



Under 16 Cancer Patient Experience Survey 2024

Quantitative Results

Sheffield Children's NHS Foundation Trust





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Executive summary

Overall PTC response rate

Nationally, 759 responded out of a total of 3,434 eligible parents, carers, and children who were sent a survey, resulting in a response rate of 22%. 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
Sheffield Children's NHS Foundation Trust	129	129	30	23%

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 <u>survey website</u>.

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 told about their child's cancer or tumour diagnosis in a sensitive way

(Question X07)



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

(Question X08)



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



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

(Question X37)



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



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

(Question X33)



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

(Question X27)



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

(Question X39)



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 2024 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 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 2024 and 31 December 2024 and were aged under 16 at the time of their discharge[†].

The fieldwork for the survey was undertaken between April and June 2025. 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 2025) as opposed to their age at the time they received care, to ensure the most ageappropriate 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.



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 <u>'Year on year comparisons'</u> section of this report presents charts showing the scores for your PTC between 2021, 2022, 2023, and 2024 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 2024 scores that are not comparable to 2021 – 2023 are not presented in this section and can be found in the data tables on the <u>survey website</u>.

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
	Yes, definitely	120	60%
Did staff offer you enough time to make decisions about your child's treatment?	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 <u>survey website</u>. Meanwhile, more details on scoring can be found in the Technical Document on the <u>survey website</u>.

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 2024 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 2024 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

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



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	129	129	30	23%

Table 2: Percent of responses by survey mode

	PTC		Nati	onal
Survey mode	n	%	n	%
Paper	20	67%	511	67%
Online	10	33%	248	33%
Phone – English	0	0%	0	0%
Phone – translation service	0	0%	0	0%
Mixed (combination of paper and online) †††	0	0%	0	0%

Table 3: Percent of responses by survey type

	PTC		Nati	onal
Survey type	n	%	n	%
0-7 Survey	*	*	353	47%
8-11 Survey	7	23%	144	19%
12-15 Survey	*	*	262	35%

[†]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.

ttt 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		Nati	ional
Ethnic group	n	%	n	%
White	*	*	548	72%
Mixed	*	*	44	6%
Asian	*	*	83	11%
Black	*	*	38	5%
Other ethnic groups	0	0%	13	2%

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

	РТС		Nati	onal
Which of the following best describes you? (asked to children aged 8-15)	n	%	n	%
Boy / Male	9	56%	204	50%
Girl / Female	7	44%	158	39%

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

	PTC		Nati	onal
Sex registered at birth	n	%	n	%
Male	16	53%	410	54%
Female	14	47%	313	41%



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

	РТС		Nati	onal
Current care or treatment stage	n	%	n	%
Recently diagnosed	*	*	6	1%
Watch and wait	*	*	55	7%
Receiving treatment	6	20%	303	40%
Finished treatment within the last one month	*	*	92	12%
In remission / long-term follow-up	14	47%	268	35%
Palliative or end of life care	0	0%	5	1%
Other	*	*	49	6%

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

	PTC		Nati	onal
Diagnostic group	n	%	n	%
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	14	47%	286	38%
Lymphomas and reticuloendothelial neoplasms	*	*	97	13%
CNS and miscellaneous intracranial and intraspinal neoplasms	8	27%	145	19%
All other	*	*	231	30%

Table 9: Percent of responses by long-term condition status **** (Question X65)

	PTC		Nati	onal
Long-term condition status	n	%	n	%
Another long-term condition	14	47%	252	33%
No other long-term condition	12	40%	419	55%
Not given	4	13%	88	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 Document, available on the <u>survey website</u>.

^{†††}Full LTC breakdown data can be found in the Excel Data Tables, available on the <u>survey website</u>.



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	*	*	185	24%
Yes, a little	16	57%	321	42%
No, not at all	*	*	215	28%

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	7	23%	137	18%
The parent or carer	5	17%	103	14%
Both the child / young patient and the parent or carer together	4	13%	136	18%
Not given	14	47%	383	50%

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)	11	37%	139	18%
2	8	27%	165	22%
3	*	*	136	18%
4	*	*	151	20%
5 (least deprived)	*	*	151	20%
Non-England	0	0%	17	2%

[†] Indices of Multiple Deprivation (IMD) classifies geographic areas into five quintiles based on relative disadvantage.



Overall care: subgroup comparisons

This section summarises the responses of various subgroups to questions asking about overall care. Further information about how these subgroups were determined can be found in the accompanying Technical Document, available on the survey website.

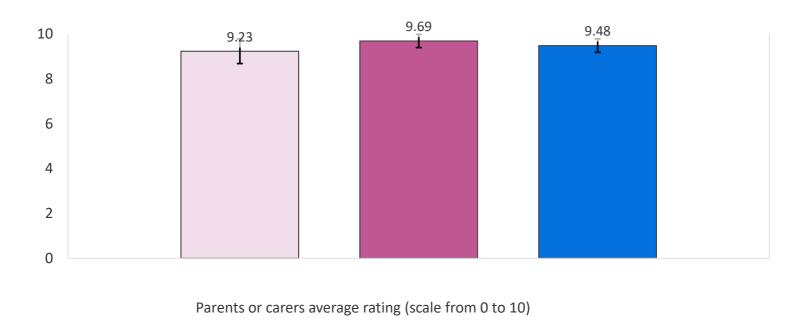
Questions asking about overall care were structured differently for children and parents or carers, therefore they cannot be directly compared. Children aged 8 and over were asked how well they were looked after for their cancer or tumour by healthcare staff and were given the options "Very well," "Quite 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 subgroup can be found in the PTC Excel Data Tables available on the <u>survey website</u>.

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 9.48 (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)



■ 8-15 survey

Question X59_mean: Asked to parents or carers of all age groups. Total responses = 29.

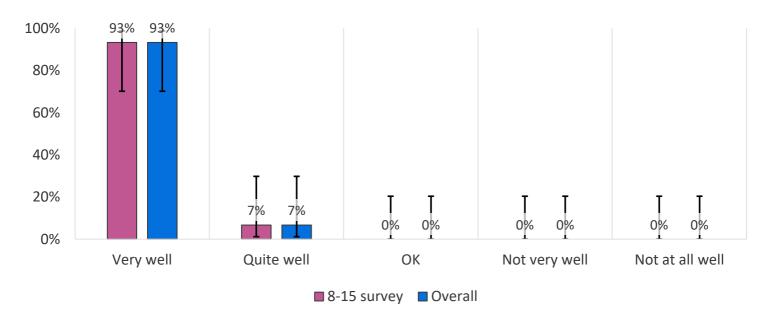
□ 0-7 survey

Overall



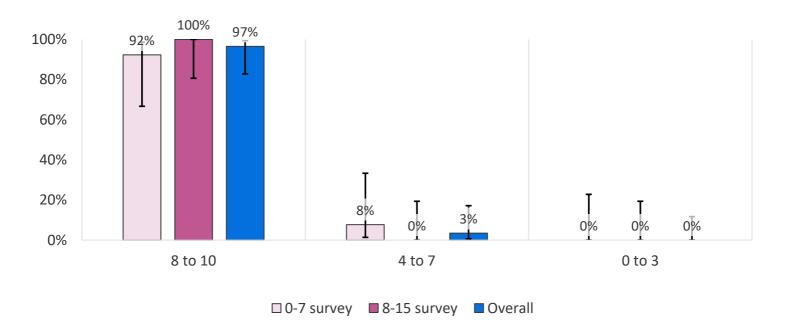
Survey type

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 = 15.

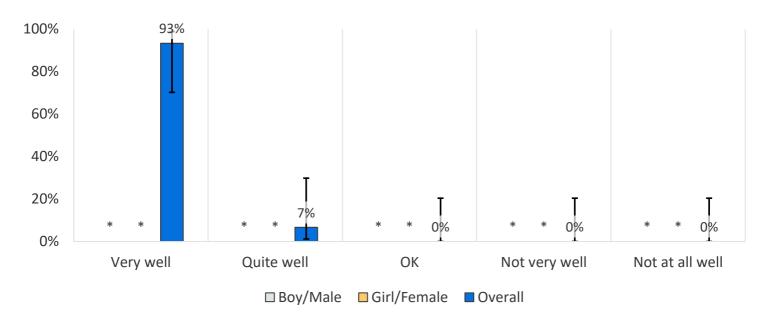
Figure 3: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)





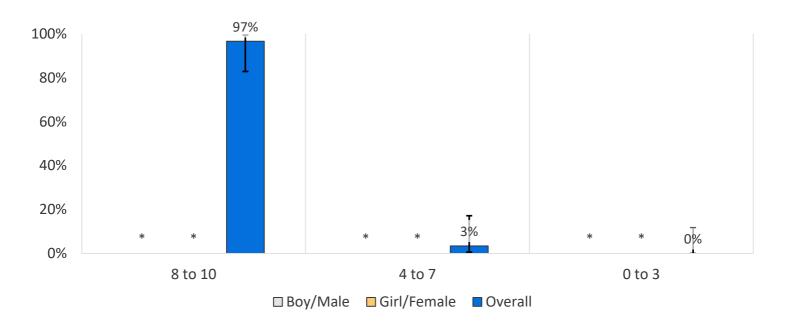
Which of the following best describes you?

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 = 15.

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

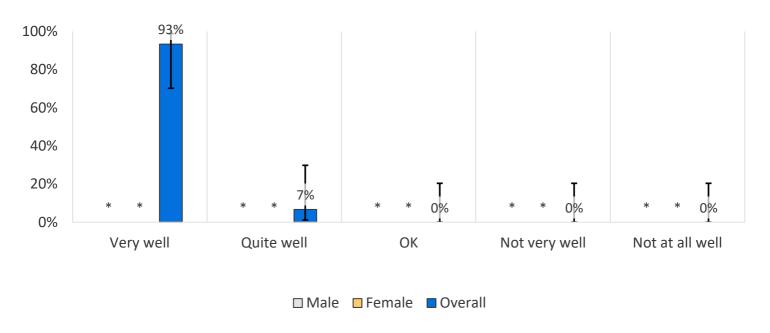


[†]Only data for boy / male and girl / female is shown, as the number of respondents answering 'I describe myself in another way' or 'prefer not to say' to this question was suppressed.



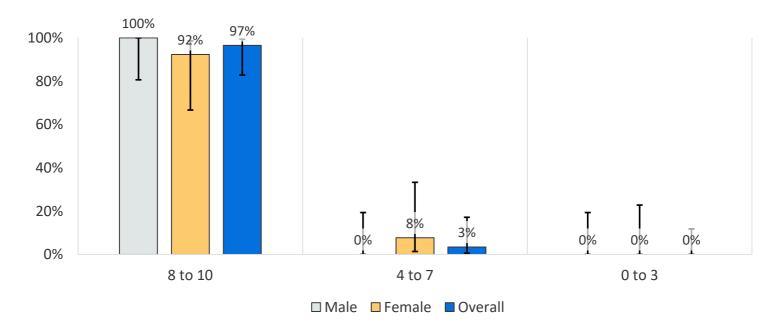
Sex registered at birth

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 = 15.

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

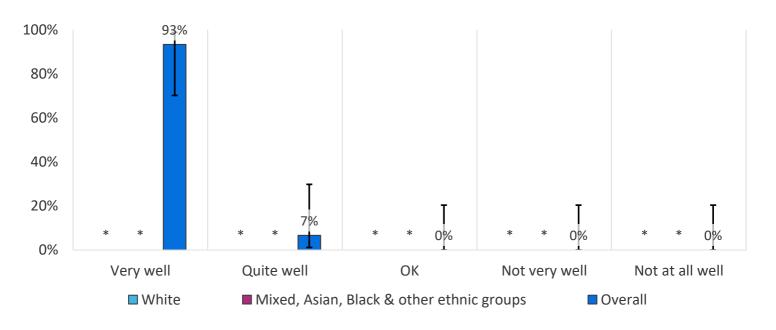


[†]Only data for male and female is shown, as the number of respondents answering 'prefer not to say' to the sex registered at birth question was suppressed.



