Development of a National Neurological Conditions Surveillance System (NNCSS)

As part of the 21st Century Cures Act, Congress authorized the Centers for Disease Control and Prevention (CDC) to develop a National Neurological Conditions Surveillance System (NNCSS) that provides useful estimates of neurological conditions in the United States. CDC is using existing data sources and emerging sources, methods, and tools to 1) estimate prevalence and explore incidence for multiple sclerosis (MS) and Parkinson's disease (PD), and 2) create efficient, reusable processes and models that can be applied to multiple conditions to provide disease-specific surveillance information.

INPUTS

Actual and anticipated resources, material and intellectual ¹



- CDC leadership and commitment
- Active and sustained collaboration with stakeholder organizations
- Access to diverse subject matter expertise, internal and external to CDC
- Human and fiscal resources dedicated to this work
- Existing technical capabilities and infrastructure Agencywide
- Access to key data resources, internal and external

ACTIVITIES

What the program does to create, or contribute to, benefits or changes ¹



- Summarize knowledge on case definitions for MS and PD
- Summarize previous work on prevalence and incidence
- Identify and summarize existing data that can be used to calculate prevalence and explore incidence (i.e. data already in-house or easily obtained)
- Prepare explanation of options to calculate prevalence and explore incidence for discussion with stakeholders
- Calculate initial estimates of prevalence, and perhaps incidence, based on work completed above
- Explain these estimates in a format suitable to stakeholders

Engage and listen to representatives of diverse stakeholder organizations

Document demonstration project processes and outcomes

- Document and explain work completed and products delivered
- Capture lessons learned to support work on these and other neurological conditions
- Articulate options to derive estimates for MS and PD
- Recommend immediate and longer-term activities based on achievements and challenges

Disseminate work completed to relevant stakeholders via appropriate channels

OUTCOMES

Expected benefits, changes, or results of the program ¹

Intended benefits or changes specific to MS and PD surveillance

- Better understand challenges and information needs specific to MS and PD
- Estimates of prevalence and incidence

Intended benefits or changes relevant to neurological conditions surveillance

- Improved knowledge and experience relevant to neurological conditions surveillance
- Continued innovation in surveillance for neurological conditions

Intended benefits or changes relevant to CDC's practices

- Expanded Data Hub utility for public health surveillance
- Expanded cross-functional collaboration under the Public Health Surveillance Strategy

Increasingly robust National Neurological Conditions Surveillance System (NNCSS)

Expanded
and improved
application of
processes and
models to provide
disease-specific
surveillance
information

Intended benefits or changes relevant to collaboration with stakeholder organizations

- Strengthened collaboration among stakeholder organizations (government and non-government) to support NNCSS
- Stakeholder organizations and public use estimates to improve awareness and support



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

 Checklist of key considerations for development of program logic models. https://wmich.edu/evaluation/checklists