An evaluation of the National Health Service [NHS] England Youth Forum

Executive Summary

A qualitative evaluation research study commissioned by NHS England and undertaken by the University of Hertfordshire

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Executive Summary

Background

More than five decades ago the Platt Report (Ministry of Health, 1959) recommended that hospitalised children needed to be treated differently to adults. It took until the 1980s for evidence to emerge that healthcare staff were beginning to implement Platt's recommendations; Davies (2010) attributes this long awaited change of approach to a new generation of practitioners and a renewed focus from the Government that acknowledged the distinct needs of children and young people. In the early 1990s James and Prout (1990) produced work to suggest that children should not be viewed as passive recipients of care but should be recognised as having their own voice, referred to as the "emergence of children's voice" (Hallett and Prout, 2003: 1). In 1991, having ratified the United Nations Convention on the Rights of the Child [UNCRC], the United Kingdom [UK] government committed to adhere to the convention:

"A universally agreed set of non-negotiable standards and obligations" (Unicef, 2015, http://www.unicef.org/ceecis/overview_1583.html)

The child's voice was one of the major themes to influence the convention and articles 12 and 24 are of particular importance in terms of guiding health professionals. Article 12 states that:

"Every child has the right to say what they think in all matters affecting them, and to have their views taken seriously" (Unicef, 2005, http://www.unicef.org/crc/files/Rights_overview.pdf)

Having signed the convention, the UK government is held internationally accountable to ensure children's rights are upheld across the scope of the government agenda and is obliged to formulate legislation, policy and practice in accordance with the convention (Unicef, 2005).

One of the seven core principles of the NHS is that patients will be at its heart (NHS Choices, 2013a). This guiding principle is one of the 'rules' governing the way that the NHS operates and is underpinned by core NHS values. The NHS Constitution

(UK DH, 2013a) outlines that the principles should be embedded at every level of the NHS and this is inclusive of both adult and children's services. Despite this, Sir Ian Kennedy's (2010) report stated that services in the NHS for children and young people have had low priority. This view has been acknowledged by others and guidance from the Chief Medical Officer's annual report in 2012 (UK DH, 2013b) supported it, hence the title "Our children deserve better: Prevention pays". The report made several recommendations based on listening to children and young people and highlighted that although there was evidence of continued effort by many professionals, as well as areas of good practice, there was an identified need for 'us to go further' (page 6)

It could be argued that the NHS has been providing an inequitable system whereby areas of good practice to involve and engage children and young people are still relatively limited. Kennedy (2010) stressed that there is no shortage of policies, guidance and frameworks released by the Department of Health in relation to children and young people, yet the difficulty remains in translating these into action. The Children and Young People's Health Outcomes Forum (2013) have published a response to the consultation on Refreshing the Mandate to NHS England 2014/15 and again it has been highlighted that children and young people:

"...struggle to get their voices heard, and are not involved in decisions about their own health" (page 6).

To redress the balance and to enable the voices of children and young people to be heard, NHS England along with Public Health England and the Department of Health launched the NHS England Youth Forum in March 2014.

Research focus

This report summarises the findings of a qualitative evaluation research study that was commissioned by National Health Service [NHS] England in October 2014 and undertaken by the University of Hertfordshire between October 2014 and March 2015.

The title of the study, as provided by NHS England, was an: *Evaluation of the NHS England Youth Forum*

In addition, the research team developed the following objective in order to refine the focus:

Objectives:

To utilise qualitative data collection approaches to enhance insight and understanding of the NHS England Youth Forum, its value, role and impact, by ascertaining the views and perceptions of:

- Young people who were members of the NHS England Youth Forum.
- Members of the Adult Reference Group that supports the NHS England Youth Forum.
- Employees who have played a pivotal role in terms of the organisation and implementation of the NHS England Youth Forum.

Methods

The evaluative nature of this research guided the approaches used with qualitative methods being drawn on to obtain data via:

- A focus group with five young people who were part of the NHS England Youth Forum.
- A focus group with five members of the Adult Reference Group that supports the NHS England Youth Forum.
- Semi-structured interviews with four employees who have played a key role in terms of the organisation and implementation of the NHS England Youth Forum.

