Under 16 Cancer Patient Experience Survey 2023

Quantitative Results

University Hospital Southampton NHS Foundation Trust

Contents

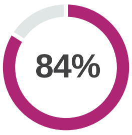
Executive summary

Overall PTC response rate

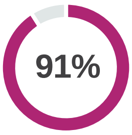
Nationally, 949 responded out of a total of 3,741 eligible parents, carers, and children who were sent a survey, resulting in a response rate of 25%. A response consists of one survey completion for a single patient, which could consist of both parent or carer and child responses. The response rate for your PTC is displayed in the table below.

PTC	Original sample size	Adjusted sample size[†]	Completed	Response rate
University Hospital Southampton NHS Foundation Trust	268	265	69	26%

Overall PTC care rating



Children reported that they were very well looked after by staff for their cancer or tumour (Question X60)



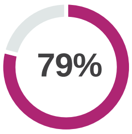
Parents or carers rated the overall experience of their child's care as 8 or more out of 10 (Question X59)

[†] The adjusted sample excludes patients who were discovered to be ineligible during fieldwork.

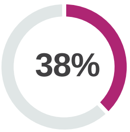
PTC key question scoring

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 PTC data tables on the survey website.

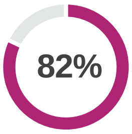
Data for questions in which the base size per question was <10 have been suppressed have been replaced with an asterisk (*). Please refer to the 'Suppression' section of this report for further details.



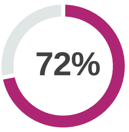
Parents or carers reported that they were definitely offered clear information about their child's treatment
(Question X36)



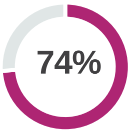
Parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way
(Question X07)



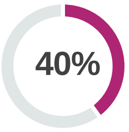
Parents or carers felt they always had confidence and trust in staff caring for their child
(Question X18)



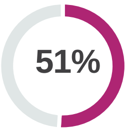
Children reported that they could always understand what staff were saying
(Question X13)



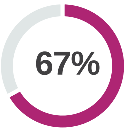
Parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment
(Question X37)



Parents or carers felt that different hospital staff were definitely aware of their child's medical history
(Question X27)



Parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital
(Question X33)



Parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand
(Question X08)

Introduction

The Under 16 Cancer Patient Experience Survey (U16 CPES) measures experiences of tumour and cancer care for children across England. It is an annual survey. This report presents the U16 CPES 2023 findings for University Hospital Southampton NHS Foundation Trust. The survey captures the experiences of children who were aged 8 to 15 at the time of their care and discharge, and parents or 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. It also allows care experiences to be monitored over time.

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 or 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 2023 and 31 December 2023 and were aged under 16 at the time of their discharge[†].

The fieldwork for the survey was undertaken between April and June 2024. One of three versions of the survey were distributed:

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

Survey version was assigned based on the patient's age at the beginning of survey fieldwork (30th March 2024) 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.

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 included an option to complete the questionnaire online or over the phone. 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.

[†] The survey asked recipients to answer about their (or their child's) cancer care during 2023. 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.

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 'Year on year comparisons' section of this report presents charts showing the scores for your PTC between 2021, 2022, and 2023 for comparable questions. This allows you to monitor changes in patient experiences over time. 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. Please note that the 2023 scores that are not comparable to 2021 or 2022 are not presented in this section and can be found in the data tables on the survey website.

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

Parents or carers felt that staff definitely offered parents or carers 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	72	37%
	No, but I would have liked this	6	3%
	No, but this was not needed	4	-
	No, but this was not possible	4	-

Full responses and scores to all questions can be found in the PTC Excel Data Tables on the survey website. 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 question numbers used on the surveys themselves.

Please take care in interpreting comparisons both between your current and historic data and against the national average, due to numbers of respondents and in the absence of statistical significance testing. Confidence interval bars are included on your PTC scores throughout the report.

How to use this data

We recommend that PTCs take caution when benchmarking 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 2023 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

- **Confidence intervals** are displayed for your PTC data throughout this report. They are shown as black bars on charts. Assuming the sample is representative of your organisation, confidence intervals are a method of describing the uncertainty around results. 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" population value 95 percent of the time (i.e. out of 100 such intervals, 95 will include the true figure), based on the sample of information we have.
- PTC scores are often based on a very small number of responses, meaning that the confidence intervals around one score can be wide and overlap with another. This indicates, when the comparison is valid, that there is not enough statistical evidence to conclude whether or not there is a "true" difference between the two results.

We recommend that PTCs review their results for the 2023 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

The Under 16 Cancer Patient Experience Survey uses two types of suppression: suppression for anonymity and suppression for reliability. These suppression methods are used to prevent individuals and their responses being identifiable in the data, and to ensure unreliable results based on very small numbers of respondents are not released.

Suppression for anonymity

The purpose of this type of suppression is to protect people’s identity and their data.

Where the data is semi-identifiable (e.g. a demographic), the eligible population at risk is 1,000 or fewer, and there are 5 or fewer respondents in a particular category, then the data has been suppressed and replaced with an asterisk (*).

Double suppression for anonymity

In instances where only data from one group has been suppressed, the data from the next lowest group has also been suppressed. This is to prevent back calculation from the total number of responses.

For example, if only one PTC has a score suppressed for a question, then the PTC with the next lowest number of respondents for that question will also be suppressed.

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 suppress the score of the PTC with the second lowest data for the 0-7 age group data for this question.

Suppression for reliability

The purpose of this type of suppression is to prevent unreliable results from being released, due to small numbers.
In cases where a result is based on less than 10 responses, the result has been suppressed replaced with an asterisk (*).
For example, if only 8 people answered a question from a particular PTC, the results are not shown for that question for that PTC. Double suppression is not required here.

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 in 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

For more information on development and methodology, please see the Survey Handbook available on the survey materials page of the website. For all other outputs including the Technical Appendix, please visit the survey website.

About the respondents[†]

Table 1: Response rate

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

	Original sample size	Adjusted sample size[††]	Completed	Response rate
PTC	268	265	69	26%

Table 2: Percent of responses by survey mode

	PTC		National	
Survey mode	**n**	**%**	**n**	**%**
Paper	49	71%	656	69%
Online	20	29%	291	31%
Phone – English	0	0%	1	0%
Phone – translation service	0	0%	1	0%
Mixed (combination of paper and online)‡	0	0%	0	0%

Table 3: Percent of responses by survey type

	PTC		National	
Survey type	**n**	**%**	**n**	**%**
0-7 Survey	40	58%	490	52%
8-11 Survey	15	22%	178	19%
12-15 Survey	14	20%	281	30%

[†] Demographic breakdowns may not equal the total number of respondents as certain response options have been aggregated, or excluded, due to small numbers at PTC level. National percentages may not total 100% as the National 'About the respondents' breakdowns include all response options. A full demographic breakdown can be found in the national report.

[††] The adjusted sample excludes patients who were discovered to be ineligible during fieldwork.

[‡] Indicates cases in which the entire parent or carer section was completed in one mode and the entire child section was completed in another mode.

Table 4: Percent of responses by ethnic group (Question X64)

	PTC		National	
Ethnic group	**n**	**%**	**n**	**%**
White	61	91%	695	73%
Mixed	*	*	56	6%
Asian	*	*	110	12%
Black	*	*	31	3%
Other ethnic groups	*	*	11	1%

Table 5: Percent of responses by 'Which of the following best describes you?' (Question X62)

	PTC		National	
Which of the following best describes you? (asked to children aged 8-15)	**n**	**%**	**n**	**%**
Boy/Male	14	56%	247	54%
Girl/Female	11	44%	173	38%

Table 6: Percent of responses by sex registered at birth (Question X63)

	PTC		National	
Sex registered at birth	**n**	**%**	**n**	**%**
Male	38	58%	528	56%
Female	27	42%	385	41%

Table 7: Percent of responses by current care or treatment stage[†] (Question X67)

	PTC		National	
Current care or treatment stage	**n**	**%**	**n**	**%**
Recently diagnosed	*	*	13	1%
Watch and wait	7	10%	89	9%
Receiving treatment	25	37%	400	42%
Finished treatment within the last one month	6	9%	79	8%
In remission / long term follow-up	31	46%	346	36%
Palliative or end of life care	0	0%	11	1%
Other	*	*	53	6%

Table 8: Percent of responses by diagnostic group[††] (from ICD-10 code in patient sample)

	PTC		National	
Diagnostic group	**n**	**%**	**n**	**%**
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	24	35%	369	39%
Lymphomas and reticuloendothelial neoplasms	10	14%	102	11%
CNS and miscellaneous intracranial and intraspinal neoplasms	17	25%	218	23%
All other	18	26%	260	27%

Table 9: Percent of responses by long term condition status[‡] (Question X65)

	PTC		National	
Long term condition status	**n**	**%**	**n**	**%**
Another long term condition	23	33%	340	36%
No other long term condition	38	55%	494	52%
Not given	8	12%	115	12%

[†] Based on a select all that apply question and therefore the total number of responses may be more than the total number of respondents.

[††] Details of how diagnostic groups were formed can be found in the Technical Appendix, available on the survey website.

[‡] Full LTC breakdown data can be found in the Excel Data Tables, available on the survey website.

Table 10: Percent of responses by 'Does the child's long term condition or cancer reduce their ability to carry out their day-to-day activities'? (Question X66)

	PTC		National	
Impact of cancer or long term condition	**n**	**%**	**n**	**%**
Yes, a lot	19	28%	253	27%
Yes, a little	30	45%	429	45%
No, not at all	18	27%	234	25%

Table 11: Percent of responses by main person who answered questions in the children's section (Question X61)

	PTC		National	
Respondent	**n**	**%**	**n**	**%**
The child / young patient	11	16%	140	15%
The parent or carer	4	6%	131	14%
Both the child / young patient and the parent or carer together	10	14%	150	16%
Not given	44	64%	528	56%

Table 12: Percent of responses by deprivation (IMD quintile)[†] (based on Index of Multiple Deprivation from postcode in patient sample)

	PTC		National	
Deprivation (IMD quintile)	**n**	**%**	**n**	**%**
1 (most deprived)	*	*	186	20%
2	8	12%	157	17%
3	22	32%	177	19%
4	16	23%	187	20%
5 (least deprived)	15	22%	221	23%
Non-England	*	*	21	2%

[†] 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.

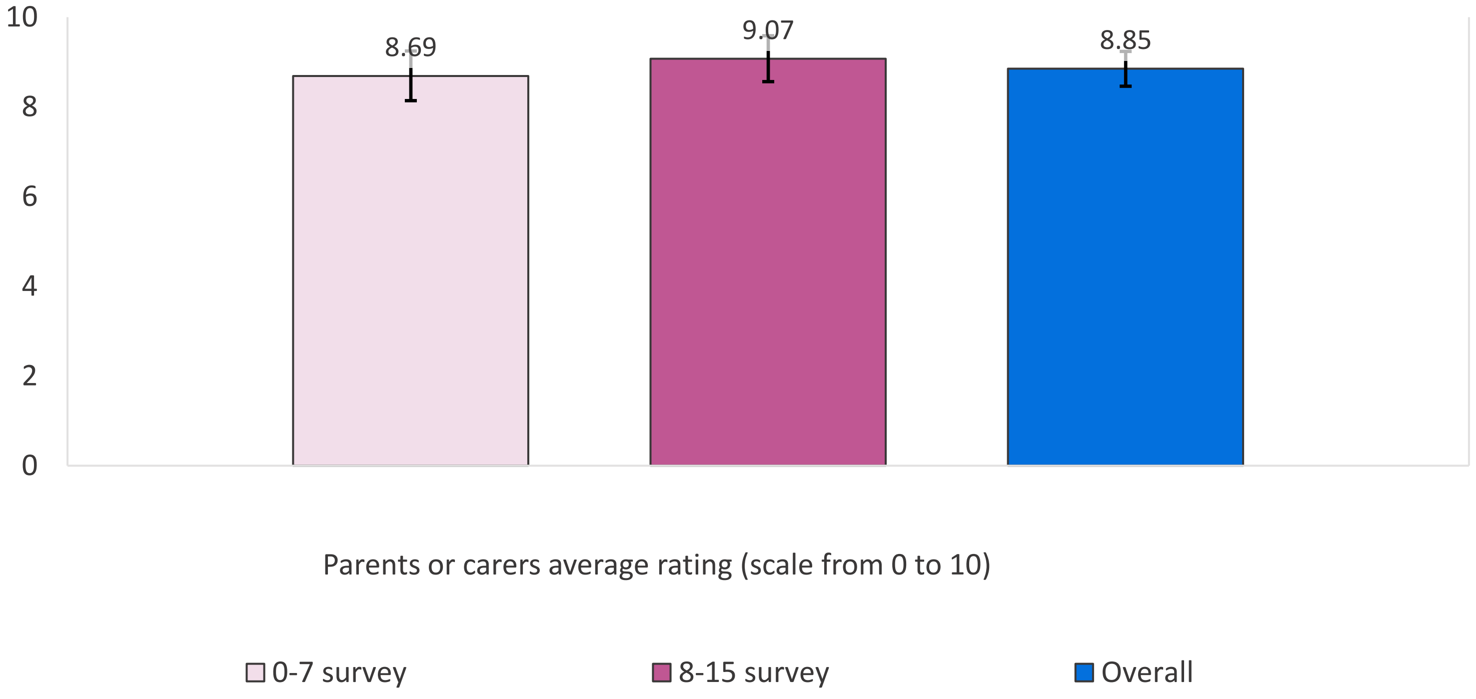
Questions asking about overall care were structured differently for children and parents or carers, therefore they cannot be directly compared. Children aged 8 and over were asked how well they were looked after for their cancer or tumour by healthcare staff and were given the options "Very well," "Quite 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 or 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 or carers overall rating of care by survey type

The average parent or carer rating of the overall experience of their child's care was 8.85 (scale from 0 to 10).

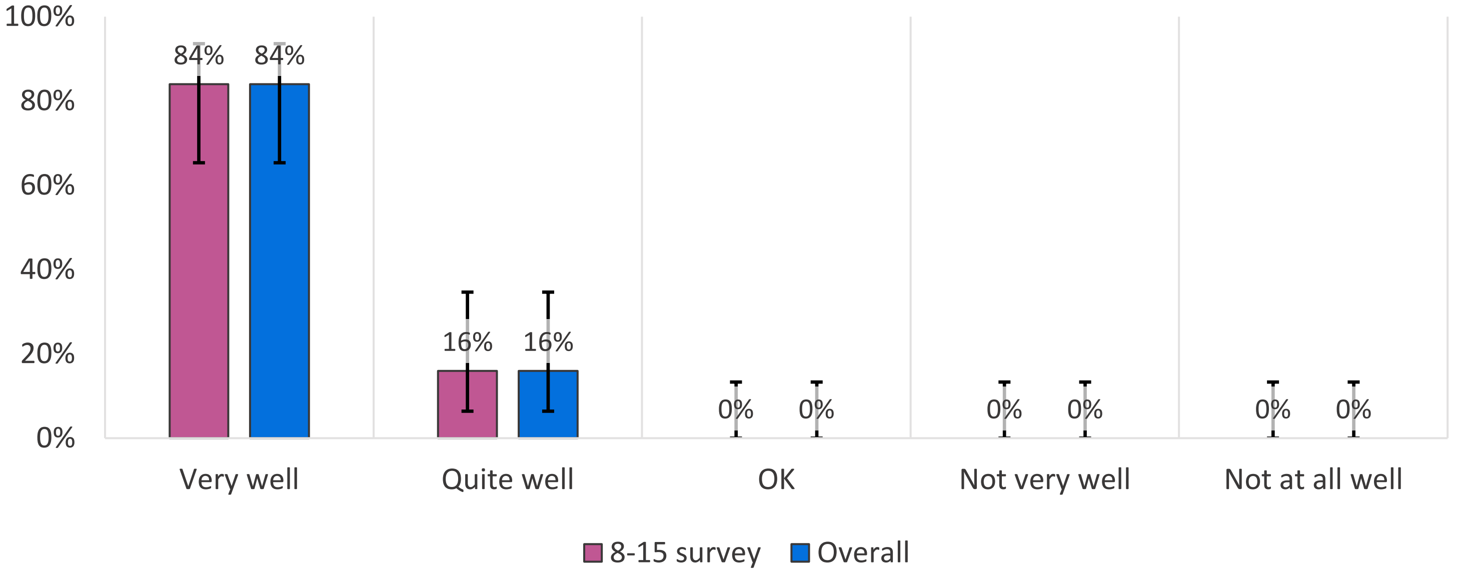
Figure 1: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59_mean: Asked to parents or carers of all age groups. Total responses = 66.

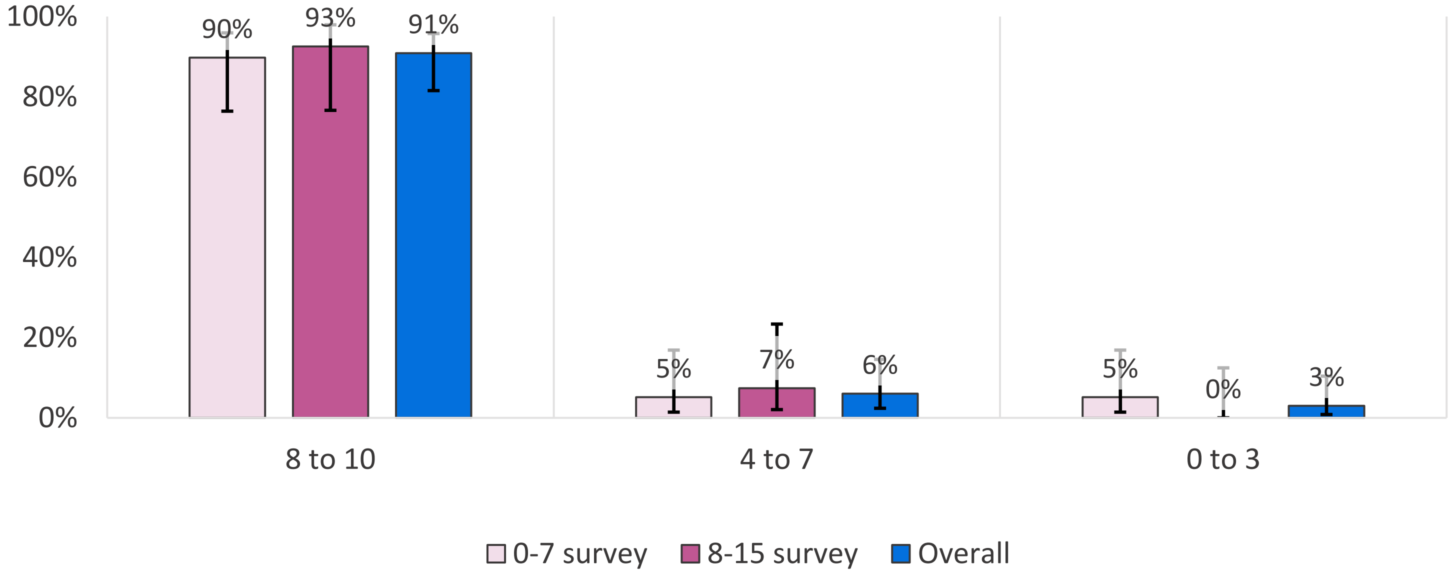
Survey type

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



Question X60: Asked to all children aged 8-15. Total responses = 25.

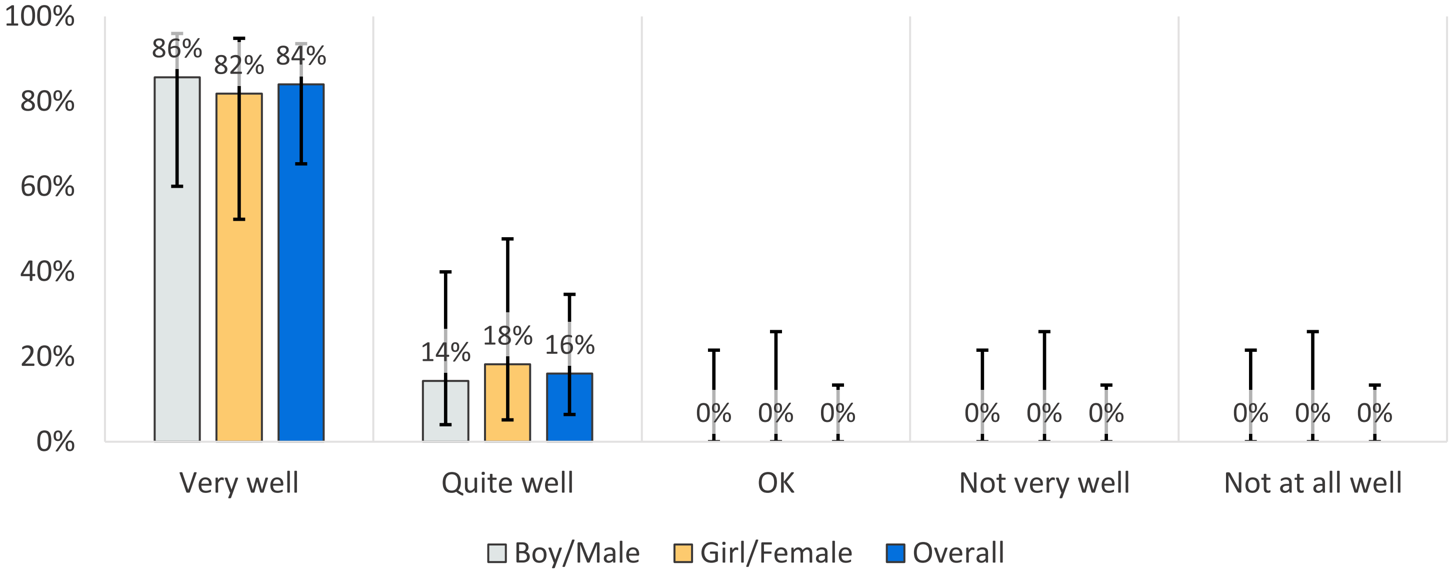
Figure 3: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

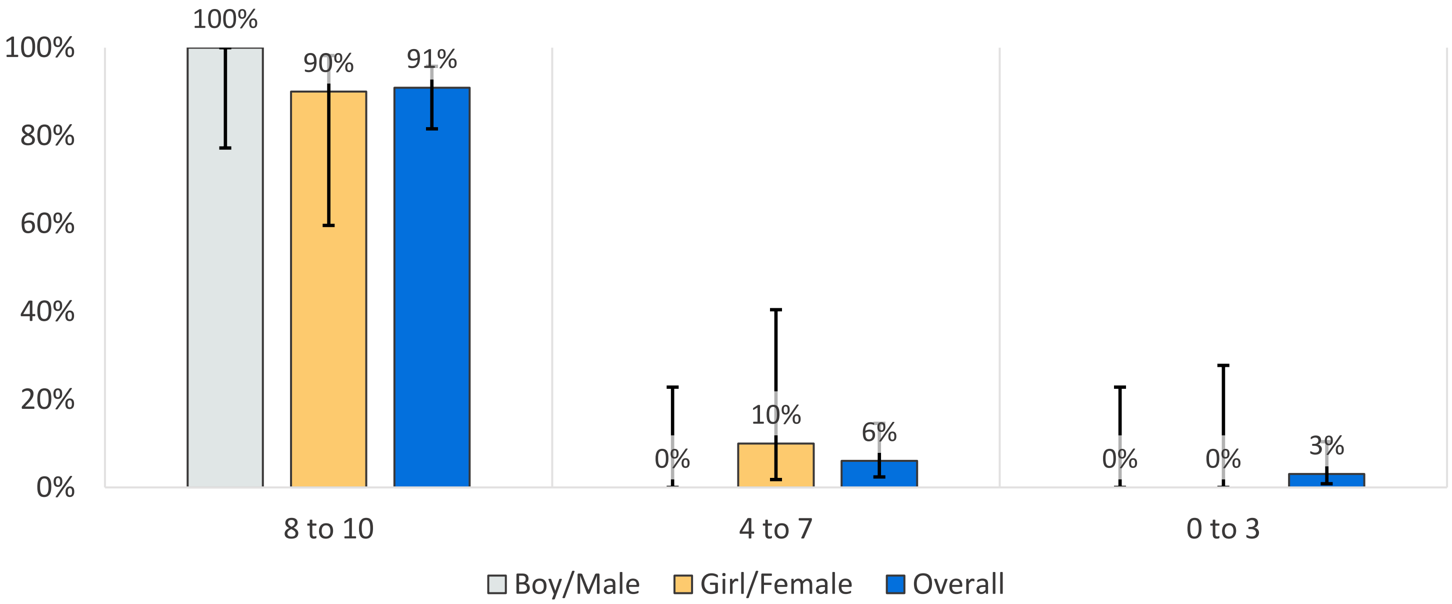
Which of the following best describes you?†

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



Question X60: Asked to all children aged 8-15. Total responses = 25.

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



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

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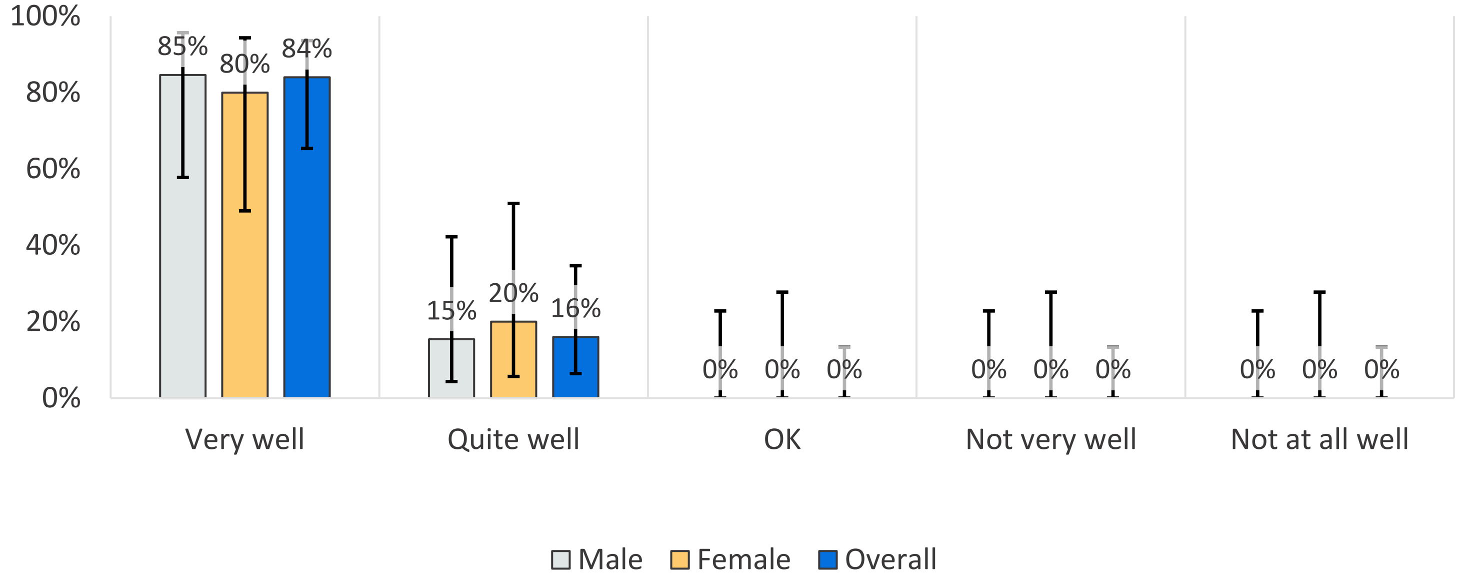
†Only data for boy/male and girl/female is shown, as the number of respondents answering 'I describe myself in another way' or 'prefer not to say' to this question was suppressed.

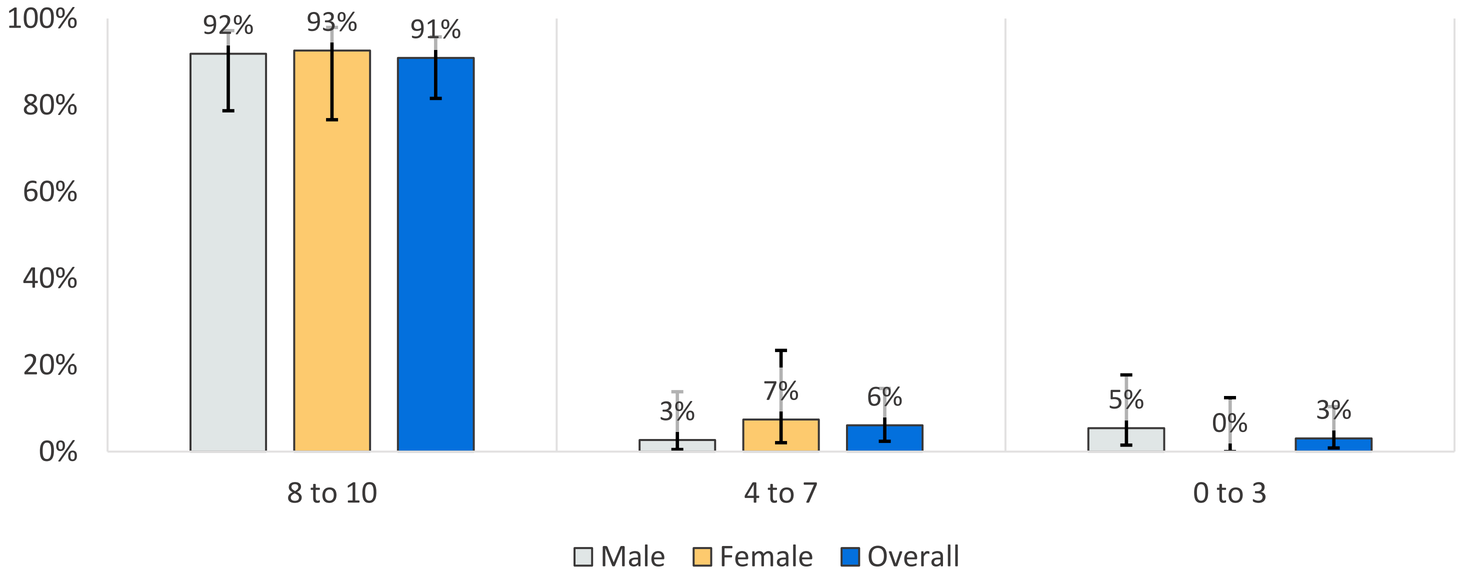
Sex registered at birth†

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



Question X60: Asked to all children aged 8-15. Total responses = 25.

