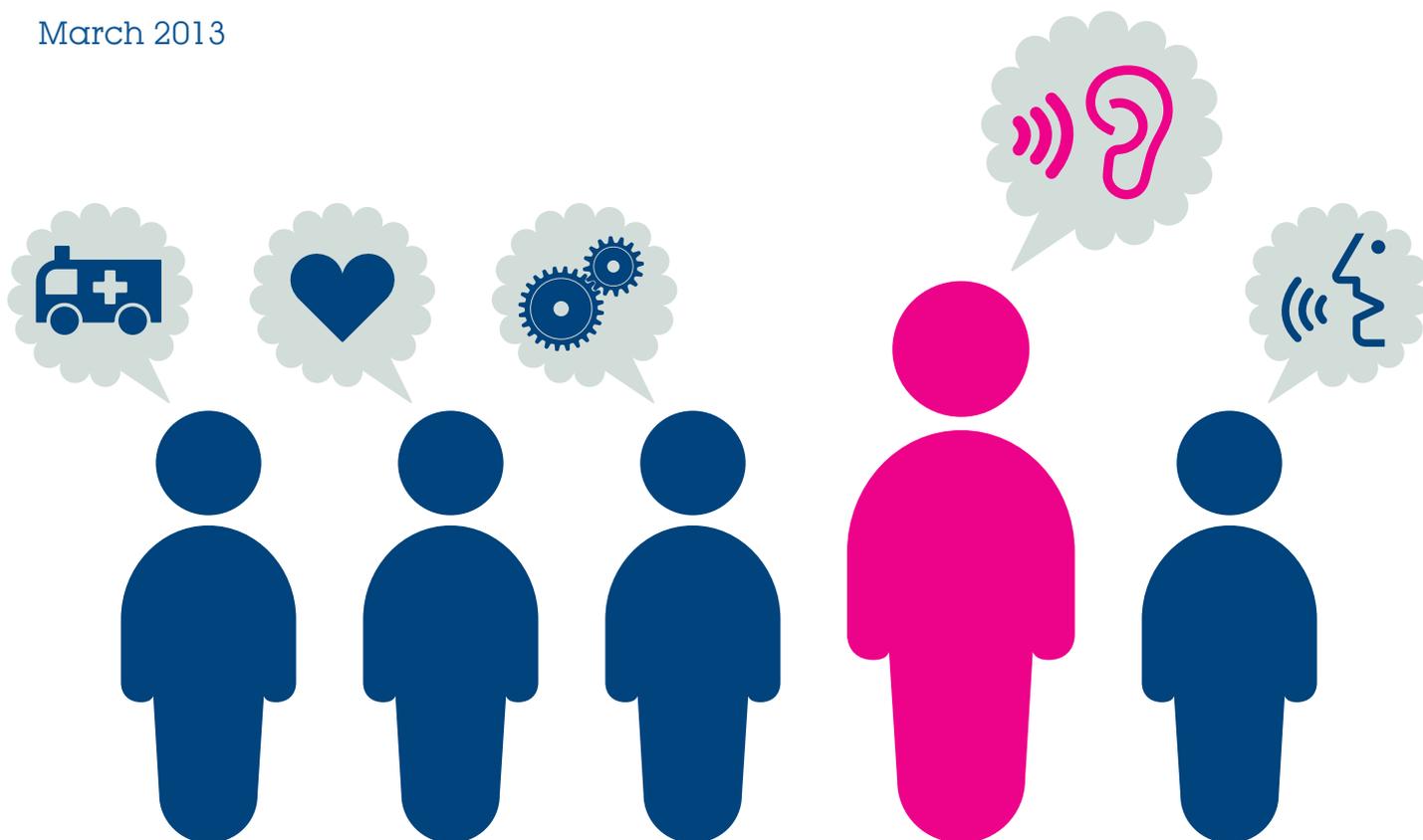


Office of the Children's Commissioner:

# We would like to make a change

Children and young people's participation  
in strategic health decision-making

March 2013



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# Table of Contents

|  |           |
|--|-----------|
| <b>Foreword by the Children's Commissioner</b>   | <b>2</b>  |
| <b>About the Office of the Children's Commissioner</b>   | <b>4</b>  |
| <b>Acknowledgements</b>  | <b>5</b>  |
| <b>Executive summary</b>   | <b>6</b>  |
| <b>Section one: Introduction</b>   | <b>12</b> |
| <b>Section two: The participation story so far</b>   | <b>18</b> |
| <b>Section three: Children's voices in the health system – policy context</b>                                    | <b>23</b> |
| <b>Section four: A current picture of children's voices in strategic health decision-making</b>                  | <b>27</b> |
| <b>Section five: How do children and young people want to take part in strategic health decision-making?</b>     | <b>38</b> |
| <b>Section six: What next for children and young people's participation in strategic health decision-making?</b> | <b>47</b> |
| <b>Section seven: Conclusions and recommendations</b>  | <b>49</b> |
| <b>Appendix A: Method</b>  | <b>54</b> |
| <b>Appendix B: Topic guides</b>  | <b>62</b> |
| <b>Appendix C: Children's voices in the health system – the policy framework</b>                                 | <b>71</b> |

# Foreword by the Children's Commissioner

Children and young people have a right to have their views heard in all matters affecting them and for these to be taken seriously. This Right is enshrined in the United Nations Convention on the Rights of the Child as Article 12. Article 24 of the convention also states that every child has the right to the best possible health care. The UK ratified this treaty in 1991, so it binds our actions when we work with children and young people. In addition to the convention the UN Committee has also recently produced general comment on Article 24, which helps guide all those responsible for the provision of children's health in realising children's rights.

The Government is also clear that patient and public involvement is at the heart of the recent reforms of the NHS, something I warmly welcome. The 2012 White Paper, *Equality and Excellence: liberating the NHS* outlines the emphasis placed on giving patients and the public a much stronger voice.

This report focuses on how good established, new and emerging health systems are at engaging children and young people in decision-making about health service design and delivery. It explores how far these structures realise children's rights to participate in decisions that will directly affect them and their health, both now and in future.

To inform the recommendations in the report, we analysed 102 local health plans. These were followed up by interviews with key health professionals, to explore how plans are put into practice, and also how young patients' involved in both the planning and implementation.

We were pleased to find good practice in some areas, and where we did, we have reported this. For example, we found one young people's council had helped to develop their local Joint Health and Wellbeing Strategy and had responsibility for allocating £50,000 public health funding to health programmes they considered vital in their area. In addition, Greater Manchester Health Trusts involved 22,000 children and young people in decisions about reconfiguring NHS services in 2011. I hope the good practice examples in the report encourage areas that are not involving children and young people in strategic health decision-making to do so.

However, good practice is not common place. We found no coherent national programme of activity to proactively encourage local bodies to include children and young people in strategic health service commissioning or other vital decision-making about NHS provision. Only 28 per cent of the plans we reviewed referenced children and young people's participation in their development, the delivery of what was in them, or the evaluation of whether practice matched their aspirations.

Department of Health guidance on producing local Joint Health and Wellbeing Strategies refers to children and young people as active citizens who are also users of health services but does not include information about children and young people's participation in decision-making. This is disappointing given that there are 2.04 million residents in England who are under 18 years of age. We also found no discernible difference in the degree to which Healthwatch pathfinder and non-pathfinder local authorities (the areas piloting the new arrangements for championing patients' involvement in health planning prior to the establishment of the national Healthwatch programme) involved children and young people in decision-making.

This is at odds with what children and young people have told us they want. They would like to take part and have their views taken seriously. They want as wide a range of children and young people to take part and to be shown that their opinions are valued.

We hope the good practice highlighted in this report:

- Provides assurance to health planners and commissioners that children and young people are sensible, knowledgeable and valuable contributors to health decision-making when given a seat at the table, asked to represent their generation, and supported to do so. They should not be treated as passive recipients who either have no views or whose views must defer to those of adults. Nor should their participation be feared because they may ask for the impossible or destabilise services if given a voice.
- Are used by areas and organisations to improve the way they involved children and young people in strategic health decision-making. Many children have regular personal experience of a range of health services. All will have had at least some contact and experience. They are services users and have a right to have their views taken into account.

Fundamental changes are taking place in the way health services are planned and commissioned. These present a real opportunity to embed, strengthen and promote the involvement of children in decision-making throughout the health system. As the statutory champion of children's rights in England, I urge that this happens, deliberately and in a sustained way, across the new NHS.

Now is the time for the Department of Health, the new NHS, and their national and local partners to implement the commitment the UK made to listening to and acting on the views of children when it ratified the United Nations Convention on the Rights of the Child.

A handwritten signature in black ink, appearing to read 'ME Atkinson', with a long, sweeping flourish at the end.

**Dr Maggie Atkinson**  
**Children's Commissioner for England**

**March 2013**

# About the Office of the Children's Commissioner

The Office of the Children's Commissioner is a national organisation led by the Children's Commissioner for England, Dr Maggie Atkinson. The post of Children's Commissioner for England was established by the Children Act 2004. The United Nations Convention on the Rights of the Child (UNCRC) underpins and frames all of our work.

The Children's Commissioner has a duty to promote the views and interests of all children in England, in particular those whose voices are least likely to be heard, to the people who make decisions about their lives. She also has a duty to speak on behalf of all children in the UK on non-devolved issues, which include immigration, for the whole of the UK, and youth justice, for England and Wales. One of the Children's Commissioner's key functions is encouraging organisations that provide services for children always to operate from the child's perspective.

Under the Children Act 2004, the Children's Commissioner is required both to publish what she finds from talking and listening to children and young people, and to draw national policymakers' and agencies' attention to the particular circumstances of a child or small group of children which should inform both policy and practice.

The Office of the Children's Commissioner is England's only statutory independent champion for children and young people. It is our statutory duty to highlight where we believe vulnerable children are not being treated appropriately and in line with duties established under international and domestic legislation.

## Acknowledgements

The authors would like to thank the Office of the Children's Commissioner for funding this study and also thank the advisory group: Lisa Davis (Office of the Children's Commissioner); Ross Hendry (Office of the Children's Commissioner); Prof. Hugh McLaughlin (Professor of Social Work, Manchester Metropolitan University); Jane Roberts (GP and Chair of the Adolescent Health Group, Royal College of GPs); Nicola Rosenberg (Policy Manager, NHS Confederation); Peder Clark (Royal College of Paediatrics and Child Health); Nicola Close (Chief Executive, Association of Directors of Public Health); Andrew Webb (Incoming Vice-President of ADCS and chair of the Children's Inter-agency Group, Stockport Corporate Director, Services to People); Samantha Ramanah (Adviser – Community Wellbeing Board and Children and Young People Board, Local Government Association); David Clark (British Youth Council); and Malcolm Alexander (National Association of LINKs (Healthwatch) Members (NALM)).

Special thanks go to the Young NCB Research Advisors and the focus group participants, and to the health and participation professionals who agreed to be interviewed for this research.

# Executive summary

This research was carried out by the National Children's Bureau (NCB) Research Centre for the Office of the Children's Commissioner for England (OCC), in conjunction with the policy team at NCB. It **presents a picture of children and young people's<sup>1</sup> participation in strategic health decision-making** ahead of the implementation of the Government's reforms to the health service from April 2013.

In this report 'children's participation' refers to children taking part and their voices being listened to in one of three ways: **inform**; **consult** or **involve**<sup>2</sup>. These categories, taken from the OCC's Wheel of Participation (see page 12), describe how children may engage in the decisions that affect their lives. The foundation for meaningful participation of any type requires children to be well informed so they can take part in consultations and help shape decisions.

By 'strategic' decision-making we mean the process of assessing local health needs, identifying priorities and making plans for how health services are delivered in local areas.

This study has focused on high level strategic decisions about health services being made *locally* by health and wellbeing boards (HWBs), local authorities (LAs) and clinical commissioning groups (CCGs), rather than decisions taken at the national level by policy makers and Parliament; or by specific service providers (such as hospitals). However, we anticipate that the findings and recommendations in this report will be applicable to policy makers; to both national and local health bodies, and to those directly providing health services.

## About the research

The overarching aims of the study were to:

- identify whether, and if so how far, new and emerging health systems and services proactively engage children and young people in decisions about health service design and delivery
- identify the most effective mechanisms for ensuring the meaningful engagement of children in health service design, commissioning, delivery, evaluation and quality assurance
- offer an analysis which might inform subsequent national guidance and linked initiatives, and local health plans which are being or will be developed, monitored and evaluated by health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch
- contribute to the on-going work of the Department of Health's national Child and Young People's Health Outcomes Forum and the onus it places on all commissioners and providers to listen to and act on the voice and views of children
- Contribute to the work of the Chief Medical Officer's newly formed Children and Young People's Health Board, working at strategic levels across the new NHS after April 2013
- Assure children and young people that their voice is heard in these vital services.

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1 Throughout this report when we refer to 'children' we mean children and young people up to the age of 18 years.

2 Office of the Children's Commissioner (2012) *Participation Strategy, Ensuring children and young people's voices are embedded in the work of the Office of the Children's Commissioner April 2012 – March 2013*.

Our methods were:

- gathering practice examples of including children in strategic health design and delivery through a comprehensive review of published research and consultation on children's views and experiences of health provision from 2007-12<sup>3</sup>
- mapping the emerging evidence on children's participation in strategic health design and delivery in the new health structures, through an analysis of:
  - The national policy framework
  - 102 local health plans (health and wellbeing board joint health and wellbeing strategies (JHWS) and joint strategic needs assessments (JSNA); clinical commissioning group commissioning strategies and engagement strategies; and local Healthwatch pathfinder bids and engagement strategies)
- and analysis of the feedback given to researchers in:
  - Eight follow-up interviews with health policy and participation professionals in local authority areas whose health plans were analysed
  - Six focus groups which explored what children said about how they want to be involved in strategic health service decisions

## Key messages

- Patient and public involvement is a core element of the Government's recent reforms to the health service. Through its pledge for improving children's health outcomes<sup>4</sup> and response to the Children and Young People's Health Outcomes Forum<sup>5</sup>, the Department of Health has signalled that those **planning health services should involve children in their decisions**. However, our policy review indicates that beyond the role of Healthwatch, there is yet to be a coherent programme of work for achieving this for all health bodies making strategic or commissioning decisions. Neither is there clarity about how they will access and share the resources and support materials they need to meaningfully engage children. For instance the well publicised "Friends and Families Test" which asks whether staff, patients and families would recommend a health setting or service to those closest to them, is relevant as things stand only when a patient is aged 18 or over. The fact that one in four patients is aged under 18 and this age group represents a significant population in its own right, is sadly paid scant regard.
- The research findings from the review of local health plans, interviews with local authority's health and participation professionals<sup>6</sup>, and focus groups with children, show that despite **some examples and efforts to improve children's participation, the current picture of children's participation in local strategic health decision-making is both mixed and fragmented**.
- The sample of over 100 local health plans analysed **indicated that they were 'works in progress'**, and a different picture may emerge once they are completed.
- **At this stage in the local planning cycle it appears that children's participation has not been sufficiently embedded into everyday practice** and largely relies on the commitment of key individuals.

3 La Valle I., Payne L. with Gibb J., Jellic H. (2012), *Listening to Children's Views on Health – A rapid review of the evidence*, London: National Children's Bureau. [http://www.ncb.org.uk/media/723497/listening\\_to\\_children\\_s\\_views\\_on\\_health\\_-\\_final\\_report\\_july\\_12.pdf](http://www.ncb.org.uk/media/723497/listening_to_children_s_views_on_health_-_final_report_july_12.pdf)

4 Department of Health (2013) *Better health outcomes for children and young people: our pledge*.

5 Department of Health (2013) *Improving Children and Young People's Health Outcomes: a system wide response*.

6 And one clinical commissioning group representative.

- Analysis of local health plans indicates **significant gaps** in the information currently available about children's participation in strategic health decision-making.
- **Only 28 per cent of all plans specifically referenced children's participation.** Many of the details – about who will be involved and how – were simply lacking. Joint health and wellbeing strategy made the least number of direct references to children's engagement. This was surprising given that these plans provide the overarching health and wellbeing strategy for each local area, and government expects them to include a summary of community views and how those views have been used.
- These findings alone suggest **greater emphasis on the involvement of children in strategic health plans is necessary**, and will need to be supported by appropriate resources, expertise, monitoring systems, and mechanisms allowing all concerned to share effective practice.
- **We found no noticeable difference between the number of Healthwatch pathfinder and non-pathfinder local authority areas** that referenced children's active participation. This is despite Healthwatch being a key vehicle for taking forward the system's necessary and solid assurance of the engagement in the new NHS of patients and the public, including children and young people.
- Follow-up interviews in a small number of local authority areas provided a wider range of examples of including children in strategic decision-making, compared with the analysis of local health plans. This probably reflects the fact that the latter are still 'works in progress'.
- In summary, the evidence from past and current practice shows that children typically are invited to take part at a **specific stage** in the decision-making cycle **mainly through consultation. In effect this signifies activity that is simply a 'sounding out' of actions or decisions that have already largely been made by adults.** However, we also found some emergent evidence of children being more actively and fully involved both in identifying what needed to be done, and making meaningful joint decisions with adults.
- Local Healthwatch and Healthwatch England, local groups, panels and information hubs clearly offer the potential to extend and share these more meaningful ways of involving children in strategic decision-making into more areas of the system, more consistently and determinedly led by adults who run it.
- Generally, the evidence from past and current practice shows that **children tend to be consulted on their health needs and service planning**, rather than on services' commissioning, delivery or evaluation.
- The analysis of current practice provided little evidence of the impact of children's participation on strategic health decisions. This was partly because some decision-making processes that included children were ongoing, or in their early stages of development.
- Children said that **effective approaches** to including them in strategic health decision-making would ideally offer a number of elements:
  - **Opportunity** – for all children to take part; this means ensuring children know about their right to have their views heard and taken seriously, and have some choice in whether and how they do so.
  - **Outreach** – to encourage a wide range of children to take part and to show that their opinions are valued, by making direct face-to-face connections (eg via schools as the universal service most used by the child population), as well as online or via social media, depending on what is practical, appropriate and fit for purpose.

- **Simplicity** – so that children are able to understand the purpose and process, and feel confident in making a contribution.
- **Variety of approaches and means**– so everyone can contribute and stay engaged in the process, including for example children and young people with learning or communication needs, of a wide range of ages including young children, or those whose first language is not English.
- **Outputs and outcomes** – to ensure children are given feedback, understand their potential to influence strategic health decision-making, feel their contribution is valued, and – wherever possible – can see change.
- During this time of reform, there is a **real opportunity** for the NHS to be bold: to embed, strengthen and promote the involvement of children in decision-making throughout the system. Now is the time for Department of Health, the new NHS and their national and local health partners to **implement their commitment** to listen and act on the views of children, in accordance with February 2013's Pledge which was signed by Dr Daniel Poulter MP on behalf of Ministers across government in response to the 2012 report of the Children and Young People's Health Outcomes Forum report.<sup>7</sup>

## Recommendations

Our recommendations are aimed at **both national and local decision-makers**. They are based on the evidence gathered from the review of local health plans, interviews with key informants from local authorities<sup>8</sup> and the focus groups with children.

### National Recommendations

- Department of Health, NHS Commissioning Board and all its Directorates, Public Health England, Health Education England and its national network of Local Education and Training Boards (LETBs), Healthwatch England, the Local Government Association, and the health professionals' various Royal Colleges, **should actively promote the participation of children in strategic decision-making**.
- These national bodies should **develop supporting materials on children's participation** in the development of joint strategic needs assessments, joint health and wellbeing strategys, clinical commissioning group commissioning and engagement strategies, public health plans and local Healthwatch priorities, building upon existing resources and examples of good practice:
  - promoting the benefits of children's participation in strategic decision-making
  - providing examples of good practice to engage children with different needs, experiences and interests
  - setting out the range of approaches that can be used effectively to work with children who are at risk of poor health outcomes or who are less likely to be heard
- Department of Health, the new NHS, and its national and local health partners should all develop child-friendly materials that set out to both raise awareness and improve understanding of the role of the NHS and other health services on the part of children and young people and their families. This should actively seek to encourage more children and young people to get involved in making decisions about their health services.

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<sup>7</sup> <http://www.dh.gov.uk/health/2012/07/cyp-report/>

<sup>8</sup> And one representative from a clinical commissioning group.

- The new Children and Young People's Health Outcomes Forum and the Chief Medical Officer's Children and Young People's Health Board should hold national and local health bodies (including local authorities) to account for fulfilling their duties to involve children in strategic decision-making. This should be one focus for the Forum's first annual summit.
- Healthwatch England and Department of Health should provide leadership to local Healthwatch organisations – as the key champions for service users – to ensure they actively engage children, promote their right to be involved in decision-making and have their views taken seriously, and are adequately resourced to do so.
- In 2014-5, Healthwatch England and Department of Health should review the extent to which local health bodies – including local Healthwatch – have effectively engaged children
- Healthwatch England should be sufficiently resourced not only to effectively involve children in their work, but also to promote effective children's participation to local health structures.

