cancer patient experience survey

NHS England

Under 16 Cancer Patient Experience Survey 2024

National Qualitative Report

November 2025

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Executive summary

Background

The Under 16 Cancer Patient Experience Survey (U16 CPES) is an annual survey that aims to understand the experiences of cancer and tumour care for children across England. This is the fifth 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 2024, aged under 16 at their time of discharge. The survey was also available to complete online or over the telephone.

The survey asked respondents a range of closed questions about their experience and also invited them to provide open-ended written feedback by being asked 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
Gratitude was expressed with a particular focus on the role staff played in care experiences. Positive attributes such as kindness & friendliness were highly praised. Areas for improvement focussed on training; continuity; & ensuring staff were listening, understanding & involving patients, parents & carers.

Communication
Features of good communication between staff & patients/parents/carers 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. The need to be kept informed was evidenced as important.

Access to care
How long it took to get a diagnosis & treatment was variable, with delays attributed to multiple issues. Staff were not always responsive to needs, with links to understaffing particularly at weekends/nights. Long waits in hospital were a frustration; with travel issues also impacting access.

Personalised care
There was a need for psychological support to be extended to wider family as well as more accessible for patients/parents/carers too. There were concerns highlighted as to the risks for immune compromised patients when in need of unexpected or urgent care, driving a call for more consideration.

Hospital food
Food played a significant role in how children & young people experienced time in hospital, with it commonly raised as an area for improvement. Issues spanned quality & choice; how well it met personal needs; as well as provision of food & adequate preparation facilities for parents/carers.

Things to do in hospital
Play staff & activities were highly valued though older age groups were less catered for & there was unmet need for access at weekends. Improvement to Wi-Fi and the use of digital entertainment was also found. Hospital education was well received with requests for extended provision, e.g. weekends and bank holidays.

Hospital environment
Noise and the ability to sleep in the hospital environment was experienced as an issue. There were also calls for increased privacy; improved comfort of beds & chairs; and in some cases cleanliness of the hospital environment was found to be problematic.

Introduction

Project background

The U16 CPES 2024 is the fifth 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 understand children and young people's experiences 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 2024 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 2024 and 31 December 2024, and were aged under 16 at the time of their discharge.

The fieldwork for the survey was undertaken between April and June 2025. One of three versions of the survey was 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 2024 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 or 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 0-7 survey does not contain a children's section and is completed by the parent/carer only.

Overall survey response rate

Overall, the survey had a response rate of 22%, with 759 respondents out of a total of 3,434 eligible parents, 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/carer and child responses.

About the respondents leaving qualitative comments

Of the 759 completed survey responses, 549 surveys included responses (qualitative data) to the open questions in the survey asking if there was anything else they would

like to say about their or their child's cancer care. This could be a parent comment, a child comment or both a parent *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): 252 records with qualitative data
- 8 to 11 questionnaire: 109 records with qualitative data
- 12 to 15 questionnaire: 188 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	28
Birmingham Women's and Children's Hospital NHS Foundation Trust	51
Cambridge University Hospitals NHS Foundation Trust	39
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	114
Leeds Teaching Hospitals NHS Foundation Trust	39
Manchester University NHS Foundation Trust	36

[1] A survey response could be a parent of 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.

Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	39
Oxford University Hospitals NHS Foundation Trust	34
Sheffield Children's NHS Foundation Trust	21
The Newcastle upon Tyne Hospitals NHS Foundation Trust	36
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	56
University Hospital Southampton NHS Foundation Trust	30
University Hospitals Bristol and Weston NHS Foundation Trust	26
TOTAL	**549**

There was a total of 1,235 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/carer and child answered both parts of the question, then this would count as four responses.

Table 2 shows the number of comments left by parents/carers and by children across each survey version. A total of 897 comments were left by parents/carers, and 338 comments were left by children.

Table 2: Number of comments by survey section

Survey version	Number of qualitative comments
0 to 7 questionnaire (parent/carer only)	433 comments
8 to 11 questionnaire	Child survey section: 123 comments Parent/carer survey section: 172 comments
12 to 15 questionnaire	Child survey section: 215 comments Parent/carer survey section: 292 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 those which simply stated 'N/A', 'No', 'I don't know'. This left 1,190 comments for the sample to be drawn from.

Due to the relatively low volume of comments from children, all 327 were included. A random sampling technique was then undertaken to select an additional 327 comments from parents or carers. This was checked to ensure that the sample was broadly spread across the different age ranges, questions and PTCs.

Once the original sample of 654 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 and / 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 sample by survey type and question.

Table 3: Number of comments in qualitative sample

Survey version	Question	No. of comments overall[2]	No. of comments in sample
8-11	Was there anything good? (child)	59	59
12-15		109	109
0-7	Was there anything particularly good? (parent/carer)	227	61
8-11		87	52
12-15		150	55
8-11	Was there anything that could be better? (child)	58	58
12-15		101	101
0-7	Was there anything that could be improved on? (parent/carer)	188	60
8-11		80	48
12-15		131	51
TOTAL		**1,190**	**654**

[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 versions/sections (1,235). 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 and Figure 1 show the response breakdown of the final qualitative sample by Principle Treatment Centre (PTC) and survey type.

Table 4: Proportion of responses per Principle Treatment Centre (PTC) in qualitative sample (N=361)

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	18	5%
Birmingham Women's and Children's Hospital NHS Foundation Trust	28	8%
Cambridge University Hospitals NHS Foundation Trust	28	8%
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	75	21%
Leeds Teaching Hospitals NHS Foundation Trust	25	7%
Manchester University NHS Foundation Trust	29	8%
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	29	8%
Oxford University Hospitals NHS Foundation Trust	24	7%
Sheffield Children's NHS Foundation Trust	13	4%
The Newcastle upon Tyne Hospitals NHS Foundation Trust	22	6%

[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

The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	34	9%
University Hospital Southampton NHS Foundation Trust	18	5%
University Hospitals Bristol and Weston NHS Foundation Trust	18	5%
TOTAL	**361**	**100%**

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

Figure 1: Proportion of responses by survey type in qualitative sample (N=361)

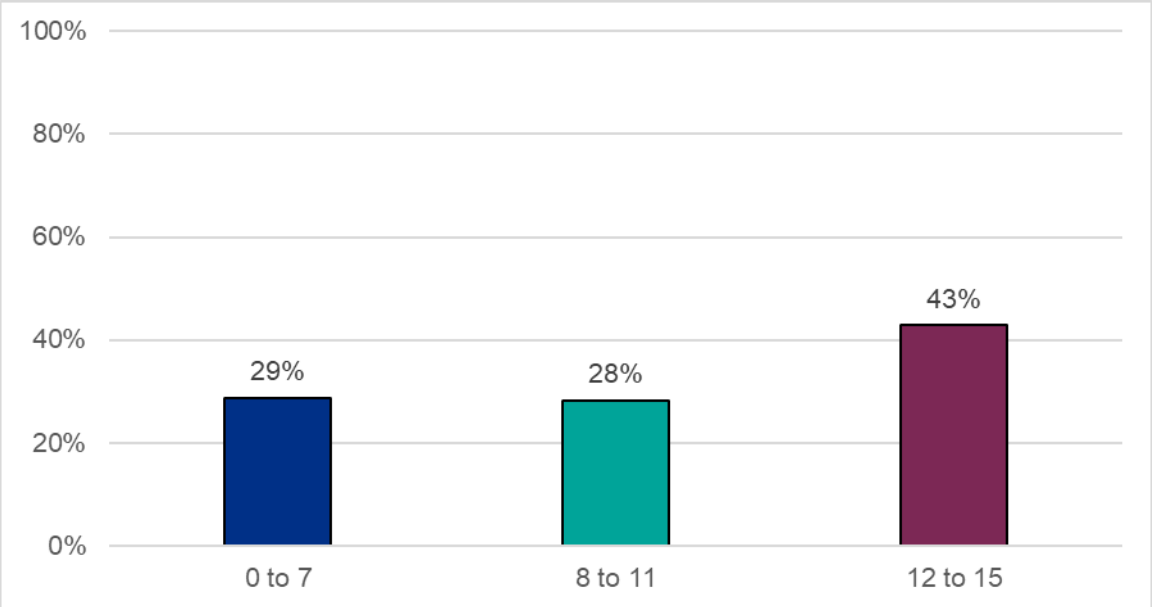


Figure 2: Proportion of responses by sex registered at birth of child in qualitative sample (N=361)

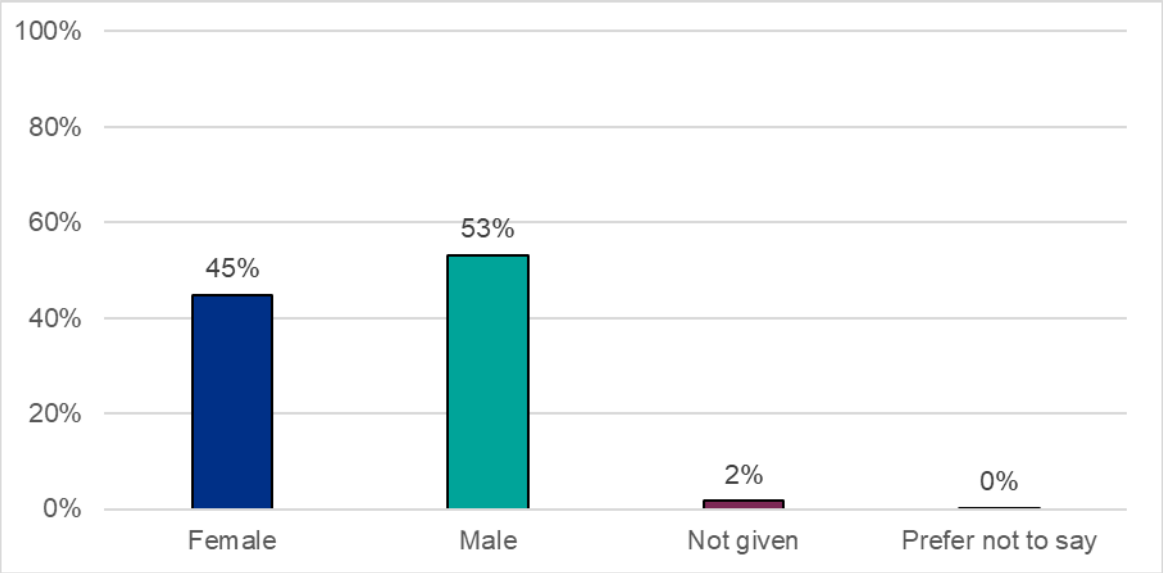


Figure 3: Proportion of responses by ethnic group in qualitative sample (N=361)

