Under 16 Cancer Patient Experience Survey 2022

Quantitative Results

Sheffield Children's NHS Foundation 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

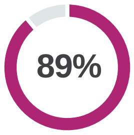
Executive summary

Overall PTC response rate

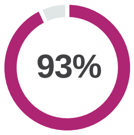
Nationally, 885 responded out of a total of 3,569 eligible parents/carers and children who were sent a survey, resulting in a response rate of 25%. A response consists of one survey completion for a single patient, which could consist of both parent/carer and child responses. The response rate for your PTC is displayed in the table below.

PTC	Original sample size	Adjusted sample size[†]	Completed	Response rate
Sheffield Children's NHS Foundation Trust	154	152	42	28%

Overall PTC care rating



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



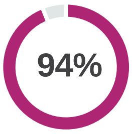
Parents/carers rated the overall experience of their child's care as 8 or more out of 10 (Question X59)

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

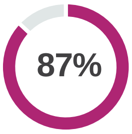
PTC key question scoring

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.

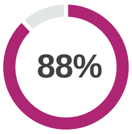
Data for questions in which the base size per question was <10 have been suppressed have been replaced with an asterisk (*). Please refer to the 'Suppression' section of this report for further details.



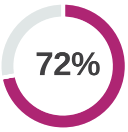
Parents/carers reported that they were offered clear information about their child's treatment
(Question X36)



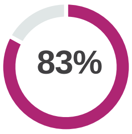
Parents/carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way
(Question X07)



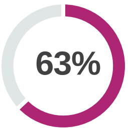
Parents/carers felt they always had confidence and trust in staff caring for their child
(Question X18)



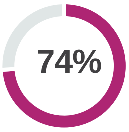
Children reported that they could always understand what staff were saying
(Question X13)



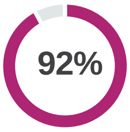
Parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment
(Question X37)



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



Parents/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 2022 findings for Sheffield Children's 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/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/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 2022 and 31 December 2022, and were aged under 16 at the time of their discharge[†].

The fieldwork for the survey was undertaken between April and June 2023. 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 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 2023) 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 also 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 2022. 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 and 2022 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 2022 scores that are not comparable to 2021 are not presented in this section and can be found in the data tables on the survey website.

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

EXAMPLE DATA ONLY

Please take care in interpreting comparisons both against your 2021 data and 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.

Staff definitely offered parents/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	74	37%
	No, but I would have liked this	6	3%
	No, but this was not needed or possible	8	-

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 question numbers used on the surveys themselves.

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 2022 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 2022 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 subgroup 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 subgroup 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 subgroups (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 2022 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	154	152	42	28%

Table 2: Percent of responses by survey mode

	PTC		National	
Survey mode	**n**	**%**	**n**	**%**
Paper	31	74%	617	70%
Online	11	26%	266	30%
Mixed (combination of paper and online)[‡]	0	0%	0	0%
Phone – English	0	0%	2	0%
Phone – Translation service	0	0%	0	0%

Table 3: Percent of responses by survey type

	PTC		National	
Survey	**n**	**%**	**n**	**%**
0-7	22	52%	450	51%
8-11	*	*	185	21%
12-15	*	*	250	28%

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

	PTC		National	
Ethnic group	**n**	**%**	**n**	**%**
White	*	*	658	74%
Mixed	*	*	65	7%
Asian	0	0%	98	11%
Black	0	0%	27	3%
Other ethnic groups	0	0%	15	2%

[†] 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. 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/carer section was completed in one mode and the entire child section was completed in another mode.

Table 5: Percent of responses for '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	8	44%	235	54%
Girl/Female	10	56%	171	39%

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

	PTC		National	
What sex was your child registered at birth?	**n**	**%**	**n**	**%**
Male	21	53%	490	55%
Female	19	48%	371	42%

Table 7: Percent of responses by current care or treatment stage[†] (Question X66)

	PTC		National	
Stage of care	**n**	**%**	**n**	**%**
Recently diagnosed	0	0%	12	1%
Watch and wait	*	*	84	10%
Currently receiving treatment	19	46%	401	46%
Finished treatment within the last one month	*	*	66	8%
In remission / long term follow-up	15	37%	327	37%
Receiving palliative or end of life care	0	0%	7	1%
Other	*	*	49	6%

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

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	19	45%	355	40%
Lymphomas and reticuloendothelial neoplasms	*	*	105	12%
CNS and miscellaneous intracranial and intraspinal neoplasms	10	24%	178	20%
All other	*	*	247	28%

Table 9: Responses by long term condition (Question X65)

	PTC		National	
Long term condition	**n**	**%**	**n**	**%**
Another long term condition	8	19%	188	21%
No other long term condition	32	76%	679	77%
Not given	2	5%	18	2%

Table 10: Responses by main person who answered questions in the children's section (Question X61)

	PTC		National	
Respondent	**n**	**%**	**n**	**%**
The child / young patient	5	12%	178	20%
The parent or carer	6	14%	95	11%
Both the child / young patient and the parent or carer together	7	17%	126	14%
Not given	24	57%	486	55%

Table 11: Responses by IMD quintile[††] (based on Index of Multiple Deprivation (IMD) from postcode in patient sample)

	PTC		National	
IMD quintile	**n**	**%**	**n**	**%**
1 (most deprived)	12	29%	160	18%
2	6	14%	160	18%
3	7	17%	150	17%
4	9	21%	197	22%
5 (least deprived)	8	19%	201	23%
Non-England	0	0%	17	2%

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

[††] 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.

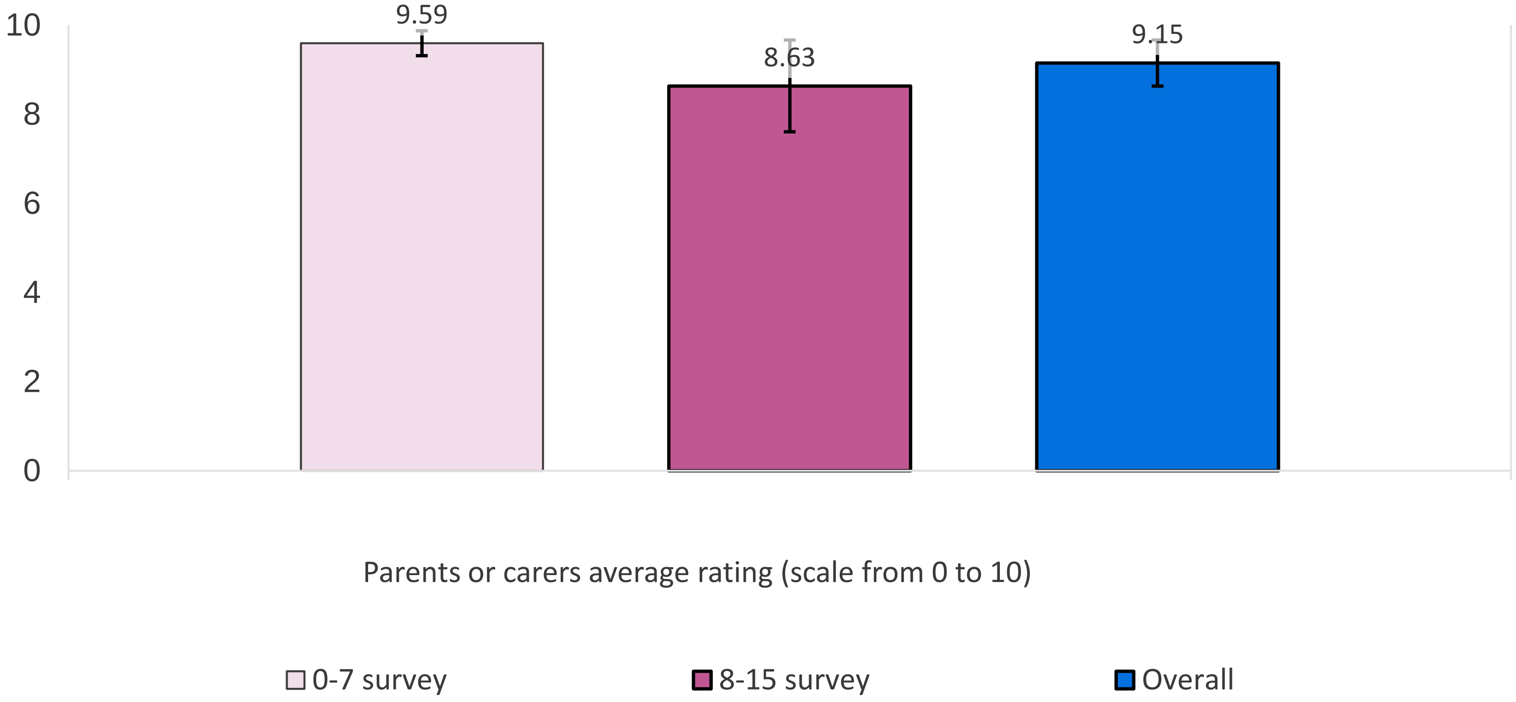
Questions asking about overall care were structured differently for children and parents/carers, therefore they cannot be directly compared. Children aged 8 and over were asked how well they were looked after for their cancer or tumour by healthcare staff and were given the options “Very well,” “Quite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

The average parent/carer rating of the overall experience of their child’s care was 9.15 (scale from 0 to 10).

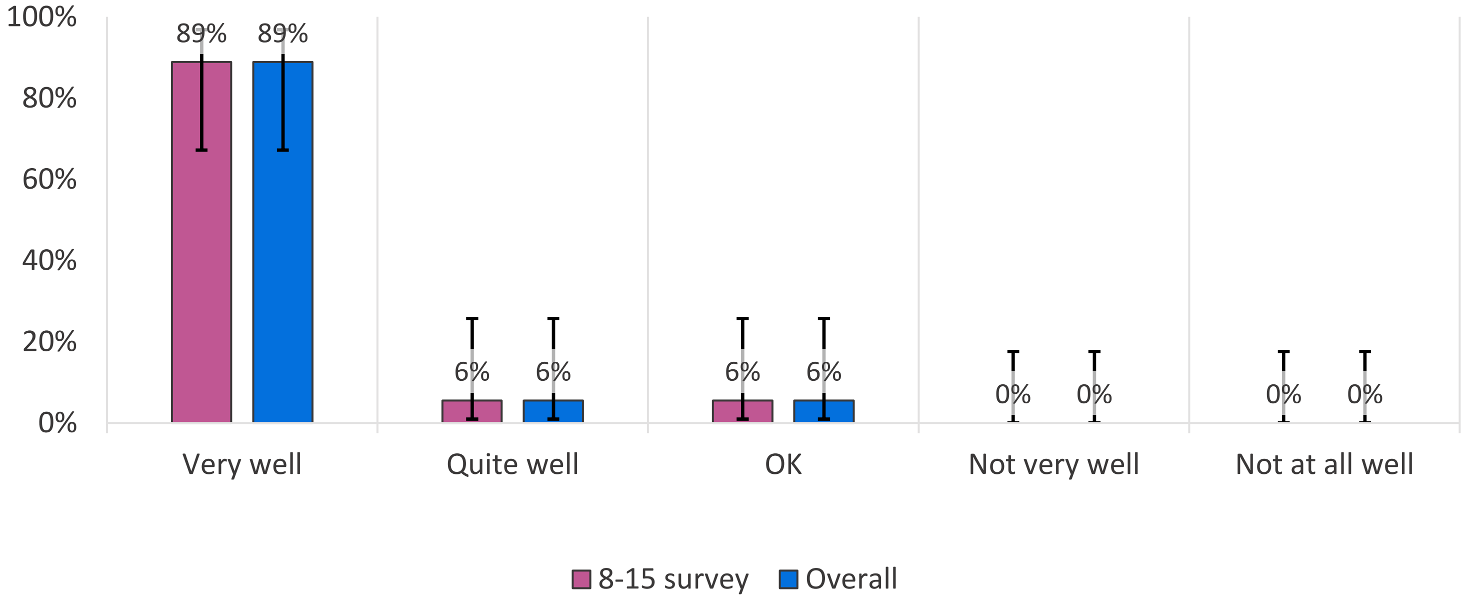
Figure 1. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59_Average: Asked to parents/carers of all age groups. Total responses = 41.

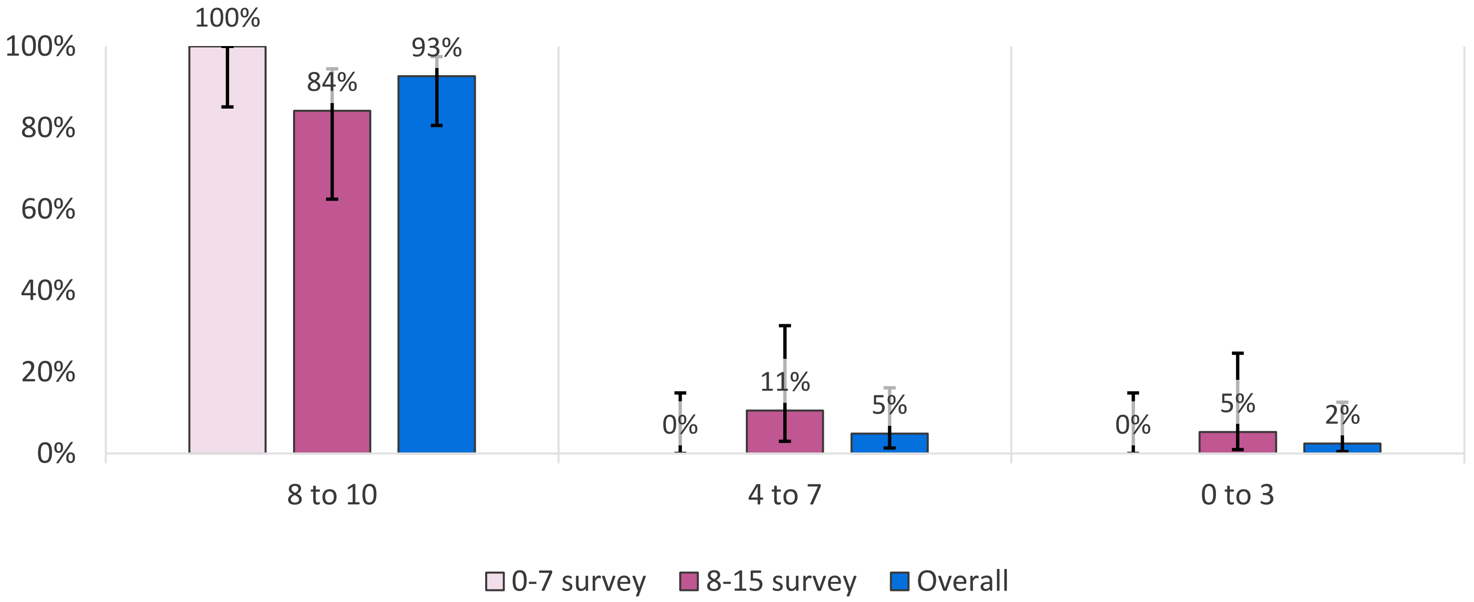
Survey type

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 = 18.

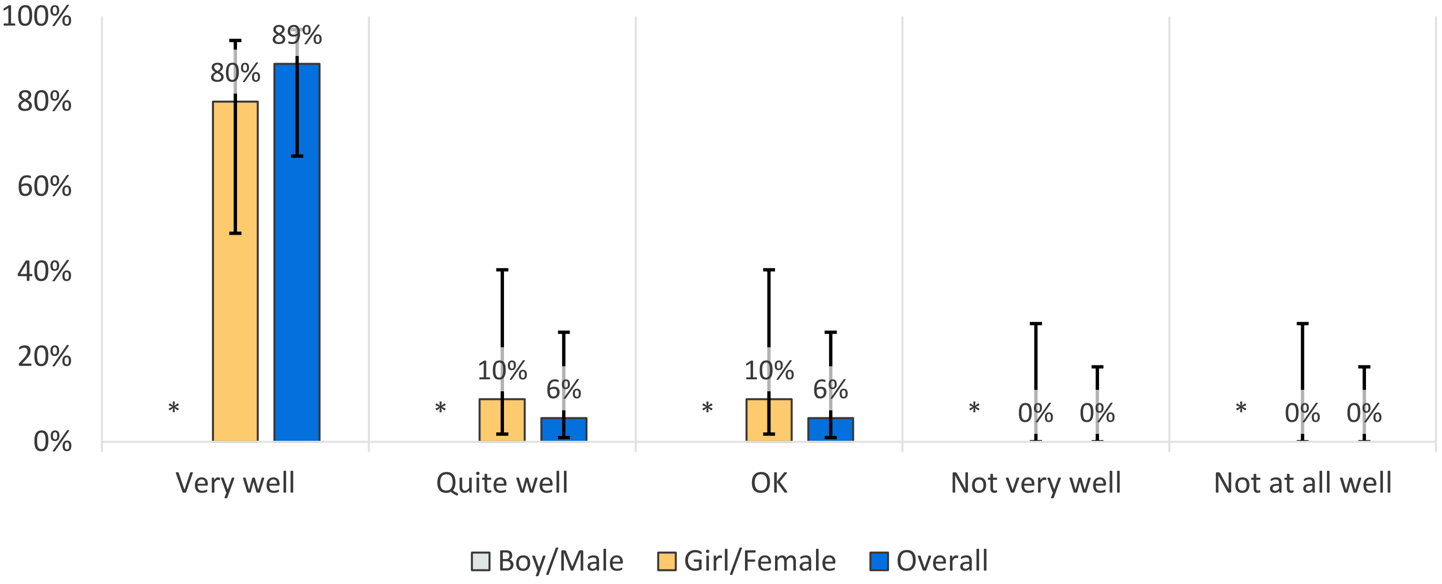
Figure 3. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents/carers of all age groups. Total responses = 41.

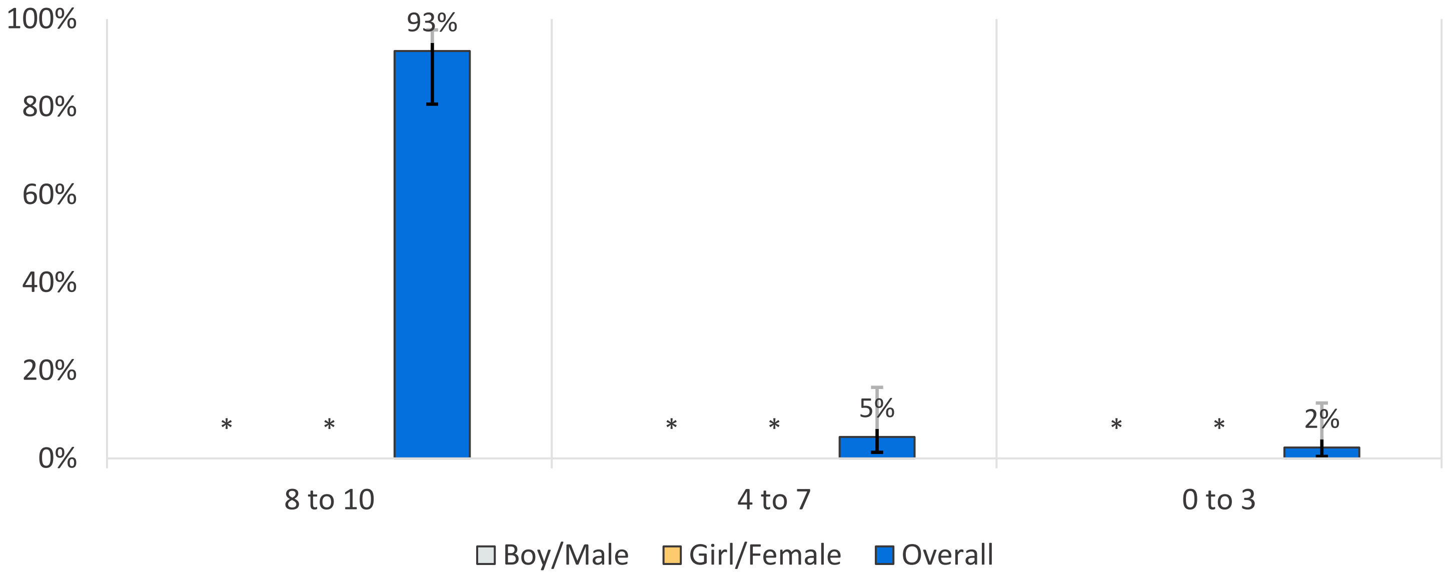
Which of the following best describes you?[†]

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 = 18.

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

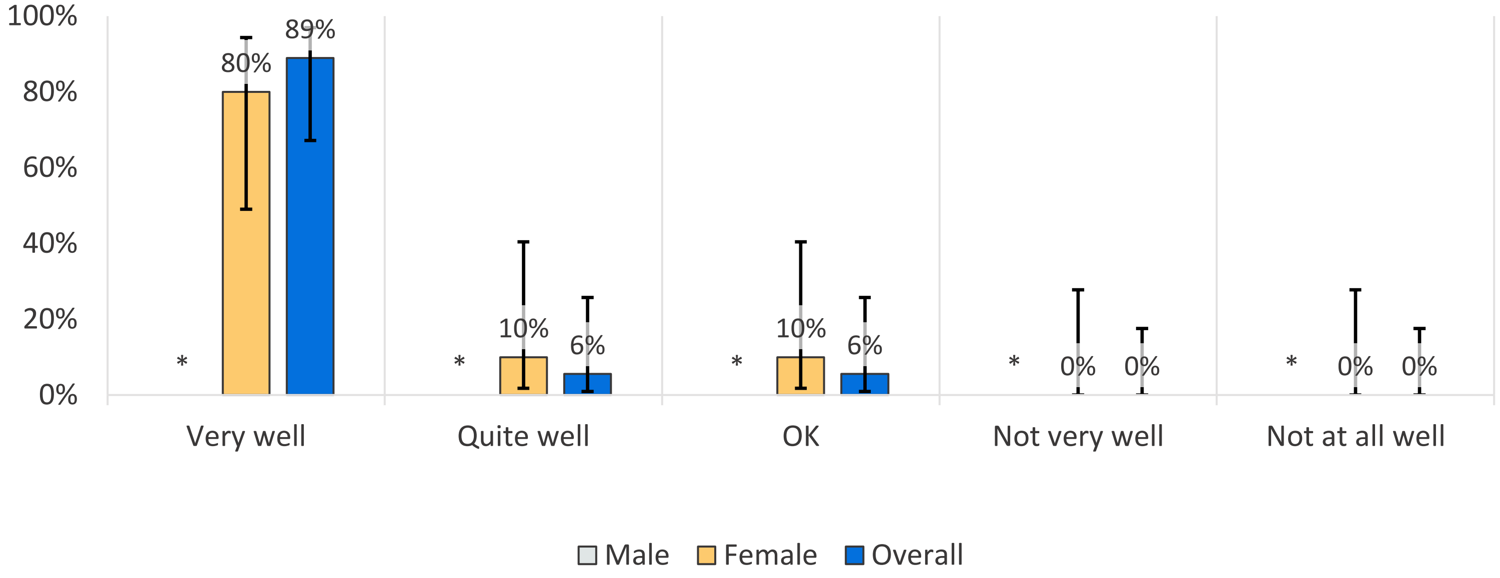


Question X59: Asked to parents/carers of all age groups. Total responses = 41.

[†] 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.

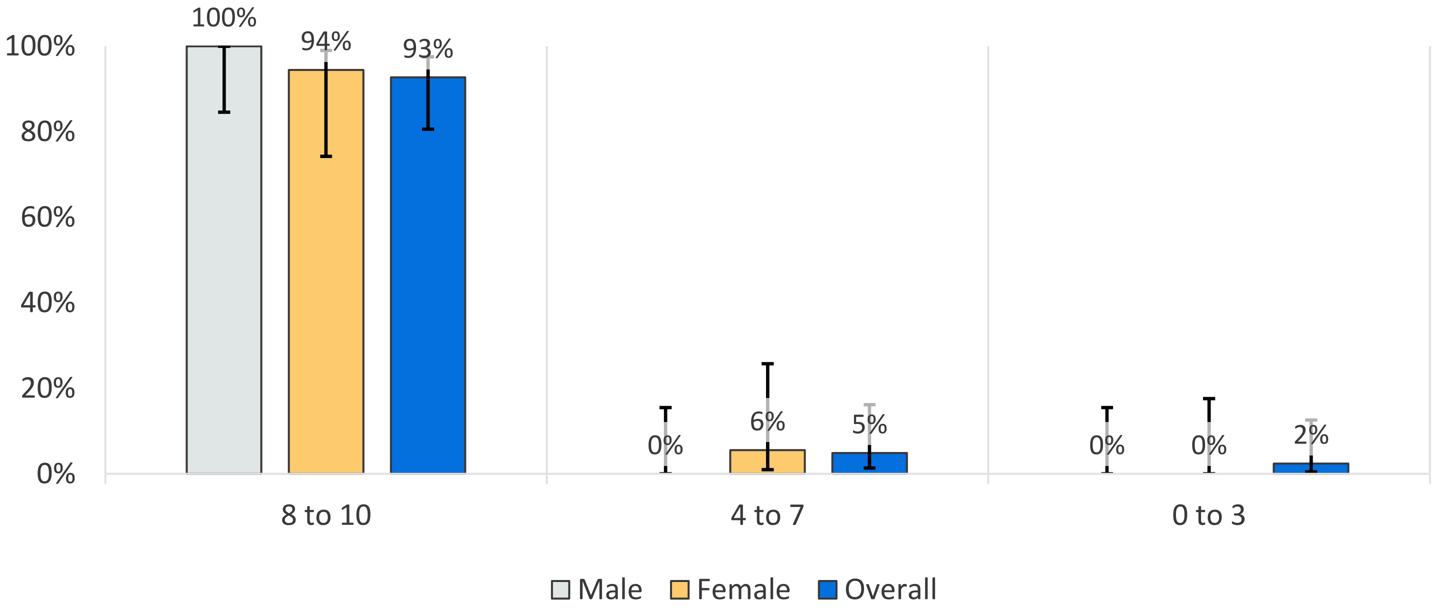
Sex registered at birth†

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 = 18.

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/carers of all age groups. Total responses = 41.

