



Brain Health in Canada: Assessment of Knowledge and Policy and Program Implementation Gaps Identified in *Mapping Connections* Four Years On

Shawna Cronin, BSc, MScOT, PhD Candidate
Institute of Health Policy, Management, and Evaluation, University of Toronto

Leslie Carlin, PhD
Research Associate, Department of Physical Therapy, University of Toronto

Susan Jaglal, BSc, MSc, PhD
Professor, Department of Physical Therapy, University of Toronto

March 2018

Production of this document was made possible thanks to the financial support of the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

Neurological Health Charities Canada

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions.

NHCC Mission

Working together to improve the lives of people affected by brain diseases, disorders and injuries in Canada.

Neurological Health Charities Canada
4211 Yonge Street, Suite 316
Toronto ON M2P 2A9
416-227-9700, ext. 3314
www.mybrainmatters.ca

Contents

Project Summary.....	6
1.0 Introduction	8
2.0 Methods.....	9
2.1 Data Collection.....	9
2.2 Analyses	10
3.0 Current Large-scale Initiatives for Neurological Conditions	11
4.0 Current Large-scale Initiatives for Dementia	12
5.0 Progress on Knowledge Gaps Identified in Mapping Connections Pertaining to Neurological Conditions	13
5.1 Gaps in Impacts of Neurological Conditions on Affected Individuals, Their Families, Caregivers, and Communities.....	14
5.2 Gaps in Health Service Provision, and Knowledge of Health Services for Neurological Conditions	15
5.3 Gaps in the Scope of Neurological Conditions.....	17
5.4 Gaps in Knowledge on Risk Factors for the Development and Progression of Neurological Conditions	19
6.0 Synthesis of Knowledge Gaps of Neurological Conditions	20
7.0 Progress on Knowledge Gaps: A Focus on Dementia	21
7.1 Gaps on Impacts of Dementia on Affected Individuals, Their Families, Caregivers, and Communities.....	21
7.2 Gaps in the Scope of Dementia.....	23
7.3 Gaps in Health Services for Dementia.....	24
7.4 Gaps in Knowledge about Risk Factors for Dementia.....	25
7.5 Synthesis of Dementia Knowledge Gaps.....	26
9.0 Obstacles to Closing Gaps for Neurological Conditions and Dementia	27
11.0 Strengths and Limitations	27
12.0 Recommendations	28
13.0 Conclusions	28
Acknowledgements.....	30
References	31
Appendix B: Survey Sent to Key Informants	37
Appendix C: Written Sources Reviewed (alphabetical)	38
Appendix D: Table of Knowledge Gaps and Pertinent Updates for Neurological Conditions	41

Appendix E: Table Demonstrating Knowledge Gaps and Pertinent Updates for Dementia from Documentary and Interview Sources..... 49

I. List of Tables

- Table 1: Summary of progress and gaps of neurological conditions
- Table 2: Description of survey respondents and key informants, by neurological condition area of expertise
- Table 3: Description of survey and interview informants
- Table 4: Geographical location of survey respondents and interview key informants

II. List of Appendices

- Appendix A: Mapping Connections Knowledge Gaps
- Appendix B: Survey Sent to Key Informants
- Appendix C: Written Sources Reviewed
- Appendix D: Table of Knowledge Gaps and Pertinent Updates for Neurological Conditions
- Appendix E: Table of Knowledge Gaps and Pertinent Updates for Dementia

III. List of Abbreviations (Alphabetically)

- AHCRN – Adult Hydrocephalus Clinical Research Network
- ALS - Amyotrophic Lateral Sclerosis
- CAHBI – Centre for Aging and Brain Health Innovation
- CCDS – Canadian Chronic Surveillance System
- CCHS – Canadian Community Health Survey
- CCNA – Canadian Consortium for Neurodegeneration and Aging
- CIHR – Canadian Institutes of Health Research
- CLSA – Canadian Longitudinal Study on Aging
- CP – Cerebral Palsy
- CTRC – Canadian Traumatic Brain Injury Research Consortium

HCRN – Hydrocephalus Clinical Research Network

KIs – key informants

MD – Muscular Dystrophy

MHCC – Mental Health Commission of Canada

MS - Multiple Sclerosis

NC - Neurological conditions

NHCC - Neurological Health Charities Canada

NPHSNC – National Population Health Study of Neurological Conditions

OBI – Ontario Brain Institute

ONF - Ontario Neurotrauma Foundation

PAC - Project Advisory Committee

PHAC - Public Health Agency of Canada

TBI – Traumatic brain injury

SCI – Spinal cord injury

SLNCC – Survey on Living with Neurological Conditions in Canada

Project Summary

In 2009, Neurological Health Charities Canada (NHCC) initiated the National Population Health Study of Neurological Conditions (NPHSNC), which was jointly planned and managed through a partnership between the NHCC, the Public Health Agency of Canada (PHAC), Health Canada, and the Canadian Institutes of Health Research (CIHR). The NPHSNC aimed to fill knowledge gaps with respect to the incidence and prevalence of neurological conditions in Canada. The NPHSNC resulted in significant progress in the areas of: impacts of neurological conditions, health services for neurological conditions, and scope of neurological conditions, while identifying risk factors for development and progression of neurological conditions. Findings of the NPHSNC were summarized in the September 2014 report, *Mapping Connections: An understanding of neurological conditions in Canada*. Despite the progress made by the NPHSNC, certain gaps in knowledge were identified. The purpose of the current report is to assess the status of the knowledge gaps identified in *Mapping Connections* since the original report was released, with a special focus on dementia.

The aim of the current report is to assess the status of knowledge gaps for all neurological conditions that were included in *Mapping Connections* to provide specific and up-to-date information that will enhance overall knowledge on existing brain health related initiatives, policies, programs and investments as well as related potential existing gaps in Canada four years after the completion of the *Mapping Connections* study. Results of this assessment, particularly as it relates to dementia, will help inform the development of Canada's National Dementia Strategy.

To assess the knowledge gaps in *Mapping Connections*, we used a rapid assessment procedure involving the collection of three sources of data: key informant interview, survey, and documentary review. Thirty-four individuals identified as 'dementia experts' were contacted to request interviews via email, while 56 individuals considered knowledgeable on other neurological conditions were emailed brief surveys to complete. Interviews were audio recorded and transcribed, and analyzed using a systematic charting and thematic analysis, consistent with the rapid assessment procedure approach.

Knowledge gaps in each of the four focus areas of *Mapping Connections* were discussed for dementia and for other neurological conditions and were summarized in a grid structure (Table 1). Areas of Table 1 that are shaded in indicate that some progress has been made for that gap and condition. Overall, findings demonstrated that many knowledge gaps persist across the spectrum of all neurological conditions, including examining First Nations, Inuit, and Métis populations, as well as populations that are socially or economically disenfranchised, as these groups are less likely to be included in research, yet, more likely to develop or have more severe progression of a neurological condition. The evaluation team compiled a list of recommendations, including:

- Increase communication and cooperation amongst researchers and stakeholder groups;
- Institute and maintain a compendium of initiatives and publications concerned with research, treatment, and policy for neurological conditions;
- Organize and continue to hold regular meetings;
- Increase focus on knowledge translation.

Table 1 Summary of progress and gaps for neurological conditions

	Dementia	ALS	Brain Tumour	Cerebral Palsy	Dystonia	Epilepsy	Huntingtons	Hydrocephalus	MS	MD	TBI/SCI	Parkinsons	Spina Bifida	Tourette	Rett Syndrome	
Impacts of Neurological Conditions																
Canadians living in varying social and economic situations	■								■		■					
First Nations, Inuit, and Metis individuals	■															
Children	■			■					■							
Formal caregivers for individuals with severe, debilitating conditions																
Canadians who were excluded from surveys such as the CCHS and the SLNCC*											■					
Canadians with less prevalent conditions, or outside scope	■										■					
Health Services for Neurological Conditions																
The inconsistent availability of multidisciplinary care								■	■		■					
The application of eligibility criteria								■								
The distribution and quality of health services across the various regions and jurisdictions of Canada	■								■		■					
The costs of providing care in home care, long-term care, and acute care	■		■	■		■			■		■	■	■			
The personal cost of medications	■		■								■					
Perceptions of providers on the accessibility, timeliness, and quality of services	■										■					
The provision of health care for First Nations, Inuit, and Metis populations, for vulnerable populations	■															
Scope and Gaps in Infrastructure																
The identification of neurological conditions at their earliest stages		■							■							
Less prevalent conditions and those not targeted by the study								■								
Populations typically excluded from participation in national surveys											■					
Standardization of diagnostic codes in provinces and territories	■															
Standardization of case definitions and algorithms	■					■			■			■				
Consideration and incorporation of newly available data											■					
Complete data capture and reporting of benign brain tumours			■													
Risk Factors for Neurological Conditions																
The clinical or public health relevance of statistically validated risk factors	■								■							
Risk factors for the progression of neurological conditions									■		■					
The relative and population attributable risk								■	■		■					

1.0 Introduction

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders, and injuries in Canada. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions. In 2009, the Public Health Agency of Canada (PHAC), Neurological Health Charities Canada, Health Canada, and the Canadian Institutes of Health Research (CIHR) initiated and planned the National Population Health Study of Neurological Conditions. This study was designed to enhance understanding of the scope of targeted neurological conditions in Canada, and their impacts on affected individuals, families, and the health care system, support the development of effective programs, and services, and reduce the burden of neurological conditions in Canada¹. In total, \$15 million was committed to thirteen research projects, three national surveys, and seven microsimulation models. The NPHSNC study included 14 neurological conditions: Alzheimer's disease and other dementias, amyotrophic lateral sclerosis (ALS), brain tumour, cerebral palsy, dystonia, epilepsy, Huntington's disease, hydrocephalus, multiple sclerosis, muscular dystrophy, neurotrauma (traumatic brain injuries and spinal cord injuries), Parkinson's disease, spina bifida, Tourette syndrome. In addition, the NPHSNC provided some coverage of migraine, spinal cord tumour, Rett syndrome, and stroke.

The NPHSNC study featured a variety of epidemiological investigations to produce new estimates of the prevalence and incidence of Canadians for some of the neurological conditions listed above, and helped to increase general awareness of neurological conditions among public health care program and policy makers. The study also helped identify and understand the impacts of neurological conditions on Canadians and point to gaps in the access to and provision of appropriate care for those living with a neurological condition.

The NPHSNC resulted in a list of knowledge gaps for each of the four focus areas of the report: 1) impacts of neurological conditions; 2) health services for neurological conditions, 3) scope (prevalence and incidence) of neurological conditions, and 4) risk factors for neurological conditions. In general, gaps for each of the focus areas emphasized a lack of data on certain specific populations, such as First Nations, Inuit, and Métis communities, children, Canadians typically excluded from national surveys, or those with less prevalent neurological conditions. Another prominent gap is data regarding the distribution, quality, and costs of health services for Canadians living with a neurological condition specific to the various regions and jurisdictions of Canada. Finally, clear and comprehensive data on risk factors for the onset and progression of neurological conditions were not available, and thus, data on primary and secondary risk factors were a significant knowledge gap of the *Mapping Connections* report¹.

The NPHSNC and resulting reporting provided a baseline of data on the neurological conditions up to 2013, however, since the release of *Mapping Connections* there has been no systematic assessment of the knowledge gaps identified in the report. The current lack of systematic follow-up on knowledge gaps may contribute to slower progress in research and initiatives that aim to identify the scope and health services needs of Canadians living with neurological conditions. Therefore, with funding from PHAC, the NHCC proposed to undertake a follow-up assessment of these gaps to provide specific and up-to-date information that will enhance overall knowledge on brain health in Canada. The

purpose of the current report is to assess the status of the knowledge gaps identified in *Mapping Connections* since the original report was released, with a special focus on dementia.

This report aimed to examine knowledge gaps for all neurological conditions that were included in *Mapping Connections*. Given that Alzheimer's and other dementias are the most prevalent of the conditions studied, and constitute a larger stake in the health system, there was particular interest in identifying progress in knowledge gaps with respect to Alzheimer's disease and other dementias. Various initiatives and investments into new projects are now under way for Alzheimer's disease and related dementias. Thus, the current report features separate sections examining the knowledge gaps and progress on gaps related to Alzheimer's disease and other dementias; this will facilitate more in-depth understanding of the gaps and progress.

2.0 Methods

To assess progress on the knowledge gaps identified in *Mapping Connections*, a rapid assessment process was applied. The rapid assessment process is described as a qualitative approach that is intensive, team based, inquiry using triangulation, iterative data analysis, and additional data to quickly develop an understanding of a situation^{2,3}, and was applied through a health services research lens⁴. This approach was selected because of the targeted purpose and rigid timeline of this project. Different sources of data were used, including key informant interviews, document review, and survey data, followed by individual and integrated analysis. The use of diverse sources of data was important for the purposes of sampling, as many key informants were recruited following return of the survey. Further, combining different sources of data and analytical approaches allowed for a complete and comprehensive evaluation of the knowledge gaps, and is thought to yield more diversity in the views and information collected.

2.1 Data Collection

To assess progress on the knowledge gaps identified in *Mapping Connections*, survey, key informant interviews, and document review were conducted between February 13 to March 15, 2018.

Key informants

A list of key informants (KIs) and individuals with knowledge of *Mapping Connections* was created with the support of the Project Advisory Committee (PAC) and the NHCC. Given the timeline of this project, the first phase prioritized individuals with knowledge of dementia by contacting them via email and directly requesting an interview. Thirty-four individuals identified as "dementia experts" were contacted to request interviews via email. In the text of the report, KIs are identified by an identification number in parentheses (e.g., (001)).

To collect information related to knowledge gaps of other neurological conditions, 56 individuals who were considered knowledgeable on relevant neurological conditions were emailed brief surveys to complete (refer to Appendix B). In total, 16 surveys were returned to the research team. The research team selectively followed up with a subset of survey respondents (six) based on a need to have coverage of knowledge gaps and neurological conditions. All interviews were audio recorded and transcribed verbatim.

Interviews were conducted with 18 key informants, representing 15 conditions [dementia = 12] based on willingness and timely availability. One interview included two respondents and one respondent preferred not to be recorded; in total, sixteen transcripts were analyzed using a rapid, targeted strategy that mapped onto the structure of the interview⁴.

Documents

Given the scope of the neurological conditions covered in this report, the document review first focused on documents recommended by the PAC and by key informants during their interviews, or as part of their survey responses. Then, websites of organizations that are part of the NHCC, and funding agencies, were searched for documentation on current initiatives and research that has been published. Documents reviewed included: reports, journal articles, and websites (to identify current initiatives and health services). Documents describing projects or the use of data collected from 2014 or later were included. Reports and journal articles from the NPHSNC study were excluded, as these findings were already accounted for within *Mapping Connections* and were not the focus of this report. Also, sources that featured international research or initiatives were excluded if they did not include the work of a Canadian researcher or were conducted in Canada.

2.2 Analyses

Interviews were conducted in English with eighteen key informants, representing 15 conditions [dementia = 12] based on willingness and timely availability (Table 2). Key informants included individuals contributing as part of various roles, including associations related to neurological conditions, academics, government or policy roles, and clinical roles (Table 3). Consistent with the rapid assessment process selected, a systematic approach to analysis of transcripts was used to allow for targeted analysis of mapping interview content specifically onto the knowledge gaps identified in *Mapping Connections*.

Table 2 Description of survey respondents and key informants, by neurological condition area of expertise

Condition	Surveys	Interviews
Alzheimer’s disease and other dementias	1	12
Amyotrophic lateral sclerosis	-	-
Brain tumour	1	1
Cerebral palsy	1	1
Dystonia	-	1
Epilepsy	2	1
Huntington's disease	1	-
Hydrocephalus	1	-
Multiple sclerosis	3	-
Muscular dystrophy	-	1
Neurotrauma	3	-
Parkinson’s disease	1	-
Spina bifida	-	-
Tourette syndrome	1	-
Rett syndrome	1	-
Stroke	-	1
Surveillance of NC (multiple conditions)		2

*columns do not add up to total survey respondents and key informants, as some participants spoke to more than one neurological condition.

Table 3 Role description of survey and interview informants

Role	Survey Respondents	Interview Key Informants
Association Representative	9	8
Academic	4	8
Government/Policy	1	2
Clinician	4	2

*columns do not add up to total survey respondents and key informants as some participants represented two different roles, for example, clinician scientists.

Table 4 Geographical location of survey respondents and key informants

Province	Survey Respondents	Interview Key Informants
British Columbia	1	1
Alberta	-	2
Manitoba	1	-
Ontario	11	14
Quebec	1	-
Nova Scotia	1	-

In total, 89 documentary sources were reviewed, however, given the specificity of the gaps, 44 were included in the analysis (see Appendix C). Analysis of documents was completely systematically by reviewing sources and mapping information onto a table of knowledge gaps. Written sources were categorized by knowledge gap and condition. Text responses from surveys were charted on the same table as the document review; this allowed for visualization of which gaps had corresponding advances, while highlighting which gaps have yet to be addressed. Data from surveys was incorporated into the same table as the document review, to allow for analysis of where current gaps are.

3.0 Current Large-scale Initiatives for Neurological Conditions

Since the release of *Mapping Connections*, funding from different entities, including federal agencies, has contributed to current initiatives and research that supports knowledge advancement with respect to impact, health services, scope, and risk factors of neurological conditions. Below are examples of current initiatives. Note that many of these are also focused on developing new treatments.

The Canadian Traumatic Brain Injury Research Consortium (CRTC) was created in December 2015 and is funded by the Canadian Institutes of Health Research (CIHR) and the Ontario Neurotrauma Foundation (ONF). The CTRC was created to enhance collaborations amongst Canadian scientists working on different aspects of the continuum of care for traumatic brain injury patients; some of the CTRC’s work has filled some of the knowledge gaps identified by *Mapping Connections*⁵.

In addition to organizations specific to brain injury, CanChild is a research network that focuses on a selection of different neurological conditions in a pediatric population. CanChild is based at McMaster University and works to generate knowledge and transform lives of children and youth with

developmental conditions and their families. Among the various conditions studied at CanChild, the following neurological conditions are studied: brain injury/concussion, cerebral palsy, spina bifida⁶. CanChild has contributed to the generation of new knowledge, and initiatives related to the impacts of neurological conditions on children. In general, CanChild is working to understand how to support the development of children and families affected by neurological conditions and prevent physical and mental morbidities from developing in the parents. Additionally, CanChild also examines questions related to the transition from pediatric health supports to adult health services⁶

The Ontario Brain Institute (OBI) is a provincially funded, not-for-profit research centre seeking to maximize the impact of neuroscience and establish Ontario as a world leader in brain research, commercialization, and care. OBI's research aims to enhance the neuroscience research community, foster the neurotechnology industry, and run activities, events, and programs to enable faster translation of research to treatment and tools, including examining the use of robotic equipment to help children with CP walk, development of a system to detect and stop seizures. OBI focuses on epilepsy, depression, cerebral palsy, neurodegenerative, and neurodevelopmental disorders for their research programs⁷.

The Hydrocephalus Clinical Research Network (HCRN) and the Adult Hydrocephalus Clinical Research Network (AHCN) are North American research networks and are based in the United States; however, both include Canadian investigators, and contribute to research initiatives that address gaps. To optimize research funding impact and other initiatives, organizations such as Hydrocephalus Canada collaborate with partner organizations in other countries; the Hydrocephalus and Adult Hydrocephalus Clinical Research Networks are an example of international collaboration^{8,9}.

The International Progressive MS Alliance is a global collaboration of MS organizations, researchers, clinicians, pharmaceutical companies, and people with progressive MS that was established in 2012. Organizations from Canada, Italy, the Netherlands, the United Kingdom, and the United States made a joint commitment to speed up the development of treatment for progressive MS. The International Progressive MS Alliance has awarded grants toward accelerating the pace of progressive MS research¹⁰⁻¹¹.

4.0 Current Large-scale Initiatives for Dementia

The Canadian Institutes of Health Research (CIHR) is contributing to a CIHR Dementia Research Strategy, co-led by the Institutes of Aging, and Neurosciences, Mental Health, and Addiction. This strategy supports research on the latest preventive, diagnostic and treatment approaches to Alzheimer's disease and other neurodegenerative diseases causing dementia. Goals of the strategy focus on the following themes: primary prevention, secondary prevention, and quality of life. The strategy includes an international component, and the Canadian Consortium on Neurodegeneration in Aging (CCNA). The CCNA, considered the "flagship initiative" of the national component of the CIHR Dementia Research Strategy, is funded in combination by the CIHR and various other partner organizations. The CCNA aims to learn about who is at risk for developing dementia, determine how early dementia can be detected, and to find out what tests are most effective at detecting dementia¹². The Canadian Longitudinal Study on Aging (CLSA) is another strategic initiative of the CIHR, consisting of a national, long-term study of 50,000 men and women who will be followed until death, or 2033¹³.

The Public Health Agency of Canada has led many initiatives to advance research knowledge of dementia. One such initiative is the implementation of the National Strategy for Alzheimer’s Disease and Other Dementias Act, which will feature a national conference, and advisory board. A key pillar of PHAC’s work is the Canadian Chronic Disease Surveillance System (CCDSS), a national network of provincial and territorial surveillance systems to estimate the prevalence and incidence of chronic conditions, as well as related risk factors, use of health services, and health outcomes. As a result of the NPHSNC, dementia, Parkinsonism, epilepsy, and multiple sclerosis were added to the CCDSS^{14,15}. Another significant pillar of PHAC’s work is the \$42 million of funding to Baycrest Health Sciences, to create the Centre for Aging and Brain Health Innovation (CABHI). CABHI is a collaboration between health care, science, industry, not-for-profit, and government partners that aims to help improve quality of life for the aging population, by focusing on aging in place, caregiver support, care coordination and navigation, and cognitive health¹⁶.

The Canada Brain Research Fund is the result of a partnership between Health Canada and Brain Canada, and was designed to encourage Canadians to increase their support of brain research, and maximize the impact and efficiency of those investments¹⁷. In 2015, Brain Canada partnered with the Alzheimer Society of Canada, to increase funding in this area. The Mental Health Commission of Canada (MHCC), originally formed in 2007 to develop a mental health strategy, is also working with Brain Canada to support a matched research funding model, act as a focal point, and support the development of researchers¹⁸.

AGE-WELL National Centre for Excellence (\$35 million) is a pan-Canadian network of over 50 researchers at 26 different institutions and over 60 industrial, clinical, community, and policy partners with a goal to stimulate technological, social, and policy innovation to benefit older adults by building areas such as artificial intelligence, e-health, information communication technologies, and mobile technologies¹⁹. Research and initiatives funded by AGE-WELL emphasize the needs of people with dementia and their caregivers with respect to technology preferences¹⁹.

The Canadian Frailty Network (CFN) is a network for older Canadians living with frailty, that is dedicated to improving care of older Canadians living with frailty and supporting their families and caregivers. The CFN is funded by the Government of Canada’s Networks of Centres of Excellence program. The research and initiatives that are funded by CFN include projects to improve care planning, transform primary health care, and linking frail Canadians with emergency departments. CFN also funds grants to support knowledge translation of previously funded CFN work²⁰.

5.0 Progress on Knowledge Gaps Identified in Mapping Connections Pertaining to Neurological Conditions

The following summary outlines the current initiatives and recent advances in addressing the knowledge gaps for all neurological conditions except dementia. Refer to Appendices D and E, for comprehensive tables outlining the findings for each knowledge gap identified in *Mapping Connections*, for neurological conditions and dementia, respectively.

5.1 Gaps in Impacts of Neurological Conditions on Affected Individuals, Their Families, Caregivers, and Communities

Knowledge gaps identified in *Mapping Connections* included considering the impact of neurological conditions on:

- Canadians living in varying social and economic situations;
- First Nations, Inuit and Métis individuals;
- Children affected by a neurological condition, and those living with an affected parent or sibling;
- Formal caregivers for individuals with severe, debilitating neurological conditions;
- Canadians who were excluded from surveys such as CCHA and SLNCC;
- Canadians with less prevalent conditions (i.e., ALS, Huntington’s disease).

The current assessment of gaps identified the following progress, manifest by the publication of new data, new initiatives that seek to address gaps, and state of new or existing gaps in this focus area:

5.1.1 Progress

i) Impact of NCs and socioeconomic status

A study led by Drs. Katharine Harding and Helen Tremlett exploring health outcomes for people with MS found that having lower SES and MS was associated with poorer outcomes, compared to those with MS with higher SES, demonstrating a discrepancy in the impacts of the condition by SES ²¹.

ii) Canadians excluded from surveys such as CCHA and SLNCC

Dr. Kathryn McIsaac (University of Toronto) explored the associations between TBI and risk of incarceration among men and women, and identified that individuals with TBI had increased likelihood of being incarcerated ¹⁸.

iii) Public awareness of the impact of NC’s

Two key informants were of the opinion that the NPHSNC had resulted in increased public awareness of impact of NCs.

5.1.2 New Initiatives

i) Impact of NC’s in varying social situations

Dr. Paul VanDonkelaar (University of British Columbia) focusing on traumatic brain injury (TBI) aims to characterize TBI in survivors of intimate partner violence, followed by the use of an integrated knowledge translation approach to disseminate this information to community organizations that support survivors of intimate partner violence⁵.

ii) Impact of NC’s on children

A team led by Dr. Doreen Bartlett aims to describe changes in balance, range of motion, strength, endurance, and participation in self-care, recreation, and leisure activities over the course of one year. This research is expected to help develop reference percentiles for children with CP, to monitor development compared to other children with CP⁶.

In pediatric populations, the MyStory project studies the mental and physical health, stressors, and overall wellbeing of adolescents and young adults with CP, filling a crucial gap in knowledge and understanding of CP in young adult populations⁶.

iii) Canadians with less prevalent conditions (i.e., ALS, Huntington’s disease)

Dr. Emily Nalder of the University of Toronto is examining interventions and supports for family caregivers managing challenging behaviour; while TBI is not considered a rare condition, managing challenging behaviour is a less frequently known impact⁵.

5.1.3 Persistent Gaps

Despite the advances listed above, one survey respondent identified that more research is needed to better understand the burden of complex neurological diseases on caregivers and households.

5.2 Gaps in Health Service Provision, and Knowledge of Health Services for Neurological Conditions

Gaps in health services for people with neurological conditions identified in *Mapping Connections* include:

- Inconsistent availability of multidisciplinary care;
- How application of eligibility criteria affect access to services for individuals with a neurological condition.

Mapping Connections also emphasized certain gaps in data and knowledge of health services for individuals with neurological conditions:

- Distribution and quality of health services across various regions and jurisdictions;
- Costs of providing care for individuals with a neurological condition in continuing care and acute care;
- Personal cost of medications for individuals with each neurological condition;
- Perceptions of health care providers on the accessibility, timeliness, and quality of health services for individuals with a neurological condition;
- Provision of health care for First Nations, Inuit, and Metis populations, for vulnerable populations, and for children with a neurological condition.

The current assessment of gaps identified the following progress, manifest by the publication of new data, new initiatives that seek to address gaps, and state of new or existing gaps in this focus area:

5.2.1 Progress

i) Distribution and quality of health services across the various regions and jurisdictions of Canada

The TRANSITION project, led by Dr. Jan Willem Gorter, measures readiness to transition into the adult healthcare system from the pediatric system⁶.

The development of clinical practice guidelines for the rehabilitation of adults with moderate to severe TBI, and for comprehensive assessment of the person with TBI^{22,23}.

Sunnybrook Health Sciences is filling a gap by running an accessible care pregnancy clinic, which cares for women who are pregnant or contemplating pregnancy, who have both invisible and visible physical disabilities, filling an important health services gap for people with cerebral palsy, multiple sclerosis, spina bifida, and neurotrauma²⁴.

In some qualitative work with Dr. Marcia Finlayson, people with MS describe the challenges of health system access as being substantial – it is hard to navigate the system, to know what is available, to get it, and that care available varies substantially from one region to another.

The Ontario Neurotrauma Foundation has published guidelines for adults with moderate to severe brain injury²², pediatric concussion brain injury, and concussion/mTBI and persistent symptoms. Healthcare providers are the target population for these clinical guidelines. The clinical guidelines lack any educational materials targeted for patients or family members, and are directed toward health providers to improve the quality of care.

ii) Costs of providing care for individuals with a neurological condition in continuing and acute care settings across the country

A comprehensive report by the Ontario Brain Institute and the Institute for Clinical Evaluative Sciences used administrative databases to estimate the costs associated with one year of health utilization for brain tumour, cerebral palsy, dementia, epilepsy, multiple sclerosis, Parkinsonism, spina bifida, and spinal cord injury²⁵.

With respect to the costs of providing care for individuals with a neurological condition, one study evaluated the cost of productivity loss due to brain injury, however, there was no estimation of the costs of medications and the potential variability in medication cost across Canada²⁵.

iii) Inconsistent availability of multidisciplinary care

Clinics that specialize in certain conditions help to fill this health services gap. For example, clinics for adult hydrocephalus allow physicians to work in more focused care models and have been opening in cities across Canada, including Toronto. An Accessible Care Pregnancy Clinic in Toronto is one example of a clinic to monitor and support pregnancies for individuals with disabilities, such as MS²⁴.

5.2.2 New Initiatives

i) Inconsistent availability of multidisciplinary care

A team of researchers based at McGill University led by Dr. Sara Ahmed is working on a project called the Biomedical Research and Informatics Living Laboratory for Innovative Advances of New Technologies in Community Mobility Rehabilitation (BRILLIANT), which will aim to support mobility of persons with brain injury²⁶.

5.2.3 Persistent Gaps

Despite the advances listed above, there continues to be a lack of consistent, coordinated multidisciplinary care for ALS, spina bifida, and hydrocephalus. In addition, health and social support for individuals with neurological conditions and other co-morbid conditions continues to be a challenge, as per a recent pan-Canadian survey²⁷.

No progress was noted with respect to the need to evaluate the provision of health care for First Nations, Inuit, and Métis individuals with neurological conditions.

