

Under 16 Cancer Patient Experience Survey: Development Report

Date: 21 October 2020

Authors: Megan Bilas, Amy Tallett, Juan Abad-Madroño

Picker

Picker is a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

© Picker 2020

Published by and available from:

Picker Institute Europe

Buxton Court

3 West Way

Oxford, OX2 0JB

England

Tel: 01865 208100

Fax: 01865 208101

Email: Info@PickerEurope.ac.uk

Website: www.picker.org

Registered Charity in England and Wales: 1081688

Registered Charity in Scotland: SC045048

Company Limited by Registered Guarantee No 3908160

Picker Institute Europe has UKAS accredited certification for ISO20252: 2012 (GB08/74322) and ISO27001:2013 (GB10/80275). We comply with Data Protection Laws including the General Data Protection Regulation, the Data Protection Act 2018 and the Market Research Society's (MRS) Code of Conduct.

Contents

Background	1
Desk research	1
Focus groups/Interviews	2
Focus group demographics	3
Interview demographics	4
Survey creation	5
Cognitive Testing Process	6
Child demographics	8
Parent/carer demographics	10
Cognitive Testing Results – Round One	11
Feedback on the covering letter	11
Overall comments on the questionnaire	11
Questionnaire and covering letter amendments	11
Cognitive Testing Results – Round Two	17
Feedback on the covering page	17
Overall comments on the questionnaire	17
Questionnaire amendments	17
Cognitive Testing Results – Round Three	21
Feedback on the covering page	21
Overall comments on the questionnaire	21
Questionnaire amendments	21
Post cognitive testing changes	24
Discussion	25
Data sharing	25
Impact of coronavirus on cancer care	26
Future considerations	26
Appendices	28
Appendix A: Organisations/groups represented in the Under 16 Cancer Patient Experience Survey Advisory Group	28
Appendix B: Focus group topic guide	29
Appendix C: Children’s interview topic guide	34

Background

One of the key ways that patient experience data for cancer patients is captured in England is through the National Cancer Patient Experience Survey (NCPES). Although the NCPES helps to highlight patient experience for adults, no formal national mechanism for capturing the experiences of children with cancer under the age of 16 currently exists. Subsequently, NHS England and NHS Improvement commissioned Picker Institute Europe (Picker) to develop and run a survey targeted towards children under the age of 16, along with their parents/carers, to understand their experiences of cancer care.

This report outlines the development process used to create and refine the Under 16 Cancer Patient Experience Survey. Development took place across four stages:

- Desk research to understand background information on cancer care for children
- Exploratory focus groups and in-depth interviews with parents and children to inform survey content
- Survey creation using agreed branding
- Refinement of the survey and covering letters through cognitive testing

An Advisory Group composed of patients, parents, commissioners, representatives from children's cancer charities, academics, hospital trust clinicians, and NHS cancer programme representatives was established early in the project. A full list of organisations and groups represented in the Advisory Group can be found in Appendix A. This group met regularly to provide methodological advice at these four key stages. The clinical members of the Advisory Group were also consulted on care pathways and treatment options to ensure that the survey design was appropriate.

The stages are described in greater detail below.

Desk research

Researchers started by analysing existing relevant literature, online content and other reference materials including the draft service specifications for children's cancer care, to ensure an appropriate background understanding of cancer care for children. The following questions were investigated during this process:

- How many children are diagnosed with cancer?
- What are the cancer types?
- What does cancer care for children look like?
 - What is the typical care pathway?
 - What are the treatment options?
 - Where is care delivered?
 - What staff are involved in care delivery?
- What language/terminology do children use?

Focus groups/Interviews

Findings from the desk research phase were used to inform the next exploratory phase of the project. Two focus groups were conducted with parents/carers of children with cancer or certain types of non-malignant tumours:

- Manchester on 22nd February 2020
- London on 23rd February 2020

Each group was composed of six parents/carers. A topic guide was used to help structure conversation (see Appendix B).

Whilst focus groups were originally planned with children, these were substituted with individual interviews with nine children between the ages of 8 and 15, due to challenges in accessing children of the same age cohort at the same date, time and location. A topic guide similar to the adult version, but with language and content tailored for children, was used to structure the interview discussions (see Appendix C). Interviews were conducted from February through March 2020. There were nine interviews in total; four interviews with children aged 8-11 and five interviews with children aged 12-15. Interviews were conducted both face to face (x3) and remotely by either phone or video call via Microsoft Teams (x6).

All focus group and interview participants were offered a £30 gift voucher as a thank you for their time. After screening potential participants to ensure that they had received care within the last six months, participants were recruited based on the following mixture of demographic and geographic characteristics:

- Address
- Age of child
- Gender
- Ethnicity
- (For parents only), relationship of the adult to child
- Child's cancer type
- Stage of child's cancer pathway
- Where the child receives the majority of their cancer care
- Availability to take part

A purposive sampling approach was used during recruitment. Picker worked with patient groups that NHS England and NHS Improvement already had contact with about the research, along with Advisory Group members (including clinicians, charities such as CLIC Sargent, and parent/young patient representatives), and provided them with an advert to publicise the research opportunity to their members via their social media channels (Twitter/Facebook), on their organisations, and/or their websites. Principal Treatment Centre children's cancer contacts and patient survey leads were similarly approached to post adverts on their social media channels and/or websites, and share with their patients.

Demographic information for child and parent/carer participants can be found in tables 1-11.

Focus group demographics

Table 1. Child gender

Gender	Count
Female	4
Male	8
Total	12

Table 2. Relationship with child

Relationship with Child	Count
Father	1
Mother	11
Total	12

Table 3. Age of the child

Age	Count
13	1
12	1
11	1
10	1
9	2
7	2
6	3
3	1
Total	12

Table 4. Hospital where child receives most of their care

Hospital	Count
Alder Hey	1
Calderdale shared care with Leeds General Infirmary	1
Clatterbridge Cancer Centre	1
Great Ormond Street Hospital	1
Kingston	2
Oxford	1
Royal Manchester Children's Hospital	3
Royal Marsden	1
St George's	1
Total	12

Table 5. Type of cancer/tumour

Type of cancer/tumour	Count
Germ cell tumour, trophoblastic tumour, and/or neoplasm of gonads	1
Langerhans Cell Histiocytosis	1
Lymphoma and/or reticuloendothelial neoplasm	1
Malignant bone tumour	1
Neuroblastoma and/or other peripheral nervous cell tumour	1
Leukaemia, myeloproliferative disease, and/or myelodysplastic disease	7
Total	12

Table 6. Time since diagnosis

Time since diagnosis	Count
Between 1 or 2 years ago	3
Over 2 years ago	9
Total	12

Interview demographics

Table 7. Child gender

Gender	Count
Female	3
Male	6
Total	9

Table 8. Age of the child

Age	Count
16	1
14	2
13	1
12	1
11	1
10	1
9	2
Total	9

Table 9. Hospital where child receives most of their care

Hospital	Count
Addenbrookes	1
Alder Hey	1
Kingston	1
Royal Manchester Children's Hospital	3
Royal Marsden	1
Southampton Central	1
St George's	1
Total	9

Table 10. Type of cancer/tumour

Type of cancer/tumour	Count
Germ cell tumour, trophoblastic tumour, and/or neoplasm of gonads	1
Langerhans Cell Histiocytosis	1
Lymphoma and/or reticuloendothelial neoplasm	1
Papillary thyroid cancer	1
Leukaemia, myeloproliferative disease, and/or myelodysplastic disease	5
Total	9

Table 11. Time since diagnosis

Time since diagnosis	Count
4 months ago	1
Between 7 and 12 months ago	1
Between 1 or 2 years ago	1
Over 2 years ago	6
Total	9

Survey creation

Data gathered during the desk research and focus groups/interviews was analysed and organised into the following themes:

- Continuity of care and smooth transitions
- Involvement and support for family and carers
- Emotional support, empathy and respect
- Clear information, communication and support for self-care
- Involvement in decisions and respect for preferences
- Fast access to reliable health advice

- Attention to physical and environmental needs
- Effective treatment delivered by trusted professionals
- “Being able to continue being me” - minimising the impact on children’s lives

These themes were presented to Advisory Group members during the March 2020 meeting. Feedback from this meeting along with advice from other experts and the draft service specifications for the Children’s Cancer Network, including Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs), helped to inform the survey content. A full breakdown of the main evidence sources behind each survey question can be found in Appendix D.

After the initial draft questions and response options were approved by NHS England and NHS Improvement, three paper surveys were designed using Adobe InDesign. A specific survey brand and logo was designed by Global Initiative¹, with input from Picker and NHS England and NHS Improvement. The three versions were as follows:

- a survey for parents/carers of children aged 0-7
- a survey for children aged 8-11 to complete, with a section for parents/carers
- a survey for children aged 12-15 to complete, with a section for parents/carers

Child-friendly survey sections were created for children aged 8 and older. The 8-11 year-old version contained smiley faces alongside scaled response options and simplified wording. The 12-15 year old child version had slightly different wording at some questions and did not contain smiley faces. Both versions contained graphics.

Following approval on the first draft questionnaires by NHS England and NHS Improvement, a session was held with the Advisory Group to provide feedback on the content. Picker then reviewed, discussed and incorporated the feedback provided during the session and through later email communications. NHS England and NHS Improvement reviewed and approved the second version of the drafted questionnaires before cognitive testing began.

Cognitive Testing Process

Following survey creation, three rounds of cognitive testing were carried out with children between the ages of 8-11 and 12-15, along with their parents. Parents of children aged 0-7 were also interviewed.

