

BRIEFING: CFDNA SCREENING PROPOSAL

April 2016



BACKGROUND

- The Department of Health are currently deciding on whether to follow a National Screening Committee recommendation that second-line cfDNA screening (NIPT – non-invasive prenatal testing) be implemented into the NHS Fetal Anomaly Screening Programme (FASP). The proposal has been [presented as a measure](#)¹ to reduce a number of miscarriages from those who undergo invasive testing.
- What has not been highlighted is that the [National Institute for Health and Research RAPID evaluation](#)² study projects that the proposed implementation will result in 102 more Down's syndrome fetuses being identified each year and, based on the [current 90%](#)³ of parents with a diagnosis that terminate a pregnancy, this is projected to result in 92 more Down's syndrome fetuses being aborted each year. The same study projects 25 fewer miscarriages per year compared to the current NHS Fetal Anomaly Screening Programme. Therefore, there will be an overall increase in loss of lives.
- Given there were [717 Down Syndrome live births in 2013](#)⁴, this would represent a 13% decrease in live births for Down's syndrome, which is likely having a profound effect on future numbers of people with Down's syndrome in the population.
- A [recent report](#)⁵ from International Bioethics Committee (IBC) of the United Nations Educational, Social, and Cultural Organisation (UNESCO) issues a stern warning about the adoption of NIPT in national screening programmes.
- The proposal also violates the UK's treaty obligations to the UN Convention on the Rights of Persons with Disabilities (CRPD) to make sure that its health policies – including antenatal screening – are informed by and reflective of a 'social model' understanding of disability.
- The [NSC cfDNA review summary](#)⁶ shows an economic analysis of the proposal & lists costs per trisomy detected as an important factor to consider. This is now expected to be £14,472 (previously £14,265).
- Private availability of cfDNA testing has [already been blamed](#)⁷ for a 34% increase in numbers of fetuses aborted with DS and other disabilities in three years.
- National Screening Committee member and RAPID co-author Jane Fisher is also Director of Antenatal Results and Choices (ARC) who have [recently announced](#)⁸ a corporate partnership with Natera, a supplier of the Panorama NIPT screening test. This is an addition to their [existing 'partnerships'](#)⁹ with a number of other NIPT testing providers.
- NIPT techniques will [shortly allow for the testing of the entire human genome](#)¹⁰, and the targeting of fetuses for abortion based on a range of illicitly considered characteristics.
- The future market for testing [could exceed \\$6 billion](#)¹¹ in the US alone.

¹ <http://www.telegraph.co.uk/news/health/news/12100309/Hundreds-of-babies-could-be-saved-after-Downs-Syndrome-blood-test-is-approved-for-NHS.html>

² http://legacy.screening.nhs.uk/policydb_download.php?doc=551

³ http://www.binocar.org/content/annrep2013_FINAL.pdf

⁴ http://www.binocar.org/content/annrep2013_FINAL_nologo.pdf

⁵ <http://unesdoc.unesco.org/images/0023/002332/233258e.pdf>

⁶ http://legacy.screening.nhs.uk/policydb_download.php?doc=545

⁷ <http://www.dailymail.co.uk/news/article-3123078/>

[New-blood-test-blamed-women-choosing-abort-babies-s-syndrome-disabilities-soars-34-three-years.html](http://www.dailymail.co.uk/news/article-3123078/New-blood-test-blamed-women-choosing-abort-babies-s-syndrome-disabilities-soars-34-three-years.html)

⁸ http://www.arc-uk.org/news/193/29/Natera-becomes-ARC-s-latest-partner/d_news-detail

⁹ <http://archive.is/38ajl>

¹⁰ <http://www.dailymail.co.uk/health/article-3258667/Would-baby-screening-test-wipe-genetic-defect.html>

¹¹ <http://www.forbes.com/sites/matthewherper/2014/02/28/>

[the-market-for-dna-sequencing-based-down-syndrome-tests-could-exceed-6-billion/#1ab59a6c4e0e](http://www.forbes.com/sites/matthewherper/2014/02/28/the-market-for-dna-sequencing-based-down-syndrome-tests-could-exceed-6-billion/#1ab59a6c4e0e)

WHAT IS THE DON'T SCREEN US OUT CAMPAIGN ASKING FOR?

That the Government:

1. Delay the implementation of cfDNA (NIPT) screening until the following medical reforms are affected.
2. Take the following steps to ensure that parents with a diagnosis of Down's syndrome are provided with balanced information and support:
 - a. **A full ethical review of the current state funded Fetal Anomaly Screening Programme** – To ensure that the programme is consistent and compliant with the CRPD and wider human rights obligations.
 - b. **Improved training and guidance requirements for medical professionals** – To ensure that doctors, obstetricians, gynaecologists, genetic counsellors, midwives, and anyone else providing care to parents receiving prenatal testing, presume a desire by them to be supported, especially to bear and raise children with disabilities, and are able to both clearly communicate a balanced information on a particular disability and provide subsequent necessary support to them. This would include the updating of materials (including the use of neutral terminology, e.g. 'chance' rather than 'risk' etc.) used to deliver informed consent. This should also include the availability leaflets or other information written by relevant disability groups being made available. Parents should also be offered contact with families with a child with a similar diagnosis without delay. If parents choose to terminate the pregnancy, a third signatory should sign the abortion form confirming that the family has the correct information and support to make an informed decision and can confirm that the abortion meets the criteria under section 1(1)(d).
 - c. **The ready and accessible provision of every needed support for parents continuing their pregnancy** – This would include information about their child's disability and how to care for their child, and the support that is available from the NHS and local/national groups for parents with their child's condition. It would also mean the proper provision of such assistance, and other forms of psychological and group support for parents who experience any longer term challenges and early introduction to people experienced in caring for children with such conditions.
 - d. **The provision of information about adoption services and short-term concurrent foster placement from birth** – Parents should be encouraged and supported to consider adoption for their child as a positive option. This could also include the development of an Adoption Register to ensure swifter matching of babies with disabilities to adoption families.
 - e. **The provision of information about and provision of palliative care for babies with a life limiting disability** – Perinatal hospice care, and an expansion of paediatric palliation as a specialism.