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

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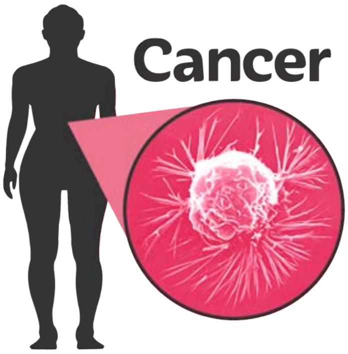
About the Under 16 Cancer Patient Experience Survey

Your body is made up of tiny cells.
Your blood has lots of tiny cells too.



Sometimes cells can change. These cells can grow and spread very quickly.

They can stop good cells from doing their job properly. We call this **cancer**.

When a group of broken cells grow and stick together in a lump, we call this a **tumour**.

Some tumours do not cause harm and are not cancer.

It is important that people get the treatment they need quickly and in the right place.

Cancer services support people who have cancer or a tumour.

We send out a questionnaire about cancer services every year.

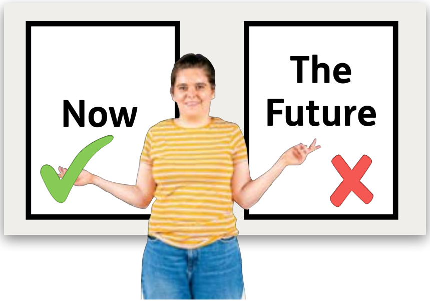
People who use cancer services are asked to fill it out. We sent it to:

- children and young people aged 8 to 15 who have cancer or a tumour

and

- parents and carers of children aged 0 to 15 who have cancer or a tumour

We sent the questionnaire to **3 thousand 741** people. **949** people filled it in and sent it back.

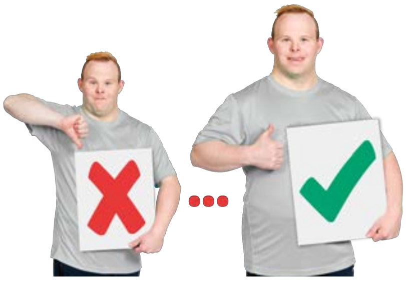


This report tells you some of the main things people said about the cancer care they got in 2023. It does not say what services need to do next.

It is really important to know the information in this report. It helps services to check:

- that their services work well for everyone

and



- what they could do better

Charities and voluntary groups can also use this information to support children and young people with cancer.

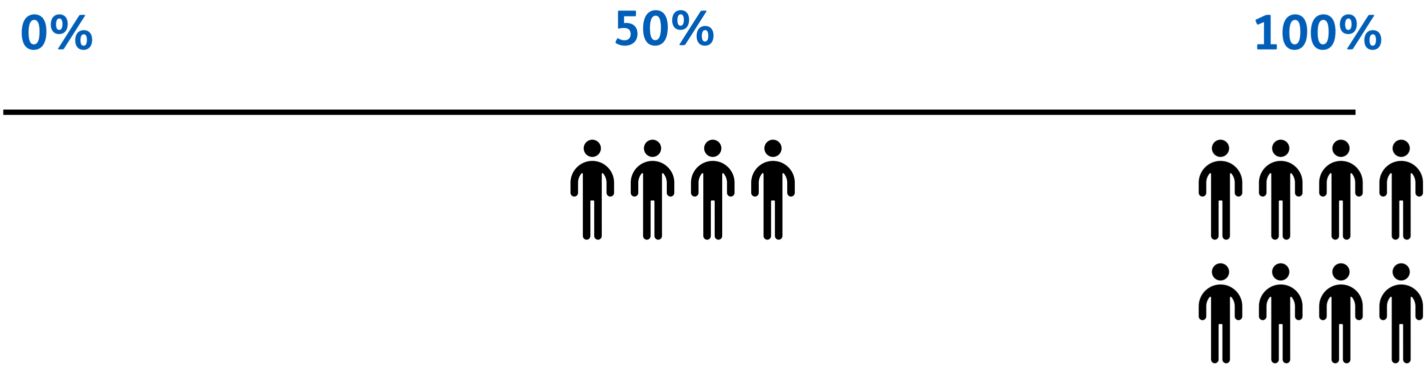
Percentages

In this report we use **percentages**. **Percentages** are a way to show how many people said something. This symbol **%** tells you it is a percentage.

