Involving children and young people in health services

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The Royal College of Paediatrics and Child Health (RCPCH) trains and supports thousands of doctors in the UK and overseas to ensure children and young people receive the highest possible standard of healthcare. We do this by:

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*Front cover images from Royal College of Paediatrics and Child Health ‘Draw to win’ competition 2006 – theme ‘me and my doctor’*
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Significant progress has been made in improving the health and well-being of children and young people over the last five years. However, some children and young people still fail to receive the highest standards of healthcare attainable – a right of all children as set out in Article 24 of the United Nations Convention on the Rights of the Child.  

Children and young people are key stakeholders of the NHS and their interests must be at the centre of health and local government services. The health and local government reforms coming into force in England will significantly affect how child health services will be commissioned and delivered. Yet, throughout the Government’s health reforms, children’s needs and aspirations have rarely been discussed and the capacity of the Departments of Health and for Education to focus on children and young people has been reduced.

In order to generate a consensus across child health professionals in the NHS and local government, the Royal College of Paediatrics and Child Health (RCPCH) and the NHS Confederation, with support from the Office for Public Management (OPM), held an event in September 2011 to discuss the key priorities for child health and the reforms. This report highlights the key findings and recommendations from the event about involving children and young people in decisions about health and well-being services and developing a culture of participation.

It makes the following key points.

- Health professionals should always act in the best interest of the child or young person they are supporting or engaging with.
- Children and young people are not an homogeneous group and the health service must be flexible in responding to their diverse needs, backgrounds, capabilities and interests.

- Participation and involvement must take place on two levels: individual involvement, with people making their own healthcare choices and being confident in their interaction with health professionals, and group involvement, either as a service user or member of the public.

- Local health systems need to have governance and policies in place to ensure that children and young people can participate in a systematic and non-tokenistic way. This links in with the Government’s aims to increase participation with the “No decisions about me without me” policy.

- It is important that children and young people understand why they are being consulted, what the process is, how their feedback will be used and, crucially, how their involvement will lead to change or help professionals.

- Children and young people need to be engaged early in the design of new health organisations and structures to ensure their views are included right from the start and regularly in the future.

- Effective monitoring and accountability processes must be in place to ensure the safe, meaningful and ethical participation of children and young people.

- Local health systems must be encouraged and supported to involve children and young people routinely in their work, sharing learning and good practice, if a culture of participation is to be cultivated across the NHS.

See our accompanying publication, Children and young people’s health – where next? available at www.nhsconfed.org/publications
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Background

Professor Sir Ian Kennedy’s review\(^2\) of services for children and young people in the NHS in 2010 found that there was considerable variation in quality, with large numbers of services needing improvement and others being pockets of excellent practice. His review highlighted areas that needed further improvement, including:

- coordination between health services, and also between health and other agencies
- information management and sharing
- a generally lower priority currently given to children’s health services compared with adult services.

There is also evidence to suggest that policies, reforms and guidance are usually written from an adult perspective (only occasionally adapted for children’s services) and children and young people’s involvement in patient and user forums, such as local involvement networks (LINks), is patchy and often unrepresentative.\(^3\)

Why involve children and young people?

The Kennedy report made a number of recommendations about the involvement of children and young people in healthcare decisions, such as establishing local partnerships specifically for planning and delivering healthcare for children and young people.

In order to address some of the challenges set out by the Kennedy report and improve the quality of services they receive, children and young people should be involved at all levels of the health system and especially in decision making, commissioning and governance. Effective and appropriate services that reflect the needs of children and young people will ultimately lead to better health outcomes.

“Participation encourages integration and inclusion, lets youth feel valued and ultimately leads to progress. It is a right and should not be tokenistic, where services merely ask youth for their views just so they fit in with a trend. I would urge all those here to include the views of children and young people wherever possible – the benefits are clear.”

