

Freedom of Information Request

Ref: 21-085

26 February 2021

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting
- **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).**

The letter that is sent for low chance results is a standardised letter that is printed. Please see the attached documents.

We don't send letters for high chance results. We phone all women to offer face to face appointment to discuss high chance result.

We discuss the result and their options. We give them our contact details and ask them to contact us if they would like an invasive/diagnostic procedure. We also ask them if we don't hear from them, that they are happy to be contacted in a couple of weeks for a follow up call. We currently don't send a letter. We realise that when we contact the lady to discuss results and options, it is a lot of information to absorb. We have created a letter that we want to send following the telephone counselling session – this letter will summarise what has been discussed and give links etc for further information. The letter is in the process of being approved for use by the FMU consultants and appropriate working parties/governance meetings. Once the letter has been ratified for use I will send a copy. We send the high chance results to the lady's home address.

NIPT is currently not available on the NHS. When we contact women to discuss their result – we discuss NIPT. We signpost them to ARC (Antenatal Choices and Results) – they discuss local providers/ test results. The clinics who perform the NIPT discuss the results. When women book their pregnancy they are signposted to the ‘ My Pregnancy at St Michael’s ‘ app and advised to read the information regarding first trimester screening. From April 2021 it is proposed that all screening information will be accessed digitally. Midwives will still be able to print off paper versions for those women that don’t have access to digital information / digital information may not be appropriate. FTCS will be discussed further at the booking appointment.

Maternity services are in the process of creating a new letter to be sent when women book for delivery at St Michael’s.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Director of Corporate Governance
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner’s Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust’s Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

**Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust**