



England

# Under 16 National Cancer Patient Experience Survey

2024 Results Webinar

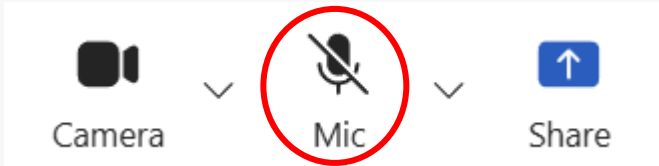


# Agenda

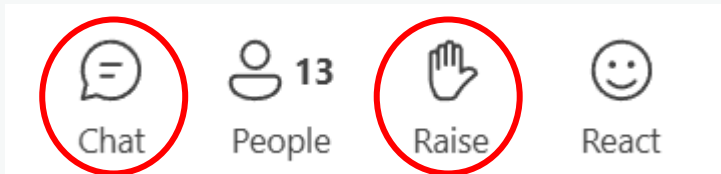
	Time	Item	Speaker
1	09:30-09:35	Introduction and housekeeping	Tamatha Webster, Insight Lead, NHS England
2	09:35-10:05	U16 CPES quantitative results (including Q&A)	Zoe Oliver, Quantitative Senior Analyst, NHS England
3	10:05-10:35	U16 CPES qualitative results (including Q&A)	Estelle Phillips, Qualitative Senior Analyst, NHS England
4	10:35-10:50	Thoughts and reflections	Open to all
5	10:50-10:55	Cancer programme perspective	Jodie Moffat, Deputy Director – Policy and Strategy NHS Cancer Programme, NHS England
6	10:55-11:00	Close and request for feedback	Tamatha Webster, Insight Lead, NHS England

# Introduction and housekeeping

Microphones will be **disabled** whilst the presentations are ongoing.



You can ask questions using the **chat function** throughout the webinar. During the Q&A, please feel free to **raise your hand** and ask questions verbally.





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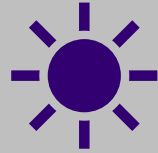
**Our ask of you  
today**



# Questions



1) What **surprises** you the most?



2) Which **insight resonates** most?



If you are in the NHS:

3) **How will you prioritise** the improvements to make from the opportunities shared?

If you are a patient/parent/carer:

3) **What actions** would you like to see based on findings from the report?



England

# 2024 quantitative results

Zoe Oliver

Quantitative Senior Analyst

NHS England



# What outputs are available?



National  
quantitative report



National  
qualitative report



National Excel  
data tables



PTC individual  
PDF reports



PTC Excel data  
tables



PTC freetext  
workbooks



Dashboard

# Accessing local results

## Principal Treatment Centre Results

2024 PTC Data Tables

2024 Alder Hey Children's NHS Foundation Trust

2024 Birmingham Women's and Children's NHS Foundation Trust

2024 Cambridge University Hospitals NHS Foundation Trust

2024 Great Ormond Street Hospital for Children and University College London Hospitals NHS Foundation Trusts

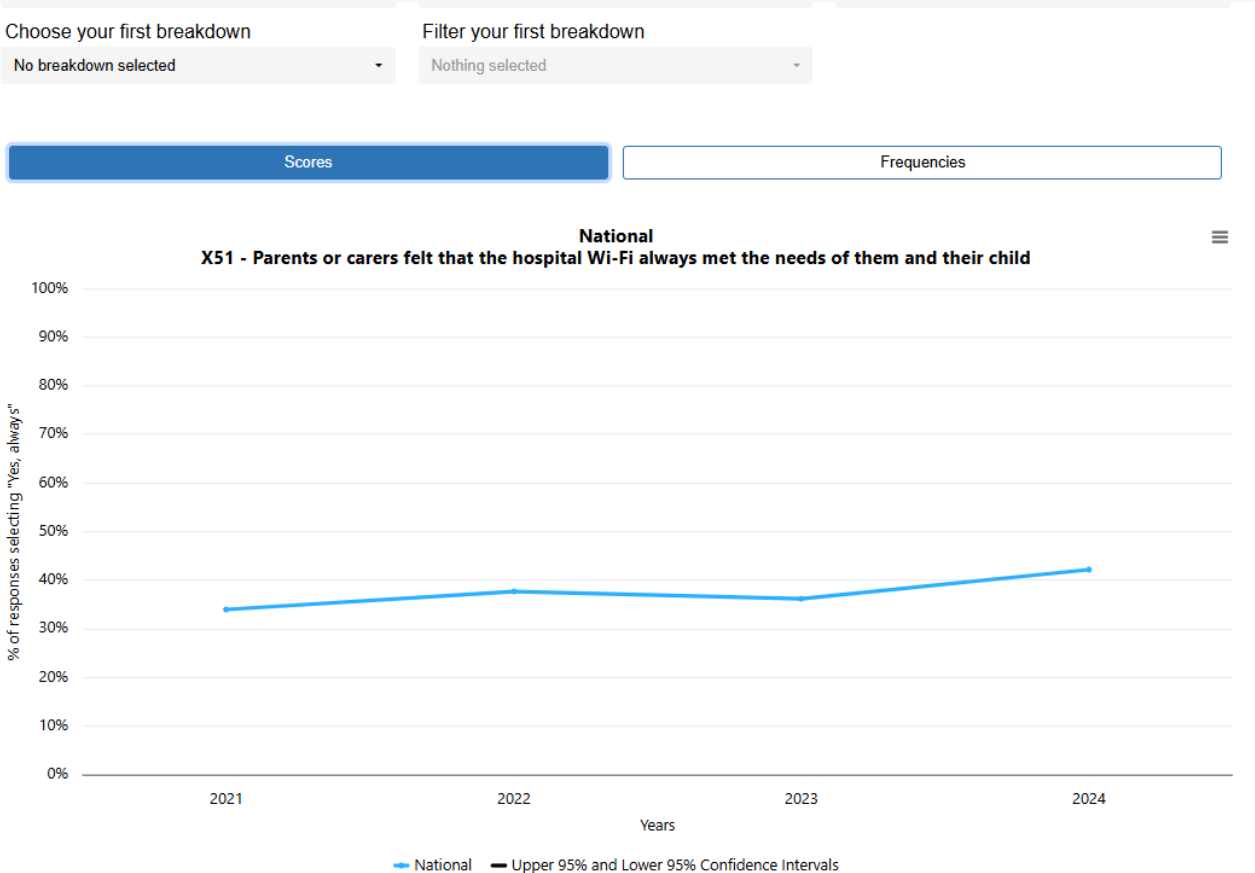
2024 Leeds Teaching Hospitals NHS Foundation Trust

2024 Manchester University NHS Foundation Trust

2024 Nottingham University Hospitals and University Hospitals of Leicester NHS Foundation Trusts

2024 Oxford University Hospitals NHS Foundation Trust

2024 Sheffield Children's NHS Foundation Trust







# About the respondents

## Subgroups include:

- Which of the following best describes you?
- Sex registered at birth
- Ethnic group
- Long-term condition
- Long-term condition status
- Does the child's long-term condition or cancer reduce their ability to carry out their day-to-day activities?
- Survey type
- IMD quintile (Deprivation)
- Diagnostic group
- Current care or treatment stage

# Response rates

The 2024 survey involved 13 NHS Principal Treatment Centres (PTCs). Out of 3,434 eligible people, 759 people responded to the survey, yielding a response rate of 22%.

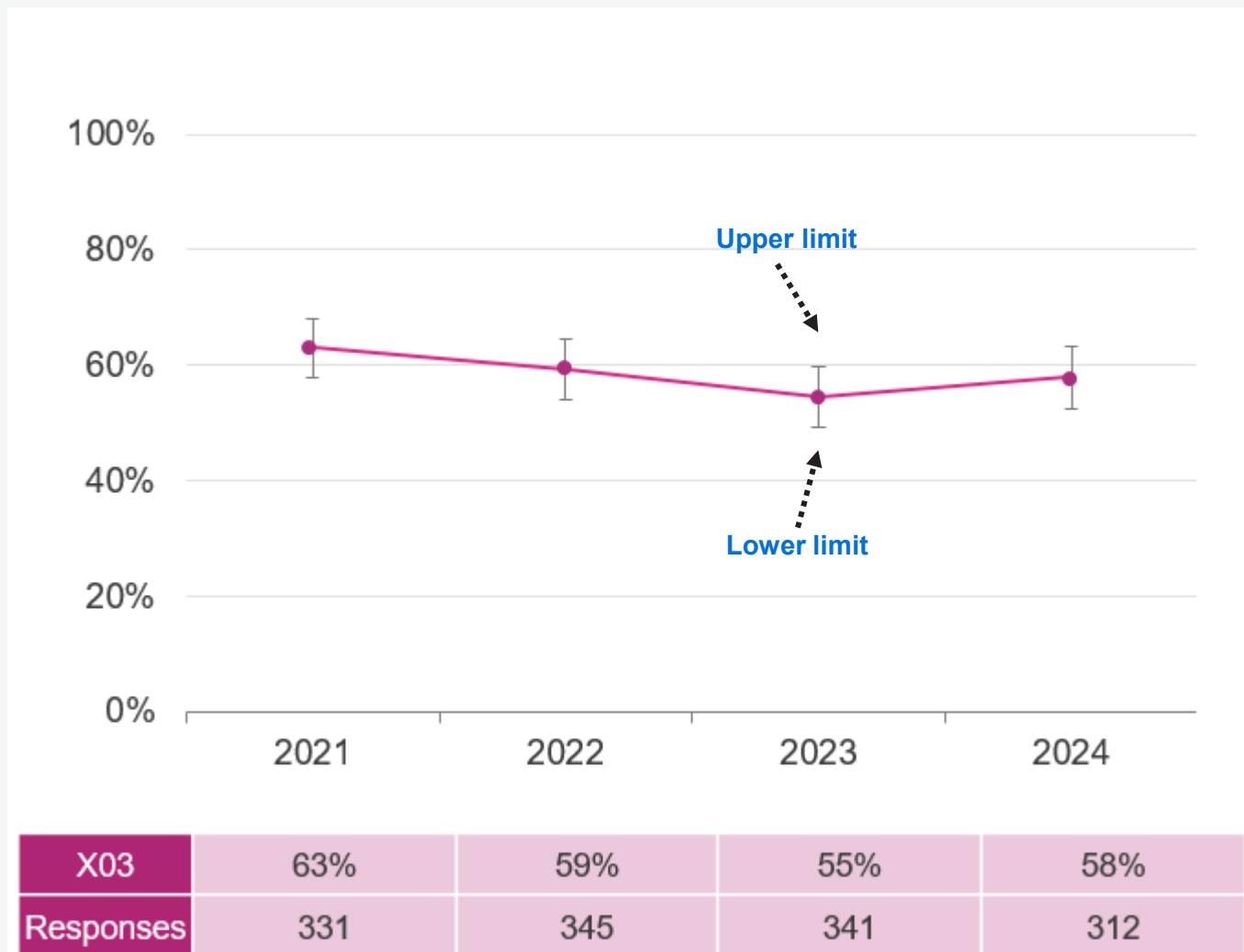
This is compared to 25% in 2023.

