

Under 16 Cancer Patient Experience Survey 2022

National Report (Quantitative)

Published November 2023



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 school

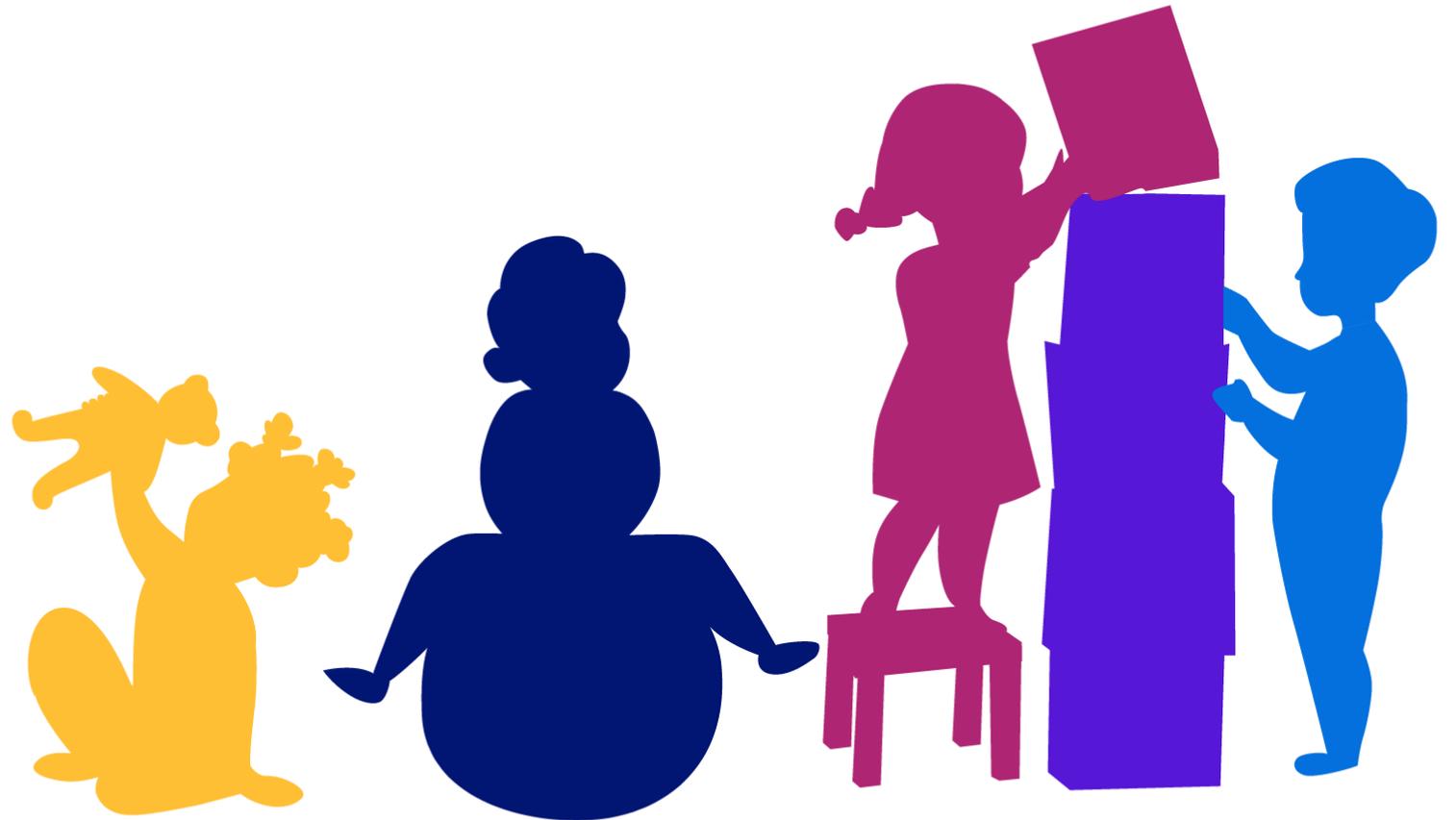
6.6 Healthcare staff

7 Year on year comparisons

8 Further information

9 Appendix

1. Executive summary



Executive summary

This report sets out the **national headline findings**. Data tables and scores for all survey questions at national and Principal Treatment Centre level are available [on the survey website](#).

Overall care rating



75% of children reported that they were **very well looked after by staff for their cancer or tumour** (Question X60) in 2022, compared to **77%** in 2021.



89% of parents/carers rated the overall experience of their child's care as **8 or more out of 10** (Question X59) in 2022, compared to **89%** in 2021.

Key question scoring †



69% of parents/carers and children reported that information at diagnosis was **definitely given in a way they could understand** (Question X08) in 2022, compared to **73%** in 2021.



73% of parents/carers reported that they were **definitely told about their child's cancer or tumour diagnosis in a sensitive way** (Question X07) in 2022, compared to **74%** in 2021.

Please take care in interpreting comparisons to 2021 data, due to numbers of respondents and in the absence of statistical significance testing. Confidence interval bars are included in charts throughout this report. More information about confidence intervals can be found in the [‘Understanding the results’](#) section.

† 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.

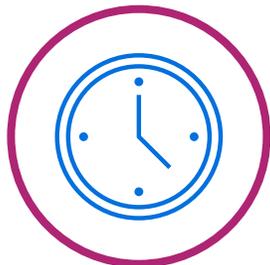
Executive summary: key question scoring †



83% of parents/carers felt they always had confidence and trust in staff caring for their child (Question X18) in 2022, compared to **84%** in 2021.



61% of parents/carers reported that they definitely had access to reliable help and support 7 days a week from the hospital (Question X33) in 2022, compared to **63%** in 2021.



79% of parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment (Question X37) in 2022, compared to **75%** in 2021.



58% of parents/carers felt that different hospital staff were definitely aware of their child's medical history (Question X27) in 2022, compared to **57%** in 2021.



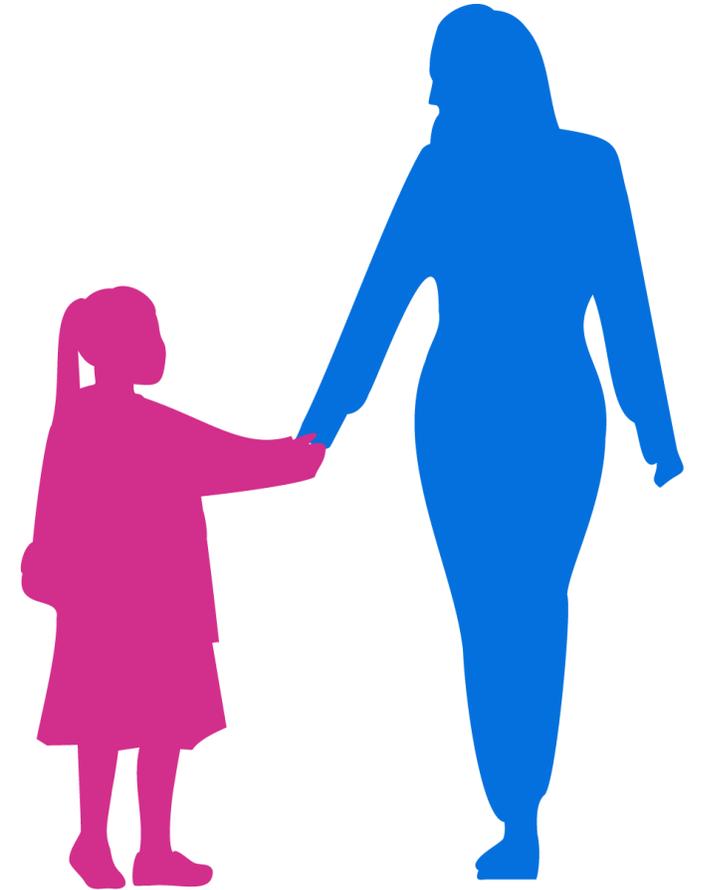
69% of children reported that they could always understand what staff were saying (Question X13) in 2022, compared to **72%** in 2021.

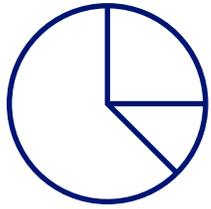


85% of parents/carers reported that they were offered clear information about their child's treatment (Question X36).

Please take care in interpreting comparisons to 2021 data, due to numbers of respondents and in the absence of statistical significance testing. Confidence interval bars are included in charts throughout this report. More information about confidence intervals can be found in the [‘Understanding the results’](#) section.

2. Introduction

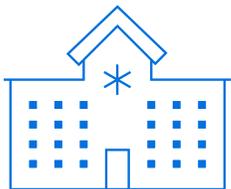




The Under 16 Cancer Patient Experience Survey (U16 CPES) measures experiences of tumour and cancer care for children across England. It is an annual survey. This report presents the U16 CPES 2022 headline findings and is the third time the survey has run.



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.



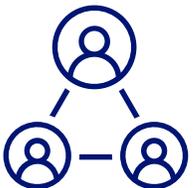
The survey has been designed to monitor national progress on experience of cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting children with cancer.



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 2022 who were aged under 16 at their time of discharge were included in the survey.



3. Methodology

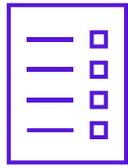




Eligibility

Patients with a confirmed cancer or tumour diagnosis who received inpatient or day case care from an NHS Principal Treatment Centre (PTC) in 2022, aged under 16 at their time of discharge.

Questionnaire and mode



- A paper questionnaire with a cover letter invitation and up to two reminders posted to parents/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 2022. There were three versions, depending on the patient's age prior to fieldwork:
 - 0 to 7 questionnaire – for completion by parents/carers of children aged 0 to 7.
 - 8 to 11 questionnaire – separate sections for the child and the parent/carer to complete.
 - 12 to 15 questionnaire – separate sections for the child/young person and the parent/carer to complete.



Fieldwork

People were asked to respond to the questionnaire between April and June 2023.



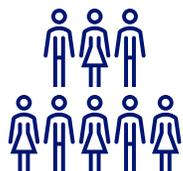
4. Understanding the results





- **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.

Sub-group comparisons allow us to explore differences in how people experience cancer care.



Some of the groups may be quite small and so please take caution when looking at results for these groups. See [‘About the Respondents’](#) for information on the number of responses for sub-groups. For sub-group 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 [survey website](#).



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



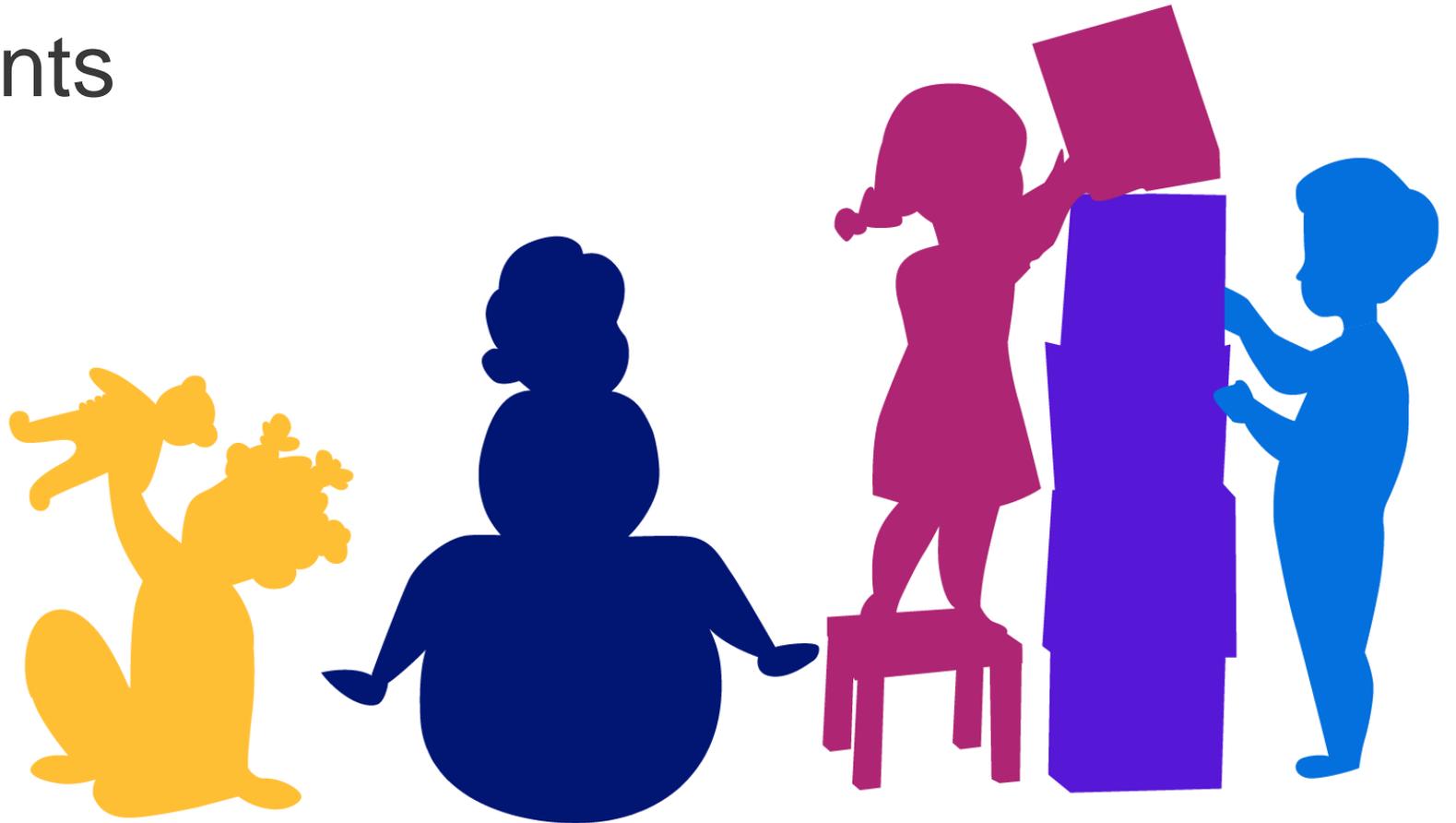
Confidence intervals: Assuming the sample is representative of the organisation, confidence intervals are a method of describing the uncertainty around results. They are shown as black bars on the charts in this report. The most common methodology, which was used here, is to produce and report 95 percent 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 (both scores and proportions) 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 sub-group AND the next smallest sub-group 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 Appendix](#).



5. About the respondents



Overall response rate

Out of **3,569** eligible parents/carers and children, **885** responded to the survey, yielding a response rate of **25%**. This is compared to 26% in 2021.



A response consists of one survey completion for a single patient, which could consist of both parent 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 Appendix available [on the survey website](#).

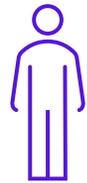
Sample size	Adjusted sample size	Completed	Response rate
3,581	3,569	885	25%

Survey mode

Response mode	Number of responses	Proportion of responses
Paper	617	70%
Online	266	30%
Mixed (combination of paper and online)	0	0%
Phone - English	2	0%
Phone – translation	0	0%
Total	885	100%



Survey type



Survey Type	Number of responses	% of responses
Parents/carers of children aged 0 to 7	450	51%
Children aged 8 to 11 (and their parents)	185	21%
Children aged 12 to 15 (and their parents)	250	28%
Total	885	100%

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

Which of the following best describes you?	No. of responses	% of responses
Boy/Male	235	54%
Girl/Female	171	39%
I describe myself in another way	1	0%
Prefer not to say	4	1%
Don't know	0	0%
Not given	24	6%
Total	435	100%

Sex registered at birth (from survey responses)

Sex registered at birth	No. of responses	% of responses
Male	490	55%
Female	371	42%
Prefer not to say	1	0%
Not given	23	3%
Total	885	100%



[†] Asked only to children aged 8-15

Ethnic background of child (from survey responses)

Ethnicity	No. of responses	% of responses
White	658	74%
Mixed	65	7%
Asian	98	11%
Black	27	3%
Other†	15	2%
Not given	22	2%
Total	885	100%



† Please note: 'Other' refers to those who selected 'Arab' or 'Any other ethnic group' in the survey question asking about ethnic background.

Diagnostic group †

Diagnostic group	No. of responses	% of responses
<u>Leukaemias</u> , myeloproliferative diseases, and myelodysplastic diseases	355	40%
Lymphomas and reticuloendothelial neoplasms	105	12%
CNS and miscellaneous intracranial and intraspinal neoplasms	178	20%
Retinoblastoma	25	3%
Renal tumours	42	5%
Hepatic tumours	10	1%
Malignant bone tumours	35	4%
All other	135	15%
Total	885	100%

IMD^{††} quintile (deprivation)

Quintile	No. of responses	% of responses
1 (most deprived)	160	18%
2	160	18%
3	150	17%
4	197	22%
5 (least deprived)	201	23%
Non-England	17	2%
Total	885	100%

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

Stage of current care or treatment (from survey responses)

Stage	No. of responses	% of responses
Recently diagnosed	12	1%
Watch and wait	84	10%
Receiving treatment	401	46%
Finished treatment within the last one month	66	8%
In remission/ long term follow-up	327	37%
Palliative or end of life care	7	1%
Other	49	6%
Total †	946	108%

Child's long term condition (from survey responses)

Long term condition unrelated to cancer or tumour	No. of responses	% of responses
Another long term condition	188	21%
No other long term condition	679	77%
Not given	18	2%
Total	885	100%



† Please note: This is a multiple choice question and therefore the total number of responses may be more than the total number of respondents

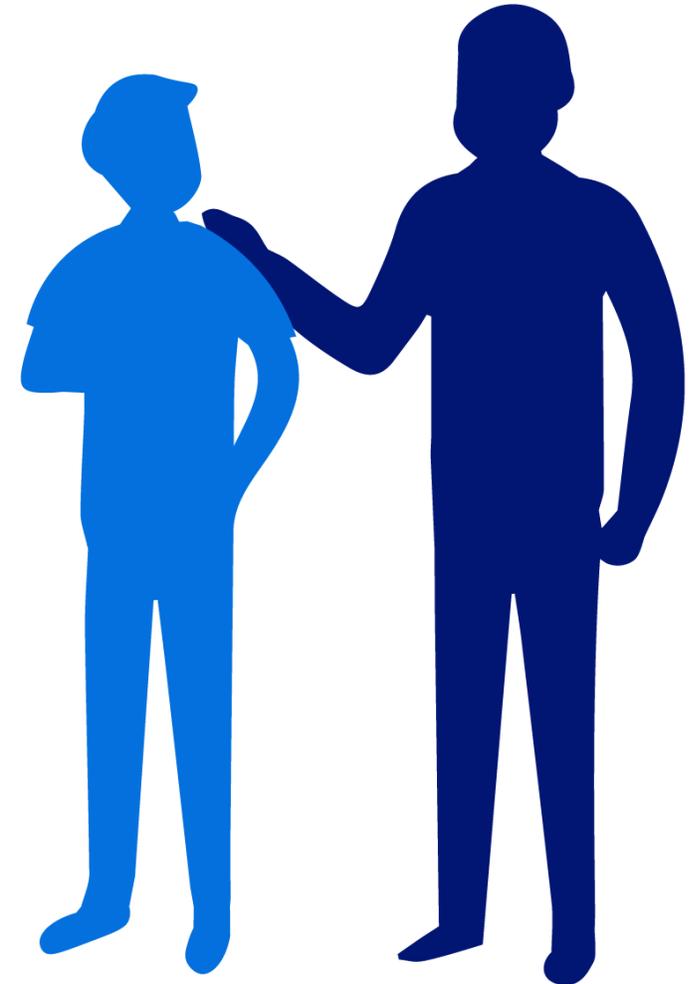


6. National results





6.1 Overall care





This section shows responses to the overall care questions by various sub-groups. Further information about how sub-groups were determined can be found in the Technical Appendix, available [on the survey website](#). Please take care when drawing conclusions from results based on small numbers of responses.



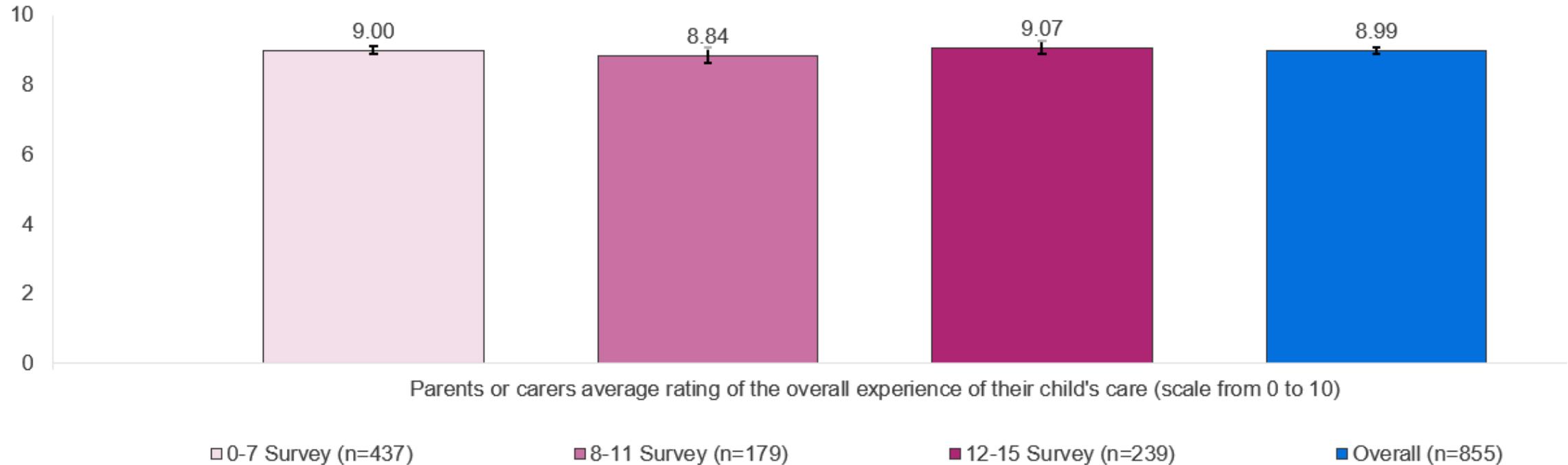
A breakdown of all survey questions and scores to each question by each sub-group can be found in the National Excel Data Tables, available [on the survey website](#) and in an [interactive dashboard](#).



Questions asking about overall care were structured differently for children and parents/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).

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

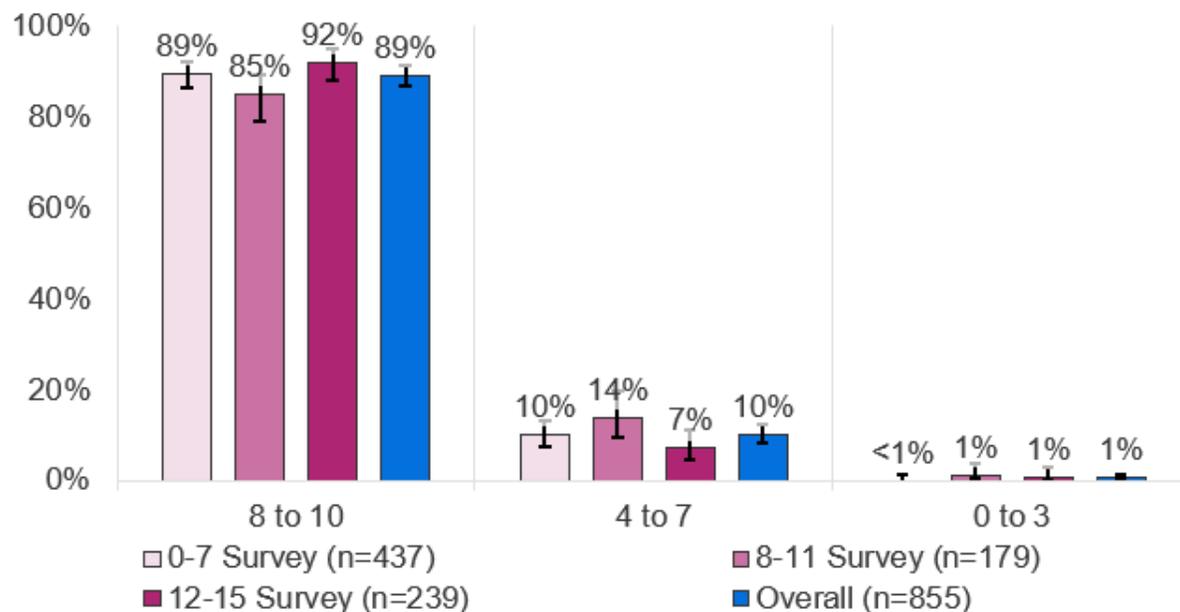


Parents or carers average rating of the overall experience of their child's care (scale from 0 to 10)

8.99 was the average parent/carer rating of the overall experience of their child's care (scale from 0 to 10). Average parent/carer ratings ranged from 8.84 to 9.07 across age groups.

Chart shows question X59_Average: Asked to parents/carers of all age groups. Total number of responses = 855

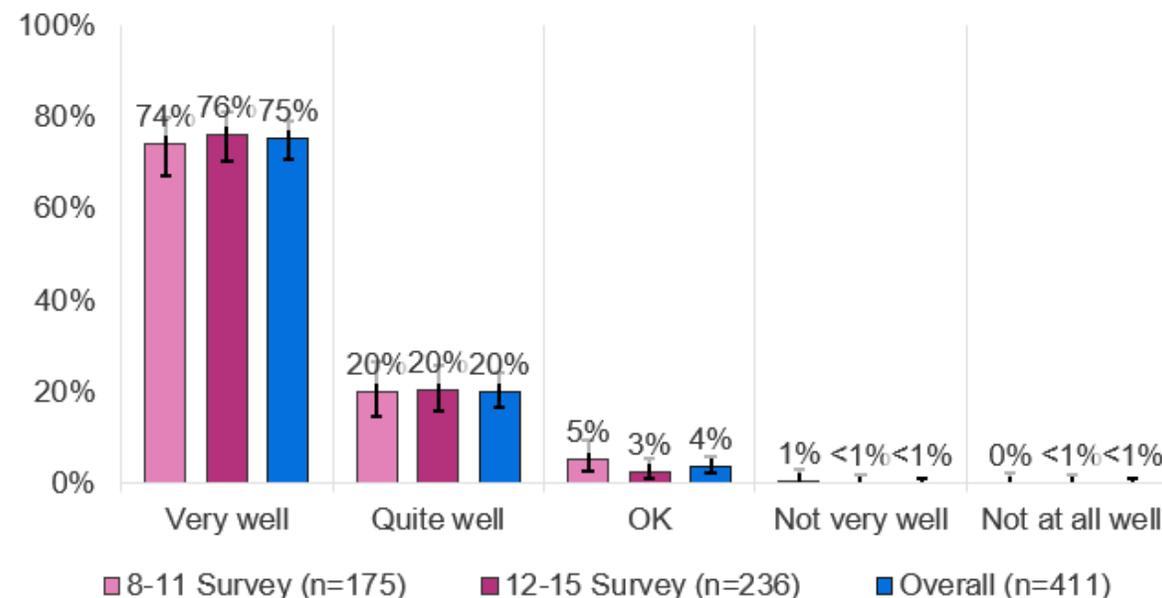
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10, ranging from 85% in the 8-11 survey to 92% in the 12-15 survey.

