

Trust Headquarters
Russell's Hall Hospital
Dudley
West Midlands
DY1 2HQ

Ref: FOI-012025-0001345

Date: 17.2.25

Address / Email:

Dear

Request Under Freedom of Information Act 2000

Thank you for requesting information under the Freedom of Information Act 2000.

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?

– Report run 1.1.24 to 31.12.24 - The number of cases is less than 5. As per NHS Digital rules the Trust does not publish numbers lower than 5 as this could lead to the identification of the person/s so Exemption Section 40(2) of the Freedom of Information Act is applied.

Questions 2 to 5 - the answer is zero. The Trust does not use the treatments (Spinraza (Nusinersen), Evrysdi (Risdiplam), Zolgensma (Onasemnogene)),

Question 2. 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).

Question 3. 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).

Question 4. 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).

Question 5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2024)?

If you are dissatisfied with our response, you have the right to appeal in line with guidance from the Information Commissioner. In the first instance you may contact the Information Governance Manager of the Trust.

Information Governance Manager
Trust Headquarters
Russell's Hall Hospital
Dudley
West Midlands
DY1 2HQ
Email: dgft.dpo@nhs.net

Should you disagree with the contents of our response to your appeal, you have the right to appeal to the Information Commissioners Office at.

Information Commissioners Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
www.ico.org.uk

If you require further clarification, please do not hesitate to contact us.

Yours sincerely

Freedom of Information Team
The Dudley Group NHS Foundation Trust