

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

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

## **Research Team:**

Dr. Lisa Whiting, Professional Lead, Children's Nursing, University of Hertfordshire  
Sheila Roberts, Senior Lecturer, Children's Nursing, University of Hertfordshire  
Jenni Etchells, Teacher/Clinical Facilitator, Children's Nursing, Hertfordshire Community NHS Trust

March 2015

**Address for correspondence:**

Dr. Lisa Whiting,  
Professional Lead, Children's Nursing,  
University of Hertfordshire,  
2F284, Wright Building,  
College Lane,  
Hatfield,  
Hertfordshire,  
AL10 9AB

[L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)

**This report should be referenced as follows:**

Whiting, L., Roberts, S. Etchells, J. (2015) *An evaluation of the NHS England Youth Forum. Final report.* University of Hertfordshire: Hatfield

**Disclaimer:**

This report presents an independent qualitative evaluation research study commissioned by NHS England and undertaken by the University of Hertfordshire. The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of NHS England. The views and opinions expressed by the participants in this report are theirs and do not necessarily reflect those of the authors or of NHS England.

**Copyright information:**

This report may be reproduced for the purposes of private research and study; in addition, excerpts may be included in professional journals or conference presentations as long as acknowledgement is given and there is no association with advertising.

## Table of Contents

| <b>Section</b> | <b>Content</b>  | <b>Page Number</b> |
|----------------|---|--------------------|
|                | Acknowledgements  | 7                  |
|                | Executive Summary   | 8                  |
| 1.0            | The Report: Introduction and background                                       | 15                 |
| 1.1            | Introduction  | 15                 |
| 1.2            | Background  | 16                 |
| 1.2.1          | Listening to patients: Setting the agenda                                     | 17                 |
| 1.2.2          | Listening to children and young people  | 19                 |
| 1.2.3          | Listening to children and young people in healthcare: Current initiatives     | 21                 |
| 1.3            | Background information: NHS England Youth Forum                               | 23                 |
| 1.4            | Definition of key concepts  | 25                 |
| 1.4.1          | Young person  | 25                 |
| 1.4.2          | Adult Reference Group member  | 25                 |
| 1.4.3          | Employee  | 25                 |
| 1.5            | Conclusion  | 25                 |
| 2.0            | Undertaking the research: Methodological approach and data collection methods | 26                 |
| 2.1            | Introduction  | 26                 |
| 2.2            | Methodological approach: Evaluation research                                  | 26                 |
| 2.3            | Data collection tools   | 28                 |
| 2.3.1          | Focus groups  | 28                 |
| 2.3.2          | Interviews  | 28                 |
| 2.4            | Recruiting the participants   | 29                 |
| 2.4.1          | Recruiting the participants: NHS England Youth Forum members                  | 30                 |

|       |  |    |
|-------|--|----|
| 2.4.2 | Recruiting the participants: Adult Reference Group members   | 30 |
| 2.4.3 | Recruiting the participants: Employees   | 31 |
| 2.5   | Data Collection procedures: Focus groups and interviews  | 32 |
| 2.6   | Ethical considerations   | 33 |
| 2.6.1 | Ethical approval   | 33 |
| 2.6.2 | Protecting the participants from harm  | 33 |
| 2.6.3 | Confidentiality  | 34 |
| 2.6.4 | Consent  | 34 |
| 2.7   | Data analysis  | 35 |
| 2.8   | Conclusion   | 36 |
| 3.0   | Findings   | 37 |
| 3.1   | Introduction   | 37 |
| 3.2   | Findings from the focus group with young people  | 37 |
| 3.2.1 | Theme: <i>"If we start debating about the age then we're missing the real point"</i> : Membership of the NHS England Forum | 38 |
| 3.2.2 | Theme: <i>"The work we do is a reward in itself"</i> : Personal commitment   | 39 |
| 3.2.3 | Theme: <i>"What we do"</i> : The role of the young people  | 40 |
| 3.2.4 | Theme: <i>"We want to influence"</i> : The impact of the NHS England Youth Forum   | 42 |
| 3.2.5 | Theme: <i>"Trying to strike a balance"</i> : Representing the voice of children and young people                           | 43 |
| 3.2.6 | Summary of findings from the focus groups with young people  | 45 |
| 3.3   | Findings from the focus group with the Adult Reference Group   | 46 |
| 3.3.1 | Theme: <i>"The main engagement"</i> : Engaging with the NHS England Youth Forum  | 47 |

|       |   |    |
|-------|---|----|
| 3.3.2 | Theme: “ <i>Coming from the young people</i> ”: The focus and value of the NHS England Youth Forum work                             | 49 |
| 3.3.3 | Theme: “ <i>Spread the word</i> ”: Engaging with the wider children and young people’s population                                   | 50 |
| 3.3.4 | Summary of findings from the focus group with the Adult Reference Group   | 51 |
| 3.4   | Findings from the interviews with the employees   | 52 |
| 3.4.1 | Theme: “ <i>So that’s a key driver</i> ”: The inception of the NHS England Youth Forum  | 52 |
| 3.4.2 | Theme: “ <i>The progress that has been made</i> ”: The achievements, to date, of the NHS England Youth Forum                        | 55 |
| 3.4.3 | Theme: “ <i>We’re not quite sure how it’s actually going to go forward</i> ”: What the future holds for the NHS England Youth Forum | 59 |
| 3.4.4 | Summary of the findings from the interviews with the employees  | 62 |
| 3.5   | Conclusion  | 63 |
| 4.0   | Conclusions   | 64 |
| 4.1   | Introduction  | 64 |
| 4.2   | A summary of the main findings  | 64 |
| 4.2.1 | Focus group with young people   | 64 |
| 4.2.2 | Focus group with the Adult Reference Group  | 65 |
| 4.2.3 | Interviews with the employees   | 66 |
| 4.3   | Recommendations   | 67 |
| 4.4   | Dissemination of the findings   | 68 |
| 4.5   | Limitations of the project  | 68 |
| 4.6   | Suggestions for future work   | 69 |
| 4.7   | Conclusion  | 69 |
|       | References  | 71 |

## **Figures within the Text**

| <b>Figure</b> | <b>Title</b>                         | <b>Page Number</b> |
|---------------|--------------------------------------|--------------------|
| Figure 1.1    | Ladder of Participation (Hart, 1992) | 20                 |

## **Tables within the Text**

| <b>Table</b> | <b>Title</b>  | <b>Page Number</b> |
|--------------|---|--------------------|
| Table 1.1    | Chronology showing involvement of patients in the NHS from 1973   | 18                 |
| Table 1.2    | Key terms used to conceptualise listening to the voice of children and young people (Participation Works, 2010) | 19                 |
| Table 2.1    | Evaluation research approaches  | 27                 |
| Table 2.2    | Employees who have played a pivotal role in relation to the NHS England Youth Forum                             | 32                 |
| Table 2.3    | Checklist of points for explanation prior to interview  | 33                 |
| Table 3.1    | Details of the young people who participated in the NHS England Youth Forum focus group                         | 37                 |
| Table 3.2    | Details of the people who participated in the Adult Reference Group focus group                                 | 46                 |

## **Appendices**

| <b>Appendix</b> | <b>Title</b>  | <b>Page Number</b> |
|-----------------|---|--------------------|
| 2.1             | Conduct sheet: Focus group facilitators                                 | 77                 |
| 2.2             | Focus group prompt questions: Schedule for young people                 | 79                 |
| 2.3             | Focus group prompt questions: Schedule for Adult Reference Group        | 81                 |
| 2.4             | Interview Prompt Questions: Schedule for Employee Interviews            | 83                 |
| 2.5             | Young People Information Sheet  | 85                 |
| 2.6             | Adult Reference Group Information Sheet                                 | 87                 |
| 2.7             | Employee Information Sheet  | 89                 |
| 2.8             | Support Services Information Sheet, young people                        | 91                 |
| 2.9             | Support Services Information Sheet, Adult Reference Group and employees | 92                 |
| 2.10            | Consent form  | 93                 |

## **Acknowledgements**

The research team would like to gratefully acknowledge the contributions made by the following people - without their participation and involvement, the study would not have been feasible:

- NHS England for commissioning and funding the project.
- All of the participants who took part in the study and who gave their time so willingly, but especially the young people from the NHS England Youth Forum.

## **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](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](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.

# The Report

## Section 1.0: Introduction and background

### 1.1 Introduction

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 are 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.*

Information in this report is derived from data collected via:

- A focus group conducted with young people who were members of the NHS England Youth Forum.
- A focus group conducted with the Adult Reference Group who support and advise the NHS England Youth Forum.
- Individual face-to-face semi-structured interviews that were undertaken with employees who have played a key role in the development and implementation of the NHS Youth Forum.

All aspects of the project, including the writing of this report, were undertaken by the research team: Lisa Whiting (Project Lead) [LW], Sheila Roberts [SR] and Jenni Etchells [JE].

## 1.2 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](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](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)

There is growing recognition that events in childhood can affect health and wellbeing in later life (UK DH, 2011a; UK DH, 2013a; Marmot, 2010). A comprehensive literature review by Moore and Kirk (2010) described how children feel ‘valued’ and ‘less anxious’ when included in their care and listened to, as opposed to ‘angry’ and ‘upset’ when they are not. In summary, there is growing appreciation that listening to children and young people’s unique views and experiences of healthcare develops their confidence, co-operation and helps them cope better with treatment (Lansdown, 2011).

### **1.2.1 Listening to patients: Setting the agenda**

Although it is claimed that patient choice in the NHS has been promoted since its inception (NHS Choices, 2015), 1973 is considered the first real attempt by government to give patients a voice in relation to healthcare design and delivery (House of Commons Health Committee, 2007). Table 1.1 highlights the key strategies that have been implemented to support the involvement of patients as service users in the NHS - although children and young people’s services are not specifically referred to, the whole foundation of the NHS has always been to deliver care from the ‘cradle to grave’ (NHS choices, 2015).

As a result, all policy relating to the NHS should also implicitly refer to children and young people.

| <b>Year and political party</b>   | <b>Legislation/policy</b>  | <b>Key points</b>   |
|---|--|---|
| 1973<br>Conservative  | <i>NHS Reorganisation Act (1973)</i>   | People were considered as consumers and began to experience some choice in treatment received (NHS choices 2013b).  |
| 1974<br>Labour  | <i>Democracy in the National Health Service (Department of Health and Social Security, 1974)</i> | Outlined plans for widening participation in Area Health Authorities (NHS choices, 2013b).  |
| 1974<br>Labour  | <i>Formation of Community Health Councils [CHCs]</i>   | <i>"The establishment of CHCs represented the first substantial attempt by Government to give the user, or potential user, of healthcare services a voice in their design and operation"</i> (House of Commons Health Committee, 2007, <a href="http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/27806.htm">http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/27806.htm</a> ). |
| Community Health Councils remained the dominant means of Patient and Public involvement for 25 years (House of Commons Health Committee, 2007). |  |   |
| 1997<br>Labour  | <i>The new NHS (UK DH, 1997) – White Paper</i>   | Relayed Blair's underpinning philosophy of the 'Third Way' - presented as a "system based on partnership and driven by performance" (UK DH, 1997: 14).  |
| 2001<br>Labour  | <i>Health and Social Care Act (2001)</i>   | Gave the NHS a duty to involve the public.  |
| 2003<br>Labour  | <i>Patient and Public Involvement Forums [PPI]</i>   | Set up to encourage public participation in contributing to the development of the local health service (House of Commons Health Committee, 2007).  |
| 2007<br>Labour  | <i>Our NHS, Our Future (UK DH, 2007a)</i>  | For the first time, a review of the NHS that directly engaged patients as well as NHS staff.  |
| 2008<br>Labour  | <i>Local Involvement Networks (LINKs)</i>  | LINKs replaced Patients' Forums and the Commission for Patient and Public Involvement in Health stopped.  |
| 2009<br>Labour  | <i>NHS Constitution</i>  | First document that identified the rights of patients and the pledges that the NHS needed to meet (NHS choices, 2013c).   |

**Table 1.1: Chronology showing involvement of patients in the NHS from 1973**

There have also been a range of key documents that have had a direct impact on children and young people, particularly in relation to the recognition of the need to listen to their voice (for example: Human Rights Act, 1998; Children Act, 1989, 2004; UK Department for Education and Skills, 2004; Department for Children, Schools and Family, 2007; UK DH, 2004, 2010a, 2012a). However, despite the many Government publications and targets, Kennedy's (2010: 88) report reiterated the need to:

*“ensure that the needs of children and young people are addressed, and in addressing them, that young people in particular are heard and listened to”.*

### 1.2.2 Listening to children and young people

Listening to children and young people embraces key terms in which a range of activities are drawn on in order to engage with them (Table 1.2).

| Term               | Definition  |
|--------------------|---|
| <i>Consult</i>     | The process by which children and young people are asked their opinions. This can be in relation to a specific issue or it can have a broader agenda. Consultation requires a commitment to listen and give due weight to the views expressed. It can be informal and every day or it can be formal and a one-off activity. |
| <i>Participate</i> | The process by which individuals, and groups of individuals, can influence decision-making and bring about change.  |
| <i>Involve</i>     | Describes the inclusion of children and young people in some form of decision-making.   |
| <i>Engage</i>      |   |

**Table 1.2: Key terms used to conceptualise listening to the voice of children and young people (Participation Works, 2010)**

Davey et al. (2010) suggests that the word ‘participation’ is the one most commonly used; Hart (1992) offered ‘The Ladder of Participation’ (Figure 1.1) which depicts eight levels that outline different forms and stages. Hart (1992) states that the first three steps of the ladder are non-participation whereas the higher rungs refer to ‘real’ participation. It has been suggested that only the top three levels commit to providing feedback and evidence to children and young people that their participation has positively influenced the development of services.

It appears to be universally agreed, both within more generic literature and government policy, that listening to children and young people requires a feedback process that informs them of how their voice has been ‘used’ to inform subsequent service delivery (Blades et al., 2013; UK DH, 2013b; UK DH, 2004). The reality of achieving this in healthcare is varied (Blades et al., 2013; La Valle & Payne, 2012; Moore & Kirk, 2010) and can be challenging.

