

# Under 16 Cancer Patient Experience Survey 2021

## Quantitative Results

Leeds Teaching Hospitals NHS Trust



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The information in this report can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact [under16cancersurvey@pickereurope.ac.uk](mailto:under16cancersurvey@pickereurope.ac.uk)

## Executive summary

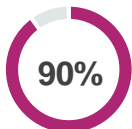
### Overall PTC response rate

73 responded out of a total of 267 eligible parents/carers and children who were sent a survey, resulting in a response rate of 27%. A response consists of one survey completion for a single patient, which could consist of both parent/carer and child responses.

PTC	Original sample size	Adjusted sample size <sup>1</sup>	Completed	Response rate
Leeds Teaching Hospitals NHS Trust	267	267	73	27%

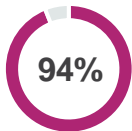
### Overall PTC care rating

Data for questions in which the base size per question was <11 have been suppressed and replaced with an asterisk (\*).



90%

**Children report being looked after very well for their cancer or tumour by healthcare staff**  
(Question X63)



94%

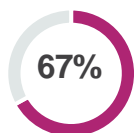
**Parents/carers rated the overall experience of their child's care as 8 or more out of 10**  
(Question X62)

<sup>1</sup>The adjusted sample excludes patients who were discovered to be ineligible during fieldwork.

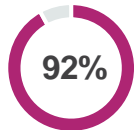
## PTC key question scoring

The key questions presented on this page have been selected by healthcare professionals as some of the most important questions in the Under 16 Cancer Patient Experience Survey for children's cancer care. Scores for all questions can be found in the '[Score tables](#)' section of this report.

Data for questions in which the base size per question was <11 have been suppressed and replaced with an asterisk (\*).



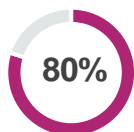
**Parents/carers reported that they were given clear written information about their child's treatment**  
(Question X39)



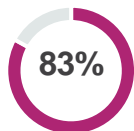
**Parents/carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way**  
(Question X07)



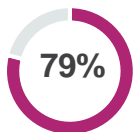
**Parents/carers always have confidence and trust in staff caring for their child**  
(Question X16)



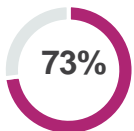
**Children reported that staff always speak to them in a way that is suitable for them**  
(Question X21)



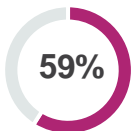
**Parents/carers and children reported that they were definitely able to have questions answered after being told about the cancer or tumour**  
(Question X09)



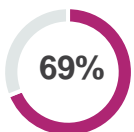
**Children reported that they could always understand what staff are saying**  
(Question X14)



**Parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment**  
(Question X40)



**Parents/carers feel that different hospital staff are definitely aware of their child's medical history**  
(Question X29)



**Parents/carers reported that they definitely have access to reliable help and support 7 days a week from the hospital**  
(Question X34)

## Introduction

- The Under 16 Cancer Patient Experience Survey (U16 CPES) measures experiences of tumour and cancer care for children across England. It is expected to run annually. This report presents the U16 CPES 2021 findings for Leeds Teaching Hospitals NHS Trust and is the second iteration of the survey. The survey captures the experiences of children who were aged 8 to 15 at the time of their care and discharge, and parents/carers of children who were aged under 16 at the time of their care and discharge.
- The survey has been designed to understand patient experiences of tumour and cancer care – both across England and at individual NHS organisations. In future years, the survey will allow care experiences to be monitored over time. This year, comparison between the 2020 and 2021 iterations of the survey is not available and the data is not comparable. There is an analytical and insight recommendation to not compare data. Please see [‘Understanding the results’](#) for further clarification.
- The survey is overseen by the Under 16 Cancer Patient Experience Survey Advisory Group made up of professionals involved in the provision of children’s cancer care, charity representatives, cancer patients and parents/carers of children with cancer. This group advises on questionnaire development, methodology and reporting outputs. The survey is managed by NHS England, who commission Picker to oversee survey development, technical design, implementation and analysis of the survey.

## Methodology

### 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) in England between 1 January 2021 and 31 December 2021, and were aged under 16 at the time of their discharge<sup>1</sup>. Please note that the sampling period occurred when some COVID-19 restrictions were in place, and this should be taken into consideration when interpreting the results. PTCs should also apply any local knowledge to the interpretation of their findings.

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

- The 0-7 questionnaire; sent to parents/carers of patients aged between 0 and 7 years old immediately prior to survey fieldwork
- The 8-11 questionnaire, sent to parents/carers of patients aged between 8 and 11 years old immediately prior to survey fieldwork
- The 12-15 questionnaire; sent to parents/carers of patients aged between 12 and 17<sup>1</sup> years old immediately prior to survey fieldwork

Survey version was assigned based on the patient’s age immediately prior to survey fieldwork (30 March 2022) as opposed to their age at the time they received care, to ensure the most age-appropriate version was sent. For instance, there were small differences in survey design, wording and the way that answer options were presented in the 8-11 and 12-15 questionnaire versions.

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

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<sup>1</sup>The survey asked recipients to answer about their (or their child’s) cancer care during 2021. 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 interpretation services for those whose first language was not English.

## Understanding the results

The 'PTC results' section of this report presents data from some of the survey questions, and shows the percentage of respondents that selected each response option. There is at least one question from each section of the questionnaire presented in a bar chart.

The 'Score tables' section of this report presents scores that have been calculated for most survey questions, excluding filter questions and demographic questions such as gender or ethnic group. 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.

From the example table below, the question would be scored as follows: **EXAMPLE DATA ONLY**

**Staff definitely offered parents/carers enough time to make decisions about their child's treatment: 60%**

Question text	Answer options	No. of responses	% of responses
Did staff offer you enough time to make decisions about your child's treatment?	Yes, definitely	60	60%
	Yes, to some extent	30	30%
	No, but I would have liked this	10	10%
	No, but this was not needed or possible	4	n/a

Full responses and scores to all questions can be found in the PTC Excel Data Tables [on the survey website](#) and on the [interactive dashboard](#). Meanwhile, more details on scoring can be found in the Technical Appendix [on the survey website](#).

**The percentages in this report have been rounded to the nearest whole percent. Therefore, in some cases the figures may not add up to 100%.**

Question numbers relate to the numbering on the data tables, not the questions used on the surveys themselves.

## How to use this data

**We recommend that PTCs do not benchmark their results against those of other PTCs, or against results at National level. This is because:**

### **1) The results are not adjusted for differences in patient profiles across PTCs**

- In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently.
- However, scores have not been adjusted for the 2021 survey due to small sample size restrictions. This means that 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. Furthermore, survey responses might be influenced by the type of care provided by PTCs, for example some provide specialised care and treatment.

### **2) PTC scores are often based on small numbers of responses, reducing statistical confidence in the results**

- The single percentage figures given as a score for each PTC 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.
- Where results are calculated from a small number of responses, the confidence intervals will be wider, indicating a larger range in which the population value may lie.
- PTC scores are often based on a very small number of responses, meaning that the confidence intervals around a PTC score are often very wide and overlapping with those of other PTCs.
- This means that we cannot be statistically confident whether differences between PTC scores are reflective of true differences in patient experience, or due to random variation.

**In addition, we recommend that PTCs do not compare the results of the 2021 survey against their 2020 results.**

The Under 16 CPES is at a relatively early point in its evolution and we continue to learn a lot about what is working well and what might need adjusting. There are differences between the 2021 and 2020 surveys which has led to the analytical and insight recommendation that comparisons should not be made between results. In line with this, comparisons between 2021 and 2020 results are not included within this report and trends are not shown. This is because:

- Feedback from cognitive interview testing with patients identified that clarification was needed on which time period patients should be reporting on. Changes have been made to the wording to accommodate this, but as these only affect this year's iteration, the 2020 and 2021 survey report on patients' experience of care across potentially different and overlapping time periods.
- Additionally, there are differences in response rates across the 2 years. Coupled with a small sample size, this reduces statistical confidence in comparisons.
- Taken together, this makes it extremely difficult to disentangle change (or lack of) in patient experience from survey change when comparing results. Work will be undertaken to enhance comparability as much as possible for future years.

**We recommend that PTCs review their results for the 2021 survey, and triangulate these with local intelligence and other data sources to identify areas for further local investigation. We recommend that this is done whilst also reviewing the information about who responded to the survey in the PTC (available in the 'About the respondents' section), to understand the patient groups that make up (and do not make up) the results.**

## Suppression

Suppression is used to protect the confidentiality of respondents in instances in which the base size (number of respondents answering a question) is low and there is a chance that the respondent could be identified.

### Question-level suppression

For sub-group scores where the base size per question is less than 11, the score will be suppressed and replaced with an asterisk (\*). The base size in the sub-group scores tab does not include non-scored response options.

For sub-group data where the total number of responses per question including non-scored options is less than 11, the values for that question and sub-group breakdown will be suppressed and replaced with an asterisk (\*).

### Double suppression

If any group within a particular sub-group breakdown (such as the diagnostic group breakdown) has less than 11 respondents, then the figure for this particular group is suppressed and replaced with an asterisk (\*). If there is only one group within the sub-group breakdown that has less than 11 respondents, and therefore suppressed, the group with the next lowest number of respondents is also suppressed and replaced with an asterisk (\*) (regardless if it is greater than or less than 11). This is done to prevent the suppressed sub-group score from being calculated from the relevant National score.

### Organisation-level suppression

Additional suppression happens if only one Principal Treatment Centre (PTC) has a score suppressed for a question (for either of the reasons above). If this happens, the PTC with the next lowest number of respondents for that question will also be suppressed. This is to prevent differencing of the suppressed PTC score from the National total for that question. This is done to prevent the suppressed PTC score from being calculated from the relevant National score.

The same rule applies to groups in each sub-group breakdown. For example, if only one PTC has the 0-7 age group data suppressed for question X19, we will need to suppress another PTC's score for the 0-7 age group data for this question. This suppression is based on the PTC that has the next lowest number of respondents in the 0-7 age group for question X19.

### Survey type sub-group and n.a. values

A special case for suppression is represented by the Survey Type breakdown. Where a question is not asked in a particular survey type, for example question X02 is not asked in the 0-7 version, the values will be represented by n.a. (not asked) and highlighted with the colour grey. In this scenario, only the other Survey Type sub-groups (8-11 Survey and 12-15 Survey) would count towards the double suppression criteria.

## Further information

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

For more information on development and methodology, please see the Survey Development Report available on the [survey materials page of the website](#). For all other outputs including the Technical Appendix, please visit the [results section of the website](#).



## About the respondents

**Table 1. Response rate**

Please note that a response means one survey completion, which could be completed by a parent/carer, a child or both.

	Original sample size	Adjusted sample size	Completed	Response rate
PTC	267	267	73	27%

**Table 2: Percent of responses by survey mode**

Survey mode	PTC		National	
	n	%	n	%
Paper	51	70%	708	74%
Online	22	30%	252	26%
Mixed (combination of paper and online) <sup>3</sup>	0	0%	0	0%
Phone – English	0	0%	0	0%
Phone – Translation service	0	0%	0	0%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

**Table 3: Percent of responses by survey type**

Survey	PTC		National	
	n	%	n	%
0-7	40	55%	518	54%
8-11	13	18%	191	20%
12-15	20	27%	251	26%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

**Table 4: Percent of responses by gender of child (Question X64)**

Gender of child	PTC		National	
	n	%	n	%
Male	37	51%	536	56%
Female	33	45%	387	40%
Prefer not to say	0	0%	8	1%
Not given	3	4%	29	3%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

<sup>2</sup>The adjusted sample excludes patients who were discovered to be ineligible during fieldwork.

<sup>3</sup>Indicates cases in which the entire parent/carer section was completed in one mode and the entire child section was completed in another mode.

**Table 5: Percent of responses by ethnic group of child (Question X67)**

Ethnic group	PTC		National	
	n	%	n	%
White	55	75%	717	75%
Mixed	3	4%	58	6%
Asian	12	16%	112	12%
Black	2	3%	36	4%
Other	1	1%	12	1%
Not given	0	0%	25	3%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

**Table 6: Percent of responses by current care or treatment stage <sup>4</sup>  
(Question X69)**

Stage of care	PTC		National	
	n	%	n	%
Recently diagnosed	1	1%	14	1%
Watch and wait	5	7%	76	8%
Currently receiving treatment	28	39%	385	41%
Finished treatment in last month	3	4%	74	8%
In remission / long-term follow-up	37	51%	395	42%
Receiving palliative or end of life care	1	1%	8	1%
Other	3	4%	65	7%
<b>Total number of respondents</b>	<b>72</b>		<b>942</b>	

**Table 7: Percent of responses by diagnostic group <sup>5</sup> (from ICD-10 code in patient sample)**

Diagnostic group	PTC		National	
	n	%	n	%
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	25	34%	385	40%
Lymphomas and reticuloendothelial neoplasms	11	15%	112	12%
CNS and miscellaneous intracranial and intraspinal neoplasms	17	23%	200	21%
Other	20	27%	263	27%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

<sup>4</sup>Based on a select all that apply question, therefore the total number of responses may be more than the total number of respondents.

<sup>5</sup>Details of how diagnostic groups were formed can be found in the Technical Appendix, available [on the survey website](#).

