



# Children and Young People's Views on the NHS Constitution: Engaging Themes



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These little illustrations shown throughout this document indicate quotes from children and young people who took part in our research.

# Executive Summary

## Children and young people's challenges for the NHS Constitution

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National Children's Bureau and the Council for Disabled Children have been speaking to children and young people about the NHS Constitution.

Building on a short consultation event in 2010<sup>1</sup>, we wanted to find out what children and young people thought about the NHS Constitution and how it related to their experiences of NHS care. What we found highlighted some challenges for the health system in making the NHS Constitution relevant to children and young people. While some of what we heard reflects challenges that apply to all patients regardless of age, children and young people's experiences of

the NHS requires a specific response that is not currently reflected in the adult-focused NHS Constitution. The short comings of the Constitution presented in this report should be clearly addressed through the continuing development of the NHS Constitution and wider policy. For more details about the policy implications of these findings please read the Shared Messages document published alongside this report and available from the CDC and NCB website.

[www.councilfordisabledchildren.org.uk/NHSConstitution](http://www.councilfordisabledchildren.org.uk/NHSConstitution)

[www.ncb.org.uk](http://www.ncb.org.uk)

## Key findings from our research

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### Lack of awareness of the NHS Constitution

Our research with children and young people highlights that recognition of the NHS Constitution remains very low. Even amongst children and young people with extensive experience of NHS services, who

were involved in participation activities, only one had heard of the Constitution and this was through a friend studying medicine, not through their engagement with the NHS.

### Unclear understanding of rights

During the focus groups we found that the children and young people only had a limited understanding that they, as patients and members of the public, had any rights

when using NHS services. They were also unsure how the rights would or should apply to them under the ages of 16 or 18.



"You can make a difference if you know this, you can put your voice out there."

"There should be more notices around, so we know our rights and what we can have, because I didn't know about some of the rights in the Constitution at all."

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<sup>1</sup> NCB (2010) *Promoting the NHS Constitution to Young People: Report on the Consultation Workshop 4th June 2010*, [www.ncb.org.uk/media/40766/nhs\\_cons\\_report\\_june2010.pdf](http://www.ncb.org.uk/media/40766/nhs_cons_report_june2010.pdf)

## Key findings from our research – *continued*

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### Parental involvement

Parents and carers often played a key role in supporting children and young people when using health services but the children and young people we spoke to were often uncertain about how this may affect their rights as patients, and if they need parental involvement to have their rights recognised.

While they had different opinions on how much they want their parents to be directly involved in their health care, almost all of the children and young people wanted to determine this, and wanted health professionals to seek their views, not just their parents.

### Developing autonomy

Children and young people wanted to know how the NHS would support them in having an appropriate understanding of their rights as they developed from early childhood to young adulthood, and empower them to take increasing ownership of these rights.

However, children and young people were very clear that gaining knowledge of their rights should not confer responsibility for

upholding them. They believed that health professionals needed to take the lead by making children and young people's rights clear throughout their work. The rights in the Constitution need to be promoted, and children and young people should be made to feel confident and welcome when exploring how these rights relate to their own use of NHS services.

### Complaints

Children and young people were intimidated by the complaints process and believed that it needs to be made more accessible

if the rights in the NHS Constitution are to apply to children and young people.

## Children and young people and the NHS Constitution

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The statutory duty on the NHS to promote the NHS Constitution makes the document a potentially powerful tool for raising children and young people's rights as a priority issue within the new NHS system.

However, the NHS Constitution does not address issues relating specifically to children and young people and there is a lack of evidence relating to how the document is being used to promote the rights of children and young people. The

Handbook to the NHS Constitution<sup>2</sup> does highlight how the NHS will need to consider how it will make the NHS Constitution relevant for children and young people.

**“In order for the Constitution to apply effectively to children and young people, this Handbook identifies situations where the NHS should aim to provide services in a manner that specifically takes account of their needs.”<sup>3</sup>**

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## What is the NHS Constitution?

The NHS Constitution brings together the key elements of policy and legislation that underpin the NHS in a single document aimed at patients and staff.

**These include:**

### The principles of the NHS

The rules that set out how the NHS should operate.

### The values of the NHS

The goals and aspirations that the NHS tries to achieve.

### Your rights

These are legal rights patients have when using the NHS. The NHS must ensure these rights are met.

### Pledges

These are not legally binding like rights, but set out what should be happening in the NHS, and if they are not met there should be a very good reason.

### Responsibilities

What patients and the public should do to help the NHS work effectively.

The NHS Constitution applies to everybody who uses the NHS and this includes children and young people as well as adults. Every part of the NHS has a duty to uphold the Constitution, and also to promote and raise awareness of it. This includes voluntary and private sector organisations that are providing NHS funded care. Local Authorities must also take the NHS Constitution into account when delivering their public health functions.

The Government hopes that the NHS Constitution can be a powerful tool for improving patients experience outcomes, but this will depend on how the NHS Constitution is used throughout the NHS.

“For the Constitution to succeed in its aims, it needs to become part of everyday life in the NHS for patients, the public and staff. Achieving this requires leadership, partnership and sustained commitment over months and years from all those involved in the provision of NHS services, to raise awareness of the Constitution and weave it into the way the NHS works at all levels.”

Handbook to the NHS Constitution 2013

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<sup>2</sup> Department of Health, Handbook to the NHS Constitution, 2013 [www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/handbook-to-the-nhs-constitution.pdf](http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/handbook-to-the-nhs-constitution.pdf)

<sup>3</sup> Handbook to the NHS Constitution 2013

## Children and young people and the NHS Constitution – *continued*

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### What we did: Research with children and young people

We spoke to over 80 children and young people in six groups around the country. Our research focused on individuals who use a diverse range of NHS services including:

- Children and young people with learning disabilities
- Children and young people with long term health conditions who have extensive experience of the health system
- Children and young people with mental health issues
- Children and young people with experience of local authority care.

### Working with a young researcher

At the start of the project we recruited a disabled young person as a co-researcher to help us design and carry out the research. The young researcher had been part of the VIPER project<sup>4</sup>, a three year research collaboration between CDC, NCB, the

Children’s Society and the Alliance for Inclusive Education that supported 16 young disabled people to develop research skills and produce a research report into disabled children’s participation.

<http://vipercouncilfordisabledchildren.org.uk>

### Young researchers view



“Having had the experience of being a young researcher on the VIPER project and being a participant in focus group research it has been key for me to make sure the sessions are young people centred, and that they have every opportunity to share their experience of using the NHS. Being involved in the project has given me the opportunity to work with a wide variety of young people in many different settings and to build upon my research skills.”

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<sup>4</sup> <http://vipercouncilfordisabledchildren.org.uk/>

# What we found

## Children and young people's views on the NHS



"I reckon we've got a brilliant service!"

