



MS in the UK - FAQs

Frequently asked questions about our updated prevalence and incidence estimates

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Frequently asked questions

What is prevalence and incidence?

Prevalence is the number of people in a population who have a disease or health condition across a specific time period.

- In this work, prevalence is the number of people with MS in the population. And we can look at population at either a UK or individual UK nation level.
- Prevalence can also be shown as a 'rate'; in this work this is how many people per 100,000 people have MS.

Incidence is the number of people that are diagnosed with a disease or health condition during a given period of time.

- In this work, incidence is worked out for a 12-month period. And we can use that to give us an estimate of how many people are likely to be diagnosed each year.
- Incidence can also be represented as an incidence 'proportion'; how many people per 100,000 people are newly diagnosed with MS during a defined period e.g. each year.

What do the estimates show?

There are more people living with MS in the UK than previously thought.

We estimate that there are over 150,000 people with MS in the UK.

This means that around **1 in every 400 people** in the UK are living with MS.

There are over 7,100 people newly diagnosed each year in the UK.

This means that **each week around 135 people are diagnosed** with MS across the UK.

Our estimates also show:

- People are most likely to find out they have MS in their thirties and forties.
- 71% of people living with MS in the UK are women. It means women are around 2.5 times more likely than men to be diagnosed with MS.
- The number of people with MS has increased in all UK nations since 2019.

How do figures compare to our previous estimates?

The new prevalence and incidence estimates are higher for the UK and all individual UK nations than previous estimates.

The estimates are higher than our previous numbers; does that mean that more people are getting MS?

Our new estimates indicate that there are more people with MS in the UK than when we last did similar work. But when considering the data, it's important to understand that:

- This data cannot tell us whether MS itself is increasing because there could be several factors affecting that number. These include, for example, people living longer or, possibly, improvements in the recognition and diagnosis of MS.
- The data does, however, clearly indicate that there are more people living with MS than previously understood.

There are methodological differences between the current and the previous study – this means they were done in slightly different ways. And there are differences in the data that is available now compared to six years ago (there is more data now). We can't rule out that these small changes could have some effect on the overall estimates, but they would not account for the big change in estimates we're seeing.

We cannot talk in detail about trend due to the factors above. This is a common challenge in any population based studies over time (longitudinal research) and not unique to this work.

Why did we update the prevalence and incidence figures?

Understanding both prevalence and incidence is vital in terms of understanding the MS population and supporting people living with MS.

Our existing figures (published in 2020/22), including our overall estimate of 130,000, are based on The Health Improvement Network® THIN dataset purchased around 6 years ago. To make sure we have confidence in the numbers we use to drive much of our work, we recognised that it was necessary to update the figures.

Where do the estimated numbers come from?

Cegedim, a healthcare data organisation, owns the THIN (The Health Improvement Network®) dataset. The data in there comes from GPs across the UK. Not all GPs are signed up to this dataset, just over 350 practices currently use THIN®.

When you register with a GP who uses THIN®, a record is created in that dataset and is updated, for example, when you're diagnosed with a condition or disease. Only your GP can see the details of who you are and other identifying information. The data we see is completely anonymised – so we don't know who any individual record relates to.

We worked with Cegedim to look at the numbers of people with MS in that dataset. And to understand more information about that group of people, including age, gender, ethnicity, region where they live, and more.

From those numbers, data scientist then worked with the data to create estimates to show the number of people with MS in the general population (prevalence), and the number of new cases each year (incidence). Further information about the methods used is available in the methodology report accessed here [to come].

Why did we use The Health Improvement Network® (THIN) data set?

The Evidence team carried out a scoping exercise in the autumn of 2023 to identify the best way to refresh our out-of-date figures (which were based on the Health Improvement Network® THIN dataset). This included speaking with similar organisations to the MS Society who have invested in updating their prevalence and incidence data.

This scoping exercise showed that the THIN® dataset remains the best available option for our organisation to model prevalence and incidence of MS in the UK.

The Health Improvement Network® (THIN) is one of the most respected and reliable data sources for anonymised primary care records, representing around 4.1% of the UK population as far back as 1994. The number of people in this dataset means that it is statistically valid. This means that the data can be used to provide estimates of what is happening in a whole population.

Why did we commission Cegedim?

Cegedim are experts in healthcare data globally. They own the THIN® data set and were able to provide the expertise needed to produce our new figures. The Cegedim team included statisticians, data scientists, and epidemiologists (these are people who look at patterns, causes, and effects of diseases in groups of people).