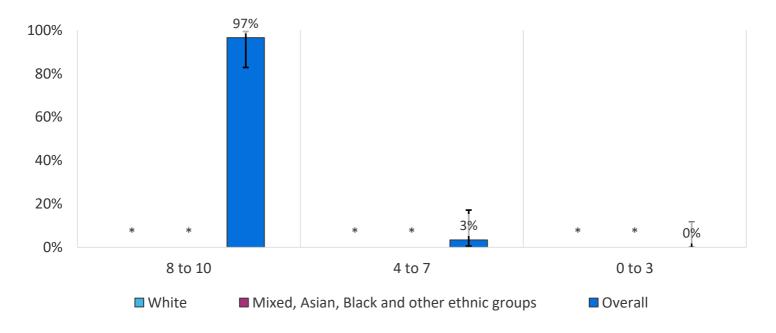
Ethnic group[†]

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 = 15.

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

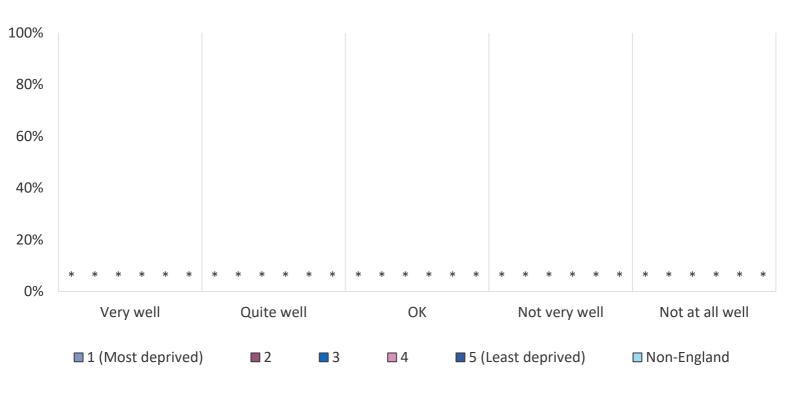


[†] Due to small numbers at PTC level, ethnic group data has been aggregated for the ethnic minority groups. It is important to note that there are often significant disparities in health outcomes between ethnic groups and caution is recommended when analysing this aggregated group i.e. poorer experience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



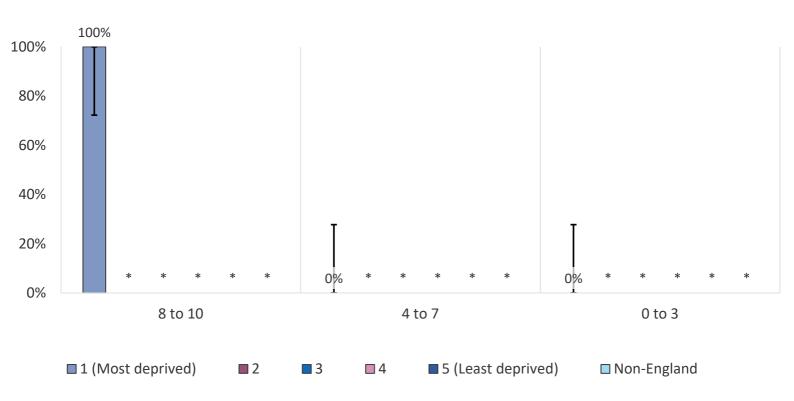
Deprivation (IMD quintile)

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 = 15.

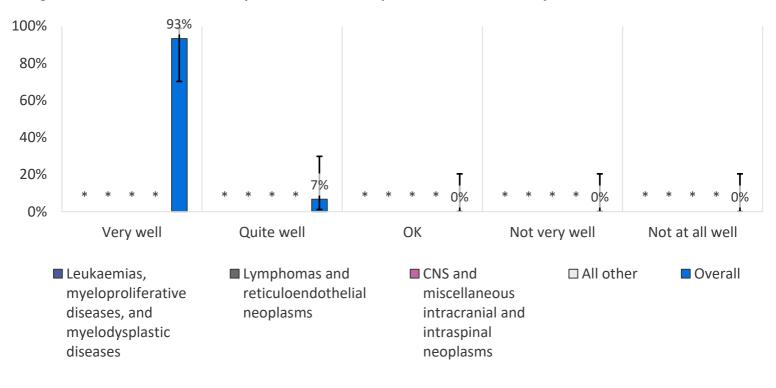
Figure 11: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)





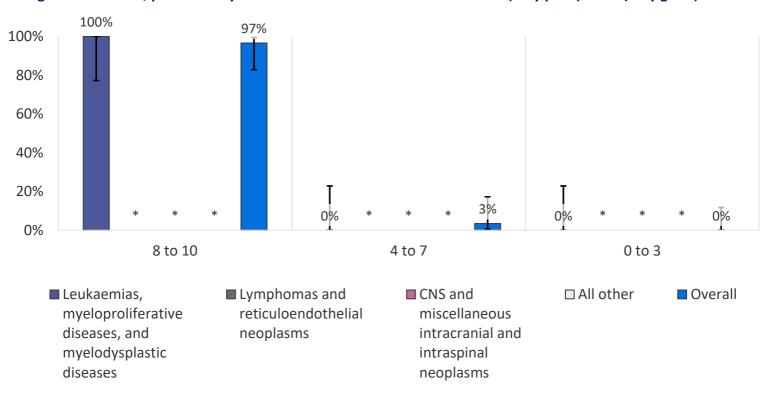
Diagnostic group

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 = 15.

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

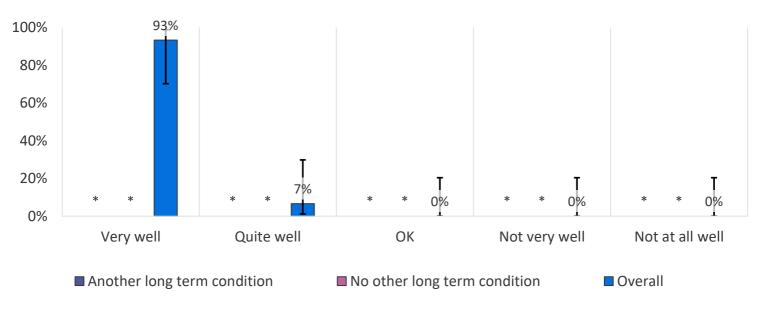


[†] Due to small numbers at PTC level, diagnostic group data has been aggregated to allow for some analysis by diagnostic group. It is, however, important to exercise caution when analysing aggregated groups i.e. poorer experience for some diagnostic groups is undetectable when aggregated.



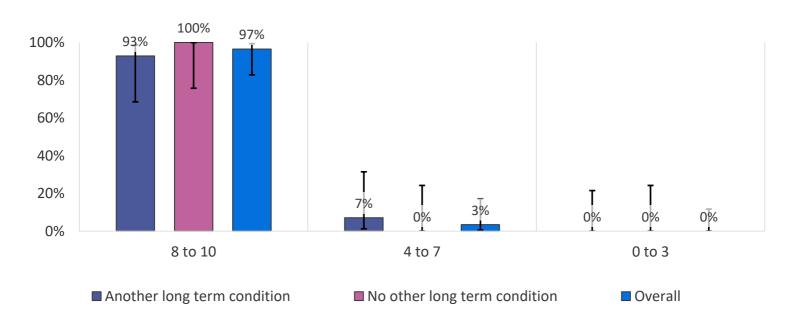
Long-term condition status

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 = 15.

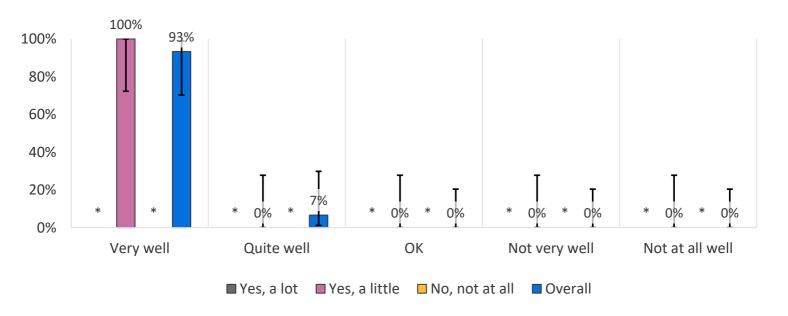
Figure 15: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)





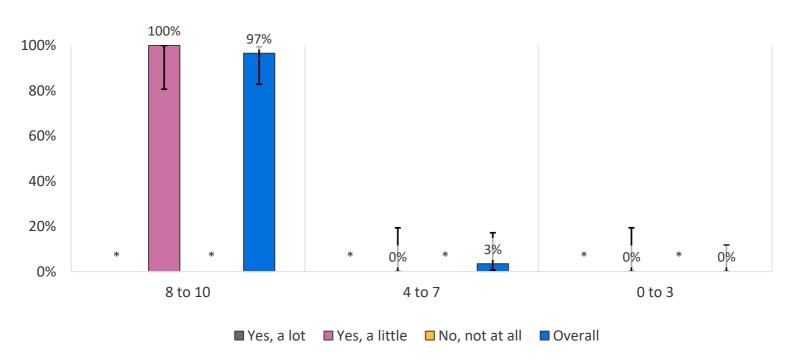
<u>Does the child's long-term condition or cancer reduce their ability to carry out their day-to-day activities?</u>

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 = 15.

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





Current care or treatment stage

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

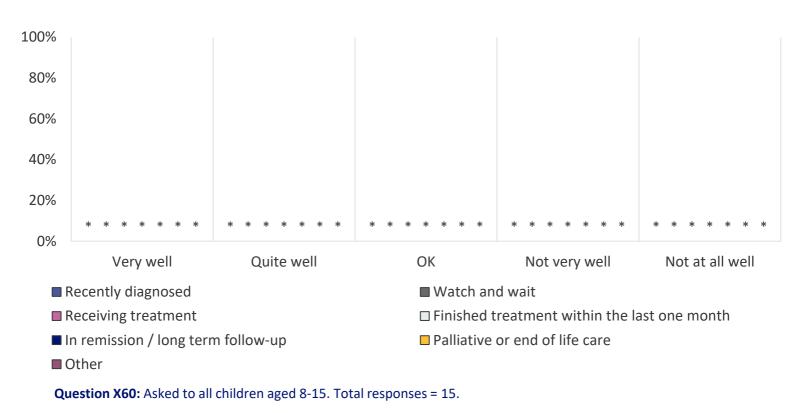
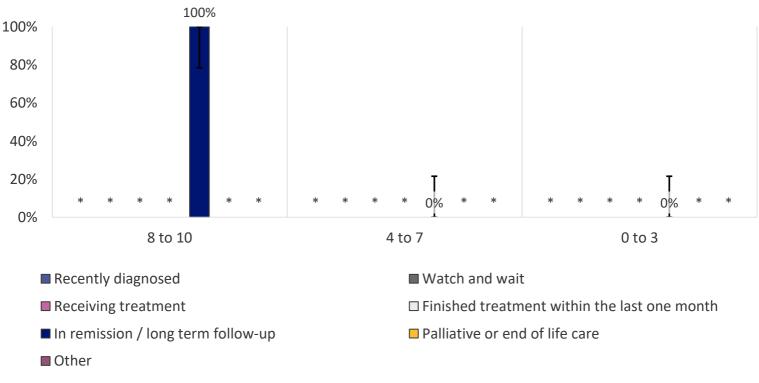


Figure 19: Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)





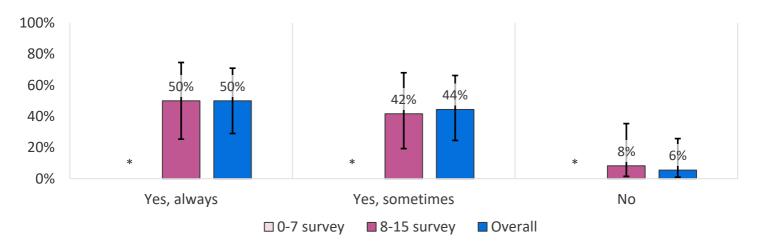
PTC results

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

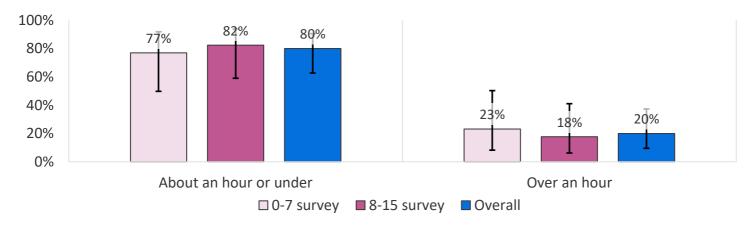
All respondents were asked how they felt about their overall care. Further results for these questions (showing breakdowns by different groups) can be found in the 'subgroup comparisons' section of this report. Two questions were asked about how well different hospitals providing cancer or tumour care 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 = 18 (excluding 11 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?