Persistent gaps in multidisciplinary care for dystonia were emphasized from interview key informants. Particularly, the rarity of the condition means skilled healthcare practitioners are few and difficult to access. For many individuals with dystonia, it is extremely challenging to get the supports they need.

5.3 Gaps in the Scope of Neurological Conditions

Mapping Connections identified the following knowledge gaps with respect to the epidemiology of some neurological conditions, as well as gaps related to the infrastructure for determining epidemiological information. Knowledge gaps related to epidemiologic and administrative data include:

- Certain neurological conditions in the early stages (e.g., multiple sclerosis and Parkinson’s disease);
- Less prevalent conditions, (e.g., ALS, dystonia and Huntington’s disease);
- Neurological conditions typically excluded from participation in national population surveys;
- Extent of neurological conditions among children (cerebral palsy, epilepsy, multiple sclerosis, brain injury, and stroke), and the persistence of these conditions into adulthood.

Gaps in the infrastructure to examine epidemiological data include:

- Standardization of diagnostic codes used in physician billing claims and hospital data in all provinces/territories;
- Standardization of case definitions and algorithms as well as their periodic review;
- Ongoing consideration and incorporation of newly available data, e.g., pharmaceutical or costing data;
- Data capture and reporting of benign brain tumours in existing provincial/territorial cancer registries.

The current assessment of gaps identified the following progress, manifest by the publication of new data, new initiatives that seek to address gaps, and state of new or existing gaps in this focus area:

5.3.1 Progress

- i) The identification of certain neurological conditions at their earliest stages
Dr. Helen Tremlett and colleagues led a study which identified a more frequent use of health care in patients with MS than in controls in the 5 years before a first demyelinating event, suggesting the existence of a measurable multiple sclerosis prodrome. These findings have implications for the establishment of an earlier window of opportunity to identify and potentially treat MS²⁸.

ii) Standardization of case definitions and algorithms

Dr. Keezer and colleagues created and validated an algorithm for identifying epilepsy using data from the Canadian Longitudinal Study on Aging²⁹. This advance will facilitate future research on individuals with epilepsy and allow for longitudinal tracking.

Dr. Butt and colleagues (2014) validated an algorithm for the identification of individuals with Parkinson's disease or Parkinsonism in administrative databases³⁰.

Dr. McChesney-Corbeil and colleagues (2017) identified the optimal classification of disease codes, case definition to identify children with TBI using data from emergency departments³¹.

Dr. Marriott and colleagues validated an algorithm to detect relapses in health administrative databases³², this progress will contribute to the body of research examining MS outcomes on a population level.

5.3.2 *New Initiatives*

i) Less prevalent conditions

The Adult Hydrocephalus Clinical Research Network is contributing to a core data project that will create a registry of individuals with adult hydrocephalus. The registry will collect patient demographics, hydrocephalus etiology, and surgical and medical management of the condition; these details will help to better understand the scope of the condition, but will also help to understand the progression and variability of adults with hydrocephalus⁸.

ii) Data capture and reporting of benign brain tumours in existing distribution and quality of health services across the various regions and jurisdictions of Canada

The Brain Tumour Foundation of Canada to develop the Canadian Brain Tumour Registry Project, a registry of individuals with brain tumour. Dr. Faith Davis was responsible for the feasibility study (concluded in 2016) and continued development of the registry. Continued work will create a surveillance report and obtain data on non-malignant brain tumours for the registry³³.

iii) The identification of certain neurological conditions at their earliest stages

Funded by the CIHR and ALS Canada, Dr. Sanjay Kalra is building on a preliminary study that aimed to look for biomarkers in brain images using MRI scans³⁴.

Dr. Helen Tremlett and colleagues led a study which identified a more frequent use of health care in patients with MS than in controls in the 5 years before a first demyelinating event, suggesting the existence of a measurable multiple sclerosis prodrome. These findings have implications for the establishment of an earlier window of opportunity to identify and potentially treat MS²⁸.

iv) Neurological conditions in populations typically excluded from participation in national population surveys

Part of the Canadian Traumatic Brain Injury Research Consortium, the Advancing Concussion Assessment in Children (A-CAP) study aims to improve the ability to diagnose pediatric concussion and make prognostic predictions about outcomes. They hope to identify mild TBI with excellent sensitivity and specificity and predict longitudinal outcomes of mTBI. This study is led by Dr. Keith Yeates⁵.

v) Ongoing consideration and incorporation of newly available data

Led by Drs. Isabelle Gagnon and Carol DeMatteo, this study seeks to establish the feasibility and utility of collecting CDE measures for children and adolescents in seven pediatric mTBI follow-up programs across Canada, contributing to development of standardized clinic and research based common data elements⁶.

5.3.3 *Persistent Gaps*

Gaps around epidemiology of NCs in First Nations and Inuit: outlook is improving with the creation of the Department of Indigenous Services, which will take on the First Nations and Inuit health branch from Health Canada.

Information gaps remain, however, around movement disorders, brain tumours, and MD.

5.4 Gaps in Knowledge on Risk Factors for the Development and Progression of Neurological Conditions

Mapping Connections identified knowledge gaps with respect to comprehensive evidence on risk factors for onset and progression of neurological conditions.

- Clinical or public health relevance of statistically validated risk factors;
- Risk factors for the progression of neurological conditions, with respect to the potential improvement or deterioration of the condition;
- Relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions, (assessment of the potential effectiveness of prevention measures at the individual and population levels).

The current assessment of gaps identified the following progress, manifest by the publication of new data, new initiatives that seek to address gaps, and state of new or existing gaps in this focus area:

5.4.1 *Progress*

i) Risk factors for the progression of neurological conditions

With respect to MS, a study led by Dr. Helen Tremlett and colleagues explored the association between gut microbiota and relapsing-remitting pediatric MS cases, which may allow for altering the course of MS³⁵⁻³⁷.

Other research for MS points to a potential prodromal period before the first symptoms of MS are experienced; this finding may lead to a potential way to diagnose MS earlier, and potentially initiate treatments sooner²⁸.

- ii) Relative and population attributable risk of modifiable risk factors for the onset of neurological conditions
Exposure to ultraviolet B rays during childhood has been linked to a reduced likelihood of developing MS later in life³⁸.

5.4.2 New Initiatives

- i) Risk factors for the progression of neurological conditions
One study, led by Drs. Jamie Hutchison, William Panenka, and Anne Wheeler, aims to identify biomarkers and clinical risk factors that predict long term quality of life and another aims to develop a prognostic model to evaluate long term prognosis of adults with severe brain injury⁵.

A study led by Dr. Carol DeMatteo at CanChild aims to determine a standardized approach to test exertion may also help to inform safe return to activity following brain injury⁶.

Dr. Ruth Ann Marrie (University of Manitoba) is conducting a study that will compare risk factors, treatments and outcomes for heart attack among people with and without MS; findings will provide important information for people with MS and their health care team about prognosis³⁹.

5.4.3 Persistent Gaps

With respect to hydrocephalus, there is no focus on preventative wellness in the medical field. The focus is on post-op rehab.

There is the need for more emphasis on prevention of MS; for example, smoking, obesity, vitamin D insufficiency are risk factors for MS, but there are no public health efforts to educate the public about this.

There is discussion about the benefits of certain activities for preventing dementia. but programs to really change behavior in terms of physical activity, social engagement, etc. are lacking.

6.0 Synthesis of Knowledge Gaps of Neurological Conditions

The knowledge gaps related to the impact of neurological conditions on individuals, their families, caregivers, and communities included an emphasis on understanding the impacts on 'hard to reach' populations. There was no new knowledge generated or current initiatives for several of the neurological conditions of interest; MS and CP were the only conditions where some progress was noted with respect to the knowledge gaps identified in *Mapping Connections*. The impacts of both CP and MS on children who have these conditions were examined. While CP is a condition that is frequently attributed to children, investigating pediatric MS and its impacts demonstrates a broadening of the knowledge on this condition. Despite the presence of research and initiatives exploring the impact of conditions on children, there continues to be a lack of knowledge on how neurological conditions impact

children indirectly, through a parent or sibling who has this disorder. In addition, there is some growing awareness of children who are also caregivers.

Knowledge of the impact of neurological conditions on First Nations, Inuit, and Métis individuals remains a gap. While research and initiatives to address the epidemiology and health services for these populations is growing, the impact of NC on these populations continues to be unknown.

Significant gaps with respect to access to multidisciplinary care for individuals with neurological conditions remain. There are, however, a few exceptions to this, as reports of clinics to offer specialized services for specific conditions, such as those for MS and hydrocephalus, are slowly increasing. However, these examples exist only in specific urban areas; it is not known if the benefits are widespread. Key informants emphasized the difficulties of individuals with neurological conditions to access the diagnostic and treatment support they require, and there is evidence that individuals who access clinics are different from those who do not, suggesting that clinics may not be providing adequate care, or may not be reaching the populations they are intended to support.

In addition to availability and accessibility of health services for people with neurological conditions, some advances in knowledge of the distribution and quality of health services were noted as evidenced by the development of clinical practice guidelines for TBI, and exploring transitions from child to adult health services for children with CP. With respect to costs of providing home and long-term care, a significant report by the Ontario Brain Institute and the Institute for Clinical Evaluative Sciences examined costs for many different neurological conditions. While this report focused exclusively within Ontario, it gives insights into areas for improved care. Costing analyses have on occasion explored the personal costs and societal costs, but costs of pharmaceuticals remain unknown.

New knowledge on risk factors for the progression of neurological conditions consists mostly of risks for the progression of MS, with new information related to gut microbiota, exposure to ultraviolet rays, and increased risk of heart attack. Additionally, some research is examining biomarkers for certain conditions, for early identification of the condition.

7.0 Progress on Knowledge Gaps: A Focus on Dementia

The following narrative summarizes progress on identified gaps in each of the foci of *Mapping Connections*, while highlighting persistent gaps. Please refer to Appendix E for a summary chart of knowledge gaps and initiatives indicating progress.

7.1 Gaps on Impacts of Dementia on Affected Individuals, Their Families, Caregivers, and Communities

Mapping Connections identified knowledge gaps related to the impacts of neurological conditions on populations of individuals that are infrequently examined in the literature, including Canadians living in varying social and economic situations, First Nations, Inuit, and Métis individuals, children, caregivers, Canadians excluded from surveys, and Canadians with less prevalent conditions¹.

Knowledge pertaining to the impacts of dementia for Canadians living in varying social and economic situations includes some contributions funded by the CCNA, where Drs. Joel Sadavoy and

Mary Chiu are examining informal caregivers that are concurrently employed in the workforce; this research explores the impact of caregiving for people with dementia on this small, but growing cohort¹². Canadians of different ethnocultural groups represent another group of interest; a study to explore the impacts of dementia for different ethnocultural groups was recently conducted by Dr. Sharon Koehn⁴⁰. This study was a result of Dr. Koehn's involvement with DementiaNET, a collaborative examining dementia health services using data from electronic medical records in primary care, the Canadian Primary Care Sentinel Surveillance Network (CPCSSN)⁴⁰.

Some initiatives are exploring the impacts of dementia in First Nations, Inuit, and Métis populations. Rural Dementia Action Research (RaDaR) is contributing to a study of the challenge of dementia in Saskatchewan First Nations populations, led by Dr. Jennifer Walker and funded by the Alzheimer Society of Canada⁴¹.

As a group of disorders, dementia can be considered a prevalent condition, however, research exploring rarer forms of dementia, such as frontotemporal dementia and early onset dementia, helps to fill in the gap of the impact of these less prevalent neurological conditions. Early onset dementia is less prevalent than dementia affecting individuals 65 years of age and older, and previously, there was limited evidence exploring the impact of early onset dementia⁴². At present, a number of studies which explore the impact of early onset dementia on familial relationships, romantic relationships, and transitions^{43,44} were identified. As part of the CCNA, Dr. Robin Hsiung is exploring impacts of frontotemporal dementia¹².

Knowledge gaps with respect to the impact of dementia on formal caregivers, and Canadians who are typically excluded from the Canadian Community Health Survey (CCHS) and the Survey on Living with Neurological Conditions Canada (SLNCC) surveys persist. There were many studies that described the impact of dementia on informal caregivers, but at present no current initiatives are examining the impact of dementia for formal caregivers, consisting of health care workers. Further research is needed to explore these outstanding gaps.

7.1.1 Key Informant Results:

Following is a summary of quotes and points extracted from key informant interviews. Several respondents describe shifts in awareness around dementia as broadly positive, resulting in public acknowledgement about the need for addressing care provision. 'Dementia-friendly' communities, public legislation (the Dementia Strategy), and a sense of reduced stigma around dementia were mentioned. One respondent described ongoing lack of knowledge: "people don't know what it is. Everything...on dementia is Alzheimer's". Another ongoing gap is knowledge around the costs of dementia, ranging from out-of-pocket costs for individuals and family to wider economic impacts associated with impact on the health system and loss to the work force both of patients and caregivers. Gaps and their impact vary across segments of the Canadian population. Provinces differ in their approaches to dementia, with Saskatchewan identified as lacking any strategy, and Nova Scotia having 'a great plan'. Indigenous/ First Nations communities have a higher incidence of dementia; both the Alzheimer Society and CIHR have funded research projects to address this gap. CIHR has renamed one of its 13 institutes as the Institute of Indigenous People's Health. The impact of dementia on different immigrant communities, on different genders, and on Canadians of African and Caribbean descent is poorly addressed, according to informants: "there hasn't really been that kind of work".

7.2 Gaps in the Scope of Dementia

With respect to the prevalence and incidence of dementia, the *Mapping Connections* report identified gaps in research as well as gaps in the infrastructure to support epidemiological estimates and projections.

As the only national data source that provides incidence information for dementia, the work of the Canadian Chronic Disease Surveillance System has been instrumental in the collection and dissemination of prevalence and incidence data for dementia. The ongoing surveillance of dementia was initiated in 2011 as part of the NPHSNC study, and continues to be updated regularly in an interactive website format, <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance.html>⁴⁵. However, it does not capture early onset dementia, and data from the province of Saskatchewan continues to be unavailable.

The gap of identifying dementia during the early stages of the disease is being addressed through two initiatives both funded by the CCNA. The first, the COMPASS-ND study, will help to identify dementia in earlier stages as the population of this study includes individuals who may or may not develop a diagnosis of dementia⁴⁶. As part of the CCNA's Theme 1, Dr. Robert Bartha's contributions will examine whether magnetic resonance imaging (MRI) can contribute to the identification of Alzheimer's disease before subjects begin to experience cognitive decline¹².

The knowledge gaps pertaining to standardization of diagnostic codes and case definitions for dementia across provinces and territories used in physician billing claims and hospital data have demonstrated progress; a case definition was developed and validated to identify physician diagnosed dementia in health administrative databases⁴⁷, while a CLSA study developed normative data and comparison standards for the cognition measures employed in the CLSA; this progress will contribute to future research through providing a robust method of measuring cognition in this longitudinal study¹³.

Text sources and key informants highlighted the contributions of interRAI Canada, a research group with a focus on promoting innovations in data, evidence, and application systems for the health and social service sectors. Data collected using the RAI instruments has expanded to 11 provinces and territories in total, demonstrating a significant increase in the capacity to understand both the prevalence of dementia, as well as the clinical and functional characteristics of these populations.