**Table 8: Responses by long-term, unrelated conditions (Question X68)**

Other long-term conditions	PTC		National	
	n	%	n	%
Reported unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more	17	23%	225	23%
No long-term, unrelated conditions	56	77%	710	74%
Not given	0	0%	25	3%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

**Table 9: Responses by main person who answered questions in the children's section (Question X66)**

Respondent	PTC		National	
	n	%	n	%
The child / young patient	11	15%	150	16%
The parent or carer	5	7%	106	11%
Both the child / young patient and the parent or carer together	14	19%	152	16%
Not given	43	59%	552	57%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

**Table 10: Responses by deprivation quintile<sup>6</sup> (based on Index of Multiple Deprivation (IMD) from postcode in patient sample)**

Deprivation quintile	PTC		National	
	n	%	n	%
1 (most deprived)	19	26%	159	17%
2	14	19%	179	19%
3	15	21%	188	20%
4	14	19%	190	20%
5 (least deprived)	11	15%	221	23%
Non-England	0	0%	23	2%
<b>Total</b>	<b>73</b>	<b>100%</b>	<b>960</b>	<b>100%</b>

<sup>6</sup> Indices of Multiple Deprivation (IMD) classifies geographic areas into five quintiles based on relative disadvantage

## Overall care: sub-group comparisons

This section summarises the responses of various sub-groups to questions asking about overall care. Further information about how these sub-groups were determined can be found in the accompanying Technical Appendix, available [on the survey website](#).

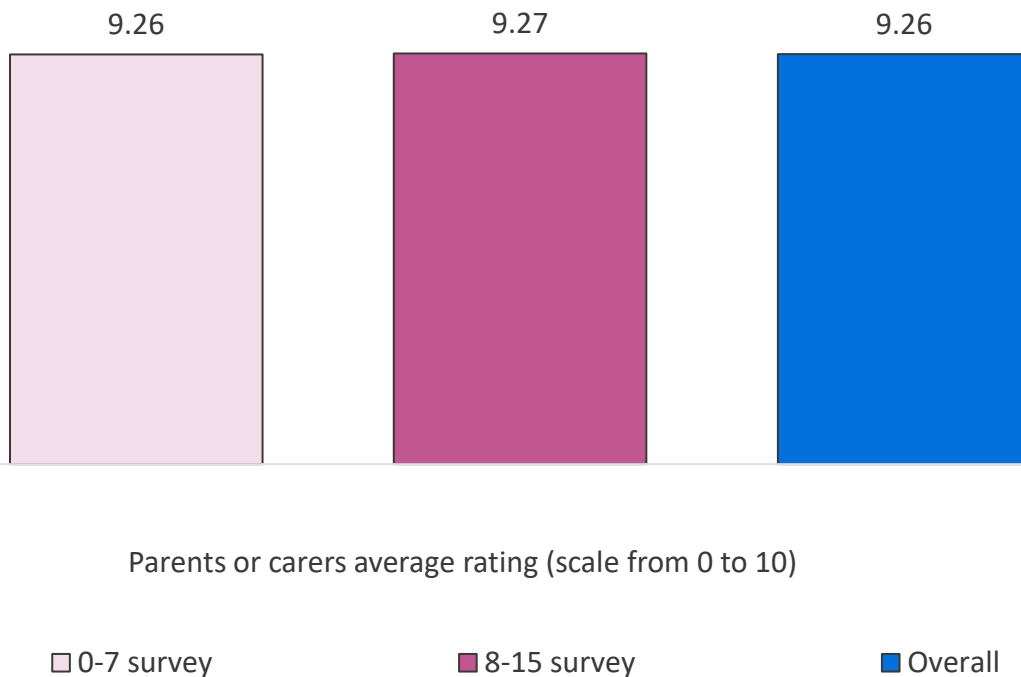
Questions asking about overall care were structured differently for children and parents/carers, therefore they cannot be directly compared. Children aged 8 and over were asked how well they were looked after for their cancer or tumour by healthcare staff and were given the options “Very well,” “Quite well,” “OK,” “Not very well” and “Not at all well.” Meanwhile, parents and carers of all age groups were asked to rank their child’s overall care on a scale of 0-10, with 0 indicating that the care was very poor and 10 indicating that the care was very good. In the results below, these parent/carer rankings have either been presented as scores of 8-10 (good), 4-7, and 0-3 (poor), or as an average rating.

A breakdown of all survey questions by each sub-group can be found in the PTC Excel data tables available [on the survey website](#).

### Parents/carers overall rating of care by survey type

9.26 was the average parent/carer rating of the overall experience of their child’s care (scale from 0 to 10).

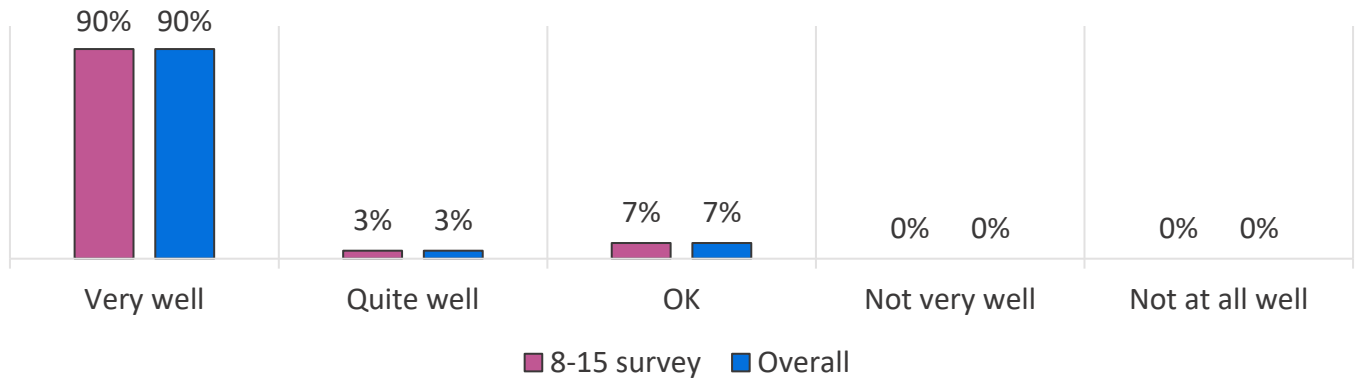
**Figure 1. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)**



**Question X62\_Average:** Asked to parents/carers of all age groups, n=72

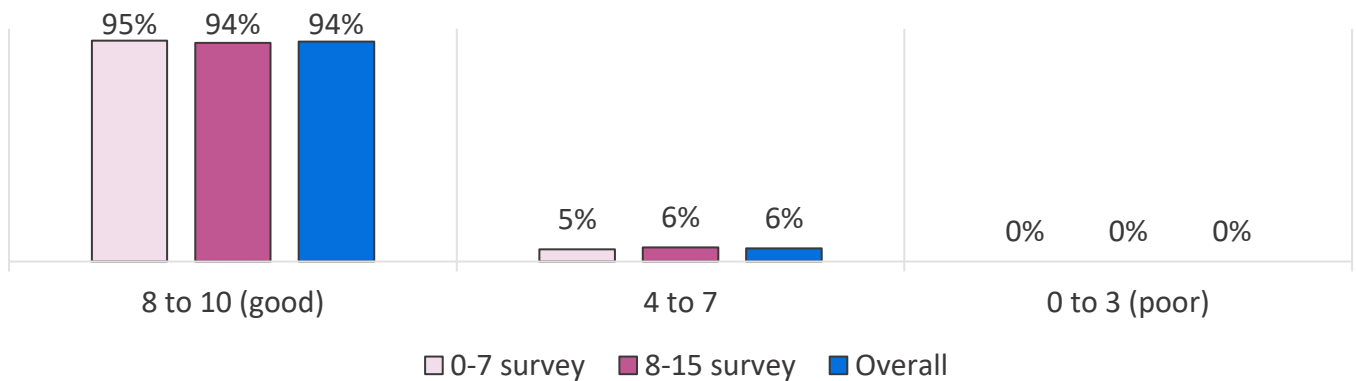
**Survey type**

**Figure 2. Overall, how well are you looked after for your cancer or tumour by the healthcare staff?**



**Question X63:** Asked to all children aged 8-15, n=30

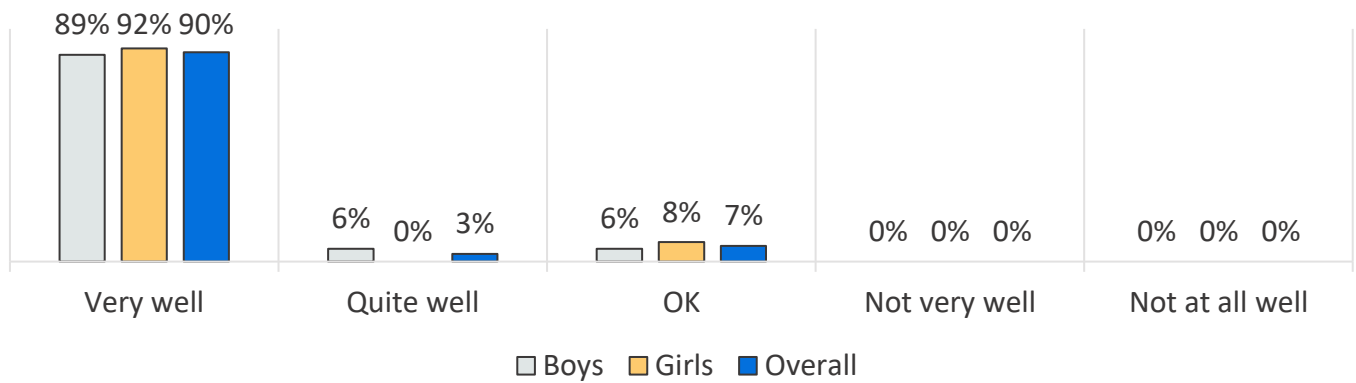
**Figure 3. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)**



**Question X62:** Asked to parents/carers of all age groups, n=72

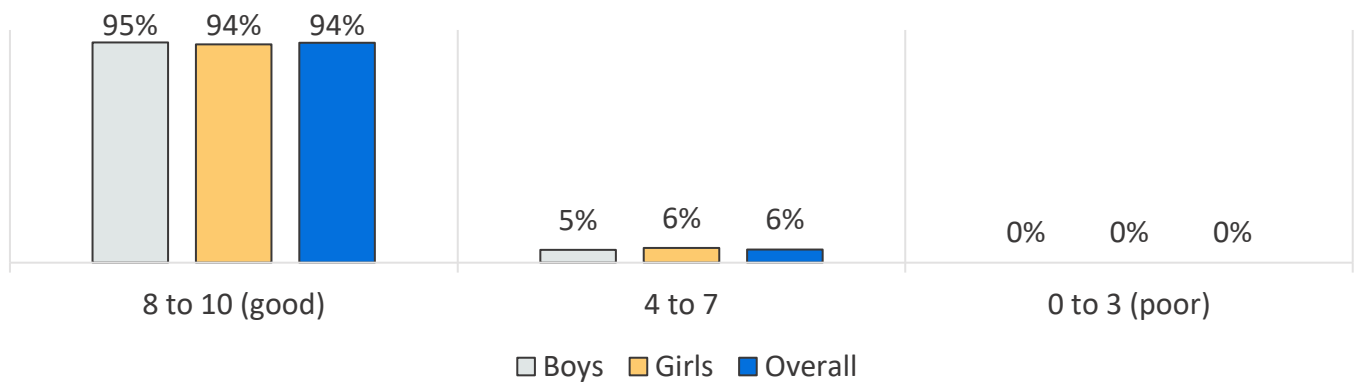
**Gender<sup>7</sup>**

**Figure 4. Overall, how well are you looked after for your cancer or tumour by the healthcare staff?**



**Question X63:** Asked to all children aged 8-15, n=30

**Figure 5. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)**

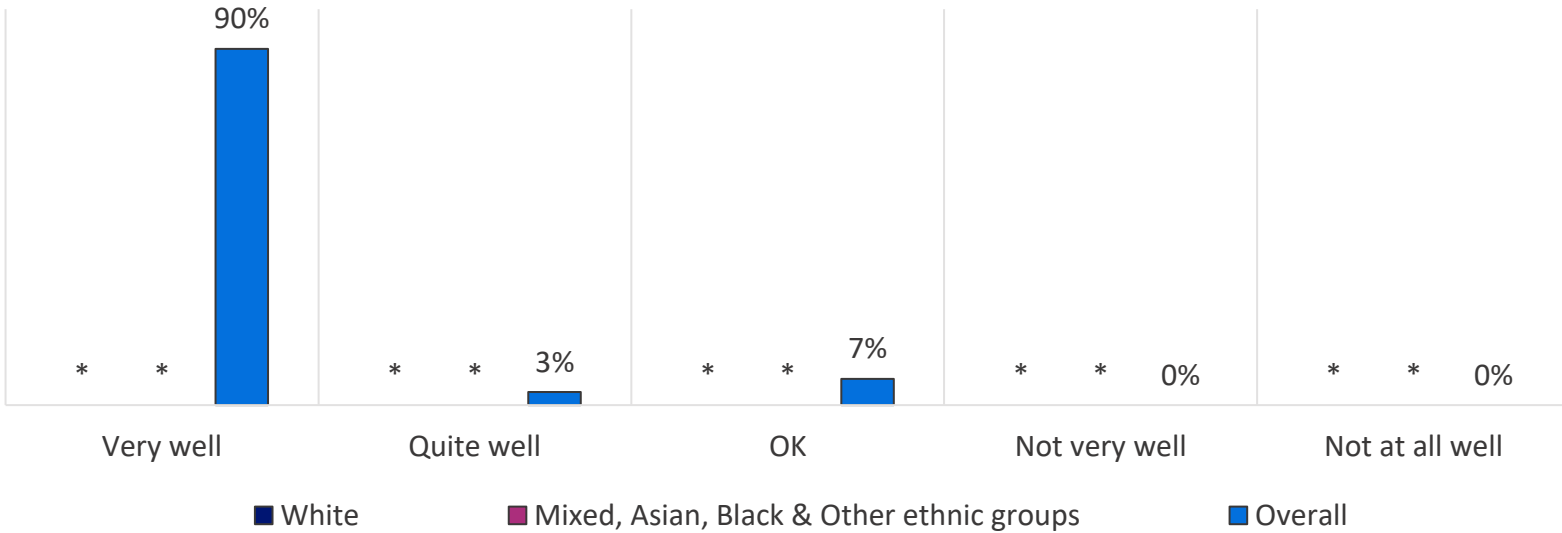


**Question X62:** Asked to parents/carers of all age groups, n=72

<sup>7</sup>Only data for boys and girls is shown, as the number of respondents answering 'prefer not to say' to the gender question was less than 11.

