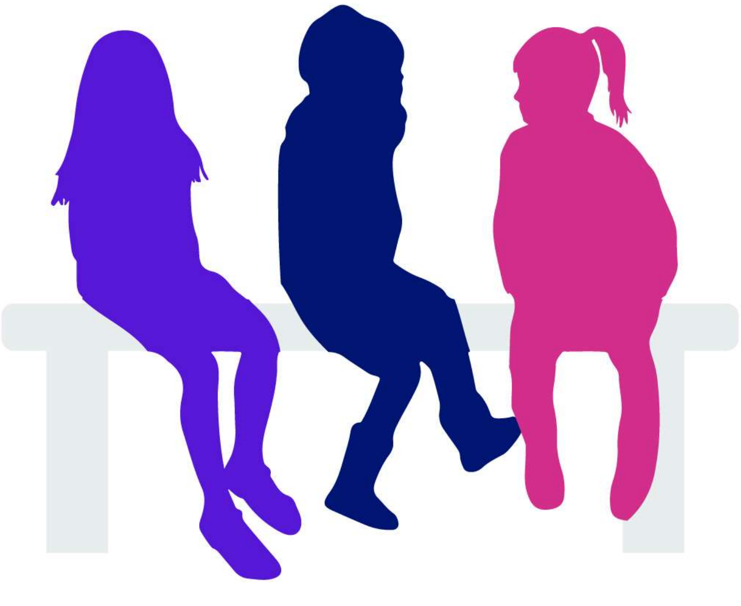
Under 16 Cancer Patient Experience Survey 2020

National Freetext Report

November 2021



P3313_U16 CPES 2020 National Freetext Report v5.0 AT CW PF BK 091121

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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. The survey captures the experiences of children who were aged 8 and above at the start of the fieldwork period, but under 16 at the time of their care, and the parents and carers of children who were aged under 16 at the time of their care. The survey was distributed via post to anyone who had received cancer treatment or care and has/had a primary diagnosis of cancer or other specific tumours and was discharged between January 1, 2020 and December 31, 2020. 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 and Improvement to conduct a thematic analysis of the open-ended written feedback to identify areas for improvement and facilitate reflection and learning across services delivering cancer care for children aged under 16.

Results

In total, 668 parent/carers and 151 children provided a response to the open-ended question. Thematic analysis of the responses revealed the following themes:

Members of staff:

Many comments relating to care and members of staff were overwhelmingly positive from both parents/carers and children, expressing gratitude towards the team that cared for them/their child.

Communication:

Effective communication was key in ensuring a holistic approach and continuity of care. It was important that communication was tailored specifically for parents/carers and children themselves. Parents/carers wanted to be provided with more information throughout the cancer journey.

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

Support:

Parents/carers and children often felt that they were ‘left to it’ once their / their child’s treatment had finished.

Support requirements during hospital stays varied by age groups, with play therapy important to 0-7 years and psychological support and independence important to 12-15 years.

Food:

A number of parent/carers and children highlighted room for improvement in the quality of hospital food provided. Some children did not like the taste of the food provided to them. Some comments were made about the food not being suitable for those that had been diagnosed with cancer, or those on steroid treatment.

Wider hospital issues:

These included;

- Lack of privacy
- Wards requiring an update
- Regulation and provision of parking
- Non-child cancer wards need to be better equipped
- Time spent ‘waiting’
- Enforcing hospital rules

Other:

Other important aspects included;

- A good Wi-Fi connection
- A need to ensure parents/carers are looked after
- Hygiene and cleanliness
- A homely experience

Most parents/carers and children who responded in freetext, expressed thanks and gratitude for the care experienced. These positive comments are typically less actionable and less detailed in comparison to comments about areas for improvement. To allow us to explore the richest opportunities for learning, this report is focussed on the more actionable and detailed comments and as such, on areas for improvement.

Further Engagement

This thematic analysis has generated a range of ideas and suggestions for improvement, to help gain a better understanding further patient engagement and involvement could help prioritise what matters most to them and consider how these recommendations can be put into practice. For example, a co-creation approach could be taken involving both patients and PTCs themselves.

Based on the findings of this research the following are highlighted as areas for further consideration.

Communication

- Consider the importance of effective communication in ensuring continuity of care and taking a holistic approach to care for children with cancer. Identify practical solutions to tackle those barriers, for example patients carrying their own notes or medical passports in order to avoid repetition of information.
- Ensure communication is tailored for parents/carers and children, ensuring that the right information is shared at the right time and in the right way. For example, introduce parent only conversations as common practice, particularly for key appointments, to enable parents to have discussions that they don’t feel comfortable having in front of their child.

Experience in hospital

- Consider how parent/carer needs are met, for example beds provided, access to a parent room, ability to order hospital food (at cost) or prepare their own food.
- Understand the importance of providing good quality food for patients, recognising that needs for this group of patients may be different to other inpatients, particularly in terms of providing highly calorific food, ensuring to avoid sugary food and ensuring that food is suitable for those on steroid treatment.
- Recognise the difference in needs for younger cancer patients (e.g. 0 – 7 years) and older cancer patients (e.g. those in teenage years) and tailor

support/experiences based on this. This includes support (play therapy vs psychological support), entertainment and ward layouts. Older children particularly highlighted the difficulties they experienced being around younger children.

Experience after hospital

- Prioritise understanding support after treatment/discharge, recognising that the cancer journey does not stop at this point. Consider how pathways can be implemented that support parents/carers and children to return to “normal” lives, signposting to services and charities that can provide the practical and emotional support required.

Introduction

Project Background

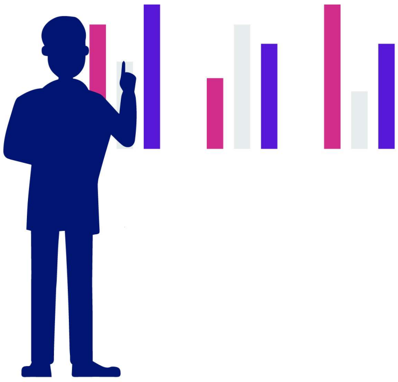
- The Under 16 Cancer Patient Experience Survey (U16 CPES) 2020 is the first iteration of a national survey that is expected to run annually to measure children's tumour and cancer care. The survey captures the experiences of children who were aged 8 and above at the start of the fieldwork period, but under 16 at the time of their care, and the parents and carers of children who were aged under 16 at the time of their care.

- The survey has been designed to measure of patient experiences of cancer care across England and to enable NHS organisations to assess their performance with other providers. In future years, the survey will also allow performance to be tracked over time.

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

- This report focusses on the analysis of the survey freetext data. A separate report is available for the quantitative (closed) survey questions which can be accessed here.

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, 2020 and December 31, 2020, and were aged under 16 at the time of their discharge. It is important to note that the sampling period took place during an unprecedented year for the health and social care sector, with the outbreak of the global COVID-19 pandemic. This had an impact on the NHS and may have influenced people's care perceptions and experiences, and therefore how they answered the survey.

The fieldwork for the survey was undertaken between April and June 2021. One of three versions of the survey were distributed:

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

Survey version was assigned based on the patient's age immediately prior to survey fieldwork as opposed to their age at the time they received care, to ensure the most age-appropriate version was sent. This was important, since there were differences in survey design, wording and the way that answer options were presented in the 8-11 and 12-15 questionnaire versions.

Questionnaires sent to those aged 8-11 and 12-15 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 0-7, 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 provide access to a translation and interpreting facility for those whose first language was not English.

Freetext 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 (8-11 and 12-15 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 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)?'.

Freetext cleaning

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

- Names of patients, staff, 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)"

Freetext analysis

Picker[2] were commissioned by NHS England and NHS Improvement 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 and NHS Improvement commissioned Explain Research[3] to independently thematically analyse the open-ended written feedback 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 survey data. The results of the thematic analysis are shared in context of the survey data, therefore. The results section of the report is structured so it leads with relevant quantitative survey findings, providing important context, for the qualitative freetext findings which follow. It is structured in this way to exploit the value of both the quantitative data, 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

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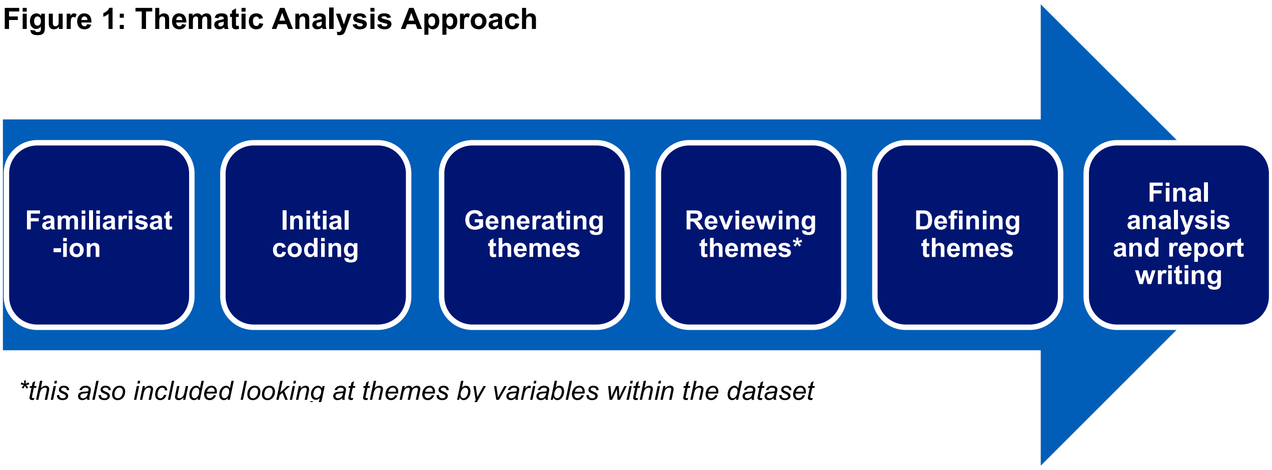
[2] https://www.picker.org
[3] https://www.explainresearch.co.uk/

experience evidenced in the survey 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.

To analyse open-ended responses, 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



*this also included looking at themes by variables within the dataset

It is important to note that a sample was not taken for the thematic analysis and all of the freetext data was analysed, i.e. every individual comment shared was included.

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

When analysing open-ended responses, seven comments provided in the child section of the survey were interpreted as likely to have been written by an adult, judging by the language used. Where this was clear (e.g. using terminology such as ‘my child’) comments were moved into the parent section of responses (x 5 comments). Where this was more subjective, the comments remained in the child section of responses (x 2 comments).

About the Respondents

Response rate

Overall, the survey had a response rate of 35% with 1,144 respondents out of a total of 3,308 eligible parents and children who were sent a survey. A response consists of one survey completion for a single patient, which could consist of both parent and child responses.

About the respondents leaving freetext comments

Of the 1,144 completed survey responses, 698 had freetext data as indicated by a response to the free-text question 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 freetext data (This could be a parent comment, a child comment, or both a parent *and* a child comment) by survey type/age group was as follows:

- 0-7 questionnaire (parent only): 392 records with freetext data
- 8-11 questionnaire: 148 records with freetext data
- 12-15 questionnaire: 158 records with freetext data

There was a total of 819 freetext comments left across all survey versions/sections. Table 1 shows the number of comments left by parents and by children across each survey version. A total of 668 comments were left by parents, and 151 comments were left by children.

Table 1. Number of comments by survey section

Survey Version	Number of freetext comments
0-7 Questionnaire (parent only)	392 comments
8-11 Questionnaire	Child survey section: 73 comments Parent survey section: 131 comments
12-15 Questionnaire	Child survey section: 78 comments Parent survey section: 145 comments

The number of freetext responses per PTC is displayed in Table 1, showing a range in the number of comments left by PTCs. **Important Note**: Please be mindful that freetext 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 freetext data*
Alder Hey Children's NHS Foundation Trust	47
Birmingham Children's Hospital NHS Foundation Trust	78
Cambridge University Hospitals NHS Foundation Trust	46
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	109
Leeds Teaching Hospitals NHS Foundation Trust	56
Manchester University NHS Foundation Trust	46
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	27
Oxford University Hospitals NHS Foundation Trust	43
Sheffield Children's NHS Foundation Trust	16
The Newcastle upon Tyne Hospitals NHS Foundation Trust	45
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	73
University Hospital Southampton NHS Foundation Trust	67
University Hospitals Bristol NHS Foundation Trust	45
TOTAL	**698**

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

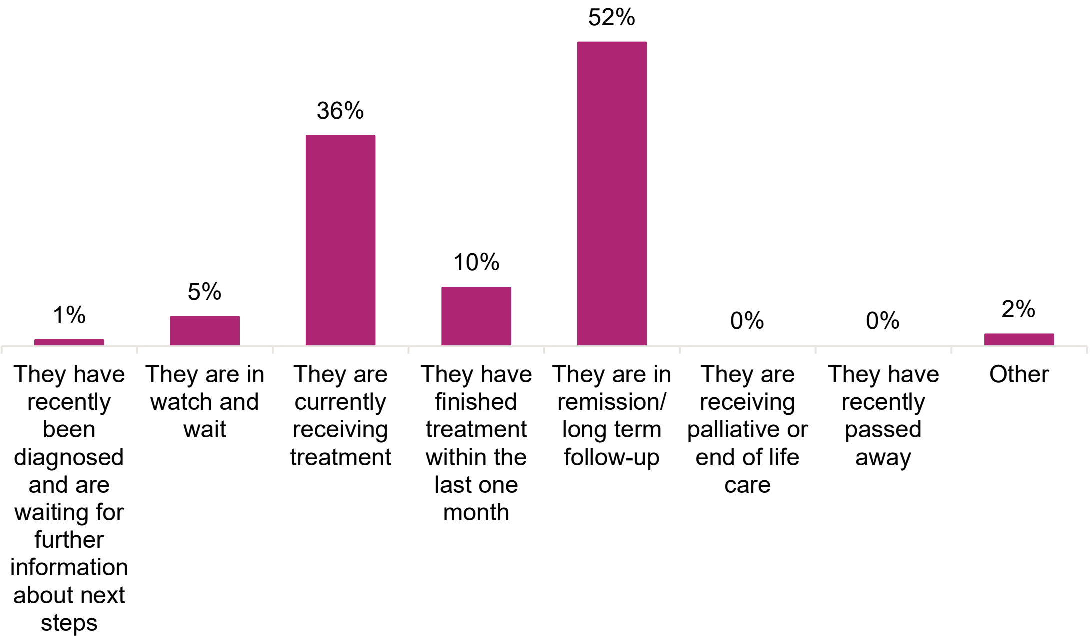
The demographic characteristics of those responding to the freetext question are described in more detail below, and largely reflects the population invited to take part in the survey.

Children

Of the 151 children who answered the freetext question, 73 (48%) were aged 8-11 and 78 (52%) were 12-15 years old.

In terms of cancer stage, a higher number of children that completed the open-ended question were currently in remission/long term follow up than any other stage in their cancer or tumour care, followed by those who were currently receiving treatment. Fewer children leaving a freetext comment were at the beginning stages of the cancer journey (e.g. diagnosis). None were currently receiving palliative or end of life care. Please note, this was a multi-coded question. See Figure 2.

Figure 2: Stage of Cancer Journey for children leaving a freetext comment (N=151)

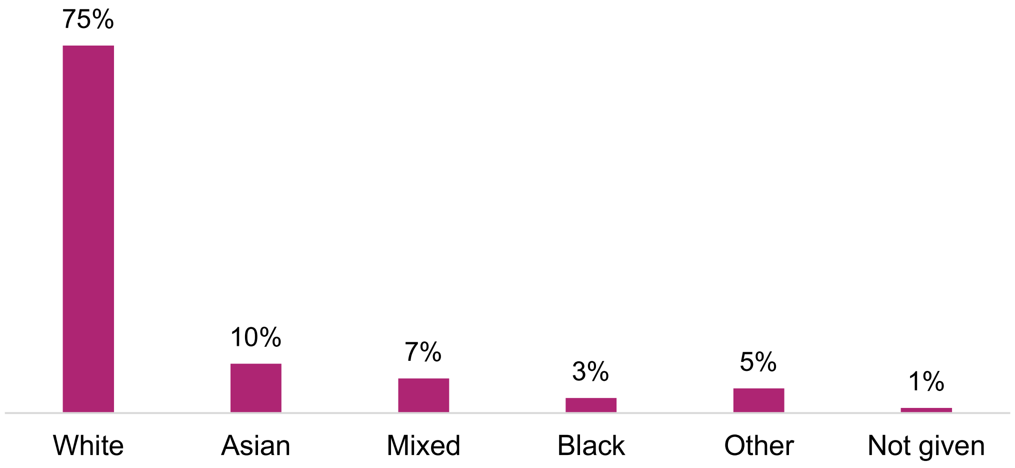


A slightly higher number of boys (83 respondents) answered the open-ended question than girls (66 respondents) – see Figure 3. Please note that more boys were invited to take part in the survey and the number of freetext responses reflects that pattern (i.e. boys are not more likely to leave freetext comments).

Figure 3: Gender of children leaving a freetext comment (N=151)

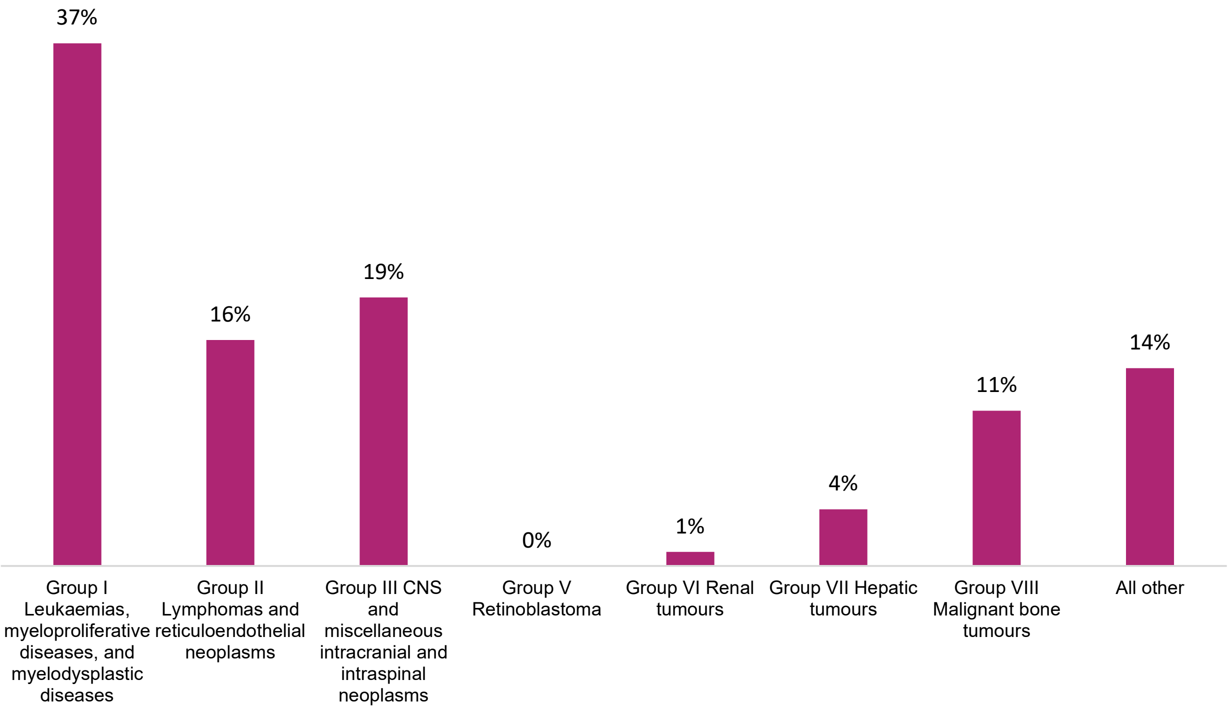
The ethnicity of children who completed the open-ended question is displayed in Figure 4. Please note the number of freetext responses by ethnicity largely reflects the pattern of those invited to take part in the survey.

