

Under 16 Cancer Patient Experience Survey 2022

Workshop 1

29th November 2023



Say hello and introduce yourselves in the chat

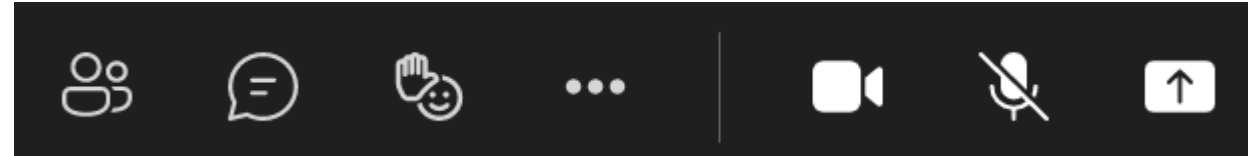


Who are you?

Where are you from?

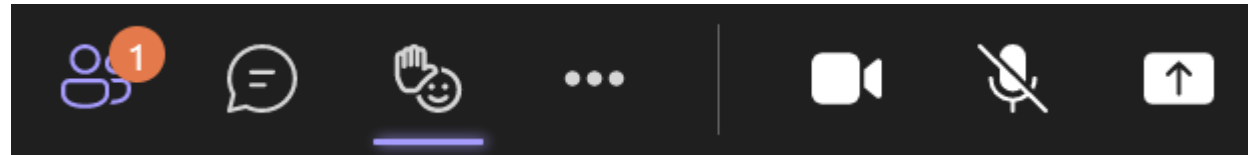
What is your role?

Please,



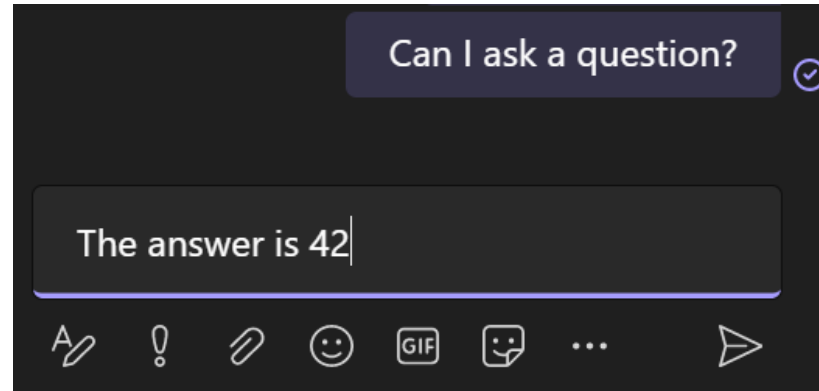
- Keep yourself muted whilst the presentations are ongoing

Please,



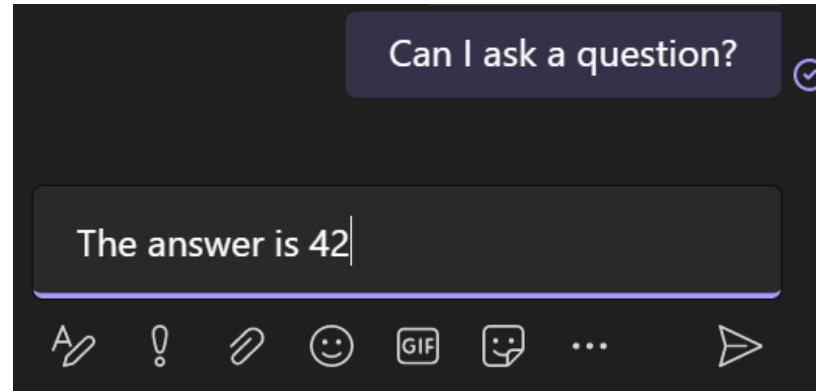
- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question

Please,



- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question
- Add your thoughts/questions to the chat

Please,



- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question
- Add your thoughts/questions to the chat
- The session will be recorded

Under 16 Cancer Patient Experience Survey 2022

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Under 16 Cancer Patient Experience Survey 2022 – Workshop 1 Agenda

29th November 2023, 10:00-11:30

Item	Details	Timing
Introduction and housekeeping	Amy Tallett , Picker	10:00-10:05
Parent talk	Henry's Story. Samantha Luk	10:05-10:25
Hearing from the NHS cancer programme	Jodie Moffat , Deputy Director – Policy and Strategy, NHS Cancer Programme	10:25-10:35
National results	Overview of national survey results Caroline Hancock , Picker	10:35-11:00
Results and outputs	Understanding and interpreting your data Amy Tallett , Picker	11:00-11:25
Close	Neil Churchill , Director for Experience, Participation & Equalities	11:25-11:30

The Parent Voice: Henry's Story

Samantha Luk



Hearing from the NHS cancer programme

NHS England

Jodie Moffat, Deputy Director – Policy and Strategy, NHS Cancer Programme



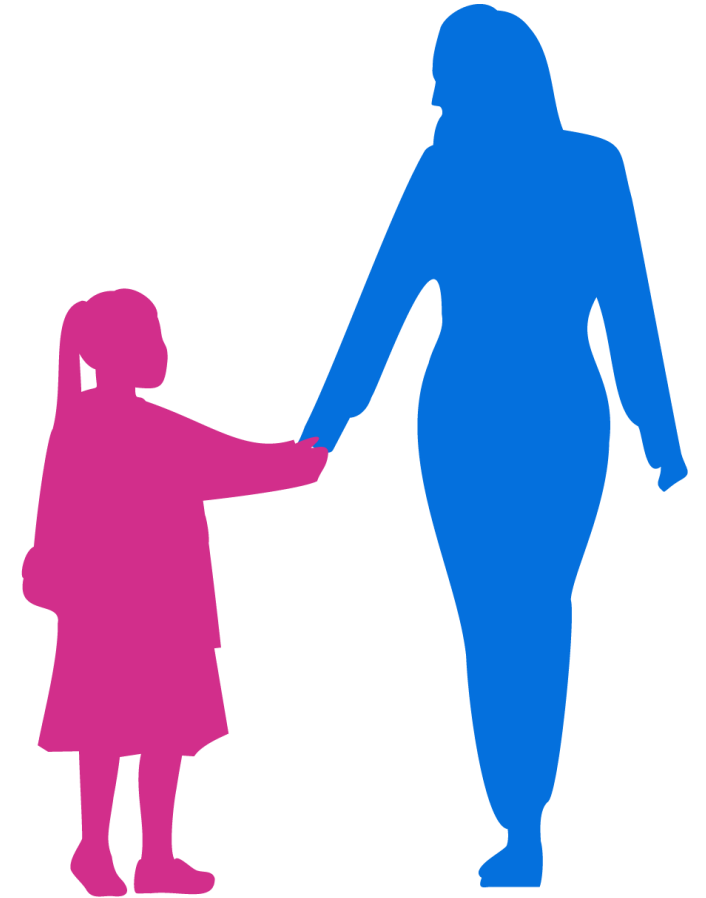
Under 16 Cancer Patient Experience Survey 2022

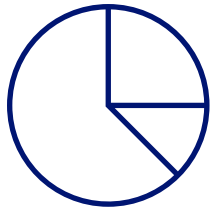
National Quantitative Results Presentation

Caroline Hancock, Picker



2. Introduction

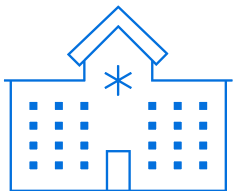




The Under 16 Cancer Patient Experience Survey (U16 CPES) measures experiences of tumour and cancer care for children across England. It is an annual survey. This report presents the U16 CPES 2022 headline findings and is the third time the survey has run.



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.



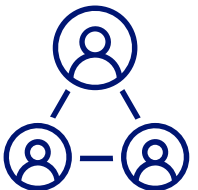
The survey has been designed to monitor national progress on experience of cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting children with cancer.



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.



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.



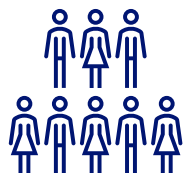
Fieldwork

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



- **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](#).

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%

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%



[†] Asked only to children aged 8-15

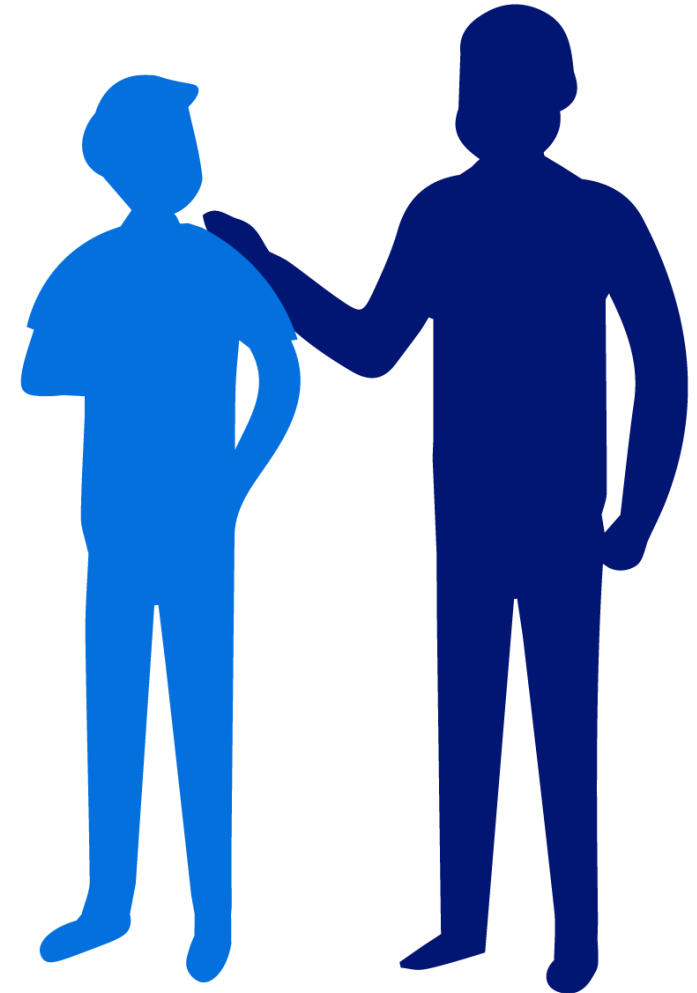


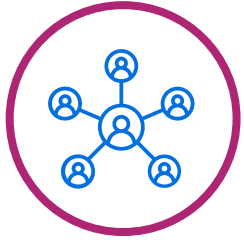
6. National results





6.1 Overall care

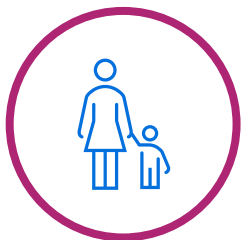




This section shows responses to the overall care questions by various sub-groups. Further information about how sub-groups were determined can be found in the Technical Appendix, available [on the survey website](#). Please take care when drawing conclusions from results based on small numbers of responses.



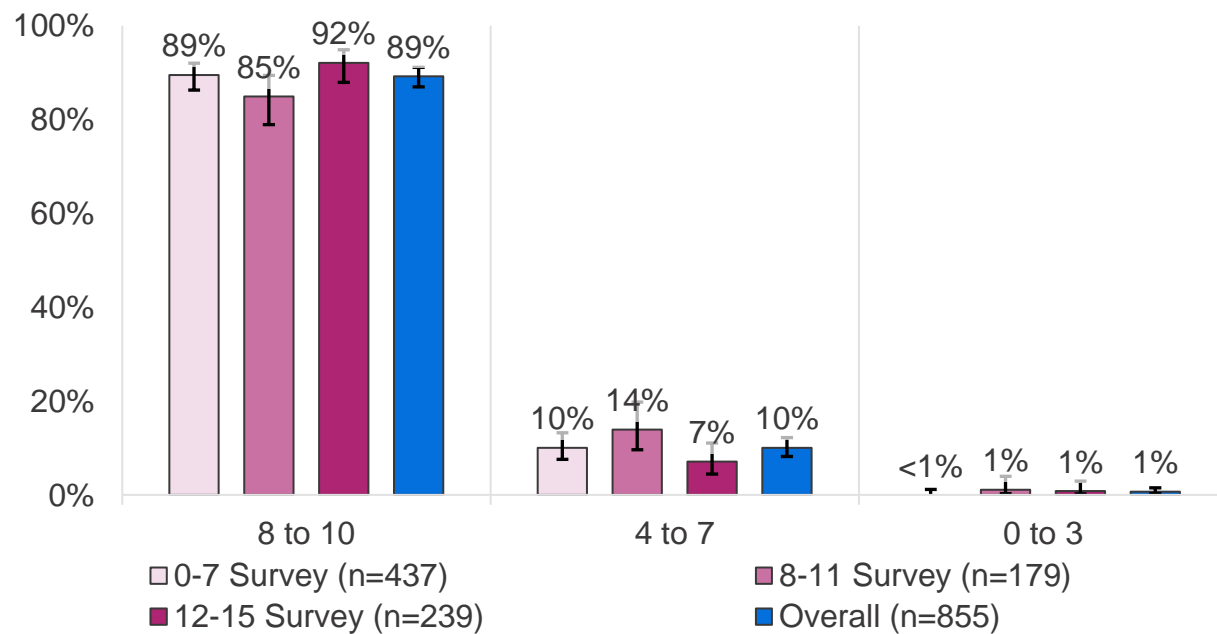
A breakdown of all survey questions and scores to each question by each sub-group can be found in the National Excel Data Tables, available [on the survey website](#) and in an [interactive dashboard](#).



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).

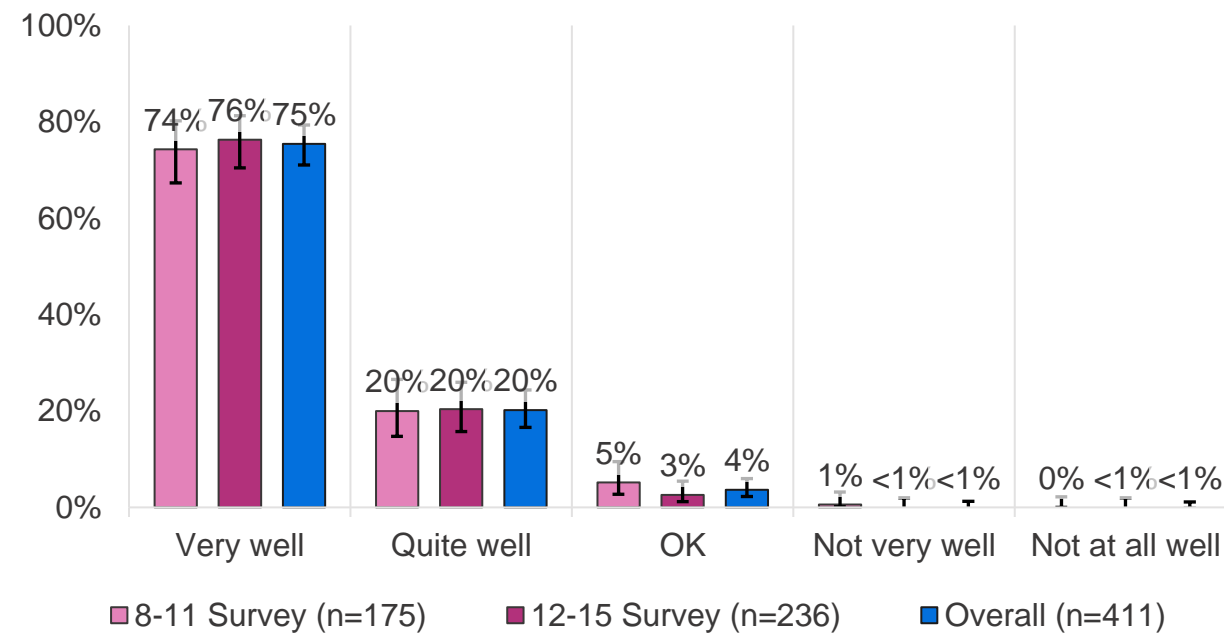
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



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

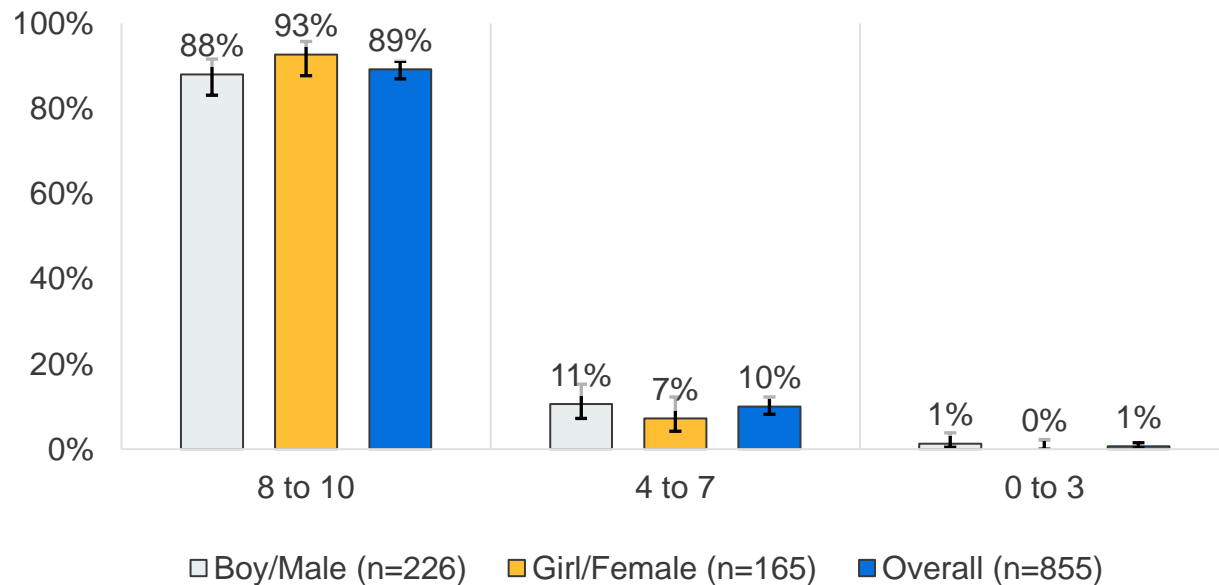
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



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 and 76% in the 12-15 survey.

