

Ref. No: 1644  
Date: 31<sup>st</sup> March 2025  
Subject: Antenatal Communication Regarding Down Syndrome

## REQUEST

I would appreciate copies of the following:

- Letters sent to expectant women advising of screening test results following combined or quadruple screening for Down Syndrome. If the content differs based on the likelihood of a high or low chance result, please provide examples of both.
- Letters or result notifications from Non-Invasive Prenatal Testing (NIPT), including examples for both high and low chance results if they differ.
- Any information shared with expectant women regarding these tests (combined/quadruple screening and NIPT), including letters, leaflets, or signposting materials.
- Any materials provided to expectant women about Down Syndrome itself, including guidance on pregnancy and care following an antenatal diagnosis.

## RESPONSE

### Whiston

- Letters sent to expectant women advising of screening test results following combined or quadruple screening for Down Syndrome. If the content differs based on the likelihood of a high or low chance result, please provide examples of both.

Standardised letters for low chance results are issued to individual women by the screening laboratory at Bolton hospital (see attached

letter). Women who receive higher chance results **do not** get letters but rather are contacted and invited to the hospital for a face to face consultation. At this consultation the higher chance results are explained in detail and women are counselled on further options / tests / support. High chance results are also given verbally on the phone at the woman's request and a face to face consultation is offered after the discussion.

Please see attached

- **Letters or result notifications from Non-Invasive Prenatal Testing (NIPT), including examples for both high and low chance results if they differ.**

Letters for low chance results are issued to women by the screening midwife (see attached letter). Women who receive higher chance results **do not** get letters but rather are contacted and invited to the hospital for a face to face consultation. At this consultation the higher chance results are explained in detail and women are counselled on further options / tests / support. High chance NIPT results are also given verbally on the phone at the woman's request and a face to face consultation is offered after the discussion.

Following a consultation, women are given the 'Your choices after a higher chance screening result' leaflet. This is available on GOV.UK website on the following link:

[Your choices after a higher chance screening result - GOV.UK](#)

Please see attached

- **Any information shared with expectant women regarding these tests (combined/quadruple screening and NIPT), including letters, leaflets, or signposting materials.**

Women are advised prior to booking appointment, to access the 'Screening tests for you and your baby' (STFYAYB) leaflet on GOV.UK website. This information is sent on the booking letter and the leaflet is available to access via the Trust's website. STFYAYB leaflets are available in English and various other languages. If women do not access the leaflet prior to the booking appointment, they can access the leaflet on the day of booking via a QR code provided by the booking midwife. Hard copies of the leaflet are available from the screening team, for women who do not have a phone or access to the internet.

Information about the available screening tests are also discussed in detail at the booking appointment by the midwife. [Antenatal Results and Choices](#)

[\(ARC\) – non-directive information and support before, during and after antenatal screening](#)  
[Screening tests for you and your baby information leaflet-PHE.pdf](#)

- **Any materials provided to expectant women about Down Syndrome itself, including guidance on pregnancy and care following an antenatal diagnosis.**

We do not currently have a patient information leaflet to give to women following diagnosis of Trisomy 21. Women are signposted to ARC and Positive About Down Syndrome [PADS].

Women/couples receive counselling from the fetal medicine team regarding Trisomy 21 and their options are discussed during their appointment including continuing pregnancy and termination of pregnancy for medical reasons. Women/couples are counselled in relation to the increased risk of structural anomalies and cardiac defects. Couples are also informed that a detailed ultrasound/fetal echocardiogram will be performed at 16 and 22 weeks gestation.

We have also arranged for women/couples to meet with a paediatrician (if they wish) as pregnancy advances to discuss what to expect postnatally if they choose to continue with the pregnancy.

[Resources for all - Downs Syndrome Association](#)