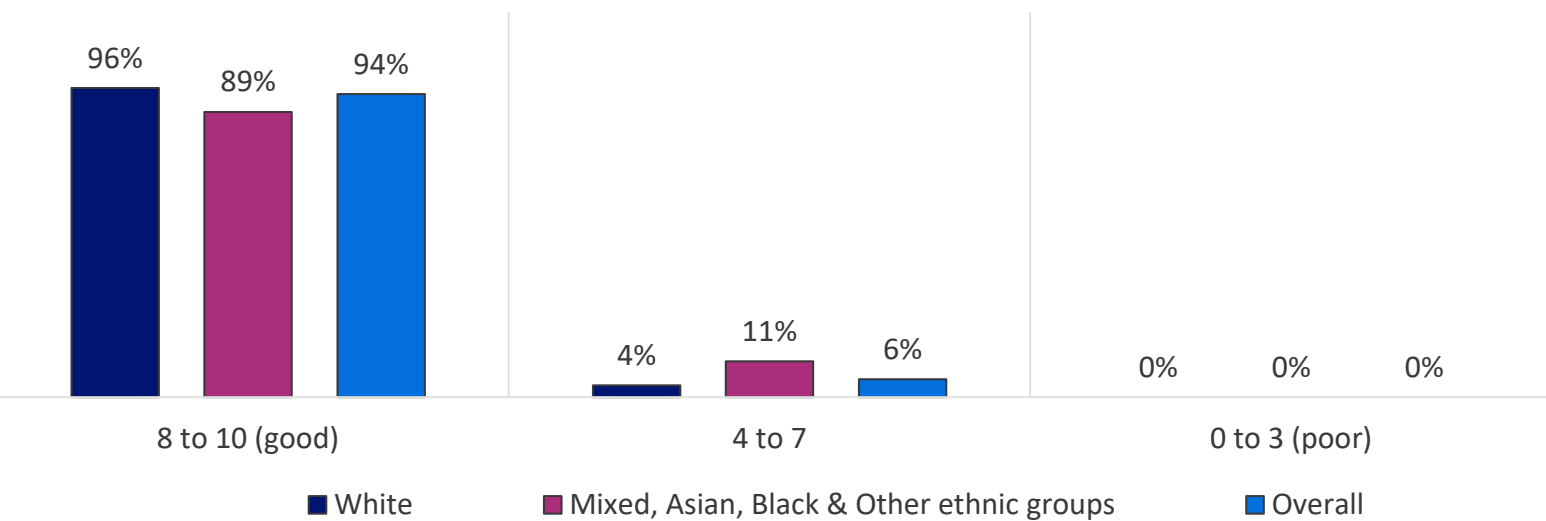
**Ethnic group**<sup>8</sup>

**Figure 6. Overall, how well are you looked after for your cancer or tumour by the healthcare staff?**



**Question X63:** Asked to all children aged 8-15, n=30

**Figure 7. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)**

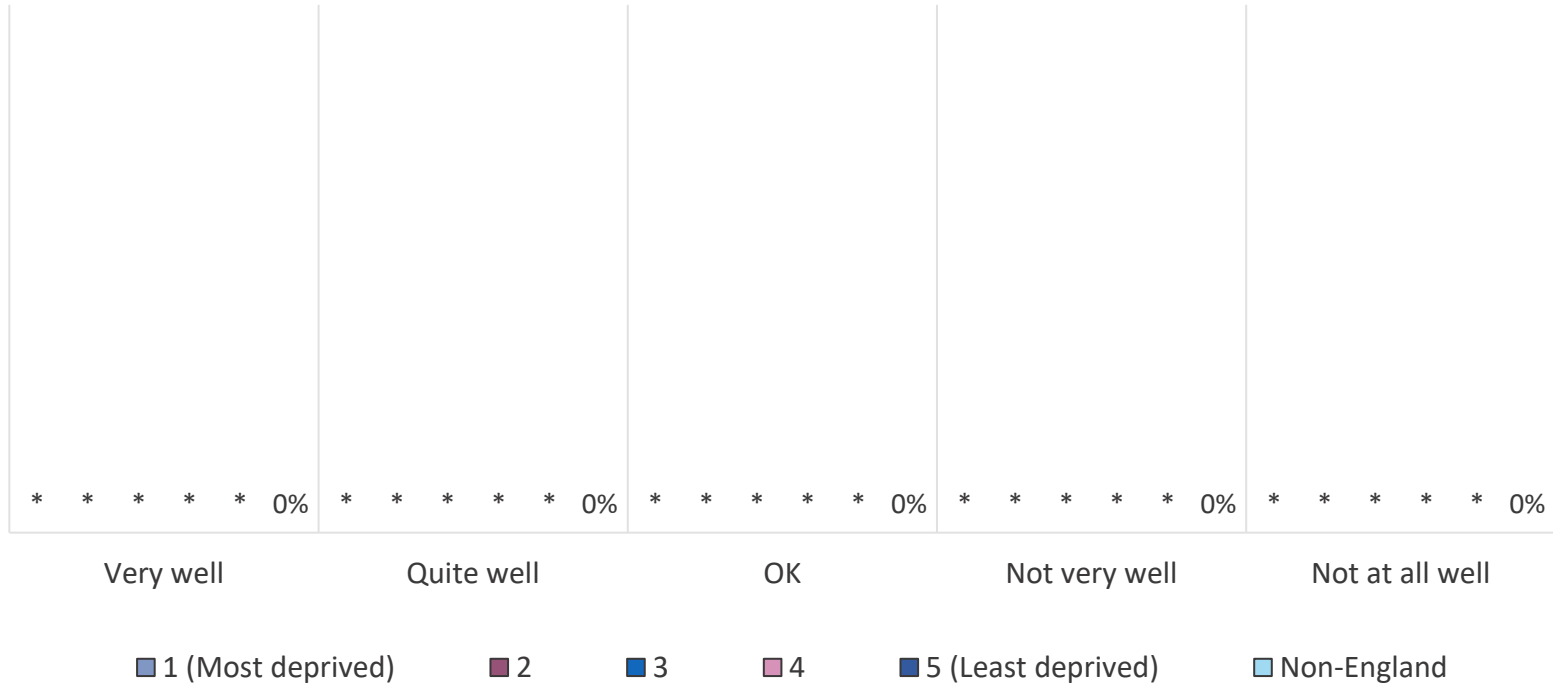


**Question X62:** Asked to parents/carers of all age groups, n=72

<sup>8</sup> Due to small numbers at PTC level, ethnic group data has been aggregated for the ethnic minority groups. It is important to note that there are often significant disparities in health outcomes between ethnic groups and caution is recommended when analysing this aggregated group i.e. poorer experience may become less obvious.

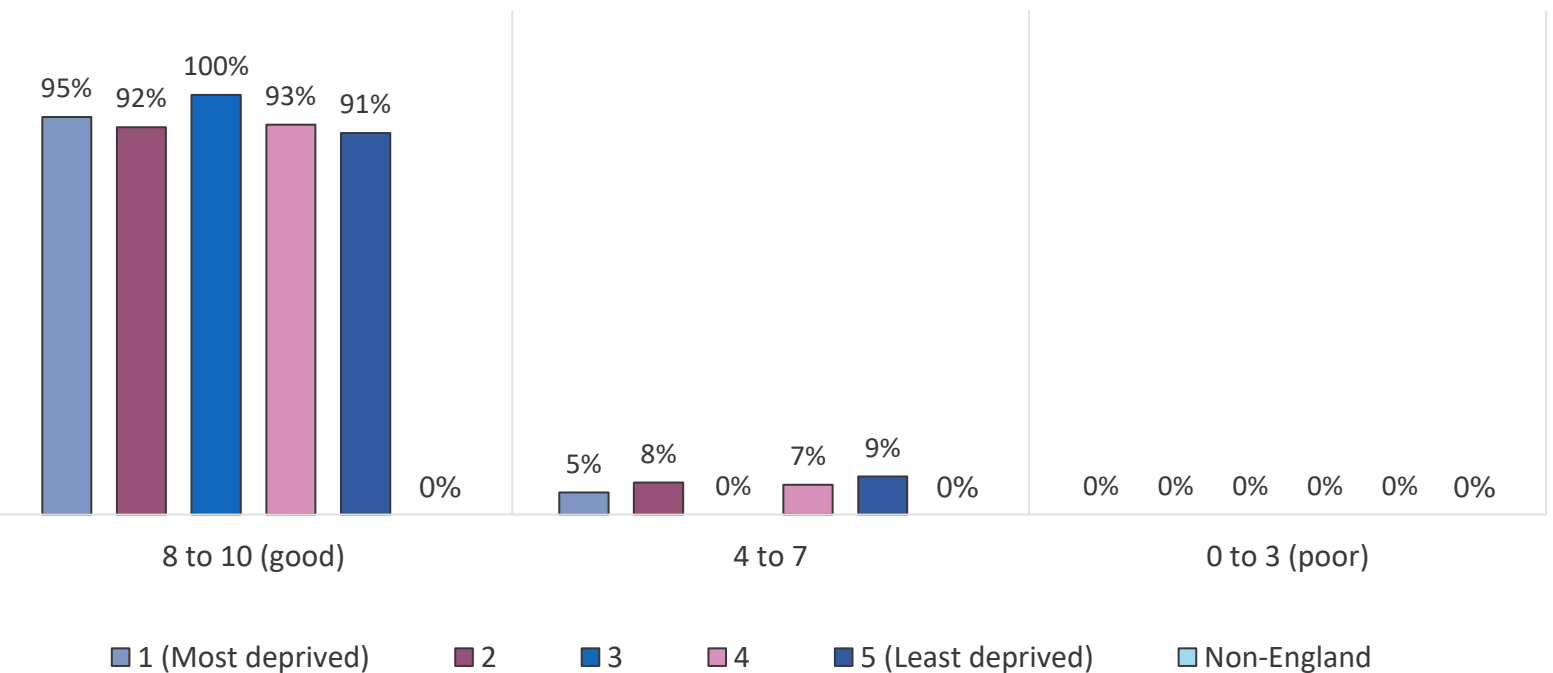
**Deprivation quintile**

**Figure 8. Overall, how well are you looked after for your cancer or tumour by the healthcare staff?**



**Question X63:** Asked to all children aged 8-15, n=30

**Figure 9. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)**

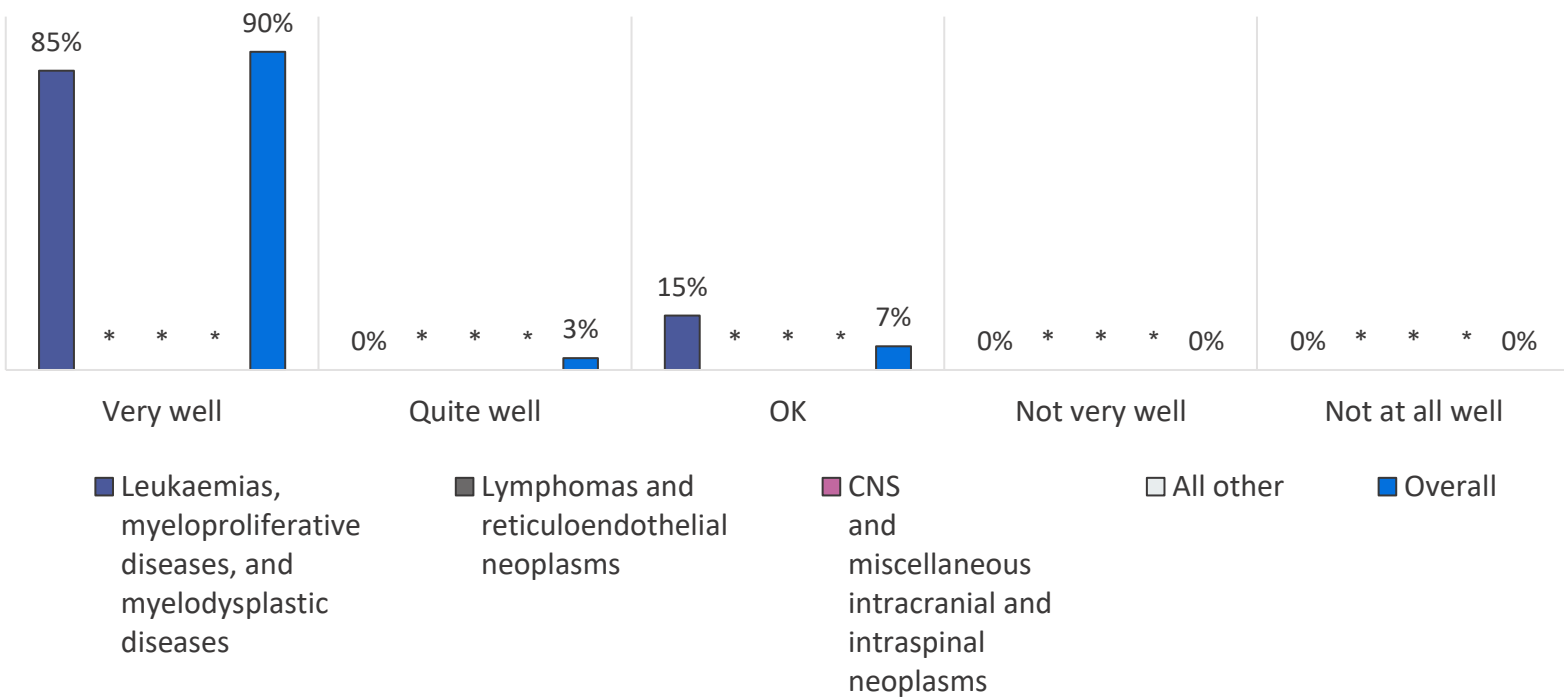


**Question X62:** Asked to parents/carers of all age groups, n=72



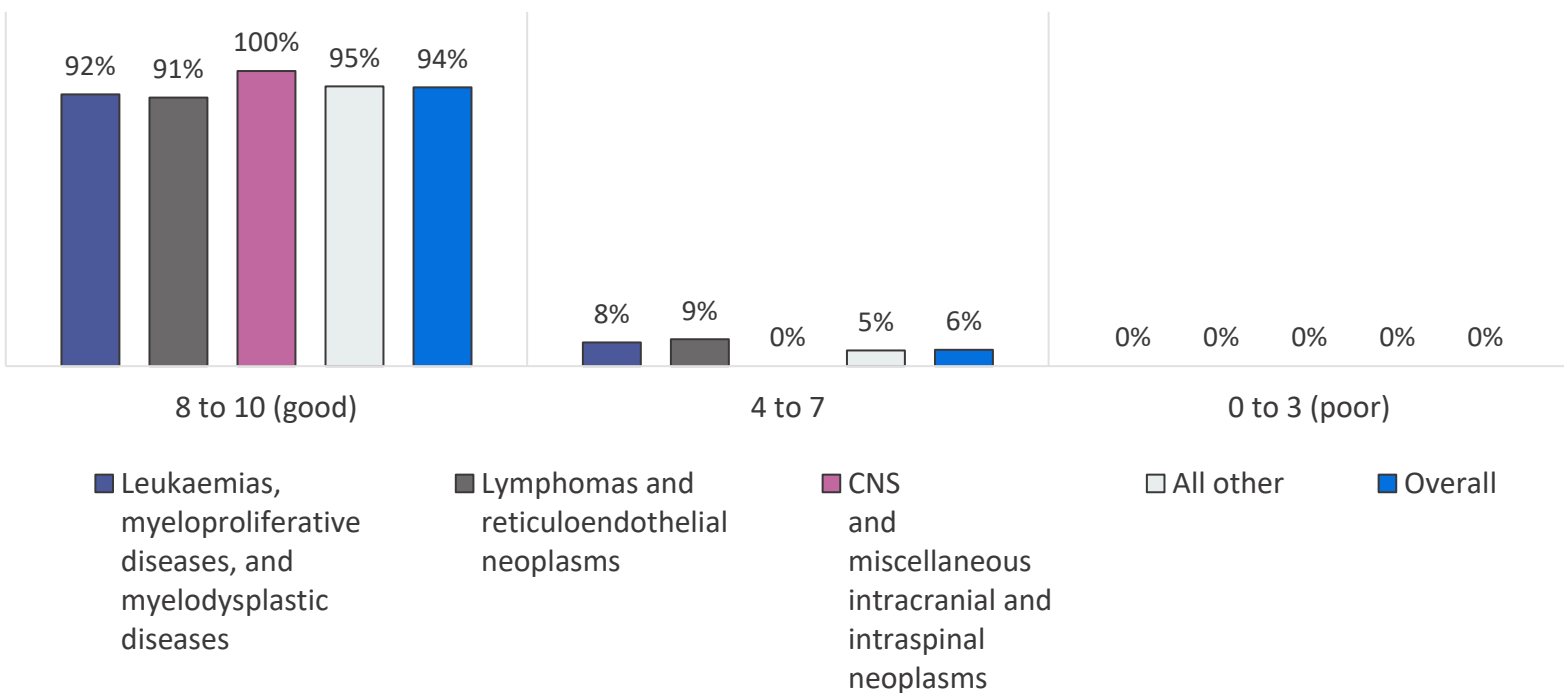
**Diagnostic Group<sup>9</sup>**

**Figure 10. Overall, how well are you looked after for your cancer or tumour by the healthcare staff?**



**Question X63:** Asked to all children aged 8-15, n=30

**Figure 11. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)**



**Question X62:** Asked to parents/carers of all age groups, n=72

<sup>9</sup> Due to small numbers at PTC level, diagnostic group data has been aggregated to allow for some analysis by diagnostic group. It is however, important to exercise caution when analysing aggregated groups i.e. poorer experience for some diagnostic groups is undetectable when aggregated.

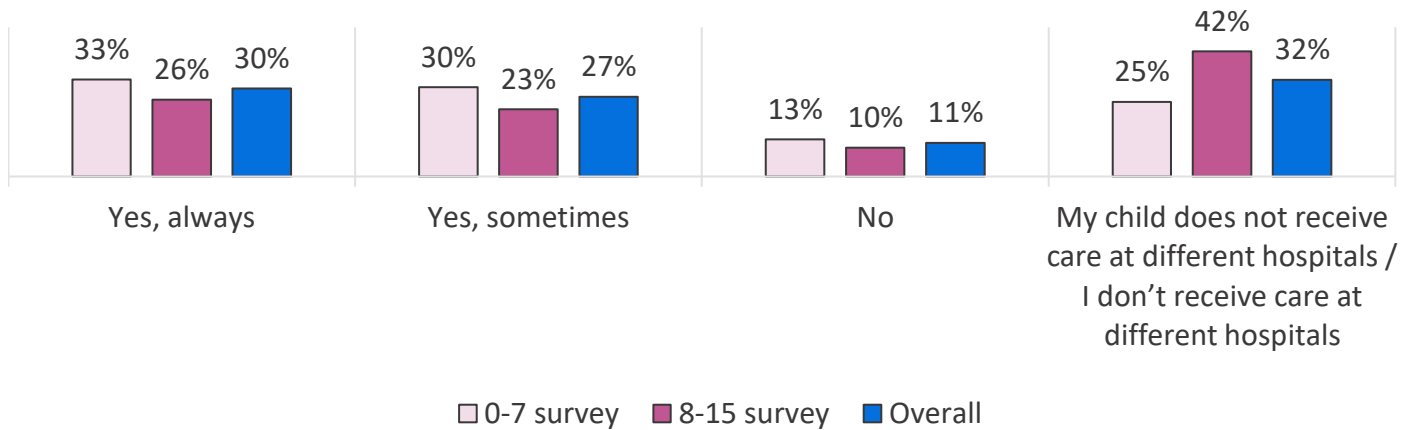
## PTC results

Key findings from each section of the questionnaire can be found below. Please note that full results can be found within the PTC Excel Data Tables (see 'Further information' section for more details).

### Overall care

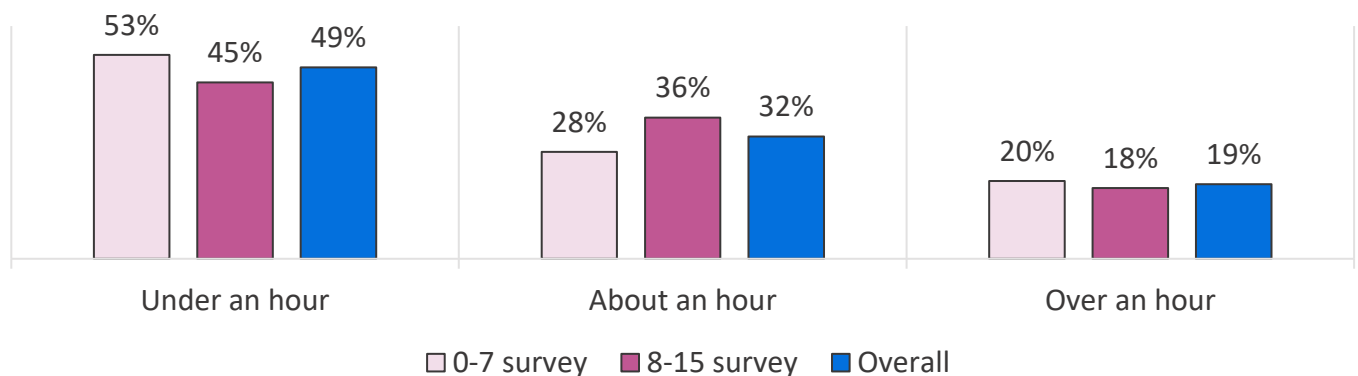
All respondents were asked how they felt about their overall care. Further results for these questions (showing breakdowns by different groups) can be found in the 'Sub-group comparisons' section of this report. Two questions were asked about how well different hospitals providing cancer or tumour care worked together and how long it takes to get to the hospital where the child received most of their cancer or tumour care. Results can be found in Figures 12 and 13 below.

**Figure 12. 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?**



**Question X60:** Asked to parents/carers of children aged 0-11, and all children aged 12-15, n=71

**Figure 13. How long does it take to get to the hospital where your child receives most of their cancer or tumour care?**

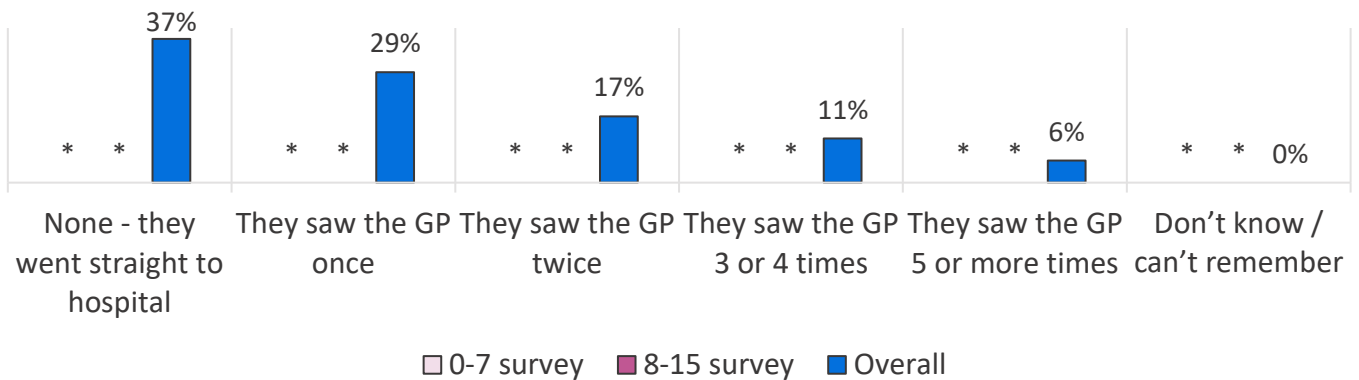


**Question X61:** Asked to parents/carers of all age groups, n=73

### Finding out about the cancer or tumour

48% (n=35) of all parents/carers reported that their children were told they had cancer or tumour during 2021 (Question X01). This group of respondents were then asked how many times they had seen their GP prior to receiving a formal diagnosis for their child's cancer or tumour (Question X03) – results are displayed in the chart below.

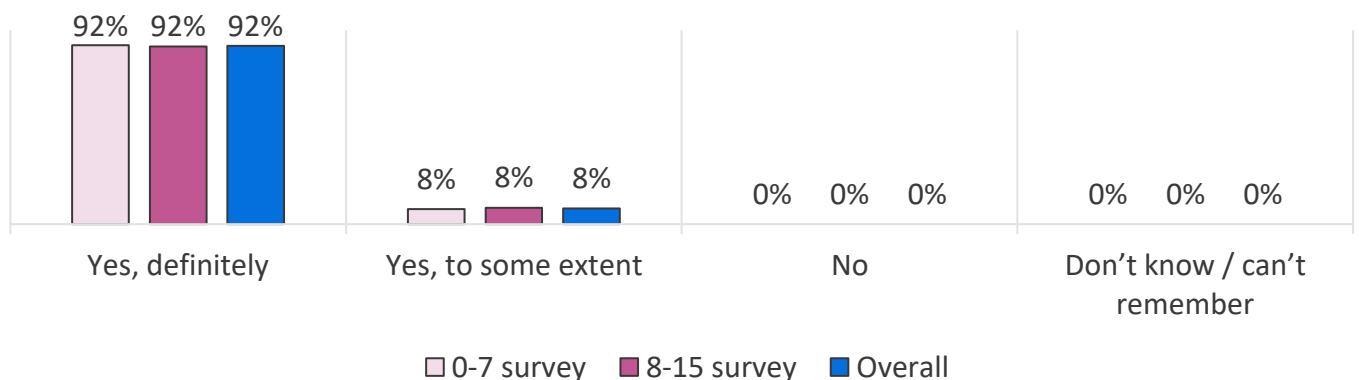
**Figure 14. Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem caused by the cancer or tumour?**



**Question X03:** Asked to parents/carers of all age groups whose children were told they had cancer or a tumour during 2021, n=35

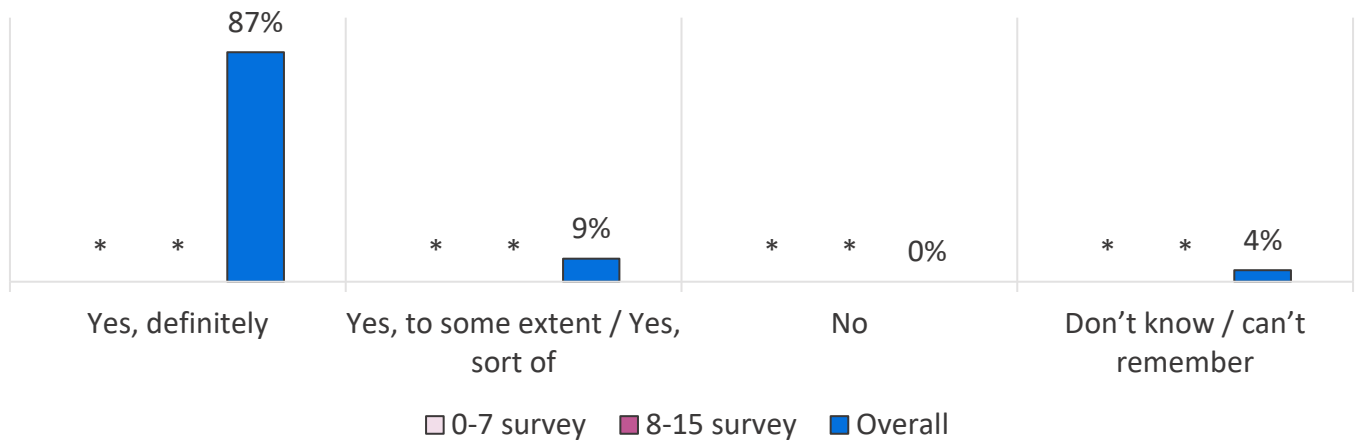
Further questions were asked to all parents/carers of children who had received diagnoses during 2021 by the hospital named in the covering letter.