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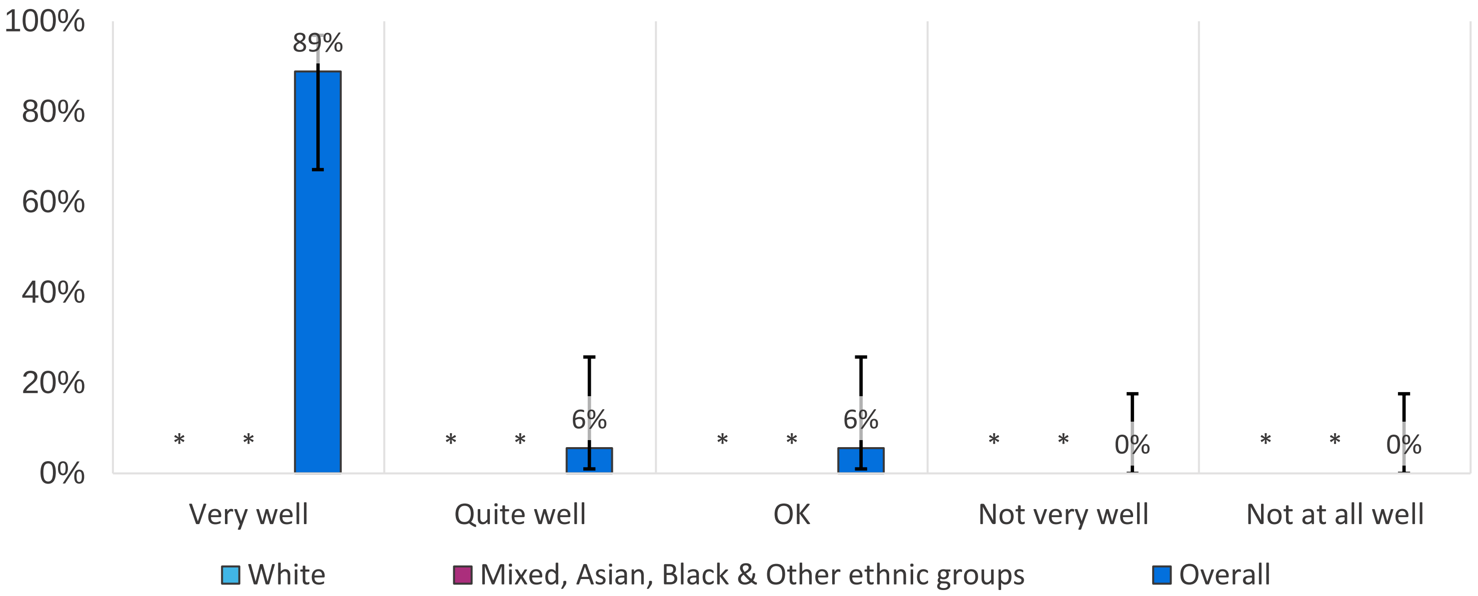
†Only data for male and female is shown, as the number of respondents answering 'prefer not to say' to the sex registered at birth question was suppressed.

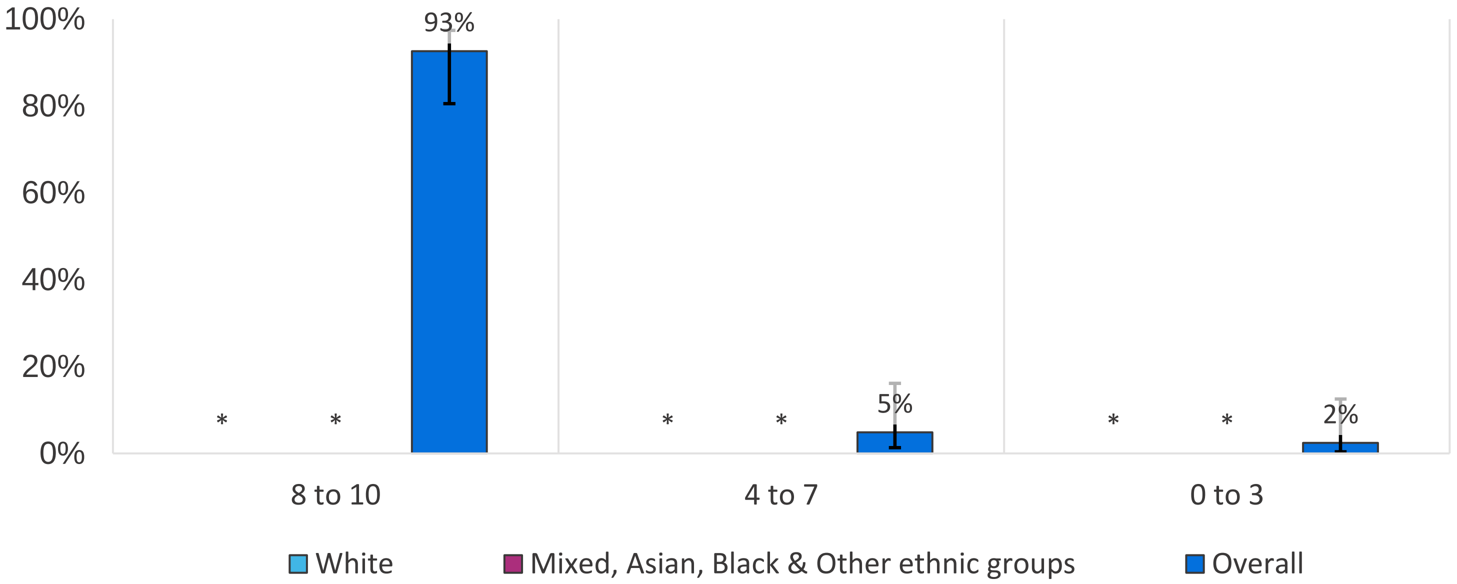
Ethnic group[†]

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 = 18.

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

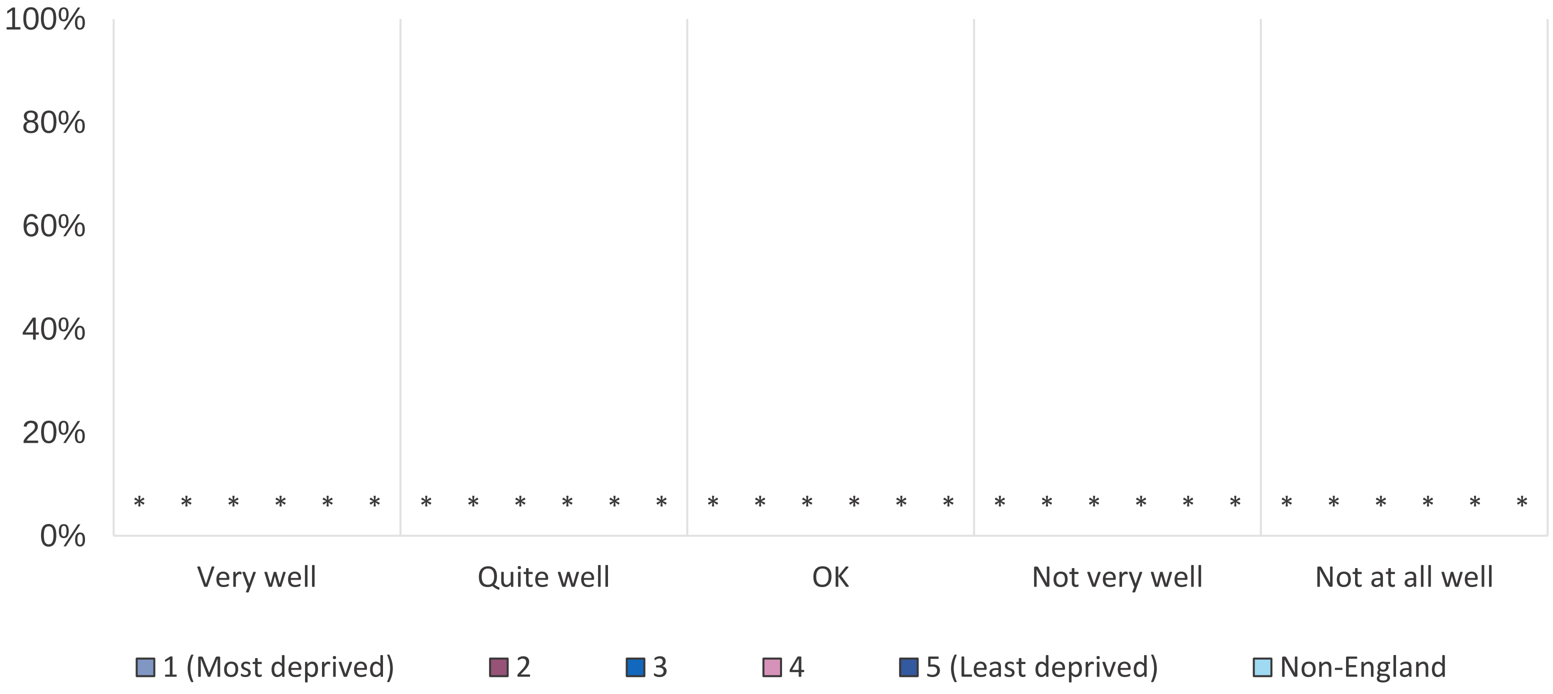


Question X59: Asked to parents/carers of all age groups. Total responses = 41.

[†] 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.

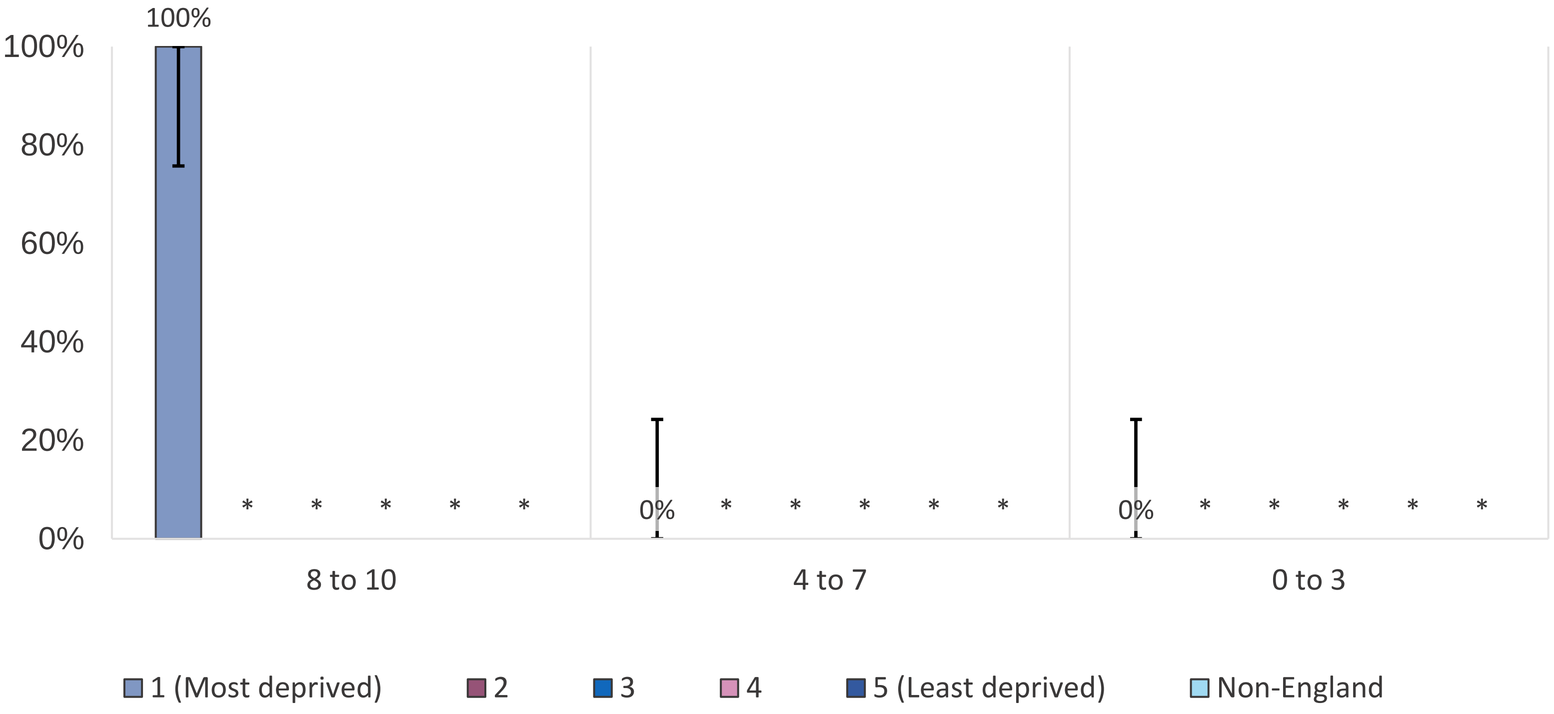
IMD quintile

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 = 18.

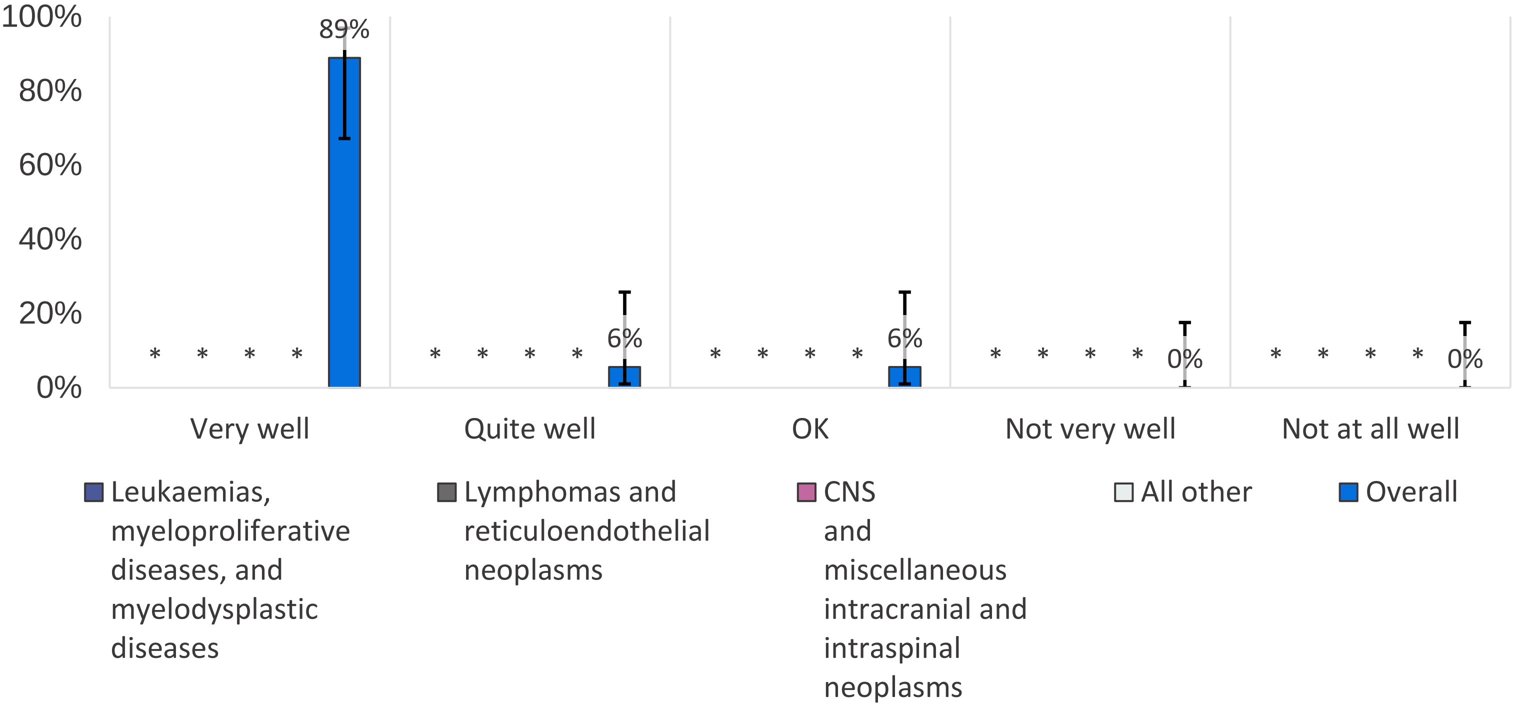
Figure 11. Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



Question X59: Asked to parents/carers of all age groups. Total responses = 41.

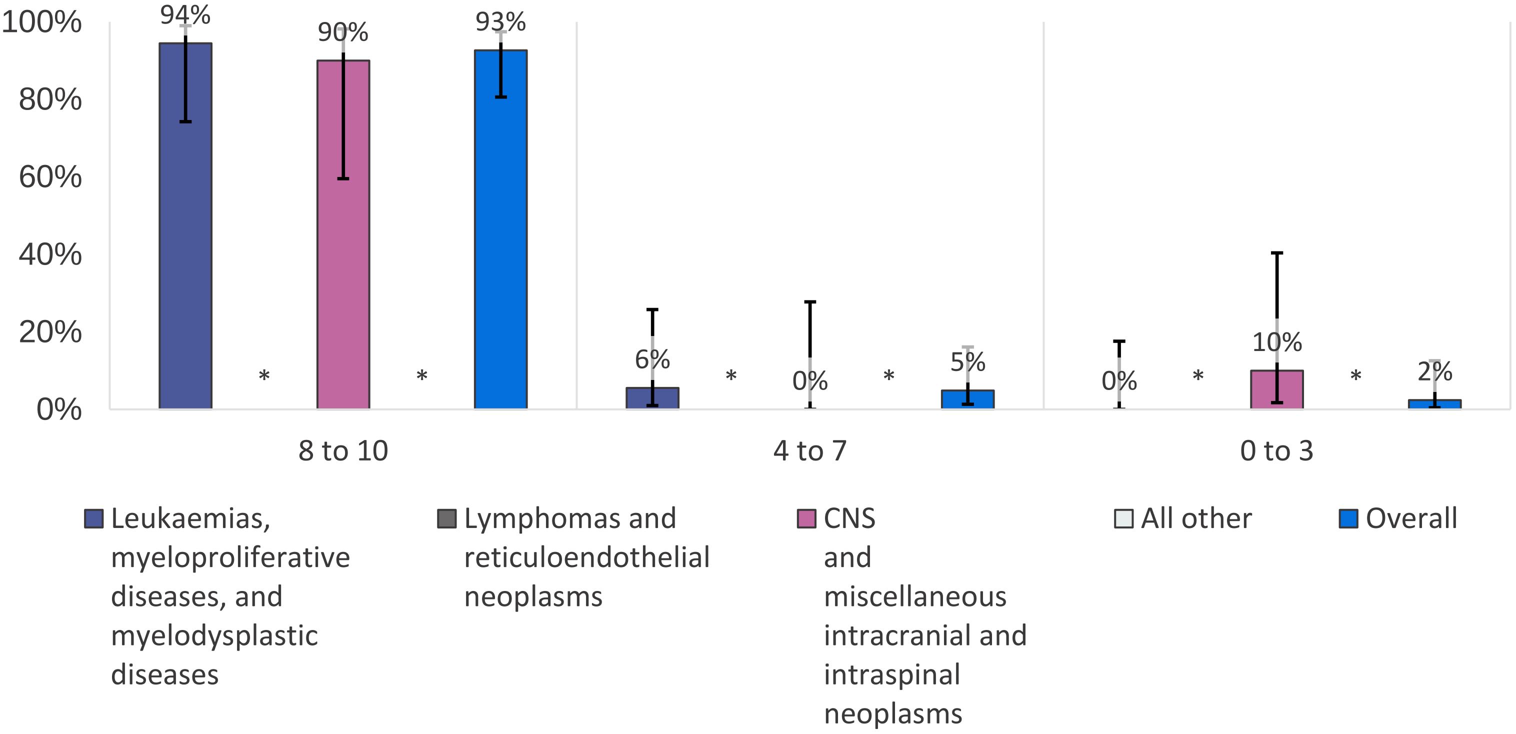
Diagnostic Group[†]

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 = 18.

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

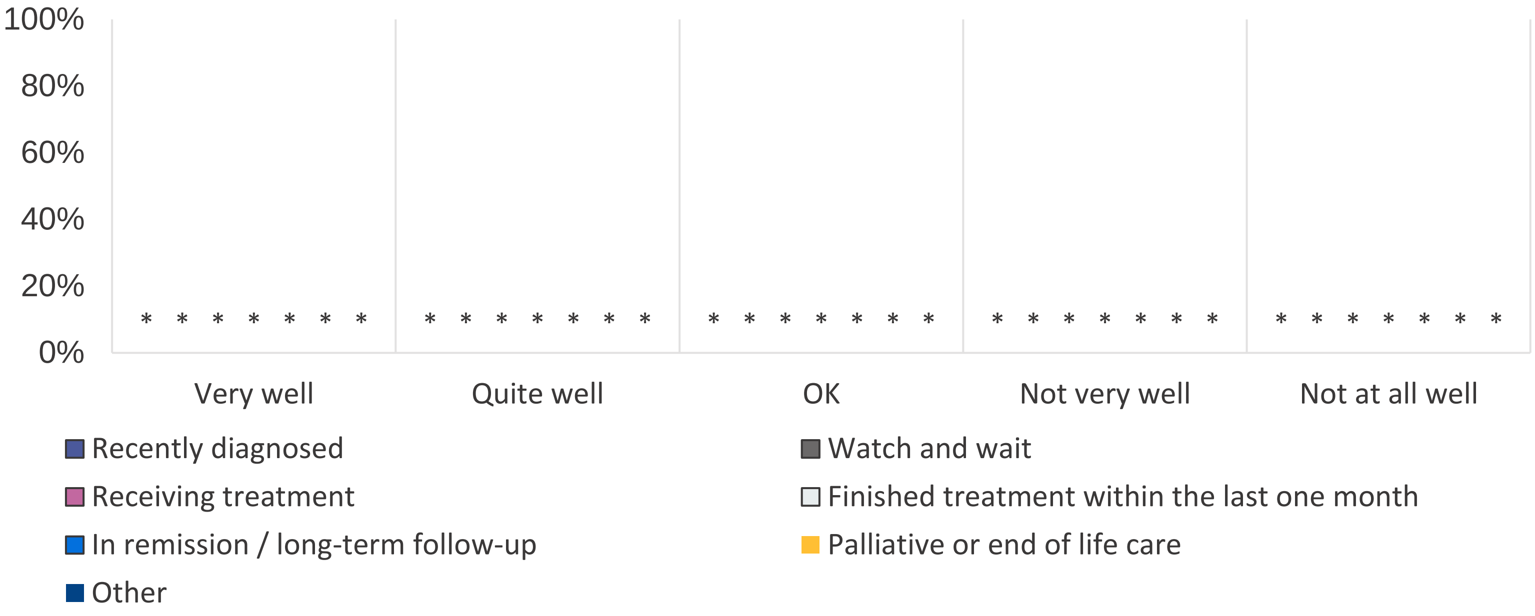


Question X59: Asked to parents/carers of all age groups. Total responses = 41.

[†] 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.

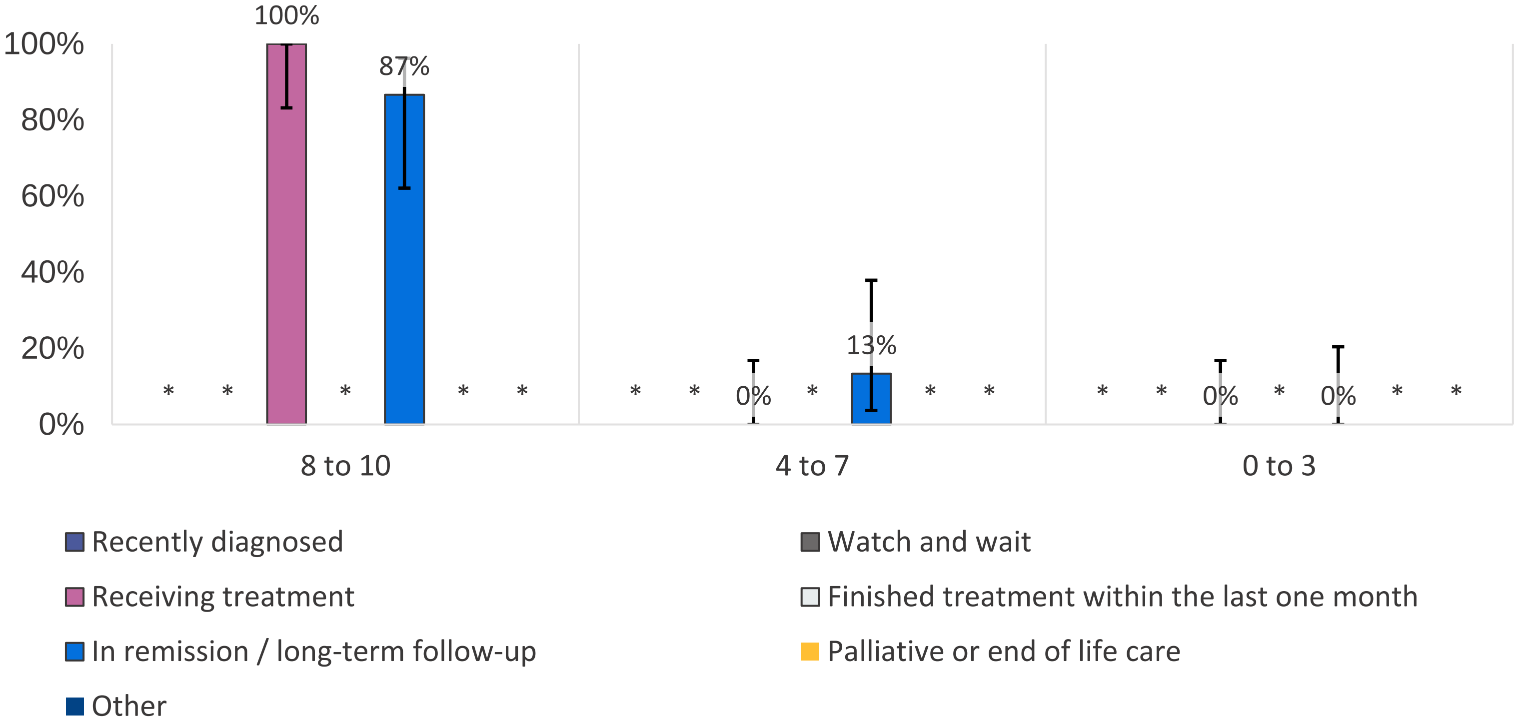
Stage of current care or treatment

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 = 18.