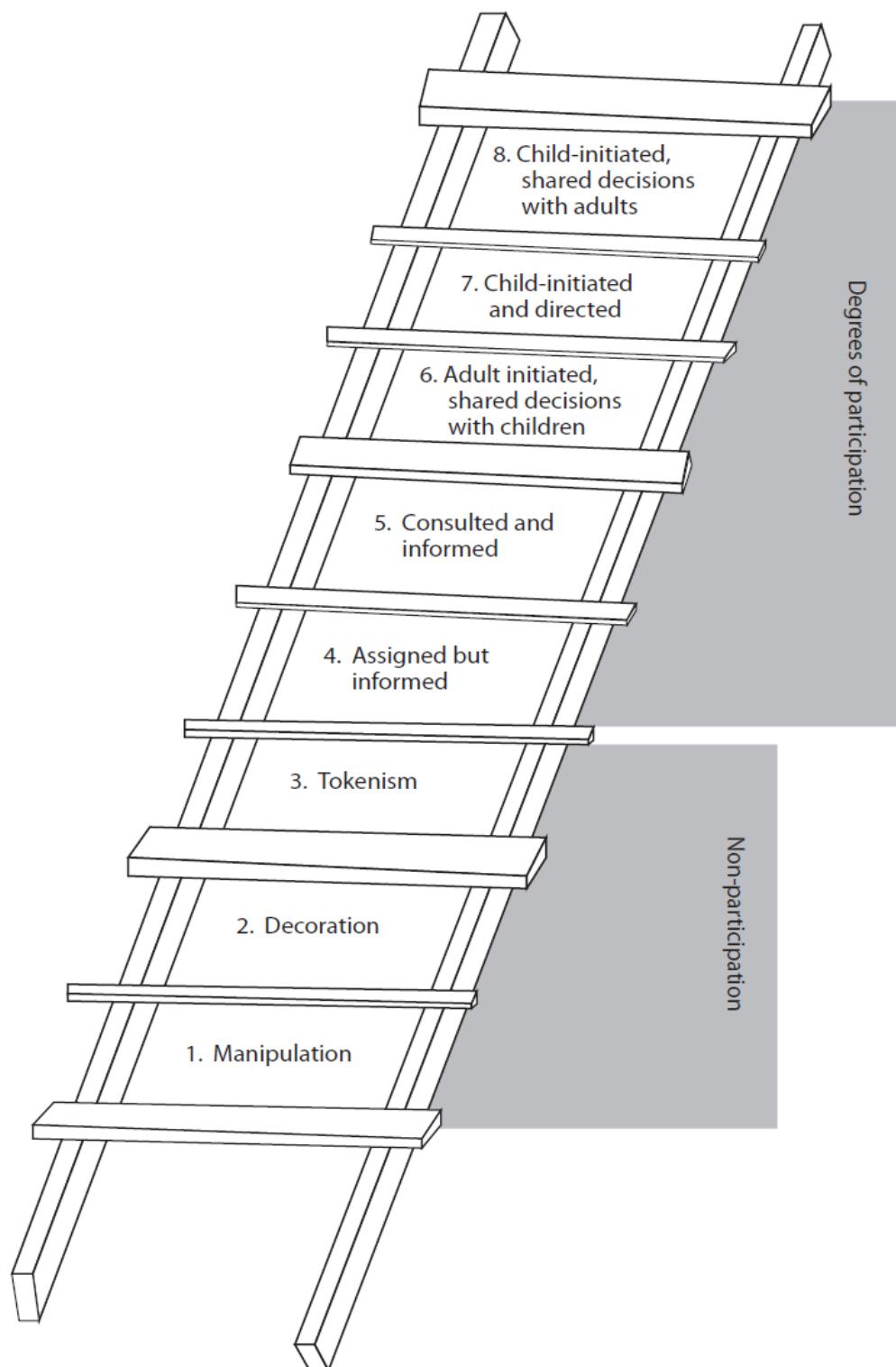


Figure 1.1: Ladder of Participation (Hart, 1992)

### **1.2.3 Listening to children and young people in healthcare: Current initiatives**

There are a number of strategies that have been designed and implemented so that the voice of the child and young person, within a health arena, can be heard. For example, at national level, the introduction of Healthwatch<sup>1</sup> occurred as a direct result of 'Equity and Excellence for Children' (UK DH, 2010b); Healthwatch is committed to capturing the voices of consumers and ensuring that they are heard by those commissioning, delivering and regulating health services (Healthwatch, 2014). Much work has been done since 2010 by the National Children's Bureau [NCB], funded by the Department of Health, to work with LINks [Local Involvement Networks] and local Healthwatch pathfinders to champion engagement with children and young people (NCB, 2013a). Additionally, extensive guidance has been published in relation to the engagement of children and young people within Healthwatch (Healthwatch England, 2013). Despite this, analysis of the Department of Health website, and the 75 pathfinder projects presented, revealed that just five mentioned children and young people (Davies and Clancy, 2013; Young Minds, 2012). Furthermore, a report by the NCB in Autumn 2013, found that local Healthwatch services were not supported well enough to involve children and young people – neither were they equipped to champion their voices (NCB, 2013b). Young Minds (2012) argues that unless children and young people are involved from the outset of Healthwatch it will be harder for them to participate in structures that have already been created. Unfortunately, there does not appear to be a formal report that has provided the views of children and young people in relation to Healthwatch at this stage.

Another national strategy to engage children and young people's voices is 'The Friends and Family Test<sup>2</sup>', which is to be rolled out to all areas of the NHS from 2015 (Patient Experience Network, 2013). Separate engagement guidance is available to promote those with particular needs, including

---

<sup>1</sup> Healthwatch was introduced as part of the Health and Social Care Act (2012) and is the national consumer champion in health and social care (Healthwatch, 2014).

<sup>2</sup> The Friends and Family test is a way of gathering feedback about patient experience and helping to drive improvement in the NHS. It intends to improve the experience of patients in line with Domain 4 of the NHS Outcomes Framework (UK DH, 2013c).

children and young people (NHS Constitution, 2014); for example, the Monkey that appears in the NHS Institute for Innovation and Improvement Primary School Resource Pack, has been developed with Monkey offering developmentally appropriate ‘Friends and Family Test’ questions to enable children’s voices to be heard (Monkey Wellbeing, 2014) - this is especially important because they have previously been excluded from patient surveys (Hargreaves & Viner, 2012). However, on examination of the children and young people’s NHS Constitution (2014) guidance, the term ‘*wherever possible*’ precedes the basis of asking children and young people to participate in the process; it is worthy of note that this phrase does not appear anywhere else in the guidance for engagement documents (NHS Constitution, 2014) or the implementation guidance (UK DH, 2012b).

Within local areas, initiatives including ‘You’re Welcome’<sup>3</sup> are still being encouraged and a renewed pledge by the Children and Young People’s Health Outcomes Forum to implement this was published in April 2014. ‘You’re Welcome’ has been operationalised on various levels throughout the country (UK DH, 2007b; UK DH, 2011a); however, as there is no national evaluation of ‘You’re Welcome’ planned (UK DH, 2011b), this again potentially creates inconsistencies in the uptake of specific initiatives and the overall commitment to embed young people’s voices at the heart of the NHS. What is promising however is that ‘You’re Welcome’ has undergone expansion since launching in 2005 and despite the change of Government, which is a known identifier for the discontinuation of policy initiatives (Handsley, 2007), there has been continued reinforcement of its benefits (Davies, 2013; Kennedy, 2010; UK DH, 2010b).

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

---

<sup>3</sup> ‘You’re Welcome: Quality criteria for young people friendly health services’ sets out principles to help commissioners and service providers to improve the suitability of NHS and non NHS services for young people (UK DH, 2011a).

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, the NHS England Youth Forum was launched in March 2014.

### **1.3 Background: NHS England Youth Forum**

In order to meet the national agenda of ensuring children and young people are represented, involved and have their voice heard across the NHS, discussions took place with key stakeholders from NHS England (Patient Experience and Public and Patient Voice), Public Health England and the Department of Health - a tripartite approach being adopted to avoid repetition across the different organisations. The NHS England Youth Forum aimed to meet key objectives of involving children and young people but also to act as a role model for other organisations such as Clinical Commissioning Groups. The British Youth Council [BYC], who has national coverage and an outreach of approximately seven million young people, were given the responsibility of managing the NHS England Youth Forum.

The BYC work closely with a range of other youth sector partners, for example Whizzkids, National Children's Bureau, Brook, Sense and the Council for Disabled Children – representatives from these organisations formed an Adult Reference Group. The Adult Reference Group, which was convened prior to the recruitment of the young people, meets every six to eight weeks and acts in a supportive and advisory capacity to the NHS England Youth Forum.

The purpose of the NHS England Youth Forum is to:

- Work with a diverse range of children and young people who can bring their perspectives and experiences of healthcare services.
- Seek advice from children and young people about key areas of strategic healthcare policies and national programmes.
- Enable young people to hold commissioners and executive board members to account.
- Listen to children and young people's experiences and ideas for health services improvement.
- Work with children and young people and their respective communities to understand how better services can be commissioned.

The NHS England Youth Forum comprises of twenty young people (aged 15-21 years). BYC were responsible for recruiting the initial members; nine young people were elected by the BYC from the nine English regions, each of these young people already held roles as, for example, youth councillors, young mayors or members of the UK Youth Parliament. They demonstrated that they were confident communicators and able to effectively challenge issues. The remaining 11 places were appointed based on the strength of the young person's application, but also ensuring that there was fair geographical, gender, age and disability representation across England; applications were received from approximately 200 interested young people and the final 11 members were selected by the original nine young people who had been appointed by BYC. The young people communicate with each other through pre-arranged residential meetings held three times a year as well as via a 'closed' Facebook page (supported and monitored by a BYC employee); in order to reach out to a wider population of children and young people there is also an 'open' Facebook page. Outside of the pre-arranged residential events, the young people are invited to a variety of meetings and conferences where they are able to engage with key stakeholders across a range of health services.

This report presents the qualitative evaluation research study that was undertaken to evaluate the NHS England Youth Forum.

## **1.4 Definition of key concepts**

For the purposes of this research study, the following definitions are offered:

### **1.4.1 Young person**

A young person refers to someone who is between the ages of 15 and 21 years (this was chosen to reflect the ages of the membership of the NHS England Youth Forum). Each young person consented to their participation in the study.

### **1.4.2 Adult Reference Group member**

An Adult Reference Group member refers to someone who formed part of the Adult Reference Group that supports and advises the NHS England Youth Forum. Each person consented to their participation in the study.

### **1.4.3 Employee**

An employee refers to someone whose work responsibilities included having a pivotal role in terms of the organisation and implementation of the NHS England Youth Forum. Each person consented to their participation in the study.

## **1.5 Conclusion**

This initial section has provided background information as well as introducing the aim and focus of the study that was undertaken. This report consists of 3 further sections together with a reference list and a series of appendices.

Section 2.0: Identifies and discusses the research data collection approaches, participant recruitment methods, ethical issues and data analysis procedures.

Section 3.0: Presents the findings that emerged following data collection and analysis.

Section 4.0: This section concludes the report by considering the contribution to knowledge that the research has made; its limitations and suggestions for further work. Finally, closing comments are offered.

## **Section 2.0: Undertaking the research: Methodological approach and data collection methods**

### **2.1 Introduction**

This section will provide an overview of each aspect of the research process that was undertaken within the study. 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.

Initially, the methodological approach will be discussed; this will be followed by an overview of the data collection tools, recruitment processes, data collection procedures, ethical considerations and analysis.

### **2.2 Methodological approach: Evaluation research**

The use of evaluation research has become well established within nursing and health professions in recent years; this is partly due to the increased need to assess the effectiveness of organisations such as the NHS (Moule and Goodman, 2014). An evaluation research approach was adopted for this study as this “*methodology is used to measure the worth or merit of something*” (Ellis, 2010: 110) – this is congruent with the key objective of the research.

Bowling (2009) identifies that evaluation research takes two forms: Formative and summative; it was the formative type that was appropriate to this study since the research focussed on collecting data whilst the NHS England Youth Forum was both in the early stages of its inception, and, was also fully active; formative evaluation research aims to develop and enhance programmes, whilst the summative version

normally occurs when assessing whether aims have been met and if a programme should be repeated (Ellis, 2010).

Moule and Goodman (2014) identify different approaches to evaluation research (Table 2.1).

**Goal-orientated:**

The aim is to measure whether an intervention has achieved specific, precise and measurable goals.

**Experimental:**

The aim is to generate findings that are generalisable; the focus is on analytical methods and quantifiable data.

**Goal-free:**

The emphasis on goals can mean that important data is missed. This approach focusses more on whether the needs of the individuals/locality are being met.

**Utilisation focused:**

This evaluation approach suggests that an intervention/programme should be judged on its usefulness to its intended users. Therefore, the primary users should be identified, engaged and involved throughout the evaluation.

**Economic:**

This form of evaluation involves quantifying and costing the resources that are involved in an intervention/programme.

**Mixed method:**

The approach utilises both quantitative and qualitative research data collection approaches.

**Table 2.1: Evaluation research approaches**

A goal-free strategy was drawn on for this study since this allows the researcher to:

*“probe aspects of the intervention that are not precise or easily measured. Data, therefore, will be qualitative, and it is likely that the researcher will interact with participants whilst collecting data, such as when conducting interviews.”* (Moule and Goodman, 2014: 226)

In goal-free evaluation research, it is common practice for personnel who are external to the programme to conduct the work (Moule and Goodman, 2014) as this enhances objectivity – this was the case with this study.

Parahoo (2014) suggests that evaluative research lends itself to qualitative and/or quantitative data collection methods, it is important however, that these reflect the overall research objectives as well as the resources available (Moule and Goodman,

2014). As this study evaluated the NHS England Youth Forum, it was imperative that the key people involved with its organisation and implementation were invited to participate in the research. A small scale study such as this lends itself to qualitative data collection processes as this not only facilitates a full and comprehensive understanding of the participants' perspective, but underpins a goal-free evaluation research approach.

## **2.3 Data collection tools**

### **2.3.1 Focus groups**

Two focus groups were conducted, one with five young people who were part of the NHS England Youth Forum and one with five members of the Adult Reference Group. Focus groups have many of the advantages of individual interviews, such as the ability to explore the participants' experiences; however, they also have the benefit of being economical with time and allowing for the gathering of data from participants who may be reluctant to be interviewed on their own or who feel that they have little to say (Lane et al., 2001). In addition, Stewart et al. (2007) suggest that focus groups are an ideal qualitative data collection approach to utilise at the beginning of a study as the information gleaned can then be explored in more depth via other methods, such as interviews; this was the strategy adopted for this research with the two focus groups being conducted prior to the four individual face-to face interviews. Guidelines for the conduction of the focus groups were drawn up (Appendix 2.1) together with a set of 'prompt' questions to maintain consistency and maximise data gathering (Appendices 2.2; 2.3).

### **2.3.2 Interviews**

Individual interviews were undertaken with four employees. Interviews are now one of the most commonly used methods of collecting data (DiCicco-Bloom and Crabtree, 2006) with a number of texts (Burns and Grove, 2005; Fontana and Frey, 2005; Polit and Beck, 2006) differentiating between their types (structured; semi-structured and unstructured). It was the semi-structured approach that was felt to be most appropriate for this study as it

provided the employed staff with the opportunity to talk about their experiences, whilst also allowing the use of a set of appropriate ‘prompt’ questions to optimise the data collection (Appendix 2.4).

