup> Action to reduce such inequalities must start before birth and continue through the life of the child.

**The Forum recommends that all organisations in the new health system take a life course approach, coherently addressing the different stages in life and the key transitions instead of tackling individual risk factors in isolation.**

The focus on pregnancy, children and young people is so critical because the consequences of poor health affect individuals throughout their lives – their ability to enjoy life, contribute to society, be healthy, form relationships and work. Children and young people do not live their lives in silos, they are not one day a smoking risk and the next day an alcohol one. The system needs to look at the individual in the round and the life course approach helps frame this.

Our priority, therefore, through this report is to increase the life chances of all children and young people, ensuring a healthier life through childhood, adulthood and old age. We want to see their safety improved, their well-being supported and most importantly their own views and opinions informing health services, as well as their own knowledge about managing their health enhanced, so that they can take responsibility for their health. Children and young people are crucial to the future wellbeing and prosperity of our nation. Improvements in their health and healthcare will result in

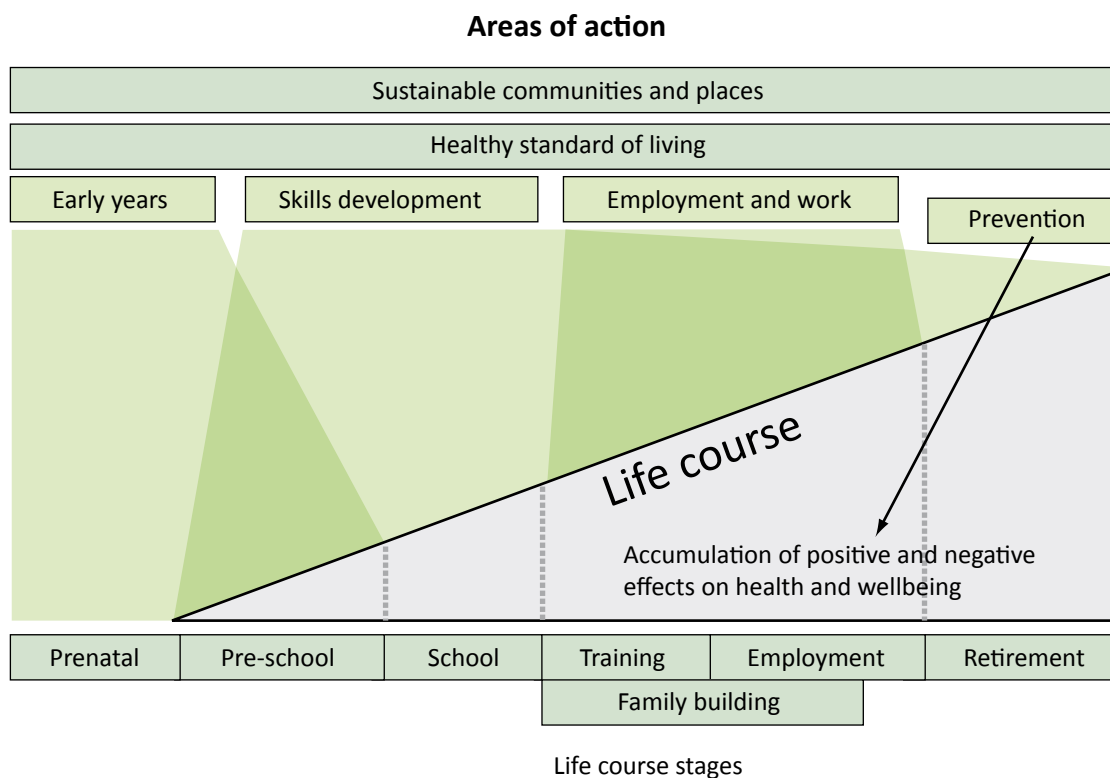
<sup>29</sup> *Fair Society, Healthy Lives* (2010) – the Marmot review of health inequalities in England, p. 94.

<sup>30</sup> Elder, GH., Jr; Johnson, MK.; Crosnoe, R. The emergence and development of life course theory. In: Mortimer, J.; Shanahan, M., editors. *Handbook of the Life Course*. New York: Plenum; 2003. p. 3–22.



healthier and more productive adults, with the reduced burden that will accrue to health and non-health agencies over decades.<sup>31</sup>

### Action across the life course



### Acting early to improve life chances

There is good evidence about the importance of good maternal and paternal health on the physical and emotional outcomes for children. Parental health lays the foundation for healthy foetal development,<sup>32</sup> a child's physical and emotional health development and in shaping the life course from childhood to adult life.<sup>33</sup> Public health and pre-pregnancy health and care<sup>34</sup> ensure the conditions and behaviours that pose a risk to healthy development are identified and managed. It is also an opportunity for the early detection and management of parents' lifestyle risks such as smoking, obesity and alcohol – these can all have long term effects on a child.

Social and biological influences on development start at conception and continue throughout pregnancy, influencing health at birth. From birth, exposure to social, economic, psychological and environmental experiences affect a child's health and wellbeing. Babies born too early or too small are more likely to have distress in labour, require intervention and consequently, place a significant demand on NHS resources. Preventing or reducing risks will improve live birth rates, reduce morbidity and offer value for money, for example by reducing the need for intervention and hospitalisation.

31 Marmot M. Social determinants of health inequalities. *Lancet* 2005 Mar 19;365(9464):1099–104.

32 Frey, K.A., Navarro, S.M., Kotelchuck, M., Lu, M.C. (2008) The clinical content of preconception care: preconception care for men. Supplement to December 2008. S389 – S395: *American Journal of Obstetrics and Gynaecology*.

33 Department of Health (2009) *Healthy Lives, Brighter Futures: the strategy for children and young people's health*.

34 Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services*.

Poverty can affect foetal development, which leads to the likelihood of poor health in later life.<sup>35,36</sup> There are well-established factors in maternal health such as obesity, diabetes and previous miscarriage, as well as other conditions such as epilepsy, undiagnosed infections and mental health problems that are key risk factors for babies. Smoking, drug and alcohol consumption can also adversely affect the baby. Some interventions to promote pre-pregnancy health and care may be more readily taken up by some groups than others, such as those who are better educated, have higher socio-economic status, or are in a stable relationship. Effective services are those that tailor their care to meet individual mothers' needs.

So the key challenges for the new public health services, early in the life course, are to prevent infant mortality, improve maternal health and maximise early child development. Poor maternal mental health during pregnancy is associated with low birth weight and increased rates of mental ill health in children. A focus on reducing the number of babies born with a low birth weight will reduce immediate and life-long risks to a child's health and development. Babies born with a low birth weight are associated with higher infant mortality, delayed physical and intellectual development in early childhood and the teenage years and, in the longer term, higher association with premature death from coronary artery disease. The data demonstrate that babies born to parents from manual work backgrounds are more likely to have low birth weight, as are those from single parents. Asian women are also found to have higher rates of low birth weight babies, as are women who smoke in pregnancy.

The need for a stronger focus on maternal health in pregnancy has never been clearer. **The Forum therefore recommends that Directors of Public Health and clinical commissioning groups work together with maternity and child health services to identify and meet the needs of their local population.**

Warm, positive parenting can help to provide the foundations for the future and there is evidence that good parenting can go some way to mediate the effects of poverty and deprivation. We also believe that there is sufficient evidence of the links between maternal mental health before and after birth and its effects on attachment that **the Forum recommends that, in 2013, DH explores the development of a new outcome measure on perinatal mental health, and implements it as soon as possible.**

We welcome the increased numbers of midwifery students and the expansion of the health visitor workforce to lead and deliver the Healthy Child Programme (pregnancy to 5), and the expansion of the Family Nurse Partnership for vulnerable teenage families. We expect that this investment will show improvements in outcomes for babies and young children over time, which will be measured by a new indicator of child development at age two and a half.

## Inequalities – using the new duty to achieve results

We welcome the new health inequalities duty in relation to access and outcomes, created through the Health and Social Care Act 2012. The Secretary of State for Health now has a clear duty to 'have regard to the need to reduce inequalities between the people of England with respect to the benefits

35 Graham, H., Power, C. (2004) Childhood disadvantage and adult health: a life course framework, Health Development Agency.

36 Low birth weight and prematurity remains an important cause of infant mortality in the UK and is influenced by the mother's socio-economic background.

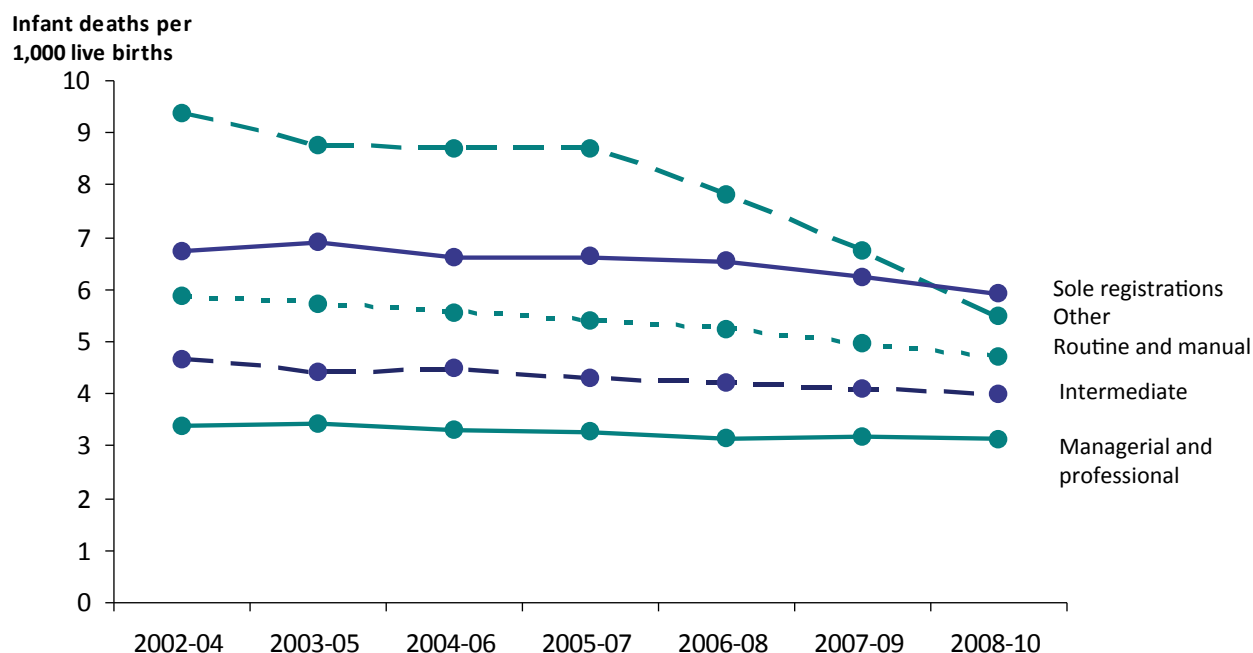
that they can obtain from the health service'. This duty will also fall on clinical commissioning groups and come into effect from April 2013. This duty, alongside other equalities duties, will need to change the way health services are planned and delivered to ensure they reach those who need them most.

Breaking the link between disadvantage and poor physical and mental health is crucial to narrowing the health gap and maximising opportunities for children and young people and the generations that follow. Data show that the gap in life expectancy continues to widen between the most and least disadvantaged areas. In England, the life expectancy for males and females in the most deprived areas is over 10 years less than in the most affluent.

Tackling this gap requires action across the social determinants that shape health and well-being, in both national and local government. It means acting in concert on key issues such as income and poverty, education, employment and environment as well as taking account of the contribution of the NHS, public health and health improvement measures.

Evidence is the key lever for action on inequalities in the health system. Modelling the impact of interventions on the infant mortality health inequalities gap shows how a social determinants approach can work – with action needed on child poverty, housing and overcrowding and teenage pregnancy as well as on smoking, nutrition and sudden and unexpected deaths in infancy.

**Infant mortality by National Statistics Socio-Economic Classification (NS-SEC)  
(insite marriage/joint registration) and for sole registration  
Three year average infant mortality rates in England and Wales, 2002–04 to 2008–10**



### Looked after children and young people and inequalities in outcomes

Children and young people who are looked after are one of a number of groups who routinely experience particularly poor health outcomes. Others are those in secure accommodation, those with disabilities or seeking asylum.

In the time available to us we could not do justice to the needs of all vulnerable groups and our focus has therefore been on those who are looked after, but it is important that all needs are addressed. Therefore **the Forum recommends that Directors of Public Health, through their health and wellbeing board, ensure that they include comprehensive data for all children and young people within their JSNA – including those requiring tailored provision, such as those who are looked after, those with disabilities and long term conditions and those in contact with the criminal justice system.**

There were 65,520 looked after children at 31 March 2011 (an increase of 2% from 2010 and of 9% since 2007).

Looked after children often enter the care system with a worse level of health than their peers, in part due to the impact of poverty, poor parenting, chaotic lifestyles and abuse or neglect. Longer-term outcomes remain worse than their peers':

- 45% of looked after children (and 72% in residential care) have a mental health disorder;
- two thirds of looked after children have at least one physical health complaint;
- almost half of young women leaving care become pregnant within 18 to 24 months;
- 32% of young people leaving care report problems with drugs or alcohol a year later; and
- looked after children and care leavers are between four and five times more likely to attempt suicide in adulthood.

Last year, 9,950 young people left care in England aged 16 or older. The number leaving care has been increasing year on year, with a 22% increase over the past 5 years. Evidence has shown that 'leaving care' services are able to provide the best services where they have good working relationships with external health, accommodation and education, training and employment agencies and there is specialist provision providing careers advice, negotiating suitable accommodation and addressing health and wellbeing needs.

The new public health role within local authorities provides real opportunities for Directors of Children's Services, working in partnership with the Directors of Public Health, clinical commissioning groups (CCGs), adult social services as well as the lead member for children, to make sure the health of the looked after and care leaver populations are part of the overall approach to meeting local health needs.

The Forum has made a number of recommendations in this area because the health outcomes for this group of children and young people are so poor, and because this can be remedied. **The Forum recommends that:**

- **CCGs with their local authority partners need to ensure sufficient clinical expertise and leadership for looked after children, including a designated doctor and nurse;**
- **Directors of Children's Services should be responsible for overseeing the overall quality and delivery of health and wellbeing for looked after children, which will lead to a measured reduction in their health inequalities;**
- **the NHS CB only accepts GPs on the local performers list who can demonstrate the level 3 competences set out in the Intercollegiate Framework document, *Looked after children: knowledge, skills and competencies of healthcare staff (2012);***

- **social care staff and others dealing with looked after children should have responsibility for ensuring they are registered with a GP and that the GP is kept informed of the details of their care;**
- **the NHS CB should ensure the current work with stakeholders, including the Royal Colleges, led by SHAs, to develop a tariff for the statutory health assessments for looked after children is implemented by CCGs and that implementation of the Responsible Commissioner guidance promotes the health and wellbeing of looked after children placed out of their local area; and**
- **CCGs and local authorities should specifically recognise care leavers in early adulthood (18–25), as well as looked after children, in their commissioning, including a requirement that children in care health teams include a focus on this group.**

There are a number of initiatives already in existence, which if applied consistently and effectively have the potential to make real inroads in supporting all vulnerable children and young people, and so address inequalities. These include:

- well planned, evaluated PSHE, Healthy Schools and Healthy FE;
- the School Nursing Development Programme;
- parenting programmes;
- the Troubled Families initiative;
- Family Nurse Partnerships; and
- children's centres.

