



MS in the UK

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 newly diagnosed. This means around **1 in every 500** people in the UK lives with MS, and each week over 130 people are diagnosed with MS.

Table 1. Estimates for the prevalence of MS in men and women in the UK

Age	Number of people with MS*		Number of people with MS (per 100,000 people) ^{†, #}	
	Women	Men	Women	Men
Under 30	2,780	1,670	23	13
30-34	3,680	1,610	166	73
35-39	6,050	2,320	281	109
40-44	7,680	2,800	376	139
45-49	10,010	4,210	431	187
50-54	13,930	4,910	588	214
55-59	13,660	4,320	644	209
60-64	10,400	4,010	567	228
65-69	10,720	4,060	598	241
70-74	8,160	3,640	503	244
75+	8,490	2,620	272	115
Total	95,560	36,160	286	111
Total persons	131,720		199	

*Numbers rounded to nearest 10, †numbers rounded to 0 decimal places, # based on an incidence rate calculated from average annual incidence 2012-2017

Table 2. Estimates for incidence of MS in men and women in the UK

Age	Number of people newly diagnosed with MS each year (average 2012-2017)*		Number of people newly diagnosed with MS each year (per 100,000 people) ^{†,#}	
	Women	Men	Women	Men
Under 30	940	310	8	2
30-34	660	210	30	9
35-39	490	230	23	11
40-44	650	280	32	14
45-49	660	300	29	13
50-54	490	300	21	13
55-59	340	160	16	8
60-64	260	110	14	6
65+	280	110	4	2
Total	4,770	2,010	14	6
Total persons	6,780		10	

*Numbers rounded to nearest 10, †numbers rounded to 0 decimal places, # based on an incidence rate calculated from average annual incidence 2012-2017

Table 3. Estimates of the prevalence and incidences of MS in the nations of the UK

Nation	Number of people with MS		Number of people newly diagnosed with MS each year	
	Total*	Per 100,000 people ^{†,**}	Total*	Per 100,000 people ^{†,#}
England	105,540 ¹	190	4,980	9
Wales	5,600	179	230	7
Scotland	15,750	290	720	13
Northern Ireland	4,830	258	250	13

*Numbers rounded to nearest 10, †numbers rounded to 0 decimal places, # based on an incidence rate calculated from average annual incidence 2012-2017

1. 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.

These estimates are an update on our last estimates in 2016 based on research by Mackenzie et al ¹.

Glossary of terms

Prevalence is the number of people with a condition in a population. In this case the population is the UK, England, Scotland, Northern Ireland or Wales

Incidence is the number of people newly diagnosed with a condition in a certain time period. In this case it is the number of people newly diagnosed with MS in one 12 month period

The new estimates suggest that over 130,000 people in the UK live with MS. In 2010, using the Mackenzie estimate and adjusting for error, we estimated the number of people in the UK living with MS was about 100,000.

The new estimates could therefore represent an increase in the number of people in the UK living with MS. Improved survival in people with MS over the past 30 years would increase prevalence and has been documented.² But this is unlikely to explain all of the increase. Others have shown the increased survival in MS has been proportional to the increased survival in the general population.³

Another reason for an increasing prevalence could be changes to the diagnostic criteria. The McDonald criteria (the accepted standard for diagnosing MS in the UK) were reviewed and updated in 2010⁴ and again in 2017⁵. This meant people could be diagnosed earlier than before and could have increased the number of diagnoses in this period. As well as meaning that people are being diagnosed earlier in life.

From the analysis we conducted, it's not possible to tell if the higher prevalence is due to a true increase in the number of cases or methodological differences. But PHE, the MS Society and our expert advisors are confident the estimate put forward is an accurate reflection of the MS prevalence in the UK.

How did we calculate these estimates?

The prevalence and incidence estimates shown here were calculated in collaboration with PHE. We took the information from a system used by GPs to record information about patients called The Health Improvement Network (THIN) dataset⁶.

We applied the number of people with MS in the THIN dataset to the whole nation population to estimate the number of people with MS in the

general population (prevalence), and the number of new cases each year (incidence).

THIN is a UK 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.

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. The GPs' systems automatically prompt them to choose a Read Code associated with each of these items.

We matched Read Codes to the International Statistical Classification of Diseases and Related Health Problems (ICD) codes, using code maps provided by NHS digital. The ICD codes are developed by the World Health Organisation (WHO) to facilitate a global standard for recording health conditions. We discussed the list of codes with leading clinicians and academics to make sure they were valid, and used a revised list of F20 codes based on feedback.

Table 4. 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

We determined the MS diagnosed population from the codes described. We didn't count records without a valid date of birth or date when an MS diagnosis code was recorded to ensure robust estimates of age and diagnosis.

We were able to determine the prevalence and incidence of MS in the UK and individual nations from this data. We measured the number of people with MS in the THIN population at the time of data collection and calculated a rate per 100,000 people. We then applied this to the total population using data from the Office of National Statistics (ONS) to estimate the number of people in the general population that may have a diagnosis of 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 do not already have a diagnosis of MS at that time (at risk population) we could calculate the cumulative incidence proportion per 100,000 people, and apply it to the total nation 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 2016/2017 ONS population to determine the UK incidence.

Things to consider about these estimates

Representation

The THIN database provides us with a great resource to be able to gather a lot of information on people in the UK who are registered with their GP and those with an MS diagnosis.

Although the THIN dataset represents around 3 million people across the UK, that only amounts to around 4.8% of the total population. On a nation level, representation is:

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

2% representation for England is low. However compared to the general population, age and gender demographics are largely representative with

females aged 20-24 and males aged 20-29 slightly underrepresented in THIN.

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. ⁷

Removal of incomplete records

Certain patient records were removed from the analysis. These included patients who didn't have a valid year of birth or date when their MS specific code was recorded. As well as those who were assumed deceased following the Acceptable Mortality Reporting (AMR) date.

We implemented these processes to make sure the data that fed into the estimates was as reliable as possible. And that it allowed for incidence and age/gender analysis, which both require valid birth and event date.

However, it also meant that 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%. We have decided not to correct for this variation at this stage. There are many other reasons why the numbers produced through this analysis could be an underestimate, many of which we can't quantify, so can't correct. Additionally, it is not clear from this analysis where the error might sit between 0 and 8%, without more investigation.

Selection of MS diagnosis records by F20 code

We discussed several different combinations of Read code with PHE, clinical and academic advisors.

MS is a variable condition with many potential symptoms presenting in different patients. 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 only codes specifically around MS diagnosis.

Through discussion with clinical and academic experts we decided to take forward only codes that are specifically about MS diagnosis (Fig 4). We did this to make sure the data used to calculate the national estimates

was robustly MS specific. This does mean there may be some patient records we excluded as they were coded as a less specific code.

References

- 1 MACKENZIE, I. S. et al. Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the General Practice Research Database. **J Neurol Neurosurg Psychiatry**, v. 85, n. 1, p. 76-84, Jan 2014. ISSN 1468-330X. Available: < <https://www.ncbi.nlm.nih.gov/pubmed/24052635> >.
- 2 BRØNNUM-HANSEN, H.; KOCH-HENRIKSEN, N.; STENAGER, E. Trends in survival and cause of death in Danish patients with multiple sclerosis. **Brain**, v. 127, n. Pt 4, p. 844-50, Apr 2004. ISSN 0006-8950. Available: < <https://www.ncbi.nlm.nih.gov/pubmed/14960501> >.
- 3 KINGWELL, E. et al. Relative mortality and survival in multiple sclerosis: findings from British Columbia, Canada. **J Neurol Neurosurg Psychiatry**, v. 83, n. 1, p. 61-6, Jan 2012. ISSN 1468-330X. Available: < <https://www.ncbi.nlm.nih.gov/pubmed/21865212> >.
- 4 POLMAN, C. H. et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. **Ann Neurol**, v. 69, n. 2, p. 292-302, Feb 2011. ISSN 1531-8249. Available: < <https://www.ncbi.nlm.nih.gov/pubmed/21387374> >.
- 5 THOMPSON, A. J. et al. Diagnosis of multiple sclerosis: 2017 revisions of the McDonald criteria. **Lancet Neurol**, v. 17, n. 2, p. 162-173, 02 2018. ISSN 1474-4465. Available: < <https://www.ncbi.nlm.nih.gov/pubmed/29275977> >.
- 6 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 licensed by IQVIA.
7. 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. 251-5, 2011. ISSN 1476-0320. Available: < <https://www.ncbi.nlm.nih.gov/pubmed/22828580> >.