We scoped different options to access and analyse THIN® data. Cegedim were able to provide the most suitable package which fit our requirements and was within budget.

You can find out more about Cegedim at: <https://www.the-health-improvement-network.com/>

What are the dates of the study and why?

Incidence study period

To find out the number of new cases of MS per year, we looked at data from a 5-year period. The 5-year study period was 1st January 2018 to 31st December 2022, which means that data between these dates was included in the analysis. Because the project started in November 2023, we didn't include 2023 data since a complete data set was not yet available.

Prevalence study period

The date selected to work out the number of people in the UK was 31/12/2020. This date was chosen in line with the incidence study period (2018-2022).

How can we be sure THIN® data represents the UK population?

Using different approaches to estimate a figure will often produce different answers. No one knows the real prevalence across the UK, or in any given nation. All the figures currently available for the UK or nations are estimates. Cegedim, the MS Society, and our epidemiological advisors are confident that the estimate put forward is a good reflection of the MS prevalence in the UK.

Limitations when calculating prevalence

It's not possible to know the actual number of people with MS for an area at any time. This is partly because there is no one data source for all care activities. Also, the number of people living with MS is constantly changing in small ways (for example, due to new diagnosis, emigration, immigration and deaths).

Instead, what must be done are calculations using the numbers that are available, which then creates estimates. All our figures – both for the whole of the UK and for each UK nation – are estimates. It is important to always understand this, and that they're not a definitive figure.

THIN® coverage for the UK and 4 nations

However, the THIN® database covers 4% of the UK population. And coverage for each of the UK nations is England 1.4%, Northern Ireland 15.6%, Scotland 17.6%, and Wales 23.3%.

The number of people in this dataset means that it is statistically valid. This means that the data can be used to provide estimates of what is happening in a whole population.

Number of GP practices and patients included in THIN®

THIN® data includes over 350 GP practices across the UK and 2.8 million active patients (patients registered with a GP). This is a substantial proportion of the population and allows us to be relatively confident in the accuracy of the estimate.

How THIN® compares to Office for National Statistics (ONS) data

The Office for National Statistics (ONS) produce population level data for the UK. In comparison to ONS data, we know the sample used in our study is a good representation of the age and gender distribution of the population.

However, THIN® data relies on GP practices that use specific software to record information. This means that participants haven't been selected to represent the geographic locations or specific characteristics like age, gender, etc. Therefore, bias may exist in the data concerning these characteristics. It is important to keep this in mind when considering these estimates.

Recording of THIN® data by primary care

The estimates rely on GP's accurately recording a diagnosis of MS for each patient following notification from a neurologist. There is some information to suggest that this may not always be done correctly. There are no specific standards or guidance for MS on recording codes, and GPs may use different codes to record MS. The MS Society has been guided by healthcare data experts to ensure that all active records are captured where possible.

Why do we only have binary male and female categories?

Only sex is captured by GP practices, and is part of the initial registration process. The following options are available within the clinical system: Female, Male, Not specified, Unknown. This is a mandatory question in the dataset we used for the study, and is based on the sex assigned at birth.

Information on gender and gender preference is not captured. However, if a person legally changes their gender and updates their GP, then the entry will be updated accordingly.

Why do we not have a breakdown by type of MS?

Type of MS is not currently collected by GPs in a standardised way and in most cases MS diagnosis is not recorded by type. Limited data on MS type meant that, unfortunately, we could not include this.

Do we know if Covid had an impact on the results?

Reduced diagnosis of MS in 2020

The study has been designed to mitigate against the impact of Covid. Possible delays in diagnosing MS would have only impacted those diagnosed from about March to December 2020. Because most people included in the study would have been diagnosed before the pandemic, we're confident that the Covid-effect is minimal.

Where can I find out more about the data?

Find out more information about our incidence and prevalence figures on the MS in the UK Webpage <https://www.mssociety.org.uk/what-we-do/our-work/our-evidence/ms-in-the-uk>.

Alternatively, please feel free to contact the evidence team at evidence@mssociety.org.uk.

MS Society 2024. The Health Improvement Network (THIN) Database (A Cegedim Proprietary Database). This work uses data provided by patients and collected by the NHS as part of their care and support.

We're the MS Society.
Our community is here for
you through the highs, lows
and everything in between.
We understand what life's
like with MS.

Together, we are strong
enough to stop MS.
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