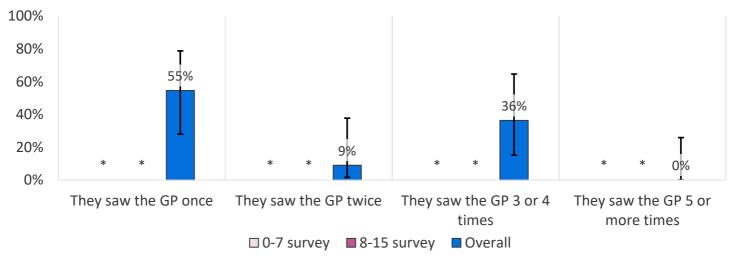




Finding out about the cancer or tumour

60% (n=18) of all parents or carers reported that their children were told they had cancer or a tumour during 2024 (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.

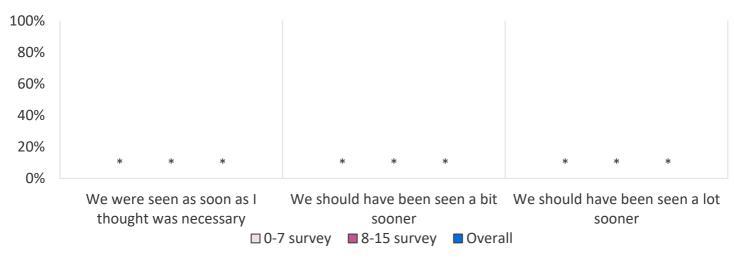
Figure 22: Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem(s) caused by the cancer or tumour?



Question X03: Asked to parents or carers of all age groups whose children were told they had cancer or a tumour. Total responses = 11 (excluding 7 responses of "None - they went straight to hospital" and excluding 0 responses of "Don't know / can't remember").

Further questions were asked to all parents or carers of children who had received diagnosis during 2024 by the hospital named in the covering letter.

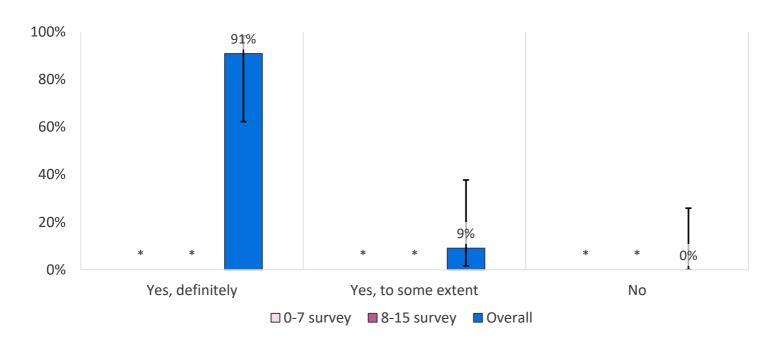
Figure 23: How did you feel about the length of time you waited between being referred by your GP to a hospital doctor until you were seen at the hospital?



Question X06: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total responses = * (excluding * responses of "We were not referred by a GP").

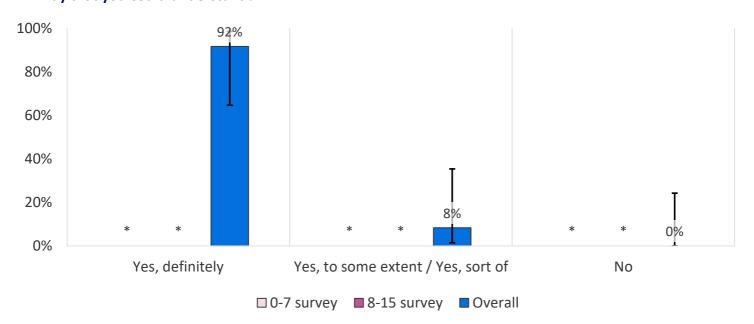


Figure 24: Were you told about your child's cancer or tumour in a sensitive way?



Question X07: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total responses = 11 (excluding 1 response of "Don't know / can't remember").

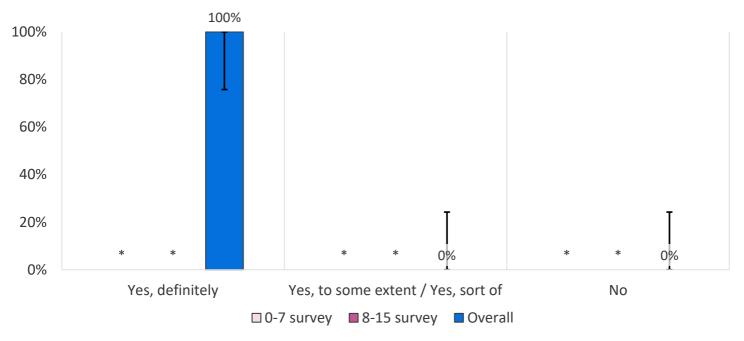
Figure 25: When you were told about your child's cancer or tumour, was information given in a way that you could understand? / When you were told about your cancer or tumour, was information given in a way that you could understand?



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").

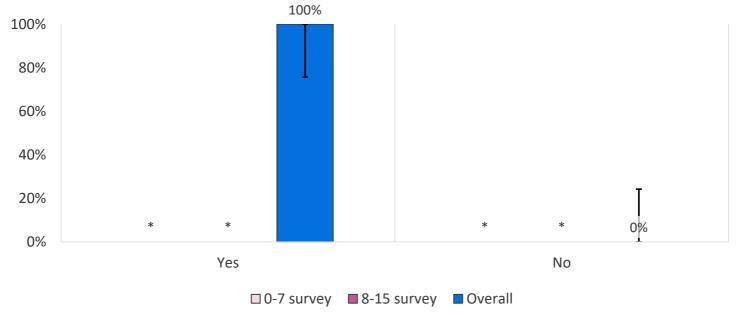


Figure 26: Were you able to have any questions answered by healthcare staff after you were told about your child's cancer or tumour? / Were you able to have any questions answered by healthcare staff after you were told about your cancer or tumour?



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").

Figure 27: Did hospital staff give you details for who to contact if you wanted more information after you were told about your child's cancer or tumour? / Did hospital staff give you details for who to contact if you wanted more information after you were told about your cancer or tumour?



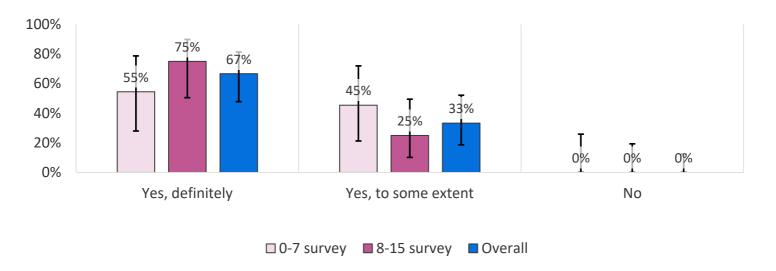
Question X11: Asked to parents or carers of children aged 0-11 who were told about their child's cancer or a tumour, and children aged 12-15 who were told they had cancer or a tumour. Total responses = 12 (excluding 0 responses of "Don't know / can't remember").



Child's care and treatment

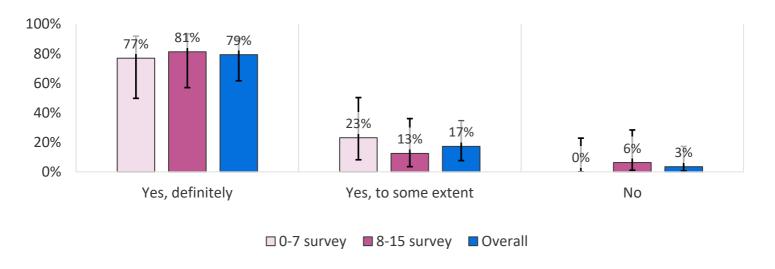
All parents and carers were asked questions about staff involved in their child's care at the hospital named in the letter that came with their survey, including questions about awareness of the child's medical history and whether they had access to help and support.

Figure 28: 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 = 27 (excluding 3 responses of "Don't know / not applicable").

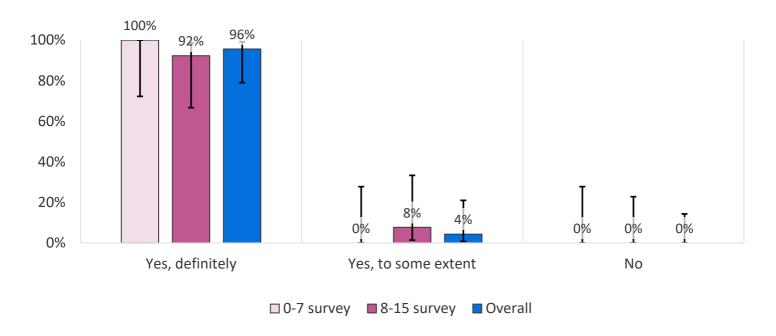
Figure 29: Do you have access to reliable help and support 7 days a week from the hospital?



Question X33: Asked to parents or carers of all age groups. Total responses = 29 (excluding 0 responses of "This is not needed").

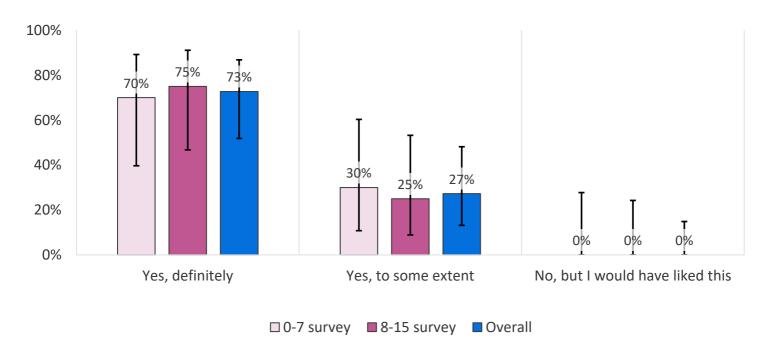


Figure 30: Were you offered clear information about your child's treatment?



