

"Being listened to is better than anything"

Children and Young People's Opinions and Experiences of Healthcare

May 2021

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Acknowledgements

This project and report have been made possible by the involvement of education settings and the participation of children and young people across England. We are hugely grateful for the involvement of each of the nine infant schools, primary schools and alternative provision settings who supported this project and allowed us to work with their pupils.

We would like to thank the following settings and their teachers, teaching assistants and all the pupils who took part in this work.

Settings that hosted the 7–11 year olds' reference groups:

Educational Diversity and the Pegasus Centre

Shoreditch Park Primary School

St John's College School

Settings that hosted the 4–7 year olds' focus groups:

Aureus Primary School

Crowle C of E First School

GLF Multi Academy Trust

Holy Trinity Primary School

Longford Park Primary School

Manor Field Infant School

St Monica's Catholic Primary School

We have also had the pleasure of working with eight young people who formed the 11–14 year olds' reference group for the last 15 months. Thank you to Chiara, Dmitrijs, Kaci, Lily, Megan, Lucie, Faith and Tommy for their time and input.

The importance of young people's voices



I have enjoyed every step of the process during my time being involved in the NCB x NICE health guidelines project, looking at how medical and health facilities should interact with children and young people and make that interaction as effective, comfortable and efficient as possible.

It was great working together with such a great variety of young people, from lots of different backgrounds and experiences, to pool together thoughts and ideas, including investigating the different types of medical help that a young person may need to access and what support we think might be helpful for the young person to have during that journey.

The project has allowed me to think about steps of the process of accessing a health service so much more in depth and look at exactly what needs to be improved to make the young person's experience throughout easier and much more comfortable, be it waiting times, facility improvement and support from parents, guardians and medical professionals, to name a few.

Young people's voices, in every sector including health, should be listened to, valued and considered to ensure that the health service can be accessible for all and to remove, even slightly, the stigma around going to the dentist or the doctor for example. This will assist young people to be more healthy in every step of their life."

Dmitrijs from the 11-14 year olds' health reference group



What I liked about doing the group is that I liked giving my opinion so that kids can be brave when they want to go to the doctors and can be healthier."

Child from the 7-11 year olds' health reference group at Shoreditch Park

Project summary

The National Children's Bureau (NCB) was commissioned by the National Guidelines Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE) to work with groups of children and young people across England to gather their experiences, thoughts and opinions on healthcare, in order to inform NGA's development of the new NICE Guideline on babies, children and young people's experiences of health.

Each session was designed and delivered by the National Children's Bureau, and involved a range of activities, discussions and games to find out what children and young people thought.

There were three parts to NCB's work with children and young people during this project:

1. **One reference group of young people between the ages of 11 and 14**, with eight young people recruited from across England. The same group of 11–14 year olds met four times for half-day sessions.
2. **Three reference groups of children aged between 7 and 11 in three settings across England**. Two of these groups had 12 members and the third had 6 members due to smaller class sizes and children's support needs. A group in each setting met four times for between 60 to 90 minutes.
3. **Six focus groups of children aged between 4 and 7 in six settings across England**. These sessions were delivered during the Covid-19 pandemic and due to different settings' requirements with school bubbles and class sizes, the size of each group varied considerably. Each focus group met once for between 45 to 60 minutes.

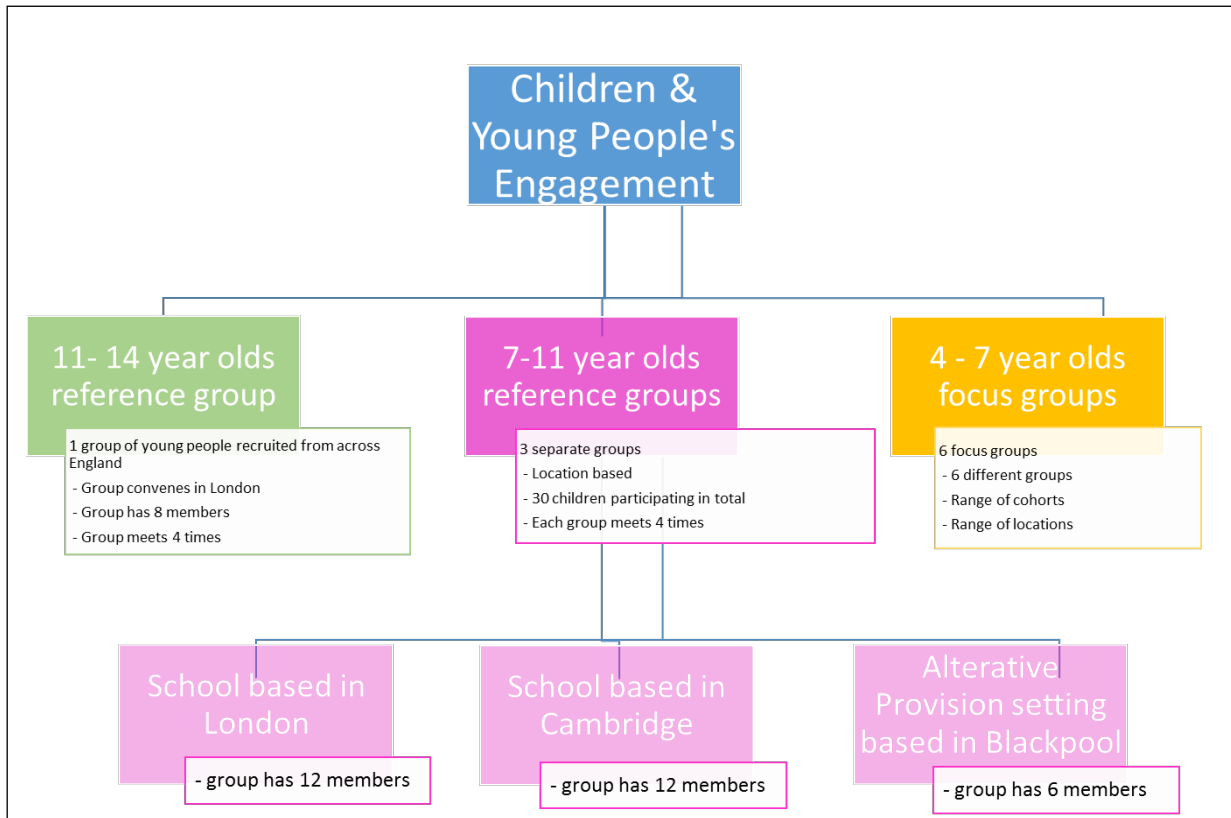
The engagement plan is summarised on the following page.

Covid-19 Pandemic

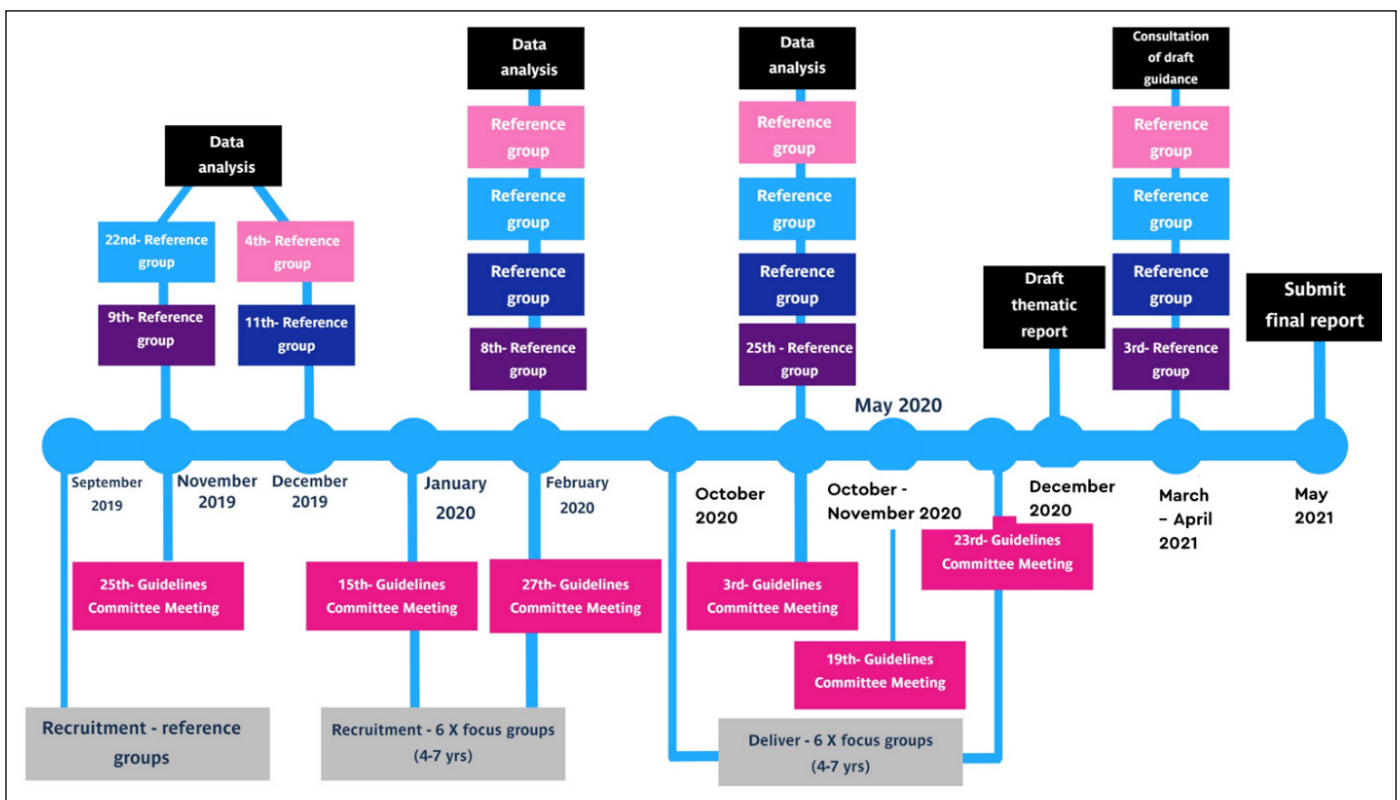
As requested by the committee, the consultation work was delayed by the outbreak of the Covid-19 pandemic in March 2020. During the Covid-19 pandemic, it became clear we would need to modify our engagement plans to be able to recruit new schools for the 4–7 year olds' focus groups and safely deliver all sessions. To this end, we offered schools the option of socially distanced in-person sessions or remote sessions delivered via Zoom, and we developed virtual session plans and materials for online use. From October 2020, we delivered in-person sessions in five settings, sometimes delivering multiple sessions to smaller groups due to the requirements of school bubbles, and held five sessions online.

The requirements of school bubbles also meant we delivered sessions to very different class sizes, ranging from 3 to 20 children. In larger groups while this meant we heard from more children, this had an impact on the detail we could get from each child.

Delivering sessions on healthcare during this time meant some children and young people expressed concerns about the Covid-19 pandemic, for more information on this, see section 9.6.



A more detailed summary of NCB's engagement with children and young people:



Recruitment and diversity of experiences

When recruiting the reference and focus groups, we were mindful of the importance of ensuring diversity in experiences and backgrounds. We therefore sought to work with educational settings from a good geographical spread across England, and worked with settings in Halifax, Didcot, Cambridge, Basingstoke, London, Blackpool and Banbury. Unfortunately, we were unable to find a school to partner with in the South West but otherwise feel there is broad representation from across England.



Green pins represent the 7–11 years old focus group

Red pins represent the 4–7 years old reference group

We worked with rural settings including village schools, as well as with inner-city schools, and worked with mainstream state primary schools, an independent prep school and an alternative provision setting.

The children we spoke to had a range of experiences and knowledge of mental and physical health services, and included children with chronic health conditions, Special Educational Needs and Disabilities, including learning disabilities, those accessing mental health services, as well as many children and young people who had very limited experiences of healthcare and had only accessed universal health services such as vaccinations and the 3 year health check.

We were unable to get a full demographic breakdown of the children and young people we spoke to, however we worked in schools where a majority of children were eligible for Free School Meals and a high number of children spoke English as an additional language (EAL) and we worked with multiple children and young people who had been adopted, fostered and who were in the care system, as well as children and young people who had been excluded from school. We did record instances of a clear demographic split, for example any differences between boys and girls or opinions that were predominantly held by looked after children, and this is included in the report.

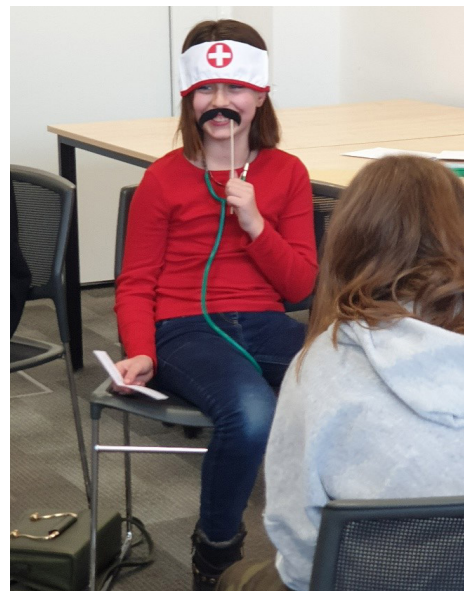
Throughout this work, we wanted to capture the voices of all children but in particular we wanted to ensure we listened to the experiences of children whose voices are seldom heard.



In the 7-11 and 11-14 age groups we used role play activities to help children think through how they would respond in different scenarios. This was a really effective tool for helping children identify questions and concerns they would have in different settings, and encouraging more children in the 7-11 age groups to participate.

We also conducted a ranking activity with all age groups to find out which factors were most important to young people's experiences of healthcare. Children and young people were given ten picture cards with aspects of care on them, for example 'the place is comfortable and feels like home' and were asked to rank them in order of priority before explaining why.

Other activities included poster and leaflet making; online voting; responding to case studies of fictional young people by mapping their 'pathway' through a service; and a range of discussions and brain storming sessions.



Key findings

In this report, we summarise the key findings from our consultation work with children and young people, highlighting their voices and experiences of healthcare, the barriers they face and concerns they have, and the factors they saw as most important to having positive experiences of health services.

1. General perceptions of healthcare

All age groups were able to identify a range of healthcare staff and settings, with the youngest groups quick to identify doctors, nurses, hospitals, dentists and ambulances. The level of knowledge increased with the age of the young people, as did some awareness of mental health or community-based services. The 11–14 reference group also identified CAMHS, therapists, asthma nurses, school nurses, flu jabs, specialists, pharmacists, orthodontists, opticians and physiotherapists as examples of health services. Despite activities to help children and young people identify a range of healthcare staff and services early on, most children and young people of all age groups referred only to doctors, dentists and nurses in their subsequent answers.

Even very young children had a good understanding of the purpose of health services and most displayed a high level of trust in them, with comments such as **"health services give people the help they need"** from a member of the 11–14 year olds' group, **"doctors are there to make you feel better"** from a child in a 7–11 year olds' group and **"the NHS keeps you safe [and] helps you not die"** from a child in a 4–7 year olds' group.

However, many children and young people also associated health services with fear, pain and injections. These opposing perceptions of health services as sources of help and sources of fear and pain were found in each reference and focus group and every group was divided by children's overall opinion of healthcare.

Just over half of the children and young people we spoke to agreed they 'felt happy and comfortable going to the doctor' and just under half agreed 'doctors and nurses are nice.' Children and young people who felt this way sometimes found it hard to explain why they felt comfortable, but gave answers such as **"because they might make you feel a little bit better"** and **"I feel comfortable because my mum is with me and I can sit on her lap."**

On the other hand, around half of children and young people did not feel happy or comfortable going to the doctor and more than half disagreed that doctors and nurses were nice. Reasons given focused on fear, injections and pain, with comments including **"I am not happy to go to the doctor because I feel nervous and scared"**, **"I don't like doctors because they hurt me"** and **"I just do not like them because they give me injections."**

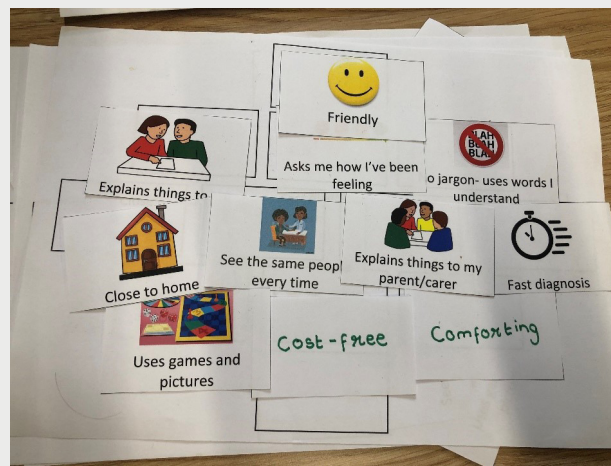
Levels of fear were fairly high for all age groups: over two thirds of the children and young people we spoke to agreed with the statement 'I think health services are scary.' As with the previous questions, reasons included fear of pain and injections but comments also showed how a lack of understanding or familiarity with health services could increase fear: **"It is scary because I don't know what is happening or what is going to happen"** and **"I am scared because I haven't ever seen [a doctor]"**.

An emerging theme from all groups was a desire from children and young people to feel listened to and have their voices heard in medical settings, but only half of children and young people agreed that 'healthcare staff care about what I think and say.' Other key points included the vital role of appropriate parental support; the value of good, accessible communication from healthcare staff; and the importance of healthcare staff building trusting relationships with young people. All of these are discussed in more detail below.

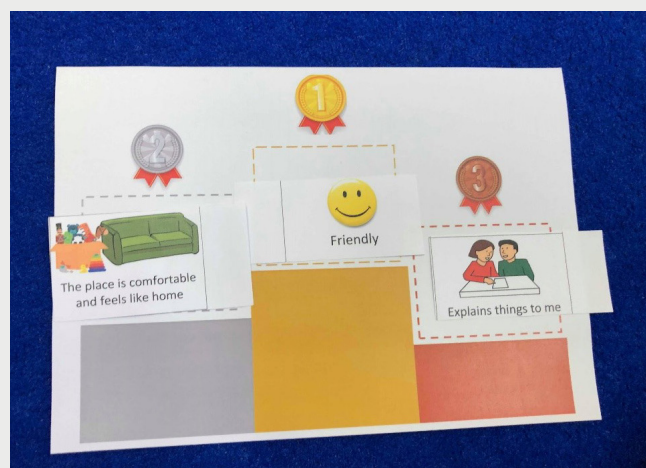
Children and young people also spoke openly about fears and barriers to good experiences of care, as well as suggesting some solutions to these barriers, from simple solutions such as reassuring words, friendliness, distractions and "giving a sticker at the end," to more inventive suggestions such as question boxes and informal meetings before a medical appointment.

Ranking activity – young service user priorities

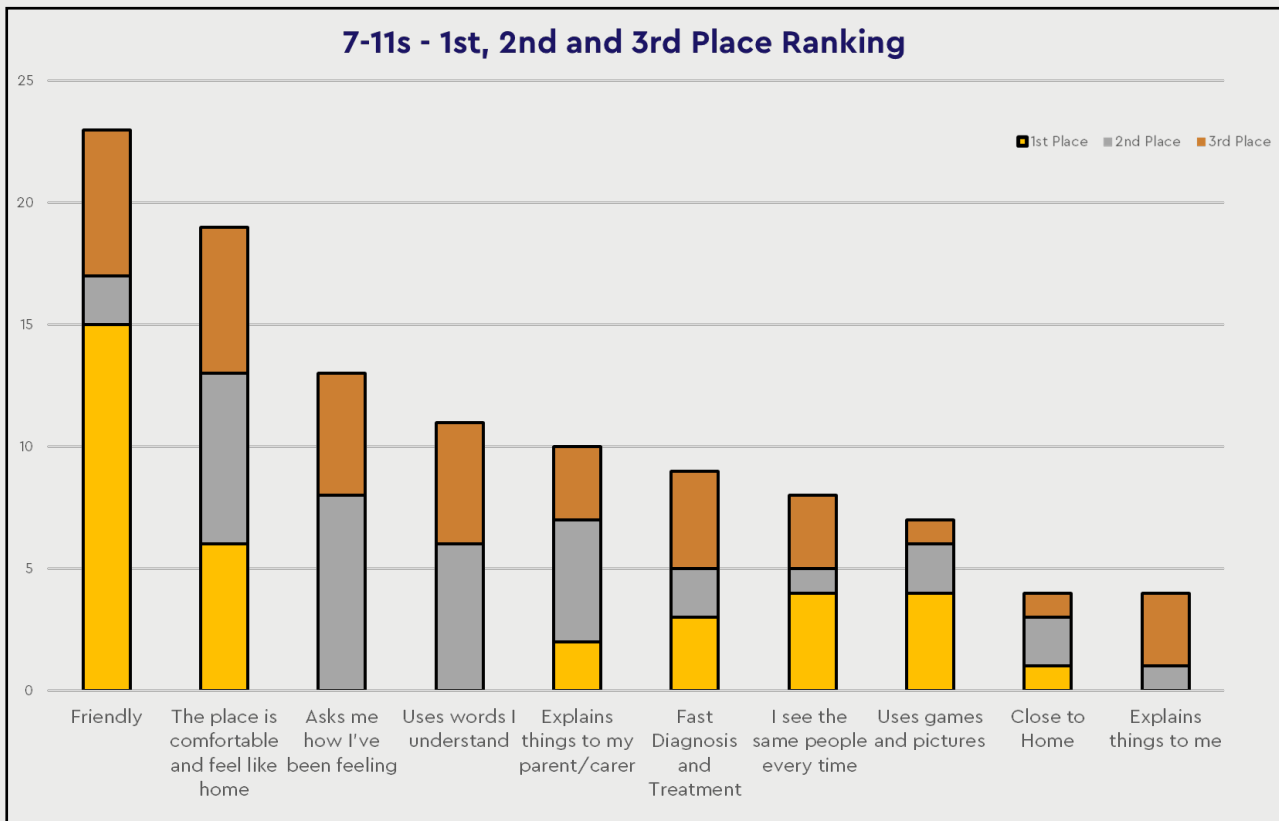
The 11–14s reference group completed a diamond ranking activity. They were given ten cards with aspects of care on them, along with blank cards so they could write their own priorities, and asked to put them in a grid based on which they thought was most important. Five of the eight young people who completed the activity put 'Friendly' as their top priority, two put 'Fast diagnosis' and one put 'Plays music.' Cards which were placed in the top position or second row by more than one young person were: Friendly (6); Explains things to me (4); Asks me how I've been feeling (4); Close to home (3); Fast (4); See the same people every time (3); Uses games and pictures (2); and No jargon, uses words I understand (2). The young people also wrote additional cards such as 'safe space', 'comfortable' and 'comforting.'



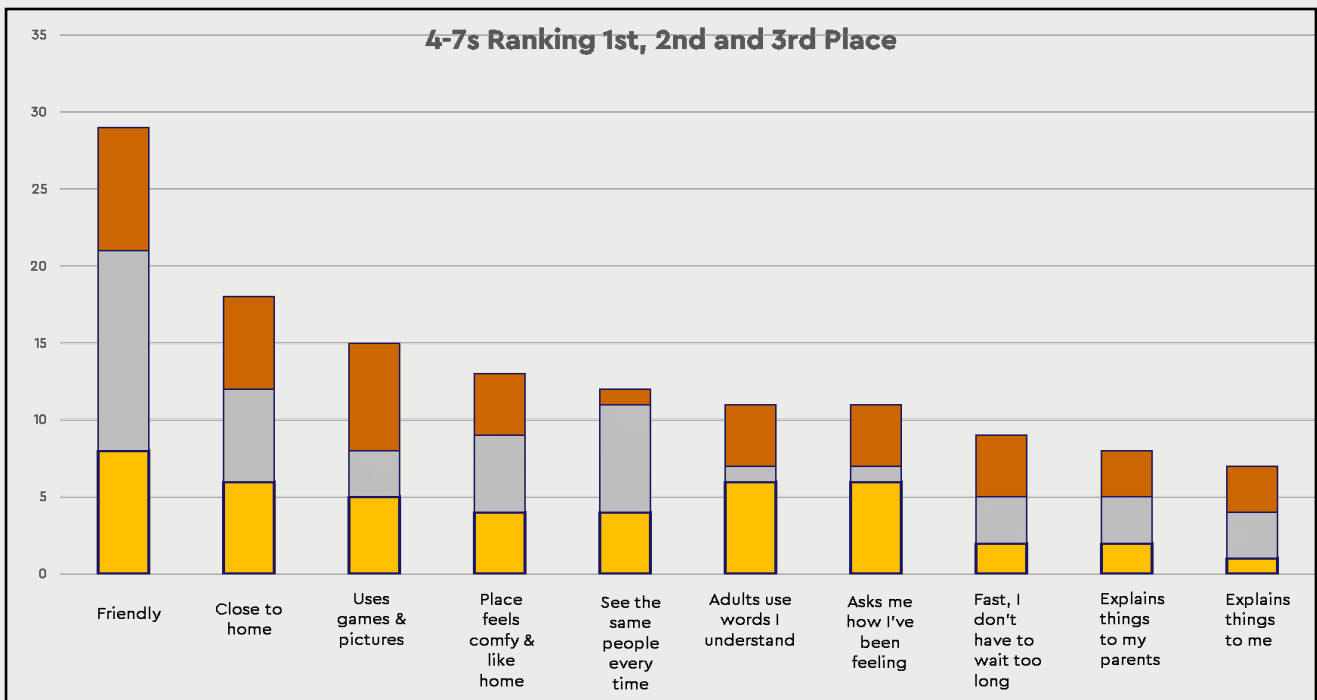
During the second round of engagement, we asked the 7–11 reference groups to identify their top three priorities from a choice of ten priority cards and put them on a 1st, 2nd and 3rd place podium. We added a card 'the place is comfortable and feels like home' based on previous discussions. The children in this age group first did a ranking exercise using cards with different foods to help them understand the activity.



'Friendly' appeared in the top position and in the top three more than any other card. The new card, 'the place is comfortable and feels like home' was the second most popular card in terms of 1st place priority and the number of children who put it in their top three.



We also conducted a simplified ranking activity with three of the 4-7 year olds' groups, though this took different formats depending on whether the sessions were run in-person or via Zoom. There was more variation in which card was selected as the top priority for this age group, however 'Friendly' was still put in the top three more than any other card.



2. The healthcare environment (NGA Review questions 4, 6, 6.1)

Children and young people talked about how the healthcare environment impacted their experience and opinions of care, and a number of key themes came up across the age groups.

2.1 Feeling comfortable and like home

A desire for the healthcare environment including waiting rooms, treatment rooms or inpatient wards to feel comfortable, relaxed and home-like came up in all groups. We did not originally include a priority card on the environment feeling comfortable or homelike in the ranking exercise for the 11-14s, however it was mentioned so frequently during their first session that we added it to subsequent ranking activities. The 7-11s put the 'the place is comfortable and feels like home' in the first-place position more than any card other than 'friendly' and likewise it appeared in the children's top three more than any card other than 'friendly'. 'The place feels comfy and like home' was the fourth most popular priority card for the 4-7s.

Outside of the ranking activity, the topic came up frequently. The 7-11 and 11-14 year olds' groups all suggested the world's best healthcare setting would be "comfy" with "soft beds" and "comfy chairs." In contrast, the world's worst setting would be "unfurnished" with "cheap seats, a lack of comfort", "hard beds" and would feel sterile. When discussing fears around accessing services, one young person explained **"if hospitals were more comfortable it would help"**, and another suggested **"it needs to be comfortable [for you] to get better."**

Children and young people also wanted healthcare settings to **"not look as professional, but look more normal"**, for example with "fish and music in the waiting room, toys, tv or a box of books" and colourful walls. Children talked about the importance of healthcare settings feeling like a home environment. Different children said it would be better if "the room felt like home," if there was a sofa or kitchen, "if it was like a bedroom", with others saying "it needs to feel like home" and suggesting they could be allowed to bring in things from home if they had to stay overnight. Outside of physical changes, children mentioned aspects of care that could mimic a home environment, with one suggesting "if you can't sleep, have a lullaby, someone to read you a bedtime story."

In a conversation about whether the location of healthcare services mattered, one child demonstrated the strength of feeling about this topic by saying:

"more important than it being close to home is if it feels like home because... if it feels like home, then you'll know it feels safe so you'll feel less sick."

2.2 Toys and games

Children and young people of all ages talked about how toys, teddies and games could make them feel more relaxed, comfortable and distracted in health settings and wanted waiting rooms and hospitals to have games and toys available. As one young person explained, **"games will help you feel better and you will forget what happened."**

In particular, children and young people in all age groups talked about having "teddies for comfort," suggesting that being given "a huge teddy to squeeze" would help them feel less afraid at the dentist. Having games and toys to play with, such as "top trumps", "sensory toys like slime" or "tech games to take our mind off things" would also help, with one child commenting "I want to have toys to play with so I am less scared of an injection." Children and young people also valued books being available and craft or colouring activities as ways of distracting them. Some young people from the 11-14 age group felt that **"normally at the doctors, games and pictures are just for toddlers and babies"** and suggested books, crafts and technology-related games could be more appropriate for their age group.

2.3 Tech

Children and young people valued technology being available in healthcare settings, with children of all ages talking about distracting games that could be played if they were allowed to bring their phone or tablet in or have access to tablets in waiting rooms and on wards. They also talked about wanted TVs so they could "watch my favourite show", having access to "a room to watch movies in... as a distraction", or being able to play games on a Wii or Xbox. Some children in the 7–11 and 11–14 year olds' groups wanted there to be "Wi-Fi available," not only to play games but also so they could talk to family or go on Zoom to talk to their friends.

2.4 Calm

As well as there being games and opportunities for fun, several children and young people stressed the need for healthcare settings to feel calm. A few children wrote that the world's best setting would **"have a more calm waiting room"** or would have "a calm room with sleepy lights." One child suggested "split[ting] the waiting room in half or having different rooms for play and calm" to strike this balance. This was really important to a small number of children, who discussed healthcare environments having "too many sensory things, not calm" or described them as "busy, claustrophobic."

