

Under 16 Cancer Patient Experience Survey 2021

National Report (Quantitative)

Published November 2022



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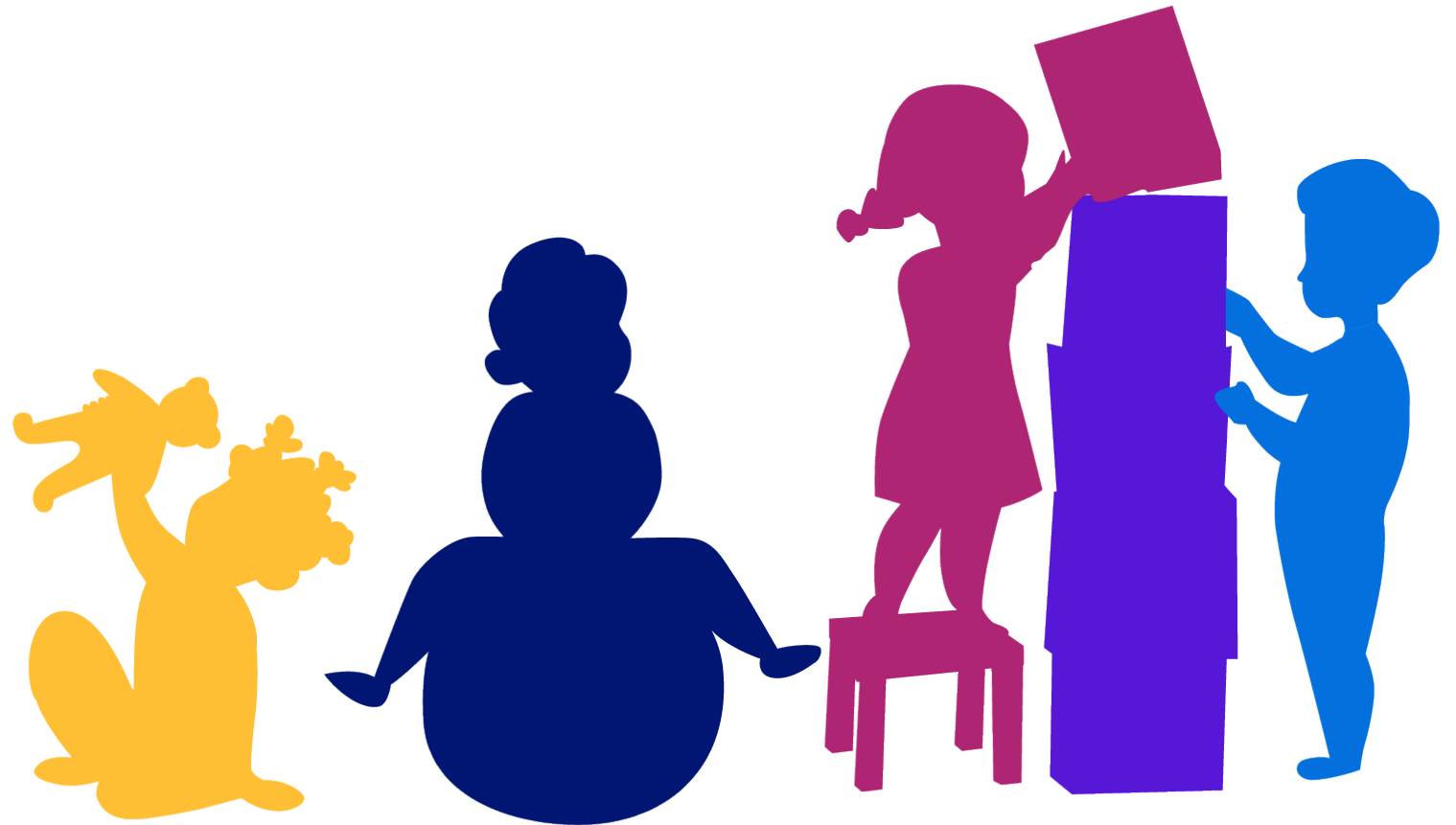
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1. Executive summary



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



77% of children report being looked after very well for their cancer or tumour by healthcare staff (Question X63, Slide 25).



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10 (Question X62, Slide 25).

Key question* scoring



78% of parents/carers reported that they were given clear written information about their child's treatment (Question X39, Slide 43).



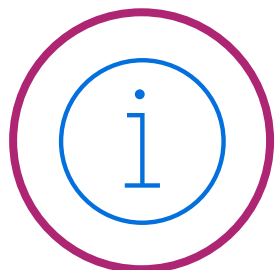
74% of parents/carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way (Question X07**).

*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.

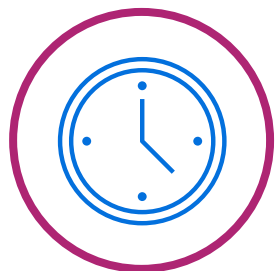
** Full response breakdowns of this question can be found in the national Excel data tables [on the survey website](#).



84% of parents/carers always have confidence and trust in staff caring for their child (Question X16, Slide 58).



85% of parents/carers felt that staff definitely give them information in a way they can understand (Question X12**).



75% of parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment (Question X40**).



72% of children reported that they could always understand what staff are saying (Question X14, Slide 61).



82% of children reported that staff always speak to them in a way that is suitable for them (Question X21**).



63% of parents/carers reported that they definitely have access to reliable help and support 7 days a week from the hospital (Question X34, Slide 44).



57% of parents/carers feel that different hospital staff are definitely aware of their child's medical history (Question X29, Slide 43).

* 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.

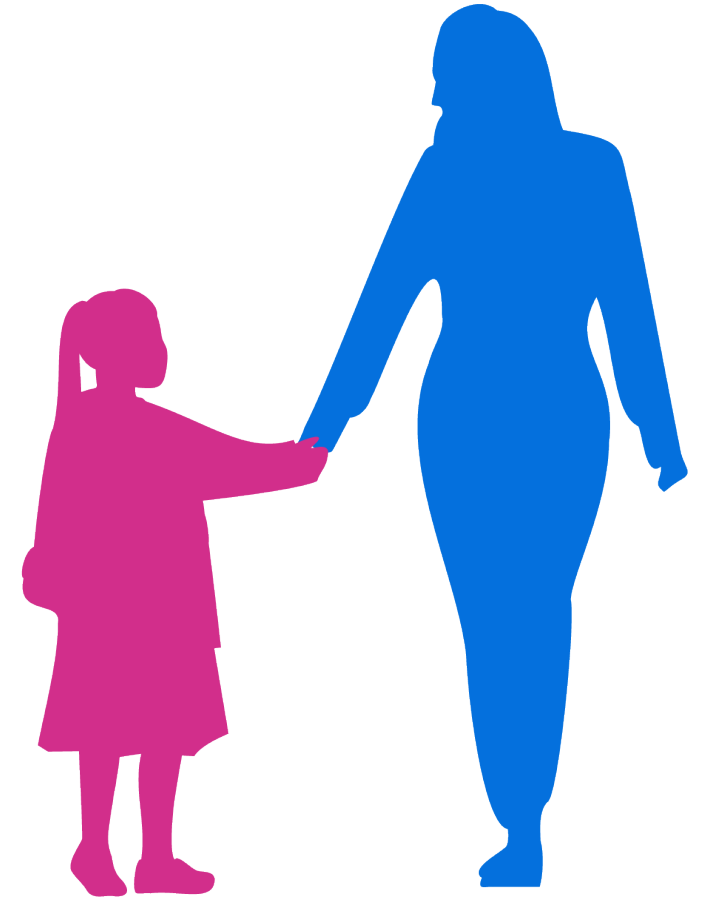
** Full response breakdowns of this question can be found in the national Excel data tables [on the survey website](#).

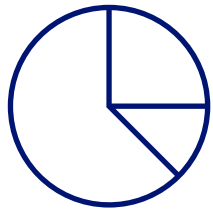


cancer patient
experience survey



2. Introduction

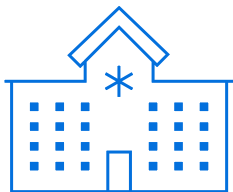




The Under 16 Cancer Patient Experience Survey (U16 CPES) measures experiences of tumour and cancer care for children across England. It is expected to run annually. This report presents the U16 CPES 2021 headline findings and is the second iteration of the survey. Please see [Understanding the results](#) for information about historical trend comparisons.



The survey's respondents are children who were aged under sixteen at the time of their care, 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 2021 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 2021, aged under 16 at their time of discharge.

Questionnaire and mode



- A paper questionnaire with a cover letter invite 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 asked about the child's care during 2021. 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 able to respond to the questionnaire between April and June 2022.

4. Understanding the results





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

To protect the identity of respondents, suppression rules have been applied to data (both scores and proportions):



- Where the total number of responses to a question is less than 11, data for the question are suppressed, indicated by an asterisk (*).
- Double suppression: where the base size for any sub-group (e.g. ethnic group or diagnostic group) is less than 11, data for that sub-group AND the next smallest sub-group are suppressed.
- Further information regarding suppression rules can be found in the [Technical Appendix](#).



Note that the sampling period occurred when some COVID-19 restrictions were in place. This should be taken into consideration when interpreting the results.



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](#).

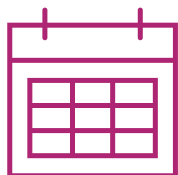
The data for each question is presented in the charts for all response options, so includes non-applicable response options such as ‘Don’t know/can’t remember’.



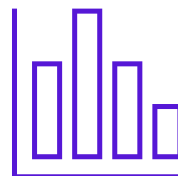
These response options are not included in the scored data. As such, the percentages within the explanatory text accompanying the charts may not always match the percentages within the charts themselves. Full data and scores, including how scores to each question are calculated, can be found within the National Excel Data Tables available on the [survey website](#).

Where the full breakdown of response options is not provided, the overall score shows the percentage of respondents who gave the most favourable response to a question.

The Under 16 CPES is at a relatively early point in its evolution and we continue to learn a lot about what is working well and what might need adjusting. There are differences between the 2021 and 2020 surveys which has led to the analytical and insight recommendation that comparisons should not be made between results. In line with this, **comparisons between 2021 and 2020 results are not included within this report and trends are not shown.** This is because:

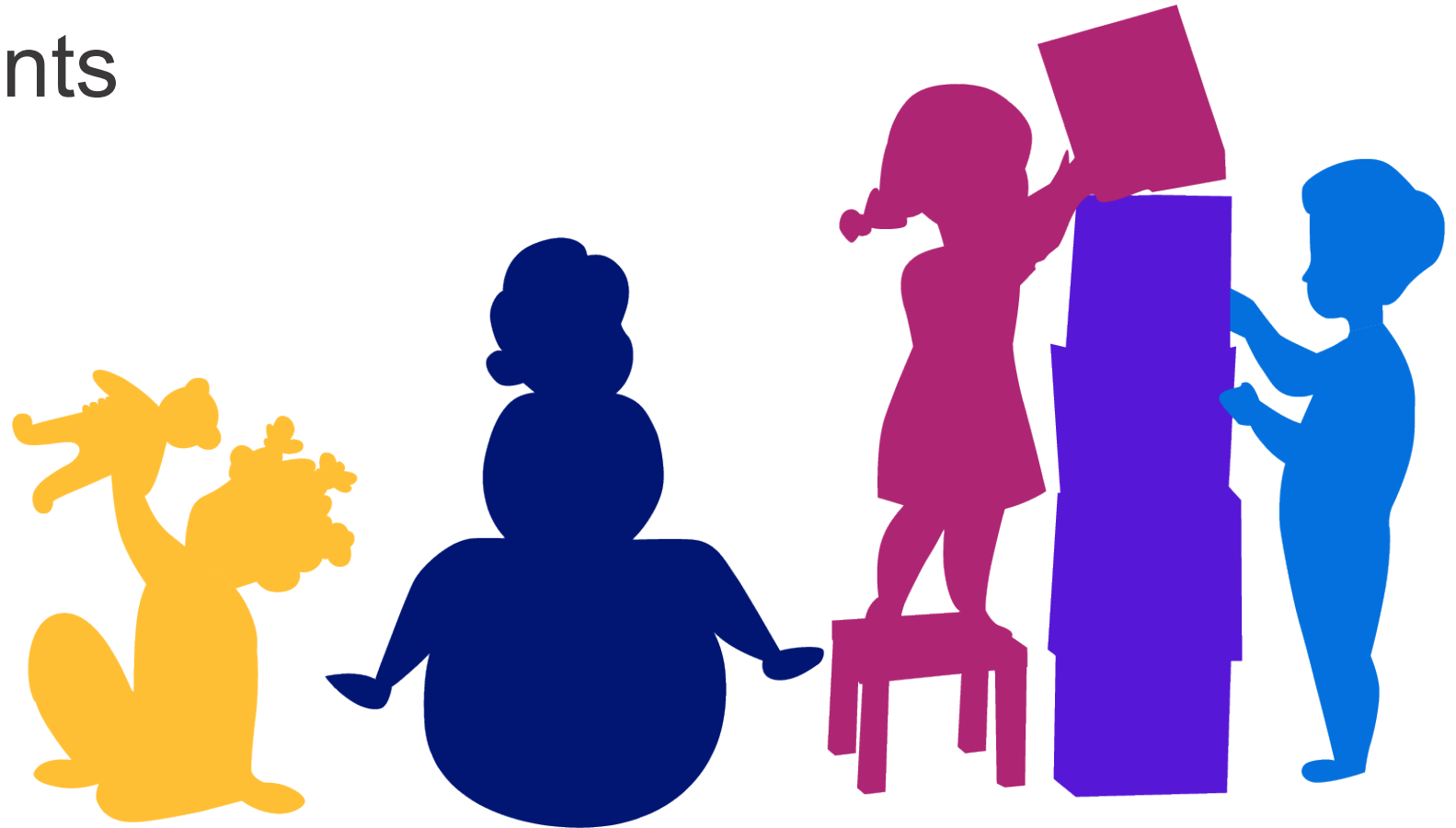


- **Feedback from cognitive interview testing with patients identified that clarification was needed on which time period patients should be reporting on.** Changes have been made to the wording to accommodate this, but as these only affect this year's iteration, the 2020 and 2021 survey report on patients' experience of care across potentially different and overlapping time periods.



- Additionally, there are **differences in response rates across the 2 years.** Coupled with a small sample size, this reduces statistical confidence in comparisons.
- Taken together, this makes it **extremely difficult to disentangle change (or lack of) in patient experience from survey change** when comparing results. Work will be undertaken to enhance comparability as much as possible for future years.

5. About the respondents



Overall response rate

Out of 3,672 eligible parents and children, 960 responded to the survey, yielding a response rate of 26%.

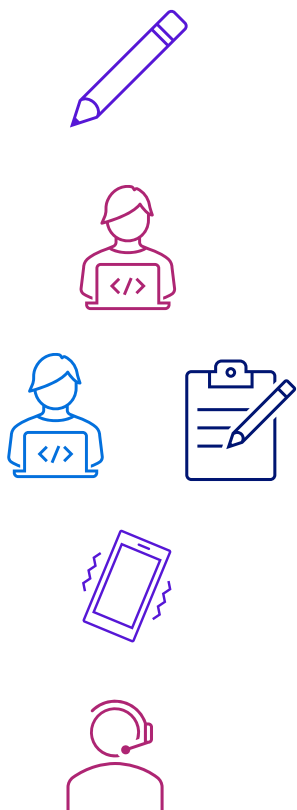


A response consists of one survey completion for a single patient, which could consist of both parent and child responses.

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
3,690	3,672	960	26%

Survey mode



Response mode	Number of responses	Proportion of responses
Paper	708	74%
Online	252	26%
Mixed (combination of paper and online)	0	0%
Phone - English	0	0%
Phone – translation	0	0%
Total	960	100%

Survey type

	Survey Type	Number of responses	% of responses
	Parents of children aged 0 to 7	518	54%
	Children aged 8 to 11 (and their parents)	191	20%
	Children aged 12 to 15 (and their parents)	251	26%
	Total	960	100%

Gender of child (from survey responses)

Gender	No. of responses	% of responses
Male	536	56%
Female	387	40%
Prefer not to say	8	1%
Not given	29	3%
Total	960	100%

Ethnic background of child (from survey responses)

Ethnicity	No. of responses	% of responses
White	717	75%
Mixed	58	6%
Asian	112	12%
Black	36	4%
Other*	12	1%
Not given	25	3%
Total	960	100%

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	225	23%
No other long term condition	710	74%
Not given	25	3%
Total	960	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
Leukaemia, myeloproliferative diseases, and myelodysplastic diseases	385	40%
Lymphomas and reticuloendothelial neoplasms	112	12%
CNS and miscellaneous intracranial and intraspinal neoplasms	200	21%
Retinoblastoma	17	2%
Renal tumours	52	5%
Hepatic tumours	16	2%
Malignant bone tumours	35	4%
All other	143	15%
Total	960	100%

IMD** quintile (deprivation)

Quintile	No. of responses	% of responses
1 (most deprived)	159	17%
2	179	19%
3	188	20%
4	190	20%
5 (least deprived)	221	23%
Outside England	23	2%
Total	960	100%

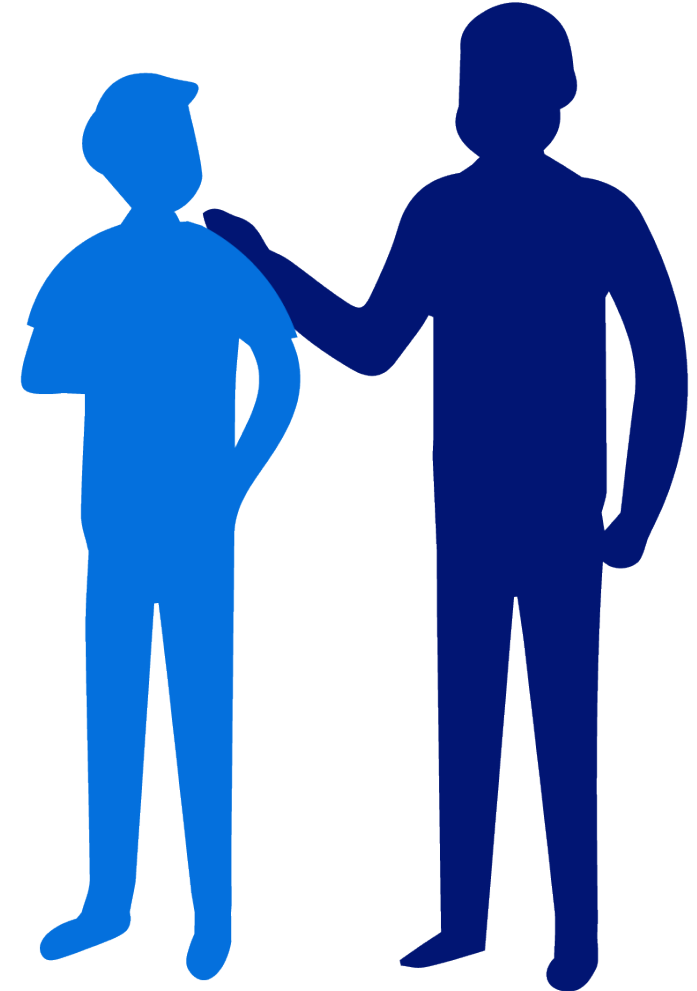
** Index of Multiple Deprivation (IMD) classifies geographic areas into five quintiles based on relative disadvantage, based on where the patient lives (not where they receive care and treatment).

6. National results





6.1 Overall care

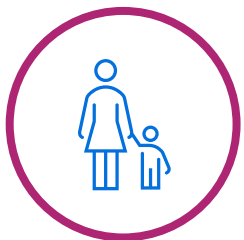




This section shows responses to the overall care questions by various sub-groups. Further information about how sub-groups were determined can be found in the Technical Appendix, available [on the survey website](#). Please take care when drawing conclusions from results based on small numbers of responses.



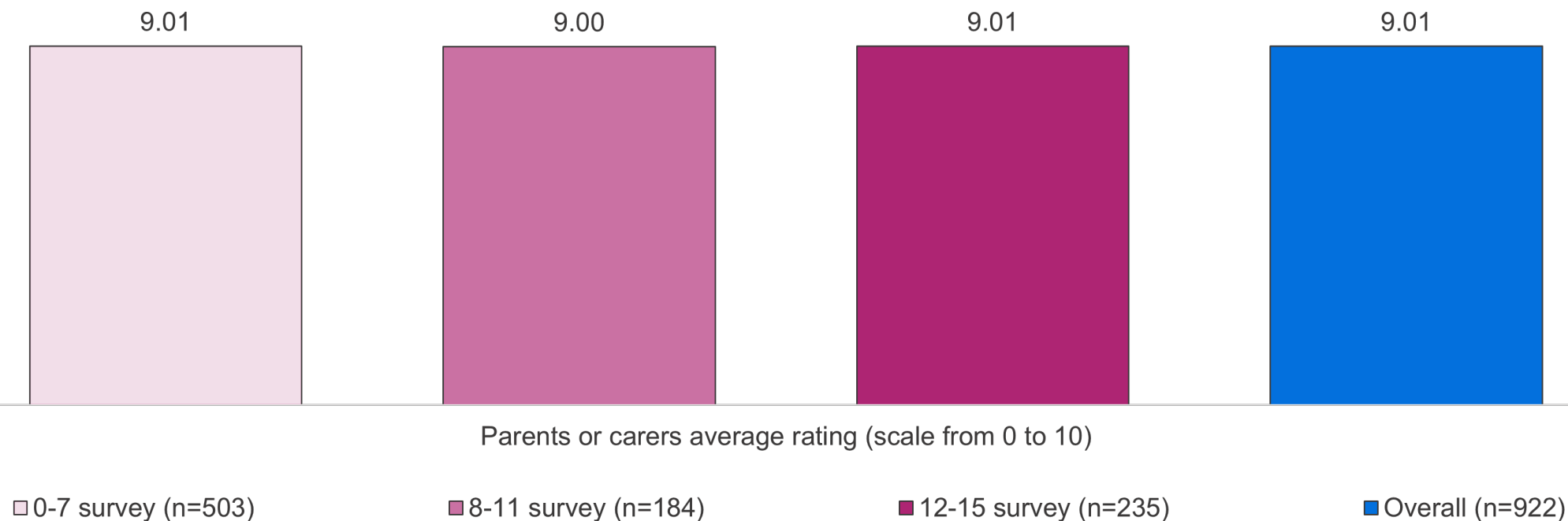
A breakdown of all survey questions and scores to each question by each sub-group can be found in the National Excel Data Tables, available [on the survey website](#) and in an [interactive dashboard](#).



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 to 10 (good), 4 to 7, and 0 to 3 (poor).

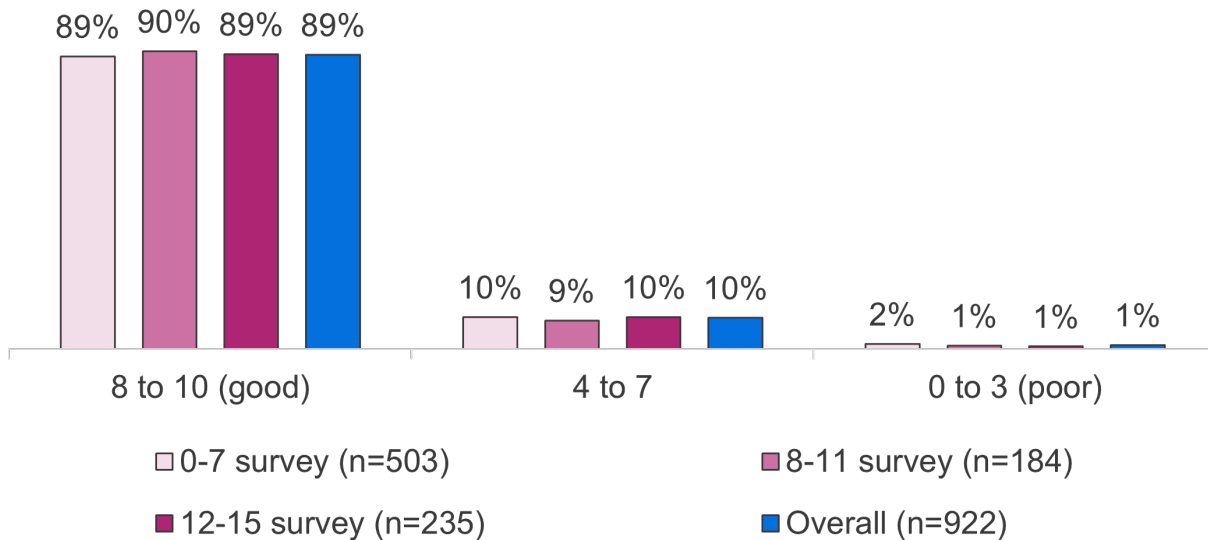
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



9.01 was the average parent/carer rating of the overall experience of their child's care (scale from 0 to 10). There was little difference in average parent/carer rating of overall care between age groups.

Chart shows question X62_Average: Asked to parents/carers of all age groups, total number of responses = 922

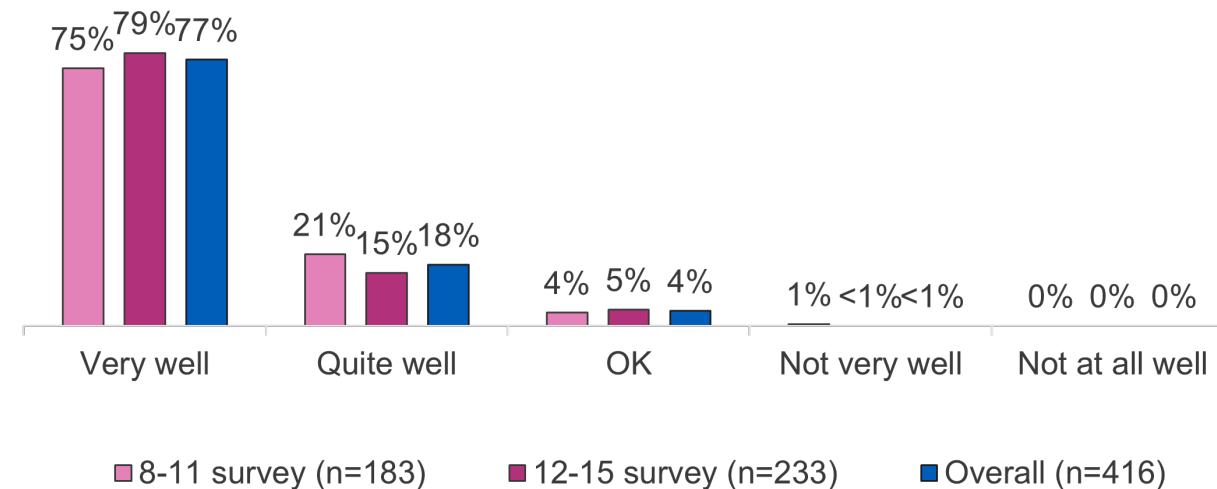
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10. Parent/carer ratings of overall care was similar across all age groups.

Chart shows question X62: Asked to parents/carers of all age groups, total number of responses = 922

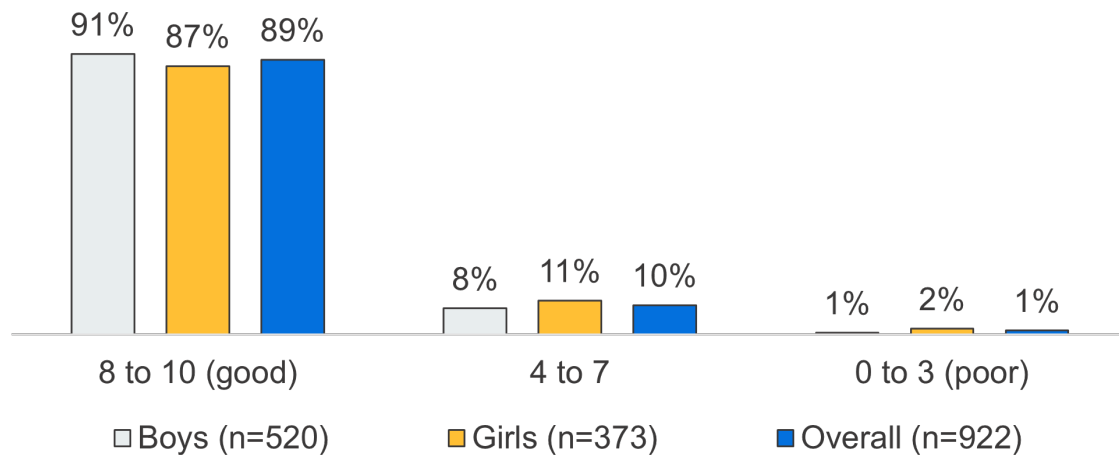
Overall, how well are you looked after for your cancer or tumour by healthcare staff?



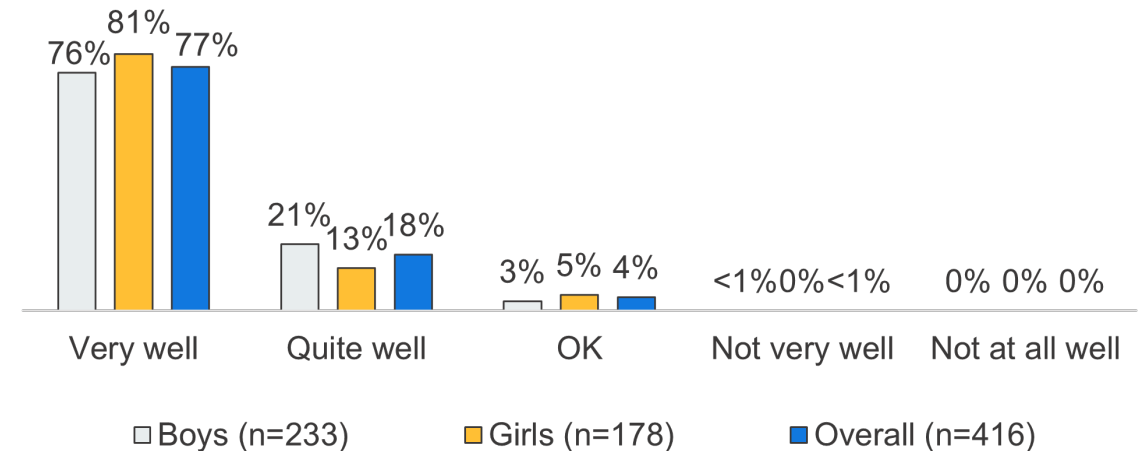
77% of children report being looked after very well for their cancer or tumour by healthcare staff. This was slightly higher for 12 to 15 year olds (79%) compared to those aged 8 to 11 (75%).

Chart shows question X63: Asked to all children aged 8 to 15, total number of responses = 416

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



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



89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10. This was the case for 91% of parents/carers of boys and for 87% of girls.

77% of children report being looked after very well for their cancer or tumour by healthcare staff. 81% of girls reported this, compared to 76% of boys.

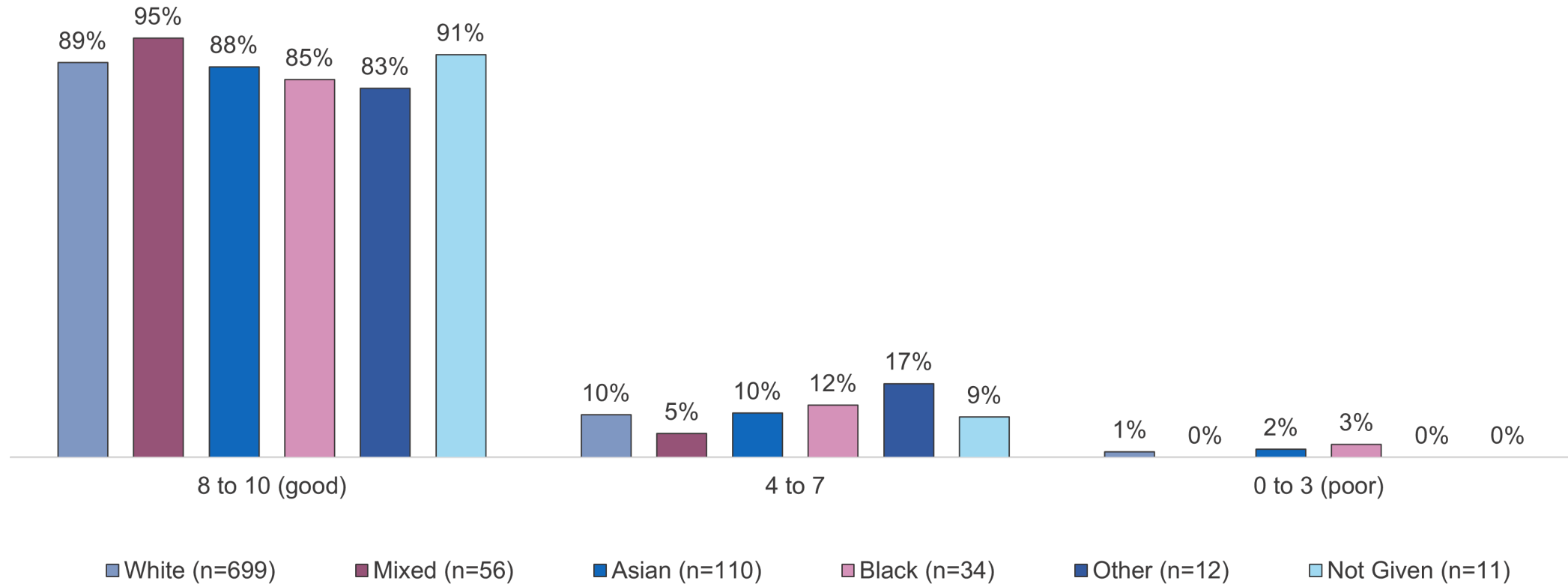
Chart shows question X62: Asked to parents/carers of all age groups, total number of responses = 922

Chart shows question X63: Asked to all children aged 8 to 15, total number of responses = 416

Only data for boys and girls is shown, as the number of respondents answering 'prefer not to say' to the gender question was small (n=8) and would be suppressed

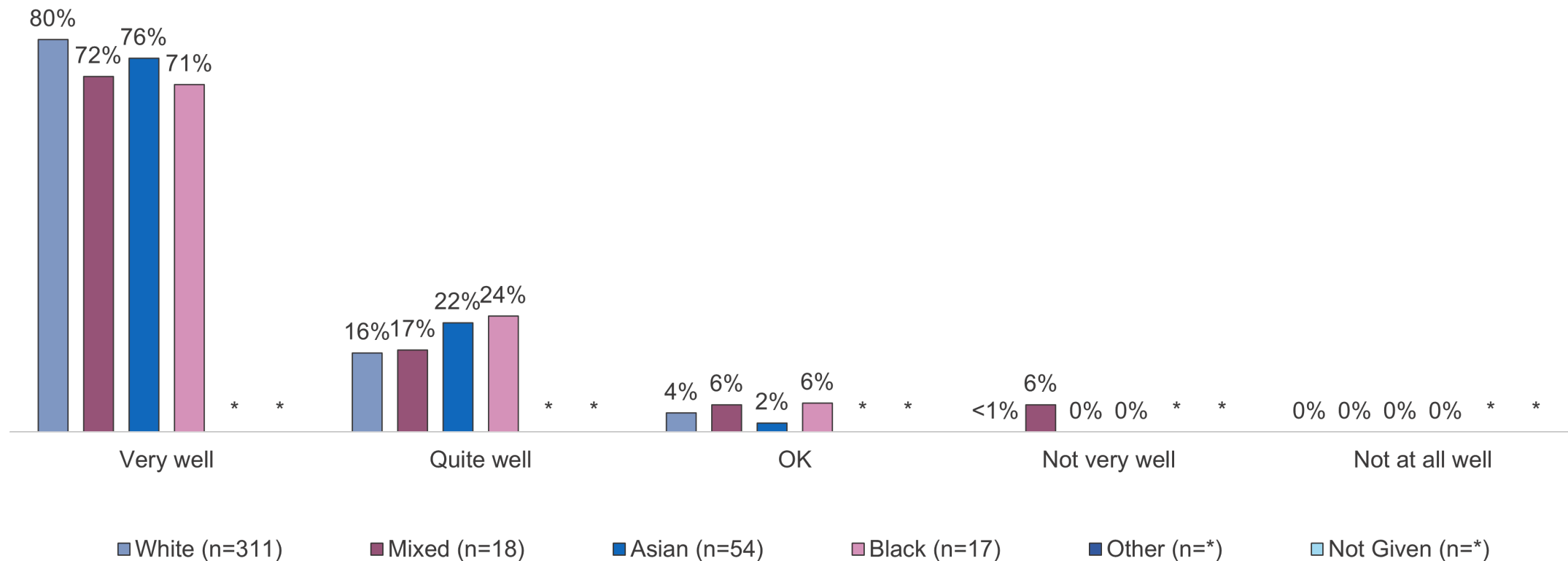
Only data for boys and girls is shown, as the number of respondents answering 'prefer not to say' to the gender question was small (n= 8) and would be suppressed

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



Parents/carers of children from a mixed ethnic background were more likely to rate the overall experience of their child's care as 8 or more out of 10 compared to other ethnic groups.

