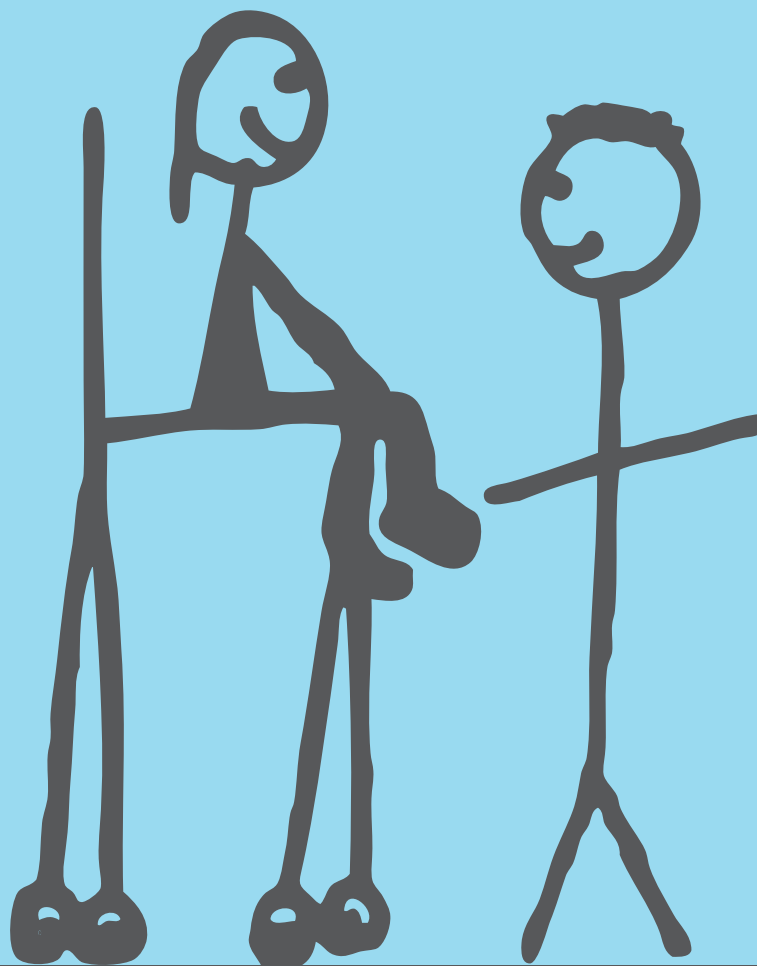


**“ Make sure  
we feel like  
we matter ”**





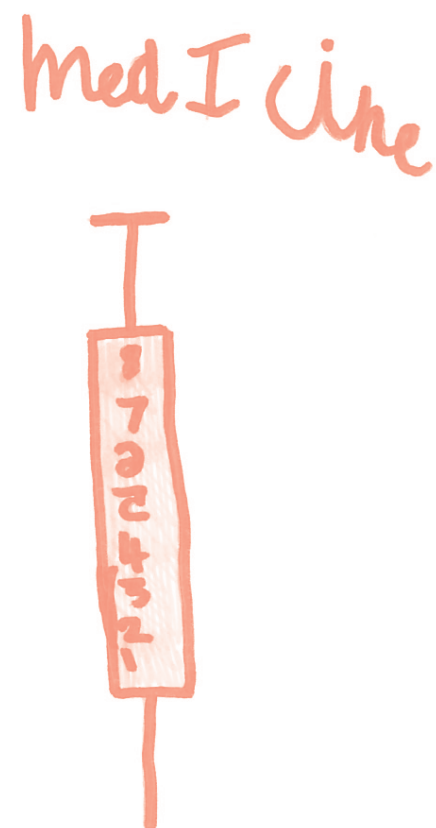
# Thanks

Thank you to the 351 children and young people who participated in this consultation. Their thoughts, opinions and experiences are hugely valuable in informing the development of policy and practice within NHS Lothian.

Thank you also to the staff from the NHS, local authorities and the voluntary sector across the Lothians who helped facilitate this consultation process with children and young people.

Services and organisations involved in the consultation:

- BLES Training
- Bridges Project, East Lothian
- Campie Primary School, East Lothian
- City of Edinburgh, Children and Families – Support to children and young people residential services
- East Lothian Looked After Young People Group
- East Lothian Youth Council
- Holy Cross After School Club, Edinburgh
- LGBT Youth Scotland
- Lothian Child and Adolescent Mental Health Service/Early Psychosis Support Service
- MEHIS
- North Edinburgh Childcare
- Pirniehall Primary School
- Through Care Group
- Trinity & Victoria After School Club
- West Lothian Youth Action Project
- West Lothian Youth Congress
- Women's Aid East and Midlothian



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“NHS should be thinking of ways of supporting individual children and young people, not seeing them as one group.”

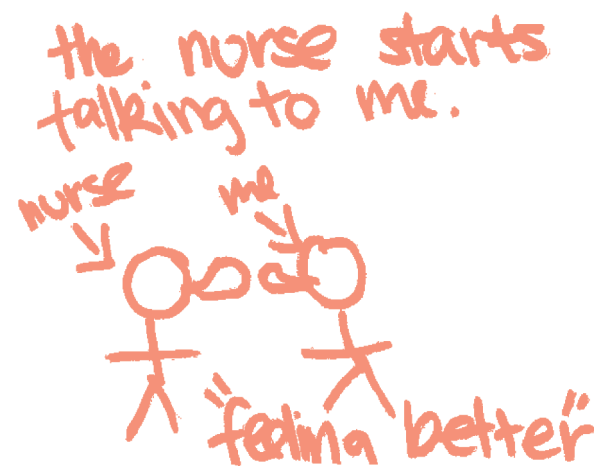
## The consultation

NHS Lothian believes that every child should have the best start in life and grow up being healthy, confident and resilient. With this in mind NHS Lothian has published a strategy titled, 'Improving the Health and Wellbeing of Lothian's Children and Young People: NHS Lothian Strategy for Children and Young People, 2014 – 2020'.