## **2.4 Recruiting the participants**

Burns and Grove (2005) suggest that the term ‘sample’ refers to the population chosen to participate in a study; as sampling can have a major impact on the findings (Burns and Grove, 2005), it is important to give appropriate consideration to the sample selection.

Sample sizes in qualitative work can be difficult to establish in advance, however, smaller numbers of participants are normally involved due to the richness and detail of data that can be obtained (Macnee, 2004); in fact Parahoo (2014) comments that time is better spent undertaking in-depth interviews, rather than being concerned with interviewing large numbers of participants. In addition, the composition and characteristics of the sample population can be more important than the size alone (Macnee, 2004). Qualitative projects frequently utilise a purposive sampling technique to help ensure that participants most suited to the needs of the study are invited to take part (Polit and Beck, 2006) – three key groups of people were recruited for this study, using a purposive sampling approach:

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

The recruitment strategies employed are detailed in the following sections (2.4.1 – 2.4.3).

#### **2.4.1 Recruiting the participants: NHS England Youth Forum members**

It was crucial to embrace the knowledge and expertise of the young people who are members of the NHS England Youth Forum, especially when this study has the potential to inform future policy that could impact on their lives as well as those of other children and young people. A BYC employee, who was the day-to-day coordinator of the NHS England Youth Forum, was approached on 24<sup>th</sup> September 2014 to ascertain if the young people could be invited to participate in the research. Following discussions, it was agreed that since they all lived in diverse geographical locations, the most appropriate consultation route was via a focus group during the next scheduled residential weekend (November 2014). Grieg et al. (2013: 174) comment on the benefits of adopting qualitative approaches such as this when participants are children or young people as this facilitates "*rich descriptions in words and pictures that capture their experiences and understandings.*"

Following the receipt of ethical approval, all 20 of the NHS England Youth Forum members were sent an Information Sheet (Appendix 2.5) by the BYC employee and invited to participate in a focus group. All five of the young people who attended the residential weekend consented to take part (please refer to Section 2.6.4) - the focus group was subsequently held in South East England on Saturday 15<sup>th</sup> November 2014.

#### **2.4.2 Recruiting the participants: Adult Reference Group members**

The World Health Organization (2010) suggest that a reference/advisory panel comprises of experts who are able to provide "*support within a particular subject, either by correspondence or at meetings to which the experts may be invited*"

([http://www.who.int/rpc/expert\\_panels/Factsheet\\_EAP2010.pdf](http://www.who.int/rpc/expert_panels/Factsheet_EAP2010.pdf)).

The members of the Adult Reference Group that supports the NHS England Youth Forum are all representatives from organisations that are involved with children and young people, examples include: Whizzkids, National Children's Bureau, Brook, Sense and the Council for Disabled Children. Their role is to

act in an advisory capacity to the NHS England Youth Forum, making suggestions relating to its organisation and development – this is done via meetings held on a six to eight weekly basis. Consultation with members of this group was therefore an important aspect of the NHS England Youth Forum evaluation.

An NHS England employee, who acts as chairperson for the Adult Reference Group, was approached to ascertain if the members could be invited to participate in the research study. It was agreed that the most appropriate consultation route was via a focus group held at the end of the next scheduled meeting. It was felt that a focus group would enable the members to share their experiences as well as being a strategy that maximised time usage.

Following the receipt of ethical approval, Information Sheets (Appendix 2.6) were provided (on 18<sup>th</sup> November 2014) for the chairperson to distribute to the Adult Reference Group membership; all five who attended the meeting consented to participate in the focus group (please refer to Section 2.6.4) which was duly held in South East England on Friday 28<sup>th</sup> November 2014.

#### **2.4.3 Recruiting the participants: Employees**

There were five employees who had played a pivotal role in the development, implementation and operationalisation of the NHS England Youth Forum. In order to identify these people, a ‘good informant’ approach was utilised; Morse (1989: 132) highlighted the following qualities of a ‘good informant’ and these attributes were used to guide the selection of participants for this aspect of the study:

1. Knowledgeable about the topic: An expert by virtue of involvement in specific life events.
2. Able to reflect and provide detailed experiential information about the phenomena.
3. Possess a willingness to talk.

The initial ‘good informant’ was an employee at NHS England who was able to identify colleagues (Table 2.2) who the team could approach to request involvement in the research.

| Pseudonym name of employee      | Employer    | Participation in Research |
|---------------------------------|-------------|---------------------------|
| Jess [initial ‘good informant’] | NHS England | Yes                       |
| Hannah                          | NHS England | Yes                       |
| Shaz                            | NHS England | No                        |
| Beth                            | BYC         | Yes                       |
| Paul                            | BYC         | Yes                       |

**Table 2.2: Employees who have played a pivotal role in relation to the NHS England Youth Forum**

Once ethical approval had been granted, each of the five employees was contacted via email inviting them to participate in a face-to-face semi-structured interview; full details of the study, including an Information Sheet (Appendix 2.7) were sent with the email. Four of the five employees accepted the invitation; a mutually convenient date and time was then arranged. All interviews were conducted in the employees’ place of work.

## **2.5 Data collection procedures: Focus groups and interviews**

Two focus groups were conducted - two members of the research team (SR and LW) were present at each one:

- Saturday 15<sup>th</sup> November 2014: Five of the young people who were members of the NHS England Youth Forum participated.
- Friday 28<sup>th</sup> November 2015: Five of the members of the Adult Reference Group participated.

The focus groups lasted for 60 minutes 13 seconds and 47 minutes 9 seconds respectively. Guidelines for the conduction of the focus groups were drawn up together with a set of ‘prompt’ questions to maintain consistency and facilitate data collection (Appendices 2.1; 2.2; 2.3).

All interviews were conducted by a member of the project team (SR) with each interview lasting for between 32 minutes 28 seconds and 68 minutes 19 seconds. An

interview checklist was prepared that identified practical arrangements and areas to be clarified with each participant (Table 2.3). In addition, ‘prompt’ questions (Appendix 2.4) were used to stimulate discussion.

- Purpose of interview.
- Clarification of topic under discussion.
- Format of interview.
- Approximate length of interview.
- Assurance of confidentiality.
- Purpose and use of digital recorder (including consent for its use).
- Assurance that the participant can seek clarification of questions.
- Assurance that the participant can decline to answer a question(s) or terminate the interview.
- Assurance that the participant can ask questions.

**Table 2.3: Checklist of points for explanation prior to interview**

Each interview and focus group was recorded using a digital-audio recorder. All participants consented to the use of the digital recording. No supplementary written notes or memos were taken during the interview/focus group as it was felt that this would be distracting.

## **2.6 Ethical Considerations**

There are a number of ethical considerations that need to be taken into account with any study if the participants are to receive the protection which they deserve. In particular, protection from harm, maintenance of confidentiality and the gaining of informed consent are crucial issues, these are addressed in Sections 2.6.1 – 2.6.4.

### **2.6.1 Ethical approval**

Ethical approval to conduct all aspects of the study was sought and gained from the University of Hertfordshire Health and Human Sciences ethics committee on 10<sup>th</sup> November 2014 [protocol number: HSK/SF/UH/00086].

### **2.6.2 Protecting the participants from harm**

Whilst it was not anticipated that the research would cause undue distress, it was acknowledged that this can always be a possibility. Richards and Schwartz (2002) identified four areas of possible risk for participants in

qualitative research: Distress and anxiety; exploitation; misrepresentation and identification of the participant in publications. Care has been taken (and will be continue to be taken) to avoid all of these potential dangers. Streubert Speziale and Carpenter (2006) advocate that time is made available at the end of each interview or focus group in case any advice is required – this suggestion was adhered to and, in addition, Support Service Information Sheets (Appendices 2.8; 2.9) were developed and made available to participants at the conclusion of their interview or focus group.

### **2.6.3 Confidentiality**

Parahoo (2014: 405) suggests that confidentiality is the:

*“assurance given by researchers that data collected from participants will not be revealed to others who are not connected with the study.”*

To assist in the protection of confidentiality, the following actions were taken:

- Participants who were involved in either interviews or focus groups were allocated a pseudonym that was used when reporting findings.
- Any personal data was kept as a hard copy as well as on an encrypted USB memory stick and stored in a locked cabinet. This material will be destroyed on completion of the project.
- All information relating to data collection (the interview/focus group recordings and transcripts) was kept in a locked filing cabinet. All data will be kept for a minimum of seven years following the conclusion of the study.
- Care has been taken when reporting the findings and when describing participants as this could lead to recognition.

### **2.6.4 Consent**

Gaining the informed consent of participants is, of course, essential (Royal College of Nursing, 2011); all of the participants were provided with relevant Information Sheets; the guidelines presented by Burns and Grove (2005) were used for the formulation of these (Appendices 2.5; 2.6; 2.7). All of the participants in this study completed a consent form (Appendix 2.10); as

parental consent had already been obtained for the young people (who were under 18 years of age) to participate in NHS England Forum activities, it was deemed appropriate for this age group to self-consent for this research.

## 2.7 Data analysis

Qualitative data analysis focussed on each of the data sets generated from:

- A focus group conducted with five young people who were members of the NHS England Youth Forum.
- A focus group conducted with five members of the Adult Reference Group that supports the NHS England Youth Forum.
- Individual face-to-face semi-structured interviews that were undertaken with four employees.

The analysis of qualitative data:

*“involves organizing, accounting for and explaining the data; in short, making sense of data in terms of the participants’ definitions of the situation, noting patterns, themes, categories and regularities.”* (Cohen et al, 2007: 461)

Each of the qualitative data sets was analysed in turn - a thematic analysis approach was chosen to facilitate this as it offers a flexible method that allows for the identification and reporting of themes or categories (Braun and Clarke, 2006). Braun and Clarke’s (2006) six stage approach was used to provide structure to the process:

1. Becoming familiar with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Each interview/focus group was transcribed into a table within Microsoft Word® and then checked for accuracy of transcription against the recordings. The use of the column/row format of the table facilitated the subsequent process of extracting data from the transcript and also allowed the quotes to be linked back to the original script. Transcription was completed within 14 days of each interview/focus group being conducted.

Initial coding was undertaken by first listening to each interview/focus group recording, this was followed by the reading of each transcript several times. This process was carried out in the chronological order that the interviews/focus groups had been conducted. Once this had been accomplished for each transcript, the documents were further examined - this facilitated the identification of themes that could then be reviewed and ‘named’. The transcripts from the focus groups/interviews with the young people, the Adult Reference Group and the four employees were analysed as three separate data sets.

Chiovitti and Piran (2003) advocate that the participants’ actual words are used when reporting the findings; it was felt that this strategy would value the participants’ contributions and facilitate the portrayal of their views – this approach is evident in Section 3.0 that follows.

## **2.8 Conclusion**

This section has provided an overview of the data collection approaches, recruitment methods, ethical considerations and data analysis procedures. The findings are presented in Section 3.0.

## **Section 3.0: Findings**

### **3.1 Introduction**

This section presents the findings that emerged from the analysis of the focus groups and semi-structured interviews. Where appropriate, discussions are supported by a range of quotations taken from the participants' transcripts. Pseudonyms are used throughout to maintain the participants' confidentiality.

### **3.2 Findings from the focus group with young people**

Section 3.2 presents the five themes that emerged from the focus group that was undertaken with five of the young people who were members of the NHS England Youth Forum. Participants' words are accompanied by a phrase that indicates the focus of each theme.

It was clear that the young people were not only passionate about the Forum and the associated work, but their commitment and motivation shone through. Table 3.1 provides further details about the participants.

| Name    | Age      | Background   |
|---------|----------|--|
| Sophie  | 21 years | Sophie lives in South West England; she is an NHS service-user and undertakes volunteer work within a health organisation.   |
| Vijay   | 20 years | Vijay was originally from outside of the UK but now lives in North West England; he is currently a University student. Vijay is involved in a range of other volunteer initiatives that focus on young people. |
| Harry   | 17 years | Harry is at school studying A-levels, he lives in South West England and is also a member of the Youth Parliament.   |
| Sam     | 18 years | Sam is currently a University student in South East England, but his home town is in the North East. Sam has had involvement in a range of other initiatives that focus on the voice of the young person.      |
| Tristan | 15 years | Tristan is at school in South East England and he is involved in other youth initiatives.  |

**Table 3.1: Details of the young people who participated in the NHS England Youth Forum focus group**

### **3.2.1 Theme: “*If we start debating about the age then we’re missing the real point*”: Membership of the NHS England Forum**

The focus group participants felt that the membership encompassed a diverse range of young people from both genders as well as a variety of backgrounds and ethnicities. The participants were able to comprehensively describe the membership selection process that was undertaken (please refer to Section 1.3) – this echoed information that had been gained via other sources (such as the Adult Reference Group and individual employee interviews), a transparent and clear process being articulated.

The participants were aware that the age range of the membership (15-21 years) did not include younger children. However, there was general agreement that it would be difficult to involve them in some of the initiatives that they were currently participating in:

*“wouldn’t probably be appropriate for them....so I think that this is the best age range for the Forum.” [Sam]*

*“in the past we’ve looked at the Gillick case and the Fraser guidelines and things like that around the ability to consent to medical treatment, so obviously, you know, younger young people may find that a bit overwhelming so I think there is some sort of an appropriate age range we’ve got.” [Harry]*

*“we kind of had this discussion at our first meeting like when does that age start, is it zero, is it four, or is it five? So we’re not really bothered about the age because if we start debating about the age then we’re missing the real point. So we’d rather focus on making sure that there’s good communication between health professionals and young people.” [Vijay]*

Vijay, however, also commented on the Young Health Champions event that he had been involved in and said that children and young people between the ages of four/five years and up to 18 or 19 years of age had attended – he therefore felt that the younger age range was participating, to some extent, via associated activities.

