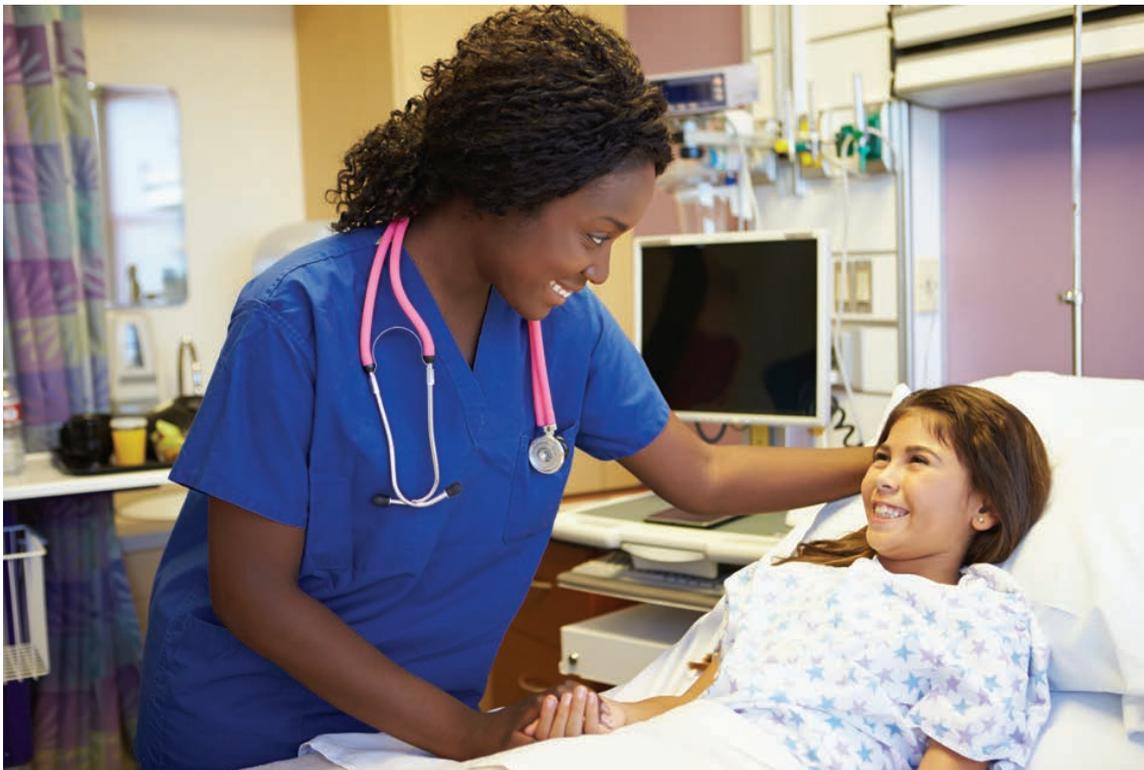


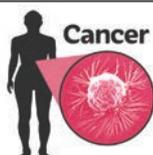


Under 16 Cancer Patient Experience Survey 2024 Qualitative report

Things children and young people told us about their cancer care. What works well and what things could be better



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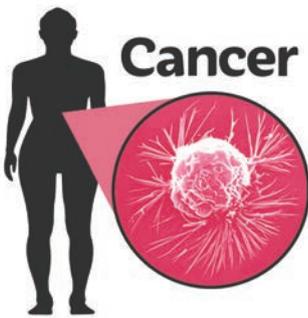


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About cancer



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



Sometimes cells can change. They 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**.



It is important that people get the treatment they need quickly.



Cancer services support people who have cancer or a tumour.

About our survey



We send out a survey about cancer services every year.



We ask children and young people and their parents and carers to fill it in.



Services can use the answers to give better care and support to patients.



This report tells you about some of the things people told us.

Staff



A lot of people said they were happy with their child's care.



A lot of people were happy with healthcare staff.



They wanted to say thank you to the staff who cared for them.



A lot of people said staff were kind, caring and helpful.



Some parents and carers said that doctors and nurses were good at their jobs.



Some people said that staff are too busy. And there are not enough staff. This is mainly at night or at the weekend.



Some people said that some staff were not kind and caring. They said staff could be rude or bossy.



Some people said staff in other parts of the hospital needed more training about cancer.



People said it is important to see the same member of staff at each appointment.



People said it is really important that staff:

- Listen to them.



- Understand their worries.



- Make sure they feel involved in decisions about their care.

Getting and sharing information

Getting information



When people have cancer, they are given a lot of information by healthcare staff.

It is important that people get the right information at the right time.



People said staff explained things clearly.



They said they had time to talk to staff and ask questions.



But these things did not always happen.



