

# Should non-invasive prenatal testing (nipt) be available in ireland?



Non-Invasive Prenatal Testing (NIPT) is a technique that is used to test for different genetic conditions and features with varying levels of certainty. It has advantages over current screening and diagnostic testing methods in that it is more accurate than some other screening tests. Significantly, it carries no risk of miscarriage and can also provide earlier results than other current screening and diagnostic tests. In 2018, NIPT was made available on the NHS in the UK for any pregnant woman who wished to avail of this test. The Nuffield Council on Bioethics produced a report in which it set out guidelines governing the ethical use of NIPT. These guidelines can be set within a framework based on the values of choice, autonomy and consent; avoidance of harm; and equality, fairness and inclusion (Nuffield Council on Bioethics, p. 112). This paper will consider the potential benefits and pitfalls in each of these areas and conclude that it is essential if NIPT is made available in Ireland, that it must adhere to current ethical guidelines.

### Choice, Autonomy and Consent

NIPT as a prenatal test of superior safety and accuracy offers the prospect of enhanced reproductive autonomy to pregnant women and couples. However, the development of and widening access to NIPT might either support or undermine choice in different ways for pregnant women and couples, future people that foetuses might become, disabled people and wider society. NIPT may offer opportunities for better-informed decision making for women, but it also raises issues relating to ‘routinisation’ and informed consent, amongst other issues (Nuffield Council on Bioethics, p. 113).

NIPT has the potential to enhance or facilitate reproductive choice for pregnant women and couples in different ways. If the fetus has a condition being tested for then this can be helpful in informing decisions about different options for clinical interventions during pregnancy and enabling women and couples to prepare psychologically and practically for the birth of a disabled child. It may also inform decisions about termination as NIPT is performed at an earlier stage than other tests. From research it is believed that a termination in the first trimester is less stressful than a termination in the second trimester (Nuffield Council on Bioethics, p. 115). Of course, women and couples might benefit from 'For information only'. In this instance, women and couples are able to find out information about the fetus, which might enhance the experience of pregnancy for prospective parents (Nuffield Council on Bioethics, p114).

However, NIPT has the potential to undermine or threaten reproductive choices of pregnant women and couples particularly in the way it is offered or delivered in different ways. This includes inaccurate or unreliable results. NIPT is not 100% accurate. The quality of information about disability, if it is inaccurate or dated, could lead to a pregnant woman or couple terminating the fetus (Nuffield Council on Bioethics, p. 114).

### Avoidance of Harm

The potential for NIPT to either reduce or give rise to harms in different groups in different contexts is of key importance when appraising the ethical issues connected with NIPT (Nuffield Council on Bioethics, p. 115). NIPT can reduce harms to pregnant women and couples in several ways. These

include: avoiding the risks of invasive testing. There is no risk of miscarriage from taking the NIPT test. The results are more accurate. NIPT can also help to avoid the harms of late terminations (Nuffield Council on Bioethics, p. 115).

However, NIPT has the potential to give rise to harms to pregnant women and couples in several ways particularly in relation to the way in which NIPT is offered or delivered, including: misleading promotional materials. Absence of support and counselling. Failed or inconclusive tests. The psychological impact of terminations (Nuffield Council on Bioethics, p. 116).

NIPT might reduce harms to fetuses as it avoids the risks of invasive testing which can be viewed as posing potential harm to the fetus, as well as to women and couples. NIPT reduces the need for women to undergo invasive testing in order to find out whether or not the fetus has a given condition. It also helps avoid the harms of late termination. Those who take a proportional or gradualist view of the fetus are likely to view earlier terminations as less harmful, and less wrong, than later terminations (Nuffield Council on Bioethics, p. 117).

However, NIPT also has the potential to give rise to the harms of fetuses by an increase in terminations. At the time of compiling this report there was concern about introducing NIPT in NHS prenatal screening for Down's, Edward's and Patau's syndromes as it might lead to an increase in terminations of pregnancies affected by these conditions (Nuffield Council on Bioethics, p. 117). NIPT might also give rise to harms to future people in a number of ways including: Privacy violations. People might be wronged by

others having access to personal information that was obtained about them through NIPT. Negative psychological impact of knowledge of adult onset conditions. Options for education, employment could also be inadvertently affected. NIPT might give rise to harms to people with conditions and impairments: less investment in research and support as NIPT technology advances. There may be less need for research or development of treatments to support such people. There may be a reduction in the population of people with a given genetic condition or disability. This in turn could harm disabled people psychologically and make them feel isolated in society (Nuffield Council on Bioethics, p. 118).

### Equality, Fairness and Inclusion

NIPT has the potential to enhance equality, fairness and inclusion for women and couples in a number of ways including: providing equality for women more generally as NIPT may enhance the ability of women to exercise control over the circumstances of parenthood. Making NIPT available on the NHS for screening or testing for some conditions means that all women can avail of the test if they wish, not just those who can afford to pay for it privately (Nuffield Council on Bioethics, p. 119).

However, NIPT has the potential to undermine equality, fairness and inclusion for disabled people by discrimination and stigma. Society may take a dimmer view on families who choose to have a child with a disability since the option to terminate the fetus is available (Nuffield Council on Bioethics, p. 119).

As mentioned earlier in this paper, NIPT is an accurate prenatal screening test for Down's, Edward's and Patau's syndromes. It can also be used to diagnose other genetic conditions and impairments in the fetus, such as cystic fibrosis and it can also determine the sex of the fetus. What sets NIPT apart from other screening and diagnostic testing methods is the ability to produce whole genome and exome sequencing. This concept is fully endorsed by Julian Savulescu, and one he defends with his principle of Procreative Beneficence, in which he states that, " couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information" (Savulescu, p. 415). Savulescu's argument is that it is not merely enough to test for Down's, Edward's and Patau's syndromes. He believes that we have a moral obligation to test for genetic contribution to non-disease states such as intelligence and to use this information in reproductive decision making (Savulescu, p. 425). A non-disease gene is a gene which causes or predisposes to some physical or psychological state of the person which is not itself a disease state. For example, height, intelligence, character. This is worrying for Michael Parker, who believes that, " while potential parents do have important obligations in relation to the foreseeable lives of their future children, these obligations are not best captured in terms of duty to have a child with the best opportunity of the best life" (Parker, p. 297). In the foreword of the Nuffield report it is acknowledged that, " Genetic knowledge has advantages, but also has great pitfalls. To ensure that we benefit from this knowledge, we need safeguards" (p. vii)

It is clear to see the tensions that exist between the potential benefits of current and possible future uses of NIPT and the risks with which these uses are associated, as well as between the ethical values to which they relate, creates challenges for public policy. Women and couples may experience many benefits from the enhanced reproductive autonomy that NIPT can provide as a prenatal test of superior accuracy and safety that can be performed earlier in pregnancy. However, NIPT could give rise to harms to women and couples, disabled people, future people and wider society, in terms of exacerbating or entrenching inequalities. In conclusion, it is essential for the introduction of NIPT in Ireland in both the private sector and also on the NHS. This will allow for equal access for all women and couples regardless of their ability to pay. However, the availability of NIPT in Ireland should adopt the ethical approach to NIPT as outlined in the Nuffield Report as a starting point.

### Bibliography

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