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



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

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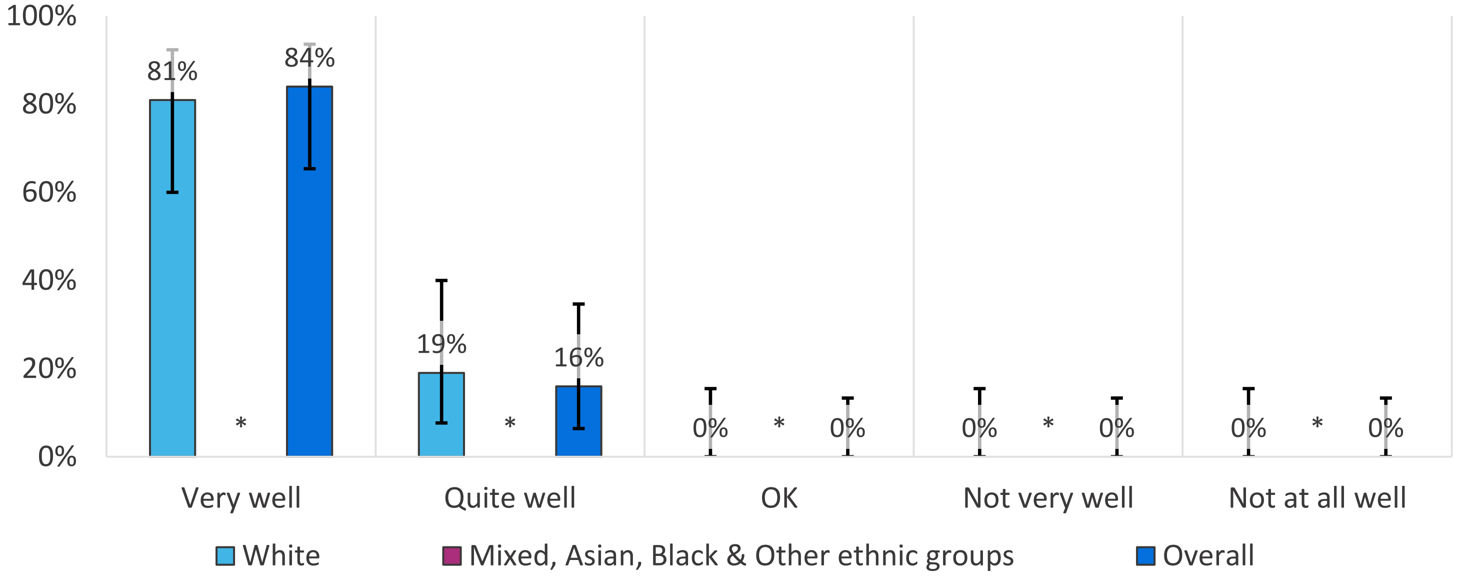
†Only data for male and female is shown, as the number of respondents answering 'prefer not to say' to the sex registered at birth question was suppressed.

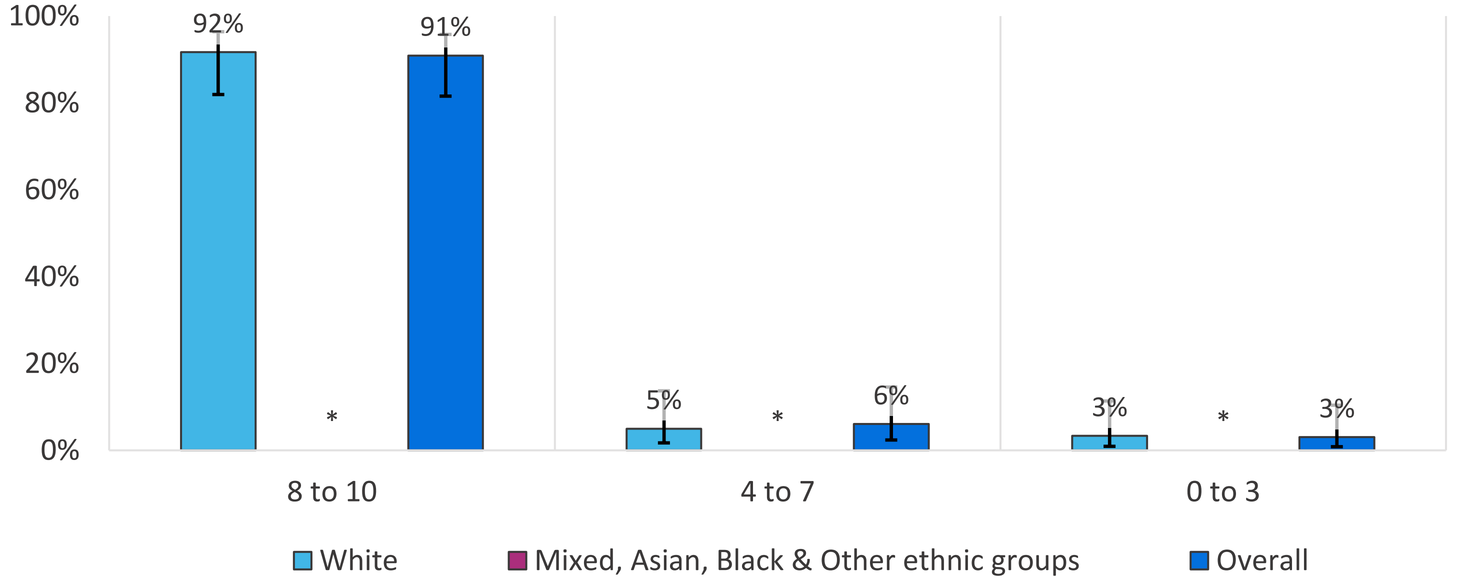
Ethnic group†

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



Question X60: Asked to all children aged 8-15. Total responses = 25.

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



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

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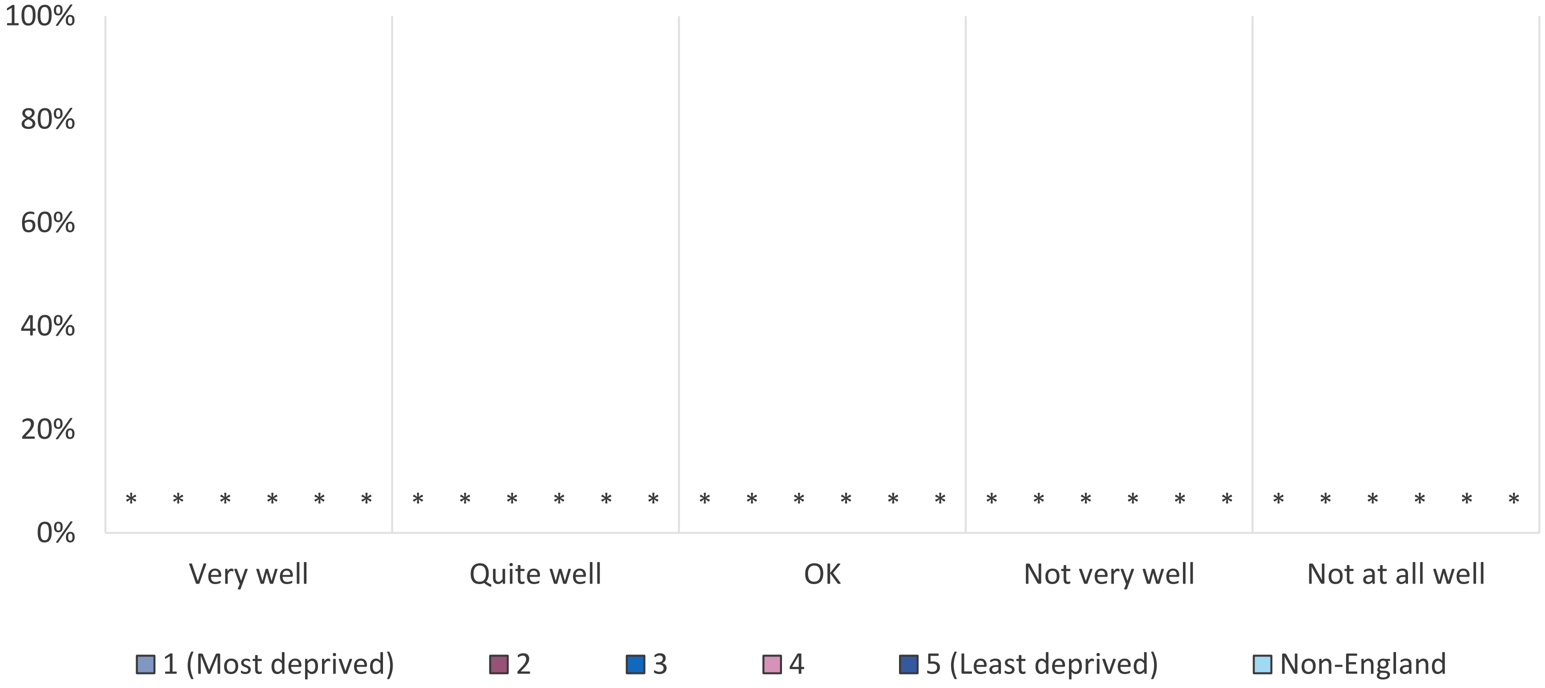
† Due to small numbers at PTC level, ethnic group data has been aggregated for the ethnic minority groups. It is important to note that there are often significant disparities in health outcomes between ethnic groups and caution is recommended when analysing this aggregated group i.e. poorer experience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

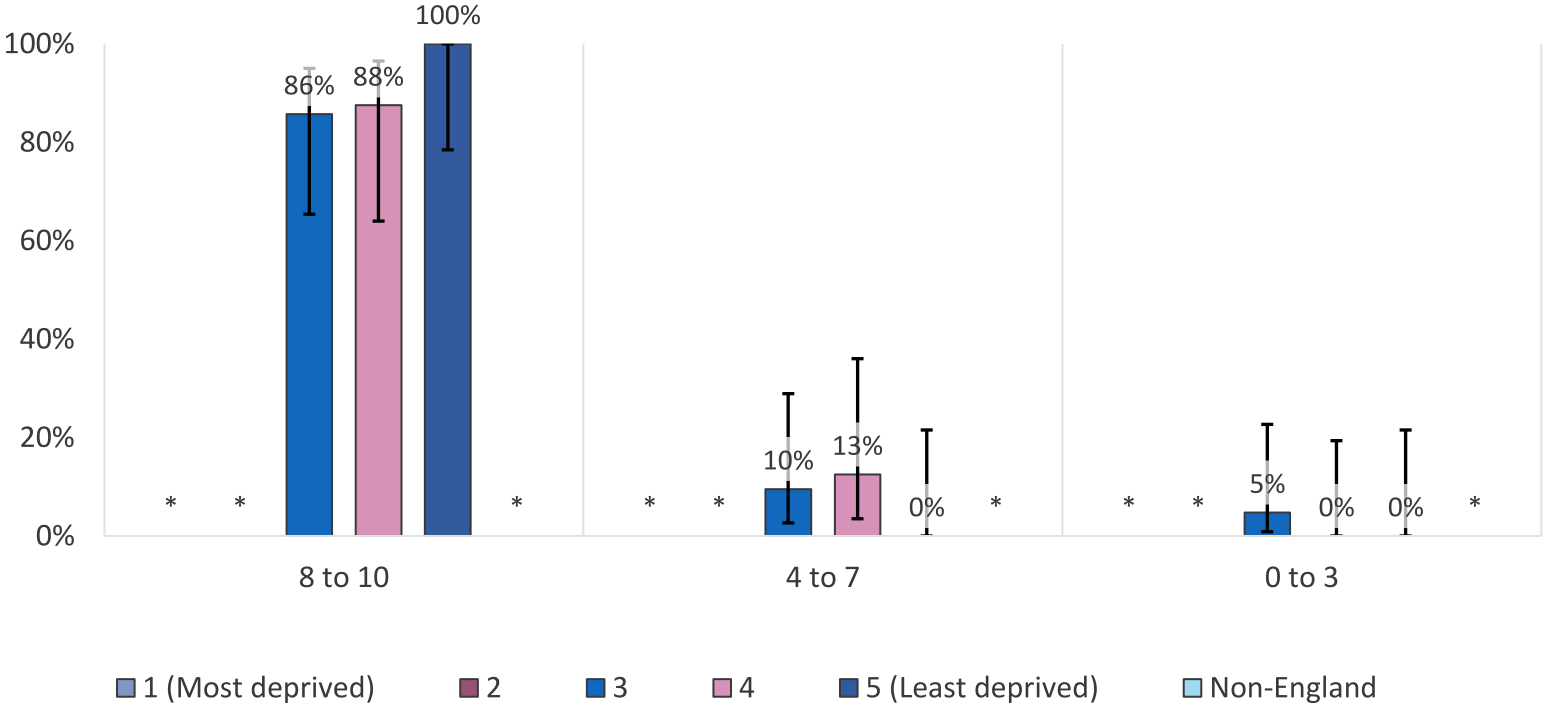
Deprivation (IMD quintile)

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



Question X60: Asked to all children aged 8-15. Total responses = 25.

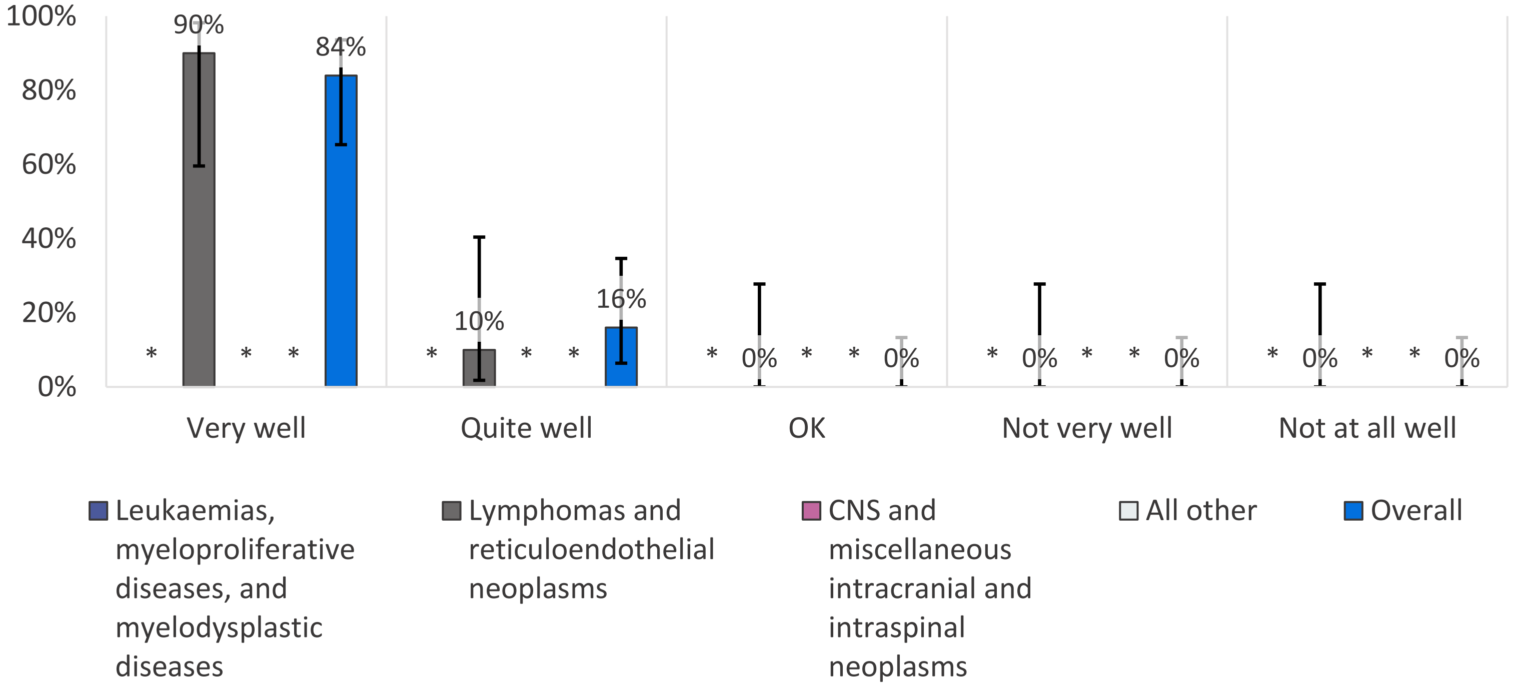
Figure 11: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

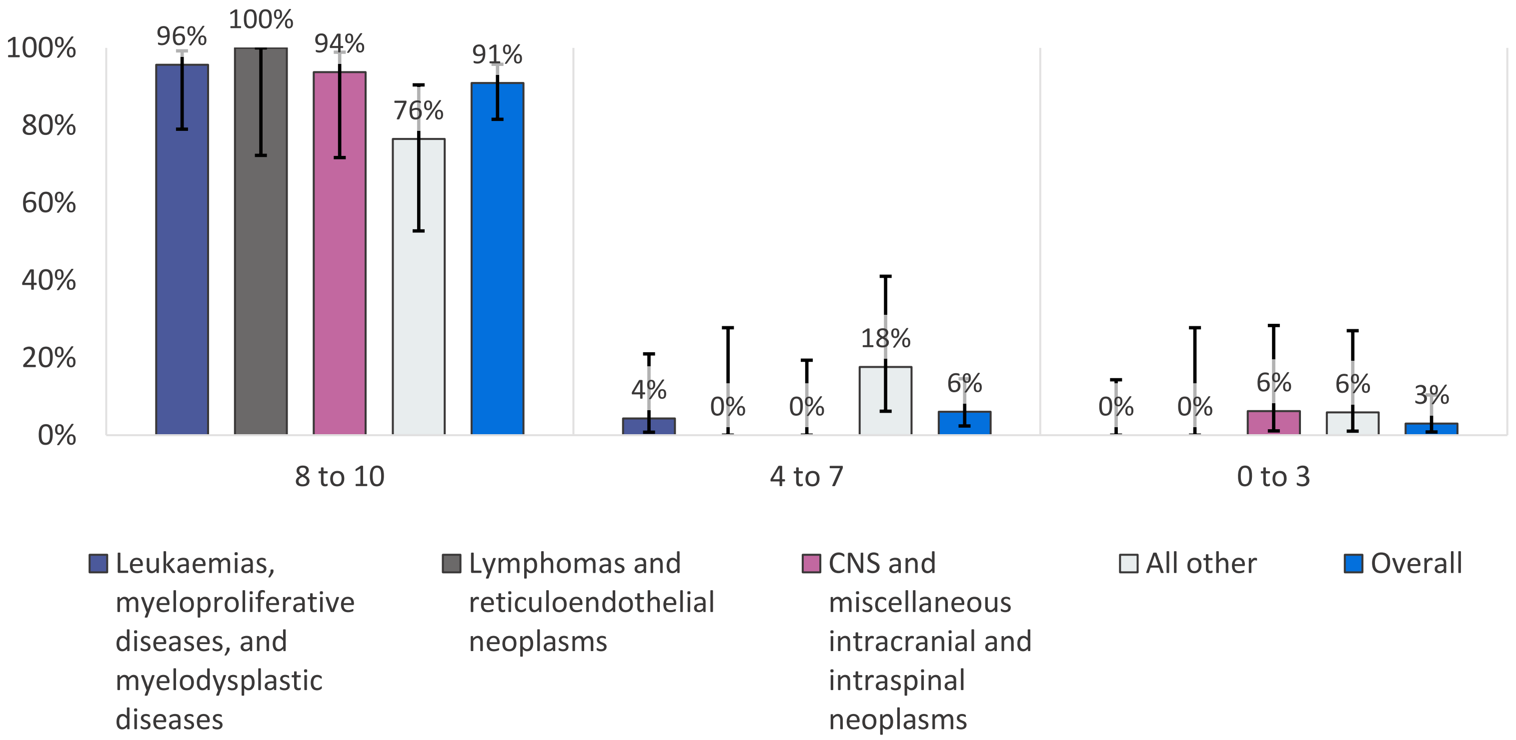
Diagnostic group[†]

Figure 12: Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



Question X60: Asked to all children aged 8-15. Total responses = 25.

Figure 13: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)

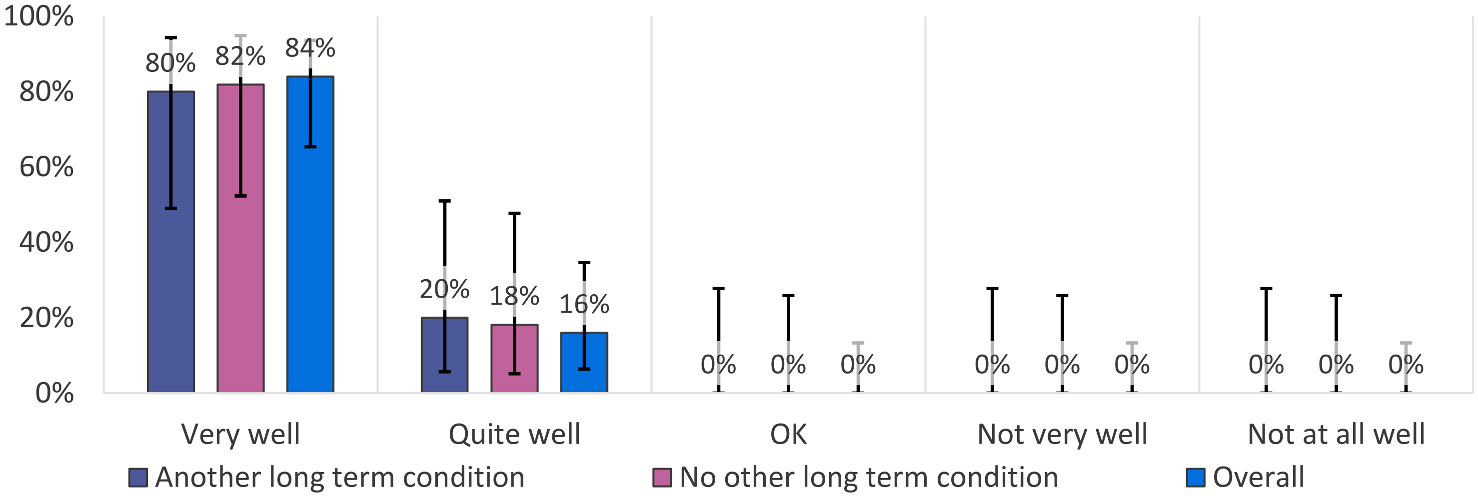


Question X59: Asked to parents or carers of all age groups. Total responses = 66.

[†] 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.

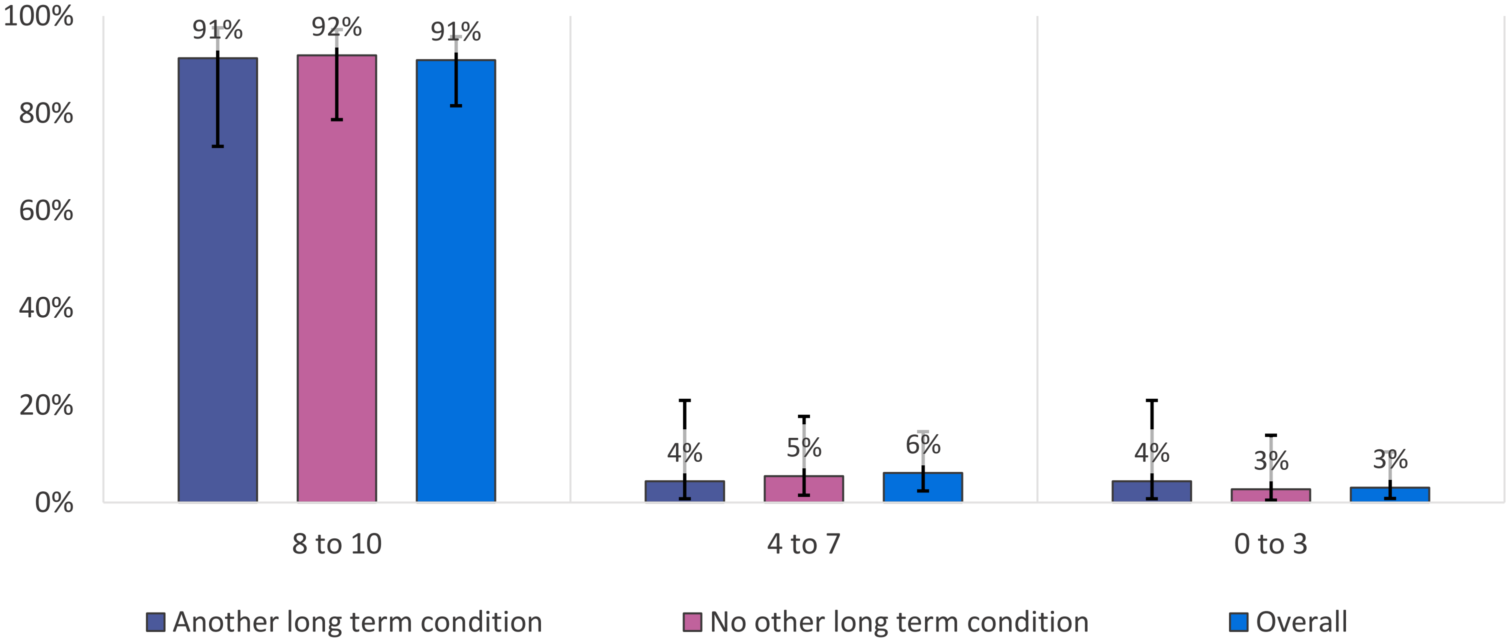
Long term condition status

Figure 14: Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



Question X60: Asked to all children aged 8-15. Total responses = 25.

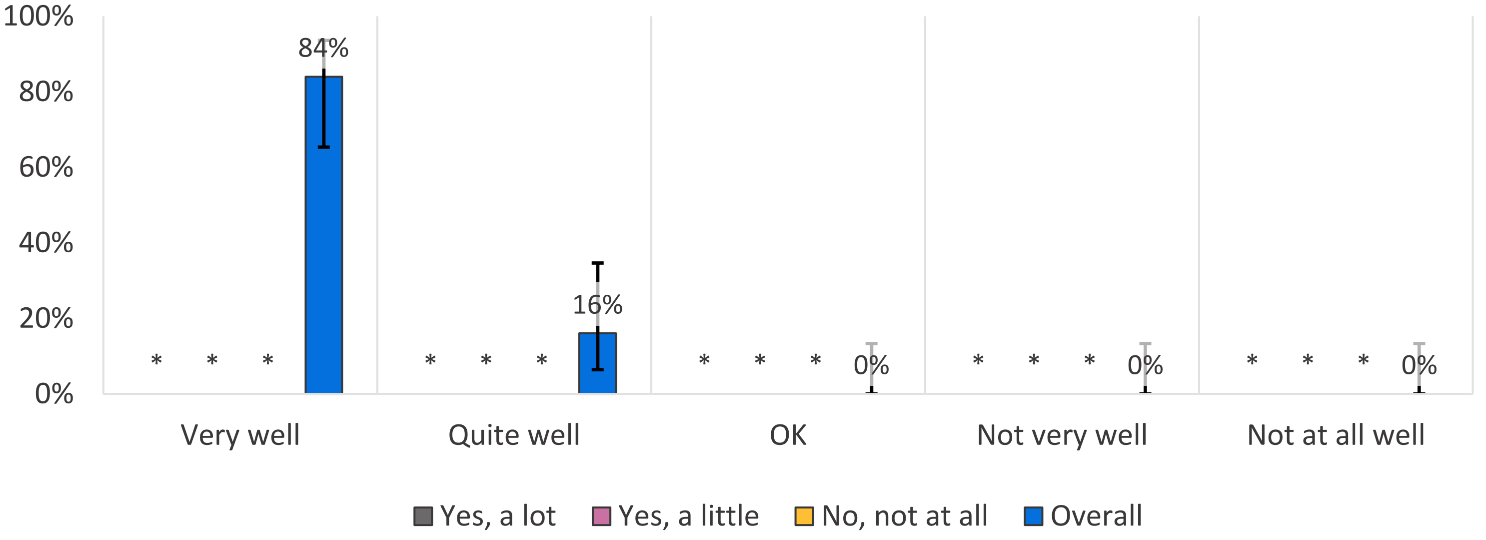
Figure 15: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

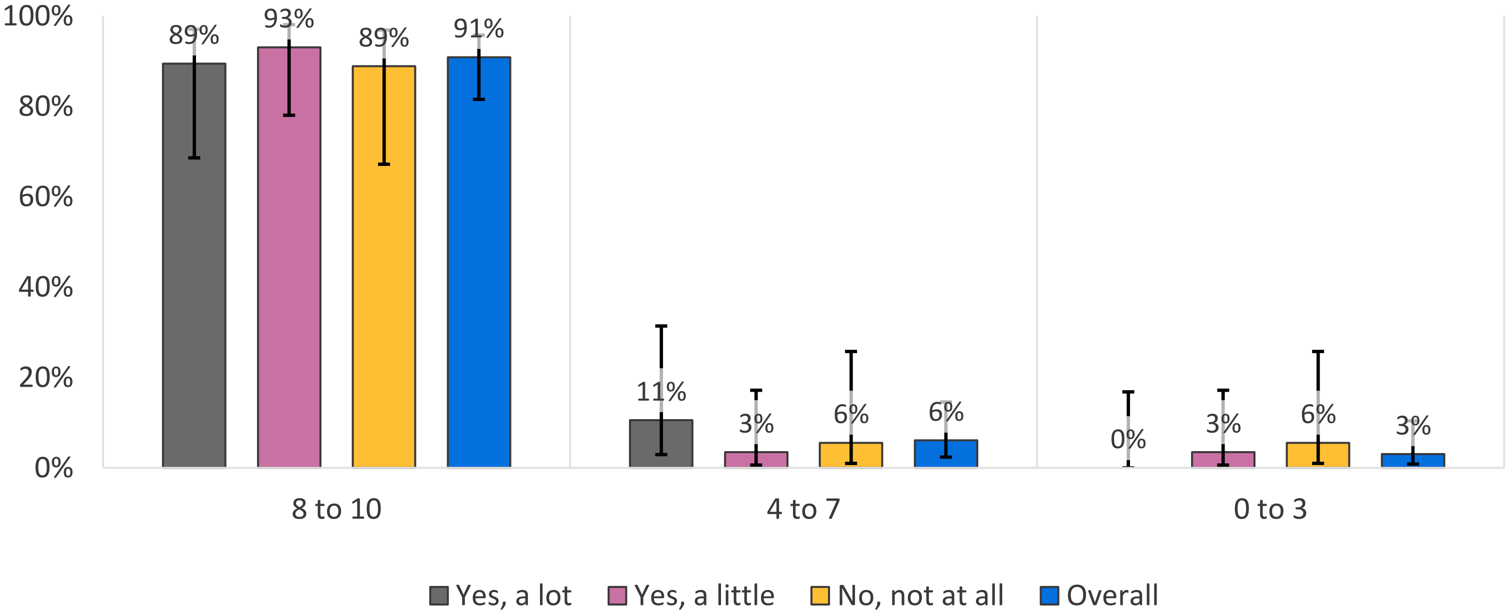
Does the child's long term condition or cancer reduce their ability to carry out their day-to-day activities?

Figure 16: Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



Question X60: Asked to all children aged 8-15. Total responses = 25.

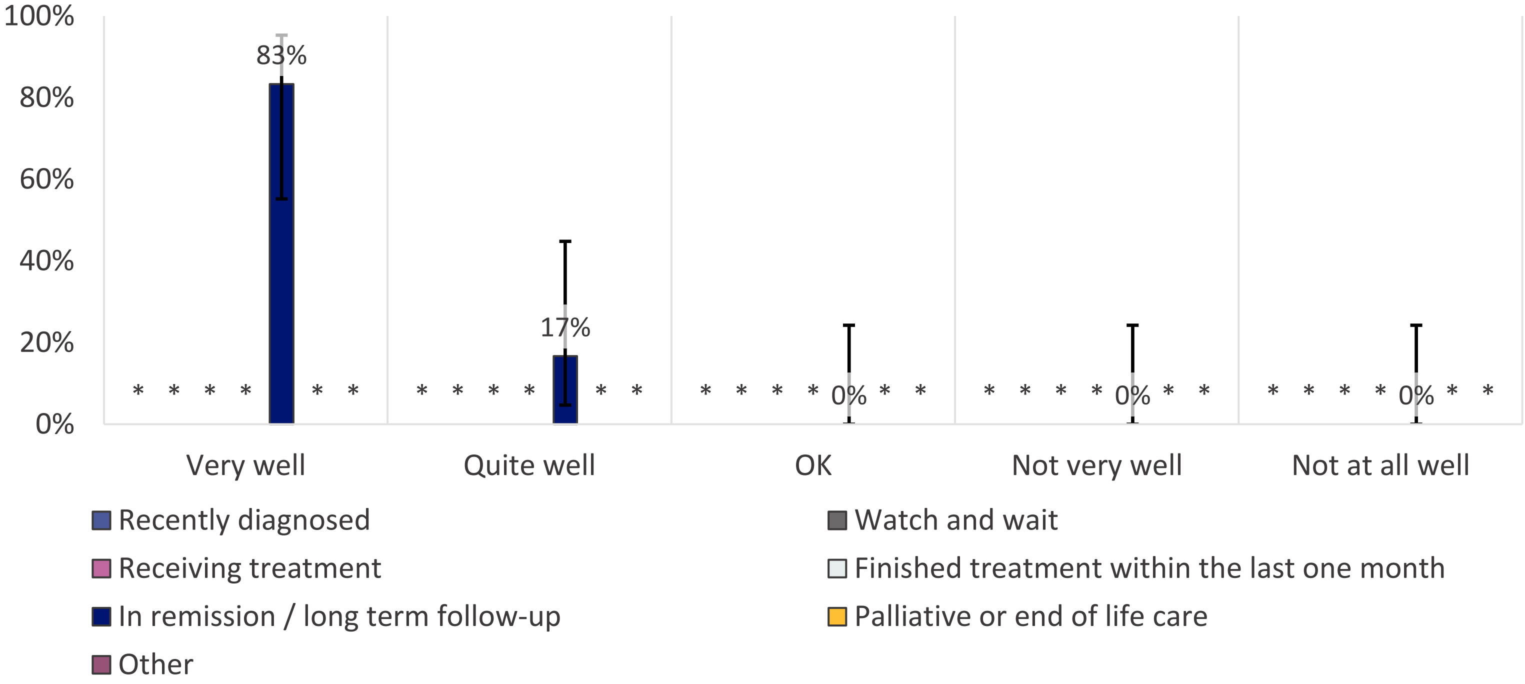
Figure 17: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

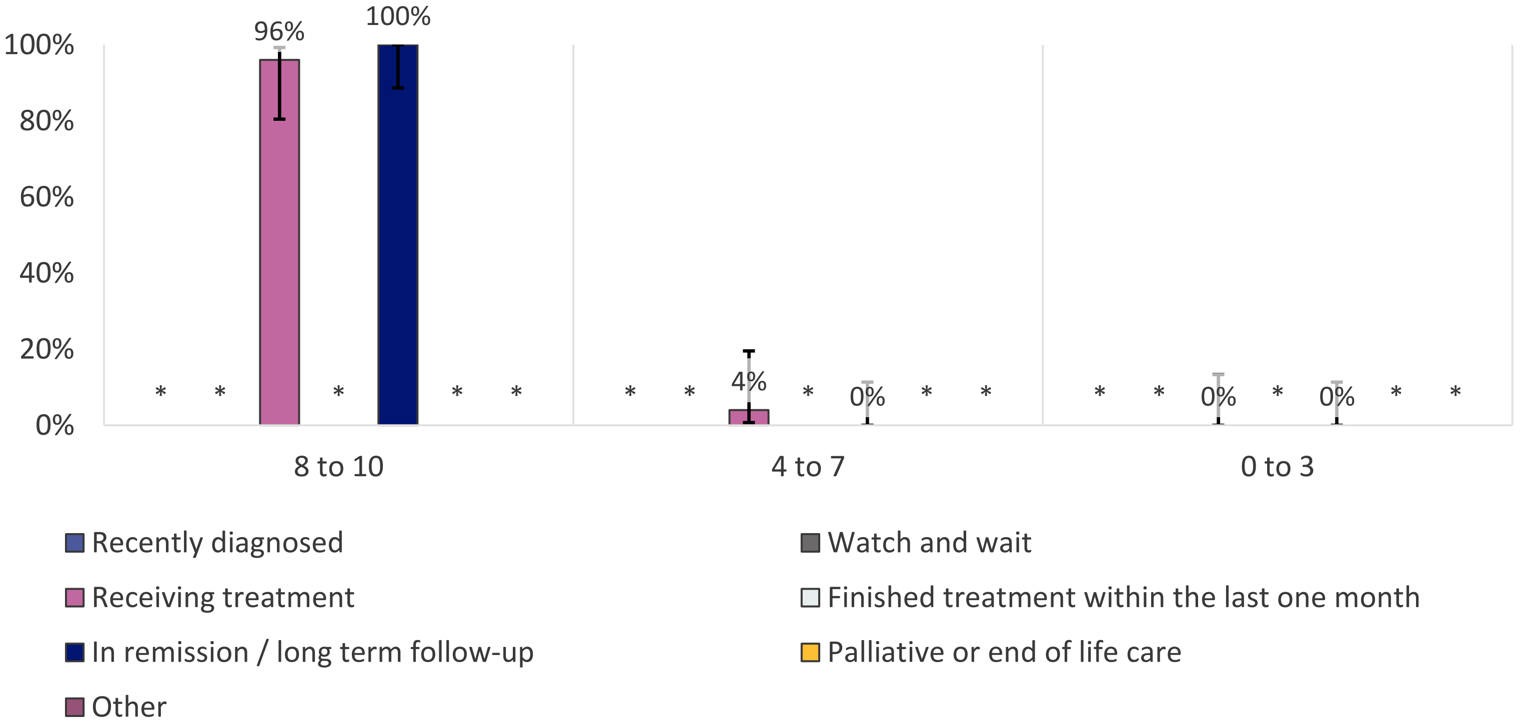
Current care or treatment stage

Figure 18: Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



Question X60: Asked to all children aged 8-15. Total responses = 25.

Figure 19: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents or carers of all age groups. Total responses = 66.

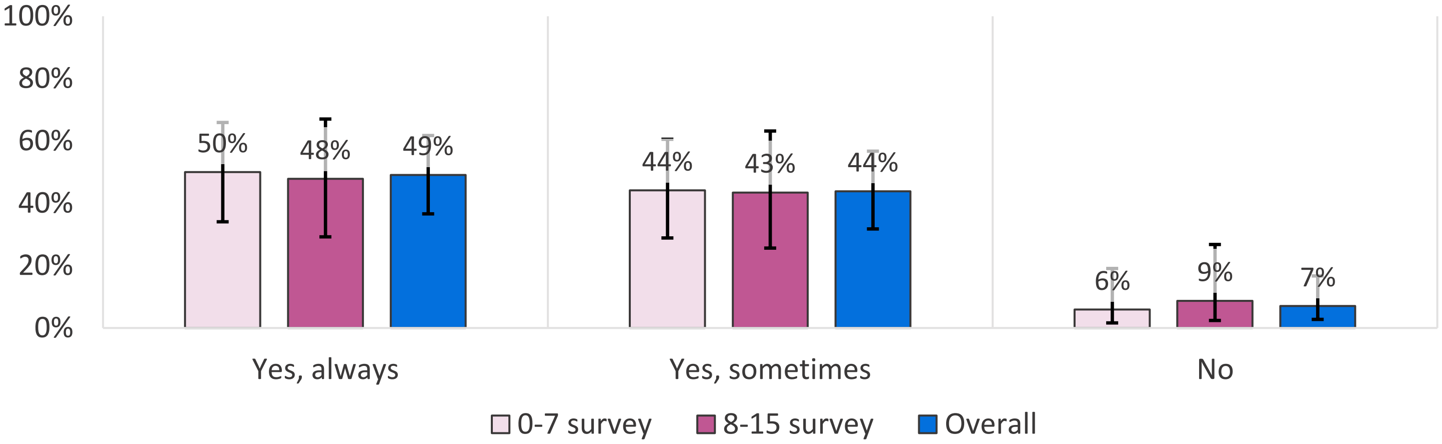
PTC results

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

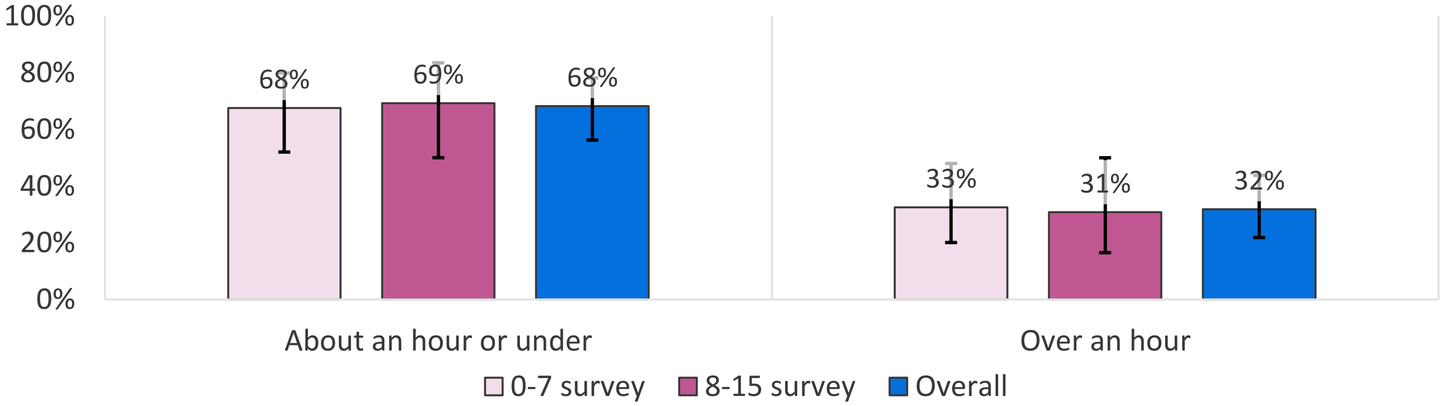
All respondents were asked how they felt about their overall care. Further results for these questions (showing breakdowns by different groups) can be found in the 'Sub-group comparisons' section of this report. Two questions were asked about how well different hospitals providing cancer or tumour care 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 20 and 21 below.

Figure 20: 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 X57: Asked to parents or carers of children aged 0-11, and children aged 12-15. Total responses = 57 (excluding 6 responses of "My child does not / I don't receive care at different hospitals").

Figure 21: How long does it take to get to the hospital where your child receives most of their cancer or tumour care?

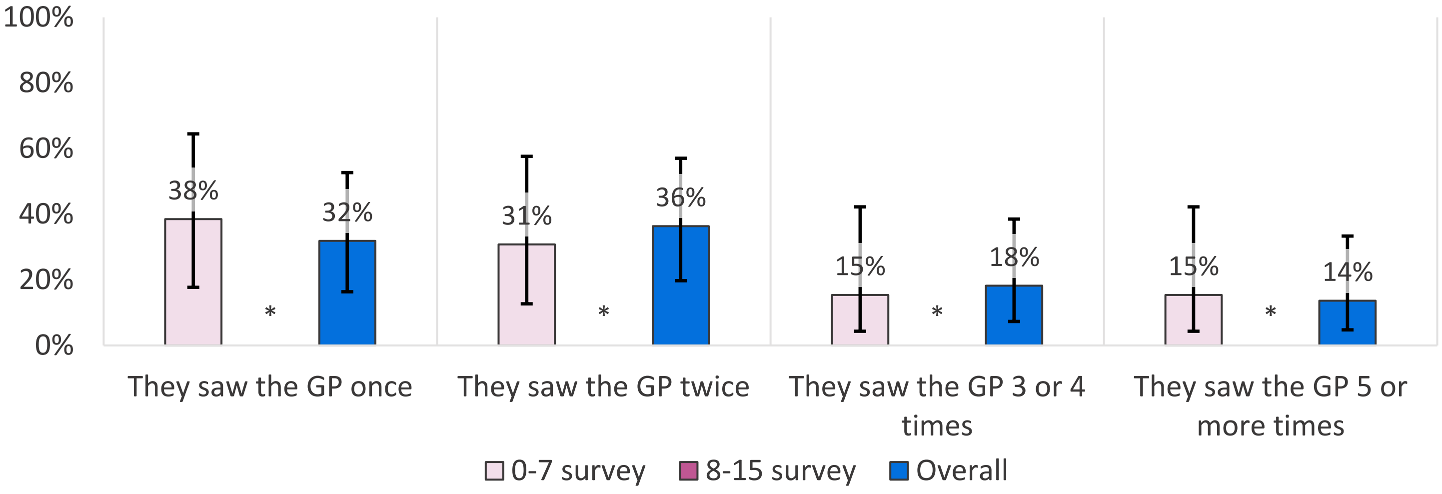


Question X58: Asked to parents or carers of all age groups. Total responses = 66.

Finding out about the cancer or tumour

45% (n=30) of all parents or carers reported that their children were told they had cancer or a tumour during 2023 (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.

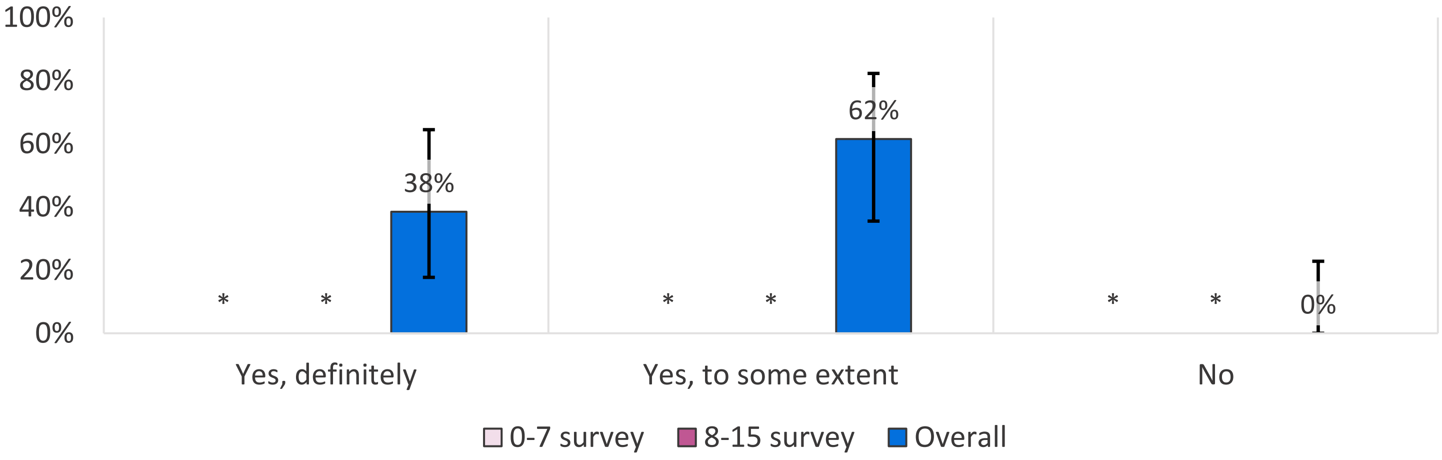
Figure 22: Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem(s) caused by the cancer or tumour?



Question X03: Asked to parents or carers of all age groups whose children were told they had cancer or a tumour. Total responses = 22 (excluding 7 responses of "None - they went straight to hospital" and excluding 1 response of "Don't know / can't remember").

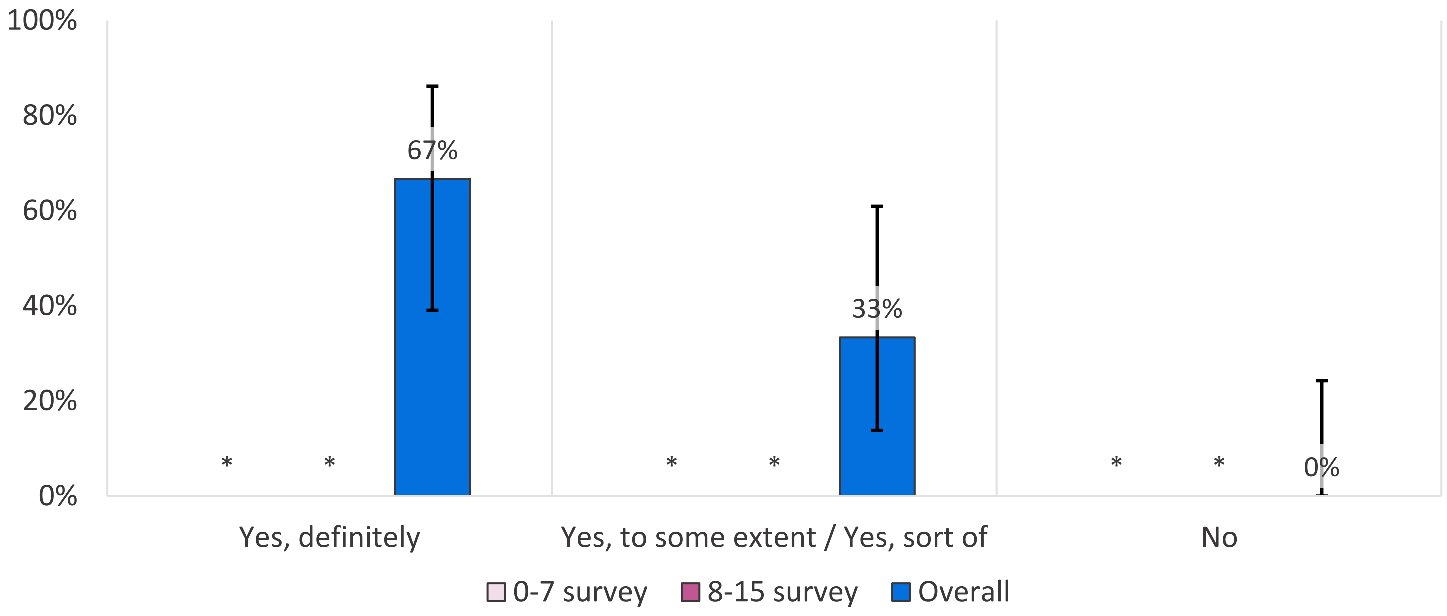
Further questions were asked to all parents or carers of children who had received diagnosis during 2023 by the hospital named in the covering letter.

Figure 23: Were you told about your child's cancer or tumour in a sensitive way?



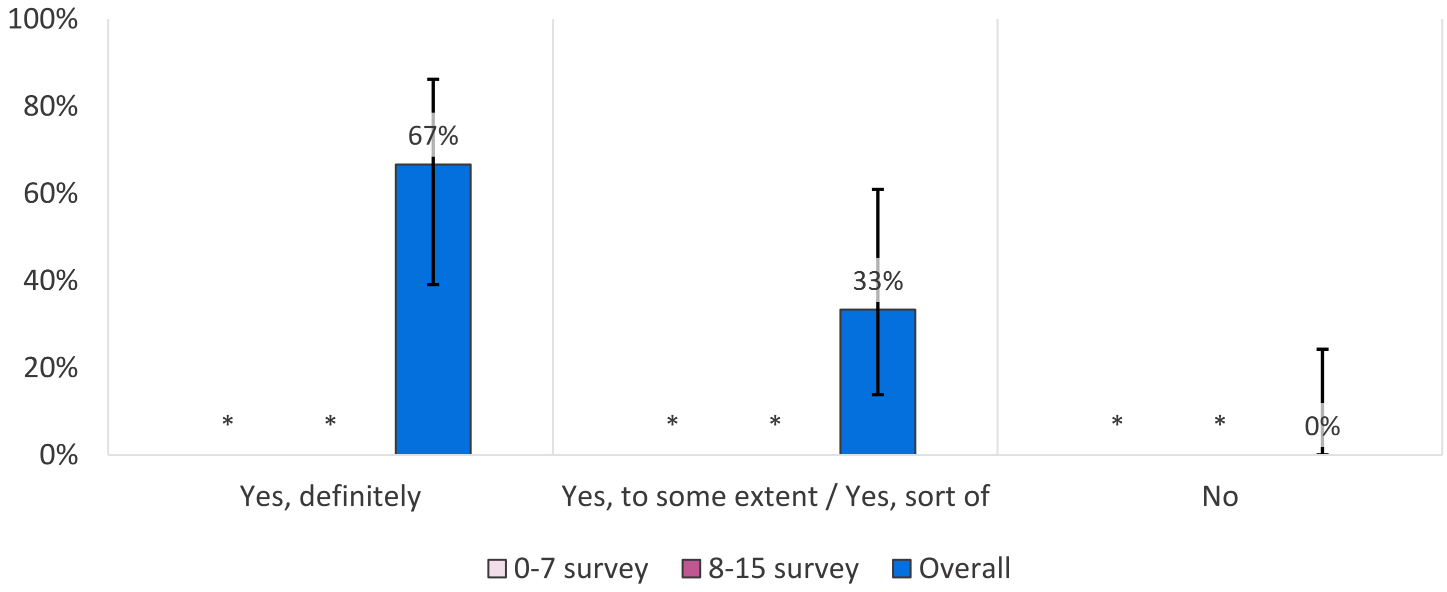
Question X07: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total responses = 13 (excluding 1 response of "Don't know / can't remember").

Figure 24: 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 or carers of 0-7s who were told about their child's cancer or a tumour, and children aged 8-15 who were told they had cancer or a tumour. Total responses = 12 (excluding 0 responses of “Don't know / can't remember”).

Figure 25: 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?

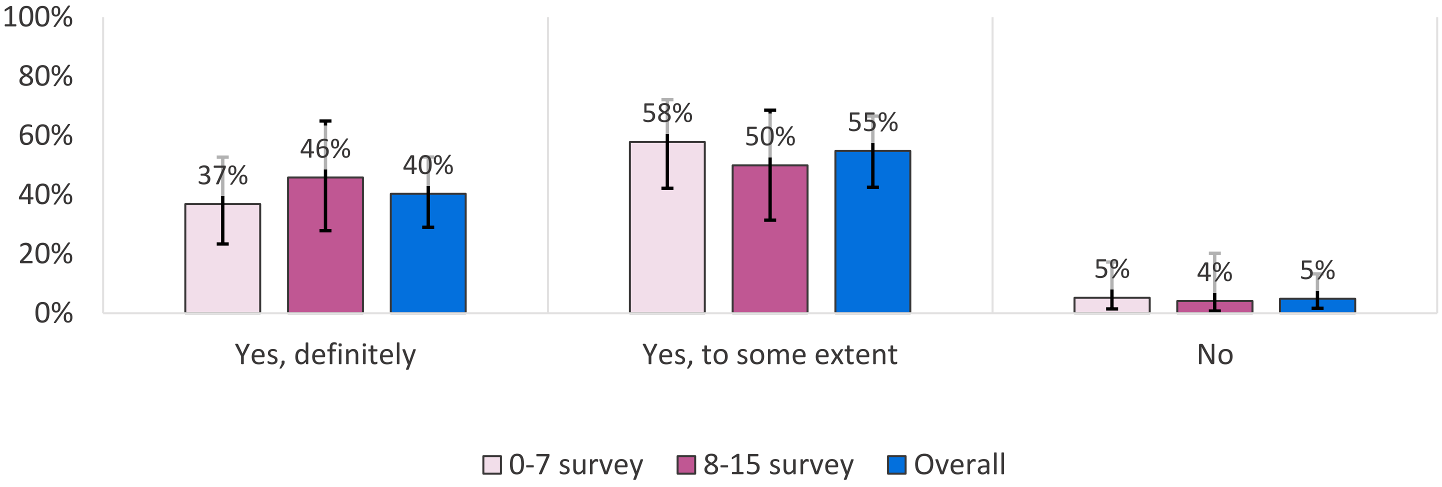


Question X09: Asked to parents or carers of 0-7s who were told about their child's cancer or a tumour, and children aged 8-15 who were told they had cancer or a tumour. Total responses = 12 (excluding 0 responses of “I did not have any questions” and excluding 0 responses of “Don't know / can't remember”).

Child's care and treatment

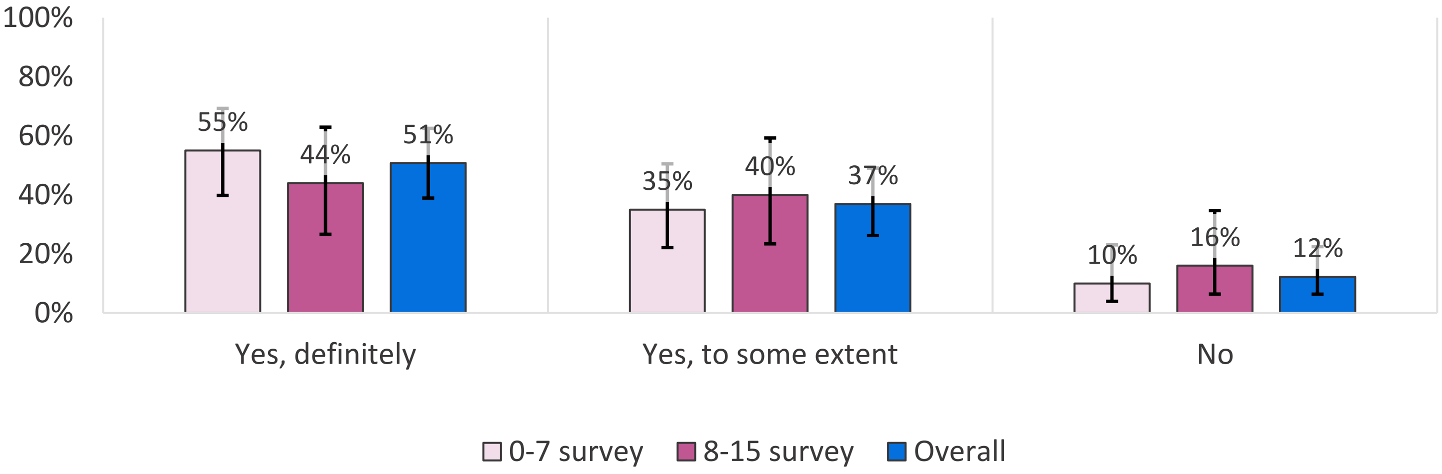
All parents and carers were asked questions about staff involved in their child's care at the hospital named in the letter that came with their survey, including questions about awareness of the child's medical history and whether they had access to help and support.

Figure 26: Are different hospital staff caring for your child aware of your child's medical history?



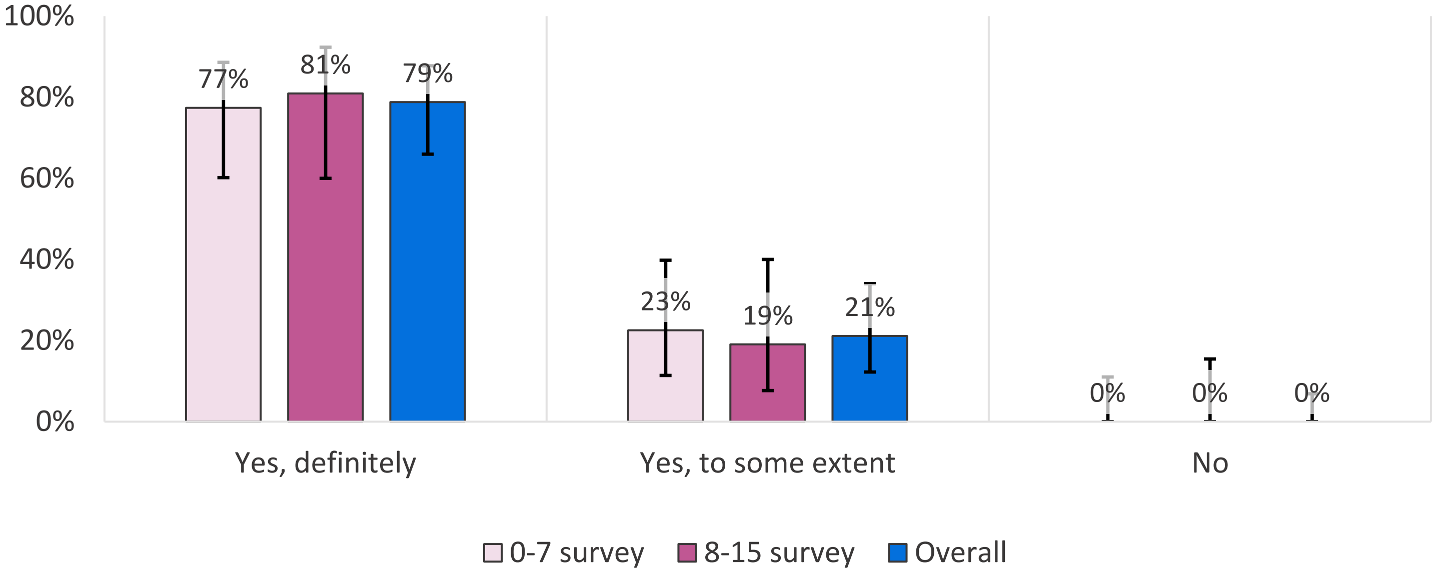
Question X27: Asked to parents or carers of all age groups. Total responses = 62 (excluding 4 responses of "Don't know / not applicable").

Figure 27: Do you have access to reliable help and support 7 days a week from the hospital?



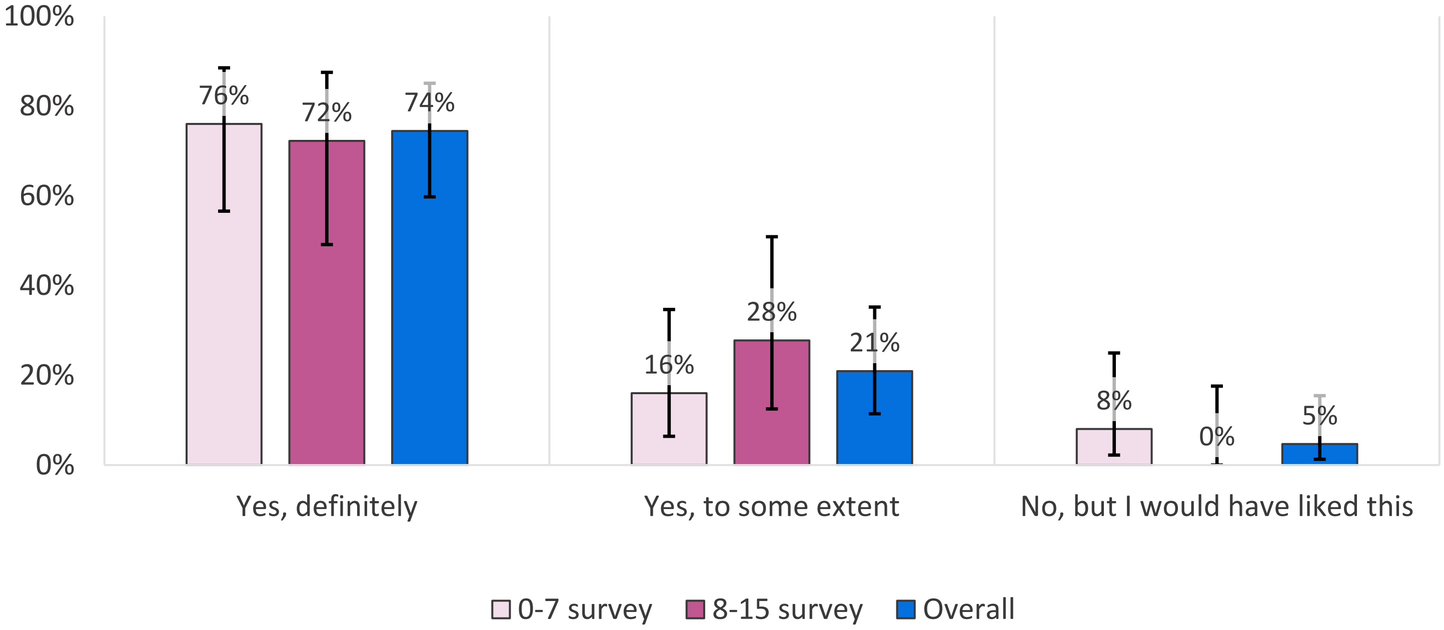
Question X33: Asked to parents or carers of all age groups. Total responses = 65 (excluding 1 response of "This is not needed").

Figure 28: Were you offered clear information about your child's treatment?



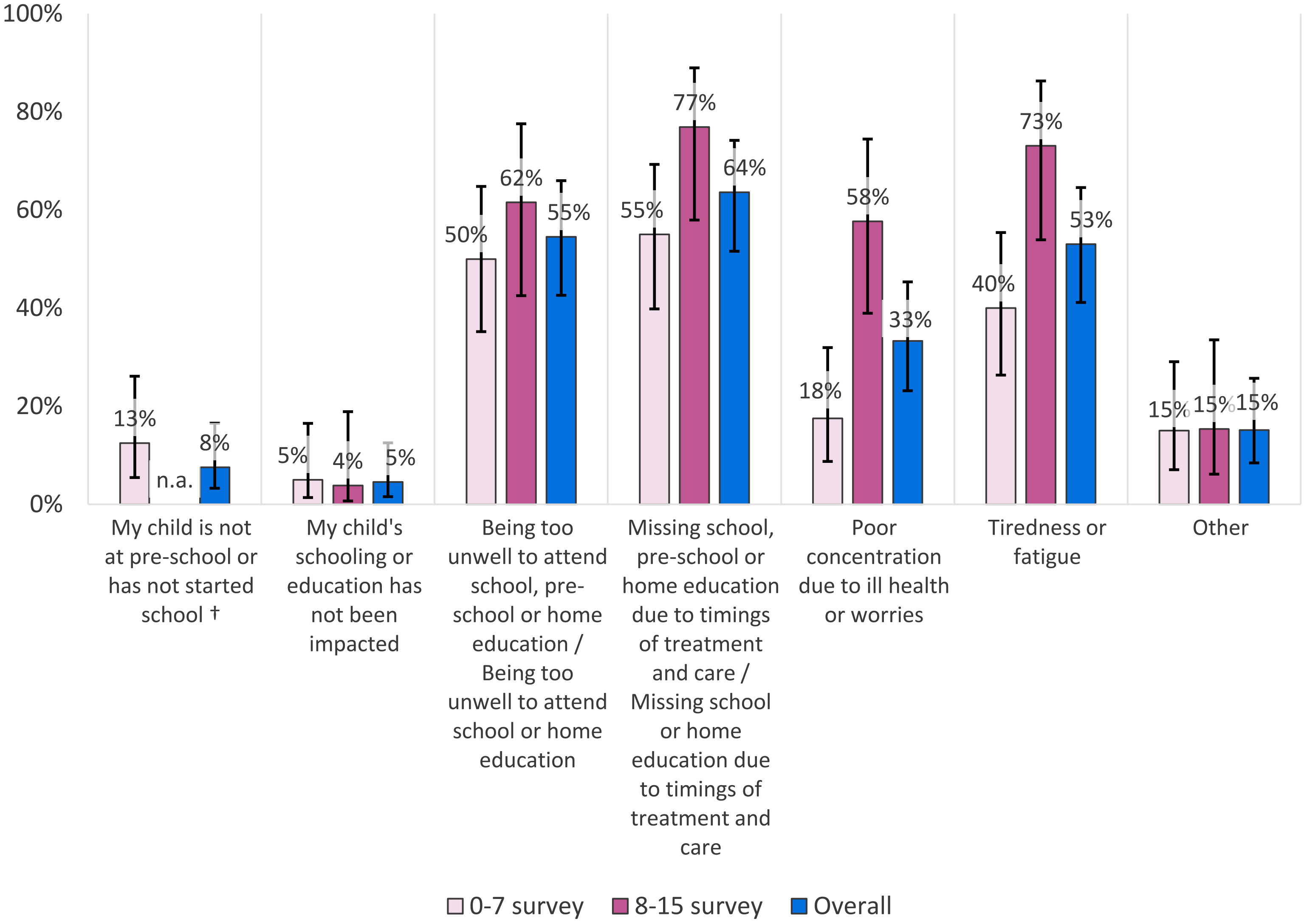
Question X36: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total responses = 52 (excluding 0 responses of “This was not needed”).

Figure 29: Did staff offer you enough time to make decisions about your child's treatment?



Question X37: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total responses = 43 (excluding 6 responses of “No, but this was not needed” and excluding 3 responses of “No, but this was not possible”).

Figure 30: Has your child's schooling and education (including pre-school) been impacted in any of the following ways by their treatment and care? / Has your child's schooling and education been impacted in any of the following ways by their treatment and care?



Question X30: Asked to parents or carers of all age groups. Total responses = 66.

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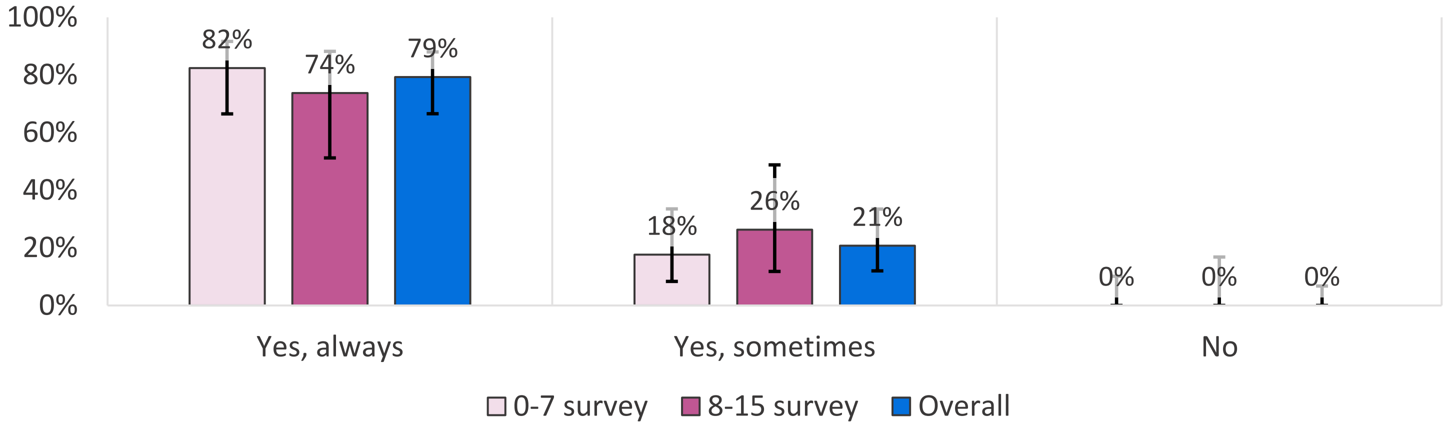
† Response option was only asked to parents or carers of 0-7 years olds

Care in hospital

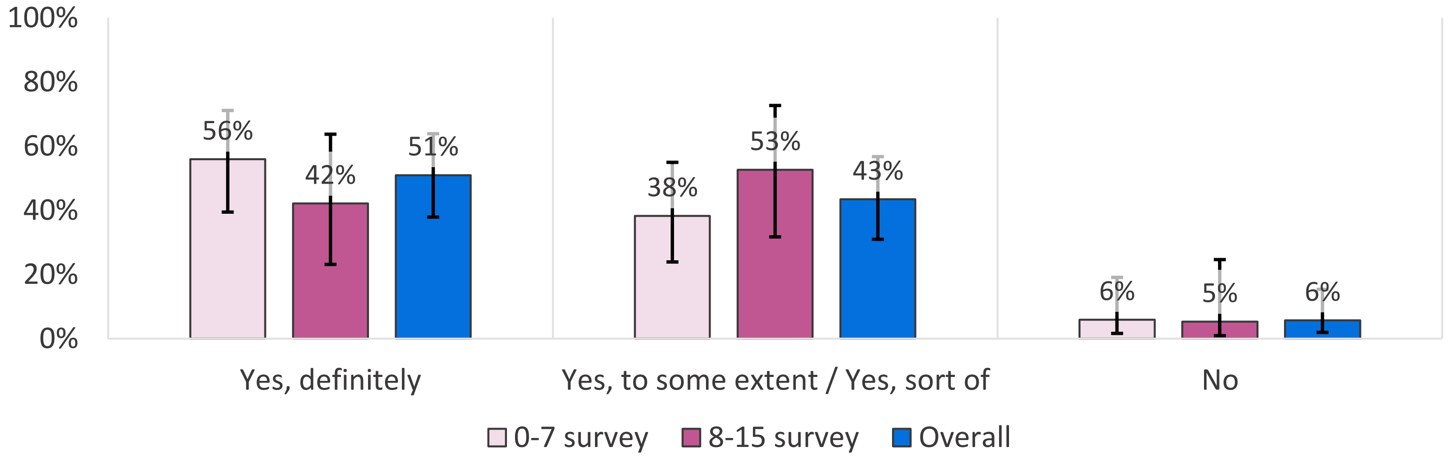
Respondents who had stayed in the hospital named in the letter that came with their survey during 2023 (receiving treatment or care in the daytime, or for an overnight stay) were asked questions about hospital staff, services and facilities. Out of all parents or carers, 84% (n=56) answered that their child had stayed in hospital during 2023 (Question X40).

Figure 31: When your child was in hospital, were they able to get help from staff on the ward when they needed it? / Could you get help from staff on the ward when you needed it?



Question X42: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who have stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total responses = 53 (excluding 0 responses of “They did not need any help / I did not need any help” and excluding 0 responses of “Don't know / can't remember”).

Figure 32: Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital?

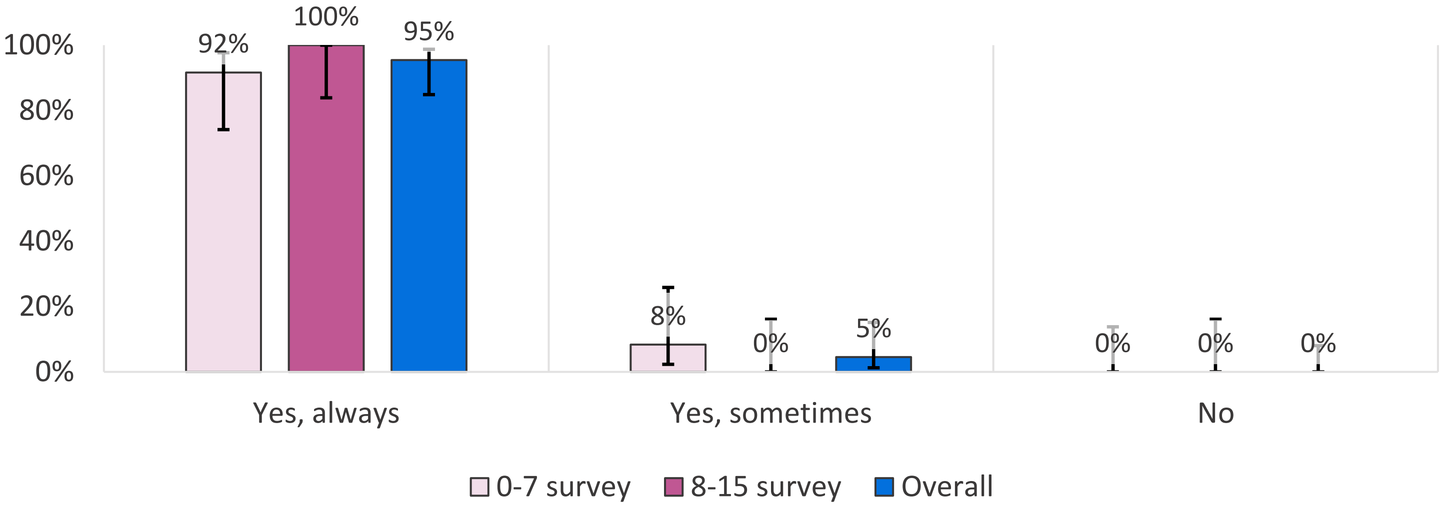


Question X43: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 53 (excluding 0 responses of “This was not needed”).

Care at home or at school

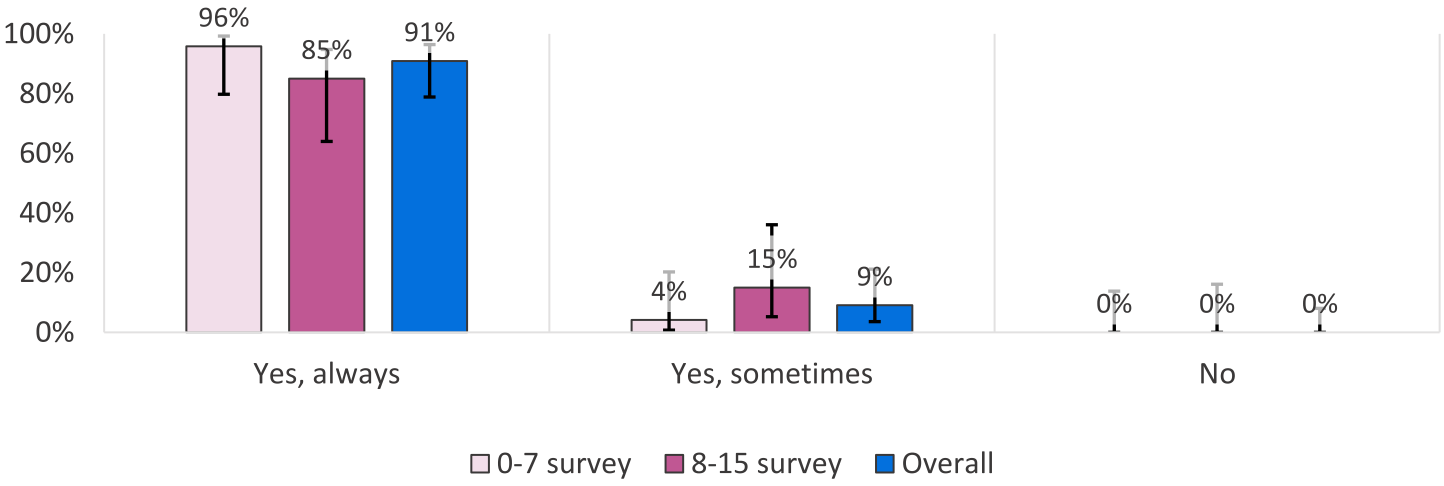
Children aged 8 and above, and parents or carers of children under the age of 8 who had been visited at home or school by a nurse during 2023 (68% (n=44) of respondents) (Question X53), for care relating to the child's cancer or tumour, were asked a short series of questions about this care. Some results from this section can be found below.

Figure 33: 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 X54: Asked to parents or carers of children aged 0-7 whose children have been visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse. Total responses = 44 (excluding 0 responses of "Don't know / can't remember").

Figure 34: When nurses speak to you, do you understand what they are saying?



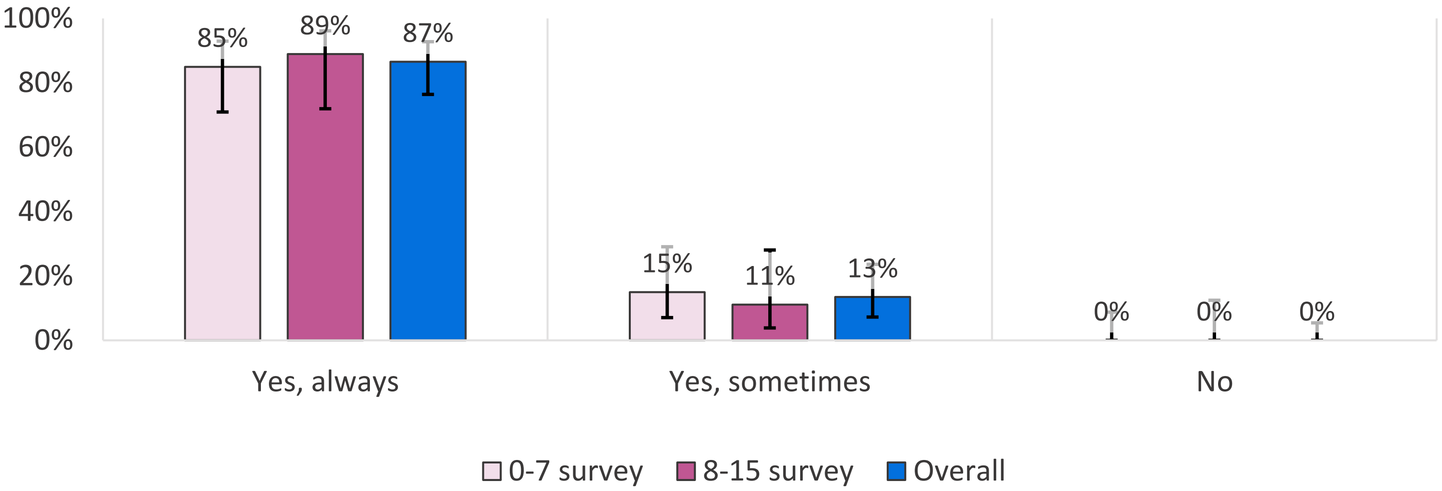
Question X55: Asked to parents or carers of children aged 0-7 whose child was visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse. Total responses = 44 (excluding 0 responses of "Don't know / can't remember").

Healthcare staff

All parents or 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.

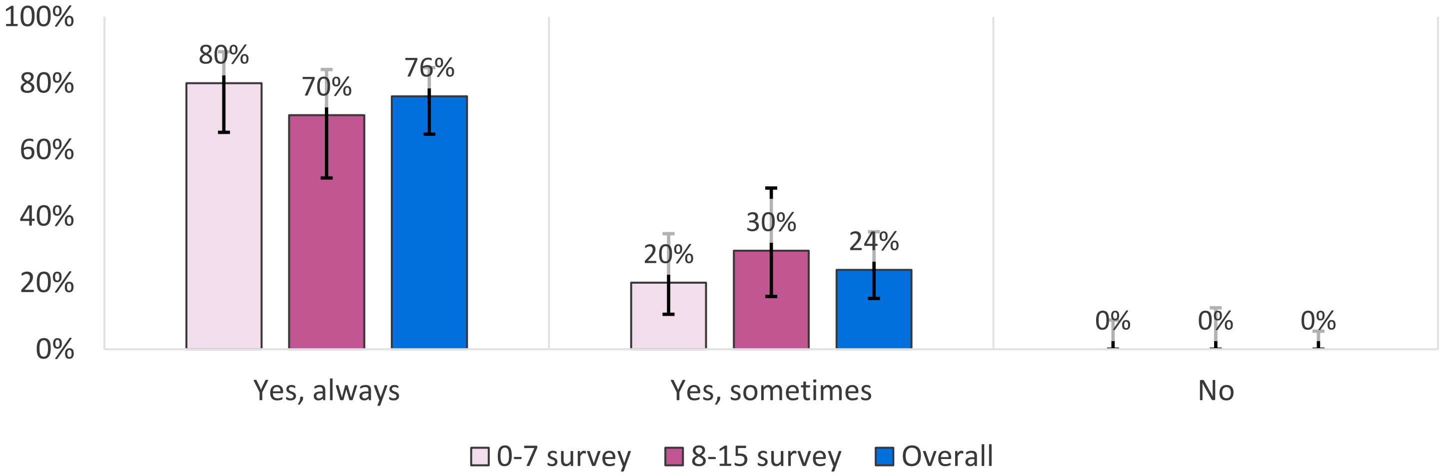
Bedside manner and trust

Figure 35: Are you and your child treated with respect and dignity by staff?



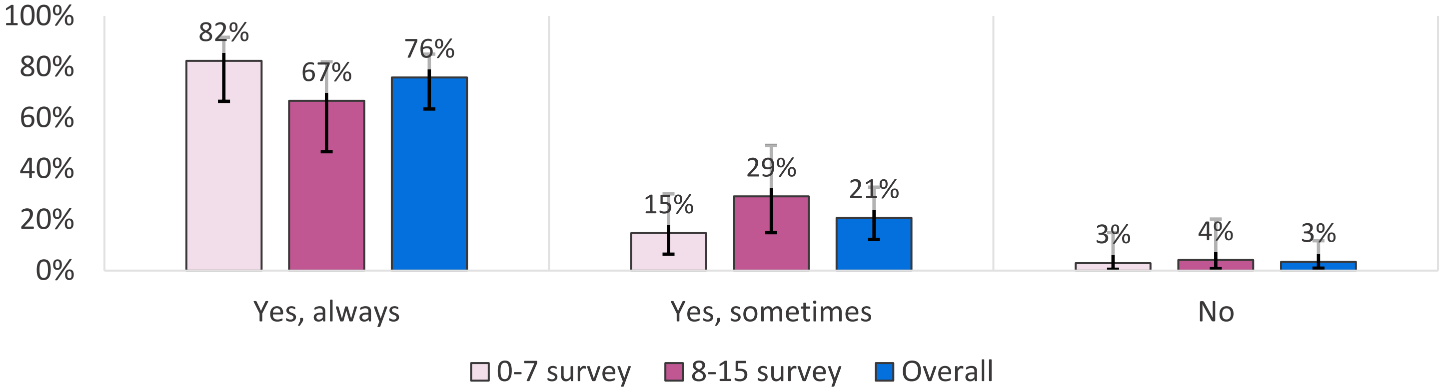
Question X17: Asked to parents or carers of all age groups. Total responses = 67.

Figure 36: Do members of staff caring for your child treat you with empathy and understanding?



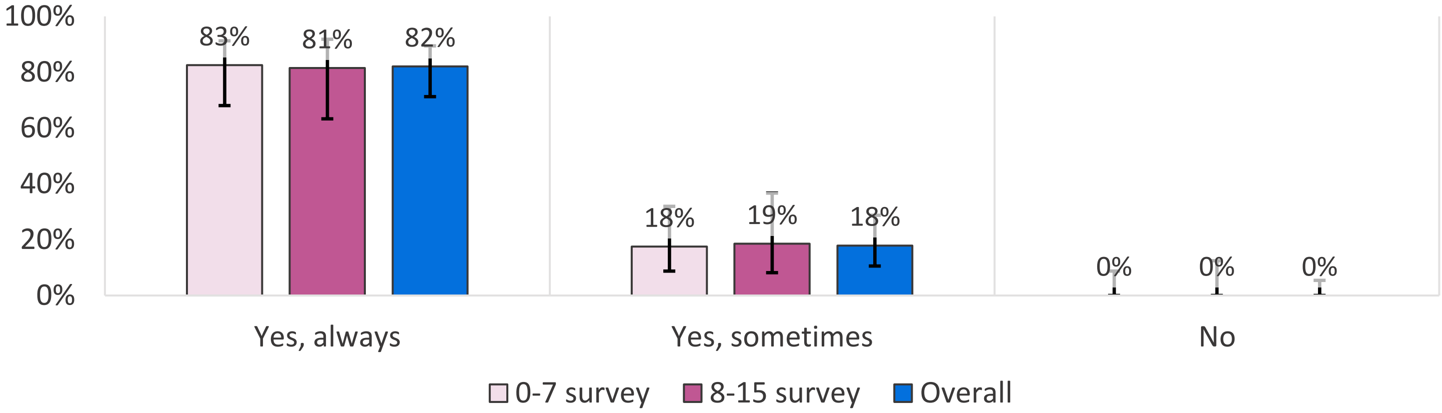
Question X19: Asked to parents or carers of all age groups. Total responses = 67.

Figure 37: Are staff sensitive to the information they share with you when your child is in the room?



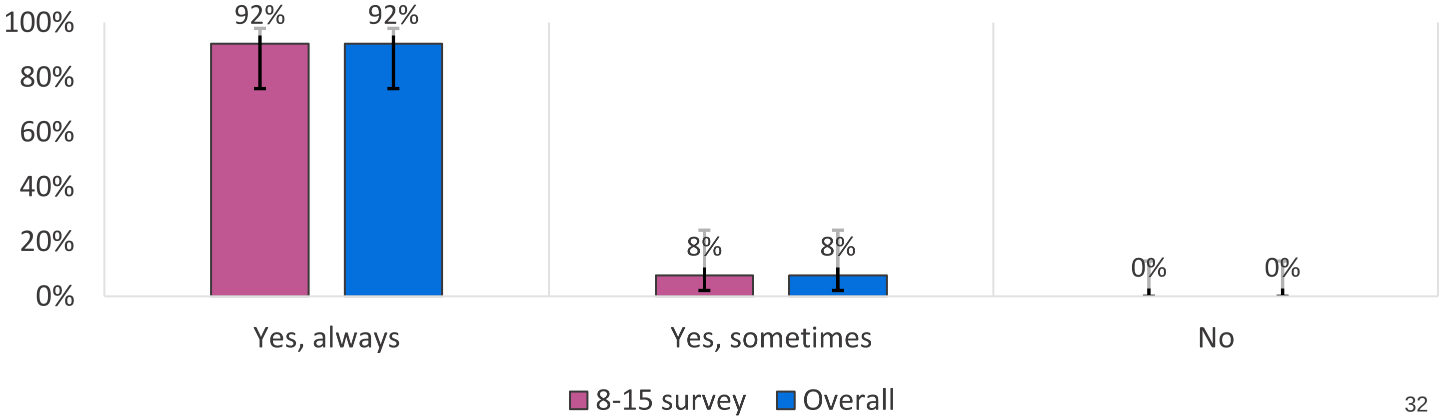
Question X21: Asked to parents or carers of all age groups. Total responses = 58 (excluding 9 responses of "This is not needed").

Figure 38: Do you have confidence and trust in the members of staff caring for your child?



Question X18: Asked to parents or carers of all age groups. Total responses = 67.

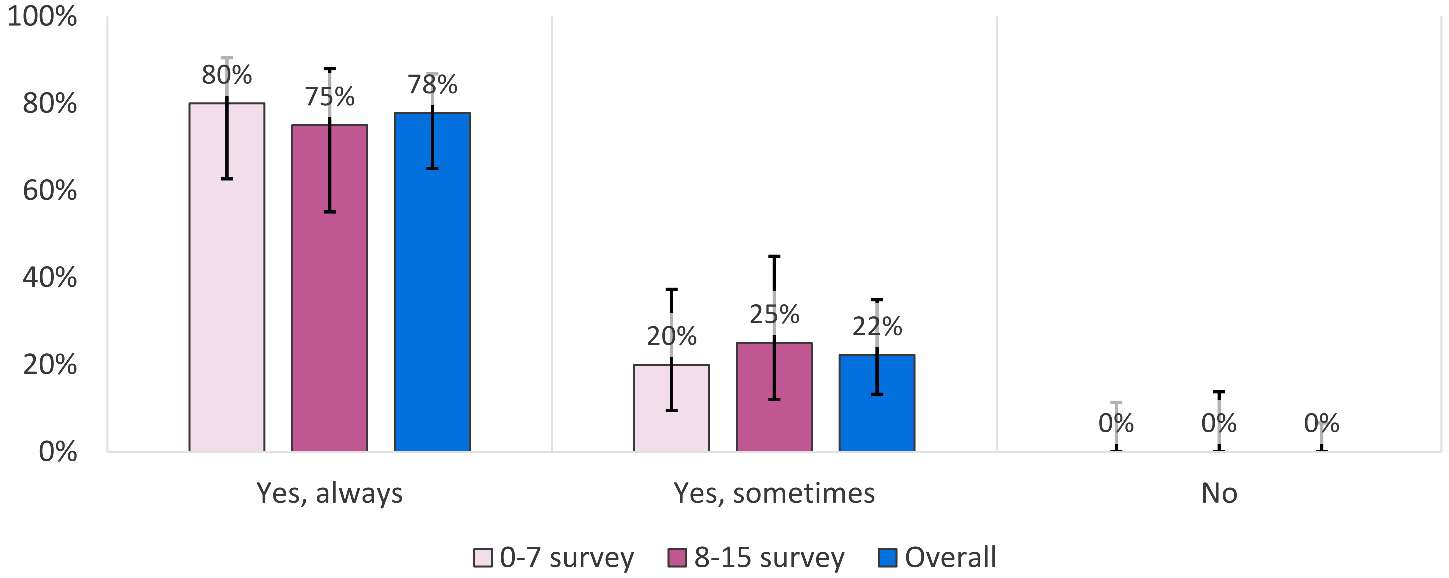
Figure 39: Do you feel that staff are friendly?



Question X12: Asked to all children aged 8-15. Total responses = 26.

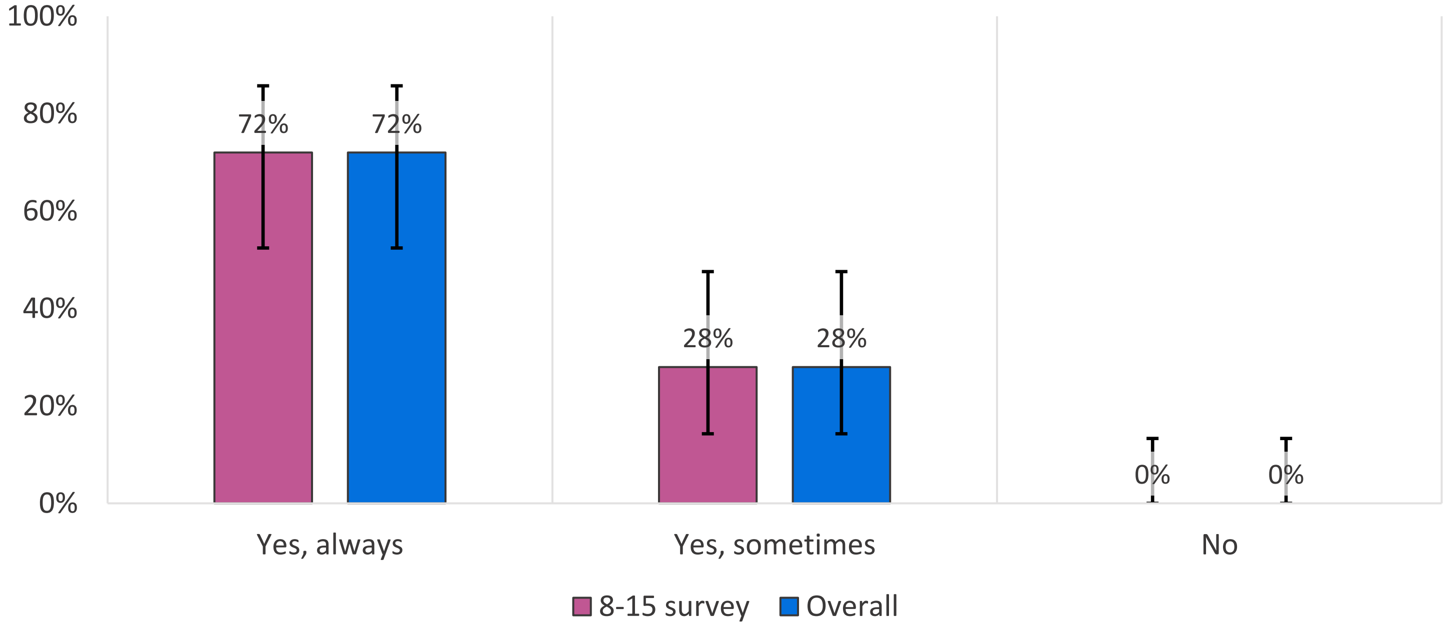
Clear communication

Figure 40: Do healthcare staff share information with your child in a way that is appropriate for them?



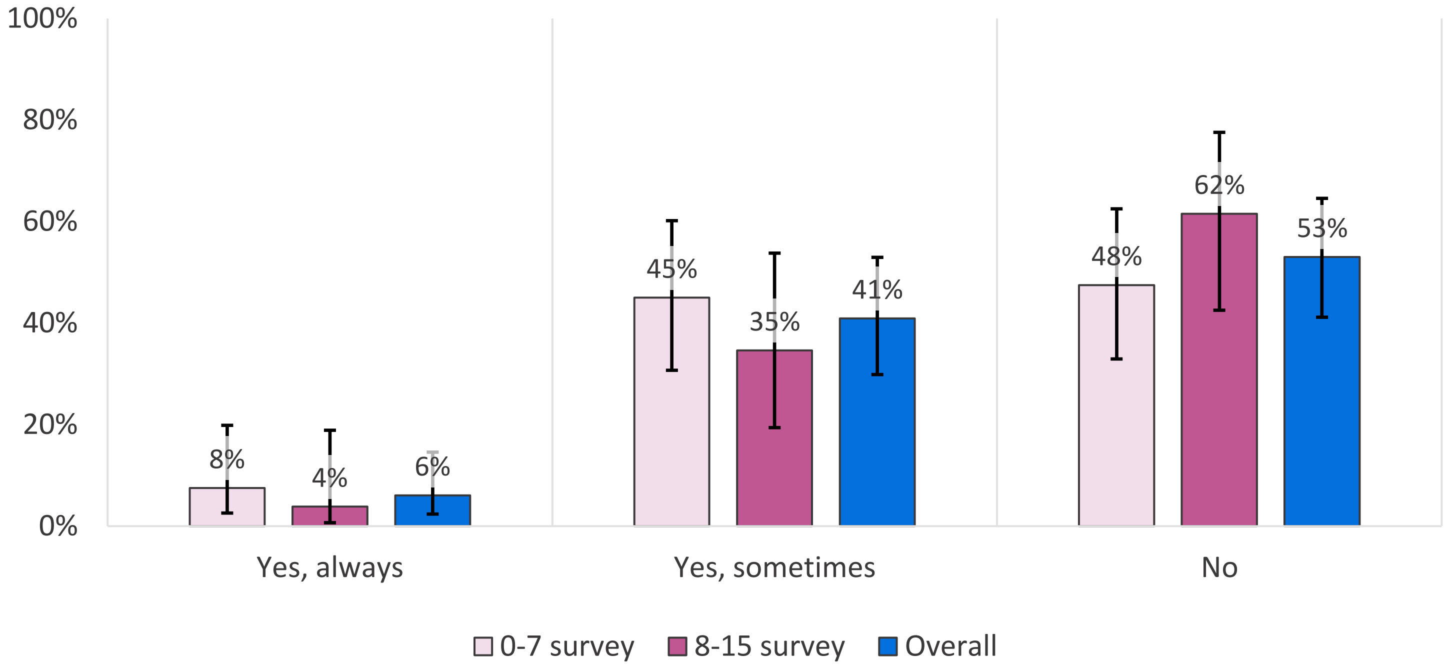
Question X22: Asked to parents or carers of all age groups. Total responses = 54 (excluding 12 responses of "This is not needed").

Figure 41: When staff speak to you, do you understand what they are saying? / Do staff speak to you in a way that you can understand?



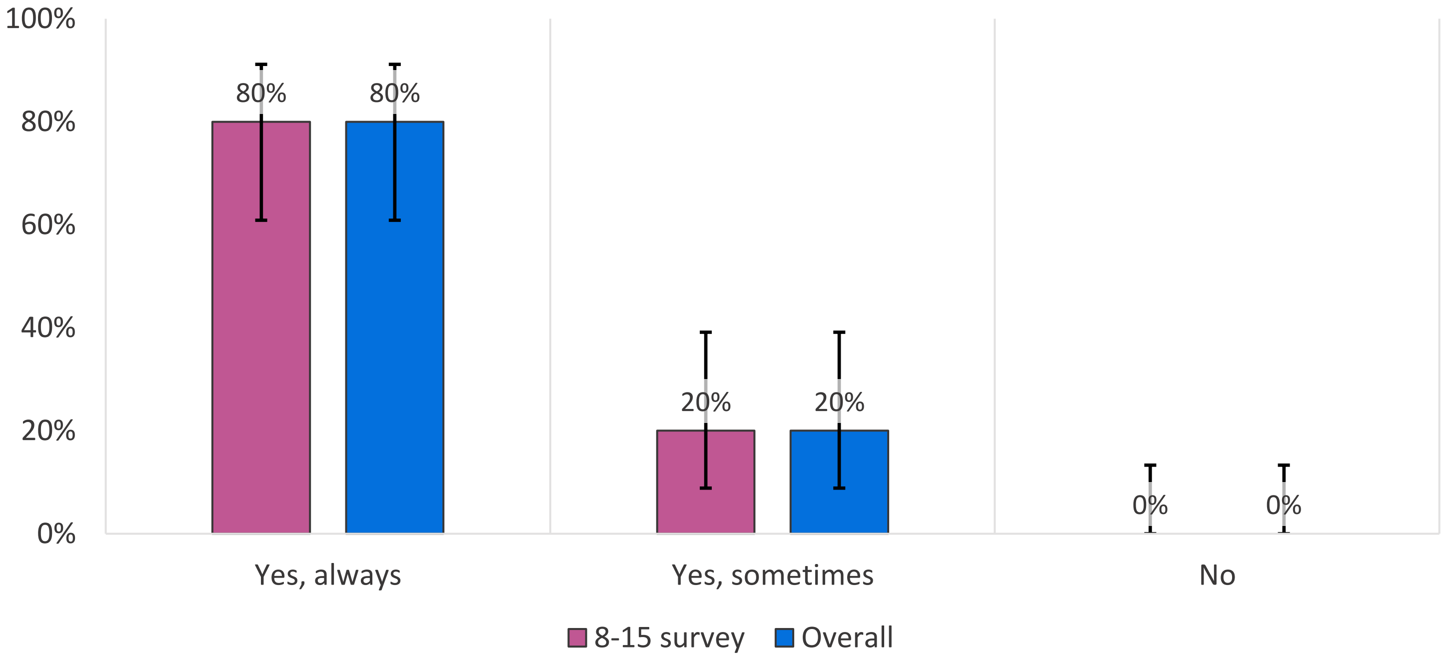
Question X13: Asked to all children aged 8-15. Total responses = 25 (excluding 1 response of "Don't know / can't remember").

Figure 42: Are you ever told different things by different members of staff, which leaves you feeling confused?



Question X20: Asked to parents or carers of 0-7s and children aged 8-15. Total responses = 66.

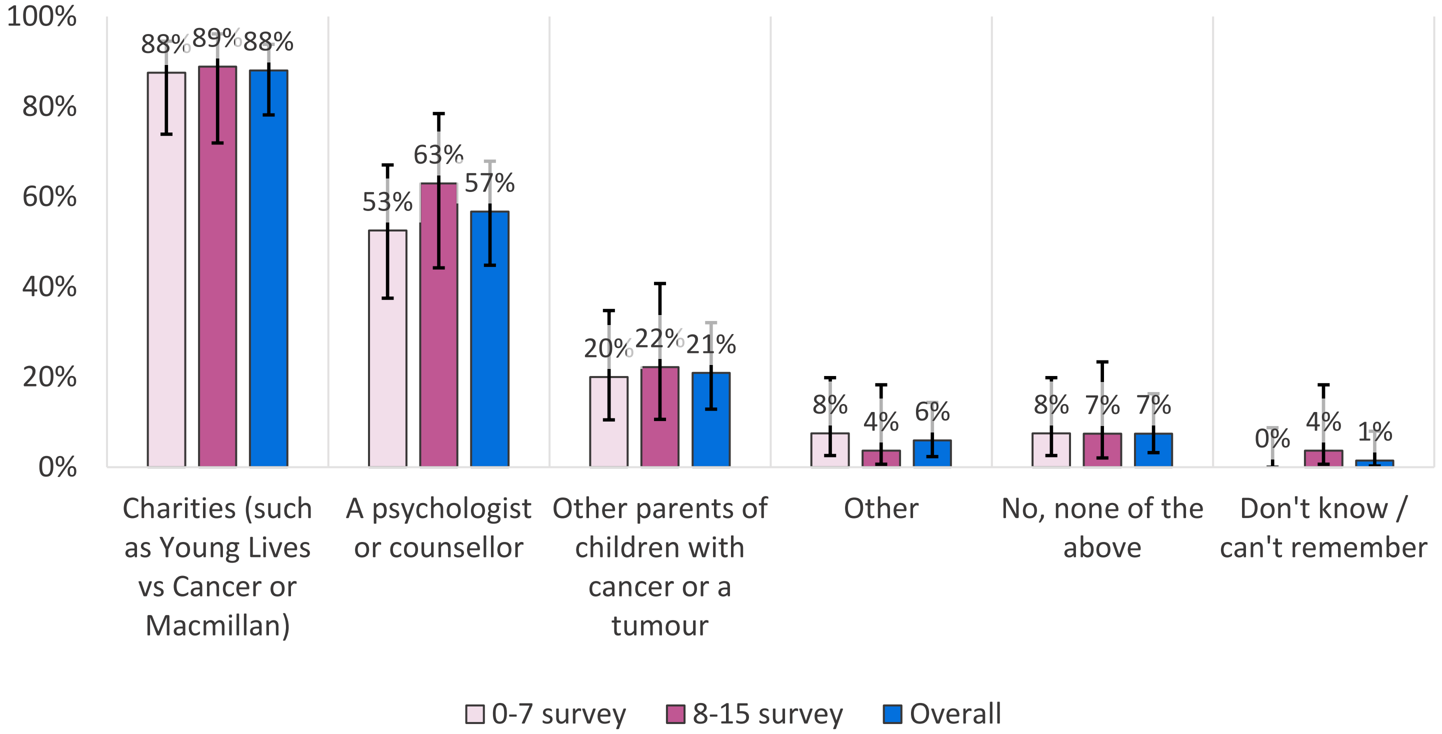
Figure 43: Do staff talk to you, not just to your parent or carer?



Question X14: Asked to all children aged 8-15. Total responses = 25.

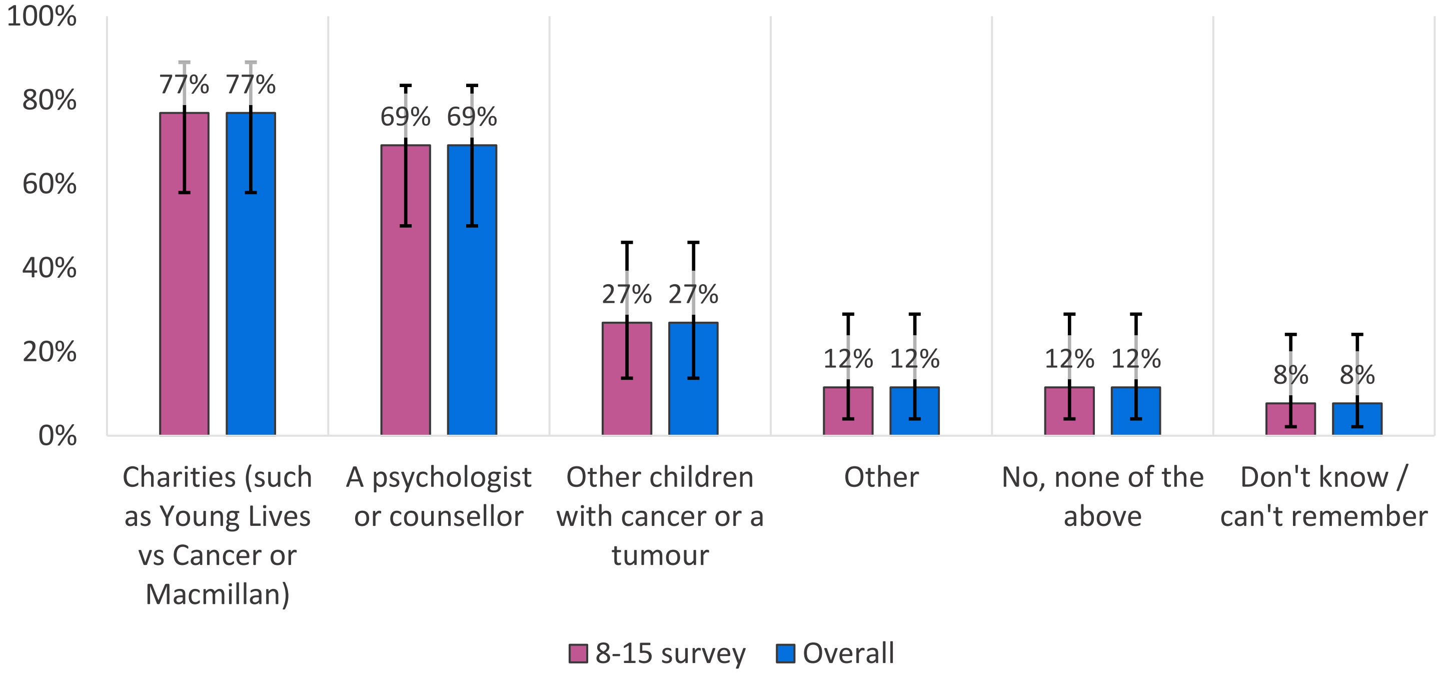
Support

Figure 44: Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour?



Question X24: Asked to parents or carers of all age groups. Total responses = 67.

Figure 45: Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour?



Question X23: Asked to all children aged 8-15. Total responses = 26.

Year on year comparisons

The line charts in this section show the national score and the score for your PTC for 2021, 2022, and 2023 for all comparable questions.

We recommend that PTCs take caution when benchmarking their results against last year, or against results at national level, due to numbers of responses. Please refer to the 'How to use this data' section for more information.

Please note that the 2023 scores that are not comparable to both 2021 and 2022 are not presented in this section and can be found in the data tables on the survey website. Full details on data comparability can be found in the Technical Appendix.

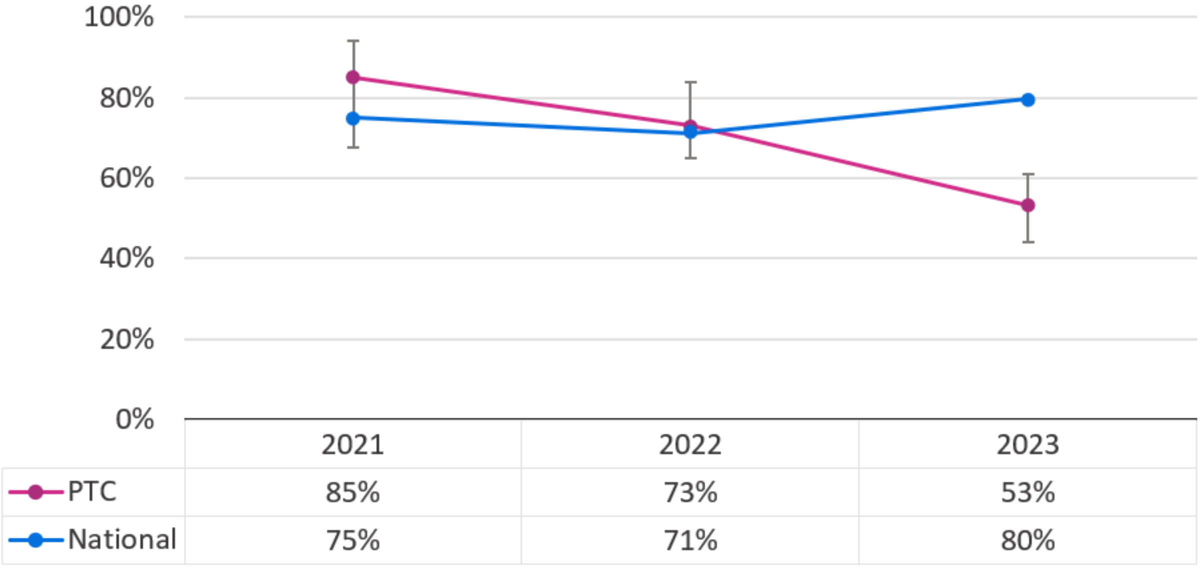
How to interpret these results

In this section, the confidence intervals surround the PTC data only and not the national data.

Assuming the sample is representative of your 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 population value 95 percent of the time (i.e. out of 100 such intervals, 95 will include the true figure).

In this example below, the PTC scored 73% in 2022, and 53% in 2023. As the confidence intervals do not overlap, you could be statistically confident that there is “true” difference between the two.

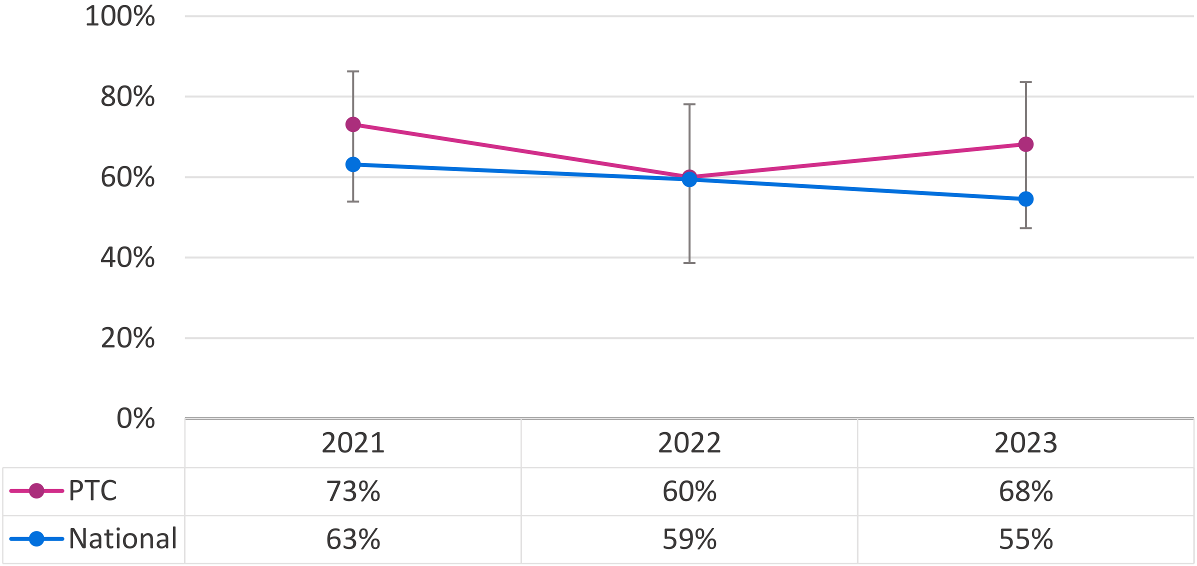
EXAMPLE DATA ONLY



	2021	2022	2023
PTC	85%	73%	53%
National	75%	71%	80%

Finding out about the cancer or tumour

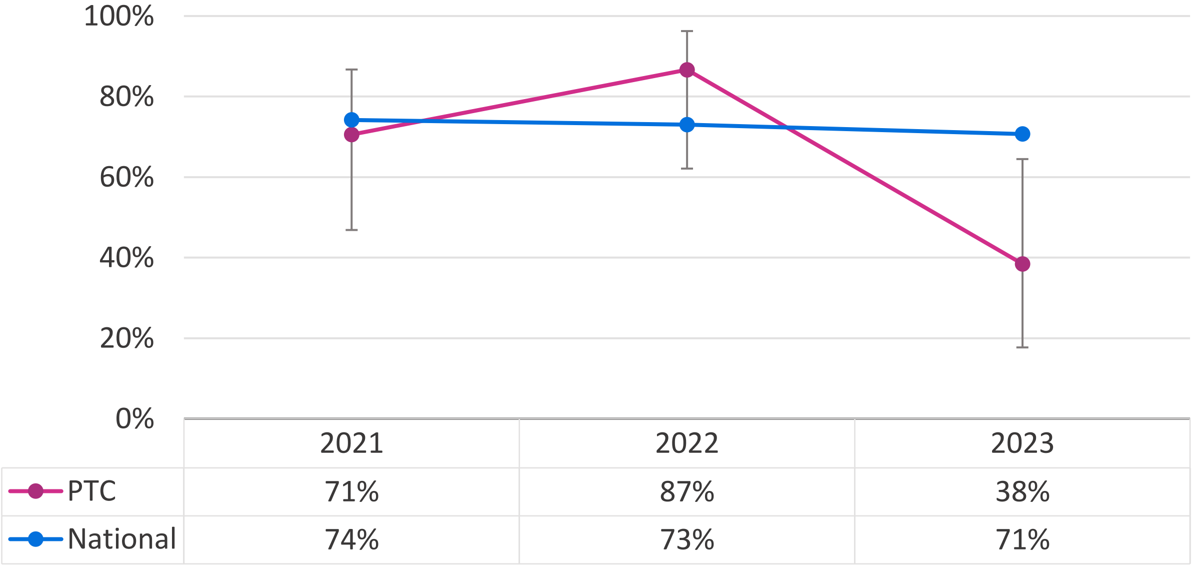
Figure 46: Parents or carers reported that their child saw a GP once or twice before they were referred to hospital



	2021	2022	2023
PTC	73%	60%	68%
National	63%	59%	55%

Question X03: Asked to parents or carers of all age groups whose children were told they had cancer or a tumour. Total PTC responses for 2021 = 26, for 2022 = 20, for 2023 = 22.

Figure 47: Parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way

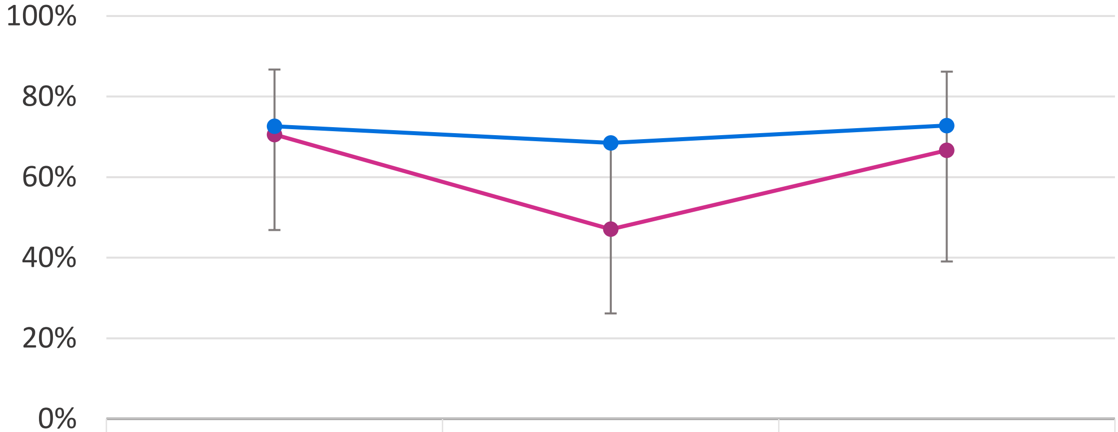


	2021	2022	2023
PTC	71%	87%	38%
National	74%	73%	71%

Question X07: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total PTC responses for 2021 = 17, for 2022 = 15, for 2023 = 13.

Finding out about the cancer or tumour

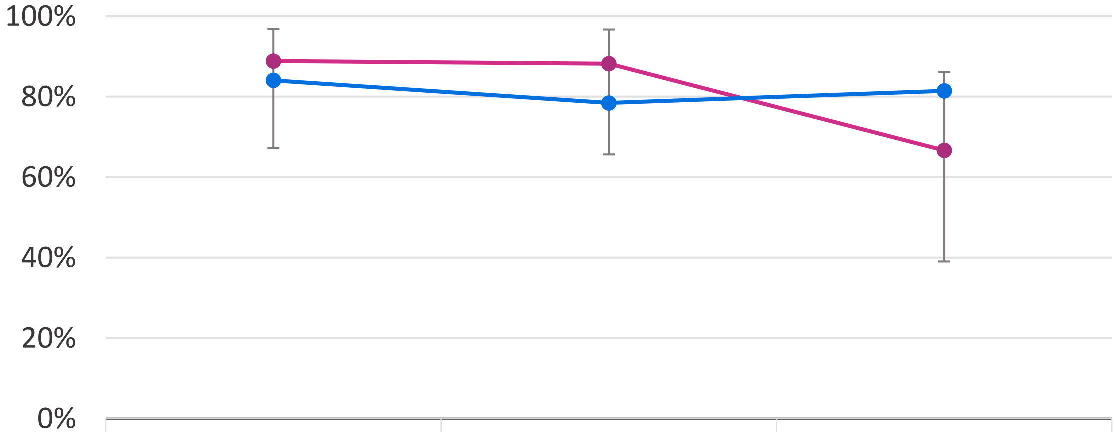
Figure 48: Parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand



	2021	2022	2023
PTC	71%	47%	67%
National	73%	69%	73%

Question X08: Asked to parents or carers of 0-7s who were told about their child's cancer or a tumour, and children aged 8-15 who were told they had cancer or a tumour. Total PTC responses for 2021 = 17, for 2022 = 17, for 2023 = 12.

Figure 49: Parents, carers, and children reported that they were definitely able to have questions answered after being told about the cancer or tumour

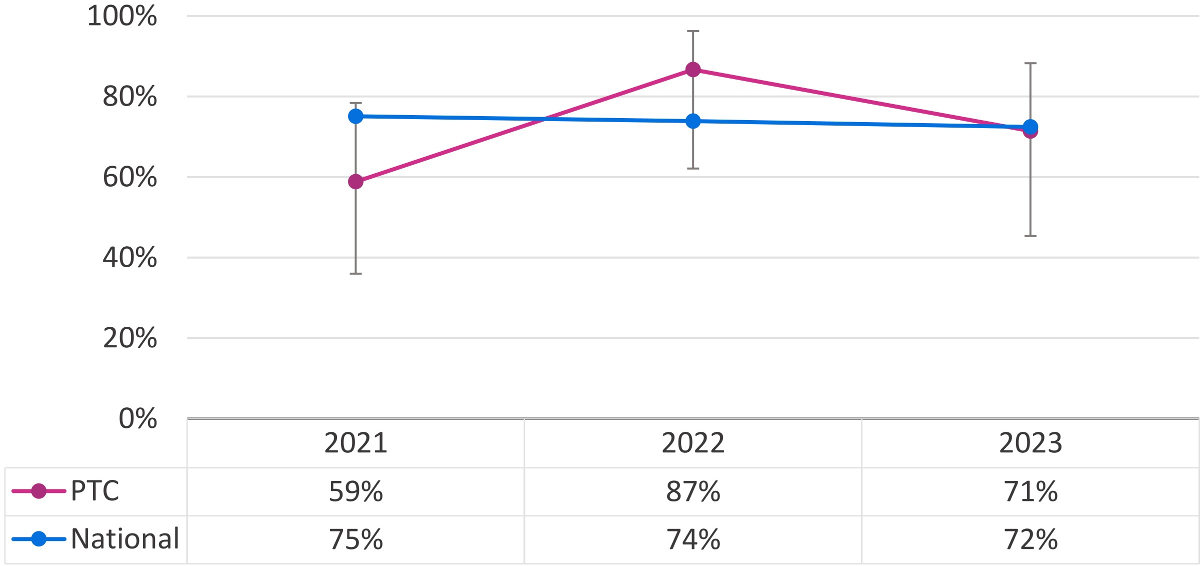


	2021	2022	2023
PTC	89%	88%	67%
National	84%	78%	81%

Question X09: Asked to parents or carers of 0-7s who were told about their child's cancer or a tumour, and children aged 8-15 who were told they had cancer or a tumour. Total PTC responses for 2021 = 18, for 2022 = 17, for 2023 = 12.

Finding out about the cancer or tumour

Figure 50: Parents or carers reported that they were definitely able to find information about their child's diagnosis

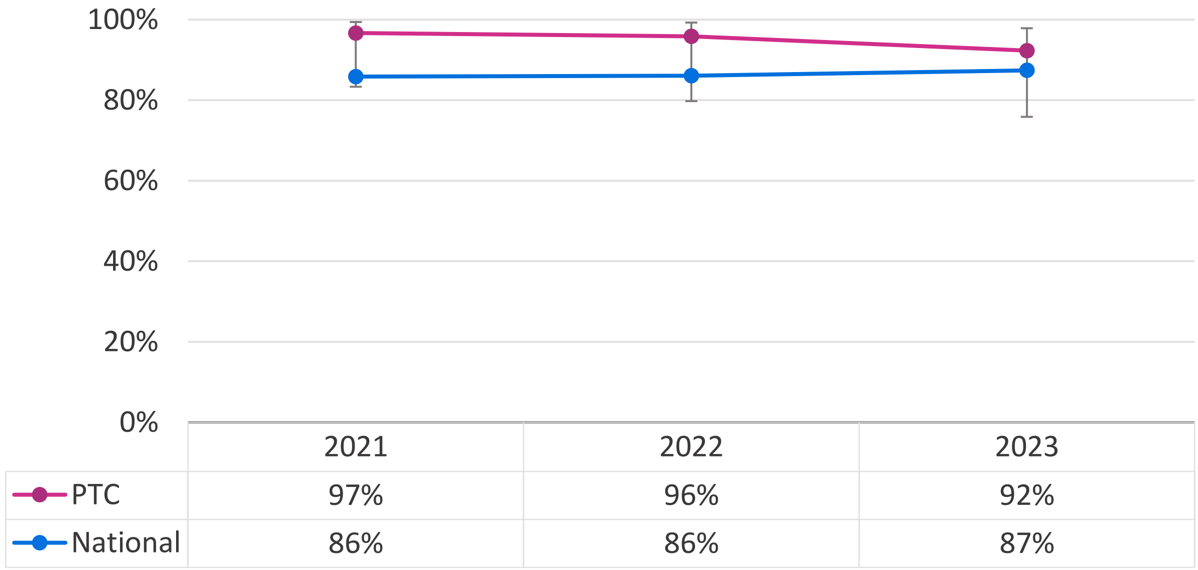


	2021	2022	2023
PTC	59%	87%	71%
National	75%	74%	72%

Question X10: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total PTC responses for 2021 = 17, for 2022 = 15, for 2023 = 14.

Healthcare staff

Figure 51: Children felt that staff were always friendly

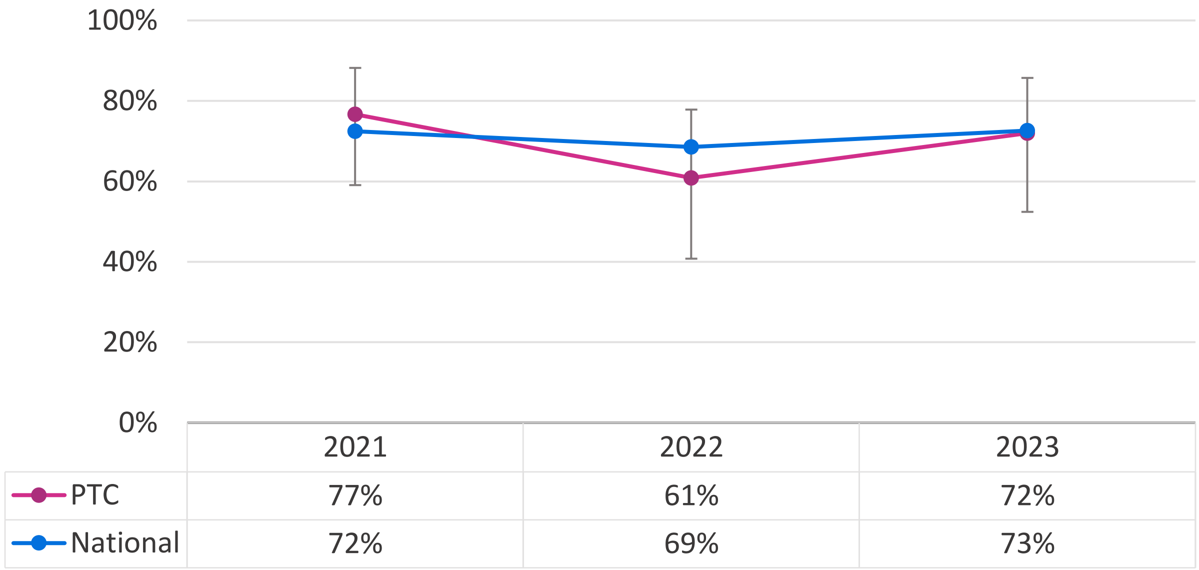


	2021	2022	2023
PTC	97%	96%	92%
National	86%	86%	87%

Question X12: Asked to all children aged 8-15. Total PTC responses for 2021 = 30, for 2022 = 24, for 2023 = 26.

Healthcare staff

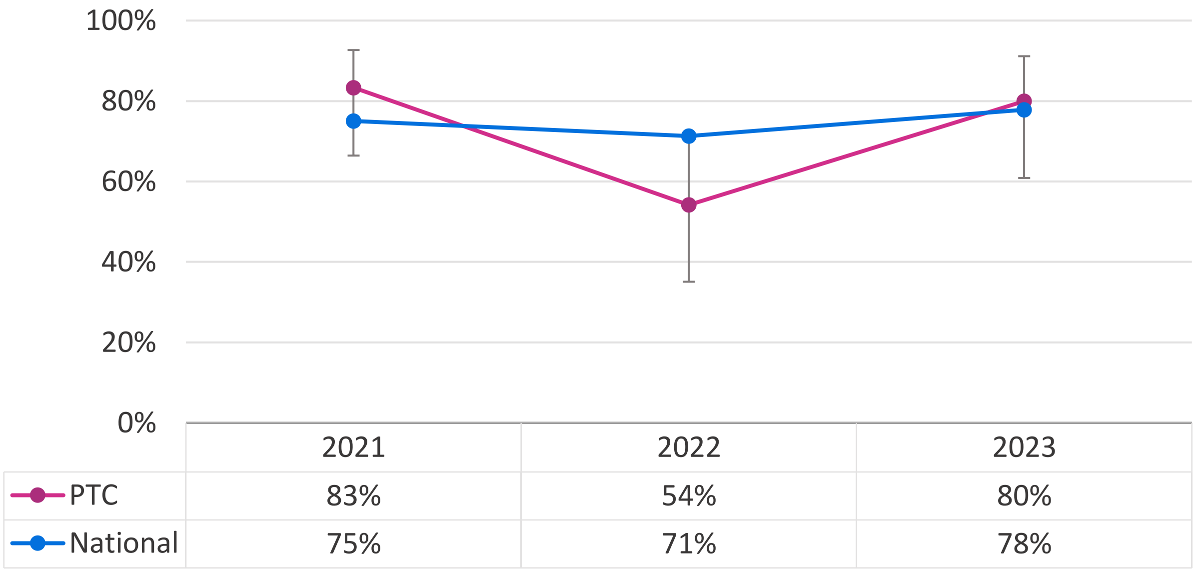
Figure 52: Children reported that they could always understand what staff were saying



	2021	2022	2023
PTC	77%	61%	72%
National	72%	69%	73%

Question X13: Asked to all children aged 8-15. Total PTC responses for 2021 = 30, for 2022 = 23, for 2023 = 25.

Figure 53: Children felt that staff always talked to them, not just their parent or carer

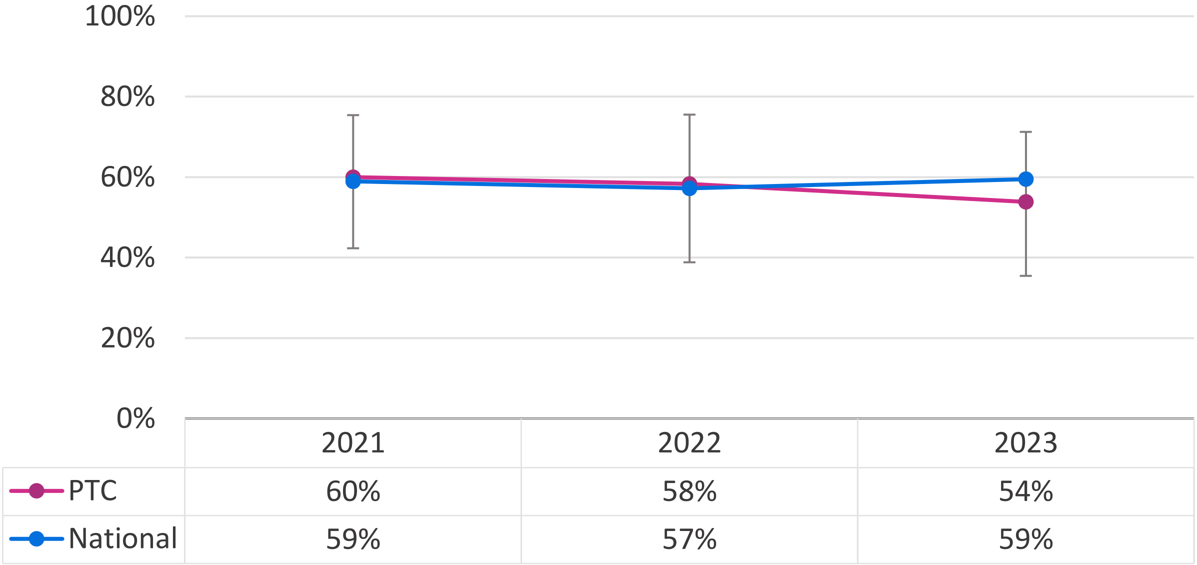


	2021	2022	2023
PTC	83%	54%	80%
National	75%	71%	78%

Question X14: Asked to all children aged 8-15. Total PTC responses for 2021 = 30, for 2022 = 24, for 2023 = 25.

Healthcare staff

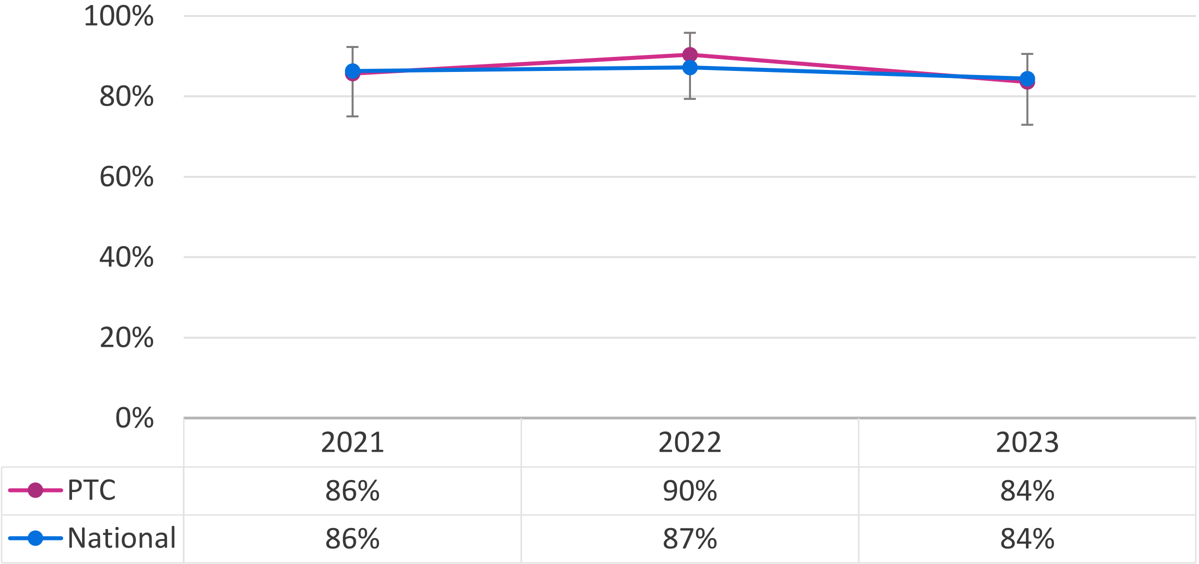
Figure 54: Children reported always or mostly seeing the same members of staff for their treatment and care



	2021	2022	2023
PTC	60%	58%	54%
National	59%	57%	59%

Question X15: Asked to all children aged 8-15. Total PTC responses for 2021 = 30, for 2022 = 24, for 2023 = 26.

Figure 55: Parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment

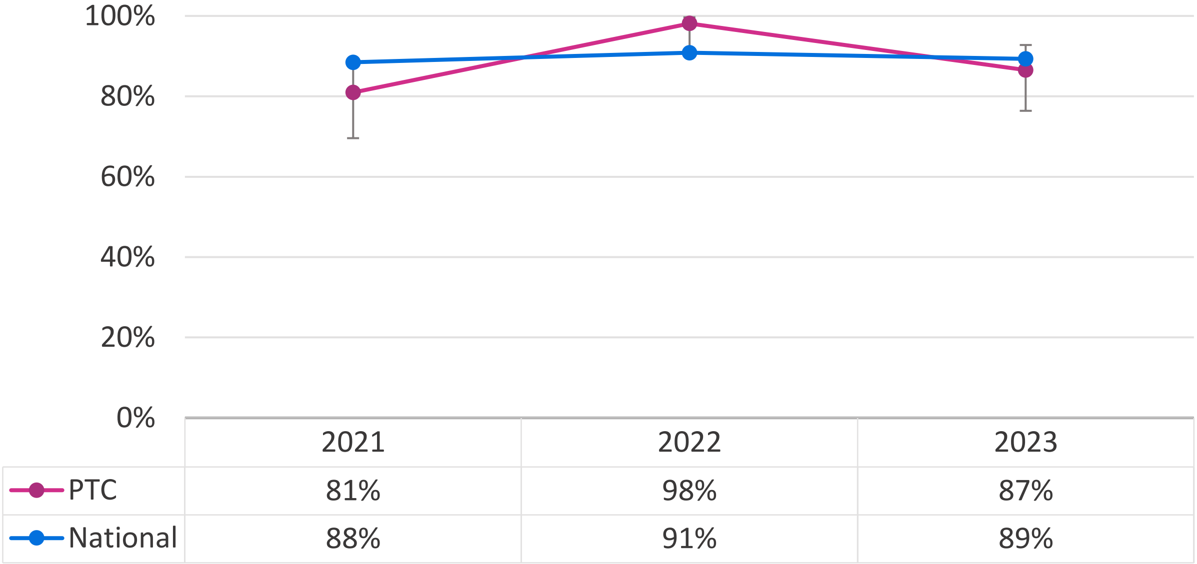


	2021	2022	2023
PTC	86%	90%	84%
National	86%	87%	84%

Question X16: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 63, for 2022 = 52, for 2023 = 67.

Healthcare staff

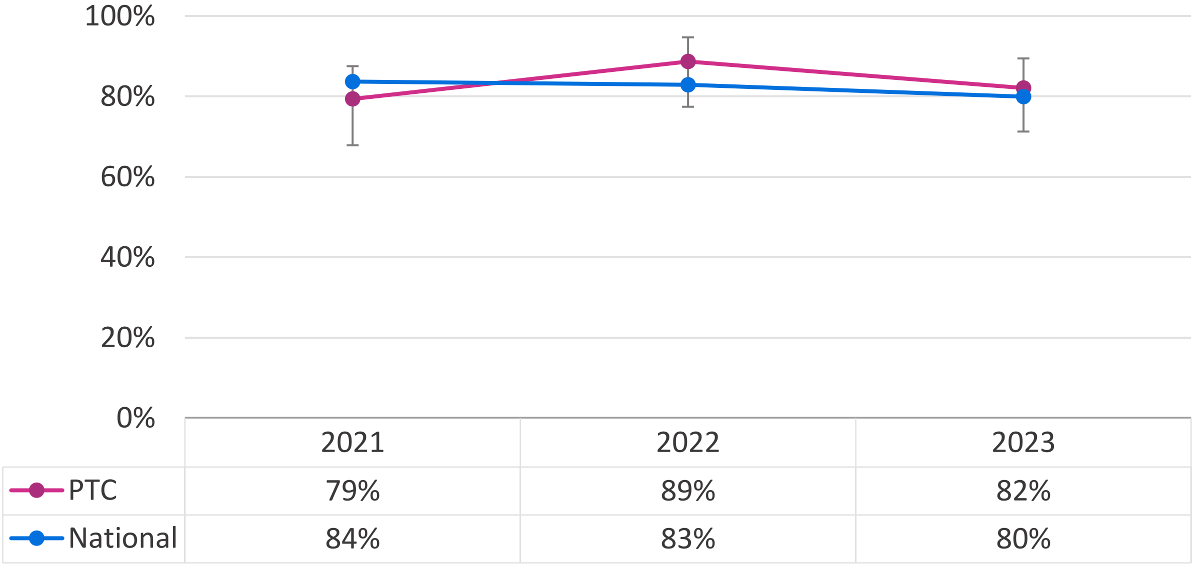
Figure 56: Parents or carers felt that they and their child were always treated with respect and dignity by staff



	2021	2022	2023
PTC	81%	98%	87%
National	88%	91%	89%

Question X17: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 63, for 2022 = 53, for 2023 = 67.

Figure 57: Parents or carers felt they always had confidence and trust in staff caring for their child

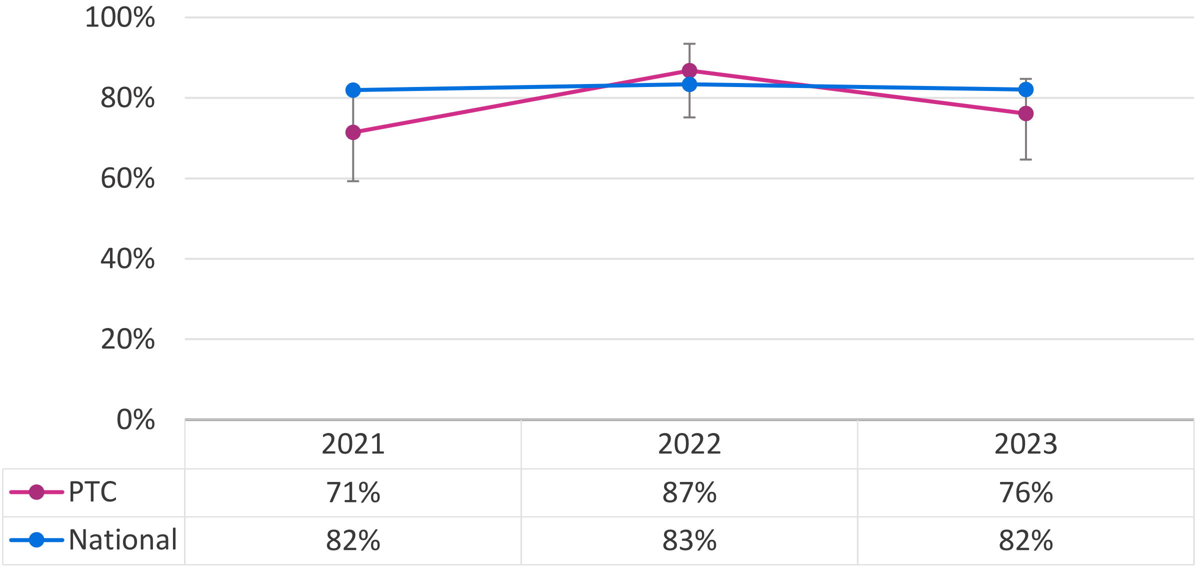


	2021	2022	2023
PTC	79%	89%	82%
National	84%	83%	80%

Question X18: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 63, for 2022 = 53, for 2023 = 67.

Healthcare staff

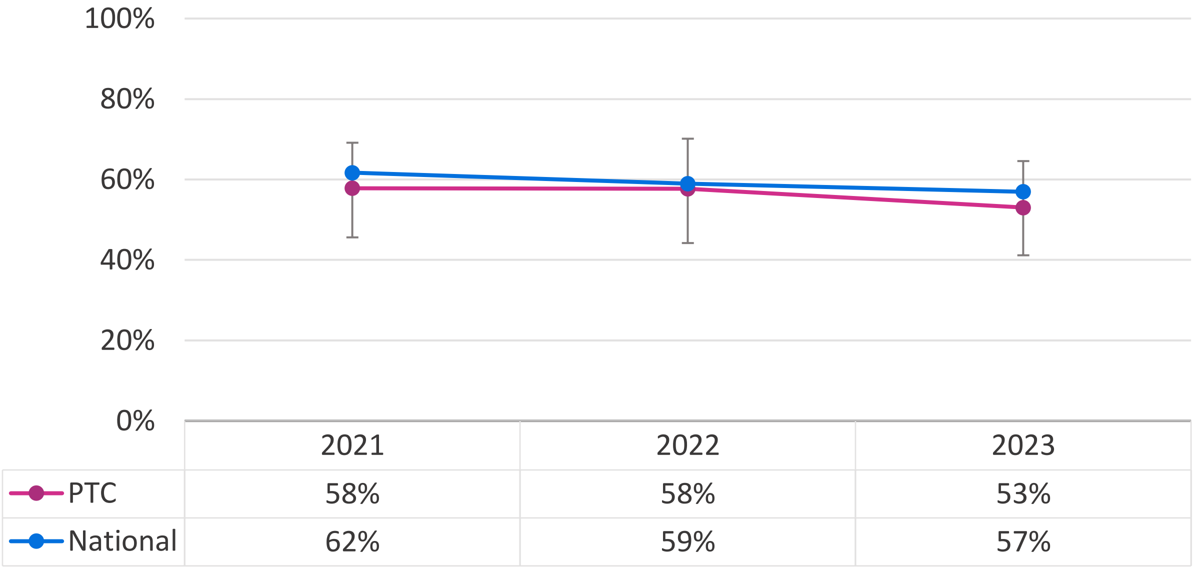
Figure 58: Parents or carers felt that they were always treated with empathy and understanding by staff caring for their child



	2021	2022	2023
PTC	71%	87%	76%
National	82%	83%	82%

Question X19: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 63, for 2022 = 53, for 2023 = 67.

Figure 59: Parents, carers, and children reported not being told different things by different members of staff that left them feeling confused

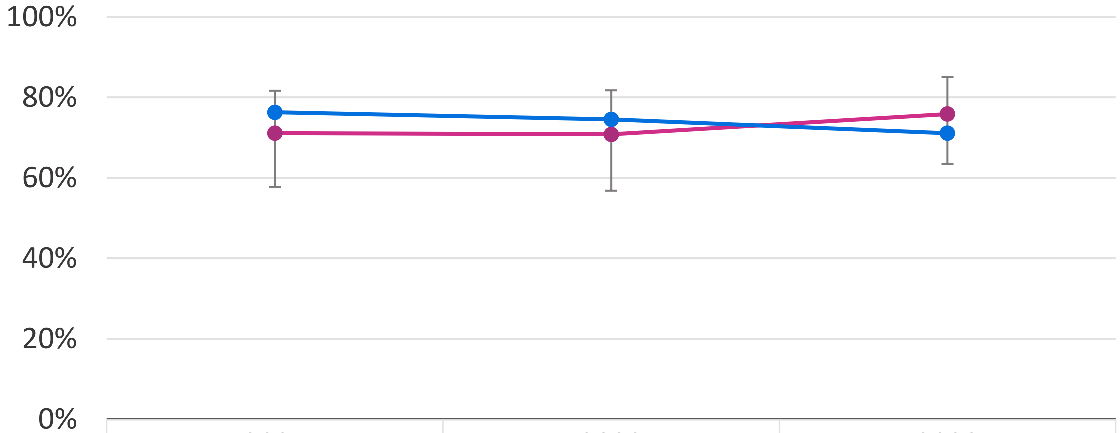


	2021	2022	2023
PTC	58%	58%	53%
National	62%	59%	57%

Question X20: Asked to parents or carers of 0-7s and children aged 8-15. Total PTC responses for 2021 = 64, for 2022 = 52, for 2023 = 66.

Healthcare staff

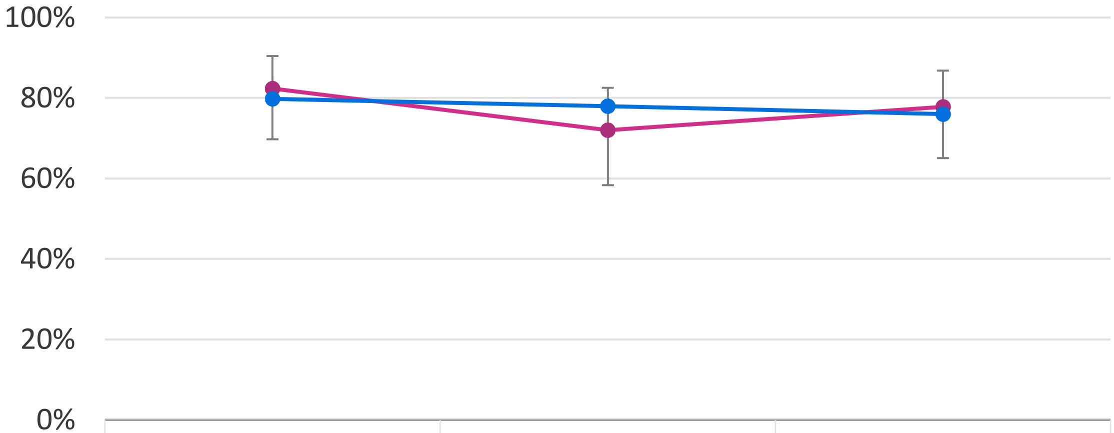
Figure 60: Parents or carers felt that staff were always sensitive to information shared with them when their child was in the room



	2021	2022	2023
PTC	71%	71%	76%
National	76%	75%	71%

Question X21: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 52, for 2022 = 48, for 2023 = 58.

Figure 61: Parents or carers felt that healthcare staff always shared information with children in a way that was appropriate

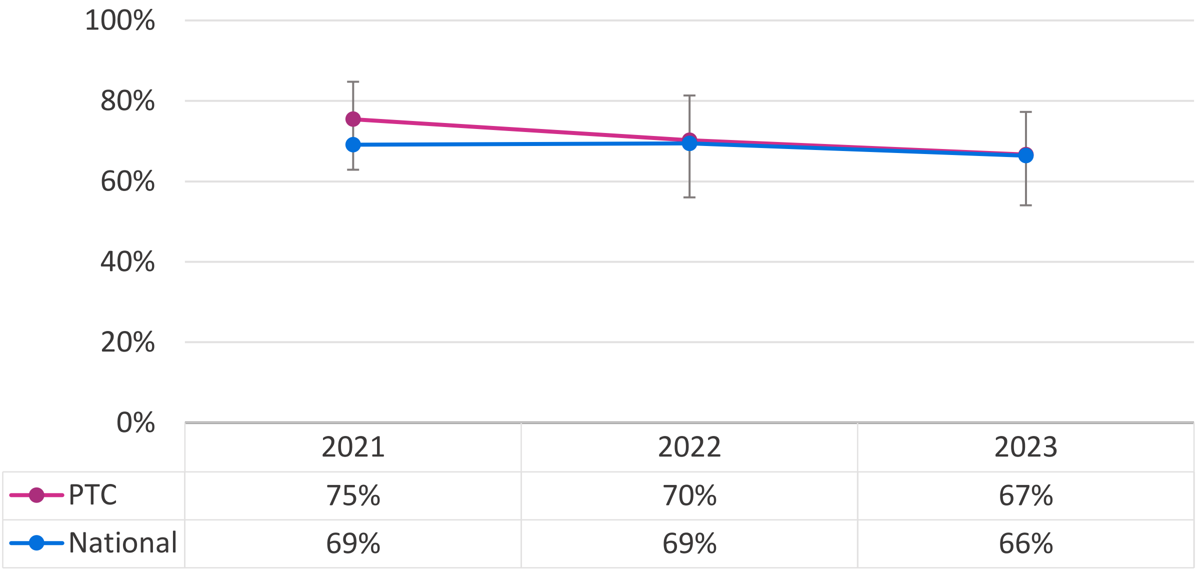


	2021	2022	2023
PTC	82%	72%	78%
National	80%	78%	76%

Question X22: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 51, for 2022 = 50, for 2023 = 54.

Healthcare staff

Figure 62: Parents or carers felt they had enough information about financial help or benefits

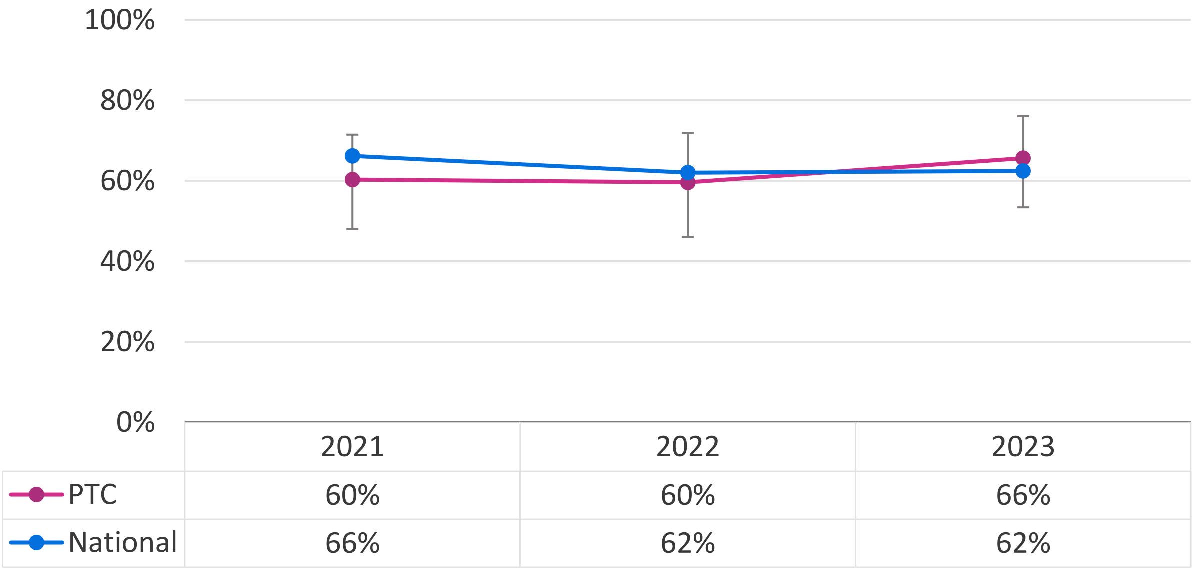


	2021	2022	2023
PTC	75%	70%	67%
National	69%	69%	66%

Question X25: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 57, for 2022 = 47, for 2023 = 60.

