

Date 17/12/2025
Your Ref
Our Ref 10863

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION – SPINAL MUSCULAR ATROPHY

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

Question:

1. Within your Trust/ Health Board, where are patients (aged 2yrs +) with a diagnosis of Spinal Muscular Atrophy referred to for treatment?
2. How many patients with Spinal Muscular Atrophy have been referred in:
 - a. The last 12 months? (or the latest 12 months of data you have available)
The last 5 years?
 - b. Could you please split this out into SMA type if possible (Type 0, 1, 2, 3, 4) – (see attached ICD-10 codes)
3. If your Trust/ Health Board receives referrals, where are these referrals made from?
4. How many patients return to local care for continued treatment once referred to a specialist centre?
5. If you have a treating centre for Spinal Muscular Atrophy in your trust, what is the average length of stay (or annual bed days) of patients being treated?

Answer:

Referrals would normally be made to Neurology / Women and Children's Services.

We cannot answer this request for the various reasons detailed below:

- We do not have ICD10 codes data linked or associated with referrals. The data we hold is on people who get referred onto a given specialty or service, not for a specific condition.
- People also do not get referred in for treatment but for a consultation with a healthcare practitioner which might or might result in treatment, we cannot tell that from our referrals data.

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102 West Port
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Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
*Lothian NHS Board is the common
name of Lothian Health Board*

- These might be differences with English boards/health systems. We think in other countries they attach ICD codes to more pathways and various stages of electronic health records.
- Because this is a rare condition, we also think numbers broken down by type (0-4) would be so low that they would need to be redacted due to SDC.
- We do not know the reason/condition for referral unless there is a specific service which we believe there is not for Spinal Muscular Atrophy.

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.

I am sorry I cannot help further 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