Under 16 Cancer Patient Experience Survey 2023

Workshop 1

5th December 2024

Agenda

cancer patient experience survey

U16 Cancer Patient Experience Survey 2023

Time	Item
10:00	Introduction and housekeeping
10:05	Welcome and opening statement
10:10	Overview of 2023 U16 CPES results - quantitative and qualitative data
10:40	Henry’s Wi-Fi legacy
10:50	Understanding the outputs
11:05	Sophie’s legacy
11:20	Closing statement

Welcome

NHS England

Jodie Moffat, Deputy Director of Policy and Strategy, National Cancer Programme, NHS England

Under 16 Cancer Patient Experience Survey 2023

National Quantitative Results Presentation

Picker

AJ Poots, Senior Insight Associate

Response rate

Overall response rate

Out of **3,741** eligible parents, carers, and children, **949** responded to the survey, yielding a response rate of **25%**. This is compared with 25% in 2022.

A response consists of one survey completion for a single patient, which could consist of both parent or carer and child responses. The adjusted sample size removes those patients who did not receive a questionnaire (returned undelivered by post) or who reported they were not eligible to take part.

Adjusted sample size	Completed	Response rate
3,741	949	25%

0 to 7 survey	8 to 11 survey	12 to 15 survey
490	178	281

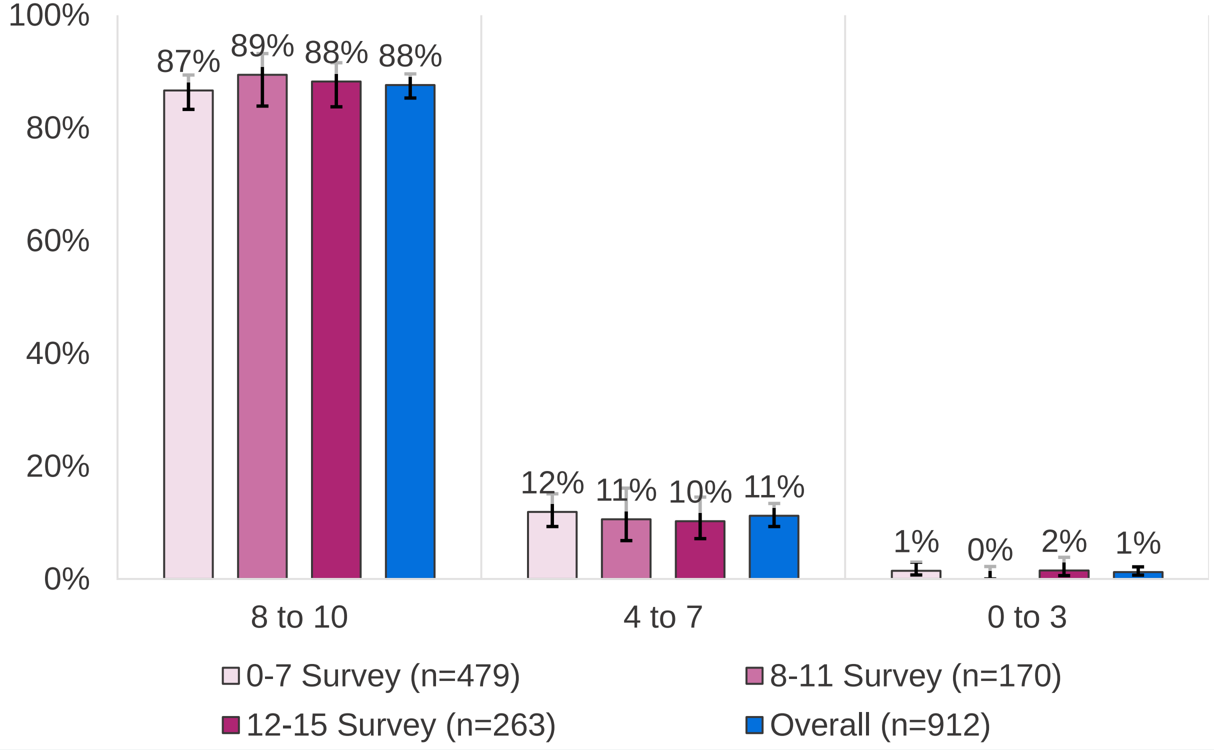
Full details are in the Technical Appendix available on the website

https://www.under16cancerexperiencesurvey.co.uk

Overall care by survey type

cancer patient experience survey

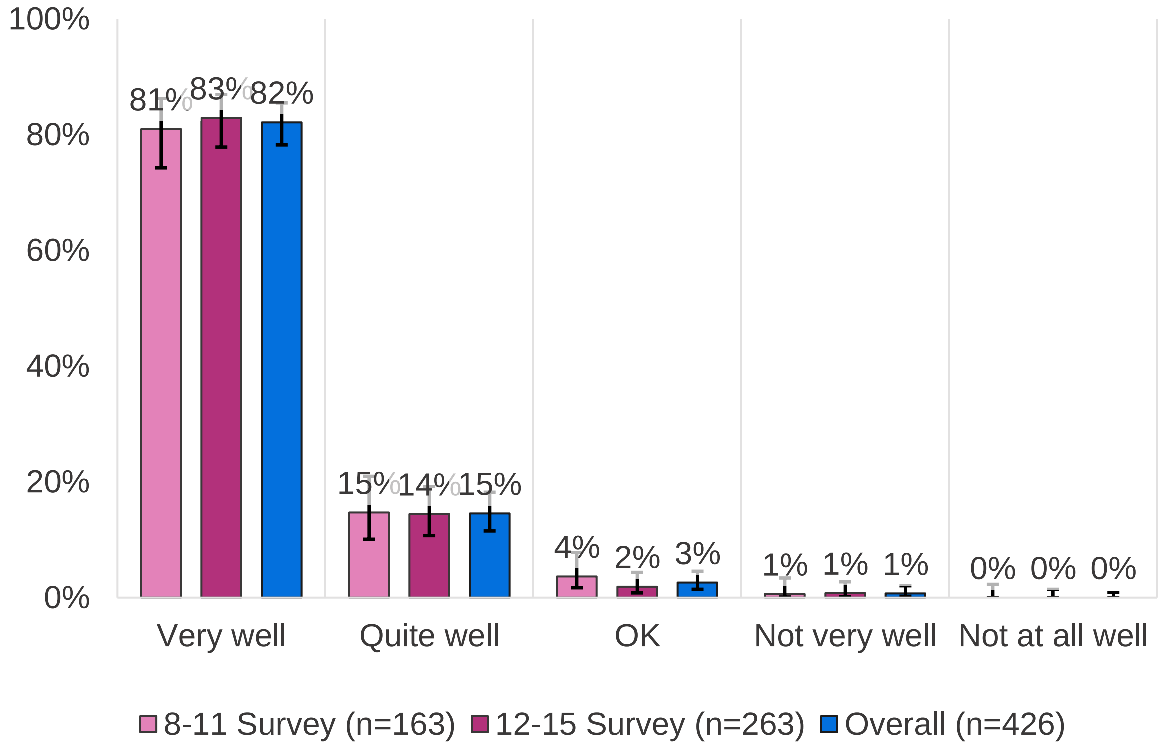
Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)



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

Chart shows question X59: Asked to parents or carers of all age groups.

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



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

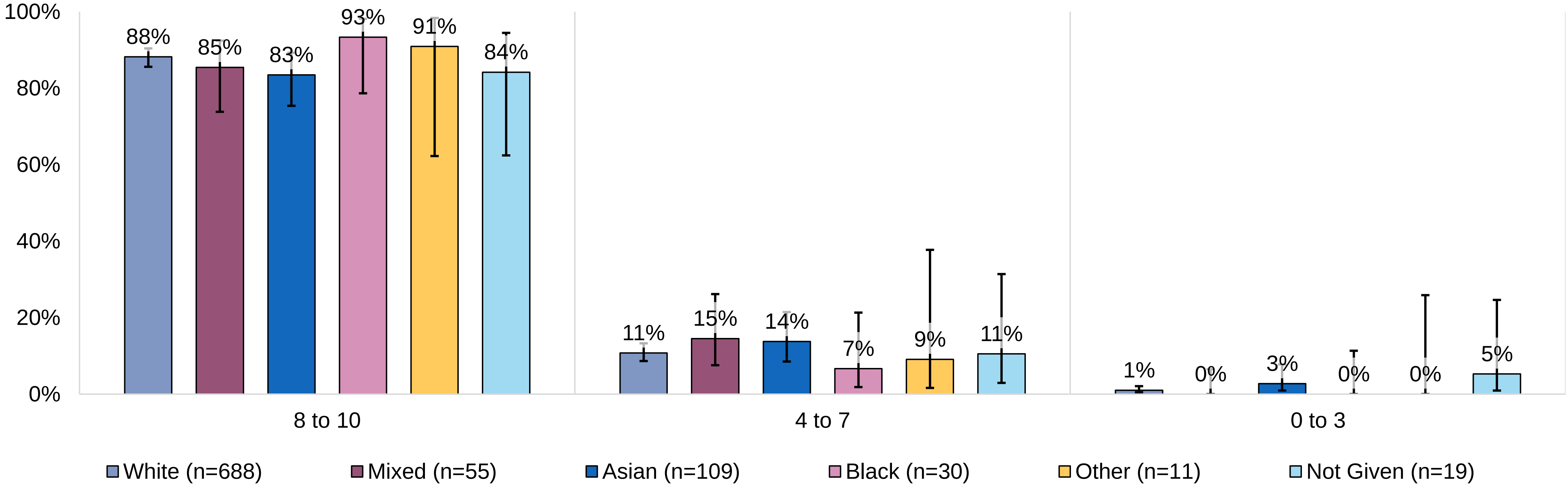
Chart shows question X60: Asked to all children aged 8-15.

Questions asking about overall care were structured differently for children and parents or carers, and therefore the results should not be directly compared.

Overall care (parent or carer) by ethnic group

U16 cancer patient experience survey

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

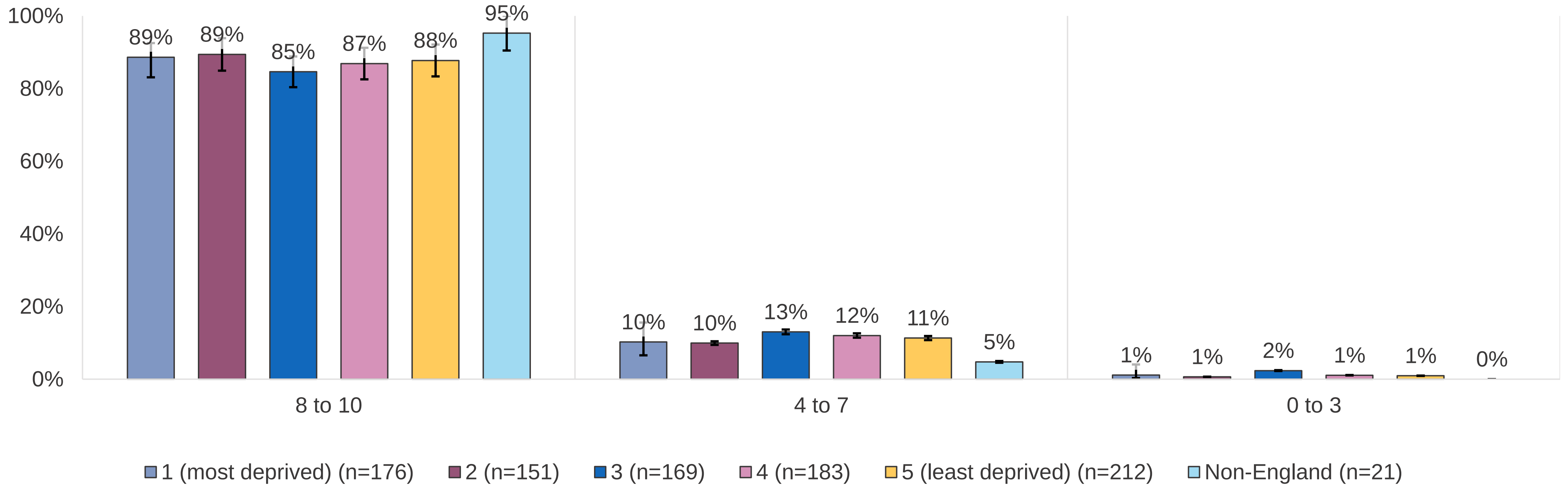


The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 83% for Asian ethnic background to 93% for Black ethnic background

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 912

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

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



The percent of parents or carers rating their child's overall care as 8 or more out of 10 ranged from 85% for the third IMD quintile to 95% for non-England.

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 912

Overall care (parent or carer) by diagnostic group

The percent of parents or carers rating their child’s overall care as 8 or more out of 10 ranged from 83% for all other to 95% for lymphomas and reticuloendothelial neoplasms.

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

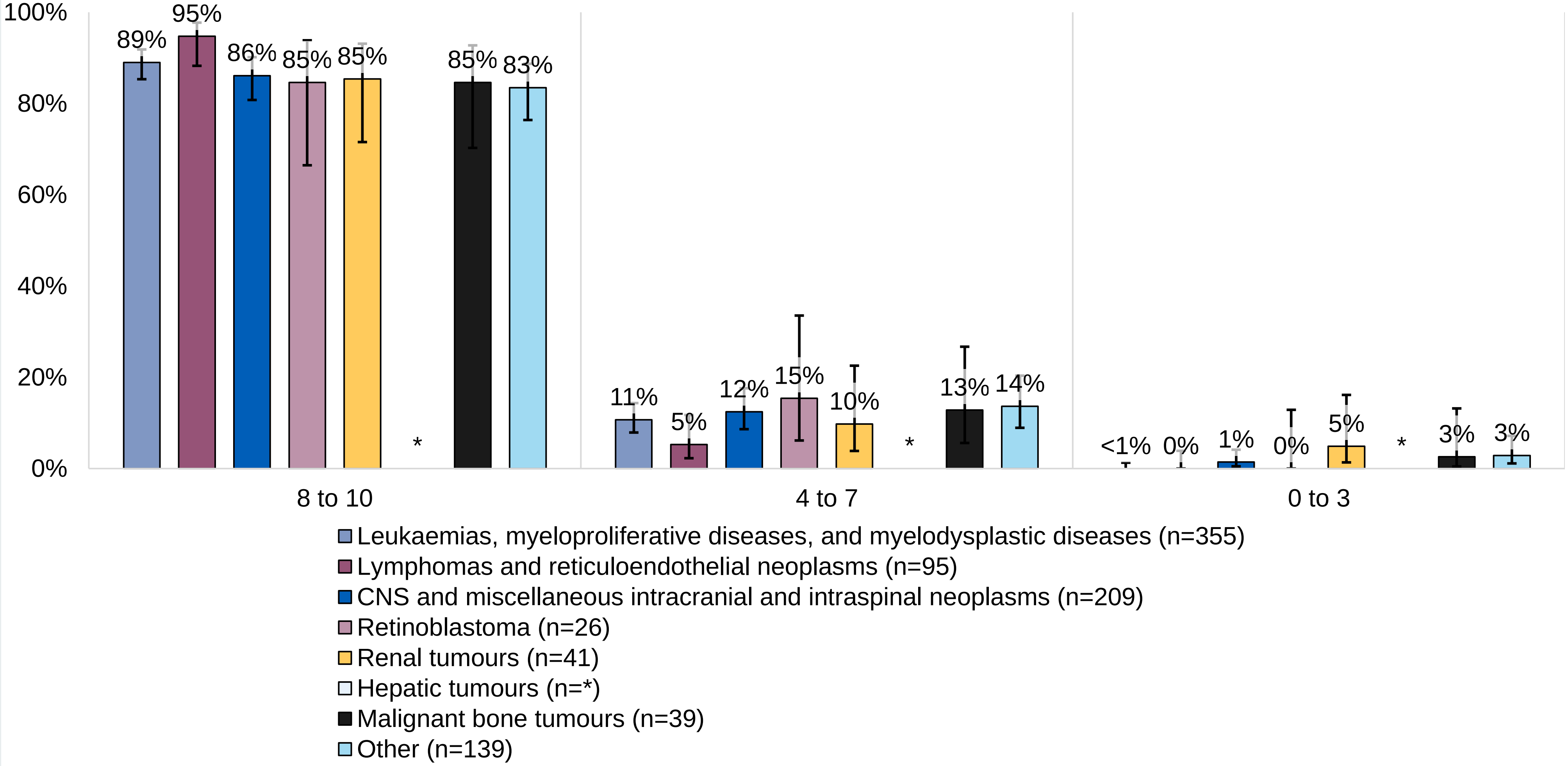
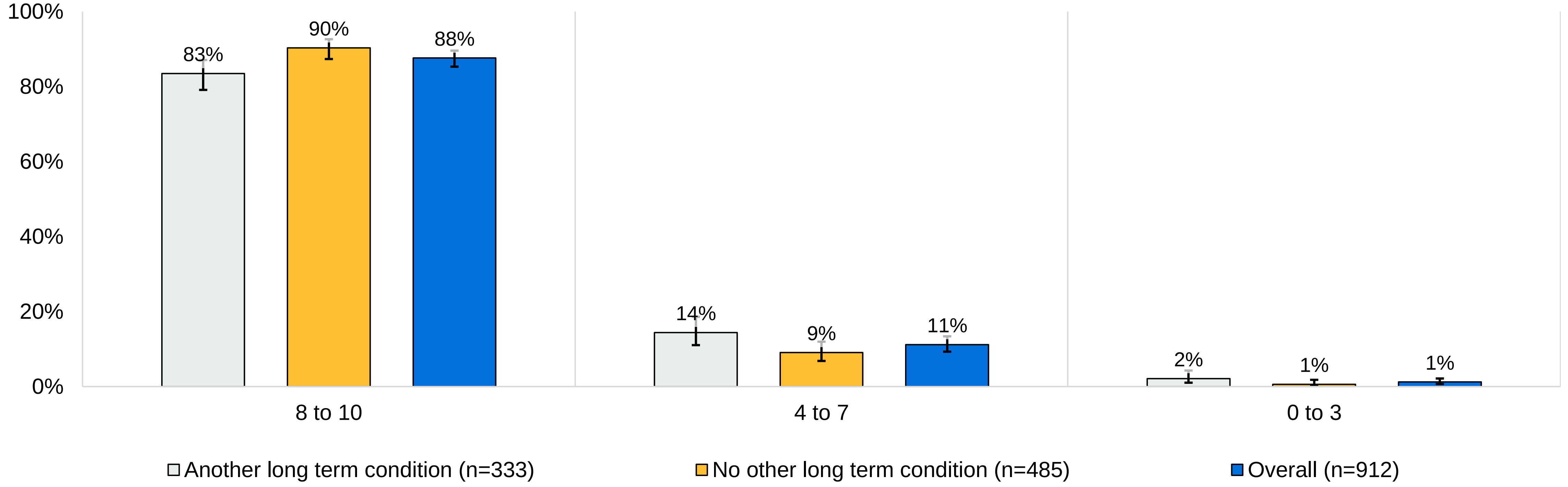


Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 912

*** An asterisk indicates that data has been suppressed**

Overall care by long term condition status

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



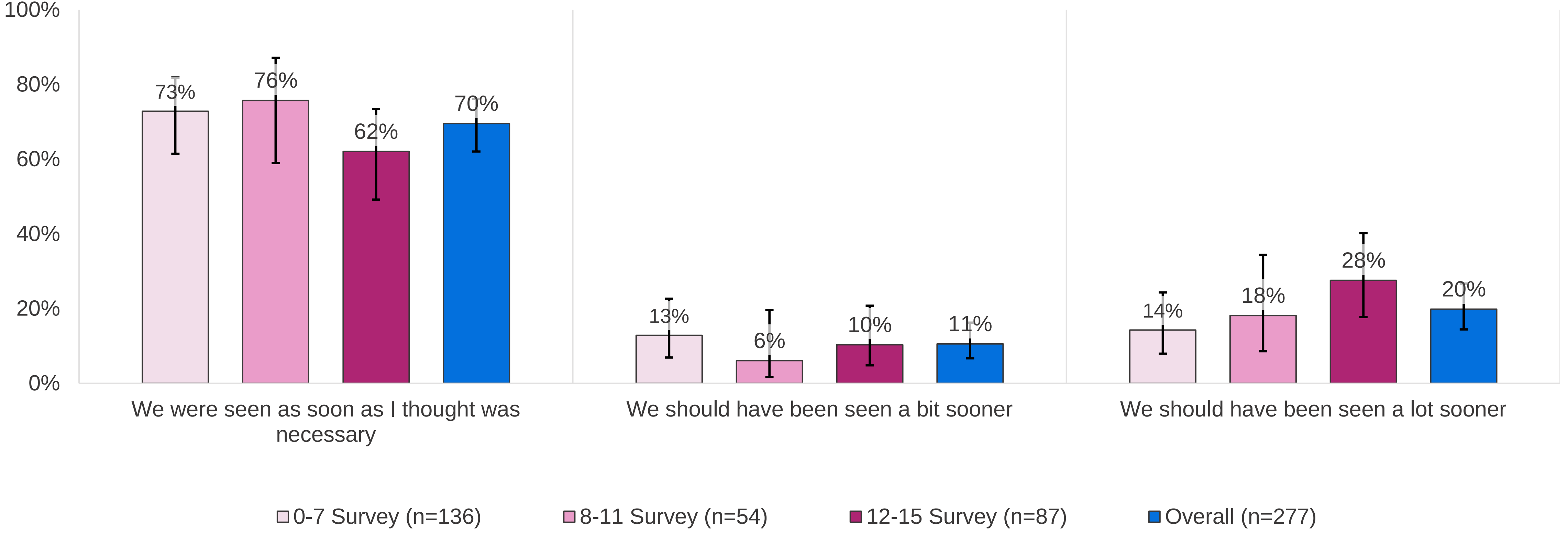
88% of parents or carers rated the overall experience of their child's care as 8 or more out of 10, ranging from 83% for another long term condition to 90% for no other long term condition.

Chart shows question X59: Asked to parents or carers of all age groups. Total number of responses = 912

Finding out about the cancer or tumour

Visiting the hospital

How did you feel about the length of time you waited between being referred by your GP to a hospital doctor until you were seen at the hospital?



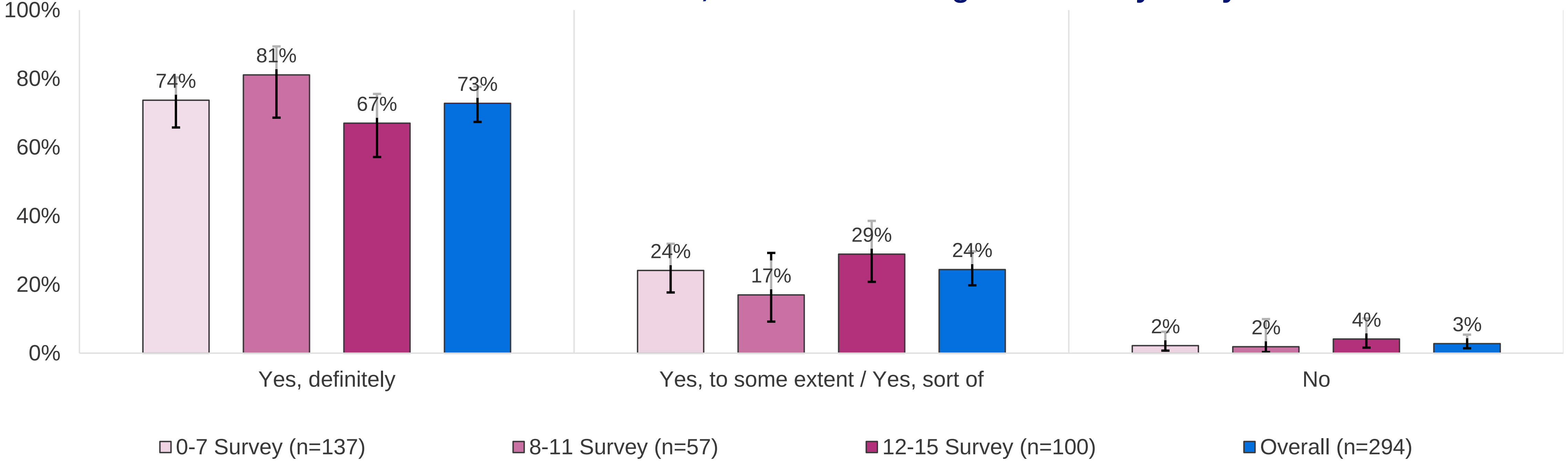
70% of parents or carers felt that they were seen at the hospital as soon as they thought was necessary after being referred by their GP.

Chart shows question X06: Asked to parents or carers of all age groups who were told about their child's cancer or a tumour. Total number of responses = 161 (excluding 116 responses of "We were not referred by a GP")

Finding out about the cancer or tumour

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

Chart shows question X08: Asked to parents or carers of 0-7s who were told about their child's cancer or a tumour, and children aged 8-15 who were told they had cancer or a tumour. Total responses = 287 (excluding 7 responses of “Don’t know / can’t remember”).

Healthcare staff

Bedside manner and trust

80% of parents or 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?

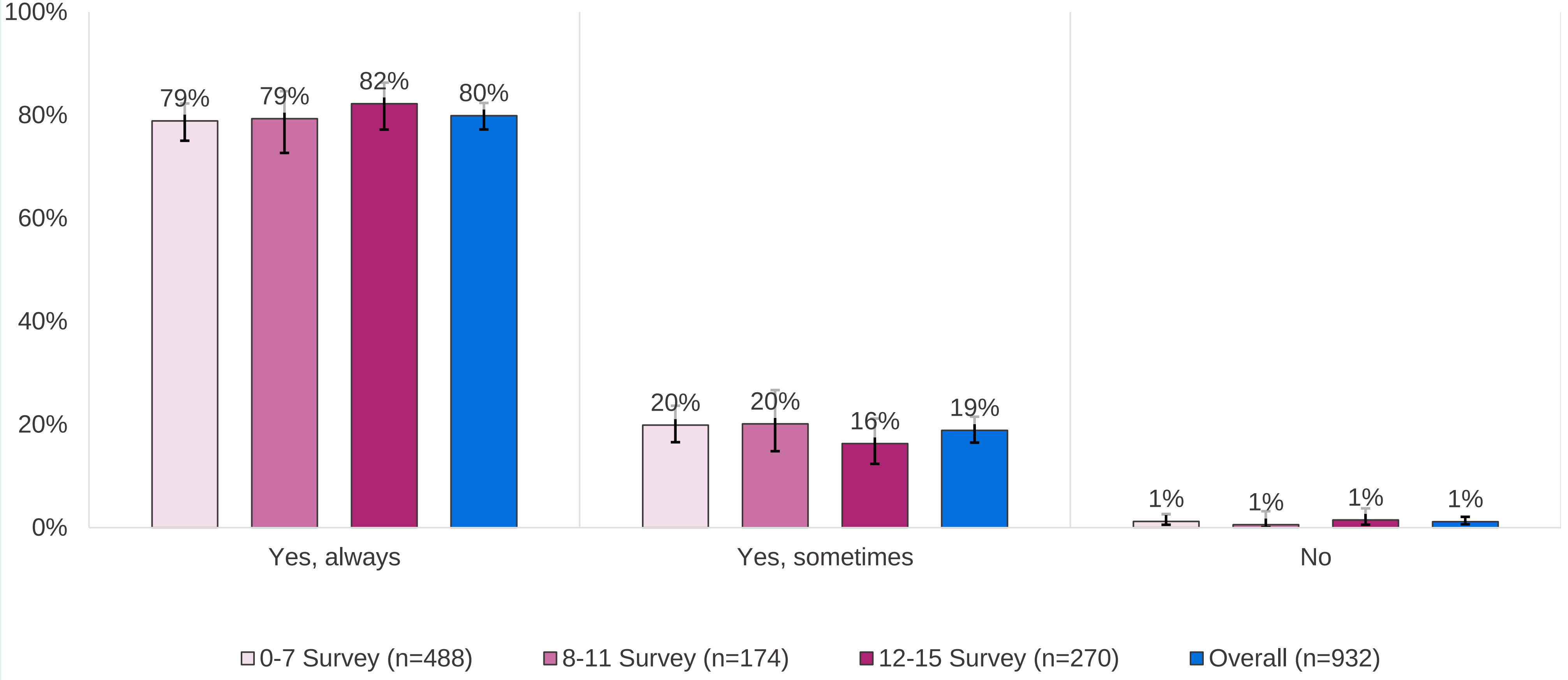


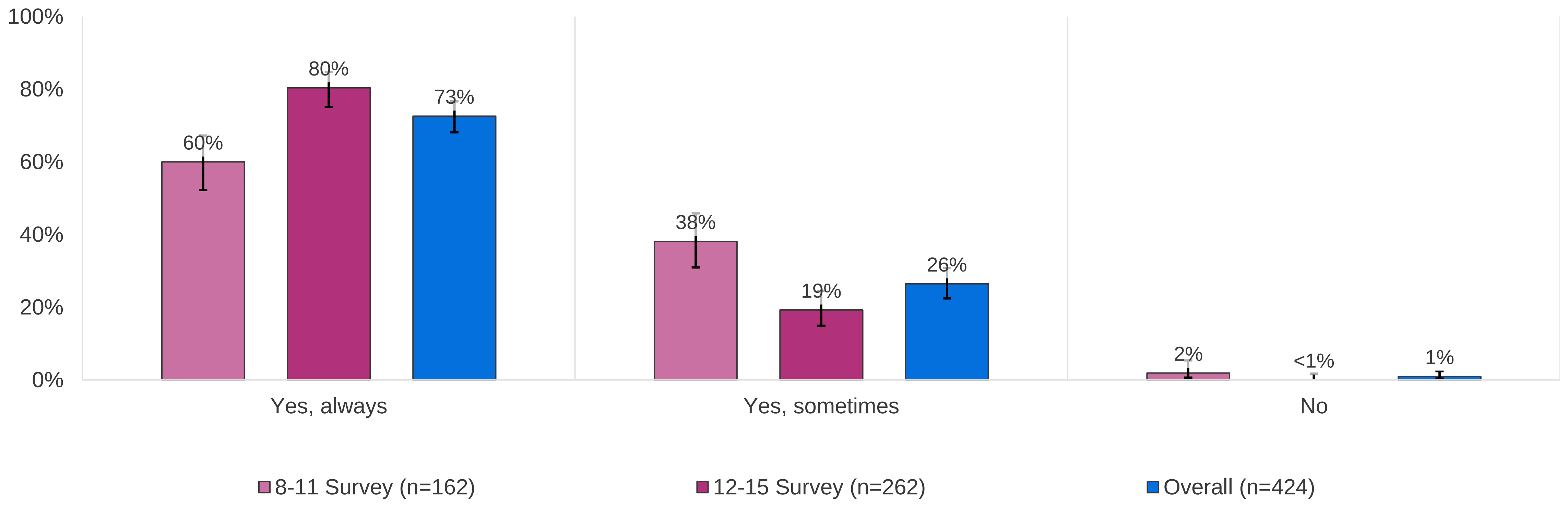
Chart shows question X18: Asked to parents or carers of all age groups. Total number of responses = 932.

Healthcare staff

u16 cancer patient experience survey

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?



73% 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 = 420 (excluding 4 responses of “Don’t know / can’t remember”).

Care in hospital

cancer patient experience survey

Staff availability in hospital

71% of parents, carers, and children felt that their child or they were always able to get help from staff on the hospital ward when they needed it

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

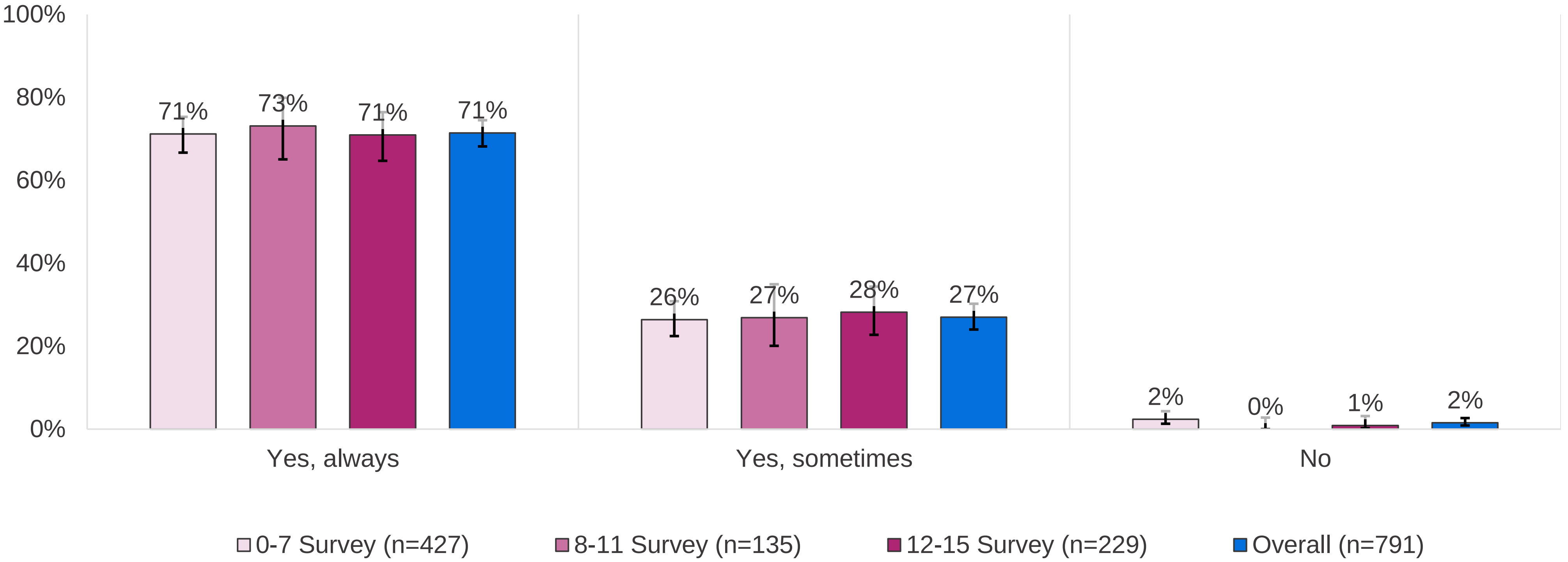


Chart shows question X42: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who have stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total number of responses = 781 (excluding 8 responses of "They / I did not need any help" and 2 responses of "Don't know / can't remember").

Child’s care and treatment

cancer patient experience survey

Support from the hospital

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

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

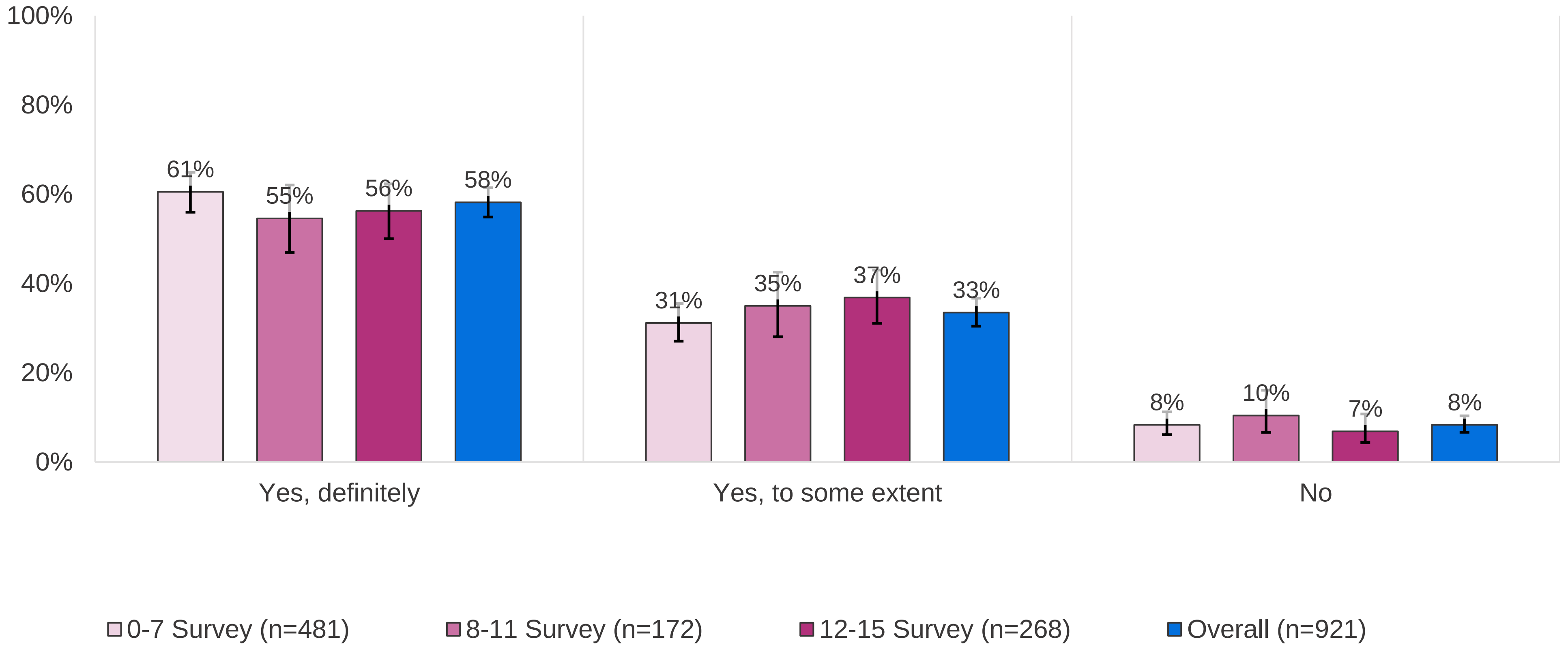


Chart shows question X33: Asked to parents or carers of all age groups. Total responses = 866 (excluding 55 responses of “This is not needed”).

Care in hospital

Hospital food

38% of parents, carers, and children felt that there was definitely a suitable choice of hospital food.

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

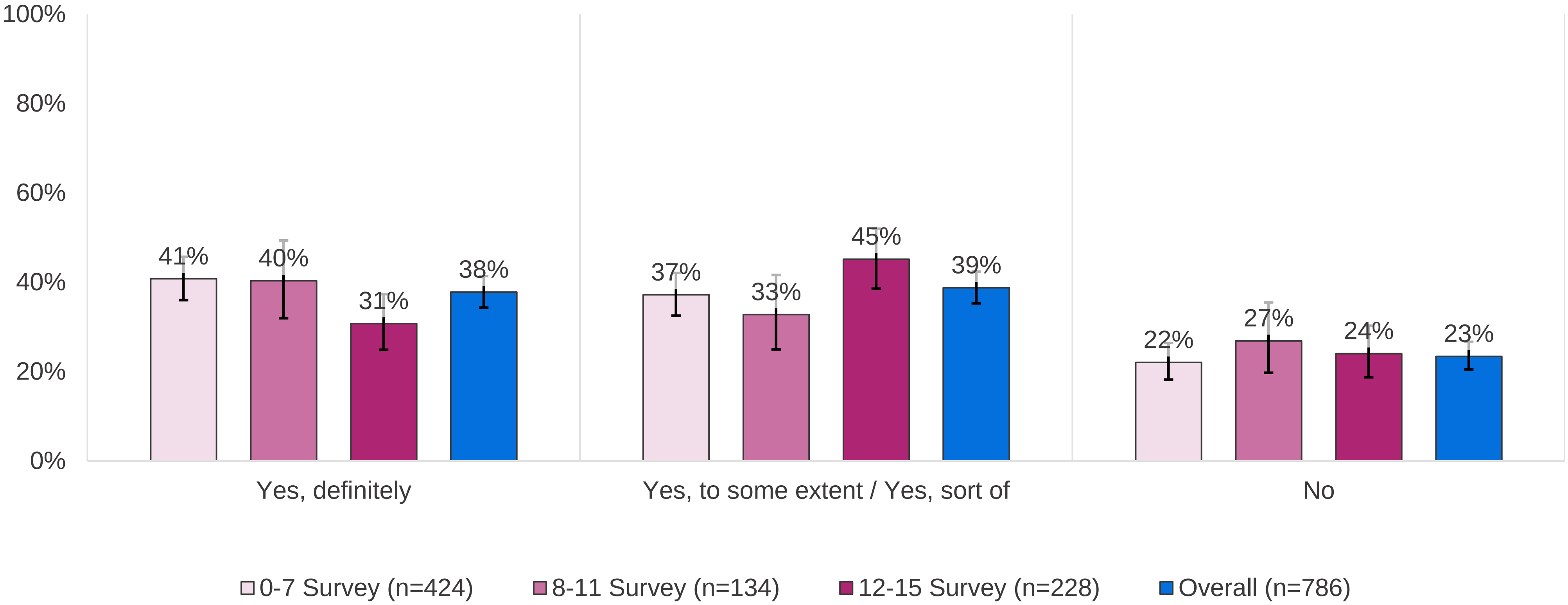


Chart shows question X44: Asked to parents or carers of children aged 0-7 whose children stayed in hospital, and children aged 8-15 who stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 717 (excluding 69 responses of "My child did not have hospital food / I did not have hospital food").

Care in hospital

Play specialist support

52% of parents or carers reported that the hospital always offered play specialist support when they needed it.

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

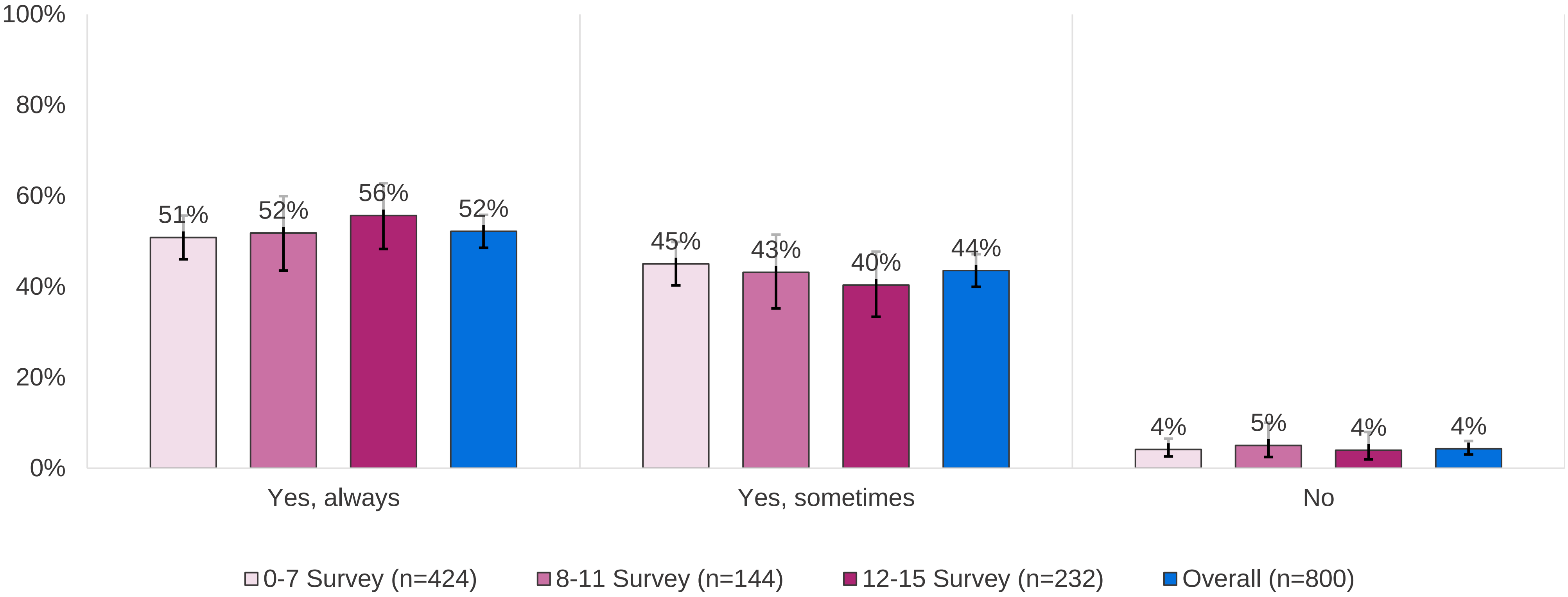


Chart shows question X46: Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime, or for an overnight stay). Total responses = 726 (excluding 74 responses of “My child did not need this”).

Care in hospital

cancer patient experience survey

Hospital Wi-Fi

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

36% of parents or carers felt that the hospital Wi-Fi always met the needs of them and their child.

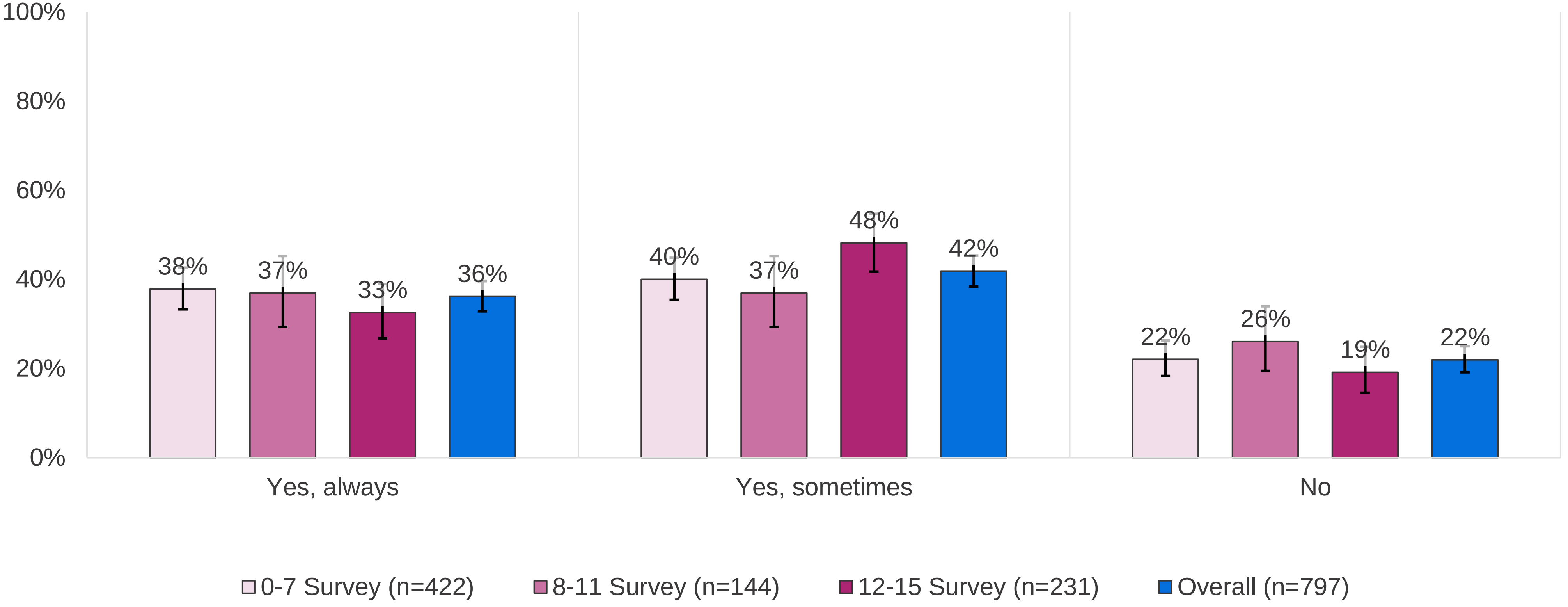


Chart shows question X51: Asked to parents or carers of all age groups whose children stayed in hospital (receiving treatment or care in the daytime or for an overnight stay). Total responses = 774 (excluding 23 responses of "This was not needed").

Under 16 Cancer Patient Experience Survey 2023

National Qualitative Findings Presentation

NHSE
Estelle Phillips, Qualitative Senior Analyst

Key theme: Staff

Staff were central to experiences of care, and positivity about their manner and personal attributes was frequently raised. Key staff attributes were friendliness and kindness, with these greatly appreciated. In addition, being listened to and understood by staff was of importance.

- Positivity about staff was the most prevalent theme in the data, i.e. they were **friendly; kind; caring; supportive; compassionate; understanding; helpful; professional**.
- Brought some happiness and fun to children, and made respondents feel calmer, supported and more comfortable.

“The staff being friendly made me feel happy.” (child aged 8-11)

“The nurses were always very kind and made me feel calmer when i was stressed or scared” (child aged 12-15)

- Staff **listening, understanding and involving** was seen to:
  - Facilitate joint decision making and a personalised approach
  - Build trust and strong relationships with staff
  - Make people feel valued and safe

“Everyone was understanding and care felt very personalised. Everyone know about me and was doing the best for me as a person, not 'just' treating my cancer.” (child aged 12-15)

- Some exceptions e.g. older children and parents/carers indicating that not all staff acted in a friendly or empathetic way. This demonstrated how **all** members of staff play a critical role in how care is experienced.

Key theme: Communication

A range of features that characterised good communication between staff and parents, carers and children were highlighted, as well as some opportunities for improvement. Issues were experienced with communication between hospitals, within hospitals as well as with parents or carers outside of hospital stays.

- Where communication with **staff** was viewed positively, value was placed on the following:

Information being clear

Staff proactively providing information

Staff being receptive to being asked questions

Opportunities provided to ask questions

Sufficient time taken to provide explanations

Staff being able to provide answers

Staff tailoring information to make it understandable

Staff addressing children, not just parents or carers

- Less frequently, respondents indicated opportunities for improvement around **privacy, sensitivity, timeliness, consistency and reassurance**, for example:
  - Careful consideration around whether info should be delivered in front of children
  - Telephone calls not always considered an appropriate or convenient way to receive sensitive info
  - Being kept updated without needing to chase staff and services

"It is difficult to have conversations with doctors about medical care when the young child is in the room and listening." (parent/carer of child aged 0-7)

"I could have been told I had cancer more sensitively, it was a shock." (child aged 8- 11)

"At times there were long gaps between seeing a consultant which lead to some confusion/ things not being explained properly." (parent/carer of child aged 0-7)

"Ensure all teams are on the same page before telling you anything." (child aged 8-11)

Key theme: Communication

- Poor communication and coordination between **different hospitals** could lead to parents/carers having to liaise between the two
- The use of different **electronic systems** was also seen to contribute poor communication

"Better communication between hospitals (local & specialist), was often led by parents." (parent/carer of child aged 0-7)

"Would be helpful if the different hospitals could share the same computer systems so they could all access her records." (parent/carer of child aged 12-15)

- Poor communication **between staff within the same hospital/service** was also observed. It was suggested that continuity of seeing the same member of staff could mitigate this.

- The ability to communicate with **services outside of hospital stays** was variable. It was suggested that being able to contact services outside of normal working hours could lead to improvements.

Key theme: Access to care

Staff were not always responsive to needs which was attributed to understaffing as well as issues during weekends/evenings/at night. There was variation in how long it took for diagnosis and treatment to start. Access could also be impacted by waits in hospital and travel issues including parking.

- **Staff assistance in hospital** not always being timely, with long waits for call bells/buzzers to be responded to and for medication, was often framed as a systemic issue linked to understaffing and staff being overstretched as a result.

> *"Some nurses were very nice, particulary on the ward at (location name) although they were often understaffed and overworked which meant my meds were sometimes missed." (child aged 12-15)*

> *"At weekends the availability of Drs is scarce and everything takes longer." (parent/carer of child aged 0-7)*

> *"Not enough support given. Most nurses were brilliant just too busy to talk or help. Too many newly qualified staff on ward, meaning senior staff too busy." (parent/carer of child aged 0-7)*

- In some cases, parents or carers had been concerned that inadequate staff or lack of specialist staff had contributed to poor clinical decisions and errors.

Key theme: Access to care

- Whilst for some care started very quickly, where there were **delays to diagnosis and treatment**, parents/carers could feel healthcare professionals were not listening or taking their concerns seriously.
- The length of time to get a GP appointment or to have tests/scans were also seen as contributing factors to delays in diagnosis.

> *“It took 3 months of my daughter being so poorly, crying in pain constantly, losing 7kg in the past 3 weeks before a doctor in (location name) to actually take her symptoms seriously and scan her to then find the tumor, I was absolutely disgusted with (location name) hospital. We were transferred to (location name) hospital withing a few hours after the tumor was found. Parents need to be believe, they know their children the best, especially when there is video evidence of their child.” (parent/carer of child aged 8-11)*

- Respondents described **long waits in hospital** for chemotherapy, operations and for pharmacy to prepare medication, along with a lack of bed availability, and how these issues could be intertwined. This contributed to long days, boredom and stress.

- There was a strong preference for **local care**.
- Where people were living further away, they suggested there should be more consideration of **accommodation for parents/carers** and **appointment times** that accounted for travel time.
- There could be **long waits for hospital transport** to arrive.

Key theme: Personalised care

There were unmet needs around psychological support for both children and parents or carers. Variable experiences were shared around whether the specific needs of autistic patients had been considered and met.

- Unmet needs around **psychological support** were seen for both children and parents/carers of all age groups, spanning multiple stages of care.
- The few positive experiences indicated that **charities** could play an important role in providing support.

"My child struggled mentally probably more than physically during her treatment. She had high levels of anxiety and would have benefited from mental health support throughout her time in hospital." (parent/carer of child aged 12-15)

"more help for parents mentally and when treatment finishes." (parent/carer of child aged 8-11)

"Input from (charity name) has been invaluable to provide the holistic support for my daughter/give the necessary psychological support for her." (parent/carer of child aged 0-7)

- Variable experiences around whether the **specific needs of autistic patients** had been considered and met.
- Some staff said to have good **awareness** and **understanding** of needs, whereas others didn't.
- The need for **routine and structure** was highlighted as being important:
  - seeing the same member of staff
  - breakdown of what would happen on treatment days.
- **Sensory needs** were not always met, suggestions for better consideration around:
  - sensory experience of the environment
  - texture of food

"Very aware of my sons autism and very accomodating." (patient/carer of child aged 12-15)

"Some staffs awareness of autism and how that impacts a child especially when they are in hospital could be improved on." (parent/carer of child aged 8-11)

Key theme: Hospital food

Hospital food was a frequently raised area for improvement with issues around quality and choice; how well food met personal needs; food preparation facilities; and provision for parents or carers to eat.

- View that the **quality** of food was poor; it lacked **nutritional value**; and children having limited **choice**.

“Food is not nutritious at all, all food is processed” (child aged 12-15)

“offer different foods not the same every meal time” (child aged 8-11)

- Specific **dietary requirements** not always considered or met, including how cancer treatment was impacting on **patients’ appetite, taste and ability to eat**.
- Food being restricted to **set times** problematic when it did not align with children’s ability to eat, inferred a degree of **flexibility** was needed.
- The few positive experiences also indicated a flexible and personalised approach was the key to success, e.g. an on-ward chef, children ordering at a time that suited them.

“longer hours for out of hours menu for children who are selective/ARFID eaters or are generally unwell or don't eat at set times.” (parent/carer of child aged 0-7)

Key theme: Hospital food

- Parents/carers expressed a need to have access to **kitchen facilities** so they could prepare and cook food themselves while their child was in hospital.
- In some cases, no facilities or where provided they could be inadequate, improvement suggestions around:
  - Larger fridges/freezers
  - More appliances e.g. toasters, air fryers
  - Some older children also wanted access to microwave, kettle, vending machine
  - Better monitoring and cleanliness

- **Parents/carers suggested hospitals should provide food for them** in addition to children. Reasons for this were:
  - Difficult to leave their child
  - Financial impact
- A few were willing to pay a fee for being fed in hospital.

"The only places to buy food were Pret or Marks & Spencers neither of which I could afford. Over the 11 days we were in I lost just under a stone. When your child is diagnosed you feel so emotional that you do not feel like you can eat plus your child does not want you to leave their side I therefore feel that offering parents food is an imperative part of maintaining good physical and mental health at a time that is one of the most heartbreaking times that any parent can go through." (parent/carer of child aged 12-15)

Key theme: Things to do in hospital

Positive experiences were shared of play, though a need for increased access and more age-appropriate offering too. Similarly, there were calls for increased access to education which on the whole was positively experienced. Improvements were needed to Wi-Fi in hospitals and use of technology.

- Children made it clear how important it was to have **play incorporated into their care**, including access to **playrooms** and **play specialists**.
- The role **charities** played was acknowledged.

“(charity name) have been an amazing support throughout my treatment. They provided games and activites to do when stuck on the ward.” (child aged 12-15)

- Need for **improvements** focused on:
  - Activities not just geared towards younger children
  - More provision for children in isolation
  - Increased access including at weekends.

“Playroom not inviting or stimulating for the older age bracket it covers. Easy to become conditioned to lying in bed even when feeling ok as other option not appealing.” (child aged 12-15)

“Weekends there was nothing to do at all, everything stopped at once. No school, therapies, play therapies, music/magician, all stopped. It was along 48 hours every week.” (parent/carer of child aged 0-7

- **Poor Wi-Fi** limited entertainment options; reduced contact with friends and family; created a barrier to schoolwork and parent/carers ability to work.
- **TV’s and video gaming** consoles weren’t always available or working.

“The wifi access needs to be enhanced in the hospital to allow parents children to use tablet's, phones, computer, this will allow for more activities.” (child aged 12-15)

“Having access to a TV whilst an in patient is really important and we didn't always have a working TV/remote control. Breaks the day up a little + provides distraction.” (child aged 12-15

Key theme: Things to do in hospital

- Children, particularly those 8-11 gave positive feedback about **hospital school** and **teachers**
- Some parents/carers provided comments that schooling had been good, and praising the quality of **education** provided by teachers.

“the teachers are fabulous and he really looks forward to seeing them and the work he is given.” (parent/carer of child aged 12-15)

- Where parents/carers were critical the focus was on **insufficient access**, with suggestions that **education** should:
  - Be provided from the start of treatment
  - Extended to weekends and school holidays

“I realise it is funding related, but not having any teacher presence through the long summer holidays in the hospital was really hard. My son missed so much of his education and through term time loved his few short visits from the teacher.” (parent/carer of child aged 0-7)

Key theme: Hospital environment

Noise at night impacting sleep was common, with suggestions of how this could be improved from some. Other issues described included comfort of sleeping arrangements for parents or carers; the temperature of rooms; and matters of privacy.

- **Noise** impacted on patients and parents/carer's **ability to sleep**. Said to be caused by other patients and visitors, but also staff and equipment.
- Improvement suggestions:
  - Staff more proactive asking people to be quieter
  - Staff more considerate of the noise they were making
  - Lights being turned down earlier
  - Rules such as headphones having to be used for electronic devices
  - Older children being in separate areas to younger children

"Some people were allowed to keep music or TV on late at night and they weren't told to turn it off or down" (child aged 8-11)

"For staff to be more quiet at night time, slamming doors, talking loud and laughing, other than that everything was fine." (parent/carer of child aged 0-7)

"Maybe keep older children together due to noise levels etc, young children & babies together as it is hard to sleep." (child aged 12-15)

Key theme: Hospital environment

- Comfort of **beds** and **sleeping arrangements for parents/carers** was a challenge to achieving a good night's sleep.
- Small number of comments saying the comfort of **seating** and **waiting rooms** could be improved.

"There are never any pillows for parents - they are like gold dust yet having to sleep there every night they are kind of essential given the sofa beds are so uncomfortable." (parent/carer of child aged 8-11)

"Beds for parents could be better (sofas are too hard to even sit on)" (child aged 8-11)

- Some said **temperature** of the hospital environment was too hot and others too cold. This could again impact on sleep.

- Children, as well as parents/carers expressed a preference for **private rooms**. A **lack of privacy** could be stressful, distressing when people were upset, and mean that **sensitive conversations** were overheard.
- Children aged 12-15 again wished to be **separate from younger children**.

"At initial diagnosis it was highly stressful to be on an open bay with no privacy." (parent/carer of child aged 0-7)

"Sharing a small area with other patients can be hard when you don't feel good and they are going through a bad time." (child aged 12-15)

"More private rooms especially for teens! (Privacy is good)." (parent/carer of child aged 12-15)

Henry’s Wi-Fi legacy

Samantha Luk – Henry’s mum

Davina Hartley – Programme Manager
North West Children’s Cancer Operational Delivery Network

Henry’s Wi-Fi legacy

What’s next?

Please share Henry’s Wi-Fi legacy

https://www.nwchildrenscancerodn.nhs.uk/professionals/henrys-wifi/

Please take 2 minutes to reflect

Understanding the outputs

Picker

Caroline Hancock, Research Associate

Outputs for U16 CPES 2023

National

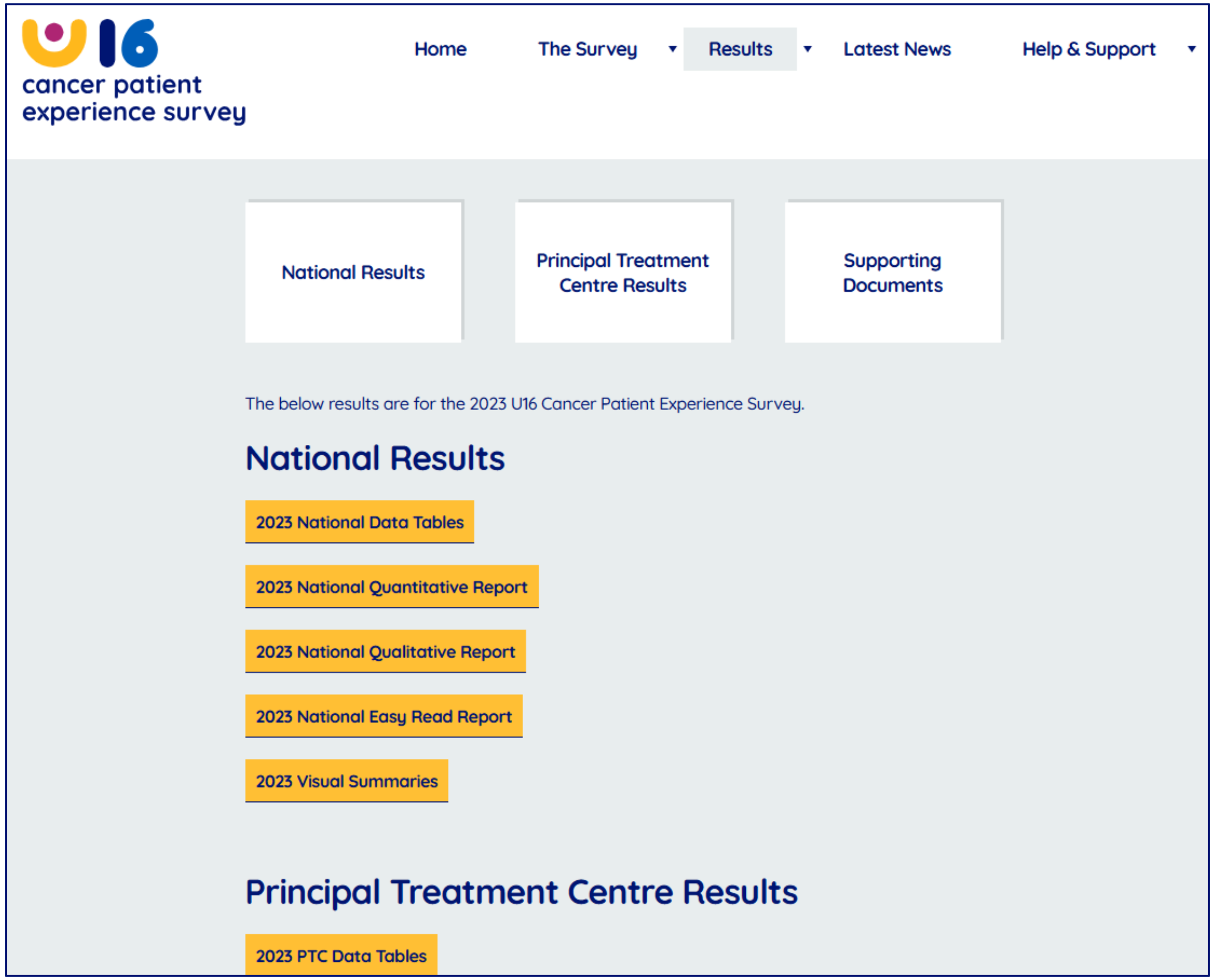
- National quantitative report (including an easy read version)
- National qualitative report
- National data tables
- Visual summaries

Principal Treatment Centre (PTC)

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

Published outputs on website

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



The below results are for the 2023 U16 Cancer Patient Experience Survey.

National Results

- 2023 National Data Tables
- 2023 National Quantitative Report
- 2023 National Qualitative Report
- 2023 National Easy Read Report
- 2023 Visual Summaries

Principal Treatment Centre Results

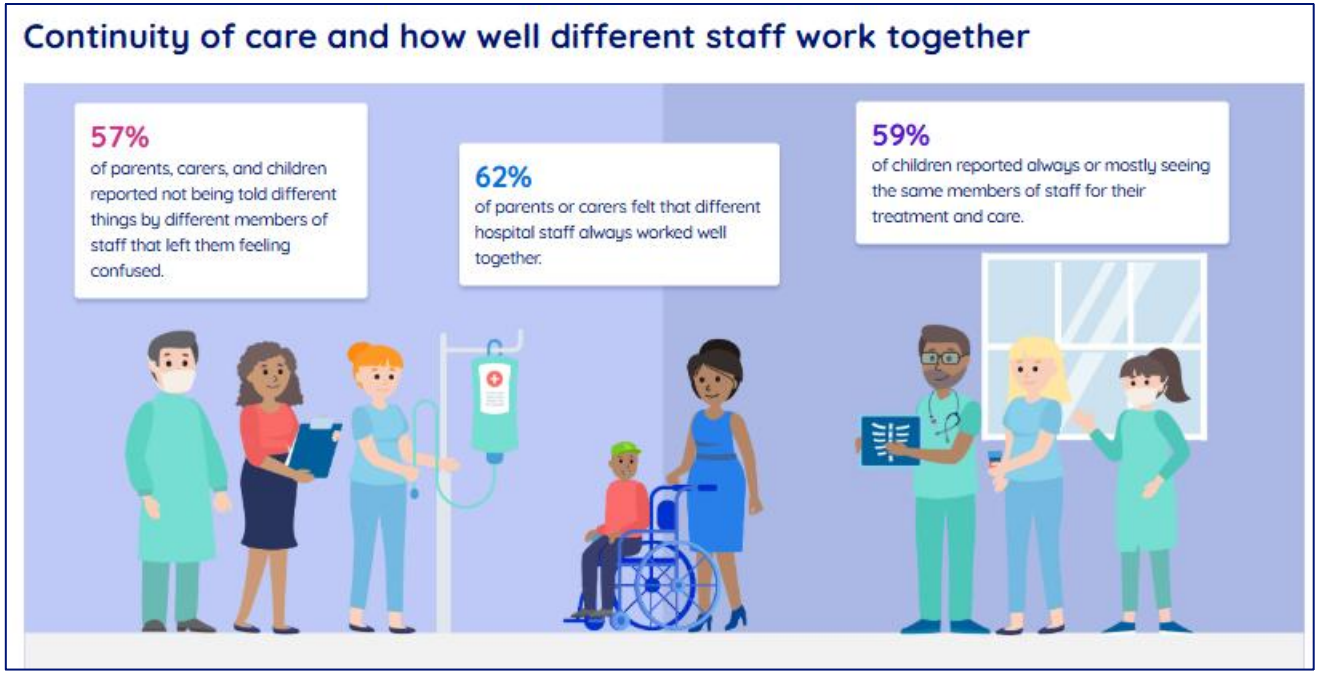
- 2023 PTC Data Tables

National: Visual summaries

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

Please find below a summary of some of the findings from the Under 16 Car … ey 2023.

Please note that comparisons to 2022 data (where available) are not included here but are available in other outputs such as the data tables and quantitative reports (see Technical Reports page here).
Downloadable versions of the visual summaries are available here

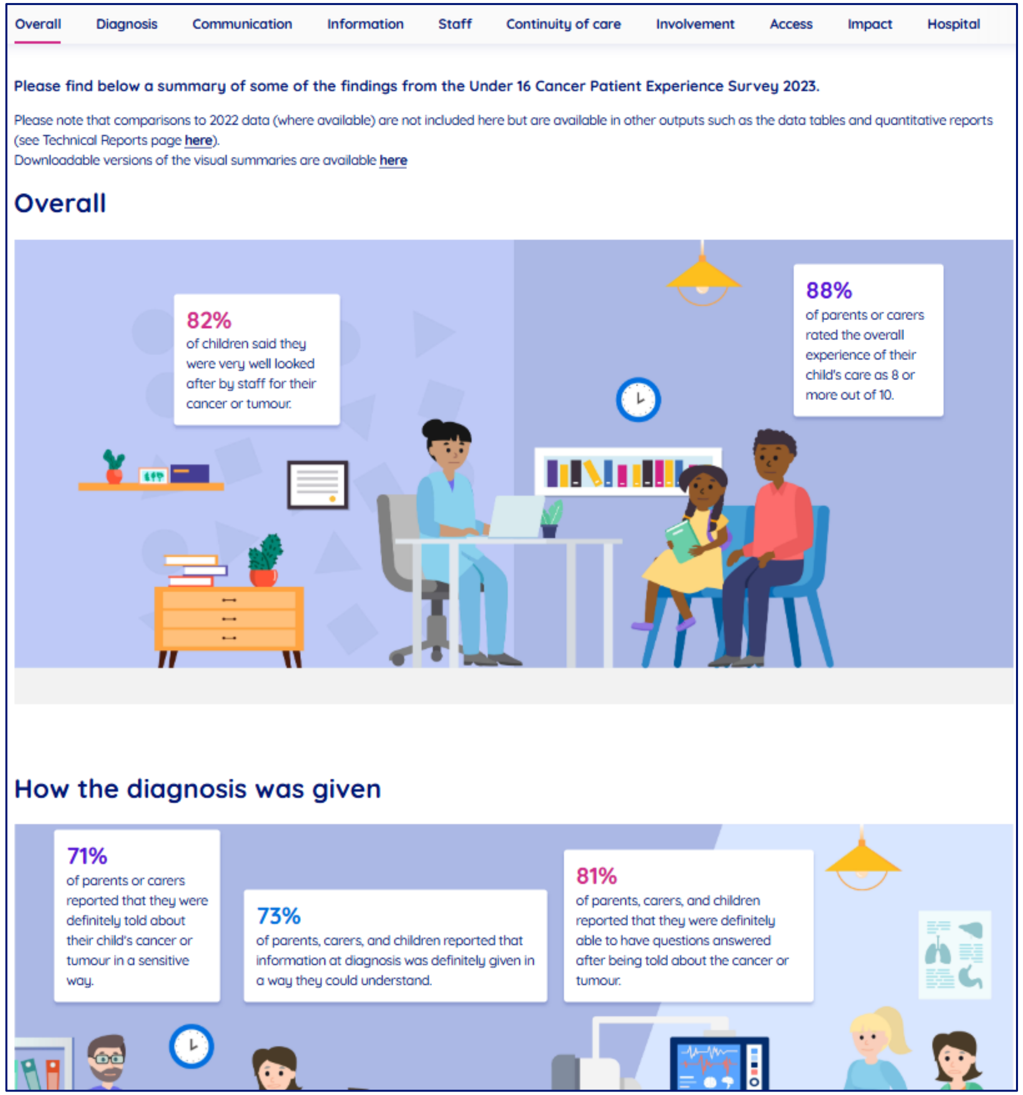


Continuity of care and how well different staff work together

57% of parents, carers, and children reported not being told different things by different members of staff that left them feeling confused.

62% of parents or carers felt that different hospital staff always worked well together.

59% of children reported always or mostly seeing the same members of staff for their treatment and care.



Please find below a summary of some of the findings from the Under 16 Cancer Patient Experience Survey 2023.

Please note that comparisons to 2022 data (where available) are not included here but are available in other outputs such as the data tables and quantitative reports (see Technical Reports page here).
Downloadable versions of the visual summaries are available here

Overall

82% of children said they were very well looked after by staff for their cancer or tumour.

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

How the diagnosis was given

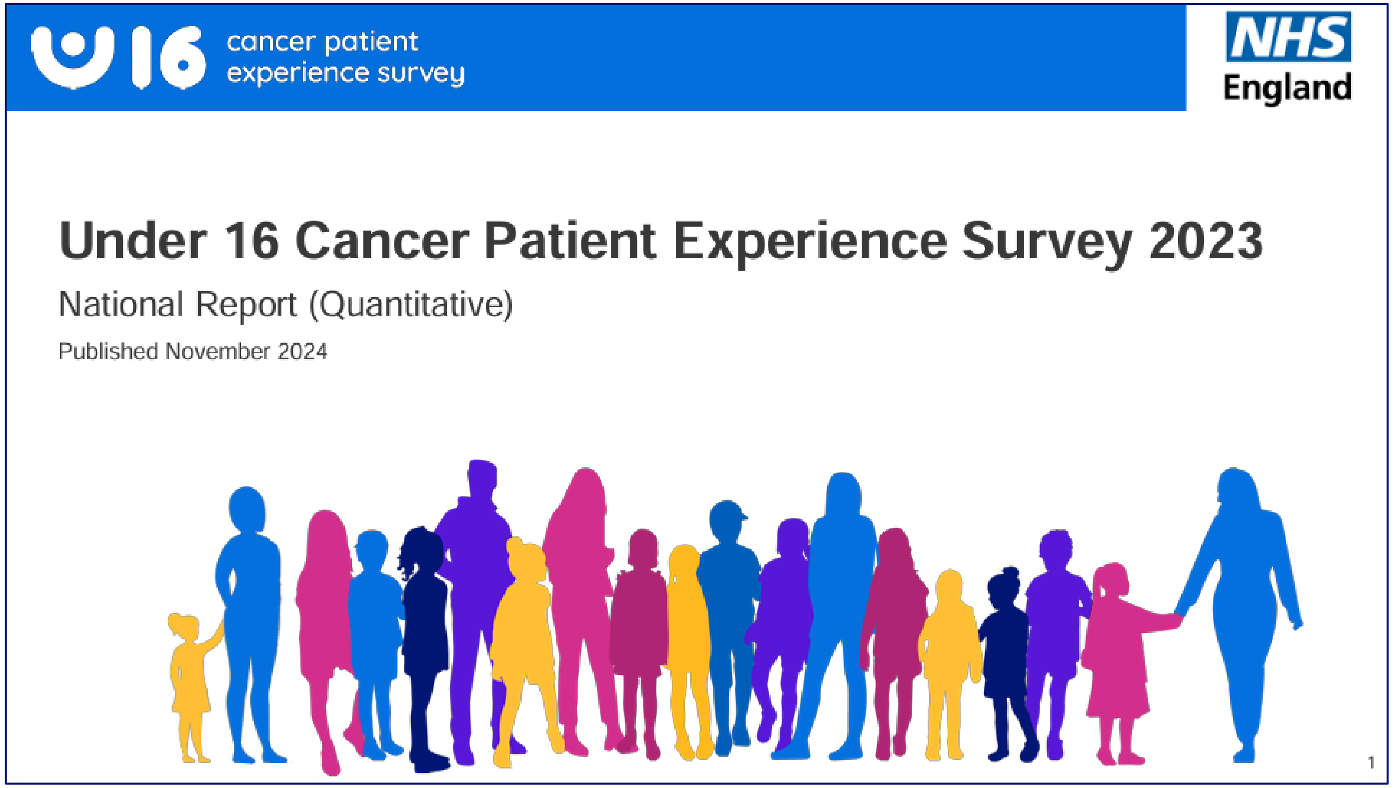
71% of parents or carers reported that they were definitely told about their child's cancer or tumour in a sensitive way.

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

81% of parents, carers, and children reported that they were definitely able to have questions answered after being told about the cancer or tumour.

National report

- National quantitative report (pdf)
- National quantitative report (Easy read)



cancer patient experience survey

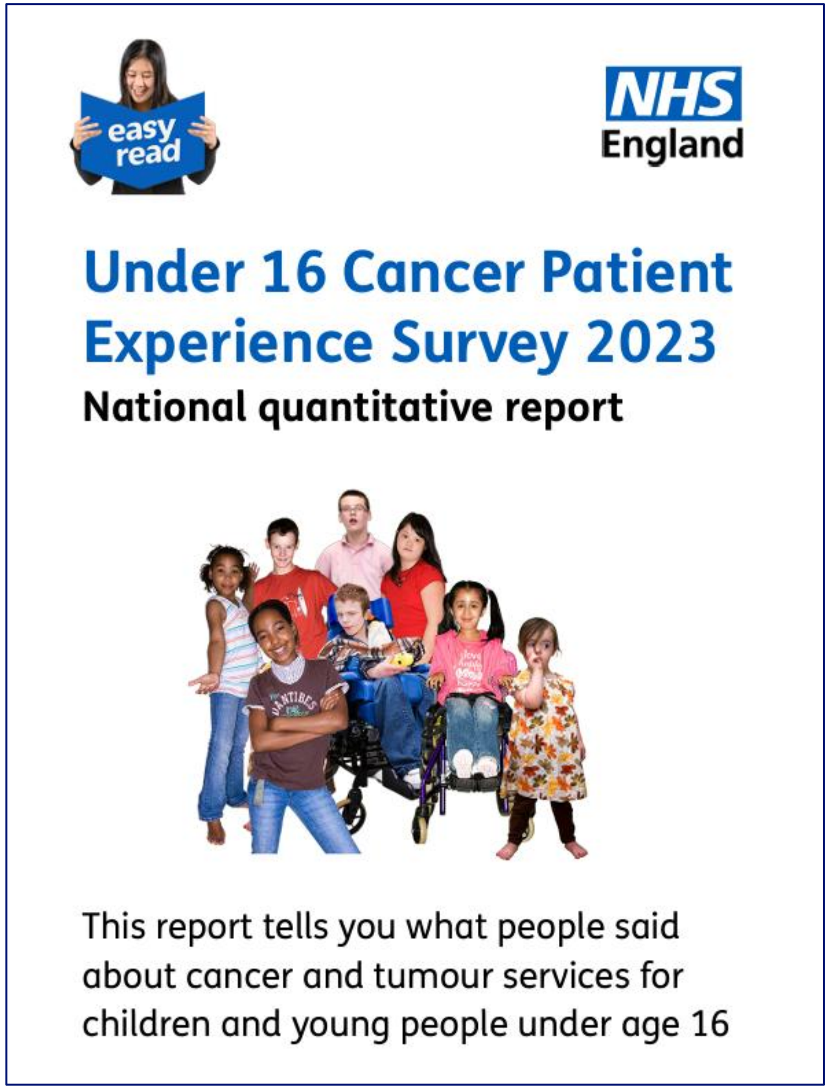
NHS England

Under 16 Cancer Patient Experience Survey 2023

National Report (Quantitative)

Published November 2024

1



easy read

NHS England

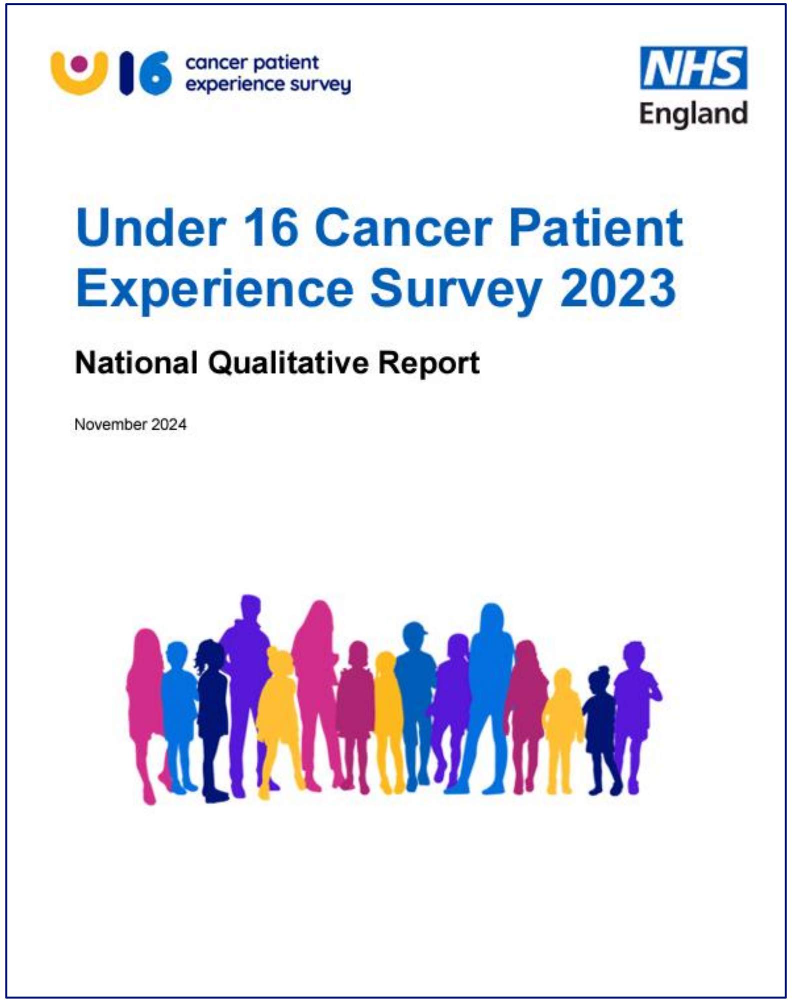
Under 16 Cancer Patient Experience Survey 2023

National quantitative report

This report tells you what people said about cancer and tumour services for children and young people under age 16

National report

- National qualitative report (pdf)



cancer patient experience survey

NHS England

Under 16 Cancer Patient Experience Survey 2023

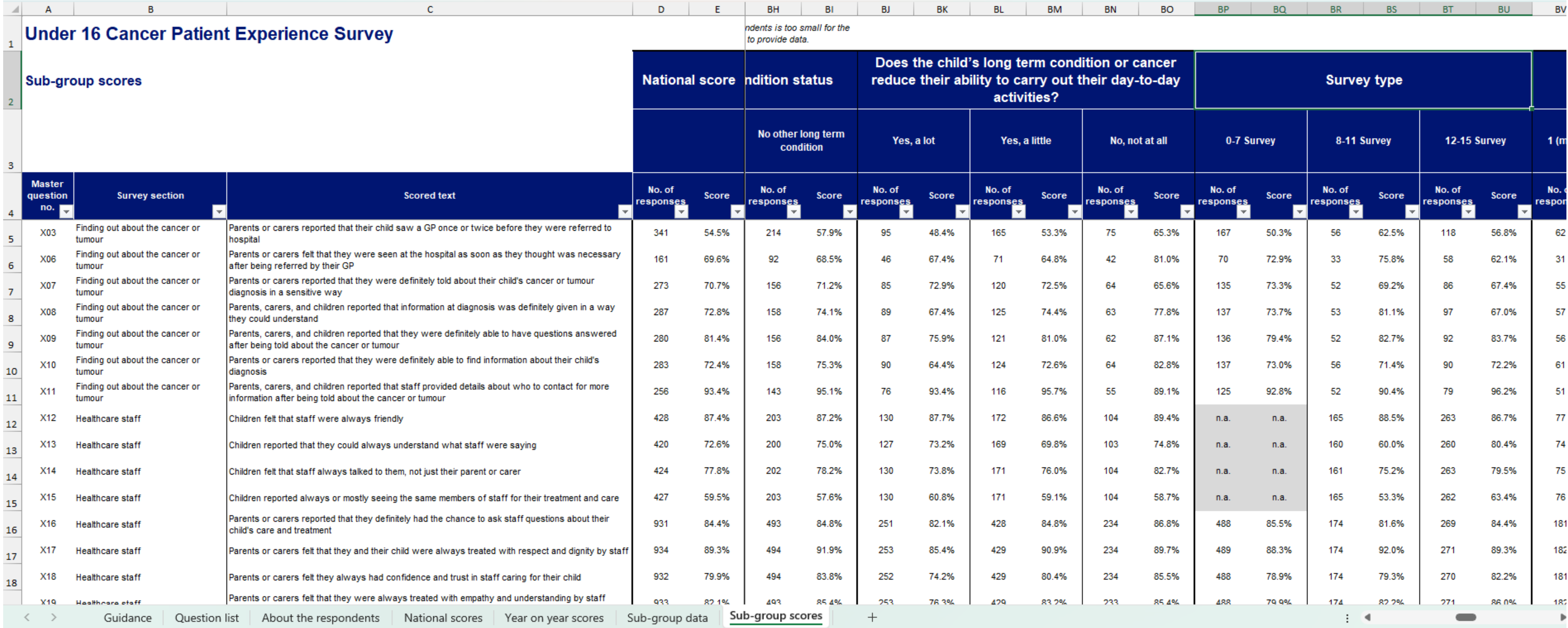
National Qualitative Report

November 2024

National & PTC data tables

cancer patient experience survey

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



Under 16 Cancer Patient Experience Survey

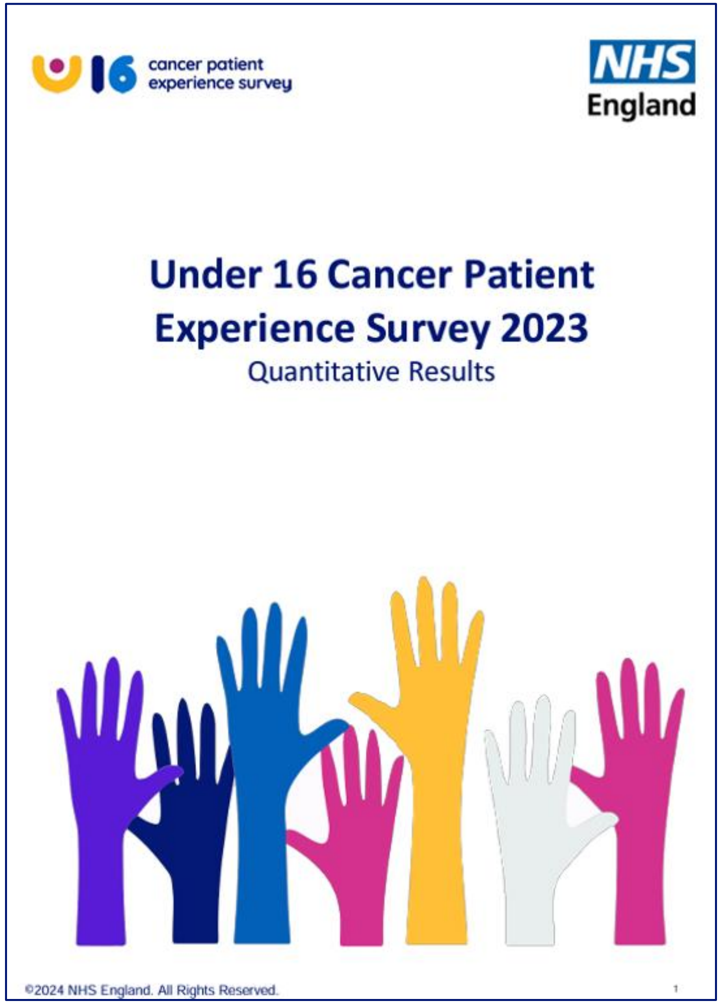
Sub-group scores

ndents is too small for the
to provide data.

