MS Society briefing on UK prevalence study

New research funded by the MS Society shows that there are likely to be around 100,000 people with MS in the UK.

Researchers at the London School of Hygiene and Tropical Medicine (LSHTM) used data from the General Practice Research Database (GPRD) to calculate a revised estimate of the number of people with MS in the UK. The GPRD is the world’s largest database of anonymised patient data from primary care, and contains patient records from 6% of GP practices in the UK. It is commonly used by academics around the world to study diseases, including studies of the prevalence of particular conditions.

In this study Dr Sara Thomas and Professor Andrew Hall from the LSHTM searched the database for codes that indicate a diagnosis of MS. Using these data and comparing them to other studies showed that there could now be 100,000 in the UK with MS. This is the first time a nationwide study of the prevalence of MS has been conducted in the UK. The new figure is a significant increase on the previous estimate of 85,000, which was based on extrapolating the data from a series of local studies.

For the first time, it has also been possible using these data to produce regional estimates, and to break the figure down by age and gender.

The raw data drawn directly from the GPRD show a much larger number of people with MS in the UK. However, studies have shown that using electronic records in this way often includes people who do not have a confirmed diagnosis of a particular condition, leading to apparently larger prevalence numbers than there are in reality.

There are several methods for assessing the accuracy of the numbers shown in the GPRD. The most robust previous study that examined the accuracy of new cases of MS recorded on the GRPD showed that approximately 82% of these people had a confirmed diagnosis of MS (adjusting the figures for possible misdiagnosis/ miscoding of MS, and excluding unconfirmed cases). It is by assuming this accuracy of 82% that our figure of 100,000 was reached. The MS Society considers this to be the most accurate estimation based on the available data.
As an alternative method of verifying the GPRD figures, researchers from the LSHTM also looked at the electronic records on the GPRD for records of neurologist visits. If the assumption is made that only those people who had had visited a neurologist around the same time as their diagnosis had MS, the estimate is slightly lower, at around 89,000. The MS Society considers this to be an overly conservative estimate as this is a less accurate method of verifying the data.

Although this type of electronic data can sometimes include people who do not have a particular condition, it has also been shown in a number of local studies that looking purely at GP records (as this study did) often misses some people. The GPRD data studied also revealed a number of people with information on their records that indicated a possible diagnosis of MS, but these people were not included in the final results.

This study is an important milestone towards having a greater understanding of MS in the UK. It is the first national project to estimate the number of people with MS in the UK, based on the best evidence available. In order to get a truly accurate and complete picture of MS in the UK, the MS Society believes that a national register is crucial. This will give us much more than just an accurate number of people living with MS in the UK: for the first time we will be able to conduct truly representative social and economic research to understand a lot more about MS in the UK and how it affects people. This could include the impact on employment, impact on carers and all other aspects of quality of life for people with MS.

MS Society
June 2009
Estimating the prevalence of multiple sclerosis in the United Kingdom
Sara L Thomas, a Rachael Williams, b Tim Williams, b Andrew J Hall, a

a Department of Epidemiology & Population Health, London School of Hygiene & Tropical Medicine
b The General Practice Research Database

Background
Estimates from a decade ago suggested that 85,000 individuals were living with an MS diagnosis in the UK, but the accuracy of this figure is unclear. We analysed UK population-based data to obtain updated estimates of the lifetime prevalence of MS and the number of individuals living with MS.

Methods
We analysed anonymised electronic medical records from the General Practice Research Database (GPRD), which covers approximately 6% of the UK population. We identified all patients registered with a GPRD practice between 2000 and 2008 with a ‘definite MS’ diagnostic code anywhere in their medical record. Prevalence of MS was calculated as the proportion of the total GPRD population who had ever had an MS diagnosis, stratified by age, sex, geographical region and calendar year. Numbers for 2007 were scaled up to the 2007 UK population, using data from the Office for National Statistics. Estimates were adjusted for possible misdiagnosis/miscoding of MS in the GPRD, using 1) a positive predictive value (PPV) of 82% for MS diagnostic codes, ascertained in a previous GPRD validation study, and 2) the proportion of MS patients who had evidence of neurologist referral and/or hospital feedback. Analyses were repeated among individuals registered with a practice for ≥1 year, to account for delayed reporting of historical MS diagnoses by practices.

Results
Crude annual prevalence of MS increased from 17.2/10^4 (95% CI:16.7-17.7) in 2000 to 19.8/10^4 (95% CI:19.3-20.3) in 2008. In 2007, prevalence was 28.1/10^4 (95% CI:27.3-28.9) among females and 10.8/10^4 (95% CI:10.3-11.3) among males, and was highest among those aged 55-64 years. Marked geographical variation was seen, with highest prevalence in 2007 in the Scottish Highlands/Islands (49.7/10^4, 95% CI:31.8-73.9) and lowest in Greater Glasgow/Clyde (12.8/10^4, 95% CI:8.8-18.1). After applying the percentage of male (72%) and female (75%) patients with neurologist referral/hospital feedback, the estimated number of individuals living with an MS diagnosis in 2007 was 88,760 (range:85,820-91,770). Using a PPV of 82% for an MS diagnostic code, the estimated number of individuals living with MS was 98,110 (range:94,820-101,450). Estimates were slightly higher when the 2007 GPRD population was restricted to those with ≥1 year’s follow-up.

Conclusion
This analysis provides updated estimates for the number of people living with MS in the UK. The apparent increase in MS prevalence over time is likely to be due in part to increased ascertainment of MS cases and improved recording of MS diagnoses. Over-estimation of the number of MS cases may have occurred, due to miscoding of tentative MS diagnoses as ‘definite MS’ cases. Conversely, MS cases may have been under-estimated, due to continuing under-ascertainment and under-recording of MS cases in general practice data, and to possible inaccuracies in the estimates of the PPV of an MS diagnostic code and the proportion of individuals with neurology referrals/hospital feedback. Future estimates of lifetime MS prevalence will be facilitated by ongoing improvements in general practice recording of diagnoses and by increasing data linkage between general practice and other medical records.