This strategy set out a vision, principles and approach for how NHS Lothian will work with children and young people, their families, the public, the voluntary sector and local authorities to improve the physical and emotional health and wellbeing of all children and young people.

NHS Lothian commissioned Children's Parliament to help them consult with children and young people on the strategy and on their health and wellbeing more generally. The consultation process was to include some direct consultation by Children's Parliament and the production of a consultation toolkit with associated training so that other agencies could also consult with children and young people. The process included:

- Development of the consultation toolkit to be used with children and young people aged 3 to 25.
- Training for practitioners working directly with children and young people on the children's rights approach and use of the toolkit.
- Direct consultation with children and young people across Lothian by trained practitioners using the toolkit developed by Children's Parliament.
- Collection and analysis of children and young people's responses from the consultation sessions.
- Production of a final report and accompanying exhibition displaying key messages from children and young people.



## The toolkit

Policy consultations are usually formal processes, therefore in order to ensure that children and young people were able to engage meaningfully with the new strategy, Children's Parliament created a toolkit to enable them to do so. This toolkit included four interactive and engaging sessions that covered the following areas:

- **Session 1: United Nations Convention on the Rights of the Child (UNCRC)**  
This session provided the space for children and young people to think about their needs, introducing their rights as described in the UNCRC, as well as the intended outcomes of the new NHS strategy.
- **Session 2: Health & Wellbeing and Life Stages**  
This session explored children and young people's views about what is important to their health and wellbeing at different stages in their lives, from birth through to young adulthood.
- **Session 3: Experience of NHS Services**  
This session explored children and young people's past experiences with and current attitudes towards NHS services.
- **Session 4: Qualities of NHS staff**  
This session asked children and young people about the qualities they would like to see in NHS staff members and about the quality of the relationships they would like have with NHS staff.

This toolkit can be viewed at:

[www.childrensparliament.org.uk/nhs-lothian-consultation.html](http://www.childrensparliament.org.uk/nhs-lothian-consultation.html).

Children's Parliament facilitated two training sessions with 35 practitioners from across the four Lothian local authorities. These sessions introduced the Children's Parliament rights-based approach to working with children and young people and modelled the use of the toolkit. The toolkit could be used with or adapted to suit the age, stage and needs of all children and young people. The toolkit included suggestions as to how some discussions could be extended, depending on the individual's experience with NHS Lothian services, for example, long stays in hospital or regular treatments for an illness.

Practitioners subsequently facilitated consultation sessions, resulting in the views of 351 children and young people being gathered in total. See Appendix 1 for demographic information. Completed consultation response forms and evidence gathered in the form of drawings and photographs were then submitted to NHS Lothian. For more about Children's Parliament, see Appendix 2.



# The report

The report is structured in the following way:

**Top 10 messages from children and young people:** This section captures the key messages from the consultation and asks the reader to reflect on whether the messages are understood and used to guide current policy and practice.

**Theme 1: Life stages – what children and young people need:** The starting point for the development of any service needs to be a process of listening to the population of interest, to help understand what their needs are from their perspective and lived experience.

**Theme 2: Feeling safe, nurtured, included and respected:** The consultation is about exploring the needs, rights and outcomes for children and young people sought by NHS Lothian. To extend our understanding, the consultation process also asked children and young people about how a service might be experienced as safe, nurturing, inclusive and respectful.

**Theme 3: NHS staff:** In recognition of the central importance of staff in delivering services, children and young people were asked about the characteristics that NHS staff should have so that the strategic plan for NHS Lothian can be implemented.

**Theme 4: Exploring outcomes for children and young people:** The new strategy is based around a series of outcomes for children and young people. These are located in the rights enshrined in the United Nations Convention on the Rights of the Child (UNCRC). This section of the report presents children and young people's views on Improving the Health and Wellbeing of Lothian's Children and Young People.

In this report, we use direct quotes from children and young people, as well as their artwork from the workshops, in order to accurately reflect their views and experiences.



## Top 10

These are the top 10 messages from children and young people about their health and wellbeing, and accessing health services. There is more about these messages throughout the report.

- 1 **GUIDE US.** Children and young people value their health and wellbeing and they want to know how to and be able to look after themselves. In order to do so, they recognise that they need support and guidance from the adults in their lives – parents and carers, teachers, health professionals and others.
- 2 **TALK TO US.** Children and young people want to be spoken to directly. NHS staff need to use their names, ask them questions and engage with them as the patient, rather than talking primarily to their parents/carers. Children and young people want to understand what is being done to them and why. *“Think first – can children and young people answer questions themselves?”*
- 3 **CONSIDER OUR FEELINGS.** Children and young people repeatedly stressed the importance of tone of voice and manner of speaking, especially when they may already be nervous or scared. *“Don’t speak in an angry voice as if I’ve done something wrong.”*
- 4 **INCLUDE US.** Children and young people want to be involved in decisions, whether about their individual healthcare, changes to services or the improvement of health and wellbeing policy. They ask that NHS staff listen respectfully to them and take their views seriously. Sometimes it can be uncomfortable or difficult for them to speak up, but it helps if NHS staff are patient and ready to pay attention.
- 5 **BUILD A RELATIONSHIP.** Children and young people want to develop relationships with health professionals. When possible, they would like to see the same doctor, dentist or nurse, and for them to take their time during appointments and treatments. They want to feel as though they are understood and that someone cares.
- 6 **EMPATHISE.** Many children and young people have never been in a hospital or other NHS service before and they can feel worried or scared about being in such an unfamiliar environment. They ask that NHS staff acknowledge and empathise with this fear, and do what they can to alleviate it.
- 7 **GIVE US A WELCOMING SPACE.** Because health services can often be unfamiliar environments for children and young people, they ask that clinics, hospitals and waiting rooms be made more comfortable and child-friendly, including toys, books, posters and technology specifically for children and young people. *“When I went to the doctors, they had a really good Roald Dahl book that mummy read to me when we were waiting. It’s good that they have good books to read because sometimes you wait for ages.”*



