cancer patient
experience survey

Under 16 Cancer Patient Experience Survey 2021

National Qualitative Report

November 2022

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Executive Summary

Background

The Under 16s Cancer Patient Experience Survey (U16 CPES) is an annual survey that aims to understand the experiences of cancer and tumour care among children and/or their parents/carers. This is the second 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 sample for the survey included all patients with a confirmed tumour or cancer diagnosis who received inpatient or day case care from NHS Principal Treatment Centres (PTCs) between January 1, 2021 and December 31, 2021, and were aged under 16 at the time of their discharge. An online version of the survey was also available.

The survey asked respondents a range of closed questions about their experience and also invited them to provide 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. Explain Research[1] were commissioned by NHS England to conduct a thematic analysis of this open-ended 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

In total, 548 parent/carers and 163 children provided a response to the open-ended question. Thematic analysis of the responses revealed the following themes:

Positive experiences

Gratitude for care received was commonly shared. Nurses and play specialists were praised with positive feedback about the impact they had on experiences of care. A range of staff attributes highly valued by parents/carers and children were found including empathy and kindness. In addition, some good practice examples of communication were captured in feedback.

Negative experiences attributed to staff

Negative attitudes and behaviours of staff highlighted the significant impact these instances can play on experience of care. Feeling unheard by staff was also found spanning primary and secondary care. A need for staff training to better support children with additional needs was a further finding of negative experiences attributed to staff.

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[1] https://www.explainresearch.co.uk/

Access issues

A perception of understaffing in hospitals was found alongside specific mentions of a need to improve access to Cancer Nurse Specialists, named consultants and play specialists. Access to care during weekends and holidays was also featured in feedback, as well as frustration of parents/carers feeling access to a ward when needed should not be via A&E.

Experience of delays

Delays were encountered at various stages across care and impacted on experience. In some cases, delays caused distress and frustration:

- Diagnosis
- Procedures (e.g. blood tests)
- Chemotherapy appointments
- Receiving medication
- Test results

Communication issues

Issues were found in communications between and within hospitals and care teams. Communications around appointment letters and notices also stood out in feedback. In addition, there were communication needs unmet in understanding treatment decisions; understanding the reasons for treatment delays; and in discussing treatment holistically as opposed to 'in segments.'

Issues with food

Improvements were needed with food across a range of issues which were encountered during hospital stays:

- Quality
- Choice
- Cancer needs unmet
- Parents/carers needs unmet
- Financial impact

Unmet needs

In addition to 'Issues with food', unmet needs included a range of examples listed below:

- Activities & entertainment
- A good night's sleep
- Needs varying by age
- Aftercare
- Mental health support
- Financial support

Wider hospital issues

Feedback about hygiene and cleanliness on wards being unacceptable was found. Further comments regarding wards identified a need for updates, e.g. to décor. Mentions were also made of Covid-19 largely regarding visitor restrictions and some facilities being inaccessible. Note that during fieldwork such restrictions had begun to ease.

Introduction

Project Background

The Under 16 Cancer Patient Experience Survey (U16 CPES) 2021 is the second iteration of a national survey that captures the experiences of the following groups:

- Children who were aged 8 and above at the start of the fieldwork period, but under 16 at the time of their care
- Parents and carers of children who were aged under 16 at the time of their care.

The survey has been designed to understand patient experiences of tumour and cancer care – both 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 here.

The survey is overseen by an Advisory Group made up of professionals who provide and commission children's cancer care, charity representatives, cancer patients, and parents of children with cancer. This group advises on questionnaire development, methodology, and reporting outputs. The survey is managed by NHS England, who commissioned Picker to oversee survey development, technical design, implementation, and analysis of the survey.

In its second iteration we continue to learn a lot about what is working well within the survey methodology and what might need adjusting for the Under 16 CPES. There are differences between the 2021 and 2020 surveys which has led to the analytical and insight recommendation that comparisons should not be made between results. These are outlined below:

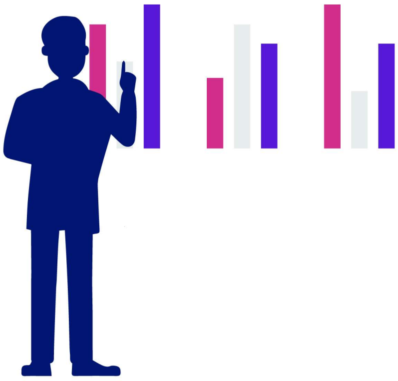
- Feedback from cognitive interview testing with patients identified that clarification was needed regarding the time period that patients should be reporting on. Changes have been made to the wording in the survey to accommodate this, but these only affect this year's (2021) iteration. Therefore, the 2020 and 2021 surveys report on patients' experience of care across potentially different and overlapping time periods.

- There are differences in response rates across the two years. Coupled with a small sample size, this reduces statistical confidence in comparisons for quantitative data.

The combined impact of both factors makes it extremely difficult to determine whether differences in results reflect true change in patient experience or change in survey wording. For this reason, this report details findings from the qualitative analysis of the 2021 data (including 2021 quantitative data for refence) in isolation.

Please note that work will be undertaken to enable comparability across time periods in future iterations of the survey. This will enable NHS trusts to understand any impact in changes of their service provision over time.

Methodology



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 January 1, 2021 and December 31, 2021, and were aged under 16 at the time of their discharge.

The fieldwork for the survey was undertaken between April and June 2022. One of three versions of the survey were distributed:

- The 0 to 7 questionnaire; sent to parents/carers of patients aged between 0 and 7 years old immediately prior to survey fieldwork
- The 8 to 11 questionnaire, sent to parents/carers of patients aged between 8 and 11 years old immediately prior to survey fieldwork
- The 12 to 15 questionnaire; sent to parents/carers of patients aged between 12 and 16 years old immediately prior to survey fieldwork

Questionnaires sent to those aged 8 to 11 and 12 to 15 contained a section for the child to complete, followed by a separate section for their parent or carer to complete. Where a child was aged 0 to 7, the questionnaire was completed entirely by their parent or carer.

The survey asked recipients to answer about their (or their child's) cancer care over the last year 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 URL/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

Each survey version included an open-ended question asking respondents if there was anything else they would like to say about their or their child's cancer or tumour care. For the children's surveys (8 to 11 and 12 to 15 versions), there were two open-ended questions – one asked in the parent section and another in the children's section.

- The parent section read 'Is there anything else you would like to tell us about your child's cancer or tumour care (e.g. anything particularly good; anything that could be improved)?'
- The children's question wording was 'Is there anything else you wanted to tell us about your cancer or tumour care (anything good, or anything that could be better)?'.

Data cleaning

Certain information from the written comments was redacted to protect the identity of survey respondents. The following information was removed:

- Names of patients, staff, hospitals, wards or units replaced with "(name)"
- Address information entered as "(address)"
- Specific dates replaced with "(date)"
- References to specific illnesses, cancer types or tumours replaced with "(illness)"

Qualitative analysis

Picker[2] were commissioned by NHS England to design and implement the survey programme, to analyse the quantitative data from the closed survey questions, and to code the comments at Principal Treatment Centre level.

Additionally, NHS England commissioned Explain Research[3] to independently thematically analyse the open-ended written feedback (qualitative data) provided within the survey to identify areas for improvement and facilitate reflection and learning across services delivering cancer care for children aged under 16.

The overall aim of the thematic analysis was to seek understanding of experiences shared in the written feedback collected within the survey. The results of the thematic analysis are 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. That said, it should not be assumed that those providing critical feedback was shared only by those giving the lowest/poorest quantitative scoring/rating. There is complexity in written descriptions of experience which are often mixed in sentiment sharing positive and negative feedback.

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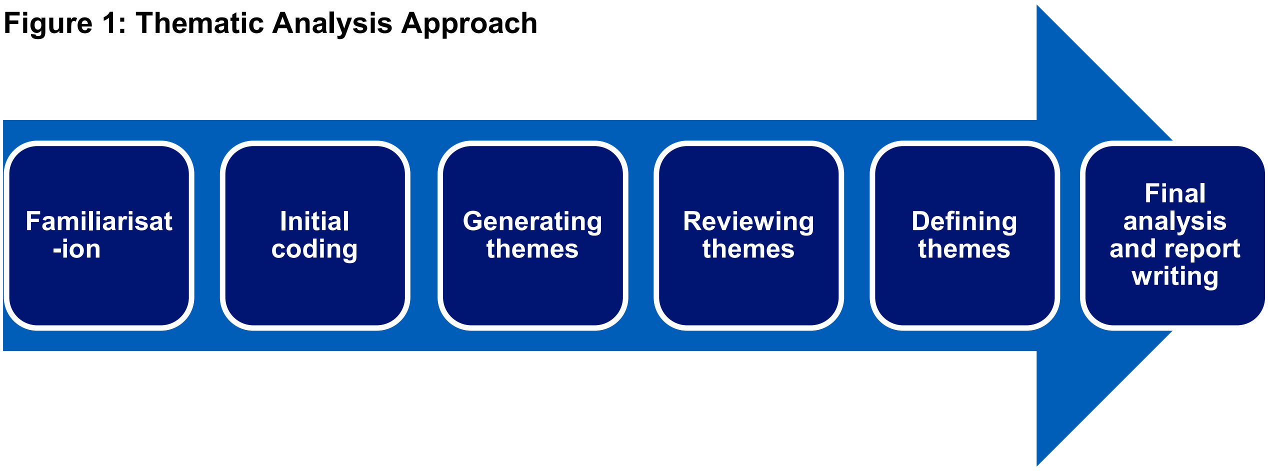
[2] https://www.picker.org
[3] https://www.explainresearch.co.uk/

To analyse qualitative data, the standard six steps of thematic analysis were used to identify common themes and patterns of meaning within the data – see Figure 1.

Figure 1: Thematic Analysis Approach



It is important to note that a sample was not taken for the thematic analysis and all of the qualitative data was analysed, i.e. every individual comment from parents/carers and children was included.

For the purposes of this report parent/carer and child responses have been analysed collectively, however the report references from which themes/comments the responses have originated (e.g. parent/carers or children).

When analysing qualitative data, eight comments provided in the child section of the survey were interpreted as likely to have been written by a parent/carer judging by the terminology used (e.g. ‘my child’). These comments were all moved into the parent section of the analysis. Conversely, one comment in the parent/carer section had been provided by a child, therefore was moved into the child section.

About the Respondents

Response rate

Overall, the survey had a response rate of 26%, with 960 respondents out of a total of 3,672 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 written comments

Of the 960 completed survey responses, 586 provided 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): 318 records with qualitative data
- 8 to 11 questionnaire: 116 records with qualitative data
- 12 to 15 questionnaire: 152 records with qualitative data

There was a total of 711 qualitative comments left across all survey versions/sections. Table 1 shows the number of comments left by parents/carers and by children across each survey version. A total of 548 comments were left by parents/carers, and 163 comments were left by children.

Table 1. Number of comments by survey section

Survey Version	Number of qualitative comments
0 to 7 Questionnaire (parent/carer only)	318 comments
8 to 11 Questionnaire	Child survey section: 68 comments Parent/carer survey section: 101 comments
12 to 15 Questionnaire	Child survey section: 95 comments Parent/carer survey section: 129 comments

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.

