



Under 16 National Cancer Patient Experience Survey 2021



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 National Cancer Patient Experience Survey

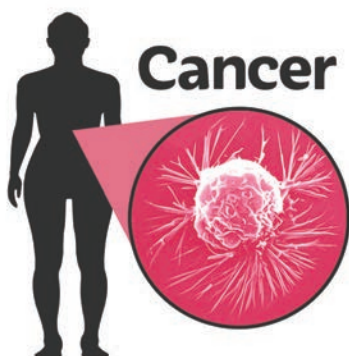


Your body is made up of tiny cells. Cancer changes the cells in your body and makes them stop working properly.



When a group of broken cells grows into a lump, we call this a **tumour**.

Some tumours do not cause harm and are not cancer.



Other tumours can grow and spread to different parts of the body. This is 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

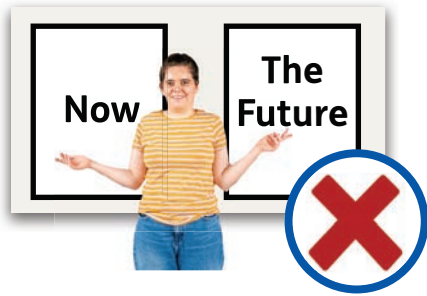
and



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



We sent the questionnaire to **3 thousand 672** people. **960** people filled it in and sent it back.



This report tells you some of the main things people said.

The report does not say what services need to do next.

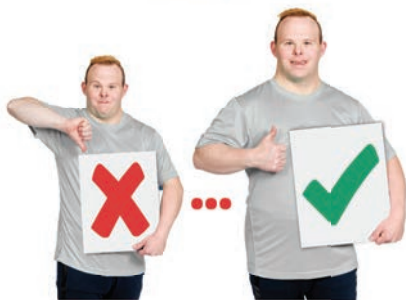


It is really important to know the information in this report. It helps services to check:

- 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.

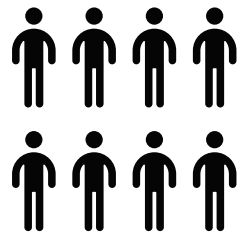
50% means half of the people we asked said it.

100% means everyone said it.

0%

50%

100%



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

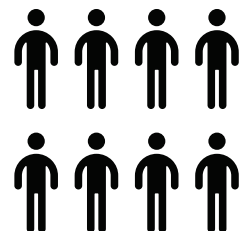
79%



0%

50%

100%



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.

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.



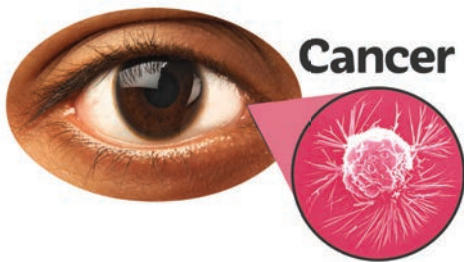
89% scored their child's overall care as 8 or more out of 10.



Parents and carers of boys gave a higher score than parents and carers of girls.



Parents or carers from a mixed ethnic background were more likely to score their child's care as 8 or more out of 10.



There are lots of different types of cancer.

Retinoblastoma is cancer in your eye.

We say it like this:

ret-in-oh-blast-oh-ma.



Parents or carers of children with **retinoblastoma** were more likely to score their child's care as 8 or more out of 10.



An area is called **deprived** if people living there have things like:

- poorer health
- less chances to get a good job
- poorer housing



Parents and carers from deprived areas scored their child's care slightly higher than those from less deprived areas.

What children and young people said about overall care

Overall Care

1. What do you think about it?

very well

quite well

not very well

A hand is shown holding a pen over the survey card.

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 helped to plan their care.

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



● very well



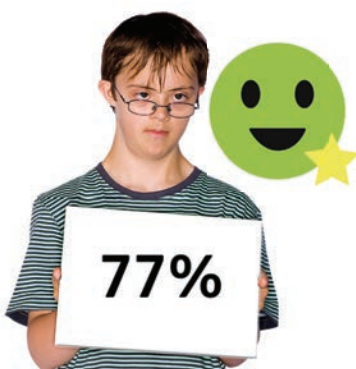
● quite well



● ok

● not very well

● not at all well



77% said they were looked after **very well**.



More children and young people aged 12 to 15 year olds said **very well** than 8 to 11 year olds.



More girls than boys said **very well**.



More white children and young people said **very well**.



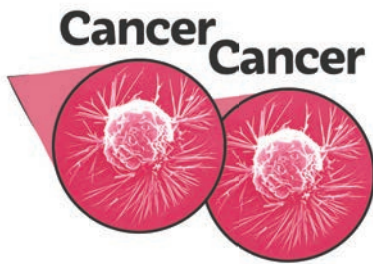
Less children and young people from mixed ethnic or black backgrounds said **very well**.



Children and young people from the least deprived areas were less likely to report being looked after **very well**.



