



Ethical aspects arising from non-invasive fetal diagnosis

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Summary Non-invasive prenatal diagnosis (NIPD) could significantly change the framework for testing and screening in pregnancy. This chapter reviews the ethical implications of this technology, including current issues in prenatal diagnosis, implications for informed consent, possible non-medical uses and options for regulation. The prospect of NIPD normalising screening and termination in pregnancy is raised as a concern. NIPD will also require monitoring to ensure women are making well-informed decisions, given that a risk to the pregnancy is absent. The question of whether NIPD will reduce anxiety needs to be established and the prospect that it will increase terminations on the grounds of disability should be recognised. The offer of NIPD external to any clinical oversight might give rise to wider social sex selection, paternity testing or testing 'for information'. The value assumptions of these uses of NIPD need to be addressed.

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Introduction

Testing or screening for fetal abnormality has fundamentally changed women's experiences of pregnancy. The advent of ultrasound, amniocentesis, chorionic villus sampling (CVS) and maternal serum screening (MSS) have enabled health professionals to offer women several sources of potentially significant information about the health of their fetus. Yet although these technologies do allow women to make informed choices in pregnancy, each is subject to limitations. Ultrasound can only detect physical abnormality, amniocentesis and CVS carry a small risk of pregnancy loss and MSS provides only a probability of harm, which can be difficult to interpret.

In the past decade, the isolation and analysis of free fetal DNA (ffDNA) or whole fetal cells in maternal blood has emerged as another method for testing during pregnancy. These technologies, explained in more detail elsewhere in this special issue, aim to offer non-invasive prenatal diagnosis (NIPD) to provide definitive molecular or chromosomal information about the health of a fetus without posing a risk to the pregnancy.¹ NIPD is now beginning to change the landscape of prenatal testing: tests on ffDNA are already proven for fetal gender, rhesus D blood type and some Mendelian conditions such as achondroplasia. More tests are under development, including aneuploidy detection and Down syndrome.² For the purposes of this chapter, NIPD is assumed to be clinically valid, with a predictive value commensurate to invasive methods.

The impact of NIPD on fetal medicine and pregnant women is predicted to be significant and ethical issues will arise.³ In contemplating the implementation of this technology, we can ask whether aspects of NIPD give rise to new

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ethical questions, or whether we are instead required to revisit existing dilemmas in prenatal diagnosis. NIPD is not the only non-invasive procedure available to women during pregnancy; ultrasound and MSS are also non-invasive. But unlike these existing methods, NIPD can offer definitive information about the health of a fetus at an early stage of pregnancy without putting the pregnancy at risk. Arguably, this gives rise to new nuances in ethical debates over prenatal diagnosis, perhaps most importantly the implications for informed consent. Yet existing issues in prenatal diagnosis will continue to be relevant, and for this reason these debates are briefly rehearsed in the following section.

Ethical issues in prenatal diagnosis

As a source of information about the health of a fetus during pregnancy, NIPD raises ethical issues familiar to anyone with experience of prenatal diagnosis (PND). Several existing issues in PND remain unresolved and, as the molecular bases of more and more conditions affecting health are identified, the dilemma of what constitutes a permissible test remains acute. The development and implementation of NIPD will raise new ethical concerns but these should also be assessed against existing debates over PND.⁴

With any offer of PND to a pregnant woman, there is an implicit value assumption that some inherited or congenital conditions give rise to a lower quality of life for those who have them. At the level of screening, there is an accepted yet unarticulated expectation that the availability of a screening programme will reduce the incidence of the condition of interest in the population, although programmes do emphasise that women should be assisted to make an informed choice. These factors are naturally sensitive and have given rise to myriad debates in the clinical and ethical literature. These debates tend to focus on two interrelated problems: whether PND is eugenic and whether it discriminates against people living with the condition (the 'disability rights critique').

Although an in-depth analysis of these debates is beyond the scope of this chapter, they should not go unnoticed. One concern with PND is whether it exemplifies eugenics—the improvement of the gene pool for the next generation through eradicating genetic disease. Although modern practice in fetal medicine and clinical genetics is nothing like the state-imposed ideals of population perfection that occurred in the early twentieth century, considerations of social justice cannot be ignored.⁵ Likewise, women require access to high-quality and unbiased information on the condition they are being tested for and they must be free to make informed choices about PND, including refusing testing.

A related concern with PND is that it devalues the lives of, or otherwise discriminates against, people living with the condition being tested for. Activists in this debate query the impact of a test on our attitudes to the condition (for example, Down syndrome) and claim that the availability of tests systematically stigmatises these groups, even if no overtly discriminatory statements are made. One response to the disability critique is that women choosing to terminate an affected pregnancy are not discriminating against or stigmatising existing people with the same condition, but that having been given a choice they are

deciding they would rather have a child without the condition. They are also choosing to select against a condition and not against a person.⁶ But as Asch recognises, choosing against a trait is difficult without also choosing against a fetus.⁷

NIPD does give rise to a small but insidious risk that screening in pregnancy and termination of affected fetuses could become normalised. Press coverage of NIPD to date has, however, concentrated on the prevention of miscarriage.⁸ There is little mention that, if offered widely, NIPD could increase the detection of abnormalities in pregnancy, potentially leading to increased terminations. Women should have access to sound and unbiased information and appropriate time to reflect before making a decision about NIPD. We should also ensure it does not lead to a perpetuation of negative conceptions of illness and disease.

Other ethical considerations arising in PND will, by implication, need to be assessed in the context of NIPD:

- In comparison with previous generations, women now experience a so-called medicalised or 'tentative pregnancy', in which they might be unable to bond with their fetus until it is known that 'all is well'. In some cases this can be quite late in the pregnancy.^{9–11}
- Is there a right 'not to know' or a right to remain in ignorance about the health of a fetus during pregnancy?¹²
- Should only 'serious' conditions be subject to PND? Or, should it be up to women and couples to autonomously decide what is 'serious' for them (and which might be 'minor' to others), based on their 'lived experience' of the condition?^{13–16}
- As a matter of professional ethics, deciding what to do when a woman or couple makes a seemingly unjustifiable request for PND.^{17,18}
- Whether and how unexpected information should be passed on to women, particularly in a context of 'targeted testing', where women are informed about only a few conditions before PND takes place.¹⁹

Advantages of NIPD

Despite the ethical issues arising in the provision of PND, NIPD might offer some practical (and therefore ethical) advantages. Primarily, NIPD could reduce the number of miscarriages caused by PND, as amniocentesis and CVS carry a small risk of pregnancy loss. A 'normal' result from NIPD—a test that poses no risk to the pregnancy—could mean that fewer women undergo further invasive testing. However, not all women might be reassured by a normal NIPD result. One North American study examining attitudes to NIPD of fetal cells suggests that nearly half of the women receiving a 'normal' result would still opt for invasive diagnosis, just to be sure.²⁰ In a resource-constrained environment like the National Health Service this is a point to consider—is there value in offering NIPD when it might not prevent women from seeking PND? However, with careful pretest information, this consequence is not a certainty.

Another benefit of NIPD is that as the test can be performed and results reported earlier in pregnancy than for CVS or amniocentesis, anxiety might be reduced. Women will be able to make decisions earlier and will

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