Chart shows question X59: Asked to parents/carers of all age groups. Total number of responses = 855

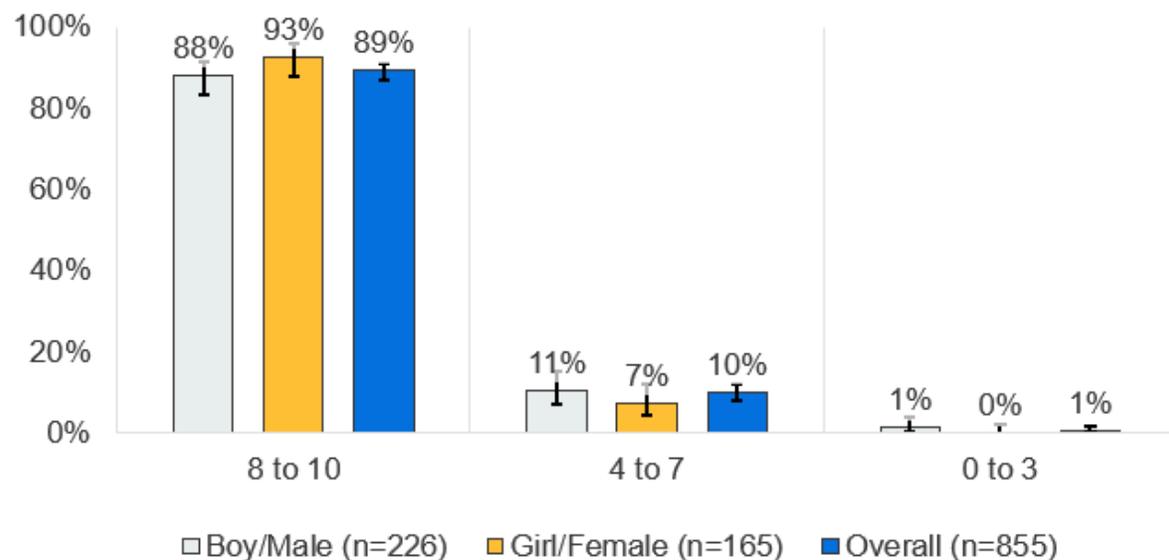
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



75% of children reported that they were very well looked after by staff for their cancer or tumour, ranging from 74% in the 8-11 survey to 76% in the 12-15 survey.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

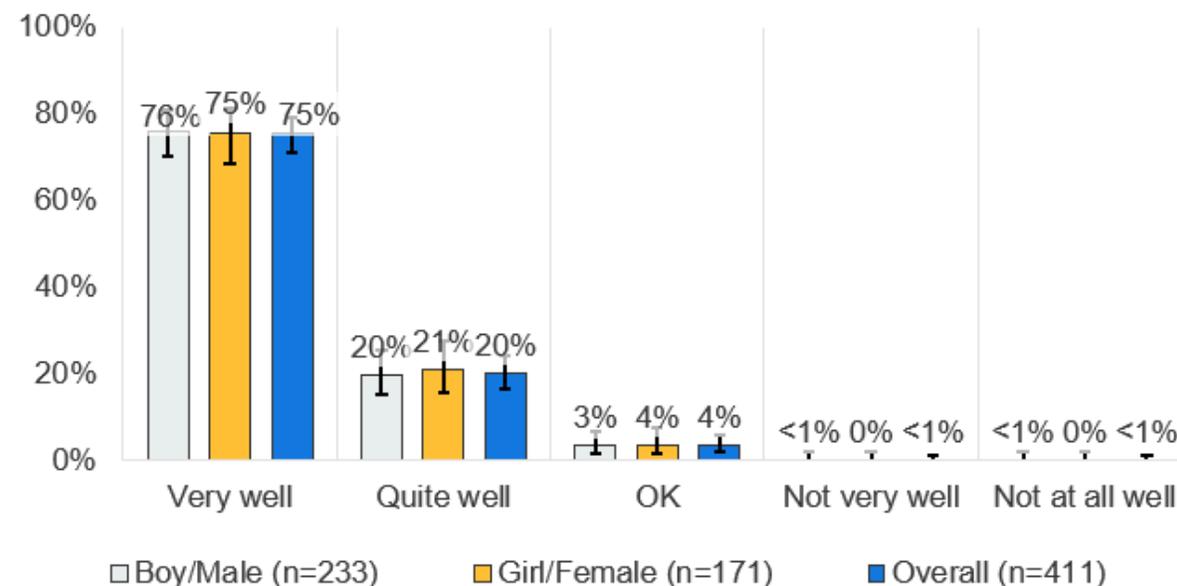
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10, ranging from 88% for boys/males to 93% for girls/females.

Chart shows question X59: Asked to parents/carers of all age groups. Total number of responses = 855. Due to small numbers, results for 'I describe myself in another way', 'don't know' and 'prefer not to say' are not shown.

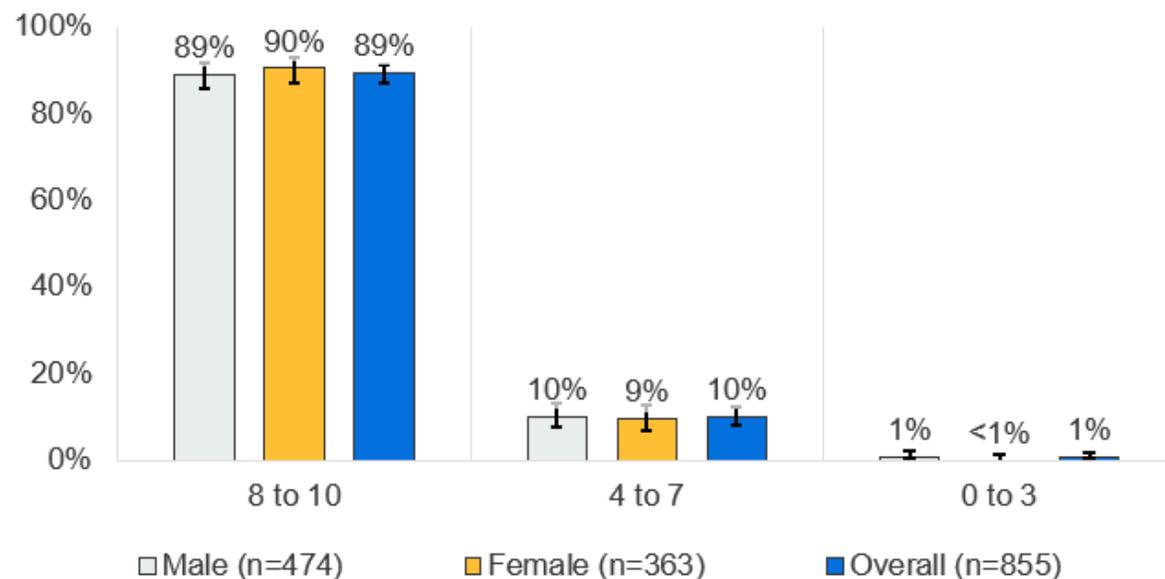
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



75% of children reported that they were very well looked after by staff for their cancer or tumour, ranging from 75% for girls/females to 76% for boys/males.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411. Due to small numbers, results for 'I describe myself in another way', 'don't know' and 'prefer not to say' are not shown.

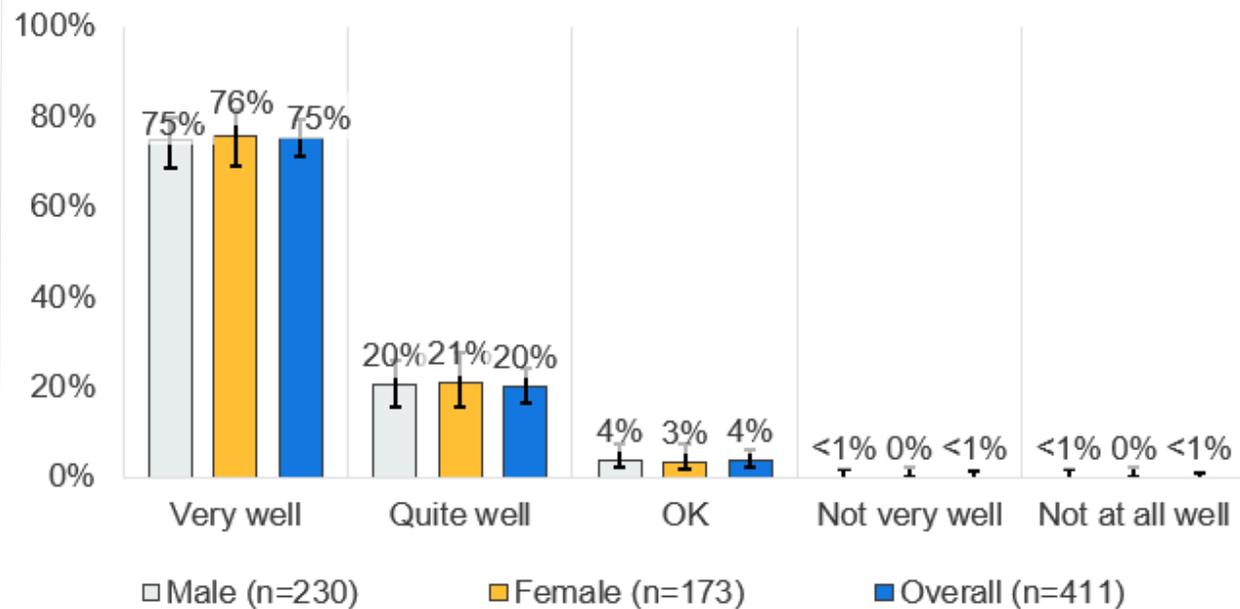
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10, ranging from 89% for males to 90% for females.

Chart shows question X59: Asked to parents/carers of all age groups. Total number of responses = 855. Due to small numbers, results for 'prefer not to say' are not shown.

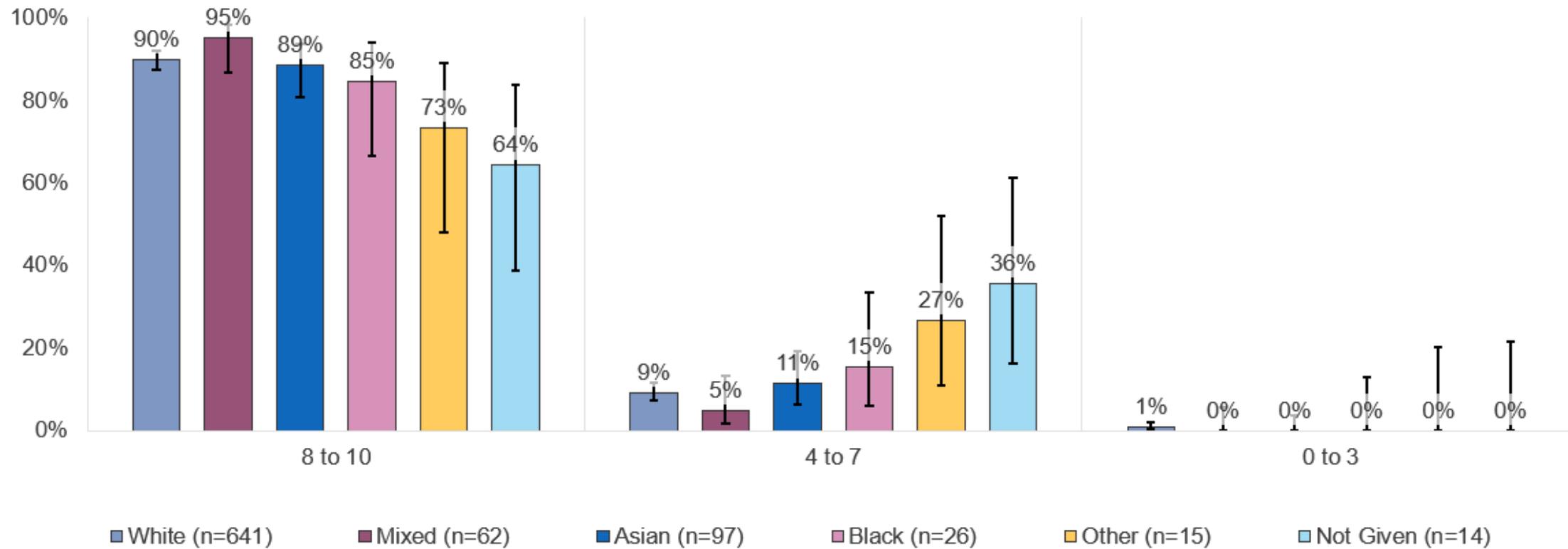
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



75% of children reported that they were very well looked after by staff for their cancer or tumour, ranging from 75% for males to 76% for females.

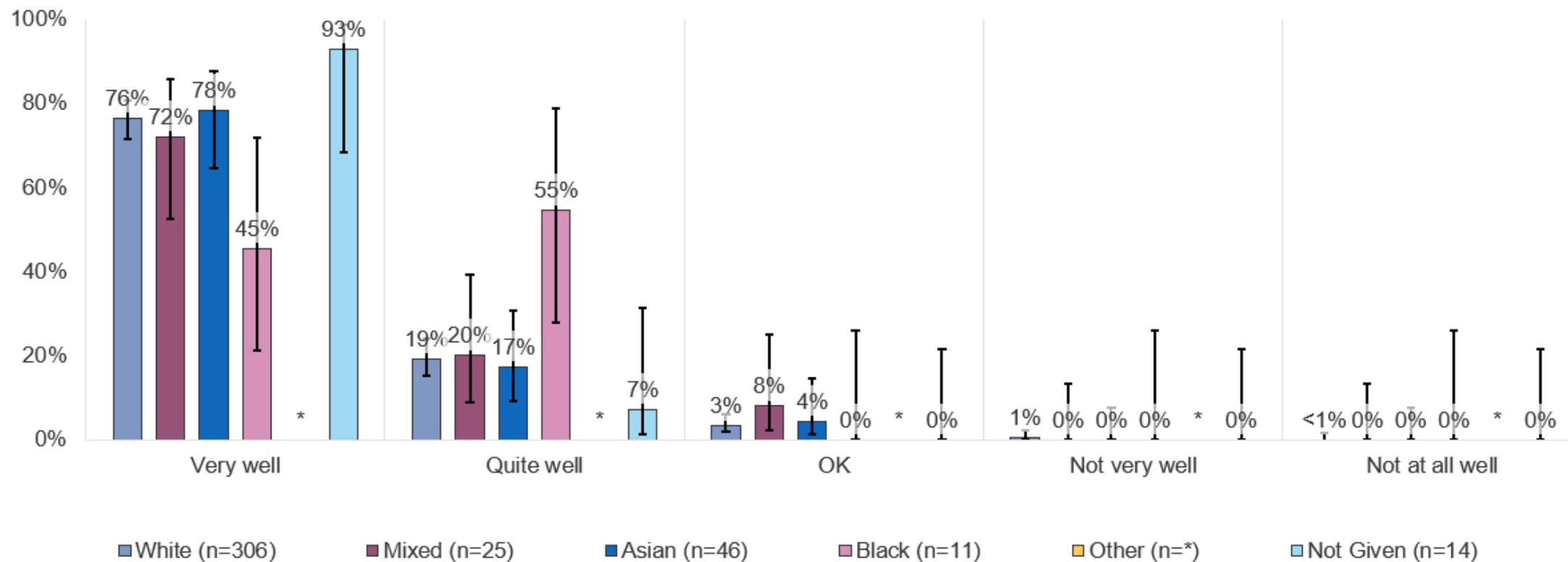
Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411. Due to small numbers, results for 'prefer not to say' are not shown.

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



The percent of parents/carers rating their child's overall care as 8 or more out of 10 ranged from 64% for not given to 95% for mixed ethnic background.

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

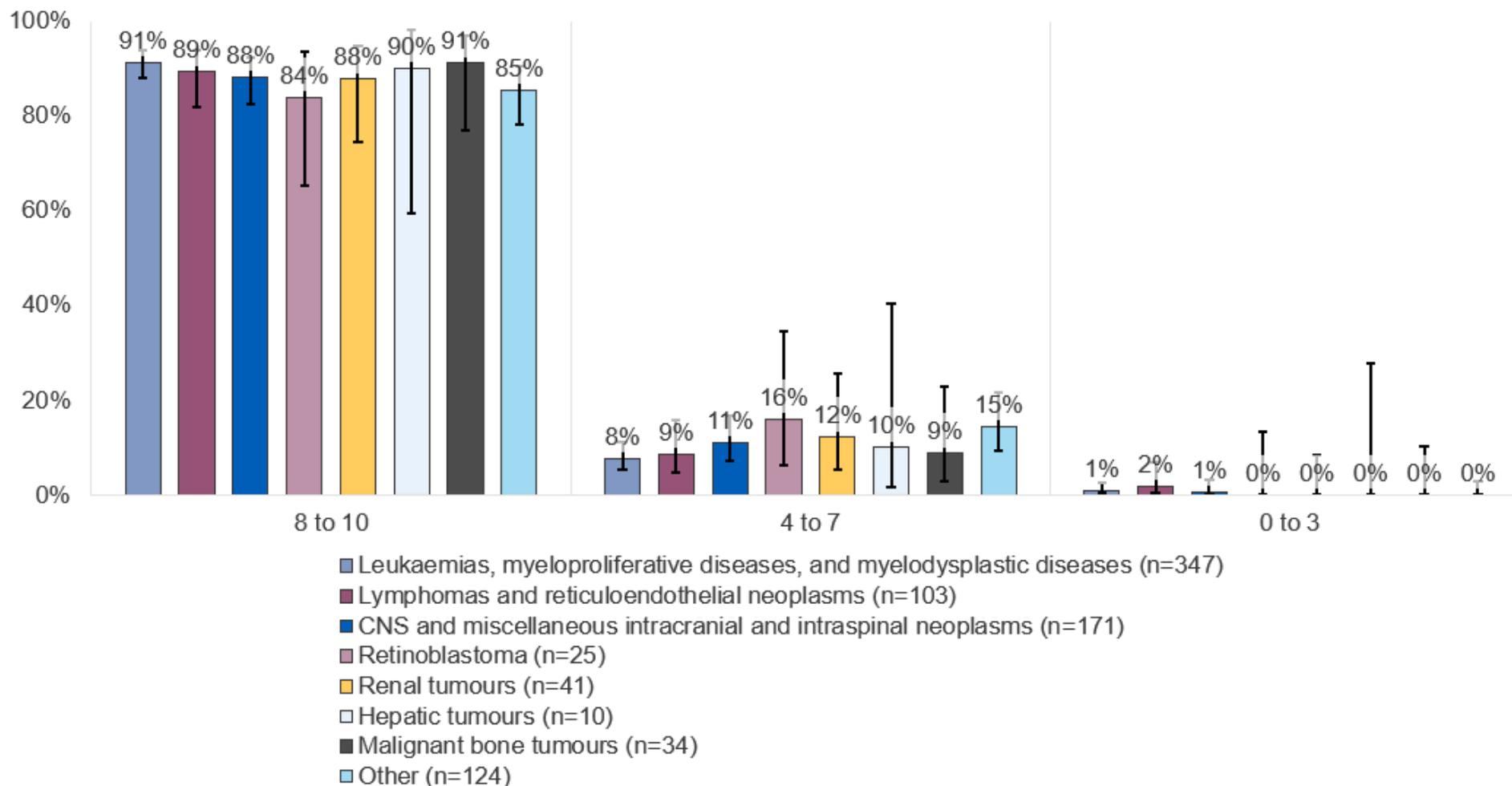


The percent of children reporting they were looked after very well ranged from 45% for black ethnic background to 93% for children whose ethnic background was not given.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

* An asterisk indicates that data has been suppressed (see [page 14](#) for details)

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



The percent of parents/carers rating their child's overall care as 8 or more out of 10 ranged from 84% for Retinoblastoma to 91% for Malignant bone tumours and Leukaemias, myeloproliferative diseases, and myelodysplastic diseases.

Chart shows question X59: Asked to parents/carers of all age groups. Total number of responses = 855

The percent of children reporting they were looked after very well ranged from 72% for CNS and miscellaneous intracranial and intraspinal neoplasms to 81% for Lymphomas and reticuloendothelial neoplasms. However, please note that data for three diagnostic groups has been suppressed due to small numbers.

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

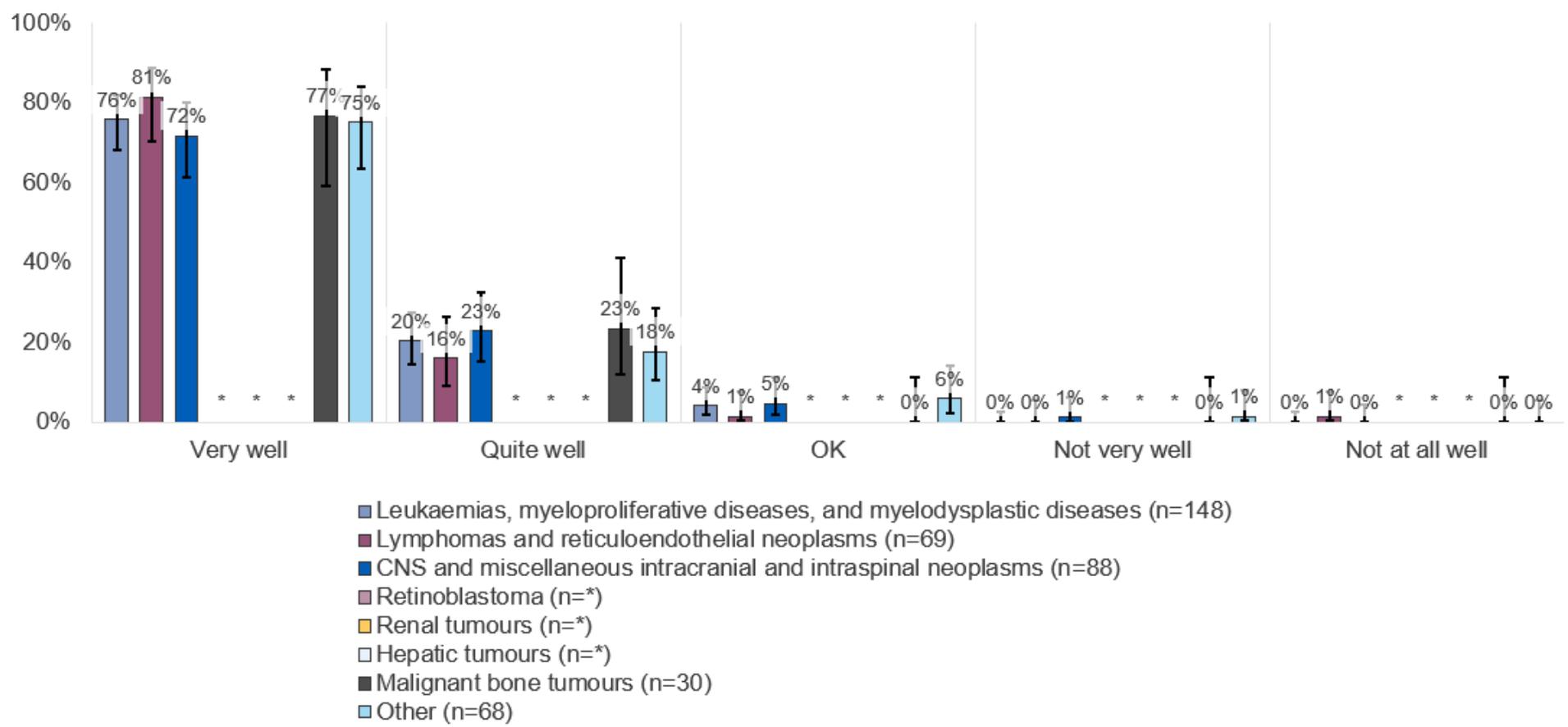
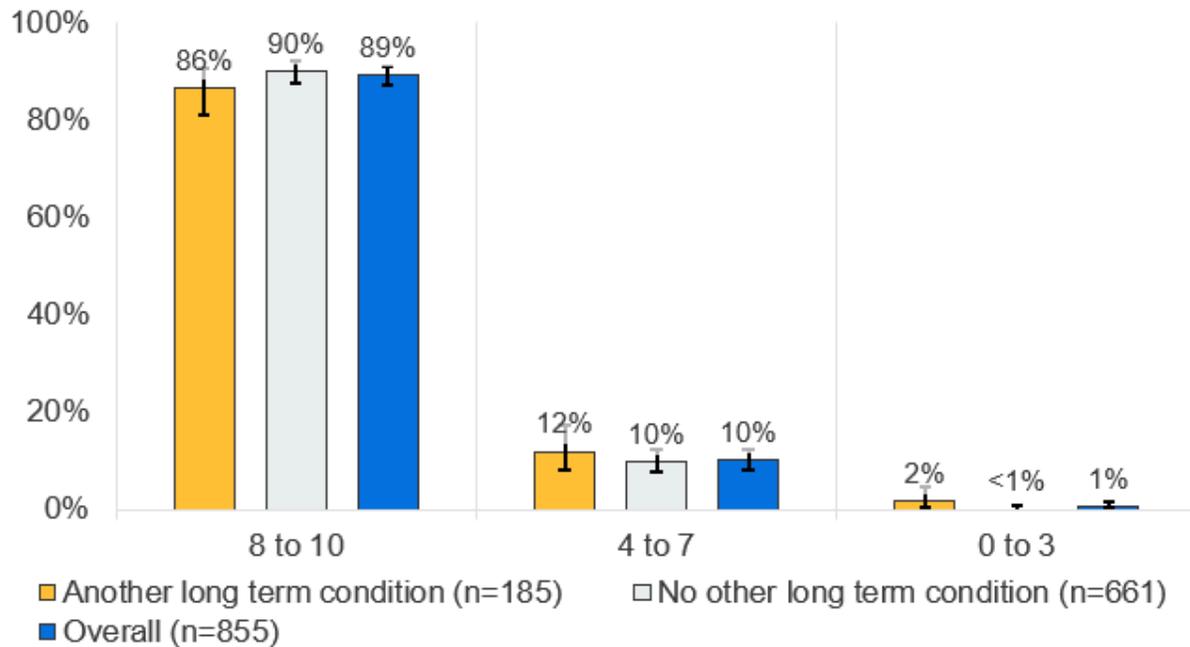


Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

* An asterisk indicates that data has been suppressed (see [page 14](#) for details)

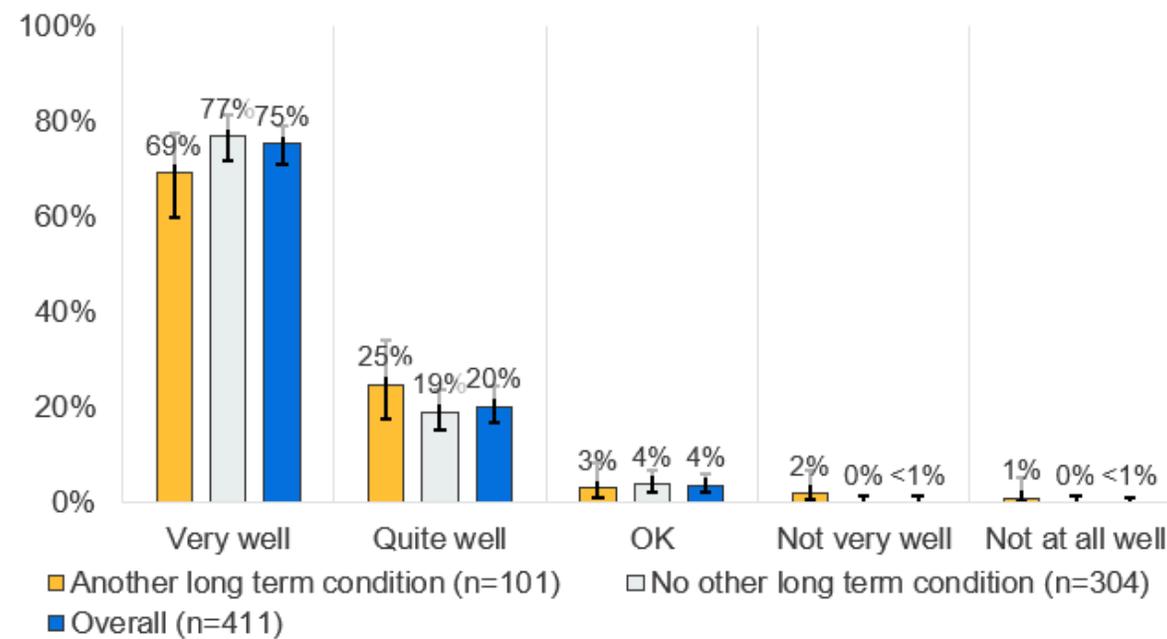
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10, ranging from 86% for another long term condition to 90% for no other long term condition.

