

# **REPORT OF THE CHILDREN AND YOUNG PEOPLE'S HEALTH OUTCOMES FORUM 2014/15 – Culture, Engagement and Voice Theme Group**

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## CULTURE, ENGAGEMENT AND VOICE

### Key questions and challenges for the system

- **The needs of children and young people should be reflected in services**

National, regional and local parts of the system – including NHS England, Public Health England, Health Education England, the Department of Health, NICE, Healthwatch, the Care Quality Commission, Ofsted, Monitor, health and wellbeing boards, clinical commissioning groups, local authorities, schools etc – must ensure that children and young people help shape their strategic planning, are engaged in their work and feed back about their services.

How are organisations ensuring this happens? How will they check it is working? How do they know what children and young people think about the services they provide, commission or monitor?

How are the needs and views of children and young people being reflected in the accountability and development of GP services? Could children and young people's views be collected in the GP patient survey or an equivalent? What progress has NHS England made with clinical commissioning groups in improving primary care services for children and young people?

- **Children and young people's engagement in their own care must be supported**

How are organisations helping children and young people to have informed input into decisions about their own care? Do services have effective training and support to enable this to happen?

What progress have organisations made to produce information for children and young people at different stages of development, maturity and abilities?

- **There must be leadership and accountability, nationally and locally, for children and young people's participation**

How are leaders and organisations being held to account, including ensuring that pledges made by the Department of Health, NHS England, Public Health England and others at Takeover Days and other engagement events are fulfilled?

Are there local lead professionals to hold the ring and effect change for individual children and young people to have their voice heard?

Why do providers and commissioners not have visible and effective children and young people's champions? What are they doing to deliver a children and young people centred culture and improved health outcomes for and with children and young people and their families and carers?

- **Equality must work in the participation agenda**

It is not clear to us that this is happening. How are organisations considering the specific needs and voices of the many diverse groups of children and young people, including those for whom communication is even more challenging?

- **There should be a review and detailed consideration of a full refresh of *You're Welcome***, to create a "Youth Health Offer" as recommended in the Chief Medical Officer's report.

How will *You're Welcome* be improved to include stronger messages on children and young people's rights in using health services, and how will it be effectively promoted across the system?

- **Local authorities, education (PSHE), Young People's Councils, Youth Parliaments and young people's champions need to interface and work with health and wellbeing boards** to get issues such as a children and young people friendly culture and children and young people's voice on their agendas, and to disseminate good practice.

Where is the evidence that this is happening? How will organisations ensure it does, and how will they check it is working?

## Children and young people's rights

Children and young people have rights to be supported in their health and wellbeing. These rights are articulated in the United Nations Convention on the Rights of the Child (UNCRC). The UK's ratification of the Convention commits the Government to realise its articles through domestic legislation and policies.

The Forum has committed to ensure that the UNCRC underpins everything it does – and that it acts as a role model for organisations to do so. Building on important work by the National Children's Bureau and the Council for Disabled Children, the Forum has put together an accessible digest of children and young people's rights in the UNCRC, domestic legislation, the NHS Constitution and elsewhere. We are putting this on our website to accompany this report and we hope it will prove valuable both for children and young people and their families and carers, and for professionals and organisations.

## Children and young people friendly culture

The Forum identified culture as a key focus of its work programme for 2014-15. We committed to work with the Department of Health to make sure the health service works towards getting the right culture for children and young people, as well as ensuring that the Forum itself has children and young people's voices at the heart of everything it does.

