NHS
Gloucestershire
Clinical Commissioning Group

Reference: **FOI 36097 GLO 11M**

Subject: **Smith-Magenis Syndrome**

QUESTION	RESPONSE
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:	
1. Total population covered by the CCG	The CCG can confirm that it does hold this information, but are exempting it under Section 21 (https://ico.org.uk/media/for-organisations/documents/1203/information-reasonably-accessible-to-the-applicant-by-other-means-sec21.pdf) of the Freedom of Information Act 2000 (FOIA) as it is reasonably accessible by other means. This is an absolute exemption. I have provided you with a link to the website which will provide you with this information: Filter by CCG Code (11M)
2. The total number of people diagnosed with Smith-Magenis syndrome within this population	I can confirm that the CCG does not hold this information. We suggest you contact the service providers, as they may be able to provide the data required; please follow the link given below: Gloucestershire Hospitals NHS Foundation Trust https://www.gloshospitals.nhs.uk/about-us/our-trust/freedom-information/ Gloucestershire Health and Care NHS Foundation Trust https://www.ghc.nhs.uk/
3. Year of Birth	
4. Male / Female	

The information provided in this response is accurate as of 15 July 2020 and has been authorised for release by Mark Walkingshaw, Deputy Accountable Officer/Director of Commissioning for NHS Gloucestershire CCG.