MAPPING CONNECTIONS

AN UNDERSTANDING OF NEUROLOGICAL CONDITIONS IN CANADA

NHCC
NEUROLOGICAL HEALTH CHARITIES CANADA

Government of Canada   Gouvernement du Canada

TO PROMOTE AND PROTECT THE HEALTH OF CANADIANS THROUGH LEADERSHIP, PARTNERSHIP, INNOVATION AND ACTION IN PUBLIC HEALTH.

—Public Health Agency of Canada

WORKING TOGETHER TO IMPROVE THE LIVES OF PEOPLE LIVING WITH CHRONIC NEUROLOGICAL DISEASES, DISORDERS AND INJURIES IN CANADA.

—Neurological Health Charities Canada

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AN UNDERSTANDING OF NEUROLOGICAL CONDITIONS IN CANADA

THE NATIONAL POPULATION HEALTH STUDY OF NEUROLOGICAL CONDITIONS

A partnership between
Neurological Health Charities Canada
The Public Health Agency of Canada
Health Canada
The Canadian Institutes of Health Research

Mapping Connections was developed and managed as a unique partnership between the Government of Canada and Neurological Health Charities Canada, a collaborative of 24 health charity organizations representing the voice of individuals and families impacted by neurological conditions across Canada.

ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

Neurological conditions (diseases, disorders, and injuries) can directly affect Canadians of all ages. Such conditions can be severe or mild, progressive or non-progressive, or uncontrolled or controlled. As these conditions may lead to symptoms and functional deficits that are often chronic in nature, they can have profound impacts on the life and well-being of affected individuals, their families, caregivers, and communities.

Because the prevalence and incidence of some of the most common neurological conditions tend to increase with age, both the number of individuals facing these challenges and the cost of associated care are expected to rise as the Canadian population ages. Worldwide, the focus on neurological conditions, the aging population, and the recognition of their impacts is increasing. In this context, the National Population Health Study of Neurological Conditions (the 'Study') was initiated, with the long-term goal of reducing the burden of neurological conditions in Canada through an increase in understanding of these conditions in a Canadian context. The table below presents the Study partners, components, focus areas, and original 14 neurological conditions selected for inclusion. In addition to these selected neurological conditions, the Study also subsequently provided some coverage of migraine, spinal cord tumour, Rett syndrome, and stroke.

An overview of the National Population Health Study of Neurological Conditions

PARTNERS	COMPONENTS	FOCUS AREAS	NEUROLOGICAL CONDITIONS
Neurological Health Charities Canada Public Health Agency of Canada Health Canada Canadian Institutes of Health Research	Federal investment of $15 million (2009–2013): 13 research projects 3 national surveys 7 microsimulation models	**Impacts** on affected individuals, their families, caregivers, and communities Use of **health services**, gaps in services, and recommended improvements **Scope** in Canada (prevalence, incidence, and comorbidities) **Risk factors** for the development and progression of these conditions	Alzheimer's disease and other dementias Amyotrophic lateral sclerosis* 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

NOTES: * Amyotrophic lateral sclerosis is also known as ALS or Lou Gehrig's disease.

Impacts of neurological conditions

The first chapter of this report presents findings related to the impact of neurological conditions on individuals, their families, and caregivers. Diseases, disorders, and injuries of the brain, spinal cord, and peripheral nervous system can have varying effects both within and across conditions. Nonetheless, individuals living with a neurological condition share many of the same functional impacts and needs.

The impacts of neurological conditions can...	• include a range of functional impairments that affect mobility, dexterity, skin and joint sensation, behaviour, bladder or bowel function, communication or speech and language, perception, cognition, consciousness, and emotion;
	• result in pain and discomfort;
	• negatively affect mental health, quality of life, educational opportunities, the ability to work and participate in activities, and financial security; and
	• lead to feelings of stigmatization.
Neurological conditions can affect...	• men and women differently, with certain neurological conditions being more prevalent in men and others more prevalent in women;
	• children at birth or at a young age, or adults at an older age, altering their life paths in different ways;
	• families of children living with a neurological condition, by causing strain on family members and giving rise to financial issues;
	• the daily lives of First Nations and Métis individuals in terms of physical, emotional, cognitive or mental health, and spirituality; and
	• informal caregivers, especially if they are caring for an individual exhibiting cognitive impairment or behavioural issues.

Health services for neurological conditions

A range of health services is necessary for addressing the needs of individuals living with a neurological condition, and those of their families and caregivers. The second chapter presents findings related to the use of health services, gaps in these services, and recommended improvements along the continuum of care. Canadians living with a neurological condition usually use more health care services than those without a neurological condition or even those with other chronic conditions, whether they are living in the community or in health care facilities, receiving alternate level of care, or obtaining the services of physicians and other health care professionals.

Canadians living with a neurological condition often…	- use more universally insured health care services than Canadians with most other chronic health conditions, with more hospital days, physician visits, prescriptions, and days in residential care; - have more alternative level of care days in hospital while awaiting placement for further care; - use more formal and informal assistance with personal care, housework, or general help with activities than their counterparts without a neurological condition; - need formal emotional support because of their condition; - have health care costs that are significantly higher compared to individuals without a diagnosis of those particular conditions; and - have considerable personal out-of-pocket costs for prescribed medications, despite the fact that most have a drug insurance plan.
Certain barriers exist in health service provision, such as…	- lack of information on, and services for, continuing education or returning to school, employment, family and caregiver support, housing, and transportation; - general difficulty in accessing specialist care, such as services from a neurologist or neuropsychiatrist, particularly in rural or remote areas; - limited availability of specialized services for individuals with less common conditions; - exclusion criteria that limit access to certain services or facilities based on psychiatric diagnoses, severe behavioural disorders, substance abuse, medical instability, or presence of comorbidities; - difficulty in accessing health care for children, whether from a general practitioner, pediatrician, or specialist; and - difficulty in obtaining services when a condition is long-standing or combined with a cognitive impairment.

Services could potentially be enhanced by targeting…	• improvements in knowledge of neurological conditions among health care providers;
	• multidisciplinary care and supporting transitions between settings;
	• social determinants of health such as education, employment, housing, and transportation;
	• appropriate placement of individuals through the use of assessment tools to define care needs of those living with chronic neurological conditions;
	• better monitoring and prescription of condition-specific medications by primary care physicians;
	• the development of clinical profiles of individuals with a neurological condition in different care settings (including home care programs), using a system like the one developed by the interRAI Project; and
	• challenges faced by First Nations and Métis individuals, including ambiguity about the level of government responsible for care provision and the need for better cultural competence among care providers.

Scope (prevalence and incidence) of neurological conditions

The third chapter presents findings related to the epidemiology of neurological conditions in Canada. Various sources and methods for estimating their prevalence and incidence were used – systematic reviews and meta-analyses, health administrative data, electronic medical records, surveys, and microsimulation models – each with strengths and limitations. Assessing the reliability of prevalence and incidence estimates from these different sources provided important information which could enhance the surveillance of neurological conditions in Canada. Also, the unequal distribution of neurological conditions between sexes and across age groups reinforces the need to consider prevalence and incidence patterns when planning health services and programs.

Estimating the prevalence and incidence of neurological conditions can be accomplished using a variety of data sources, such as…	• systematic reviews, that examine the existing literature for sound evidence on prevalence and incidence estimates as well as on data coding and sources;
	• health administrative databases;
	• surveys, for population-based estimates of more prevalent conditions (but not for less common conditions);
	• electronic medical records, for prevalence estimates and further context based on sociodemographic characteristics;
	• mail-in questionnaires, to capture cases of neurological conditions in long-term care facilities; and
	• registries and condition-specific surveillance programs, for rare conditions.

Surveillance of neurological conditions can be accomplished through multiple strategies, including the use of…	• the Canadian Chronic Disease Surveillance System, which is a collaborative network of provincial and territorial surveillance systems led by the Public Health Agency of Canada to collect data on chronic conditions (including neurological conditions); • electronic medical records, building on existing networks such as the Canadian Primary Care Sentinel Surveillance Network; and • comprehensive guidelines and a toolkit, like those produced by the Registry Guidelines Project for the development, implementation, and maintenance of registries of neurological conditions in Canada.

Risk factors for neurological conditions

The final chapter touches upon a component of the Study which sought to identify insights into the biological, lifestyle, socioeconomic, environmental, and psychosocial factors that are potentially associated with the development of neurological conditions. Associations that could be modified by available interventions are particularly relevant, as they offer the potential for the prevention or mitigation of neurological conditions.

Potential modifiable risk factors for the onset of neurological conditions were highlighted, such as…	• cardiovascular risk factors, including smoking and diabetes, which are not only associated with the development of stroke, but also with Alzheimer's disease and other dementias; • brain injury, a neurological condition in itself, which is also identified as a risk factor for Alzheimer's disease and other dementias in men, and for epilepsy in both sexes; • falls in the aging population, which would help reduce the risks associated with traumatic brain and spinal cord injuries; • vitamin D deficiency, which is associated with multiple sclerosis; • exposure to pesticides, which is associated with Alzheimer's disease and other dementias, ALS, brain tumours, and Parkinson's disease; and • complications of pregnancy and delivery, which are associated with several neurological conditions in children.
It should be recognized that…	• the presence of a factor associated with a condition does not necessarily imply that it is the cause of the condition, and conversely, its absence would not guarantee that an individual would not develop the condition; • identified risk factors may be associated with only a small percentage of the cases of a specific neurological condition, or may only apply to specific populations; • there is a need to assess both the clinical and public health significance of risk factors; and • existing data sources, such as those of the Canadian Primary Care Sentinel Surveillance Network, interRAI Project, or Cerebral Palsy Registry Project, could be developed further to yield insights into the lifestyle, socioeconomic, and environmental factors that may increase the risk for developing specific neurological conditions.

Looking ahead: 2011 to 2031

To estimate health outcomes and costs over the next 20 years for seven of the neurological conditions targeted by the Study,[1] microsimulation models were developed by the Public Health Agency of Canada with Statistics Canada. The models accounted for future changes in the Canadian population from births, immigration, emigration, and aging, but not for changes in risk factors or in the prevention, diagnosis, treatment, or management of neurological conditions.

Based on these status quo assumptions, projections from the seven microsimulation models indicate that by 2031…

- as a consequence of the increased prevalence of the selected neurological conditions, an increased number of Canadians will live with severe disability (as defined by the Health Utilities Index-Mark 3, HUI-3), require care provided by informal caregivers, and die with a neurological condition;

- the indirect economic costs due to working-age disability and premature death related to neurological conditions will increase;

- total annual health sector costs will increase modestly for five of the seven modelled neurological conditions, but will be twice as high for Canadians age 40 years and older living with Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism;

- the most prevalent of the seven neurological conditions will continue to be traumatic brain injury, Alzheimer's disease and other dementias, and epilepsy;

- the numbers of new cases of cerebral palsy, epilepsy, multiple sclerosis, and spinal cord injury will rise with the growth of the population, the numbers of new cases of Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism will double, and the number of new hospitalizations with brain injury will increase by 28%; and

- the number of Canadians age 65 years and older living with each of the modelled neurological conditions will more than double.

Knowledge gaps

While generating new information related to the focus areas of this Study, gaps were also identified. Generally, 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, remain scarce. Data are still lacking or deficient 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. Currently, clear and comprehensive data on risk factors for the onset and progression of neurological conditions are not yet available, but steps have been initiated to facilitate access to these data in the future. Provided the availability of epidemiological and intervention data, the introduction of alternative

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[1] Alzheimer's disease and other dementias, cerebral palsy, epilepsy, multiple sclerosis, Parkinson's disease/parkinsonism, hospitalized traumatic brain injury, and hospitalized traumatic spinal cord injury.

scenarios to status quo assumptions in microsimulation models would offer the opportunity to understand the potential effects of better prevention strategies, earlier interventions, new treatments, and rehabilitation approaches on the diverse impacts of neurological conditions. Identifying these gaps is a valuable step in guiding future research endeavours.

In conclusion

This report describes key findings emerging from the Study, identified during a comprehensive and inclusive synthesis process. Overall, the Study offers extensive information on the diverse and often debilitating impacts of neurological conditions, but also presents commonalities in experiences shared by Canadians living with or affected by these conditions. This strengthened the understanding of the often extensive and complex health service needs of those affected by neurological conditions, and the identification of important gaps in access to, and provision of, appropriate care. The Study identified ways to meet and manage these needs. Among the positive outcomes of the Study, several Study projects produced new estimates of the prevalence and incidence of neurological conditions in Canada, and provided substantial evidence to support national surveillance of these conditions. In addition, specific projects have gathered preliminary evidence on factors associated with the onset of some of these conditions.

This Study of neurological conditions was the largest of its kind ever to be undertaken in Canada, and the collaborative effort of all who played a role in its achievements should be recognized. The new evidence generated by the Study, combined with a general increase in awareness, may support Neurological Health Charities Canada, governments, and other stakeholders in their work to reduce the impact and burden of neurological conditions in Canada.

For more information about the findings from the different components of the Study, please visit the Neurological Health Charities Canada (**www.mybrainmatters.ca**) or the Public Health Agency of Canada (**www.phac-aspc.gc.ca/cd-mc/nc-mn/ns-en-eng.php**) websites.

INTRODUCTION

Neurological diseases, disorders, and injuries, referred to collectively as neurological conditions, have been estimated to affect 3.6 million Canadians living in the community and a further 170,000 Canadians living in long-term care facilities.[2] The existence of a neurological condition affects not only the individual living with the condition, but also family members and caregivers both within and outside the health care system, thereby increasing the number of Canadians touched by these conditions.

Canadians living with a neurological condition – whether severe or mild, progressive or non-progressive, uncontrolled or controlled – face unique challenges and have specific needs. Symptoms related to these conditions can include paralyzed or weakened muscles, impaired coordination, loss of sensation, seizures, confusion, pain, and altered memory and capacity to think. Neurological conditions can often have an impact on the general physical and mental health of those affected, as well as their relationships with others, capacity to work, and ability to socialize. In the case of children with a neurological condition, their life paths may be altered significantly.

Neurological conditions can occur in individuals of all age groups. Certain conditions that affect the brain, spinal cord, or peripheral nervous system have an onset during infancy or childhood, while others present during adulthood. The prevalence and incidence of some of the most common neurological conditions tend to increase with age.

The aging of the Canadian population

Over a 20-year period from 2011 to 2031, the Canadian population is projected to grow to more than 40 million people. A shift in the population age structure will result in an increase in the number of Canadians age 65 years and older; this proportion will rise from 15% in 2011 to close to one quarter (23%) by 2031 (Figure I-1).[3] Since the incidence of some of the more common neurological conditions increases with age, as our population ages and grows, both the number of individuals facing the challenges associated with neurological conditions and the cost of caring for these individuals are expected to rise. This burden on health and disability, as well as the need for informal caregiving by families and friends, will result in economic consequences to individuals, caregivers, and the health care system.

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[2] Based on self-reported data from national population surveys. Please refer to the CCHS 2010–2011 Project [3] and the SNCIC 2011–2012 Project [17] in Appendix 1.

[3] Please refer to the Microsimulation Project [10] in Appendix 1.

FIGURE I-1: Projected population distribution, by age group, Canada, 2011 and 2031
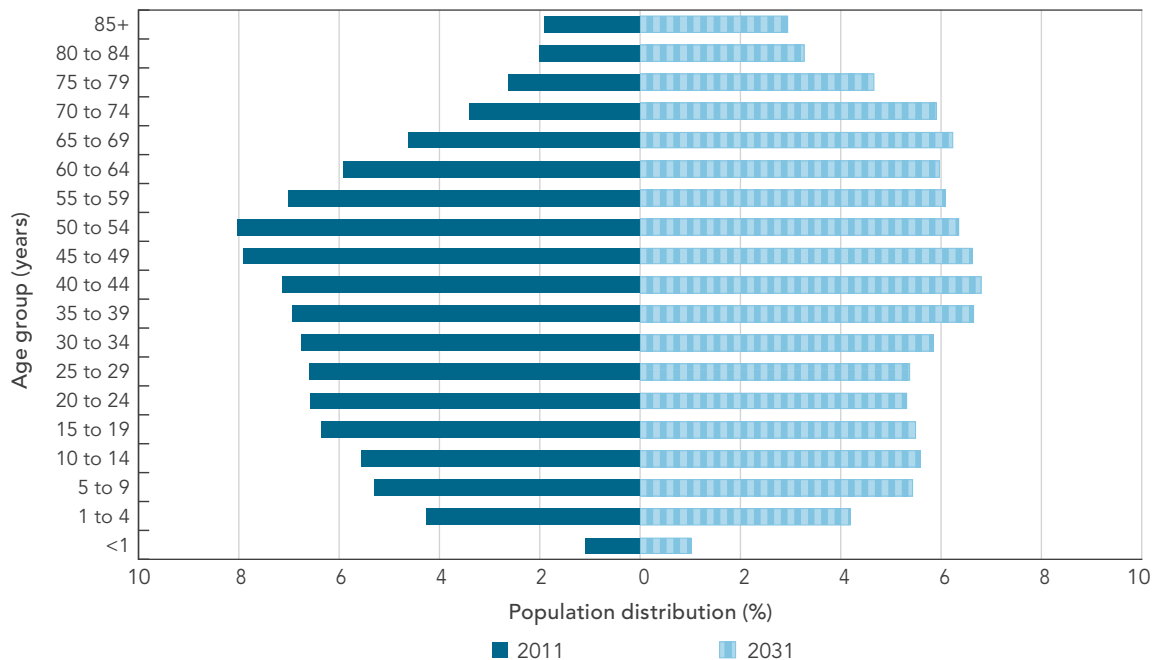
SOURCE: POHEM-Neurological, cerebral palsy model (Statistics Canada and Public Health Agency of Canada).

Worldwide, there has been an increasing focus on neurological conditions and their relationship to the aging population. In 2006, the World Health Organization (WHO) released a publication entitled 'Neurological disorders: Public health challenges',[4] which brought global awareness to the approaching challenges associated with neurological conditions and an aging population. In Canada, a 2007 report released by the Canadian Institute for Health Information (CIHI), the Canadian Neurological Sciences Federation (CNSF), and the Canadian Brain and Nerve Health Coalition (CBANHC) entitled 'The burden of neurological diseases, disorders and injuries in Canada' echoed the call by the WHO for collective action on neurological conditions.[5] Cognizant of the mounting evidence gathered from Canadian health data, in addition to the ever-increasing health care costs and aging of the population, neurological health charities came together to support these calls for coordinated action in addressing neurological conditions.[6]

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[4]   World Health Organization. Neurological disorders: Public health challenges. Geneva (CH): WHO Press, 2006. 218 p.

[5]   Canadian Institute for Health Information. The burden of neurological diseases, disorders and injuries in Canada. Ottawa (ON): CIHI; 2007. 130 p.

[6]   Caesar-Chavannes CR, MacDonald S. National Population Health Study of Neurological Conditions in Canada. Chronic Diseases and Injuries in Canada. 2013 Jun;33(3):188-91.

The National Population Health Study of Neurological Conditions

The National Population Health Study of Neurological Conditions (the 'Study') was jointly planned and initiated in 2009 through a unique partnership between Neurological Health Charities Canada (NHCC), the Public Health Agency of Canada (the 'Agency'), Health Canada, and the Canadian Institutes of Health Research (CIHR). 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 Canada.

The four focus areas covered by the National Population Health Study of Neurological Conditions

After receiving advice from advisory groups comprised of over 50 experts from the Canadian neurological research community, and with consideration to both the potential population disease burden and key knowledge gaps, the Study was designed to investigate neurological conditions across four focus areas:

1. The **impacts** on affected individuals, their families, caregivers, and communities;
2. The use of **health services**, gaps in services, and recommended improvements;
3. The **scope** in Canada (in terms of prevalence, incidence, and comorbidities); and
4. The **risk factors** for the development and progression of these conditions.