The Forum's full report on these areas and supporting materials includes:

- The Children's Commissioner's Report for the Forum on Inequalities in Health Outcomes and how they might be addressed.
- Fair Society, Healthy Lives ('The Marmot Review') (2011) <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>.

## 5. Integration and partnership

'I only want to have to tell my story once'

'I don't want to start again when I go to different places'

'Will I have to repeat myself? Will I get lost between services?'

Integration means that the joins both between services and between commissioning responsibilities are invisible because organisations are working in partnership to deliver the best outcomes for children and young people. It means that children, young people and parents don't have to keep repeating their information, that records are not lost or duplicated, that individuals and their needs do not fall between gaps, and that resources are focused on the same goals.

Two complementary definitions of integration:

*'What is integration? For me, it means not having to repeat myself 30 times to every different person or part of the system.'*

Jacqui Double, parent member of Child Health Forum

*'The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system.'*

World Health Organization 2008 (Technical Brief 1)

Integration of care around the needs of children, young people and their families is absolutely fundamental to improving their health outcomes. It also reduces duplication and waste and saves significant sums of public money that can be spent on service improvement.

It is particularly important for children and young people with disabilities or at risk of developing disabilities, with long term conditions, with complex needs or with mental health disorders. For example, the most effective commissioning for disabled children integrates specialist healthcare, community services like NHS therapists and local authority educational support services, special schools and children's social care services. So we welcome the new duties on the health system that were established in the Health and Social Care Act 2012. In addition to these duties we strongly welcome the government's commitment to strengthening integration in legislation through a new joint commissioning duty on the NHS and local authorities. Without this new duty we believe the current fragmented services remain.

*Support and Aspiration: A New approach to special education needs and disability. Progress and Next Steps* and the forthcoming Children and Families Bill.

<http://media.education.gov.uk/assets/files/pdf/s/support%20and%20aspiration%20a%20new%20approach%20to%20special%20educational%20needs%20and%20disability%20%20%20progress%20and%20next%20steps.pdf>

That said, effective integration depends on much more than legislation. Local cultures and behaviours grounded in partnership working and focused on common goals are key – and strong, collaborative leadership is needed to drive high-quality integrated care. We say more about this in chapter 9.

We believe that the starting point for integration must be how the service is experienced by the child, young person or family – not based around the system, professionals or institutions or the location of services. The way we measure and assess integration should reflect this. Any definition and measurement of integration should include needs across the whole life course.

There are three additional features we identified as essential to integration:

- focusing on whole care pathways;
- sharing information between services; and
- building local partnerships.

Service design and commissioning should be based on care pathways, where all the component parts are identified, in place and working well together. The parts chosen are based on best evidence and delivered by competent teams, which may be hosted by different organisations, working collaboratively together to improve effectiveness, efficiency and equity. Local provider networks centred on local partnerships also play a very important role in delivering properly integrated, safe and sustainable local services and can help in taking a pathway approach.

To be integrated, different providers need the same knowledge, often concurrently, about the factors that matter to the child or young person and family. The present situation, as they experience it, is frequently poor. There is a wide lack of understanding of the rules about information sharing and children and families often get poor service as a result. This must change in order to improve outcomes. The NHS Number is ideally placed to be used as a unique identifier, providing the cornerstone of interagency care records. This is why we have recommended that it be used across all settings (chapter 3). It will bring together information on health interventions and their impact on different stages in a child's life. It will also enable schools and commissioners to understand the impact of long term medical conditions, disability or disadvantage (including children being looked after) and educational attainment. **Work should start on this immediately, led by DH, NHS CB and DfE.**

The full range of health and care services, from prevention and primary care to specialised treatment and support, is essential to improving outcomes for children and young people; and services that support health and care for children and young people do not just take place in health settings. Schools and settings such as children's centres and youth settings are also important contributors, as is care provided for children in their homes. Good schools and colleges with the right culture and ethos are vital in supporting children and young people's well-being. They embed the skills, behaviour and support systems to remove barriers to learning and build confidence and self-esteem.

The Forum therefore **recommends that the National Curriculum Review currently taking place includes the promotion of health and well-being within the 'statutory aims' of the revised national curriculum.** This will ensure that all school children, not just some, have access to the right support. The role of schools in supporting good physical and mental outcomes in children and young people

is so important that we have included a factsheet for School Governors to support them fulfill their responsibilities.

Partnership through the local health and wellbeing boards, which include CCGs, provider organisations, the local authority and the NHS CB, is at the heart of the new system. We fully recognise and endorse the enormous opportunity health and wellbeing boards present to improve outcomes for children and young people by joining up the way services are commissioned for them.

Health and wellbeing boards will bring together those who commission services across the NHS, public health, social care and children's services, elected representatives and representatives from local Healthwatch to strategically plan the right services for their area. They will look at all health and care needs together in Joint Strategic Needs Assessments (JSNAs), ensuring that each member of the health and wellbeing board can draw on their strengths, whether that is clinical expertise, local knowledge, or understanding of and expertise in the needs of the local community including children and young people. They will then agree joint priorities in Joint Health and Wellbeing Strategies, which will shape commissioning strategies to meet the identified local needs.

This may mean use of formal joint commissioning and pooled budgets, particularly for children with complex needs across services. We believe that transparency over budgets and resources is essential so that local people can understand – and influence – how they are spent.

We are mindful that as the new system takes shape there is a potential risk to continuity of services as commissioning for early years is transferred from the NHS CB to local authorities. We expect that the NHS CB will recognise this risk and plan early for a smooth transfer.

The Forum has considered the key success factors and challenges for health and wellbeing boards in their role for children and young people and these are set out in the factsheet referenced at the end of this chapter. Three of the most important points are:

- a local partnership based round the needs of the whole local community, explicitly including children and young people, to be reflected in the governance of health and wellbeing boards;
- the commissioning of NHS services for children and young people must sit alongside the commissioning of all services for children; and
- the value of focusing on early intervention within an overall understanding of a life course approach.

To support integration and partnership working, **the Forum recommends that:**

- **the NHS CB and Monitor prioritise and promote integrated care provision in their regulatory and performance roles within the NHS, and that they work with CQC and Ofsted in developing a framework across providers in other sectors providing services for children and young people;**
- **DH works with other government departments and partners – such as the Local Government Association (LGA), the Society of Local Authority Chief Executives (SOLACE) and the Association of Directors of Children's Services (ADCS) – to support better integration of health with education, social care and other local authority led services;**
- **DH should work with partners to select some sentinel conditions and pathways which reflect needs along the life course in order to assess significant risk of gaps in services, including prevention, and identify action to improve integration of care as experienced by the child, young person and family;**



- **DH should support health and wellbeing boards by encouraging them to use a broad range of quantitative and qualitative evidence, in a range of formats, including reflecting the contribution and insights of a wide range of local service providers, and local communities themselves.** It should include comprehensive data not only on the number of children and young people in their areas but also groups within that population such as looked after children, those with long term conditions and those with disabilities;
- **the LGA, ADCS and SOLACE promote the health and wellbeing board factsheet locally as health and wellbeing boards develop;**
- **the NHS CB consider how to harness the enormous potential for electronic care records to provide an accessible comprehensive record to inform professionals – and alleviate frustration of young people and their families; and**
- **DH provide, as a matter of urgency, clarification on information sharing between professionals and across systems.**

The Forum's full report on integration and partnership includes:

- The health and wellbeing board factsheet for children, young people and families
- The Forum's Making Data and Information Work for Children and Young People factsheet
- The Forum's factsheet for School Governors

## 6. Safe and sustainable services

'How do I know I am getting the very best treatment in the world?'

'How do I know my treatment and care is safe?'

We share the ambition to provide world class services and outcomes, delivered using the best available evidence.

This applies both to preventative and care services.