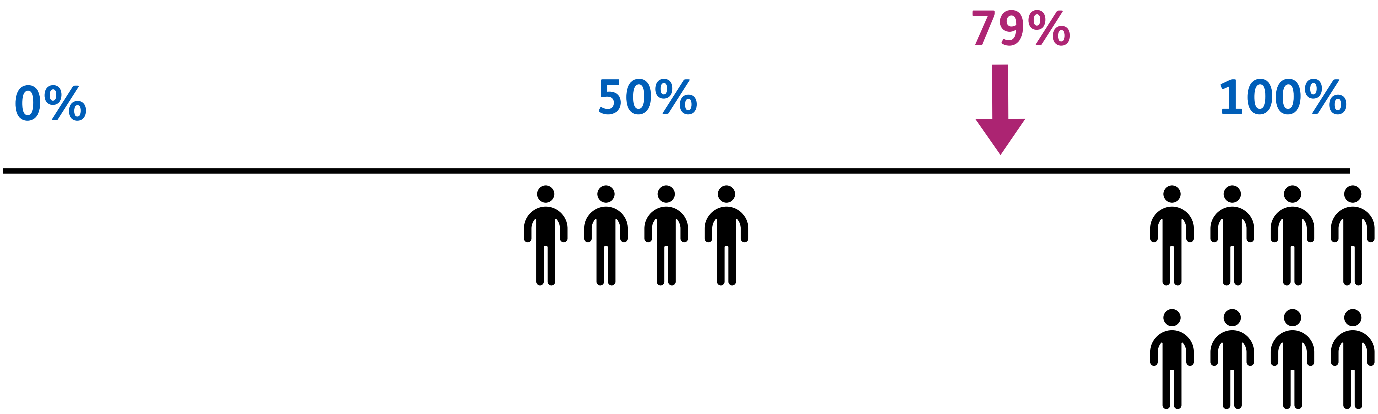
0% means nobody said it.

50% means half of the people we asked said it.

100% means everyone said it.



In this report we might say a different number like **79%**. This would be about here on the line:



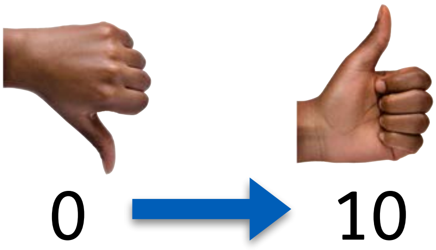
1. What people thought about overall care

We asked people about their **overall care**.

This means thinking about how good all their care and treatment was during 2023.

How parents and carers scored their child's overall care

We asked parents and carers to say how good their child's care was out of 10.



0 meant it was really bad and 10 was very good.

88% scored their child's overall care as 8 or more out of 10.

What children and young people said about overall care

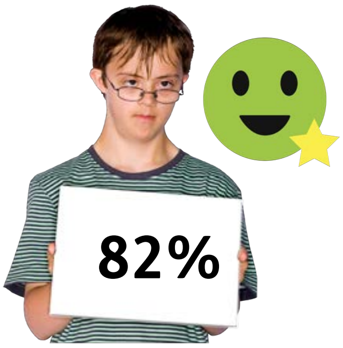
We wrote our questions in a different way for children and young people. This was to make it easier for them to understand.

We asked children and young people to tell us about their cancer care.

We asked them to think about all the people who looked after them and gave them care.

We asked them to answer by choosing one of these answers:

- very well
- quite well
- ok
- not very well
- not at all well



82% said they were looked after **very well**.

Extra things people said about their overall care experience

50% of parents, carers and children said that different hospitals who give cancer care work well together.

66% of parents and carers said they had to travel for around 1 hour or less to get to the hospital.

2. Finding out that your child had cancer or a tumour

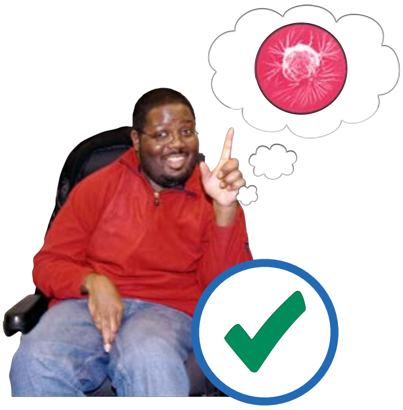
We asked parents and carers about when they were told their child had cancer or a tumour.

We asked how many times their child went to the local doctor before going to the hospital.

This is what parents and carers told us:

55% of parents and carers said they saw their local doctor 1 or 2 times first before going to the hospital.

70% of parents and carers of children thought that their child was seen by a hospital doctor at the right time.



73% of parents, carers and children said they were definitely given information about their cancer or tumour in a way they could understand.

93% of parents, carers and children said they were told by staff who to go to if they wanted more information.

72% of parents and carers said they were definitely able to find information about their child's cancer or tumour.

81% of parents, carers and children said if they asked a question, they were definitely able to get an answer.

We asked parents and carers how they felt about the way they were told their child had cancer or a tumour.

71% said that staff were kind and caring when they were told about the cancer or tumour.

3. Child's care and treatment

We asked parents, carers and children what they thought about their care and treatment. Here is what they said:

54% of parents and carers felt that the staff caring for their child definitely knew about their **medical history**.

This is when staff look into what health issues a child has had before.

83% said that they were given clear information about what treatment their child would get.

58% said they got the help they needed from the hospital 7 days a week.

62% felt they got enough support after their child's treatment had finished.

69% of parents, carers and children said they were definitely involved in their child’s care and treatment.

76% of parents and carers felt that staff gave them enough time to make decisions about their child's treatment.

We asked parents and carers if their child’s schooling had been affected by their care and treatment.

Some people told us their child's schooling was not affected.

For parents and carers whose child’s schooling had been affected, the main reasons were:

- their child had to miss school to go to appointments at the hospital

or

- their child was too unwell to go to school. This could be because they were too poorly or tired from their treatment

4. Care in hospital

We asked parents, carers and children about the time they spent in hospital.

71% of parents, carers and children said the child was always able to get help from the staff at the hospital, when they needed it.

47% of parents, carers and children said there were definitely enough things for children to do when they were in hospital.

52% of parents and carers said their child was always offered support from a **play specialist** when they needed it.

These are staff that are trained to use play as therapy for children.

36% of parents and carers thought the **WiFi** was always good enough.

WiFi is used to connect a phone, tablet or computer to the internet.

38% of parents, carers and children thought there was definitely a good choice of food that meets people's needs.

40% of parents and carers said they could make their own meals in the hospital if they wanted to.

25% of parents, carers and children said it was always quiet enough to sleep in the hospital.

5. Care at home or at school

We asked parents, carers and children what they thought about the nurses they saw at home and at school.

95% thought the nurses were always friendly.

86% said they could always understand what the nurses were saying.

6. Healthcare staff

We asked parents and carers if they have trust in the staff that care for their child.

80% said they always trusted staff and thought that staff knew what they were doing.

89% said they felt that staff always treated them and their child fairly and with respect.

82% said they felt staff listened to their child, were kind and understood them.

We asked parents and carers how they felt when staff had to tell them things about their child that might be upsetting.

71% said staff were good at this and did not tell them upsetting things when their child was in the room.

87% of children felt that staff were always friendly.

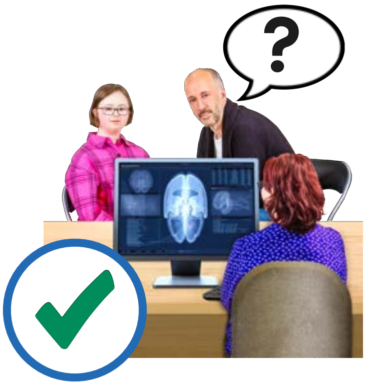
Communication with staff

We asked parents, carers and children about how well they understood what staff said to them.

73% of children said they could always understand what staff said.

76% of parents and carers felt that staff always shared information with children in the best way for them.

57% of parents, carers and children said they were not told different things by different members of staff.



84% of parents and carers said they could definitely ask questions about their child’s care and treatment.

78% of children felt that staff always talked straight to them and not just to their parents or carer.

We asked parents and carers if staff gave them information about people they could talk to about their child's cancer.

83% said staff told them about cancer charities that give support.

56% said staff told them where they could go to see a **counsellor**. A **counsellor** is someone you can speak to about how you are feeling.

We asked children and young people if staff gave them information about people they could talk to about their cancer.

73% said staff told them about a cancer charity that could help them.

57% said staff told them where they could go to see a counsellor.

Thank you for reading our report.

More information

This is an easy read version of a bigger report. You can look at the big report on this **website**:

www.under16cancerexperiencesurvey.co.uk/technical-reports

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