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/carers of all age groups. Total responses = 41.

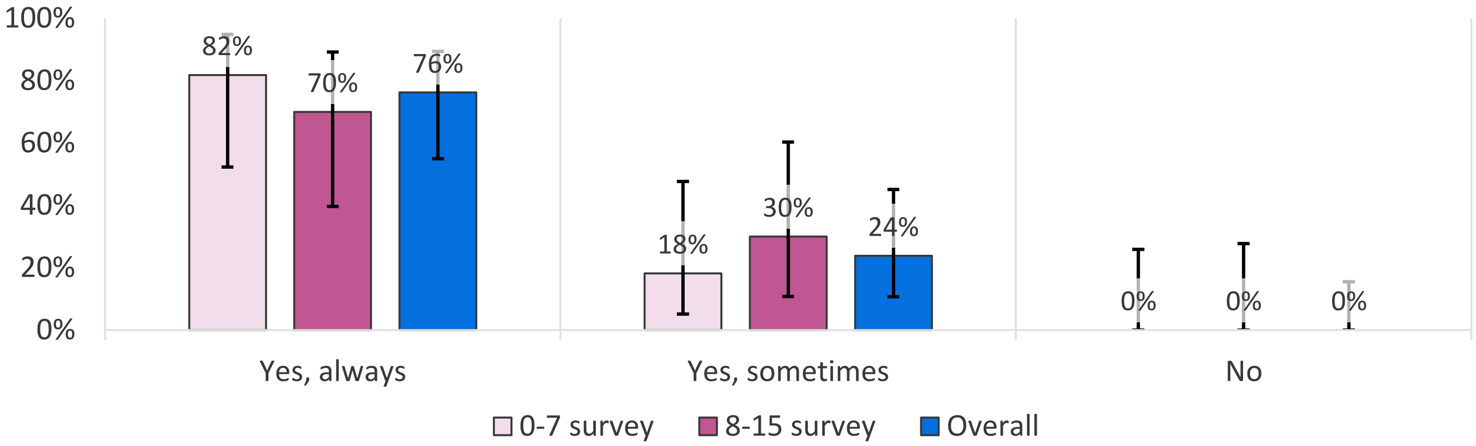
PTC results

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

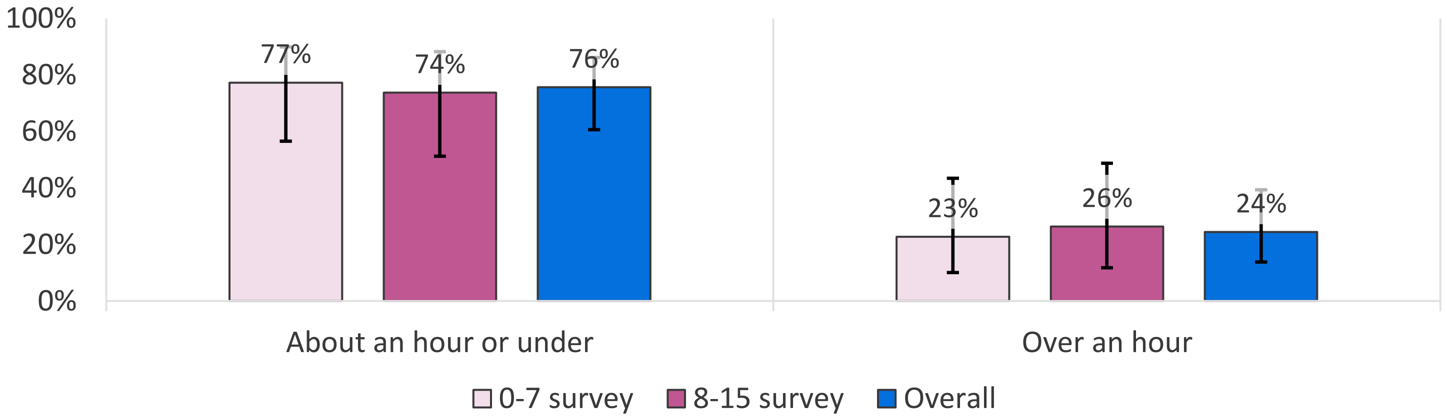
All respondents were asked how they felt about their overall care. Further results for these questions (showing breakdowns by different groups) can be found in the 'Sub-group comparisons' section of this report. Two questions were asked about how well different hospitals providing cancer or tumour care 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 16 and 17 below.

Figure 16. 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/carers of children aged 0-11, and children aged 12-15. Total responses = 21 (excluding 19 response(s) of "My child does not/ I don't receive care at different hospitals").

Figure 17. How long does it take to get to the hospital where your child receives most of their cancer or tumour care?

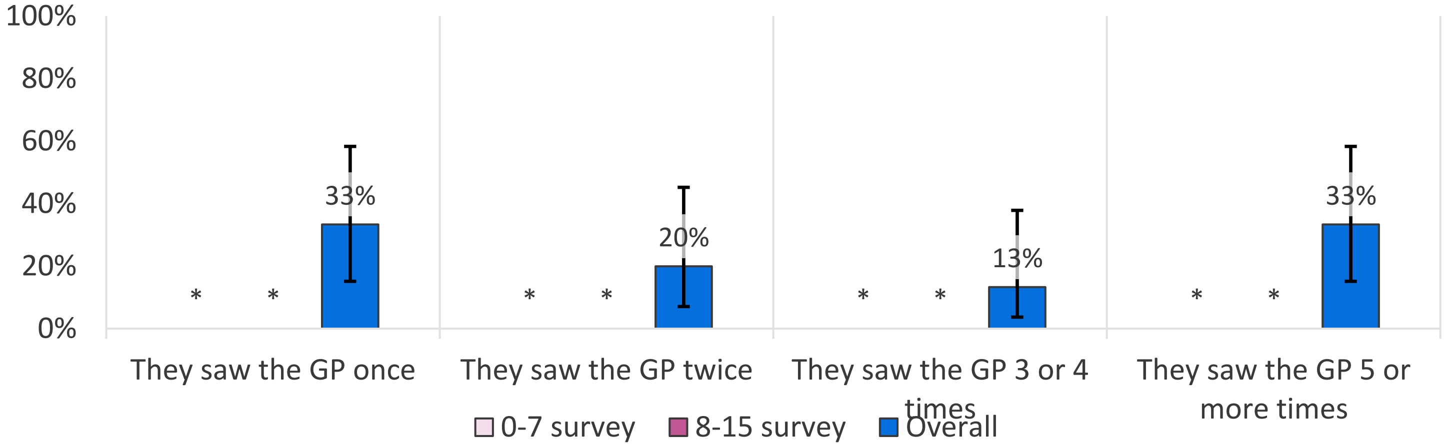


Question X58: Asked to parents/carers of all age groups. Total responses = 41.

Finding out about the cancer or tumour

54% (n=22) of all parents/carers reported that their children were told they had cancer or a tumour during 2022 (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.

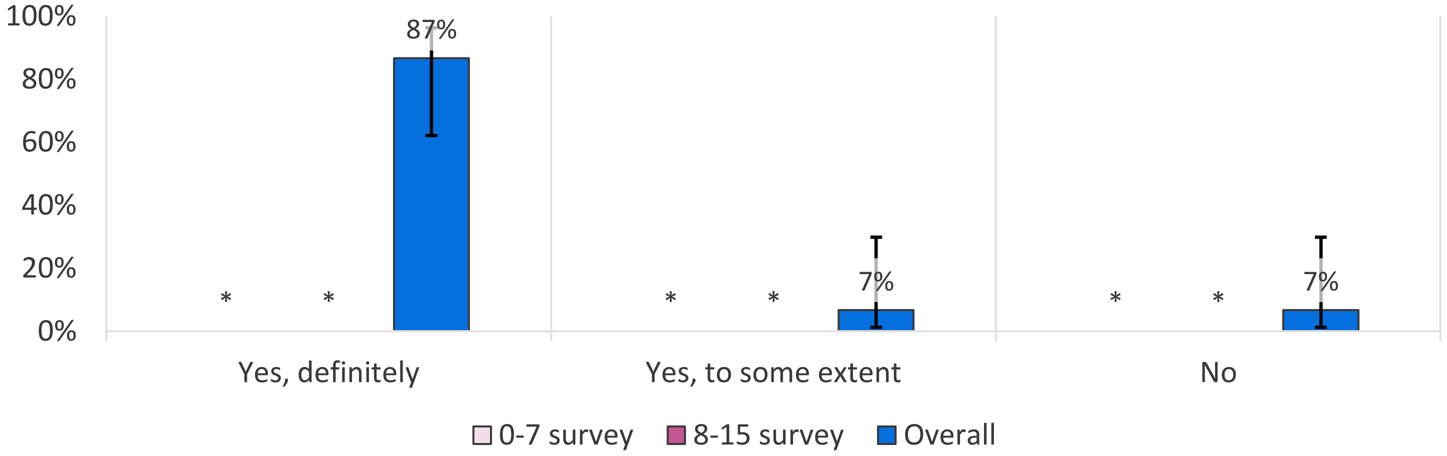
Figure 18. Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem(s) caused by the cancer or tumour?



Question X03: Asked to parents/carers of all age groups whose children were told they had cancer or a tumour during 2022. Total responses = 15 (excluding 7 response(s) of "None- they went straight to hospital" and excluding 0 response(s) of "Don't know / can't remember").

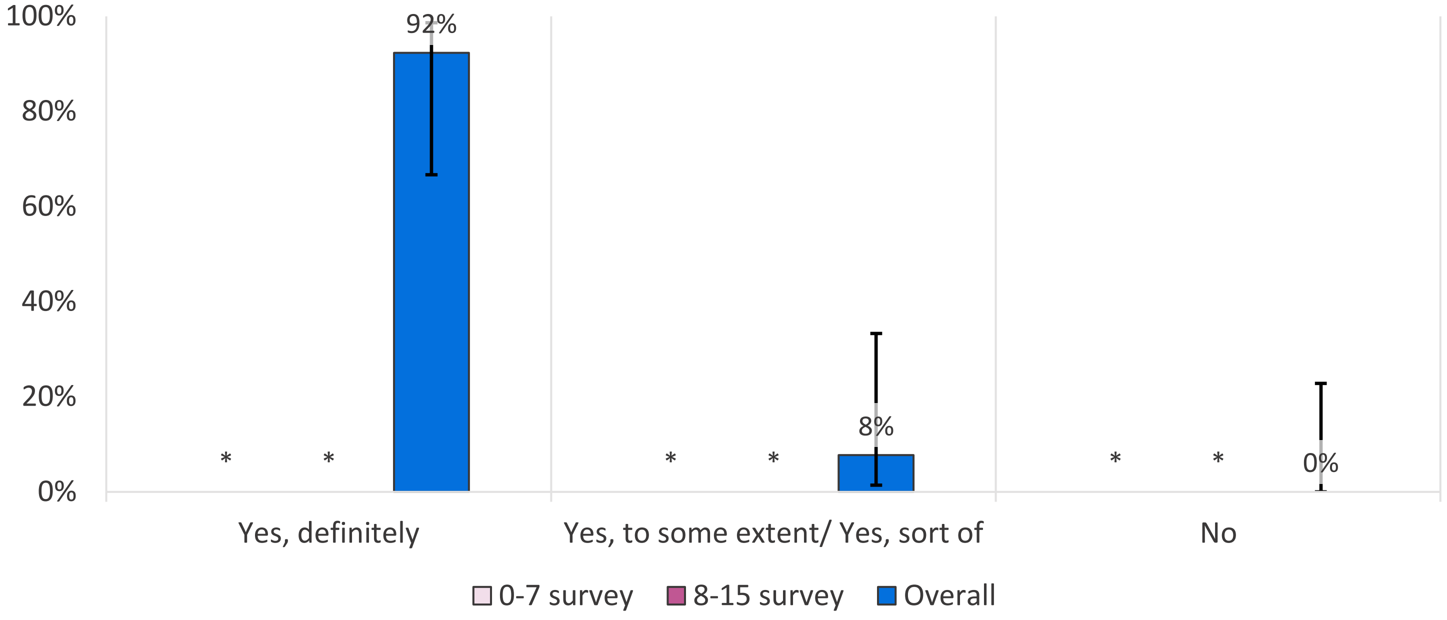
Further questions were asked to all parents/carers of children who had received diagnoses during 2022 by the hospital named in the covering letter.

Figure 19. Were you told about your child's cancer or tumour in a sensitive way?



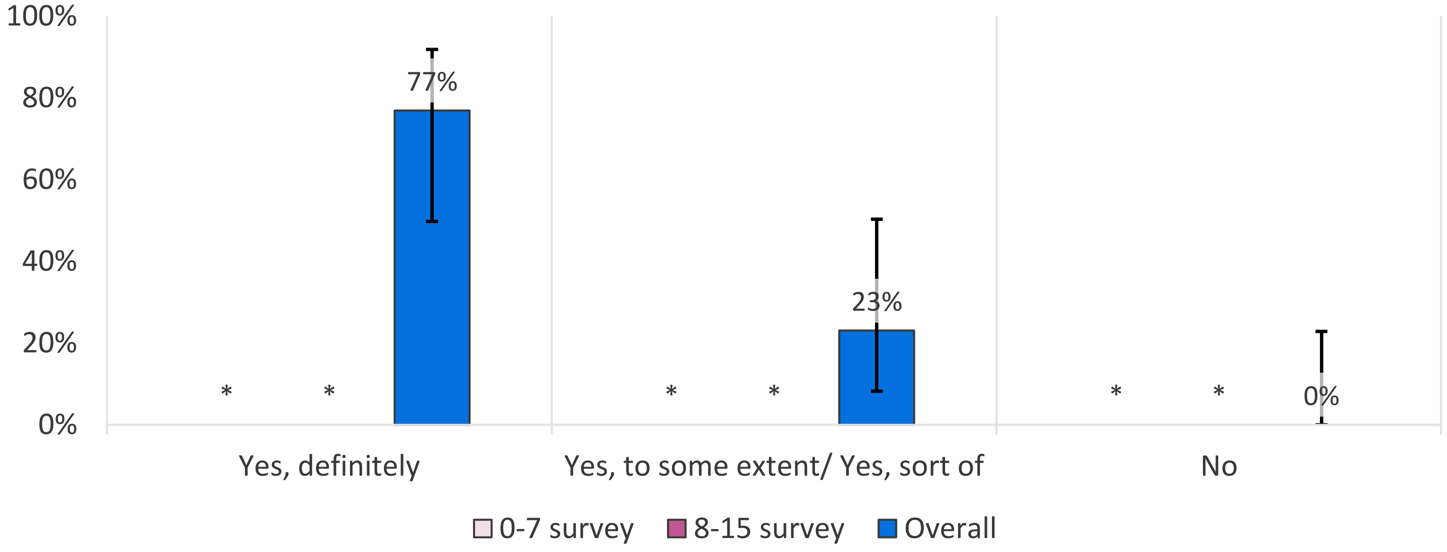
Question X07: Asked to parents/carers of all age groups who were told about their child's cancer or a tumour during 2022. Total responses = 15 (excluding 0 response(s) of "Don't know / can't remember").

Figure 20. 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 2022, and children aged 8-15 who were told they had cancer or a tumour during 2022. Total responses = 13 (excluding 0 response(s) of “Don't know / can't remember”).

Figure 21. 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?

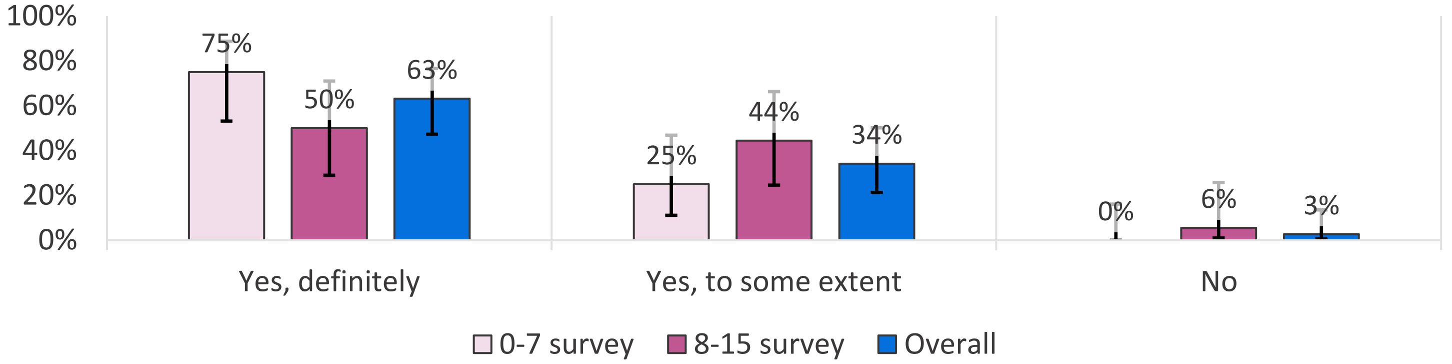


Question X09: Asked to parents/carers of 0-7s who were told about their child's cancer or a tumour during 2022, and children aged 8-15 who were told they had cancer or a tumour during 2022. Total responses = 13 (excluding 0 response(s) of “I did not have any questions” and excluding 0 response(s) of “Don't know / can't remember”).

Child's care and treatment

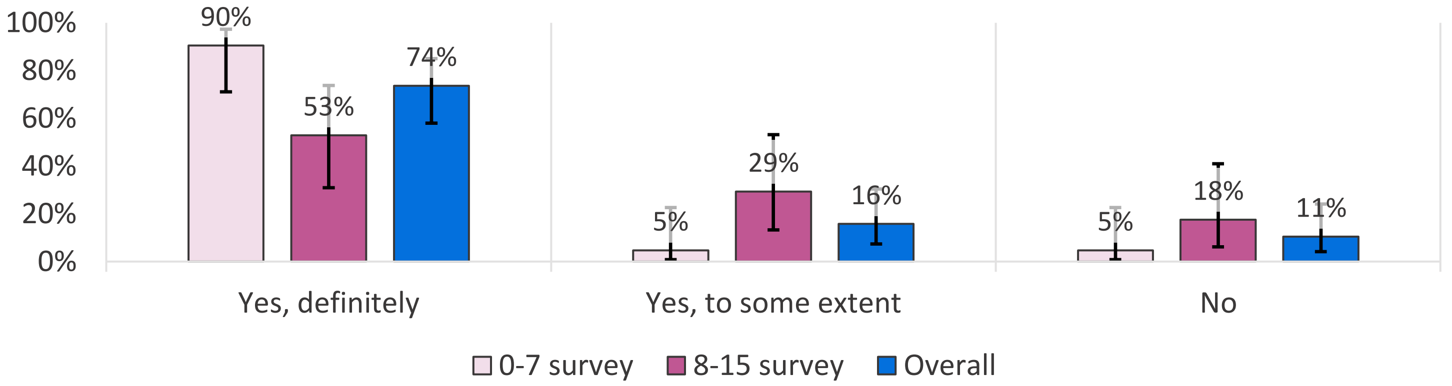
All parents and carers were asked questions about staff involved in their child's care at the hospital named in the letter that came with their survey, including questions about awareness of the child's medical history and whether they had access to help and support.

Figure 22. Are different hospital staff caring for your child aware of your child's medical history?



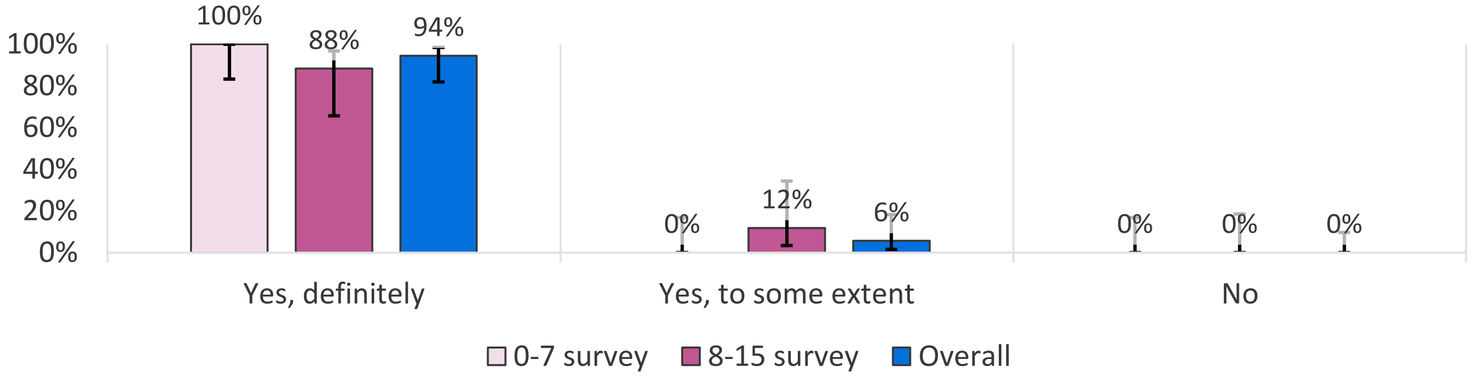
Question X27: Asked to parents/carers of all age groups. Total responses = 38 (excluding 3 response(s) of "Don't know / not applicable").

Figure 23. Do you have access to reliable help and support 7 days a week from the hospital?



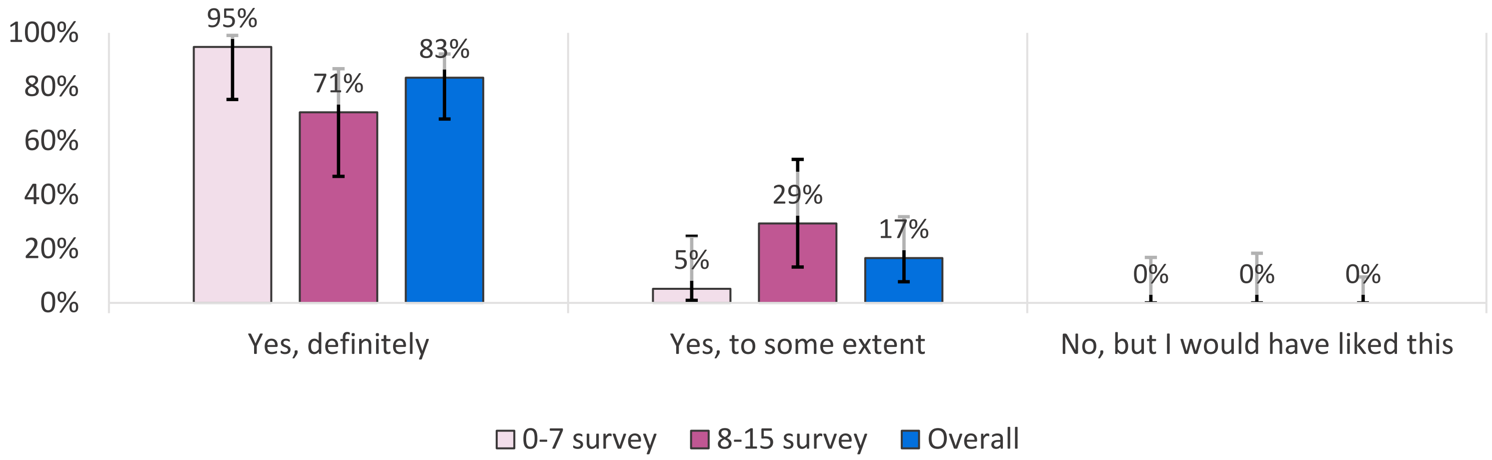
Question X33: Asked to parents/carers of all age groups. Total responses = 38 (excluding 3 response(s) of "This is not needed").

Figure 24. Were you offered clear information about your child's treatment?



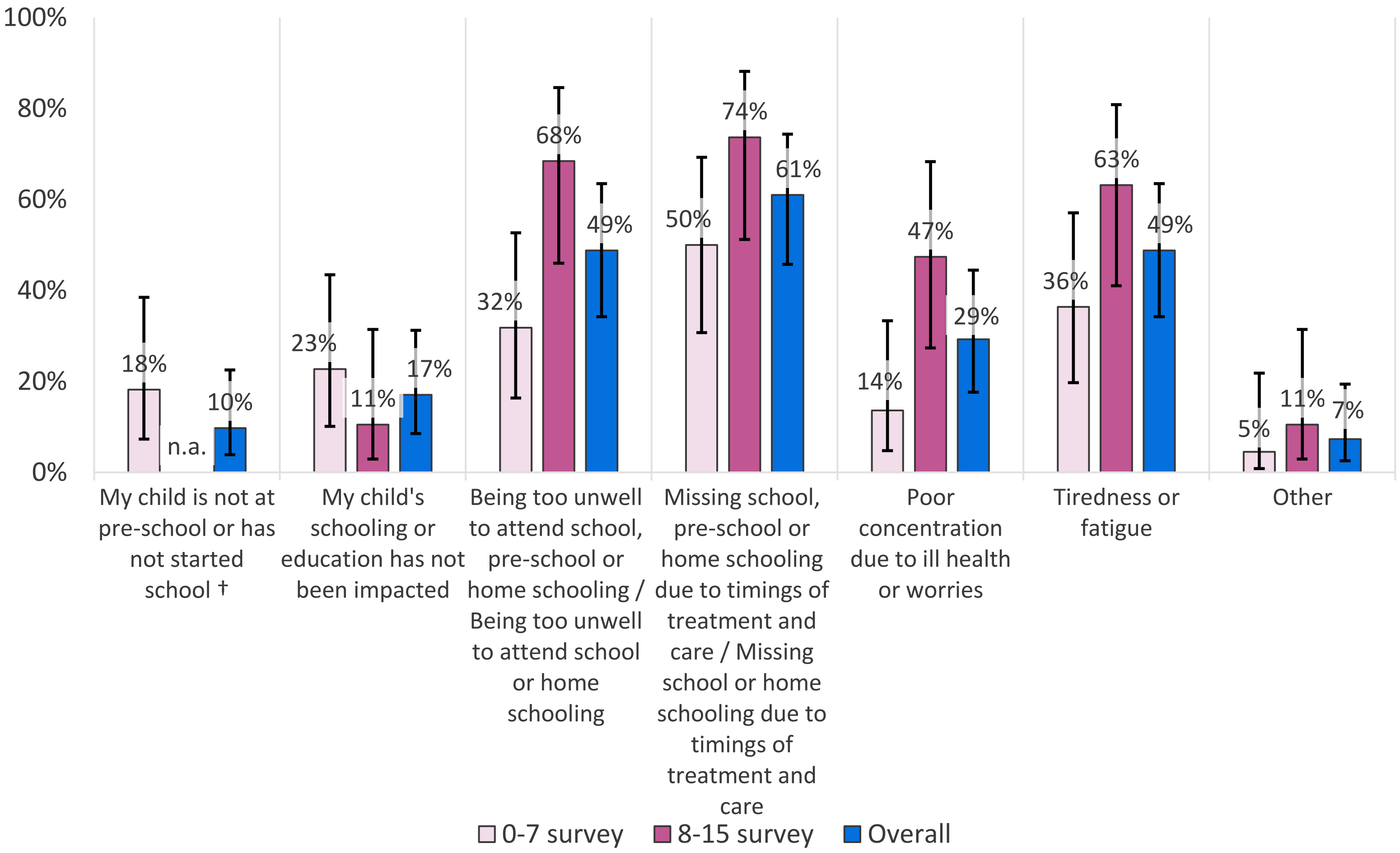
Question X36: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2022. Total responses = 36 (excluding 0 response(s) of "This was not needed").