Some parents and carers said they were not happy with the way staff shared information.



They wanted more privacy. This means talking in a quiet place with no other people close by.



Some people said they were told different things by different healthcare staff.

Sharing information



People said that staff and hospitals need to be better at sharing information.



People said staff from different services or hospitals did not have the right information about patients.



Medical records were not always shared.

Medical records are things that doctors and nurses write down about people's health.



Support after being in hospital

Some people said they could not contact healthcare staff when their child came home from hospital.



They could not get through to staff on the phone. Or they could only call at some times of the day.



People said there should be different ways to contact staff.

Being kept up to date



Some parents and carers said they were not always told what was happening with their child's health and treatment.



Some people said they had to ask staff for the information.

Getting care and treatment

Getting a diagnosis and starting treatment



A **diagnosis** is when a doctor does some tests and says you have cancer.



Finding cancer quickly can make it easier to get the right care and treatment.



Some people got a diagnosis quickly.



Other people had to wait a long time.



People said long wait times caused them to feel stressed and upset.

Waiting times

People said they had to wait a long time for things like:



- Having scans and getting test results.



- Getting a bed in a hospital ward.



- Getting treatment or having an operation.



- Being sent home from hospital.



Some people said they had to wait a long time at the hospital to get their child's medicine.



Sometimes you are not allowed to eat before an operation or a scan.



Some people said their child had to wait a long time for their scan or operation.



This meant they couldn't eat any food for a long time.

Getting to the hospital or the doctors



Some people said they wanted to travel less to get their care and treatment



A few people said they wanted to know more about parking at the hospital.

Thinking about people's needs

Mental health

Mental health is things like your thoughts, feelings and how you cope in everyday life.



Having cancer can affect your mental health. It can cause you to feel very worried or sad.



People said they wanted more support for their mental health.



They wanted support for their family's mental health too.

Accident and emergency



Accident and Emergency is called **A and E** for short. It is an important part of a hospital.



You go to A and E if you are very ill or had an accident.



A and E can be very busy. You might have to wait a long time to see a doctor.



Some parents were worried about their child needing to go to A and E.



They did not want their child to catch an illness from other people in the waiting area.

Hospital food



A few children said they liked the hospital food.



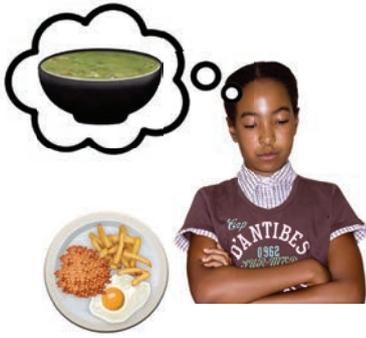
But lots of children and young people said it was not very good.



They said there was not a lot of choice.



Some people have problems eating after cancer treatment.



A few people said the hospital food was not good for people who can only eat some foods.



Parents and carers wanted shops and cafes in the hospital to be open longer. And to be open at the weekend.



They wanted somewhere to make their own food. Things like a microwave, fridge or toaster.

Things to do in hospital



Some people said there was enough things for children to do in hospital.



They said there were play areas, staff to play with and other children to talk to.



But some older children said there was not as much for them to do.



People also wanted more things to do at the weekend and at times like Christmas.

Using the internet

The **internet** is something on a computer, phone or tablet.



You can use the internet to do things like:

- Play games.



- Watch TV programmes.



- Contact your friends and family.



To get on the internet, you use something called **WiFi**.





People said it is important for hospitals to have good WiFi.

Hospital school

Children with cancer can miss a lot of school. This might be because they have to go to appointments or stay in hospital.



Some hospitals have a school in them. Children can learn in a classroom or on the ward.



People liked hospital school.



A few people said they wanted hospital school to happen at weekends too.

Staying in hospital



A lot of people said hospitals are very noisy.



And the lights are very bright too.



People said these things made it hard for them to sleep.



Lots of people wanted their own room.



Older children did not want to be on the same ward as younger children.



People said the beds and chairs were not very comfortable.



Some people said hospitals were really clean.



But other people said places like the bathrooms were dirty.

Other things people told us:



Bathrooms and toilets need to be bigger and meet people's needs.



There needs to be outdoor spaces for people to get outside and get fresh air.



Hospitals need better signs with brighter colours and words that sound less scary.



There should be somewhere for parents and carers to wash clothes.



TVs and game consoles should be looked after. If they are broken they should be fixed.

What will happen now



The survey showed lots of good things are happening in cancer care.



But we know there is more work to be done.



Listening to more cancer patients will help us to understand what matters most to people.



And help us to understand how to help people in the best way.

More information



This is the easy read 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 you want to talk to us about this report, you can:



Email us

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