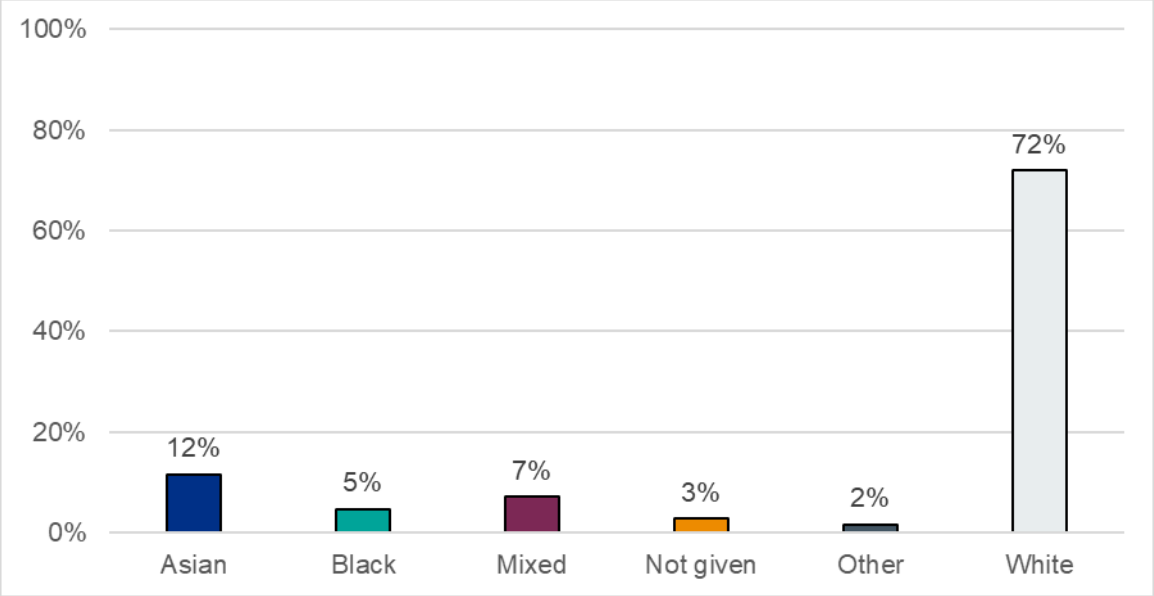


Figure 4: Proportion of responses by deprivation (IMD quintile) of child in qualitative sample (N=361)

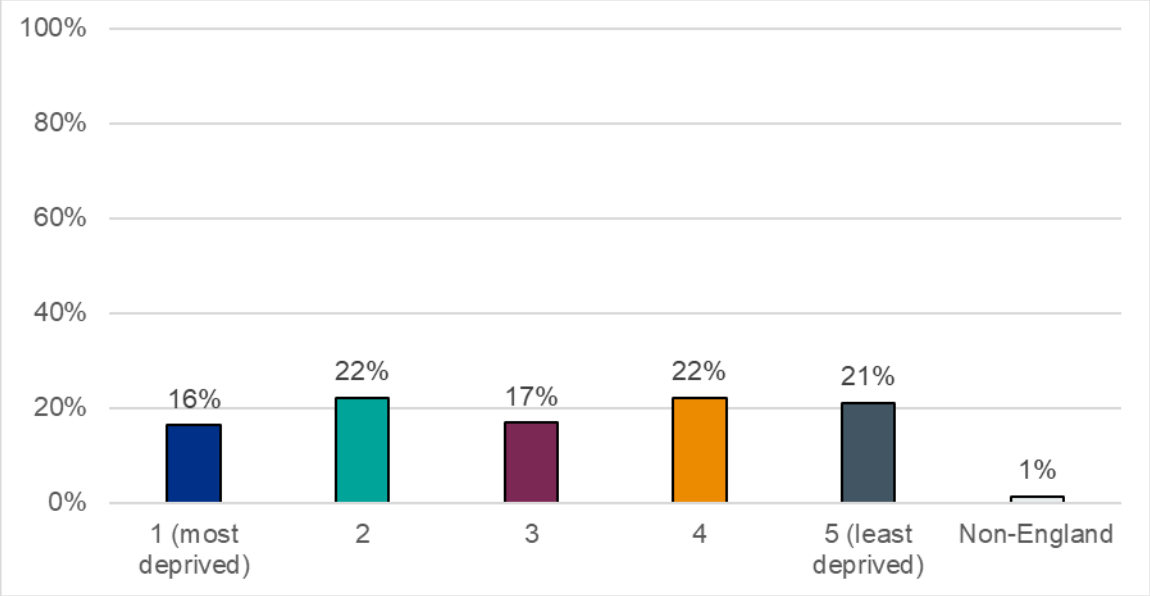
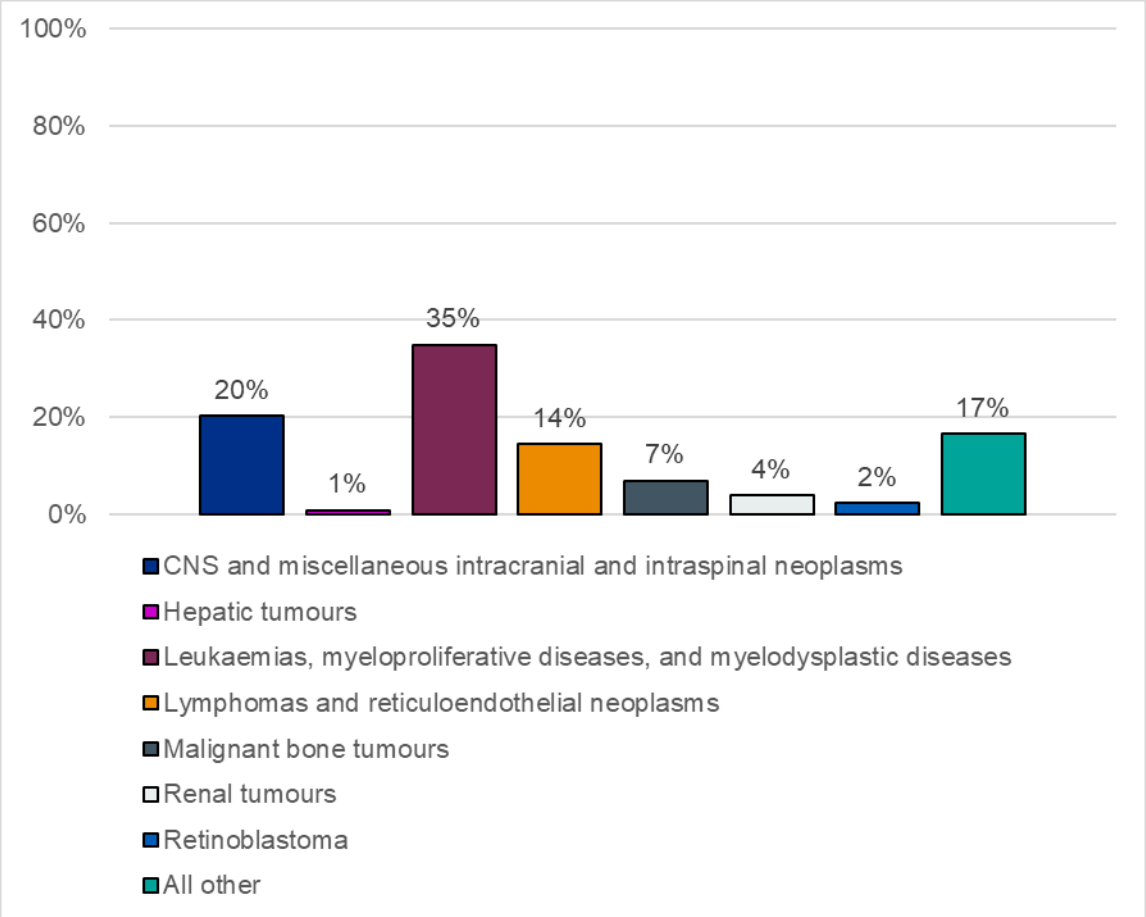


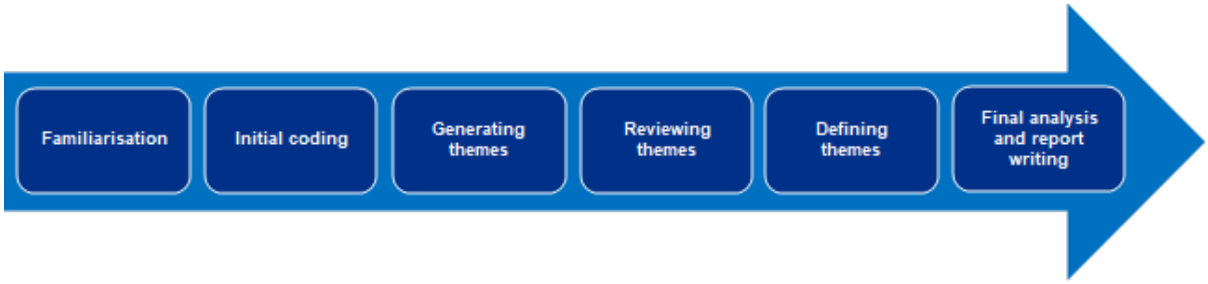
Figure 5: Proportion of responses by diagnostic group in qualitative sample (N=361)



Thematic analysis approach

Given the high levels of consistency seen across the 2021 and 2023 qualitative insight, a deductive approach was taken for the 2024 data analysis. The standard six steps of thematic analysis were used to identify patterns of meaning within the data and explore commonality and contrast – see Figure 6. The thematic codes created in the qualitative analysis of 2023 data were used for the initial coding of the 2024 sampled data, with a small number of minor changes made over the course of the analysis to ensure that they reflected the 2024 data.

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. 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. All 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 individual staff members referenced. A summary is shared below of the information that has been removed:

- Names of patients or staff replaced with "(patient name)" or "(staff name)"
- Names of wards, units or hospitals replace with "(location name)"
- Names of cancer charities replaced with "(charity name)"
- Dates replaced with "(date)"

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/carer judging by 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 nurses were good, without saying what was good about them. This limited the analytical insights that could be drawn, though it did give a high-level sense of what respondents appreciated about their care and what was meaningful to them.

Whilst 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 detailed. For example, comments from older children and parents/carers typically consisted of a sentence for each topic raised, but in some cases extended to a longer paragraph.

In summary, the qualitative data collected in 2024 is described to be 'thin' meaning it typically lacks detail and depth. While this has been true of qualitative data captured by this survey previously and reported in 2021 and 2023, this was observed for 2024 to be the 'thinnest' yield of qualitative data. This is reflected in the report as compared to previous publications of qualitative insight, there is less detail and depth when describing some of the sub-themes. While absolute causation cannot be determined due to a range of variables that could impact on this beyond analysts' knowledge, it may be useful to consider that a high proportion of respondents have been asked to complete the survey across multiple years.

Comparability

While this is the third qualitative analysis report published for the U16 CPES, the first being for the 2021 survey, and the second in 2023, we advise that results are not directly comparable. 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, in recognition of the challenge in tracking qualitative insight from a survey over time, a deductive approach to analysis was used for the U16 CPES 2024. This involved applying a consistent framework to the data, allowing us to see patterns and connections between years. While much was alike, to reflect nuance found in 2024, the framework was adjusted and includes a small number of 'new' sub-themes, which weren't so apparent in 2023. The conclusions section covers these differences in more depth.

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 30 sub-themes in total.

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

Staff

General gratitude

What does the quantitative data tell us?

- 91% of parents or carers rated the overall experience of their child's care as 8 or more out of 10 (X59)
- 78% of children reported that they were very well looked after by staff for their cancer or tumour (X60)

Overarching statements expressing gratitude for care and a wish to pass on heartfelt thanks, were prominent in the data. This feedback indicated how valued staff and whole services were by respondents. Comments commonly described care as “good”, “amazing” and “excellent”.

- *“(location name) is the best hospital in the UK. If it wasn't for them, I wont be here now. (location name) safed my life. I want to say a big thank you to (location name), and (location name) for all the help you gave me and saving my life.” (child aged 8-11)*
- *“The level of care provided for our daughter was very good. (patient name) oncologist has been amazing & her after care nurse.” (parent/carer of child aged 12-15)*

- *"(patient name) has been going through, treatment since (date) and the care we have received is really good. Our medical team are amazing and they have gone far and beyond for her we cannot speak more highly of them all. We will forever be grateful. (parent/carer of child aged 8-11)*

Staff attributes

What does the quantitative data tell us?

- 86% of children felt that staff were always friendly (X12)
- 86% of parents or carers felt that they were always treated with empathy and understanding by staff caring for their child (X19)
- 94% 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 and professional attributes that they displayed. Where specific staff roles were stated, these were primarily nurses, play staff, doctors, consultants, 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. While mentioned less frequently, other types of staff such as physiotherapists, catering, facilities, admin and charity staff, were also referenced. This demonstrated how every contact counts and the potential for each person encountered to have an impact significantly on experiences of care.

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:

Where respondents provided more detail, the impact of these staff attributes was in making children feel safe, comfortable and special. There was also feedback that it made a mentally difficult time feel more bearable for both children and parents or carers and helped build trust in staff too.

- *"The staff are incredibly kind and I feel so safe and comfortable to talk to. Thank you." (child aged 12-15)*
- *"You were all very kind but it was horrible sometimes, but there was not your fault, it made me better. You are kind, (staff name) and (staff name) and (staff name) are my best people. I think you care a lot about us and that made me feel safe. Thank you" (child aged 8-11)*
- *"I really love all the staff at (location name). They made me feel special, loved and cared for." (child aged 12-15)*
- *"The staff on (location name) ward at the (location name) were amazing! They were caring, professional and always made us feel so looked after. We are so grateful to them all. The nurses, Doctors, play team, school team, catering, cleaning, physio, occupational health, aromatherapy and all the support staff were all so kind and made our stays at hospital so much more manageable. Thank you." (child aged 12-15)*
- *"The nurses were the kindest, supportive and cheerful people which helped with the fear and trauma being on an Oncology Children's Ward." (parent/carer of child aged 12-15)*
- *"All staff have always been friendly and helpful... Our consultant (name) is very lovely and made me (mum) feel that I can trust her fully." (parent/carer of child aged 0-7)*

In some cases, the positive manner and attributes of staff had contributed to parents or carers viewing them as akin to family and the hospital as a second home.

- *"It has been brilliant throughout. We were made to feel likes the hospital was our 2nd home. All of the team are kind and caring and helped us through every stage." (parent/carer of child aged 12-15)*
- *"Ward (location name) nurses were incredible and supportive. We couldn't fault them, they turned a horrendous experience into something you feel you could deal with.*

They treated my whole family like their family. We are truly grateful." (parent/carer of child aged 0-7)

- *"Hospital was like a home where everybody was friendly and helpful." (parent/carer of child aged 0-7)*

Some respondents also acknowledged how knowledgeable, skilled and experienced nurses, doctors and consultants were.

- *"Thouroughly trusted the skill and knowledge of treatment of consultants." (parent/carer of child aged 12-15)*
- *"There is a strong team of experienced nurses on day case" (parent/carer of child aged 8-11)*

While the positive experiences of staff manner and attributes were prevalent, there were exceptions which are noteworthy as they demonstrate some variation in the data. Respondents could use language such as "some" or "most" staff when describing the attributes they displayed, indicating that not all interactions with staff were positively experienced. There were also explicit mentions of staff displaying negative attitudes such as rudeness, having poor bedside manner and in one case racism, as well as a need expressed for some staff to be friendlier and more empathetic.

- *"A lot of the staff where kind but sometimes rarely some of the staff were not" (child aged 12-15)*
- *"Most of the nurses are amazing - massively empathetic to both children and parents." (parent/carer of child aged 8-11)*
- *"Yes, some nurses are not nice. Also, strict and feel a bit racism." (child aged 8-11)*
- *"Dr at (location name) to have more bedside manner." (parent/carer of child aged 0-7)*

Although negative experiences were less commonly mentioned, they again illustrate that all members of staff play a critical role in how care is experienced.

Staff training

What does the quantitative data tell us?

- 83% of parents or carers felt they always had confidence and trust in staff caring for their child (X18)

Where calls for improved staff training were seen, these focused on staff who were providing care for cancer patients in A&E, local hospitals as part of shared cancer care or non-cancer wards within a hospital. Within these settings there were concerns that there was insufficient staff understanding, experience and training to meet the specific needs of cancer patients, which was often framed in contrast to staff on dedicated oncology wards. This appeared to undermine respondents' sense of trust and safety.

Where respondents were more specific, skills around the use of central lines were identified as an example of where improvements were needed, e.g. Hickman lines were raised multiple times.

- *"Ensuring appropriate and up to date training is in place in shared care hospitals." (parent/carer of child aged 0-7)*
- *"Staff all trained and felt safe on an oncology ward compared to local hospital." (parent/carer of child aged 0-7)*
- *"We understand that there is nothing else that can be done when the oncology ward is full, but we feel uncomfortable when we have an unexpected stay and have to go to another ward where the staff are perhaps not as experienced with dealing with a child with cancer." (parent/carer of child aged 12-15)*
- *"Extremely variable amount of trust in his care through this pathway often quite traumatic recurrent attempts at inserting chest line for IV. Nurses not sufficient training for this in A+E. Never play support for the procedure + staff not understanding of the distress + knock on this has for a child who required recurrent line access for treatment." (parent/carer of child aged 0-7)*
- *"The only thing we can think of for improvement is, local hospitals, which are sometimes needed in emergency situations, need more training on line entries/use. Hickman line is what our daughter had and our local hospital accessed several times and didn't do it very professional. Further training." (parent/carer of child aged 0-7)*

To note, there were inferences in this feedback that issues with hospital capacity could contribute to patients not always seeing the most appropriately trained staff.

Staff listening, understanding and involving

What does the quantitative data tell us?

- 91% of parents or carers felt that they and their child were always treated with respect and dignity by staff (X17)
- 69% of parents, carers, and children felt they were definitely involved in their child's or their care and treatment (X29)

The ability of staff to listen, understand and involve children, parents or carers was seen to be variable with some experiencing this positively and others feeling that this did not happen or improvements were needed.

Staff engaging on a personal level was valued, for example by greeting patients, parents or carers; recognising and remembering them; and having casual/friendly conversations. Although brief in terms of detail, this was indicated to have benefits in making people feel welcomed, supported and safe. There were also examples where staff considered the personal circumstances of families when making care arrangements.

- *"I loved how the staff got to know me and greeted / greet me every time I see them. They make me feel safe." (child aged 12-15)*
- *"We've had some very caring stand-out staff - the ones that remember our names and have a conversation (even if they aren't treating us). Makes us feel welcome and supported." (child aged 8-11)*
- *"The staff are excellent, they talk to (patient name) about his interests, remember him from previous visits." (parent/carer of child aged 12-15)*
- *"My son's consultant was both efficient and caring. He arranged to carry out our son's surgery during the summer holidays but before our family holiday." (Parent/care of child aged 12-15)*
- *"(staff name) is a credit to the hospital. She knows (patient name), despite all the patients she sees and understands out concerns as a family… She has*

accommodated myself and my ex partner separately on occasions if we couldn't attend ourselves." (Parent/carer of child aged 8-11)

When this experience was lacking, as it did not happen for all, it further demonstrated the importance and how making conversation impacted on experiences of care. While this feedback was not typical, it was observed to have been raised by respondents for the 12-15 age group particularly.

- *"Bedside manner often lacking with much of the staff team, this is even Just general chat with teenage patients. General nursing was fine but children need to feel comfortable and confident with their nurses." (parent/carer of child aged 12-15)*
- *"The nurses at (location name) weren't very attentive. Hardly any made conversation with you. They weren't very approachable." (child aged 12-15)*

There were mixed experiences around the extent to which children, parents or carers felt that they were being listened to and involved in joint decision making. The positive comments were brief, with respondents simply saying they felt listened to; opportunities were provided to contribute to care decisions and those decisions being respected; and that children were involved in the administration of their treatment.

- *"Our CNSs have been great - they always listen to my concerns" (parent/carer of child aged 8-11)*
- *"Treated child with respect, dignity and allow her to make decisions." (parent/carer of child aged 12-15)*
- *"Dr (staff name) made us feel very at ease and heard in every aspect of choosing (patient name) treatment + beyond." (parent/carer of child aged 0-7)*
- *"Some staff let me help with things that involve me like my care." (child aged 12-15)*

In contrast, some respondents felt unheard and explained that this invalidated their concerns and feelings. It is noteworthy that in two examples shared below, a different member of staff had intervened or interjected to support the parents or carers involved which was positively experienced.

- *"We found the CNS's to be rude at times. We found many staff would only talk to Dad despite Mum being there. We found our consultant to not listen & think he knew our*

child better than us as parents." (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)

- *"During chemo, I didn't like being told on several occasions by one particular doctor that I needed to 'be positive' it felt insensitive and infuriating." (child aged 12-15)*
- *"We were put under a lot of pressure to have an NG tube (by one consultant in particular) and that was the only time it felt like we were being branded as being unhelpful when we felt we were doing what was best for our child. In the end (patient name) completed the treatment fine without it (albeit with it becoming our full time job to help him eat little and often all day every day; and his own bravery in committing to taking all his meds orally, no matter how disgusting!) We felt there could have been more support for him making that decision for himself (even though he was v young). We said we would never stand in the way of anything medically necessary, but it felt this was being pushed right from the beginning as it would make the nurses/consultants life easier. I should say we did find support for (patient name) decision amongst the nurses, which helped us keep going." (parent/carer of child aged 0-7)*
- *"One doctor was very arrogant and not prepared to listen to valid concerns from us as parents until convinced by a ward deputy sister (who was amazing)." (parent/carer of child aged 12-15)*

Not being listened to and having health concerns dismissed by healthcare professionals was also seen as a reason for delayed diagnosis. More detail on this is shared within the 'Diagnosis and starting treatment' sub-theme of this report.

Staff continuity

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)
- 43% of parents, carers, and children reported that the same nurses always came to their home or school (X56)

Respondents expressed a preference for children and young people to be cared for by the same staff. Negative examples were shared where this hadn't happened.

- *"Staff continuity needs to be much improved!" (parent/carer of child aged 12-15)*
- *"Seeing our own consultant consistently was very rare and not helpful." (parent/carer of child aged 12-15)*
- *"Having a consistent contact / consultant that we see on each visit. Son's consultant changed and we still haven't officially met the new one. (parent/carer of child aged 8-11)*

While these comments lacked depth, there was inference that staff continuity would have benefits, particularly in terms of building relationships and improved communication.

Linked to the sub-theme on 'Staff listening, understanding and involving', it was indicated that continuity of care facilitated relationships with staff as it created the opportunity to get to know patients and their families over time and for bonds to develop. The downside was when close relationships formed were lost when patients began seeing different staff and/or when staff with whom they had established a bond had left. Mitigating this due to the negative impacts on children and young people, was suggested.