Chart shows question X59: Asked to parents/carers of all age groups. Total number of responses = 855

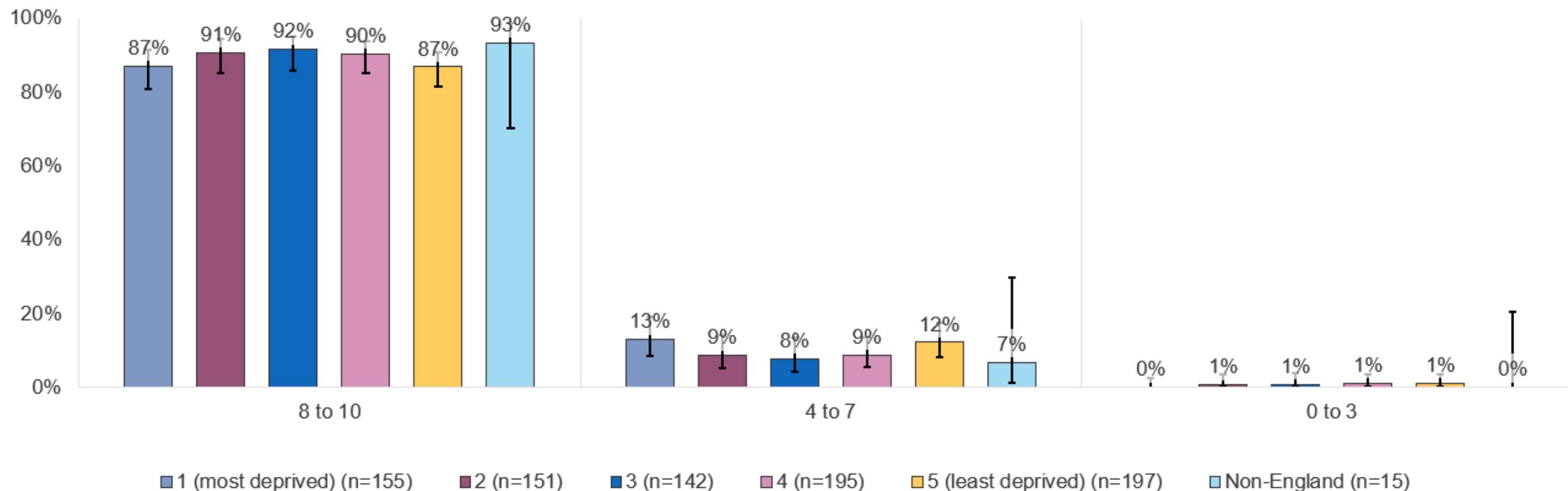
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



75% of children reported that they were very well looked after by staff for their cancer or tumour, ranging from 69% for another long term condition to 77% for no other long term condition.

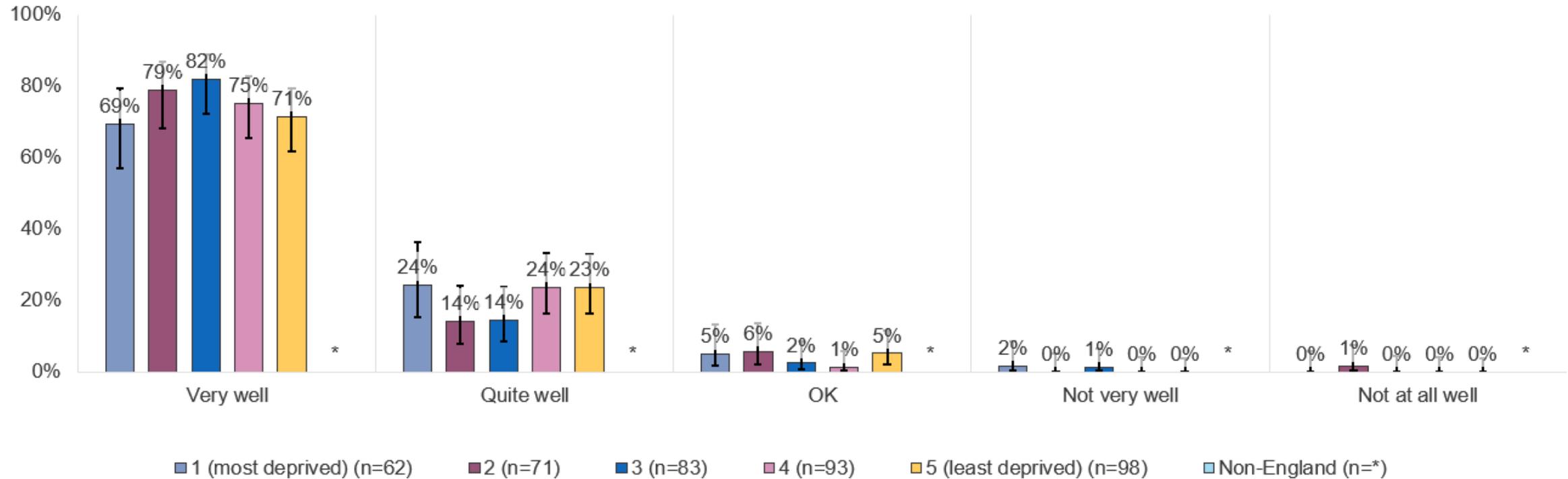
Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

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



The percent of parents/carers rating their child's overall care as 8 or more out of 10 ranged from 87% for the most deprived and for the least deprived quintile to 93% for non-England.

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

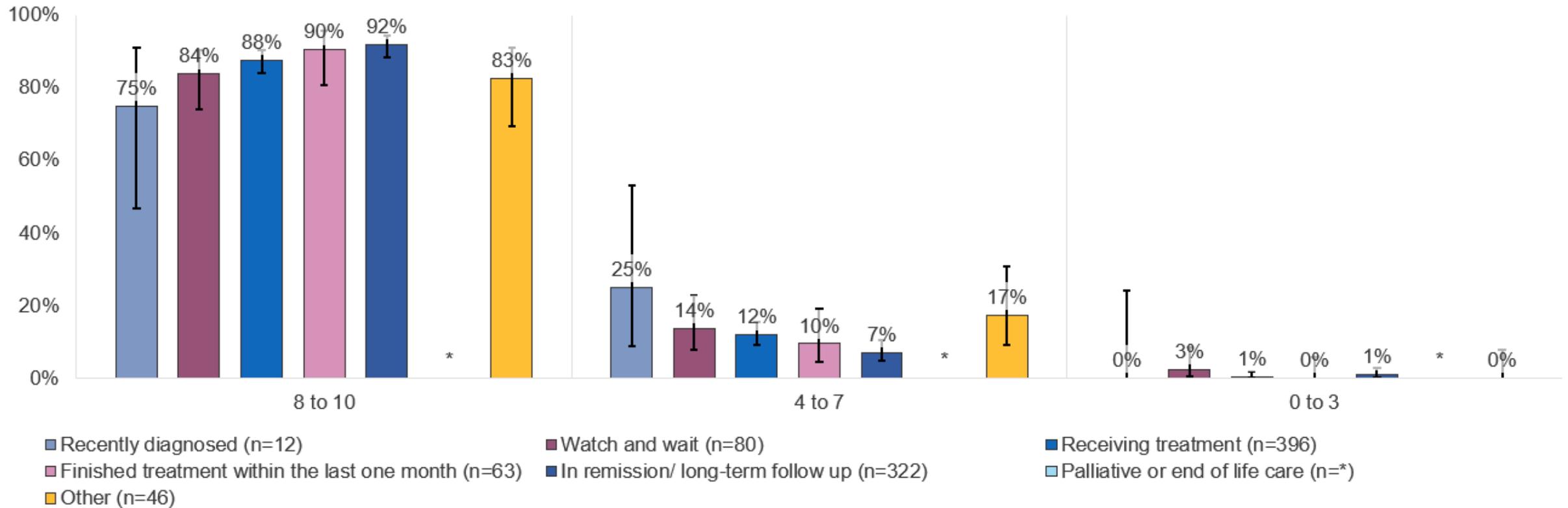


Children reporting that they were very well looked after by healthcare staff ranged from 69% for the most deprived to 82% for those in the third IMD quintile.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

* An asterisk indicates that data has been suppressed (see [page 14](#) for details)

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

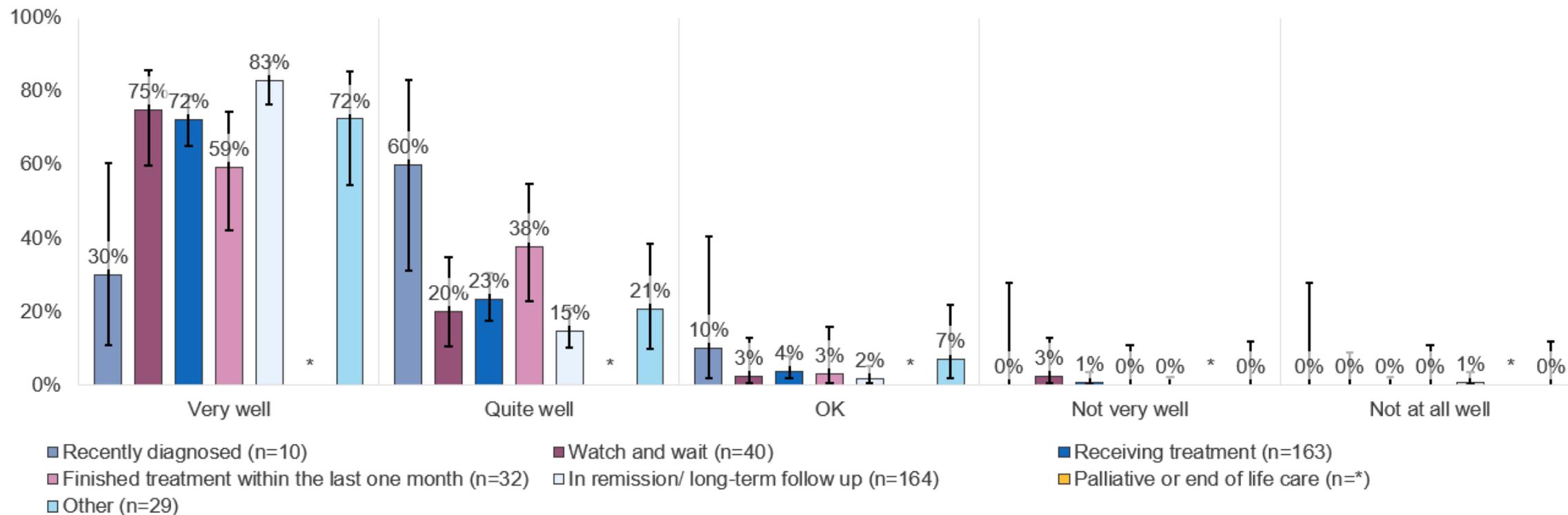


Parents/carers rating their child's overall care as 8 or more out of 10 ranged from 75% for those who were recently diagnosed to 92% for those in remission / long term follow up.

Chart shows question X59: Asked to parents/carers of all age groups. Total number of responses = 855

* An asterisk indicates that data has been suppressed (see [page 14](#) for details)

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 30% for those who were recently diagnosed to 83% for those in remission / long term follow up.

Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

* An asterisk indicates that data has been suppressed (see [page 14](#) for details)

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/carers of children aged 0-11, and children aged 12-15. Total number of responses = 653

Travel to the hospital



66% of parents/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/carers of all age groups. Total number of responses = 870

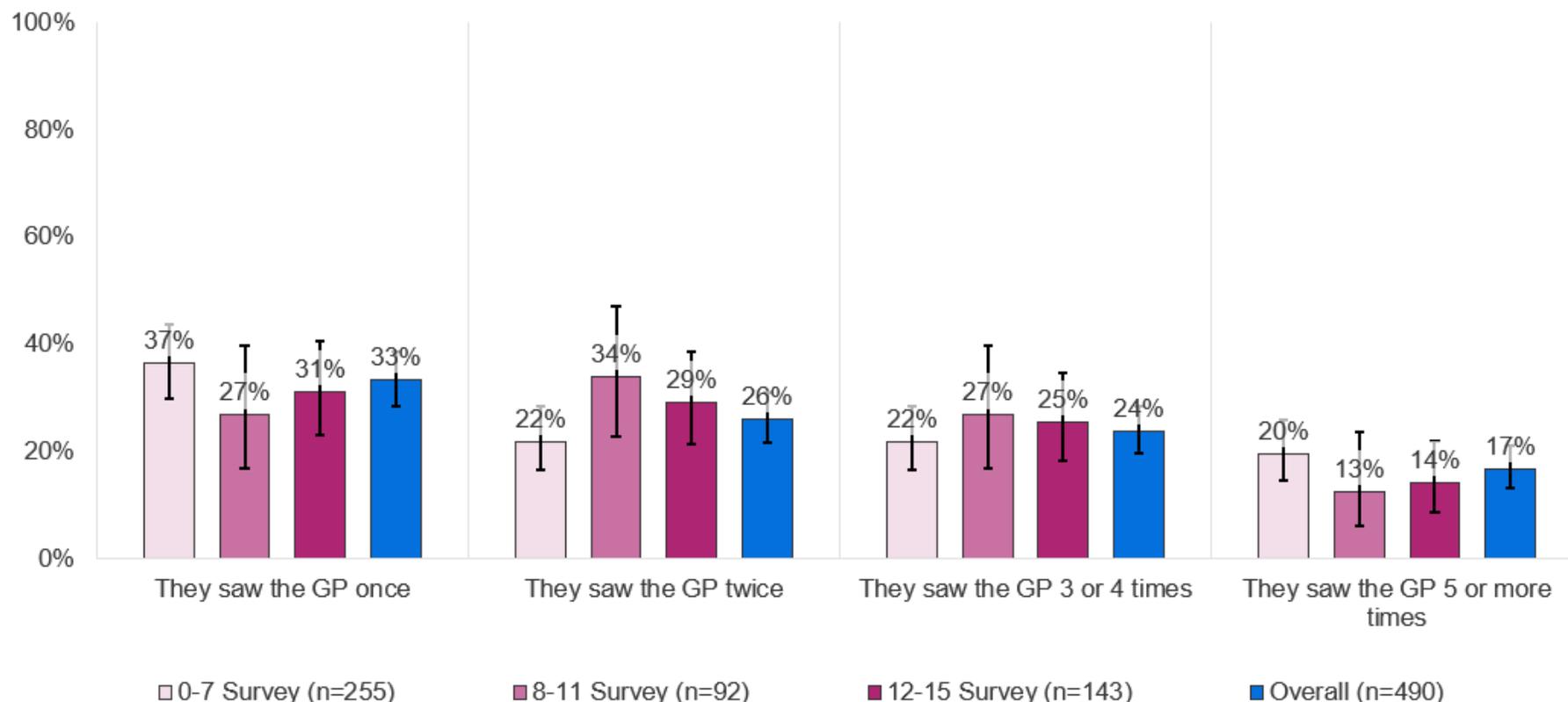
6.2

Finding out about the cancer or tumour



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?



59% of parents/carers reported that their child saw a GP once or twice before they were referred to hospital.

Chart shows question X03: Asked to parents/carers of all age groups whose children were told they had cancer or a tumour during 2022. Total responses = 345 (excluding 135 responses of “None – they went straight to hospital” and 10 responses of “Don’t know/ can’t remember”)

Visiting the hospital

67% of parents/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/carers of children aged 0-7).

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?

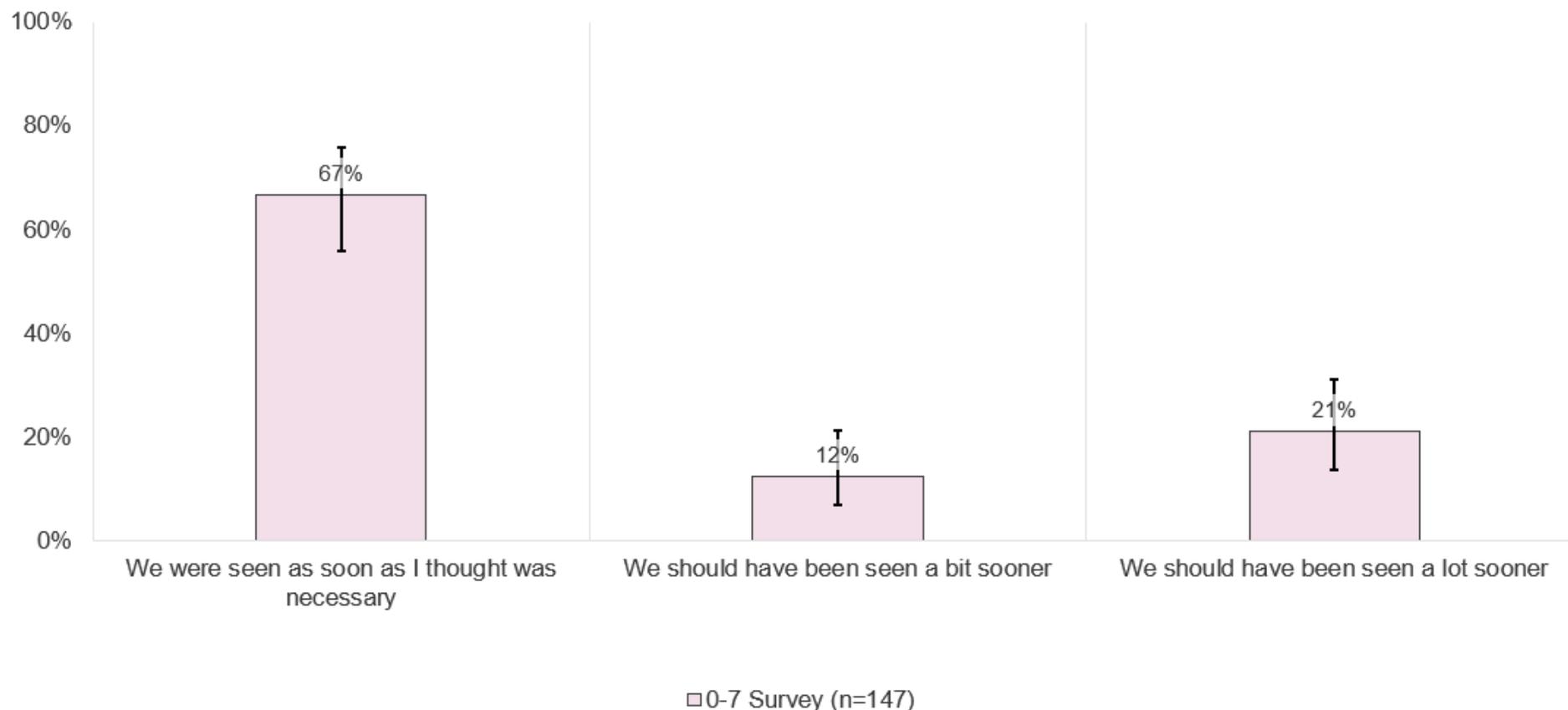


Chart shows question X06a: Asked to parents/carers of children aged 0-7 who were told about their child's cancer or a tumour during 2022. Total number of responses = 81 (excluding 66 responses of "We were not referred by a GP")

Visiting the hospital

64% of parents/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/carers of children aged 8-15).

How do 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?

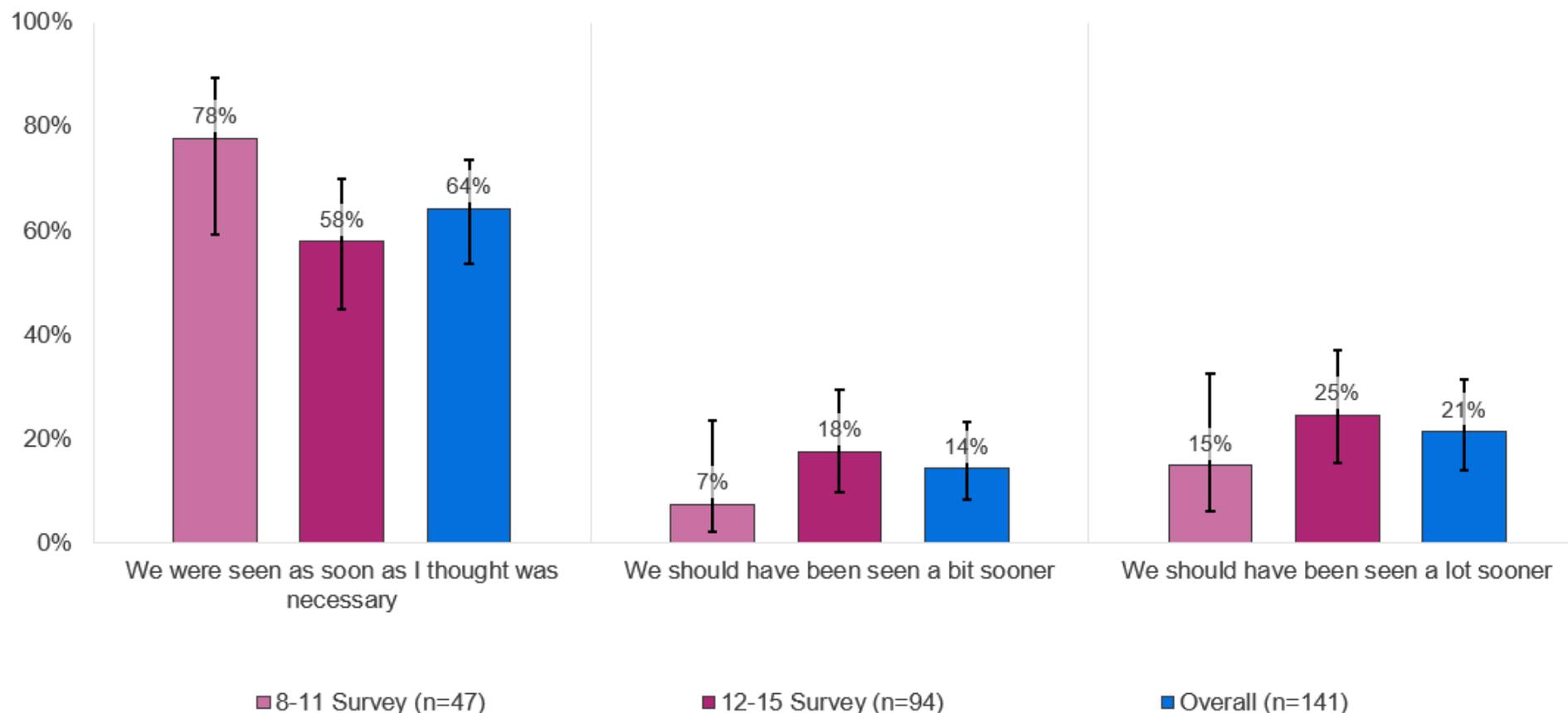


Chart shows question X06b: Asked to parents/carers of children aged 8-15 who were told about their child's cancer or a tumour during 2022. Total number of responses = 84 (excluding 57 responses of "We were not referred by a GP")

† The overall data is the score for 8-15 year olds only.

Answering questions



78% 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/carers of 0-7s who were told about their child's cancer or a tumour during 2022, and children aged 8-15 who were told they had cancer or a tumour during 2022. Total number of responses = 288 (excluding 6 responses of "I did not have any questions" and excluding 4 response(s) of "Don't know / can't remember").

Information

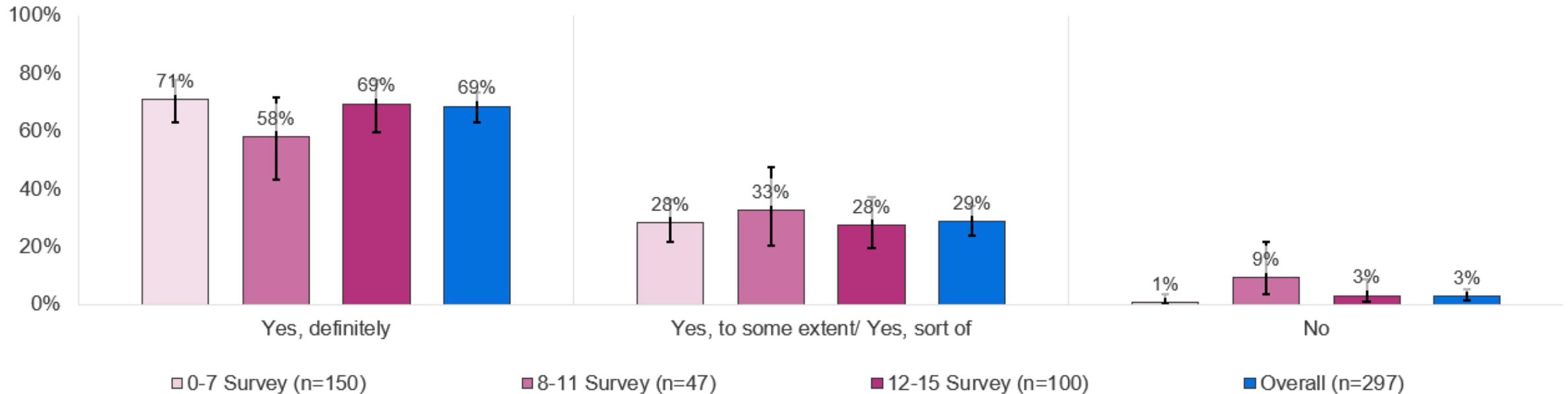


69% of parents/carers and children reported that information at diagnosis was definitely given in a way they could understand.

Question X08: Asked to parents/carers of 0-7s who were told about their child's cancer or a tumour during 2022, and children aged 8-15 who were told they had cancer or a tumour during 2022. Total number of responses = 289 (excluding 8 responses of "Don't know/ can't remember").

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?



69% of parents/carers and children reported that information at diagnosis was definitely given in a way they could understand.

