

Ref: FOIA Reference 2024/25-697

Date 5th March 2025

Email [foi@uhn.nhs.uk](mailto:foi@uhn.nhs.uk)

Dear Sir/Madam

I am writing to acknowledge receipt of your email 14th January 2025 requesting information under the Freedom of Information Act (2000) regarding Spinal Muscular Atrophy

**Q1 We have a freedom of information request related to the diagnosis and treatment of Spinal Muscular Atrophy. Your answers to the following questions would be greatly appreciated.**

**Question 1. How many patients have a current diagnosis for Spinal Muscular Atrophy (ICD-10 Code G12.0, G12.1, G12.8 and G12.9) at your Trust?**

**A1** I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally but may be recorded in health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

**Q2 How many patients have been treated in the last 4 months (September to December 2024) with the following products:**

- Evrysdi (Risdiplam) - total patients
- Spinraza (Nusinersen) - total patients
- Zolgensma (Onasemnogene) - total patients
- Evrysdi (Risdiplam) – new\* patients
- Spinraza (Nusinersen) – new\* patients
- Zolgensma (Onasemnogene) – new\* patients

\*new patients are defined as patients who were not treated with any of Spinraza (Nusinersen), Evrysdi (Risdiplam) or Zolgensma (Onasemnogene) in the previous 4-month period (May to August 2024).

A2 Please refer to the table below.

Evrysdi (Risdiplam) total patients	None
Spinraza (Nusinersen) total patients	10
Zolgensma (Onasemnogene) total patients	None
Evrysdi (Risdiplam) – new* patients	None
Spinraza (Nusinersen) – new* patients	None
Zolgensma (Onasemnogene) – new* patients	None

**Q3 Of the total patients treated in the last 4 months (September to December 2024) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2024).**

A3 None

**Q4 Of the total patients treated in the last 4 months (September to December 2024) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2024).**

A4 None

**Q5 How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2024)?**

A5 None

\*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

***UHNH NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.***

Where the Trust owns the copyright in information provided, you may re-use the information in line with the conditions set out in the Open Government Licence v3 which is available at <http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/>. Where information was created by third parties, you should contact them directly for permission to re-use the information.

An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries relating to the response please contact my office

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via [www.ico.org.uk](http://www.ico.org.uk).

Yours,



**Leah Carlisle**  
Head of Data, Security & Protection and Health Records  
Data Protection Officer