In summary, knowledge gaps related to the scope of dementia are currently being addressed by various initiatives; there has been progress in creating and validating standardized case definitions to identify people with dementia in administrative databases, and a continued focus on the prevalence and incidence of dementia for First Nations, Inuit, and Métis populations. However, the difficulty of incorporating data from the province of Saskatchewan remains a significant infrastructure gap. Further, the incidence and prevalence of other, rarer forms of dementia, such as Wernicke-Korsakoff syndrome, are not explicitly identified in current initiatives.

7.2.1 Key Informant Results:

Following is a summary of quotes and points extracted from key informant interviews. The key informants suggest that data collection for epidemiology of dementia in Canada has improved, though not everywhere. Saskatchewan stands out as one place where an information gap remains. New

technology (e.g., wearable devices) should, in the near future, lead to even better data capture around biological markers (see reference to David Naylor's report on innovation). Gaps however remain regarding the actual number of people with dementia in Canada; work needs to continue. The Canadian Longitudinal Study on Aging is a key tool for data collection. Not enough time has elapsed since 2014 to judge success/improvement.

7.3 Gaps in Health Services for Dementia

Knowledge gaps from *Mapping Connections* that were related to health services for individuals with neurological conditions included: inconsistent availability of multidisciplinary care, restricted access to programs based on eligibility criteria, the distribution and quality of health services across jurisdictions, societal and personal costs of providing care for individuals with neurological conditions, perceptions of health care providers, and provision of health care for First Nations, Inuit and Métis populations.

There exists an array of initiatives that address the distribution and quality of health services for people with dementia. Drs. Howard Bergman and Isabelle Vedel, funded by CCNA, are evaluating and implementing initiatives to improve the capacity of primary care physicians to diagnose and treat older persons with Alzheimer's disease and support their caregivers¹².

As demonstrated, the provision of care for First Nations, Inuit, and Métis individuals with dementia has been supported in recent years. A prominent example is Dr. Debra Morgan's Rural Dementia Action Research (RaDaR) team, which investigates both issues of provision of rural dementia care, as well as provision of care for First Nations, Inuit, and Métis populations. With funding from the CCNA as well as the Alzheimer Society, Dr. Morgan and her team explore strategies for delivering comprehensive, integrated primary health care for people with dementia across diverse rural settings. Dr. Megan O'Connell's team, as part of RaDaR, are exploring issues of connectivity infrastructure and the needs of older adults who are Indigenous, or who are residing in rural areas^{12,41}.

With respect to the costs of providing care for Canadians with dementia, a notable contribution has been the report supported by the Alzheimer Society, *The Prevalence and Monetary Costs of Dementia (2016)*. This report included a detailed description of different sources of cost estimates and projections for dementia, as well as a breakdown of the costs of dementia care in different health system sectors. Estimated costs of care provision incurred by the individual or family of the individual with dementia, and cost of prescription medications for individuals with dementia are included in the analyses⁴⁸.

From the interviews, key informants identified work exploring health services for First Nations, Inuit, and Métis populations as an area that appears to be a topic of discussion and that represents a notable change in discussions, but question whether there is meaningful progress being made for these individuals.

7.3.1 Key Informant Results

Following is a summary of quotes and points extracted from key informant interviews. The Dementia Strategy has brought \$100 million to Ontario over the next 5 years to invest in health services and homecare. Innovative programs such as 'First Link' aim to connect people at diagnosis with ongoing

support; use of a ‘facilitation model’ shows promise in terms of creating ‘circles of support’ in remote or rural areas. Gaps do remain in delivery of healthcare services for dementia. “I don’t think there’s been a major change in how healthcare is delivered”. Another pointed out that although effort is being made to keep people in their homes as long as possible, “...there doesn’t seem to be the shift in the funding allocation” to support that approach. Inequities exist in terms of access to care and support for dementia, but there are some interesting inroads such as work by Dr. Sharon Koehn and others with the Korean and Punjabi communities in the Fraser Valley Health Authority in British Columbia.

In terms of uptake of health services, there is greater awareness of prevention or delay of dementia onset, “including exercise and diet”. This is, of course, good but also puts ‘additional strain on the healthcare system’.

7.4 Gaps in Knowledge about Risk Factors for Dementia

Mapping Connections identified knowledge gaps with respect to comprehensive evidence on risk factors for onset and progression of neurological conditions including dementia

The COMPASS-ND study is contributing to the knowledge of risk factors for dementia. Through examining a population of people with cognitive complaints longitudinally, this study will identify risk factors for the development, and for the progression of impairments related to dementia⁴⁶. The CCNA is contributing to this knowledge gap through different projects. Dr. Carol Greenwood (CCNA Theme 1) is examining nutrition strategies that support optimal cognitive function with aging¹². Dr. Manuel Montero-Odasso (CCNA Theme 2) is exploring the relationship between physical activity, motor performance, and the progression of cognitive decline, suggesting a potential role for physical activity in slowing the progression of dementia¹². As part of the CCNA’s Theme 3, Dr. Melissa Andrew has been examining how multimorbidity, such as pre-existing diabetes, heart conditions, or hypertension, modifies the risk of dementia and patterns of disease expression¹².

On a population level, Dr. Cheryl Wellington is examining the genetic and environmental risk factors for dementia, by studying lipid and lipoprotein metabolism, and how these might change an individual’s risk¹².

Contributions from the Health and Stroke Foundation include the release of their 2016 report, *Mind the Connection: Preventing Stroke and Dementia*. This report emphasized the link between stroke and vascular dementia, specifically highlighting research by Dr. Eric Smith as part of the Prospective Urban Rural Epidemiologic (PURE-MIND) study, which will examine how covert strokes are related to problems with memory and thinking⁴⁹. Also highlighted by the Heart and Stroke Foundation report, Dr. Eric Thorin is identifying interventions, including the role of exercise, to protect Canadians with a history of stroke from developing dementia⁴⁹.

As a large, longitudinal study already underway, the CLSA offers opportunities to study risk factors. Dr. Barbara Fenesi is using CLSA data to explore the interplay of physical activity, sleep, and cognition, while, Dr. Guanmin Chen will explore gender differences in vascular risk factors, early cognitive impairment, and eventual progression to dementia¹³.

Key informants that were interviewed described progress on the knowledge of risk factors for dementia, particularly with respect to advances in understanding of the cardiovascular risk factors for

dementia. However, they identified that many risk factors for dementia, including age, are not modifiable, but felt that gaps continue to exist for different types of dementia, including vascular. Finally, key informants emphasized the challenges of predicting who in the general population will develop an incident neurological condition, as there is no data in that context yet.

Overall, knowledge of risk factors for primary and secondary prevention of dementia has demonstrated some gains in knowledge about the cardiovascular risk factors, while many investigations from the CCNA and CLSA appear to add to the current knowledge and not only strengthen our understanding of risk factors but operationalize them to contribute to care for people with dementia. Despite these advances, key informants expressed concern that the most significant risk factors are not modifiable, indicating that further research may be warranted, to quantify the influence of vascular risk factors and physical activity interventions.

7.4.1 Key Informant Results:

Following is a summary of quotes and points extracted from key informant interviews. The most significant risk factor is ‘advancing age’ The biggest modifiable risk factor was acknowledged to be cardiovascular disease and stroke, modifiable through improved diet and increased exercise. Opinion was divided amongst key informants regarding research into other risk factors; said one, “Well, there are risk factors, but if we can’t do anything about them, what’s the point?”. Psychosocial issues around risk assessment for dementia were also mentioned as ‘tricky’. The role of sex and gender is something that “hasn’t been addressed very well”. Indigenous populations are a focus now; dementia is a particular issue because of the higher incidence in these groups of heart disease. South Asian and African-Canadian communities also need attention: “There’s lots of vulnerabilities. We don’t understand those yet”.

7.5 Synthesis of Dementia Knowledge Gaps

The findings from this assessment demonstrate progress on many of the knowledge gaps identified in *Mapping Connections*, particularly with respect to chronic disease surveillance, risk factors, distribution, and quality of health services. Participants emphasized the significant knowledge generated and the positive outcomes of the NPHSNC study, particularly with respect to collaborations with other researchers, and access to funding to continue to study neurological conditions.

Gaps related to the prevalence and incidence of dementia were addressed through ongoing surveillance, and reports exploring both the health system and societal costs. Knowledge gaps related to the impacts of rarer forms of dementia were addressed through some research that targeted Frontotemporal and early onset dementia. Notably, advances with respect to knowledge of cardiovascular risk factors have helped to address gaps related to risk factors. Additionally, prior knowledge gaps related to First Nations, Inuit, and Métis populations have demonstrated some progress.

There was significant investment in dementia research during the past four years; however, some knowledge gaps identified in *Mapping Connections* were not addressed: formal caregivers, perceptions of health care workers, and impacts and scope of dementia for Canadians who are excluded from national surveys. On the other hand, initiatives such as the CCNA, CABHI, and Brain Canada demonstrate significant progress for improving health care and quality of life of Canadians with

dementia. For example, CABHI features significant investment into innovations and technological approaches for services or supports that inform or comprise the development of a product. Many of the projects supported by these initiatives focus on intervention approaches and seek to fill knowledge gaps by developing and testing intervention approaches; these approaches do not address the specific knowledge gaps identified in *Mapping Connections*, however, they do represent significant contributions to the clinical management, and quality of life of Canadians with dementia.

9.0 Obstacles to Closing Gaps for Neurological Conditions and Dementia

Key informants and survey respondents identified a number of barriers to advancing the knowledge gaps of neurological conditions:

- Inadequate resources for timely and appropriate healthcare;
- Difficulty of obtaining permission to conduct needed research amongst First Nations or Inuit groups;
- Administrative requirements around accessing and utilization of data clash with funding timelines;
- Re dementia, lack of coordination and collaboration around filling knowledge gaps; ownership rather than alliance;
- Many of the stakeholders and survey respondents identified lack of funding as a barrier to generating new knowledge;
- Need to increase capacity for dementia care as the population ages;
- Systematic barriers to trying innovative technologies in healthcare (lack of incentives).

11.0 Strengths and Limitations

This project, which examined the status of the knowledge gaps identified in *Mapping Connections*, includes some notable strengths. First, the highly directed nature of the data collection, followed by targeted and systematic analyses of the data allowed for efficient and clear presentation of evidence within time constraints. Second, this project benefitted from a supportive and resourceful advisory committee that contributed to the report through leveraging their content knowledge and relevant contacts. Finally, this project featured different sources of data, as well as a heterogeneous group of key informants that were interviewed; this coverage allowed for more comprehensive coverage of this broad topic area, given the limited time. The rapid assessment procedure we used is conducive to team based, time limited projects.

There are certain limitations within this project that must be acknowledged. This project had a broad scope, focusing on fourteen neurological conditions, and seeking representation from across the country. Given the time and resource limitations associated with this project, it was not feasible to achieve adequate representation from across the country, and from each condition. Further, a large proportion of key informants were based within Ontario, which highlights an inequity in the distribution of research initiatives and funding.

While the heterogeneous sample of key informants added to the comprehensiveness of views in the data collected, ultimately, not all key informants interviewed could speak to specific progress and

examples on the knowledge gaps identified; in this regard, we relied on data from other sources to supplement an understanding of the current state of knowledge gaps.

Finally, this evaluation is not considered a research study. Thus, a rigorous methodological approach was not used, and the approach to data analysis placed greater emphasis on the extraction of information than on examining themes. This evaluation highlighted some considerations that are likely to be better addressed with a more comprehensive, and rigorous approach to examining the current knowledge.

12.0 Recommendations

Throughout this evaluation exercise examining the progress on knowledge gaps identified in *Mapping Connections*, a number of recommendations to encourage continued generation of new research in epidemiology and health services for individuals with NC's, have surfaced. Additionally, recommendations that point to advancing currently available knowledge and initiatives are also relevant. Collaboration, coordination, and sustainability, along with access to resources (data, funds) have all been identified as crucial to filling the gaps that persist in the research and treatment landscape of neurological conditions in Canada.

To this end, recommendations include:

- 1) Increase communication and cooperation amongst researchers and stakeholder groups focused on NCs. Specifically, a coordinated approach to identifying priorities and next steps for new projects.
- 2) Institute and maintain a compendium of initiatives and publications (peer-reviewed and gray literature) concerned with research, treatment, and policy for NCs; distribute news about additions to the compendium on a regular basis to researchers, policy-makers, and stakeholders.
- 3) Organize and continue to hold regular meetings / conferences of interested parties (researchers, stakeholders, policy-makers) for face-to-face discussions to encourage greater consensus with respect to next steps, and when action versus research is indicated.
- 4) Increase focus on knowledge translation, making use of the basic research already amassed.

13.0 Conclusions

The NPHSNC can be seen to have brought together groups and people interested in a common and critical cause to investigate and improve the state of neurological health in Canada. The funding from the PHAC spawned important research and helped to generate data that are useful in themselves and serve to spur on the continued amassing information on health and health care around neurological conditions.

Findings from this report demonstrated the current emphasis on Alzheimer's and other dementias, while other neurological conditions demonstrated less frequent, if any, advances in knowledge gaps. For some of these, the respective non-governmental organizations for these conditions support research projects related to basic science, treatments, or curative approaches to the conditions. This in itself is significant, as it demonstrates a potential need to diversity research agendas to include health services, epidemiological, and risk factors for these conditions.

A recurrent and persistent knowledge gap was concerned with representation from “hard to reach” populations. Despite some progress in investigations of health services, knowledge gaps associated with First Nations, Inuit, and Métis populations continue to be largely unaddressed. Further, research focusing on marginalized and populations of varying socioeconomic status demonstrated little progress for most neurological conditions, with the exception of dementia.

Key informants, selected for their stakeholder status, research expertise, or involvement in relevant health policy, varied in their perspective on the knowledge gaps under investigation. They sometimes provided contradictory information or offered opinions that clashed. To some extent this ‘discord’ has been minimized in our report, but it might also be considered a finding, insofar as the landscape of perceived progress, ongoing needs, and priorities and barriers is in some way a contested one.

