



Ref: FOIA Reference 2022/23-596

Royal Stoke University Hospital
Data, Security and Protection
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 10th March 2023

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 17th January 2023 requesting information under the Freedom of Information Act (2000) regarding Spinal Muscular Atrophy

On the same day we contacted you via email as we required the following clarification:

What do you mean by 'have a current diagnosis'? Are you after the number patients on our waiting lists who have Spinal Muscular Atrophy? Or the number of patients waiting to be seen by a consultant who specialises in Spinal Muscular Atrophy?

On 30th January 2023 you replied via email with:
'We require "current inpatient and outpatients records'

We replied the same day via email with:
I have been informed that your answer below does not answer our question, therefore:

Are you after the number patients on our waiting lists who have Spinal Muscular Atrophy? Or the number of patients waiting to be seen by a consultant who specialises in Spinal Muscular Atrophy, to note some of these patients may not be diagnosed yet?

On 27th February 2023 you replied via email with:
'We require the patient who has been treated for Spinal Muscular Atrophy.'

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 We 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?

A1 We do not record on the outpatient attendance any treatments that have occurred and to ascertain those who have been admitted as an inpatient and treated for Spinal Muscular

Atrophy an manual audit of those with the given clinical coding would need to be undertaken as Spinal Muscular Atrophy is a co-morbidity and will be applied to the patients inpatient record whether the reason for the admission was due to SMA or not, therefore section 12 exemption as detailed below:

I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all individual health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all individual health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

Q2 How many patients have been treated in the last 4 months (September to December 2022) with the following products?

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

***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 2022).**

A2 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

Evrysdi (Risdiplam) - total patients = 0
Spinraza (Nusinersen) - total patients = 15
Zolgensma (Onasemnogene) - total patients = 0
Evrysdi (Risdiplam) - new* patients = 0
Spinraza (Nusinersen) - new* patients = <5
Zolgensma (Onasemnogene) - new* patients = 0

Q3 Of the total patients treated in the last 4 months (September to December 2022) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).

A3 None

Q4 Of the total patients treated in the last 4 months (September to December 2022) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).

A4 None

Q5 How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022)?

A5 None

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

Where the Trust owns the copyright in information provided, you may re-use the information in line with the conditions set out in the Open Government Licence v3 which is available at <http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/>. Where information was created by third parties, you should contact them directly for permission to re-use the information.

An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



Rachel Montinaro
Data Security and Protection Manager - Records