"I'm so glad it's there. I'm so glad there is an NHS service."

"They're just a quality service that's there for free. Not many other countries in the world have anything like that."

"A lot of stuff is down to the doctors and how good your doctor is, how good your nurse is, and from my experience they're all pretty much top notch."

"Lad, [the NHS] saved his life. They bloody done good."

Children and young people who took part in the research sessions generally had positive views and experiences of the NHS. Many expressed a personal sense of gratitude for the care and treatment the NHS had provided to them and their family members.

Despite these positive views of the NHS, when the discussion moved to their experiences of NHS services, children and young people across all the research groups described a range of less positive experiences that were relevant to the rights in the NHS Constitution.

### Views on the rights in the NHS Constitution

The rest of this report will set out children and young people's views on the NHS Constitution grouped into eight key themes. These eight areas reflect the issues children and young people raised with us and allow for an analysis of NHS policies and drivers that is grounded in children and young people's experiences. An analysis of the

rights and commitments in each of the eight themes is set out in our separate policy analysis report published alongside this document.

[www.councilfordisabledchildren.org.uk/nhsconstitution](http://www.councilfordisabledchildren.org.uk/nhsconstitution)

[www.ncb.org.uk](http://www.ncb.org.uk)

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**“I think we take for granted how lucky we actually are, because we have it at our doorstep, no matter what, twenty four hours a day, seven days a week, and if anything’s wrong with us we have different hotlines we can call, obviously we go to our GP, we can walk into hospital and get seen, even though there might be a bit of a wait. So I feel that we take it for granted.”**

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## **ONE AVAILABILITY & ACCESS OF SERVICES**

**How can I use  
the services  
I need?**



# Availability & access of services

## How can I use the services I need?

### What do children and young people think about the rights and pledges?

Providing access to the appropriate services at the right time is one of the fundamental tenets of the NHS, and this is enshrined in a number of rights in the NHS Constitution.

### Summary of children and young people's views on availability and access

Being able to access the service they needed was a key concern for children and young people across all the groups we spoke to. No matter how good a service was, if they couldn't access it, then it couldn't help them.

They expected the NHS to make sure services were accessible when they needed them, rather than requiring to reach a crisis point and/or an emergency admission.

Despite its importance, children and young people did not clearly understand the rules relating to access to NHS services and felt that the processes were not explained to them properly by staff. They felt that if the process was explained to them in an appropriate way then they would understand the need to wait for some services and would feel reassured but a lack of information could cause uncertainty and anxiety over whether they will be able to access the service when they needed it.

### Right to receive NHS services free of charge

All children and young people were aware that NHS services were free, and they strongly supported this principle. The existence of the right meant children and

young people felt confident in engaging with services when they needed them, without any worries about having to pay.



"If he has something wrong with him, he'll have to go to the hospital and get something checked. But if he needs to pay for it, he wouldn't, he wouldn't like to go. If it was free he would like to go."

## How can I use the services I need? – continued

### Right to timely access to services and not to be turned away unreasonably

This right was seen as very important but some children and young people felt that they had struggled to access the services they felt they needed in a timely fashion due to physical barriers or the application of eligibility criteria. They worried about the impact this would have on their health, both physical and mental, but were unsure about how to address these issues. They wanted more information about what the right in the Constitution

should mean in practice, and how they could use it to find out why they had to wait for services and to gain assurance that this wouldn't place their health at risk.

Some young people also highlighted how accessing health appointments could have a knock-on effect on other aspects of their lives such as their progress in school and their relationship with friends and family.



"I feel I don't have access to tests and treatments I need because I can't access them."

"I think because it's for children it has to be scheduled around their parents ... and for people who are maybe in exam period for GCSEs or A levels."

"Even the people that do care – when they go and try to admit you to a ward the people are like: well, what's actually wrong with them? Nothing's wrong with them physically so we can't admit them or whatever, unless you're a danger and you can prove that, you're wasting your time going to A&E."

"It took me over five months just to get referred. I went to the doctor's three times and then on the third time I got referred because they weren't listening to what I was saying before."

"A doctor at a GP surgery refused to come downstairs for an appointment, and held it upstairs even though it was hard for the patient to get upstairs."

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## Right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status

Children and young people were against discrimination in any aspect of NHS provision. There was a strong belief that the NHS was an entitlement for all those who need it and that this might require the NHS to put specific services in place for different groups to ensure they had equal access.

Few children and young people had experienced direct discrimination from the NHS. However, a number of children and young people with experience of being in local authority care or using mental health services believed that this information affected the way they were treated by health professionals and wanted NHS staff to have greater awareness of these issues when working with children and young people.



“It’s important because you’re not being exclusive to one single person. The next person could be of a different race or origin, and they shouldn’t have to wait longer.”

“No one should be denied healthcare. It’s a basic human right.”

“She was being very chatty and nice to all the young people that were my age and teenagers who were there for physical stuff and then when she got to me she sighed and she was like, ‘What have we here?’ And then she said something like, ‘Why have you attacked yourself?’”

“Sometimes when using the service you think we get treated different because you’re a LAC (looked after child), and they always think somebody else is travelling with you.”

## How can I use the services I need? – *continued*

### Right to access certain services commissioned by NHS bodies within maximum waiting times

While children and young people generally understood the need to wait for NHS services to ensure fairness for everyone, they did not understand rules around waiting times.

This ranged from those who had no knowledge of waiting times in the NHS to those whose own experiences had given

them some detailed knowledge but were confused and frustrated with how the rules had been applied in their own cases. This lack of knowledge left children and young people concerned and anxious that long waits could lead to a potential deterioration in their health.



“You get referred to another one but then the target again is still 13 weeks, it doesn’t get shorter, yeah, some people can’t cope for another 13 weeks, they don’t realise that.”

“Waiting times are important because then you can get problems sorted out quickly and you do not have to be worried for as long.”

“When I go to the doctors sometimes I’ve got to wait for ages because they’ve got other patients in, so they say, ‘I’m sorry that you had to wait for a long time for your appointment’, and we say that it’s all right because I’ve got to wait for a couple of minutes till it’s my turn.”

“I was put on a waiting list for psychotherapy and I’m still waiting for it now. I got told that it would take six to eight weeks when I’d already waited nine weeks for a primary care referral – so overall, from realising I wanted to get re-referred it’s going to be sixteen weeks, just way too long. And he said, ‘Oh, I’ll call you with updates,’ but I’ve had no updates.”

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**“High quality services are important because you want to be treated less but with good care instead of lots of treatment that doesn’t completely fit it. So the better the quality of treatment, the quicker you’re on the mend.”**

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## **TWO CLINICAL QUALITY**

**Will it work,  
is it safe?**

# Clinical quality

## Will it work, is it safe?

### What do children and young people think about the rights and pledges?

All patients expect NHS services to be of the highest possible clinical quality, and the NHS Constitution features a number of rights relating to safety and effectiveness.