With a commitment of $15 million over four years (2009 to 2013), thirteen research projects were funded, along with three national surveys (see Appendix 1 for descriptions). In addition, a set of seven microsimulation models was developed by the Agency with Statistics Canada to project the health outcomes and costs of selected neurological conditions. Finally, the Agency's Canadian Chronic Disease Surveillance System (CCDSS) was expanded to use provincial and territorial health administrative data for the surveillance of selected neurological conditions.

MICROSIMULATION MODELS

A set of seven microsimulation models, POHEM-Neurological, was developed to project the health outcomes and costs in Canada associated with some of the more common neurological conditions over the next 20 years: Alzheimer's disease and other dementias, cerebral palsy, epilepsy, multiple sclerosis, Parkinson's disease/parkinsonism, hospitalized traumatic brain injury, and hospitalized traumatic spinal cord injury. In addition to other data, these models were based on new research findings from the Study itself. Each model accounted for changes in the Canadian population from births, immigration, emigration, and aging, but not for changes in risk factors or in the prevention, diagnosis, treatment, or management of neurological conditions.

Microsimulation is an increasingly important tool for linking evidence to health policy. Such models can be used to explore 'what if' scenarios, comparing alternative interventions in terms of their costs and the outcomes obtained (including changes in patterns of health services utilization, employment, and quality of life). The development of POHEM-Neurological was a significant scientific contribution as these are the most comprehensive models of this type yet to be developed in Canada. However, interpretation of projected epidemiological, health, and economic trends should consider the uncertainty inherent in extending current (status quo) data into the future. Common to all models, inputs and assumptions require updating to reflect changing conditions and to take into consideration new knowledge as understanding of these conditions evolves. Also, future users could develop the models to simulate the impact of changes in modifiable risk factors or in the influence of prevention strategies, early intervention, treatment, and rehabilitation.

Neurological conditions covered by the National Population Health Study of Neurological Conditions

At the onset, 14 diseases, disorders, and injuries of the brain, spinal cord, and peripheral nervous system were selected as part of the Study (Table I-1).[7] While some research projects and components of the Study focused on subsets or broader groupings of these conditions, others expanded their scope to include additional conditions such as migraine, spinal cord tumour, Rett syndrome, and stroke (Appendix A; Table A-1). Taking into consideration the varying focus on individual conditions, in addition to certain data limitations (especially for less common conditions), it was not always possible to provide uniform coverage of each neurological condition under study in this report.

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[7]   Refer to the Glossary of this report or to the NHCC website (www.mybrainmatters.ca/brain-conditions) for the definitions of these conditions.

TABLE I-1: Conditions originally considered in the National Population Health Study of Neurological Conditions

NEUROLOGICAL CONDITIONS
Alzheimer's disease and other dementias
Amyotrophic lateral sclerosis*
Brain tumour
Cerebral palsy
Dystonia
Epilepsy
Huntington's disease
Hydrocephalus
Multiple sclerosis
Muscular dystrophy
Neurotrauma (traumatic brain[†] and spinal cord injuries)
Parkinson's disease
Spina bifida
Tourette syndrome

NOTES: * Amyotrophic lateral sclerosis is also known as ALS or Lou Gehrig's disease. † Although this report focuses on traumatic brain injuries, it should be noted that a large number of individuals who suffer a brain injury are not the victim of a traumatic event but rather incur their injury by other means, such as brain aneurysm, meningitis, viral infection, complications arising from brain surgery, or anoxia. Indeed, based on national survey data, nearly 30% of Canadians who reported a brain injury stated that it was not caused by a traumatic injury, although an exact cause was not given (2011–2012 Survey on Living with Neurological Conditions in Canada data (Statistics Canada)).

A synthesis of the findings from the National Population Health Study of Neurological Conditions

This report describes key findings of the Study, which were identified during a comprehensive synthesis process managed by the Study Implementation Committee that focused on reports prepared by a Scientific Advisory Committee and Synthesis Panel (Appendices 4 to 6). After content review by the Scientific Advisory Committee, the Synthesis Panel reviewed each project and highlighted key findings, knowledge gaps, and main themes in relation to the four focus areas of the Study. In this report, each study component (project or survey) is referred to by its 'short title' or '[reference number]' identified in Appendix 1. Given the vast extent of the issues and topics covered in the Study, this report only attempts to provide a high level overview of the findings from the Study's various components.

The first chapter of this report touches upon the wide spectrum of impacts experienced by Canadians living with a neurological condition – men and women, adults and children, and First Nations and Métis individuals. Impacts on informal caregivers are also presented.

LISTENING TO THE COMMUNITY

NHCC member organizations, individuals living with neurological conditions, and other stakeholders were consulted by NHCC throughout the duration of the Study. In addition, a comprehensive consultation process brought the neurological community together using face-to-face and virtual meetings, an online survey, and through the creation of a Stakeholder Engagement Panel (Appendix 7), which provided stakeholders with opportunities to share feedback on drafts of this report. These stakeholder perspectives supported the development of the final report that speaks to the perceptions, needs, and experiences of those affected by neurological conditions.

The quotations in this report are from stakeholders who took part in the consultation process or in the Study projects. Their original words and phrases are used, wherever possible.

Informed by the diversity and complexity of the impacts of neurological conditions on affected individuals and their families, the second chapter highlights how these impacts translate into unique health service needs across the continuum of care. Although some needs are common across conditions, others are specific to each neurological condition or vary according to the age of the individual affected. The second chapter also presents the health service needs of informal caregivers as well as estimated costs associated with the use of health services for neurological conditions.

To better plan for health service needs and related costs, estimating the number of Canadians living with a neurological condition (as well as the number of new cases that develop each year) is essential. The third chapter presents prevalence and incidence estimates of neurological conditions in Canada, by age and sex for some conditions, and information on their comorbidities. This chapter also explains the necessary requirements for the surveillance of neurological conditions based on valid and accurate estimates.

The human, health service, and economic implications of neurological conditions in Canada constitute strong motivations for an improved understanding of their risk factors. The fourth chapter of this report presents preliminary insights gained by the Study relating to risk factors for neurological conditions, and the remaining challenges associated with the identification of risk factors that are not only supported by statistical evidence but are also relevant from a clinical and public health perspective.

Finally, throughout the report, projections obtained from the microsimulation models are incorporated, to provide insights into the health outcomes and costs of selected neurological conditions in the future. As the understanding of the four focus areas of this Study continues to improve – the impacts (Chapter 1), health service use and needs (Chapter 2), scope (burden) (Chapter 3), and risk factors (Chapter 4) for neurological conditions – governments, health care providers, and stakeholders will have access to a stronger evidence base that can inform policies and the development of strategies that best meet the health and social needs of affected Canadians and their families.

FOR MORE INFORMATION

Considering the magnitude of new information generated by this Study, and because this is a field in constant evolution, it was not possible to summarize all the major findings in one report. Therefore, this report aims to provide key findings of clinical and public health relevance, and should be regarded as a guide to help navigation through this new knowledge.

For additional or more detailed information about the findings from the different components of the Study, please visit the NHCC website (**www.mybrainmatters.ca**), the Agency website (**www.phac-aspc.gc.ca/cd-mc/nc-mn/ns-en-eng.php**), or consult the Chronic Disease Infobase (**www.infobase.phac-aspc.gc.ca**).

1. IMPACTS OF NEUROLOGICAL CONDITIONS

Diseases, disorders, and injuries of the brain, spinal cord, and peripheral nervous system can have varying impacts both within and across conditions. These conditions can affect the mobility, dexterity, skin and joint sensation, behaviour, bladder or bowel function, communication or speech and language, perception, cognition, consciousness, and emotion of the affected individual. Although certain neurological conditions, such as epilepsy or injuries, may be highly amenable to treatment and can, in effect, be cured, the course of most of these functional deficits is often chronic, and may be episodic, static, or progressive. Depending on their severity, which can range from little to no functional impairment to debilitating incapacity, these deficits often have profound consequences on the life and well-being of individuals living with a neurological condition, their families, caregivers, and communities. Several Study projects [1][2][5][8][9][10][11] and surveys [3][16] specifically investigated these impacts in quantitative and qualitative terms.

1.1 Neurological conditions affect many aspects of life

In collaboration with the Agency, Statistics Canada added a neurological conditions module to the 2010 and 2011 annual Canadian Community Health Survey (CCHS), where respondents were asked whether they, or a household member living in the same private dwelling, had one of 18 neurological conditions [3].[8] Further, the Agency and Statistics Canada conducted follow-up interviews with a subsample of these respondents or their household member about their neurological condition and its impacts. The response rate for this new survey, entitled the 'Survey on Living with Neurological Conditions in Canada' (SLNCC), was high, at 81.6%. Findings from the SLNCC 2011–2012 Project [16] were based on structured interviews with 4,409 Canadians (or their proxy respondents)

> " There is no normal anymore…everything you took for granted in your life has just kind of gone out the window, and you don't even know what's going to be thrown at you next. It can be different every time.
>
> *– Individual living with a neurological condition*

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[8] Alzheimer's disease and other dementias, amyotrophic lateral sclerosis (ALS), traumatic brain injury, brain tumour, cerebral palsy, dystonia, epilepsy, Huntington's disease, hydrocephalus, migraine, multiple sclerosis, muscular dystrophy, Parkinson's disease, spina bifida, spinal cord injury, spinal cord tumour, stroke, and Tourette syndrome. Although the survey specifically asked about 'a neurological condition caused by a…': brain injury; brain tumour; spinal cord injury; or spinal cord tumour, in this report, these are simply referred to as 'injury' or 'tumour'. Similarly, the survey asked about respondents who were 'suffering from the effects of a stroke'; in this report, this is simply referred to as 'stroke'. The number of respondents was too small to assess outcomes for some of these conditions individually.

about their condition. When transposed to the Canadian population using Statistics Canada population weights, this sample represented close to 1,738,000 private household residents with a neurological condition. When possible, results from the SLNCC were reported for all 18 neurological conditions together and for each condition individually.

Another Study project, the Everyday Experience of Living with and Managing a Neurological Condition (LINC) Project [9], conducted a survey between 2010 and 2012 on 754 volunteer adults with a neurological condition concerning the impacts of their condition.[9] Although the LINC survey may not have been fully representative of the overall population with the targeted neurological conditions, most LINC Project [9] findings were concordant with those of the SLNCC. Considered together, these projects documented the diversity, extent, and intensity of the impacts of neurological conditions on affected individuals.

Having a neurological condition affects one's general health. Overall, 25.4% of Canadians age 18 years and older with a neurological condition reported only 'fair' or 'poor' general health compared with 10.2% in the Canadian population without neurological conditions [3]. Even when these proportions were age-standardized, Canadians with a neurological condition reported a proportion that was 2.6 times higher than that of their counterparts without neurological conditions. Further, when migraine was removed from the population with a neurological condition, the proportion of Canadians with a neurological condition reporting 'fair' or 'poor' general health jumped to 46.2%; this proportion was 3.7 times higher than that seen in the age-standardized Canadian population without neurological conditions. Over half of Canadians who reported brain or spinal cord tumour, Parkinson's disease, or stroke had 'fair' or 'poor' general health (Figure 1-1)[16]. To varying degrees, the majority of Canadians with other neurological conditions reported 'good', 'very good', or 'excellent' general health.

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[9]   A convenience sample recruited through their NHCC-affiliated or other organizations.

FIGURE 1-1: General health among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.
SOURCE: 2011–2012 SLNCC data (Statistics Canada).

Having a neurological condition affects one's mental health. A quarter of respondents to the LINC survey perceived their mental health to be 'fair' or 'poor' [9]. High stress was experienced by a third of Canadian adults with a neurological condition, with 34.9% having reported that most days were 'quite a bit' or 'extremely' stressful compared with 22.0% in the Canadian population without neurological conditions [3]. When age-standardized, stress levels among Canadians living with a neurological condition were 1.5 times higher than among those without neurological conditions. Levels of high stress varied by neurological condition, from 18.0% for those with cerebral palsy to 47.3% for those with dystonia [16].

The prevalence of self-reported diagnosed mood or anxiety disorder among Canadian adults with a neurological condition was 22.6%, compared with 8.6% in the Canadian population without neurological conditions [3].[10] Differences in age distribution did not change this finding. The highest prevalence of self-reported diagnosed mood disorders was seen in those with a traumatic brain injury (38.3%) or brain tumour (35.5%) (Figure 1-2)[16]. Among LINC respondents, 11.5% reported a diagnosis of depression that was 'moderate' or 'severe' [9]. In the CCHS national survey, 17.1% of Canadian adults with a neurological condition reported

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[10] The CCHS asked respondents to report mood disorders (such as depression, bipolar disorder, mania, or dysthymia) and anxiety disorders (such as phobia, obsessive-compulsive disorder, or panic disorder) diagnosed by a health professional and that was expected to last or had already lasted six months or more.

symptoms consistent with depression, compared with 7.8% in those without neurological conditions [3]. When age-standardized, this rate was still about twice as high in those living with a neurological condition than in their counterparts without neurological conditions.

FIGURE 1-2: Prevalence of mood disorders among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.
SOURCE: 2011–2012 SLNCC data (Statistics Canada).

Having a neurological condition leads to feelings of stigmatization. Based on results from the SLNCC for various neurological conditions, 5% to 36% of Canadians age 15 years and older with a neurological condition perceived that others felt uncomfortable around them or avoided them, that they were left out of activities, or that they were embarrassed by their condition [16].

Having a neurological condition poses limitations on daily life for the majority of Canadians living with one of these conditions. Limitations in at least one usual activity were experienced by 89.3% of Canadians with a neurological condition age 15 years and older, ranging from 66.3% for Tourette syndrome to 92.7% for migraine [16]. Half (50.6%) of Canadians age 18 years and older with a neurological condition 'sometimes' or 'often' experienced activity limitations, compared with 26.7% in the Canadian population without neurological conditions [3]. Even when age differences were controlled, the proportion of Canadians with a neurological condition reporting activity limitations was twice as high as

the proportion among those without neurological conditions. Excluding migraine, 76.9% of Canadians age 18 years and older with a neurological condition experienced limitations of their usual activities (compared with 28.1% among those without neurological conditions), and when these proportions were age-standardized, the proportion of those living with a neurological condition reporting activity limitations was three times higher than in the Canadian population without neurological conditions. Along the same lines, 69.5% of respondents in the LINC convenience sample (which excluded migraine) reported that their activities were 'often' restricted, compared with 38.4% of Canadians reporting two or more other chronic conditions [9].[11]

Having a neurological condition causes impairments of function that affect quality of life. Functional impairments were documented in two ways using national survey data [10][16]. The first was based on categories for certain functional attributes included in the Health Utilities Index-Mark 3 (HUI-3) (cognition, mobility, dexterity, speech, vision, hearing, emotion, and pain and discomfort) [16].[12] The second was based on global HUI-3 scores for those with specific neurological conditions, with scores falling between a minimum value of -0.36 (worse than dead), through to 0.0 (dead), to a maximum value of 1.0 (full health) [10].

- *Impaired cognition:* The highest prevalence of impaired cognition was seen among Canadians with Alzheimer's disease and other dementias (93.7%),[13] although respondents with other neurological conditions also reported difficulty with memory and their ability to think or solve problems (Figure 1-3) [16].

- *Impaired mobility:* About half of Canadians with Alzheimer's disease and other dementias, cerebral palsy, multiple sclerosis, muscular dystrophy, Parkinson's disease, spinal cord injury or tumour, and stroke reported limitations on their mobility (Figure 1-4) [16].

- *Pain and discomfort:* Moderate or severe pain varied in the Canadian population living with a neurological condition (Figure 1-5) [16]. In 36.6% of individuals with a traumatic spinal cord injury, the pain was significant enough to prevent their ability to engage in most activities.

- *Impaired dexterity:* The prevalence of hand-finger dexterity impairment was less than 10% among respondents to the SLNCC [16]. The low prevalence of impaired upper limb function estimated in this survey was not consistent with findings from the LINC Project [9], where 42.5% of adults had upper limb dysfunction rated as 'moderate' or 'severe'.[14]

> " I just had to pick an activity that matched my ability level. Maybe the activity wasn't quite the same as what I truly desired, but I was willing to bargain with my multiple sclerosis.
>
> *– Individual living with a neurological condition*

---

[11] Including asthma, arthritis, back problems, high blood pressure, chronic bronchitis or emphysema, diabetes, heart disease, cancer, ulcers, bladder incontinence, bowel disorders, mood disorders, or anxiety disorders.

[12] In this report, the HUI-3 version was used, which was developed in Canada at McMaster University by Health Utilities Inc.: Feeny DH, Furlong WJ, Torrance GW, Goldsmith CH, Zhu Z, DePauw S, Denton M, et al. Multi-attribute and single-attribute utility functions for the Health Utilities Index Mark 3 system. Med Care. 2002 Feb;40(2):113-28.

[13] For Alzheimer's disease and other dementias, 74% of respondents were represented by a proxy (responses provided by another member of the household on behalf of the individual with the condition).

[14] Further, these findings from the SLNCC 2011–2012 Project [16] were not consistent with clinical experience, particularly for stroke, where upper limb impairment is typically greater than that of the lower limb.

FIGURE 1-3: Prevalence of impaired cognition among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.

SOURCE: 2011–2012 SLNCC data (Statistics Canada).

FIGURE 1-4: Prevalence of impaired mobility among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.

SOURCE: 2011–2012 SLNCC data (Statistics Canada).

FIGURE 1-5: Prevalence of pain and discomfort among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.
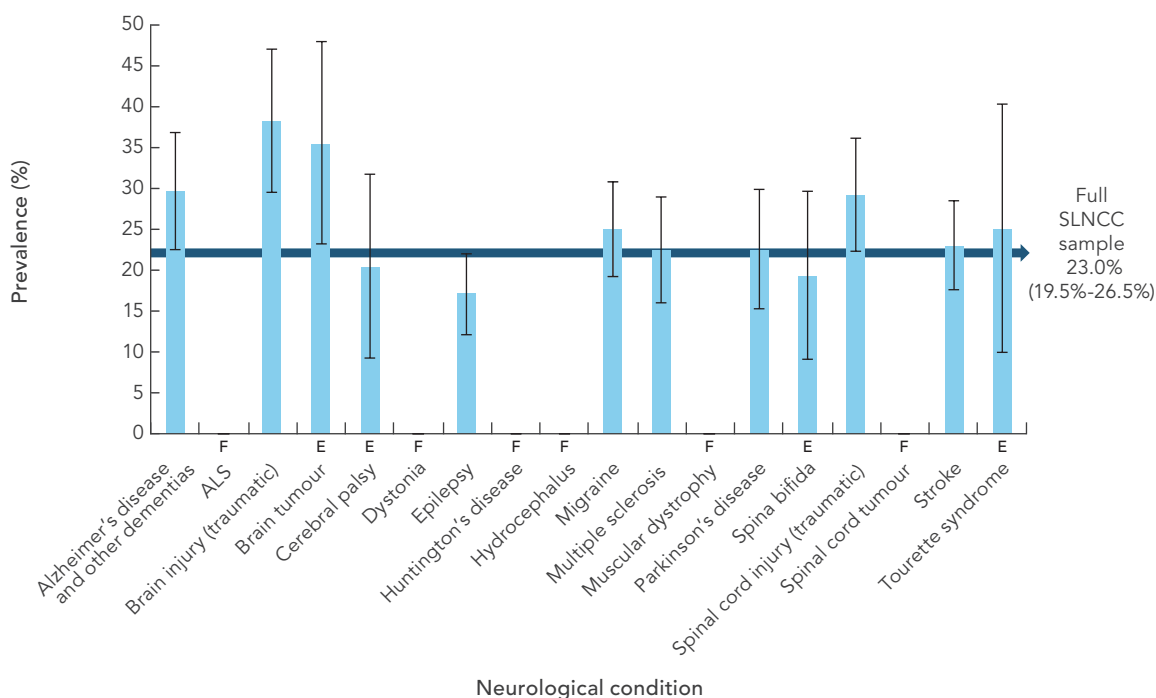**SOURCE:** 2011–2012 SLNCC data (Statistics Canada).

