Under 16 Cancer Patient Experience Survey 2023

National Qualitative Report

November 2024

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Executive summary

Background

The Under 16 Cancer Patient Experience Survey (U16 CPES) is an annual survey that measures experiences of cancer and tumour care for children across England. This is the fourth year the survey has been conducted.

The survey captures the experiences of children who were aged 8 and above at the start of the fieldwork period, but under 16 at the time of their care, and the parents and carers of children who were aged under 16 at the time of their care. The survey was distributed via post to parents or carers of anyone who had a confirmed cancer or tumour diagnosis and received inpatient or day case care from an NHS Principal Treatment Centre in 2023, aged under 16 at their time of discharge. An online version of the survey was also available.

The survey asked respondents a range of closed questions about their experience and also invited them to provide written feedback by asking if there was anything else they would like to say about their (or their child's) cancer care. NHS England have conducted a thematic analysis of this written feedback (qualitative data) to identify areas for improvement and facilitate reflection and learning across services delivering cancer care for children aged under 16.

Results

Thematic analysis of the qualitative data revealed the following key themes:

Staff

Staff were central to experiences of care, and positivity about their manner and personal attributes was frequently raised. Key staff attributes were friendliness and kindness, with these greatly appreciated. In addition, being listened to and understood by staff was of importance.

Communication

A range of features that characterised good communication between staff and parents, carers and children were highlighted, as well as some opportunities for improvement. Issues were experienced with communication between hospitals, within hospitals as well as with parents or carers outside of hospital stays.

Access to care

Staff were not always responsive to needs which was attributed to understaffing as well as issues during weekends/evenings/at night. There was variation in how long it took for diagnosis and treatment to start. Access could also be impacted by waits in hospital and travel issues including parking.

Personalised care

There were unmet needs around psychological support for both children and parents or carers. Variable experiences were shared around whether the specific needs of autistic patients had been considered and met.

Hospital food

Hospital food was a frequently raised area for improvement with issues around quality and choice; how well food met personal needs; food preparation facilities; and provision for parents or carers to eat.

Things to do in hospital

Positive experiences were shared of play, though a need for increased access and more age appropriate offering too. Similarly there were calls for increased access to education which on the whole was positively experienced. Improvements were needed to Wi-Fi in hospitals and use of technology.

Hospital environment

Noise at night impacting sleep was common, with suggestions of how this could be improved from some. Other issues described included comfort of sleeping arrangements for parents or carers; the temperature of rooms; and matters of privacy.

Introduction

Project background

The U16 CPES 2023 is the fourth iteration of an annual national survey to measure children's cancer and tumour care provided by the NHS in England.

The survey has been designed to better understand children and young people's experience of tumour and cancer care across England and at individual NHS organisations. This report focusses on the analysis of the qualitative (written) data. A separate report is available for the quantitative (numerical) data which can be accessed on the survey website.

The 2023 survey was carried out by Picker Institute Europe on behalf of NHS England. The survey captures the experiences of children who were aged 8 and above at the start of the fieldwork period, but under 16 at the time of their care or discharge, and the parents and carers of children who were aged under 16 at the time of their care or discharge.

The survey is overseen by an Advisory Group made up of professionals who provide children's cancer care, charity representatives, cancer patients, and parents of children with cancer. This group advises on questionnaire development, methodology, and reporting outputs.

Survey methods and fieldwork

The survey sample included all patients with a confirmed tumour or cancer diagnosis who received inpatient or day case care from an NHS Principal Treatment Centre (PTC) between 1 January 2023 and 31 December 2023, and were aged under 16 at the time of their discharge.

The fieldwork for the survey was undertaken between April and June 2024. One of three versions of the survey were distributed, depending on the patient's age immediately prior to fieldwork:

- 0-7 questionnaire – for completion by parents or carers of children aged 0-7.
- 8-11 questionnaire – separate sections for the child and the parent/carer to complete.
- 12-15 questionnaire – separate sections for the child/young person and the parent/carer to complete.

The survey asked recipients to answer about their (or their child's) cancer care during 2023 and used a mixed mode methodology. Questionnaires were sent by post and addressed to the parent or carer of the child, with two reminders sent to non-responders, and included an option to complete the questionnaire online, accessed via a QR code or website address. A freephone helpline and email address were available for respondents to opt-out, ask questions about the survey, complete their questionnaire over the phone, and obtain access to a translation and interpreting facility for those whose first language was not English.

Qualitative data collection

Respondents were given the opportunity to state anything else they would like to tell us about their/their child's cancer or tumour care. This was captured through two separate open-ended questions, one asking for positive feedback and one asking for areas of improvements.

All parent/carer sections asked the following two questions:

- 'Was there anything particularly good?'
- 'Was there anything that could be improved on?'

Similarly, the children's sections in the 8 to 11, and 12 to 15 versions of the survey, asked the following two questions:

- 'Was there anything good?'
- 'Was there anything that could be better?'

The children's section in the 0-7 version of the survey, did not include any open-ended questions.

Overall survey response rate

Overall, the survey had a response rate of 25%, with 949 respondents out of a total of 3,741 eligible parents or carers, and children who were invited to take part. A response consists of one survey completion for a single patient, which could consist of both parent or carer and child responses.

About the respondents leaving qualitative comments

Of the 949 completed survey responses, 664 surveys included responses (qualitative data) to the open questions in the survey. This could be a parent or carer comment, a child comment or both a parent or carer *and* a child comment.

The number of completed surveys with qualitative data by survey type (based on age at the time the first survey is sent out) was as follows:

- 0 to 7 questionnaire (parent only): 345 records with qualitative data
- 8 to 11 questionnaire: 121 records with qualitative data
- 12 to 15 questionnaire: 198 records with qualitative data

The number of qualitative responses per PTC is displayed in Table 1. **Important note**: please be mindful that qualitative responses may be influenced by the type of care provided by PTCs, for example not all provide the same specialised care and treatment.

Throughout this report we refer to both ‘comments’ and ‘responses’. A comment is an answer to one of the four qualitative questions asked in each survey. Therefore, for each survey there could be a maximum of four comments. A response is defined as a survey that has any comments across the four qualitative questions asked. Therefore, each survey response could be made up of one or up to four comments.

Table 1: Number of responses per Principal Treatment Centre (PTC)

Principal Treatment Centre (PTC)	Number of survey responses with qualitative data[1]
Alder Hey Children’s NHS Foundation Trust	41
Birmingham Children’s Hospital NHS Foundation Trust	60
Cambridge University Hospitals NHS Foundation Trust	39
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	123
Leeds Teaching Hospitals NHS Foundation Trust	44
Manchester University NHS Foundation Trust	48
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	43
Oxford University Hospitals NHS Foundation Trust	35

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[1] A survey response could be a parent or carer comment, a child comment or both a parent or carer and a child comment. Therefore, the total number of responses will be lower than the total number of comments.

Sheffield Children’s NHS Foundation Trust	22
The Newcastle upon Tyne Hospitals NHS Foundation Trust	41
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	70
University Hospital Southampton NHS Foundation Trust	47
University Hospitals Bristol and Weston NHS Foundation Trust	51
TOTAL	**664**

There was a total of 1,456 qualitative comments left across all survey versions/sections. The comments for the two parts of the question (anything good and what could be better) are counted as separate comments. For example, if both the parent or carer and child answered both parts of the question, then this would count as four comments.

Table 2 shows the number of comments left by parents or carers and by children across each survey type. A total of 1,092 comments were left by parents or carers, and 364 comments were left by children.

Table 2: Number of comments by survey section

Survey type	Number of qualitative comments
0 to 7 questionnaire	Parent or carer only: 601 comments
8 to 11 questionnaire	Child survey section: 133 comments Parent or carer survey section: 173 comments
12 to 15 questionnaire	Child survey section: 231 comments Parent or carer survey section: 318 comments

Qualitative analysis methodology

Sampling

Before sampling, data cleaning was carried out to identify and remove comments which were of no analytical value. For example, comments which simply stated ‘N/A’, ‘No’, ‘I don’t know’. This left 1,355 comments for the sample to be drawn from.

Due to the relatively low volume of comments from children, all 334 were included. A random sampling technique was then undertaken to select an additional 334 comments from parents or carers. This was checked to ensure that the sample was broadly spread across the different age ranges, questions and PTC's.

Once the original sample of 668 comments had been analysed it was seen that data saturation had been reached, i.e. no new themes were emerging from the data. Had this not been achieved additional parent or carer comments would have been added to the sample as necessary, in line with best practice in qualitative analysis.

Table 3 shows the full comment breakdown of the final qualitative sample by survey type and question.

Table 3: Number of comments in qualitative sample

Survey type	Question	No. of comments overall[2]	No. of comments in sample
8-11	Was there anything good? (child)	67	67
12-15		110	110
0-7	Was there anything particularly good? (parent or carer)	301	61
8-11		89	56
12-15		159	64
8-11	Was there anything that could be better? (child)	57	57
12-15		100	100
0-7	Was there anything that could be improved on? (parent or carer)	264	60
8-11		77	47
12-15		131	46
TOTAL		**1,355**	**668**

Table 4 and Figure 1 show the response breakdown of the final qualitative sample by Principal Treatment Centre (PTC) and survey type. This is broadly similar to the overall profile of survey respondents by PTC and survey type.

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[2] Sample comments are drawn from cleaned data. Therefore, the total number of comments in Table 3 will be less than the overall qualitative comments left across all survey types/sections (1,456). Data cleaning removed comments which were of no analytical value, for example those which simply stated 'N/A', 'No', 'I don't know'.