Principal Treatment Centre (PTC)	**Number of survey responses with** qualitative **data***
Alder Hey Children’s NHS Foundation Trust	24
Birmingham Children’s Hospital NHS Foundation Trust	63
Cambridge University Hospitals NHS Foundation Trust	38
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	111
Leeds Teaching Hospitals NHS Foundation Trust	38
Manchester University NHS Foundation Trust	32
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	40
Oxford University Hospitals NHS Foundation Trust	39
Sheffield Children’s NHS Foundation Trust	24
The Newcastle upon Tyne Hospitals NHS Foundation Trust	35
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	71
University Hospital Southampton NHS Foundation Trust	33
University Hospitals Bristol NHS Foundation Trust	38
TOTAL	**586**

** This could be a parent/carer comment, a child comment or both a parent/carer and a child comment*

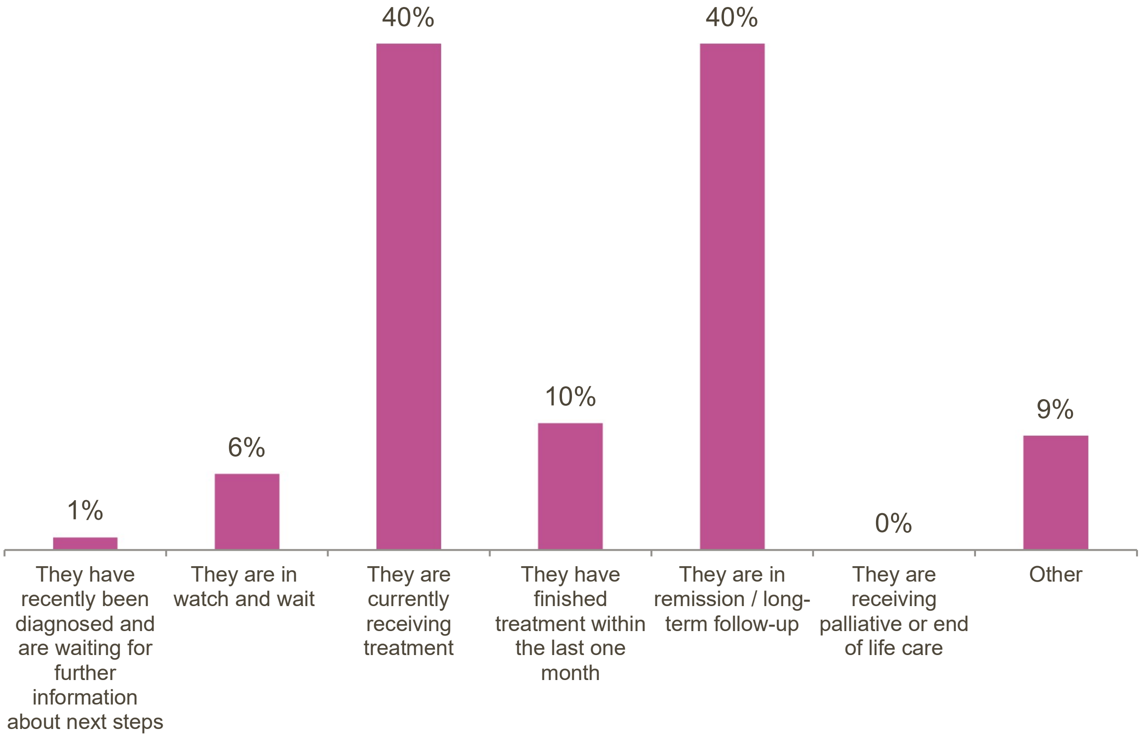
The demographic characteristics of those responding to the open question are described in more detail below, and largely reflect the population invited to take part in the survey.

Children

Of the 163 children who answered the open question, 68 (42%) were aged 8 to 11 and 95 (58%) were 12 to 15 years old.

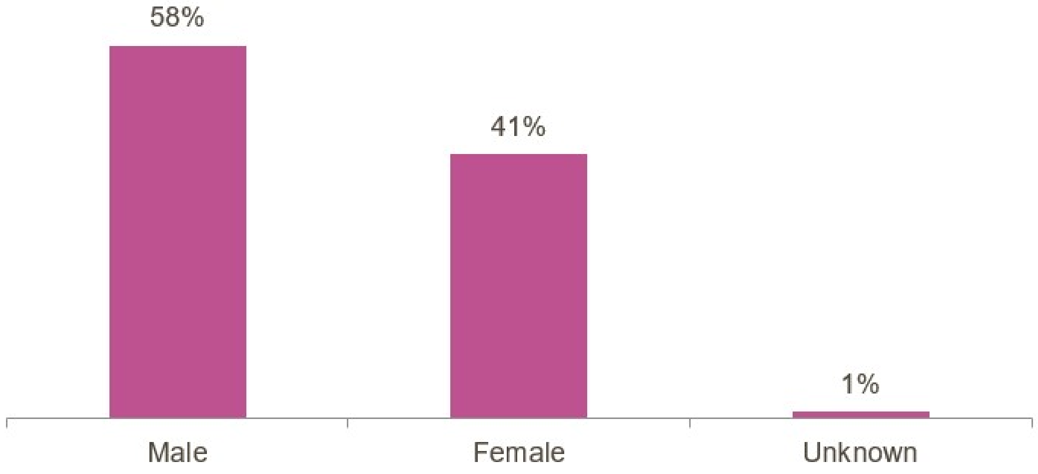
In terms of cancer stage (see figure 2), the majority of children that completed the open-ended question were either currently receiving treatment or in remission/long term follow up. Fewer children had finished treatment within the last month, and fewer still were in watch and wait. None were currently receiving palliative or end of life care. Please note, this was a multi-coded question.

Figure 2: Stage of Cancer Journey for children leaving a qualitative comment (N=163)



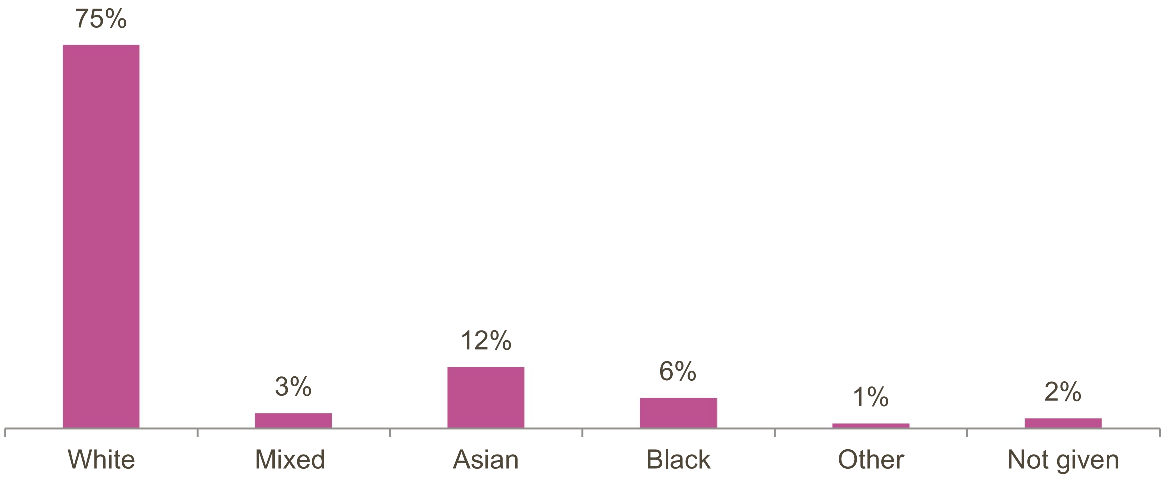
A higher number of boys (95 respondents) answered the open question than girls (67 respondents) – see Figure 3. Please note that may be because more boys were invited to take part in the survey and the number of qualitative responses reflects that pattern (i.e. it does not indicate that boys are more likely to leave qualitative comments).

Figure 3: Gender (from survey) of children leaving a qualitative comment (N=163)



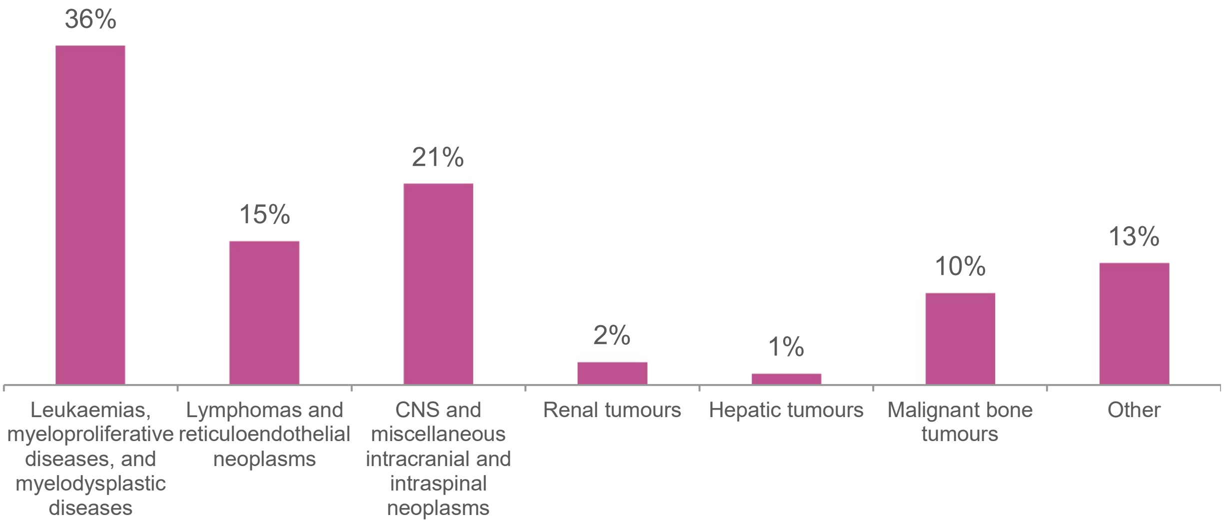
The ethnic group of children who completed the open question is displayed in Figure 4. Please note the number of qualitative responses by ethnic group largely reflects the pattern of those invited to take part in the survey.

Figure 4: Ethnic group of children leaving a qualitative comment (N=163)



Regarding the diagnostic groups of children who answered the open question (figure 5), there was a greater representation of Leukaemias, myeloproliferative diseases, and myelodysplastic diseases (36%, n=59), Lymphomas and reticuloendothelial neoplasms (15%, n=25), CNS and miscellaneous intracranial and intraspinal neoplasms (21%, n=35) and Malignant bone tumours (10%, n=16) than Renal tumours (2%, n=4) and Hepatic tumours (1%, n=2).

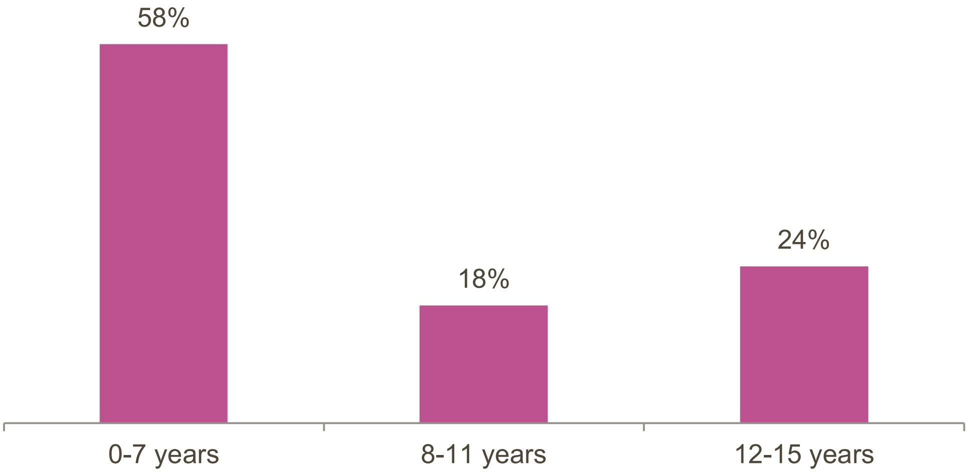
Figure 5: Diagnostic group of children leaving a qualitative comment (N=163)



Parents/carers

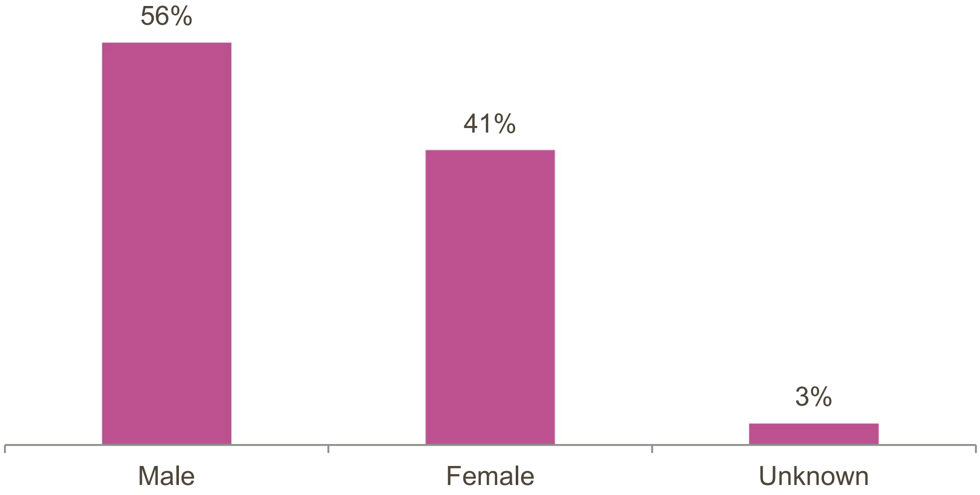
Of the 548 parents/carers who answered the open question, a higher proportion were from the 0 to 7 survey version relative to the 8 to 11 and 12 to 15 versions – see Figure 6, reflecting the pattern of those invited to take part in the survey.

Figure 6: Survey version for parents/carers leaving a qualitative comment (N=548)



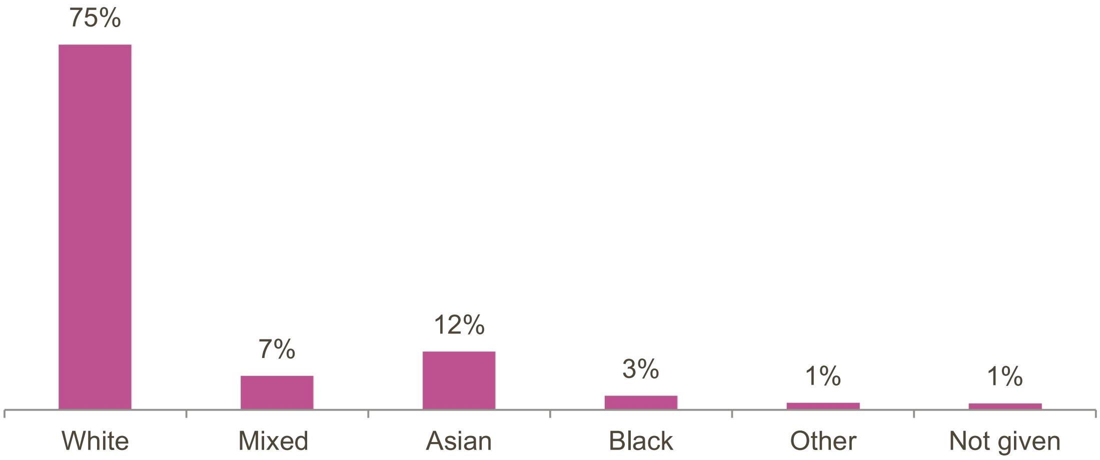
More open responses were left by parents/carers of boys than girls – see Figure 7. Please note that more boys were invited to take part in the survey and the number of qualitative responses reflects that pattern (i.e. it does not indicate that parents/carers of boys are more likely to leave qualitative comments).

Figure 7: Gender (from survey) of children of parents/carers leaving a qualitative comment (N=532)



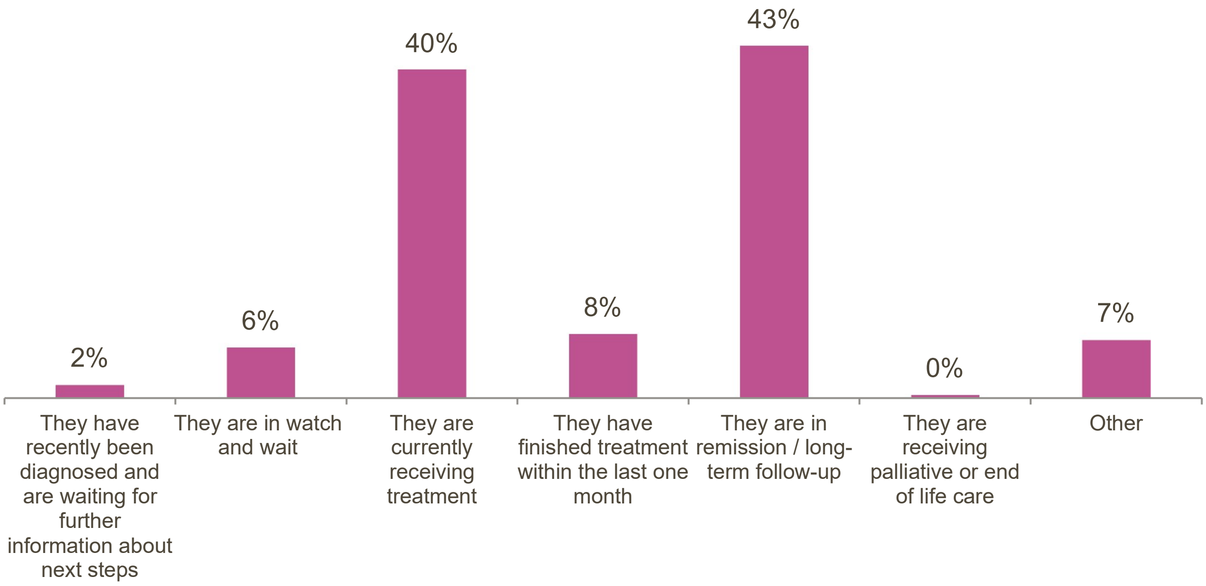
The ethnic group of children whose parents/carers left a qualitative comment are displayed in Figure 8. Please note the number of qualitative responses by ethnic group largely reflects the pattern of those invited to take part in the survey.

Figure 8: Ethnic group of children for parents/carers leaving a qualitative comment (N=548)



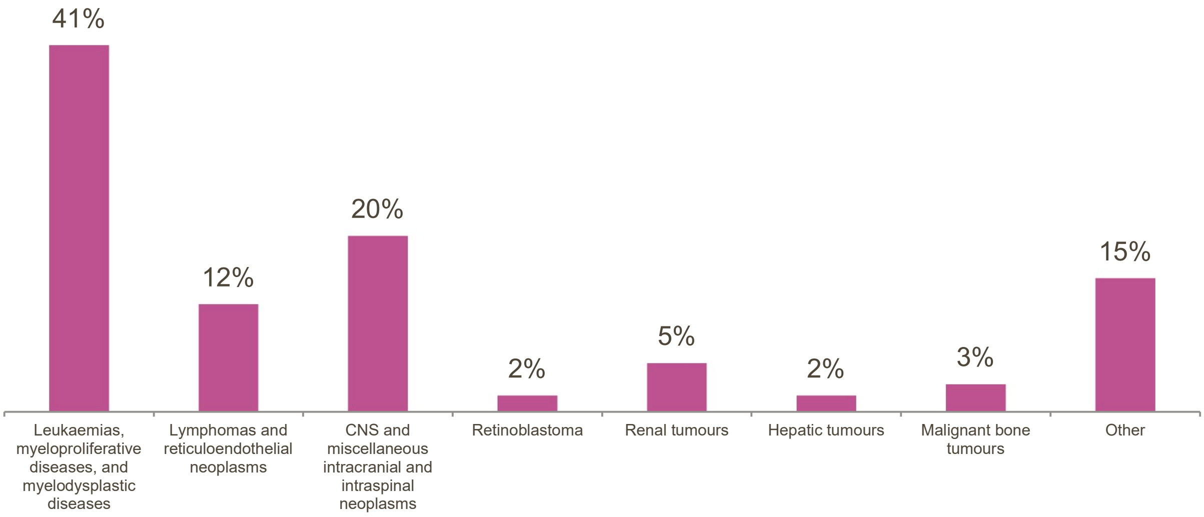
Parents/carers that completed the open question had children who were at varying stages of the cancer journey, with fewer at the beginning stages of the journey (e.g. diagnosis) and the majority either currently receiving treatment or in remission/long-term follow-up – see Figure 9. Please note, this was a multi-coded question.

Figure 9: Stage of children's cancer journey of parents/carers leaving a qualitative comment (N=548)



Similar to child responses, some diagnostic groups were less represented in the parent/carers qualitative data. These were; Retinoblastoma, Renal tumours, Hepatic tumours, and Malignant bone tumours. See Figure 10.

Figure 10: Diagnostic group of children for parents/carers leaving a qualitative comment (N=548)



Interpreting the Results

Context setting and wider considerations

Context setting when interpreting results

Within the qualitative responses a high number of positive comments were provided, expressing thankfulness and appreciation of both the medical care received and wider experiences throughout the cancer journey. The high volume of positive comments reflects the positive overall experience of care scores for parents and children.

- Parents/carers rated the overall experience of their child’s care as 9.01 on average on a scale of 0 to 10 (Q X62)
- 89% of parents/carers (of 0 to 15s) rated their child's overall cancer or tumour care as 8 or more out of ten (question X62, answered by 922 respondents)
- 77% of children aged 8 to 15 said they are looked after very well for their cancer or tumour (question X63, answered by 416 respondents).

It is important that the findings of this report are understood within this positive context and take into consideration also that these positive comments lack in detail as to actionable insight. In contrast, comments shared about areas for improvement and experience of care which were less positive, are typically more actionable and detailed. Notably, many comments are mixed in sentiment sharing gratitude for example, alongside critical feedback. As a result, this report is focussed on the more actionable and detailed comments and as such the areas for improvement. This allows us to explore the richest opportunities for learning.

To note, references within ‘Results: Key Themes’ as to proportionality such as use of ‘many’ and ‘few’ are made in context of the qualitative sample and thematic insight, and should not be misread as commentary as to the sentiment or experience of the whole survey sample.

Cancer specific insight

When interpreting these results, it is helpful to note that some suggestions made relate to wider services/experiences and are not necessarily specific to the under 16 cancer patient audience.

Although all findings are included for insight, it should be acknowledged that some of the wider suggestions (e.g. those that are not specifically related to care for children under the age of 16 and/or cancer patients) may be less actionable.

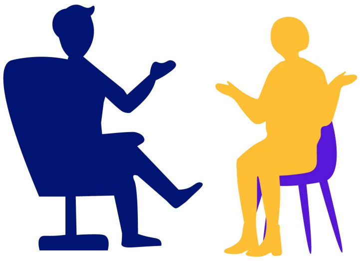
Care setting

In addition to comments relating to secondary care, several comments were also made in relation to primary care, for example comments relating to GPs specifically. These results have been included alongside the secondary care comments and where distinction is made clearly in the data this has been highlighted. Where the language used in comments is not explicitly clear as to whether care took place in primary or secondary care, this can sometimes be inferred, e.g. references to consultants would infer a hospital setting; references to a GP would infer a primary care setting.

Other

For the purposes of this report, parent/carer and child responses have been analysed collectively. Please note when interpreting themes that fewer children responded to the open question (163) in comparison to parent/carers (548).

Results: Key Themes



The following key themes were identified from thematic analysis of qualitative data written by parents/carers and children:

- Positive experiences
- Negative experiences attributed to staff
- Access issues
- Experience of delays
- Communication issues
- Issues with food
- Unmet needs
- Wider hospital issues

Where there is quantitative survey data relating to the theme, this has been shared as context to support understanding of the experience described. As noted above, the opportunity for learning and for improvement lies in the qualitative data which can support us in understanding why not every child or parent/carer gave the best scores possible throughout the survey.

Positive Experiences

What does the quantitative survey data tell us?

- Parents/carers rated the overall experience of their child’s care as 9.01 on average - on a scale of 0 to 10 (Q X62)

Gratitude

There were many positive comments about the care provided, with parents/carers and children expressing their gratitude for the care they received.

- *“The NHS takes a lot of criticism. I sometimes think the public forget the amazing, life changing care that is provided every day with such compassion. We will be eternally grateful for the care we have received. I want to thank my son’s consultant and wider team for choosing this specialism and for developing services, thank you for giving children and* *parents a voice, thank you for being there when we needed you" (parent/carer of child aged 12 to 15)*

- *"I could not be more grateful for the care my son has received and for his life saving treatment. Both he and we have all been thoroughly supported throughout the 3 years of his treatment and I have trusted them totally. We are forever grateful" (parent/carer of child aged 8 to 11)*
- *"The care we are receiving for our 2 year old daughter couldn't be better from the first instant we were admitted into the ward, each and every member of staff have been incredible" (parent/carer of child aged 0 to 7)*
- *"I/we received fantastic care during all my episodes of treatment at the hospital and my aftercare was also fantastic" (child aged 12 to 15)*
- *"I just want to say a huge thank you to everyone who has taken care of me throughout this process, that includes family, friends, doctors, nurses everyone! Thank you!" (child aged 12 to 15)*

Valuing staff attributes

What does the quantitative survey data tell us?

- 97% of parent/carers and children felt that the nurses who came to their home or school were always friendly (Q X57)
- 88% of parents/carers felt that they and their children were always treated with respect and dignity by staff (Q X15)
- 84% of parents/carers always had confidence and trust in staff caring for their child (Q X16)
- 86% of children felt that staff were always friendly (Q X23)

The vast majority of comments about members of staff were overwhelmingly positive, with respondents expressing their gratitude for the care they received. Respondents were often complimentary about the traits of staff members. In particular, they noted value in the following characteristics:

Empathetic **Friendly** **Kind** **Helpful** **Professional**

- *"The staff were absolutely amazing: supportive, empathetic, patient and always positive despite the challenges faced by them and the children and parents on the ward" (parent/carer of child aged 8 to 11)*
- *"We feel we have been very well looked after, all staff are friendly and understanding, and helpful" (parent/carer of child aged 12 to 15)*
- *"Very helpful, kind and willing to help in any way" (parent/carer of child aged 0 to 7)*
- *"I was so scared at first but they made me feel better and understand more very quickly thank you" (child aged 12 to 15)*
- *"Everyone is always friendly easy to talk to and always helpful" (child aged 8 to 11)*

Positive experiences with nurses

Respondents were particularly complimentary about the nurses in giving praise for staff, describing them as hard-working, caring and attentive.

- *"The nurses are really good with my child who is very young, they help him when things are scary for him and have a lot of ideas on how to keep him distracted during treatments" (parent/carer of child aged 0 to 7)*
- *"We would also like to extend our appreciation to all the nurses in both the day unit and ward (name), as they were extremely conscientious when looking after my daughter on a day-to-day basis" (parent/carer of child aged 0 to 7)*
- *"The nursing staff were also wonderful - we could not believe how hard they worked; and how dedicated and compassionate they were" (parent/carer of child aged 0 to 7)*
- *"The nurses were friendly and easy to talk to" (child aged 12 to 15)*

Positive experiences with play specialists

Children and parents/carers expressed their gratitude for the provision of play specialists in helping keep them/their children entertained, occupied and happy during their hospital stays.

- *"Thank you to the play specialist (name) you made me very happy" (child aged 8 to 11)*
- *"The play specialists are brilliant, they really help during the waits by keeping him entertained" (parent/career of child aged 0 to 7)*
- *"Play therapists have also been an amazing help on this journey, engaging with children and us as parents. Helping to keep the days spent in hospital entertaining for the children whether that be through play, arts and crafts and have provided a lovely distraction. Play specialists*

have worked with our daughter to help her overcome areas of upset and stress over port access or anaesthesia or preparing and undergoing radio" (parent/carer of child aged 0 to 7)

- *"The play specialist support at the hospital is invaluable. They provide consistency/familiar faces during multiple hospital visits. They bridge the gap between families and the medical staff during treatment times, providing additional support" (parent/carer of child aged 0 to 7)*
- *"The school room and play team did a great job at keeping me occupied during long hospital stays" (child aged 12 to 15)*
- *"The play specialists were always there for me and made me smile" (child aged 8 to 11)*

Examples of good communication

What does the quantitative survey data tell us?

- 76% parents/carers felt that staff were always sensitive to information sharing when their child was in the room (Q X19)
- 82% of children reported that staff always speak to them in a way that is suitable for them (Q X21)
- 72% of children reported that they could always understand what staff are saying (Q X14)
- 86% parents/carers reported that they definitely had the chance to ask questions about their child's care and treatment (Q X13)
- 66% parents/carers and children reported always knowing what was happening with their child's/their care (Q X30)

There were several positive comments made regarding communication with parents/carers and children. Several examples were shared highlighting good practice.

- *"Communication throughout the entire time & team - extending to the wonderful community nurses - has been amazing and consistent, which has helped so much" (parent/carer of child aged 0 to 7)*
- *"All of my child's oncology team at (name) are very easy to talk to, I can ask questions and get plenty of information to help us through this journey" (parent/carer of child aged 0 to 7)*
- *"As parents we have felt included, informed and heard throughout the whole process" (parent/carer of child aged 12 to 15)*
- *"Doctors explained to me in the form of Lego. This helped me understand. (Name) always talks to me and asks me. He is brilliant" (child aged 12 to 15)*

Negative experiences attributed to staff

Poor attitudes and behaviours of staff

What does the quantitative survey data tell us?

- 82% of parents/carers felt they were always treated with empathy and understanding by staff caring for their child (Q X17)
- 97% of parent/carers and children felt that the nurses who came to their home or school were always friendly (Q X57)
- 88% of parents/carers felt that they and their children were always treated with respect and dignity by staff (Q X15)
- 86% of children felt that staff were always friendly (Q X23)

There were some negative comments made about members of staff, with both parents/carers and children describing attitudes and behaviours which had negatively impacted on their experience of care.

Some perceived staff members to be unfriendly and lacking in empathy. While these comments were less common than those made praising staff attributes, importantly this feedback highlights the impact these instances can have on experiences of care.

- *“Not all nurses show empathy they need to understand from a parent's point of view” (parent/carer of child aged 0 to 7)*
- *“When children are first diagnosed staff could be slightly more empathetic. You are chucked into world of childhood cancer which is inevitable but some comments are unnecessary such as `just shave your child’s hair' I know the staff become slightly used to it all but it is hard for parents no matter what” (parent/carer of child aged 0 to 7)*
- *“There have been times when the night staff have been short with my daughter (receiving the treatment) and my older daughter (who stays in for chemo with her at times) when they have asked for help” (parent/carer of child aged 12 to 15)*
- *“This was the hardest hospital admission we had because the staff were really difficult to deal with and it made a difficult and really tiring time, even worse” (parent/carer of child aged 0 to 7)*
- *“Some nurses are rude. We are forgotten about when waiting for chemo and when we ask we get attitude” (child aged 12 to 15)*

- *"Some of the nurses were kind, other were not. If I was sick and my Mum or Dad weren't there - it seemed that none of the nurses were going to clear up my sick. This made me feel bad" (child aged 8 to 11)*

What does the quantitative survey data tell us?

- 76% parents/carers felt that staff were always sensitive to information sharing when their child was in the room (Q X19)
- 82% of children reported that staff always speak to them in a way that is suitable for them (Q X21)

It was also highlighted by both parents/carers and children that staff need to be considerate of what they say in front of children, being mindful of discussing results or saying things that may cause upset. This included being more discrete as well as careful of the wording or manner used to discuss results and treatment.

- *"I have had lots of infections and have felt really poorly so I don't always like to eat and I felt a bit worried when someone mentioned I should not be losing any more weight. I think they should have said it to my mum rather than me" (child aged 12 to 15)*
- *"Oncologist nurses thought I knew I had cancer. It was my 1st time staying at (name) for Chemotherapy. She told me and it was a shock. My Mum advised me the Consultant was going to tell me after I'd completed my first phase of chemotherapy. This was a huge shock to me especially when I found out I was going to lose my hair. Oncology nurses need to ensure they're careful about how they approach children and must always check with parents first as to what the child knows" (child aged 8 to 11)*
- *"When breaking news of certain result milestones please have the empathy to take parents to a separate room away from the child as it is very upsetting when progress is not as expected/hoped & this news is given on a busy ward in front of child & others" (parent/carer of child aged 0 to 7)*

  "Some doctors need to be a bit more considerate when discussing weight gain and weight issues when the child is present. Steroids and lack of exercise play a huge part in weight gain during treatment….Don't need weight related issues to worry about in the future with my child just because a doctor cannot be discreet around a child" (parent/carer of child aged 0 to 7)

Feeling unheard

What does the quantitative survey data tell us?

- 63% of parents/carers reported that their child saw a GP once or twice before they were referred to hospital (Q X03)

A further theme identified in relation to staff was that some parents/carers and children felt doctors and other staff members didn't listen to them when they were expressing concerns. Examples referenced treatment in hospitals most frequently and did also stretch back to initial presentation of symptoms to their GP. In these instances, feeling unheard was linked to a sense that diagnosis was delayed.

- *"The doctors at the local hospital (not oncologist) didn't listen, and treated me as though I was stupid at times, this made our stays very hard as not once did I treat them with anything but respect however I know my child I am with her most of the time, when antibiotics made her worse I was ignored. She deteriorated and no one listened until her oncologist came in by which time she was really ill. There were several occasions where things like this happened and its my daughter that suffered" (parent of carer aged 8 to 11)*
- *"I have witnessed on a number of occasions, the staff not explaining or brushing off parents which has concerned me as I worry for their child, & how much they understand" (parent/carer of child aged 0 to 7)*
- *"Listening to the parents when they tell you the child can't cope with too much noise/sensory stimulation but being dismissed like you're an over reacting parent is just not acceptable. I'm not a qualified doctor with a degree but one thing I do know is I know my child better than any doctor and if I am offering up information on the situation, it's because I know I'm right and I am only trying to help my children get through what might be a terrifying and awful experience for them. I really wish some professionals would actually take this on board - the parent really does know best sometimes so work with us and not against us" (parent/carer of child aged 8 to 11)*
- *"There have also been occasions when I have asked for samples to be taken as was worried that she had another or recurring (illness) (which proved to be correct) and this was refused, which meant she was in pain for another 10 days as no further meds were given" (parent/carer of child aged 12 to 15)*
- *"Nurses need to listen to children. I kept on telling the nurses one of the tablets made me sick. However they insisted on giving it to me and then were surprised when I was sick. Whilst I appreciate that I must try and take all medication, please listen to children/parents when they advise nurses it makes them sick" (child aged 8 to 11)*
- *"I wish my child diagnosis had been done lot quicker. Wish the GP has taken seriously all my concern and worries" (Parent/carer of child aged 12 to 15)*
- *"My GP and a few hospitals we were in all did not find the issue even though I kept describing the symptoms" (child aged 0 to 7)*
- *"The GP surgery could have listened to me more in the 3 months leading up to me having to take him to the hospital A&E where the hospital did scans and x-rays and found the tumour. The GP surgery just kept palming us off with 'growing pains' and take Ibuprofen" (parent/carer of child aged 8 to 11)*

Additional needs training

It was highlighted by some parents/carers of children with additional needs that these needs weren’t always met by staff members, and some suggested staff needed training on how to better support them.

- *“There is a need to train all staff to deal with special needs” (parent/carer of child aged 0 to 7)*
- *“There were a couple of occasions where more junior doctors could have demonstrated better understanding and awareness when dealing with my son in terms of his complex disabilities” (parent/carer of child aged 12 to 15)*
- *“Unfortunately, there's one very important factor which sometimes hospital care system is missing. It's special needs/mental disability of the child. It should be always taken under consideration when planning any procedure/treatment” (parent/carer of child aged 0 to 7)*
- *“My child has additional needs and I find staff are definitely not aware or trained for children who have these types of problems” (parent/carer of child aged 8 to 11)*

Access issues

What does the quantitative survey data tell us?

- 59% of children reported always or mostly seeing the same members of staff for their treatment and care (Q X24)
- 76% of parents/carers and children felt that the child was always able to get help from hospital staff when they needed it (Q X45)
- 63% of parents/carers reported that they definitely had access to reliable help and support 7 days a week from the hospital (Q X34)
- 86% parents/carers reported that they definitely had the chance to ask questions about their child’s care and treatment (Q X13)

Understaffing

Children and their parents/carers commented that hospitals seemed understaffed. The most common way in which this manifested was in difficulties experienced accessing care from nurses when using call bells/buzzers to request care on wards.

- *“More nurses are needed during busy times on the day unit” (parent/carer of child aged 12 to 15)*
- *“(Name) does seem understaffed sometimes as the nurses forget your request and you as soon as they step outside your room, so assuming they are very busy” (parent/carer of child aged 0 to 7)*
- *“Nurses on day wards are very busy and don’t seem to have time to explain anything to carers or child about what’s happening and where in hospital to go” (parent/carer of child aged 12 to 15)*
- *“Nurses extremely busy, parents having to give medicine themselves whilst in hospital and long wait times for responses to buzzers” (parent/carer of child aged 0 to 7)*
- *“Due to some staffing limitations, there were times when my child's alarms went answered for longer periods of time” (parent/carer of child aged 12 to 15)*
- *“I sometimes press buzzer, and no one comes as they are so busy” (child aged 8 to 11)*
- *“We were always kept waiting and waiting as nurses so busy without explanation” (child aged 8 to 11)*
- *“My machine alarms didn't get answered for quite a long time” (child aged 12 to 15)*

Clinical Nurse Specialists

There were several comments reporting a lack of access to and responsiveness from Clinical Nurse Specialists (CNS) specifically. Phone calls not being answered, and emails not being replied to were described.

- *“Our primary contacts with the hospital are the CNS. Overall, they are doing a very good job, but I wish they were a little more responsive to enquiries and proactive in providing advice and support” (parent/carer of child aged 12 to 15)*
- *“We've had no contact from specialist nurse throughout, even when I asked questions via emails & text” (parent/carer of child aged 0 to 7)*
- *“The Clinical Nurse Specialist is always nearly impossible to get hold of” (parent/carer of child aged 12 to 15)*
- *“The only thing I will mention is when calling our CNSs. They never/very rarely answer the phones. Or they are not there and appreciated message is set. 9/10 when I call they don't answer very frustrating & disappointing” (parent/carer of child aged 0 to 7)*
- *“We can never get in touch with our designated haematology nurse at (name) so we feel disconnected in that regard” (parent/carer of child aged 0 to 7)*

Additionally, there were several comments relating to problems arising when an allocated CNS was changed or unavailable through sickness or leave.