Ravi Mistry, Youth Advisory Panel Member, RCPCH, 2011

Policy and legal drivers

There are important policy and legal drivers to ensure children and young people are actively involved in health services. The Children Act 1989\(^4\) places a duty on local authorities to consider the wishes and feelings of children when adults make decisions about them. Good Medical Practice\(^5\) describes what is expected of all doctors registered with the General Medical Council (GMC), including the duty to respect, listen to and work in partnership with patients. The United Nations Convention on the Rights of the Child\(^6\) outlines the right for children to give their views on matters affecting them, including decisions made in education and public services, and also in local and national policies.

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010, and the Care Quality Commission (Registration) Regulations 2009 require providers of services to involve service users at all stages of their care. This must include children and young people.

The Government’s response\(^7\) to the Kennedy report reiterates its commitment to the engagement of children and young people in healthcare and, specifically, an emphasis on:

- choice of provider and treatment
• shared decision making as the norm
• personalised care through better joint working
• increased control and access to health information and records
• increased voice of the patient and feedback from patients on the quality of hospitals.

The health service reforms in England place an increasingly important emphasis on the policy “No decisions about me without me”, with a proposed strengthening of the involvement of patients and service users in health and social care service design and delivery through HealthWatch.

HealthWatch is proposed to act as the local leadership for ensuring children and young people and their families are engaged in the design and delivery of local health systems. As well as this, the increased use of personalisation and choice in treatment and providers should further empower children and young people in relation to their healthcare. The personal budget pilots in children’s services have also been testing out health funding streams and this may add impetus to personalised health services for children and young people.

The NHS Outcomes Framework identifies key indicators that will report on performance across five ‘domains’ or areas. Each of the five domains has a number of specific subcategories or improvement areas. The improvement areas relating to children’s health cover infant mortality, unplanned hospital admissions, lower respiratory tract infections, maternity services and the general healthcare experience of children. The proposed Public Health Outcomes Framework also sets out improvement areas relating to children’s health and well-being.

**Developing a culture of participation – key principles underpinning health services**

The key message from the child health event was that the proposed changes to the health system will only work for children and young people if engagement becomes the norm. The following principles were identified as forming the basis of effective engagement.

• Child health services need to promote the best interest of the child/young person first and foremost. This includes ensuring engagement is carried out in a safe way that does not place children and young people at risk.

• Engagement of children and young people in health services must be at all levels and embedded into the culture and day-to-day practice of health professionals and organisations.

• Health professionals need to continually share learning and good practice and work in partnership with others.

• Engagement with children and young people must be meaningful and non-tokenistic. This means listening, being clear about the purpose, and feeding back to children and young people about changes made as a result of engagement.

• There must be a wide range of approaches to participation because there is no one way of engaging with children and young people. Any approach should recognise diversity and the different perspectives that children and young people may have.
Engagement and future healthcare systems

At a local level there is little incentive for organisations to work across boundaries and with other partners to systematically ensure a good and consistent standard of service for children and young people through their whole health journey. While paediatric units in hospitals may have local standards, they frequently use parent participation as a proxy for engagement of children and young people.

The “You’re Welcome” quality criteria, produced by the Department of Health, set out principles to help commissioners and providers improve health services for children and young people. Standards cover general practice, secondary care, acute and community services and there are specific standards for specialist and targeted services. However, implementation of these criteria is left to local discretion. The Department of Health reports that:

“In England, 81 per cent of commissioners have recommended that local services implement the guidelines and 64 per cent are involving young people in rating and evaluating experiences of health services.”

The transition to new NHS structures under the reforms may limit progress in this area. As existing structures for engagement are dismantled, new structures may fail to fully embed engagement principles and practice for children and young people.

There are good examples of how children and young people can be involved in commissioning and key strategic decision making processes. For example, young commissioners’ programmes have been implemented in a range of areas across the country. Many areas will also routinely collect information about the experiences of children and young people as part of the Joint Strategic Needs Assessment.