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

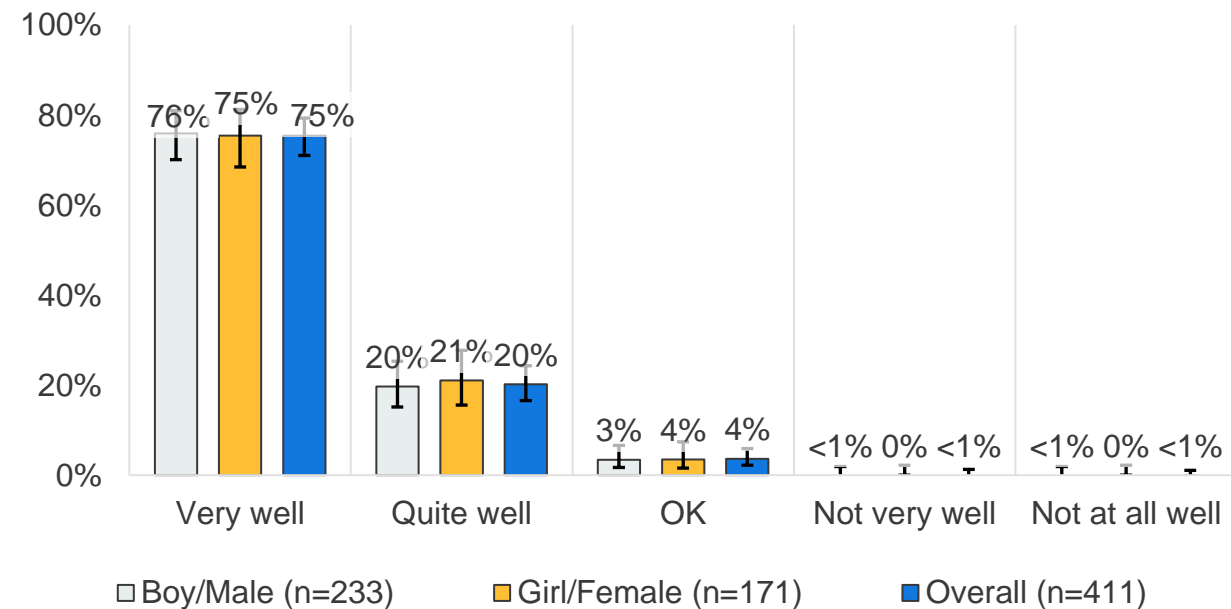
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



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.

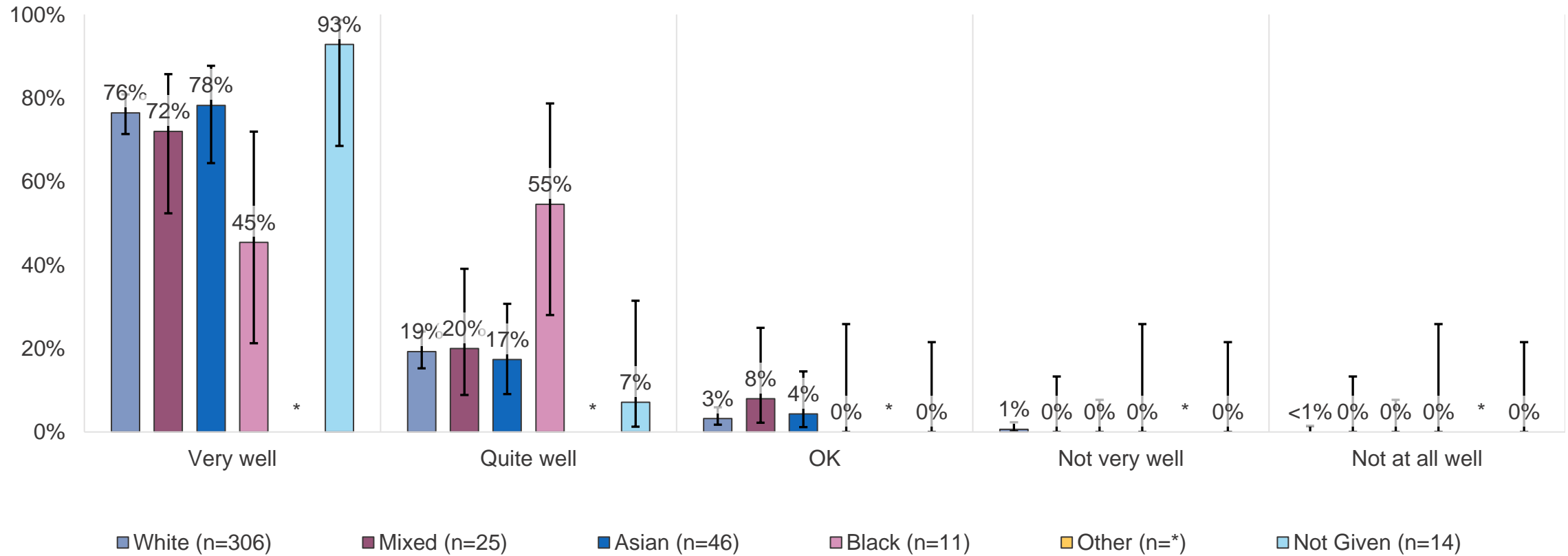
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



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, 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)

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?

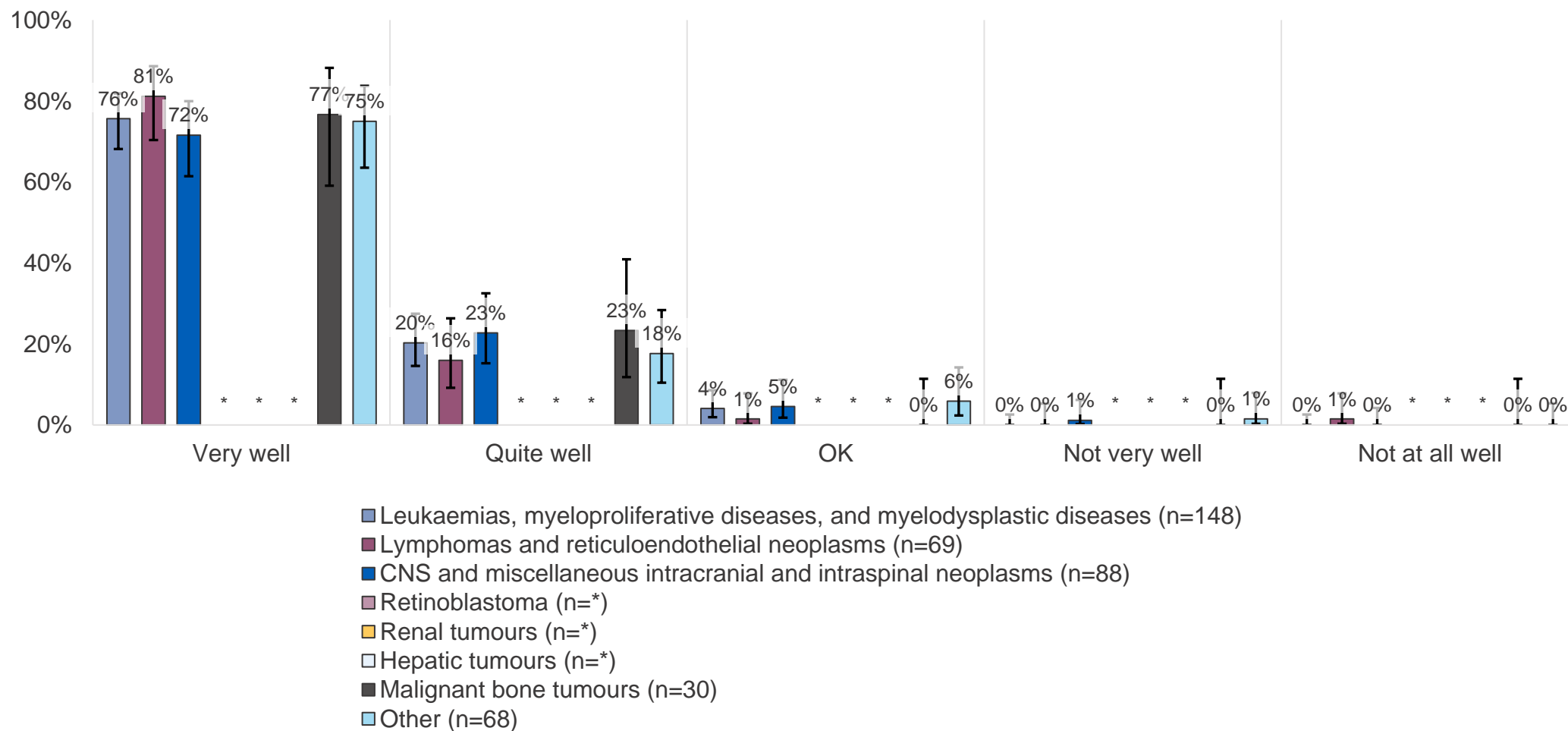
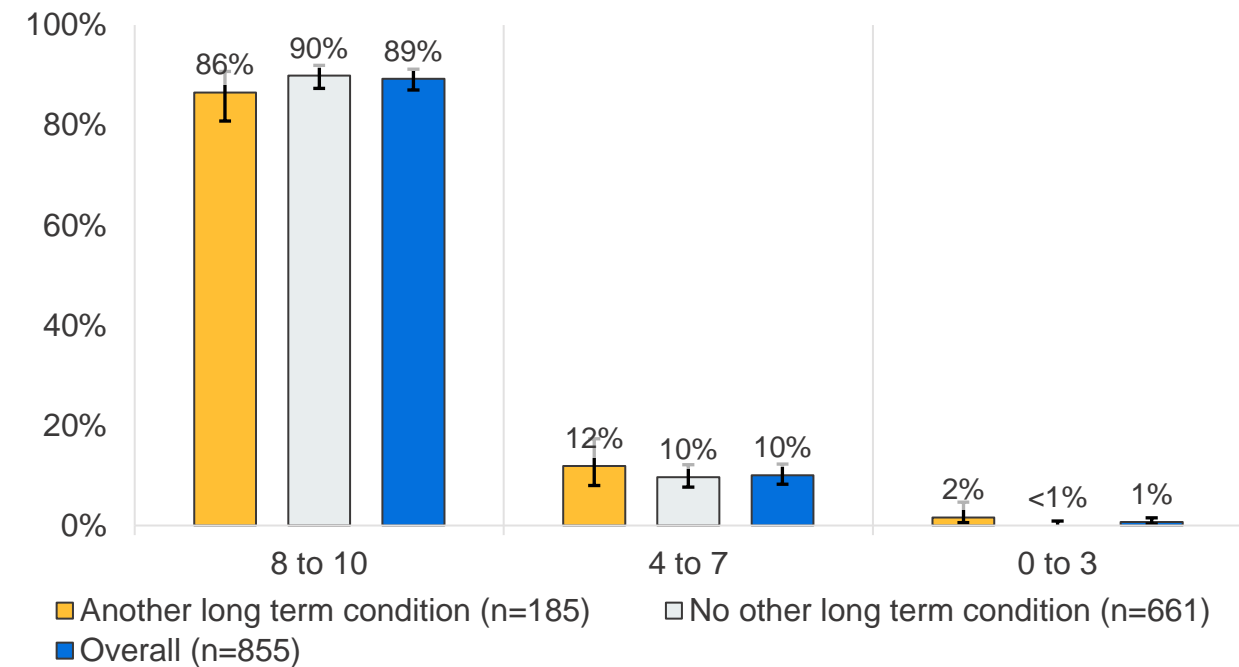


Chart shows question X60: Asked to all children aged 8-15. Total number of responses = 411

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

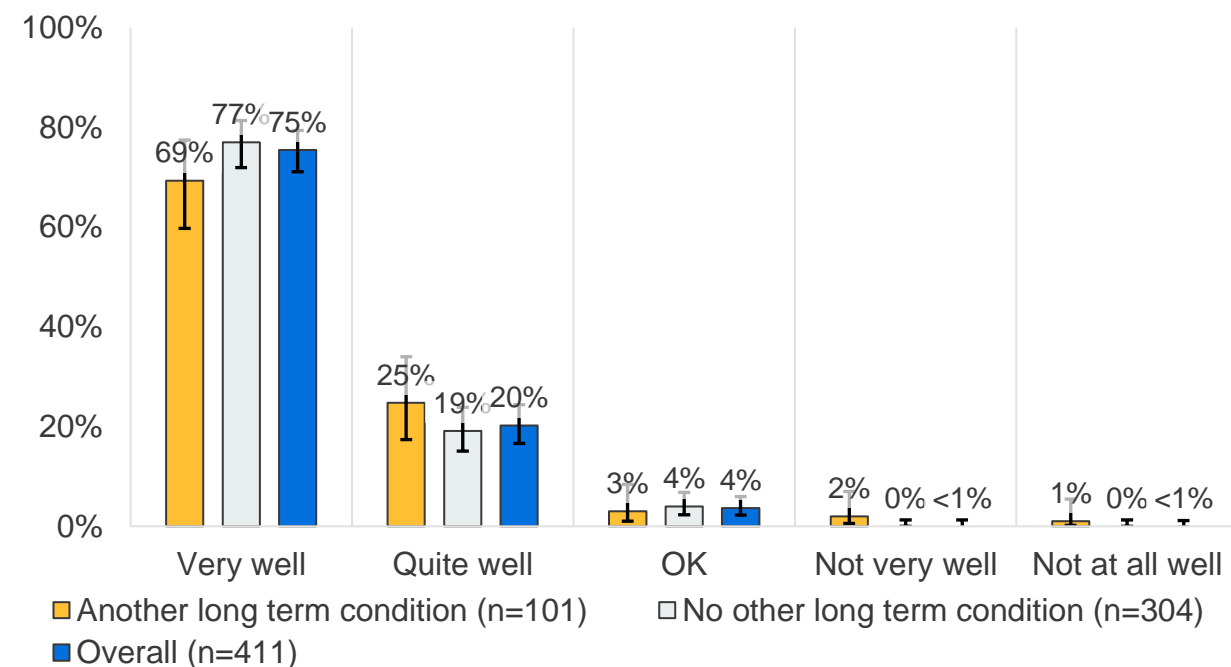
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



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

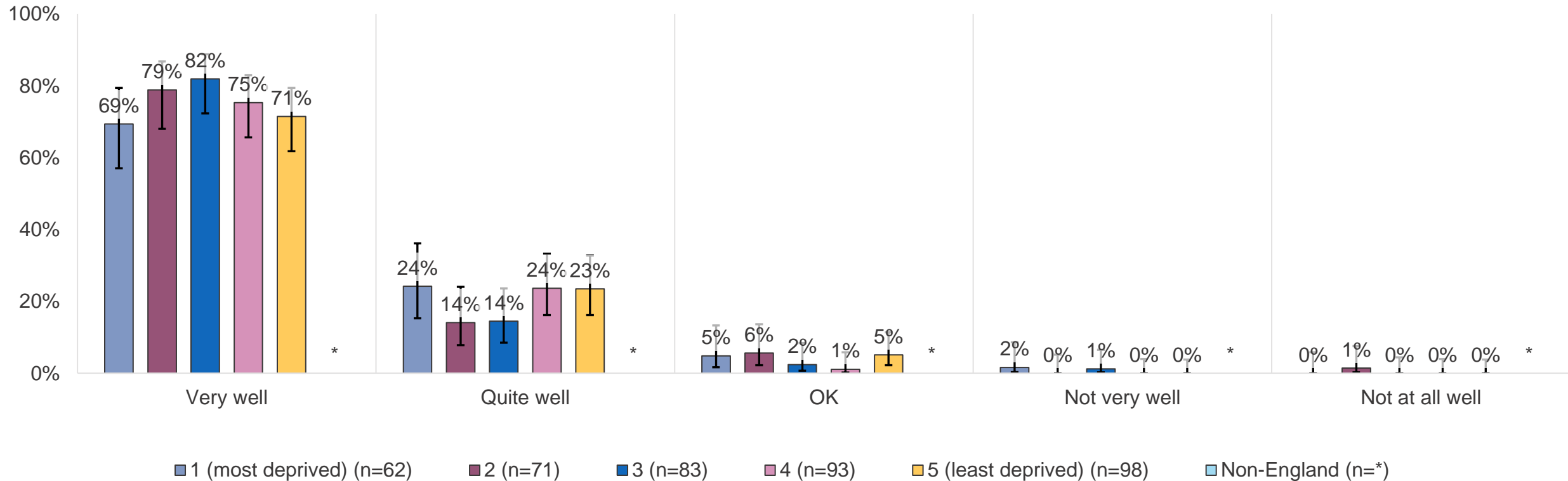
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?