- 8 DON'T JUDGE US. Children and young people can easily feel labelled by adults, as members of specific groups (e.g. LGBT young people, asylum seekers, children and young people in care, children and young people with mental health issues, etc.). They ask NHS staff to be non-judgemental and not have any preconceptions.
- 9 GET TECH SAVVY. Children and young people recognise the role of technology in accessing health information. Some of them felt more comfortable with the anonymity of being able to search and ask questions online, while others were concerned about the quality of information available. They ask for a reliable, easy-to-access resource online for children and young people. **"It needs to be appropriate information because some websites are dodgy. I don't think I'd ever trust it on advice and diagnosis."**
- 10 TALK TO EACH OTHER & SEE US IN THE ROUND. Children and young people discuss the experience of accessing services holistically. Each part of the experience – driving in the car/taxi/ambulance, waiting in reception, interactions with reception, assessment and treatment – is recalled in detail and is just a part of an overall experience. This is a reminder that all staff need to think about how they engage with children and young people and the impact they have on the individual's experience.

# Theme 1

## Life Stages – what children and young people need

**"Health is very important and everyone should know how to be healthy."**

NHS Lothian is committed to using children's rights as the foundation for this new health strategy for children and young people. Children's rights are those rights outlined in the United Nations Convention on the Rights of the Child (UNCRC).

A child-friendly version of the UNCRC can be found here:

[www.childrensparliament.org.uk/assets/me+us/resource-pack/Me+Us-UNCRC.pdf](http://www.childrensparliament.org.uk/assets/me+us/resource-pack/Me+Us-UNCRC.pdf).

In Scotland, children's health and wellbeing is of paramount consideration, reflected in the Getting it Right for Every Child (GIRFEC) approach, which aims to ensure all children grow up being safe, healthy, achieving, nurtured, active, respected, responsible and included (known in the context of GIRFEC as the wellbeing indicators). Aspects of GIRFEC are now enshrined in law in the Children and Young People Act (Scotland) 2014. As practitioners, NHS staff and other professionals have an obligation to listen to children and young people's views and opinions on matters that affect them. This should be reflected in the way we engage with children and young people, both individually and strategically.

The consultation began then with an exploration of needs, helping identify those things that were absolutely essential for children and young people to live a safe, healthy and happy life. Using the life stages approach outlined in the strategy, children and young people shared their thoughts on what they needed throughout their lives to be healthy and well. They recognised and appreciated the fact that as they grew up, their needs for living a full and healthy life can change.

### Early years

#### Parents/carers

Children and young people identified what new parents need to ensure the best start for their children, especially emotional and social support. They also thought about the financial impact of having a child and the need to ensure that families had enough money to support their children. They also recognised that it was necessary to know a child's background and familial health risks if the child was not the biological child of the parents or carers.

Doctors and midwives  
The right nutrition  
Child benefits  
Quite a lot of money  
A job  
New born childcare classes and education programmes  
Family interaction and bonding  
Social interaction with other new parents  
Help with paperwork if you have difficulty reading and writing  
Help with decisions  
Single parents need help and support  
Child minder  
Child's best interests at heart  
Prenatal health and regular scans  
Be sensible and mature  
Someone to talk to if they need help  
A home



### Newborns

Children and young people understood that there were specific things babies needed in order to get the best start in life. In addition to the things that will aid their physical health, children and young people emphasised the love, care and attention babies should receive from parents or carers so that they are healthy, happy and safe.

Food  
Milk  
Baby crib  
Lots of sleep  
A safe environment  
The child should be first  
The best start in life  
No gender stereotypes  
Jags  
The right nutrition  
Love and care  
Medical care and medicine  
Entertainment  
Shelter  
Baby's need breast milk  
Toys and play  
Stimulation  
Attention from parents  
Water  
Clothes  
Cuddles and kisses  
A pram  
Nappies

### Pre-school - up to 4 years old

Children and young people discussed how important it was for young children to be allowed to properly explore their environment and who they are in relation to other children. They emphasised the need for good communication with adults and the formation of positive relationships to help young children develop their own ability to communicate and play.

Love care and support  
A home  
No gender stereotypes  
A bigger bed  
Healthy food and water  
Care homes  
To learn about health  
Challenges  
Good teachers and a good education  
Friends  
Time to play and have fun  
Learn about different kinds of love and families  
Someone they can trust to look after them and love them  
Basic communication skills  
Healthy amount of discipline  
A friendly nursery teacher  
Exercise  
Doctors  
Right nutrition  
Friendship and sharing

### Primary school - 5 to 11 years old

Children and young people experience more autonomy and responsibility at this stage and it is important that they have choices and are able to make decisions about their lives. As they explore their identities and develop physically and emotionally, it is important that they have the information, support and care to allow them to progress in the healthiest way possible. "Sometimes the dentist comes to the school which is good because sometimes my mum can't take me because she's busy. It's easier when they come to the school."