**Figure 15. Were you told about your child's cancer or tumour in a sensitive way?**



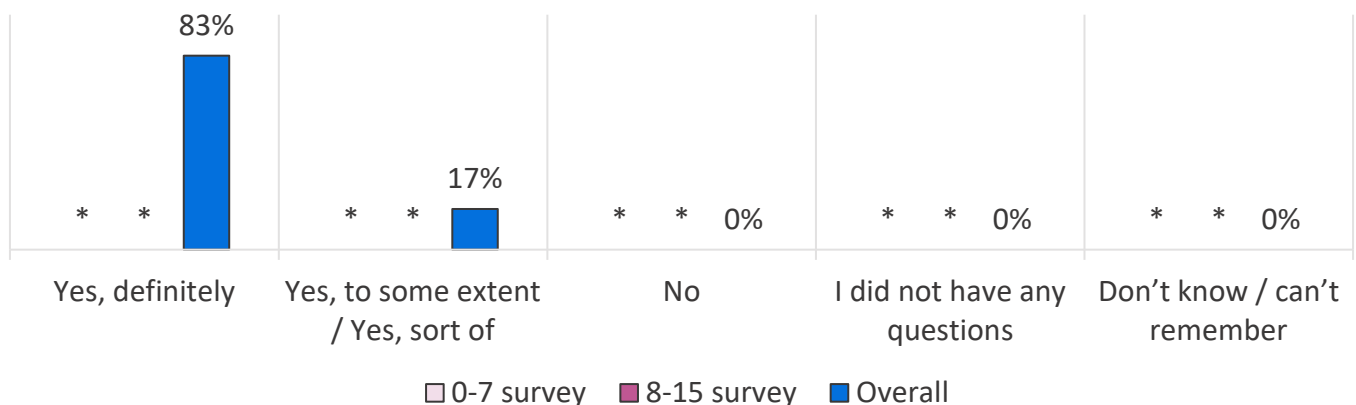
**Question X07:** Asked to parents/carers of all age groups who were told about their child's cancer or a tumour during 2021, n=25

**Figure 16. 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?**



**Question X08:** Asked to parents/carers of 0-7s who were told about their child's cancer or a tumour during 2021, and children aged 8-15 who were told they had cancer or a tumour during 2021, n=23

**Figure 17. 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?**

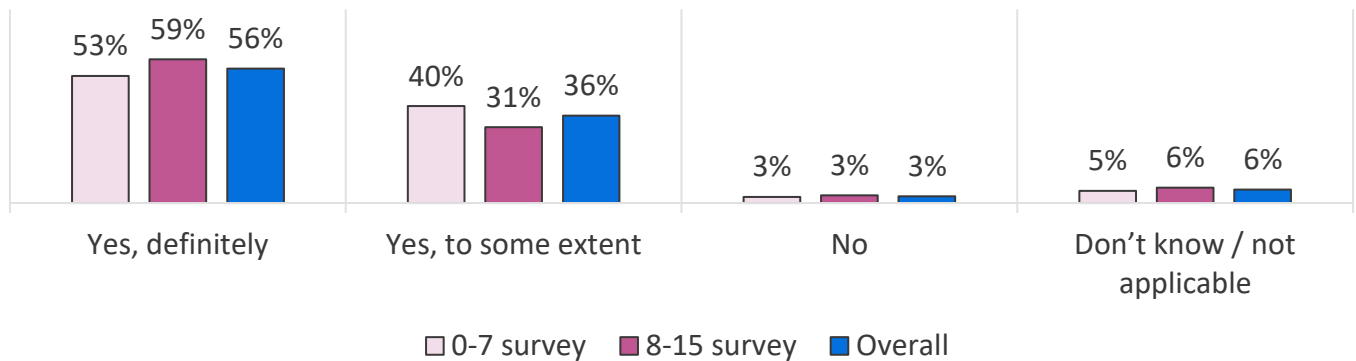


**Question X09:** Asked to parents/carers of 0-7s who were told about their child's cancer or a tumour during 2021, and children aged 8-15 who were told they had cancer or a tumour during 2021, n=23

## Child's care and treatment

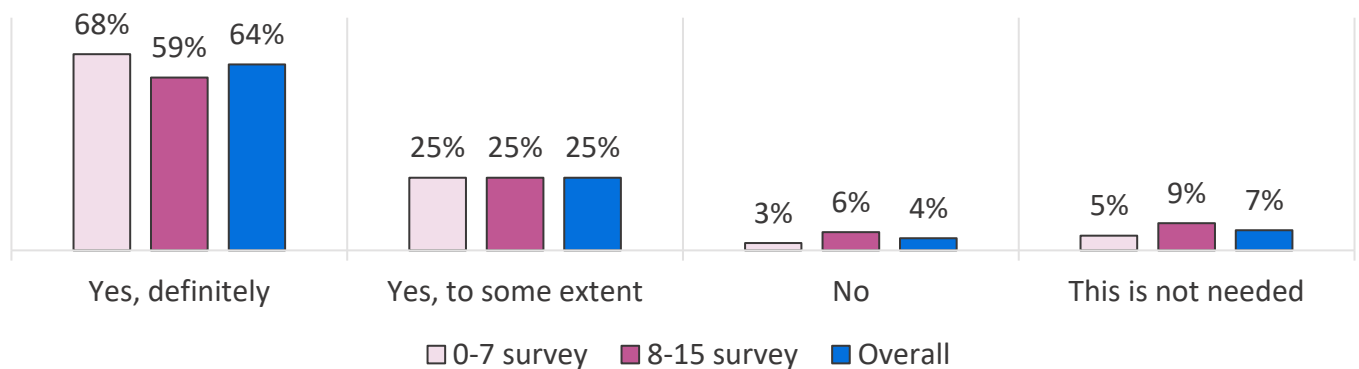
All parents and carers were asked questions about staff involved in their child's care at the hospital named in the letter that came with their survey, including questions about awareness of the child's medical history and whether they had access to help and support.

**Figure 18. Are different hospital staff caring for your child aware of your child's medical history?**



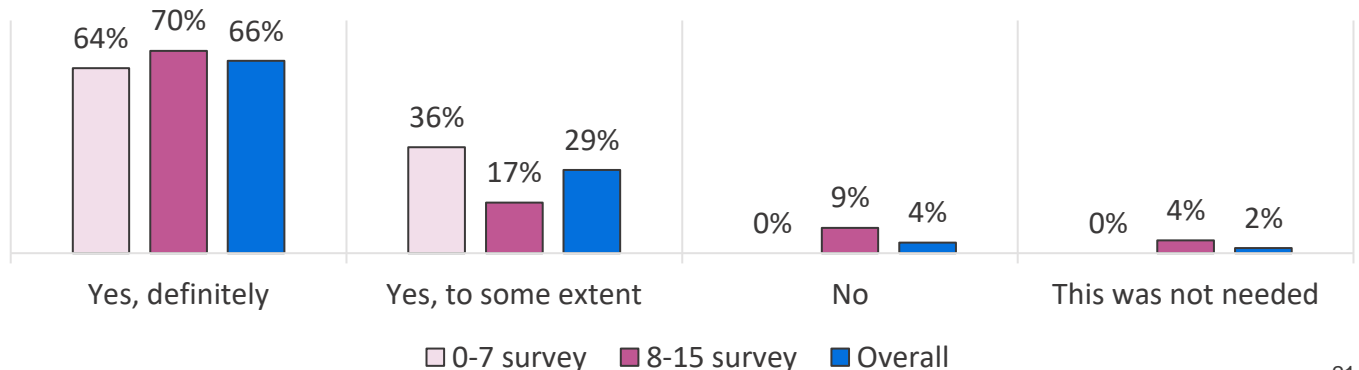
**Question X29:** Asked to parents/carers of all age groups, n=72

**Figure 19. Do you have access to reliable help and support 7 days a week from the hospital?**



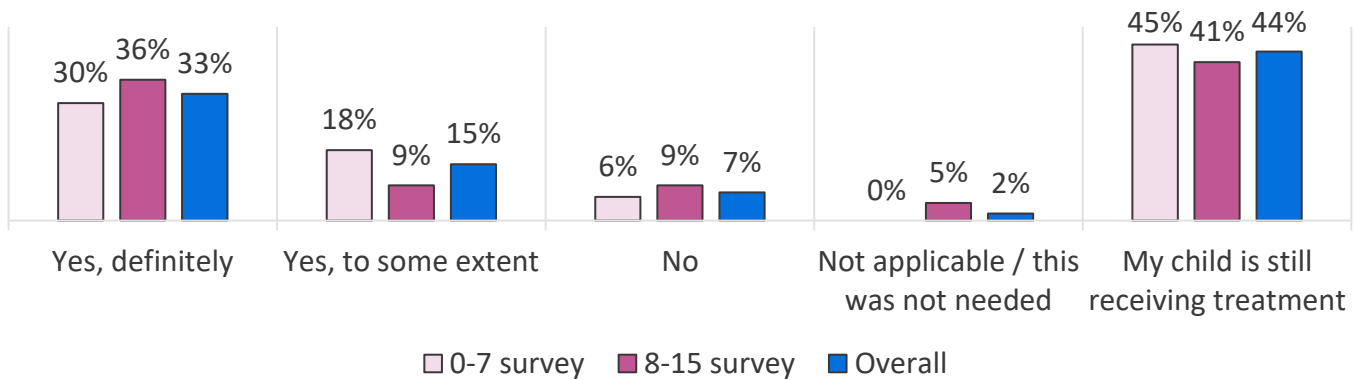
**Question X34:** Asked to parents/carers of all age groups, n=72

**Figure 20. Were you given clear written information about your child's treatment?**



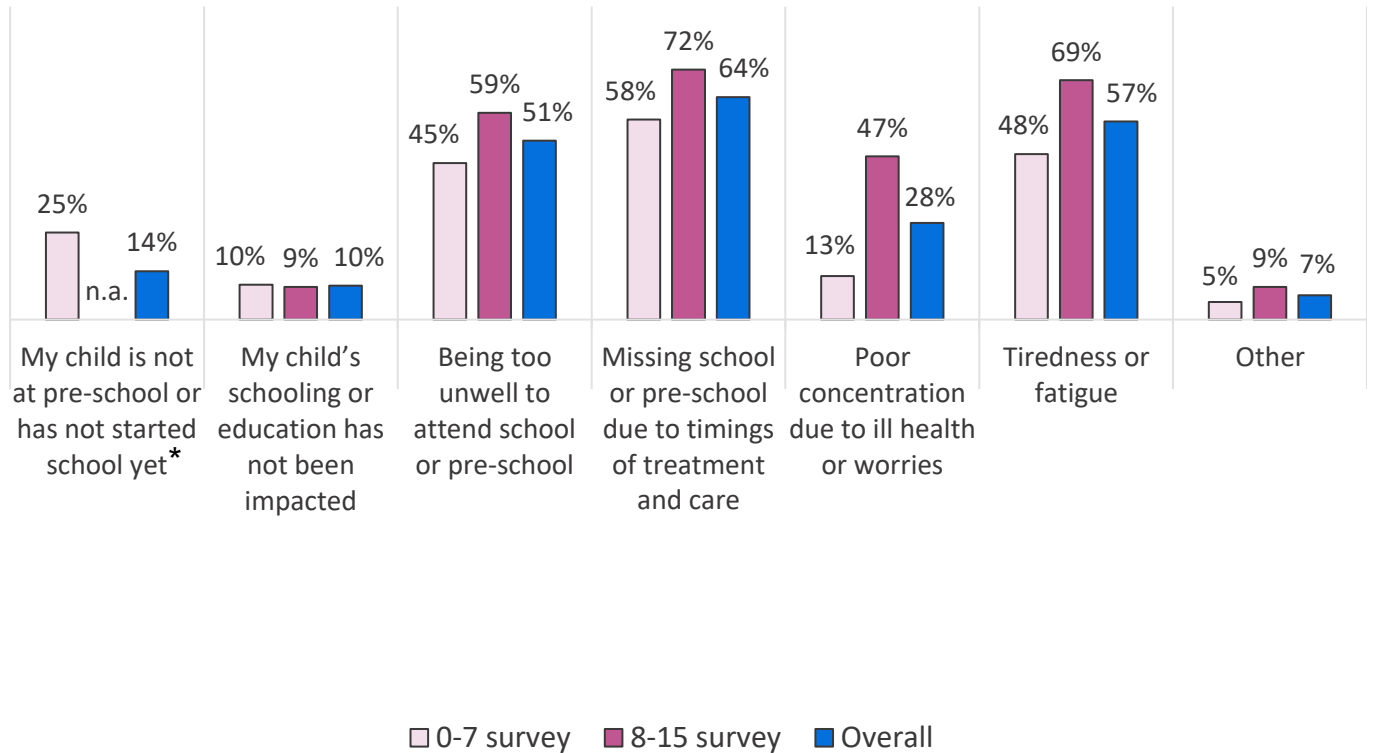
**Question X39:** Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2021, n=56

