



Under 16 Cancer Patient Experience Survey 2024

National Report (Quantitative)

Published November 2025



Contents



1 Executive summary

2 Introduction

3 Methodology

4 Understanding the results

5 About the respondents

6 National results

6.1 Overall care

6.2 Finding out about the cancer or tumour

6.3 Child's care and treatment

6.4 Care in hospital

6.5 Care at home or at school

6.6 Healthcare staff

7 Year on year comparisons

8 Further information

9 Appendix





1. Executive summary



Executive summary













Overall care

Overall care

Finding out about the cancer or tumour

Finding out about the cancer or tumour

Healthcare staff

78%

of children reported that they were very well looked after by staff for their cancer or tumour (82% in 2023).

91%

of parents or carers rated the overall experience of their child's care as 8 or more out of 10 (88% in 2023).

70%

of parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way (71% in 2023). **75%**

of parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand (73% in 2023).

83%

of parents or carers felt they always had confidence and trust in staff caring for their child (80% in 2023).

Executive summary













Child's care and treatment

Healthcare staff

Child's care and treatment

Child's care and treatment

Child's care and treatment

79%

of parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment (76% in 2023). **69%**

of children reported that they could always understand what staff were saying (73% in 2023).

63%

of parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital (58% in 2023).

60%

of parents or carers felt that different hospital staff were definitely aware of their child's medical history (**54%** in 2023). 63%

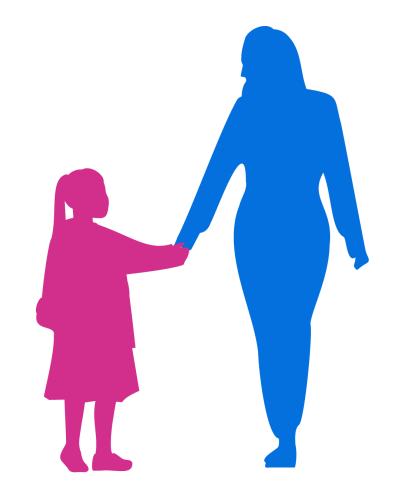
of parents or carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended (62% in 2023).

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.





2. Introduction



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 headline findings and is the fifth time the survey has run.



The survey respondents are children who were aged under 16 at the time of their care and discharge, as well as their parents or carers.



The survey has been designed to monitor national progress on experience of cancer care, to provide information to drive local quality improvements, to assist commissioners and providers of cancer care, and to inform the work of the various charities and stakeholder groups supporting children with cancer.

Introduction





NHS England manages the survey, commissioning Picker to oversee survey development, technical design, implementation, and analysis of the survey.



The survey is overseen by an Advisory Group of expert stakeholders including healthcare professionals who provide cancer care to children, charity representatives, patients, and parents or carers. The group advises on survey methodology, questionnaire development, and reporting.



13 Principal Treatment Centres providing cancer or tumour care to children during 2024 who were aged under 16 at their time of discharge were included in the survey.





3. Methodology



Methodology





Eligibility

Patients with a confirmed cancer or tumour diagnosis who received inpatient or day case care from an NHS Principal Treatment Centre (PTC) in 2024, aged under 16 at their time of discharge.



Questionnaire and mode

- A paper questionnaire with a cover invitation and up to two reminders posted to parents or carers. An option to complete the survey online via a survey URL or QR code, or via telephone.
- Freephone helpline and email for respondents to opt out, ask questions about the survey, enable them to complete their
 questionnaire over the phone and provide access to translation services for those whose first language was not English.
 Questions were asked about the child's care during 2024. There were three versions, depending on the patient's age prior to
 fieldwork:



- 0 to 7 questionnaire for completion by parents or carers of children aged 0 to 7.
- 8 to 11 questionnaire separate sections for the child and the parent or carer to complete.
- 12 to 15 questionnaire separate sections for the child or young person and the parent or carer to complete.



Fieldwork

People were asked to respond to the questionnaire between April and June 2025.





4. Understanding the results



Understanding the results



- For data presented in charts, the percentage of each scored response option is shown. Figures have been rounded to the nearest whole percentage, therefore they may not always equal 100%.
- Question numbers relate to the numbering on the data tables, not the question numbers used on the questionnaires themselves.



Subgroup comparisons allow us to explore differences in how people experience cancer care.

Some of the groups may be quite small, so please take caution when looking at results for these groups. See 'About the respondents' for information on the number of responses for subgroups. For subgroup comparisons to all survey questions at a national level, please see the National Excel Data Tables available on the survey website.



For scored questions, the data presented in the charts excludes non-applicable response options such as 'Don't know / can't remember'. Full data, including how scores to each question are calculated, can be found within the National Excel Data Tables available on the <u>survey website</u>.



No statistical significance testing has been done for subgroup comparisons, therefore please interpret any differences with caution.

Understanding the results

%

Confidence intervals: Assuming the sample is representative of the organisation, confidence intervals are a method of describing the uncertainty around results. They are shown as black bars on the charts in this report. 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 result 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. Where confidence intervals overlap, and the comparison is valid, there is not enough statistical evidence to conclude whether or not there is a "true" difference between the two).

Suppression rules have been applied to data to protect the anonymity of respondents and to prevent the release of unreliable results due to small numbers:



- 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: where data has been suppressed for anonymity, data for that subgroup AND the next smallest subgroup are suppressed. This is to prevent back calculation.
- Where the total number of responses to a question is less than 10, data for the question are suppressed, indicated by an asterisk (*).
- Further information regarding suppression rules can be found in the **Technical Document**.







Response rate

Overall response rate

Out of **3,434** eligible parents, carers, and children, **759** responded to the survey, yielding a response rate of **22%**. This is compared with 25% in 2023.



A response consists of one survey completion for a single patient, which could consist of both parent or carer and child responses.

The adjusted sample size removes those patients who did not receive a questionnaire (returned undelivered by post) or who reported they were not eligible to take part. Full details about how the response rate was calculated can be found in the Technical Document available on the <u>survey website</u>.

Original sample size	Adjusted sample size	Completed	Response rate
3,435	3,434	759	22%



Survey mode













Survey mode	Number of responses	Proportion of responses
Paper	511	67%
Online	248	33%
Phone – English	0	0%
Phone – translation service	0	0%
Mixed (combination of paper and online)	0	0%
Total	759	100%



Survey type

Survey type	Number of responses	Proportion of responses
Parents or carers of children aged 0 to 7	353	47%
Children aged 8 to 11 (and their parents or carers)	144	19%
Children aged 12 to 15 (and their parents or carers)	262	35%
Total	759	100%



Which of the following best describes you? (from survey responses)†

Which of the following best describes you?	Number of responses	Proportion of responses
Boy/Male	204	50%
Girl/Female	158	39%
I describe myself in another way	2	0%
Prefer not to say	1	0%
Don't know	1	0%
Not given	40	10%
Total	406	100%

Sex registered at birth (from survey responses)

Sex registered at birth	Number of responses	Proportion of responses
Male	410	54%
Female	313	41%
Prefer not to say	1	0%
Not given	35	5%
Total	759	100%



Ethnic group (from survey responses)

Ethnic group	Number of responses	Proportion of responses
White	548	72%
Mixed	44	6%
Asian	83	11%
Black	38	5%
Other [†]	13	2%
Not given	33	4%
Total	759	100%

^{† &#}x27;Other' refers to those who selected 'Arab' or 'Any other ethnic group' in the survey question asking about ethnic background.



Diagnostic group[†]

Diagnostic group	Number of responses	Proportion of responses
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	286	38%
Lymphomas and reticuloendothelial neoplasms	97	13%
CNS and miscellaneous intracranial and intraspinal neoplasms	145	19%
Retinoblastoma	28	4%
Renal tumours	37	5%
Hepatic tumours	8	1%
Malignant bone tumours	44	6%
All other	114	15%
Total	759	100%

[†] Details of how diagnostic groups were formed can be found in the Technical Document available on the <u>survey website</u>.



Deprivation (IMD† quintile)

Deprivation (IMD quintile)	Number of responses	Proportion of responses
1 (most deprived)	139	18%
2	165	22%
3	136	18%
4	151	20%
5 (least deprived)	151	20%
Non-England	17	2%
Total	759	100%

Current care or treatment stage (from survey responses)

Current care or treatment stage	Number of responses	Proportion of responses
Recently diagnosed	6	1%
Watch and wait	55	7%
Receiving treatment	303	40%
Finished treatment within the last one month	92	12%
In remission / long-term follow-up	268	35%
Palliative or end of life care	5	1%
Other	49	6%
Not given	26	3%
Total ^{††}	804	106%

[†] Index of Multiple Deprivation (IMD quintile) classifies geographic areas into five quintiles based on relative disadvantage, based on where the patient lives (not where they receive care and treatment).

^{††} This is a multiple choice question and therefore the total number of responses may be more than the total number of respondents.



Long-term condition status (from survey responses)

Long-term condition status	Number of responses	Proportion of responses
Another long-term condition	252	33%
No other long-term condition	419	55%
Not given	88	12%
Total	759	100%

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

Does the child's long-term condition or cancer reduce their ability to carry out their day-to-day activities?	Number of responses	Proportion of responses
Yes, a lot	185	24%
Yes, a little	321	42%
No, not at all	215	28%
Not given	38	5%
Total	759	100%



Long-term condition (from survey responses)

Long-term condition	Number of responses	Proportion of responses
Attention Deficit Hyperactivity Disorder (ADHD)	34	4%
Autism or autism spectrum condition	66	9%
Bowel condition, such as Crohn's disease	6	1%
Breathing problem, such as asthma	33	4%
Blindness or partial sight	52	7%
Chromosomal condition, such as Down's syndrome or Prader-Willi	12	2%
Deafness or hearing loss	24	3%
Diabetes	6	1%

Long-term condition (cont'd)	Number of responses	Proportion of responses
Heart problem	9	1%
Joint problem	16	2%
Kidney or liver disease	10	1%
Learning disability	44	6%
Mental health condition	14	2%
Neurological condition, such as epilepsy	21	3%
Other long-term condition	70	9%
No other long-term condition	419	55%
Not given	88	12%
Total [†]	924	122%

[†] This is a multiple choice question and therefore the total number of responses may be more than the total number of respondents.





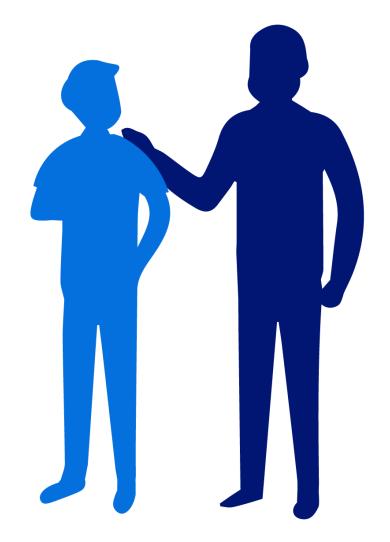
6. National results







6.1 Overall care



Overall care: subgroup comparisons



This section shows responses to the overall care questions by various subgroups. Further information about how subgroups were determined can be found in the Technical Document, available on the <u>survey website</u>. Please take care when drawing conclusions from results based on small numbers of responses.



A breakdown of all survey questions and scores to each question by each subgroup can be found in the National Excel Data Tables, available on the <u>survey website</u> and in an <u>interactive dashboard</u>.



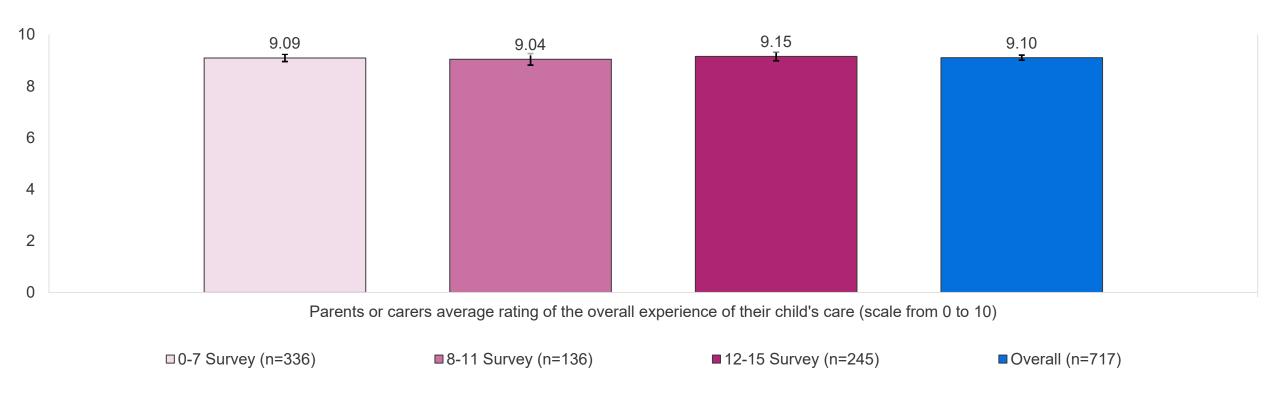
Questions asking about overall care were structured differently for children and parents or carers, and therefore they are not comparable:

- 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.
- Parents and carers of all age groups were asked to rank their child's overall care on a scale of 0 (very poor) to 10 (very good). These rankings have been grouped into 8-10 (good), 4-7, and 0-3 (poor).

Parents or carers average rating of care by survey type | U|6



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

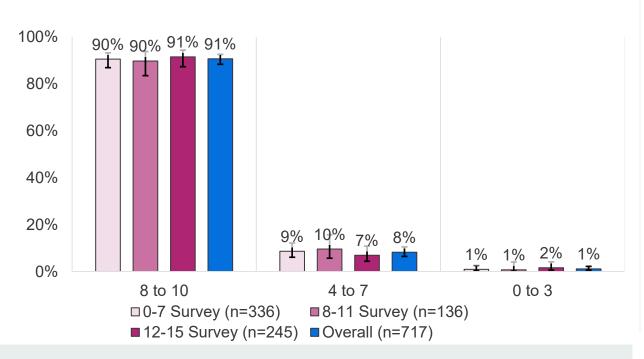


9.10 was the average parent or carer rating of the overall experience of their child's care (scale from 0 to 10). Average parent or carer ratings ranged from 9.04 to 9.15 across age groups.