Key findings

Summary of findings from the focus groups with young people

- Whilst it was only feasible for five members of the NHS England Youth Forum to participate in the focus group, there is evidence to suggest that young people are not only very capable of being involved in decision-making, but that they are highly motivated and committed to ensuring that the youth voice is represented and heard.
- The young people were fully aware of the selection and recruitment process that had underpinned the development of the NHS England Youth Forum – this was affirmed via other sources such as the Adult Reference Group focus group as well as the employee interviews; the whole process was transparent and appropriate.
- The young people were participating in a tremendous breadth of activities and initiatives; examples were also provided in relation to the impact that some of their work was having (for example, a review of the complaints process for young people – please refer to Section 3.2.4 of the main report).
- Whilst this study did not specifically focus on the benefits to the young people
 of being NHS England Forum members, the findings revealed that their
 involvement had been a very rewarding experience for them.
- There has been strong recognition of the work and role of the NHS England Youth Forum within a wide range of different arenas.
- There was a suggestion that the website associated with the NHS England Youth Forum could be further developed.
- The young people suggested that there were some challenges associated with being a member of the NHS England Youth Forum, these primarily focussed on the practicalities in terms of time and travel.
- There were differences of opinion amongst the Youth Forum members about the form that interaction with the wider public, in particular young people, should take.

Summary of findings from the focus group with the Adult Reference Group

- The participants who took part in the focus group spoke very highly of the NHS England Youth Forum and displayed a committed and enthusiastic approach to its work.
- The focus group revealed that the engagement between the Adult Reference Group and the NHS England Youth Forum was varied with some members taking more active roles than others. It was recognised that work responsibilities (related to their employed role) needed to be prioritised, but that, on occasions, more information could be provided about activities that the Adult Reference Group could potentially be involved in. The participants expressed a desire to be more overtly involved in the Forum work and for their skills, knowledge and expertise to be more fully drawn on.
- The participants affirmed that the young people were the decision-makers in terms of identifying the NHS England Youth Forum's agenda.
- The group suggested that there was potential to enhance the engagement of children and young people who are not themselves members of the NHS England Youth Forum.

Summary of findings from the interviews with the employees

- The NHS England Youth Forum was formed partially in response to key documents, but also due to the commitment of the employees in terms of enabling the voice of the young person to be heard.
- The funding for the NHS England Youth Forum has been provided by NHS England.
- The employees have provided considerable support to the NHS England Youth Forum.
- The partnership between the British Youth Council [BYC] and NHS England
 was highlighted and discussed very positively; however, it was suggested that
 the tripartite relationship between the Department of Health, Public health
 England and NHS England could be further developed.
- It was suggested that the production of regular short reports documenting activities and achievements of the NHS England Youth Forum would be beneficial.

- The role and remit of the Adult Reference Group was not clear to all participants.
- There were concerns in relation to the potential demands on the young people

 this appears to have increased as the NHS England Youth Forum has become more widely recognised.
- The development of the NHS England Youth Forum has been fast and productive.
- The NHS England Youth Forum is a unique model.

Recommendations

The findings from this evaluation research study have raised areas that may be worthy of further consideration in terms of the future development and work of the NHS England Youth Forum; the following recommendations are offered:

- Funding for the NHS England Youth Forum has been provided by NHS
 England, it is strongly recommended that funding continues as there is
 evidence of the very positive work that has been achieved to date; on-going
 funding will allow the Forum to further develop so that a broad range of
 children and young people can benefit in the future. It is suggested that
 potential co-funding from the other organisations in the tripartite relationship is
 explored.
- Regular documentation of (for example, on a quarterly basis) of the work being undertaken by the NHS England Youth Forum (in terms of both the time commitment and activities) would be beneficial – this would facilitate a record of the achievements, but also help to identify the staff and financial resources required to facilitate future development.
- The NHS England Youth Forum is strongly supported by the work of a number of personnel, both those employed by the BYC as well as NHS England itself; it is recommended that this continues as it will enable the young people to have access to the advice and support that they need, but will also ensure that the wealth of invitations to events are screened and prioritised.
- It is suggested that the tripartite relationship (between the Department of Health, Public Health England and NHS England), is reflected on and that consideration is given to how this potentially excellent partnership can be strengthened and developed.

- It is advocated that further consideration be given to how the work of the NHS England Youth Forum can be disseminated more widely so that a broader range of children, young people and health professionals have greater insight and understanding of its role and its achievements. One aspect of this could be the development of the NHS England Youth Forum website.
- It is suggested that it would be timely to reflect on the role of the Adult Reference Group to consider how it could potentially inform the future development of the NHS England Youth Forum.
- The NHS England Youth Forum appears to be a unique and inspirational model that has the potential to be widely and internationally recognised, it is therefore recommended that its work is strategically disseminated to provide insight to other countries who may wish to draw on a similar approach.