Cognitive testing is a research method which tests questionnaire items and any associated materials (e.g. covering letters) with lay people to check that they are understood as intended. It also tests whether respondents are able to answer questions appropriately using the response options provided. Cognitive testing involves holding interviews with potential

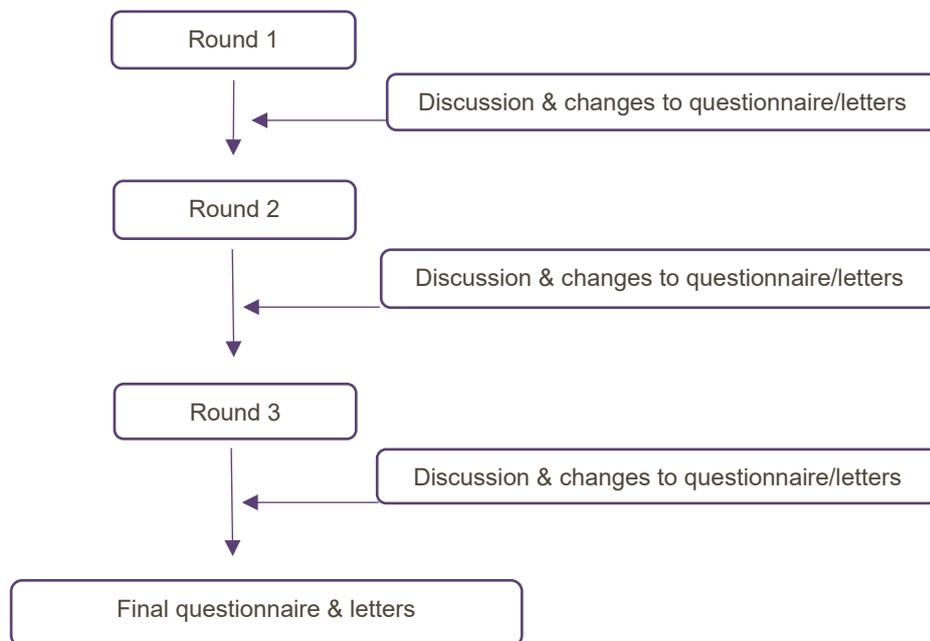
¹ <https://www.global-initiative.com/>

survey respondents and asking them to complete the questionnaire, reading out loud the questions and their response, explaining the reasoning behind their answers.

The interviewer observes the responses that the participant makes and periodically asks questions such as whether they understood the question and what they thought it meant, what their circumstances were and what they were thinking about when considering their answer. The interviewer also pays attention to whether the respondent appears to hesitate or struggle when answering certain questions, and whether the instructions were read and followed correctly.

Cognitive testing ensures that the instructions, questions and response options are relevant and understood. Refinements are made to the questionnaire and associated materials following each round of cognitive testing in response to any issues that were evidenced by the interviews. This process is summarised in Figure 1.

Figure 1: Cognitive testing process



The interviewees were recruited via a range of mechanisms. Picker prepared advertisements that were shared with patient groups that NHS England and NHS Improvement and Picker had already contacted about the research (including focus group and interview participants that had agreed to be re-contacted), and with Advisory Group members. These advertisements were also posted to Picker social media accounts (e.g. Facebook/Twitter). Two Principal Treatment Centre survey leads who had been very responsive in helping with focus group recruitment activities were also approached to post advertisements on their social media sites.

Interviews were conducted from May through July 2020. There were 36 interviews in total, split evenly amongst the three survey versions. Participants were given £30 in ‘Love2Shop’

or Amazon vouchers as a thank you for their time. Due to social distancing measures at the time and the vulnerability of children receiving treatment, all interviews were conducted remotely by either phone or video call via Microsoft Teams. Participants were sent survey materials (a covering letter and the questionnaire) via email and were asked to print the materials out if they were able, although some participants viewed the materials on their computer or phone screens. Overall demographic information of child and parent/carer participants can be found in tables 12-19.

Child demographics

Table 12. Child gender

Gender	Count
Male	17
Female	19
Total	36

Table 13. Child ethnicity

Ethnicity	Count
Asian or Asian British	2
Black or Black British	1
Mixed or multiple ethnic groups	7
White or White British	26
Total	36

Table 14. Child Geographic location

Location	Count
East Midlands	2
East of England	3
London	4
North East	2
North West	3
South East	12
South West	3
West Midlands	1
Yorkshire and Humber	6
Total	36

Table 15. Type of cancer/tumour

Cancer/tumour type	Count
A non-malignant brain, other central nervous system or intracranial tumour	3
CNS and/or miscellaneous intracranial and intraspinal neoplasm	1
Leukaemia, myeloproliferative disease, and/or myelodysplastic disease	14
Lymphoma and/or reticuloendothelial neoplasm	4
Malignant bone tumour	3
Neuroblastoma and/or other peripheral nervous cell tumour	1
Other*	8
Soft tissue and/or other extra osseous sarcoma	2
Total	36

*Other: Langerhans Cell Histiocytosis; Genetic condition NF1 Bilateral optic pathway gliomas; Malignant melanoma; Relapsed Medulloblastoma in the brain and spine; Rosette forming glioneuronal tumour; Medulloblastoma; Rhabdomyosarcoma

Table 16. Stage in cancer care pathway

Stage	Count
Watch and wait	3
Currently receiving treatment	24
Have finished treatment within the last month	3
In remission/long-term follow-up	5
Other	1
Total	36

Table 17. Most recent type of cancer care

Type of Care	Count
Inpatient hospital stay	9
Day case	13
Outpatient appointment	13
Other	1
Total	36

Parent/carer demographics

All adults interviewed were parents of the children.

Table 18. Parent gender

Gender	Count
Male	5
Female	31
Total	36

Table 19. Parent ethnicity

Ethnicity	Count
Asian or Asian British	3
Black or Black British	1
Mixed or multiple ethnic groups	2
White or White British	30
Total	36

Cognitive Testing Results – Round One

Twelve cognitive interviews were conducted in round one, which were evenly split amongst the three survey versions: parents of 0-7 year-olds; 8-11 year-olds and their parents; and 12-15 year-olds and their parents.

Feedback on the covering letter

Some first round participants thought that the second page of the covering letter was too long and contained too much information, resulting in participants either scanning through the second page or not reading it all. A decision was made to leave the second page as is, due to the need to provide detailed information for those who wanted it.

Overall comments on the questionnaire

Participant views on the length of the questionnaire were varied, but most were fine with the length. Participants agreed that the questionnaire was comprehensive and covered most phases of care. Although one participant disliked the graphics, most participants liked the colourful formatting. Overall, most first round participants thought that the questionnaires were easy to read and useful.

Questionnaire and covering letter amendments

The following amendments were made to the covering letter/questionnaire:

Covering letter/Survey instruction text

Round 1 version	Round 2 version
Please answer the following questions about any healthcare staff you have seen for your child’s cancer or tumour in the last year <u>at the NHS trust named in the covering letter.</u>	Please answer the following questions about any healthcare staff you have seen for your child’s cancer or tumour in the last year <u>at the hospital named in the covering letter.</u>

Change: Changed from ‘NHS Trust’ to ‘hospital’ in the covering letter and survey instruction text.

Rationale: To make the covering letters and the survey clearer to the respondents, as they are more likely to know the name of the hospital rather than the trust. This is particularly important for this patient population who are likely to receive care at multiple NHS hospitals in a short space of time, to ensure the results are attributable to a specific site.

Question 1 (0-7)/Question 29 (8-11)/Question 32 (12-15)

Round 1 version	Round 2 version
<p>1 Which of the following best describes the current care or treatment relating to your child's cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are currently receiving treatment</p> <p>3 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>4 <input type="checkbox"/> They are in remission/ long-term follow-up</p> <p>5 <input type="checkbox"/> They are receiving end of life/ palliative care</p> <p>6 <input type="checkbox"/> They have recently passed away</p> <p>7 <input type="checkbox"/> Other</p>	<p>1 Which of the following best describes the current care or treatment relating to your child's cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment to reduce or remove their cancer</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving end of life/ palliative care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>

Changes: Answer option 'They are currently receiving treatment' amended to 'They are currently receiving treatment to reduce or remove their cancer.' 'They are in watch and wait' added as a response option.

Rationale: Some participants raised that the treatment was unrelated to the cancer itself and was, instead, meant to deal with long term side effects of cancer. A few participants reported that their child was in watch and wait.

Question 15 (0-7)/ Question 11 (8-11) and (12-15)

Round 1 version	Round 2 version
<p>11 Sometimes one member of staff will tell you one thing and another will tell you something different. Does this happen to you?</p> <p>1  <input type="checkbox"/> Yes, always</p> <p>2  <input type="checkbox"/> Yes, sometimes</p> <p>3  <input type="checkbox"/> No</p>	<p>15 Are you ever told different things by different members of staff, which leaves you feeling confused?</p> <p>1 <input type="checkbox"/> Yes, always</p> <p>2 <input type="checkbox"/> Yes, sometimes</p> <p>3 <input type="checkbox"/> No</p>

Change: Question text re-worded to 'Are you ever told different things by different members of staff, which leaves you feeling confused?'

Rationale: The previous question wording was open to misunderstanding as respondents could be provided with alternative possibilities without any of those being an issue.

Question 22 (0-7)

Round 1 version	Round 2 version
<p>22 Do you always know what is happening with your child’s cancer or tumour care, including what will happen next?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> This is not needed</p>	<p>22 Do you always know what is happening with your child’s cancer or tumour care?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> This is not needed</p>

Change: Removed 'including what will happen next' from the question text.

Rationale: This question was asking about two separate things: short-term and long-term care. The general feeling amongst respondents was that they knew what was happening at that moment, but did not necessarily know about the future. Some felt HCPs have held back information on future steps since what happens next may depend on the outcome of what is happening now.

Question 27 (0-7)

Round 1 version	Round 2 version
<p>27 Is your child’s care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?</p> <p>1 <input type="checkbox"/> Yes, always</p> <p>2 <input type="checkbox"/> Yes, sometimes</p> <p>3 <input type="checkbox"/> No</p>	<p>27 Is your child’s care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?</p> <p>1 <input type="checkbox"/> Yes, always</p> <p>2 <input type="checkbox"/> Yes, sometimes</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> This is not needed</p>

Change: Added a 'This is not needed' response option.

Rationale: One participant wanted a 'Not applicable' response option added since her work is flexible. While she eventually she chose 'Yes, always,' the change was deemed necessary in order to more accurately capture similar responses.

Question 28 (0-7)

Round 1 version	Round 2 version
<p>28 Has your child received treatment for their cancer or tumour in the last one year?</p> <p>1 <input type="checkbox"/> Yes Go to Question 29</p> <p>2 <input type="checkbox"/> No Go to Question 34</p>	<p>28 Has your child received treatment for their cancer or tumour in the last year?</p> <p>1 <input type="checkbox"/> Yes Go to Question 29</p> <p>2 <input type="checkbox"/> No Go to Question 34</p>

Change: Removed the word 'one.'