Overall care by survey type



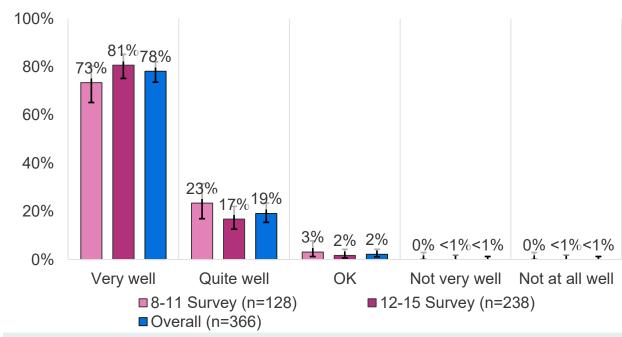
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 90% in the 8-11 survey to 91% in the 12-15 survey.

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 717

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



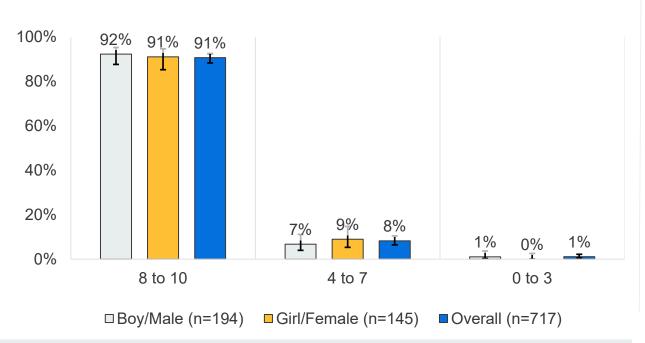
The percent of children reporting they were looked after very well ranged from 73% in the 8-11 survey to 81% in the 12-15 survey.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 366

Overall care by how patients describe themselves



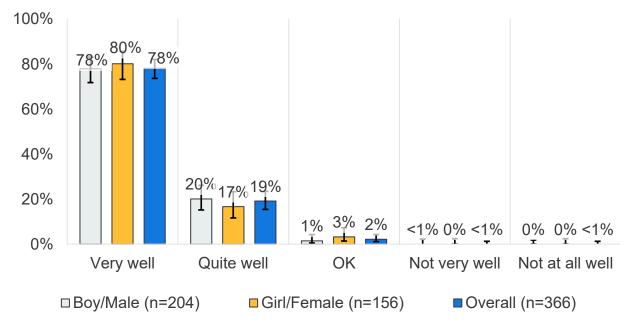
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 91% for girls/females to 92% for boys/males.

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 717. Due to small numbers, results for 'I describe myself in another way', 'don't know' and 'prefer not to say' are not shown.

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



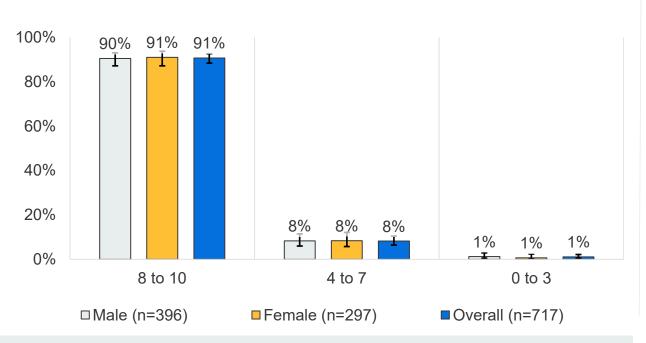
The percent of children reporting they were looked after very well ranged from 78% for boys/males to 80% for girls/females.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 366. Due to small numbers, results for 'I describe myself in another way', 'don't know' and 'prefer not to say' are not shown.

Overall care by sex registered at birth



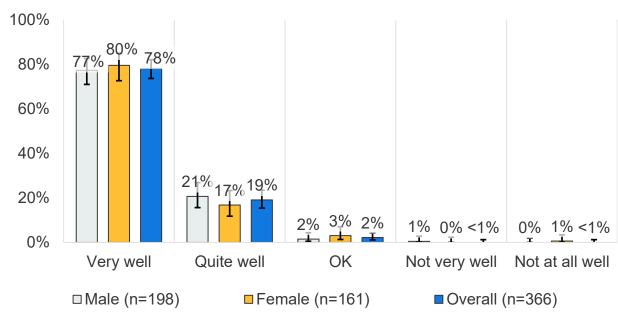
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 90% for males to 91% for females.

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 717. Due to small numbers, results for 'prefer not to say' are not shown.

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



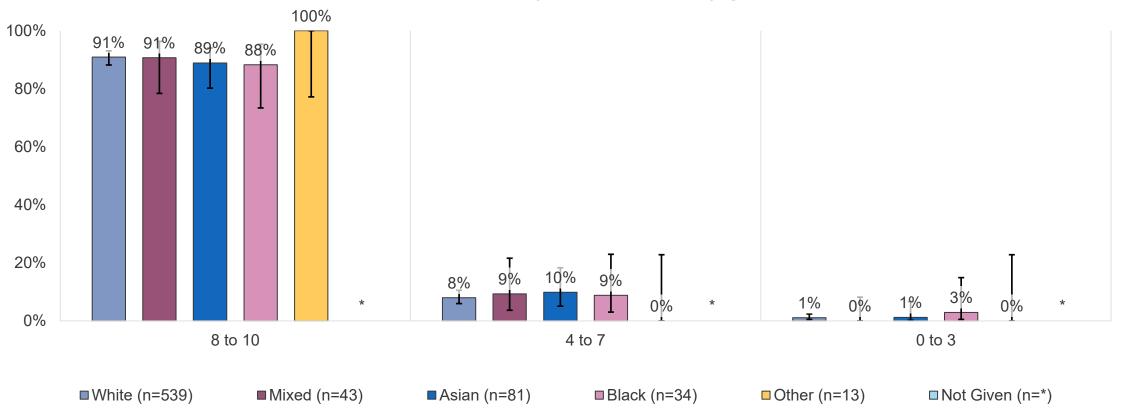
The percent of children reporting they were looked after very well ranged from 77% for males to 80% for females.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 366. Due to small numbers, results for 'prefer not to say' are not shown.

Overall care (parent or carer) by ethnic group



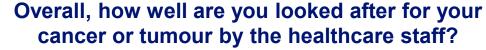
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)

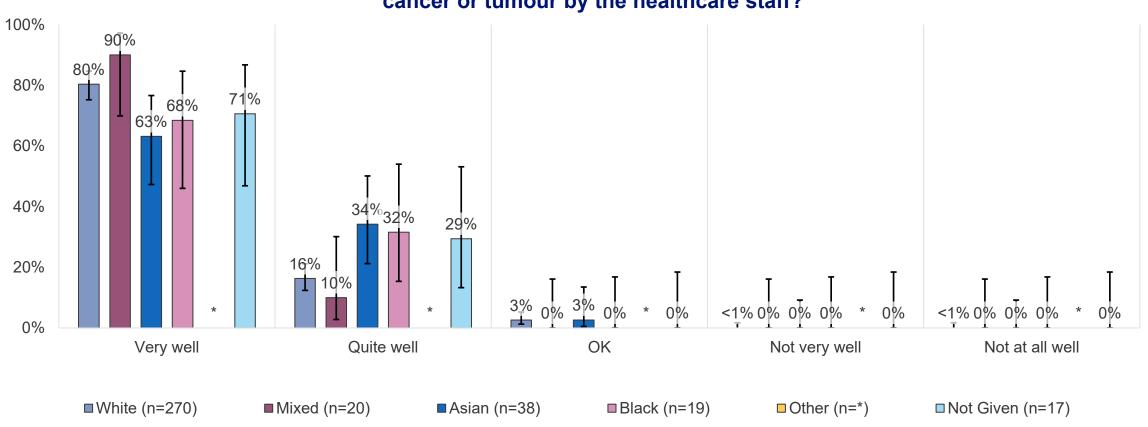


The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 88% for black ethnic background to 100% for other ethnic backgrounds.

Overall care (children) by ethnic group



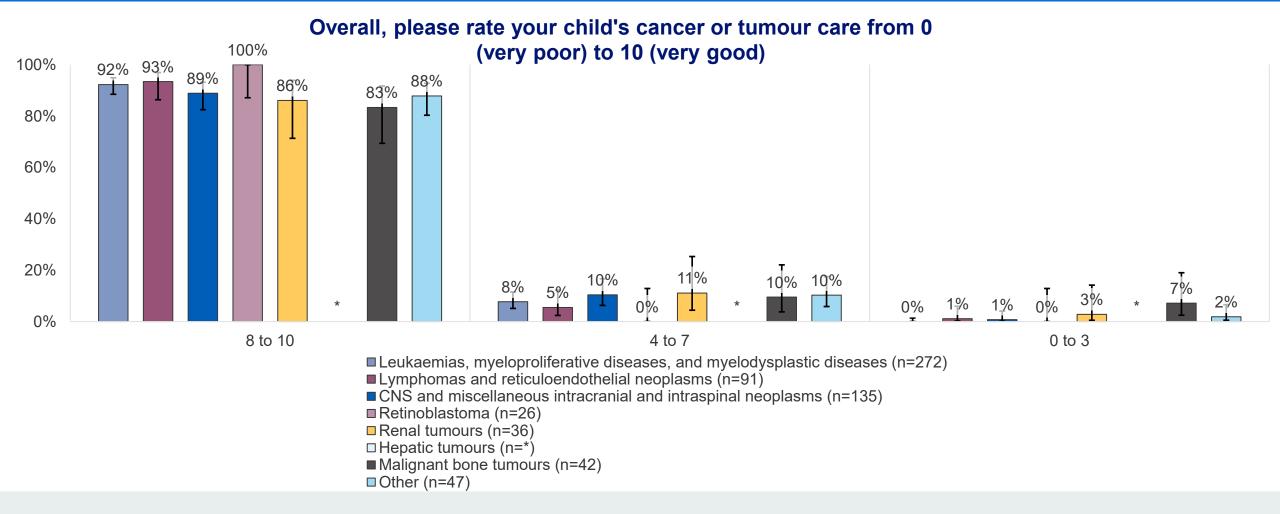




The percent of children reporting they were looked after very well ranged from 63% for Asian ethnic background to 90% for mixed ethnic background.

Overall care (parent or carer) by diagnostic group

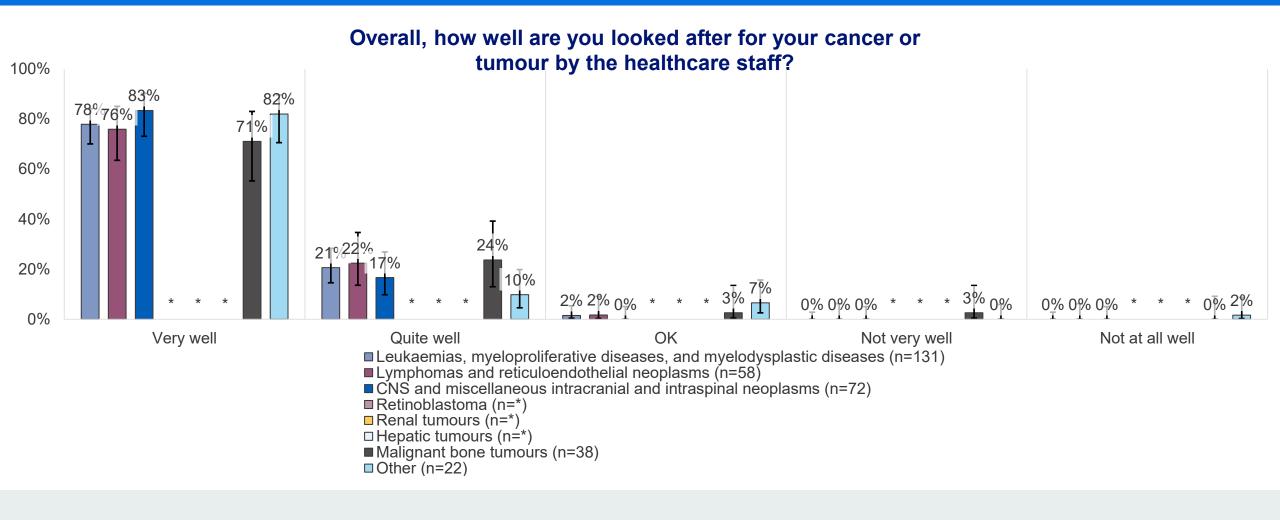




The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 83% for malignant bone tumours to 100% for retinoblastoma.

Overall care (children) by diagnostic group



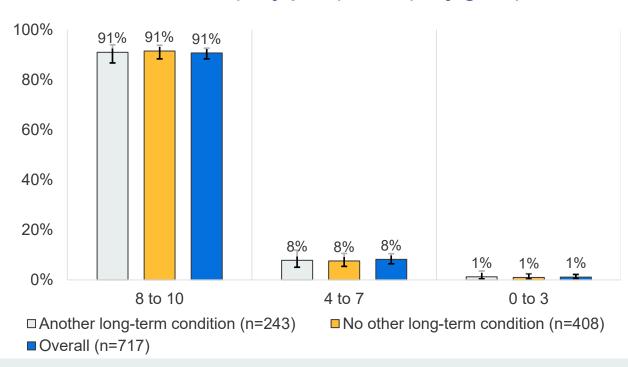


The percent of children reporting they were looked after very well ranged from 71% for malignant bone tumours to 83% for CNS and miscellaneous intracranial and intraspinal neoplasms.

Overall care by long-term condition status



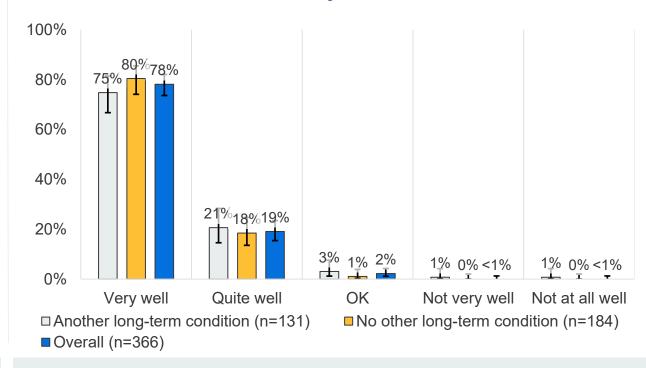
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 91% for another long-term condition to 91% for no other long-term condition.

