

Freedom of Information Act 2000 - Request Reference Fol/20/217
Smith-Magenis Syndrome

Request details

I am writing to you under the Freedom of Information Act 2000 to request the following information from the Cardiff and Vale Health Authority:

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 health authority

The total population of Cardiff and the Vale of Glamorgan at the last census was 445,000.

2. The total number of people diagnosed with Smith-Magenis syndrome within this population

Cardiff and Vale University Health Board (the UHB) does not hold this information. However, to comply with our Section 16 obligation, the duty to provide advice and assistance, the UHB is able to confirm that it does hold some related information which may be of use to you.

The UHB can advise that 82 patients are recorded as having a recorded diagnosis of ICD-10 code 'Q935', which includes but is not limited to Smith-Magenis Syndrome. This information is captured via coded clinical data, which is compiled upon discharge from hospital using international coding classifications. This data does not represent activity outside of the inpatient or daycase setting (e.g. outpatient or Primary Care setting).

3. Year of Birth and whether male or female

Number of Patients Per Year	M	F	Total
1944		1	1
1955	1		1
1961		1	1
1963	1		1
1965	1		1
1981	1	1	2
1984	1		1
1986	1	1	2
1988	3		3
1990	1		1
1991		1	1
1992		1	1
1993		2	2
1995	3		3
1996	2	1	3
1997		2	2

1998	1		1
2000		2	2
2001	2		2
2002		1	1
2003	1		1
2004	1	1	2
2005	2	2	4
2006	4	3	7
2007	1	2	3
2008		1	1
2009	2	3	5
2011	5	2	7
2012		1	1
2014	4	1	5
2015	1	3	4
2016	3	2	5
2017	3	1	4
2019		1	1
Total	45	37	82