Figure 4: Ethnicity of children leaving a freetext comment (N=151)



Regarding the diagnostic groups of children who answered the open-ended question, there was a greater representation of Group I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases (37%, n=56), Group II Lymphomas and reticuloendothelial neoplasms (16%, n=24), Group III CNS and miscellaneous intracranial and intraspinal neoplasms (19%, n=28) and Group VIII Malignant bone tumours (11%, n=17) than Group VI Renal tumours (1%, n=1) and Group VII Hepatic tumours (3%, n=4). See Figure 5.

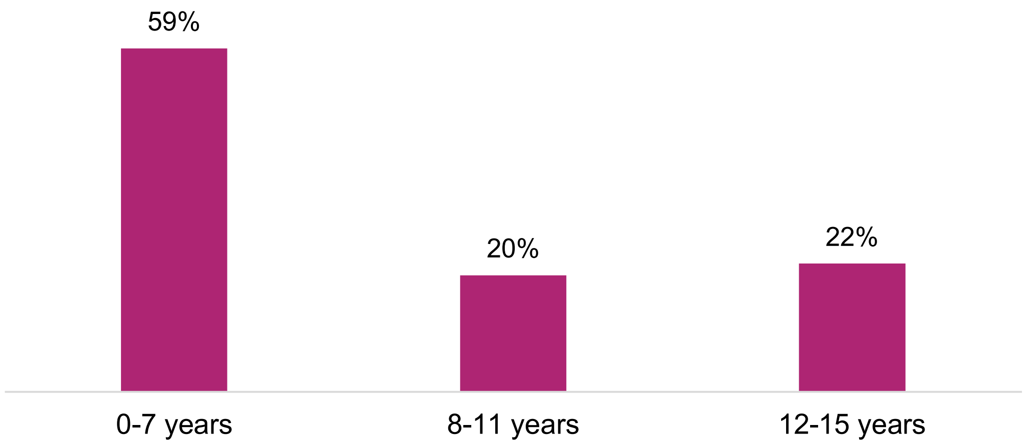
Figure 5: Diagnostic group of children leaving a freetext comment (N=151)



Parents/carers

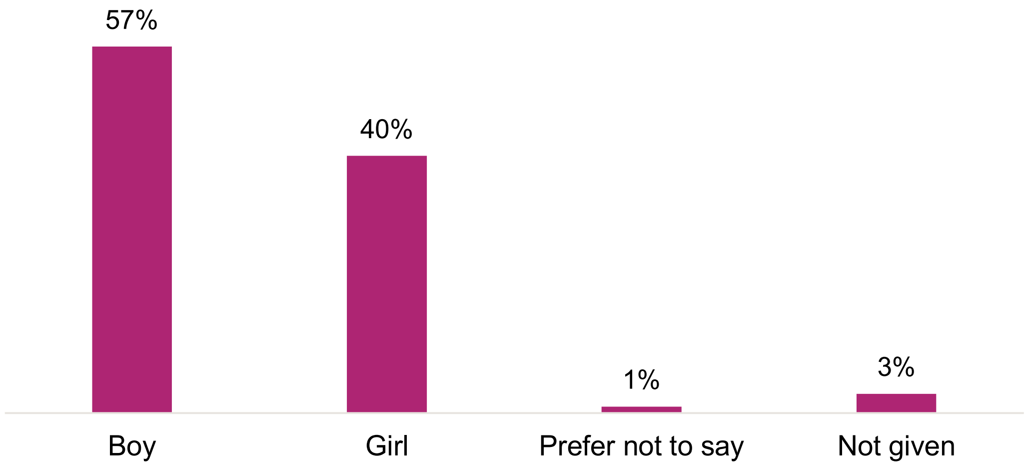
Of the 668 parents/carers who answered the open-ended question, a higher proportion were from the 0-7 survey version relative to the 8-11 and 12-15 versions – see Figure 6, reflecting the pattern of those invited to take part in the survey.

Figure 6: Survey version for parents/carers leaving a freetext comment (N=668)



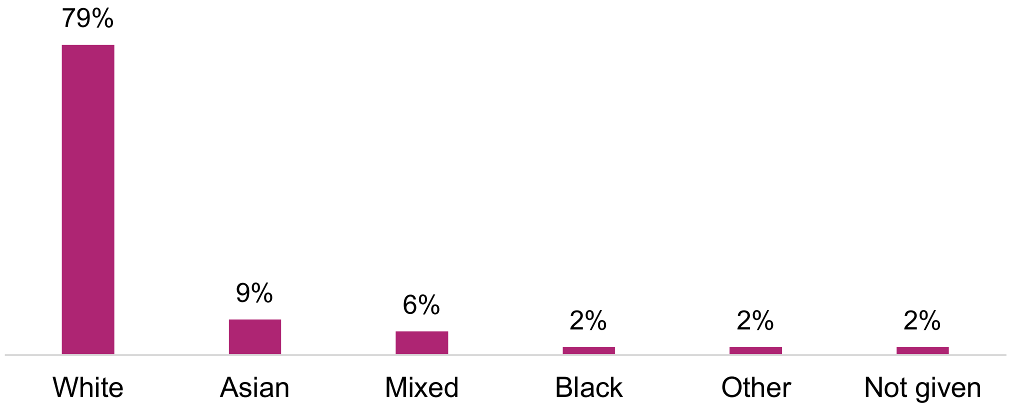
More open responses were left by parents of boys than girls – see Figure 7. Please note that more boys were invited to take part in the survey and the number of freetext responses reflects that pattern (i.e. boys are not more likely to leave freetext comments).

Figure 7: Gender of children for parents/carers leaving a freetext comment (N=668)



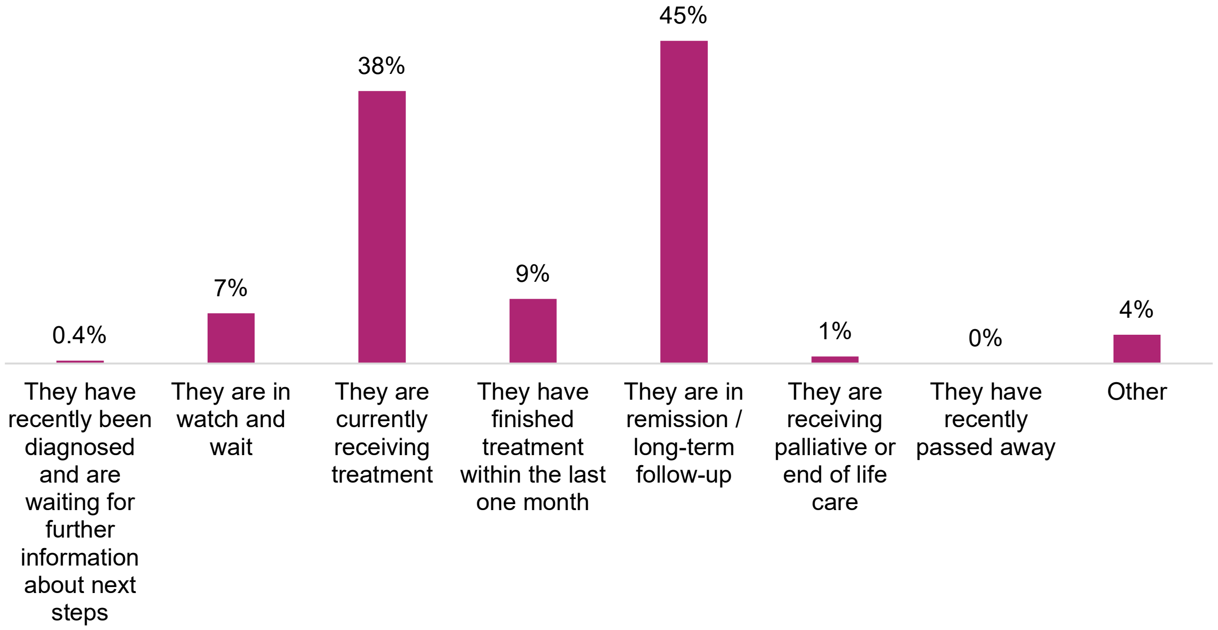
The ethnic backgrounds of children whose parents/carers left a freetext comment are displayed in Figure 8. Please note the number of freetext responses by ethnicity largely reflects the pattern of those invited to take part in the survey.

Figure 8: Ethnicity of children for parents/carers leaving a freetext comment (N=668)



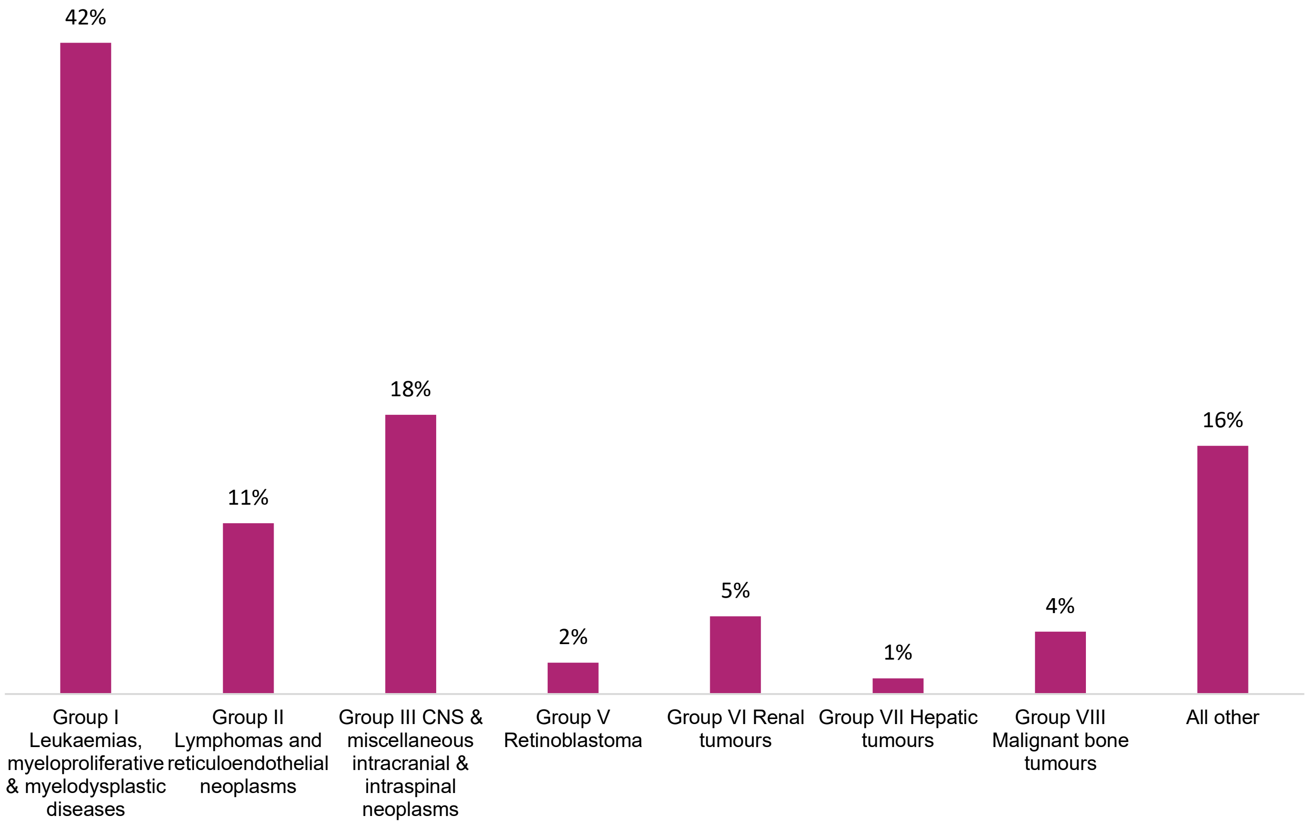
Parents/carers that completed the open question had children who were at varying stages of the cancer journey, with fewer at the beginning stages of the journey (e.g. diagnosis) – see Figure 9. Please note, this was a multi-coded question.