Chart shows question X08: Asked to parents/carers of 0-7s who were told about their child's cancer or a tumour during 2022, and children aged 8-15 who were told they had cancer or a tumour during 2022. Total responses = 289 (excluding 8 responses of "Don't know/ can't remember").

Information

90% of parents/ carers and children reported that staff provided details about who to contact for more information after being told about their 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 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?

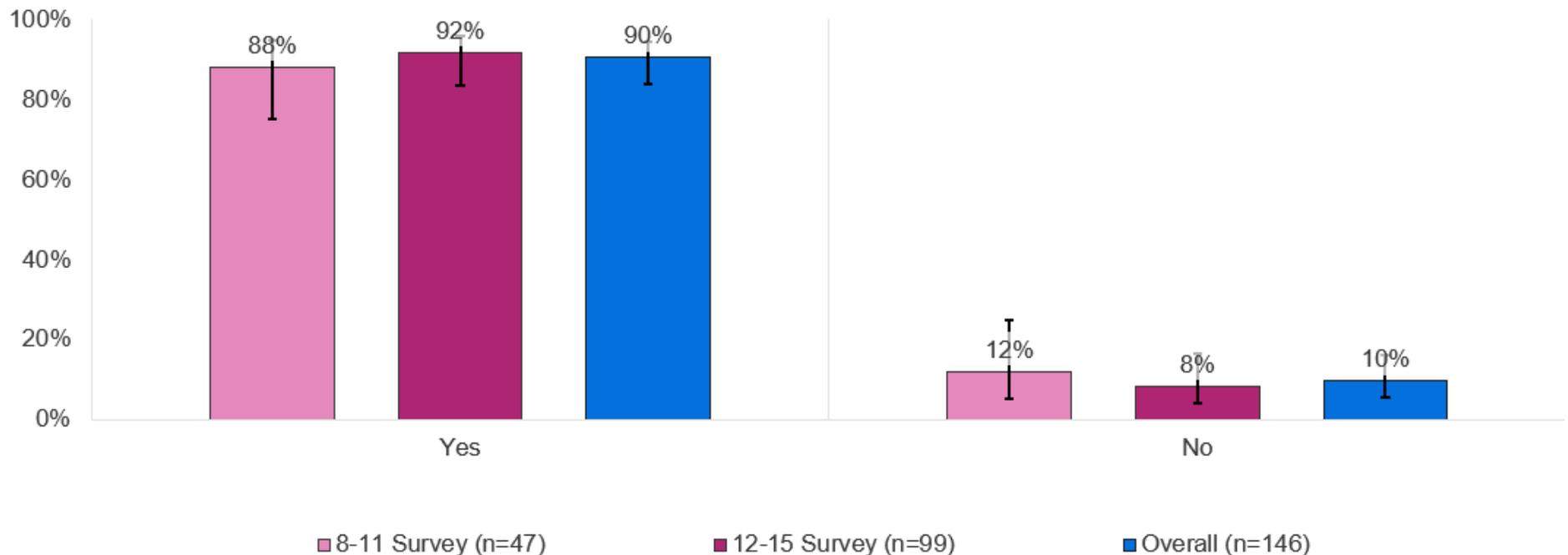
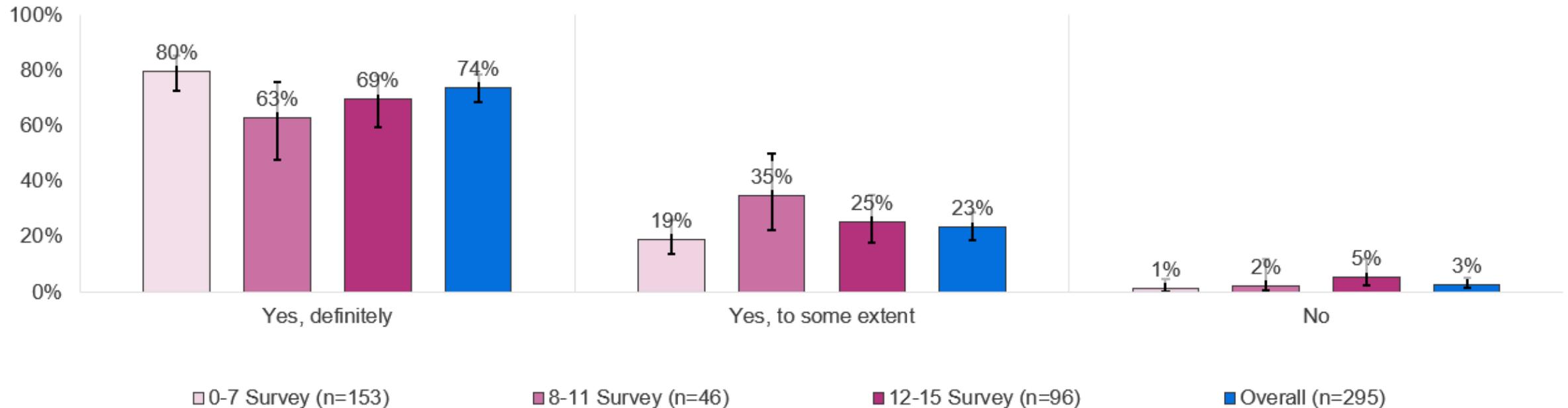


Chart shows question X11: Asked to parents/carers of children aged 8-11 who were told about their child's cancer or a tumour during 2022, and children aged 12-15 who were told they had cancer or a tumour during 2022. Total responses = 125 (excluding 21 responses of "Don't know/ can't remember").

Information

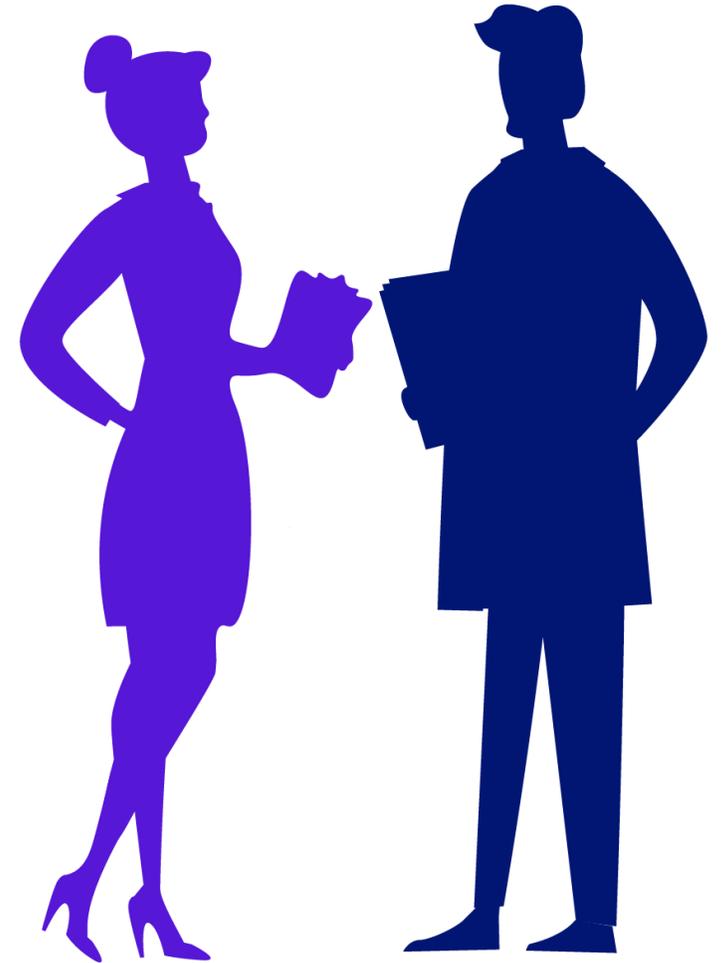
Have you been able to find the information that you need about your child's diagnosis?



74% of parents/carers reported that they were definitely able to find information about their child's diagnosis.

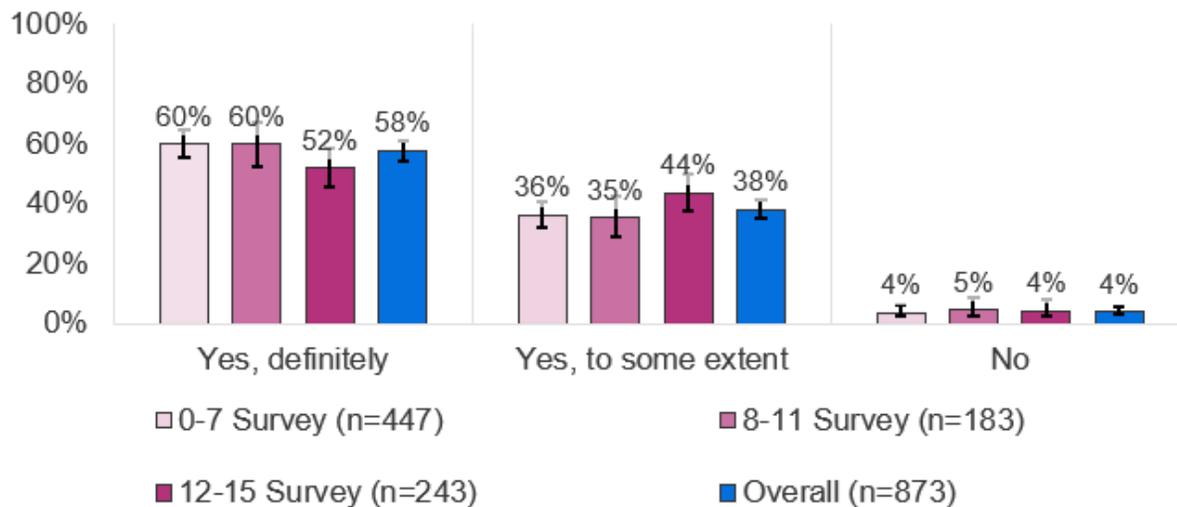
Chart shows question X10: Asked to parents/carers of all age groups who were told about their child's cancer or a tumour during 2022. Total responses = 291 (excluding 4 responses of "This was not needed").

6.3 Child's care and treatment



Medical history

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

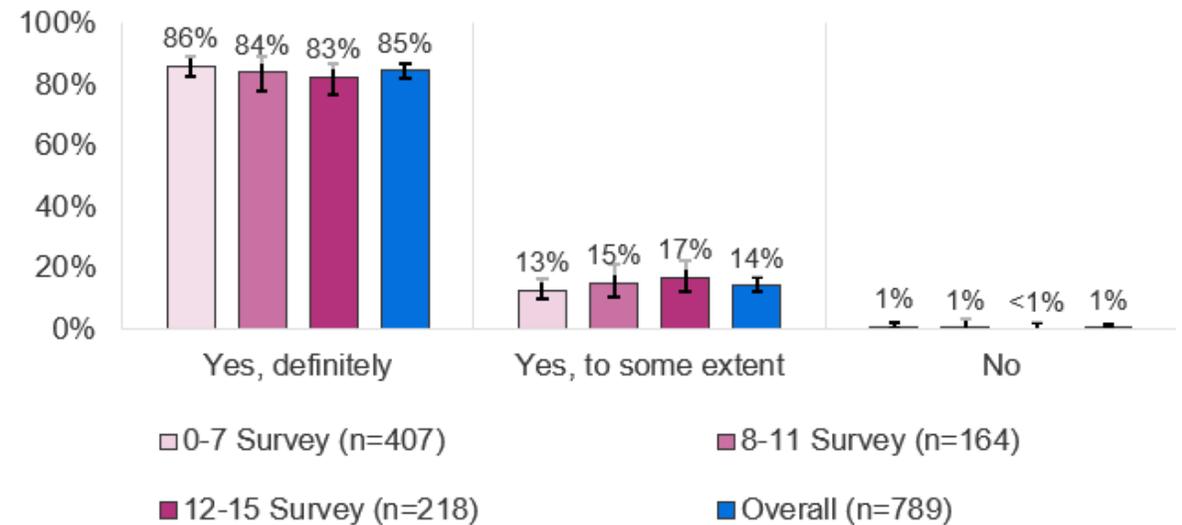


58% of parents/carers felt that different hospital staff were definitely aware of their child's medical history.

Chart shows question X27: Asked to parents/carers of all age groups. Total responses = 837 (excluding 36 responses of "Don't know/ Not applicable").

Written information

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

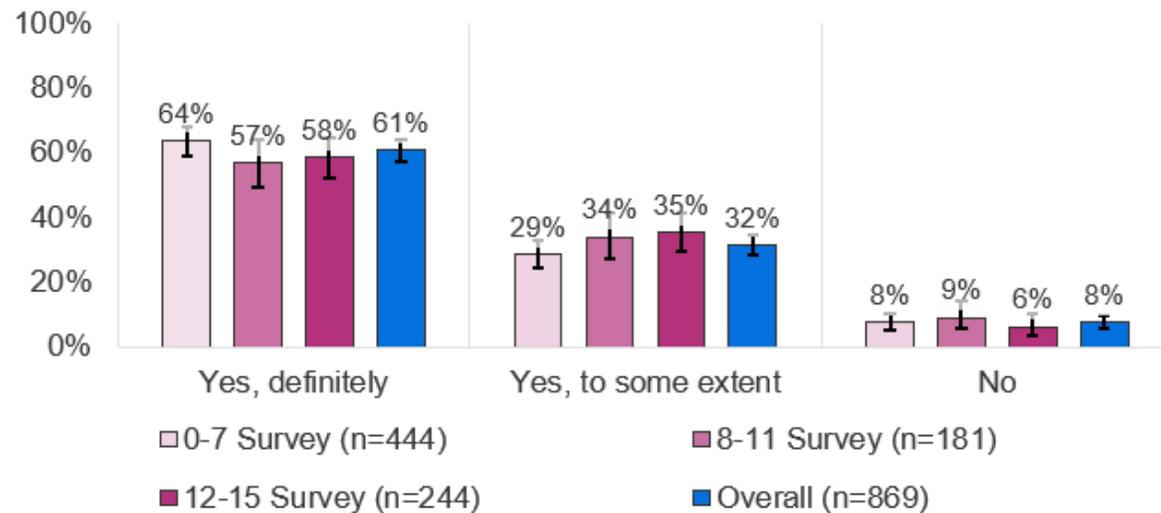


85% of parents/carers reported that they were offered clear information about their child's treatment.

Chart shows question X36: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2022. Total responses = 787 (excluding 2 responses of "This was not needed").

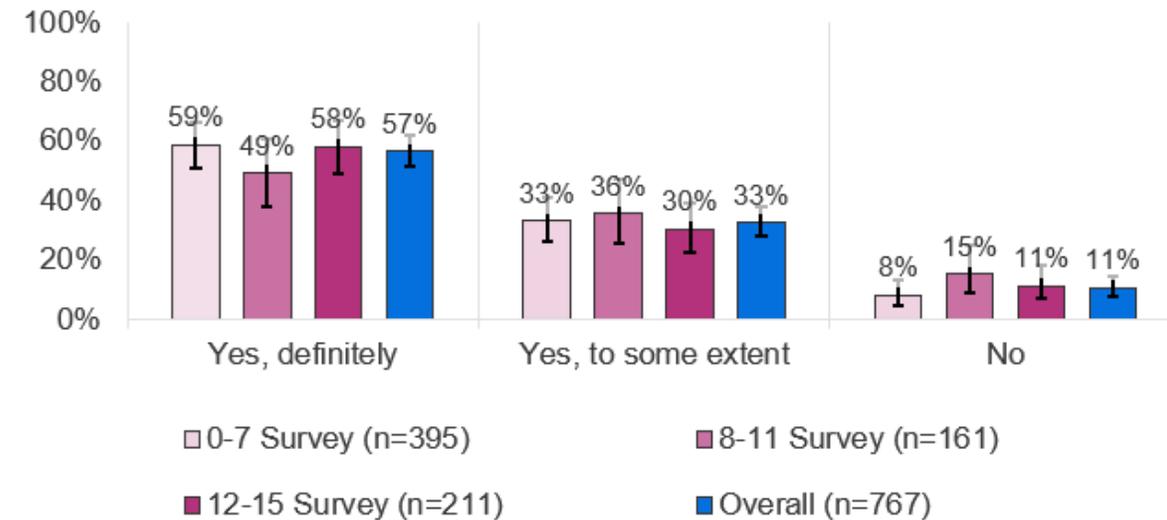
Support from the hospital

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



61% of parents/carers reported that they definitely had access to reliable help and support 7 days a week from the hospital.

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



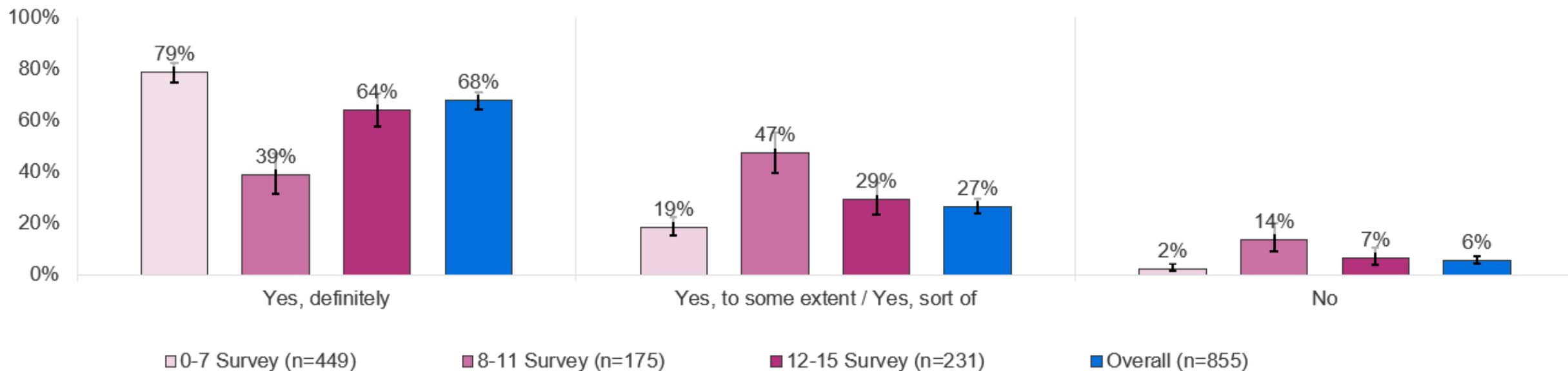
57% of parents/carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended.

Chart shows question X33: Asked to parents/carers of all age groups. Total responses = 823 (excluding 46 responses of "This is not needed").

Chart shows question X39: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2022. Total responses = 348 (excluding 29 responses of "Not applicable / this was not needed" and excluding 390 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?



68% of parents/carers and children felt they were definitely involved in their child's/ their care and treatment.

Chart shows question X29: Asked to parents/carers of 0-7s and all children aged 8-15. Total responses = 804 (excluding 51 responses of "No, but this is not needed or possible").

Impact of care and treatment on schooling and education

Across all surveys, parents/ carers reported that their child's schooling and education had been impacted by missing school due to timings of treatment and care, more so than other response options.

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

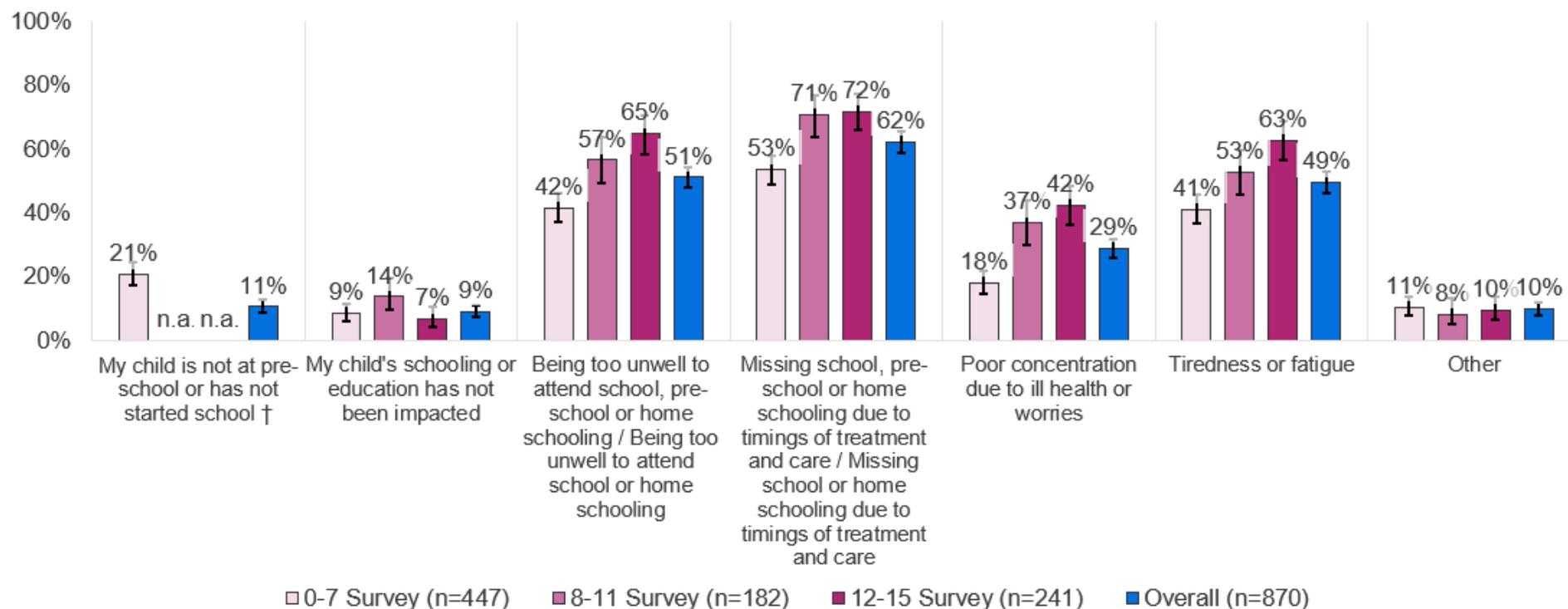


Chart shows question X30: Asked to parents/carers of all age groups. Total number of responses = 870.

† Response option was only asked to parents of 0-7 years old

6.4 Care in hospital



Staff availability in hospital

70% of parents/ carers and children felt that their child/they were always able to get help from staff on the hospital ward when they needed it.

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?

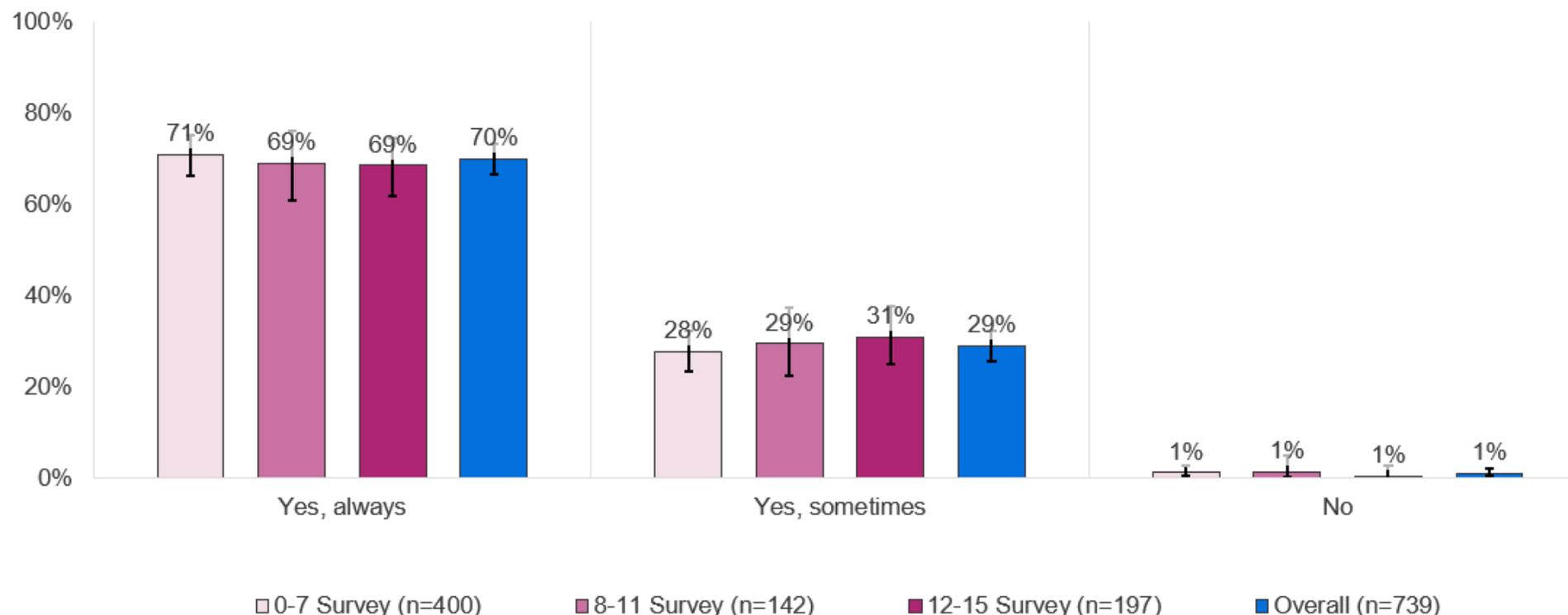
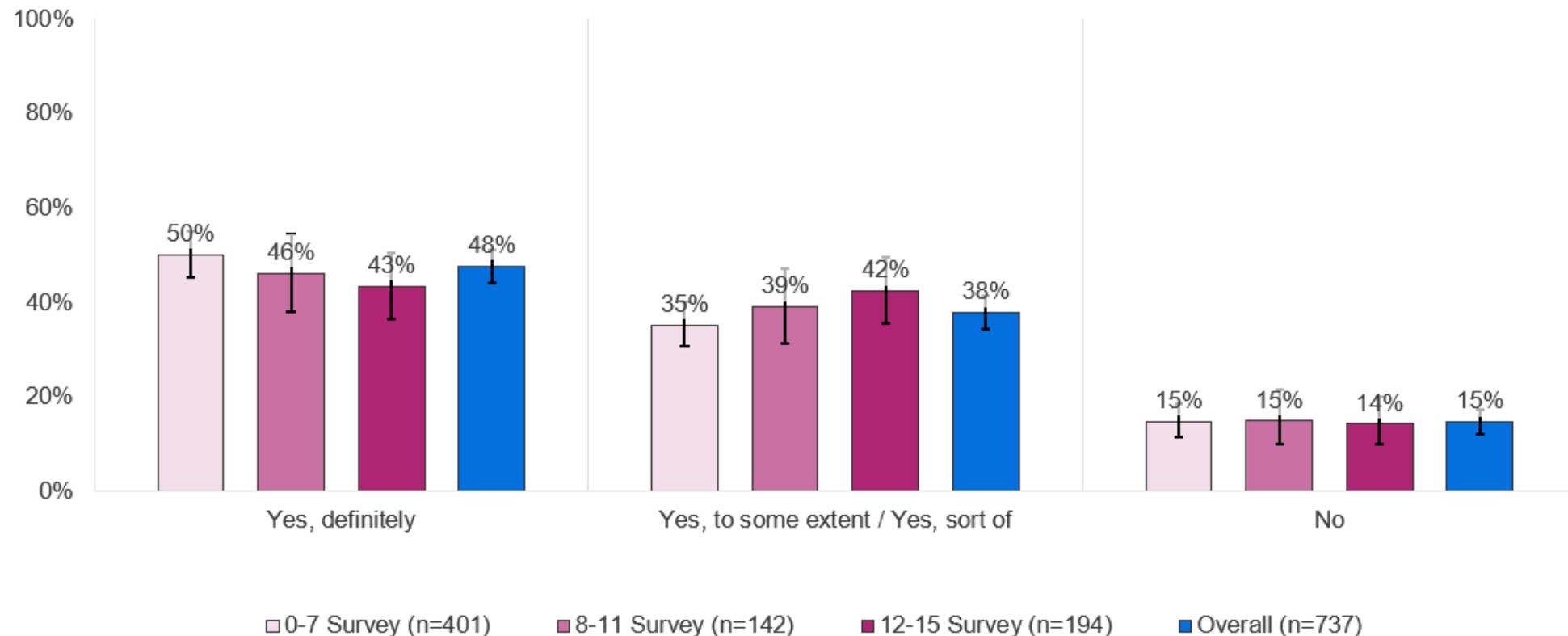


Chart shows question X42: Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2022, and children aged 8-15 who have stayed in hospital during 2022 (receiving treatment or care in the daytime or for an overnight stay). Total number of responses = 728 (excluding 9 responses of “They/ I did not need any help” and 2 responses of “Don’t know/ can’t remember”).

