

Under 16 Cancer Patient Experience Survey 2020

Technical Appendix

October 2021



Contents

Introduction	3
Eligibility, fieldwork and survey methods.....	3
Question Numbering	4
Scoring	6
Adjusted response rate.....	6
Suppression and not applicable values	7
Question-level suppression.....	7
Double suppression	7
Not applicable values.....	7
Confidence intervals	8
Introduction.....	8
How to interpret the results	8
Methodology	8
Benchmarking	8
Diagnostic groupings	9
Respondent burden calculation	10
Further information	10
Appendix A.....	11

Introduction

This document sets out the methodology used in the analysis of the response data to the 2020 Under 16 Cancer Patient Experience Survey (U16 CPES) and gives guidance on how to interpret the results. This includes the following:

- how percentage scores have been derived for each scored question
- rules on suppression and where it was applied
- how statistical confidence intervals around scores have been calculated
- how benchmarking charts have been calculated

All results are available at <https://www.under16cancerexperiencesurvey.co.uk>

Eligibility, fieldwork and survey methods

The sample for the survey included all patients with a confirmed tumour or cancer diagnosis who received inpatient or day case care from NHS Principal Treatment Centres (PTCs) between January 1, 2020 and December 31, 2020, and were aged under 16 at the time of their discharge. It is important to note that the sampling period took place during an unprecedented year for the health and social care sector, with the outbreak of the global Covid19 pandemic. This had an impact on the NHS and may have influenced people's care perceptions and experiences, and therefore how they answered the survey. In addition to considering the pandemic, Principal Treatment Centres should also apply any local knowledge to the interpretation of their findings.

The fieldwork for the survey was undertaken between April and June 2021.

One of three versions of the survey were distributed:

- The 0-7 questionnaire; sent to parents/carers of patients aged between 0 and 7 years old immediately prior to survey fieldwork (30th March 2021)
- The 8-11 questionnaire, sent to parents/carers of patients aged between 8 and 11 years old immediately prior to survey fieldwork (30th March 2021)
- The 12-15 questionnaire; sent to parents/carers of patients aged between 12 and 15 years old immediately prior to survey fieldwork (30th March 2021)

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

Please note that survey version was assigned based on the patient's age immediately prior to survey fieldwork (on 30th March 2021) as opposed to their age at the time they received care. This assignment was made to better suit the needs of child participants. For instance, there were small differences in wording and the way that answer options were presented in the 8-11 and 12-15 questionnaire versions. It was also thought that sending the most age appropriate version to child participants might increase response rates.

The survey asked recipients to answer about their (or their child's) cancer care over the last year. Some patients may have been 16 or 17 years old at the time they received the questionnaire if

they were 15 years old at the time of their discharge but then had a birthday or two prior to the survey being sent out.

The survey used a mixed mode methodology. Questionnaires were sent by post and addressed to the parent or carer of the child, with two reminders sent to non-responders, and also included an option to complete the questionnaire online. A Freephone helpline and email address were available for respondents to opt-out, ask questions about the survey, enable respondents to complete their questionnaire over the phone and provide access to a translation and interpreting facility for those whose first language was not English.

Question Numbering

A master question number has been created for reporting purposes. This master question number is referenced in the data tables and final reports and differs to the question numbers in the actual surveys. The 'Question list' tab in the Excel data tables indicate the question numbers in the surveys that correspond to each master question number (see example extract on the following page).