- *“Lack of communication between CNS and patients since her CNS replacement due to MAT cover we haven’t met CNS or introduce to us. So we didn’t know her CNS left and we couldn’t reach out for help when we needed” (parent/carer of child aged 8 to 11)*
- *“We have no direct line of contact, instead having to go through our CNS to ask questions or chase appointments but the person fulfilling this role changes almost monthly, with no communication to say the last person has left or to introduce the new one. There have been multiple occasions where a CNS wasn't working and recently even emails have gone unanswered” (parent/carer of child aged 0 to 7)*
- *“Initially we were informed there would be a specialist liaison nurse who would be available to answer questions and ensure smooth communication with the oncology team. This person was off sick for months and no interim person was appointed. This would have been invaluable especially in the early days” (parent/carer of child aged 12 to 15)*

Named consultant

A further issue regarding access was that some parents/carers felt they didn’t see their named consultant regularly enough.

- *“There were unacceptable periods of time without access to named consultant due to maternity leave/illness absences” (parent/carer of child aged 12 to 15)*
- *“We would have liked to have more frequent talks with the consultant, or doctors” (parent/carer of child aged 12 to 15)*
- *“The primary consultant rarely came to see my son while we were inpatient, which we found inadequate. Our Key Worker was our middleman to our consultant and was almost impossible to reach. This lack of communication was below par for such a serious disease & decisions to be made on behalf of our child” (parent/carer of child aged 0 to 7)*
- *“I was initially disappointed that the Consultant in charge of my son's care didn't want to see us or had no time to see us” (parent/carer of child aged 0 to 7)*
- *“We sometimes feel that although we have a named consultant, we rarely get to see them. This in itself isn’t a huge problem as the ANPs are great but things like results on bone marrows aren’t discussed. It would be nice to have a sit-down meeting scheduled during frontline treatment to alleviate concerns and focus treatment” (parent/carer of child aged 0 to 7)*
- *We did not have enough direct communication to our primary oncologist/consultant at (address), to discuss my son's treatment plan & relevant questions as needed (parent/carer aged 0 to 7)*

Play specialists

What does the quantitative survey data tell us?

- 90% of parents/carers reported that the hospital offered play specialist support (Q X49)

While positive experiences of play therapy were noted earlier in the report, it was also commented upon by parents/carers and children that access to play specialists should be more frequent including at weekends.

- *“More play interactions should be offered to children by the play team they never have time & always seem to be short staffed” (parent/carer of child aged 8 to 11)*
- *“My child had barely any play specialist input in hospital I feel younger children are ignored more as they have less understanding and play by themselves. However this is harder for parents especially when children are stuck in bed due to treatment” (parent/career of child aged 0 to 7)*
- *“On the day unit we quite often don't see a play team member & with a 4 year old this is a bit of a shame” (parent/carer of child aged 0 to 7)*

- *"The day-care playroom has toys available however play specialists are not usually seen/often seen" (parent/carer of child aged 0 to 7)*
- *"We were offered access to a play specialist but she only had time to see us once for about 15 mins. To improve I would request better access to play specialists 7 days a week" (parent/carer of child aged (0 to 7)*
- *"I wanted the play specialist to be there on the ward full-time" (child aged 12 to 15)*
- *"Wish play therapy was available at weekends" (child aged 8 to 11)*

Care at weekends / holidays

What does the quantitative survey data tell us?

- 63% of parents/carers reported that they definitely had access to reliable help and support 7 days a week from the hospital (Q X34)

In addition to an ask for play therapy to be more accessible, some parents/carers expressed frustration that other services/care/treatment were not available during weekends, bank holidays, and school holidays.

- *"Downsides to (name) Hospital are, no specialist Dr in the evenings or very few at the weekend" (parent/carer of child aged 0 to 7)*
- *"There is little to no staff over weekends and holiday periods nothing regarding treatment happens so if it is the weekend/ summer/ xmas bank holiday you have to wait until consultants return" (parent/carer of child aged 12 to 15)*
- *"Better care at weekends /bank holidays no progress made, no decisions made, no play specialists, no CNS" (parent/carer of child aged 0 to 7)*

Access to wards via A&E

Several parents/carers expressed their dissatisfaction at having to use A&E to gain access to the correct ward if their child had a temperature spike or became ill. These parents/carers felt they should be able to access the ward directly, particularly as the waiting times in A&E could be long and the staff were felt to have no knowledge of their child's treatment.

- *"When my daughter develops high temperature at home and she needs to be admitted to the ward, the 6-10 hours we have to wait at the A&E for getting a bed on the ward is too long, especially when we arrive in the evening and I have to spend the night on an A&E chair without any sleep" (parent/carer of child aged 8 to 11)*

- *“If my son spikes a temperature he has to go to hospital for antibiotics and blood tests. At (name) this means going via A&E where we often have to wait around 10 hours before being moved to a ward. It's tiring and stressful for us both. They're busy and know nothing about my son's medical history” (parent/carer of child aged 0 to 7)*
- *“If unexpected illness during treatment the procedure is A&E for admissions. This can be stressful for child and family as they have limited knowledge and experience of oncology patients - port access etc.” (parent/carer of child aged 0 to 7)*
- *“A&E waiting times for admission are diabolical (over 24hrs more than once)” (parent/carer of child aged 0 to 7)*

Experience of delays

What does the quantitative survey data tell us?

- 63% of parents/carers reported that their child saw a GP once or twice before they were referred to hospital (Q X03)
- 80% of parents/carers felt that their child was first seen by a hospital doctor as soon as they thought was necessary (Q X06)

A key theme identified in the qualitative comments related to the experience of delays encountered across the various stages of the patient journey. The main areas in which parents/carers described delays were:

- **Diagnosis**
- **Chemotherapy once in hospital**
- **Procedures, e.g blood tests**
- **Receiving medication**
- **Test results**

Diagnosis

Feedback was shared about issues experienced in primary care mostly in relation to delays in diagnosis. Alongside difficulties in getting a GP appointment, parents/carers sometimes felt they were not being listened to by medical professionals including GPs.

- *“Our GP let us down, it took 3 months to get diagnosed after having to pay privately for a GP & scan” (parent/carer of child aged 8 to 11)*
- *“Saw GP at start of illness - Diagnosed viral infection. Child got worse, doctors receptionist refused its on appointment so went to A&E” (child/parent of carer aged 0 to 7)*
- *"We experienced problems getting a blood test as son fell ill, due to us pushing the GP we managed to get a blood test and diagnosis soon followed from this. It would have been great if we could have got this test done sooner to confirm his diagnosis” (parent/carer of child aged 0 to 7)*
- *“If GP would have done better job and find my cancer at early stage” (child aged 12 to 15)*

Chemotherapy once in hospital

Comments relating to delays in chemotherapy after arrival in a clinical unit also stood out as key to parents/carers perception of delays. This was articulated in various ways, as examples demonstrate.

- *“Chemo could be quick and simple but they stand chatting when OBS could be done and chemo started. Too much social life chats whilst children sit waiting which isn't nice especially in covid times” (parent/carer of child aged 12 to 15)*
- *“Sometimes miss communication or chemo not ready on time from pharmacy” (parent/carer of child aged 8 to 11)*
- *The (name) has introduced a new waiting system, with a 2 hour wait before your 'chair time' for chemotherapy after attending the chemo clinic. I don't know the reason for this but is a big fail from a patient/parent perspective and has made days there markedly worse” (parent/carer of child aged 8 to 11)*
- *“My only complaint would be the waiting times between seeing the doctors and having chemo, however, this is completely understandable” (parent/carer of child aged 0 to 7)*
- *“Waiting time for the treatment to commence upon the arrival to the ward should be shorter. Each child had a time booked, so the treatment should commence without any delay, but this is not the case. Quite often chemo was not ready on time as well” (parent/carer of child aged 8 to 11)*
- *“Waiting time in the clinic is too long for me, when I go for my treatment” (child aged 8 to 11)*

Procedures, e.g. blood tests

Parents/carers and children also described delays across a range of other procedures. Examples spanned delays with blood tests through to waits for beds and scans.

- *“Our already long stays in the hospital are often unnecessarily extended by many hours - even days - due to delays with bloods, transfusions, etc.” (parent/carer of child aged 12 to 15)*
- *“Waiting around in the ward is too long. Wait ages for simple finger prick blood tests” (parent/carer of child aged 12 to 15)*
- *“The treatment takes approx. 30 mins to administer but we are regularly waiting at (name) at least 6-7 hours. On one occasion we were waiting 2 1/2 hours for his lumbar puncture in the waiting area” (parent/carer of child aged 0 to 7)*
- *“Only negative was the moving around of beds/wards when we stayed at (name) & the delays in waiting to move ward/bed” (parent/carer of child aged 0 to 7)*
- *“Being kept waiting for no reason is very frustrating, not being kept updated on why a delay” (child aged 12 to 15)*

Receiving medication

Parents/carers also described delays in receiving medication and commonly attributed this to issues at the hospital pharmacy. The impact typically was on discharge being delayed consequently.

- *"To get any prescribed meds we waited for 5 hours even though I told the pharmacy what I needed at the beginning of the week and told them when we were leaving" (parent/carer of child aged 0 to 7)*
- *"Although we are very satisfied with the care provided but we have had to wait excruciating amounts of time in the hospital if she needed to get medicine from the pharmacy. This was really difficult for us" (parent/carer of child aged 8 to 11)*
- *"Pharmacy times is ridiculous also. Lots of time lost waiting for medication to take home" (parent/carer of child aged 0 to 7)*
- *"Discharge from Ward (name) was often slow due to pharmacy delays for dispensing medications" (parent/carer of child aged 0 to 7)*
- *"There are often delays for prescriptions from the pharmacy after treatment. We often have to wait over an hour after our chemo has finished to pick up drugs, and sometimes they come in the wrong form (syrup instead of the tablets we require). It is very frustrating to have to experience these delays when you've often been at the hospital for 4 hours already" (parent/carer of child aged 8 to 11)*
- *"Pharmacy prescriptions rarely on time delaying treatment and discharge" (parent/carer of child aged 0 to 7)*
- *"Need to ensure the chemotherapy drugs are available when the child is staying at the hospital. We waited 8 hours (arrived at midday) and were then told that the chemotherapy drugs had not been made up by the Pharmacists. This delayed treatment by a day (as were told that chemo drugs could not be given to child overnight). This happened to numerous children. On my child's 2nd phase I was asking nurses every half hour if chemo drugs were available. After 5pm I was asking every 10 minutes as I knew if chemo drugs were not ready by 6pm then they could not be "started on them. This was extremely stressful" (parent/carer of child aged 8 to 11)*

Test results

A further way in which the negative impact of delays was articulated was in the stress and worry caused by waiting for test results. Parents/carers emphasised the need to receive results as soon as possible.

- *"I do wish results could be given ASAP after scans - if its good news - a phone call to say that even without any detail would be amazing - detail & Dr's can wait to be spoken to - a simple*

'Clear Scan' phone call is so hard to wait for but so easy for anyone to do!" (parent/carer of child aged 8 to 11)

- *"I have one request to the team of NHS to kindly provide the MRI follow up results soon as being in waiting list of such illnesses like cancer is the worst" (parent/carer of child aged 12 to 15)*
- *"MRI results: the worse time in the world is waiting for these results, which can take between 1-2 weeks if not longer. We would love a quicker system!" (parent/carer of child aged 0 to 7)*
- *"My only other feedback is around the results turnaround time. 3 weeks of limbo not knowing if your child's cancer is nothing short of torture. Anything at all that can be done to improve this would greatly improve parents' mental well-being" (parent/carer of child aged 0 to 7)*
- *"We expected serology results back within a few weeks - these have not naturalised 5 months later. An eye test due 2 months after care thou 7 months after and we are still waiting for a both follow up appointment. Hoping no news is good news" (parent/carer of child aged 8 to 11)*

Communication issues

Communication between hospitals

What does the quantitative survey data tell us?

- 54% parents/carers and children reported that different hospitals providing cancer or tumour care always worked well together (Q X60)

Some parents/carers felt that communication between hospitals was lacking and they were left to share information themselves. There was also an expressed need for more joined up, holistic care.

