cancer patient
experience survey

NHS

Under 16 Cancer Patient Experience Survey 2020

Sheffield Children's NHS Foundation Trust

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Executive Summary

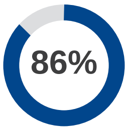
Overall PTC response rate

37 responded out of a total of 116 eligible parents and children who were sent a survey, resulting in a response rate of 32%. Please note that a response consists of one survey completion, which could consist of both parent and child responses.

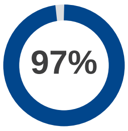
	Original sample size	Adjusted sample size[1]	Completed	Response rate
PTC	117	116	37	32%

Overall PTC care rating

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



Children are looked after very well for their cancer or tumour by healthcare staff (Question X65)



Parents or carers rated the overall experience of their child's care as 8 or more out of 10 (Question X64)

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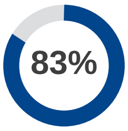
[1] The adjusted sample excludes patients who were discovered to be ineligible during fieldwork.

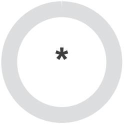
PTC key question scoring

The following questions were rated as the most important items for providing a good patient experience by professionals involved in children’s tumour and cancer care. Scores for all questions can be found in the PTC Excel Data Tables, available on the survey website: https://www.under16cancerexperiencesurvey.co.uk/technical-reports

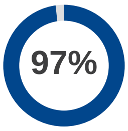
Data for questions in which the base size per question was <11 have been suppressed and replaced with an asterisk (*).



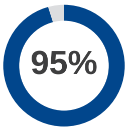
Parents or carers definitely given clear written information about treatment (Question X40)



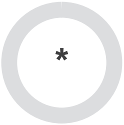
Parents or carers definitely told about cancer or tumour in a sensitive way (Question X08)



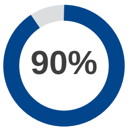
Parents or carers always have confidence and trust in staff caring for their child (Question X17)



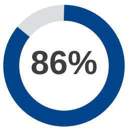
Child reported that staff always speak to them in a way that is suitable to them (Question X22)



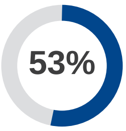
Information definitely given in a way parents/carers and children could understand (Question X09)



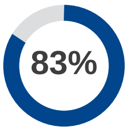
Children always understand what staff are saying (Question X15)



Staff definitely offered parents or carers enough time to make decisions about child's treatment (Question X41)



Parents or carers feel that different staff are definitely aware of their child's medical history (Question X30)



Parents or carers definitely have access to reliable help and support 7 days a week from the hospital (Question X35)

Introduction

- The Under 16 Cancer Patient Experience Survey 2020 is the first iteration of a national survey that is expected to run on an annual basis to measure children's tumour and cancer care. The survey captures the experiences of children who were aged 8 and above at the start of the fieldwork period, but under 16 at the time of their care, and the parents and carers of children who were aged under 16 at the time of their care.
- The survey has been designed to establish a baseline measure of patient experiences of cancer care across England and to enable NHS organisations to assess their performance with other providers. In future years, the survey will also allow national trends to be tracked over time, along with allowing NHS organisations to compare their performance with earlier waves of data collection.
- The survey is overseen by an Under 16's National 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 of children with cancer. This group advises on questionnaire development, methodology and reporting outputs. The survey is managed by NHS England and NHS Improvement, 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) between January 1, 2020 and December 31, 2020, and were aged under 16 at the time of their discharge. It is important to note that the sampling period took place during an unprecedented year for the health and social care sector, with the outbreak of the global Covid19 pandemic. This had an impact on the NHS and may have influenced people's care perceptions and experiences, and therefore how they answered the survey. In addition to considering the pandemic, Principal Treatment Centres should also apply any local knowledge to the interpretation of their findings.

The fieldwork for the survey was undertaken between April and June 2021. One of three versions of the survey were distributed:

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

Survey version was assigned based on the patient's age immediately prior to survey fieldwork 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 asked recipients to answer about their (or their child's) cancer care over the last year. Some patients may have been 16 or 17 years old at the time they received the questionnaire if they were 15 years old at the time of their discharge but then had a birthday or two prior to the survey being sent out.

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

Suppression

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

Question-level suppression

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

Double suppression

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

Scoring methodology

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

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

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

Question text	Answer options	No. of responses	% responses
Did staff offer you enough time to make decisions about your child’s treatment?	Yes, definitely	120	60%
	Yes, to some extent	74	37%
	No, but I would have liked this	6	3%
	No, but this was not needed or possible	n/a	n/a

Important Note: Scores have been calculated using unadjusted data. In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently. For example, previous analysis indicates that Black and Asian patients report a less positive experience than White patients on patient experience survey questions. Thereby, PTCs with differing populations could potentially lead to results appearing better or worse than they would if they had a slightly different profile of patients. Scores have not been adjusted on the 2020 survey due to small sample size restrictions. Furthermore, PTCs should be mindful that survey responses may be influenced by the type of care provided by PTCs, for example some provide specialised care and treatment.

PTCs should therefore be mindful of differences in types of care provision, size and possible demographic makeup when comparing their results against the performance of other PTCs.

Full scores to each scored question can be found in the PTC Excel Data Tables, available here: https://www.under16cancerexperiencesurvey.co.uk/technical-reports Meanwhile, more details on scoring can be found in the Technical Document on the survey website (see the ‘Further information’ section below).

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. Frequency tables for all survey questions (including non-scored questions) can be found in the PTC Excel Data Tables, available here: https://www.under16cancerexperiencesurvey.co.uk/technical-reports

The sub-group comparisons section of this report shows how different groups of respondents answered the overall care questions in the survey (for example by age/survey type, gender, ethnicity and diagnostic group). The benchmarking charts and score tables sections allow you to compare your scored results against the average of all 13 PTCs.

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

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

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 2020 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 and Technical Document, available on the survey website. For all other outputs, please visit the results section of the website at https://www.under16cancerexperiencesurvey.co.uk/technical-reports

About the respondents

Table 1. Response rate

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

	Original sample size	Adjusted sample size[2]	Completed	Response rate
PTC	117	116	37	32%

Table 2. Responses by survey mode

Response mode	n	%
Paper	27	73%
Online	10	27%
Mixed (combination of paper and online)[3]	0	0%
Phone – English	0	0%
Phone – Translation service	0	0%
Total	**37**	**100%**

Table 3. Responses by survey type

Survey	n	%
0-7	14	38%
8-11	11	30%
12-15	12	32%
Total	**37**	**100%**

Table 4. Responses by gender of child (Question X66)

Gender of child	n	%
Male	24	65%
Female	12	32%
Prefer not to say	0	0%
Not given	1	3%
Total	**37**	**100%**

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

[3] 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. Responses by ethnicity of child (Question X69)

Ethnicity of child	n	%
White	34	92%
Mixed, Asian, Black	3	8%
Other and Not Given	0	0%
Total	**37**	**100%**

Table 6. Responses by current care or treatment stage[4] (Question X01)

Stage of care	n	%
Recently diagnosed	0	0%
Watch and wait	3	9%
Currently receiving treatment	12	34%
Finished treatment in last month	2	6%
In remission / long-term follow-up	17	49%
Receiving palliative or end of life care	0	0%
Recently passed away	0	0%
Other	2	6%
Number of respondents	**35**	**100%**

Table 7. Responses by diagnostic group[5] (from ICD-10 code in patient sample)

Diagnostic group	n	%
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	21	57%
Lymphomas and reticuloendothelial neoplasms	4	11%
CNS and miscellaneous intracranial and intraspinal neoplasms	9	24%
Other	3	8%
Total	**37**	**100%**

Table 8. Responses by long-term, unrelated conditions (Question X70)

Other long-term conditions	n	%
Reported unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more	7	19%
No long-term, unrelated conditions	30	81%
Total	**37**	**100%**

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[4] Based on a select all that apply question.

[5] Details of how diagnostic groups were formed can be found in the technical appendix, available on the survey website: https://www.under16cancerexperiencesurvey.co.uk/technical-reports

Table 9. Responses by main person who answered questions in the children’s section (Question X68)

Respondent	n	%
The child / young patient	8	36%
The parent or carer	8	36%
Both the child / young patient and the parent or carer together	6	27%
Total	**22**	**100%**

Table 10. Responses by deprivation[6] (based on IMD from postcode in patient sample)

Deprivation	n	%
1 (most deprived)	5	14%
2	9	24%
3	7	19%
4	7	19%
5 (least deprived)	9	24%
Non-England	0	0%
Total	**37**	**100%**

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

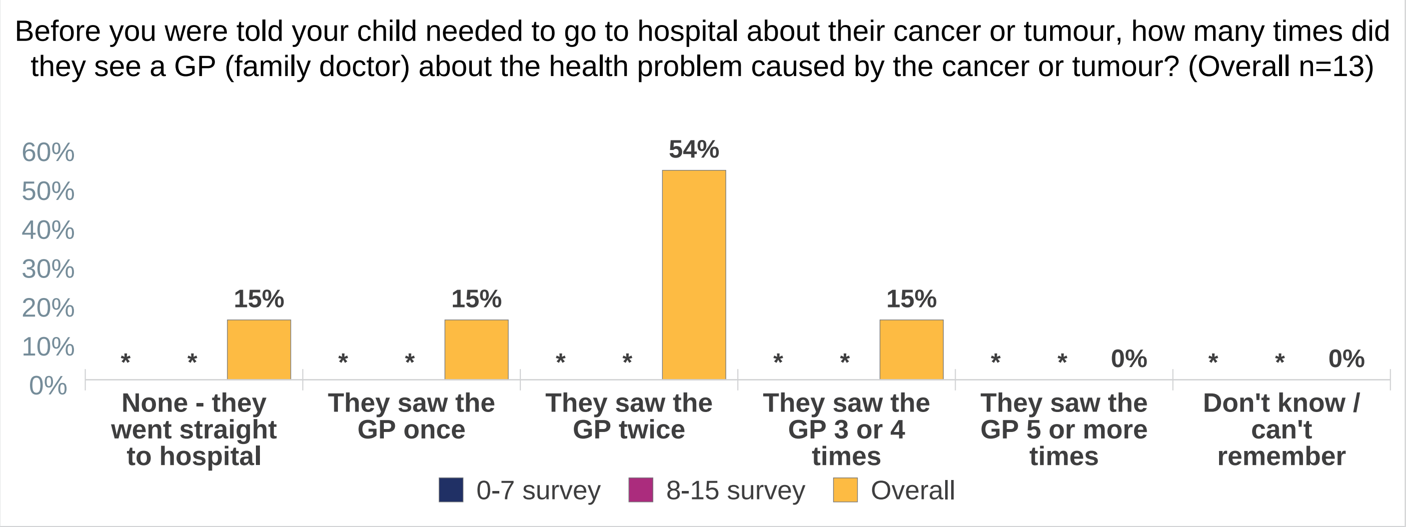
PTC results

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).

Finding out about the cancer or tumour

37% (n=13) of all parents/carers reported that their children were told they had cancer or tumour within the last year (Question X02). Of this group, 69% (n=9) saw their GP once or twice before being told they needed to go to hospital while 15% (n=2) saw their GP three or more times (Question X04). More details can be found below.

Figure 1. Answered by parents/carers of all age groups whose children were told they had cancer or a tumour within the last year (Question X04)



Further questions were asked to all parents/carers of children who had received diagnoses in the past year by the hospital named in the covering letter. Of these parents/carers, * (n=*) reported that they were seen as soon as they thought was necessary (Question X07). Meanwhile, * (n=*) were definitely told about their child's cancer or tumour in a sensitive way (Question X08) and * (n=*) have definitely been able to find the information they needed about their child's diagnosis (Question X12).

Parents/carers of children under the age of 8, along with children aged 8 and above at the time of fieldwork, who were diagnosed in the past year by the hospital named in the covering letter were asked questions concerning how information was given and whether they could have questions answered. Results can be found in the figures below.

Figure 2. Answered by parents/carers of 0-7s whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter (Question X09)

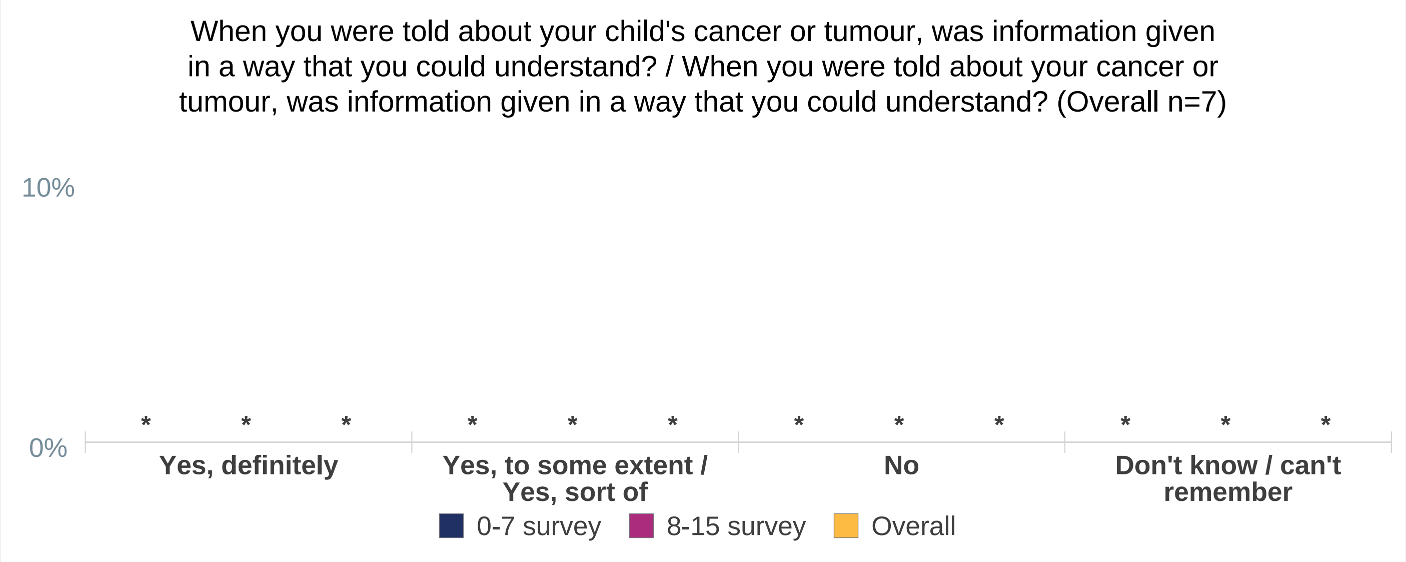
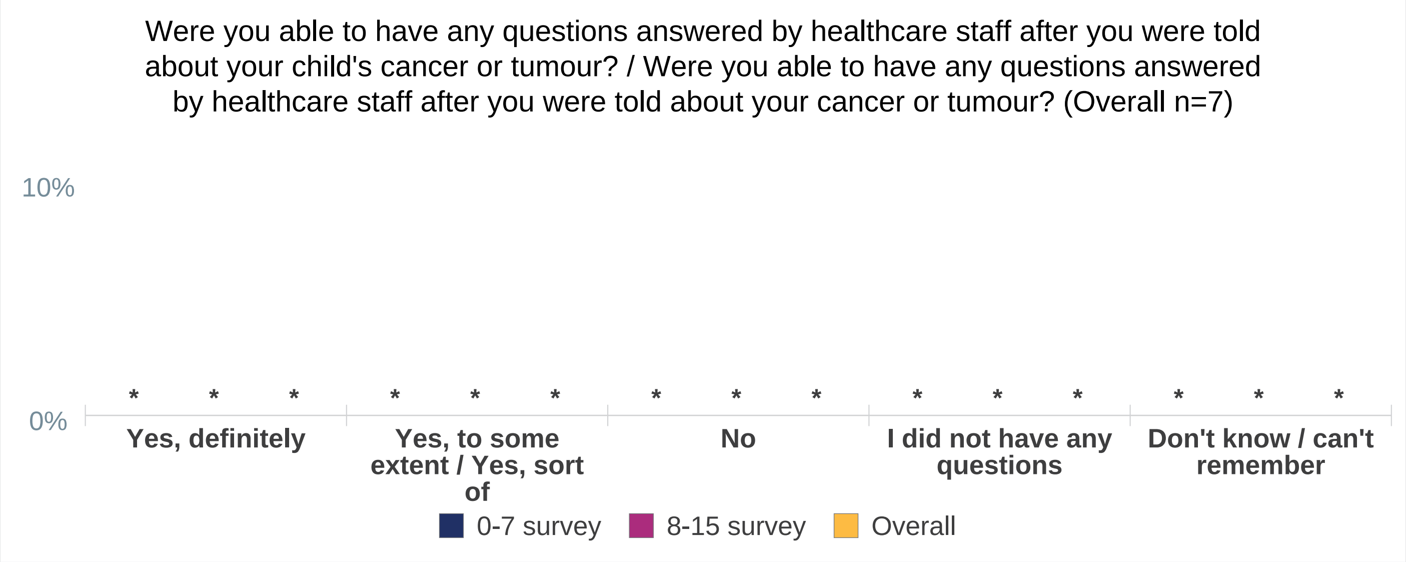