More children and young people without long term conditions said they were looked after **very well**.



When we looked at children and young people with different types of cancer we found:



A **lymphoma** is cancer of the part of the body that fights off germs.

We say it like this **lim-fo-ma**.

Children and young people with **lymphomas** were more likely to say they were looked after **very well**.

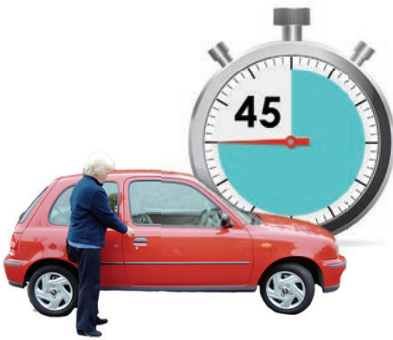


Children and young people with bone tumours were less likely to say they were looked after **very well**.



Extra things people said about their overall care experience

54% of parents, carers and children said that hospitals who give cancer care work well together.



47% of all parents and carers said they had to travel less than 1 hour 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:



32% of parents and carers went straight to hospital instead of going to the doctor first.



63% of parents and carers who went to their local doctors first, said they saw the doctor 1 or 2 times.



More parents and carers of children under age 7 saw their local doctor 5 times or more.



80% thought that their child was seen by a hospital doctor at the right time.



10% of parents and carers thought their child should have been seen a lot sooner.



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

74% said that staff were kind and caring when they were told about the cancer or tumour.



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



75% said they were able to find information about their child's cancer or tumour.



84% of parents, carers and children said they felt able to ask questions after they were told their child had cancer or a tumour.



95% of children said they were told by staff who to go to if they wanted more information.

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:



57% felt that the staff caring for their child knew about their **medical history**.

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



78% said that written information was clear about what treatment their child would get.



63% said they got the help they needed from the hospital 7 days a week.



57% felt they got enough support after their child's treatment had finished.



68% of parents, carers and children said they were definitely involved in the child's care and treatment.



11% of children aged 8 to 11 felt they were not included at all.



75% felt that staff gave them enough time to make decisions about their child's treatment.



More parents and carers of children aged 12 to 15 said their child's schooling had been affected by being 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 or carers and children about the time they spent in hospital.



76% of parents, carers and children said the child was always able to get help from the staff at the hospital, when they needed it.



43% of parents, carers and children said there were enough things for children to do when they were in hospital.



There were more things to do for children aged 0 to 7 than for children and young people aged 8 to 15.



90% of parents and carers said their child was offered support from a **play specialist**.

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



34% of parents, carers and children thought the **WiFi** was good enough.

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



52% of parents and carers thought there was a good choice of food in hospital.



36% of parents and carers said they could make their own meals in the hospital.



28% of parents, carers and children said it was 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.



97% thought the nurses were friendly.



87% thought the nurses were easy to understand.

6. Healthcare staff



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



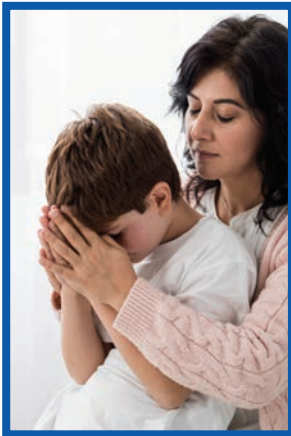
84% said they always trusted staff and thought staff knew what they were doing.



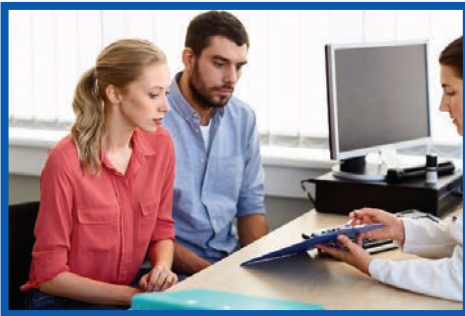
88% said they felt that staff always treated them and their child fairly and with respect.



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.



76% said staff were good at this and did not tell them upsetting things when their child was in the room.



86% 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.



Here are some things children and young people said:

72% said they could always understand what staff said.



More children and young people aged 12 to 15 said they could understand what staff said than children aged 8 to 11 years.



A small number of children and young people said they didn't understand staff.



75% felt that staff always talked straight to them and not just to their parents or carer.

82% said staff spoke to them in the best way for them.



We asked children and young people if they were given information about talking to other children with cancer.



More children and young people aged 12 to 15 said staff had given them information on how to chat to other children with cancer.



Here are some things parents and carers told us about communication with staff:



80% felt that staff always share information with children in the best way for them.



Parents and carers of children aged 12 to 15 scored the highest on this.

Those who care for children under age 7 scored the lowest.



62% of parents, carers and children said they were not told different things by different members of staff.



Most parents and carers said they were given information on cancer charities that give support.



More information

Thank you for reading our report.



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



If you have any questions or want to talk to us about this report, you can:

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