2.5 Privacy

Several children and young people talked about the importance of the environment feeling private and not being overheard or overlooked. This was mentioned as a way of helping them feel less afraid when in healthcare settings, less embarrassed and also more able to participate in their care. Suggestions included having an individual room, a small room with a door or replacing the curtains so no noise could be heard.

2.6 Hygienic and clean

It was important to many children and young people that healthcare settings felt hygienic and clean, and this often came up in conversations about what they did not like about health services. When discussing the world's worst healthcare settings, they suggested it would be 'unhygienic' and 'dirty', with 'grubby sheets.' Children talked about there being bad smells and dirty chairs and rooms. One child explained: **"sometimes when you go the doctors', it is a little bit dirty, the seats are not clean. It makes me feel disgusted."**

2.7 Child only spaces

Children discussed the importance of having spaces that were just for them, with one saying **"it would help to have a young children's area for under 10s for appointments."** A few children mentioned that the world's worst healthcare would "not be tailored to us" or would have "only adults there." In conversations about how to reduce embarrassment or nervousness in health settings, one young person suggested the solution was **"to have separate areas just for children."**

2.8 Interaction with others

A few children and young people who had stayed in hospital talked about being left on their own and feeling lonely, with comments including **"there's no attention when on a ward"**, and suggestions that they should be allowed to **"be around people you actually like rather than being left alone in the children's ward."** This also came up in discussions of the world's best healthcare settings, with suggestions including having "a window so you can talk to your friends and see out" and being shown

a button you could press overnight if you needed someone to come and see you. Children wanted to be able to interact with others whilst in healthcare settings, and suggestions included "having games to play with other children" in the hospital, or being supported to "go on Zoom with your friends."

2.9 Food

Hospital food was frequently mentioned, with children talking about **"bad, poorly prepared food"**, **"being forced to eat food I don't like and can't eat"** or commenting **"hospital food is rubbish."** Children mentioned wanting a choice of food and being rewarded for being brave by having food they enjoyed. Some children also talked about feeling hungry in healthcare environments which contributed to a negative experience, **"you're not allowed to have food at the doctors and this means you get hungry."**

3. Qualities of healthcare staff (NGA Review questions 3.2, 4)

The qualities, behaviours and attitudes of healthcare staff formed a key part of children and young people's experiences of healthcare and this was often the first thing they talked about. A positive interaction with a friendly and kind health professional could transform their views of healthcare. In conversations about fears or barriers to accessing services, children and young people often suggested that the solutions lay with healthcare professionals. For example, when discussing feeling embarrassed, the children suggested "have a funny doctor" or someone that "made people laugh"; if feeling frightened, a solution was to have a caring doctor who would take time to make sure you were okay. When asked what would make them feel less nervous, more comfortable speaking and more involved in their care, answers often came back to the attributes of healthcare staff.

Approach to communication and communication style is a significant part of this topic, and children's views around communication is explained in more detail in Section 4 below. Alongside this, young people identified a range of positive qualities which they looked for in those caring for them, including that they were friendly, trustworthy, confidential, patient, a good listener, did not overreact and someone who was capable, skilled and would help them. The most frequently mentioned qualities are detailed below:

3.1 Friendly

Friendly healthcare staff was chosen as the top priority in the ranking exercise more than any other card, for every age group. Three quarters of children in the 7–11 and 11–14 year olds' groups chose friendly as one of their top priorities, as did over two thirds of those aged 4–7. This clearly demonstrates the importance of this to children and young people and to their experiences of healthcare.

Children and young people talked about the world's best healthcare experience being one where "doctors and nurses are friendly and welcoming" and the word 'friendly' was mentioned dozens of times across groups. When asked what they meant by 'friendly', children mentioned staff who smiled and were engaged with them: "doctors who have a big, friendly smile", "when they say hello", "come up and introduce themselves," "ask you how you are feeling", "smiling and make you feel relaxed." They thought the world's worst experience would involve 'unfriendly' staff, for example "when doctors don't give you stickers", "doctors being rude" and used words like short tempered, unwelcoming and distracted.

When discussing the ranking activity, children highlighted how important the friendliness of staff was to them and the impact it could have on building trust. Comments included **"if the doctor is friendly then the child will feel safer... and like there is nothing to worry about,"** **"I would feel even more scared if they were not friendly"** and **"[they] need to be really friendly so you feel you have known them for a long time so you can trust them more."**

One child also explained that the attitude of healthcare staff was more important than the situation and words they used, saying "if they're not friendly they might ask you 'how have you been feeling today?' in a cross voice and it won't help you answer, but if they are friendly, they might say 'how have you been feeling today' in a kind voice, and you will answer."

3.2 Caring

Linked to this, children and young people talked about wanting healthcare staff to be caring. This involved being a comforting presence, with one child saying the world's best healthcare professional would be **"a parent-like person who just comforts, rather than treats"**, and another explaining doctors and nurses should "speak to them and comfort them." Young people in the 11-14 age group also mentioned the importance of those helping them being empathetic and trying to understand them, explaining that an ideal person would **"understand what the child is thinking and why they are feeling that way."**

They wanted someone who "genuinely cared" and who could "make sure I'm okay." This was in contrast to the qualities they associated with the world's worst healthcare professional, who they described as "not caring about your feelings," "ignoring you", "blaming you" or "not giving you something to help you."

3.3 Calm

In the same way some children highly valued a calm environment, several children and young people mentioned the importance of healthcare staff remaining calm and relaxed, with one child describing an ideal doctor as someone that would "go with the flow."

This came up more often in conversations about negative experiences, with children describing healthcare staff as "stressful" and raising their voice. One child explained **"they make it sound urgent and I don't like urgency... Doctors are supposed to make you calm but they make me more nervous. I would prefer it if they told me things in a calm way."**

3.4 Funny

Some children, particularly boys in the 7-11 age group, really valued healthcare staff being funny and making them laugh. This came up as a way of reducing their fear in healthcare settings, distracting them during something unpleasant, and reducing feelings of embarrassment and shyness. To them, the ideal healthcare staff could "make people laugh", "make a funny joke," "be a funny doctor" and would "do something fun" to diffuse the situation and make them feel relaxed.

3.5 Take you seriously

While most children wanted healthcare staff to be friendly and informal, it was also really important that healthcare staff demonstrated that they took them and their concerns seriously. 'Not being taken seriously by the doctor or nurse' was a common worry for children we spoke to. This involved not being believed by healthcare staff, but more often being dismissed and having their concerns belittled. Examples included being ignored, having conversations that were a **"swift two seconds [before] you need to get out,"** or being rushed out of hospital despite having a broken leg.

3.6 Capable, competent, experienced

Children and young people were also concerned with healthcare staff being experienced, competent and able to help them. Children in a 7–11 year olds' group said the world's best healthcare staff would be those who are "good at their job" and "prepared for any scenario," while a child in a 4–7 year olds' group wanted a nurse who "looks like she would know what to do."

This was linked to ideas about training and experience, with one explaining that "proper training" meant you could "trust the person knows what is going to happen," and one young person saying that they wanted **"someone who has done the job before, not someone who is new and inexperienced."**

In contrast, 11–14 year olds' group thought the world's worst healthcare setting would have "unqualified" professionals and the **"inexperienced staff doing it wrong."** Concerns about inexperienced staff making mistakes were fairly common, with children and young people worried about being given the "wrong prescriptions", "wrong medication", "wrong diagnosis", "doctors doing the procedure wrong," or "losing details between appointments."

3.7 Trust

Feeling able to trust healthcare staff was a key concern for the children and young people we spoke to. Many young people who said they were not scared in health settings explained this was because they trusted healthcare staff, particularly ones they knew, with one child saying **"it's okay being alone if I trust them."**

However, not all children and young people trusted healthcare staff or knew how to work out if they were trustworthy. In fact, many had concerns about healthcare staff treating them badly, particularly if no other adults were present. When looking at non-smiling pictures of doctors, several children in the 4–7 year olds' groups made comments such as "he looks like he will do something bad to someone" or "she looks like she will hurt someone." Likewise, children in the 7–11 age groups expressed concerns about healthcare staff trapping them, pretending to be someone else, **"say[ing] something to our parents about what we have done which isn't true"** with several children worrying that **"they might do something bad to you," "they might ask your mum and dad to leave then say mean things to you... like 'why are you so stupid?'"** and **"they might do something or say something when your adult is out the room that will make you cry."**

It was important to children that they felt they could trust healthcare staff and did not have these worries, but this was particularly difficult if they had never met the healthcare professional before: **"if they are new you don't know if you can trust them or not."** Several children agreed that **"if you see the same person every time, it will help you trust them."** This was also true for their trust in other adults, including how they felt about teachers, as trust was something they felt built up over time.

In situations where they needed to meet a healthcare professional for the first time, children wanted to get to know them a bit in order to build up trust. One child explained it was good when "a doctor meet[s] you at the door – introduces themselves and says a bit about yourself," while one young person suggested the importance of having the opportunity for an informal conversation to **"get to know each other's likes and dislikes"** to build trust.

3.8 Clothes

The way healthcare staff dressed was linked to ideas of competence and trust for some of the children and young people we spoke to. One young person in the 11–14 year olds' group wanted someone supporting them to be **"Professionally and well dressed"** as this will **"help you to trust them, I wouldn't trust them if they are just in jeans."**

Likewise, during the picture activity with the 4–7 age groups, several children quickly pointed to a picture of a man in a white coat with a stethoscope as an example of the 'world's best doctor,' despite him frowning. There were lots of comments that "he looks like a doctor," "the thing around his neck makes him look like a doctor," with one child saying "it is better for them to wear a white coat than everyday clothes" and another commenting that it made him look "smart" and like he would help others.

A relatively small number of children mentioned clothes in the sessions, however all who did so expressed a preference for healthcare staff to be smartly dressed, wearing clothes that could easily identify them.



4. Communication and access to information (NGA review questions 1, 1.1, 1.2, 2, 2.1, 2.2, 3.2)

Children and young people frequently pointed to the importance of accessible, reassuring and informative communication from healthcare staff throughout the sessions. They felt that many barriers to accessing healthcare services, including fear and misinformation, could be overcome by improved communication from healthcare staff.

While children and young people had different perspectives on how much detail they wanted to be told, most emphasised the importance of good communication and the world's worst healthcare service was described as being one with **"no talking... no explanations, not knowing what is happening"** where healthcare staff **"give you treatment and you don't know why"** or **"don't tell us anything."**

Children and young people emphasised the importance of informal, friendly communication, praising healthcare staff who introduce themselves to children, ask them questions about their interests, "speak to them and comfort them" and give them information about what will happen. One child explained they wanted communication to be more informal, while another added healthcare staff should "be on our level" in the way they communicate.

4.1 Talking to children and young people

Several children mentioned the value in healthcare staff addressing them directly, with one child saying they felt happy to go to the doctors because "they talk to me" and another explaining "I like telling them about my holidays."

Most children felt it was important for healthcare staff to talk to and explain things to them as well as to their parents, and this increased to every young person in the 11–14s group. They thought the world's best healthcare staff would talk to them as well, and ask a child some questions too: "the best would ask 'what do you like and what don't you like?'" and "ask how we are feeling." However, many children and young people did not feel that this matched their experiences of healthcare, with one saying "they never really explain things to me."

4.2 Using words children and young people understand

A crucial part of communicating with children and young people is using words that they can easily understand, but the failure to do this was frequently identified as a negative part of healthcare experiences and as a main barrier to children and young people's understanding of and access to services.

83% of children and young people we asked disagreed with the statement 'Nurses and doctors use words I understand.' This was particularly a key issue for the 4–7 age group, one of whom said **"I never know what they mean."** Although they did not often experience it, 95% of children and young people we asked agreed with the statement 'I like it when nurses and doctors use words I understand.' When we asked children why they liked it when healthcare staff used words they understood, children of all ages linked poor communication with increased fear, as these three answers emphasise: **"It makes me feel scared when I don't understand", "I think health services are scary because I don't know what is happening or what is going to happen, "if they use words I don't understand, I don't know what is happening."** Children also expressed reluctance to ask healthcare staff any questions about their treatment because they assumed they would not understand the answers healthcare staff gave.

Children wanted healthcare staff to **"use normal common words please"** and **"break it down"** into simple language. They explained this involved removing jargon and medical terminology and instead using **"nice, easy words so [children] don't have to ask questions as much,"** something a few children referred to as 'translating.' They suggested healthcare staff should **"get down to the level of the young person"** in the way they communicated to **"make it more informal"** and **"explain in a way we speak to our friends."** As well as using clear, age appropriate words, some children suggested healthcare staff could use pictures, diagrams and props to explain things more clearly.

Using words that children and young people can easily understand is likely to have other positive effects beyond reducing fear, for example increasing children's ability to engage and participate in their care. One child summarised, **"if they use the complicated words I prefer if [healthcare staff] talk to mum and dad but if they use words I understand I prefer them talking to me."**

4.3 Reassuring and enabling language

When discussing what would help children feel more comfortable in healthcare settings generally or in specific situations such as a GP appointment or having an injection, many children gave examples of reassuring and empowering communication they would like to hear from healthcare staff. This was particularly true for the 7–11 age group. One child explained that when receiving information, they also wanted doctors to **"reassure me and encourage me not to be scared."** Similarly, other children asked **"tell me 'it's okay, you'll be ok'", "tell me I'm not going to die",** and suggested healthcare staff should make comments like **"don't worry, it's quick."**

Likewise, children suggested healthcare staff should **"tell me I'm strong,"** and when discussing a case study of a boy who was scared of the dentist, other children suggested healthcare staff should **"tell him he is brave"** or **"have anyone tell him he is brave"** in order to reduce his fear. Similarly, one child say they liked the way healthcare staff talked to them **"because they tell me I'm big and strong."**

4.4 Communication style

Half the 7–11 year old's we asked said they liked the way healthcare staff talked to them, and those who did pointed to the reasons discussed above, such as reassuring and informal language. Another key point was a desire for communication to be impartial and non-judgemental in order to reduce feelings of embarrassment.

On the other hand, children described negative communication from healthcare staff which included shouting, **"harsh voices", "a loud voice,"** and communication that sounded cross and accusatory. Children also described healthcare staff **"reading from pages"** with **"no eye contact"** as examples of bad communication which led to negative experiences.

4.5 What information do young people want?

Although it did not rank highly in the ranking exercise, the importance of explaining things to children emerged as a clear priority from other conversations, and many children talked frequently about wanting healthcare staff to explain things to them. They described the world's best healthcare professional as "someone to explain what happens next" whereas the world's worst would give "no explanations." Receiving clear information about their treatment could reduce feelings of apprehension and fear, with one child explaining **"I don't know what an instrument is and when I don't know what it is and they use it on me, it feels a bit strange and scary."**

Around three quarters of the children we asked said they wanted healthcare staff to tell them what they were going to do beforehand and explain their treatment to them. One child explained "I want to know what's going to happen before it does as it makes me feel less worried" and others talked about how being informed would make them feel less scared beforehand and less surprised during intervention such as an examination, injection or treatment. One child said **"I don't want anything to happen if they lied or did not explain it, I want them to tell me the truth."**

A few children used their own experiences to support this view, with one saying **"I once had something on my elbow and they told me everything and I can't even imagine what it would be like if they didn't tell me."** A younger child in a different group mentioned that they had recently had an injection and had not been told what would happen or why, so it was a big surprise and it hurt. They said the best doctor would have "helped me understand."

This applied to a range of circumstances, with several children explaining that if they were seriously ill they "would want to know what is going on." Some young people talked about wanting to know if there was something wrong with them before their parents did, and another added "I like it because I get to know what is happening and it gives me a chance to be brave."

However, around a quarter of children did not want to be given information in advance as they thought it may make them more scared. One child explained **"sometimes it makes you freak out when you know what they're going to do"** and said they would want to be put to sleep without knowing beforehand.

Whilst a majority of children thought that receiving information would be an improvement, some concluded that it would be best to have the choice whether to be given this information or not.

4.6 Explaining risks and benefits

Young people in the 11-14 year olds' group felt that not knowing about side effects, risks or risks to fertility could put them off accessing support. They thought that "having information about the risks" would make them feel calmer. Likewise, one 7-11 year olds' group agreed a key barrier was feeling nervous about things going wrong, and suggested that children should be given more information and an explanation of what would happen if something did go wrong to address these concerns.

The 7-11-year olds we spoke to were more divided about whether they would want information about risks, with just over half agreeing they would, many feeling unsure, and some saying they wouldn't. One said they wanted to know in advance **"so it isn't a big bad surprise"**, with another adding **"if I know the risks it would make me feel better."** Often children imagined worse risks than were realistic, for example being concerned about dying when having an injection, and therefore thought "knowing it's not going to kill you" would help them feel better. However, some children disagreed and thought being informed of risks may make them feel frightened or stop them from accessing support: **"I'd get really scared and say to my dad I didn't want to do this anymore."**

Several children suggested healthcare staff could explain the risks but then take time to explain what they were doing to prevent those risks from happening, this style of communication would inform them without increasing their fears. Most children wanted the benefits or reasons behind treatment

to be explained to them, suggesting healthcare staff "tell [him] that the medicine will make him feel better" or explain that a filling "prevents infection to the tooth."

We spent more time discussing this topic with the 11–14 year olds' group. They were given materials about having an appendix removed, receiving a vaccine at school and getting a filling, with information about the benefits, risks and the likelihood of each risk based on information from the NHS website. They were then asked to produce materials communicating the benefits and risks they would want to know about in the way they would want them to be explained.

All the young people included some information on risks in their materials but framed these with reassuring language, for example **"don't worry, talk to us if you are concerned."** All emphasised that risks and complications were unusual, writing **"these are the risks but they are very rare"**, **"sometimes, some people may have side effects. But don't worry, it's rare!"** and **"you can have an allergic reaction but 1 in 100 people get that."** They focused more on the benefits of the intervention, writing **"it helps your immune system"** or **"there may be temporary side effects but I'm much more protected now."** They agreed that they would want to be made aware of the risks and benefits and that this would help them understand what was happening.

4.7 How do young people want to access information?

Children and young people continued to value face-to-face interaction with healthcare staff as a way of accessing information. Some also suggested phone calls and video calls may be useful, explaining that they thought it was "better to have a chat" compared to written forms of communication.

However, one young person suggested that there should be "a lot more flexibility" with how healthcare staff communicated and how children received information, and several young people suggested a range of alternatives that children may want to pick from. Children and young people suggested they could be shown what was going to happen to them through videos on YouTube or TikTok. Some wanted to receive information via text as this meant "you can read it when you want" and could reduce barriers for young people who were reluctant to have face-to-face conversations.

Other suggestions included pamphlets and leaflets in schools and health settings, as well as pamphlets to increase parental awareness of services. Young people also suggested outreach events and workshops in schools and homes to increase the level of knowledge and confidence young people have in healthcare settings, but also to improve the knowledge of parents, carers and teachers who can then pass on that information to children.

5. Voice, involvement in care and decision making (NGA review questions 1.1, 3.1, 3.2, 3.3, 3.4, 5)

The level of involvement that children and young people wanted in their care varied, from being able to talk to a healthcare staff and ask questions at one end to being allowed to make their own decisions about their health and care at the other end. Despite this variation, nearly all the children we spoke to valued feeling heard and included in healthcare experiences, with only 5% saying that being listened to was not important to them. As one child put it, **"being listened to is better than anything, they can listen to you whether it is an emergency or not."**

Over 80% of children we asked said they would like to give their opinions when in health settings and they gave a range of reasons why this was important. A key reason was the need for medical professionals to get an accurate understanding of their health, to **"know the truth"** and **"understand what is wrong with you."** Many children of all ages wanted the opportunity to talk to healthcare staff themselves as they felt they could represent what was happening to them better than a parent or carer could. As one child explained, **"I like to talk to the doctor because it is my body."** A few children explained that speaking to healthcare staff themselves would stop their parents from

misunderstanding or not believing them, with one commenting **"sometimes my parents say 'you're not unwell, you just want to miss school' when I really hurt."** Some children also said that giving information to healthcare staff made them feel better, with one child in the 7–11 age group commenting **"you might get emotionally stressed... if you hold onto something that is really important."**

The children and young people who were undecided or who did not want to share their thoughts with healthcare staff often felt this way because of worries, including fears of being laughed at or told off, or because they were embarrassed **"if the thing you want to say is a bit personal."**

5.1 Asking questions

A key aspect of being involved in their own care was the ability and confidence to ask questions, which was linked to building trust in healthcare staff and reducing fear. During an activity with the 7–11 and 11–14 year olds' groups, it became clear that most children and young people had numerous questions in typical healthcare scenarios. Children were given different scenarios, including having an injection, being prescribed a new medication, having an X-ray, being told they had a problem with their appendix and would need an operation, having a check-up at the dentist or being referred to a specialist, and were asked what questions they would have in that situation.

Children and young people identified questions to help them understand, such as 'what is an appendix?' or 'how does an X-ray work?' They also had practical questions, for example 'how many times a day should I take the medicine?' or 'when is the appointment?' In each group, there were lots of questions around pain ('will it hurt?'), about staff making a mistake such as giving the wrong medication, and fears about dying ('will I die?') which was often the first question children identified and which came up in scenarios including injections, being at the dentist, having an X-ray and having an operation.

While most children had lots of questions, around half said they would not feel comfortable asking any of them. More children felt comfortable asking practical questions, with fewer saying they would ask questions about pain or side effects and only one child saying that they would feel comfortable asking whether they would die, even though that was a common concern. Children were also less likely to ask a question they thought was embarrassing, either because it was too personal or if they felt they should already know the answer, for example 'what is an appendix?'

While two thirds of children felt comfortable asking a teacher a question if they did not understand something, only a quarter felt comfortable asking a nurse or doctor a question if they did not understand. One child explained, **"you're used to your teacher as you see them every day but you don't see the doctors every day, you don't know them as well so you could get really nervous."**

Although many children felt unable to voice the questions they had, many of them thought being able to ask questions would make them feel better and less afraid, with one child suggesting "instead of going into turtle [curling up and panicking] you could ask questions about why this is happening."

5.2 Decision making and choice

As well as wanting to share their opinions and ask questions, many children and young people wanted to be involved in making decisions about their health. 16 out of 36 children (44%) aged 7–14 agreed with the statement 'I like to make my own decisions about my health', while 13 (36%) were in the middle and 7 (20%) disagreed. While wanting to make their own decisions was the most common response from the children we spoke to, this did not mean they wanted to do so alone or unsupported. Over half agreed with the statement 'I want my parents or carers to help me make decisions about my health,' compared to 30% who were in the middle and 17% who disagreed.

There was significant variation in how children felt about who should make decisions about their health and bodies. Whilst a majority talked about shared decision making between themselves, healthcare staff and their parents or carers, some children strongly thought they should be able to

make decisions for themselves, and others wanted adults to decide for them. Each of these view points are explained below.

A) Making own decisions

Some children from as young as 7 felt they knew themselves best and therefore should get to make their own decisions, with one explaining they did not want adults to make decisions for them **"because I know what is right for me,"** while a child in the 11–14 year olds group commented **"it is your body so you should choose what to do with it."**

One young person explained that their parents could not know how they were feeling and therefore may make the wrong decision: **"if you can decide for yourself, if you had tummy ache and your mum and dad did not believe you, it's not about your mum and dad deciding."** Another explained that they were not involved in decisions at all when their parents were in the room: **"when [parents] start nattering on about everything, you don't get to make a choice in the end."** Other reasons given were enjoying feeling independent and the need to learn how to make decisions later on in life: **"when we grow up we have to make decisions for ourselves...we have to learn how to progress it and learn how to do it so we can do it when we're older."**

B) Joint decision making

A majority of children wanted support from parents or other adults to help them make decisions. Comments included **"I want to make my own choices but I also need help – we need to make joint decisions."** Some children felt they should have the right to decide what happened to them but that parents provided necessary help to support them: **"parents can help talk it through with you, they can help you make good decisions"** with another commenting **"it is your choice but if something is too complicated... you might choose not to do it when it is vital."** Other children explained that their parents knew more than them and could act in their best interests: **"your parents may know better because they have been alive more."**

Most children felt decision making should be shared in some way, with some believing **"we should make our own choices but [parents] should have an input on what happens"** and others feeling **"parents and the actual person it is happening to should have an equal say."** This principle of joint decision making also applied to healthcare professionals too; when discussing the world's best healthcare staff, the 11–14 year olds' group suggested it would be someone **"who helps you make decisions but does not tell you what to do."**

C) Adults deciding

Some children did not want to be involved in decision making. They felt their parents would act in their best interests better than they could, with comments including **"my parents know what I need", "what if I have to take medicine, but I don't want to take it"** and **"I would just eat chocolate and chips. This is not good for you. Your mum would know what's best for you."** Other children were worried they would make the wrong decisions, with several comments such as **"I could be wrong."**

Overall, most children aged 7–14 wanted to be involved in decisions about their health and care or consulted in some way. Even those who mostly wanted adults to make decisions talked about the harm that could occur if they were not consulted at all: **"[adults] know the best for you. But if you don't want to take something and they force you, you would get really nervous"; "they have more experience so know what to do...but at the same time, if you're in the dentist and you don't want to do it and they make you, you might start shaking and then things will go wrong with your teeth."**

Outside of conversations about decision making, children talked about wanting the choice to stop situations they found particularly difficult. Some children had positive experiences of this: **"if it does hurt, you can tell them and they will listen,"** whereas another explained she didn't trust doctors **"because they gave me a shot once and I said 'ow' and they didn't listen."** The 11–14s group also explained that the 'world's' best healthcare setting' should have a **"tool like a panic button to use when you want a procedure or treatment to stop."**

5.3 Barriers to involvement and decision making

Children and young people identified several barriers that reduced or prevented them from participating in their own care. The most commonly identified barrier was a lack of understanding. As mentioned above, many children felt they did not understand what was happening in medical settings, and most struggled to comprehend what healthcare staff talked about, with 83% disagreeing that 'nurses and doctors use words I understand'. This lack of understanding reduced their confidence to share their opinions or be involved in decision making. Lack of understanding was a wider issue for many children and young people, please see section 4.2 for more information.

Another barrier to participation was feeling embarrassed, with one young person from the 11–14 year olds' group commenting **"I get scared and embarrassed, too nervous to say it out loud"** and a child from a 7–11 year olds' group similarly stating **"something might be really important but you can feel too embarrassed telling them."** Others talked about wanting to be more involved but not thinking they were allowed to be, while some were concerned they would be told off if they said how they really felt: **"if I say no then I would be worried about getting in trouble with my parents."** Finally, some children and young people strongly disliked telling others how they were feeling and said they were unlikely to tell either healthcare staff or a parent or carer if they were unwell or had any questions, this seemed to be particularly the case for children in the alternative provision setting and for looked after children.

5.4 Supporting children's participation

Many children and young people emphasised that they needed support from healthcare staff and parents in order to be involved and the 11–14 age group felt that the younger children were, the more support they would need. One young person explained how **"the setting makes a difference but also the health person makes a difference"** to how comfortable they felt participating.

Some children said they did not know what would help them to participate but many others emphasised the importance of healthcare staff explicitly giving them permission to share their feelings and inviting them to talk. One young person suggested that the main factor in enabling them share their opinion was **"the willingness of the doctor to let you have a say"**, suggesting **"they should tell you that at the beginning"**. A child in a different group said a doctor should tell you straight away that you are allowed to ask questions, 'tell me I can speak'. The importance of being *invited* to talk came up in multiple groups of 7–11 year olds, with children commenting **"doctors should say 'what do you want to ask?'"**, **"they should ask you for your questions and thoughts"**, **"ask me 'what do you think?'"**

Children also wanted healthcare staff to give them the information they needed to better understand the situation. One child explained, **"when starting to make your own decisions you need lots of support, doctors need to explain and provide lots of information to help you do this."** This information could be provided **"using clear words you understand"**, to reduce the need for children to ask too many clarifying questions which they may be too reluctant to do. One young person in the 11–14 year olds' group suggested that there could be 'a bank of resources' including pamphlets and videos to help young people understand different situations and feel more able to speak up.

Several children suggested that it would be easier to participate in non-verbal ways, with one suggesting there should be the option to **"write it down, text it, draw it"** and another suggesting **"writing questions down or a question box"** which would help ahead of a face-to-face session. Other comments focused on privacy, and the importance of not feeling overheard and being in an individual room. Some children mentioned the importance of building a trusting relationship with healthcare staff, as "feeling you have known them for a long time and you can trust them more" may make a child feel comfortable asking questions, sharing concerns or expressing preferences.

Other factors which children identified as contributing to a positive health and care experience overall were mentioned again in these discussions, including being in a home-like and comfortable space, friendly staff, a member of staff of the same gender and playing distracting games while talking.

6. How children and young people want to be supported (NGA review questions 3, 3.1, 3.2, 3.3, 3.4)

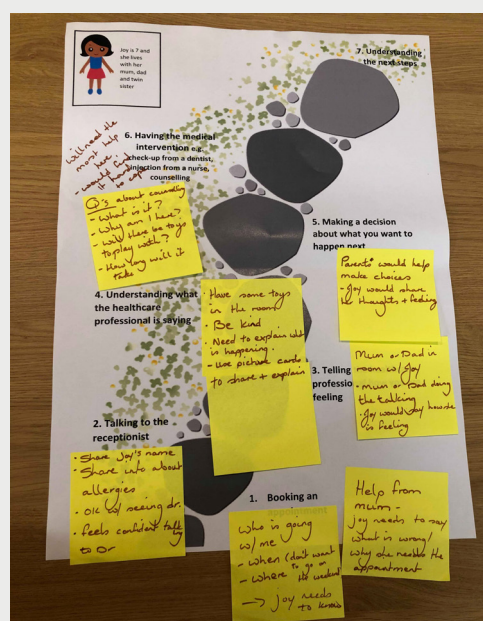
Children and young people emphasised the value of being well supported when in healthcare settings and explained they wanted those supporting them to provide comfort, understanding and help with decision making. One child explained that **"parent support is really important, especially for younger children,"** while others talked about the importance of support from friends which "helps us not be lonely," and explained how a **"lack of support from teachers, parents and the general environment around you"** could contribute to negative experiences of healthcare and could act as a barrier to accessing services in the first place. Children often felt they were unequipped to handle healthcare situations due to their age and needed adults to support them. One child explained **"when you're a ten year old kid like me, you might be quite unaware of things so you might need your parent or guardian to help you in those times."** There is more detail below on how children told us they want to be supported and what they see as the role of supporters in their care, including the role of parents and carers.

