Our Ref:85

May 2026

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust

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.

a. 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?
We currently have 0 patients with a diagnosis of Spinal Muscular Atrophy in the trust.

b. Question 2. How many patients have been treated in the last 4 months (January to April 2026) with the following products:

c. • Evrysdi (Risdiplam)

d. If available, please provide the split of the number of patients treated with Evrysdi (Risdiplam) by TABLET and SOLUTION formulations.

e. • Spinraza (Nusinersen)

f. • Zolgensma (Onasemnogene)

DBTH holds the information on the subject you have requested. However, I advise you that we will not be able to answer your request without exceeding the appropriate limit. This is because our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this data, the Trust would need to perform an audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.

. Section 12 of the Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit, We have estimated that it would take more than 18 hours to carry out a manual search to locate, retrieve, and extract all the information you have requested. In this situation the associated cost would therefore exceed the appropriate fee limit of £450 set out under Freedom of Information & Data Protection (Appropriate Limit and Fees) Regulations 2007.

The fee limit specified in regulations for NHS trusts represents the cost of one person spending 2½ working days at a rate of £25 per hour determining whether the Trust holds the information sought and then locating, retrieving and extracting that information.

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

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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
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
Website: https://ico.org.uk/make-a-complaint/