

Dear

FREEDOM OF INFORMATION – SPINAL MUSCULAR ATROPHY

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

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?

Answer:

We do not know how many individuals currently living within the health board have SMA. We could provide information around the number of patients who have had a diagnosis attached to an inpatient stay over a given time period if helpful.

Question:

2. How many patients have been treated in the last 4 months (January to April 2026) with the following products:
 - Evrysdi (Risdiplam)
 If available, please provide the split of the number of patients treated with Evrysdi (Risdiplam) by TABLET and SOLUTION formulations.
 - Spinraza (Nusinersen)
 - Zolgensma (Onasemnogene)

Answer:

January 2026 - April 2026	
Medication	Patient Count
Risdiplam (Evrysdi) Solution	8
Risdiplam (Evrysdi) Tablets	5<
Spinraza (Nusinersen)	Information Unavailable
Zolgensma (Onasemnogene)	0



To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table above. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).

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