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

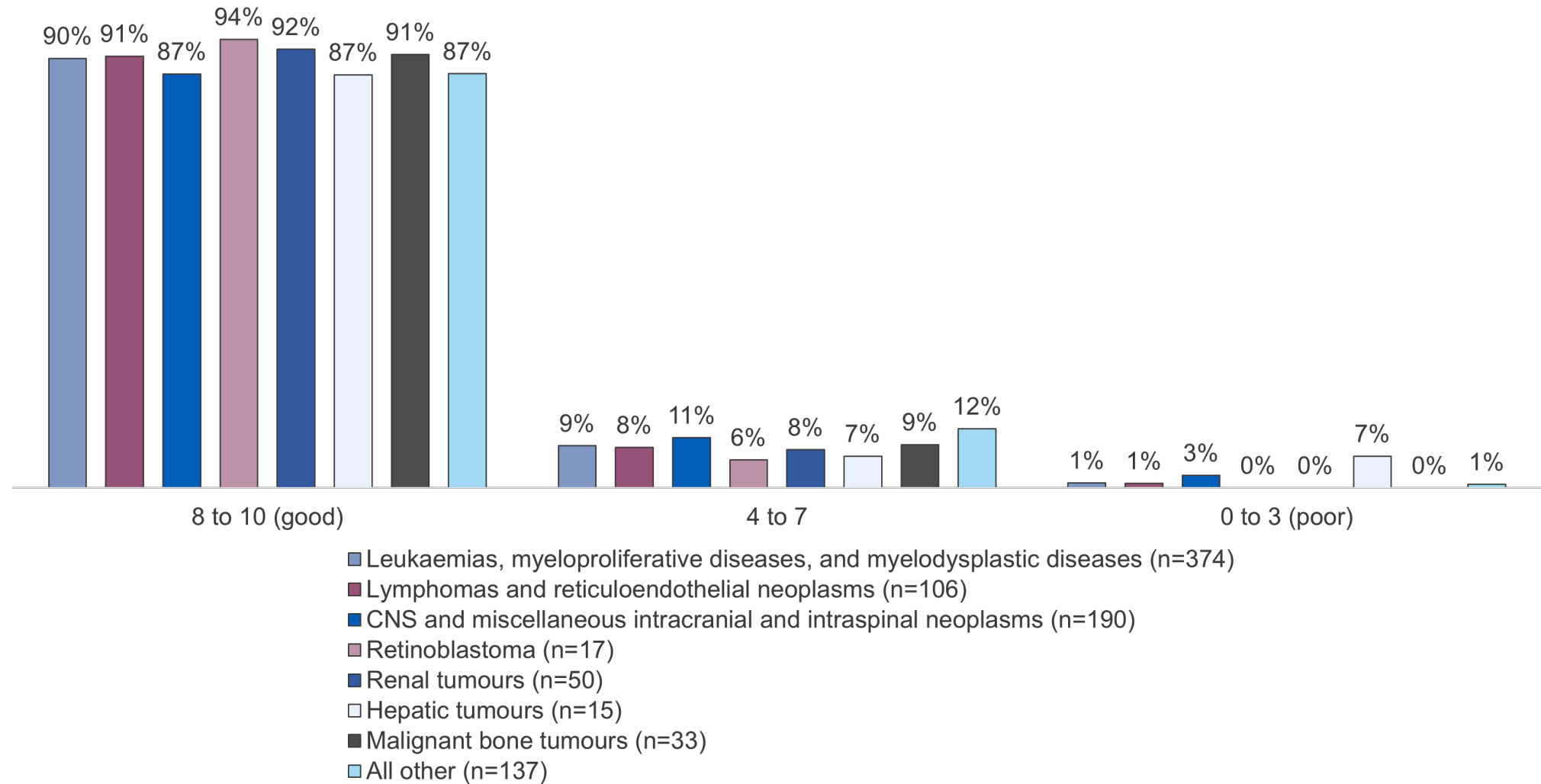


Patients from a white ethnic background were more likely to say they were looked after very well compared to Asian, mixed or black respondents.

Chart shows question X63: Asked to all children aged 8 to 15, total number of responses = 416

* An asterisk indicates that data has been suppressed (see page 12 for details)

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



Parents/carers of children with Retinoblastoma were more likely to rate the overall experience of their child's care as 8 or more out of 10 than other diagnostic groups.

Chart shows question X62: Asked to parents/carers of all age groups, total number of responses = 922

Children with Lymphomas and reticuloendothelial neoplasms were more likely to say they were looked after very well compared to groups with Leukaemias, myeloproliferative diseases, and myelodysplastic diseases, and with CNS and miscellaneous intracranial and intraspinal neoplasms.

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

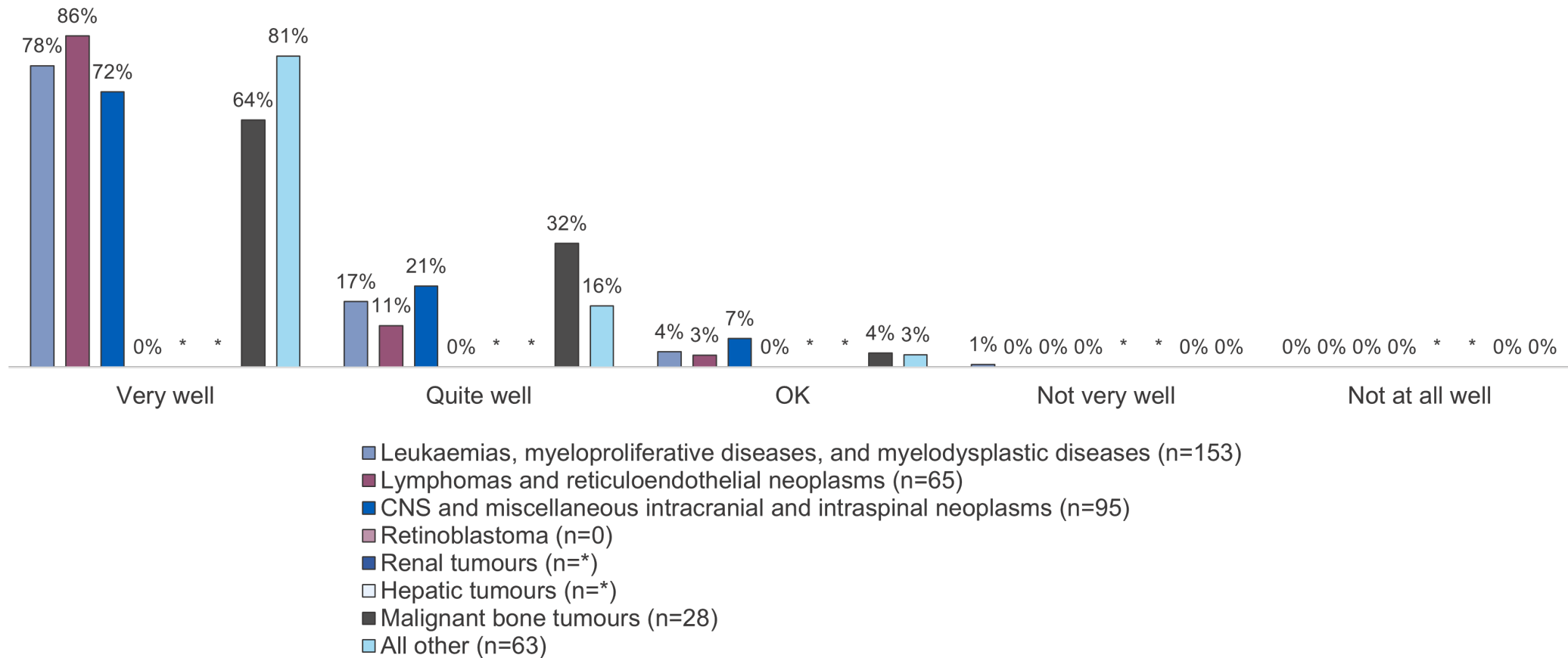
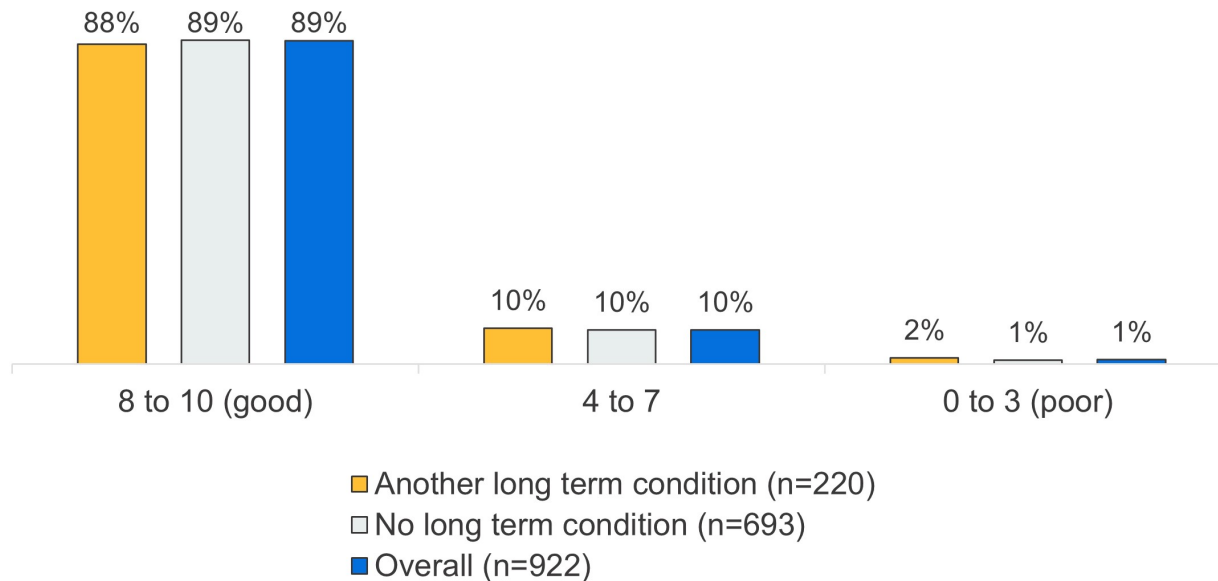


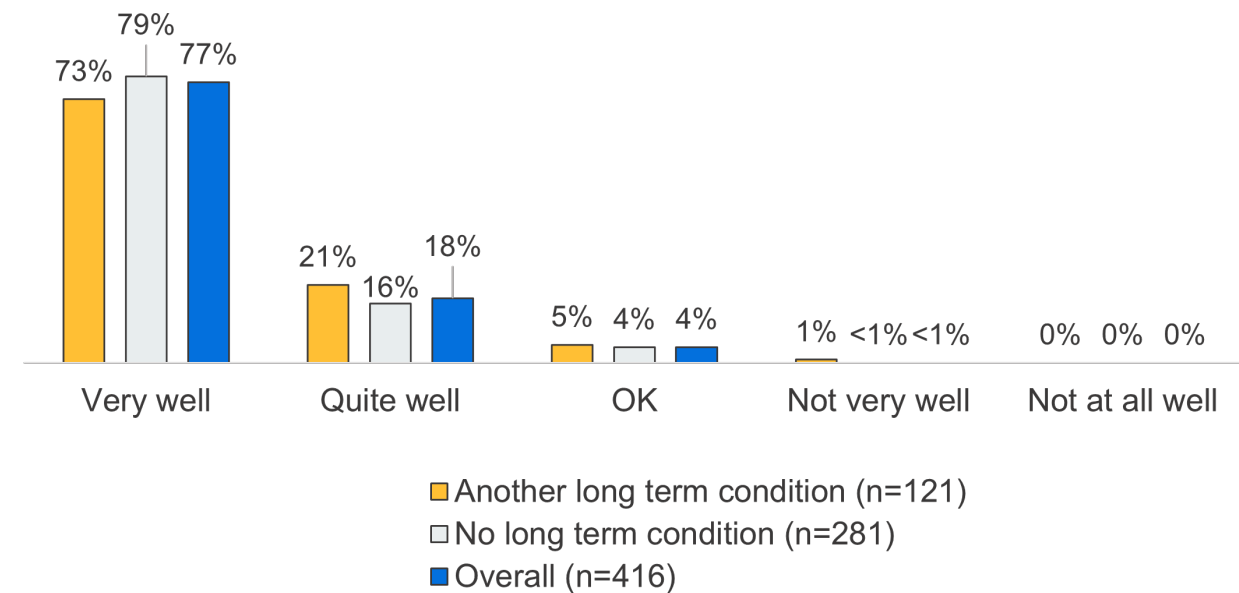
Chart shows question X63: Asked to all children aged 8 to 15, total number of responses = 416

* An asterisk indicates that data has been suppressed (see page 12 for details)

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



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



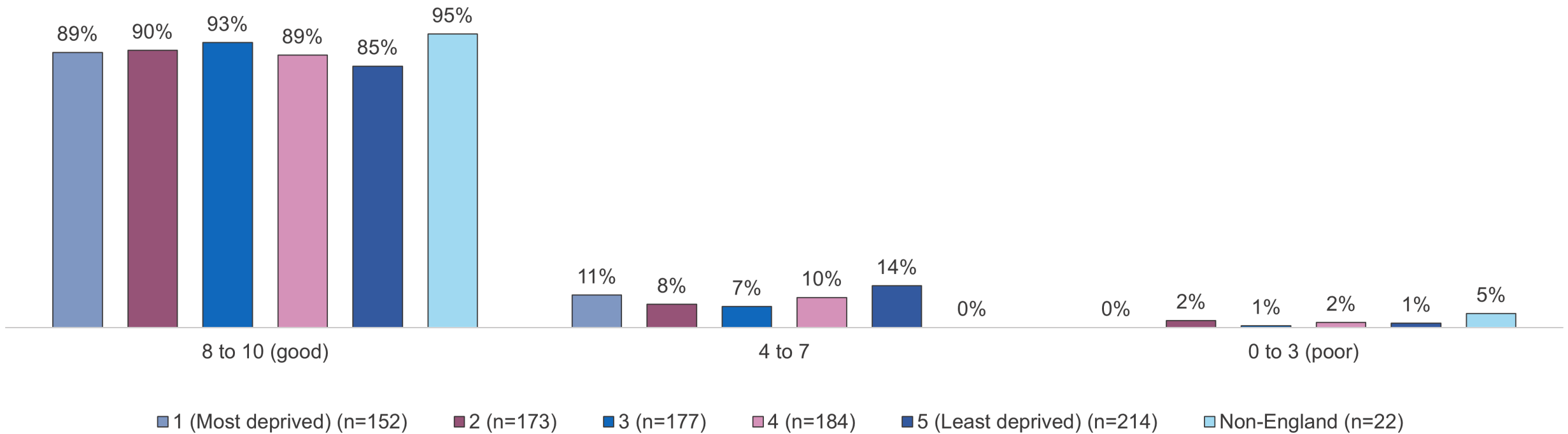
89% of parents/carers rated the overall experience of their child's care as 8 or more out of 10. This was very similar for parents/carers of children with (88%) and without (89%) another long term condition.

77% of children report being looked after very well for their cancer or tumour by healthcare staff. This was slightly higher for those without another long term condition (79%) compared to those with another condition (73%).

Chart shows question X62: Asked to parents/carers of all age groups, total number of responses = 922

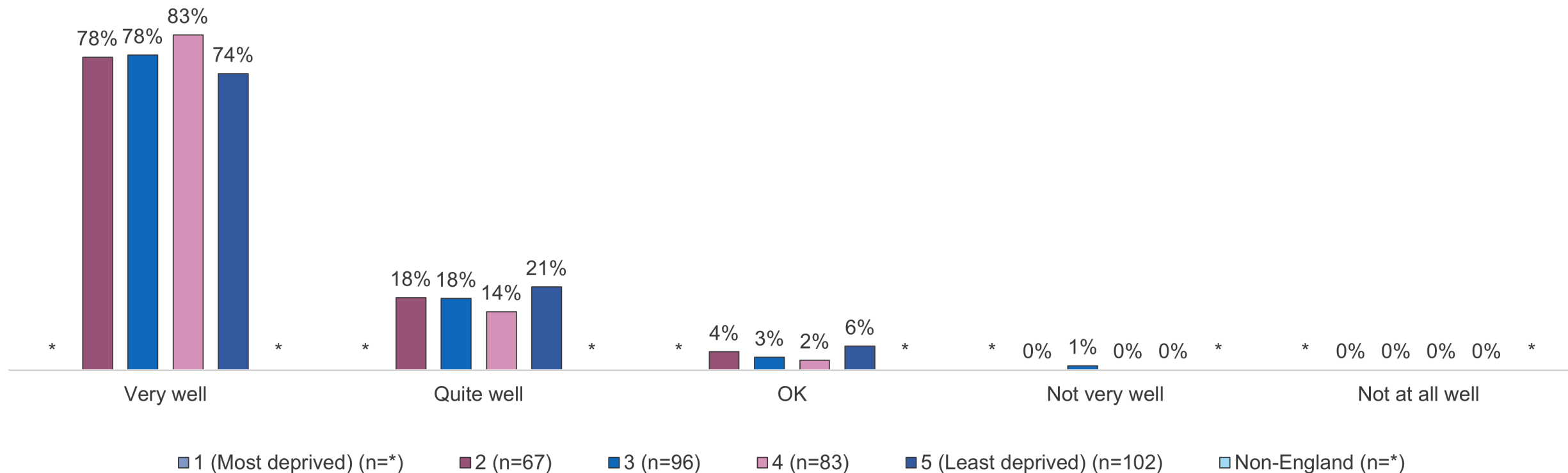
Chart shows question X63: Asked to all children aged 8 to 15, total number of responses = 416

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



Parents/carers of children from the least deprived area (based on IMD quintile) were slightly less likely to rate the overall experience of their child's care as 8 or more out of 10 compared to those from more deprived areas.

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



Children from the least deprived areas (based on IMD quintile) were less likely to report being looked after very well for their cancer or tumour by healthcare staff compared to those from more deprived areas.

Chart shows question X63: Asked to all children aged 8 to 15, total number of responses = 416

* An asterisk indicates that data has been suppressed (see page 12 for details)

Hospitals working together



54% of parents/carers and children report that different hospitals providing cancer or tumour care always work well together.

Question X60: Asked to parents/carers of children aged 0 to 11, and all children aged 12 to 15, total number of responses = 927

Travel to the hospital



47% of parents/carers report that the hospital where their child receives most of their care is under one hours travel from their child's home.

Question X61: Asked to parents/carers of all age groups, total number of responses = 935

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 caused by the cancer or tumour?

63% of parents/carers reported that their child saw a GP once or twice before they were referred to hospital (including scored responses only).

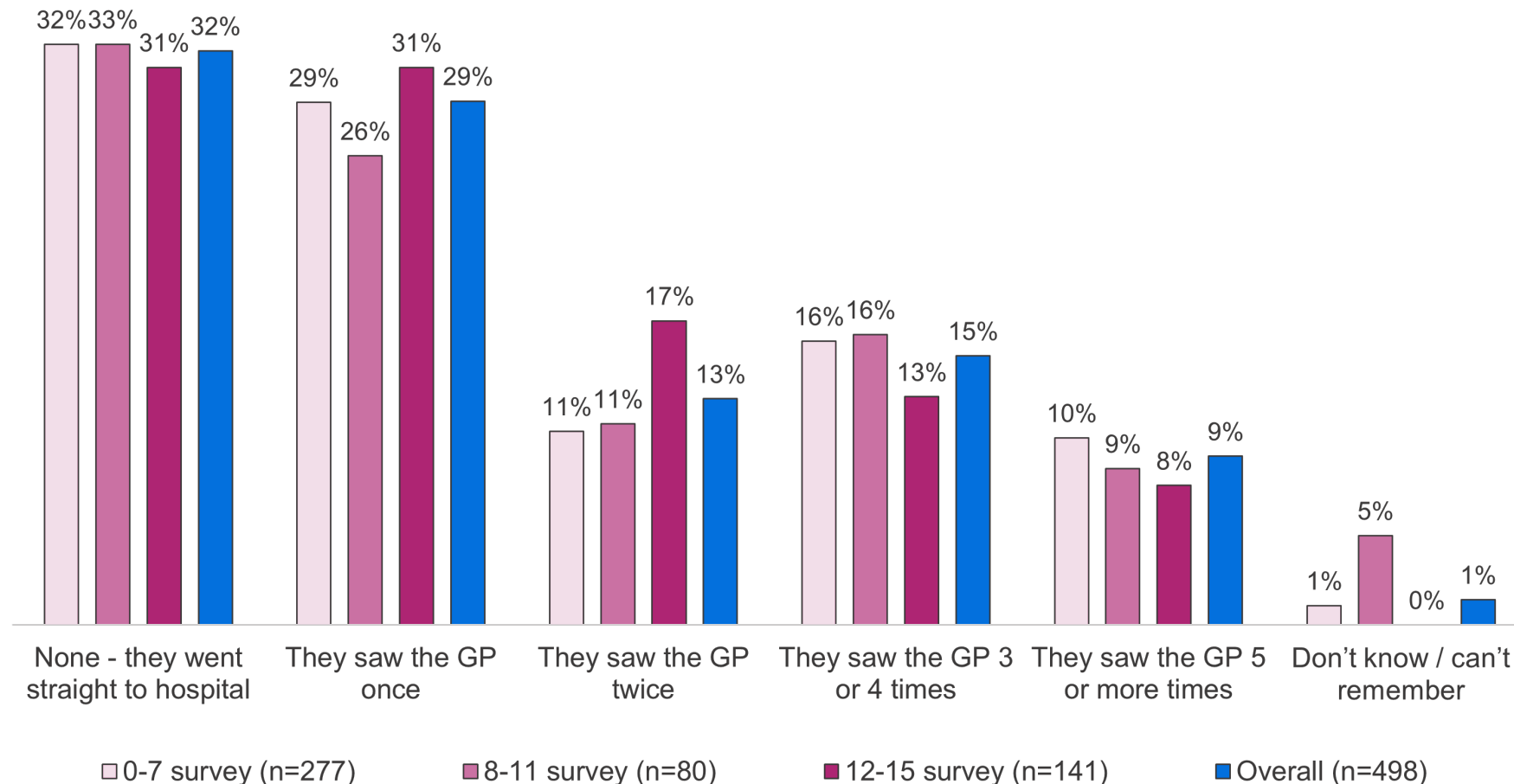


Chart shows question X03: Asked to parents/carers of all age groups whose children were told they had cancer or a tumour during 2021. Total responses = 498, of which 331 were scored (excluding 160 responses of “None – they went straight to hospital” and 7 responses of “Don't know/ can't remember”).

Visiting the hospital

80% of parents/carers felt that their child was first seen by a hospital doctor as soon as they thought was necessary (including scored responses only).

How do you feel about the length of time you had to wait before your child's first appointment with a hospital doctor?

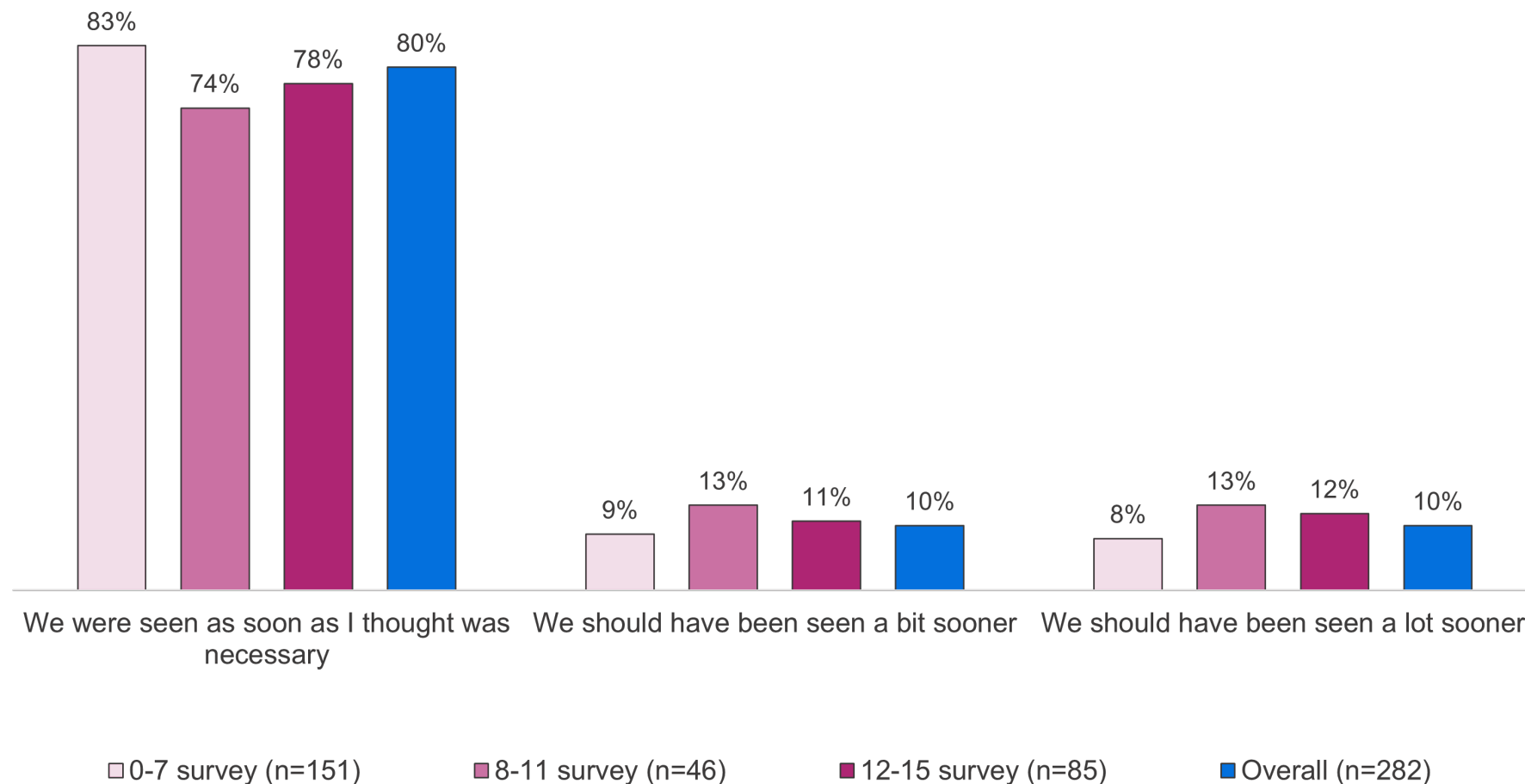


Chart shows question X06: Asked to parents/carers of all age groups who were told about their child's cancer or a tumour during 2021. Total number of responses = 282.

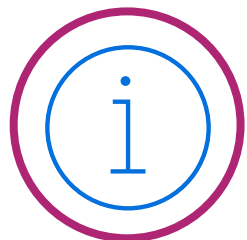
Answering questions



84% 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).

Question X09: Asked to parents/carers of 0 to 7s who were told about their child's cancer or a tumour during 2021, and children aged 8 to 15 who were told they had cancer or a tumour during 2021, total number of responses = 284

Information

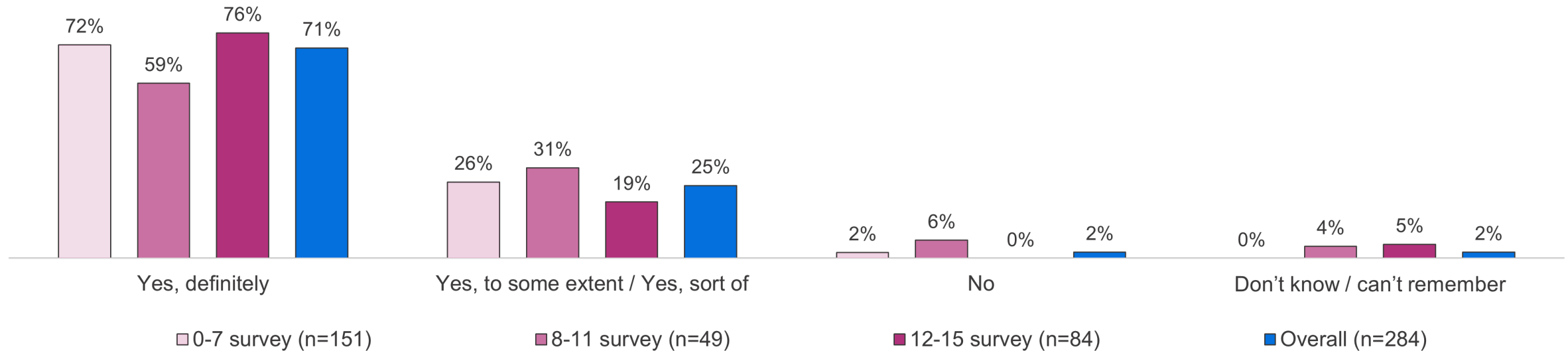


73% of parents/carers and children reported that information at diagnosis was definitely given in a way they could understand (Question X08).

Question X08: Asked to parents/carers of 0 to 7s who were told about their child's cancer or a tumour during 2021, and children aged 8 to 15 who were told they had cancer or a tumour during 2021, total number of responses = 284

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?



73% of parents/carers and children reported that information at diagnosis was definitely given in a way they could understand (including scored responses only).

Chart shows question X08: Asked to parents/carers of 0 to 7s who were told about their child's cancer or a tumour during 2021, and children aged 8 to 15 who were told they had cancer or a tumour during 2021.

Total responses = 284, of which 278 were scored (excluding 6 responses of “Don't know/ can't remember”).

Information

95% of children reported that staff provided details about who to speak to/contact for more information after being told about their cancer or tumour (including scored responses only).

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

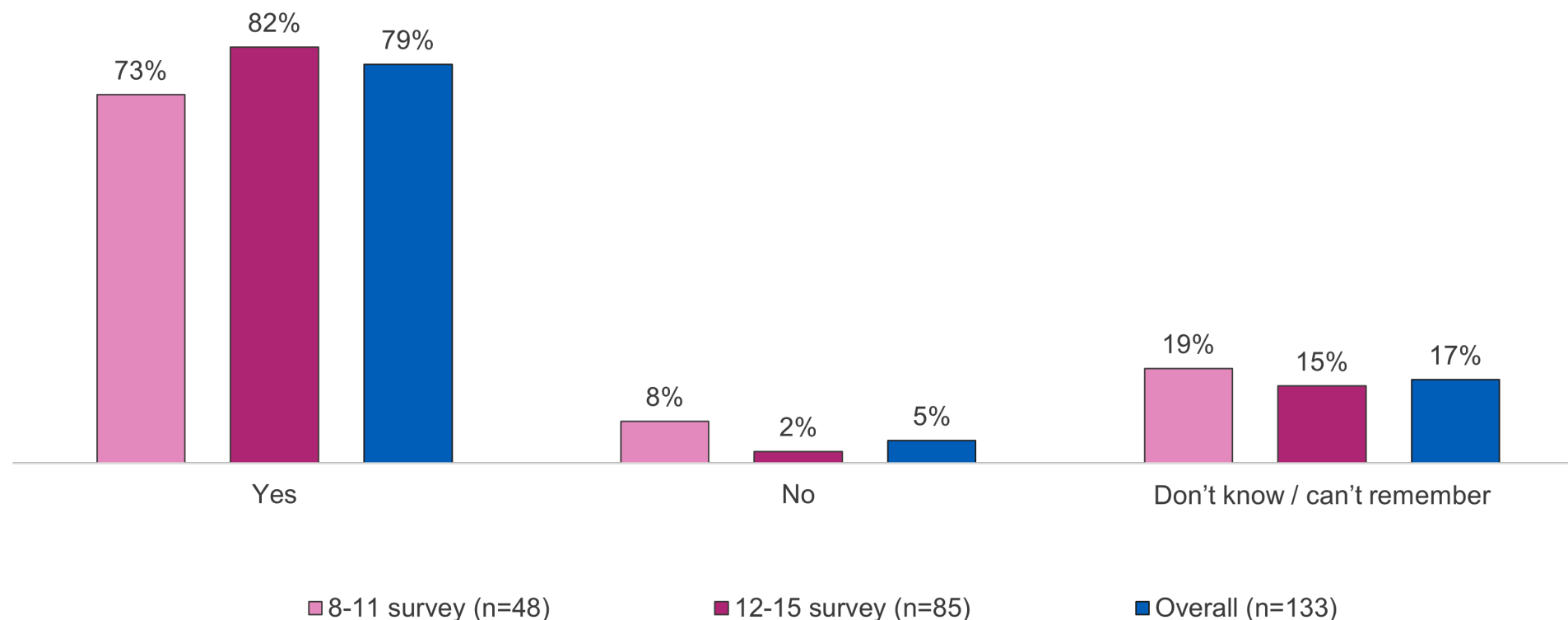
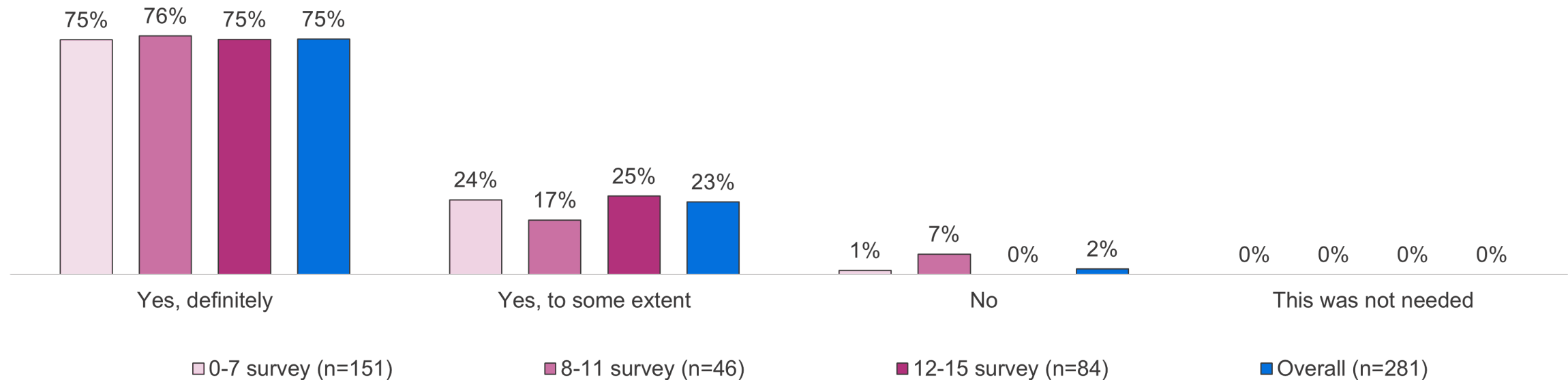


Chart shows question X10: Asked to children aged 8 to 15 who were told they had cancer or a tumour during 2021. Total responses = 133, of which 111 were scored, (excluding 22 responses of "Don't know/ can't remember").

Information

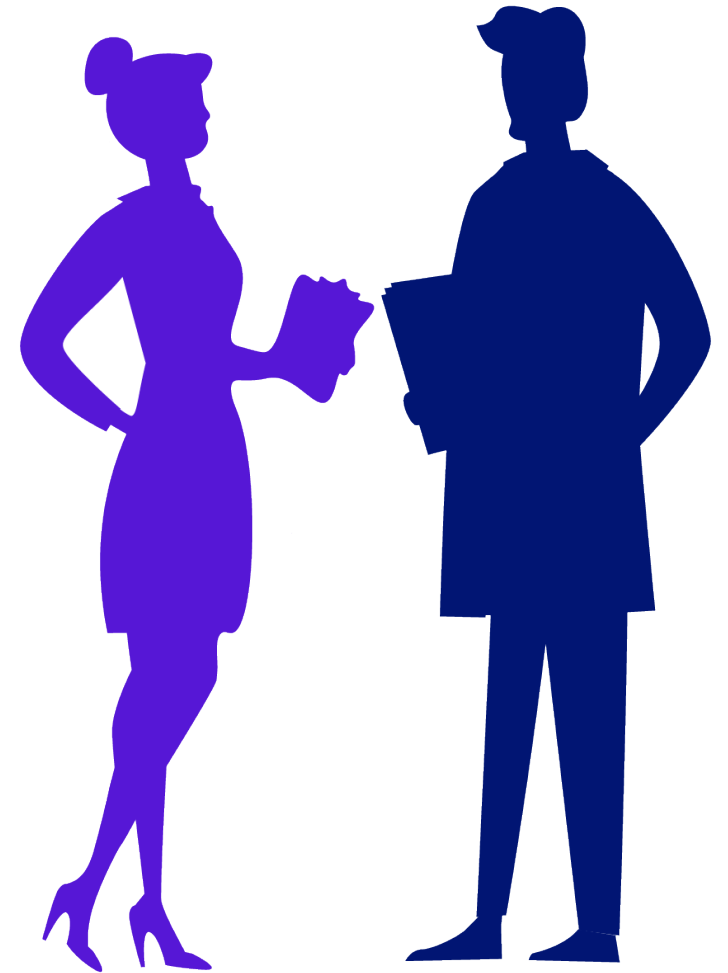
Have you been able to find the information that you need about your child's diagnosis?



75% of parents/carers reported that they were definitely able to find information about child's diagnosis (including scored responses only).

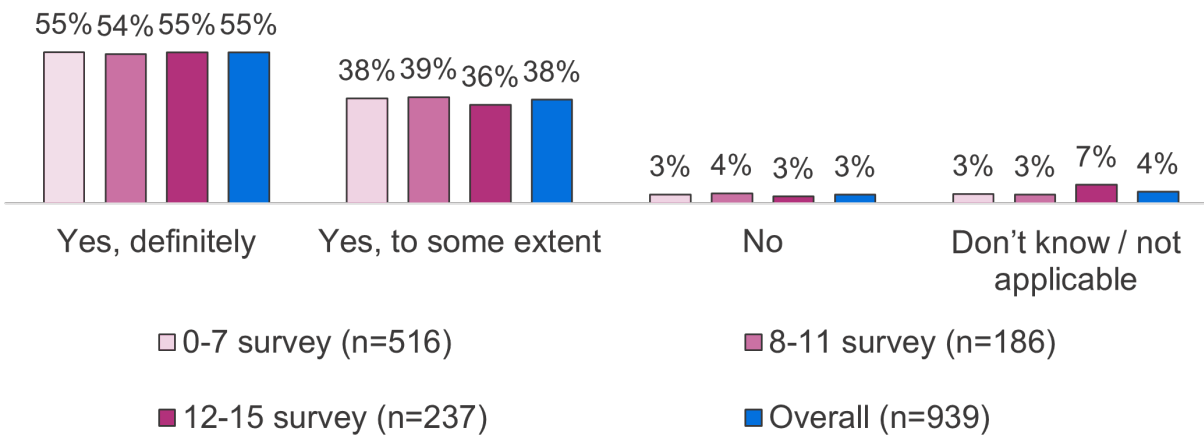
Chart shows question X11 : Asked to parents/carers of all age groups who were told about their child's cancer or a tumour during 2021. Total responses = 281, of which 281 were scored.

