

Art to Art: Understanding children's feelings about hospital care

Published: June 2025

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Context and aims

1.1 Background

Young Healthwatch East Sussex (YHWES) has previously undertaken work to look at paediatric services for children and young people (CYP) under 18 in Conquest Hospital Hastings and Eastbourne District General Hospital (EDGH).

This work has included visiting the paediatric department at Conquest hospital in 2023 and visiting the paediatric department and paediatric section of A&E at EDGH in 2024. These visits were undertaken with young volunteers, who gave feedback on the departments and spoke to staff, parents and carers about their views and experiences.

One of the limitations of this activity was that we received little feedback from young people who were receiving treatment themselves during our visits. We reflected that, to help us address this gap, it would be worthwhile holding a focus group for CYP, enabling them to share their views and experiences of paediatric care at a time and place outside of the hospital environment.

In January 2025, we received funding from NHS Sussex to deliver an activity-based focus group for children aged 11 and under, to allow children to share their own experiences of hospital care, rather than sharing feedback only through a parent or guardian.

The aims and objectives of this work were:

- To hold an activity-based focus group, allowing children to share their views and experiences of hospital care directly, rather than through a parent/guardian
- To understand parents/guardians' views and experiences relating to their child's hospital care, and whether they differ from their child's views/experiences

Methodology

2.1 What did we do

We identified Culture Shift as a facilitator for our focus group due to their experience working with young people and facilitating creative groups. We worked with them to hold an arts-based focus group, which allowed participants to take part in arts and crafts activities while discussing their experiences of paediatric care.

To reach prospective participants, we promoted the focus group using flyers and social media posts, which were shared through Healthwatch East Sussex and Culture Shift channels. We also promoted the session via local partner organisations, ESHT, and word of mouth.

Participants took part in a range of activities including badge making, book making, and printing on fabric, and discussed their experiences of hospital care with the facilitator while taking part in these activities. Some of these discussions were one-to-one, while others involved multiple young people. Parents also shared their experiences with the facilitator, with the majority of these discussions being one-to-one.



Methodology

2.1 What did we do (continued)

Discussions aimed to look at a range of themes but, to ensure that the session was flexible and relaxed, we did not use set questions. As part of the focus group, we aimed to look at the following themes:

- The hospital environment
- Experience of interacting with staff
- Understanding of what was happening
- Feedback on the care and support children received for their condition

At the end of the group, participants were asked to complete feedback forms and were each given a £15 voucher to recognise their contribution. Children were given a Kids Stuff Toys voucher, and adults were given an Every Wish voucher.

2.2 Participants

Parents/guardians signed themselves and their child/children up to the group via a smartsurvey link, and were asked to provide their name and contact details, along with their child's name, age, which hospital they had visited and the condition their child received treatment for. Six young people and three parents signed up for the focus group.

On the day, five young people between the ages of 7 and 11 (three male, two female) and two parents attended and gave feedback as part of the focus group.

To ensure the anonymity of the young people involved, all young people's names have been changed for this report, and parents are referred to as the mum/dad of the relevant child.

Key findings and themes

3.1 What we found

The young people in our focus group shared a range of different views and experiences related to their hospital visit(s), with common themes of discussion focusing on:

- Interactions with staff
- Activities and the hospital environment
- Feeling scared
- Peer perception and understanding of hospital care

Parents also discussed their experiences of attending hospital with their child, giving further insight into the experience and the background behind their child's visit to hospital. A mixture of positive and negative experiences were shared, with an outline of the feedback received for the most common discussion points shared below.

3.2 Interactions with staff

As part of the focus group, young people discussed their experiences of interacting with hospital staff. Some of these stories were positive, with young people reporting that the doctors and nurses who treated them were friendly, explained what was going on, and tried to make them feel comfortable

For instance, Lizzie (8) and her dad told us about their experience with one of the nurses when Lizzie had her tonsils removed. They talked about a nurse making Lizzie laugh before the operation by painting her teeth black, helping her to feel more comfortable before going in for surgery. Jackson (10) also shared that when he went for an x-ray, the doctors explained to him what was going to happen and how the x-ray worked, so that he understood what was happening.