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?**



48% of parents/ carers and children felt that there were definitely enough things for their child to do in the hospital.

Chart shows question X43: Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2022, and children aged 8-15 who stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 725 (excluding 12 responses of "This was not needed").

Play specialist support

53% of parents/carers reported that the hospital always offered play specialist support when they needed it.

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)?

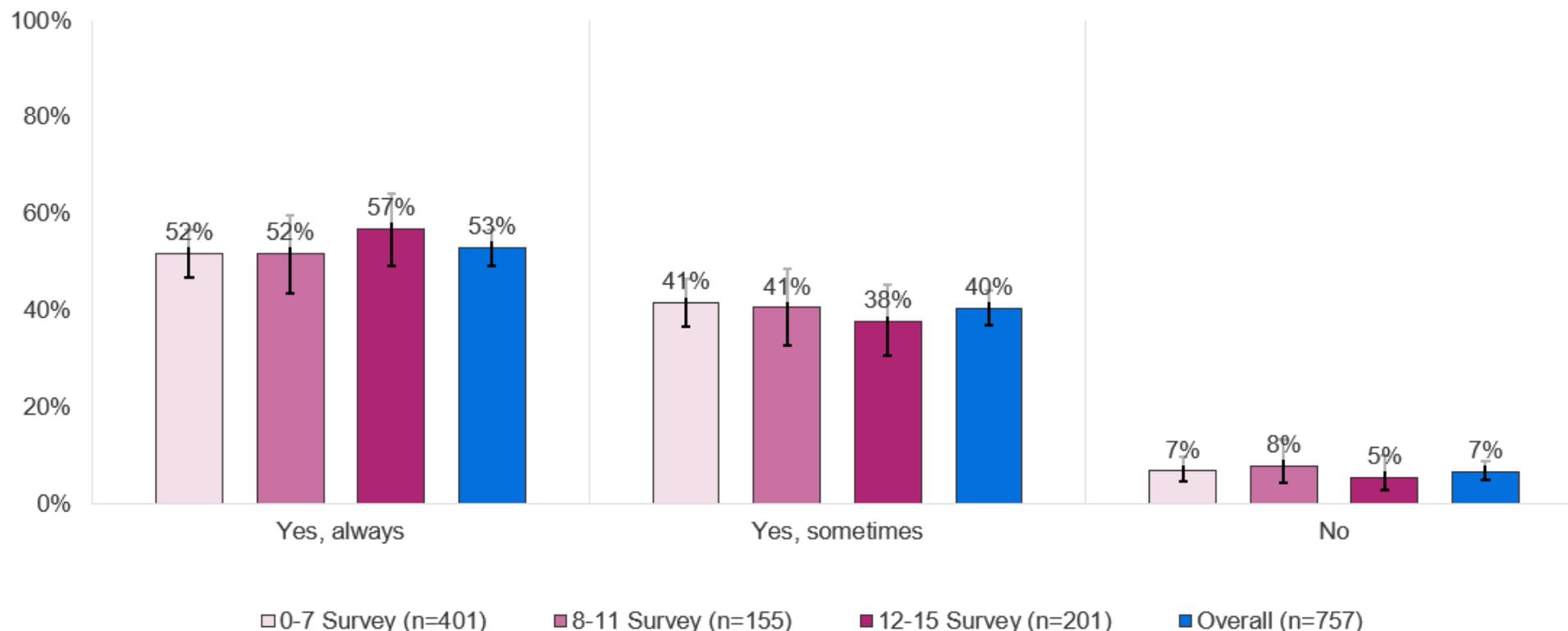


Chart shows question X46: Asked to parents/carers of all age groups whose children stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 696 (excluding 61 responses of “My child did not need this”).

Hospital Wi-Fi

38% of parents/carers felt that the hospital Wi-Fi always met the needs of them and their child.

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

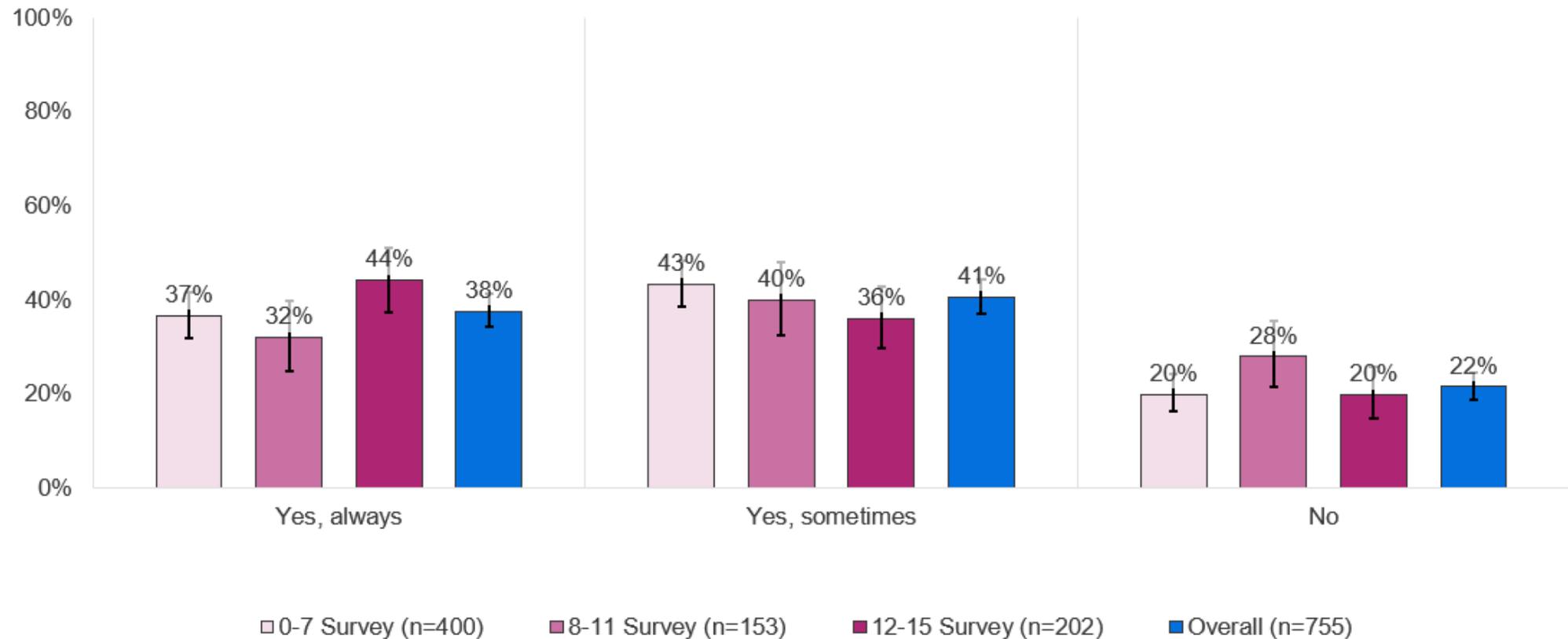


Chart shows question X51: Asked to parents/carers of all age groups whose children stayed in hospital during 2022 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 732 (excluding 23 responses of "This was not needed").

Hospital food

57% of parents/ carers and children felt that there was definitely a choice of hospital food.

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

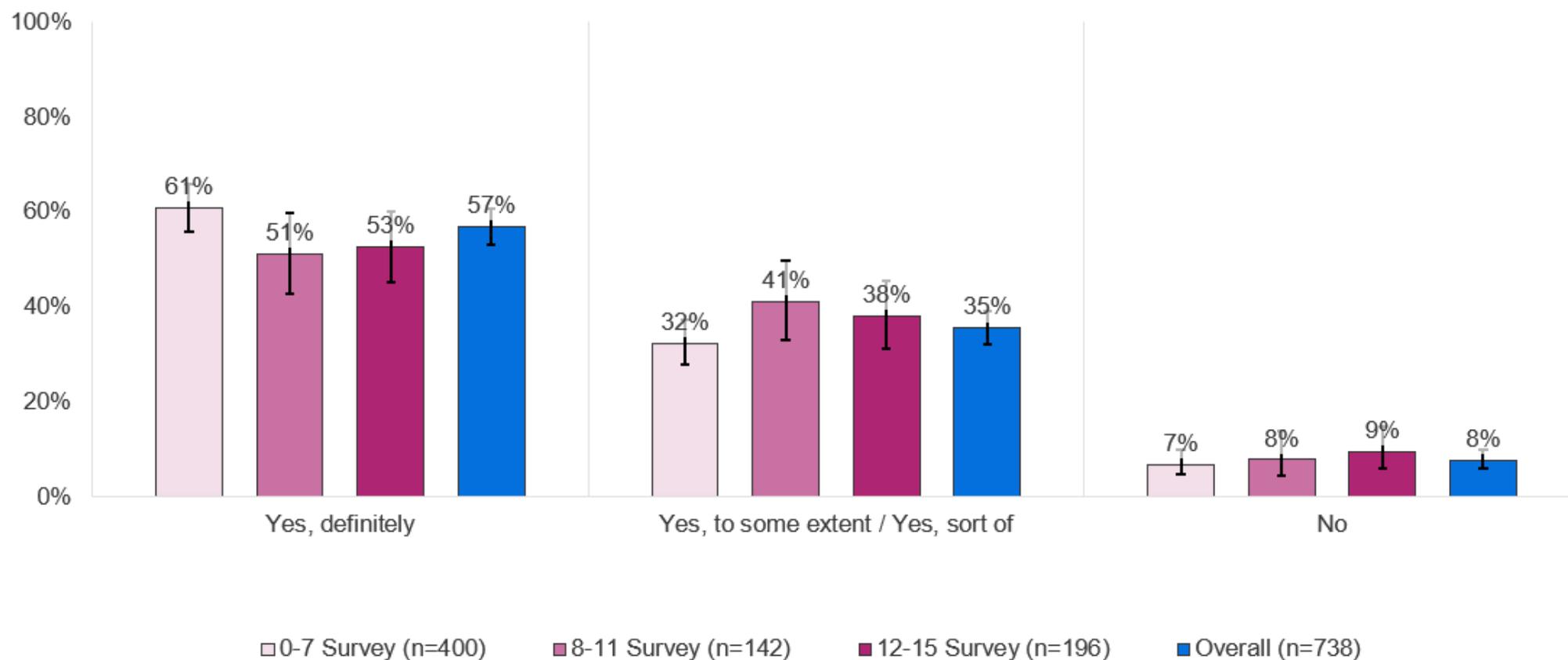


Chart shows question X44: Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2022, and children aged 8-15 who stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 668 (excluding 70 responses of “My child did not have hospital food/ I did not have hospital food”).

Hospital food

38% of parents/carers reported they were definitely able to prepare food in the hospital if they wanted to.

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

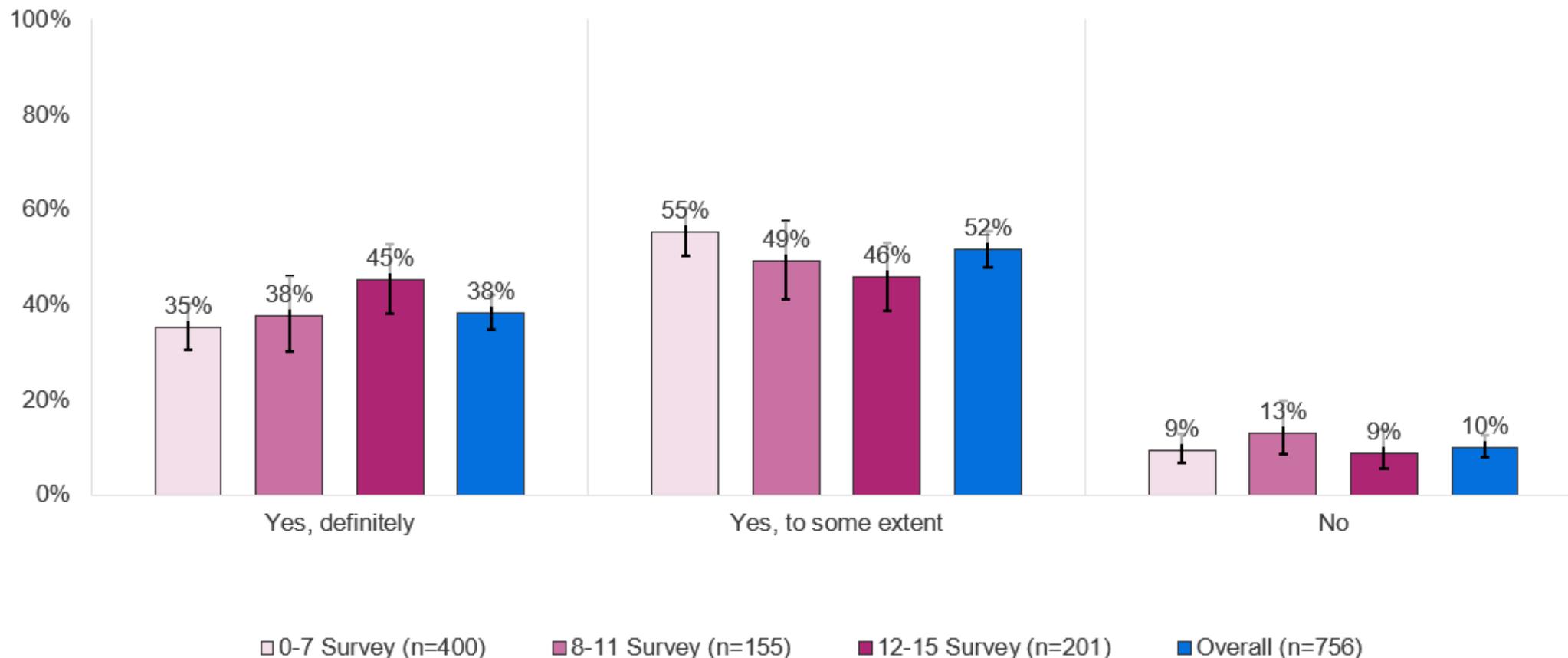
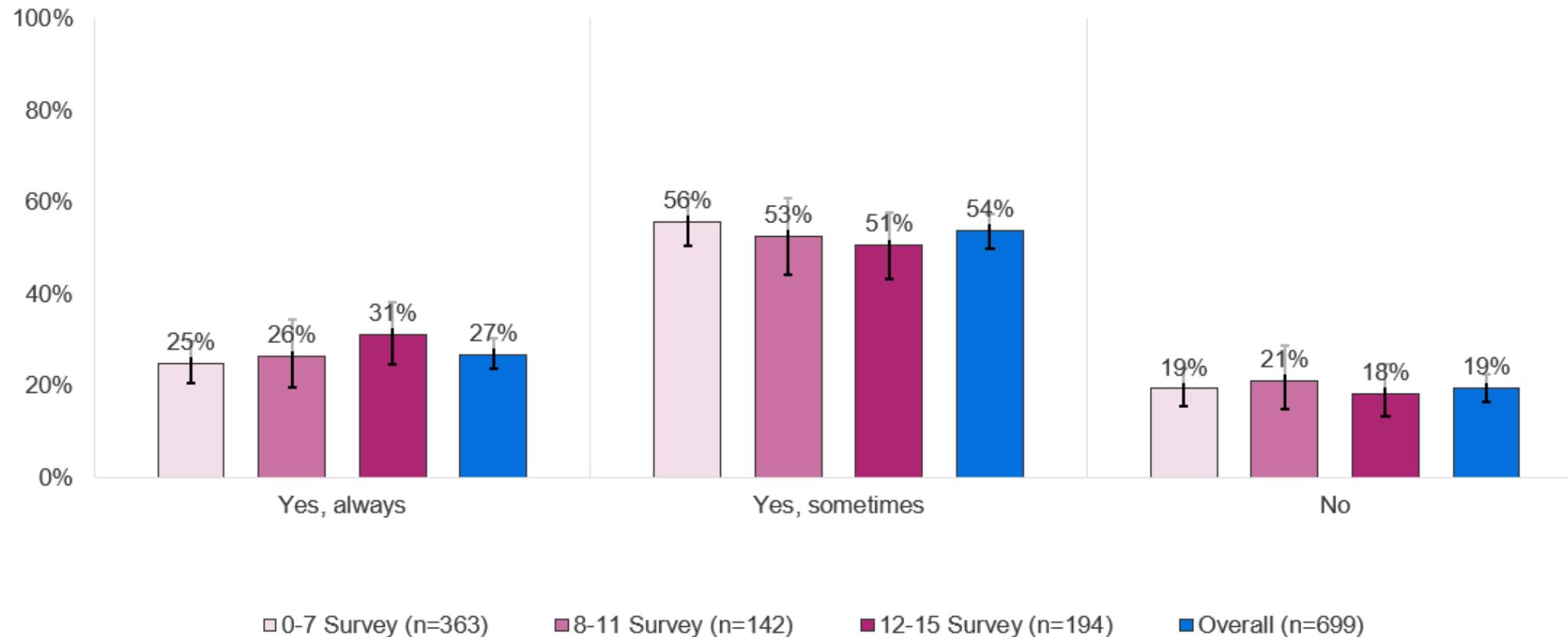


Chart shows question X50: Asked to parents/carers of all age groups whose children stayed in hospital during 2022 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 680 (excluding 76 responses of "I did not want to prepare food").

Hospital environment

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



27% of parents/ carers and children reported that it was always quiet enough for them to sleep in the hospital.

Chart shows question X49: Asked to parents/carers of children aged 0-7 whose children stayed in hospital and who stayed overnight with them during 2022, and children aged 8-15 who stayed in hospital during 2022 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 675 (excluding 24 responses of "I did not need to sleep in the hospital").



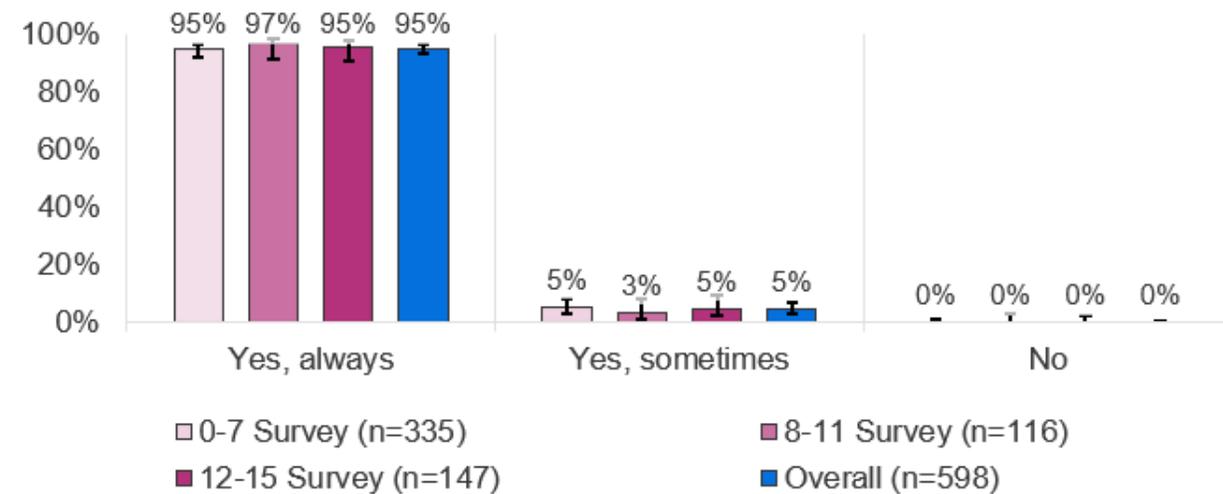
6.5

Care at home or 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?

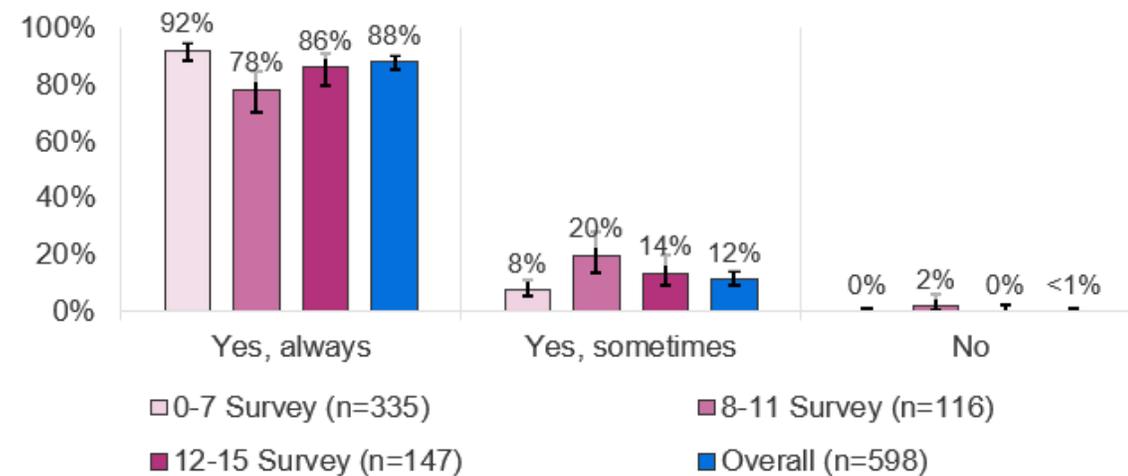


95% of parents/carers and children felt that the nurses who came to their home or school were always friendly.

Chart shows question X54: Asked to parents/carers of children aged 0-7 whose children have been visited at home or school by a nurse during 2022, and children aged 8-15 who were visited at home or school by a nurse during 2022. Total number of responses = 598 (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?



88% 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/ carers of children aged 0-7 whose child was visited at home or school by a nurse during 2022, and children aged 8-15 who were visited at home or school by a nurse during 2022. Total number of responses = 598 (excluding 0 responses of "Don't know/ can't remember").

6.6 Healthcare staff



Bedside manner and trust

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

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

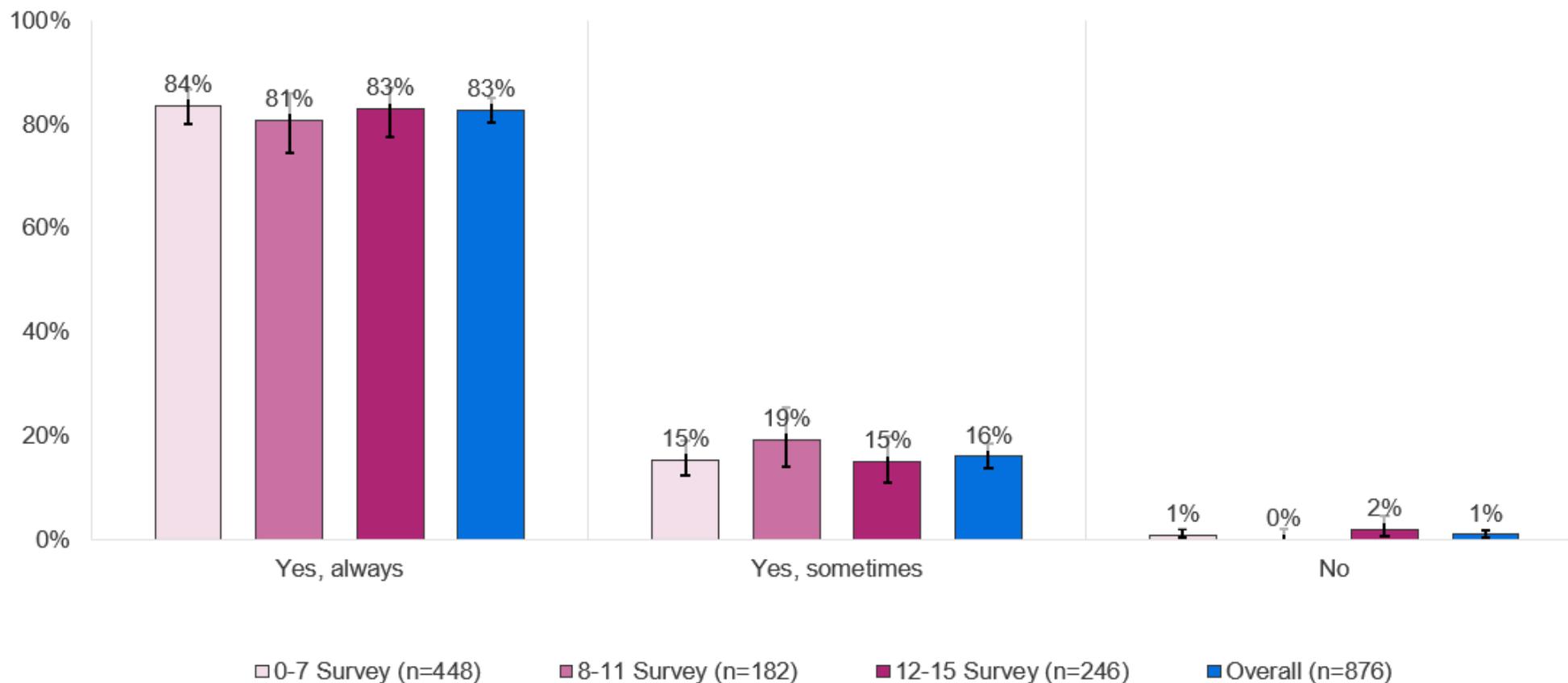
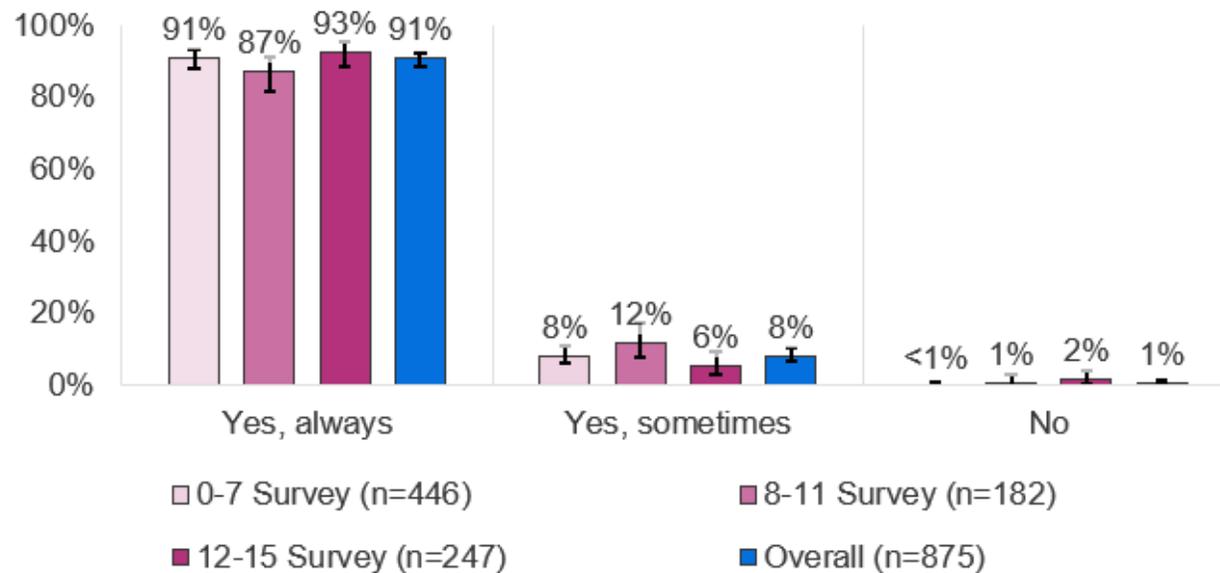


Chart shows question X18: Asked to parents/carers of all age groups. Total number of responses = 876.