6.3 Child's care and treatment



Medical history

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

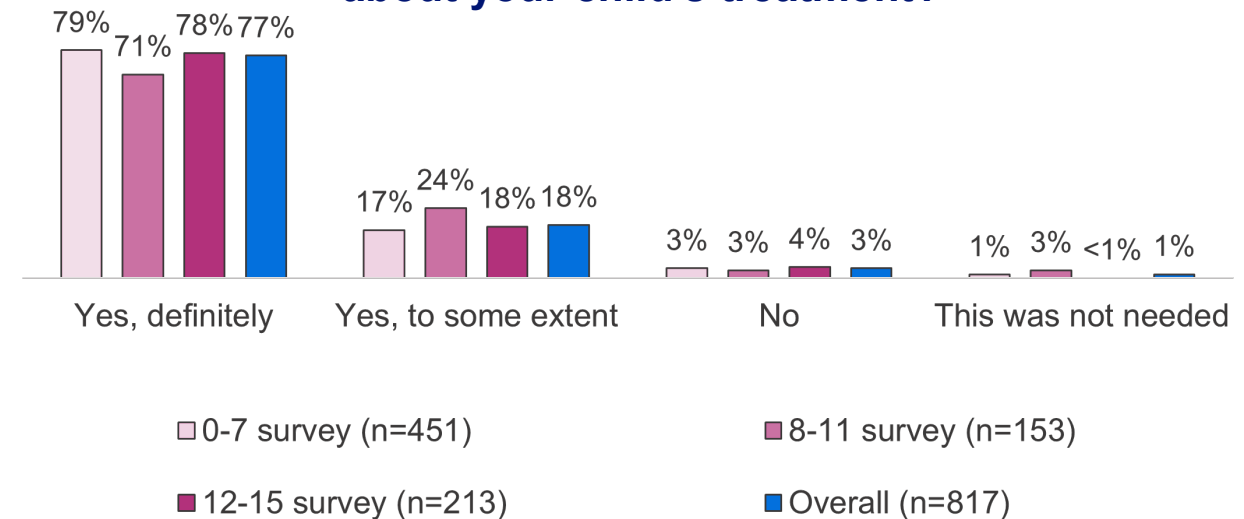


57% of parents/carers feel that different hospital staff are definitely aware of their child's medical history (including scored responses only).

Chart shows question X29: Asked to parents/carers of all age groups. Total responses = 939, of which 899 were scored (excluding 40 responses of "Don't know/can't remember").

Written information

Were you given clear written information about your child's treatment?

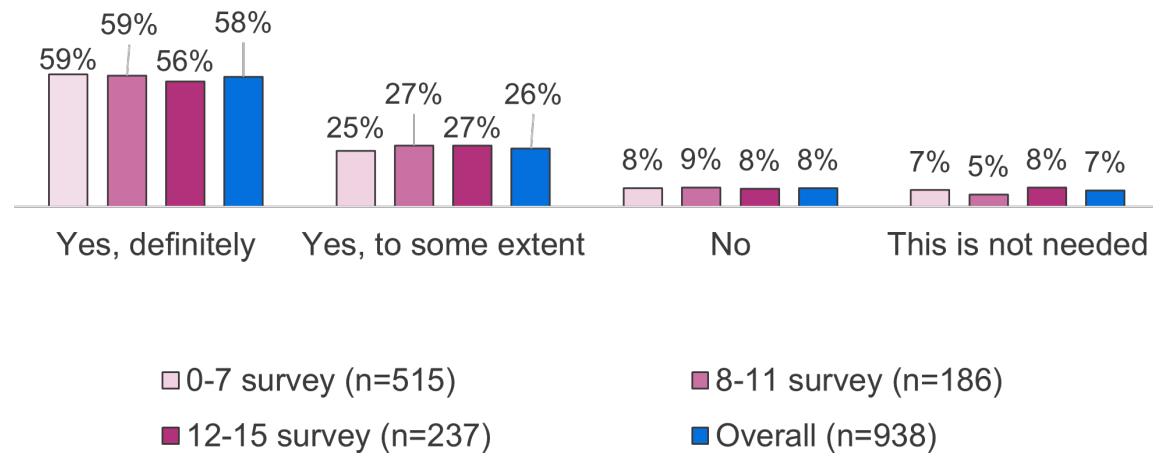


78% of parents/carers reported that they were given clear written information about their child's treatment (including scored responses only).

Chart shows question X39: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2021. Total responses = 817, of which 807 were scored (excluding 10 responses of "This was not needed").

Support from the hospital

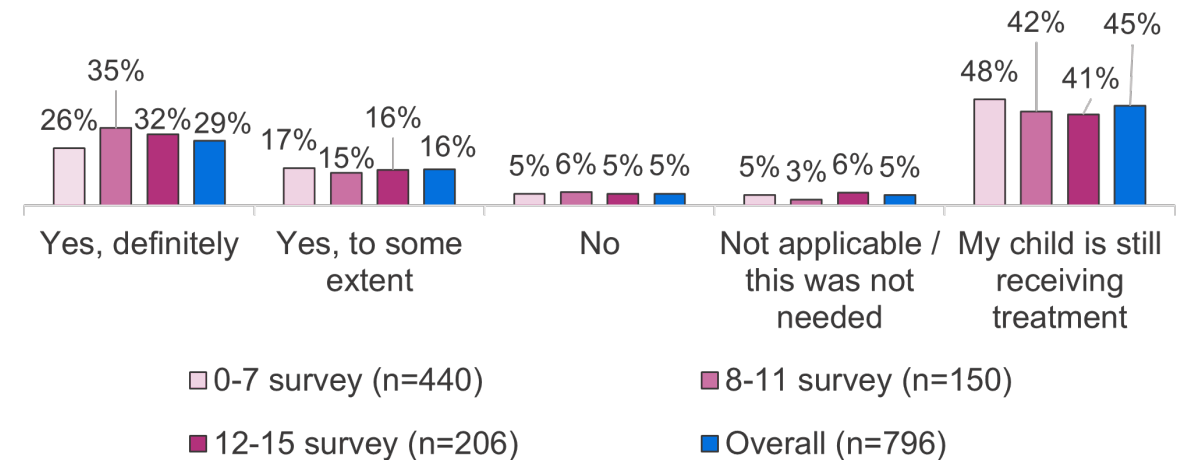
Do you have access to reliable help and support 7 days a week from the hospital?



63% of parents/carers reported that they definitely have access to reliable help and support 7 days a week from the hospital (including scored responses only).

Chart shows question X34: Asked to parents/carers of all age groups. Total responses = 938, of which 870 were scored (excluding 68 responses of "This is not needed").

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

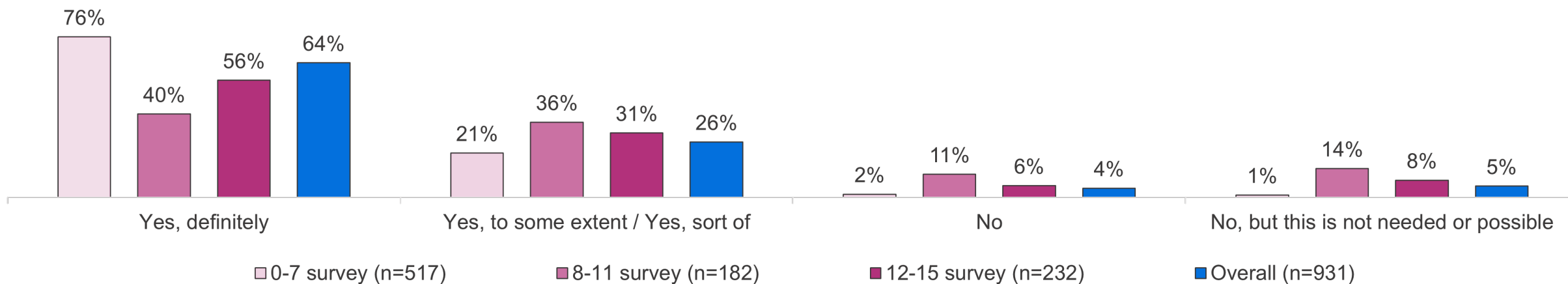


57% of parents/carers definitely received enough ongoing support from the hospital after their child's treatment finished (including scored responses only).

Chart shows question X42: Asked to parents/carers of all age groups whose children received treatment for their cancer or tumour during 2021. Total responses = 796, of which 403 were scored (excluding 37 responses of "Not applicable / this was not needed" and 356 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? / Are you involved in decisions about your care and treatment?



68% of parents/carers and children are definitely involved in their child's/their care and treatment (including scored responses only).

Chart shows question X31: Asked to parents/carers of children aged 0 to 7, and all children aged 8 to 15. Total responses = 931, of which 881 were scored (excluding 50 responses of "No, but this is not needed or possible").

Impact of care and treatment on schooling and education

Parents/carers of children aged 12 to 15 were more likely to report that their child's schooling and education has been impacted by being too unwell to attend school, poor concentration due to ill health or worries, and by tiredness or fatigue, than parents/carers of children aged 11 and under.

Has your child's schooling and education been impacted in any of the following ways by their treatment and care?

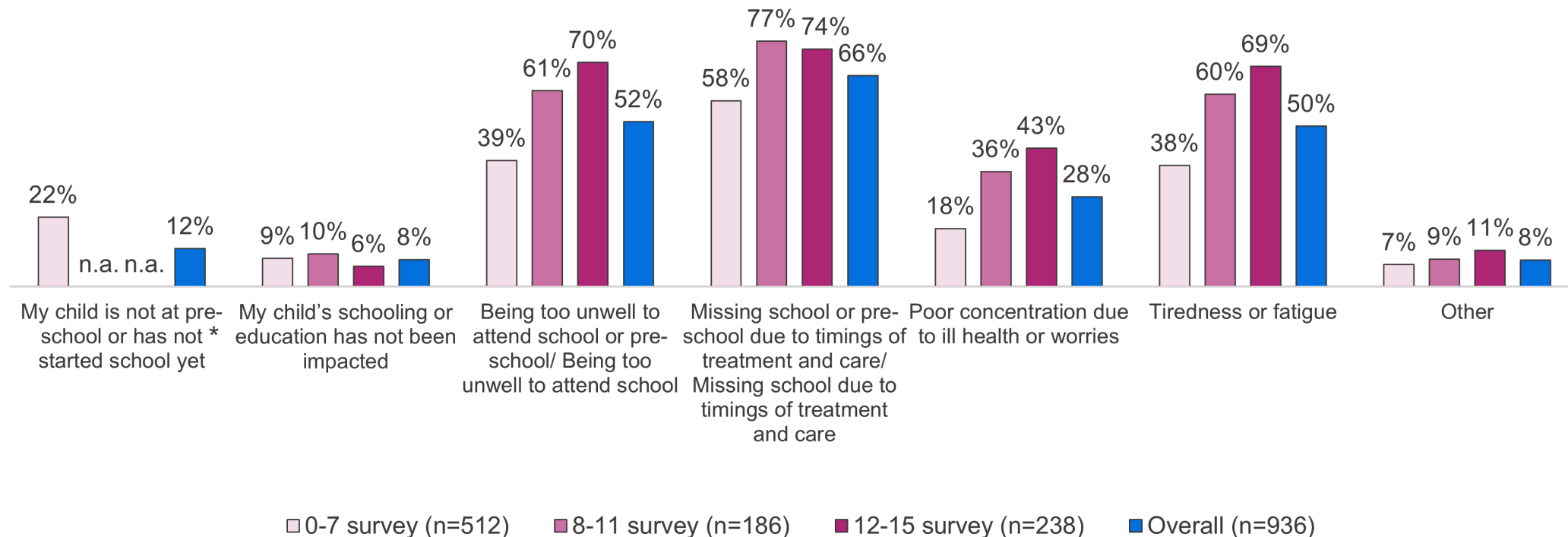


Chart shows question X32: Asked to parents/carers of all age groups, total number of responses = 936

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

6.4 Care in hospital



Staff availability in hospital

76% of parents/carers and children felt that the child was always able to get help from hospital staff when they needed it.

When your child was in hospital, were they able to get help from hospital staff when they needed it? / When you were in hospital, were you able to get help from hospital staff when you needed it?

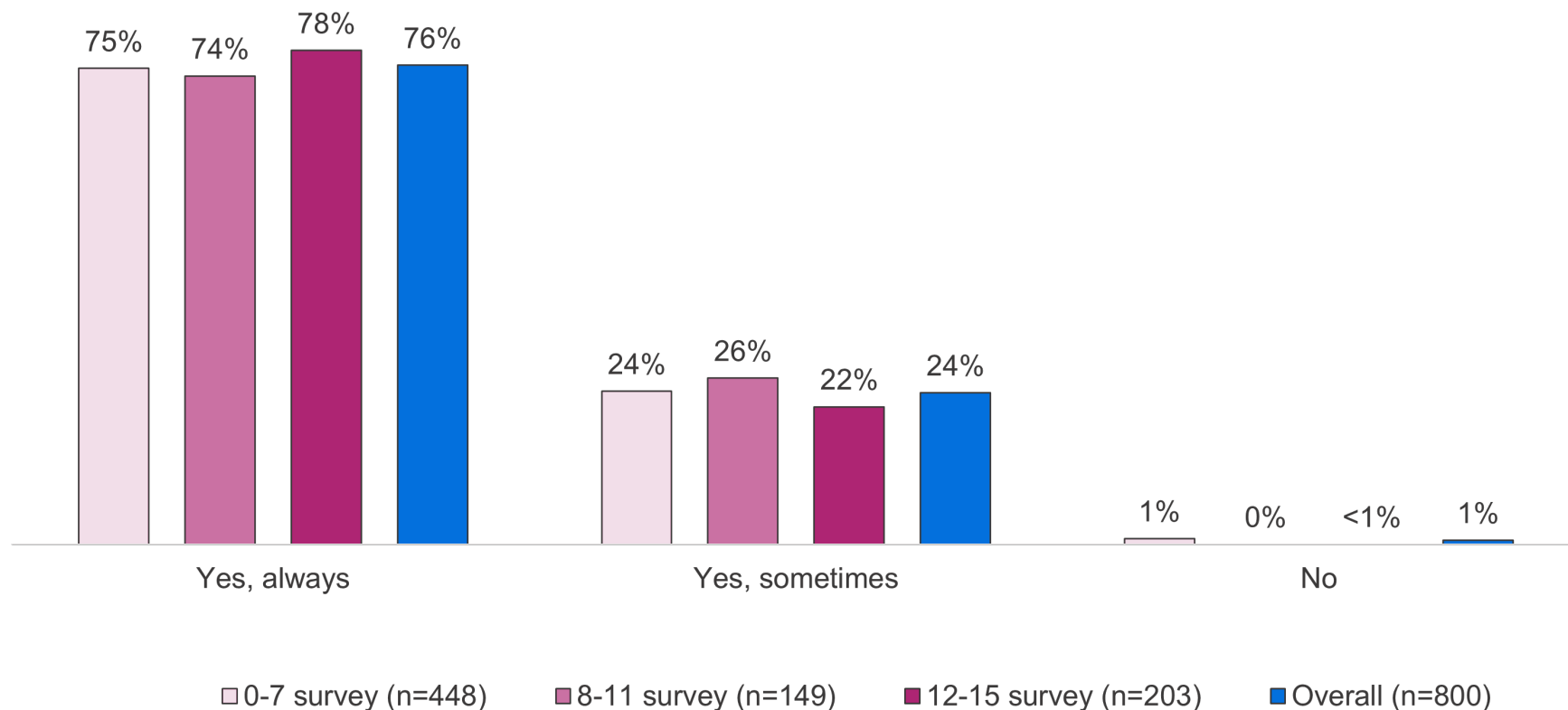


Chart shows question X45: Asked to parents/carers of children aged 0 to 7 whose children stayed in hospital during 2021, and children aged 8 to 15 who stayed in hospital during 2021 (receiving treatment or care in the daytime or for an overnight stay), total number of responses = 800

Things for children to do in hospital

43% of parents/carers and children felt that there were definitely enough things for the child to do in the hospital (including scored responses only). This was lower for children aged 8 to 11 and 12 to 15 than parents/carers of children aged 0-7.

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

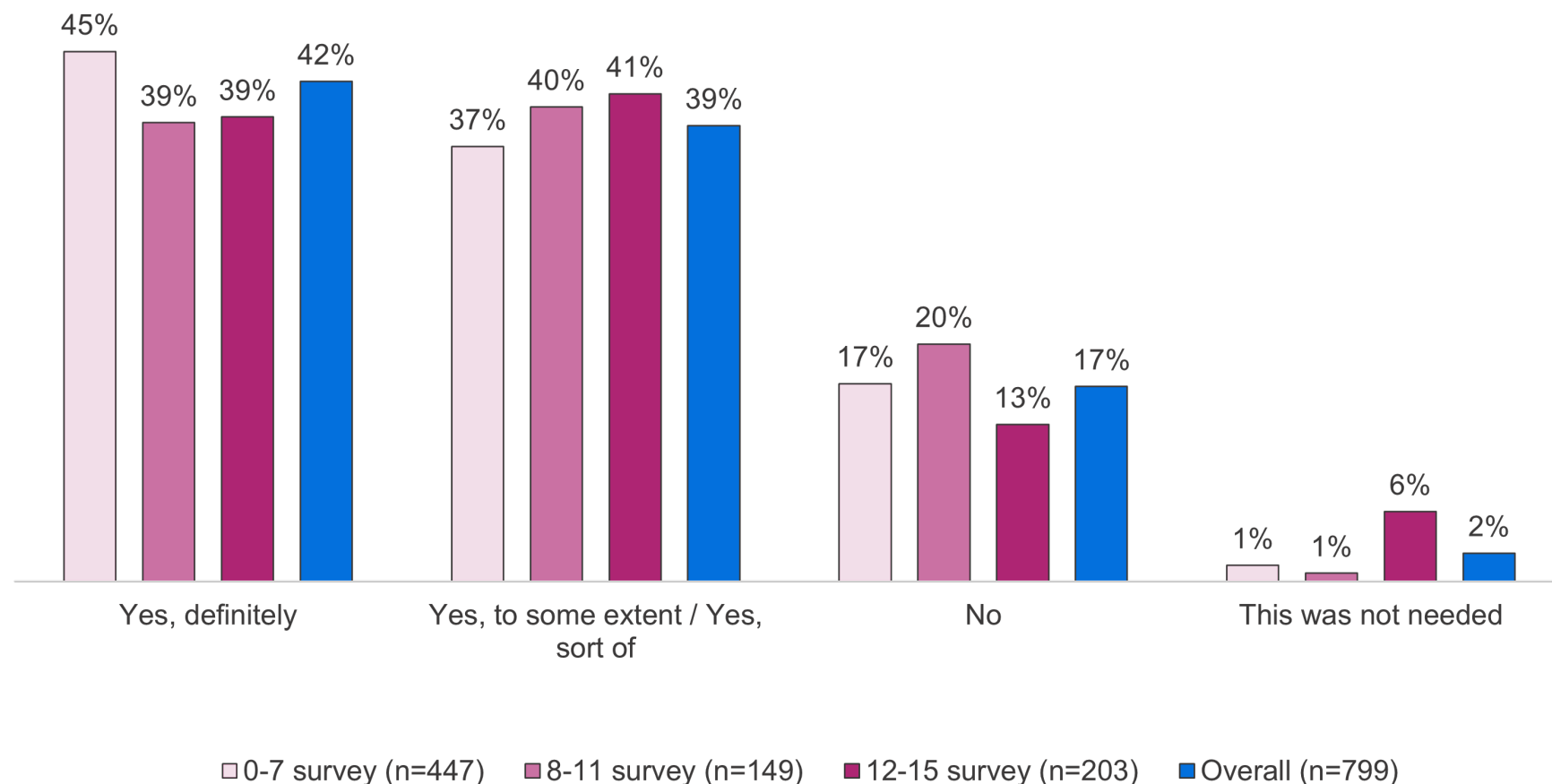
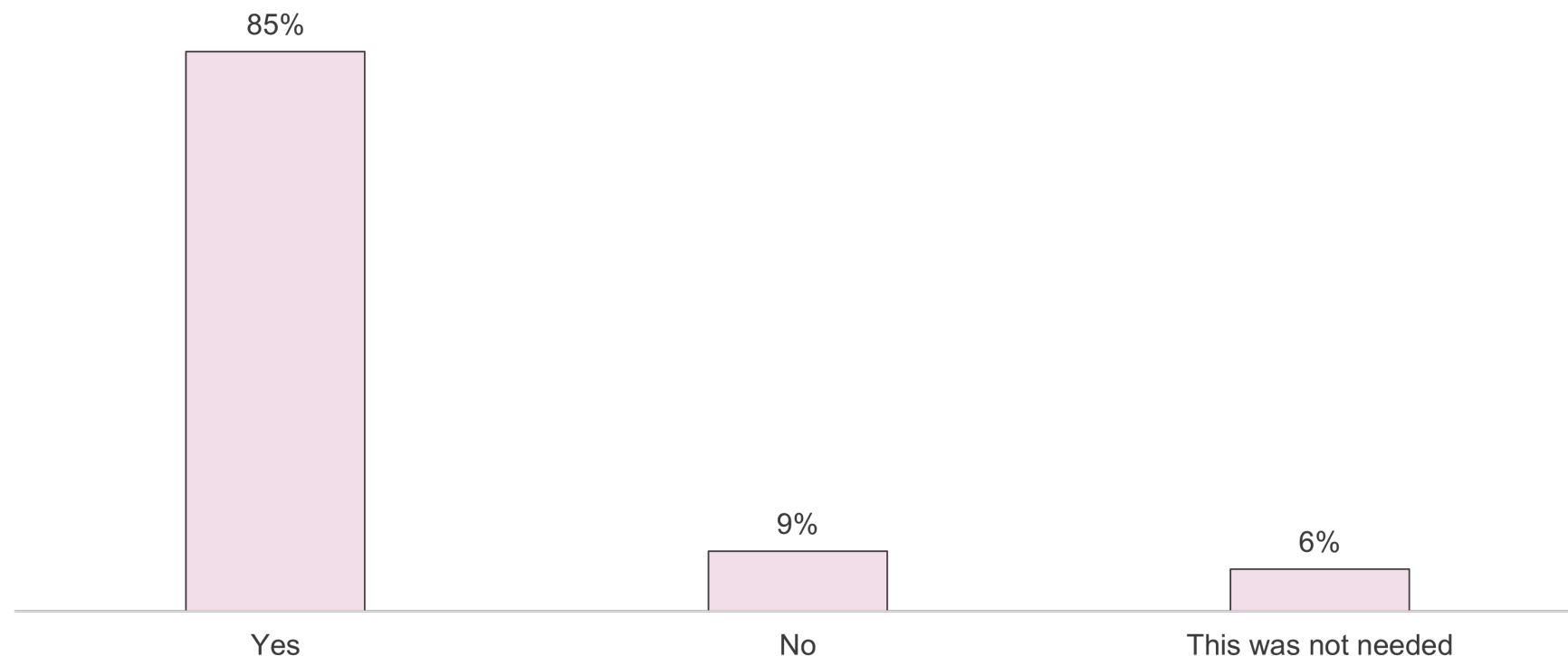