Figure 9: Stage of children's cancer journey of parents/carers leaving a freetext comment (N=668)



Similar to child responses, some diagnostic groups were less represented in the parent freetext data. These were; Group V Retinoblastoma, Group VI Renal tumours, Group VIII Malignant bone tumours and particularly Group VII Hepatic tumours. See Figure 10.

Figure 10: Diagnostic group of children for parents/carers leaving a freetext comment (N=668)



Interpreting the Results

Context setting and wider considerations

Context setting when interpreting results

Within open-ended 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 echoes the positive overall experience of care scores for parents and children.

Typically the positive comments give thanks and express gratitude for the overall care received. The positive comments are less actionable and less detailed. In contrast, comments shared about areas for improvement and experience of care which were less positive, are typically more actionable and detailed. This report as a result, 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.

The high number of positive freetext comments relate to the positive ratings of overall care given in the survey:

- 92% of parents (of 0-15's) rated their child's overall cancer or tumour care as 8 or more out of ten (question X64, answered by 1,102 respondents)
- 80% of children aged 8-15 said they are looked after very well for their cancer or tumour (question X65, answered by 489 respondents).

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 aged and/or cancer patients) may be less actionable.

COVID-19 pandemic

It is important to note that the survey sampling period took place during an unprecedented year for the health and social care sector, with the outbreak of the global COVID-19 pandemic. This had an impact on the NHS and may have influenced people's care perceptions and experiences, and therefore how they answered the survey.For example, the COVID-19 pandemic meant that there were restrictions in place in terms of services available, visiting rules, access to facilities, hygiene protocols and many more aspects of care.

It is important when interpreting the results in this report to consider findings alongside these wider circumstances, particularly as most restrictions were set in place by the government and were therefore the standard way of operating during these times.

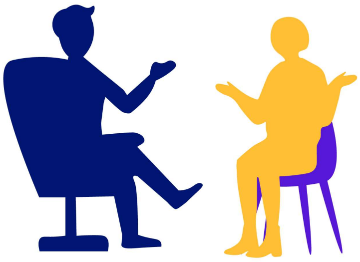
Primary care

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 but have been presented separately in this report.

Other

For the purposes of this report parent/carer and child responses have been analysed collectively. Please note when interpreting themes that less children completed the survey (151) in comparison to parent/carers (668).

Results: Key Themes



The following key themes were identified amongst freetext comments left by parents/carers and children.

- Members of Staff
- Communication
- Support
- Food
- Wider hospital issues
- Other

Each of these themes are described in further detail below.

Where there is survey data relating to the theme identified in freetext data, 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 freetext data which can support us in understanding why not every child, parent/carer gave the best scores possible throughout the survey.

Members of Staff

What does the survey data tell us?

- 92% of parents (of 0-15's) rated their child's overall cancer or tumour care as 8 or more out of ten (question X64, answered by 1,102 respondents)
- 80% of children aged 8-15 said they are looked after very well for their cancer or tumour (question X65, answered by 489 respondents).

Gratitude about overall care received throughout journey and members of staff

There were many positive comments about overall care experiences, with references to specific members of staff, wards and hospitals. Some examples can be found below.

- *“Some nurses are amazing and funny” (child aged 12-15)*

- *“All staff are welcoming, friendly and positive and this helps reduce the stress of both the child and their family. These small gestures make such enormous differences” (parent/carer of child aged 12-15)*
- *We want to express our thanks to several individual staff, who we have had a lot of contact within the past year” (parent/carer of child aged 12-15)*
- *“Thank you to all the staff that treated me” (child aged 12-15)*
- *“Most of the nurses are nice and chat and gentle the lady who brings me toast and milk are very happy and chat and kind” (child aged 12-15)*
- *“Most of the staff are fab and caring and nurture my child” (parent/carer of child aged 0-7)*
- *“We had an amazing consultant, by far the best consultant in Oncology” (parent/carer of child aged 0-7)*
- *“The Oncologist team, nurses are very good, professional and attentive. The nurses (majority) alongside the nurses are brilliant and caring” (parent/carer of child aged 8-11)*
- *“I cannot praise the doctors and nurses enough; they have been such a help through everything” (parent/carer of child aged 0-7)*
- *“The care and support received was second to none” (parent/carer of child aged 12-15)*
- *“As a family we feel we received a very good and high standard of care for our son” (parent/carer of child aged 12-15)*

As demonstrated above, positive comments tended to be more generic in nature, making it difficult to identify specific best practice.

The impact of one negative experience with staff

What does the survey data tell us?

- 86% of parents/carers felt that staff always treat them with empathy and understanding (question X18, answered by 1,134 respondents)
- 89% of children felt that staff are always friendly (question X24, answered by 487 respondents)

As described, the majority of comments relating to members of staff were overwhelmingly positive from both parents/carers and children, expressing a great deal of gratitude towards the team that cared for them/their child. There were, however, some comments that highlighted a specific negative experience with staff. It was clear from comments that this was not a view of the holistic care received but instead references were made to one or two specific members of staff and the impact they had.

- *“If there was ever any more negative experience it was either because of particular nurse staff (unfortunately not all were great) or passing-by doctors who had no idea who our daughter was” (parent/carer of child aged 0-7)*
- *“If a member of staff didn't like this parent or you voiced some kind of opinion certain nurses would mistreat the child. I.e. my daughter was isolating for an injection & threw up everywhere, the nurse dealing with us left her in sick for 50 minutes ignoring my calls and plea’s” (parent/carer of child aged 0-7)*
- *“I was often put in uncomfortable situations by members of staff where they would discuss sensitive information, such as hair growth, in a public waiting room. Having said all of this, I am grateful to the NHS staff that effectively saved my life and I acknowledge they are mostly hardworking, lovely people. These experiences that I have listed above do not reflect every NHS member that I have worked with and cared for me, just some on my care team that I found insensitive and disrespectful” (child aged 12-15)*

The freetext comments highlighted the qualities in members of staff that were clearly important to parents/carers and children, in particular the following:

Empathy

Friendliness

Kindness

Approachability and attentiveness

- *“Ward care - kindness and empathy to family and child is not always shown can feel very isolating as a carer” (parent/carer of child aged 8-11)*
- *“However, my experience was less than ideal due to poor communication and a lack of respect and empathy/compassion from a minority of nursing staff” (parent/carer of child aged 8-11)*
- *“Some of the nurses lacked a bit of empathy and were task orientated - often too busy to notice if you were upset. Our specialist nurse was really busy and really lovely. We are very lucky to have such an amazing facility” (parent/carer of child aged 12-15)*

- *“The staff are short, sometimes rude and brisk and we are made to feel that we are 'bothering them' for asking for help or basic information like when our child's next lumbar puncture is!” (parent/carer of child aged 0-7)*
- *“I often feel forgotten when I'm in X. I don't see anybody from the play team and the nurses don't stop to play or talk to me either” (child aged 8-11)*
- *“Nurses can be nicer; they can be short with you” (child aged 8-11)*
- *“Some nurses snap at me when I am trying to be happy, have fun and interact with them” (child aged 12-15)*

Explicitly in relation to cancer care, some respondents felt that members of staff would benefit from additional training to ensure that patients are cared for appropriately during their stay in hospital due to the severity of the condition.

- *“I feel as though the local hospital would benefit with additional training on how to care for a child receiving chemotherapy” (parent/carer of child aged 0-7)*
- *“Some of the carers were on training because cancer or tumour is a serious condition, that's why I think all the staff should be well trained” (parent/carer of child aged 0-7)*

Communication

More effective communication to ensure continuity of care

What does the survey data tell us?

Two survey questions asked about care provided by different staff and by different hospitals, and showed:

- 70% of parents or carers felt that different members of hospital staff always work well together (question X29, answered by 1,101 respondents).
- 54% of parents/carers and children who receive care at different hospitals said that different hospitals providing cancer/tumour care “always work well together”' (question X62, answered by 844 respondents).

The consistency of information from different staff members was asked in the survey, and showed that:

- 64% of parents/carers and children are never told different things by different members of staff (question X19, answered by 1,104 respondents)

Amongst open-ended responses, several positive comments were made in relation to communication between patients, parents/carers and members of staff.

However, one theme that was identified amongst both parent/carer and child responses was in relation to communication both within and between care teams. Some felt that there was a lack of communication about their/their child's care needs between members of staff within hospitals and between hospitals. This was particularly important to ensure continuity of care and a holistic approach to treatment.