Table 4: Proportion of responses per Principal Treatment Centre (PTC) in qualitative sample (N=400)

Principal Treatment Centre (PTC)	No. of responses with qualitative data[3]	Proportion of responses with qualitative data[4]
Alder Hey Children's NHS Foundation Trust	23	6%
Birmingham Women's and Children's NHS Foundation Trust	30	8%
Cambridge University Hospitals NHS Foundation Trust	25	6%
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	66	17%
Leeds Teaching Hospitals NHS Trust	27	7%
Manchester University NHS Foundation Trust	32	8%
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	30	8%
Oxford University Hospitals NHS Foundation Trust	25	6%
Sheffield Children's NHS Foundation Trust	16	4%
The Newcastle upon Tyne Hospitals NHS Foundation Trust	26	7%
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	36	9%
University Hospital Southampton NHS Foundation Trust	25	6%
University Hospitals Bristol and Weston NHS Foundation Trust	39	10%
TOTAL	**400**	**100%**

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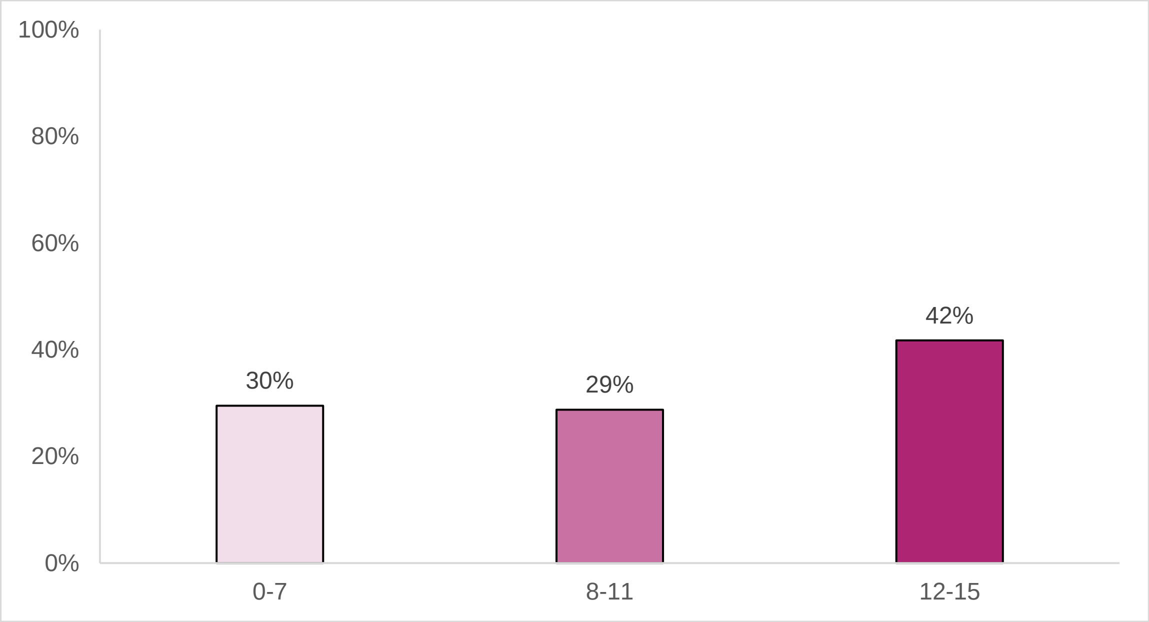
[3] A response could be a parent or carer comment, a child comment or both a parent or carer and a child comment.

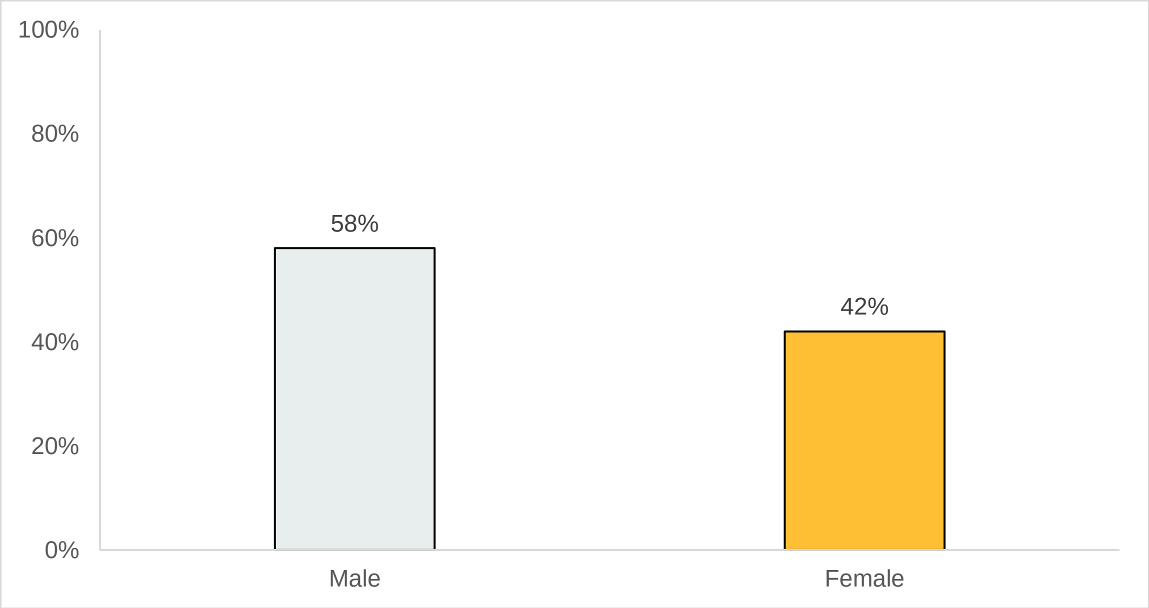
[4] Figures have been rounded to the nearest whole percentage.

Figure 1: Proportion of responses by survey type in qualitative sample (N=400)



The following charts show the demographic breakdown by age group; gender; ethnic group; deprivation level; as well as diagnostic group for respondents who had responses included in the qualitative sample. These are broadly similar to the overall demographic profile of survey respondents.

Figure 2: Proportion of responses by gender of child in qualitative sample (N=400)[5]



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[5] Gender is based on the survey sample data provided by Principal Treatment Centres.

Figure 3: Proportion of responses by ethnic group of child in qualitative sample (N=400)

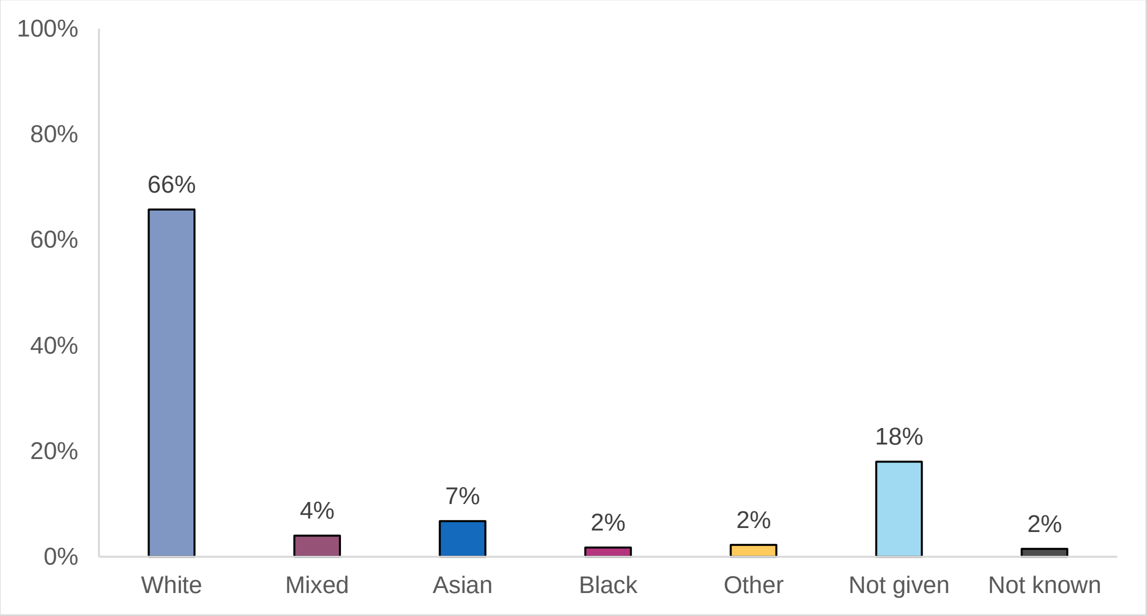


Figure 4: Proportion of responses by deprivation (IMD quintile) of child in qualitative sample (N=400)

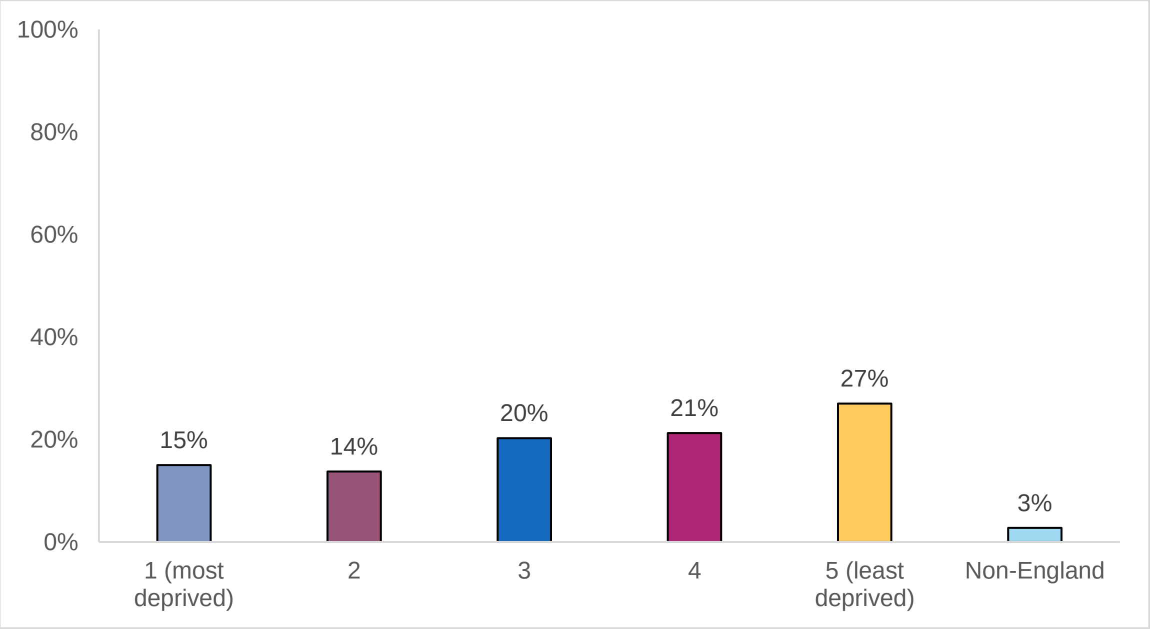
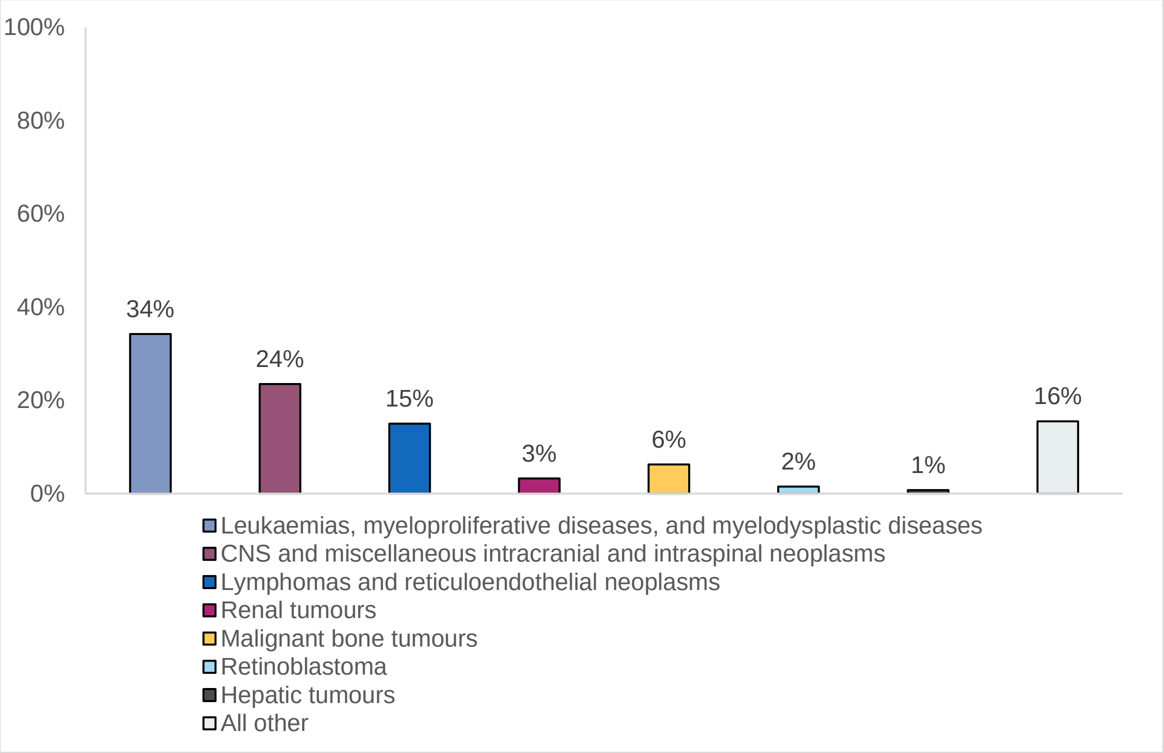