## Local recommendations

- Every health and wellbeing board should be required to ensure children are a clear priority population when gathering the public's views to inform the joint strategic needs assessment and joint health and wellbeing strategy. As well as including the Director of Children's Services in membership, each health and wellbeing board should actively consider how best to engage with local children and young people's participation and involvement organisations and groups, which are now common in most local authority areas.
- **All health and wellbeing boards should identify a champion** who is responsible for promoting children and young people's right to be proactively and meaningfully involved in strategic decision-making as part of the work of the Board, in Las' work on health issues including Public Health, in clinical commissioning groups and local Healthwatch.
- health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch organisations should have clear arrangements in place for **promoting and explaining to children** the work they do and for **monitoring** how children are involved in health decision-making. This should include recording: what data is collected, what methods are used to engage different groups of children, how the views of children are used, and what impact their involvement has had.
- **health and wellbeing boards, in particular, should do more to share publicly how they have involved and continue to involve children and young people in the development of their joint strategic needs assessment and joint health and wellbeing strategy, and any other strategic health plans.**
- health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch should consistently provide children with a **variety of opportunities** to be involved in strategic health decision-making, so that there are options that suit different children's needs and interests.
- Wherever appropriate, children should be given opportunities to make genuinely shared strategic decisions with adults, for example, working together to decide how a proportion of the public health budget will be spent. Where this entails training and educating children and young people to do such co-construction, funding this should be factored into budgets
- health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch should make use of existing materials, resources and mechanisms for engaging

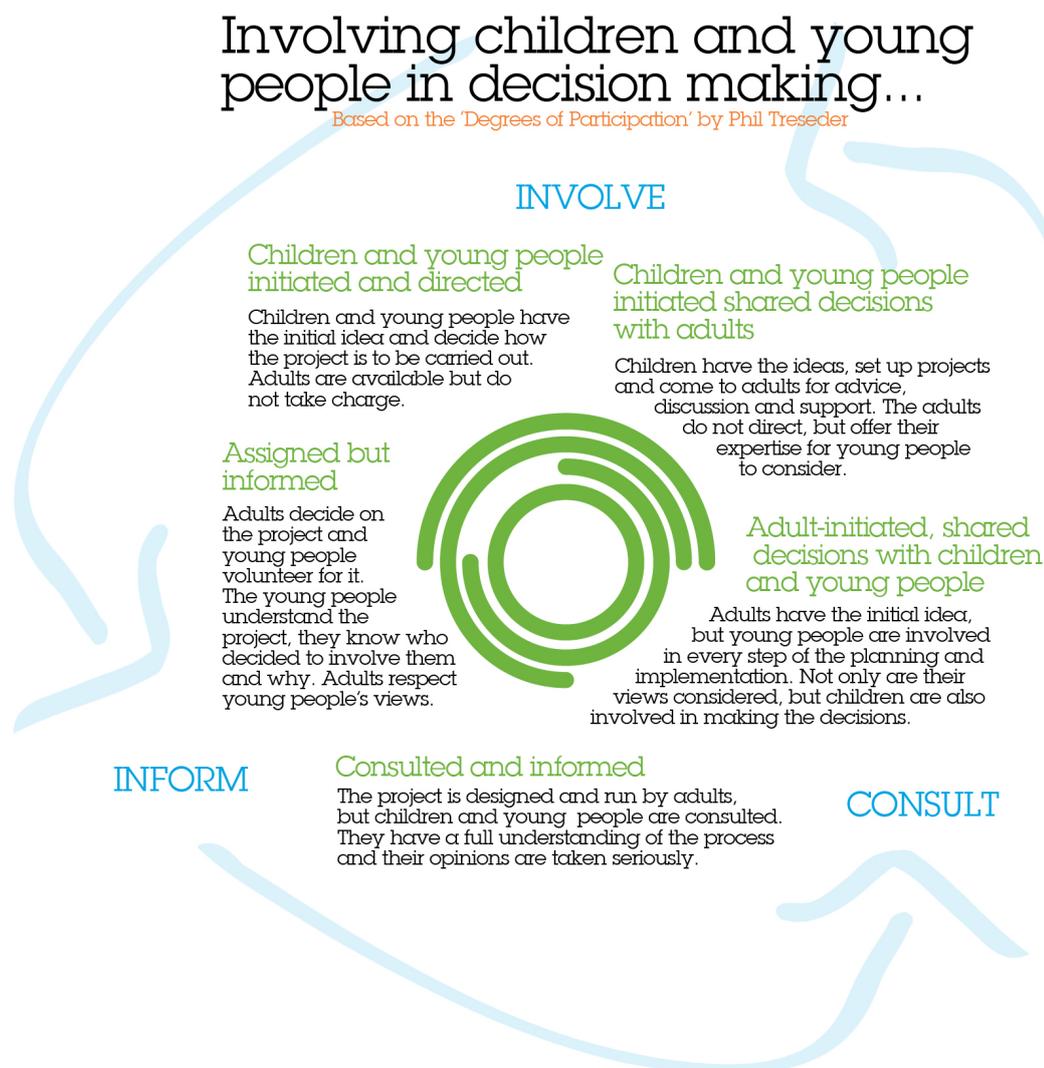
children, including working with schools, youth groups, voluntary organisations and children in care councils.

- These bodies should also monitor whether they are hearing the same voices repeatedly, **striving to provide opportunities to those who might not normally be heard**, including children with poor health outcomes and complex health needs, such as:
  - looked after children,
  - young offenders,
  - disabled children and
  - children living in poverty.
- As well as directly involving children in decision-making, Health and Well-being Boards, local authorities, clinical commissioning groups and local Healthwatch should **draw on children's views about specific services, and on their *individual* experiences of care, to inform strategic decisions**.
- Healthwatch England and local Healthwatch bodies should consider how the latter might act as ambassadors for children's participation in the local health sector by trialling, demonstrating and sharing good practice.

## Section one: Introduction

- 1.1 This research was carried out by the National Children's Bureau (NCB) Research Centre for the Office of the Children's Commissioner for England (OCC), in conjunction with the policy team at NCB. It **presents a picture of children and young people's participation in strategic health decision-making** ahead of the implementation of the Government's reforms to the health service from April 2013.
- 1.2 **Section one** sets out the structure of the report, the aims of the research and methods used. In this report 'children's<sup>9</sup> participation' refers to children taking part and their voices being listened to in one of three ways: **inform; consult or involve**. These categories, taken from the OCC's Wheel of Participation<sup>10</sup>, describe how children may engage in the decisions that affect their lives as shown in the diagram below. The foundation for meaningful participation of any type requires children to be well informed so they can take part in consultations and help shape decisions.

**Figure 1.1 OCC's Wheel of Participation**



9 Throughout the rest of the report 'children' refers to children and young people up to age of 18 years.

10 Office of the Children's Commissioner (2012) *Participation Strategy, Ensuring children and young people's voices are embedded in the work of the Office of the Children's Commissioner April 2012 – March 2013*.

- 1.3 By 'strategic' we mean the process of assessing local health needs, identifying priorities and making plans for how health services are delivered in local areas. This study has focused on high level strategic decisions about health services being made *locally* by health and wellbeing boards (HWBs), local authorities (LAs) and clinical commissioning groups (CCGs), rather than decisions taken at the national level or by specific service providers (such as hospitals). However, we anticipate that key findings and messages will be of use to national and local health bodies, and those directly providing health services.
- 1.4 This report provides timely reflection on:
- the scope and scale of children's participation in strategic health decision-making a key aspect of the Government's drive to improve patient and public involvement in the health service
  - how children's participation can be further strengthened during this time of opportunity and change
- 1.5 The remainder of the report has the following sections:
- **Section two** provides a review of children's participation in strategic health decision-making based on evidence from 2007-12.
  - **Section three** presents a summary of the existing policy context, with a detailed account provided in Appendix C.
  - **Section four** sets out how children are participating in assessing local health needs, identifying priorities and making plans for how health services are delivered in local areas.
  - **Section five** describes how children want to take part in strategic health decision-making.
  - **Section six** identifies what the research found about local authority's and health partners' plans for implementing local health strategies including children.
  - **Section seven** presents the conclusions and recommendations.

## Study aims

- 1.6 The overarching aims of the study were to:
- identify whether and how far new and emerging health systems proactively engage children in decisions about health service design and delivery
  - identify the most effective mechanisms for ensuring the meaningful engagement of children in health service design, delivery, evaluation and quality assurance
  - offer an analysis which might inform national guidance and initiatives, and local health plans developed by health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch
  - contribute to the ongoing work of the Department of Health's national Child and Young People's Health Outcomes Forum and the onus it places on all commissioners and providers to listen to and act on the voice and views of children

## Method

### 1.7 Our methodology included:

- gathering practice examples of involving children in strategic health design and delivery through a comprehensive review of published research and consultation on children's views and experiences of health provision
- mapping the emerging evidence on children's participation in strategic health design and delivery in the new health structures, through an analysis of the national policy framework and local plans, and interviews with health policy and participation professionals in local authorities<sup>11</sup>
- assessing how children want to be involved in strategic health service decisions through focus groups.

This study was informed by **Young NCB Research Advisers**<sup>12</sup>. They contributed to the data collection instrument design; commented on the findings from Stages one and two of the research; contributed to the report recommendations through the focus groups, and produced a child-friendly report.

An **advisory group** of professionals (see Acknowledgements) contributed to the research design and commented on the findings. The methodological approach is summarised below: A detailed account of the method is presented in Appendix A.

### Stage one: analysis of past practice involving children in strategic health decision-making

#### 1.8 NCB recently carried out a comprehensive review of published research and consultation on children's views and experiences of health provision<sup>13</sup>. The responses were reviewed for this report to explore children's participation in strategic health decision-making<sup>14</sup>. In analysing this evidence from 2007-12, we explored:

- the focus and topics to establish at what point children were involved in the decision-making process
- the impetus for the consultations – eg service improvement
- how children participated and their level of participation
- what were the outcomes, and children's views and experiences of taking part in these

### Stage two: review of emerging evidence

#### 1.9 The research team carried out a review of national policy from **DH**<sup>15</sup> and other government departments to provide the background to the study. The review assessed:

- the degree to which these documents promote engagement with children

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11 And one interview with a clinical commissioning group representative.

12 Young NCB Research Advisers are a pre-existing group that are regularly involved in informing and shaping the design and delivery of NCB research projects.

13 La Valle I., Payne L. with Gibb J., Jelacic H. (2012), *Listening to Children's Views on Health – A rapid review of the evidence*, London: National Children's Bureau. [http://www.ncb.org.uk/media/723497/listening\\_to\\_children\\_s\\_views\\_on\\_health\\_-\\_final\\_report\\_july\\_12.pdf](http://www.ncb.org.uk/media/723497/listening_to_children_s_views_on_health_-_final_report_july_12.pdf)

14 The NCB review focused on evidence from England, from 1997-2011. More information on how the review was carried out, including the organisations that responded to the call for evidence, can be found in the review report (La Valle et al., 2012, op. cit.).

15 Including analysis of the NHS Commissioning Board plans for engaging children and young people as they could cover the commission of specialist services (eg in custody, long term/complex conditions).

- the processes and mechanisms they suggested

1.10 **Local plans** developed by health and wellbeing boards, clinical commissioning groups and Healthwatch pathfinders were analysed and represent three key parts of the emerging local health system (see Table 1.1):

- local strategic planning for health and wellbeing
- new local NHS commissioning arrangements
- and local patient and public engagement

1.11 The review of local plans explored the **scope and scale** of children's participation in strategic health decision-making. We assessed how adequately these plans appeared to explain children's participation and to what extent the participation was **meaningful**, drawing on the OCC's participation strategy and NCB's own knowledge and experience of good participation. The criteria for reviewing the plans are detailed in Appendix A.

## Sample

1.12 A total of **102 local plans** from 38 local authority areas were analysed. The sample was selected to be broadly representative of England, covering a range of:

- geographical areas (different parts of the country, rural vs. urban)
- levels of deprivation
- ethnic composition
- Healthwatch pathfinders and non-pathfinders

1.13 Table 1.1 provides an overview of the number and type of plans reviewed and what each covers.

**Table 1.1: Overview of the number and type of plans reviewed**

| Type of plan   | Purpose   | Number of plans reviewed |
|--|---|--------------------------|
| Clinical commissioning group (CCG) commissioning strategy                | Sets out the clinical commissioning group's plans for commissioning local NHS services  | 19                       |
| Clinical commissioning group (CCG) communication and engagement strategy | Sets out how the clinical commissioning group will take forward its duty to involve patients and the public in planning and making changes to the local health services they commission | 13                       |
| Joint health and wellbeing strategy (JHWS)                               | Published by the health and wellbeing board, setting out its overarching plans for improving the health and wellbeing of the population   | 21                       |
| Joint strategic needs assessment (JSNA)                                  | Prepared by the health and wellbeing board, to identify local health and wellbeing needs to inform priorities in the joint health and wellbeing strategy                                | 24                       |
| Local Healthwatch pathfinder engagement strategy                         | Describes how the local Healthwatch organisation will engage the community in its work  | 1                        |
| Healthwatch pathfinder bid   | Submitted to the Department of Health by local authorities seeking to become a Healthwatch pathfinder   | 24                       |
| <b>Total</b>   |   | <b>102</b>               |

1.14 **A core sample of 25 local authority areas**<sup>16</sup> was selected, for which **all available local health plans** being developed by Healthwatch pathfinders, clinical commissioning groups and health and wellbeing boards were reviewed. The plans included clinical commissioning group communication and engagement strategies which focused specifically on public and patient involvement (including children). These were reviewed in addition to or instead of clinical commissioning group commissioning strategies where these were not published at the time of our review<sup>17</sup>.

1.15 The core sample (all available health plans) included 12 local areas that were Healthwatch pathfinders and 13 that were not, to assess whether being a pathfinder resulted in any significant differences in local areas' approaches to children's engagement. To ensure a comparable number of Healthwatch pathfinder bids were analysed, the team reviewed bids developed by 13 additional local authority areas in a **supplementary sample** (Healthwatch pathfinder bids only).

1.16 In addition, the research team undertook eight **follow-up interviews**<sup>18</sup> with key informants from the core sample (all available plans) to build on the evidence gathered through the review of local plans and aim to better understand:

- how children have been involved in strategic health decision-making
- why, and on the basis of what evidence, they were involved in these ways

16 12 were Healthwatch pathfinders, 13 were not.

17 August – October 2012.

18 In seven of the core sample areas, mostly with local authorities, and one clinical commissioning group representative.

- what proven positive difference their involvement has made
- how children may be engaged in future and what outcomes are expected

### Stage three: focus groups with children

1.17 After data from Stage one and two was gathered and analysed, researchers held **six focus groups** with children to:

- discuss their **previous experiences** (if any) of health decision-making, what worked well and less well
- discuss and comment on **past practice** examples of involving children in strategic health decisions (ie stage one findings)
- discuss **Department of Health guidance and initiatives and current local plans** for involving children (ie stage two findings), how adequate these plans were and what else may need to be done to ensure more meaningful involvement
- explore what they knew about **children's rights** and whether they thought children's voices are being heard
- draw up a list of **recommendations** on how ideally children would like to be involved locally in assessing needs, identifying priorities and making plans for how health services are delivered in local areas

### Sample and recruitment

1.18 Children were recruited via several channels to form four 'general' groups<sup>19</sup>. There was one focus group with children in or leaving care, and one group of children in the youth justice system. Looked after children and young offenders were purposefully targeted to ensure the involvement of different children with a range of health experiences and views. Thirty seven children took part over six focus groups between late October and early December 2012. Participant data is presented in Appendix A.

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<sup>19</sup> Two groups were run with the Young NCB Research Advisors, members of a pre-existing group that are regularly involved in informing and shaping the design and delivery of NCB research projects.

## Section two: The participation story so far

2.1 This section offers an overview of children's participation in strategic health decision-making in recent years. It is based on a rapid review of evidence from 2007-12 which has explored children's experiences and their views of health provision carried out by NCB<sup>20</sup>. In analysing this evidence the following aspects were explored:

- the focus and topic of consultations and other activities to establish at what point children were engaged in the strategic decision-making process
- the impetus for the consultations – eg whether these were: seen as part of the service improvement process; underpinned by the children's rights perspective; carried out to comply with government guidance
- how children participated and their level of participation
- what were the outcomes from the consultations and other activities, and children's views and experiences of taking part in these

### Children's participation in strategic health decision-making

2.2 The consultations reviewed were typically **focused on a particular stage of the strategic decision-making process** rather than an entire local health strategy. For example, consultations were carried out to understand children's needs in relation to a particular health service (eg Child and Adolescent Mental Health Services (CAMHS), transition from children to adult services). Others were carried out to inform the development of new provision, make existing services more child-friendly, or to improve access and provision for specific groups (eg children in care, young people in secure settings). There were activities that included children in the monitoring, evaluation and inspection of services (eg inspections of adolescent units, *You're Welcome* inspections of health centres). Children had also taken part in service configuration (eg what a service should look like to be child-friendly) and procurement (eg taking part in the selection of contractors)<sup>21</sup>.

2.3 In all these examples, consultations and other activities **tended to be a one-off event**. Even if they involved children's participation over a limited period of time, they focused on a specific stage of the strategic decision-making process with no apparent link to the rest of the decision-making cycle. However, there were some notable exceptions as indicated in Boxes 2.1<sup>22</sup> and 2.2<sup>23</sup>.

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20 La Valle et al. (2012) op. cit.

21 Dorset NHS Foundation Trust (2009), *Dorset Health Scrutiny Committee Informal Panel*.  
Dorset NHS Foundation Trust (2009), *Young People's Visits to Potential Sites of the Adolescent Inpatient Unit*.  
Uxbridge Health Centre (2009), *Your Welcome Visit*.

22 Greater Manchester, East Cheshire, High Peak and Rosendale health care services (2007), *Making it Better Consultation. Patient and public engagement*.

23 NHS North West (2011), *A Guide for Commissioners of Children's Young People's and Maternal Health and Wellbeing Services*.

### Box 2.1: Making it Better Consultation

The 'Making it Better Consultation' is described as the largest and most complex piece of patient and public engagement in the country. It was carried out by Greater Manchester, East Cheshire, High Peak and Rossendale health care services in the mid 2000s to inform service reconfiguration required by the revision of the Operating Framework for NHS in England 2010-11. The consultation involved over 22,000 children, as well parents, carers, health professionals, and practitioners, who took part in 300 separate projects. Three key elements underpinned the approach to the consultation:

- Going beyond traditional consultation methods and adopting a range of innovative approaches (eg surveys, art and play, interviews, focus groups) to ensure meaningful consultation with a diverse population and an effective engagement model for the future.
- Good information, effective communication and open debate were seen as essential to engage all key stakeholders (including children). Proposals and options for the consultations had to be shaped by those who were being consulted (including children). The initial development stage identified the issues stakeholders wanted to focus on. Then, through a series of iterative events, a set of recommendations for reconfiguration of local health services was produced.
- Great emphasis was placed on working with local communities. It was considered particularly important when consulting children to get the support of local groups and organisations (eg youth clubs, schools, scouts), that work with children and therefore understand them and what participation methods may be most appropriate to meaningfully involve them.

### Box 2.2: A Guide for commissioners

The NHS North West 'Guide for Commissioners of Children, Young People's and Maternal Health and Wellbeing Services' was written after a consultation through online discussion groups with parents, children and young people, and discussions at Young Minister for Health events. The Guide stresses the need to consider the views and experiences of children when developing health services, in order to ensure services meet local needs and provide good value for money. The Guide outlines the different ways in which children can be involved, including commissioning services, recruiting and selecting staff, ensuring the governance of health services and in developing health research. A wide range of methods are outlined (eg surveys, focus and advisory groups, interactive media, youth councils and, for mystery shopping, young inspectors and young researchers). The Guide also provides a list of action points for successful participation:

- Embedding participation into the commissioning process and ensuring it is supported by the principles and ethos of the organisation.
- Preparing support staff and children to ensure that they get the most out of the work.
- Evaluating to ensure we are getting it right and it is making a difference.
- Making use of those with expertise and knowledge of participation.
- Being flexible and clear about the aims of the participation and what is expected from children and young people.
- Using incentives to encourage children and young people to be involved, and celebrating the successes of all those involved.

## Why children were asked to participate in strategic health decision-making

- 2.4 **Service improvement was a key driver** for engaging children in consultations and other activities, sometimes as a result of inspections. We found that consultations with children were carried out in response to Care Quality Commission (CQC) reports that had identified a need to improve health services for looked after children<sup>24</sup>; and inspections of Youth Offending Services (particularly around young offenders' health assessments and follow-up actions<sup>25</sup>).
- 2.5 Children's right to participate, as outlined in Article 12 of the UN Convention on the Rights of the Child (see Section three), was less commonly mentioned as a driver for children's participation. This does not mean that the decision to involve children was not underpinned by the belief in children's right to have a say in decisions that affect their lives and to have these views taken seriously. However, it was not explicitly mentioned (alongside service improvement) as one of the reasons for engaging children. References to current and recent government guidance and initiatives, which highlight the need to involve children in the decision-making process, were mentioned in some of the documents reviewed. These include: *You're Welcome Standards*; the Every Child Matters framework; and the National Service Framework for Children, Young People and Maternity Services<sup>26</sup>. Non-government guidance promoted by the voluntary sector was also mentioned (eg *Healthier Inside* and *Hear by Right*<sup>27</sup>).

## How children participated in strategic health decision-making

- 2.6 **Many different methods were used**, from online surveys and focus groups to creative activities, particularly when involving young children and covering sensitive topics. Specific roles were also created for certain activities. For example, Disabled Quality of Life Auditors were asked to develop good practice guidance to ensure that those who are vulnerable have a good quality patient experience when using health services<sup>28</sup>. In another example, we found that Young Ministers for Health were asked to identify areas where health services were not meeting children's needs<sup>29</sup>.
- 2.7 In relation to the degree of participation using the OCC's Wheel of Participation, apart from a few examples (eg Boxes 2.1 and 2.2), it seemed that, on the whole, the activities which children took part in **tended to be about 'informing' and 'consulting'**, rather than engaging the full involvement with children initiating ideas and setting the agenda. Typically, by the time children were invited to take part in a consultation event or another activity, the body that decided to carry out the consultation or activity had already set the agenda and decided the focus of the exercise. How children were to be recruited and the methods for gathering their views had also been decided.
- 2.8 This could partly reflect the nature of the examples reviewed which tended to focus on very specific topics (eg how to improve the health of looked after children; how to make a specific service more child-friendly; how to reduce under 18s conceptions). While recruitment and

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24 Cheshire West and Chester NHS, Children in Care Council (2012) *Me and My Health Guide*.  
NHS Western Cheshire (2011) *Leaving Care Health Guide Updated Report*.

25 Norfolk Youth Offending Services and NHS Norfolk (2009), *Health Needs Assessment*. Nottinghamshire Primary Care Trust (2009), *Let Us Grab Your Attention 2*.

26 Department of Health (2011), *You're welcome – Quality criteria for young people friendly health services*. Crown Copyright.  
Department for Children Schools and Families (DCSF) (2002) *Every Child Matters*, London: DCSF. Department of Health (2004), *The National Service Framework for Children, Young People and Maternity Services*, Crown Copyright.