Rationale: Some participants thought that the word 'one' was odd. In addition, this was the only question that used 'in the last one year,' while the rest of the questions used 'in the last year.'

Question 33 (0-7)

Round 1 version	Round 2 version
<p>33 If your child's treatment has finished, did you receive enough ongoing support after it ended?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> This was not needed</p> <p>5 <input type="checkbox"/> My child is still receiving treatment</p>	<p>33 If your child's treatment has finished, did you receive enough ongoing support after it ended from the hospital?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> Not applicable / This was not needed</p> <p>5 <input type="checkbox"/> My child is still receiving treatment</p>

Change: Amended response option 4 to 'Not applicable/ This was not needed.'

Rationale: A few participants had finished treatment but then relapsed and thought that a 'Not applicable' option would best describe their situation.

General (8-11) and (12-15)

Round 1 version	Round 2 version
<p style="text-align: center;">FINDING OUT ABOUT YOUR CANCER OR TUMOUR</p> <p>If you have been told you have had a tumour or cancer more than once, please think about the most recent time when answering the following questions.</p> <p>1 Were you told you had cancer or a tumour within the last year?</p> <p>1 <input type="checkbox"/> Yes Go to Question 2</p> <p>2 <input type="checkbox"/> No Go to Question 6</p> <hr/> <p>2 Were you told you had cancer or a tumour at the NHS Trust named in the letter that came with this questionnaire?</p>	<p style="text-align: center;">FINDING OUT ABOUT YOUR CANCER OR TUMOUR</p> <p>If you have had cancer or a tumour more than once, please think about the most recent time when answering the following questions.</p> <p>1 Were you told you had cancer or a tumour within the last year?</p> <p>1 <input type="checkbox"/> Yes Go to Question 2</p> <p>2 <input type="checkbox"/> No Go to Question 6</p> <hr/> <p>2 Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?</p>

Change: Yellow font changed to blue.

Rationale: One participant raised that the yellow colour was difficult to read. Furthermore, there were concerns about how clear the yellow would appear when printed on white paper.

Question 12 (8-11) and (12-15)

Round 1 version	Round 2 version
<p>12 Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> Charities such as Macmillan or CLIC Sargent</p> <p>2 <input type="checkbox"/> A psychologist or counsellor</p> <p>3 <input type="checkbox"/> Places I can meet other children with cancer or a tumour</p> <p>4 <input type="checkbox"/> Other</p> <p>5 <input type="checkbox"/> No, none of the above</p>	<p>12 Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> Charities (such as Macmillan or CLIC Sargent)</p> <p>2 <input type="checkbox"/> A psychologist or counsellor</p> <p>3 <input type="checkbox"/> Other children with cancer or a tumour</p> <p>4 <input type="checkbox"/> Other</p> <p>5 <input type="checkbox"/> No, none of the above</p>

Changes: Amended response option 1 to put the examples in brackets i.e. 'Charities (such as...)'. Changed response option 3 to 'Other children with cancer or a tumour' and in the parents section to 'Other parents with children with cancer or a tumour.'

Rationale: The change in response option 1 resulted from some participants thinking that only Macmillan or CLIC Sargent should be considered. Response option 3 was amended to better reflect that it is asking about people rather than places.

Question 15 (8-11)

Round 1 version	Round 2 version
<p>15 Has your care or treatment changed what you are normally able to do, such as seeing friends, doing hobbies or going to school?</p> <p>1 😞 <input type="checkbox"/> Yes, definitely Go to Question 16</p> <p>2 😊 <input type="checkbox"/> Yes, sort of Go to Question 16</p> <p>3 😊 <input type="checkbox"/> No Go to Question 17</p>	<p>51 Has your child's care or treatment changed what they are normally able to do, such as seeing friends, doing hobbies or going to school?</p> <p>1 <input type="checkbox"/> Yes, definitely Go to Question 52</p> <p>2 <input type="checkbox"/> Yes, sort of Go to Question 52</p> <p>3 <input type="checkbox"/> No Go to Question 53</p>

Change: This question was deleted from the children's section and moved to the parents/carers section within the 8-11 year-old version of the questionnaire.

Rationale: This question was difficult for 8-11 year-old participants to understand.

Question 16 (8-11)

Round 1 version	Round 2 version
<p>16 Have you spoken to staff about this?</p> <p>1  <input type="checkbox"/> Yes</p> <p>2  <input type="checkbox"/> No, but I would like to</p> <p>3  <input type="checkbox"/> This is not needed</p>	<p>52 Have you spoken to staff about this?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, but I would like to</p> <p>3 <input type="checkbox"/> This is not needed</p>

Change: This question was moved from the children’s section to the parents/carers section within the 8-11 year-old version of the questionnaire.

Rationale: The previous question was difficult for 8-11 year-old participants to understand. This question is a follow up of the previous question.

Question 25 (8-11)/ Question 27 (12-15)

Round 1 version	Round 2 version
<p>27 Overall, what do you think about your cancer or tumour care? Please think about the NHS trust named in the covering letter that came with this questionnaire.</p> <p>1  <input type="checkbox"/> Very good</p> <p>2  <input type="checkbox"/> Good</p> <p>3  <input type="checkbox"/> OK</p> <p>4  <input type="checkbox"/> Bad</p> <p>5  <input type="checkbox"/> Very Bad</p>	<p>25 Overall, how well are you looked after for your cancer or tumour by the healthcare staff?</p> <p>1  <input type="checkbox"/> Very well</p> <p>2  <input type="checkbox"/> Quite well</p> <p>3  <input type="checkbox"/> OK</p> <p>4  <input type="checkbox"/> Not very well</p> <p>5  <input type="checkbox"/> Not at all well</p>

Change: Question wording amended.

Rationale: Child participants were thinking about specific treatments, rather than about their overall experiences of care. The original wording was especially difficult for 8-11 year olds to understand. Some answered negatively as they did not like having cancer and associated care, rather than thinking about the quality of their care.

Cognitive Testing Results – Round Two

Ten cognitive interviews were conducted in round two – consisting of four interviews with parents of 0-7 year-olds, four interviews with 8-11 year-olds and their parents, and two interviews with 12-15 year-olds and their parents.

Feedback on the covering page

Interview participants thought that the first page of the covering letter was clear. However, some suggested that the back page containing more details about privacy was too long and should be shortened. One participant suggested that more details should be provided about the benefits of the survey.

No amendments were made to the covering page due to the need to keep all of the details about privacy within the letter for those who wanted it. However, NHS England and NHS Improvement may wish to consider adding more details about how the survey has impacted children’s cancer and tumour care at some point in the future.

Overall comments on the questionnaire

Participants thought that although the questionnaire was long, it was comprehensive and covered most phases of care. The parent’s section was clear. However, the children’s section, especially the 8-11 year-old version, required some adjusting in order to make some questions more understandable.

Questionnaire amendments

The following amendments were made to the questionnaire:

Question 1 (0-7)/Question 29 (8-11)/Question 32 (12-15)

Round 2 version	Round 3 version
<p>1 Which of the following best describes the current care or treatment relating to your child’s cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment to reduce or remove their cancer</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving end of life/ palliative care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>	<p>32 Which of the following best describes the current care or treatment relating to your child’s cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving end of life/ palliative care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>

Change: Answer option 'They are currently receiving treatment to reduce or remove their cancer' changed to 'They are currently receiving treatment to reduce or get rid of their cancer.'

Rationale: Some participants with blood cancer argued that these kind of cancers are not removed (in the same sense that a physical tumour would be), but are instead eliminated.

Question 11 (0-7)

Round 2 version	Round 3 version
<p>11 When you ask staff questions about your child's care or treatment, do you get answers that you can understand?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I have not asked questions</p> <p>5 <input type="checkbox"/> I have not had a chance to ask questions</p>	<p>11 Have you had chance to ask staff questions about your child's care and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I have not had any questions</p>

Change: Question wording and intent changed.

Rationale: Question 11 was very similar to question 10. Question 11 was changed to ask about the ability to ask questions to healthcare staff.

Question 18 (0-7)/Question 12&43 (8-11) and (12-15)

Round 2 version	Round 3 version
<p>18 Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> Charities (such as Macmillan or CLIC Sargent)</p> <p>2 <input type="checkbox"/> A psychologist or counsellor</p> <p>3 <input type="checkbox"/> Other parents of children with cancer or a tumour</p> <p>4 <input type="checkbox"/> Other</p> <p>5 <input type="checkbox"/> No, none of the above</p>	<p>18 Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> Charities (such as CLIC Sargent or Macmillan)</p> <p>2 <input type="checkbox"/> A psychologist or counsellor</p> <p>3 <input type="checkbox"/> Other parents of children with cancer or a tumour</p> <p>4 <input type="checkbox"/> Other</p> <p>5 <input type="checkbox"/> No, none of the above</p>

Change: Swapped CLIC Sargent with Macmillan in brackets.

Rationale: CLIC Sargent is a better known charity for the families of children with cancer or tumours, due to the age of the target population of this survey (under 16 years).

Question 19 (0-7)/Question 44 (8-11)/Question 47 (12-15)

Round 2 version	Round 3 version
<p>19 Do you have information about how to get financial help or any benefits you might be entitled to?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, but I would like this information</p> <p>3 <input type="checkbox"/> This was not needed</p> <p>4 <input type="checkbox"/> Don't know / can't remember</p>	<p>19 Do you have enough information about how to get financial help or any benefits you might be entitled to?</p> <p>1 <input type="checkbox"/> Yes, I have enough information</p> <p>2 <input type="checkbox"/> Some, but not enough information</p> <p>3 <input type="checkbox"/> No, but I would like this information</p> <p>4 <input type="checkbox"/> This was not needed</p> <p>5 <input type="checkbox"/> Don't know / can't remember</p>

Change: Changed question text to 'Do you have enough information...'. Changed response options to 'Yes, enough information' and 'Some, but not enough information.'

Rationale: Some participants felt that the question was lacking the response options needed to express that they had received information, but not enough.