Under 16 Cancer Patient Experience Survey 2020 Question List

Master Question No.	Question No. (0-7)	Question No. (8-11)	Question No. (12-15)	Question text	Section	Scored question	Answered by
X01	Q01	Q29	Q32	Which of the following best describes the current care or treatment relating to your child's cancer or tumour?	About the child	No	Parents/carers of all age groups
X02	Q02	Q30	Q33	Was your child told they had cancer or a tumour within the last year?	Finding out about the cancer or tumour	No	Parents/carers of all age groups
X03		Q01	Q01	Were you told you had cancer or a tumour within the last year?	Finding out about the cancer or tumour	No	All children aged 8-15
X04	Q03	Q31	Q34	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?	Finding out about the cancer or tumour	Yes	Parents/carers of all age groups whose children were told they had cancer or a tumour within the last year
X05	Q04	Q32	Q35	Was your child told they had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	Finding out about the cancer or tumour	No	Parents/carers of all age groups whose children were told they had cancer or a tumour within the last year
X06		Q02	Q02	Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	Finding out about the cancer or tumour	No	Children aged 8-15 who were told they had cancer or a tumour in the last year
X07	Q05	Q33	Q36	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Finding out about the cancer or tumour	Yes	Parents/carers of all age groups whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter
X08	Q06	Q34	Q37	Were you told about your child's cancer or tumour in a sensitive way?	Finding out about the cancer or tumour	Yes	Parents/carers of all age groups whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter
X09	Q07	Q03	Q03	When you were told about your child's cancer or tumour, was information given in a way that you could understand? / When you were told about your cancer or tumour, was information given in a way that you could understand?	Finding out about the cancer or tumour	Yes	Parents/carers of 0-7s whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter
X10	Q08	Q04	Q04	Were you able to have any questions answered by healthcare staff after you were told about your child's cancer or tumour? / Were you able to have any questions answered by healthcare staff after you were told about your cancer or tumour?	Finding out about the cancer or tumour	Yes	Parents/carers of 0-7s whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter

Scoring

A score has been created for questions that address performance in relation to patient experience (this applies to most survey questions, excluding filter questions and demographic questions such as gender or ethnicity). The score shows the percentage of respondents who gave the most favourable response to a question. Any response options that are not applicable are removed before the score is calculated. This summary score can be used to monitor results over time, and to show how organisations compare to one another, and/or to the national average.

From the example below, the question would be scored as follows:

Staff definitely offered parents enough time to make decisions about their child’s treatment: 60%

Question text	Answer options	No. of responses	% responses
Did staff offer you enough time to make decisions about your child’s treatment?	Yes, definitely	120	60%
	Yes, to some extent	74	37%
	No, but I would have liked this	6	3%

See [Appendix A](#) for the mapping of scores for all questions.

Adjusted response rate

During fieldwork for the 2020 survey, all patients were coded with an outcome code depending on their response to being sent the questionnaire. Please note that a response means one survey completion, which could be completed by both a parent/carer and a child.

The outcome codes were as follows:

- Outcome 1a = respondent completed the paper questionnaire
- Outcome 1b = respondent completed the online questionnaire
- Outcome 1c = respondent completed the questionnaire in English by phone
- Outcome 1d = respondent used Language Line to complete the questionnaire with a translator in a language other than English
- Outcome 1e = respondent completed paper questionnaire and online questionnaire (e.g. a parent may have completed the online survey and a child completed the paper survey)
- Outcome 2 = questionnaire was returned undelivered (i.e. respondent did not receive the questionnaire)
- Outcome 3 = patient deceased after the sample was drawn
- Outcome 4 = respondent opted out of the survey (i.e. called the helpline, emailed or returned a blank questionnaire)
- Outcome 5 = patient is ineligible for the survey (i.e. patient was sampled incorrectly and does not meet the eligibility criteria for the survey)
- Outcome 6 = unknown (i.e. there has been no response from the respondent)

To calculate the adjusted response rate, the numerator was the total number of respondents with an outcome of '1a', '1b', '1c', '1d', and '1e.' The denominator was the total number of respondents with an outcome of '1a', '1b', '1c', '1d', '1e', '3', '4', and '6'. Please note that patients who were deceased after the sample was drawn are included in the calculation since their parent or carer would have had the opportunity to complete the survey. Respondents that did not receive a questionnaire (Outcome code 2) or were not eligible to take part (Outcome code 5) were excluded from this calculation.

Suppression and not applicable values

Question-level suppression

For scored questions, when the base size per question is < 11, the score will be suppressed and replaced with an asterisk (*). The base size will not include non-scored response options.

For unscored questions, any frequencies will be suppressed when the base size per question is <11.

Double suppression

Results for any sub-group breakdown adhere to the same suppression level as the question-level suppression but have an additional double suppression rule. Where any of the groups within the sub-group breakdown had < 11 respondents then the data for this particular group was suppressed and replaced with an asterisk (*). If there was only one group within the sub-group that had < 11 respondents and was therefore suppressed, the group with the next lowest number of respondents (regardless of whether it was greater than or less than 11) was also suppressed and replaced with an asterisk (*). This rule applies to scores and proportions.

Not applicable values

Within the Excel Data Tables and reports, values of 'n.a.' appear in the following instances:

- where a question was not asked to a particular sub-group at all. For instance, values of 'n.a.' appear at questions asked only to children aged 8 and above when examining results for the 0-7 survey type sub-group.
- where no responses were received from a particular sub-group.

Confidence intervals

Introduction

The single percentage figures given as a score for each organisation for each question are an estimate of the score from the population, based on the responses received. Assuming the sample is representative of the organisation, confidence intervals are a method of describing the uncertainty around these estimates. The most common methodology, which was used here, is to produce and report 95 percent confidence intervals around the results. At the 95 percent confidence level, the confidence intervals are expected to contain the true value 95 percent of the time (i.e. out of 100 such intervals, 95 will include the true figure).

How to interpret the results

The following example shows the unadjusted score for an organisation with 500 respondents to a question asking about whether parents or carers were told about their child’s tumour in a sensitive way. In this case, the unadjusted score is 83% and the confidence interval is calculated as between 79% and 86%.

Question Text	No. of responses	National Score	Lower 95% Wilson Confidence Interval	Upper 95% Wilson Confidence Interval
Parents or carers definitely told about cancer or tumour in a sensitive way	500	83%	79%	86%

Methodology

Confidence intervals for unadjusted scores for all questions were calculated using Wilson’s Confidence Intervals. This approach was chosen as it is more robust for small numbers (both numerators and denominators), and for results close to 0% or 100%.

Benchmarking

All benchmarking charts have been calculated using unadjusted scores. In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently. For example, Black and Asian patients often report a less positive experience than White patients. Thereby, PTCs with differing populations could potentially lead to results appearing better or worse than they would if they had a slightly different profile of patients.

Scores have not been adjusted on the 2020 survey due to small sample size restrictions. PTCs should, therefore, be mindful of differences in size and possible demographic makeup when comparing their results against the performance of other PTCs.

Diagnostic groupings

Please note that the diagnostic groupings available at the national level differ from those available at the PTC level. This is due to the greater number of groups that would be suppressed at the PTC level.

At the national level, the following groups are available:

Diagnostic Group – National	ICD10 Codes
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	C91-C95, D46
Lymphomas and reticuloendothelial neoplasms	C81-C90, C96
CNS and miscellaneous intracranial and intraspinal neoplasms	C70-C72, C75.1-C75.3, D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5
Retinoblastoma	C69.2
Renal tumours	C64
Hepatic tumours	C22
Malignant bone tumours	C40-C41

All other eligible ICD-10 codes fall under the 'Other' diagnostic group.

At the PTC level, the following groups are available:

Diagnostic Group - PTC	ICD10 Codes
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	C91-C95, D46
Lymphomas and reticuloendothelial neoplasms	C81-C90, C96
CNS and miscellaneous intracranial and intraspinal neoplasms	C70-C72, C75.1-C75.3, D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5

All other eligible ICD-10 codes fall under the 'Other' diagnostic group.

Respondent burden calculation

The Under 16 Cancer Patient Experience Survey (U16 CPES) complies with the Code of Practice for Statistics. Within the code, Practice V5.5 requires producers of statistics to monitor the burden on respondents providing their information. In order to achieve this, the following calculation is done for online U16 CPES completions:

Number of responses x Average time spent completing the survey

There were 300 online responses to the 2020 U16 CPES. The median completion time based on online completion was 11 minutes per survey. Therefore, respondent burden calculated results for the 2020 CPES are:

300 responses x 11 minutes = 55 hours spent completing the survey.