## Respondents by survey mode

Response mode	Number of respondents	Proportion of respondents
Paper	511	67%
Online	248	33%
Phone	0	0%
Translation service	0	0%
Mixed – paper and online	0	0%
<b>Total</b>	<b>759</b>	<b>100%</b>

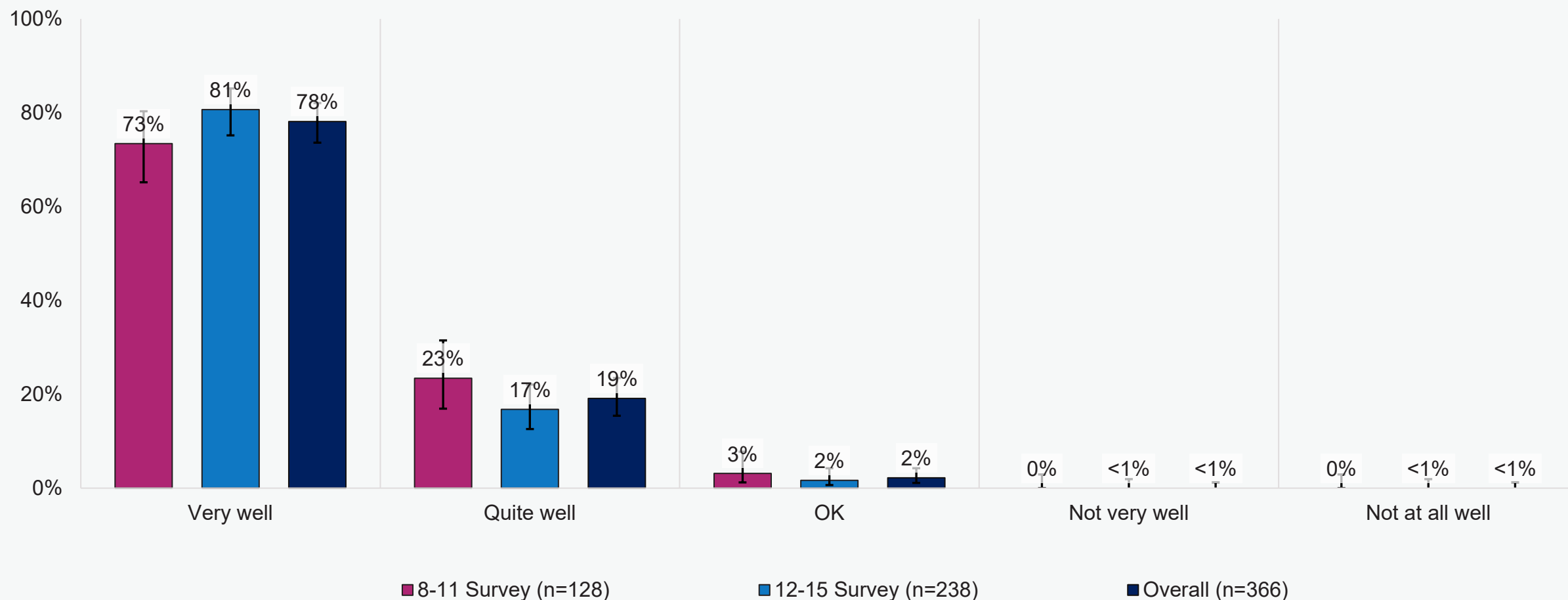
# ‘Notable differences’

- Notable differences > when confidence intervals do not overlap
- The **upper and lower** limits indicate the **range** in which the true value is likely to lie, based on the information we have.
- In this example, the confidence intervals overlap, indicating there are no notable differences. There is not enough statistical evidence to conclude whether or not there is a “true” difference between the two.



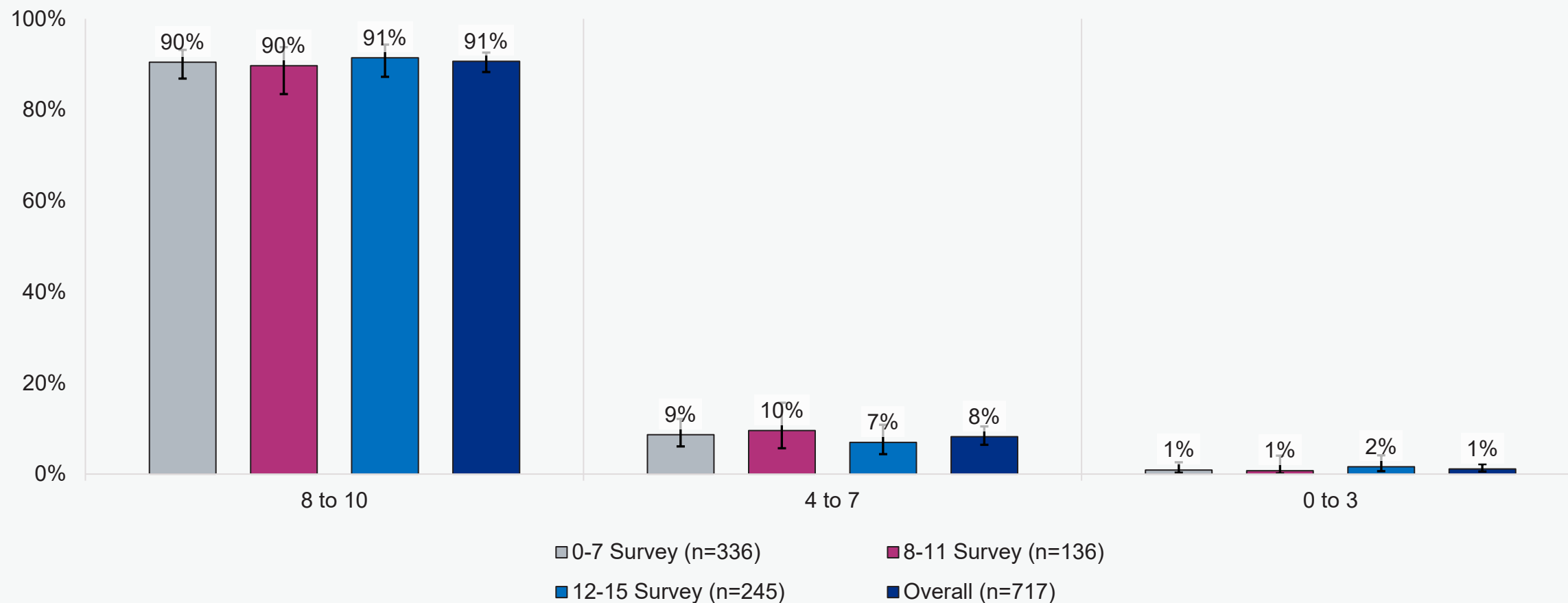
# Overall experience (children and young people)

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



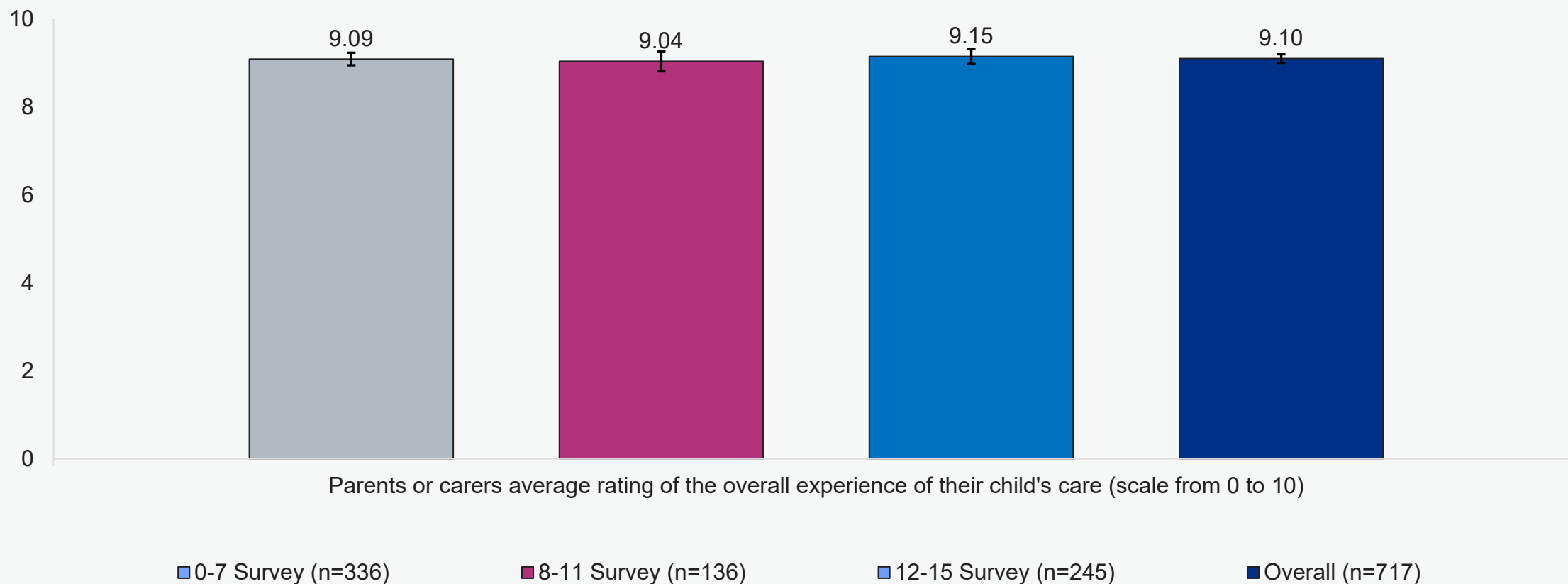
# Overall experience (parent and carers)

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



# Overall experience (parent and carers)

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



# Parent's overall experience by subgroup

- Experience scores range from **8.13** to **9.58** out of 10 across different respondent subgroups.
- Across most demographic subgroups, no notable differences were seen in overall experience when compared to the national average (**9.10**).
- However, there were a few notable differences for diagnostic group, impact of cancer or long-term condition and current care or treatment stage.

Higher than national average	Lower than national average
▲ Retinoblastoma ( <b>9.58</b> )	▼ Long-term condition or cancer impacted their day-to-day activities <b>a lot</b> ( <b>8.70</b> )
▲ Long-term condition or cancer <b>did not</b> impact their day-to-day activities at all ( <b>9.38</b> )	
▲ In remission or long-term follow up ( <b>9.34</b> )	

# Highest scoring questions (2024)

In 2024, five questions scored over 90%:

## Contact for further information

- **97%** of parents, carers and children reported that **staff provided details** about who to **contact for more information** after being told about their child's/their cancer or tumour.

## Overall experience

- **91%** of parents and carers rated the **overall experience** of their child's care as 8 or more out of 10.

## Respect, dignity and friendliness

- **94%** of parents, carers and children felt that the **nurses** who came to their home or school were **always friendly**.
- **91%** of parents and carers felt that they and their child were always treated with **respect and dignity** by staff.

## Having a main contact

- **90%** of parents and carers reported that there was a **main person** in the team looking after their child **that they could contact** about their care or treatment.





# Lowest scoring questions (2024)

In 2024, six questions scored below 50%:

## Food satisfaction

- 40% of parents, carers, and children felt that there was definitely a **suitable choice** of hospital food
- 42% of parents and carers were definitely able to **prepare food in the hospital** if they wanted to.

## Overnight facilities

- 35% of parents and carers reported that **facilities for them to stay overnight** were **very good**.
- 26% of parents, carers and children reported that it was **always quiet enough** for them to **sleep** in hospital.

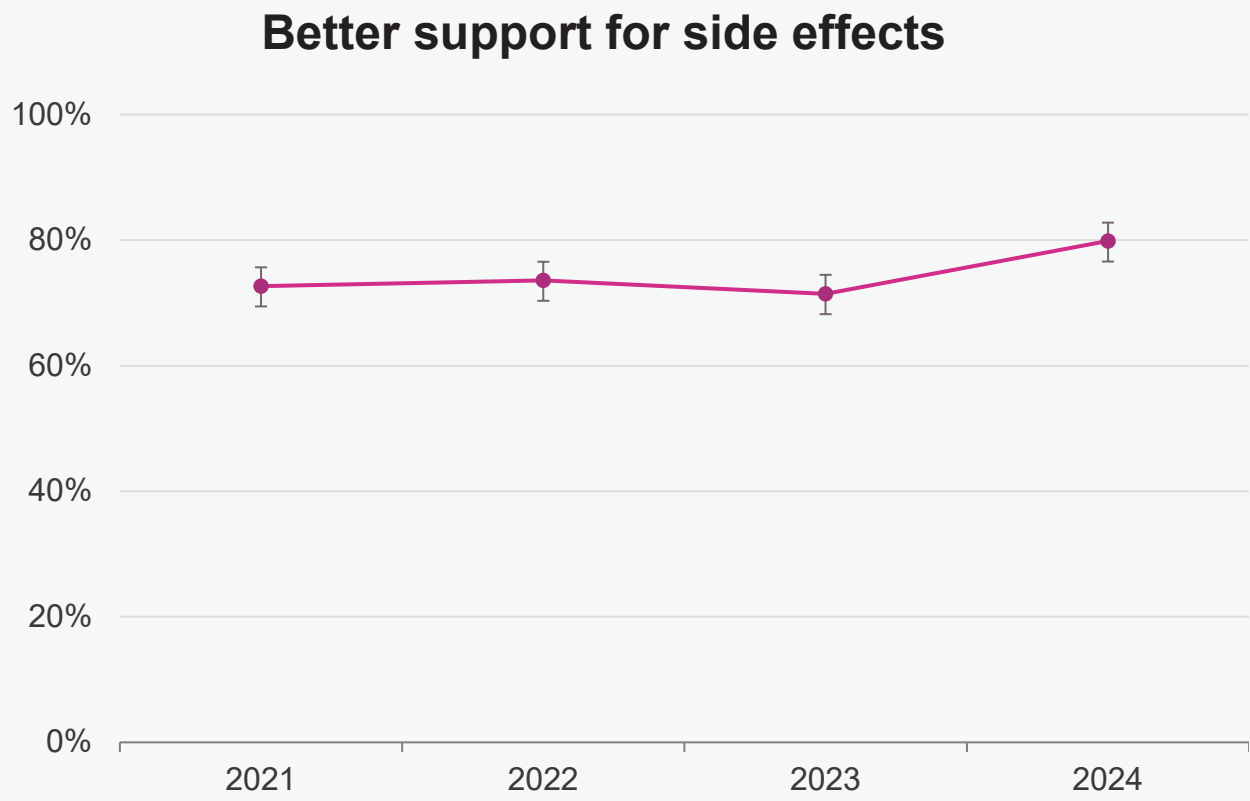
## Wi-Fi adequacy

- 42% of parents and carers felt that the **hospital Wi-Fi always met the needs** of them and their child.

## Nurse continuity

- 43% of parents, carers, and children reported that the **same nurses always came to their home or school**.

# Improvements over 1 year period (2023-2024)

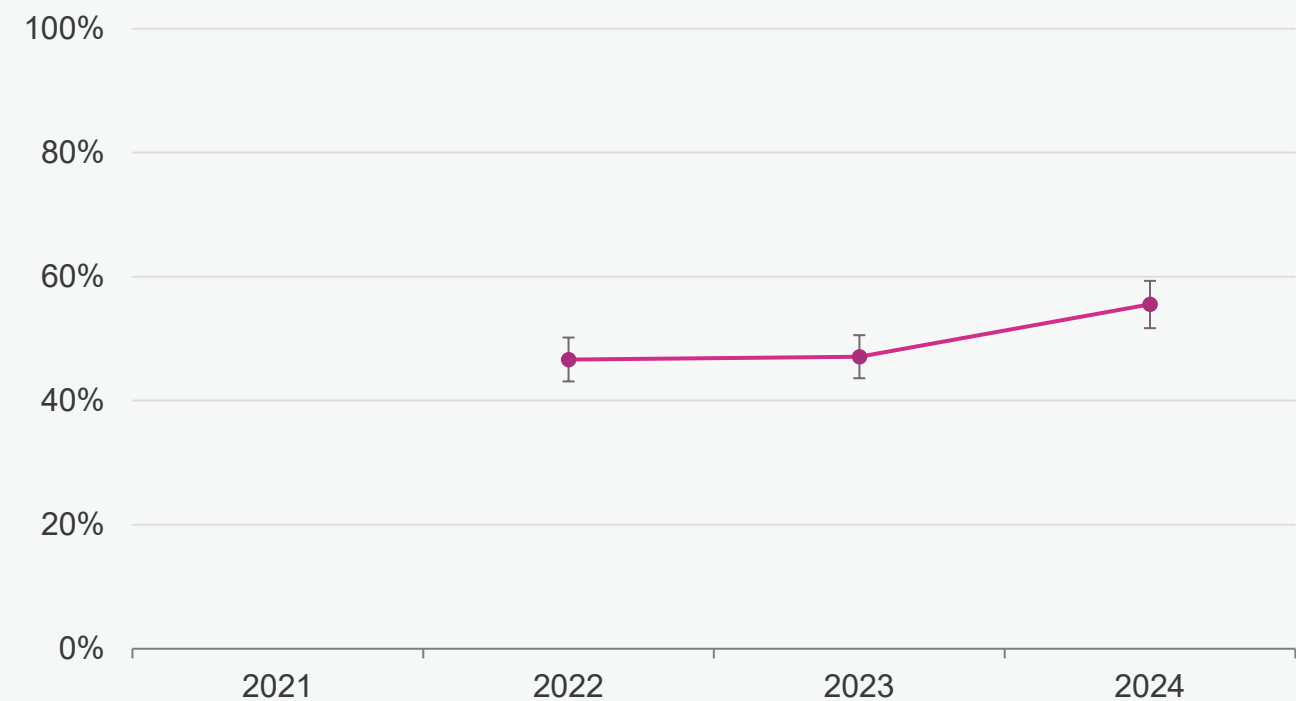


**80%** of parents and carers reported that staff definitely offered them support to help **manage their child's treatment side effects**, an increase from 71% in 2023.

X38	73%	74%	71%	80%
Responses	783	768	795	641

# Improvements over 1 year period (2023-2024)

## Improved ease of communication with main contact

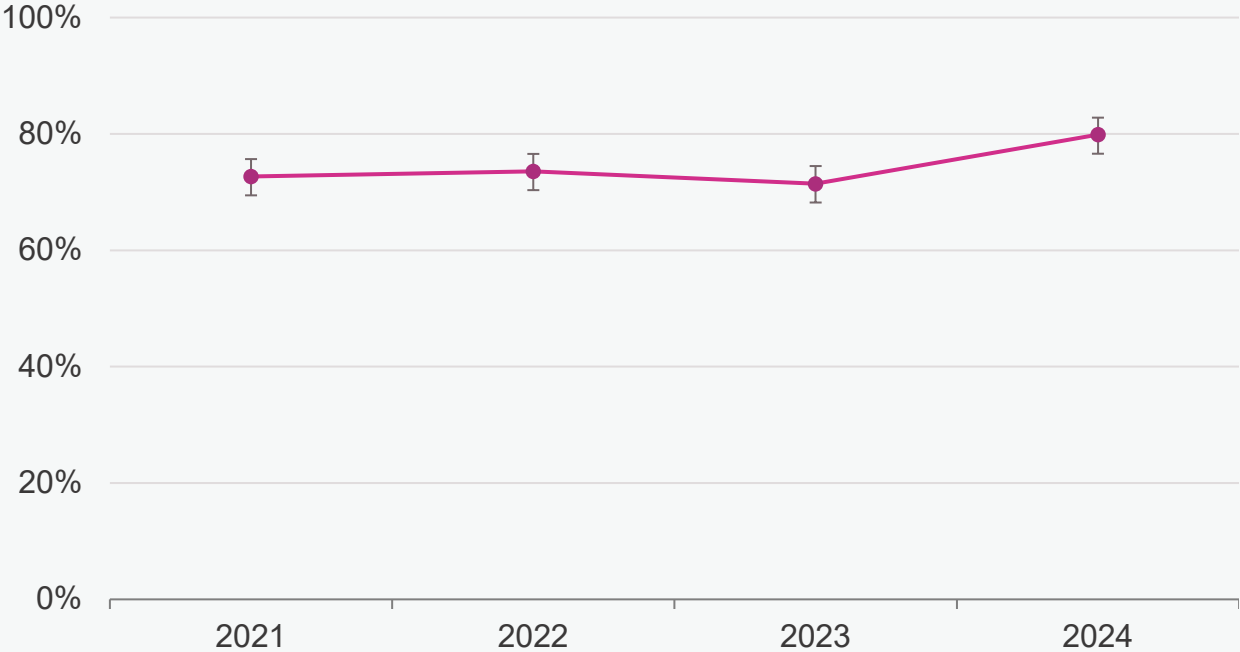


56% of parents and carers reported that it was **very easy to contact the main person** in the team looking after their child, an increase from 47% in 2023.

X32	-	47%	47%	56%
Responses	-	759	790	648

# Improvements over 4 year period (2021-2024)

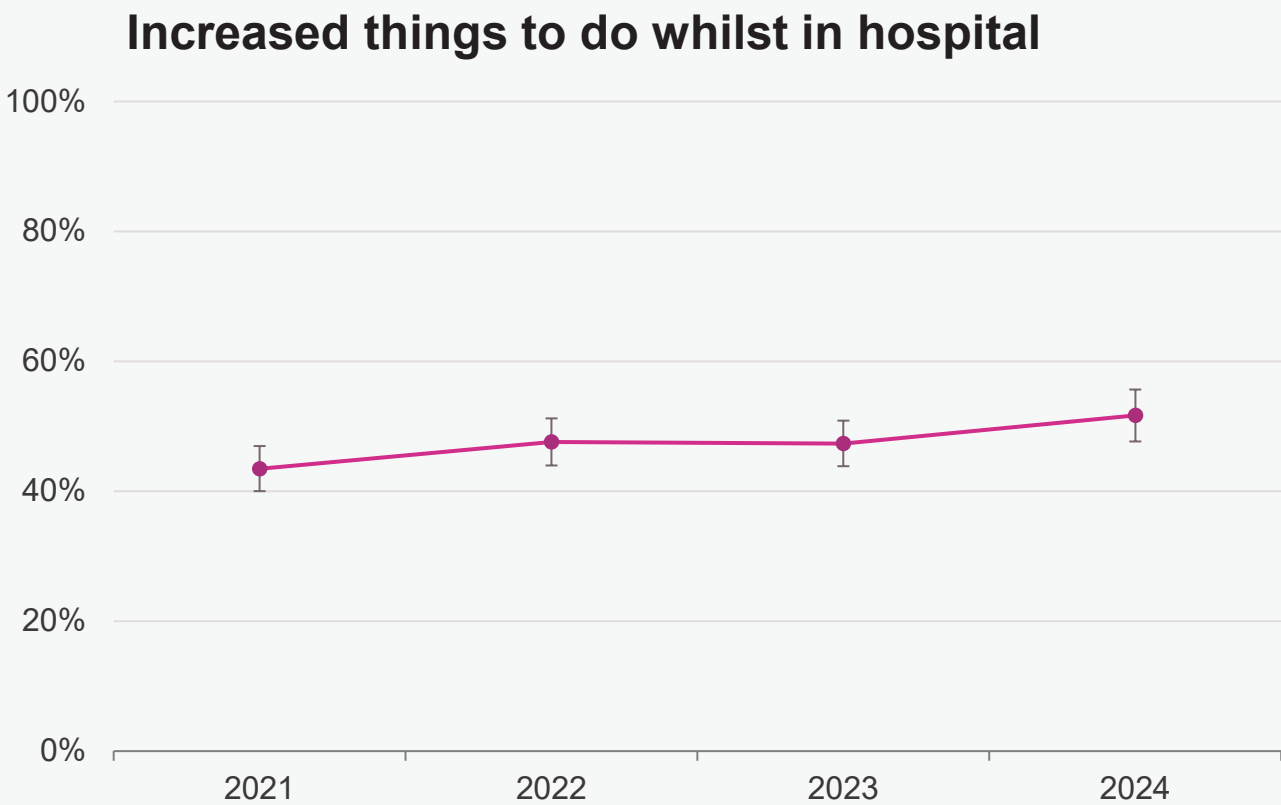
Better support for side effects



80% of parents and carers reported that staff definitely offered them support to help **manage their child's treatment side effects**, an increase from 73% in 2021.

X38	73%	74%	71%	80%
Responses	783	768	795	641

# Improvements over 4 year period (2021-2024)

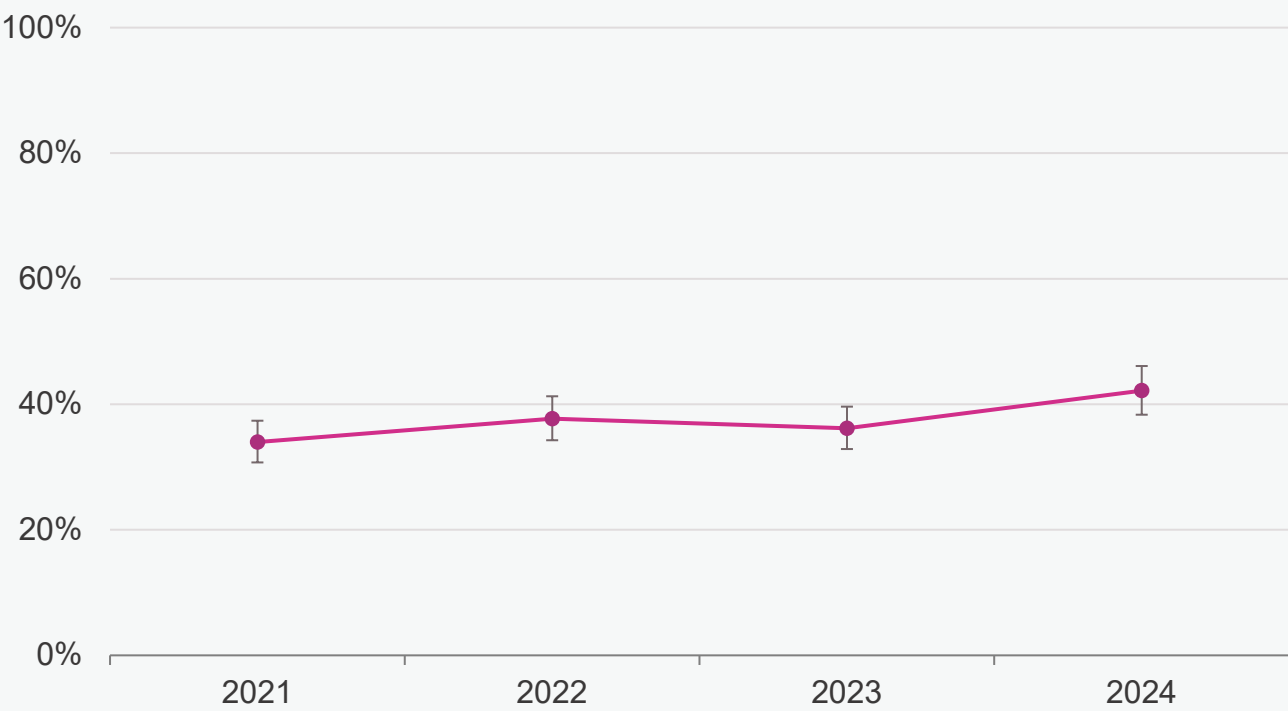


52% of parents, carers, and children felt that there were **definitely enough things for them/their child to do** in the hospital, an increase from 43% in 2021.

X43	43%	48%	47%	52%
Responses	780	725	775	596

# Improvements over 4 year period (2021-2024)

Wi-Fi adequacy in hospital



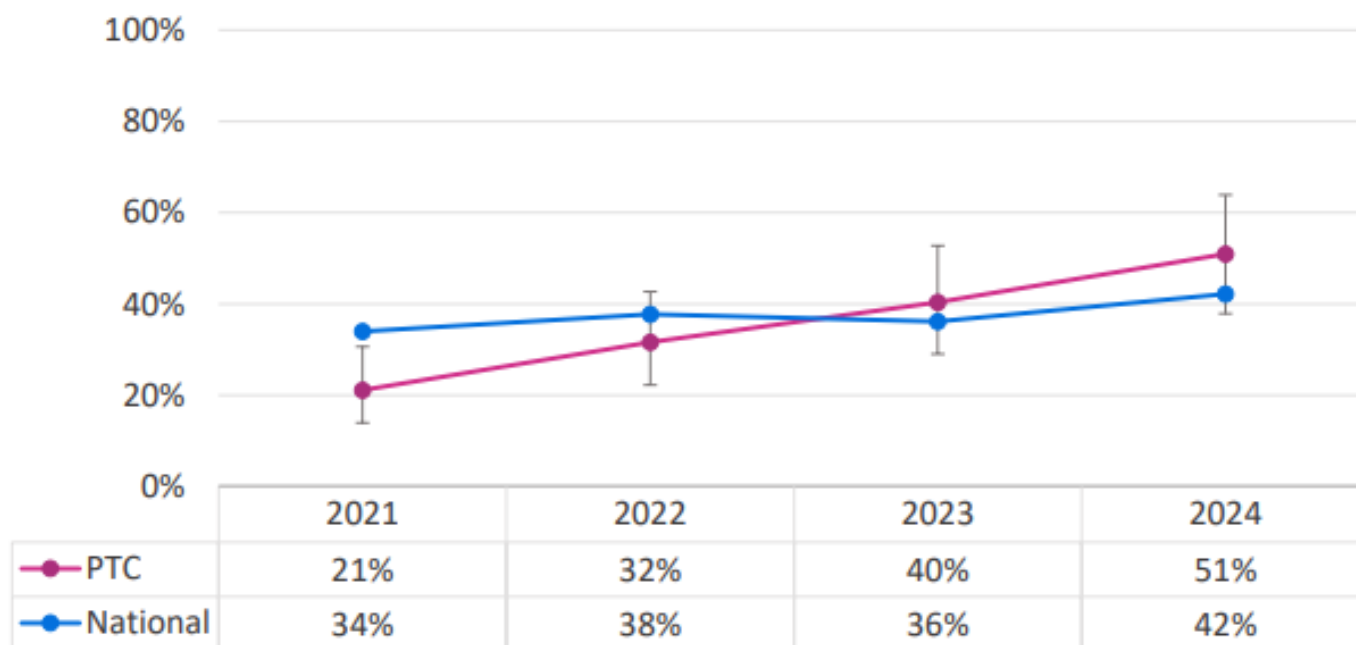
42% of parents and carers felt that the **hospital Wi-Fi** always met the needs of them and their child, an increase from 34% in 2021.

X51	34%	38%	36%	42%
Responses	777	732	774	619

# PTCs with notable improvements for X51

The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust

Figure 88: Parents or carers felt that the hospital Wi-Fi always met the needs of them and their child



“There was a Teenage Cancer Trust funded booster at the centre in Sutton in 2022, around a similar time, the whole site internet access also improved.