Figure 3. Answered by parents/carers of 0-7s whose children were told they had cancer or a tumour within the last year & at the hospital named in the letter, and children aged 8-15 who were told they had cancer or a tumour in the last year at the hospital named in the covering letter (Question X10)



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 the survey. 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 4. Answered by parents/carers of all age groups (Question X16)

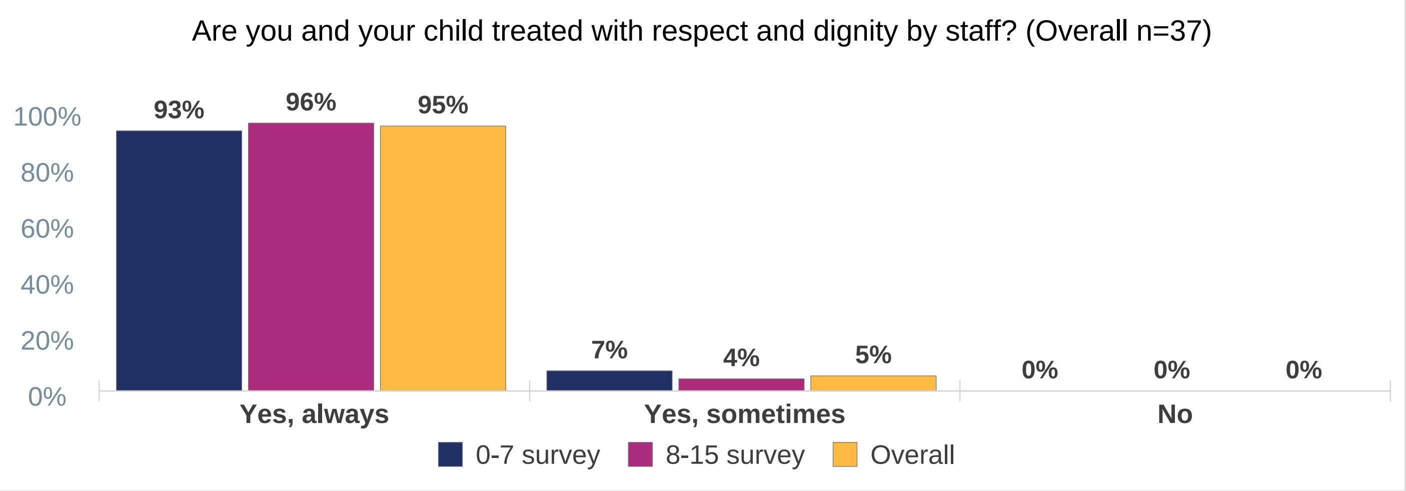


Figure 5. Answered by parents/carers of all age groups (Question X18)

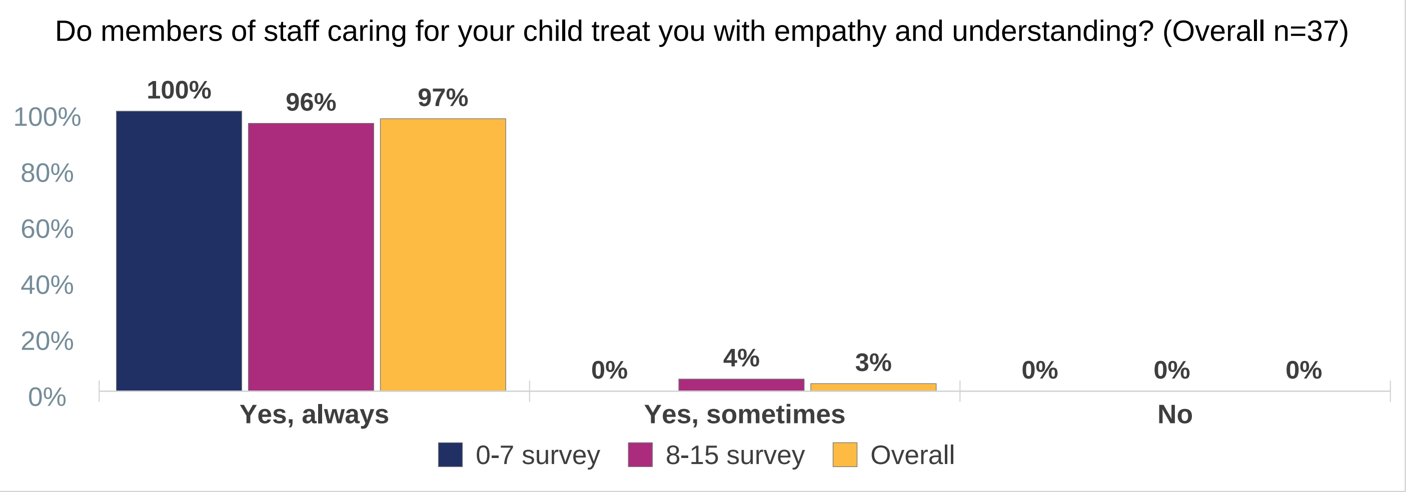


Figure 6. Answered by parents/carers of all age groups (Question X20)

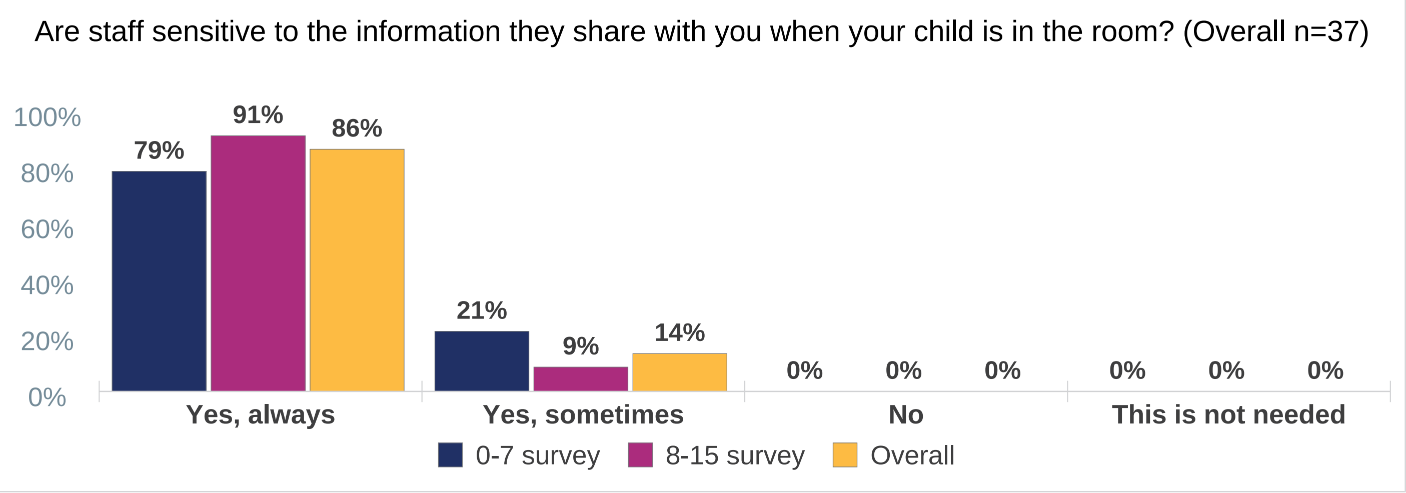


Figure 7. Answered by parents/carers of all age groups (Question X17)

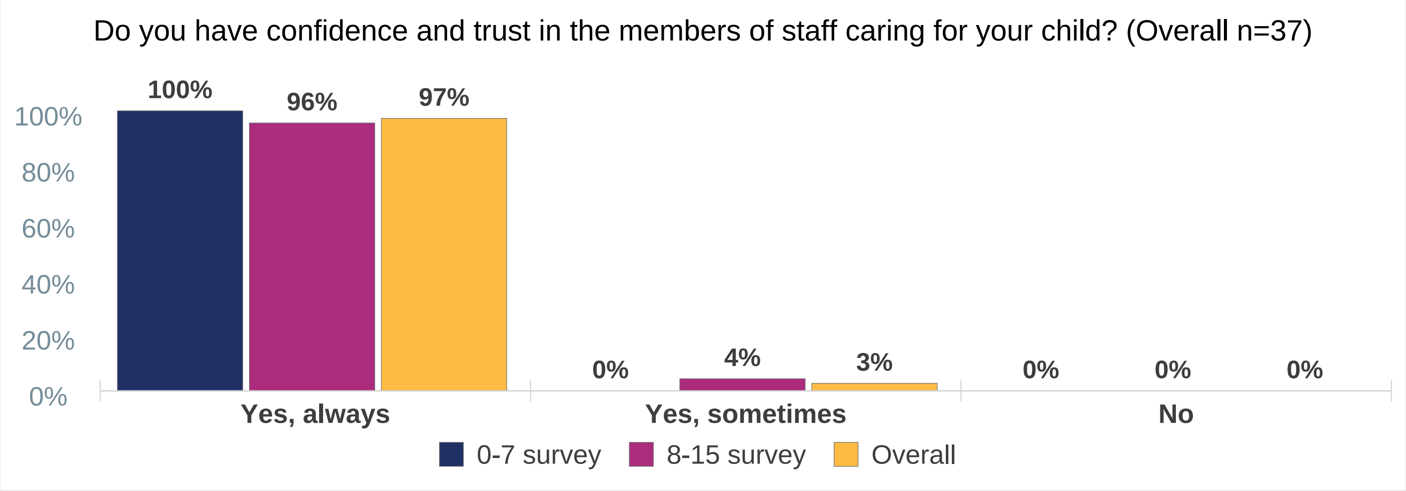
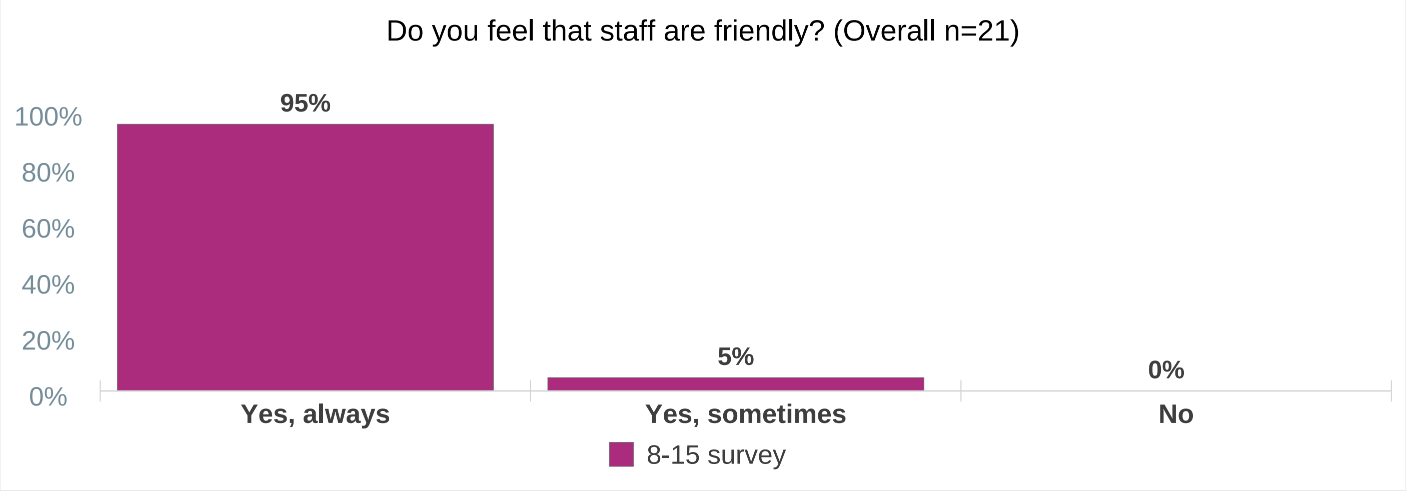


Figure 8. Answered by all children aged 8-15 (Question X24)



Clear communication

Figure 9. Answered by parents/carers of all age groups (Question X21)