### **3.2.2 Theme: “*The work we do is a reward in itself*”: Personal commitment**

The young people’s commitment to the work of the NHS England Youth was very evident throughout the focus group discussion and it was clear that the work necessitated the allocation of a substantial amount of personal time. Whilst Harry suggested that he spent approximately two hours per week at “*a local level*”, in the main, the young people felt it was difficult to quantify the time required for their role, for example:

*“I think our work is not so much dependent on how many hours we do, so for example if things come along we do it, we don’t really think about the hours we do. We get lots of e-mails from the British Youth Council about what is happening and you have to contribute to certain happenings or give our views and be very active in social media, we stay connected with the group through our Facebook group and Twitter, so we do things, it’s constant.” [Vijay]*

It was clear that the young people received a large number of invitations to both local and national events, in order to manage this, Sam commented that:

*“generally speaking we tend to go to the ones that are travel convenient to us so that we’re not all travelling all over the country.”*

The young people said that they participated in the NHS England Youth Forum on a voluntary basis, but that they received travel expenses, it was evident that there was no expectation of financial remuneration and that they very much valued the opportunity of being involved in the work:

*“I mean the work we do is a reward in itself and the benefits that we get are seeing change happen. I think that’s the main benefit for us.” [Harry]*

*“We’re here because we want to be here, as Harry said we want to contribute positively to the future generation....So in a way it’s a privilege to be able to influence the decision makers....So to be able to be at a table where you are part of the decision making process, it’s something important in itself. It’s rewarding and it’s good that we get travel expenses and everything, that’s very good because it makes it easier for us....” [Vijay]*

*“we’ve been the, almost kind of the poster organisation for a whole movement across the whole country which I think is kind of a reward in*

*itself to see that happen and for you to know that that's what you've contributed to.” [Tristan]*

### **3.2.3 Theme: “What we do”: The role of the young people**

The young people identified that they participated in a range of activities - these included attendance at residential weekends (organised by NHS England and the BYC), presence at both national and local events, response to email correspondence as well as engagement with the Forum Facebook pages and Twitter account. Some invitations to events were sent directly to the young people, but the majority were via the BYC coordinator – this latter approach ensured that the initiatives and activities were appropriately selected.

The young people explained that at one of the initial NHS England Youth Forum meetings, they identified areas to focus on in the first year; Vijay explained that they had:

*“over 30 or 50 different priorities that we wanted to focus on and we had to break it down to three to make it more realistic so that we can achieve it over the year.”*

The three areas that were finally selected were: Mental health, communication between clinicians and young people, and sexual health. The residential weekends primarily focussed on the three priority areas, mainly from a national perspective; however, it was highlighted that the NHS England Youth Forum members were contacted by their local healthcare decision-makers about a range of matters that did not always directly relate to the priority areas. The residential weekends were also used to plan other events such as the Children’s Commissioner’s ‘Takeover Day’<sup>4</sup>. The young people felt that their involvement in the planning of this event made sure that:

*“Takeover Day is really something which practically works and isn't tokenism or something like that.” [Tristan]*

---

<sup>4</sup> The day was arranged to give children and young people the chance to work with adults for the day and be involved in decision-making.

*"we really want to make it more effective, so the young people will get something out of it.....so the board member who is being shadowed, will get an insight into the person's perspective and young person's life. Because it's like two-way traffic and we learn so much from the adults and the adults can learn from us...." [Vijay]*

As well as the national focus, the members of the Forum also had roles in local initiatives and events; for example, Harry explained that he had recently been involved in the development of local "pre-CAMHS" [Child and Adolescent Mental Health Services] facilities – this involved liaising with a range of personnel including young people (who had accessed CAMHS) as well as youth workers.

In addition to the above points, the young people suggested that a key focus of the NHS England Youth Forum role centred on the importance of collaboration and engagement with others in order that the work of the Forum was disseminated – Tristan referred to this as a "*ripple effect*". As a result, it was clear that the Forum was being widely recognised:

*"We get contacted quite regularly with people either through Facebook or Twitter saying 'have you got any resources so that we can do this in our local area and get young people involved in decision making.....And you find it pops up in the weirdest of places, so it can be just that you're chatting to someone about mental health and then they mention 'oh, the NHS Youth Forum are doing some work on that, maybe we could link up with them.'" [Tristan]*

*"so I think we are starting to be recognised across the country in all sorts of organisations, so that's great." [Harry]*

The young people were invited to a range of key events (such as the NHS Annual General Meeting, an NHS Citizens event), they commented that this enabled them to speak informally to influential people, such as the Chief Executive of the NHS, it was recognised that these conversations could be very beneficial:

*"And so it's speaking to people kind of on a personal level...you might ask a question at the NHS AGM but you would be very unlikely to get a straight answer, and it's, if you go and have a discussion with someone afterwards you can go more in depth and you can really talk about what issues need to be tackled and work out a plan of how*

*you're going to work together to do it....it's like you might have a chat with someone after an event and then suddenly you have a slot at the Chief Nurses' conference or something....” [Tristan]*

It was evident from the focus group discussion that the young people were participating in an extremely broad spectrum of events and initiatives.

### **3.2.4 Theme: “We want to influence”: The impact of the NHS England Youth Forum**

The young people were confident that their work with the NHS England Youth Forum had been recognised and acknowledged. Concrete examples were provided in relation to the influence that the young people had had, for instance, Sam explained that:

*“the first success we had was at the first residential, one of the young people mentioned that they went into hospital and they went to the PALS service, which is the Patient Advice Liaison Service, and they wanted to complain and X, Y and Z and they turned around and went ‘no, you’re under 18. Get your mum to complain’. So after a conversation with the appropriate important person they changed the guidance to specifically say that under 18s are permitted to complain, which is sort of a small but good step forward.”*

Vijay provided another illustration by describing how he had recently been involved in a Young People Leading Change event, he said that a report was about to be produced explaining how the young people’s contributions would be drawn on to influence change.

However, the participants agreed with Sam when he commented that sometimes:

*“it’s quite hard to quantify some of the change. Some of the change is very much a culture shift...in terms of being interested in young people, they might think ‘oh, how do I engage with young people? Oh, we’ll go and speak to Jess<sup>5</sup> or the NHS England Youth Forum’ which is quite a hard thing to quantify.”*

---

<sup>5</sup> Pseudonym for one of the NHS England employees who was interviewed.

The young people also mentioned the challenges associated with the Forum, these primarily related to travel distances and the logistics of managing the number of events and activities that they could potentially be involved in. However, Harry also highlighted a broader and potentially very important issue:

*"I was just going to say a challenge we talked about last night is that we might be starting to get some of the directors of the NHS on our side, the directors of NHS England on our side and possibly Public Health included as well, but that doesn't necessarily mean the Department of Health or Whitehall are kind of as supportive of us. So I think we've, that could be a potential challenge in the future."*

### **3.2.5 Theme: “*Trying to strike a balance*”: Representing the voice of children and young people**

The young people were very aware that one of their key NHS England Youth Forum roles was to not only present their own views, but to also represent the views of others, for example, Tristan made the following comment:

*“Trying to strike a balance between representing your own views and representing the views of all children and young people.”*

Sam made the point that he himself was not a frequent or regular service-user, but that he was:

*“absorbing lots of information and learning new things so I represent people’s views rather than my own views.”*

The young people discussed how others could become involved in the NHS England Youth Forum and share their thoughts and opinions; it was acknowledged that this was a challenge. The Forum has a Facebook page and Twitter account that are open to the general public – this means that the Forum members can be contacted directly to invite attendance at an event, whilst this is overseen by the BYC coordinator it means that there can be a large numbers of requests which need to be responded to.

There was acknowledgement that a frequent question that was asked of the members was: *How do I get involved with the work of the NHS England Youth Forum?* [Sam]. It was also agreed that this could be difficult to respond to, the group agreed with Sam when he stated that:

*“The answer is like the Facebook page and contribute to that, but it always, that seems from the young person’s point of view very passive and it’s not like they’re going to feel like they’re part of it, which perhaps is something we could improve on but I’m not quite sure...”*

The young people did not fully agree about the type of involvement that others, outside the Forum membership, should have; Tristan felt that:

*“I don’t think there’s a need necessarily for a big kind of public presence unless we’re kind of getting views from it. Because I think we don’t want them to know that we’re there, we want them to see the effects of what we do.”*

However, Sophie had a different opinion:

*“I disagree, sorry, I slightly disagree in that it should be more open so that we’re more approachable, otherwise it feels like we’re an enclosed little group in our own things and it becomes... because on the local level I’ll kind of say to somebody ‘I’m a member of the NHS Youth Forum’ and they’re a health professional and they don’t know what it is, and they work with young people.”*

A range of suggestions were made about how young people, external to the membership could be involved, these included: An on-line survey, development of a youth network, local activity and initiatives, developing links with schools, hospital newsletters and comment cards. However, it was also suggested:

*“we are in fact kind of only 20 people and I think people have to remember that at the end of the day and that whilst we will spend our time going and speaking to individual young people, we have to kind of reach into organisations to get the wider young people’s view that they represent, and so it’s almost like a kind of two-tier process but then the first tier also speak to the bottom, and it all melts into one.”* [Tristan]

*“I think we’re doing all we can to make things better.”* [Vijay]

Finally, Sophie also expressed concern in relation to the NHS England Youth Forum website:

*“But if you Google the NHS Youth Forum, it’s rubbish, it’s awful. So if you hear something about the NHS Youth Forum, like ‘oh, I want to know more about that’ and you go online and it’s like ‘oh, there’s not really a lot there’.”*

Some of the participants agreed with Sophie, but suggested that the Forum was still in its infancy and that there might be future thoughts about developing the website.

### **3.2.6 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).
- 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.

### **3.3 Findings from the focus group with the Adult Reference Group**

This section presents the three themes that emerged from the focus group that was undertaken with five members of the Adult Reference Group. Participants' words are accompanied by a phrase that indicates the focus of each theme.

Table 3.2 provides further details about the participants, illustrating the diversity of their backgrounds.

| Name             | Background  |
|------------------|---|
| <b>Emma</b>      | Emma represented Sense, an organisation working with and supporting people of all ages who are deafblind or have associated disabilities. In addition, Emma represented the Disability Partnership which comprises of Mencap, Sense, Scope and the National Autistic Society.   |
| <b>Mira</b>      | Mira represented Sense and was responsible for involving children and young people in their campaigns.  |
| <b>Kimberley</b> | Kimberley represented Brook which provides sexual health and wellbeing services for over 275,000 young people UK-wide, each year. Brook is part of the Young People's Health Partnership (a seven-strong consortium of organisations working with the Department of Health, Public Health England and NHS England as strategic partners to raise the profile of the health agenda across the voluntary youth sector). |
| <b>Edmund</b>    | Edmund represented Public Health England (whose aim is to protect and improve the nation's health and wellbeing, and reduce health inequalities).   |
| <b>Lindsay</b>   | Lindsay represented the National Children's Bureau [NCB]. NCB is part of the Voluntary Sector Strategic Partner Programme which was launched in April 2009 to improve communication and dialogue between the Department and third sector health and social care organisations across England.   |

**Table 3.2: Details of the people who participated in the Adult Reference Group focus group**

The Adult Reference Group was convened before the inception of the NHS England Youth Forum and had been established for approximately one year at the time that the focus group took place (28<sup>th</sup> November 2014). The members had primarily been approached by NHS England employees to join the Adult Reference Group; one participant mentioned that a young person from Whizzkids was also part of the

membership, however, further details about his involvement were difficult for them to recall.

During the focus group discussions, it was very evident that the participants not only thought very highly of the NHS England Youth Forum and its associated work, but they were “*really proud to be involved....it’s great to be part of it and I think the work that’s been achieved is fantastic.*” [Emma]

### **3.3.1 Theme: “*The main engagement*”: Engaging with the NHS England Youth Forum**

The focus group discussed how they engaged with the NHS England Youth Forum - this was primarily via the meetings that were held on a six to eight weekly basis, for example:

*I think the main input and engagement we have with the forum is via the reference group meetings, apart from that I don’t actually have much involvement between the meetings.” [Emma]*

*“the main engagement for us is through the reference group meetings.” [Lindsay]*

However, some of the participants then later described other aspects of their engagement with the NHS England Forum, these included the facilitation of workshops, involvement in residential weekends and disseminating information:

*“so for instance they [NHS England Youth Forum] ran an event about mental health back in July and we were asked to run some workshops and activities at the event. So that’s a bit more ad hoc.” [Lindsay]*

*“I attended one of the Youth Forum’s residencials [sic], well their first residential weekend that they did.” [Kimberley]*

There was general agreement from the participants that their paid work responsibilities could be demanding and that these needed to be prioritised, this was summarised by Kimberley:

*"although the work of, you know, this group is really vital and obviously the Youth Forum is absolutely amazing, when you've got a lot of pulls on your time, but your organisation is not seeing financial recognition for that involvement, it can sometimes be difficult to prioritise that involvement."*

Despite the challenge of accommodating the NHS England Forum work alongside their main employment duties, the participants displayed a strong commitment to their Adult Reference Group role and there was a feeling that, at times, they could be further informed about activities:

*"sometimes when I come to meetings I find out about things I didn't know about until the meetings that maybe we could have got involved in but didn't know about, and then they've happened." [Emma]*

Edmund was the one participant who commented that he had stronger links with the Forum and this was as a result of his work within Public Health England; it was also clear that Edmund had valued the experience and insight that he had gained:

*"we've got quite a strong relationship with the organisations and the individuals involved so with both BYC and NHS England....Just to say that the priorities young people have identified fortunately coincide with our priorities as well at the Public Health Agency so....I think for us because the priorities overlap then it just feels like it's much easier to support the work of the Forum as well....I take a lot away from the way that the Forum's been leading its work around engagements, children and young people as well, I feel that we're quite a way off the page so to speak as an organisation, so it's been really helpful to have an insight into the way it's been working."*

The participants stated that they received feedback about the NHS England Youth Forum activities primarily via the six to eight weekly meetings, but one participant [Kimberley] also commented on informal feedback that had been provided at a residential event that she had attended.

### **3.3.2 Theme: “Coming from the young people”: The focus and value of the NHS England Youth Forum work**

The participants all affirmed that the NHS England Youth Forum agenda was being driven by the young people themselves and that they had “*invested in it personally*” [Emma]; whilst some of the group were very pleased with the three priority areas that the young people had selected (mental health, communication between clinicians and young people, and, sexual health), they emphasised that they had not been part of this decision-making process:

*“it was very clear that actually the decision making around those priorities were going to be coming from the young people....And then when I came on the second day and they’d already decided on sexual health as being one of those priorities I was absolutely delighted, but it very genuinely wasn’t something that I think any of us had placed onto them.”* [Kimberley]

*“I would completely agree with that, I was delighted to see communication with health professionals come up as a topic and I wasn’t at that weekend away at all so, and I had no input so it was fantastic actually.”* [Emma]

There was an extremely positive perception of the work of the NHS England Youth Forum and this was for two key reasons: Firstly, the participants felt that the young people themselves were able to benefit enormously in terms of “confidence building” [Lindsay]; “skills development” [Lindsay]; “empowerment” [Emma]. Secondly, it was clear that the group felt that the work of the Forum was providing a “platform” [Kimberley] for young people to liaise with senior personnel and that there was a direct and positive impact on health care services:

*“I think everybody is seeing the difference that it’s making to the health system partners in the way that they work and the decisions that they’re making and the way that they’re pushing forward with their own work and I think everybody can see what input, and the benefit of the input that it has, from having this direct link to young people’s voices.”* [Lindsay]

The participants thought that the skills that the young people had developed had meant that they had been able to take their work and ideas back to their

local areas (this echoes some of the points raised by the young people themselves in their own focus group):

*"I just get the sense from speaking to them [the young people], and when I've been around the country, that many of them have been great ambassadors about these issues locally as well. So it's not just what they're bringing into the Forum but it's what they're taking out of it and using locally which is really helpful." [Edmund]*

The importance of maintaining the momentum of the NHS England Youth Forum work, at both national and local levels, was highlighted.