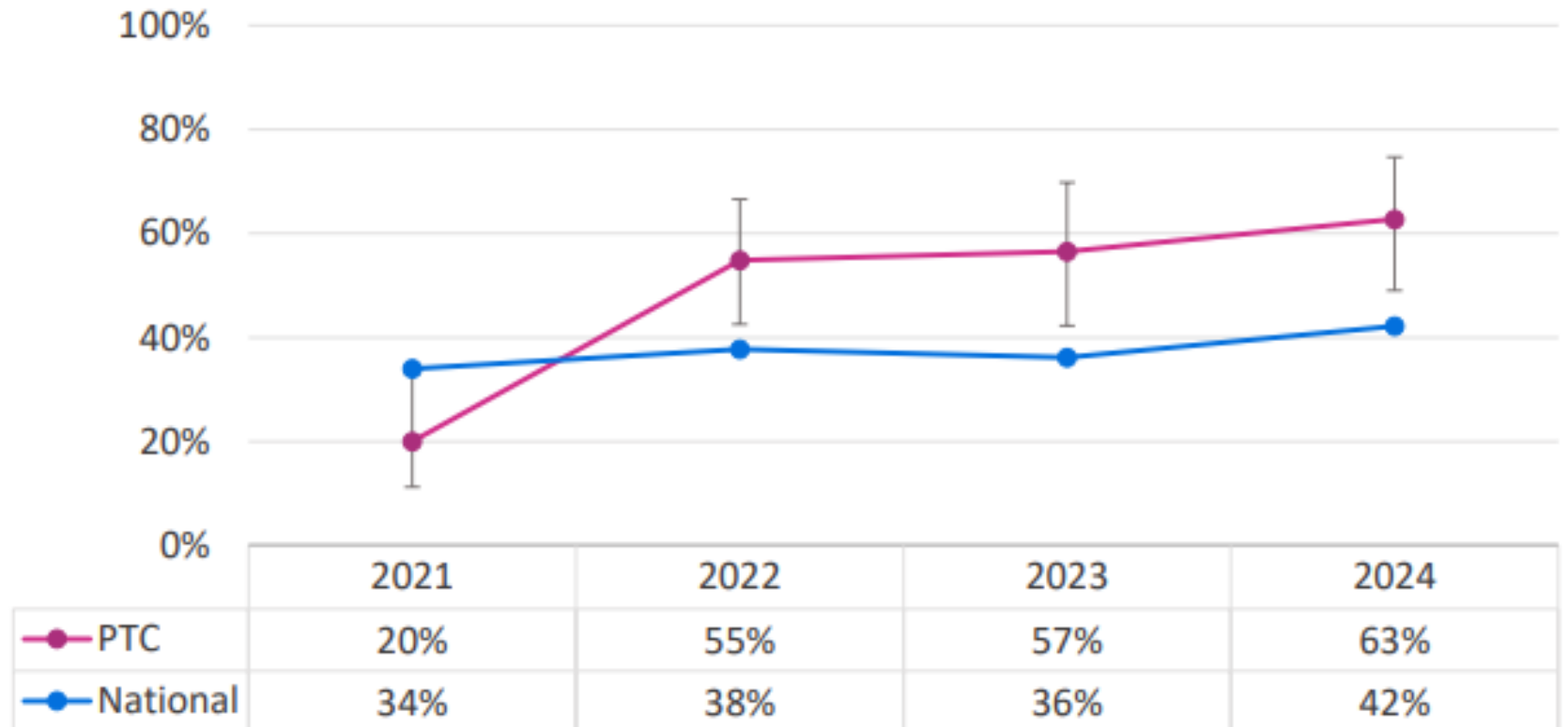
Staff said it's really easy to get on and off internet now but if a child wants to play online games there is still some bandwidth issue.”

# PTCs with notable improvements for X51

Cambridge University Hospitals NHS Foundation Trust

“There have been improvements made Trust-wide to the Wi-Fi availability across the whole of CUH.”

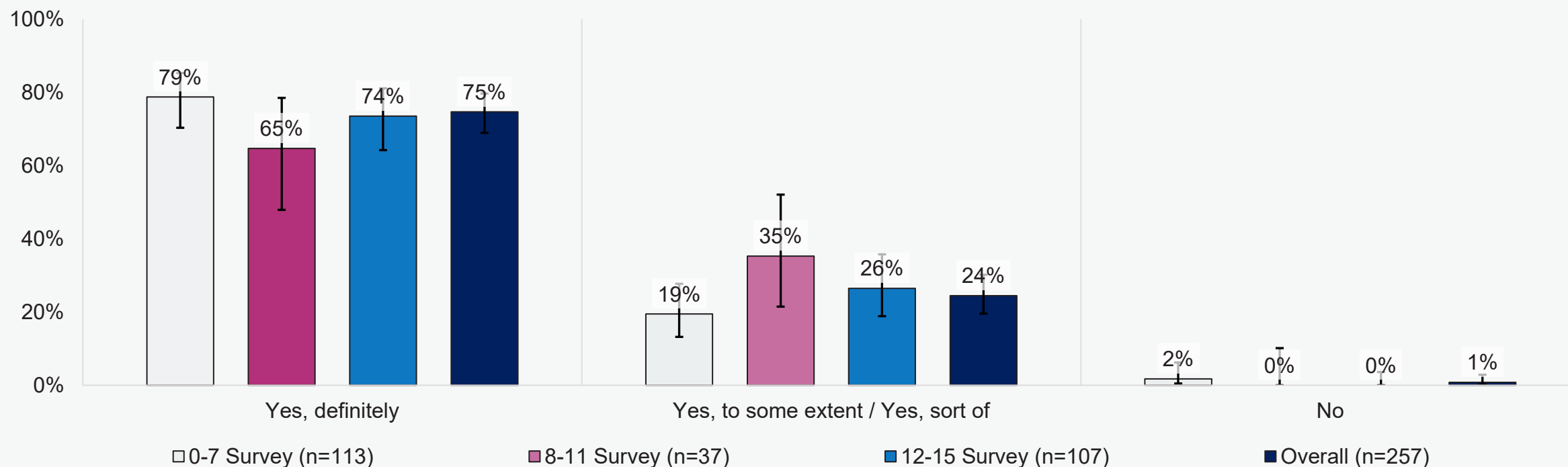
**Figure 88: Parents or carers felt that the hospital Wi-Fi always met the needs of them and their child**





# Information at diagnosis

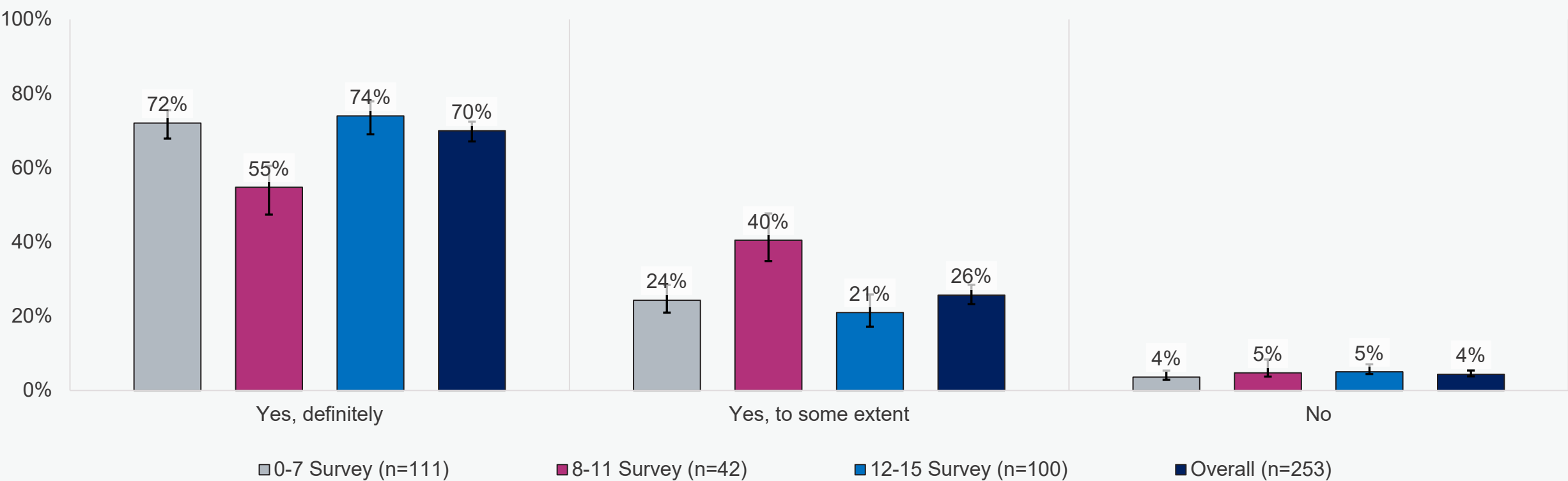
When you were told about your / your child's cancer or tumour, was information given in a way that you could understand?



75% of parents, carers, and children reported that information at diagnosis was definitely given in a way they could understand.

# Sensitivity of diagnosis

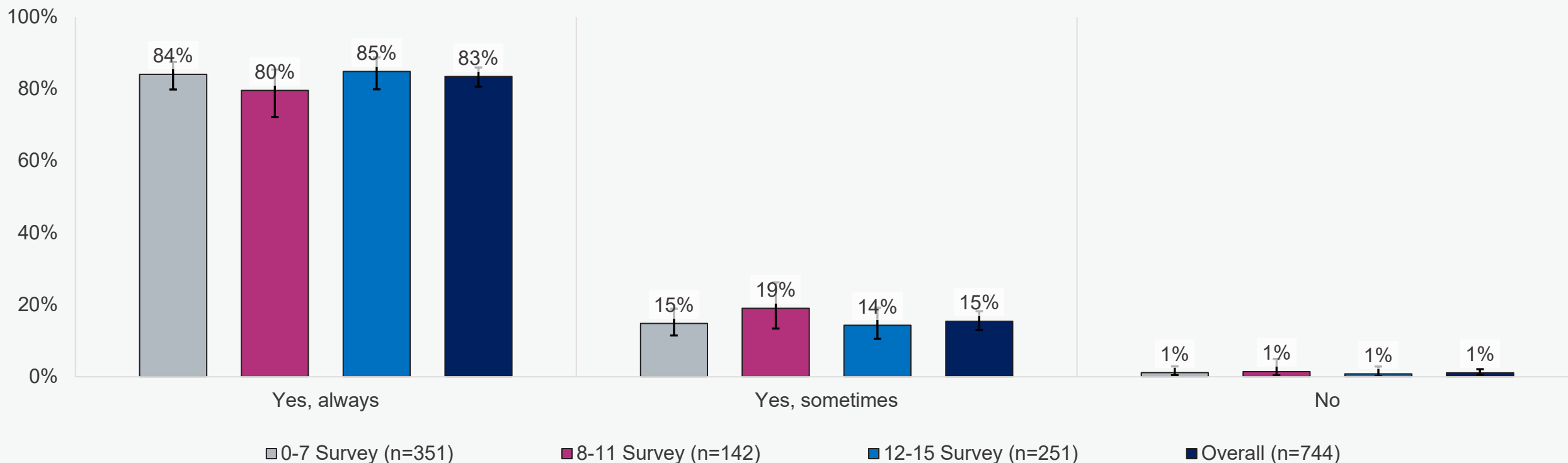
Were you told about your child's cancer or tumour in a sensitive way?



70% of parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way.