Figure 25. Did staff offer you enough time to make decisions about your child's treatment?



Question X37: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2022. Total responses = 36 (excluding 0 response(s) of “No, but this was not needed or possible”).

Figure 26. Has your child's schooling and education (including pre-school) been impacted in any of the following ways by their treatment and care? Please select all that apply.



Question X30: Asked to parents/carers of all age groups. Total responses = 41.

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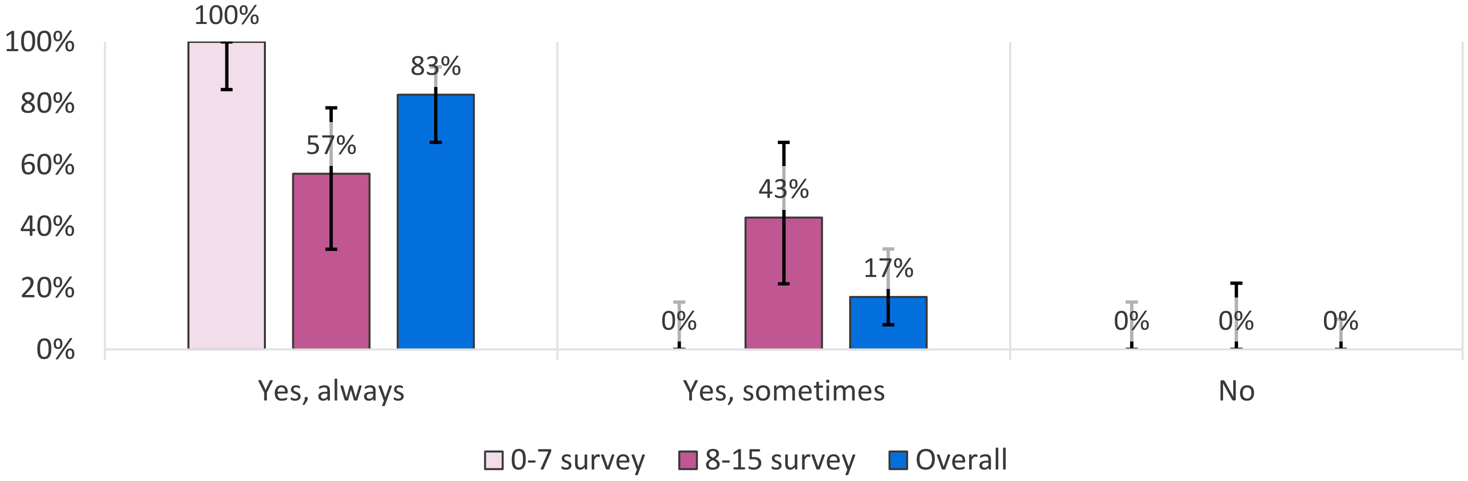
† Response option was only asked to parents/carers of 0-7 years olds

Care in hospital

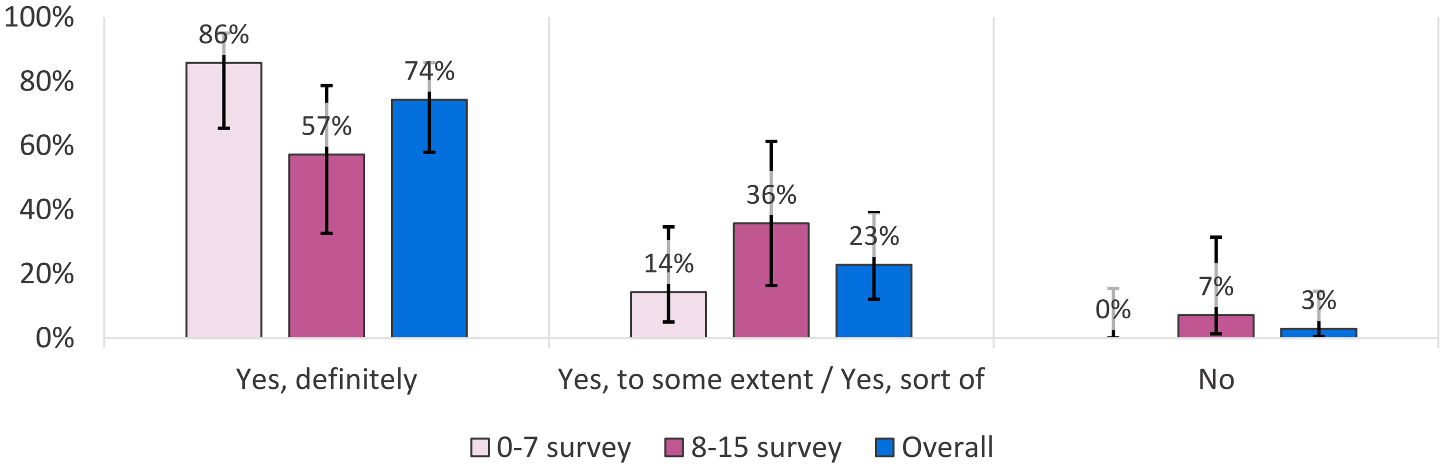
Respondents who had stayed in the hospital named in the letter that came with their survey during 2022 (receiving treatment or care in the daytime, or for an overnight stay) were asked questions about hospital staff, services and facilities. Out of all parents/carers, 88% (n=36) answered that their child had stayed in hospital during 2022 (Question X40).

Figure 27. 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/carers of children aged 0-7 whose children stayed in hospital during 2022, and children aged 8-15 who have stayed in hospital during 2022 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 35 (excluding 0 response(s) of “They/ I did not need any help” and excluding 0 response(s) of “Don't know/ can't remember”).

Figure 28. Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital?

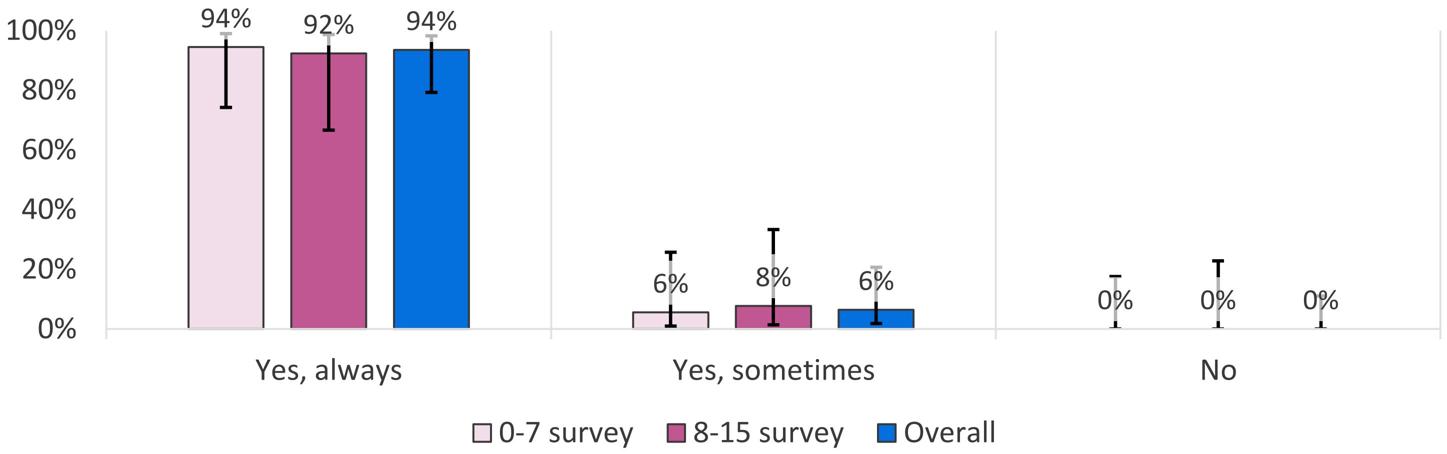


Question X43: Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2022, and children aged 8-15 who stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 35 (excluding 0 response(s) of “This was not needed”).

Care at home or school

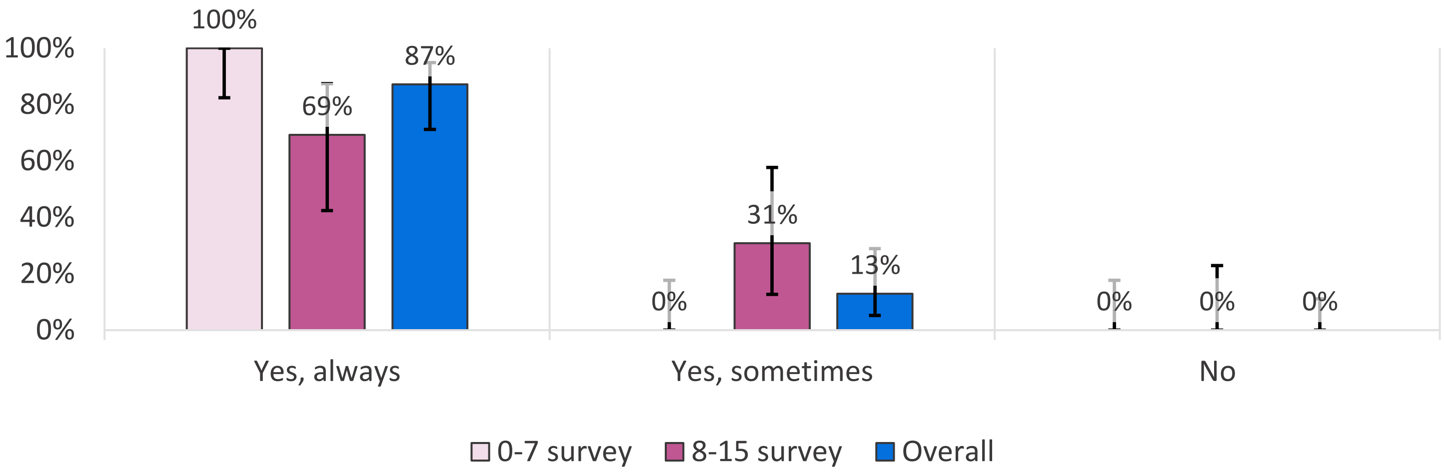
Children aged 8 and above and parents/carers of children under the age of 8 who had been visited at home or school by a nurse during 2022 (79% (n=31) of respondents) (Question X53), for care relating to the child’s cancer or tumour, were asked a short series of questions about this care. Some results from this section can be found below.

Figure 29. 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/carers of children aged 0-7 whose children have been visited at home or school by a nurse during 2022, and children aged 8-15 who were visited at home or school by a nurse during 2022. Total responses = 31 (excluding 0 response(s) of “Don't know / can't remember”).

Figure 30. When nurses speak to you, do you understand what they are saying?



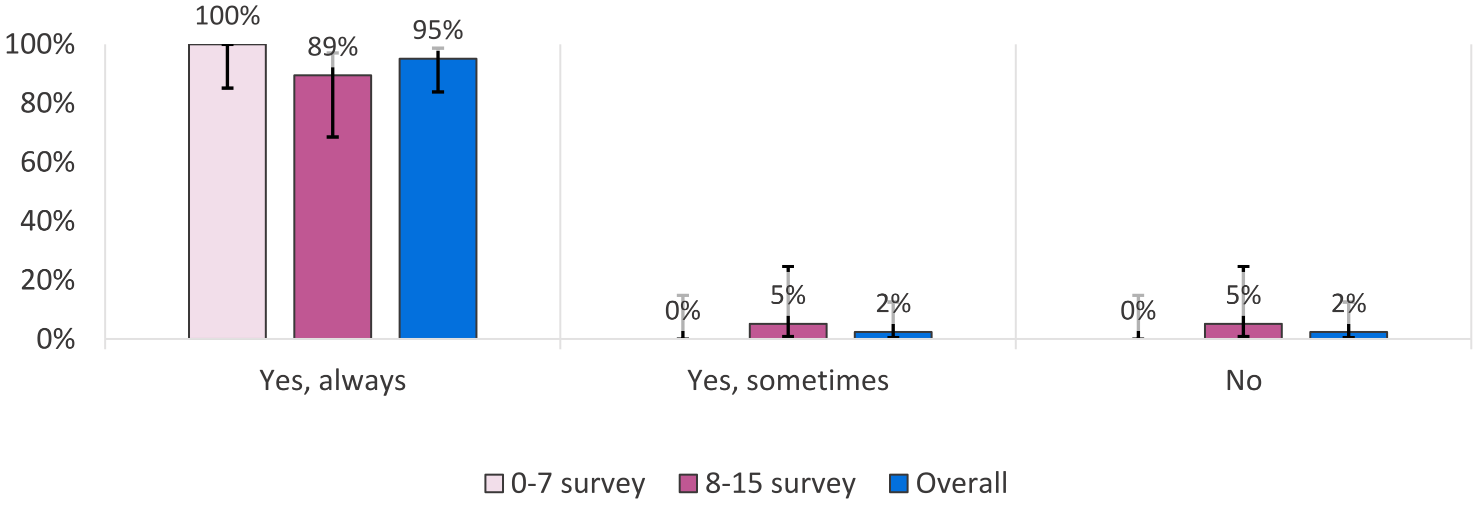
Question X55: Asked to parents/ carers of children aged 0-7 whose child was visited at home or school by a nurse during 2022, and children aged 8-15 who were visited at home or school by a nurse during 2022. Total responses = 31 (excluding 0 response(s) of “Don't know / can't remember”).

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.

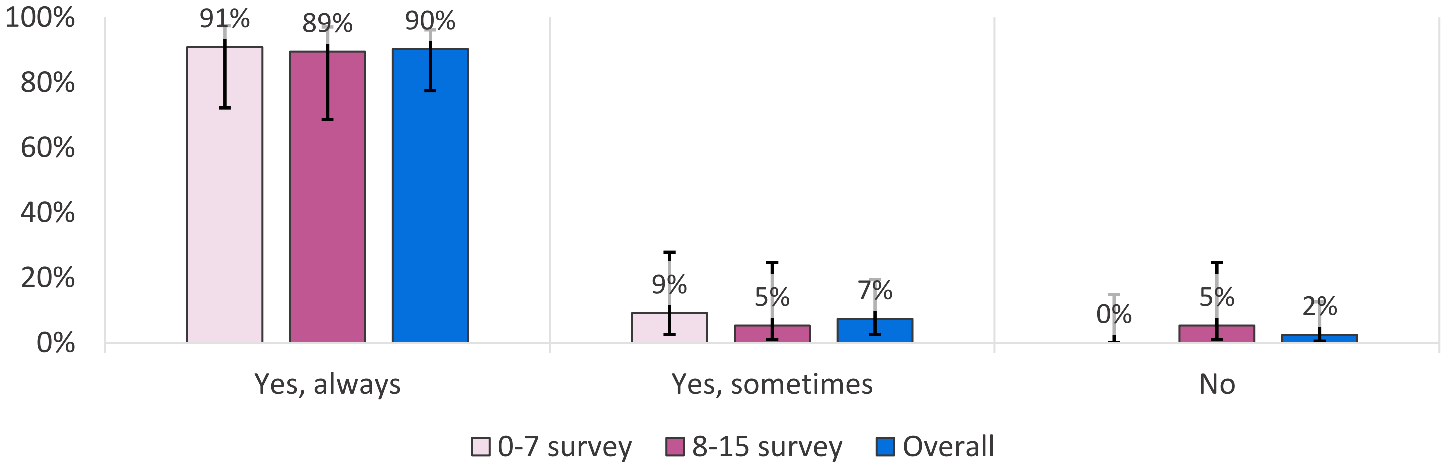
Bedside manner and trust

Figure 31. Are you and your child treated with respect and dignity by staff?



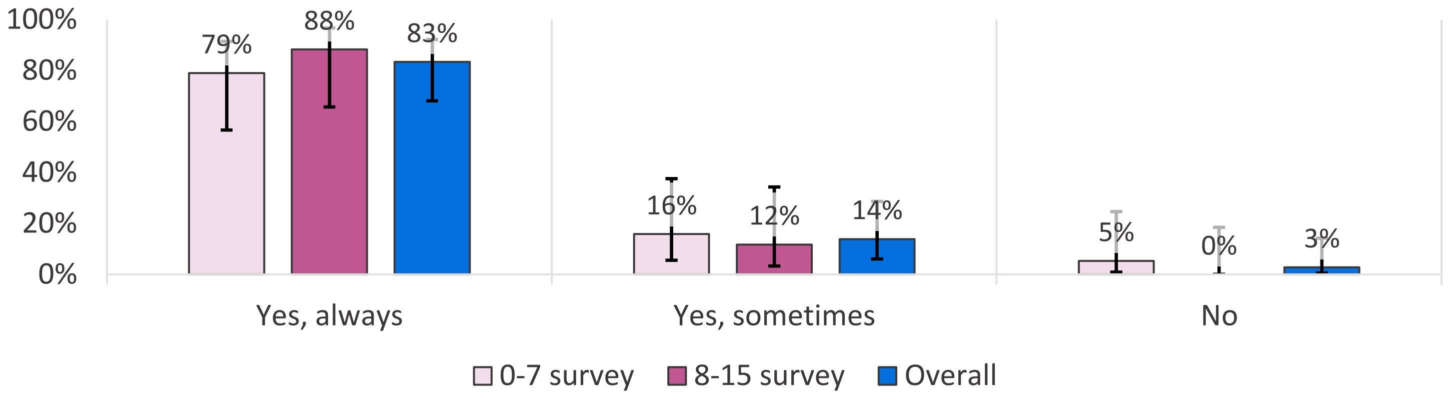
Question X17: Asked to parents/carers of all age groups. Total responses = 41.

Figure 32. Do members of staff caring for your child treat you with empathy and understanding?



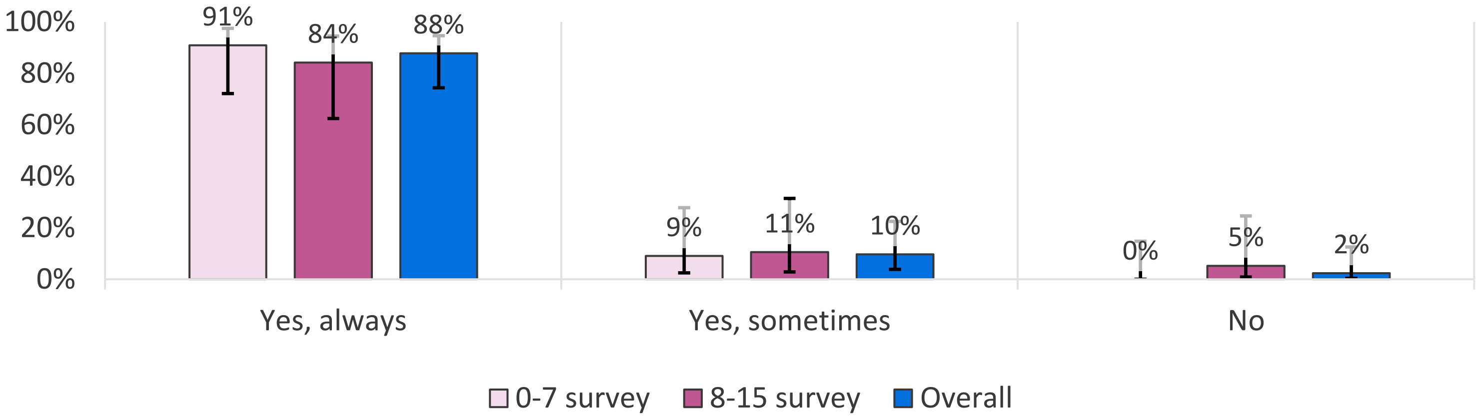
Question X19: Asked to parents/carers of all age groups. Total responses = 41.

Figure 33. Are staff sensitive to the information they share with you when your child is in the room?



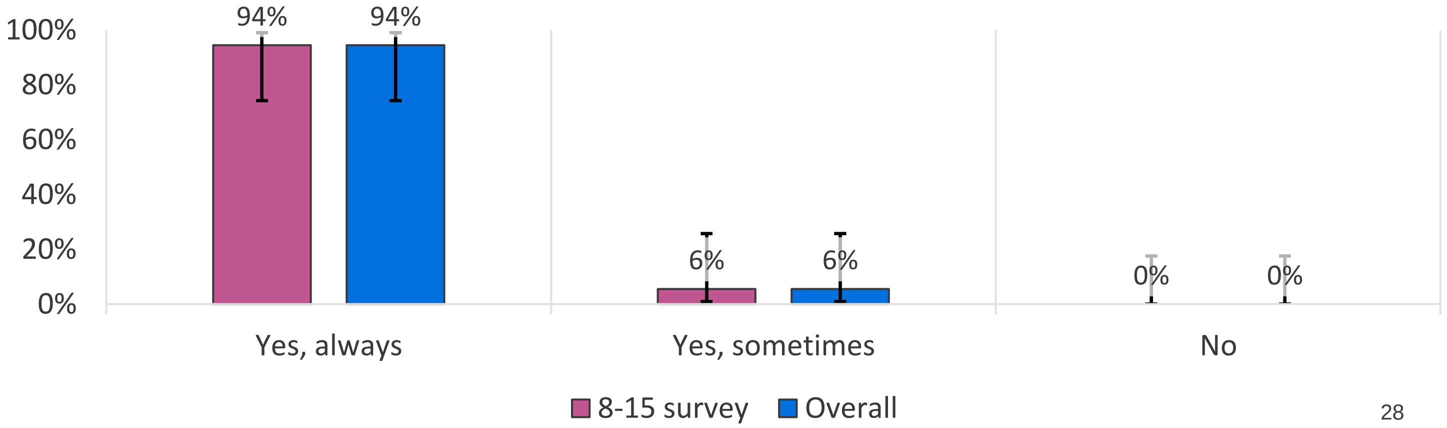
Question X21: Asked to parents/carers of all age groups. Total responses = 36 (excluding 5 response(s) of “This is not needed”).

Figure 34. Do you have confidence and trust in the members of staff caring for your child?



Question X18: Asked to parents/carers of all age groups. Total responses = 41.

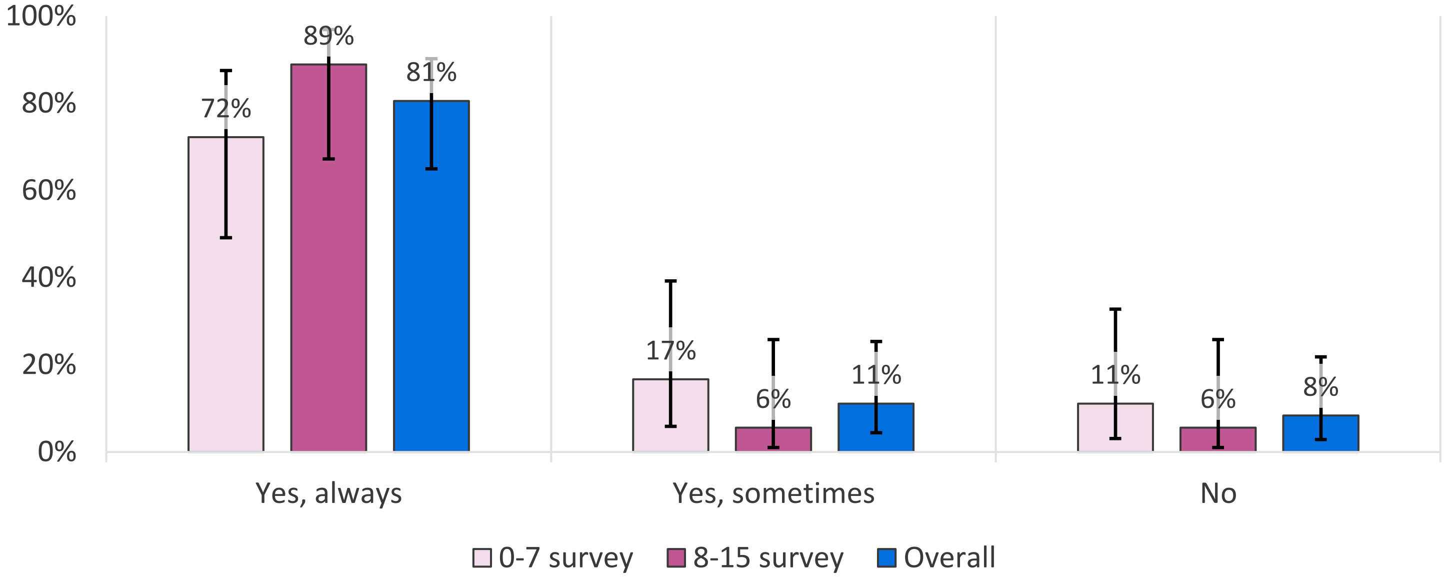
Figure 35. Do you feel that staff are friendly?



Question X12: Asked to all children aged 8-15. Total responses = 18.

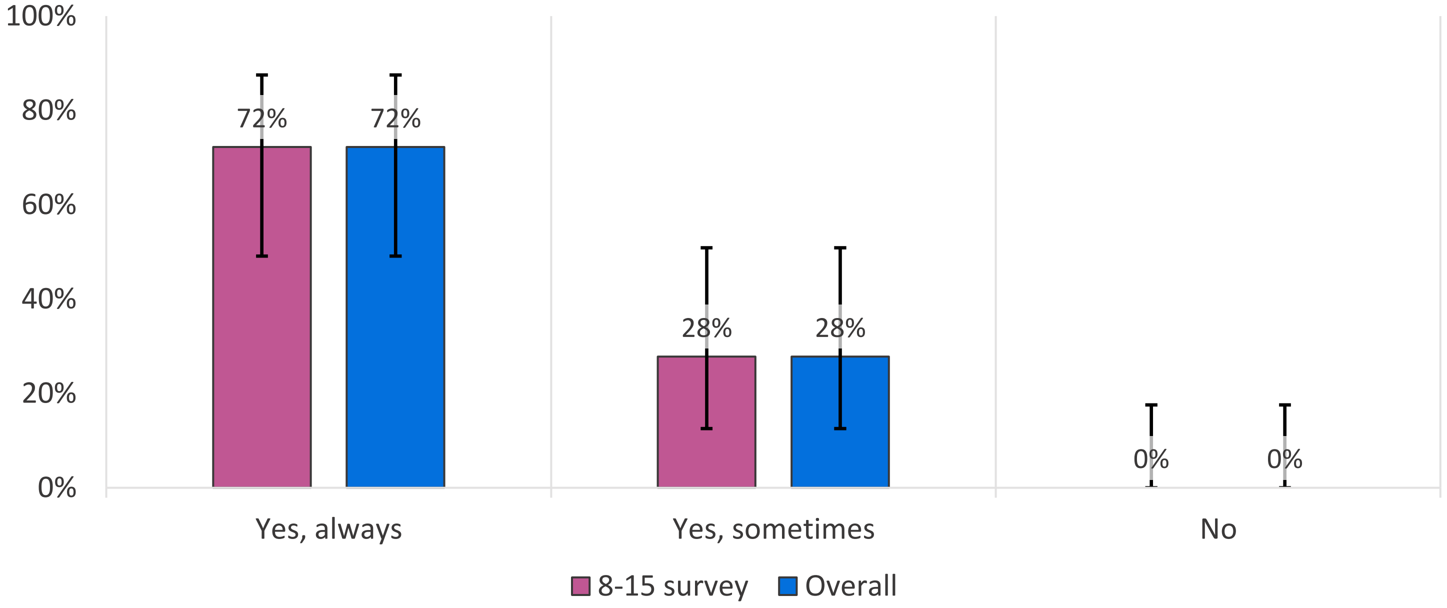
Clear communication

Figure 36. Do healthcare staff share information with your child in a way that is appropriate for them?



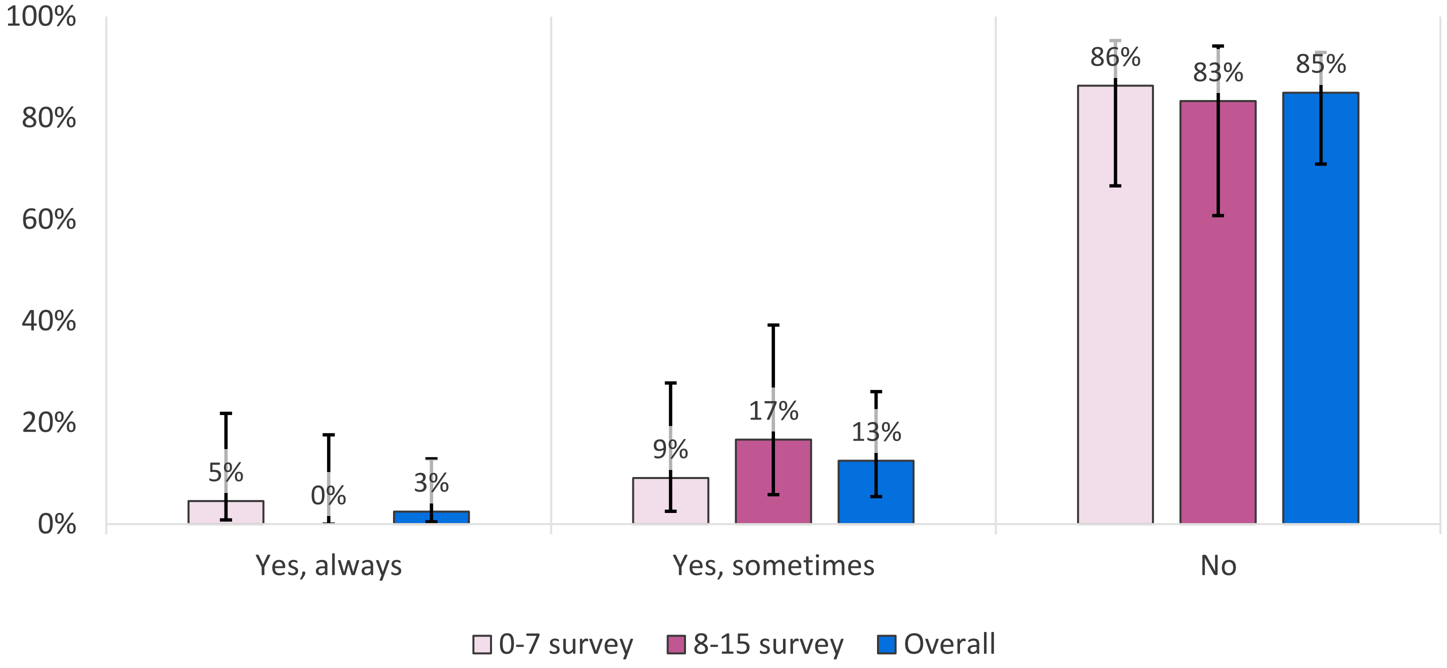
Question X22: Asked to parents/carers of all age groups. Total responses = 36 (excluding 5 response(s) of “This is not needed”).

Figure 37. When staff speak to you, do you understand what they are saying? / Do staff speak to you in a way that you can understand?



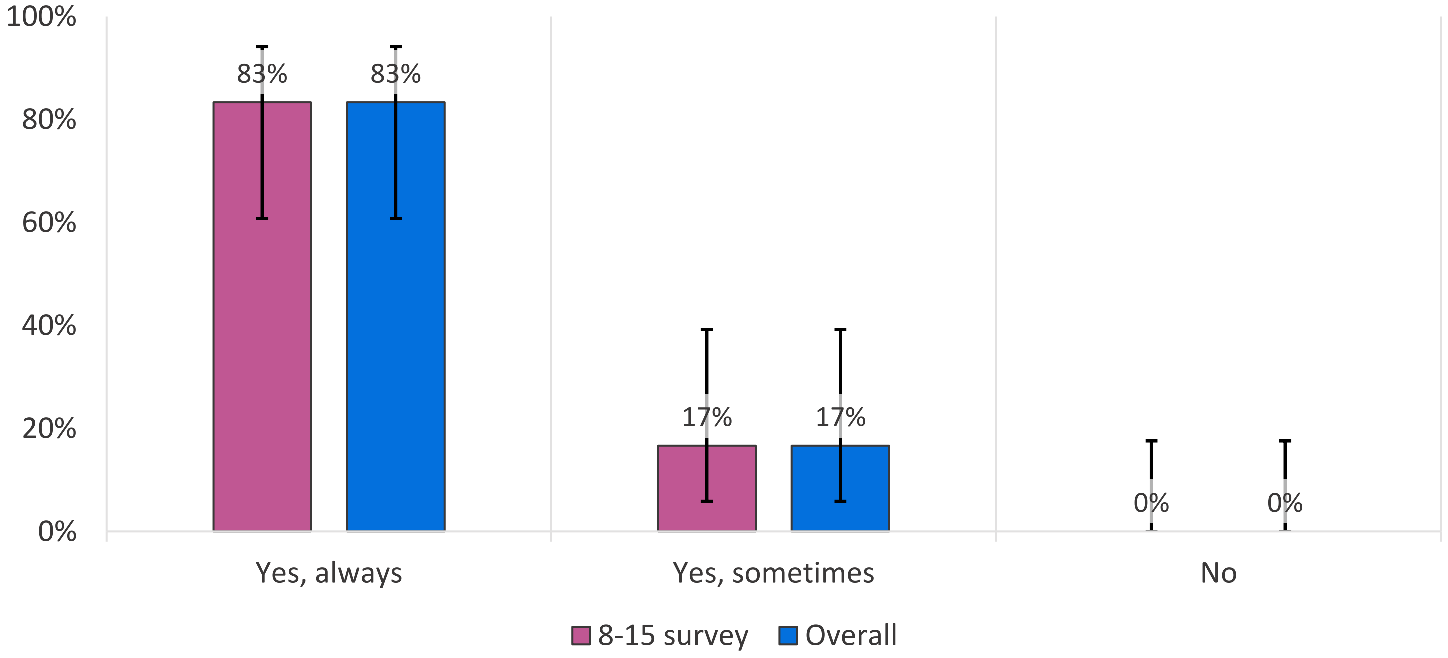
Question X13: Asked to all children aged 8-15. Total responses = 18 (excluding 0 response(s) of “Don't know / can't remember”).

Figure 38. Are you ever told different things by different members of staff, which leaves you feeling confused?



Question X20: Asked to parents/carers of 0-7s and children aged 8-15. Total responses = 40.

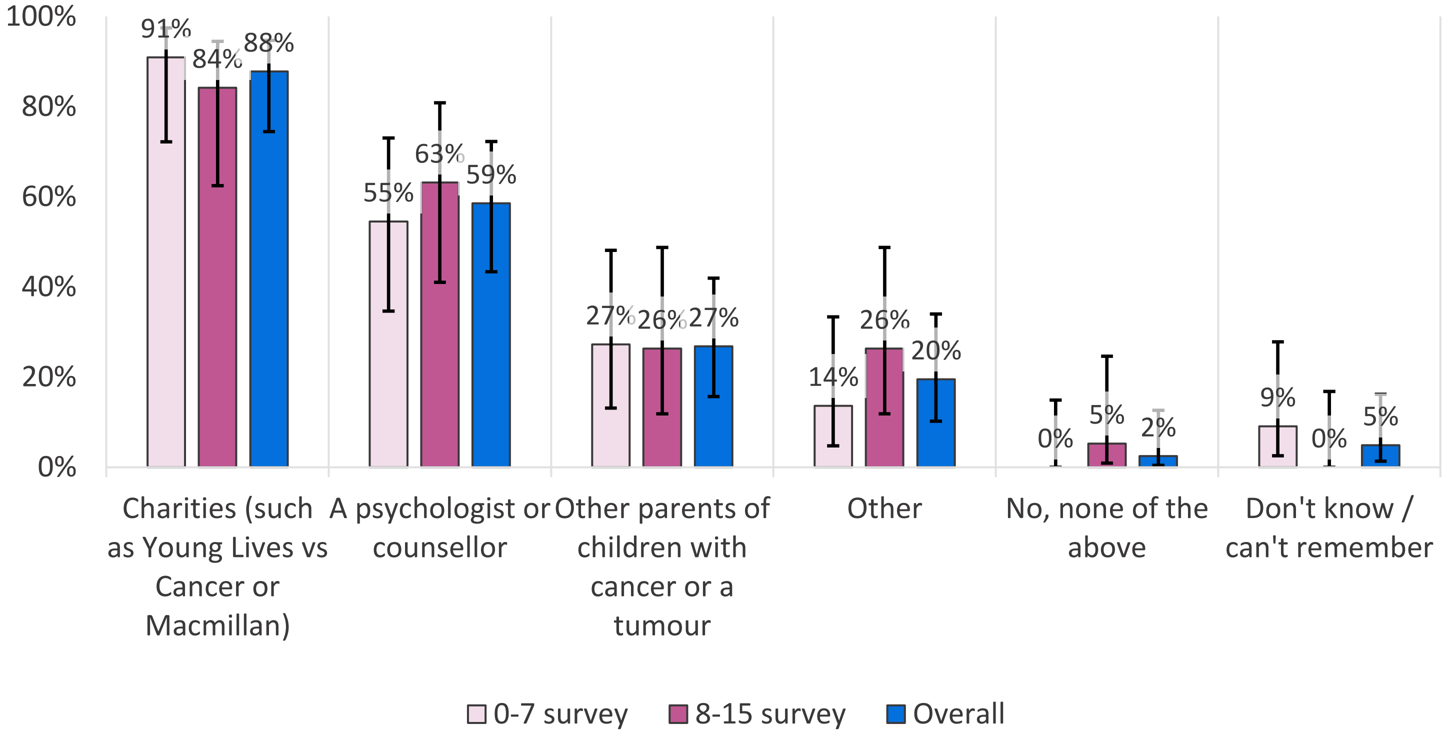
Figure 39. Do staff talk to you, not just to your parent or carer?



Question X14: Asked to all children aged 8-15. Total responses = 18.

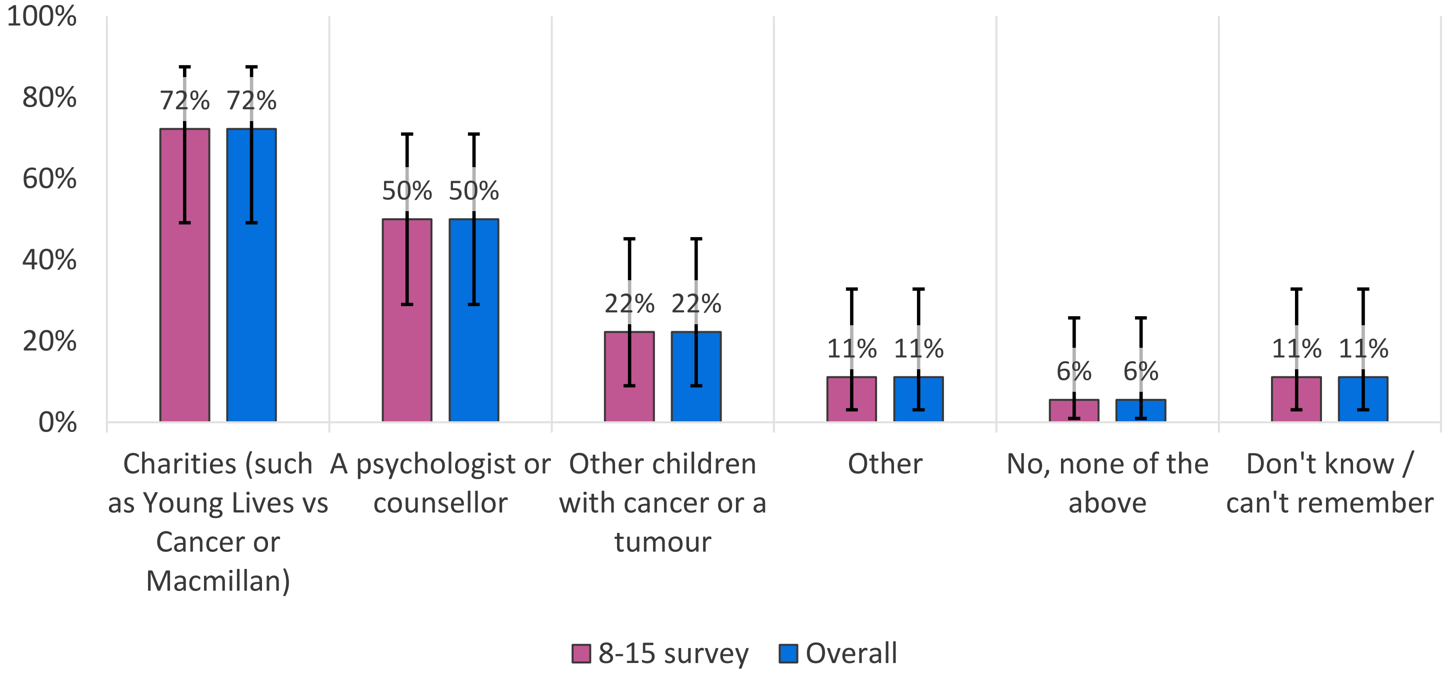
Support

Figure 40. 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/carers of all age groups. Total responses = 41.

Figure 41. 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 = 18.

Year on year comparisons

The line charts in this section show the national score and the score for your PTC for 2021 and 2022 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 2022 scores that are not comparable to 2021 are not presented in this section and can be found in the data tables on the survey website.

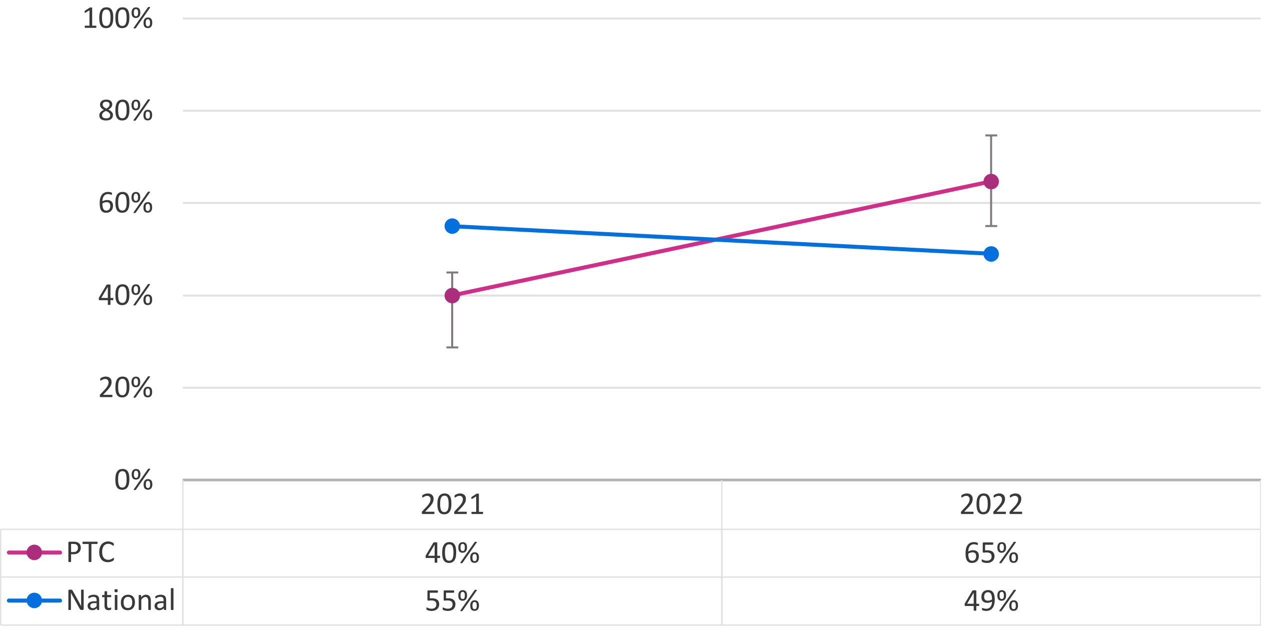
How to interpret these results

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).

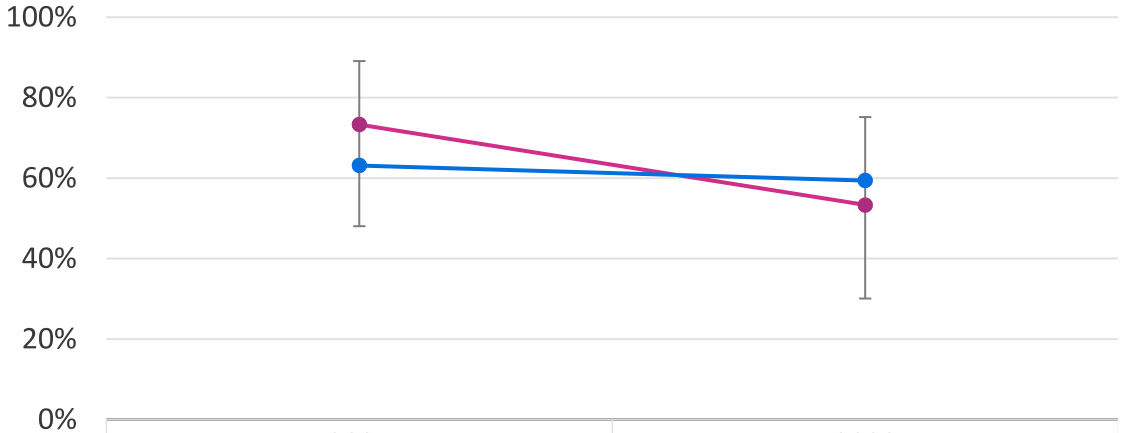
In this example below, the PTC scored 40% in 2021, and 65% in 2022. As the confidence intervals do not overlap, you could be statistically confident that there is “true” difference between the two.

EXAMPLE DATA ONLY



Finding out about the cancer or tumour

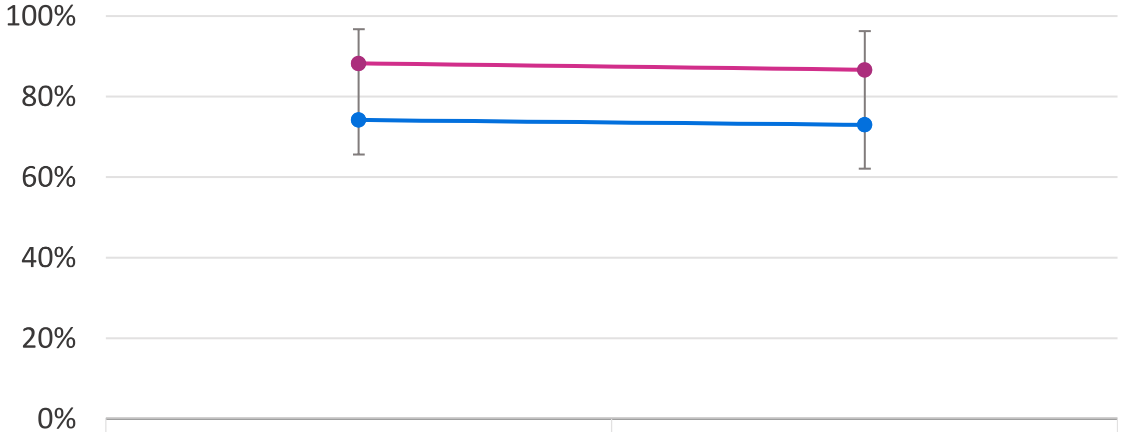
Figure 42. Parents/carers reported that their child saw a GP once or twice before they were referred to hospital



	2021	2022
PTC	73%	53%
National	63%	59%

Question X03: Asked to parents/carers of all age groups whose children were told they had cancer or a tumour. Total PTC responses for 2021 = 15, for 2022 = 15.

Figure 43. Parents/carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way

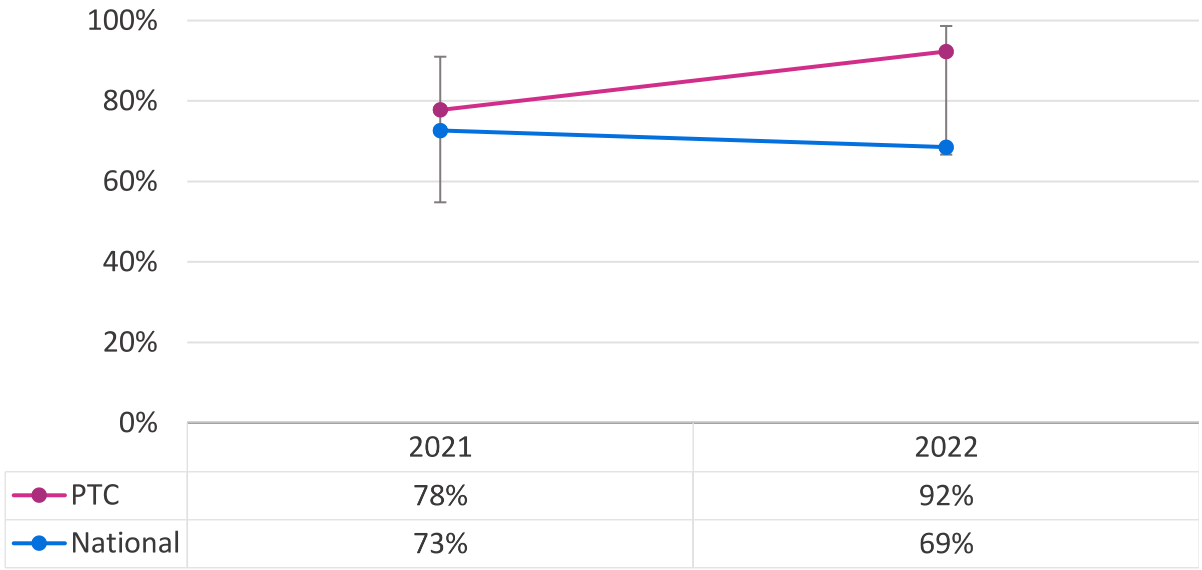


	2021	2022
PTC	88%	87%
National	74%	73%

Question X07: Asked to parents/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.

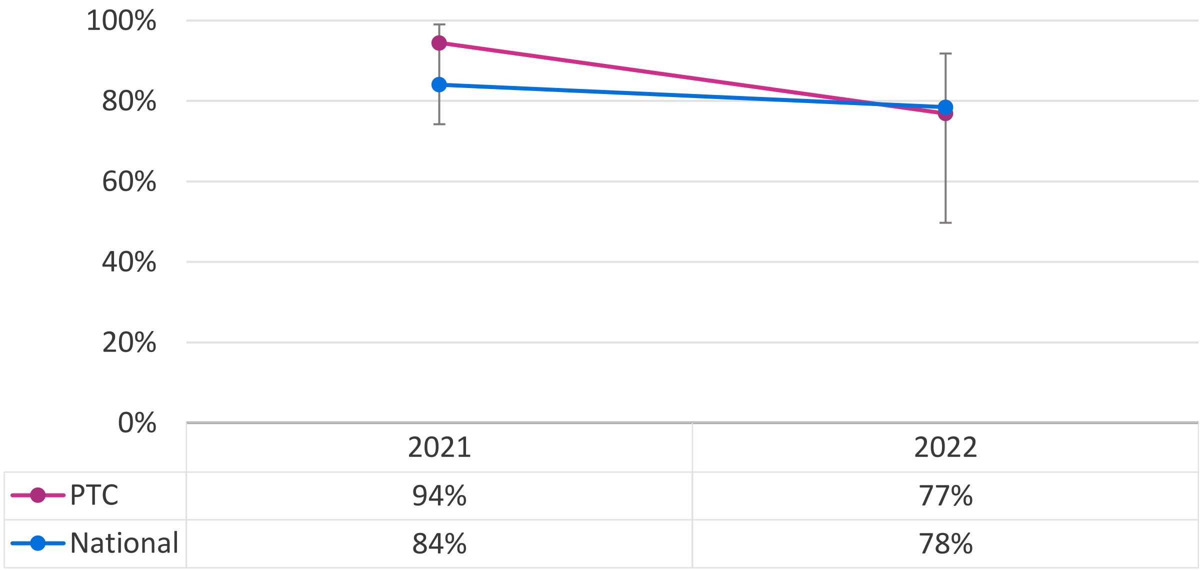
Finding out about the cancer or tumour

Figure 44. Parents/carers and children reported that information at diagnosis was definitely given in a way they could understand



Question X08: Asked to parents/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 = 13.

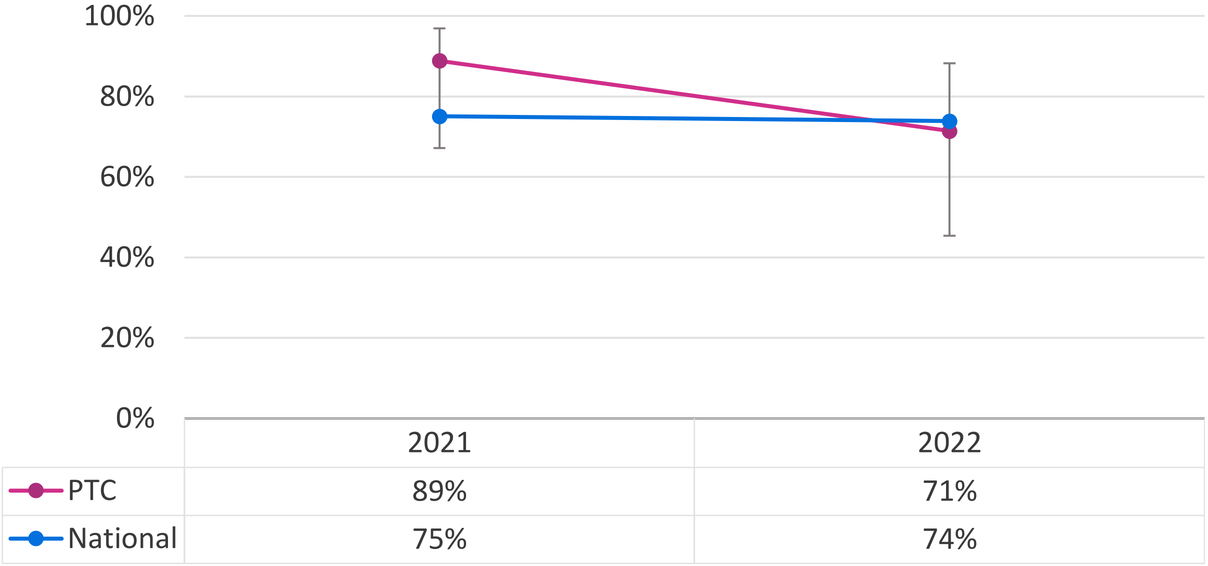
Figure 45. Parents/carers and children reported that they were definitely able to have questions answered after being told about the cancer or tumour



Question X09: Asked to parents/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 = 13.

Finding out about the cancer or tumour

Figure 46. Parents/carers reported that they were definitely able to find information about their child's diagnosis

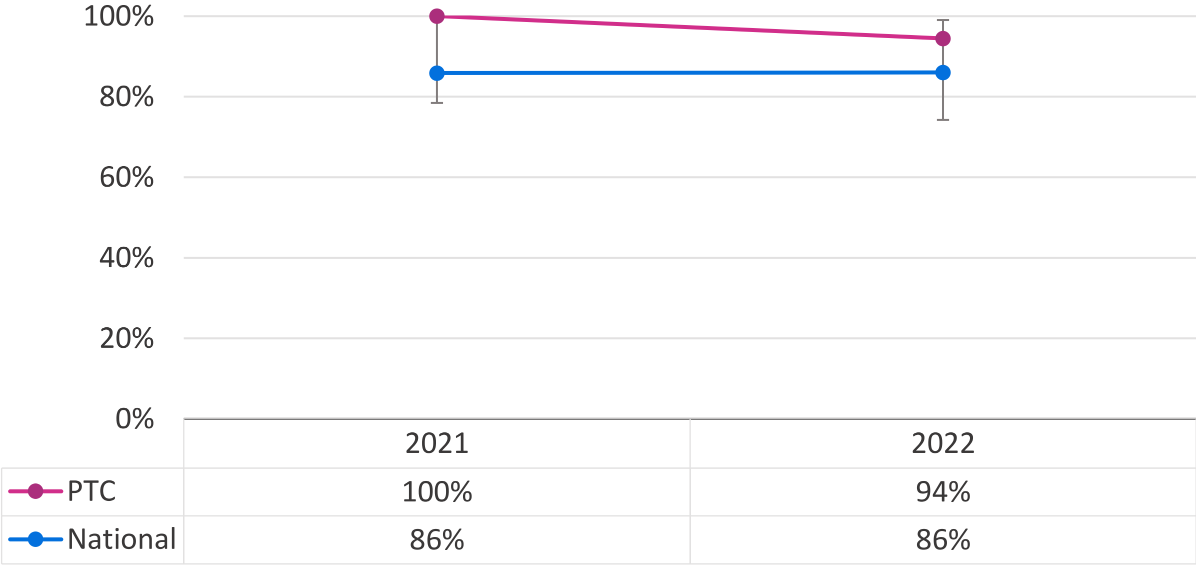


	2021	2022
PTC	89%	71%
National	75%	74%

Question X10: Asked to parents/carers of all age groups who were told about their child's cancer or a tumour. Total PTC responses for 2021 = 18, for 2022 = 14.

Healthcare staff

Figure 47. Children felt that staff were always friendly

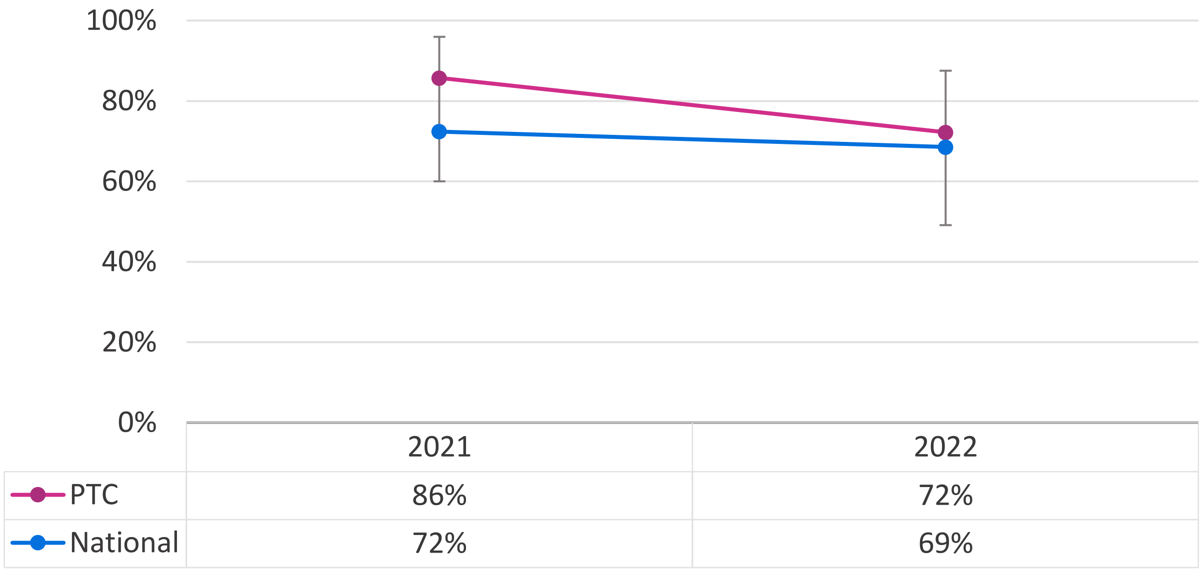


	2021	2022
PTC	100%	94%
National	86%	86%

Question X12: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, for 2022 = 18.

Healthcare staff

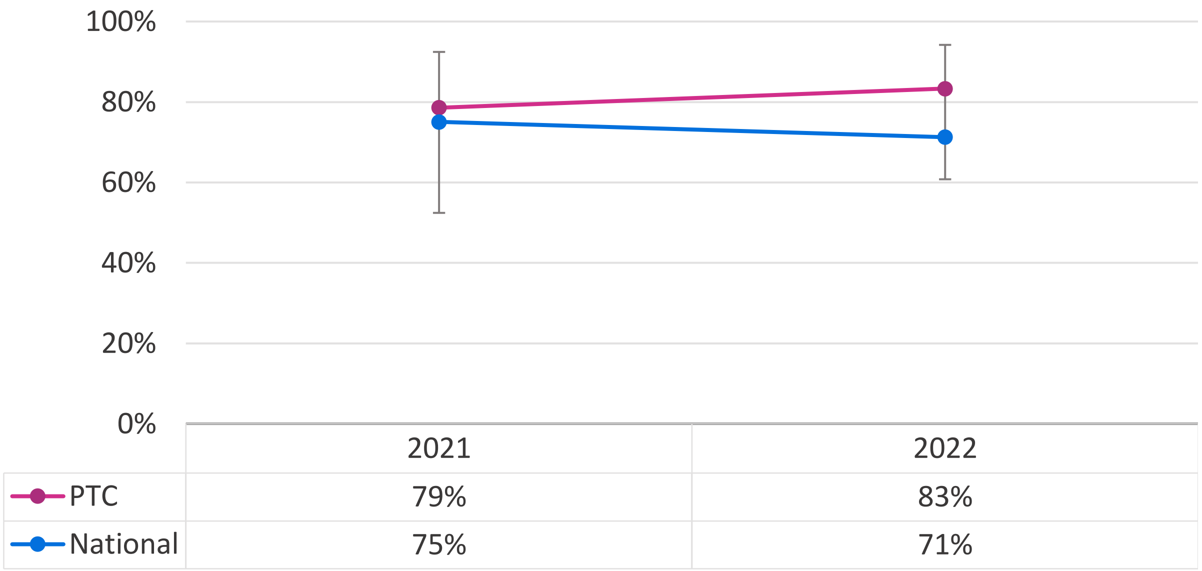
Figure 48. Children reported that they could always understand what staff were saying



	2021	2022
PTC	86%	72%
National	72%	69%

Question X13: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, for 2022 = 18.

Figure 49. Children felt that staff always talked to them, not just their parent or carer

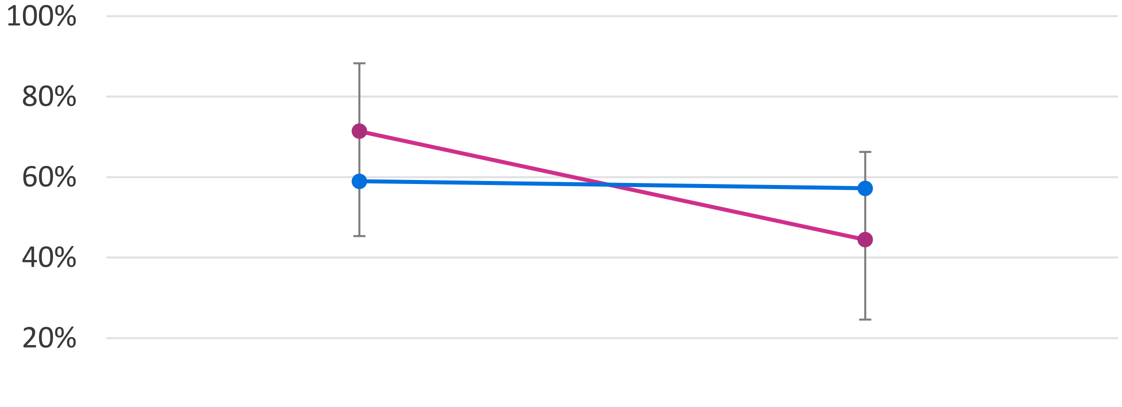


	2021	2022
PTC	79%	83%
National	75%	71%

Question X14: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, for 2022 = 18.

Healthcare staff

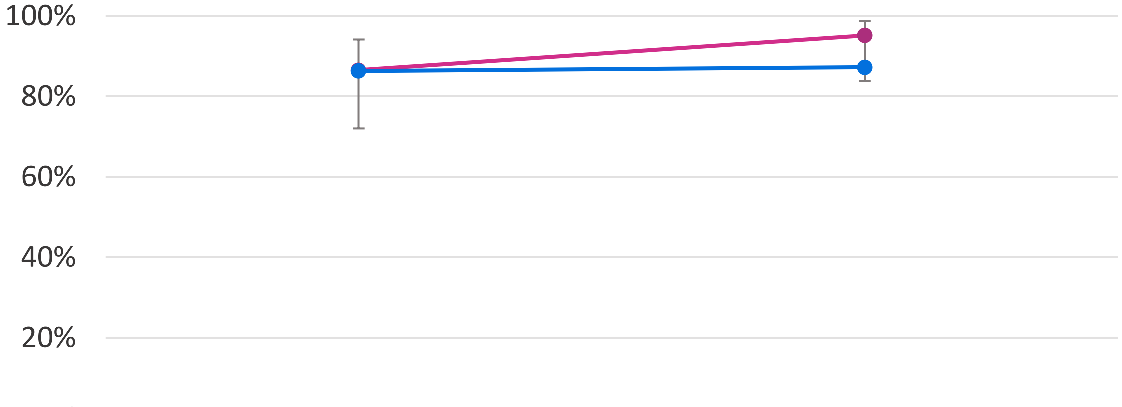
Figure 50. Children reported always or mostly seeing the same members of staff for their treatment and care



	2021	2022
PTC	71%	44%
National	59%	57%

Question X15: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, for 2022 = 18.

Figure 51. Parents/carers reported that they definitely had the chance to ask staff questions about their child's care and treatment

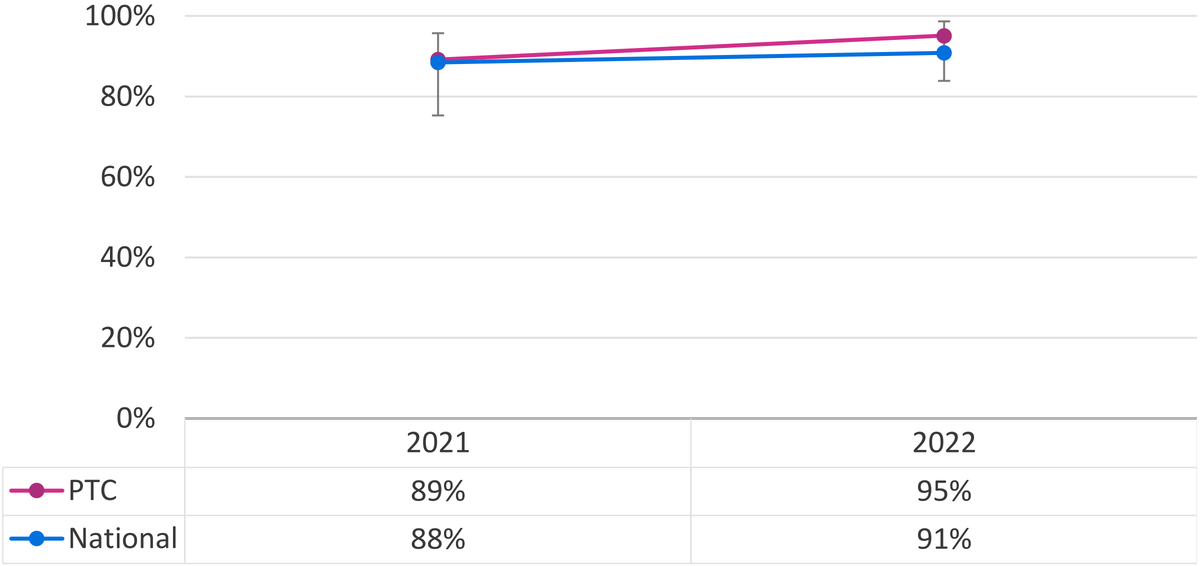


	2021	2022
PTC	86%	95%
National	86%	87%

Question X16: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 37, for 2022 = 41.

Healthcare staff

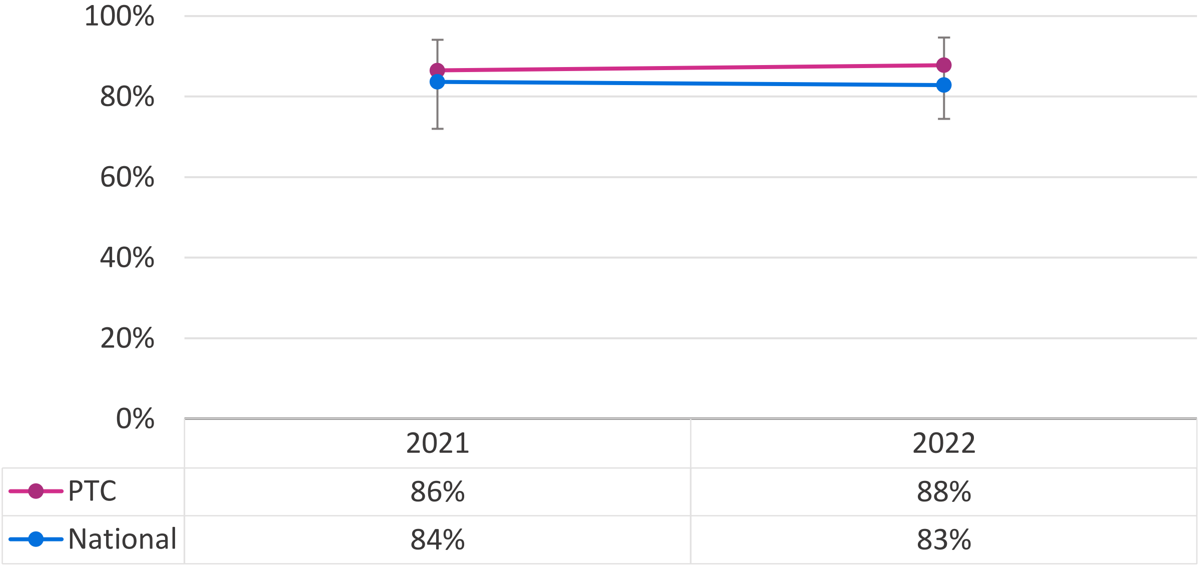
Figure 52. Parents/carers felt that they and their child were always treated with respect and dignity by staff



	2021	2022
PTC	89%	95%
National	88%	91%

Question X17: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 37, for 2022 = 41.

Figure 53. Parents/carers felt they always had confidence and trust in staff caring for their child

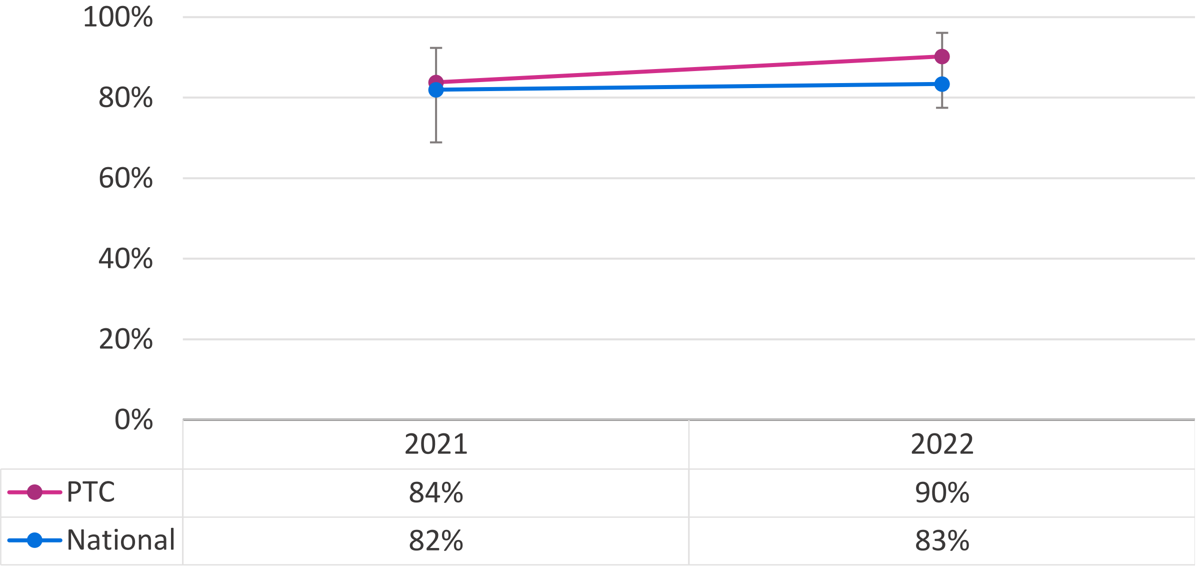


	2021	2022
PTC	86%	88%
National	84%	83%

Question X18: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 37, for 2022 = 41.

Healthcare staff

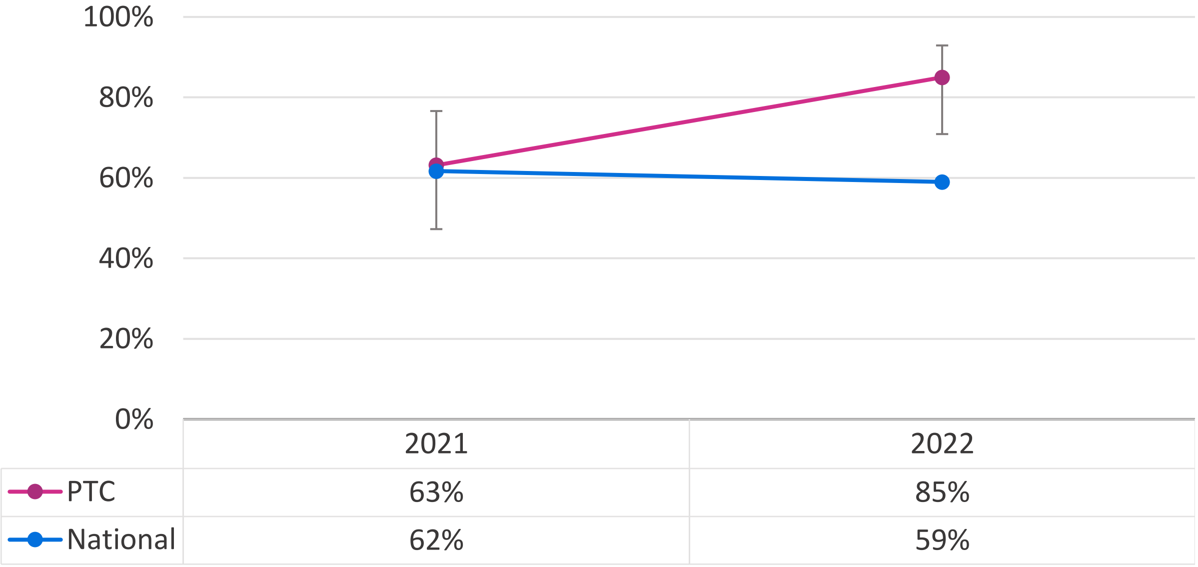
Figure 54. Parents/carers felt that they were always treated with empathy and understanding by staff caring for their child



	2021	2022
PTC	84%	90%
National	82%	83%

Question X19: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 37, for 2022 = 41.

Figure 55. Parents/carers and children reported not being told different things by different members of staff that left them feeling confused

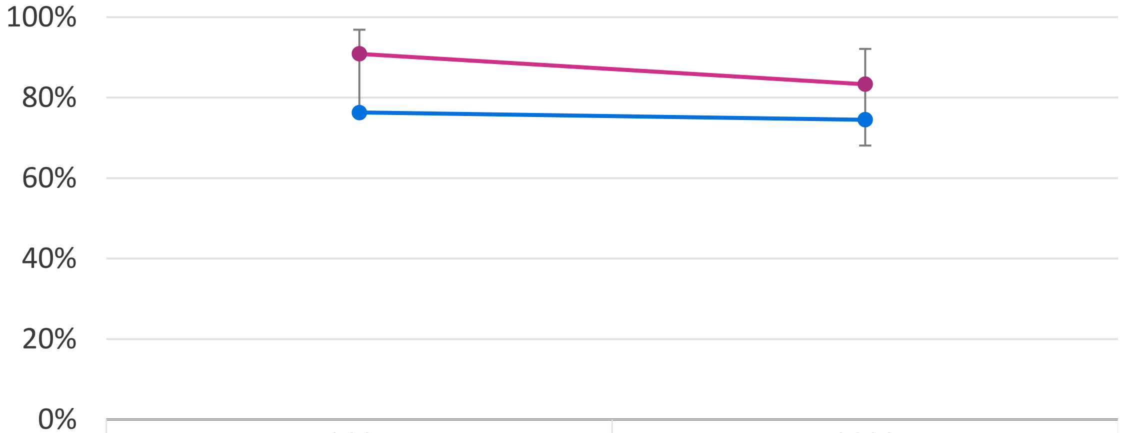


	2021	2022
PTC	63%	85%
National	62%	59%

Question X20: Asked to parents/carers of 0-7s and children aged 8-15. Total PTC responses for 2021 = 38, for 2022 = 40.