Further information

For further information on the methodology and details of the statistical analysis, please contact under16cancersurvey@pickereurope.ac.uk.

Appendix A

The following lists all questions in the survey – question text, who answered and response options. It excludes the qualitative free-text questions.

For each scored question, each response option has been identified as either a positive, negative or neutral response. Scores are calculated using the total number of positive responses as the numerator and the total number of positive and negative responses as the denominator. Neutral scores (e.g. ‘Don’t know / can’t remember’) are excluded from this calculation.

The mapping of positive, negative and neutral scores for all questions can be found below.

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
X01	Q1	Q29	Q32	Parents/care rs of all age groups	Which of the following best describes the current care or treatment relating to your child’s cancer or tumour?	1	They have been diagnosed and are waiting for further information about next steps	n/a
						2	They are in watch and wait	n/a
						3	They are currently receiving treatment (e.g. to reduce or get rid of their cancer)	n/a
						4	They have finished treatment within the last one month	n/a
						5	They are in remission / long-term follow-up	n/a
						6	They are receiving palliative or end of life care	n/a
						7	They have recently passed away	n/a
						8	Other	n/a
X02	Q2	Q30	Q33	Parents/care rs of all age groups	Was your child told they had cancer or a tumour within the last year?	1	Yes	n/a
						2	No	n/a
X03		Q1	Q1	All children aged 8-15	Were you told you had cancer or a tumour within the last year?	1	Yes	n/a
						2	No	n/a
X04	Q3	Q31	Q34	Parents/care rs of all age groups whose children	Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see	1	None - they went straight to hospital	n/a
						2	They saw the GP once	1
						3	They saw the GP twice	1
						4	They saw the GP 3 or 4 times	0

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				were told they had cancer or a tumour within the last year	a GP (family doctor) about the health problem caused by the cancer or tumour?	5	They saw the GP 5 or more times	0
				were told they had cancer or a tumour within the last year	a GP (family doctor) about the health problem caused by the cancer or tumour?	6	Don't know / can't remember	n/a
X05	Q4	Q32	Q35	Parents/care rs of all age groups whose children were told they had cancer or a tumour within the last year	Was your child told they had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	1	Yes	n/a
				Parents/care rs of all age groups whose children were told they had cancer or a tumour within the last year	Was your child told they had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	2	No	n/a
X06		Q2	Q2	Children aged 8-15 who were told they had cancer or a tumour in the last year	Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	1	Yes	n/a
				Children aged 8-15 who were told they had cancer or a tumour in the last year	Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	2	No	n/a
X07	Q5	Q33	Q36	Parents/care rs of all age groups whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	1	I was seen as soon as I thought was necessary	1
				Parents/care rs of all age groups whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	2	I should have been seen a bit sooner	0
				Parents/care rs of all age groups whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	3	I should have been seen a lot sooner	0
X08	Q6	Q34	Q37	Parents/care rs of all age groups	Were you told about your child's cancer or tumour in a sensitive way?	1	Yes, definitely	1
				Parents/care rs of all age groups	Were you told about your child's cancer or tumour in a sensitive way?	2	Yes, to some extent	0

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter		3	No	0
						4	Don't know / can't remember	n/a
X09	Q7	Q3	Q3	Parents/care rs of 0-7s whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter	When you were told about your child's cancer or tumour, was information given in a way that you could understand? / When you were told about your cancer or tumour, was information given in a way that you could understand?	1	Yes, definitely	1
						2	Yes, to some extent / Yes, sort of	0
						3	No	0
						4	Don't know / can't remember	n/a
X10	Q8	Q4	Q4	Parents/care rs of 0-7s whose children were told they had cancer or a	Were you able to have any questions answered by healthcare staff after you were told about your/your child's cancer or tumour?	1	Yes, definitely	1
						2	Yes, to some extent / Yes, sort of	0
						3	No	0