- *"(staff name) - Disappeared, stopped supporting me after 1 month. No contact and left me with no one to talk to." (child aged 12-15)*
- *"My only thought was that my 15 year old son got attached to one of the trainee nurses and he would talk to her about his worries when he wouldn't talk to me or the rest of his nursing team. I understand that they have to rotate on for their training but I did feel that there should be a little leeway for them to stay on if a child particularly bonds with them. He never bonded quite as well with anyone else as he did with her. This is not knocking the rest of the team but the trainees are the ones who sometimes have that time to talk and chat and bring a bit of joy at a dark time." (parent/carer of child aged 12-15)*

A lack of staff continuity and having to see different staff was also linked to issues with information provision and communication and could impact on how consistent, timely and thorough this was.

- *"Also the number of different dr's seen, it'd be better if we only saw 2 or 3 different rather than 6 or 7 who all said different things." (parent/carer of child aged 0-7)"*
- *"Our specialist nurse went part time (no fault or her own) but we were never given a full time replacement or another part time nurse so we would only get half information/Communication." (parent/carer of child aged 8-11)*
- *""Decision making amongst staff needs autonomy. Continual staff changes cause much confusion over decisions to be made." (parent/carer of child aged 12-15)*

Communication

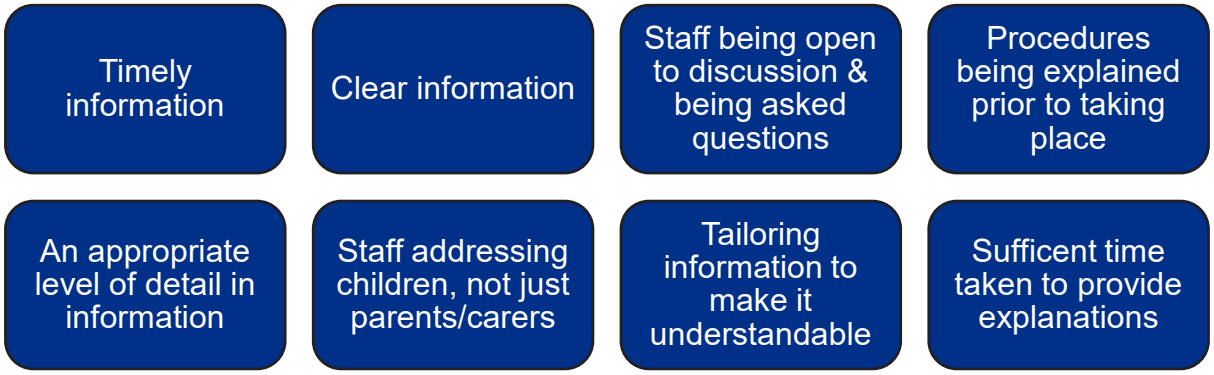
Between staff and parents or carers and children

What does the quantitative data tell us?

- 75% of parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand (X08)
- 85% of parents, carers, and children reported that they were definitely able to have questions answered after being told about the cancer or tumour (X09)
- 69% of children reported that they could always understand what staff were saying (X13)
- 71% of children felt that staff always talked to them, not just their parent or carer (X14)
- 89% of parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment (X16)
- 80% of parents or carers felt that healthcare staff always shared information with children in a way that was appropriate (X22)
- 82% of parents, carers, and children reported that they always understood what nurses visiting their home or school were saying (X55)

The ability of staff providing care to communicate well with children and parents or carers was seen to be of importance. Where stated, good communication had positive impacts in terms of making children feel calm, comfortable, and more at ease.

Although comments lacked detail, both children and parents or carers provided insight into what characterised good communication with staff, with value placed on the following aspects:

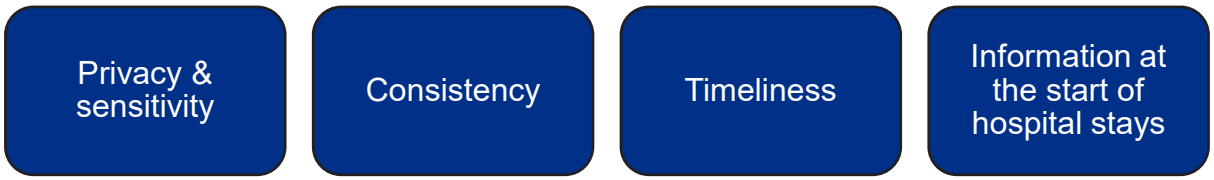


- *"My childs consultant has always been good at explaining the situation we face. She also understands how important to us it is to know the situation we need to face as soon as possible so we are not left waiting for scan results for example" (parent/carer of child aged 8-11)*
- *" (consultant name) is very informative and very clear with what he's saying, great to communicate with - no question is too silly!" (parent/carer of child aged 0-7)*
- *"Nurses explained my course very clearly and answered all questions in a way I'd understand." (Child aged 8-11)*
- *"The doctors talked to me before my operation and told me what was going to happen and helped keep me calm." (child aged 12-15)*
- *"we felt care providers were sensitive to giving us enough informaiton to inform, but not too much or speculative information that would unnecessarily worry is. It was a great balance. However we were also made aware of risks." (parent/carer of child aged 0-7)*
- *"As (patient name) is now 16 I appreciate the way the Dr + nurses speak directly with him and respect his anatomy." (parent/carer of child aged 12-15)*

- *"All of the staff in day care very much met my son (age 4 at the time) where he was at. He had a lot of questions & a very good understanding about what was going on & they spoke to him accordingly." (parent/carer of child aged 0-7)*

- *"They take the time to explain everything thoroughly and are very patient with our questions." (parent/carer of child aged 0-7)*

Where respondents were dissatisfied with communication from staff, their comments indicated that consideration of the following aspects could help bring about improvements:



Examples were given where parents or carers felt that staff should have been more sensitive as to who was around when diagnosis information was being shared. There was a desire for this information to be exchanged in a private way, which could be away from their child and/or other service users. A child also highlighted that similar consideration could be applied to the number of staff that are present, with children empowered to have a say in this.

What does the quantitative data tell us?

- 70% of parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way (X07)
- 77% of parents or carers felt that staff were always sensitive to information shared with them when their child was in the room (X21)
- 57% of parents, carers, and children reported always being given somewhere private to talk to staff when their child was in hospital (X45)

- *"Other members of staff should speak discreetly to childrens parents before discussing the childs diagnosis / treatment or daily updates, infront of the child." (parent/carer of child aged 12-15)*

- *"I wasn't happy with the way we was told about my son's tumour. After an anxious wait to find out whether the tumour was cancerous or benign, the doctors came to see us with cancer books in hand whilst examining my child, at this point we new nothing but the cancer books gave it away. Was taken to a room to be told then when i came back on the ward upset everyone was asking if I was ok like they didn't know the news we had just been told. One lady actually asked what was a matter." (parent/carer of child aged 0-7)*

- *"When I was told my diagnosis there were around 8 doctors I was unfamiliar with in the room and it made me feel pitied/worse than I was. Even though I was asked if it was okay for the staff to be in the room I was asked when they were all there already so I felt like I couldn't say no" (child aged 12-15)*

Regarding consistency, brief comments reported that conflicting information was sometimes received from staff.

What does the quantitative data tell us?

- 58% of parents, carers, and children reported not being told different things by different members of staff that left them feeling confused (X20)

- *"Mixed messages from staff" (child aged 12-15)*

- *"We should have been informed that an amputation could always be an option but we were informed that wouldn't happen and it did." (parent/carer of child aged 8-11)*

Linked to 'Staff continuity' it was suggested that having contact with fewer staff would help improve receiving conflicting information and would lead to more consistent messaging.

Issues around timeliness of information could arise from a lack of staff availability (i.e. at weekends) or the relevant staff not being easily contactable.

- *"Need to see and speak to Drs / consultants who know my child. I am fed up of talking to ANP's, they can't make any decisions and go away to ask questions to consultants and don't come back. We should be able to see a known consultant it makes us feel like we don't matter." (parent/carer of child aged 0-7)*

- *"It would be great if we could access someone to talk to at weekends - there is a big drop in the level of advice available. (parent/carer of child aged 0-7)*

There were also comments from parents or carers that it would be helpful for staff to provide more information at the start of hospital stays and treatment, including detail about the practicalities of life on the ward given this was unfamiliar to them at first.

- *"A bit more attention to explaining the machines on the first visit would help. Parents should be taught how to silence the alarm on their unit whilst ringing the call button for attention." (parent/care of child aged 0-7)*

- *"When we were first admitted to (location name) we felt very out of our depth and felt that there was no real 'induction' to life on the ward. Some nurses assumed we would know the protocols around being 'barriered' etc when we were like rabbits in the headlights." (patient/carer of child aged 8-11)*

- *"New to treatment education left a lot of knowledge gaps." (parent/carer of child aged 8-11)*

Within hospitals

What does the quantitative data tell us?

- 66% of parents or carers felt that different hospital staff always worked well together (X26)

Poor communication between staff or departments within the same hospital was similarly identified as an area for improvement by children aged 12-15, as well as parents or carers across age groups. This included staff not having the same degree of information about patients, which was sometimes attributed to staff not thoroughly reading notes made by others or notes being lost. Comments were brief though indicated this could lead to confusion around care decisions, delays, parents or carers having to intervene to relay information to staff themselves.

- *"Communication between staff, especially in different departments was often poor and requires improvement." (parent/carer of child aged 8-11)*

- *"Often information was lost from shift to shift, or nursing staff were giving contradicting information." (child aged 12-15)*
- *"Doctors / nurses unfamiliar with never protocols and can give different information." (parent/carer of child aged 0-7)*
- *"Poor communication between departments leading to delays with operations, medicines. We are regularly left extremely frustrated due to communication." (parent/carer of child aged 0-7)*
- *"Interface between different teams e.g. with radiology. I often have to follow up referrals or scans and communicate any changes." (parent/carer of child aged 0-7)*

A contributing factor to poor communication within hospitals was noted to be issues of 'Staff continuity', linking to the earlier sub-theme.

Between hospitals

What does the quantitative data tell us?

- 60% of parents or carers felt that different hospital staff were definitely aware of their child's medical history (X27)
- 51% of parents, carers, and children reported that different hospitals providing cancer or tumour care always worked well together (X57)

Poor communication including record sharing between different hospitals, was an area for improvement identified by children aged 12-15, as well as parents or carers across age groups. Although briefly described, there was a sense that messages between services weren't always clear or timely, which could lead to parents or carers having to relay information themselves, as well as impact regarding delays to treatment.

- *"Communication between more hospitals involved was shocking at times." (child aged 12-15)*
- *"Shared care. It was good but they didnt have any notes from any other hospital so we had to go over everything every time we went" (child aged 12-15)*

- *"Sometimes communication with our local care provider can be slow heading to blood transfusions etc. taking longer than necessary." (parent/carer of child aged 8-11)*

- *"We have had blood tests go missing *(from (location name) to (location name)) at least 7 times in 5 months. This is stressful for continued blood tests for my son and also delaying and causing worry re: dosing of medication as we wait for blood results. Need better shared systems between (location name) and (location name)." (parent/carer of child aged 12-15)*

- *"Records between the (location name) and (location name) Hospital struggled to be updated at times, the communication (records & treatment) plan could help with showed treatment between 2 hospitals." (parent/carer of child aged 8-11)*

Out of hospital stays

What does the quantitative data tell us?

