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Children and Young People's Views on the 'NHS: An Information Revolution' and Local HealthWatch



A summary of the event and key recommendations for government and health agencies



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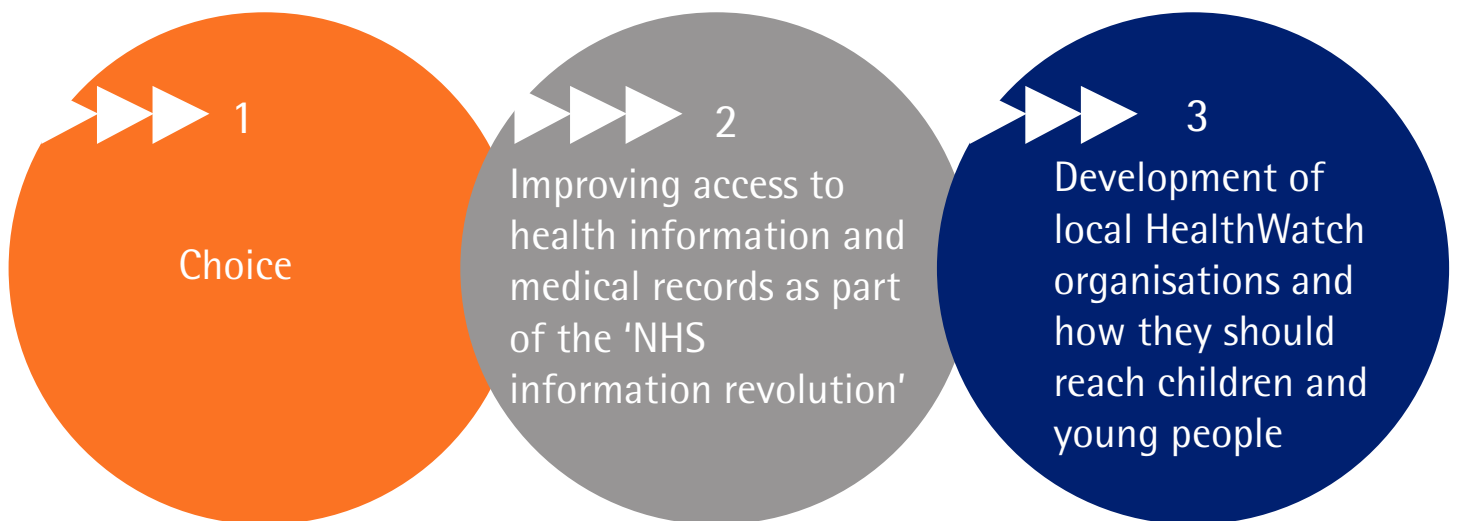
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Introduction ▶▶▶

On 28 October 2011 NCB organised a consultation event for children and young people. The aim of this was to formulate recommendations, informed by children and young people themselves, on three key aspects of current health reforms:



Views were sought on:

- ▶ How the children and young people would go about getting health information and advice.
- ▶ How health information could be made more accessible.
- ▶ How to ensure that HealthWatch can engage them.

21 children and young people, aged between 10 and 17, contributed their views through a range of activities.

This report summarises the findings of the event, making recommendations to government and health agencies for addressing these issues.

A photograph of several children sitting around a table, looking at a large sheet of paper with colorful diagrams. One child in the foreground is wearing glasses and a red shirt. The background shows other children and a classroom setting.

SUMMARY OF RECOMMENDATIONS

Implementation of policy promoting patient involvement and choice should take account of the fact that children and young people, including those under 18, will play a role in making their health decisions and have their own views about the quality of services.

NICE guidance and quality standards should reflect children and young people's views and ideas for improving services, improving patient information and promoting choice.

Government, local and national HealthWatch and the NHS should work with children and young people and organisations that work with them to ensure that development of health apps, online information and advice and other health resources as part of the information revolution is appropriate for and appealing to children and young people's needs including with regards to:

- ▶ Access to confidential advice
- ▶ Assurances of trustworthiness of the source of information
- ▶ Appropriate visual cues to help understanding
- ▶ Real-life examples
- ▶ Signposting to further information
- ▶ Avoiding or explaining any jargon
- ▶ Practical, introductory and frank information
- ▶ A choice of formats that ensures accessibility for all.

Active steps should be taken to involve children and young people in the development of health information resources at the national, sub-national and local level.

Improved management of information about an individual's care should not just focus on patient control of medical records but also include:



- ▶ More cohesive and consistent methods for medical professionals to share information about children and young people's individual health and treatment.
- ▶ Accessible follow-up information for children and young people to take away from consultations to help them understand any diagnosis, treatment or advice given. This should be based on what children and young people say would be useful.