### **3.3.3 Theme: “*Spread the word*”: Engaging with the wider children and young people’s population**

There was agreement from the participants that, whilst there was some wider engagement of children and young people (who were not part of the NHS England Youth Forum) through events such as ‘Takeover Day’, that this could be further developed in the future. Kimberley offered some “*blue sky thinking*” suggesting that:

*“ideally it would be really fantastic to have a model where, you know, each of the organisations that are part of the reference group could be funded to directly support groups of young people to feed in to that core group of the Youth Forum.”*

However, more immediate, realistic and practical examples of how to facilitate broader engagement included the enhancement of social media communication as well as the use of the networks of children and young people that the Adult Reference Groups had access to, for example:

*“I just think that for us we probably could spread the word about the work of the Forum with our network of young people. So we have a large young people’s membership and that reaches out to obviously lots of other children and young people across the country.” [Lindsay]*

The participants appreciated that they themselves could do more in respect of enhancing engagement with a broader range of children and young people, but they felt that their involvement was hindered in two ways: Limited

information about Forum activities in-between the six to eight weekly meetings, and work priorities:

*"young people we're working with they might need much greater support to be involved....I mean it could be provided for example through our work but it just needs to be, you know, planned and well communicated. [Mira]*

*"we need more advance warning of what's going on rather than just finding out about things in reference groups....I contribute to the meeting, and then I don't do anything in between. But then I think post hoc, 'oh we could have been involved in that'....I think it would be good to have a more tangible way we can get involved....potentially it's a wasted opportunity, but it could be a really strong partnership going forwards." [Emma]*

*"I feel like I could probably do more to try and engage young people in the digital communication stream. I think that could be being used more effectively than it currently is now....but I think again it probably does come back to, you know, capacity to be able to dedicate time to do that effectively." [Kimberley]*

*"I think it would be beneficial to have a bit of a clearer steer about what the reference group organisations can be doing in a more practical way." [Lindsay]*

The participants all felt that their employers were supportive of their involvement in the Adult Reference Group, but Kimberley did say that her employer had asked if she was being paid for her involvement: *"I get asked the question regularly enough to feel that it's appropriate to share that with you here."* It is important to note that others had not had a similar experience.

### **3.3.4 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.

### **3.4 Findings from the interviews with the employees**

Interviews were conducted with four key employees (Table 2.2) who had had a pivotal role in the development and implementation of the NHS England Youth Forum. A series of prompt questions (Appendix 2.4) were used to facilitate discussion. Participants' words are accompanied by a phrase that indicates the focus of each theme.

#### **3.4.1 Theme: “So that’s a key driver”: The inception of the NHS England Youth Forum**

The participants articulated the precursors for the inception of the NHS England Youth Forum, this focussed on two main areas; firstly, it was acknowledged that there were key documents that identified the need to enhance care for children and young people, and to also engage with them, for example:

*“The Health and Social Care Act of 2012 makes it very clear that participation and engagement, from both the personal perspective in people’s own healthcare, but also at a societal level in terms of influencing the design and delivery of healthcare services, is absolutely critical, and so that’s a key driver.” [Jess]*

*“that’s about meeting some of our objectives in the constitution, the NHS Mandate and also the Health and Social Care Act, of which there’s two duties, duties to involve and that’s about involving patients and the public more.” [Hannah]*

Secondly, the participants personally felt a commitment to the engagement of children and young people – this stance being underpinned by current and/or previous work responsibilities as well as a need to role model:

*“So with my remit and being a Children’s Nurse by background I was very aware that we needed to ensure that the voice of children and young people needed to be amplified right across the whole of the NHS....NHS England needed to be seen as a system role model and that we couldn’t expect local area teams, regional teams, Clinical Commissioning Groups or providers of services to be truly embedding young people’s voice unless we were doing it as a national organisation.”* [Jess]

*“In fact my background has been working with vulnerable young people for quite a long time prior to this....So I was really keen that we set, that we were able to set up a National Youth Forum.... it’s about role modelling as an organisation that we are actively valuing and listening to the voices of young people, but we’re also allowing young people to hold us to account and drive some priorities of their own.”* [Hannah]

The employees revealed that the goal of enhancing engagement with children and young people began with “*a year of discussions*” [Jess] to ascertain the most appropriate way forward. Advice and consultation took place with a range of prominent organisations (such as the BYC and NCB) as well as key personnel within NHS England itself. These discussions culminated in the securing of funds from NHS England and the commissioning of the BYC to facilitate the development and implementation of the NHS England Youth Forum. Hannah commented that she was:

*“Really clear why we picked BYC as a delivery partner....because they have the structural democratic reach in all of those geographies.”*

The initial plan had been to have a tripartite relationship between NHS England, the Department of Health and Public Health England, however:

*“I feel as though it’s been very much NHS England-led, and it would have been, I think that we could have done a better job at perhaps really engaging Public Health England and the Department of Health....Not entirely sure how, but I think sort of that would have actually provided us with greater strength as we go forward....But in some ways, often in these models you need a lead organisation to actually make stuff happen.”* [Jess]

*“So it’s important that it’s tripartite, but a challenge for us next year is to get that, to get much stronger input from DH [Department of Health] and PHE [Public Health England] rather than just pitching up to meetings and I think they need to put money in the game. But we’ll kind of, you know, these are slow battles and if we get money in the game in five years’ time and we’ve a really strong youth forum I’ll be really happy.”* [Hannah]

Despite the fact that the tripartite relationship was not fully operational, it was clear that there was a strong partnership between the NHS England and BYC staff:

*“I’ve never worked on a project where our partners have been this hands on and I think that makes a difference....we’re all partners, we all want to make this work.”* [Beth]

In terms of the recruitment to the NHS England Forum, the process described in Section 1.3, and within both of the focus groups, was affirmed. However, participants alluded to the fact that engagement from the young people had been variable:

*“what’s always been really pleasing has been how some of the young people have really engaged; they’ve been incredibly enthusiastic, really driven and highly motivated. And on the flipside of that it’s been a bit sad that some of them haven’t engaged, and that’s life, because they’ve got many other commitments.”* [Jess]

*“what we’ve seen is quite a significant drop off....If you think about attrition for young people that’s also really normal because young people’s lives kick in, and when they first start something this seems really interesting and important and then exams come in and social lives come in and new relationships come in and dramas happen.”* [Hannah]

*“The majority of them and I would say 85% have been very, very active and committed, but there are a few that haven’t been quite so....Then at the next residential we’ll look at how many spaces we’ve got free and how we’re going to look at recruiting to fill those spaces.”* [Beth]

Once the NHS England Forum had been established, a member of the BYC was identified to engage with the membership on a day to day basis, via both email and social media sites. The employees all reiterated that the three priority areas had been selected by the young people themselves – “*what we*

*did was work on what the young people wanted to change about their experience of the NHS” [Paul]; at the same time, the employees had had an important role in terms of ‘opening doors’ for the young people, for example, Jess described an event that had taken place in July 2014 which had focussed on mental health issues – the staff supporting the NHS England Youth Forum had been able to facilitate invitations to key people as well as organise and undertake the associated administrative work. On another occasion, Hannah explained how the young people had been able to meet with “*national directors*” and that “*when young people can have a direct conversation with somebody that’s when influence happens.*”*

### **3.4.2 Theme: “*The progress that has been made*”: The achievements, to date, of the NHS England Youth Forum**

The participants provided a synopsis of the NHS England Youth Forum’s achievements to date, such as the success of the ‘Takeover Day’; however, discussions particularly highlighted the progress that had been made in relation to the three priority areas that had been selected by the young people (mental health, communication between clinicians and young people, and, sexual health). There was agreement that the work within the area of mental health had been very tangible with the identification of specific examples of activities undertaken:

*“We had an event for 200 young people and practitioners in London and really tried to raise the profile of good mental health practices.... The report is coming out very soon.” [Paul]*

*“We had a fabulous event in July focusing on mental health.” [Jess]*

Similarly, the area of communication had led to the development of materials to inform young people about:

*“their rights around complaining, consent and things like that.... So we’ve been through some agreed text which has been youth proofed by 300 young people.... So we had a win within the first couple of hours [of the NHS England Youth Forum meeting] which was fantastic to see that action happened.... We’re waiting for it to be released.... The idea is that we’re going to launch them [posters] in*

*about a month's time....Then hopefully they'll be free to download online and people can start to use them and hopefully they'll be accessible in that way. We currently don't have the budget to mass disseminate them, but hopefully if they're great someone will find the money." [Paul]*

Two participants suggested that the identification of three priority areas may have been “*too many*” [Hannah] and too “*ambitious*” [Paul] for the first year and that sexual health would need to be carried over to the second year of the NHS England Youth Forum’s work; however, it was generally agreed that: “*Actually I’m quite comfortable with the two [priority areas] that we’ve done and the progress that has been made.*” [Paul]

The NHS England Forum had also provided an opportunity to ascertain the views of young people in relation to topical and current health issues; Hannah gave an example:

*“the Prime Minister makes an announcement that A&E will be reviewed....it gives us some space in the model to say ‘actually, for the next time we meet we want to bring this up on the agenda....’”*

The participants felt that one of the highest achievements was the:

*“willingness to listen....It’s a massive cultural shift.” [Jess]*

*“We’ve been really good at getting senior level stakeholders to endorse the work of the Youth Forum....I think probably that is its greatest achievement that actually senior decision makers within NHS England have been very open door about it and really see it as their Youth Forum, which really means just acknowledging it and talking about it gives it a status, which is fantastic.” [Paul]*

*“the amount of key people that are backing it and that makes a massive difference.” [Beth]*

The participants also mentioned some of the work that the young people had been participating in, this included local activities - whilst some of these had been started prior to the inception of the NHS England Youth Forum, others had begun as a direct result of the Forum being established which was “*great*” [Jess]. It was recognised that involvement in the Youth Forum activities had had a very positive impact on the young people as they had “*grown in*

*experience*" [Paul]; were "*empowered*" [Beth]; had gained "*confidence*" [Beth] and this was "*fantastic*" [Paul] – this supports the opinions of the members of Adult Reference Group (Section 3.3.2).

The participants were not always able to quantify the amount of their time taken in supporting the NHS England Youth Forum activities, but it was clear that there had been significant investment in this respect and that this was on-going:

*"so quite a lot but also not enough....I probably spend half a day a week on youth issues."* [Hannah]

Understandably, one of the BYC employees spent the most time supporting the young people:

*"It depends, because obviously I spend considerably more time when we're having the residential[sic]. I guess it's on average about eight hours a week, I would imagine, sometimes more, sometimes less, it depends."* [Beth]

Some of the time had initially been spent in organising, designing and planning the Forum, and whilst it was now established, the day-to-day time management that was still required was both overt as well as less obvious; for example, the overseeing of the social media sites was more tangible:

*My day to day communications are generally revolving around, I manage the Facebook closed group....So that's the way that I can generally communicate with all of them [the young people] on an equal footing, which I think is important....That's their space so they can just talk about anything openly and confidentially....so I'm on there every day, they're on there every day and also when they post messages, if I don't happen to be on there that comes straight through to my e-mails on my phone so I can make sure that I'm keeping up with them. I obviously e-mail them all as a group. If we specifically want to discuss anything really confidential to do with documents....we'll do that via e-mail....I also speak with them regularly on the phone, so that's my, kind of, general day to day....So I'm very much just like their PA."* [Beth]

However, other aspects were less immediately visible:

*"if you send a young person to a conference there's all the time that goes into risk assessing that, booking the travel. If they're under a certain age they need to be accompanied and stuff like that and it all adds up in time and money." [Paul]*

The participants also had some concerns about the number of events that the young people were invited to (now that the NHS England Forum was more widely recognised: *"I mean I literally get bombarded with them [requests] on a daily basis"* [Beth]); they questioned whether this approach was fulfilling the Forum's aims:

*"So one of our challenges is we've got more requests than we can fulfil.....you know, you can't just ring us on a Tuesday and say 'I've got a meeting next Tuesday and I want a young person'. Because this isn't a tick box exercise, and A: what's the role of that young person, what do you want them to do, you know, do you want to hear youth voice or are you just wanting to say you had a young person there? And Tuesday and ten o'clock on a school day's not very appropriate."* [Hannah]

In addition, it was suggested that too many of these types of activities could have an impact on other aspects of the young people's lives, especially school/University work.

The role and membership of the Adult Reference Group was raised; Hannah explained that the group had initially been established prior to the inception of the NHS England Youth Forum to *"help us build a model"*; however, whilst it was recognised as being a method to inform and engage a range of personnel, the specific remit of the group was not clear to all the participants. One participant also questioned the need to have a young person on the membership – it was suggested that this may not be necessary as young people were already fully involved in the decision-making aspects of the NHS England Youth Forum.

Overall, there was definitely a feeling amongst the participants that the NHS England Youth Forum had been very productive, for example:

*“I think [it] has been really successful....I think the way that the NHS has wanted to hear, listen and change things for young people has been fantastic....I think that [it] makes a difference when you’re working with people who want it to work and I think from like a small amount of money they’ve got a good deal in terms of what young people slowly are pushing to change.”* [Paul]

*“I’m very satisfied that we’re mostly meeting objectives.”* [Hannah]

*“So I think it’s exceeded what it was set up to achieve. It’s vastly exceeded.”* [Beth]

### **3.4.3 Theme: “We’re not quite sure how it’s actually going to go forward”: What the future holds for the NHS England Youth Forum**

The participants recognised that the future development of the NHS England Youth Forum was not fully crystallised and that it was also a potential challenge. It is important to recognise that “*NHS England’s [Youth Forum] model is quite unique internationally*” [Jess], therefore, there was no previous work to draw on and gain insight from. It was acknowledged that disseminating the work, as well as involving a broader range of young people, was an important aspect; however, “*it’s not really the role of the forum to be representative of every young person in Britain; they can’t do that*” [Hannah]. In terms of publicising the work of the Forum, some action had already been taken; examples included the presence of the NHS England Youth Forum at key events, such as NHS England Expo and the production of a short film for the NHS England website. However, there were suggestions for the future:

*“And now as we go forward we’re just looking at a model of can we award some grants to the regions to develop regional youth forums as well. So it’s beginning to actually filter down in different ways.”* [Jess]

*“Our next challenge is how do we build and support our regional teams and area teams to do something similar; that’s next year’s programme.”* [Hannah]

*“I think it’s important to sit down and unpick and focus on what all the successes have been ranging from that very early win [reference to the revision of the complaints procedure for young people] to things that they’ve done which are going to be embedded in the future...the young people have got things that they see as key objectives, but there are key objectives within the NHS....let’s work on both of these things and*

*have mutual objectives....I think it's not only more strategic but it could be even more meaningful.” [Beth]*

Other examples included developing links with other youth groups/forums that are allied to NHS Trusts or prominent organisations, and the use of social media:

*“We have this other thing called an open Facebook page and that’s the way we communicate with the world....they [the young people] do that themselves which I think is important because then they’ve got ownership and they do that very regularly.” [Beth]*

*“I do a weekly mail to all the kind of people running youth councils and youth forums and young mayors and UK Youth Parliament.” [Beth]*

*“where we’ve probably failed mostly, I think, is using the [Adult] Reference Group to access their young people and feeding in and that’s one of the things that we’ve said we need to look at for next year, is about how do we engage those young people?....They’re probably on the social media group and some of them will be attending our events, but we need to be seen to be engaging this group of other young people....So it’s trying to build up the networks that already exist....I’d love to be able to say we have reached all young people.” [Paul]*

It was also suggested that if all young people across NHS England services were to have a voice, this would involve “*skilling up a workforce who are already stretched and getting them to understand youth work as well*” [Paul].