Chart shows question X46: Asked to parents/carers of children aged 0 to 7 whose children stayed in hospital during 2021, and children aged 8 to 15 who stayed in hospital during 2021 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 799, of which 780 were scored (excluding 19 responses of “This was not needed”).

Play specialist support

90% of parents/carers reported that the hospital offered play specialist support (including scored responses only).

Did the hospital offer play specialist support for your child?



□ 0-7 survey (n=441)

Chart shows question X49: Asked to parents/carers of children aged 0 to 7 whose children stayed in hospital during 2021 (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 441, of which 413 were scored (excluding 28 responses of “This was not needed”).

Hospital Wi-Fi

34% of parents/carers felt that the hospital Wi-Fi always met the needs of them and their children (including scored responses only).

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

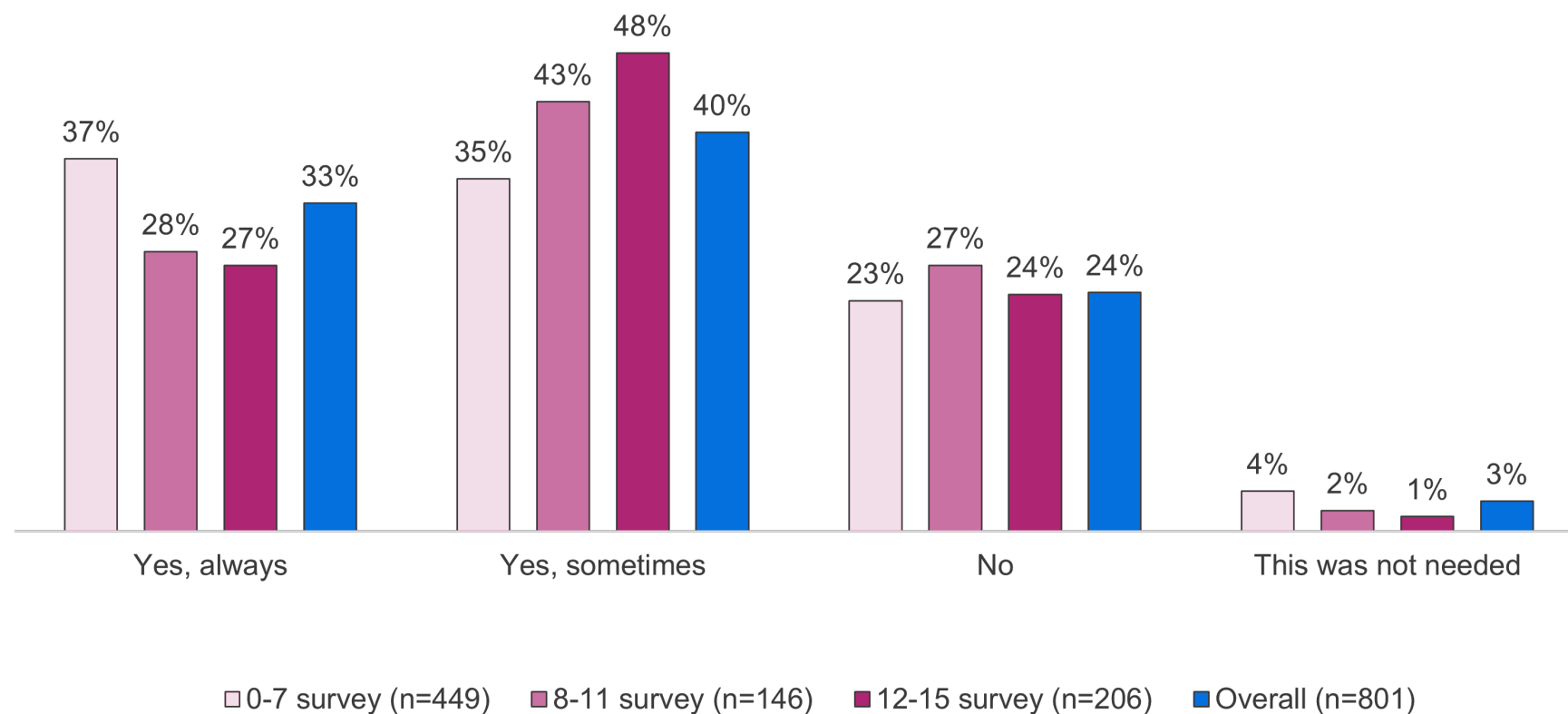


Chart shows question X54: Asked to parents/carers of all age groups whose children stayed in hospital during 2021. Total responses = 801, of which 777 were scored (excluding 24 responses of "This was not needed").

Hospital food

52% of parents/carers and children felt that there was definitely a choice of hospital food (including scored responses only).

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

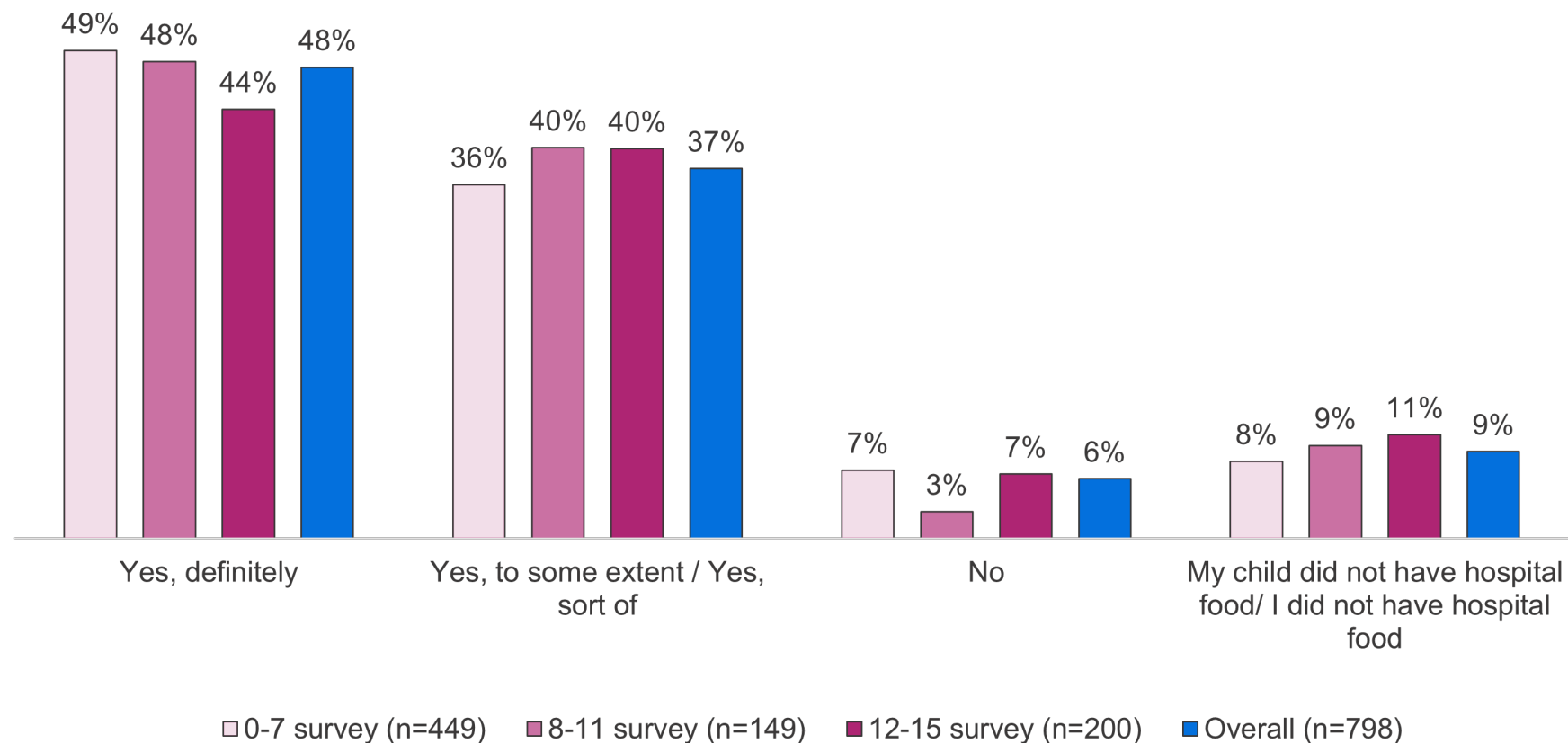


Chart shows question X47: Asked to parents/carers of children aged 0 to 7 whose children stayed in hospital during 2021, and children aged 8 to 15 who stayed in hospital during 2021 (receiving treatment or care in the daytime or for an overnight stay). Total responses = 798, of which 728 were scored (excluding 70 responses of “My child did not have hospital food/ I did not have hospital food”).

Hospital food

36% of parents/carers were definitely able to prepare food in the hospital if they wanted to (including scored responses only).

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

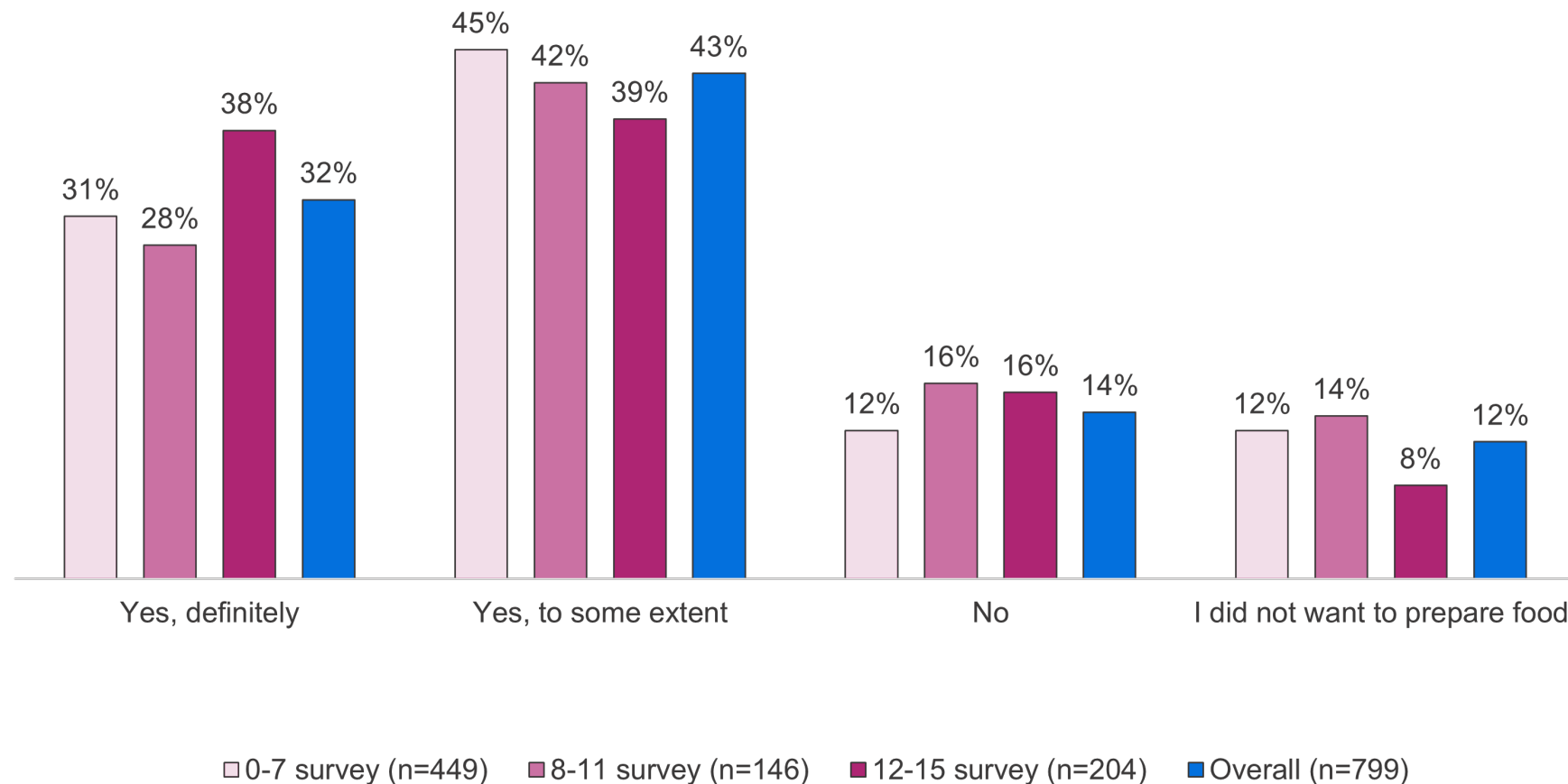


Chart shows question X53: Asked to parents/carers of all age groups whose children stayed in hospital during 2021. Total responses = 799, of which 707 were scored (excluding 92 responses of “I did not want to prepare food”).

Hospital environment

28% of parents/carers and children reported that it was always quiet enough for them to sleep in the hospital (including scored responses only).

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

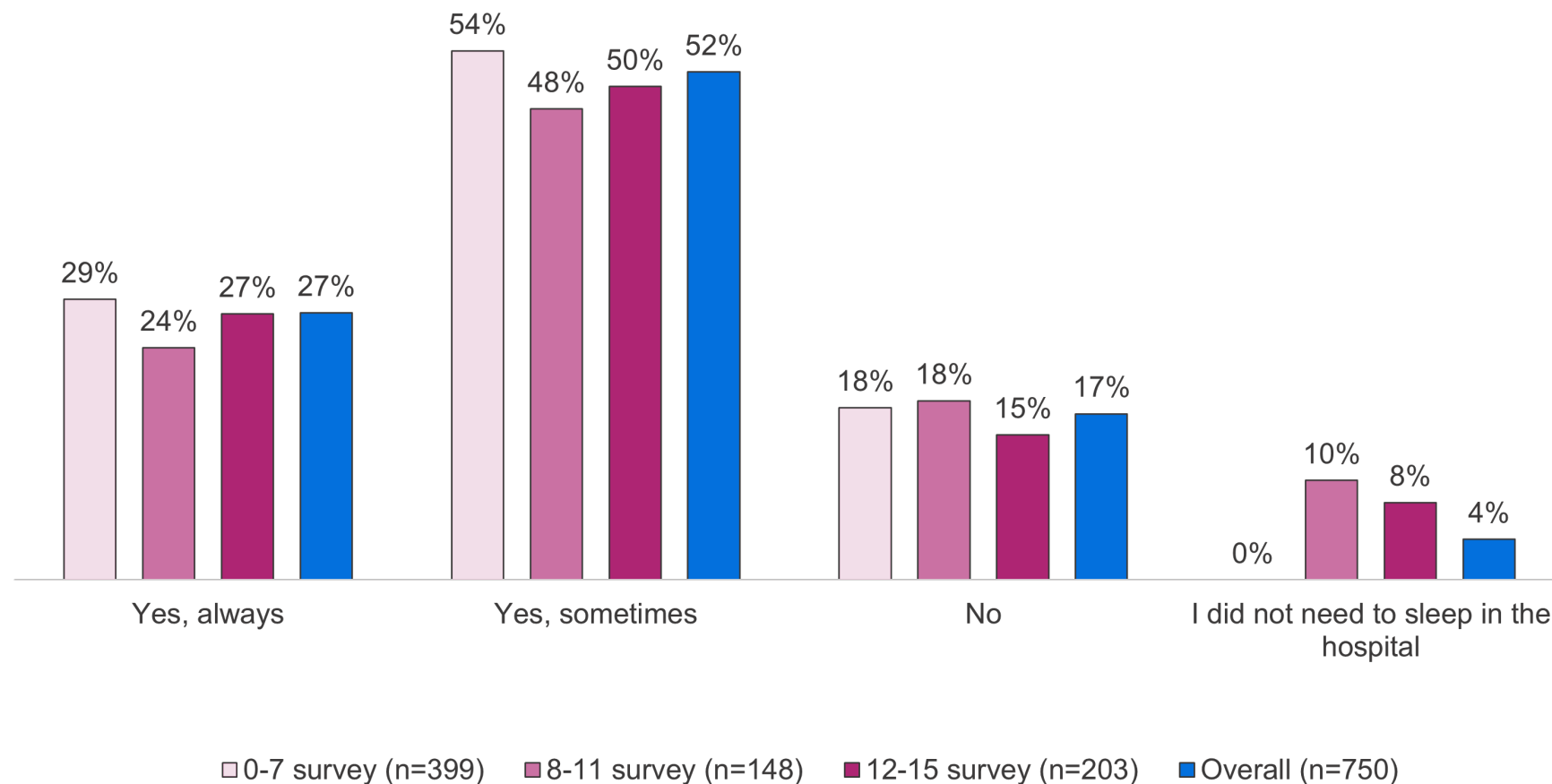


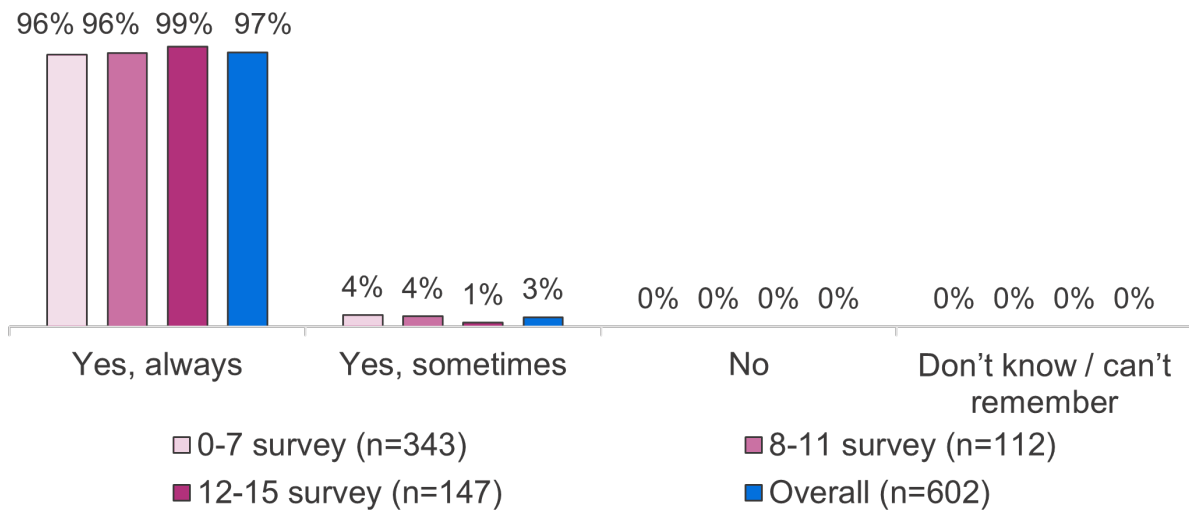
Chart shows question X52: Asked to parents/carers of children aged 0 to 7 whose children stayed overnight in hospital during 2021, and children aged 8 to 15 who stayed in hospital during 2021. Total responses = 750, of which 719 were scored (excluding 31 responses of “I did not need to sleep in the hospital”).