**Figure 21. If your child's treatment has finished, did you receive enough ongoing support after it ended from the hospital?**



**Question X42:** Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2021, n=55

**Figure 22. Has your child's schooling and education been impacted in any of the following ways by their treatment and care?**



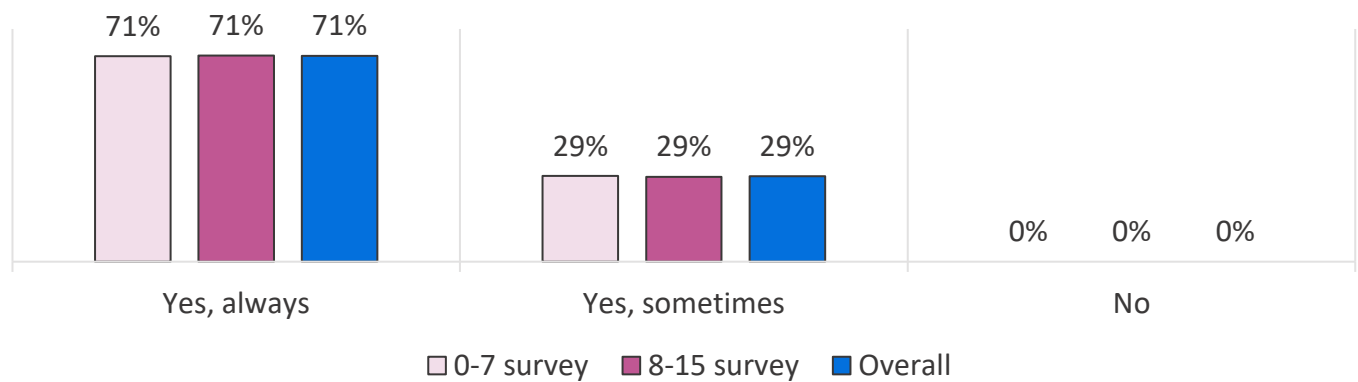
**Question X32:** Asked to parents/carers of all age groups, n=72

\* Response option was only asked to parents/carers of 0-7 years old

## Care in hospital

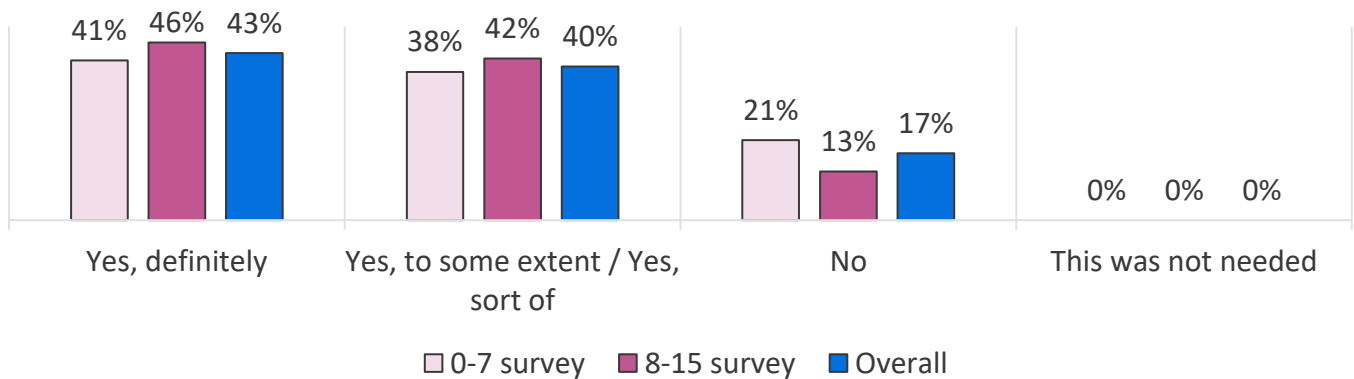
Respondents who had stayed in the hospital named in the letter that came with their survey during 2021 (receiving treatment or care in the daytime, or for an overnight stay) were asked questions about hospital staff, services and facilities. Out of all parents/carers, 81% (n=59) answered that their child had stayed in hospital during 2021 (Question X43).

**Figure 23. 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?**



**Question X45:** Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2021, and children aged 8-15 who stayed in hospital during 2021 (receiving treatment or care in the daytime or for an overnight stay), n=58

**Figure 24. Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital?**

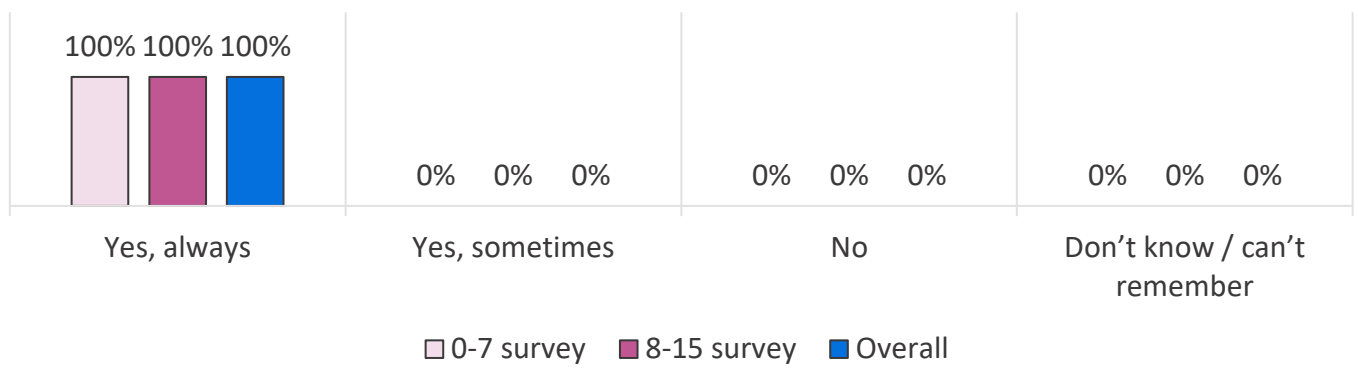


**Question X46:** Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2021, and children aged 8-15 who stayed in hospital during 2021 (receiving treatment or care in the daytime or for an overnight stay), n=58

## Care at home or school

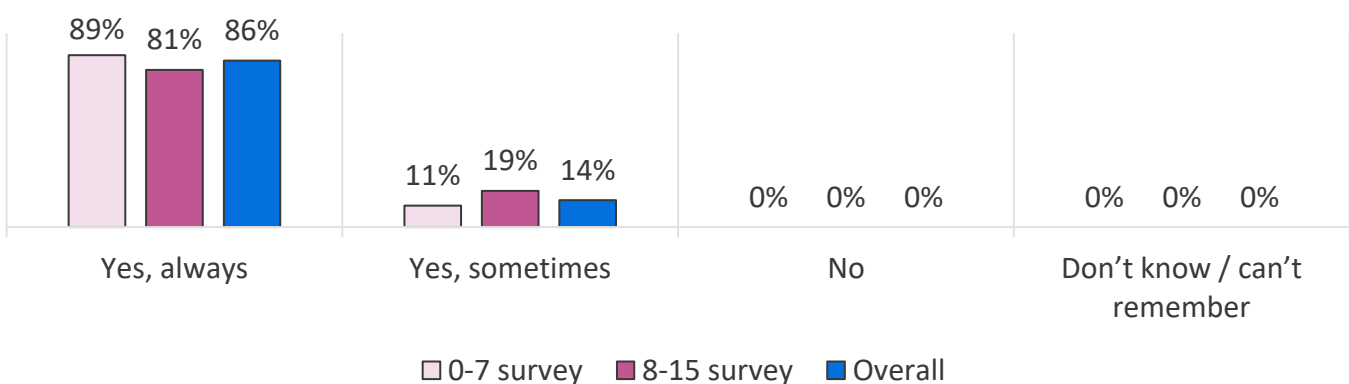
Children aged 8 and above and parents/carers of children under the age of 8 who had been visited at home or school by a nurse during 2021 (61% (n=43) of respondents) (Question X56), for care relating to the child's cancer or tumour, were asked a short series of questions about this care. Some results from this section can be found below.

**Figure 25. Were the nurses that came to your home or your child's school friendly / Were the nurses that came to your home or school friendly?**



**Question X57:** Asked to parents/carers of children aged 0-7 whose children have been visited at home or school by a nurse during 2021, and children aged 8-15 who were visited at home or school by a nurse during 2021, n=43

**Figure 26. When nurses speak to you, do you understand what they are saying?**



**Question X58:** Asked to parents/carers of children aged 0-7 whose children have been visited at home or school by a nurse during 2021, and children aged 8-15 who were visited at home or school by a nurse during 2021, n=43

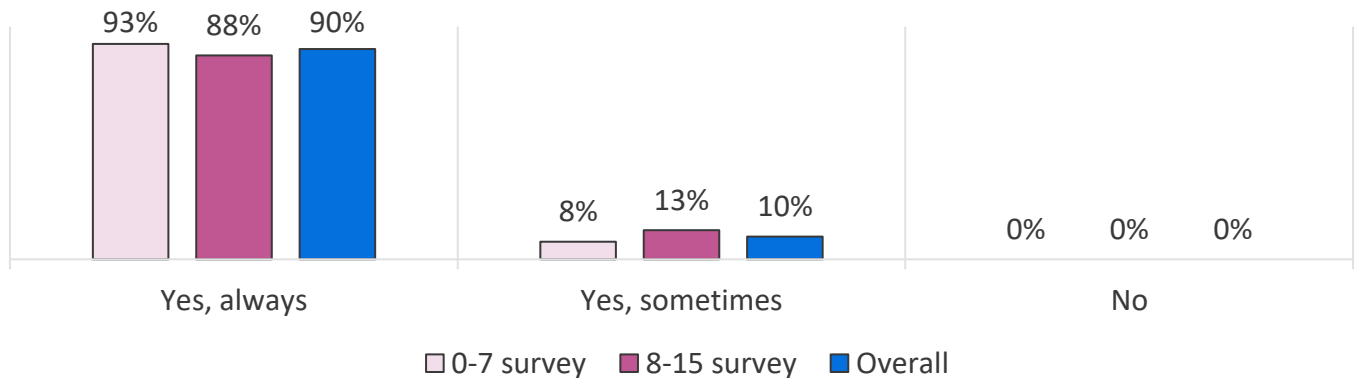


## Healthcare staff

All parents/carers of children aged under 16 at the time of their care and children aged 8 and above at the time of their care were asked questions about their interactions with healthcare staff at the hospital named in the letter that came with their questionnaire. The results for this section have been broken down into three main themes below: bedside manner and trust, clear communication and support.

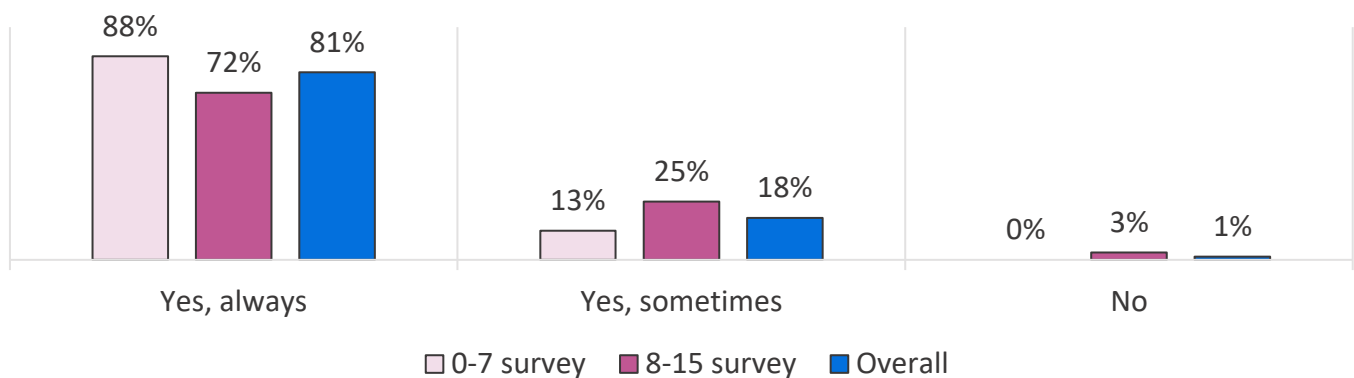
### Bedside manner and trust

**Figure 27. Are you and your child treated with respect and dignity by staff?**



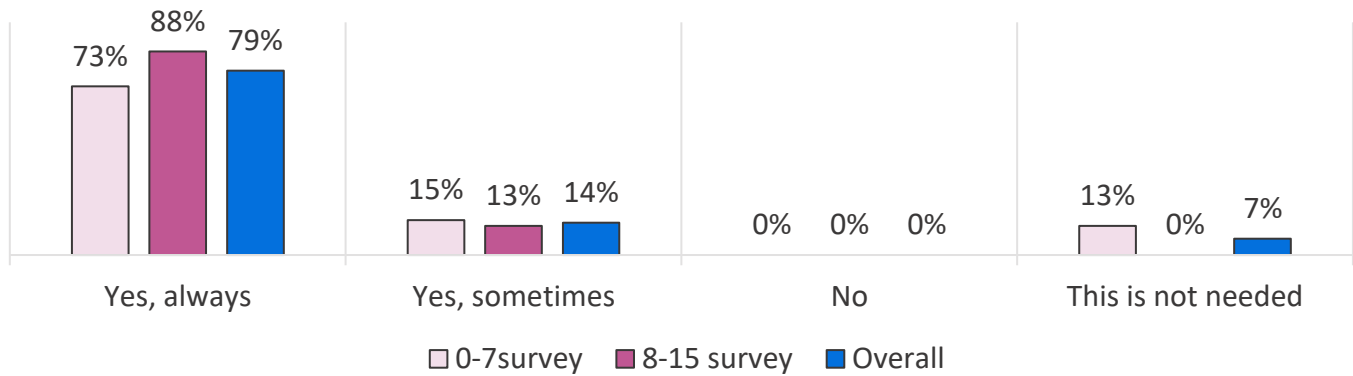
**Question X15:** Asked to parents/carers of all age groups, n=72

**Figure 28. Do members of staff caring for your child treat you with empathy and understanding?**



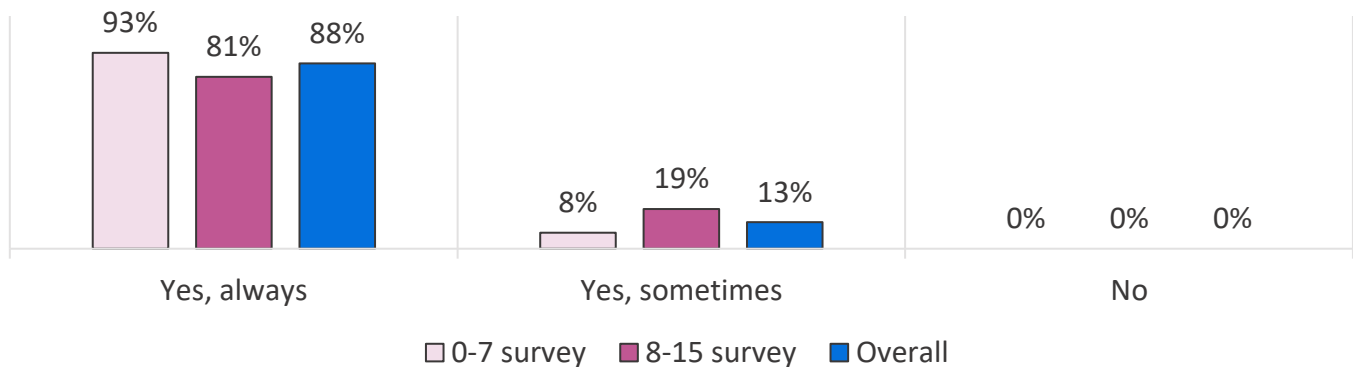
**Question X17:** Asked to parents/carers of all age groups, n=72

**Figure 29. Are staff sensitive to the information they share with you when your child is in the room?**



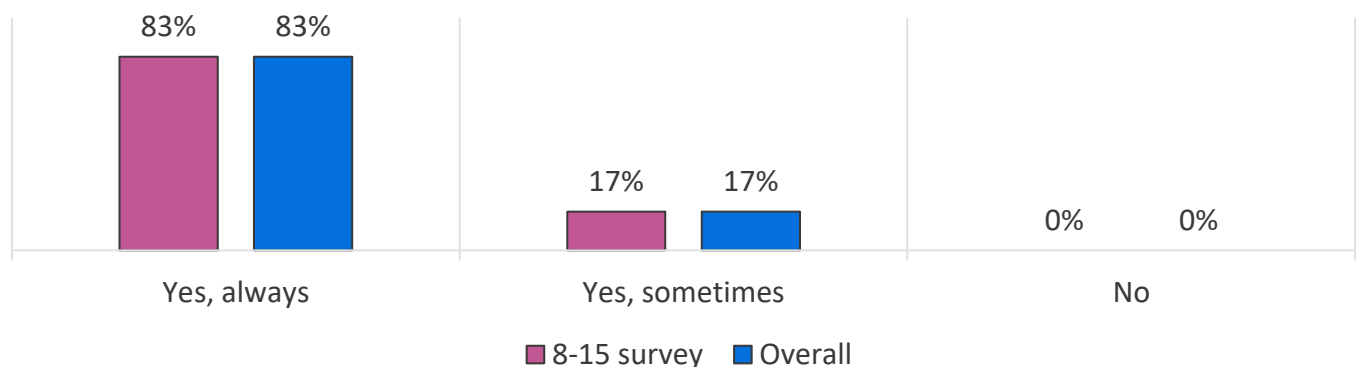
**Question X19:** Asked to parents/carers of all age groups, n=72

**Figure 30. Do you have confidence and trust in the members of staff caring for your child?**



**Question X16:** Asked to parents/carers of all age groups, n=72

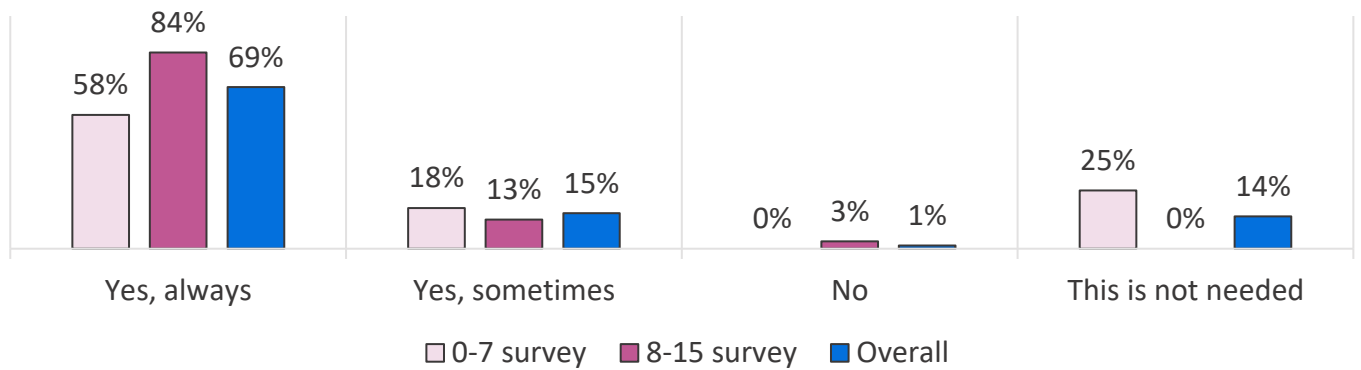
**Figure 31. Do you feel that staff are friendly?**



**Question X23:** Asked to all children aged 8-15, n=30

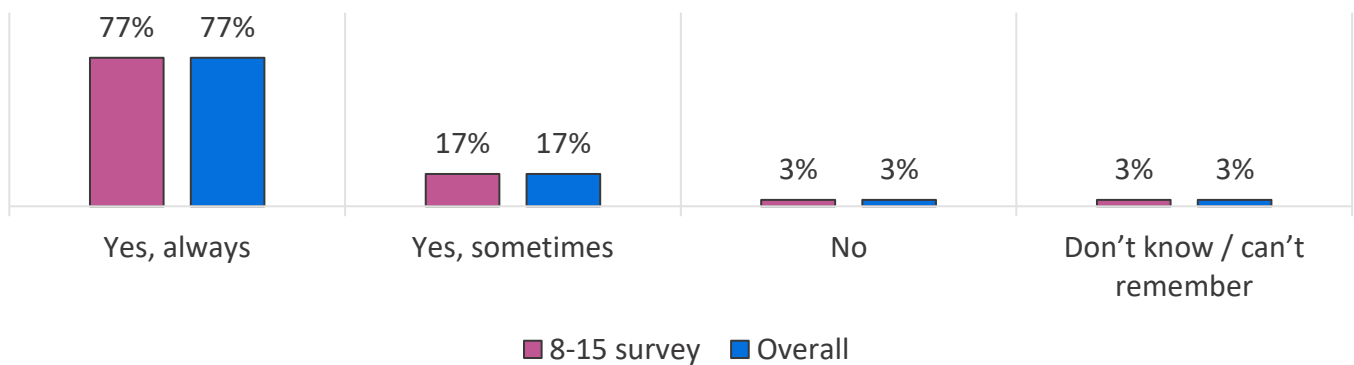
Clear communication

Figure 32. Do healthcare staff share information with your child in a way that is appropriate for them?



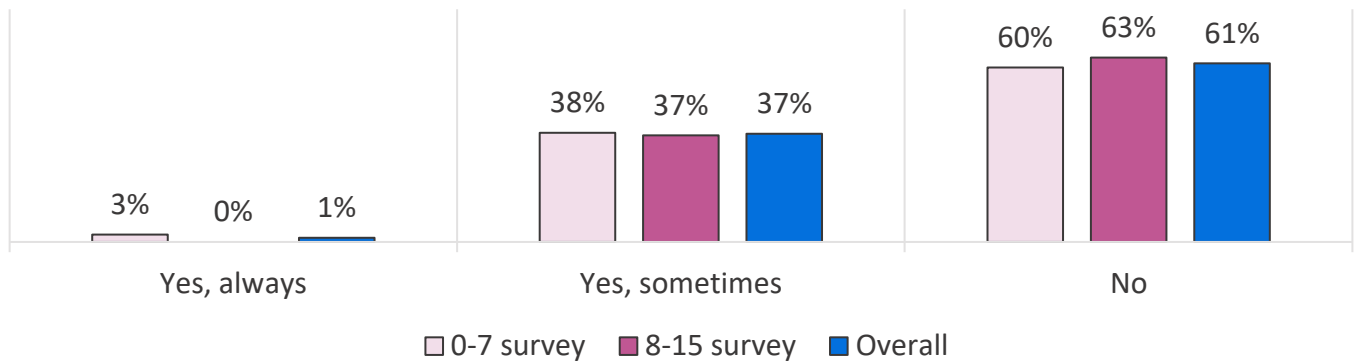
Question X20: Asked to parents/carers of all age groups, n=72

Figure 33. When staff speak to you, do you understand what they are saying / Do staff speak to you in a way that you can understand?



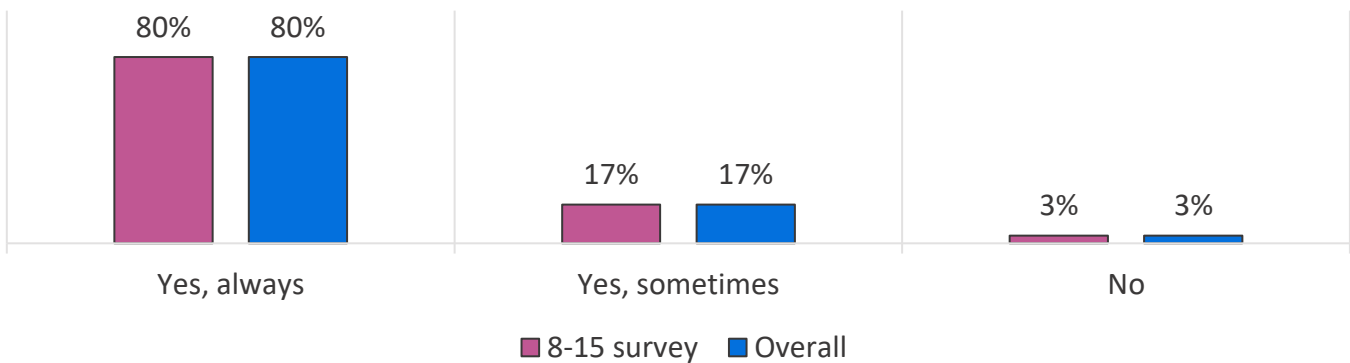
Question X14: Asked to all children aged 8-15, n=30

**Figure 34. Are you ever told different things by different members of staff, which leaves you feeling confused?**



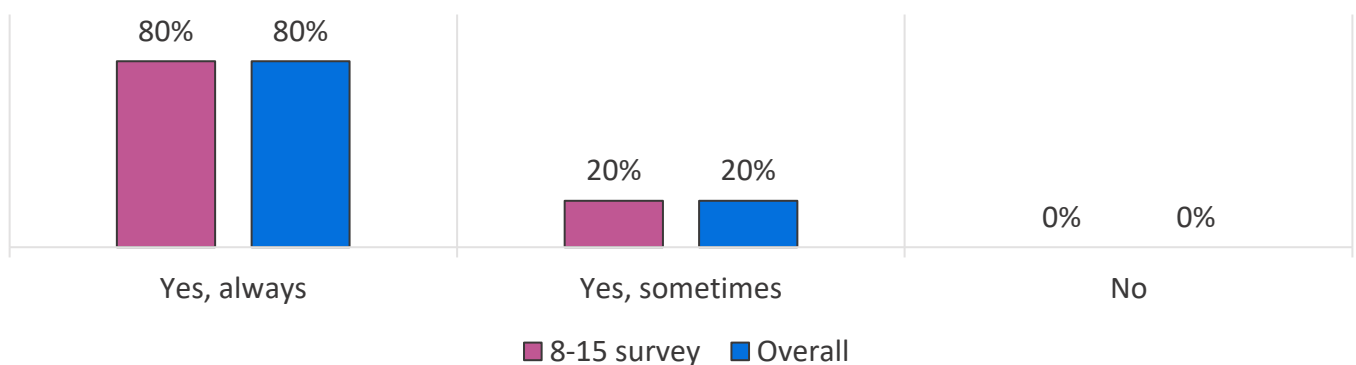
**Question X18:** Asked to parents/carers of children aged 0-7, and all children aged 8-15, n=70

