



NIPT: A new test for pregnant women

What the government and other people need to think about



Who are we?

NUFFIELD
COUNCIL ON
BIOETHICS

We are called the
Nuffield Council on Bioethics.



We give the government and other people advice about important things.

What is this report about?



There is a test that pregnant women can have called **NIPT**.

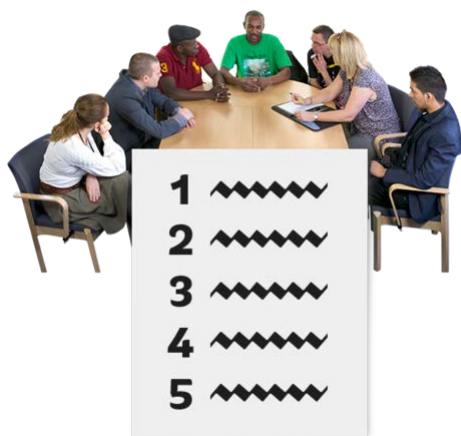
NIPT is short for non-invasive prenatal testing.

It is quite a new test.

The test can find out things about a baby before it is born.



From 2018, the NHS will start giving some women an NIPT test if they want one.



People asked us to look at the NIPT test to think about:

- how it can help
- what problems there may be
- what the government and other people need to think about



We asked lots of people what they thought about this.

This report tells you what we found out.

Some things in this report might be hard to think about.

What are NIPT tests?



NIPT tests are like blood tests.

Some blood is taken from a woman's arm when she is pregnant.



NIPT tests can show if the baby **might be** born with some conditions or disabilities.

Like Down's syndrome, Edwards' syndrome or Patau's syndrome.



The woman will sometimes need another test after this to be sure.



NIPT tests can also tell if a baby **will be** born with some conditions like cystic fibrosis.

NIPT tests can also show if the baby will be a girl or a boy.

How NIPT tests can help

We found out that:



- NIPT tests can help people decide what is right for them.

For example, they can help people decide early on whether or not to have the baby.



- Sometimes NIPT tests can give people an answer sooner than other tests.



- The NIPT test means that less women will need another test afterwards.

The other test can show for sure if the baby **will be born** with a condition or disability.



But the other test can sometimes be unsafe for the baby.

There is a small chance that the baby could die.

And the other test can be painful for women.



The NIPT test means that less women will need the other test.

Some problems with NIPT tests

We found out that:



- People might not get the right information or support from healthcare staff, like doctors and nurses.

For example, healthcare staff might only tell them bad things about having a disabled child.



People might find it hard to make the right choices because of this.



- People might not know enough about NIPT tests and what might happen.

They might think that the NIPT test is better than it is.



- NIPT tests do not give people an answer they can trust for all health conditions.

This can make people worried.

They might want another test to be sure. The other test is less safe.



- People might use the NIPT test to choose whether to have a girl or boy.



- NIPT tests might make life harder for disabled people and their families.

For example, more people might think that it is bad to have a disabled child.



- In the future, NIPT tests could find out more about a baby before it is born.

For example, conditions that are not very serious, or the colour of its eyes.

This might cause problems or be unfair for the baby.

What we think should happen



People should have an NIPT test if they want one.

But only to check if their baby might be born with a serious health condition or disability.



But we think some important things should happen:

1. Disabled people should be treated fairly and have a good life

Disabled people are just as important as everyone else.

The government should:

- help people know this
- make sure disabled people get everything they need to have a good life





This might help people feel less worried about having a disabled child.

2. People who have NIPT tests should get very good information and support

People who have NIPT tests should get all the information and support they need.

This could be:

- information about NIPT tests and whether they can trust the results
- information about disabled people and their lives
- support for people if they are not sure what to do



This will help people choose what is right for them.





Doctors and nurses should have the right training to support people.



There should be rules for doctors and nurses to follow about NIPT tests.

This will help them know what to do.



3. NIPT tests should only be used if people can trust the answer

At the moment only some types of NIPT tests give people an answer they can trust.

4. NIPT tests in the future



We think that NIPT tests should not be used to find out some things about a baby before it is born.

For example, NIPT tests should not be used to find out:

- health conditions that are not serious
- health conditions that will not start until the person is an adult
- if the baby will be a boy or a girl
- what colour eyes the baby will have or how clever it might be



We think this might cause problems and be unfair for the baby.