- *Greater overall disability:* Figure 1-6 presents global HUI-3 scores by neurological condition [10]. The global HUI-3 score (which is derived from eight HUI-3 attributes) for each of the targeted neurological conditions (except migraine and Tourette syndrome) was less than 0.7, which generally indicates a significant impairment in quality of life (severe disability).[15] For migraine, the global HUI-3 score of 0.79 corresponded to a level of moderate disability. The lowest global HUI-3 score of 0.21 was associated with Alzheimer's disease and other dementias.[16] Although not shown, the proportion of Canadians with a neurological condition within the 'severe' or 'moderate' disability categories ranged from 42.4% for migraine to 94.9% for Alzheimer's disease and other dementias. Further, the individual scores for three HUI-3 attributes – cognition, mobility, and pain and discomfort – were similar in range, irrespective of the type of neurological condition. These findings underscore the commonalities in functional disabilities shared by many of those living with different neurological conditions.

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[15] Feng Y, Bernier J, McIntosh C, Orpana H. Validation of disability categories derived from Health Utilities Index Mark 3 scores. Health Rep. 2009 Jun;20(2):43-50.

[16] The inclusion of responses from individuals with the neurological condition as well as proxy responses from a household member in the calculation of these scores may have influenced the results.

FIGURE 1-6: Average Health Utilities Index global score among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, Microsimulation Project [10]
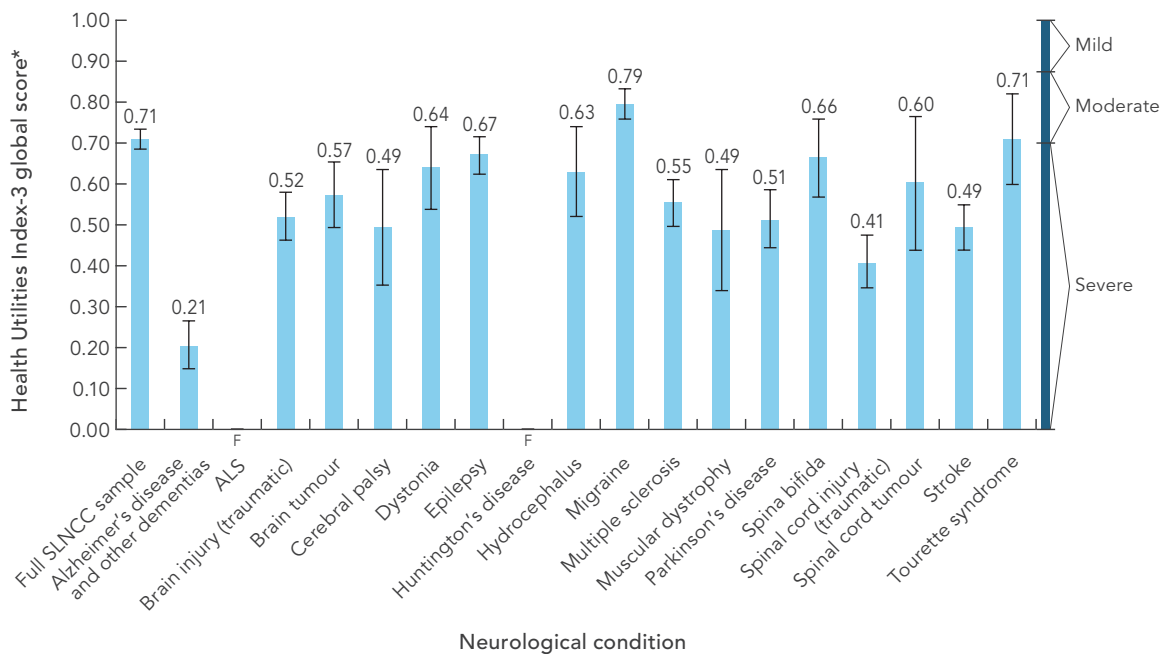
NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true value 19 times out of 20. * A score of 1.0 = no disability; 0.89-0.99 = mild disability; 0.70-0.88 = moderate disability; <0.70 = severe disability. F Data were unreportable due to small sample size or high sampling variability.

SOURCE: 2011–2012 SLNCC data (Statistics Canada).

In addition to impairments measured by HUI-3 scores and its components, the SLNCC 2011–2012 Project [16] found that bladder and bowel incontinence was a frequent symptom for those with certain neurological conditions (Figure 1-7). The prevalence of bladder incontinence was greatest among those with Alzheimer's disease and other dementias, multiple sclerosis, and Parkinson's disease. Moreover, this project also demonstrated that medication side effects also interfered with quality of life. Of the 51.9% of Canadians with a neurological condition who were taking medication for their condition, 29.7% reported medication side effects that affected their lives 'moderately' (23.8%), 'quite a bit' (17.4%), or 'severely' (7.1%) [16].

FIGURE 1-7: Prevalence of bladder and bowel incontinence among respondents age 15+ years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.

SOURCE: 2011–2012 SLNCC data (Statistics Canada).

Having a neurological condition affects one's ability to work. Based on findings from two national surveys, 8.1% of adults age 18 to 64 years with a neurological condition were permanently unable to work, compared with 1.7% among those without neurological conditions [3]. Excluding migraine, this proportion increased to a quarter (25.4%) of the working-age population living with a neurological condition being permanently unable to work. When age-standardized, the prevalence of permanent unemployment among those with a neurological condition was five times higher than in the population without neurological conditions, and 12 times higher when migraine was removed from analysis [3]. Figure 1-8 shows the wide variability in working status for Canadians age 18 to 64 years living with a neurological condition [16].

> ❝ I'm self-employed and I've lost clients because of my condition.
>
> *– Individual living with a neurological condition*

FIGURE 1-8: Working status among respondents age 18 to 64 years living with a neurological condition, Canada, 2011–2012, SLNCC 2011–2012 Project [16]
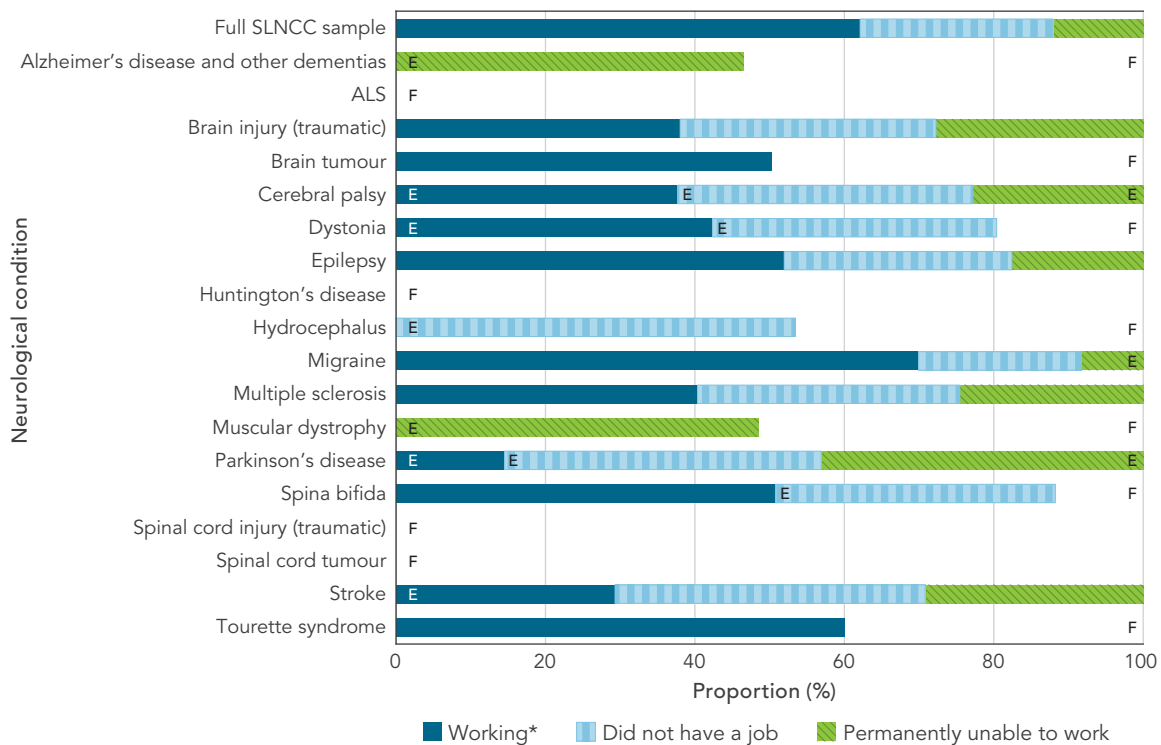
NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. * 'Working' indicates respondent had a job or business in the last week. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.
SOURCE: 2011–2012 SLNCC data (Statistics Canada).

Having a neurological condition contributes to financial insecurity.
A third (35%) of adults with a neurological condition surveyed in the LINC Project [9] reported that their family had experienced a financial crisis in the previous year, and 14% of those who were employed had been demoted or had taken a cut in pay.

> We couldn't consider leaving our employment situations, as we had young family members and financial obligations. So we had to reduce our involvement in household activities or leisure pursuits in order to have sufficient energy to work full time.
>
> *– LINC Project participant*

1.2 Neurological conditions affect children and their families

The LINC Project [9] investigated the impact of neurological conditions on parents and their children. Based on a survey of 74 parents and subsequent interviews with 47 parents from a cohort study, this project provided insights on the experiences of children living with a neurological condition and those of their parents.

> "Parents of children with neurological conditions repeatedly noted that they had to call in to work to say they were either going to be late or they were unable to report that day. The lack of predictability around their children's needs added to the need for flexibility.
>
> *– Project researcher*

> "Mothers felt they were forced to trade in their role as a financial contributor to the household for a role of full-time, unpaid caregiving.
>
> *– Project researcher*

Having a neurological condition affects the quality of life of children. Children with a neurological condition obtained lower scores on a pediatric quality of life scale than children with other chronic conditions or without any of these conditions. Based on their parents' assessment, the majority of children with a neurological condition had good general health. However, fewer parents reported that their child had good mental health, with about a third stating that their child's mental health was 'fair' or 'poor'.

Children living with a neurological condition face barriers in daily living and future opportunities. In the LINC project [9], about 15% of children living with a neurological condition were described by their parents as housebound. Close to half of parents reported that their child required the use of assistive devices. Over 40% of parents felt that their child had limited educational opportunities.

Neurological conditions affect the quality of life of parents. The LINC Project [9] not only assessed the impact of neurological conditions on children, but also considered the impact on their parents. Parents largely reported good general and mental health, yet a third of interviewed parents reported having personally accessed mental health assistance. Altogether, close to a quarter of parents reported financial issues in the year prior to the survey, whether a financial crisis, pay cut or demotion, or the fact that caregiving impeded a parent's ability to work outside the home. In spite of these difficulties, the majority of parents reported being satisfied with life.

1.3   Neurological conditions affect First Nations and Métis individuals in different facets of their lives

The Native Women's Association of Canada (NWAC) Project **[11]** team performed a qualitative analysis of material obtained from interviews with 17 individuals with a neurological condition or their caregivers, 22 key informants, and 41 participants in four research circles. Aboriginal women were the target population of this project and, as a result, the majority of participants were women (69 women, 11 men). Overall, 65 participants were First Nations individuals, seven were Métis, and eight were non-Aboriginal individuals. No Inuit participants were interviewed.

The four interconnected categories of impacts identified in this project as occurring in the day-to-day lives of First Nations and Métis individuals were:

- *Physical impacts:* Pain, exhaustion, mobility impairment, dependence, and other physical symptoms such as dizziness, nausea, and tremors.

- *Emotional impacts:* Fear, anger, anxiety, loneliness, guilt, and helplessness.

- *Cognitive or mental health impacts:* Confusion and disorientation, short-term memory loss, and depression.

- *Spiritual impacts:* Spiritual impacts were identified in terms of how individuals used their spiritual-being to cope with other impacts, either as an individual coping with a neurological condition or as a caregiver. In some cases, their spiritual needs were not met; therefore, it was more challenging to use spirituality as a coping mechanism. Important aspects of spirituality were the teachings from their traditions, a positive attitude, access to traditional ceremonies (some participants noted difficulty in having such needs met at health care facilities), and seeking the advice and guidance of Elders (some participants noted difficulty in finding Elders to help them with their journey).

First Nations and Métis individuals, particularly women (as few men were included in the data collection), were affected by social and health inequities. Many participants suffered from multiple conditions (such as diabetes or cardiovascular diseases) in addition to their neurological condition, and this tended to augment the impacts they had to endure. The project team concluded that culturally relevant, patient-centred care that considers the whole person (including their other ailments) rather than specialized reductionist approaches to healing neurological conditions would likely result in better outcomes for First Nations and Métis individuals.

> " It does affect the family and I think because pain is something that brings out anger a lot in everybody. We get angry because we're always in pain, and they get angry because they don't want to see it in their loved ones…there are certain things that we can't control in life, and one of them is illness.
>
> *– NWAC Project participant*

> " Aboriginal people are affected doubly by stigmatization. People mix stereotypes about neurological conditions and social conditions.
>
> *– Physician*

> " People with a neurological condition don't live in a vacuum – the impacts of these conditions hit their family and friends as well. We don't talk about that often enough. Patients come with families, and we don't do a very good job of caring for them.
>
> *– Physician*

> " When you take on the role of a caregiver, you enter a life-altering mode. In one phase of your life, you are doing all sorts of wonderful things as a couple, and then in the next phase you are changing your spouse's diaper. This quantum leap in relationships is burdened with all sorts of psychological and emotional overlays.
>
> *– Informal caregiver*

1.4 Neurological conditions affect informal caregivers[17]

The interRAI Project [8] investigated the extent and impact of neurological conditions on informal caregivers of individuals in long-term care programs (home care and long-term facilities). For a third of individuals in a home care program, the caregiver (who often lived with the individual affected by a neurological condition and was often their spouse or child) provided assistance with daily living support for 22 or more hours per week. Among individuals in a home care program with ALS, 58% received this level of care.

The level of distress doubles when caring for an individual with a neurological condition. Distress was experienced by 28% of caregivers to individuals with a neurological condition, but only by 13% of caregivers to individuals without a neurological condition.[18]

Caregiver distress is greater if the neurological condition is accompanied by cognitive impairment or behavioural issues. The caregivers of more than a third of residents with Alzheimer's disease and other dementias and Huntington's disease reported distress. The interRAI Project [8] also determined that the priority level assigned to an individual with a neurological condition, as determined by the interRAI 'Method for Assigning Priority Levels' (MAPLe), (used by case managers to determine the urgency of service requirements, regardless of type of care needed) also predicted the likelihood of caregiver distress.

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[17] The term 'informal care' was used throughout the Study to describe care provided by family, friends, and neighbours.

[18] Data from 541,515 home care clients in Ontario and Manitoba, 211,331 of whom had a neurological condition.

1.5 Looking ahead: 2011 to 2031

Results from the Microsimulation Project [10], which are based on status quo assumptions,[19] project that:

- The average health status (as defined by HUI-3 scores) of Canadians living with the seven modelled neurological conditions will remain relatively stable over the next 20 years, with the global HUI-3 score being lowest for Alzheimer's disease and other dementias and highest for epilepsy (but still remaining below the 0.7 threshold indicating severe disability).[20]

- By 2031, more Canadians living with the seven modelled neurological conditions will experience severe disability. In particular, the number of Canadians living with Alzheimer's disease and other dementias experiencing severe disability is projected to increase to the level seen for Canadians with hospitalized traumatic brain injury. However, hospitalized traumatic brain injury will continue to have the greatest number of individuals experiencing severe disability.

- Individuals who develop a neurological condition will experience a substantial number of years living with restricted health, more so than their counterparts without these conditions. Individuals born during the current decade (2010 to 2020) are projected to lose, on average, between 14 to 41 equivalent years of life living in full health (depending on the condition) (Table 1-1).

TABLE 1-1: Average number of years in full health lost* due to disability and premature death, by select neurological condition and sex, Canada, Microsimulation Project [10]

	YEARS OF LIFE IN FULL HEALTH LOST	
	Men	Women
Alzheimer's disease and other dementias	16.0	15.2
Brain injury (traumatic)†	19.8	21.2
Cerebral palsy	33.2	41.3
Epilepsy	14.1	15.3
Multiple sclerosis	17.2	19.8
Parkinson's disease/parkinsonism	15.1	15.7
Spinal cord injury (traumatic)†	22.0	24.7

NOTES: * The average number of years living in full health lost over the projected lifespan of the 2010 to 2020 birth cohort was estimated as the difference between the life expectancy and the health-adjusted life expectancy for each of the selected neurological conditions.
† Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

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[19] The model accounted for changes in the Canadian population from births, immigration, emigration, and aging, but not for changes in risk factors or in the prevention, diagnosis, treatment, or management of neurological conditions.

[20] HUI-3 projections were based on a robust predictive model developed from the longitudinal National Population Health Survey, which is inclusive of residents of both households and facilities.

- In general, indirect economic costs due to working-age deaths (age 15 to 74 years) are projected to decrease. In contrast to the overall increase in the number of individuals living with a neurological condition, the proportion of deaths expected to occur during the working years will generally decrease. More specifically, the number of working-age deaths will decrease within the core workforce (age 15 to 64 years) and increase for older workers (age 65 to 74 years). As a result, projections show a complex pattern of deaths and derived indirect costs to the economy.

- The impact of working-age deaths on indirect economic costs varies by neurological condition – an increase is projected for Alzheimer's disease and other dementias, a decrease is projected for spinal cord injury, and an initial increase then decrease is projected for the remaining conditions. Indirect economic costs due to premature death will be greatest for hospitalized traumatic brain injury ($63 million in 2011 and $49 million in 2031), followed by epilepsy ($41 million in 2011 and $32 million in 2031).

- Indirect economic costs due to working-age disability will increase, however. These costs will be greatest for hospitalized traumatic brain injury (rising from $7.3 billion in 2011 to $8.2 billion in 2031), followed by epilepsy (from $2.5 billion in 2011 to $2.8 billion in 2031).

- The total indirect economic cost, which combines working-age premature death and disability, will increase for each neurological condition and will vary between $0.3 billion to $8.2 billion in 2031 (depending on the condition) (Figure 1-9).