- *“The coordination between the various care teams is also very poor, and parents are usually expected to communicate the decisions to each hospital themselves” (parent/carer of child aged 8 to 11)*
- *“I feel the communication between the hospitals could be improved. On a few occasions I have had to chase up appointments that haven't been made” (parent/carer of child aged 0 to 7)*
- *“Additionally there seems to be a lack of communication between hospitals. Our son recently had to have a procedure carried out at a (name) hospital under another trust. It was understandable that they didn't have his medical history for our initial appointment but they were still lacking background and scans weeks later and it felt like a lot of responsibility for us to communicate over 2.5 years of complex medical history” (parent/carer of child aged 0 to 7)*
- *“Sometimes communication between shared hospitals broke down, due to having different IT systems, and this caused delays in treatment and wasted journeys, as appointments couldn't take place” (parent/carer of child aged 12 to 15)*
- *“On occasion I have felt (name) (our local hospital for chemo) have not been joined up - specifically in relation to covid testing prior to admission at (name). I have had to act like a go between which is stressful and exhausting!” (parent/carer of child aged 0 to 7)*
- *“There were problems with the interaction between our local and main hospital. Whilst the care at (name) was often really good, the care at (name) was appalling and there was a lack of communication between the two centres” (parent/carer of child aged 12 to 15)*

- *“The coordination between the various care teams is also very poor, and parents are usually expected to communicate the decisions to each hospital themselves” (parent/carer of child aged 8 to 11)*

- *“Communication between hospitals is slow and sometimes non-existent. If this was made better then I feel it would benefit everyone” (child aged 12 to 15)*

Communication within hospitals

What does the quantitative survey data tell us?

- 66% of parents/carers felt that different hospital staff always work well together (Q X28)
- 57% of parents/carers feel that different hospital staff are definitely aware of their child's medical history (Q X29)

Some parents/carers also commented on poor communication between teams and staff members within the hospital. Several described having to update different teams within the hospital, sometimes leading to delays in receiving treatment or medication.

- *"The communication between hospitals and even with staff within hospitals leaves a lot to be desired" (parent/carer of child aged 12 to 15)*
- *"Staff don't communicate well, so we are forever telling them updates, chasing bloods and times" (parent/carer of child aged 0 to 7)*
- *"Sometimes there felt to be communication issues between the ward and other parts of the hospital, especially the link to theatre" (parent/carer of child aged 0 to 7)*
- *"Communication regarding patients notes, due to some medical notes are not up to date, having to repeat information regularly and updating nurses / team members" (parent/carer of child aged 0 to 7)*
- *"However, there appears to be a lack of coordination between oncology and other departments e.g. Surgeon, MRI, US, etc., leading to inefficient visits to the hospital (lots of waiting, potentially unnecessary return visits, etc)" (parent/carer of child aged 12 to 15)*
- *"Disjointed communication between departments (radiotherapy vs clinical oncology Vs day wards Vs surgical wards)" (parent/carer of child aged 0 to 7)*

There were comments from some parents/carers that poor communication had led to a lack of knowledge and understanding of previous treatment or circumstances surrounding care. A small number of parents/carers articulated that this caused avoidable distress.

- *"Lack of understanding of child's complex needs causes unnecessary distress largely due to inconsistent communication & follow up appointment" (parent/carer of child aged 8 to 11)*
- *"The only slight issue I would have is with how much our local hospital knows about our child, it's frustrating how often we go in to our local hospital and how little they know about our son's complex needs and we then have to explain and relive every traumatic event again as we explain to them" (parent/carer of child aged 0 to 7)*

An additional aspect of poor communication within hospitals related to how patients were introduced to wards. Some parents/carers thought it would have been useful to have been given information regarding the hospital on their first visit. This would support them to know where to find and access things including food and drinks, and how processes within the hospital work.

- *"Nobody offered to make me one or told me where to do it in at first visit of 6 days stays. The domestic showed me in day 3 and how to order my daughter's food" (Parent/carer of child aged 12 to 15)*
- *"Didn't even get told where to get drink for my child or where toilets are etc" (Parent/carer of child aged 12 to 15)*
- *"There should be an introductory pack about the hospital that they should give to all parents, as nurses or Dr failed to tell us about the fact that we could claim congestion charge from (name). By the time we found out, & got receipts from TFL, it was too late to claim from (name). They also failed to tell us about transport that is offered by the hospital for drop off & pick up. Just general things like there is a canteen I did not know, until months later" (parent/carer of child aged 0 to 7)*
- *"It is a very scary place on your first visit and I had to attend alone with my son due to covid. It would have been nice on the first visit to be greeted by a nurse to explain the unit, process and provide some support. Instead we were just told to take a seat by the ward clerk and had a long wait until the consultant was ready to see us" (parent/carer of child aged 0 to 7)*

Communication about treatment

What does the quantitative survey data tell us?

- 86% of parents/carers reported that they definitely had the chance to ask questions about their child's care and treatment (Q X13)
- 66% of parents/carers and children reported always knowing what was happening with their child's/their care (Q X30)
- 73% of parents/carers and children reported that information at diagnosis was definitely given in a way they could understand (Q X08)

Several issues were identified relating to experiences of communication within the context of treatment. Regarding the overall treatment plan some parents/carers felt that information sharing was too focused on segments of treatment pathways.

- *"His care falls short when it comes to understanding his overall treatment plan" (parent/carer of child aged 0 to 7)*

- *"It would have been helpful to have more information about the whole journey instead of 'snip its'" (parent/carer of child aged 0 to 7)*
- *"Improved information for parents on longevity of treatment at point of diagnosis, so parents can better plan their lives, including care of other siblings" (parent/carer of child aged 12 to 15)*

A further theme identified in the qualitative comments regarding treatment was a lack of communication if there were any delays.

- *"There have been occasions where my son has been waiting for hours for his treatment and there has been little or no communication" (parent/carer of child aged 12 to 15)*
- *"I appreciate that we might have to wait sometimes, I have no issue with this but I think it would be preferable if staff related this rather than just leaving it until the point at which you ask. I would sooner that people let you know what was happening" (parent/carer of child aged 12 to 15)*
- *"Being kept waiting for no reason is very frustrating, not being kept updated on why a delay" (child aged 12 to 15)*

Additionally, some parents/carers felt that communication surrounding treatment was lacking. In particular parents/carers said that decisions made about their children's care were not explained and therefore remained unclear, and that different treatment options were not discussed.

- *"Some decisions have been unclear and unexplained and the endo doctors do contradict each other with their after care plans" (parent/carer of child aged 0 to 7)*
- *"With my son's diagnosis we weren't really given any treatment options, it was 'this is, what is going to happen', no choice, nor alternate options" (parent/carer of child aged 0 to 7)*
- *"When we were told about cancer, it was made out not serious about things moved so quickly that other options were not discussed" (parent/carer of child aged 0 to 7)*
- *"Some decisions have been unclear and unexplained" (parent/carer of child aged 0 to 7)*

Communication surrounding appointments

What does the quantitative survey data tell us?

- 42% of parents/carers reported that their child's care and treatment is definitely offered at a time suitable for them and their family (Q X35)

Parents/carers also identified the communication surrounding appointments as an area requiring improvement. Examples of the issues which caused frustration included a lack of advanced notice for an appointment; communication of conflicting appointment times; and parents having to chase for appointments.

- *“Many letters are sent out with conflicting times/dates on which is frustrating at times” (parent/carer of child aged 12 to 15)*
- *“I have had appointments made for procedures without me having been told about them until the booking call-this shouldn't happen” (parent/carer of child aged 12 to 15)*
- *“Last minute communication when we wait to see if we are going in for our appointment to have chemo. This is always a last-minute rush for my child's father to get the time off work, as its always after 12pm and he could need to be in for his appointment in an hour or two after we've been told he does need to come in” (parent/carer of child aged 0 to 7)*
- *“Our daughter is in remission it becomes very frustrating that we have to constantly chase to find out when her next scans are. We understand there is a back log of ultrasound scans due to Covid, but you have enough anxiety as a parent with a child in remission, it does not need to be increased by issues in obtaining appointments for scans” (parent/carer of child aged 0 to 7)*
- *“Admin support seems to be lacking resulting in communication break down and confusion over appointments. A robust admin system would greatly improve communication between hospitals and would enable appropriate written communication to be possible for the parents. We have often felt confused as to who knows what about the appointments we’ve had as letters have not often been received following appointments” (parent/carer of child aged 0 to 7)*
- *“Very short notice for changing treatment appointments have been difficult in relation to childcare for other children and work” (parent/carer of child aged 8 to 11)*

Issues with food

A significant unmet need, issues with hospital food was a focus for many parents/carers and children too, with several areas of improvement identified as follows:

Quality | **Choice** | **Cancer needs unmet** | **Parents/carers needs unmet** | **Financial impact**

Quality

Some parents/carers and children felt that the food provided during their hospital stay could be improved in quality both in terms of taste and how it was prepared.

- *"The food was disgusting I wouldn't feed it to a dog never mind children with cancer it never improved even though everyone on the ward complained we were told at diagnosis that the biggest risk to my daughter's life was infections and poor nutrition and we were not protected from either whilst being in hospital" (parent/carer of child aged 0 to 7)*
- *"The food provided at (name) was not great generally overcooked" (parent/carer of child aged 0 to 7)*
- *"The food while we were on (name) was a disgrace I had many challenges due to the food not being edible (raw, undercooked)" (parent/carer of child aged 0 to 7)*
- *"I think the hospital food could be a lot better" (child aged 12 to 15)*
- *"Food is too awful to eat" (child aged 12 to 15)*

Both children and parents/carers discussed the need to improve the nutritional quality of the food provided also.

- *"Better hospital food as nutrition was lacking for a child with cancer" (parent/carer of child aged 0 to 7)*
- *"My child loves salad and veg. There wasn't much choice of this with certain foods" (parent/carer of child aged 12 to 15)*
- *"More fruit & veg and lower sugars options (e.g. yoghurts with natural sugars not e numbers)" (parent/carer of child aged 0 to 7)*
- *"Needs more fruit/veg on it" (child aged 8 to 11)*
- *"The food at (name) is so beige and unhealthy. It is hard to get the children back onto a healthy diet once they get used to everything with chips. My son also liked strong flavours when on treatment and most of the food is tasteless" (parent/carer of child aged 8 to 11)*

Choice

What does the quantitative survey data tell us?

- When asked if there was a choice of hospital food, 52% of parents/carers and children said there definitely was a choice (Q X47)

It was also felt that there should be more choices of food available, with the menu found to be repetitive by both parents/carers and children.

- *"The menu was very repetitive and same foods were offered everyday" (parent/carer of child aged 0 to 7)*
- *"Please add more food options, simple things like eggs or pancakes" (parent/carer of child aged 12 to 15)*
- *"I think there should be a better choice of food on a hospital stay" (child aged 8 to 11)*
- *"The food could be better. It was the same choices everyday" (child aged 12 to 15)*

Cancer needs unmet

Importantly, the need for variety in the food provided was felt to be of particular importance to cancer patients. It was understood that the nature of treatment could impact a patient's ability to eat some foods and their ability to eat at the set mealtimes on a ward.

- *"The only thing my child struggled with through treatment was the variety of different foods given on menus. As my daughter received chemotherapy this left her with very little appetite, and the little choices of food never really suited our situation at the time. I feel like more variety should be given to suit oncology patients more, i.e., more options to choose from" (parent/carer of child aged 0 to 7)*
- *"The hospitals don't provide dinners that are sensory-friendly or appropriate for children who are fussy eaters. Our child has been a fussy eater since starting cancer treatment as it affects her appetite and tastebuds. A family member has to bring our child food from our home when our child is inpatient" (parent/carer of child aged 0 to 7)*
- *"Due to steroids, child craved proteins, unable to order specific foods off the menu as taste buds v. sensitive" (parent/carer of child aged 0 to 7)*
- *"More choice of food for me to eat when I wanted to eat it and not at 4.30" (child aged 8 to 11)*

Parents/carers needs unmet

It was suggested that food should be provided for parents/carers as well as children, as it is often difficult for parents/carers to leave their child. This was particularly pressing when children were young.

