



Ref: FOIA Reference 2020/21-521

Date: 4<sup>th</sup> March 2021

Email [foi@uhn.nhs.uk](mailto:foi@uhn.nhs.uk)

Dear

I am writing in response to your email dated 15<sup>th</sup> February 2021 requesting information under the Freedom of Information Act (2000) regarding Down syndrome.

***The University Hospitals of North Midlands Trust is committed to the Freedom of Information Act 2000.***

***However, the NHS is facing unprecedented challenges relating to the coronavirus (COVID-19) pandemic at the current time. Understandably, our resources have been diverted to support our front-line colleagues who are working tremendously hard to provide care for our patients, and to those in need of our services.***

***We strive to be transparent and to work with an open culture. But at this time, whilst care of our patients and the safety of our staff takes precedent, it is likely that responses to some requests for information will be delayed. We apologise for this position in advance, and will endeavour to provide you with as much information as we can, as soon as we are able.***

***The Information Commissioners Office has recognised the current situation in the NHS***

As of 1<sup>st</sup> November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

**Q1 As part of my studies I am researching perceptions around Down syndrome in antenatal care and would like to make a request for examples of communication sent to expectant women. Please can you send me examples of the following?**

**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.**

**A1** Information not held. The results letter goes directly from the laboratory to the patient with low risk results. For high risk results the laboratory send the result to the screening office and the screening team contacts the patient to discuss the results and arrange a consultation to discuss further investigations, no high risk letter is sent. Our electronic maternity notes are updated with the result by the screening team as we receive a copy from the laboratory.

**Q2 Letters/results from Non-Invasive Prenatal Testing (NIPT), again high and low chance examples if different.**

A2 Information not held, NIPT results are taken from the online result source by the screening team and then the patient is contacted by telephone to discuss the result and then the electronic maternity record is updated with the result.

**Q3 Examples of information eg. letters, leaflets, signposting etc. shared with expectant women about these tests (combined/quadruple screening and NIPT).**

A3 At booking the screening tests for you and your baby information booklet are shared with all pregnant people, this is available as a paper copy or digital copy. The main maternity page on the UHNM site has several links with screening information including NIPT, see below. Please note that this is supplied under section 21: *freely available*.

<https://www.uhnm.nhs.uk/our-services/maternity>

**Q4 Any information shared with expectant women about Down Syndrome itself (including guidance on pregnancy/care when given an antenatal diagnosis).**

A4 At booking the screening tests for you and your baby information booklet are shared with all pregnant people, this is available as a paper copy or digital copy. The main maternity page on the UHNM site has links and screening information including NIPT = As answer 3.

If a known diagnosis of downs syndrome then we forward to local and national charity information where appropriate.

<https://www.downs-syndrome.org.uk>

Stoke & Staffordshire Downs Syndrome Social Group

\*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

***UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.***

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

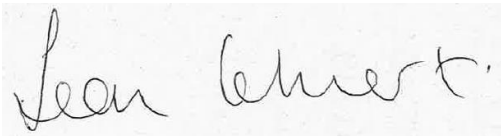
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via [www.ico.org.uk](http://www.ico.org.uk).

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



Jean Lehnert  
**Data, Security & Protection Manager**