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?

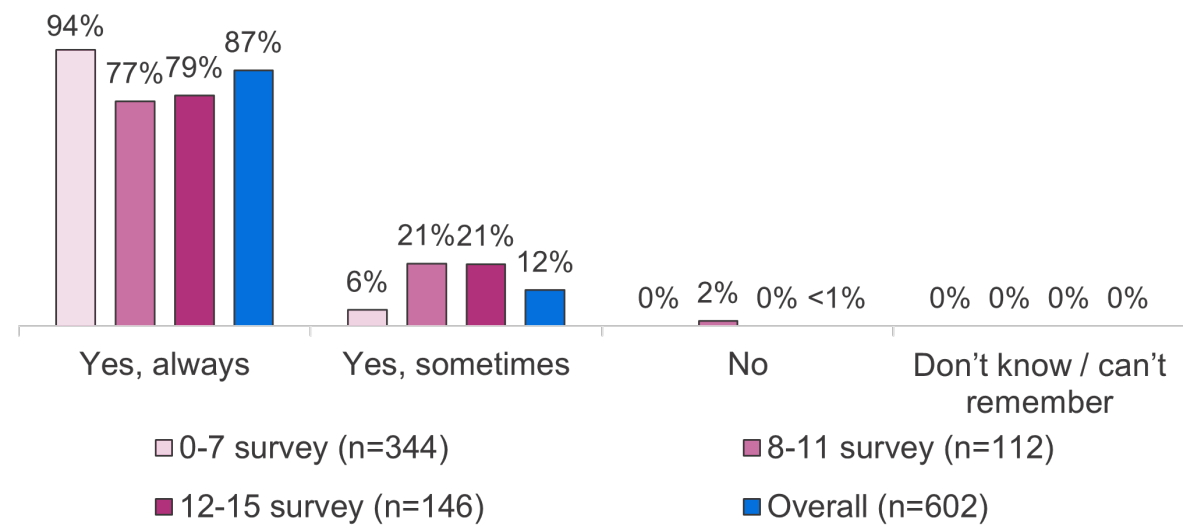


97% of parents/carers and children felt that the nurses who came to their home or school were always friendly.

Chart shows question X57: Asked to parents/carers of children aged 0 to 7 whose children have been visited at home or school by a nurse during 2021, and children aged 8 to 15 who were visited at home or school by a nurse during 2021, total number of responses = 602

Bedside manner and trust

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



87% of parents/carers and children reported that they always understand what nurses visiting their home or school are saying.

Chart shows question X58: Asked to parents/carers of children aged 0 to 7 whose children have been visited at home or school by a nurse during 2021, and children aged 8 to 15 who were visited at home or school by a nurse during 2021, total number of responses = 602



6.6 Healthcare staff



Bedside manner and trust

84% of parents/carers always have confidence and trust in staff caring for their child. This was slightly lower for parents/carers of those aged 8 to 11 (82%) compared to parents/carers of those aged 0 to 7 (84%) and 12 to 15 (84%).

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

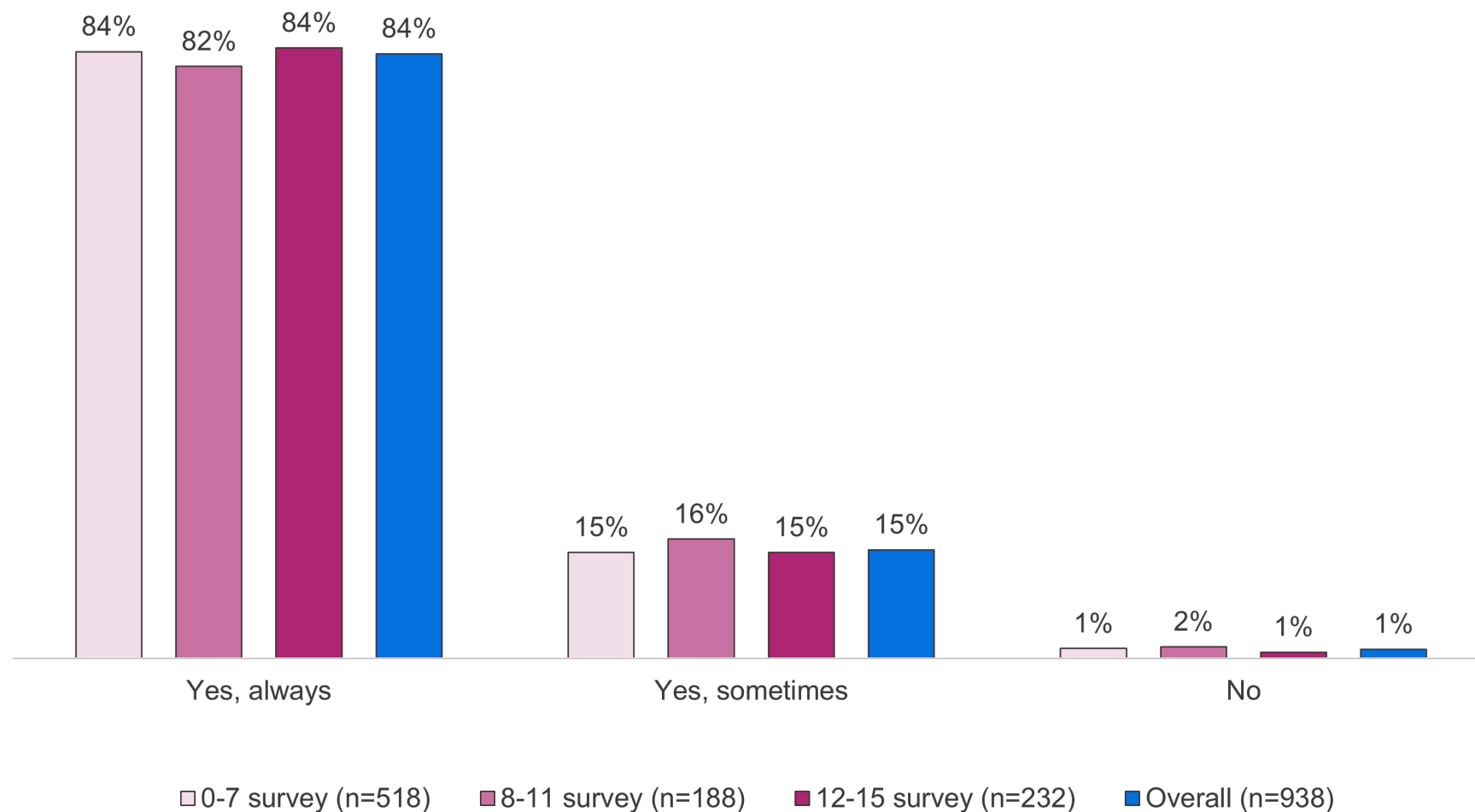
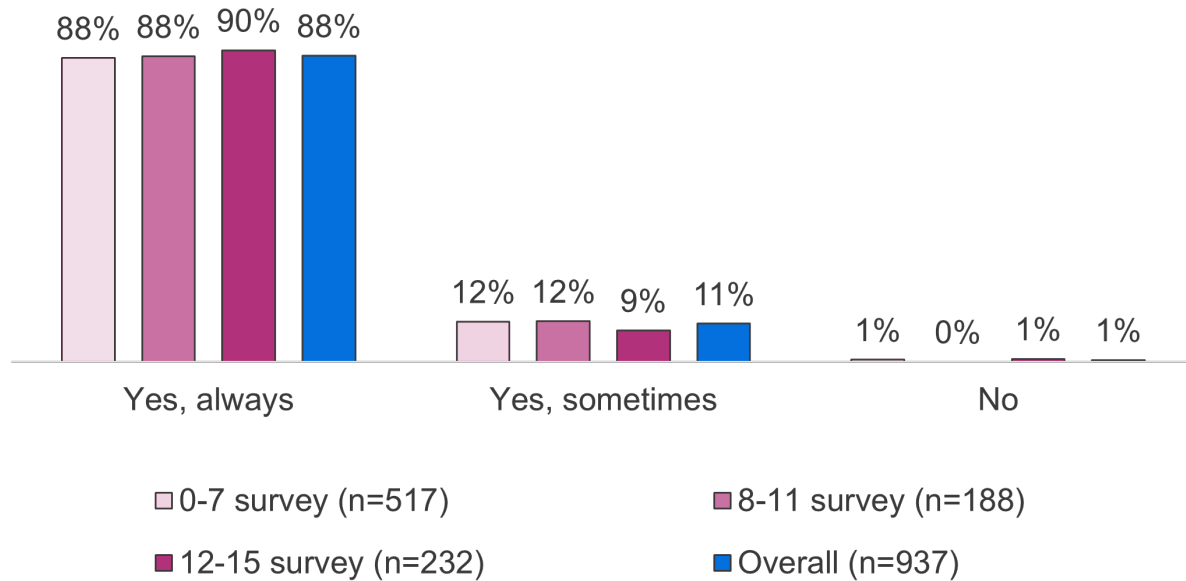


Chart shows question X16: Asked to parents/carers of all age groups, total number of responses = 938

Bedside manner and trust

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

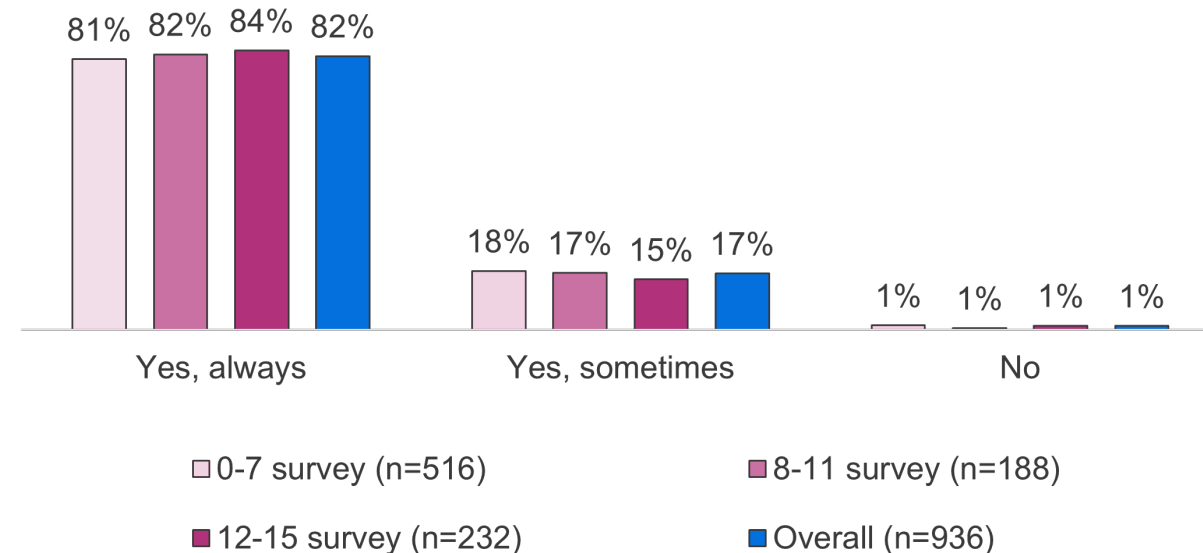


88% of parents/carers feel that they and their children are always treated with respect and dignity by staff.

Chart shows question X15: Asked to parents/carers of all age groups, total number of responses = 937

Bedside manner and trust

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

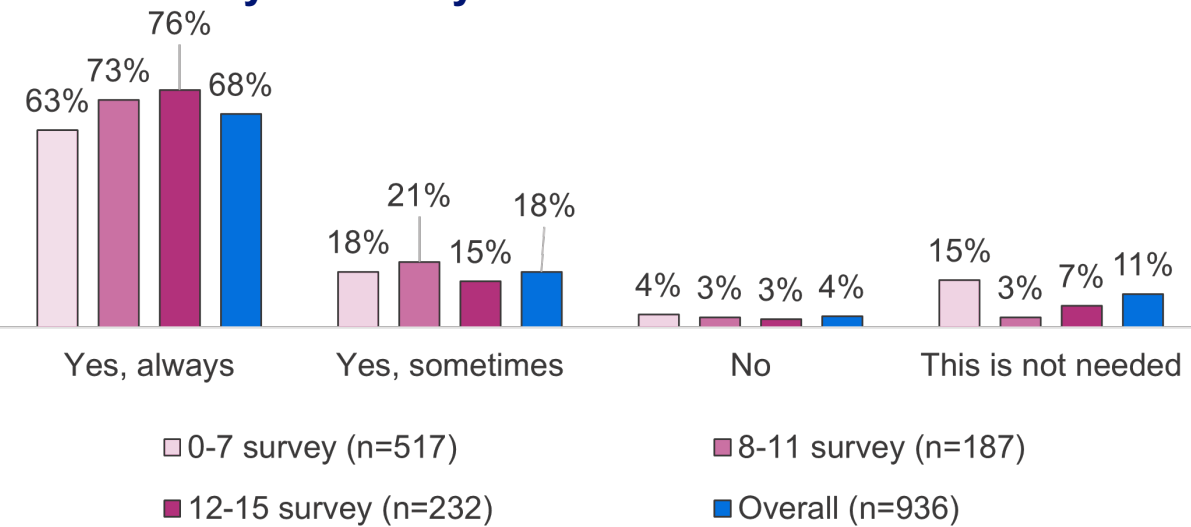


82% of parents/carers feel that they are always treated with empathy and understanding by staff caring for their child.

Chart shows question X17: Asked to parents/carers of all age groups, total number of responses = 936

Bedside manner and trust

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

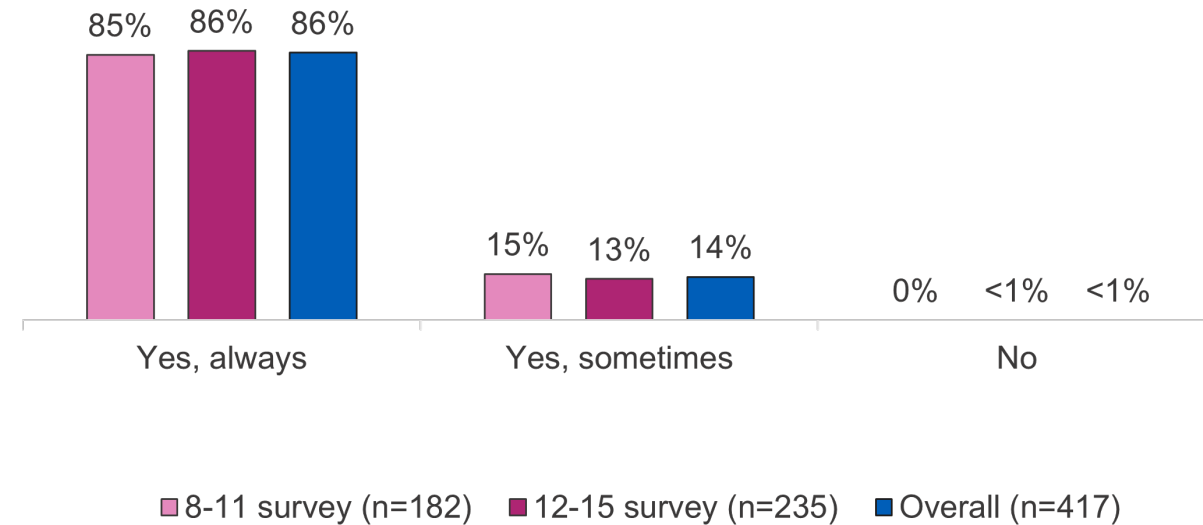


76% of parents/carers feel that staff are always sensitive to information shared with them when their child is in the room (including scored responses only).

Chart shows question X19: Asked to parents/carers of all age groups. Total responses = 936, of which 836 were scored (excluding 100 responses of "This is not needed").

Bedside manner and trust

Do you feel that staff are friendly?