There is a clear focus on moving the emphasis of care closer to home, from hospitals into primary care, the community, schools and home, and in integrating services around children and their families. Nevertheless, at the same time children and young people with relatively unusual complex conditions such as congenital heart disease, or epilepsy requiring surgery, have a requirement for improved outcomes, and need access to rare expertise and skilled specialist teams. Children with more common conditions also require the appropriate expertise in the right place to improve outcomes whilst maximising their quality of life.

Meeting all these needs is going to be very challenging.

In this section, we identify the components of safe and quality driven services. New service models are appearing using new technologies which have the potential to reach many more children, young people and their families. We also address specific aspects of safety and quality.

There is the need to address the whole pathway for children and young people's physical and mental health within healthcare, from birth or initial presentation, through diagnostic assessment to interventions including self-care and discharge or follow up:

- healthcare should be accessible and delivered to the same standard on a 24 hour seven day a week basis – this means improvements are required in what has traditionally been labelled 'out of hours' services;
- at the first point of care, delivered by GPs, emergency departments, ambulance services, telephone help lines such as 111 or pharmacists, all staff need to be able to demonstrate that they have had the training needed to be competent to work effectively with children, young people and their families and are able to deliver 'safety net' advice;
- providers need to explore ways of improving children and young people's care using new technologies;
- children, young people and families need sufficient information to help them make choices and decisions about their treatment, care and lives;
- the Forum welcomes increased number of midwifery students, the expansion of the health visiting service and the Family Nurse Partnership programme<sup>37</sup> – these practitioners and others, including midwives and allied health professionals, in particular should be available to support parents in effective parenting approaches and to deliver the improved health outcomes which are needed;

<sup>37</sup> Department of Health Family Nurse Partnership Programme. For more information, see [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_118530](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_118530)

- nursing services – particularly school nursing – should promote good health by supporting school age children and young people in all educational settings;
- diagnostic and therapeutic services, whilst often omitted from consideration, are an essential part of children and young people's care;
- care for children with acute, complex or palliative care needs should be delivered as close to home as possible, whilst accepting that for many children and young people, centralised care for some of the more highly technical interventions will deliver improved outcomes and experience – this includes the need for highly skilled teams in hospitals, linked with comprehensive 24 hour, 7 days a week community children's nursing teams; and
- highly specialised services should be delivered in the right place by skilled teams meeting defined quality standards and, where safe and appropriate to do so, near the child's home.

There have been a number of reports over recent years, from professional bodies and DH, highlighting the issues that need to be faced in meeting these challenges.<sup>38,39</sup> Many of the solutions proposed are rooted in service reconfiguration. These include:

- the move to provide more acute care and care for long term conditions in the community;
- the need for several local provider services to network and provide both 8-until-late and 24 hour access to acute assessment at different sites;
- robust local networked solutions for children requiring new born, general and specialist surgery;
- comprehensive mental health services; and
- safe, sustainable and co-dependent highly specialised services.

**The Forum recommends that the NHS CB ensure there is a nationally designated, strategic managed network for children and young people. This should include maternity and neo-natal care. The network should incorporate:**

- all children and young people's services within the Specialised Services Definition Set; and
- all parts of relevant pathways, from specialist centres through district general hospitals to community service provision and primary care. The NHS CB must ensure explicit links between the specialist elements of the pathway, commissioned by them and those areas of the pathway commissioned by CCGs.

**CCGs need to develop local networks and partnerships with providers to address and deliver the sustainable provision of local acute, surgical, mental health and community children's services and to ensure both care closer to home and no gaps in provision.**

Some CCGs will have to work together to achieve this. NHSCB should include this in their assessment of each CCG.

**The Forum recommends that the NHS CB, with CCGs, address service configuration to meet the needs of children and young people on a sustainable, safe and high quality basis.**

We recognise that this will mean that services will have to change: some will be re-designated and others will close.

38 Royal College of Paediatrics and Child Health. Facing the Future: Standards for Paediatric Services. 2011. London.

39 Department of Health. Commissioning safe and sustainable specialised paediatric services: a framework of critical interdependencies. 2008. London.

## Improving patient safety – medicines

The scale of medicines use in the NHS for adults and children is enormous, and with this the room for error. Staff are encouraged to report safety incidents to the National Reporting and Learning System (NRLS),<sup>40</sup> but reporting is voluntary and the consensus view is that only a minority come to light through this route.

In 2008, there were 33,000 safety incidents reported in children. Of these, 19% – or 6,300 – were for a medication problem. In addition, there were 19,000 safety incidents reported in neonatal patients, where 18% of reports – or 2,340 – were for a medication problem. These problems are serious and sadly sometimes result in avoidable mortality. There are a number of very simple measures which could save lives and these are in the full report.

To help understand fully and therefore tackle the serious problem of medication errors in children, **the Forum recommends that:**

- **DH adapts the indicator in Domain 5 of the NHS Outcomes Framework to measure all drug errors that reach patients;**
- **the Medicines and Healthcare products Regulatory Agency (MHRA), with immediate effect, prioritises pharmacovigilance of children's medicines, including medication errors and off-label use, in line with the new EU legislation effective in July 2012;**
- **from April 2013, the reporting of these errors to the NRLS becomes mandatory as part of the reporting for the NHS Outcomes Framework and that this becomes part of the regulatory framework for CQC and Monitor; and**
- **with immediate effect, the Royal Pharmaceutical Society works with the Colleges and the NHS Institute for Innovation and Improvement to develop a bundle of interventions in order to eliminate or reduce drug errors.** This would be of benefit not just to children but to patients of all ages, including those over 75 years old who also suffer significant incidence of drug errors.

There are particular issues relating to the issue of the licensing of medicines which also cause avoidable drug errors. The MHRA was instrumental in ensuring EU legislation came into force in 2007, which led to a requirement on the industry to consider testing all new medicines in children as well as adults before they are brought into the market. However, new medicines account for a relatively small percentage of those used by children, and those introduced before this legislation largely remain unregulated and, critically, therefore possibly untested formally in children. This contributes to the high number of drug errors and leads to wider implications – including the fact that the National Institute for Health and Clinical Excellence (NICE) will not give advice on unlicensed medicines and this limits the guidance that they can offer on care for children.

The Forum believes there is an important role for the MHRA as the medicines regulator in addressing this problem and so improving child safety.

The Forum believes that the situation with regard to the absence of licensing for the majority of children and young people's medicines in this country is unacceptable.

<sup>40</sup> <http://www.nrls.npsa.nhs.uk/>

**The Forum therefore recommends that DH:**

- commissions a study in 2013 to quantify the harm to children and the costs that arise due to errors from unlicensed and off-label prescribing and through lack of age-appropriate formulations; and
- using the findings, works with the industry and academia to develop properly the use of all medicines, whether old or new, starting with those medicines producing the most harm.
- There would be value in other organisations with this intelligence (for example the NHS Litigation Authority and medical defence organisations) releasing information on cases where medication errors have caused serious harm.

The Forum's full report on these areas and supporting information includes:

- Patient care pathway.
- Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies DH 2008 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_088068](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_088068).
- Improving services for children in hospital. Healthcare Commission 2007.

## 7. Workforce, education and training

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

'My doctor is trained to work with children but only really youngsters. I am a teenager, what good is he to me?'

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. Although the children's workforce has evolved over many decades to meet the specific needs of children, and this has accelerated in recent years, we know that too many staff are still not adequately skilled. Some staff have training only in adult healthcare, whilst others do not have sufficient training in children and young people's physical and mental health to enable them to undertake their work safely and well. This is one of the most important reasons why children and young people's health outcomes are poor in so many areas.

This has to change.

### The new system for workforce planning and education

From April 2013, a new organisation, Health Education England (HEE), will have responsibility for ensuring that the health workforce has the right skills, behaviours and training and is available in the right numbers to provide health services for the population of England, including, of course, children and young people.

Local Education and Training Boards (LETBs) are being set up as the vehicles for health service providers and professionals to work with HEE to improve the quality of education and training outcomes so that they meet the needs of the public, patients and service providers. We appreciate the importance of LETBs in the essential development of local service and workforce requirements with the added recognition that for some areas, such as the children's workforce, there remains the need to have a wider overview of national requirements.

Professional standards will continue to be set by the different professional bodies.

To address the issues above, **the Forum recommends that:**

- **HEE prioritise children and young people, providing early strategic direction for workforce planning, education and training for the core and specialist children's health workforce; and**
- **HEE identify a lead LETB to co-ordinate education, training and workforce development to reduce variability and maintain national standards.**

To support the desire of the majority of children and young people with long term conditions and disability to have their care closer to home, provided it is safe and appropriate to do so, **the Forum recommends that HEE address the workforce education, training and development requirements (including capacity and capability) to refocus service provision at home or closer to home.**

## The healthcare workforce for children and young people

The children's workforce is multidisciplinary and multi-professional, often working in complex teams. It includes those working solely in public health posts through to those working in treatment and care. The workforce encompasses the full range of nurses, health visitors and midwives, allied health professionals (AHPs), ambulance personnel, social workers as well as psychologists, healthcare scientists, doctors and surgeons with a range of general and specialist knowledge and skills. There is increasing emphasis on developing new roles in children's healthcare but there has not been a really systematic approach to this.

There have been a number of reports over recent years, from professional bodies and DH, highlighting the challenges of providing a sustainable children's healthcare system to meet the required standards, with limited opportunities for workforce expansion.<sup>41,42,43</sup> Problems include:

- maintaining paediatric medical staffing of all current in-patient units, because of the number of consultants required and the need to comply with the European Working Time Directive;
- the variation in community children's nursing provision across the country, with only relatively few having 24 hour services 7 days a week;
- inconsistent provision of school nursing services;
- the difficulty in training and recruiting adequate numbers of AHPs, and the vulnerability of AHP posts to cost improvement programmes in comparison with medical posts;
- the increasing challenge of maintaining competency for surgeons and anaesthetists who treat children in a number of specialties in district general hospitals, and the increasing difficulty in new appointees having or maintaining adequate skills;
- the move to provide services closer to home; and
- the need for clinicians trained in highly specialised, less common disease areas and the need for sustainable specialised services into the future.

There is also a need to provide a workforce that is trained in the needs of teenagers and young adults as well as those needed for infants and children.

The Forum supports the need for high quality, sustainable services that are not just safe, but provide outcomes that are comparable with the best in the world. Many of the indicators in our recommendations address these areas but to be successful there needs to be a significant shift in the disposition of the current children's healthcare workforce, whilst meeting the current financial challenges.

**The Forum recommends that, as a matter of priority, the Centre for Workforce Intelligence, in conjunction with key professional bodies including the Royal College of Nursing (RCN), RCPCH, the Royal College of General Practitioners (RCGP), Royal College of Psychiatrists (RCPsych), British Psychological Society (BPS), AHP bodies and other medical Colleges whose members provide services to children and young people, undertake a scoping project to identify and address the issues of providing a safe and sustainable children and young people's healthcare workforce.**

41 Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. 2010. London, DH.

42 Department of Health. Commissioning safe and sustainable specialised paediatric services: a framework of critical interdependencies. 2008. London.

43 Royal College of Paediatrics and Child Health. Facing the Future: Standards for Paediatric Services. 2011. London.

## General practice workforce

The Kennedy report identified that many GPs had little or no formal paediatric training. Fewer than 50% of GP trainees receive in-hospital paediatric experience.<sup>44,45</sup>

We heard from children and young people how good general practice can be when it works well. But we also heard that too often they have experienced poor or delayed diagnosis in general practice, which they think has impacted on their health. Families recognise that general practice is the most frequent point of contact for children and young people, but report that too often their needs are not met.

Children and young people form a very significant proportion of the workload in general practice. They represent 22% of the population and, typically, pre-school children see their GP six times a year. The quality of care, including accessibility and timeliness, they receive in general practice can have significant implications for attendance and admissions in urgent and emergency care – and in shaping attitudes to healthy behaviour, to self-care and to healthcare services and the NHS for the rest of a child's life.

There is general agreement amongst GPs, paediatricians and psychiatrists that formal training in paediatric medicine and child health, both physical and mental, for GPs is inadequate in the current GP Scheme. The RCGP has therefore submitted a proposal to Medical Education England for a fourth year of training to allow more in-depth coverage of these critical areas. This proposal has passed the first of three stages, and formed the basis of one of the Forum's early recommendations to the Secretary of State for Health. The Forum welcomes this proposal from the RCGP. However, members believe that this should be a priority for the College to start to address in partnership with others, with or without success in its four year extension plans.

In addition to new GPs taking up their posts there remain a large number of GPs already practising, and for whom continuing professional development in all aspects of children and young people's health is important if they are going to see children and young people as part of their practice.

It is also particularly important that all general practice staff, whether they are practice nurses, receptionists or any other members of the team, are specifically trained in relation to children and young people. Poor experiences and poor care in childhood affect the whole life course, at great potential cost to the individual and to the NHS.

In view of this, **the Forum recommends that:**

- **the RCGP proposal to extend GP training to allow for adequate training in paediatrics and physical and mental child health is supported;**
- **all GPs who care for children and young people should have appropriately validated continuing professional development** reflecting the proportion of their time spent with children and young people;
- **all the relevant Royal Colleges work together to agree skills and competencies in child health;**
- **all general practices that see children and young people should have a named medical and nursing lead; and**

44 Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. 2010. London, DH.

45 NHS Future Forum. Education and Training – next stage. A report from the NHS Future Forum. 2012. London



- **all general practice staff, whether they are practice nurses or other members of the team, are adequately trained to deal with children and young people.**

For the Forum's full report on workforce, education and training see:

- The Forum's Health Workforce, Education and Training Factsheet
- RCPCH Facing the Future December 2010 <http://www.rcpch.ac.uk/facingthefuture>

## 8. Knowledge and evidence

'If we count, count us'

'Why aren't my child's notes available again?'

'Where will I get best treatment?'

Turning information into knowledge and evidence, together with research, is central to the drive for better outcomes. This chapter sets out our view of the priorities – so that all involved in improving children and young people's healthcare outcomes know whether their interventions are working.

### Background – data and information

Good quality data and information are the lifeblood of any system improvement. They are required to construct intelligence, enable insight into challenges, provide evidence about what works and support improvement in outcomes.

Patient-level data provide information for decision making about treatment and care of individuals. These data, anonymised and aggregated at a population level, enable service planning and tracking of health outcomes. However, many collections of data simply do not include or separately identify children and young people aged under 19.

### Interpreting child health data

There are now as many or more children in the second decade of life (10–19 years) as in the first decade (0–9 years).<sup>46</sup> Yet current data systems and the current Outcomes Frameworks aggregate data at a very high level (0–19, 15–44 or 15–65 years, for example), making it almost impossible to assess the health of similarly aged groups of children and young people. This is why we have recommended (Chapter 3) with immediate effect, all data collected about children and young people are presented in 5 year age bands through childhood and the teenage years, as used by the World Health Organization (WHO). This will allow for international comparison.

Although these feel like narrow bands, these are times of significant and rapid change in children's lives and development. These bands also allow for identification of data that take account of significant transition points in childhood, such as joining secondary school and transition to adult life, which will enable better and more effective interventions. This will make it easier for health and wellbeing boards and commissioners to compare their area both with others and to published literature, and commission improved services accordingly.

We suggest the following age bands: infancy (under 1 year), 1–4 years, 5–9, 10–14, 15–19 and 20–24 years.

<sup>46</sup> ONS. [www.statistics.gov.uk](http://www.statistics.gov.uk)

## Access to the latest health records

The healthcare system has a legacy of disjointed care records, often held on paper. Children with challenging ill health accumulate multiple records in different organisations, both within and outside the health system. This is true for all patients but growing children, with changing needs, contacts with education and children's social care and the important role of the family, often suffer more from this complexity than others. The same questions are asked multiple times, causing frustration and lack of confidence in the system. Parents and carers become the custodians of the health history whilst struggling professionals try to use partial records. Parents and carers, and children and young people themselves, once they are old enough, should take ownership of their own care records. But allowing this to become the main mechanism by default, when the history is not replicated in formal care records, introduces unnecessary risks to the handover of care, especially within emergency settings. This risk must be addressed.