**Figure 35. Do staff speak to you in a way that is suitable for you?**



**Question X21:** Asked to all children aged 8-15, n=30

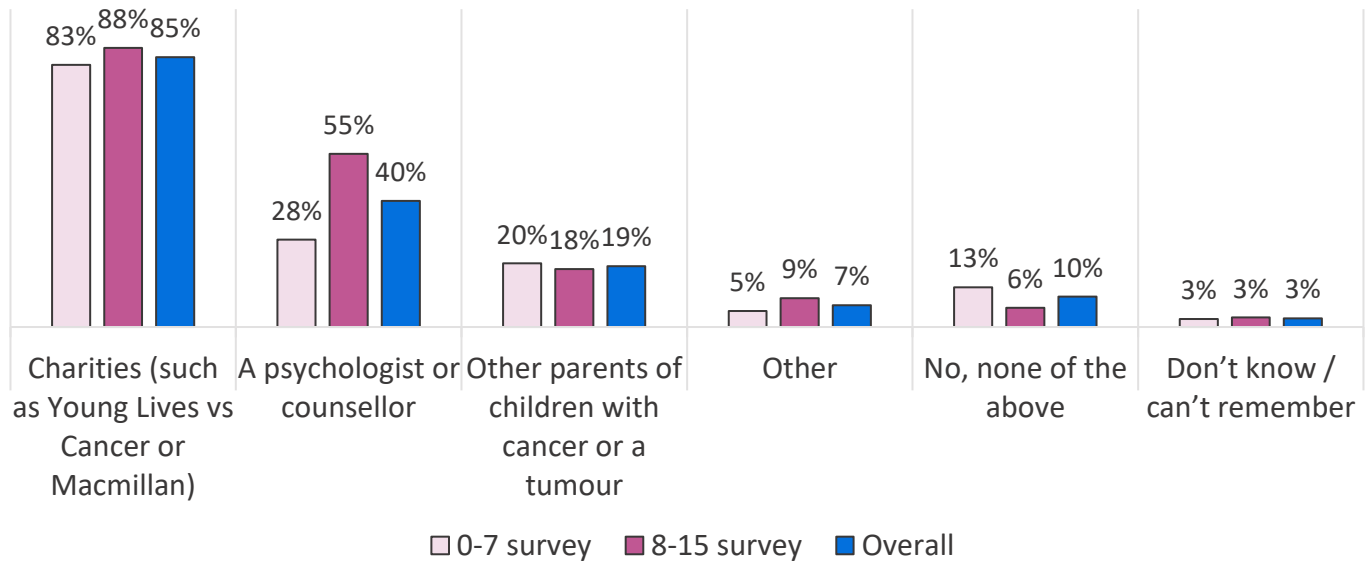
**Figure 36. Do staff talk to you, not just to your parent or carer?**



**Question X22:** Asked to all children aged 8-15, n=30

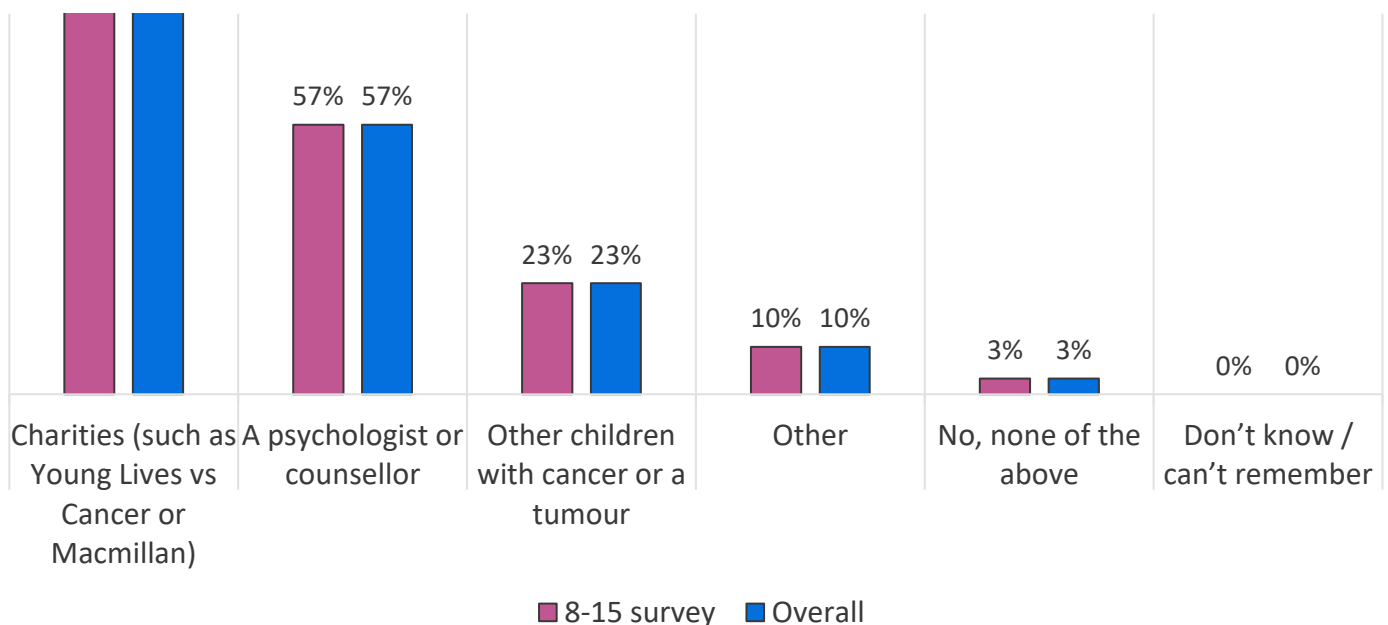
## Support

**Figure 37. Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour?**



**Question X25:** Asked to parents/carers of all age groups, n=73

**Figure 38. Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour?**



**Question X26:** Asked to all children aged 8-15, n=30

## Score tables

The following tables present reported care experiences for your PTC alongside the average score for all 13 participating PTCs ('national score').

The single percentage figures given as a score for each PTC 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. In instances where a score is calculated from a small base size, the confidence intervals will be wider.

The table below gives examples of the width of confidence intervals for scores of 90%, 70% and 50%, on a range of base sizes:

### Approximate confidence intervals at a range of base sizes

Base size for a question	Level 1: Score of 90%			Level 2: Score of 70%			Level 3: Score of 50%		
	Score (%)	Lower CI (%)	Upper CI (%)	Score (%)	Lower CI (%)	Upper CI (%)	Score (%)	Lower CI (%)	Upper CI (%)
15	90.00	66.03	97.66	70.00	44.83	87.01	50.00	27.42	72.58
45	90.00	77.87	95.84	70.00	55.48	81.37	50.00	35.98	64.02
75	90.00	81.15	94.95	70.00	58.86	79.19	50.00	38.96	61.04
100	90.00	82.56	94.48	70.00	60.42	78.11	50.00	40.38	59.62

For example, if 15 people responded to a question and 90% of these answered with a positive scored response, the confidence interval range is from 66.03% to 97.66%. This means that we can be fairly confident (95%) that the true population value lies within this range of scores, had everyone eligible for the survey responded to the question. However, if 100 people responded to the question and 90% of these answered with a positive scored response, the confidence interval range would be much smaller (82.56% to 94.48%).

**Please note that some scores in the following tables may be based on small numbers of respondents. Findings for these questions will often have especially wide confidence intervals, and so should therefore be regarded as indicative rather than robust.**

To view scores for your PTC alongside their calculated confidence intervals, please see the PTC Excel data tables [on the survey website](#).

For more information on how confidence intervals have been calculated and how to interpret these, please see the Technical Appendix [on the survey website](#).

## Score tables

**Please note:** Scores have been calculated using unadjusted data. In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently. However, scores have not been adjusted for the 2021 survey due to small sample size restrictions.

This means that 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. Furthermore, survey responses might be influenced by the type of care provided by PTCs, for example some provide specialised care and treatment.

**PTCs should therefore be mindful of potential differences in types of care provision, size and demographic makeup when viewing their results alongside those of other PTCs, and alongside National results.**

Data for questions in which the base size per question was <11 have been suppressed and replaced with an asterisk (\*).

### Overall care

Question	Scored Text	PTC Score		National Score	
		n	%	n	%
X60	Parents/carers and children report that different hospitals providing cancer or tumour care always work well together	48	44%	711	54%
X61	Parents/carers report that the hospital where their child receives most of their care is under one hours travel from their child's home	73	49%	935	47%
X62	Parents/carers rated the overall experience of their child's care as 8 or more out of 10	72	94%	922	89%
X63	Children report being looked after very well for their cancer or tumour by healthcare staff	30	90%	416	77%

### Overall care: mean

Question	Scored Text	PTC Score		National Score	
		n	Mean	n	Mean
X62_Average	Parents/carers rated the overall experience of their child's care as 8 or more out of 10	72	9.26	922	9.01

### Finding out about the cancer or tumour

Question	Scored Text	PTC Score		National Score	
		n	%	n	%
X03	Parents/carers reported that their child saw a GP once or twice before they were referred to hospital	22	73%	331	63%
X06	Parents/carers felt that their child was first seen by a hospital doctor as soon as they thought was necessary	25	92%	282	80%
X07	Parents/carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way	25	92%	275	74%
X08	Parents/carers and children reported that information at diagnosis was definitely given in a way they could understand	22	91%	278	73%
X09	Parents/carers and children reported that they were definitely able to have questions answered after being told about the cancer or tumour	23	83%	276	84%
X10	Children reported that staff provided details about who to speak to/contact for more information after being told about their cancer or tumour	9	*	111	95%
X11	Parents/carers reported that they were definitely able to find information about child's diagnosis	25	72%	281	75%



## Child's care and treatment

Question	Scored Text	PTC Score		National Score	
		n	%	n	%
X28	Parents/carers feel that different hospital staff always work well together	70	64%	905	66%
X29	Parents/carers feel that different hospital staff are definitely aware of their child's medical history	68	59%	899	57%
X30	Parents/carers and children always know what is happening with their child's/ their care	70	60%	920	66%
X31	Parents/carers and children are definitely involved in their child's/their care and treatment	68	69%	881	68%
X33	Parents/carers have a named member of staff at the hospital who can be contacted about their child's care and treatment	72	92%	940	90%
X34	Parents/carers reported that they definitely have access to reliable help and support 7 days a week from the hospital	67	69%	870	63%
X35	Parents/carers reported that their child's care and treatment is definitely offered at a time suitable for them and their family	60	35%	807	42%
X36	Parents/carers and children felt that treatment or care has not changed what their child is/they are normally able to do, such as seeing friends, doing hobbies or going to school	31	23%	420	20%
X37	Parents/carers and children spoke with staff about care or treatment changing things the child is normally able to do	13	77%	219	92%
X39	Parents/carers reported that they were given clear written information about their child's treatment	55	67%	807	78%
X40	Parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment	52	73%	727	75%
X41	Parents/carers reported that staff definitely offered them support to help manage their child's treatment side effects	52	73%	783	73%
X42	Parents/carers definitely received enough ongoing support from the hospital after their child's treatment finished	30	60%	403	57%

## Care in hospital

Question	Scored Text	PTC Score		National Score	
		n	%	n	%
X45	Parents/carers and children felt that the child was always able to get help from hospital staff when they needed it	58	71%	800	76%
X46	Parents/carers and children felt that there were definitely enough things for the child to do in the hospital	58	43%	780	43%
X47	Parents/carers and children felt that there was definitely a choice of hospital food	50	42%	728	52%
X48	Parents/carers and children were always given somewhere private to talk to staff when the child was in hospital	47	40%	644	52%
X49	Parents/carers reported that the hospital offered play specialist support	31	94%	413	90%
X51	Parents/carers reported that facilities for them to stay overnight were very good	52	25%	695	32%
X52	Parents/carers and children reported that it was always quiet enough for them to sleep in the hospital	52	15%	719	28%
X53	Parents/carers were definitely able to prepare food in the hospital if they wanted to	55	45%	707	36%
X54	Parents/carers felt that the hospital Wi-Fi always met the needs of them and their children	56	18%	777	34%
X55	Parents/carers reported that their child had access to hospital school services during their stay in hospital	33	73%	412	69%

## Care at home or school

Question	Scored Text	PTC Score		National Score	
		n	%	n	%
X57	Parents/carers and children felt that the nurses who came to their home or school were always friendly	43	100%	602	97%
X58	Parents/carers and children reported that they always understand what nurses visiting their home or school are saying	43	86%	602	87%
X59	Parents/carers and children report that the same nurses always come to their home or school	41	37%	587	41%

## Healthcare staff

Question	Scored Text	PTC Score		National Score	
		n	%	n	%
X12	Parents/carers felt that staff definitely give them information in a way they can understand	71	90%	934	85%
X13	Parents/carers reported that they definitely had the chance to ask staff questions about their child's care and treatment	72	90%	935	86%
X14	Children reported that they could always understand what staff are saying	29	79%	417	72%
X15	Parents/carers feel that they and their children are always treated with respect and dignity by staff	72	90%	937	88%
X16	Parents/carers always have confidence and trust in staff caring for their child	72	88%	938	84%
X17	Parents/carers feel that they are always treated with empathy and understanding by staff caring for their child	72	81%	936	82%
X18	Parents/carers and children are not told different things by different members of staff that leaves them feeling confused	70	61%	932	62%
X19	Parents/carers feel that staff are always sensitive to information shared with them when their child is in the room	67	85%	836	76%
X20	Parents/carers feel that staff always share information with children in a way that is appropriate	62	81%	816	80%
X21	Children reported that staff always speak to them in a way that is suitable for them	30	80%	417	82%
X22	Children feel that staff always talk to them, not just their parent/carer	30	80%	413	75%
X23	Children feel that staff are always friendly	30	83%	417	86%
X24	Children reported always or mostly seeing the same members of staff for their treatment and care	29	62%	412	59%
X27	Parents/carers have enough information about financial help or benefits	67	72%	832	69%

## Further information



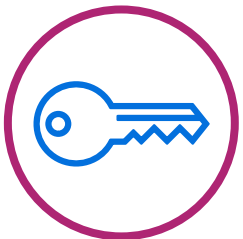
For more information on the Under 16 Cancer Patient Experience Survey visit [the survey website](#).



If you have any questions about the survey please do not hesitate to get in touch [via email](#).



For full data tables showing results to all survey questions, please see the [survey website](#).



The information in this report can be made available in alternative formats, such as easy read, or large print, and may be available in alternative languages, upon request. Please contact [under16cancersurvey@pickereurope.ac.uk](mailto:under16cancersurvey@pickereurope.ac.uk)

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