

# Process Evaluation to Document Crucial Moments in Development of the National Neurological Conditions Surveillance System at the U.S. Centers for Disease Control and Prevention

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**Background:** Neurological conditions or disorders strike roughly 50 million Americans annually but accurate and comprehensive national estimates for many of these conditions are not available. In 2019, Congress provided \$5 million to Centers for Disease Control and Prevention (CDC) to establish the National Neurological Conditions Surveillance System (NNCSS). CDC focused initial activities on multiple sclerosis and Parkinson's disease.

**Purpose:** We conducted a process evaluation to document and understand multifaceted work to implement a new surveillance activity for two neurological conditions.

**Setting:** We conducted this evaluation with government personnel internal to the Center for Surveillance, Epidemiology, and Laboratory Services at the Centers for Disease Control and Prevention in Atlanta, GA.

**Intervention:** A new public health surveillance activity for two neurological conditions, multiple sclerosis and Parkinson's disease, that uses existing data resources and systems.

**Research design:** The evaluation included interviews with CDC personnel and review of administrative and programmatic information. Data were analyzed and interpreted to identify crucial moments in the first year of funded work on NNCSS. The study revealed that this surveillance activity required diverse contributions and collaboration within the federal government and with non-governmental organizations. The findings can be used to guide work to enhance surveillance for many neurological conditions.

**Findings:** The study revealed that this surveillance activity required diverse contributions and collaboration within the federal government and with non-governmental organizations. While collaboration is a cornerstone of public health practice, it is not always well-documented in planning or implementation of surveillance or other data-related activities.

**Keywords:** *program evaluation; surveillance; neurological conditions; neurological disorders; multiple sclerosis; Parkinson's disease.*

## Introduction

Neurological conditions or disorders touch the lives of millions of Americans and cost hundreds of billions of dollars in medical expenses and lost productivity (National Institute of Neurological Disorders and Stroke, 2019). Yet, we do not have accurate and comprehensive information on incidence or prevalence for many of these conditions (Pringsheim et al., 2014). This lack of information can hinder attention to the conditions and remains a concern among patients, their families, and advocacy organizations. In 2016, as part of the 21st Century Cures Act (2016), Congress authorized the U.S. Centers for Disease Control and Prevention (CDC) to develop a National Neurological Conditions Surveillance System (NNCSS). In Fiscal Year 2019, Congress provided \$5 million to CDC to support work on this new surveillance activity. As a starting point, CDC (2020a) aimed to understand the interests and needs of diverse stakeholders; identify and assess potential data sources and analytic methods; produce national estimates of prevalence and incidence for multiple sclerosis (MS) and Parkinson's disease (PD); and capture lessons learned that can be used to enhance surveillance for these and other neurological conditions. In the NNCSS logic model, additional outcomes of the work included robust and ongoing collaboration among government and non-government organizations and expanded use of existing, internal data resources to support surveillance for neurologic conditions (CDC, 2020b). For example, CDC Data Hub provides centralized acquisition of external health care data for programs agency-wide (Division of Health Informatics and Surveillance, 2019). Personnel used this enterprise-level, shared resource to access a range of data relevant to MS and PD. No primary data collection or new information technology-based system was needed to develop this surveillance activity. CDC-based stakeholders viewed work on NNCSS as an opportunity to contribute to cross-functional collaboration under the Public Health Surveillance Strategy (CDC, 2018). We used process evaluation to document and understand a full complement of activities in the first year of funded work.

Information from this evaluation was used to improve current work on national estimates of incidence and prevalence for MS and PD and can be used to support future work on surveillance for other neurological conditions.

## Data Collection, Analysis, and Interpretation

Program evaluation refers to “the systematic collection of information about the activities, characteristics, and results of programs to make judgments about the program, improve or further develop program effectiveness, inform decisions about future programming, and/or [sic] increase understanding” (Patton, 2008, p.39). In this case, we used process evaluation to examine what was included in initial work on this surveillance activity and how it occurred over time (CDC, 2008). Process evaluations provide information on the implementation of an activity or program and can address how resources were used and roles and participation across contributors or other stakeholders, for example (Limbani et al., 2019; Moore et al., 2015). This evaluation addressed two questions: (1) how did contributors establish surveillance for two neurological conditions, and (2) what can be learned from this work that can be used to improve surveillance for these and other neurological conditions? Data collection methods to address these questions included key informant interviews with personnel in the Center for Surveillance, Epidemiology, and Laboratory Services at the CDC and review of administrative and operational documents internal to CDC and on a public-facing webpage. Eleven participants explained their work on this surveillance activity in eight, one-hour interviews. For example, they discussed individual roles and responsibilities, practical challenges in their work on this activity, and decisions made in language understandable by someone unfamiliar with public health practice or surveillance, specifically. The information was captured in notes and analyzed to create a single list of twenty-eight decisions and tasks articulated by interviewees as important aspects of the work process. The list included the specific items that participants identified as necessary to

stand up this new surveillance activity. In many cases, interviewees talked about the same activities or tasks from different perspectives. A subset of interviewees reviewed this list to validate the information. Review of the program description, logic model, and work plans did not produce additions to the list but aided in understanding the order of items and any interrelationships between or among items. While each contribution was important, this evaluation aimed to document and understand decisions and tasks seen as crucial to early progress to establish surveillance for MS and PD. This information can be used to enhance continued work on surveillance for these conditions and support work to initiate or improve surveillance for other neurological conditions.

Personnel identified discrete criteria to determine whether a decision or task that surfaced via this evaluation represented a crucial moment in the first year of funding for NNCSS activities. Crucial moments were defined as essential junctures where CDC personnel and stakeholders made decisions, set a direction, or took action. Specifically, decisions or tasks interpreted as crucial moments met six criteria: aligned to content in the public-facing logic model; were understood as high-stakes items; addressed a commitment or mandate of some sort; were a culminating action, decision, event, or product; improved the credibility, transparency, or visibility of this surveillance activity; or required all, or nearly all, work streams to implement the item. For example, each decision or task interpreted as crucial can be mapped to specific content in the NNCSS logic model. Decisions or tasks were viewed as high stakes when, if not done, a process or product could be delayed, fail entirely, or create a risk to resources or progress toward intended outcomes. The criterion that addressed a commitment or mandate to undertake an item included requirements in Congressional language, expectations articulated by Department of Health and Human Services or CDC leadership, a cooperative agreement or contract that specifies the work, or agreements with other stakeholders. Items that represented key milestones in the project and required substantial collaboration across

work streams were also considered crucial. Finally, decisions or tasks seen as vital to improve the credibility, transparency, or visibility of this surveillance activity among stakeholders (internal or external to the agency) were also understood as crucial.

## Findings

This evaluation produced detailed information on multiple streams of work in the first year of funding for the NNCSS. Specifically, the in-depth interviews and review of principal documents produced a series of twenty-eight decisions and tasks relevant to administrative and planning functions, collaboration (internal and external to the agency), communications, data sources and analytics, leadership and management, legislative and policy activities, program evaluation, and science-related activities to fully understand MS and PD as a foundation to many aspects of this surveillance activity. From the twenty-eight decisions and tasks articulated as important aspects of the work process, we identified fifteen crucial moments via application of the six criteria discussed previously. The decisions and tasks identified as crucial moments met all six of these criteria. In Figure 1, we visualize the crucial moments in an annotated timeline in plain language. For each crucial moment in Figure 1, there is a brief description of the decision or task, associated dates, and whether the item is ongoing. Current and future staff and stakeholders can use the information to understand initial activities and accomplishments to develop this surveillance activity. The crucial moments summarize what was done, how, and when. For example, the annotated timeline reveals that work to initiate this public health surveillance activity was interdisciplinary; it was not done solely by epidemiologists or subject matter experts in a specific condition or disorder. We also see that only five of the fifteen crucial moments presented in Figure 1 focus entirely on data-related activities or tasks. Most crucial moments depict a coalition of diverse, multidisciplinary contributors, internal and external to the agency. For example, several crucial moments include communications work: internal communications,

communications with stakeholders external to the agency, and communication materials or products shared with the public.

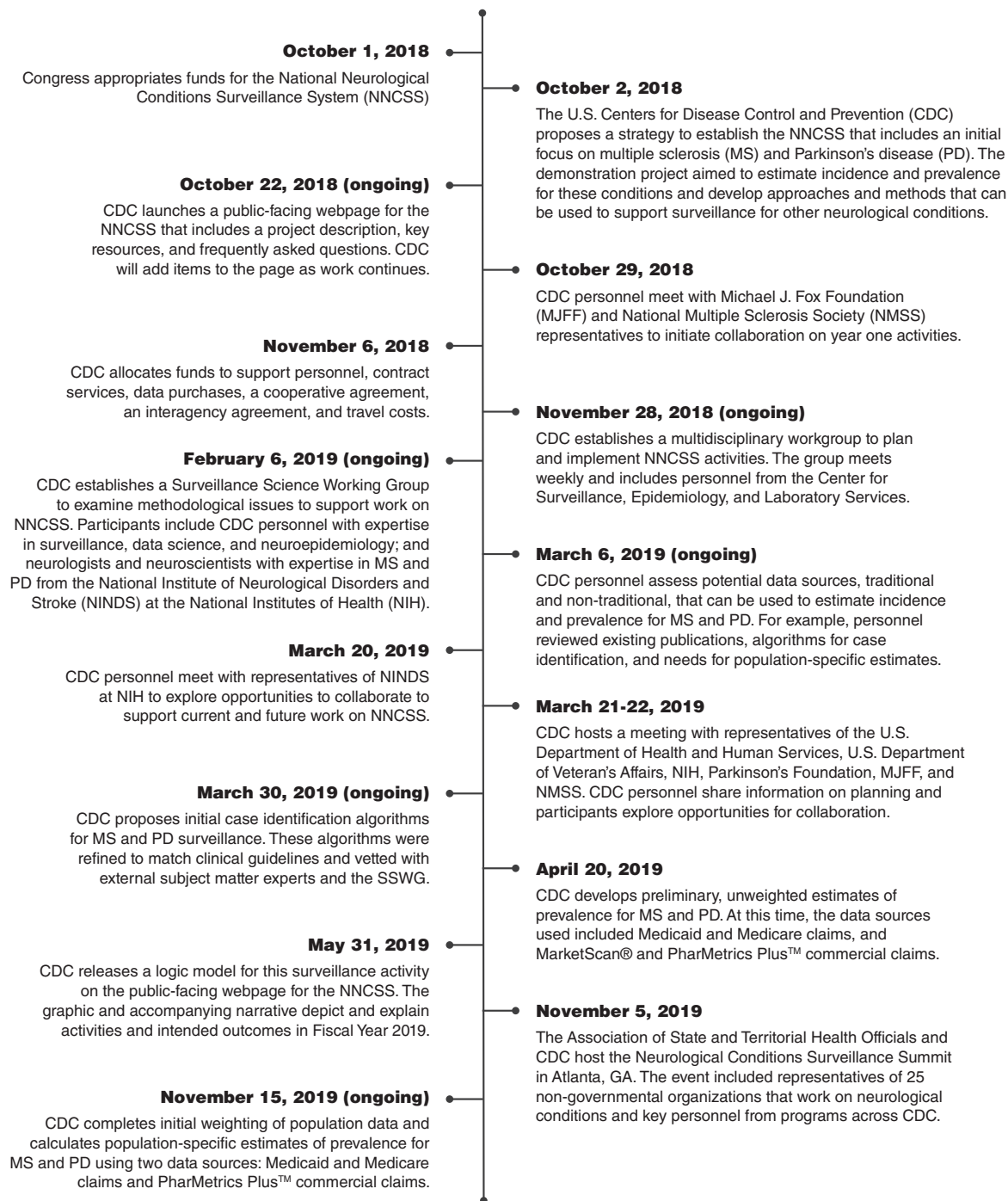


Figure 1. Annotated timeline of crucial moments to establish the national neurological conditions surveillance system (October 1, 2018 - December 31, 2019)

## Conclusions

This evaluation aimed to document activities to establish a model surveillance approach with an initial focus on two neurological conditions. We used process evaluation to identify and understand a series of crucial moments in funded work for a fifteen-month period. The series of crucial moments presented in this practice brief represent real-world, tangible junctures where CDC personnel and stakeholders made decisions, set a direction, or took action. Looking more closely, each of these moments is marked by collaboration, internal or external to the agency. Certainly, collaboration is widely accepted as necessary to effective program implementation in public health (Frieden, 2014). Yet, collaboration it is not always well-documented in relation to planning or implementation of public health surveillance or other data-related activities. The evaluation revealed that initial work on NNCSS included diverse contributions in addition to the epidemiological expertise common to public health surveillance activities.

While the annotated timeline presents crucial moments in sequential order beginning in October 2018, it does not explain the substantial work that occurred prior to legislative action to establish the NNCSS and support the activity. Similarly, the annotated timeline presents the crucial moments in a level of detail that does not include the daily or weekly work needed to complete or produce each crucial moment. Nonetheless, the consistency aids readers to understand the overall progression of early work on NNCSS and provides a window into a collaborative, multidisciplinary public health surveillance activity that is not always well-documented.

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## Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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