

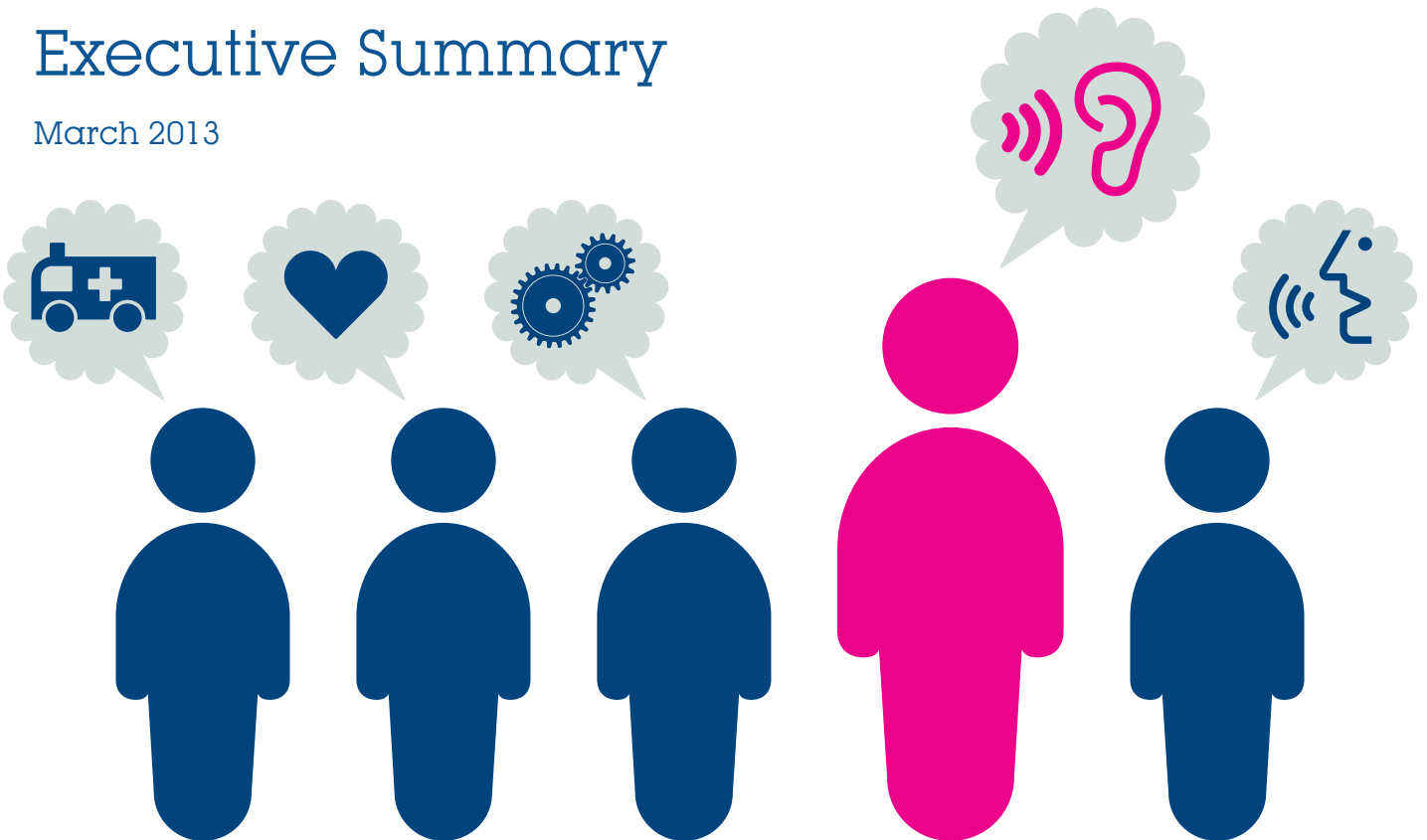
Office of the Children's Commissioner:

We would like to make a change

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

Executive Summary

March 2013



Authors:

Rachel Blades, Zoe Renton, Ivana La Valle
with **Keith Clements, Jennifer Gibb and Joanna Lea**
National Children's Bureau

www.childrenscommissioner.gov.uk



Table of Contents

Foreword by the Children's Commissioner	2
About the Office of the Children's Commissioner	4
Acknowledgements	5
Executive summary	6

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.



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's¹ 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**². These categories, taken from the OCC's Wheel of Participation (see page 12 in the full report), 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.

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 2007-12³
- 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 outcomes⁴ and response to the Children and Young People's Health Outcomes Forum⁵, 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 professionals⁶, 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

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.⁷

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 authorities⁸ 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.

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

⁸ 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.



Office of the Children's Commissioner

33 Greycoat Street
London
SW1P 2QF

Tel: 020 7783 8330

Email: info.request@childrenscommissioner.gsi.gov.uk

Website: www.childrenscommissioner.gov.uk