

24 February 2021

**Our Ref:** RFI 37604

Dear

**Freedom of Information Act 2000  
Information in relation to ascertaining the language/terminology used when  
screening/diagnostic results for Down syndrome are given expectant  
parents.**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to above which you requested on 3 February 2021.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital ([informationgovernance@setrust.hscni.net](mailto:informationgovernance@setrust.hscni.net)) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

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**Rebecca Manning**  
**Information Governance Assistant**

**Q1. I wish 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:**

- **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.**
- **Templates reporting low chance combined or quadruple screen results.**
- **Templates reporting high chance combined or quadruple screen results.**
- **Templates reporting low chance NIPT results.**
- **Templates reporting high chance NIPT results.**
- **Templates reporting 'no result' NIPT results.**
- **Templates reporting negative QF-PCR/FISH CVS results.**
- **Templates reporting positive QF-PCR/FISH CVS results.**
- **Templates reporting negative full karyotype CVS results.**
- **Templates reporting positive full karyotype CVS results.**
- **Templates reporting negative amniocentesis result.**
- **Templates reporting positive amniocentesis result.**

A1. The Trust follows the current NHS Fetal Anomaly Screening guidance.

The Trust is currently developing a patient information sheet on screening for Down syndrome.

Due to the current Covid – 19 pandemic, the Trust is unable to offer any screening for Down syndrome to expectant women at this time.

The Trust does not report results for Amnio/CVS tests. This role is undertaken by the Belfast Health & Social Care Trust (Belfast Trust) and the information you requested maybe held by the Belfast Trust. Should you wish to pursue this request I suggest you contact the Belfast Trust on [publicliaison@belfasttrust.hscni.net](mailto:publicliaison@belfasttrust.hscni.net).

The Trust does not perform NIPT tests. These tests are completed in the independent healthcare sector.