Question 21 (0-7)

Round 2 version	Round 3 version
<p>21 Are different hospital members of staff caring for your child aware of their medical history?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> Don't know / not applicable</p>	<p>21 Are different hospital members of staff caring for your child aware of your child's medical history?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> Don't know / not applicable</p>

Change: Replaced 'their' with 'your child's' in the question text.

Rationale: Some participants were confused by the question, as they did not understand that the question was referring to the medical history of the child.

Question 27 (0-7)/Question 50 (8-11)/Question 53 (12-15)

Round 2 version	Round 3 version
<p>27 Is your child's care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?</p> <p>1 <input type="checkbox"/> Yes, always</p> <p>2 <input type="checkbox"/> Yes, sometimes</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> This is not needed</p>	<p>50 Is your child's care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked this</p> <p>4 <input type="checkbox"/> No, but this was not needed or possible</p>

Change: Changed response options from 'No, but I would like this' to 'No but this was not needed or possible.'

Rationale: Some participants felt that the question was lacking the response options needed for a set treatment in which it was not possible to arrange for the treatment at a suitable time.

Question 34 (0-7) /Question 59 (8-11)/Question 60 (12-15)

Round 2 version	Round 3 version
<p>34 Has your child stayed on a hospital ward (as a day patient or for an overnight stay) for care relating to their cancer or tumour, in the last year?</p> <p>1 <input type="checkbox"/> Yes Go to Question 35</p> <p>2 <input type="checkbox"/> No Go to Question 46</p>	<p>60 Has your child stayed on a hospital ward (as a day patient or for an overnight stay) for care relating to their cancer or tumour, in the last year?</p> <p>1 <input type="checkbox"/> Yes Go to Question 61</p> <p>2 <input type="checkbox"/> No Go to Question 66</p>

Change: Bolded the word 'hospital ward.'

Rationale: To avoid confusion with potential treatment in outpatient clinics.

Cognitive Testing Results – Round Three

Fourteen interviews were conducted in round three – consisting of four interviews with parents of 0-7 year-olds, four interviews with 8-11 year-olds and their parents, and six interviews with 12-15 year-olds and their parents.

Feedback on the covering page

Most participants thought that the covering page contained all the information they needed and clearly understood the content. One participant thought that the back page containing more information about privacy could be simplified and shortened.

No amendments were made to the covering page due to the majority of participants agreeing that they understood the content and did not have any further questions.

Overall comments on the questionnaire

Round three participants generally thought that the length and flow of the questionnaire was good. Participants particularly liked the colour-coded sections and that there were separate sections for children and parents to complete. Most participants agreed that the questionnaire was comprehensive and covered all the issues they would want to feedback on. Two participants who had encountered issues with misdiagnosis noted that there were no questions that specifically covered this. However, they mentioned that they would have provided more feedback about this within the free-text comments section.

Questionnaire amendments

The following amendments were made to the questionnaire:

Question 14 (12-15)

Round 3 version	Final version
<p>14 Are you involved in decisions about your care and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, sort of</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> This is not needed</p>	<p>14 Are you involved in decisions about your care and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, sort of</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> No, but this is not needed or possible</p>

Change: Answer option “This is not needed” changed to “No, but this was not needed or possible”.

Rationale: Some participants were not involved in decisions about their care and treatment due to the expediency at which treatment needed to be started or because there were no other options. In these instances, it was not immediately clear whether they should choose “Yes, sort of,” “No” or “This is not needed.” The last answer option was modified to better

accommodate instances in which it was not possible for respondents to be involved in decisions about their care and treatment.

Question 1 (0-7)/Question 29 (8-11)/Question 32 (12-15)

Round 3 version	Final version
<p>32 Which of the following best describes the current care or treatment relating to your child's cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving end of life/ palliative care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>	<p>32 Which of the following best describes the current care or treatment relating to your child's cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and are waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving palliative or end of life care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>

Change: The option “They are receiving end of life/palliative care” was changed to “They are receiving palliative care or end of life care.”

Rationale: Participants pointed out that palliative care is not always the same as end of life care. Participants were much more hesitant to choose “They are receiving end of life/palliative care” when the palliative care their child was receiving was not related to end of life care.

Question 37 (8-11)/Question 40 (12-15)

Round 3 version	Final version
<p>37 Have you had chance to ask staff questions about your chid's care and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I have not had any questions</p>	<p>40 Have you had the chance to ask staff questions about your child's care and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I have not had any questions</p>

Change: Spelling and grammatical errors were corrected (‘Have you had chance’ changed to ‘Have you had the chance’ and ‘chid’s’ changed to ‘child’s’).

Rationale: There were two typos at this question. Please note that these typos were only present in round three following a change made to the question at the end of round two.

Question 18 (0-7)/Questions 12&43 (8-11)/Question 12&46 (12-15)

Round 3 version	Final version
<p>43 Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> Charities (such as CLIC Sargent or Macmillan)</p> <p>2 <input type="checkbox"/> A psychologist or counsellor</p> <p>3 <input type="checkbox"/> Other parents of children with cancer or a tumour</p> <p>4 <input type="checkbox"/> Other</p> <p>5 <input type="checkbox"/> No, none of the above</p>	<p>46 Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> Charities (such as CLIC Sargent or Macmillan)</p> <p>2 <input type="checkbox"/> A psychologist or counsellor</p> <p>3 <input type="checkbox"/> Other parents of children with cancer or a tumour</p> <p>4 <input type="checkbox"/> Other</p> <p>5 <input type="checkbox"/> No, none of the above</p> <p>6 <input type="checkbox"/> Don't know / can't remember</p>

Change: Added a 'Don't know / can't remember' option.

Rationale: The information that this question asks about is typically provided at diagnosis or the start of treatment. Therefore, it can be difficult for some respondents to remember this information, especially if they are further along in their care pathway. This answer option was added to reduce non-response or inaccuracies.

Question 68 (8-11) and (12-15)

Round 3 version	Final version
<p>68 Who was the main person who answered the questions in the children's section of the questionnaire?</p> <p>1 <input type="checkbox"/> The child / young patient</p> <p>2 <input type="checkbox"/> The parent or carer</p> <p>3 <input type="checkbox"/> Both the child / young patient and the parent or carer together</p>	<p>68 Who was the main person who answered the questions in the children's section of the questionnaire?</p> <p>1 <input type="checkbox"/> The child / young patient</p> <p>2 <input type="checkbox"/> The parent or carer</p> <p>3 <input type="checkbox"/> Both the child / young patient and the parent or carer together</p>

Change: The words 'children's section' were bolded.

Rationale: Respondents who might be quickly reading through the questionnaire could miss that this question is asking about who completed the children's section, especially after having just completed the parent's section.

Question 69

Round 3 version	Final version
<p>69 Other than your child’s cancer or tumour, do they have any unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>	<p>69 Other than your child’s cancer or tumour, do they have any unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>

Change: The word “unrelated” was bolded.

Rationale: Respondents who might be quickly reading through the questionnaire could miss that this is asking about unrelated conditions.

Post cognitive testing changes

Minor font colour and heading changes were made to the final questionnaires post cognitive testing. In addition, a change was made to the following question:

Question 1 (0-7)/Question 29 (8-11)/Question 32 (12-15)

Round 3 version	Final version
<p>1 Which of the following best describes the current care or treatment relating to your child’s cancer or tumour?</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and are waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving palliative or end of life care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>	<p>1 Which of the following best describes the current care or treatment relating to your child’s cancer or tumour? Please select all that apply.</p> <p>1 <input type="checkbox"/> They have recently been diagnosed and are waiting for further information about next steps</p> <p>2 <input type="checkbox"/> They are in watch and wait</p> <p>3 <input type="checkbox"/> They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>4 <input type="checkbox"/> They have finished treatment within the last one month</p> <p>5 <input type="checkbox"/> They are in remission /long-term follow-up</p> <p>6 <input type="checkbox"/> They are receiving palliative or end of life care</p> <p>7 <input type="checkbox"/> They have recently passed away</p> <p>8 <input type="checkbox"/> Other</p>

Change: “Please select all that apply” was added to the end of the question.

Rationale: While reviewing the draft survey handbook, Great Ormond Street Hospital provided feedback that patients who are in remission are often still receiving treatment, and therefore may fall into more than one category. In addition, previous conversations with NHS England and NHS Improvement and Advisory Group members indicated other areas of overlap. For example, someone could have finished treatment within the last one month and

also be receiving palliative care. This evidence, combined with a few cognitive interviews in which participants had difficulty choosing between options, indicated that this question should allow for multiple selections to be made.

Discussion

The Under 16s Cancer Patient Experience Survey was developed and refined based on extensive discussions with children and their parents. Advisory Group members and NHS England and NHS Improvement were continuously consulted throughout the process.

The final questionnaire was composed of 57 questions in the 0-7 year-old version and 71 questions in the 8-11 and 12-15 year-old versions. Following cognitive testing, there were 28 questions in total for 8-11 year-old children to answer and 43 questions for their parent/carer to answer. Meanwhile, there were 31 questions for 12-15 year-old children to answer and 41 questions for their parent/carer to answer. This difference is due to the movement of two questions from the children's section to the parent/carer section in the 8-11 year-old version of the questionnaire, which is described in more detail within the round one cognitive testing results. Each questionnaire version contained one open, free-text question in each child and parent section to allow for the collection of any additional thoughts on aspects of care that were good or could be improved. Due to printing restrictions requiring that all questions fit within an eight page booklet, the space for free-text commentary was limited in the 8-11 and 12-15 year-old versions. However, more space was allotted for the children's question in order to accommodate larger handwriting. Aside from a space for children to write in their age and a numeric scale question asking parents/carers to rate their child's overall cancer or tumour care, the rest of the survey was composed of multiple-choice questions.

Separate to the survey development, a sampling strategy was developed in consultation with Advisory Group members, PTCs and POSCUs. The sampling strategy defines the inclusion and exclusion criteria, and guides service providers to extract a sample of patients to be included in the survey.

Data sharing

All of the cognitive testing participants mentioned that they would be happy to complete the questionnaire. Only two concerns were raised around completion, with one participant raising a question about whether she would receive duplicate surveys due to her child receiving care from multiple hospitals. This concern should be addressed through the de-duplication process between different PTC sample files following their approval. Another participant mentioned that bereaved parents/carers might be less inclined to answer the questionnaire. This concern should largely be addressed through DBS checks to remove deceased patients during the sampling process and before each of the survey mailings is sent. NHS England and NHS Improvement however acknowledges the importance of hearing from bereaved parents through other, appropriate methods.

Most participants were also fine with their data being shared with Public Health England for data linkage purposes. However, a few participants wanted to know why their child's NHS

number would be shared and whether their child would be identifiable through the combination of NHS number, postcode and date of birth. These concerns are addressed within the covering letter and on the survey website:
www.under16cancerpatientexperiencesurvey.co.uk.

Impact of coronavirus on cancer care

Some participants, especially those who were currently receiving treatment, mentioned the impact that coronavirus had on their care and treatment. This arose at particular questions:

- Has your care or treatment changed what you are normally able to do, such as seeing friends, doing hobbies or going to school?
- When you were in hospital, were you able to get help from hospital staff when you needed it?
- Were there enough things for you to do in hospital?
- Were you given somewhere private to talk to staff when you were in hospital?
- Have you been visited at home by a nurse in the last year, for care for your cancer or tumour?
- When nurses speak to you, do you understand what they are saying?
- Which of the following best describes the current care or treatment relating to your child's cancer or tumour?
- If your child's treatment has finished, did you receive enough ongoing support after it ended?
- Were you able to prepare food in the hospital if you wanted to?
- Did your child have access to hospital school services during their stay in hospital?
- Are you involved as much as you want to be in decisions about your child's care and treatment?
- Do staff caring for your child give you information in a way that you can understand?

Participants mentioned that due to coronavirus restrictions, some services were limited. For instance within hospitals, school services, play rooms and games rooms had been closed. In addition, follow-up care services had been impacted with some tests being cancelled. In general, the aforementioned questions may be negatively impacted by coronavirus restrictions – resulting in a greater number of “No” responses. However, some participants did report an improvement in services, with shorter time spent in hospital.

Future considerations

While most key points have been taken on-board during the questionnaire development and refinement process, there are certain items that NHS England and NHS Improvement may want to consider after the survey has finished fieldwork. From a practical standpoint, the

decision was made to not include additional pages for free-text commentary or to indicate that respondents could provide their own pages due to not knowing how readily these questions would be completed or how much space the majority of respondents would need. NHS England and NHS Improvement may wish to reconsider this in the future. Alternatively, the data could indicate potential redundancy between questions that was not picked up during cognitive testing – leading to question reduction that could provide more free-text space.

Another issue that was raised during cognitive testing was the possible need for more “Don’t know/can’t remember” responses in the children’s section of the questionnaire, particularly for children with impaired cognitive function due to cancer/tumour treatment and younger children. However, it is thought that parents/carers will assist children who need help answering questions and that the question asking who completed the children’s section of the questionnaire will provide more insight into these instances. It is possible that children will receive less help from their parents/carers when completing the online version of the survey and this may be worth exploring through future cognitive testing of the online questionnaire.

An additional point worth future consideration is distinguishing between day-cases and overnight stays, particularly in regard to questions within the ‘Hospital Ward’ section of the questionnaire. Some cognitive testing participants raised that there is a difference between day-cases and overnight stays in regard to having enough privacy and being able to sleep. Participants who had recent experiences with both types of stays most often provided an average response. For example, they chose “Yes, to some extent” if it was not quiet enough for them to sleep during a day-case visit but it was quiet enough during their overnight stay.

Finally, NHS England and NHS Improvement may wish to consider switching the question “Which of the following best describes the current care or treatment relating to your child’s cancer or tumour?” from multi-select to single-select following wave one results. As previously mentioned, this question was cognitively tested as a single-select question but was changed to a multi-select question due to potential overlap between answer options. It would be worthwhile to analyse how many respondents choose multiple options following the first round of data collection.

Appendices

Appendix A: Organisations/groups represented in the Under 16 Cancer Patient Experience Survey Advisory Group

Alder Hey Children's Hospital
Anthony Nolan
Blood Cancer UK
Children and Young People Clinical Reference Group
Children's Cancer and Leukaemia Group (CCLG)
CLIC Sargent
Coventry University
Department of Health and Social Care
HealthWatch England
Leeds Teaching Hospitals
Newcastle Upon Tyne Hospitals
NHS England and NHS Improvement
Parent and patient representatives
Public Health England
Picker Institute Europe
Royal College of Nursing
Royal Manchester Children's Hospital
Royal Marsden Hospital
Royal Surrey County Hospital
Teenage Cancer Trust
The Brain Tumour Charity
University College London Hospitals
University of Nottingham
University of Surrey

Appendix B: Focus group topic guide

Introduction and aims- 5 mins

Welcome to this discussion group. Thank you for coming. My name is XXX, and this is XXX. We come from Picker, and we speak to lots of children, parents and adults about the care they receive to try and make things better

We are here today to ask about your (or your child's) cancer care. This will help us develop a new questionnaire that will be sent to thousands of children with cancer, and their parents.

We want to make sure that the questions we include are about areas of cancer care and treatment that are important to children and their parents

So, as children/ parents/ carers of someone with cancer, who have experience of going to hospital for cancer or have received cancer treatment, we would like your help to decide on what questions to include.

CHECK IF EVERYONE KNOWS WHAT A QUESTIONNAIRE IS?

Discussion Group protocol- 5 mins

- Before we start – Health and Safety – fire alarm, toilets, refreshments, etc.
- Mention safeguarding - If anyone reports anything worrying that suggests you may be at risk of harm, then we will need to pass this on.
- Re-check they have read the information sheet (read out loud the key points) and signed consent form (initial check made during recruitment set-up telephone call, take verbal consent and consent forms signed).
- Explain that it is voluntary.
- How a focus group works- Q&A. Role of facilitator. No right or wrong answers etc.
- Talk about your cancer care but only to extent that you are comfortable.
- No doctors or staff providing your care are involved, so you can be as honest as you like WILL NOT AFFECT TREATMENT etc.
- Will take about 90 minutes – but any of you can stop anytime and take a break/finish early. People may respond in different ways when talking about their experiences, or hearing about other peoples' experiences. It's ok if you need to step out or take a break- just let one of the facilitators know. You can go to see parents if wish to. For parents, ok to step out if your child needs attention.
- Recorded – to help analysis.
- Will be confidential, no names, nobody will know who has said what. Keep within room.
- Ground rules: Need to speak one at a time, give everybody a chance to talk
- Incentives – ensure everyone is given a £30 voucher at the end of the group
- Ask permission to turn on digital recorder.

Ice Breaker - 5 mins

Participant background

To provide demographic and other background details as a context for the main discussion. Asking participants to think of their favourite may help to start them thinking about prioritisation.

Introduce **yourself** and then ask each individual in turn to introduce themselves:

- Their name
- Where they live
- Who they live with
- Who/what is their favourite (superhero, chocolate bar, song, band, TV programme [Could vary between age groups.])

Activities

ACTIVITY 1 Road Map *(to understand where they are in their experience of cancer care and the different possible stages) 10 minutes

Provide a **map / road with images to represent key points** e.g. having tests, diagnosis/finding out about having cancer, having treatment, not having treatment, relapse.

Group members to think about **where they are on the map** and place a post it note where they think they are.

When they place their post-it note on the map, researchers to ask why they put it there to ensure they and we are all aware of where they currently are.

Provide blank post it notes for members of the group to add any **key points that have been missed** on the map.

ACTIVITY 2- shouty outy (to understand the range of places where people receive cancer care and who from). 10 minutes

(Researcher to write each thing shouted out onto a post it note and stick somewhere visible – this is to act as a prompt for the later discussion stages).

1. Where do you/ your child receive care?

e.g. hospital (on a ward? Overnight?), at home, at a doctor surgery

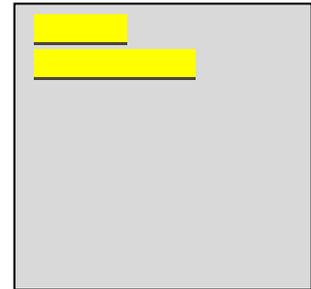
2. Who do you/your child receive care from?

e.g. doctors, nurses, other?

Group discussions

ACTIVITY 3

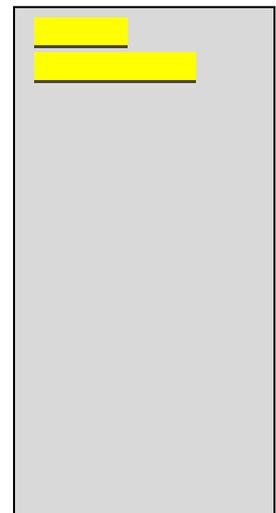
- Provide introduction to the activity
- Important note for researchers – key themes from participants will need to be put on post-it notes ready for the prioritisation activity.
- OPTIONAL ACTIVITY: For younger age groups, if the group is flagging, then consider adding activities between key topics, e.g. Ask the group a statement (e.g. Do you feel you received enough information at diagnosis?), and ask them to stand up/ run to one side of the room if their answer is ‘yes’ or sit down/ run to the other side of the room if their answer is ‘no’.



A) Staff - e.g relationships and communication (15 minutes)

Probing questions

- How **friendly are the staff** that you see? Are they helpful?
- Do you feel **comfortable asking staff** if you have questions or need something?
- How do you feel about the way that staff talk to you?
 - For children: Do they **talk to you**, not just your parent?
 - Do they talk to you in a way that **you can understand**?
 - For children: Do they talk to you in a way that **is suitable for your age**?
- Do doctors and nurses **talk to each other** about your/ your child’s cancer care? (e.g. doctor surgeries, hospitals and speciality treatment centres)
- **How do you feel about continuity of care?** How is information shared across care providers? Do you feel like all the people who care for you know enough about your individual care and treatment?
- Do you always **know what is happening** with your/ your child’s care?
- Do you feel **involved in decisions** about your/ your child’s care and treatment?