27 <http://ncb.org.uk/healthy-outlooks/resources/young-people-in-custody> <http://www.nya.org.uk/quality/hear-by-right>

28 West Bromwich (2011), *Adolescent Health and Teenage Pregnancy Peer Research Report*. *Changing our Lives*.

29 Cheshire & Merseyside Child Health Development Programme (2009), *School Health Services Project, Cheshire & Merseyside Child Health Development Programme*.

participation methods were decided in advance, when evidence was provided on how these exercises were carried out, it shows a good understanding of the principles underpinning inclusive and meaningful participation. This was reflected in the methods they used to recruit children and gather information from them<sup>30</sup>.

## Children's experiences of strategic health decision-making and its outcomes

- 2.9 The majority of documents reviewed included a set of recommendations that either **came directly from children** or were drawn from the evidence gathered from children. However, when evidence was also gathered from parents and carers in a participative activity, it was not always clear when recommendations were based on the respective views of children or parents/carers. Neither was it clear whether views between these two groups were similar or diverged. The NCB review showed that on some health issues children's and their parents' views differed<sup>31</sup>. This evidence mainly relates to personal health decisions, but could be equally applied to strategic health decision-making, and therefore it would seem important to report children's and parents' views separately.
- 2.10 Some of the consultation documents specifically mentioned what had changed as a result of what children had said. For example, the views of children who had been consulted about tackling under-age drinking were used to develop an educational video. A consultation with children about the Patient Advice Liaison Service (PALS) demonstrated children's involvement in designing a job **description for a Young Person's Involvement Worker and to be part of the job interview panel**; developing a plan for a Year 9 PSHE lesson on PALS; and creating a diary for children in hospital. In Cheshire and Merseyside, Young Ministers for Health identified the need for improving school health services, which resulted in changes to the role of the school nurse to deliver a wider range of health advice, including pregnancy testing, Chlamydia screening and emergency contraception<sup>32</sup>.
- 2.11 As part of some consultation exercises and other activities, feedback was gathered from children about their experiences of and views on taking part. These were generally positive indicating that **children enjoyed the experience and benefited** from it, particularly in terms of increased confidence and skills. **Children were very keen to give their views** on a range of health issues and said that they should have a say in the way health services are run, as well as on decisions about their own health. A shortfall in many consultation exercises and other activities was a clear **mechanism for feeding back** to children after the consultation exercise. If feedback was not offered, children were unaware of how their input had been used, whether it had made any difference, or why some of their recommendations were not acted on.

30 Examples of this include: Liverpool 16-18 Team (2008), *Liverpool 16-18 Team Very Important People (VIP) Project: Where are we now?*, Alder Hey Children's NHS Foundation Trust; NCB (2009), *PALS: getting it right for children and young people – Good Practice case studies*, London: NCB; British Youth Council (2011), *Our school nurse: Young people's views on the role of the school nurse*, London: British Youth Council; ChaMPs (2011), *Alcohol – Young women peer research*, ChaMPs & North West Regional Youth Work Unit & CYPI; Council for Disabled Children (CDC) (2011), *Managing my way*, London: CDC.

31 La Valle et al. (2012) op. cit.

32 Williams N. (2011), "Lose your bottle: young people and alcohol." *Safer Communities* 10(1): 9-15.  
 NCB (2009), *PALS: getting it right for children and young people – Good Practice case studies*, London: NCB.  
 Hopwood B., Tallett A. (2011), "Little voice: giving young patients a say." *Nursing Times* 107(49-50): 18-20.  
 Cheshire & Merseyside Child Health Development Programme (2009), *School Health Services Project, Cheshire & Merseyside Child Health Development Programme*.

## Conclusion

- 2.12 The evidence gathered in early 2012 shows that **in the previous five years** children were asked their views on specific aspects of health service decision-making and this was undertaken in a **range of ways**. The examples we analysed, appear to indicate that their participation was somewhat fragmented. Participation was more typically associated with a **specific stage** of the decision-making cycle, rather than the entire cycle – eg from needs analysis through to service planning, monitoring and review. Full involvement as conceived by OCC would imply children's participation in the whole cycle, continuity, and links made between their participation at different stages.
- 2.13 **Service improvement** was a key a driver for children's participation, while the children's rights agenda was less explicitly mentioned. A more definite focus on children's rights (alongside service improvement), coupled with practical guidance on methods of children's participation, may help to shift activities more towards full involvement as envisaged by OCC.
- 2.14 Recommendations appear to be an integral part of participation events and activities, although only some documents were written after recommendations were taken on board and could therefore report on what changed as a result of children's participation.
- 2.15 A clear gap emerging from the review was the **failure to report back** to children on if and how their input had made a difference. If children participated in the whole decision-making cycle it would enable them to see what difference, if any, they have made. In cases when children are not continually involved for whatever reason, **a mechanism is required to tell them the outcome of their participation**.

## Section three: Children's voices in the health system – policy context

- 3.1 This section provides a summary of the policy context; a more detailed account can be found in Appendix C.
- 3.2 In 1991, the UK Government ratified the United Nations Convention on the Rights of the Child (**UNCRC**). Through ratification the Government committed to promoting and protecting all the rights of the child outlined in the Convention. The UNCRC makes clear that all children have rights, and implies a duty on all adults to ensure they are implemented.
- 3.3 In particular, the UNCRC states:
- **Article 12:** children have the right to have a say in all decisions affecting them and their views should be given due weight according to their age and maturity.<sup>33</sup> The UN Committee on the Rights of the Child has been clear that Article 12 applies to collective decision-making processes, as well as matters affecting the individual child<sup>34</sup>.
  - **Article 24:** children have the right to the best possible health. This includes an expectation that states take appropriate measures to ensure all children are provided with necessary medical assistance and health care, with an emphasis on the development of primary health care. The Committee is in the process of drafting a General Comment on this right, which will provide a conceptual framework and recommendations for concrete actions required by States Parties, and non-State actors, to fulfil their obligations.
- 3.4 The Government's 2010 White Paper, *Equity and Excellence: Liberating the NHS*<sup>35</sup>, places emphasis on giving patients and the public a stronger voice when decisions are made. It states that "Shared decision-making will become the norm: **no decision about me without me**"<sup>36</sup>. The reforms have pursued this ideal through measures aimed at:
- promoting the involvement of patients in decisions about their individual care
  - increasing the use of information about patients own experiences to hold services to account
  - giving the public a clearer say in strategic health decisions
- 3.5 Improving the strategic involvement of patients and the public is being taken forward chiefly through:
- requirements placed on commissioners of health services
  - the setting up of local health and wellbeing boards
  - the establishment of a health and social care consumer champion, Healthwatch

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33 United Nations Convention on the Rights of the Child <http://www.unicef.org/crc/>

34 United Nations Committee on the Rights of the Child (2009). General comment no.12. The right of the child to be heard. p8.

35 Department of Health (2010), *Equity and Excellence: Liberating the NHS*, Crown Copyright.

36 Department of Health (2010), *Equity and Excellence: Liberating the NHS*, p3.

- 3.6 From April 2013, **clinical commissioning groups** will be the local bodies that commission most health services. The **NHS Commissioning Board** will oversee clinical commissioning groups, as well as commission some primary care and specialist services, both nationally and through its regional and local teams. Under the Health and Social Care Act 2012, both of these organisations have duties to involve the public in their commissioning decisions<sup>37</sup> and to promote the NHS Constitution<sup>38</sup>, which refers to public involvement in the planning of services<sup>39</sup>. Clinical commissioning groups will also have a specific duty to consult people they commission services for on the development of their annual commissioning plans.<sup>40</sup> Duties on these NHS organisations were strengthened on the advice of the independent future forum<sup>41</sup>, which explicitly referred to the voices of children in their report. In its mandate to the NHS Commissioning Board, Government have committed<sup>42</sup> to work with the Board to consider how best to ensure that the views of children, especially those with specific healthcare needs, are listened to. This intention is also reflected in the Department for Education's statement on policies for young people aged 13 to 19, *Positive for Youth*, which highlights the role of health commissioners in involving young people.<sup>43</sup>
- 3.7 Responsibility for commissioning **public health services** will be transferred from Primary Care Trusts to local authorities from April 2013. Public Health England, part of the Department of Health, will be responsible for public health nationally. Although policy in this area refers to public involvement in decisions less frequently, local authorities already have a duty to consult representatives of service users.<sup>44</sup> Government has suggested that part of the rationale for these reforms is that local authorities have considerable expertise in community and public involvement.<sup>45</sup>
- 3.8 From April 2013, each upper tier local authority will have a **health and wellbeing board** to bring local partners together to plan NHS, public health and social care services. health and wellbeing boards will be under duties to involve both their local Healthwatch (see below) and the people who live and work in the local area in preparing the joint health and wellbeing strategy which should inform commissioning of local health services<sup>46</sup>. Draft guidance<sup>47</sup> for health and wellbeing boards published in mid-2012 confirms, albeit in a footnote, that this duty applies as much in the case of children as in adults. It encourages health and wellbeing boards to:
- involve Healthwatch and the population continuously throughout the joint strategic needs assessment (assessing health and social care needs in the area) and strategy development process
  - consider inclusive ways of involving different parts of the community

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37 Sections 13Q and 14Z2 of the NHS Act 2006.

38 Sections 13C and 14P of the NHS Act 2006.

39 Department of Health (2012), *The NHS Constitution for England*, Crown Copyright.

40 Section 14Z13 of the NHS Act 2006.

41 This group was set up by Government to undertake further public and stakeholder engagement on the reforms during a pause in the legislative process. (2011)*NHS Future Forum: Summary report on proposed changes to the NHS*, p26.

42 Department of Health (2012): *The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*, Crown Copyright.

43 Department for Education (2011), *Positive for Youth: A new approach to cross-government policy for young people aged 13 to 19*, Crown Copyright, p16.

44 Section 3(2) of the Local Government Act 1999.

45 Department of Health (2011) *Public Health in Local Government*, Crown Copyright, p1.

46 Section 116A(5) of the Local Government and Public Involvement in Health Act 2007.

47 Department of Health (2011), *Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies – draft guidance*, Crown Copyright.

- publish an accessible strategy that includes a summary of views of the local population

In addition, a practical guide for health and wellbeing boards on patient and public engagement, published by the NHS Confederation and supported by the Department of Health and Local Government Association, highlights the need for Boards to take steps to engage children and young people<sup>48</sup>.

- 3.9 Each upper tier local authority area will have a **local Healthwatch**, from April 2013, to promote and support the involvement of people in the commissioning, provision and scrutiny of local health and social care services. This includes seeking people's views on services, publishing reports and recommendations (which health services and organisations have to take note of and respond to) and having a seat on the health and wellbeing board. Healthwatch's functions must, by law<sup>49</sup>, be carried out in a way that is representative of the local people and service users. Government acknowledged in 2012 that local Healthwatch's predecessors, Local Involvement Networks (LiNs), struggled to involve a wide range of people of all ages, and have suggested that Healthwatch will represent an improvement and be able to carry out its functions in an inclusive way.<sup>50</sup> The Department of Health is working with Healthwatch England, the Local Government Association and the voluntary sector to promote children's involvement in local Healthwatch.
- 3.10 Local Healthwatch will be supported by **Healthwatch England**, through activities such as aggregating information from Healthwatch at a national level, advising national bodies and promoting access to examples of best practice in engagement.
- 3.11 To assess the overall tone of government policy relating to listening to children's voices in the health system, it is important to consider other forms of patient and public involvement. The NHS Outcomes Framework, which sets out indicators against which the performance of the NHS is to be measured, contains a single measure on children's experience of in-patient hospital services (currently under development),<sup>51</sup> although the many other measures of patient experience of other health services currently excludes under-16s. In terms of involvement in decisions about one's own care, Government acknowledged in 2010 that "*Children and young people should be involved in decisions and choices about their healthcare as much as possible.*"<sup>52</sup> More recent documents related to this subject, however, do not explicitly reflect this.
- 3.12 In January 2012, Government appointed a Children and Young People's Health Outcomes Forum to advise on how the health system could deliver better outcomes for children<sup>53</sup>. The Children's Commissioner for England is a member of this Forum, which delivered its report and challenges to government and the health system late in 2012. In February 2013, Department of Health published a 'system wide' response to the recommendations of the Forum<sup>54</sup>, along with a pledge<sup>55</sup> which promises to improve children's health outcomes, which it hopes all parts of the health systems will sign. Both documents include specific reference to the importance of involving children in decision-making in the health service:

48 NHS Confederation (2012) Patient and public engagement: a practical guide for health and wellbeing boards.

49 Section 221(6) of the Local Government and Public Involvement in Health Act 2007.

50 Department of Health (2012), *Local Healthwatch: A strong voice for people – the policy explained*, Crown Copyright.

51 Department of Health (2012) *The NHS Outcomes Framework 2013/14*, Crown Copyright.

52 Department of Health (2010) *Liberating the NHS: Greater choice and control*, Crown Copyright, p29.

53 Children and Young People's Health Outcomes Forum (2012) *Report of the Children and Young People's Health Outcomes Forum*.

54 Department of Health (2013) *Improving Children and Young People's Health Outcomes: a system wide response*.

55 Department of Health (2013) *Better health outcomes for children and young people: our pledge*.

- one of the five ambitions set out in the pledge states: “Children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority”
- a commitment that Department of Health will continue promoting the *You’re Welcome* quality framework with all partners as they develop their commissioning and delivery plans
- Healthwatch England carrying out targeted engagement with organisations representing children and young people, and appointing an advocate for children to its Board
- the Care Quality Commission involving children and young people in its inspection activity

3.13 In conclusion, patient and public involvement was a key pillar of the Government’s health service reforms programme. Through its pledge and system wide response, the NHS Mandate, the implementation of local Healthwatch and draft statutory guidance for health and wellbeing boards, Department of Health has signalled that **those planning health services should involve children in their decisions**. However, the challenge will be to translate these messages into reality for the national and local health bodies that are under a duty to involve the public, including children, in strategic decisions. Beyond the role of Healthwatch, there is yet to be a coherent programme of work for achieving this, nor clarity about how health bodies will access and share the resources and support materials they need to meaningfully engage children.

3.14 At this time of significant reform, there is a **real opportunity** to embed the involvement of children in decision-making throughout the health system. Now is the time for Department of Health and its national and local health partners to **act on their commitment** to listen and respond to the views of children and young people.

## Section four: A current picture of children's voices in strategic health decision-making

- 4.1 This section presents an overview of children's participation in strategic health decision-making within the new local health structures. It sets out how children are taking part in assessing local health needs, identifying priorities and making plans for how health services are delivered in local areas.
- 4.2 In particular it focuses on the extent to which children have been engaged in strategic decisions and what difference their participation has made, drawing on the findings from the review of local health plans (published by health and wellbeing boards, local authorities, local Healthwatch and clinical commissioning groups), and interviews with health policy and participation professionals.

### An overview of children's participation in strategic decision-making in local health plans

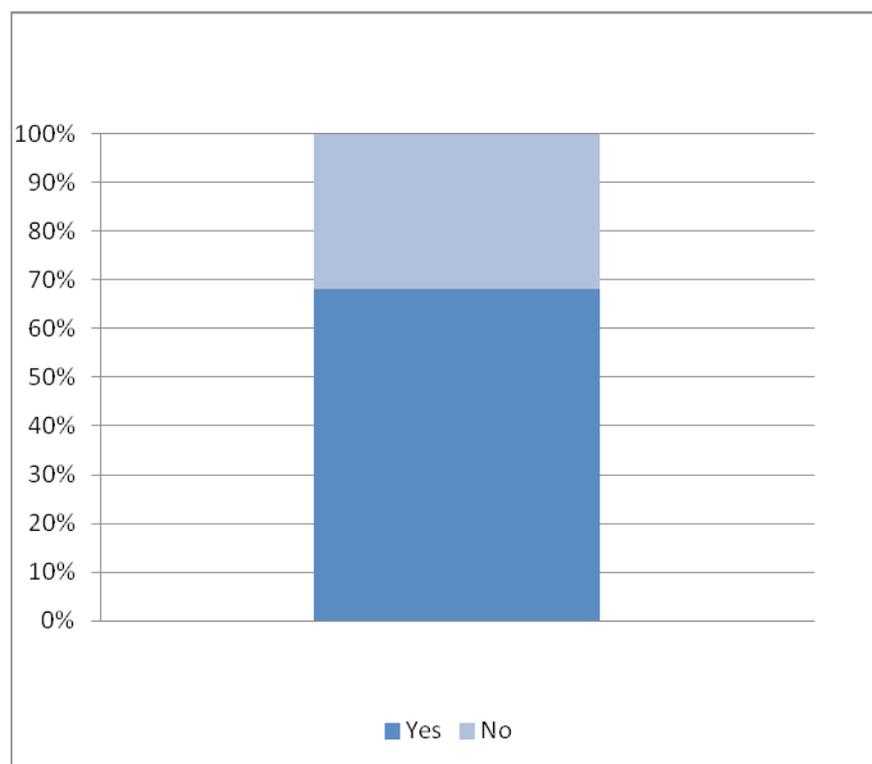
- 4.3 Table 1.1 provides an overview of the number and type of plans reviewed. There were 102 in total and in summary they included:
- Clinical commissioning group commissioning strategies
  - Clinical commissioning group engagement strategies
  - Joint health and wellbeing strategy
  - Joint strategic needs assessments
  - Local Healthwatch pathfinder engagement strategy
  - Healthwatch pathfinder bids
- 4.4 The plans were analysed at two levels:
- by local authority area to explore the scope of children's participation in strategic health decision-making at a local level
  - by different types of plans to provide an indication of which most frequently referred to children's participation and what level of information they provided

While the plans that were analysed **were 'works in progress'**, and a different picture might emerge by the time they are completed, **at this stage in the local planning cycle it appears that the principles of children's participation have not been embedded** and largely rely on the commitment of key individuals. The analysis of over 100 local health plans **shows large gaps** in the information currently available about children's participation in strategic health decision-making.

### Review of local health plans – findings by local authority area

The study team reviewed **3-4 plans per local authority area**, and this analysis shows that **68 per cent of local authority areas had one or more plans that made a specific reference(s)** to children's participation (Figure 4.1).

**Figure 4.1: Percentage of local authority areas that referenced children’s participation in their health plans**

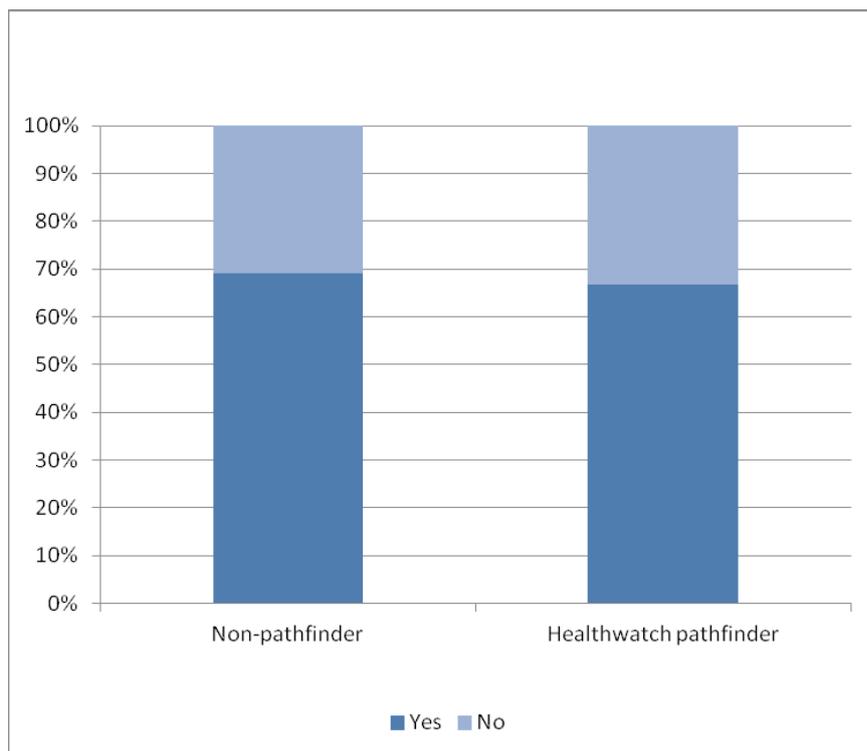


Base: sample of 25 areas where a total of 89 plans were analysed

#### Comparing Healthwatch pathfinder and non-pathfinder areas

4.5 Although **Healthwatch is supposed to be the key vehicle** for taking forward public and patient engagement, including children, the research found **no noticeable difference** between the number of Healthwatch pathfinder and non-pathfinder local authority areas that referenced children’s participation, with the respective figures being 67 per cent and 69 per cent (Figure 4.2).

**Figure 4.2: Percentage of Healthwatch pathfinder and non-pathfinder areas that referenced children's participation in their health plans**



Base: sample of 25 areas where a total of 89 plans were analysed

4.6 At the time of this research, 42 per cent of Healthwatch pathfinder and 54 per cent of non-pathfinder areas had already engaged children, but the plans did not provide sufficient information to assess the *level* of children's participation. Given these results it was not surprising to find that Healthwatch pathfinders were somewhat more likely to report future plans for engaging children (50 per cent) than non-pathfinders (23 per cent). Overall this analysis shows that some local authority areas were planning further engagement with children, and therefore it provides a partial picture of the extent of children's participation once the planning cycle has been completed.

#### Review of local health plans – findings by type of plan

4.7 Moving onto the analysis by type of plan, when looking at individual plans, **only 28 per cent specifically referenced children's participation**. This compares with almost all (94 per cent) that referred to broader public and patient involvement (PPI). The breakdown by type of plan is provided in Table 4.1.