FIGURE 1-9: Projected indirect economic costs due to working-age death and disability, by select neurological condition and age group, Canada, 2011, 2021, and 2031, Microsimulation Project [10]
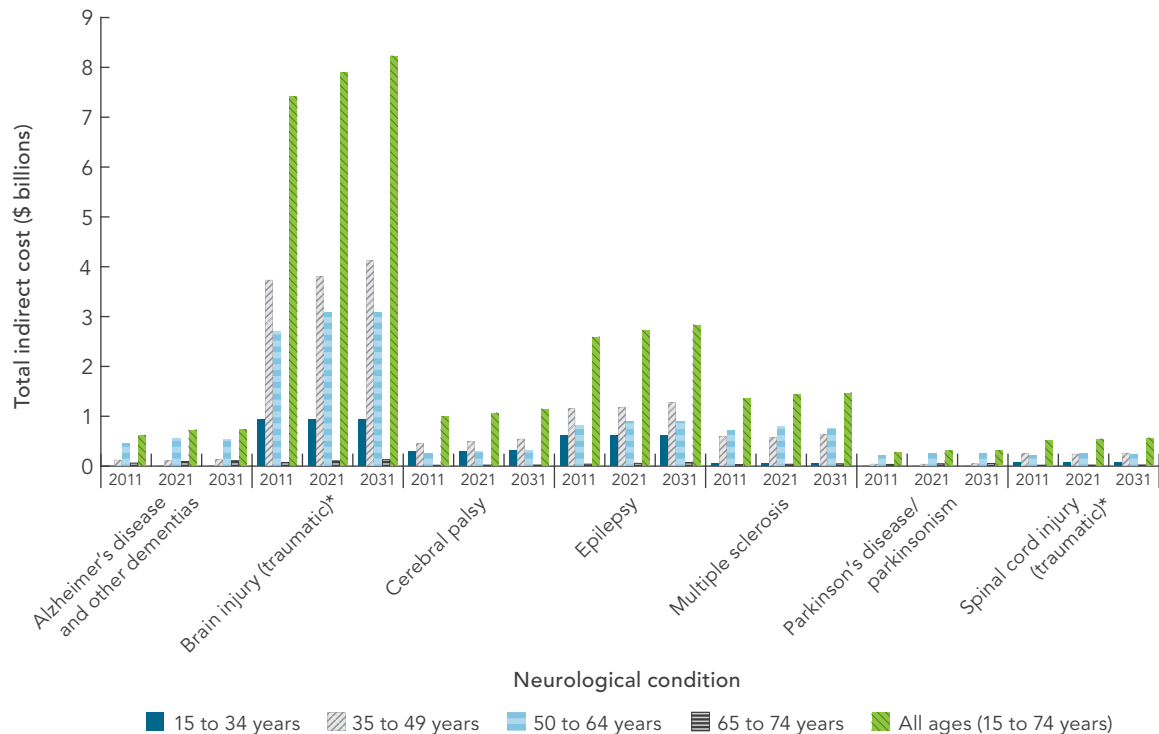
NOTES: Data were expressed in 2010 Canadian dollars. * Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

1.6 Knowledge gaps

While generating a wealth of new information pertaining to the impacts of neurological conditions, the Study also pointed to gaps that may guide future research endeavours. The synthesis of Study findings identified knowledge gaps in the impacts of neurological conditions on:

• Canadians living in varying social and economic situations;

• First Nations, Inuit, and Métis individuals, with a need for fulsome representation of each of these Aboriginal groups;[21]

• Children, both those affected by a neurological condition and those living with an affected parent or sibling;

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[21] Diverse approaches could be taken to address this need, including a better representation of First Nations, Inuit, and Métis individuals in survey data. The Aboriginal Peoples Survey, which is managed by Statistics Canada, aims at identifying the needs of First Nations individuals living off reserves, Inuit, and Métis, and focuses on social and health issues. The First Nations Regional Health Survey, which is managed by the First Nations Information Governance Centre, collects health and well-being information from on-reserve and northern First Nations individuals. However, currently neither survey collects information on neurological conditions.

- Formal caregivers for individuals with severe, debilitating neurological conditions;

- Canadians who were excluded from surveys such as the CCHS and the SLNCC;[22] and

- Canadians with less prevalent neurological conditions, such as those outside the scope of this Study or those affected by less common conditions such as ALS, Huntington's disease, and dystonia.

Maximizing the use of existing data collection processes (such as those identified by the interRAI Project [8] or other processes not presented in this report like the functional scale of the *Système de mesures de l'autonomie fonctionnelle*)[23] or incorporating data on the impacts of neurological conditions into existing national data resources (such as the Canadian Longitudinal Study on Aging [5],[24] health administrative data [2], or electronic medical record networks [6]) could help address some of these gaps in pan-Canadian data on the impacts of neurological conditions.

1.7   Key themes

In this chapter on the impacts of neurological conditions in Canada, it was noted that:

- Individuals with different neurological conditions share many of the same impacts. This means that the functional needs of the affected individual may be consistent, to varying degrees, across conditions.

- The manifestations of neurological conditions, which are often progressive, vary with the stage of the condition as well as the age of the affected individual.

- Neurological conditions impose significant impacts on the well-being and financial security of individuals with the condition, their caregivers, and the community.

- The capacity of individuals to respond to the disabilities associated with their neurological condition can be influenced by social determinants of health, such as their economic situation, educational status, or access to community resources.

- In particular, financial insecurity and cognitive impairment are major barriers to self-efficacy and self-management for Canadians living with a neurological condition.

- Stigmatization can be a substantial additional burden for those with a neurological condition.

- First Nations and Métis individuals experience unique impacts of neurological conditions, in addition to the impacts encountered by non-Aboriginal individuals.

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[22] The CCHS covers the population age 12 years and older living in private dwellings in the ten provinces and the three territories. The CCHS does not include individuals living on reserves or in other Aboriginal settlements in the provinces, full-time members of the Canadian Forces, the institutionalized population), and individuals living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James. The CCHS covers 90% of private households in the Yukon, 97% in the Northwest Territories, and 92% in Nunavut. Overall, these exclusions represent less than 3% of the target population. In addition to these exclusions, the SLNCC did not include residents of the territories.

[23] Hébert R, Desrosiers J, Dubuc N, Tousignant M, Guilbeault J, Pinsonnault E. Le système de mesure de l'autonomie fonctionnelle (SMAF). Revue de Gériatrie. 2003 Apr;28(4):323-36.

[24] A national level study following approximately 50,000 Canadians over a 20-year timeframe to collect health, lifestyle, and economic data in order to determine factors that impact health status.

Microsimulation modelling of seven neurological conditions projects that by 2031:

- An increased number of Canadians will experience severe disability, based on a validated HUI-3 score of their health status.

- Individuals with each of the modelled conditions will experience more years of restricted health than their counterparts without these conditions.

- The combined indirect economic cost based on both working-age premature death and disability will increase for each of the modelled neurological conditions.

2. HEALTH SERVICES FOR NEUROLOGICAL CONDITIONS

Neurological conditions are associated with a broad spectrum of health impacts that vary both in nature and in severity (Chapter 1). A range of health services for individuals living with a neurological condition, their families, and caregivers is necessary to appropriately address these impacts. In Canada, health is a shared responsibility between federal and provincial governments, with provinces and territories in charge of the organization of their health services. Thus, a true understanding of the issues related to health services in Canada would require data collection at the provincial and territorial levels in order to develop knowledge relevant to each jurisdiction.

> " It takes strong and sustained advocacy to access and coordinate the range of services required. Services for our daughter come from: the health authority, money set aside for physiotherapy, a disability group, a community living fund, foundations, etc.
>
> *– Informal caregiver*

Several projects of the Study explored the need for, and adequacy of, health services for those with a neurological condition along the continuum of health care provision [1][2][4][6][7][8][9][10][11][16]. These projects included the perspectives of individuals living with a neurological condition, informal caregivers, health care providers, and policy makers. In this chapter, health services were investigated in terms of utilization, costs, role of informal caregivers, perceptions (of administrators, patients, and caregivers) on their adequacy, delivery of continuing care, care of children, and specific needs of Aboriginal Canadians.

2.1 Individuals with a neurological condition use a considerable amount of health care services across the continuum of care

The LINC Project [9] survey, based on a convenience sample of 754 volunteer adults living with a neurological condition in the community, found that these individuals used more universally insured health services than Canadians with other chronic health conditions (Figure 2-1).[25] This finding was related to specialist physician services in particular, but was also applicable to service providers that were not always accessible through public funding, such as nurses, physiotherapists, psychologists, social workers, and counsellors.

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[25] Compared to respondents to the CCHS (2009–2010) who reported having two or more chronic conditions.

FIGURE 2-1: Health service utilization in the past year among Canadians with and without neurological or other chronic health conditions, by health professional type, Canada, 2010–2012, LINC Project [9]

Legend:
- General Canadian population[†]
- Canadian population with one or more chronic conditions[†]
- Canadian population with two or more chronic conditions[†]
- LINC study participants[‡]
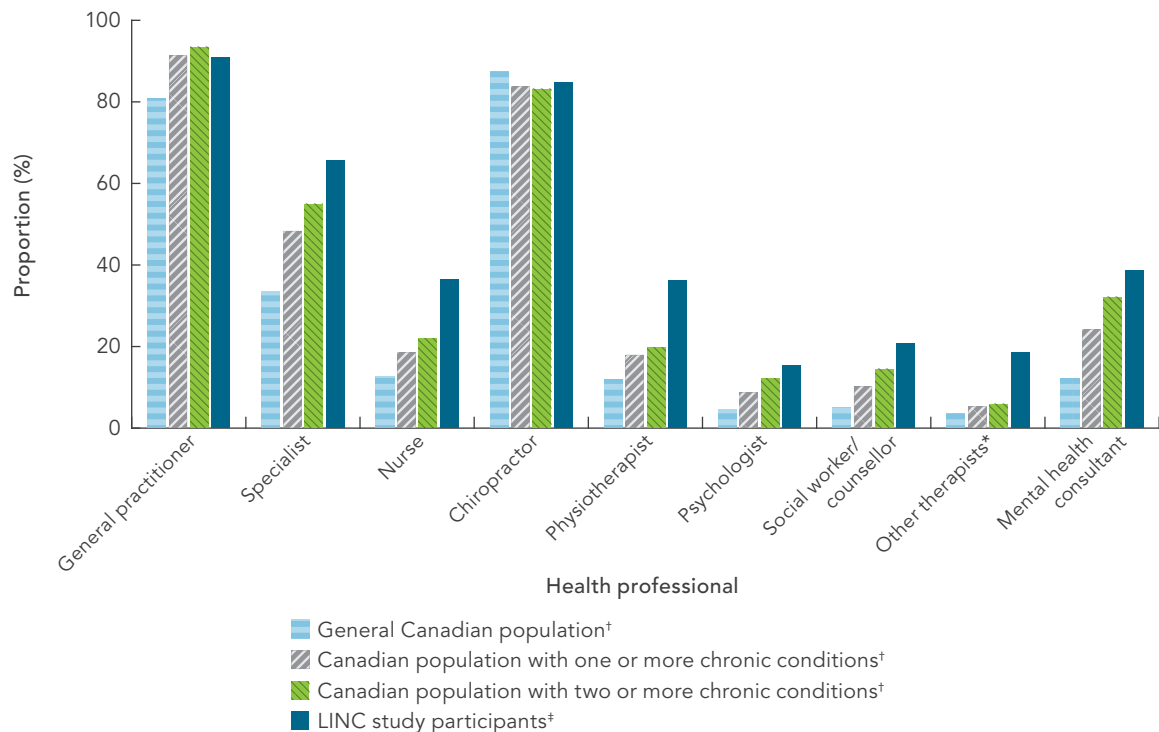
NOTES: LINC = The Everyday Experience of Living with and Managing a Neurological Condition. CCHS = Canadian Community Health Survey. * Other therapists included occupational therapists, audiologists, and speech therapists. † 2009–2010 CCHS data; data were weighted to represent the Canadian population living in the community and were age-sex-standardized to the LINC population. Chronic conditions included asthma, arthritis, back problems, high blood pressure, chronic bronchitis/emphysema, diabetes, heart disease, cancer, ulcers, urinary incontinence, bowel disorders, mood disorders, or anxiety disorders. ‡ LINC data.
SOURCES: LINC survey (LINC Project [11]); 2009–2010 CCHS (Statistics Canada).

Up to a quarter of the population living with a neurological condition in the community accesses formal assistance. Twenty-five per cent of respondents to the LINC survey made extensive use of formal caregiving, mainly for personal care (eating, dressing, bathing, and toileting) or for house and yard work [9]. Similarly, when respondents with migraine were removed from SLNCC data,[26] 21.2% of Canadians living with a neurological condition reported accessing formal assistance during the previous year [16]. In Ontario, individuals with a neurological condition in registered home care programs used more health care services than did those receiving home care for other conditions [8].

The usage of various types of formal and informal assistance, as noted by the SLNCC (excluding migraine), is shown in Figure 2-2 [16]. Most often, formal assistance was used for general help with activities (51.7%) or personal care (48.6%). Although not shown, when formal assistance was used, it was used frequently, at least once a week or daily, and was used in conjunction with informal assistance [10][16].

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[26]   Done to make data more comparable, since the LINC survey did not include migraine.

FIGURE 2-2: Formal and informal assistance use among respondents age 15+ years living with a neurological condition (excluding migraine), by type of assistance, Canada, 2011–2012, SLNCC 2011–2012 Project [16]
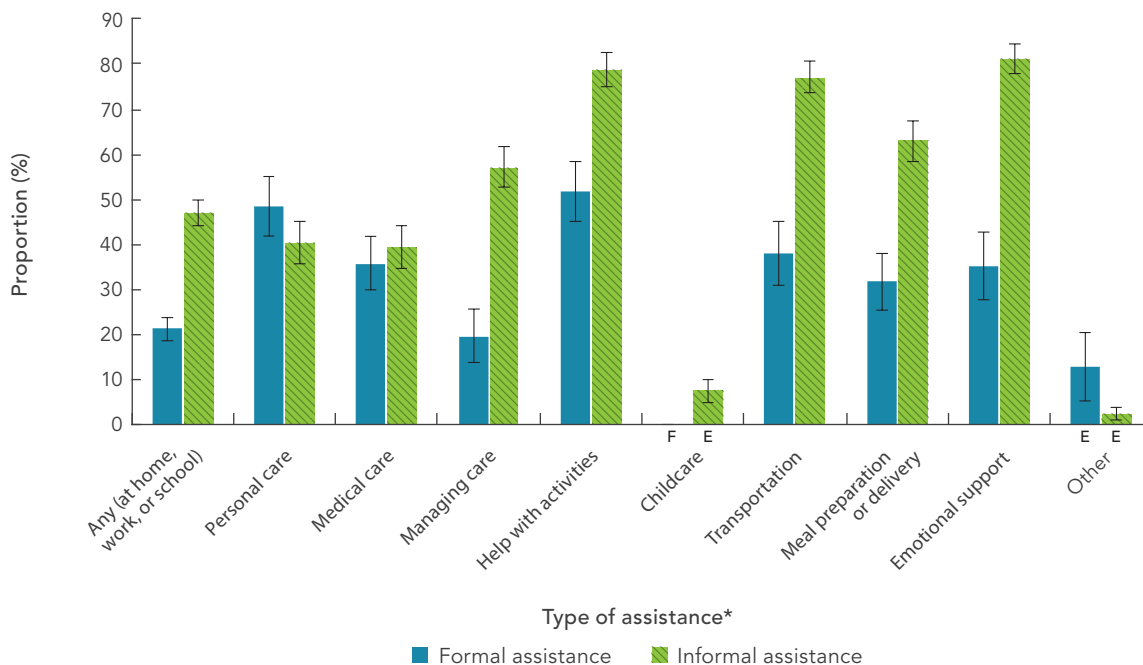
NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true value 19 times out of 20. * 'Type of assistance' was limited to the population receiving assistance. Categories were not mutually exclusive. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability.
SOURCE: 2011–2012 SLNCC data (Statistics Canada).

Canadians living with a neurological condition use health care services more often than those without that neurological condition. Investigators of the British Columbia (BC) Administrative Data Project [1] found that of individuals who sought health care services, those diagnosed with targeted neurological conditions had more hospital days, physician visits, prescriptions, and days in residential care compared to individuals without these neurological conditions:

- *Acute hospital utilization:* Per capita hospital days ranged from 2.2 days for women with multiple sclerosis to 64.7 days for men with spinal cord injury. This rate of utilization was 3.5 to 110 times higher for individuals with a specific neurological condition than for individuals without that condition in British Columbia during the fiscal year 2010/2011.[27,28] The high per capita hospital days for those with brain and spinal cord injury likely reflected the length of time that individuals with these conditions spent in rehabilitation.[29]

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[27] In this report, fiscal years are reported as '20xx/20yy', whereas '20xx–20yy' is used to indicate surveys conducted over a two-year period.

[28] Calculated by dividing the costs associated with each neurological condition by the costs incurred by those without that specific condition.

[29] British Columbia administrative data for acute care hospitals also included rehabilitation hospitals and day surgery.

- *Physician services utilization:* Physician visits, a reflection of the utilization of services by individuals both in the community and in acute care hospitals, were 1.4 to 5.6 times higher among individuals with a neurological condition than among those without that condition in British Columbia in 2010/2011. Individuals that presented with spinal cord injury (92.9 visits for men), traumatic brain injury (79.5 visits for women), Alzheimer's disease and other dementias (55.1 visits for men), and brain and spinal cord tumours (53.7 visits for men) had the greatest numbers of per capita physician visits.

- *Prescription medication utilization:* Use of prescribed medications, expressed as per capita dispensed prescription days, was highest in British Columbia in 2010/2011 for those with parkinsonism, which included Parkinson's disease (1,689.9 prescription days for men; 1,952.2 for women). Usage of prescribed medications was similarly high for individuals with Alzheimer's disease and other dementias (1,732.6 for men; 1,898.4 for women), and slightly lower for those with Huntington's disease (1,348.0 for men; 1,522.1 for women) and anterior horn cell disease, which included ALS (1,080.1 for men; 1,277.5 for women). For all neurological conditions studied by the BC Administrative Data Project [1], women had higher dispensed prescription days compared to men.

- *Residential care utilization:* The number of days in residential care per capita was approximately three to 200 times higher among individuals with a specific neurological condition than among those without that condition in British Columbia in 2009/2010. The number of days in residential care was highest for individuals with Huntington's disease (231.6 per capita days for men; 248.6 for women). Per capita days of residential care were also high for those with Alzheimer's disease and other dementias (97.1 for men; 134.3 for women), cerebral palsy (80.0 for men, 81.3 for women), and parkinsonism (50.5 for men, 76.1 for women).

The interRAI Project [8] noted that individuals with a neurological condition also used more alternate level of care (ALC) days in hospital while awaiting nursing home placement. Approximately half of identified ALC patients had Alzheimer's disease and other dementias, while parkinsonism was the next most common neurological condition, albeit present in less than 10% of ALC patients. Responsive or challenging behaviours were present in three quarters of ALC patients with Alzheimer's disease and other dementias.

Based on results from the LINC Project [9], children living with a neurological condition also used the health care system more frequently. Although children with a neurological condition used generalist physician services at a level similar to Canadian children overall, those with a neurological condition were more likely to have a hospital stay, contact a specialist physician, receive mental health services, or consult with a social worker or counsellor.

> " The impacts of these medical conditions on every facet of our lives are enormous – who could possibly think that people living with a neurological condition wouldn't need mental health care?
>
> *– Individual living with a neurological condition*

> " The lack of neuropsychiatrists is a huge gap in the health care system. We also need more team-based care to enable one stop shopping.
>
> *– Individual living with a neurological condition*

The mental health service needs of Canadians living with a neurological condition are significant. The impacts of neurological conditions on the mental health of affected individuals were considerable (Chapter 1), and consequently led to an increased need for supportive care, where 34.8% of Canadians with a neurological condition reported receiving formal emotional support because of their condition [16].[30]

In contrast to the documented use of mental health services, results from the Health Services Project [7] suggested that such needs were not always being adequately met. Based on results from an online survey completed by administrators of publicly funded acute care hospitals, long-term care facilities, and community outpatient centres from all regions of Canada, 33% of respondents indicated that their facility did not accept patients with psychiatric diagnoses or severe behavioural disorders. Only 9% of these service providers had access to a neuropsychologist, and only 3% had access to a neuropsychiatrist.

2.2 Costs of health services for Canadians with a neurological condition are greater than for those without a neurological condition

Estimating costs of health services for Canadians with a neurological condition, relative to Canadians without these conditions, is a complex endeavour influenced by a variety of factors, which in turn may vary by jurisdiction. Certain projects of the Study [1][8][9][10] contributed new evidence on this issue, but these findings may be limited in their generalizability across Canada.