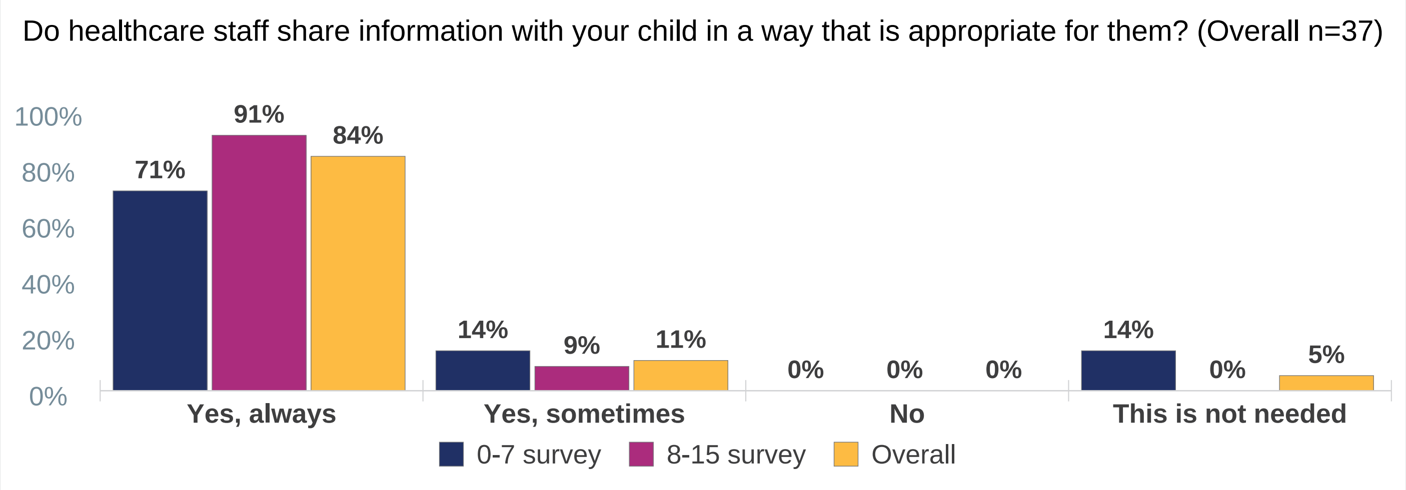


Figure 10. Answered by all children aged 8-15 (Question X15)

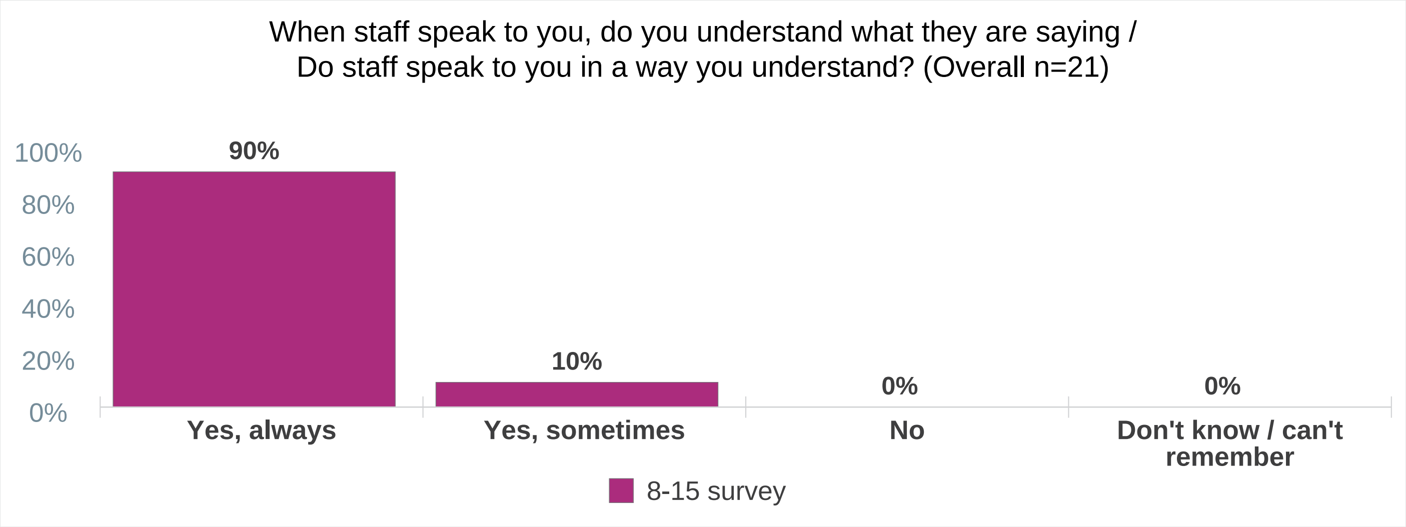


Figure 11. Answered by parents/carers of children aged 0-7, and all children aged 8-15 (Question X19)

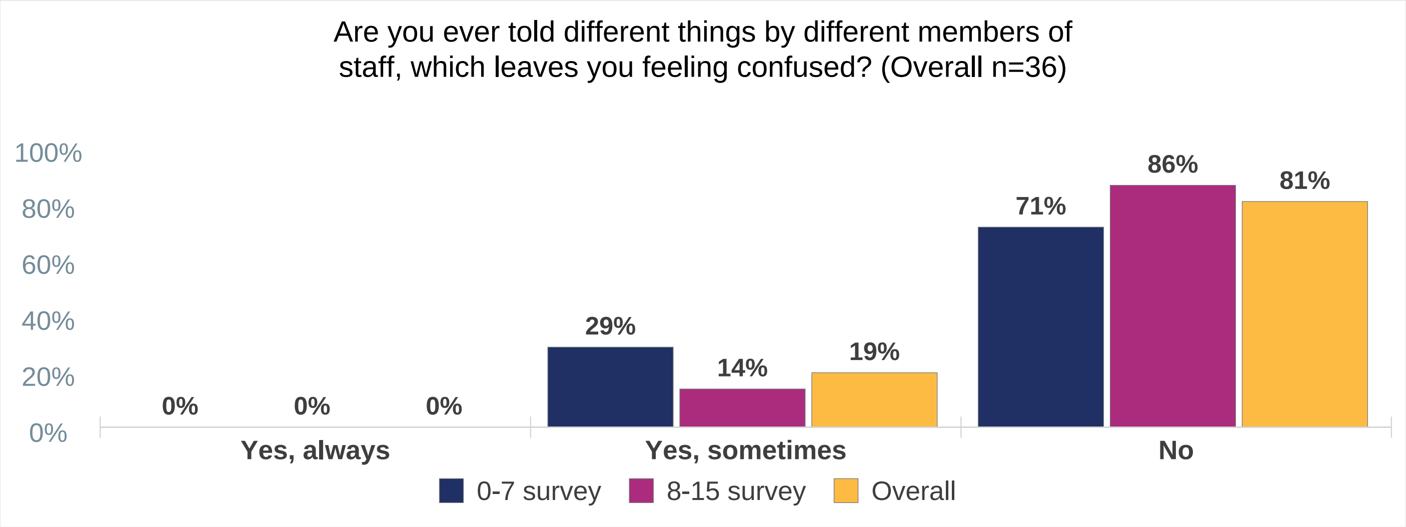


Figure 12. Answered by all children aged 8-15 (Question X22)

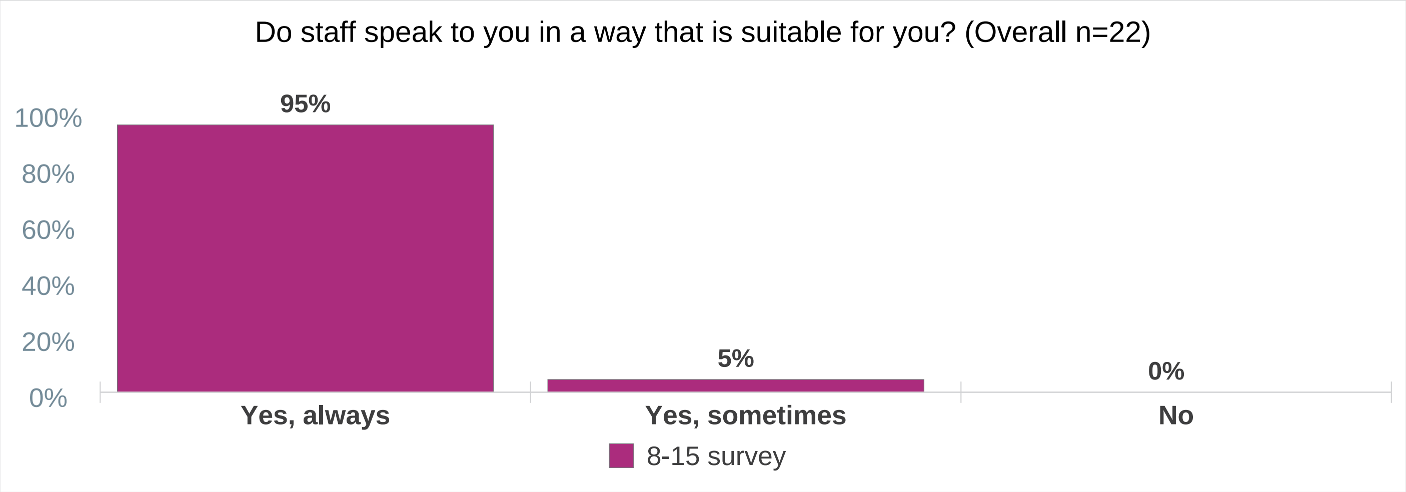
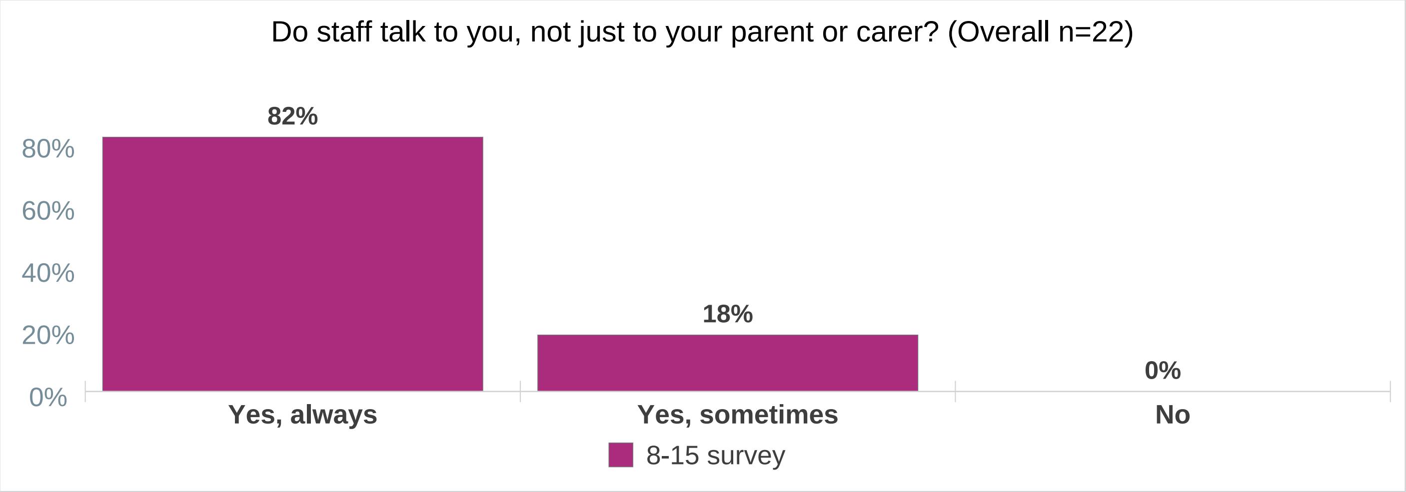


Figure 13. Answered by all children aged 8-15 (Question X23)



Support

Figure 14. Answered by parents/carers of all age groups (Question X26)

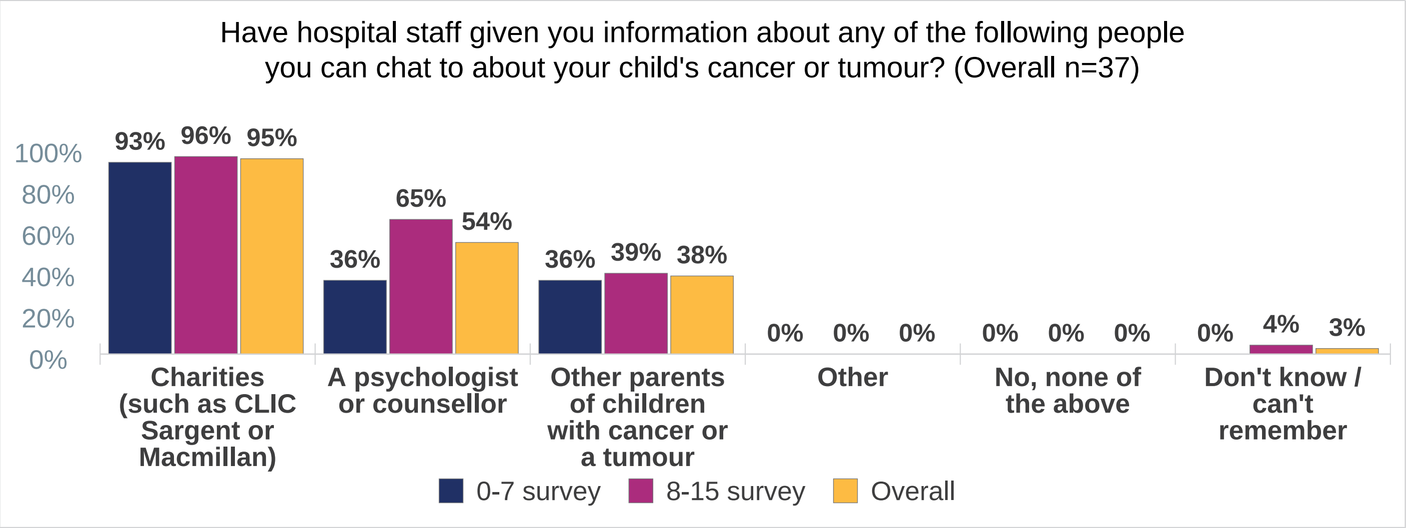
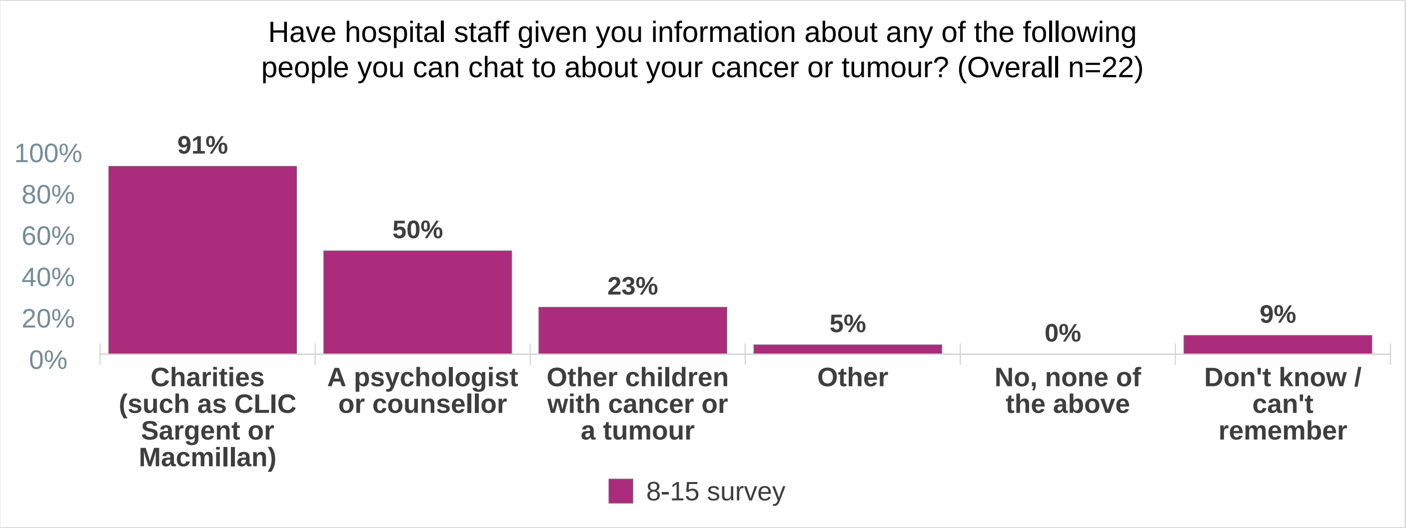


Figure 15. Answered by all children aged 8-15 (Question X27)



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 including awareness of the child’s medical history and whether they had access to help and support.