Figure 5: Proportion of responses by diagnostic group of child in qualitative sample (N=400)



Thematic analysis approach

The overall aim of the thematic analysis was to seek understanding of experiences shared in the survey data. To analyse qualitative data, the standard six steps of thematic analysis were used to identify common themes and patterns of meaning within the data – see Figure 6.

Figure 6: Thematic analysis approach

This approach involved each qualitative comment included in the sample being manually read multiple times and coded to relevant themes. This was done inductively meaning that the themes were developed ‘ground up’ when they emerged in the data, rather than being pre-defined before the analysis started. To help identify any differences in comments between children and parents or carers, the children’s comments were coded first, followed by the parents or carers. The focus began on data for the first open question asking about positive experiences, and was then repeated on the data for the second open question asking about areas for improvement. Once coded and initial themes generated, all of the data was then considered collectively when reviewing and defining themes and writing the findings.

Interpreting the results

Quantitative data findings

The results of the qualitative thematic analysis have been shared in context of the quantitative survey data and the results section of the report is structured so it leads with relevant quantitative findings. This structure exploits the value of both the quantitative findings, which tells us **the proportion** of respondents feeling a certain way, and the qualitative findings which tells us **why** people feel that way. For example, where there is a high degree of agreement / positive experience evidenced in the quantitative data, the thematic findings offer an opportunity to support our understanding why there was not 100% agreement / positive experience and therein, where the opportunities lie for improvement.

Use of illustrative quotes

Throughout the report, quotes taken from respondents’ comments are used to illustrate experiences in their own words and substantiate the findings. Please note that the data is not edited in the interests of correct spelling and punctuation for example, to stay as true to the words of respondents as is possible.

Certain information from the quotes has been redacted to protect the identity of survey respondents and any other individuals referenced including staff. A summary is shared below of the information that has been removed:

- Names including patients and staff replaced with “(name)”
- Names of wards, units or hospitals replace with “(location name)”
- Names of cancer charities replaced with “(charity name)”

When analysing the comments provided in the child section of the survey, a small number of these were interpreted as likely to have been written by a parent or carer in context of the terminology used (e.g. ‘my child’). Where quotes from these comments have been used, that is indicated in brackets following the quote.

Age-specific findings

A small number of the findings were specific to the age of the patients, e.g. some issues were apparent for those aged 12 to 15, which were not as applicable to younger age groups. Where that was the case, it is stated in the findings.

Characteristics of the qualitative data

Responses to the questions *“Was there anything good?”/”Was there anything particularly good?”* tended to be very short and lacking in detail. This was particularly the case for responses from children, which typically consisted of just a few words or a short sentence on the topic they had in mind and often lacked specificity, e.g. they may say they liked staff, without saying what it was that they liked about them. This limited the analytical insights that could be drawn; however, it did give a high-level sense of what respondents appreciated about their care and what was meaningful to them.

While responses to the questions *“Was there anything that could be better?”/”Was there anything that could be improved on?”* were also restrictive in terms of the analytical insight that could be drawn, they did tend to be slightly longer and more detailed. For example, comments from older children and parents or carers typically consisted of a sentence for each topic raised and in some cases extended to a longer paragraph.

Comparability

While this is the second qualitative analysis report published for the U16 CPES, the first being for the 2021 survey, we advise that results are not directly comparable. There are several reasons for this:

- The open questions have changed over time.
- Other questionnaire changes have been made over time.
- The nature of the data collection means that an absence of respondents raising an issue, does not mean that this issue does not exist, it could be that respondents have simply chosen not to comment on it.

- However, it can be confidently interpreted that if insight is repeated over time, this signifies a continuation and or repetition in the experiences described. In the context of improvement, it makes for a compelling case for change that an issue is reoccurring for example.

Results

Key themes

Seven key themes were identified from the thematic analysis, listed below. Within each key theme are a number of sub-themes which support with interpretation and use of the insights. There are 28 sub-themes in total.

- Staff
- Communication
- Access to care
- Personalised care
- Hospital food
- Things to do in hospital
- Hospital environment

Staff

Positive staff manner and attributes

What does the quantitative data tell us?

- 87% of children felt that staff were always friendly (X12)
- 89% of parents or carers felt that they and their child were always treated with respect and dignity by staff (X17)
- 80% of parents or carers felt they always had confidence and trust in staff caring for their child (X18)
- 82% of parents or carers felt that they were always treated with empathy and understanding by staff caring for their child (X19)
- 95% of parents, carers, and children felt that the nurses who came to their home or school were always friendly (X54)

The most prevalent theme in the data was positivity about staff, their manner and the personal attributes that they displayed. Where specific staff roles were stated, these were primarily nurses, doctors, consultants, play staff and surgeons. In some cases, respondents took the opportunity to name individual members of staff who had played a significant role in their experiences and whom they wished to praise.

The importance of staff was central to comments from both children and parents or carers around what was good about their care, with the following appearing as key staff attributes appreciated by respondents:

Friendly	Kind	Caring	Supportive
Compassionate	Understanding	Helpful	Professional

Where respondents provided more detail, staff acting in the manner outlined above was seen to have a positive impact in terms of bringing children some happiness and fun; and making children and parents or carers feel calmer, supported and comfortable during a challenging time:

- *"The staff being friendly made me feel happy." (child aged 8-11)*
- *"Everyone tried their best for me. It was a hard time for me but certain nurses really made me smile. (name) and (name) were my most favorite." (child aged 12-15)*
- *"The nurses were always very kind and made me feel calmer when i was stressed or scared" (child aged 12-15)*
- *"The nurses and doctors were very friendly and easy to talk to, and I always felt supported and comfortable." (child aged 12-15)*
- *"Staff make our child feel comfortable in the environment and make him laugh, which makes it easier for us." (parent/carer of child aged 8-11)*

- *"I was so grateful for the amazing support team from the very start - we were naturally in a stunned bubble when he was diagnosed but (location name) were just amazing and helped me through - and more importantly, ensured my son felt thoroughly supported, that he understood and made him feel like that this WASN'T a hospital but a place of welcome, help and fun, which they carried out perfectly." (parent/carer of child aged 12-15)*

In some cases, the relationships were described to be so strong and relayed how hospital staff had come to feel like family and how children were very fond of them:

- *"I felt like the ward was my family." (child aged 8-11)*
- *"I see them as family and I had a lot of fun and won't forget about them. I'm also going to come visit when I'm free. They are amazing." (child aged 12-15)*
- *"My daughter loved the play team, and still regularly talks about them. Dr (name) was caring and provide excellent support. She has a very personal approach, and my daughter responded well to her. we are very grateful to have a consultant like her." (parent/carer of child aged 0-7)*

Some parents/carers also commented on staff being knowledgeable and skilled, which in turn facilitated trust, confidence and hope in the standard of their child's care.

Staff listening, understanding and involving

What does the quantitative data tell us?

- 69% of parents, carers, and children felt they were definitely involved in their child's or their care and treatment (X29)
- 76% of parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment (X37)

Being listened to and understood by staff was seen to facilitate joint decision making and a personalised approach, which was experienced positively. Although little detail was provided, it was said that this could have benefits in terms of building trust and strong relationships with staff, feeling valued and safe.

Some of the ways which helped respondents feel understood and involved holistically included staff remembering patients; finding out about them as a person beyond their medical situation; and involving the whole family:

- *"Everyone was understanding and care felt very personalised. Everyone know about me and was doing the best for me as a person, not 'just' treating my cancer." (child aged 12-15)*
- *"Brilliant (name) and wonderful (name). Both treated my son as an individual and tailored his treatment and care and ALWAYS listened to us with respect. We worked collaboratively on my son's care." (parent/carer of child aged 0-7)*
- *"Everyone makes an effort to get to know the child and the family and they do everything to make this horrible experience as 'nice' as possible. (name) always does her best to ensure that treatment days can be moved to accommodate things like birthdays and we feel our child is getting the treatment possible in every respect." (parent/carer of child aged 8-11)*

General gratitude

What does the quantitative data tell us?

- 88% of parents or carers rated the overall experience of their child's care as 8 or more out of 10 (X59)
- 82% of children reported that they were very well looked after by staff for their cancer or tumour (X60)

Overarching statements expressing gratitude for care received and how they wished to pass on their thanks also indicated how valued staff and whole services were by respondents. These comments tended to be brief though impactful in chosen language using words ranging from "good" to "excellent" and "amazing" to describe care overall:

- *"All of it has been good. The general care has been great." (child aged 8-11)*
- *"The care at (location name) was outstanding. We will always be forever grateful to the team and everything they did for our son." (parent/carer of child aged 0-7)*
- *"Everything was good we want to say once again huge thank you NHS and (location name)." (parent/carer of child aged 0-7)*

- *"The support available and care provided was amazing. We are so thankful our daughter was treated at (location name)." (parent/carer of child aged 12-15)*

Noteworthy exceptions

While the positive experiences of staff were prevalent there were exceptions which are noteworthy in demonstrating there is variation evident in the data. These experiences may be less common though exemplify further that all members of staff play a critical role in how care is experienced.