However, unless new commissioners are up-skilled in involving children and young people in commissioning, the gains of recent years and skills of commissioners in carrying out effective engagement with children and young people may be threatened as the health system is reformed and organisational memory is lost. There is an opportunity for the voluntary and community sector to help bridge this gap in skills and knowledge of engagement as the NHS reconfigures.

Case study: Seeking involvement across the commissioning cycle

Bexley NHS Care Trust aims to involve children and young people across the whole commissioning cycle. They are developing a children and young people’s council and have carried out detailed engagement with children and young people on understanding and prioritising need, reviewing service delivery mechanisms and how to monitor service performance. Commissioners worked closely with children and young people to prepare costed specifications for new services and developed action plans to implement these. The engagement is ongoing, with the young people continuing research with their peers in the community and the commissioners reporting back on the action undertaken.
The development of new local structures needs to build on previous experiences. For example, building on the former responsibilities of local authorities to actively seek views from children and young people as part of the Children’s Trust arrangements or the Joint Strategic Needs Assessment, or looking at the experience from local involvement networks (LINks), should help to produce a picture of what works or does not work. Commissioners may be able to share resources with other organisations, for example, school councils and established forums in the voluntary and community sectors and in children’s social care.

Providers often have effective channels of communication and engagement with children and young people, and working in partnership with them is important.

**Recommendations**

- All organisations supporting children and young people (including the NHS Commissioning Board, clinical commissioning groups, GP practices, local authorities and all healthcare providers) should adopt the You’re Welcome standards, which should be written into their contracts. Agencies may consider a children’s charter setting out what children and young people can expect from a service and how they will be involved. Action for Sick Children has drawn up a ten-point Charter for NHS Services and the Every Disabled Child Matters campaign has produced a number of charters covering disabled children’s care and support.

- Local health and wellbeing boards should have the engagement of children and young people as a core feature of their set-up, governance and ongoing systems and processes. This is in addition to the need for local HealthWatch organisations, as they are established, to engage directly with children and young people. This could be through youth clubs and schools and also with existing parents’ and family support groups, such as parent and carer forums for disabled children.

- As local HealthWatch organisations are formed, they need to have a clear remit to involve children and young people and ensure their voice is heard. A children and young people’s strategy should be developed, implemented and monitored. Having a child focus to local patient advice liaison services (PALS) should supplement this. These organisations should be held accountable and local partners should provide support and guidance to ensure they are effectively engaging with children and young people, either directly or through existing groups.

- There should be senior leadership for participation of children and young people within each organisation commissioning or providing services to children. In the absence of a dedicated children and young people’s participation officer, this remit should become part of the job description of senior directors and be routinely monitored via performance and line management.

“As existing structures for engagement are dismantled, new structures may fail to fully embed engagement principles and practice for children and young people.”
• The Joint Strategic Needs Assessment (JSNA) should make use of experiential or qualitative data from children and young people. The JSNA and other strategies should consider the needs of children who rarely use health services.

• The relationship with providers should set out the requirement to meaningfully engage with children and young people, for example by specifying this in contracts.

• It is crucial to train commissioners and those providing commissioning support to understand the importance of participation and how to do this effectively with children and young people.

“Providers often have effective channels of communication and engagement with children and young people, and working in partnership with them is important.”

Case study: Using online information and data

Newcastle has a shared online information and data analysis resource spanning health and well-being for everyone who commissions, provides or uses health, social and children’s services in the city. For more details, see www.newcastlejsna.org.uk

By providing uptake data for both childhood and adult vaccines on a ward level, the Nottingham City Joint Strategic Needs Assessment highlights areas where improvements in uptake are most urgent. For more details, see www.nottinghaminsight.org.uk/insight/jsna/adults/jsna-immunisations-and-vaccinations.aspx
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Service design and delivery

At a service level, ensuring children and young people receive feedback after they have participated is of utmost importance. Seeing that action has been taken as a result of their input is empowering. Feedback from the young people involved in producing this report is that:

“All too often children and young people never see the fruits of their feedback and feel they are just ‘another person’ in the process.”