Total direct health care costs are high for Canadians living with a neurological condition. Total and per capita direct health care costs for 13 neurological conditions investigated in British Columbia for fiscal year 2010/2011 were three to 41 times higher among individuals diagnosed with any of the investigated neurological conditions compared to age-standardized data for individuals without those particular conditions (Table 2-1) [1].[31] The particularly high per capita costs seen for traumatic brain and spinal cord injuries were mostly associated with the hospital costs required for their treatment.

> " We have spent a lot of money on mobility equipment and supplies. Home modifications are very expensive. We don't go on vacation.
>
> *– Individual living with a neurological condition*

Large as these figures were, they underestimated the true costs for each condition because this project only had access to direct costs in addition to limited out-of-pocket expenses (which included prescription drugs not covered by British Columbia Pharmacare). Services provided by salaried physicians and many indirect costs (such as patient and caregiver time away from work or on long-term disability) could not be determined from the available data.

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[30] The nature of 'formal emotional support' was not specified in the survey.

[31] Acute hospital costs, physician services (billed in and out of hospital), Pharmacare, and Pharma Net (self-paid or third party-paid costs not covered by Pharmacare), but not including community- or facility-based continuing care costs.

TABLE 2-1: Direct health care costs, by select neurological condition, British Columbia, 2010/2011, BC Administrative Data Project [1]

	TOTAL DIRECT HEALTH CARE COST ($)*	PER CAPITA COST ($)†		RATIO OF COST
		with the specified neurological condition	without the specified neurological condition	with/without the specified neurological condition
Alzheimer's disease and other dementias	527,494,000	5,200	1,700	3.0
Anterior horn cell disease	8,405,000	13,000	1,800	7.1
Brain injury (traumatic)	86,839,000	26,900	1,800	14.6
Brain tumour (malignant)	25,624,000	13,200	1,800	7.2
Cerebral palsy	50,520,000	6,100	1,800	3.4
Epilepsy	208,679,000	5,800	1,800	3.2
Huntington's disease	2,160,000	10,800	1,900	5.8
Hydrocephalus	44,923,000	12,000	1,800	6.6
Multiple sclerosis	70,462,000	6,900	1,800	3.7
Muscular dystrophy	4,257,000	11,300	1,800	6.2
Parkinsonism	120,358,000	11,100	1,800	6.0
Spina bifida	7,009,000	9,200	1,800	5.0
Spinal cord injury	17,720,000	75,200	1,800	40.6

NOTES: BC = British Columbia. * Data were rounded to the nearest thousand. † Data were rounded to the nearest hundred.
SOURCE: Population Health Surveillance and Epidemiology, British Columbia Ministry of Health (September 2011).

Another project also demonstrated that the costs of caring for individuals with a neurological condition in home care programs or in chronic care facilities were greater than those for individuals with other conditions [8].

Average out-of-pocket expenses are high. Sixty percent of respondents in the LINC Project [9] reported out-of-pocket costs for prescribed medications, despite the fact that 85% of the sample reported having a drug insurance plan. Nearly 20% had paid more than $1,000 in out-of-pocket expenses in the previous year. Questions about average annual out-of-pocket expenses per respondent were also part of the SLNCC,[32] but estimates were likely much lower than the true costs actually experienced by Canadians, since average costs do not reflect individual experiences (Table 2-2).

> **"** Money for food, rent, or prescriptions should not be a decision faced by people with disabilities on a regular basis.
>
> *– Individual living with a neurological condition*

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[32] The denominator of these averages included those respondents who reported zero costs.

TABLE 2-2: Average annual out-of-pocket costs, by select neurological condition, Canada, 2011–2012, Microsimulation Project **[10]**

	ANNUAL OUT-OF-POCKET COST PER RESPONDENT ($)
Alzheimer's disease and other dementias	1,000
Brain injury (traumatic)	800
Epilepsy	500
Multiple sclerosis	1,000[E]
Spinal cord injury (traumatic)	1,200
Parkinson's disease	1,100
Stroke	800

NOTES: Data were rounded to the nearest hundred. E Interpret with caution; coefficient of variation between 16.6% and 33.3%.
SOURCE: 2011–2012 SLNCC data (Statistics Canada) provided by POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

The British Columbia PharmaNet database provided information about the costs of medications not covered by British Columbia Pharmacare, although self-paid and third-party payments were not separable. For three neurological conditions in 2010/2011, these costs (out-of-pocket, at least in part) were more than $1,000: brain tumour – $1,095 (age-standardized comparison group without the condition – $313); multiple sclerosis – $1,270 (comparison group – $311); and parkinsonism – $1,071 (comparison group – $311) **[1]**.

2.3   Limitations in health care services have been identified

To assess the provision of health services in Canada, the Health Services Project **[7]** aimed to identify needs, gaps, current policies, and best practices. The project team performed a literature review of 723 articles, held structured interviews with 180 key informants from across Canada (39% health care professionals, 47% non-health care professionals, and 14% policy makers), and conducted an online survey completed by administrators in 645 of the 2,783 publically funded health care facilities in Canada (acute care hospitals, long-term care facilities, community outpatient centres, and home care organizations).

> **"** Funds are available in my province for home renovations, but they're hard to get.
>
> *– Informal caregiver*

The scoping review and key informant interviews documented a lack of knowledge or awareness regarding neurological conditions among service providers and a limited availability of much needed services for Canadians living with a neurological condition, particularly for those living in rural areas.

More health services are available for common neurological conditions than for rare conditions. A high proportion of care providers offered services for individuals with stroke (71%), Parkinson's disease (65%), Alzheimer's disease (65%), traumatic brain injury (59%), and multiple sclerosis (57%). However, only a small proportion of care providers reported services for individuals with less common conditions such as dystonia (28%), Tourette syndrome (17%), or Rett syndrome (13%).

The availability of certain support services is limited. There was a lack of information on, and services for, education or return to school, employment, family and caregiver support, housing, and transportation. Informed by their interviews with service providers and policy makers, the Health Services Project [7] team developed a 'chronic care model for neurological conditions'. This model provided the vision for a comprehensive system change, aimed at improving the quality of life for individuals living with these conditions and increasing collaboration between the health system, the community, and the socioeconomic and political sectors.

Access to services for individuals with a neurological condition is sometimes limited by exclusion criteria. Although data could not be differentiated by type of facility, most service providers reported exclusion criteria for accessing their services. This may have been appropriate if the service provider was not equipped to address the needs of the patient. In addition to 33% of reporting facilities having exclusion criteria for psychiatric diagnoses, severe behavioural disorders, or for substance abuse or substance dependence, a further 32% of reporting facilities reported exclusions for medical instability, degenerative medical conditions, or the presence of comorbidities, while 21% reported exclusions on the basis of age. Only 28% of service providers reported no exclusion criteria. It was noted that the implementation of these criteria may not only vary by facility, but may also vary by health sector or jurisdiction.

Service delivery is affected by resource allocation and by the physical environment. Nearly half (47%) of service providers cited staff ratios and 37% cited physical environment as barriers to their ability to adequately provide services.

> **"** Families often know more about neurological conditions than health professionals. Many times a family member or a voluntary health organization representative needs to be with an affected individual. This is an added burden for families and patients.
>
> *– Individual living with a neurological condition*

> **"** What about the stigma with healthcare professionals at the general practitioner level? They don't want you. You could be a difficult client and take up a lot of time.
>
> *– Individual living with a neurological condition*

2.4 Canadians with a neurological condition and their informal caregivers typically rate the adequacy of health services lower than do their health care providers

The Health Services Project [7] compared the perspectives of 100 LINC Project [9] participants with the perspectives of 100 health care providers. Individuals from each group were questioned about the perceived adequacy of various aspects of health care services,[33] with a qualitative rating scale of providing: 'little or no', 'basic or intermediate', 'advanced', or 'optimal' support. Overall, Canadians living with a neurological condition (or their caregivers) rated health care services lower than did service providers; mean scores given by patients were all in the 'little or no' to 'basic or intermediate' support ranges, while provider's scores were in the 'basic or intermediate' to 'advanced' range.

> " There really isn't a system: the transition points just aren't there. People are operating independently in silos. So each time you go somewhere new you have to do a new assessment. No one trusts the previous one.
>
> *– Health care provider*

> " When kids turn 18 they fall off the cliff. The adult system is fragmented and is based on episodic care for chronic conditions.
>
> *– Health care provider*

Improvements are required for goal setting and continuity of care. Goal setting, follow-up, and coordination received the lowest rankings by patients, with mean scores that indicated 'little or no' support. Health care providers also gave their lowest score to this aspect of health care services, but their ratings were in the 'basic or intermediate' range.

Integrated multidisciplinary care is important. Neither patients nor health care providers rated any aspect of service provision as 'optimally integrated' for chronic illness. About a third of respondents in the LINC Project [9] reported having access difficulties when seeking a specialist appointment. The Health Services Project [7] also demonstrated gaps in access to, and availability of, current services to support transitions between settings (e.g. pediatric to adult, community to long-term care) and reiterated the existing need to address social determinants of health such as education, employment, housing and transportation.

Satisfaction is high for some health services. In general, high levels of overall satisfaction were expressed by the 30% of LINC Project [9] respondents who accessed community-based services. Also, a sample of 104 parents of children with cerebral palsy rated the services their children had received quite highly using the Measure of Process of Care questionnaire [4].[34]

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[33] The aspects assessed in this survey included the following: community partnerships and resources; continuity of care; evidence-based guidelines; self-management support; practice team function and leadership; provider education; information provided to patients about guidelines; specialist involvement; and follow-up.

[34] King SM, Rosenbaum PL, King GA. Parents' perceptions of care-giving: Development and validation of a measure of processes. Dev Med Child Neurol. 1996 Sep; 38(9):757-72.

2.5 An obligation is placed on family and friends to provide care

Care provided by family, friends, and neighbours, termed 'informal caregiving' throughout the Study, is an important service required and received by many individuals with a neurological condition. Almost half (45%) of LINC respondents reported that they received informal care [9]. At a national level, 39.6% of Canadians with a neurological condition (excluding migraine) received informal assistance that included general help with activities (78.7%), transportation (77.1%), and meal preparation and delivery (63.0%) (Figure 2-2, section 2.1) [16]. Among Canadians living with a neurological condition (excluding migraine), 81.3% were receiving informal assistance for emotional support, which was the most frequently reported category. Excluding migraine, women were more likely to use informal assistance compared to men. When migraine was also considered, the proportion of informal assistance used on a monthly basis or less increased for both men and women (Figure 2-3).

> " You have to take on so many roles: be a medical expert, put on makeup, style hair, be both hands on and philosophical.
>
> *– Informal caregiver*

> " When I go shopping, I have to take both my mother, who has dementia, and my 18-year-old daughter, who has a severe intellectual handicap, with me. I rely on my healthy 8-year-old son to keep them from wandering off while I am at the check-out or getting the car from the parking lot.
>
> *– Informal caregiver*

FIGURE 2-3: Frequency of informal assistance use among respondents age 15+ years living with a neurological condition (including and excluding migraine), by sex, Canada, 2011–2012, SLNCC 2011–2012 Project [16]
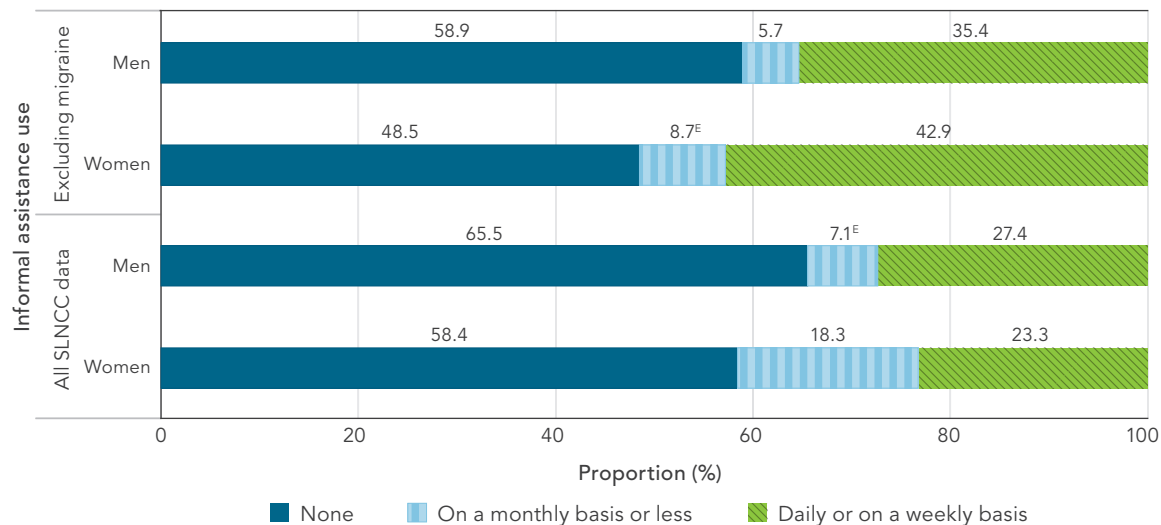
NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. E Interpret with caution; coefficient of variation between 16.6% and 33.3%.

SOURCE: 2011–2012 SLNCC data (Statistics Canada).

2.6 Information concerning the health service needs for children with a neurological condition is limited

Although data concerning health services for children with a neurological condition were scarce in the Study, available findings suggested that health services for some children may have been sub-optimal or would have benefited from clearer care pathways.

> Kids growing up with neurological conditions have a different life experience. And my needs as a parent are different from parents taking care of individuals with spinal cord injury or spina bifida.
>
> *– Informal caregiver*

Children living with a neurological condition require regular use of health services, but these services are sometimes lacking. It was estimated that a fifth of children with a neurological condition in the LINC Project [9] had not seen a general practitioner or pediatrician in the previous year, and only two-thirds had received specialist physician care. Children with newly diagnosed cerebral palsy utilized a range of rehabilitation services [4], but it was noted that services such as these were often not available when a condition was long-standing or if the condition was combined with a cognitive impairment [8]. In general, the Health Services Project [7] survey of providers found that there were fewer services offered for children (age 0 to 17 years) when compared to those available to adults.

2.7   The health service needs for First Nations and Métis individuals with a neurological condition pose unique challenges

The NWAC Project [11] team identified several challenges met by First Nations and Métis individuals requiring health care services for neurological conditions. They included the following:

- The lack of accessible specialized health care and diagnostic services in northern, rural, or remote locations;

- Transportation to health care services, especially for individuals living in remote areas;

- Difficulties navigating the health system in relation to which level of government was responsible;

- Lack of support and training for families with a member affected by a neurological condition;

- The need for better cultural competence among health care providers;

- The lack of understandable information regarding neurological conditions; and

- The need for greater awareness in First Nations and Métis populations about neurological conditions to address stigma associated with these conditions.

Overcoming these challenges would entail actions such as working more closely with First Nations and Métis individuals, increasing the availability of services in their respective communities, instituting holistic approaches to healing, providing opportunities for traditional ceremonies and gatherings, and making advocates or guides available to First Nations and Métis individuals accessing the health care system.

> "We go to case conferences where the doctor makes a treatment plan for one of us with a neurological condition. But it's not carried out up north because there's really nothing up there – especially for young people and elders.
>
> *– NWAC Project participant*

> "Many Aboriginal people don't trust – and therefore don't use – mainstream health care services because they don't feel safe from stereotyping and racism, and because the Western approach to health care can feel alienating and intimidating.
>
> *– NWAC Project participant*

2.8 The prediction and evaluation of health care needs can be informed by Study findings

Comprehensive assessment tools, such as the interRAI suite of assessment instruments, can improve accuracy when defining the care needs of individuals with chronic neurological conditions rather than basing decisions on diagnostic information alone. For example, the interRAI Project [8] noted that health care needs in chronic care settings were better defined by the type of functional impairment rather than by diagnostic category.

> **"** Focusing on function rather than diagnosis is where we should start with system change for people with neurological conditions. Once this is in place, the rest will evolve.
>
> *– Health care provider*

Other projects of the Study also identified areas that merit further evaluation. By using data extracted from the electronic medical records (EMRs) of primary care physicians, the EMR Project [6] determined that significant numbers of patients with dementia or parkinsonism were not being prescribed potentially beneficial condition-specific medications by their primary care physicians. With respect to rehabilitative services, the interRAI Project [8] found that the combination of a neurological condition and cognitive impairment was a significant barrier, where individuals with cognitive impairment were less likely to receive occupational therapy and life skills training than individuals without cognitive impairment.

2.9 Looking ahead: 2011 to 2031

Results from the Microsimulation Project [10], which are based on status quo assumptions,[35] project that:

- Total annual health care costs for individuals age 40 years and older with Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism will double between 2011 and 2031. For the other five modelled neurological conditions, direct health care costs will increase, but not as significantly.

> **"** If dementia doubles in 20 years as has been predicted, we need to know where people are going to go, and what each one costs in terms of resources, implications for rehabilitation, and quality of life.
>
> *– Individual living with a neurological condition*

- Acute hospitalizations will remain as the largest contributor to total direct health care costs for all the modelled neurological conditions except for Alzheimer's disease and other dementias, where facilities-based long-term care will remain as the largest contributor.
- By 2031, total direct health care costs for Canadians with the seven modelled neurological conditions will be, depending on the condition, $0.6 billion to $13.3 billion greater than the health care costs of Canadians without these conditions. Thus, if within the next 20 years, innovations in care, prevention, and treatment allowed health care utilization by Canadians with the modelled neurological conditions to move toward the utilization seen in those without these conditions, a substantial amount of health care resources could be used to meet other needs.

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[35] The model accounted for changes in the Canadian population from births, immigration, emigration, and aging, but not for changes in risk factors or in the prevention, diagnosis, treatment, or management of neurological conditions.

- Based on health status (defined by HUI-3 scores rather than unmet care needs), the numbers of Canadians with Alzheimer's disease and other dementias or Parkinson's disease/ parkinsonism who are likely candidates for informal care will nearly double in the next 20 years (Figure 2-4). For other conditions modelled in the Microsimulation Project [10], the need for informal care is expected to rise moderately. Given current sociodemographic changes in Canada (such as smaller families and greater geographic dispersion) it is likely that innovative changes will be required to meet these increased care demands.

FIGURE 2-4: Projected number of Canadians who are likely candidates for informal care, by select neurological condition, Canada, 2011, 2016, 2021, 2026, and 2031, Microsimulation Project [10]
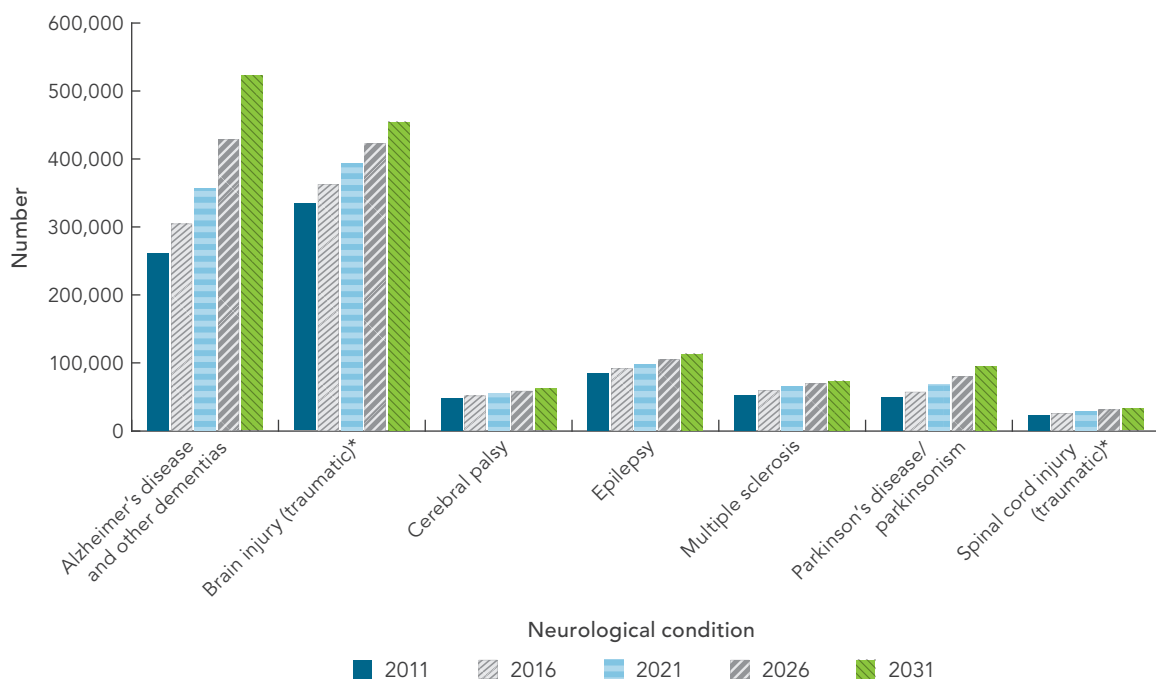
NOTES: * Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

- Although data are not shown, the number of hours of informal care needed each week by an individual living with one of the seven modelled neurological conditions will remain relatively stable in 2031 compared to 2011, where an estimated average of 18 hours of informal care per week is required for those with hospitalized traumatic brain injury, while 74 hours per week is required for those with Alzheimer's disease and other dementias.

- The total number of hours of informal care provided per week is substantial, and is projected to increase over the next 20 years for all seven modelled neurological conditions (Figure 2-5). In particular, while the number of hours of informal care provided per week for Alzheimer's disease and other dementias is already significantly higher when compared to the other modelled conditions, this number is expected to double by 2031.

FIGURE 2-5: Projected number of hours of informal caregiving per week, by select neurological condition, Canada, 2011, 2016, 2021, 2026, and 2031, Microsimulation Project [10]
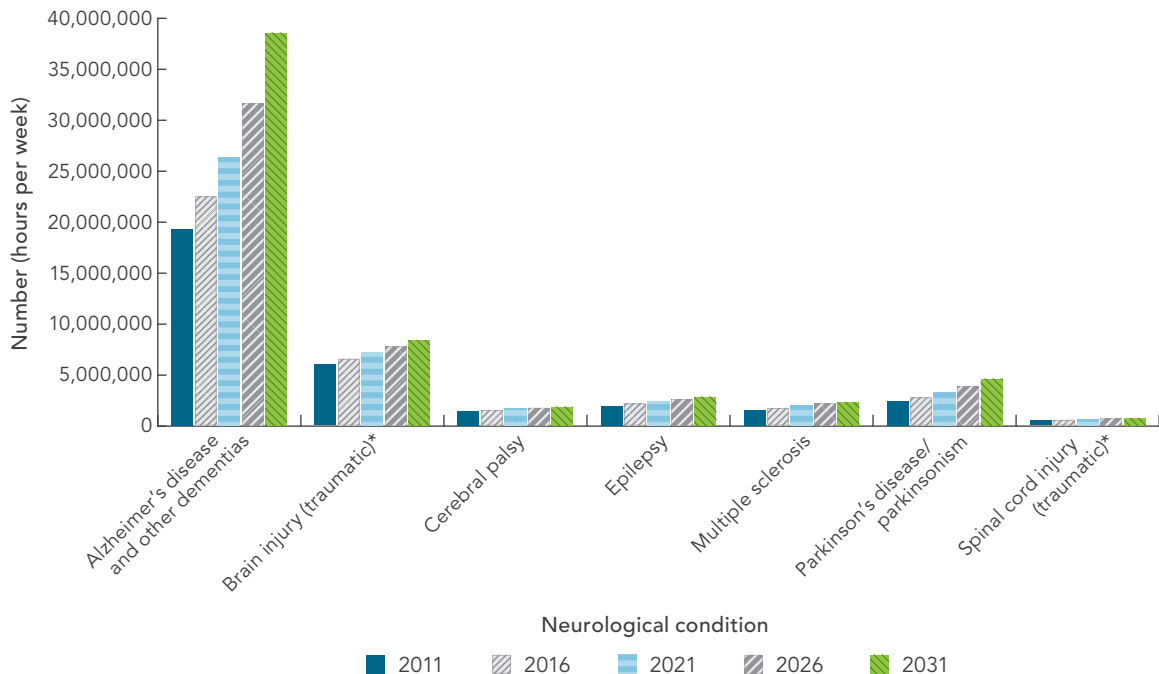
NOTES: * Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

- Out-of-pocket costs for caregivers will remain stable, ranging from approximately $1.7 thousand annually per individual living with epilepsy, to approximately $4.6 thousand annually per individual living with Alzheimer's disease and other dementias. These projections could be affected by changes in policy concerning universally insured health care.

2.10 Knowledge gaps

Individual Study projects were limited in their coverage of health services for every Canadian jurisdiction, and were not designed to fully ascertain the wide range of out-of-pocket costs that individuals may accrue because of their neurological condition. Specifically, health service gaps were identified, such as:

- The inconsistent availability of multidisciplinary care;
- 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 condition.

Data on health services for Canadians living with a neurological condition were lacking or deficient regarding:

- The distribution and quality of health services across the various regions and jurisdictions of Canada;

- 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;

- The personal cost of medications for individuals with each neurological condition, especially given that all provincial and territorial drug plans involve co-payments;

- The perceptions of health care providers on the accessibility, timeliness, and quality of health services for individuals with a neurological condition;

- The provision of health care for First Nations, Inuit, and Métis populations, for vulnerable populations, and for children with a neurological condition.

Applying the best currently available knowledge gained from Study projects, such as addressing potential barriers in access to care or the physical and mental health needs identified by Canadians living with a neurological condition, can help improve the adequacy of the health care system for individuals navigating through the care options for their neurological condition.

2.11 Key themes

In this chapter, which examined existing health services for individuals living with or affected by a neurological condition in Canada, it was noted that:

- Community-based services as well as hospital-based health care programs and resources are both important components of effective health service delivery.

- Many of those with a neurological condition receive extensive services from informal caregivers, and these caregivers often require emotional and financial support.

- Cultural background and language must be considered in the delivery of health care services for individuals with a neurological condition.

- Functional ability, as well as diagnosis, needs to be considered when developing care plans for individuals living with a neurological condition.

- Individuals with milder forms of neurological conditions also have specific needs that require recognition and support.

- It is important to recognize the impact and complexities of mental health comorbidities in individuals with a neurological condition and their caregivers. Currently, there are insufficient services and service providers to address the coexistence of mental health disorders and neurological conditions, in spite of evidence documenting this need.

- Individuals with a neurological condition need transition support as they move along the continuum of care, which is often directed by the progression of their condition.

- Individuals with a neurological condition would benefit from the current moves in some jurisdictions to modify chronic care; these changes could be guided by models, such as the recently developed revised chronic care model that incorporates environmental, social, and educational factors.

- The utilization and cost of drugs, including co-payments, is a significant component of overall health care costs, both for individuals living with a neurological condition and for the health care system.

Microsimulation modelling of seven neurological conditions projects that by 2031:

- Total annual health care costs (direct costs) will increase for each of the seven modelled neurological conditions, and will be twice as high for Canadians age 40 years and older with Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism.

- Acute hospitalizations will continue to be the largest contributor to total direct health care costs for all the modelled neurological conditions except Alzheimer's disease and other dementias, where facilities-based long-term care will remain as the largest contributor.

- Increased numbers of Canadians with the seven modelled neurological conditions will become likely candidates for informal care (based on their health status as defined by their HUI-3 score), and for those with Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism, the number of candidates for informal care will nearly double.

3. SCOPE (PREVALENCE AND INCIDENCE) OF NEUROLOGICAL CONDITIONS

To best address the health impacts (Chapter 1) and health service needs (Chapter 2) of Canadians living with a neurological condition as well as their families and caregivers, program and policy planning is informed by different types of evidence. Understanding the magnitude of neurological conditions in Canada, in terms of how many Canadians are living with these conditions, constitutes a core piece of this process.

In this Study, projects focusing on the prevalence (extent of the population affected) and incidence (new occurrence) of neurological conditions in Canada were carried out to document the burden of these conditions [1][2][3][4][5][6][8][10][12][15][17][18]. A wide range of data sources and methods for estimating prevalence and incidence were used, each with strengths and limitations. Assessing the validity and reliability of prevalence and incidence estimates from these different data sources – systematic reviews and meta-analyses, health administrative databases, EMRs, surveys, and microsimulation models – provided important information for the surveillance and monitoring of neurological conditions in Canada. In this chapter, findings were generally referred to as 'estimates', because their calculation was based on samples of the population, and not on the entire population.

> " The data from the Study are so important – without solid numbers, asking for program funding is based on anecdotal reports. Now there is so much more.
>
> *– Volunteer, health organization employee*

3.1 Determining prevalence and incidence estimates of neurological conditions is complex

The Study produced the first reliable Canadian prevalence and incidence estimates for many of the targeted neurological conditions. Because systematic reviews of the published literature identified few Canadian studies presenting prevalence and incidence for the neurological conditions targeted in the Study [18], the prevalence and incidence data produced by individual Study projects resulted in novel information for many of these neurological conditions in a Canadian context. Confidence in prevalence or incidence estimates is strengthened if they are confirmed by more than one source; as such, these new estimates were compared to estimates based on meta-analyses of studies (mostly from outside of Canada) that met predetermined criteria for quality and homogeneity. Canadian prevalence estimates produced by Study projects are presented in Table 3-1 by data source,

and are positioned relative to the findings derived from meta-analyses. Table 3-2 provides new prevalence estimates of neurological conditions specific to Canadians living in long-term care facilities.

CRITICALLY ASSESSING NEW ESTIMATES OF PREVALENCE AND INCIDENCE

- *Meta-analyses as a comparator:* By combining data from multiple published studies, meta-analyses have the potential to generate a prevalence or incidence estimate that is more precise than that of a single study. The precision of such estimates is dependent on the quality and uniformity of the studies included in the meta-analyses. If the 95% **confidence interval** of a new estimate generated by this Study overlaps with the 95% confidence interval of the meta-analysis estimate, it may support the value of this new estimate. If the 95% confidence interval of the new estimate generated by this Study only overlaps with the **range** of estimates included in the meta-analysis, then this new estimate may need to be used with caution. New estimates that are outside of the ranges seen in published data may be of questionable reliability, because they currently cannot be confirmed by other data sources.

- *Variations in estimates:* For some neurological conditions, wide variations in estimates exist. Part of this variance may be due to differences in methodology, populations studied, case ascertainment, or definitions used. Differences in incidence and prevalence of these neurological conditions may also be influenced by environmental, geographic, genetic, or demographic factors.

TABLE 3-1: Prevalence of neurological conditions, by data source, Systematic Reviews Project [1], BC Administrative Data Project [1], CCHS 2010-2011 Project [3]

	META-ANALYSES AND SYSTEMATIC REVIEWS[1] (worldwide unless otherwise specified)				ADMINISTRATIVE DATA[2] (British Columbia)		SURVEY DATA[3] (Canada)	
	Prevalence range in individual studies (rate per 100,000 population)	Number of studies included	Pooled point prevalence — Rate per 100,000 population	(95% confidence interval)	Period prevalence — Rate per 100,000 population	(95% confidence interval)	Weighted period prevalence — Rate per 100,000 population	(95% confidence interval)
Alzheimer's disease and other dementias								
Community, age 65+ years	800-37,218	29	5,234	(4,142-6,613)	-	-	2,130	(1,910-2,340)
Community and long-term care facilities, age 65+ years	1,948-64,706	13	15,544	(9,070-26,638)	7,594.6	(7,540.9-7,648.6)	-	-
Amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease)	1.6-7.9	5	4.4	(2.7-7.2)	10.2[4]	(9.5-11.0)	10[E]	(10-20)
Brain injury (traumatic)	2,136-5,700	2	3490.1[5]	(1,333.9-9,131.6)	835.6	(827.1-844.2)	410	(380-450)
Brain tumour	130.8-221.8[5]	2	-	-	38.1[6]	(36.4-39.8)	140[7]	(120-160)
Cerebral palsy	110-390	28	211[8]	(198-225)	191.9[9]	(187.5-196.3)	130	(110-150)
Dystonia	10.1-37.1	5	16.4[10]	(12.1-22.3)	-	-	40	(30-50)
Epilepsy Overall	321-1,550	33	746	(678-817)	1,246.2[9]	(1,235.8-1,256.6)	-	-
Epilepsy Active	73-10,500	93	596	(538-661)	-	-	400	(360-430)
Huntington's disease	1.6-12.7	10	5.7[11]	(4.4-7.4)	4.0	(3.6-4.5)	10[E]	(10-10)
Hydrocephalus All	30.7-310.1	7	93.0	(51.4-168.4)	74.7[9]	(72.2-77.2)	-	-
Hydrocephalus Age <4 years	-	-	-	-	76.0	(63.8-89.8)	70[E]	(30-110)
Hydrocephalus Seniors[12]	198.7-350.3	3	238.6	(146.3-389.2)	139.8	(130.9-148.8)	40[E]	(20-60)
Migraine	-	-	-	-	-	-	8,270	(8,100-8,450)
Multiple sclerosis	40-298	10	208.4[13]	-	177.4	(174.1-180.8)	290	(260-320)
Muscular dystrophy	6.3-25.5	5	16.1[14]	(11.2-23.2)	106.8[15]	(104.0-109.5)	70	(60-90)
Parkinson's disease[16] Age group (years) All	405-19,030	47	-	-	147.0[9]	(144.0-150.1)	170	(140-200)
40+	-	-	-	-	342.0	(334.6-349.5)	330	(280-380)
45+	-	-	-	-	396.6	(387.9-405.3)	390	(330-450)
40 to 49	-	-	40.5	(20.3-81.0)	26.9	(23.1-30.7)	F	
50 to 59	-	-	106.7	(53.9-211.2)	79.5	(72.8-86.2)	90[E]	(60-120)
60 to 69	-	-	428.5	(235.5-779.8)	301.5	(285.8-317.1)	410[E]	(260-560)
70 to 79	-	-	1,086.5	(627.0-1,883.0)	913.4	(878.1-948.7)	1,030	(810-1,240)
80+	-	-	1,903.0	(1,132.2-3,198.4)	1,697.7	(1,640.4-1,754.9)	1,420	(1,050-1,790)

	META-ANALYSES AND SYSTEMATIC REVIEWS[1] (worldwide unless otherwise specified)				ADMINISTRATIVE DATA[2] (British Columbia)		SURVEY DATA[3] (Canada)	
	Prevalence range in individual studies (rate per 100,000 population)	Number of studies included	Pooled point prevalence		Period prevalence		Weighted period prevalence	
			Rate per 100,000 population	(95% confidence interval)	Rate per 100,000 population	(95% confidence interval)	Rate per 100,000 population	(95% confidence interval)
Spina bifida								
Folate intake unknown	1.4-580.8	147	46.4[5]	(42.2-51.0)	17.0[9]	(15.7-18.4)	110	(90-120)
Folate supplemented	1.4-82.1	13	25.1[5]	(19.9-31.7)	-	-	-	-
Spinal cord injury (traumatic)	-	1	3.7	-	67.3	(65.1-69.7)	360	(330-400)
Spinal cord tumour	-	-	-	-	38.1[6]	(36.4-39.8)	30	(20-30)
Stroke	-	-	-	-	-	-	980	(920-1,030)
Tourette syndrome								
Age group (years) 0+	-	-	-	-	-	-	100	(80-120)
6 to 15	100-5,260	13	770	(390-1,510)	-	-	370	(260-480)
0 to 17	-	-	-	-	-	-	250	(180-310)

NOTES:

BC = British Columbia. CCHS = Canadian Community Health Survey. ALS = Amyotrophic lateral sclerosis. ICD = International Classification of Diseases. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20.

1 Systematic reviews based on studies from 1985 to 2011, except for ALS (1994–2011) and Alzheimer's disease and other dementias (Canadian studies: 1985–2011; international studies: 2000-2011). Age grouping information was not available for most conditions.

2 Administrative data were from British Columbia (2009/2010). Data were for age 1+ years for most conditions, unless otherwise specified. Note that Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, parkinsonism, and stroke are currently being added to the Canadian Chronic Disease Surveillance System to obtain Canadian estimates on an ongoing basis.

3 CCHS data were from 2010–2011 and were based on self- or proxy-report of diagnosed neurological conditions. Data were weighted to represent the Canadian population living in the community and were rounded to the nearest ten. Data were for age 0+ years for most conditions, unless otherwise specified.

4 These data were based on ICD coding for anterior horn cell disease, which includes ALS.

5 Period prevalence.

6 These data were based on ICD coding for malignant central nervous system tumours, which includes brain and spinal cord tumours. Data were for age 0+ years.

7 These data were based on any brain tumour (malignant or benign).

8 Prevalence per 100,000 live births.

9 Data were for age 0+ years.

10 These data were based on studies related to primary dystonia. The Systematic Reviews Project [18] also analysed prevalence for focal (segmental), cervical, and blepharospasm dystonia (data not shown).

11 These data were based on studies from North America, Europe, and Australia.

12 This group was noted as elderly in the systematic reviews and were based on studies from Japan. Data for British Columbia and CCHS were for age 65+ years.

13 Estimate was based on median prevalence from a sample of Canadian studies.

14 These data were based on studies related to any muscular dystrophy. The Systematic Reviews Project [18] also analysed prevalence for Duchenne, Becker, myotonic, facio-scapulo-humeral, limb-girdle, Emery-Dreifus, and congenital muscular dystrophy (data not shown).

15 These data were based on ICD coding for myopathies, which includes muscular dystrophy. Data were for age 0+ years.

16 All data for British Columbia were based on ICD coding for parkinsonism, which includes Parkinson's disease.

E Interpret with caution; coefficient of variation between 16.6% and 33.3%.

F Data were unreportable due to small sample size or high sampling variability.

TABLE 3-2: Prevalence of neurological conditions among Canadians living in long-term care facilities, by sex, Canada, 2011–2012, SNCIC 2011–2012 Project [17]

| | WEIGHTED PERIOD PREVALENCE | | | |
| | Men | | Women | |
	Rate per 100,000 population	(95% confidence interval)	Rate per 100,000 population	(95% confidence interval)
Full SNCIC sample	61,760	(60,580-62,950)	66,440	(65,250-67,630)
Alzheimer's disease and other dementias	36,910	(36,020-37,800)	49,150	(48,150-50,140)
ALS	130	(110-160)	70	(60-90)
Brain injury (traumatic)	3,710	(3,520-3,900)	1,240	(1,150-1,340)
Brain or spinal cord tumour	410	(320-510)	390	(270-500)
Cerebral palsy	2,410	(2,270-2,560)	1,230	(1,150-1,310)
Dystonia	300	(250-350)	210	(170-240)
Epilepsy	5,710	(5,470-5,950)	3,160	(3,040-3,290)
Huntington's disease	290	(260-330)	220	(190-240)
Hydrocephalus	620	(560-680)	350	(310-380)
Multiple sclerosis	1,300	(1,200-1,400)	1,540	(1,450-1,620)
Muscular dystrophy	310	(260-370)	120	(90-150)
Parkinson's disease	6,300	(6,090-6,510)	3,950	(3,820-4,080)
Spina bifida	190	(160-230)	130	(110-150)
Spinal cord injury (traumatic)	770	(690-850)	290	(250-320)
Stroke	16,500	(16,050-16,960)	14,430	(14,060-14,800)
Tourette syndrome	290	(260-320)	50	(40-60)

NOTES: SNCIC = Survey of Neurological Conditions in Institutions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living in long-term care facilities. Data were rounded to the nearest ten. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20.
SOURCE: 2011–2012 SNCIC data (Statistics Canada).