The participants discussed the age range of the NHS England Youth Forum membership and suggested that there had been an aim to involve children and young people between the ages of 11-24 years (at the time of this report, the actual age range was 15-21 years); there was an awareness from Jess that:

*“that we’ve got a very big gap with regard to younger children’s voice as well and one of the things we do there is work very closely with our strategic partners, the National Children’s Bureau, and one of their remits is to capture the input of younger children....So it’s not perfect by any way, shape or form, so I think, yeah, we’ve definitely got opportunities with regard to younger young people.” [Jess]*

However, the other participants did not think that there was a need to broaden the age range as “*in reality if we had somebody who was 12 I think they’d really struggle to keep up with some of the stuff that’s going on....*” [Hannah] - this echoed the point that was raised within the focus group undertaken with the young people (Section 3.2.1).

Another area that was recognised as being an area for development was the provision of feedback to the young people; whilst there were some mechanisms in place, such as face-to-face feedback during residential weekends and on-line discussions, there was a suggestion that: “*We could definitely do better*” [Jess] in this respect. One participant expressed a need for slightly more formal feedback to assess how well the NHS England Youth Forum model had worked from the perspective of the young people as well as the adults who were more directly involved. In addition, Hannah felt that regular reports would be beneficial:

*“I think we need to kind of just have some tighter project management on it in terms of getting monthly or quarterly reports of things like specific activity, like how much Facebook activity was there, how much Twitter activity was there....not an onerous, but a short report on how many requests have we had, who were they from, to try and gauge what the need is and what the burden might be, or might grow to be on the young people, on requests of young people....I don’t think we do anything written at all so that then doesn’t get circulated around the wider group.”*

It is important, however, to recognise that Beth commented on the reports being written by the young people themselves, these focussed on events and activities that they had participated in:

*“A lot of them have spent considerable time working with me developing reports and I can definitely say for some of them they’ve written some cracking reports and that process has been very interesting, so they’ve learnt lots of skills in lots of different ways.”*

Finally, funding, politics and the complexity of the NHS were raised in relation to this theme; it was suggested that the NHS England Youth Forum may need to consider the future funding of staff time to enable all the necessary support to be provided:

*"this was part funded in terms of the staffing and actually we need more staff time for \*\*\*\* [name removed] to dedicate to the group if you want her to do all the extra stuff that comes out of it." [Paul]*

*"the money comes from our [NHS England] budget and we have an annual budget initially of £40,000 to recruit, set up, hold three residentials [sic]....And we've also asked for additional resource....we've put in enough money to cover the forum operation but when they came up with their three priorities, which obviously need actions and activity, we hadn't put in enough money for that so we've added that in....then we brought in extra money to do the mental health conference." [Hannah]*

It was felt that the financial side of the NHS England Youth Forum was important *"because people will challenge us about the spending of public money"* [Hannah]; in addition, it was accepted that *"value for money"* [Hannah] was required for the Forum to be sustainable.

It was acknowledged that the forthcoming general election in May 2015 could be influential in terms of the future development of the NHS England Youth Forum; and, the intricacies of the NHS meant that changes could be challenging and time-consuming to implement.

### **3.4.4 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 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 appears to be a unique model.

### **3.5 Conclusion**

Section 3.0 has provided an account of the findings that emerged from the two focus groups and the four individual interviews that were conducted. Section 4.0 concludes the report by summarising the findings, making recommendations for practice and further study, as well as recognising some of the limitations of the project

## **Section 4.0: Conclusions**

### **4.1 Introduction**

Through the use of qualitative data collection approaches, this evaluation research study sought to provide insight and understanding of the role and impact of the NHS England Youth Forum.

This concluding section initially summarises the main findings and provides recommendations for the future development of the NHS England Forum. This is followed by a consideration of the plans for dissemination, an acknowledgement of the limitations of the research and suggestions for future work.

### **4.2 A summary of the main findings**

#### **4.2.1 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).
- 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.

#### **4.2.2 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.

#### **4.2.3 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 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 appears to be a unique model.

#### **4.3 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 (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.

#### **4.4 Dissemination of the findings**

Dissemination of results is a key aspect of any project (Locke et al, 2000). Firstly, and perhaps most importantly, it is advisable to report the findings to participants (Macnee, 2004; Nieswiadomy, 2002); all those who were involved were provided with an Information Sheet (Appendices 2.5; 2.6; 2.7) in which it was stated that a copy of the report would be available to them, should they wish to receive one; if participants have requested a copy, this will be sent following submission of the final document to NHS England.

This research has been commissioned and funded by NHS England, therefore, discussions will take place to identify suitable and joint methods of dissemination to the wider professional population – it is anticipated that this will be via conference presentations and journal publications.

#### **4.5 Limitations of the project**

Having considered the findings from this study, it is important to also acknowledge some of the limitations:

- Consultation with members of the NHS England Youth Forum took place; however, just five young people were able to participate in the focus group; it must, therefore, be acknowledged that the views may not be wholly representative of all 20 members of the Forum.
- Five members of the Adult Reference Group participated in a focus group, but once again, the views may have not have been fully representative of their colleagues who were unable to attend.
- Interviews were conducted with four employees who had played a pivotal role in the development and implementation of the NHS England Youth Forum, but it is acknowledged that there were other employees who may also have been able to offer their insight - time constraints restricted the number of personnel who were invited to be interviewed.

- It is acknowledged that this evaluation research drew on qualitative data collection approaches; the use of quantitative methods would have provided a different perspective.

#### **4.6 Suggestions for future work**

As a consequence of the study, other areas that would merit further investigation have emerged:

- Consultation with Health professionals to ascertain their knowledge of the NHS England Youth Forum and how this influences their day to day clinical practice.
- Research with children and young people, who are not part of the NHS England Youth Forum, may be valuable to facilitate suggestions about how the work of the Forum could potentially further embrace and engage with the wider population.
- It would be timely to further examine the personal benefits (and challenges) that participation in the NHS England Youth Forum has had on the young people who have been involved in its work.

#### **4.7 Conclusion**

The NHS England Youth Forum is now gaining strong recognition within a wide range of arenas, it is therefore essential that the excellent work that it is doing is ‘captured’ and further developed so that children and young people can be involved in all aspects of health service decision-making. There is no doubt that the work of the Forum has already had a positive impact on children and young people’s services, this was succinctly summarised by one of the participants who took part in this study:

*“everybody is seeing the difference that it’s making to the health system partners in the way that they work and the decisions that they’re making and the way that they’re pushing forward with their own work....everybody can see what input, and the benefit of the input that it has, from having this direct link to young people’s voices.”*  
 [Lindsay]

If this impact is to continue to reach its full potential, it requires the commitment and expertise of not just those who are immediately involved with it, but also that of

health professionals who are working directly with children and young people. It is therefore important that the NHS England workforce is responsive to, and engaged with, the Forum both at a local and national level to ensure that service provision is supported by its work.

The NHS England Youth Forum has developed rapidly and this is undoubtedly due to the total commitment, motivation and enthusiasm of all those involved, especially the young people who have given their time so willingly. This research has confirmed that young people are not only extremely capable of participating in decision-making, but that they want to be involved and very much value the opportunity – it is therefore imperative that this approach is role modelled by others so that, in future, there really is '*no decision about me, without me*' (UK DH, 2012c).

It is hoped that the findings from this study have provided data that has the potential to inform the future planning of the NHS England Youth Forum so that health service provision for children and young people can continue to be enhanced.

## References

- Blades, R., Renton, Z., La Vellewith, I., Clements, K., Gibb, J. & Lea, J. (2013) *Office of the Children's Commissioner: We would like to make a change. Children and young people's participation in strategic health decision-making.* Office of the Children's commissioner: London
- Bowling, A. (2009) *Research methods in health: Investigating health and health services.* 2<sup>nd</sup> Ed. Open University Press: Buckingham
- Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology.* 3(2) 77-101
- Burns, N. & Grove, S. K. (2005) *The practice of nursing research. Conduct, critique and utilization.* 5<sup>th</sup> Ed. W. B. Saunders: Philadelphia
- Children Act (1989) The Stationery Office: London
- Children Act (2004) The Stationery Office: London
- Children and Young People Health Outcomes (2013) *Final response to the consultation on Refreshing the Mandate to NHS England: 2014-15.* Accessed on 10<sup>th</sup> February 2015 from:  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/307474/Forum - Recommendations NHS England mandate Sept 14.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/307474/Forum - Recommendations NHS England mandate Sept 14.pdf)
- Chiovitti, R. F & Piran, N. (2003) Rigour and grounded theory research. *Journal of Advanced Nursing.* 44(4) 427-435
- Cohen, L., Manion, L. & Morrison, K. (2007) *Research methods in education.* 6<sup>th</sup> Ed. Routledge: London
- Davey, C., Lea, J., Shaw, C. & Burke, T. (2010) *Children's participation in decision-making. A Children's views report.* Participation Works for Children's Rights Alliance England and National Children's Bureau: London
- Davies, S. (2013) *Annual Report of the Chief Medical Officer 2012. Our Children Deserve Better: Prevention Pays.* Department of Health: London
- Davies, F. & Clancy, M. (2013) Surveying child patients in emergency care is possible. *Emergency Medicine Journal* 31(4) 262
- Davies, R. (2010) Marking the 50th anniversary of the Platt Report: from exclusion, to toleration and parental participation in the care of the hospitalized child. *Journal of Child Health Care* 14(1) 6-23
- Department of Health and Social Security (1974) *Democracy in the National Health Service.* Accessed on 11<sup>th</sup> March 2015 from:  
<http://filestore.nationalarchives.gov.uk/pdfs/small/cab-129-176-c-49.pdf>

DiCicco-Bloom, B. & Crabtree, B. F. (2006) The qualitative research interview. *Medical Education* 40(4) 314-321

Ellis, P. (2010) *Understanding research for nursing students*. Learning Matters Ltd: Exeter

Fontana, A. & Frey, J. (2005) The interview: from neutral stance to political involvement. In Denzin, N. & Lincoln, Y. (Eds) *The Sage handbook of qualitative research*. 3<sup>rd</sup> Ed. Sage: Thousand oaks, California

Grieg, A., Taylor, J. & Mackay, T. (2013) *Doing research with children*. 3<sup>rd</sup> Ed. Sage Publications Ltd: London

Hallett, C. & Prout, C. (2003) Introduction. In C. Hallett & A. Prout (Eds.), *Hearing the voice of children: Social policy for a new century*. (pgs. 1-8) Routledge Falmer: London

Handsley, S. (2007) The potential for promoting public health at a local level. In Lloyd, C., Handsley, S., Douglas, J., Earle, S. & Spur, S. (Eds.). *Policy and practice in promoting public health*. (pgs. 191-222). The Open University: Milton Keynes

Hargreaves, D. & Viner, R. (2011) Children's and young people's experience of the National Health Service in England: a review of national surveys 2001-2011. *Archives of Disease in Childhood* 97(7) 661-666

Hart, R. (1992) *Children's participation: From tokenism to citizenship*. Innocenti Research Centre, UNICEF: Florence

Health and Social Care Act (2001) Accessed on 11<sup>th</sup> March 2015 from: <http://www.legislation.gov.uk/ukpga/2001/15/contents>

Health and Social Care Act (2012) Accessed on 11<sup>th</sup> March 2015 from: <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

Healthwatch. (2014). *About us*. Accessed on 10<sup>th</sup> February 2015 from: <http://www.healthwatch.co.uk/about-us>

Healthwatch England (2013) *Creating a children and young people friendly local Healthwatch. A first step toolkit and resources guide*. Accessed on 10<sup>th</sup> February 2015 from:

[http://www.healthwatch.co.uk/sites/default/files/healthwatch\\_child\\_report\\_web-w.pdf](http://www.healthwatch.co.uk/sites/default/files/healthwatch_child_report_web-w.pdf)

House of Commons Health Committee (2007) *Patient and Public Involvement in the NHS. Third report of session 2006-07*. The Stationery Office: London Accessed on 11<sup>th</sup> March 2015 from:

<http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/27806.htm>

Human Rights Act (1998) The Stationery Office: London

James, A. & Prout, A. (1990) *Constructing and Reconstructing childhood: Contemporary issues in sociological study of children*. London: Falmer

Kennedy, I. (2010) *Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs*. Department of Health: London

Lane, P., McKenna, H., Ryan, A. & Torrence, C. (2001) Focus group methodology. *Nurse Researcher* 8(3) 45-59

Lansdown, G. (2011) *Every child's right to be heard: a resource guide on the UN committee on the rights of the child general comment no.12*. Save the Children UK on behalf of Save the Children and UNICEF: London

La Valle, I. & Payne, L. (2012) *Listening to Children's view on health provision – a rapid review of the evidence*. National Children's Bureau: London

Locke, L. F., Wyrick Spirduso, W. & Silverman, S. J. (2000) *Proposals that work. A guide for planning dissertations and grant proposals*. 4<sup>th</sup> Ed. Sage Publications: London

Marmot, M. (2010) *Marmot Review. Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England Post 2010*. Marmot Review: London

Macnee, C. (2004) *Understanding nursing research*. Lippincott Williams & Wilkins: Philadelphia

Ministry of Health (1959) *The Welfare of Children in Hospital, Platt Report*. HMSO: London

Monkey Wellbeing (2014) Friends and Family Test (FFT). Accessed on 25<sup>th</sup> February from: <https://www.monkeywellbeing.com/friends-family-test-fft-downloads/>

Moore, L., & Kirk, S. (2010) A literature review of children's and young people's participation in decisions relating to health care. *Journal of Clinical Nursing* 19(15-16) 2215-2225