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 717

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



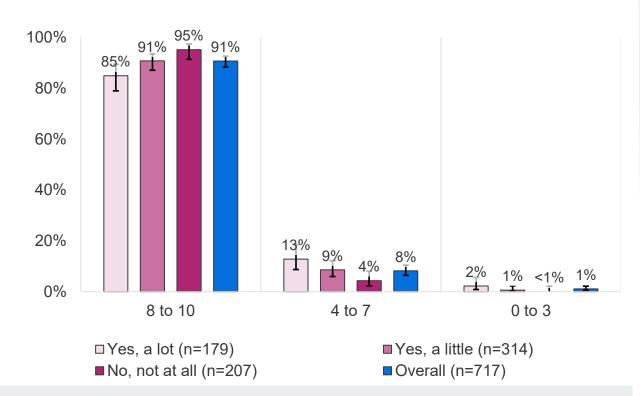
The percent of children reporting they were looked after very well ranged from 75% for another long-term condition to 80% for no other long-term condition.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 366

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

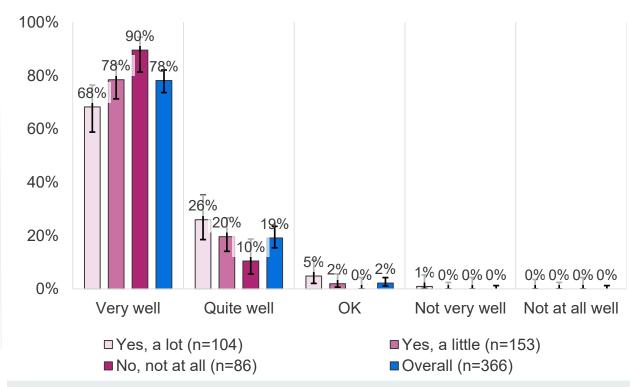


Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 85% for those who responded 'Yes, a lot' to 95% for those who responded 'No, not at all'.

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

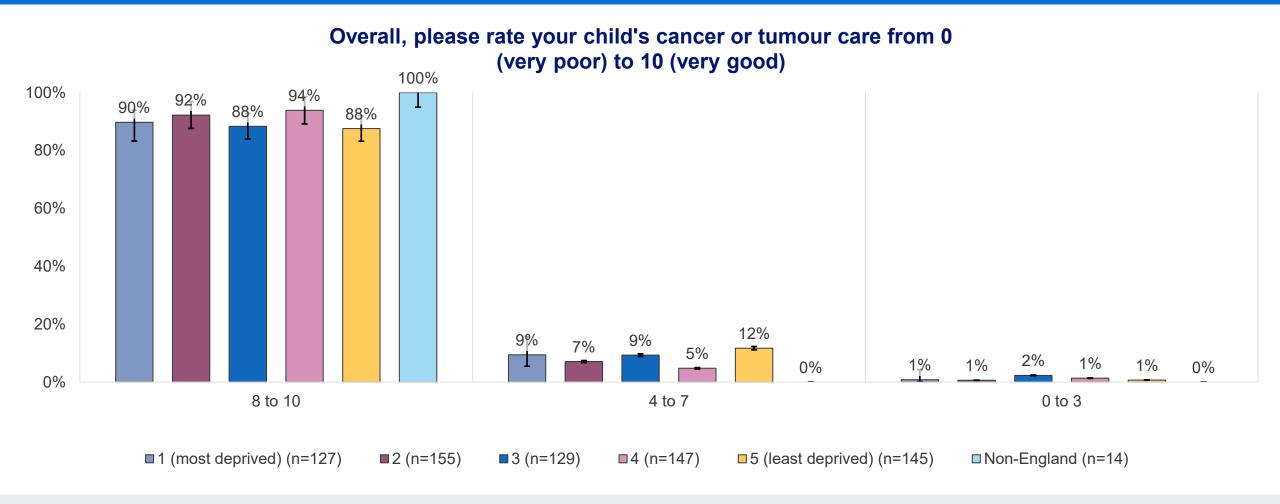


The percent of children reporting they were looked after very well ranged from 68% for those who responded 'Yes, a lot' to 90% for those who responded 'No, not at all'.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 366

Overall care (parent or carer) by deprivation (IMD quintile)

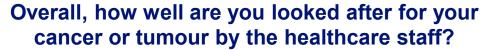


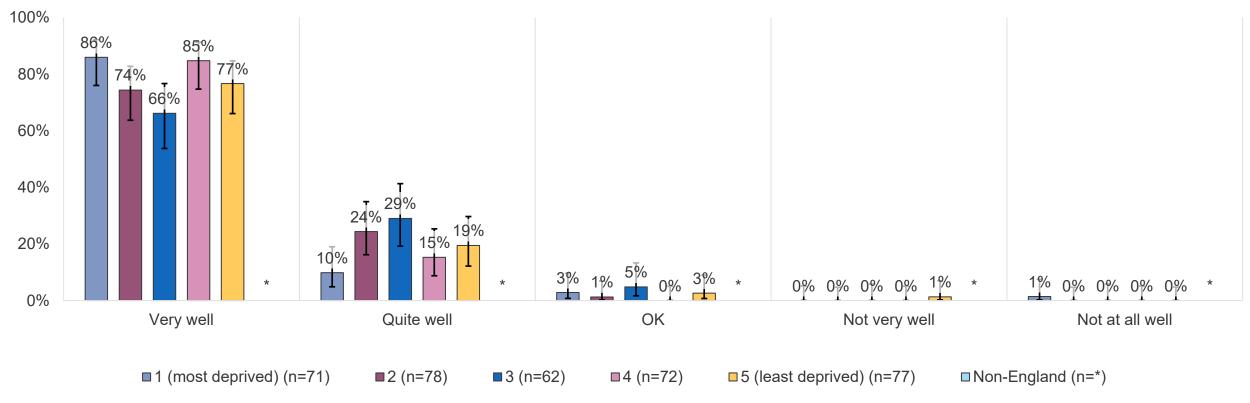


The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 88% for the least deprived to 100% for non-England.

Overall care (children) by deprivation (IMD quintile)





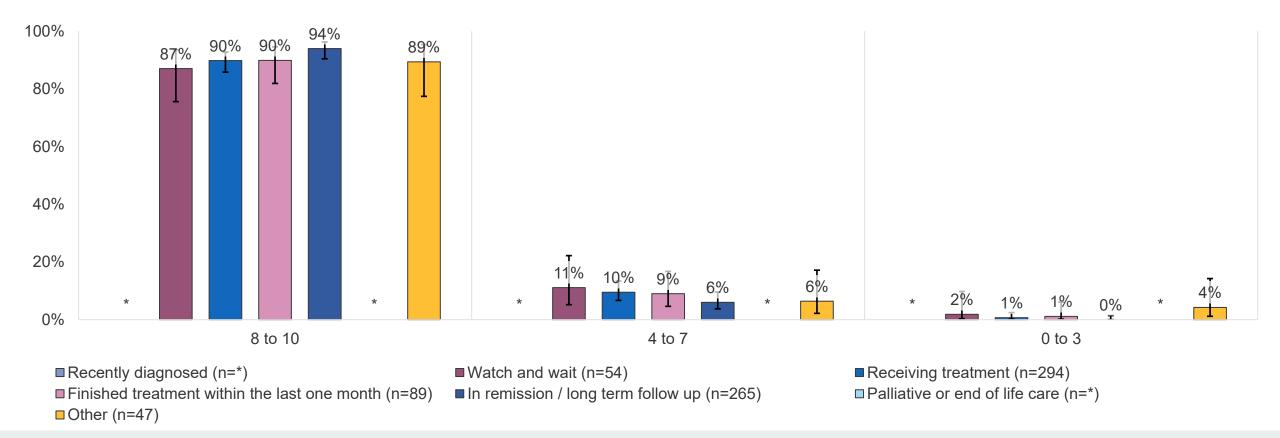


The percent of children reporting they were looked after very well ranged from 66% for the third IMD quintile to 86% for the most deprived.

Overall care (parent or carer) by current care or treatment stage



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

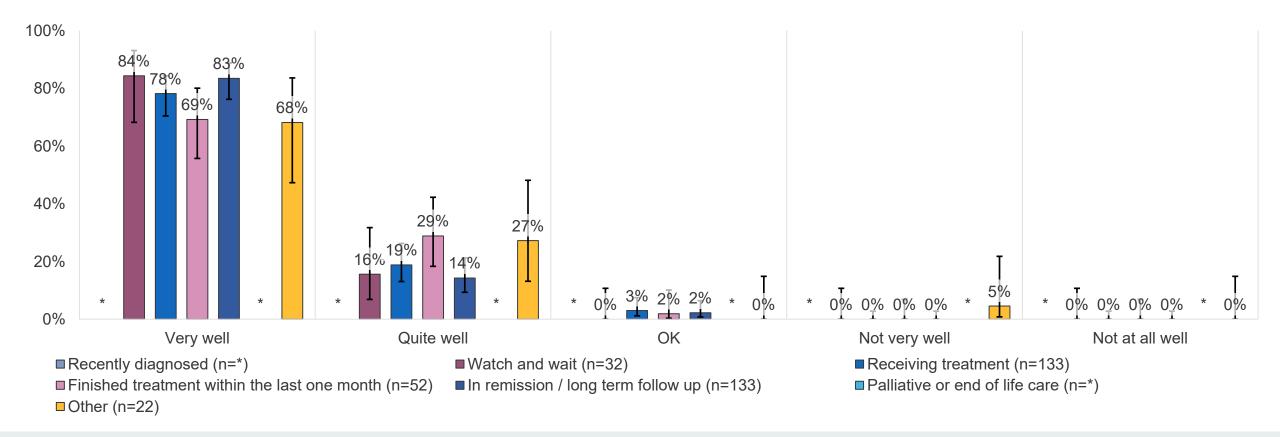


The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 87% for those in watch and wait to 94% for those in remission / long term follow up.

Overall care (children) by current care or treatment stage



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



The percent of children reporting they were looked after very well ranged from 68% for other to 84% for those in watch and wait.



Hospitals working together



51% of 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 number of responses = 568

Travel to the hospital



62% of 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 number of responses = 732



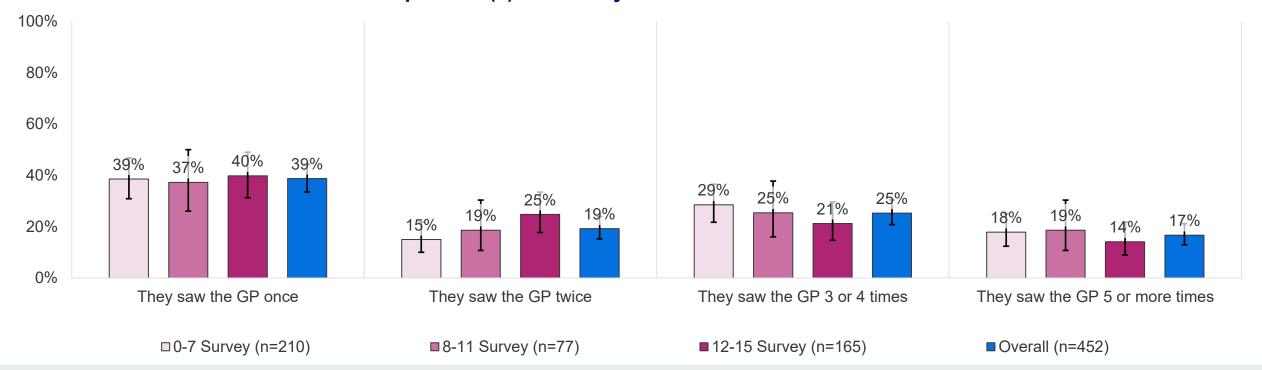






Visiting the GP

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?

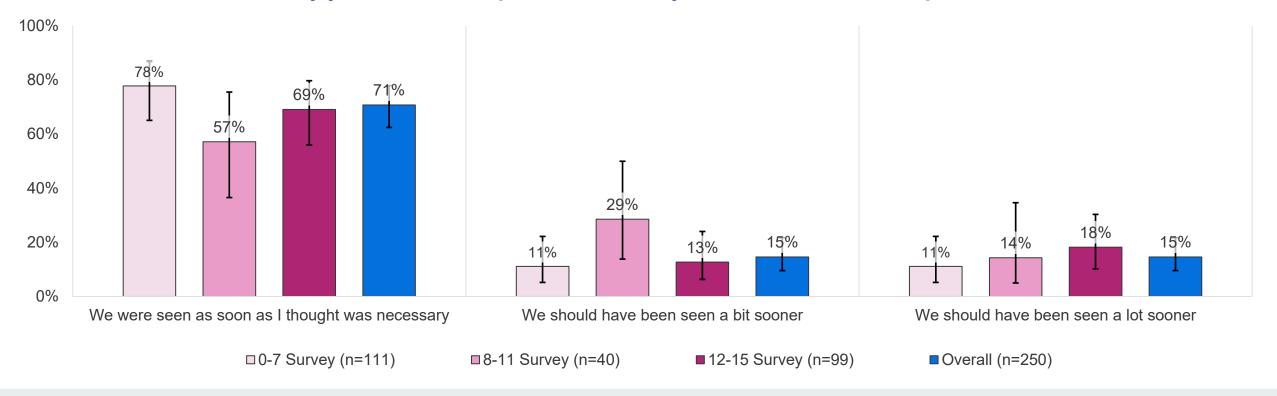


58% of parents or carers reported that their child saw a GP once or twice before they were referred to hospital.



Visiting the hospital

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?