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

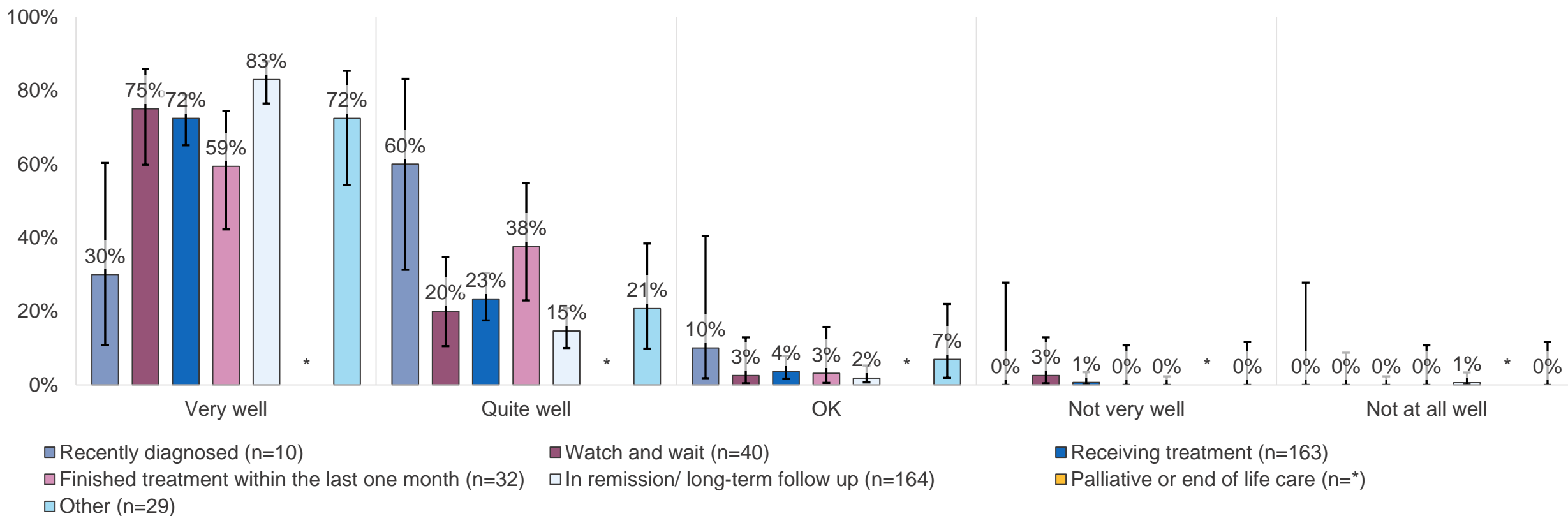


Children reporting that they were very well looked after by healthcare staff ranged from 69% for the most deprived to 82% for those in the third IMD quintile.

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, 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)

6.2 Finding out about the cancer or tumour



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?

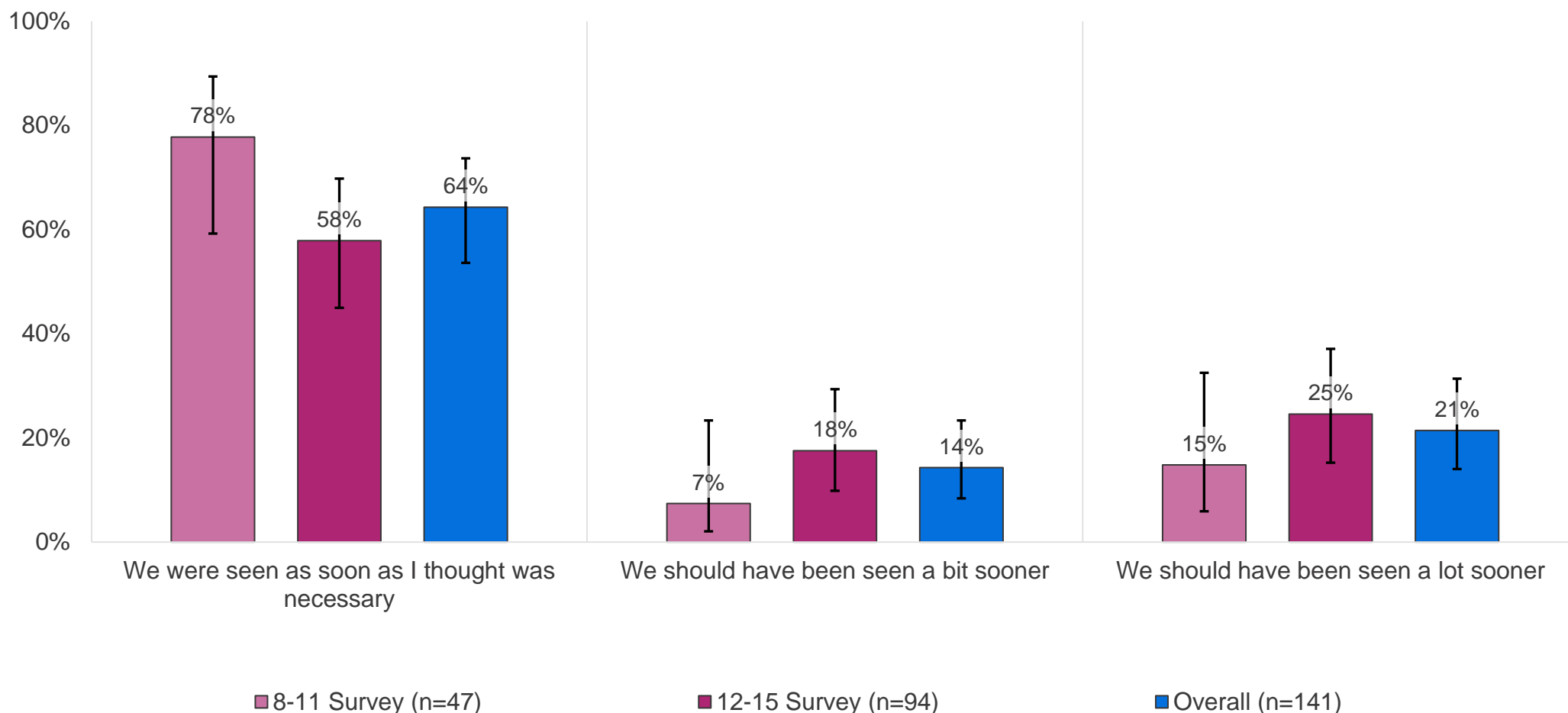
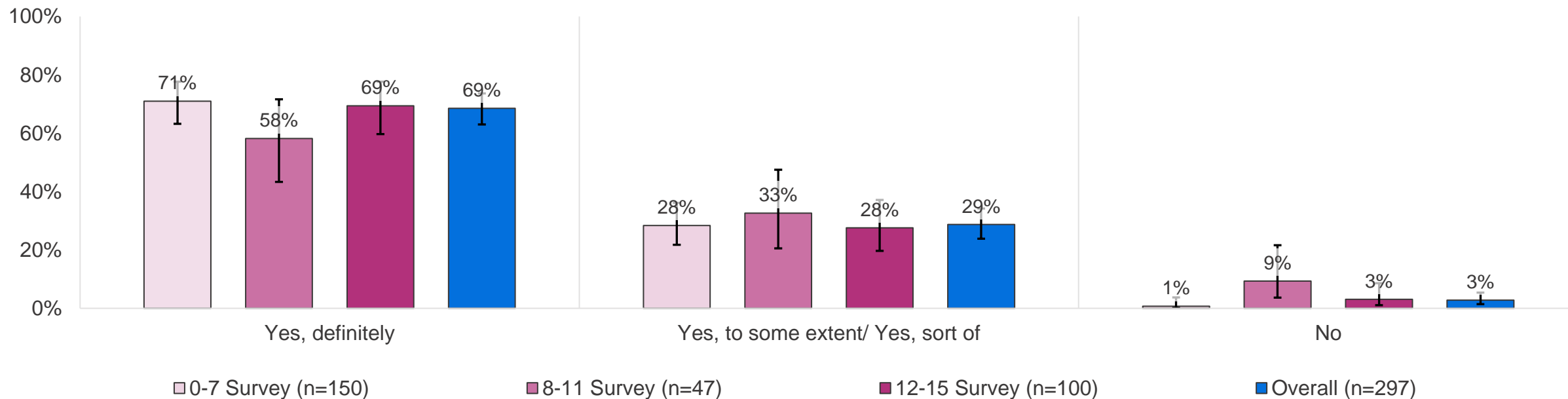


Chart shows question X06b: Asked to parents/carers of children aged 8-15 who were told about their child's cancer or a tumour during 2022. Total number of responses = 84 (excluding 57 responses of "We were not referred by a GP")

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

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?

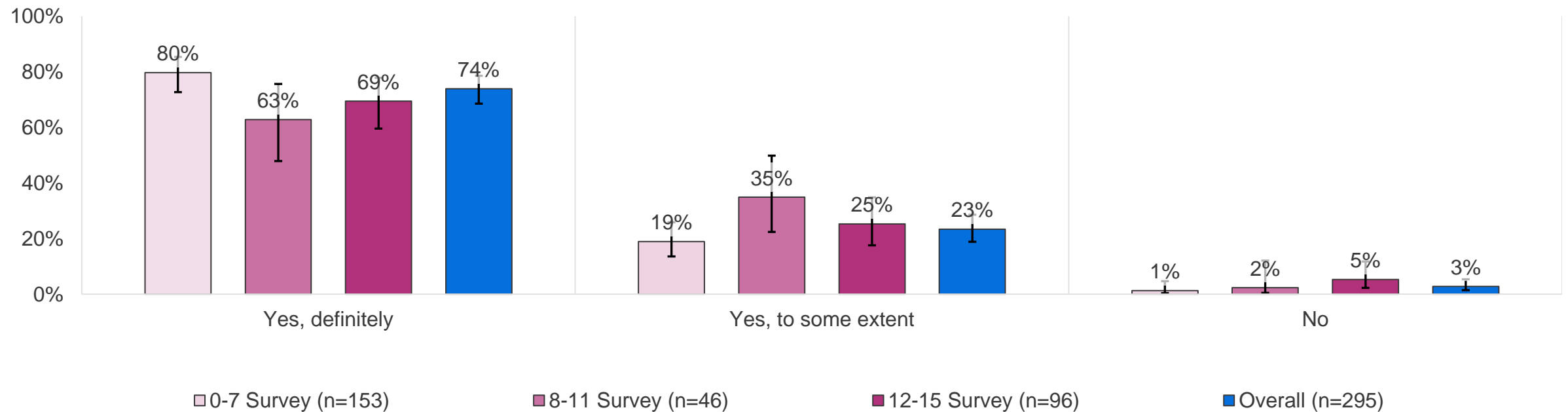


69% of parents/carers and children reported that information at diagnosis was definitely given in a way they could understand.

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

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

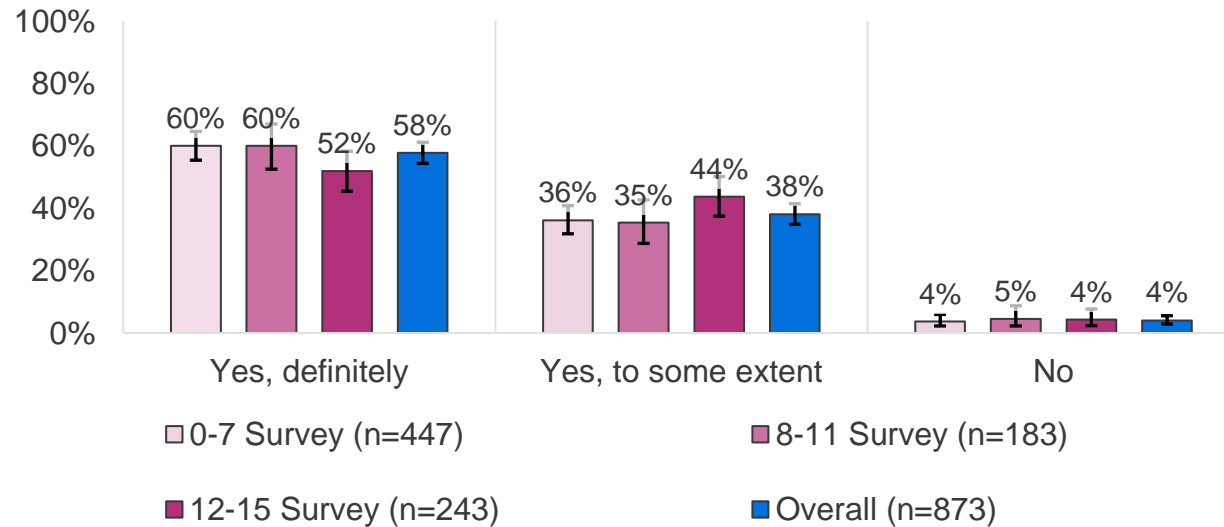


74% of parents/carers reported that they were definitely able to find information about their child's diagnosis.

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").

Medical history

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

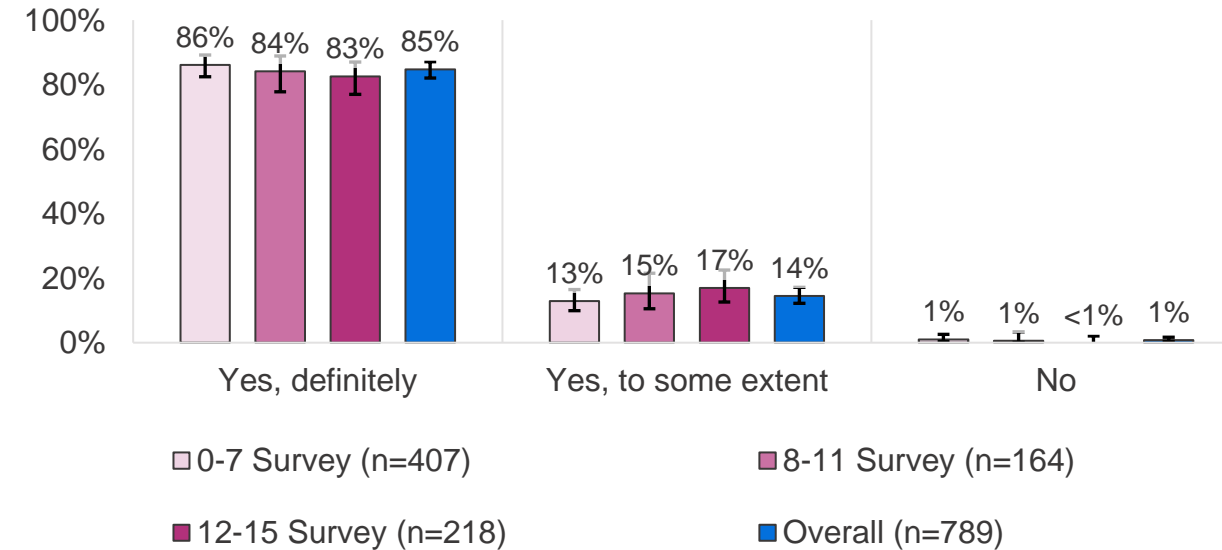


58% of parents/carers felt that different hospital staff were definitely aware of their child's medical history.

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?

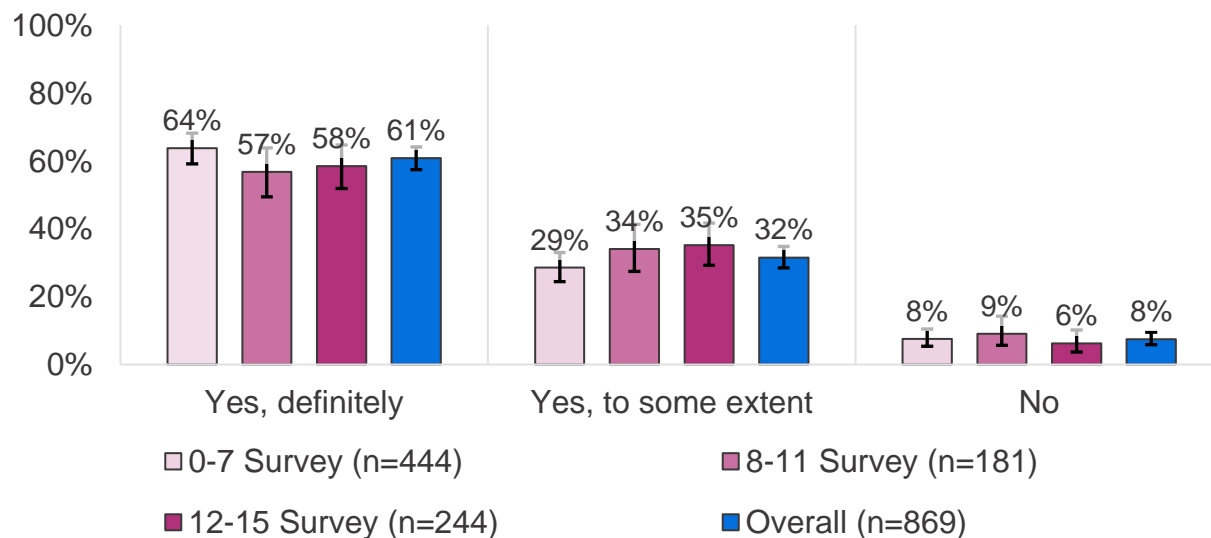


85% of parents/carers reported that they were offered clear information about their child's treatment.