# Confidence and trust in staff

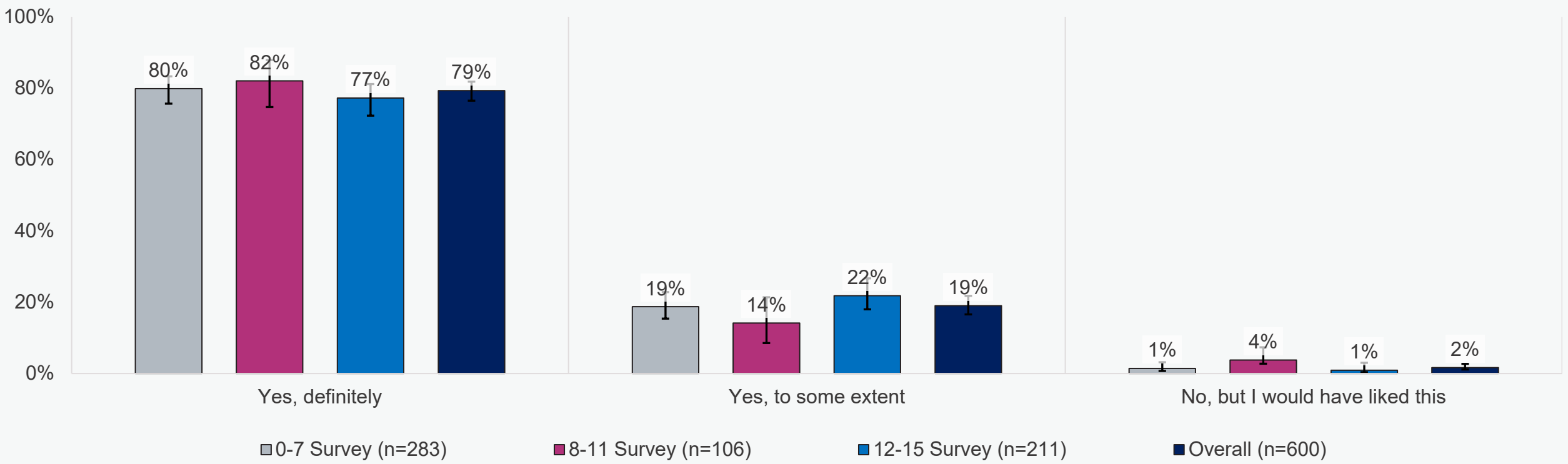
Do you have confidence and trust in the members of staff caring for your child?



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

# Time to make decisions

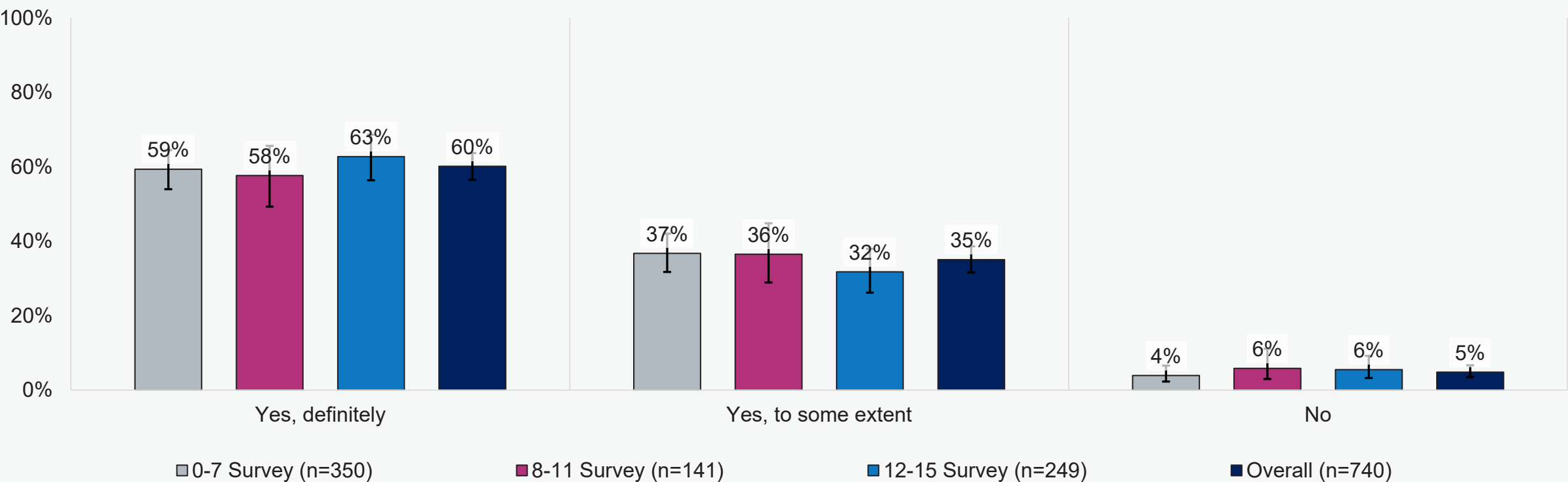
Did staff offer you enough time to make decisions about your child's treatment?



79% of parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment.

# Awareness of child's medical history

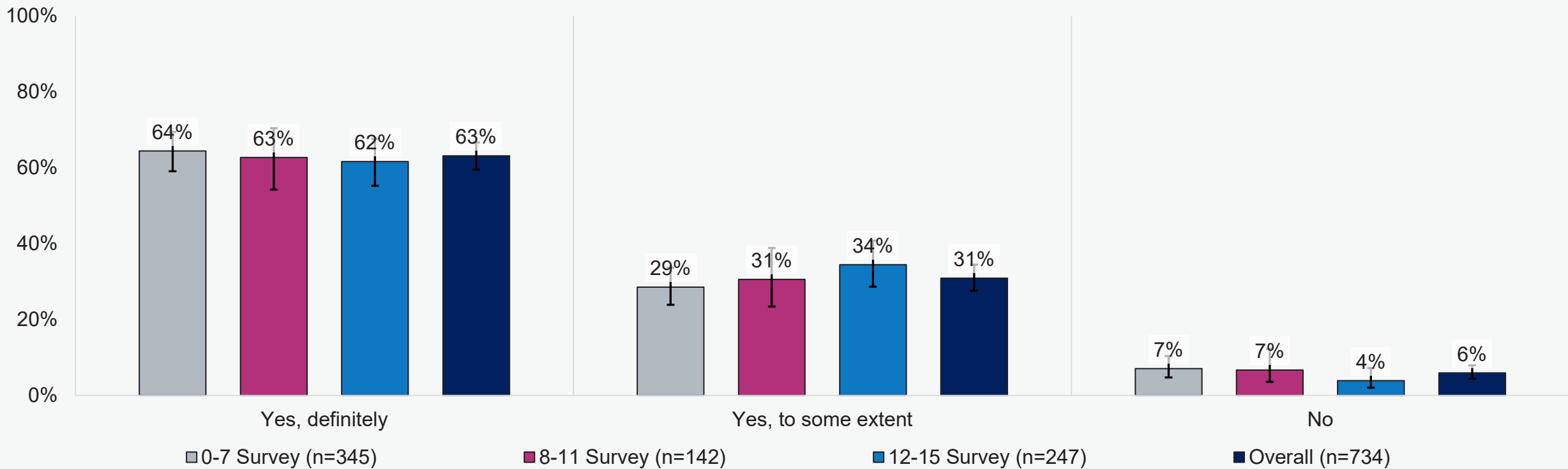
Are different hospital staff caring for your child aware of your child's medical history?



60% of parents or carers felt that different hospital staff were definitely aware of their child's medical history.

# Access to reliable help and support

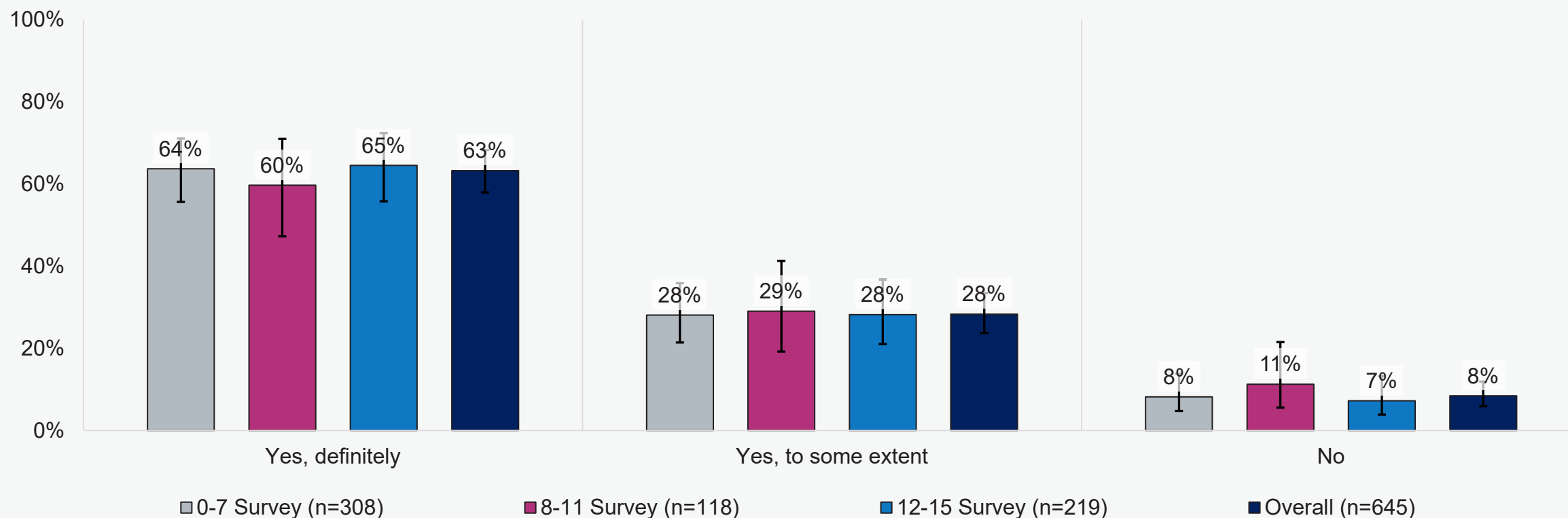
Do you have access to reliable help and support 7 days a week from the hospital?



63% of parents or carers reported that they definitely had access to reliable help and support 7 days a week from the hospital.

# Ongoing support following treatment

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



63% of parents or carers felt they definitely received enough ongoing support from the hospital after their child's treatment ended.