- *"It was hard to leave my child to make food for myself. It would be better if parents were offered a meal as well as the child" (parent/carer of child aged 0 to 7)*
- *"Parents / carers should be supplied with free meals when children are admitted to the ward for overnight stays" (parent/carer of child aged 8 to 11)*
- *"To help the parent get sandwiches to eat during the stay, otherwise the parent stays hungry. As a single parent I became malnourished after all of the lengthy hospital stays as I struggled to get food as I don't have much family to help either" (parent/carer of child aged 0 to 7)*
- *"It was difficult to have to leave my child to go and get food" (parent/carer of child aged 12 to 15)*
- *"I also think food should be provided for a parent who must stay with their child full time. At the time my daughter was 2, and found it hard to walk to parent kitchen with her especially as she often felt unwell and was connected to a machine. It's a lot to carry back to the room and eat while carrying a child who struggled to wait and push the carry stuff for me and would not leave her as she was too scared. So to supply a stay in parent food would benefit as I often went hungry" (parent/carer of child aged 0 to 7)*
- *"It would be good if my mum could have some food too as she doesn't always want a microwave dinner" (child aged 8 to 11)*

Some parents/carers said they would be willing to pay for their own food from the hospital if it could be provided to them on the ward alongside the food given to their children.

- *"There are no options to get food alongside your child even if it meant providing a payment or payment contribution. If your child is sick, you don't want to have to leave them to go to the canteen for example" (parent/carer of child aged 12 to 15)*
- *"Even if payment is required, I would pay for food on the ward so that I can look after myself as well as my child" (parent/carer of child aged 0 to 7)*
- *"My daughter was admitted for chemotherapy at less than two weeks old. There is no access to food unless you are prepared to leave your poorly baby alone, which you should not be expected to do. The solution I was given was to ask nurses to prepare food for me but they are too busy and keep forgetting. Their workload is too high for this. Why not give breastfeeding mothers the option to pay for hospital meals?" (parent/carer of child aged 0 to 7)*

- **36%** of parents/carers were definitely able to prepare food in the hospital if they wanted to

What does the quantitative survey data tell us?

- 36% of parents/carers were definitely able to prepare food in the hospital if they wanted to (Q X53)

On the topic of catering for parents/carers, it was also suggested that provisions should be improved for parents/carers to be able to store and heat up their own food.

- *“When I went in the kitchen fridge not working hot water was not working and this is very stressful time for me we can't afford food from outside” (parent/carer of child aged 0 to 7)*
- *“Facilities to make food are extremely limited” (parent/carer of child aged 12 to 15)*
- *“Something which would have made our main stay easier would be better kitchen facilities for parents” (parent/carer of child aged 0 to 7)*
- *“When you have to live somewhere for days, weeks or months at a time, the ward environment isn't really suitable. For example at home my child would follow me to the kitchen or help make something - in hospital he doesn't really like to be left alone, but the kitchen is a long way away and children aren't allowed in” (parent/carer of child aged 0 to 7)*

Financial impact

It was identified that the lack of provisions for parents, alongside poor quality of food and lack of choice offered for children, had financial implications. Parents/carers reported purchasing takeaways or using local shops frequently to access food for themselves and their children which was described as ‘expensive’.

- *“When we're inpatient us parents aren't allowed to have breakfast, lunch or dinner, only the children are fed. I think this is disgusting. As a family who are on a low income we cannot afford to buy breakfast, lunch and dinner when in hospital so whoever is inpatient with my child (either myself or her father) do not eat for that duration, which is sometimes weeks on end” (parent/carer of child aged 0 to 7)*
- *“We were given a lunch box to put our shopping in in the communal fridge which was no where near big enough to hold more than a days food which meant we had to pop out for 15 minutes (we couldn't leave our 2 year old for longer than that to go to a cheaper supermarket) to the m&s to stock up each day costing us over £4000 during the 6 month stay” (parent/carer of child aged 0 to 7)*

- *"While on the ward most of the parents ended up having to visit McDonalds and other takeaway outlets so at least the kids would eat. The cost of this is still affecting us now as a family as with not working and travel costs food costs ended up going on credit cards, a food cost for us for a normal day was around £20 and the length of time we were in to start 6-7 weeks, then visits 3/4 days during temps then BMT for over 13 weeks the costs soon mount up we ended up with debts of around £3500 due to this . I know you can't put a price on given your children what they want at a time when they need it most but having no other choice as the hospital food was so bad. The company should have to compensate parents"*
  (parent/carer of child aged 0 to 7)

Unmet needs

In addition to ‘Issues with food’, a range of unmet needs for children and parents/carers were found and are detailed within this section.

Activities and entertainment

What does the quantitative survey data tell us?

- 43% of parents/carers and children felt there were definitely enough things for the child to do in the hospital (Q X46)

For younger children (0 to 7 years) there was a particular need for greater support whilst in hospital to ensure they were occupied and entertained. For example, offering toys or outside play areas. Note that these comments were distinct from the asks for improved access to play therapy outlined earlier in the report.

- *“There were no areas for the children to get any fresh air or play” (parent/carer of child aged 0 to 7)*
- *“My child did not get offered any toys” (parent/carer of child aged 0 to 7)*
- *“More things/activities for long days/overnight admissions” (parent/carer of child aged 0 to 7)*
- *“The social aspect needs lots of work and the children need lots more engagement” (parent/carer of child aged 0 to 7)*
- *“Staff expect even young children to behave and stick to the rules - my son gets very bored and likes to explore - constantly telling him he can't do things is exhausting and make us both stressed” (parent/carer of child aged 0 to 7)*

For children aged 12 to 15 years, there was a sense that activities for their age range were limited and that age appropriate activities were inadequately provided.

- *“There needs to be greater support for teens. There has been no consistent TYA (Teenage and Young Adult) support” (child aged 12 to 15)*
- *“More things for people 9 to 13 to do” (child aged 12 to 15)*
- *“Could do with an area for older children when in day unit” (child aged 12 to 15)*
- *“I wish the Den was bigger - the playroom is too young for me” (child aged 8 to 11)*
- *“There was nothing for any children aged 10 and up to do, parents had to provide entertainment” (child aged 12 to 15)*

What does the quantitative survey data tell us?

- 34% of parents/carers felt that hospital Wi-Fi always met the needs of them and their children (Q X54)

The need to have a good Wi-Fi connection was highlighted by children as well as parent/carers. Poor Wi-Fi contributed to several issues including isolation from friends and family; boredom; and impact on schoolwork.

- *“The Wi-Fi could be improved, we were lucky that we had our own to bring with us” (parent/carer of child aged 0 to 7)*
- *“Internet & TV's didn't work, very hard when stuck in a room for 6 months” (parent/carer of child aged 0 to 7)*
- *“The Wi-Fi was also poor / patchy and could do with an overhaul. It was difficult for us to stay in touch with family or friends and the outside world” (parent/carer of child aged 8 to 11)*
- *“Better Wi-Fi would allow parents to work during long chemotherapy days” (parent/carer of child aged 0 to 7)*
- *“The Internet is also very bad and I couldn't use many things that I needed. Even when there was Internet, it wasn't strong enough” (parent/carer of child aged 12 to 15)*
- *“The Wi-Fi was not good so I could not face time very well” (child aged 8 to 11)*
- *“Wi-Fi was terrible which meant it was hard to do online school and stopped me playing games online with my friends which would have helped me to stay in touch with them when I was in hospital for a long time” (child aged 12 to 15)*
- *“It is a shame that they have so much great electronic equipment for kids to use in the Pad but none of it works because the internet isn't good enough” (child aged 8 to 11)*

A good night’s sleep

What does the quantitative survey data tell us?

- When asked about the facilities for them to stay overnight, 32% of parents/carers reported they were very good (Q X51)
- 28% of parents/carers and children reported that it was always quiet enough for them to sleep in the hospital (Q X52)

- *“Improve facilities for parents staying overnight” (parent/carer of child aged 0 to 7)*

- *“They had no bed for me & could not find me a pillow which they looked at me as if that was not a problem” (parent/carer of child aged 8 to 11)*
- *“Red chairs for beds hurt your back and so uncomfortable especially when in for a period of months” (parent/carer of child aged 0 to 7)*
- *“I felt uncomfortable sleeping in front of any nurse who can walk in through the night. Therefore, I really appreciated when the bed had a curtain, but unfortunately only a few rooms have a curtain” (parent/carer of child aged 0 to 7)*
- *“Cramped conditions prevented parent or child sleeping in 2, 3 & 4 bedded bays” (parent/carer of child aged 8 to 11)*
- *“The parent beds were extremely uncomfortable, and I still experience back problems now” (parent/carer of child aged 12 to 15)*
- *“Comfortable chair could have been provided for parents or carer who have been staying with patient and a comfortable bed for long stays in hospital” (parent/carer of child aged 0 to 7)*
- *“One area that I felt could be improved was the over-night put-me-up beds for adults, that were very uncomfortable & kept moving” (parent/carer of child aged 12 to 15)*

One parent had a particularly poor experience in terms of being supported as a new mother. While very specific as an example, this demonstrates powerfully the importance of comfort for parents/carers and the multiple ways this can impact both them and their child.

- *“What must be improved in (name) is the care of new mothers. I first attended ward (name) as a day case when my daughter was less than a week old. Therefore, I had given birth mere days before. I wasn't given any thought, no care, not even a comfortable chair. I had a plastic chair with no armrests to breastfeed and hold my baby in for 8 hours. I resorted to resting my bag on the windowsill and leaning on there. Unfortunately it's the same story on (name)…. Mothers who have just given birth and are breastfeeding cannot adequately rest/care for their baby throughout the night on the narrow camp beds provided. I had to beg for a hospital bed to be able to sit up and feed. The same goes for a chair. A little comfort goes a long way when caring for an unsettled, poorly newborn baby. You need to care for the mother” (parent/carer of child aged 0 to 7)*

Noise on the ward was described as disruptive and for some distressing. Noise at night was the most common issue presented as impacting children’s quality of sleep. To achieve a good night’s sleep, it was recommended that rules regarding noise should be enforced by staff.

- *“The open ward is noisy and very stress-inducing and upsetting for my child. There are several patients in distress, and this is emotionally very upsetting for my child, and he has disliked his time at (name) every time” (parent/carer of child aged 8 to 11)*
- *“This was a very noisy environment most of the time. Apart from beeping machines which were essential most families were not sensitive to the noise levels, e.g. from tablets or phone.*

Introducing a policy reminder to all for making noise levels down would be good" (parent/carer of child aged 0 to 7)

- *"The weird environment on a night is very noisy and disrespectful" (parent/carer of child aged 12 to 15)*
- *"Disturbed sleep by other patients, their parents and machines inc buzzers was ridiculous. Most nights were HORRENDOUS. Inconsideration by others was horrific. I believe people can cope with most situations better with a good nights sleep and healing takes place when you sleep" (parent/carer of child aged 12 to 15)*
- *"The only negatives have been that the ward has often been very noisy until quite late at night - often with other patients or their parents watching TV and / or making loud calls until late into the evening or night - 10pm or 11pm sometimes" (parent/carer of child aged 8 to 11)*

While most comments concerning noise related to other patients, three comments detailed noise being caused by staff which is important to highlight.

- *"Night staff use very bright torches and are not very quiet" (child aged 12 to 15)*
- *"Medical door at night bangs all night. Nurses are so loud in the mornings. Nurses are loud at night and do not turn lights off" (parent/carer of child aged 0 to 7)*
- *"Some nurses at night when in a few years ago are so noisy" (child aged 8 to 11)*

Needs varying by age

Some parents/carers of older children suggested similar ages should be grouped together recognising their needs were different from those younger. Additionally, some older children expressed a desire to be placed on teenage wards; and there was also a need highlighted by some for privacy of older children to be considered too.

- *"Wonder whether older children could be separated slightly from younger ones, like teenagers on a separate bay" (parent/carer of child aged 8 to 11)*
- *"We are 9/10 admitted onto a red bay and a lot of the time with very young children. If possible age groupings should be together" (parent/carer of child aged 8 to 11)*
- *"The only thing which [child name] does not like is being put on a bay with babies. At 9 year old she does not like when she can't sleep for babies crying" (parent/carer of child aged 8 to 11)*
- *"I was a teenager on a ward full of young and noisy infants, with no privacy. There were beds available on the Teenager ward, but because I wasn't yet 16 I was refused to move there, and subsequently my stay was pretty awful" (child aged 12 to 15)*
- *"There needs to be improvements in level of privacy on wards/at bedtime" (child aged 12 to 15)*

- *“It is preferable that when we are in-patients to have single rooms. This can provide a lot of privacy for the child and parent” (parent/carer of child aged 12 to 15)*

Aftercare

What does the quantitative survey data tell us?

- 57% of parents/carers felt that they definitely received enough ongoing support from the hospital after their child’s treatment finished (Q X42)

It was particularly important for both parent/carers and children to receive ongoing support after treatment had ended. Many felt that aftercare was absent or inadequate. They discussed feeling alone at the end of treatment; finding it daunting to return to ‘normal’ without any support following the traumatic experience of dealing with cancer.

