

Freedom of Information Act Request

I am writing to request information under the Freedom of Information Act 2000.

I 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?

Description	Total (Since March 2018 to date)
G120: Infantile spinal muscular atrophy, type I [Werdnig-Hoffman]	#
G121: Other inherited spinal muscular atrophy	#
G129: Spinal muscular atrophy, unspecified	6

Nothing for G128.

In line with the Freedom of Information Act 2000, numbers fewer than five have been suppressed and shown as “#” to reduce the risk of identification.

Question 2. How many patients have been treated in the last 4 months (September to December 2025) with the following products:

- Evrysdi (Risdiplam) - total patients **0**
- Spinraza (Nusinersen) - total patients **0**
- Zolgensma (Onasemnogene) - total patients **0**
- Evrysdi (Risdiplam) – new* patients **0**
- Spinraza (Nusinersen) – new* patients **0**
- Zolgensma (Onasemnogene) – new* patients **0**

*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 2025).

If you are not satisfied with the handling of your request, you have the right to request an internal review. Requests for an internal review should be submitted within 40 working days from the date of this response, and should be addressed to d.wraith@nhs.net.

If you remain dissatisfied after the internal review, you have the right to appeal to the Information Commissioner’s Office (ICO). The ICO can be contacted at:

Information Commissioner's Office

Our Ref: 44
January 2026

Wycliffe House

Water Lane

Wilmslow

Cheshire

SK9 5AF

Tel: 0303 123 1113

Website: <https://ico.org.uk/make-a-complaint/>