Implementation of increased patient access to medical records should take account of children and young people's desire to be involved in decisions about their health as well as their concerns about data protection.

Government should work with local HealthWatch pathfinders to ensure that emerging local HealthWatch organisations are built around children and young people's needs. This could include:

- ▶ Advertising the HealthWatch to young people
- ▶ Regular communication via social media and schools
- ▶ A commitment to young people being listened to, respected and treated equally to adults
- ▶ Promoting an inclusive atmosphere
- ▶ Creating a code of conduct for all HealthWatch members to sign in order to ensure that everyone gets a fair and equal say.
- ▶ Meetings that are:
 - ▶ Scheduled to enable participation around school and other commitments,
 - ▶ Clear in their purpose
 - ▶ Accessible and welcoming with accessible formats for documentation
- ▶ Creative and social activities
- ▶ Regular discussion of issues relevant to young people

- ▶ Access to decision makers
- ▶ Feedback on impact

HealthWatch England should establish standards for engaging children and young people based on these ideas, existing good practice (www.participationworks.org.uk) and further consultation, and provide on-going support for local HealthWatch to develop and maintain their effective engagement of children and young people.

Children and young people making health choices ▶▶▶

In general the children and young people at the consultation thought that they should have a say in decisions about their health and be allowed to take a lead where they were capable.

They thought that the extent to which a young person would be able to make a decision would vary between individuals depending on age and maturity and the nature of the decision being made.

The children and young people valued the support and advice of their parents particularly for making big decisions about their health. Most were wary of the idea of making decisions without this support but felt that they should have the final say. They felt it was important for there to be the option of making a decision themselves or deferring to their parents/carers. There was agreement that parents/carers have their child's best interests at heart and some young people thought that parents' experience made them the best people to make important health decisions for the child. It was also stressed that the extent to which a child/young person made their own decisions would develop as they grew up and that they should not suddenly become responsible once they turned a certain age.

Children and young people have their own strong views about what they want

from health services. They said that good health services should:

- ▶ Offer a choice of appointment times and avoid clashing with school
- ▶ Have the right staff present and on time so that they can be seen quickly
- ▶ Treat people equally and with dignity and respect
- ▶ Have staff that are empathetic and friendly
- ▶ Offer entertainment in waiting rooms, such as magazines, books and (age appropriate) toys
- ▶ Offer a choice of doctor, particularly choice of gender
- ▶ Be clean and hygienic
- ▶ Offer good information about their condition, health concern, and/treatment, including information that can be taken away after the appointment
- ▶ Follow up on consultations with two-way communication via phone and email.

This picture of how children and young people are involved in health decisions and their views on services underlines the importance of building children and young people in to the development of policies about patient involvement and choice. The

RECOMMENDATION

Implementation of policy promoting patient involvement and choice should take account of the fact that children and young people under 18 want to play a role in making their health decisions and have their own views about the quality of services.

NICE guidance and quality standards should reflect children and young people's views and ideas for improving services, improving patient information and promoting choice.



'NHS information revolution' proposed by government and the development of local and national HealthWatch are key planks of this agenda and children and young people will need to be a priority.

An information revolution ▶▶▶

The White Paper *Equality and Excellence: Liberating the NHS*¹ sets out the government's intention to 'bring about an NHS information revolution'. This includes giving people access to comprehensive, trustworthy and easy to understand information from a range of sources on conditions, treatments, lifestyle choices and how to look after their own and their family's health as well as giving them control over their own health records.

This section reports on young people's views on accessing general health information and advice and on personalised information for understanding their own treatment and care, including access to medical records.

MAKING HEALTH INFORMATION ACCESSIBLE AND ENGAGING FOR CHILDREN AND YOUNG PEOPLE

Children and young people seek information from a range of sources, including traditional and social media and personal and public sources. When asked where young people with particular health issues would look for health information, for example, they listed:

- ▶ GP
- ▶ School nurse
- ▶ School counsellor and other health professionals

1. Department of Health (2010), *Equity and excellence: Liberating the NHS*, pp13-16

- ▶ Internet, young people’s websites and Google.

It was noteworthy how much young people valued face-to-face advice and guidance from someone they know, particularly a parent, over anything available on social media or the internet.

