

Date 7 October 2026
Your Ref
Our Ref 11912

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION – SPINAL MUSCULAR ATROPHY PRESCRIBING

I write in response to your request for information in relation to Spinal Muscular Atrophy prescribing.

Question:

- The diagnosis and treatment of Spinal Muscular Atrophy.
Within your trust, how many patients currently have a diagnosis for:
SMA Type 1, aged less than 6 months (ICD-10 Code G12.0)
SMA Type 2, aged 6–17 months (ICD-10 Code G12.1)
SMA Type 3, aged 18 months–17 years (ICD-10 Code G12.1)
SMA Type 4, aged 18 years and over (ICD-10 Code G12.1)
SMA Unspecified (ICD-10 Code G12.9)

Answer:

We cannot answer due to it being diagnoses specific. Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

Question:

- Please provide the number of total patients and new patients* who have been treated in the last 4 months (May to August 2026) with the following products:

Answer:

May 2026 - August 2026			
Medication		Total Patients	New Patients*
Evrysdi (Risdiplam)	Total	7	5<
	Tablets	5<	0

	Oral Solution	5<	5<
Spinraza (Nusinersen)	Total	Information Unavailable	
	12 mg/5 mL Intrathecal Injection		
	28 mg/5 mL Intrathecal Injection		
Zolgensma (Onasemnogene)	Total	0	0

*New patients are defined as patients who were not treated with any of Spinraza (Nusinersen), Evrysdi (Risdiplam), or Zolgensma (Onasemnogene abeparvovec) in the previous 4-month period (January to April 2026). Patients who switch between formulations, strengths, or routes of administration of these therapies are not considered new patients.

Question:

3. Of the total patients treated in the last 4 months (May to August 2026) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (January to April 2026).
4. Of the total patients treated in the last 4 months (May to August 2026) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (January to April 2026).
5. Of the total patients treated in the last 4 months (May to August 2026) with Spinraza (Nusinersen), please provide the number of patients that were treated with Evrysdi (Risdiplam) in the previous 4 months (January to April 2026).

Answer:

We are unable to provide an answer as Zolgensma (Onasemnogene) is not available in our system, and patient-specific issues related to Spinraza (Nusinersen) mean it cannot be identified.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive