



Interim Report to Congress on
**National Neurological Conditions
Surveillance System**



MAY 2020



**U.S. Department of
Health and Human Services**
Centers for Disease
Control and Prevention



National Neurological Conditions Surveillance System

INTERIM REPORT TO CONGRESS
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In December 2016, Congress authorized CDC to develop a National Neurological Conditions Surveillance System (NNCSS) in the [21st Century Cures Act](#). This report was prepared in response to a requirement in the legislation pursuant to Section 2061, for an interim report regarding “aggregate information collected . . . and epidemiological analysis, as appropriate.” With the initial appropriation in fiscal year 2019, CDC

- Met with stakeholders to understand their need,
- Developed a three-stage strategy to establish integrated surveillance for a wide range of different neurological conditions by building upon existing data systems, and
- Initiated the first stage of the NNCSS strategy, involving demonstration projects to determine how we can best estimate rates of disease for two conditions: multiple sclerosis (MS) and Parkinson’s disease (PD).

CDC selected MS and PD as neurological conditions with different characteristics so we could learn as much as possible that might be relevant to a range of neurological conditions. For example, PD primarily affects people over 60 years old (although younger people can also be affected) and is slightly more common in men. Diagnosis is complicated by a lack of biomarkers and the symptoms of PD are shared by a few other neurodegenerative disorders. MS often starts when people are between the ages of 20 and 40 years, it is more common in females than males, there are standard diagnostic criteria, and most of the drugs used for MS are specific to MS. Similarities between PD and MS also made them a good pair of candidates for demonstration projects: both involve significant morbidity, both place a substantial burden on patients and their families, and both have engaged stakeholders who were committed as part of an informal coalition to get surveillance for MS and PD as well as other neurologic conditions.

CDC is actively identifying efficient, sustainable, and replicable approaches that could be used for ongoing surveillance of a range of neurological conditions. As part of our commitment to [public health data modernization](#), the approach to surveillance being developed will demonstrate the use of state-of-the-art tools and robust analytic methods as part of a systems approach to data collection, surveillance, and the derivation of actionable and timely information.

Only one year into our work, we have made substantial progress. We have produced surveillance information for MS and PD by bringing together a variety of data sources and creating a replicable approach to surveillance building on existing data systems. We are now checking our findings, generating additional information for stakeholders, and developing user-friendly and informative formats for sharing data broadly with stakeholders and the general public.

WHY IT MATTERS

Millions of people across the United States face substantial and sometimes devastating consequences from neurological disorders. Focused and augmented surveillance will expand understanding of these conditions and the information will be used to improve health outcomes for people of all ages. Ultimately, CDC's approach with partners will be a robust system that can



Calculate estimates of prevalence (number of people with a condition) and mortality for a range of neurological conditions, and explore how prevalence and mortality vary by demographic characteristics (e.g. age, sex, and race/ethnicity) and presence of co-morbidities (other diseases or conditions)



Improve overall surveillance and understanding of neurological conditions



Strengthen stakeholder collaboration and shared resources



Generate additional awareness for neurological conditions and support impacted patients and families



Catalyze research into the causes of neurological conditions and ways to improve their diagnosis and treatment

THE THREE STAGES OF THE STRATEGY FOR DEVELOPING THE NNCS

CDC is building an approach to the surveillance of neurologic conditions in three stages. Stages two and three are dependent upon resources.

1

STAGE ONE: Learning what Works

Stage one will take two years and will extend from FY 2019 through FY 2020. The stage one demonstration projects involve evaluating a variety of data sources and analytic methods for surveillance of MS and PD—the two conditions initially being evaluated. We are actively producing national estimates of prevalence (i.e., the number of people living with MS or PD) and working to determine overall mortality estimates for MS and PD. We are also collecting information on related demographic characteristics (e.g., differences by gender, age, race/ethnicity, or geographic location), and assessing co-morbidities (e.g., presence of other diseases) and indicators of disease burden (e.g., healthcare usage and long-term care).

Throughout this stage, we are documenting what works and capturing lessons learned in order to scale up and roll out efficient, flexible, replicable, and sustainable approaches to use for ongoing national surveillance of MS, PD, and other neurological conditions.

2

STAGE TWO: Building National Surveillance Capacity

Stage two will take approximately one year, beginning late in FY 2020 and extending through FY 2021. During stage two, CDC will implement a proposed approach for ongoing surveillance of MS and PD. The approach largely relies on existing data infrastructure to maximize efficiencies and leverages other assets such as survey data and more timely electronic health record data for augmenting what is known about these conditions. We will assess costs and staffing needs and document additional lessons learned to make any necessary adjustments to our approach, so we can scale up and extend surveillance capacity to other neurological conditions.

3

STAGE THREE: Extending NNCSS to Other Conditions

Stage three will commence in FY 2022. During this stage, we will apply the approach developed in stages one and two to extend to other neurological conditions. We will also periodically reassess data sources and methods to assure best practices. There are hundreds of debilitating neurological conditions that can be devastating, with a severe impact on affected individuals and their families. We are exploring various methods and criteria for determining which condition(s) may be included in the future. Criteria could include such things as morbidity; mortality; impact on quality of life for patients and their loved ones; economic burden on the patient, their family, the health care system, and society; demographics; and the availability of treatment options, to name a few. Our current focus is to create a replicable surveillance approach that can be scaled and sustained for the ongoing surveillance of a range of neurologic conditions.

PROGRESS TO DATE

CDC has maximized speed and efficiency for this project by first assessing in-house data sources, while simultaneously developing mechanisms to secure access to the additional sources. Evaluating a large number of potential [data sources](#) has been important because diagnosing neurological conditions is complex, important diagnostic information may be missing from data sources, and diagnostic criteria change over time. Both traditional data sources and new data sources and methods are under consideration. Traditional data sources include administrative data (such as claims from Medicare, Medicaid, or commercial entities, as well as hospital discharge data), survey data (from the National Center for Health Statistics and elsewhere), and vital records data. New data sources that are already widely available include electronic health records. CDC is exploring non-traditional surveillance approaches and modern analytic methods such as linking electronic health records and claims, collaborating with clinical networks, and exploring the value of machine learning for increasing efficiencies. Assessing the value of these data sources and methods is paving the way for developing a new model to efficiently initiate surveillance for additional neurological conditions.

Additionally, we are exploring the use of [electronic case reporting](#), where case reports from electronic health records are automatically generated and sent to public health agencies for review and action, thereby reducing the reporting burden on healthcare providers and enabling a cost-effective, interoperable exchange of information between health care and public health providers. Electronic case reporting, which is being implemented with the PD registries in California and Nebraska, can help facilitate patient recruitment for clinical trials and catalyze data sharing for research.

CDC developed a partnership with the National Institutes of Health’s National Institute of Neurological Disorders and Stroke to secure additional subject matter expertise and enhance future research. Additionally, CDC secured local assistance from neurologists specializing in MS and PD from the Emory School of Medicine and the U.S. Department of Veterans Affairs.

In collaboration with the neurologists and neuroscientists, CDC is assessing the current state of science used to estimate prevalence and incidence of MS and PD, a critical first step in a population-based approach to improving the health of affected patients and prevention. The review findings, combined with information about current diagnostic standards, are helping us to develop and refine algorithms to identify PD and MS cases in a range of different types of data sources. We continue to use these algorithms to produce MS and PD prevalence estimates and explore demographic differences.

Throughout the project, CDC has remained committed to the identification of efficient, sustainable, and replicable approaches that can be used for ongoing surveillance of a range of neurologic conditions.

PRINCIPAL EFFORTS

 <p>Consulted with national and international experts on MS and PD to determine the most robust ways to estimate rates of these conditions</p>	 <p>Developed a partnership with the National Institute of Neurological Disorders and Stroke at the National Institutes of Health to enhance future research</p>	 <p>Collaborated with stakeholders to ensure representation of patient perspectives</p>
 <p>Established working relationships with PD registries in California and Nebraska, exploring the use of electronic case reporting for surveillance and catalyzing research</p>	 <p>Identified, acquired, and evaluated potential sources of data for PD and MS surveillance</p>	 <p>Assessed the current state of the science for estimating MS and PD rates</p>
 <p>Developed algorithms for identifying PD and MS cases to use in a range of different types of data sources</p>	 <p>Applied the algorithms to explore MS and PD prevalence estimates and demographic differences</p>	 <p>Made substantial progress towards identifying efficient, sustainable, and replicable approaches for ongoing surveillance of a range of neurological conditions that build on existing data systems, are scalable, and look to increase interoperability</p>

COLLABORATION WITH STAKEHOLDERS AND FEDERAL COLLEAGUES

As noted above, CDC has proactively engaged principal stakeholders and has been actively collaborating with patient advocacy organizations such as the National Multiple Sclerosis Society and the Michael J. Fox Foundation for Parkinson's Research who represent those impacted by devastating neurological diseases and conditions. CDC is also collaborating with other federal colleagues at the National Institutes of Health's National Institute of Neurological Disorders and Stroke as well as the U.S. Department of Veteran's Affairs.

In March 2019, CDC coordinated an initial stakeholder meeting in Washington, DC. During this event, CDC and primary stakeholders representing MS and PD and federal colleagues discussed the project and covered topics related to science, policy, and communication. Participants exchanged information and learned more about CDC's approach to standing up surveillance. Attendees also had an opportunity to review and provide feedback on the [logic model](#) for fiscal year 2019.

On November 5, 2019, CDC collaborated with the Association of State and Territorial Health Officials to bring together 34 patient advocates representing a broad range of neurological conditions to discuss public health surveillance needs and provide updates on the progress. Major themes emerging from the roundtable discussion at the meeting included: data, analytics, and the analysis needs; stakeholder engagement requests; patient mental health and wellbeing concerns; criteria for choosing the next neurological condition for surveillance; financial and cost considerations; and policy and communication needs.

To keep partners and stakeholders updated, CDC has created a suite of materials and resources that are publicly available [online](#).

CONCLUSION

The approach to surveillance developed through the demonstration projects integrates data from a variety of data sources to create a replicable surveillance approach with existing systems. This approach can be scaled and sustained for the ongoing surveillance of a range of neurologic conditions. Information from the surveillance system will enable CDC to assist in generating a greater understanding of neurological disorders, catalyze research, and help to improve the health and economic consequences for the millions of people affected by these devastating conditions.