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").

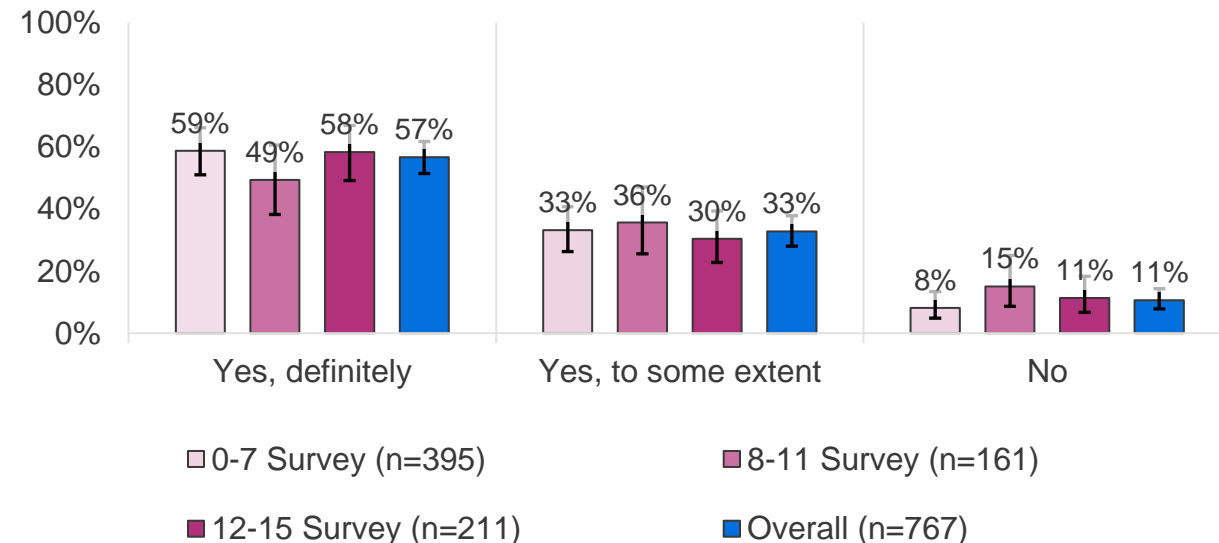
Support from the hospital

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?



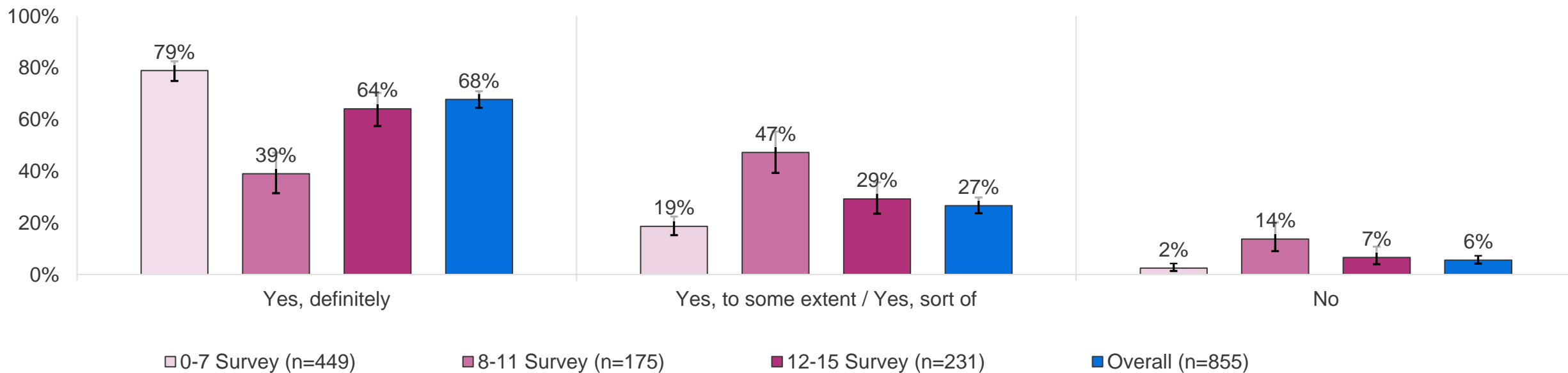
57% of parents/carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended.

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.

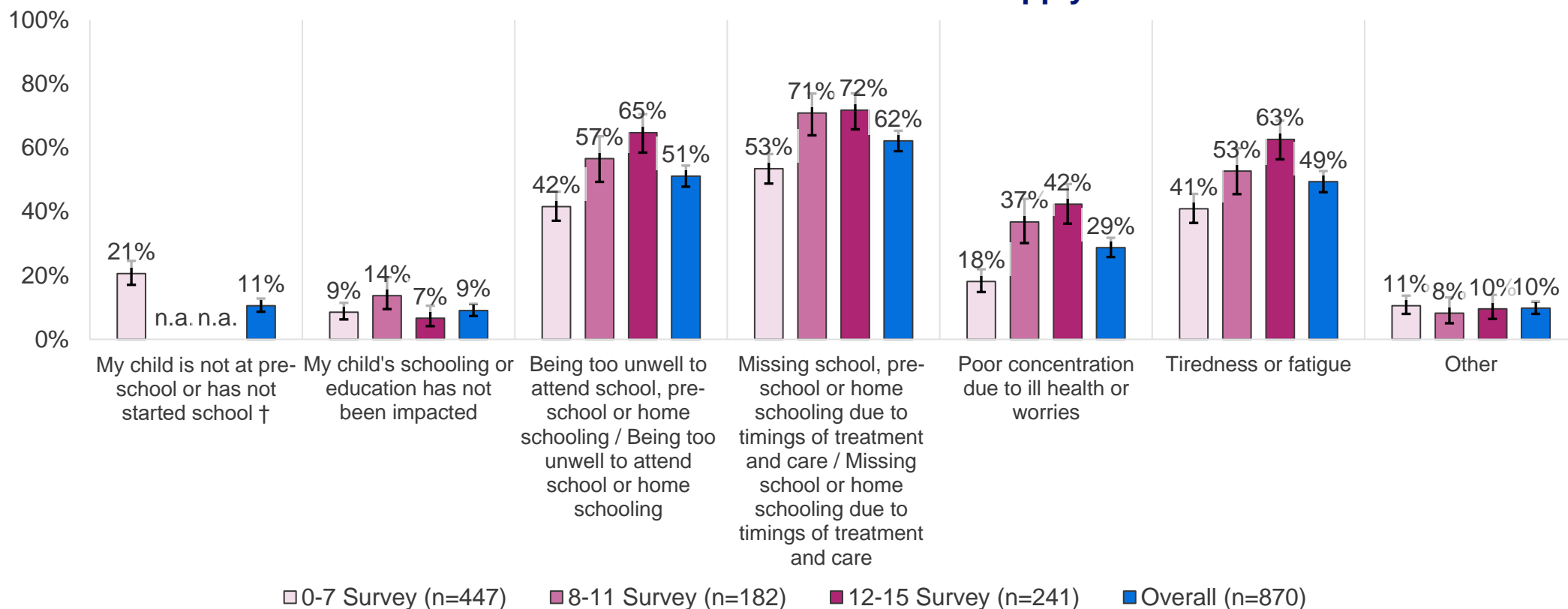
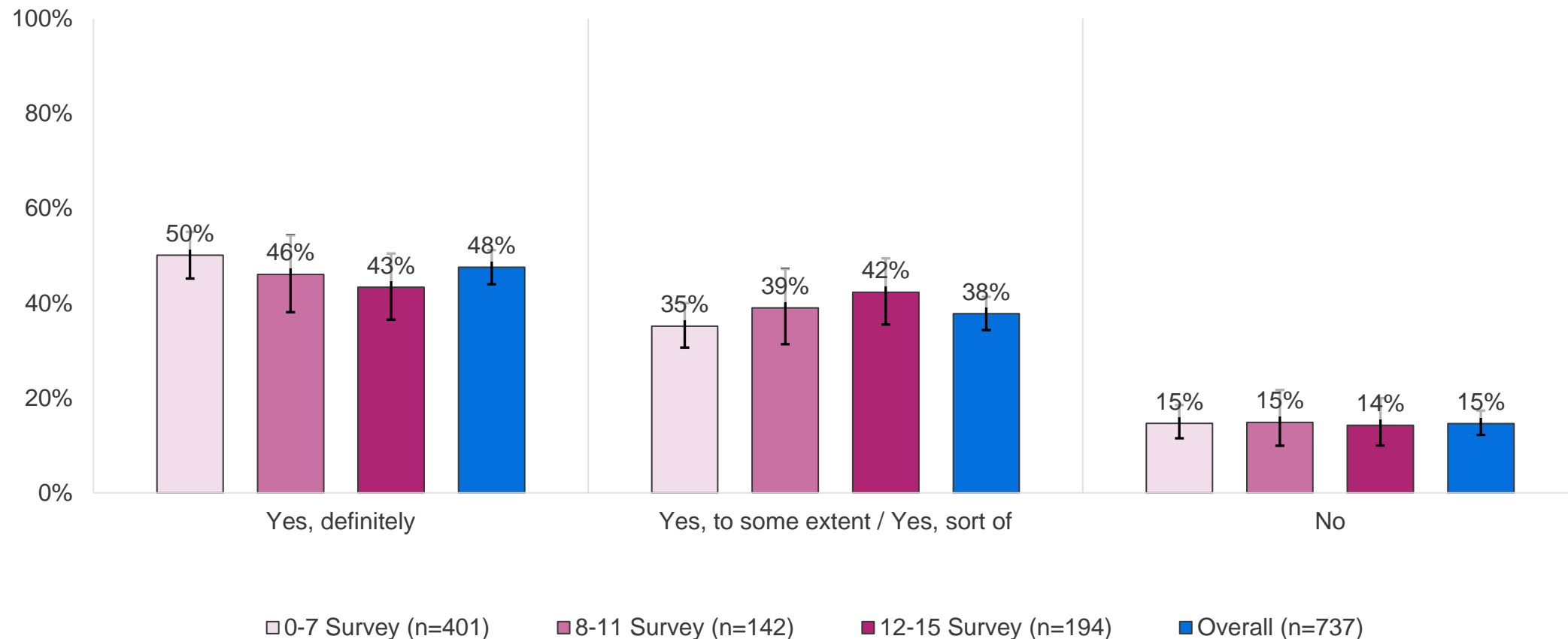


Chart shows question X30: Asked to parents/carers of all age groups. Total number of responses = 870.

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

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

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)?

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

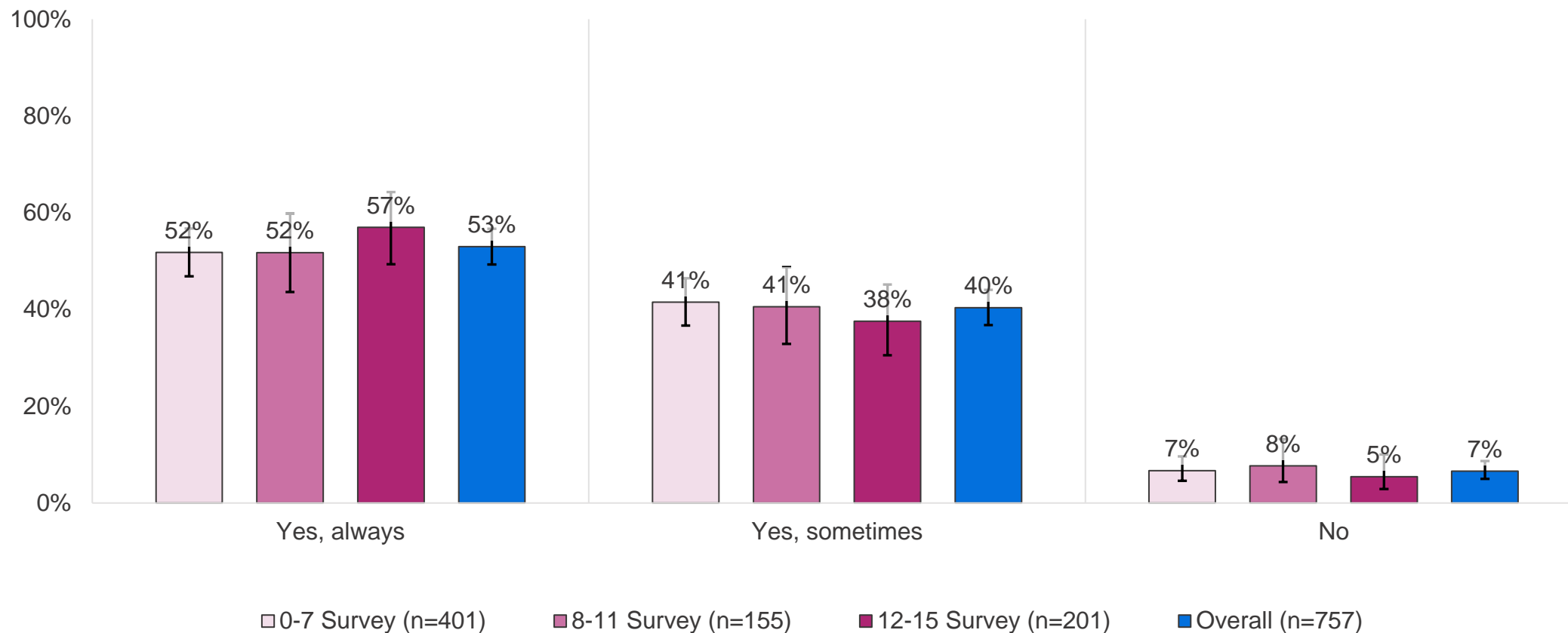


Chart shows question X46: Asked to parents/carers of all age groups whose children stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 696 (excluding 61 responses of “My child did not need this”).

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?

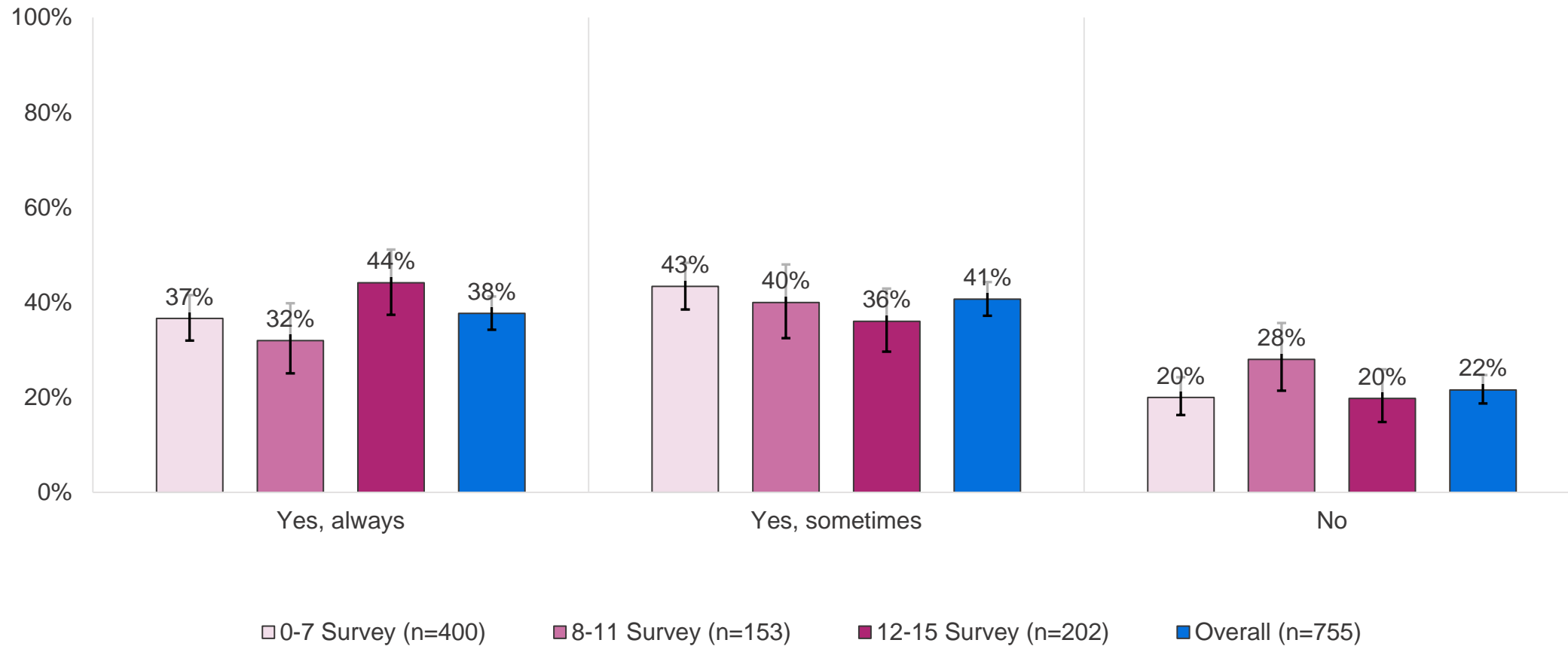


Chart shows question X51: Asked to parents/carers of all age groups whose children stayed in hospital during 2022 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 732 (excluding 23 responses of "This was not needed").