Love care and support  
A home  
No gender stereotypes  
A bigger bed  
Healthy food and water  
Care homes  
To learn about health  
Challenges  
Good teachers and a good education  
Friends  
Time to play and have fun  
Learn about different kinds of love and families  
Someone they can trust to look after them and love them  
Basic communication skills  
Healthy amount of discipline  
A friendly nursery teacher  
Exercise  
Doctors  
Right nutrition  
Friendship and sharing

### Secondary school - 12 to 16 years old

Children and young people expressed the desire to learn more about their health and wellbeing. In school, they said, they talked about smoking and drinking, knife crime and 'how not to get pregnant'. They found that all of these issues were presented in a way that suggested that all young people were irresponsible and made bad decisions. They proposed a life skills class "so you would know how to take care of yourself, especially when you leave home. We want to know these things, but we don't know them or learn them in school. I wouldn't feel prepared to leave home." They said they would like to learn more about mental health, cyber bullying, additional support needs, other issues that may arise for children and young people, and where to go to get help. "Some schools have 2 weeks on health, some schools only have 2 days."

Close friends  
Exercise and sport  
Enough sleep  
A good education  
Coping strategies  
More independence  
To have confidence and be happy not scared and shy  
To get good advice from parents or confidential services  
To have privacy when you need it  
To have good advice from parents or confidential services  
Boundaries supervision sometimes and discipline sometimes  
Help and guidance to make good decisions  
Mental health awareness  
Clubs or youth groups  
Personal hygiene  
Inspiration

### Young adults - 16 to 25 years old

Children and young people discussed this stage of life in terms of independence and responsibility. They saw this as a period when they could explore the world on their own terms and make decisions about their health and happiness. Access to information and services were viewed as increasingly important as young people transitioned into adulthood. "They don't cover mental health in school health information – just how to look after your body. I had depression for two years and no one knew until a year and a half into it."

Education and money  
Friends and relationships with people  
Healthcare  
To get a job  
Exercise  
More independence  
Sexual health services and access to information and safe sex supplies  
Information about relationships and abuse  
Good food  
Sometimes counsellors/therapists  
A house or a safe place to live  
Heating in your house  
LGBT awareness and inclusion  
Free driving lessons  
A chance  
Shop discounts

The purpose of the information in this section is to ask the reader:  
"Are you recognising children and young people's voices and needs?"



## Theme 2

Feeling safe, nurtured, included and respected

**"I spend half my life in hospital."**

The consultation explores needs, rights and the outcomes for children and young people sought by NHS Lothian. To extend our understanding, the consultation process also asked children and young people about how a service might also be experienced as safe, nurturing, inclusive and respectful.

### Feeling safe means...

- A calm, quiet and clean environment.
- Doctors and nurses should wash their hands in front of you.
- Having someone to talk to without fear of being judged.
- Parents should be allowed to stay with you at night until you're 16.
- Not being left on your own.
- Having a choice of doctor (male or female).
- Knowing you can contact a nurse 24/7.
- 24/7 access to phone when in hospital.
- The nurses/doctors should let you know what process you are/will be going through before you go through it.
- Good security, CCTV and fire safety information.
- Maybe I don't want to have a certain nurse or doctor, someone should listen to why I may feel that way.
- Providing places of refuge for young people.

**"They saved my mum's life from cancer. It would have been better if they let me stay in hospital to look after her."**

### Feeling nurtured means...

- TV and toys to make you feel like you're at home and make you less scared about being sick.
- Talking to children to make them understand and listening to them.
- Calling you by your first name.
- Doctors can come and see you regularly.
- Everyone you meet should be friendly and smiley.
- Comparing things you don't know to things you know to make you feel less scared.

- Showing positivity around children.
- More relaxed and colourful waiting areas with TV or music.
- Good choices of food in hospital.
- Cuddles when parents aren't there.
- If a doctor or nurse knows you, then it's nice to see the same one again.
- Trust & confidentiality.
- Lots of TLC!
- More places for families to stay.
- Taking time to get to know you, especially if you're in hospital for a long time.
- Being a bit more playful.

"Having clocks that I can read, like ones with just the numbers and not the hands, then I would know what time it is."

#### Feeling included means...

- Being listened to and asked for your opinion.
- Allowing you to know everything that is happening with your healthcare, not just some stuff.
- Telling everyone the news (good or bad) together.
- Doctors speak to you directly, not just to your parents.
- Giving us more of a chance to make decisions about our healthcare.
- Being interested in what we are saying.
- Asking me how I want things done before doing them.
- Asking us questions and make us feel comfortable to ask you questions back.
- More awareness that the child/young person can make decisions in regards to their healthcare.
- Being prepared to explain things without jargon or being patronizing.
- Being able to use technology such as texting and being able to use our computers when in hospital is really important to us so that we can stay in touch with our friends.
- Children's evaluation cards – "just a bit of paper that's given to children every time they visit the doctors or hospital and we can say what we think." (Kids could design it!)
- Having visits to hospitals to see what's going on, some of us don't really know about hospitals as we have not been.
- Leaflets at the doctors could be more child-friendly so we want to and do read them as well.

- NHS staff should come and visit childcare places and talk to them so they have an idea of what will happen should they need to visit healthcare services.
- Due to being a minority group, some LGBT young people feel that they are slightly on the fringe of some general youth or health services. They are worried about the possible unintended barriers to participation in and access to support and immediate crisis intervention for such things as domestic abuse and mental health support.
- My consultant always asked whether I had any questions, and that if I thought of any further questions, I could call this number. This makes me feel I have been listened to.
- Feeling that sometimes when NHS staff did ask children stuff, they didn't always give them time to answer.