The children and young people were largely positive about the use of digital technology such as smartphone apps and Facebook but still thought that, as with other channels, its usefulness would depend on a number of factors. They thought that the following was important in accessing information and advice:

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| <p>▶ Access confidential advice</p> | <p>Children and young people want to preserve their privacy, for example, by being able to access online advice anonymously and talk to people who come to school to discuss health issues without their teacher in the room.</p> |
| <p>▶ Assurances of the trustworthiness of the source of information</p> | <p>Children and young people were reassured by the NHS logo on the NHS choices app but were sceptical about being sent information via SMS as they would find it hard to distinguish from ‘spam’ messages, for example.</p> |
| <p>▶ Appropriate visual cues to help understanding</p> | <p>The use of pictures and diagrams should be regular and relevant to aid understanding. One of the things that the children and young people did not like about the Department of Health website was that it had a lot of plain text and little positive representation of young people.</p> |

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| <p>▶ Real-life examples</p> | <p>The young people highly valued hearing from people, including young people, that have had experienced similar health challenges. This was suggested as being in person, via reviews of services or through social media.</p> |
| <p>▶ Signposting to further information</p> | <p>Children and young people thought that it was important to know where to go for more detailed trustworthy advice and who they could talk to in person. They had views about ways of finding information online, for example on the Department of Health website, liking the use of tag clouds but being disappointed that the search function did not always return relevant results.</p> |
| <p>▶ Avoiding any jargon</p> | <p>Children and young people do not like the use of complicated terms and language. Some of the young people thought it would be useful to be signposted to a definition or webpage explaining the term, in a similar way to how articles on Wikipedia are linked.</p> |
| <p>▶ Practical introductory and frank information</p> | <p>When experiencing a health concern children and young people would like information about symptoms, prognosis and what to expect in terms of treatment. They thought that resources should focus on presenting this kind of information clearly and signpost to further advice. They also wanted information about the location of facilities and the costs involved in accessing any treatment or service, particularly where this changes with age, for example after 16 or 18.</p> |
| <p>▶ A choice of formats that ensures accessibility for all</p> | <p>Information should be provided in a number of formats, in different languages and to cater for varying communication needs.</p> |

nhs-constitution

A hand-drawn map of 'Health High St' is shown, featuring a network of grey roads with white dashed lines. The map is populated with numerous colorful sticky notes of various shapes and colors (pink, green, yellow, red, orange, purple) that represent different community services and facilities. A white rectangular box at the top center contains the text 'Health High St'. A white pen lies horizontally across the middle of the map. The background is a wooden surface.

Health High St

RECOMMENDATION

Government, local and national HealthWatch and the NHS should work with children and young people and organisations that work with them to ensure that development of health apps, online information and advice and other health resources as part of the information revolution caters for children and young people's needs.



CHILDREN AND YOUNG PEOPLE, MEDICAL RECORDS AND UNDERSTANDING CARE

In terms of ensuring that health professionals have information about their needs and treatment, most of the children and young people thought that the focus should be on **professionals sharing information properly**. Many were surprised that, for example, a hospital consultant would not automatically and easily have access to their medical records managed by their GP. They thought that they should be able to have **access to medical records** if they wanted to, but generally did not want it to be their responsibility to hold the information and pass it to new medical professionals.

There was some concern expressed about **security and data protection** with regards to accessing full medical records electronically. They suggested that it could be useful to carry a card that held information about intolerances and allergies and that a simple, standardised way of sharing information with health professionals about appointments and symptoms over time could be helpful.

One of the things that the children and young people thought a good health service should provide is **information to take away** to help them understand the diagnosis, treatment or advice they had been given. They made a number of suggestions about what kind of information would enable them to get the most from a consultation and be involved in developing the plan for ongoing care.

Many [young people] were surprised that a hospital consultant would not automatically and easily have access to their medical records managed by their GP.

- ▶ A printout from the doctor when leaving a consultation with the diagnosis and instructions for treatment (when to take medication etc).
- ▶ Being sent an email following a consultation with a link to general information about the symptoms discussed, and any diagnosis made or treatment prescribed.
- ▶ More specific information about when they should come back to review their symptoms/treatment and prompts/assistance to make the appointment.
- ▶ A log book kept up to date with information about appointments actions agreed by patients and doctors. The information should be in bullet points with any medical terms explained in plain English.



RECOMMENDATIONS

Improved management of information about individual's care should not just focus on patient control of medical records but also include:

- ▶ More coherent and consistent methods for medical professionals to share information about children and young people's individual health and treatment.
- ▶ Accessible follow-up information for children and young people to take from consultations to help them understand any diagnosis, treatment or advice given. This should be based on what children and young people themselves say would be useful.

Implementation of increased patient access to medical records should take account of children and young people's desire to be involved in decisions about their health as well as their concerns about data protection.