**Table 4.1: Number and percentage of plans that reference children’s participation by type of plan**

| Plan  | % of plans that reference children’s participation | % of plans that reference PPI participation | Total no. plans |
|---|--|---|-----------------|
| Clinical commissioning group commissioning strategies   | 26   | 100   | 19              |
| Clinical commissioning group communication & engagement | 38   | 92  | 13              |
| Joint health and wellbeing strategy                     | 14   | 100   | 21              |
| Joint strategic needs assessment                        | 42   | 92  | 24              |
| Healthwatch pathfinder engagement strategy              | 0  | 100   | 1               |
| Healthwatch pathfinder bid                              | 25   | 87  | 24              |
| <b>Average for all plans</b>                            | <b>28</b>  | <b>94</b>                                   | <b>102</b>      |

Base: all plans analysed from 38 areas

- 4.8 Table 4.1 shows that **joint strategic needs assessments were most likely to reference children’s participation (42 per cent)**. We only reviewed one Healthwatch pathfinder engagement strategy and this did not mention children’s participation. Also only 14 per cent of **joint health and wellbeing strategy included directly references to children’s engagement (14 per cent)**, while both Healthwatch strategies and joint health and wellbeing strategy mentioned public and patient engagement. Joint health and wellbeing strategy provide the overarching local health and wellbeing strategy, and they are required by government guidance to include a summary of community views and how they have informed the plan. However, these findings seem to indicate that so far users’ engagement is rather narrowly conceived, as very few plans specifically mentioned children’s engagement.
- 4.9 **It was not clear if children were involved in the examples of broader public and patient involvement referred to in the majority of plans.** While it is possible that they were or will be engaged in some way, there was no evidence among these examples that suggests that the views of children have been or will be pro-actively sought in appropriate ways. Neither was there information about how children’s views can inform strategic health decision-making. From the information provided in the plans it is not possible to assess whether children’s views were or were not being taken seriously.
- 4.10 Joint strategic needs assessments and clinical commissioning group plans generally provided **more detail** about children’s participation across the different areas reviewed (eg target groups, topics, methods, etc.) as can be seen in Table 4.2. This was in part due to the review incorporating clinical commissioning group communication and engagement strategies, which focused specifically on patient and public involvement. Later in this section we explore these findings in more detail.

**Table 4.2: Number and percentage of plans that reference children's participation by type of plan and area of review**

| Plan                                | % plans described target group | % plans described topics | % plans described methods | % plans described outcomes of children's participation | Number plans reviewed |
|-------------------------------------|--------------------------------|--------------------------|---------------------------|--|-----------------------|
| Clinical commissioning groups       | 16                             | 16                       | 26                        | 11   | 19                    |
| Clinical commissioning groups other | 8                              | 23                       | 39                        | 8  | 13                    |
| Joint health and wellbeing strategy | 0                              | 14                       | 24                        | 10   | 21                    |
| Joint strategic needs assessment    | 25                             | 29                       | 33                        | 4  | 24                    |
| Healthwatch pathfinder other        | 0                              | 0                        | 0                         | 0  | 1                     |
| Healthwatch pathfinder bid          | 13                             | 25                       | 8                         | 0  | 24                    |
| <b>Average for all plans</b>        | <b>13</b>                      | <b>22</b>                | <b>25</b>                 | <b>6</b>   | <b>102</b>            |

Base: all plans analysed from 38 areas

### Follow-up interview findings

4.11 Through the **follow-up interviews** with key informants<sup>56</sup> predominantly working in local authorities, we found **much more evidence of children's participation in these areas** than apparent from the review of local plans. For example, in three areas where the plans reported no children's participation, we learned that they had, in fact, been engaged in health decision-making processes (eg informed about and consulted on the development of strategies).

4.12 The picture of children's participation emerging from the interviews did not change significantly, but we did gather a more detailed and refined picture as would be expected from qualitative research. This picture shows that, on the whole, activities including children fell into the 'inform' and 'consult' categories of the OCC definition of participation – that is mainly sounding out of actions or decisions that had *already* been made by adults (eg helping to assess local health needs). **The research did not identify many examples where children and young people were also involved in making joint decisions with adults**, as the example in Box 4.1 illustrates.

56 In seven of the sample areas, mostly with local authorities, and one clinical commissioning group representative.

#### Box 4.1: Involving an established group of children on an ongoing basis

In one area, a Young People's Council focused on many different strategic health decisions, effectively illustrating different types of involvement. This example also highlights the tendency for decision-makers in our sample of local authority areas to build on the work of established groups. The Young People's Council had a residential meeting where they came up with a shortlist identifying the biggest issues affecting young people in the area. This was to inform the development of the Children and Young People's Plan and the joint health and wellbeing strategy. The group, alongside other children's groups, then ranked these priorities to help shape the plans. In addition, the Young People's Council ran a procurement process to help allocate a ring-fenced pot of £50,000 of public health funding. In doing so they reviewed bids, helped to design interview questions, and sat on selection panels including one for local Healthwatch. Here, **children were informed, consulted and involved** in strategic health decision-making processes, evidencing all of the OCC's participation categories.

- 4.13 Interviewees' own assessment of the level of children's participation in health decision-making locally varied. Some believed that children's participation in decision-making was embedded in local health policy and practice, or was at the very least starting to become so. Some expressed a **high level of awareness** of the need to include children and the benefits of doing so, eg in helping to shape service delivery that better meets their needs, and in generating new and different ideas. In some cases interviewees also articulated a desire to make children's participation [more] meaningful, and said they **would welcome further guidance** on doing so in the future. Given the abundance of guidelines on participation it was **not clear if there are gaps in current guidance, or people need to be better signposted to make sure they are aware of what is already available**.
- 4.14 **This raises a question about why this information was not included in the local plans.** The variations we found between the plans and the evidence from the interviews raise a number of issues that need to be considered in judging the picture emerging from these two sources. Variations could be partly due to the **passage of time** following the development of the plans. Some plans were in draft form at the time of this review (eg 76 per cent of joint health and wellbeing strategy and 21 per cent of clinical commissioning group commissioning strategies), therefore local authorities and partners were still developing participation activities. In addition, local health bodies may have been aiming to publish health plans that were as succinct as possible, preventing them from providing additional detail about the specifics of participation activities with children. At the same time, it raises the question of whether government's messages about patient and public involvement needing to include children (outlined in Section three) have been strong enough to induce local health bodies to highlight such activity in their plans.

## The scope and scale of children's participation in strategic health decision-making

- 4.15 This section presents more information about the children who participated, what they did and the method of engagement. Examples demonstrate reference to Department of Health guidance or initiatives, and a summary of reported outputs and outcomes.

## Which children have taken part in strategic health decision-making?

4.16 Only 13 per cent (Table 4.2) of local plans which referenced children's participation identified particular target groups of children, compared with 67 per cent that referenced target groups for public and patient involvement. This provides a partial picture of who was engaged. Target groups of children largely referred to completed activities as opposed to activities that were ongoing or planned. The most commonly referenced group of children was looked after children. In two areas it was asserted that the following children were engaged:

- those not in education, training or employment (NEET)
- children living in 'economically disadvantaged areas'/in 'poverty'

And each of these groups was referenced once:

- children identified as 'vulnerable'
- children with disabilities
- young offenders

4.17 In the small sample of areas where interviews were conducted, a broader range of children were said to have participated. In addition to the groups identified above, young carers, care leavers, and young parents have been engaged, although these groups were not common to all local authority areas that took part in the interviews. In each example, the target groups may be interdependent and therefore perhaps not the most helpful categorisations.

4.18 Across the sample, many participation examples built on **active links with established groups**, such as local children and youth boards, and children and young people's parliaments. Children often **self-selected** through personal interest. Other children were engaged as **service users** through, for example, CAMHS and Young Voices in Care. **Often the numbers of children consulted were relatively small because of this.** Similar patterns were evident from the focus groups. Children who had previous experience of strategic health consultations generally had a long history of participation through established groups like Young NCB. They volunteered to take part and said they tended to see the **same faces** at these types of events. This highlights a **challenge** for health decision-makers – how to meaningfully engage a full range of representative children in strategic decision-making.

4.19 The **data available from the plans and the interviews at the time of the research was not sufficient to determine the scale of children's participation** and whether this lack of evidence reflected a lack of commitment or whether the fact that the plans were still 'works in progress'. It was not obvious who is doing what to monitor children's participation in strategic health decision-making, what data is collected or how this information is used. The evidence suggests that to better understand and demonstrate the scope, scale, potential and impact of work in this area, it will be important for local authority leads and partners to share and build on this information, and identify a lead or champion for participation by children. In the local authority this needs to be at least one officer and one politician.

## What type of strategic health decisions have children participated in?

4.20 Eighty-one per cent of plans that mentioned public and patient engagement gave information on **consultation topics**. This compares to **only 22 per cent of plans listing the topics**

**which children and young people were asked about (Table 4.2).** The most common topics found in the plans and confirmed in the interviews and focus groups included<sup>57</sup>:

- **needs analysis** – eg children took part in a Top Trumps style card game to explore joint strategic needs assessment priorities and identify the most important health needs – the results of which will be used to inform the development of the document
- **service planning** – eg focus groups were held in a range of education settings and designed to explore what kind of structure and type of involvement children wanted in Healthwatch – they (like adults who took part) did not want to commit their time, but instead wanted convenient ways to raise issues including social media and the internet
- **the development of the plan itself** – eg workshops with children aged 5-15 on health and wellbeing strategic priorities – children emphasised the importance of wider wellbeing rather than health issues per se and the strategic priorities were changed as a result

4.21 Children and young people had also given feedback on service delivery – the quality of services, service user experiences and gaps in services, and were asked about specific issues such as health inequalities and mental health. In one local authority area, the plans stated that decision-makers explored other topics such as lifestyle choices, information to support healthy choices, and access to leisure, but there was no information on how the findings were used. Another local area consulted children on wider wellbeing issues like bullying, and in particular cyber-bullying.

How have children and young people taken part in strategic health decision-making?

4.22 The majority of local health plans outlined consultation **methods** (82 per cent) for public and patient involvement. However, only 25 per cent stated how children and young people were engaged. Rarely did plans provide further description of the method, but based on the limited information available it seems a range of methods were used to engage children.

4.23 These included **surveys**, which in some cases were accessible online as well as on paper. One of the largest surveys designed for children and young people was administered to approximately 4,000 pupils in secondary schools, to explore their views and experiences of health and lifestyles to inform the local joint strategic needs assessment. Analysis was ongoing but in this example, partnering with schools enabled health professionals to engage large numbers of children.

4.24 While surveys were used with the intention of reaching large numbers of children, **responses were sometimes reported to be low, whether surveys were designed specifically for children or not.** This research did not find many examples of surveys designed with children in mind. In one case an interviewee enlisted the help of the local youth service and partners to encourage children to complete a ‘user-friendly’ survey that was designed for the wider public. There was, however, little evidence of this kind of targeted support to encourage children to take part in surveys. Focus group participants said that it was **important to design child friendly (short and simple) surveys and supporting material, and to analyse children’s responses separately from those of adults,** in order to be able to demonstrate differing needs and views:

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<sup>57</sup> The analysis is based on topics for completed participation activities.

*"If you want to do a survey to reach a specific age group, you need to make sure it goes out to that specific age group. Otherwise I don't think you are going to get many results"*

- 4.25 Several local authority areas re-evaluated their approach to engaging children when surveys did not work. Instead they incorporated face-to-face tailored consultations like workshops, and one local authority area explored children's views through art as part of discussions. **This shows that if there is a clear commitment to participation, resources and expertise can be secured to make sure children's participation is meaningful.**
- 4.26 Examples of face-to-face activities in the plans tended to take the form of **focus groups and workshops**. The largest face-to-face consultation from the available information was 160 children, predominantly aged 11–19 (aged 25 for those with disabilities), who took part in focus groups to discuss what kind of structure and involvement they wanted in Healthwatch. The data from the consultation was being analysed at the time of the research.
- 4.27 Face-to-face activities were commonly carried out via schools (eg through School Councils) and established groups (eg local authorities' Children and Youth Boards, Assemblies, Councils or Parliaments, Children In Care Councils). **As we have previously highlighted, consulting predominantly established groups meant capturing the views and experiences of more 'active' children who were regularly involved in having their say.** There remains an issue to be addressed by all concerned if they are to reach those children and young people who sit outside these already engaged groups.
- 4.28 Some children and young people, who took part in the researchers' focus groups, were already engaged in decision-making via established groups for young people, and in a few cases, established adult or wider community groups. For example, one participant used to be the Chair of the local LINKs Board, while another represented children on the board of a hospital trust. Both roles covered a range of the topics outlined in 4.22 above. They held mixed views:
- "It's good they've got some kind of young representation but I've been trying to push to get maybe another young person or maybe a couple on there as well cause you need like a more diverse mix ... to some extent it is tokenistic because I'm the only young person on there but I make sure I do have a strong say on what their proposals are ..."*
- 4.29 The follow-up interviews with key informants from local authority areas also provided examples of children's representation on adult groups, for example, on the local Healthwatch executive board; but it was too early to assess how successful this was.

What has happened as a result of children's participation in strategic health decision-making?

- 4.30 **Only 6 per cent of plans made any reference to actual or anticipated outputs or outcomes of children's participation** (Table 4.2), compared with 22 per cent health plans which described outputs or outcomes for public and patient involvement.
- 4.31 Outputs of children's involvement, rather than outcomes, were most commonly recorded, such as children's voices feeding into the development of a joint health and wellbeing strategy and consultation report. In this example however, children's views were not analysed and reported separately from the opinions of the wider population.

4.32 Follow up interviewees usually said it was too soon to say what the outcomes were, and so the information they shared was at times vague, but below are some of the examples they provided:

- A strategy was wider reaching and included a larger range of services because children were consulted.
- A community clinic remained opened against the threat of closure because children told commissioners of its popularity and benefits (prior to current round of engagement activities).
- Children generated ideas which were used to market sexual health services.
- Children influenced the commissioning process by scoring tenders with adults; although when asked if they wanted to be involved in all aspects of bid appraisal, children said no, preferring to receive training on bid summaries over reading full documents and delivery plans. As a result they did not have an equal say.
- Children's participation in *You're Welcome* reviews led to changes in specific health services (Box 4.2).

#### Box 4.2: Outcomes

Children undertaking *You're Welcome* reviews recommended changes to a sexual health clinic. While they were very positive about the staff and the service, they did not like the 'clinical' reception area which they said was visible from the road nearby and did not offer a confidential space within which to speak to the receptionist. In response, the clinical commissioning group agreed to set aside £50,000 to re-shape the reception area and asked children to help with the design. This is an example of strategic involvement, where **children played an active role** and made joint decisions with adults.

In the same area the *You're Welcome* group led further **change at service level**. Young parents successfully brought in training to help fathers bond with their babies after identifying a support need, and a psychiatric service re-designed its website with the help of service users after the *You're Welcome* group said it was not young people friendly. These examples, reflecting more typical levels of health decision-making and associated outcomes, are examples where children have been **consulted and informed**, and their opinions have been taken seriously and acted upon.

How have local authorities referred to Department of Health guidance or initiatives?

4.33 Forty per cent of plans we reviewed made reference to Department of Health guidance. These references were often minimal, pointing only to their duty to collect the views of the public to inform the development and delivery of health services, and with no specific reference to children as a key group to engage. Boxes 4.3 and 4.4 provide examples where decision-makers referred to Department of Health guidance and initiatives when working with **established groups**.

### Box 4.3: *You're Welcome* quality criteria: making health services young people friendly

For the last two years a *You're Welcome* group of 15 children (including looked after children, young parents and children engaged via local youth clubs) have reviewed services, and more recently, raised priorities for local Healthwatch – including out of hours mental health support and help to stop smoking. The group will take part in future research exploring children's experiences of these issues, and is also helping to set priorities for the joint health and wellbeing strategy and CAMHS strategy.

### Box 4.4: Children and Young People's Quality Assessment Framework

Children will help to assess individual services via the Children's Quality Investment Group, building on the local authority's duty to take into account the views of local people, including children and young people. The framework includes a children's charter incorporating the following promises requested by its children and young people's council; 'listen to what you think' and 'show you how to complain'. It will be used to assess whether services in the local area meet existing evidence-based programmes like the *You're Welcome* quality criteria, *Hear by Right*, and looked after children health framework standards.

## Section five: How do children and young people want to take part in strategic health decision-making?

5.1 In this section **children and young people's voices** – gathered through focus groups with those from a range of backgrounds and personal health service stories – illustrate their experiences of strategic health decision-making. This is followed by an analysis of what children said about their right to have their views heard, on the decisions that affect their lives, and for their views to be taken seriously. This section then details how children would like to be involved in health service decision-making. Throughout, examples of what works are offered from the perspectives of children and young people who took part in this research.

### What do children and young people think about taking part in strategic health decision-making?

5.2 The focus groups included both those who had experience of helping to make strategic health decisions and those who had not. Those who had experience had typically been consulted on health needs and service planning by local hospitals, GP's surgeries, and in several examples, national charities (eg for government consultations). **Past experiences** gave children **insight, knowledge and confidence** to take up new opportunities to participate. This was often the case for active group members, who took part because they **understood** their contribution, its impact and next steps:

*"It was good because for each one we knew specifically what it was for and because they were one off consultations we wanted to get as much in as you could so it made you really want to go for it and contribute ... and they pretty much guaranteed there would be further action ... and we did get the report afterwards."*

5.3 In these situations they felt appreciated and informed, and were more likely to volunteer again. Children and young people learned from the process, enjoyed it and often made new friends. **When professionals were present** at face-to-face events, they felt their voices were being heard, and not translated or diluted in any way:

*"I think it depends on who's there at the time and then if they'd had people like someone in charge like in power ... if they were there and they were listening to what we have to say I think it would have more of an impact because they're hearing it from us."*

5.4 **Those who had no previous experience** were intrigued by the idea and showed surprise, interest and a degree of uncertainty. The researchers explained that 'strategic' decisions were big decisions about health – ie decisions about how services are planned and organised, and how they are delivered, and provided examples. But despite this, some children **did not truly understand the meaning of 'strategic'** and thought some children might choose not to participate for this reason. They believed it was important for children to **be prepared** before taking part:

*"For young people to take interest in these groups or actually be attracted to them is if they know, they could have the knowledge about it, about the NHS, about what's going on with the political parties and how's that affecting the NHS, like what services are around the area, different health problems, you know actually have some sort of an understanding before you*

*go in because it can be kind of intimidating in front of a group of people to talk about health when you actually have no understanding of it."*

- 5.5 When reflecting on his experience of sitting on a governance review panel, one participant recalled how children and young people's views were immediately discounted by the adults in charge, on the grounds that their ideas were not feasible and without an analysis of whether or not this was true. He felt frustrated and disappointed because he had done what he was asked to do and had tried his best. This individual, and others like him, were keen to point out that they could not be expected to share the knowledge and experience of doctors.
- 5.6 Examples like these illustrate **how important it is for health bodies and professionals to provide information in a format that is easily accessible to children and to engage them in appropriate ways.**
- 5.7 The difficulties some children had in understanding the meaning of strategic health decision-making might also have been due to their lack of expectation. **Several focus group participants believed that everything they said (on health and other issues) would not make a difference.** This was the case for those in the Young Offender Institution (YOI), and some children in other groups:
- "I wouldn't bother [complaining] cause nothing would change."*
- 5.8 A further issue was that **children sometimes found it difficult to see if or how their feedback might be used to improve the delivery of services** in their area:
- "Maybe out of the thousands, I don't actually know because we don't get the results or anything, feedback."*
- 5.9 This reflects the findings from the evidence review reported in Section two, which found that, typically, participation activities lacked any mechanisms for feeding back to children if and how their input has made a difference.
- 5.10 **On the whole** children said that strategic health decision-making **was more meaningful** if the decision centred on a **topic they knew about or had a strong view on.** This might be because they had been ill or had a disability, or because they wanted to complain about the quality of a service they had received. They did not think that strategic decision-making was **of interest to everyone,** even if they felt it should be, as one boy explained when talking about his friends:
- "They're not interested in that kind of thing – they just sit at home playing video games all day. I don't know what they'd do – they'd probably just leave it to their parents or something like that. A lot of people would just leave it to health experts or their parents ... I don't actually think that's reasonable, because it's their health stuff that's depending on it, so they should at least try to help."*
- 5.11 Health professionals seeking to engage children need to use their skills and expertise to make strategic health decisions relevant to more children. **Children shared a general aspiration to increase the diversity of children's participation in strategic health decision-making.** Participants wanted more children to have a say because they believed good health was an important issue for everyone. In much the same way, the adults we spoke to for the follow-up interviews wanted to achieve better representation.

5.12 However, children and young people said that their ages influenced the extent to which they were able to make a meaningful contribution, and questioned whether it was appropriate for children of all ages to take part. For example, they said that from the age of 13 children began to take notice of the health service, and to understand what it did, and by aged 16, children had experiences and opinions of services, which they would be able to share. But they held mixed views on whether younger children should be included in strategic health decision-making:

*“You can’t talk to a 5 year old and use words like strategic and all these different things because they are not going to get it ... There is no harm in involving younger people but I think the difference between a 5, 6, 7, 8 year old and 13, 14, 15 year old is that a 15 year old will be able to commit to meetings and take more of an interest, whereas the younger person should be more asked as a one-off.”*

The question of age influenced children’s views on whether they had a right to have a say because some did not know what, if anything, they might be able to add:

*“Some of our opinions might be irrelevant to the fact that like obvious opinions that are obviously there which don’t add to the progression of health services, doesn’t really do anything.”*

It was also suggested that children might not always say what is right, for example, by making ‘naughty’ or nonsensical comments or asking for ‘stupid’ things.

## What do children and young people think about children’s right for their opinions to be heard and taken seriously?

5.13 Some focus group participants **were aware of their right to have their right to have views heard** and taken seriously. They had learnt about this through PSHE lessons in schools, and in some cases via their links with national charities like Unicef, the Children’s Rights Alliance for England and Whizz Kids.

5.14 Children’s awareness of their **right to the best possible health** (ie to be healthy, have access to health services and to have a say about health issues under Article 24 of the UNCRC) seems to come from a range of sources, including campaigns like Change4life, school nurses, and information specifically targeted at children in hospitals:

*“I just kind of realised, people have access to healthcare no matter whether they’re deprived or what illness they have because of the NHS being free everyone has a right to have healthcare ... to have it covered.”*

5.15 Some were **unsure** if children had the right to have a say, as one child (with participation experience) explained ...