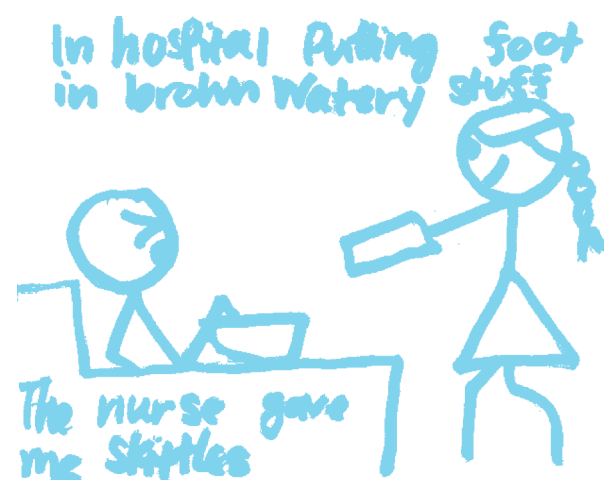
"I think you should have children's surveys too. My mum does surveys when she's at the doctors but I have never been asked to do one."

#### Feeling respected means...

- Not being treated impolitely or differently because of your age.
- Even though you're a child, your privacy should always be respected.
- Staff should always ask you if you have any questions, and properly wait for your answer, before they do anything to you.
- Not laughing at you or ignoring you.
- Talking to you directly, not to your mum and dad about you.
- LGBT-inclusive information and services.
- Training staff how to talk to children and young people, particularly teenagers, as it's a difficult time.
- Being prepared to explain.
- Encouraging children and young people to access services.
- Using simpler language.
- Not making fun of children and young people's problems.
- Not making people wait for ages.

"I went to sick kids and they said I didn't have tonsillitis, but when I went back to the doctors they said I did. Me and my dad were confused."

The purpose of the information in this section is to ask the reader:  
"What can you do to make this happen?"



## Theme 3

### NHS staff

**"They should think, 'Children are nice and I like them.'"**

In recognition of the central importance of staff in delivering services, children and young people were asked about the characteristics that NHS staff should have so that the strategic plan for NHS Lothian can be implemented. In short, the quality of NHS Lothian services, and the experience of children and young people, is grounded in the quality of the relationships between provider and service user.

#### **When NHS staff speak to children and young people, they should...**

- Use reassuring words.
- Make every person feel important.
- Be respectful.
- Not judge.
- Use inclusive language.
- Have something to say to avoid awkward silences.
- Show interest.
- Speak calmly, not loudly.
- Always say hello first and introduce themselves.
- Speak more to the children rather than the parents.
- Not be patronizing.
- Remember that if you have the same nurse or doctor and they get to know you, then you can speak to each in a friendly way because you have already got to know them.
- Speak less formally to us.

**"Can staff go on training on how to talk to children of different ages?"**

#### **When NHS staff think about children and young people, they should...**

- Think we are special.
- Think about how children will feel about different things.
- Act positively.
- Have best intentions.
- Be open-minded.
- Try to put themselves in the young person's situation.
- Believe what a child says to them.

- Ask themselves how they can help this young person according to their needs and wants.
- Think of you as fragile when you are hurt.
- Not be judgemental.
- Try to overcome the fear in children.
- Think about what else is going on in their life or if they have stuff going on at home.
- Have no preconceptions.

**"I like getting stickers at the dentist."**

#### **When NHS staff engage with children and young people, they should be...**

- Happy and smile at children.
- Patient and take their time.
- Smart.
- Confident.
- Kind, caring, polite, understanding and have good manners.
- Hospitable.
- Compassionate.
- Encouraging.
- Gentle.
- Patient.
- Inclusive.
- Genuine.
- Organised.
- Big hearted.
- Modest.
- Easy to connect with.
- Calm.
- Funny.
- Arty.
- Sensitive.
- A good listener.
- Comforting.
- LGBT trained.

The purpose of the information in this section is to ask the reader:  
**"Is this you?"**

## Theme 4

### Exploring outcomes for children and young people

#### **"It'll benefit us and we'll be healthier!"**

NHS Lothian has aligned each of the outcomes of the strategy Improving the Health and Wellbeing of Lothian's Children and Young People with specific articles of the UNCRC (see Appendix 3 for a list of the outcomes as they appear in the strategy). The children and young people involved in this consultation felt strongly that all children need to learn more about their rights, especially how they connect to and impact upon their health and wellbeing.

Using modified language, the outcomes of the strategy were shared with children and young people and they had the opportunity to discuss and comment on them. Their views and opinions provide insight into how children and young people understand and experience health services.

#### **Children and young people should get medical care when they need it.**

All participants agreed that they should be able to get medical care whenever they needed it. They felt very strongly that this was a basic human right that should not be denied to anyone.

**"I strongly agree because medical care is a basic need, you just need it. And it's your right to get it if you need it."**

**"It's standard. We take it for granted, we don't think about it."**

**"It'll benefit us and we'll be healthier."**

#### **Children and young people should have access to information to keep them healthy.**

Most children agreed that they should have access to information to keep them healthy, and that this was an essential part of their education at home and at school. They raised concerns about too much information making younger children unnecessarily worried, but this was far outweighed by the belief that children need to know how to look after themselves and about their health generally. The role of parents and carers in helping children to understand information and choices was recognised. They also appreciated that some children might not have home circumstances where they are adequately supported and so other sources of information may be required.

**"You should be able to get the information you need to stay healthy, but not too much that it makes you really worried. You should get enough to know how to take care of yourself and understand your body and its symptoms."**

**"If you don't know something, then how can you be expected to make good choices and be healthy?"**



"If you are growing up in a bad situation, then you aren't necessarily learning the best stuff or how to take care of yourself. You need good information."

"Getting good information is power. If we get told, this makes us feel better and gives us choices."

"I thought that you should get information, but that maybe your parents should have control of the information you get, and they should check it first so that they can make sure that the information you're getting is correct, and the advice you're getting is the best advice."

