MS in the UK

Estimates of incidence and
prevalence of MS in the UK

May 2022

Let's stop MS **together**

Contents

1. How many people have MS in the UK?

We estimate that there are over **130,000** people with MS in the UK, and that each year nearly **7,000** people are diagnosed with MS. This means around **1 in every 500** people in the UK lives with MS, and each week over 130 people are diagnosed with MS.

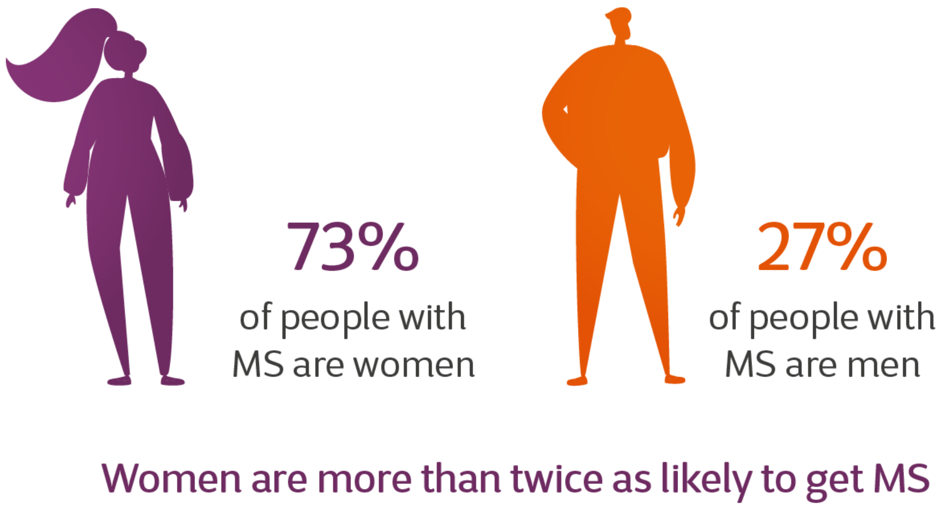
Gender

Table 1. Prevalence and incidence of MS in men and women in the UK

	Number of people with MS		**Number of people diagnosed with MS each year**	
	Total*	**Per 100,000 people**	**Total***	**Per 100,000 people**
Women	97,730	286	4,880	14
Men	36,940	111	2,100	6
Total	134,790	199	6,980	10

*Rounded to nearest 10

Figure 2: Percentage of men and women living with MS in the UK



Age

Table 2. Incidence of MS by age in the UK

	Number of people diagnosed with MS each year	
	Total*	**Per 100,000 people**
Under 30	1,250	5
30-34	880	19
35-39	730	17
40-44	920	23
45-49	890	21
50-54	770	17
55-59	530	12
60-64	390	10
65 and over	400	3

*Rounded to nearest 10

Table 3. Prevalence of MS by age in the UK

	Number of people with MS	
	Total*	**Per 100,000 people**
0-30	4,450	18
30-34	5,410	120
35-39	8,600	195
40-44	10,560	258
45-49	13,380	311
50-54	18,630	404
55-59	19,390	430
60-64	15,450	401
65-69	14,270	425
70-74	12,750	379
75+	11,900	205

*Rounded to nearest 10

Table 4. Prevalence of MS by age and gender in the UK

	Number of people with MS		Number of people with MS (per 100,000 of population)	
Age	**Women**	**Men**	**Women**	**Men**
Under 30	2,720	1,620	23	13
30-34	3,750	1,650	166	73
35-39	6,250	2,380	281	109
40-44	7,740	2,820	376	139
45-49	9,390	3,980	431	187
50-54	13,800	4,860	588	214
55-59	14,770	4,630	644	209
60-64	11,150	4,310	567	228
56-69	10,350	3,910	598	241
70-74	8,840	3,920	503	244
75+	8,970	2,860	272	115
Total	97,730	36,940	286	111
Total persons	134,670		199	

*Rounded to nearest 10

Nation

Figure 5. Number of people living with MS in each UK nation (rounded to the nearest 10)

4,890
in Northern Ireland (that's 1 in every 400 people)

15,870
in Scotland (that's 1 in every 350 people)

107,300
in England (that's 1 in every 500 people)

5,680
in Wales (that's 1 in every 550 people)

Table 5. Prevalence and incidence of MS across the UK

	Number of people with MS		Number of people diagnosed with MS each year	
	Total*	**Per 100,000 people**	**Total***	**Per 100,000 people**
England	107,300	190	5,060	9
Wales	5,680	179	230	7
Scotland	15,870	290	720	13
Northern Ireland	4,890	258	250	13

*Rounded to nearest 10

Our number for England is slightly lower than the one in Public Health England's report because we collected data in a particular way to protect patient anonymity and used different methodology to calculate prevalence and incidence for the nations of the UK.

2. How did we calculate these estimates?

The estimates shown here have been calculated in collaboration with Public Health England using The Health Improvement Network (THIN) dataset[1].