B) Information and support (15 minutes)

Probing questions

- Do you get **enough information** about your/ your child’s cancer and care? What about your (child/parent)?
 - Probes – ask in relation to each of the points on the road map, e.g.:
 - diagnosis,
 - treatment (before and after),
 - side effects (short and long term),
 - care at home
- **How** did you receive this information (i.e. through speaking to someone or in a leaflet)?
- Have you received **any counselling/ emotional support** (differentiate between NHS only or have they sought this out independently/privately?) N.B. important to

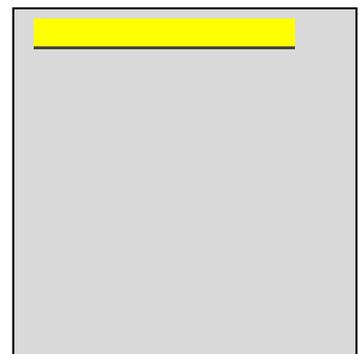
differentiate between children and their parents/siblings/wider family and whether or not they have been offered this.

- Has this been **timely** enough?
- Have you received **enough information** and signposting to counselling/emotional support option?
- **Voluntary services/ charities** (forums, support groups, website, phone lines, other?)
- **Social care at home?**
- **Medical care at home?**
- **Education?** (NHS, charities such as CLIC Sargent, word of mouth, support groups, books, internet etc.)
 - Have you had to stop school at all because of your cancer care?
 - **Support for returning to school (a 'new normal')**
 - How has access to social workers/psychologists/peer support/other networks, been?
 - Home schooling?
 - Have you been able to **meet others with cancer/ with children who have cancer** (e.g. support groups)?
 - If yes, was this helpful?
 - If no, would this be helpful?
- Were you able to still see your friends? Were there other children the same age on the ward?
- **Parent section on logistical information.** Probe for information around:
 - Navigating the hospital and ward, parking, employment, finances

C) Impact of cancer treatment and care on quality of life (15 minutes)

Probing questions

- How has receiving treatment for cancer affected your **everyday life**?
 - **Social/ family?** (how manage friendships, relationships)
 - **School/ work?**
 - **Physical?** (includes side effects but also physical wellbeing),
 - Does your cancer **stop you doing some things that you would want to do?**
 - **Emotional?** (includes side effects but also emotional wellbeing and Mental Health)
 - **Hospital environment**
 - Was there **enough to do** in hospital?
 - Could you have **visitors** when wanted?
 - **Facilities** e.g. Did WiFi work ok, refreshments available, was ward stayed on appropriate for age, cleanliness, privacy?
 - **Finances?**



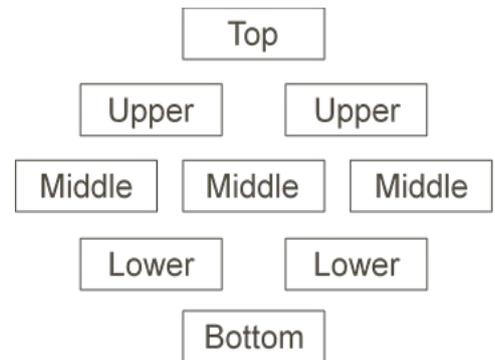
D) ANYTHING ELSE (5 minutes)

- Is there anything else that we haven't yet discussed that is important to you or stands out (either good or bad) about your cancer care?

To understand what children and parents consider the most important aspects of the experience of receiving cancer treatment and care.

ACTIVITY 4 - [Based on what has been collated above for activity 3- Top 3 ranking and Diamond Ranking] 10 mins

- 1) We will ask the participants to individually **rank the top 3 themes/topics** covered from each of the 4 discussions above (A-D). Since we are recalling on their memory we will point them to the POST-IT notes collated to ease this activity.
- 2) **Diamond ranking:** We will ask them as a group to discuss their top 3, and then to reorganise the POST-IT notes in a diamond/pyramid shape. Being the ones in the top the **MOST** relevant and the ones in the bottom the **LEAST** important regarding their care. The group will need to reach consensus on the most and least important topics to be included in the questionnaire.



Close and thanks – 5 mins

- Ask group to summarise main points
- Thank group for their participation
- Confirm confidentiality and anonymity
- How to contact research team if any queries
- Contact details for further support, e.g. CLIC Sargent.
- Thank you payment

Appendix C: Children's interview topic guide

Depth Interview Topic Guide – Under 16 Cancer Patient Experience Survey

Depth Interviews with Children

NOTE FOR RESEARCHERS

This research aims to understand children's experience of cancer care and treatment in the NHS, as well as that of their parents and carers. Within this, we will be focussing specifically on:

- Understanding experiences of diagnosis
- Exploring experiences of receiving care – including communication and information provision
- Investigating experiences of treatment
- Exploring what's most important to children and their parents/carers about cancer care and treatment

The following topic guide provides an overview of the questions and activities to explore with children taking part in interviews. Some children might need more prompts than others.

- Check what is meant by terms participants use - to check they have the same understanding as we would have (doesn't have to mean technical language, could be something like 'laborious').
- Remember to ask *why* they felt the way they did (probe deeper).

Useful probes/ prompts:

- Tell me about/ tell me more about ...?
- What else would you see as ...?
- What other reasons are there for... ?
- What happened after you were ...?
- What did you think when ...?
- How did you feel when ...?
- Was there anything that surprised/ worried you?
- What was really good/ bad?
- Why (do you think that happened/ did you feel like that/ was that good or bad)?
- What could be changed to make it better?
- What's it like for you now?
- You said this (...), can you help me understand that a little better?

Start of Interview

- Introduce yourself and then cover the detail in the box below

Introduction and aims - 2 mins

Interview protocol - 5 mins

- Re-check they have read the information sheet (read out loud the key points) and signed consent form.
- Explain that it is voluntary. There are no right or wrong answers etc
- Talk about your cancer care but only to extent that you are comfortable. Sensitive topic.
- No doctors or staff providing your care are involved, so you can be as honest as you like **WILL NOT AFFECT TREATMENT** etc.
- I am not a medical professional- so may ask you to explain medical terms I don't recognise.
- Mention safeguarding - If anyone reports anything worrying that suggests they or others may be at risk of harm, then we will need to pass this on.
- Will take up to an hour – but you can stop anytime or let me know if you'd like to take a short break. We can contact your mum/dad/ carer if you'd like us to.
- Will be confidential, no names, nobody will know who has said what.
- You will be given a £30 voucher at the end of the interview
- Recorded – to help analysis.
- Ask permission to turn on digital recorder.
- Take verbal consent.

Ice Breaker - 3 mins

[PURPOSE: To provide demographic and other background details as a context for the interview. Asking participants to think of their favourite XXX may help to start them thinking about prioritisation.]

Introduce **yourself** and then ask the individual to introduce themselves:

- Their name and a little bit about themselves (eg Where they live, who they live with)
- What is the thing they most like to do in their spare time? Do they have a favourite (game, superhero, YouTube channel, chocolate bar, song, band, TV programme [Could vary between age groups.]

Interview Topics

A) Background (5 minutes)

[PURPOSE: to provide background on the participant's cancer; including where they have been seen for their cancer care, types of care and treatment received, what staff members they have been in contact with etc]

Probing questions

- **How long ago** were you diagnosed with cancer?
- What **type of cancer** have you been diagnosed with?
 - IF NOT SURE, PROMPT is it a blood cancer or cancer of a particular body part
 - NOTE: How do they describe it in their own words
- **Where do you go for treatment/ check-ups** for your cancer care? E.g. hospital, at home, at a doctor surgery?
 - NOTE: How do they describe it in their own words
- **And, who do you see?** E.g. doctors, nurses, other?
- **What types of care have you had** (e.g. overnight hospital stays; treatment on wards in the day time or night time; single hospital appointments)

B) Staff - e.g relationships and communication (10 minutes)

Probing questions

- How **friendly are the staff** that you see? Are they helpful?
- Do you feel **comfortable asking staff** if you have questions or need something?
- How do you feel about the way that staff talk to you?
 - Do they **talk to you** (not just your parent)?
 - Do they talk to you in a way that **you can understand**?
 - Do they talk to you in a way that **is suitable for your age**?
 - Do they **ask you** if you have any questions?
- Do you feel **involved in decisions** about your care and treatment?
- Do you always **know what is happening** with your care? (E.g. current and future treatments)
- Do the different types of doctors and nurses, who you see, **talk to each other** about your cancer care? (E.g. doctor surgeries, hospitals and specialty treatment centres)
 - Do you feel like all the people who care for you know enough about your individual care and treatment?
- Do you have any **Medical care/ treatment at home**?
 - How do you find treatment/ care at home? Who gives this medical care/ treatment?
 - What's good about home care?
 - What's not so good about receiving care/ treatment at home?
- Do you have any equipment at home to help with your cancer? Do you have anybody come in and help you at home (other than family, friends or district nurse) [**Social care at home**]

C) Information and support (10 minutes)

Probing questions

- Do you get **enough information** about your cancer and care?
- Probes – ask in relation to each of the key care touchpoints e.g.:
 - Diagnosis
 - How did you find out you had cancer, who told you?

- Where were you when you were told?
- What did you understand at that time e.g. how much information did you have, did you know what type of cancer, what treatment etc..?
 - treatment (before and after),
 - side effects (short and long term),
 - care at home
 - ongoing care / check-ups e.g. following treatment
- **How** do you receive information (i.e. through speaking to someone or in a leaflet)?
- **How would you prefer** to get information about your cancer or treatments?
- **Do you use** forums, support groups, website, phone lines, other? (**Voluntary services/ charities**)
- Where do **you get information about your cancer** (NHS, charities such as CLIC Sargent, word of mouth, support groups, books, internet etc.)

- Have you **talked to anybody** (other than family & friends) about how you feel about having cancer? Was this **offered at the right time**?
 - Have you wanted to?
 - Has anybody suggested you might like to speak to somebody? Who suggested this?
- Have you received **enough information** and signposting to counselling/emotional support options?

D) Impact of cancer treatment and care on quality of life (10 minutes)

Probing questions

- How has having cancer and treatment affected your **everyday life**?
 - **Friends and family?** (how manage friendships, relationships)
 - **School/education?**
 - Have you had to have a break away from school at all because of your cancer?
 - **Support for returning to school (a 'new normal')**
 - Home schooling?

- Have you been able to **meet others with cancer/ with children who have cancer** (e.g. support groups)?
 - If yes, was this helpful?
 - If no, would this be helpful?