Bedside manner and trust

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

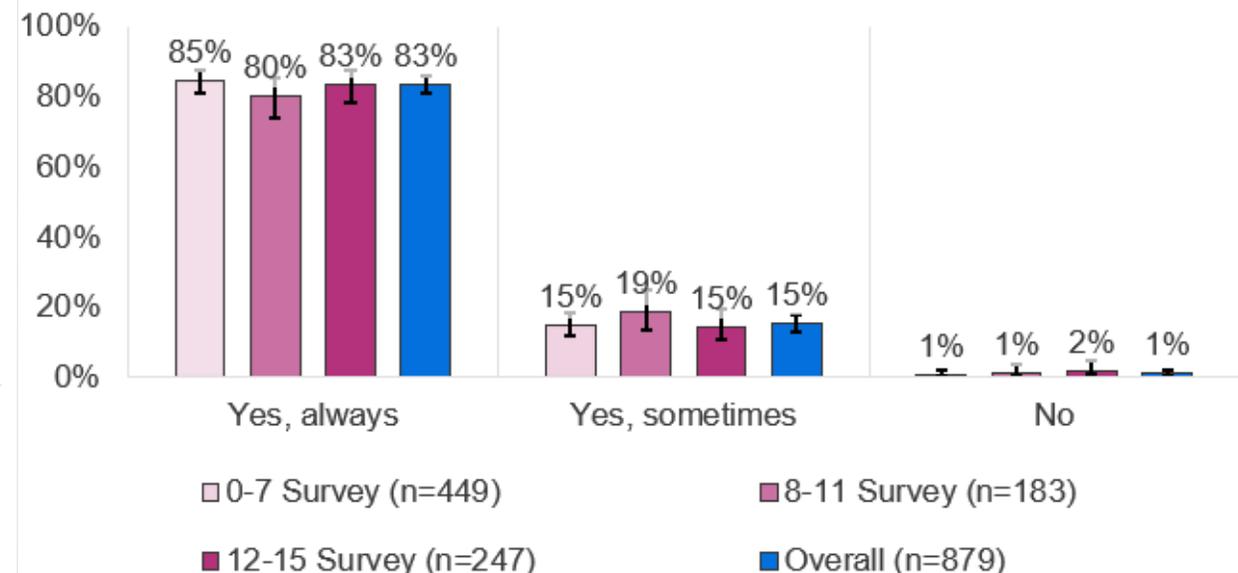


91% of parents/carers felt that they and their child were always treated with respect and dignity by staff.

Chart shows question X17: Asked to parents/carers of all age groups. Total number of responses = 875.

Bedside manner and trust

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

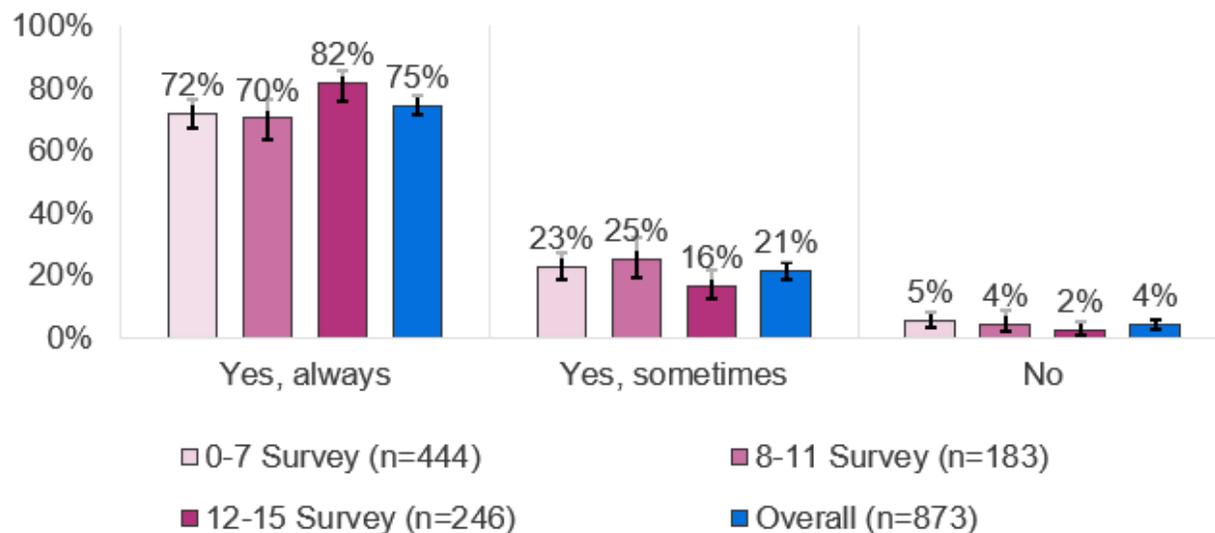


83% of parents/carers felt that they were always treated with empathy and understanding by staff caring for their child.

Chart shows question X19: Asked to parents/carers of all age groups. Total number of responses = 879.

Bedside manner and trust

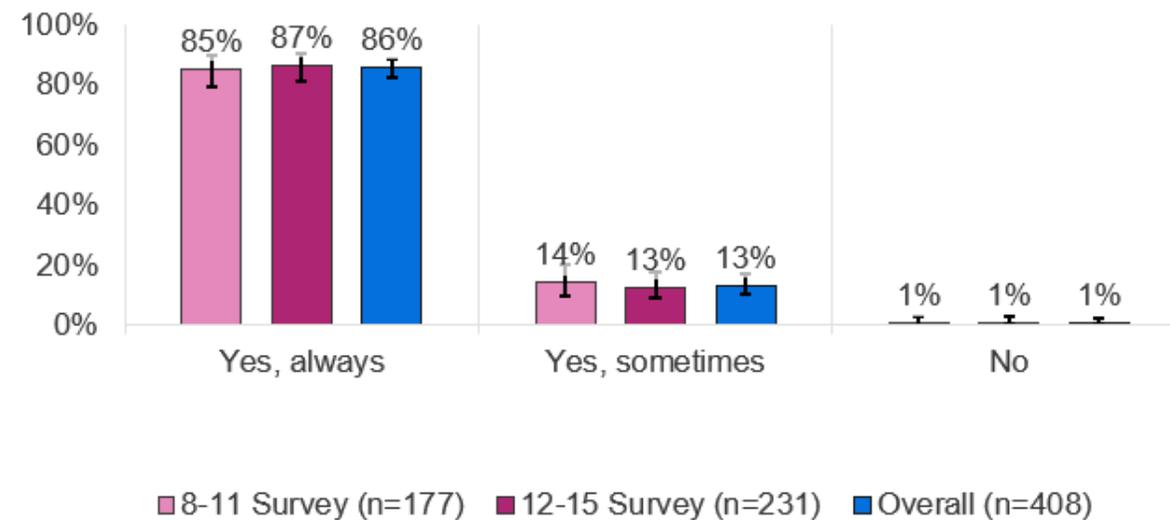
Are staff sensitive to the information they share with you when your child is in the room?



75% of parents/carers felt that staff were always sensitive to information shared with them when their child was in the room.

Bedside manner and trust

Do you feel that staff are friendly?



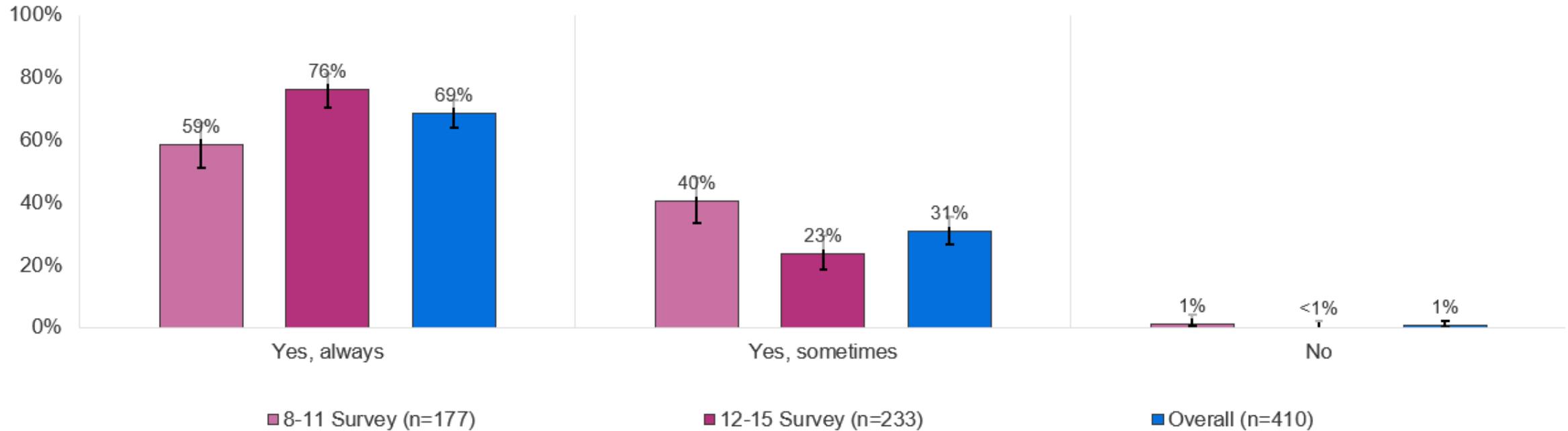
86% of children felt that staff were always friendly.

Chart shows question X21: Asked to parents/carers of all age groups. Total responses = 785 (excluding 88 responses of "This is not needed").

Chart shows question X12: Asked to all children aged 8-15. Total number of responses = 408.

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?

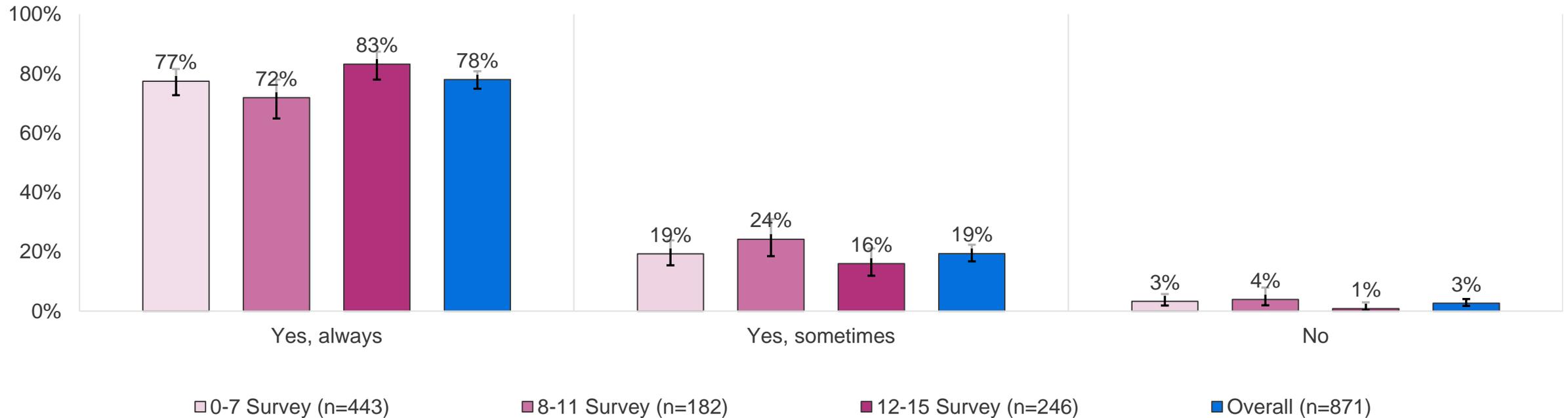


69% of children reported that they could always understand what staff were saying.

Chart shows question X13: Asked to all children aged 8-15. Total responses = 407 (excluding 3 responses of “Don’t know / can’t remember”).

Communication

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



78% of parents/carers felt that healthcare staff always shared information with children in a way that was appropriate.

Chart shows question X22: Asked to parents/carers of all age groups. Total responses = 759 (excluding 112 responses of “This is not needed”).

Communication



59% 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/carers of 0-7s and children aged 8-15. Total number of responses = 858.

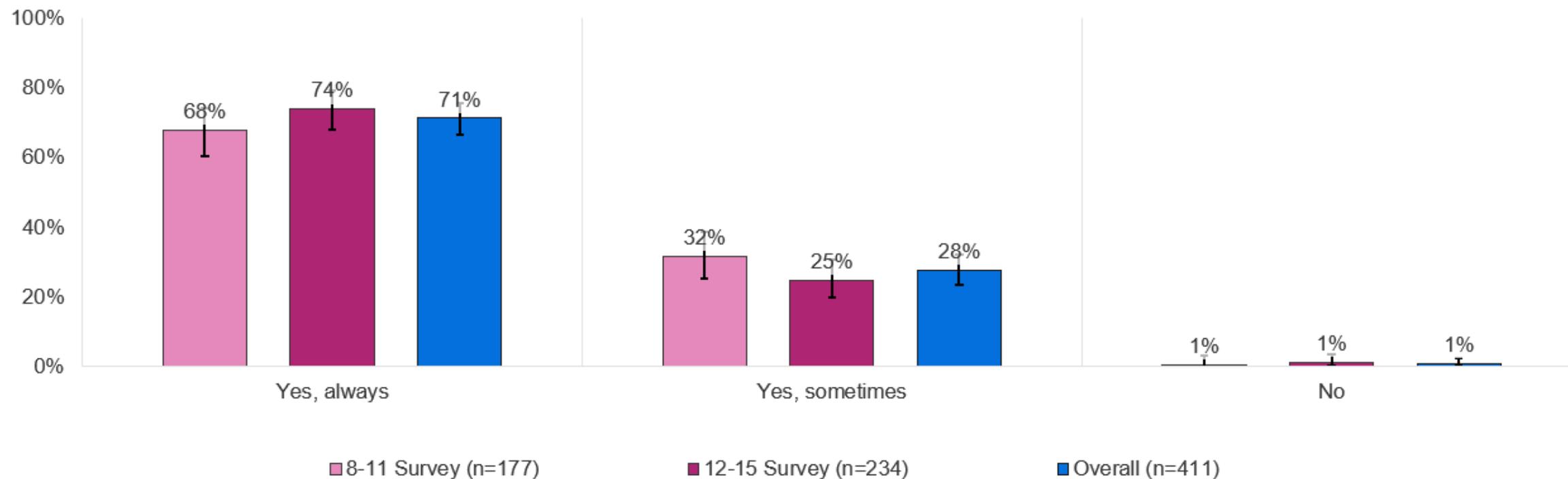


87% of parents/carers reported that they definitely had the chance to ask staff questions about their child's care and treatment.

Question X16: Asked to parents/carers of all age groups. Total number of responses = 868 (excluding 6 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.

Chart shows question X14: Asked to all children aged 8-15. Total number of responses = 411.

Support for parents/carers

The percent of parents/ carers reporting being given information about a psychologist or counsellor ranged from 52% in the 8-11 survey to 67% in the 12-15 survey.

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

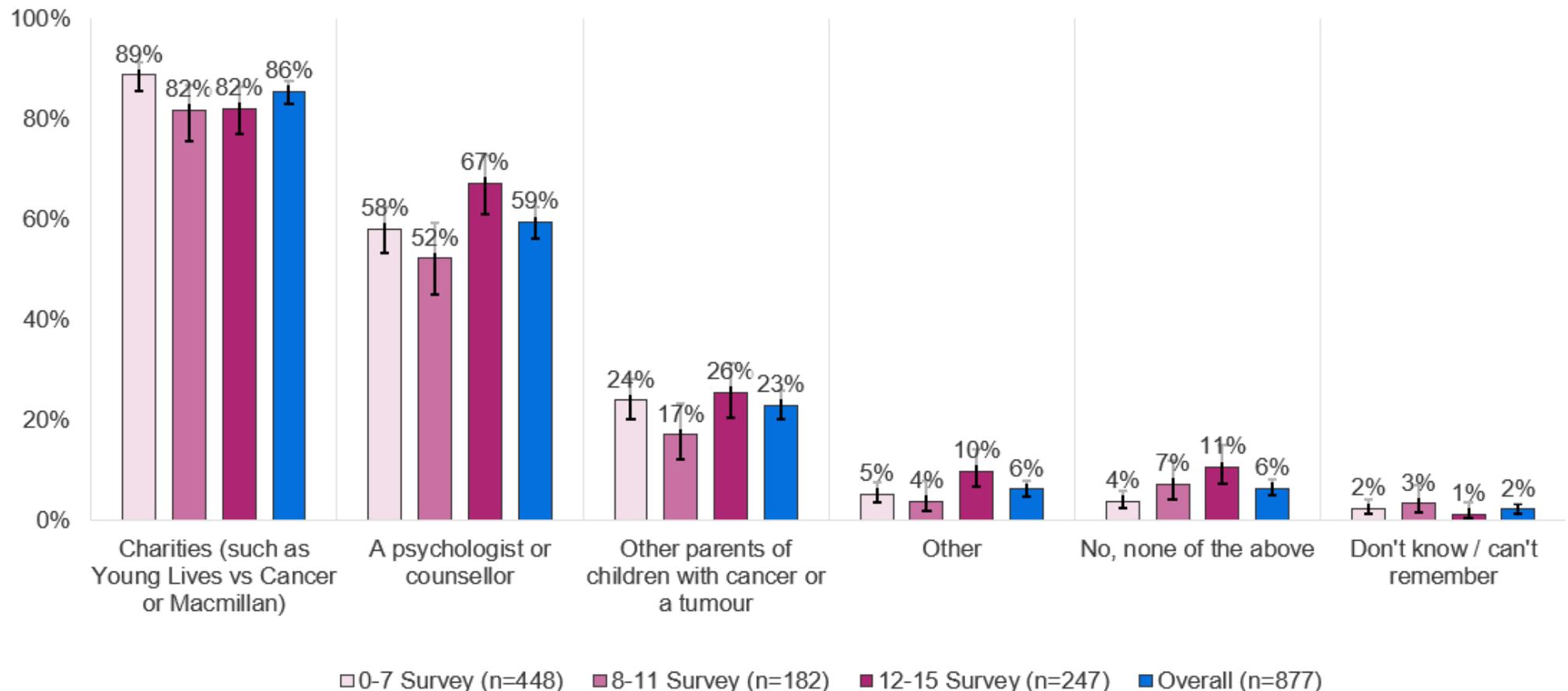


Chart shows question X24: Asked to parents/carers of all age groups. Total number of responses = 877.

Support (Children aged 8-15)

The percent of children reporting being given information about a psychologist or counsellor ranged from 42% in the 8-11 survey to 63% in the 12-15 survey.

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

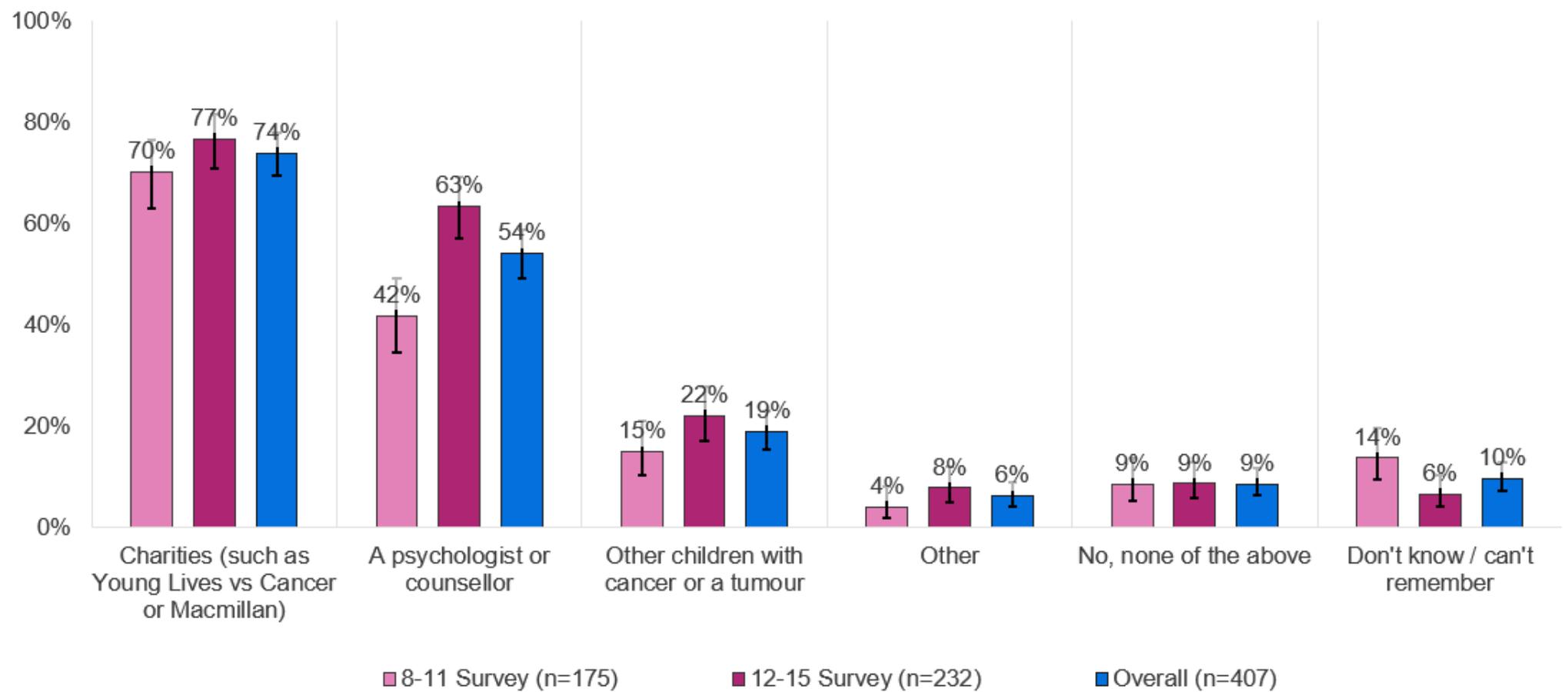


Chart shows question X23: Asked to all children aged 8-15. Total number of responses = 407.



7. Year on year comparisons





This section presents 2022 scores alongside 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 [survey website](#).



The charts present both 2021 and 2022 scores, where comparable. The coloured bars indicate the score, and black bars 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).



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

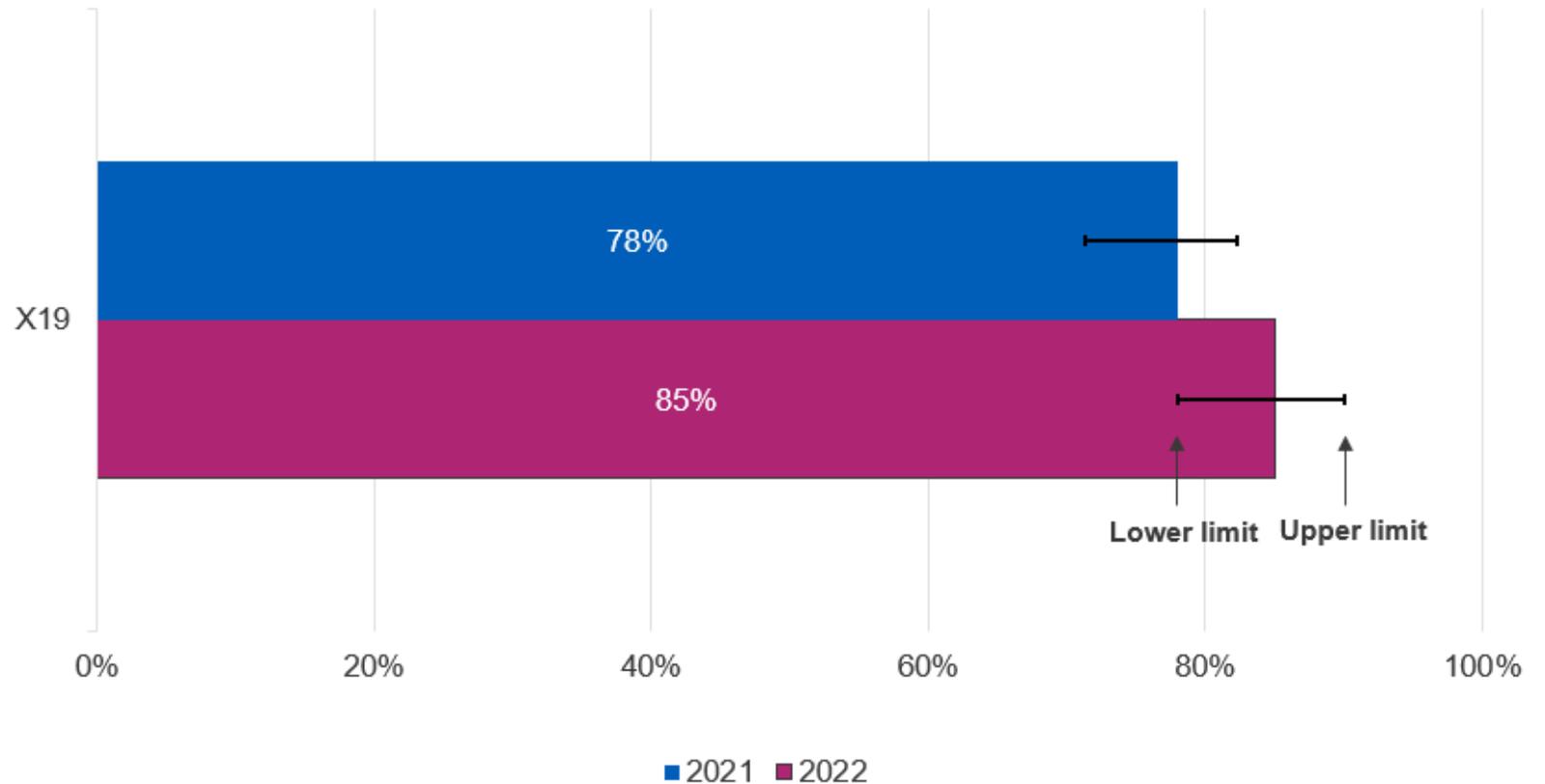
In this example, the score for X19 was **85%**, compared with **78% in 2021**. However, the confidence intervals provide us with a bigger picture.