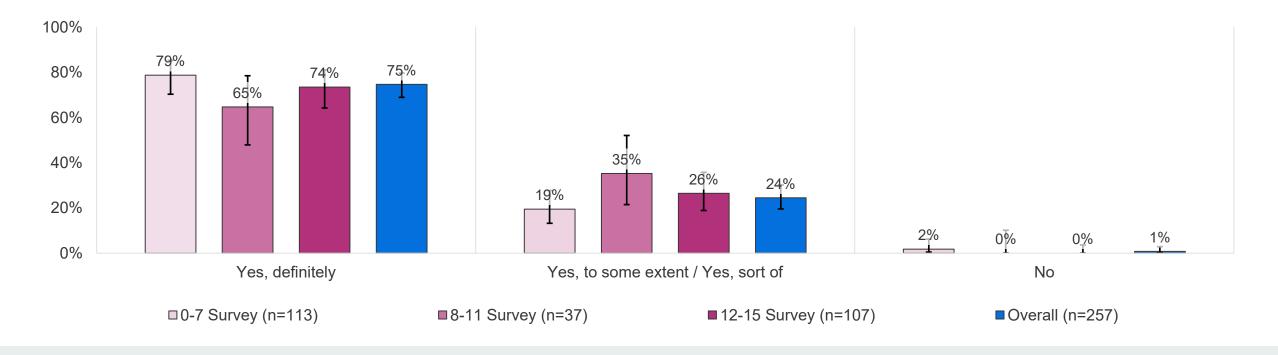


71% of parents or carers felt that they were seen at the hospital as soon as they thought was necessary after being referred by their GP.



Information

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?

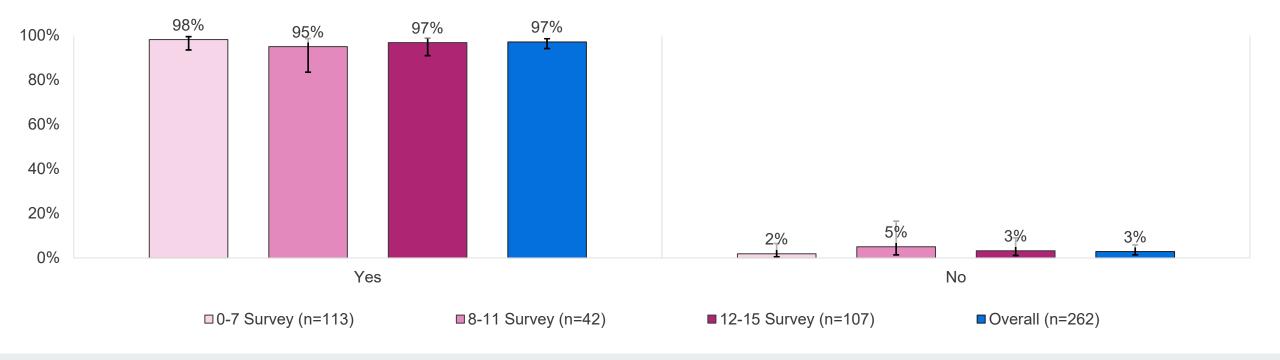


75% of parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand.



Information

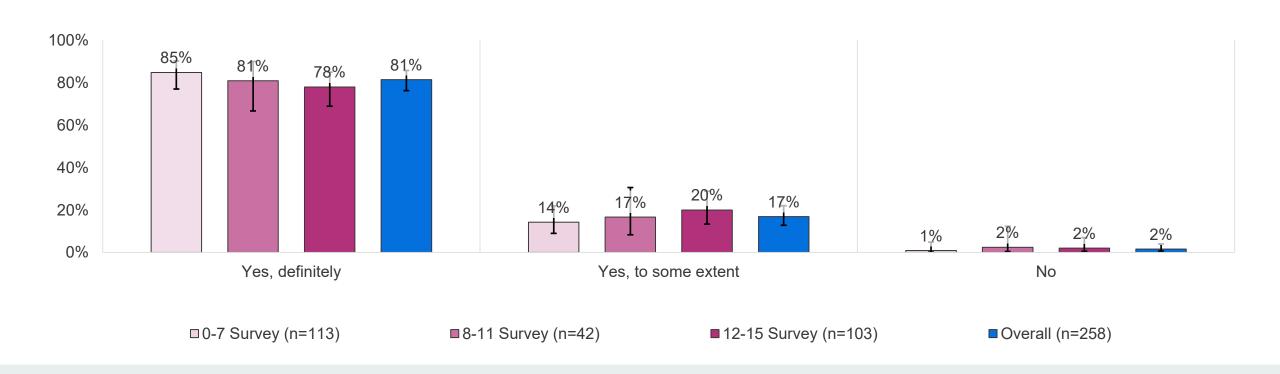
Did hospital staff give you details for who to contact if you wanted more information after you were told about your child's cancer or tumour? / Did hospital staff give you details for who to contact if you wanted more information after you were told about your cancer or tumour?



97% of parents, carers, and children reported that staff provided details about who to contact for more information after being told about the cancer or tumour.

Information

Have you been able to find the information that you need about your child's diagnosis?



81% of parents or carers reported that they were definitely able to find information about their child's diagnosis.



Answering questions



85% of 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 number of responses = 245 (excluding 7 responses of "I did not have any questions" and excluding 5 responses of "Don't know / can't remember").

Information

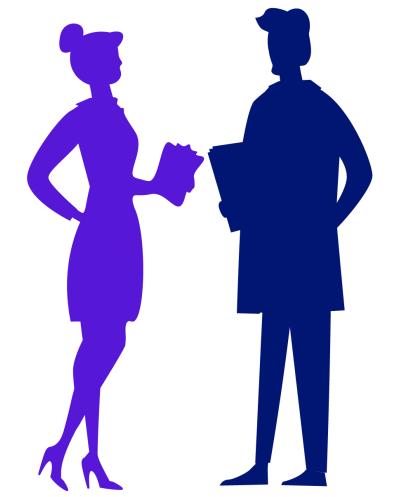


70% of parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way.

Question X07: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total number of responses = 253 (excluding 5 responses of "Don't know / can't remember").



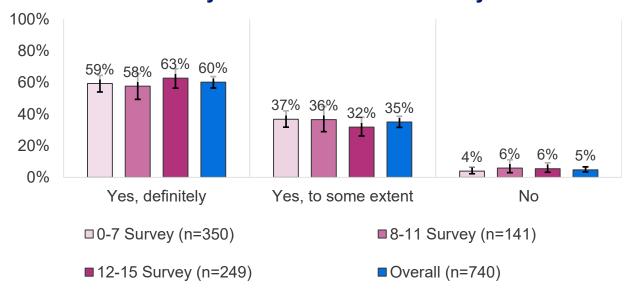






Medical history

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

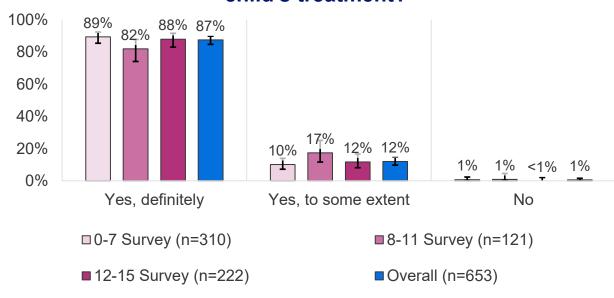


60% of parents or carers felt that different hospital staff were definitely aware of their child's medical history.

Chart shows question X27: Asked to parents or carers of all age groups. Total responses = 705 (excluding 35 responses of "Don't know / Not applicable").

Information

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



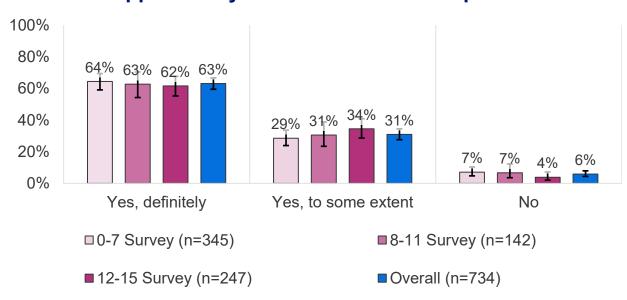
87% of parents or carers reported that they were definitely offered clear information about their child's treatment.

Chart shows question X36: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total responses = 651 (excluding 2 responses of "This was not needed").



Support from the hospital

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

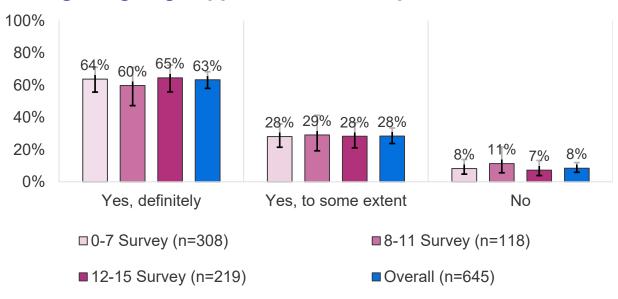


63% of parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital.

Chart shows question X33: Asked to parents or carers of all age groups. Total responses = 692 (excluding 42 responses of "This is not needed").

Support from the hospital

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



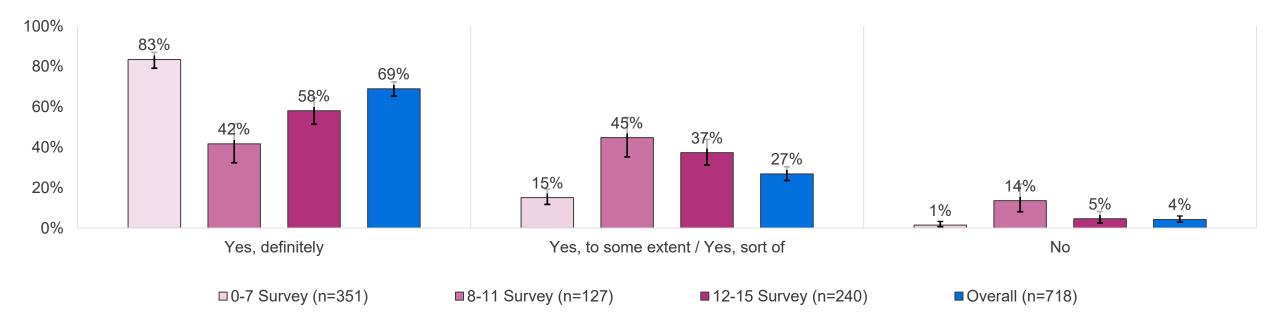
63% of parents or carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended.

Chart shows question X39: Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour. Total responses = 332 (excluding 30 responses of "Not applicable / this was not needed" and excluding 283 responses of "My child is still receiving treatment").



Decisions about care and treatment

Are you involved as much as you want to be in decisions about your child's care and treatment? / Do you have a say in deciding what happens with your care and treatment? / Are you involved in decisions about your care and treatment?



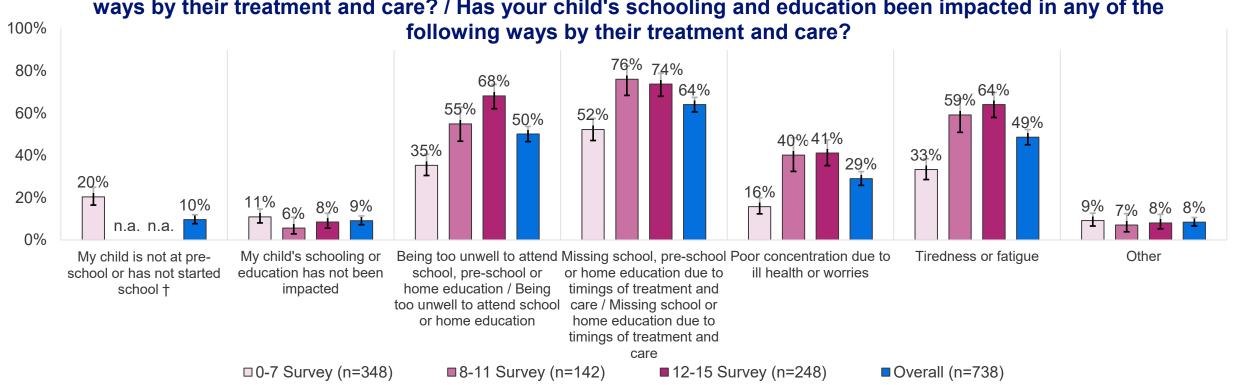
69% of parents, carers, and children felt they were definitely involved in their child's or their care and treatment.

Chart shows question X29: Asked to parents or carers of 0-7s and all children aged 8-15. Total responses = 657 (excluding 40 responses of "No, but this is not needed" and 21 responses of "No, but this is not possible").



Impact of care and treatment on schooling and education

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



Across all surveys, parents or carers reported that missing school, pre-school or home education due to timings of treatment and care / missing school or home education due to timings of treatment and care had the greatest impact on their child's education.

Chart shows question X30: Asked to parents or carers of all age groups. Total number of responses = 738.





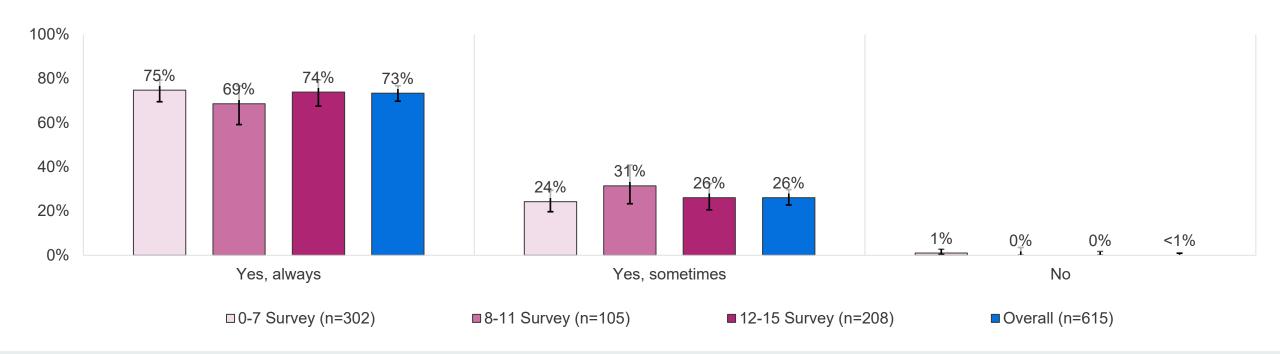
6.4 Care in hospital





Staff availability in hospital

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?