Administrative data are a valid source of prevalence data. Using a well-established Ontario database that links EMRs to administrative data, the Ontario (ON) Administrative Data Project [12] team carried out groundwork for the use of administrative data in the surveillance of neurological conditions. By identifying patients with certain neurological conditions using EMR data and then developing algorithms to capture these patients with administrative data, the ON Administrative Data Project [12] produced validated case definitions for Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, and parkinsonism. This, in part, informed the work performed by the BC Administrative Data Project [1] team (Table 3-1, above).

Based on findings from British Columbia health administrative data, prevalence estimates for most neurological conditions were concordant with those obtained by systematic reviews and meta-analyses [1][18]. Ontario estimates for Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, and parkinsonism (data not shown) also approximated those of the BC Administrative Data Project [1][12]. These findings suggest that, for the most part,

health administrative data will be a promising source of data for the national surveillance of neurological conditions.[36] However, in instances where a condition is defined using the fourth or fifth digits of International Classification of Diseases (ICD) coding, specificity may be lost if hospital or physician claim databases do not capture this level of detail. In most provinces and territories, the physician claim database does not provide the level of digit required for specificity; therefore, a broader category of illness is captured, such as parkinsonism instead of Parkinson's disease, anterior horn cell disease instead of ALS, or myopathy instead of muscular dystrophy.

EMR data are a promising source of information. The EMR Project [6] was successful in producing prevalence estimates for Alzheimer's disease and other dementias, epilepsy, and parkinsonism that were congruent with the estimates obtained from meta-analysis [18]. These findings suggest that the EMRs of family physicians are another potential source of readily accessible epidemiological data on neurological conditions.

Survey data provide reliable prevalence estimates for certain neurological conditions. The CCHS 2010–2011 Project [3] produced prevalence estimates that were comparable to those obtained from meta-analysis for hydrocephalus (infants and children) and Parkinson's disease [18]. For Alzheimer's disease and other dementias, brain tumour, cerebral palsy, dystonia, epilepsy, Huntington's disease, multiple sclerosis, spina bifida, and Tourette syndrome, prevalence estimates were outside the confidence intervals of the pooled estimates obtained through meta-analysis, but remained within the ranges presented by the individual studies included in the meta-analysis (Table 3-1, above). Of note, the prevalence estimate for Alzheimer's disease and other dementias that was derived from the CCHS (2010–2011) was much lower than the estimate obtained from meta-analysis. This implies that self-reported survey data for Canadians living in the community may not be reliable for certain rare or debilitating neurological conditions, regardless of whether proxy responses are included.[37]

Incidence data can be obtained from administrative data. Estimates for newly diagnosed cases, as opposed to existing cases, of selected neurological conditions were provided by the BC Administrative Data Project [1].[38] For Alzheimer's disease and other dementias, ALS, malignant brain tumours, Huntington's disease, parkinsonism (when compared by age group), and spinal cord injury (when pre-hospital mortality was excluded), the 95% confidence intervals for British Columbia data estimates overlapped with those of the meta-analysis [18]. For epilepsy, hydrocephalus (in infants under one year of age), and multiple sclerosis, estimates from British Columbia were within the ranges of the component studies

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[36] The Synthesis Panel noted that for surveillance purposes, administrative data have the advantage of capturing real patient encounters with health care providers. They are limited, however, in the amount of information they capture about individuals and their experiences living with a neurological condition beyond basic demographics and the use of health services. National surveillance using administrative data is only possible when each jurisdiction captures administrative data in a consistent way. Also, the quality of billing codes depends on the diligence and accuracy of their input into databases, and on how often these codes are revised based on new understandings of the conditions.

[37] The Synthesis Panel noted that self-report surveys can be used to estimate prevalence and have the advantage of providing consistent national coverage relatively quickly for surveillance purposes. Yet, survey results need to be interpreted with caution as certain neurological conditions can interfere with survey participation (e.g. due to the cognitive status of a respondent with dementia) or may be too rare to be appropriately captured in the selected sample. Response bias due to stigma also needs to be considered.

[38] Alzheimer's disease and other dementias, ALS, traumatic brain injury, brain tumours, epilepsy, Huntington's disease, hydrocephalus, multiple sclerosis, muscular dystrophy, parkinsonism, spina bifida, and spinal cord injury.

of the meta-analysis. The CCDSS is currently being expanded to include Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, parkinsonism, and stroke to allow for the ongoing collection of incidence data for these conditions at the national level [2].

Data collected in long-term care facilities show a high prevalence of neurological conditions in these populations. Certain populations can be hard to reach using existing data sources. Most national surveys currently exclude populations living in facilities. While EMR and administrative data may count these populations to some degree, they may not be able to identify them as living in long-term care facilities. The Survey of Neurological Conditions in Institutions in Canada (SNCIC) 2011–2012 Project [17], which employed a mail-in questionnaire to Canadian long-term care facilities, was considered successful with a response rate of 63.5%.

Although it was no surprise that neurological conditions were more prevalent among those in long-term care facilities and in home care programs than among those living in the community at large, the actual figures remained striking. According to results from the interRAI Project [8] (in jurisdictions where data were available), more than half of individuals in formal home care programs (Ontario) or long-term care facilities (Ontario and several other provinces and territories) had at least one neurological condition. The SNCIC 2011–2012 Project [17] also estimated that 64.8% of residents in long-term care facilities in Canada had at least one of the neurological conditions targeted by the survey. The majority (69.3%) of diagnoses reported by administrators were for Alzheimer's disease and other dementias (Table 3-2, above).[39]

3.2 The distribution of neurological conditions and their comorbidities can differ by age and sex

Data from the CCHS 2010–2011 Project [3] confirmed that multiple sclerosis and migraine affected more women than men, while Tourette syndrome, Parkinson's disease, and brain or spinal cord injury occurred more frequently among men. These data also showed that the overall prevalence of the selected neurological conditions increased with age, peaking at age 80 years and older. This peak was driven mainly by Alzheimer's disease and other dementias, stroke, and Parkinson's disease – neurological conditions that are more prevalent in older age groups. Certain neurological conditions primarily affected younger and middle-age adults, such as multiple sclerosis or traumatic brain injury, while some tended to present in childhood (e.g. cerebral palsy, spina bifida, and hydrocephalus). Moreover, the prevalence of neurological conditions typically present at birth may be affected by the gestational age of the infant. For instance, the Systematic Reviews Project [18] noted that the prevalence of cerebral palsy per 100,000 live births was 11,180 for pre-term infants, compared to a prevalence of 211 when infants of any gestational age were considered.

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[39] SNCIC data were derived from a mail-in survey of administrators of registered long-term care facilities across Canada, but data were not further validated [17]. The interRAI project [8] based its data on the diagnosis recorded through periodic resident assessments. The validation work performed on this instrument has been published (Foebel AD, Hirdes JP, Heckman GA, Kergoat MJ, Patten S, Marrie RA. Diagnostic data for neurological conditions in interRAI assessments in home care, nursing home and mental health care settings: A validity study. BMC Health Serv Res. 2013 Nov;13:457).

The burden of certain neurological conditions varies by sex and over the life course.
Prevalence data from the BC Administrative Data Project [1] depicted clear age and
sex patterns:

- *Alzheimer's disease and other dementias:* Figure 3-1 illustrates how the rates of Alzheimer's
  disease and other dementias increased similarly in men and women until 80 years of age
  (approximately doubling every five years after age 70), when the increase became greater
  in women.

- *Parkinsonism:* Parkinsonism, which mainly includes Parkinson's disease, was rare under
  the age of 45 years, but steadily increased thereafter, affecting more men than women
  (Figure 3-2).

- *Multiple sclerosis:* The prevalence of multiple sclerosis was higher among women than men
  for all age groups, but peaked at age 55 to 59 years for both sexes (Figure 3-3).

- *Traumatic brain injury:* The prevalence of traumatic brain injuries peaked at age 25 to
  29 years and declined until age 65 to 69 years, when it started to rise again (Figure 3-4).
  Regardless of age group, traumatic brain injuries were higher among men than women.

- *Spinal cord injury:* Finally, for spinal cord injuries, the data showed that regardless of age
  group, the prevalence was generally higher among men than women (Figure 3-5).

The unequal distribution of the burden of neurological conditions between sexes and across
age groups reinforced the need to consider prevalence and incidence patterns when planning
for health services and programs.

FIGURE 3-1: Prevalence of Alzheimer's disease and other dementias, by sex and age group,
British Columbia, 2009/2010, BC Administrative Data Project [1]
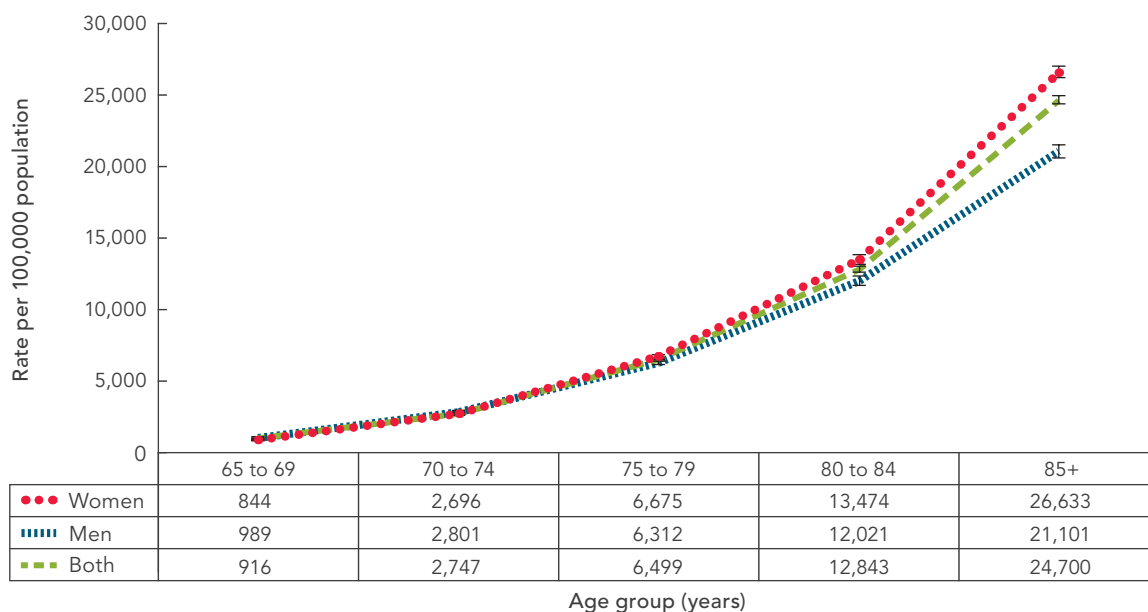
	65 to 69	70 to 74	75 to 79	80 to 84	85+
••• Women	844	2,696	6,675	13,474	26,633
⦙⦙⦙ Men	989	2,801	6,312	12,021	21,101
- - - Both	916	2,747	6,499	12,843	24,700

Age group (years)

NOTES: BC = British Columbia. The 95% confidence interval shows an estimated range of values which is likely to include the true
prevalence 19 times out of 20.
SOURCE: Population Health Surveillance and Epidemiology, British Columbia Ministry of Health (March 2014).

FIGURE 3-2: Prevalence of parkinsonism*, by sex and age group, British Columbia, 2009/2010, BC Administrative Data Project [1]
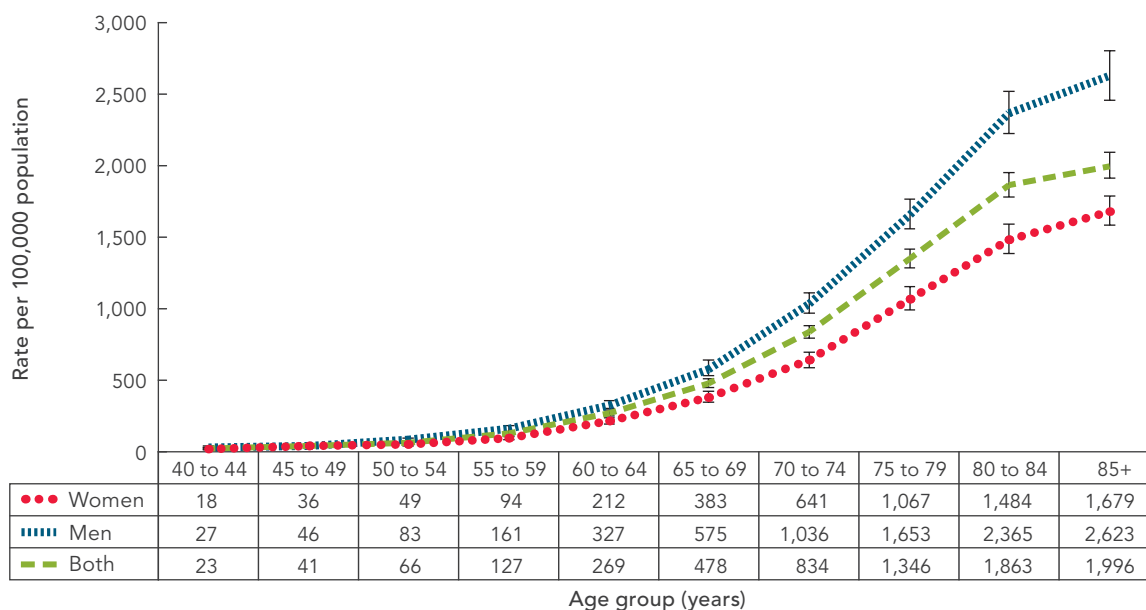
	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85+
●●● Women	18	36	49	94	212	383	641	1,067	1,484	1,679
▪▪▪▪▪ Men	27	46	83	161	327	575	1,036	1,653	2,365	2,623
– – Both	23	41	66	127	269	478	834	1,346	1,863	1,996

Age group (years)

NOTES: BC = British Columbia. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. * Parkinsonism includes Parkinson's disease.

SOURCE: Population Health Surveillance and Epidemiology, British Columbia Ministry of Health (March 2014).

FIGURE 3-3: Prevalence of multiple sclerosis, by sex and age group, British Columbia, 2009/2010, BC Administrative Data Project [1]
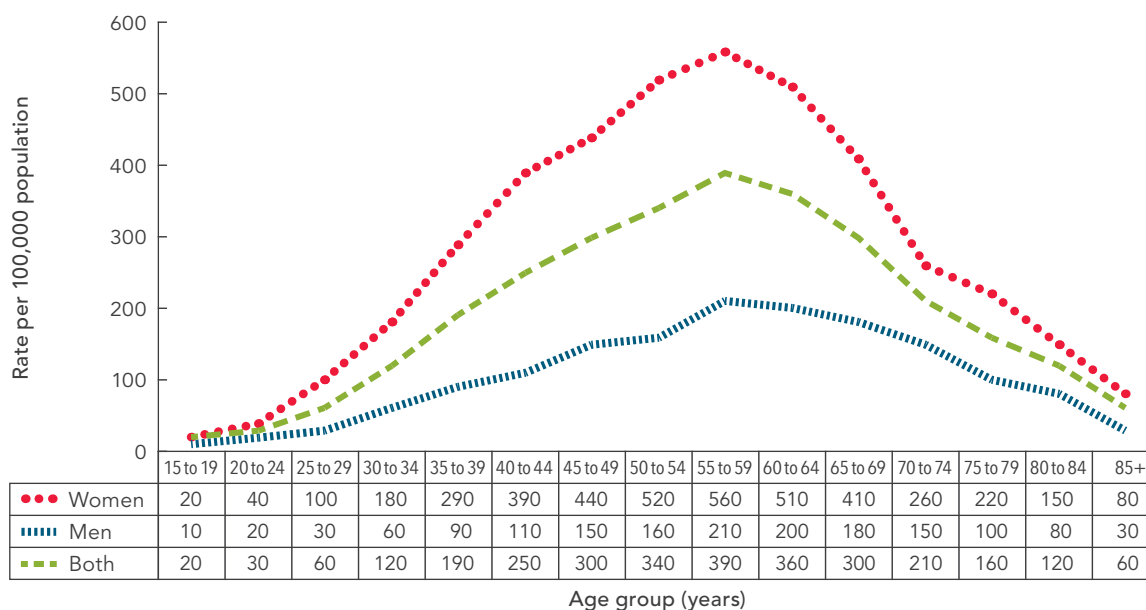
	15 to 19	20 to 24	25 to 29	30 to 34	35 to 39	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85+
●●● Women	20	40	100	180	290	390	440	520	560	510	410	260	220	150	80
▪▪▪▪▪ Men	10	20	30	60	90	110	150	160	210	200	180	150	100	80	30
– – Both	20	30	60	120	190	250	300	340	390	360	300	210	160	120	60

Age group (years)

NOTES: BC = British Columbia. Data were rounded to the nearest ten.

SOURCE: Population Health Surveillance and Epidemiology, British Columbia Ministry of Health (September 2011).

FIGURE 3-4: Prevalence of traumatic brain injury, by sex and age group, British Columbia, 2009/2010, BC Administrative Data Project [1]
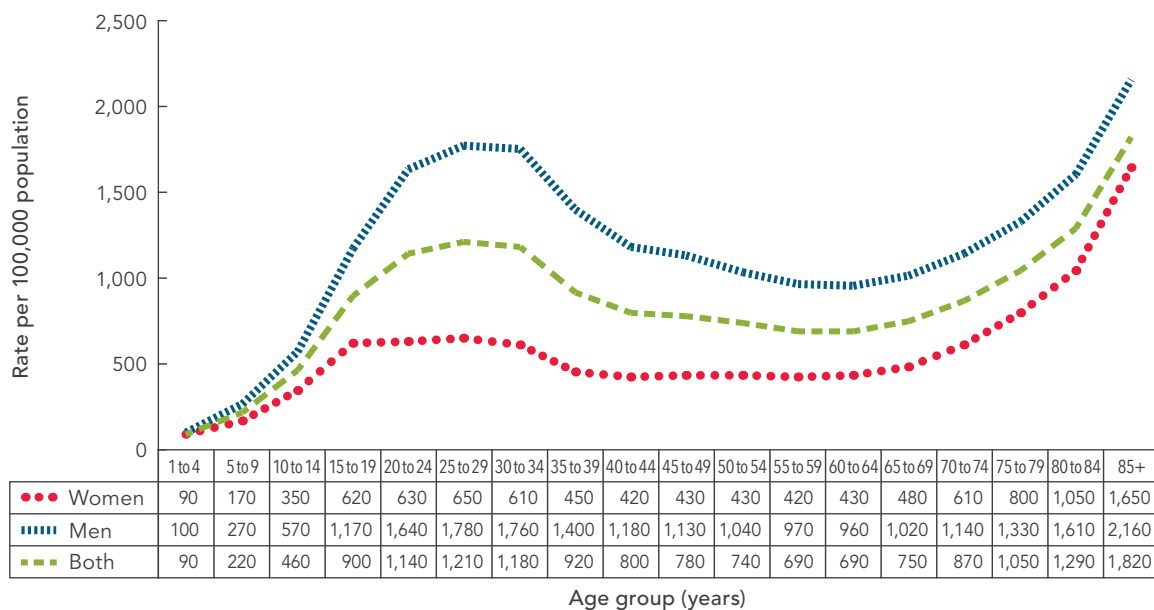
	1 to 4	5 to 9	10 to 14	15 to 19	20 to 24	25 to 29	30 to 34	35 to 39	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85+
●●● Women	90	170	350	620	630	650	610	450	420	430	430	420	430	480	610	800	1,050	1,650
∥∥∥ Men	100	270	570	1,170	1,640	1,780	1,760	1,400	1,180	1,130	1,040	970	960	1,020	1,140	1,330	1,610	2,160
▪▪▪ Both	90	220	460	900	1,140	1,210	1,180	920	800	780	740	690	690	750	870	1,050	1,290	1,820

Age group (years)

NOTES: BC = British Columbia. Data were rounded to the nearest ten.
SOURCE: Population Health Surveillance and Epidemiology, British Columbia Ministry of Health (September 2011).

