

New pregnancy testing technique needs limits says ethics body

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Pregnancy test. Credit: public domain

A new report on non-invasive prenatal testing (NIPT) by the UK's Nuffield Council on Bioethics expresses concerns about the way the test is being sold by private providers. In addition, the Council calls for better information and support; calls for a moratorium on the use of NIPT in sequencing the whole genome of fetuses; and calls for a ban on its use in finding out the sex of the fetus.

NIPT is a major breakthrough in prenatal screening and testing for a range of genetic conditions. It uses a blood sample taken from the pregnant woman and can be done from 9 or 10 weeks of pregnancy. It

analyses DNA from the placenta that circulates in the woman's blood to estimate the chance that the fetus has Down's, Edwards' or Patau's syndromes. It can also be used to diagnose other genetic conditions, such as cystic fibrosis and achondroplasia; or to determine the sex of the fetus.

The test is currently available in the UK through private hospitals and clinics, and in some NHS hospitals. Last year, the UK Government announced that from 2018, the NHS will offer NIPT to pregnant women who have been found through initial screening to have at least a 1 in 150 likelihood of having a fetus with Down's, Patau's or Edwards' syndromes. Its introduction should mean fewer false results and fewer diagnostic tests, which carry a small risk of miscarriage. The use of NIPT for testing for Down's syndrome attracted considerable media attention last year.

The Council considered, at this early stage of its use, how NIPT could change the way we view pregnancy, disability and difference, and what the wider consequences of its increasing use might be.

The report recommends that NIPT should only be used for significant medical conditions and impairments that affect the child at birth or in early life as this information can allow women and couples to make meaningful reproductive choices.

The Council says it should not normally be used for less significant medical conditions and impairments, for those that appear in later life, or for non-medical traits (such as sex). Information on all of these kinds of genetic features, and more, could be obtained if NIPT was used to sequence the whole genome of the fetus. The Council therefore calls for a moratorium in the use of NIPT for whole genome sequencing and a ban on its use in finding out the sex of the fetus.

The key reasons for these restrictions are:

- The current uncertainty about the significance of many genetic changes
- The lack of medical benefit to knowing about many genetic changes
- The risk the mother may have a termination, or become unduly anxious, because of this early information
- The right of a future child to find out their own genome for themselves

Professor Tom Shakespeare, Chair of the Nuffield Council's Working Group on NIPT and Professor of Disability Research at the University of East Anglia said: "We support the introduction of this test for Down's syndrome on the NHS next year, so long as it is accompanied by good balanced information and support. But, if the test is used without limits for other kinds of genetic conditions and traits, it could lead to more anxiety, more invasive [diagnostic tests](#), and could change what we think of as a 'healthy' or 'normal' baby. We therefore think the test should generally be used only for significant [medical conditions](#) that would affect a baby at birth or in childhood."

He added: "That's why we are calling for a moratorium on its use in sequencing the whole genome of the fetus. We also strongly believe there should be a ban on its use to find out the sex of the [fetus](#), as this could lead to sex-selective abortions."

In considering the question of attitudes to disability, he said: "If women and couples are to make a truly free decision, they have to be confident that they will be supported equally in whatever choice they make, and if they do go ahead and have a disabled child, that society will support them and their family in future."

Dr Louise Bryant, member of the Council's Working Group on NIPT and Associate Professor in Medical Psychology at the University of Leeds, said: "Although we heard of examples of good practice, the information currently provided to women and couples by the private sector is frequently incomplete, unsubstantiated, inaccurate or misleading, and sometimes uses emotive language."

She cautioned that women and couples need to understand the limitations as well as the benefits of NIPT, especially when used to test for conditions other than Down's syndrome: "We are concerned that some private providers may give out information that emphasises the accuracy of the test but does not make clear its limitations. We are concerned that some women are not being supported well enough to make informed decisions, and that some private services may be failing to provide adequate aftercare for those with positive NIPT results.

"Parents should also be provided with an up-to-date picture of what life is like for people with the condition. The impact of Down's syndrome for example varies from person to person. In some cases it can have minor effects on people's lives, whilst in others the effects are more significant. Women and couples must get balanced information and support to help them make decisions that are right for them".

Provided by Nuffield Council on Bioethics

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