Pathways activity

Young people in the 11–14-year olds' group were given a 'Pathways' activity where they were asked to think through what support different children might want at different stages of accessing healthcare. The healthcare journey was broken down into 7 steps:

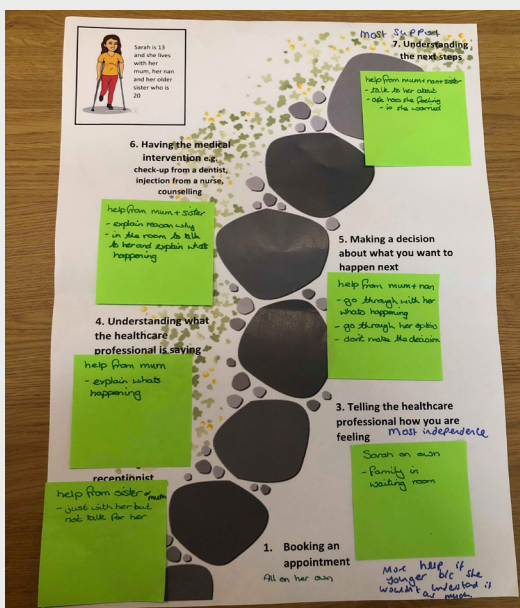
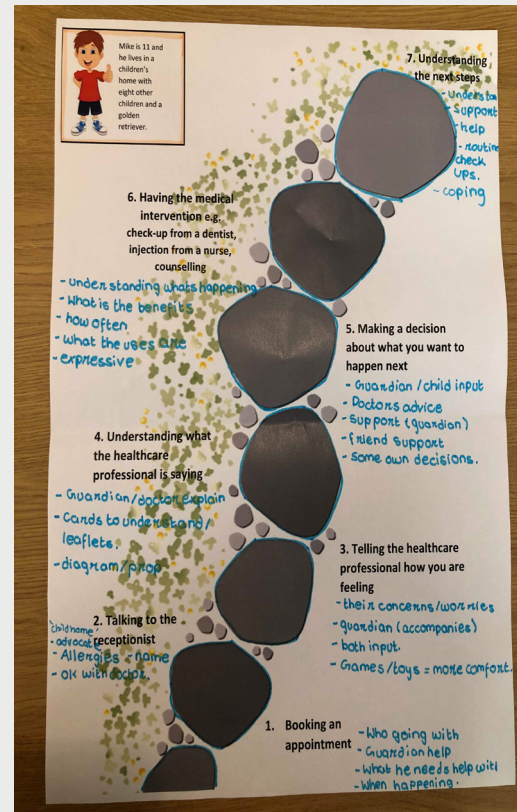
1. Booking an appointment
2. Talking to the receptionist
3. Telling the healthcare professional how you are feeling
4. Understanding what the healthcare professional is saying
5. Making a decision about what you want to happen next
6. Having the medical intervention e.g. check up from a dentist, injection from a nurse, counselling
7. Understanding the next steps

Several young people worked on the case study of Joy, a 7-year-old who lives with her mum, dad and twin sister. They thought she would need quite a lot of help and support from her parents throughout because of her young age and thought she may be "too young to understand fully." They thought Joy would need practical help, for example with booking an appointment. The young people also thought Joy would need emotional support as she might be "nervous and intimidated because of lots of people, big hospitals etc" and this emotional support was particularly important when a medical intervention, such as an examination or injection, was taking place: **"Joy needs her parents by her side to give her moral support."** The young people thought Joy's parents would play a very important role in helping her understand what the healthcare professionals were saying, suggesting **"her parents will explain it in a way which is comfortable for her and easier to understand."**



Healthcare professionals would also need to support her to understand by using simple language and picture cards, and they suggested that "a nurse who is really good with children" would help at all stages. All the young people we spoke to felt that Joy should talk to the healthcare professional herself and tell them how she was feeling. Whilst the young people thought Joy's parents should make the vital decisions for her, they thought Joy should be allowed to share her thoughts and one young person said Joy should be supported to make some decisions for herself.

Others considered a case study of Mike who was 11 and lives in a children's home. The young people thought Mike "should have a little bit of help but enough independence so he knows what to do when he is older." They thought Mike's support could come from his guardian, foster parents or a 'child home advocate' and thought Mike would need practical help with booking the appointment and talking to the receptionist. However, they felt Mike should do most of the talking to tell the healthcare professional how he was feeling and what was wrong. Privacy was seen as more important at this age, and several young people suggested Mike might want to be in the room by himself at times where appropriate. They agreed that Mike would need support to understand what the healthcare professional was saying, and that the adults with him and the healthcare staff both had a role to play in helping him to understand. Young people suggested they could use cards, leaflets, diagrams and props to help him understand. The young people thought he would want most support during the healthcare intervention in itself, both to understand what was happening and why but also moral and emotional support. They also agreed that Mike should have some input into decisions and next steps, as should his guardian or foster parent and the healthcare professionals involved.



Three of the young people worked on a case study of Sarah who is 13 and lives with her mum, her nan and her older sister who is 20. The young people thought she should have more independence and, importantly, more privacy and agency "because she is more mature" but all agreed that she would still need support. The young people had different opinions about whether she would need practical help with booking an appointment and talking to a receptionist, with some thinking she would need most support with this stage. All agreed that the most important step was for Sarah to talk to the healthcare professional directly and tell them how she was feeling, and all felt she should be actively involved in the consultation. Two out of three young people thought she might want to be in the room on her own for this part, with her family in the waiting room.

They agreed that Sarah would need some support from her mum, nan or sister and from healthcare professionals with understanding, particularly understanding any next steps. All three felt Sarah would need the most support when having an intervention. The young people agreed that at 13, Sarah should have a say in decisions about her care but that she would need support and input from her mum, nan or sister with this. One wrote **"adults can tell her whether hers is a good decision and help her make a good decision,"** and another thought Sarah's family should go through all her options with her but that the ultimate decision should be hers.

The Pathways activity revealed a significant amount of agreement between the young people who all felt that the older children were, the more independence and agency they should have and the younger they were, the more support they would need throughout the process. They thought that all children and young people would need some support from parents or carers and from healthcare staff, but most of the young people differentiated between different types of support that would be needed.

Overall, they felt children and young people of all ages would need the most support during an intervention or examination when they were most likely to be feeling frightened and would rely on the moral and emotional support provided by family. Children and young people would also need support with practical elements of accessing healthcare, as well as with understanding what healthcare staff was saying, though the amount of help they needed should reduce with age. There was considerable consensus over the importance of children of all ages being able to talk for themselves and share their concerns with healthcare professionals directly. Finally, they thought all children should be included in decision making to some extent, but the balance between the parents and carers and the child's views would shift as the child got older.

6.2 The role of parents

Parents and carers have a crucial role to play in their children's experiences of healthcare. Children valued many different aspects of the support their parents gave them in health settings, including practical support; emotional support; 'translating' what healthcare staff were saying and helping children understand what was happening; support with joint decision making; advocating for their best interests; providing reassurance; safety and security; and providing comfort.

Children and young people said they valued parental involvement because otherwise they **"would feel scared and a bit lonely"** and because they felt **"more supported and more comfortable with [their] parents"** than with healthcare professionals alone. They wanted parents to physically comfort them, commenting **"when I feel unwell it is nice to get cuddles from mummy"** as well as help with communication, explaining **"parents are very supportive and can help you understand what is going on"** and **"our parents might tell [the doctor] something important."** This also helped reduce their fears, with one young child explaining **"I don't like it when the doctors check my mouth so...I need my mummy to help me with the scared."**

The ability for parents to provide comfort and security in situations which otherwise made children feel uncertain or scared was mentioned by children of all ages and was particularly valued. Nearly all children and young people we spoke to (over 90%) wanted their parents with them during an intervention such as an injection, in order to provide comfort and reduce fear. The world's best healthcare experience was described by a child from the 4–7 age group as being one where **"mummy and daddy can stay,"** and likewise a child in the 7–11 age group said it would be one where **"parents come into appointments and injections with you."**

However, while children valued parental support, not all children and young people wanted their

parents with them at every stage of the healthcare process or agreed on what the role of parents should be. 40% of 7–11 year olds and, perhaps more surprisingly, 40% of the 4–7 year olds we spoke to agreed with the statement “I would want to see and speak to the doctor on my own” It is interesting that this was the same percentage for both younger age groups, while a slightly smaller proportion of the 11–14 age group felt that way. Even the youngest children who felt this way were able to explain their reasons, including a desire for privacy, having high levels of trust in healthcare professionals, and feeling more comfortable with healthcare staff alone.

Some children of all age groups also explained how parental presence during appointments could be actively unhelpful. Children explained their parents **“might interrupt,”** and that their level of concern could be stressful and disruptive: **“my mum gets too worried and is annoying”, “they might make a big deal out of it....”** One child explained, **“sometimes having [parents] involved makes it more difficult... [when] they start nattering on about everything, you don't get to make a choice in the end.”** Some children also expressed the less encouraging motivation of not wanting to worry their parents or be a burden.

Nevertheless, most children (60%) did not want to talk to doctors on their own because of the support their parents offered. These children explained how their parents acted as translators in medical settings and helped them comprehend the situation: **“I don't understand the things the doctors say, so my mum will tell me”** and made them feel safe, including from worries around pain and concerns around strangers coming in if they were left alone. Most of the group agreed their parents “help you understand and relax a bit” and were “more supportive” than talking to healthcare staff alone.

Children also differed in their view of the role that parents should take during conversations with healthcare staff. Just over half of the children and young people we spoke to preferred it when healthcare staff talked to them more than their parents and they wanted their parents to support them to participate and share their opinions, with one child explaining **“mum and dad might help but they might not know as well as me.”** On the other hand, the other half wanted healthcare staff to talk mostly to their parents, because **“parents might tell the doctor something important.”** Overall, most children wanted their parents to support them to understand and feel less afraid, and to be more involved or more in the background of conversations in ways that supported that end.

6.3 Others: advocates, teachers and friends

Children and young people valued support from a range of trusted adults and from their friends, not just from parents. Children and young people from the 7–11 and 11–14 year olds' groups suggested they would also get support from adult siblings, “family friends you trust”, teachers, grandparents, friends, priests, carers, youth group and club leaders, school nurses, childminders, uncles and aunts, first aiders and pets. Children and young people talked about the importance of being able to tell trusted adults they were unwell, having adults go with them to healthcare settings so they were not alone, and having wider family and friends visit them if they were staying in health settings.

For some children this was valuable in addition to the primary support they received from their parents but for a small number of children we spoke to, this support was more important and appropriate to them than support from parental figures. One child explained that they did not want their parents to be with them in health settings but said **“I want my friends to come and take care of me instead.”** Another child explained they would want support from “an adult I trust,” but for them, that did not include their parent. Several children in the 7–11 year olds' groups felt it might be difficult for a child to tell their parents that they were unwell and ask for help but thought they might be able to tell a trusted and well known teacher instead, who could then communicate with their parents for them.

We discussed advocates with the 11–14 year olds' group, but there was limited awareness of what the role meant and no personal experience of interactions with healthcare advocates in the group, other than one young person who had a family member who was an advocate in a non-health setting. There was an awareness that people could have “training on how to support others” and we discussed the

qualities the young people would look for in an advocate and for anyone giving them support in a health setting. The young people emphasised the importance of them being available to help and not turning them away; not overreacting and staying calm; being empathetic and understanding; good listening skills; being confident; and being confidential.

Children in the 7–11 age group were given case studies of children with different home lives and asked to think about what barriers they might face and what support they would need. In this context, more children were able to recognise that not all children would want or be able to access support from a parent and they were able to identify other sources of support. For a child living a foster home, support could come from **"the owner of the foster home he likes and trusts," "a best friend [who could] tell the adults"** and having their **"closest friend come with them."** When discussing the needs of a child with three siblings and a single parent, children in our groups suggested his parent might be too busy to support him with healthcare, particularly "if they work long hours" but thought he could ask a childminder, teaching assistant or best friend for support instead. There was agreement that all children and young people needed support from others to help them access health services, understand what was happening, make decisions but above all, receive comfort and reassurance from those supporting them.

The importance of wanting comfort and emotional support was also the reason that many children also talked about wanting support from pets and animals in healthcare settings. **"Playing with animals", "support from dogs", "animal therapy", "dogs to keep him calm and feel comforted"** are examples of some children's suggestions, with one child explaining **"Before I had surgery, I was scared as hell... my mum was crying, I would have liked to have an animal to calm me down, it would have helped me feel calm."**

7. Independence, privacy and confidentiality (NGA review questions 1.1, 1.3)

7.1 Independence

As explained, some children and young people wanted to have greater independence in healthcare settings and rely less on parental or other support. Reasons included a desire for privacy, feeling more embarrassed with parents in the room, wanting a chance to be independent and to be brave, seeing independence in healthcare settings as a way of preparing for adulthood, and not wanting to worry parents or deal with parents' emotions. Several children, particularly those in the Alternative Provision setting, expressed that they "feel uncomfortable with my parents there" and expressed a distrust in other sources of support. Several of the children and young people who expressed a desire for independence explained that it had changed over time and they had wanted more support when they were younger. One young person in the 11–14 year olds' group commented that they "definitely" wanted to discuss things with their doctor on their own **"but this has changed over time... I would have picked my parent when I was younger."**

A few children and young people wanted to be by themselves but did not think they had the right to any independence or privacy in health settings. One young person in the 11–14 year old group expressed a strong preference to be by themselves in medical appointments but did not think that was possible, explaining **"definitely I would rather be by myself but I'm not sure if I could as there is a requirement not to be on your own if you are under 16."** This was similar to a child in a 7–11 year old group who said they may want to talk to a doctor without their parents but **"If I say that I might get into trouble, I would be worried about getting in trouble with my parents."**

7.2 Privacy

The children and young people we spoke to mostly had a good understanding of privacy, both in relation to parts of the body that were private but also more generally feeling they "needed some private space" and wanted privacy in healthcare settings "when you don't want people to see you."

Children and young people talked about the importance of not being overlooked or overheard in health settings, having conversations in private rooms and having 1-on-1 appointments. One child urged **"make the doctors more private,"** in order improve their experiences of care. Increased privacy was suggested as a solution to children and young people's feelings of embarrassment or worries about people laughing at them.

Most young people in the 11-14 year olds' group wanted a chance to be on their own if talking to a healthcare professional about something private, with one explaining "if it was private, I would not want anyone to know." However, some wanted their parents to be with them for support.

However, all the young people in the 11-14 year olds' group agreed that healthcare staff should talk to both themselves and their parents about consent, privacy and confidentiality, with young people emphasising that it was important these conversations took place.

7.3 Confidentiality

Whilst many of the children and young people we spoke to understood the definition of the word 'privacy', far fewer could define 'confidentiality' and often confused it with confidence. However, when we gave them a definition, many young people were quick to tell us why they thought it was important, and it was a topic which had come up organically in previous sessions as well. The children and young people we spoke to thought confidentiality was an important feature of positive health experiences, and expressed numerous concerns and misunderstandings about personal health information not remaining confidential and being widely shared.

When discussing confidentiality, one child commented "this worries me a lot." Some of them worried that if they told a doctor something personal, the doctor might tell their wider family, their school, or even put it online and they were concerned that their friends and wider contacts would find out they were unwell and judge them. Comments included **"I don't want people to find out I have something bad with me"** and **"sometimes you don't know where your information is going to go. Don't want it to go somewhere not appropriate like going on the internet."**

Most children were not worried about their parents being told any information, with one child explaining **"It is fine because my family would never say it to anyone else."** However, a few children were concerned about what doctors told their parents about them when they were not in the room. One child explained, **"sometimes when they make me leave I don't think the doctors will keep everything confidential...they'll say can you leave the room and I don't like that because...they don't keep everything private."**

Children aged 4-11 in particular expressed a lot of unknowns and uncertainties about confidentiality and what healthcare staff would say about them and to whom. Whilst some children and young people said a solution was for healthcare staff not to tell others anything they had told them, this may well not be possible. However other children that the solution was for healthcare staff to explain to them what would happen to the information they shared with them, what would remain confidential, what would be shared, and who it would be shared. Being transparent with children and young people about confidentiality could reduce their concerns that their private information was going to be shared with their schools, their friends and even on the internet, which was often linked to feelings of embarrassment or stigma.

8. Access to and continuity of healthcare (NGA review questions 4, 8, 8.2)

8.1 Accessibility of health services

Some of the children and young people we spoke to also raised concerns about access to services. This included inaccessible or inflexible appointment times, with one child explaining **"the GP closes too early so you can't make any appointments."** Another explained they could not see the doctor because it was during school hours and suggested healthcare services should give children and families a wider range of appointment times because, in their view, "adults are more flexible than children."

Alongside comments about inaccessible appointments, some young people talked about not being able to access services at all. A young person from the 11–14s group mentioned that there was a high threshold for mental health services, **"so you might not be able to get help."** They suggested that in an ideal world, children's mental health services should "not be based on severity" with "more funding and more services" available.

Several children from the 7–11 year olds' groups also criticised long waiting times for services or inability to access services at all. One child commented **"doctors and nurses are too busy to see you,"** and another suggested that in the world's best system, there would be **"more doctors so you don't have to wait as long."**

8.2 Speed of treatment

Alongside timely access to services, some children and young people also wanted the care and treatment they received to be quick. Children described the world's best healthcare service as **"as quick as possible", "swift in and out"** with **"staff who are able to respond/help straight away."** This was valuable to children for a number of reasons, including that they could become more unwell in the time they were waiting for help, with one child saying "you could be dead by the time they reach you." Another explained that quick services more easily fit in around normal life, saying "you might have other places to be, or if you are late you could get fired from work."

A few children mentioned the importance of speed being balanced with a high standard of care, with one stating **"I want it to be fast... but not too fast or they might make mistakes."**

8.3 Location of services

Children also expressed a preference for health services to be close to home. When services were far away from their home, in an inconvenient place or required lots of travelling to get to, some children said they would be less likely to go.

Proximity of services to home was particularly important in emergency situations, with one child stating **"if I was in a lot of pain, it would be really bad going to a doctor that was too far away,"** while others focused on the risks of hospitals being too far away "you can't go too far or you might die" and "you might bleed out before getting to hospital." One child explained that it was still important for health services to be close by for routine appointments "so you can easily go there and back."

8.4 Continuity of care and seeing the same professional every time

A majority of the children and young people we asked said they wanted to see the same member of staff every time, and this was particularly important for children in the youngest age group, all but one of whom agreed they wanted to see the same person when asked in an agree/disagree line activity.

For some children, seeing the same healthcare professional mattered far less than the qualities and attitude of the healthcare professional when they saw them. A child in the youngest age group

explained **"if I saw a doctor and they were rude to me, I wouldn't want to see them again. If I saw a different doctor every time but they were kind to me, I would be fine to see a different one every time."** Likewise, a child in the 7–11 age group explained, **"I don't mind, because I just care if they are kind to me."** Other children acknowledged that it may not always be possible to see the same person, for example "if you have broken your arm and are in a rush."

However, for many children and young people the ability to see the same healthcare staff was a really important feature of a positive healthcare experience. As mentioned above, for many children seeing the same professional multiple times built trust and reduced many of the worries associated with healthcare settings. One child commented **"if you see the same person every time it will help you trust them"** and another explained **"I want to see the same doctor every time because if there was a new doctor they might be not nice. Makes you less nervous and scared."** Linked to this, several children thought they were less likely to be hurt, either by mistake or intentionally hurt by a healthcare professional they had already met. Interacting with a new person involved many unknowns and fears for some children, and there was a sense of predictability with seeing someone they had already had positive, or at least neutral experiences of.

Others, including children who had more complex medical experiences, mentioned the benefit of not needing to explain everything again to a new person. One child commented **"the doctor knows me and they know my past so I won't have to explain again."** Another young person explained that if **"the next day you see a different doctor, you will have to explain again, and they are going to do different things"** and this lack of consistency would make them uncomfortable.

Several children identified this as the main factor that could enable them to have a more positive healthcare experience, with one emphasising **"if you can't see the same doctor every time it makes a big difference."**

8.5 Choice

A few children and young people wanted to be able to choose which healthcare professional they saw or at least to have the choice to swap to a different healthcare professional if they had a negative experience or relationship with the medical professional supporting them. They suggested that in an ideal system, they would be able to "pick a [different] counsellor if you didn't like the other one, someone you like who is friendly – I could ask to go and see someone else if I found out which doctor I was going to and knew I didn't like them."

9. Pain and fears (NGA review questions 4, 8.1)

The children and young people we spoke with had lots of worries and fears associated with healthcare, but it became clear that most children would not tell parents or healthcare staff about these fears and concerns. Comments about pain and being concerned about things hurting came up in almost every activity and conversation, and children voiced other concerns such as healthcare professionals making mistakes, fears of dying and, in the third round of engagement, fears about catching Covid-19. One child from a 7–11 year old group explained their experiences of healthcare in a way that summarises many similar concerns from children of all ages: **"worried about dying", "worried about needles", "worried it might hurt."**

9.1 Pain

Children of all ages talked about pain in healthcare settings but the youngest groups most closely associated healthcare staff and settings with causing pain, with multiple comments such as **"I don't like doctors because they hurt me."** The fact that children's experiences of healthcare often involved pain was linked to the level of trust they had in healthcare staff and services, with one child explaining

they could not trust healthcare staff **"because they always hurt."** Pain was also closely linked to overall perceptions of healthcare, with one child in the 7–11 year olds' group saying that health services were scary because **"they do things that hurt me."** When discussing what made them feel worried about accessing healthcare, children of all ages expressed concerns such as **"they could hurt you," "it might be very painful," "I'm worried about it hurting."**

Children identified a range of aspects of healthcare that could hurt them, including going to the dentist and having an injection, and healthcare staff increasing existing pain. One child explained "doctors can make you feel uncomfortable if you're in pain. For example, if you hurt your arm and then they want to touch and move your arm." Children in the 7–11 year olds' group explained they would have concerns about pain in most healthcare situations and have questions such as 'will it hurt?', 'how sore will it be?', 'how much will it hurt?' although most would not usually feel comfortable asking these.

Children in the 7–11 and 11–14-year-old groups closely linked pain with the world's worst health experiences. The world's worst healthcare service was when **"treatment hurts," "when they hurt your mouth," "when they really hurt you."** In contrast, the world's best staff and services would be "gentle," could stop things hurting them, and "would put me under anaesthetic" or let young people sleep if something was going to hurt a lot.

9.2 Injections

Multiple children in every session we delivered talked about injections, with children and young people of all ages closely associating them with healthcare services. Experience of injections was often behind children's negative perceptions of healthcare. This was particularly true of children aged 4–11 as for many of them, injections had been their only interaction, or at least their only memorable interaction, with health services. One child explained health services are **"scary because they give me injections."** Another child felt that they would not be afraid in healthcare settings if there were no injections, explaining **"sometimes I get nervous and don't like what they have to do. I don't like it if they are giving an injection, but I would be happy if they didn't have to give an injection and just gave me medicine."**

The 7–11-year olds' group described the world's best healthcare services as "not giving injections when you are afraid," and said they "should not give injections." Similarly, children from the 4–7 year olds' groups described the world's worst healthcare professional as "giving you injections," "giving you pointy injections" and "using a thing sharp knife to give you injections."

9.3 Fear

Many children and young people thought health services in general were scary, with comments such as **"I am not happy to go to the doctor because I feel a bit nervous and scared."** Children and young people had a wide range of fears, alongside concerns about fears and pain.

Some children expressed general worries, such as **"at the dentist I was scared because I thought something bad might happen to my teeth."** Other children were worried about the healthcare staff being cruel or harming them in some way: **"he looks like he will do something bad to someone," "they might ask your mum and dad to leave and then say mean things to you.. like 'why are you so stupid?'"** and **"doctors might do something bad to you."**

There were other concerns, such as worries about being left alone: **"what if a stranger came in and the doctor was in a different room? Wouldn't want to be left on my own if the doctor went out the room,"** as well as fears such as **"what if my arm falls off?"** when having an X-ray and **"what if I wake up?"** during an operation.

Lack of understanding and familiarity with health settings often made these fears worse, with one

child in a 4–7 year olds' group explaining they were **"scared [of healthcare staff] because I haven't seen one"** and another saying children were frightened because **"you don't know what will happen. If you go to the dentist you don't know if they will drill your teeth out."**

Children in one 4–7 year old group explained that having "mum and dad with me always" could help reduce these fears, as could seeing the same doctor every time, having things explained to them, getting a lollypop or sticker afterwards, and being distracted by "having toys to play with so I am less scared of an injection."

9.4 Mistakes

Some children and young people were worried about healthcare staff making mistakes, whether that was **"getting the wrong diagnosis," "being given treatment you don't need",** having **"the wrong prescriptions," "doing something on the wrong part of the body"** or **"doctors doing the procedure wrong."** When explaining why they did not trust healthcare staff, one child explained it was because **"they might make mistakes."** Being worried about things going wrong led to some of the questions children had about healthcare, with several children wanting to ask healthcare staff "will you be careful?" before an intervention took place.

9.5 Dying

As was mentioned earlier in this report, many children felt worried about dying when they were in healthcare settings, even in routine situations such as having an injection. When discussing barriers to accessing healthcare, one young person just wrote "death!!!" while others talked about "worrying about dying" and needing to be close to hospital "or you might die."

When describing what they wanted to say to healthcare staff, several children made comments such as **"I don't want to die," "will I survive?"** and **"please don't kill me."** One child asked for reassurance from healthcare staff: **"tell me 'you're not going to die.'"**

9.6 Covid-19

During the third round of engagement in October 2020, several children referred to Covid-19 and had fears associated with the virus. Even before to the Covid-19 pandemic, one young person had expressed a worry that they could "catch an illness or contagious thing from another patient" when in healthcare settings, and some children continued to feel this way during the Covid-19 pandemic.

Fears of catching Covid-19 were seen as a barrier to accessing healthcare by several children and young people in the 7–11 and 11–14 year old group, particularly in the Alternative Provision setting in Blackpool where all the children mentioned this as a concern. Some children were aware the virus could kill people and expressed concerns about this, for example **"I am worried because if I have a temperature and might have the virus, it makes me worried because I can die."** There were also a few mentions of the 'NHS Covid-19 app'. However, the numbers of children who mentioned Covid-19 were quite low across the cohort.

Interestingly, several children mentioned Covid-19 in the context of confidentiality and expressed that they would not want anyone to know if they had it. One child commented that if they have the virus they would be **"worried if the doctor will tell my parents, they will tell everyone and get worried",** while another explained **"if I had the virus or something I would not want my parents to know"** and a third said **"I would not want my friends to know if I had coronavirus."** This expressed the level of stigma around catching Covid-19 that was not associated with other forms of ill-health we discussed during the sessions.

10. Barriers and solutions (NGA review questions 4, 8.1)

Throughout the sessions, children and young people mentioned numerous barriers and concerns that made it harder for them to access healthcare or stopped them from accessing services altogether. In the third round of engagement, we designed activities for the 7–11 and 11–14 age groups to think specifically about any factors which get in the way of them accessing care, and to begin to identify some solutions and suggestions to overcome these obstacles. Children and young people in the three reference groups for 7–11 year olds and the 11–14 year old reference group identified a significant number of barriers, which are summarised in the tables below.

As well as fears, which were discussed in section 9, and not understanding healthcare situations which was discussed in section 4.2, the other most common barriers were:

10.1 Feeling embarrassed

Many children and young people we spoke to, particularly in the 7–11 age group, said feeling embarrassed could stop them from accessing health services, telling anyone they were unwell or talking to healthcare professionals. Some children were embarrassed just by talking about their bodies, one child worried **"if the thing you want to say is a bit personal then people can laugh when you say it,"** another was **"embarrassed about how I look,"** and one child explained they were **"worried my parents might be embarrassed as well"** if they needed to discuss their child's health and body.

The children and young people suggested some solutions to reduce feelings of embarrassment, including having separate areas for children; making health settings more private; letting children choose what to talk about and how to talk about their bodies, particularly 'private parts'; and encouraging children to share what they were feeling with healthcare staff.

10.2 Not being taken seriously by healthcare staff

Some children also worried about not being taken seriously by healthcare staff and this acted as a barrier to them seeking help. They were worried about being laughed at or dismissed by healthcare staff, not being listened to properly and not being believed. This was sometimes children's experience of telling parents and carers that they were unwell, and some children worried this would also happen in healthcare settings and there was therefore little point in them asking for help.

We asked two of the smaller groups of 7–11 year olds to rank which barriers they thought were most significant in preventing them from accessing healthcare, and 5 out of 7 children we asked put 'not being taken seriously by healthcare staff' as a key barrier to accessing treatment, more than any other barrier. Instead, children wanted healthcare staff to demonstrate that they were listening to their concerns or symptoms and not dismiss them. Children suggested healthcare professionals should **"act more serious[ly] by really focusing"** in conversations rather than seeming dismissive or distracted, and could demonstrate this by and **"not just saying 'ok' but actually listening to me and saying what will help."**

10.3 Worries about being blamed and told off

Some children we spoke to were worried about being told off in healthcare settings or blamed for what had happened, and this put some children off wanting to seek help. Younger children in particular worried about healthcare staff that **"might shout at you and tell you that you did something wrong,"** being **"told off"** and did not want to hear comments such as **"you should have been careful!"** and **"why did you do it like that?"** These comments appear to be reflective of children's general experiences with adults rather than of healthcare settings per se, but this was therefore a concern

they carried over when thinking about healthcare. Children and young people explained that they wanted to know they were not in trouble when accessing health services and wanted healthcare staff to be understanding and non-judgmental rather than accusatory.

10.4 Gender of healthcare professionals

Some children and young people in all three age groups thought the gender of the healthcare professional they had to see could be a barrier to accessing or feeling comfortable accessing health services. This was the case most often for girls who expressed a preference to see a female doctor or nurse. Seeing healthcare staff of the same gender was described as being part of 'the world's best healthcare services' by some girls in the 11–14 age group, and one girl in a 7–11 year old group explained **"I really don't want to see a boy doctor because boys are different to girls and they don't know what we like...boys are a bit rough."** There were also a few boys we spoke to from the 7–11 year old groups who said they would "rather see a boy doctor." While the gender of healthcare staff did not matter to most children we spoke to, it was really important for a small number of children, particularly girls who said they would not feel comfortable and may not access some healthcare services if they had to see a male healthcare professional.