### **Children with a disability should get the care and support they need to live a full and healthy life.**

Without exception, all children believed that adequate, and sometimes additional, support and care was essential for those with disabilities, in order that they might be able to live full and healthy lives. Care and support should be based on the needs of the individual. A full healthy life is about physical and mental wellbeing, but it is also about learning and wider opportunities.

"They're still children even if they have a disability, and every child should have the same access to health care - it is something everybody should have."

"Children with disabilities are no different to anyone else and should therefore receive the same opportunities to live a full life."

"More help with travel to services."

"Services should be the same for all but individualised."

"There needs to be recognition of all disabilities and proper testing for learning difficulties like dyspraxia and dyslexia in schools, and proper support given so you don't leave school just feeling stupid."

"It is important all of us are treated the same and have the same opportunities if we can."

### **Children and young people should have a say in decisions that affect their health.**

The majority of children and young people felt that they should have a say in decisions that affect their health. They believed that they were capable, in most circumstances, of understanding their health conditions and medical advice given by doctors and nurses. Whenever this was the case, they saw no reason why they could not be a part of the decision-making process as regards their treatment. Concerns were only raised in regard to very young children.

"Sometimes the adults underestimate the minds of the children and think that they don't understand things when actually most of the time, they do. And when I am sick and I go to the doctor and he asks my mum what is wrong with me, when I'm standing there, and I'm the one who has the sore throat, it gets me annoyed."

"They can only see so much and they can't know everything that's going on inside us unless they ask."

"We should know what's being done to us. It makes you feel better to have a say because if you're not comfortable then you can stand up for yourself."

"They should be informed of what is going on but if they are under the age of medical consent then parents should have the final say."

### **When NHS staff make decisions about the healthcare of children and young people, they should have the child or young person's best interests in mind.**

All participants agreed that their best interests should be of paramount concern to NHS staff. They thought that if staff had other things on their minds when they were treating children and young people, then this might affect the quality of care they received. They suggested that competing concerns, like time and money, might decrease the quality of healthcare that children and young people received from NHS staff.

"I think it's their job to always do what's best for the child."

"This is very important as their decisions could impact the lives of young people. They should always have their best interests in mind so as not to harm anyone."

"Staff should see each case or patient as unique and fully consider any worries the child or young person might have with their health care and properly discuss possible options or solutions that they can both agree together."

"Because if they don't, then it could be dangerous. If they were just thinking of being quicker or something like that, then they might miss something, and then you won't get better properly."

"They should always think about us, not money or anything else."

### **NHS Lothian should work to improve the health and wellbeing of the children and young people who are most vulnerable.**

Children and young people talked about how they understood the idea of 'vulnerability'. One participant summed up their understanding as follows, "Like when you're bullied and not confident and open to threats, and maybe you're really little, or can't say what you think. Yea, I think we have to take care of people like that."

Participants firmly believed that the NHS should make sure that vulnerable people are well looked after and cared for. They showed awareness of the difficulties some people might have in seeking help, and thought that the NHS needed to find a way to make sure they received the help and healthcare they needed, despite additional difficulties. However, there was also concern that a focus on children and young people identified as vulnerable might lead to other children and young people not receiving the necessary services, support and care.

"So they don't feel like they're missing out because of something they can't change."

"They might be the last ones to ask for help because they don't want to draw attention to themselves. They might need extra help to say what they think."

"People have different levels of resilience and this may lead to discrimination if different factors aren't considered when evaluating who is most in need. How do we judge who is vulnerable?"

"Help shouldn't be taken away from Person A just because Person B needs it more."

#### **NHS Lothian should improve the quality and types of healthcare services for children and young people.**

The majority of children and young people agree that improvements should continue to be made where necessary, with a large number also acknowledging the positives about the care they already received from NHS Lothian. Some children spoke strongly about giving credit to the NHS staff for the work that they were already doing with only small suggestions for improvement.

"I do think the care is good, I know the nurses are friendly, but maybe it needs to be speeded up a bit. I have heard of some people waiting like five hours or something like that when they go to the doctors. It could be better organised - a lot of people's doctor's appointments run over."

"You can't say everything is bad or everything needs to be better because NHS staff need praise when things are done well. I think they already have excellent types of healthcare, although improvements could be made to make the children more comfortable in hospitals."

Young people did, however, express some concern about a need to improve support for mental health and the importance of not seeing LGBT identity as problematic.

"My experience with NHS Lothian is that children and young people within mental health services are neglected. Support is mainly offered when a crisis occurs rather than providing preventative care."

"As soon as you come out as LGB or T to a staff member, any issues you may be struggling with in relation to mental health are attributed to your sexual orientation and/or gender identity."

#### **NHS Lothian should have staff who are knowledgeable and skilled and who know about children's rights.**

Children and young people agreed that having staff who are knowledgeable, skilled and cognisant of children's rights was essential to improving the health and wellbeing of children and young people in Scotland. They said it was important to be able to communicate effectively with children and understand them, even when they struggled to fully verbalise their thoughts and feelings. There was some recognition that staff's knowledge and skills can be inconsistent, and vary between services.

"If doctors are nervous then I might feel nervous too."

"They need to be able to work with young people otherwise they won't be taken care of properly. Like when they talk, they need to be able to say tricky things in a way that lets you understand it and know what's wrong with you. That makes it less scary. Doctors should be friendlier like that."

"Children have a different way of thinking and adults need to be aware of that."

"I think this is very important because unskilled staff could harm children or cause damage. Young people can be vulnerable and so need to feel safe in the company of the staff."

"In general, I do think [they are knowledgeable and skilled], but for marginalised groups like asylum seekers/refugees or specific things in relation to legislation or relevant health provision, the level of awareness and understanding is completely different with each service."