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

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

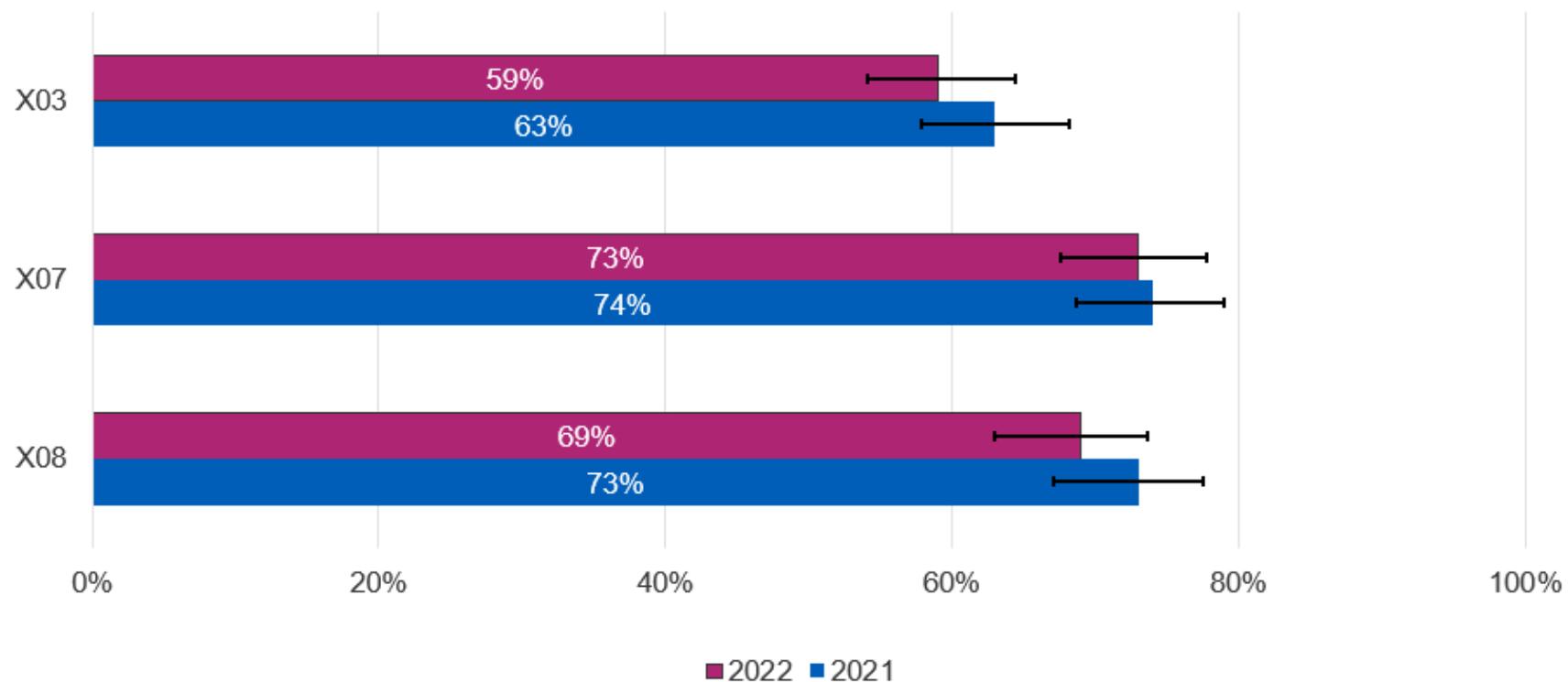
In this example, the confidence intervals overlap, indicating that although the overall score is higher than 2021, there is not enough statistical evidence to conclude whether or not there is a “true” difference between the two.

Example data only:



Finding out about the cancer or tumour

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 331, for 2022 = 345.

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

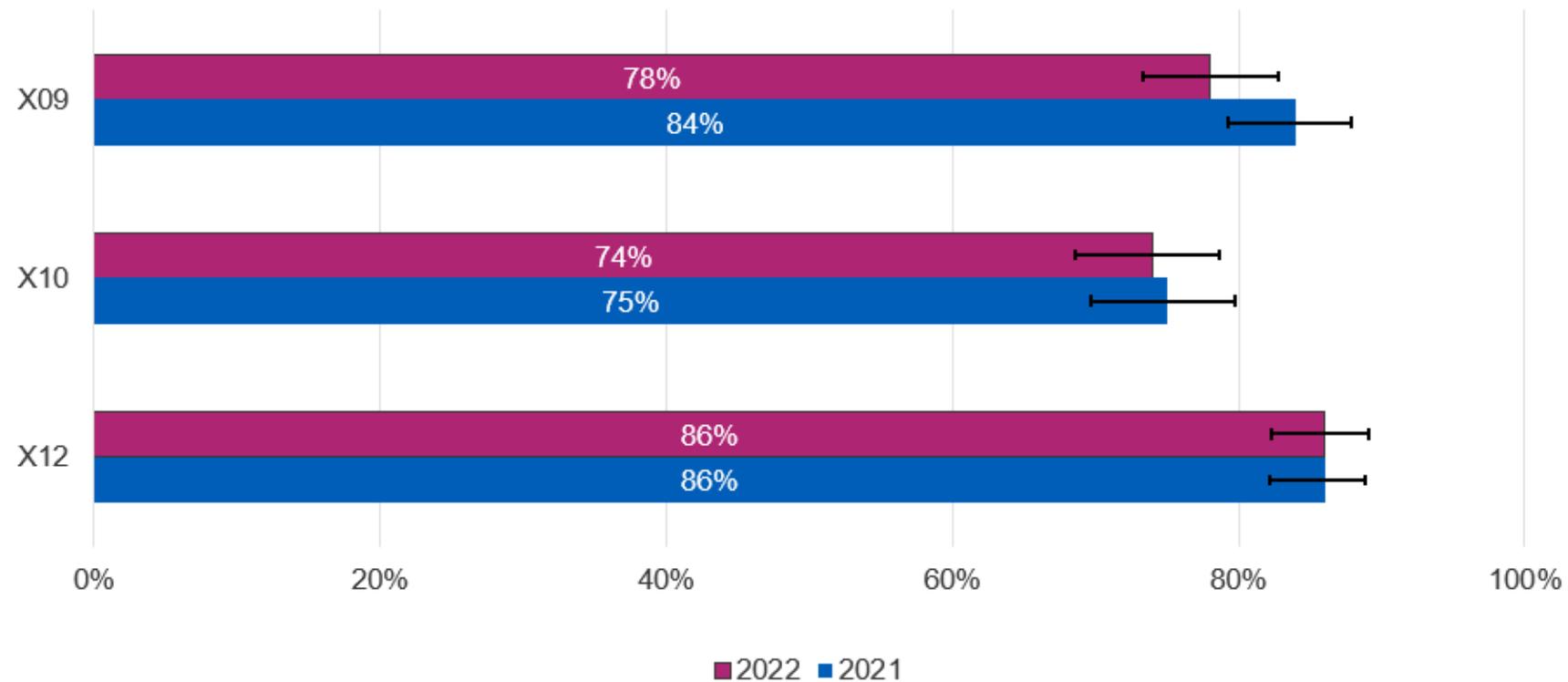
Total number of responses for 2021 = 275, for 2022 = 289.

X08: Parents/carers and children reported that information at diagnosis was definitely given in a way they could understand. Asked to parents/carers of 0-7s who were told about their child's cancer or a tumour, and children aged 8-15 who were told they had cancer or a tumour.

Total number of responses for 2021 = 278, for 2022 = 289.

Finding out about the cancer or tumour

Year on year score comparisons between 2021 and 2022



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/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 for 2021 = 276, for 2022 = 288.

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

Total number of responses for 2021 = 281, for 2022 = 291.

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

Total number of responses for 2021 = 417, for 2022 = 408.

Healthcare staff

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

Total number of responses for 2021 = 417, for 2022 = 407.

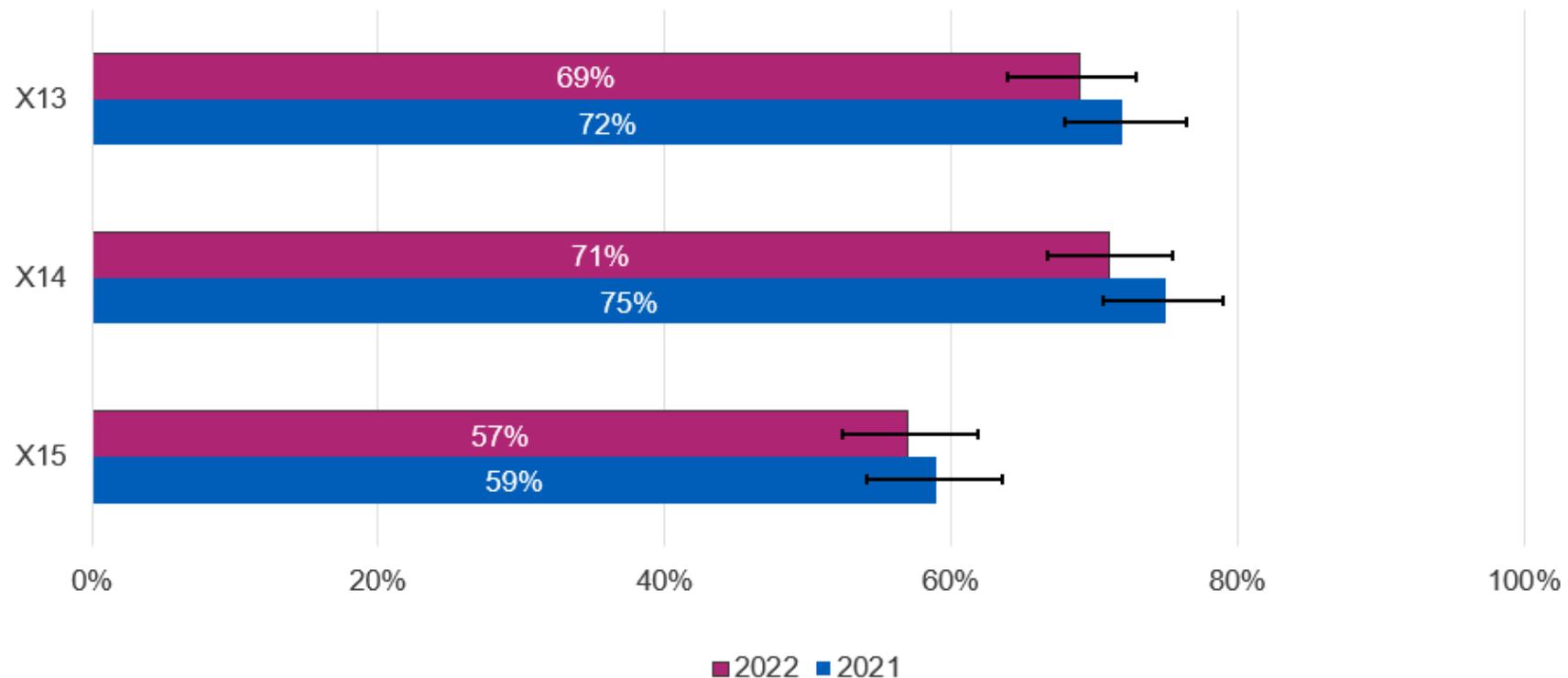
X14: Children felt that staff always talked to them, not just their parent or carer. Asked to all children aged 8-15.

Total number of responses for 2021 = 413, for 2022 = 411.

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

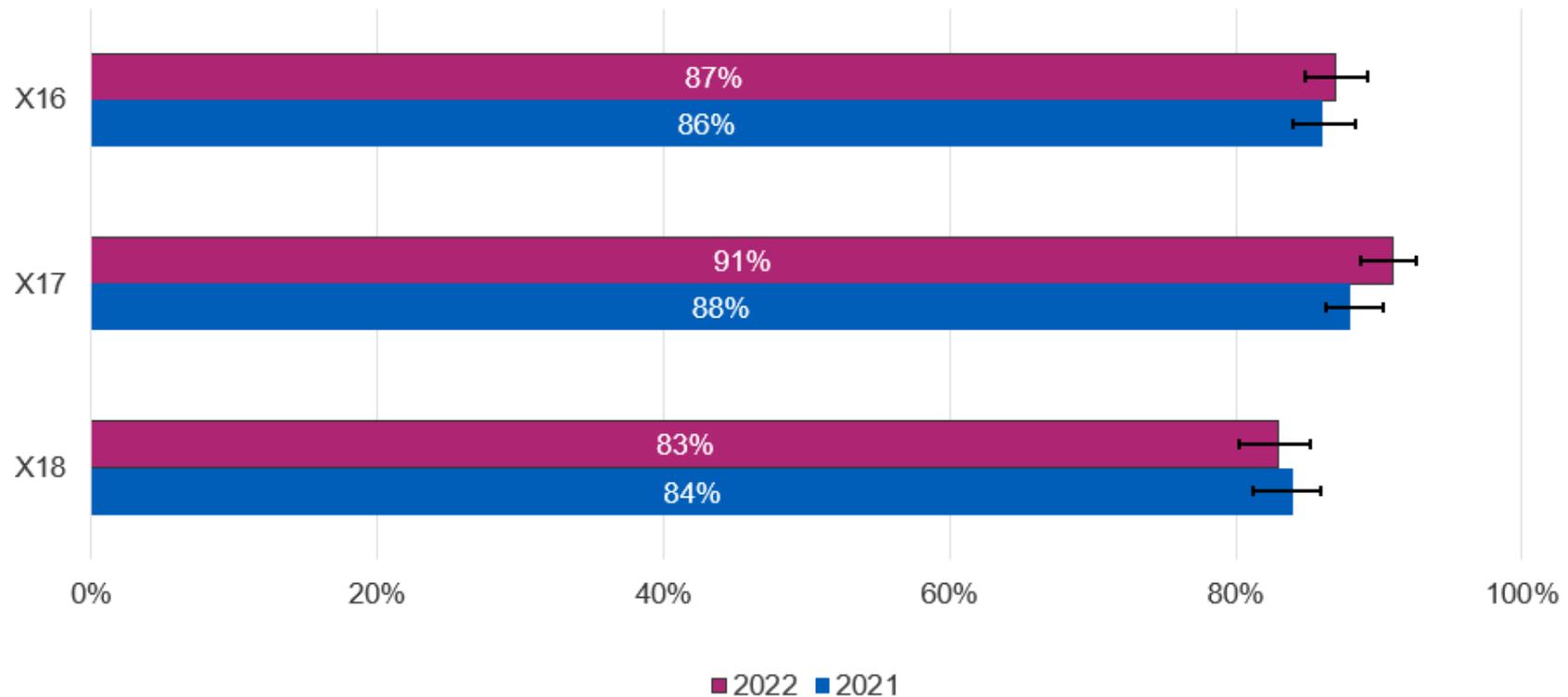
Total number of responses for 2021 = 412, for 2022 = 409.

Year on year score comparisons between 2021 and 2022



Healthcare staff

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 935, for 2022 = 868.

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

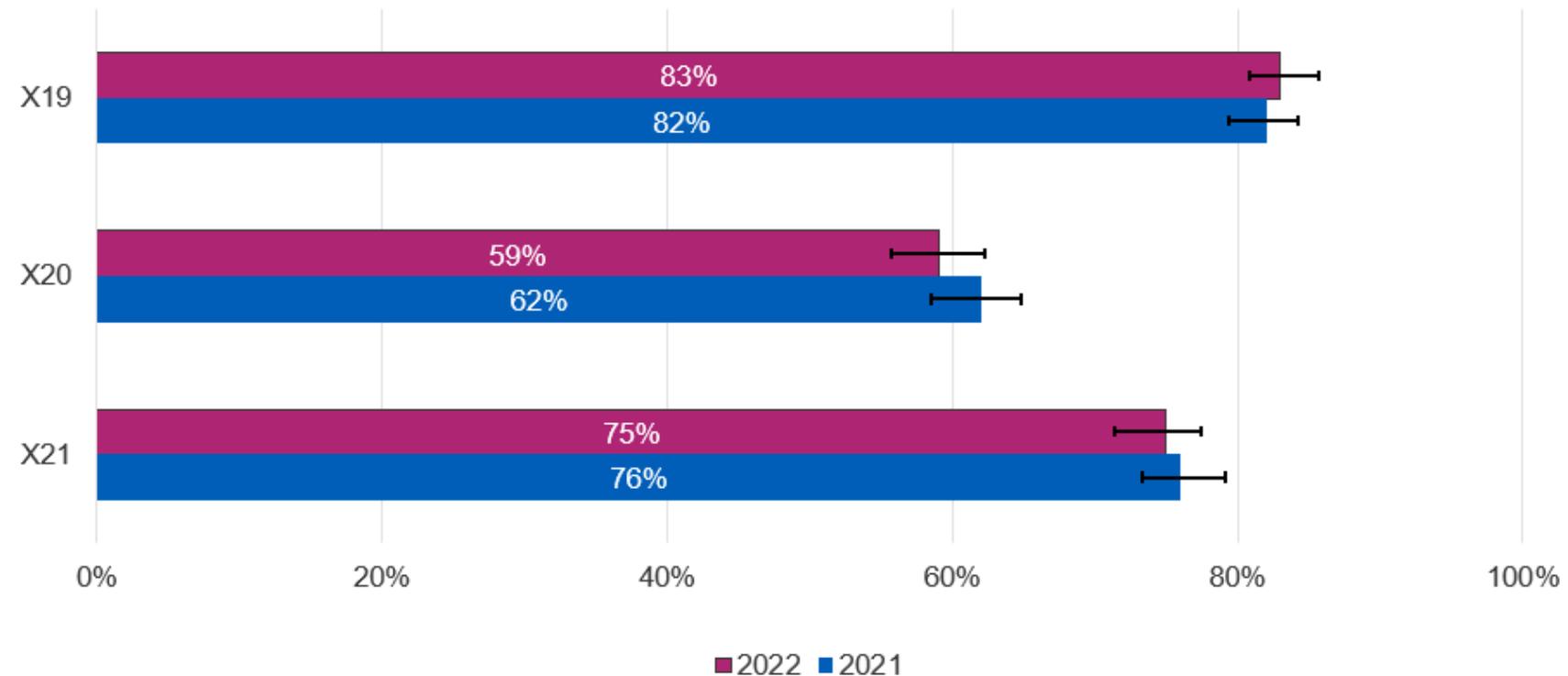
Total number of responses for 2021 = 937, for 2022 = 875.

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

Total number of responses for 2021 = 938, for 2022 = 876.

Healthcare staff

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 936, for 2022 = 879.

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

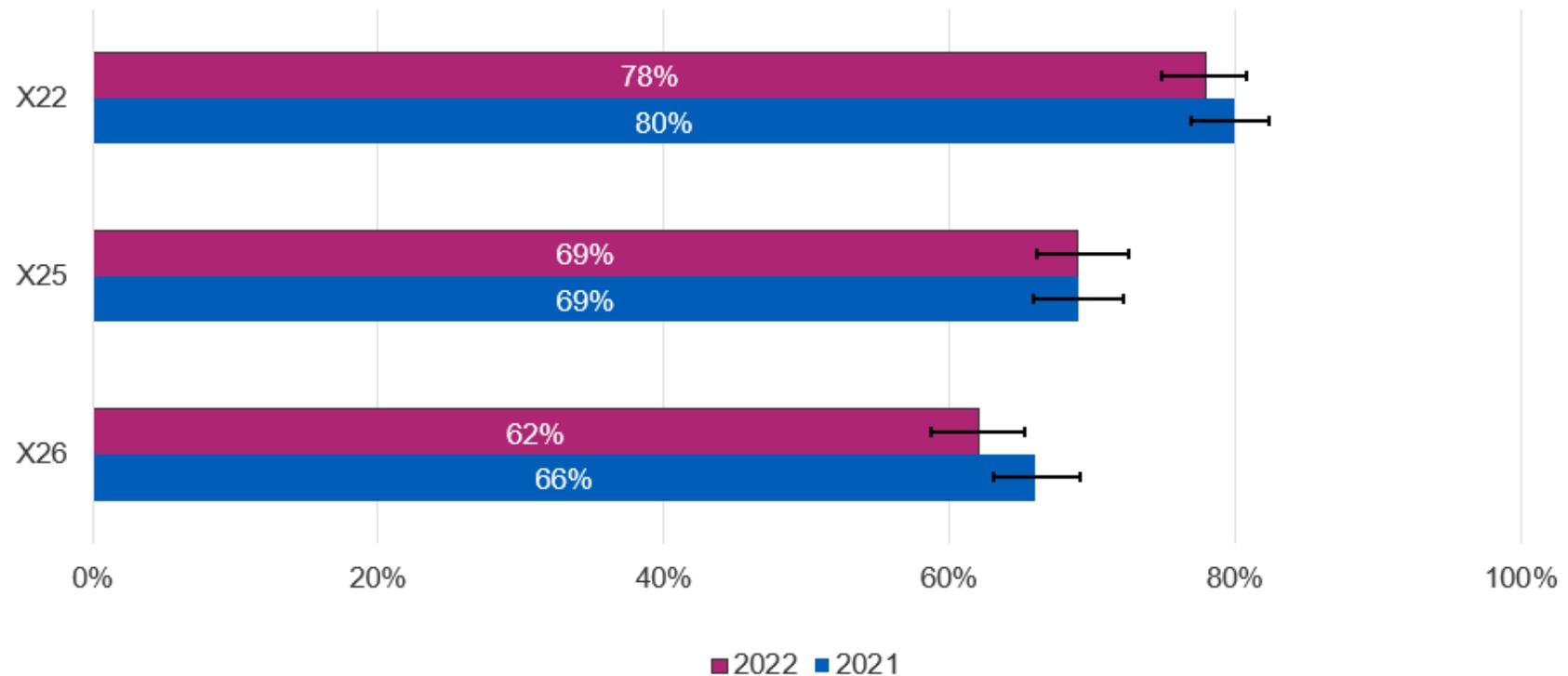
Total number of responses for 2021 = 932, for 2022 = 858.

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

Total number of responses for 2021 = 836, for 2022 = 785.

Healthcare staff & Child's care and treatment

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 816, for 2022 = 759.

X25: Parents/carers felt they had enough information about financial help or benefits. Asked to parents/carers of all age groups.

Total number of responses for 2021 = 832, for 2022 = 779.

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

Total number of responses for 2021 = 905, for 2022 = 853.

Child's care and treatment

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

Total number of responses for 2021 = 899, for 2022 = 837.

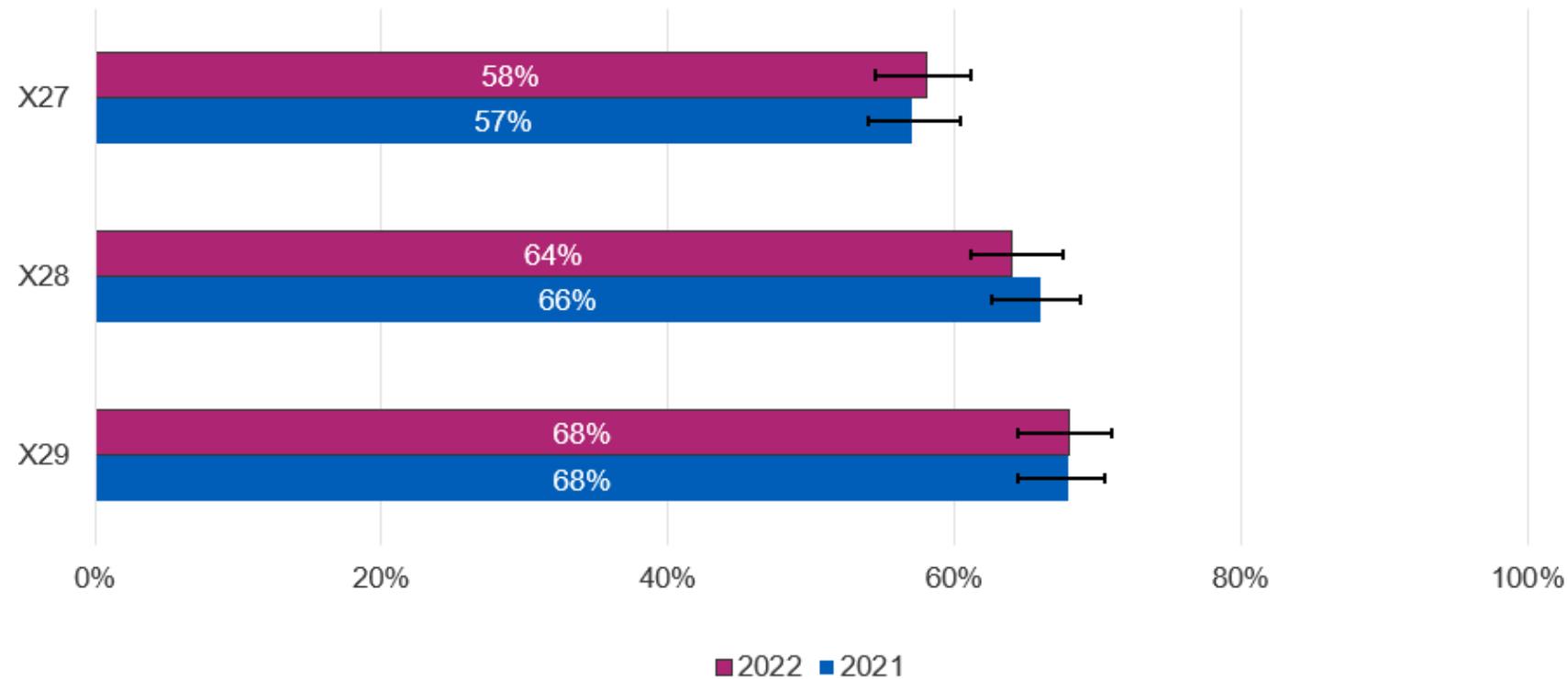
X28: Parents/carers and children felt they always knew what was happening with their child's/ their care. Asked to parents/carers of 0-7s and all children aged 8-15.

Total number of responses for 2021 = 920, for 2022 = 847.