Engaging with specific groups of children may be particularly challenging for health service managers. For example, a recent evaluation of participation in short-break services for disabled children found that while involvement of children and young people in commissioning these services was increasing, “local areas continue to report difficulties in engaging effectively with disabled children and young people from black and minority ethnic groups.”

The evaluation report, by Together for Disabled Children, also gives a number of case studies showing how a range of professionals are actively engaging with children and young people in the design of services.

Recognition and improvement

Health professionals need to recognise when children and young people have taken the time to engage and provide useful feedback and, where appropriate, provide rewards and incentives. Services should have a clear policy on recognising the participation of children and young people and also understand that not all children and young people require a financial incentive: “The obvious incentive is knowing you will be contributing to improving the service.” Often, it is far more important to ensure meaningful engagement when children and young people know there is genuine commitment and that their input is valued and recognised.

Each health organisation should review existing policies and practices with children and young people on a rolling basis to understand how they can be improved. Policies should also clearly set out how participation will promote safeguarding and protect children and young people from harm.

Engaging through social media

The use of technology and social media is key for engaging with children and young people. Tools include communication using social media such as Facebook, YouTube and Twitter. Young people may want to give feedback via text messages or smartphone apps. It is important to keep surveys short, ask the right questions and use technology that makes it easy for people to respond.

More innovative ways for children and young people to give feedback on services include

Case study: Designing services with young people in mind

Royal Manchester Children’s Hospital actively engaged young people in its review of healthcare delivery. This included informing treatment plans, design of physical environments for children and young people and development of child information and communication materials.

Birmingham Children’s Hospital Young People’s Advisory Group raised concerns and offered solutions and recommendations to the NHS Future Forum, senior management and the Chief Medical Officer.

Nottingham University Hospitals NHS Trust recently facilitated the participation of young people in the recruitment of paediatricians.
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Keeping a patient diary, having a ‘Big Brother’ diary room, fun and interactive activities such as an event to assemble ideas, virtual discussion forums, and online seminars (webinars). Simple methods for young children, such as play, drawing and writing techniques to describe a prospective patient journey, or using canvas for painting, are also effective.

Technology and media need to be appropriate, accessible and easy to use for target ages. Some forms of online networking are not secure or confidential (for example, Facebook or open chatrooms) so more moderated forms of online engagement may be preferable from a child protection perspective.

**Recommendations for service managers**

- Processes should be created to enable children and young people to hold to account senior leadership within health services.
- Feedback should routinely be given about what has changed following engagement – or reasons why things have not changed. This should be put in the context of ensuring confidentiality and trust.
- The service environment and infrastructure should support children and young people to feel reassured, safe and valued, for example, by being child-friendly and asking what a different service (such as children’s food in hospitals) would look like.
- Services should engage with children and young people in an inclusive way, proactively challenge discrimination, and ensure all children and young people, including those who may be marginalised and have particular vulnerabilities (for example, disabled children, young people in the youth justice system and young carers) are supported to engage and influence health services.
- Health professionals should work with other organisations, such as schools, sports clubs, youth organisations, youth offending teams, youth referral units and child and adolescent mental health services (CAMHS) to share learning and good practice.
- Children and young people should be involved in the human resources, training and workforce elements of a service, for example, having young people on interview panels and training managers and staff to understand their views, experiences and suggestions.

The RCPCH publication, *Not just a phase: a guide to the participation of children and young people in health services*, recommends working alongside community services or statutory groups who already deliver health and well-being services for vulnerable groups (for example, looked after children teams).18

**Case study: Youth panels and staff selection**

Since 2005, the Paediatric Rheumatology Service at Nottingham Children’s Hospital has involved young people in staff selection. A youth worker recruits four young people who meet on the interview day and start with an icebreaking session followed by a session on the details of the post and their roles and responsibilities within the selection process. The youth worker acts purely in an advisory capacity as the youth panel devise their own questions and scoring system. The conventional interview process and ranking occur first. The youth panel provide comment on their assessment of each candidate to the trust’s interview panel.19
Children and young people, like adults, are not one homogeneous group and come from a diverse range of backgrounds, with different capabilities and competencies. Health professionals must consider the specific needs of individual children with disabilities (including those with mental health problems or with communication difficulties) and ensure that all children experience equality regardless of age, sex, religion, ethnicity and socio-economic status.