- 90% 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)
- 56% of parents or carers reported that it was very easy to contact the main person in the team looking after their child (X32)
- 63% of parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital (X33)

Respondents had contrasting experiences around the ability to communicate with services and staff outside of hospital stays. Some reported not getting any response when they tried to contact key staff; or were unable to access the relevant staff; whereas others found staff easy to contact and were able to do so directly.

- *"Communication was lacking on a number of occasions, difficult to contact relevant nurses." (child aged 12-15)*

- *"Our CNSs have been great - they always listen to my concerns are are easy to contact." (parent/carer of child aged 8-11)*

- *"The communication between hospitals and us has been confusing at times and we don't always know why we are having different scans. We don't seen to have a direct contact to help when this happens." (parent/carer of child aged 12-15)*

It was found that flexibility as to when people could contact services was important, e.g. contact not being restricted to certain times. Similarly utilising different methods of communication to align with needs appeared to play a role in positive experiences, suggesting there could be value in services exploring with patients, parents or carers when best to utilise telephone calls, online calls or apps and giving choice as to which is most suitable.

- *"Maybe a phone line for out of hours queries? I currently call (location name) as my son was an inpatient there, but having an out of hours line could be reassuring." (parent/carer of child aged 8-11)*
- *"The oncology / haemotology advice line 24/7 mobile phone on (location name) has been a lifesaver - access like this to an expert is so important." (parent/carer of child aged 8-11)*
- *"We were able to ask our nurse specialist questions from home, which was good since we lived outside London" (child aged 12-15)*
- *"Zoom meetings with consultant to save travel." (parent/carer of child aged 8-11)*
- *"The response via the app is always rapid which is really reassuring!" (parent/carer aged 0-7)*

Being kept informed

What does the quantitative data tell us?

- 66% of parents, carers, and children felt they always knew what was happening with their child's or their care (X28)
- 87% of parents or carers reported that they were definitely offered clear information about their child's treatment (X36)

Concerns were raised, typically by parents or carers, that there was a lack of proactive communication regarding crucial medical updates, and in some cases, information

was not shared at all. This particularly related to test results, but also cancer levels, decisions for next stages of treatment and more generally finding out what would happen next. This left people without reassurance, a sense of anxiety and a need to chase for information. There was a solitary suggestion that the use of an app to share results in a timely way would help. As this feedback was typically not explicit or specific as to where this communication issue occurred, it has been articulated as a distinct sub-theme which to be considered relevant to improve communications broadly.

- *"Was never told results from any scans. I always had to ask in the end." (parent/carer of child aged 12-15)*
- *"To inform us one the cancer level. Is it high or low. Bone marrow results (lumber puncture)." (parent/carer of child aged 0-7)*
- *"Critically, updates on the recession of the cancer, in this case all, are and only weekly bloods to go by. One feels very alone as a carer." (parent/carer of child aged 8-11)*
- *"Written treatment plan. We were very much in the dark about what was coming next + what could happen at each stage if chemo wasn't working. Results from bone marrow tests were not shared unless asked regular letters on progress + stages would help." (parent/carer of child aged 12-15)*
- *"Better, more frequent communication to parents when onward - a lot of not knowing what is happening / why / when. The times when (location name) has been fully & we've been put on other wards does make us feel vulnerable. Often left for a long time not knowing what is going on." (parent/carer of child aged 8-11)*
- *"Being informed of blood results earlier or at all. Quite often I have to chase. (Maybe an app for parents to access themselves would be hugely benificial)" (parent/carer of child aged 12-15)*

A particularly impactful example was shared where there has so far been over a three year wait for genome sequencing results, which has led to an erosion of trust.

- *"I felt reassuring and promising that when my newborn was diagnosed with a brain tumour the cancer consultant told us her tumour would be taken to the lab for genome sequencing. It was explained to us it was important to understand the composition as this could determine if we should have any more children and what*

else they could learn for my daughters care. However, this was back in (date) and we still have not had a response even though it should have happened within two months. We have tried to get this information for almost 3 years and no one can give us any answers, not even to say the test or results have been lost. So something that started as a good and positive outcome has turned into a nightmare as we don't know if is something we carry or likely to cause our daughter further problems. We have lost trust and can no longer believe everything we are told." (parent/carer of child aged 0-7)

Access to care

Diagnosis and starting treatment

What does the quantitative data tell us?

- 58% of parents or carers reported that their child saw a GP once or twice before they were referred to hospital (X03)
- 71% 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 receive treatment. For some this happened very quickly while others spoke of the harmful impacts when diagnosis took longer than they believed necessary.

- *"Very speedy diagonsis to treatment." (parent/carer of child 8-11)*
- *"The speed in which all the staff at (location name) worked when my child was first diagnosed was amazing." (parent/carer of child aged 12-15)*
- *"We should of been seen quicker, we kept going to GP and they contacted (location name) but were not seen any quicker even though symptoms were getting worse." (parent/carer of child aged 12-15)*
- *"The diagnosis took almost a year & was apalling. If our daughter was diagnosed earlier she may not have had a huge seizure, lost her peripheral vision or be diagnosed with such an aggressive tumour." (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)

In comparison to positive experiences, feedback on negative experiences was far more detailed and shed light on why patients, parents or carers believed a delay with diagnosis was experienced. This covered a range of interrelated issues, summarised as follows:

A key reason presented for delays with diagnosis was not being listened to and having concerns dismissed by healthcare professionals, including by GPs and at Accident and Emergency Care. It is inferred from the comments that the lack of urgency shown by healthcare professions, meant that progressing care in a timelier way required a degree of self-advocacy from patients, and parents or carers. Several comments outlined the serious implications that could arise when health concerns were not taken seriously.

- *"I needed to be listened to more. I said that my legs were sore for months. Turned out I was right - tumours in femurs." (child aged 12-15)*
- *"Prior to diagnosis, I had many disappointing trips to A&E and the GP, where things were missed and I was made to feel like I was overreacting." (child aged 12-15)*
- *"I felt that we were brushed off by doctors when we were first went in with our child. If we didn't go with our instinct I feel my child's health would have been in great danger. Doctors in A and E should take patients a bit more seriously." (parent/carer of child aged 8-11)*
- *"Believing parent our guidance, before we found out what was wrong with our daughter we went to the GP and in more than 10 times and every time we were made to look like we were just making up there symptoms. Up until things were really bad that when we were believed and sent for more test. It still kills me to think that she had to go there all of that." (parent/carer of child aged 8-11)*
- *"There were lots of delays in initially getting a thyroid cancer diagnosis - our Gp told us that there was nothing to worry about as our daughter was fit and well other than*

the lump - her ultrasound was marked as routine so the hospital would not give us an appointment and said we would have to wait for one to arrive in the post. It's only because I work in the NHS that I managed to speak to a consultant and speed things up, he spoke to her Gp and had her referred in as a 2WW otherwise I think we would have waited months. We were transferred from our local hospital to (location name) and experienced a long waiting time for FNA and then for results to confirm diagnosis - we had repeatedly chased this and no one would speak to us which made things feel very frightening and scary." (parent/carer of child aged 8-11)

Other reasons mentioned for treatment not being carried out in a timely way were scans not happening, long waits for scans and their results, and missed diagnosis following a scan.

- *"During the treatment of the tumor a scan should have been performed after one cycle of Chemotherapy, this was not done and after the second cycle a scan was done, we were informed it would be a easy operation to remove the tumor and return to normal. This was not the case and the tumor had grown and my daughters leg had to be amputated. If a scan had been completed after cycle one her leg may have been able to be saved." (parent/carer of child aged 8-11)*

- *"Waiting to long for results had to be that day or a few days later not weeks." (parent/carer of child aged 0-7)*

- *"My sons tumor was initially missed in his first MRI and was found in his second MRI 3 months later. We hope this could be something that can be looked upon and hope it dont happen to again or anyone else. (parent/carer of child aged 0-7)*

Comments also pointed out how distressing it could be to endure long waits, further emphasising the need for this to be as rapid as possible.

- *"The lead up to getting a diagnosis could be much better. We were misdiagnosed several times. Also once biopsy had taken place it was an agonising wait to receive the awful news." (child aged 12-15)*

- *"It look around 7 wks to receive a diagnosis. We were quickly referred by or GP to the local hospital but it then took weeks of back & forth to then get referred to (location name) for diagnosis. During this time our son was very unwell & it was a very difficult worrying time. Earlier diagnosis would have improved this." (parent/carer of child aged 12-15)*

Staffing levels and responsiveness

What does the quantitative data tell us?

- 73% 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, that services could seem understaffed and that more staff were needed, with nurses most cited. This was evident in long waits for alarms to be responded to, for medication to be supplied, and staff not being available to answer questions.

- *"Nurses seemed rushed of their feet." (child aged 12-15)*
- *"More staff at busy times." (child aged 8-11)*
- *"Sometimes I waited ages for a nurse to give me pain relief." (child aged 12-15)*
- *"The nurses at (location name) weren't very attentive…I felt like I was burdoning them everytime my alarm went off. Sometimes my alarm would be going for 15 min before they would sort the collusion on my etopigide." (child aged 12-15)*

Where more specificity was provided, day care units were mentioned multiple times, indicating it would be pertinent for services to ensure staffing levels were sufficient within these services.

- *"Ensure all 'day care' appointments have enough staff available for the treatment needed for that day. Sometimes there are enough nurses but not enough chemo trained nurses on. (As most apts on that side are chemo required)." (parent/carer of child aged 0-7)*
- *"We have been in day care a lot. There is often quite a long wait to be seen by the nurses for standard daycare procedures due to low staffing. This lack of staff resources has been very noticeable since 2023. My son started treatment end 2020 and over time I have really seen staff on ward being stretched - far fewer personnel trying to do the same level of care. It leaves the patient and family feeling bad having to interrupt the nurses to ask simple questions or for help or just ask when it's their turn to be seen as appointments have been well over the expected time to be completed . The nurses apologise all the time but it's not their fault." (parent/carer of child aged 12-15)*

Comments indicated that that a lack of staff was particularly apparent at weekends and at night.

- *"Some services, like diabetes team, has been unavailable over the weekend. Many times, if we had requests, it took 5-7 times asking the nurses for it to be completed." (child aged 12-15)*
- *"Shortage of staff, some time after rang the nurse bell we need to wait 30 minutes some time more than specialy night time, some for doctors night time." (parent/carer of child aged 0-7)*
- *"Even though the week day care was 1st class, weekends and evenings was a lot harder as oncology finished at 5pm, which ment you had, to wait for the next working day for answers that is oncology relaxed specialist." (parent/carer of child aged 8-11)*

However, it should be noted that these negative experiences were not universal, with some respondents experiencing staff to be responsive when they needed assistance.

- *"I thought they were very nice and prompt where I pressed the call button." (child aged 12-15)*
- *"Ward staff supportive despite being very busy." (child aged 12-15)*

Waits in hospital

Respondents expressed frustration with the long waits encountered in hospital. These spanned a range of scenarios including waits for tests, treatment, beds, medication and operations or a combination of these, and were encountered during day care, hospital admission, discharge and at A&E. The time taken for medications to be available from the pharmacy was a key point where delays were experienced, leading to extended periods of time where patients and parents or carers were waiting around when they were ready to go home.