Key findings and themes

3.2 Interactions with staff (continued)

Although most of the feedback given about staff was positive, some of the stories about interactions with staff were less so. Lizzie and her dad shared an experience of going to A&E due to her asthma. Once her immediate symptoms had improved, they said that a doctor came in to tell them that they didn't think that Lizzie was asthmatic and took her asthma pump away. They were later seen by the asthma specialist, who confirmed that Lizzie was in fact asthmatic, despite what the previous doctor had said. Lizzie's dad said that he felt that the first doctor was "quite negligent", particularly given that the specialist confirmed that she was asthmatic.

3.3 Activities and the hospital environment

When discussing the A&E department at Conquest, Mason (8) said that he didn't like being there because it was "stinky and noisy" and Jackson felt that there wasn't much for him to do while waiting. He said that he had brought his iPad with him, so he had something to do while waiting to be seen, but would have been bored otherwise.

When discussing the paediatric department at Conquest, young people felt that the area was "nice and colourful". However, when discussing her experience of remaining in the ward overnight, Lizzie said that she didn't feel like there was much to do. Similarly to Jackson, she said that she was glad that she took her iPad with her, so she could use this while on the ward.

Jackson, Maddie (11) and Lizzie shared what they felt was most important to bring when going into hospital and talked about multiple items including a favourite teddy and comfortable pajamas. Bringing an iPad/digital device was considered the most important thing to bring with them when going into hospital to ensure they had something to do while waiting, with all three young people saying that they wouldn't want to be in hospital without things to do.

Key findings and themes

3.3 Feeling scared

Many of the young people in our focus group said that they felt scared during their experience in hospital.

When discussing his visits to A&E, Mason (8) discussed how he found the waiting area to be noisy and busy, which made him uncomfortable, particularly because it was during the night. Jackson (10) said that he felt scared because, even though the doctors told him about what was happening, he had never had an x-ray before. He said that because of the warning signs in the x-ray room, he felt that having an x-ray was dangerous, even though he was told it wasn't:

"They x-rayed my foot because they thought it was broken – but it was sprained. The doctors told me what was going to happen, but it was scary because I've never had an x-ray before. It [going for an x-ray] felt dangerous because there was a nuclear sign on it"

Jackson – 10

When discussing her experience of having her tonsils out, Lizzie said that she was scared and that she cried before getting them out because she was so nervous. She said that she would feel better about going again now that she has had the experience, as she wouldn't feel so scared about it. She also said that if she was giving advice to someone who was about to have a similar experience, she would tell them to "trust the process, it's worth it to go".

Key findings and themes

3.4 Peer perception and understanding of hospital care

Many of the young people in our focus group talked about what their friends and other people their age thought about going to hospital. Young people said that having support and understanding from friends was important. Lizzie said that after having her tonsils out, she had a week off school. She shared that her friends were “really nice” once she returned to school, and that she was able to talk about the experience with one of her friends who had also had their tonsils out and understood what it was like. She said her friends were supportive, and encouraged her to eat lots of savoury food and ice cream to help her feel better.

Lizzie, Maddie and Jackson all felt that other people their age would feel scared or worried about going into hospital, sharing that they felt that little is known about going to hospital if you haven’t experienced it yourself.

“I wouldn’t want to be in hospital for a long time, you don’t know much about it if you don’t have to go”
Maddie – 11

“Lots of people my age would be scared about going into hospital”
Lizzie – 8

From our discussions we understood that young people don’t know much about going to hospital and having treatment until they get there. This means that young people have limited understanding of what hospital is like if they have not experienced it for themselves, which can make the experience of going to the hospital scarier.