10.5 Interrupting daily life

Children in the 7–11 and 11–14 age groups expressed that they were less likely to want to access health services if that meant interrupting daily life too much or missing out on opportunities. Some children talked about not having enough time to fit in seeing a doctor even if they were unwell, with comments including "if you have a busy schedule you might not have enough time" or that they had "too many plans." Some children similarly talked about their parents being "too busy" to take them or make appointments.

Comments also focused on what may be missed if time was spent accessing health services instead, with children mentioning it **"interrupting social life," "want[ing] to go to a friends house" or "club you really like!"** and **"missing out on education."**

10.6 Worries and confidentiality

For some children and young people, not knowing what would happen with private information about their bodies and health was a significant barrier to accessing services and telling healthcare professionals they were unwell. Children talked about their worries that healthcare staff could **"tell everyone"** and **"tell lots of other people"** they were unwell or had a health condition and then other people would make fun of them. Some children expressed concerns that healthcare staff would tell their schools personal information about them and that this could get out more widely. A few children also talked about not being sure about what would happen to the information they gave the doctor and were worried about their privacy being breached, with one child explaining **"sometimes you don't know where your information is going to. If you didn't want anyone else to know you... don't want it to go somewhere not appropriate for you like going on the internet."** Instead, they asked for healthcare staff to be open and transparent about what would happen to their information and be clear about who would be told about their health and about any other private information which they shared in health settings.

The table on the following page summarises the barriers to accessing health services that were identified by children in all age groups, as well as the suggestions they had of how these barriers could be addressed or overcome. In many ways, this table summarises much of the information in the rest of this report as the barriers and enablers children discussed cut across all themes, including communication, support from healthcare staff and parents, fears and pain, and the healthcare environment.

10.7 All barriers and enablers

<u>Barriers</u>	<u>Solutions suggested by children and young people</u>
Feeling embarrassed	<ul style="list-style-type: none"> • Have separate areas for children • Make the doctors more private • Choosing what to talk about, i.e. "when to talk about private parts" • "Have a funny doctor" that can "make people laugh" • Encourage children to tell healthcare staff why they are embarrassed "maybe telling them why are you feeling embarrassed, they could help you" • Support from others, go with a friend
Feeling scared (including fears of the doctor, of hospitals, of death)	<ul style="list-style-type: none"> • "Have a funny doctor that makes jokes" • Calm health care staff • Being distracted, "make the focus something else" • Have toys to play with and teddies or pets to cuddle (all age groups wanted this) • Clearly explain what will happen or "show what is going to happen to me on a YouTube video" • Use reassuring and enabling language "tell him he is brave and strong" • Parental comfort and support • "See a doctor who knows my past so I don't have to explain" • Get a sweet or sticker afterwards • Drop-in, informal or video sessions to get to know the health staff • "Knowing the risks, knowing its not going to kill you"
Worries about pain	<ul style="list-style-type: none"> • Explain what is going to happen • Be gentle • <i>"Put me under anaesthetic"</i>
Concerns about catching Covid-19 and other "germs spread from someone who is poorly" in health settings	<ul style="list-style-type: none"> • Doctors and nurses should explain how to stay safe • Children and young people should ask healthcare staff <i>"how do I not catch the germs?"</i>

<p>Worried about not being taken seriously or believed</p>	<ul style="list-style-type: none"> • Healthcare staff could listen to acknowledge how young people are feeling • Healthcare staff <i>"not acting silly, acting serious and really focusing"</i> • Doctor not just saying 'ok' but actually listening and saying what will help
<p>Health services are too far away from home/take a long time to travel to</p>	<ul style="list-style-type: none"> • <i>"Come to my home"</i> • <i>"Come into school"</i> • Travel bursary • Services in each area to reduce the need to travel
<p>Not understanding what healthcare staff say</p>	<ul style="list-style-type: none"> • Healthcare staff could use clear, accessible language, as well as non-verbal methods such as props and pictures to explain things in a way children can understand • <i>"Break it down for us"</i> • <i>"Explain in a way we speak to our friends"</i> • <i>"If you don't speak English, have a translator"</i>
<p>Inaccessible appointment times <i>"the days and times might be difficult"</i> <i>"GP closes too early and you can't make any appointments"</i></p>	<ul style="list-style-type: none"> • More flexibility in appointment times • Appointments during lunch time so they don't miss school • Healthcare staff to <i>"ask what time is best"</i>
<p>Having to see a new doctor for the first time and not knowing if you can trust them</p>	<ul style="list-style-type: none"> • Having the option to <i>"see the same doctor"</i> • Previous healthcare staff could recommend new healthcare staff so young people know they are <i>"nice ones"</i> • New healthcare staff could introduce themselves to children and explain something about themselves to build trust • <i>"If they knew all doctors were friendly, it would be okay"</i> • Getting to know them first in a more relaxed environment e.g. video call or at school
<p>Gender of doctor</p>	<ul style="list-style-type: none"> • Find out if this matters to a child or young person • Giving children and young people the choice to see a male or female,

<p>Concerns about mistakes and side effects</p>	<ul style="list-style-type: none"> • Explain things to children so they understand what will happen and give them the opportunity to discuss the likelihood/feasibility of any mistakes or side effects they are worried about. • Discuss steps taken to mitigate any mistakes and how they would be handled • Reassure children and young people
<p>Don't like needles and injections</p>	<ul style="list-style-type: none"> • Many children suggested "don't give injections." • One child mentioned a nose spray.
<p>Concerns about information remaining private and confidential</p> <p><i>"Sometimes you don't know where your information is going to. If you didn't want anyone else to know you... don't want it to go somewhere not appropriate for you"</i></p>	<ul style="list-style-type: none"> • Children and young people could ask healthcare staff to explain what is happening with the information they share with them • Healthcare staff could explain to children what will happen to their information • Children and young people could ask doctors not to tell others before they share
<p>Not seeing friends if in healthcare settings</p>	<ul style="list-style-type: none"> • Have games to play with other children • Access to technology, "maybe you could go on Zoom with your friends" • Friends to visit • Play team in health settings to support children to interact with others "when you met the doctor, the play team could come in with games and if you did not have a virus you could walk around" <p><i>"if you had a virus they could bring games to you and if you didn't you could go and find games to play with other children and make friends there"</i></p>
<p>Not have internet to make an appointment or be able to attend online</p>	<p><i>No solutions identified</i></p>
<p>Worried about being told off or blamed</p>	<ul style="list-style-type: none"> • Healthcare should be understanding and non-judgemental rather than accusatory • Explaining to children they are not in trouble

<p>Health services interrupting normal life and children missing out on opportunities</p> <p><i>"interrupting social life" or "Missing out on education... I enjoy science, there's no experiments if you have to go to hospital"</i></p>	<ul style="list-style-type: none"> • More flexibility in appointment times • Accessing education if in health settings for extended period • Opportunities to remain social and play in health settings
<p>Worries about health services costing money or being too expensive, particularly when thinking about going to the dentist or opticians</p>	<ul style="list-style-type: none"> • Greater awareness of free services
<p>Children and young people not having enough knowledge or information about health services</p>	<ul style="list-style-type: none"> • Health services could communicate more with children and young people and the community. Suggestions including healthcare staff going into secondary schools, giving workshops to children and families, delivering support in schools. • Leaflets and information available in schools and at clubs • Videos on YouTube and TikTok to explain what will happen • Healthcare staff to explain what will happen
<p>Parent is unable to support their child to access services e.g. because they are too busy</p>	<ul style="list-style-type: none"> • Children should have access to other forms of support e.g. trusted teachers • More flexibility with appointment times
<p>Children not feeling able to admit they are unwell</p> <p><i>"not telling anyone you feel unwell"</i></p>	<ul style="list-style-type: none"> • Adults inviting children to talk to them, asking them questions and specifically asking them if they are okay • Other methods of communication such as question boxes being available or being allowed to write down or draw their concerns may help some children to share how they are feeling
<p>Long waiting times or delays to access services</p>	<ul style="list-style-type: none"> • More services • Faster access to treatment

In addition to the barriers listed above which were mentioned across groups, children in the 11–14 year old's group identified some additional barriers such as thresholds, concerns about fertility, and worries about being a burden. All additional barriers are listed below.

<p>Young people want to be in a familiar environment and to be in bed when they are unwell, rather than be in medical settings</p>	<ul style="list-style-type: none"> • "If hospitals were more comfortable it would help" • "Being able to read books to escape" • Access to phone and wifi • Trusted people e.g. family members allowed to stay with them in hospital "rather than being left alone in the children's ward" • Recreating a more home-like environment "not having it look as professional, having it look more normal"
<p>Worries about how medicines or treatment could affect fertility</p>	<ul style="list-style-type: none"> • Give young people information about the risks • Ask young people to talk about their concerns
<p>Mental health thresholds and not being able to get help</p>	<ul style="list-style-type: none"> • "Not basing it on severity, more funding, more services" • Greater availability of mental health services
<p>Being a burden, both to services which they saw as overstretched and to parents who would worry</p> <p><i>"worrying about being a burden... there could be someone with a lot worse than you and you would take up too much time when they should"</i></p>	<p><i>No solutions identified but this was a key concern for several young people</i></p>
<p>Sensory barriers such as bright lights, loud noises and sounds that are overwhelming</p>	<ul style="list-style-type: none"> • Calm spaces available, "quiet room could help" • Accessible services that take into account young people's additional needs
<p>Physical access barriers for children and young people with disabilities</p>	<ul style="list-style-type: none"> • "Making all services accessible"

11. Feedback on the Draft Guideline

Following the development of a draft Guideline by the Guideline Committee, NCB delivered a final round of engagement with the young people in the 11–14 reference group and with the three 7–11 settings we had previously worked with. In these sessions, we went through sections of the draft Guideline and asked children and young people what they thought of the recommendations, if they would change anything or if there was anything missing. We used a range of interactive tools, including priority lines, ranking exercises, interactive Miro boards and rating activities, as well as longer-form discussions, to explain the Guideline in accessible ways and to make it easy for the children and young people to share their opinions. Based on the committee's priorities and due to limited time with the children and young people, we focused on the sections on Communication, Information, Advocacy and Support, Risks and Benefit, Decision Making and Improving Healthcare Experiences. We also talked about the Guideline as a whole, the language used and any gaps or priorities the young people could identify.

Overall, the children and young people we spoke to were largely positive about the recommendations and thought they were important elements of delivering high-quality care to other children. Several children said that they thought the Guideline would make things better in the future and the young people felt that most of the recommendations had captured their previous comments and priorities, with one young person reflecting *"I really like that it feels you all care about my opinion."* Whilst the content of the recommendations was popular, much of the language and some of the concepts were hard for both age groups to understand, including concepts of 'judgemental,' 'privacy,' 'cultural sensitivity' and more complicated language like 'directional signposting' or 'dietically appropriate.' We often had to change the language into more accessible wording before we discussed it with them, and most found direct quotes from the Guideline quite hard to engage with.

The children and young people's views on each section of the Guideline we reviewed are summarised below.

11.1 Communication

We asked all four groups about the recommendations on communication. The children and young people were very positive about the recommendations in the section, one young person commented **"this encompasses everything we have spoken about"** and another added "this is a really good list."

All children and young people agreed it was very important that healthcare professionals communicated with kindness and compassion (1.2.2); used their names and talked directly to them; and that communication was friendly (1.2.1). While being friendly was important, the current wording: 'have a positive experience by being friendly' was only rated 5/10 because the young people thought it was not clear enough and would benefit from examples of what friendly communication meant. One young person explained, **"Your friendly might be different than their friendly.** This doesn't really sum it up, put in some examples." Another commented "What do you mean by friendly? Tell us what that means, say 'reassure them, be smiley, be welcoming."

All young people in the 11–14 group agreed it was important that communication put them at ease (1.2.1), encouraged them to participate (1.2.1) and that healthcare staff listened to and addressed their concerns (1.2.4). Most agreed it was also very important that healthcare staff checked their understanding (1.2.9), and gave them information in writing (1.2.20).

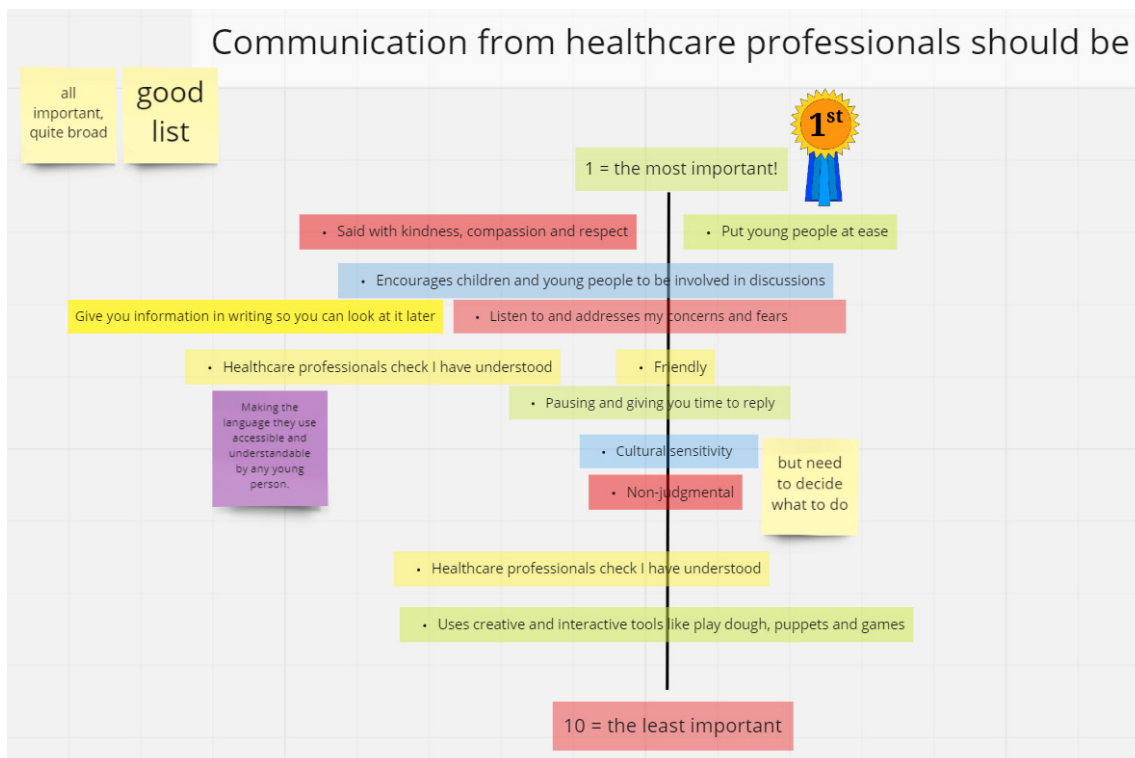
While less than half of the children we asked thought it was important that healthcare staff paused and gave them time to reply (1.2.8), several children thought this would help them a lot, with one explaining "I need time to process." Similarly, while only 35% thought it was important for healthcare staff to introduce themselves, this recommendation was highly valued by a small number of children. In the Alternative Provision setting, where levels of trust in healthcare professionals had been lower than in other groups, one boy explained that this would help him "know they're not a stranger," while another said that if a doctor did not introduce themselves "they might be a psychopath, so [it is] nice to know a bit about them first if they want you to share."