Our discussions with children and young people focused on what their experiences and views on what high quality services meant to them.

### Summary of children and young people's views on rights relating to clinical quality

Children and young people expected NHS services to be of the highest possible clinical quality and most children and young people believed they had received this standard of care. However, some

children and young people felt they had experienced, directly or indirectly, poor clinical outcomes from NHS services, and this affected their view of the quality of NHS services overall.

### Right to be treated with a professional standard of care, by appropriately qualified and experienced staff

Children and young people had a sense that there was a level of quality that NHS services should meet. High quality services were described as those that were able to treat children and young people effectively, quickly and safely when they were ill, and to support them to remain healthy.

The right to a professional standard of care was seen as being in everyone's interest, as poor quality services were regarded as more expensive in the long run, since they do not effectively deal with a problem when it first emerges.



"Doctors need to be good because your life is in their hands. Facilities and services are no different because if you don't have a properly trained doctor he might do something wrong to the patient, it will make you feel safer if they are properly trained."

"Well, you're not going to get anywhere if it's low quality. It's just going to make you worse and it's just going to end up costing more."

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Children and young people associated this with clean and safe environments and well-trained, conscientious staff who liked working with children and young people. These elements helped reassure them about the effectiveness and safety of the services they were receiving.

This view endorses the importance of the NHS Pledge that “The NHS commits to ensure that services are provided in a clean and safe environment that is fit for purpose, based on national best practice.”



“If somebody goes in a disgraceful hospital that hasn’t been cleaned properly they won’t come back.”

## Rights to access approved treatment

Most children and young people had confidence that they would receive the services appropriate for them. However a small number described problems accessing what they felt was age-appropriate care. This included confusion about suitable environments and the use of a medication

that was not recommended or approved for under 18s. The children and young people who had experienced this felt that the issues had not been explained to them clearly and thought that the NHS Constitution would help give children and young people more confidence in the same situation.



“I get migraines and I went to the GP about them. I’d tried two different medications already that hadn’t worked, and they were like, ‘Oh, well, you could try a preventative one,’ but he was like, ‘Oh, You can’t use, they’re not recommended for under 18s.’ So I went, ‘All right’, and so he put me on a different one and when I went home and looked at the leaflet it said: under no circumstances use this tablet on under 18 year olds. I was like, ‘Great’, but they worked.”

“I’ve just been re-referred and turned down and they sent me to primary care and then primary care want to send me to adult services. I’m not an adult, I’m a child, so why am I going to adult services? It’s stupid.”

## Will it work, is it safe? – continued

This right was seen as important in a context where some young people were concerned about the impact of funding cuts on the quality services they may receive. They felt this right should mean that access to services or treatment they needed should be independent of decisions funding.

“All the cutbacks as well in the NHS service, health is one of the most important things that you can have, they shouldn’t have cutbacks on any health or medication.”



### Right to expect continuous improvements in the quality of NHS healthcare. This includes improvements to the safety, effectiveness and experience of services.

A small number of children and young people were reassured by this right and the idea that the NHS would work to improve services and address the problems they encountered.

When talking about what this right could mean in practice, they focused on two issues they related to negative experiences.

The first was a need for training for staff to ensure they knew how to work with children and young people. Many participants reported this as a significant concern which could have an impact on their experience of services.



“The point of the hospital is to regain health, if the hospital can’t offer quality care it will not achieve its sole purpose.”

“Like they’re not trained to deal with kids.”

“They can look at services and say, ‘Well we can do a bit more of that and a bit more of this.’”

The second issue was raised by children and young people who had experience of mental health services, who believed that NHS staff in a wide range of settings needed additional training on mental health issues to be able to provide the right support.

Some children and young people believed that a lack of training and knowledge around children’s mental health issues had led to situations where they or their friends felt vulnerable and unsupported.





“I actually think if A&E staff had more training in mental health it would save lives.”

“People with moods and depression, they go to the Royal Hospital to get help and they’re just turned away. I think that’s a big issue... I think they just don’t take mental health seriously.”

“I’ve got a friend who’s got anorexia and she went to the doctor when she was still a healthy weight saying, I’ve not been eating and stuff, and she was really upset and they said, oh well, yeah, you’re a healthy weight so come back if you get worse. And then she ended up being sectioned and in hospital for years and stuff and it’s just not right.”

## NHS Pledge: On appropriate accommodation

The NHS Handbook states that the pledge on single sex accommodation may apply differently to children and young people who may choose to share with others of the same age rather than gender.

Most participants said they would prefer to be with children and young people of their own age rather than be segregated by sex, but there would be a need for privacy when sharing rooms with the opposite sex.

This was a raised as a particular issue by older children and young people who felt that both young children’s wards and adult wards could be unsuitable for their needs. A small number of young people had experience of being placed in settings they felt were not appropriate, or that there was disagreement within the health service about what accommodation was appropriate for them.



“There was a girl in there, she was 13, and she was never leaving the hospital. She couldn’t go home at weekends. And she was in with all of the babies just on her own, I wouldn’t want to be like that, would you?”

“I got put in an adult ward and they were like, ‘Oh, what are you doing here? You’re so small, how old are you? You’re not old enough to be in here.’ And like, those people said that I was.”

“You can have different things for different children, so maybe, if you’re 12 years old you might be a bit outgrowing stuff in the children’s ward, so then once you turn 13 you’ll be able to go into a teenagers’ ward.”

## Will it work, is it safe? – continued

### Views of younger children

As part of our research we spoke to a group of younger children (5–10 years old) about their views on what they liked most about hospital. Their answers clearly endorsed

the need for children’s wards for younger children, but also highlighted the potential tension in meeting the needs of both younger and older children:



“I love the noises along the corridors coming from the pictures.”

“Toys to play with!”

“Character visits (Mickey Mouse) and a magician who visits the outpatient clinics and on the wards.”

“Craft activities – sticking on plasters.”

Younger children frequently mentioned being treated nicely by kind staff as a reason they liked their hospital.

**They named the following qualities they liked in staff:**

“Friendly”

“Loveable”

“Nice”

“Don’t worry you”

“Stay calm”

“Don’t say nothing’s wrong with you”



Drawings of friendly staff by children aged 4-8 years

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**“The most important thing for me is the staff and how people treat us, especially young people and children in care. If you treat them like kids then it works both ways and they expect our respect but some staff don’t give it back.”**

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## **THREE COMMUNICATION, CONFIDENTIALITY & RESPECT**

**How am I  
treated by  
staff?**

# Communication, confidentiality & respect

## How am I treated by staff?

### What do children and young people think about the rights and pledges?

How health professionals communicate with the public and patients is central to individuals' experiences of the NHS. How the NHS deals with patient information is also hugely important for patients,

and there are a number of rights that relate to patient confidentiality, respect, and the communication and provision of information.