THIN is a UK General Practice (GP) registration database including around 385 GP practices and 3 million active patients representing 4.8% of the UK population. The dataset is based on extracts from GP systems that are taken every 4 months. This analysis is based on data recorded from practices up to 17 January 2018 (THIN1801). The earliest record date was from 1 January 1986.

We applied the number of people with MS in the THIN dataset to the UK population to estimate the number of people with MS in the UK population (prevalence), and the number of new cases each year (incidence).

To identify the MS population in the THIN dataset we used a series of MS specific codes called Read codes. Read Codes are used by GPs to record any symptoms, tests and diagnosis they discuss with their patients in the patient's electronic record.

We matched Read Codes to the International Statistical Classification of Diseases and Related Health Problems (ICD) codes, using code maps provided by NHS digital. We discussed the list of codes with a group of clinicians and academics to make sure they were valid, and used a revised list of F20 codes based on feedback.

Table 5. F20 Read Codes used to determine MS prevalence and incidence dataset

Code	**Description**
F20.00	Multiple sclerosis
F20.11	Disseminated sclerosis
F200.00	Multiple sclerosis of the brain stem
F201.00	Multiple sclerosis of the spinal cord
F202.00	Generalised multiple sclerosis
F203.00	Exacerbation of multiple sclerosis
F204.00	Benign multiple sclerosis
F205.00	Malignant multiple sclerosis
F206.00	Primary progressive multiple sclerosis
F207.00	Relapsing and remitting multiple sclerosis
F208.00	Secondary progressive multiple sclerosis

To ensure robust estimates of age and diagnosis, we didn't count records without a valid date of birth or a date when an MS diagnosis code was recorded.

We used this data to calculate a rate per 100,000 people for MS incidence and prevalence in the UK and each of its 4 nations. We then applied this to the latest population data from the Office of National Statistics (ONS) to estimate the number of people in the general population that have MS.

To calculate incidence, we calculated the number of people with MS in the THIN population for each financial year. By determining the number of people in THIN that didn’t already have a diagnosis of MS at that time (the ‘at risk’ population) we could calculate the cumulative incidence proportion per 100,000 people, and apply it to the total population.

To calculate age and gender adjusted incidence, we first calculated a cumulative incidence per financial year for 2012 – 2017. This was due to small numbers in the data set and concerns around anonymity. We then determined the average incidence in the THIN dataset and used this number to calculate an incidence rate, based on the at risk population for the 2016/2017 financial year. This rate was applied to the latest ONS population data to determine incidence.

Things to consider about these estimates

Representation

The THIN database gathers a lot of information about people who are registered with their GP. It represents around 3 million people across the UK, around 4.8% of the total population. Coverage is different for each nation:

- England 2%
- Northern Ireland 14%
- Scotland 17%
- Wales 22%

So representation for England is lowest. There are limited studies that look at the demographic and geographical representation of the THIN database, especially in recent years, which is important as membership to the system that feeds the database is changing, and numbers seem to have reduced over the years.

Some estimates state that England representation was previously around 6%. The ones we could find generally state THIN is broadly representative of the general population with minor variation that could be combated with data weighting if deemed appropriate[2].

Age and gender demographics of the THIN population are largely representative of the total population. Females aged 20-24 and males aged 20-29 are slightly underrepresented in THIN.

Removal of incomplete records

Certain patient records were removed from the analysis. These included;

- patients who didn't have a valid year of birth
- patients who didn't have a date when their MS code was recorded
- patients who were assumed deceased following the Acceptable Mortality Reporting (AMR) date.

We implemented these processes to make sure the data feeding into our estimates was as reliable as possible. And that it allowed for incidence and age/gender analysis. This meant an average of 4% of records across the UK were removed (8% in England, 3% in Northern Ireland, 2% in Scotland, 4% in Wales).

This suggests the data could underestimate the prevalence of MS by up to 8%. It's not clear from our analysis where the error might sit between 0 and 8%, without more investigation. We decided not to correct for this variation at this stage. There are many other reasons why our estimates could be an underestimate, many of which we can't quantify or correct.

Selection of MS diagnosis records by F20 code

We discussed several different combinations of Read code with Public Health England and our clinical and academic advisors. MS is a variable condition with many potential symptoms. So, we considered groups of codes. From very broad range, encompassing many clinical presentations and administrative codes that would include administrative tasks and clinical examinations. To a group that included a smaller set of codes specifically around MS diagnosis.

Through discussion with our clinical and academic experts we decided to take forward only codes that were specifically about MS diagnosis (Table 5). We did this to make sure the data used to calculate the national estimates was highly MS specific. This does mean there may be some patient records we excluded as they were coded as a less specific code.

References

1. SRC Reference Number: 18THIN087. THIN is a registered trademark of Cegedim SA in the United Kingdom and other countries. Reference made to the THIN database is intended to be descriptive of the data asset licenced by IQVIA.
2. Blak, B.T. et al. Generalisability of The Health Improvement Network (THIN) database: demographics, chronic disease prevalence and mortality rates. Inform Prim Care, v.19, n.4, p.251-255, 2011. ISSN 1476—320

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everything in between.
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