Acknowledgements

Neurological Health Charities Canada would like to acknowledge the following members of the project advisory committee (PAC) for their valuable consultative input to this report:

Garth M. Bray, BSc. BSc(Med), MD, FRCPC

McGill University

Nathalie Jetté, MSc. MD, FRCPC

Professor, Icahn School of Medicine at Mount Sinai

Tanya Packer, BSc(OT), MSc., PhD

Professor, School of Occupational Therapy, Dalhousie University

Richard Riopelle, MD, FRCPC, FCAHS

McGill University

Deanna Groetzinger, MA

Manager, Neurological Health Charities Canada

References

1. The Government of Canada. *Mapping Connections an Understanding of Neurological Conditions.*; 2014. doi:978-1-100-24442-6.
2. Beebe J. *Rapid Assessment Process: An Introduction*. Walnut Creek, CA: Altamira Press; 2001.
3. Cole C. Rapid Assessment Process in Qualitative Inquiry. *Forum Qual Soc Res.* 2002;3(4).
4. Hamilton AB. Qualitative Methods in Rapid Turn-Around Health Services Research. In: *Veteran's Affairs Health Services Research & Development*; 2013. https://www.hsrdr.research.va.gov/for_researchers/cyber_seminars/archives/780-notes.pdf.
5. Canadian Traumatic Brain Injury Research Consortium. Canadian Traumatic Brain Injury Research Consortium Projects. <http://www.ctrcc-crta.ca/>. Published 2016.
6. CanChild. CanChild - Current Studies. McMaster University. <https://www.canchild.ca/en/research-in-practice/current-studies>. Published 2018.
7. Institute OB. About OBI. <http://braininstitute.ca/>. Published 2017. Accessed March 20, 2018.
8. Adult Hydrocephalus Clinical Research Network. Adult Hydrocephalus Clinical Research Network Core Data Project. <http://www.ahcrn.org/>. Published 2018.
9. Hydrocephalus Clinical Research Network. Hydrocephalus Clinical Research Network Research. hcrn.org. Published 2018. Accessed March 16, 2018.
10. Multiple Sclerosis Society of Canada. Multiple Sclerosis Society of Canada - Accelerating Research. <https://mssociety.ca/about-us/accelerating-research>. Published 2018. Accessed March 19, 2018.
11. International Progressive MS Alliance. International Progressive MS Alliance Research. <http://www.progressivemsa.org/research/>. Accessed March 16, 2018.
12. Canadian Consortium on Neurodegeneration in Aging. Canadian Consortium on Neurodegeneration in Aging. <http://ccna-ccnv.ca/>. Published 2018. Accessed March 8, 2018.
13. Canadian Longitudinal Study on Aging. Canadian Longitudinal Study on Aging. <https://www.clsa-elcv.ca/>. Published 2018. Accessed March 7, 2018.
14. Lix L, Reimer K. The Canadian Chronic Disease Surveillance System : A Distributed Surveillance Model. In: *International Society for Disease Surveillance*. Vol 9. ; 2017:2579.
15. Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian Chronic Disease Surveillance System. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance.html>. Published 2017. Accessed March 8, 2018.
16. Centre for Aging and Brain Health Innovation, Baycrest. Centre for Aging and Brain Health Innovation.
17. The Brain Canada Foundation. *Brain Canada Foundation Annual Report 2016*. Montreal, QC; 2016.
18. MacCourt P, Family Caregivers Advisory Committee, Mental Health Commission of Canada.

- National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses.*; 2013. <http://www.mentalhealthcommission.ca>.
19. AGE WELL. About AGE-WELL. <http://agewell-nce.ca/about-us>. Published 2018. Accessed March 27, 2018.
 20. Canadian Frailty Network. Canadian Frailty Network Research Evidence. <http://www.cfn-nce.ca/improving-evidence-through-research-and-kt/our-research-and-kt-portfolio/2015-transformative-grant-program-pilot-studies/>. Published 2018. Accessed March 27, 2018.
 21. Harding K, Kingwell E, Wardle M, Zhu F, Robertson N, Tremlett H. Socioeconomic status and progression of disability in MS. In: *Association of British Neurologists Annual Meeting*. Vol 0. Birmingham: Association of British Neurologists; 2018:95. <https://www.theabn.org/events/forthcoming-abn-events/abn-annual-meeting-2018.html>.
 22. Ontario Neurotrauma Foundation, Institut national d'excellence en santé et en services sociaux. Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe TBI: Fundamental and Priority Recommendations. 2016;(October).
 23. The FOR, Of R, Moderate W, Severe TO. Brain Injury - Principles for Organizing Rehabilitation Services Key Components of TBI Rehabilitation A SECTION I : Components of the Optimal TBI Rehabilitation System. 2016;(October).
 24. Sunnybrook Health Sciences Centre. Accessible Care Pregnancy Clinic. <https://sunnybrook.ca/content/?page=accessible-care-pregnancy-clinic>. Published 2018. Accessed March 22, 2018.
 25. Ng R, Maxwell C, Yates E, et al. *Brain Disorders in Ontario : Prevalence, Incidence and Costs from Health Administrative Data*. Toronto: Institute for Clinical Evaluative Sciences; 2015.
 26. McGill University News. CFI Grant Awarded to Sara Ahmed and Team. <https://www.mcgill.ca/channels/channels/news/cfi-grant-awarded-sara-ahmed-and-team-282888>. Published 2017. Accessed March 12, 2018.
 27. Munce SEP, Pitzul KB, Guilcher SJT, et al. Health and Community-Based Services for Individuals with Neurological Conditions. *Can J Neurol Sci / J Can des Sci Neurol*. 2017;44(6):670-675. doi:10.1017/cjn.2017.207.
 28. Wijnands JMA, Kingwell E, Zhu F, et al. Health-care use before a first demyelinating event suggestive of a multiple sclerosis prodrome: a matched cohort study. *Lancet Neurol*. 2017;16(6):445-451. doi:10.1016/S1474-4422(17)30076-5.
 29. Keezer MR, Pelletier A, Stechysin B, Veilleux M, Jetté N, Wolfson C. The diagnostic test accuracy of a screening questionnaire and algorithm in the identification of adults with epilepsy. *Epilepsia*. 2014;55(11):1763-1771. doi:10.1111/epi.12805.
 30. Butt DA, Tu K, Young J, et al. A validation study of administrative data algorithms to identify patients with parkinsonism with prevalence and incidence trends. *Neuroepidemiology*. 2014;43(1):28-37. doi:10.1159/000365590.
 31. McChesney-Corbeil J, Barlow K, Quan H, Chen G, Wiebe S, Jette N. Validation of a Case Definition for Pediatric Brain Injury Using Administrative Data. *Can J Neurol Sci*. 2017;44(2):161-169. doi:10.1017/cjn.2016.419.

32. Marriott JJ, Chen H, Fransoo R, Marrie RA. Validation of an algorithm to detect severe MS relapses in administrative health databases. *Mult Scler Relat Disord*. 2018;19(November 2017):134-139. doi:10.1016/j.msard.2017.11.022.
33. Brain Tumour Foundation of Canada. Issue: Counting Every Brain Tumour. <https://www.braintumour.ca/4573/issue-cou>. Published 2019. Accessed March 20, 2018.
34. ALS Canada Research Program. Finding new ways to diagnose ALS faster with advanced imaging. <https://www.als.ca/research/als-canada-approach/projects-funded/>. Published 2017.
35. Aaen G, Belman A, Benson L, et al. Associations between the gut microbiota and host immune markers in pediatric multiple sclerosis and controls. *BMC Neurol*. 2016;16(1):1-9. doi:10.1186/s12883-016-0703-3.
36. Tremlett H, Fadrosh DW, Faruqi AA, et al. Gut microbiota in early pediatric multiple sclerosis: a case-control study. *Eur J Neurol*. 2016;23(8):1308-1321. doi:10.1111/ene.13026.
37. Tremlett H, Fadrosh DW, Faruqi AA, et al. Gut microbiota composition and relapse risk in pediatric MS: A pilot study. *J Neurol Sci*. 2016;363:153-157. doi:10.1016/j.jns.2016.02.042.
38. Simpson S, Van Der Mei I, Lucas RM, et al. Sun exposure across the life course significantly modulates early multiple sclerosis clinical course. *Front Neurol*. 2018;9(FEB):1-17. doi:10.3389/fneur.2018.00016.
39. Multiple Sclerosis Society of Canada. *Research Summaries 2017.*; 2017. <https://mssociety.ca/about-us/accelerating-research>.
40. Koehn S, Badger M, Cohen C, McCleary L, Drummond N. Negotiating access to a diagnosis of dementia: Implications for policies in health and social care. *Dementia*. 2016. doi:10.1177/1471301214563551.
41. Kosteniuk JG, Morgan DG, O'Connell M, Kirk D, Stewart NJ. *A Baseline Study of the Dementia Care Landscape in Sun Country Health Region: A Report by the Rural Dementia Action Research Team*. Saskatoon, Saskatchewan; 2016.
42. Roach P, Drummond N, Keady J. "Nobody would say that it is Alzheimer's or dementia at this age": Family adjustment following a diagnosis of early-onset dementia. *J Aging Stud*. 2016;36:26-32. doi:10.1016/j.jaging.2015.12.001.
43. Ducharme F, Kergoat MJ, Coulombe R, Lvesque L, Antoine P, Pasquier F. Unmet support needs of early-onset dementia family caregivers: A mixed-design study. *BMC Nurs*. 2014;13(1):1-10. doi:10.1186/s12912-014-0049-3.
44. Wawrziczny E, Antoine P, Ducharme F, Kergoat MJ, Pasquier F. Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia*. 2016;15(5):1082-1099. doi:10.1177/1471301214554720.
45. Public Health Agency of Canada. *Dementia in Canada, Including Alzheimer's Disease: Highlights from the Canadian Chronic Disease Surveillance System.*; 2017. doi:HP35-84/2017E-PDF.
46. Canadian Consortium on Neurodegeneration in Aging. COMPASS-ND Study. <http://ccna-ccnv.ca/compass-nd-study/>. Published 2018. Accessed March 8, 2018.
47. Liisa Jaakkimainen R, Bronskill SE, Tierney MC, et al. Identification of physician-diagnosed

- Alzheimer's disease and related dementias in population-based administrative data: A validation study using family physicians' electronic medical records. *J Alzheimer's Dis.* 2016;54(1):337-349. doi:10.3233/JAD-160105.
48. Alzheimer Society of Canada. Prevalence and monetary costs of dementia in Canada (2016): a report by the Alzheimer Society of Canada. *Heal Promot Chronic Dis Prev Can.* 2016;36(10):231-232. doi:10.1017/CBO9781107415324.004.
 49. Bogart J. *Mind the Connection : Preventing Stroke and Dementia.*; 2016. <https://www.heartandstroke.ca/-/media/pdf-files/canada/stroke-report/hsf-stroke-report-2016.ashx?la=en&hash=B84FFD2C434B4E3F5CF4585D9CB35713E6C406E5>.
 50. Mclsaac KE, Moser A, Moineddin R, et al. Association between traumatic brain injury and incarceration: a population-based cohort study. *C Open.* 2016;4(4):E746-E753. doi:10.9778/cmajo.20160072.
 51. Mckay KA, Tremlett H, Zhu F, Kastrukoff L, Marrie RA, Kingwell E. A population-based study comparing multiple sclerosis clinic users and non-users in British Columbia, Canada. *Eur J Neurol.* 2016;23(6):1093-1100. doi:10.1111/ene.12990.
 52. The Canadian Alzheimer's Disease and Dementia Partnership A collective vision for a national dementia strategy for Canada THE CANADIAN ALZHEIMER'S DISEASE AND DEMENTIA PARTNERSHIP (CADDP). http://www.alzheimer.ca/~ /media/Files/national/Advocacy/CADDP_Strategic_Objectives_e.pdf.
 53. Morgan D, Crossley M, Stewart N, et al. Evolution of a Community-Based Participatory Approach in a Rural and Remote Dementia Care Research Program. *Prog Community Heal Partnerships Res Educ Action.* 2014. doi:10.1353/cpr.2014.0040.
 54. Morgan DG, Kosteniuk JG, Stewart NJ, et al. Availability and Primary Health Care Orientation of Dementia-Related Services in Rural Saskatchewan, Canada. *Home Health Care Serv Q.* 2015. doi:10.1080/01621424.2015.1092907.
 55. Tam-Tham H, Nettel-Aguirre A, Silvius J, et al. Provision of dementia-related services in Canada: a comparative study. *BMC Health Serv Res.* 2016;16(1):184. doi:10.1186/s12913-016-1435-1.
 56. Canadian Centre for Health and Safety in Agriculture. Rural Dementia Action Research. <https://cchsa-ccssma.usask.ca/ruraldementiacare/index.php>. Published 2018.
 57. The Economist Intelligence. *Assessing the Socioeconomic Impact of Alzheimer's Disease in Western Europe and Canada.*; 2017. <http://www.ceafa.es/files/2017/05/Evaluación del impacto socioeconómico de la enfermedad de Alzheimer en Europa Occidental y Canadá.pdf>.
 58. Liisa Jaakkimainen R, Bronskill SE, Tierney MC, et al. Identification of Physician-Diagnosed Alzheimer's Disease and Related Dementias in Population-Based Administrative Data: A Validation Study Using Family Physicians' Electronic Medical Records. *J Alzheimer's Dis.* 2016;54:337-349. doi:10.3233/JAD-160105.
 59. Pilon M-H, Poulin S, Fortin M-P, et al. Differences in Rate of Cognitive Decline and Caregiver Burden between Alzheimer's Disease and Vascular Dementia: a Retrospective Study. *Neurol.* 2016;2(6):278-286. <http://www.ncbi.nlm.nih.gov/pubmed/27747317> <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5065347>.

Appendix A: Mapping Connections Knowledge Gaps

1. Gaps in the knowledge of the impacts of neurological conditions on affected individuals, their families, caregivers, and communities:

- Impact of neurological conditions on Canadians living in varying social and economic situations;
- The impact of neurological conditions on First Nations, Inuit and Metis individuals;
- The impact of neurological conditions on children affected by a neurological condition, and those living with an affected parent or sibling;
- Impact on formal caregivers for individuals with severe, debilitating neurological conditions;
- Canadians who were excluded from surveys such as CCHA and SLNCC;
- Canadians with less prevalent conditions (i.e.: ALS, Huntington’s disease).

2. Gaps in knowledge of health services use, availability of services to benefit people with neurological conditions, and recommended improvements to services for people with neurological conditions:

- Inconsistent availability of multidisciplinary care;
- How application of eligibility criteria affect access to services for individuals with a neurological condition;
- Data on health services for Canadians living with a neurological condition were lacking or deficient in:
 - Distribution and quality of health services across various regions and jurisdictions;
 - Costs of providing care for individuals with a neurological condition in continuing care and acute care;
 - Personal cost of medications for individuals with each neurological condition;
 - Perceptions of health care providers on the accessibility, timeliness and quality of health services for individuals with a neurological condition;
 - Provision of health care for First Nations, Inuit and Metis populations, for vulnerable populations, and for children with a neurological condition.

3. Gaps in knowledge of the scope of neurological conditions, including prevalence, incidence, and comorbidities.

- Lack of epidemiologic and administrative data on:
 - Certain neurological conditions in the early stages (e.g., multiple sclerosis and Parkinson’s disease);
 - Less prevalent conditions, (e.g., ALS, dystonia and Huntington’s disease);
 - Neurological conditions typically excluded from participation in national population surveys;
 - Extent of neurological conditions among children (cerebral palsy, epilepsy, multiple sclerosis, brain injury and stroke), and the persistence of these conditions into adulthood.
- Infrastructure gaps included the need for:
 - Standardization of diagnostic codes used in physician billing claims and hospital data in all provinces/territories;
 - Standardization of case definitions and algorithms as well as their periodic review;
 - Ongoing consideration and incorporation of newly available data, e.g., pharmaceutical or costing data;
 - Data capture and reporting of benign brain tumours in existing provincial/territorial cancer registries.

4. Gaps in knowledge about the risk factors for the development and progression of neurological conditions consist of a deficiency of lack of data on risk factors for neurological conditions:

- Clinical or public health relevance of statistically validated risk factors;
- Risk factors for the progression of neurological conditions, with respect to the potential improvement or deterioration of the condition;
- Relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions, (assessment of the potential effectiveness of prevention measures at the individual and population levels).