*“... because I haven’t actually heard much about children actually having a say, I have like at conferences ... I don’t know how to explain it ... [decision-makers] never really use a child’s quotes [unless at big events].”*

5.16 Even those with previous experience of participating in strategic health decision-making were somewhat sceptical when reflecting on children’s rights to have a say about health issues, because they did not know if what they said would make a difference. One child said he did not know that children had a right to have a say about health *“because I wasn’t told about it”*.

Therefore reinforcing that **children need to know** they have a right to give their views, before they can decide if they want to contribute.

5.17 Focus group participants told us that a **good way of raising children and young people's awareness would be in school**, at assemblies and via leaflets presented in lots of different and accessible ways, to help ensure that children become informed and engaged. This may involve peer messengers/recruiters, where children try and engage other children by telling them their participation stories.

5.18 Children's **impressions about whether their views were being heard were more variable**. Overall, they believed that people listened **to them some of the time**. Inadequate preparation (eg not having pre-prepared questions, activities and resources) led children to believe their views would not be taken seriously. **Participants' views on whether children were being heard by health decision-makers were particularly negative** because some did not know they had a right to have a say about health issues, and others did not think their voices were heard due to **a lack of opportunity, feedback and visible change**. There was some distrust towards health professionals:

*"I think there's this general problem with how health service managers are perceived as well, I think young people generally take their lead from their parents and if you've got parents saying well so and so is on 10 billion pounds ... they're not in it for us, that's been covered up. I think young people actually distrust their health service so if I said something derogatory they are going to cover it up ... I know they're not like that."*

*"I think they need to gain our trust ... sometimes they might just look at us like they're 15 what do they know, they might like maybe like take an opinion, understand it and not just judge it, take it into consideration and develop it maybe."*

5.19 Rather than ask for children's views because they were interested in what they had to say, some participants felt professionals asked because they had to:

*"Some people are interviewed but they don't do anything about it ... just do it because they were told to do it."*

5.20 Furthermore, many who took part **did not think that all children's views were being heard**. Children said that adults targeted 'alright or good kids' and ignored those 'outside' of this ideal. They felt that some children were listened to more than others, and said younger children and children in care were less likely to be heard, perhaps because they were not given the same opportunities and because it was not easy for everyone to speak their mind. There was also a perception that children should take some responsibility for finding out about opportunities if they want to be heard:

*"Average young people who just go through life and just go to school, do after school sports clubs and just do things like that ... they don't kind of then go look for ways to get their voice heard ... and they don't get it as much. Whereas disadvantaged young people and organisations who work with them will approach them and help them to get their voices heard and then other young people who want to be heard will look for places to do that and schools will help them where as people who go through life just like ah I just do my everyday stuff and that's all they don't kind of get their voices heard as much because they don't ask to be heard."*

## Children's aspirations for strategic health service decision-making

5.21 **Overall** children said that strategic health decision-making would ideally offer certain elements:

- **Opportunity** – for all children to take part, this means ensuring children know about their right to have a say and have some choice in whether and how they do so.
- **Outreach** – to encourage a wide range of children to take part and show their opinions are valued by making direct face-to-face connections (eg via schools), as well as online or via social media, depending on what is practical, appropriate and fit for purpose.
- **Simplicity** – so children are able to understand the purpose and process, and feel confident in making a contribution.
- **Variety** – so everyone can contribute and stay engaged in the process.
- **Outputs and outcomes** – to ensure children are given feedback, understand their potential to influence strategic health decision-making, feel their contribution is valued, and wherever possible – can see change.

## What strategic health decisions do children and young people want to influence?

5.22 Children and young people wanted to have a say on their **experiences of services, eg the quality of services, gaps in services and ensuring they were appropriate for their age groups**. Focus group participants told us they had a lot to say about service delivery and wanted to give feedback on a range of things including:

- appointment times so they were better able to attend
- waiting times to better understand and speed up the consultation process
- health professionals and reception staffs' treatment of them to ensure they felt comfortable, were able to understand any diagnosis or treatment, and did not feel patronised
- child-friendly reception areas that did not feel so 'daunting' or look 'drab'
- potential new services/ways in which their needs could be met, for example, sports-related injury prevention clinics
- ways of relieving stress (eg more varied opportunities for physical exercise, more contact with family, better treatment from staff) and better food were mentioned by those who took part in a focus group at the YOI

5.23 They wanted to give their views on how to communicate with children in relation to service delivery and the quality of services. For example, some participants aspired to improve how GP reception staff and family doctors communicate with children, and to limit how much GPs talk to them via their parents, although it was noted that some do talk directly. They also wanted to help plan services and improve the information that is available on topics they found relevant, like out of hours services and what to do in emergencies. Another aspiration was to work with health professionals to make services more teenage friendly. They hoped this would encourage their peers to use services if they needed to do so.

- 5.24 Some focus group participants believed that the health service should tailor its communications to younger audiences to **raise awareness and improve understanding** of the issues and organisations involved:

*“The way the NHS is promoted ... you have the leaflets and posters but it doesn't appeal to us and the information is so abstract and covers lots of different areas, it has its message but you don't think much about it, it's more for adults in a way... ‘Catch it bin it kill it’ that was quite good because of the slogan people were more aware but things like that could make a difference in a way, things which young people can actually remember and it is something they do know.”*

- 5.25 The implication was that by improving communication, children and health professionals would be able to engage in a more mutually beneficial way. This could also increase children's interest in strategic health service decision-making. However, both children and decision-makers need to appreciate the potential impact of children's contribution to the decision-making cycle, and professionals need to let children know how their input has made a difference to make this happen.
- 5.26 Children and young people's emphasis on different aspects of service delivery mirrors decision-makers' intentions that emerged from the analysis of plans and the follow-up interviews. This suggests that there may be good **potential** for children to be consulted on issues they find relevant, **if** they are able to connect with decision-makers, and there mechanisms in place to facilitate effective communication and information flow.

## How would children like to take part in strategic health service decision-making?

- 5.27 Focus group participants said that **how** children and young people take part is very important; this was seen by some as even more important than the topic of the participation activity. Face-to-face methods such as **focus groups** in **schools** were generally preferred for strategic health decision-making. Focus groups were said to be an effective way of getting a meaningful response because they offered children the opportunity to interact with one another, find out about their peers' views, and learn new things. These potential benefits were said to be increased if decision-makers took part in the discussions with children:

*“If you had people coming in and talking to you, you could get a better understanding and put your ideas forward and hope it improves.”*

There was a perception that if professionals went in to schools to talk to pupils they could help those pupils to understand the topics they were presenting, and their roles in the services concerned. Participants believed this would encourage pupils to put forward their ideas. Enabling factors included allocating time to take part (eg through citizenship lessons), and the support of teaching staff.

Some participants predicted a snowball effect, believing that children who first experienced participation in this way might then go on to take part elsewhere. But they said that professionals should be mindful of making issues sound important and interesting, and should wear ‘relaxed clothing’ to help put children at ease. They also need to be able to deliver information in a child-friendly way if they want to successfully engage children:

*“Let's be honest, your first thoughts going to be “this guy's cheesy” or “this guy's good.”*

5.28 Children and young people liked working in **groups**, particularly when activities:

- were ‘really **broken down**’
- delivered, discussed and fed back in sections
- **were simple** but **varied**
- gave participants opportunities to think, express and record their views in numerous ways to keep things interesting

It was sometimes said to be helpful to receive information in advance,

*“We got case studies to think about, mine was Emmanuel and he had like health conditions and stuff but didn’t want to tell his parents so it gave you chance to sort of put yourself in his shoes and think about what you might do so you sort of thought it through and so you could collect information and take it with you on the day, so things like that you get to be quite imaginative.”*

It was very important for children and young people to feel prepared. They said they did not want to be the only one there who did not know about the topic. To ensure all of them feel prepared, participants said information must be available in alternative formats such as talking books and large print. One child also said that Notetakers (with Braille display and speech output) would be useful for visually impaired children who might want to join in.

5.29 **Tangible and interactive activities** were especially popular among those who had experience of these, for example, asking children to post ideas in a [physical] letter box. Also incorporating voting (such as red, amber, green cards, awareness scales etc), as part of discussions, like we did in our session to explore children’s rights, was believed to be a good way of looking at issues that might be difficult to discuss. Participants felt that these types of activities ensured that everyone in the group contributed to some degree.

5.30 Overall, focus groups were considered to be **appropriate** for all age groups. But there were mixed views on whether groups should be organised broadly according to age. Some participants believed it was important to have children of different ages within the same focus group so that they could learn from each other. Others highlighted the importance of being surrounded by people their own age. They said this gave them the confidence to speak up, unlike if they were the only or younger child in a group. Small group work was generally thought to be beneficial for everyone taking part.

5.31 There was **no consensus regarding whether children should participate separately or with adults**. Some children said separation would cause discrimination. Others said that children’s views in mixed groups might not be taken seriously nor distinguished from those of the wider public. However, there was agreement that it was **situation dependant**. If children were attending meetings with adults they wanted to be told what to expect (eg casual meeting, no need to dress formally) and should be supported to take part, through, for example, ice breakers and the establishment of ground rules.

### Box 5.1: What works to engage children in strategic health participation – methods

- Give children a **choice in the type and level of commitment they make**:
  - through ongoing/established groups (which can offer a sense of belonging, progress and achievement) and one-off activities that they can dip in and out of
- Offer a range of **different methods** of taking part to engage more and different children or ask children how they would like to take part:
  - different ways to feedback about service use – online and paper surveys, mini-discussion groups at schools feeding into young people's councils, and young people council representation on health groups
  - 'health surgeries' perhaps at school or Connexions offices
  - interactive discussion groups that vary in pace, activity focus (eg talking, writing, drawing, voting)
- Be **age appropriate** when recruiting, designing and delivering participation activities:
  - pilot different approaches
  - ask for respondents' ages when recruiting for groups or designing surveys (including ones for the general public)
  - use plain English, and modify questions when asking about difficult topics, complex structures or processes
- Ensure children can give their views **in confidence**:
  - avoid asking them to complete surveys in public areas
- **Prepare all** children to share their views whether face-to-face or not:
  - both in the introduction to a survey or discussion group, and any associated reference material, or supporting information (including alternative formats, such as large print and talking books)
- Ensure children **understand** and feel their contribution is valued:
  - ask clear, specific questions (avoid 'have we got our priorities right' and other broad questions)
  - explain why it's important, and how the information they give will be used
  - demonstrate adults' preparation (eg support materials, pre-prepared flip-chart sheets)
- **Make 'strategic' relevant and meaningful**:
  - for example, how service user feedback can be used to make services better, explain who will do what, why and when, and how they will know their views have been taken seriously and feedback, if and when change happens
  - when planning how to involve children in clinical commissioning group programme budgeting; eg focus on key themes like mental health or long term conditions to help make it relevant, manageable and help to focus their discussion and ideas
- Ask children **what they want**, as well as what they think about adult-led options or opportunities

## What would children like to see as a result of taking part in strategic health decision-making?

5.32 Whatever the method of participation, it was most important for children to get feedback. Ideally, they also wanted to affect change as they explain in their own words below:

*“In an ideal world I would like to have some evidence that views were taken forward, either by a report or just by saying well actually this has happened since the meeting and it’s because of something you said or the group said, like maybe giving the review that is sent out to them and then maybe like the results from that if there is any later on to be sent to them as well just so they know they’re views are being heard and they will be more likely to do something in the future.”*

*“Like you know that it’s helped make a change so it’s going to benefit society cause more people are going to come in [to sexual health clinic] like ... before they would have been too embarrassed to go there and before they might have had it [infection] and not been able to get rid of it.”*

Feedback, or the lack of it, was a key issue affecting how successful and meaningful children’s participation was for everyone involved. Children said they would understand if things were not going to change, but they would like to be told the reasons why.

Incentives were also said to be important, both as a reason to take part in the first place (eg free food, vouchers, free membership to something), and as an output from taking part (eg training, certification), which participants would be able to add to their CVs.

### Box 5.2: What works to engage children in strategic health participation – outputs and outcomes

- **Ask children for their feedback** on the participation process, always invaluable and often essential:
  - for example, following children’s recommendations, one local authority shortened training days for a tendering process, asking children to give feedback after each interview rather than at the end of the day so each interview was fresh in their minds, which worked well for everyone.
- **Follow up** with children on what happens next, any **changes** as a result of their participation, or the **reasons why** things haven’t changed:
  - ensure their input is **meaningful**, they are not put off participating again in future, do not quickly forget what they’ve done and are able to learn
  - this may include some form of **incentive, thank you, or recognition** (such as a certificate), which can help children feel valued
- **Promote and share learning in practice** building on existing mechanisms to share what works:
  - for example, pan-London co-ordinators for *You’re Welcome* sharing good practice and benchmarking panel to quality assure across the city
  - or an online practitioners hub for practitioners to upload ideas and tools or icebreakers, timesheets, rewards to support the development and continuation of good practice

## Section six: What next for children and young people's participation in strategic health decision-making?

6.1 This section outlines what is known about local authorities and health partners' **plans for engaging children in implementing local health strategies**, drawing on the review of local plans and the follow-up interviews. **The gaps in the evidence we collected are** highlighted to provide context for some of the recommendations in the final section of this report.

### Future plans for children's participation in strategic health decision-making at the local level

6.2 At the time of this research, there was **little information about future plans** for children's participation, which made it **difficult to build a comprehensive picture of what the future may look like**. From the available information it seems that local authorities and partners were largely planning to build on what they were **already doing** to engage children. Planned target groups, topics, and methods of engagement reported in the plans and interviews were **similar to current activities; but with more** emphasis on service delivery.

6.3 Very few local health plans outlined **particular target groups that would be engaged in future**. These were looked after children, young offenders, children with disabilities and young carers, although not all plans mentioned all of these. In terms of **potential gaps**, the review did not find any information about plans to engage children living in poverty or areas of deprivation. This might be because these children have already been targeted, and it does not necessarily mean that these children will not be targeted, but that we do not know. **Engaging children living in poverty will be an important factor to help better understand the impact of children's home and local environment on their health and their ability to be healthy.**

6.4 The limited information in the plans indicates that topics are likely to include:

- service planning
- health needs (including the needs of specific groups)
- children's experiences of services
- children's views on the quality of services

6.5 This reflects the findings from the review of past practice (Section two) and the analysis of activities that had already been carried out (Section four). From the available evidence it seems that, in future, the focus will remain on a **specific stage of the decision-making process**, (eg service planning) with no clear evidence to indicate a shift towards the continuous involvement of children throughout the decision-making cycle.

6.6 **Rarely did the local health plans outline methods**, beyond how children will be accessed or recruited through schools, youth groups, and voluntary sector organisations. Each of the following methods was mentioned: surveys; decision-making groups; focus groups; and an online forum. **There were also unspecified mentions of 'appropriate methods' and 'channels suited to young people', which do not provide sufficient evidence to judge whether the participation would be meaningful.**

- 6.7 From the follow-up interviews we learned that **social media** (such as Facebook and Twitter) discussion groups may be set up to promote participation opportunities and allow children to ‘dip in and out’ when they choose. Focus group participants also identified the potential of social media. They were, however, mindful that these public forums were not appropriate for discussions about personal or complex issues, and indeed that they were not used by all children.
- 6.8 **In a few local authority areas there were indications that children’s participation is becoming embedded.** From the follow-up interviews we learned that one local authority area intends to create a **decision-making champions group**. The group will involve a clinical commissioning group commissioning manager and other local authority managers working together to establish how to take forward children’s recommendations. In other areas there are plans to increase the numbers of children involved in *You’re Welcome* service reviews, once a core group is well established and practiced; and also plans to provide children with **accreditation and training**, with service-specific assessment toolkits.
- 6.9 **Interviewees referred to Healthwatch** as a vehicle through which more children will participate, given its role as the consumer champion for health and social care service users. The need to **embed** participation in contractual agreements, and to **monitor** progress and the impact of children’s participation on strategic health service decisions, was highlighted by one interviewee, who said there would be a contract clause that requires local Healthwatch to demonstrate how it has engaged children and how their views have been used to shape its work each year.

## Section seven: Conclusions and recommendations

7.1 This report has highlighted the timeliness of the study, as the Government's health service reforms will shortly be put into practice. Key messages and recommendations are presented below.

### Key messages

- Patient and public involvement is a core element of the Government's recent reforms to the health service. Through its pledge for improving children's health outcomes<sup>58</sup> and response to the Children and Young People's Health Outcomes Forum<sup>59</sup>, the Department of Health has signalled that those **planning health services should involve children in their decisions**. However, our policy review indicates that beyond the role of Healthwatch, there is yet to be a coherent programme of work for achieving this for all health bodies making strategic or commissioning decisions. Neither is there clarity about how they will access and share the resources and support materials they need to meaningfully engage children. For instance the well publicised "Friends and Families Test" which asks whether staff, patients and families would recommend a health setting or service to those closest to them, is relevant as things stand only when a patient is aged 18 or over. The fact that one in four patients is aged under 18 and this age group represents a significant population in its own right, is sadly paid scant regard.
- The research findings from the review of local health plans, interviews with local authority's health and participation professionals<sup>60</sup>, and focus groups with children, show that despite **some examples and efforts to improve children's participation, the current picture of children's participation in local strategic health decision-making is both mixed and fragmented**.
- The sample of over 100 local health plans analysed **indicated that they were 'works in progress'**, and a different picture may emerge once they are completed.
- **At this stage in the local planning cycle it appears that children's participation has not been sufficiently embedded into everyday practice** and largely relies on the commitment of key individuals.
- Analysis of local health plans indicates **significant gaps** in the information currently available about children's participation in strategic health decision-making.
- **Only 28 per cent of all plans specifically referenced children's participation**. Many of the details – about who will be involved and how – were simply lacking. Joint health and wellbeing strategy made the least number of direct references to children's engagement. This was surprising given that these plans provide the overarching health and wellbeing strategy for each local area, and government expects them to include a summary of community views and how those views have been used.
- These findings alone suggest **greater emphasis on the involvement of children in strategic health plans is necessary**, and will need to be supported by appropriate resources, expertise, monitoring systems, and mechanisms allowing all concerned to share effective practice.
- **We found no noticeable difference between the number of Healthwatch pathfinder and non-pathfinder local authority areas** that referenced children's active participation. This is despite Healthwatch being a key vehicle for taking forward the system's necessary and solid

58 Department of Health (2013) *Better health outcomes for children and young people: our pledge*.

59 Department of Health (2013) *Improving Children and Young People's Health Outcomes: a system wide response*.

60 And one clinical commissioning group representative.

assurance of the engagement in the new NHS of patients and the public, including children and young people.

- Follow-up interviews in a small number of local authority areas provided a wider range of examples of including children in strategic decision-making, compared with the analysis of local health plans. This probably reflects the fact that the latter are still ‘works in progress’.
- In summary, the evidence from past and current practice shows that children typically are invited to take part at a **specific stage** in the decision-making cycle **mainly through consultation. In effect this signifies activity that is simply a ‘sounding out’ of actions or decisions that have already largely been made by adults.** However, we also found some emergent evidence of children being more actively and fully involved both in identifying what needed to be done, and making meaningful joint decisions with adults.
- Local Healthwatch and Healthwatch England, local groups, panels and information hubs clearly offer the potential to extend and share these more meaningful ways of involving children in strategic decision-making into more areas of the system, more consistently and determinedly led by adults who run it.
- Generally, the evidence from past and current practice shows that **children tend to be consulted on their health needs and service planning**, rather than on services’ commissioning, delivery or evaluation.
- The analysis of current practice provided little evidence of the impact of children’s participation on strategic health decisions. This was partly because some decision-making processes that included children were ongoing, or in their early stages of development.
- Children said that **effective approaches** to including them in strategic health decision-making would ideally offer a number of elements:
  - **Opportunity** – for all children to take part; this means ensuring children know about their right to have their views heard and taken seriously, and have some choice in whether and how they do so.
  - **Outreach** – to encourage a wide range of children to take part and to show that their opinions are valued, by making direct face-to-face connections (eg via schools as the universal service most used by the child population), as well as online or via social media, depending on what is practical, appropriate and fit for purpose.
  - **Simplicity** – so that children are able to understand the purpose and process, and feel confident in making a contribution.
  - **Variety of approaches and means**– so everyone can contribute and stay engaged in the process, including for example children and young people with learning or communication needs, of a wide range of ages including young children, or those whose first language is not English.
  - **Outputs and outcomes** – to ensure children are given feedback, understand their potential to influence strategic health decision-making, feel their contribution is valued, and – wherever possible – can see change.
- During this time of reform, there is a **real opportunity** for the NHS to be bold: to embed, strengthen and promote the involvement of children in decision-making throughout the system. Now is the time for Department of Health, the new NHS and their national and local health partners to **implement their commitment** to listen and act on the views of children, in accordance with February 2013’s Pledge which was signed by Dr Daniel Poulter MP on behalf of

Ministers across government in response to the 2012 report of the Children and Young People's Health Outcomes Forum report.<sup>61</sup>

## Recommendations

Our recommendations are aimed at **both national and local decision-makers**. They are based on the evidence gathered from the review of local health plans, interviews with key informants from local authorities<sup>62</sup> and the focus groups with children.

### National Recommendations

- Department of Health, NHS Commissioning Board and all its Directorates, Public Health England, Health Education England and its national network of Local Education and Training Boards (LETBs), Healthwatch England, the Local Government Association, and the health professionals' various Royal Colleges, **should actively promote the participation of children in strategic decision-making**.
- These national bodies should **develop supporting materials on children's participation** in the development of joint strategic needs assessments, joint health and wellbeing strategies, clinical commissioning group commissioning and engagement strategies, public health plans and local Healthwatch priorities, building upon existing resources and examples of good practice:
  - promoting the benefits of children's participation in strategic decision-making
  - providing examples of good practice to engage children with different needs, experiences and interests
  - setting out the range of approaches that can be used effectively to work with children who are at risk of poor health outcomes or who are less likely to be heard
- Department of Health, the new NHS, and its national and local health partners should all develop child-friendly materials that set out to both raise awareness and improve understanding of the role of the NHS and other health services on the part of children and young people and their families. This should actively seek to encourage more children and young people to get involved in making decisions about their health services.
- The new Children and Young People's Health Outcomes Forum and the Chief Medical Officer's Children and Young People's Health Board should hold national and local health bodies (including local authorities) to account for fulfilling their duties to involve children in strategic decision-making. This should be one focus for the Forum's first annual summit.
- Healthwatch England and Department of Health should provide leadership to local Healthwatch organisations – as the key champions for service users – to ensure they actively engage children, promote their right to be involved in decision-making and have their views taken seriously, and are adequately resourced to do so.
- In 2014-5, Healthwatch England and Department of Health should review the extent to which local health bodies – including local Healthwatch – have effectively engaged children
- Healthwatch England should be sufficiently resourced not only to effectively involve children in their work, but also to promote effective children's participation to local health structures.