### Summary of children and young people's views on rights relating to clinical quality

How they are spoken to and treated by both clinical and non-clinical staff in the NHS, was one of the most significant factors in how children and young people perceived their care.

While many children and young people had positive views of the way that they were treated by health staff a significant number had experienced a number of negative issues when they were using health services.

## Right to be treated with dignity and respect, in accordance with your human rights

Children and young people saw being treated with respect and dignity as a basic requirement for all services. Children and young people had a basic, but often unclear, understanding of human rights and they were unclear about how these rights would relate to their treatment by the NHS. They viewed this right in terms of how health professionals interacted with them, and

having their views listened to. They wanted to be treated as an individual by a health professional who was confident dealing with children and young people. This involved having an informal, calm and caring approach that helped children and young people feel genuinely cared about as individuals, rather than simply satisfying job requirements.



“Listen to children and understand how to respond to their opinions... be happier and kinder and less formal.”

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At the other end of the spectrum, poor communication from professionals and services left children and young people feeling like they had not been respected.

Children and young people described this as a scale ranging from a sense of indifference from health professionals, through petty disrespect or even hostile interactions.



“It’s an attitude and the way it’s presented. I think a lot of doctors think they’re better than you and I don’t understand how they can’t know that, it’s just being decent to other people, isn’t it?”

“Because doctors do speak to you in a horrible way, even if a doctor’s talking to another doctor in a horrible way and then that doctor goes and treats someone and he takes, they take it out on their patients.”

“I was so really angry because I’d been told I could go home in an hour, that’s why I was a bit upset and started crying and he went, well see this is why, you’re a very sad girl and so I had a massive proper crisis because of that.”

“More communication between professionals and young people... I think there’s too many professionals coming in and out of young people’s lives and young adult’s lives. It’s hard to trust them, then what happens when you become an adult you lose all the trust in any NHS service or any professionals that come into your life.”

“They can be like, ‘We have people with illnesses, we’ve got people actually dying here’, and its like, ‘You’re wasting my time’, and that’s really horrible.”

“I got told to shut up and eat my breakfast by one of the nurses.”

## How am I treated by staff? – continued

### The role of parents in communicating with health professionals

One of the most consistent issues raised by children and young people was the role that their parents played in communication with health professionals.

Children and young people felt that their parents played an important role in supporting them at appointments and communicating with NHS staff. However, this could become marginalising if health professionals were communicating with parents and excluding them.

For some children and young people, the presence of parents was seen as necessary to ensure they were able to understand what they were being told by health professionals.

“Because they understand about doctors...And that, so yeah, I have to have a parent in, so they can make sure that the medication’s right and all that.”



While children and young people wanted differing levels of parental involvement, they believed that this should be their choice, and that health professionals should always communicate with children and young people. For some young people this

also meant being able to decide at each appointment how much they wanted their parents to be involved, and professionals offering the opportunity of some one-to-one time with them.



“Because the parents just know what’s going to happen. The child doesn’t know, so that means the child will be a lot more scared than what they could be if they asked someone what was it like, and then the nurse could tell them exactly what it’s like, but instead they tell the parents.”

“I want to be able to talk just with a doctor, not always but it should be an option.”

Despite the importance of consent, even the children and young people with extensive experience of the NHS were not clear on their specific rights about consent or in what circumstances a decision could be made in their best interest, and by whom. This was especially noted in children under the age of 16.

“Well when I went in they just told, they didn’t ask me, they just said to me because I was 14 I didn’t have the mental capacity to make my own decisions.”



Children and young people highlighted the need for health professionals' communication to be adapted to individuals' needs and capabilities, rather than having an arbitrary age, like 16, at which the approach to communication and involvement suddenly changes.



"Ten year olds are quite intelligent, you'd be surprised how much they know, so you could have a conversation with a ten year old."

"They'd always ask my mum what was wrong with me and it was like 'Hang on, it's my body, I think I know what's wrong.' Now I'm 16 I feel as if I'm listened to more at the doctor's."

"Dramatically over one day apparently I'm now an adult."

## Right to have your privacy and confidentiality taken seriously by professionals and services

Confidentiality and privacy was a real concern for children and young people. They expressed a clear sense of ownership over issues relating to their health, and wanted

to be able to control other people's access to their health information as they were worried about the consequences of people having access to this without their consent.



"No-one should know what you've done in the NHS or any medical sort of thing overall because it's your privacy. It's your personal things."

"How would you like it if someone, I don't know, told someone things that you don't want them to know or that would be embarrassing or makes you feel vulnerable?"

"It's your health, nobody else's. Only those you choose to let know should know about it."

"Your things should be private if wanted. Don't make them feel under pressure by showing everything."

## How am I treated by staff? – continued

Knowing that they had a right to privacy was important in making children and young people feel more secure when using services. It should be the responsibility of the service or professional to make it clear that children and young people have the right to privacy. Lack of clarity made

children and young people feel nervous about aspects of their health care and concerned about using health services. This uncertainty also meant some children and young people felt that the NHS had not always taken their privacy seriously.



“So basically you know yourself, but when you go the doctor’s they should be making sure that they make you feel better by telling you it doesn’t go anywhere else and stuff like that. ....So they should be making sure that you do feel comfortable going and saying, it is private.”

“At the GP I’ve had the receptionist call me, telling me about a referral and she shouldn’t know about it.”

“She was just pretty awful and she left the room and she left case notes for the day in the room and I just thought: that’s ridiculous, I can just look through all of that.”

“I think that hospitals should have closed offices as well because, you know the way you’ve got your own curtain and whatever, when they come out they’ll be discussing who’s just been in that cubicle, discussing what’s wrong with them, and they haven’t got a door. It’s just an open office, and the person in the next cubicle can hear what’s going on. So I think they should have separate proper rooms or separate offices or something.”



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## Role of parents in confidentiality

A number of children and young people were particularly concerned about confidentiality in relation to the information that would be shared with their parents.



“The NHS don’t listen to you very well if you don’t want your parents to know. I wouldn’t feel very comfortable and I wouldn’t want my parents to be involved as it wouldn’t make me feel happy.”

“I think that what’s important about the NHS is if you have a medical emergency and you’re older and you don’t really want your parents to know about it because you should have the right to have the privacy to who is told.”

However there was no standard understanding in the group about how confidentiality should apply in different circumstances.



“I think for under 16s though they have to, don’t they? They have to tell the parents.”

“That’s a legal thing though, they kind of have to tell your parents if you’re a danger to yourself, not for that, not for that they don’t.”