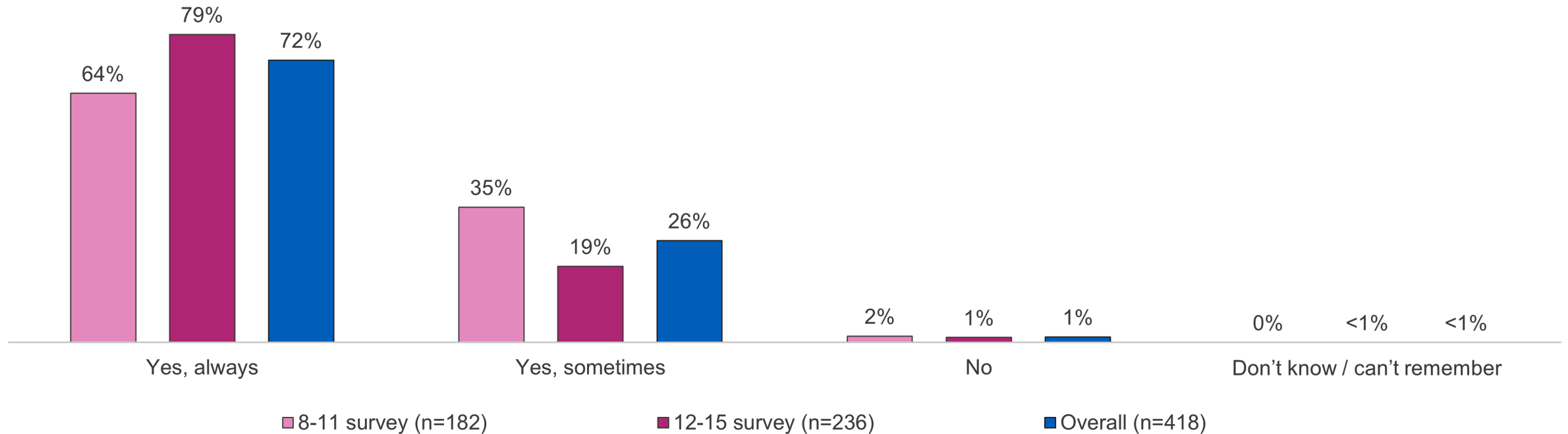


86% of children feel that staff are always friendly.

Chart shows question X23: Asked to all children aged 8 to 15, total number of responses = 417

Communication

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

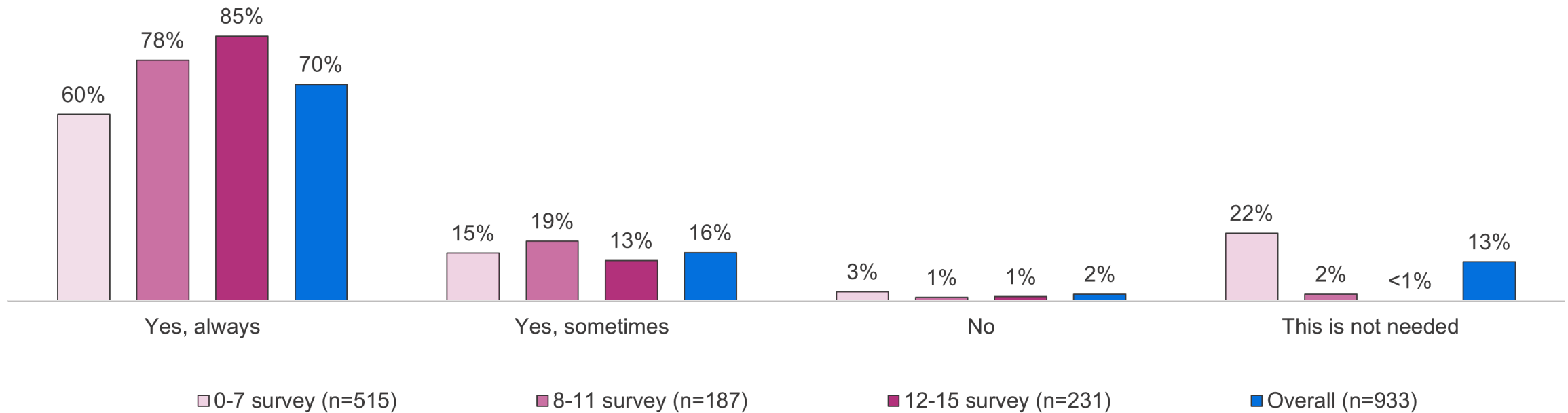


72% of children reported that they could always understand what staff are saying (including scored responses only). This was higher for children aged 12 to 15 compared to those aged 8 to 11 years.

Chart shows question X14: Asked to all children aged 8 to 15. Total responses = 418, of which 417 were scored (excluding 1 response of "Don't know / can't remember").

Communication

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



80% of parents/carers feel that staff always share information with children in a way that is appropriate (including scored responses only). Differences by age group showed that this was highest for parents/carers of children aged 12 to 15 and lowest for parents/carers of those aged 0 to 7.

Chart shows question X20: Asked to parents/carers of all age groups. Total responses = 933, of which 816 were scored (excluding 117 responses of "This is not needed").

Communication



62% of parents/carers and children are not told different things by different members of staff that leaves them feeling confused.

Question X18: Asked to parents/carers of children aged 0 to 7, and all children aged 8 to 15, total number of responses = 932



82% of children reported that staff always speak to them in a way that is suitable for them.

Question X21: Asked to all children aged 8 to 15, total number of responses = 417

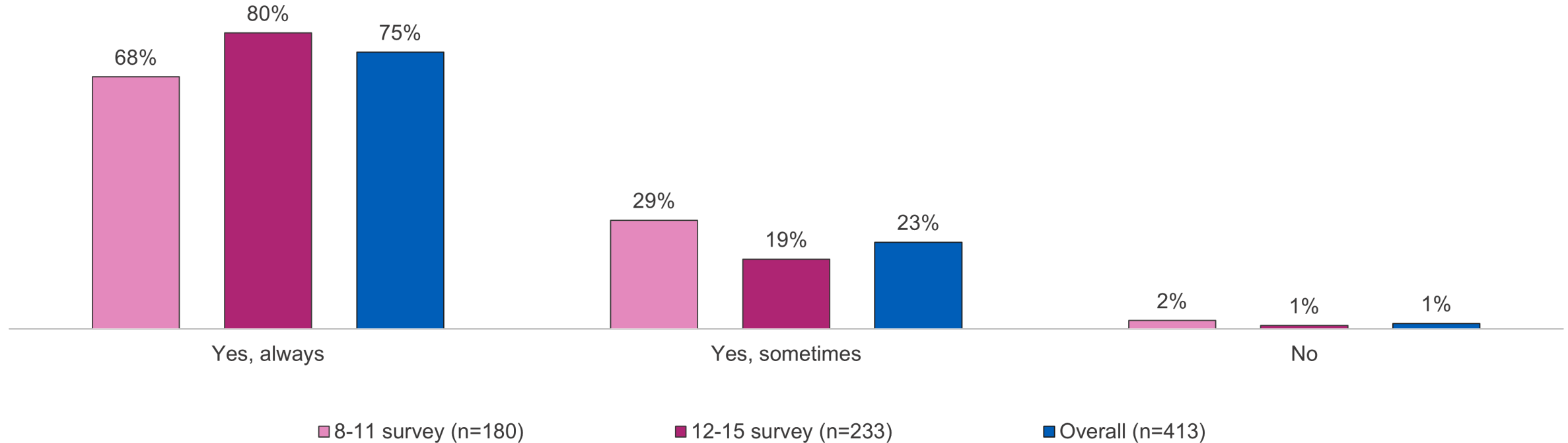


75% of children feel that staff always talk to them, not just their parent/ carer.

Question X22: Asked to all children aged 8 to 15, total number of responses = 413

Communication

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



75% of children feel that staff always talk to them, not just their parent/ carer. Comparisons by age group show that this was highest for children aged 12 to 15 and lowest for children aged 8 to 11.

Chart shows question X22: Asked to all children aged 8 to 15, total number of responses = 413

Support for parents/carers

Parents/carers of all age groups were more likely to report being given information about how to get in touch with charities compared to being given information about other types of support.

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

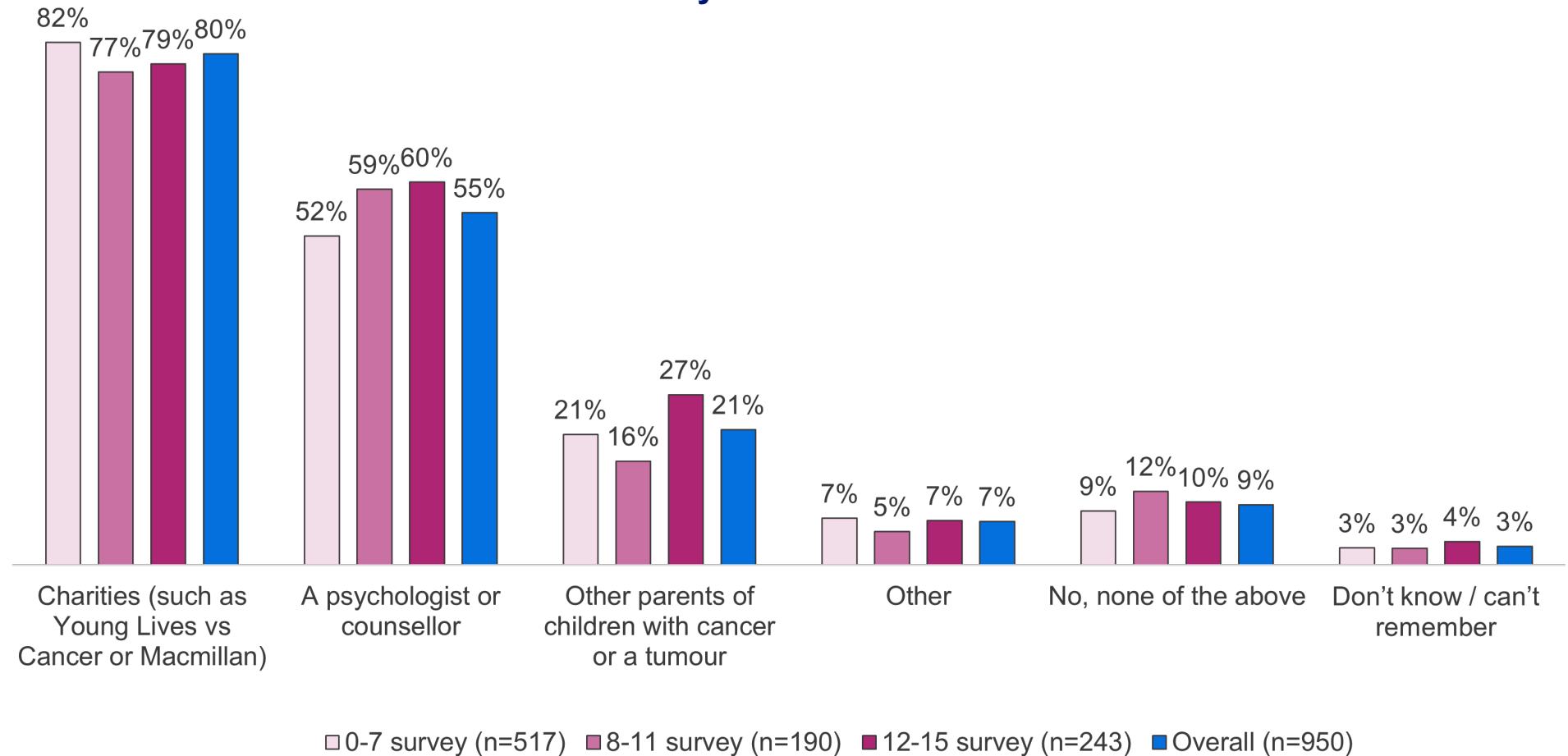


Chart shows question X25: Asked to parents/carers of all age groups, total number of responses = 950

Support (Children aged 8 to 15)

Children aged 12 to 15 were more likely to report hospital staff giving them information about how to chat to other children with cancer or a tumour than those aged 8 to 11.

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

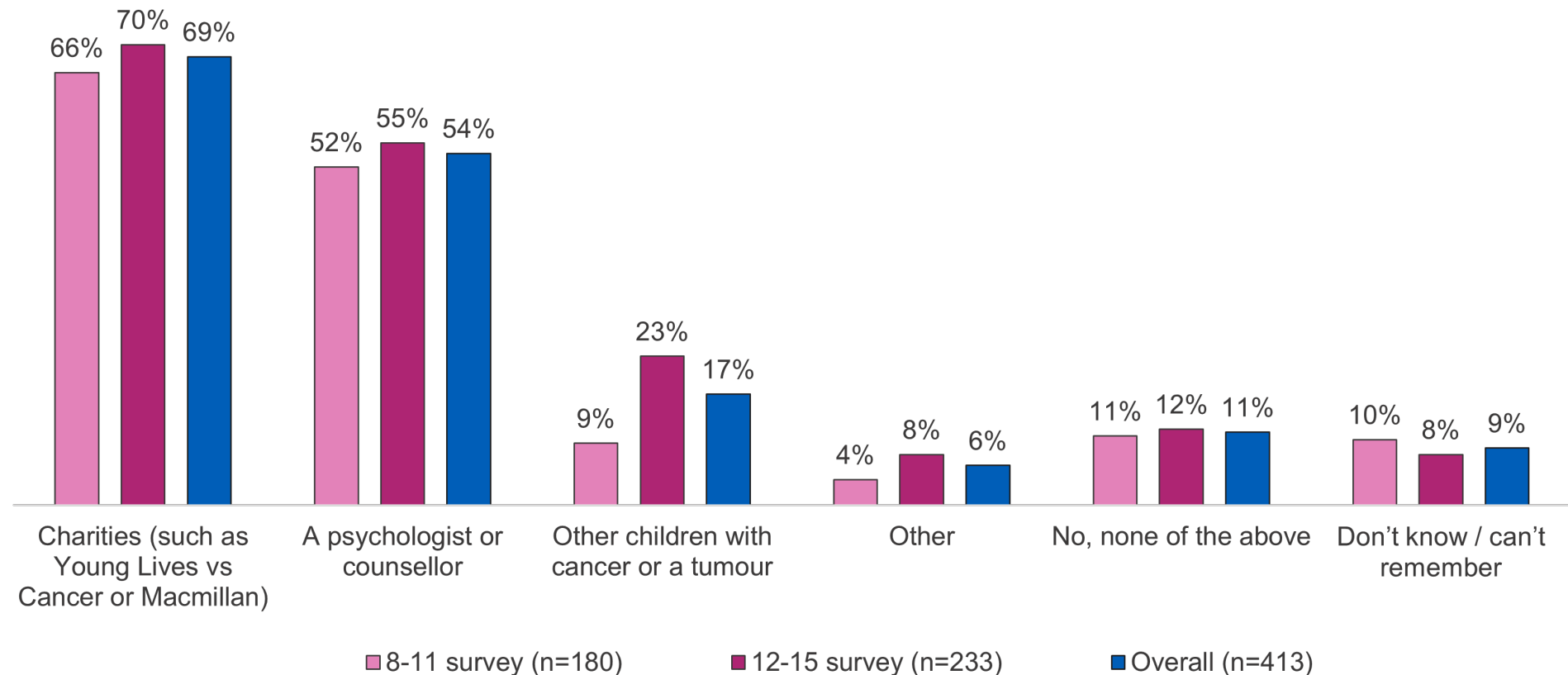


Chart shows question X26: Asked to all children aged 8 to 15, total number of responses = 413



7. 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](#).

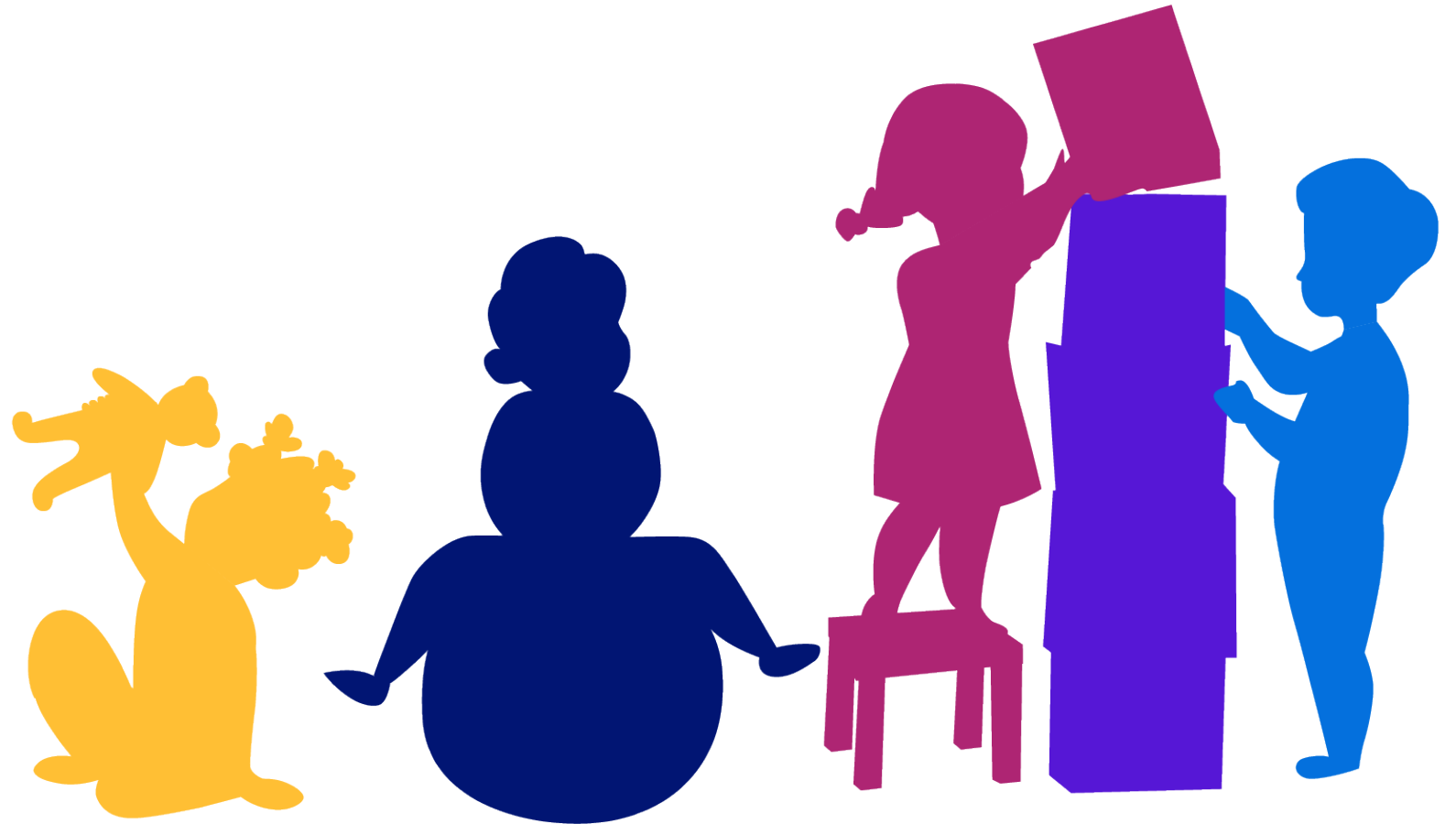


For full data tables showing results to all survey questions, please see [the survey website](#).

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 2021 survey data has been produced and published in line with the Code of Practice for Official Statistics.

8. Appendix



Treatment centre	Number of responses	% of responses
Alder Hey Children's NHS Foundation Trust	43	4%
Birmingham Children's Hospital NHS Foundation Trust	111	12%
Cambridge University Hospitals NHS Foundation Trust	56	6%
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	179	19%
Leeds Teaching Hospitals NHS Foundation Trust	73	8%
Manchester University NHS Foundation Trust	55	6%
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	61	6%
Oxford University Hospitals NHS Foundation Trust	62	6%
Sheffield Children's NHS Foundation Trust	38	4%
The Newcastle upon Tyne Hospitals NHS Foundation Trust	55	6%
The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	110	11%
University Hospital Southampton NHS Foundation Trust	64	7%
University Hospitals Bristol and Weston NHS Foundation Trust	53	6%
Total	960	100%