Nuffield Council on Bioethics survey on non-invasive prenatal testing

Introduction

We would like to hear about your experiences and views on non-invasive prenatal testing (NIPT).

We use the term NIPT to mean all kinds of prenatal genetic testing using fetal DNA from the placenta extracted from a sample of the mother's blood. More information about NIPT can be found here.

The survey is part of a project by the Nuffield Council on Bioethics that is considering the ethical issues (i.e. the potential benefits and concerns) raised by the increasing availability and use of NIPT, particularly through NHS antenatal care. The findings and recommendations of the project will be published around the end of 2016. The Nuffield Council is an independent body based in the UK. Find out more about the Council and the project here.

This survey is for anyone with a personal or professional interest in NIPT and is anonymous. A list of all the questions in the survey can be viewed in advance here. It should take around 20-30 minutes to complete in full. However, not all the questions in the survey will be relevant to everyone, so please answer as many or as few questions as you like.

We have also published a longer set of questions in Word format that may be more suitable for people responding on behalf of an organisation. People whose work focuses on the ethical issues raised by NIPT, such as academics working in the field, may also prefer to use this document. Please see: www.nuffieldbioethics.org/views-on-NIPT

If you know someone with learning difficulties who would like to contribute to the Council's project on NIPT, please contact Anna Wilkinson on awilkinson@nuffieldbioethics.org at the Nuffield Council on Bioethics.

Please contact Anna Wilkinson if you have any other questions.

Thank you very much for taking the time to complete the survey and we look forward to reading your responses.

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1. Which statement describes why you are interested in NIPT? Please tick as many as apply

- [ ] I or my partner has had non-invasive prenatal testing
- [ ] I or my partner have recently been or are pregnant
- [ ] I am a healthcare professional involved in offering prenatal testing
- [ ] I carry out research on or relevant to prenatal testing
- [ ] I have another kind of professional interest in prenatal testing
- [ ] I have a genetic condition
- [ ] A member of my family or a close friend has a genetic condition
- [ ] I have a general interest in prenatal testing
- [ ] I don't have a particular interest

Other (please specify) or use this space if you want to tell us more about your interest in NIPT

The UK National Screening Committee has recommended that NIPT for Down Syndrome, Patau Syndrome and Edwards Syndrome be offered on the NHS to pregnant women whose babies are found to have a high risk of having one of these conditions following the 11-14 week screening tests. **Find out more**

2. What benefits or concerns do you think offering NIPT as part of NHS antenatal care might raise for pregnant women and their partners?

3. What do you think might be the implications of offering NIPT as part of NHS antenatal care for the healthcare professionals involved in providing prenatal screening ?

4. Do you have personal or professional experience of the information and/or counselling currently provided by the NHS to pregnant women and their partners to help them make decisions about currently available prenatal screening (e.g. using ultrasound) for genetic conditions during pregnancy?

- ◯ Yes
- ◯ No
- ◯ I don't know

5. If yes, how would you rate that information and/or counselling?

- ◯ Excellent
- ◯ Good
- ◯ Adequate
- ◯ Poor
- ◯ Variable

Please give reasons for your answer or tell us more about your experience of this

6. Do you have personal or professional experience of the NHS providing information and/or counselling about NIPT available as part of research studies or through the private sector?

- ◯ Yes
- ◯ No
- ◯ I don't know

7. If yes, how would you rate that information and/or counselling?

- ◯ Excellent
- ◯ Good
- ◯ Adequate
- ◯ Poor
- ◯ Variable

Please give reasons for your answer or tell us more about your experience of this

8. Do you have personal or professional experience of the information and/or counselling currently provided by private healthcare clinics to pregnant women and their partners to help them make decisions about NIPT?

- Yes
- No
- I don't know

9. If yes, how would you rate that information and/or counselling?

- Excellent
- Good
- Adequate
- Poor
- Variable

Please give reasons for your answer or tell us more about your experience of this

10. Broadly what information about NIPT and the conditions being tested for do you think should be conveyed to pregnant women and their partners?

11. How do you think that information could best be conveyed and by whom?

12. Potential parents can find out the sex of their unborn baby for non-medical reasons from 10 weeks of pregnancy using NIPT. Do you think this should be allowed?

- ◯ Yes
- ◯ No
- ◯ I don't know

Please give reasons for your answer

In the future, NIPT may allow pregnant women and their partners to test their unborn babies for a wider range of genetic conditions, including those that develop in adulthood, from 10 weeks of pregnancy. It may also be possible to find out information relating to the behaviour and characteristics of the future child.

13. Do you think parents should be allowed to find out the following genetic information about their unborn baby using NIPT in future?

	Yes	No	I don't know
Information relating to conditions where all babies die before birth or shortly afterwards and for which there is no treatment	○	○	○
Information relating to serious conditions that will affect the child from early in life, for which there is no effective treatment	○	○	○
Information relating to serious conditions that will affect the child from early in life, for which there is effective treatment	○	○	○
Information relating to serious conditions that will affect the person in adulthood, for which there is no effective treatment	○	○	○
Information relating to serious conditions that will affect the person in adulthood, for which there is effective treatment	○	○	○
Information relating to less serious health conditions, for which there is no effective treatment	○	○	○
Information relating to less serious health conditions, for which there is effective treatment	○	○	○
Information about the physical appearance or characteristics of the future child that is not related to a health condition	○	○	○

Please provide comments or reasons for your answers here if you wish

It is technically possible to use NIPT for 'whole genome sequencing', which reveals the complete DNA make-up of the unborn baby. At the moment this is very difficult and expensive, but it may become cheaper and easier in future.

14. Do you think whole genome sequencing of unborn babies using NIPT should be allowed in future?

- ◯ Yes
- ◯ No
- ◯ I don't know

Please give reasons for your answer

15. What, if anything, might the increasing availability and use of NIPT mean for people living with genetic conditions and disabilities? Please provide examples if possible

16. Please use this space to tell us anything else you would like to raise in relation to NIPT.

17. We may want to quote parts of your anonymous answers in a summary of the survey findings. Are you happy for us to do this?

- ◯ Yes
- ◯ No

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Thank you

Thank you for taking the time to complete this survey.

If you would you like to receive a copy of the findings of the project and be kept informed of future activities relating to the project, you can register for updates about the project here.

We are looking for people to take part in small focus group discussions about the issues covered in this survey. We are particularly looking for women who are or have recently been pregnant and/or their partners. The discussions may be conducted online if this better suits the participants. If you are interested in taking part in a focus group discussion, we would be grateful if you would contact Catherine Joynson at the Nuffield Council on Bioethics: cjoynson@nuffieldbioethics.org