

Reference:	FOI.16743.25
Subject:	Friedreich Ataxia Services
Date of Request:	4 March 2025

Requested:

1. Of all patients diagnosed with Hereditary Ataxia (ICD-10 Code G11), how many have a specific diagnosis of Friedreich Ataxia?
 - 1a. How many Friedreich Ataxia patients have been diagnosed in the last 12 months?
 - 1b. How many Friedreich Ataxia patients have had an appointment in the last 12 months in the following departments?
 - Cardiology
 - Neurology
 - Neuromuscular
 - Specialist movement disorders
 - Any other department
 - 1c. How many Friedreich Ataxia patients fall within the following age groups?
 - 0-13
 - 14-15
 - 16-40
 - 40+
 - 1d. How many Friedreich Ataxia patients have you discharged in the last 12 months?
 - 1e. How many Friedreich Ataxia patients have you referred to another specialist centre?
2. Does your centre have a specialist movement disorders clinic?
 - If so, how many patients with a diagnosis of Friedreich Ataxia have visited the clinic in the last 12 months?
3. Does your centre have a specialist Ataxia Clinic, as part of the specialist movement disorders clinic?
 - If so, how many patients with a diagnosis of Friedreich Ataxia have visited the clinic in the last 12 months?

Clarification

For question 1 - The date range which we needed is from 1st March 2024 till 28th April 2025.

Response:

1. Hywel Dda University Health Board (UHB) is unable to provide you with the information requested as there is a potential risk of identifying individuals if these details were disclosed, due to the low number of patients involved (less than 5). The UHB is therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000 (FoIA).

This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

2. The UHB confirms it does not have a specialist movement disorders clinic.
3. The UHB confirms it does not have a specialist Ataxia Clinic as part of the specialist movement disorders clinic.