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61 <http://www.dh.gov.uk/health/2012/07/cyp-report/>

62 And one representative from a clinical commissioning group.

## Local recommendations

- Every health and wellbeing board should be required to ensure children are a clear priority population when gathering the public's views to inform the joint strategic needs assessment and joint health and wellbeing strategy. As well as including the Director of Children's Services in membership, each health and wellbeing board should actively consider how best to engage with local children and young people's participation and involvement organisations and groups, which are now common in most local authority areas.
- **All health and wellbeing boards should identify a champion** who is responsible for promoting children and young people's right to be proactively and meaningfully involved in strategic decision-making as part of the work of the Board, in Las' work on health issues including Public Health, in clinical commissioning groups and local Healthwatch.
- health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch organisations should have clear arrangements in place for **promoting and explaining to children** the work they do and for **monitoring** how children are involved in health decision-making. This should include recording: what data is collected, what methods are used to engage different groups of children, how the views of children are used, and what impact their involvement has had.
- **health and wellbeing boards, in particular, should do more to share publicly how they have involved and continue to involve children and young people in the development of their joint strategic needs assessment and joint health and wellbeing strategy, and any other strategic health plans.**
- health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch should consistently provide children with a **variety of opportunities** to be involved in strategic health decision-making, so that there are options that suit different children's needs and interests.
- Wherever appropriate, children should be given opportunities to make genuinely shared strategic decisions with adults, for example, working together to decide how a proportion of the public health budget will be spent. Where this entails training and educating children and young people to do such co-construction, funding this should be factored into budgets
- health and wellbeing boards, local authorities, clinical commissioning groups and local Healthwatch should make use of existing materials, resources and mechanisms for engaging children, including working with schools, youth groups, voluntary organisations and children in care councils.
- These bodies should also monitor whether they are hearing the same voices repeatedly, **striving to provide opportunities to those who might not normally be heard**, including children with poor health outcomes and complex health needs, such as:
  - looked after children,
  - young offenders,
  - disabled children and
  - children living in poverty.
- As well as directly involving children in decision-making, Health and Well-being Boards, local authorities, clinical commissioning groups and local Healthwatch should **draw on children's**

**views about specific services, and on their *individual* experiences of care, to inform strategic decisions.**

- Healthwatch England and local Healthwatch bodies should consider how the latter might act as ambassadors for children's participation in the local health sector by trialling, demonstrating and sharing good practice.

# Appendix A: Method

## Study aims

A.1 The overarching aims of the study were to:

- identify whether and how far new and emerging health systems proactively engage children<sup>63</sup> in decisions about health service design and delivery
- identify the most effective mechanisms for ensuring the meaningful engagement of children in health service design, delivery, evaluation and quality assurance
- offer an analysis which might inform national guidance and initiatives, and local health plans developed by Health and Well-being Boards (health and wellbeing boards), local authorities (local authorities), Clinical Commissioning Groups (clinical commissioning groups) and local Healthwatch
- contribute to the ongoing work of the Department of Health's national Child and Young People's Health Outcomes Forum and the onus it places on all commissioners and providers to listen to and act on the voice and views of children

## Method

A.2 Our methodology included:

- gathering practice examples of involving children in strategic health design and delivery through a comprehensive review of published research and consultation on children's views and experiences of health provision
- mapping the emerging evidence on children's participation in strategic health design and delivery in the new health structures, through an analysis of the national policy framework and local plans, and interviews with health policy and participation professionals in local authorities<sup>64</sup>
- assessing how children want to be involved in strategic health service decisions through focus groups

This study was informed by **Young NCB Research Advisers**<sup>65</sup>. They contributed to the data collection instrument design; commented on the findings from stages one and two of the research; contributed to the report recommendations through the focus groups, and produced a child-friendly report.

An advisory group of professionals (see Acknowledgements) contributed to the research design, and commented on the findings.

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63 Throughout the rest of this report appendix when we refer to 'children' we mean children and young people up to the age of 18 years.

64 And one interview with a clinical commissioning group representative.

65 Young NCB Research Advisers are a pre-existing group that are regularly involved in informing and shaping the design and delivery of NCB research projects.

## Stage one: analysis of past practice involving children in health decision-making

A.3 NCB recently carried out a comprehensive review of published research and consultation on children's views and experiences of health provision<sup>66</sup>. The responses were reviewed for this report to explore children's participation in strategic health decision-making<sup>67</sup>. In analysing this evidence from 2007-12, we explored:

- the focus and topics to establish at what point children were involved in the decision-making process
- the impetus for the consultations – eg service improvement
- how children participated and their level of participation
- what were the outcomes, and children's views and experiences of taking part in these

## Stage two: review of emerging evidence

A.4 The research team carried out a review of national policy from **Department of Health<sup>68</sup> and other government departments** to provide the background to study. The review assessed:

- the degree to which these documents promote engagement with children
- the processes and mechanisms they suggested

A.5 **Local plans** developed by health and wellbeing boards, clinical commissioning groups and Healthwatch pathfinders were analysed and represent three key parts of the emerging local health system (see Table 1.1):

- local strategic planning for health and wellbeing
- new local NHS commissioning arrangements
- local patient and public engagement

A.6 The review of local plans explored the **scope and scale** of children's participation in strategic health decision-making. We assessed how adequately these plans appeared to explain children's participation, and to what extent the participation was **meaningful**, drawing on the OCC's participation strategy and NCB's own knowledge and experience of good participation.

A.7 In particular the following aspects were explored:

- the extent to which plans specifically referenced or detailed children's participation, as opposed to wider patient and public participation
- the views of which groups of children in particular were of interest
- number of children involved

66 La Valle I., Payne L. with Gibb J., Jellic H. (2012), *Listening to Children's Views on Health – A rapid review of the evidence*, London: National Children's Bureau. [http://www.ncb.org.uk/media/723497/listening\\_to\\_children\\_s\\_views\\_on\\_health\\_-\\_final\\_report\\_july\\_12.pdf](http://www.ncb.org.uk/media/723497/listening_to_children_s_views_on_health_-_final_report_july_12.pdf)

67 The NCB review focused on evidence from England, from 1997-2011. More information on how the review was carried out, including the organisations that responded to the call for evidence, can be found in the review report (La Valle et al., 2012, op. cit.).

68 Including analysis of the NHS Commissioning Board plans for engaging children and young people as they could cover the commission of specialist services (eg in custody, long term/complex conditions).

- the focus and topics to establish at what point children were involved in the decision-making process
- how children participated and their level of participation
- the presence or absence of support and rewards/reimbursement
- the presence or absence of follow up activities – eg initial feedback, evaluation, dissemination
- what were the outputs and outcomes from the activities or what were expected
- any references to Department of Health guidance or initiatives to explore if and how these were used

The review framework was created in Excel, with input from our advisory group and Young NCB Research Advisors, who were involved in all stages of the study, and the data analysed in Excel and SPSS.

## Sample

- A.8 A total of **102 local plans** from 38 local authority areas were analysed. The sample was selected to be broadly representative of England, covering a range of:
- geographical areas (different parts of the country, rural vs. urban)
  - levels of deprivation
  - ethnic composition
  - Healthwatch pathfinders and non-pathfinders
- A.9 Table 1.1 provides an overview of the number and type of plans reviewed and what each covers.

**Table 1.1: Overview of the number and type of plans reviewed**

| Type of plan   | Purpose   | Number of plans reviewed |
|--|---|--------------------------|
| Clinical commissioning group (CCG) commissioning strategy                | Sets out the clinical commissioning group's plans for commissioning local NHS services  | 19                       |
| Clinical commissioning group (CCG) communication and engagement strategy | Sets out how the clinical commissioning group will take forward its duty to involve patients and the public in planning and making changes to the local health services they commission | 13                       |
| Joint health and wellbeing strategy (JHWS)                               | Published by the health and wellbeing board, setting out its overarching plans for improving the health and wellbeing of the population   | 21                       |
| Joint strategic needs assessment (JSNA)                                  | Prepared by the health and wellbeing board, to identify local health and wellbeing needs to inform priorities in the joint health and wellbeing strategy                                | 24                       |
| Local Healthwatch pathfinder engagement strategy                         | Describes how the local Healthwatch organisation will engage the community in its work  | 1                        |
| Healthwatch pathfinder bid   | Submitted to the Department of Health by local authorities seeking to become a Healthwatch pathfinder   | 24                       |
| <b>Total</b>   |   | <b>102</b>               |

A.10 **A core sample of 25 local authority areas**<sup>69</sup> was selected, for which **all available local health plans** being developed by Healthwatch pathfinders, clinical commissioning groups and health and wellbeing boards were reviewed. The plans included clinical commissioning group communication and engagement strategies which focused specifically on public and patient involvement (including children). These were reviewed in addition to or instead of clinical commissioning group commissioning strategies, where these were not published at the time of our review<sup>70</sup>.

A.11 The core sample (all available health plans) included 12 local areas that were Healthwatch pathfinders, and 13 that were not, to assess whether being a pathfinder resulted in any significant differences in local areas' approaches to children's engagement. To ensure a comparable number of Healthwatch pathfinder bids were analysed, the team reviewed bids developed by 13 additional local authority areas in a **supplementary sample** (Healthwatch pathfinder bids only).

A.12 In addition, the research team undertook eight **follow-up interviews**<sup>71</sup> with key informants from the core sample (all available plans) to build on the evidence gathered through the review of local plans and aim to better understand:

69 12 were Healthwatch pathfinders, 13 were not.

70 August – October 2012.

71 In seven of the core sample areas, mostly with local authorities, and one clinical commissioning group representative.

- how children have been involved in strategic health decision-making
- why
- what difference their involvement has made
- how children may be engaged in future and what outcomes are expected

### Stage three: focus groups with children

A.13 After data from Stage one and two was gathered and analysed, researchers held **six focus groups** with children to:

- discuss their **previous experiences** (if any) of health decision-making, what worked well and less well
- discuss and comment on **past practice** examples of involving children in strategic health decisions (ie stage one findings)
- discuss **Department of Health guidance and initiatives and current local plans** for involving children (ie stage two findings), how adequate these plans were and what else may need to be done to ensure more meaningful involvement
- explore what they knew about **children's rights** and whether they thought children's voices are being heard
- draw up a list of **recommendations** on how ideally children would like to be involved locally in assessing needs, identifying priorities and making plans for how health services are delivered in local areas

### Sample and recruitment

A.14 Children were recruited via several channels to form four 'general' groups<sup>72</sup>. There was one focus group with children in or leaving care, and one group of children in the youth justice system. Looked after children and young offenders were purposefully targeted to ensure the involvement of different children with a range of health experiences and views. Thirty seven children took part over six focus groups between late October and early December 2012.

A.15 Young NCB, a diverse membership of children who come together to speak out about the issues that are important to them and participate in the decisions that affect their lives, invited children to attend through the monthly 'Young NCB Opportunities e-bulletin', and on the website, [www.youngncb.org.uk](http://www.youngncb.org.uk). The opportunity was also promoted via a range of organisations that NCB works with, to ensure its membership remains diverse. These organisations included children in care councils, youth councils, youth parliaments, pupil referral units and organisations working with children with disabilities. It is through Young NCB's relationship with a local authority that we were able to engage children in or leaving care.

A.16 We gained access to a group of children currently residing in a Young Offender Institution (YOI) via existing links with a support worker on site, having received approval from the YOI's management and the National Offender Management Service.

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<sup>72</sup> Two groups were run with the Young NCB Research Advisors, members of a pre-existing group that are regularly involved in informing and shaping the design and delivery of NCB research projects.

- A.17 Our Young NCB Research Advisors were invited to take part as members of a pre-existing group that are regularly involved in informing and shaping the design and delivery of NCB research projects.
- A.18 Children travelled from different areas of England to attend the focus groups which took place in Birmingham and London. We sought their informed consent, provided information sheets in advance, and asked for their verbal consent at the start of each focus group; reminding them of their right to withdraw at any point should they so wish. Parental consent was also required for children under the age of 16. Participants received a £15 voucher as a thank you for their time<sup>73</sup>. A summary of the demographic data children provided us with is presented in 1.19 and the data is displayed in full in Table 1.2.

### Focus group participant data

- A.19 Thirty seven children took part over six focus groups compared with our target of 48. The reasons why the numbers were lower included the tight timescale for this study coinciding with the half-term break for some children; a change in the membership of the Young NCB Research Advisors (meaning that some did not attend their final meeting); and only four children in the YOI took part in the group, where we had negotiated to run a group with around 8-10.
- A.20 Participants were asked if they were willing to complete the OCC's equality form, which monitors: gender; age; sexuality; ethnic background; religion; whether children have a disability; are in care or a care leaver; or are a young carer. Table 1.2 shows that 33 out of 37 children completed a form and of these:
- just over half were girls
  - more than two thirds were aged 15 or above
  - almost half were of White ethnic origin, one in five Black African, and fewer of Asian, mixed ethnicity or other ethnic group
  - three children considered themselves to have a disability
  - ten children were in care
  - five were young carers

**Table 1.2: Focus group participant data**

|   | Gender | Age | Sexuality    | Ethnicity           | Eth 2     | Religion    | Disability | In care | Young carer |
|---|--------|-----|--------------|---------------------|-----------|-------------|------------|---------|-------------|
| 1 | F      | 16  | Heterosexual | Other               | Arab      | Muslim      | No         | No      | No          |
| 2 | F      | 16  | -            | Asian/Asian British | Indian    | Hindu       | No         | No      | No          |
| 3 | F      | 11  | -            | Asian/Asian British | Indian    | Hindu       | No         | No      | No          |
| 4 | F      | 18  | Heterosexual | Asian/Asian British | Pakistani | Muslim      | No         | No      | No          |
| 5 | F      | 15  | Heterosexual | Other               | Iranian   | No religion | No         | No      | No          |
| 6 | F      | 14  | Heterosexual | White               | British   | No religion | Yes        | No      | No          |
| 7 | F      | 15  | Heterosexual | White               | British   | No religion | No         | No      | Yes         |
| 8 | M      | 16  | Heterosexual | White               | British   | Christian   | Yes        | No      | No          |

<sup>73</sup> Aside from children in the YOI who received a £5 contribution to their spending money at the request of the prison governor.

|    | Gender | Age | Sexuality    | Ethnicity                         | Eth 2                  | Religion    | Disability | In care | Young carer |
|----|--------|-----|--------------|-----------------------------------|------------------------|-------------|------------|---------|-------------|
| 9  | F      | 18  | Heterosexual | White                             | Any other              | Christian   | No         | No      | Yes         |
| 10 | F      | 16  | Heterosexual | Asian/Asian British               | Indian                 | Other       | No         | No      | No          |
| 11 | M      | 15  | Heterosexual | White                             | British                | No religion | Yes        | No      | Yes         |
| 12 | F      | 16  | Heterosexual | White                             | British                | Christian   | No         | Yes     | No          |
| 13 | M      | 14  | Heterosexual | White                             | Brit/Irish             | No religion | No         | Yes     | No          |
| 14 | M      | 15  | –            | Asian/Asian British               | Any other              | Muslim      | No         | Yes     | No          |
| 15 | F      | 14  | –            | Black/African/Carib/black British | Any other              | No religion | No         | Yes     | No          |
| 16 | F      | 15  | –            | Black/African/Carib/black British | African                | Christian   | No         | Yes     | Yes         |
| 17 | F      | 14  | Bisexual     | Mixed/Multiple ethnic backgrounds | Chinese & black French | Other       | No         | Yes     | No          |
| 18 | F      | 13  | –            | White                             | British                | No religion | No         | Yes     | No          |
| 19 | F      | 13  | –            | Black/African/Carib/black British | African                | Christian   | No         | Yes     | No          |
| 20 | M      | 17  | Heterosexual | White                             | British                | Christian   | No         | No      | No          |
| 21 | F      | 19  | Heterosexual | Black/African/Carib/black British | Caribbean              | Christian   | No         | No      | No          |
| 22 | M      | 17  | Heterosexual | White                             | British                | Christian   | No         | No      | No          |
| 23 | F      | 18  | Heterosexual | Mixed/Multiple ethnic backgrounds | White & Asian          | Hindu       | No         | No      | No          |
| 24 | M      | 16  | Heterosexual | Black/African/Carib/black British | African                | Christian   | No         | No      | No          |
| 25 | M      | 16  | Heterosexual | Black/African/Carib/black British | Caribbean              | Christian   | No         | No      | No          |
| 26 | M      | 18  | Heterosexual | White                             | British                | Christian   | No         | No      | No          |
| 27 | M      | 15  | Heterosexual | White                             | British                | Christian   | No         | No      | No          |
| 28 | M      | 12  |              | Mixed/Multiple ethnic backgrounds | Any other              | Christian   | No         | No      | No          |
| 29 | F      | 16  | Heterosexual | White                             | Any other              | No religion | No         | No      | No          |
| 30 |        |     |              | Black/African/Carib/black British | African and Caribbean  | NR          | No         | Yes     | Yes         |
| 31 | M      | 17  | Heterosexual | White                             | British                | Other       | No         | No      | No          |
| 32 | M      | 16  | Heterosexual | White                             | British                | Other       | No         | No      | No          |
| 33 | M      | 15  | Heterosexual | White                             | British                | Christian   | No         | Yes     | No          |

## Data collection and analysis

The focus groups took place between late October and early December 2012, each lasting two hours, and were digitally recorded with the participants' permission. The data was analysed using Framework, a rigorous and systematic method that allows in-depth thematic and within case analysis. A matrix was drawn up for each theme, with the columns representing key sub themes and the rows representing different focus groups. Data from notes and the recordings was summarised in the appropriate cell, with illustrative verbatim quotations. The final matrices provided a full picture of

each group's views, displayed the range of views described by participants and allowed the accounts of different groups of participants to be compared.

## Appendix B: Topic guides

### Children and young people's participation in strategic health decisions

#### Topic Guide for follow-up interviews

- The primary aim of these interviews is to build on the evidence we have gathered through the review of local plans, to better understand how children and young people have been involved in health service decisions, why, and what difference their involvement has made – or indeed – how they may be in future and what outcomes are expected.
- We are targeting follow up interviews to a) fill the gaps and b) develop our examples of children and young people's involvement in health decision-making.
  - The topic guide is a prompt for the interviewer and not a script.
  - The guide does not contain pre-set questions, but rather lists the key themes and sub-themes to be explored and these will need to be tailored as appropriate.
  - Questions and wording should be adapted according to the circumstances of the interview.
  - It does not include comprehensive follow-up questions because these will be specific to the interviewee/area, but it is expected that answers are fully explored using prompts and probes throughout.
  - The interviewer should prepare by reading the review of the local area's plans in the framework, and highlighting key areas and points for discussion beforehand.
  - In this instance it will be useful to print a new topic guide for each interview, highlighting points on paper, together with any notes, to aid questioning. These may also be used for reference at the analysis stage and so should be kept on file.

#### Introduction

- Introduce self and NCB, study funded by Office of the Children's Commissioner for England
- Introduce study:
  - Review of past and emerging practice in involving children and young people in strategic health decision-making
  - Provide learning to inform Department of Health guidance, and local health strategies and plans being developed by Healthwatch and Health and Well-being Boards and Clinical Commissioning Groups
  - Guided by the UNCRC, and particularly children and young people's right to participate in decisions that affect their lives, and have these views taken seriously.
  - Involves gathering examples of good practice, mapping emerging evidence from review of local plans, and assessing children and young people's views, including how they want to be involved
- Taking notes and recording – check OK, and reassure re: confidentiality, anonymity

- How we'll report findings
- Reminder of interview length – (around 20 mins (if checking facts or limited focus) up to 45 mins (if full discussion/follow up) check OK
- Any questions/concerns?

## Completed consultations with children and young people

We know from our review of local plans that you have done some work with ... on ...

We would like to find out more information about ...

If unknown at present, please indicate when further information will be available (to note)

### 1. Who was involved and how

- Which young people, if unspecified why
- Number young people
- Which adults (lead, roles, teams)
- Accessibility and recruitment (eg gatekeepers/partner organisation, other and why):
  - If a 'consultation group' was used – define and explain
  - Similarly explore any other terms of reference
- Methods (eg new and specifically developed for this exercise or existing and why)
- Support/rewards
- If 'ongoing' explain (in what ways, how often ...)

### 2. What exactly was the focus

- Why (and how decided)
- What topics (eg identifying gaps in services, which services and why)
- Any joint decisions (and if so, child or adult initiated)
- Any links between this work and the work around the clinical commissioning group strategy/health and wellbeing board strategy/other

### 3. Why decided to involve children and young people

- Aim/aspiration
- What drives children and young people's involvement/service user involvement
- How would they describe their particular way of involving children (ie level of participation, eg predominantly informing, involving, consulting, other ...)
- Awareness/reference to relevant guidance/obligations (Department of Health, UNCRC, human rights law)

#### **4. Outcomes**

- Difference made
- How known
- Follow up (what, when, how)

#### **5. Lessons learned**

- What worked well
- Tips/advice
- Any challenges and how dealt with
- Whether approach was fit for purpose
- What, if anything would do differently

>> Moving on to talk about the future

### Planned consultations with children and young people

We know from our review of local plans that you are planning to do some work with ... on ...

We would like to find out more information about ...

If unknown at present, please indicate when further information will be available (to note)

#### **6. Who will be involved and how**

- Which young people, if unspecified why
- Ballpark number young people
- Which adults (lead, roles, teams)
- Accessibility and recruitment (eg gatekeepers/partner organisation, other and why):
  - If a 'consultation group' will be used – define and explain
  - Similarly explore any other terms of reference
- Methods (eg new and specifically developed for this exercise or existing and why)
- Support/rewards

#### **7. What exactly will the focus be**

- Why (and how decided)
- What topics (eg identifying gaps in services, which services and why)
- Any joint decisions (and if so, child or adult initiated)
- Any links between this work and the work around the clinical commissioning group strategy/health and wellbeing board strategy/other

## 8. Why decide to involve children and young people

- Aim/aspiration
- How would they describe their particular way of involving children (eg predominantly informing, involving, consulting, other ...)
- Awareness/reference to relevant guidance/obligations (Department of Health, UNCRC, human rights law)

## 9. Outcomes

- Expected
- How will they know
- Planned follow up (what, when, how)

## Closing

## 10. Anything else

- Sources of additional information
- Dates for publication
- Contact details
- Other

# Children and young people's participation in strategic health decisions

## Topic guide for focus groups

- The primary aim of these focus groups is to find out what children and young people think about what we learned from reviewing examples of past practice and local health plans, and how children and young people think they could be involved in strategic health decision-making.
  - The topic guide is a prompt for the moderator and not a script.
  - The guide does not contain pre-set questions, but rather lists the key themes and sub-themes to be explored and these will need to be tailored as appropriate.
  - Questions and wording should be adapted according to the circumstances of the focus group.
  - It does not include comprehensive follow-up questions because these will be specific to the group, but it is expected that answers are fully explored using prompts and probes throughout.
  - The structure is flexible and moderators should adapt to meet the needs of the group and the flow of discussions on the day.

## Introduction

**10 mins**

- Introduce self and NCB, study funded by Office of the Children's Commissioner for England
- Introduce study:
  - Looking at how children and young people are being involved in making big decisions about health – ie decisions about how services are planned and organised, how they're delivered, how they might need to change, etc. – rather than decisions about children and young peoples' own health ....
  - Gathering information to help people who work in the health service and Government to involve children and young people more and in better ways
  - Involves gathering examples to show what's happened in the past, looking over local health plans to see what people are doing now, and talking to them to find out what they think and how they want to be involved in making decisions about health
  - Briefly explain that the NHS is changing
- Taking notes and recording – check OK, and reassure re: confidentiality, anonymity
- How we'll report findings
- Reminder of focus group length – (up to 2 hours, with a break) – check OK
- Any questions/concerns?

## >> Warm up

Resources: typed stickers with professions

The aim of the game is to get the group talking to one another. Each person will have a sticker on their backs with a medical profession. Explain that each person has been given a job at the NHS and they have to find the person with the same job as them. To do this, they have to ask each other questions (eg 'do I carry out operations?'), but these questions can only be answered 'yes' or 'no' or 'maybe'. The group has 4 minutes to find their colleagues!

1. School councillor
2. Paramedic
3. Radiologist (someone who carries out x-rays)
4. Dietician (who recommends what food to eat)

Develop '**Group Agreement**' (respect confidentiality, etc., emphasise that we want to know about experiences of health decision-making rather than disclosing personal experiences/conditions)

Name and age

Where they live

What they think of health services in their area in one word

Previous involvement in health consultations/decision-making about services

**Experiences to date – how have they been involved in health decision-making**

**20 mins**

Remind them that the main focus is strategic health decision-making ie decisions about how services are planned and organised, how they're delivered, how they might need to change etc.

What, Why, Who (incl. target groups), When, Where, How

What happened next (what changed, what, if any, feedback)?

Discuss:

- any common experiences
- any differences
- what they learned
- what others learned (who and how)
- thoughts/feelings at the time and afterwards

If some have not/no one has been involved in health consultations ...

Discuss:

- most recent experiences of health services (not asking them to discuss personal/sensitive issues)
- whether they would like to have had a say
- what they would have said
- why, who to, when, where, how

### Ideal health consultation – how would they like to be involved in STRATEGIC health decision-making

**20 mins**

NB: Explain – what the health service wants to look like in the future, involves making big decisions about how services are planned and organised, how they are delivered, how they might need to change, etc. to make things better for patients and the public.

Notes on flipchart, ask them to vote with stickers to identify one issue (ie the ‘what’) and work through the why, who, etc. as a group. If time, move onto the next most common answer and repeat and so on.

What, Why, Who (incl. target groups), When, Where, How:

- Appropriateness for different ages

What they would like to happen next:

- What changes they would like to see as result of taking part
- What difference involving children and young people would they make ‘in an ideal world’
- How they would like to get feedback
- The best ways of keeping children and young people engaged
- Any challenges/problems with their ideal

>> 10 min BREAK

### Children and young people’s rights

**10 mins**

NHS Constitution – the right to be involved in planning healthcare services, any changes in the way services are provided, and in decisions affecting how services operate.

NHS pledges to provide patients and the public with the information they need to influence and scrutinise the planning and delivery of NHS services.

NB: Introduce and ask young people to stand on a line on an awareness scale and explain their position.

Awareness of and feelings about right to have a say (children and young people have a right to have their views heard and taken seriously (Article 12))

Awareness of, and feelings about, right to health (being healthy, access to health services, right to have a say about health services, etc.)

Explore whether they think their views are being heard

Explore whether this is the same for all children and young people

How best to increase children and young people's awareness of rights

## Views on practice examples

**20 mins**

**5 min feedback**

> > Split into two groups

### **a) Strategic examples**

Present two examples

Explore views on:

- consultation topic
- focus
- methods
- any rewards
- what known about outcomes

Discuss:

- appropriateness (incl. for different ages)
- usefulness
- if they were to do the same thing, how might they do it differently and why

### **b) More typical examples**

Present two examples

Explore views on:

- consultation topic
- focus
- methods

- any rewards
- what known about outcomes

Discuss:

- appropriateness (incl. for different ages)
- usefulness
- if they were to do the same thing, how might they do it differently and why

Feedback to whole group and discuss:

- what they think about examples and why
- how this compare with the OCC's involvement categories (inform, consult, involve)
- meaningfulness

## Recommendations

### **15 mins**

Recap – thinking about how they have been involved in health decision-making AND how they say they would like to be involved in the future ...

What would they like to say to the following groups?

- Local health services eg GP, etc.
- Local councils
- Government
- OCC
- Other?

## Closing

### **5 mins**

Recap – thinking about how they have been involved in health decision-making AND how they say they would like to be involved in the future ...

Report

Any other thoughts, ideas, comments, questions

**THANK YOU**

## Appendix C: Children's voices in the health system – the policy framework

This appendix summarises the current policy framework relating to patient and public involvement in health decision-making, and the voice of children in the new health system. While the focus is on the involvement of the public and/or children in strategic health decision-making, the section touches upon involvement in decisions about individual care and experience of services.

### 1. UN Convention on the Rights of the Child

In 1991, the UK Government ratified the United Nations Convention on the Rights of the Child (UNCRC). Through ratification, the Government committed to promoting and protecting all the rights of the child outlined in the Convention. The UNCRC makes clear that all children have rights, and implies a duty on all adults to ensure they are implemented.

In particular, the UNCRC states:

- **Article 12:** children have the right to have a say in all decisions affecting them and their views should be given due weight according to their age and maturity.<sup>74</sup> The UN Committee on the Rights of the Child has been clear that Article 12 applies to collective decision-making processes, as well as matters affecting the individual child<sup>75</sup>.
- **Article 24:** children have the right to the best possible health. This includes an expectation that states take appropriate measures to ensure all children are provided with necessary medical assistance and health care, with an emphasis on the development of primary health care. The Committee is in the process of drafting a General Comment on this right, which will provide a conceptual framework and recommendations for concrete actions required by States Parties, and non-State actors, to fulfil their obligations.

### 2. The Health and Social Care Act

The Health and Social Care Act 2012 provides the legislative framework for a number of changes to the way health services are arranged in England:

It established GP-led **clinical commissioning groups** (CCGs) to carry out local commissioning of most NHS services, taking over this role from Primary Care Trusts (PCTs) which are to be abolished.

- It established the **NHS Commissioning Board** as a national body overseeing the NHS and commissioning NHS services that cannot be commissioned by clinical commissioning groups. Its role largely replaces that of Strategic Health Authorities, which are also to be abolished. It will authorise, allocate funding to, and performance manage clinical commissioning groups. It will also commission some services.
- It transfers from PCTs to **local authorities responsibility for public health**, promoting and protecting the health of people in their local areas.
- It requires every local authority to have a **Health and Wellbeing Board** (HWB) to bring together local partners to plan NHS, public health and social care services. health and wellbeing boards will carry out the Joint Strategic Needs Assessment (JSNA) and produce a Joint Health and Wellbeing

74 United Nations Convention on the Rights of the Child <http://www2.ohchr.org/english/law/crc.htm>

75 United Nations Committee on the Rights of the Child (2009). General comment no.12. The right of the child to be heard. p8.

Strategy (JHWS), to set out priorities to guide commissioning by the local authority, clinical commissioning groups and the NHS Commissioning Board.

- It requires every local authority to have a **local Healthwatch** to act as a consumer champion for health and social care (including children's social care) services users.
- local authorities are commissioning local Healthwatch to establish **Healthwatch England** (as a sub-committee of the Care Quality Commission) to support local Healthwatch, and gather and promote learning from the work of the local Healthwatch network.

The majority of these reforms will come into force in April 2013, although changes were introduced in shadow form during 2011 and 2012.

Further detail on these new organisations and their role in involving children, is provided throughout this appendix.

### 3. Overarching messages on the reform of the NHS

#### 3.1 Equity and excellence: Liberating the NHS (July 2010) and Liberating the NHS: legislative framework and next steps (December 2010)

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_117794.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf)

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_122707.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122707.pdf)

The *Equity and excellence* White Paper was the first policy document setting out the Government's ambitions for making significant reforms to the way in which NHS services are planned, commissioned and delivered. From the start, there was an emphasis on giving patients and the public a stronger voice when decisions are made, not only about their care, but about the delivery of health services more broadly (ie strategic health decision-making):

*"Shared decision-making will become the norm: no decision about me without me ... We will strengthen the collective voice of patients and the public through arrangements led by local authorities, and at national level, through a powerful new consumer champion, Healthwatch England, located in the Care Quality Commission"* (p. 3).

In addition, the White Paper placed an emphasis on ensuring that patients and the public had access to information about their own health and care, but also about the performance of providers and commissioners. Government hopes that this will enable the public to hold services and commissioners to account. Measures included the wider use and publication of Patient-Reported Outcome Measures, gathering patient experience data and feedback, and publishing information about services on a commissioner basis, so that the public know how they are performing and "so that they are held to account for their use of public money" (p.14).

In its response to the NHS White Paper consultation, Government announced that local Healthwatch pathfinders would be established to explore some of the issues raised by respondents to the consultation. Addressing whether local Healthwatch would play a role in dealing with NHS complaints, the response stated that Government would "provide flexibility concerning whom local authorities will commission NHS complaints advocacy services from – this could be either local Healthwatch, or other organisations with Healthwatch signposting these services to people" (p.27).

### 3.2 NHS Future Forum report on proposed changes to the NHS and Government's response (June 2011)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_127443](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127443)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_127444](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127444)

During the passage of the Health and Social Care Act, in response to widespread criticism of the proposed measures, Government 'paused' proceedings and established a group of independent experts and patient representatives (the NHS Future Forum) to carry out a 'listening exercise' – inviting the views of patients and other stakeholders – and to report back to Government. The listening exercise ran from April to June 2011. The Forum reported that one of the three key priorities relating to patient and public engagement was that people wanted to see “the voice of patients and the public hard wired into every level of the health system, **including the voices of children**, vulnerable adults, carers and those who are often excluded” (own emphasis, p.26). The Forum made no specific recommendations in relation to children's involvement in decision-making, although relevant recommendations included:

- that the definition of 'patient involvement' in relation to the duty 'to involve' and duty 'to promote patient involvement' be made stronger and clearer in the Bill
- that there be independent representation on clinical commissioning group governing bodies, with specific responsibility for ensuring that their 'duty to involve' is effectively fulfilled

The Government's response to the Forum detailed a set of proposed amendments it would make to the Bill to address the Forum's recommendations. It does not explicitly respond to the Forum's message regarding the voices of children being 'hard-wired into every level of the health system'. However, key actions relating to patient involvement included:

- requiring the Care Quality Commission to respond to advice from its Healthwatch England subcommittee
- requiring the Secretary of State to consult Healthwatch England on the mandate to the NHS Commissioning Board
- requiring that local Healthwatch engages those who are representative of different service users, including carers
- ensuring that the NHS Commissioning Board has a national director-level role with responsibility for patient and public engagement
- giving health and wellbeing boards a duty to involve users and the public
- requiring clinical commissioning groups to set out in their annual commissioning plans as to how they intend to involve patients and the public in their commissioning decisions, and requiring them to consult on these plans
- that the NHS Commissioning Board will assess how effectively clinical commissioning groups have discharged their duty to involve patients and the public as part of their annual assessment
- requiring commissioners and providers to have due regard to findings from local Healthwatch organisations

## 4. The impact of the reforms for children

### 4.1 Achieving equity and excellence for children: how liberating the NHS will help us meet the needs of children and young people (September 2010)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_119449](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449)

*Following concerns from the children's sector that the NHS White Paper did not sufficiently address the implications of the proposed reforms for children, including how patient and public engagement would work for children, the Government published Achieving equity and excellence for children. Much of the document revisited proposals set out in the NHS White Paper, highlighting how these measures will have a positive impact on the health of children. However, it stated explicitly that local Healthwatch will be expected to promote the voices of children and families to inform health commissioning, and ensure shared decision-making about their care.*

### 4.2 Report of the children and young people's health outcomes forum (July 2012), Improving Children and Young People's Health Outcomes: a system-wide response (February 2013), and Better health outcomes for children and young people: our pledge (February 2013)

<http://healthandcare.dh.gov.uk/forum-recommendations/>

<http://www.dh.gov.uk/health/2013/02/national-pledge-cyp/>

In January 2012, responding to continuing concerns that the Health and Social Care Bill would not necessarily deliver improvements in children's health services, the then Secretary of State for Health appointed a Children and Young People's Health Outcomes Forum to help develop a new strategy for improving care for children. Made up of experts from the voluntary sector, NHS and local government, the Forum developed around 170 recommendations for how children could be better reflected in the NHS and Public Health Outcomes Frameworks (see below), as well as what the reformed health system would need to do better to achieve these outcomes.

The Forum's key recommendations relating to children's involvement in strategic health decision-making included:

- All health organisations should demonstrate how they have listened to the voice of children, and how this will improve their health outcomes.
- Healthwatch England gives appropriate consideration to the importance of the voice of all children in informing its work programme, and is able to demonstrate this through its annual report.
- Local Healthwatch ensures that children's voices are core to their work and demonstrates this through their reporting mechanisms.
- The revised NHS Constitution is drafted in such a way as to be applicable to all children, and their families.
- Department of Health should bring together all relevant partners to co-produce a children's health charter based on the principles of the UNCRC Article 12 Principles, and align these with the NHS Constitution. The application of these principles should be audited through the regulators.
- By 2013–14, the Department of Health and the NHS Commissioning Board will incorporate the views of children into existing national patient surveys in all care settings – primary care, community health care, acute/in-patients, neonatal units and outpatients.

In February 2013, the Government published a sector-wide response to the Forum's recommendations, in partnership with a range of national bodies responsible for overseeing the health system, including Public Health England, the Care Quality Commission, and the Royal College of General Practitioners. Alongside this, Department of Health signed a pledge to secure better health outcomes for children, and has encouraged other parts of the health system to do so. Specific actions to promote the involvement of children in strategic health decision-making include:

- (one of the five ambitions in the pledge states:) "Children, young people and their families will be at the heart of the decision-making, with the health outcomes that matter most to them taking priority"
- a commitment that Department of Health will continue to promote the *You're Welcome* quality framework with all partners, as they develop their commissioning and delivery plans
- Healthwatch England carrying out targeted engagement with organisations representing children, and appointing an advocate for children to its Board
- CQC involving children in its inspection activity, and developing child friendly information about its work and what to expect from NHS providers
- an expectation that Directors of Children's Services and lead members have key responsibility for listening and responding to the views of children about health services

In addition, the Chief Medical Officer will lead a Children and Young People's Health Board, bringing together child health leaders across the system to drive forward improvements, and a new Children and Young People's Health Outcomes Forum will provide challenge to the system, including through an annual child health summit to monitor progress.

## 5. The NHS

The Health and Social Care Act 2012 requires the NHS Commissioning Board and clinical commissioning groups to involve patients and the public in planning and making changes to the health services they commission. Clinical commissioning groups must set out their approach to doing this in their Constitution, and have regard to guidance published by the NHS Commissioning Board – who will consider the fulfilment of these duties as part of their annual assessment of clinical commissioning groups.

Clinical commissioning groups must also:

- consult people they commission services for on the development of their annual commissioning plan
- have a lay member of their governing body appointed to champion patient interests
- hold their board meetings in public
- Also under the 2012 Act, Monitor (the economic regulator of health and social care) must carry out appropriate public and patient involvement in the exercise of its functions.

## 5.1 The NHS Constitution: the NHS belongs to us all (March 2012) and consultation on strengthening the NHS Constitution (November 2012 to January 2013)

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>

<http://www.dh.gov.uk/health/2012/11/constitution-consultation/>

The NHS Constitution (which has statutory status under the Health Act 2009) sets out: the principles and values of the NHS in England; the rights and responsibilities of patients, the public and staff; and pledges which the NHS is committed to achieve. Here we set out aspects of the Constitution relevant to young patient and public involvement in strategic decision-making.

One of the seven principles that must guide the NHS is: NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment (principle 4).

The Constitution confers upon patients and the public the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services. In it, the NHS also pledges: to provide patients and the public with the information they need to influence and scrutinise the planning and delivery of NHS services; and to work in partnership with patients, their family, carers and representatives. The Constitution places a number of duties and expectations on NHS staff, including:

- the expectation that staff play their part in sustainably improving services by working in partnership with patients, the public and communities
- the expectation that staff view the services they provide from the standpoint of a patient, and involve patients, their families and carers in the services they provide

At the end of January 2013, Department of Health completed a consultation on possible changes to the Constitution, including proposals that aim to make it clearer that patients, their families and carers should be fully involved in all discussions and decisions about their care and treatment.

## 5.2 The NHS Mandate (November 2012), Outcomes Framework (December 2011) and Operating Framework (November 2011)

<https://www.wp.dh.gov.uk/publications/files/2012/11/mandate.pdf>

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_131723.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131723.pdf)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_131360](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131360)

The **Secretary of State's Mandate to the NHS Commissioning Board**, provided for in the Health and Social Care Act 2012, aims to set out the Government's ambitions for the health service, shaping the way the Commissioning Board takes forward its role overseeing clinical commissioning groups and commissioning specialist services. It stresses that:

*"Where local clinicians are proposing significant change to services, we want to see better informed local decision-making about services, in which the public are fully consulted and involved."*

It also states that Government will:

*"... work with the NHS Commissioning Board, and Healthwatch England, to consider how best to ensure that the views of children, especially those with specific healthcare needs, are listened to."*

The Mandate also contains objectives for the NHS Commissioning board to:

- ensure changes to services meet four tests, including strong patient and public involvement
- make improvements in involving patients and their carers in managing their conditions, and making decisions about their treatment
- make progress in measuring how people feel about their care
- uphold the rights and commitments in the NHS Constitution

**The NHS Outcomes Framework 2012/13** aims to: provide a national level overview of how well the NHS is performing; provide an accountability mechanism between the Secretary of State for Health and the NHS Commissioning Board; and act as a catalyst for driving quality improvement and outcome measurement throughout the NHS, including a stronger focus on tackling health inequalities. While measures in the framework focus on the outcomes resulting from services – taken together the measures should provide information for health service leaders and commissioners to inform their strategic decisions. One of the five domains of the framework is ‘ensuring that people have a positive experience of care’. While the majority of measures under this domain relate to adults or persons aged 16+, there is a ‘placeholder’ for improving children’s experience of healthcare, with work underway to develop a measure from the Children’s Patient Experience Questionnaire. This should enable national and local commissioners to get a broad picture of the overall experiences of children of the health services they use, which could, in turn, inform strategic decision-making.

The **NHS Operating Framework 2012/13**, which sets out the business and planning arrangements for the NHS in England, highlights the importance of patients having a central role in NHS decision-making, with an emphasis on the NHS using data on patients’ experiences of care, to inform service development. Under domain 4 – ensuring that people have a positive experience of care – it states “NHS organisations must actively seek out, respond positively and improve services in line with patient feedback. This includes acting on complaints, patient comments, local and national surveys and results from ‘real time’ data techniques” (p.17-18). It adds that national patient experience surveys should be monitored and used, although it should be noted that these are surveys that notably often exclude under 16 year-olds. Patient experience of hospital care is included as a national performance measure under domain 4.

The National Standard Contract – used by commissioners when commissioning NHS-funded acute, ambulance, community and mental health, and learning disability services – will include the expectation that service providers carry out more frequent local patient surveys, publish the results – including data on complaints – and respond appropriately where improvements need to be made. On a more strategic level, the Framework states that: “where cost improvement programmes are required, these must be agreed by Medical Directors and Directors of Nursing, **involve patients in their design** and include in-built assurance of patient safety and quality” (p.9, own emphasis).

A key message in the NHS Operating Framework is the need for NHS organisations to continue to progress in achieving against the QIPP challenge – quality, innovation, productivity and prevention. Prevention includes patient involvement.

### 5.3 The NHS Commissioning Board business plan October 2012 to March 2013 (October 2012)

<http://www.commissioningboard.nhs.uk/publications/>

The NHS Commissioning Board business plan for October 2012 to March 2013 makes reference to a commitment to transparency and the engagement of the public in decision-making, including:

- one of the Board's success factors is that by April 2013 it "can demonstrate that patients, the public and their representatives have participated in, and the NHS CB has responded to, their views on, the establishment of the NHS CB" (p.18)
- the Board will carry out its activities through a number of 'lenses': quality; clinical leadership; **patient and public voice; equality and health inequalities**; and innovation and change model
- one of its key values is "a commitment to putting patients, clinicians and carers at the heart of decision-making" (p.20)

The Board has a National Director for Patients and Information.