Question X36: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total responses = 23 (excluding 0 responses of "This was not needed").

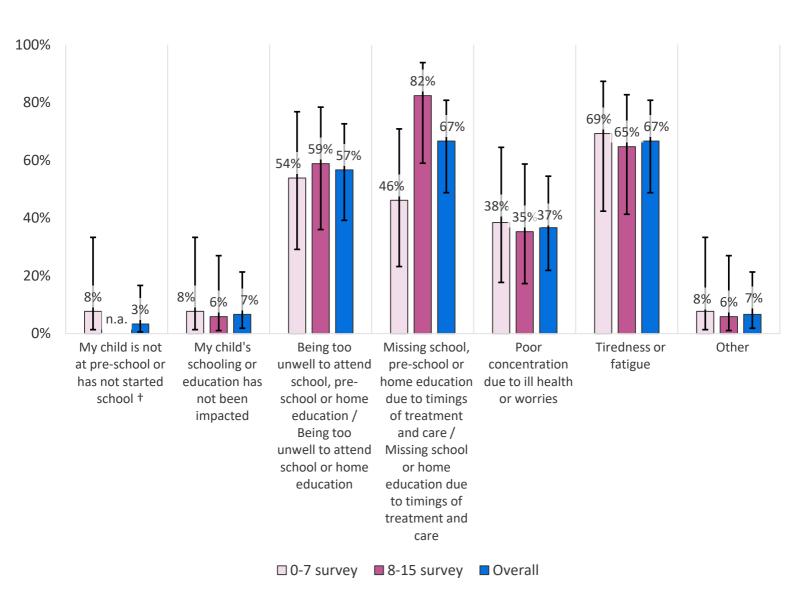
Figure 31: Did staff offer you enough time to make decisions about your child's treatment?



Question X37: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total responses = 22 (excluding 0 responses of "No, but this was not needed" and excluding 1 response of "No, but this was not possible").



Figure 32: 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?



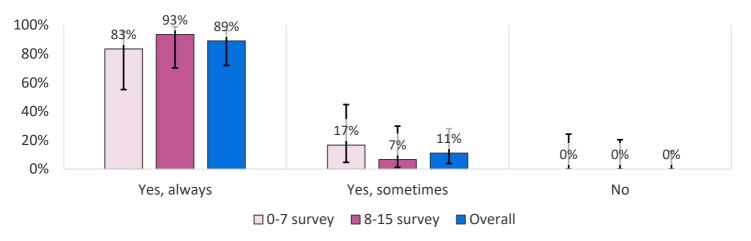
Question X30: Asked to parents or carers of all age groups. Total responses = 30.



Care in hospital

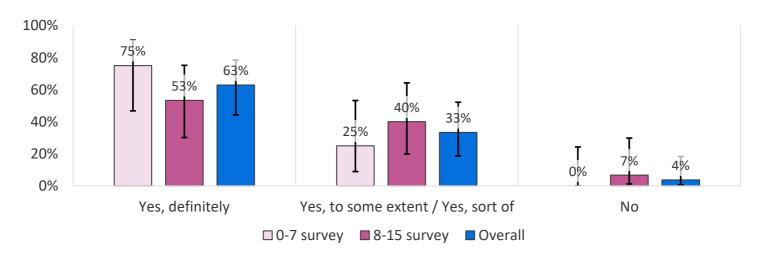
Respondents who had stayed in the hospital named in the letter that came with their survey during 2024 (receiving treatment or care in the daytime, or for an overnight stay) were asked questions about hospital staff, services and facilities. Out of all parents or carers, 97% (n=28) answered that their child had stayed in hospital during 2024 (Question X40).

Figure 33: 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 = 27 (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 34: Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital?



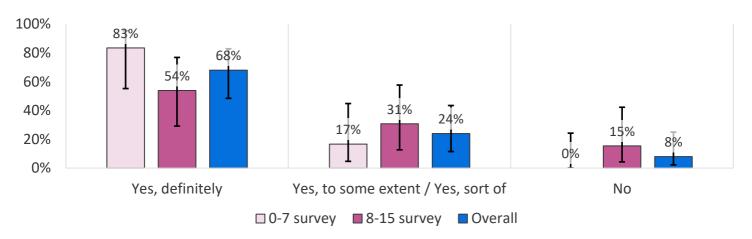
Question X43: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 27 (excluding 0 responses of "This was not needed").



Care in hospital

Respondents who had stayed in the hospital named in the letter that came with their survey during 2024 (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, 97% (n=28) answered that their child had stayed in hospital during 2024 (Question X40).

Figure 35: Was there a suitable choice of hospital food for your child? / Was there a suitable choice of hospital food?



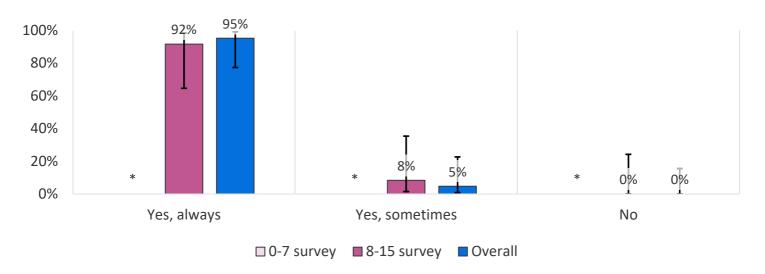
Question X44: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 25 (excluding 2 responses of "My child did not have hospital food / I did not have hospital food"



Care at home or at school

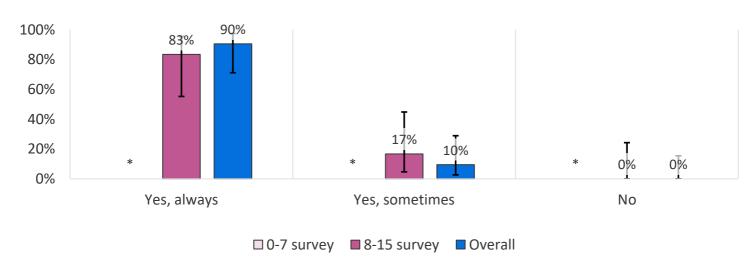
Children aged 8 and above, and parents or carers of children under the age of 8 who had been visited at home or school by a nurse during 2024 (75% (n=21) of respondents) (Question X53), for care relating to the child's cancer or tumour, were asked a short series of questions about this care. Some results from this section can be found below.

Figure 36: 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 = 21 (excluding 0 responses of "Don't know / can't remember").

Figure 37: 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 = 21 (excluding 0 responses of "Don't know / can't remember").

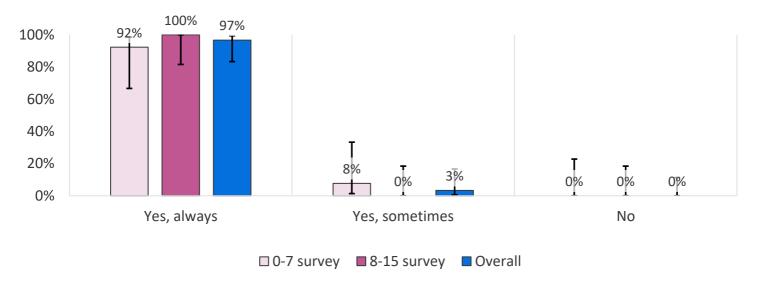


Healthcare staff

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 38: 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 = 30.

Figure 39: Do members of staff caring for your child treat you with empathy and understanding?

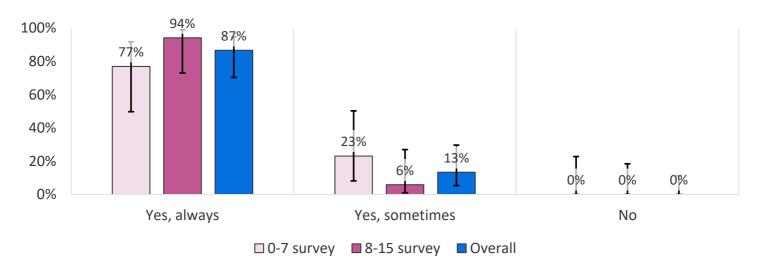
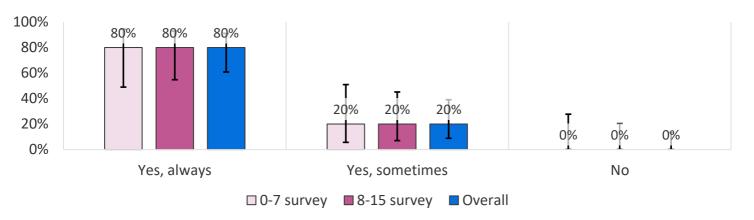
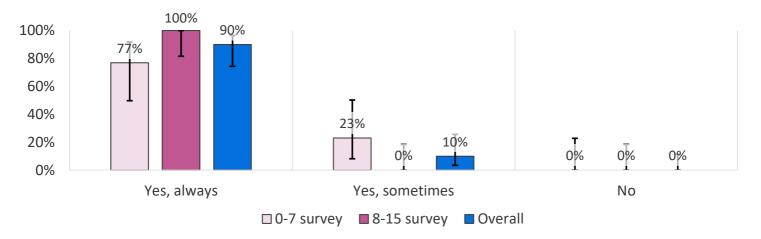


Figure 40: Are staff sensitive to the information they share with you when your child is in the room?



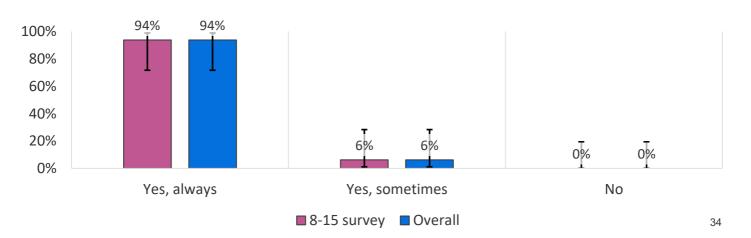
Question X21: Asked to parents or carers of all age groups. Total responses = 25 (excluding 5 responses of "This is not needed").

Figure 41: 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 = 30.

Figure 42: Do you feel that staff are friendly?

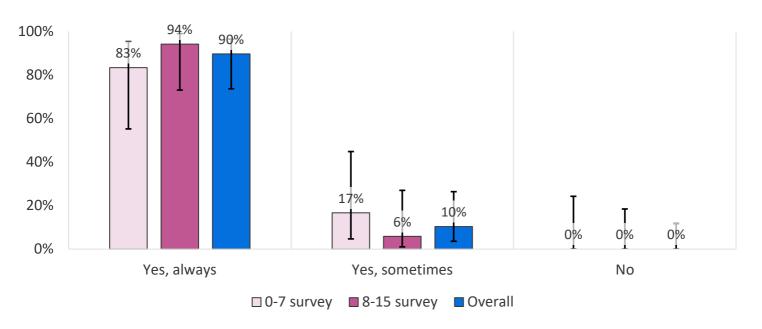


Question X12: Asked to all children aged 8-15. Total responses = 16.



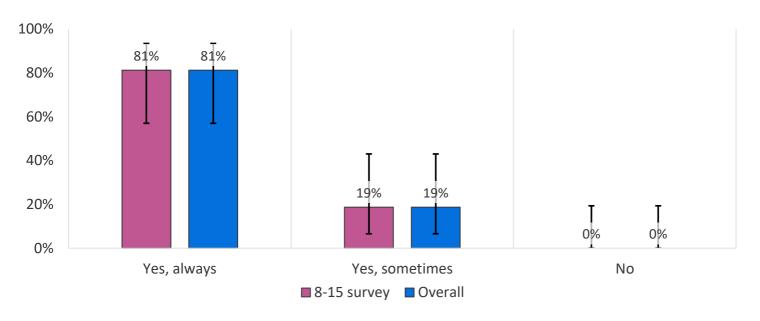
Clear communication

Figure 43: 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 = 29 (excluding 1 response of "This is not needed").