## How am I treated by staff? – continued

This was a particular concern for those with experience of mental health issues who raised specific concerns about parents being given information if professionals felt

young people posed a risk to themselves, and this causing more pressure and stress on family relationships.



“They had to tell my mum because it’s going to get worse before it gets better and as it gets worse, even though I wasn’t thinking of harming myself at that time, as it got worse I could be thinking of it in the future.”

“I didn’t want my mum to know because I didn’t want her to stress out, like a lot of young people. Because a lot of young people, if they’ve got mental health problems, people in their family have mental health problems and by telling them you don’t want to make them worse.”

“Yeah, if you’re in danger they do, but if you’re not they don’t. I wasn’t in danger so she didn’t have to tell my parents.”

## Right to access to health records

Children and young people had different views on the importance of the right to access health records. Some were not interested, some actively preferred not to see their records and some number wanted to know if they had the right to access them. Some children and young people were concerned that health records might contain

important information about their condition and treatment that was not known to them.

For the children and young people who were interested in, or had experience of trying to access their health records, the lack of clarity about how this process should operate was a major issue.



“I don’t think you should be able to look through your own health records.”

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Some children and young people reported being asked to pay for access to their records and were unsure if this was right<sup>5</sup>; others said they had been denied access to their health records due to being under 16, or

had been told they needed a parent or an adult with them to access them. They felt that the NHS Constitution should provide clarity about these issues.



“I got denied twice and then we had to get a solicitor to get them.”

“You need to know what is wrong with you and it could be really serious and you might not know, you might know some of the stuff but not all of it so you need to go to ask for the health records, and when I went to ask they told me its public and you can’t ask for yours unless you have an adult with you.”

“It would be useful if, if say you weren’t getting on with someone you could look at your records and see what they’re actually writing.”

“People need to know that they can look at them because I never knew.”

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<sup>5</sup> [www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/what\\_to\\_do.aspx](http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/what_to_do.aspx)

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**“No decisions were explained to me, they used to refuse, I’d get told to wait outside while they were all talking about me. And it’s your life and it’s your decision, so I think that’s really important that you have your own say about your life and have control over your life.”**

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## **FOUR INDIVIDUAL INVOLVEMENT & CONSENT**

**Having a say  
in my care  
and treatment**

# Individual involvement & consent

## Having a say in my care and treatment

### What do children and young people think about the rights and pledges?

Being involved in decisions about treatment and support, and providing informed consent, are at the core of person centred care and support.

This importance of patient involvement in their care is enshrined in a number of rights in the NHS Constitution, including a fundamental right of consent to treatment.

### Summary of children and young people's views on rights to individual involvement, choice and consent

Being involved in decisions about their care and giving consent to treatment was empowering for children and young people and something they really valued. They wanted their opinions listened to and taken seriously by health professionals. This made them feel valued and reassured, during what can be distressing and vulnerable times.

Children and young people also felt that their involvement in decision-making led to better clinical decisions, diagnosis and treatment. When health professionals listened to them, and took their views seriously, then they felt more confident that the treatment would be what they actually needed in those circumstances, rather than a general, "one size fits all approach".

## Right to be involved in decisions about your care

Being involved in decision making was valued as empowering and children and young people all strongly supported this right. Even if they did not always want to exercise it, they wanted to know they had the right to take part in decision making. Children and young people recognised they wouldn't always make all choices

themselves, but instead wanted to be part of the process and understand what was happening. This may range from making decisions independently or with health professionals, to choosing from options, to being informed of what is going on, and this may change as the child develops.



"Because the patient is the most important person, it's important that they should have a say in the treatment they receive."

"The right to be involved in decision making about your own care will give young people a sense of having more power, like the doctors have all the power."

## Having a say in my care and treatment – *continued*



“You should always have a say and a right to have a choice. As it’s happening to you it should at least be partially your decision.”

“Sometimes it’s good to choose it for yourself because then you know it’s what you want to do and what’s better for you, but if someone else chooses it for you it could be better, as well, because they’ve got more experience of it.”

“It’s your choice, not somebody else’s.”

“It’s your life so you should choose what happens.”

There was a strong belief across the groups about the benefits of involving children and young people in decision making. It helps leads to better choices, experiences and outcomes. When children and young people were not involved in decision making about

their care they felt marginalised and frustrated. They also felt that the decisions made without them might not be in their best interest, or suitable for them, and so they may not want to follow through with their treatment.



“So they should look into things more and not just palm you off with what they think, because it’s not the same symptoms or something like that.”

“It took me over five months just to get referred. I went to the doctor’s three times and then on the third time I got referred because they weren’t listening to what I was saying before.”

“Because if you don’t want it to happen there is no point wasting resources on making it happen.”

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## NHS Pledge: All information should be provided in a way that can be clearly understood by children and young people to help them take part in decision making

Having the right information about their health and care was something that was crucially important to children and young people. Good information provision meant more to children and young people than health professionals relaying factual

information. It also involved supporting children and young people to be able to understand the implications of that information, what it means to them and the impact it will have on their life, in a straightforward way.



“They should be opening it up to children, as well, because... Adults will probably understand what’s happening more than some children would, yeah, so they should probably take a different approach.”

“He can do sign language with the kids, they, the sign language people, know what they’re saying.”

“Children and young people want to know more about their conditions, what they’re going through and their treatments... it’s good if the doctor can explain it again if they say they can’t understand it.”

“You need to know what’s happening... maybe even if it’s just a nurse who comes and spends a good five, ten minutes in making sure that all questions can be answered and you won’t be judged.”

Having the right information helped children and young people to feel confident and reassured before seeing

a health professional. Without it, they could feel nervous and even scared.



“You need the proper information to make choices, and if you have a disability you should know what disability you have and that could make it easier and maybe you don’t get all frustrated with your disability.”

“I think you should always have a right for information though about tests and treatment. They need to give you time and explain things to you and give you the opportunity to talk about it.”

## Having a say in my care and treatment – *continued*

In some cases, children and young people reported having been asked about tests and treatments that were not explained to them, and they had no understanding

of what they were being asked to do or the impact this would have on diagnosis and treatment decisions.



“She made me fill in some forms that were clearly for her that said something, like I know quite a lot about mental health things but I didn’t even understand... it was some really confusing things about psychosis and stuff like that.”

“Also I’m just sick so I don’t understand some things unless... I struggle with too much information at once, so when you’re at the doctor’s you’re just getting bombarded with information and I don’t remember any of it. So they should take into consideration how they’re able to listen to what people are saying.”

### Right to choose your GP practice

Children and young people said they were not directly involved in making decisions about the GP practice that they used. It

was a decision made for them by parents, which they had little input into and was not a priority.

### NHS Right: Requesting a doctor in your GP practice

Being able to request a doctor was something that children and young people felt was important. They wanted to choose doctors they felt comfortable with and were able to build a relationship with. They did not want to see a stranger, repeat themselves, or hear the same information from different doctors each time. Familiarity with one doctor also made them feel more

confident about confidentiality and more comfortable disclosing personal health issues.

Children and young people had different experiences of the right to request a GP. Some were offered a choice of doctor in the GP surgery when they turned up to make an appointment, but others were allocated a doctor without being aware that they had the right to express a preference.



“I think that’s important but I don’t think I’ve ever met anyone that wasn’t aware of that because when you’re in reception they usually say, who do you want to see?”

“If I go to the doctor’s they’ll be like, ‘Oh, you’ve got someone’. They don’t say, ‘Who do you want?’ You’ve got to ask them then you probably wouldn’t get them anyway because they’re booked up.”





“I feel really annoyed when reception say you can’t see your own doctor. It makes me so angry that I just want to punch them.”

“When you go in and make an appointment they just give you whatever doctor’s there. They don’t say to you, you can request your own.”

## Right to consent to treatment

Children and young people wanted a say in decisions about their health, and the right to consent to treatment was regarded as a crucial part of this. Without consent, children and young people may not comply with treatment and this would be a waste of resources.

In most circumstances children and young people wanted to be the ultimate decision-maker because the consequences of decisions would affect them directly. To give or withhold consent, children and young people would need accessible information about the issues and consequences relating to treatment.



“I think all young people are capable of making their own decisions, don’t treat us like we don’t understand. Some obviously don’t but if you’re physically and mentally able to make a decision then why shouldn’t you be able to make decisions about your own healthcare when it’s you who it’s happening to.”

“You have the right to consent to treatment, that should just be grilled into doctors and I don’t know why. There should be no excuse for not using that, you shouldn’t have to know that’s a right, like I shouldn’t have had to sit there and say, you’re supposed to tell me what this drug’s for, that’s just ridiculous.”

“You should always have a say, and say no or yes to the doctor.”

## Having a say in my care and treatment – continued

Children and young people with experience of mental health issues raised the issue consent in relation to the Mental Capacity Act<sup>6</sup> and Mental Health Act<sup>7</sup>. While they were aware that treatment can be given without

consent, and some directly raised the issue of “being sectioned”, their discussion highlighted how the principles and processes had not been explained to them.



“This is important because you should get a say in what happens to you, but only if they’re in the right frame of mind.”

“The only thing I can come up with is if you’ve been sectioned then you don’t have a right to consent to treatment.”

“Like on what basis do they differentiate between people who have a mental health condition so severe that they can’t make their own decisions to the ones that may have a mental health problem but they’re still able to make their own decisions?”

“I don’t know what the law says about that.”

## The role of parents in making decisions

Children and young people felt that parents’ involvement in their treatment and care could be very important, given that meetings with medical professionals

could be stressful and complex. Having their parents there to support them, and to understand what the professional was saying, could be helpful.



“If they are younger then the parents can make the decision for them but when they’re older they can make the decision for themselves.”

“They actually listen and take into account what I’m saying and if I can’t explain things properly then, yeah, they’ll still ask a parent but they do listen to me.”

“It depends on the temperament of the child, so you’d have to speak to the parents to know what the child’s like, rather than just assuming that child’s like the child they had before and just doing exactly the same thing.”

<sup>6</sup> Mental Capacity Act 2005, [www.gov.uk/government/collections/mental-capacity-act-making-decisions](http://www.gov.uk/government/collections/mental-capacity-act-making-decisions)

<sup>7</sup> Mental Health Act 1983 [www.legislation.gov.uk/ukpga/1983/20/contents](http://www.legislation.gov.uk/ukpga/1983/20/contents)

Many children and young people were concerned that health professionals viewed their parents as the primary



“Before I turned 16 they’d always ask my mum what was wrong with me and it was like, hang on it’s my body, I think I know what’s wrong. They don’t really listen to younger children, now I’m 16 I feel as if I’m listened to more at the doctor’s.”

decision maker and addressed discussions about care to their parents and not to the child or young person themselves.

“They need to learn how to speak to people, when I was on my own they spoke to me like I was a child and as soon as my parents came they spoke to me like I was an adult. They even told me that they wouldn’t tell me everything that was happening, so I was sat there on my own, I hadn’t got a clue what was going on.”

For children and young people in care there were additional issues regarding the local authority’s role as a corporate parent. There was confusion about the roles and responsibilities of children and young people



“I had to hold until two days later because we had to wait for the social worker to come out, so I was on nil by mouth for God knows how many hours.”

themselves, foster carers, and various social workers and medical professionals when it came to consent and confidentiality, and this could have knock on effects on the their care.

“A girl who I used to live with, she had to get something done to her ear, and her foster carer couldn’t sign to say she could have that operation. They had to get a service manager to come to the hospital and sit in there, in the hospital, while she had that operation.”

Children and young people in care expressed a sense of feeling like a problem passed around between professionals, and wanted



“So they pass it off as somebody else’s job because you’re in care.”

one consistent social worker contacting and visiting them if they were admitted to hospital.

“They see social services as a massive institute. If you had a parent they wouldn’t say, oh, your parent can deal with it. It’s because social services is a massive institute, it’s like, oh, we can push it on to them.”

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**“The right to be involved in local NHS decision making, means you can make a difference to the NHS by making your own choice. You can make a difference in it if you know this, you can get your voice out there.”**

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## **FIVE COLLECTIVE INVOLVEMENT**

**Getting  
involved  
in my area**

# Collective involvement

## Getting involved in my area

### What do children and young people think about the rights and pledges?

Public and patient engagement is central to ensuring the NHS responds to the needs of local populations, and this is reflected in rights in the NHS Constitution.

### Summary of children and young people's views on rights to collective involvement

This theme was a lower priority than others for some children and young people, but a proportion were interested in taking part in local decisions about how the NHS worked in their area and felt this would lead to better decisions being made

in relation to children's services. However, they felt that NHS organisations made an assumption that children and young people are not interested in taking part in local decisions.

### Right to take part in local decisions

A number of children and young people were interested in collective involvement, both at an individual service level, such as a hospital, and at a local strategic level. They felt this was an important right, but not one that is well understood by either services or children and young people.

Some children and young people felt NHS organisations assumed children and young people were not interested in taking part in local decisions and did not actively promote these opportunities to them. The result was that children and young people could easily be overlooked in adult decision-making processes.



"I think probably the general ones aren't really young people friendly but then I think ... there's a big push now... on patients' views because there's posts all the time. But I don't think they're really young person friendly."

## Getting involved in my area – continued

Children and young people who already participated in collective involvement via forums that discussed local and strategic issues, such as children and young people’s patient participation forums, valued these experiences. They saw inputting into decisions in their hospital as a route to influencing their local NHS.

