

1 million live with MS



New study doubles the previous estimate in the U.S.

by Mary E. King, PhD

Nearly 1 million people in the U.S. are now living with multiple sclerosis, more than twice the number previously estimated. This new prevalence number comes from a pivotal four-year study of millions of health records. The prevalence project, which developed a new, better way to count individuals with MS in addition to providing the new estimate, was funded by the National Multiple Sclerosis Society.

Nicholas LaRocca, PhD, former vice president of health care delivery and policy research for the Society and now an independent contractor, worked with a group of epidemiologists, neurologists and statisticians on the design and implementation of the study. "The last national study of the prevalence of MS was completed in 1976, more than 40 years ago," LaRocca says. "The earlier estimate has long been viewed with skepticism as probably much too low by people with MS as well as by researchers and clinicians."



**Mitchell T. Wallin, MD,
chaired the U.S. MS
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Photo courtesy of Mitchell T.
Wallin, MD

LaRocca says the Society, along with other advocacy groups, had gone to Congress a number of times to ask for funds for a better system to track neurologic conditions, including MS, “but the bill we supported wasn’t voted on until 2016 and was only funded in the fall of 2018. In 2013, while we were waiting for Congress to act, we decided that people with MS couldn’t wait any longer for a better estimate, and so the Society stepped up to provide funding for a national study of MS prevalence.”

Researchers don’t know yet exactly why the new prevalence number is twice the older number. (Statisticians refer to the number of people currently living with a disease as the “prevalence” of the disease.) It could reflect overall population growth, better diagnosis, the impact of disease-modifying drugs on extending the life of those with MS, the use of a new approach to the study of prevalence or other factors that simply aren’t understood.

However, LaRocca stresses a key message from this study: “Now that we know that there are twice as many people with MS, we have to work twice as hard and redouble our efforts on pathways to a cure.”

Importance of measuring prevalence

Mitchell T. Wallin, MD, chaired the U.S. MS Prevalence Workgroup that undertook the research and published the results in three papers in the journal *Neurology*. “It is important to periodically count the number of MS patients to provide proper advocacy for clinical infrastructure, education and research,” says Dr. Wallin, who is associate professor of neurology, George Washington University and University of Maryland School of Medicine, and

director of the VA MS Center of Excellence–East. “Having an accurate MS prevalence estimate helps to more optimally plan for clinical care needs.”

Dr. Wallin stresses that this estimate is important for researchers, too. “It can also provide helpful clues for researchers to better understand risk factors for MS onset and progression.” LaRocca agrees. “Having accurate estimates of prevalence allows researchers to investigate exposure to environmental risk factors and protective factors for MS in healthy individuals compared with people living with MS,” he says. In addition, using the new approach to measure prevalence of MS will provide a pathway to other data sources and registries, thereby improving the scope of MS research.

“This will enhance our ability to study environmental aspects of MS and expand opportunities to do this type of work,” La Rocca says.

A new way to measure

The traditional way of counting people with a disease involved a lot of personnel, LaRocca explains. “In 1976, researchers had to contact doctors in hospitals, clinics and practice settings, and ask office staff to review each individual patient chart and manually count how many of each doctor’s patients had MS,” he says. Then those numbers had to be collated and processed to come up with a final number.



William R. Mac Kenzie, MD, says that the National Neurological Conditions Surveillance System project will help researchers collect data to determine MS prevalence. Photo courtesy of William R. Mac Kenzie, MD

While we might think that the adoption of electronic medical records (EMR) by most physicians would simplify this type of counting today, unfortunately, not all EMR systems can communicate with each other or with a central researcher. It would still take many people a long time to collect data from EMRs, LaRocca says. He also points out that privacy concerns could make this challenging as well.

The MS prevalence study group had to come up with a new way to count people with MS. Group members turned to administrative datasets used by healthcare payers, such as private insurers, Medicare, Medicaid and the Veterans Administration. These records use a single diagnostic code for any outpatient or inpatient medical visit that involves MS or possible MS. Privacy is maintained since the actual data are anonymous and do not include patient identifiers.

The formula that the study group devised and validated is a bit more complicated than simply counting the MS codes. It involves looking at various combinations of outpatient and inpatient visits and prescriptions for MS disease-modifying medications to accurately estimate the number of individuals who are likely to have a confirmed diagnosis of MS.

The global perspective

Global numbers are also critical to funding, patient care and MS research. The MS International Federation (MSIF) has begun a project to reassess the global prevalence of MS called the Atlas of MS, Third Edition, to be published in 2020.

“In 2013, the MSIF estimated that 2.3 million people worldwide live with MS. That data showed that most people with MS lived in North America or Europe. East Asia and Sub-Saharan Africa had the lowest prevalence of MS,” says Nick Rijke, interim deputy CEO of MSIF. “Interestingly, evidence from a number of studies shows that when people migrate from low to high prevalence areas, over time the risk that they and their offspring will develop MS becomes much closer to the risk level of their adopted home country. When MSIF publishes the third edition of the Atlas of MS, it will be very interesting to see how rates of MS in North America and Europe compare to other parts of the world,” he says.

The future of data collection

As part of the 21st Century Cures Act of 2016, Congress authorized the Centers for Disease Control and Prevention (CDC) to develop the National Neurological Conditions Surveillance System (NNCSS) to collect data to increase understanding of neurological disorders and support future research. The project, a top policy priority of the National Multiple Sclerosis Society for several years, had remained unfunded until recently. Congress has since appropriated \$5 million for NNCSS for fiscal year 2019.

The CDC is exploring the best ways to collect and synthesize data about various neurologic conditions. The data they will collect as part of the NNCSS include a variety of essential

information about neurologic diseases.

The first stage of this venture will create demonstration projects that focus on MS and Parkinson's disease (PD). During this initial phase, the CDC hopes to learn how to provide the most useful data for incidence and prevalence and have the biggest impact by exploring data sources (e.g., government healthcare databases such as Medicare, Medicaid and surveys) and new method sources (e.g., MS registries and electronic health records). The second stage involves using successful approaches from stage one to maintain MS and PD surveillance over time and assessing what resources and costs this requires. The CDC hopes to take the lessons learned from stages one and two to broaden NNCSS to additional neurologic conditions in the third stage.

William R. Mac Kenzie, MD, deputy director for Science, Center for Surveillance, Epidemiology, and Laboratory Services, CDC, says this program has important impacts for people with MS. "The NNCSS initiative will help researchers and clinicians determine whether MS cases are increasing, decreasing or staying the same," he says. "We will look for differences in age, race, ethnicity and geographic clusters. This important information will help drive future research to prevent and control MS."

Mary E. King, PhD, is a medical writer in Boulder, Colorado.

Learn more about the [MS prevalence study](#).

Learn about details of the [National Neurological Conditions Surveillance System](#).