#### **NHS Lothian should have a plan to check that healthcare services for children and young people are as good as they can be.**

Children and young people appreciated the value of having a system in place in order to ensure that the NHS was providing the best possible care. Older children and young people suggested that this could prevent money being wasted on unnecessary extras and ensure that the NHS continued to improve. Participants in this consultation process recognised the importance and value of direct engagement and feedback from children and young people using NHS services.

"This would be really good. Can they get inspected like schools and after school clubs?"

"It's good that the NHS are asking children and young people what they think of services and how they feel about their previous experiences or where they'd like services to improve."

"Children and young people should be involved in deciding what should be checked when evaluating services and how they could be improved."

"Yes, they should be easy to access and young people should be able to feed back in creative ways, like play or arts. And the internet can help with this."

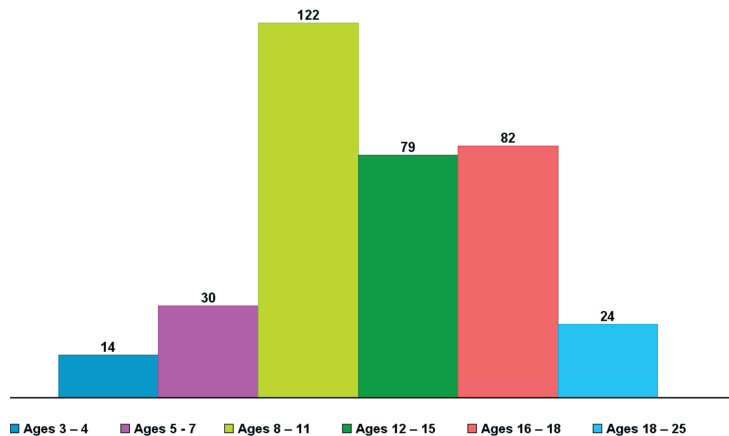
"Just a bit of paper that's given to children every time they visit the doctors or hospital and we can say what we think."



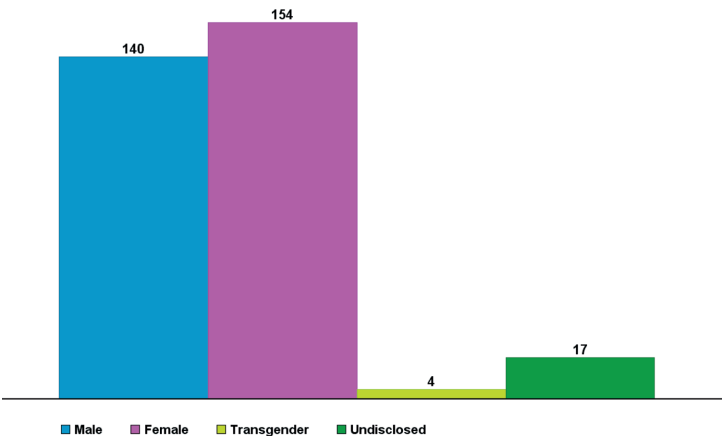
# Appendix 1

In total, 351 children and young people were involved in the consultation.

