

Ref no: 185160419
From: Public
Date: 16/04/19
Subject: Advising expectant women of ante natal screening/diagnostic results for Down syndrome

REQUEST

I wish to make a FOI request to ascertain the **language/terminology used** when **screening/diagnostic results** for **Down syndrome** are given in a **written format**, eg letter by post, email etc to **expectant parents**.

Please could you send me examples of the contents of such letters/emails used to report results of screening tests. (Please also indicate if you don't report such results in written format, but only verbally).

If different hospitals/maternity units within your Trust use different letters/emails, please send me examples of each units' correspondence identifying name of each hospital/maternity unit.

Please send me an example of all of the following that are in use:

- a) Letter/email reporting low chance combined or quadruple screen results
- b) Letter/email reporting high chance combined or quadruple screen results
- c) Letter/email reporting low chance NIPT results
- d) Letter/email reporting high chance NIPT results
- e) Letter/email reporting 'no result' NIPT results
- f) Letter/email reporting negative QF-PCR/FISH CVS results
- g) Letter/email reporting positive QF-PCR/FISH CVS results

- h) Letter/email reporting negative full karyotype CVS results
- i) Letter/email reporting positive full karyotype CVS results
- j) Letter/email reporting negative amniocentesis result
- k) Letter/email reporting positive amniocentesis result

RESPONSE

- a) A low chance screening result from the combined or the quadruple test is sent out expectant woman’s home address within 10 working days of the blood draw and reads as follows:

Dear

I am pleased to inform you that the result of your recent antenatal screening blood test for the following conditions is:

T21 Down’s syndrome	LOWER CHANCE <input checked="" type="checkbox"/>	DECLINED	<input type="checkbox"/>
Edwards & Patau	LOWER CHANCE <input checked="" type="checkbox"/>	DECLINED	<input type="checkbox"/>
Too Late			<input type="checkbox"/>

This means you will not be offered any further diagnostic testing i.e. you will not be offered a chorionic villus sampling test or amniocentesis test; as your screening result for the conditions you consented to, have fallen into the lower chance group.

It is important to understand that a lower chance result means exactly that. It does not mean that there is no chance at all that the baby’s chromosomes are affected, just that it is unlikely. There is still a small chance, because some babies with these conditions are not detected by screening tests. (“Screening tests for you and your baby” National Screening Committee 2017).

We look forward to seeing you at your 16 week antenatal appointment when the result of the screening test and all other blood results will be entered into your notes and discussed with you.

Please note if your baby had an increased nuchal translucency measurement on the back of the neck at your dating scan, you must still attend the fetal cardiac scan that has been arranged.

Yours sincerely

- b) A high chance screening result is never sent out in letter format. The expectant woman is contacted by telephone and invited in for a face to face appointment (we will make 3 attempts at a phone call, then contact NOK and if no response request a community Midwife visit, to give out the appointment date and time). If the woman requests to have the result over the telephone, her name, DOB and address is confirmed and the discussion will be had via telephone. A face to face appointment will then be offered at the earliest opportunity to discuss further.
- c) The Trust does not offer the NIPT screening test.
- d) The Trust does not offer the NIPT screening test.
- e) The Trust does not offer the NIPT screening test.
- f) The Trust offers referral to the Liverpool Women's Hospital (or other fetal medicine unit if the Woman desires) for CVS. The expectant woman is given the result by the Trust in which the procedure took place, which is usually via telephone conversation and they will also inform the screening Midwife here at Whiston. Once this information has been received, the screening Midwife will contact the expectant woman by telephone to ensure she understands the result and aware of her pregnancy care plan going forward.
- g) The Trust offers referral to the Liverpool Women's Hospital (or other fetal medicine unit if the Woman desires) for CVS. The expectant woman is given the result by the trust in which the procedure took place, which is usually via telephone conversation and they will also inform the screening Midwife here at Whiston. Once this information has been received, the screening Midwife will contact the woman by telephone to ensure she understands the result and aware of her pregnancy care plan going forward.
- h) The expectant woman is given the full karyotype result by the trust in which the procedure took place, which is usually via telephone conversation and they will also inform the screening Midwife here at Whiston. Once this information has been received, the screening Midwife will contact the expectant woman by telephone to ensure she understands the result and aware of her pregnancy care plan going forward. The responsible Trust usually confirms this result with a written letter to the woman, with the Screening Midwife and Obstetric Consultant copied in.
- i) The circumstances of the full Karyotype result from CVS will differ for each pregnant person. Therefore, I cannot give a definitive pathway for giving these results. However I can confirm that depending on the initial PCR and

the expectant woman's choice of pathway, this full result is given compassionately, usually via telephone or in person.

- j) Following amniocentesis, contact telephone numbers are confirmed and the pregnant person is advised that she will receive a result within a given timeframe. The chance of potential delay is always discussed and the person will be kept updated by the screening Midwife. A phone call is made to the expectant woman and they are offered the opportunity to have the result over the telephone or attend for a face to face appointment. This result is never given out via letter.
- k) As above, an amniocentesis result is never sent out via letter. A phone call is made to the expectant woman and they are offered the opportunity to have the result over the telephone or attend for a face to face appointment. This appointment is given at the earliest opportunity and an ongoing care pathway is discussed and arranged with the expectant woman at this time.