Morse, J. (1989) Strategies for sampling. In Morse, J. (Ed) *Qualitative nursing research. A contemporary dialogue*. Sage Publications Ltd: Newbury park

Moule, P. & Goodman, M. (2014) *Nursing research. An introduction*. 2<sup>nd</sup> Ed. Sage Publications Ltd: London

National Children's Bureau (2013a) *Bringing children and young people to the heart of Healthwatch. Reflections from LINKs*. Accessed on 10<sup>th</sup> February 2015 from: [http://www.ncb.org.uk/media/968116/ncb\\_healthwatch\\_print.pdf](http://www.ncb.org.uk/media/968116/ncb_healthwatch_print.pdf)

National Children's Bureau (2013b) *Child health in the new NHS. Results of a survey by the National Children's Bureau and the NHS Confederation Autumn 2013*. Accessed on 10<sup>th</sup> February 2015 from:

[http://www.ncb.org.uk/media/1100604/child\\_health\\_survey\\_report\\_final.pdf](http://www.ncb.org.uk/media/1100604/child_health_survey_report_final.pdf)

NHS Choices (2013a). *About the NHS*. Accessed on 10<sup>th</sup> February 2015 from: <http://www.nhs.uk/NHSEngland/thenhs/about/Pages/nhscoreprinciples.aspx>

NHS Choices (2013b) *The history of the NHS in England*. Accessed on 10<sup>th</sup> February 2015 from:

<http://www.nhs.uk/NHSEngland/thenhs/nhshistory/Pages/NHShistory1948.aspx>

NHS Choices (2013c) *The NHS constitution*. Accessed on 10<sup>th</sup> February 2015 from: <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>

NHS Choices. (2015) *Patient choice in the NHS*. Accessed on 10<sup>th</sup> February 2015 from: <http://www.nhs.uk/Tools/Pages/Patientchoice.aspx>

NHS Constitution (2014) *NHS Friends and Family test. Draft access for all guidance for engagement*. Accessed on 10<sup>th</sup> February 2015 from:

<http://www.england.nhs.uk/wp-content/uploads/2014/04/fft-guid-afa-eng.pdf>

NHS Reorganisation Act (1973) Accessed on 11<sup>th</sup> March 2015 from: <http://www.legislation.gov.uk/ukpga/1973/32/contents/enacted>

Nieswiadomy, R. M. (2002) *Foundations of nursing research*. 4<sup>th</sup> Ed. Pearson Education Inc, New Jersey

Patient Experience Network (2013). *Improving Patient Experience for Children and Young People. A Report prepared by The Patient Experience Network for NHS England*. Accessed on 10<sup>th</sup> February 2015 from:

<http://patientexperiencenetwork.org/wp-content/uploads/2013/11/PEN-Improving-PE-for-Children-Young-People-Report-FINAL-Electronic-file.pdf>

Parahoo, K. (2014) *Nursing research. Principles, process and issues*. 3<sup>rd</sup> Ed. Palgrave Macmillan: Basingstoke

Polit, D. F. & Beck, C. T. (2006) *Essentials of nursing research. Methods, appraisal, and utilization*. 6<sup>th</sup> Ed. Lippincott Williams & Wilkins: Philadelphia

Richards, H. M. & Schwartz, L. J. (2002) Ethics of qualitative research: Are there special issues for health services research? *Family Practice* 19(2) 135-135

Royal College of Nursing (2011) *Informed consent in health and social care research RCN guidance for nurses*. 2<sup>nd</sup> Ed. RCN: London

Stewart, D. W., Shamdasani, P. N. & Rook, D. W. (2007) *Focus groups: Theory and practice*. 2<sup>nd</sup> Ed. Sage Publications: Thousand Oaks, California

Streubert Speziale H. J. & Carpenter, D. R. (2006) *Qualitative research in nursing. Advancing the humanistic imperative*. 4th ed. Lippincott: Philadelphia

Unicef (2005). *Fact Sheet: A summary of the rights under the Convention on the Rights of the Child*. Accessed on 10<sup>th</sup> February 2015 from: [http://www.unicef.org/crc/files/Rights\\_overview.pdf](http://www.unicef.org/crc/files/Rights_overview.pdf)

Unicef (2015) *Convention on the Rights of the Child*. Accessed on 10<sup>th</sup> February 2015 from: [http://www.unicef.org/ceecis/overview\\_1583.html](http://www.unicef.org/ceecis/overview_1583.html)

United Kingdom Department for Children, Schools and Families (2007) *The Children's Plan: Building brighter futures*. The Stationery Office: London

United Kingdom Department for Education and Skills (2004) *Every child matters: change for children*. Department for Education and Skills: London

United Kingdom Department of Health (1997) *The New NHS*. The Stationery Office: London

United Kingdom Department of Health (2004) *National service framework for children, young people and maternity services*. Department of Health: London

United Kingdom Department of Health (2007b) *Our NHS Our future: NHS next stage review - interim report*. Accessed on 11<sup>th</sup> March 2015 from:

[http://webarchive.nationalarchives.gov.uk/+/dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_079077](http://webarchive.nationalarchives.gov.uk/+/dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079077)

United Kingdom Department of Health (2007b) *You're Welcome quality criteria: Making health services young people friendly*. HMSO: London

United Kingdom Department of Health (2010a) *Equity & Excellence: Liberating the NHS*. The Stationery Office: London

United Kingdom Department of Health (2010b) *Equity and Excellence for Children: How liberating the NHS will help us meet the needs of children and young people*. The Stationery Office: London

United Kingdom Department of Health (2011a) *You're Welcome - Quality criteria for young people friendly health services*. Accessed on 10<sup>th</sup> February 2015 from: <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>

United Kingdom Department of Health (2011b) *You're Welcome - Quality criteria for young people friendly health services. Q&A update – February 2011*. Accessed on 10<sup>th</sup> February 2015 from: [http://www.yphsig.org.uk/service\\_development](http://www.yphsig.org.uk/service_development)

United Kingdom. Department of Health. (2012a). *Have your Say on Children and Young People's Health Outcomes*. Accessed on 10<sup>th</sup> February 2015 from: <https://www.gov.uk/government/news/have-your-say-on-children-and-young-people-s-health>

United Kingdom Department of Health (2012b) *The NHS Friends and Family Test. Implementation Guidance*. Department of Health London

United Kingdom Department of Health (2012c) *Liberating the NHS: No decision about me, without me*. Department of Health London

United Kingdom Department of Health (2013a) *Handbook to the NHS Constitution*. Department of Health: London

United Kingdom Department of Health (2013b) *CMO's annual report 2012: Our Children Deserve Better: CMO's Summary as a web page*. Accessed on 10<sup>th</sup> February 2015 from: <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays/cmos-annual-report-2012-our-children-deserve-better-cmos-summary-as-a-web-page>

United Kingdom Department of Health (2013c) The NHS Outcomes Framework 2014/15. Accessed on 12<sup>th</sup> March 2015 from:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256456/NHS\\_outcomes.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256456/NHS_outcomes.pdf)

World Health Organization (2010) *Expert advisory panels and committees*. World Health Organization: Geneva. Accessed on 25<sup>th</sup> February 2015 from:

[http://www.who.int/rpc/expert\\_panels/Factsheet\\_EAP2010.pdf](http://www.who.int/rpc/expert_panels/Factsheet_EAP2010.pdf)

Young Minds (2012) *Changes to NHS landscape devalue young people's participation*. Accessed on 10<sup>th</sup> February 2015 from:

[http://www.youngminds.org.uk/news/news/528\\_changes\\_to\\_nhs\\_landscape\\_devalue\\_young\\_people\\_s\\_participation](http://www.youngminds.org.uk/news/news/528_changes_to_nhs_landscape_devalue_young_people_s_participation)

## **Appendix 2.1**

### **Conduct sheet: Focus group facilitators**

- Check that you have everything you will need before meeting the participants, including:
  1. Interview guide
  2. Digital recorder
  3. Spare batteries
  4. Contact details for follow-up support, if required
  5. Sticky labels for name badges
- Make sure that you have a quiet, private room, with no interruptions.
- Check beforehand that the digital recorder is working (also check after a few minutes of the interview).
- Regularly check that the digital recorder is still working.
- Ask the participants to introduce themselves by first name only, and to try and remember to introduce each contribution with their first name (it makes it much easier to identify them when transcribing the recording).
- Make sure that you get their consent again before beginning.
- Read carefully through the first part of the interview schedule to make sure that the focus group members understand what is going to happen and consent to everything.
- Go over the ground rules:
  1. Confidentiality
  2. Each participant has as valid a point as the next one
  3. Health issues will not be discussed
  4. Each participant has an equal right to express themselves
  5. No disagreements/arguments to be taken outside of the group
  6. All are equal within the group.
- Stress confidentiality, and that nothing that is said inside the group is taken outside of it - apart from the digital recording.

## **Role of the facilitator during the discussion**

- Begin with the opening question to get the participants talking and feeling comfortable.
- Allow plenty of time for discussion around key questions.
- The focus group facilitator should keep a low profile as possible once the discussion has begun.
- The facilitator should have a low level of involvement when allowing participants to explore ideas and concepts.
- However, there should be a high level of involvement when comparing new participants with findings from previous groups (the idea is not to go over old ground but to explore new ideas and concepts).
- Be prepared to bring the group back to the topic if they have strayed too far - more important in a group than in one-to-one interviews.
- Encourage reluctant participants.
- Be aware of possible role differentials and how this could affect the group dynamics.
- Act as a:
  1. Facilitator
  2. Controller
  3. Listener
- Possible problems to be aware of:
  1. Participants have different ideas about the purpose of the group
  2. Silence
  3. Participant/s who will not join in
  4. Everyone talking at once - control the group so that only one person at a time talks
  5. Running out of time - not getting round to all key questions because of too much discussion (often of irrelevant points)
- Finish by summarising, switch off the digital recorder, and then de-brief.
- Thank everybody for coming and for his or her contributions.

## **Appendix 2.2**

### **Focus Group Prompt Questions: Schedule for Young People**

- Introductions, including:
  - Purpose of the focus group
  - Clarification of topic under discussion
  - Clarification that health issues will not be discussed
  - Format of the focus group
  - Approximate length of the focus group
  - Assurance of confidentiality
  - Purpose and use of digital recorder (including consent for its use)
  - Assurance that the participants can seek clarification of questions
  - Assurance that the participants can decline to answer a question(s)
  - Assurance that the participants can ask questions

**Please also refer to 'Conduct sheet: Focus group facilitators' for further information**

- In order to understand the demographics of the membership of the NHS Youth Forum, please can you tell me your age and the general area where you live in England?
- Do you think that, as a group, you provide good representation of young people in England?
- I notice that you are all teenagers, or older – what do you think about the appropriateness of the age range span?
- When were you recruited as a member of the NHS Youth Forum?
- How were you recruited to the Forum?
- How much time do you spend on NHS Youth Forum activities?
- How is your time recognised? For example, is there any financial reimbursement (including travel expenses)?
- What activities have you been involved in?
- Who organises the activities?
- Who decides what these activities should consist of?

- I understand the NHS Youth Forum identified some priorities, these being: Communicating with health professionals, mental health and sexual heath - have these priorities been reflected in the activities you have undertaken? If so how?
- Do you receive feedback following any activities undertaken?
- What format does this feedback take?
- What do you consider are the benefits of being a member of the NHS Youth Forum?
- What have been some of the challenges of being involved in the Forum?
- Would you, or would you not, encourage other young people to be involved? Why?
- Do you feel that your voice, either individually or as a Forum, has been listened to? Can you give an example to illustrate your response?
- Have you been informed of any changes as a result of your Forum activities?
- How does the Forum engage with children or young people who are not members?
- How is information disseminated to a wider audience?
- Do you consider that the voice of the 'everyday' child / young person is heard?
- Have you got any suggestions about how the NHS Forum could be developed?
- What suggestions have you got that might help NHS England to increase their strategies to listen to the child and young person's voice?
- Do you have anything else you would like to add?

**Thank you**

## **Appendix 2.3**

### **Focus Group Prompt Questions: Schedule for Adult Reference Group**

- Introductions, including:
  - Purpose of the focus group
  - Clarification of topic under discussion
  - Format of the focus group
  - Approximate length of the focus group
  - Assurance of confidentiality
  - Purpose and use of digital recorder (including consent for its use)
  - Assurance that the participants can seek clarification of questions
  - Assurance that the participants can decline to answer a question(s)
  - Assurance that the participants can ask questions

**Please also refer to ‘Conduct sheet: Focus group facilitators’ for further information**

- In order to understand the membership of the NHS Youth Forum Reference Group please can you tell me which organisations are represented on this group?
- When was the Reference Group founded?
- How and why were you recruited to the Reference Group?
- What is your role in the NHS Youth Forum?
- How does the Reference Group link to the Youth Forum?
- How much time do you spend on NHS Youth Forum activities?
- How is your time recognised? For example, is there any financial reimbursement (including travel expenses)?
- What activities have you been involved in?
- Who organises the activities?
- Who makes the decisions relating to what activities the young people are involved in?
- I understand the NHS Youth Forum priorities are: Communicating with health professionals, mental health and sexual health - how was the decision made to focus on these areas?

- Do you consider that these priorities have been reflected in the activities undertaken by the young people in the Youth Forum? If so how?
- Do the young people receive any feedback following the activities they undertake?
- What format does this feedback take?
- What do you consider are the benefits to the young people of being a member of the NHS Youth Forum?
- What challenges has the Youth Forum encountered:
  - At the planning stage?
  - During the implementation stage?
  - During the management stage?
- How does the NHS Youth Forum engage with children or young people who are not members?
- How is information disseminated to a wider audience?
- How do you envisage that the NHS Youth Forum will be developed?
- Do you think that the voice of the ‘everyday’ child / young person is heard?
- Do you have anything else you would like to add?

**Thank you**

## **Appendix 2.4**

### **Interview Prompt Questions: Schedule for Employee Interviews**

- Introductions, including:
  - Purpose of interview
  - Clarification of topic under discussion
  - Format of interview
  - Approximate length of interview
  - Assurance of confidentiality
  - Purpose and use of digital recorder (including consent for its use)
  - Assurance that the participant can seek clarification of questions
  - Assurance that the participant can decline to answer a question(s) or terminate the interview
  - Assurance that the participant can ask questions
- What is your current role/job title?
- What are your key responsibilities in relation to the NHS Youth Forum?
- Could you explain the background of the NHS Youth Forum and the rationale for its implementation?
- Please could you explain how the Youth Forum is funded?
- How much time do you personally spend engaging with / working for the NHS Youth Forum?
- Why did you decide on this particular approach to engaging with and listening to young people?
- Why this age group?
- Are there any plans to broaden the age range?
- Please explain the membership of the NHS Youth Forum and how the young people were recruited?
- Why was this particular recruitment strategy used?
- What challenges have you encountered:
  - At the planning stage?
  - During the implementation stage?
  - During the management stage?