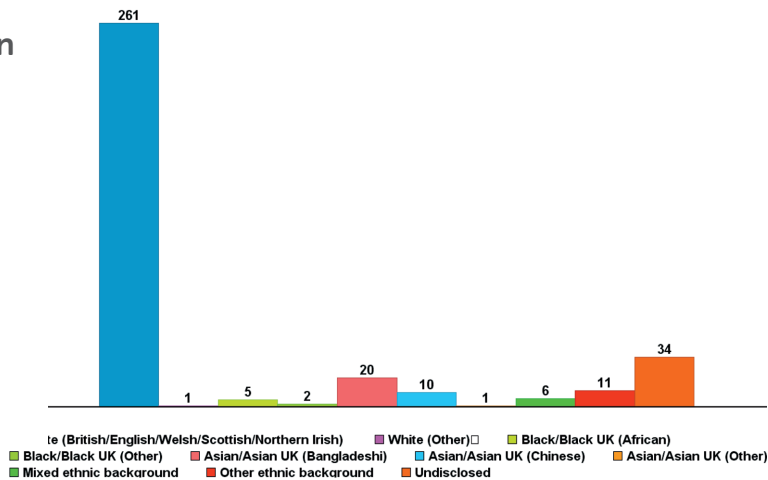
Age



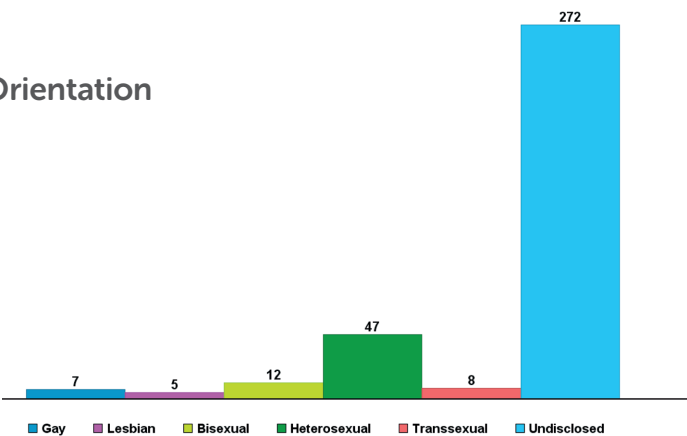
Gender



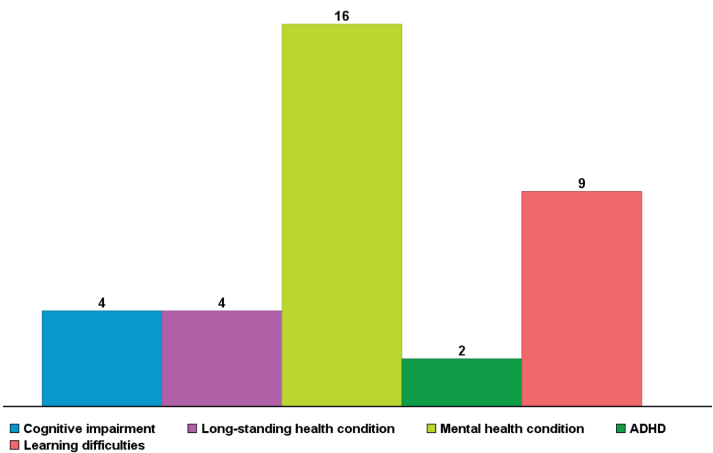
Ethnic Origin



Sexual Orientation



Disability - 10% of participants recorded a disability



## Appendix 2

### About Children's Parliament

Children's Parliament is Scotland's Centre for Excellence for Children's Rights and Participation. We give children and young people the opportunity to voice their ideas, thoughts and feelings so that their concerns and opinions can be listened to and included in our social and political landscape. We seek to increase awareness, knowledge and understanding of children's rights embedded in Scottish and international human rights policy and legislation.

Children's Parliament aims to improve outcomes for children and young people across Scotland through a rights-based approach. We do this in two ways. Firstly, we work directly with children and young people in projects, consultations and programmes which allow them to develop the skills, knowledge, behaviours and values necessary to engage in civic life. We focus on the development of respectful relationships and safe, supportive environments where all children can flourish. Secondly, we work with adults – parents and carers, government officials, teachers and other professionals – to raise awareness of children's rights and to equip them with the knowledge and skills to replicate Children's Parliament's approach in their own settings.

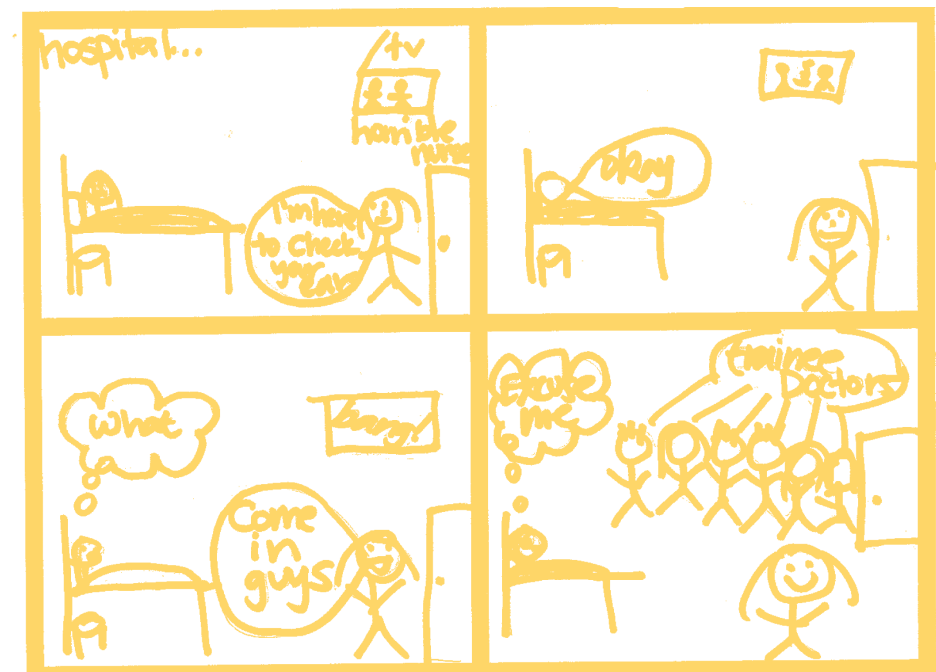
Through the unique combination of a rights-based approach and the creative arts, Children's Parliament allows adults to hear directly from children and young people in an engaging and innovative manner. Children's Parliament believes that children and young people are experts in their own lives and that they should be included in any discussion that will impact upon them. It is essential that their voices are heard in regard to life at home, at school, in the community and the wider world. By gaining a clearer understanding of children and young people's experiences and ideas, we (as policy makers, service managers and practitioners) will experience better relationships with the children and young people with whom we work and be better informed when making decisions.

For more about the work of Children's Parliament visit our website:  
[www.childrensparliament.org.uk](http://www.childrensparliament.org.uk)

## Appendix 3

### NHS Lothian Strategic Outcomes – extract from 'Improving the Health and Wellbeing of Lothian's Children and Young People

- Every child and young person will have access to high quality healthcare that is accessible and appropriate to all children and their families, delivered proportionately to need and at the earliest opportunity (Article 24 UNCRC)
- Disabled children and young people will have their additional needs met (Article 23 UNCRC)
- Children, young people and their families will be involved in decisions that affect their health and wellbeing (Article 12 UNCRC)
- NHS Lothian staff will have an increased understanding of the needs of the younger population and will use this understanding to inform the planning and delivery of services (Article 3 UNCRC)
- To improve health and resilience in those more vulnerable to poor health, NHS Lothian and its partners will work to reduce the impact of social circumstances on health by strengthening universal provision and targeted interventions (Article 24 UNCRC)
- The range and quality of healthcare services for children and young people will be improved through the re-provision of the Royal Hospital for Sick Children, the integration of children's services, and the development of services at St John's Hospital (Articles 24 & 42 UNCRC)
- NHS Lothian will have an effective and efficient workforce that is fit to meet the demands of a growing population of children and young people (Article 42 UNCRC)
- Robust governance and performance improvement arrangements will be in place for overseeing implementation of this strategy (Articles 43 - 54 UNCRC)





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