Healthcare staff

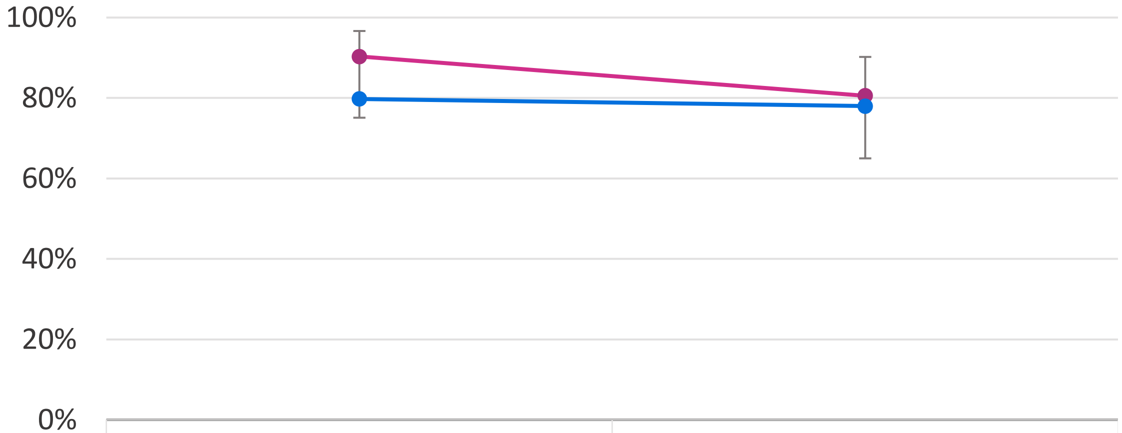
Figure 56. Parents/carers felt that staff were always sensitive to information shared with them when their child was in the room



	2021	2022
PTC	91%	83%
National	76%	75%

Question X21: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 33, for 2022 = 36.

Figure 57. Parents/carers felt that healthcare staff always shared information with children in a way that was appropriate

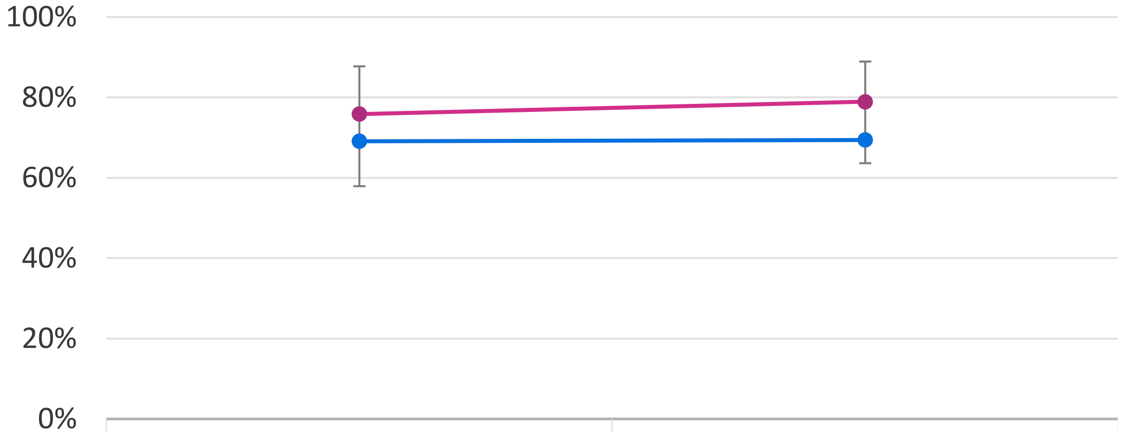


	2021	2022
PTC	90%	81%
National	80%	78%

Question X22: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 31, for 2022 = 36.

Healthcare staff

Figure 58. Parents/carers felt they had enough information about financial help or benefits

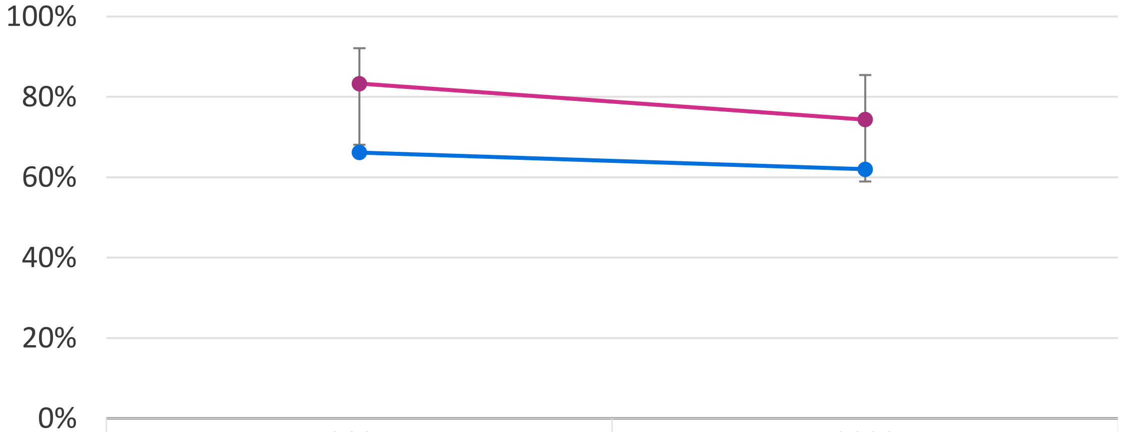


	2021	2022
● PTC	76%	79%
● National	69%	69%

Question X25: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 29, for 2022 = 38.

Child's care and treatment

Figure 59. Parents/carers felt that different hospital staff always worked well together

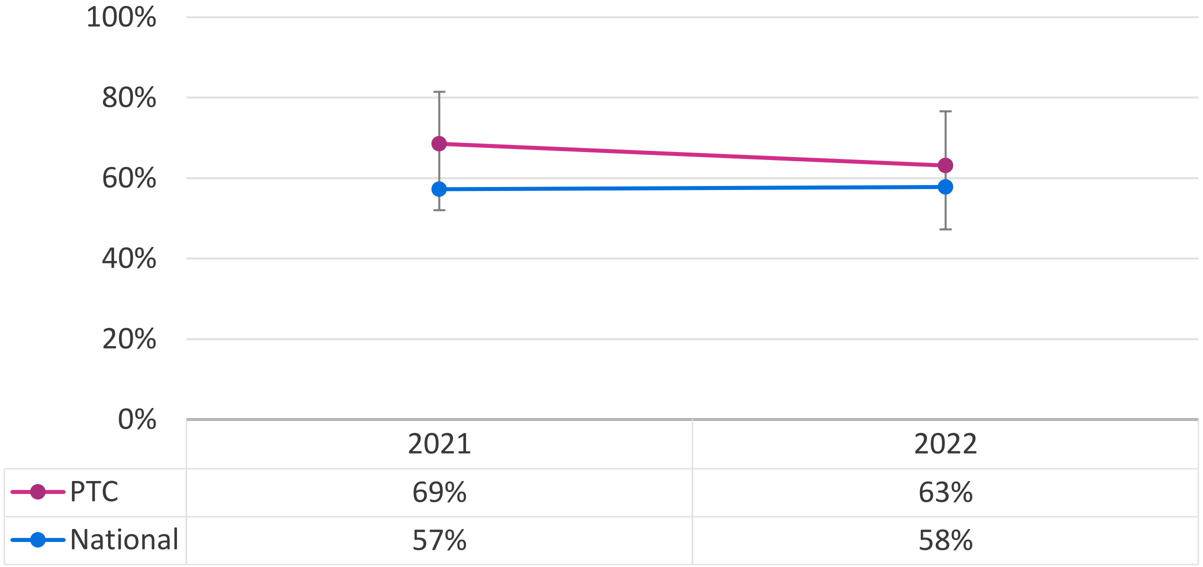


	2021	2022
● PTC	83%	74%
● National	66%	62%

Question X26: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 36, for 2022 = 39.

Child's care and treatment

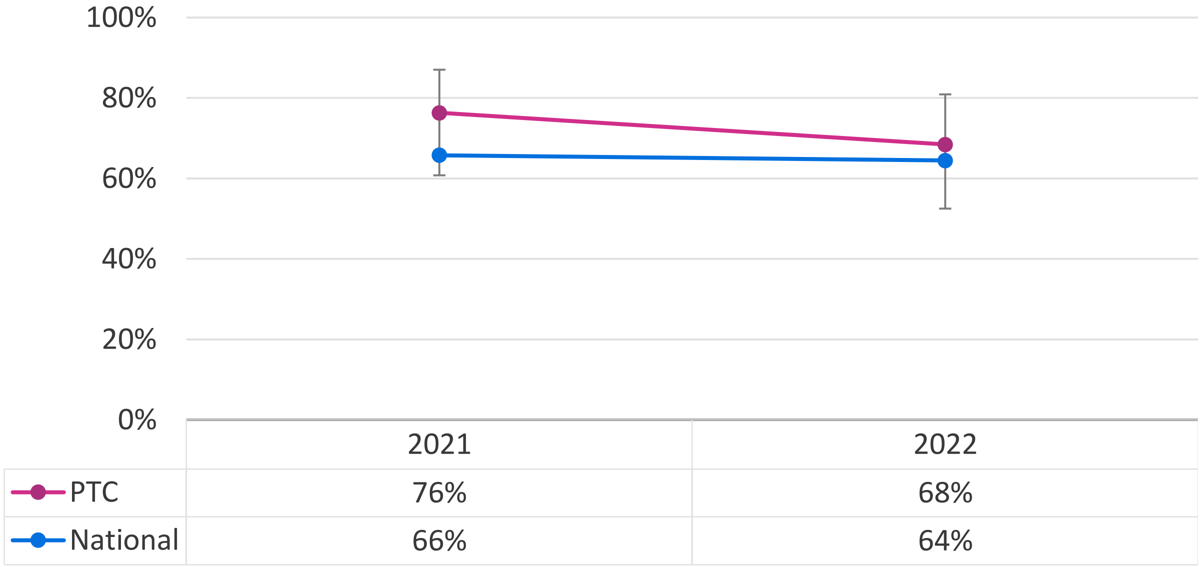
Figure 60. Parents/carers felt that different hospital staff were definitely aware of their child's medical history



	2021	2022
PTC	69%	63%
National	57%	58%

Question X27: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 35, for 2022 = 38.

Figure 61. Parents/carers and children felt they always knew what was happening with their child's/ their care

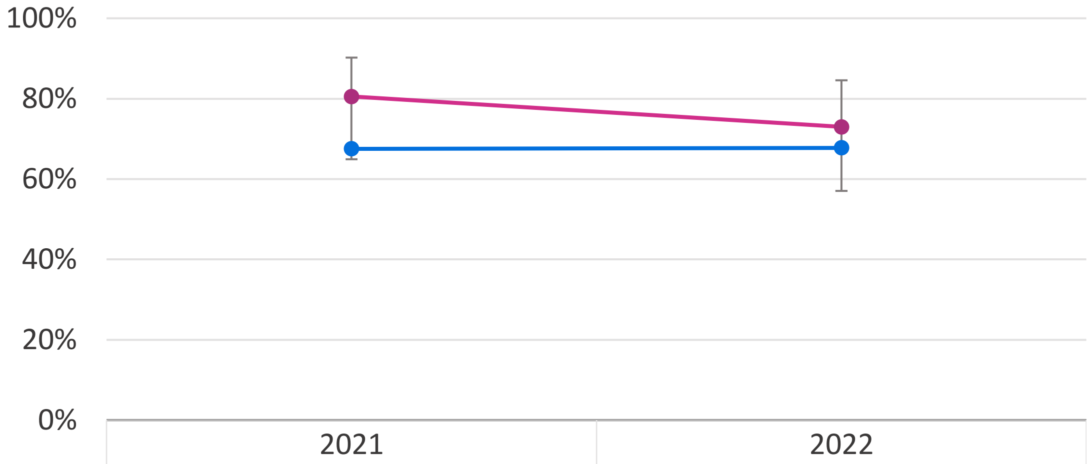


	2021	2022
PTC	76%	68%
National	66%	64%

Question X28: Asked to parents/carers of 0-7s and all children aged 8-15. Total PTC responses for 2021 = 38, for 2022 = 38.

Child's care and treatment

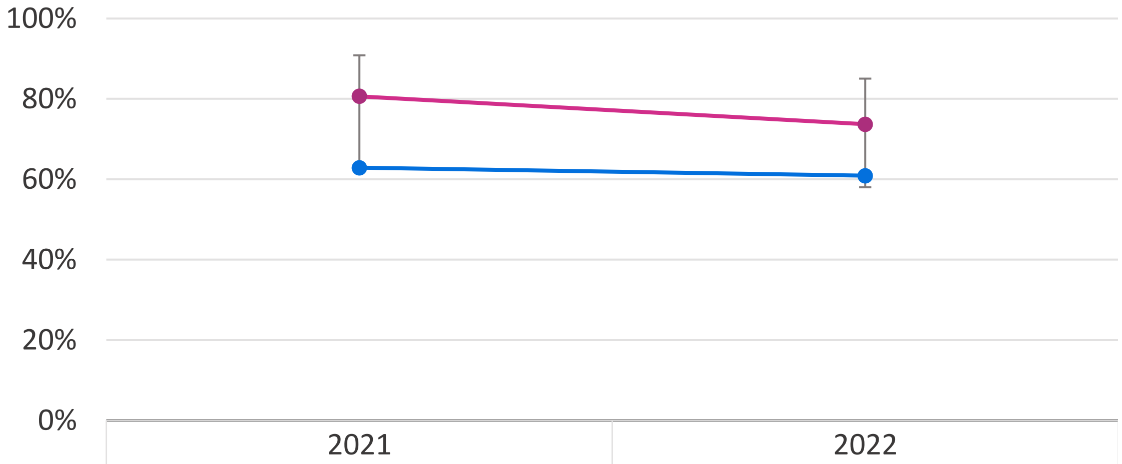
Figure 62. Parents/carers and children felt they were definitely involved in their child's/ their care and treatment



	2021	2022
PTC	81%	73%
National	68%	68%

Question X29: Asked to parents/carers of 0-7s and all children aged 8-15 . Total PTC responses for 2021 = 36, for 2022 = 37.

Figure 63. Parents/carers reported that they definitely had access to reliable help and support 7 days a week from the hospital

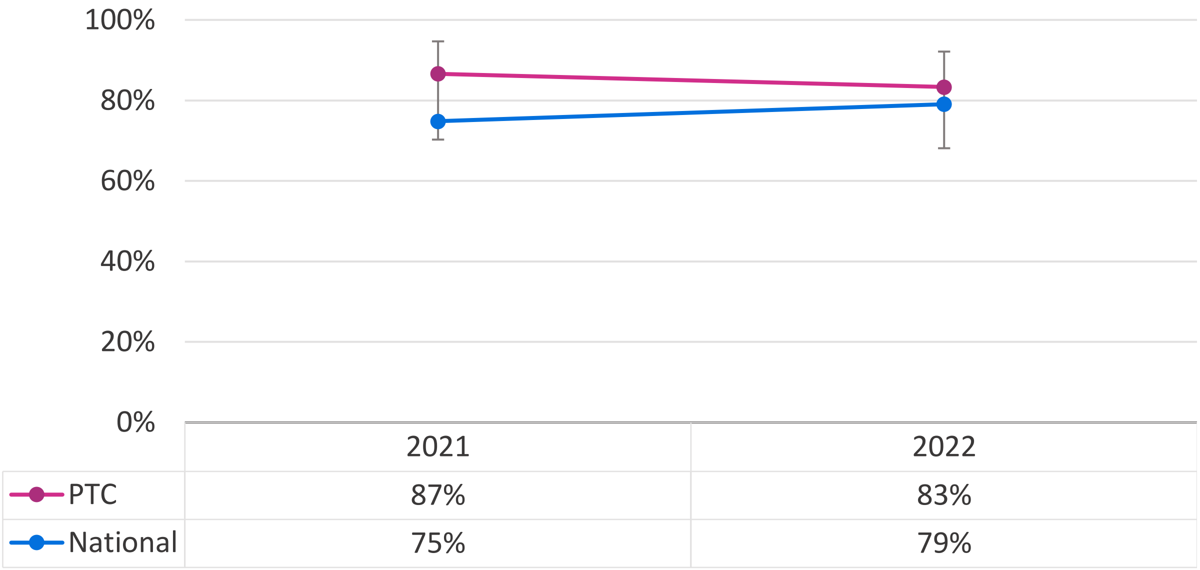


	2021	2022
PTC	81%	74%
National	63%	61%

Question X33: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 31, for 2022 = 38.

Child's care and treatment

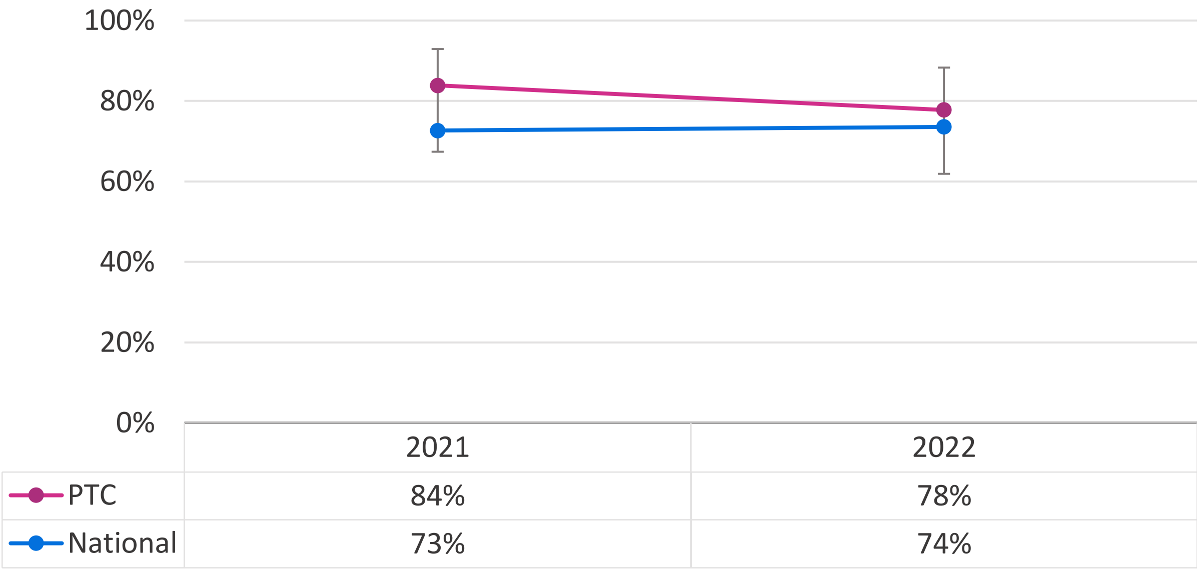
Figure 64. Parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment



	2021	2022
PTC	87%	83%
National	75%	79%

Question X37: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = 30, for 2022 = 36.

Figure 65. Parents/carers reported that staff definitely offered them support to help manage their child's treatment side effects

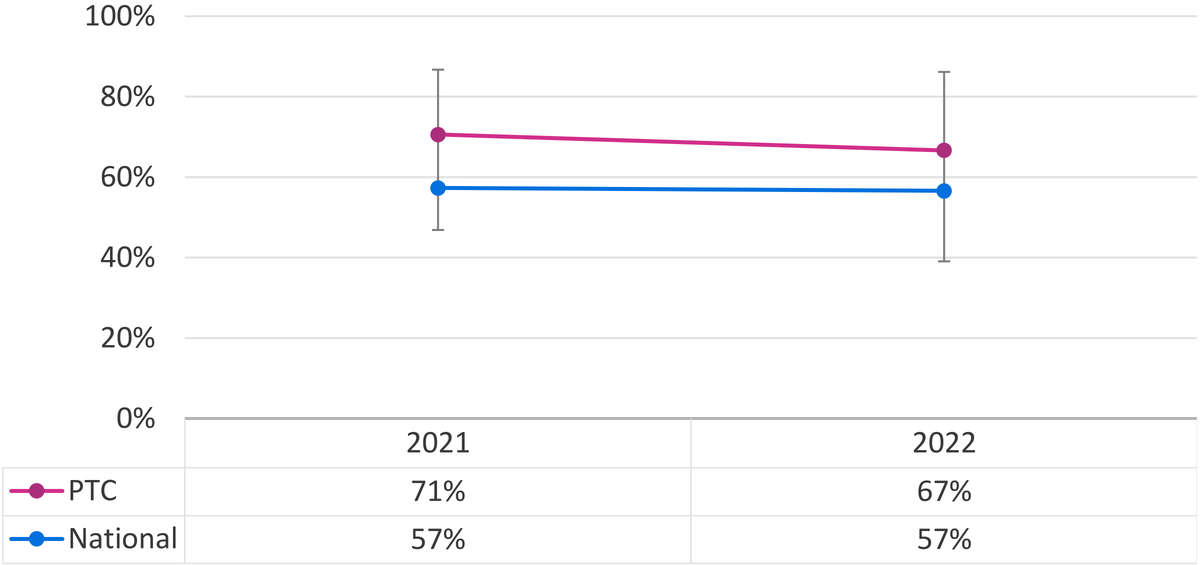


	2021	2022
PTC	84%	78%
National	73%	74%

Question X38: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = 31, for 2022 = 36.

Child's care and treatment

Figure 66. Parents/carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended

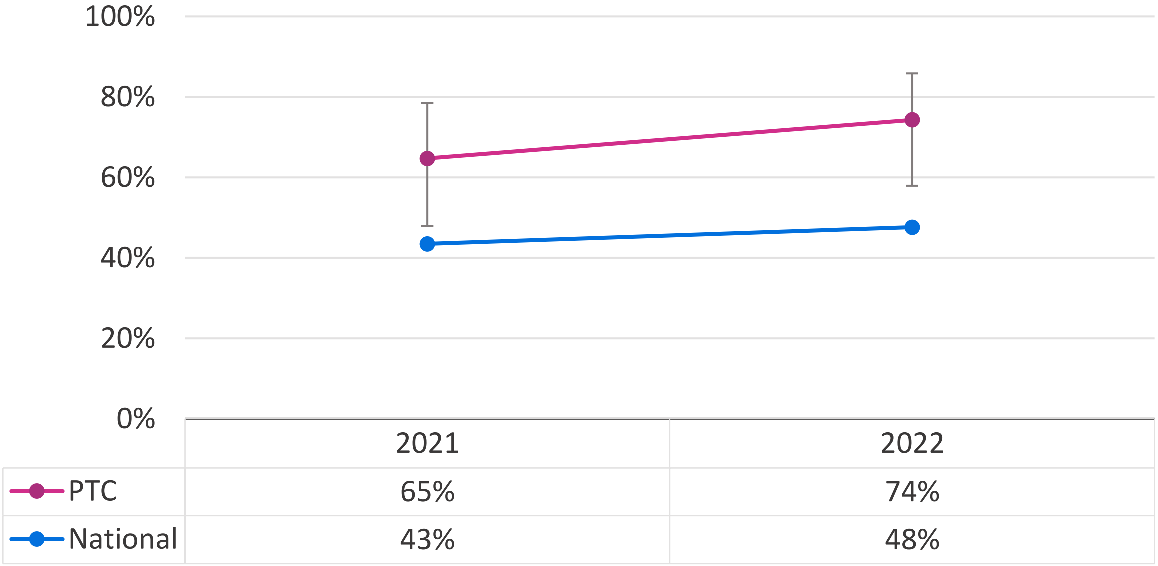


	2021	2022
PTC	71%	67%
National	57%	57%

Question X39: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = 17, for 2022 = 12.

Care in hospital

Figure 67. Parents/carers and children felt that there were definitely enough things for their child to do in the hospital

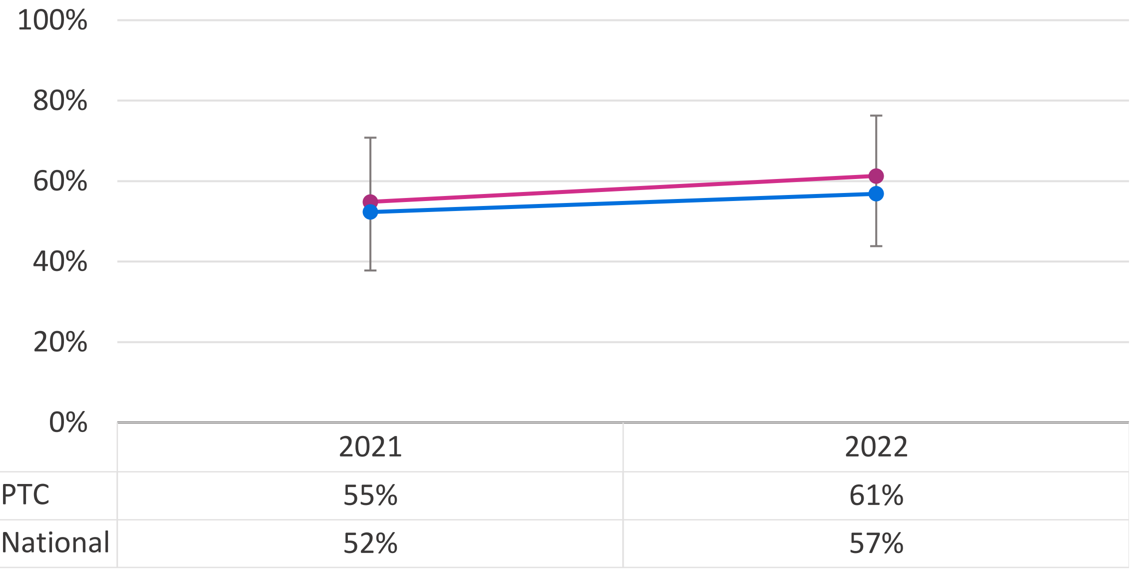


	2021	2022
PTC	65%	74%
National	43%	48%

Question X43: Asked to parents/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 = 34, for 2022 = 35.