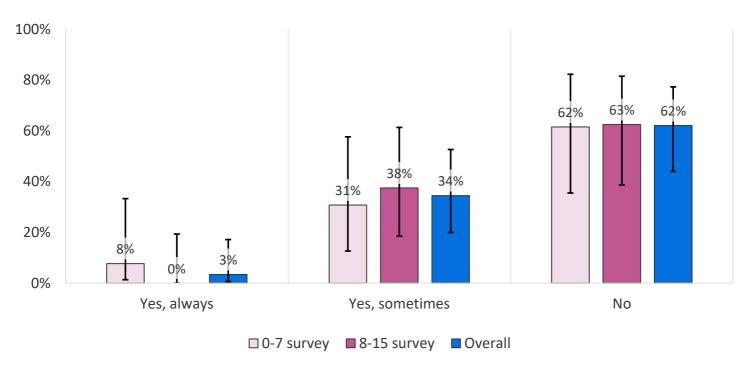
Figure 44: When staff speak to you, do you understand what they are saying? / Do staff speak to you in a way that you can understand?



Question X13: Asked to all children aged 8-15. Total responses = 16 (excluding 0 responses of "Don't know / can't remember").

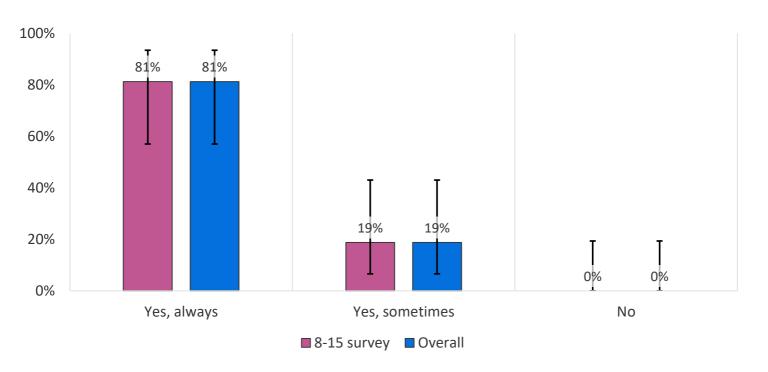


Figure 45: Are you ever told different things by different members of staff, which leaves you feeling confused?



Question X20: Asked to parents or carers of 0-7s and children aged 8-15. Total responses = 29.

Figure 46: Do staff talk to you, not just to your parent or carer?

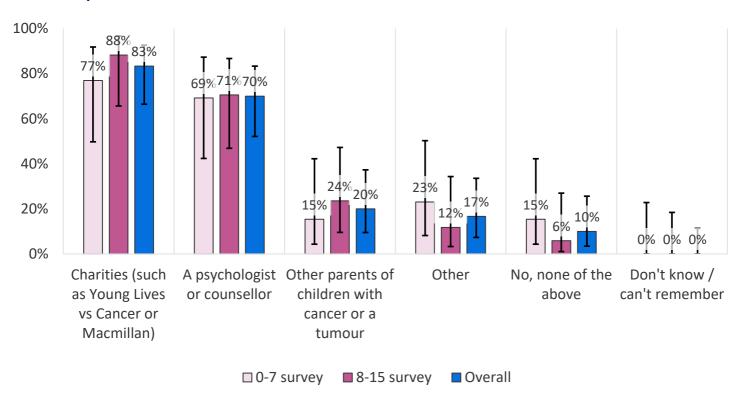


Question X14: Asked to all children aged 8-15. Total responses = 16.



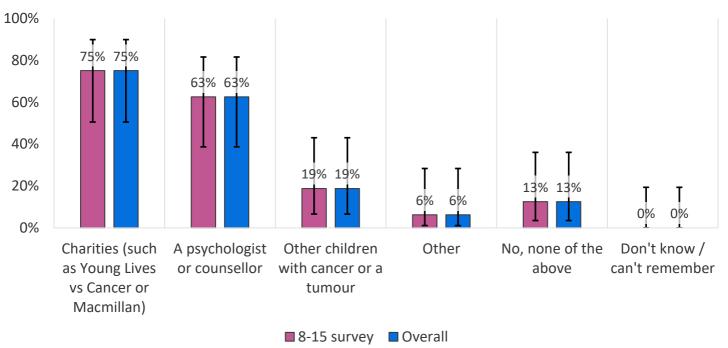
Support

Figure 47: 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 = 30.

Figure 48: Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour?





Year on year comparisons

The line charts in this section show the national score and the score for your PTC for 2021, 2022, 2023 and 2024 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 2024 scores that are not comparable to 2021, 2022 or 2023 are not presented in this section and can be found in the data tables on the <u>survey website</u>. Full details on data comparability can be found in the Technical Document.

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 75% in 2023, and 58% in 2024. As the confidence intervals do not overlap, you could be statistically confident that there is "true" difference between the two.

EXAMPLE DATA ONLY

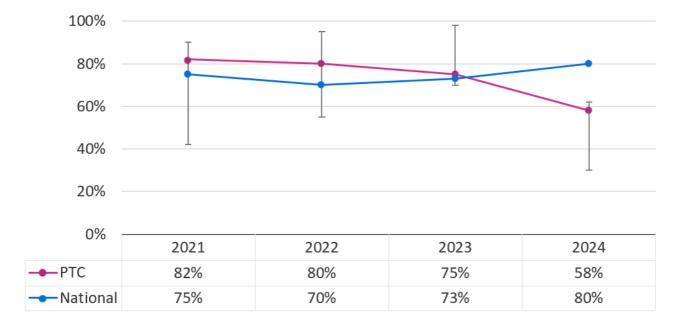
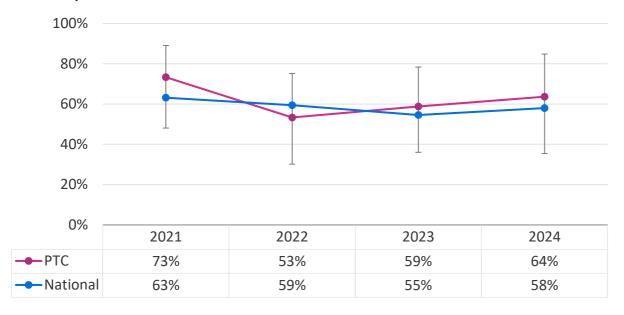


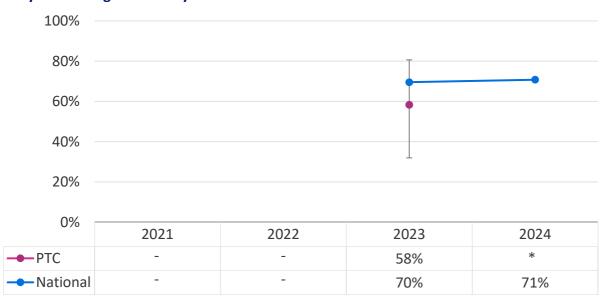


Figure 49: Parents or carers reported that their child saw a GP once or twice before they were referred to hospital



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 = 15, 2022 = 15, 2023 = 17, and 2024 = 11.

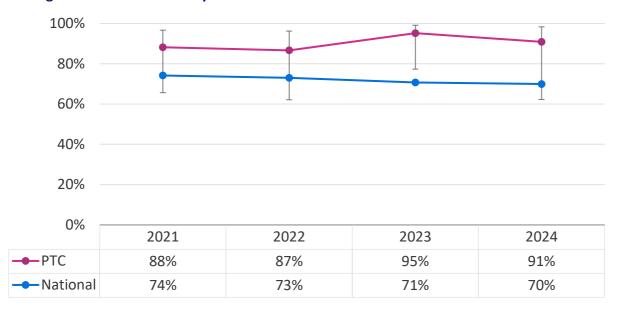
Figure 50: Parents or carers felt that they were seen at the hospital as soon as they thought was necessary after being referred by their GP



Question X06: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total PTC responses for 2023 = 12, and 2024 = *.

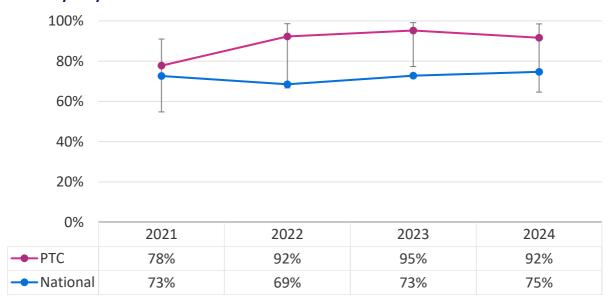


Figure 51: Parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way



Question X07: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total PTC responses for 2021 = 17, 2022 = 15, 2023 = 21, and 2024 = 11.

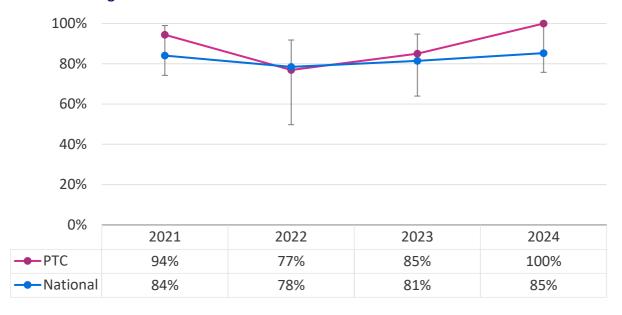
Figure 52: Parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand



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 PTC responses for 2021 = 18, 2022 = 13, 2023 = 21, and 2024 = 12.

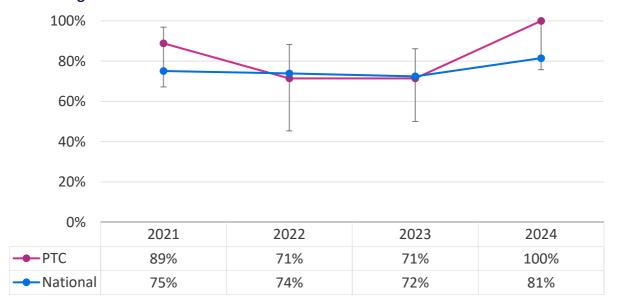


Figure 53: Parents, carers, and children reported that they were definitely able to have questions answered after being told about the cancer or tumour



Question X09: Asked to parents 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, 2022 = 13, 2023 = 20, and 2024 = 12.

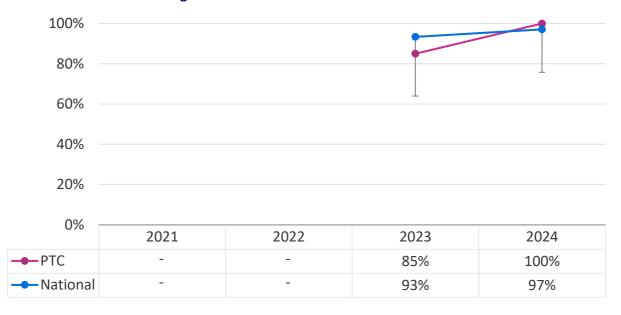
Figure 54: Parents or carers reported that they were definitely able to find information about their child's diagnosis



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 = 18, 2022 = 14, 2023 = 21, and 2024 = 12.