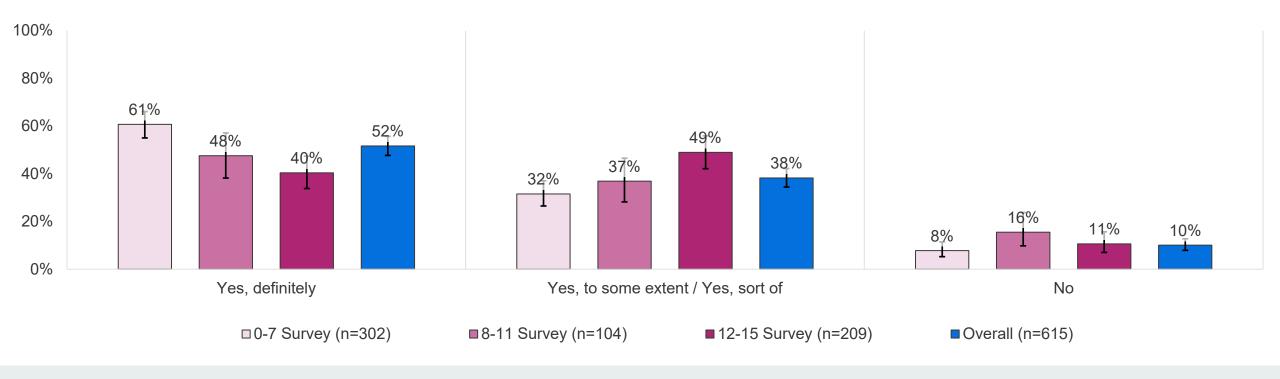


73% of parents, carers, and children felt that their child or they were always able to get help from staff on the hospital ward when they needed it.



Things for children to do in hospital

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

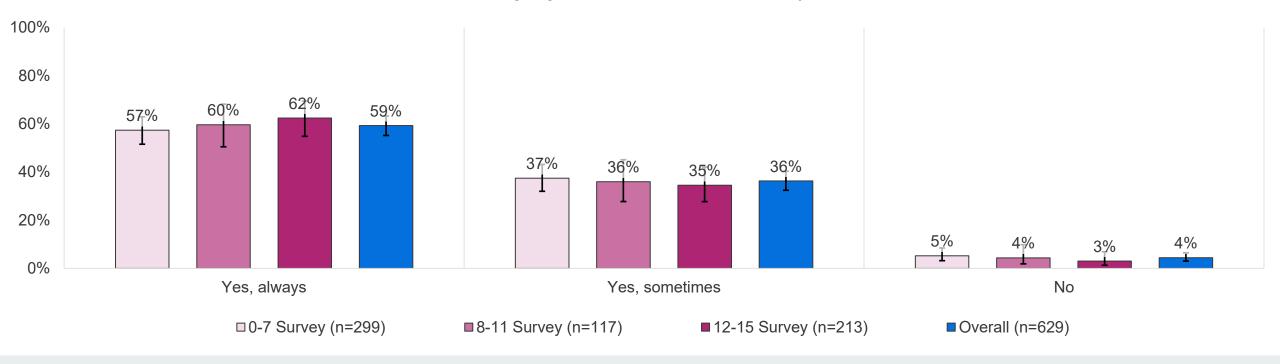


52% of parents, carers, and children felt that there were definitely enough things for their child to do in the hospital.



Play specialist support

Was play support available in hospital when your child needed it (i.e. from a Health Play Specialist who uses play and activities to support patients and/or prepare them for treatments)?

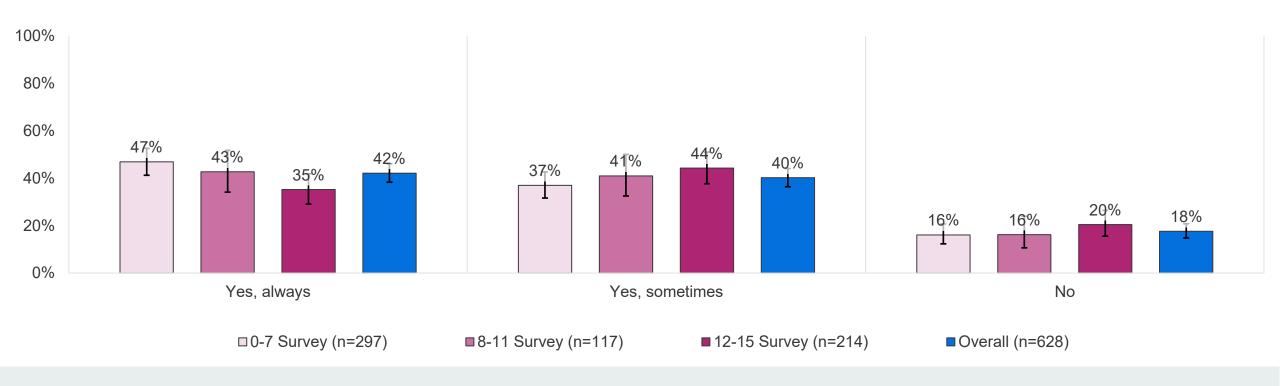


59% of parents or carers reported that the hospital always offered play specialist support when they needed it.



Hospital Wi-Fi

Did the hospital Wi-Fi meet your and your child's needs?

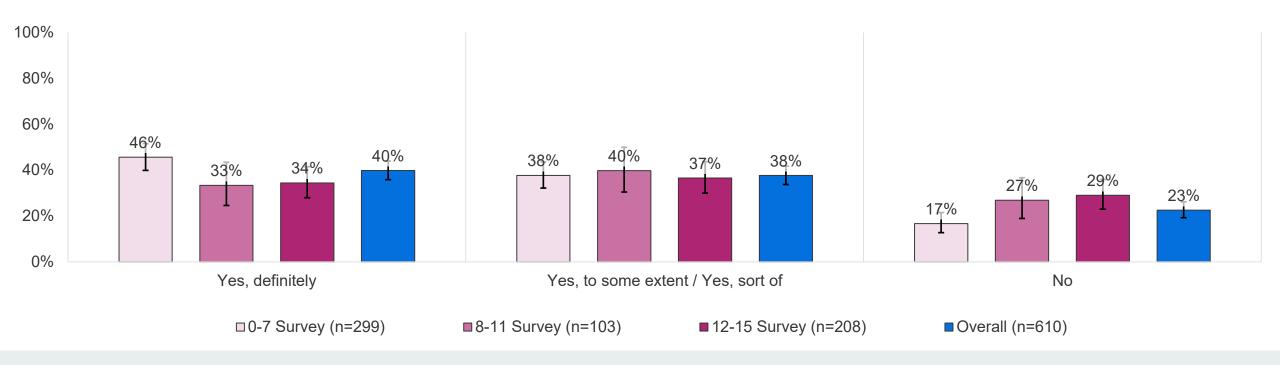


42% of parents or carers felt that the hospital Wi-Fi always met the needs of them and their child.



Hospital food

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

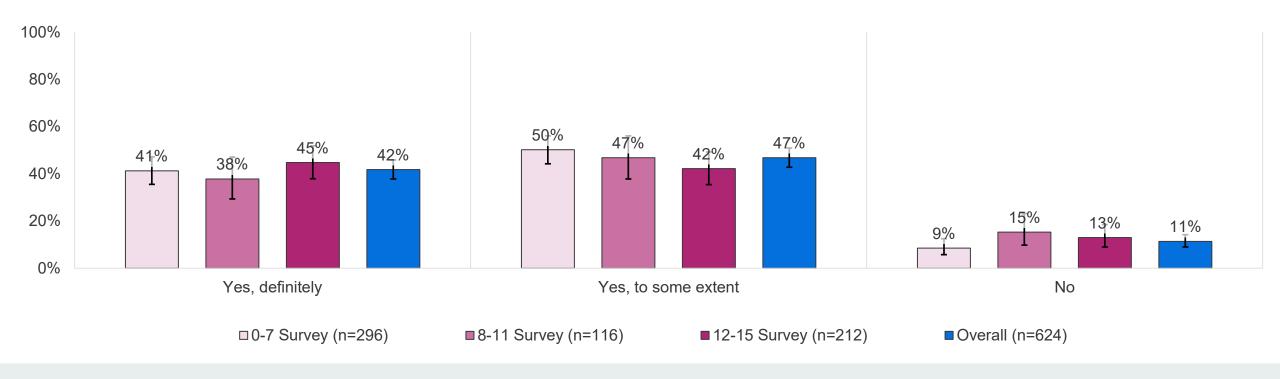


40% of parents, carers, and children felt that there was definitely a suitable choice of hospital food.



Hospital food

Were you able to prepare food in the hospital if you wanted to?

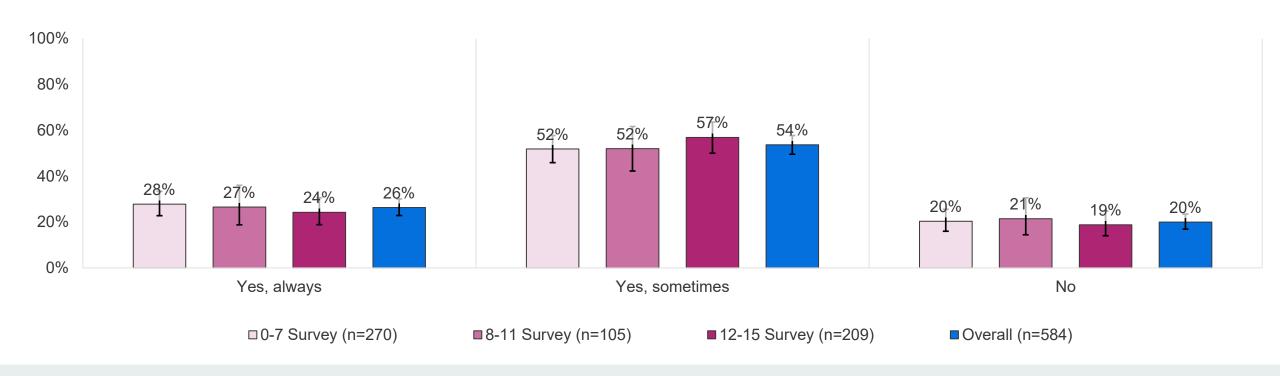


42% of parents or carers reported they were definitely able to prepare food in the hospital if they wanted to.



Hospital environment

Was it quiet enough for you to sleep in the hospital?

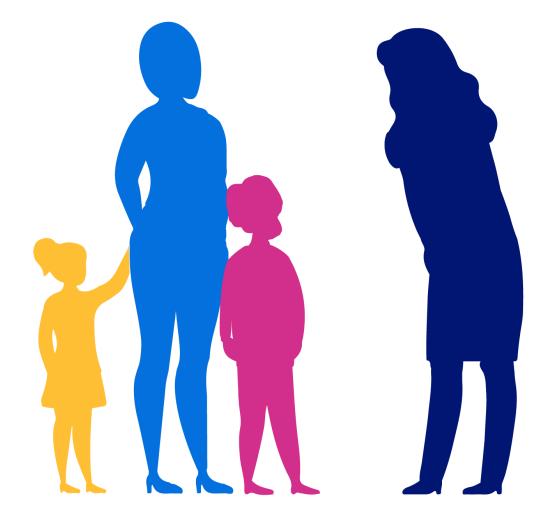


26% of parents, carers, and children reported that it was always quiet enough for them to sleep in the hospital.





6.5 Care at home or at school

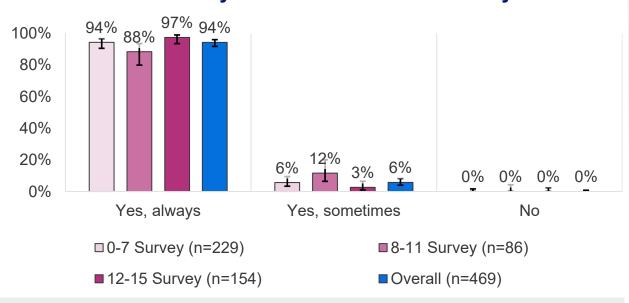


Care at home or at school



Bedside manner and trust

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?

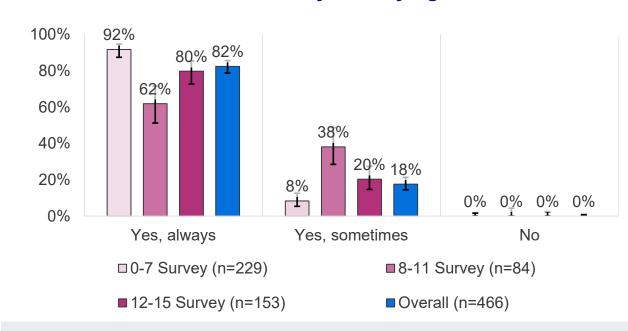


94% of parents, carers, and children felt that the nurses who came to their home or school were always friendly.

Chart shows 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 number of responses = 469 (excluding 0 responses of "Don't know / can't remember").

Bedside manner and trust

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



82% of parents, carers, and children reported that they always understood what nurses visiting their home or school were saying.

Chart shows 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 number of responses = 466 (excluding 0 responses of "Don't know / can't remember").



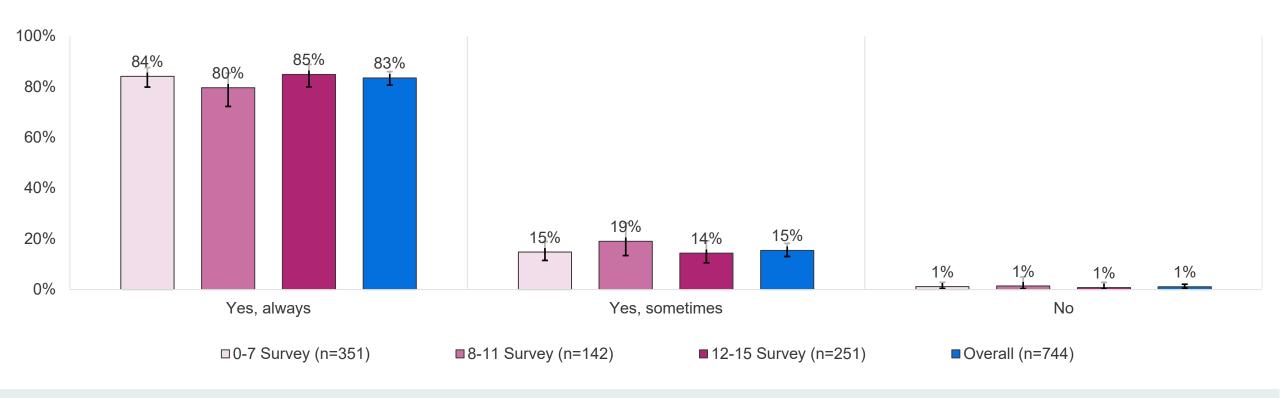






Bedside manner and trust

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

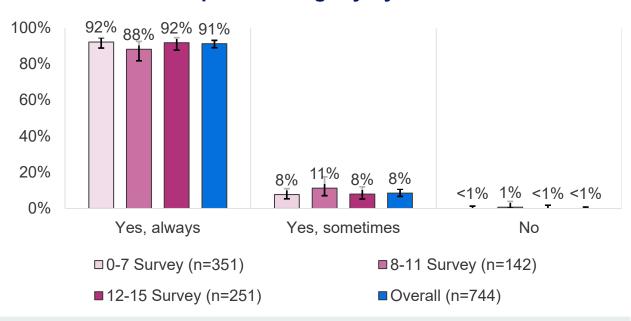


83% of parents or carers felt they always had confidence and trust in staff caring for their child.