In its response to Ministers on the broad issues, as they relate to children and young people, raised in the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry by Robert Francis QC, the Forum called for a "universal children and young people friendly culture", in which the specific needs of children young people and their families are explicitly recognised and met. Informed by the views of children and young people themselves – expressed for example through the National Children's Bureau's consultation on the Forum's behalf regarding Francis, as well as through their direct feedback at the Forum's meetings – we have agreed a succinct definition of what a children and young people friendly culture looks like:

- Involving children and young people (and their families) in meaningful ongoing engagement in decisions about themselves, including consent to treatment – and providing them with a voice.
- Communicating with children and young people in ways that reflect the diversity of needs and methods required.
- Empowering children and young people themselves, promoting a common understanding of their rights as patients, and facilitating young people's independent access to services where they want it.
- Considering children and young people as whole beings, not as a physical condition needing attention, and with a focus on prevention and wellbeing.
- Treating children and young people in age and stage appropriate environments (eg appropriate for infants/ children/ young people/ wheelchair users etc), seeing the environment from a child's perspective and taking due account of the child's right to privacy and dignity.
- Recognising the importance of children and young people's families and of family-centred care and working in partnerships, and the impact of illness on all family members including siblings.
- Seeing children and young people in the context of their family and the community in which they live – including hearing their voices at the strategic level and taking their experiences and views seriously, as a measure of success and as a resource to inform improvement in all settings.

## Children and young people's engagement with the Forum

The Forum has sought to continue to improve its own engagement with children and young people, ensuring they actively shape our work and our key challenges back to the system. We are grateful for the work that the Association for Young People's Health, Brook, the National Children's Bureau, the Young People's Health Partnership and others have done to facilitate this.

Young people attended the Forum's Summit in June 2014 and have attended each meeting of the Forum since. Some of the issues they have highlighted are the need -

- to consider the role of advocates or ambassadors;
- to improve training of professionals;
- for better communication with young people;
- to find ways to publicise young people's rights;
- to recognise the importance of the voluntary and community sector's support for children and young people's engagement;
- for Healthwatch and others to be more innovative in recruiting young people with whom to engage; and
- to consider rewards for engagement.

The National Children's Bureau recently consulted with children under the age of 12 on how to improve communication with health professionals. The findings are consistent with those of much recent work addressing the issues around how health professionals talk with and listen to children and young people. Key messages were:

- healthcare staff need to be able to make younger children feel comfortable and able to talk;
- whilst the views of younger children generally reflect those of older children – for example, the universal importance of health professionals speaking directly to the child – there may be additional considerations to ensure shared understanding with younger children (such as the use of images in consultation); and
- consistency and continuity are important factors in helping younger children to feel able to talk with healthcare staff.

## Children and young people's national engagement

Significant work is being done at a national level to engage with children and young people. NHS England intends to roll out the Friends and Family Test to all areas, including children and young people, this year. The Care Quality Commission began a survey in autumn 2014 of the experiences of children and young people in inpatient and day care settings. We welcome this survey which will cover a number of areas identified as key gaps by the Forum, such as staying on an age-appropriate ward, feeling safe, and the provision of information about their condition in a way that the child or young person understands.

NHS England launched a new Youth Forum in March 2014, in collaboration with Public Health England and the Department of Health and supported by the British Youth Council. It has recruited young people from across England with a range of experiences of using health services. The Youth Forum has highlighted concerns relating to mental health, sexual health and communication, and is undertaking youth engagement work on these issues to influence service commissioners and providers.

The Forum has considered with Department of Health officials practical measures which could help the development of a children and young people friendly culture in the health service. This generated a proposal to produce a training film for health service staff, which would help change attitudes by encouraging staff to see their services through the eyes of children and young people. We were delighted when the Secretary of State for Health approved a grant towards the costs of making such a film.

The Evelina London Children's Hospital within Guy's and St Thomas' NHS Foundation Trust is collaborating on this project with Great Ormond Street Hospital for Children NHS Foundation Trust. The two Trusts have agreed to work with members of the Forum, as well as the Department of Health and NHS England. Children and young people themselves will be closely engaged in shaping the storyboard and making the film. We shall also help to consider how to maximise the film's impact and explore possibilities for producing sequels which could consider a range of conditions or stages.

The Forum would like to thank all the children and young people, and their families, who have engaged with us in shaping our work, and in particular this document.