

## Bardet – Biedl Syndrome

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Reference Number: RDF1184-23

Date of Response: 31/01/2023

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

1. [If you treat Bardet-biedle Syndrome, how many unique patients have you treated in the last 12 months?. Joint Eastern and Northern response.](#)

Eastern Service response - 37 unique patients.

Northern Service response : \*<5 unique patients.

\*<5

In accordance with Section 40 (2) of the Freedom of Information Act 2000, we are unable to provide figures where the number of patients is less than or equal to five and could risk the identification of those patients/staff and breach Caldicott principles.

In these cases ≤5 is used to indicate that a figure between 1 and 5 is being suppressed.

This follows NHS Digital (formerly HSCIC) analysis guidance (2014) which states that small numbers within local authorities, wards, postcode districts, CCG's providers and Trusts may allow identification of patients/staff and should not be published.

2. [What % of these patients get a genetic diagnosis prior to them being referred onto specialist centres?.](#)

[Trust East and North joint response:-](#) Genetic testing/diagnosis is not a prerequisite for referral to a specialist centre – a referral can be made on suspicion of (as defined in the national service specification), or diagnosis of a syndrome that overlaps or is confused with Bardet-Biedl syndrome.

The Trust has considered your request in question 2, however, to provide you with the information requested would require the manual extraction and manipulation of information from various sources. The only way of answering this question would be to do a full chart and/or notes review of each individual patient to ascertain their status with respect to genetic diagnosis.

To carry out this work would exceed the appropriate cost limit as set out in Section 12 (1) of the Freedom of Information Act 2000 and is therefore exempt.

Under the Freedom of Information Act 2000 Section 12 (1) and defined in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004, a public authority is not obliged to comply with a request for information if it estimates that the cost of complying would exceed the appropriate limit. The limit of £450 represents the estimated cost of one person spending two and a half days in determining whether the Trust holds the information, locating, retrieving and extracting that information.

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

This question is not applicable.