- *“As we have just finished feeling a bit alone & anxious” (parent/carer of child aged 0 to 7)*
- *“We do miss the support that we had during her treatment and would benefit from some more ongoing support as we learn to navigate a new normal” (parent/carer of child aged 0 to 7)*
- *“After care for parents is not great when parents finally are able to come to terms with everything its almost like they are forgotten as treatment is over” (parent/carer of child aged 0 to 7)*
- *“Lack of support / information given when 6 months of system chemo has finished” (parent/carer of child aged 0 to 7)*
- *“After active treatment has finished there needs to be better support for the whole family. A transition period should be implemented where reduced support is in place - this needs to be made clear to parents - what to expect, who to contact, who will help if there are concerns. What to do” (parent/carer of child aged 0 to 7)*
- *“The transition to after treatment is scary and daunting with many psychological/emotional effects to work through. After treatment surveillance & monitoring - teams need to work together better to ensure better communication” (parent/carer of child aged 0 to 7)*
- *“This would highlight the need for 'after care' improvement to those families that are having to navigate themselves back into society post trauma. From first-hand experience, this is very hard as the support you receive in hospital is quickly dropped following remission or even child loss” (parent/carer of child aged 8 to 11)*
- *“Counselling regarding life when treatment has finished should be offered to all children and parents. I could have asked for this, but it would be better if offered by staff. Please don’t underestimate how scary it is for the child and the whole family without the safety net of the professionals which have taken such good care of us. I feel guilty as my child is one of the*

lucky ones. It honestly feels like we have post-traumatic stress" (parent/carer of child aged 12 to 15)

- *"The only thing we found hard or could have had more support with would be the psychological support as a family post treatment + beyond. Nothing prepared us for how hard / lonely it is afterwards" (parent/carer of child aged 12 to 15)*
- *"After treatment counselling for the patient and also siblings & parents has never been an option. It would be nice to know where to find support if we needed it" (parent/carer of child aged 0 to 7)*

Mental health support

As many comments above demonstrate there was an unmet need for mental health support as part of aftercare. In addition, many parents/carers reported a lack of mental health support during their child's treatment and would have welcomed this.

- *"The mental health support for patients and parents could be improved. Sometimes signposting isn't enough support" (parent/carer of child aged 8 to 11)*
- *"The diagnosis process was quite difficult to be honest. We would have valued psychological support/check in during this time" (parent/carer of child aged 0 to 7)*
- *"I would have appreciated more support or counselling at difficult times, especially during PICU, and counselling on social care from the family at home" (parent/carer of child aged 0 to 7)*
- *"The lack of mental health care both at diagnosis and on an ongoing basis has been a real negative and at times has undermined the effect of the physical / medical care" (parent/carer of child aged 8 to 11)*

Financial support

What does the quantitative survey data tell us?

- 69% of parents/carers felt they had enough information about financial help or benefits (Q X27)

A handful of parents/carers discussed the financial impact upon families when a child undergoes cancer treatment. They discussed the need for financial advice and support.

- *"Financial help should be given to families and the patients for cancer, heart, kidney hepatitis etc" (parent/carer of child aged 8 to 11)*

- *"A cancer diagnosis has a serious financial impact on families. My husband had to retrain in a new area within his field so that he could work from home, taking a significant pay cut. We've had to rely on the generosity of actual strangers via crowd funding service to survive. The financial impact on family's needs to be addressed and helped in a real way where families are offered financial support. We now have no savings and are living pay cheque to pay cheque, and our dream of owning a home is gone" (parent/carer of child aged 0 to 7)*

Contributing to financial pressures experienced by parents/carers, parking was described as 'too expensive'. Parking costs were found to cause additional stress at an already difficult time. This issue was more commonly expressed for parents/carers of those aged 0 to 7.

- *"Parking is a nightmare and very expensive!!" (parent/carer of child aged 0 to 7)*
- *"Parking was a bit awful though, and the cost of the parking over the road from the hospital at both car parks even with the discount was so high" (parent/carer of child aged 0 to 7)*
- *"Somehow lower the cost of car-parking" (parent/carer of child aged 0 to 7)*

Earlier in the report the financial impact of purchasing food during hospital stays was also highlighted and provides a further example to demonstrate the need for financial support for families.

Wider hospital issues

Several suggestions for other improvements were made in relation to wider hospital facilities and policies. These are detailed below.

Hygiene and cleanliness

Some parents/carers felt that wards were not clean enough in general and that members of cleaning staff were not working to a high enough standard. Hygiene was felt to be particularly important due to the impaired immunity of many cancer patients.

- *"The past couple of times (name) has been admitted into hospital with a temperature we have had to spend one or more nights in (name). My wife and I both think that the (name) ward is dirty and not kept to the same standard as (name). In the parent toilets the bins were overflowing for more than 24 hours" (parent/carer of child aged 0 to 7)*
- *"The cleanliness of the hospital was terrible. Immune suppressed children should not be cared for in a dirty environment we complained many, many times to the ward manager and nothing was done, the cleaners were extremely poor never cleaning under beds, windows, soap dispensers, chairs, bed legs etc and my child caught many infections while in hospital I did my very best to clean myself bringing my own cleaning supplies in. we had one bathroom to share with 8 other families and it was filthy. the ward had norovirus over 10 times during our stay and we were moved rooms several times each time we moved I would have to deep clean the room myself due to it being filthy I have pictures to back this up" (parent/carer of child aged 0 to 7)*
- *"The oncology ward could certainly be cleaner. (Name) cleaners simply pour a cup of water on the floor and push a mop around in it - which doesn't disinfect anything or pick up dust & hair. (I have witnessed this numerous times)" (parent/carer of child aged 0 to 7)*

Ward updates

A number of parents/carers felt that the ward they were staying on was outdated. Examples spanned several different hospitals.

- *"The wards and facilities at (name) are now 50 years old and in desperate need of updating" (parent/carer of child aged 0 to 7)*
- *"We have so much that needs improving at (name). It's meant to be the best children's hospital but our wards are so run down" (parent/carer of child aged 0 to 7)*
- *"The ward needs updating though as it's getting dated esp. the bathrooms" (parent/carer of child aged 8 to 11)*

Impact of COVID-19

COVID-19 restrictions in England had begun to ease during the sampling period for this survey. There were only a few comments made in relation to COVID-19 which were most commonly about the number of visitors allowed.

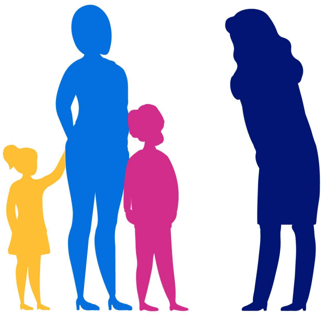
Parents/carers reported difficulty in attending appointments alone and children felt unhappy that only one parent/carer was allowed to visit at a time. These comments were more prevalent amongst parents/carers of children aged 0 to 7.

- *“Only problem we had/have is only 1 parent being allowed in at a time. We live 2 1/2 hours away and would never travel alone with our son but once at hospital one of us is expected to leave” (parent/carer of child aged 0 to 7)*
- *“Due to covid rules it was very difficult being away from husband. I did think households should or been allowed in together” (parent/carer of child aged 0 to 7)*
- *“Parents and siblings need to be able to go in and spend time with the child being treated” (parent/carer of child aged 0 to 7)*
- *“I was only allowed one parent with me at a time and sometimes I wanted both of them together” (child aged 8 to 11)*
- *“I wasn’t able to have visitors in hospital and that was really hard. I couldn’t see my sister or my dog” (child aged 12 to 15)*

There were also a small number of comments about facilities, for example play areas or kitchens, being closed due to COVID-19.

- *“It would be good if covid restrictions could be removed soon. Play areas at the hospital are still closed and visiting is still restricted. This makes visits more difficult than they need to be” (parent/carer of child aged 0 to 7)*
- *“Due to covid, there were restrictions in place, which made preparing food as a parent difficult at times” (parent/carer of child aged 8 to 11)*
- *“Due to covid, social space for teens is shut. We had 3 separate stays each lasting 3 1/2-4 weeks, with no socialising for my son. This was very isolating” (parent/carer of child aged 12 to 15)*

Conclusions



The insight from this analysis has generated a range of ideas for improvement to experiences of cancer care in England for children as well as for their parents/carers. The findings should be considered in context of activity already underway and are most appropriately positioned as conversation starters to further explore what matters most and would make the greatest difference to children and their parents/carers.

The Cancer Experience of Care Improvement Collaborative brings together groups of cancer healthcare professionals and people with lived experience from different organisations to improve services. The aim of the Improvement Collaborative is for each project team to use insight and feedback (Principle Treatment Centre Under 16 Cancer Patient Experience Survey results) to improve the experience of care for cancer patients and their friends and family who may provide unpaid care and support. Project teams can make improvements based on what matters to people who use cancer services that align with local, regional, and national priorities.

The 2022-23 Cancer Experience of Care Improvement Collaborative is focused on improving experience of cancer care for children under 16 and their parents and/or carers. Eleven teams across England are leading improvement projects under one of the following four themes; communication and information, emotional support, play, and home comforts and facilities.

A summary of key findings from the qualitative data thematically analysed for this report have been summarised and shared below to further inform improvement activity.

Positive experiences

Expressions of gratitude for care received was commonly found with attributes of staff valued by children as well as parents/carers to include empathy and kindness. Nurses and play specialists received praise and were described as ‘wonderful’ and ‘invaluable.’ Positive examples were also shared of communications which had worked especially well including one doctor’s use of Lego to engage with a child.

Negative experiences attributed to staff

While comments describing staff as unfriendly or lacking in empathy were not as common as those giving praise, quotes revealed the significant impact these instances can have on experiences of care. Feeling unheard was a further finding at root of negative experiences with staff members; examples spanned primary care and diagnosis, through to treatment in hospital. A need for staff training to better support children with additional needs was a further finding within this broader theme.

Access issues

The perception of understaffing in hospitals was a key insight within this theme and a common example used to demonstrate this was unanswered call bells/buzzers on wards. There was mention of difficulties also in accessing Cancer Nurse Specialists; named consultants; and play specialists. Access to care 24/7 was a further insight and mentions of unmet need over holiday periods, weekends and bank-holidays highlighted. Having to access care via A&E was a point of frustration raised by parents/carers also, as a final finding within the theme on access issues.

Experience of delays

A range of examples were shared where delays were experienced across the journey of cancer care. Delayed diagnosis was highlighted with difficulty described in getting a GP appointment a concern alongside feelings of being unheard as noted earlier. In the context of secondary care delays spanned procedures (e.g. blood tests) through to receiving test results, as well as delays around chemotherapy appointments and waits for medication impacting on discharge.

Communication issues

Issues with communication between and within hospitals and care teams were evidenced in feedback. Communication of appointment letters and notices were also cited as examples of where communication failed to meet expectations. In the context of treatment, improvement was found to be needed in communication of delays; in discussing treatment holistically as opposed to in ‘segments’; and in ensuring explanations of decision-making were always given and were always clear.

Issues with food

There were a number of issues identified with food spanning quality; choice; the needs of cancer patients being unmet (both in terms of availability and nutrition); parents/carers needs being unmet (both in terms of access to food and facilities to make and store food); and the financial impact of sourcing food within this context of poor quality, choice and no provision for parents/carers.

Unmet needs

The most prominent unmet need within the feedback was regarding food so much so that it warranted a dedicated section to fully unpack the range of issues articulated as outlined above. Other unmet needs included more activities and entertainment (e.g. toys; outdoor play areas; Wi-Fi); ensuring a ‘good nights sleep’ could be achieved (through parent/carer facilities and reduced noise at night); and enabling older children space away from those younger. Descriptions of being ‘abandoned’ following discharge were also included within this theme as well as unmet needs for mental health and financial support expressed by parents/carers. In regard to the latter, costs of parking, food and the impact on employment were all noted as contributing stressors.

Wider hospital issues

In a few instances, cleanliness and hygiene was a concern for parents/carers in context of their child having a compromised immune system. Other parents/carers expressed a need for wards to be updated with an example being to improve the décor. Finally, the ongoing visiting restrictions around Covid-19 which had begun to relax during the fieldwork period, were commented upon by several parents/carers who found this challenging.

Further information

This research was carried out in accordance with the internal standard for organisations conducting social research (accreditation to ISO27001:2013; certificate number GB10/80275). The 2021 survey data has been produced and published in line with the Code of Practice for Official Statistics.

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

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