**Any  
questions?**







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# 2024 qualitative results

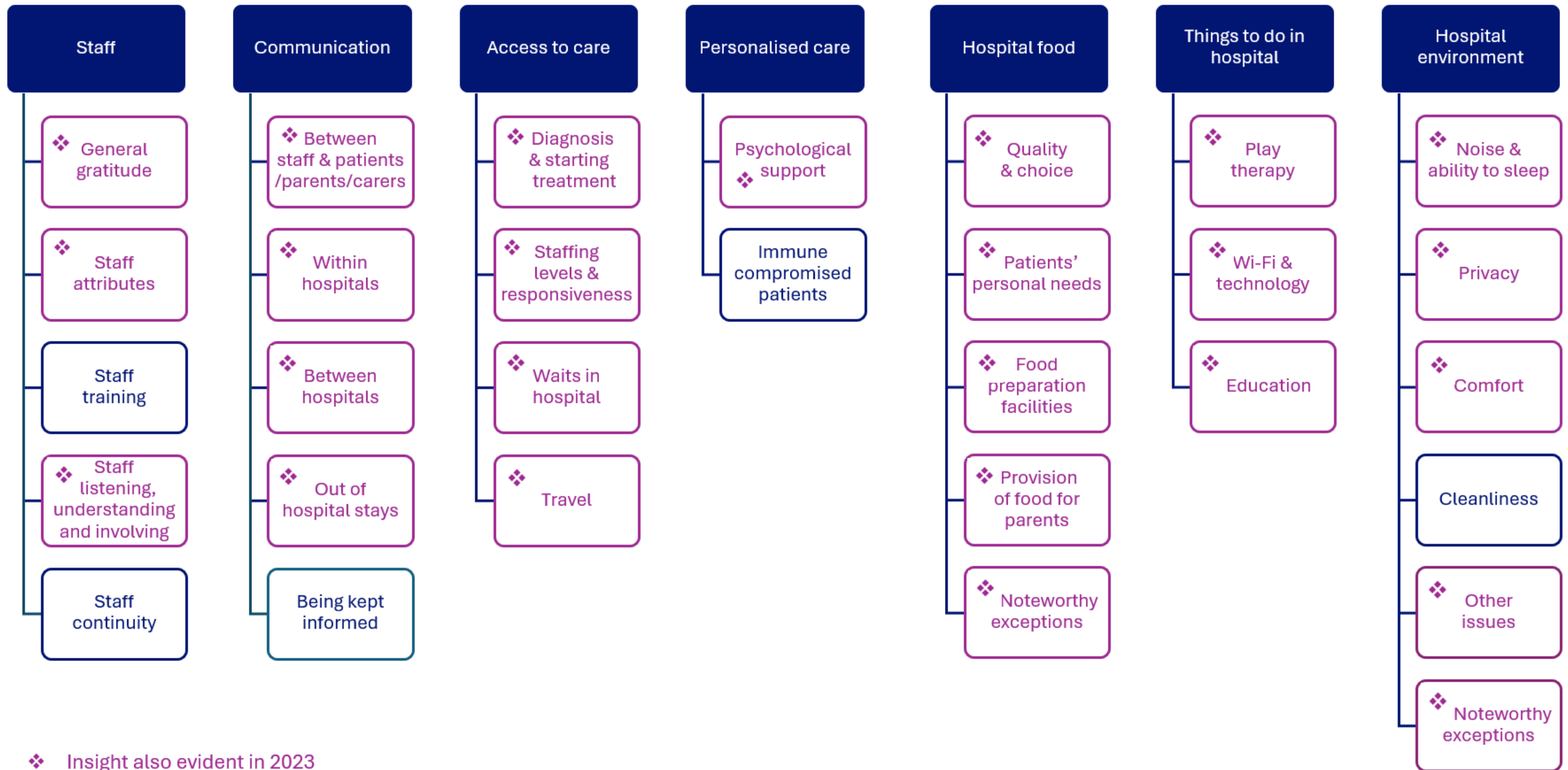
Estelle Phillips

Qualitative Senior Analyst

NHS England



# Overview of themes



Gratitude was expressed with a particular focus on the role staff played in care experiences. Positive attributes such as kindness & friendliness were highly praised. Areas for improvement focussed on training; continuity; & ensuring staff were listening, understanding & involving patients, parents & carers.



- Positivity about staff was the most prevalent theme in the data, key attributes praised were **kind; friendly; helpful; caring; supportive; professional; dedicated; compassionate**.
  - Made children feel safe, comfortable, special, and built trust. Made difficult time more bearable for children, parents or carers.
- "The staff are incredibly kind and I feel so safe and comfortable to talk to. Thank you." (child aged 12-15)*
- "The nurses were the kindest, supportive and cheerful people which helped with the fear and trauma being on an Oncology Children's Ward." (parent/carer of child aged 12-15)*
- There were exceptions, e.g. some staff were rude, needed to be friendlier or more empathetic. This demonstrated how **all** staff interactions play a critical role in how care is experienced.
  - Calls for improved **staff training** in A&E, local hospitals or non-cancer wards in hospital to meet cancer patient needs.
- "We understand that there is nothing else that can be done when the oncology ward is full, but we feel uncomfortable when we have an unexpected stay and have to go to another ward where the staff are perhaps not as experienced with dealing with a child with cancer." (parent/carer of child aged 12-15)*



- Staff **listening, understanding and involving** was seen as important:
  - Engaging on a personal level could make people feel welcome, supported and safe.
  - Being listened to allowed involvement in joint decision making.
  - Improvements needed where concerns and feelings went unheard or were invalidated, with a link to delayed diagnosis.
- Preference for children to be cared for by the same staff, with it inferred **staff continuity** would have benefits in terms of building relationships and improved communication.

*"We've had some very caring stand-out staff - the ones that remember our names and have a conversation (even if they aren't treating us). Makes us feel welcome and supported." (child aged 8-11)*

*"During chemo, I didn't like being told on several occasions by one particular doctor that I needed to 'be positive' it felt insensitive and infuriating." (child aged 12-15)*

*"Seeing our own consultant consistently was very rare and not helpful." (parent/carer of child aged 12-15)*

*"(staff name) - Disappeared, stopped supporting me after 1 month. No contact and left me with no one to talk to." (child aged 12-15)*

Features of good communication between staff & patients/parents/carers 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. The need to be kept informed was evidenced as important.



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

Timely  
information

Clear  
information

Staff being open  
to discussion  
and being  
asked questions

Procedures  
being explained  
prior to taking  
place

An appropriate  
level of detail in  
information

Staff addressing  
children, not just  
parents or  
carers

Tailoring  
information to  
make it  
understandable

Sufficient time  
taken to provide  
explanations

- Where people were less satisfied, it was indicated that consideration of **privacy, consistency, timeliness, and information at the start of hospital stays**, could bring about improvements, for example:
  - Consideration of who was present when diagnosis information was shared, incorporating the child, staff members, other service users
  - Improving staff continuity and availability to facilitate information being consistent and timely, including at weekends
  - Providing practical information about life on the ward

*"When I was told my diagnosis there were around 8 doctors I was unfamiliar with in the room and it made me feel pitied/worse than I was. Even though I was asked if it was okay for the staff to be in the room I was asked when they were all there already so I felt like I couldn't say no" (child aged 12-15)*

*"It would be great if we could access someone to talk to at weekends - there is a big drop in the level of advice available. (parent/carer of child aged 0-7)*

*"When we were first admitted to (location name) we felt very out of our depth and felt that there was no real 'induction' to life on the ward. Some nurses assumed we would know the protocols around being 'barriered' etc when we were like rabbits in the headlights." (patient/carer of child aged 8-11)*

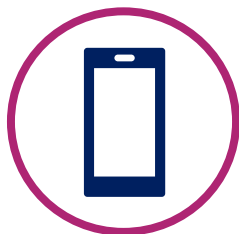


- Poor communication **within hospitals** was observed, including staff not always having the same degree of info about patients. This could lead to confusion, delays and parents/carers having to intervene. Issues of staff continuity were a contributing factor to this.

*"Often information was lost from shift to shift, or nursing staff were giving contradicting information." (child aged 12-15)*

*"Interface between different teams e.g. with radiology. I often have to follow up referrals or scans and communicate any changes." (parent/carer of child aged 0-7)*

- Similarly poor communication and record sharing **between hospitals** was seen, leading to parents/carers having to relay information, and delays to treatment.



- The ability to communicate with **services outside of hospital stays** was variable. Flexibility as to when people could contact services was of importance, as well as using different methods which best aligned with needs.

*"Maybe a phone line for out of hours queries? I currently call (location name) as my son was an inpatient there, but having an out of hours line could be reassuring." (parent/carer of child aged 8-11)*

*"The response via the app is always rapid which is really reassuring!" (parent/carer aged 0-7)*

- More generally, parents/carers were not always proactively **kept informed** about test results, cancer levels, treatment decisions or generally what would happen next, leaving them without reassurance.

How long it took to get a diagnosis & treatment was variable, with delays attributed to multiple issues. Staff were not always responsive to needs, with links to understaffing particularly at weekends/nights. Long waits in hospital were a frustration; with travel issues also impacting access.



- Whilst for some **diagnosis and receiving treatment** happened very **quickly**, others shared **harmful impacts** when diagnosis took longer than they believed necessary. **Delays** pointed to the following interrelated issues:

Not being listened to,  
including by GPs and  
at A&E

Lack of urgency  
around further  
investigation and  
referrals

Long waits for scans  
and their results

Missed symptoms and  
diagnosis

*"Believing parent our guidance, before we found out what was wrong with our daughter we went to the GP and in more than 10 times and every time we were made to look like we were just making up there symptoms. Up until things were really bad that when we were believed and sent for more test. It still kills me to think that she had to go there all of that." (parent/carer of child aged 8-11)*

*"My sons tumor was initially missed in his first MRI and was found in his second MRI 3 months later. We hope this could be something that can be looked upon and hope it dont happen to again or anyone else. (parent/carer of child aged 0-7)*





- Services could seem **understaffed**, with the need for more **nurses** most cited. This was evident in **long waits** for alarms to be responded to, medication to be supplied, and staff not being available to answer questions.
- **Day care units** were specifically highlighted in relation to staffing levels, and more generally a lack of staff was particularly apparent at weekends and at night.

*“Ensure all 'day care' appointments have enough staff available for the treatment needed for that day. Sometimes there are enough nurses but not enough chemo trained nurses on.” (parent/carer of child aged 0-7)*

*“Shortage of staff, some time after rang the nurse bell we need to wait 30 minutes some time more than specialty night time, some for doctors night time.” (parent/carer of child aged 0-7)*



- Respondents were frustrated by **long waits in hospital** for tests, treatment, **beds**, **medication** and operations or a combination of these. These scenarios spanned day care, hospital admission, discharge and at A&E.

*“Discharge is the very worst! We could be told we would be discharged at 8am and still be in the room at 2pm waiting for someone to sign off discharge or pharmacy to complete medication. There never seems to be an urgent need to get people home even when beds are full and patients are desperate to return home for just a few days before coming back for another treatment.” (parent/carer of child aged 12-15)*



- Desire for services to be **close to home**, efficient **hospital transport**, and ease of **parking** but experiences of these were mixed.
- Suggested it would be helpful for information about parking to be provided in advance.



There was a need for psychological support to be extended to wider family as well as more accessible for patients/parents/carers too. There were concerns highlighted as to the risks for immune compromised patients when in need of unexpected or urgent care, driving a call for more consideration.

- Absent or insufficient **psychological support** identified.
- Further consideration could also be given to:
  - Better signposting to charities that could provide support
  - Facilitating connections between parents or carers as a source of support

*"We were not offered any mental health support or counselling which is vital for the whole family when you have a child with cancer. We sourced this ourselves through charities, but it should be offered at hospital." (parent/carer of child aged 8-11)*

*"The psychologist wasn't available & the appointments weren't regular and would be cancelled or nobody would turn up. This didn't help my child's anxiety and I feel this area definitely needs improving to provide full support" (parent/carer of child aged 12-15)*

- Concerns around risks to **immune compromised patients** when access to care is via A&E or they are placed on non-cancer wards, with more consideration needed to the pathways used.

