

National Population Health Study on Neurological Conditions: Planning for 2014



CDRAKE - April 11, 2013



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

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NPHSNC

- 4-year study co-led by NHCC & the Public Health Agency of Canada
- Research teams across Canada building a better understanding of neurological conditions in Canada:
 - Incidence, prevalence and co-morbidities
 - Impact on individuals & families
 - Risk factors for onset & prognostic factors
 - Best practice health & support services



Governance of NPHSNC

- The Honourable Leona Aglukkaq, Minister of Health
- Director General, Chronic Disease, PHAC
- Implementation Committee
 - Co-Chairs, PHAC & NHCC
 - Representation from CIHR, PHAC, HC & NHCC
- Scientific Advisory Committee
- Principal Investigators & Project Managers



Conditions to be Studied

- ALS
- Alzheimer's disease & other dementia
- Brain Injury
- Brain Tumour
- Cerebral palsy
- Dystonia
- Epilepsy
- Huntington's disease
- Hydrocephalus
- Migraine
- Multiple sclerosis
- Muscular dystrophy
- Parkinson's disease
- Spina bifida
- Spinal cord injury
- Spinal cord tumour
- Stroke
- Tourette's syndrome

Components of the NPHSNC

3 National Surveys

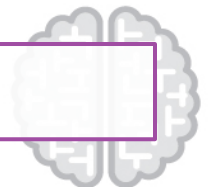
13 Pan Canadian Research Projects

Micro-Simulation project

Expansion of the Canadian Chronic Disease Surveillance System (CCDSS)

Synthesis Process

Report to the Implementation Committee



Scope (Incidence, Prevalence)

StatsCan

- Canadian Community Health Survey: Neurological Conditions 2010-2011
- Survey of Neurological Conditions in Institutions in Canada.

Projects

- **Validation of Administrative Data Algorithms to determine Population Prevalence and Incidence of Alzheimer's Disease, Dementia, Multiple Sclerosis, Epilepsy and Parkinson's Disease;** PI: Dr. Karen Tu, ICES/University of Toronto,
- **Canadian Primary Care Sentinel Surveillance Network: CPCSSN Neurodegenerative Conditions;** PI: Dr. Richard Birtwhistle, Queen's University, Dr. Neil Drummond, PhD, University of Calgary,
- **Neurological Conditions in British Columbia;** PI: Kim Reimer, B.C. Ministry of Health
- **Understanding the Epidemiology of Neurological Conditions and Building the Methodological Foundation for Surveillance;** PI: Dr. Nathalie Jetté, University of Calgary

PHAC

- Expansion of the Canadian Chronic Disease Surveillance System



Registries

Projects

- **Neurological Registry Best Practice Guidelines and Implementation Toolkit**
 - Principal Investigator: Dr. Lawrence Korngut, University of Calgary
- **Expansion of a Canadian Multi-Regional Population Based Cerebral Palsy Registry**
 - Principal Investigator: Dr. Michael Shevell, NeuroDevNet



Impact

StatsCan

- The Survey on Living with Neurological Conditions in Canada (SLNCC)

Projects

- **The Everyday Experience of Living with and Managing a Neurological Condition (The LINC Study);** PI: Dr. Tanya Packer, Dr. Joan Versnel, Dalhousie University
- **Canadian Longitudinal Study of Aging: Neurological Conditions Initiative (CLSA-NCI);** PI: Dr. Christina Wolfson, PhD, McGill University
- **Understanding from Within: Developing Community-Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal Peoples;** PI: Dr. Carrie Bourassa, First Nations University



Health Services

Projects

- **Innovations in Data, Evidence and Applications for Persons with Neurological Conditions (ideas PNC)**
 - *Principal Investigator:* John P. Hirdes, PhD, University of Waterloo
- **Use and Gaps in Health and Community-Based Services for Neurological Populations: A Systems Analysis**
 - *Principal Investigator:* Dr. Susan Jaglal, University of Toronto