Bedside manner and trust

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

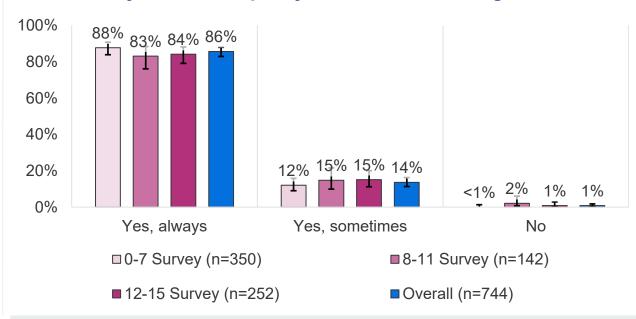


91% of parents or carers felt that they and their child were always treated with respect and dignity by staff.

Chart shows question X17: Asked to parents or carers of all age groups. Total number of responses = 744.

Bedside manner and trust

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



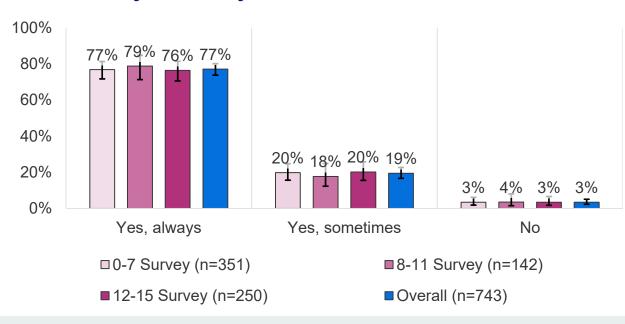
86% of parents or carers felt that they were always treated with empathy and understanding by staff caring for their child.

Chart shows question X19: Asked to parents or carers of all age groups. Total number of responses = 744.



Bedside manner and trust

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

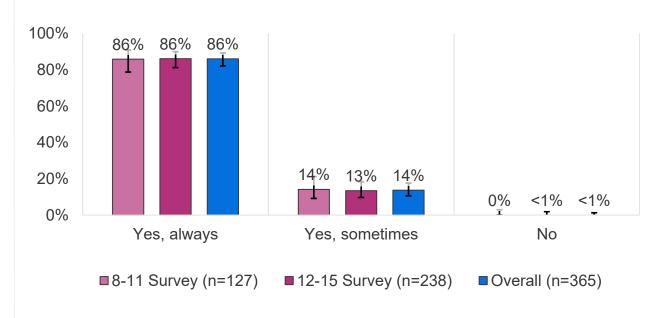


77% of parents or carers felt that staff were always sensitive to information shared with them when their child was in the room.

Chart shows question X21: Asked to parents or carers of all age groups. Total responses = 667 (excluding 76 responses of "This is not needed").

Bedside manner and trust

Do you feel that staff are friendly?



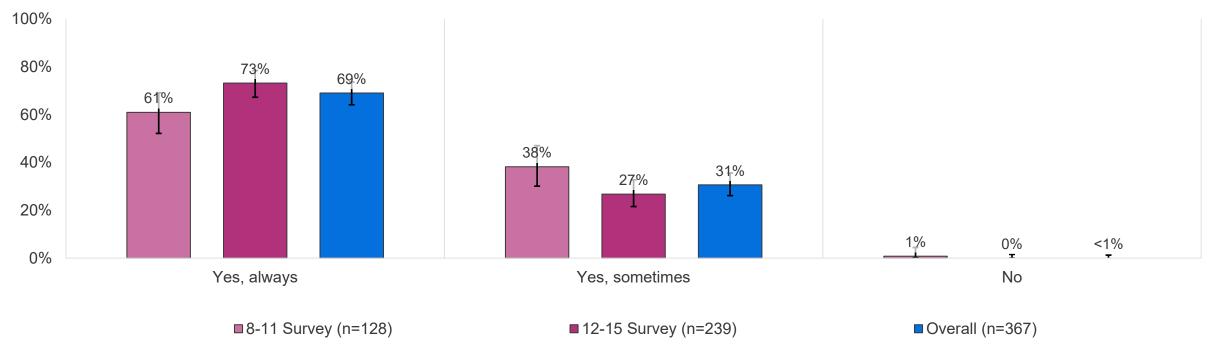
86% of children felt that staff were always friendly.

Chart shows question X12: Asked to all children aged 8-15. Total number of responses = 365.



Communication

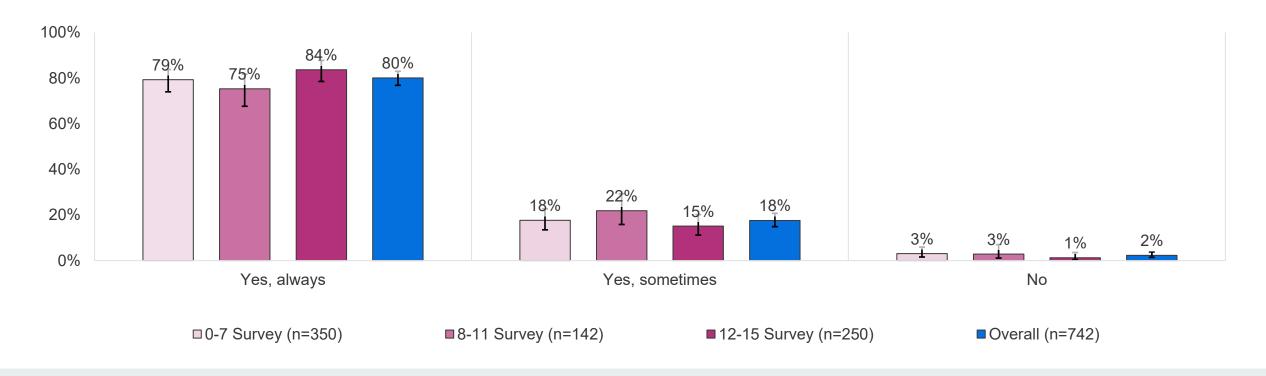
When staff speak to you, do you understand what they are saying? / Do staff speak to you in a way that you can understand?



69% of children reported that they could always understand what staff were saying.

Communication

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



80% of parents or carers felt that healthcare staff always shared information with children in a way that was appropriate.



Communication



58% of 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 number of responses = 716.



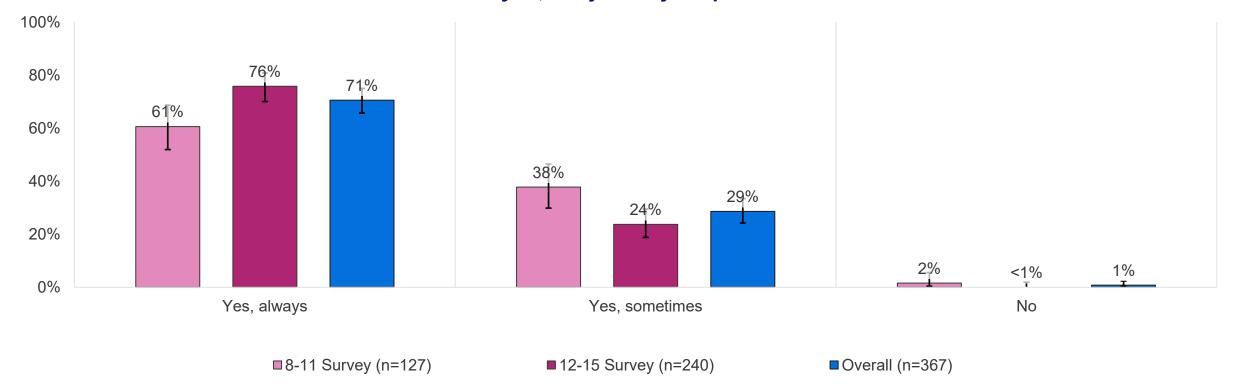
89% of parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment.

Question X16: Asked to parents or carers of all age groups. Total number of responses = 742 (excluding 3 responses of "I have not had any questions").



Communication

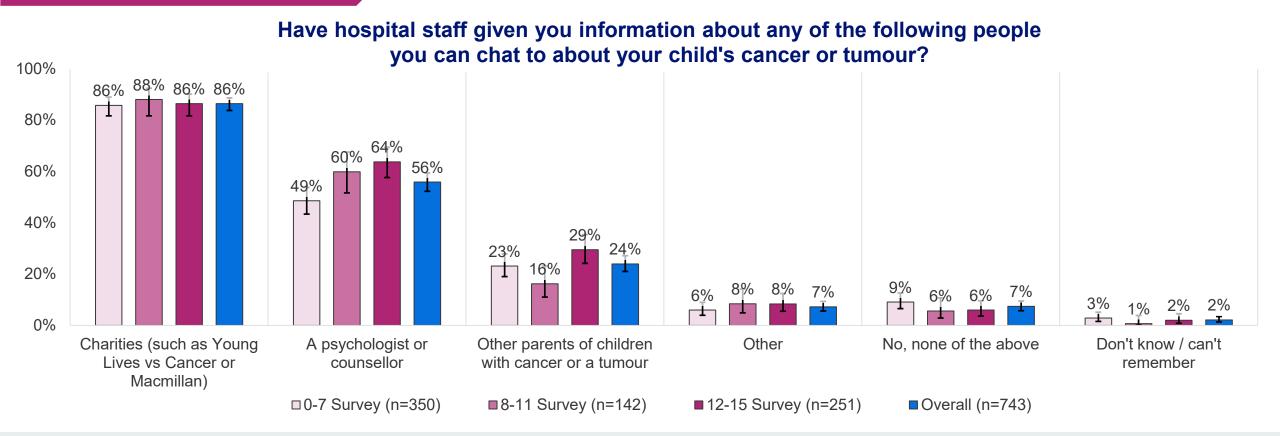
Do staff talk to you, not just to your parent or carer?



71% of children felt that staff always talked to them, not just their parent or carer.



Support for parents or carers

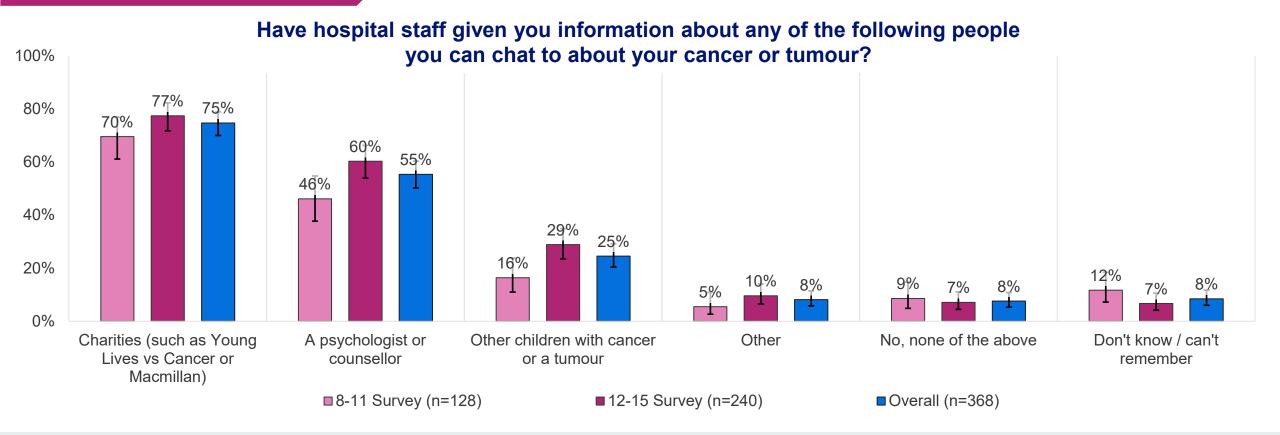


The percent of parents or carers reporting being given information about a psychologist or counsellor ranged from 49% in the 0-7 survey to 64% in the 12-15 survey.

Healthcare staff



Support



The percent of children reporting being given information about a psychologist or counsellor ranged from 46% in the 8-11 survey.





7.

Year on year comparisons







This section presents 2024 scores alongside 2023, 2022 and 2021 scores for comparable questions. Full data, including how scores for each question are calculated, can be found within the National Excel Data Tables available on the <u>survey website</u>.

The charts present 2021, 2022, 2023, and 2024 scores, where comparable. The coloured line indicates the score, and black lines show the confidence intervals.



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

Where 2021, 2022, or 2023 data is not available or not comparable this is represented with a dash, please see <u>Technical</u> Document for a full breakdown.



No statistical significance testing has been done for year on year comparisons, therefore please interpret any differences with caution.

Year on year comparisons: visual aid example



In this example, the score for X03 was **58%**, compared with **55% in 2023**, **59% 2022**, and **63% in 2021**. However, the confidence intervals provide us with a bigger picture.

The **upper and lower** limits indicate the **range** in which the true value is likely to lie, based on the information we have.

The longer the black bars are, the greater the range in which the true population value is likely to lie, and vice versa.

In this example, the confidence intervals overlap, indicating that although the 2024 overall score is higher than 2023, there is not enough statistical evidence to conclude whether or not there is a "true" difference between the two.

