

Reference Number: FOI202223/508
From: Private Individual
Date: 05 January 2023
Subject: Treatment of patients with Bardet-biedle Syndrome

Q1 If you treat Bardet-biedle Syndrome, how many unique patients have you treated in the last 12 months?

A1 Information exempted under Section 40: Personal data. Providing this information would likely identify individuals involved.

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

A2 Information exempted under Section 40: Personal data. Providing this information would likely identify individuals involved.

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

A3 Not applicable, as we do treat this syndrome

The Trust is unable to respond to all or specific elements of your request where the response would indicate five or less individuals. The Trust is withholding this information under Section 40 (Personal Information) of the Freedom of Information Act (FOIA) 2000 to reduce the risk of any individuals being identified. The Trust is of the view that disclosure of such information would significantly increase the risk of individuals being identified and as such would constitute a breach of their personal data.

The Trust has applied exemption Section 40(2) of the FOIA and is therefore withholding the information as disclosure which may identify an individual would breach their rights under the Data Protection Act 2018. The grounds for application of this exemption include:

- Any data relating to patients or staff is third party data, furthermore health data is classified as sensitive personal data within the Data Protection Act 2018. As such, Section 40 (2) of the FOIA applies along with the Trusts duty of confidentiality. Therefore under s.2 (3) (f) (ii) of the FOIA, there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle.
- The Trust has a duty under the Data Protection Act 2018 and specifically the First Data Protection Principle to ensure personal data regarding staff and patients is processed fairly and lawfully. Disclosure of such data which may identify an individual, either through the data alone or other data in conjunction with that data which may identify an individual would therefore breach this principle.
- The Data Protection Act 2018 defines sensitive personal data to include data relating to the “physical or mental health or condition” of a person. Any such information about specific individuals falls within this category and disclosure of such data including statistical data,

with any potential likelihood of identification would breach the Data Protection Act 2018.