An interesting pattern was observed in the data whereby amongst older aged children 12-15 and parents or carers across age groups, the positive experiences of staff used language such as 'majority,' 'most' and 'some.' This indicated that not all staff were positively experienced. Further to this, there were explicit examples describing a need for staff to have been friendlier and/or more empathetic. There were also examples of improvement being needed in regards to listening, understanding and involvement:

- *"Some members cared less and did not want to listen to me or my mum. It was clear that some members of staff were jsut there doing a job and were not as empathtic as others." (child aged 12-15)*

- *"Some of the consultants are very kind and understanding and take time to re-assure you. Some nurses are competant and kind." (parent/carer of child aged 0-7)*

- *"Staff were not child focussed and it was distressing for my son. However, when I raised this I was contacted by the staff at the hospital and spent time discussing this. It was handled amazingly. We felt that his voice was heard." (parent/carer of child aged 8-11)*

Communication

Between staff and parents, carers and children

What does the quantitative data tell us?

- 73% of parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand (X08)

- 81% of parents, carers, and children reported that they were definitely able to have questions answered after being told about the cancer or tumour (X09)
- 73% of children reported that they could always understand what staff were saying (X13)
- 78% of children felt that staff always talked to them, not just their parent or carer (X14)
- 84% of parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment (X16)
- 86% of parents, carers, and children reported that they always understood what nurses visiting their home or school were saying (X55)

The ability of staff to communicate well with children and parents or carers about their treatment, test results and care in general was another common theme in the data. The impact of good communication was that it put people at ease.

Both children and parents or carers provided insight into what characterised good communication with staff. Where communication was viewed positively, value was placed on the following aspects:

Information being clear

Staff proactively providing information

Staff being receptive to being asked questions

Opportunities provided to ask questions

Sufficient time taken to provide explanations

Staff being able to provide answers

Staff tailoring information to make it understandable

Staff addressing children, not just parents/carers

- *“The staff all talked to me, not just my parents.” (child aged 8-11)*
- *“explanations made so we understand and not made to feel like we are asking silly questions.” (child aged 8-11)*

- *“Staff were excellent at explaining honestly and consideratly what was happening and used terminology that was understandable to non medical people.” (child aged 12-15)*
- *“His consultant (name) has always kept us fully updated and informed. He always takes time to explain and answer any of our questions.” (parent/carer of child aged 0-7)*
- *“They have informed us of everythng. Any question answered, they always have an answer.” (parent/carer of child aged 0-7)*
- *“Dr (name) is always there to answer questions and really patient every time I brought a list to him” (parent/carer of child aged 8-11)*
- *“staff is always talking directly to my son, in a child friendly language to make sure that he understands everything and whats gonna happen during the proceedings.” (parent/carer of child aged 12-15)*
- *“As I am pre-verbal the healthcare staff very quickly learnt how to communicate with me using Makaton signs & symbols which was brilliant.” (child aged 12-15)*

While less prevalent than good experiences of communication with staff, there were several issues identified by respondents which indicated opportunities for improvement spanned a range of topics as follows:

Privacy

Sensitivity

Timeliness

Consistency

Reassurance

Parents or carers shared some examples where staff needed to more carefully consider when information should be delivered in front of children or whether some conversations would be better to have with parents or carers privately. In some examples the child had heard information that had a negative impact on them and this could have been avoided:

What does the quantitative data tell us?

- 71% of parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way (X07)

- 71% of parents or carers felt that staff were always sensitive to information shared with them when their child was in the room (X21)
- 76% of parents or carers felt that healthcare staff always shared information with children in a way that was appropriate (X22)
- 50% of parents, carers, and children reported always being given somewhere private to talk to staff when their child was in hospital (X45)

- *“It is difficult to have conversations with doctors about medical care when the young child is in the room and listening.” (parent/carer of child aged 0-7)*
- *“I wish I would have more opportunities to speak to staff members privately, especially at the start of diagnosis. This should be provided by doctors when patient is under 16 years old. My child was diagnost at age of 12 and I had no opportunities to speak to the doctors privately. If I would ask for it my child would be very anxious.” (child aged 12-15 – please note that whilst this answer came from the child section of the survey, it appears to have been completed by a parent/carer)*
- *“The anaesthetist told us that if he bleed it would be serious and with no an and e it would be tricky. This really scared my son and it put him on edge. Thankfully that has only happened once and it being said in his ear shot wasn’t good for him.” (parent/carer of child aged 8-11)*

There were also general comments from children which emphasised that information needed to be delivered in a sensitive way, with privacy also being a consideration:

- *“I could have been told I had cancer more sensitively, it was a shock.” (child aged 8-11)*
- *“Sometimes felt we had no say when it came to private discussions particularly 'sensitive' discussions in terms of how it was conducted & the amount of staff needed in the room at the time given it can be a distressing time for us all.” (child aged 8-11)*

Some parents or carers also highlighted that they were not getting information in a timely way because they were not seeing staff often enough or the relevant staff were not easily contactable. The importance of information being consistent across staff was also raised as this was not always experienced to be the case:

What does the quantitative data tell us?

- 57% of parents, carers, and children reported not being told different things by different members of staff that left them feeling confused (X20)

- *"At times there were long gaps between seeing a consultant which lead to some confusion/things not being explained properly." (parent/carer of child aged 0-7)*

- *"I've researched about my child's cancer and have so many questions but I barely see my consultant. Whenever I request my child's treatment record/history etc, he says 'ask nurses' and no one knows when we discussed about my child's prognosis or MRD. I wanted to know exact numbers and more information but he considered that I don't know / I don't have to know. I want more information about my child's test results." (parent carer of child aged 0-7)*

- *"Found it difficult to get answers from staff everytime we phoned. In the end, I communicated directly to oncologists as they were the only person who could answer my questions, but they weren't easy to get a hold of." (parent/carer of child aged 12-15)*

- *"Ensure all teams are on the same page before telling you anything." (child aged 8-11)*

Another issue for parents or carers could be information being shared over the telephone when this was not considered to be an appropriate or convenient method to receive sensitive information:

- *"I feel that sensitive conversations of a relapse/quality of life or further treatment should be done face to face or virtually. Not over the telephone." (parent/carer of child aged 8-11)*

- *"More clarity from the consultant during a couple of telephone consultations near the start of the treatment process; recognition that driving to school at 8.40am with children listening in is not a good time to talk about cancer treatment, and the same at 3.15pm on the school playground at school pick up time." (parent/carer of child aged 8-11)*

- *"You shouldn't have to find out that your daughter has cancer over a phone call. I was in the middle of shopping at ASDA when I got the phone call." (parent/carer of child aged 12-15)*

Issues were also seen with respondents not always being kept updated or informed about the patients' treatment (including information for parents or carers while it was happening), medical condition or test results. This could cause worry and a need to chase staff and services. Many examples described a need for reassurance during these times which had not been sufficiently met:

What does the quantitative data tell us?

- 64% of parents, carers, and children felt they always knew what was happening with their child's or their care (X28)
- 83% of parents or carers reported that they were definitely offered clear information about their child's treatment (X36)

- *"During the surgery (9hours!) there were no updates or reassurances that things were ok. We were frantic by the end. A quick phone call to the nurses station from the theatre to reassure us would've saved us so much heartache." (parent/carer of child 12-15)*
- *"Sometimes communication between nurses/doctors and parents is an issue. You can be waiting hours with no update as to what is going on. Sometimes you are waiting for a doctor to come and see you but you are left in a room to wait with no updates or communication" (parent/carer of child aged 0-7)*
- *"When I have the 6 monthly MRI scans, I do not get informed the results, I had to chase them myself after 2 months. I think this is stressful. No news is a good news, but still it would be helpful to get a letter on a phone call saying it is all day" (child aged 12-15)*
- *"The regularity of written correspondence with his parents regarding his medical history and condition could be improved upon." (parent/carer of child aged 12-15)*

Between hospitals

What does the quantitative data tell us?

- 50% of parents, carers, and children reported that different hospitals providing cancer or tumour care always worked well together (X57)

An interesting pattern was found where children aged 12-15 alongside parents or carers across age groups, noted that there was poor communication between services, particularly when care was received across different hospitals. The consequence was typically a feeling of poor co-ordination which could position parents or carers to have to then liaise between to aid the communication issues:

- *"When at a local hospital, communication between there and the (location name) is not good." (child aged 12-15)*
- *"Better communication between hospitals (local & specialist), was often led by parents." (parent/carer of child aged 0-7)*
- *"(location name) & (location name) at times did not communicate in a timely way especially for test done at (location name)." (child aged 12-15)*
- *"Communication between (location name) and (location name) Hospital, as allergies discovered at (location name) Hospital were transmitted to (location name) and were not followed, leading to a very large allergic reaction." (child aged 12-15)*
- *"My child's care was spread over 3 hospitals that were an average of 140 miles apart. I understand this was necessary, but because there were two different health boards involved it seemed like they had trouble communicating. So there were sometimes delays in treatment steps". (parent/carer of child aged 0-7)*
- *"The communication between our local hospital and this hospital where we received cancer treatment was always problematic and a lot of anxiety was caused because we felt their communication and policies differed. I think it would have saved a lot of stress if we were able to go straight to our main hospital where we receive treatment." (parent/carer of child aged 0-7)*

- *"I feel that the joint care over the 3 hospitals does not work. As a patient it seemed as though no one took, responsibility for (name)'s care and we were passed from pillar to post." (parent/carer aged 8-11)*

What does the quantitative data tell us?

- 54% of parents or carers felt that different hospital staff were definitely aware of their child's medical history (X27)

Some respondents specified that hospitals using different electronic record management systems to one another contributed to poor communication, with the inference that more 'joined up' systems would improve experiences:

- *"(location name) Hospital and (location name) to communicate better. Should be an electronic system place to view full records and bloods when at (location name). (child aged 12-15)*

- *"(location name) hospital liaison. They didn't understand (location name) blood test codes + their computer system doesn't talk to (location name) one." (parent/carer of child aged 12-15)*

- *"Would be helpful if the different hospitals could share the same computer systems so they could all access her records." (parent/carer of child aged 12-15)*

A small number of further comments highlighted the importance of patient records being up-to-date, comprehensive, available and familiar to all relevant staff:

- *"Post operative follow up from (location name) following lower leg amputation - this could have been a bit more comprehensive as they performed the operation and then left the after care to the home nurses and to the (location name) nurses but they could have had some handover notes explaining the exact nature of the stitches as there was quite alot of piecing it all together. This would have been unnecessary with a proper handover/paper chain" (parent/carer of child aged 0-7)*

Within hospitals

What does the quantitative data tell us?

- 59% of children reported always or mostly seeing the same members of staff for their treatment and care (X15)

- 62% of parents or carers felt that different hospital staff always worked well together (X26)

Poor communication between departments within one hospital or between staff within the same service within the same hospital were also observed in feedback. There was a suggestion that to combat this there could be improvement regarding continuity of care as seeing the same staff would be preferable and mitigate this:

- *“Communication between departments eg x ray & ward.” (parent/carer of child aged 8-11)*
- *“We are aware that there was a weekly 'planning meeting' but communication between the day unit staff and ward is poor.” (parent/carer of child aged 0-7)*
- *“Communication between the 2 hospitals & different doctors within the same hospital. I felt like I had to repeat myself a lot by telling different doctor's my child's medical history.” (parent/carer of child aged 0-7)*
- *“Seeing your own consultant each time would be much better. There is often a lack of communication between members of staff.” (parent/carer of child aged 8-11)*

Outside of hospital stays

What does the quantitative data tell us?

- 87% of parents or carers reported that there was a main person in the team looking after their child that they could contact about their care or treatment (X31)
- 47% of parents or carers reported that it was very easy to contact the main person in the team looking after their child (X32)
- 58% of parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital (X33)

The ability to communicate with services and staff outside of hospital stays was observed to be variable with some experiencing this positively and others not. While some respondents said that staff were accessible at any time, others reported that it could be difficult to get in touch with clinical nurse specialists or other key professionals. Some who experienced difficulties suggested that communication should extend beyond normal working hours to aid with this issue:

- *"My son's community nurse is outstanding. She is always at the end of the phone" (parent/carer of child aged 8-11)*
- *"Having mobile number to our hospital unit and knowing I can call any time of the day or night made me (parent) feel more save and less stressed." (parent/carer of child aged 12-15)*
- *"Our key support worker was often not available and did not return calls." (parent/carer of child aged 0-7)*
- *"It can be quite hard to make contact with a clinical nurse specialist." (parent/carer of child aged 8-11)*
- *"Care for cancer patients should be available 24/7. As it stands I am only able to contact our team Monday - Friday, 8-5." (parent/carer of child 8-11)*

Access to care

Diagnosis and starting treatment

What does the quantitative data tell us?

- 55% of parents or carers reported that their child saw a GP once or twice before they were referred to hospital (X03)
- 70% of parents or carers felt that they were seen at the hospital as soon as they thought was necessary after being referred by their GP (X06)

Respondents shared both positive and negative experiences around how long it took for children to be diagnosed and start treatment. For some this happened very quickly:

- *"Seen by GP am, sent to Local Hospital pm and then to (location name), started treatment the next day." (parent/carer of child aged 12-15)*
- *"Our child was admitted and treated immediately following diagnosis. This assured us that the disease would be treated swiftly." (parent/carer of child aged 0-7)*

- *"The speed at which the treatment started was phenomenal." (parent/carer of child aged 8-11)*

For others there were delays in diagnosis and treatment starting. Parents or carers could feel that healthcare professionals were not listening or taking seriously their concerns about their child's health. The length of time taken to get a GP appointment or to have tests/scans, were also seen as contributing factors to delays in diagnosis:

- *"It took 3 months of my daughter being so poorly, crying in pain constantly, losing 7 kg in the past 3 weeks before a doctor in (location name) to actually take her symptoms seriously and scan her to then find the tumor, I was absolutely disgusted with (location name) hospital. We were transferred to (location name) hospital withing a few hours after the tumor was found. Parents need to be believe, they know their children the best, especially when there is video evidence of their child." (parent/carer of child aged 8-11)*

- *"Please review how you approach out of area referrals (it should be possible for GPs to get patient into (location name) if local hospital a&e and paediatric dept are refusing to take concerns seriously). Also please educate and do outreach to neighbouring Trusts. Our child was put at significant risk by past GPs and our local hospital paediatric dept i.e., (location name). We had to see a private neurologist in order to obtain an MRI and diagnosis despite long history of severe repeated hemiplegic migraines and finally a seizure. Only one healthcare professional (a GP) prior to private consultation took child's symptoms seriously." (parent/carer of child aged 12-15)*

- *"Getting that GP appointment at the beginning could have been improved. It took months and then weeks to get a blood test that diagnosed that something was very wrong." (parent/carer of child aged 12-15)*

- *"My main area of concern was that it took a long time for an Mri scan after he had a seizure. After investigation a scan was only given a few months later as a precautionary check. A scan straight away was not offered and other symptoms were not joined together." (parent/carer of child aged 12-15)*

Staffing levels and responsiveness

What does the quantitative data tell us?

- 71% of parents, carers, and children felt that their child or they were always able to get help from staff on the hospital ward when they needed it (X42)

Children and parents or carers commented that staff were not always responsive to their needs and that hospitals seemed understaffed, meaning those that were there were overstretched. This was seen to have a variety of negative impacts including long waits for assistance and call bells/buzzers being responded to; as well as for chemotherapy and medication. Rather than being critical of staff this was often framed as a systemic issue, with calls for staff to be better supported:

- *"things take a long time to happen, like waiting for staff or medicine." (child aged 8-11)*
- *"Sometimes I had to wait a long time after pressing my buzzer." (child aged 12-15)*
- *"Some nurses were very nice, particulary on the ward at (location name) although they were often understaffed and overworked which meant my meds were sometimes missed." (child aged 12-15)*
- *"Everyday when my chemo was scheduled for 11am, it actually started after 12 as nurses were always busy. My drip was constantly stopping and beeping but no nurses around. For example, my chemo was planned for 11 am and for 2 h so should finish after 1pm but always that would take 4-5h just because there was noone around and nurses were busy." (child aged 12-15)*
- *"Poor communication nurses on ward too busy. Not enough support given. Most nurses were brilliant just too busy to talk or help. Too many newly qualified staff on ward, meaning senior staff too busy." (parent/carer of child aged 0-7)*
- *"Managing pain and ward presence from nurses could be improved. It feels like nurses aren't around very much and it's very short staffed." (parent/carer of child aged 8-11)*
- *"I think staff are stretched and overworked. They are not machines, please look after them." (parent/carer of child aged 0-7)*

- *"Times some nurses are extremely busy and don't have opportunities to have break, maybe some extra staff so ease the pressure however everyone was extremely professional and never let this effect care needs" (child aged 12-15)*

Comments indicated that a lack of staff and responsiveness was more apparent at weekends, during the evening and at night:

- *"Reaction to nurse bells, mainly late at night." (child aged 8-11)*
- *"At weekends the availability of Drs is scarce and everything takes longer." (parent/carer of child aged 0-7)*
- *"Staff especially care nurse specialist's should be available 24/7. When there is an issue in the evenings or weekends, it's very difficult to get help." (parent/carer of child aged 12-15)*
- *"We felt that night and weekend staffing levels were a little low. Our child on several occasions had a few medical issues in the night ie seizure. Although staff were quick to help the reduced amount of staff could sometimes make us feel anxious." (child aged 12-15)*

In some cases, parents or carers had been concerned that inadequate staffing levels or a lack of specialist staff had contributed to poor clinical decisions and errors:

- *"My child receives care at a satellite centre. We have always found it difficult to feel that he is in safe hands during the out of hours times (evenings/weekends/nights/annual leave) when there is no oncology medical cover, some poor decisions are sometimes made." (parent/carer of child aged 8-11)*
- *"there were a few mistakes made with treatment, due to lack of (I feel) enough staff and miscommunication between staff at handovers, which has lead me to watch and double check everything the nurses are doing." (parent/carer of child aged 8-11)*

When respondents highlighted a need for an increase in specific staff types, this included play staff, psychologists and school teachers. There were also calls for more funding for staff broadly.

Waits in hospital

When coming into hospital, including via A&E, respondents described experiencing waits for treatment, specifically chemotherapy, or operations. Long waits for the pharmacy to prepare medication was also an issue and one of the commonly raised reasons for delays, along with a lack of bed availability. The comments also illustrated that waits in hospital could have a negative impact on both children and parents or carers wellbeing by creating long days, boredom and stress:

- *“Waiting for treatment and dispensing meds can take all day and tires our child out.” (parent/carer of child aged 8-11)*
- *“Waiting times, the first day of treatment for each cycle was always very slow, because the chemo was not ready.” (child aged 12-15)*
- *“Sometimes the chemo was not started until the afternoon and then it would be hours treatment which meant that sometimes we weren't getting home until 10 o'clock at night.” (parent/carer of child aged 12-15)*
- *“Not waiting to be allocated a bed (sometimes 8 hrs wait) when treatment is planned.” (parent/carer of child aged 12-15)*
- *“Not knowing if you will have a bed or not for the next round of chemo until the morning it is due is very stressful.” (child aged 8-11)*
- *“Infuriating that chemo was always delayed because not enough beds” (parent/carer of child aged 12-15)*
- *“In case of high temperature when we had to rush to the A&E of the hospital for intravenous antibiotics, there was usually 6-10 hours waiting at the A&E quite often during evening and night time before my daughter could get a bed at the oncology ward.” (parent/carer of child aged 8-11)*
- *“Delays in cancer treatment due to bed availability. Delaying treatment impacts success/outcomes of treatment. I do not think the delays in bed availability in cancer care is acceptable.” (Child aged 8-11)*
- *“Having to wait for a bed to become available in order to have my operation was not very nice as just wanted to get surgery out of the way” (child aged 12-15)*

- *"Pharmacy delays often stopped me from starting chemo when I was supposed to and sometimes waiting for TTA drugs kept me in hospital later than necessary." (child aged 12-15)*

It was apparent that some of the issues could be intertwined. For example, it was inferred that if pharmacy waits improved this could increase beds available:

- *"We waited in recovery after one operation for several hours because there was no bed. The hold up seemed to be at the pharmacy, inpatients were waiting for their medication before they could be discharged so it held up the beds. But we considered ourselves very lucky that day as all other operations were cancelled because there were no beds in the children's wards." (parent/carer aged 12-15)*

Travel

What does the quantitative data tell us?