Child's care and treatment

Figure 63: Parents or carers felt that different hospital staff always worked well together

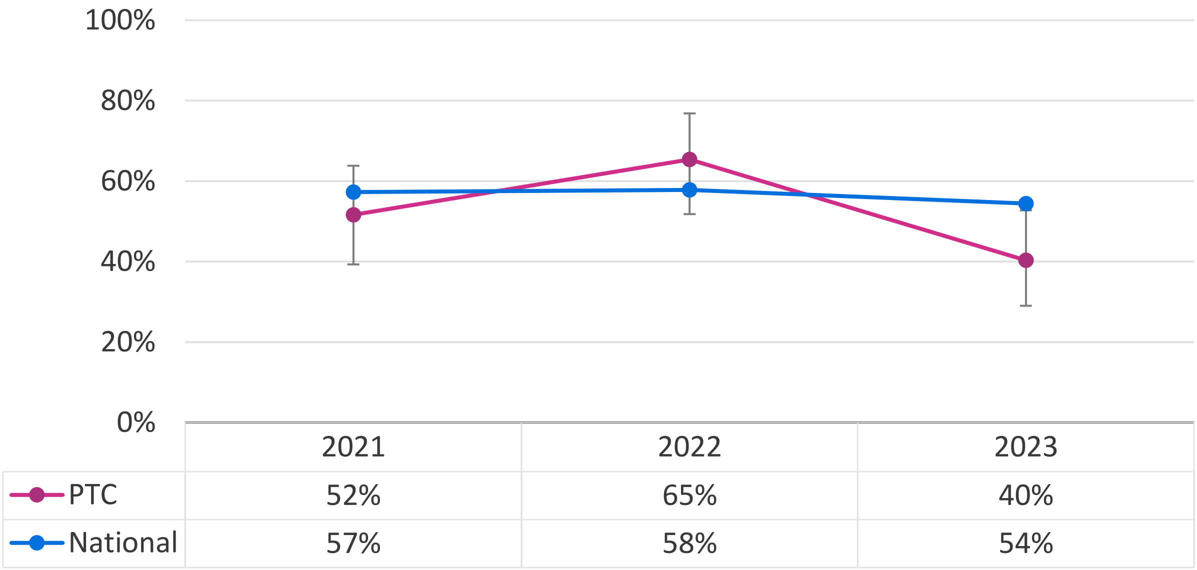


	2021	2022	2023
PTC	60%	60%	66%
National	66%	62%	62%

Question X26: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 63, for 2022 = 52, for 2023 = 64.

Child's care and treatment

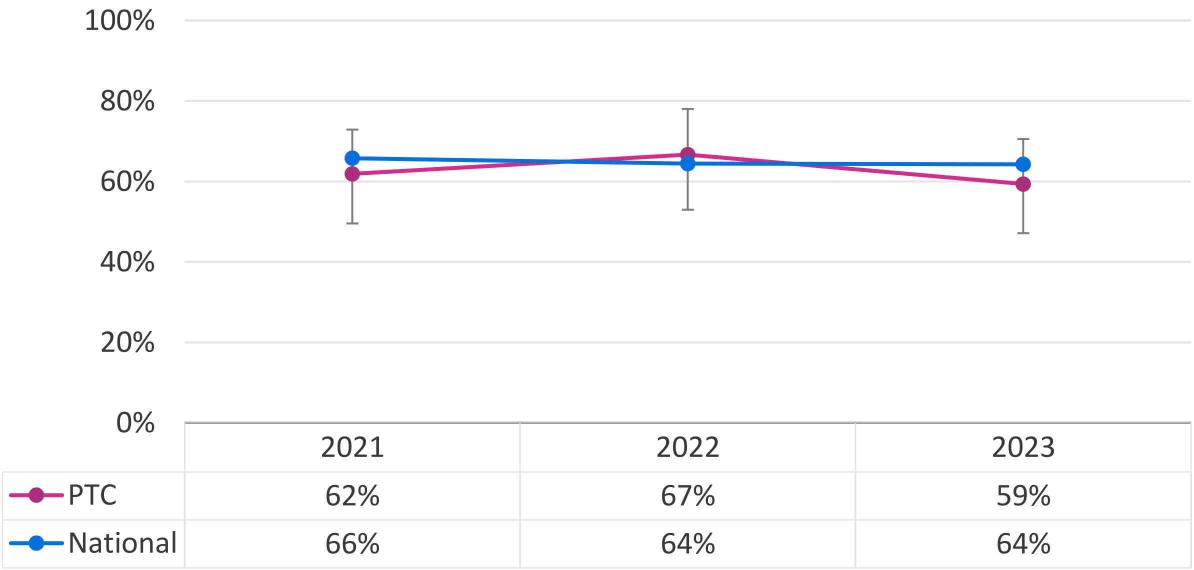
Figure 64: Parents or carers felt that different hospital staff were definitely aware of their child's medical history



	2021	2022	2023
PTC	52%	65%	40%
National	57%	58%	54%

Question X27: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 60, for 2022 = 52, for 2023 = 62.

Figure 65: Parents, carers, and children felt they always knew what was happening with their child's or their care

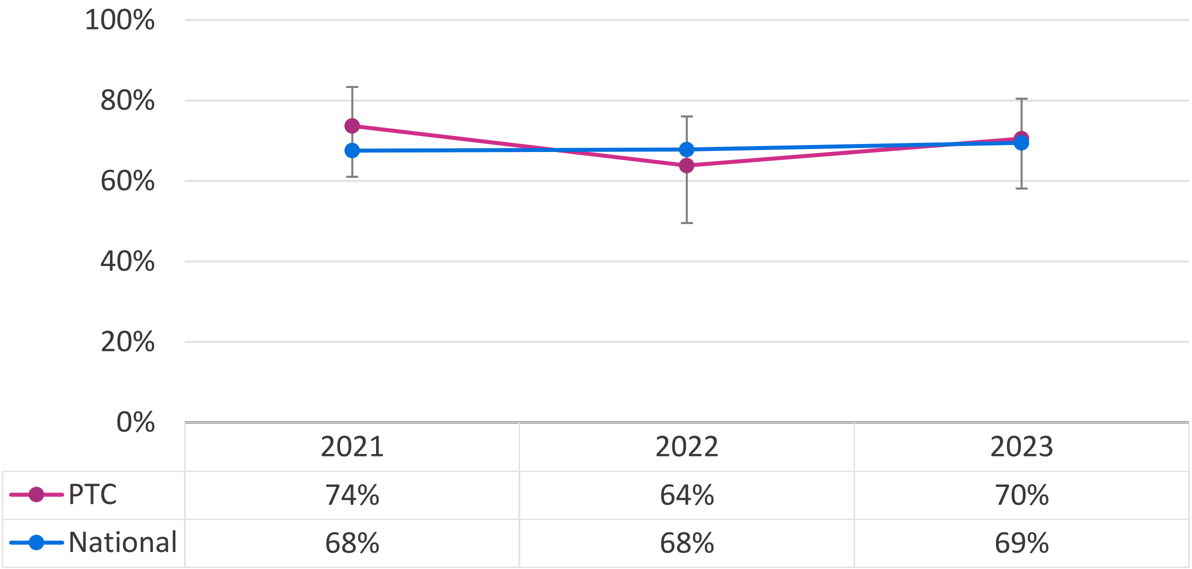


	2021	2022	2023
PTC	62%	67%	59%
National	66%	64%	64%

Question X28: Asked to parents or carers of 0-7s and all children aged 8-15. Total PTC responses for 2021 = 63, for 2022 = 51, for 2023 = 64.

Child's care and treatment

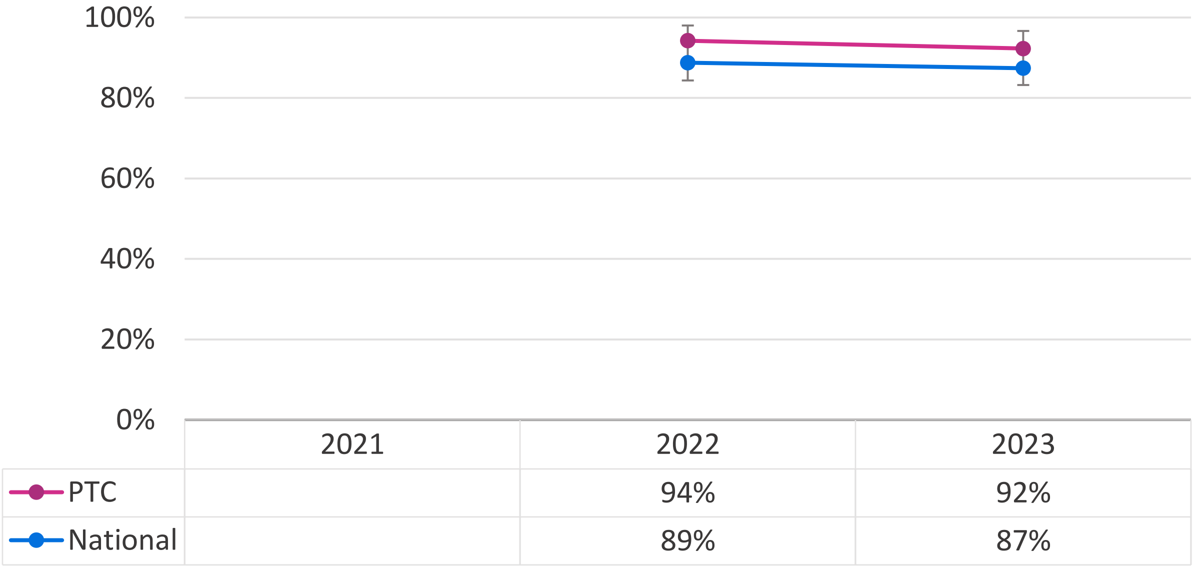
Figure 66: Parents, carers, and children felt they were definitely involved in their child's or their care and treatment



	2021	2022	2023
PTC	74%	64%	70%
National	68%	68%	69%

Question X29: Asked to parents or carers of 0-7s and all children aged 8-15 . Total PTC responses for 2021 = 57, for 2022 = 47, for 2023 = 61.

Figure 67: Parents or carers reported that there was a main person in the team looking after their child that they could contact about their care or treatment

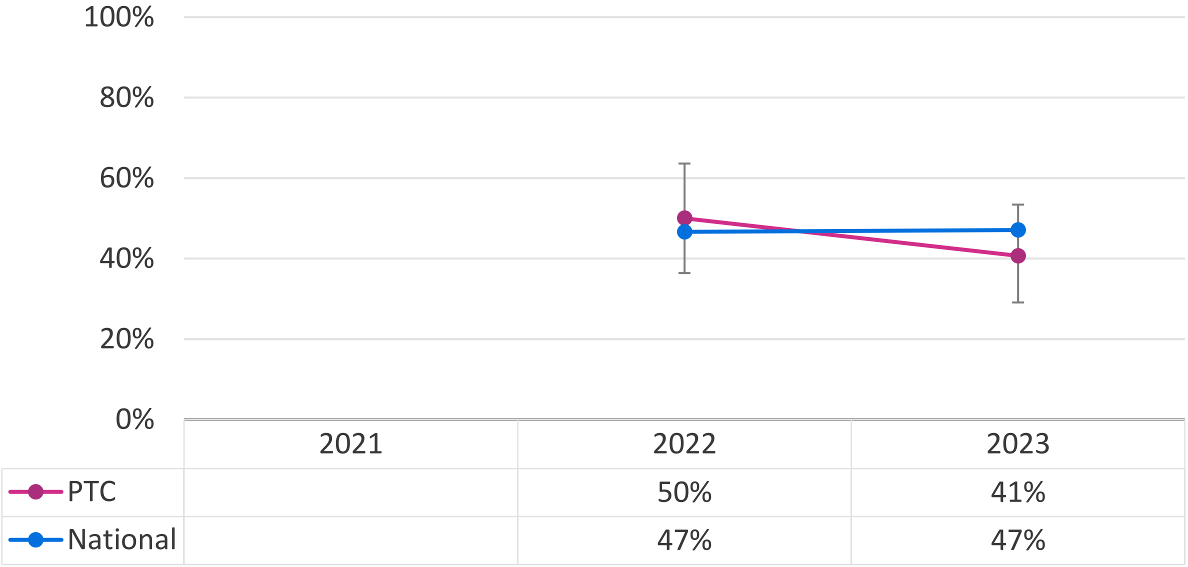


	2021	2022	2023
PTC		94%	92%
National		89%	87%

Question X31: Asked to parents or carers of all age groups. Total PTC responses for 2022 = 52, for 2023 = 65.

Child's care and treatment

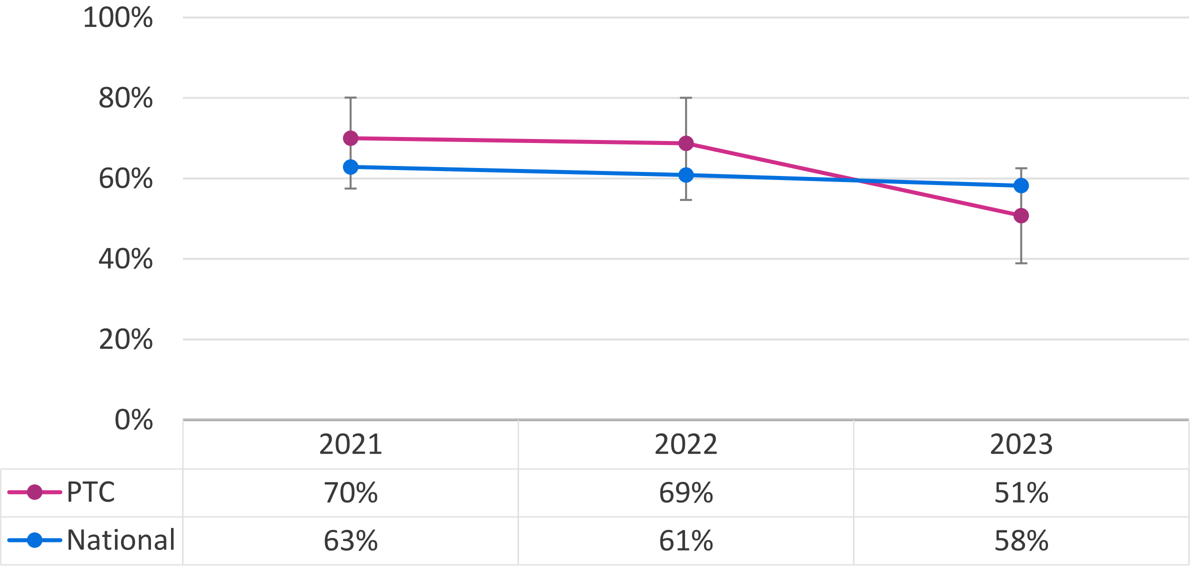
Figure 68: Parents or carers reported that it was very easy to contact the main person in the team looking after their child



	2021	2022	2023
PTC		50%	41%
National		47%	47%

Question X32[†]: Asked to parents or carers of all age groups who could contact the main person looking after their child if needed. Total PTC responses for 2022 = 48, for 2023 = 59.

Figure 69: Parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital



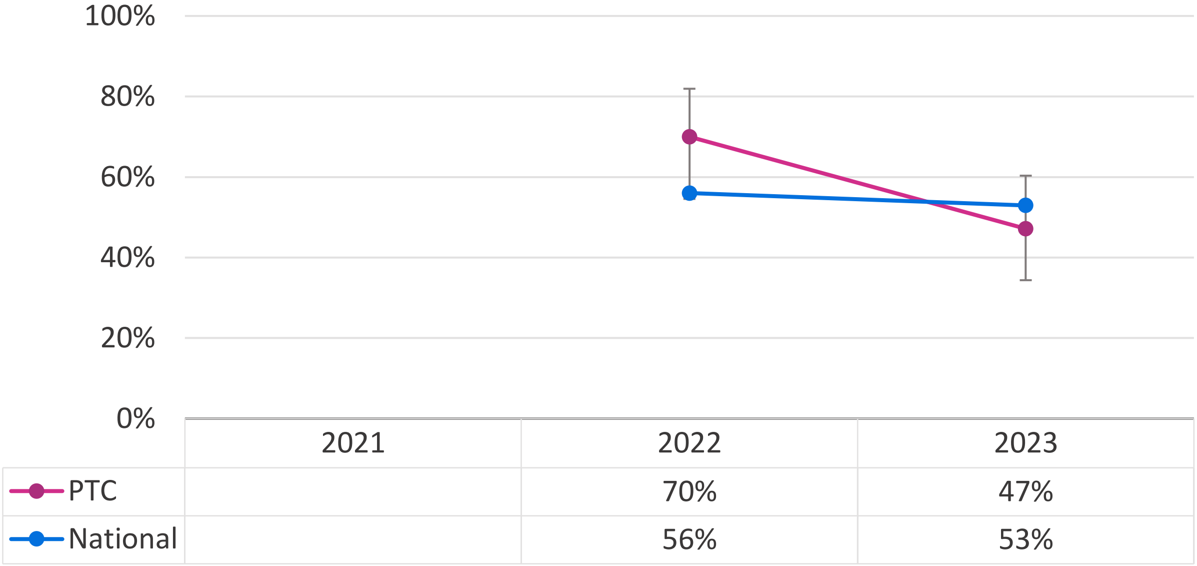
	2021	2022	2023
PTC	70%	69%	51%
National	63%	61%	58%

Question X33: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 60, for 2022 = 48, for 2023 = 65.

[†] Due to changes in scoring X32, the 2022 score has been recalculated and so scores from published 2022 reports will not be comparable to this year's results.

Child's care and treatment

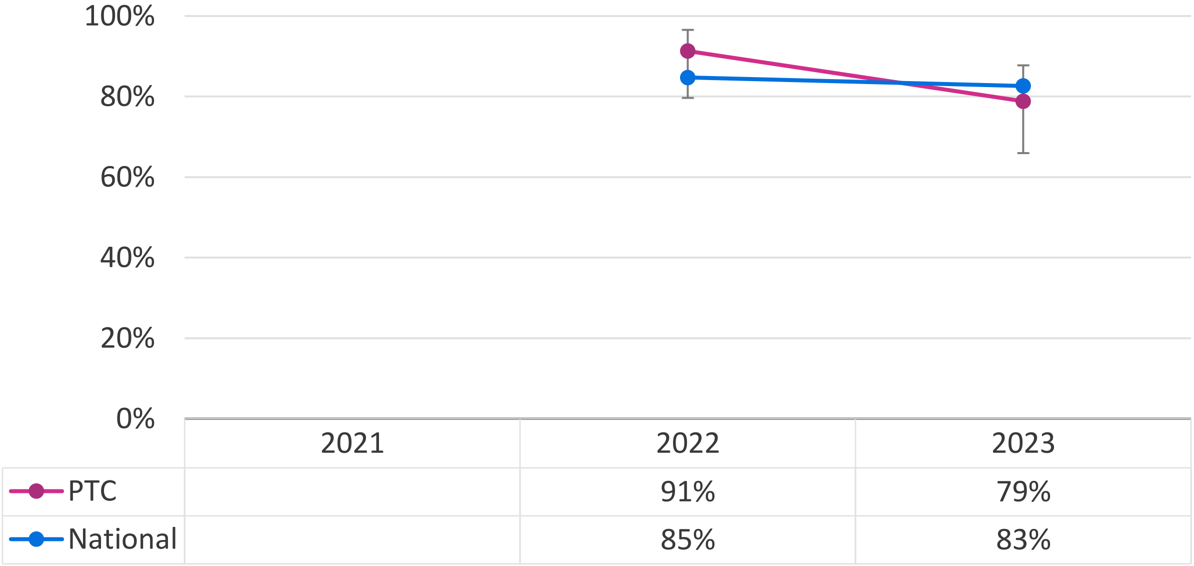
Figure 70: Parents or carers reported that their child's care and treatment was definitely offered at a time suitable for them and their family



	2021	2022	2023
PTC		70%	47%
National		56%	53%

Question X34: Asked to parents or carers of all age groups. Total PTC responses for 2022 = 40, for 2023 = 53.

Figure 71: Parents or carers reported that they were definitely offered clear information about their child's treatment

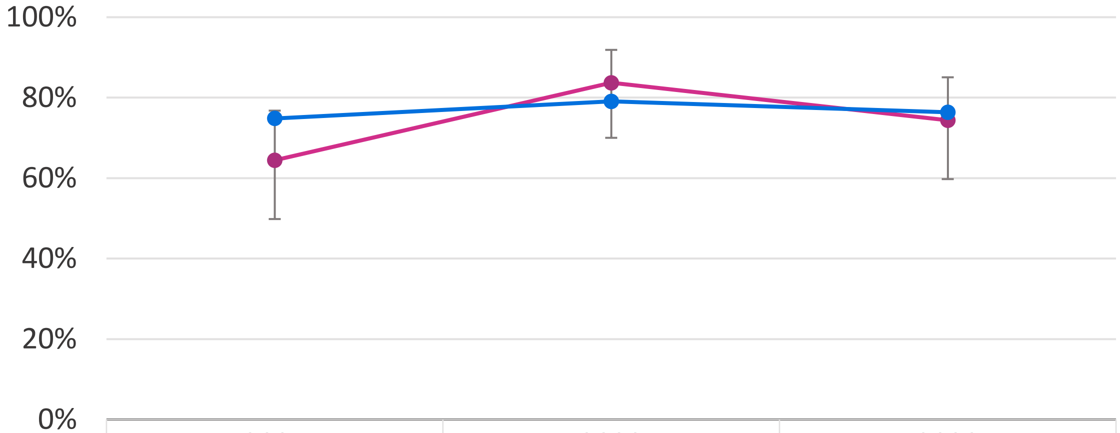


	2021	2022	2023
PTC		91%	79%
National		85%	83%

Question X36: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2022 = 46, for 2023 = 52.

Child's care and treatment

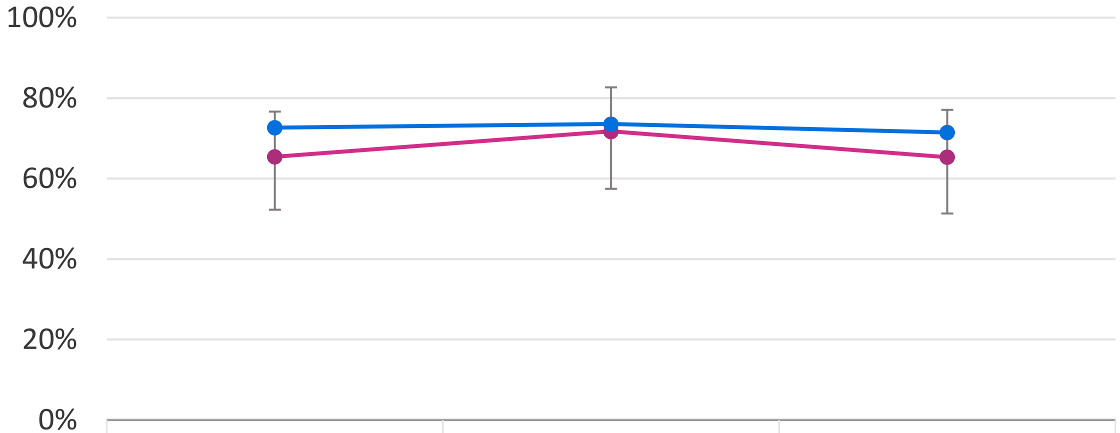
Figure 72: Parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment



	2021	2022	2023
PTC	64%	84%	74%
National	75%	79%	76%

Question X37: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = 45, for 2022 = 43, for 2023 = 43.

Figure 73: Parents or carers reported that staff definitely offered them support to help manage their child's treatment side effects

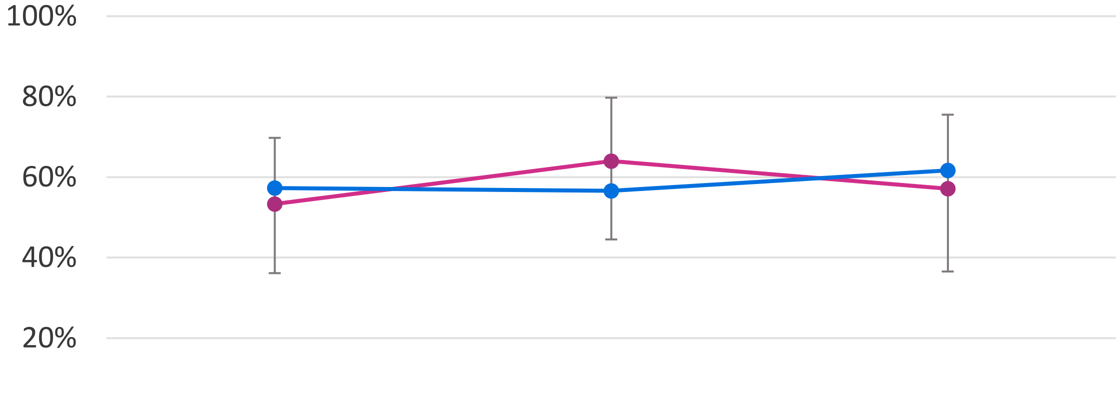


	2021	2022	2023
PTC	65%	72%	65%
National	73%	74%	71%

Question X38: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = 55, for 2022 = 46, for 2023 = 49.

Care in hospital

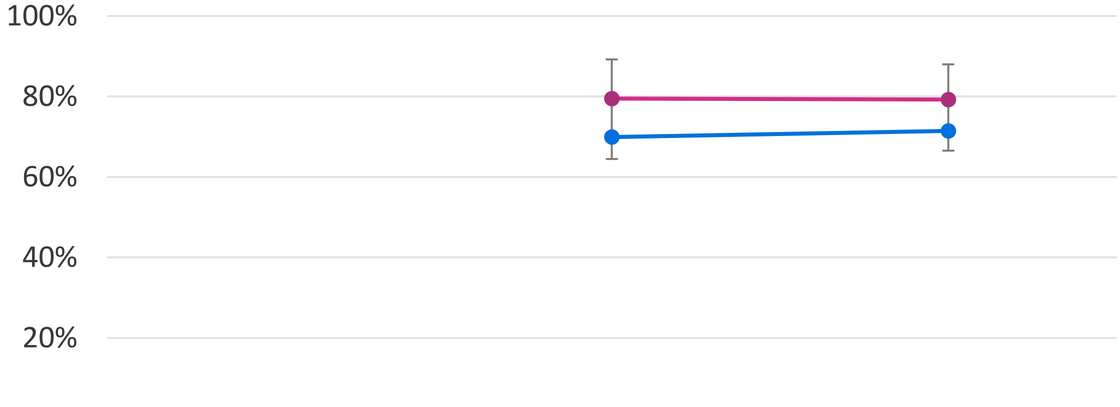
Figure 74: Parents or carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended



	2021	2022	2023
PTC	53%	64%	57%
National	57%	57%	62%

Question X39: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = 30, for 2022 = 25, for 2023 = 21.

Figure 75: Parents, carers, and children felt that their child or they were always able to get help from staff on the hospital ward when they needed it

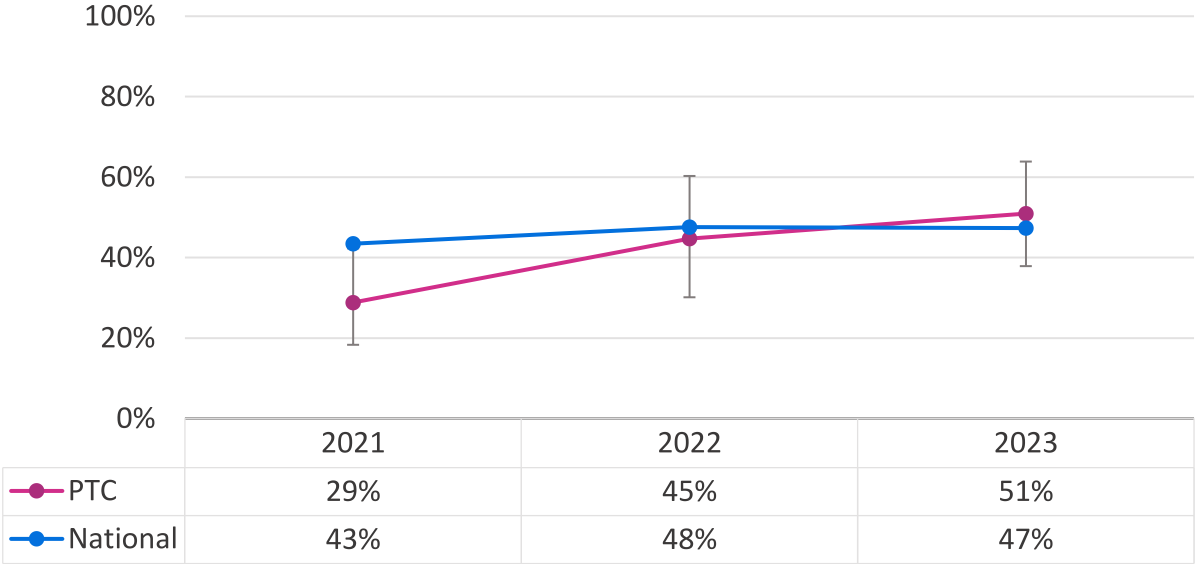


	2021	2022	2023
PTC		79%	79%
National		70%	71%

Question X42: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who have stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total PTC responses for 2022 = 39, for 2023 = 53.

