

Freedom of Information Request	FOI 21-070	15 <sup>th</sup> March 2021
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**I wish to make a Freedom of Information request to ascertain the language/terminology used when screening/ diagnostic results for Down Syndrome are given to expectant parents.**

**When results can be provided verbally and/or written, please provide content of each:**

- Those given in a written format eg. letter/email
- Those given verbally - kindly provide any guidelines, templates or scripts used or referenced.

**Please also indicate if you do not report such results directly, for example if another provider is responsible.**

**If different hospitals/maternity units within your board use different correspondence, please send examples from each unit, identifying the name of each hospital/maternity unit.**

**Please send an example of all the following that are in use;**

- a) **Copies of written materials/information provided to expectant women appertaining to antenatal screening test for Down Syndrome including information about both the tests and Down Syndrome.**
- b) **Templates reporting low chance combined or quadruple screen results**
- c) **Templates reporting high chance combined or quadruple screen results**
- d) **Templates reporting low chance NIPT results**
- e) **Templates reporting high chance NIPT results**
- f) **Templates reporting 'no result' NIPT results**
- g) **Templates reporting negative QF-PCR/FISH CVS results**
- h) **Templates reporting positive QF-PCR/FISH CVS results**
- i) **Templates reporting negative full karyotype CVS results**
- j) **Templates reporting positive full karyotype CVS results**
- k) **Templates reporting negative amniocentesis result**
- l) **Templates reporting positive amniocentesis result**

The Health Board provides screening/diagnostic results for Down syndrome in accordance with Antenatal Screening Wales policy standards and protocols.

Please see link: [Antenatal Screening Wales Policy Standards and Protocols 2019.pdf](#).

Throughout their care pathway expectant mothers are provided with information about screening for Down's syndrome. The Health Board does not use a script or

a template for this as the conversation is led by the individual around their needs and any information provided is determined by this conversation

At first point of contact with the community midwife, expectant mothers are provided with a paper copy of the Antenatal Screening Wales (ASW) booklet. This contains information on Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome in pregnancy [available here [Antenatal Screening Test Leaflet - Public Health Wales \(nhs.wales\)](https://www.nhs.uk/publications/antenatal-screening-test-leaflet-public-health-wales/)]. This booklet is available in Welsh and English.

The information is also available on the ASW website in easy read, British sign language and as an audio booklet. The booklet contains a link to a video which explains the screening pathway. A link to this video and the booklet can be emailed to those who consent for information to be sent to them by email from the community midwives.

The Midwife will discuss the purpose, implications and limitations of screening pathway for Down's syndrome, Edwards' syndrome and Patau's syndrome with the expectant mother. The individual is given time to discuss and consider this information prior to making a personalised and informed choice about whether she wants screening and a record of the discussion is made in the individual's Maternity Record.

Where a family member has Down's syndrome, Edwards' syndrome or Patau's syndrome, which increases the likelihood of occurrence due to familial translocation, the community midwife will discuss and offer a referral to the All Wales Medical Genetics Service which offers parental karyotyping or NIPT.

At the expectant mothers dating appointment, the way in which they wish to receive their antenatal screening results is agreed. Individuals are advised that if they do have a lower possibility then the result will be discussed at their 16 week antenatal appointment; however, if there is a higher possibility of occurrence then the Antenatal Clinic Midwife will telephone them to discuss the results.

All our Midwives who give screening/diagnostic results are trained so that they have the skills and knowledge to discuss these in an appropriate way and throughout the care pathway the individual's decisions are supported and respected.

All individuals are provided with information to access the Antenatal Screening Wales information booklet 'Information for women offered further tests for suspected chromosomal conditions', the Down's Syndrome Association website, the ARC (Antenatal Results and Choices) website and Positive About Down's Syndrome support website.

At face to face meetings, Covid-19 pandemic permitting, the Health Board uses decision aid tools provided by Antenatal Screening Wales. These are pictorial cards to help individuals better understand Down's syndrome and their screening results. At these meetings we also discuss the information contained in the Antenatal Screening Wales information booklet 'Information for women offered further tests for suspected chromosomal conditions'.

When someone is believed to be carrying a Down syndrome child the individuals are provided information and support to help make a decision about their

pregnancy. They are able to discuss the result with the Foetal Medicine Obstetrician and with the Foetal Medicine midwife specialising in antenatal screening. They will also be offered a referral to All Wales Medical Genetics Services.

When screening expectant mothers and where we believe that there is a potential for Down syndrome the expectant parent is referred to Cardiff and Vale University Health Board. Please contact them direct via the following link:  
<https://cavuhb.nhs.wales/contact-us/requests-for-information-freedom-of-information/>