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

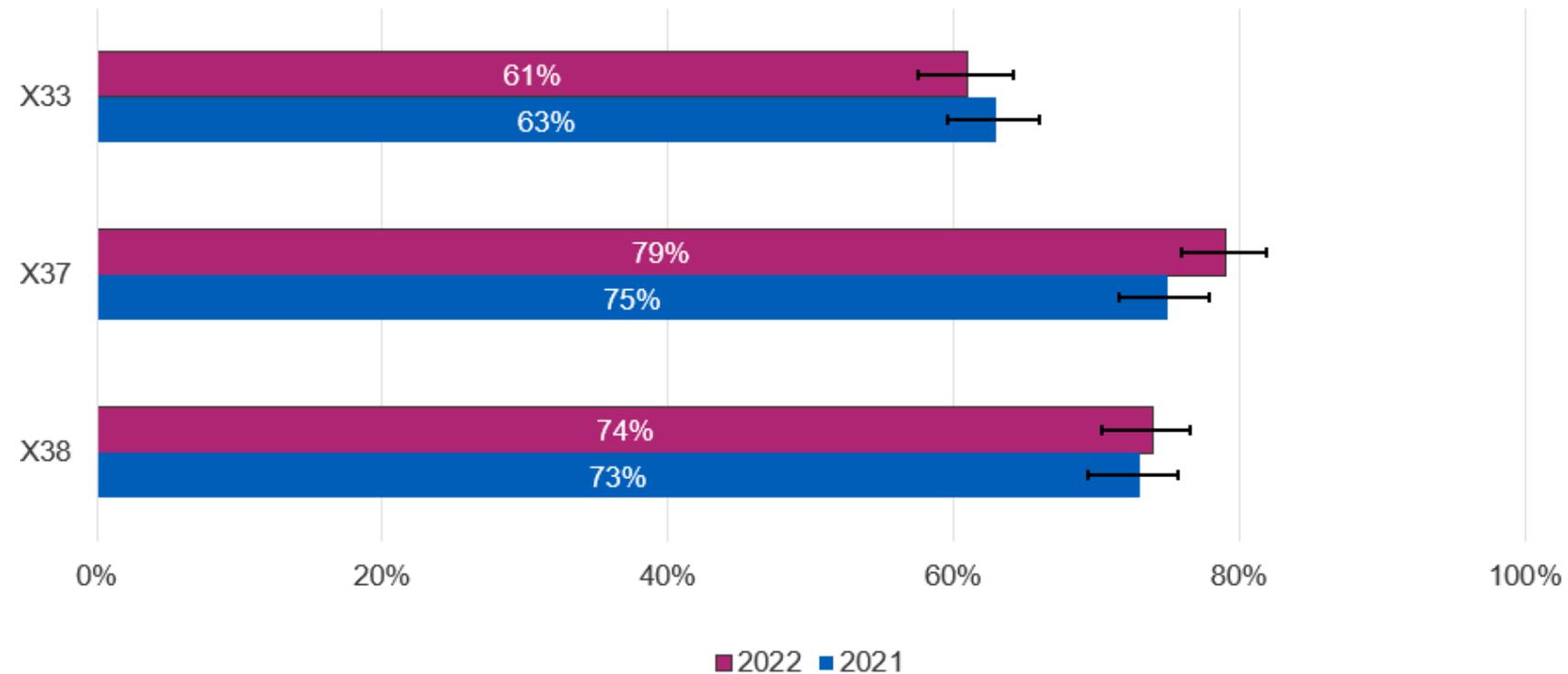
Total number of responses for 2021 = 881, for 2022 = 804.

Year on year score comparisons between 2021 and 2022



Child's care and treatment

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 870, for 2022 = 823.

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

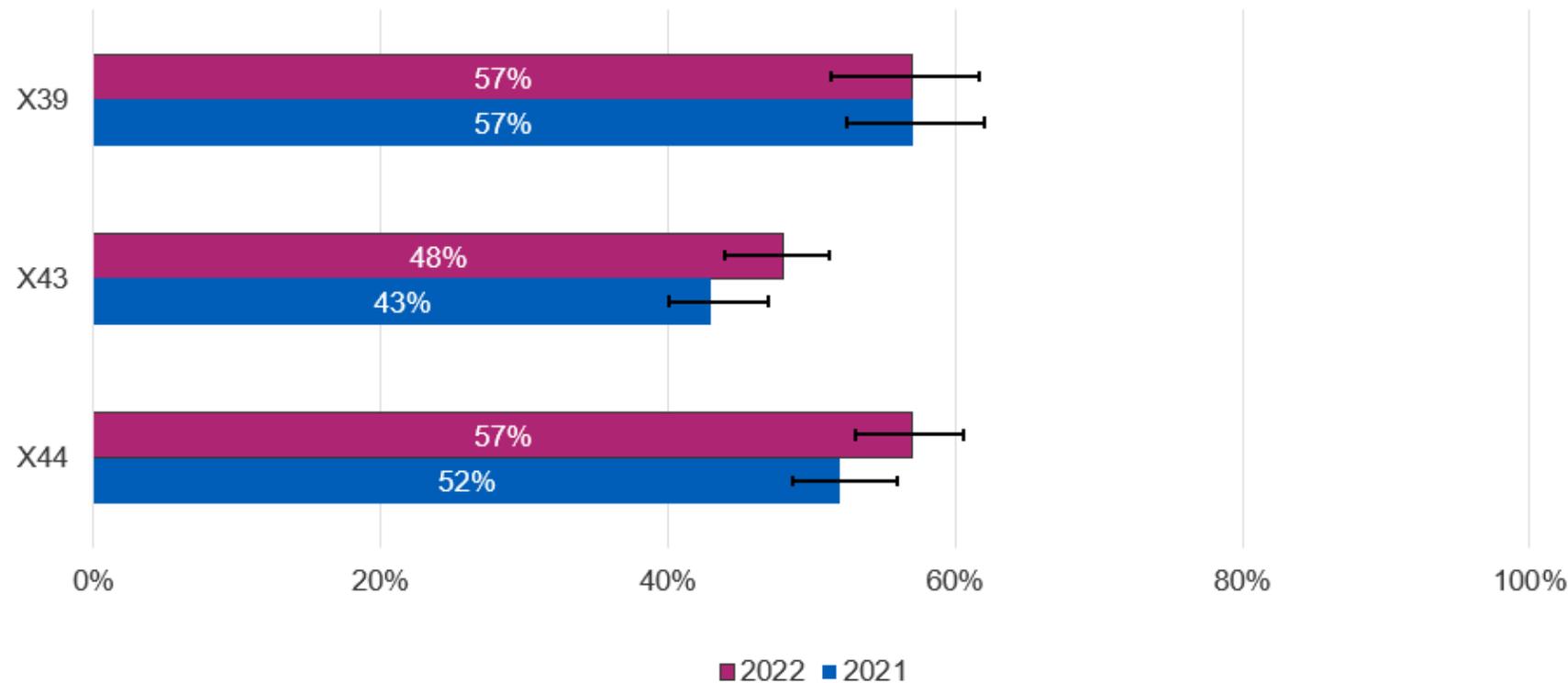
Total number of responses for 2021 = 727, for 2022 = 708.

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

Total number of responses for 2021 = 783, for 2022 = 768.

Child's care and treatment & Care in hospital

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 403, for 2022 = 348.

X43: Parents/carers and children felt that there were definitely enough things for their child to do in the hospital. Asked to parents/carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay).

Total number of responses for 2021 = 780, for 2022 = 725.

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

Total number of responses for 2021 = 728, for 2022 = 668.

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/carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime or for an overnight stay).

Total number of responses for 2021 = 644, for 2022 = 589.

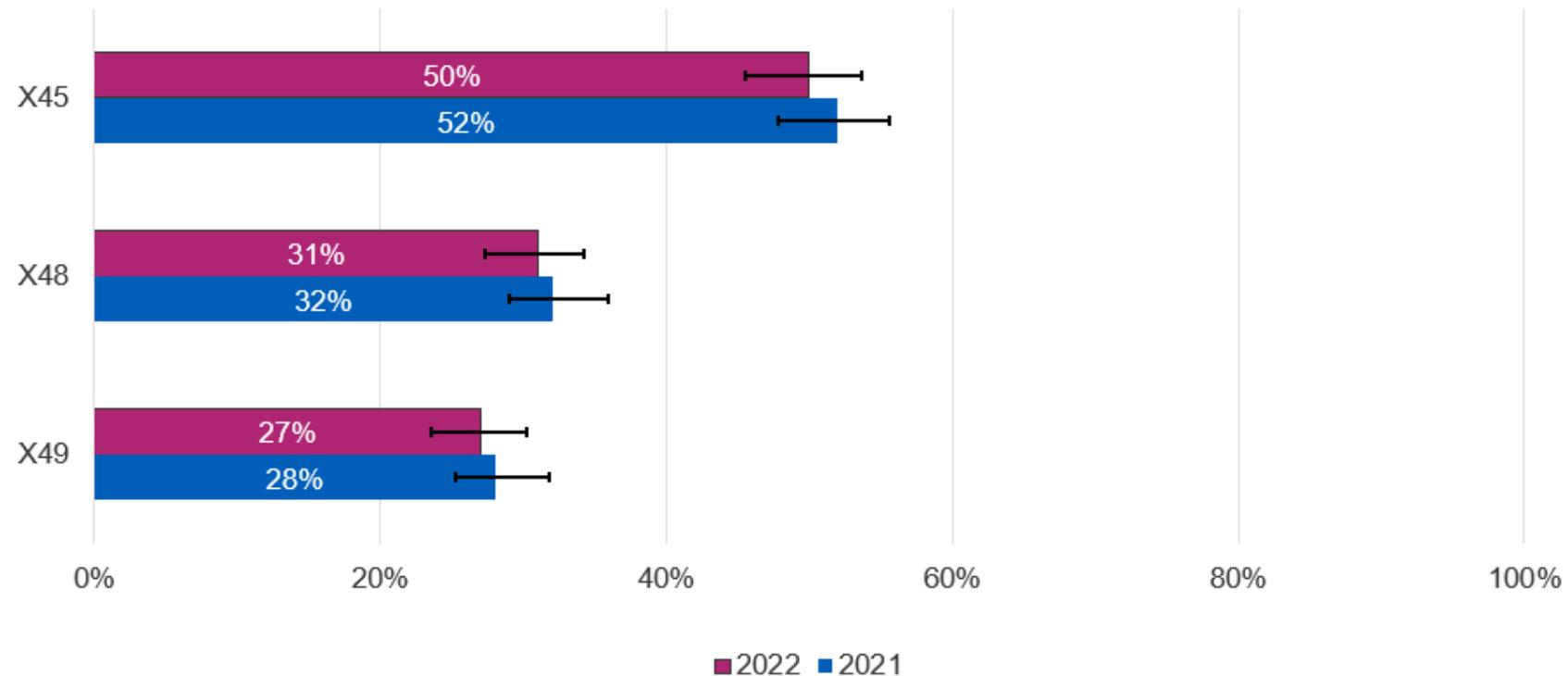
X48: Parents/carers reported that facilities for them to stay overnight were very good. Asked to parents/carers of all age groups whose children stayed in hospital and who stayed overnight with them (receiving treatment or care in the daytime, or for an overnight stay).

Total number of responses for 2021 = 695, for 2022 = 668.

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

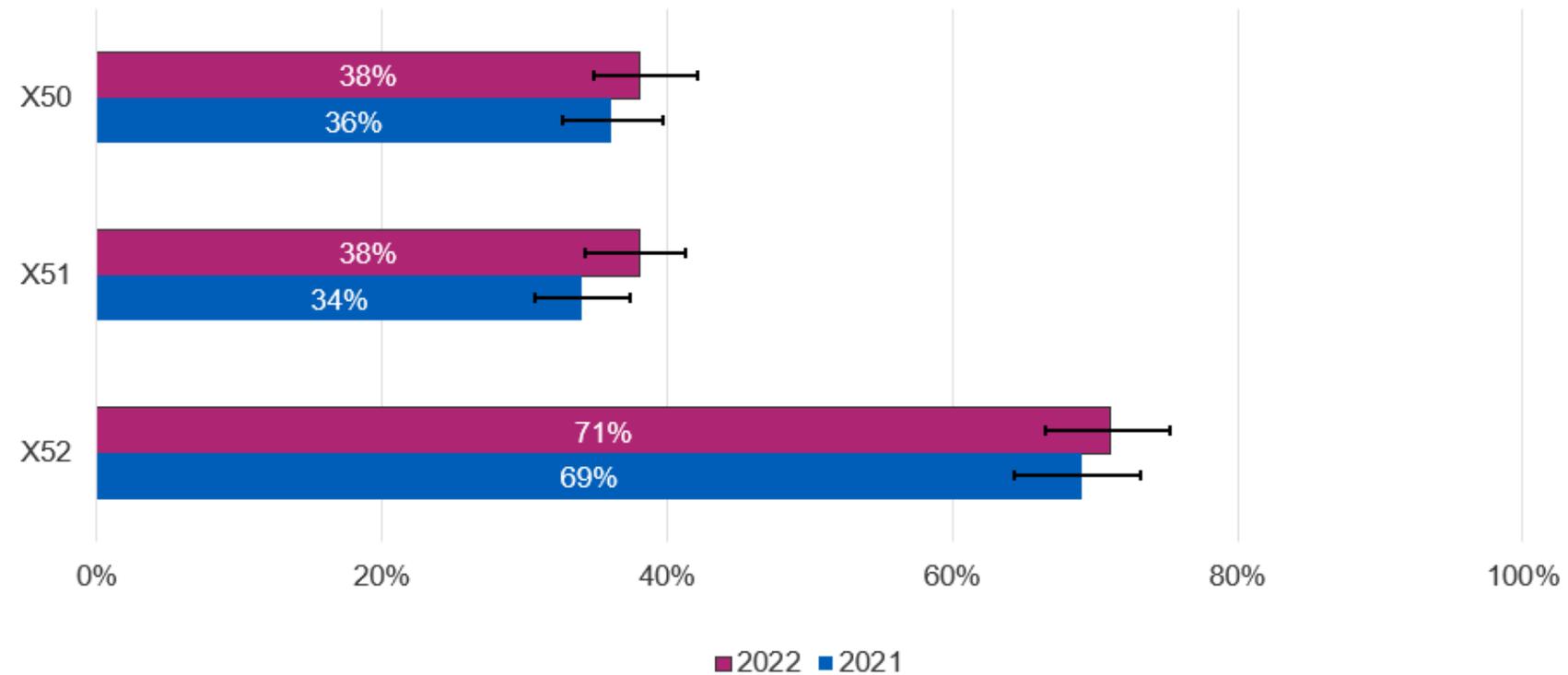
Total number of responses for 2021 = 719, for 2022 = 675.

Year on year score comparisons between 2021 and 2022



Care in hospital

Year on year score comparisons between 2021 and 2022



X50: Parents/carers reported they were definitely able to prepare food in the hospital if they wanted to. Asked to parents/carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay).

Total number of responses for 2021 = 707, for 2022 = 680.

X51: Parents/carers felt that the hospital Wi-Fi always met the needs of them and their child. Asked to parents/carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay).

Total number of responses for 2021 = 777, for 2022 = 732.

X52: Parents/carers reported that their child had access to hospital school services during their stay in hospital. Asked to parents/carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay).

Total number of responses for 2021 = 412, for 2022 = 411.

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/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 for 2021 = 602, for 2022 = 598.

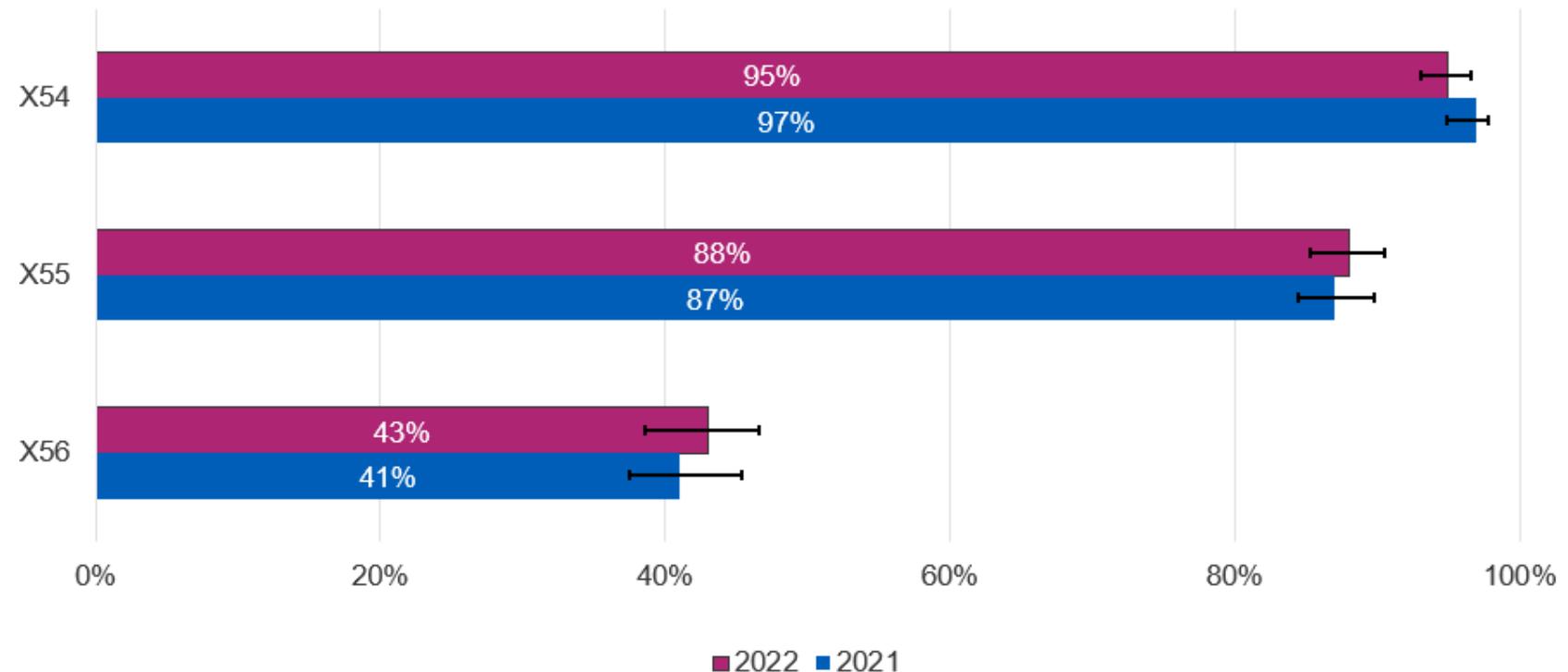
X55: Parents/carers and children reported that they always understood what nurses visiting their home or school were saying. Asked to parents/ carers of children aged 0-7 whose child was visited at home or school by a nurse , and children aged 8-15 who were visited at home or school by a nurse.

Total number of responses for 2021 = 602, for 2022 = 598.

X56: Parents/carers and children reported that the same nurses always came to their home or school. Asked to parents/carers of children aged 0-7 whose child was visited at home or school by a nurse, and children aged 8-15 who were visited at home or school by a nurse.

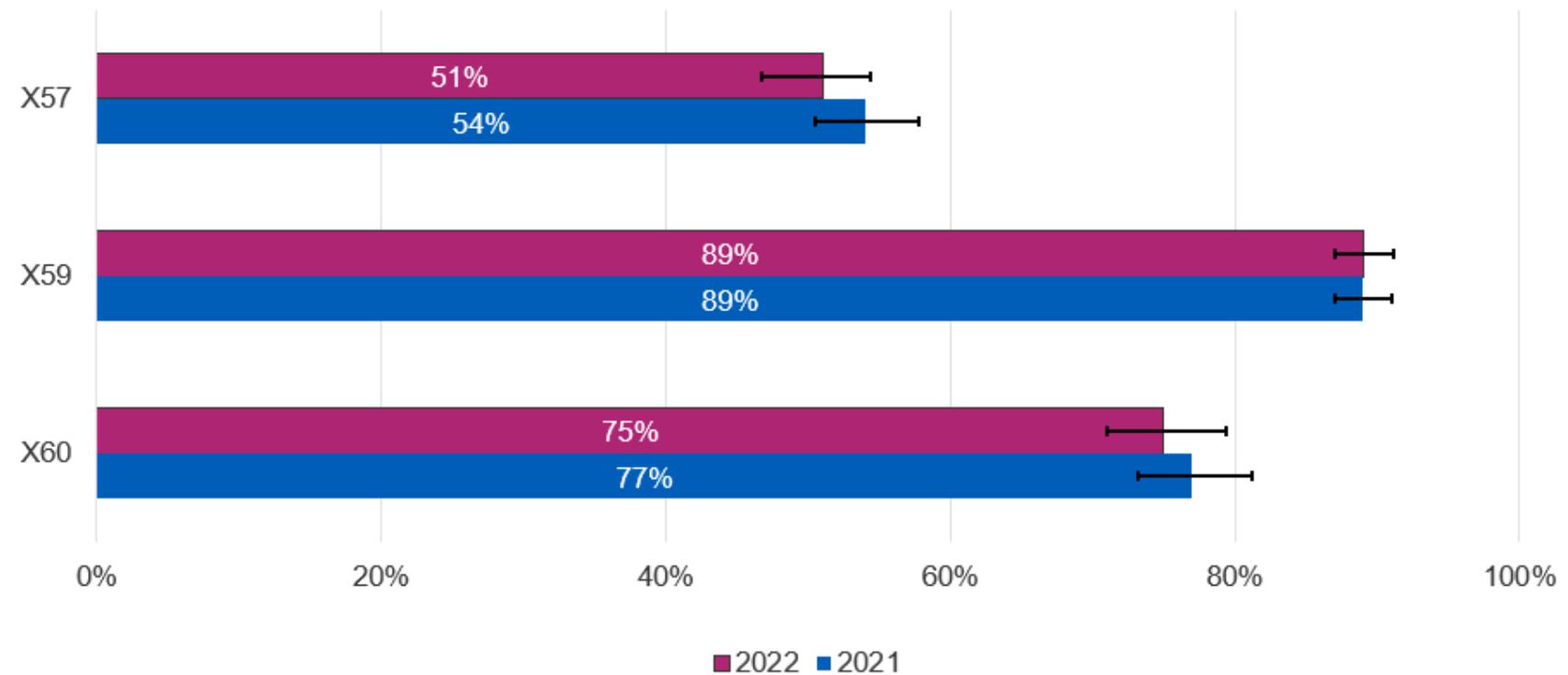
Total number of responses for 2021 = 587, for 2022 = 578.

Year on year score comparisons between 2021 and 2022



Overall care

Year on year score comparisons between 2021 and 2022



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

Total number of responses for 2021 = 711, for 2022 = 653.

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

Total number of responses for 2021 = 922, for 2022 = 855.

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

Total number of responses for 2021 = 416, for 2022 = 411.



8. Further information





For more information on the Under 16 Cancer Patient Experience Survey, visit [the survey website](#).



If you have any questions about the survey, please do not hesitate to get in touch [via email](#).

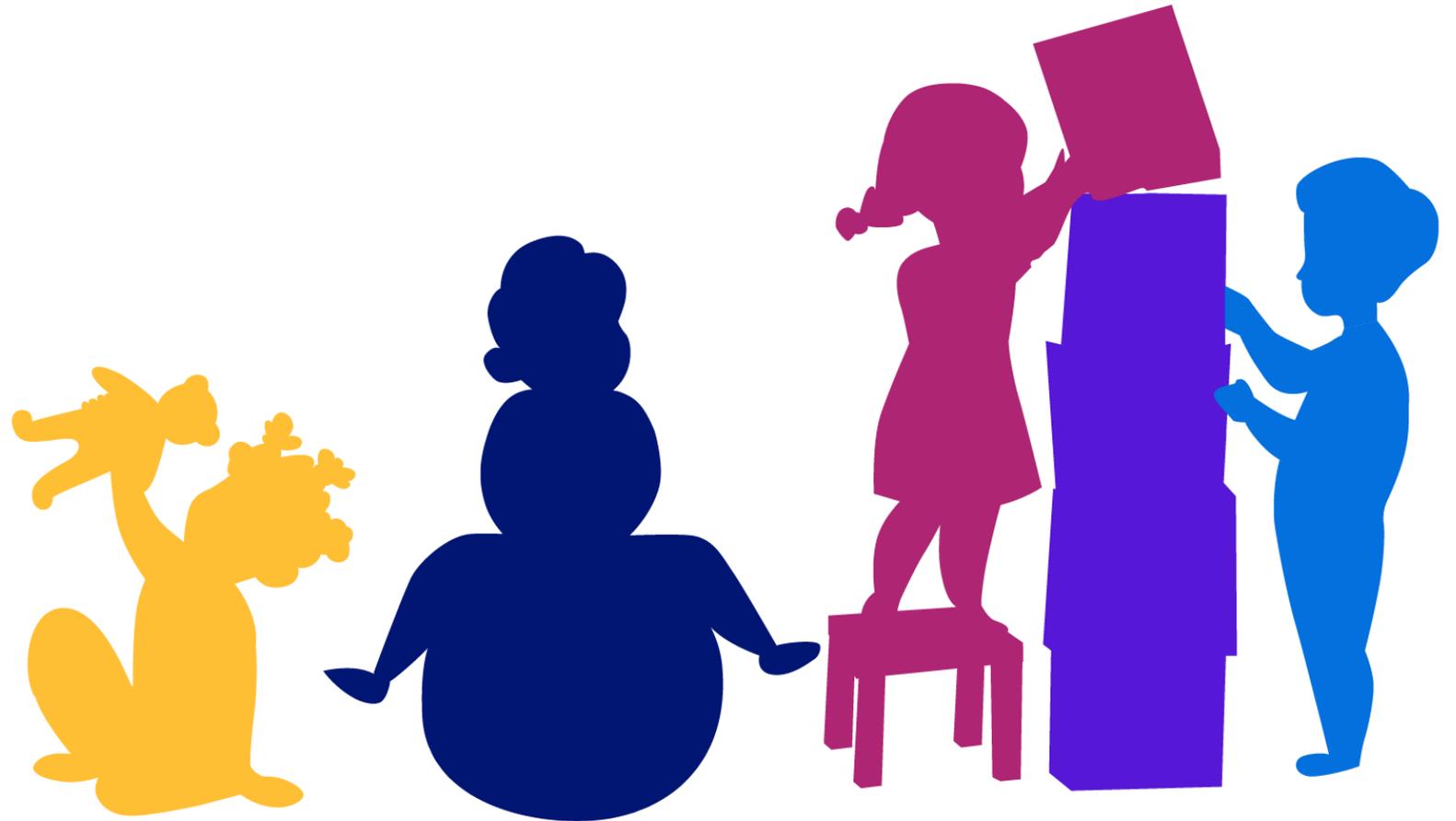


For full data tables showing results to all survey questions, please see [the survey website](#).

An [interactive dashboard](#) allowing you to explore the survey data by sub-group (e.g. by diagnostic group, ethnicity, age and more) is also available.

This research was carried out in accordance with the internal standard for organisations conducting social research (accreditation to ISO27001:2013; certificate number GB10/80275). The 2022 survey data has been produced and published in line with the Code of Practice for Official Statistics.

9. Appendix



Principal Treatment Centre (PTC)	Number of responses	% of responses
Alder Hey Children's NHS Foundation Trust	46	5%
Birmingham Children's Hospital NHS Foundation Trust	96	11%
Cambridge University Hospitals NHS Foundation Trust	69	8%
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	148	17%
Leeds Teaching Hospitals NHS Trust	70	8%
Manchester University NHS Foundation Trust	56	6%
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	41	5%
Oxford University Hospitals NHS Foundation Trust	46	5%
Sheffield Children's NHS Foundation Trust	42	5%
The Newcastle upon Tyne Hospitals NHS Foundation Trust	70	8%
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	100	11%
University Hospital Southampton NHS Foundation Trust	53	6%
University Hospitals Bristol and Weston NHS Foundation Trust	48	5%
Total	885	100%