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From: Research
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Subject: Maternity services

REQUEST

I am carrying out research into perceptions around Down Syndrome in antenatal care and would like to make a request for examples of communication sent to expectant women within your Trust.

- Letters sent to expectant women advising of screening tests following combined/quadruple screen testing for Down Syndrome. I understand the letter may be different depending on whether results are low or high chance so please send examples of each.
- Letters/results from Non-Invasive Prenatal Testing (NIPT), again high and low chance examples if different.
- Examples of information eg. letters, leaflets, signposting etc. shared with expectant women about these tests (combined/quadruple screening and NIPT).
- Any information shared with expectant women about Down Syndrome itself (including guidance on pregnancy/care when given an antenatal diagnosis).

RESPONSE

The women are sent a link to access, 'Screening Tests for you and Your Baby booklet' www.gov.uk/phe/screening-leaflets with their booking appointment. These booklets were sent out in the past but they are no longer, due to the drive towards digital technology. This booklet was updated recently due to the evaluative roll out of NIPT (Non Invasive pre-natal Testing).

The women are sent a low chance letter following receipt of their result from Bolton Laboratory. We do not have higher chance letters as we call the women directly within 3 days of receipt of results and offer a telephone consultation or a face to face assessment if preferred.

We will discuss each pathway with the women and signpost the women to the digital version of, 'Down's syndrome Edwards syndrome and Patau's

syndrome options after a higher chance screening result phescreening.blog.gov.uk/leaflets or print a copy off if required.

There is also an easy read guide called, 'Screening for Down's syndrome, Edwards syndrome and Patau's syndrome', also available on phe.screening.blog.gov.uk

If the woman is considering a diagnostic test such as CVS or Amniocentesis, we have leaflets provided by the NHS Fetal Anomaly Screening Programme www.nhs.uk/downs and www.Nhs.uk/sct there is also a print version called, 'Screening in pregnancy: CVS and amniocentesis information for parents. This is available on Phescreening.blog.gov.uk/leaflets

This information includes additional resources such as Antenatal Results and Choices (ARC) DSA (Down's Syndrome Association) and SOFT UK that also provides information and support to families about Edward's syndrome and Patau's syndrome.