Figure 55: Parents, carers, and children reported that staff provided details about who to contact for more information after being told about the cancer or tumour



Question X11: Asked to parents or carers of children aged 0-11 who were told about their child's cancer or a tumour, and children aged 12-15 who were told they had cancer or a tumour. Total PTC responses for 2023 = 20, and 2024 = 12.

Healthcare staff

Figure 56: Children felt that staff were always friendly

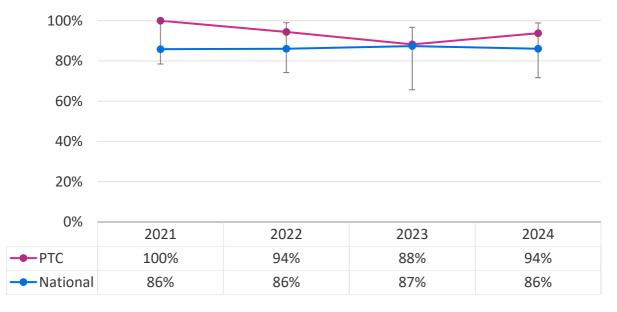
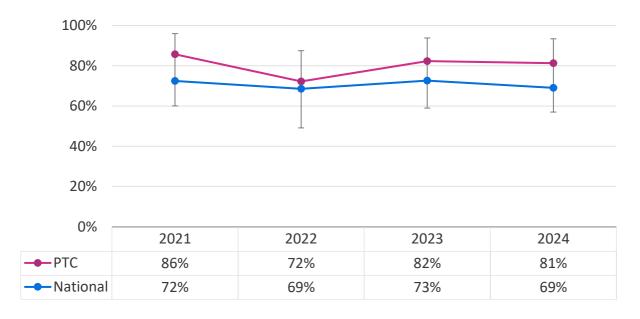


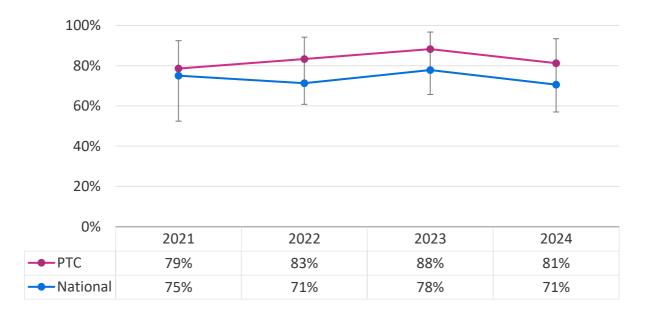


Figure 57: Children reported that they could always understand what staff were saying



Question X13: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, 2022 = 18, 2023 = 17, and 2024 = 16.

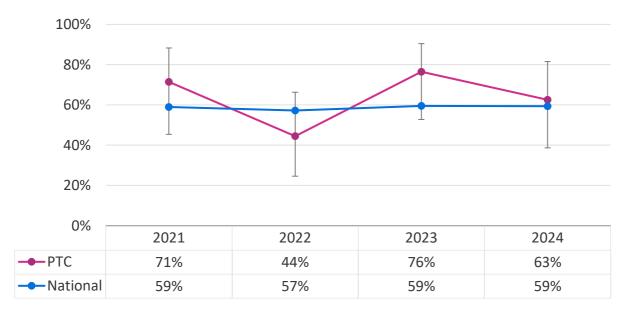
Figure 58: Children felt that staff always talked to them, not just their parent or carer



Question X14: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, 2022 = 18, 2023 = 17, and 2024 = 16.

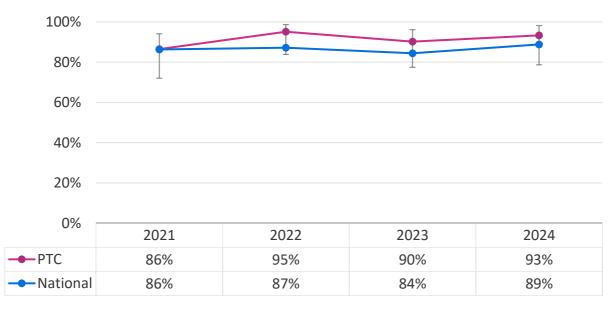


Figure 59: Children reported always or mostly seeing the same members of staff for their treatment and care



Question X15: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, 2022 = 18, 2023 = 17, and 2024 = 16.

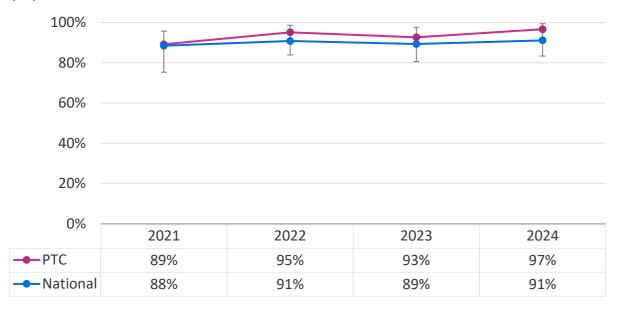
Figure 60: Parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment



Question X16: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 37, 2022 = 41, 2023 = 41, and 2024 = 30.

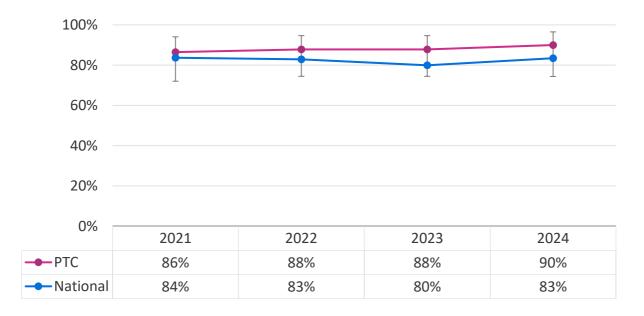


Figure 61: Parents or carers felt that they and their child were always treated with respect and dignity by staff



Question X17: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 37, 2022 = 41, 2023 = 41, and 2024 = 30.

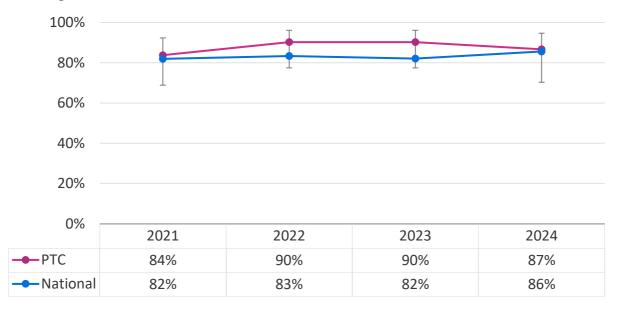
Figure 62: Parents or carers felt they always had confidence and trust in staff caring for their child



Question X18: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 37, 2022 = 41, 2023 = 41, and 2024 = 30.

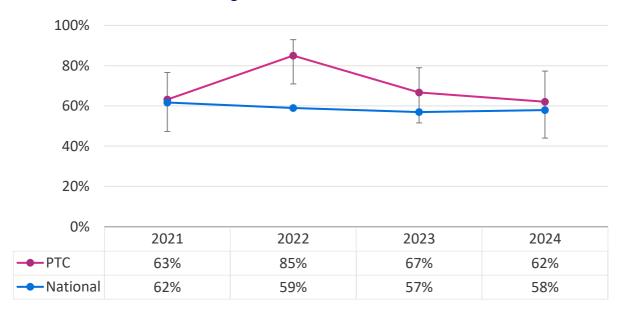


Figure 63: Parents or carers felt that they were always treated with empathy and understanding by staff caring for their child



Question X19: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 37, 2022 = 41, 2023 = 41, and 2024 = 30.

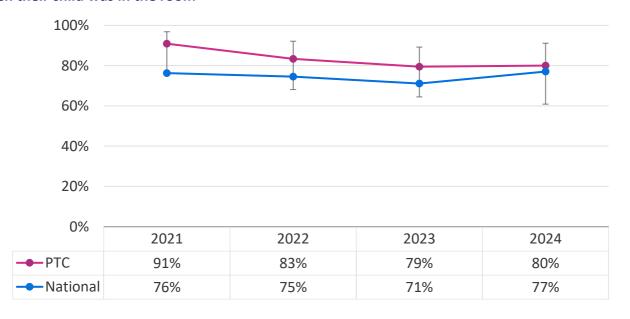
Figure 64: Parents, carers, and children reported not being told different things by different members of staff that left them feeling confused



Question X20: Asked to parents or carers of 0-7s and children aged 8-15. Total PTC responses for 2021 = 38, 2022 = 40, 2023 = 42, and 2024 = 29.

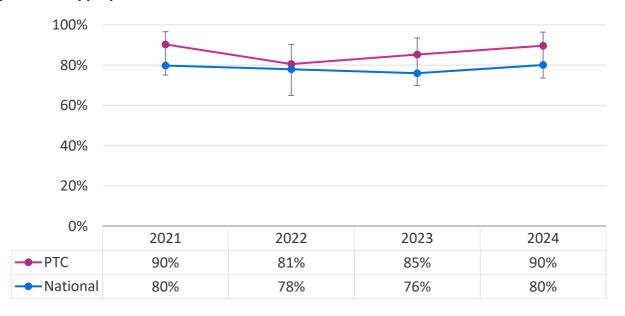


Figure 65: Parents or carers felt that staff were always sensitive to information shared with them when their child was in the room



Question X21: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 33, 2022 = 36, 2023 = 39, and 2024 = 25.

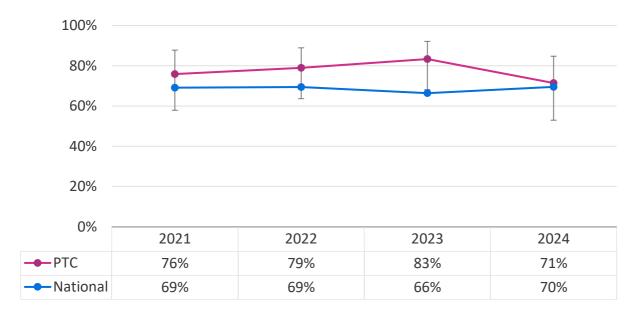
Figure 66: Parents or carers felt that healthcare staff always shared information with children in a way that was appropriate



Question X22: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 31, 2022 = 36, 2023 = 34, and 2024 = 29.



Figure 67: Parents or carers felt they had enough information about financial help or benefits



Question X25: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 29, 2022 = 38, 2023 = 36, and 2024 = 28.

Child's care and treatment

Figure 68: Parents or carers felt that different hospital staff always worked well together

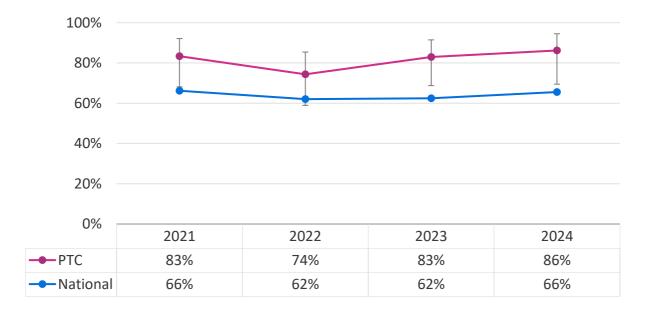
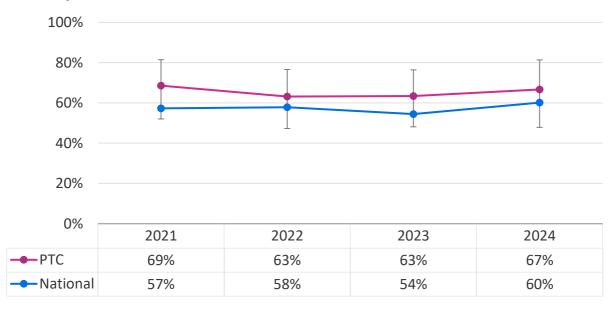


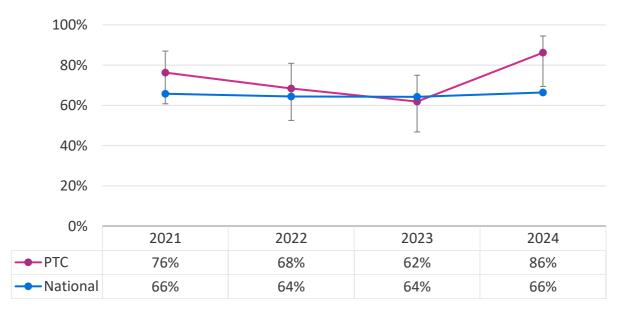


Figure 69: Parents or carers felt that different hospital staff were definitely aware of their child's medical history



Question X27: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 35, 2022 = 38, 2023 = 41, and 2024 = 27.