Figure 16. Answered by parents/carers of all age groups (Question X30)

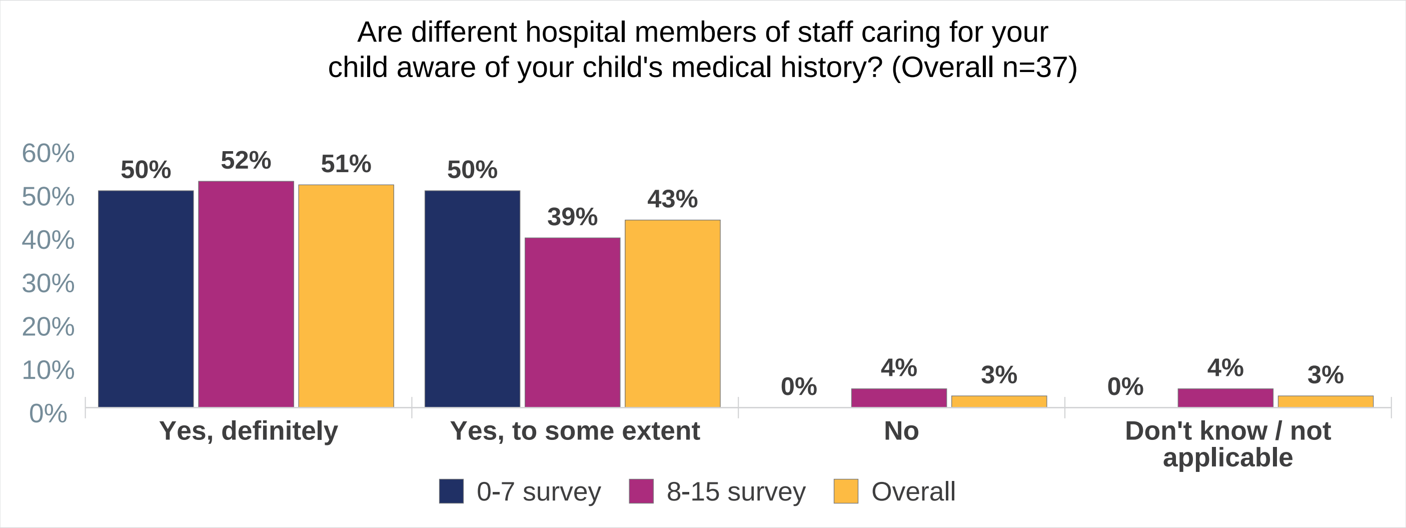


Figure 17. Answered by parents/carers of all age groups (Question X35)

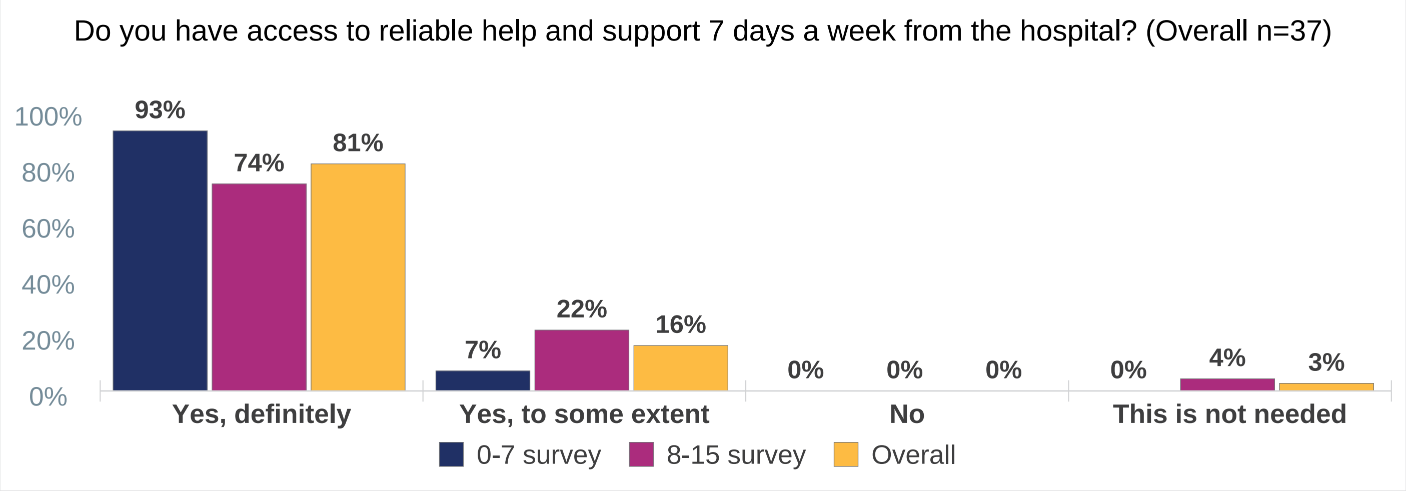


Figure 18. Answered by parents/carers of all age groups whose children received treatment for their cancer or tumour in the last year (Question X40)

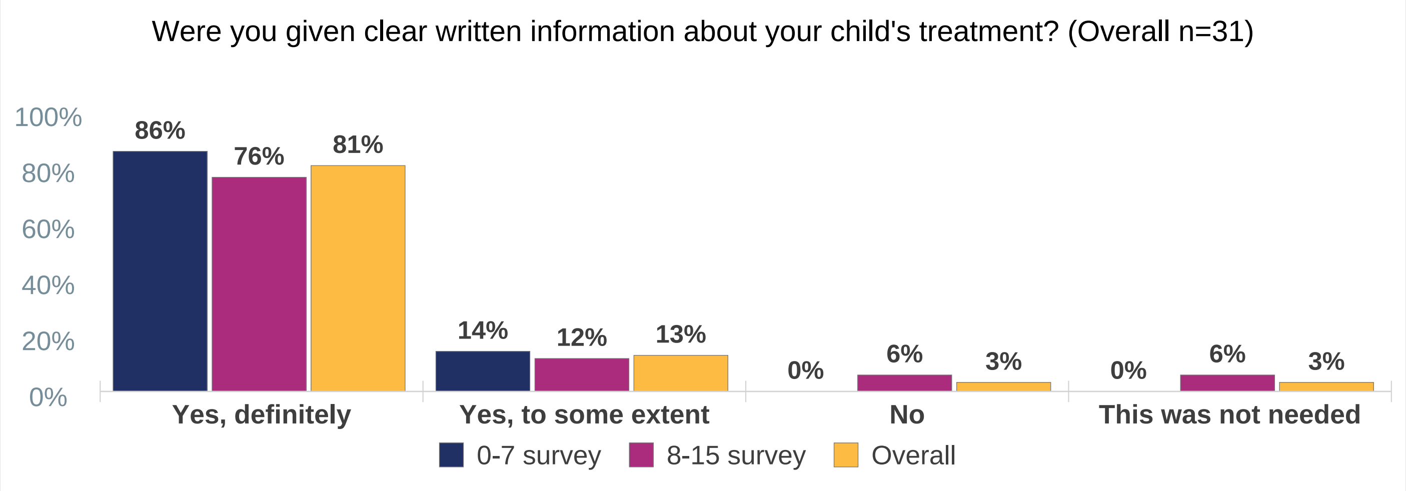


Figure 19. Answered by parents/carers of all age groups whose children received treatment for their cancer or tumour in the last year (Question X44)

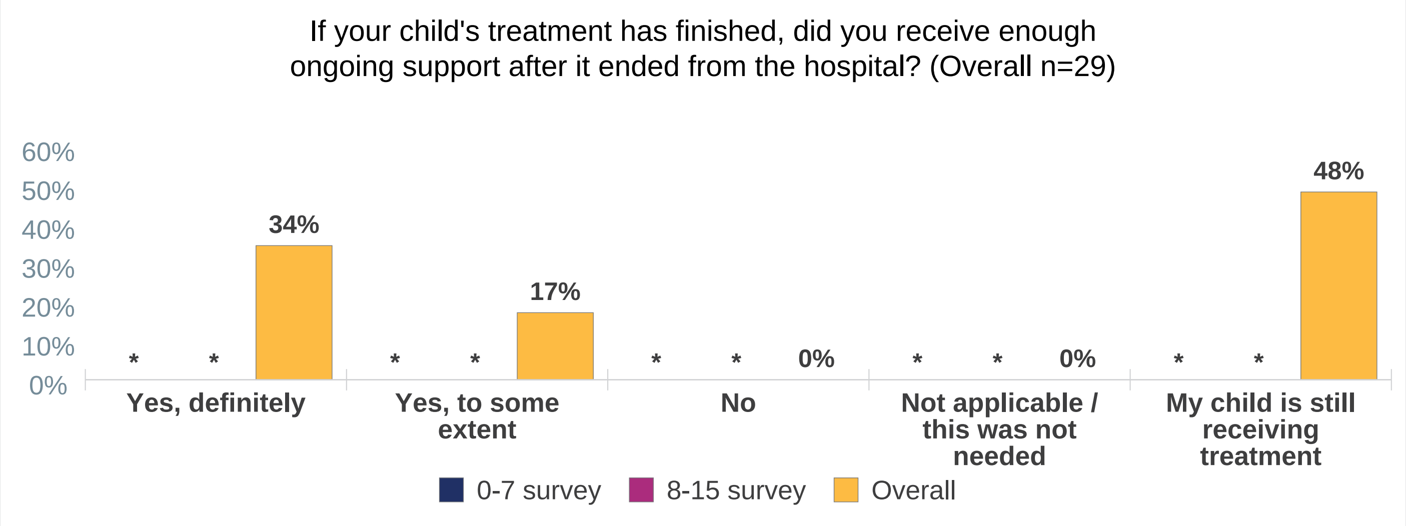
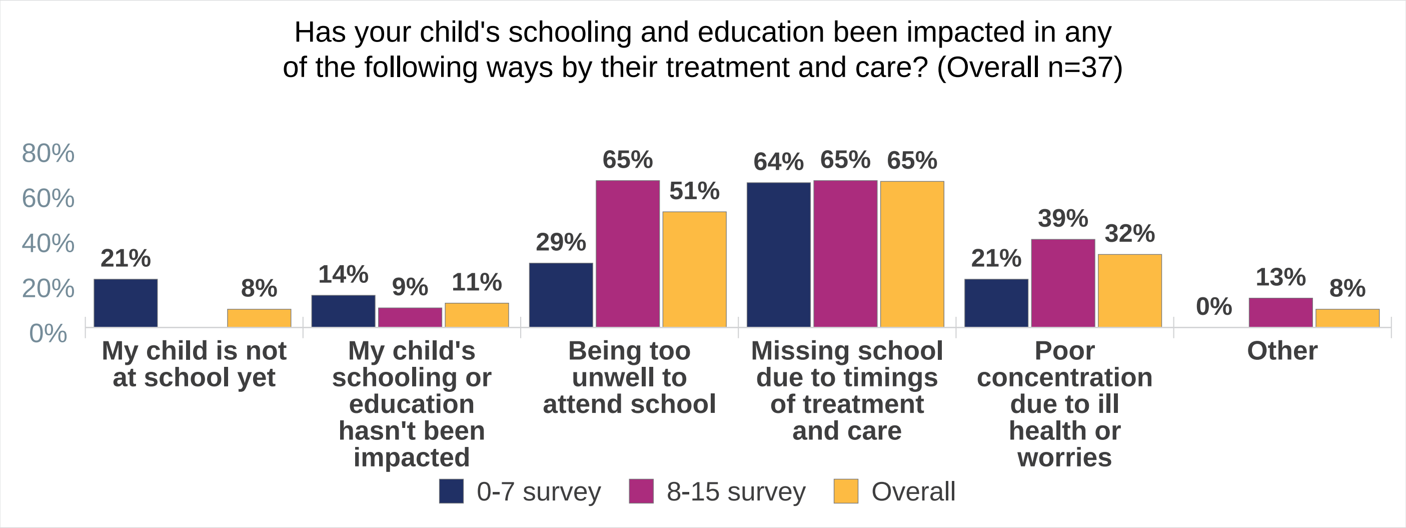


Figure 20. Answered by parents/carers of all age groups[5] (Question X33)



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[5] Please note that response option 1 (my child is not at school yet) was only asked to parents of 0-7 year olds.

Hospital ward

Respondents who had stayed on a hospital ward at the hospital named in the letter that came with their survey (as a day case or for an overnight stay) in the last year were asked questions about hospital staff along with questions regarding services and facilities.

