National Cancer Patient Experience Survey 2021

Qualitative deep dive report

Looking in detail at what people told us

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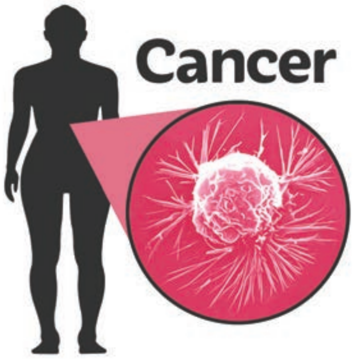


Cancer is a disease people can get. It is very serious.

Every year, we find out what cancer patients think about their care and treatment.

We send out a survey. The people who answer the questions have used cancer services.

In 2021, we asked people lots of different questions about their care and treatment.


easy read

NHS England

National Cancer Patient Experience Survey 2021

We wrote a big easy read report about what we found out. You can look at our big report here:

www.ncpes.co.uk/wp-content/uploads/2022/07/CPES21_Easy-Read-National-Report_040722_FINAL.pdf

About this qualitative deep dive report

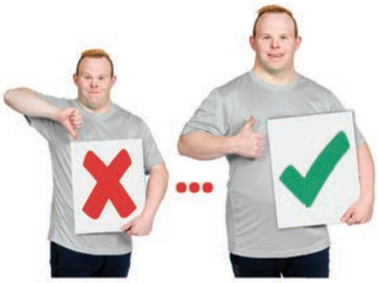
In 2021, lots of people said they were very happy and grateful for their cancer care and treatment.

But some people said they were less happy.

We looked in more detail at answers from people from different groups. This is a called a **deep dive**.

A **deep dive** can help us to better understand people's experiences of cancer care.

It can help us understand why some groups have had a different experience to others.



1 question in the 2021 survey asked people if there was anything that could be better with their care and treatment.

We looked at the answers from 5 groups of people.

easy read

NHS England

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Lots of the answers said the same things as the big report.

This report tells you about the things people from the 5 groups said that were different.

Group 1: People from deprived areas

A **deprived** area is an area where there are more people who may:

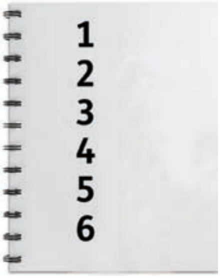
- have poorer health or a disability

- have a low income or may not have a job

- have had a poorer education

- live in poorer housing

- see more crime



People from this group told us **6 main areas** we need to work on:

Group 1: People from deprived areas

1. Transport

Transport is things like taxis, buses and cars.

Patients in this group had lots of different problems with transport.

Some people said that transport to get to appointments was tiring and too expensive.

Some people said they had to travel a long way to get to appointments.

Some people thought the hospital should arrange transport for patients.

Group 1: People from deprived areas

A few people said they:

- had a long wait for hospital transport after care or treatment

- didn't get the right information about appointment times. This affected their transport

- had to ask family and friends for lifts to and from health appointments

Group 1: People from deprived areas

2. Help with money

Some patients told us they did not get support with money quick enough.

Some patients said they didn't get any help with money at all.

Some patients said they need better information, advice and support around money.

A few people said that staff in hospitals did not always give good support around money.

Staff need to be clear about what support people can get. For example, free hospital parking and help with benefits.

Group 1: People from deprived areas

3. Support with mental health

Having cancer and going through treatment can have a big affect on your mental health.

Patients in this group said they need better information about mental health services. Things like:

- where to go for help

and

- what different services can do to help

Some patients said they should be offered support at different times of their care and treatment.

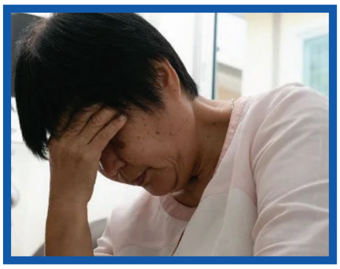
4. Support from Macmillan Cancer Support

Macmillan Cancer Support is a charity that supports cancer patients. People often call it **Macmillan** for short.

Some patients told us Macmillan did not always give them the help and support they needed.

People told us Macmillan needs to do better with things like:

- answering people's calls and emails



- mental health support

- support with money

5. Telling people bad news

Patients said that staff didn't always tell people they had cancer in the best way.

Some people said staff need to be kind. They should tell patients they have cancer in a way that meets their needs.

6. Quality of care

Some people felt they did not get the care they thought they should have.

Some people felt staff need to take more care with patients.

They said staff need to be kind and gentle when looking after people.

Staff should check patients often to try to stop them from getting infections.

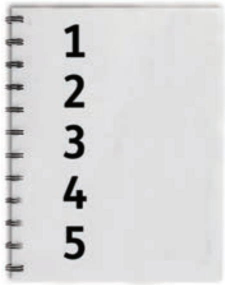
Group 2: People from ethnic minority groups

This big group is made up of 4 smaller groups:

- black

- Asian
- mixed ethnic group

- other ethnic groups



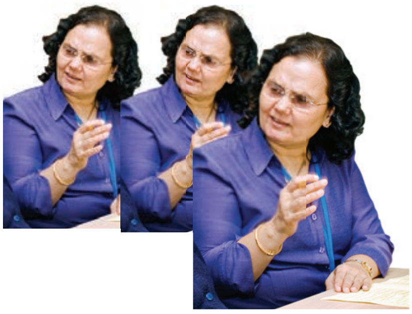
People from the big group told us **5 main areas** we need to work on:

1. Interpreters

An **interpreter** listens to what someone says and then says the words again in a different language.

You might need an interpreter at an appointment if you do not speak English.

Group 2: People from ethnic minority groups



People in Asian, mixed ethnic and other ethnic groups said there needs to be more **interpreters**.

A few people said written information was not in a language they could understand.

2. Communication with family

A few Asian patients told us there needs to be better communication with families.

A few people said their families were not always kept up to date about the patient's care.

For example with test results and when the person had to stay in hospital.

Group 2: People from ethnic minority groups

3. Administration

Administration means things like making appointments, sending letters or reminders.

Some people from black and mixed ethnic groups said:

- there were problems with letters from the hospital

- it could take a long time to get a letter about an appointment

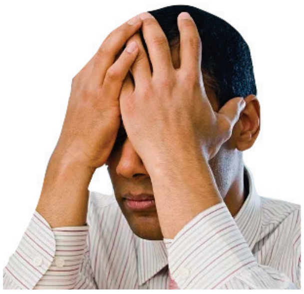
- letters were sent with the wrong information on

Group 2: People from ethnic minority groups

4. Help with money

People from black and mixed ethnic groups said they need clear information on how to get support with money.

People said that having cancer can be expensive. For example paying for transport and parking costs.



This is really stressful when you are already poorly.

5. Bad experiences

2 black patients felt they had been treated unfairly because of their ethnic minority group:

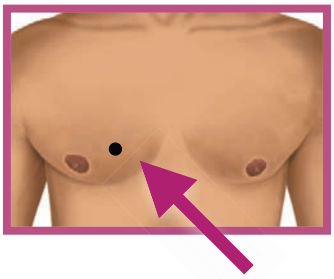
Group 2: People from ethnic minority groups

- 1 was an African patient who felt they were not treated fairly by an African doctor.

This person felt they were treated better by doctors from other ethnic minority groups.

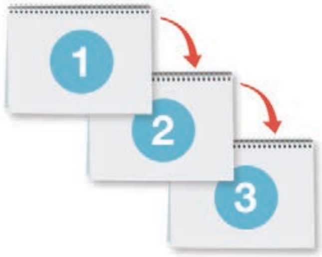
- 1 black patient said they were not given the right colour tattoo for their skin colour.

Sometimes patients are given a tattoo for a short time by the hospital.



The tattoo marks where the treatment will be given.

Group 3: People with a mental health condition



People from this group told us **3 main areas** we need to work on:

1. Administration

Administration means things like making appointments, sending letters or reminders.

Some patients in this group said there were problems with:

- waiting a long time for letters

- getting appointment times mixed up

- appointments being changed or cancelled

Group 3: People with a mental health condition

- the wrong information being sent out

- too many text messages

2. Telling people bad news

Some people said that staff need to be more caring when they talk to patients about cancer.

Some people said they wanted to have a private space and be told bad news face to face.

Some people said they wanted plenty of time for news to think things through and to ask questions.

Group 3: People with a mental health condition

3. Support with mental health

People said it should be easier to get support from mental health services.

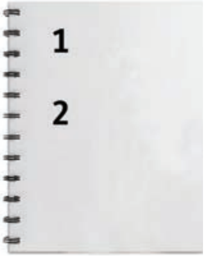
Some people said they were not offered any mental health support at all.

Other people said waiting times for mental health services were too long.

Some people said they need more support after their cancer treatment has finished. For example, support going back to work.