- *"There can be some really long waits when at the hospital for treatment." (child aged 12-15)*
- *"Waiting times in day care can be frustrating." (child aged 8-11)*

- *"General considerations for child + parents often in A+E for 6+ hours." (parent/carer of child aged 0-7)*
- *"Waiting times can be too long. Especially at scans. A lot of the time it takes 2 to 3 hours to be taken into theatres and for young or autistic children that is torturous." (parent/carer of child aged 8-11)*
- *"Medication to be prescribed on ward on time. Consider patient well being & severe trauma & stress delays bring. (Child aged 12-15)*
- *"Long waits to see doctors and for medications to take home, especially when we have been told I can go home. It was 6 hrs last time waiting for my chemo tablets." (child aged 12-15)*
- *"Pharmacy in Oncology Day care ward is very slow to dispense medication to us they are already aware we are collecting. We can be waiting over 1 hour at times." (parent/carer of child aged 0-7)*
- *"Discharge is the very worst! We could be told we would be discharged at 8am and still be in the room at 2pm waiting for someone to sign off discharge or pharmacy to complete medication. There never seems to be an urgent need to get people home even when beds are full and patients are desperate to return home for just a few days before coming back for another treatment." (parent/carer of child aged 12-15)*

As indicated by the quote above, long waits could be interlinked to issues around bed availability, with it inferred that when patients were not discharged from hospital in a timely manner this contributed to a lack of bed availability, thereby creating delays for patients waiting for a bed. There was also some suggestion from parents or carers that being kept updated about the length of waits would be beneficial.

- *"The ward was quite small which was good but meant sometimes there was no bed for chemo, delaying - twice." (child aged 12-15)*
- *"During one inpatient stay, my child was left waiting over 7 hours for a bed with no updates. I had to keep chasing it up when the bed was ready, no one came to inform us and kept us in the play room." (parent/carer of child aged 0-7)*

Another negative impact of long waits for treatment or surgery was children having to go without food for significant periods of time.

- *"The time we have to wait when laser / chemo is in the afternoon is too long. It's unacceptable to keep a child without food for so long… There is only so much you can do to distract a hungry child. On his last chemo on (date) there was an emergency in theatre in by the time my son could eat, he had been without food for 23 hrs" (parent/carer of child aged 0-7)*

- *"Just the waiting times is too long as my son, since 2.am his last meal and hospital from 0800 a.m he didn't get operated on till 1200 midday." (parent/carer of child aged 0-7)*

Travel

What does the quantitative data tell us?

- 62% of 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)

The data showed that respondents wanted services to be convenient to travel to in terms of locations being close to home, efficient hospital transport, and ease of parking, although experiences of these was mixed. Where travel distances were long, this was said to have a negative impact as it reduced the amount of time patients could spend with family, which was inferred to be detrimental to their mental wellbeing.

- *"The hospital is far away from home and i miss my friends and family." (child aged 12-15)*

- *"Why is there no other treatment centre further south? When your child is seriously unwell and wants to spend as much time as possible in their family home with their parents and siblings, why is a constant 3 hour drive each way necessary, why are (location name) or (location name) not given more services to complete these treatments in the south west?" (parent/carer of child aged 12-15)*

- *"The transport (taxi) provided by hospital was very helpful." (child aged 8-11)*

- *"Another issue was hospital transport to and from radiotherapy as that was at (location name). Transport was often very delayed which meant we were left at*

radiotherapy with no facilties for food after (patient name) had been starved due to a general anesthetic" (parent/carer of child aged 8-11).

- *"Ability to park more easily" (parent/carer of child aged 8-11)*
- *"Having the parking permit for day clinic is very good." (parent/carer of child aged 0-7)*

Comments highlighted that it would have been helpful if advice and information about parking had been provided in advance of appointments and hospital visits.

- *"Weren't given early enough advice that we could apply for Blue Badge which could have making appointments." (child aged 12-15)*
- *"More information needs to be given to parents / patients before arrival at the hospital, when arriving when your child who had just had a cancer diagnosis and never been to (location name) before, not being able to park is very stressful and no information given around alternative car parks and costs. Qr code system in hospital is convoluted and difficult to use at times, as well as having to leave your child to scan qr code at machine etc. very few staff members understand the process adding to the confusion." (parent/carer of child aged 12-15)*

Personalised care

Psychological support

There was an expressed need for improved psychological support for both children and parents or carers, with suggestion also made that this support should be extended to wider family members also. For some there appeared to be a complete absence of support, whereas for others the support was available, however insufficient.

- *"More mental health / psychologist support for children" (child aged 8-11)*
- *"The psychologist wasn't available & the appointments weren't regular and would be cancelled or nobody would turn up. This didn't help my child's anxiety and I feel this area definitely needs improving to provide full support" (parent/carer of child aged 12-15)*

- *"Support such as counselling for parents / carers - very poor." (parent/carer of child aged 0-7)*

- *"We were not offered any mental health support or counselling which is vital for the whole family when you have a child with cancer. We sourced this ourselves through charities, but it should be offered at hospital." (parent/carer of child aged 8-11)*

It was inferred from the data that there could be more thought given to people's mental wellbeing in general, including better signposting to charities that could provide support, and services facilitating connections between parents or carers as a source of peer support.

Immune compromised patients

There were concerns that access to care via A&E or placement on non-cancer wards, presented a risk for immune compromised patients. There was inference across this sub-theme that more consideration needed to be given to the pathways used for cancer patients when they need to access services unexpectedly or in an emergency.

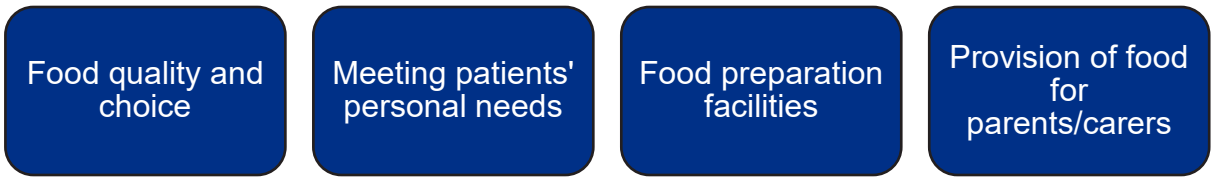
- *"Disagree with being admitted via A&E - it's dirty, not good for immuno supported." (parent/carer of child aged 0-7)*

- *"Had children with different types of illnesses which we were concerned about being around our child with a low immune system due to chemotherapy. We thought he should have been on an oncology ward." (parent/carer of child aged 0-7)*

- *"Other departments to be more knowledgeable on cancer patients. Eg, we had to spend an evening on (location name) when we came in through A&E on an evening we spent at home. None of the nurses used PPE when dealing with our daughter who is immune compromised, which resulted in her contracting RSV which made her extremely poorly and had to be readmitted onto (location name)." (parent/carer of child aged 0-7)*

Hospital food

Food was a frequently raised topic by children, indicating that it played a significant role in how they experienced their time in hospital. It was a reoccurring and consistently negative experience for both children and parents or carers, with the analysis indicating that the following would be pertinent areas to focus on to bring about improvements:



Food quality and choice

What does the quantitative data tell us?

- 40% of parents, carers, and children felt that there was definitely a suitable choice of hospital food (X44)

While comments tended to be brief, children aged 8-15 conveyed a strong sense that they disliked the food that was provided; that there were limited options; and it lacked nutritional value. It was also suggested that food could be tailored more to teenagers, although there was no further detail of how that could be achieved.

- Examples from children aged 8-11: *"I didn't like the food very much", "The food: on the ward there should be fresh food that is not a ready meal that haas been cooked from frozen.", "There are not many options for food. But we take from home snacks and something we can heat or prepare quick at the ward kitchen.", "I had to stay in hospital for a very long time and I wished there was a food menu for long term stay children so it wasn't always the same food.", "A healthier and more varied selection of meals available.", "The hospital food wasn't good as there would be uncooked nice."*

- Examples from children aged 12-15: *"Food is terrible, never been able to eat one meal in hospital", "Hospital food was not nutritious or healthy.", "I think the food menu could have a bit more choices and the food could have a bit more flavour.", "The food options in the ward were not sufficient especially being a teenager and wanting to*

have better choices", "I thought the hospital food provided could be improved. E.g, could you provide an older children's/teenagers menu?"

This sentiment was echoed by parents or carers, with some outlining how they resorted to supplying their own food because of the poor quality of food provided.

- *"Quality of the food, had to prepare or buy as the Quality wasn't very good" (parent/carer of child aged 12-15)*
- *"The hospital food is not very pleasent and my child very rarely ate it. The shop's within the hospital are very expensive and when you are staying for 3-5 days at a time food costs add up. When my child attended hospital for treatment it felt like we were moving house due to the amount of food I would bring to my and keep the cost down." (parent/carer of child aged 12-15)*
- *"The food was dreadful. My child and myself had to live off the expensive and unhealthy processed food sold in the hospital concourse because the quality of the food on the ward is so poor that my child refused to eat it. The hospital should have an on-site restaurant kitchen cooking and serving healthy and tasty food to all patients and any carers forced to stay. The ward served chocolate bars, biscuits and crisps every day to my son as snacks throughout the day at his bedside." (parent/carer aged 8-11)*

Patients' personal needs

Feedback highlighted further needs around food that were not being met or inadequately considered around catering for different religions (e.g. halal food) and cultures, as well as other dietary requirements such as allergies, veganism, and vegetarianism.

- *"I think that the hospital food could be better more healthier options and including things like halal, vegetarian or vegan foods(because while I was there the only halal foods was the curry and rice menue)" (child aged 12-15)*
- *"Maybe they can offer something halal for the Muslim people for the lunch." (child aged 12-15)*

- *"I felt like the food for vegetarians was quite limited and honestly not great." (child aged 12-15)*
- *"More choices of food for the kids. To include African British kids." (parent/carer of child aged 8-11)*
- *"Food options that are child friendly for children with allergies" (child aged 8-11)*

Other needs included consideration of how cancer treatment was impacting on patients' appetite, taste, ability to eat, as well as where food was being served and eaten.

- *"Choice of food didn't always appeal during chemo" (child 12-15)*
- *"Not having the food trolley in the hallway on the ward, when I was having my chemotherapy treatment." (child aged 12-15)*
- *"Somewhere for older children to eat. Not good to encourage eating in bed where they slept and did everything especially difficult when barried eating with a commode in front of them." (parent/carer of child aged 8-11)*

Food preparation facilities

What does the quantitative data tell us?

- 42% of parents or carers reported they were definitely able to prepare food in the hospital if they wanted to (X50)

While comments about the food preparation facilities available to parents and carers in hospital were brief, the needs listed below point to areas for improvement:

- Additional appliances to microwaves e.g. a toaster, plus more cutlery
- Better maintenance of kitchen equipment and improved cleanliness
- More fridge and/or freezer space

Provision of food for parents or carers

Parents or carers suggested that where this was not already happening, food should be provided for them, when their child was in hospital. Where reasons for this were stated, it was explained that they felt unable to leave their child to get food when they were too young or ill, and it would help eliminate some stress and expense.

Alongside these comments, it was also suggested that shops and cafes in hospitals could be open longer hours and on additional days (e.g. at the weekend) as well as stock a wider range of healthier food beyond noodle pots and sandwiches.