- 53% of parents or carers reported that their child's care and treatment was definitely offered at a time suitable for them and their family (X34)
- 66% pf parents or carers reported that the hospital where their child received most of their care is about or under an hour's travel from their child's home (X58)

Respondents that commented on the location of care showed a strong preference for this to be local to where they lived. When care had been close to home this was positively experienced in contrast to when there was long travel distances required, which were mostly described to be challenging and an area for improvement.

There were a small number of comments which suggested that more consideration of accommodation for parents or carers, and appointment times which accounted for travel time, would help those living further away:

- *"We feel very fortunate to have a cancer service in our area. Life would have been even more difficult without it." (parent/carer of child aged 8-11)*
- *"Treatment when had would of made life a lot easier, less stressful and time consuming if had been given in local hospital not having to travel 2 hrs both ways (traffic depending). Always sick, uncomfortable and stoppage for toilet and stretching." (child aged 8-11)*

- *"We think that there needs to be a holistic approach to a families needs, particularly if they live a long way away. My parents had to pay for accomodation & my mum had given up her job to look after me. This added to their stress." (child aged 12-15)*

- *"Giving more notice in advance of any surgical procedures. Most times we have been contacted to have an operation we have been given a weeks notice. We live nearly 2 hours away so this makes organising things a bit harder." (parent/carer of child aged 12-15)*

Linked to the matter of location were comments about hospital transport. While respondents appreciated that hospital transport was provided, they also said that there could be long waits for it to arrive and they wanted to see improvements to this:

- *"Hospital transport took a long long time to arrive." (child aged 8-11)*

- *"The only problem that we had was with the transport. The nurses arrange us a transport from the hospital to our home but the waiting time for a car was 3 and under 3 hours." (parent/carer of child aged 0-7)*

Issues with car parking were also raised and often mentioned the cost as well as the consideration required when parents or carers were with sick and disabled children:

- *"Parking around the hospital cost a fortune. Parking spaces are tiny, trying to get children out is impossible when you have a larger car." (parent/carer of child aged 0-7)*

- *"The parking for the hospital is incredibly stressful after a long journey to reach the hospital. It is very difficult to get a very unwell child from the car parks (a long walk up steep hills) with overnight bags etc. all the way up to the oncology ward." (parent/care of child aged 0-7)*

Personalised care

Psychological support

The data indicated that there were unmet needs around psychological support for both children and parents or carers of all age groups, spanning multiple stages of care:

- *"I think the system lacks in psychological support for the patient" (parent/carer of child aged 0-7)*

- *"Ward councellor to help during the shock for parents and young people. (parent/carer of child aged 0-7)*

- *"From a parent perspective more emotional / psychological support is needed & care was clinically excellent but seriously lacking in the emotional welfare side for parents. I was not asked once how I was coping which left me feeling isolated and lonley." (child aged 8-11 – please note that whilst this answer came from the child section of the survey, it appears to have been completed by a parent/carer)*

- *"My child struggled mentally probably more than physically during her treatment. She had high levels of anxiety and would have benefited from mental health support throughout her time in hospital." (parent/carer of child aged 12-15)*

- *"more help for parents mentally and when treatment finishes." (parent/carer of child aged 8-11)*

In the few positive experiences shared, references were made to how charities were involved in providing support, indicating that they could play an important role:

- *"Input from (charity name) has been invaluable to provide the holistic support for my daughter/give the necessary psychological support for her." (parent/carer of child aged 0-7)*

Support for autistic people

Variable experiences were shared around whether the specific needs of autistic patients had been considered and met. Some staff were said to have a good awareness and understanding of needs, whereas others didn't:

- *"Very aware of my sons autism and very accomodating." (patient/carer of child aged 12-15)*

- *"Dr (name) understanding of (name)'s autism needs." (parent/carer of child aged 12-15)*

- *"Some staffs awareness of autism and how that impacts a child especially when they are in hospital could be improved on." (parent/carer of child aged 8-11)*

The need for routine and structure was also highlighted as being important, in one case seeing the same member of staff had helped with this. However, for others this had been an issue, with one respondent making a detailed suggestion of how this could be improved:

- *"it could be helpful for families to have a rough breakdown of a treatment day. Eg, port access, bloods, height and weight, see dr, treatment, port removal, home. Our daughter is autistic and (name) always had picture cards ready to show her the breakdown of the day, which was so helpful. The days can be long and I know it might sound silly but I don't think we necessarily realised that you can't see the dr until the blood results are back, for example. Knowing a rough breakdown of the day (and the reasons for each step) might help manage expectations that the day will be long and it's not just an in-out appointment. I think this could be helpful for all families, not just families with neurodivergent children." (parent/carer of child aged 8-11)*

Similarly, there were mixed experiences in relation to sensory needs. Where respondents saw this as an area for improvement, suggestions were made that there needed to be better consideration of the texture of food and access to areas for sensory breaks. While too few and too brief to form a sub-theme, sensory needs were also mentioned in context of learning disabilities and attention deficit hyperactivity disorder (ADHD). This further demonstrates the importance of considering all patients' sensory needs.

Hospital food

Hospital food was one of the most frequently raised topics by children, indicating that it played a significant role in how they experienced their time in hospital.

Food was a reoccurring negative theme in the data with both children and parents or carers highlighting consistently that hospital food was an area that could be improved in a range of ways:

- Food quality and choice
- Patients personal needs
- Food preparation facilities
- Provision of food for parents/carers

Food quality and choice

What does the quantitative data tell us?

- 38% of parents, carers, and children felt that there was definitely a suitable choice of hospital food (X44)

While comments were typically brief they often shared a view about the quality of food being poor; there being a lack of nutritional value; and children having limited choice. This was true across age groups for children as well as parents or carers:

- Examples from children aged 8-11: *"Food at hospital"; "The food was pretty poor especially for a child who was really struggling to eat anyway."; "Food is inedible"; "It was really boring having to choose from the same food every day."; "More food choices."; "The food needs to be more appealing to all children and offer different foods not the same every meal time"*

- Examples from children aged 12-15: *"The hospital food"; "The food was unhealthy and disgusting."; "Food is not nutritious at all, all food is processed."; "Please there should be enough meal choice. The food must be better."; "Could be more variety of food for people who are in hospital for ages."*

- Examples from parents or carers across age groups: *"The food is diabolical."; "Food, it's shocking. Tastes awful and lots is not kid friendly. Also same 4/5 choices twice a day every day."; "Better nutrition, the food is awful quality."; "Inpatient food options are awful. The menu seems big but it is all convenience food and poor quality."; "In patient food at (location name) is a disgrace."*

Patients' personal needs

There were several examples shared of needs which were not being met or inadequately considered in relation to hospital food. This included dietary requirements such as coeliac disease, veganism, vegetarianism, and gluten/dairy free options. It also included consideration of autism relating to the texture of food. Other needs included consideration as to how cancer treatment was impacting on the patients' appetite, taste and ability to eat and how this was not taken into account:

- *"When I was having radiotherapy, I was on the low iodine diet and I am also a vegetarian so the choices were extremely limited. There was only one choice for me." (child aged 12-15)*

- *“Because of my condition the hospital food makes me sick. Other food choices for cancer patients would be good. (child aged 8-11)*
- *“I think that the quality of food offered to cancer patients could be improved dramatically as well as the variety, to cope with the varying tastes due to side effects of chemotherapy.” (child aged 12-15)*
- *“Autistic children have certain texture food which is not even considered.” (child aged 12-15)*
- *“The food choices could have been better with fresher options and better dietary offers eg. gluten/dairy free, organic.” (child aged 8-11)*

The provision of food being restricted to set times was also experienced to be problematic for some patients, given that these times did not always align with the times children arrived at hospital or their ability to eat. These comments inferred that a degree of flexibility was needed to meet individual needs:

- *“longer hours for out of hours menu for children who are selective/ARFID eaters or are generally unwell or don't eat at set times.” (parent/carer of child aged 0-7)*
- *“When arrive in the afternoon to stay overnight, they don't provide hot meal for dinner (5pm). There is nothing to eat for my kid as she doesn't eat sandwich.” (parent/carer of child aged 0-7)*

Food preparation facilities

What does the quantitative data tell us?

- 40% of parents or carers reported they were definitely able to prepare food in the hospital if they wanted to (X50)

Parents or carers expressed a need to have access to kitchen facilities so they could prepare and cook food themselves while their child was in hospital. In some cases, it was indicated that no facilities were provided. Others outlined that while facilities were available, they were inadequate and suggestions for improvement included:

- Larger fridges and freezers
- Provision of additional appliances, such as toasters and air fryers

- Better monitoring and maintenance of the cleanliness of kitchen facilities

While the data for this finding predominately came from parents or carers a couple of children in the older 12-15 age group also said that they would appreciate having access to a microwave, kettle or vending machine for their own use.

Provision of food for parents or carers

Parents or carers suggested that hospitals should provide food for them, in addition to children. Where reasons for this were stated, it was often explained that they found it difficult to leave their child, which in some cases had impacted negatively on their own health. A notable few would be willing to pay a fee for being fed in hospital:

- *“If you stay could be offered hot food even if you had to pay nominal fee. (I didn't want to leave as daughter only young).” (parent/carer of child aged 0-7)*
- *“It that was an opportunity for parents to have food on the ward, even if purchaged. It is difficult to leave your child to buy food off of the ward when they are sick, so at times you go without. When you're far away from home too, family aren't near to help, bring food etc.” (parent/carer of child aged 12-15)*
- *“When my son was diagnosed in 2022 the support was really good however parents were not offered meals on the ward. The only places to buy food were Pret or Marks & Spencers neither of which I could afford. Over the 11 days we were in I lost just under a stone. When your child is diagnosed you feel so emotional that you do not feel like you can eat plus your child does not want you to leave their side I therefore feel that offering parents food is an imperative part of maintaining good physical and mental health at a time that is one of the most heartbreaking times that any parent can go through.” (parent/carer of child aged 12-15)*

As indicated by the quote above, another aspect of parents having to provide their own food was the financial impact, with not everyone being able to afford it:

- *“Being in hospital especially for long-term illness and treatment, parents suffer financial difficulties, it would be helpful if parents can have part of their meal from hospital especially parents who cannot leave their child to get food.” (child aged 8-11)*

Noteworthy exceptions

There were fewer though noteworthy examples of positive experience in relation to hospital food. Across the examples the key to success appeared to be the flexible and personalised approach being taken:

- *“good that children can order what they want when they want for food…” (parent/carer of child aged 0-7)*
- *“great to have ward’s own chef” (parent/carer of child aged 0-7)*
- *“Special food on ward was good.” (child aged 8-11)*
- *“On ward cook is amazing and really tries hard to make the children happy and fed.” (parent/carer of child aged 8-11)*
- *“Dinner lady always made sure I had something to eat that I liked even if it wasn't on the menu.” (child aged 12-15)*

There were also two examples shared of hospitals feeding parents which indicated the schemes to be appreciated and working well:

- *“Our local hospital (location name) is piloting a scheme to feed parents at mealtimes with the children. This makes an enormous difference and would be really helpful if trialled at (location name). (parent/carer of child aged 8-11)*
- *“the sandwich voucher.” (parent/carer of child aged 12-15)*

Things to do in hospital

Play therapy

What does the quantitative data tell us?

- 47% of parents, carers, and children felt that there were definitely enough things for their child to do in the hospital (X43)
- 52% of parent of carers reported that the hospital always offered play specialist support when they needed it (X46)

There was a spread of both positive and negative experiences shared in relation to play therapy for children. It was clear from children's positive comments how important it was to have play incorporated into their care, including having access to playrooms and play specialists. These examples conveyed appreciation for play staff and a range of activities, including arts and crafts, music, visits from dogs, themed days and events:

- *"Being able to play in the toy room" (child aged 8-11)*
- *"When I was on the neuro ward they had a play week with different themed days & I got to join in with rocksteady on (location name). The play specialists were very good." (child aged 8-11)*
- *"The play team are amazing and I love all the dogs that visit the hospital and come to see me." (child aged 8-11)*
- *"Whilst in (location name), the play specialist was very inviting and gave me lots of stuff to do and make. Also Daisy the therapy dog gave me a big boost after the day of my surgery." (child aged 12-15)*
- *"There were two people came and played instruments and sang, which made me happy" (child aged 12-15)*

There was also acknowledgement of the positive role that charities had played, including an appreciation of the gifts they had provided, e.g. beads and ducks to children in the younger age groups. Charity names were recalled by children across different NHS Trusts demonstrating widespread impact:

- *"(charity name) have been an amazing support throughout my treatment. They provided games and activites to do when stuck on the ward." (child aged 12-15)*
- *"i really like (name) from (charity name) coming to craft with me when i had to stay overnight." (child aged 12-15)*

When children highlighted that improvements were needed this was predominantly in relation to activities being more age appropriate, with a sense that they were currently geared towards younger children. Some parents or carers also raised this:

- *“More things to do for my age group. I prefer (location name) to (location name) as all the toys etc in the play room suit younger children, I find it quite babyish. It needs a tween area.” (child aged 8-11)*
- *“More to do for older kids 12 and above. Very geared to younger children. Didnt fit in the teenage ward as just too young and really didnt fit the childrens ward. Staff tried but there time was more proportioned to the younger kids.” (child aged 12-15)*
- *“More things for teenagers in there area also making the teenage area for TEENS only not other parents or under 13s” (child aged 12-15)*
- *“Age appropriate space off the ward to spend time. Playroom not inviting or stimulating for the older age bracket it covers. Easy to become conditioned to lying in bed even when feeling ok as other option not appealing.” (child aged 12-15)*
- *“Better toys for ages 6+. Play areas too babyish, but not allowed into areas with more suitable toys, gaming equipment etc as for teenagers only.” (parent/carer of child aged 0-7)*

There were also comments that more needed to be provided for children in isolation:

- *“more things to do when in isolation rooms.” (child aged 8-11)*
- *“Play specialists daughter was isolated for first few days of being admitted, due to coming from another hospital. Play specialists were never seen, thus meaning nothing was provided to entertain her whilst in the isolation period.” (parent/carer of child aged 0-7)*

Respondents also raised that there should be increased access to play and activities, play therapy, and play specialists, including at weekends:

- *“Weekends there was nothing to do at all, everything stopped at once. No school, therapies, play therapies, music/magician, all stopped. It was along 48 hours every week.” (parent/carer of child aged 0-7)*
- *“we would appreciate greater access to play team and youth workers at the weekend and holidays - these are when kids need some fun and interactions with other people as the wards are quiet at these times.” (parent/carer of child aged 12-15)*

- *"There is almost no guided play. The playroom is full of toys but these are not rotated. I feel some play team led activities/sessions would be hugely beneficial for my child. The play therapists are not very present in the play room." (parent/carer of child aged 0-7)*

Wi-Fi and technology

What does the quantitative data tell us?

- 36% of parents or carers felt that the hospital Wi-Fi always met the needs of them and their child (X51)

Both children and parents or carers highlighted the need to have a good Wi-Fi connection. Poor Wi-Fi contributed to several issues for children such as limiting entertainment options; reduced contact with friends and family; and acting as a barrier to schoolwork. Poor Wi-Fi also impacted on parents or carers and their ability to work:

- *"Wifi I really missed playing my online games with my friends, fortnight and Roblox. The hospital blocks these to protect us but I am always with my mum so I am ok. This made me sad." (child aged 8-11)*

- *"The wifi access needs to be enhanced in the hospital to allow parents children to use tablet's, phones, computer, this will allow for more activities." (child aged 12-15)*

- *"Wifi, it's appaling and we all live our lives needing it so please make it useable." (parent/carer of child aged 8-11)*

- *"Better Wi-Fi would be much appreciated. Our daughter has been in hospital for treatment for many weeks at a time and has been in isolation for much of this. Good Wi-Fi is vital for her entertainment as well as being able to video call family and friends. As parents we also need good Wi-Fi for recreation and also work activities." (parent/carer of child aged 12-15)*

The comments also showed that patients would like access to TVs and video/gaming consoles (which could require good Wi-Fi), as a form of entertainment, but these weren't always available or working:

- *“Having access to a TV whilst an in patient is really important and we didn't always have a working TV/remote control. Breaks the day up a little + provides distraction.” (child aged 12-15)*

- *“Just replace silly tv with smart tv and decent wifi (provide good access for kids).” (parent/carer of child aged 0-7)*

While less common there were examples of children with access to TVs and consoles indicating this experience does vary from one hospital to another:

- *“Use of TV and X-Box in my room with choice of multiple DVDs.” (child aged 12-15)*

Education

What does the quantitative data tell us?

- 70% of parents or carers reported that their child had access to hospital school services during their stay in hospital (X52)

Children, particularly those aged 8-11, gave positive feedback about hospital school and teachers. Comments were extremely brief and indicated that they saw schooling as an extension of ‘things to do’ in addition to other activities and entertainment, and they highlighted the lessons that they particularly enjoyed:

- *“School was really good with lots to do.” (child aged 8-11)*

- *“school teachers (all) coding, music, science.” (child aged 8-11)*

- *“I like art lessons” (child aged 8-11)*

Some parents or carers also provided very general comments that schooling had been good, as well as praising the quality of the education provided by teachers:

- *“the teachers are fabulous and he really looks forward to seeing them and the work he is given.” (parent/carer of child aged 12-15)*

- *“When teaching were available it was of high quality.” (parent/carer of child aged 0-7)*

Where parents or carers were critical of education arrangements this could span home and/or in hospital schooling, and the focus was on insufficient access. This included suggestions that education should be provided from the start of treatment and extended to weekends and during school holidays:

- *"We were able to access at home tuition and play therapy but this came at the end of treatment. This would have been is helpful at the start rather than after 6 months." (parent/carer of child aged 8-11)*

- *"Also no help with education. I know there are teachers in other hospitals that help support childrens education. I think this would be very valuable. My son missed a lot of school" (parent/carer of child aged 8-11)*

- *"I realise it is funding related, but not having any teacher presence through the long summer holidays in the hospital was really hard. My son missed so much of his education and through term time loved his few short visits from the teacher. He was entitled to a.n hour everyday in term although he rarely received more than 3 visits per week. It would be great if they were available everyday in term and even just a couple of times a week through the holiday. It broke the day up and if there was more availability might have helped him not get so far behind at school a bit at least." (parent/carer of child aged 0-7)*

- *"The 121 support at home during the heavy treatment was not provided by his school and the hospital school was not able to take further action to continue education during treatment. The hospital school should be empowered to talk with the council and report these situations where school is withdrawing support for children under cancer treatment." (parent care of child aged 8-11)*

Hospital environment

Noise at night

What does the quantitative data tell us?

- 25% of parents, carers, and children reported that it was always quiet enough for them to sleep in the hospital (X49)

The hospital environment being too noisy was a common theme, with this impacting on patients' and parents or carers ability to sleep. This was said to be caused by other patients and visitors for most, but could also come from staff and equipment.

Suggestions of ways to improve noise at night included staff being more proactive in asking patients to be quieter; staff being more considerate of the noise they were making; lights being turned down earlier; and rules such as headphones being required for those using electronic devices:

- *“Pumps alarming day & night, hard to sleep, but that cannot be altered.” (child aged 8-11)*
- *“Some people were allowed to keep music or TV on late at night and they weren't told to turn it off or down” (child aged 8-11)*
- *“Would be helpful if the nurses could be more proactive about the noise of other patients when in the ward.” (child aged 12-15)*
- *“when staying overnight i was always tired but the lights never went out untill 10ish and i wanted to sleep before then. Through the night people would watch on their TVs which was slightly irritating but i totally understand if they couldn't sleep or were worried etc.” (child aged 12-15)*
- *“Staying overnight is difficult - my child needs 121 all the time and the noise levels on wards is impossible some nights due to the level of noise coming from the nurses stations.” (parent/carer of child aged 8-11)*
- *“For staff to be more quiet at night time, slamming doors, talking loud and laughing, other than that everything was fine.” (parent/carer of child aged 0-7)*

Another suggestion, particularly from children aged 12-15, was to separate them from younger children due to the noise they made which could impact on sleep:

- *“Maybe keep older children together due to noise levels etc, young children & babies together as it is hard to sleep.” (child aged 12-15)*
- *“Not being near screaming babies / children after brain surgery.” (child aged 12-15)*
- *“Teenager area, get me away from little kids - I'm 15!” (child aged 12-15)*
- *“The ward was very loud during night time with all the toddlers. It was better when the teenagers were in a seperate bay.” (child aged 12-15)*

Comfort

Respondents also highlighted that the comfort of beds and sleeping arrangements for parents or carers was a challenge to achieving a good night's sleep.

What does the quantitative data tell us?

