

Title DECIPHER Genomics

Reference Number: RDF1626-23

Date of Response: 05/07/2023

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

Please be aware that the Royal Devon University Healthcare NHS Foundation Trust (Royal Devon) has existed since 1st April 2022 following the integration of the Northern Devon Healthcare NHS Trust (known as Northern Services) and the Royal Devon and Exeter NHS Foundation Trust (known as Eastern Services).

Please provide us with the following information covering the last 5 years.

- 1) How many patients with genetic issues did you submit/contribute to the DECIPHER Genomics database?

Exemption - Section 12 (1) – Time/Cost (over 18hrs work)

The Trust has considered your request for How many patients with genetic issues did you submit/contribute to the DECIPHER Genomics database, however to provide you with the information requested would require the manual extraction and manipulation of information from various sources The DECIPHER database is an external resource, which has no way of filtering the entries by entry date, we are therefore unable to limit the query to the last 5 years. We have no quick way of identifying those cases locally, short of a manual trawl of the data that would exceed the reasonable limits of cost and staff time under the FOI Act. 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.

The numbers we have provided below are therefore our best efforts to be cooperative under Section 16 of the Freedom of Information Act, and provide something, which is the total number of variants we have submitted.

The Trust clinical genetics team add patients they see to a research dataset within Decipher (470 DDD patients), and the laboratory add the variants of patients we have tested to the NHS area of the dataset (9215 NHS-Exeter). A

total of 9685 Since DECIPHER started (~20 years). The information is currently being housed at the EMBL's European Bioinformatics Institute.

2) [What are the DECIPHER patient ID numbers of those patients?](#)

Exemption - Section 40(2) personal data

This information is held by the Trust.

This request would mean accessing personal data and is exempt under Section 40 (2) of the Freedom of Information Act.

The personal data of individual patients is exempt from disclosure in compliance with the Article 9 of the UK GDPR - special category data as the data requested is Genetic data.

The Trust also believes that the release of such sensitive information meets the definition of personal data and disclosing the information would contravene Principle (a) as set out in Article 5 of the UK GDPR as the processing would not be lawful, fair and transparent. These patients would not expect to have their information published into the public domain. We have no legal basis for disclosure of information which could lead to the identification of individual patients.