- *"Has a parent. When I was in - parents never got fed. I wrote a letter in to say. Parents need food. When your child is ill, you can't leave their bed. So, parents went hungary. Now, they get fed. If it was not my family bringing in food I'd go hungary." (child aged 12-15 – please note that whilst this answer came from the child section of the survey, it appears it may have been completed by a parent/carer)*
- *"In (location name) meals for parents would be appreciated when child is an inpatient. (location name) provides this which means one less thing to worry about and not just relying on shop bought noodle pots & sandwiches." (parent/carer of child aged 12-15)*
- *"Parents should be fed in hospital - very few options at (location name) vs (location name) and no cafe at weekends." (parent/carer of child aged 12-15)*

Noteworthy exceptions

While there were far fewer positive comments about food in hospital, there were some exceptions. In these comments children typically said that the food was "good" or "nice", but some picked out specific foods that they particularly enjoyed (e.g. ice cream, pizza, apples). There were also two experiences where flexibility was shown in terms of catering staff trying to find preferred food and personal requests being met.

- *"Food was very good" (child aged 12-15)*
- *"The apples were yummy" (child aged 8-11)*
- *"The catering staff were good when it came to choice of food for the children." (parent/carer of child aged 8-11)*

There were also indications in the data that there was some variation in relation to if and how different hospitals made food available to parents or carers. This included two examples where parents or carers had received food vouchers, which they were grateful for.

Things to do in hospital

Play therapy

What does the quantitative data tell us?

- 52% of parents, carers, and children felt that there were definitely enough things for their child to do in the hospital (X43)
- 59% of parents or carers reported that the hospital always offered play specialist support when they needed it (X46)

There was a mixture of both positive and negative experiences in relation to play therapy, with it clear how important it was to have play and activities incorporated into time in hospital and for patients to be kept occupied where possible.

Where positive experiences were shared, there was appreciation for access to play, play areas, and play staff, with children highlighting activities that they particularly enjoyed. It was also noted how this could have impact in terms of providing fun and helping children relax.

- *"Play specialist (staff name) at (location name) was amazing she made me feel very special. I enjoyed visiting (location name) due to the play room & the fun I had with (staff name)." (child aged 8-11)*
- *"Play team did there best an even there was no play, will come and chat with me, plaiying cards. * Loved The Music Therapy am a music fan, singing, playing instrument or making own music." (child aged 8-11)*
- *"They had nice play room facilities. I liked the therapy dog." (child aged 12-15)*
- *"The pool table in the teenager area of oncology helps to pass time and keep me relaxed." (child aged 12-15)*

The positive role that charities had played in supplying gifts, entertainment and events was also valued, with the names of different charities being recalled by children and parents or carers.

- *"(charity name) provided activities and things to do and play with e.g. box." (child aged 12-15)*
- *"The play team and (charity name) always helped to make hospital visits happy, they were amazing." (parent/carer of child aged 8-11)*

In terms of improvements, it was highlighted by children, particularly those aged 8-11, that activities needed to be more age appropriate, with play provision geared towards younger children they felt.

- *"In my local hospital, the playroom had only baby toys." (child aged 8-11)*
- *"Activities for older children needs improving" (child aged 8-11)*
- *"More events for teenagers" (child aged 12-15)*
- *"More activities / things to do when feeling well enough in the cancer ward. (location name) was fun for children my age as it had table football, books, music + video games. (location name) was for younger children so I didn't really leave my room. I know this may not be possible due to space." (child aged 12-15)*

With needs varying by age in mind, there was a tension found across the feedback whereby pre-teens/'tweens' (and their parents or carers) wanted access to teen areas, and teens (and their parents or carers) felt teen areas should be for teens only.

- *"There is nowhere for the tweens to go because the ward, play room is for baby's and the teen room is perfect but we are not allowed." (child aged 8-11)*
- *"Let the kids under 13 use the teenage bit sometimes please. As I was 9/10 and it would have been nice - I know its for teenagers but just 1 day a week for tweenies." (child aged 8-11)*
- *"More facilities for children of 10-11. Teenage room nearly always as empty and offerings of entertainmt as 11 year olds could not go in. Were biased to younger children books on offer younger children. Play dough childrens drawing alway left out was for younger children." (parent/carer of child aged 8-11)*

While age appropriateness of play provision was not raised as an issue for children aged 0-7, not always being able to access play staff and opportunities came up as an area for improvement for this age group. This was also a feature in feedback for those aged 8-11 and present for the older group aged 12-15 as well, though to a lesser extent. While some comments were general, others specified that this was particularly an issue during weekends and bank holidays.

- Examples from parents/carers of children aged 0-7: "*The play room open more often.", "Play specialists non existent on the ward.", "Play team to be available at weekends.", "If there was something to do on the weekends for kids while inpatient."*

- Examples from children aged 8-11: *"Nothing to do on bank holiday when can't leave hospital.", "More entertainment could come round", "Sometimes there were no play specialists.", "Weekends / bank holidays on the ward are really quiet and boring."*

A lack of entertainment was explained to be particularly significant when patients were in hospital for a long time, in isolation, a long way from home, or when there were long waits.

Additional suggestions and comments around what could be improved in relation to play therapy included:

- Ensuring parents or carers of younger children were aware of play areas and support and were proactively offered it
- Fidget toys to be available
- Putting on Christmas events for children who are in hospital during this period
- Ensuring play staff offered support around scans or treatment, for example when IV lines were inserted or using Virtual Reality to help prepare for an MRI scan

Wi-Fi and technology

What does the quantitative data tell us?

- 42% 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 for hospitals to have a good

Wi-Fi connection, however where it was raised experiences of this were typically poor. This limited entertainment options for children, restricted contact with family and friends, and impacted on parents or carers' ability to work.

- *"The WiFi- this was my main way of being distracted and it didn't always work." (child aged 12-15)*
- *"Wifi. Sometimes internet access is not possible due to location inside hospital & signal. Wifi means access to family & entertainment" (child aged 12-15)*
- *"Internet connection is bad in part of hospital & connection to free wifi is impossible due to to many connected." (child aged 8-11)*
- *"WiFi is awful! I was working in the ward on many occasions and need better WiFi." (parent/carer of child aged 0-7)*

Other barriers were also seen around access to digital entertainment in terms of TVs not working, video game consoles requiring updates, and PAT testing not being carried out. This suggested ongoing maintenance of equipment was required to bring about improvements.

- *"Not all TV's work and usually had to play hunt the remote." (child aged 12-15)*
- *"I noticed that many of the extension leads, the washing machine, the tumble dryer, and even the TV ect all had outdated PAT tests and required updating. Moreover, the video games consoles provided by the play team needed updating as well before the children could use them, which discouraged the kids from playing. I believe the play team should regularly keep these games and equipment updated so they are always ready and enjoyable for the children." (parent/carer of child aged 12-15)*

While less common there were examples where Wi-Fi connection was said to be good, and children had access to digital entertainment, showing variation in experiences.

- *"The Wi-Fi was very strong, which was useful." (child aged 12-15)*
- *"It was good I could play on the play station and nintendo switch. And I liked where could go to have fun." (child aged 8-11)*

Education

What does the quantitative data tell us?

- 77% of parents or carers reported that their child had access to hospital school services during their stay in hospital (X52)

Although limited in detail, respondents provided positive feedback on their experiences of hospital school and teachers.

- *"the school was fun." (child aged 8-11)*
- *"had a brilliant time in hospital school." (child aged 12-15)*
- *"The (location name) hospital school was very good. The teachers built a wonderful rapport with my daughter. They also went above and beyond to arrange interesting lessons for my daughter." (parent/carer of child aged 8-11)*

Where feedback was critical, this focussed on the need for education provision to be increased.

- *"Weekend provision very limited (eg school) vs weekday." (child aged 12-15)*
- *"Another challenge is that (location name) Hospital does not currently offer a school service for children who stay as inpatients for extended periods. The longest my son has stayed on these wards was seven days, and during that time, the absence of educational support was noticeable." (parent/carer of child aged 12-15)*

On the topic of education, a very small number of comments spoke about schooling beyond the hospital and a need for improvement there also. In one instance, the NHS had taken on a role to advocate for the patient's needs whereby a specialist nurse had contacted the child's school to remind them of their duty of care. This was much appreciated by the respondents and further demonstrates the importance placed during cancer treatment for children and young people on continuing with education.

Hospital environment

Noise and ability to sleep

What does the quantitative data tell us?

- 26% of parents, carers, and children reported that it was always quiet enough for them to sleep in the hospital (X49)

Respondents reported that they found the hospital environment too noisy, with this often said to be caused by people on the ward talking loudly, beeping machines, sounds from TVs, as well as staff being excessively noisy while carrying out their tasks. This could be particularly acute at night, when it impacted on patients' ability to sleep. Additional sensory issues, such as the brightness of the environment could further exacerbate this.

- *"Sometimes it could be quite noisy in the bay as lots of other kids machines would beep throughout the night… at times the cleaning staff would be making a lot of noise really early in the morning" (child aged 12-15)*
- *"Be more strict on bed times to make sure the lights go out at 8pm and everyone on the ward knows this. It was so annoying that the noises from people talking so loudly etc did not help me sleep" (child aged 8-11)*
- *"Also, when babies are in wards with older kids it's hard for anyone to get sleep . Often it takes a very long time for machine beeps to be stopped in the night. At times it is constant." (parent/carer of child aged 8-11)*
- *"at night, it should be made clear to all parents that lights go out at 8pm to allow the children to rest and sleep after their gruelling treatment. The nighttime experience wasn't great. Staff were coming in over night and opening doors loudly or making a lot of noise. Students in particular waking my child to do their obs when my child doesn't really mind having obs done while he's asleep!! There's no need to wake the child. Also overnight doctors on call coming in to the room if there were concerns and putting all the lights on!!! Just lack of consideration." (parent/carer of child aged 8-11)*

As indicated by the quotes above, a range of suggestions were made for services to consider in how to create a more restful environment:

- Having and enforcing rules around bedtimes to reduce noise and light levels

- Using machines that did not audibly beep
- Having smaller wards or individual rooms
- Separating younger children from older children and young people
- Provision of headphones to be used with electronic equipment, e.g. TVs
- More consideration by staff on if/how they were disturbing sleep unnecessarily

Privacy

Children as well as parents or carers across age groups expressed a preference for private rooms, with this linked to having dignity upheld and having a quieter personal space to aid sleep as well as recovery more broadly.

- *"When sleeping in a bay Curtains most be open during the day that's give me no priority what so ever. When I didn't feel to great or wanted to sleep everybody was watching me. I felt like I couldn't be comfortable in a bay." (child aged 8-11)*

- *"Window bays are better than corridor bays. Some bays make you feel very exposed." (child aged 8-11)*

- *"My other observation was that some hard procedures ie feeding tubes etc going are done behind curtains in wards when other kids hear the screams and get v distressed ." (parent/carer of child aged 8-11)*

- *"More privacy for treatment, there wasn't always a bed on day ward & she likes to lay down during chemo. She didn't like having it in play room or hallway."*

- *"The worst experience was after shunt surgery when my daughter was in pain and said the noise was hurting her head. We were on a noisy ward and I felt helpless and that no-one understood she was in pain, because she wasn't making a fuss. My husband had asked if she could have a room, and I later overheard a conversation that made it seem like we were acting `entitled' because she'd previously had a private room. We were told other patients' TVs could not be turned down and it was only when I was caught crying in despair that she was moved. Priority should be given to those who have had brain surgeries." (parent/carer of child aged 8-11)*

Although it wasn't always explicitly said to be for reasons of privacy, for respondents aged 12-15 it was also seen to be of importance that they were separated from younger children.

- *"Being a 14/15 year old during my treatment, I found it quite difficult to be on the ward with other kids, as they were all much younger than me. I found it awkward and difficult to pee and poo in thencardboard as I was quite self conscious about it. (child aged 12-15)*

- *"As a 14/15 year old it was often hard being put with very young children on a ward. The staff always tried to seperate us but maybe a choice of using the teenage ward would have been good on occasions when there were a lot of young children on (location name)." (child aged 12-15)*

Comfort

What does the quantitative data tell us?

- 35% of parents or carers reported that facilities for them to stay overnight were very good (X48)

The comfort of beds, and availability of bedding was raised as an issue, not just for children, but also for parents or carers when they needed to sleep at the hospital.

- *"Lack of bedding." (child aged 12-15)*

- *"perhaps the beds as I find them very tiny." (child aged 8-11)*

- *"Having a proper pull out bed for the parent/carer to sleep on would be good. The sofa was not very comfortable." (parent/carer of child aged 8-11)*

- *"Sleeping arrangements for parents that are in for long term. The hospital could do with more camper beds. We were in hospital for approx 7 months consecutively. We ended up buying our own camper bed and inflatable bed as the chairs are very uncomfortable." (parent/carer of child aged 0-7)*

- *"Fold down beds/mattresses unclean and not comfortable. Shortage of pillows." (parent/carer of child aged 12-15)*

Similarly, it was thought that there could be improvements relating to the comfort and availability of seating for children, including during day care.

- *"Chairs in day care are uncomfortable. Child should get a reclining easy chair." (child aged 8-11)*
- *"Day care: Better seating area if not allocated a bed." (parent/carer of child aged 8-11)*
- *"Please make sure more places for chemotherapy patients sometime the patient is more and places is less and they are tired sick and they don't have any place to sit." (parent/carer of child aged 12-15)*

Cleanliness

Various experiences were shared around hospital cleanliness. Where this was an issue, it was often in relation to bathroom facilities. Unpleasant smells in the hospital environment also inferred insufficient cleaning, and bedding could be dirty also.

- *"Hospital was dirty, rubbish left in toilet during a 5 day stay start - finish... Blood stain beds in A&E." (child aged 12-15)*
- *"Only other thought is something could be done to help with the smell. Maybe air freshners in the bay bathroom as the collected urine often smells quite bad and makes nausea worse." (parent/carer of child aged 12-15)*
- *"During one overnight stay with my son, I went to use the bathroom and was shocked to find cockroaches on the floor." (parent/carer of child aged 12-15)*

In contrast, there were also brief comments expressing positivity about how clean respondents had found wards and the hospital environment more generally. This again speaks to the importance of cleanliness during hospital stays as to how it impacts experiences of care.

- *"Cleanliness of my ward was amazing." (child aged 12-15)*
- *"A big thank you to cleaning staff, they are doing best job to keep premises, ward hygiene." (child aged 12-15)*
- *"Also, hospital cleanliness was really good." (parent/carer of child aged 12-15)*

Other issues

Although limited in terms of volume, detail and/or coherence across comments to constitute sub-themes, a range of other issues and suggestions relating to how the hospital environment could be improved were found in the data as follows:

- Additional showers, as well as better designed and maintained bathroom facilities for parents and carers
- Accessible bathroom facilities, e.g. for those attached to machines or wheelchair users
- Children's toilets to be separate from those used by hospital visitors (including parents and carers), particularly where patients were immunosuppressed
- More toileting equipment for younger children, e.g. a toilet seat, a commode by the bed
- Larger wards and clinic rooms
- Access to spaces where people could decompress, e.g. away from beds, outdoor spaces, in daylight and fresh air
- Ensuring that the temperature of the environment could be adjusted to meet patients' needs
- Colourful welcome signage, and sensitivity to the wording used on signs, e.g. a sign saying brain tumour ward was experienced to be frightening
- Facilities for washing and drying clothes
- Prompt attention to maintenance issues

Noteworthy exceptions

A small number of comments were found which framed aspects of the hospital environment positively. These tended to be very general describing facilities as "good", "lovely" or "amazing", with examples also provided of rooms being spacious.

Other

Additional topics that were noted during the analysis process, but did not inform themes or sub-themes, due to a lack of volume or depth and detail are listed below for completeness:

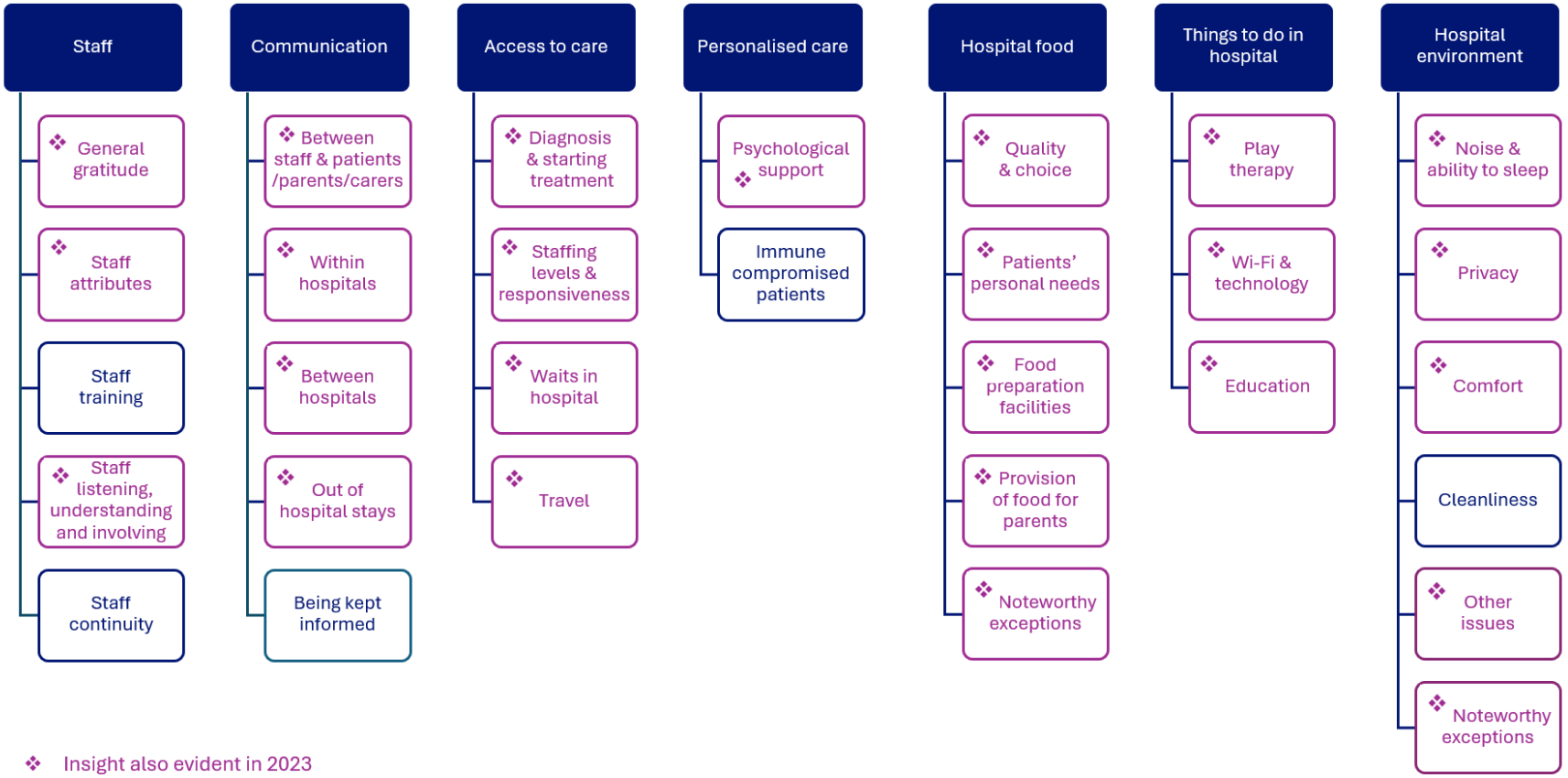
- Poor understanding of autistic patient's needs, with these inadequately considered and supported
- Services needing to ensure medications are given at appropriate times and that dosages are correct
- Improved administration and scheduling of appointments, with enough notice given of dates and cancellations
- Suggestion that ultrasound scans should be used when inserting cannulas to minimise the number of attempts needed
- Suggestion that cannulas should be inserted by experiences nurses
- Negative and positive experiences shared of surgical procedures
- Lack of advice on diet and nutrition
- Facilitating connections between children so they could meet and talk to each other
- Additional financial support for parents and carers whose child is in hospital for extended periods of time
- Staff misgendering a female child as male due to her hair loss
- A complaint not being followed up
- Gratitude at being given access to proton beam therapy
- Positivity around the use of Virtual Reality (VR) during procedures
- General comments that services were efficient
- Appreciation of the support provided by cancer charities, e.g. providing some financial support and help filling in forms

Conclusions

In recognition of the challenge in tracking qualitative insight from a survey over time, a deductive approach to analysis was used for the U16 CPES 2024. This involved applying a consistent framework to the data, allowing us to see patterns and connections between years. While much was alike in subject and tone, to reflect nuance found in 2024 the framework was adjusted and includes several ‘new’ sub-themes. A visual summary is provided on the next page of what is consistent across 2023 and what is nuanced like this, and/or ‘new’. Please note that without knowing the full context behind each response, it's difficult to say whether differences in sub-themes between 2023 and 2024 reflect real changes in care experiences or simply changes in what people decided to share.

Much of the insight is mirrored from 2023 to 2024. Children and young people continue to heavily focus on the importance of staff manner, hospital food and things to do in hospital including play, Wi-Fi and education. The findings also demonstrate a degree of complexity with some issues impacting across multiple sub-themes. For example, the impact of staff/hospital capacity runs across ‘staff training,’ 'staffing levels and responsiveness,' and 'waits in hospital.’ Similarly, the importance of staff listening appears in 'diagnosis and starting treatment'; ‘staff continuity’ and within the ‘communication’ theme. This indicates that improvements in these areas could lead to a range of benefits across multiple aspects of care experiences.

Where possible the impact of experience is detailed throughout the findings to support interpretation and assessment of greatest need/priority. It is recommended to triangulate the insights shared in this report with other existing datasets that are relevant, and to consider new collections and/or engagement activities which would support an understanding of priorities for cancer patients. Ongoing listening and involvement are of course paramount to ensure any efforts nationally or locally will have the greatest gains to improve experiences of cancer care.


Staff
General gratitude
Staff attributes
Staff training
Staff listening, understanding and involving
Staff continuity
Communication
Between staff & patients /parents/carers
Within hospitals
Between hospitals
Out of hospital stays
Being kept informed
Access to care
Diagnosis & starting treatment
Staffing levels & responsiveness
Waits in hospital
Travel
Personalised care
Psychological support
Immune compromised patients
Hospital food
Quality & choice
Patients' 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 & ability to sleep
Privacy
Comfort
Cleanliness
Other issues
Noteworthy exceptions
Insight also evident in 2023

Further information

For more information on development and methodology, please see the Survey Handbook and Technical Document. 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.