

Freedom of Information request 53-21

Request

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;

- 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

Response

Please find below information regarding the language/terminology used when screening/diagnostic results for Down Syndrome are given to expectant parents within NHS Borders:

- Borders do not use templates; original results are made available.
- Low chance results are posted out and documented on the electronic record where the patient can access them.
- Increased chance results are telephoned by a Pregnancy Assessment Unit (PAU) midwife. Follow up with a consultant is arranged for further counselling. After the patient has been informed, the result is also documented on the electronic record and the patient is offered a paper copy at their follow up consultant appointment.
- There are no scripts, the information is conveyed by a small team of 4 trained PAU midwives.

- a) Please find attached 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:



V8_You're pregnant!
_Scans and tests_010



V19_Your pregnancy
your choice_NIPT_00



Second trimester
screening - what happens



version 3 CUB
screening-what happens

- b) Please find below templates reporting low chance combined or quadruple screen results:



1st tri low chance
result.pdf



2nd tri low chance
result.pdf



eRecord 1st tri low
chance result.pdf

- c) Templates reporting high chance combined or quadruple screen results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- d) Templates reporting low chance NIPT results



NIPT low chance
result.pdf

- e) Templates reporting high chance NIPT results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- f) Templates reporting 'no result' NIPT results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- g) Templates reporting negative QF-PCR/FISH CVS results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- h) Templates reporting positive QF-PCR/FISH CVS results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- i) Templates reporting negative full karyotype CVS results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- j) Templates reporting positive full karyotype CVS results

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- k) Templates reporting negative amniocentesis result

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

- l) Templates reporting positive amniocentesis result

No templates are held. Therefore under Section 17 of the FOI(S)A 2002 we cannot provide.

The principles around the verbal and non-verbal communication within the NHS Borders fetal medicine team are based on the article below by the Head of the Fetal Medicine department:

<https://pubmed.ncbi.nlm.nih.gov/22875522/>

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **53-21** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.