



Ref: FOIA Reference 2022/23-564

Date: 13th January 2023

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 5th January 2023 requesting information under the Freedom of Information Act (2000) regarding Bardet-biedle Syndrome

As of 1st 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 Could i please request information relating to the below

If you treat Bardet-biedle Syndrome, how many unique patients have you treated in the last 12 months?

A1 We have <5 patient(s) with this syndrome and they are under the care of our Paediatric Endocrine team the patient(s) is also under the care of Birmingham's Women and Children's Hospital (BWCH) which has a specialised clinic and team for this particular syndrome. We would refer patients here as standard practice. UHNM does not treat adults with this syndrome; University Hospitals Birmingham NHS Foundation Trust may hold this information.

We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

Q2 What % of these patients get a genetic diagnosis prior to them being referred onto specialist centres?

A2 As answer 1

Q3 If you do not treat Bardet-biedle Syndrome, could I request where these patients are referred to?

A3 As answer 1

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

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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.

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

Yours,



University Hospitals
of North Midlands
NHS Trust

Rachel Montinaro
Data Security and Protection Manager - Records