	A	B	C	D	E	BH	BI	BJ	BK	BL	BM	BN	BO	BP	BQ	BR	BS	BT	BU	BV
2				National score		ndition status		Does the child's long term condition or cancer reduce their ability to carry out their day-to-day activities?						Survey type						
3						No other long term condition		Yes, a lot		Yes, a little		No, not at all		0-7 Survey		8-11 Survey		12-15 Survey		1 (m
4	Master question no.	Survey section	Scored text	No. of responses	Score	No. of responses	Score	No. of responses	Score	No. of responses	Score	No. of responses	Score	No. of responses	Score	No. of responses	Score	No. of responses	Score	No. of respon
5	X03	Finding out about the cancer or tumour	Parents or carers reported that their child saw a GP once or twice before they were referred to hospital	341	54.5%	214	57.9%	95	48.4%	165	53.3%	75	65.3%	167	50.3%	56	62.5%	118	56.8%	62
6	X06	Finding out about the cancer or tumour	Parents or carers felt that they were seen at the hospital as soon as they thought was necessary after being referred by their GP	161	69.6%	92	68.5%	46	67.4%	71	64.8%	42	81.0%	70	72.9%	33	75.8%	58	62.1%	31
7	X07	Finding out about the cancer or tumour	Parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way	273	70.7%	156	71.2%	85	72.9%	120	72.5%	64	65.6%	135	73.3%	52	69.2%	86	67.4%	55
8	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	287	72.8%	158	74.1%	89	67.4%	125	74.4%	63	77.8%	137	73.7%	53	81.1%	97	67.0%	57
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	280	81.4%	156	84.0%	87	75.9%	121	81.0%	62	87.1%	136	79.4%	52	82.7%	92	83.7%	56
10	X10	Finding out about the cancer or tumour	Parents or carers reported that they were definitely able to find information about their child's diagnosis	283	72.4%	158	75.3%	90	64.4%	124	72.6%	64	82.8%	137	73.0%	56	71.4%	90	72.2%	61
11	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 the cancer or tumour	256	93.4%	143	95.1%	76	93.4%	116	95.7%	55	89.1%	125	92.8%	52	90.4%	79	96.2%	51
12	X12	Healthcare staff	Children felt that staff were always friendly	428	87.4%	203	87.2%	130	87.7%	172	86.6%	104	89.4%	n.a.	n.a.	165	88.5%	263	86.7%	77
13	X13	Healthcare staff	Children reported that they could always understand what staff were saying	420	72.6%	200	75.0%	127	73.2%	169	69.8%	103	74.8%	n.a.	n.a.	160	60.0%	260	80.4%	74
14	X14	Healthcare staff	Children felt that staff always talked to them, not just their parent or carer	424	77.8%	202	78.2%	130	73.8%	171	76.0%	104	82.7%	n.a.	n.a.	161	75.2%	263	79.5%	75
15	X15	Healthcare staff	Children reported always or mostly seeing the same members of staff for their treatment and care	427	59.5%	203	57.6%	130	60.8%	171	59.1%	104	58.7%	n.a.	n.a.	165	53.3%	262	63.4%	76
16	X16	Healthcare staff	Parents or carers reported that they definitely had the chance to ask staff questions about their child's care and treatment	931	84.4%	493	84.8%	251	82.1%	428	84.8%	234	86.8%	488	85.5%	174	81.6%	269	84.4%	181
17	X17	Healthcare staff	Parents or carers felt that they and their child were always treated with respect and dignity by staff	934	89.3%	494	91.9%	253	85.4%	429	90.9%	234	89.7%	489	88.3%	174	92.0%	271	89.3%	182
18	X18	Healthcare staff	Parents or carers felt they always had confidence and trust in staff caring for their child	932	79.9%	494	83.8%	252	74.2%	429	80.4%	234	85.5%	488	78.9%	174	79.3%	270	82.2%	181
19	X19	Healthcare staff	Parents or carers felt that they were always treated with empathy and understanding by staff	933	82.1%	493	85.4%	253	76.3%	429	83.2%	233	85.4%	488	79.9%	174	82.2%	271	86.0%	18

PTC report

- PTC quantitative report (pdf)



NHS England

Under 16 Cancer Patient Experience Survey 2023

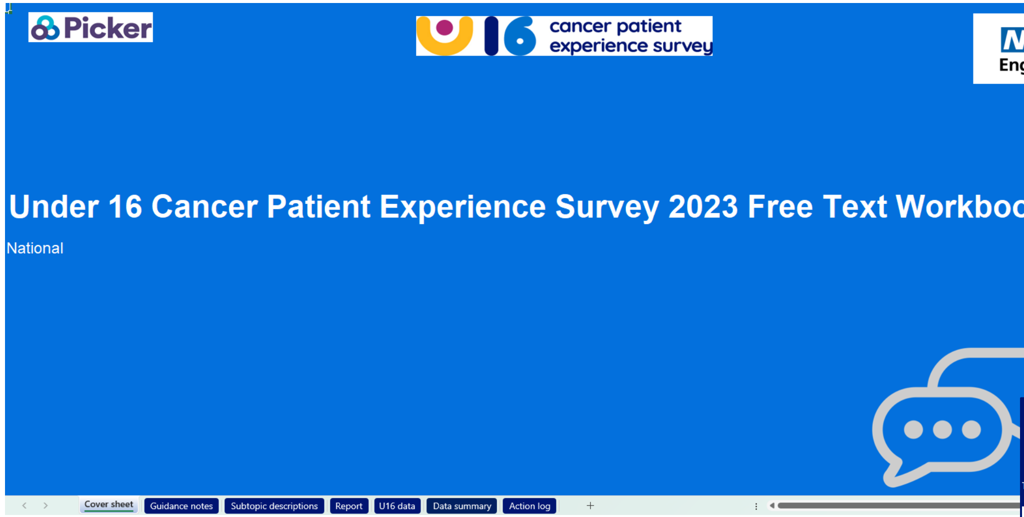
Quantitative Results

PTC report

- PTC quantitative report (pdf)
  - Introduction, methodology and how to use the data sections
  - About the respondents split by various characteristics
  - Overall care split into subgroups
  - Results split by survey section
  - Year on year trend data is shown for all comparable questions.

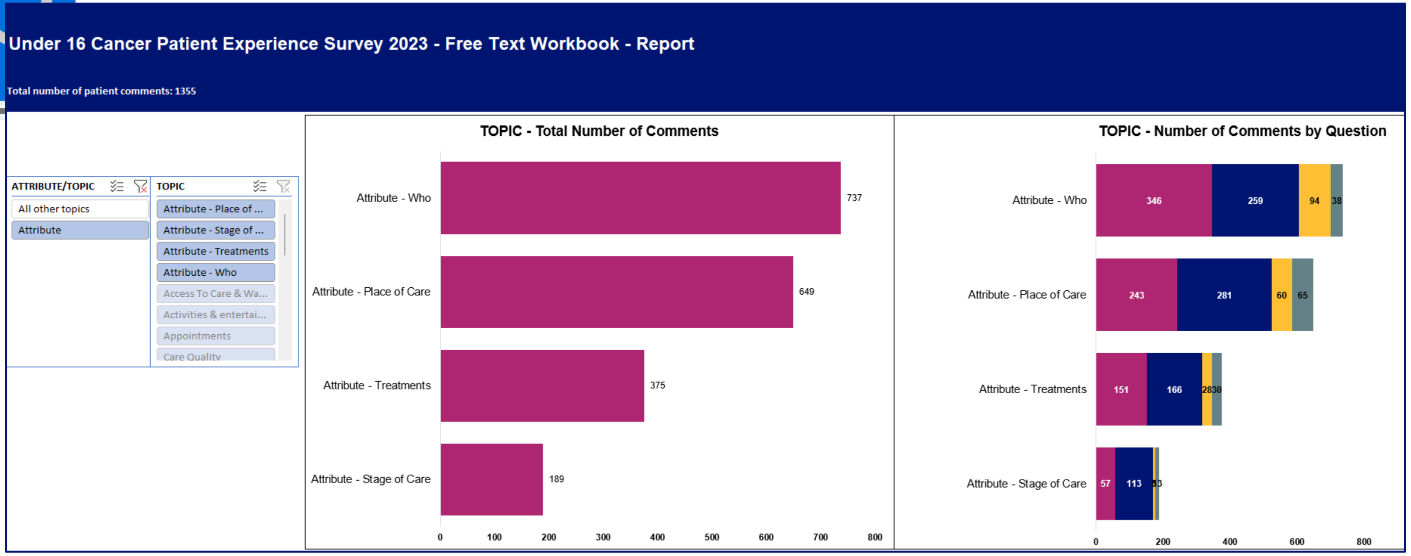
PTC Freetext workbook

- Emailed to PTCs on publication day



Under 16 Cancer Patient Experience Survey 2023 Free Text Workbook

National

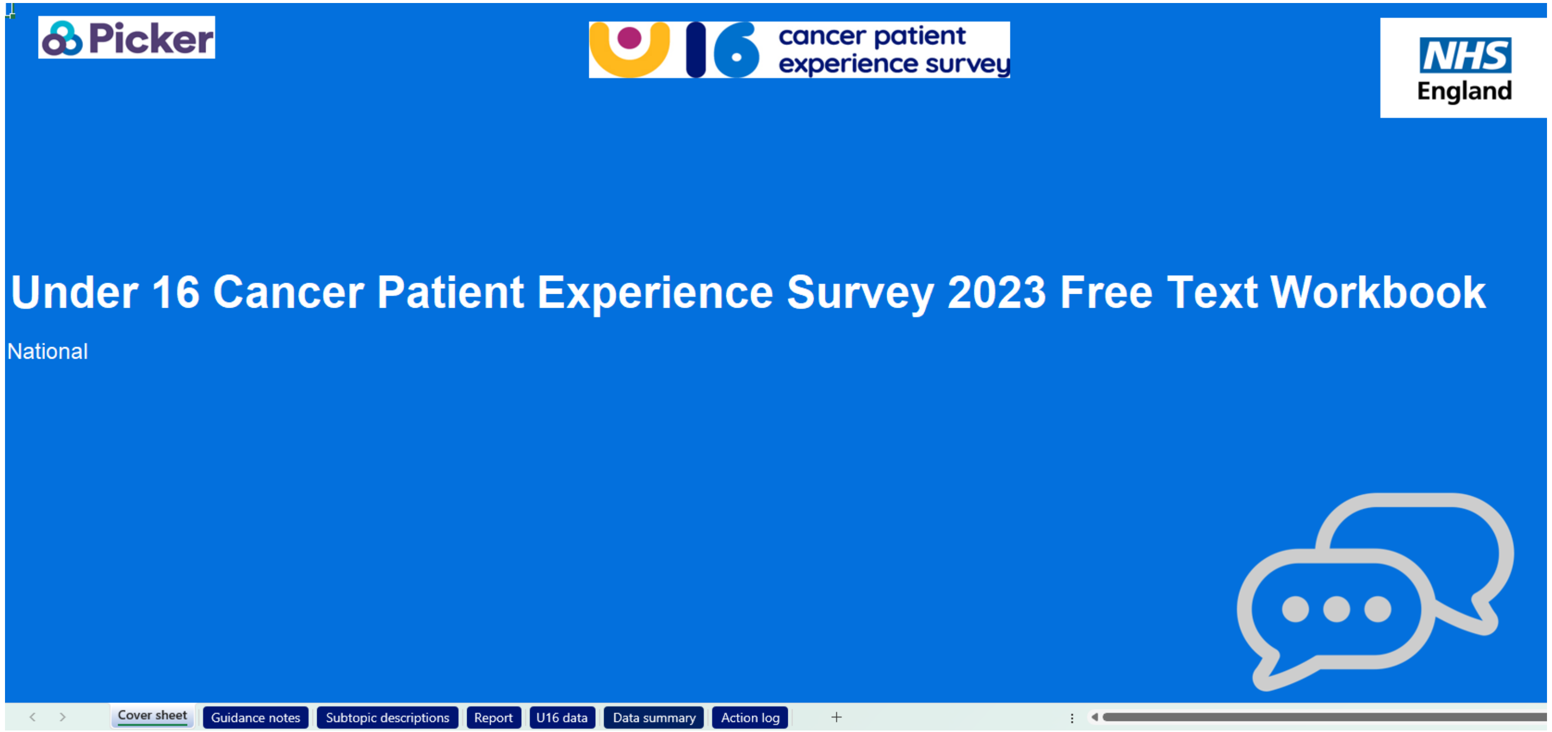


Under 16 Cancer Patient Experience Survey 2023 - Free Text Workbook - Report

Total number of patient comments: 1355

PTC Freetext workbook

- Detailed explanation of how to use the workbooks available on the CPES website: https://www.ncpes.co.uk/latest-results/

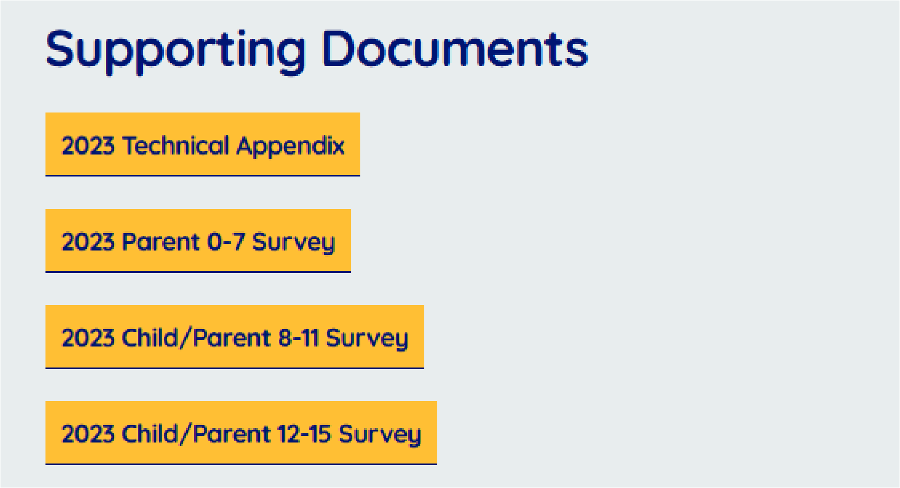


Under 16 Cancer Patient Experience Survey 2023 Free Text Workbook

National

Technical appendix

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



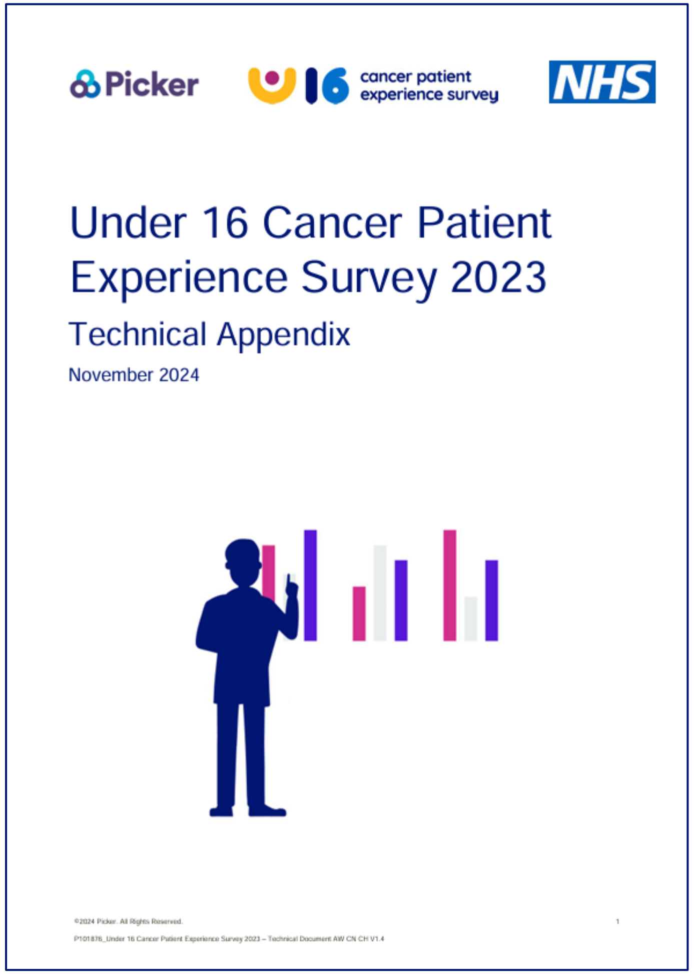
Supporting Documents

2023 Technical Appendix

2023 Parent 0-7 Survey

2023 Child/Parent 8-11 Survey

2023 Child/Parent 12-15 Survey



Under 16 Cancer Patient Experience Survey 2023

Technical Appendix

November 2024

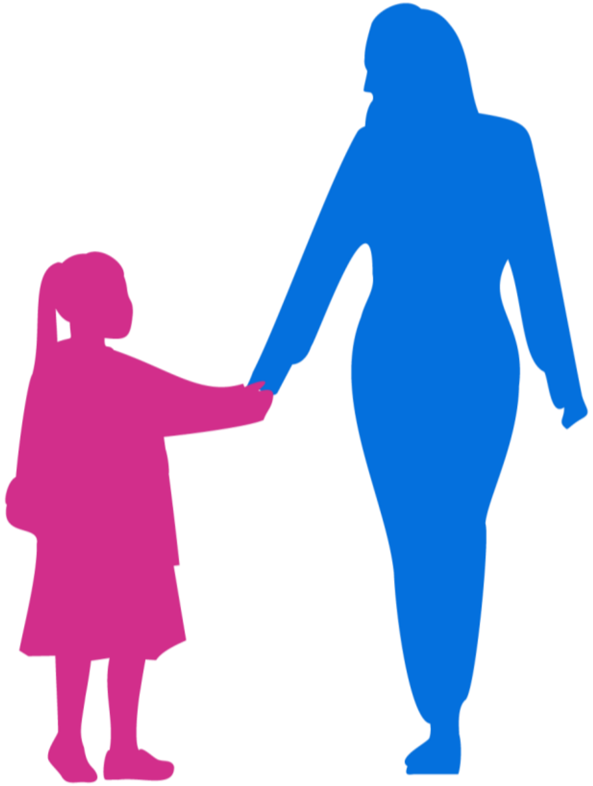
©2024 Picker. All Rights Reserved. 1

P101876_Under 16 Cancer Patient Experience Survey 2023 – Technical Document AW CN CH V1.4

Sophie's legacy

Charlotte Fairall – Sophie's Mum, CEO Sophie's Legacy

Sara Berry – Senior Project Manager, NHS England

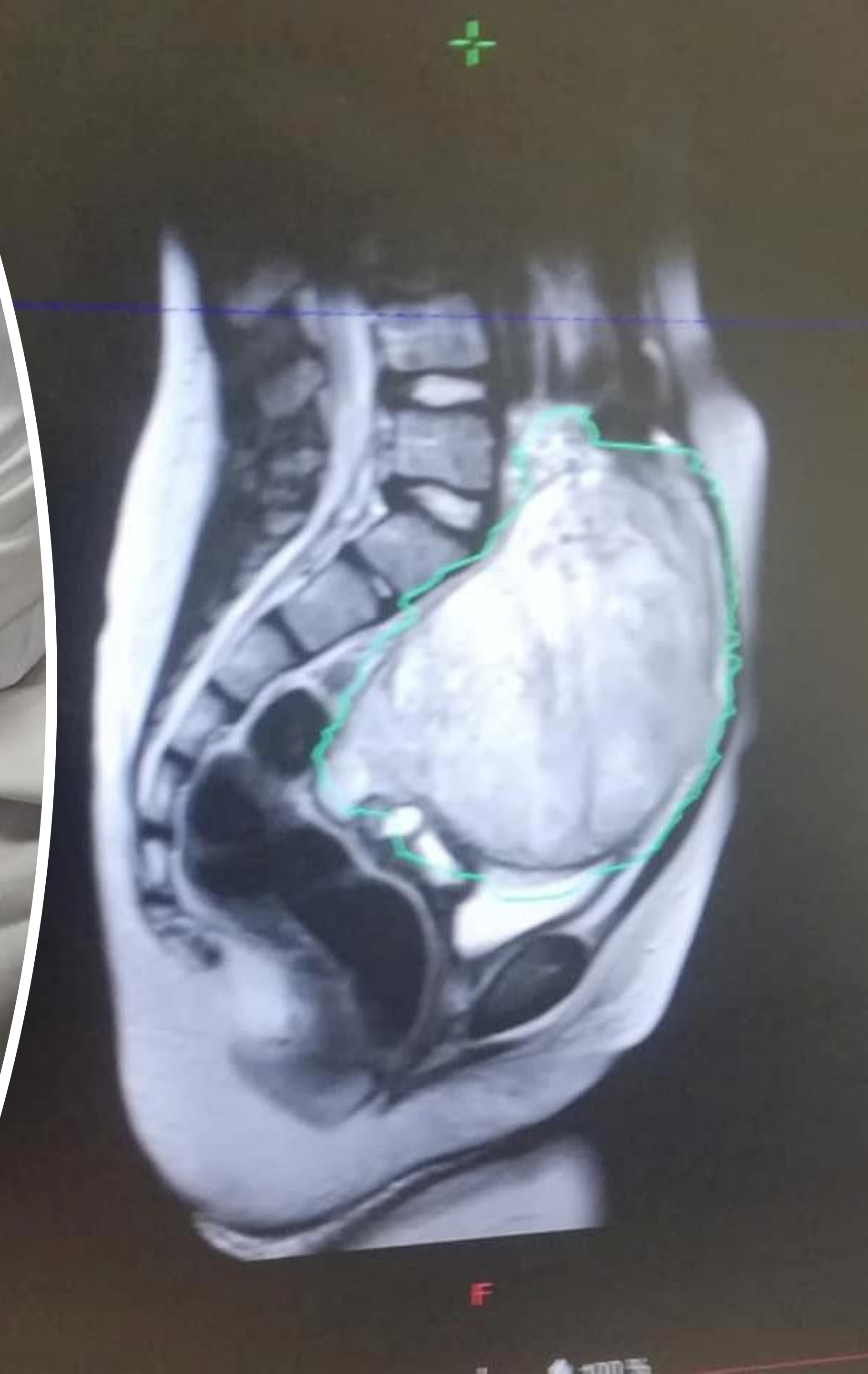



Sophie's
LEGACY
CREATING CHANGE
A RAINBOW OF CHANGE
SL
LOOK FOR RAINBOWS!

We were just your average family

Until our world came crashing down…

- 12cm tumour (Rhabdomyosarcoma) in her abdomen
- 9 rounds of very aggressive chemotherapy
- 7 weeks of radiotherapy in UCLH – London
- All treatment was through Covid times
- I lost my job as I couldn't get the time off to care for Sophie



Sophie died in September 2021 of cancer aged 10, she wanted things to change


Sophie's
LEGACY
PARENTS TO BE
FED IN HOSPITAL
IT'S AN ESSENTIAL NEED
CREATING CHANGE

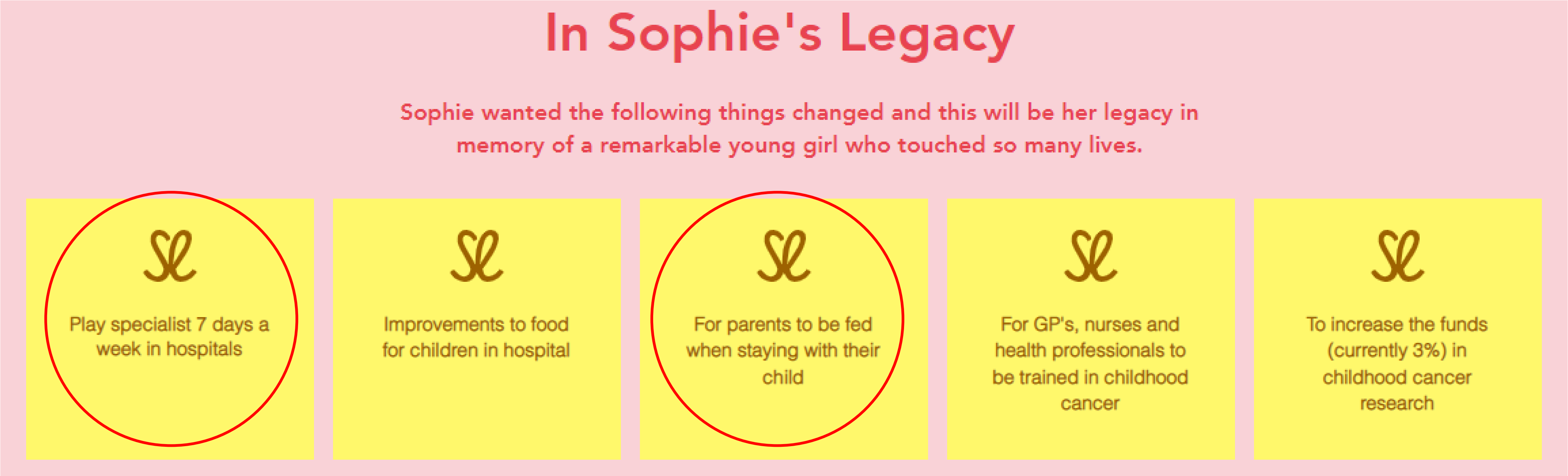

Sophie's
LEGACY
BETTER CHILDREN'S
HOSPITAL FOOD
FOR HEALTH & EMOTIONAL WELLBEING
CREATING CHANGE


Sophie's
LEGACY
PLAY SPECIALISTS
7 DAYS A WEEK
IN ALL HOSPITALS AROUND THE UK
CREATING CHANGE

Sophie fought to the bitter end to show others not to give up. We now need to achieve change for her…

Background

- Sophie had just turned 9 when she was diagnosed with cancer in September 2020.
- Sophie spent long periods of time in hospital receiving treatment, during which she created a ‘bucket list’ of wishes; these included areas where Sophie felt strongly that care could be improved for other children and young people and their families/carers
- Charlotte Fairall, Sophie’s mum, contacted NHSE in the summer of 2021 to share Sophie’s Legacy



In Sophie's Legacy

Sophie wanted the following things changed and this will be her legacy in memory of a remarkable young girl who touched so many lives.

- Play specialist 7 days a week in hospitals
- Improvements to food for children in hospital
- For parents to be fed when staying with their child
- For GP's, nurses and health professionals to be trained in childhood cancer
- To increase the funds (currently 3%) in childhood cancer research

Progress to date

NHSE have been working with Sophie’s Legacy and Starlight Foundation

- In July 2023, a survey was circulated to all trusts to understand the provision of play and food, The results demonstrated that whilst there is a common understanding for the need to support CYP with play facilities and food for their parents and carers, this is not always being provided and done as consistently as possible.

- Standards, guidance and best practice for the provision of play and play specialists has been developed through a taskforce, to support ICBs and providers to tackle variation in play provision.

- NHSE have supported 10 Childrens Hospital Alliance trusts in April 23, with funding to pilot free/subsidised offers of breakfast, lunch, dinner for resident parents. The pilots significantly helped poverty-proof inpatient services releasing the financial and emotional burdens for patients and parents/carers

- Sophies Legacy are currently funding 15 trusts to offer the free provision of breakfast, lunch, dinner for resident parents. NHSE are working with the charity and the trusts to support these pilots and ensure sustainability of food provision.

Food pilot initiatives

Here are some examples of the types of initiatives being trialled

- Voucher scheme to be used within on-site catering facilities
- Frozen meal supplies which parents and carers can heat using an I-wave
- Expansion of digital ordering system to allow parents/carers to order a meal at the same time as their child
- Provision of hot meal to the partner of the mother on neo natal unit

Sophie's LEGACY

STARLIGHT

Parents Feedback from the Food Pilots

U16 cancer patient experience survey

““Yes, it's made a huge difference whilst my child has been in hospital as an emergency admission for over a week”.

“I haven’t had to leave the ward to eat breakfast, so my child was able to still have my support whilst they were ill and in pain, as otherwise, I wouldn't have been able to eat. It had also been a lifesaver as it has also enabled me to eat 3 healthy meals a day, as otherwise I would not have been able to afford to buy meals to eat”.

“In previous stays, I have only been able to eat any leftovers from my child eating.

This has made a huge difference to me and my child, as I've been able to stay and help support my child on their most difficult and poorly days as I'm not hungry and am able to give better support”.

“This has also ensured that I have not had to go into debt to afford to eat whilst my child is staying in the hospital and I cannot work”.

Next steps

- Complete the 2024 pilots, evaluate the feedback and learnings and produce a summary report.
- Publish the play provision standards and guidance and disseminate through networks.
- Embed the requirement to provide parents/carers with food when staying overnight with a child in hospital within the Food Standards (due for publication in 2025)
- Create an understanding of other improvements within the CYP areas and within “Sophie’s Legacy” including higher quality food, wider choice, and availability, recognising that CYP mealtimes need to be celebrated.

For more information, please contact

- charlotte.fairall@sophieslegacy.org.uk; sara.berry@nhs.net; helen.benn3@nhs.net

Please take 2 minutes to reflect

Closing statement

NHS England

Neil Churchill, Director for People and Communities

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.

Thank you!