

Ref: FOI/GS/ID 7948

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Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Spinal Muscular Atrophy SMA.

You asked:

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?

Question 2. How many patients have been treated in the last 4 months (September to December 2022) with the following products:

- a. Evrysdi (Risdiplam) - total patients*
- b. Spinraza (Nusinersen) - total patients*
- c. Zolgensma (Onasemnogene) - total patients*
- d. Evrysdi (Risdiplam) - new* patients*
- e. Spinraza (Nusinersen) - new* patients*
- f. 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).*

Question 3. 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).

Question 4. 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).

Question 5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022)?

Trust response:

1. The Trust does not record an outpatient's diagnosis code. There have been no patients with a primary diagnosis code of ICD-10 Code G12.0, G12.1, G12.8 and G12.9) admitted in 2022.
2. Maidstone and Tunbridge Wells NHS Trust are not a treatment centre for the condition that these drugs are licensed for (5q spinal muscular atrophy (SMA)). The Trust has not dispensed any of the listed drugs in the time-frame requested.

All remaining questions are not applicable.