Figure 21. Answered by parents/carers of children aged 0-7 whose children stayed on a hospital ward in the last year, and children aged 8-15 who stayed on a hospital ward in the last year (Question X47)

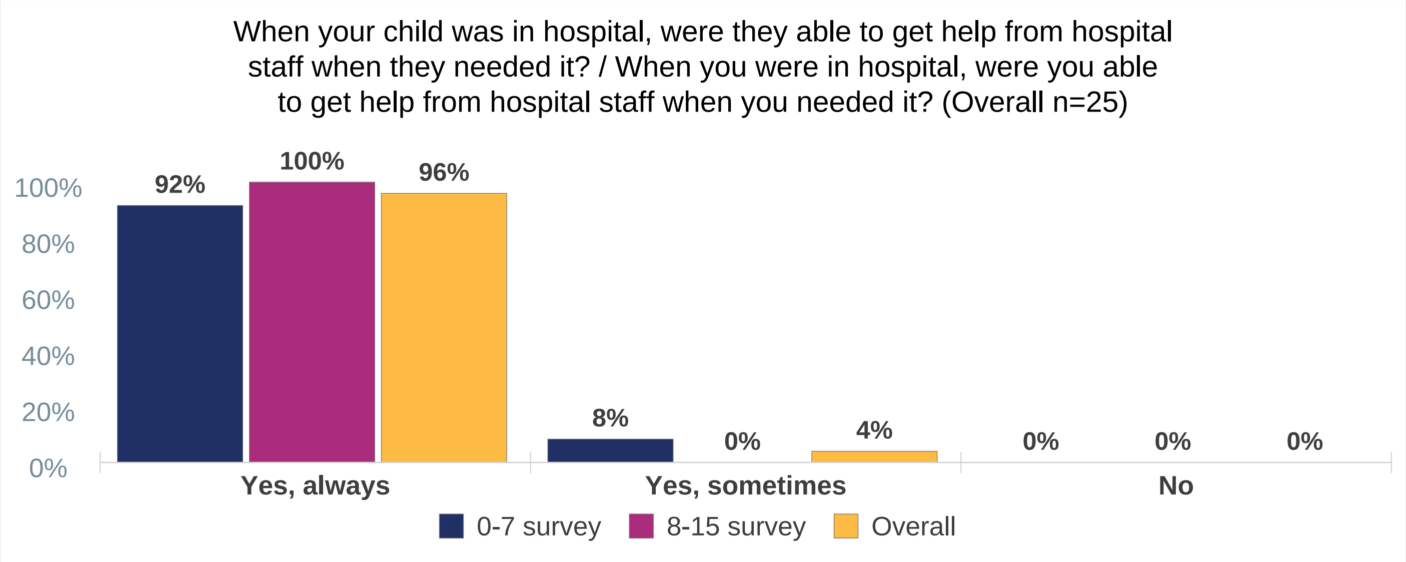
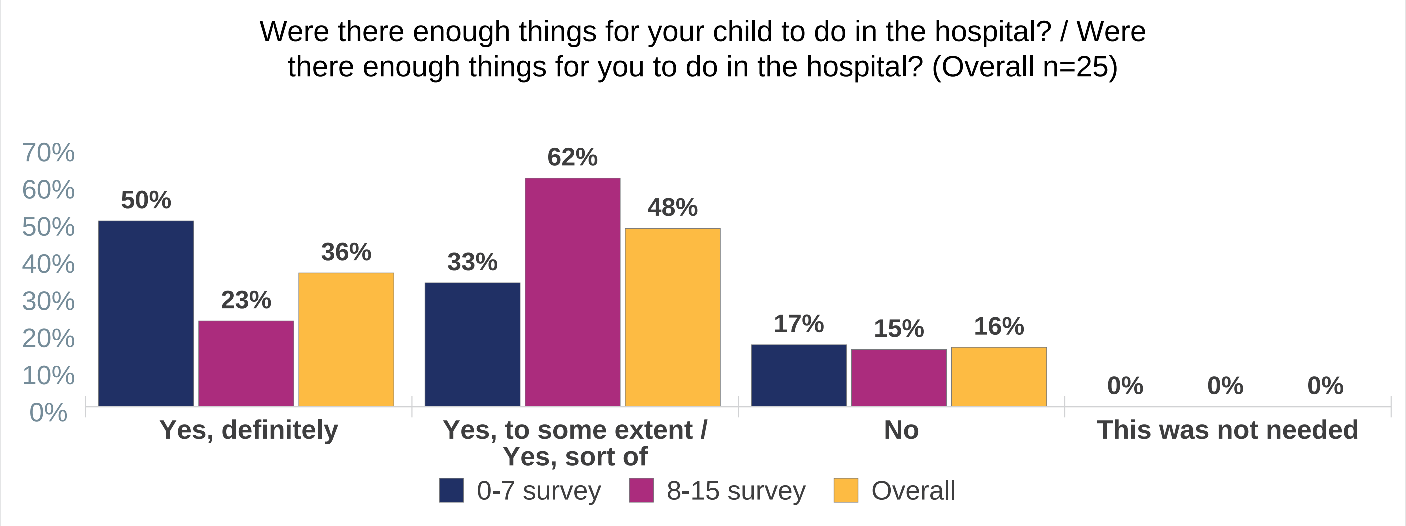


Figure 22. Answered by parents/carers of children aged 0-7 whose children stayed on a hospital ward in the last year, and children aged 8-15 who stayed on a hospital ward in the last year (Question X48)



Care at home

Children aged 8 and above and parents/carers of children under the age of 8 who had been visited at home by a nurse in the last year, for care relating to the child’s cancer or tumour, were asked a short series of questions about care at home. Some results from this section can be found below.

Figure 23. Answered by parents/carers of children aged 0-7 whose children have been visited at home by a nurse in the last year, and children aged 8-15 who were visited at home by a nurse in the last year (Question X59)

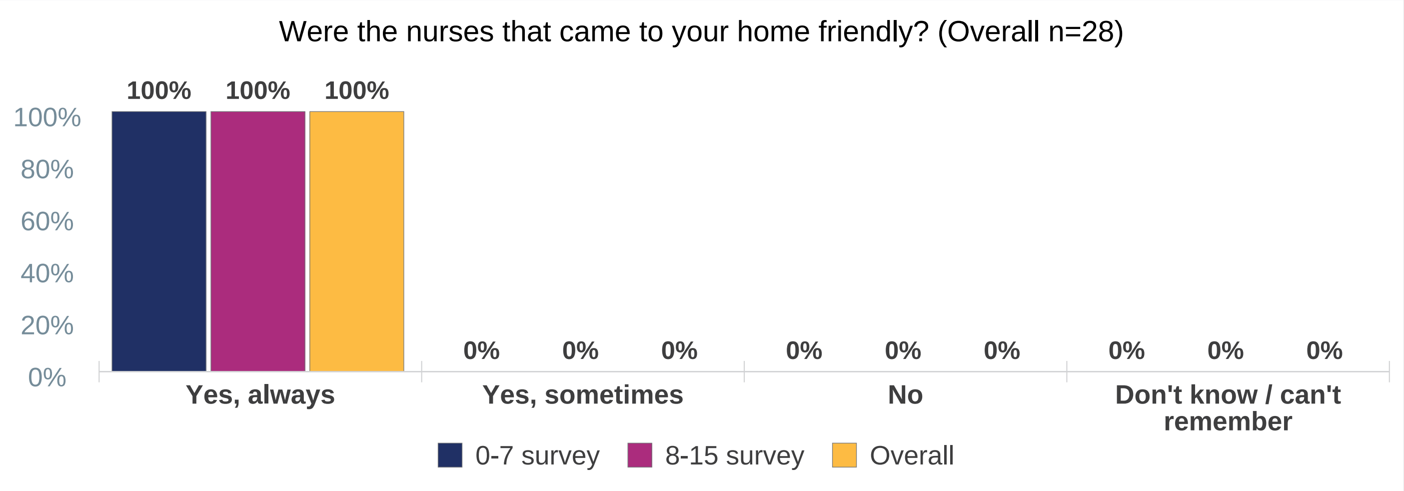
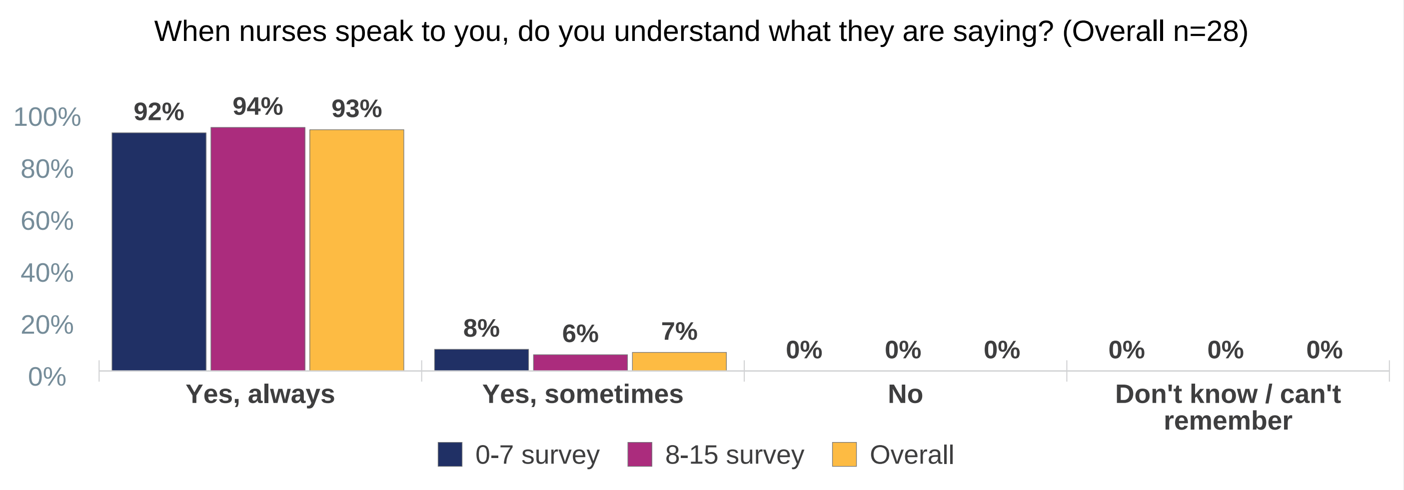


Figure 24. Answered by parents/carers of children aged 0-7 whose children have been visited at home by a nurse in the last year, and children aged 8-15 who were visited at home by a nurse in the last year (Question X60)



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 additional questions were asked about how well different hospitals providing cancer or tumour care worked together and whether the hospital where the child received most of their cancer or tumour care was under one hours travel time from their home. Results can be found in Figures 25 and 26 below.

Figure 25. Answered by parents/carers of children aged 0-7 (parent survey), and parents/ carers of children aged 8-11 and children aged 12-15 (children’s survey) (Question X62)

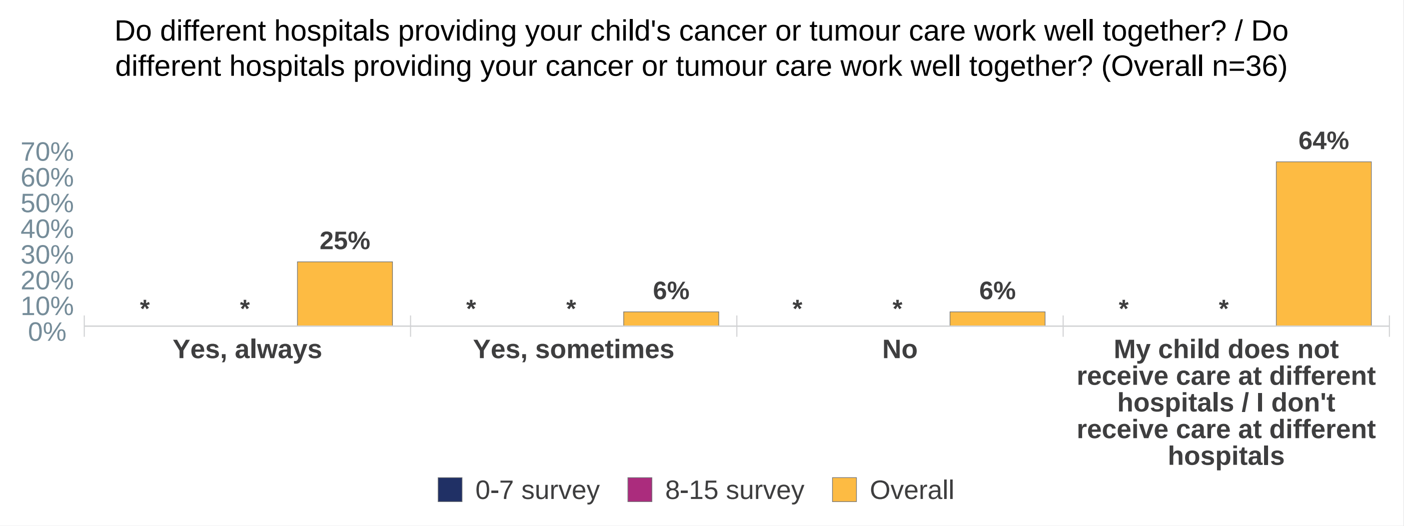
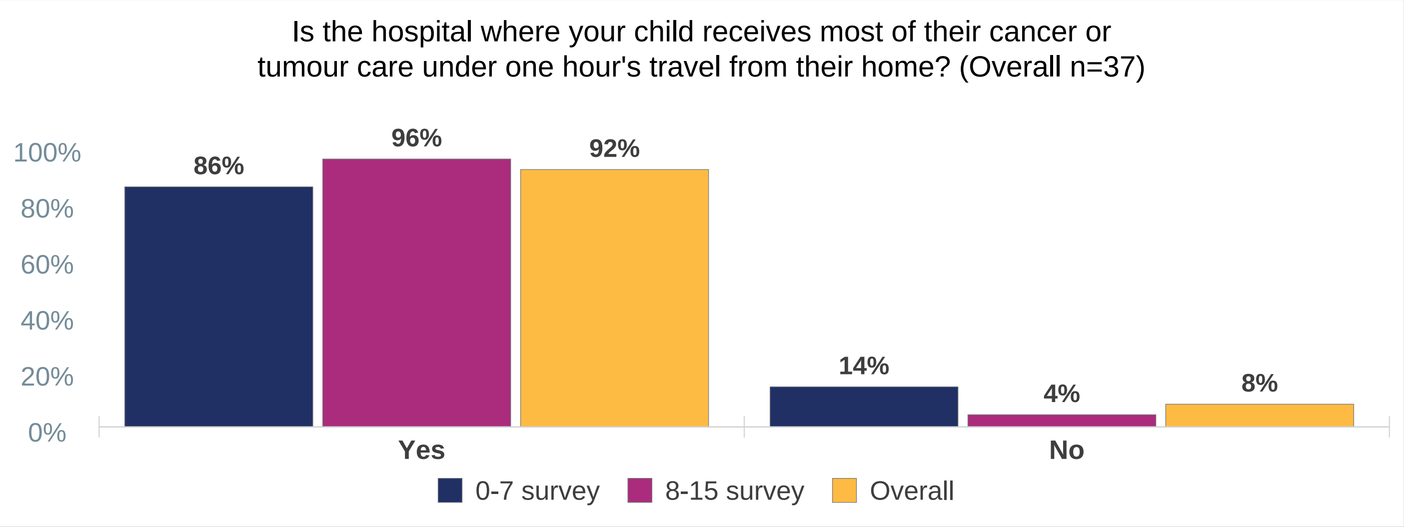


Figure 26. Answered by parents/carers of all age groups (Question X63)



Sub-group comparisons

This section summarises the responses of various sub-groups 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: https://www.under16cancerexperiencesurvey.co.uk/technical-reports.

A breakdown of all survey questions by each sub-group can be found in the PTC Excel Data Tables.

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. These rankings have been grouped into 0-3 (poor), 4-7, and 8-10 (good) in the results below.