Example data only:





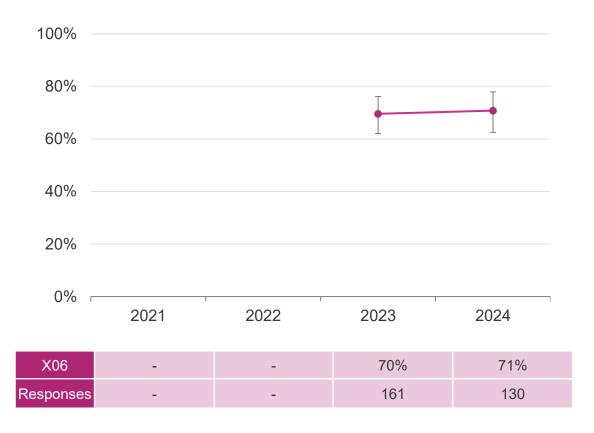
Finding out about the cancer or tumour

X03: Parents or carers reported that their child saw a GP once or twice before they were referred to hospital. Asked to parents or carers of all age groups whose children were told they had cancer or a tumour.



Finding out about the cancer or tumour

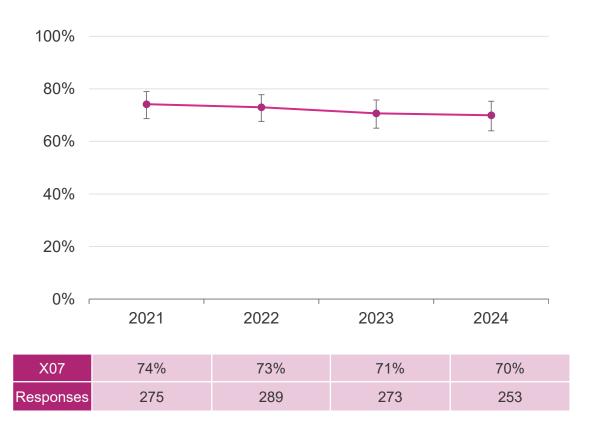
X06: Parents or carers felt that they were seen at the hospital as soon as they thought was necessary after being referred by their GP. Asked to parents or carers of all age groups who were told about their child's cancer or a tumour.





Finding out about the cancer or tumour

X07: Parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way. Asked to parents or carers of all age groups who were told about their child's cancer or a tumour.



Finding out about the cancer or tumour

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





Finding out about the cancer or tumour

X09: Parents, carers, and children reported that they were definitely able to have questions answered after being told about the cancer or tumour. 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.



Finding out about the cancer or tumour

X10: Parents or carers reported that they were definitely able to find information about their child's diagnosis. Asked to parents or carers of all age groups who were told about their child's cancer or a tumour.





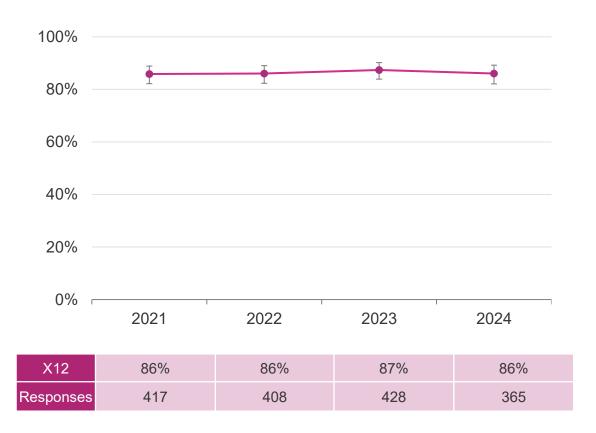
Finding out about the cancer or tumour

X11: Parents, carers, and children reported that staff provided details about who to contact for more information after being told about the cancer or tumour. 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.



Healthcare staff

X12: Children felt that staff were always friendly. Asked to all children aged 8-15.





Healthcare staff

X13: Children reported that they could always understand what staff were saying. Asked to all children aged 8-15.



Healthcare staff

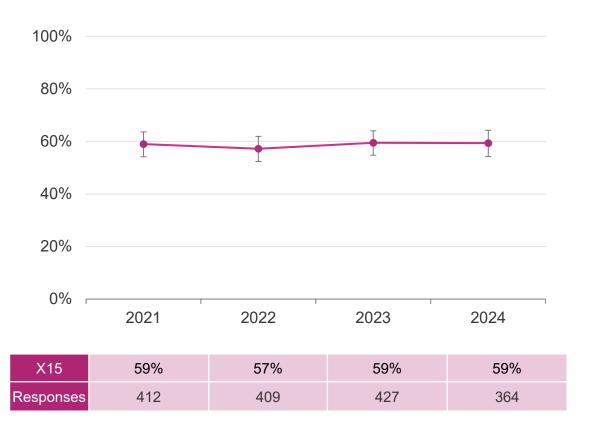
X14: Children felt that staff always talked to them, not just their parent or carer. Asked to all children aged 8-15.





Healthcare staff

X15: Children reported always or mostly seeing the same members of staff for their treatment and care. Asked to all children aged 8-15.



Healthcare staff

X16: Parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment. Asked to parents or carers of all age groups.





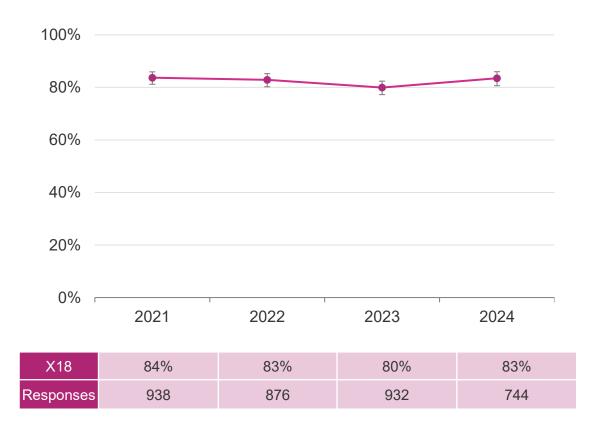
Healthcare staff

X17: Parents or carers felt that they and their child were always treated with respect and dignity by staff. Asked to parents or carers of all age groups.



Healthcare staff

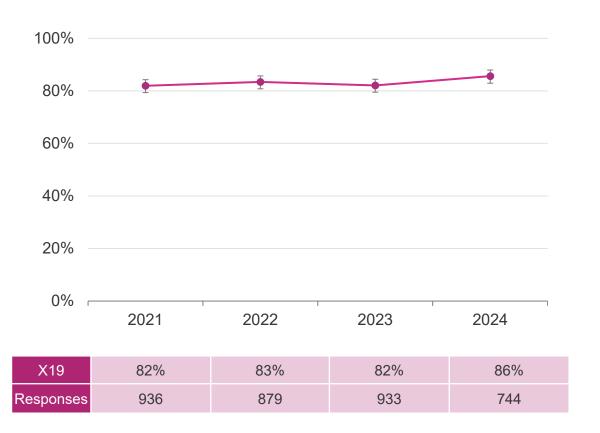
X18: Parents or carers felt they always had confidence and trust in staff caring for their child. Asked to parents or carers of all age groups.





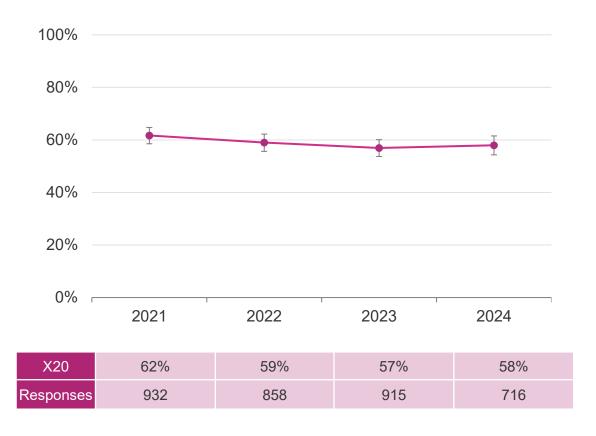
Healthcare staff

X19: Parents or carers felt that they were always treated with empathy and understanding by staff caring for their child. Asked to parents or carers of all age groups.



Healthcare staff

X20: Parents, carers, and children reported not being told different things by different members of staff that left them feeling confused. Asked to parents or carers of 0-7s and children aged 8-15.





Healthcare staff

X21: Parents or carers felt that staff were always sensitive to information shared with them when their child was in the room. Asked to parents or carers of all age groups.



Healthcare staff

X22: Parents or carers felt that healthcare staff always shared information with children in a way that was appropriate. Asked to parents or carers of all age groups.

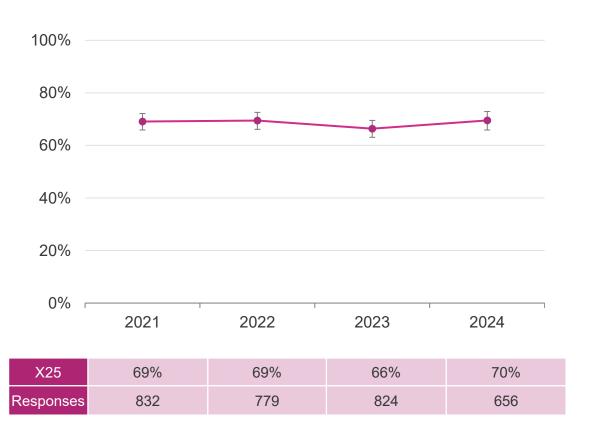




Healthcare staff

X25: Parents or carers felt they had enough information about financial help or benefits.

Asked to parents or carers of all age groups.



Child's care and treatment

X26: Parents or carers felt that different hospital staff always worked well together. Asked to parents or carers of all age groups.





Child's care and treatment

X27: Parents or carers felt that different hospital staff were definitely aware of their child's medical history. Asked to parents or carers of all age groups.



Child's care and treatment

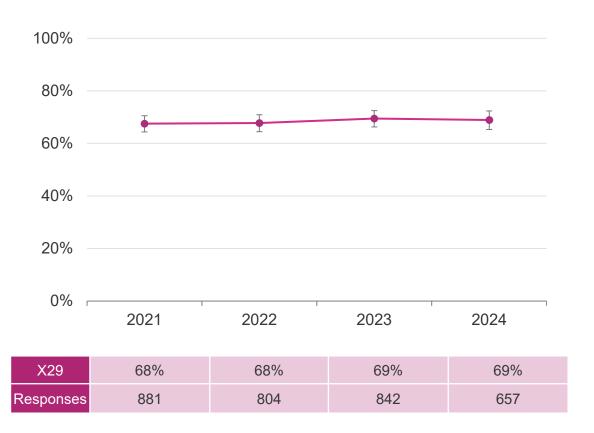
X28: Parents, carers, and children felt they always knew what was happening with their child's or their care. Asked to parents or carers of 0-7s and all children aged 8-15.





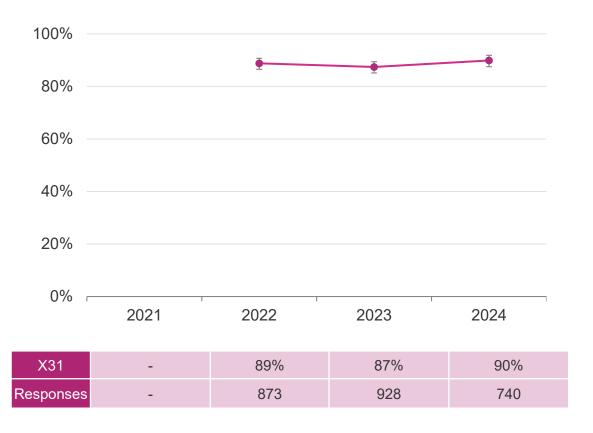
Child's care and treatment

X29: Parents, carers, and children felt they were definitely involved in their child's or their care and treatment. Asked to parents or carers of 0-7s and all children aged 8-15.



Child's care and treatment

X31: 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. Asked to parents or carers of all age groups.





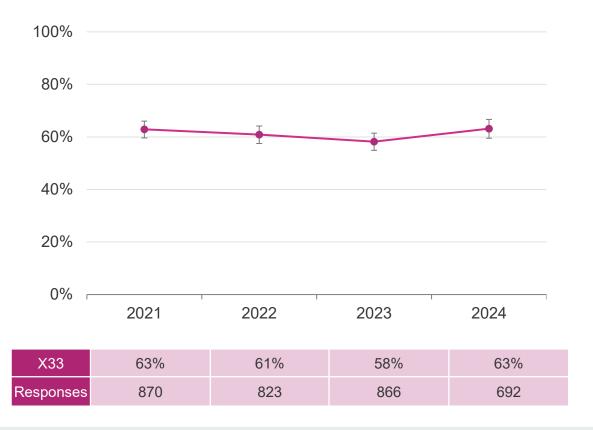
Child's care and treatment

X32[†]: Parents or carers reported that it was very easy to contact the main person in the team looking after their child. Asked to parents or carers of all age groups who could contact the main person looking after their child if needed.



Child's care and treatment

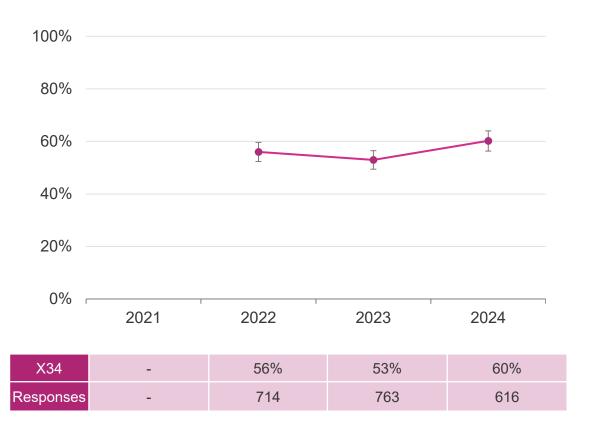
X33: Parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital. Asked to parents or carers of all age groups.





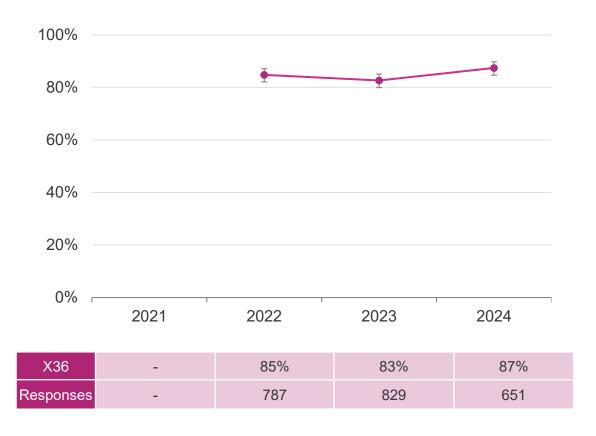
Child's care and treatment

X34: Parents or carers reported that their child's care and treatment was definitely offered at a time suitable for them and their family. Asked to parents or carers of all age groups.



Child's care and treatment

X36: Parents or carers reported that they were definitely offered clear information about their child's treatment. Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour.





Child's care and treatment

X37: Parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment. Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour.



Child's care and treatment

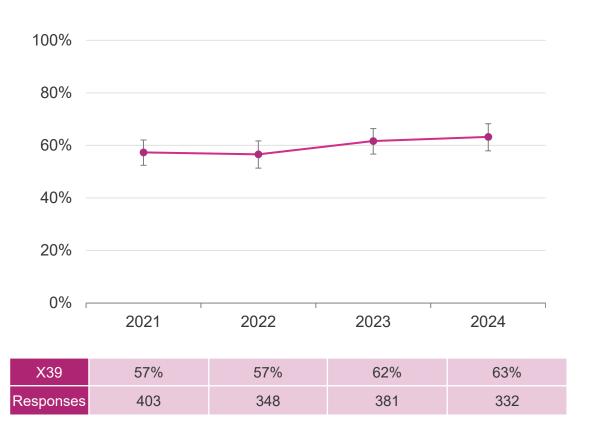
X38: Parents or carers reported that staff definitely offered them support to help manage their child's treatment side effects. Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour.





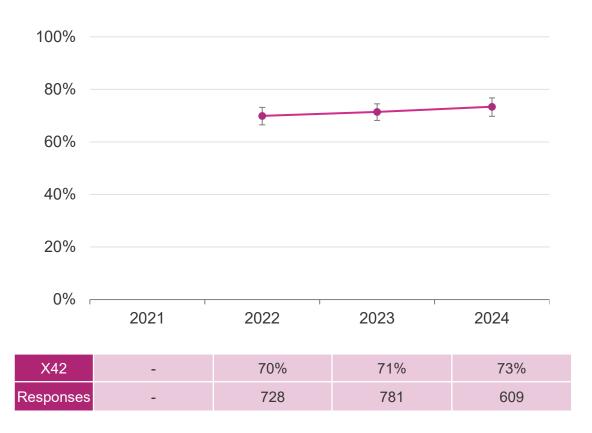
Child's care and treatment

X39: Parents or carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended. Asked to parents or carers of all age groups whose children received treatment for their cancer or tumour.



Care in hospital

X42: 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. 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).





Care in hospital

X43: Parents, carers, and children felt that there were definitely enough things for their child to do in the hospital. 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).



Care in hospital

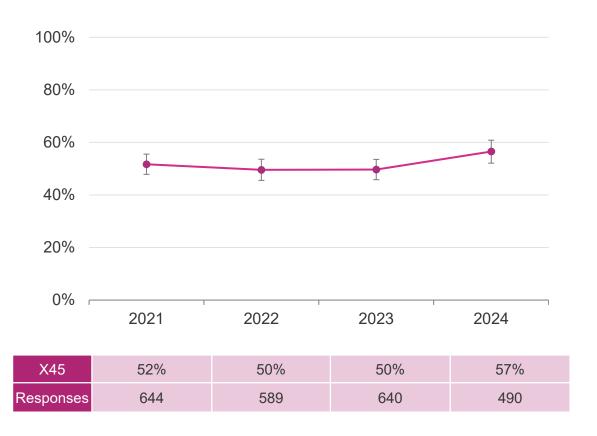
X44: Parents, carers, and children felt that there was definitely a suitable choice of hospital food. Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay).





Care in hospital

X45: Parents, carers, and children reported always being given somewhere private to talk to staff when their child was in hospital. 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).



Care in hospital

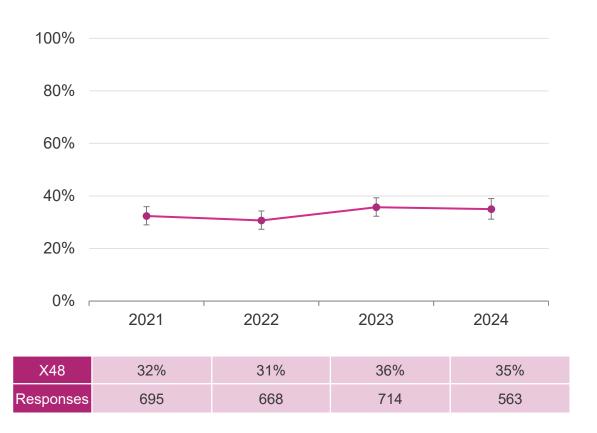
X46: Parents or carers reported that the hospital always offered play specialist support when they needed it. Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay).





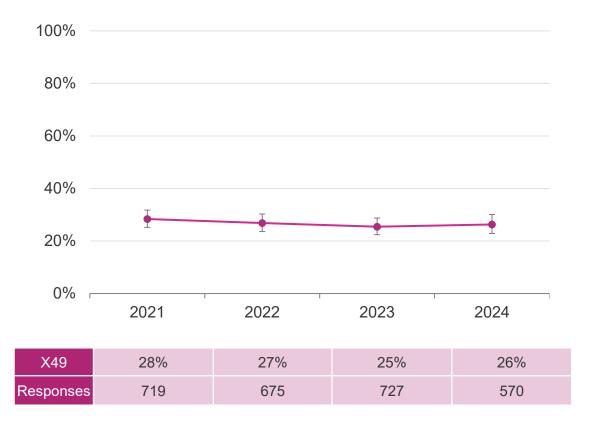
Care in hospital

X48: Parents or carers reported that facilities for them to stay overnight were very good. 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).



Care in hospital

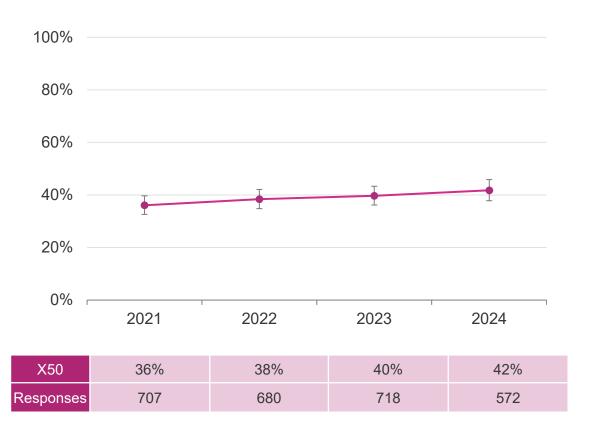
X49: Parents, carers, and children reported that it was always quiet enough for them to sleep in the hospital. Asked to parents or carers of children aged 0-7 whose children stayed in hospital and who stayed overnight with them, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime or for an overnight stay).





Care in hospital

X50: Parents or carers reported they were definitely able to prepare food in the hospital if they wanted to. 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).



Care in hospital

X51: Parents or carers felt that the hospital Wi-Fi always met the needs of them and their child. 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).





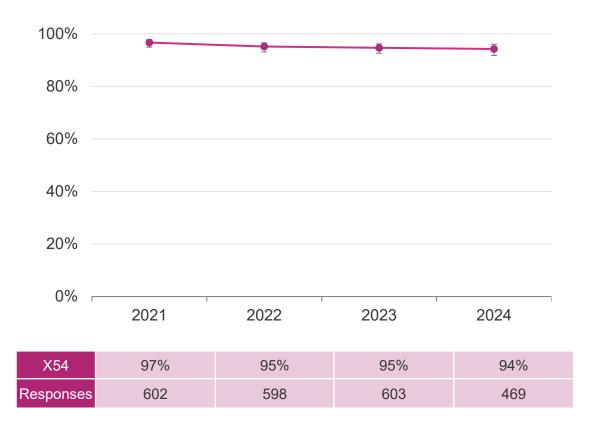
Care in hospital

X52: Parents or carers reported that their child had access to hospital school services during their stay in hospital. 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).



Care at home or at school

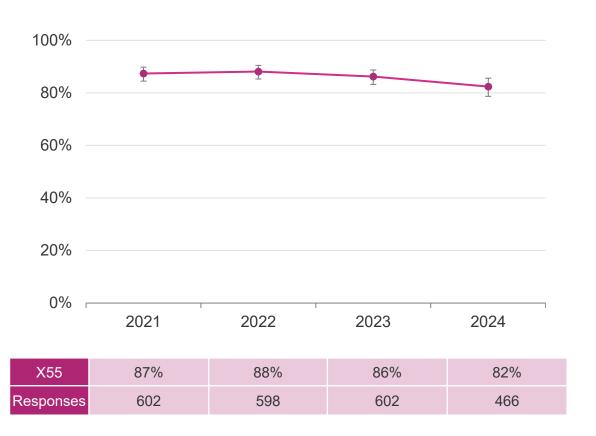
X54: Parents, carers, and children felt that the nurses who came to their home or school were always friendly. Asked to parents or carers of children aged 0-7 whose children have been visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse.





Care at home or at school

X55: Parents, carers, and children reported that they always understood what nurses visiting their home or school were saying. 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.



Care at home or at school

X56: Parents, carers, and children reported that the same nurses always came to their home or school. 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.





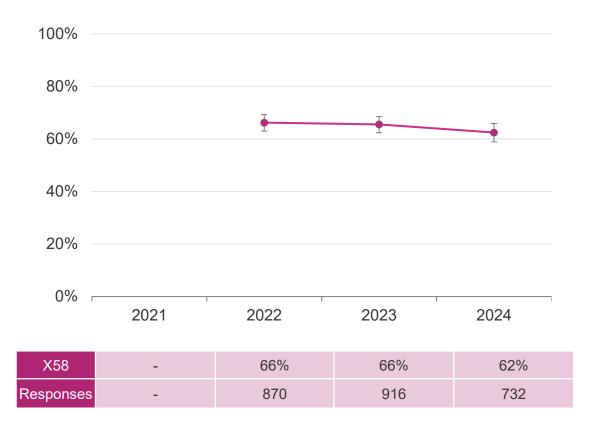
Overall care

X57: Parents, carers, and children reported that different hospitals providing cancer or tumour care always worked well together. Asked to parents or carers of children aged 0-11, and children aged 12-15.



Overall care

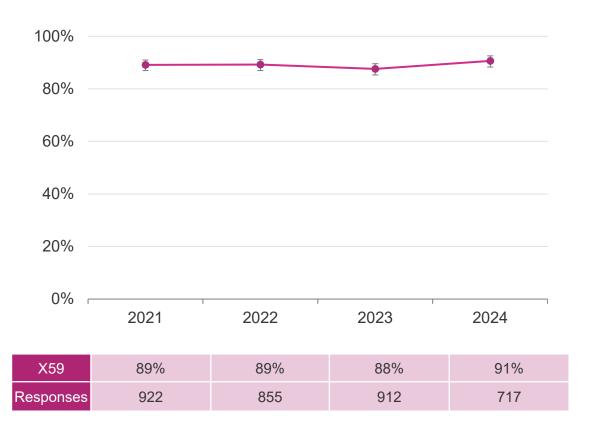
X58: Parents or carers reported that the hospital where their child received most of their care is about or under an hour's travel from their child's home. Asked to parents or carers of all age groups.





Overall care

X59: Parents or carers rated the overall experience of their child's care as 8 or more out of 10. Asked to parents or carers of all age groups.



Overall care

X60: Children reported that they were very well looked after by staff for their cancer or tumour. Asked to all children aged 8-15.







8. Further information



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 via email.



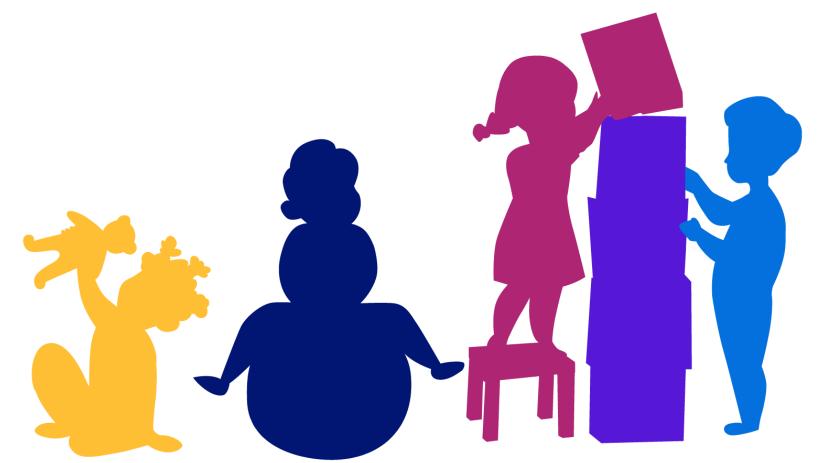
For full data tables showing results to all survey questions, please see the <u>survey website</u>.

An <u>interactive dashboard</u> allowing you to explore the survey data by subgroup (e.g. by diagnostic group, ethnicity, age and more) is also available.





9. Appendix



Appendix: Proportion of responses from each PTC



Principal Treatment Centre (PTC)	Number of responses	Proportion of responses
Alder Hey Children's NHS Foundation Trust	42	6%
Birmingham Children's Hospital NHS Foundation Trust	79	10%
Cambridge University Hospitals NHS Foundation Trust	54	7%
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	143	19%
Leeds Teaching Hospitals NHS Trust	57	8%
Manchester University NHS Foundation Trust	51	7%
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	48	6%
Oxford University Hospitals NHS Foundation Trust	44	6%
Sheffield Children's NHS Foundation Trust	30	4%
The Newcastle upon Tyne Hospitals NHS Foundation Trust	54	7%
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	76	10%
University Hospital Southampton NHS Foundation Trust	50	7%
University Hospitals Bristol and Weston NHS Foundation Trust	31	4%
Total	759	100%