Most children and young people were unsure of what 'cultural sensitivity' meant but once it was explained, a majority agreed it was quite important for healthcare staff to communicate with cultural sensitivity (1.2.2). The 11-14 group also discussed whether it was valuable for healthcare staff to communicate with a non-judgemental attitude (1.2.2). There was some confusion around the differences between being judgemental and being able to make a judgement, with one young person commenting "surely they should be a bit judgemental so they can decide what to do if you are ill or something, so they can take some time and make the right decisions." The group decided that it was important for healthcare staff to be non-judgemental, as long as they could still be decisive.

Only 43% of the children agreed it was important that healthcare staff communicated with them how they preferred, for example using picture boards or sign language. However, it is important to note that while the groups include some children with speech and language communication needs (SLCN), a majority of the children did not have any significant SLCN and were therefore confused about what their 'preferred communicate method' might be. In other questions, they indicated that being able to choose how to communicate was important to them, for example wanting the option to write things down rather than say it out loud. But even once we had discussed different communication options, three quarters (74%) of children said they would not feel comfortable or able to tell healthcare staff how they wanted to communicate.

The only recommendation on communication that most children and young people disliked was 1.2.7: "Use developmentally appropriate creative and interactive tools to help effective communications with babies, children and young people (for example, play dough, puppets, games)." Just 10% of children in the 7-11 groups thought this was important, and the 11-14 group also thought this was the least important recommendation on communication. Comments in both groups focused on the examples given in the Guideline, with the younger children suggesting healthcare staff could use pictures, photographs, "a diagram" or "use another human being" to demonstrate, instead of play dough and puppets which they did not think would be helpful. Likewise, a young person in the 11-14s group thought the recommendation was "better for younger children. **Puppets and stuff are not really helpful or appropriate for us.**" Instead, one young person suggested "**interactive tools that are better for older kids like drawing and writing,**" while another thought "using pictures and photos would be better and easier for the doctor and us." A third suggested a question box would be a more useful interactive tool that "might be better for teens and young adults too."

Young people in the 11-14 group made many comments about the value in healthcare professionals using clear language, and thought this was a gap in this section of the guidance. One young person suggested that the Guideline section on communication should say "**make all language used accessible and understandable by any young person.**" Another explained that while it was important for healthcare staff to check their understanding (1.2.4), it would be better if they "use simple language so it is easier to understand straight away." A third young person explained "this is important because while you might say you have understood, you might not really have understood... **making the language simple means you know people will have really understood it.**"



Ranking exercise from the 11–14 group

11.2 Information

We spoke to one 7–11 group and the 11–14 group about recommendations on providing information. All of them agreed it was very important for information to be relevant to their needs, age and development (1.2.19 and 1.3.6); evidence-based (1.2.19); applicable to them; and all wanted healthcare staff to call or text them directly with information about their health or treatment (1.2.17 and 1.2.18). Two thirds of the 7–11 group agreed it was important for information to be easy to understand (1.2.19) "so you can know what is happening and not be stressed about it." One child explained this was particularly important to her **"because your parents might not speak English and they won't understand it so... you will need to understand it."**

The 11–14 group agreed that it was important for information given to children and young people to be presented in accessible formats (1.2.19), however they thought the wording of this recommendation was not strong enough. One young person commented "it needs to say more about this because it is so important and it's not really clear what this means." Another part of the recommendation in the Guideline says information should be "easy to understand, avoids jargon and explains medical terms" (1.2.19), and the young people suggested it "should also say... to use clear words."

While this section of the Guideline was mostly highly regarded, only one out of eight children in the 7–11 setting wanted to receive information regularly, while the others worried "it could be too much." None of young people in the 11–14 group thought it was important to receive information on their rights to make decisions, although most felt indifferently about this recommendation and did not think it would make their experiences of care worse.

11.3 Shared decision making

The draft recommendations on shared decision making were highly praised, and all children strongly agreed that healthcare staff should help them to make decisions about their own health. All children agreed it was important that they were involved in their own healthcare (1.3.1); given opportunities

to share their opinion; that healthcare staff explained options in words they could understand (1.3.3); and they thought it would be beneficial if healthcare staff remembered their previous opinions and checked if these had changed (1.1.3, 1.3.1) because preferences may change "when you grow up and learn."

It was seen as least important that healthcare staff give children choices over decisions which have little impact on health outcomes, for example what colour plaster cast they would prefer (1.3.1), although a few children were very enthusiastic about this recommendation too.

11.4 Risks and benefits

We spoke to one 7–11 setting about the recommendations on risks and benefits. All the children agreed they wanted to be given lots of opportunities to talk about risks and benefits (1.3.7); three quarters wanted staff to check more than once about their understanding of the risks and benefits (1.3.8, 1.3.9); and two thirds said they would always want to know about the risks and benefits. We had previously covered the recommendations on providing information and the children expressed that having clear, understandable and relevant information about risks and benefit would be important to them.

However, less than half of the children we spoke to thought it would be useful to be offered a break when discussing risks (1.3.7), with one explaining "you might want to get it over and done with and you won't want to waste time." Only one child wanted the option to discuss risks and benefits without their parents there (1.3.7), with one explaining "your parents should be there to support you."

Several children suggested that discussions on risks and benefits should be backed up by reassuring and encouraging language, with healthcare professionals "tell[ing] you that you can do it," or doing things "to make your worry disappear" such as giving stickers for being brave when agreeing to do something that might be uncomfortable. Another child thought that while understanding risks are important, healthcare professionals should focus on the benefits when presenting information because "if they just tell you the risks, you might not want to do it." Whilst the children agreed it is "good to know what is going to happen," one child suggested that healthcare professionals could also "tell you what you could do to prevent [any risks from] happening."

11.5 Advocacy and support: involvement of parents and carers

We spoke to one 7–11 group about the recommendations on parental involvement and broadly the children liked the focus on encouraging them to express their views, and on getting support from their parents or carers. 10 out of 11 thought it was really important that healthcare staff asked how much they wanted their parents or carers to be involved (1.5.1), and 10/11 said they would want their parents there sometimes or most of the time, but not always (1.5.2). Whilst 90% wanted to be asked about their parents' level of involvement, only 63% said they would actually feel able to make the choice about how involved they wanted their parents to be (1.5.1) and might need some support with this. Only 5 out of the 11 children thought it was important that healthcare staff offered to see them on their own (1.5.1).

5 out of 11 thought it was important that they could get support from other adults such as a social worker, youth worker, nurse or play specialist, if they could not be supported by their parents (1.5.5). Those who disagreed did so because they did not relate to the examples given, and one child suggested that "maybe a guardian... or someone in your family who is not your parent, like your sister or your aunt" would be better options instead.

11.6 Advocacy and support: self-advocacy

The children and young people were hugely positive about the recommendations on self-advocacy. All children and young people we spoke to agreed it was important that healthcare professionals actively encouraged them to express their opinions (1.5.14); for appointments to allow enough time

(1.2.8, 1.5.13); and they all agreed it was important they were central to discussions about their health (1.5.15) and that they were empowered to do so.

The young people particularly liked the wording of 1.5.14: "Assume that all children and young people have views and opinions about their own healthcare, and actively encourage them to express what matters to them" and rated it a 10 out of 10.

11.7 Food

We discussed the recommendations around food with the 11–14-year olds' group. Whilst they agreed that food should be balanced and there should be a choice of food that was culturally and dietetically appropriate (1.6.1), they felt a lot was missing from this section of the Guideline and could not see how it reflected their previous comments on food in healthcare settings. They rated it a 4 out of 10, which was the lowest rated section of the Guideline.

In addition to the current wording, they suggested a recommendation about having enjoyable food that children and young people want to eat. One young person explained "although [food being] balanced health-wise is important, there needs to be a wide range of options to meet needs and wants" because "it would make you feel worse if there is only food you really hate." All the young people agreed that the current wording focuses exclusively on need, and thought there should be something added about food meeting both needs and wants. They also suggested that children should be have choice and variety: "can they ask what we want?" "it is important that we have a few options we can pick from."

The young people thought there should be a recommendation to offer children "fresh food, rather than frozen food or stuff that comes out of the microwave, because this is much nicer and will help you feel better." Several young people mentioned how important it was to not be hungry in healthcare settings, which several of them had experienced previously, and suggested healthcare settings should make healthy snacks easily available to young people "in vending machines or in the room." They were less sure about the recommendation for young people to be involved in menu design (1.6.1), with one young person commenting "I think it is more important that there is a variety of food young people can choose from than a few young people having a say in the menu."



11.8 Pain

The young people really liked the section of the Guideline on 'Pain-related anxiety' (1.6.2–1.6.3), agreed with each recommendation, and did not identify any gaps. They felt that if the Guideline was in place, it would significantly improve children's experiences of healthcare, and they rated it an average of 8.5 out of 10. The young people liked each part of this section, and thought all recommendations were equally important. One young person commented "don't say something is not going to hurt if it is going to hurt – I like that it says to be honest about pain," while another added "taking a young person seriously if they say they are hurt is very, very important."

However, they had a few suggestions for changes to the wording of this section. A few young people

did not like that the title of this section was 'pain-related anxiety'. One young person suggested "maybe just call it 'pain' or 'managing pain.' I am not sure why it mentions anxiety at all?" Another young person asked, "why does it say anxiety, if this is about real pain?" They also suggested a small change to the first sentence of this recommendation, which is to "minimise the fear and anxiety about pain," which they felt could be confusing because of a later recommendation to not minimize young people's experience of pain. One young person suggested that instead, the Guideline could recommend healthcare professionals "reduce -(not minimize)- the fear and anxiety about pain."

11.9 Healthcare environment

We asked one 7-11 setting about the recommendations on healthcare environment. This seemed to be a section where the words and concepts used were particularly difficult to understand, including concepts of 'privacy,' 'dignity,' and 'directional signposting.' However, once the concepts were explained, all children agreed it was important the healthcare environment was comfortable (1.8.3); homely or felt like home (1.8.3); private (1.8.2); child-focused and age-appropriate(1.8.3); and they could have their parents with them (1.8.2).

The children also suggested there could be a recommendation to "add some colour to the room, like wallpaper" posters and decorations so the environment felt less clinical. They talked about the importance of toys and TVs and the environment being warm enough and not overly bright. All of the children in that class emphasised the importance of having calm and relaxing spaces available to them so they did not experience too many sensory things at once or feel overwhelmed. One child commented that they "need a quiet area to chill out," another suggested "a quiet area... so you don't get frustrated" or "annoyed" while a third explained "if you are injured, don't want to be in a busy crowded place." The current wording "quiet enough for rest and sleep" (1.8.3) did not seem to fully capture why this was important to the children we spoke to.

11.10 Priorities and gaps

The young people felt that the Guideline had captured most of the things that they felt were important to improving children and young people's experiences of healthcare. However, we discussed any area they felt had been left out and the young people told us how they felt about certain topics being missed out of the draft Guideline. The gaps the 11-14s identified were:

- **Injections** – although they understood that fear and concerns about injections were covered implicitly across the Guideline, the young people thought it would be good for injections to be talked about explicitly in the Guideline because of how important they were to children and young people across the previous sessions. One commented, "it would be good for the Guidelines to address the stigma around injections" while another explained "they should put it in because we mentioned it lots."
- **Meet needs quickly** – the young people questioned whether there were any specific recommendations on the importance of health services meeting needs quickly and not leaving children and young people waiting for a long time, ignored or with unmet health needs. One young person commented "this is really necessary, it is really important that they are quick," and the young people said they felt 'angry' it had been left out.
- **Reassuring language** – the young people thought there could be more in the Guideline about the value of reassurance, for example telling children 'you are brave, you are strong.' When discussing the recommendation in section 1.2.4 to listen to and address concerns, one young person commented "Listening and addressing [fears] is important but so is reassuring us that everything is going to be okay. The whole emotion bit at the end is important too". Another young person commented "they should do this, particularly when you are little", and expressed

that they were disappointed that reassurance seemed to be missing from the sections they had seen.

- **Calm atmosphere and calm communication** – the young people thought that recommendations on the healthcare environment being a calm space were missing from the Guideline, although this was not a top priority for the 11–14 group. However, this did emerge as a consistent gap across the 7–11 settings. When discussing the healthcare environment, all children from the Blackpool group thought it was really important that the environment was calm and they had access to quiet areas because this would prevent them from getting 'frustrated', 'annoyed' or 'overwhelmed.' When discussing communication, all children from the Cambridge setting wanted healthcare staff to be calm, and they rated this 10 out of 10 in terms of importance.

Final conclusions

Over the past eighteen months, NCB have held 26 sessions with children and young people to hear their experiences of and views on healthcare. Whilst many children and young people of all ages found healthcare settings scary and confusing at times, they also told us how valuable health services were for helping them feel better and for keeping people safe. Children and young people told us how crucial it was to have interactions with healthcare professionals who were friendly, kind and who helped them understand what was happening. Even from a very young age, almost all children wanted to share their opinions with healthcare professionals and wanted to feel they had been listened to and, perhaps surprisingly, the vast majority wanted to be involved in their care in some way.

We discussed a diverse range of topics with the groups, including the role of parents and carers in supporting them; the fears they have in medical settings and barriers to accessing support; the healthcare environment; and how they wanted to receive information about and be included in their own healthcare.

We used a wide variety of activities to help children and young people think about and share their feelings on these important topics, including ranking exercises, role play, ball games, poster making, agree-disagree lines, Miro boards, drawing, discussions, and more. Despite healthcare being a seldom discussed topic for most of the children and young people, we found that almost every child we asked had something important to share about how healthcare services should treat children.

Engaging with children and young people is valuable for clinicians and policy-makers, but it can also be a hugely positive experience for the children who take part. We collected feedback at the end of each session and the responses were overwhelmingly enthusiastic. Children told us "I like you listening to my views, it's awesome!" said "I had a lot of fun giving my opinion" and felt the groups were "really fun, supportive and inclusive." After hearing parts of the draft Guideline during the final round of consultation, children and young people shared "I really like that it feels you all care about my opinion" and felt they had been "part of something important," which reflects the ways their views and priorities were captured in the Guideline.

We are so grateful to all of the children we worked with for sharing their views and telling us so clearly what mattered to them. They were able to share things about how they experience healthcare settings which, as adults, we may not otherwise have realised, including their worries about dying, confusion at medical jargon, desire to have a say in their care, and love of stickers! It is vital that children's views and experiences are listened to and valued when creating the policies that will affect them, and it has therefore been a real pleasure to work with the Guideline Committee who have been committed to centring children's voices throughout this work. The message that came through loud and clear and which is relevant both to healthcare settings and the wider shaping of policies, is that for children and young people, "being listened to is better than anything."

United for a better childhood

The National Children's Bureau brings people and organisations together to drive change in society and deliver a better childhood for the UK. We interrogate policy, uncover evidence and develop better ways of supporting children and families.

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