Gender[7]

Figure 27. Answered by all children aged 8-15 (Question X65)

Overall, how well are you looked after for your cancer or tumour by the healthcare staff? (Overall n=22)

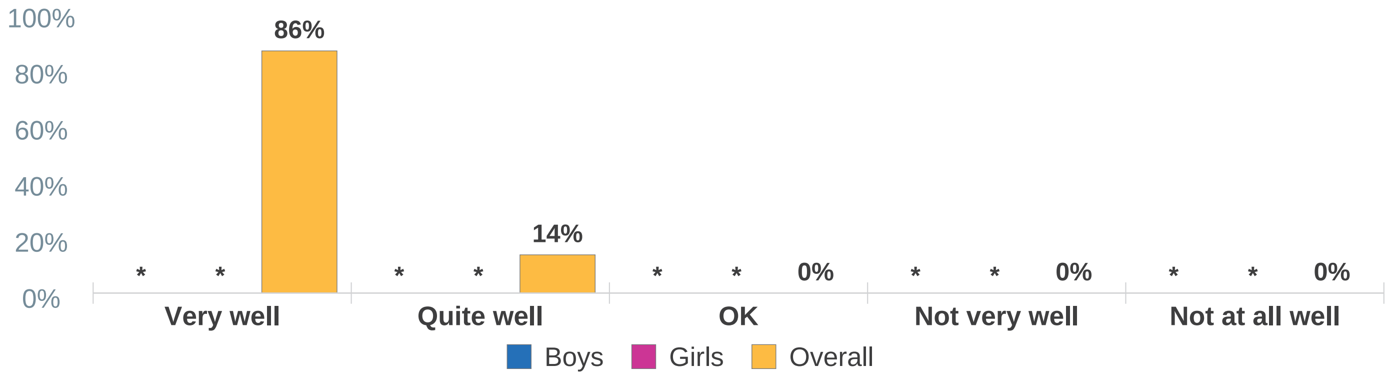
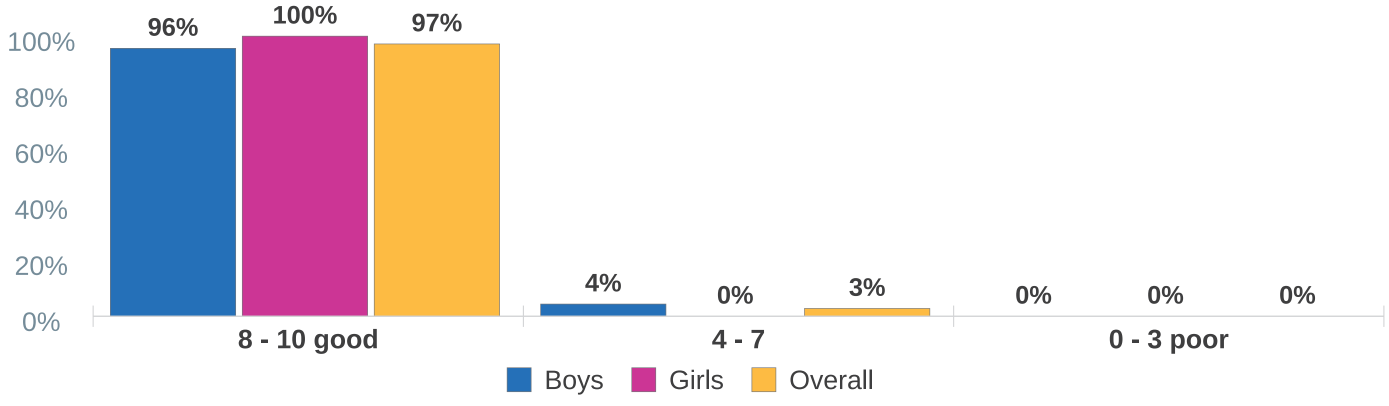


Figure 28. Answered by parents/carers of all age groups (Question X64 grouped)

Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good) (Overall n=36)



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[7] Only data for boys and girls is shown, as the number of respondents answering ‘prefer not to say’ to the gender question was less than 11.

Survey type

Figure 29. Answered by all children aged 8-15 (Question X65)

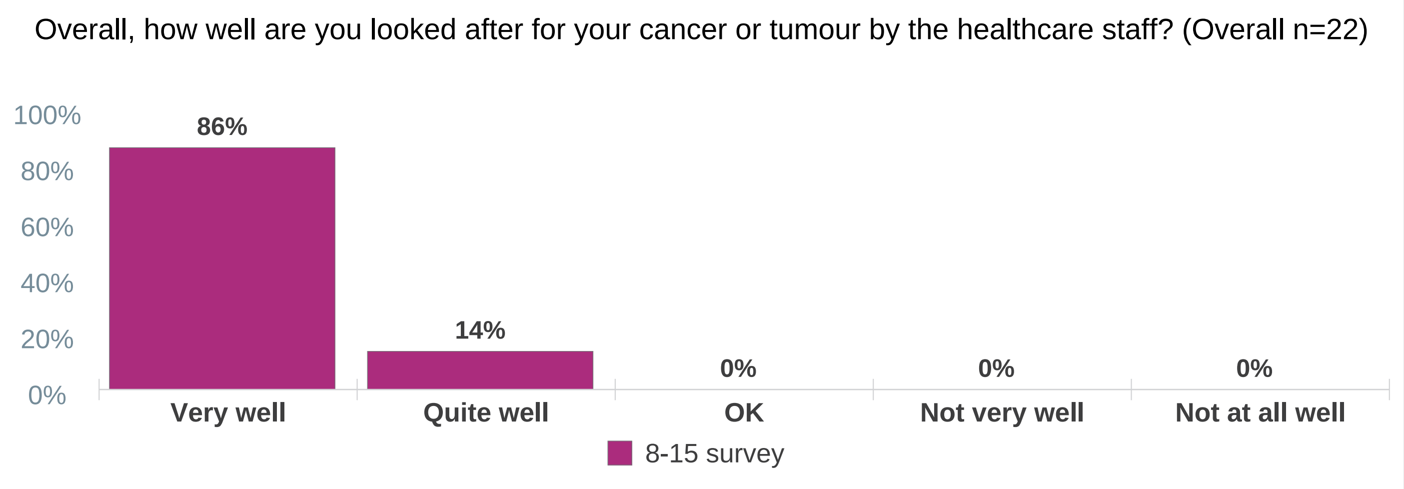
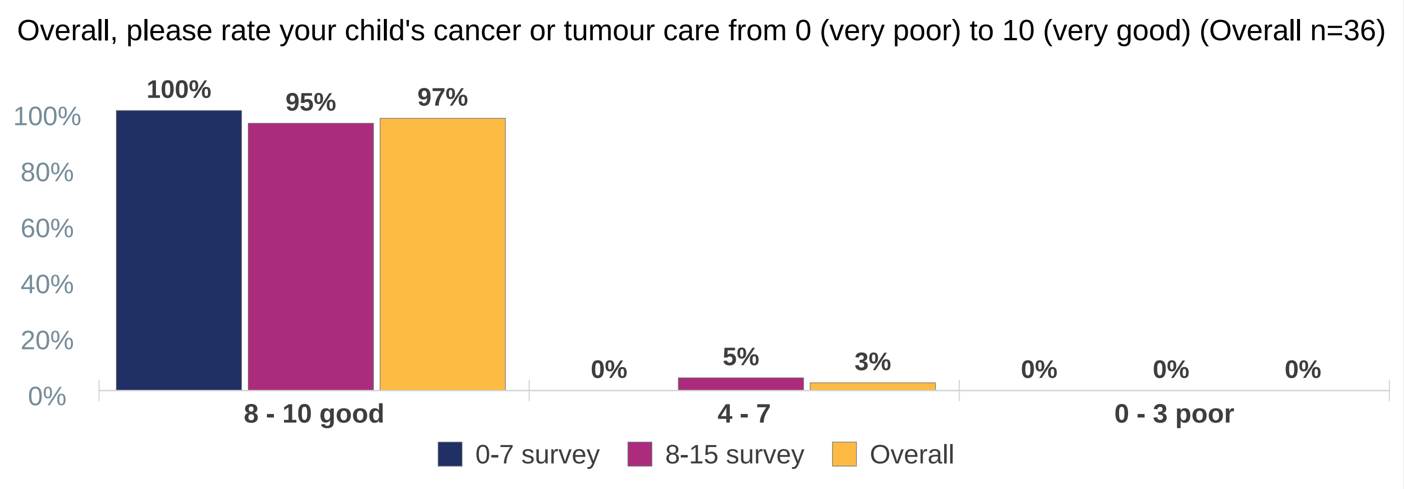


Figure 30. Answered by parents/carers of all age groups (Question X64 grouped)



Ethnicity

Figure 31. Answered by all children aged 8-15 (Question X65)

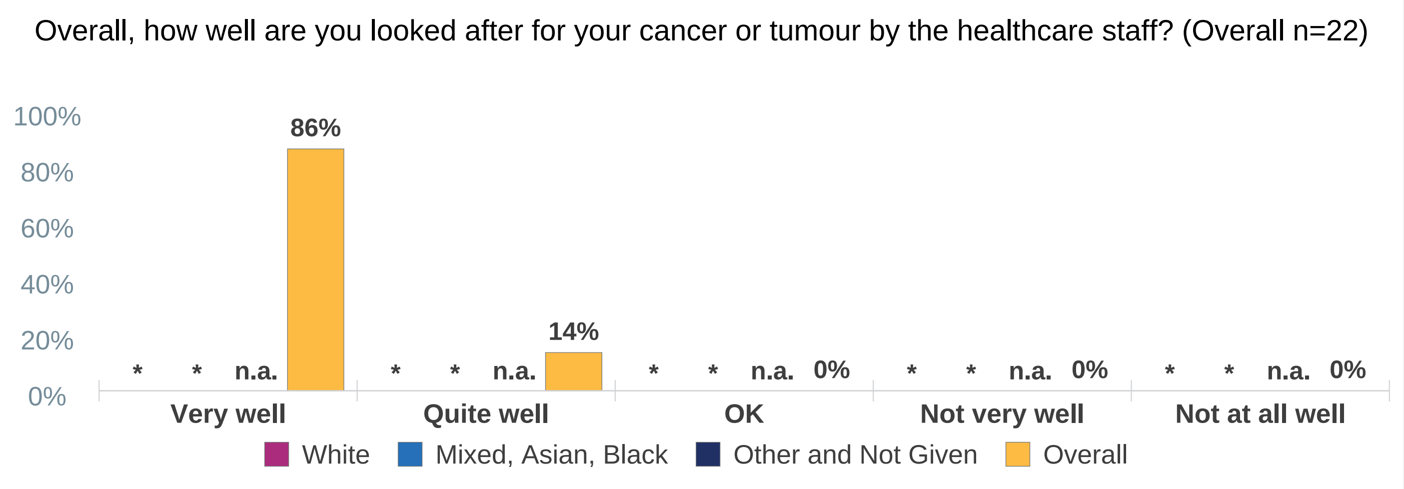
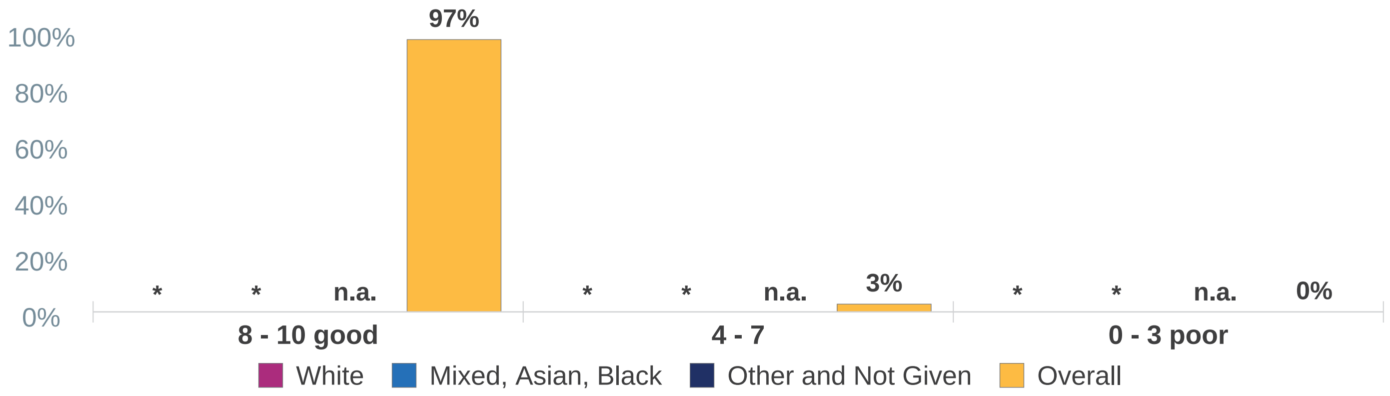


Figure 32. Answered by parents/carers of all age groups (Question X64 grouped)

Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good) (Overall n=36)



Deprivation

Figure 33. Answered by all children aged 8-15 (Question X65)

Overall, how well are you looked after for your cancer or tumour by the healthcare staff? (Overall n=22)

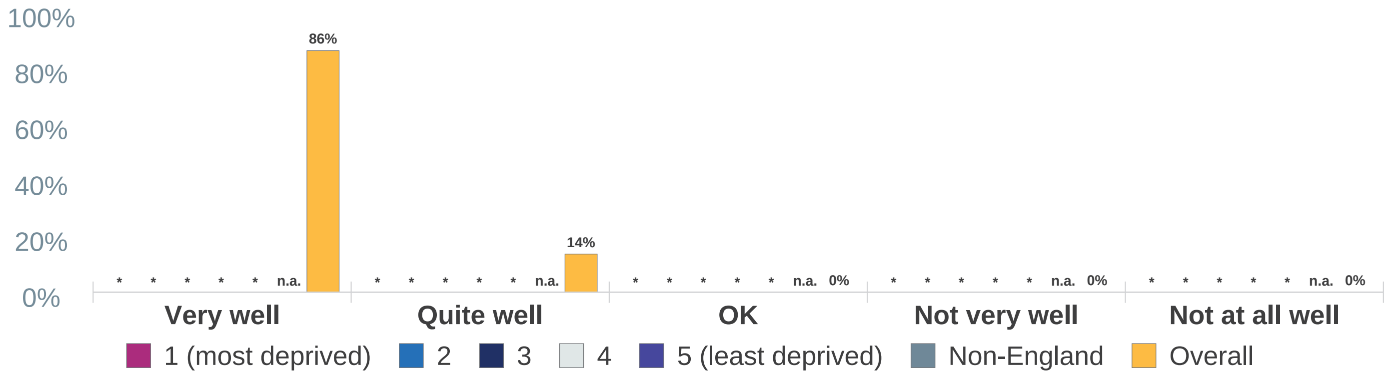
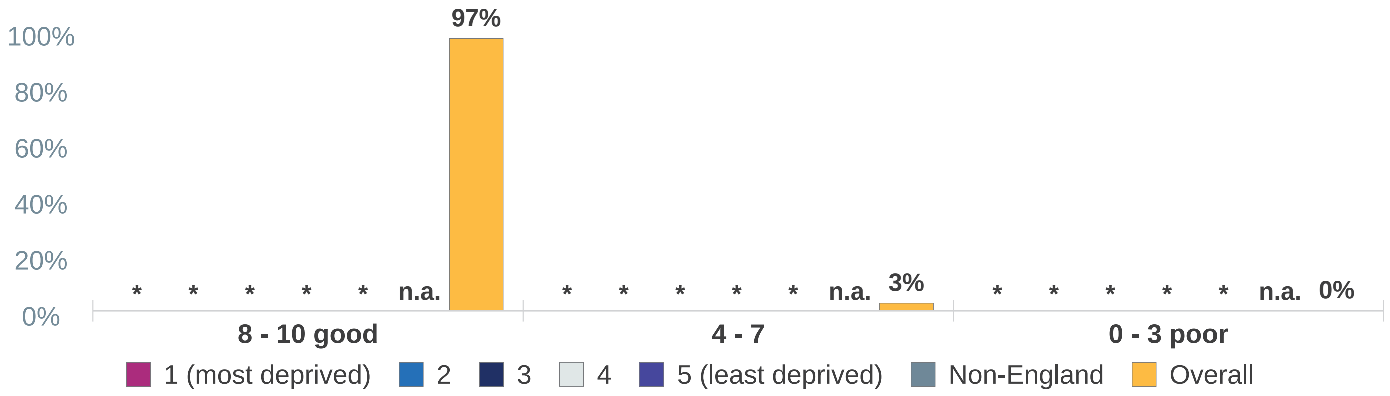