- What do you consider are the benefits to the young people of being a member of the NHS Youth Forum?
- What do you consider to have been the benefits of the Youth Forum to young people not directly involved with it?
- How were the three key priority areas (sexual health; mental health; communicating with health professionals) decided?
- What activities do the young people undertake?
- How are the young people's activities organised and monitored?
- Who makes the decisions relating to what activities the young people are involved in?
- What feedback is provided to the young people following these activities?
- How do the young people engage with other Forum members?
- How do the young people engage with children and young people who are not Forum members?
- What plans does NHS England have to continue to listen to the voice of children and young people?
- How is the 'everyday' child or young person's voice taken into consideration?
- Is there a method of dissemination from the Youth Forum to a wider audience of children and young people?
- Do you think that the voice of the young people has been heard? Please explain, do you have any evidence for your answer?
- Do you have anything else you would like to add?

**Thank you**

## **Appendix 2.5**

### **Young People Information Sheet**

#### **Evaluation of NHS England Youth Forum**

**Project Lead: Dr. Lisa Whiting, University of Hertfordshire**

Hi,

My name is Lisa Whiting. I am a Registered Children's Nurse, employed as a Principal Lecturer in Children's Nursing at the University of Hertfordshire. My colleagues and I have been asked to undertake a project on behalf of NHS England.

As you are aware, NHS England launched their Youth Forum in March of this year; as the Forum has now been running for several months, NHS England would like some feedback about it. We would very much value your knowledge and expertise in terms of informing the project.

#### **What is the purpose of the project?**

The project aims to find out what you think about the NHS England Youth Forum, your experiences of it and how well you think it is working. This information will help NHS England to consider how they can help to ensure that the opinions of children and young people are listened to in the future.

#### **Why have you been invited to take part?**

You have been invited to take part in this project as you are a member of the NHS England Youth Forum; I have spoken to \*\*\*\* [name and post title removed] and she has agreed that we can approach you to ask you for your views.

#### **Do I have to take part?**

No. It is entirely up to you.

#### **What is involved?**

We would like you to be involved in a discussion (focus group) of between 6-10 young people (who are all members of the NHS England Youth Forum) to ascertain your views about the Youth Forum and also your experiences of being involved in it. We will conduct the focus group at your next residential weekend in November and I will arrange this with \*\*\*\* [name removed] so that it is at a time that is convenient to you; it is anticipated that the focus group will take approximately 50-60 minutes.

### **What will happen with the information?**

The focus group recordings and transcripts will only be accessible to the project team and will be kept securely in accordance with the Data Protection Act. At the end of the project, the recordings will be destroyed and the transcripts will not identify you as pseudonyms will be used. The transcripts will be analysed and data from them will be used in the final report that is written for NHS England; part of this may be presented at conferences or published in professional journals. You may have a copy of the report if you like; you will also be sent a gift voucher and a formal thank you letter.

### **What are the possible benefits of taking part?**

It is important that young people are given the chance to express their views about the NHS England Youth Forum and the ways in which children and young people can be listened to; this project will give that opportunity; although the project may not specifically benefit you, it could provide important information for the future.

### **What are the possible disadvantages of taking part?**

There are no foreseeable risks to taking part, but if you should find any aspect of the focus group uncomfortable, you can choose to not answer the question(s). If you feel that you need to access additional support services, please contact a member of the project team (details below).

### **Who is organising and funding the project?**

The project is being led by me, Lisa Whiting; it is funded by NHS England. Ethical approval has been received from the University of Hertfordshire Ethics Committee (Protocol number: HSK/SF/UH/00086) to undertake this project.

### **What if you have some questions about the project?**

If you would like to find out more about this project before agreeing to be involved, you can contact one of the team members detailed below.

#### **Project Team:**

**Lisa Whiting (Project Lead):** 01707 285291; [L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)

**Sheila Roberts:** 01707 284749; [S.A.Roberts@herts.ac.uk](mailto:S.A.Roberts@herts.ac.uk)

**Jenni Etchells:** 01923 471200; [jenni.etchells@hchs.nhs.uk](mailto:jenni.etchells@hchs.nhs.uk)

We would like to take this opportunity to thank you for taking the time to read this information sheet.

*If you would like to be involved in a focus group at your next residential weekend, please let \*\*\*\* [name removed] know. Thank you.*

## **Appendix 2.6**

### **Adult Reference Group Information Sheet**

#### **Evaluation of NHS England Youth Forum**

**Project Lead: Dr. Lisa Whiting, University of Hertfordshire**

Thank you for taking the time to read this information sheet. My name is Lisa Whiting. I am a Registered Children's Nurse, employed as a Principal Lecturer in Children's Nursing at the University of Hertfordshire.

The information contained in this sheet relates to a project that the University is undertaking on behalf of NHS England. As you are aware, NHS England launched their Youth Forum in March of this year; as the Forum has now been running for several months, NHS England would like to evaluate it. We would very much value your knowledge and expertise in terms of informing the project.

#### **What is the purpose of the project?**

The project aims to evaluate the overall impact of the NHS England Youth Forum. This information will help NHS England to consider how they can help to ensure that the opinions of children and young people are listened to in the future.

#### **Why have you been invited to take part?**

You have been invited to take part in this project as you are a member of the NHS England Reference Group; I have spoken to \*\*\*\* [name and post title removed] who is the Chairperson for your Reference Group and she has agreed that we can approach you to ask you for your views.

#### **Do I have to take part?**

No. It is entirely up to you.

#### **What is involved?**

We would like you to be involved in a focus group of between 6-10 people (who are all members of the NHS England Reference Group) to ascertain your views about the Youth Forum and also your experiences of being involved in it. We will conduct the focus group at one of your future meetings and will arrange this with \*\*\*\* [name removed] so that it is at a time that is convenient to you; it is anticipated that the focus group will take approximately 50-60 minutes.

### **What will happen with the information?**

The focus group recordings and transcripts will only be accessible to the project team and will be kept securely in accordance with the Data Protection Act. At the end of the project, the recordings will be destroyed and the transcripts will not identify you as pseudonyms will be used. The transcripts will be analysed and data from them will be used in the final report that is written for NHS England; part of this may be presented at conferences or published in professional journals. You may have a copy of the report if you like.

### **What are the possible benefits of taking part?**

It is important that the Reference Group are given the chance to express their views about the NHS England Youth Forum and the ways in which children and young people can be listened to; this project will give that opportunity; although the project may not specifically benefit you, it could provide important information for the future.

### **What are the possible disadvantages of taking part?**

There are no foreseeable risks to taking part, but if you should find any aspect of the focus group uncomfortable, you can choose to not answer the question(s). If you feel that you need to access additional support services, please contact a member of the project team (details below).

### **Who is organising and funding the project?**

The project is being led by me, Lisa Whiting; it is funded by NHS England. Ethical approval has been received from the University of Hertfordshire Ethics Committee (Protocol number: HSK/SF/UH/00086) to undertake this project.

### **What if you have some questions about the project?**

If you would like to find out more about this project before agreeing to be involved, you can contact one of the team members detailed below.

#### **Project Team:**

**Lisa Whiting (Project Lead):** 01707 285291; [L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)

**Sheila Roberts:** 01707 284749; [S.A.Roberts@herts.ac.uk](mailto:S.A.Roberts@herts.ac.uk)

**Jenni Etchells:** 01923 471200; [jenni.etchells@hchs.nhs.uk](mailto:jenni.etchells@hchs.nhs.uk)

We would like to take this opportunity to thank you for taking the time to read this information sheet.

*If you would like to be involved in a focus group at one of your forthcoming meetings, please contact \*\*\*\* [name removed]. Thank you.*

## **Appendix 2.7**

### **Employee Information Sheet**

#### **Evaluation of NHS England Youth Forum**

**Project Lead: Dr. Lisa Whiting, University of Hertfordshire**

Thank you for taking the time to read this information sheet. My name is Lisa Whiting. I am a Registered Children's Nurse, employed as a Principal Lecturer in Children's Nursing at the University of Hertfordshire.

The information contained in this sheet relates to a project that the University is undertaking on behalf of NHS England. As you are aware, NHS England launched their Youth Forum in March of this year; as the Forum has now been running for several months, NHS England would like to evaluate it. We would very much value your knowledge and expertise in terms of informing the project.

#### **What is the purpose of the project?**

The project aims to evaluate the overall impact of the NHS England Youth Forum. This information will help NHS England to consider how they can help to ensure that the opinions of children and young people are listened to in the future.

#### **Why have you been invited to take part?**

You have been invited to take part in this project as you have had a key role in relation to the planning, implementation and on-going management of the NHS England Youth Forum and we would very much like to hear your views and opinions.

#### **Do I have to take part?**

No. It is entirely up to you.

#### **What is involved?**

We would like to conduct a face-to-face interview with you at your place of work to ascertain your views and experiences of being involved in the planning, implementation and management of the NHS Youth Forum. It is anticipated that the interview will take approximately 50-60 minutes of your time.

### **What will happen with the information?**

The interview recordings and transcripts will only be accessible to the project team and will be kept securely in accordance with the Data Protection Act. At the end of the project, the recordings will be destroyed and the transcripts will not identify you as pseudonyms will be used. The transcripts will be analysed and data from them will be used in the final report that is written for NHS England; part of this may be presented at conferences or published in professional journals. You will be provided with a copy of the final report.

### **What are the possible benefits of taking part?**

It is anticipated that the project will provide further insight into how NHS England can facilitate listening to children and young people; although the project may not specifically benefit you, it could provide important information for the future.

### **What are the possible disadvantages of taking part?**

There are no foreseeable risks to taking part, but if you find any aspect of the interview uncomfortable, you can choose to leave the question or terminate the whole interview. If you feel that you need to access additional support services, please contact a member of the project team (details below).

### **Who is organising and funding the project?**

The project is being led by me, Lisa Whiting; it is funded by NHS England. Ethical approval has been received from the University of Hertfordshire Ethics Committee (Protocol number: HSK/SF/UH/00086) to undertake this project.

### **What if you have some questions about the project?**

If you would like to find out more about this project before agreeing to be involved, you can contact one of the team members detailed below.

#### **Project Team:**

**Lisa Whiting (Project Lead):** 01707 285291; [L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)

**Sheila Roberts:** 01707 284749; [S.A.Roberts@herts.ac.uk](mailto:S.A.Roberts@herts.ac.uk)

**Jenni Etchells:** 01923 471200; [jenni.etchells@hchs.nhs.uk](mailto:jenni.etchells@hchs.nhs.uk)

We would like to take this opportunity to thank you for taking the time to read this information sheet.

*If you would like to participate in an individual face-to face interview, please contact Lisa Whiting ([L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)) to arrange a mutually convenient date and time. Thank you.*

## **Appendix 2.8**

### **Support services Information Sheet, young people**

#### **Evaluation of NHS England Youth Forum**

**Project Lead: Dr. Lisa Whiting, University of Hertfordshire**

**Ethics protocol number: HSK/SF/UH/00086**

Thank you so much for helping us to evaluate the NHS England Youth Forum – we appreciate how busy you are and are very grateful for the time that you have given.

If you should have any further queries, or feel that you would like some support or advice following your involvement, please contact one of the following:

**Project Team:**

Lisa Whiting (Project Lead): 01707 285291; [L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)  
Sheila Roberts: 01707 284749; [S.A.Roberts@herts.ac.uk](mailto:S.A.Roberts@herts.ac.uk)  
Jenni Etchells: 01923 471200; [jenni.etchells@hchs.nhs.uk](mailto:jenni.etchells@hchs.nhs.uk)

**SupportLine Telephone Helpline:**

**Telephone:** 01708 765200

**Email:** [info@supportline.org.uk](mailto:info@supportline.org.uk)

**Address:** SupportLine PO Box 2860, Romford, Essex RM7 1JA

This service provides confidential emotional support to children, young people and adults; if required, the organisation will also refer people to other helplines, counsellors and support groups throughout the UK.

**Get Connected:**

**Telephone:** 0808 808 4994

**Email:** [www.getconnected.org.uk](http://www.getconnected.org.uk)

Get Connected will connect a young person to any UK helpline.

Thank you again for your support with this initiative.

The Project Team

## **Appendix 2.9**

### **Support services Information Sheet, Adult Reference Group and employees**

#### **Evaluation of NHS England Youth Forum**

**Project Lead: Dr. Lisa Whiting, University of Hertfordshire**

**Ethics protocol number: HSK/SF/UH/00086**

Thank you so much for helping us to evaluate the NHS England Youth Forum – we appreciate how busy you are and are very grateful for the time that you have given.

If you should have any further queries, or feel that you would like some support or advice following your involvement, please contact one of the following:

**Project Team:**

Lisa Whiting (Project Lead): 01707 285291; [L.Whiting@herts.ac.uk](mailto:L.Whiting@herts.ac.uk)

Sheila Roberts: 01707 284749; [S.A.Roberts@herts.ac.uk](mailto:S.A.Roberts@herts.ac.uk)

Jenni Etchells: 01923 471200; [jenni.etchells@hchs.nhs.uk](mailto:jenni.etchells@hchs.nhs.uk)

**SupportLine Telephone Helpline:**

**Telephone:** 01708 765200

**Email:** [info@supportline.org.uk](mailto:info@supportline.org.uk)

**Address:** SupportLine PO Box 2860, Romford, Essex RM7 1JA

This service provides confidential emotional support to children, young people and adults; if required, the organisation will also refer people to other helplines, counsellors and support groups throughout the UK.

**Samaritans:**

**Telephone:** 08457 90 90 90

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

**Address:** Freepost RSRB-KKBY-CYJK, Chris, PO Box 90 90, Stirling, FK8 2SA

Samaritans provides the chance to talk to someone in total confidence, about anything and everything.

Thank you again for your support with this initiative.

The Project Team

## **Appendix 2.10**

### **Consent Form**

#### **Evaluation of NHS England Youth Forum**

**Project Lead: Dr. Lisa Whiting, University of Hertfordshire**

**Ethics protocol number: HSK/SF/UH/00086**

|  | <b>Please initial<br/>(Participant)</b> |
|--|---|
| 1. I have read and understood the information sheet (version 1.0) for the above project. I have had any questions about the project answered to my satisfaction. |   |
| 2. I agree to take part in the project and understand that I can decide to leave it at any time without giving a reason.   |   |

**Details of person participating in the project:**

**Name (please print): .....**

**Please indicate your designation with a tick [√]**

- NHS England Youth Forum member
- Reference Group member
- Member of staff with designated responsibility for facilitating the NHS England Youth Forum, please specify role title:  
.....

**Signature: .....**

**Date: .....**

**Name of person taking consent:**

**Name: .....**

**Date: .....**

**Signature: .....**

**Copy for participant and copy for project file**