Care in hospital

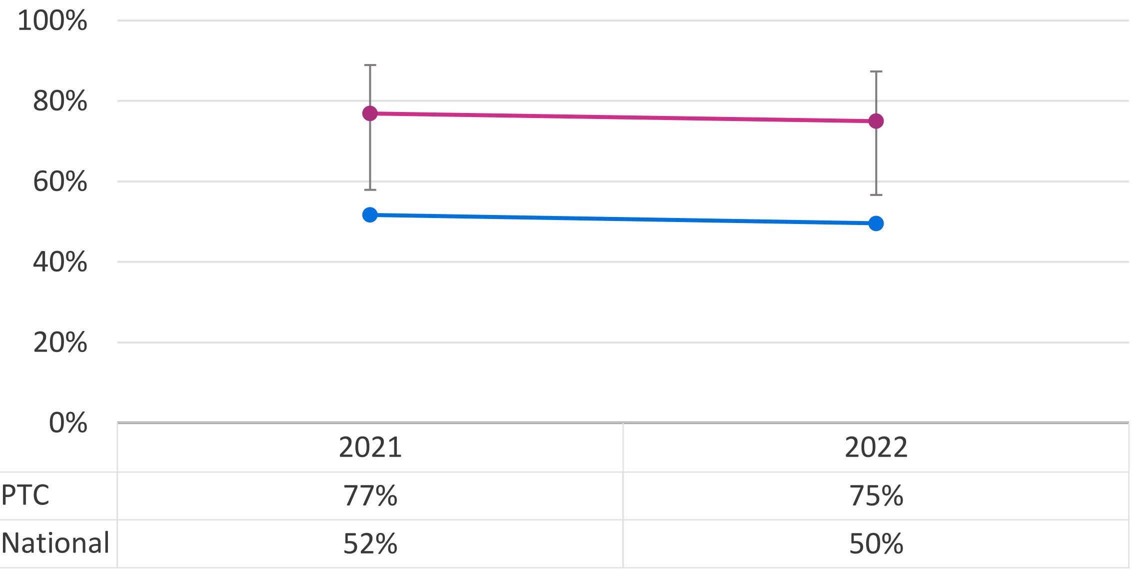
Figure 68. Parents/carers and children felt that there was definitely a choice of hospital food



	2021	2022
PTC	55%	61%
National	52%	57%

Question X44: Asked to parents/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 = 31, for 2022 = 31.

Figure 69. Parents/carers and children reported always being given somewhere private to talk to staff when their child was in hospital

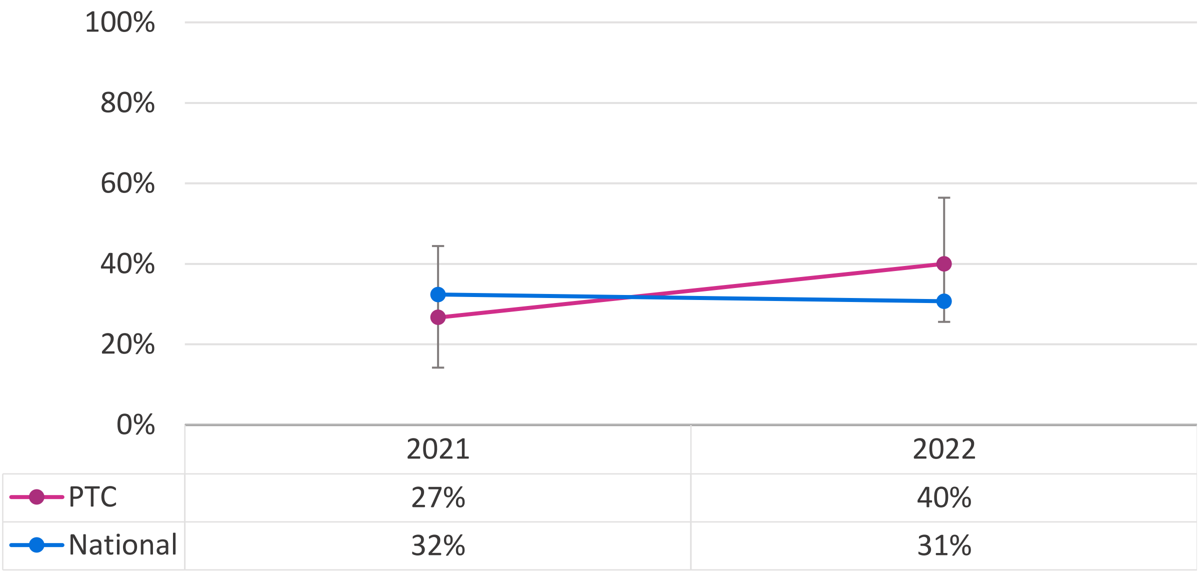


	2021	2022
PTC	77%	75%
National	52%	50%

Question X45: Asked to parents/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 = 26, for 2022 = 28.

Care in hospital

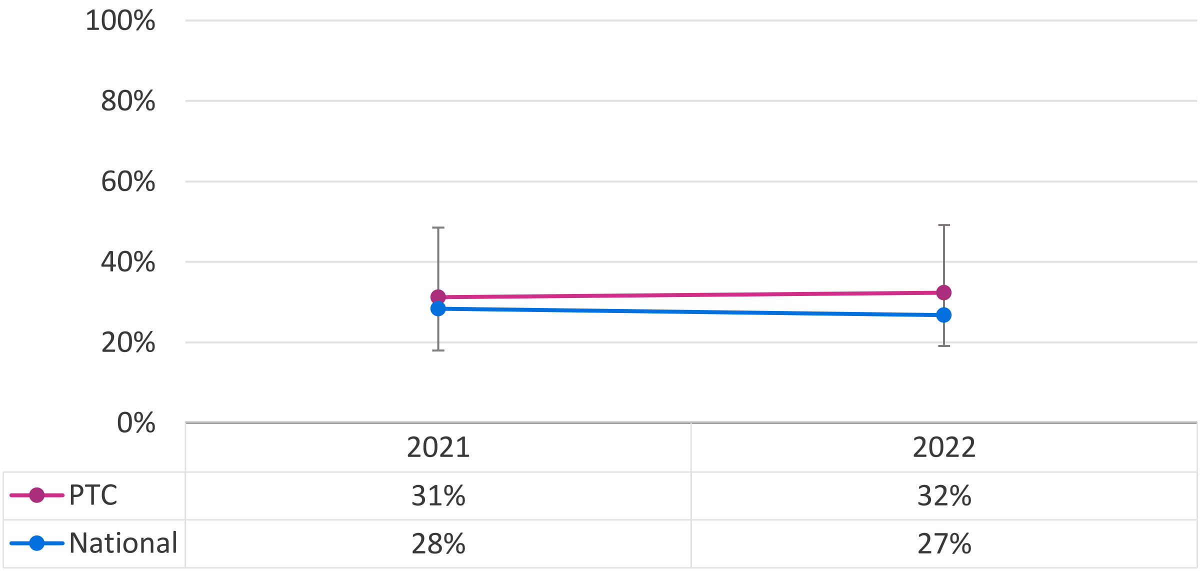
Figure 70. Parents/carers reported that facilities for them to stay overnight were very good



	2021	2022
PTC	27%	40%
National	32%	31%

Question X48: Asked to parents/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 = 30, for 2022 = 35.

Figure 71. Parents/carers and children reported that it was always quiet enough for them to sleep in the hospital

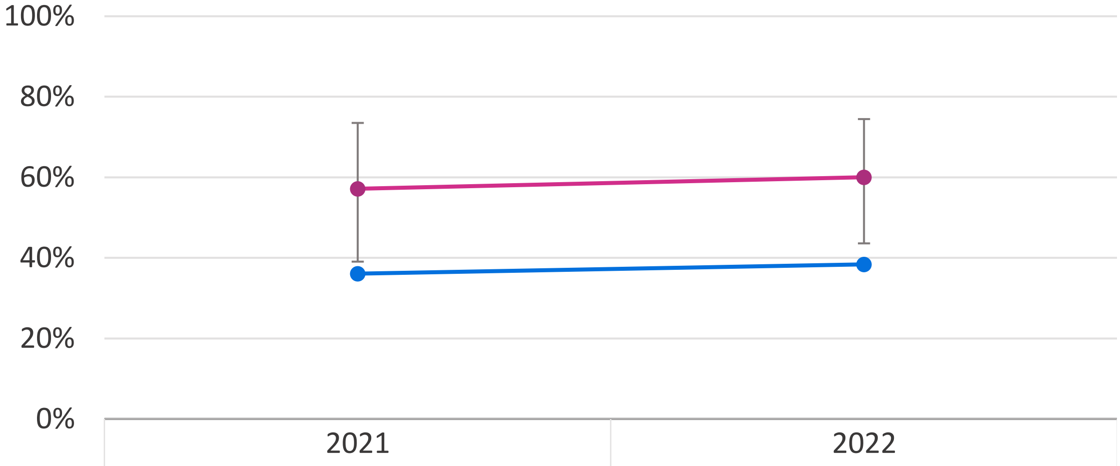


	2021	2022
PTC	31%	32%
National	28%	27%

Question X49: Asked to parents/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 = 32, for 2022 = 34.

Care in hospital

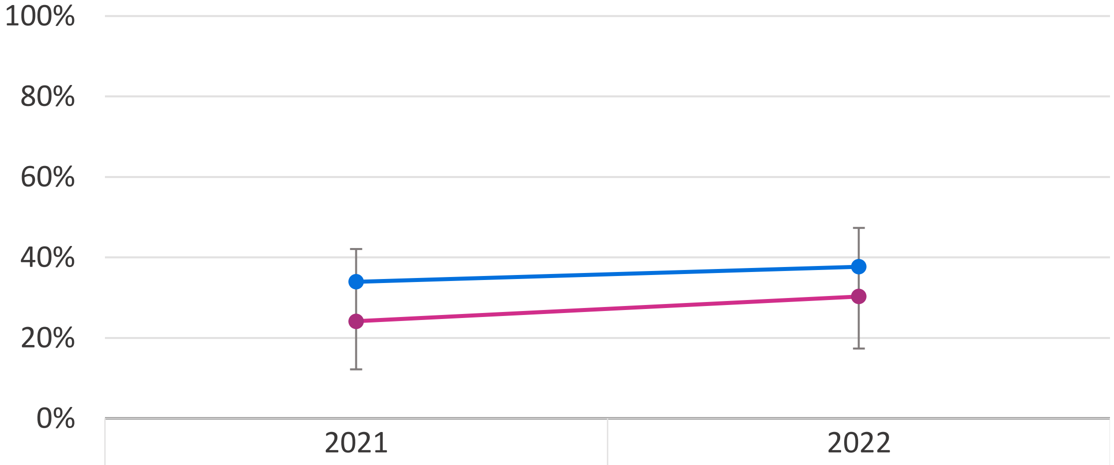
Figure 72. Parents/carers reported they were definitely able to prepare food in the hospital if they wanted to



	2021	2022
PTC	57%	60%
National	36%	38%

Question X50: Asked to parents/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 = 28, for 2022 = 35.

Figure 73. Parents/carers felt that the hospital Wi-Fi always met the needs of them and their child

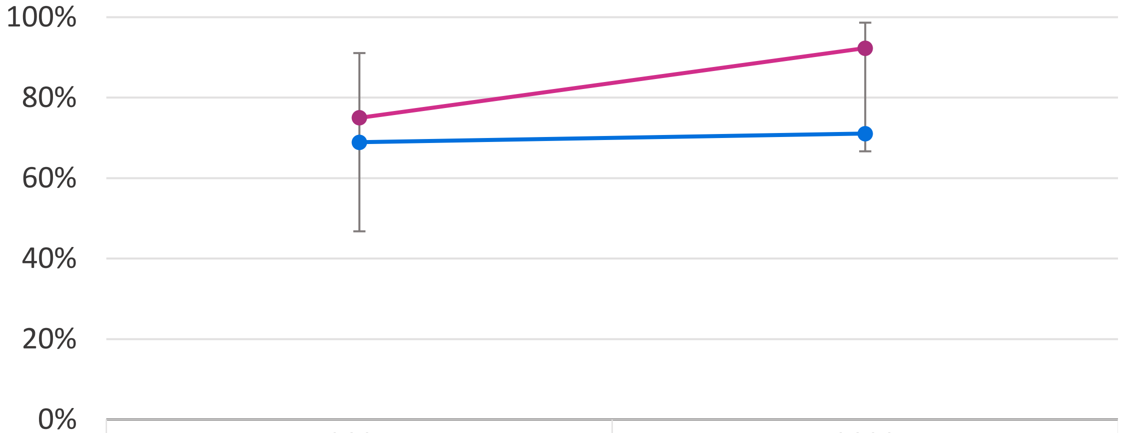


	2021	2022
PTC	24%	30%
National	34%	38%

Question X51: Asked to parents/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 = 29, for 2022 = 33.

Care in hospital

Figure 74. Parents/carers reported that their child had access to hospital school services during their stay in hospital

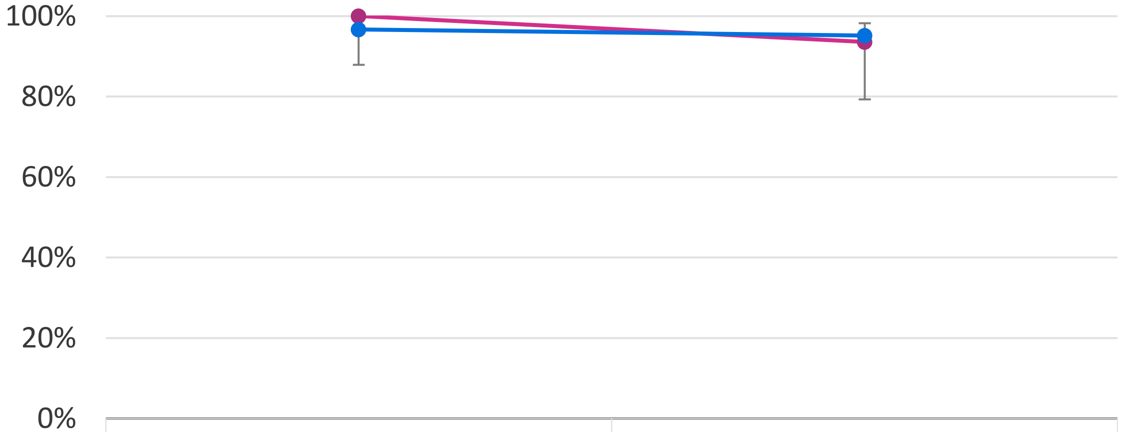


	2021	2022
PTC	75%	92%
National	69%	71%

Question X52: Asked to parents/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 = 12, for 2022 = 13.

Care at home or at school

Figure 75. Parents/carers and children felt that the nurses who came to their home or school were always friendly

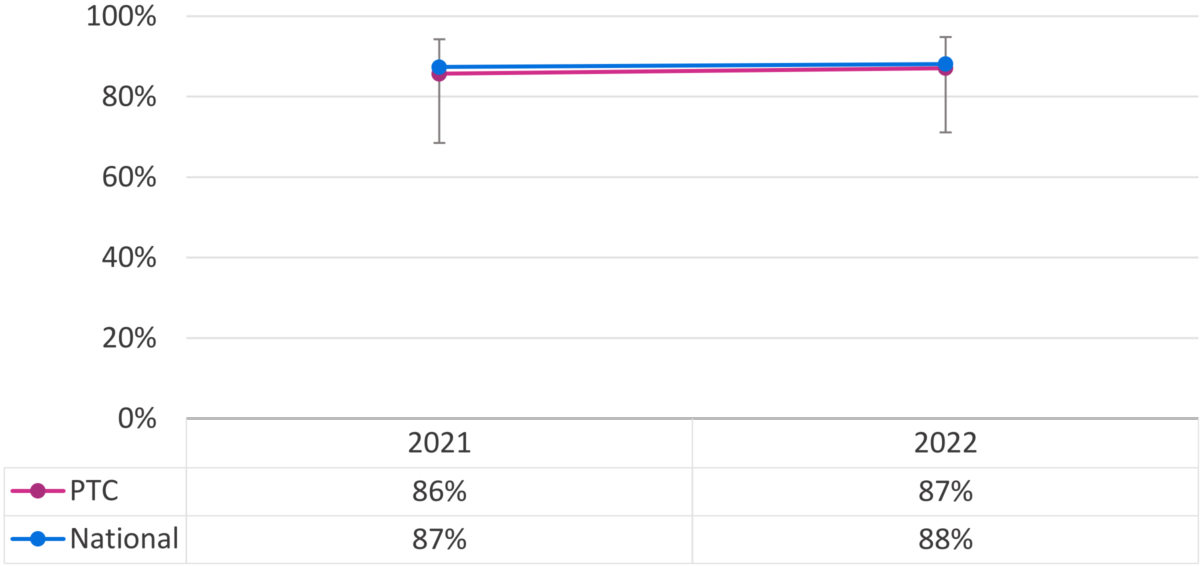


	2021	2022
PTC	100%	94%
National	97%	95%

Question X54: Asked to parents/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 = 28, for 2022 = 31.

Care at home or at school

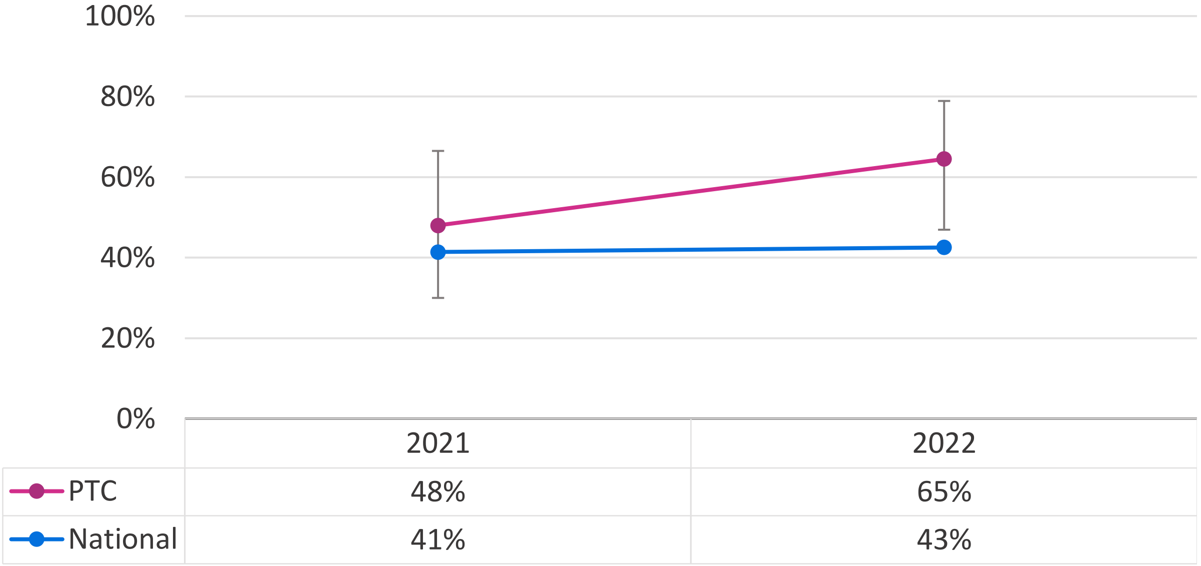
Figure 76. Parents/carers and children reported that they always understood what nurses visiting their home or school were saying



	2021	2022
PTC	86%	87%
National	87%	88%

Question X55: Asked to parents/ 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 = 28, for 2022 = 31.

Figure 77. Parents/carers and children reported that the same nurses always came to their home or school

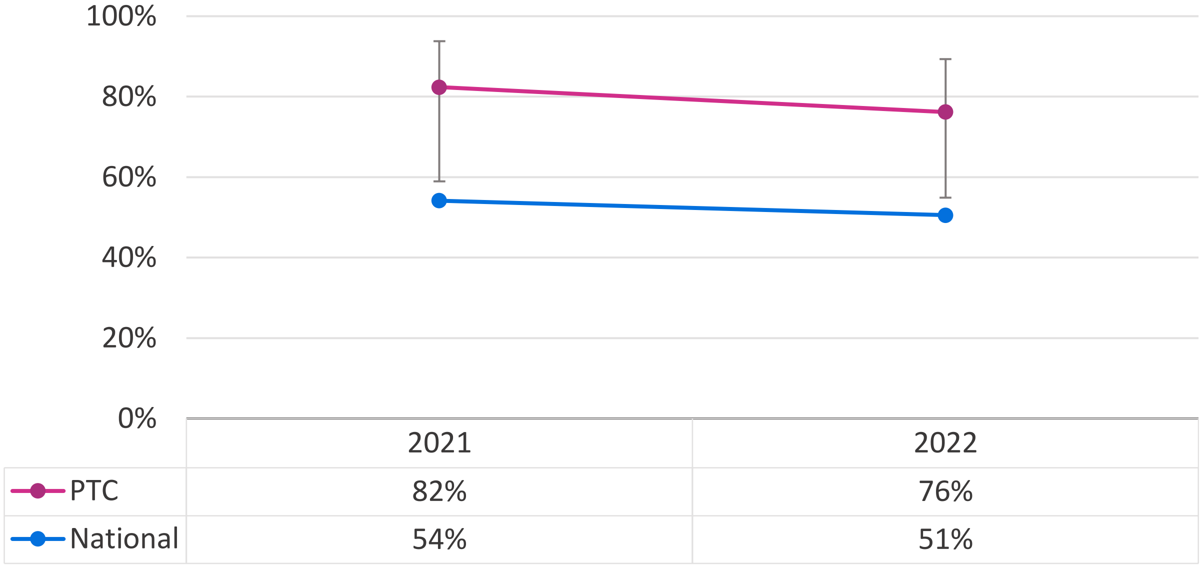


	2021	2022
PTC	48%	65%
National	41%	43%

Question X56: Asked to parents/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 = 25, for 2022 = 31.

Overall care

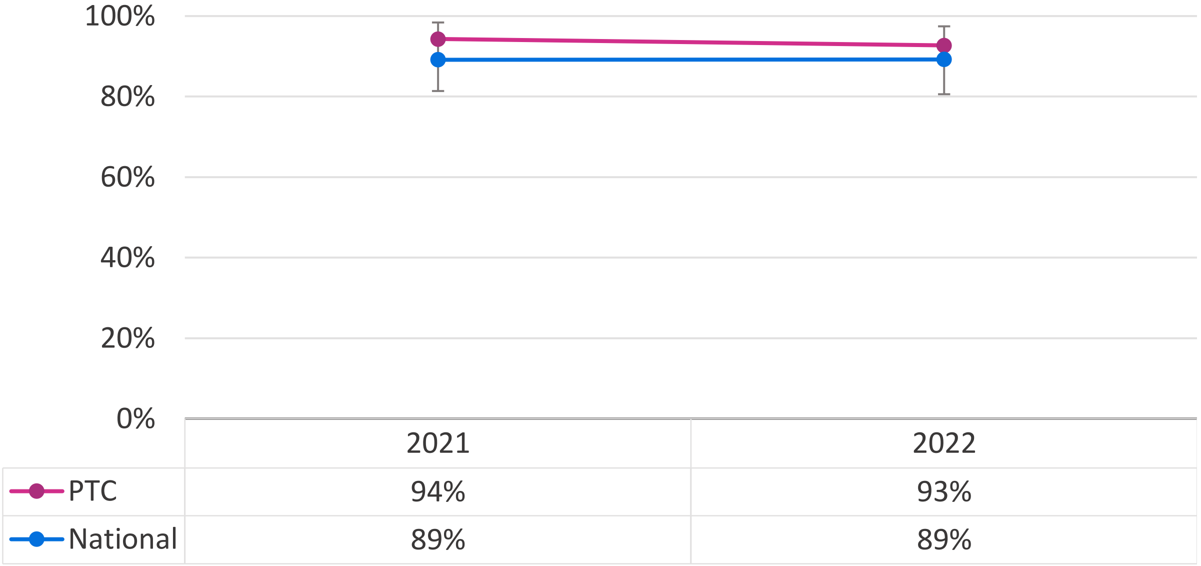
Figure 78. Parents/carers and children reported that different hospitals providing cancer or tumour care always worked well together



	2021	2022
PTC	82%	76%
National	54%	51%

Question X57: Asked to parents/carers of children aged 0-11, and children aged 12-15. Total PTC responses for 2021 = 17, for 2022 = 21.

Figure 79. Parents/carers rated the overall experience of their child's care as 8 or more out of 10

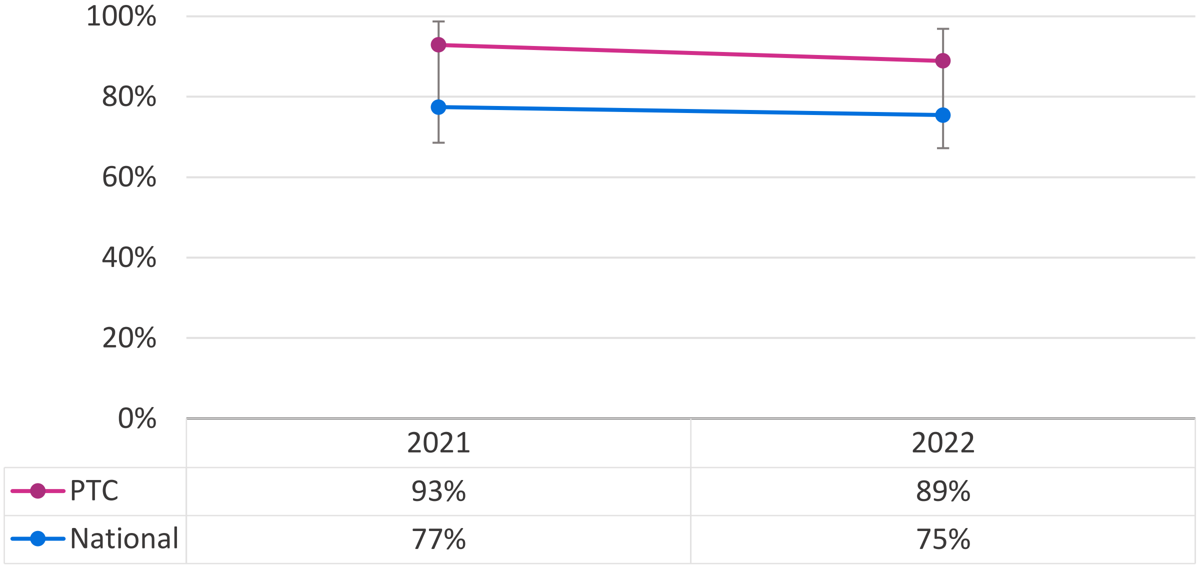


	2021	2022
PTC	94%	93%
National	89%	89%

Question X59: Asked to parents/carers of all age groups. Total PTC responses for 2021 = 35, for 2022 = 41.

Overall care

Figure 80. Children reported that they were very well looked after by staff for their cancer or tumour



	2021	2022
PTC	93%	89%
National	77%	75%

Question X60: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, for 2022 = 18.

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

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 2022 survey data has been produced and published in line with the Code of Practice for Official Statistics.