By working together with other children and young people they felt more likely to achieve change but also gain confidence, which was in stark contrast to their lack of confidence about making individual complaints.



“I think it’s important because then I think a lot of perspectives are taken into consideration, young people’s and adults’ alike, and I think because it’s important, because a lot of people make those decisions aren’t patients themselves so if they haven’t had experience they just think, oh, this is what I think a patient would want, but if you’re asking a patient themselves it’ll be like this is what a patient wants.”

### NHS Right: To have local decisions explained to you

Children and young people who felt that their treatment or access to services were affected by decisions taken by the NHS at a local level, such as the type of services that were commissioned or age limits for services, wanted to know how and why these decisions were taken. This needed to be explained in ways that children and young people could understand. Children and young people are aware of economic

constraints on the NHS; they can, and want to, understand justifications behind the use of finite resources, and engaging with them around this could help manage their expectations.

Some children and young people described not feeling able to ask questions or challenge the explanations they were given if they did not understand them.



“If you needed treatment that the NHS does not offer it needs to think about giving it to you and if it doesn’t it needs explaining to you clearly, yeah.”

“Like when they just say, ‘Oh, well there are no services, sorry’, or, ‘There aren’t any services that are right for you’, then that’s like, ‘Oh OK.’”

“I’ve had experience of the local area in providing two, fortnightly appointments, I couldn’t access weekly appointments because apparently that isn’t what our local area offers. I did have it explained but it wasn’t really, acceptable even if they’ve explained it.”

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**“We were too scared to make a complaint, I was in hospital one minute... and next it was all gone and they didn’t tell us and it was so confusing but we were too scared to complain, we knew that nothing would be done about it so there was no point.”**

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## **SIX COMPLAINTS**

**What do I do if  
I’m not happy  
with the NHS?**

# Complaints

## What do I do if I'm not happy with the NHS?

### What do children and young people think about the rights and pledges?

The NHS Constitution contains a number of rights that set out the various steps and the frames involved in the process of making a complaint and how the NHS should handle and respond to them.

We did not present the full details of the complaints process to children and young people, rather we spoke to them about their general right to make a complaint, and their experience of the process.

### Summary of children and young people's views on complaints

The right to make a complaint was important for children and young people. They wanted to be able to let the NHS know that they had had an unsatisfactory experience, to validate their experience and to make sure that the situation could

be improved so other children and young people did not undergo the same problems. They saw complaints as an important way for children and young people to help improve services.

### Right to make a complaint

Knowing they had the right to make a complaint was valued by some children and young people, who thought that it

could be an important way of improving their experiences and wider services.



"The right to make a complaint is important because if you don't feel like something is fair or right then you should tell someone so next time it is better for others... it is good."

"I think if people know them it empowers them to make complaints as well, so they understand them. I think complaints have to be made to make improvements and you have to complain to get an improvement."

In order to have confidence in the complaints process, children and young people wanted it to be simple and, confidential, with clear information provided about the outcome of the complaint.



"There should be complaint booklets, like a leaflet on how to do it on every table in the waiting room of every NHS service."



Actual experiences of the complaints process tended to be much less positive. For some children and young people having to write a formal letter was a



“That’s not children friendly, is it, because they don’t have the capacity or some people, even if you can, children wouldn’t want to sit down and write a formal letter and go and post it.”

barrier to making a complaint and left them feeling like they weren’t able to meet the standard set by the service.

“I wrote a letter, it wasn’t a very good letter because I couldn’t get my thoughts straight or anything and then I couldn’t really type it, so I just put at the end, ‘Sorry if this doesn’t make sense,’ and that sort of thing.”

Other comments reflected anxiety about a number of aspects of the complaints process. Children and young people were concerned that complaining would



“We were too scared to complain, we knew that nothing would be done about it so there was no point.”

“I have made a complaint, it was horrible.”

affect their care, be an unpleasant and intimidating experience, or that someone would be offended. They also expressed a lack of faith that complaining would achieve the desired outcome.

“You could complain, yeah, but it’s one person’s complaint, no matter how passionate you felt about it... That’s why I just don’t waste my time with complaints, because one person’s opinion doesn’t change a service.”

## NHS Pledge: To encourage and welcome feedback on your health and care experiences and use this to improve services

Children and young people wanted to be enabled to provide feedback to services and have the option of giving it to individuals other than those delivering their care.

They hoped that if services acted on this feedback at an early stage, the need for lots of complaints would be avoided.



“This is important because if you think something can be improved you should inform someone and the NHS should know, they should also respond.”

“You’d know then that they can always make things better, and it’s better for us to spot something wrong and to tell them so they can fix what’s wrong...”

## What do I do if I'm not happy with the NHS? – *continued*

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### NHS Pledge: Redress

It was important for children and young people that the NHS should admit when it had got something wrong. They did not expect punishment for professionals or

services, but wanted recognition of their experience, which would increase rather than diminish their faith in the organisation.



“Admit to their mistakes or put their hands up or something. I think that’s a big issue. I just wanted to get that out.”

A lack of redress could leave children and young people frustrated with the complaint process.



“Until you get it resolved, it like, causes you more stress than it’s worth.”

“I think they were just making excuses for her. That was how I felt.”

### Role of parents in complaints

A number of children and young people believed that they would want their parents to be involved in the complaints process, either supporting them or making the complaint on their behalf. However it was

important that services did not assume that their parents should have to, or would be able to, help them go through the complaints process.



“See, if I’d had a complaint before I wouldn’t have bothered, I think my mum would have done it but now I will do it.”

“I sometimes have parents (help me make a complaint) and sometimes I don’t.”

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**“Transition services are the poorest part, especially within mental health. I think they fall down extremely badly and there’s a really big inequality across the country of what happens. And I know a big thing is that people say they’re not been given any information – they’ve just been told, you’re off to another service.”**

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## **SEVEN INTEGRATION & TRANSITION**

**Everyone  
working  
together to  
support me**

# Integration & transition

## Everyone working together to support me

### What do children and young people think about the rights and pledges?

While there are no rights in the NHS constitution relating to the integration of services and support when making

a transition between services, there are two pledges that relate to patients being supported across services.

### Summary of children and young people's views on integration and transition

For children and young people who had experience of being supported by multiple professionals across NHS agencies or who had moved between services, integration and transition really mattered. They were

also areas in which the NHS often failed to meet their expectations and this was a cause of anxiety for young people approaching, or involved in transition between services.

## NHS Pledge: Services will work together to make the transition in and out of services, and between different services, as smooth as possible

This pledge was important for children and young people in three key contexts:

**1** The integration of NHS care when treatment and support depended on different NHS services and health professionals cooperating with each other to provide the best possible care.

This required the appropriate sharing of information and involvement of children and young people and their families in planning.



"I was on a paediatric ward and I was supposed to be being discharged because I was fine and the doctor came over and was like, 'We're really sorry but someone forgot to ring up CAMHS to check you could be discharged and let them know, and you're going to have to stay in overnight.'"

**2** How health services and professionals work with other organisations and professionals that contribute to children and young people's health and wellbeing, such as social care professionals and schools. This was an

issue that was particularly important to children and young people with experience of local authority care, who felt that there was a gap between NHS staff and social workers and they did not work together effectively.



"I feel angry because of the waiting times and I miss school and I miss lessons. I miss a lesson and it takes forever to go and see a doctor and it's really annoying."

"What if you haven't told social services? And then they don't do nothing with that information, or other people have said, well, we don't know where to take the information. Well, it's your job to know where it goes so you're clearly not doing your job, why are you there? Do you get what I mean?"

**3** The transition between paediatrics and adult services was a major source of concern for older children and young people. There were a range of experiences among the young people

going through the transition between services ranging from very positive and empowering, to negative experiences where the young people had felt unsupported and forgotten by services.



"I've just been re-referred and turned down and they sent me to primary care and then primary care want to send me to adult services. I'm not an adult I'm a child, so why am I going to adult services? It's stupid."

## Everyone working together to support me – *continued*

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The importance of this pledge, especially in relation to the transition to adult services, was highlighted by those young people who had positive experiences. When young people were provided with clear

information by health professionals about what to expect, and were supported to make decisions about how their transition would work, they felt ready for adult services and positive about what was happening.



“It should be part of it where the child makes the decision when they want the transition, so as soon as you turn 16 it doesn’t necessarily mean that you should be transferred, especially if you’re under a consultant. So, and I’m still under a consultant at Alder Hey, even though I’m 17, almost 18, so, and I haven’t wanted to change over because I trust my consultant, and that’s it.”

Other young people, including those going through a transition between services, felt their transition had not been adequate. They did not have a clear understanding of the transition process between children’s

and adult services in different areas, and in some cases had not understood their own transition. This resulted in some very negative experiences that left young people worried about what was happening to them.



“But in that week or that two to three week wait I was out of the younger services, I wasn’t in the older services, which was a huge panic for me because I didn’t know if I was just going to get left.”

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## **Pledge: The NHS commits to ensure those involved in your care and treatment have access to your health information so they can care for you safely and effectively**

The importance children and young people placed on the confidentiality of their information did not mean they thought that no information should ever be shared about them. Appropriate sharing of health information by medical professionals was something some children and young people wanted in order to reduce the emphasis on

them as the sole holder of this information, and the need to retell this information multiple times. They were frustrated when it was left up to them to coordinate information between services; they didn't want the responsibility of explaining things to the different health professionals in their lives.



“Because if you’ve got a personal problem, you don’t like going in seeing some stranger...it’s like I see a different doctor all the time, you feel like you’re repeating yourself all the time over and over again.”

“If you had a physical illness like cancer they wouldn’t say, can you go tell your GP you’ve got cancer, please. But in mental health services they say, can you please go tell your GP you’ve got a mental health illness and see what they can do. If you did have cancer they wouldn’t say, go tell them you’re in the middle of chemo and see if they can help you.”

This was another area where even children and young people with extensive experience of using lots of different services didn't understand how information was shared

between services, and some young people also doubted that health staff understood how things should work.



“My physio, because they’ve changed the booking system so that they’re not allowed to do it from their own diary, so it’s all computerised so they can’t prioritise. So she actually told me to make a complaint to get an appointment, she told me to.”

“And people think that staff don’t know the protocol as well, like it’s not just them that doesn’t know what’s going on. They felt that staff don’t understand the process and it gets to it and they don’t know what to do.”

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**“Health is the most important thing. So you want to feel as though you have the opportunity to stay healthy.”**

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## **EIGHT WELLBEING & PREVENTION**

**Being supported to stay healthy**



# Wellbeing and prevention

## Being supported to stay healthy

### What is in the Constitution in this area for children and young people?

The NHS Constitution does not contain rights around the promotion of wellbeing and prevention, highlighting the sometimes complex relationship between the NHS and public health promotion. For more information about the relationship

between the NHS Constitution and other health system drivers to improve prevention and promote health wellbeing, please download our policy analysis document published alongside this report.

### Pledge: NHS staff will take every appropriate opportunity to encourage and support patients and colleagues to improve their health and wellbeing

There was some brief discussion around wellbeing and prevention in our workshops, with a number of children and young people believing that the NHS did not do enough to promote health and wellbeing and had too much focus on responding to existing health problems rather than investing in prevention. Increased knowledge of this

commitment could encourage children and young people to raise issues of health and wellbeing with NHS staff. This also highlights the need to ensure that children and young people are aware of how the NHS and the local authorities public health functions work together to promote improved public health for children and young people in their area.



“They just think medication cures everything. They’re not about prevention. The NHS is not about prevention. It’s just not.”

“I think they push a lot more in inpatient care rather than in the community.”

“It’s like they’re not doing what you need, they’re just doing their job and nothing beyond that.”

# Conclusion

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## **This report has highlighted the importance of children and young people's views on the NHS Constitution**

The value that the children and young people placed on knowing their rights demonstrates the potential for the NHS Constitution to empower children and young people to understand that they have rights when using the NHS. However the lack of knowledge and understanding regarding their rights when using a health service is an issue that needs to be addressed by both policy makers and professionals working with children and young people in the NHS.

In addition to the need for awareness raising this report also presents a number of issues where the adult model of the NHS Constitution does not take into the realities of children and young people's experiences of using the NHS. This requires an overreaching response setting out the clear legal and policy expectations for children and young people when using the NHS. For more details about the policy implications of these findings please read the Shared Messages document published alongside this report and available from the CDC and NCB website.

These messages should help voluntary and community organisations working to think about how they promote the rights in the NHS Constitution to the children and young people they work with. The messages in this document can also be used to inform approaches to working with the NHS at both a national and local level to ensure that policies and practice support clearly the rights of children and young people in the NHS Constitution.



This report is one of 2 reports published by CDC and NCB on the NHS Constitution

This report and the accompanying publication can be downloaded from  
**[www.councilfordisabledchildren.org.uk/nhsconstitution](http://www.councilfordisabledchildren.org.uk/nhsconstitution)**

The National Children's Bureau is a leading research and development charity that for 50 years has been working to improve the lives of children and young people, reducing the impact of inequalities. We work with children, for children to influence government policy, be a strong voice for young people and front-line professionals, and provide practical solutions on a range of social issues.

For more information visit **[www.ncb.org.uk](http://www.ncb.org.uk)**

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with special educational needs and their families.

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