Furthermore, different groups of children will have different ways of wanting to be engaged. Practitioners should recognise the uniqueness of individual children and young people and their differing levels of understanding and how to support their timely involvement. For example, some children and young people will only know what they want, or discover questions they need answers to, when they have gone through a certain aspect of the condition or treatment.

Consent, competency and ethics

Once children reach the age of 16 in England, Scotland, Wales and Northern Ireland, they are presumed in law to have the capacity to consent to treatment unless there is evidence to the contrary. This covers surgical, medical or dental treatment, and any associated procedures, such as investigations, anaesthesia or nursing care.20

In England, Wales and Northern Ireland, the Gillick Competence determined that children under 16 can be legally competent if they have “sufficient understanding and maturity to enable them to understand fully what is proposed”. However, it is still vital in these cases to involve the parents unless the young person has specifically refused parental involvement.21

In Scotland, the Age of Legal Capacity (Scotland) Act 1991 states that a competent person under the age of 16 can consent on their own behalf to medical treatment provided they are capable of understanding the nature and consequences of the treatment.22

Children and young people under 16 should be involved as much as possible in decisions about their care, even when they are not able to make decisions on their own. If children are not competent or do not have the capacity to give consent for themselves, health professionals will need consent from someone with parental responsibility for them, unless it is an emergency and it would be unreasonable to wait.
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There is guidance\(^2^4\) for health professionals on ethical considerations as well as communications guidance when supporting children and young people. This highlights the importance of explaining things using language or other forms of communication they can understand (it should be considered whether interpretation or translation services are needed). It may also be helpful to consider the guidance on unaccompanied children and young people, as well as the impact that the presence of a parent or chaperone can have on communication with the child or young person.\(^2^5\) Children and young people value the time and opportunity to have an open dialogue with their health professionals.

**Recommendations for practitioners and health professionals**

- Paediatricians and community teams should consider non-attendance at clinics as a serious issue that should always be followed up. Schemes to encourage attendance, such as following up or reminders through text messaging or social media, should be considered.

- Clinical appointments should be timed to accommodate the activities of young people and families. For example, non-attendance at a 3pm clinic may be due to a parent needing to collect other children from school.

- All practitioners working with children should undertake training in: communicating effectively with children and young people; working with children and young people with disabilities, engaging families, including siblings, and adolescent healthcare. This could be through the use of free resources from e-Learning for Healthcare, such as the Adolescent Health project.\(^2^6\)

- All practitioners should have access to information and leaflets on support services for children, young people and families (including counselling, benefits advice, sexual health information and so on) which they can mention and discuss during consultations should there be an indication that additional support is needed.

**Tools to keep you in focus**

*Focus on: emergency and urgent care pathway for children and young people* is an NHS Institute for Innovation and Improvement document offering practical guidance on this area of healthcare. The document describes case studies and ways to measure for improvement and is accompanied by a tool on how to engage with children and young people to improve the planning and delivery of emergency and urgent healthcare services. There is a lesson plan for schools which includes how to contribute towards the design of better information and communications.\(^2^7\)

“All practitioners working with children should undertake training in communicating effectively with children and young people.”
A crucial aspect of engagement is to be able to monitor, quality assure, measure and identify the impact that the activity has made. The impact of engagement can be considered in the light of any associated improvements in service and facilities, as well as the level of investment. As part of this, it is important to separate out process measurement (evaluating the effectiveness of the engagement process) from impact measurement (evaluating the success of the engagement activity in improving outcomes or services).

Data collection is an essential part of measuring the level and success of engagement activities. This should be done together with providers, commissioners and other agencies to ensure it is robust.