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?

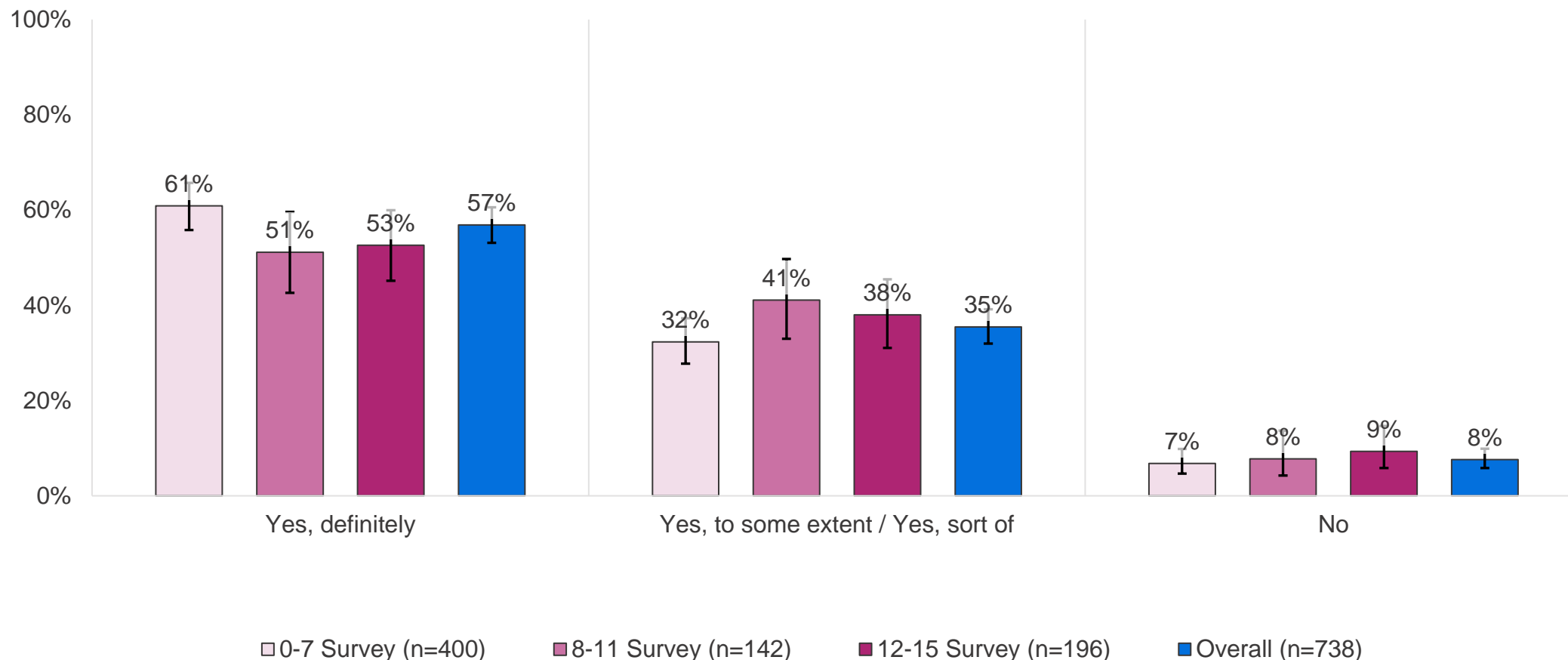
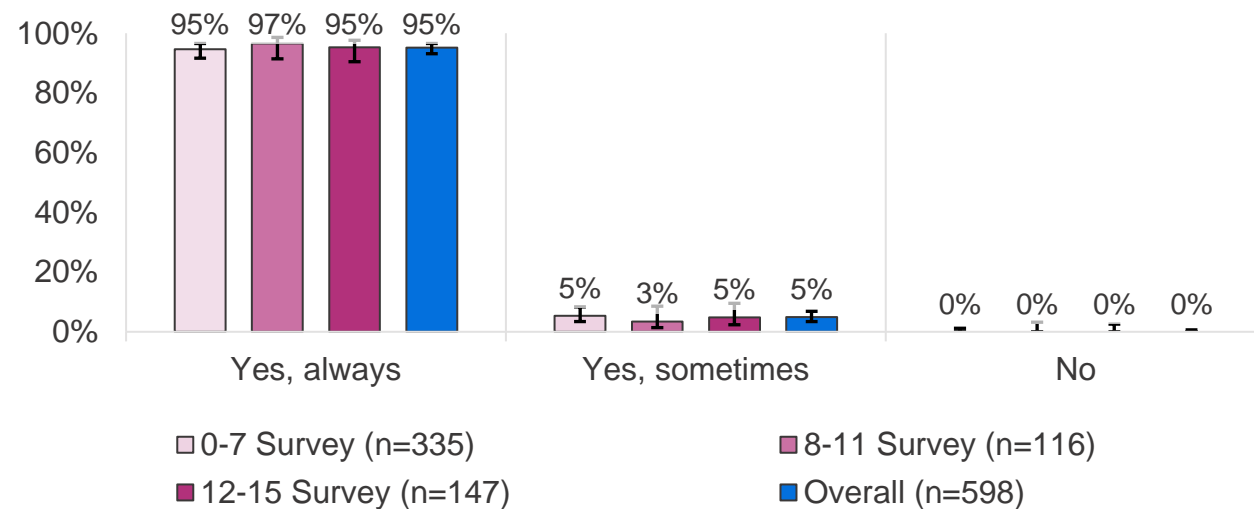


Chart shows question X44: Asked to parents/carers of children aged 0-7 whose children stayed in hospital during 2022, and children aged 8-15 who stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 668 (excluding 70 responses of “My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

Bedside manner and trust

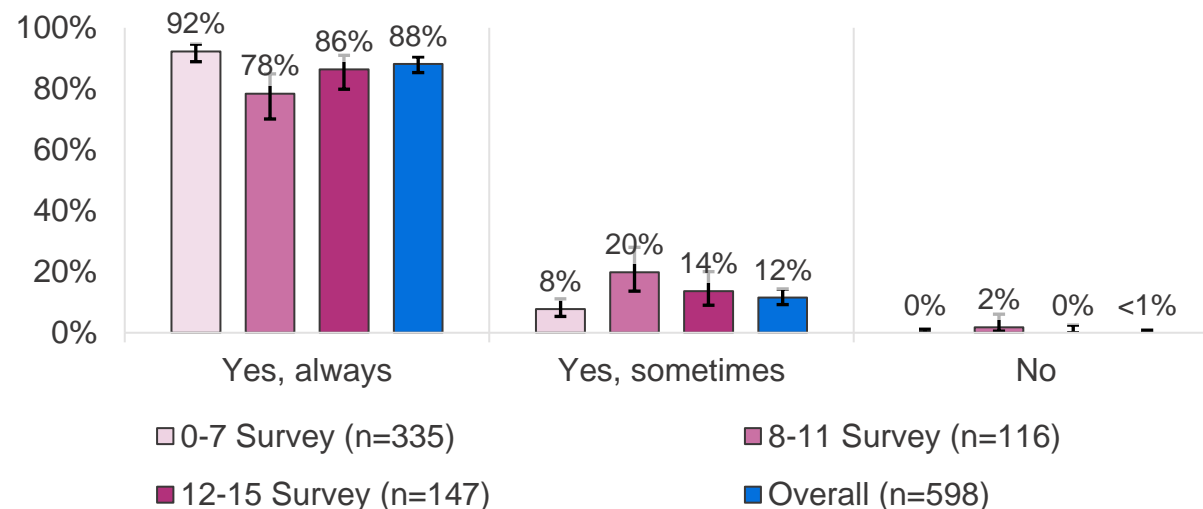
Were the nurses that came to your home or your child's school friendly? / Were the nurses that came to your home or school friendly?



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

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 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").

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").

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?

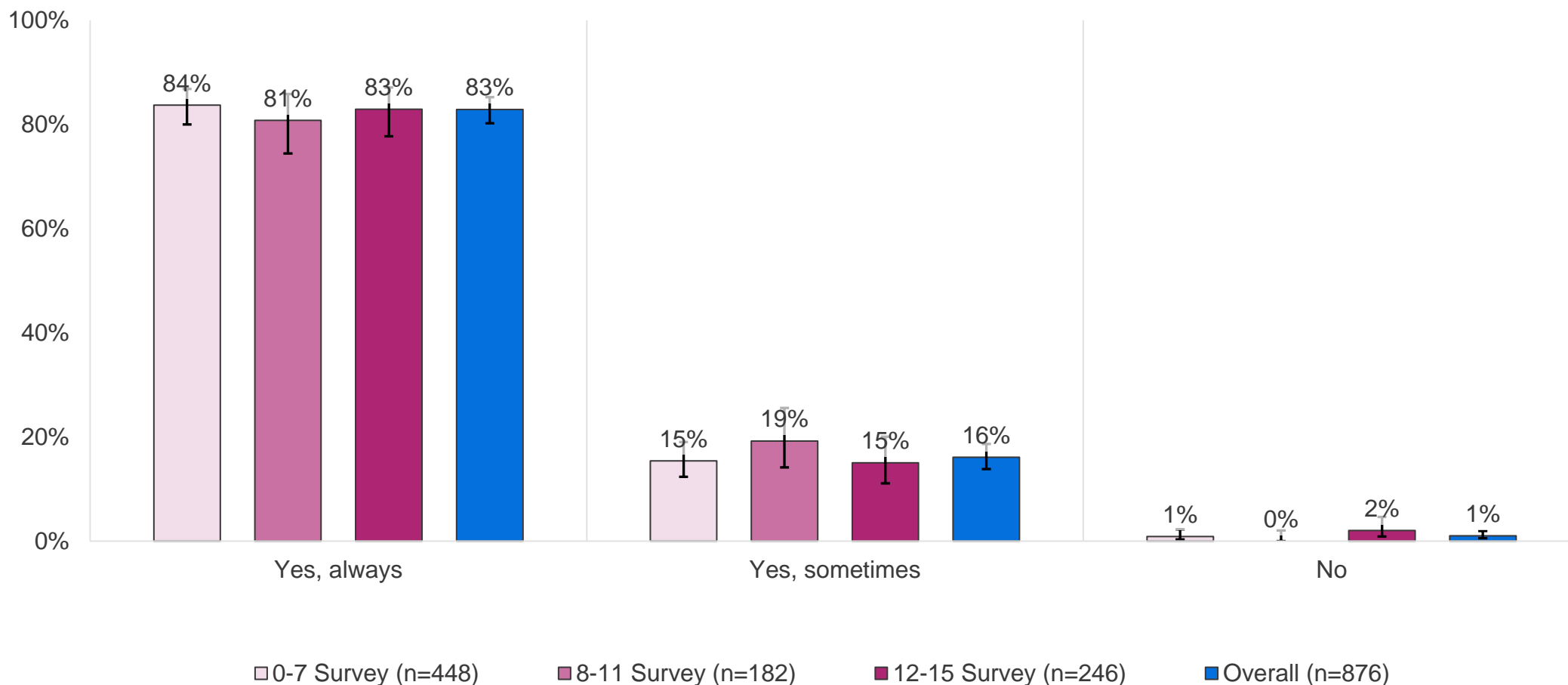
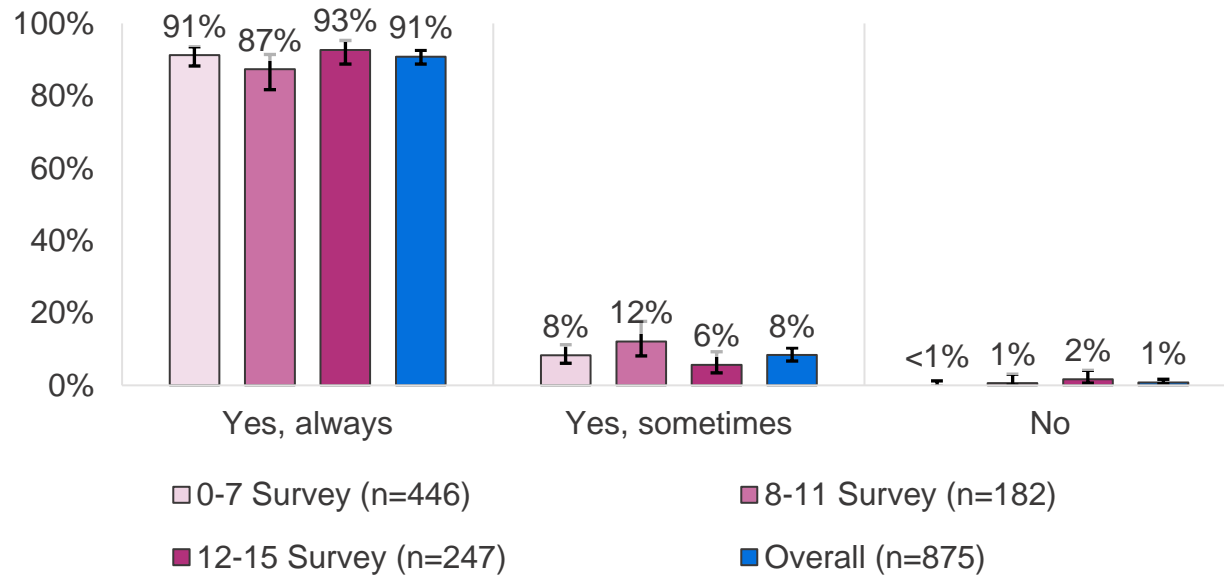


Chart shows question X18: Asked to parents/carers of all age groups. Total number of responses = 876.

Bedside manner and trust

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

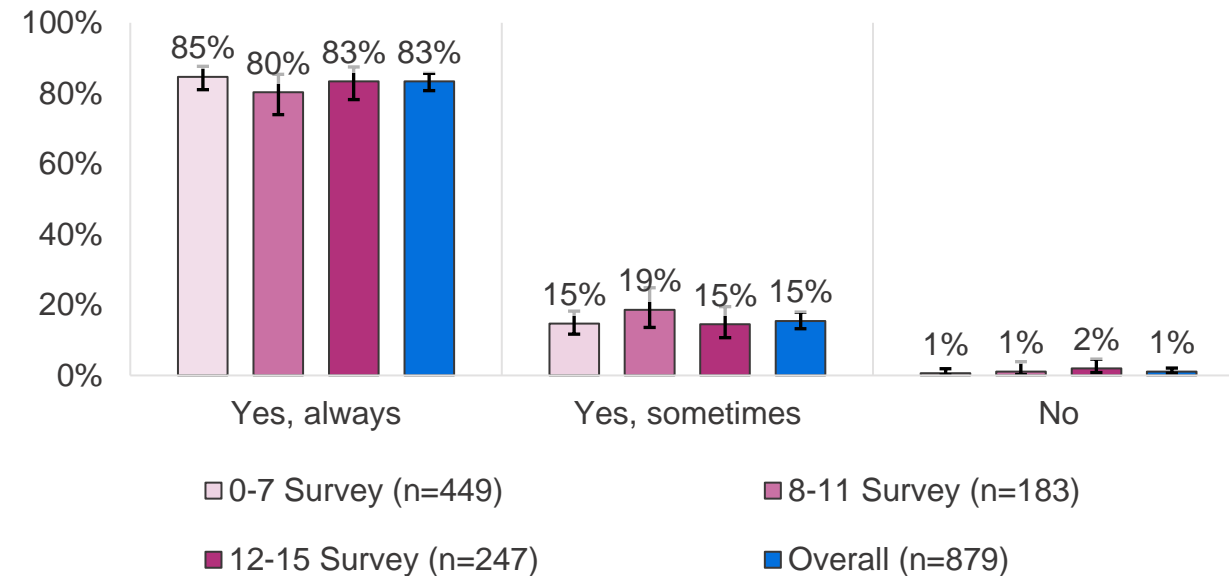


91% of parents/carers felt that they and their child were always treated with respect and dignity by staff.

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?

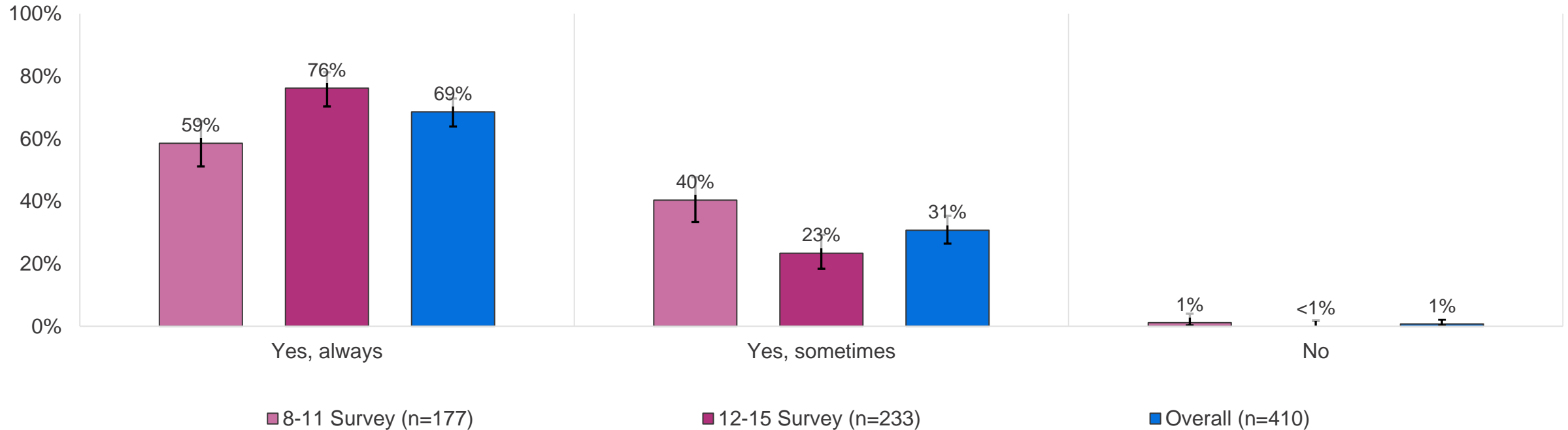


83% of parents/carers felt that they were always treated with empathy and understanding by staff caring for their child.

