

<b>Reference:</b>	FOI.16984.25
<b>Subject:</b>	Antenatal Communication regarding Down Syndrome
<b>Date of Request:</b>	28 March 2025

**Requested:**

I am conducting research into perceptions of Down Syndrome in antenatal care and would like to request copies of communication materials sent to expectant women within your Trust.

Specifically, I would appreciate copies of the following:

1. 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.
2. Letters or result notifications from Non-Invasive Prenatal Testing (NIPT), including examples for both high and low chance results if they differ.
3. Any information shared with expectant women regarding these tests (combined/quadruple screening and NIPT), including letters, leaflets, or signposting materials.
4. Any materials provided to expectant women about Down Syndrome itself, including guidance on pregnancy and care following an antenatal diagnosis.

**Response**

1. Hywel Dda University Health Board (UHB) confirms that if an expectant mother has a lower chance combined screening for Down Syndrome, then a letter is sent to the mother to inform them of the lower chance result. In accordance with the Antenatal Screening Wales policy and standards, expectant mothers are also informed of their lower chance result by their community midwife at their 16-week antenatal visit. This is also documented in their All-Wales handheld notes. The result is also documented on the Wales Patient Administration System (WPAS) in the 'Maternity View' screening section. A paper copy of their results is filed within their handheld notes when they attend their Fetal Anomaly Scan at 20 weeks of pregnancy. A copy of this letter can be found at Attachment 1, page 1.

Furthermore, if the expectant mother has a lower chance quadruple screening for Down Syndrome, then a letter is sent to the mother to inform them of the lower chance result. These results are also documented in their All-Wales handheld notes at their next community midwife appointment as well as on WPAS. A paper copy of their results is filed in their All-Wales handheld notes when they attend the Antenatal Clinic for their Fetal Anomaly Scan at 20 weeks. A copy of this letter can be found at Attachment 1, page 2.

The UHB is unable to provide a copy of a letter informing an expectant mother of a higher chance result following combined or quadruple screening for Down Syndrome, as this information is shared either the same or next working day via telephone call. The mother is asked if they are happy to receive results over the phone at the time when the sample is taken.

The results are explained to the mother by the screening or experienced midwife working in the Antenatal Clinic and options are discussed, which includes making appointments for further screening should the expectant mother desire. Expectant mothers are also offered the

opportunity to attend the Antenatal Clinic in person for further discussion if they wish. Following this, a link to the Antenatal Screening Wales website, where patient information resources can be accessed is emailed from the Antenatal Clinic generic email account to the patient, this can also be signposted during the telephone call. Paper copies of this information is also available should it be preferable to the expectant mother.

A link to the Antenatal Screening Wales website can be found below:

[Information Resources - Public Health Wales](#)

2. The UHB does not hold the information requested as all results are sent to the Antenatal Clinic's generic email address. All expectant mothers have telephone calls to discuss Non-Invasive Prenatal Testing (NIPT) results regardless of the result being higher or lower chance. Consent is obtained for this when the sample is taken. Expectant mothers are also invited into the Antenatal Clinic to further discuss their results and options for invasive testing should they wish, where higher chance results are received. These results are filed in the expectant mothers All-Wales handheld notes when they next attend an appointment in the Antenatal Clinic and are also documented in the screening section on WPAS.
3. Expectant mothers are emailed, signposted to and provided with links and QR codes which direct them to the Antenatal Screening Wales website, where there is detailed patient information on both combined and quadruple screening, along with further information regarding a higher chance result. Paper copies are also available upon request.
4. The UHB provides links to the websites which the service directs expectant mothers to below.

[Antenatal Results and Choices \(ARC\) – non-directive information and support before, during and after antenatal screening](#)

[Positive About Down Syndrome – A website by parents for parents and parents-to-be](#)

Additionally, leaflets are also available on how to access these sites should they be required by the expectant mother.