The best care, linked to the best possible health outcomes, requires that clinical professionals have immediate access to information about the child's background, their current health status and any existing care plans. This realistically needs a comprehensive, electronic child health record, accessible to all clinical professionals involved in the care process – as well as to the patient and their family. Modern communications technologies will be required to make this work in clinical, mobile and home based settings.

The NHS Number, a unique patient identifier, is mandated for use within the NHS, providing the mechanism for linking up separately held care records. This initiative does not currently extend into non-NHS settings such as social care or education, giving the health system a restricted view of a child's circumstances. For example, emergency departments have access, at best, to a partial local record of children subject to a child protection plan, so staff are not always fully informed when dealing with vulnerable children.

The Forum were pleased to learn of a proposed part-solution to this particular issue and support the DH child protection – information sharing project that would enhance IT systems in emergency departments and other unscheduled care settings, in order to include information – with the appropriate confidential safeguards – from local authorities regarding individual child protection plans and statutory orders.

But this is sticking plaster, and does not address the wider issue of the real benefits of information sharing across all agencies working with children and young people.

In addition, many preventative services such as screening, immunisation, health education and additional support for children with disabilities, complex needs or long term conditions are organised via health services for younger children and via education settings for older children and young people. Despite this, there is no explicit linkage mechanism for care records held within these different agencies and settings. As a result, hospital admissions for children with long term conditions are seen to peak as they return to school after the long summer holiday, with teachers, classroom assistants and school nurses struggling to access the information they need to manage the condition appropriately.

This is an issue not just for health outcomes but also for those wider, longer term outcomes which are linked to educational attendance and attainment for these children and young people. This is why

we are recommending the use of the NHS number as a unique identifier to link care records across all relevant settings, including education and social care.

## Access to good personal health information

Parents and carers, and ultimately children and young people themselves, are best placed to manage their own health and wellbeing. But they cannot do this unless they have good quality, definitive information about lifestyles, health behaviours, preventative services, managing their particular condition and how to access support when it is required. Public campaigns need to have relevance to children and young people, as well as adults.

**Public Health England (PHE) should develop national campaigns specifically focused on children and young people, with their input.**

Health professionals need to be able to direct children, young people and their families to appropriate sources of information and advice, and help them access it, for example using NHS Choices. This can also be achieved by sharing on-line health records providing an information channel via which other sources of information, both age appropriate and condition appropriate, can be filtered.

## The new maternity and child health dataset

Population level information on child health is poor, including background information, preventative interventions, primary care, community care and health outcomes. The maternity and child health dataset, which is currently being implemented, will improve this, assembling clinical data from maternity, child health and child and adolescent mental health services, linking mothers to children and linking child health records from diverse settings.<sup>47</sup> The initial scope will support tracking of a wide range of health outcomes as well as providing the infrastructure for data collection for this population.

**The Forum strongly recommends that, once established, the coverage of this dataset will need to be extended, in particular to enable tracking of:**

- **child development outcomes at age 2–2½ years, as included in the Public Health Outcomes Framework;**
- **care and outcomes associated with the Improving Access to Psychological Therapies (IAPT) initiative;<sup>48</sup> and**
- **care and outcomes for children with disabilities and complex conditions.**

## Other key data sources

Some comprehensive data collections on children and young people's outcomes exist at a local level. These include primary care records held by GP practices and child death review data held by Child Death Overview Panels.<sup>49</sup> Furthermore, established clinical networks for example trauma, paediatric intensive care, diabetes and neonatal services hold detailed datasets and audit information. There is scope for assembling these datasets at a national level, driving up standards for coverage and data

<sup>47</sup> [www.ic.nhs.uk/maternityandchildren](http://www.ic.nhs.uk/maternityandchildren)

<sup>48</sup> <http://www.iapt.nhs.uk/>

<sup>49</sup> <http://www.education.gov.uk/childrenandyoungpeople/healthandwellbeing/safeguardingchildren/childdeathreview/a0070758/child-death-data-collection>

quality and using them to identify further which service interventions drive improvement in health outcomes.

## Improving national data and intelligence

Currently, ChiMat,<sup>50</sup> the national Child and Maternal Health Observatory, works across the NHS and other agencies to provide data, information and intelligence on the health and wellbeing of children, young people and their families. The initiative is driven by health and supported by education, the children's voluntary sector and academia.

To drive improvements in outcomes for children and young people, a dedicated intelligence network will be required, which can bridge all settings and agencies, including but not limited to both healthcare services and public health. Such a network will ensure that decision makers at all levels within the system will have the information and intelligence which they need to drive improvements in services and in health outcomes for children and young people.

In summary, meeting the information challenge will require a move away from paper based records and disjointed episodes of care to a holistic, electronically enabled, child centred view which spans organisations and agencies and is enhanced by modern communications technologies. The quality and coverage of data available to professionals and planners will be driven up by regular use and specific additions for disadvantaged groups. Value will be added to data and information by the use of system wide enablers, mining the data for trends and transforming it into readily accessible packages of benchmarked intelligence which support local planning and prioritisation. Finally, children and young people, their parents and carers will own and access their own information in co-production with clinical professionals.

### The Forum recommends that:

- **the NHS CB, with support from the Health and Social Care Information Centre (HSCIC), establish electronic child health records, accessible for both patients and professionals.** This will enable 'real time' working and make the most of modern technologies and varied communications channels. Work should start immediately and be completed by 2015;
- **the NHS CB, with support from HSCIC, improve the quality of routinely collected data, collecting them once and using them for multiple purposes, as well as making secondary uses data readily available to and useable by clinical professionals;**
- **in addition, the content of existing datasets is improved – in particular, Public Health England (PHE) and HSCIC to improve the flow of data from primary care by 2014; PHE and DfE to improve the aggregation and use of data from Child Death Overview Panels by 2014; and DH, DfE and PHE to improve data about children with disability and complex needs by 2015;**
- **the Chief Medical Officer consider how an intelligence network for children and young people's healthcare, which crosses all settings, can be established by 2013, to drive up standards and effective use of data, information and intelligence in decision making, in order to support the Forum's recommendation on a research strategy; and**
- **the interoperability standards, to be required in the future of NHS information systems under new DH guidance, be applied also to interoperability with education and social care systems.**

<sup>50</sup> <http://www.chimat.org.uk/>

This could be approached by building on the work of ChiMat, and linking it to other key registries and data collections, ensuring a strong focus on children and young people within the evidence and intelligence function of PHE and the NHS.

## Evidence

Key to this strategy and to improving outcomes is the provision of high quality evidence and standards. The NHS CB will issue guidance to local commissioners that will set out how they should achieve improved outcomes for patients through commissioning services that are better quality, more efficient and fairer. This guidance will be based on Quality Standards referred by the National Quality Board and issued by NICE. This will be supported by other accredited evidence, including guidance from the Royal Colleges, specialist societies and other professional bodies.

There was a paucity of Quality Standards relevant to children and young people in the initial tranche from NICE, but the Forum is pleased to note that a range of relevant topics have appeared on the NICE website.<sup>51</sup> This includes several child and adolescent mental health topics, a further 26 medical and surgical topics specifically for children and young people and a number of additional topics which are said to include children.

Four topics are currently listed 'in development' (asthma, bacterial meningitis and meningococcal septicaemia, eczema and epilepsy in children) are all important areas for promoting improved outcomes through incentives such as CqulNs (Commissioning for quality and Innovation). What is less clear is the timescale for development and completion of these and other topics, many of which are also very important for improving quality outcomes.