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter		4	I did not have any questions	n/a
				tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter		5	Don't know / can't remember	n/a
X11		Q5	Q5	Children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter	Did hospital staff give you details for who to contact if you wanted more information after you were told about your cancer or tumour?	1	Yes	1
						2	No	0
						3	Don't know / can't remember	n/a
X12	Q9	Q35	Q38	Parents/care rs of all age groups whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter	Have you been able to find the information that you need about your child's diagnosis?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	This was not needed	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
X13	Q10	Q36	Q39	Parents/careers of all age groups	Do staff caring for your child give you information in a way that you can understand?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
X14	Q11	Q37	Q40	Parents/careers of all age groups	Have you had the chance to ask staff questions about your child's care and treatment?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	I have not had any questions	n/a
X15		Q7	Q7	All children aged 8-15	When staff speak to you, do you understand what they are saying / Do staff speak to you in a way you understand?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	Don't know / can't remember	n/a
X16	Q12	Q38	Q41	Parents/careers of all age groups	Are you and your child treated with respect and dignity by staff?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
X17	Q13	Q39	Q42	Parents/careers of all age groups	Do you have confidence and trust in the members of staff caring for your child?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
X18	Q14	Q40	Q43	Parents/careers of all age groups	Do members of staff caring for your child treat you with empathy and understanding?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
X19	Q15	Q11	Q11	Parents/careers of children aged 0-7, and all children aged 8-15	Are you ever told different things by different members of staff, which leaves you feeling confused?	1	Yes, always	0
						2	Yes, sometimes	0
						3	No	1
X20	Q16	Q41	Q44	Parents/careers of all age groups	Are staff sensitive to the information they share with you when your child is in the room?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	This is not needed	n/a
X21	Q17	Q42	Q45			1	Yes, always	1

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				Parents/careers of all age groups	Do healthcare staff share information with your child in a way that is appropriate for them?	2	Yes, sometimes	0
			3			No	0	
			4			This is not needed	n/a	
X22		Q8	Q8	All children aged 8-15	Do staff speak to you in a way that is suitable for you?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
X23		Q9	Q9	All children aged 8-15	Do staff talk to you, not just to your parent or carer?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
X24		Q6	Q6	All children aged 8-15	Do you feel that staff are friendly?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
X25		Q10	Q10	All children aged 8-15	Do you see the same members of staff for your treatment and care?	1	Yes, always or mostly	1
						2	Yes, sometimes	0
						3	No	0
X26	Q18	Q43	Q46	Parents/careers of all age groups	Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour?	1	Charities (such as CLIC Sargent or Macmillan)	n/a
						2	A psychologist or counsellor	n/a
						3	Other parents of children with cancer or a tumour	n/a
						4	Other	n/a
						5	No, none of the above	n/a
						6	Don't know / can't remember	n/a
X27		Q12	Q12	All children aged 8-15	Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour?	1	Charities (such as CLIC Sargent or Macmillan)	n/a
						2	A psychologist or counsellor	n/a
						3	Other children with cancer or a tumour	n/a
						4	Other	n/a
						5	No, none of the above	n/a
						6	Don't know / can't remember	n/a
X28	Q19	Q44	Q47			1	Yes, I have enough information	1