### 5.4 Clinical commissioning groups: authorisation and the Clinical Commissioning Group Outcomes Indicator Set (2012)

<http://www.commissioningboard.nhs.uk/resources/resources-for-ccgs/auth/>

<http://www.nice.org.uk/aboutnice/cof/cof.jsp>

Guidance published by the NHS Commissioning Board sets out the criteria, thresholds and evidence it will use to determine whether a clinical commissioning group can be 'authorised' and thus formally established. The criteria are set out under six domains. As well as criteria and thresholds, each domain includes a vision for how clinical commissioning groups can develop and innovate in that area over the longer-term, beyond authorisation.

Domain 2 is 'Meaningful engagement with patients, carers and their communities'. Under this domain, clinical commissioning groups are expected to:

- demonstrate how they will ensure the inclusion of patients, carers, public and communities of interest and geography
- have mechanisms for gaining a broad range of views, and analysing and acting on those views
- demonstrate how the views of individual patients are translated into commissioning decisions, and how the voice of each practice population will be sought and acted on
- promote shared decision-making with patients, about their care

The criteria and thresholds for authorisation include:

- **Criteria: ensure inclusion of patients, carers, public, communities of interest and geography, health and wellbeing boards, local authorities and other stakeholders:**
  - threshold for authorisation: constituent communities and groups within the population served by the clinical commissioning group identified
  - evidence needed to meet threshold: the clinical commissioning group has mapped and analysed constituent communities and groups; analysis of the health needs of constituent communities and groups is reflected in clinical commissioning group integrated plan; the clinical

commissioning group has outline plans in place to communicate and engage with strategic partners and diverse groups and communities

- **Criteria: analysing and acting on information from engagement to translate into priorities for improvement:**
  - threshold for authorisation: plans, processes and resources are in place to measure and use insight from patients, carers, partners and stakeholders to improve services
  - evidence needed to meet threshold: arrangements are in place to ensure appropriate on-going patient and public involvement in clinical commissioning group decision-making; systems and processes for monitoring and acting on patient feedback
- **Criteria: voice of each practice population to be sought and acted on:**
  - threshold for authorisation: arrangements in place for patient views to be sought at practice level to inform and receive feedback on clinical commissioning group priority setting
  - evidence needed to meet threshold: accountability between clinical commissioning group and member practices is reflected in its constitution and in any broader governance arrangements; examples of clinical commissioning group engaging different groups and communities through a range of communications channels in the development of its vision, plan, or in broader clinical commissioning group decision-making processes
- **Criteria: Views of individual patients are reflected in shared decision-making and translated into commissioning decisions:**
  - threshold for authorisation 1: arrangements in place to promote the involvement of patients and carers in decisions about their own care and treatment, including exercising choice
  - evidence needed to meet threshold: clinical commissioning group understands its statutory duties in relation to enabling patients to make choices and to promote the involvement of patients, carers and relatives in decisions about their care and treatment; systems in place to convert insights about patient choice/s in practice consultations into plans and decision-making
  - threshold for authorisation 2: plans in place to manage and respond to concerns raised about its own operations or the services it commissions, to monitor patient/public perceptions of its responsiveness as a NHS organisation, and to learn from concerns raised to improve its performance
  - evidence needed to meet threshold: arrangements for handling complaints raised with the clinical commissioning group are compliant with the statutory framework for complaints handling; arrangements for handling concerns raised with the clinical commissioning group deliver equivalent outcomes; arrangements for handling concerns and complaints raised with the clinical commissioning group, and actions taken as a result, are clearly communicated to the public; clear line of accountability for patient safety including regular reporting to the National Reporting and Learning System

The NHS Commissioning Board and the National Institute for Health and Clinical Excellence (NICE) are developing a **Clinical Commissioning Group Outcome Indicator Set (CCG OIS)** (formerly known as the 'Commissioning Outcomes Framework' or 'COF') to measure the health outcomes and quality of care achieved by services commissioned by clinical commissioning groups. This includes some patient reported outcome measures and measures of patients' experiences of care. The NHS Commissioning Board and NICE expect commissioning groups to use the CCG OIS to monitor their performance and identify priorities for improvement. The indicators mainly draw upon those in the NHS

Outcomes Framework, and therefore focus on the experiences of care among over-16s or over-18s. However, in an earlier consultation on the COF in February 2012, NICE sets out indicators which have been identified for potential inclusion in the COF, pending development, including children's experiences of care<sup>76</sup>.

## 5.5 No health without mental health: a cross-government mental health outcomes strategy for people of all ages (February 2011)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_123766](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766)

This mental health strategy sets out shared objectives for improving mental health, and is explicitly a strategy for people of all ages. Under the objective that service users have a positive experience of care and support, there is an aspiration that, wherever possible, services should listen to and involve carers and others. The strategy explores the wider role of society in promoting good mental health and mental health services, and includes an ambition that people get more directly involved in local decision-making (p.30). The role of Healthwatch is highlighted, including how local Healthwatch will provide a voice for patients, service users and carers throughout the commissioning cycle. It states that Healthwatch England "will help to ensure that the voices of people with mental health problems, including children and their families – who can often be marginalised – are central to the assessment of quality in specialist mental health services and in health services more generally" (p.53). It points out that tailored, age- and developmentally-appropriate methods are needed to communicate with children, so that they can understand their mental health problems and the choices they have about their treatment and care.

## 5.6 Positive for Youth: A new approach to cross-government policy for young people aged 13 to 19 (February 2012)

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-00133-2011>

Following a period of engagement, the Department for Education published this policy statement bringing together Government's policies for young people aged 13 to 19. It emphasises Government's expectation that young people are given a voice in decision-making about local services – including health. It states: "The Positive for Youth consultation confirmed that young people want a say in their health services", and confirms that local Healthwatch and Healthwatch England will be one means of giving voice to young people, including those who are ill or disabled. It makes clear that Healthwatch will draw on existing mechanisms for engaging young people (p.45). There is also explicit mention of the role of local health commissioners in involving young people (p.16), and of young people having a role to play at each stage of commissioning, and the need to engage diverse groups of young people and those who might not be heard (p.65). It states:

*"The Government urges every local area to establish and maintain arrangements for ensuring that the voice of young people is heard in local decision-making and that young people have a role in inspecting and reporting on the quality of service delivery" (p66).*

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76 NICE (2012) *Consultation on potential COF indicators* <http://www.nice.org.uk/media/076/44/NICECOFIndicatorConsultationDocument.pdf>

## 6. Public Health

### 6.1 Healthy lives, healthy people: our strategy for public health in England (November 2010) and Healthy lives, healthy people: update and way forward (July 2011)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_121941](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121941)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_128120](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128120)

The *Healthy lives, healthy people* White Paper set out reforms to the way responsibility for improving health is taken forward nationally and locally. It details plans for: the establishment of Public Health England; transferring responsibility for improving public health from PCTs to local authorities (taken forward in the Health and Social Care Act 2012); the Government's approach to intervention to promote healthy choices; and the expected contribution of business, individuals and government policy to the improvement of public health and the reduction of health inequalities. The document also sets out how public health is to be included in the remit of health and wellbeing boards and the joint strategic needs assessment and joint health and wellbeing strategy (see below), and expectations for its integration with NHS and social care services. While children's decision-making is mentioned, there is little detail on how they will be supported from a young age to be involved in decisions about their health or local health services.

The 2011 paper sets out an update on plans for the implementation of moves of public health duties to local government, the new Public Health England and new NHS bodies. It reasserted a commitment made in the Government response to the Future Forum report to give health and wellbeing boards a strong role in leading on local public involvement (see below). It set out more detail of the role of Public Health England which is said to include developing and implementing "innovative approaches to empower individuals and communities to improve health and wellbeing working with partners throughout the public sector and in civil society" (p.18).

### 6.2 The Public Health Outcomes Framework 2013-16 (January 2012)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_132358](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358)

The Public Health Outcomes Framework is one of the ways in which central government sets the direction for the new public health system. Like the NHS Outcomes Framework, it consists of indicator measures that are intended to show the extent of progress being made in improving health and reducing inequalities. Local authorities will be under a duty to have regard to it in carrying out their new public health responsibilities, and Government is developing ways to provide incentive payments to local authorities for measured improvements in certain areas (a 'health premium'). The framework consists of two overarching outcomes – increasing healthy life expectancy and reducing differences in life expectancy – and a wider range of indicators grouped under four domains: improving the wider determinants of health (such as child poverty and fuel poverty); health improvement (such as prevalence of health behaviours); health protection (ie reducing the spread of disease); and healthcare public health and preventing premature mortality. There are a number of indicators that measure outcomes specifically for children, or for children of particular ages. However, some indicators for the wider population do not record outcomes for children, including a measure of 'self-reported wellbeing'. There are no measures relating to the public's views about local public health services.

### 6.3 Public Health England's Operating Model (December 2011)

<http://healthandcare.dh.gov.uk/public-health-system/>

This collection of factsheets, published at the same time as those on *Public Health in Local Government*, gives an update on the proposed detailed design of Public Health England. This includes information on its mission and values, functions, organisational design and status. It says that Public Health England will “ensure interventions and services are designed and implemented in ways that meet the needs of different groups in society”, and will “support local authorities in their new role by providing services, expertise, information and advice in a way that is responsive to local needs” (Factsheet: Mission and values, p.1-2).

### 6.4 The local authority's role in public health: Public Health in Local Government (December 2011)

<http://healthandcare.dh.gov.uk/public-health-system/>

This collection of factsheets was published by the Department of Health to provide a further update on the development of plans for local government's enhanced role in public health as set out in the *Healthy Lives, Healthy People* documents. This includes a vision of how local authorities will be able to lead on public health, as well as updates on the intended role of the Director of Public Health and commissioning responsibilities. When discussing the rationale for the transfer of responsibilities to local government, it gives the most explicit indication yet that the public should be involved in strategic decisions around health improvement:

“[Local authorities] have considerable expertise in building and sustaining strong relationships with local citizens and service users through community and public involvement arrangements, which will help extend the engagement of local people in the broader health improvement agenda” (Factsheet: Local government leading for public health, p.1).

It suggests that the Director of Public Health will “engage with wider civil society to enlist them in fostering health and wellbeing” (Factsheet: The role of the Director of Public Health, p.3).

In carrying out its in commissioning public health services, a local authority is subject to a general duty to involve representatives of the local community and subject to statutory guidance, which states:

“Authorities must consult representatives of council tax payers, those who use or are likely to use services provided by the authority, and those appearing to the authority to have an interest in any area within which the authority carries out functions ... This should apply at all stages of the commissioning cycle, including when considering the decommissioning of services.”<sup>77</sup>

More detailed guidance on the ‘duty to involve’ was revoked in 2011.

### 6.5 Healthy Lives, Healthy People: Towards a workforce strategy for the public health system (March 2012)

[http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_133219](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_133219)

This consultation on the development of a workforce strategy for the public health system discusses the roles of Directors of Public Health and public health experts and consultants, and touches on the roles of the wider (non-clinical) workforce that supports health. It sets out proposed values of

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<sup>77</sup> Department for Communities and Local Government (2011) *Best Value Statutory Guidance*, p.1. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/5906/1976926.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/5906/1976926.pdf)

the public health workforce which includes “autonomy – respecting the individual’s right to make their own choices” (p.19) alongside beneficence, non-maleficence and justice. Involvement of the wider public is discussed in terms of enabling communities to contribute directly to improved health, and developing personal responsibility for wellbeing, rather than influencing the commissioning of services, with a proposal that “directors of public health, working across local government, should work with clinical commissioning groups to enable local people to develop their own community assets and source local solutions to their needs” (p.27).

## 7. Health and Wellbeing Boards

From April 2013, each local authority must have a health and wellbeing board (HWB), responsible for:

- assessing local health and wellbeing needs through the joint strategic needs assessment (JSNA)
- developing a plan for meeting those needs through a joint health and wellbeing strategy (JHWS)
- bringing together planning for NHS, public health, social care and other services

Statutory membership includes, among others: representatives of local clinical commissioning groups, Directors of Public Health, Children’s Services and Adult Services, local Healthwatch, and a local councillor. health and wellbeing boards are under a duty to involve the people who live and work in the local area (as well as the local Healthwatch) in preparing the joint health and wellbeing strategy. Many local areas set up a shadow health and wellbeing board before April 2013, as part of an early implementer programme, and in order to initiate activity on the joint strategic needs assessment and joint health and wellbeing strategy.

### 7.1 Operating principles for health and wellbeing boards (October 2011)

<http://www.nhsconfed.org/Publications/reports/Pages/Operating-principles.aspx>

This document, developed by the NHS Confederation and endorsed by the Department of Health, outlines four broad principles for effective partnerships across local government and the NHS. It stresses the importance of leaders taking collective responsibility for engaging a range of stakeholders, including communities, and working in partnership with Healthwatch to engage patients, services users and the community. Suggested prompts for assessing progress include specific reference to involving children in the planning and delivery of services.

### 7.2 Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies – draft statutory guidance (July 2012)

<http://www.dh.gov.uk/health/2012/07/consultation-jsna/>

The Department of Health has published draft statutory guidance for health and wellbeing boards on carrying out the joint strategic needs assessment and joint health and wellbeing strategy. It summarises all the relevant duties regarding these processes and sets out the expected approach to timing, the range of evidence used, their role in setting priorities and in promoting integration, as well as giving guidance on engaging organisations beyond the mandatory members of the health and wellbeing board. It states that:

“Health and wellbeing boards must involve the local Healthwatch organisation and the local community, and this should be continuous throughout the joint strategic needs assessment and joint health and wellbeing strategy process. When involving the local community, health and wellbeing boards **should consider inclusive ways to involve people from different parts of the community** to ensure that differing health and social care needs are reflected and can be

addressed by commissioners, recognising the need to engage with parts of the community that are socially excluded and vulnerable” (p.7, own emphasis).

It makes clear that the duty to involve the local population in the development of the joint health and wellbeing strategy extends to adults and children, and includes youth services, troubled families co-ordinators and schools, as partners that should be engaged to get a thorough understanding of local needs and how to address them. It highlights the role of local Healthwatch and the voluntary and community sector in providing information about the needs and views of people in vulnerable circumstances. When publishing the joint health and wellbeing strategy, the health and wellbeing board should provide a summary of community views and how they have been considered.

The brief statutory guidance will be accompanied by a range of other support materials, yet to be developed or published.

## 8. Healthwatch England and local Healthwatch

The Health and Social Care Act requires every local authority to have a **local Healthwatch organisation** from April 2013. Replacing Local Involvement Networks (LINks), local Healthwatch will:

- promote and support the involvement of people in the commissioning, provision and scrutiny of local care (health and social care) services, including health and social care for children
- enable people to monitor and review the standard of local care services and how they could and should be improved
- obtain the views of people about their needs for, and their experiences of, local care services
- make the views of patients, and reports and recommendations on how care services could be improved, available to providers, commissioners and overview and scrutiny committees (which will be under a duty to have regard to those views, reports and recommendations)
- provide information and advice about local care services and about choice [taking on the role of Patient Advice and Liaison Services (PALs) in PCTs which are abolished, although PALs in NHS Trusts are expected to stay]
- report local views to Healthwatch England, and advise Healthwatch England and CQC on what reviews and investigations it should carry out
- sit as statutory member of the local Health and Well-being Board, and therefore be involved in carrying out the local joint strategic needs assessment and preparing the joint health and wellbeing strategy

The legislation does not include explicit measures about the role of Healthwatch in involving children. It does include the provision, however, that Healthwatch must carry out its functions for people who are representative of local residents and service users. During 2012, the Department funded a number of local authorities to act as local Healthwatch pathfinders.

The Health and Social Care Act also established **Healthwatch England**, as a subcommittee of the Care Quality Commission (the regulator of health and adult social care services). Launched in October 2012, Healthwatch England will:

- provide leadership and support to local Healthwatch

- advise the Secretary of State for Health, the NHS Commissioning Board, English local authorities and Monitor, as well as the CQC, about concerns raised by local Healthwatch (with a duty on those bodies to respond)
- request that the CQC carries out an investigation if it has evidence of poorly performing services

CQC will be under a duty to respond to advice and requests from Healthwatch England.

### 8.1 Local Healthwatch: Local Healthwatch: a strong voice for people – the policy explained (March 2012); Local Healthwatch Regulations (December 2012); Establishing Local Healthwatch: engaging with children and young people (2012)

<http://healthandcare.dh.gov.uk/healthwatch-policy/>

<http://www.legislation.gov.uk/ukxi/2012/3094/contents/made>

[http://www.local.gov.uk/web/guest/publications/-/journal\\_content/56/10171/3776832/PUBLICATION-TEMPLATE](http://www.local.gov.uk/web/guest/publications/-/journal_content/56/10171/3776832/PUBLICATION-TEMPLATE)

**Local Healthwatch: a strong voice for people** sets out the Government's vision for local Healthwatch, its functions, responsibilities, roles and relationships in the post-NHS reform landscape. It highlights some of the flaws of past and existing systems of patient and public involvement, including that LINks "struggled to involve a wide range of people of all ages and different sections of the community" (p.6). It suggests that the new policy will help to give local people a stronger voice to influence national health and social care bodies, such as the Care Quality Commission and the NHS Commissioning Board, and will create public involvement mechanisms that are more inclusive and representative.

**Regulations** laid before Parliament in December 2012 make clear that local Healthwatch should gather the views of service users about children's social care (previously excluded from the role of LINks). While local Healthwatch will not have the power to enter and view children's social care services (as they will be able to do for all health and adult social care services), child social care providers will be required to respond to reports and recommendations from local Healthwatch. Department of Health's report<sup>78</sup> following consultation on the regulations, states that:

"It is important for children and young people's voice to be heard by commissioners and providers of health and social care ... It is vital that Healthwatch works collaboratively, with existing representatives, groups and organisations, in the statutory and voluntary sectors, that are data-rich because they already gather such information from children and young people; this will help to inform the collective local intelligence Healthwatch will present through their seat on the statutory health and wellbeing board" (p11-12).

The Local Government Association has played a lead role in supporting the implementation of local Healthwatch and has developed a 'quality framework' for local Healthwatch, including the briefing: **Establishing Local Healthwatch: engaging with children and young people**. Key messages in the briefing include:

- Local Healthwatch needs to develop strategies for effectively involving children, particularly those who are most disadvantaged.

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78 Department of Health (2012) *Summary Report: Issues relating to local Healthwatch regulations* <http://www.dh.gov.uk/health/2012/07/healthwatch-engagement/>

- Children should be well represented in local Healthwatch membership, and be involved in the development of local Healthwatch priorities, and work plan to ensure the agenda is not dominated by adult issues.
- All local Healthwatch spokespeople, including the representative sitting on the local Health and Wellbeing Board (HWB), should be sufficiently knowledgeable to speak on children's behalf.
- Local Healthwatch organisations need to have access to the capacity and skills to work with children, drawing on good practice from current Local Involvement Networks (LINks) and other voluntary sector organisations.
- Local Healthwatch should work collaboratively with existing groups and organisations that already gather information from children, to inform the local intelligence local Healthwatch presents to the health and wellbeing board.
- In engaging with children, local Healthwatch could consider the use of social media as well as (but not instead of) face-to-face activities, but should involve children in advising on ways of doing so.
- The local Healthwatch staff and volunteers must have a good understanding of local safeguarding arrangements for children in the area.

## 8.2 Healthwatch England narrative (January 2012)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_132416](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132416)

This document provides more detail than the Act on the proposed functions of Healthwatch England, stating that it will provide national leadership, guidance and support to local Healthwatch organisations, to help create greater consistency across local Healthwatch organisations, for example, through the sharing of best practice. It states that:

“In order to act as the national consumer champion, it is important that Healthwatch England has a membership [6-12 Committee members appointed by the Chair<sup>79</sup>] that is **representative of a range of interests including patients, service users, carers and the public**, and from a range of organisations including; local Healthwatch, voluntary and community-based groups, **including those organisations that work with hard-to-reach groups**” (p11, own emphasis).

## 9. Involving patients in decisions about their individual care

### 9.1 Liberating the NHS: Greater choice and control (2010) and The power of information: putting all of us in control of the health and care information we need (2012)

[http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_119651](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_119651)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_134181](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_134181)

Following the publication of its NHS White Paper, Department of Health published ***Liberating the NHS: Greater choice and control***, consulting on more detailed proposals to give patients more choice and control over their own healthcare. It sets out plans and ambitions to: offer people more choice of the hospital/clinic of consultant/lead team that is to provide care or diagnostic services for them; extend personalized care planning for people with long term conditions; offer people a choice

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<sup>79</sup> Department of Health (2012) *Healthwatch England Regulations: Department of Health Response to Consultation* <http://www.dh.gov.uk/health/2012/06/healthwatch/>

of appropriate treatments as a matter of course; and provide more information to support choice (see also the Department of Health's information strategy<sup>80</sup>).

It also sought views on how people can be more involved in decisions about their care, and stated that:

**“Children and young people, and adults who lack the capacity to make some decisions, should be involved in decisions and choices about their healthcare as much as possible**, even when they are unable to make decisions and choices by themselves. The level of involvement that they are able to have will depend on their individual circumstances and ability and how information is presented to them, and it may often be in partnership with their parents, family and other representatives as appropriate” (p.29, own emphasis).

Government issued two responses following this consultation, covering implementation of a patient's right to choose any qualified provider<sup>81</sup> and to choose a consultant-led team<sup>82</sup>.

This year, Department of Health published a further consultation – ***Liberating the NHS: No decision about me, without me*** – with proposals focusing on patients having a choice of provider, for example, in primary care, diagnostic testing, at and after referral. The document says little about what shared decision-making could or should look like for children, and even refers to “treating all patients and the public as **grown-ups** – by giving them more opportunities to be involved in decisions about their care and treatment” (p.8, own emphasis).

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80 Department of Health (2012) *The power of information: putting all of us in control of the health and care information we need*. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_134181](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_134181)

81 [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_128539.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128539.pdf)

82 [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_130448.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_130448.pdf)



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