**The Forum recommends that NICE and the NHS CB work with the RCPCH and other Colleges and professional bodies to expand and prioritise the Quality Standards work programme as it applies to children and young people.**

## Research

Research into child health and illness has had a mixed history over recent years. There have been some remarkable and successful national developments, such as the Medicines for Children Research Network (MCRN), which as part of the National Institute for Health Research (NIHR) Clinical Research Network has significantly improved the opportunities for children's focused research and collaborations with industry. There are a number of highly successful national collaborations and groups in several high profile specialist areas such as cancer (CCLG), critical care (PICANET) and the National Neonatal Audit Programme. The study of patterns and causes of disease (epidemiology) in children is also highly regarded. Information provided by the Public Health Observatories through ChiMat is excellent.

On the other hand, there is a relative paucity of world class research in many equally high profile areas and there has been a major reduction in Higher Education Funding Council for England (HEFCE) funded university departments of child health over recent years as the research emphasis within universities has shifted from 'craft' based departments such as paediatrics to cross cutting translational research themes.

<sup>51</sup> <http://www.nice.org.uk/guidance/qualitystandards/indevelopment/qualitystandardsindevelopment.jsp>

In the introduction to this report we present some of the data about known outcomes and outcome measures. In the main these cast the nation in a poor light in comparison to other countries, and with wide variations within this country. In carrying out its work, the Forum has also been struck by the lack of research based evidence relating to many of the outcomes and indicators identified as being important to children, young people and their families.

Scrutinising child health data on outcomes, it is clear there are three major questions that need to be addressed as a matter of urgency:

1. Is it true that children and young people's health outcomes in many areas are as poor in comparison to other countries as the data suggest?
2. If so, why?
3. What action needs to be taken to improve these outcomes?

The poor outcomes appear to occur throughout all the various pathways and throughout the life stages of children and young people. The Forum believes that to address these questions, there is a need to improve both the capacity and capability of child health related research. The success of MCRN and other groups outlined above should serve as models for future development in non-medicines related areas, but consideration also needs to be given as to how to undertake research in a wide range of relevant areas.

**The Forum therefore recommends that the Chief Medical Officer uses her role as head of research and development to stimulate the development of academic child health, both physical and mental, and the evidence base for practice and improving outcomes.**

The Forum's full report on these areas and supporting information includes:

- The Forum's Factsheet 'Making data and information work for children and young people.'
- CHiMAT [www.chimat.org.uk](http://www.chimat.org.uk).

## 9. Leadership, accountability and assurance

'I want to know that there is someone who is representing me to ensure that I and other children matter when it comes to performance'

'I would like a local champion in a senior position who had responsibility and authority to look right across the system for children and young people'

New organisations in the system are setting up their structures and operating models to enable them to deliver their responsibilities. We recognise they will do this in different ways. This provides a real opportunity for them to build in from the start mechanisms for improving health outcomes for children and young people.

In the new health and care system, every organisation needs to show that it understands the journey people take through life and how it can best contribute to their health and wellbeing at every stage. Pregnancy, childhood and teenage years play a particularly important role in shaping our health for the rest of our lives. We believe that leadership and accountability for improving health outcomes across the whole life course must be embedded and demonstrated throughout the system.

With new organisations in the NHS commissioning health services there is a real opportunity to address previous inadequacies in the commissioning of children and young people's health services. Our factsheet is designed to support the new organisations in their commissioning roles.

All organisations in the new health system, including DH, Public Health England (PHE), the NHS CB, Monitor, CQC, Health Education England (HEE), local authorities and CCGs, should clearly set out annually:

- their ambition for improving the health outcomes for children, young people and their families, recognising their specific needs within the whole life course;
- how they exercise their responsibility for improving the health and well-being of children and young people at every level of their organisations – national, regional and local; and
- their plans for expenditure to deliver and improve child health.

**The Forum therefore recommends that:**

- **DH hold to account explicitly for improving health outcomes for children and young people every statutory organisation that it funds,**
- It can do this in a variety of ways, including through Framework Agreements, the mandate to the NHS CB and accountability reviews and reports; and
- **the NHS CB should do similarly with all organisations that it funds.**



## Clinical leadership

Clinical leadership and accountability are important principles of the new system and should be visible at every level. Clinical leadership which has deep understanding and experience of the issues affecting children and young people is essential to leading strategies to improve health outcomes for these groups. Wider experience in working with children, young people and families should also be at the heart of local commissioning decisions.

**The Forum therefore recommends that:**

- **DH, the NHS CB and PHE should identify national clinical leadership on children and young people, for example through a deputy reporting to the Chief Medical Officer in DH and a National Clinical Director reporting to the Medical Director within the NHS CB;**
- **local commissioners, including CCGs and local authorities, should identify a senior clinical lead for children and young people; and**
- **these senior clinical leads should be part of the health and wellbeing board advisory process.**

## Role of the regulators

The regulators also have an important role in system assurance. They can help ensure that the life course approach drives improvements in outcomes for all. We welcome Monitor's proposal to establish a working group in September 2012 to look at the way it can discharge its responsibilities to ensure integration of services for children and young people across different providers.

We note that the roles of both CQC and Monitor extend to adult social care but not children's social care, which is regulated by Ofsted. Whilst we understand this, it does give rise to issues for children and young people, such as those with a disability, whose needs clearly cross from health to social care and for whom integrated provision is essential.

**The Forum therefore recommends that:**

- **CQC should make maximum use of thematic reviews to examine aspects of the new health system from a children and families' perspective; and**
- **Monitor, CQC and Ofsted collectively produce a clear joint statement which demonstrates how they will work together to foster integration of key services and partnership across sectors.**

## Accountability for safeguarding children and young people

Professor Eileen Munro, in her review of child protection,<sup>52</sup> expressed concerns about how the reformed NHS would safeguard children. The Forum shares this view and that is why we have focused on safeguarding within our report.

Under the Health and Social Care Act 2012, statutory duties for safeguarding will transfer from PCTs and SHAs to CCGs and the NHS CB. The statutory responsibilities of NHS providers will not change (non-NHS providers are not covered).

In response to the concerns of Professor Munro and others, the DH has been developing an 'accountability framework' to set out the roles and responsibilities of the NHS CB, CCGs, NHS and independent sector providers, CQC and Monitor. This is still work in progress, and a full accountability

<sup>52</sup> Munro E. The Munro Review of Child Protection: Final Report. A Child-Centred System. Department for Education. 2011.

framework has yet to be produced, although it is expected to generate NHS CB commissioning guidance to help CCGs in preparing for authorisation.

Work on the 'accountability framework' has also helped inform revision of the statutory inter-agency guidance, *Working Together to Safeguard Children*, to which the Government committed in response to the Munro review. DfE launched a consultation on radically shortened draft guidance in June.

We do not believe that the draft revised statutory guidance gives sufficient information on roles and responsibilities, and members of the Forum plan to respond to the consultation accordingly.

We are not confident that the CCG authorisation process in itself will guarantee that CCGs will be able to discharge their safeguarding responsibilities adequately.

**The Forum therefore recommends that DH and the NHS CB should publish a full accountability framework for safeguarding children in the wider health system as soon as possible. This should include the responsibilities of commissioners and providers of adult services**

GPs and their practice staff have a vital role to play in safeguarding children, and to do so they need to be appropriately competent.

**The Forum recommends that the NHS CB accept on local performers lists only GPs who can demonstrate level 3 competences as set out in the intercollegiate document *Safeguarding Children and Young People: roles and competences for health care staff (2010)*.**

The Director of Public Health will be responsible for ensuring that the needs of vulnerable children, including those at risk of significant harm, are a key part of the JSNA. While this is an important role, we believe that there are too few public health staff with dedicated maternal health and child health responsibilities.