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

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?

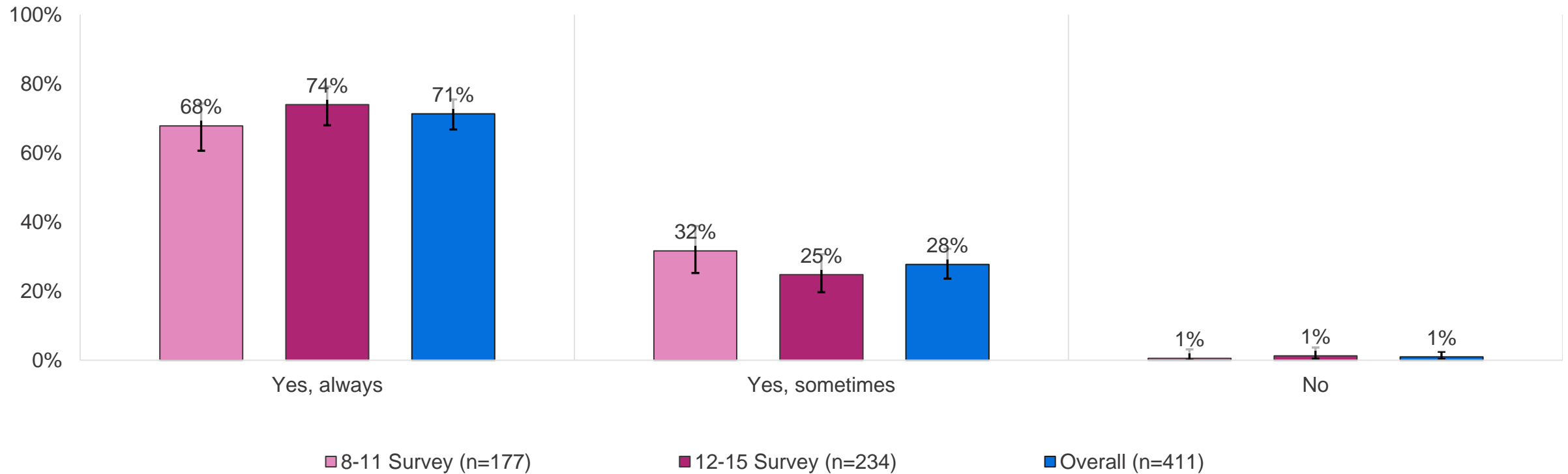


69% of children reported that they could always understand what staff were saying.

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



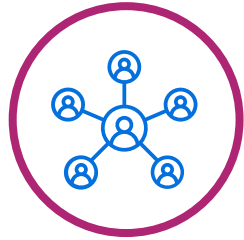
71% of children felt that staff always talked to them, not just their parent or carer.

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



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.

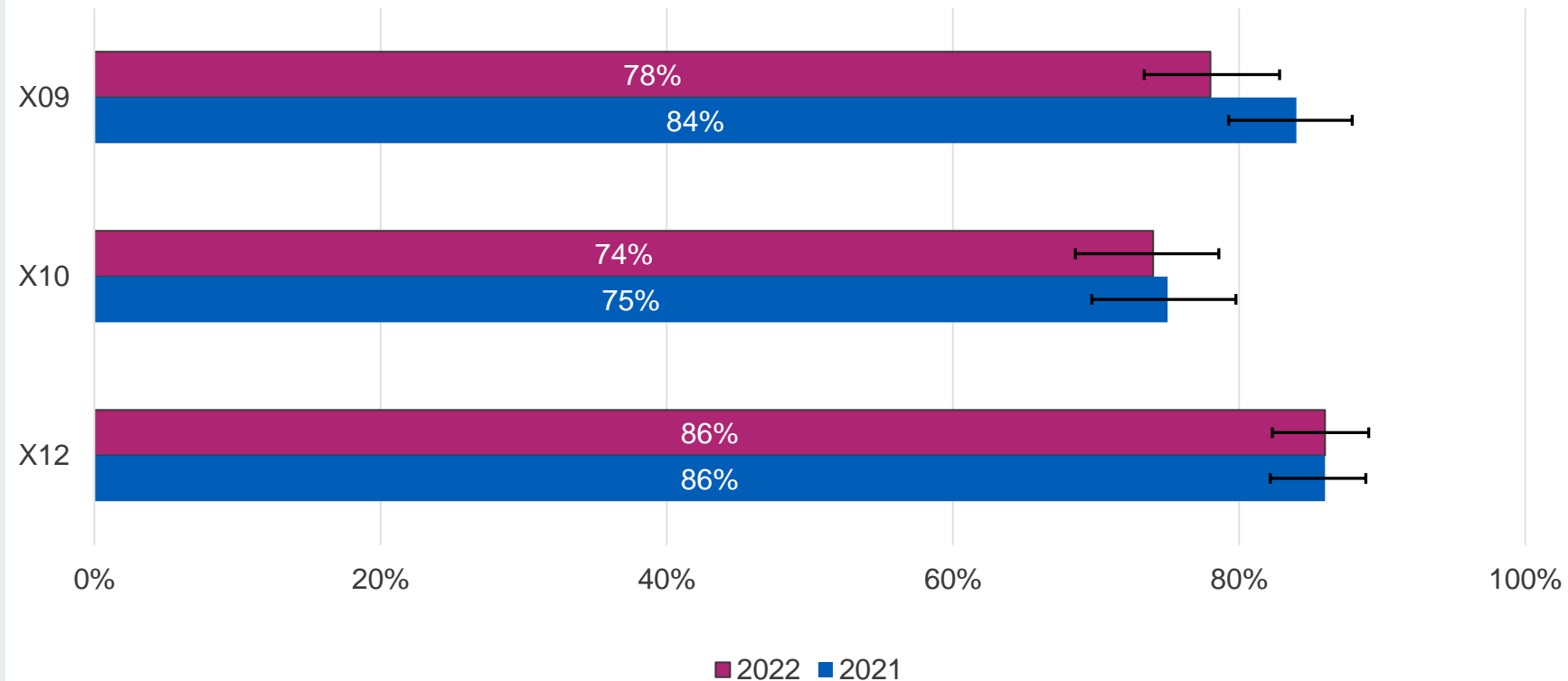
Assuming the sample is representative of the organisation, confidence intervals are a method of describing the uncertainty around these estimates. The most common methodology, which was used here, is to produce and report 95 percent confidence intervals around the results. At the 95 percent confidence 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.

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.

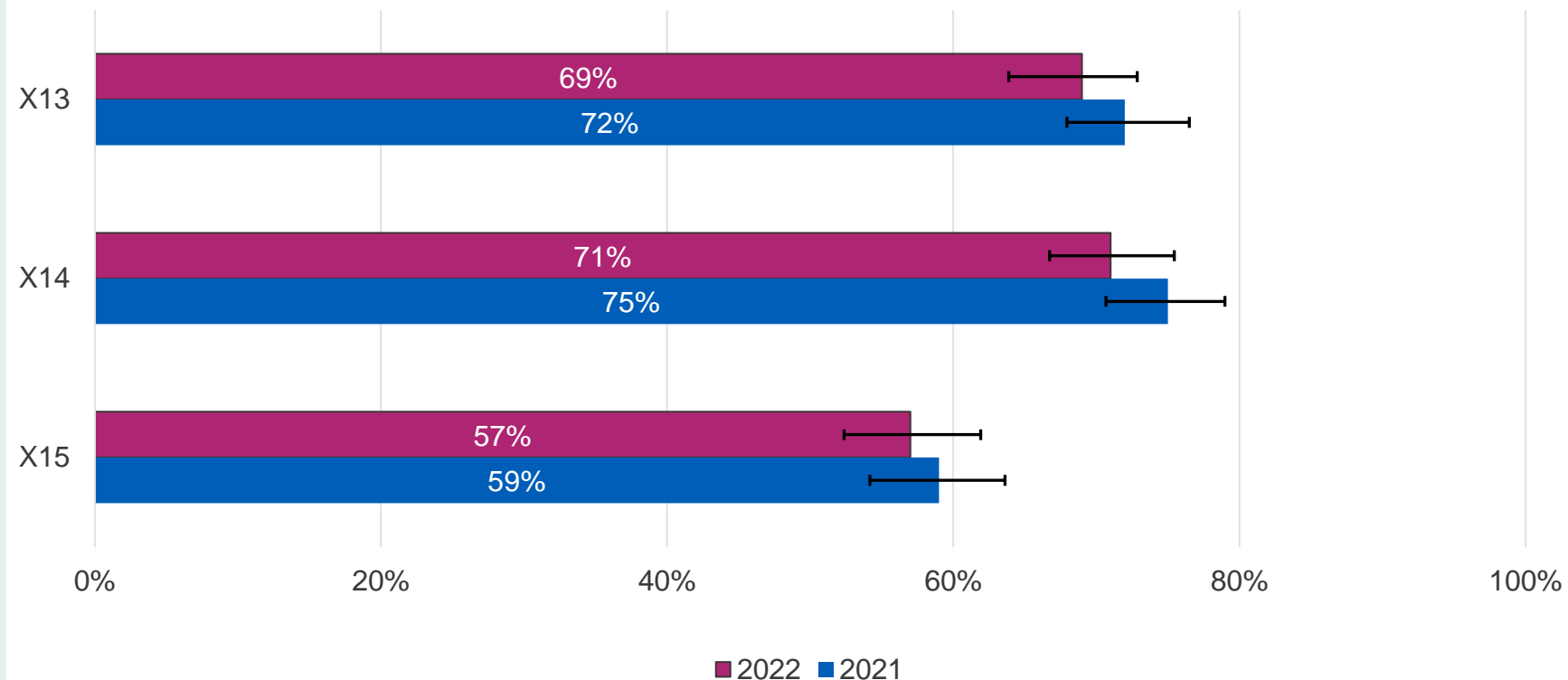
X14: Children felt that staff always talked to them, not just their parent or carer. Asked to all children aged 8-15.

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



Understanding and Interpreting the Data

Amy Tallett, Picker



National

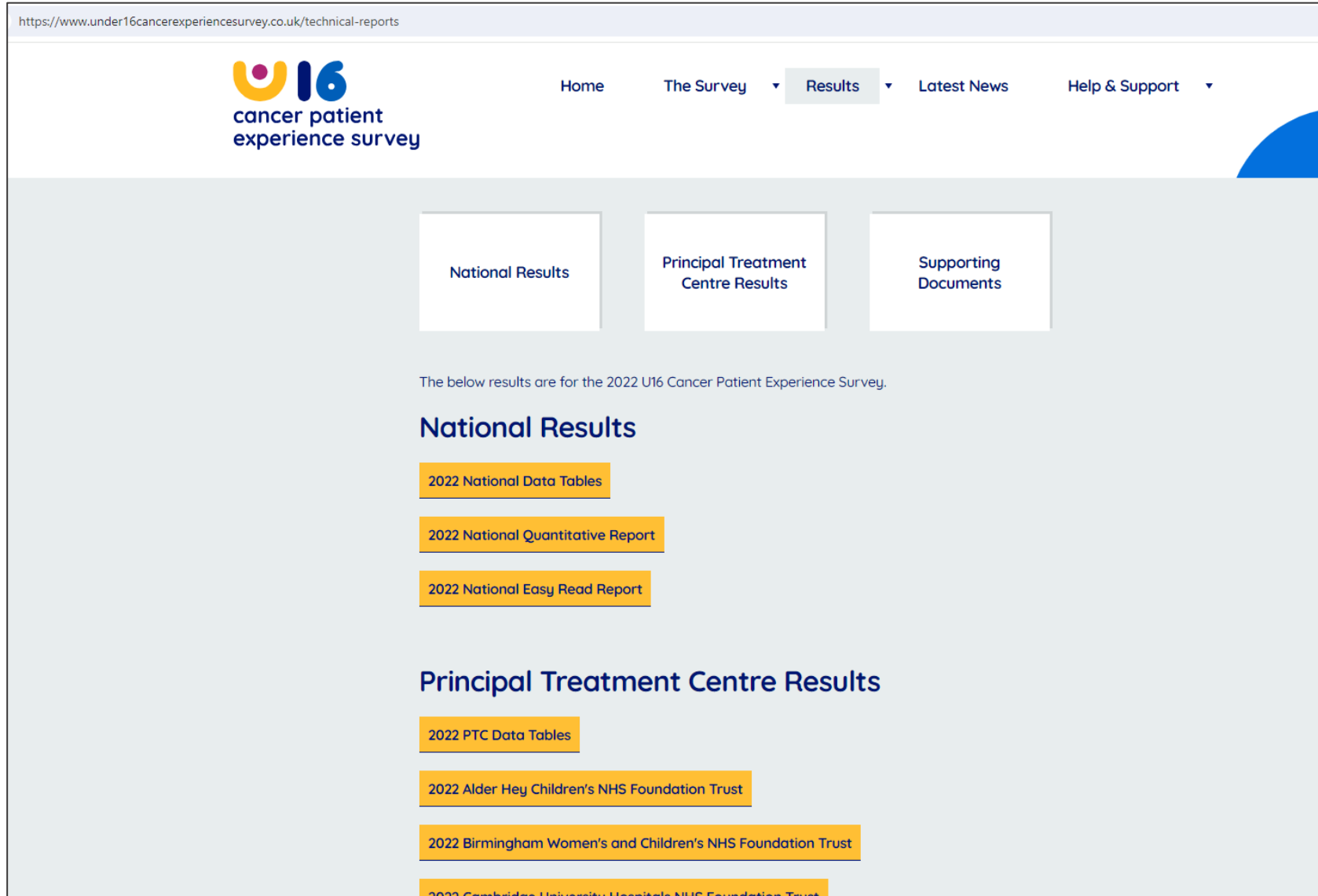


- National quantitative report (including an easy read version)
- National data tables
- Visual summaries
- Interactive dashboard

Principal Treatment Centre (PTC)


- PTC quantitative reports x 13
- PTC data tables
- Interactive dashboard
- PTC freetext workbooks

<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>



The screenshot shows the 'technical-reports' page of the U16 Cancer Patient Experience Survey website. The page features a navigation menu with 'Home', 'The Survey', 'Results', 'Latest News', and 'Help & Support'. Below the navigation, there are three main categories: 'National Results', 'Principal Treatment Centre Results', and 'Supporting Documents'. A text block states: 'The below results are for the 2022 U16 Cancer Patient Experience Survey.' Under 'National Results', there are three links: '2022 National Data Tables', '2022 National Quantitative Report', and '2022 National Easy Read Report'. Under 'Principal Treatment Centre Results', there are three links: '2022 PTC Data Tables', '2022 Alder Hey Children's NHS Foundation Trust', and '2022 Birmingham Women's and Children's NHS Foundation Trust'. A fourth link, '2022 Cambridge University Hospitals NHS Foundation Trust', is partially visible at the bottom.

<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>

 Home The Survey **Results** Latest News Help & Support

National Results Principal Treatment Centre Results Supporting Documents

The below results are for the 2022 U16 Cancer Patient Experience Survey.

National Results

- [2022 National Data Tables](#)
- [2022 National Quantitative Report](#)
- [2022 National Easy Read Report](#)

Principal Treatment Centre Results

- [2022 PTC Data Tables](#)
- [2022 Alder Hey Children's NHS Foundation Trust](#)
- [2022 Birmingham Women's and Children's NHS Foundation Trust](#)
- [2022 Cambridge University Hospitals NHS Foundation Trust](#)

<https://www.under16cancerexperiencesurvey.co.uk/visual-summaries>

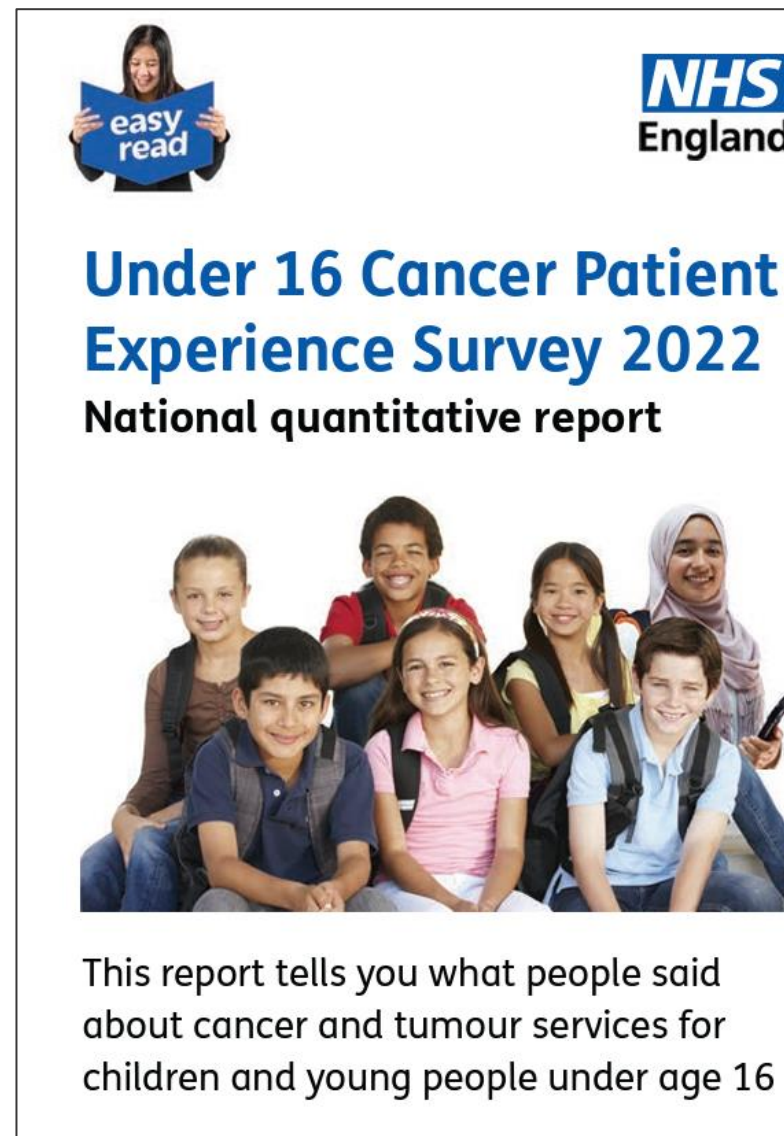
The screenshot shows the website's navigation menu. The 'Results' dropdown menu is open, showing options: 'Technical reports', 'Visual summaries' (highlighted), 'Interactive dashboard', and 'Past results'. Other menu items include 'Home', 'The Survey', 'Latest News', and 'Help & Support'. Below the navigation, a summary of findings from the 2022 survey is partially visible.

This screenshot displays the 'Overall' findings page. It features a navigation bar with categories: Overall, Diagnosis, Communication, Information, Staff, Continuity of care, Involvement, Access, Impact, and Hospital. The main content area includes an introductory paragraph and a large illustration of a doctor consulting with a family. Two callout boxes highlight key statistics: 75% of children said they were very well looked after by staff, and 89% of parents or carers rated the overall experience as 8 or more out of 10. Below this, the 'How the diagnosis was given' section is partially visible, showing statistics like 73% of parents or carers felt they were definitely told about their child's cancer in a sensitive way.

This infographic is divided into two sections. The top section, 'Information about treatment', features an illustration of a family in a waiting room. It contains three callout boxes: 85% of parents or carers reported clear information about treatment; 78% of parents or carers felt healthcare staff always shared information appropriately; and 75% of parents or carers felt staff were always sensitive to information shared in the room. The bottom section, 'Bedside manner and trust in staff', features an illustration of a nurse at a patient's bedside. It contains two callout boxes: 91% of parents or carers felt their child was always treated with respect and dignity; and 83% of parents or carers always had confidence and trust in staff caring for their child. A separate callout box states that 86% of children felt staff were always friendly.

<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>

- Easy read version available



- National and PTC tables available at <https://www.under16cancerexperiencesurvey.co.uk/technical-reports>

Under 16 Cancer Patient Experience Survey			National score				Which of the following best describes you?				Sex of child registered at birth				Ethnic group (6 g				
Sub-group Scores 2022			National score		Boy/Male		Girl/Female		Male		Female		White		Mixed		Asian		
Master Question No.	Survey section	Scored Text	No. of respons	Score	No. of respons	Score	No. of respons	Score	No. of respons	Score	No. of respons	Score	No. of respons	Score	No. of respons	Score	No. of respons	Score	
X03	Finding out about the cancer or tumour	Parents/carers reported that their child saw a GP once or twice before they were referred to hospital	345	59.4%	88	55.7%	62	69.4%	183	56.8%	153	64.1%	261	58.6%	21	57.1%	44	65.9%	*
X06a	Finding out about the cancer or tumour	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)	81	66.7%	*	*	*	*	42	76.2%	39	56.4%	57	70.2%	*	*	15	60.0%	*
X06b	Finding out about the cancer or tumour	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)	84	64.3%	47	63.8%	30	63.3%	48	64.6%	34	64.7%	60	63.3%	*	*	13	69.2%	*
X07	Finding out about the cancer or tumour	Parents/carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way	289	73.0%	75	68.0%	56	73.2%	158	75.9%	127	70.9%	217	71.9%	20	85.0%	35	80.0%	*
X08	Finding out about the cancer or tumour	Parents/carers and children reported that information at diagnosis was definitely given in a way they could understand	289	68.5%	81	66.7%	57	64.9%	163	71.2%	124	65.3%	212	66.0%	19	84.2%	38	78.9%	*
X09	Finding out about the cancer or tumour	Parents/carers and children reported that they were definitely able to have questions answered after being told about the cancer or tumour	288	78.5%	78	83.3%	57	70.2%	159	84.3%	127	71.7%	211	75.4%	20	85.0%	37	91.9%	*
X10	Finding out about the cancer or tumour	Parents/carers reported that they were definitely able to find information about their child's diagnosis	291	73.9%	73	72.6%	54	66.7%	158	79.1%	128	70.3%	218	72.9%	19	73.7%	38	81.6%	*
X11	Finding out about the cancer or tumour	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	125	90.4%	71	88.7%	48	93.8%	74	89.2%	50	94.0%	93	88.2%	*	*	14	92.9%	*
X12	Healthcare staff	Children felt that staff were always friendly	408	86.0%	233	88.0%	169	83.4%	230	87.4%	170	84.1%	303	84.2%	24	87.5%	46	97.8%	12
X13	Healthcare staff	Children reported that they could always understand what staff were saying	407	68.6%	233	70.8%	167	65.9%	230	70.9%	169	66.3%	301	65.4%	25	68.0%	46	87.0%	12
X14	Healthcare staff	Children felt that staff always talked to them, not just their parent or carer	411	71.3%	234	69.7%	170	73.5%	231	69.7%	172	74.4%	305	69.2%	25	72.0%	46	78.3%	12
X15	Healthcare staff	Children reported always or mostly seeing the same members of staff for their treatment and care	409	57.2%	233	56.2%	169	58.0%	230	56.5%	171	58.5%	303	57.1%	25	60.0%	46	65.2%	12
X16	Healthcare staff	Parents/carers reported that they definitely had the chance to ask staff questions about their child's care and treatment	868	87.2%	230	87.4%	168	85.7%	483	88.2%	363	86.8%	649	86.1%	63	92.1%	98	89.8%	27
X17	Healthcare staff	Parents/carers felt that they and their child were always treated with respect and dignity by staff	875	90.9%	232	93.1%	168	88.7%	486	92.2%	367	89.9%	654	89.4%	65	92.3%	97	96.9%	27
X18	Healthcare staff	Parents/carers felt they always had confidence and trust in staff caring for their child	876	82.9%	232	84.9%	168	79.8%	486	83.1%	368	82.9%	655	81.8%	65	84.6%	98	89.8%	26
X19	Healthcare staff	Parents/carers felt that they were always treated with empathy and understanding by staff caring for their child	879	83.4%	233	84.5%	168	81.0%	489	84.9%	368	82.1%	657	81.6%	65	87.7%	98	90.8%	27
X20	Healthcare staff	Parents/carers and children reported not being told different things by different members of staff that left them feeling confused	858	59.0%	234	67.1%	168	60.7%	485	60.6%	363	55.9%	638	56.1%	65	61.5%	96	66.7%	24
X21	Healthcare staff	Parents/carers felt that staff were always sensitive to information shared with them when their child was in the room	785	74.5%	225	74.2%	165	83.6%	440	73.4%	326	76.1%	586	75.3%	57	75.4%	89	70.8%	24
X22	Healthcare staff	Parents/carers felt that healthcare staff always shared information with children in a way that was appropriate	759	78.0%	228	78.5%	166	80.7%	425	77.4%	313	78.9%	567	76.7%	50	82.0%	86	82.6%	25

- Background, methods and how to interpret results
- About the respondents

About the respondents[†]

Table 1. Response rate

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

	Original sample size	Adjusted sample size ^{††}	Completed	Response rate
PTC	217	217	70	32%

Table 2: Percent of respon

Survey type

National

Survey mode	n	%	n	%
Paper	49	70%	617	70%
Online	21	30%	266	30%
Mixed (combination of paper and online) [†]	0	0%	0	0%
Phone – English	0	0%	2	0%
Phone – Translation service	0	0%	0	0%

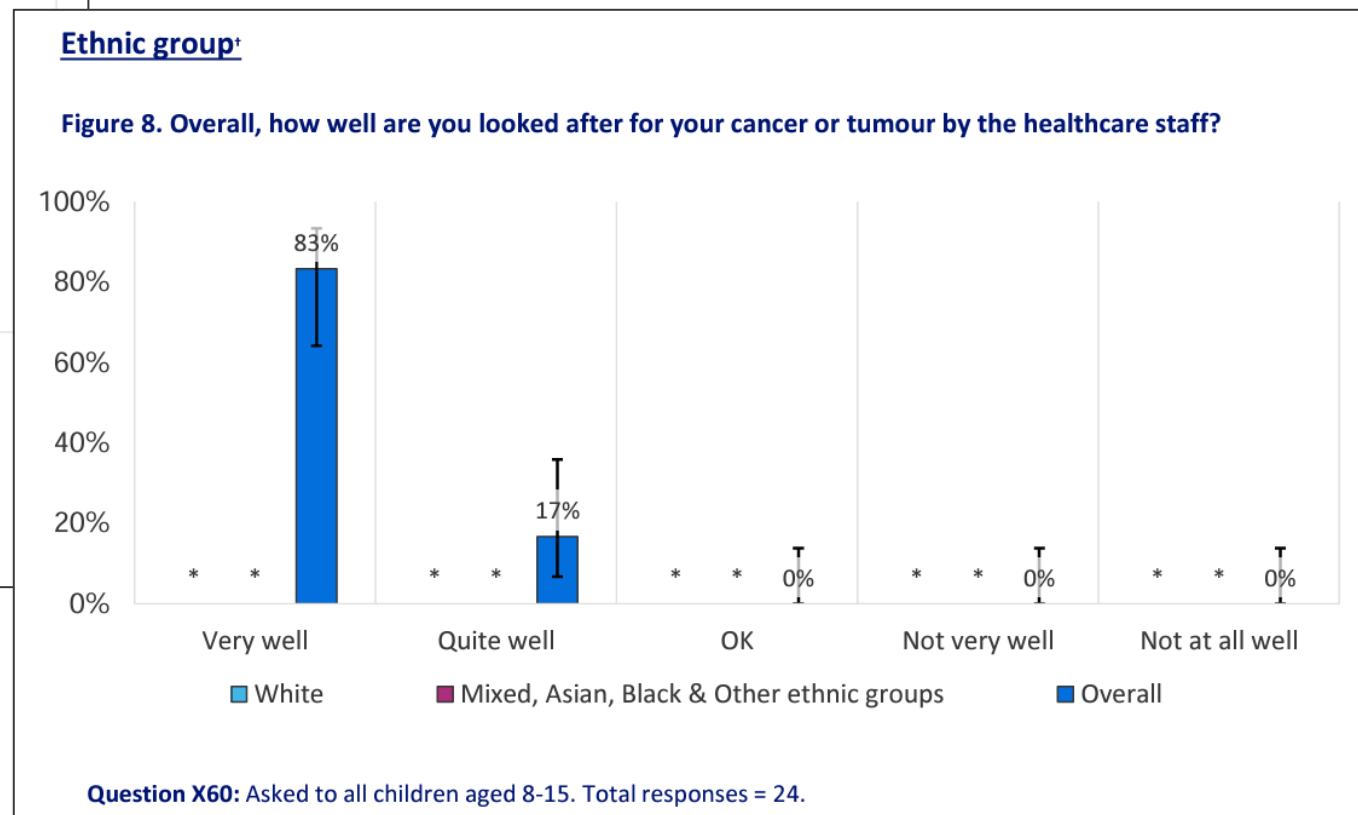
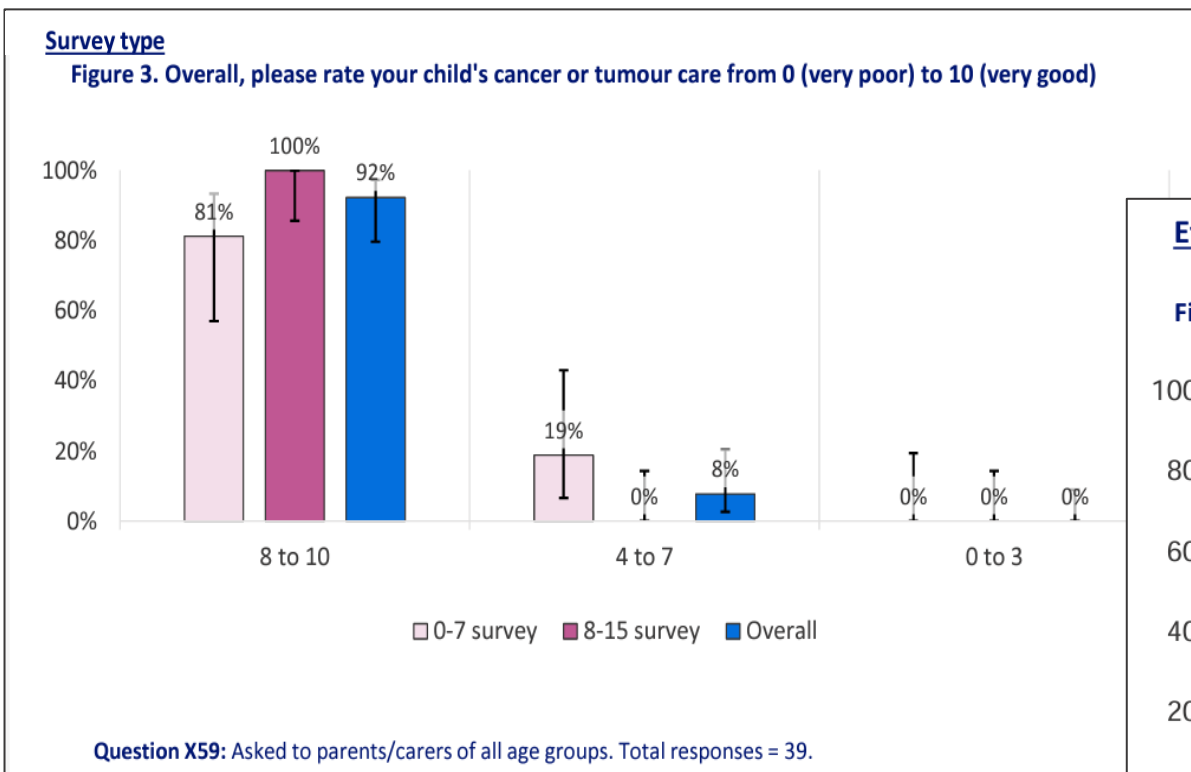
Table 3: Percent of responses by survey type

PTC

National

Survey	n	%	n	%
0-7	35	50%	450	51%
8-11	16	23%	185	21%
12-15	19	27%	250	28%

- Overall care – subgroup comparisons



- Results by survey section

[Finding out about the cancer or tumour](#).....

[Child's care and treatment](#).....

[Care in hospital](#).....

[Care at home or school](#).....

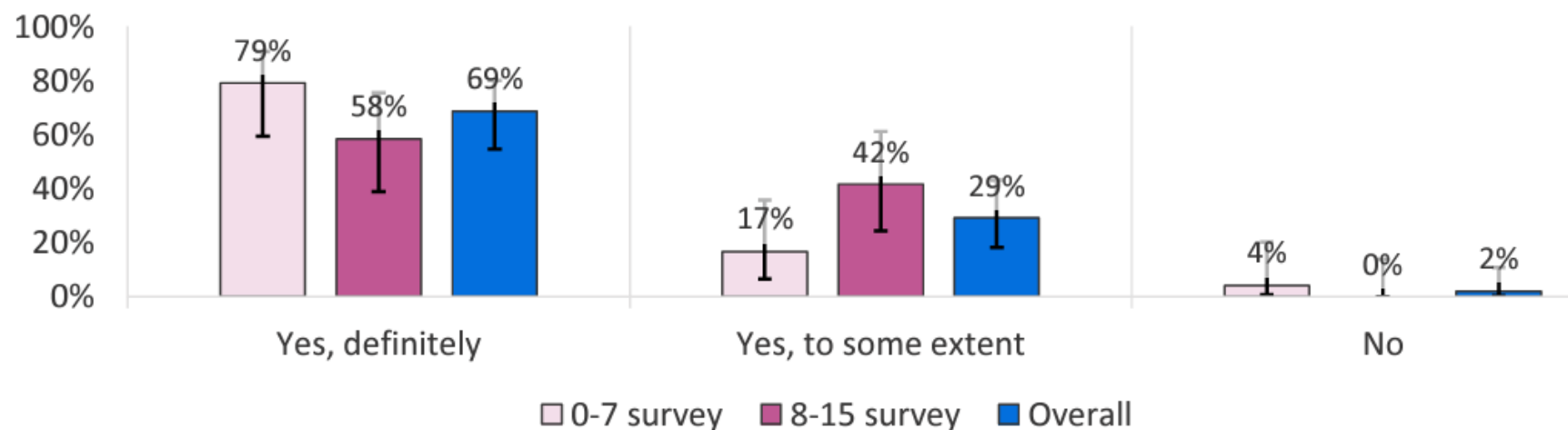
[Healthcare staff](#).....