Outcomes need to reflect the impact on children and families and include non-clinical outcomes, such as quality of life, longer-term impact on health, and clinical transition out of health services. There may also be explicit outcomes for specific groups. In the widest sense, outcomes may need to look at the rights that children and young people have exercised as a result of participation, and how this has increased their control over their lives. Outcomes may also be achieved in other parts of children and young people’s lives.

**Recommendations**

- There should be service-specific monitoring of engagement activity, identified and agreed at the start of a programme. All health services – including commissioners and service managers in primary, community and acute sectors – need to measure the engagement they carry out with children and young people, asking: Have we done it? Was it meaningful? What did we achieve as a result?

- Senior managers should put in place quality monitoring processes for the workforce and for providers. This should involve looking at training programmes, competency assessments, pre-consultant exams, school nurses and so on. For providers it may be possible to link engagement to quality, for example, through Commissioning for Quality and Innovation (CQUIN).

- All provider services should self-assess against Outcome One of the Care Quality Commission’s Essential Standards for Quality and Safety, using the tools available.

- With the consent of the young people involved, health services should publish results of engagement in visual representation as well as tangible evidence of the presence of children and young people at meetings and events.

- Health services should use a range of methods of collecting data about the quality of the service as experienced by the child or young person, for example, use of satisfaction surveys, did not attend figures and reasons for non-attendance. They should look at whether children and young people returned to the service and information gathered on social media forums and through other online approaches. Effective ways of involving young people in data gathering can include ‘mystery shopper’ surveys or patient reported experience measures (PREMs) developed with and for children and young people – as well as involving children and young people in patient environment action teams.

- Local partnerships should explore how young people can be involved in better quality assurance, for example: setting up a local young inspectors’ scheme; influencing Quality Impact Assessments that trusts complete; and considering impact on participation, using the Health and Wellbeing Board as a forum for accountability.
Supporting good practice

There is a key role at a national level for policy-makers to reinforce the importance of engagement with children and young people in healthcare. While the Government has set out its ambitions for ensuring children and young people are involved in their healthcare, the following recommendations will also help to ensure these are embedded.

Recommendations

- The National Commissioning Board and National HealthWatch should monitor, advise and help improve the participation of children and young people in local health structures and consider how effectively local agencies are involving them in the commissioning, planning, reviewing and governance of health services.

- There is a need to develop an evidence base about participation. This should look at participation methods, cost effectiveness (for example, evaluation of the Expert Patients Programme\textsuperscript{30}), research about the health benefits of engagement and evaluation of barriers to participation and how care is currently provided.

- The media profile of children and young people at national and sub-national levels needs to be improved. This includes focusing on messages around what makes a healthy child, rather than focusing on deficiencies and ill health.

- There is a need to develop a rolling programme of measurement that is underpinned by a national approach to sharing learning, for example, the development of a health and well-being measurement\textsuperscript{31} for and by children and young people and sharing guidance vertically. This needs leadership from sector bodies.

- The Care Quality Commission must ensure that participation of children and young people in service design and delivery is a requirement in inspection and self-assessment of provider services, as set out in Outcome One of the essential Standards for Quality and Safety.

- Ofsted must ensure that its inspection programme includes specific reference to involvement of children and young people in health services and report this in a way that can affect the Care Quality Commission’s risk assessment programme for service providers.

“There is a key role at a national level for policy-makers to reinforce the importance of engagement with children and young people in healthcare.”
Conclusion

Children and young people are key stakeholders in the health service and not just beneficiaries or passive recipients of services. Meaningful participation of children and young people in all aspects of the health system is important if health services are to remain relevant, high quality and holistic, and empower children and young people to feel valued, ultimately increasing their well-being.

The health reforms offer an excellent opportunity to ensure that health services for children and young people are fully participatory and responsive to their needs. In particular, local partnerships such as the Health and Wellbeing Board, local HealthWatch and new local plans and strategies, need to engage with children and young people as they are being set up to ensure that involvement is a core feature of health services in the future.