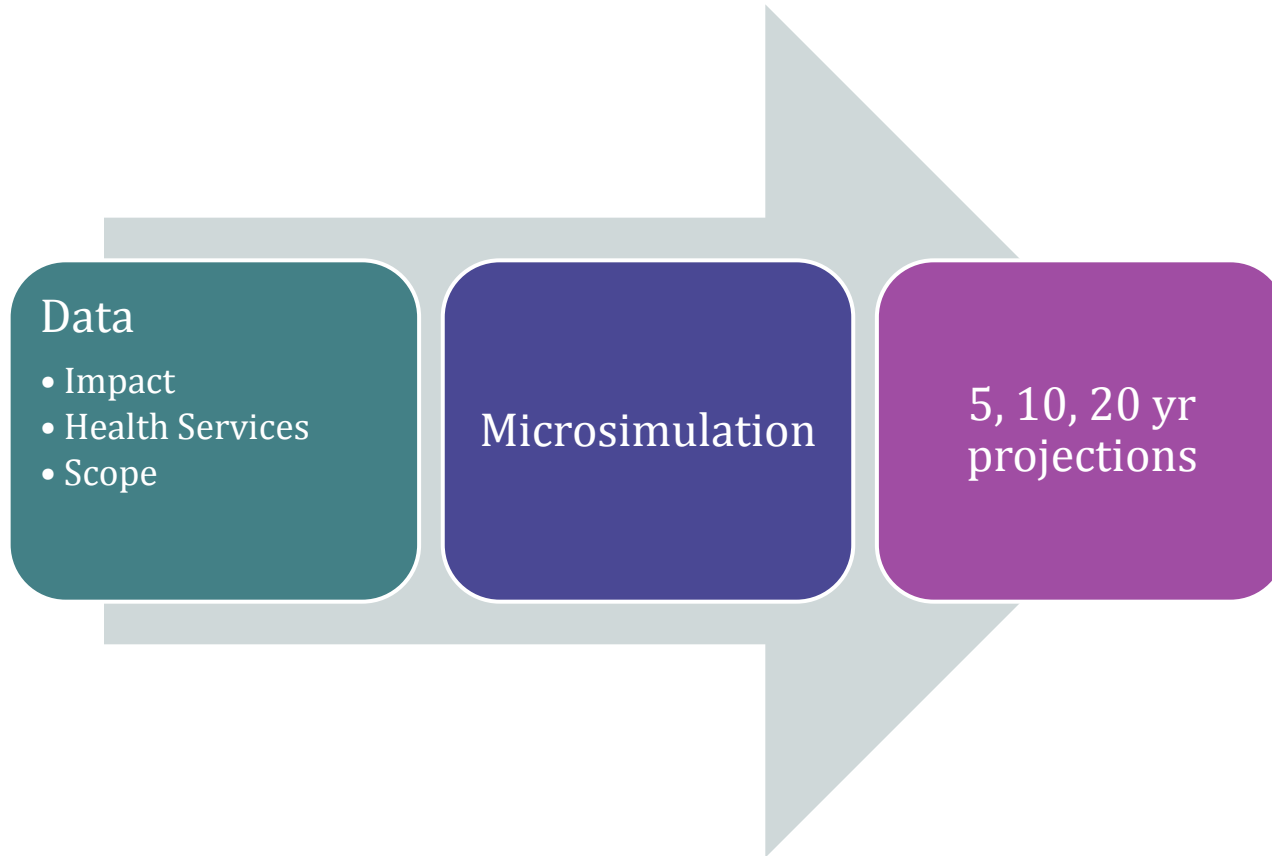
Risk (Onset and Progression)

Projects

- **Systematic Review of Factors Influencing the Onset and Progression of Neurological Conditions**
- PI: Dr. Daniel Krewski, University of Ottawa



Microsimulation



The Team

Researchers

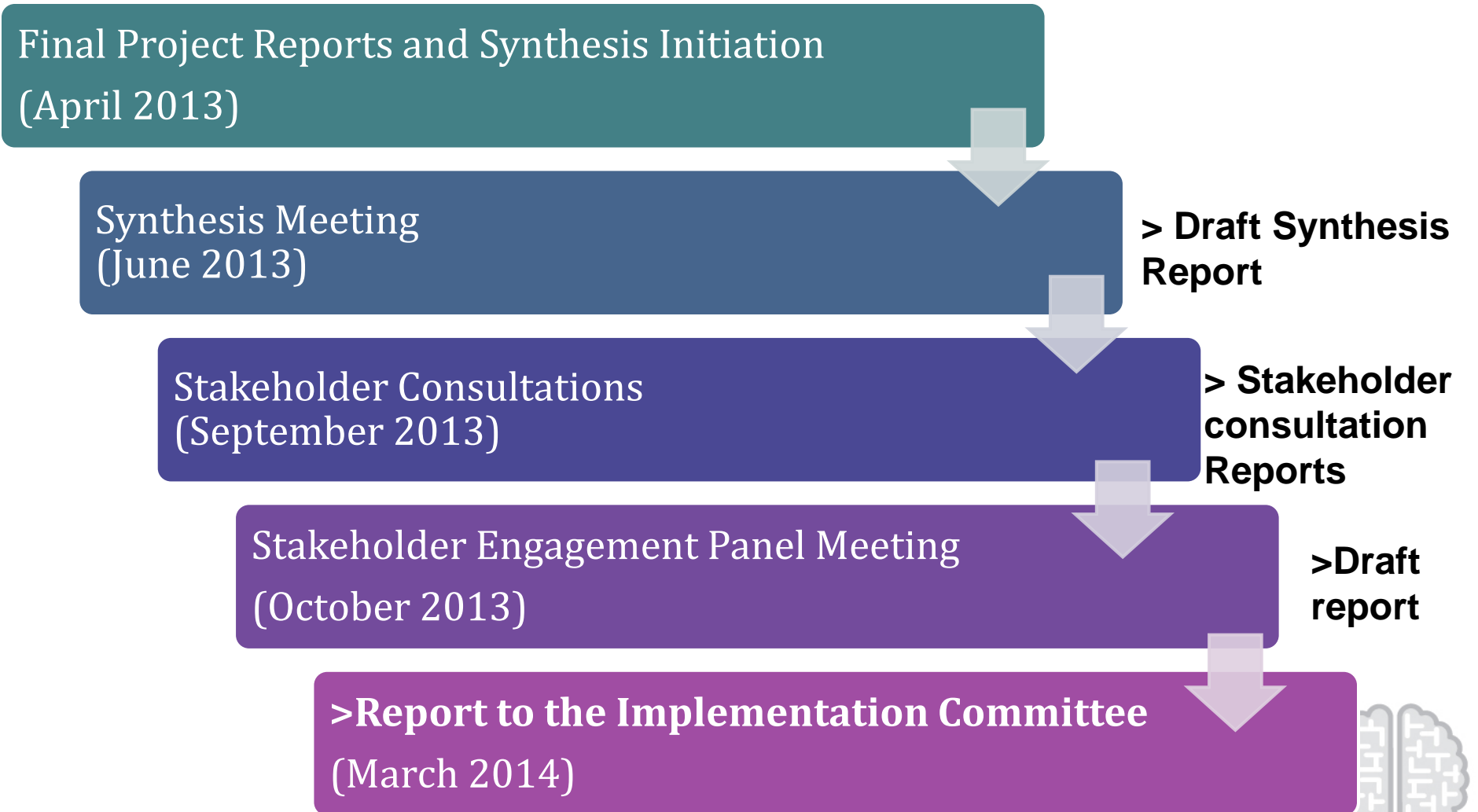
- 127 Researchers
- 26 Working on multiple projects within the Study
- 31 Institutions
- BC, AB, MB, ON, QB, NFLD, NS, PEI
- USA and Europe

Projects

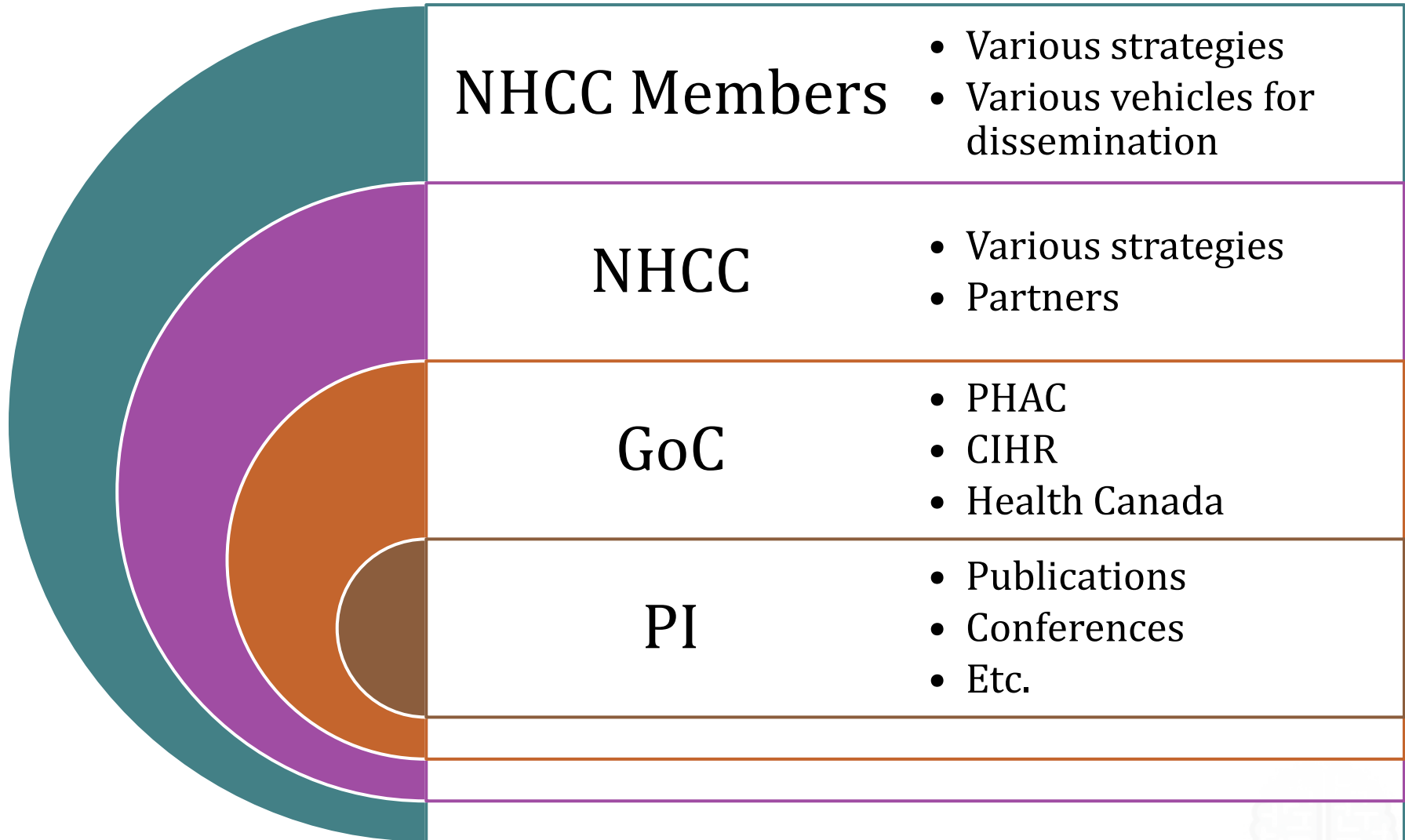
- 3 Surveys
- 13 Pan-Canadian Research Projects
- 1 Microsimulation
- Synthesis Process



Synthesis Process



Partners – KT and Dissemination



Getting Involved

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