**The Forum therefore recommends that PHE should work in partnership with HEE to assess at the earliest opportunity the workforce required to support Directors of Public Health in ensuring the needs of children and young people are met locally, and create a public health workforce development programme with maternity, children and young people at its heart.**

In response to the Munro report, CQC is working with the other inspectorates to develop a new safeguarding children joint inspection framework for 2013, which will focus on the child's journey. They launched a consultation on the draft framework in July.

**The Forum recommends that, as part of the new multi-agency inspections, CQC consider how all parts of the health system, including relevant adult services (mental health, drug and alcohol services for example) contribute to effective local safeguarding.**

The scale of the impact of abuse and neglect on children, young people and their families remains seriously underestimated by all parts of the system and there are no clear data. The published NHS Outcomes Framework includes no indicators relevant to safeguarding. A number of indicators in the Public Health Outcomes Framework are relevant. These need to be used alongside other information, including the new performance information data for safeguarding children recently published by DfE.

More needs to be done to ensure that the new system will have sufficient information in order to provide assurance that local services are keeping children safe.

**The Forum therefore recommends that further work be undertaken on indicators that would drive improvement to protect and promote the welfare of children and young people. This should include a focus on measuring the effectiveness of early help/early intervention.**

A Quality Standard for safeguarding children would be a significant lever in the new system but there are no plans at present to develop one. A Quality Standard could be based on the existing NICE clinical guideline on *When to suspect child maltreatment*.<sup>53</sup>

**The Forum therefore recommends that NICE is commissioned to develop a Quality Standard for safeguarding children. We would also support proposals for further relevant NICE guidelines.**

**We recommend that the NHSCB, Monitor, CQC, HEE, the LGA, ADCS and SOLACE promote the information in the safeguarding factsheet in order to support wide understanding of the issues to address.**

The Forum's full report includes:

- The health and wellbeing factsheet for children, young people and families.
- The Forum's Commissioning factsheet.

<sup>53</sup> National Institute of Health and Clinical Excellence. When to suspect child maltreatment. 2009 Clinical Guidelines CG 89. <http://www.nice.org.uk/CG89> (accessed 15.7.12).

# 10. Incentives for driving service improvement

## Financial flows

The current financial context for the NHS is stretching, with a requirement to make more than £20 billion efficiency savings overall by 2015, and with the expectation that this will be achieved whilst improving quality and outcomes overall.

The structural and commissioning changes currently taking place within the health and social care system will lead to changes in funding flows – for example, public health will become the responsibility of local authorities. Child health services are complex and will cross these new boundaries bringing a potential financial risk to a number of services. Examples include the public health role of midwives during antenatal and postnatal care, and the provision of comprehensive sexual health services for young people. It is important to ensure that, with new commissioning roles in the system, these funding flows do not become a barrier to good service provision and instead introduce perverse incentives.

**The Forum recommends that DH, in its system oversight role, maintain a focus on the pattern of funding flows across the NHS, local authorities, public health and, where relevant, wider care or wellbeing, to ensure that perverse incentives are not adversely affecting patient care or service provision.**

## Commissioning for integrated care

The Forum has put the provision of integrated care at the heart of services for children and young people and it forms a separate section of this report. Nevertheless, we view it as essential to consider the question of integrated care in this section on finance and incentives. Most financial incentives have historically been aimed at individual providers, whether in primary care, community services, hospitals, social care, or for children, education.

There is no real incentive within the current funding mechanisms for encouraging integration of care between primary and secondary or specialised care. This is essential if we are to see improved outcomes in areas such as reducing hospital emergency attendances and admissions, improving mental health care, and the management of long term conditions close to home.<sup>54</sup>

We have made it clear throughout that for services to be successful from the perspective of children and their families, different elements of each child's pathway need to work coherently and without the added complexity of funding mechanisms that provide perverse incentives or conflict.

**The Forum recommends that:**

- **the NHS CB and Monitor prioritise and promote the issue of integrated care provision in their funding, regulatory and performance roles within the NHS; and**

<sup>54</sup> NHS Future Forum. Integration. A report from the NHS Future Forum. 2012. London.

- **DH address this issue across government for those services that fall within the remit of local authorities, education, or other government departments.**

## Incentives within the NHS

The schemes within the NHS designed to incentivise improved quality, whilst maximising the use of financial resources, include the Quality and Outcomes Framework (QOF) for primary care, Payment by Results (PbR), Commissioning for Quality and Innovation (CQUiNs) and Quality, Innovation, Prevention, and Productivity (QIPP) programmes.

### *General practice incentives*

The Quality and Outcomes Framework (QOF) has been successful in incentivising primary care to improve adult health services. However, children and young people make up an unacceptably small part of the QOF with the only clinical area included being asthma in over 8 year olds. Child health checks and child protection receive some attention elsewhere but the points attributed to children and young people make up less than 3% of the total score out of 1000 points. This is a completely inadequate reflection of the workload of general practice or the potential quality gains that could be achieved by improving primary care.

**The Forum recommends that the NHS CB prioritise the development of an appropriate range of incentives within the QOF for general practice to provide high quality care reflecting the needs of children and young people.**

### *Funding and incentives for hospital and community provider services*

The Forum wishes to emphasise the importance of including the full range of services for children and young people within the various NHS funding and incentive schemes.

The Payment by Results scheme has for some years incorporated children and young people's hospital services as a substantial element of its work, has maintained excellent relationships with children's providers, and is advised by a children's PbR subgroup. Some of the earliest implemented 'best practice tariffs' and 'Year of Care' tariffs have been for particular children's services and there has been a clear recognition that specialist children's services require a focused approach to funding some of the most complex children treated in England.

There has been less development in areas such as Child and Adolescent Mental Health Services (CAMHS) and community services, although some of these are starting to evolve. These need to be included within the incentives schemes.

**The Forum recommends that Monitor and the NHS CB should ensure that they continue with the outcome-orientated development of PbR currencies and tariffs on child health related areas, and that they continue to engage appropriate expertise, including through the Expert PbR Advisory Group on Children.**

The Forum strongly supports moves to provide care for children and young people closer to home – particularly at home or in community settings, rather than in hospital. This means the whole system needs to provide specialist services for children, round the clock general acute services and strong local community services for children at home. Current funding arrangements may not incentivise care to be provided in the most optimal place for the individual child.

We recognise that the changes necessary to achieve safer care, closer to home will result in services being redesigned, and in some cases closing.

**The Forum recommends that:**

- **the NHS CB and CCGs are mindful of potential consequences to providers of general and specialist services and consider how they will adopt a risk sharing approach between different provider organisations in developing their commissioning plans for delivering care closer to home; and**
- **Monitor ensure that evolving PbR mechanisms have sufficient flexibility to reflect these tensions and cost changes in a timely fashion.**

As far as we are aware, there are no incentive schemes for improvements in public health for children.

We are aware that some economies have used QIPP and CQuIN schemes to try to drive up quality at local and regional level for children and young people. Whilst we welcome this, it has not been universal. We wish to encourage all economies to take up and expand these schemes, using the evidence base from NICE and the recommendations within this report. In addition to individual indicators, we wish to emphasise once again the importance of incentivising integrated care across sectors and in providing robust services across the whole pathway.

**The Forum recommends that:**

- **the NHS CB and local commissioners should develop CQuIN schemes to drive improvement in the areas prioritised in this report;**
- **PHE develop an incentive scheme to address improvements in the public health outcomes prioritised; and**
- **the NHS CB should include children and young people's healthcare outcomes in the next phase of QIPP.**

# 11. Conclusions

The Forum has set out recommendations for the new health system which, if accepted and put in place, will start to address the key obstacles to improving children and young people's health outcomes that exist now.

The implementation of these recommendations is crucial. The Forum is clear that without consistent attention and further development of the strategy then this report could go the way of many of its predecessors and fail to secure the benefits that our children and families need, and the country requires.

So this work should be seen as the first phase in the new Children and Young People's Health Outcomes Strategy. This is a real opportunity for improvement and the Forum therefore urges government and all organisations in the wider health system to accept these recommendations and act now.