

# Under 16 Cancer Patient Experience Survey 2020

National Results



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# Executive summary

Under 16 Cancer Patient Experience Survey 2020



Results for some key questions in the survey are summarised below (scored data). Further data is presented throughout this report, and data tables and scores for all survey questions can be found on the survey website:

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

## Overall care rating



**80%** of children aged 8-15 reported that they were looked after very well for their cancer or tumour by healthcare staff (Question X65)

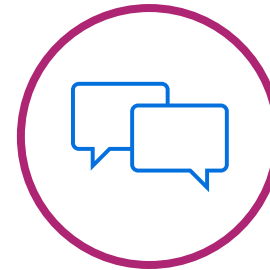


**92%** of parents/carers rated the overall experience of their child's care as 8 or more out of 10 (Question X64)

## Key question\* scoring



**79%** of parents/carers were definitely given clear written information about their child's treatment (Question X40)



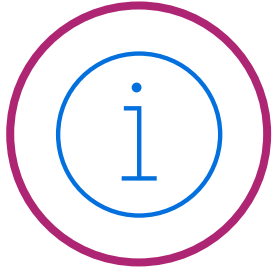
**79%** of parents/carers were definitely told about their child's cancer or tumour in a sensitive way (Question X08)

\* Key questions have been selected by healthcare professionals as the most important questions in the Under 16 Cancer Patient Experience Survey for children's cancer care

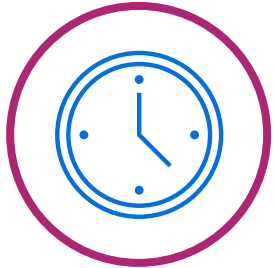
## Key question\* scoring



**85%** of parents/carers always had confidence and trust in staff caring for their child (Question X17)



**70%** of parents/carers and children said information was definitely given to them in a way they could understand (Question X09)



**76%** of parents/carers agreed that staff definitely offered enough time to make decisions about their child's treatment (Question X41)



**70%** of children always understood what staff were saying (Question X15)



**84%** of children reported that staff always spoke to them in a way that was suitable to them (Question X22)



**66%** of parents/carers definitely had access to reliable help and support 7 days a week from the hospital (Question X35)



**61%** of parents/carers felt that different staff were definitely aware of their child's medical history (Question X30)

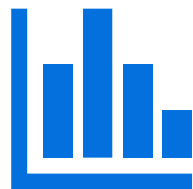
\* Key questions have been selected by healthcare professionals as the most important questions in the Under 16 Cancer Patient Experience Survey for children's cancer care

# Introduction

Under 16 Cancer Patient Experience Survey 2020



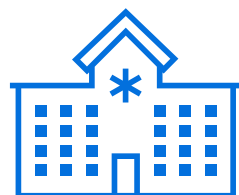
## U16 Cancer Patient Experience Survey 2020



The Under 16 Cancer Patient Experience Survey (U16 CPES) measures experiences of tumour and cancer care in children across England. The 2020 survey was its first iteration and is expected to run annually.



The survey captures the experiences of children aged under 16 at the time of their care, and that of their parents or carers.



The survey enables Principal Treatment Centres (PTCs) to compare themselves against others. Please refer to the PTC reports for further details and considerations when comparing results. In subsequent years, monitoring performance over time will be possible.

## U16 Cancer Patient Experience Survey 2020



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.



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



# Methodology

Under 16 Cancer Patient Experience Survey 2020



## U16 Cancer Patient Experience Survey 2020



### Eligibility

Patients with a confirmed cancer or tumour diagnosis who received inpatient or day case care from an NHS Principal Treatment Centre (PTC) in 2020, aged under 16 at their time of discharge.



### Mode

A paper questionnaire with a cover letter invite and up to two reminders posted to parents. People had the option to complete the survey online via a survey URL or QR code.



### Questionnaire

Questions asked about the child's care over the past year. There were three versions, depending on the patient's age immediately prior to fieldwork:

0-7 questionnaire – for completion by parents/carers of children aged 0-7.

8-11 questionnaire – separate sections for the child and the parent/carer to complete.

12-15 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 2021.

Full information can be found in the technical appendix, available on the survey website:

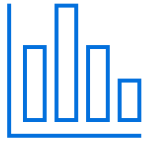
<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>

# Understanding the results

Under 16 Cancer Patient Experience Survey 2020



## U16 Cancer Patient Experience Survey 2020



- 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 exactly 100%.
- Question numbers relate to the numbering on the data tables, not the questions used on the surveys 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 <11, data for the question are suppressed, indicated by an asterisk (\*).
- Double suppression: where the base size for any groups for sub-group comparisons (e.g. a specific diagnostic/cancer group) is <11, data for that sub-group AND the next smallest sub-group are suppressed.



Note that the sampling period was during the Covid-19 pandemic. This may have impacted care and services, along with people's perceptions of their care and treatment, and of the NHS generally. This must be taken into consideration when interpreting the results.

Not all questions are presented in this report. To see results for all questions, including non-scored questions, please refer to the survey website: <https://www.under16cancerexperiencesurvey.co.uk/technical-reports>

# About the respondents

Under 16 Cancer Patient Experience Survey 2020



## Overall response rate



The survey received achieved a 35% response rate (there were 1,144 respondents out of a total of 3,308 eligible parents and children who were sent a survey).






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

Additional details about how the response rate was calculated can be found in the Technical Appendix available on the survey website:




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

Sample size	Adjusted sample size	Completed	Response rate
3,339	3,308	1,144	35%

## Survey mode

	Response mode	Number of responses	Proportion of responses
	Paper	842	74%
	Online	300	26%
	Mixed (combination of paper and online)	1	<1%
	Phone - English	0	-
	Phone – Translation	1	<1%
	<b>Total</b>	<b>1,144</b>	<b>100%</b>

## Survey type

	Survey Type	Number of responses	Proportion of responses
	Parents of children aged 0-7	619	54%
	Children aged 8-11 (and their parents)	260	23%
	Children aged 12-15 (and their parents)	265	23%
	<b>Total</b>	<b>1,144</b>	<b>100%</b>



# About the Respondents

## Ethnic background of child (from survey)

Ethnicity	No. of responses	% of responses
White	894	78%
Mixed	61	5%
Asian	109	10%
Black	31	3%
Other	20	2%
Not given	29	3%
<b>Total</b>	<b>1,144</b>	<b>100%</b>

## Gender of child (from survey)

Gender	No. of responses	% of responses
Male	643	56%
Female	452	40%
Prefer not to say	5	<1%
No response	44	4%
<b>Total</b>	<b>1,144</b>	<b>100%</b>



## Diagnostic group\*

Diagnostic group	No. of responses	% of responses
Group I - Leukaemia, myeloproliferative diseases, and myelodysplastic diseases	487	43%
Group II - Lymphomas and reticuloendothelial neoplasms	122	11%
Group III - CNS and miscellaneous intracranial and intraspinal neoplasms	225	20%
Group V - Retinoblastoma	24	2%
Group VI - Renal tumours	53	5%
Group VII - Hepatic tumours	15	1%
Group VIII - Malignant bone tumours	49	4%
All other	169	15%
<b>Total</b>	<b>1,144</b>	<b>100%</b>

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

## IMD\* quintile (deprivation)

Quintile	No. of responses	% of responses
1 (most deprived)	176	15%
2	184	16%
3	235	21%
4	252	22%
5 (least deprived)	264	23%
Outside England	33	3%
<b>Total</b>	<b>1,144</b>	<b>100%</b>

\* Indices of Multiple Deprivation (IMD) classifies geographic areas into five quintiles based on relative disadvantage

# National results

Under 16 Cancer Patient Experience Survey 2020



- 01 Finding out about the cancer or tumour
- 02 Healthcare staff
- 03 Child's care and treatment
- 04 Hospital ward
- 05 Care at home
- 06 Overall care

# Finding out about the cancer or tumour

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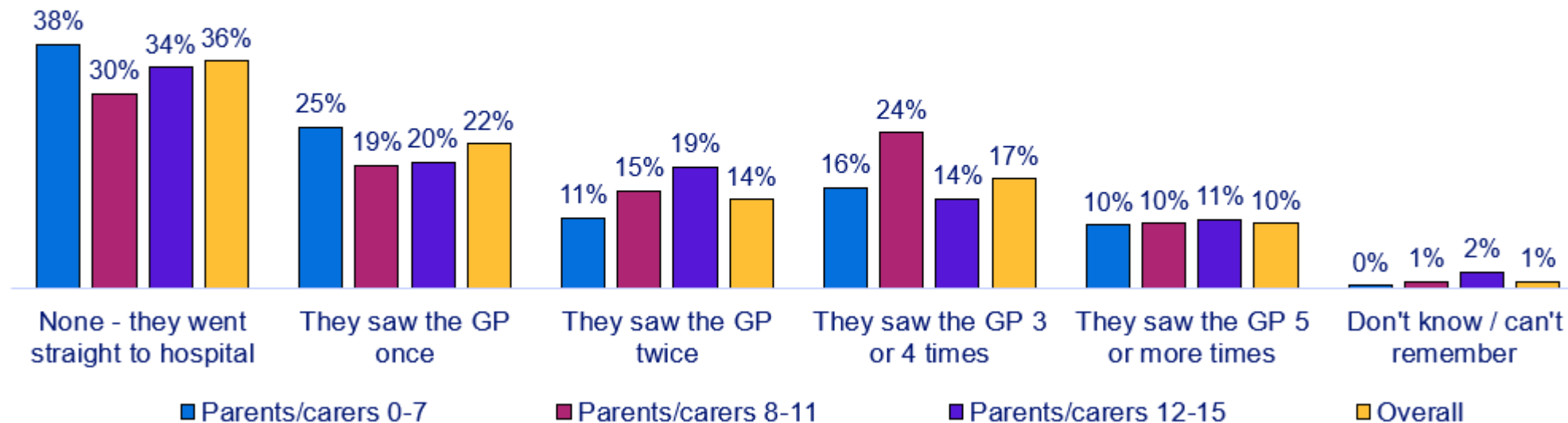


## Visiting the GP



Parents/carers of 0-7s were more likely than parents/carers of other age groups to **go straight to the hospital, or to see the GP only once** before then going to the hospital about their child's cancer or tumour (Question X04).

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? (Question X04)

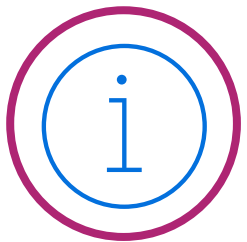


## Answering questions



**82%** of parents/carers of 0-7s and children aged 8-15 who were told they had cancer or a tumour in the last year **were definitely able to have questions answered after being told about the cancer or tumour** (Question X10).

## Information giving



**70%** of parents/carers of 0-7s and children aged 8-15 who were told they had cancer or a tumour in the last year **were definitely given information in a way they could understand** (Question X09).

QX10: Asked of Parents/carers of 0-7s & children aged 8-15 who were told they had cancer or a tumour within the last year, excluding those who did not have any questions or answered 'don't know/can't remember', n=258

QX09: Asked of Parents/carers of 0-7s & children aged 8-15 who were told they had cancer or a tumour within the last year, excluding those who answered 'don't know/can't remember', n=264

# Healthcare staff

Under 16 Cancer Patient Experience Survey 2020





## Bedside manner and trust

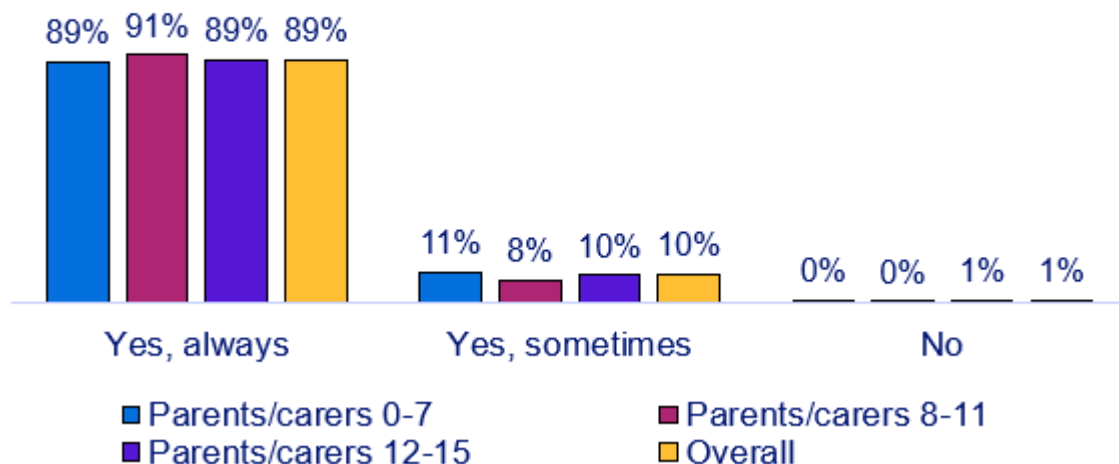


**89%** of parents/carers felt that they and their child were always treated with **respect and dignity by staff** (Question X16).

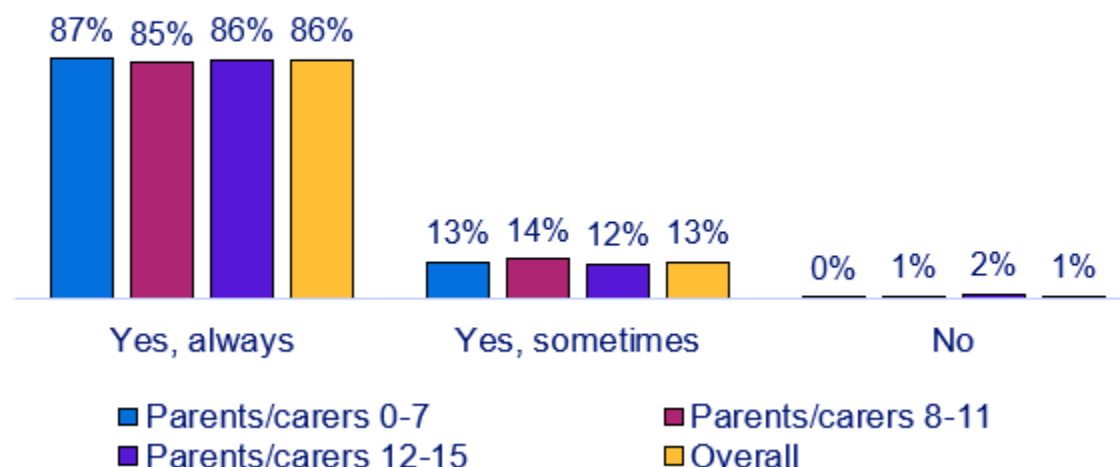
**85%** of parents/carers said they always had **confidence and trust** in the staff caring for their child (Question X17).

**86%** of parents/carers said that staff always treated them with **empathy and understanding** (Question X18).

Are you and your child treated with respect and dignity by staff? (Question X16)



Do members of staff caring for your child treat you with empathy and understanding? (Question X18)

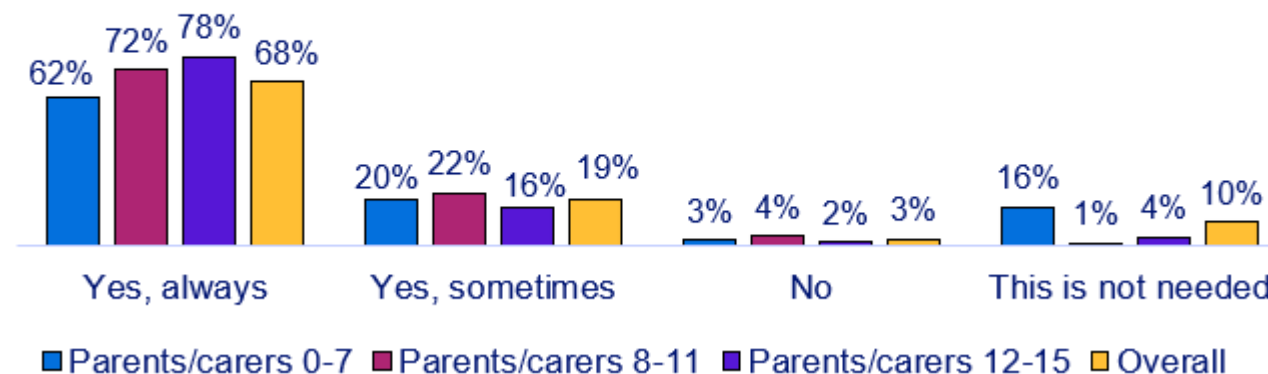


## Bedside manner and trust



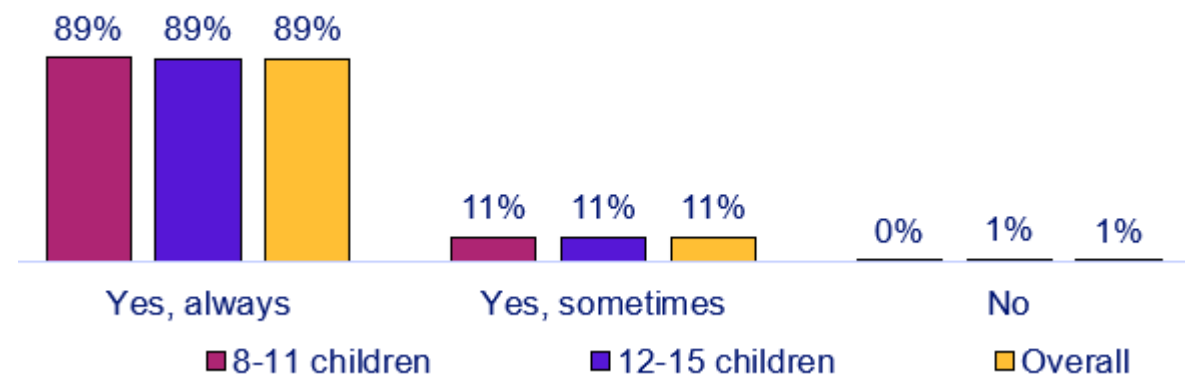
The older the patient, the more likely that parents/carers would state that **staff were always sensitive to the information that was shared with them when the child was present** (Question X20).

Are staff sensitive to the information they share with you when your child is in the room? (Question X20)



**89%** of children aged 8-15 said that **staff were always friendly**. There were no notable differences by age group (Question X24).

Do you feel that staff are friendly? (Question X24)

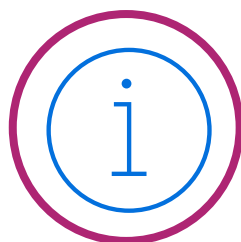
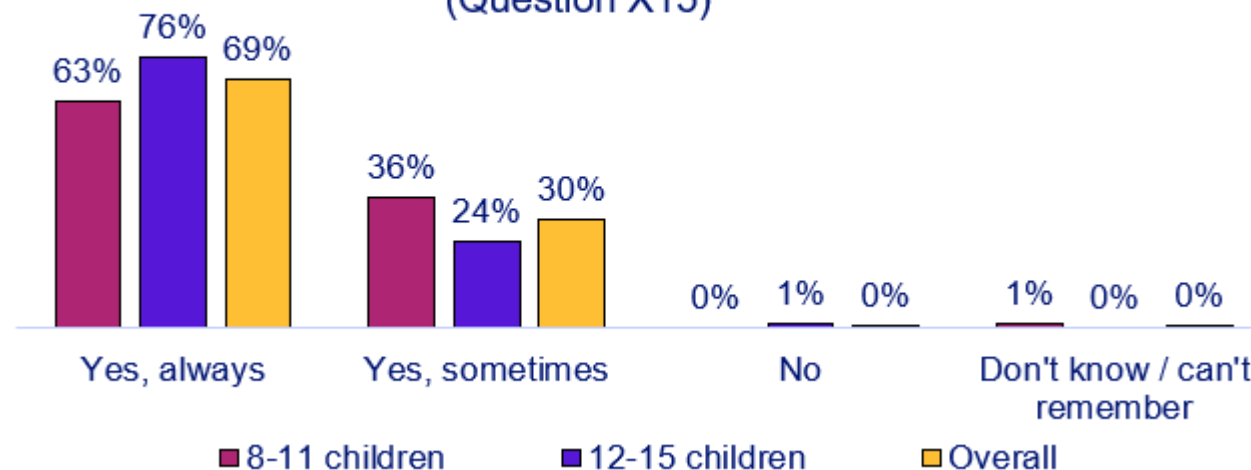


## Clear communication



Older children were more likely to report that **staff always spoke to them in a way they could understand. 76% of 12-15s** reported this, compared to **63% of 8-11s** (Question X15).

When staff speak to you, do you understand what they are saying / Do staff speak to you in a way you understand?  
(Question X15)



**79%** of parents/carers said that staff **always shared information that was appropriate for their child** (Question X21 - scored data). Parents/carers of older patients were more likely to say that staff always shared information that was appropriate for their child:

- **78%** for parents/carers of children aged 0-7 and 8-11
- **84%** for parents/carers of 12-15s

## Clear communication



**64%** of parents/carers of children aged 0-7 and children aged 8-15 report that they were **never told different things by different members of staff** (Question X19).



**84%** of children aged 8-15 **reported that staff always spoke to them in a way that was suitable to them** (Question X22).



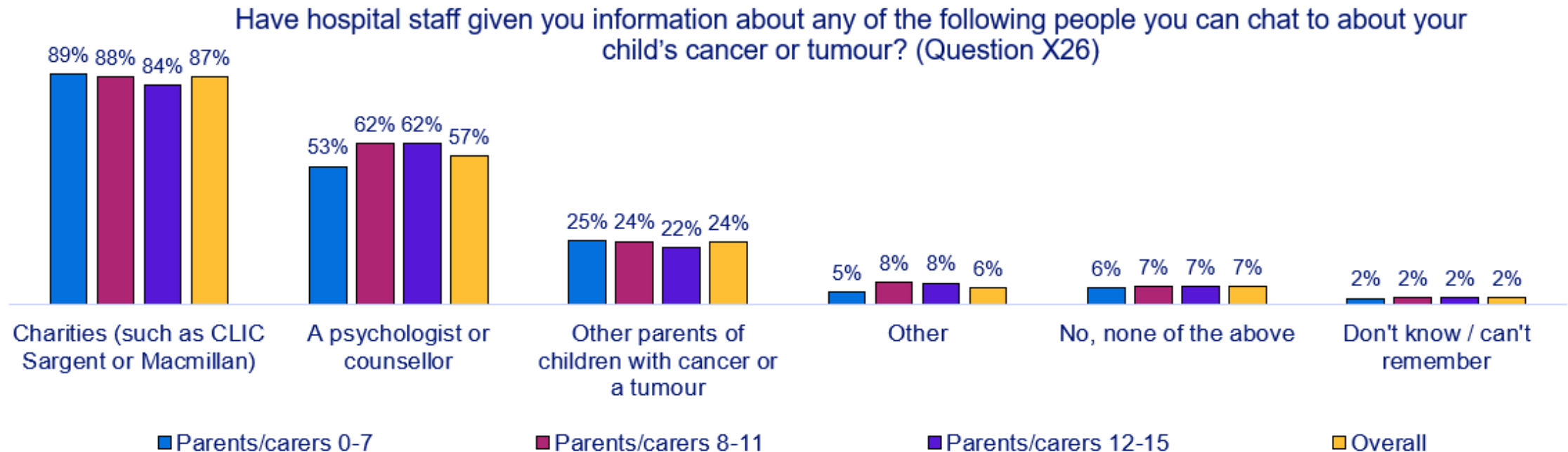
**79%** of children aged 8-15 felt that **staff always talked to them, not just their parent or carer** (Question X23).

## Support – parents/carers



The majority of parents/carers (87%) were given information by hospital staff about charities they could talk to about their child's cancer or tumour.

Parents/carers of older children were more likely to be given information about a psychologist or counsellor (62% for parents/carers of 8-15s versus 53% for parents/carers of 0-7s). A quarter (24%) were given information about other parents of children with cancer or a tumour (Question X26).



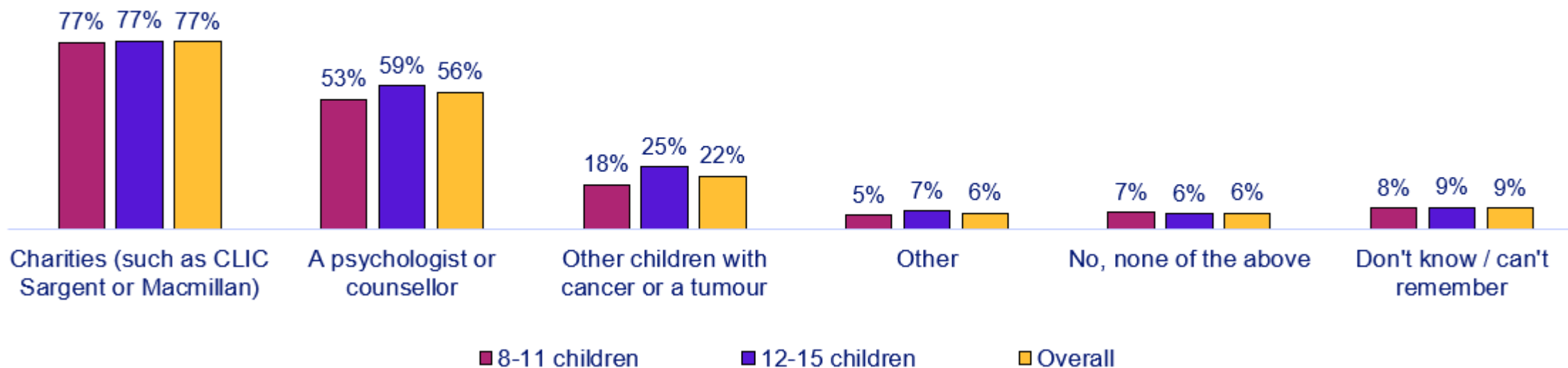
## Support – children aged 8-15



**77%** of children aged 8-15 were given information by hospital staff about charities they could talk to about their cancer or tumour, with no differences by age group (Question X27).

In line with the parents/carers results, **older children were more likely to be given information about a psychologist or counsellor** (59% for 12-15s versus 53% for 8-11s). Older children (12-15s) were also more likely to have been **given information relating to other children with cancer or a tumour** (25% of 12-15s compared to 18% of 8-11s).

Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? (Question X27)



# Child's care and treatment

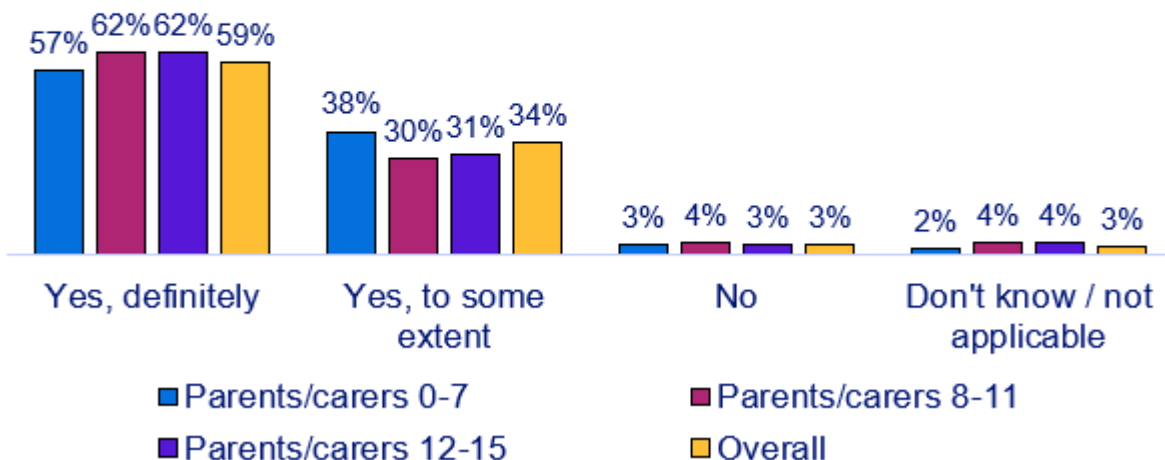
Under 16 Cancer Patient Experience Survey 2020



## Medical history

59% of parents/carers felt that **different members of hospital staff were definitely aware of their child's medical history** (Question X30).

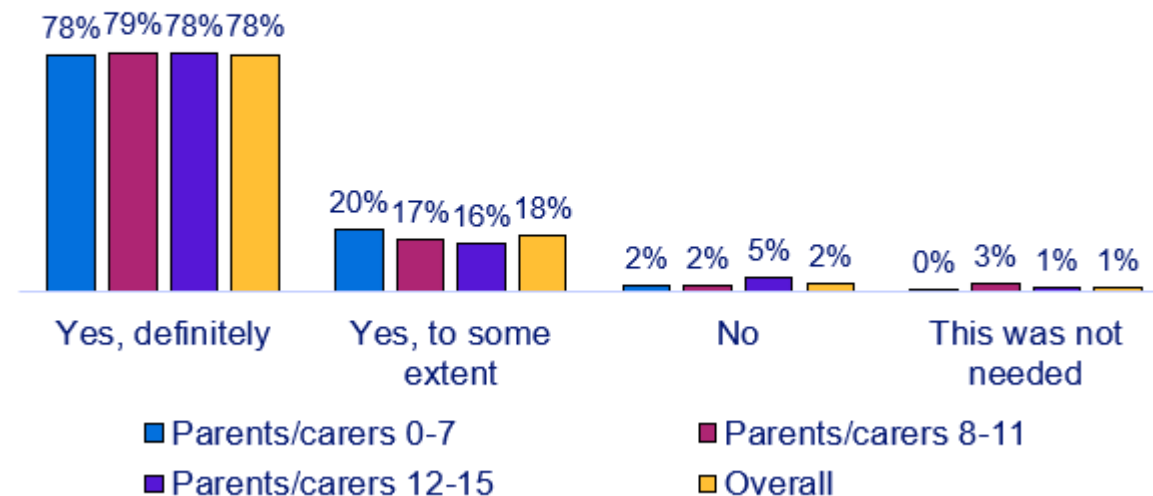
Are different hospital members of staff caring for your child aware of your child's medical history? (Question X30)



## Clear written information

78% of parents/carers said that they were **definitely given clear written information about their child's treatment** (Question X40).

Were you given clear written information about your child's treatment? (Question X40)

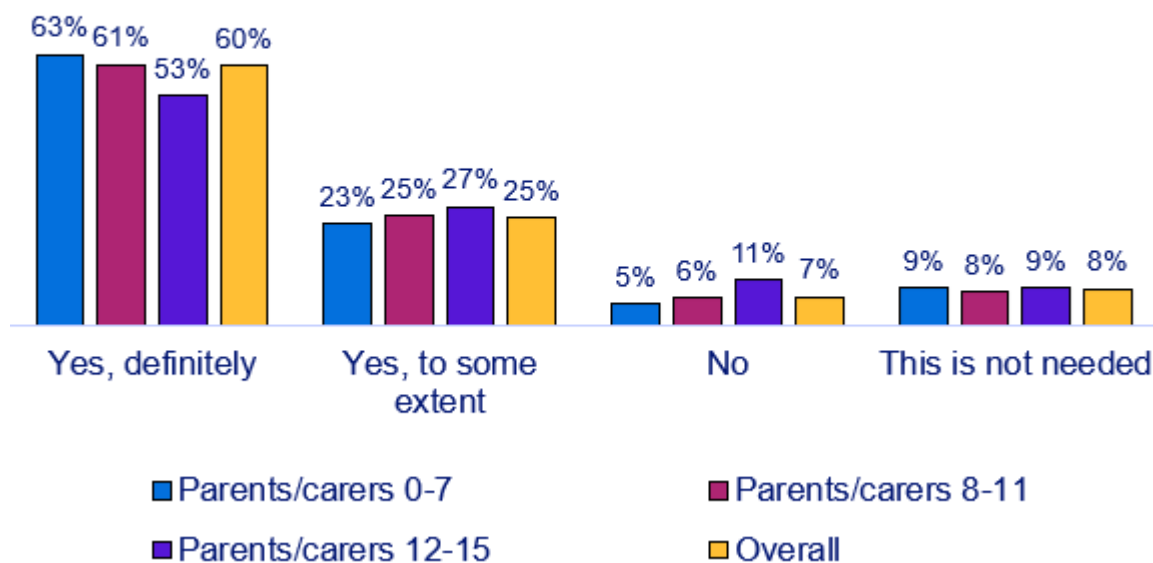




## Support 7 days a week

**60%** of parents/carers felt that they **definitely had access to reliable help and support 7 days a week from the hospital** (Question X35).

Do you have access to reliable help and support 7 days a week from the hospital? (Question X35)



## Support – parents/carers

Of patients who had received treatment for their cancer or tumour in the past year, treatment was still ongoing for around half of them (49%) (Question X44).

Of those whose treatment had finished, **57% of parents said that the hospital definitely gave them enough ongoing support** (Question X44 – scored data).

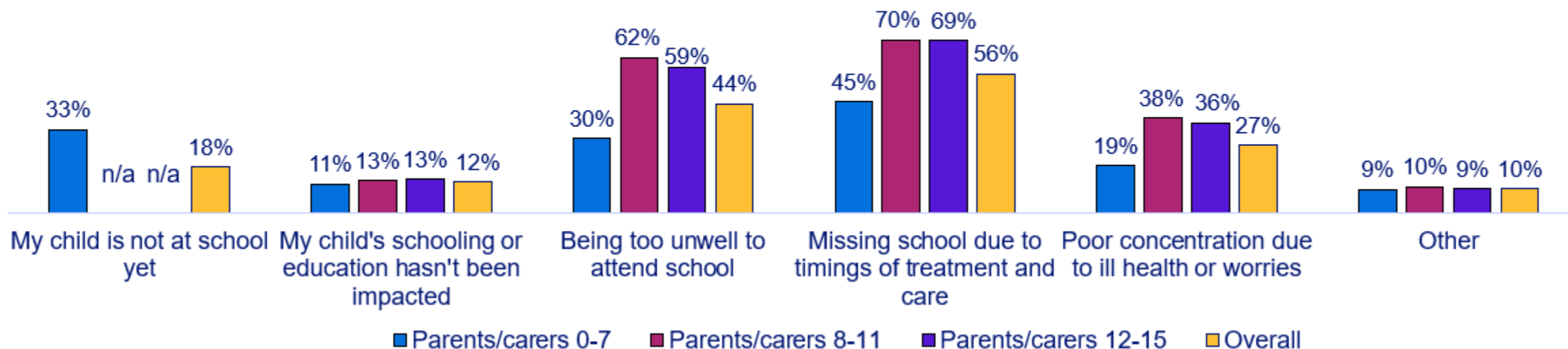
Parents/carers of children aged 12-15 were less likely to say they **definitely received enough ongoing support** (54%), than parents/carers of children aged 0-7 (57%) and 8-11 (61%) (Question X44 – scored data).

## Impact of care and treatment on schooling and education



Parents/carers reported the following impacts of treatment and care on their child's schooling and education: their **children missing school due to timings of treatment and care (56%)**, **being too unwell to attend school (44%)** and **having poor concentration due to ill health or worries (27%)** (Question X33).

Has your child's schooling and education been impacted in any of the following ways by their treatment and care? (Question X33)



# Hospital ward

Under 16 Cancer Patient Experience Survey 2020

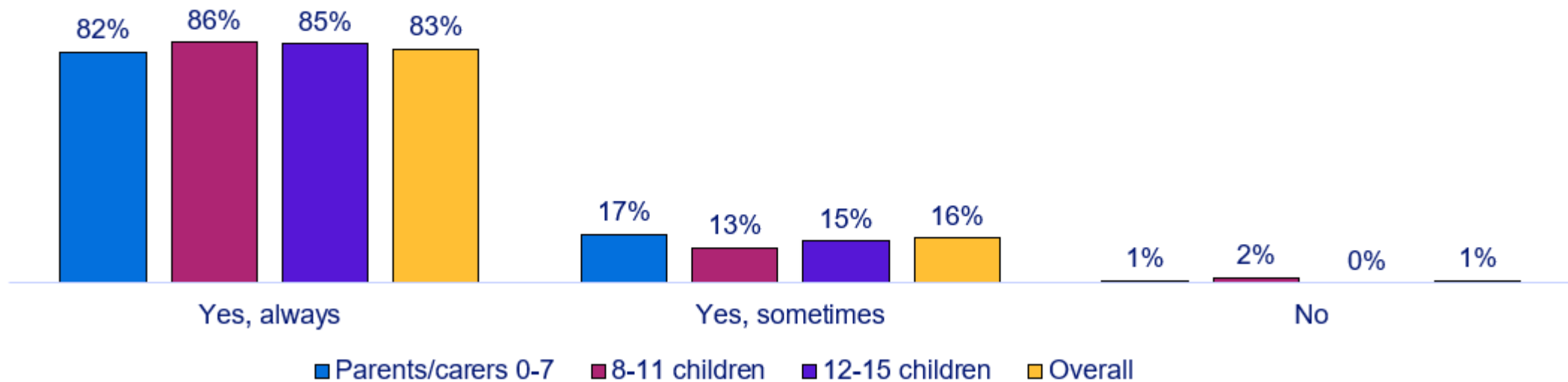


## Staff availability to give help



The majority of parents/carers of younger children aged 0-7 (82%) and children aged 8-11 (86%) and 12-15 (85%) reported that **hospital staff were always available to give help when needed** (Question X47).

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? (Question X47)

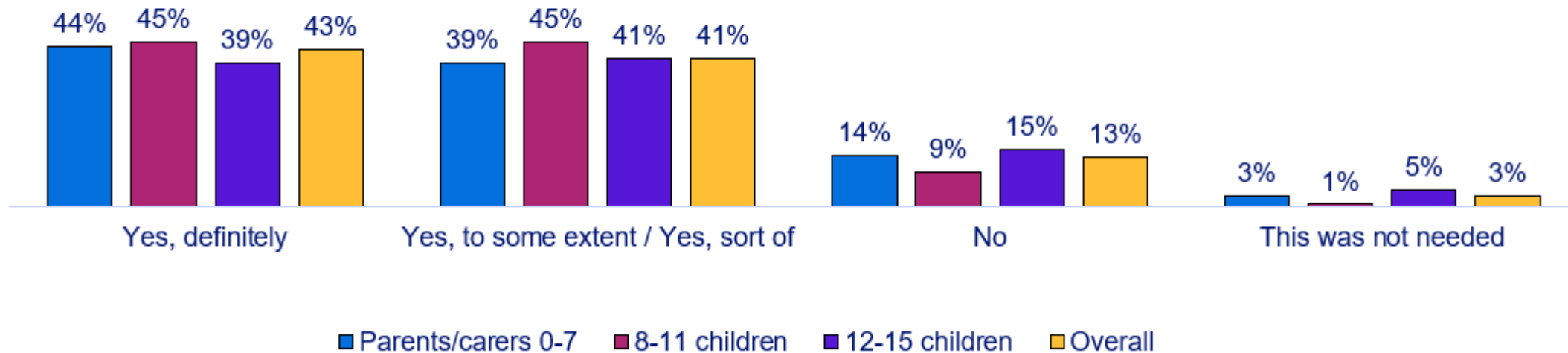


## Things for children to do in hospital



**43%** of parents of children aged 0-7 and children aged 8-15 said that **there were definitely enough things to do in the hospital**. Children aged 12-15 were least likely to say that there was definitely enough things to do (39%) – though 5% said this was not needed (Question X48).

Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital? (Question X48)



## Care at home

Under 16 Cancer Patient Experience Survey 2020



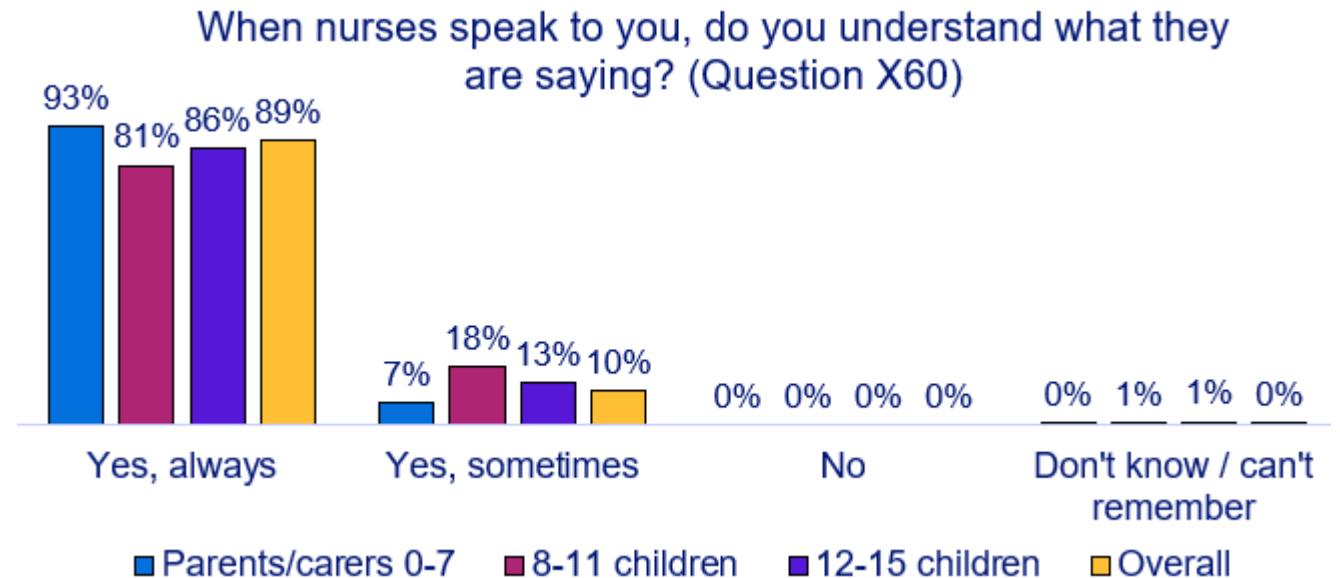
## Friendliness of nurses at home



The vast majority of parents of children aged 0-7 (96%) and children aged 8-15 (98%) said that the **nurses who gave care at home were always friendly**. No respondents said that the nurses were not friendly (Question X59).

## Understanding what nurses at home say

Overall, most people (89%) **could always understand what the nurses were saying**. This was higher for parents/carers of 0-7s (93%) compared to children aged 8-11 (81%) and children aged 12-15 (86%). **Nobody said they did not understand what the nurses are saying** (Question X60).



QX59 & QX60: Parents/carers of children aged 0-7 whose children have been visited at home by a nurse in the last year, and children aged 8-15 who were visited at home by a nurse in the last year, QX59, Overall n=737; QX60, Overall n=736

# Overall care

Under 16 Cancer Patient Experience Survey 2020





## Overall care



**54%** of parents/carers (0-11) and children (12-15) who receive care from different hospitals said that **the different hospitals providing cancer or tumour care always worked well together** (Question X62: scored data).



**75%** of parents/carers report that **the hospital where their child receives the most of their care was under one hours travel** from their child's home (Question X63).

## Overall care



This section shows responses to the overall care questions by various sub-groups. Further information about how subgroups were determined can be found in the technical document, available on the survey website: <https://www.under16cancerexperiencesurvey.co.uk/technical-reports>



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



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

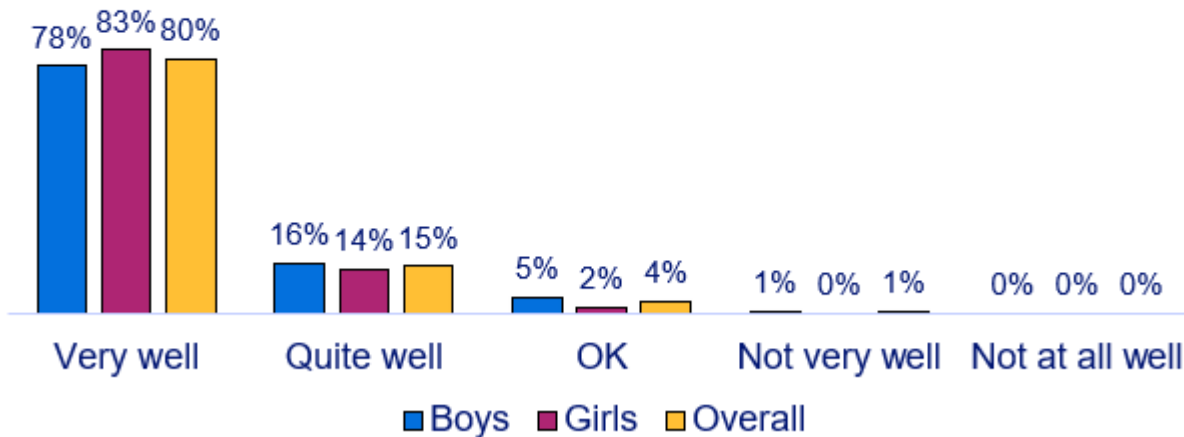
- Children aged 8 and over were asked how well they were looked after for their cancer or tumour by healthcare staff and were given the options “Very well,” “Quite well,” “OK,” “Not very well” and “Not at all well.”
- Parents and carers of all age groups were asked to rank their child’s overall care on a scale of 0 (very poor) to 10 (very good). These rankings have been grouped into 0-3 (poor), 4-7, and 8-10 (good).

## Overall Care

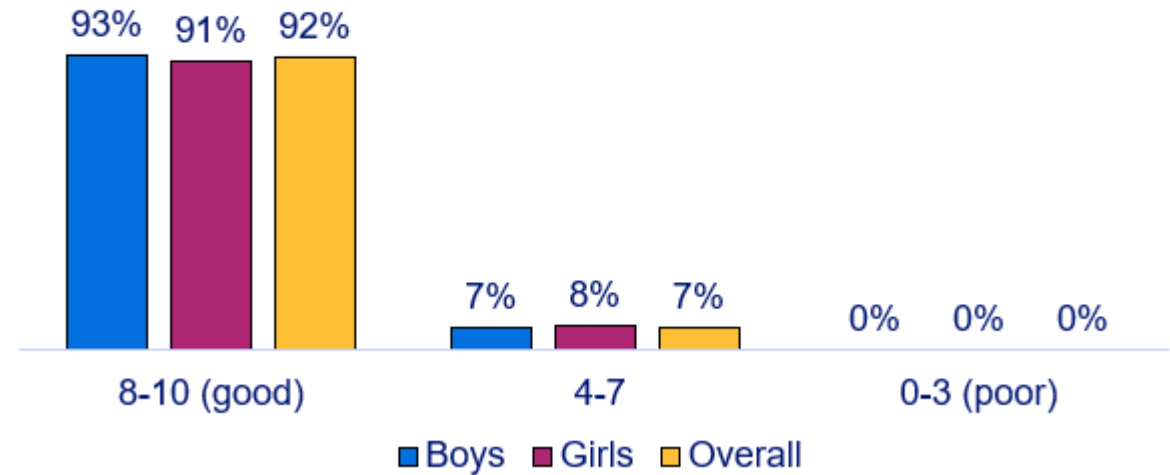
**80%** of children aged 8-15 said that they were **looked after 'very well' by healthcare staff**. Girls were more likely to say they were looked after very well (83%, compared to 78% of boys). Few patients said they were not looked after well (1%).

The majority of parents said that their **child's cancer or tumour care was 'good' (92%** giving a rating of 8-10). Few parents rated their child's care as 'poor' (<1%). There were no differences by gender of the patient.

Overall, how well are you looked after for your cancer or tumour by the healthcare staff? (Question X65)



Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good). (Question X64)



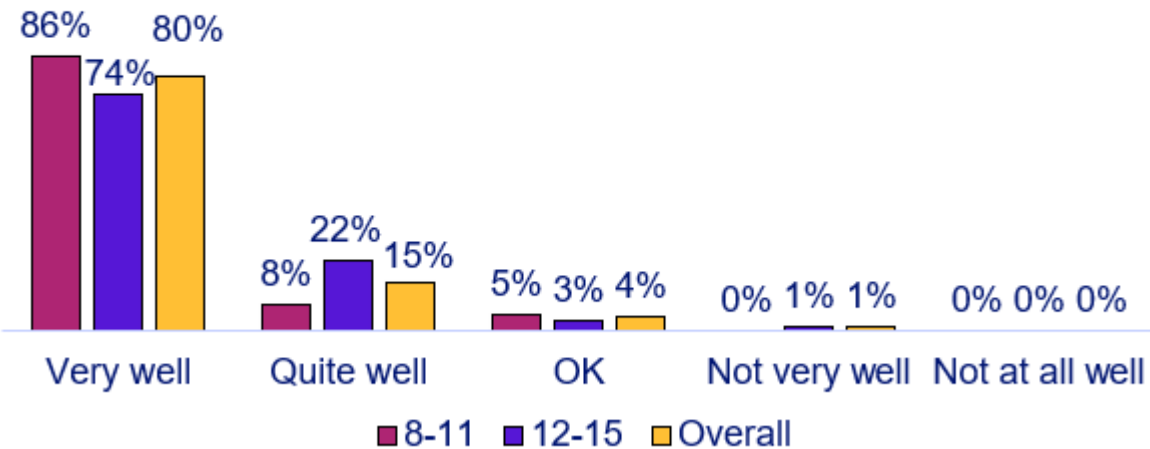
- QX65: Asked to all children aged 8-15, Overall, n=489; QX64: Asked to parents/carers of all age groups, Overall, n=1,102
- Only data for boys and girls is shown, as the number of respondents answering 'prefer not to say' to the gender question was small (n=5)

## Overall Care

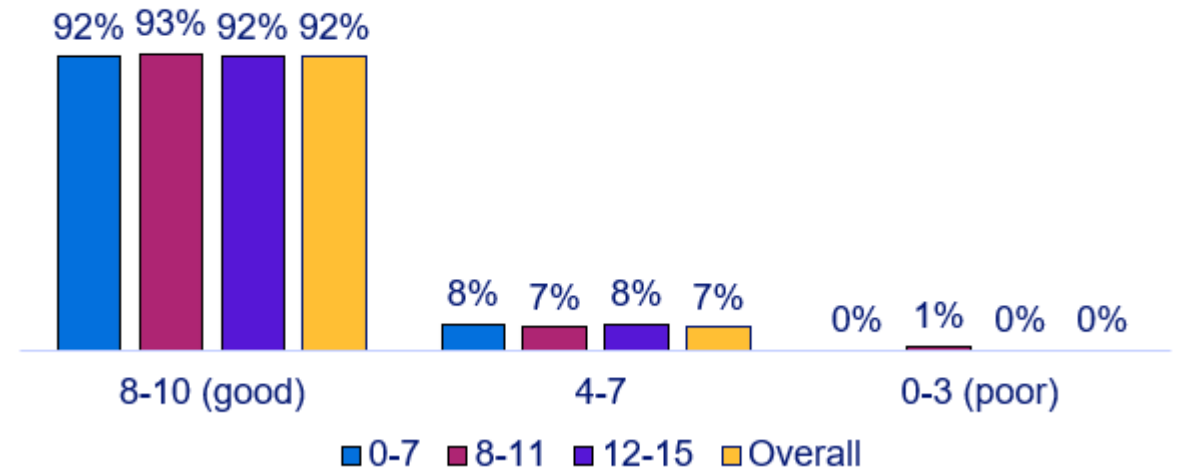
Patients aged 8-11 were more likely to state that they **were looked after 'very well' (86%)** than those aged 12-15 (**74%**).

The majority of parents across all age groups (**92%**) rated their child's cancer or tumour care as 8 or more out of ten.

Overall, how well are you looked after for your cancer or tumour by the healthcare staff? (Question X65)



Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good). (Question X64)

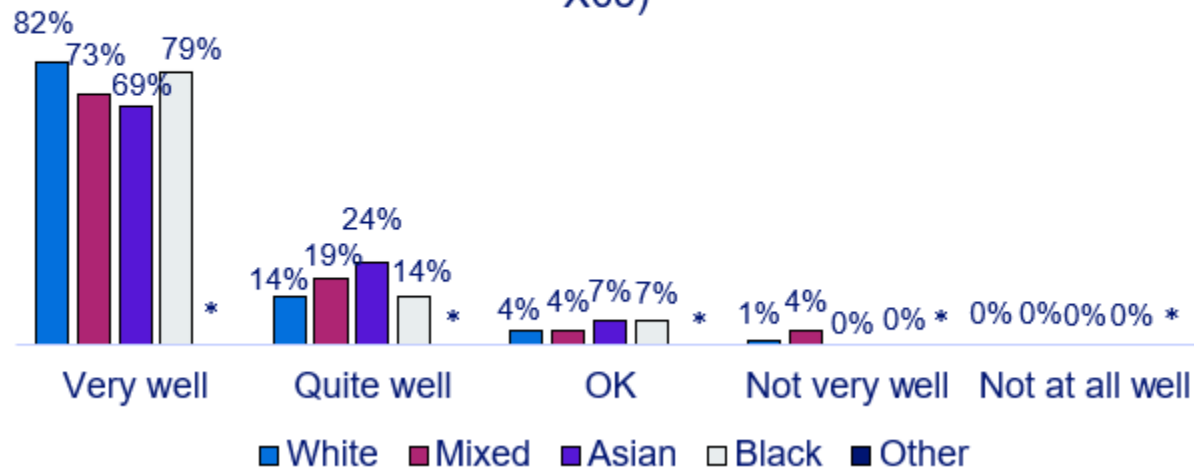


## Overall Care

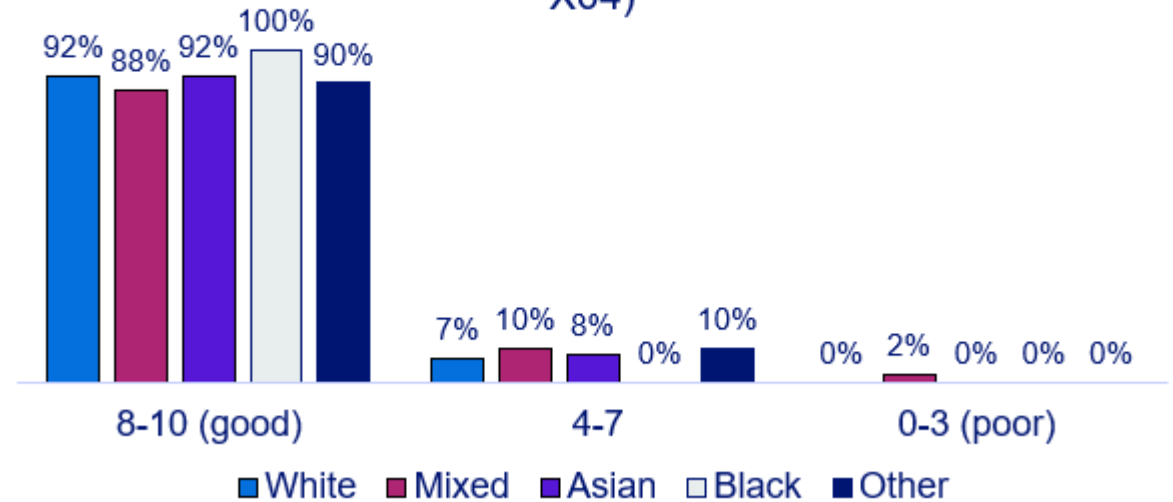
Children’s evaluation of overall care varied by ethnic group. Patients of White ethnicity were most likely to say **they were looked after ‘very well’ by staff (82%)**, compared to 79% of Black, 73% of Mixed and 69% of Asian patients.

The majority of parents stated that their child’s care was ‘good, regardless of their child’s ethnicity. All parents of patients of Black ethnicity **rated their child’s overall care as 8 or more out of 10**.

Overall, how well are you looked after for your cancer or tumour by the healthcare staff? (Question X65)

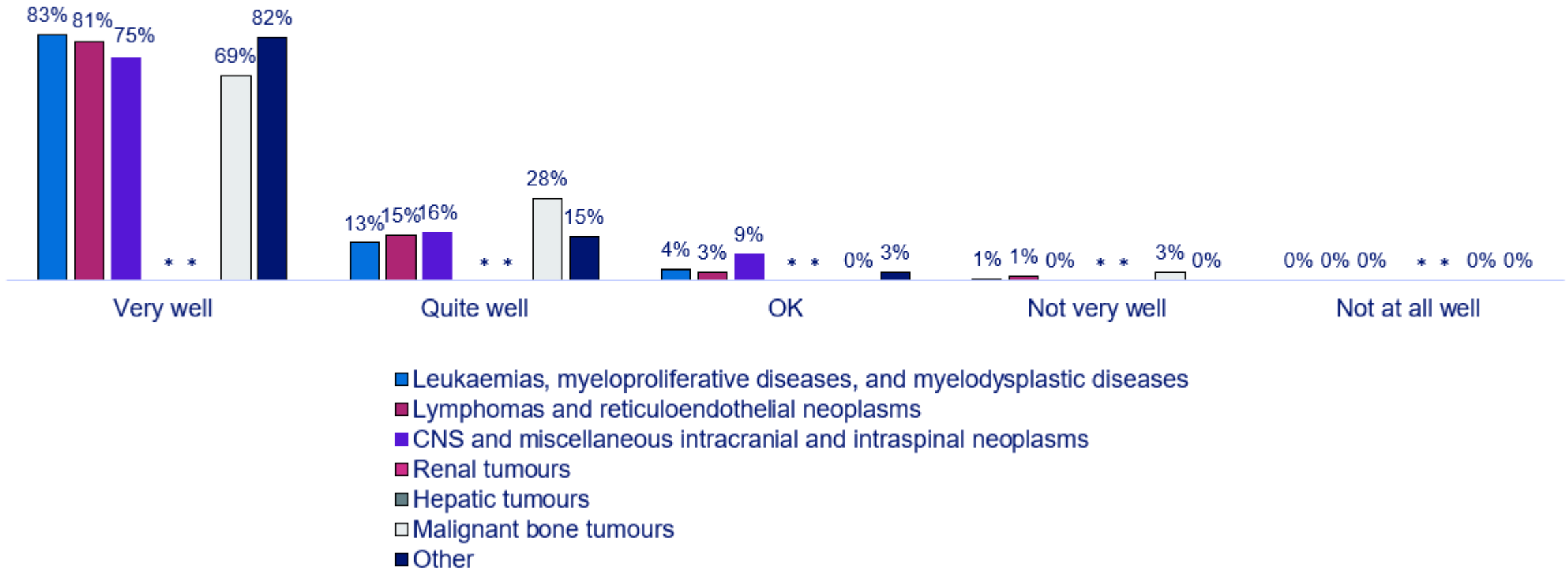


Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good). (Question X64)



## Overall Care – Children

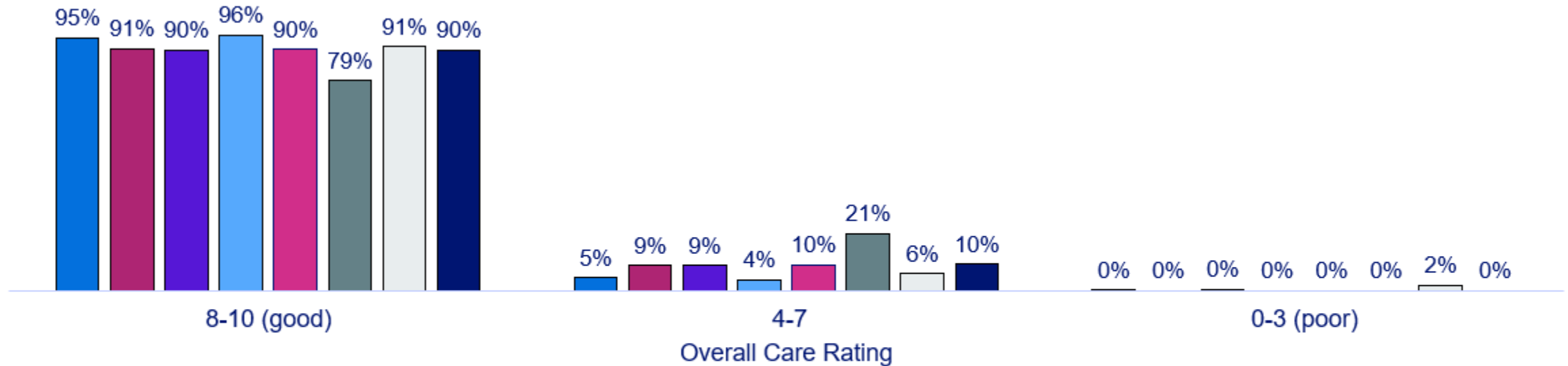
Overall, how well are you looked after for your cancer or tumour by the healthcare staff?  
(Question X65)



# Overall Care by Diagnostic Group

## Overall Care – Parent/carer

Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good).  
(Question X64)



- Leukaemias, myeloproliferative diseases, and myelodysplastic diseases
- Lymphomas and reticuloendothelial neoplasms
- CNS and miscellaneous intracranial and intraspinal neoplasms
- Retinoblastoma
- Renal tumours
- Hepatic tumours
- Malignant bone tumours
- Other

# Appendix

Under 16 Cancer Patient Experience Survey 2020





# Appendix: Proportion of responses from each PTC

## Responses by Principal Treatment Centre (PTC)

Treatment centre	No. of responses	% of responses
Alder Hey Children's NHS Foundation Trust	73	6%
Birmingham Children's Hospital NHS Foundation Trust	141	12%
Cambridge University Hospitals NHS Foundation Trust	81	7%
Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	166	15%
Leeds Teaching Hospitals NHS Foundation Trust	84	7%
Manchester University NHS Foundation Trust	68	6%
Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	43	4%
Oxford University Hospitals NHS Foundation Trust	75	7%
Sheffield Children's NHS Foundation Trust	37	3%
The Newcastle upon Tyne Hospitals NHS Foundation Trust	73	6%
The Royal Marsden NHS FT & St George's University Hospitals NHS FT	135	12%
University Hospital Southampton NHS Foundation Trust	97	8%
University Hospitals Bristol and Weston NHS Foundation Trust	71	6%
<b>Total</b>	<b>1,144</b>	<b>100%</b>

# Further information

Under 16 Cancer Patient Experience Survey 2020



For more information on the Under 16 Cancer Patient Experience Survey visit:



<https://www.under16cancerexperiencesurvey.co.uk>

If you have any questions about the survey please do not hesitate to get in touch:



[under16cancersurvey@pickereurope.ac.uk](mailto:under16cancersurvey@pickereurope.ac.uk)

For full data tables showing results to all survey questions, please see the survey website:



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

This research was carried out in accordance with the internal standard for organisations conducting social research (accreditation to ISO27001:2013; certificate number GB10/80275). The 2020 survey data has been produced and published in line with the Code of Practice for Official Statistics.