- *"Sometimes I don't think messages get passed between members of staff - home visiting nurses, hospital doctors and specialist nurses. This does not apply to very important information" (parent/carer of child aged 12-15)*
- *"Lack of communication between departments and hospitals was and is always a problem we have found massively" (child aged 8-11)*
- *"I sometimes feel there is a delay in sharing information between the hospitals - this can be stressful if we then have to explain things repeatedly, especially if it's an emergency admission for blood transfusion and antibiotics for an infection" (parent/carer of child aged 0-7)*
- *"Liaison between departments and shared care hospitals - good to be a bit better" (parent/carer of child aged 12-15)*

Some parent/carers commented that the responsibility to share information both between and within hospitals (e.g. different departments) was left to the parent/carer.

- *"We receive shared care from X. Whenever we go in to see a doctor for an unusual occurrence, other than X, they have no idea of our son's diagnosis or treatment. We are always directed to a cubicle, but I do feel that there is a lack of record checking when the doctors come to see us and this then means we have to go over the whole of our sons care before being able to get any help, which due to his complicated case, takes a long time" (parent/carer of child aged 0-7)*
- *"It would be useful if person/staff ringing us was aware of our son's history, treatment plan and blood results instead of querying us" (parent/carer of child aged 0-7)*

Some commented that this lack of communication and information sharing also led to things being missed in terms of tests and treatment.

- *"Often things were missed as we were passed over and X often didn't know that we were under them again. This resulted in a few missed blood tests and long waiting times for us when our son needed blood" (parent/carer of child aged 0-7)*

It was also important that information communicated was accurate and that members of staff involved with the care for that child were delivering consistent information to families. This was in relation to members of staff at all levels and within differing roles (e.g. secretaries, surgeons, nurses etc.).

- *"With regards to post treatment issues, I am often told different opinions by our local and X about certain things such as vaccination schedule. It would be helpful if information given was the same throughout" (parent/carer of child aged 0-7)*
- *"NHS staff tell you unhelpful information about cancer treatment (such as names of drugs etc) and yet leave out information that could be helpful - certain side effects and long-term side effects" (child aged 12-15)*

Some parent/carers commented that the inconsistency in advice and information that they were receiving from different members of staff led them to feel increased levels of stress and anxiety, particularly in relation to medication and side effects of treatment.

Several parents/carers also felt that they were having to chase members of staff themselves to understand progress and next steps. Comments around this were most prevalent amongst those whose child was receiving treatment or in remission/long-term follow up.

- *"I also feel that if I wasn't on top of what is going on, my time in hospital would be far greater, as I always have to chase staff" (parent/carer of child aged 0-7)*
- *"We feel we have to do lots of chasing ourselves with next steps. Chasing results, asking for specific tests, always being pro-active ourselves" (parent/carer of child aged 0-7)*

Tailored communication for parents/carers and children

What does the survey data tell us?

Several questions in the survey asked about quality of communication between healthcare staff and patients, and between healthcare staff and parents/carers. For example:

- 87% of parents/carers said that staff definitely give parents or carers information in a way they can understand (question X13, answered by 1,132 respondents)
- 87% of parents or carers definitely had the chance to ask staff questions about a child's care and treatment (question X14, answered by 1,133 respondents)
- 70% said that information was definitely given in a way parents/carers and children could understand (question X09, answered by 264 respondents)
- 82% of parents/carers and children were definitely able to have questions answered after being told about the cancer or tumour (question X10, answered by 258 respondents)

Several questions in the survey asked about whether communication needs of children were met. For example:

- 70% of children always understand what staff are saying (question X15, answered by 489 respondents)
- 79% of parents/carers felt that staff always share information with children in a way that is appropriate (question X21, answered by 995 respondents)
- 84% of children reported that staff always speak to them in a way that is suitable to them (question X22, answered by 492 respondents)

Some comments left by parents/carers indicated a need for more overall communication between parents/carers and healthcare professionals that were involved in caring for their child.

- *“I do think it’s right for health professionals to speak to the patient, but it would have been nice to be spoken to as well. Going through COVID at the same time. I felt very lonely & isolated. Couldn't face time as internet so poor, nurses could have interacted with me more and it would have been nice to be acknowledged” (parent/carer of child aged 12-15)*
- *“More information regarding the treatment and type of cancer at the start. This would of helped us all understand the process and procedure, rather than having to google the condition which was not good reading” (parent/carer of child aged 12-15)*

Explicitly in relation to cancer, there were some comments from parents/carers about being overloaded with information during the initial diagnosis in which they were in a state of shock and therefore were often unable to recall the information at a later date. Suggestions were to have a recap of information later, once the initial diagnosis and shock had been processed.

- *“A possible recap of initial information maybe a week or two into treatment/ after initial shock hear other parents talk about 'initial blast count' high/ low risk etc.” (parent/carer of child aged 12-15)*
- *“On first diagnosis (date removed) I was bombarded with information and leaflets far too early. I needed a day or two to process what was happening. I think I may have been told things in this time that I just don't remember being told (and who knows where the leaflets went!)” (parent/carer of child aged 0-7)*

Some also felt that they were not being listened to by doctors and felt that doctors should listen to parents/carers more. This was particularly in relation to the diagnosis and treatment stages when parents/carers had concerns over their child’s health and felt they knew best when something wasn’t right.

- *“Despite expressing my extreme concern for my daughter’s health, I had dismissive and rude feedback from some of the doctors (one doctor asked me 'am I the doctor or you?' when I told them my daughter's health is terrible)” (parent/carer of child aged 0-7)*
- *“Sometimes doctors don't listen but the parent knows when something is wrong so they should listen to the parent's concerns” (parent/carer of child aged 8-11)*

Another key theme identified around communication between doctors and parent/carers was the desire for parents/carers to speak with doctors without their child being present.

Explicitly in relation to cancer, there were a number of parents who felt that there were often difficult questions that they would like to ask doctors and consultants but felt uncomfortable doing this with their child present as they were worried that they might worry their child or cause them distress.

- *“I would have appreciated the space and time to talk separately with her doctors - to voice my concerns and fears. I can never be honest about what I'm really worried about in front of her as I don't want to scare her. She is too young to always understand the implications of her condition or to ask the really hard questions, but I don't ever get the chance to have a private chat. And I worry that asking for extra time with very busy staff will be seen as selfish” (parent of child aged 12-15)*
- *“The only comment I would make is that consultations are always with your child present, which can make asking difficult questions very tricky” (parent/carer of child aged 8-11)*

In terms of children themselves, it was important that they were communicated with differently to parent/carers in the sense that they sometimes felt doctors were using too much jargon that they didn’t understand. This was prevalent amongst responses from older children (12–15-year-olds) and highlights the importance of tailoring communication for both children and adults.

- *“I am told about my treatment. I don't think I have any choices it is what it is. Doctors sometimes say things that I don't necessarily understand” (child aged 12-15)*

Furthermore, some also felt that they were spoken down to in a patronising manner when members of staff were communicating with them.

- *“As I was on a children's ward, I often felt patronised and spoken down to by staff as they were used to dealing with young children.” (child aged 12-15)*

Information sharing

What does the survey data tell us?

- 69% of parents/carers and children always know what is happening with the child’s care (question X31, answered by 1,080 respondents)

There was a general consensus that parent/carers wanted to be provided with more information proactively, both prior to and during treatment.

Parents/carers wanted to be more informed about what to expect and felt that they needed more information to be prepared for the journey ahead.

Specific individual suggestions are shared below as examples to demonstrate the wide variety of ideas given by parents/carers to improve their experience:

- **A ‘who’s who’ of staff members**
- **An introduction into how chemotherapy works**
- **An app with information about wider support available**
- **Information about charity/ counsellor/ psychologist support**
- **Information about financial support**
- **Library of medical information**
- **Information/tips for parents in that situation**
- **More information on cancer type/treatment and outcome**

- *“The only thing that I think I could have more information about is charities and more financial help” (parent/carer of child aged 0-7)*
- *“Provide a who's who of staff members with photos” (parent/carer of child aged 0-7)*
- *“Provide an app with all details of who to contact etc, charity details, all info you need” (parent/carer of child aged 0-7)*
- *“There needs to be 'intro' into how chemo works I walked out of SGH in tears many times as made to feel like I should have known. Many parents feel like this” (parent/carer of child aged 0-7)*
- *“More information regarding the treatment and type of cancer at the start. This would of helped us all understand the process and procedure, rather than having to google the condition which was not good reading” (parent/carer of child aged 12-15)*
- *“The only one we feel could be improved is fuller explanation of the cancer type, expected outcome/ likely outcome. We have had to do a lot of research on the type of brain tumour to better understand it” (parent/carer of child aged 12-15)*

Support

Support required after treatment/discharge

What does the survey data tell us?

- 57% of parents of carers definitely received enough ongoing support from the hospital after treatment finished (question X44, answered by 405 respondents)

When parents were asked if hospital staff had given them information about any of the following people to chat to about their child's cancer or tumour (question X26, answered by 1,134 respondents):

- 87% said charities
- 57% said a psychologist or counsellor
- 24% said other parents of children with cancer or a tumour

When children were asked if hospital staff had given them information about any of the following people to chat to about their cancer or tumour (question X27, answered by 486 respondents):

- 77% said charities
- 56% said a psychologist or counsellor
- 22% said other children with cancer or a tumour

It was particularly important for both parent/carers and children to receive ongoing support after treatment had ended, with some feeling they did not receive sufficient ongoing support. Often, parent/carers were left feeling that they were just 'left to it' once their child's treatment had ended and were unsure what to expect over the coming weeks/months/years. They felt that setting expectations and providing information/guidance about the journey ahead would have been beneficial. This theme was most identified amongst parents/carers whose child was currently in remission/long-term follow up.

- *"We weren't sure what to expect for after treatment care and some extra support might have been good and not just monthly clinics" (parent/carer of child aged 0-7)*
- *"I feel very much alone following treatment with not enough information and advice about my child's medical conditions caused by the tumour" (parent/carer of child aged 8-11)*

The need for more psychological support was particularly prevalent amongst parent/carer responses in those whose child was in remission/long term follow up. This was in relation to support for both children and for parent/carers.

- *"I would have liked my son to have had someone to maybe talk to him in the form of counselling. Teenagers do not always want to talk about or say they would like to talk about things, especially in front of their parent. My experience is that he always said he was fine, I do worry he has not talked about what he has gone through and continues his day to day as if it has never happened. He shows no form of distress but wonder if this is normal for a teenager?" (parent/carer of child aged 12-15)*
- *"I would say that more support for parents/carers would be helpful. I feel like mental health support should be more available during such a stressful time" (parent/carer of child aged 0-7)*

In a number of instances, parents had involved social services in their child's care due to stress or had developed a stress induced health issue themselves. Suggestions were for appointments with counsellors to be available to ensure that both parent/carers and children were receiving adequate emotional support to deal with the stress and trauma of their experience.

Support required during hospital stay for younger children (0-7 years) specifically

What does the survey data tell us?

- 88% of parents/carers of 0-7 year olds said the hospital ward offered play specialist support (question X51, answered by 467 respondents)

It was apparent that both parents/carers and children required additional support during their time in hospital and throughout the diagnosis and treatment stages of their cancer journey. For younger children (0-7 years) there was a particular need for more play support/play therapy during their stay in hospital. This was generally in terms of needing improved access to play therapists and for them to spend a longer time with their child, being both present and engaging.

- *"The play specialist is friendly but not present" (parent/carer of child aged 0-7)*
- *"I've been disappointed by the lack of interaction / offers of entertainment by the Play team here, compared with 2 other hospitals we've visited (as day patients) I'd expect the same or more as in patients" (parent/carer of child aged 0-7)*

Support required during hospital stay for teenagers (12-15 years) specifically

What does the survey data tell us?

- 44% of parents/carers and children felt that there were definitely enough things for the child to do in the hospital (question X48, answered by 828 respondents)

For children aged 12-15 years, there were comments relating to feeling ‘removed’ from the younger age groups (0-7 years) and requiring different support/care to those who were younger. There was also a greater need for more psychological support for children of this age range highlighted in the freetext survey comments.

- *“My daughter was 12 when diagnosed but her treatment has lasted until she was 14.5. She has never received any support from X which is disappointing as teenagers have very particular needs” (parent/carer of child aged 12-15)*
- *“More support for teenagers/ young people earlier for emotional issues/ questions” (parent/carer of child aged 12-15)*

Children of this age group also wanted to have some time away from younger children (e.g. access to quieter rooms) and felt that a lot of the support and entertainment that was available was targeted towards younger children (e.g. toys/therapists).

- *“More equipment/ facilities available for teenage patients. Quiet rooms for teenagers away from younger children occasionally” (child aged 12-15)*
- *“It was quite difficult to be a teenager on a child's ward as I felt I was a bit too old for all of the things the play therapists were suggesting” (child aged 12-15)*

Some comments suggested that this had been made more difficult due to the ongoing pandemic which had led to further restrictions in terms of what was available for teenagers.

- *“It has been rubbish not being able to use the teens activity room or do any socialising with teens like me” (child aged 12-15)*

Support required during treatment

As well as wider support during a hospital stay, parents/carers felt that they and their child needed additional support during the treatment process that was wider than in relation to treatment itself.

Specific individual suggestions are shared below as examples to demonstrate the wide variety of ideas given by parents/carers to improve their experience:

Emotional and psychological support for both parent/carer and child

Behavioural support for child

Sleep support for child

Nutritional support for child

Occupational therapy for child

- *“More support for teenagers/ young people earlier for emotional issues/ questions” (parent/carer of child aged 12-15)*
- *“I have had to advocate for nutrition support, sleep support and behavioural support & often experienced a sense that their issues were secondary to the tumour/treatment. I would recommend looking at how children and families can continue to be treated and received if more holistic care was without the need for parents to continuously seek help” (parent/carer of child aged 0-7)*
- *“Treatment focus is just medication - it would be nice to see other support (mental health, OT, etc) better integrated rather than on after thought” (parent/carer of child aged 8-11)*
- *“We need more help and support because my child is unable to walk. The chemotherapy that he received over the last few years caused brain damage which impact on his ability to walk and speak. My child needs more support to overcome this situation” (parent/carer of child aged 0-7)*

A need to ensure parents/carers are looked after

What does the survey data tell us?

- 35% said facilities for parents or carers staying overnight were very good (question X53, answered by 740 respondents)
- 39% of parents or carers were definitely able to prepare food in the hospital (question X55, answered by 772 respondents)

Responses from both parent/carers and children highlighted the importance of parents/carers being looked after and cared for during their child’s hospital stay, in addition to the child themselves. Examples included ensuring they get good quality sleep and providing comfortable beds. This was particularly important as parents/carers may need to stay with their child for a substantial period of time.

- *“The beds that convert to a chair for parents are extremely uncomfortable and cause back pain” (parent/carer of child aged 12-15)*
- *“The pull-out chairs have springs digging in all your back. And this is really not ideal especially when you have to stay in for 3 weeks like we have had to do before” (parent/carer of child aged 12-15)*
- *“The chairs that turned into beds for the parents to sleep on need to be changed, as these are not comfortable at all” (parent/carer of child aged 12-15)*

The need to ensure parents/carers are provided with food was also mentioned, predominantly by parents/carers but by one child too.

Some parents/carers were not provided with food and due to their child’s young age or severity of their illness they were unable to leave their child to buy or make their own food. Some commented that they would be willing to pay for this and just wanted the option to purchase meals without leaving their child.

- *“Could parents order a meal from the kitchen and pay for this? It would remove a huge amount of stress of preparing or buying meals for some, particularly when you know your child is very unwell or very young and you don't want to leave them. I know this would take some organising and setting up at first, but I think it would bring huge benefits. Perhaps this could be done online?” (parent/carer of child aged 0-7)*
- *“Food should / could be provided to parents even if at a cost. This is a problem for parents who are unable to leave their child due to illness or young age” (parent/carer of child aged 0-7)*
- *“Some single parents don't have anyone to deliver them food to the hospital. I often went without eating properly for days during isolation stays and doing this often over 2 years added to my malnutrition problems and stress. There was no where I could step out to get a sandwich for myself being stuck in isolation with my child, and my child didn't eat properly either. Maybe if there could be some leniency to allow parents to step out and buy themselves food and tea would really help, in emergency situations like isolation, e.g. allow them to wear a mask so they can go out” (parent/carer of child aged 0-7)*
- *“I couldn't leave my daughter so didn’t get a decent meal” (parent/carer of child aged 0-7)*

This was most mentioned by parents of younger children, aged between 0-7 but was also mentioned in relation to a 12-15 year old.

- *"It has been extremely tough through Covid to not be able to have family and friends close by and visiting. A lot of the time we have spent shielded but the parent does not get meals and is then at risk having to shop" (child aged 12-15)*

In addition, some parents/carers felt that they would benefit from an area for parents/carers specifically, for example where they could eat.

- *"The only thing I could recommend would be to have a room where parents staying overnight to be able to eat" (parent/care of child aged 0-7)*
- *"When they were allowed onto ward it was much easier, facilities for parents on certain wards like liver/kidney ward could be improved & access to food for parents when they are completely on their own with their child" (parent/carer of child aged 0-7)*
- *"Provision for parents on shared wards" (parent/carer of child aged 8-11)*

Food

Hospital food was mentioned in numerous freetext comments.

Improving food for patients

What does the survey data tell us?

- 57% of parents/carers and children felt that there was definitely a choice of hospital food on the ward (question X49, answered by 768 respondents)

Some parent/carers and children felt that the food provided during their child's hospital stay could be improved in terms of quality.

- *"Food is appalling and really does need addressing. You should not be having charities donating food to the parents and children on the ward" (parent/carer of child aged 0-7)*
- *"The food on the wards was terrible when were in and from what I've seen its not improved much" (parent/carer of child aged 0-7)*
- *"The only thing that is in need of a vast overhaul is the food that, most of the time is inedible" (parent/carer of child aged 8-11)*
- *"Hospital food is very poor. Limited choices, very poor quality" (parent/carer of child aged 0-7)*

A number of children did not like the taste of the food provided to them and in some cases, were not eating it. This was highlighted by older children/teenagers aged 12-15 years in particular.

- *"The hospital food isn't very nice" (child aged 12-15)*
- *"I was very well cared for, the food wasn't great but mum and dad always had healthy and variety of food so I could find something that I could eat to help me feel a bit better because I didn't fancy things much but eating a little bit of this and that helped me, being hungry would have been much worse and made me feel more sick" (child aged 8-11)*
- *"The hospital food was not nice I had my parents bring me food in daily. This was because the food was always microwaved and not healthy for a child going through treatment. Fresh food cooked on the ward is the way forward!" (child aged 12-15)*

Another theme that emerged from responses was that there was a limited choice of food available, and menus were often repeated; children wanted more options.

- *"I think they should have way of knowing what food, the patients may like, or provide more options" (child aged 12-15)*
- *"The menu was always the same, it could not be changed" (child aged 8-11)*

In addition, there were a small number of comments about the food options being limited for those that were vegetarian or who had food preferences for religious reasons.

- *"As a vegetarian my choices at mealtimes were limited and repetitive" (child aged 12-15)*
- *"Hospital food for halal menu is very limited, also same choice. Varied to needs of children would be great, i.e. pizza's, burgers, Spaghetti Bolognese, tuna pasta bake etc." (child aged 8-11)*

Issues with food provided was often leading to parents/carers leaving the hospital and buying food from somewhere else to bring it in for their child. In some cases, parents/carers were doing this for every meal and highlighted the financial impact that this had.

- *"Food for children is very limited and repetitive. My child/young person never ate food while in hospital, I supplied their meals" (parent/carer of child aged 12-15)*
- *"The food in hospital is particularly awful. We often had to go out to buy food which gets very costly when the closest store was M&S" (parent/carer of child aged 0-7)*
- *"It would have been very helpful if the children's ward had a children's menu as my child would not eat any of the hospitals food" (parent/carer of child aged 12-15)*

Explicitly in relation to being a cancer patient, some comments were made about the food provided not being suitable for those that had been diagnosed with cancer, for example foods that were high in sugar.

Parents/carers felt that it was key for children to have highly calorific food for their recovery but that the food provided to them on the ward was not suitable for this, making recovery more difficult/lengthy.

