

Freedom of Information Request

Ref: 23-008

12 January 2023

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

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

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

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

The Trust's coding system only records congenital malformation syndromes and we are unable to break this down. Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

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:

Data Protection Officer
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