

Direct Line: 01623 672232  
Our Ref: 1237  
E-mail: [sfh-tr.foi.requests@nhs.net](mailto:sfh-tr.foi.requests@nhs.net)

**King's Mill Hospital**  
Mansfield Road  
Sutton in Ashfield  
Nottinghamshire  
NG17 4JL

**13<sup>th</sup> January 2025**

Tel: 01623 622515  
Join today: [www.sfh-tr.nhs.uk](http://www.sfh-tr.nhs.uk)

Dear Sir/Madam

**Freedom of Information Act (FOI) 2000 - Request for Information Reference:** Spinal Muscular Atrophy (SMA) Treatment

I am writing in response to your request for information under the FOI 2000.

I can confirm in accordance with Section 1 (1) of the Freedom of Information Act 2000 that we do hold the information you have requested. A response to each part of your request is provided below. Please accept our apologies for the delay.

**Home, Community, Hospital.**

FOI Request / Question	Question Response	Is there an exemption?	Exemption	Exemption Details
1. Within your Trust/ Health Board, where are patients (aged 2yrs +) with a diagnosis of Spinal Muscular Atrophy referred to for treatment?	Nottingham Paediatric Neurology and Great Ormond Street Hospital for some			
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) b) The last 5 years?  • Could you please split this out into SMA type if possible (Type 0, 1, 2, 3, 4) – (see below ICD-10 codes): o G12.0: Infantile spinal muscular atrophy, type I (Werdnig-Hoffmann) o G12.1: Other inherited spinal muscular atrophy o G12.8: Other spinal muscular atrophies and related syndromes o G12.9: Spinal muscular atrophy, unspecified	– 0 – We do not receive referrals for this issue.			
3. If your Trust/ Health Board receives referrals, where are these referrals made from?	N/A			
4. How many patients return to local care for continued treatment once referred to a specialist centre?	Shared care is continued with the 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?	N/A			
--	-----	--	--	--

I trust this information answers your request. Should you have any further enquiries or queries about this response please do not hesitate to contact me. However, if you are unhappy with the way in which your request has been handled, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to: Sally Brook Shanahan, Director of Corporate Affairs, King's Mill Hospital, Mansfield Road, Sutton in Ashfield, Nottinghamshire, NG17 4JL or email [sally.brookshanahan@nhs.net](mailto:sally.brookshanahan@nhs.net).

If you are dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office, who will consider whether we have complied with our obligations under the Act and can require us to remedy any problems. Generally, the Information Commissioner's Office cannot decide unless you have exhausted the internal review procedure. You can find out more about how to do this, and about the Act in general, on the Information Commissioner's Office website at: <https://ico.org.uk/your-data-matters/official-information/>.

Complaints to the Information Commissioner's Office should be sent to FOI/EIR Complaints Resolution, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Telephone 0303 1231113, email [casework@ico.org.uk](mailto:caserwork@ico.org.uk).

If you would like this letter or information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call us on 01623 672232 or email [sfh-tr.foi.requests@nhs.net](mailto:sfh-tr.foi.requests@nhs.net).

Yours faithfully

#### Information Governance Team

All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the [Open Government Licence](#) (OGL) a request to re-use is not required, but the licence conditions must be met. You must not re-use any previously unreleased information without having the consent from Sherwood Forest Hospitals NHS Foundation Trust. Should you wish to re-use previously unreleased information then you must make your request in writing. All requests for re-use will be responded to within 20 working days of receipt.