- **Physical?** (includes side effects but also physical wellbeing)

- **Emotional?** (includes side effects but also emotional wellbeing and Mental Health)
 - Do Doctors/ Nurses **ask how you are?**
 - Do they ask about any symptoms from your cancer? Are they able to help? Do you talk to them about any symptoms? explain
 - Do they ask about any side effects from your treatment? Are they able to help? Do you talk to them about any side effects? Explain
 - Does your cancer **stop you doing some things that you want to do?** (if so, what? And how? What could be better or changed?)

- If they have stayed in: **Hospital environment**
 - Was there **enough to do** in hospital?
 - Could you have **visitors** when wanted? Were you able to still **see your friends**?
 - Were there other **children the same age on the ward?**
 - PROBE ALL: **Facilities (Inpatient and Outpatient)** e.g. Did WiFi work ok, refreshments available, was ward stayed on appropriate for age, cleanliness, privacy?

Appendix D: Survey evidence source

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Which of the following best describes the current care or treatment relating to your child's cancer or tumour?	<p>They have recently been diagnosed and waiting for further information about next steps</p> <p>They are in watch and wait</p> <p>They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>They have finished treatment within the last one month</p> <p>They are in remission/long-term follow-up</p> <p>They are receiving palliative or end of life care</p> <p>They have recently passed away</p> <p>Other</p>	Which of the following best describes the current care or treatment relating to your child's cancer or tumour?	<p>They have recently been diagnosed and waiting for further information about next steps</p> <p>They are in watch and wait</p> <p>They are currently receiving treatment (e.g. to reduce or get rid of their cancer)</p> <p>They have finished treatment within the last one month</p> <p>They are in remission/long-term follow-up</p> <p>They are receiving palliative or end of life care</p> <p>They have recently passed away</p> <p>Other</p>	Child Interviews
Were you told you had cancer or a tumour within the last year?	<p>Yes (Go to Question x)</p> <p>No (Go to Question x)</p>	Was your child told they had cancer or a tumour within the last year?	<p>Yes (Go to Question x)</p> <p>No (Go to Question x)</p>	Child Interviews Parents Focus Group
Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	<p>Yes (Go to Question x)</p> <p>No (Go to Question x)</p>	Was your child told they had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	<p>Yes (Go to Question x)</p> <p>No (Go to Question x)</p>	Child Interviews Parents Focus Group

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem caused by the cancer or tumour?	None- they went straight to hospital They saw the GP once They saw the GP twice They saw the GP 3 or 4 times They saw the GP 5 or more times Don't know/ can't remember	Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem caused by the cancer or tumour?	None- they went straight to hospital They saw the GP once They saw the GP twice They saw the GP 3 or 4 times They saw the GP 5 or more times Don't know/ can't remember	Sarah Benger, Strategy Lead for the NHS England National Cancer Programme
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	I was seen as soon as I thought was necessary I should have been seen a bit sooner I should have been seen a lot sooner	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	I was seen as soon as I thought was necessary I should have been seen a bit sooner I should have been seen a lot sooner	Literature
Were you told about your child's cancer or tumour in a sensitive way?	Yes, definitely Yes, to some extent No Don't know / can't remember	Were you told about your child's cancer or tumour in a sensitive way?	Yes, definitely Yes, to some extent No Don't know / can't remember	Child Interviews Parents Focus Group
When you were told about your cancer or tumour, was information given in a way that you could understand?	Yes, definitely Yes, sort of No Don't know / can't remember	When you were told about your child's cancer/ tumour, was information given in a way that you could understand?	Yes, definitely Yes, to some extent No Don't know / can't remember	Child Interviews Parents Focus Group

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Were you able to have any questions answered by healthcare staff after you were told about your cancer or tumour?	Yes, definitely Yes, sort of No I did not have any questions Don't know / can't remember	Were you able to have any questions answered by healthcare staff after you were told about your child's cancer or tumour?	Yes, definitely Yes, to some extent No I did not have any questions Don't know / can't remember	Child Interviews Parents Focus Group
Have you been able to find the information that you need about your child's diagnosis?	Yes, definitely Yes, to some extent No This was not needed	Have you been able to find the information that you need about your child's diagnosis?	Yes, definitely Yes, to some extent No This was not needed	Parents Focus Group
Did hospital staff give you details for who to contact if you wanted more information after you were told about your cancer or tumour?	Yes No Don't know / can't remember	n/a	n/a	Child Interviews
Do you feel that staff are friendly?	Yes, always Yes, sometimes No	n/a	n/a	Child Interviews Options appraisal report
Do staff caring for your child give you information in a way that you can understand?	Yes, definitely Yes, to some extent No	Do staff caring for your child give you information in a way that you can understand?	Yes, definitely Yes, to some extent No	Child Interviews Parents Focus Group
When staff speak to you, do you understand what they are saying?	Yes, always Yes, sometimes No Don't know/can't remember	n/a	n/a	Child Interviews Service spec

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Do staff speak to you in a way that is suitable for you?	Yes, always Yes, sometimes No	n/a	n/a	Child Interviews Service spec- care should be appropriate for age
Do staff talk to you, not just to your parent or carer?	Yes, always Yes, sometimes No	n/a	n/a	Options appraisal report
Have you had the chance to ask staff questions about your child's care and treatment?	Yes, definitely Yes, to some extent No I have not asked questions I have not had a chance to ask questions	Have you had the chance to ask staff questions about your child's care and treatment?	Yes, definitely Yes, to some extent No I have not asked questions I have not had a chance to ask questions	Child Interviews Parents Focus Group
Do you see the same members of staff for your treatment and care?	Yes, always or mostly Yes, sometimes No	n/a	n/a	Child Interviews
Are you and your child treated with respect and dignity by staff?	Yes, always Yes, sometimes No	Are you and your child treated with respect and dignity by staff?	Yes, always Yes, sometimes No	Options appraisal report
Do you have confidence and trust in the members of staff caring for your child?	Yes, always Yes, sometimes No	Do you have confidence and trust in the members of staff caring for your child?	Yes, always Yes, sometimes No	Parents Focus Group
Do members of staff caring for your child treat you with empathy and understanding?	Yes, always Yes, sometimes No	Do members of staff caring for your child treat you with empathy and understanding?	Yes, always Yes, sometimes No	Parents Focus Group

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Are you ever told different things by different members of staff, which leaves you feeling confused?	Yes, always Yes, sometimes No	Are you ever told different things by different members of staff, which leaves you feeling confused?	Yes, always Yes, sometimes No	Parents Focus Group Child Interviews
Are staff sensitive to the information they share with you when your child is in the room?	Yes, always Yes, sometimes No This is not needed	Are staff sensitive to the information they share with you when your child is in the room?	Yes, always Yes, sometimes No This is not needed	Parents Focus Group
Do healthcare staff share information with your child in a way that is appropriate for them?	Yes, always Yes, sometimes No This is not needed	Do healthcare staff share information with your child in a way that is appropriate for them?	Yes, always Yes, sometimes No This is not needed	Parents Focus Group
Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? Please select all that apply	Charities (such as CLIC Sargent or Macmillan) A psychologist or counsellor Other children with cancer or a tumour that I can talk to Other No, none of the above	n/a	n/a	Child Interviews Service spec
Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour if you wanted to? Please select all that apply	Charities (such as CLIC Sargent or Macmillan) A psychologist or counsellor Other parents of children with cancer or a tumour that I can talk to Other No, none of the above	Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour? Please select all that apply	Charities (such as CLIC Sargent or Macmillan) A psychologist or counsellor Other parents of children with cancer or a tumour that I can talk to Other No, none of the above	Child Interviews Service spec

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Do you have enough information about how to get financial help or any benefits you might be entitled to?	Yes, I have enough information Some, but not enough information No, but I would like this information This was not needed Don't know / can't remember	Do you have enough information about how to get financial help or any benefits you might be entitled to?	Yes, I have enough information Some, but not enough information No, but I would like this information This was not needed Don't know / can't remember	Parents Focus Group Sarah Benger, Strategy Lead for the NHS England National Cancer Programme
In your opinion, do different members of staff caring for your child work well together?	Yes, always Yes, sometimes No Don't know	In your opinion, do different members of staff caring for your child work well together?	Yes, always Yes, sometimes No Don't know	Parents Focus Group Service spec
Are different members of staff caring for your child aware of your child's medical history?	Yes, definitely Yes, to some extent No Don't know/ not applicable	Are different members of staff caring for your child aware of your child's medical history?	Yes, definitely Yes, to some extent No Don't know/ not applicable	Parents Focus Group Service spec
Do you always know what is happening with your cancer or tumour care?	Yes, definitely Yes, sort of No This is not needed	Do you always know what is happening with your child's cancer or tumour care?	Yes, definitely Yes, to some extent No This is not needed	Child Interviews Parents Focus Group Options appraisal report Service spec
Do you have a say in deciding what happens with your care?	Yes, definitely Yes, sort of No No, but this is not possible or needed	Are you involved as much as you want to be in decisions about your child's care and treatment?	Yes, definitely Yes, to some extent No No, but this is not possible or needed	Parents Focus Group Child Interviews Service spec Options appraisal report

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Has your child's care or treatment changed what they are normally able to do, such as seeing friends, doing hobbies or going to school?	Yes, definitely (Go to Question X) Yes, sort of (Go to Question X) No (Go to Question X)	n/a	n/a	Child Interviews Parents Focus Group
Have you spoken to staff about this?	Yes No, but I would like to This is not needed	n/a	n/a	Child Interviews
Has your care or treatment changed what you are normally able to do, such as seeing friends, doing hobbies or going to school?	Yes, definitely (Go to Question X) Yes, sort of (Go to Question X) No (Go to Question X)	n/a	n/a	Child Interviews Parents Focus Group
Have you spoken to staff about this?	Yes No, but I would like to This is not needed	n/a	n/a	Child Interviews
Has your child's schooling and education been impacted in any of the following ways by their treatment and care? Please select all that apply	My child's schooling or education hasn't been impacted Being too unwell to attend school Missing school due to timings of treatment and care Poor concentration due to ill health or worries Other	Has your child's schooling and education been impacted in any of the following ways by their treatment and care? Please select all that apply	My child is not at school yet My child's schooling or education hasn't been impacted Being too unwell to attend school Missing school due to timings of treatment and care Poor concentration due to ill health or worries Other	Child Interviews Parents Focus Group