[Bedside manner and trust](#).....

[Clear communication](#).....

[Support](#).....

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



Question X33: Asked to parents/carers of all age groups. Total responses = 48 (excluding 5 response(s) of "This is not needed").

- Comparisons to 2021 survey

Year on year comparisons

The line charts in this section show the national score and the score for your PTC for 2021 and 2022 for all comparable questions.

We recommend that PTCs take caution when benchmarking their results against last year, or against results at national level, due to numbers of responses. Please refer to the ['How to use this data'](#) section for more information.

Please note that the 2022 scores that are not comparable to 2021 are not presented in this section and can be found in the data tables on the [survey website](#).

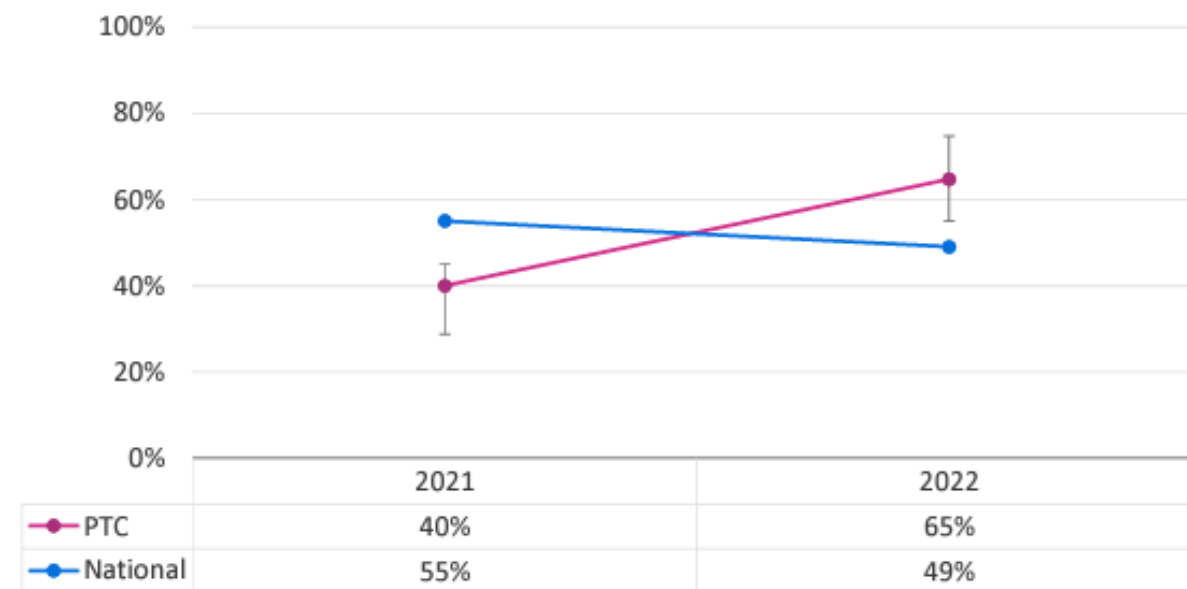
How to interpret these results

In this section, the confidence intervals surround the PTC data only and not the national data.

Assuming the sample is representative of your organisation, confidence intervals are a method of describing the uncertainty around these estimates. The most common methodology, which was used here, is to produce and report 95 percent confidence intervals around the results. At the 95 percent confidence level, the confidence intervals are expected to contain the true population value 95 percent of the time (i.e. out of 100 such intervals, 95 will include the true figure).

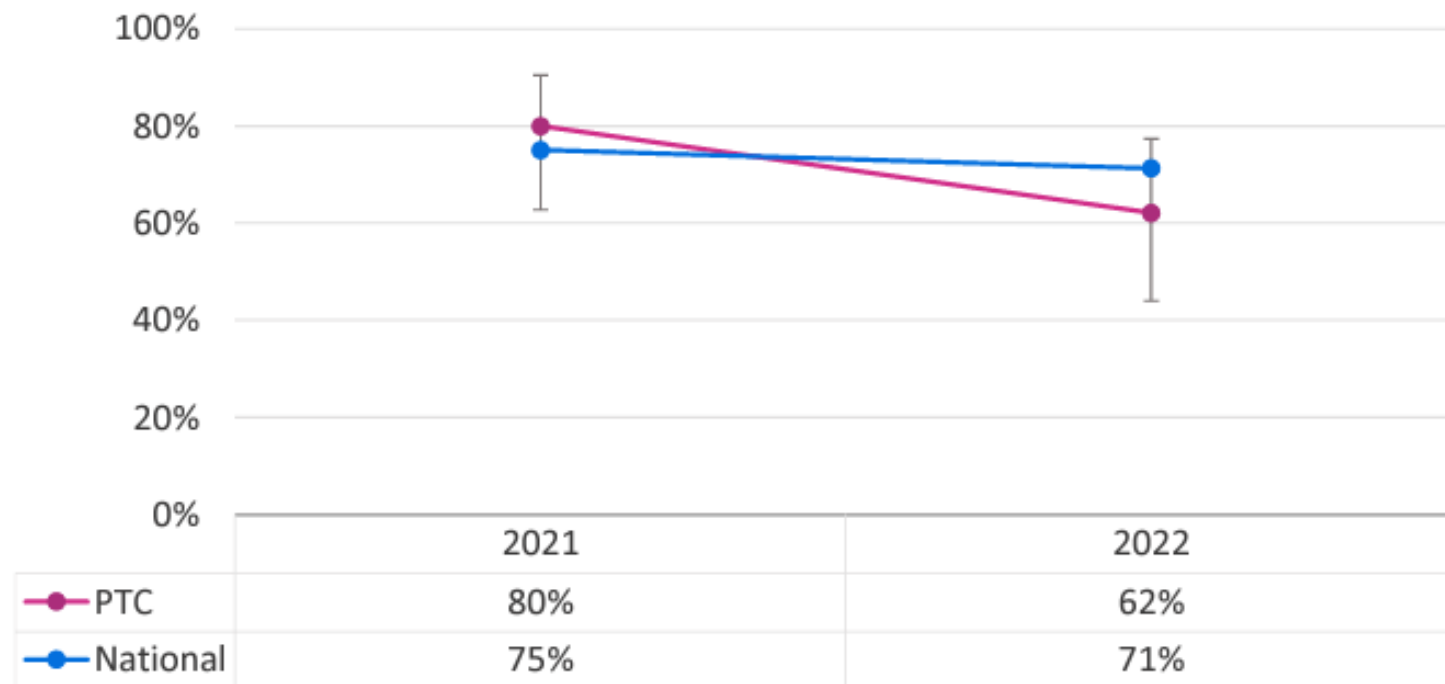
In this example below, the PTC scored 40% in 2021, and 65% in 2022. As the confidence intervals do not overlap, you could be statistically confident that there is “true” difference between the two.

EXAMPLE DATA ONLY



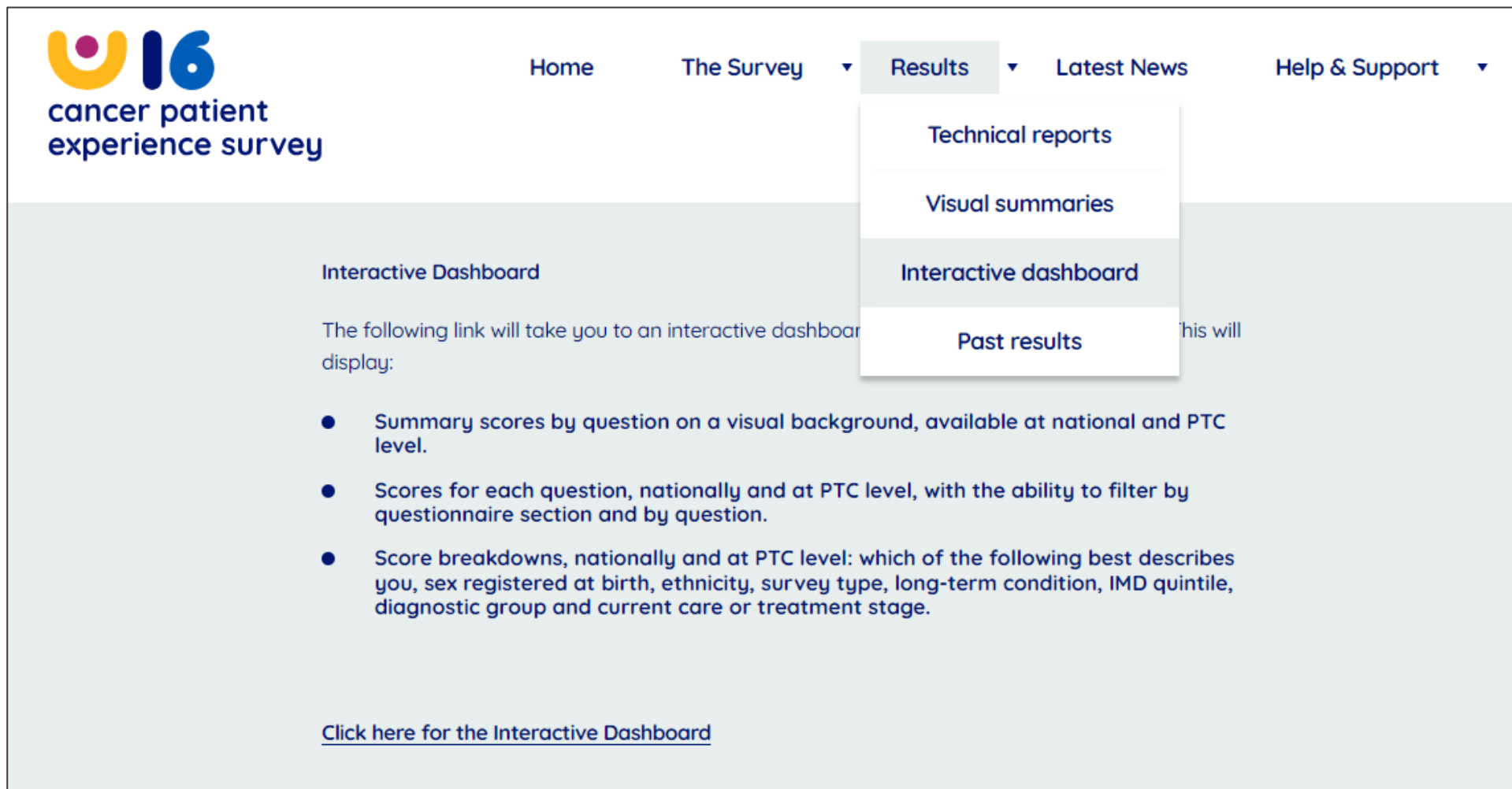
- Comparisons to 2021 survey

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



Question X14: Asked to all children aged 8-15. Total PTC responses for 2021 = 30, for 2022 = 29.

<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>



The screenshot shows the website's navigation menu with the 'Results' dropdown open. The 'Interactive dashboard' option is highlighted. Below the menu, the page content includes a heading 'Interactive Dashboard', a paragraph explaining the link, and a bulleted list of features. A link to the dashboard is provided at the bottom.

U16
cancer patient
experience survey

Home The Survey ▾ **Results** ▾ Latest News Help & Support ▾

Technical reports

Visual summaries

Interactive dashboard

Past results

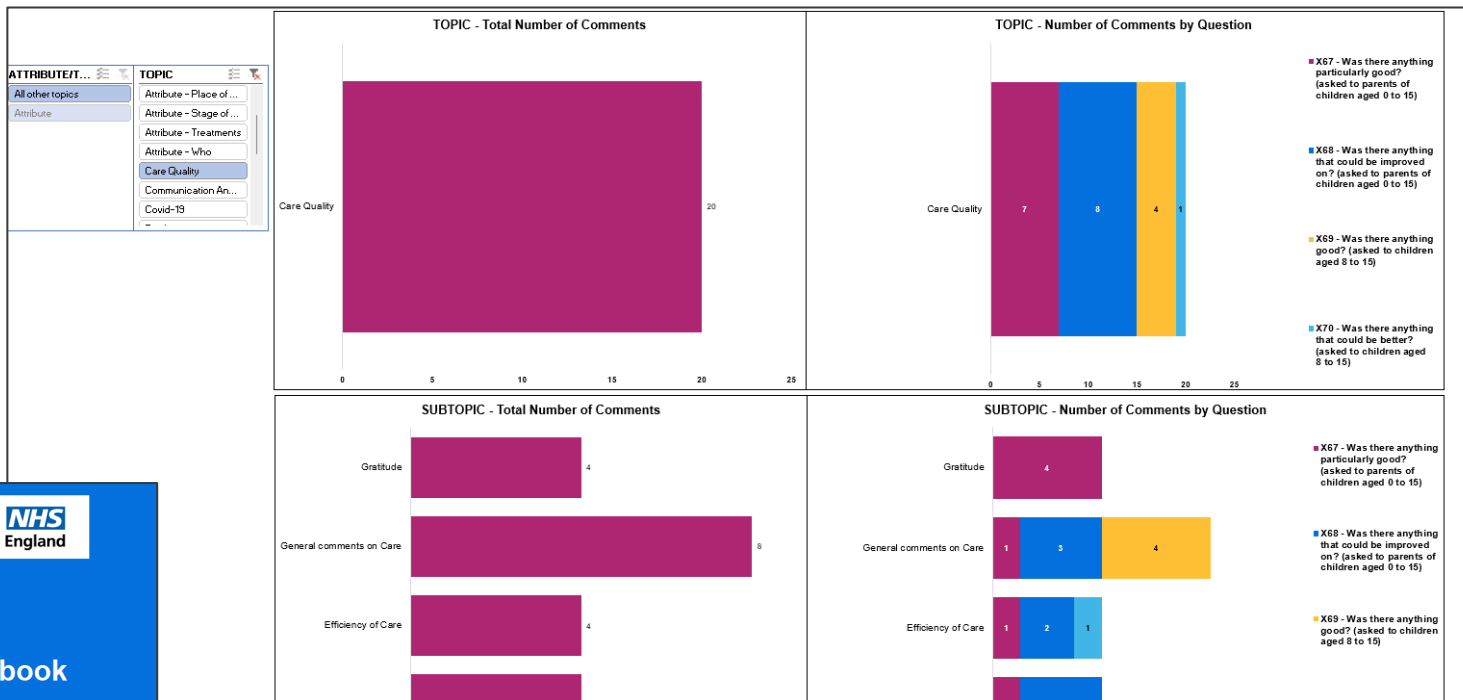
Interactive Dashboard

The following link will take you to an interactive dashboard which will display:

- Summary scores by question on a visual background, available at national and PTC level.
- Scores for each question, nationally and at PTC level, with the ability to filter by questionnaire section and by question.
- Score breakdowns, nationally and at PTC level: which of the following best describes you, sex registered at birth, ethnicity, survey type, long-term condition, IMD quintile, diagnostic group and current care or treatment stage.

[Click here for the Interactive Dashboard](#)

- Emailed to PTCs on publication day



The cover of the workbook features the logos for Picker, U16 cancer patient experience survey, and NHS England. The title is 'Under 16 Cancer Patient Experience Survey 2022 Free Text Workbook'. Below the title is a field for 'Your PTC Name' and a speech bubble icon at the bottom right.

<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>

Supporting Documents

2022 Technical Appendix

2022 Parent 0-7 Survey

2022 Child/Parent 8-11 Survey

2022 Child/Parent 12-15 Survey

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Next Steps



Dates	Task
Wednesday 24 th January 2024, morning	U16 CPES 2022 workshop 2 – more information to follow
Ongoing until January 2024	Cognitive testing of 2023 Surveys
December 2023	U16 CPES 2023 Sampling instructions (Patient List Template, Sample Checker User Guide, Declaration Form, DSA) available to Trusts
Wednesday 10 th January 2024, 14:00-15:30	U16 CPES 2023 Sampling Webinar
January-February 2024	Sampling starts – Trusts to submit DSAs, Declaration Forms, Patient Samples & Covering Letter Information to Picker

Please help improve children's cancer care by testing a patient survey!

- Has your child been diagnosed with cancer or a tumour? Picker is a healthcare research charity, working with NHS England to run the Under 16 Cancer Patient Experience Survey.
- We would like children under 16 with recent experience of cancer or tumour care, and their parents/carers, to help us test a patient survey to improve patient care.

For more information and to sign up visit:
<https://bit.ly/Under16CPSEExperience>



£60

Love2Shop or
Amazon gift
voucher per
interview

Survey year	Number of responses	Response rate
2020	1,144 out of 3,339	35%
2021	960 out of 3,672	26%
2022	885 out of 3,569	25%



Next Workshop

Wednesday 24th January 2024

In your organisation:

- What are you proud of?
- What are you looking to improve?
- Where would you like to learn from others?



Close

NHS England

Neil Churchill, Director for Experience, Participation & Equalities,





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.