Figure 34. Answered by parents/carers of all age groups (Question X64 grouped)

Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good) (Overall n=36)



Diagnostic group

Figure 35. Answered by all children aged 8-15 (Question X65)

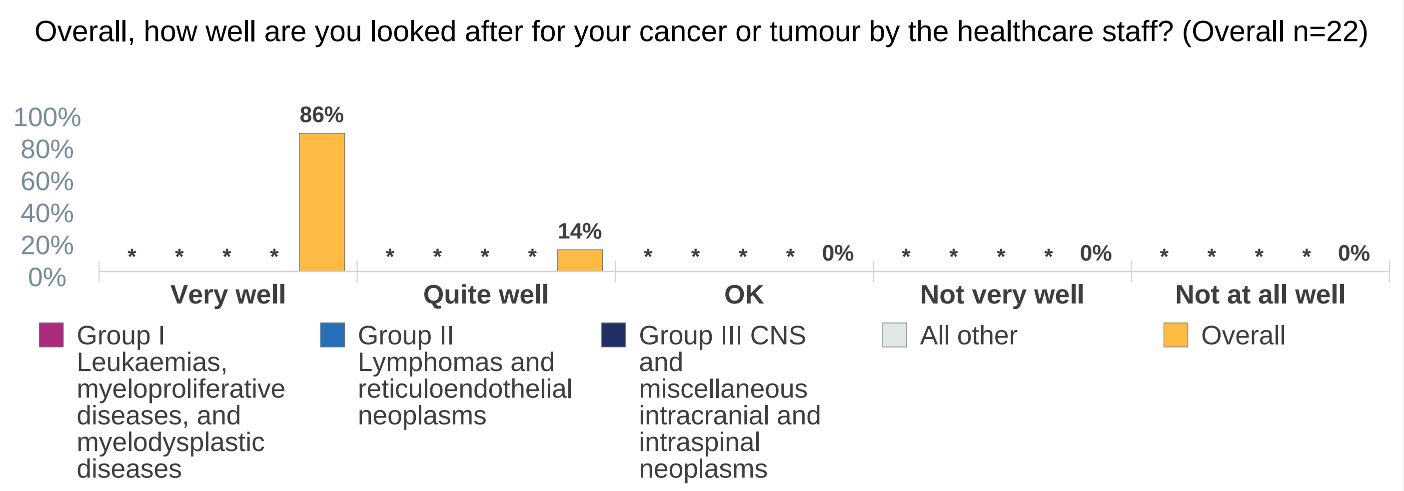
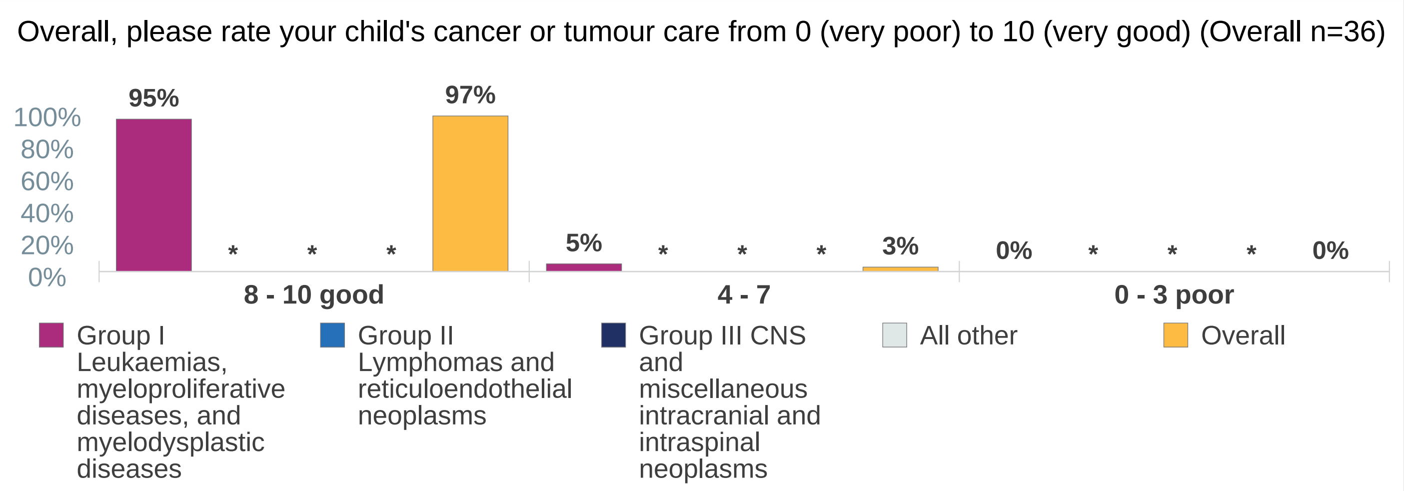


Figure 36. Answered by parents/carers of all age groups (Question X64 grouped)



Benchmarking Charts

Benchmarking charts compare experiences in your PTC with those of other PTCs. This allows you to understand where your performance sits in relation to the National average, and compared to the range of scores across all PTCs. Each blue bar shows the range of scores across PTCs, from best performance (to the right) to the poorest performance (to the left). Your PTC score is displayed by the yellow diamond, and the black line shows the National average.

The exact scores for your PTC and for the national average score, for each scored question, can be found in the next section “scoring tables”.

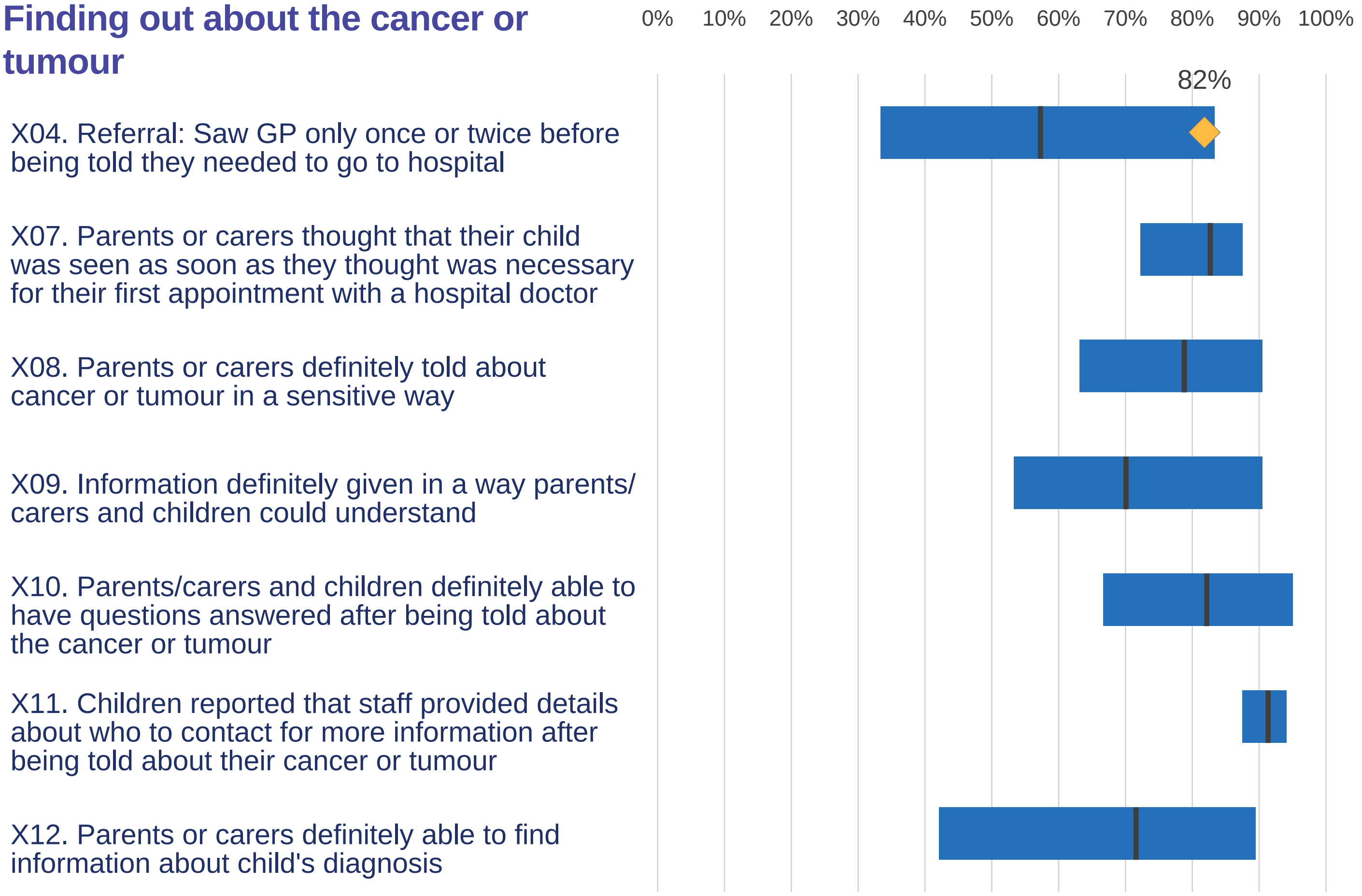
Important Note: Scores have been calculated using unadjusted data. In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently. For example, previous analysis indicates that Black and Asian patients report a less positive experience than White patients on patient experience survey questions. Thereby, PTCs with differing populations could potentially lead to results appearing better or worse than they would if they had a slightly different profile of patients. Scores have not been adjusted on the 2020 survey due to small sample size restrictions. Furthermore, PTCs should be mindful that survey responses may be influenced by the type of care provided by PTCs, for example some provide specialised care and treatment.

PTCs should therefore be mindful of differences in types of care provision, size and possible demographic makeup when comparing their results against the performance of other PTCs.

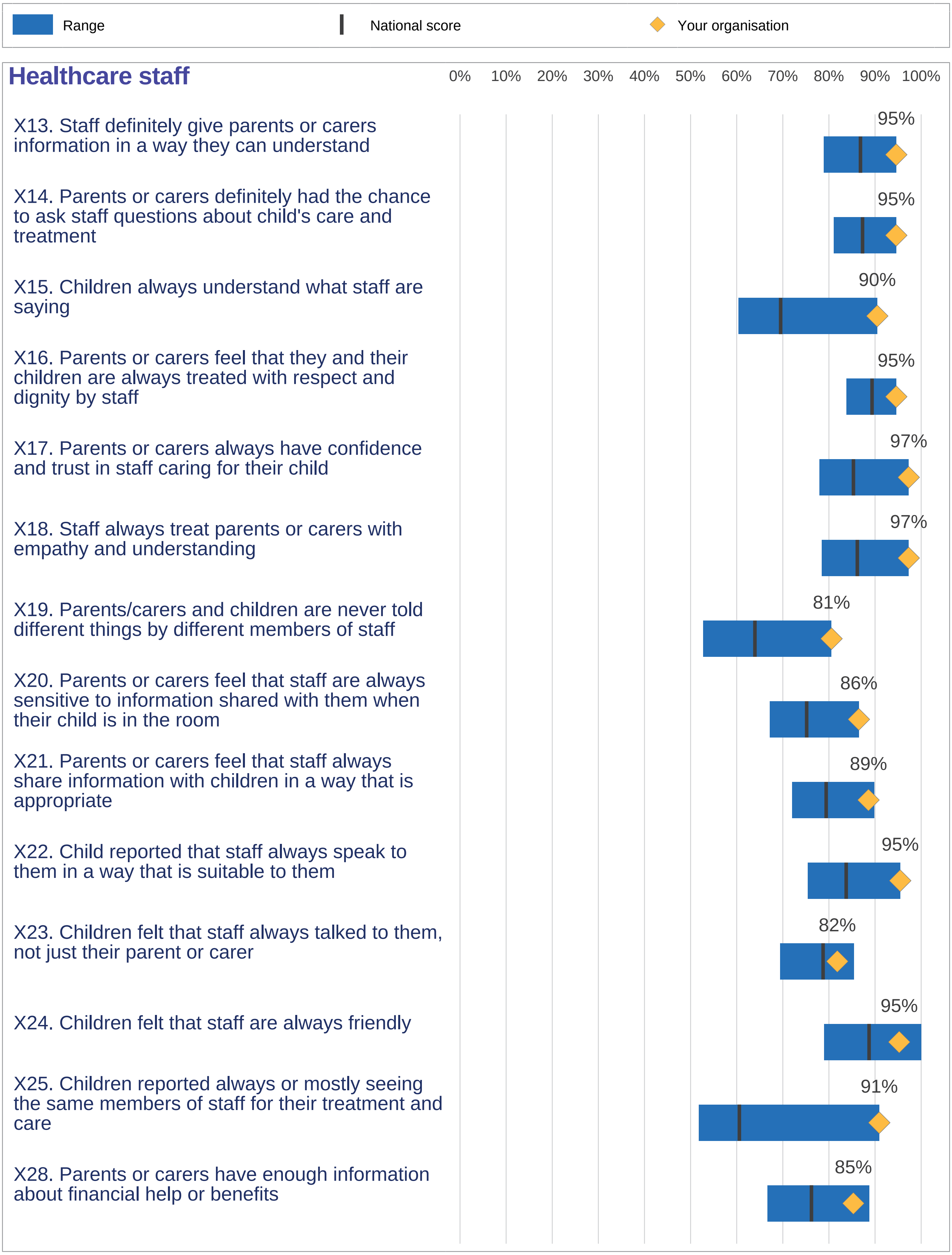
Data for questions in which the base size per question was <11 have been suppressed, and therefore no diamond for your organisation score will be displayed.

🟦 Range | National score ◆ Your organisation

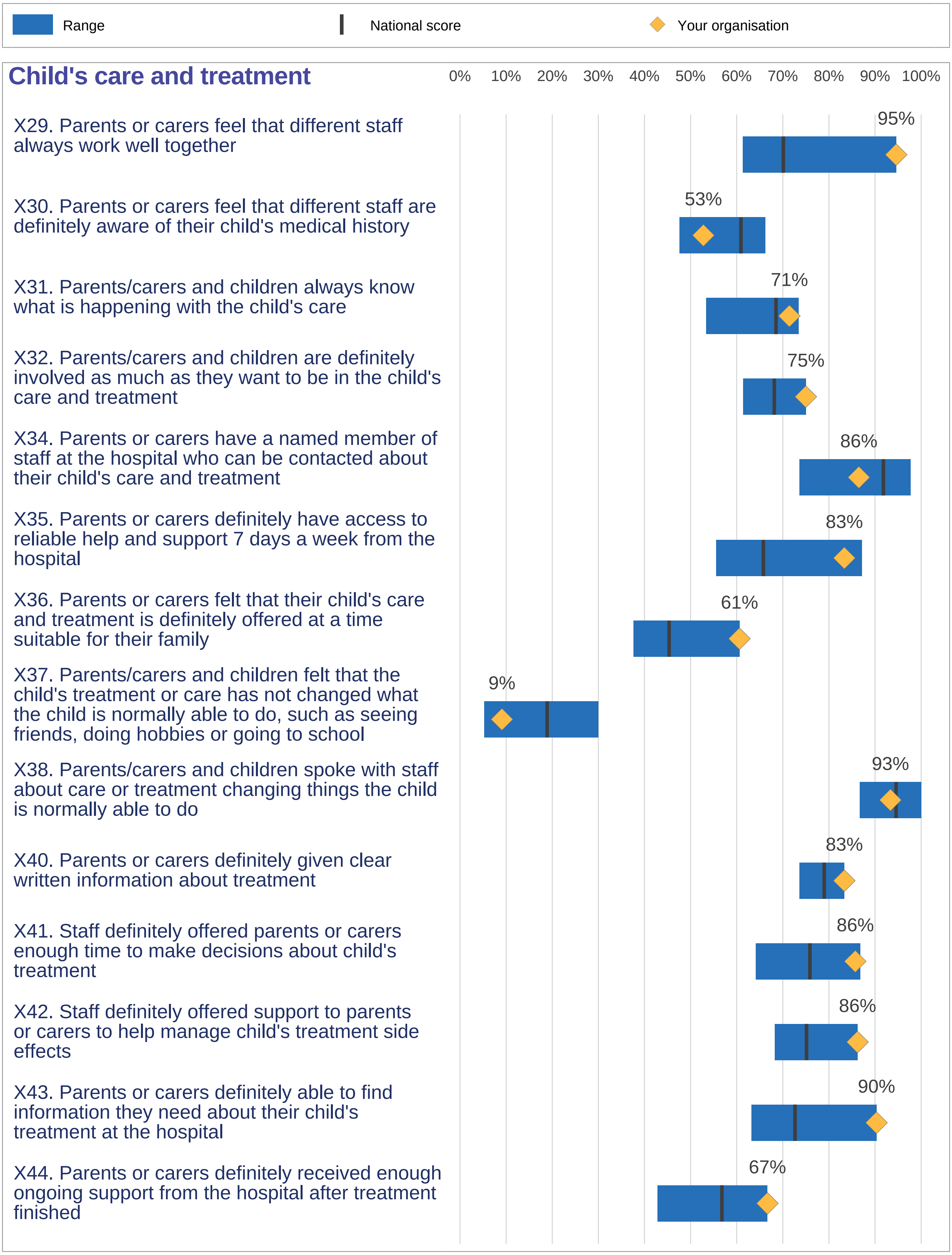
Finding out about the cancer or tumour



Healthcare staff

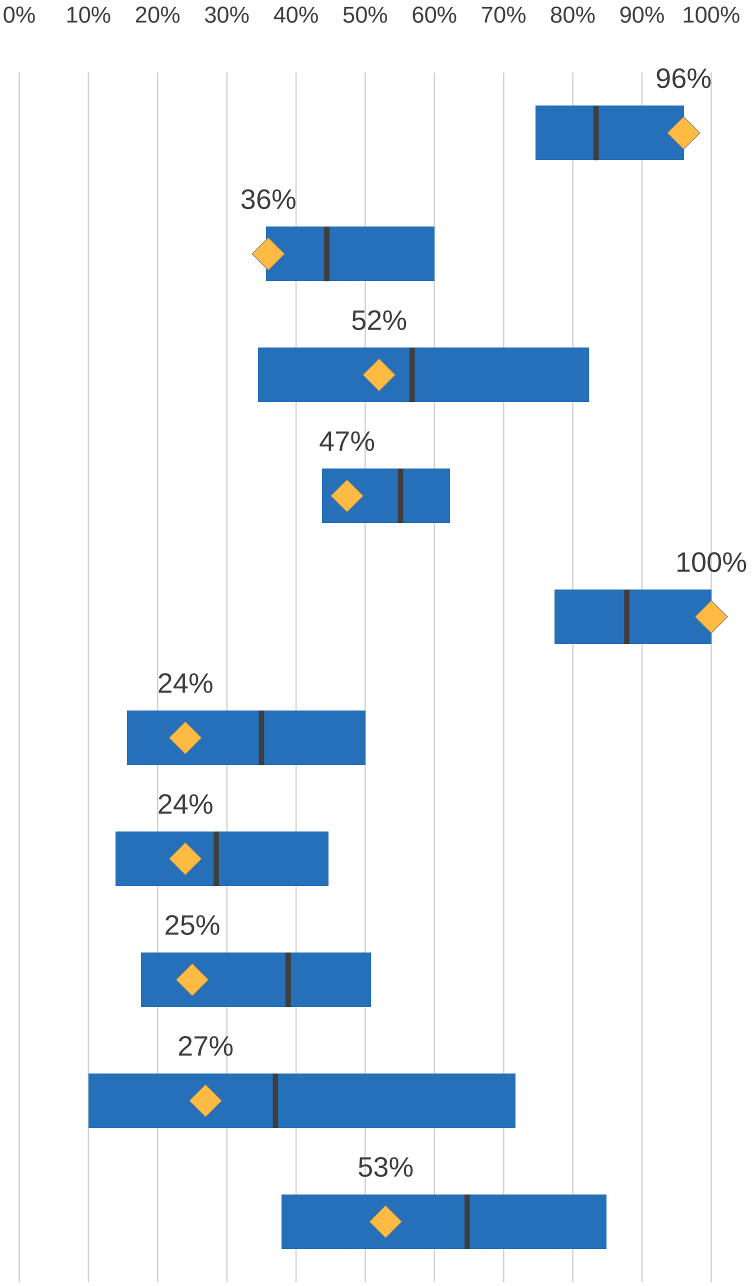


Child's care and treatment



▬ Range | National score ◆ Your organisation

Hospital ward



X47. Parents/carers and children felt that the child was always able to get help from hospital ward staff when they needed it

X48. Parents/carers and children felt that there were definitely enough things for the child to do in the hospital

X49. Parents/carers and children felt that there was definitely a choice of hospital food on the ward

X50. Parents/carers and children always given somewhere private to talk to staff when the child was on a hospital ward

X51. Hospital ward offered play specialist support

X53. Facilities for parents or carers staying overnight were very good

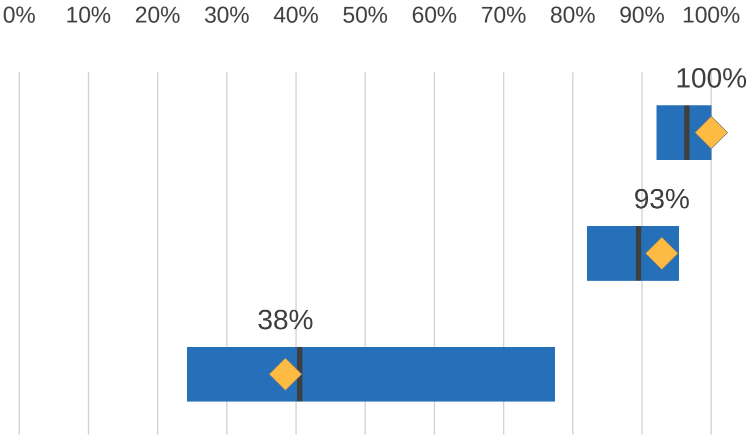
X54. Always quiet enough for parents/carers and children to sleep in the hospital

X55. Parents or carers were definitely able to prepare food in the hospital

X56. Parents or carers felt that the hospital Wi-Fi always met the needs of them and their children

X57. Parents or carers reported that child had access to hospital school services during their stay in hospital

Care at home



X59. Parents/carers and children felt that nurses who came to their home were always friendly

X60. Parents/carers and children always understand what nurses visiting their home are saying

X61. Parents/carers and children report that the same nurses always come to their child's home

🟦 Range | National score ◆ Your organisation

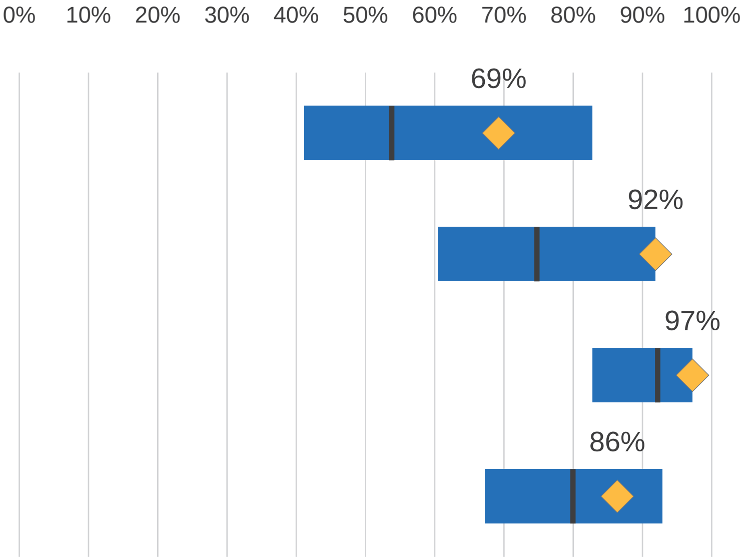
Overall care

X62. Different hospitals providing cancer or tumour care always work well together

X63. Parents or carers report that the hospital where their child receives most care is under one hours travel from their child's home

X64. Parents or carers rated the overall experience of their child's care as 8 or more out of 10

X65. Children are looked after very well for their cancer or tumour by healthcare staff



Score Tables

The following tables compare experiences of care in your PTC with the average for all 13 participating PTCs. This allows you to understand where your performance sits in relation to the National average.

Important Note: Scores have been calculated using unadjusted data. In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently. For example, previous analysis indicates that Black and Asian patients report a less positive experience than White patients on patient experience survey questions. Thereby, PTCs with differing populations could potentially lead to results appearing better or worse than they would if they had a slightly different profile of patients. Scores have not been adjusted on the 2020 survey due to small sample size restrictions. Furthermore, PTCs should be mindful that survey responses may be influenced by the type of care provided by PTCs, for example some provide specialised care and treatment.

PTCs should therefore be mindful of differences in types of care provision, size and possible demographic makeup when comparing their results against the performance of other PTCs.

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

Finding out about the cancer or tumour

Question	Scored Text	PTC Score	National Score
X04	Referral: Saw GP only once or twice before being told they needed to go to hospital	82%	57%
X07	Parents or carers thought that their child was seen as soon as they thought was necessary for their first appointment with a hospital doctor	*	83%
X08	Parents or carers definitely told about cancer or tumour in a sensitive way	*	79%
X09	Information definitely given in a way parents/carers and children could understand	*	70%
X10	Parents/carers and children definitely able to have questions answered after being told about the cancer or tumour	*	82%
X11	Children reported that staff provided details about who to contact for more information after being told about their cancer or tumour	*	91%
X12	Parents or carers definitely able to find information about child's diagnosis	*	72%

Healthcare staff

Question	Scored Text	PTC Score	National Score
X13	Staff definitely give parents or carers information in a way they can understand	95%	87%
X14	Parents or carers definitely had the chance to ask staff questions about child's care and treatment	95%	87%
X15	Children always understand what staff are saying	90%	70%
X16	Parents or carers feel that they and their children are always treated with respect and dignity by staff	95%	89%
X17	Parents or carers always have confidence and trust in staff caring for their child	97%	85%
X18	Staff always treat parents or carers with empathy and understanding	97%	86%
X19	Parents/carers and children are never told different things by different members of staff	81%	64%
X20	Parents or carers feel that staff are always sensitive to information shared with them when their child is in the room	86%	75%
X21	Parents or carers feel that staff always share information with children in a way that is appropriate	89%	79%
X22	Child reported that staff always speak to them in a way that is suitable to them	95%	84%
X23	Children felt that staff always talked to them, not just their parent or carer	82%	79%
X24	Children felt that staff are always friendly	95%	89%
X25	Children reported always or mostly seeing the same members of staff for their treatment and care	91%	61%
X28	Parents or carers have enough information about financial help or benefits	85%	76%

Child's care and treatment

Question	Scored Text	PTC Score	National Score
X29	Parents or carers feel that different staff always work well together	95%	70%
X30	Parents or carers feel that different staff are definitely aware of their child's medical history	53%	61%
X31	Parents/carers and children always know what is happening with the child's care	71%	69%
X32	Parents/carers and children are definitely involved as much as they want to be in the child's care and treatment	75%	68%
X34	Parents or carers have a named member of staff at the hospital who can be contacted about their child's care and treatment	86%	92%
X35	Parents or carers definitely have access to reliable help and support 7 days a week from the hospital	83%	66%
X36	Parents or carers felt that their child's care and treatment is definitely offered at a time suitable for their family	61%	45%
X37	Parents/carers and children felt that the child's treatment or care has not changed what the child is normally able to do, such as seeing friends, doing hobbies or going to school	9%	19%
X38	Parents/carers and children spoke with staff about care or treatment changing things the child is normally able to do	93%	95%
X40	Parents or carers definitely given clear written information about treatment	83%	79%
X41	Staff definitely offered parents or carers enough time to make decisions about child's treatment	86%	76%
X42	Staff definitely offered support to parents or carers to help manage child's treatment side effects	86%	75%
X43	Parents or carers definitely able to find information they need about their child's treatment at the hospital	90%	73%
X44	Parents or carers definitely received enough ongoing support from the hospital after treatment finished	67%	57%

Hospital ward

Question	Scored Text	PTC Score	National Score
X47	Parents/carers and children felt that the child was always able to get help from hospital ward staff when they needed it	96%	83%
X48	Parents/carers and children felt that there were definitely enough things for the child to do in the hospital	36%	44%
X49	Parents/carers and children felt that there was definitely a choice of hospital food on the ward	52%	57%
X50	Parents/carers and children always given somewhere private to talk to staff when the child was on a hospital ward	47%	55%
X51	Hospital ward offered play specialist support	100%	88%
X53	Facilities for parents or carers staying overnight were very good	24%	35%
X54	Always quiet enough for parents/carers and children to sleep in the hospital	24%	28%
X55	Parents or carers were definitely able to prepare food in the hospital	25%	39%
X56	Parents or carers felt that the hospital Wi-Fi always met the needs of them and their children	27%	37%
X57	Parents or carers reported that child had access to hospital school services during their stay in hospital	53%	65%

Care at home

Question	Scored Text	PTC Score	National Score
X59	Parents/carers and children felt that nurses who came to their home were always friendly	100%	96%
X60	Parents/carers and children always understand what nurses visiting their home are saying	93%	89%
X61	Parents/carers and children report that the same nurses always come to their child's home	38%	41%

Overall care

Question	Scored Text	PTC Score	National Score
X62	Different hospitals providing cancer or tumour care always work well together	69%	54%
X63	Parents or carers report that the hospital where their child receives most care is under one hours travel from their child's home	92%	75%
X64	Parents or carers rated the overall experience of their child's care as 8 or more out of 10	97%	92%
X65	Children are looked after very well for their cancer or tumour by healthcare staff	86%	80%