Group 4: People with a learning disability

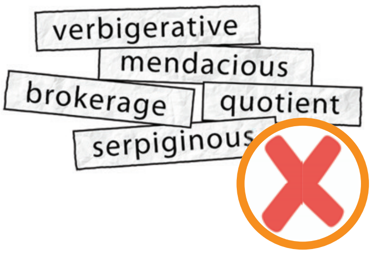
There were only a few people in this group.



People in this group told us **2 main areas** we need to work on:

1. Telling people bad news

People said staff need to be understanding when telling people they have cancer.



Staff need to think about the words they use.

Some people said that staff need to be more caring when they talk to patients about cancer.

Group 4: People with a learning disability

2. Reasonable adjustments

Reasonable adjustments means changing the way we do things to meet people's needs.

Things like giving information in easy read, or having a quiet room for people to wait in.

The law says hospitals must make reasonable adjustments so everyone can use their service.

Patients with a learning disability said they weren't given the reasonable adjustments they need.

People said staff need training on how to support patients with a learning disability and autism.

Group 4: People with a learning disability

Some people felt they were treated differently because of their learning disability.

Everyone is different and needs to have their needs met in different ways.

Staff should try to understand and meet people’s needs.

Lots of people said that staff need to communicate with people in the way that is best for them.

Things like:

- having more time to talk

- face to face appointments

- putting information in easy read

Group 5: People aged 16 to 44

Less people in this group were happy with their care overall.

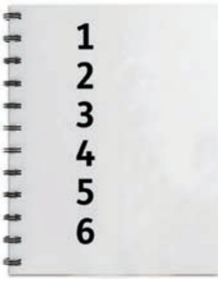
This group was split into 2 groups:

- 16 to 24

and

- 25 to 44

There were not many people in the 16 to 24 group. Most of the answers were from the 25 to 44 group.



People from this group told us **6 main areas** we need to work on:

Group 5: People aged 16 to 44

1. Being involved in decisions

Some people aged 25 to 44 felt they should be more involved in making decisions about their treatment.

Some people also felt they should be told about different treatments they could have. Things like:

- looking at your diet. This is the things you eat and drink

or

- other things you could try as well as the hospital treatments. Things like yoga or breathing exercises

Group 5: People aged 16 to 44

2. Menopause

The **menopause** is when a female body goes through a change. Things that happen at this time include:

- feeling really tired

- finding it hard to remember things

- feeling really hot

At the end of this change, you don't have periods any more.

A **period** is when you bleed from your vagina every month.

Group 5: People aged 16 to 44

Sometimes having cancer treatment can cause the menopause.

You might need treatment to make you go through the menopause early. This could be to stop your cancer from coming back.

Women who had the early menopause said they needed extra support and information.

3. Help with money

People aged 25 to 44 said they needed more information about help with money.

Group 5: People aged 16 to 44

clinical nurse specialist

4. Support from a clinical nurse specialist

A **clinical nurse specialist** is someone who has lots of training and supports patients.

Some people said they did not have enough contact with their clinical nurse specialist. It was not easy to get in touch with them.

breast cancer nurse

People with breast cancer have a **breast cancer nurse** for their clinical nurse specialist.

Some people found it hard to get in touch with their breast cancer nurses.

Group 5: People aged 16 to 44

Other people said they did not meet with their breast cancer nurse often enough.

5. Administration

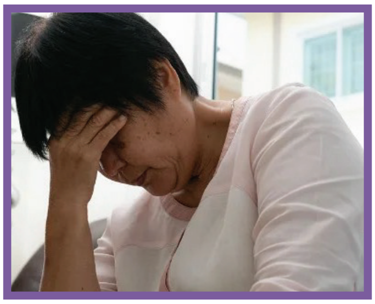
Lots of people aged 25 to 44 said letters about appointments need to be better. For example:

- letters should be sent on time

- information should be correct

- using different ways to communicate with patients

Group 5: People aged 16 to 44



6. Support with mental health

Lots of people said there needs to be more understanding and support for people with mental health problems.

Some people felt that they didn't get the right support and information.

What next

There are 4 areas that stood out for lots of the groups:

- **administration**. This means things like making appointments, sending letters or reminders

- support with mental health

- help with money

- telling people bad news

This report tells us what people said about these areas.

It does not tell us why these areas affect some people more than others.

Listening to people in the 5 groups will help us to find out more about what matters to them.

We can use what people tell us to make changes to our services.

The changes will help us make sure cancer services are the best they can be for everyone.