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				Parents/care rs of all age groups	Do you have enough information about how to get financial help or any benefits you might be entitled to?	2	Some, but not enough information	0
			3			No, but I would like this information	0	
			4			This was not needed	n/a	
			5			Don't know / can't remember	n/a	
X29	Q20	Q45	Q48	Parents/care rs of all age groups	In your opinion, do different hospital members of staff caring for your child work well together?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	Don't know	n/a
X30	Q21	Q46	Q49	Parents/care rs of all age groups	Are different hospital members of staff caring for your child aware of your child's medical history?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	Don't know / not applicable	n/a
X31	Q22	Q13	Q13	Parents/care rs of children aged 0-7, and all children aged 8-15	Do you always know what is happening with your child's cancer or tumour care? / Do you always know what is happening with your cancer or tumour care?	1	Yes, definitely	1
						2	Yes, to some extent / Yes, sort of	0
						3	No	0
						4	This is not needed	n/a
X32	Q23	Q14	Q14	Parents/care rs of children aged 0-7, and all children aged 8-15	Are you involved as much as you want to be in decisions about your child's care and treatment? / Do you have a say in deciding what happens with your care? / Are you involved in decisions about your care and treatment?	1	Yes, definitely	1
						2	Yes, to some extent / Yes, sort of	0
						3	No	0
						4	No, but this is not needed or possible	n/a
X33	Q24	Q47	Q50	Parents/care rs of all age groups	Has your child's schooling and education been impacted in any of the following ways by their treatment and care?	1	My child is not at school yet*	n/a
						2	My child's schooling or education hasn't been impacted	n/a
						3	Being too unwell to attend school	n/a
						4	Missing school due to timings of treatment and care	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
						5	Poor concentration due to ill health or worries	n/a
						6	Other	n/a
X34	Q25	Q48	Q51	Parents/care rs of all age groups	Do you have a named member of staff who you can contact about your child's care and treatment at the hospital?	1	Yes	1
						2	No	0
X35	Q26	Q49	Q52	Parents/care rs of all age groups	Do you have access to reliable help and support 7 days a week from the hospital?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	This is not needed	n/a
X36	Q27	Q50	Q53	Parents/care rs of all age groups	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)?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No, but I would have liked this	0
						4	No, but this was not needed or possible	n/a
X37		Q51	Q15	Parents/care rs of children aged 8-11, and all children aged 12-15	Has your/your child's care or treatment changed what you/they are normally able to do, such as seeing friends, doing hobbies or going to school?	1	Yes, definitely	0
						2	Yes, to some extent / Yes, sort of	0
						3	No	1
X38		Q52	Q16	Parents/care rs of children aged 8-11 whose child's treatment changed what they are normally able to do, and all children aged 12-15 whose	Have you spoken to staff about this?	1	Yes	1
						2	No, but I would like to	0
						3	This is not needed	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				treatment changed what they are normally able to do				
X39	Q28	Q53	Q54	Parents/care rs of all age groups	Has your child received treatment for their cancer or tumour in the last year?	1	Yes	n/a
						2	No	n/a
X40	Q29	Q54	Q55	Parents/care rs of all age groups whose children received treatment for their cancer or tumour in the last year	Were you given clear written information about your child's treatment?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	This was not needed	n/a
X41	Q30	Q55	Q56	Parents/care rs of all age groups whose children received treatment for their cancer or tumour in the last year	Did staff offer you enough time to make decisions about your child's treatment?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No, but I would have liked this	0
						4	No, but this was not needed or possible	n/a
X42	Q31	Q56	Q57	Parents/care rs of all age groups whose children received treatment for their cancer or tumour in the last year	Did staff offer support to help manage side effects from your child's treatment?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	This was not needed	n/a
X43	Q32	Q57	Q58	Parents/care rs of all age	Have you been able to find the information that	1	Yes, definitely	1
						2	Yes, to some extent	0

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				groups whose children received treatment for their cancer or tumour in the last year	you need about your child's treatment at the hospital?	3	No	0
						4	This was not needed	n/a
X44	Q33	Q58	Q59	Parents/care rs of all age groups whose children received treatment for their cancer or tumour in the last year	If your child's treatment has finished, did you receive enough ongoing support after it ended from the hospital?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	Not applicable / this was not needed	n/a
						5	My child is still receiving treatment	n/a
X45	Q34	Q59	Q60	Parents/care rs of all age groups	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?	1	Yes	n/a
						2	No	n/a
X46		Q15	Q17	All children aged 8-15	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?	1	Yes	n/a
						2	No	n/a
X47	Q35	Q16	Q18	Parents/care rs of children aged 0-7 whose children stayed on a hospital ward in the last year, and children aged 8-15 who stayed	When your child was in hospital, were they able to get help from hospital staff when they needed it? / When you were in hospital, were you able to get help from hospital staff when you needed it?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				on a hospital ward in the last year				
X48	Q36	Q17	Q19	Parents/care rs of children aged 0-7 whose children stayed on a hospital ward in the last year, and children aged 8-15 who stayed on a hospital ward in the last year	Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital?	1	Yes, definitely	1
						2	Yes, to some extent / Yes, sort of	0
						3	No	0
						4	This was not needed	n/a
X49	Q37	Q18	Q20	Parents/care rs of children aged 0-7 whose children stayed on a hospital ward in the last year, and children aged 8-15 who stayed on a hospital ward in the last year	Was there a choice of hospital food for your child? / Was there a choice of hospital food?	1	Yes, definitely	1
						2	Yes, to some extent / Yes, sort of	0
						3	No	0
						4	This was not needed / I did not have hospital food	n/a
X50	Q38	Q19	Q21	Parents/care rs of children aged 0-7 whose children stayed on a hospital ward in the last year,	Were you given somewhere private to talk to staff when your child was in hospital? / Were you given somewhere private to talk to staff when you were in hospital?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	This was not needed	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				and children aged 8-15 who stayed on a hospital ward in the last year				
X51	Q39			Parents/care rs of children aged 0-7 whose children stayed on a hospital ward in the last year	Did the hospital offer play specialist support for your child?	1	Yes	1
						2	No	0
						3	This was not needed	n/a
X52	Q40	Q60	Q61	Parents/care rs of all age groups whose children received treatment for their cancer or tumour in the last year	If your child stayed overnight, did you stay overnight with them?	1	Yes	n/a
						2	No	n/a
						3	My child did not stay overnight	n/a
X53	Q41	Q61	Q62	Parents/care rs of all age groups whose children stayed overnight on a hospital ward in the last year and who stayed overnight with them	How would you rate the facilities for parents or carers staying overnight?	1	Very good	1
						2	Good	0
						3	Fair	0
						4	Poor	0
						5	Very Poor	0
X54	Q42	Q20	Q22	Parents/care rs of children		1	Yes, always	1

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				aged 0-7 whose children stayed overnight on a hospital ward in the last year, and children aged 8-15 who stayed on a hospital ward in the last year	Was it quiet enough for you to sleep in the hospital?	2	Yes, sometimes	0
						3	No	0
						4	I did not need to sleep in the hospital	n/a
X55	Q43	Q62	Q63	Parents/care rs of all age groups whose children stayed on a hospital ward in the last year	Were you able to prepare food in the hospital if you wanted to?	1	Yes, definitely	1
						2	Yes, to some extent	0
						3	No	0
						4	I did not want to prepare food	n/a
X56	Q44	Q63	Q64	Parents/care rs of all age groups whose children stayed on a hospital ward in the last year	Did the hospital Wi-Fi meet your and your child's needs?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	This was not needed	n/a
X57	Q45	Q64	Q65	Parents/care rs of all age groups whose children stayed on a hospital ward in the last year	Did your child have access to hospital school services during their stay in hospital?	1	Yes	1
						2	No	0
						3	This was not needed	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
X58	Q46	Q21	Q23	Parents/care rs of children aged 0-7, and all children aged 8-15	Have you been visited at home by a nurse in the last year, for care for your child's cancer or tumour? / Have you been visited at home by a nurse in the last year, for care for your cancer or tumour?	1	Yes	n/a
						2	No	n/a
						3	Don't know / can't remember	n/a
X59	Q47	Q22	Q24	Parents/care rs of children aged 0-7 whose children have been visited at home by a nurse in the last year, and children aged 8-15 who were visited at home by a nurse in the last year	Were the nurses that came to your home friendly?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	Don't know / can't remember	n/a
X60	Q48	Q23	Q25	Parents/care rs of children aged 0-7 whose children have been visited at home by a nurse in the last year, and children aged 8-15 who were visited at home by a	When nurses speak to you, do you understand what they are saying?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	Don't know / can't remember	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
				nurse in the last year				
X61	Q49	Q24	Q26	Parents/care rs of children aged 0-7 whose children have been visited at home by a nurse in the last year, and children aged 8-15 who were visited at home by a nurse in the last year	Did the same nurses come to your home?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	Don't know / can't remember	n/a
						5	I have only been visited once	n/a
X62	Q50	Q65	Q28	Parents/care rs of children aged 0-11, and all children aged 12-15	Do different hospitals providing your child's cancer or tumour care work well together? / Do different hospitals providing your cancer or tumour care work well together?	1	Yes, always	1
						2	Yes, sometimes	0
						3	No	0
						4	My child does not receive care at different hospitals / I don't receive care at different hospitals	n/a
X63	Q51	Q66	Q66	Parents/care rs of all age groups	Is the hospital where your child receives most of their cancer or tumour care under one hours travel from their home?	1	Yes	1
						2	No	0
X64	Q52	Q67	Q67	Parents/care rs of all age groups	Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)	0	0 (My child's cancer or tumour care is very poor)	0
						1	1	0
						2	2	0
						3	3	0
						4	4	0
						5	5	0