Key findings and themes

3.5 The views of parents

Overall, the feedback shared by parents correlated with the feedback from young people. Parents discussed their children's experiences, as well as their own thoughts and feelings. Our discussion with parents highlighted that going into hospital was a scary experience not only for the young person, but also for their parent(s).

Lizzie's dad told us that he found the experience of seeing Lizzie being put under anesthetic for her operation difficult, saying that it was "the one thing they didn't prepare us for".

Mason's mum also said that she found the experience of waiting overnight in A&E with Mason to be "awful". She said that he was in pain, and they were waiting all night to be seen, with Mason being unable to sleep as he was in pain and didn't like the waiting area. She said that it was difficult because there was nothing she could do for him other than wait to be seen.

Speaking to the young people's parents also allowed us to understand the background to the children's experiences, and sometimes this included parents describing things their children would not have been aware of. For instance, Ben's dad shared his experience of Ben being unwell and eventually being diagnosed with a heart condition when he was a baby. He said that Ben was admitted to hospital at 9 days old, and a nurse "casually" told them that Ben might have leukemia. This transpired not to be the case, but Ben's dad told us that it was very hard to hear, particularly when delivered in a casual manner. He said that over the next three months, doctors openly speculated about and suggested conditions that Ben might have, which made the process harder to deal with:

*"I didn't like the fact they kept saying what they **thought** it was. I'd rather not know until it **is**"*
Ben's Dad

What worked well and challenges

4.1 What worked well

The focus group was well-received by the young people and their parents, with all young people reporting that they felt the group gave them the chance to talk about their thoughts, feelings, and experiences of going to hospital. Young people reported that they enjoyed the session, giving it an average rating of 4 stars out of 5.



Young people said that they enjoyed taking part in the activities offered, and parents felt that the group was appropriate for their children. Parents also said that the group allowed them to share their experiences of attending hospital with their child.

Having activities for young people to take part in ensured that the group remained relaxed, and the feedback suggested that this was an appropriate way to engage with this age group.

4.2 Challenges

Whilst we were able to gather in-depth information about young people's experiences of hospital, and received positive feedback about the group, one of the key issues we faced was getting enough families to sign up to the focus group.

The group was advertised in several ways, including via social media, flyers and posters, newsletters, and promotion via partner organisations and local children's and parent and carer groups. Despite this, uptake for the focus group remained low, with six sign ups, and five young people attending on the day.

What worked well and challenges

4.2 Challenges (continued)

While we cannot be sure of the reasons for the low uptake, we did identify some factors that may have contributed and which we would learn from if delivering similar activity in future.

One reason may have been that we only began promotion of the activity just over a month before the group was held. It may have been useful to have given ourselves a longer timeframe to promote the group, to ensure that families had plenty of notice for attendance. Promoting the group earlier would also have given us more opportunity to respond to the low number of people signing up to the group and would have given us the option of trying different approaches or moving it to a different day if necessary.

We also identified that the date of the focus group may have contributed to the low number of sign ups. We held the group during the Easter school holidays, believing that more families would be available to take part in the group if it was outside of school term time. However, it was noted that many families use the school holidays to visit friends and family, and to go on holiday themselves, and so would not be available to take part in the group. In future, it may be useful to hold a similar activity during term time after school, or during the weekend in order to reach a greater number of young people.



Recommendations

Following our work, we identified a number of recommendations based on the feedback received from young people and their parents:

- **For ESHT: Appointment letters should include suggestions about items that young people and parents are allowed to bring with them and might want to remember to bring for their own comfort and to ensure they have something to do, particularly when staying overnight.**
- **For ESHT: Consider developing age-appropriate information and guidance packs to provide to young people ahead of their appointment (if these are not already in place) so that young people know what to expect.**
- **For NHS Sussex: Work with established youth groups/organisations to enable them to develop information for children and young people about hospitals that can be shared via schools, to reduce the fear factor around these settings.**
- **For Healthwatch East Sussex: Continue to use arts-based engagement for future work with young people.**





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