*"Disagree with being admitted via A&E - it's dirty, not good for immuno supported." (parent/carer of child aged 0-7)*

*"Had children with different types of illnesses which we were concerned about being around our child with a low immune system due to chemotherapy. We thought he should have been on an oncology ward." (parent/carer of child aged 0-7)*

Food played a significant role in how children & young people experienced time in hospital, with it commonly raised as an area for improvement. Issues spanned quality & choice; how well it met personal needs; as well as provision of food & adequate preparation facilities for parents/carers.



- Children expressed strong dislike of food provided, highlighting **limited options** and lack of **nutritional value**.
- Parents or carers could resort to supplying food because of the **poor quality** of that provided.

*"The food: on the ward there should be fresh food that is not a ready meal that haas been cooked from frozen" (child aged 8-11)*

*"I think the food menu could have a bit more choices and the food could have a bit more flavour" (child aged 12-15)*

- Catering needs for different religions, cultures, as well as other **dietary requirements** not always considered or met.
- Consideration also needed to how treatment was impacting on **appetite, taste, ability to eat**, as well as **where food was served** and eaten.

*"I think that the hospital food could be better more healthier options and including things like halal, vegetarian or vegan foods(because while I was there the only halal foods was the curry and rice menu)" (child aged 12-15)*

*"Not good to encourage eating in bed where they slept and did everything especially difficult when barried eating with a commode in front of them" (parent/carer of child aged 8-11)*

- In the few positive exceptions, children described food as "good" or "nice", or flexibility was shown to meet personal requests.



- Parents/carers made improvement suggestions for **food preparation facilities** around:
  - Additional appliances such as microwaves, toaster, plus more cutlery
  - Better maintenance of kitchen equipment and improved cleanliness
  - More fridge and/or freezer space
- Where not already happening, **parents/carers suggested hospitals should provide food for them**. Reasons for this were:
  - They felt unable to leave their child when they were too young or ill
  - To eliminate stress and expense
- Also suggested shops and cafes in hospitals could be open longer hours and at weekends; and stock a wider range of food.

*“In (location name) meals for parents would be appreciated when child is an inpatient. (location name) provides this which means one less thing to worry about and not just relying on shop bought noodle pots & sandwiches.” (parent/carer of child aged 12-15)*

# Key theme: Things to do in hospital

Play staff & activities were highly valued though older age groups were less catered for & there was unmet need for access at weekends. Improvement to Wi-Fi and the use of digital entertainment was also found. Hospital education was well received with requests for extended provision, e.g. weekends and bank holidays.



- Children made it clear how important it was to have **play and activities incorporated into their care**, which provided fun and helped them relax.
- The positive role **charities** played was acknowledged in terms of gifts, entertainment and events.

*"The pool table in the teenager area of oncology helps to pass time and keep me relaxed." (child aged 12-15)*

- Need for **improvements** focused on:
  - Activities not just geared towards younger children, with more age-appropriate areas for tweens and teenagers
  - Increased access to play staff and opportunities, including at weekends and bank holidays

*"There is nowhere for the tweens to go because the ward, play room is for baby's and the teen room is perfect but we are not allowed." (child aged 8-11)*



- **Poor Wi-Fi** limited entertainment options; restricted contact with friends and family; impacted parent/carers ability to work.

*"The WiFi- this was my main way of being distracted and it didn't always work." (child aged 12-15)*

- **TV's and video gaming** consoles weren't always available or working.

*"Not all TV's work and usually had to play hunt the remote." (child aged 12-15)*

# Key theme: Things to do in hospital

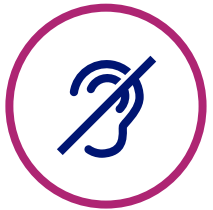


- Positive feedback on experiences of **hospital school** and **teachers**.
- Where critical focus was on need for **provision to be increased**.

*"The (location name) hospital school was very good. The teachers built a wonderful rapport with my daughter. They also went above and beyond to arrange interesting lessons for my daughter."*  
(parent/carer of child aged 8-11)

*"Hospital does not currently offer a school service for children who stay as inpatients for extended periods. The longest my son has stayed on these wards was seven days, and during that time, the absence of educational support was noticeable."* (parent/carer of child aged 12-15)

Noise and the ability to sleep in the hospital environment was experienced as an issue. There were also calls for increased privacy; improved comfort of beds & chairs; and in some cases cleanliness of the hospital environment was found to be problematic.



- Experiences that the hospital environment was too **noisy**, impacting on **ability to sleep**. Said to be caused by loud talking, beeping machines; TV's; staff carrying out tasks.
- **Brightness** of environment could exacerbate this.
- Improvement suggestions to create more restful environment:
  - Having and enforcing rules around bedtimes
  - Machines that did not audibly beep
  - Smaller wards or individual rooms
  - Separating younger children from older children
  - Provision of headphones
  - Staff considering if/how they were disturbing sleep unnecessarily

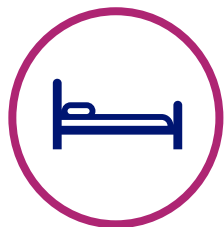
*"Sometimes it could be quite noisy in the bay as lots of other kids machines would beep throughout the night... at times the cleaning staff would be making a lot of noise really early in the morning" (child aged 12-15)*

*"at night, it should be made clear to all parents that lights go out at 8pm to allow the children to rest and sleep after their gruelling treatment. The nighttime experience wasn't great. Staff were coming in over night and opening doors loudly or making a lot of noise... Also overnight doctors on call coming in to the room if there were concerns and putting all the lights on!!! Just lack of consideration." (parent/carer of child aged 8-11)*

- There was a preference for **private rooms**. This was linked to having **dignity** upheld and having a **quieter personal space** to aid recovery.
- Children aged 12-15 saw it as important to be **separate from younger children**.

*"Being a 14/15 year old during my treatment, I found it quite difficult to be on the ward with other kids, as they were all much younger than me. I found it awkward and difficult to pee and poo in the cardboard as I was quite self conscious about it." (child aged 12-15)*

*"My other observation was that some hard procedures ie feeding tubes etc going are done behind curtains in wards when other kids hear the screams and get v distressed ." (parent/carer of child aged 8-11)*



- Comfort of **beds** and availability of **bedding** raised as issue for children, and parents or carers
- Issues with comfort and availability of **seating** for children, including in **day care**

*"Fold down beds/mattresses unclean and not comfortable. Shortage of pillows." (parent/carer of child aged 12-15)*

*"Please make sure more places for chemotherapy patients sometime the patient is more and places is less and they are tired sick and they don't have any place to sit." (parent/carer of child aged 12-15)*



- Variable experiences around **hospital cleanliness**. Highlighted issues often related to **bathroom facilities**, as well as **unpleasant smells**, and **dirty bedding**.

**Any  
questions?**







England

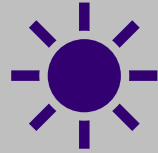
# Thoughts and reflections



# Questions



1) What **surprises** you the most?



2) Which **insight resonates** most?



If you are in the NHS:

3) **How will you prioritise** the improvements to make from the opportunities shared?

If you are a patient/parent/carer:

3) **What actions** would you like to see based on findings from the report?



England

# Cancer programme perspective

**Jodie Moffat**

Deputy Director, Policy and Strategy

NHS Cancer Programme

NHS England



# Powerful ways to make the case and spread the word

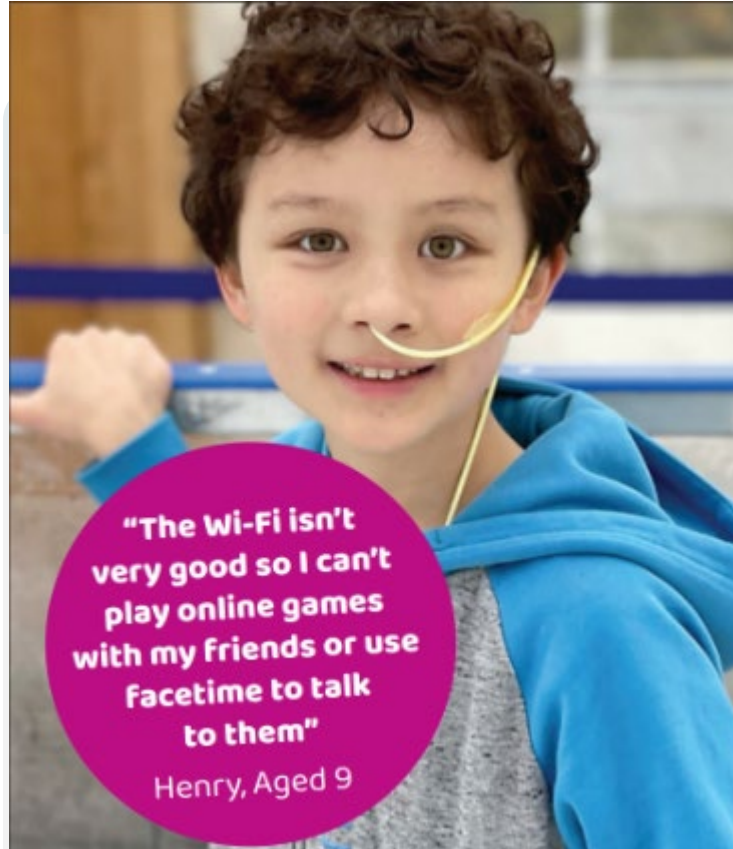


Driving improvements in:

- Play
- Food, for children and for parents

- [Sophie's legacy website](#)

- [Charity video \(Instagram\)](#)



**"The Wi-Fi isn't  
very good so I can't  
play online games  
with my friends or use  
Facetime to talk  
to them"**

Henry, Aged 9

Driving improvements in Wi-Fi

[Henry's Wi-Fi Legacy - North West Children's  
Cancer Operational Delivery Network](#)



# Cancer Experience of Care Improvement Collaborative

The NHS Cancer Programme uses the U16 CPES results and other insight and feedback to inform the focus of the Cancer Improvement Collaborative (CIC).

If you haven't heard about the CIC before it is a coaching and quality improvement framework through which the NHS Cancer Programme encourages the system to work with patients on improvement projects.

We work together with people affected by cancer and use the language of 'coproduction'.

**We use data like U16 CPES to inform focus and measure change.**

We began using the U16 CPES in 2022-23, which focused improvements solely on children and young people. Since then, every CIC has focused on improvements on all ages.

This year (CIC7) we have 16 project teams working with us - this includes a children's hospice and the North West Teenage and Young Adult Cancer Specialised Services Clinical Network (SSCN) – focusing on improving experiences.

# Thank you

Please share your feedback:

<https://forms.office.com/e/rkPUu66ppd>