Care in hospital

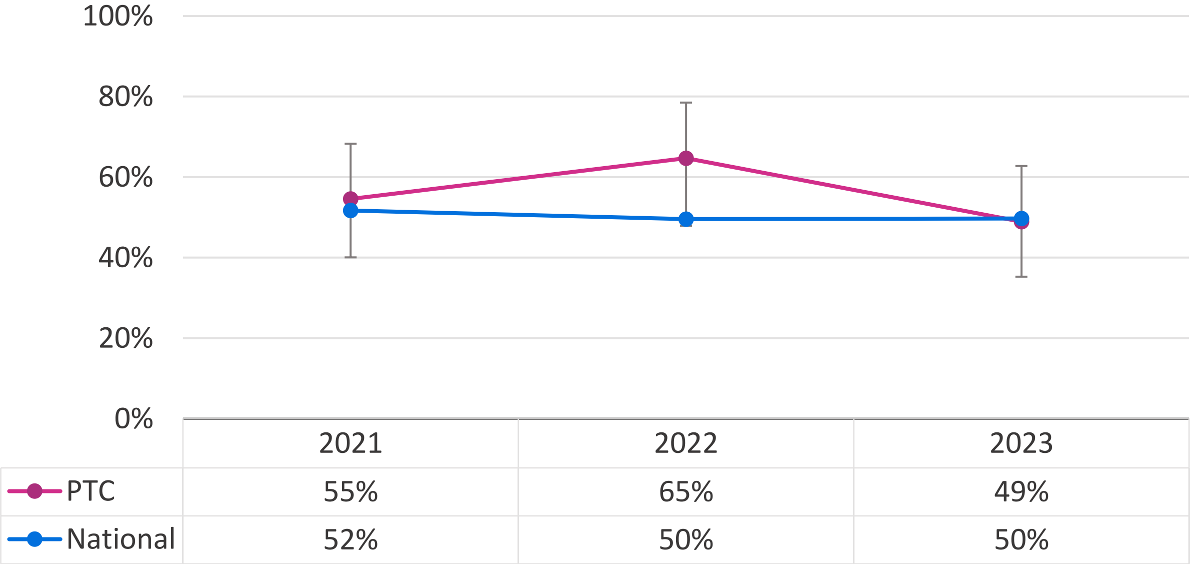
Figure 76: Parents, carers, and children felt that there were definitely enough things for their child to do in the hospital



	2021	2022	2023
PTC	29%	45%	51%
National	43%	48%	47%

Question X43: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total PTC responses for 2021 = 52, for 2022 = 38, for 2023 = 53.

Figure 77: Parents, carers, and children reported always being given somewhere private to talk to staff when their child was in hospital

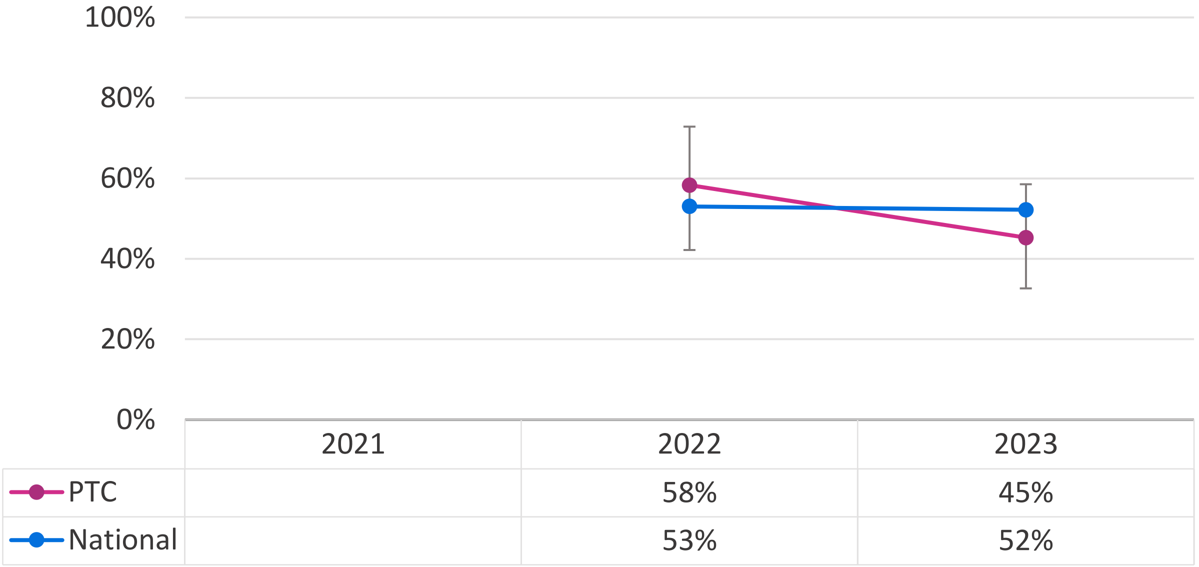


	2021	2022	2023
PTC	55%	65%	49%
National	52%	50%	50%

Question X45: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total PTC responses for 2021 = 44, for 2022 = 34, for 2023 = 47.

Care in hospital

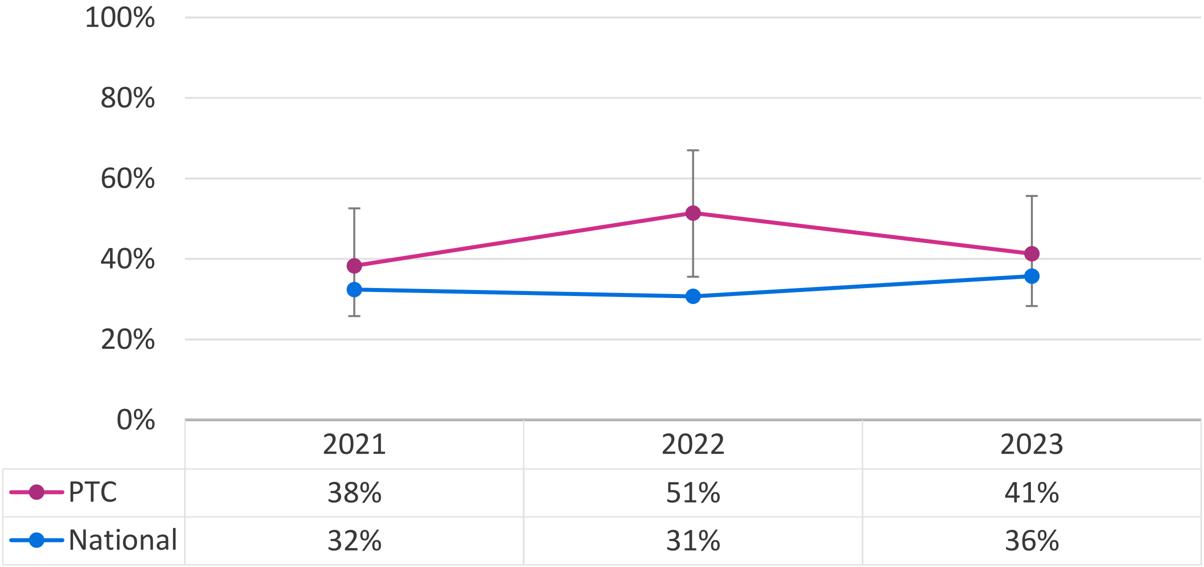
Figure 78: Parents or carers reported that the hospital always offered play specialist support when they needed it



	2021	2022	2023
PTC		58%	45%
National		53%	52%

Question X46: Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total PTC responses for 2022 = 36, for 2023 = 53.

Figure 79: Parents or carers reported that facilities for them to stay overnight were very good

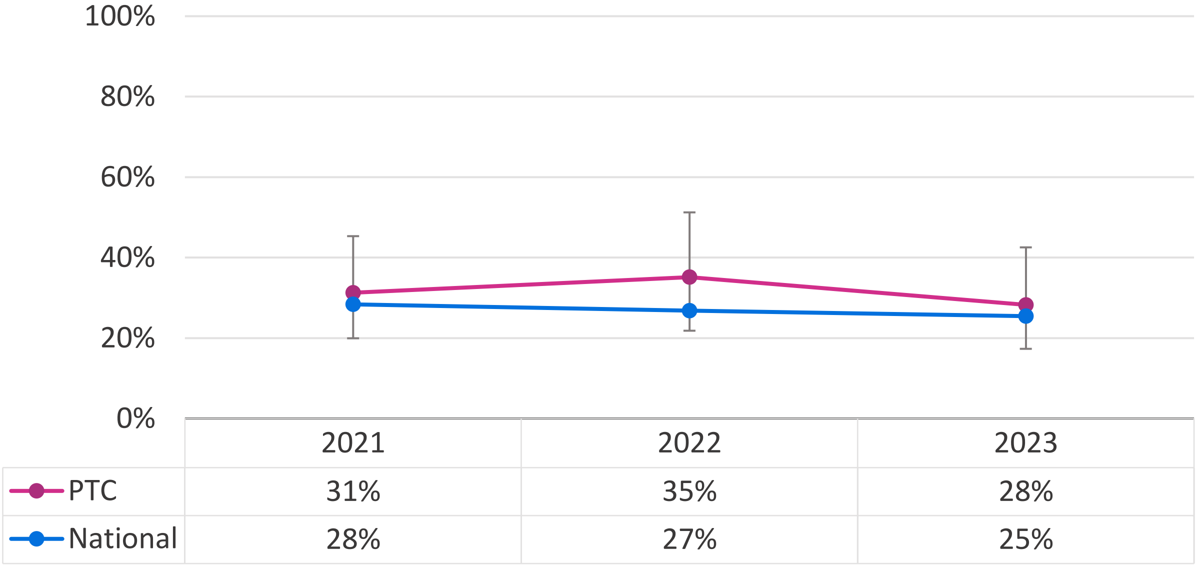


	2021	2022	2023
PTC	38%	51%	41%
National	32%	31%	36%

Question X48: Asked to parents or carers of all age groups whose children stayed in hospital and who stayed overnight with them (receiving treatment or care in the daytime, or for an overnight stay). Total PTC responses for 2021 = 47, for 2022 = 35, for 2023 = 46.

Care in hospital

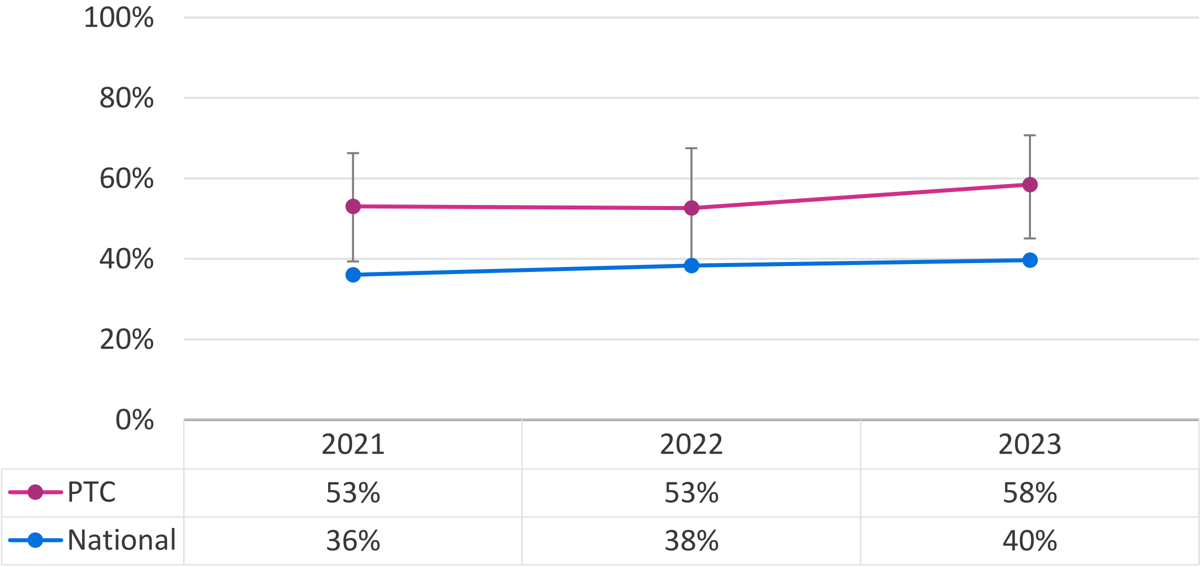
Figure 80: Parents, carers, and children reported that it was always quiet enough for them to sleep in the hospital



	2021	2022	2023
PTC	31%	35%	28%
National	28%	27%	25%

Question X49: Asked to parents or carers of children aged 0-7 whose children stayed in hospital and who stayed overnight with them, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total PTC responses for 2021 = 48, for 2022 = 37, for 2023 = 46.

Figure 81: Parents or carers reported they were definitely able to prepare food in the hospital if they wanted to

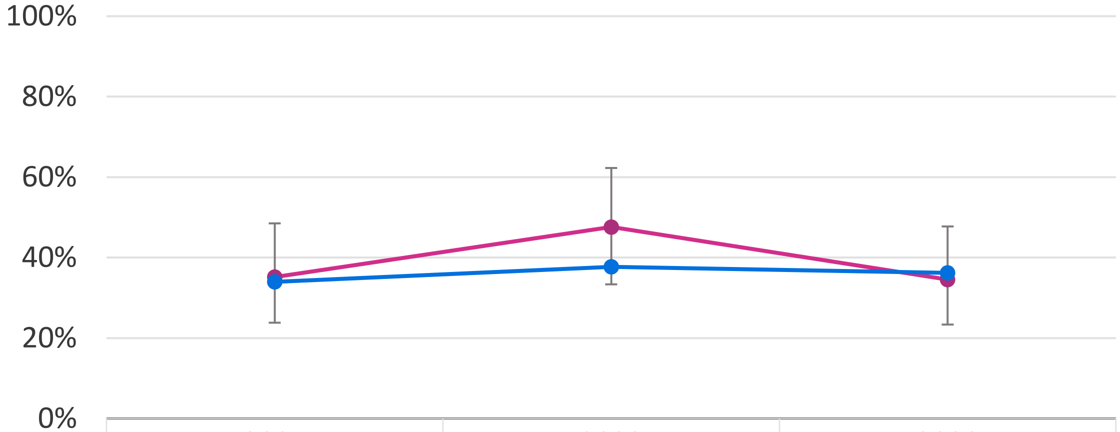


	2021	2022	2023
PTC	53%	53%	58%
National	36%	38%	40%

Question X50: Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total PTC responses for 2021 = 49, for 2022 = 38, for 2023 = 53.

Care in hospital

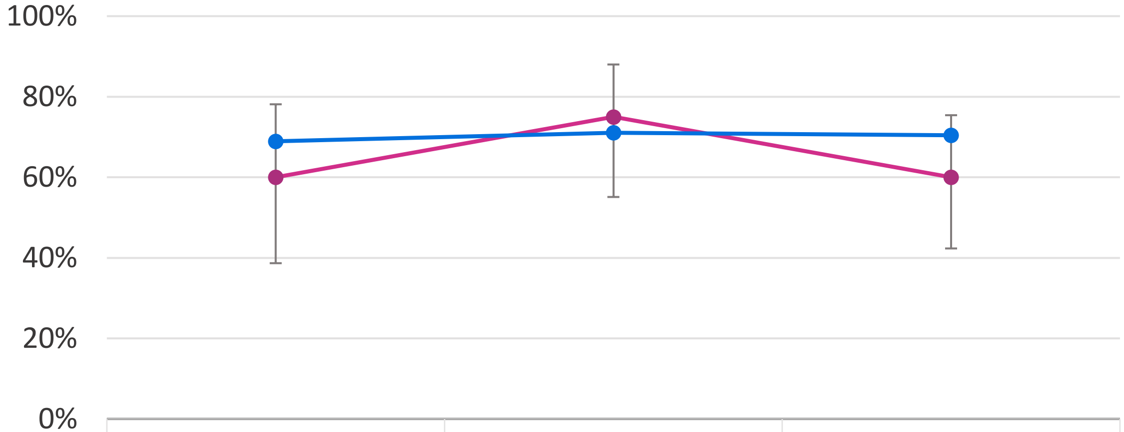
Figure 82: Parents or carers felt that the hospital Wi-Fi always met the needs of them and their child



	2021	2022	2023
PTC	35%	48%	35%
National	34%	38%	36%

Question X51: Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total PTC responses for 2021 = 54, for 2022 = 42, for 2023 = 55.

Figure 83: Parents or carers reported that their child had access to hospital school services during their stay in hospital

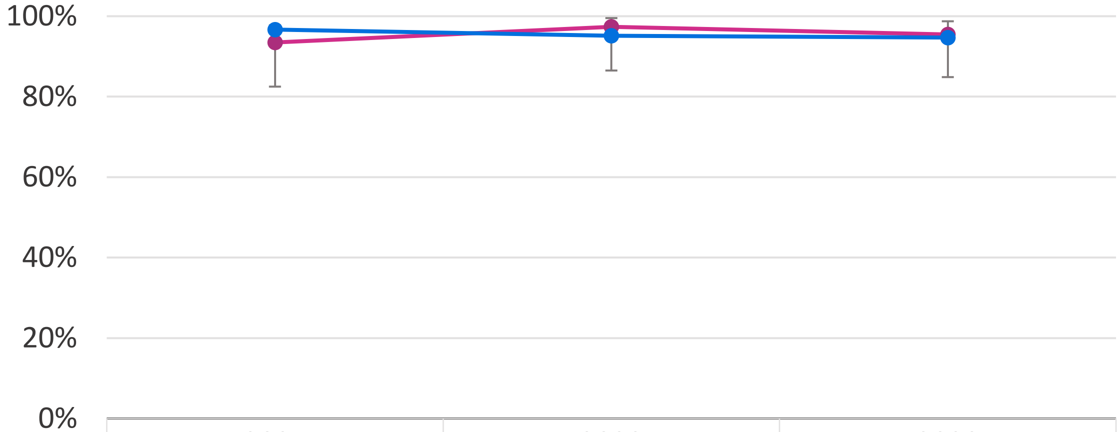


	2021	2022	2023
PTC	60%	75%	60%
National	69%	71%	70%

Question X52: Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total PTC responses for 2021 = 20, for 2022 = 24, for 2023 = 30.

Care at home or at school

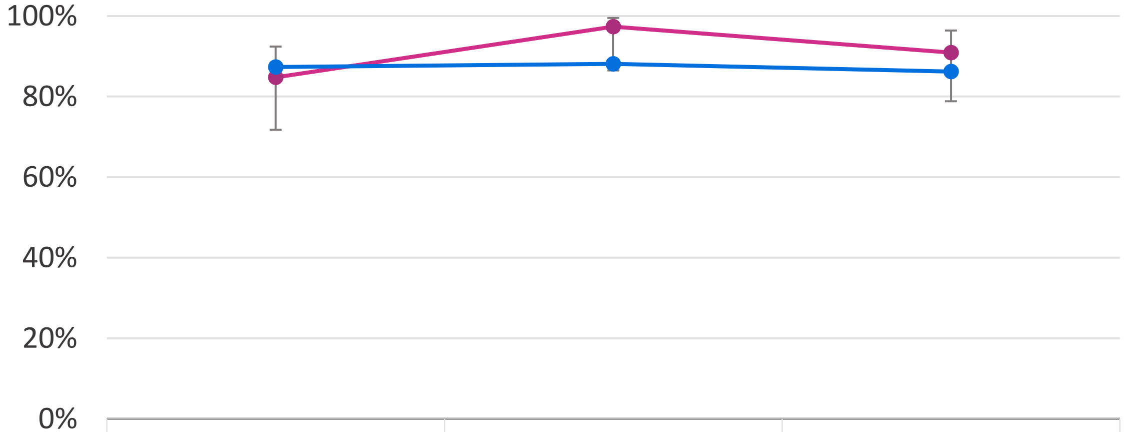
Figure 84: Parents, carers, and children felt that the nurses who came to their home or school were always friendly



	2021	2022	2023
PTC	93%	97%	95%
National	97%	95%	95%

Question X54: Asked to parents or carers of children aged 0-7 whose children have been visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse. Total PTC responses for 2021 = 46, for 2022 = 38, for 2023 = 44.

Figure 85: Parents, carers, and children reported that they always understood what nurses visiting their home or school were saying

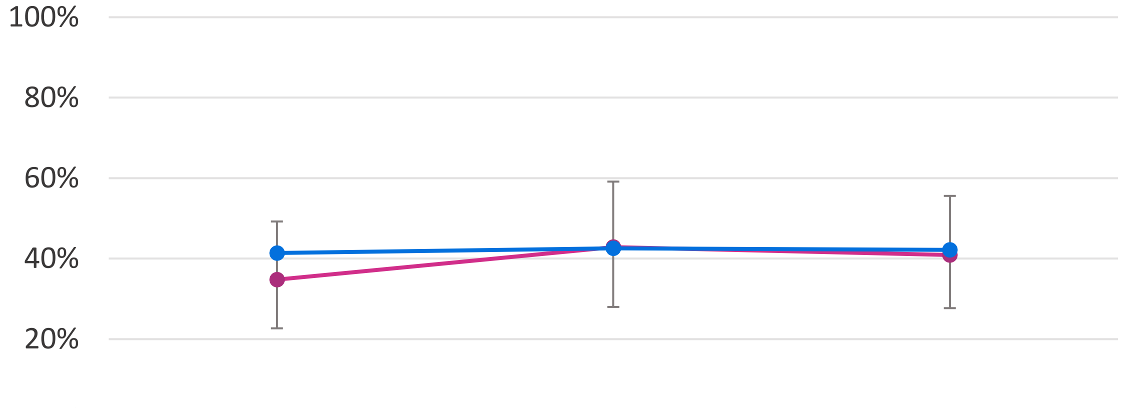


	2021	2022	2023
PTC	85%	97%	91%
National	87%	88%	86%

Question X55: Asked to parents or carers of children aged 0-7 whose child was visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse. Total PTC responses for 2021 = 46, for 2022 = 38, for 2023 = 44.

Care at home or at school

Figure 86: Parents, carers, and children reported that the same nurses always came to their home or school

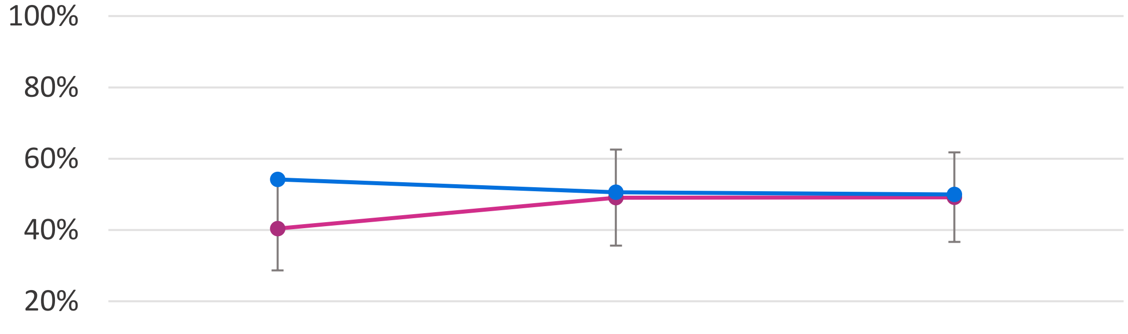


	2021	2022	2023
PTC	35%	43%	41%
National	41%	43%	42%

Question X56: Asked to parents or carers of children aged 0-7 whose child was visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse. Total PTC responses for 2021 = 46, for 2022 = 35, for 2023 = 44.

Overall care

Figure 87: Parents, carers, and children reported that different hospitals providing cancer or tumour care always worked well together

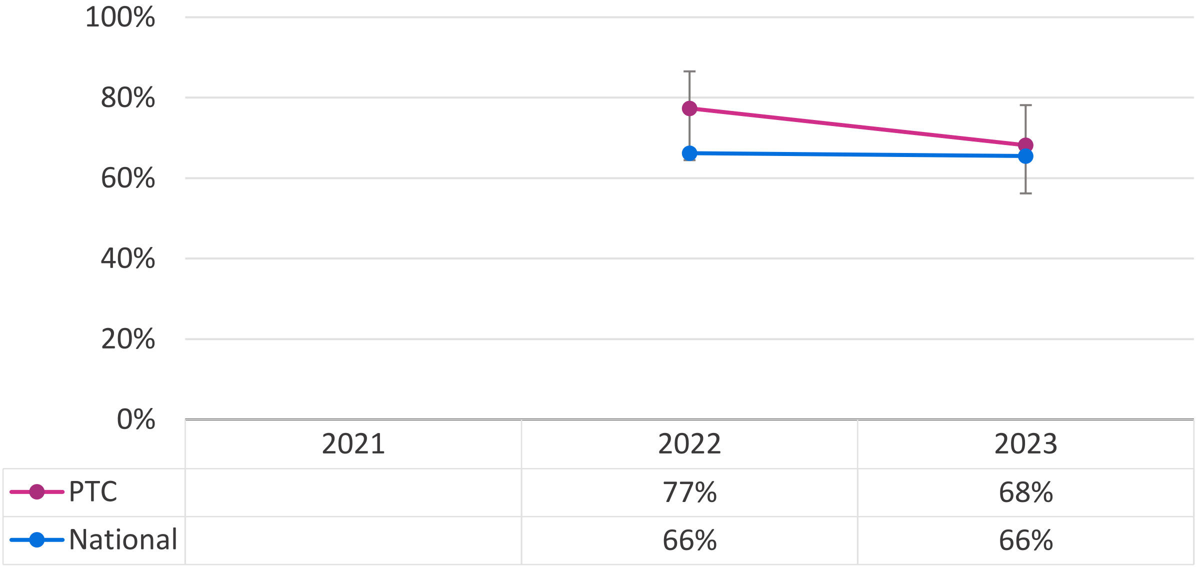


	2021	2022	2023
PTC	40%	49%	49%
National	54%	51%	50%

Question X57: Asked to parents or carers of children aged 0-11, and children aged 12-15. Total PTC responses for 2021 = 57, for 2022 = 49, for 2023 = 57.

Overall care

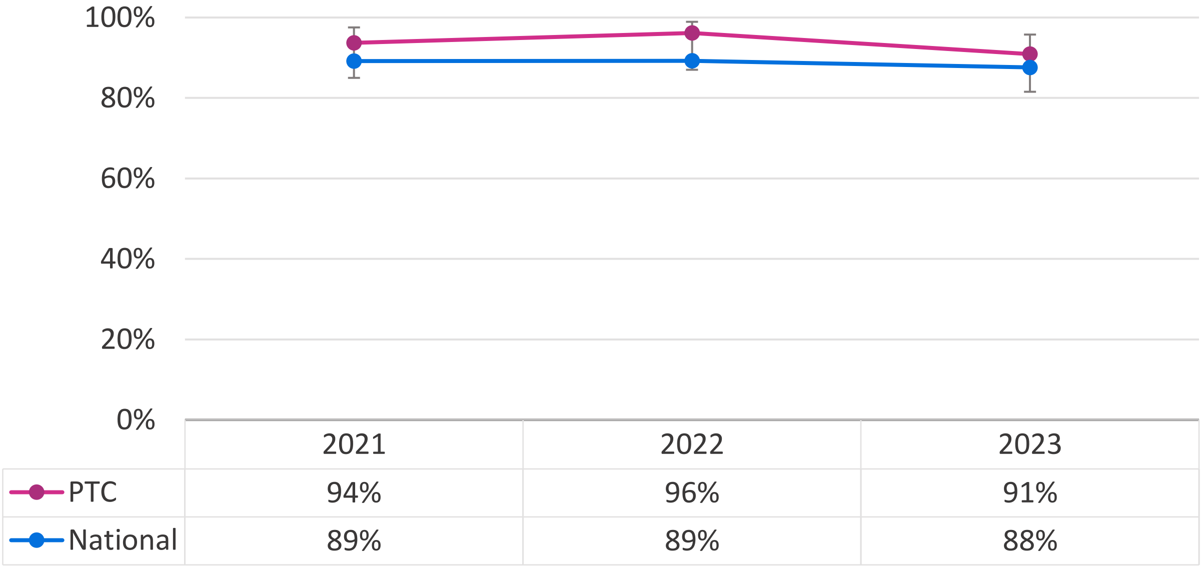
Figure 88: Parents or carers reported that the hospital where their child received most of their care is about or under an hour's travel from their child's home



	2021	2022	2023
PTC		77%	68%
National		66%	66%

Question X58: Asked to parents or carers of all age groups. Total PTC responses for 2022 = 53, for 2023 = 66.

Figure 89: Parents or carers rated the overall experience of their child's care as 8 or more out of 10

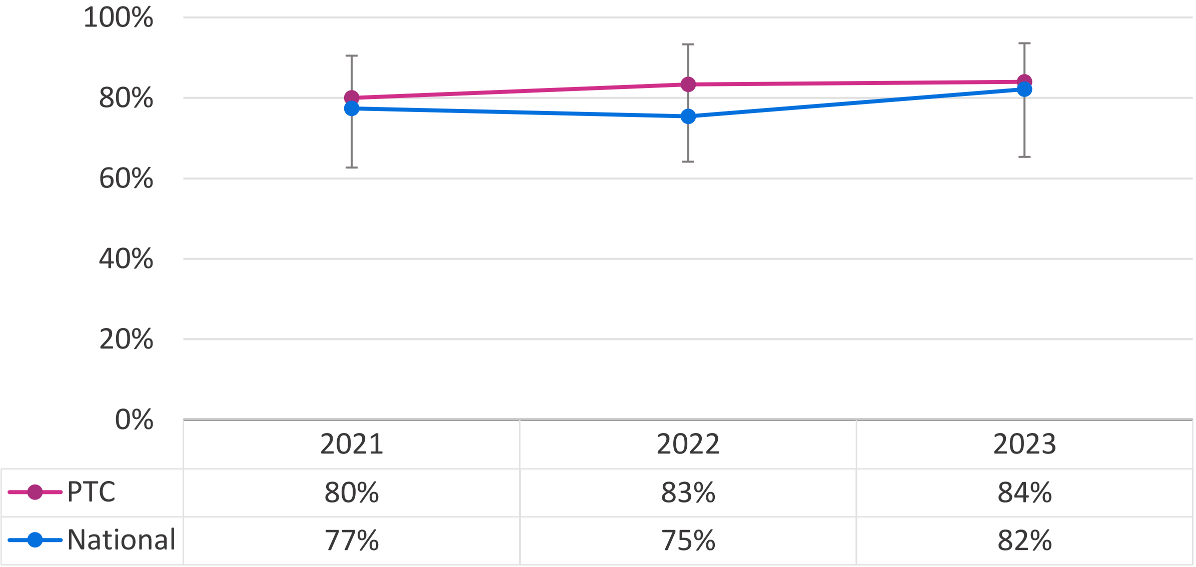


	2021	2022	2023
PTC	94%	96%	91%
National	89%	89%	88%

Question X59: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 64, for 2022 = 52, for 2023 = 66.

Overall care

Figure 90: Children reported that they were very well looked after by staff for their cancer or tumour



	2021	2022	2023
● PTC	80%	83%	84%
● National	77%	75%	82%

Question X60: Asked to all children aged 8-15. Total PTC responses for 2021 = 30, for 2022 = 24, for 2023 = 25.

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.