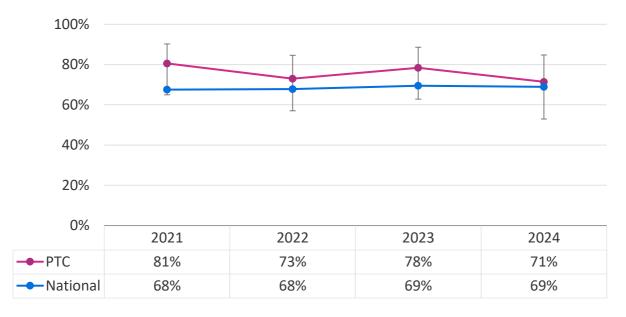
Figure 70: Parents, carers, and children felt they always knew what was happening with their child's or their care



Question X28: Asked to parents or carers of 0-7s and all children aged 8-15. Total PTC responses for 2021 = 38,2022 = 38,2023 = 42, and 2024 = 29.

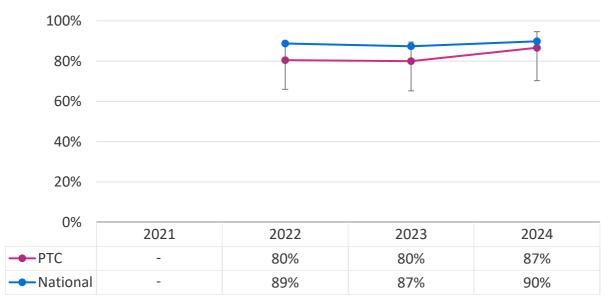


Figure 71: Parents, carers, and children felt they were definitely involved in their child's or their care and treatment



Question X29: Asked to parents or carers of 0-7s and all children aged 8-15. Total PTC responses for 2021 = 36, 2022 = 37, 2023 = 37,and 2024 = 28.

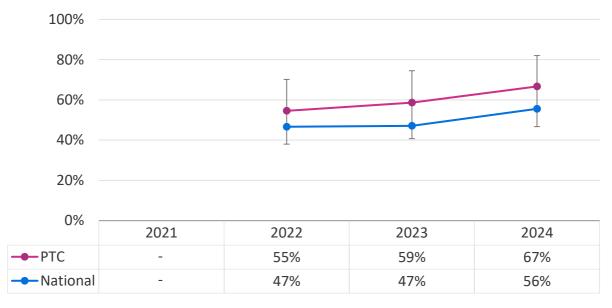
Figure 72: Parents or carers reported that there was a main person in the team looking after their child that they could contact about their care or treatment



Question X31: Asked to parents or carers of all age groups. Total PTC responses for 2022 = 41, 2023 = 40, and 2024 = 30.

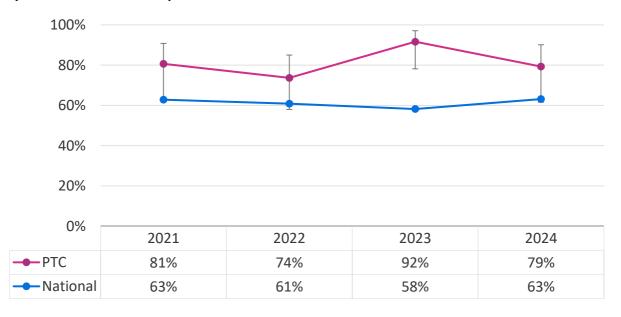


Figure 73: Parents or carers reported that it was very easy to contact the main person in the team looking after their child



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 = 33, 2023 = 29, and 2024 = 24.

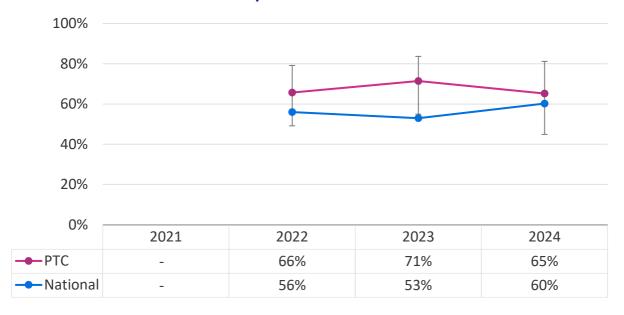
Figure 74: Parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital



Question X33: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 31, 2022 = 38, 2023 = 36, and 2024 = 29.

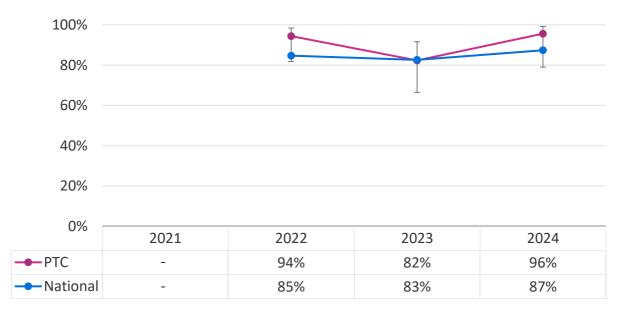


Figure 75: Parents or carers reported that their child's care and treatment was definitely offered at a time suitable for them and their family



Question X34: Asked to parents or carers of all age groups. Total PTC responses for 2021 = -, 2022 = 35, 2023 = 35, and 2024 = 23.

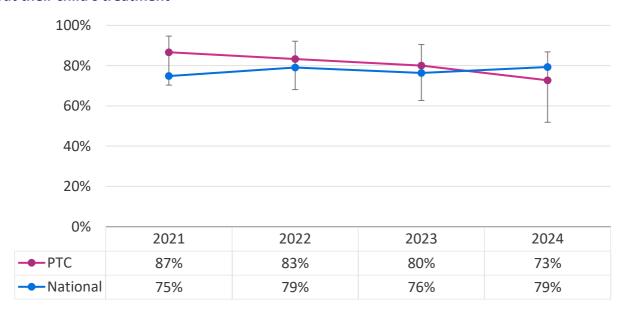
Figure 76: Parents or carers reported that they were definitely offered clear information about their child's treatment



Question X36: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total PTC responses for 2021 = -, 2022 = 36, 2023 = 34, and 2024 = 23.

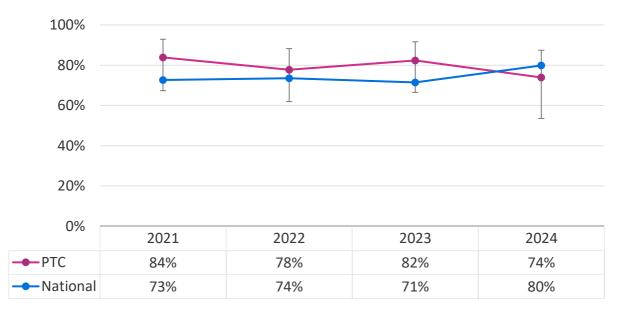


Figure 77: Parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment



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 = 30, 2022 = 36, 2023 = 30, and 2024 = 22.

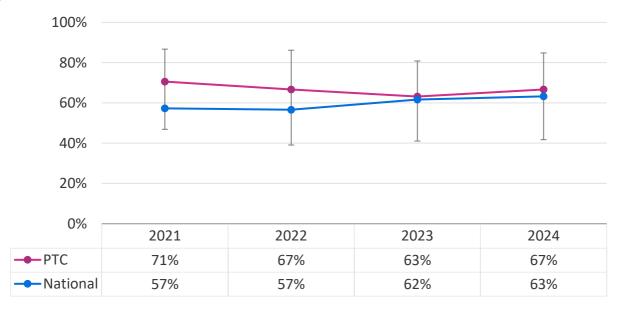
Figure 78: Parents or carers reported that staff definitely offered them support to help manage their child's treatment side effects



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 = 31, 2022 = 36, 2023 = 34, and 2024 = 23.

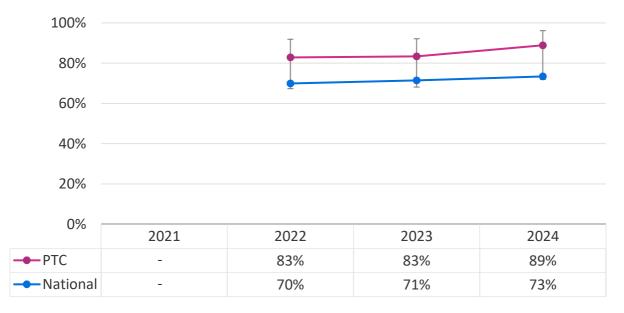


Figure 79: Parents or carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended



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 = 17, 2022 = 12, 2023 = 19, and 2024 = 15.

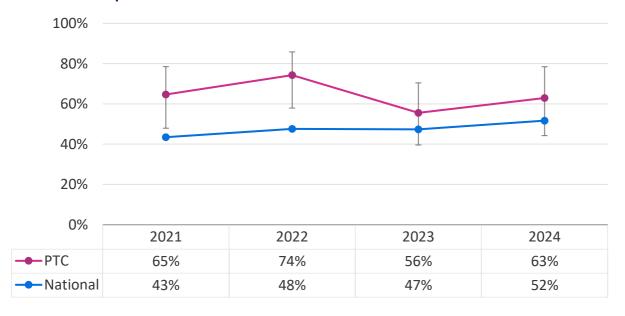
Figure 80: Parents, carers, and children felt that their child or they were always able to get help from staff on the hospital ward when they needed it



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 2021 = -, 2022 = 35, 2023 = 36, and 2024 = 27.

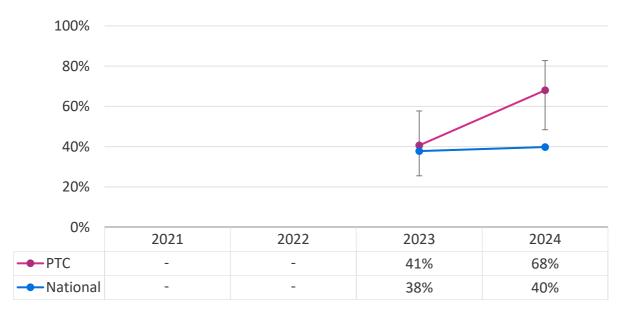


Figure 81: Parents, carers, and children felt that there were definitely enough things for their child to do in the hospital



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 PTC responses for 2021 = 34, 2022 = 35, 2023 = 36, and 2024 = 27.

