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Why information and choice won't solve all of NIPT's ethical problems

30 August 2016

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Jane Fisher and Lyn Chitty highlight in [BioNews 864](#) that it's been almost nine months since the UK National Screening Committee (NSC) recommended an 'evaluative implementation of NIPT into the NHS's [antenatal screening programme](#) (1) – a recommendation that still awaits ministerial decision. The NSC have recommended the staged implementation of NIPT as a contingent screen. It will be offered as an additional second-line test to women who have already had the currently available screening test and have been found to have a probability of greater than 1 in 150 of giving birth to a child with trisomy 13, 18 or 21.

In the constraints of a publicly funded healthcare system, this step-wise implementation arguably makes ethical as well as scientific sense when compared to a model in which NIPT replaces current screening. It may reduce concerns such as routinisation of screening, the possible loss of moral and temporal 'thinking space' (2), and population harm resulting from overdiagnosis in pregnant women (see [BioNews 797](#)). Further, the oversight of testing by a public health body may mitigate the issue of equity of access to testing while accurately presenting the test's [positive predictive value](#). While data now supports the use of NIPT in women from a range of risk backgrounds, it remains an 'advanced screening test' and is not yet diagnostic (3).

This pragmatic and measured approach to the introduction of NIPT into a publicly funded healthcare setting is laudable, but ethical issues inevitably remain. Two particular aspects of the implementation of NIPT require further deliberation: (i) the ongoing prevalence of information-driven conceptions of reproductive autonomy; and (ii) the need to include a richer and more nuanced account of disability. I'll consider each in turn.

First, the claim we should provide appropriate information to promote autonomy in women considering NIPT is intuitive. Fisher and Chitty, for example, assert that: 'A central tenet of prenatal

testing is to promote reproductive autonomy by providing women with information that can assist in pregnancy management.¹

However, information has a more complex bearing on autonomy than we might initially assume, as Hildt argues in the context of predictive genetic testing (4). Philosophers have played down direct correlations between information and autonomy, or information and consent (5). Providing information alone cannot facilitate reproductive autonomy, and taking a maximisation approach to information and choice could cause harm. Instead of relying on information-driven conceptions of autonomy, facilitating authentic reproductive autonomy is more complex. This involves acknowledging relational aspects (namely that our decisions are influenced by our social context and relationships with others) and encouraging self-reflection to act in accordance with broader life goals. It will be important to build opportunities to undertake such reflection into the roll-out of NIPT.

My second concern relates to conceptions of disability in prenatal testing. There has long been a polarised debate over whether testing in pregnancy properly accounts for disability. This tends to manifest as an impasse between disability advocates and test advocates. Disability advocates voice concerns about the disappearance of the conditions screened for. Test advocates have a tendency to frame disability medically, using terms such as 'suffering' and 'difficulties'.

While one practical way to approach this issue is to ensure any chromosomal condition is framed in a balanced way when discussing screening, this is not sufficient. Academics active in this area emphasise that we should be wary of thinking of disability as one entity or of ignoring its subjective, experiential aspects. We require richer and more complex deliberations on difference, opportunity and belonging. We need to pay attention to language and move away from solely individualised notions of disability to one that also encompasses shared experience and vulnerability.

The implementation and evaluation of a staged rollout of NIPT offers an unprecedented opportunity for quality and in-depth deliberation on concepts such as reproductive autonomy and disability. Stakeholders in NIPT should aim to avoid speaking past each other, particularly given the importance of conversations on whether, how or why it is appropriate to make choices that impact the children we have.

SOURCES & REFERENCES

[1\) The UK NSC recommendation on Fetal anomaly screening in pregnancy](#)

Current UK NSC recommendations | *01 January 2016*

[2\) Scully J, Porz R, Rehmann-Sutter C. 'You don't make genetic test decisions from one day to the next - using time to preserve moral space'](#)

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¹ I acknowledge Dr Lisa Dive and Associate Professor Catherine Mills. Dr Dive's ongoing work on autonomy in bioethics (as part of an MPhil at the University of Sydney) has informed my thinking on this topic. Associate Professor Mills recently convened a roundtable on disability and reproductive choice at Monash University. My role as commentator at this event allowed me the opportunity to assemble the thoughts I have provided in this Commentary.

[3\) Benn P, Chapman AR. 'Ethical and practical challenges in providing noninvasive prenatal testing for chromosome abnormalities: an update'](#)

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[4\) Hildt, E. 'Predictive Genetic Testing, Autonomy and Responsibility for Future Health'](#)

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[5\) O'Neill, O. 'Some limits of informed consent'](#)

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