Gathering children and young people's views through local HealthWatch ▶▶▶

As part of the NHS reforms² local HealthWatch organisations will be set up to champion patients' views and experiences, reporting them to local commissioners and HealthWatch England. It will also have role in supporting access to information on health choices and complaints advocacy. HealthWatch England will support local HealthWatch organisations and advise the national NHS Commissioning Board, Care Quality Commission (CQC) and government on patients' views across the country.

Local HealthWatch organisations will be taking over from existing Local Involvement Networks (LINKs). A recent report by NCB³ found that these organisations often struggle to engage children and young people.

To help LINKs/local HealthWatch to effectively engage children and young people those involved in the consultation recommend that local HealthWatch should provide for the following:

- ▶ **Advertising that is visible to young people** – HealthWatch should reach out to them through clear advertising. They suggested posters on public transport; leaflets in schools, community centres and local shops and advertising on social media.
- ▶ **Regular communication via social media and schools** – Access to live information about HealthWatch. activity. They suggested this could be brought to them through regular updates on Facebook and through representatives of HealthWatch coming to schools to talk to them.



2. Department of Health (2010), *Equity and excellence: Liberating the NHS*, pp17-20

3. NCB (2011), *LINKs' involvement of children and young people* http://www.ncb.org.uk/media/48063/links_vss_report_final2.pdf



- ▶ **Young people to be listened to, respected and treated equally to adults** - They stressed that they wanted HealthWatch to be children friendly, to respect them as much as adults and to take on board their views as they are serious about what they want from their health services.
- ▶ **An inclusive atmosphere** – HealthWatch should be be welcoming and treat everyone equally and include a range of different people across ages, abilities and genders. Some young people suggested that HealthWatch members sign up to an agreement of conduct to ensure that everyone gets a fair and equal say.
- ▶ **Meetings scheduled to enable participation around school and other commitments** – the timing of meetings is important. They suggested that times should be suitable for all and should be after school or college or at weekends.
- ▶ **Clarity about the purpose of meetings** - there should be a clear structure of what the local HealthWatch needs to achieve in a given year and agendas should be given out well in advance of meetings so that they can decide which meetings to attend.
- ▶ **Creative and social activities** – they want engaging opportunities such as educational workshops, social events and creative activities and debates.
- ▶ **Accessible and welcoming venues for meetings** - the location of meetings should be easily accessible, with connections for public transport, travel expenses paid and food provided.

- ▶ **Regular discussion of issues relevant to young people** – children and young people want interesting topics to be on the agenda at meetings including young people’s issues.
- ▶ **Accessible format for meetings** – meetings should not be too formal and want the use of medical jargon to be avoided.
- ▶ **Access to decision makers** – they want to engage with the people who have the power to act on their views. They really value decision-makers being present at meetings, not just reading the notes from them.
- ▶ **Feedback on impact** – children and young people think it is important to know what has changed as a result of their engagement so that they feel like they are making difference.

RECOMMENDATIONS

Government should work with local HealthWatch pathfinders to ensure that emerging local HealthWatch organisations are built around children and young people’s needs including providing for the above.

HealthWatch England should establish standards for engaging children and young people based on these ideas, existing good practice and further consultation, and provide ongoing support for local HealthWatch to develop and maintain effective engagement of children and young people.



Further information and resources

NCB

LINKs reports and case studies - www.ncb.org.uk/vss/links-and-healthwatch

NCB young people's consultation reports - www.ncb.org.uk/vss/policy/consultations

Young NCB - www.youngncb.org.uk/home.aspx

Participation Works - www.participationwork.org.uk

NHS Constitution poster - www.ncb.org.uk/vss/policy/nhs-constitutions

Know your Rights at the Doctor - http://www.gmc-uk.org/static/documents/content/GMC_Poster_%28English%29.pdf

PALs resources for children and young people - <http://resources.ncb.org.uk/resources/free-resources/pals-project>



LINKS/HEALTHWATCH

NHS: <http://www.nhs.uk/NHSEngland/links/Pages/links-make-it-happen.aspx>

LINKs regulations: <http://www.legislation.gov.uk/ukxi/2008/528/contents/made>

LINKs legislation: <http://www.legislation.gov.uk/ukpga/2007/28/section/221>

LINKs exchange: <http://www.lx.nhs.uk/>

National Association of LINKs members (NALM): <http://www.nalm2010.org.uk/index.html>

Care Quality Commission (CQC): <http://www.cqc.org.uk/public/about-us/partnerships-other-organisations/healthwatch>

Department of Health: <http://www.dh.gov.uk/health/tag/healthwatch/>