- *“Food on the ward for the children is of poor quality and often high in sugar & artificial ingredients which isn't appropriate for cancer patients as cancer loves sugar” (parent/carer of child aged 0-7)*
- *“The only thing I would suggest is getting better food in, when children with cancer lose their appetite they lose so much weight like my daughter, but when she did want to eat there was nothing she liked. The food is appalling. It’s really essential these kids get the calories back on, but with food like that it doesn't help” (parent/carer of child aged 12-15)*
- *Food needs to be more suited to cancer wards, when children have lost weight they need decent food not health food. Food with strong tastes should be offered and not bland food” (parent/carer of child aged 12-15)*
- *“Research shows that gut health is a key contributor to outcomes post-transplant yet there has been no improvement to the menu or quality of food in the last 7 years we have been X patients. There is no flexibility for children undergoing cancer treatments who therefore do not eat normally and poor facilities for parents. This had a significant detrimental impact on my sons health at a time when nutrition is essential to recovery” (parent/carer of child aged 8-11)*

In addition, some comments were made about the unsuitability of food provided for those who were having steroid treatment.

- *“The ward itself is in need or refurbishment along with areas children's meals could be prepared especially when they are on steroids as hospital set meals are not adequate for those children whilst on steroids” (parent/carer of child aged 0-7)*
- *“It's not good enough, half the kids are on steroids so want rubbish food like burgers & nuggets fresh wet and boiled like the chips. The fresh is frozen rubbish and that ward needs a chef on hand to cook what the kids want” (parent/carer of child aged 0-7)*

Wider hospital issues

Several wider suggestions were made in relation to hospital facilities and services. These are detailed below.

Privacy

An important aspect mentioned in some comments was the need for privacy during hospital stays. This was particularly important because some patients felt uncomfortable being physically unwell (e.g. sickness) in close proximity to others.

- *“I didn't feel good about vomiting while other people were next to me” (child aged 8-11)*
- *“If I don’t get a room then I have to go on the ward and share a toilet with patients and parents which is not very good when I’m poorly” (child aged 12-15)*

Ward updates needed

A number of parents/carers felt that the ward they were staying in was outdated and in some cases unsuitable for children as it was. This was mentioned in relation to several different hospitals.

- *“The parent accommodation for PICU needs updating, as well as the general children’s wards, but I gather this is already being carried out soon” (parent/carer of child aged 12-15)*
- *“The ward needs updating” (parent/carer of child aged 12-15)*
- *“I want to make clear that all my negative comments were about the physical ward, it was a very dire place to stay and not at all children friendly” (parent/carer of child aged 0-7)*
- *“Child ward overall facilities at X are poor for patients, parents and staff compared to X. I understand plans are being put in place to improve X’s child wards/care - I hope this happens soon for future patients, parents and staff wellbeing and care” (parent/carer of child aged 0-7)*

Regulation and provision of parking

It was important for parents/carers to always have access to car parking. In some instances, some felt that free parking should be given to parents/carers of children who receiving treatment for cancer as the car parking costs were an additional and unwelcomed pressure during this time.

- *“Regulating and provision of parking could be increased many times observed workers builders utilising space as well as other adult cancer suffered using the spaces allocated to children’s parking” (parent/carer of child aged 0-7)*
- *“My only issue would be the parking can be near impossible at times. But once inside, I cannot fault our experience” (parent/carer of child aged 0-7)*
- *“The one negative was parking cost as I had over two hours travel each way and early stages of treatment visits to the X were often and frequent, with fuel costs and maintenance to my car plus*

some loss of earnings cost spiral then I was having to pay daily charges until I could pay for a monthly pass which was still a lot to my dwindling bank balance" (parent/carer of child aged 12-15)

- *"Parking at the X should be free for parents of children who are receiving treatment for cancer, our son was in hospital for weeks at a time, this would be added pressure and would of cost us a fortune in parking" (parent/carer aged 12-15)*

Non-child-cancer wards need to be better equipped

When child cancer wards were at capacity, sometimes children were moved to other wards within the hospital. Some felt that these wards were not equipped to care for cancer patients under 16.

- *"It can sometimes be frustrating when ward (name) is full and you're sent to another ward instead. They don't have facilities for long stay patients, or entertainment, DVD's, X boxes, or crafts to keep children busy. You can also feel isolated as ward (name), staff and other parents become family" (parent/carer of child aged 8-11)*
- *"It is difficult if you are put on another ward, delay in treatment & discharge" (parent/carer of child aged 0-7)*
- *"Ward (name) is not set up for children. No food or drinks ever offered, no pillows or blankets for them. They are not well trained in ports" (parent/carer of child aged 0-7)*
- *"Overall, the care has been excellent, however on occasion when we've stayed on different wards (not (name) ward) there have been delays getting the necessary medications administered. I appreciate that on other wards oncology is outside of what the nurses are used to, and there are restrictions on who can give chemo medicines, but on occasion we were left waiting hours for medication to be brought/administered" (parent/carer of child aged 0-7)*

Time spent waiting

Time spent waiting was mentioned in relation to appointments, scans, treatment, results, medication and generally in terms of having to wait for things to happen, for example simple procedures. It is important to note the issue relayed was not necessarily about a perceived delay, but a general feeling of waiting more than was expected for things to happen while in hospital.

- *"MRI results took quite a long time. But people who helped me were amazing" (child aged 12-15)*
- *"Pharmacy quite often fail to supply immunotherapy when I'm in as an outpatient. I've had to wait for hours sometimes" (child aged 12-15)*
- *"Everything took a long time. When I used to go to hospital I would be there all day. I used to be a bit bored. The nurses were lovely!" (child aged 8-11)*

- *"The waiting times in clinic are very long. Ours is a bit better now we have switched to afternoon clinics but if you come to a morning clinic you can expect to wait 2 hours plus" (parent/carer aged 0-7)*
- *"The only thing that I think could be improved on is the length of waiting time was too long just for a simple procedure for example - a port flush. This could take up to a couple of hours!" (parent/carer of child aged 8-11)*

Enforcing hospital rules

What does the survey data tell us?

- 29% said it was always quiet enough for parents/carers and children to sleep in the hospital (question X54, answered by 713 respondents)

Some felt that rules within hospitals, such as loud talking at night, and lights being on/off, needed to be enforced more by members of staff that were on duty. This was important to ensure that children and their parents/carers could sleep.

- *"Ward rules need improving & sticking to. We shared rooms with ppl who had TV on all night, ppl did video calls with family late at night" (parent/carer of child aged 0-7)*
- *"Need stricter rules re parents noise/phone calls, facetime calls, eating on ward after curfew etc." (parent/carer of child aged 0-7)*
- *"Some wards tolerate very high levels of noise late at night. Keeping the kids awake" (parent/carer of child aged 0-7)*
- *"I understand that hospitals are not quiet places and therefore a somewhat disrupted night's sleep is to be expected, however, when you are being kept awake because the patient in the bed next to you has their TV on loud until 23.00 at night, it can become somewhat frustrating and having politely asked them if they would mind turning the TV down or using the headphones provided with no success, it would have been nice if a member of staff could have reinforced the request made" (parent/carer of child aged 0-7)*

Bank staff/staff on weekends/bank holidays/half-term

There were a few comments relating to a decline in care/services during weekends, bank holidays and during school holidays, for example half term.

- *"Everything stops at weekends and bank holidays, but cancer doesn't, and the treatment is still needed" (parent/carer of child aged 12-15)*

- *“We also really struggled to get hold of anybody to talk to and weren't offered an appointment with a consultant until a week after original diagnosis, which was absolute torture. It was on a Friday and just before half term, so it was also monumentally difficult to get hold of anybody” (parent/carer of child aged 0-7)*

Impact of COVID-19

As mentioned at the outset, the COVID-19 pandemic was ongoing throughout survey sampling period and therefore circumstances were outside of the ‘norm’ in terms of the way the NHS was operating. For example, the COVID-19 pandemic meant that there were restrictions in place in terms of services available, visiting rules, access to facilities, hygiene protocols and many more aspects of care.

Some freetext comments related to the impact that the COVID-19 pandemic had on their care and experience.

a) Impact on who can stay with child

One of the key themes that was identified in terms of the impact of COVID-19 was a restriction on who can attend and stay with the child in hospital, as typically only one parent was able to attend appointments and/or stay with their child. Several parent/carers commented on the detrimental impact this had on their wellbeing, particularly because many conversations and decisions to be made were extremely important, and they felt that both parents should be present for these.

- *“Whilst we cannot fault the care provided for our daughter in hospital, there are serious shortfalls in the understanding and compassion shown to parents regarding the one parent rule. Despite both having negative covid test, both isolating, and both being in the same household bubble, myself and my daughter’s father were unable to stay with her in hospital. As she is a baby, and predominantly breastfed, her care fell on me and I found our long stay in hospital, in isolation, without the practical support from my partner extremely detrimental to my mental health, and this impacted my ability to care for my daughter. I implore the NHS to use common sense with regards to current covid regulations and the impact they are having on families going through an already difficult period. Whilst I understand the need to protect those receiving treatment, there are now sufficient means of testing parents as well as patients to ensure everyone is risk free” (parent/carer of child aged 0-7)*
- *“My only criticism is that only one parent is allowed to attend with a child. This makes things much more difficult when receiving bad news, and dealing with a toddler coming round from GA. Also, we have a 2.5hr drive to get to X for an 8am appointment and my husband has to just wait in the car for hours. I really hope that this will be reviewed soon, particularly with restrictions lifting & the availability of lateral flow tests” (parent/carer of child aged 0-7)*

- *“It was very hard with only allowing 1 patient during our hospital stay, which meant life changing decisions were decided in corridors” (parent/carer of child aged 8-11)*

Many felt that as wider COVID-19 restrictions ease and with routine testing in place, these restrictions within hospitals should also be reviewed and changed.

b) Impact on visiting

The pandemic also had an impact on both parents/carers and children in terms of restrictions in place on visiting. Children were spending long periods of time without any outside visitors and found this difficult to cope with. Parents/carers also found this difficult, with some expressing feelings of isolation.