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Do you have a named member of staff who you can contact about your child's care and treatment?	Yes No	Do you have a named member of staff who you can contact about your child's care and treatment?	Yes No	Parents Focus Group Service spec-care across pathway
Do you have access to reliable help and support 7 days a week?	Yes, definitely Yes, to some extent No This is not needed	Do you have access to reliable help and support 7 days a week?	Yes, definitely Yes, to some extent No This is not needed	Parents Focus Group
Is your child's care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?	Yes, definitely Yes, to some extent No, but I would have liked this No, but this was not needed or possible	Is your child's care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?	Yes, definitely Yes, to some extent No, but I would have liked this No, but this was not needed or possible	Child Interviews Service spec-support for family
Has your child received treatment for their cancer or tumour in the last year?	Yes (Go to question X) No (Go to Question x)	Has your child received treatment for their cancer or tumour in the last year?	Yes (Go to question X) No (Go to Question x)	Parents Focus Group
Were you given clear written information about your child's treatment?	Yes, definitely Yes, to some extent No This was not needed	Were you given clear written information about your child's treatment?	Yes, definitely Yes, to some extent No This was not needed	Service Spec
Did staff offer you enough time to make decisions about your child's treatment?	Yes, definitely Yes, to some extent No	Did staff offer you enough time to make decisions about your child's treatment?	Yes, definitely Yes, to some extent No	Parents Focus Group
Did staff offer support to help manage side effects from your child's treatment?	Yes, definitely Yes, to some extent No This was not needed	Did staff offer support to help manage side effects from your child's treatment?	Yes, definitely Yes, to some extent No This was not needed	Parents Focus Group Service Spec

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Have you been able to find the information that you need about your child's treatment?	Yes, definitely Yes, to some extent No This was not needed	Have you been able to find the information that you need about your child's treatment?	Yes, definitely Yes, to some extent No This was not needed	Parents Focus Group Service Spec
If your child's treatment has finished, did you receive enough ongoing support after it ended?	Yes, definitely Yes, to some extent No Not applicable / This was not needed My child is still receiving treatment	If your child's treatment has finished, did you receive enough ongoing support after it ended?	Yes, definitely Yes, to some extent No Not applicable / This was not needed My child is still receiving treatment	Parents Focus Group
Have you stayed on a hospital ward (as a day patient or for an overnight stay) for care about your cancer or tumour, in the last year?	Yes (Go to Question x) No (Go to Question x)	n/a	n/a	Routing Question
Has your child stayed on a hospital ward (as a day patient or for an overnight stay) for care relating to their cancer or tumour, in the last year?	Yes (Go to Question x) No (Go to Question x)	Has your child stayed on a hospital ward (as a day patient or for an overnight stay) for care relating to their cancer or tumour, in the last year?	Yes (Go to Question x) No (Go to Question x)	Routing Question
When you were in hospital, were you able to get help from hospital staff when you needed it?	Yes, always Yes, sometimes No	When your child was in hospital, were they able to get help from hospital staff when they needed it?	Yes, always Yes, sometimes No	Child Interviews
Were there enough things for you to do in the hospital?	Yes, definitely Yes, sort of No This was not needed	Were there enough things for your child to do in the hospital?	Yes, definitely Yes, sort of No This was not needed	Child Interviews Options appraisal report

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Was there a choice of hospital food?	Yes, definitely Yes, sort of No I did not have hospital food	Was there a choice of hospital food for your child?	Yes, definitely Yes, to some extent No My child did not have hospital food	Child Interviews Options appraisal report
Were you given somewhere private to talk to staff when you were in hospital?	Yes, always Yes, sometimes No This was not needed	Were you given somewhere private to talk to staff when your child was in hospital?	Yes, always Yes, sometimes No This was not needed	Options appraisal report
n/a	n/a	Did the hospital offer play specialist support for your child?	Yes No This was not needed	Parents Focus Group
If your child stayed overnight, did you stay overnight with them?	Yes (Go to question xx) No (Go to question xx) My child did not stay overnight (Go to question xx)	If your child stayed overnight, did you stay overnight with them?	Yes (Go to question xx) No (Go to question xx) My child did not stay overnight (Go to question xx)	Child Interviews
How would you rate the facilities for parents or carers staying overnight?	Very good Good Fair Poor Very poor	How would you rate the facilities for parents or carers staying overnight?	Very good Good Fair Poor Very poor	Child Interviews
Was it quiet enough for you to sleep in the hospital?	Yes, always Yes, sometimes No I did not need to sleep in the hospital	Was it quiet enough for you to sleep in the hospital?	Yes, always Yes, sometimes No I did not need to sleep in the hospital	Options appraisal report
Were you able to prepare food in the hospital if you wanted to?	Yes, definitely Yes, to some extent No I did not want to prepare food	Were you able to prepare food in the hospital if you wanted to?	Yes, definitely Yes, to some extent No I did not want to prepare food	Child Interviews

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Did the hospital WiFi meet yours and your child's needs?	Yes, always Yes, sometimes No This was not needed	Did the hospital WiFi meet yours and your child's needs?	Yes, always Yes, sometimes No This was not needed	Child Interviews
Did your child have access to hospital school services during their stay in hospital?	Yes No This was not needed	Did your child have access to hospital school services during their stay in hospital?	Yes No This was not needed	Child Interviews Parents Focus Group Options appraisal report
Have you been visited at home by a nurse in the last year, for care for your cancer or tumour?	Yes (Go to Question X) No (Go to Question X) Don't know/can't remember (Go to Question X)	Have you been visited at home by a nurse in the last year, for care for your child's cancer or tumour?	Yes (Go to Question X) No (Go to Question X) Don't know/can't remember (Go to Question X)	Child Interviews
Were the nurses that came to your home friendly?	Yes, always Yes, sometimes No Don't know/can't remember	Were the nurses that came to your home friendly?	Yes, always Yes, sometimes No Don't know/can't remember	Child Interviews
When nurses speak to you, do you understand what they are saying?	Yes, always Yes, sometimes No Don't know/can't remember	When nurses speak to you, do you understand what they are saying?	Yes, always Yes, sometimes No Don't know/can't remember	Child Interviews
Did the same nurses come to your home?	Yes, always Yes, sometimes No Don't know/can't remember I have only been visited once	Did the same nurses come to your home?	Yes, always Yes, sometimes No Don't know/can't remember I have only been visited once	Child Interviews
Is the hospital where your child receives most of your cancer or tumour care under	Yes No	Is the hospital where your child receives most of your cancer or tumour care under	Yes No	Service spec Also in 'Ideas' tab- from Mike

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
one hours travel from your home?		one hours travel from your home?		Ryalls paediatric consultant / NICE
Do different hospitals providing your cancer or tumour care work well together?	Yes, always Yes, sometimes No I don't receive care at different hospitals	n/a	n/a	Service spec Parents Focus Group
Do different hospitals providing your child's cancer or tumour care work well together?	Yes, always Yes, sometimes No My child does not receive care at different hospitals	Do different hospitals providing your child's cancer or tumour care work well together?	Yes, always Yes, sometimes No My child does not receive care at different hospitals	Service spec Parents Focus Group
Overall, how well are you looked after for your cancer or tumour by the hospital? Please think about the hospital named in the covering letter that came with this questionnaire	Very well Quite well Not very well Not at all well	n/a	n/a	Overall experience question
Please think about the hospital named in the covering letter that came with this questionnaire Overall...(please circle a number)	Horizontal scale of 0 to 10 (with marked increments for each 1-point on scale). 0 is 'My child's cancer or tumour care is very poor' 10 is 'My child's cancer or tumour care is very good'	Please think about the hospital named in the covering letter that came with this questionnaire Overall...(please circle a number)	Horizontal scale of 0 to 10 (with marked increments for each 1-point on scale). 0 is 'My child's cancer or tumour care is very poor' 10 is 'My child's cancer or tumour care is very good'	Overall experience question

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Who was the main person who answered the questions in the children's section of the questionnaire?	The child/ young patient The parent or carer Both the child/young patient and the parent or carer together	n/a	n/a	To understand children's involvement
Are you a boy or a girl?	Boy Girl I do not want to say	Is your child male or female?	Male Female Prefer not to say	Demographic question
How old are you today?	_ years old	How old is your child?	_ years old	Demographic question

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Which of these best describes your child's ethnic background? (Cross ONE only)	<ul style="list-style-type: none"> • White English/ Welsh/ Scottish/ Northern Irish/ British Irish Gypsy or Irish Traveller Any other White background • Mixed/multiple ethnic groups White and Black Caribbean White and Black African White and Asian Any other mixed or multiple ethnic background • Asian/Asian British Indian Pakistani Bangladeshi Chinese Any other Asian background • Black/African/Caribbean/ Black British African Caribbean Any other Black/ African/ Caribbean background Arab Any other ethnic group 	Which of these best describes your child's ethnic background? (Cross ONE only)	<ul style="list-style-type: none"> • White English/ Welsh/ Scottish/ Northern Irish/ British Irish Gypsy or Irish Traveller Any other White background • Mixed/multiple ethnic groups White and Black Caribbean White and Black African White and Asian Any other mixed or multiple ethnic background • Asian/Asian British Indian Pakistani Bangladeshi Chinese Any other Asian background • Black/African/Caribbean/ Black British African Caribbean Any other Black/ African/ Caribbean background Arab Any other ethnic group 	Demographic question

Questions Children's (8-15) Surveys	Response Options (8-15)	Questions 0 to 7 survey	Response Options (0-7)	Evidence Source
Other than your child's cancer or tumour, do they have any unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?	Yes No	Other than your child's cancer or tumour, do they have any unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?		
Is there anything else you wanted to tell us about your cancer or tumour care (anything good, or anything that could be better)?	(Large box for participant to write free text response)			
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), please do so here:	(Large box for participant to write free text response)	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), please do so here:		



Picker Institute Europe
Buxton Court
3 West Way
Oxford OX2 0JB

Tel: +44 (0) 1865 208100
Fax: +44 (0) 1865 208101

info@pickereurope.ac.uk
www.picker.org

Charity registered in England and Wales: 1081688
Charity registered in Scotland: SC045048
Company limited by guarantee registered in England and Wales: 3908160