- 36% of parents or carers reported that facilities for them to stay overnight were very good (X48)

- *"Beds for parents could be better (sofas are too hard to even sit on)" (child aged 8-11)*

- *"There are never any pillows for parents - they are like gold dust yet having to sleep there every night they are kind of essential given the sofa beds are so uncomfortable." (parent/carer of child aged 8-11)*

- *"The parent facilities were generally poorer. The beds in the shared wards in (location name) are not great! There is a purple sofa bed which is not fit for purpose in a modern care setting! (parent/carer of child aged 0-7)*

- *"Ensuring there enough parents bed as I had to sleep in chair as no bed could be find." (parent/carer of child aged 12-15)*

On the theme of comfort there were also a small number of comments about seating and waiting rooms which could be improved:

- *"Waiting room was not very comfortable, not enough & seats for everyone in treatment room." (child aged 12-15)*

- *"Better waiting area with more comfortable seating." (parent/carer of child aged 8-11)*

Temperature

Another sensory issue that came up multiple times in the data was the temperature of the hospital environment, with some respondents declaring it was too hot and others too cold. The temperature was commented upon in context of sleep as well as without specificity:

- *"One of the rooms on the ward was very cold." (child aged 8-11)*

- *"Staying on the ward wass horrible… No sleep, 2 cold." (child aged 8-11)*

- *“Adjustable room temp as it was alway so hot.” (child aged 8-11)*
- *“The parent's room on D2 is bakingly hot” (parent/carer of child aged 8-11)*

Privacy

Children as well as parents or carers across age groups expressed a preference for private rooms. Where reasons were shared for this, they included that it could be stressful; it could be distressing when people were upset; or it was felt necessary for when sensitive conversations could be otherwise overheard:

- *“Sometimes at clinic when you are in the waiting area with everyone else there is no privacy when someone gets upset, everything is in earshot of everyone else.” (child aged 8-11)*
- *“The 4-bed rooms are stressful and spending 6 nights there for one of the rounds is very stressful.” (child aged 8-11)*
- *“Sharing a small area with other patients can be hard when you don't feel good and they are going through a bad time.” (child aged 12-15)*
- *“At initial diagnosis it was highly stressful to be on an open bay with no privacy.” (parent/carer of child aged 0-7)*
- *“More private spaces to speak to staff or be seen in i.e for blood tests.” (parent/carer of child aged 8-11)*

Making the case again for separation from younger children, those aged 12-15 expressed desires to be in private rooms mostly when commenting on the ward arrangements in hospitals:

- *“Yes not putting a teenage in a baby ward and open ward.” (child aged 12-15)*
- *“More private rooms especially for teens! (Privacy is good).” (parent/carer of child aged 12-15)*
- *“In ward, separate small children from teens, painful listening to endless nursery rhymes when stressed already.” (parent/carer of child aged 12-15)*

Other issues

A range of other ideas were suggested as ways to improve the hospital environment. While each was most often unique and mentioned singularly, as a collective these examples demonstrate that a focus on improving the hospital environment for children and parents or carers, would be beneficial in efforts to improve experiences of care. Ideas found in the data included:

- Larger rooms
- Improved layouts, e.g. areas not feeling hidden
- Better bathroom facilities for parents
- More facilities for washing clothes
- Provision of exercise facilities for parents
- Better lighting in parking areas
- Clear/efficient ways to report maintenance issues, e.g. broken taps, TVs
- Poor cleanliness
- Access to an outdoor space

Noteworthy exceptions

A small number of positive comments were found which framed experience of the hospital environment positively. These comments were very brief and lacked detail to underpin what was working well in these examples, though they included the cleanliness of the hospital environment; being able to access a garden; the provision of equipment and amenities; as well as the general ambience of spaces.

- *“I liked the outdoor garden” (child aged 12-15)*

- *“My room was cleaned regularly and the sheets were changed regularly.” (child aged 12-15)*

- *“I liked the room. and the bed at (location name).” (child aged 12-15)*

- *“The environment is always very welcoming.” (parent/carer of child aged 8-11)*

Other

A range of other topics were commented upon in the data which were noted during the analysis process. There lacked volume of comments, depth and detail in this data to inform themes. Listed below are the topics:

- Experiences of cannulas and a request for ultrasounds
- The impact of cancer treatment on children’s teeth and a need for dentistry
- Use of Virtual Reality (VR) during procedures
- Calls for discharge from hospital to be earlier in the day
- Difficulty with access to aftercare
- Aftercare needing to include holistic wellbeing support
- Experiences of the transition from child to adult services

Conclusions

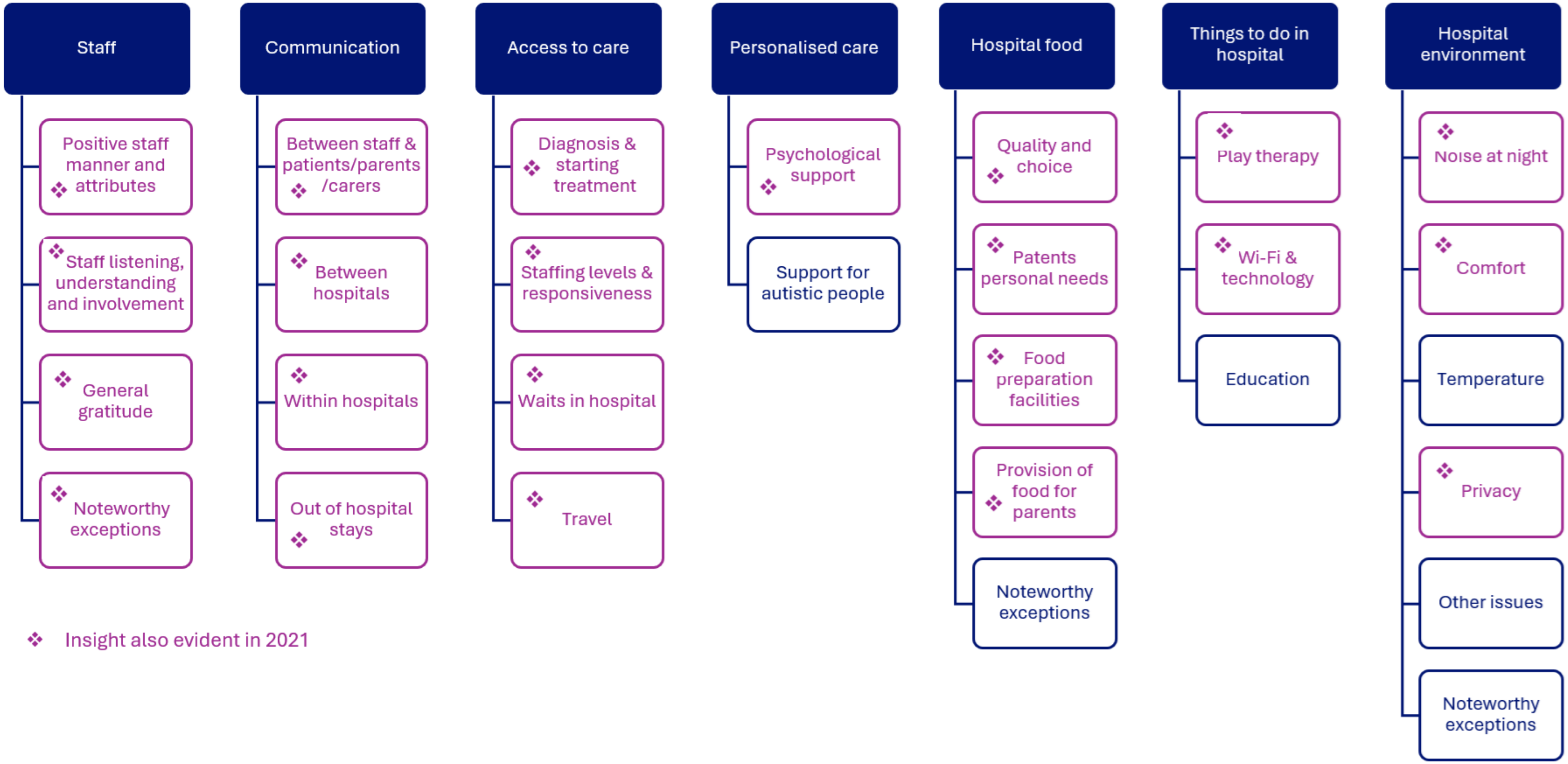
As the second national qualitative report for U16 CPES, it is anticipated that a lot of interest lies in what has changed since the previous publication for the 2021 survey.

As noted earlier in the report direct comparisons are not possible due to changes with the questionnaire over time, including the specific open questions. The consequence to this is that we cannot be confident the absence of an insight from 2021 to 2023, or the presence of ‘new’ insight from 2023, is the result of real change in experiences of care. There are also unknown variables which may have impacted on whether respondents chose to include or exclude particular experiences.

We can be confident that the recurrence of insight overtime makes a compelling case that there remains opportunities for improvement. A visual summary is shown on the page which follows, to highlight which of the 28 sub-themes from 2023 were evident also in 2021. This could mean the insight was either core or part of either a key theme or sub-theme as previously reported in 2021.

As visualised, there is a lot of recurrence in the insight from 2021 to 2023. Alongside the ‘novel’ insights from 2021 and 2023 combined, the result of two analyses and reports is an ever-growing list of areas for focus without a strong steer on prioritisation. This reflects the limitations of qualitative data collected through survey methods which don’t allow for prompting, probing or deeper discussion.

In context, the conclusion of this report is the importance of triangulating this insight with other existing datasets that are relevant, and to consider new collections and/or engagement activities which would support better understanding of priorities for patients, parents or carers. Ongoing listening and involvement is of course paramount to ensure any efforts nationally or locally will have the greatest gains to improve the experiences of children and young people, their families and carers.



- Staff
  - ❖ Positive staff manner and attributes
  - ❖ Staff listening, understanding and involvement
  - ❖ General gratitude
  - ❖ Noteworthy exceptions
- Communication
  - ❖ Between staff & patients/parents /carers
  - ❖ Between hospitals
  - ❖ Within hospitals
  - ❖ Out of hospital stays
- Access to care
  - ❖ Diagnosis & starting treatment
  - ❖ Staffing levels & responsiveness
  - ❖ Waits in hospital
  - ❖ Travel
- Personalised care
  - ❖ Psychological support
  - Support for autistic people
- Hospital food
  - ❖ Quality and choice
  - ❖ Patents personal needs
  - ❖ Food preparation facilities
  - ❖ Provision of food for parents
  - Noteworthy exceptions
- Things to do in hospital
  - ❖ Play therapy
  - ❖ Wi-Fi & technology
  - Education
- Hospital environment
  - ❖ Noise at night
  - ❖ Comfort
  - Temperature
  - ❖ Privacy
  - Other issues
  - Noteworthy exceptions

❖ Insight also evident in 2021

Further information

For more information on development and methodology, please see the Survey Development Report and Technical Appendix. These documents can be viewed along with the survey guidance on the website: www.under16cancerexperiencesurvey.co.uk.

For the quantitative survey results, please go to:
www.under16cancerexperiencesurvey.co.uk/technical-reports