

Scientists call for transparent reporting of pregnancy outcomes following screening for Down's Syndrome

- *Scientists at the University of Aberdeen looked at existing studies to find out which countries provide screening for Down's syndrome during pregnancy using a new non-invasive blood test (NIPT), and how it has impacted pregnancy outcomes.*
- *They found that eight percent of pregnancies flagged as having a high chance of Down's syndrome through the non-invasive test ended up in a live birth.*
- *However, only seven out of the 31 studies included in the wider project provided data on the number of live births after receiving a 'high chance' result from NIPT.*
- *The scientists therefore urge caution in the interpretation of this finding and are calling for more transparent reporting of pregnancy outcomes following screening.*

Scientists who conducted a study revealing that only eight percent of pregnancies identified with a high risk of Down's syndrome through non-invasive prenatal testing (NIPT) ended in a live birth, are advising people to be careful when interpreting these numbers.

The findings were made as part of a wider University of Aberdeen study examining the global implementation of NIPT as a new pregnancy screening test for Down's syndrome.

In Scotland, screening for Down's syndrome during pregnancy has been offered for many decades.

Starting from September 2020, pregnant women identified with a higher chance of having a baby with Down's syndrome through the initial screening are now offered NIPT as a second screening test. NIPT helps determine whether the baby has a high or low chance of having Down's syndrome, and if positive, women are offered an invasive test to confirm the diagnosis.

The Aberdeen study – published in PLOS ONE - tried to understand whether introducing NIPT in other countries has changed the decisions made during pregnancy about getting screened and whether to continue the pregnancy.

[You can read a full overview of the University of Aberdeen project here.](#)

The systematic review of published literature looked at 31 studies published by governments and scientists. These studies covered the use of NIPT screening in 27 countries or autonomous regions where it has been implemented. Some analyses also included information on outcomes after NIPT screening in specific hospitals and health centres.

The team found information from seven studies that showed how many babies with Down's syndrome were liveborn from pregnancies identified as having a high chance of Down's syndrome through NIPT.

When the researchers analysed data from these seven studies, they found that, overall 8% of pregnancies with a high chance of Down's syndrome resulted in a live birth (with a 95% confidence interval of between 3% and 21%).

In a different analysis, of seven other studies, it was discovered that 69% of pregnancies with a high chance of Down's syndrome through NIPT resulted in a termination of pregnancy. The confidence interval for this percentage falls between 52% and 82%.

[You can read the full published paper here.](#)

Yet, the researchers advise careful consideration when looking at these specific figures due to several reasons:

1. The combined analysis for live births and terminations is based on a relatively small sample size – only seven studies out of the 31 included in the main study had this specific information, resulting in the high variability around the reported values.
2. The variations in healthcare systems, resources, and cultural/social norms are immense among different countries. It's challenging to account for all these potential influencing factors when comparing values between countries.
3. There is a lack of data from the time before the implementation of NIPT that can be directly compared.

According to the researchers, the key takeaway from these figures is that this information isn't being documented and shared openly. They believe more efforts are needed to record and report this data transparently before making any definite conclusions in this specific area.

A spokesperson for the study team said: "The introduction of non-invasive prenatal testing (NIPT) is a significant development in care for pregnant women and their unborn babies and it is important that we study its impact widely.

"This review of literature highlights many important implications since the implementation of NIPT – including how many women chose to take this new test and how many go on to have an invasive diagnostic test when NIPT indicates there is a high chance of their baby having Down's syndrome. We know many will be particularly interested in the data regarding live births and terminations involving mothers who received high chance NIPT results for Down's syndrome, and we recognise that these results are incredibly sensitive.

"While important that these figures be examined, we urge caution in their interpretation and appreciation of the fact that only seven of the 31 studies reported data for these measures, resulting in the wide variability in the reported values.

"Something that is abundantly clear from our study is that there needs to be wider and more transparent reporting of these figures at a national level in order to produce enough data to be able to draw meaningful comparisons.

"We recognise the value that people with Down's syndrome have in society, and the information and choices that many parents wish to have when they are expecting a baby with Down's syndrome. However, we do not yet have the full picture of the impact that availability of NIPT is having on the chance of a baby being born with Down's syndrome."

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