- *“I just found it hard not seeing friends and family and having activities closed down due to the pandemic” (child aged 12-15)*
- *“Not all normal facilities were available due to Covid, nor were we allowed visitors. We were very alone, the staff compensated well but feel our experiences are not reflective of normal practice” (parent/carer of child aged 0-7)*
- *“It is a shame that covid has added to the feeling of isolation” (parent/carer of child aged 12-15)*
- *“It has been extremely tough through Covid to not be able to have family and friends close by and visiting” (child aged 12-15)*

c) Impact on facilities/entertainment/activities/schooling

Some children were unable to access some of the play facilities within the ward due to the pandemic and restrictions around face-to-face contact with others. This also impacted schooling and going outside.

- *“We didn't unfortunately get to use many of the facilities on the ward, due to covid restrictions, also the visiting arrangements have been awful. I am sure that in 'normal circumstances' the whole experience would have been better had covid not been around. We were inpatients for approx. 5 months” (parent/carer of child aged 12-15)*
- *“Sadly, covid prevented any schooling to take place from March 2020 and also going in the playroom and outside” (parent/carer of child aged 0-7)*
- *“Covid has caused a lot of changes and reduced normal services drastically. The staff have tried to make it feel the same, but you can tell the lack of services especially 'fun' aspects like playing, meeting others similar and visitors” (parent/carer of child aged 0-7)*

d) Impact on treatment/scans

Some comments were made about the impact of the pandemic on the care received, particularly increased waiting times for tests, scans and treatment.

- *"In relation to extra covid restrictions, it has sometimes been difficult and stressful to arrange the required additional tests prior to treatment e.g. covid swab appointments only available until 2pm x 2 days before. Sometimes wait times have been 4-5+ hours due to staff shortages" (parent/carer of child aged 0-7)*
- *"Follow-up screening has been impacted by covid supposed to have six-month follow-up with Dermatology - now over 12 months and appt has just been cancelled again" (parent/carer of child aged 12-15)*
- *"All my son's care has been great through the hospital, the only problem we had was the length of time it took to get an appointment for a scan due to Covid" (parent/carer of child aged 8-11)*

Other

Access to a good Wi-Fi connection

What does the survey data tell us?

- 37% of parents or carers felt that the hospital Wi-Fi always met the needs of them and their children (question X56, answered by 859 respondents)

Access to a good Wi-Fi connection was important to both parent/carers and to older children. This was essential in terms of keeping in contact with friends/family and the outside world, keeping children entertained and for parent/carers to be able to continue to work whilst caring for their child if they needed to.

- *"Wi-Fi connectivity poor. A good/strong connection children may be able to have access to Netflix/Disney & etc. Parents may also be able to have access, allowing them to continue working if needed. This could alleviate some of the stresses (financial) and bring some form of normality during a difficult period" (parent/carer of child aged 0-7)*
- *"The only improvement would be better Wi-Fi especially for stays on the ward. I know the play team have tried to look into this" (parent/carer of child aged 0-7)*
- *"The only improvement I suggest for the wards would be better Wi-Fi" (parent/carer of child aged 0-7)*
- *"Better Wi-Fi or have sky on tv provided so I can watch football, it keeps me from stopping thinking about hospital and makes my time go quicker" (child aged 8-11)*
- *"Wi-Fi needs improving, especially for children staying in and isolation to entertain them" (parent/carer of child aged 0-7)*

Hygiene and cleanliness

Hygiene and cleanliness were important to both parent/carers and children. Some parent/carers felt that wards were not clean enough in general and that members of cleaning staff were not cleaning the areas of the ward to a sufficient level. Cleaning and hygiene were also particularly important during the COVID-19 pandemic. Some parents/carers stated that they had to clean areas themselves.

- *“Domestic staff cleaning rooms including toilets, then shortly after would be in the kitchen preparing patients food, this seemed extremely unhygienic. The patient rooms were never fully cleaned properly” (parent/carer of child aged 0-7)*
- *“The cleaning was terrible” (parent/carer of child aged 0-7)*

Cleanliness was really important in bathroom facilities on the ward.

- *“A clean ward and clean toilet facilities please” (child aged 8-11)*
- *“The bathrooms, toilets and parents’ kitchen are never clean” (parent/carer of child aged 8-11)*
- *“My son refused to have showers due to the grime in them. I cleaned them myself” (parent/carer of child aged 8-11)*

Creating a more ‘homely’ experience

Some children wanted to have a more ‘homely’ experience whilst they were staying in hospital. This was specifically mentioned in relation to bedding, in which some felt was uncomfortable. It was suggested that children would like more “normal” duvet covers and pillowcases to have a more ‘at home’ feel.

- *“Better food choices, comfortable space for mummy and daddy when with me, more at home feel (like “normal” duvet covers and pillowcases), better pillows - I always brought one for home (when remembered) as the hospital pillows were hot and sweaty and uncomfortable” (child aged 8-11)*
- *“Beds are hard, and covers are scratchy” (child aged 8-11)*

Comments relating to primary care

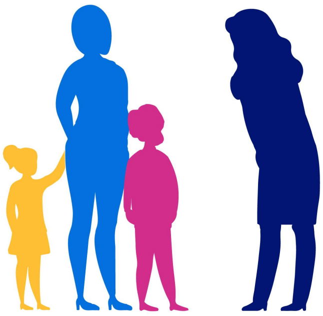
What does the survey data tell us?

- Parents/carers were asked how many times their child saw a GP before being told they needed to go to hospital about their cancer or tumour (question X04, answered by 302 respondents). It is particularly difficult to know if this data is comparable to what might be expected outside of the pandemic period. **36%** of parents/carers said their child saw a GP once or twice before going to hospital, **17%** said that their child saw a GP three or four times, and **10%** said that their child saw a GP five or more times. **36%** of parents/carers said their child went straight to hospital.

In addition to the key themes identified in relation to hospital and community care, there were several comments in relation to primary care. These tended to be in relation to diagnosis and parent/carers feeling that the GP they dealt with did not recognise and/or diagnose their child as quickly as they should have done. A number of parent/carers felt that GPs needed more training on recognising childhood cancer, particularly of early warning signs.

- *“GPs need more knowledge on childhood cancers” (parent/carer of child aged 12-15)*
- *“It is not related to itself, but I wish that the GP would pay more attention and don't delay or belittle problems regarding child’s health” (parent/carer of child aged 12-15)*
- *“We felt the GP should have recommended a hospital visit but instead waited to see” (parent/carer of child aged 0-7)*
- *“GP and 111 need more training on early warning sign of brain tumours” (parent/carer of child aged 12-15)*
- *“Diagnosis - we were bounced back & forth to A+E and GP four or five times before a scan was done and the tumour found. He was very poor health by then. A scan could have been done months sooner & tumour found earlier” (parent/carer of child aged 0-7)*

Conclusions



A summary of key findings from this thematic analysis have been shared below. A range of ideas and suggestions for improvement have been identified from the freetext data collected. It is recommended that the themes detailed within the report are considered conversation starters and that further patient engagement would support understanding of priorities and what matters the most to patients and their parents/carers.

Hospital Staff

Most comments relating to members of staff were overwhelmingly positive from both parents/carers and children, expressing a great deal of gratitude towards the team that cared for them/their child. There were, however, some comments that highlighted the impact of having one negative experience with staff on parents/carers and children's overall experience in hospital. It was clear from comments that this was not a view of the holistic care received but instead often referenced just one or two specific staff members, with examples relating to (lack of) empathy and friendliness of staff.

More effective communication to ensure continuity of care

Effective communication was key in ensuring a holistic approach and continuity of care. This included communication both within and between hospitals. Poor communication led to parents/carers having to chase members of staff themselves.

It was important that communication was tailored specifically for parents/carers and children themselves. Parent/carer expectations were;

- To be listened to more
- To have more information throughout the cancer journey
- To not be overloaded with information at diagnosis delivery
- To be able to speak to doctors/consultants without their child present

Child expectations were;

- To not feel patronised when spoken to

- To be spoken to with child-appropriate language, e.g. less use of jargon

Parent/carers wanted to be provided with more information proactively both prior to and during treatment. Parents/carers wanted to be more informed about what to expect and felt that they needed more information to be prepared for the journey ahead.

Support

Parents/carers and children often felt that they were ‘left to it’ once treatment had finished, with limited ongoing support. The need for more psychological support was particularly prevalent amongst parents/carers of children in remission/long term follow up. Suggestions were for appointments with counsellors to be available to ensure that both parent/carers and children were receiving adequate emotional support to deal with the stress and trauma of their experience. Parents/carers felt that it was key for children to have highly calorific food for their recovery but that the food provided to them on the ward was not suitable for this, making recovery more difficult/lengthy.

There was a need for more play support/play therapy provided for younger children (0-7 years) during their stay in hospital. This was generally in terms of needing more play therapists and for them to spend a longer time with their child. Support that was needed for older children/teenagers differed from those who were younger. There was a greater need for psychological support for children aged 12-15. Privacy was also really important to these older children, who felt uncomfortable being physically unwell in front of others, and wanted their own space away from younger patients.

It was important that parents/carers are looked after and cared for in addition to the child themselves, when in hospital, in particular in relation to providing comfortable beds and ensuring that they were provided with food. Access to a good Wi-Fi connection was really important to both parent/carers and to older children. This was essential in terms of keeping in contact with friends/family and the outside world, keeping children entertained and for parent/carers to be able to continue to work whilst caring for their child if they needed to.

Improving food for patients

Several parent/carers and children felt that improvements to the choice and/or quality of hospital food provided could be made. Some children did not like the taste of the food, and parents having to deal with the financial burden of purchasing food from elsewhere for their child to eat when staying in hospital. Some also felt that there was a very limited choice in food available, with menus not changing.

Wider hospital issues

Wider hospital issues were mentioned in the freetext comments. These related to privacy, outdated wards, car parking (availability and expense), waiting, and a decline in care/services during weekends, bank holidays and during school holidays.

Other

Some comments referred to the impact of the COVID-19 pandemic on their care and experience. This included visiting restrictions and limited access to play facilities.

Comments around primary care tended to be in relation to diagnosis and parent/carers feeling that the GP they dealt with did not recognise and/or diagnose their child as quickly as they should have done.

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 2020 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 Document. 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

P3313_U16 CPES 2020 National Freetext Report v5.0 AT CW PF BK 091121