“… we cannot afford to continue as we are, the health of our children is at stake and we need to address real issues, with real change that brings about real positive impact on the health outcomes for children and young people.”
Professor Terence Stephenson, President, RCPCH

Next steps – events in 2012

Further work will continue in 2012 to monitor implementation of the recommendations raised in this report. We will focus on the core elements required to enable children’s health to benefit from the changes to the NHS by conducting regional workshops with child health professionals within commissioning and provider organisations.

For more details of our work in this area and details about the events, please contact:

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References

1. www2.ohchr.org/english/law/crc.htm#preamble
2. Kennedy, IA: Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs, Department of Health, September 2010
3. New report to be published in December from Contact a Family. www.cafamily.org.uk/campaigns/index.html
5. www.gmc-uk.org/guidance/good_medical_practice.asp
6. www2.ohchr.org/english/law/crc.htm#preamble
8. Healthy lives, healthy people: transparency in outcomes, proposals for a public health outcomes framework, Department of Health, December 2010
9. Quality criteria for young people friendly health services, Department of Health, May 2011
11. Not just a phase: a guide to the participation of children and young people in health services, Royal College of Paediatrics and Child Health, 2010
14. The joint strategic needs assessment: a vital tool to guide commissioning, NHS Confederation, July 2011
15. Is the voice of the child having an impact on the development of short breaks for disabled children? Together for Disabled Children, November 2010
16. Positive for youth – response to discussion paper young people’s health and wellbeing, Royal College of Paediatrics and Child Health, September 2011
17. Royal College of Paediatrics and Child Health, youth advisory panel
18. Not just a phase: a guide to the participation of children and young people in health services, Royal College of Paediatrics and Child Health, 2010
19. Not just a phase: a guide to the participation of children and young people in health services, Royal College of Paediatrics and Child Health, 2010
22. Parental responsibility, British Medical Association (BMA), February 2009
23. www.nhs.uk/young-cancer-care/Pages/index.aspx
24 GMC ethical guidance, 0–18 years: guidance for all doctors. www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp


26 www.e-lfh.org.uk/projects/ah/index.html

27 www.institute.nhs.uk/quality_and_value/high_volume_care/focus_on%3A_emergency_and_urgent_care_pathway.html


29 RCPCH has developed a Patient Reported Experience Measure for emergency services. www.rcpch.ac.uk/child-health/research-projects/prem/patient-reported-experience-measure-prem-urgent-and-emergency-ca

30 www.medicine.manchester.ac.uk/primarycare/npcrdc-archive/archive/PublicationDetail.cfm/ID/225.htm

31 As part of the Government’s new National Wellbeing Project, which aims to measure the well-being of the population, the Office of National Statistics has initiated a workstream to separately look at measures of children’s and young people’s well-being. www.ons.gov.uk/ons/rel/social-trends-rd/social-trends/uk-measures-of-national-well-being/measuring-national-well-being--discussion-paper-on-domains-and-measures.html

32 Professor Terence Stephenson, My right to the highest standard of health – Handbook, RCPCH, March 2011
Significant progress has been made in improving the health and well-being of children and young people over the last five years. However, some children and young people still fail to receive the highest standards of healthcare attainable – a right of all children as set out in Article 24 of the UN Convention on the Rights of the Child.

Children and young people are key stakeholders of the NHS and their interests must be at the centre of health and local government services. Meaningful participation of children and young people in all aspects of the health system is important if health services are to remain relevant, high quality and holistic.

The health reforms offer an excellent opportunity to ensure that health services for children and young people are fully participatory and responsive to their needs.

In order to generate consensus across child health professionals in the NHS and local government, the Royal College of Paediatrics and Child Health and the NHS Confederation, with support from the Office for Public Management, held an event in September 2011 to discuss the key priorities for child health and the reforms. This report highlights the key findings and recommendations from that event.