

<b>Reference:</b>	FOI.3390.20
<b>Subject:</b>	Smith-Magenis syndrome
<b>Date of Request:</b>	17 June 2020

**Requested:**

Information regarding the population of individuals with Smith-Magenis Syndrome, this is identified by a mutation or deletion of RAI1 gene on chromosome 17p11.2:

- Total population covered by the health authority
- The total number of people diagnosed with Smith-Magenis syndrome within this population
- Year of Birth
- Male / Female

**Response:**

Hywel Dda University Health Board (UHB) provides, within the table overleaf, the number of male and female patients who have been coded on the UHB's patient administration system, Myrddin, as Q935, Smith-Magenis syndrome. Please note, this data could also include patients with different diagnosis as the code also covers 'other deletions of part of a chromosome'.

Gender	Number
Female	8
Male	18

The UHB is only able to provide the information recorded for patients who have been admitted to hospital, with either a primary or secondary reason of Smith-Magenis syndrome. Therefore, there may be some patients within the community who are not included within the figures provided. However, these details would need to be sought from individual GP practices. Contact details for each of the UHB's GP Practices can be found via the following link:

<http://www.wales.nhs.uk/sitesplus/862/directory/gps/>

The UHB is unable to provide you with the exact number of patients broken down by year of birth due to the low numbers of cases (5 and under), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the Data Protection Act 2018/ General Data Protection Regulations 2016 (GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles 6 and 9 of the GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

In reaching this decision, the Data Protection Act 2018/General Data Protection Regulations 2016 defines personal data as data which relates to a living individual who can be identified solely from that data or from that data and other information which is in the possession of the data controller.

The total population covered by the UHB is information already within the public domain; therefore, the UHB has applied an exemption under Section 21 of the Freedom of Information Act 2000, as the information is accessible by another means. The information requested is available on the UHB's website.

For ease of reference please click on the attached link, which will take you directly to the UHB's webpage:

<http://www.wales.nhs.uk/sitesplus/862/page/40317>