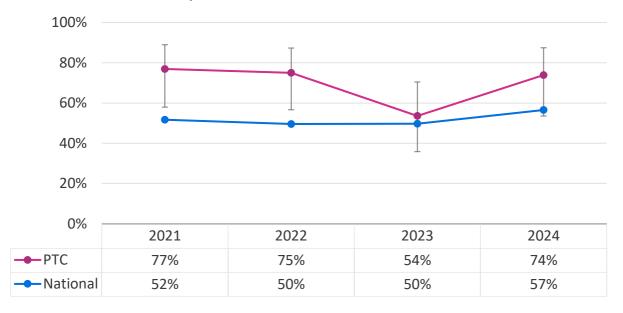
Figure 82: Parents, carers, and children felt that there was definitely a suitable choice of hospital food



Question X44: 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 2023 = 32, and 2024 = 25.

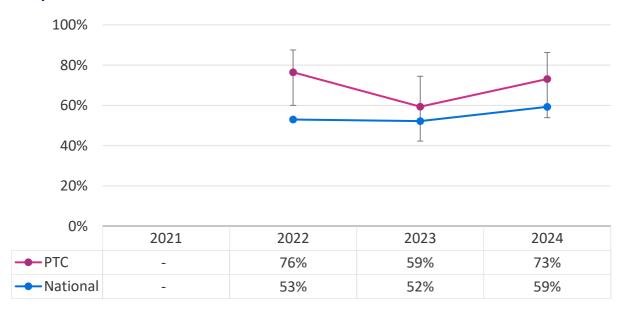


Figure 83: Parents, carers, and children reported always being given somewhere private to talk to staff when their child was in hospital



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 = 26, 2022 = 28, 2023 = 28, and 2024 = 23.

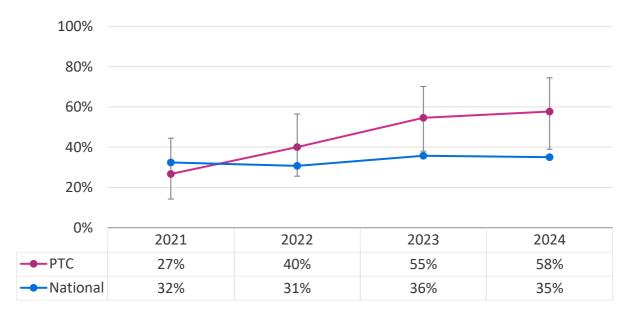
Figure 84: Parents or carers reported that the hospital always offered play specialist support when they needed it



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 2021 = -, 2022 = 34, 2023 = 32, and 2024 = 26.

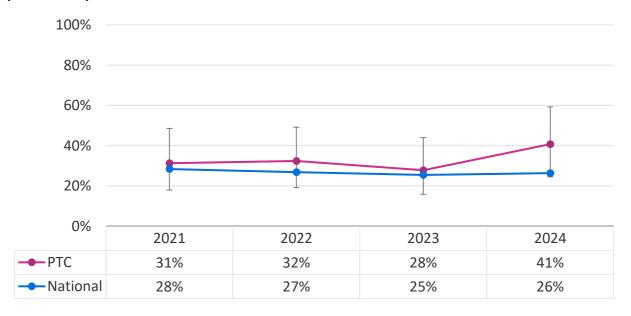


Figure 85: Parents or carers reported that facilities for them to stay overnight were very good



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 = 30, 2022 = 35, 2023 = 33, and 2024 = 26.

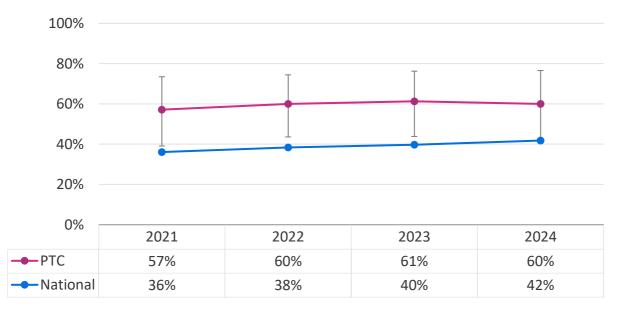
Figure 86: Parents, carers, and children reported that it was always quiet enough for them to sleep in the hospital



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 = 32, 2022 = 34, 2023 = 36, and 2024 = 27.

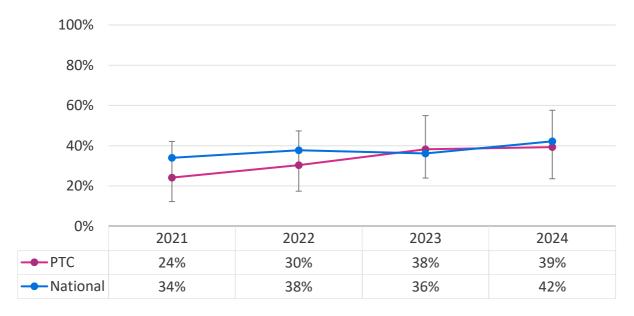


Figure 87: Parents or carers reported they were definitely able to prepare food in the hospital if they wanted to



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 = 28, 2022 = 35, 2023 = 31, and 2024 = 25.

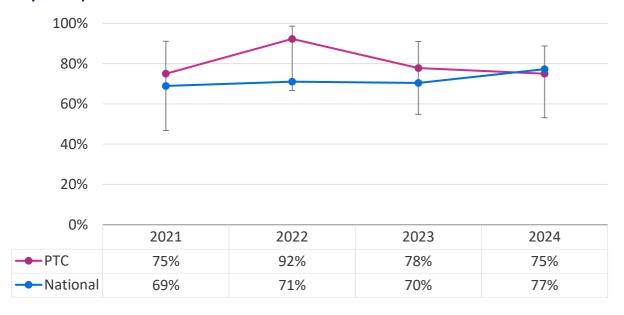
Figure 88: Parents or carers felt that the hospital Wi-Fi always met the needs of them and their child



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 = 29, 2022 = 33, 2023 = 34, and 2024 = 28.



Figure 89: Parents or carers reported that their child had access to hospital school services during their stay in hospital



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 = 12, 2022 = 13, 2023 = 18, and 2024 = 20.

Care at home or at school

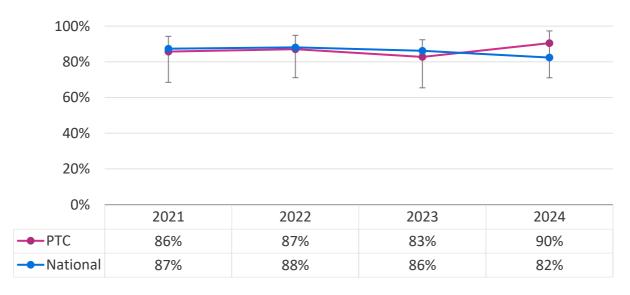
Figure 90: Parents, carers, and children felt that the nurses who came to their home or school were always friendly





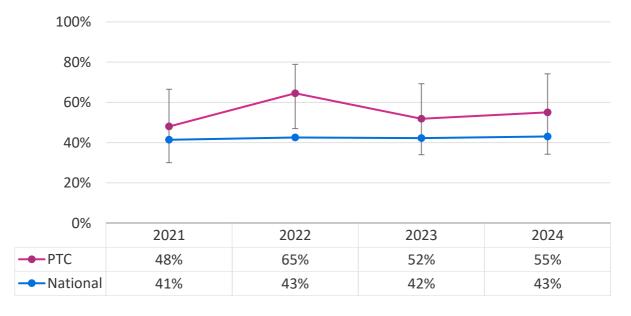
Care at home or at school

Figure 91: Parents, carers, and children reported that they always understood what nurses visiting their home or school were 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 PTC responses for 2021 = 28, 2022 = 31, 2023 = 29, and 2024 = 21.

Figure 92: Parents, carers, and children reported that the same nurses always came to their home or school

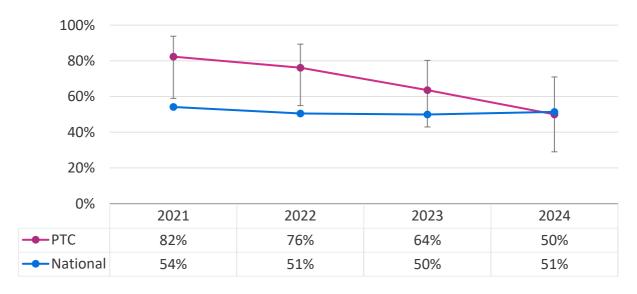


Question X56: Asked to parents or carers of children aged 0-7 whose child was visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse. Total PTC responses for 2021 = 25, 2022 = 31, 2023 = 27, and 2024 = 20.



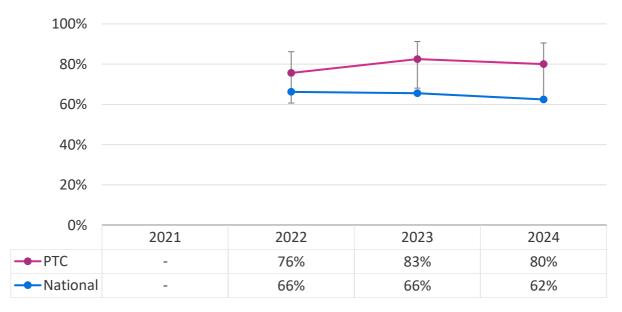
Overall care

Figure 93: Parents, carers, and children reported that different hospitals providing cancer or tumour care always worked well together



Question X57: Asked to parents or carers of children aged 0-11, and children aged 12-15. Total PTC responses for 2021 = 17, 2022 = 21, 2023 = 22, and 2024 = 18.

Figure 94: 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

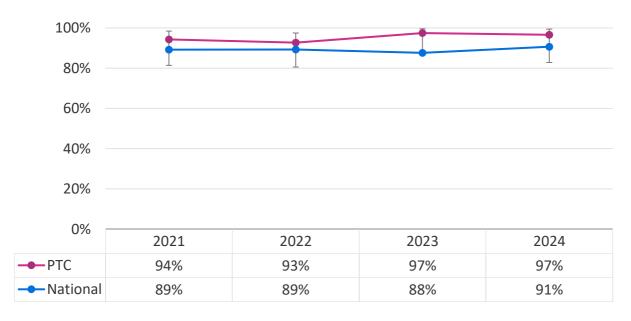


Question X58: Asked to parents or carers of all age groups. Total PTC responses for 2021 = -, 2022 = 41, 2023 = 40, and 2024 = 30.



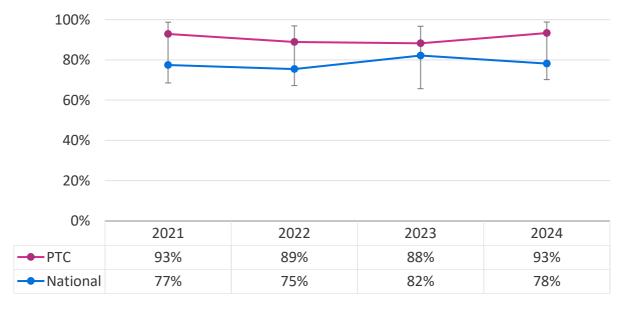
Overall care

Figure 95: Parents or carers rated the overall experience of their child's care as 8 or more out of 10



Question X59: Asked to parents or carers of all age groups. Total PTC responses for 2021 = 35, 2022 = 41, 2023 = 39, and 2024 = 29.

Figure 96: Children reported that they were very well looked after by staff for their cancer or tumour



Question X60: Asked to all children aged 8-15. Total PTC responses for 2021 = 14, 2022 = 18, 2023 = 17, and 2024 = 15.



Further information



For more information on the Under 16 Cancer Patient Experience Survey visit the <u>survey website</u>.



If you have any questions about the survey, please do not hesitate to get in touch <u>via email</u>.



For full data tables showing results to all survey questions, please see the <u>survey website</u>.