Appendix B: Survey Sent to Key Informants

Please respond and return to Deanna.groetzinger@mybrainmatters.ca by Wednesday, February 21. There is no limit to the length of your answer.

1. Your name, phone number, role, focus (condition), geographic location:
2. In the last few years, what progress have you noticed with respect to research, policy or care relating to neurological conditions in Canada? Please feel free to focus on the condition that you know best or on more than one, if that is appropriate.
 - a. Please describe the changes, including who they affect, where they are taking place, and why they constitute progress. Examples are useful (if they don't breach confidentiality!).
 - b. What obstacles may be preventing beneficial change from taking place? What would you advise to improve the situation?
3. What do you see as priorities for the next five years?
4. If you have other comments you would like to share with us, please do so here.
5. If you have or know of documents (reports, results of studies, journal articles) that would be of interest to us, please share them with us, as links, attachments, or simply titles.
6. Is there someone else we should be contacting? If yes, please provide name, organization, email and telephone number.

Thank you so very much for sharing your time and thoughts.

In addition, we would like to contact some of you for a phone conversation (about 15-20 minutes long) at your convenience, to ask for more in-depth feedback. If you do NOT want us to contact you, please let us know here.

I do not wish to be contacted further

Appendix C: Written Sources Reviewed (alphabetical)

- Aaen G, Belman A, Benson L, et al. Associations between the gut microbiota and host immune markers in pediatric multiple sclerosis and controls. *BMC Neurol*. 2016;16(1):1-9. doi:10.1186/s12883-016-0703-3.
- Adult Hydrocephalus Clinical Research Network. Adult Hydrocephalus Clinical Research Network Core Data Project. <http://www.ahcrn.org/>. Published 2018.
- ALS Canada Research Program. Finding new ways to diagnose ALS faster with advanced imaging. <https://www.als.ca/research/als-canada-approach/projects-funded/>. Published 2017.
- Alzheimer Society of Canada. Prevalence and monetary costs of dementia in Canada (2016): a report by the Alzheimer Society of Canada. *Heal Promot Chronic Dis Prev Can*. 2016;36(10):231-232. doi:10.1017/CBO9781107415324.004.
- Bogart J. *Mind the Connection : Preventing Stroke and Dementia*.; 2016. <https://www.heartandstroke.ca/-/media/pdf-files/canada/stroke-report/hsf-stroke-report-2016.ashx?la=en&hash=B84FFD2C434B4E3F5CF4585D9CB35713E6C406E5>.
- Butt DA, Tu K, Young J, et al. A validation study of administrative data algorithms to identify patients with parkinsonism with prevalence and incidence trends. *Neuroepidemiology*. 2014;43(1):28-37. doi:10.1159/000365590.
- Brain Tumour Foundation of Canada. Issue: Counting Every Brain Tumour. <https://www.braintumour.ca/4573/issue-cou>. Published 2019. Accessed March 20, 2018.
- Canadian Consortium on Neurodegeneration in Aging. Canadian Consortium on Neurodegeneration in Aging. <http://ccna-ccnv.ca/>. Published 2018. Accessed March 8, 2018.
- Canadian Traumatic Brain Injury Research Consortium. Canadian Traumatic Brain Injury Research Consortium Projects. <http://www.ctrcc-crct.ca/>. Published 2016.
- CanChild. CanChild - Current Studies. McMaster University. <https://www.canchild.ca/en/research-in-practice/current-studies>. Published 2018.
- Canadian Longitudinal Study on Aging. Canadian Longitudinal Study on Aging. <https://www.clsa-elcv.ca/>. Published 2018. Accessed March 7, 2018.
- Centre for Aging and Brain Health Innovation, Baycrest. Centre for Aging and Brain Health Innovation.
- Ducharme F, Kergoat MJ, Coulombe R, Lvesque L, Antoine P, Pasquier F. Unmet support needs of early-onset dementia family caregivers: A mixed-design study. *BMC Nurs*. 2014;13(1):1-10. doi:10.1186/s12912-014-0049-3.
- Harding K, Kingwell E, Wardle M, Zhu F, Robertson N, Tremlett H. Socioeconomic status and progression of disability in MS. In: *Association of British Neurologists Annual Meeting*. Vol 0. Birmingham: Association of British Neurologists; 2018:95. <https://www.theabn.org/events/forthcoming-abn-events/abn-annual-meeting-2018.html>.
- Hydrocephalus Clinical Research Network. Hydrocephalus Clinical Research Network Research. hcrn.org. Published 2018. Accessed March 16, 2018.
- Institute OB. About OBI. <http://braininstitute.ca/>. Published 2017. Accessed March 20, 2018.
- International Progressive MS Alliance. International Progressive MS Alliance Research. <http://www.progressivemsalliance.org/research/>. Accessed March 16, 2018.
- Keezer MR, Pelletier A, Stechysin B, Veilleux M, Jetté N, Wolfson C. The diagnostic test accuracy of a screening

- questionnaire and algorithm in the identification of adults with epilepsy. *Epilepsia*. 2014;55(11):1763-1771. doi:10.1111/epi.12805.
- Koehn S, Badger M, Cohen C, McCleary L, Drummond N. Negotiating access to a diagnosis of dementia: Implications for policies in health and social care. *Dementia*. 2016. doi:10.1177/1471301214563551.
- Liisa Jaakkimainen R, Bronskill SE, Tierney MC, et al. Identification of Physician-Diagnosed Alzheimer's Disease and Related Dementias in Population-Based Administrative Data: A Validation Study Using Family Physicians' Electronic Medical Records. *J Alzheimer's Dis*. 2016;54:337-349. doi:10.3233/JAD-160105.
- Lix L, Reimer K. The Canadian Chronic Disease Surveillance System : A Distributed Surveillance Model. In: *International Society for Disease Surveillance*. Vol 9. ; 2017:2579.
- MacCourt P, Family Caregivers Advisory Committee, Mental Health Commission of Canada. *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses*.; 2013. <http://www.mentalhealthcommission.ca>.
- McChesney-Corbeil J, Barlow K, Quan H, Chen G, Wiebe S, Jette N. Validation of a Case Definition for Pediatric Brain Injury Using Administrative Data. *Can J Neurol Sci*. 2017;44(2):161-169. doi:10.1017/cjn.2016.419.
- Marriott JJ, Chen H, Fransoo R, Marrie RA. Validation of an algorithm to detect severe MS relapses in administrative health databases. *Mult Scler Relat Disord*. 2018;19(November 2017):134-139. doi:10.1016/j.msard.2017.11.022.
- McIsaac KE, Moser A, Moineddin R, et al. Association between traumatic brain injury and incarceration: a population-based cohort study. *C Open*. 2016;4(4):E746-E753. doi:10.9778/cmajo.20160072.
- Morgan DG, Kosteniuk JG, Stewart NJ, et al. Availability and Primary Health Care Orientation of Dementia-Related Services in Rural Saskatchewan, Canada. *Home Health Care Serv Q*. 2015. doi:10.1080/01621424.2015.1092907.
- McGill University News. CFI Grant Awarded to Sara Ahmed and Team. <https://www.mcgill.ca/channels/channels/news/cfi-grant-awarded-sara-ahmed-and-team-282888>. Published 2017. Accessed March 12, 2018.
- Multiple Sclerosis Society of Canada. *Research Summaries 2017*.; 2017. <https://mssociety.ca/about-us/accelerating-research>
- Munce SEP, Pitzul KB, Guilcher SJT, et al. Health and Community-Based Services for Individuals with Neurological Conditions. *Can J Neurol Sci / J Can des Sci Neurol*. 2017;44(6):670-675. doi:10.1017/cjn.2017.207.
- Multiple Sclerosis Society of Canada. Multiple Sclerosis Society of Canada - Accelerating Research. <https://mssociety.ca/about-us/accelerating-research>. Published 2018. Accessed March 19, 2018.
- Ng R, Maxwell C, Yates E, et al. *Brain Disorders in Ontario : Prevalence, Incidence and Costs from Health Administrative Data*. Toronto: Institute for Clinical Evaluative Sciences; 2015.
- Ontario Neurotrauma Foundation, Institut national d'excellence en santé et en services sociaux. Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe TBI: Fundamental and Priority Recommendations. 2016;(October).
- Pilon M-H, Poulin S, Fortin M-P, et al. Differences in Rate of Cognitive Decline and Caregiver Burden between Alzheimer's Disease and Vascular Dementia: a Retrospective Study. *Neurol*. 2016;2(6):278-286. <http://www.ncbi.nlm.nih.gov/pubmed/27747317><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5065347>.
- Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian Chronic Disease Surveillance System. <https://www.canada.ca/en/public->

- health/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance.html. Published 2017. Accessed March 8, 2018.
- Roach P, Drummond N, Keady J. "Nobody would say that it is Alzheimer's or dementia at this age": Family adjustment following a diagnosis of early-onset dementia. *J Aging Stud.* 2016;36:26-32. doi:10.1016/j.jaging.2015.12.001.
- Simpson S, Van Der Mei I, Lucas RM, et al. Sun exposure across the life course significantly modulates early multiple sclerosis clinical course. *Front Neurol.* 2018;9(FEB):1-17. doi:10.3389/fneur.2018.00016.
- Sunnybrook Health Sciences Centre. Accessible Care Pregnancy Clinic. <https://sunnybrook.ca/content/?page=accessible-care-pregnancy-clinic>. Published 2018. Accessed March 22, 2018.
- Tam-Tham H, Nettel-Aguirre A, Silvius J, et al. Provision of dementia-related services in Canada: a comparative study. *BMC Health Serv Res.* 2016;16(1):184. doi:10.1186/s12913-016-1435-1
- The Brain Canada Foundation. *Brain Canada Foundation Annual Report 2016*. Montreal, QC; 2016.
- The FOR, Of R, Moderate W, Severe TO. Brain Injury - Principles for Organizing Rehabilitation Services Key Components of TBI Rehabilitation A SECTION I : Components of the Optimal TBI Rehabilitation System. 2016;(October).
- Tremlett H, Fadrosch DW, Faruqi AA, et al. Gut microbiota in early pediatric multiple sclerosis: a case-control study. *Eur J Neurol.* 2016;23(8):1308-1321. doi:10.1111/ene.13026.
- Tremlett H, Fadrosch DW, Faruqi AA, et al. Gut microbiota composition and relapse risk in pediatric MS: A pilot study. *J Neurol Sci.* 2016;363:153-157. doi:10.1016/j.jns.2016.02.042.
- Wawrziczny E, Antoine P, Ducharme F, Kergoat MJ, Pasquier F. Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia.* 2016;15(5):1082-1099. doi:10.1177/1471301214554720.
- Wijnands JMA, Kingwell E, Zhu F, et al. Health-care use before a first demyelinating event suggestive of a multiple sclerosis prodrome: a matched cohort study. *Lancet Neurol.* 2017;16(6):445-451. doi:10.1016/S1474-4422(17)30076-5.

Appendix D: Table of Knowledge Gaps and Pertinent Updates for Neurological Conditions

*Numbered references are used to indicate documentary sources, and ‘S1’ etc. is used to indicate the number of the survey response.

Focus	Gap	New Knowledge to Address Gap
Impacts of Neurological Conditions	Canadians living in varying social and economic situations	<p style="text-align: center;"><i>Documents</i></p> <p>As part of the CTIRC, Dr. Paul VanDonkelaar is characterizing TBI in the particular population of survivors of intimate partner violence (IPV) and using an integrated knowledge translation approach to disseminate this information to community organizations who serve survivors of IPV. (www.ctirc-ccrt.ca/).</p> <p>Dr. Katharine Harding and Dr. Helen Tremlett (UBC) led a study examining MS; they identified that lower socioeconomic status is associated with poorer long term prognosis, potentially due to lifestyle or comorbidity ²¹.</p>
	First Nations, Inuit, and Metis individuals, with a need for fulsome representation of each of these Aboriginal groups	
	Children, both those affected by a neurological condition and those living with an affected parent or sibling.	<p style="text-align: center;"><i>Documents</i></p> <p>Led by principal investigator Dr. Doreen Bartlett and funded by the CIHR, the “On Track Study” is a large multisite study. It aims to describe the changes in balance, range of motion limitations, strength, and endurance, number and impact of health conditions, and participation in self-care, recreation, and leisure activities over a one-year period in young children with CP⁶.</p> <p>A collaborative grant funded by the MS Society of Canada, and led by Dr. Banwell and Dr. Ruth Ann Marrie (Health Science Centre Winnipeg), aims to continue to examine the impact of MS in children and adolescents, looking at quality of life, health care service utilization, brain development, cognitive performance, and the immune system³⁹.</p> <p style="text-align: center;"><i>Survey</i></p> <p>S11: We (CanChild) are seeking to change and expand the dialogue on how to support child and family development in the face of neurodisabilities, and to prevent the well-recognized physical and mental health morbidity experienced by parents raising kids with conditions like CP, Autism Spectrum Disorder (ASD), intellectual impairments, and so on. We currently have a funded international study to explore these questions, and a \$500k</p>

		project going to CIHR in the spring of 2018, to pursue these issues more fully. Our interests lie especially in studying the life course of children with impairments and their families.
	Formal caregivers for individuals with severe, debilitating conditions	
	Canadians who were excluded from surveys such as the CCHS and the SLNCC*.	<i>Documents</i>
		The objective of a study led by Kathryn E. Mclsaac (Dalla Lana School of Public Health, University of Toronto), was to explore the association between TBI and risk of incarceration among men and women in Ontario; they found that the incidence of incarceration was higher among participants with prior TBI compared with those without a prior TBI. This research highlights the importance of designing primary, secondary, and tertiary strategies to mitigate risk of TBI and incarceration ⁵⁰ .
		<i>Survey</i>
		S8: Research is being focused on the over-representation of those with ABI in the prison system and in homeless populations. Recent survey by the Department of Justice on Justice System reform indicated a possible social services aspect to dealing with those who commit crime by looking at the root cause of the crime (i.e. unemployment, mental health, addictions, homelessness). ABI in many cases is the root cause of all of those issues but is not on their radar at all.
	Canadians with less prevalent neurological conditions, such as those outside the scope of the NPHSNC study or those affected by less common conditions such as ALS, Huntington's disease, and dystonia.	<i>Documents</i>
		As part of the Canadian Traumatic Brain Injury Research Consortium, Dr. Emily Nalder is leading a study to identify interventions to support family caregivers with managing challenging behaviors of individuals with brain injury ⁵ .
		Led by principal investigator Dr. Jan Willem Gorter, (CanChild), the MyStory Project will study the physical health, mental health, chronic stress, and overall wellbeing in adolescents and young adults with CP between 16 and 30. This study fills a critical gap in the understanding of developmental trajectories of adolescents and young adults with CP ⁶ .
		<i>Survey</i>
		S12: We need more research invested into better understanding the burden of complex neuro diseases (Huntington's) on caregivers and households.
		<i>Documents</i>

<p>Health Services for Neurological Conditions- health service gaps</p>	<p>The inconsistent availability of multidisciplinary care</p>	<p>The Biomedical Research and Informatics Living Laboratory for Innovative Advances of New Technologies in Community Mobility Rehabilitation (BRILLIANT) aims to optimize mobility of persons with ABI across the lifespan, through development and deployment of a clinical and community based mobility monitoring system to evaluate the factors results in poor mobility²⁶.</p>
		<p>McKay and colleagues compared incident MS cases who attended MS clinics, to people with MS who did not attend clinics using retrospective record linkage. They found that while gender and socioeconomic status were similar, people with MS who did not attend clinics were older and had a higher burden of comorbidity. Researchers concluded that the needs of MS patients managed in the community may differ from those referred to an MS clinic, and ultimately, more investigations are needed⁵¹.</p>
		<p style="text-align: center;"><i>Survey</i></p>
		<p>S4: Support for persons with co-morbidities has been identified as a current barrier as noted in a pan-Canadian survey published in CJNS 2017²⁷.</p>
		<p>S8: Within the ABI industry there is more of a focus on the current issues affecting individuals with ABI and the need for change. Appropriate long-term housing, regional disparity of access to services (change point-of-care), community engagement, mental health (in many cases ABI and mental illness are connected, but most treatments will only focus on one), access to services restricted by access to funds, respite care for families.</p>
		<p>S14: Lack of consistent, coordinated multi-disciplinary care across Canada for ALS.</p>
		<p>S16: Development of new Adult Hydrocephalus Clinics. Now dedicated clinics in Calgary, Vancouver with physicians developing more focused care models in Victoria, London Ontario, Halifax and recently Toronto. Prior to 2008 there were no dedicated adult clinics.</p>
		<p>S16: Continued lack of transitional multidisciplinary care programs for those with spina bifida and/or hydrocephalus in many major Canadian cities to ensure that when children reach adult age that appropriate care continues. Coordination of services through primary care providers is sporadic and insufficient. When referrals are made to specialists, many refuse to take on cases because they are “too complex”. Need health care to make this a priority and adequately fund clinics and education of physicians and nurses to work in these clinics.</p>
		<p style="text-align: center;"><i>Survey</i></p>

	<p>The application of eligibility criteria, especially restrictions on the provision of care for individuals with mental health disorders, and an assessment of the burden that these restrictions place on patients with a neurological condition compared to those without a neurological conditions.</p>	<p>S16: There is little to no support or access in the adult world for treatment options that are available in the pediatric setting. For example, bowel management option Malone Antegrade Continence Enema (MACE). This procedure is being done in the pediatric population for spina bifida and spinal cord injury to manage a neurogenic bowel but is not offered in the adult health care settings. Hence, if the surgery is performed when the patient is a child there is no one to oversee function status of the procedure when transitioned to adult health care providers. We have heard that many adults are travelling to the US to have this procedure done because it can potentially enhance employability, social relationships and overall quality of health and life.</p>
<p>Health Services for Neurological Conditions – Data gaps</p>	<p>The distribution and quality of health services across the various regions and jurisdictions of Canada</p>	<p><i>Documents</i></p>
		<p>The development of clinical practice guidelines for the rehabilitation of adults with moderate to severe TBI, and for comprehensive assessment of the person with TBI ²².</p>
		<p>The TRANSITION project, led by Dr. Jan Willem Gorter, measures readiness to transition into the adult healthcare system from the pediatric system⁶.</p>
		<p>Sunnybrook Health Sciences is filling a gap by running an accessible care pregnancy clinic, which cares for women who are pregnant or contemplating pregnancy, who have both invisible and visible physical disabilities, filling an important health services gap for people with cerebral palsy, multiple sclerosis, spina bifida, and neurotrauma²⁴.</p>
		<p><i>Survey</i></p>
		<p>S1: Need to look at how care is delivered at systems level – so that we understand better where and how people interact with the health system and how we can improve that care, as well as how to make it equitable across the country. In some qualitative work with Dr. Marcia Finlayson, people with MS describe the challenges of health system access as being substantial – it is hard to navigate the system, to know what is available, to get it, and that care available varies substantially from one region to another.</p>
		<p>S2: In terms of care, dystonia patients continue to struggle as dystonia is not universally recognized as a disorder that requires long term disability – so for many of them, it is extremely challenging to get the supports they need (and very much up to their primary care giver to champion this for them).</p>
		<p>S4: Persons with SCI in 7 rehabilitation sites in 4 provinces that account for >80% of the Canadian SCI demographic, now meeting and exceeding Accreditation Canada Required Organizational Practice (ROP) standards.</p>

<p>The current costs of providing care for individuals with a neurological condition in continuing care (home care programs, long-term care facilities) as well as in acute care settings across the country.</p>	<p style="text-align: center;"><i>Document</i></p> <p>A 2015 report by the Ontario Brain Institute and the Institute for Clinical Evaluative Sciences investigated the distribution of costs associated with one year of health system use for persons with one of the examined brain disorders, by age group. Proportion of costs associated with one year of health system use for persons with one of the examined brain disorders, by type of health care service and age group. They examined: brain tumour (both primary malignant and benign), cerebral palsy, dementia, epilepsy, motor neuron disease, multiple sclerosis, parkinsonism, spina bifida, spinal cord injury, traumatic brain injury ²⁵.</p>
<p>The personal cost of medications for individuals with each neurological condition, especially given that all provincial and territorial drug plans involve co-payments</p>	<p style="text-align: center;"><i>Survey</i></p> <p>S15: Our health care system is severely challenged at the moment which is impacting our patients in a really profound way. Cancelled surgeries, no access to oral drug treatments, no support services for patients or financial supports for caregivers. We need to work nationally with both provincial and federal governments to change some of these things. I don't know how exactly this would roll out, however a meeting with the Minister of Health may be a good starting place. [brain tumour]</p> <p>S9: The cost of brain injury is astronomical; in the billions and will rise in the coming decades. A set of recent studies evaluated and forecasted the healthcare and lost productivity cost due to brain injury. The researchers investigated 17 brain disorders, diseases and injuries. From Alzheimer's to Parkinson's they found that brain injury is more costly than the next 16 domains combined (Bray & Huggett, 2016; Colantonio, Hsueh, Petgrave, Hirdes, & Berg, 2015; Munce, 2017)</p>
<p>The perceptions of health care providers on the accessibility, timeliness, and quality of health services for individuals with a neurological condition</p>	<p style="text-align: center;"><i>Survey</i></p> <p>S9: Another domain of interest with researchers revolved around clinical guidelines. Significant development has occurred in the last few years regarding clinical guidelines. The Ontario Neurotrauma Foundation has published guidelines for adults with moderate to severe brain injury²², pediatric concussion brain injury, and concussion/mTBI and persistent symptoms. Healthcare providers are the target population for these clinical guidelines. The clinical guidelines lack any educational materials targeted for patients or family members. Rather, the guidelines only direct the healthcare provider to provide education to patients and families.</p>

	The provision of health care for First Nations, Inuit, and Metis populations, for vulnerable populations.	
Scope	The identification of certain neurological conditions, such as multiple sclerosis or Parkinson's disease, at their earliest stages	<i>Documents</i>
		Dr. Helen Tremlett and colleagues led a study which identified a more frequent use of health care in patients with MS than in controls in the 5 years before a first demyelinating event, suggesting the existence of a measurable multiple sclerosis prodrome. These findings have implications for the establishment of an earlier window of opportunity to identify and potentially treat MS ²⁸ .
		Funded by the CIHR and ALS Canada, Dr. Sanjay Kalra is building on a preliminary study that aimed to look for biomarkers in brain images using MRI scans ³⁴ .
	Less prevalent conditions such as ADL, dystonia, and Huntington's disease, as well as other neurological conditions not targeted by the study.	<i>Documents</i>
		The Adult Hydrocephalus Clinical Research Network is working on an adult hydrocephalus Core Data Project, led by Dr. Mark Hamilton, University of Calgary. The registry will include AHCRCN centres in the United States and Canada, for adults 18 years of age or older ⁸ .
	Neurological conditions in populations typically excluded from participation in national population surveys	<i>Documents</i>
Part of the Canadian Traumatic Brain Injury Research Consortium, the Advancing Concussion Assessment in Children (A-CAP) study aims to improve the ability to diagnose pediatric concussion and make prognostic predictions about outcomes. They hope to identify mild TBI with excellent sensitivity and specificity and predict longitudinal outcomes of mTBI. This study is led by Dr. Keith Yeates ⁵ .		
Scope: Gaps in Infrastructure	Standardization of diagnostic codes used in physician billing claims and hospital data in all provinces and territories	<i>Survey</i>
		S6: Surveillance for other conditions hampered by lack of specificity in diagnostic coding systems (administrative data), infrequent use of diagnostic codes for some conditions (administrative data), lack of clinical registries.
	Standardization of case definitions and algorithms as well as their periodic review	<i>Documents</i>
		Keezer and colleagues created an algorithm for the identification of people with epilepsy in the Canadian Longitudinal Study on Aging and validated their epilepsy ascertainment algorithm. The algorithm was found to have a high sensitivity and specificity for adults with lifetime history of epilepsy or active epilepsy, but validation in other age groups is required ²⁹ .

	Ongoing consideration and incorporation of newly available data (eg: pharmaceutical or costing data)	<i>Documents</i> Led by Dr. Isabelle Gagnon and Carol DeMatteo, this study seeks to establish the feasibility and utility of collecting CDE measures for children and adolescents in 7 pediatric mTBI follow-up programs across Canada, contributing to development of standardized clinic and research based common data elements ⁶ .
	Complete data capture and reporting of benign brain tumours in existing provincial and territorial cancer registries	<i>Documents</i> In 2011, Brain Tumour Foundation of Canada invested \$122,000 to conduct a Canadian feasibility study to determine what information already existed and how difficult it would be to correlate this information into one centralized database. Dr. Faith Davis led this project; she helped to develop the US registry. The feasibility study is now complete; therefore, the following aims will be sought: supplement registry activities to obtain data on non-malignant brain tumours, create a surveillance report, develop approaches to support collaborative research, (www.braintumour.ca). It is expected that by 2019, a project to identify clinical cases and coding for patients on Avastin may provide insight on the efficacy of this drug treatment for a larger brain tumour population ³³ . <i>Survey</i> S15: We have never had a process of capturing nonmalignant data which ties into the neurological realm – this research will be key in moving us forward. This is similar to other neurological disease groups as well.
Risk Factors for Neurological Conditions	The clinical or public health relevance of statistically validated risk factors	<i>Survey</i> S1: Need more emphasis on prevention of these conditions. For example, smoking, obesity, vitamin D insufficiency are risk factors for MS - but there are no public health efforts to educate the public about this. People with family members who have MS, and people with other immune diseases are most likely to respond to this message and it could reduce risk. We talk about the benefits of certain activities for preventing dementia – but programs to really change behavior in terms of physical activity, social engagement, etc. are lacking.
	Risk factors for the progression of neurological conditions, with respect to the potential improvement or deterioration of the condition	<i>Documents</i> As part of the CTSC, Dr. Carolyn Emery is leading a study investigating how to stop youth ice hockey players from sustaining a concussion by understanding the risk factors for concussion, if they get a concussion, how to make sure that they recover fully and prevent re-injury. This project is expected to inform the reduction of concussion risk and prolonged symptoms associated with concussion in youth ⁵ .

		<p>As part of the CTRC, Drs. Jamie Hutchison, William Panenka, and Anne Wheeler, are developing and validating prognostic models using novel molecular, electroencephalography (EEG) and magnetic resonance imaging, biomarkers, and psychosocial and clinical risk factors to predict long term quality of life following brain injury. They also aim to evaluate the added value of pre-injury health care utilization information from provincial and national databases with the risk factors form objective 1 to predict post-injury health care utilization. This study also covers both children and adults⁵.</p>
		<p>Another CTRC study led by Dr. Alexis Turgeon will develop a prognostic model (decision aid) to evaluate the term prognosis of critically ill adults with severe TBI⁵.</p>
		<p>Led by Carol DeMatteo and Dr. Brian Timmons (CanChild), this study seeks to determine if standardized exertion testing could help contribute to decision making for safe return to sport and activity following mTBI; EEG techniques will also be explored, to prevent prolonged recovery following mTBI⁵.</p>
		<p>A pilot study led by Tremlett and colleagues (2016) explored the association between gut microbiota and relapsing remitting pediatric MS cases, and found that the absence of a certain type of bacteria (Fusobacteria) was associated with relapse risk; findings from this study could offer new targets to alter the MS disease course. In a similar study, the same group examined alterations in the microbial community profiles, comparing between early onset pediatric multiple sclerosis and control children for similar age and sex³⁵⁻³⁷.</p>
		<p>Dr. Ruth Ann Marrie (University of Manitoba) is conducting a study that will compare risk factors, treatments and outcomes for heart attack among people with and without MS; findings will provide important information for people with MS and their health care team about prognosis³⁹.</p>
		<p><i>Survey</i></p>
		<p>S1: In MS, we have more approved treatments to slow disease progressive in the early phase of the disease – offering improved efficacy, and more choices for people living with the disease including oral therapies instead of injectable therapies.</p>
<p>The relative and population attributable risk of modifiable risk factors for the onset of neurological conditions, which would allow for the assessment of the potential</p>		<p><i>Documents</i></p>
		<p>A recent study found that people who live in areas where they are exposed to more of the sun’s rays, specifically UV-B rays, may be less likely to develop MS later in life. Exposure in childhood and young adulthood may also reduce risk³⁸.</p>
		<p><i>Survey</i></p>

effectiveness of prevention measures at the individual and population levels	S17: There is no focus on preventative wellness in the medical field. The focus is on post-op rehab (hydrocephalus).
	S9: Concussion education programs have been examined from a number of perspectives that include: effectiveness of concussion programs (Bagley et al., 2012; Caron, Bloom, Falcão, & Sweet, 2015), as a preventative measure in sports (Provvidenza et al., 2013), teaching coaches (Covassin, Elbin, & Sarmiento, 2012), protocol implementation in high schools (Hachem, Kourtis, Mylabathula, & Tator, 2016), hockey teams (Echlin et al., 2010), and knowledge translation (Mrazik et al., 2015). The majority of the literature focused on the mild or concussion end of the brain injury severity spectrum. A small number of articles demonstrated that concussion education was beneficial. For example, athletes were more likely to inform their coach of a suspected concussion (Bramley, Patrick, Lehman, & Silvis, 2012).

Appendix E: Table Demonstrating Knowledge Gaps and Pertinent Updates for Dementia from Documentary and Interview Sources

*References are included for documentary sources, KI1, refers to information from key informants.

Focus	Gap	New Knowledge to Address Gap
Impacts of Dementia	Canadians living in varying social and economic situations	As part of CCNA Theme 3, Drs. Sadavoy and Mary Chiu are undertaking a research program to better understand and improve the psychosocial experiences of family caregivers who are caring for individuals with dementia and concurrently employed in the Canadian workforce, “working caregiver research”, contributing to the knowledge base regarding a population ¹² .
		Dr. Sharon Koehn, as a member of the DementiaNET collaborative, led a team in a national study to understand the pathways to a diagnosis of dementia experienced by elders from different ethnocultural groups ⁴⁰ .
	First Nations, Inuit, and Metis individuals, with a need for fulsome representation of each of these Aboriginal groups	Funded by the Alzheimer’s Society, Dr. Jennifer Walker is examining the challenge of dementia in Saskatchewan First Nations populations ⁵² .

<p>Children, both those affected by a neurological condition and those living with an affected parent or sibling.</p>	<p>Examining intergenerational dynamics and family transition in early onset dementia. (Roach et al. 2016).⁴²</p>
<p>Formal caregivers for individuals with severe, debilitating conditions</p>	
<p>Canadians who were excluded from surveys such as the CCHS and the SLNCC*.</p>	
<p>Canadians with less prevalent neurological conditions, such as those outside the scope of the NPHSNC study or those affected by less common conditions such as ALS, Huntington's disease, and dystonia.</p>	<p>Study exploring the needs of individuals caring for those with early onset dementia (Ducharme et al. 2014).</p>
	<p>Examining the experiences of couples and characterizing the interactions since diagnosis of early onset dementia (Wawrziczny et al. 2016).⁴⁴</p>
	<p>As part of the CCNA in Theme 2, Dr. Robin Hsiung explores Frontotemporal dementia. (ccna-ccnv.ca).</p>
<p>Additional points from key informants:</p>	<p>R1: “I think what’s changed is there is greater recognition of...the non-health impact. There’s more interest now on issues of stigma and how people with dementia are viewed by others. And there’s been a movement into what’s called dementia-friendly communities and trying to make where we live more hospitable to people who have unfortunately developed dementia and an effort to maintain their dignity and also their independence longer in that they can stay living where they wish to live rather than being maybe ghettoized or walled off from the rest of society.”</p> <p>R2: “People are much more aware...or issues relating to dementia...”</p> <p>R3: “There’s an increase in acknowledgement that the impact is great. People are starting to talk about it more, even in the context of the legislative context. For instance, the fact that we’re moving towards creating a national dementia strategy is because, I think, federal government is understanding the impact....That, in the last two and a half, three years, as this legislation has moved to being law now, it is a pretty significant piece, but there’s still that gap in that we don’t have a strategy, for instance.”</p>

		<p>Study by Roach and colleagues explored transitions experienced by families in early onset dementia, can be significantly impacted by the opportunity of meaningful activities or purposeful roles. .⁴²</p>
		<p>CCNA Theme 3: Drs. Gary Naglie and Mark Rapoport supporting decision making and needs of drivers with dementia¹².</p>
		<p>R5: Lori Mitchell led work, role of neurological conditions in predicting caregiver distress in home care, as well as other functional characteristics; there is an effect of specific diagnoses on caregiver distress. Looked at family characteristics. (An understanding that the functional and contextual provides more info than the diagnosis).</p>
		<p>R3: Increased realisation of need for more healthcare services: “In Ontario, with \$100 million dementia strategy, most of that \$100 million will be invested over the next five years on various health services, homecare, et cetera.” ... All of that, because people, I think, have realized the impact and are trying to mitigate that. Of course, the impact on the healthcare system, in particular, the increasing cost.</p>
		<p>The Rural Dementia Action Research (RADAR) Team, led by Dr. Debra Morgan, is in the early stages of the development of a toolkit, for delivering comprehensive, integrated primary health care for dementia across diverse rural settings⁵³. With respect to rural areas in Saskatchewan, basic health services, such as pharmacists, family physicians, palliative care, adult day programs, home care, long term care, are available in most communities. However, dementia specific services were typically unavailable. ⁵⁴</p>
<p>Health Services for Dementia</p>	<p>The distribution and quality of health services across the various regions and jurisdictions of Canada</p>	<p>The provision of services other than educational and social services is variable. For example, day programs and services to support future planning for people with dementia and their families are variable. ⁵⁵</p> <p>As part of AGE-WELL, Dr. Megan O’Connell and her team will explore issues of connectivity infrastructure and other user needs experiences by rural and Indigenous older adults⁵⁶. .</p> <p>As part of CCNA, Theme 3, Dr. Debra Morgan co-leads with Dr. Kristen Jacklin and Dr. Carrie Bourassa to focus on rural and Indigenous issues in dementia care, addressing community based primary health care, appropriate tools, and capacity building¹²</p>

	<p>As part of CCNA’s Theme 3, Drs. Howard Bergman and Isabelle Vedel created a team dedicated to the evaluation and implementation of initiatives to improve the capacity of primary care to diagnose and treat older persons with Alzheimer’s disease, and their caregivers¹².</p> <p>A report based on document review and a consultative approach concluded that several reports on the cost of dementia in Canada have been published in recent years it is believe that the government is aware of the economic burden of dementia ⁵⁷</p>
The current costs of providing care for individuals with a neurological condition in continuing care (home care programs, long-term care facilities) as well as in acute care settings across the country.	<p>A recent report supported by the Alzheimer’s Society, The Prevalence and Monetary Costs of Dementia report provides an overview of the different sources of cost estimates, and a comparative breakdown of contributors to the cost. Methods for costing, and sources of costing information are also discussed⁴⁸.</p>
	<p>A report based on consultative approaches and document review indicated that families absorb about 39% of the costs related to Alzheimer’s.⁵⁷</p>
The personal cost of medications for individuals with each neurological condition, especially given that all provincial and territorial drug plans involve co-payments	<p>Out-of-pocket and prescription medication costs are estimated in the Alzheimer’s Society report, little discussion of the provincial and territorial variation ⁴⁸</p>
The perceptions of health care providers on the accessibility, timeliness, and quality of health services for individuals with a neurological condition	<p>R2: “I do know that there are projects, which are attempting to bring to the members of immigrant communities in Canada into much greater awareness and knowledge of the services that are available to you, or to them.... A gerontologist at Simon Fraser University, and she's leading a study that’s looking at the Korean community and the Punjabi community in the Fraser Valley Health Authority, and the whole point of that is to identify barriers to access in those communities specifically. And that’s just an example of work being undertaken to try to plug a gap.”</p>
The provision of health care for First Nations, Inuit, and Metis populations, for vulnerable populations.	<p>R3: “SK has no dementia plan; NS and ON do. With CIHR, CCNA; now, within last 5 years, ‘talking a lot more’ about impact on indigenous communities; re immigrant communities: “I don’t see a lot of that happening”—but there are some specialized support groups in Vancouver and Toronto;</p>

		As part of AGE-WELL, Dr. Megan O’Connell and her team will explore issues of connectivity infrastructure and other user needs experiences by rural and Indigenous older adults ⁵⁶ .
		COMPASS-ND study (CCNA) aims to improve identification of dementia in early stages ⁴⁶ .
Scope	The identification of certain neurological conditions, such as multiple sclerosis or Parkinson's disease, at their earliest stages	Part of CCNA Theme 1, Prevention, Robert Bartha exploring if Alzheimer’s disease can be detected by MRI before subjects begin to experience cognitive decline ¹² .
		R5: Publish some of that from the NHCC funding, was some of the first work in that area, we were able to look at some of these more rare conditions like ALS and Huntington’s. We haven’t done any further work since then.
	Less prevalent conditions such as ADL, dystonia, and Huntington's disease, as well as other neurological conditions not targeted by the study.	The limited available evidence suggests that rates of dementia have been increasing more rapidly among Indigenous people compared to the general population, and that dementia onset may be earlier in Indigenous people. (Jacklin & Walker, 2012, as quoted by Petrasek McDonald, Ward, and Halseth, 2018).
	Neurological conditions in populations typically excluded from participation in national population surveys	R4: “And while it’s difficult to point to very specific kinds of things that are changing, I guess the most notable change would be that this past fall/winter, the First Nations Inuit health branch at Health Canada was transferred to the newly created Department of Indigenous Services. And so, that from a surveillance standpoint in terms of getting at incidence and prevalence in terms of getting health service utilization, the First Nations Inuit Health Branch has always had a very sophisticated surveillance in health services data kind of a program. It’s always just been more a question of what their priorities have been and where they’ve been able to focus their energies. I have no idea of what it’s transferred to a new department means in practical terms for neurological conditions. But the impression one might get is that this current government is devoting more resources to this whole area of federal government, and so there may be benefits that go along with that from addressing these kinds of gaps sort of perspective.” R5: “First Nations Communities in Alberta have done several large scale pilots of the interRAI home care assessments. Northwest Territories has recently announced that they’re implementing the RAI standard, Nunavut is actively considering it. We’re at a point now where we may soon have very good-quality data for First Nations communities, related to neurological conditions, that are the exact same measures as the rest of the country is using

		<p>in home care and long-term care. That will be a dramatic step forward when that happens. There's still issues to be worked out in terms of how the data are managed under First Nations data control protocols, but the availability of those data has been a huge step forward in the last five years."</p> <p>R3: "Around epi question: SK numbers are always omitted. There's still a very important gap in Saskatchewan. Saskatchewan numbers are always omitted, because of the way the healthcare coding happens in that province..."</p>
	Gaps in infrastructure: standardization of diagnostic codes used in physician billing claims and hospital data in all provinces and territories	R5: Yeah, so it's like, home care, and nursing home, and mental health. We published a paper on the prevalence of these 11 different conditions in those three care settings in multiple provinces. When we published that, it was based on a smaller, earlier data set that really only covered a handful of provinces. We're now at a point that there's 11 provinces and territories implementing at least one of these systems, including two territories, Northwest Territories and the Yukon. We've got increasing capacity to understand the prevalence of these characteristics in health care populations, and the clinical characteristics of those folks.
	Standardization of diagnostic codes (eg. ICD-10-CA) used in physician billing claims and hospital data in all provinces and territories	Funded by the PHAC, Jaakkimainen and colleagues developed and validated an algorithm to identify physician diagnosed dementia in health administrative databases. ⁵⁸ .
	Standardization of case definitions and algorithms as well as their periodic review	<p>Dr. Holly Tuokko using CLSA data to develop of normative data and comparison standards for the cognition measures employed in CLSA¹³.</p> <p>The CSHA remains the single best population data source to use as a basis to build estimates; experts recommended that prevalence estimates be routinely generated from provincial health administrative data, using population based studies such as the CLSA to validate these estimates⁴⁸.</p>
	Ongoing consideration and incorporation of newly available data (eg: pharmaceutical or costing data)	<p>R5: "interRAI systems in 11 provinces and territories. For home care and nursing home, increasingly mental health as well. Mainly for adult populations, 9.6 million assessments, on over 3.3 million Canadians".</p> <p>R1: "I think there's still arguments around the country about how many people with dementia there are. Though maybe not important to know actual number; range is adequate."</p>

	<p>Additional points from key informants:</p>	<p>R2: “We can try to improve our understanding of the epidemiology. I think we do. We’re doing quite a lot of work... looking at the epidemiology of dementia, and Parkinson’s disease, and epilepsy.... But are we doing enough? Well, probably not, but should we be spending money on doing more? I’m not sure.”</p>
		<p>R1: “I think we know that the biggest, most significant risk factor for dementia is age, advancing age, and I think clearly, we can identify other risk factors but I don’t think it’s ever going to undermine the aspect that age is the most important risk factor. And after that, your family predilection to dementia. Unfortunately, some families have a genetic mutation which will lead to dementia and some of us carry a risk factor, a genetic risk factor for developing dementia.”</p>
<p>Risk Factors for Dementia</p>	<p>The clinical or public health relevance of statistically validated risk factors</p>	<p>There exists a significant difference between the rates of decline for patients with Alzheimer’s disease compared to those with vascular dementia, with Alzheimer’s patients declining the fastest.⁵⁹</p>
	<p>Risk factors for the progression of neurological conditions, with respect to the potential improvement or deterioration of the condition</p>	<p>COMPASS-ND, longitudinal study to examine risk factors for development of dementia among those with cognitive impairments⁵².</p>
		<p>As part of CCNA Theme 1, Prevention, Dr. Carol Greenwood examining nutrition strategies that support optimal cognitive function with aging¹². (ccna-ccnv.ca)</p>
		<p>As part of CCNA, Theme 3, How Multimorbidity modifies the risk of dementia and the patterns of disease expression. Melissa Andrew examines how multimorbidity modifies the risk of dementia and patterns of disease expression¹². (ccna-ccnv.ca)</p>
		<p>As part of CCNA, Theme 2, Dr. Manuel Montero-Odasso is exploring how the relationship between physical activity and motor performance may slow cognitive decline. (ccna-ccnv.ca)</p>
	<p>R3: Doing much better on knowledge of risk factors, ‘we’re getting more and more concluded on that’ but still much to learn about progression and different types of dementia. “if you look at vascular dementia, for instance, is 30% of all dementias in Canada....Diabetes is an important risk factor in dementia....we could do a much better job, because many of those risk factors are very aligned”.</p>	

	<p>The relative and population attributable risk of modifiable risk factors for the onset of neurological conditions, which would allow for the assessment of the potential effectiveness of prevention measures at the individual and population levels</p>	<p>R2: “If you take risk factors, I think we’re actually not doing too badly in trying to understand risk factors for dementia.... I think we’re much more aware now than we were five years ago about the cardiovascular risk factors for dementia. It’s interesting...the incidence of cardiovascular disease is falling in Canada, and if that’s true, then we might see the incidence of dementia start to fall.” – though confounding factors include immigration and increasing life expectancy... “...Maybe there are some risk factors that we can identify and that we can do something about, which has been an issue. Well, there are risk factors, but if we can't do anything about them, what's the point? There's no point knowing about them if we can't change something. And I think that’s a change, I think that’s an improvement.” “Other risk factors e.g., exercise (modifying dementia via CVD) need ‘long lead time’ to evaluate- look abroad at longitudinal datasets, e.g., Dutch, but ‘that’s a different population’.”</p> <p>R5: “We’re not going to be able to do much about predicting who in the general population will develop an incident neurological condition because there’s really no data in that context yet. But if we look at the earlier parts of the health system, like home care, we’re actually quite data-rich in that environment now.</p> <p>Cheryl Wellington is examining genetic and environmental risk factors for dementia by examining lipid and lipoprotein metabolism, part of CCNA Theme 1, Prevention¹²</p> <p>The CLSA will contribute to developing a better understanding of non-medical factors that impact people as they age. Specifically, Dr. Barbara Fenesi will explore the interplay of physical activity, sleep, and cognition¹³.</p> <p>Using data from the CLSA, Dr. Guanmin Chen will explore gender differences in vascular risk factors, early cognitive impairment, and progression to dementia¹³.</p> <p>The PURE-MIND study will examine how covert strokes are related to problems with memory and thinking, for people in their 30’s, 40’s, and 50’s⁴⁹.</p>
--	--	--

PROGRESS ON KNOWLEDGE GAPS IDENTIFIED IN MAPPING CONNECTIONS

		Dr. Eric Thorin will help to identify interventions and prevention strategies including the role of exercise to protect Canadians with stroke from developing dementia ⁴⁹ .
--	--	--

*Excluded from the CCHS and SLNCC surveys: persons living on reserves and other Aboriginal settlements; full-time members of the Canadian Forces; the institutionalized population and persons living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James. Altogether, these exclusions represent less than 3% of the overall Canadian population.

(Source: Statistics Canada, <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5182#a2> and <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3226#a2>)