

Reference Number: FOI202223/534
From: Commercial
Date: 17 January 2023
Subject: Information regarding diagnosis and treatment of Spinal Muscular Atrophy

Q1 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 21

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

A2 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to confirm treatment following medication being dispensed, the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to confirm treatment following medication being dispensed, the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to confirm treatment following medication being dispensed, the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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

A5 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to confirm treatment

following medication being dispensed, the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.