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
						6	6	0
						7	7	0
						8	8	1
						9	9	1
						10	10 (My child's cancer or tumour care is very good)	1
X65		Q25	Q27	All children aged 8-15	Overall, how well are you looked after for your cancer or tumour by the healthcare staff?	1	Very well	1
						2	Quite well	0
						3	OK	0
						4	Not very well	0
						5	Not at all well	0
X66	Q53	Q26	Q29	Parents/care rs of children aged 0-7, and all children aged 8-15	Is your child male or female? / Are you a boy or a girl?	1	Male / Boy	n/a
						2	Female / Girl	n/a
						3	Prefer not to say / I do not want to say	n/a
X67	Q54	Q27	Q30	Parents/care rs of children aged 0-7, and all children aged 8-15	How old is your child? / How old are you today?	0	0	n/a
						1	1	n/a
						2	2	n/a
						3	3	n/a
						4	4	n/a
						5	5	n/a
						6	6	n/a
						7	7	n/a
						8	8	n/a
						9	9	n/a
						10	10	n/a
						11	11	n/a
						12	12	n/a
						13	13	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
						14	14	n/a
						15	15	n/a
						16	16	n/a
						17	17	n/a
X68		Q68	Q68	Parents of children aged 8-15	Who was the main person who answered the questions in the children's section of the questionnaire?	1	The child / young patient	n/a
						2	The parent or carer	n/a
						3	Both the child / young patient and the parent or carer together	n/a
X69	Q55	Q70	Q70	Parents/carers of all age groups	Which of these best describes your child's ethnic background?	1	English / Welsh / Scottish / Northern Irish / British	n/a
						2	Irish	n/a
						3	Gypsy or Irish Traveller	n/a
						4	Any other White background	n/a
						5	White and Black Caribbean	n/a
						6	White and Black African	n/a
						7	White and Asian	n/a
						8	Any other mixed or multiple ethnic background	n/a
						9	Indian	n/a
						10	Pakistani	n/a
						11	Bangladeshi	n/a
						12	Chinese	n/a
						13	Any other Asian background	n/a
						14	African	n/a
						15	Caribbean	n/a
						16	Any other Black / African / Caribbean background	n/a
						17	Arab	n/a
						18	Any other ethnic group	n/a
X70	Q56	Q69	Q69	Parents/carers of all age groups	Other than your child's cancer or tumour, do they have any unrelated	1	Yes	n/a

Master Question number	Question number (0-7)	Question number (8-11)	Question number (12-15)	Answered by	Question text	Answer option	Option text	Scoring
					physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?	2	No	n/a

*Note for X33: *Response option 1 from X33 was only asked to parents of 0-7 year olds*