FIGURE 3-5: Prevalence of traumatic spinal cord injury, by sex and age group, British Columbia, 2009/2010, BC Administrative Data Project [1]

	1 to 4	5 to 9	10 to 14	15 to 19	20 to 24	25 to 29	30 to 34	35 to 39	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85+
●●● Women	0	4	6	10	26	36	46	41	45	39	51	32	33	36	41	50	75	65
∥∥∥ Men	0	3	7	26	75	95	133	149	142	140	143	132	124	132	130	142	116	88
▪▪▪ Both	0	3	6	18	51	65	89	94	93	89	97	82	78	83	84	94	93	73

Age group (years)
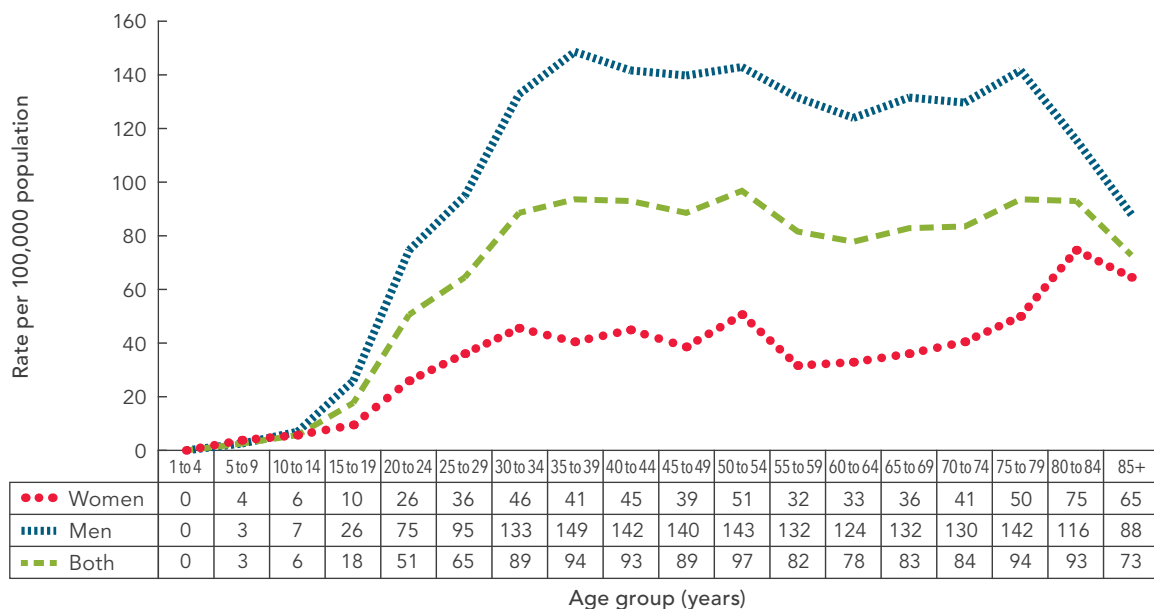
NOTES: BC = British Columbia.
SOURCE: Population Health Surveillance and Epidemiology, British Columbia Ministry of Health (September 2011).

The age at onset of symptoms and diagnosis differ by neurological condition. The age at onset of symptoms and age at diagnosis differed by neurological condition (Table 3-3) [16]. However, based on survey data, differences were not statistically significant by sex except for the age at diagnosis for Alzheimer's disease and other dementias.[40] A better analysis of sex differences in the age of onset of various neurological conditions could be addressed with a longitudinal cohort analysis or through the use of administrative data.

TABLE 3-3: Age at onset of symptoms and diagnosis for neurological conditions, by sex, Canada, 2011–2012, SLNCC 2011–2012 Project [16]

| | MEN | | | | WOMEN | | | |
| | Age at symptom onset | | Age at diagnosis | | Age at symptom onset | | Age at diagnosis | |
	Mean	(95% confidence interval)	Mean	(95% confidence interval)	Mean	(95% confidence interval)	Mean	(95% confidence interval)
Alzheimer's disease and other dementias	70.2	(68.1-72.3)	72.2	(70.1-74.2)	73.6	(71.6-75.5)	75.8	(74.4-77.2)
ALS	F		F		F		F	
Brain injury (traumatic)	N/A		29.3	(25.5-33.1)	N/A		31.7	(26.7-36.6)
Brain tumour	35.5	(29.9-41.1)	37.2	(31.4-43.0)	37.8	(32.0-43.6)	40.0	(34.6-45.7)
Cerebral palsy	F		F		F		2.1^E	(0.8-3.4)
Dystonia	31.0^E	(20.4-41.6)	34.0^E	(22.2-45.8)	33.8	(23.4-44.2)	42.2	(30.3-54.0)
Epilepsy	21.3	(18.1-24.5)	21.8	(18.6-25.0)	19.5	(17.0-22.1)	20.7	(18.0-23.3)
Huntington's disease	F		F		F		F	
Hydrocephalus	F		F		19.3^E	(10.0-28.7)	20.4^E	(12.1-28.7)
Migraine	24.2	(20.6-27.8)	26.6	(23.3-29.8)	22.8	(21.3-24.3)	26.4	(24.9-28.0)
Multiple sclerosis	31.9	(29.2-34.5)	34.8	(31.9-37.6)	32.3	(30.3-34.4)	37.8	(35.5-40.2)
Muscular dystrophy	22.6	(16.6-28.6)	24.9	(19.0-30.8)	25.5^E	(14.6-36.5)	28.1^E	(16.7-39.5)
Parkinson's disease	63.2	(60.0-66.3)	64.2	(61.0-67.4)	65.1	(61.7-68.5)	66.9	(64.0-69.8)
Spina bifida	N/A		N/A		N/A		N/A	
Spinal cord injury (traumatic)	N/A		34.7	(32.5-37.0)	N/A		38.3	(34.4-42.3)
Spinal cord tumour	49.5	(43.9-55.1)	48.0	(42.0-53.9)	33.9^E	(17.7-50.2)	36.3^E	(20.6-51.9)
Stroke	56.7	(53.2-60.2)	N/A		54.8	(51.0-58.6)	N/A	
Tourette syndrome	8.2	(6.5-9.9)	13.1	(9.6-16.5)	10.8^E	(6.4-15.2)	11.6^E	(5.9-17.2)

NOTES: SLNCC = Survey on Living with Neurological Conditions in Canada. ALS = Amyotrophic lateral sclerosis. Data were weighted to represent the Canadian population living with a neurological condition and were based on self- or proxy-report. The 95% confidence interval shows an estimated range of values which is likely to include the true value 19 times out of 20. Based on the 95% confidence intervals, age of symptom onset and diagnosis were not statistically significant by sex except for Alzheimer's disease and other dementias, which differed for age at diagnosis. E Interpret with caution; coefficient of variation between 16.6% and 33.3%. F Data were unreportable due to small sample size or high sampling variability. N/A For this condition, inquiring about the age of symptom onset and/or age of diagnosis did not apply.

SOURCE: 2011–2012 SLNCC data (Statistics Canada).

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40   These data were based on a mix of self- and proxy-report.

There are common comorbidities associated with neurological conditions. Men and women differed in their experiences of the physical and social aspects of neurological conditions. Chronic conditions such as neurological conditions may impact men and women at different stages in life, affecting their professional or familial roles. Because the onset of many of these neurological conditions occurs in later life, Canadians may be faced with various comorbidities, and women, who tend to live longer than men, may face additional burdens.

Certain chronic conditions, such as arthritis and high blood pressure, were common comorbidities for the overall population with a neurological condition (excluding migraine) (Table 3-4)[3].[41] The prevalence of asthma, arthritis, and bowel disease was higher among women than men, while heart disease was higher among men than women. The BC Administrative Data Project [1] also listed the eight most common 'other diagnoses' throughout 2005/2006 to 2009/2010 that were associated with each of the 13 neurological conditions addressed in this project, but these associations were a mix of causes and complications related to neurological conditions.

TABLE 3-4: Prevalence of selected chronic conditions among respondents age 12+ years living with a neurological condition (excluding migraine), by sex, Canada, 2010–2011, CCHS 2010–2011 Project [3]

	MEN		WOMEN	
	Prevalence (%)	(95% confidence interval)	Prevalence (%)	(95% confidence interval)
Asthma*	8.2	(6.5-9.9)	13.6	(11.4-15.8)
Arthritis*†	33.0	(29.7-36.4)	42.4	(38.9-46.0)
High blood pressure	35.7	(32.8-38.6)	38.6	(34.9-42.3)
COPD‡	10.4	(7.9-12.8)	10.2	(8.0-12.5)
Diabetes	15.2	(12.6-17.7)	12.0	(10.0-14.1)
Heart disease*	20.8	(18.0-23.5)	13.6	(11.6-15.7)
Cancer	6.4	(5.0-7.8)	5.2	(3.7-6.7)
Stomach/intestinal ulcer	7.0	(5.1-8.9)	6.9	(5.4-8.4)
Bowel disorder*	8.0	(6.0-9.9)	12.9	(10.8-15.1)
Mood disorder	17.2	(14.6-19.8)	20.5	(17.7-23.3)
Depression	13.2	(9.1-17.4)	17.2	(12.8-21.6)
Anxiety disorder	13.2	(11.1-15.2)	16.3	(13.6-19.0)

NOTES: CCHS = Canadian Community Health Survey. COPD = Chronic obstructive pulmonary disease. Data were weighted to represent the Canadian population living in the community and were based on self-report. The 95% confidence interval shows an estimated range of values which is likely to include the true prevalence 19 times out of 20. * Statistically significant difference based on the 95% confidence interval. † Respondents age 14+ years. ‡ Respondents age 35+ years.
SOURCE: 2010–2011 CCHS data (Statistics Canada).

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[41] At present, it is uncertain the extent to which mood disorders are associated with certain neurological conditions as a risk factor, manifestation of the neurological condition, or comorbidity. These possibilities are not mutually exclusive, and such relationships are likely to be complex.

3.3 Building capacity for the surveillance of neurological conditions is well underway

One of the goals of the Study was to provide evidence that could inform the development of a surveillance system for neurological conditions in Canada. Progress towards this goal was advanced through four interdependent approaches: systematic reviews and meta-analyses [18], new developments at the Agency to add neurological conditions to the CCDSS [2], the estimates of prevalence and incidence based on different data sources by the projects and surveys of the Study [1] [3][6][10][12][17], and the development of guidelines and toolkit for the creation and management of registries [4][15]. In general, none of the data sources examined in the Study was able to produce reliable prevalence estimates for certain targeted neurological conditions, specifically, those that were less prevalent. There were also varying levels of concordance among prevalence estimates for certain conditions, in part because of non-uniform case definitions applied by the different projects or because their coverage was limited to certain jurisdictions.

> " There is a real opportunity to extend the chronic disease surveillance system, and this report has highlighted several promising areas for further investigation.
>
> *– Federal public servant*

Systematic reviews of the literature provide evidence for data coding and sources.
To determine the best sources of ascertainment (identification of cases) for 15 neurological conditions, the Systematic Reviews Project [18] identified 30 studies that validated ICD coding of case definitions in health administrative data. The project team also evaluated the sources of ascertainment from over 1,200 studies for prevalence and incidence of neurological conditions and, in consultation with 50 experts, identified the most frequently used sources of data for each condition. They also prepared an inventory of neurological registries.

The results of this investigation supported the development of surveillance for some neurological conditions. Findings from this project demonstrated that the accuracy of ICD coding had been validated for Alzheimer's disease and other dementias, motor neuron disease,[42] epilepsy, multiple sclerosis, Parkinson's disease, spinal cord injury, and traumatic brain injury, but not for specific brain tumours, cerebral palsy, dystonia, Huntington's disease, hydrocephalus, muscular dystrophy, spina bifida, or Tourette syndrome.[43] The project team also concluded that the following sources of ascertainment were the most appropriate for the surveillance of certain neurological conditions:

- *Multiple sources:* Alzheimer's disease and other dementias, ALS, cerebral palsy, Huntington's disease, hydrocephalus, multiple sclerosis, muscular dystrophy, Parkinson's disease, and traumatic brain injury.
- *Registries:* Brain tumours, cerebral palsy, spinal cord injury, and rare disorders.
- *Administrative data or EMRs:* Epilepsy.

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[42] The category in the ICD-9 coding system that includes ALS.

[43] Migraine, spinal cord tumour, and stroke were not investigated as part of this project.

- *Population-based random sampling, door-to-door surveys,*[44] *or school-based studies:* Dystonia and Tourette syndrome.
- *Specific surveillance programs:* Congenital anomaly surveillance programs for spina bifida.

The addition of neurological conditions to the CCDSS is progressing. The CCDSS is a collaborative network of provincial and territorial surveillance systems led by the Agency to collect data on chronic conditions (such as diabetes or hypertension). In conjunction with some of the other projects of the Study [1][10][12][18], the CCDSS Neurological Conditions Working Group conducted development work to add four neurological conditions to the CCDSS (Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, and parkinsonism) [2]. The inclusion of stroke in the CCDSS has been ongoing and is led by the CCDSS Stroke Working Group.

Studies to validate algorithms for these five conditions were performed by the ON Administrative Data Project [12]. This represented a major step toward the development of the CCDSS for the pan-Canadian surveillance of neurological conditions, as it allowed for the identification of the best performing algorithms. In 2013/2014, these five neurological conditions were included in the CCDSS national pilot, a process in which all provinces and territories test the case definitions in their jurisdiction. Careful analysis of national pilot data will ensure that the selected case definitions consistently apply across all Canadian provinces and territories. With the formal inclusion of these conditions in the CCDSS in the near future, this component of the Study will continue on an ongoing basis as part of the Agency's national public health surveillance mandate.

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) has been expanded to include neurological conditions. The EMR Project [6] used the existing CPCSSN platform to develop case definitions for Alzheimer's disease and other dementias, epilepsy, and parkinsonism. Findings from this project suggest that EMRs could be used for regular surveillance of these conditions in community-based primary care when ascertainment algorithms are appropriately validated.

> " Creating a combined data registry to highlight the commonalities between and among neurological conditions – could this be linked or combined with chronic disease surveillance?
>
> *– Volunteer, researcher*

Guidelines have been created for the development and maintenance of registries. For neurological conditions not well suited to surveillance through surveys and/or administrative data, the creation of a registry may be another approach. Disease or patient registries are collections of data related to patients with a specific diagnosis or condition. The Registry Guidelines Project [15] carried out extensive literature reviews, held three structured focus group meetings and two consensus conferences, and used a modified Delphi consultation process to produce comprehensive guidelines for the development, implementation, and maintenance of

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[44] Considering the very high costs and logistical challenges associated with door-to-door surveys, these are rarely conducted in Canada.

registries of neurological conditions in Canada. These guidelines have been published,[45] and an implementation toolkit will assist in the planning of future registries for neurological conditions. This project delineated the key elements of:

- *Good registry design:* Participant informed consent, transparency, an advisory council, clear data ownership, appropriate data security, data release procedures, multi-modal patient recruitment, patient follow-up, planned data linkage, standard operating procedures, a data management plan, and appropriate data collection.

- *A high quality registry:* A quality management plan; standardized methodologies to address data collection and source inconsistencies; the use of an iterative or pilot-tested data collection method; rigorous, consistent and documented processes for data cleaning and correction; trained personnel; and a defined audit system with initialization triggers.

- *A registry with high impact:* Advance planning, adequate human and financial resources, regular communication with participants and stakeholders, efficient data collection, and transparent operation.

Although Canadian patients were generally supportive of the concept of disease and patient registries and were willing to participate in such registries, certain considerations emerged from the structured focus groups:

- *Before providing their consent to participate in a registry, patients wanted to know certain features of the registry:* Its purpose; its capacity to facilitate ethical research with meaningful results; that it is well managed and sustainable; that participation will not be onerous; and that they may withdraw at any time.

- *Patients also had difficulty understanding the need to share other information such as:* Personal information including age, occupation, income, provincial health number, and marital status. They also did not wish to provide their Social Insurance Number to a registry, even if they knew this was the only national individual identifier.

The Cerebral Palsy Registry Project **[4]** also produced information about the key challenges involved in expanding an existing registry. Although the experiences of this project team were specific to cerebral palsy, lessons learned could be helpful in the development of registries for other neurological conditions.

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[45] Neurological Registry Best Practice Guidelines. Can J Neurol Sci. 2013 Jul;40(Suppl. 2):S1-S78.

3.4   Looking ahead: 2011 to 2031

Results from the Microsimulation Project **[10]**, which are based on status quo assumptions,[46] project that between 2011 and 2031:

- The number of Canadians living with Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism (based on prevalence numbers) will almost double (Table 3-5).

TABLE 3-5: Projected prevalence, by select neurological condition, Canada, 2011, 2016, 2021, 2026, and 2031, Microsimulation Project **[10]**

| | PROJECTION YEAR | | | | |
	2011	2016	2021	2026	2031
	Number of prevalent cases* **(rate per 100,000 population in projection year)***				
Alzheimer's disease and other dementias	340,200	395,000	461,700	554,200	674,000
	(2,000)	(2,200)	(2,400)	(2,700)	(3,100)
Brain injury (traumatic)†	550,900	595,700	640,100	685,600	730,300
	(1,600)	(1,700)	(1,700)	(1,800)	(1,800)
Cerebral palsy	75,200	79,800	84,300	89,300	94,200
	(200)	(200)	(200)	(200)	(200)
Epilepsy	321,700	345,400	368,100	392,100	415,800
	(1,000)	(1,000)	(1,000)	(1,000)	(1,000)
Multiple sclerosis	98,800	108,600	117,800	126,200	133,600
	(400)	(400)	(400)	(400)	(400)
Parkinson's disease/ parkinsonism	84,700	99,000	116,800	138,800	163,700
	(500)	(500)	(600)	(700)	(700)
Spinal cord injury (traumatic)†	35,000	38,400	41,800	45,200	48,100
	(100)	(100)	(100)	(100)	(100)

NOTES: Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism projections were for a population age 40+ years. Multiple sclerosis projections were for a population age 20+ years. Traumatic spinal cord injury projections were for a population age 5+ years. Traumatic brain injury, cerebral palsy, and epilepsy projections were for a population age 0+ years. * Data were rounded to the nearest hundred. † Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

- In the population age 65 years and older, there will be at least twice as many, if not more, Canadians living with each of the seven modelled neurological conditions (based on prevalence numbers) (Table 3-6).

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[46]   The model accounted for changes in the Canadian population from births, immigration, emigration, and aging, but not for changes in risk factors or in the prevention, diagnosis, treatment, or management of neurological conditions.

TABLE 3-6: Projected number of Canadians age 65+ years living with a neurological condition, Canada, 2011 and 2031, Microsimulation Project **[10]**

	PROJECTION YEAR	
	2011	**2031**
	Number of prevalent cases*	
Alzheimer's disease and other dementias	310,000	639,700
Brain injury (traumatic)[†]	119,100	258,700
Cerebral palsy	6,000	15,000
Epilepsy	56,700	123,800
Multiple sclerosis	28,100	58,000
Parkinson's disease/parkinsonism	71,500	148,800
Spinal cord injury (traumatic)[†]	8,600	19,300

NOTES: * Data were rounded to the nearest hundred. † Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

- The number of Canadians newly diagnosed (incidence count) with cerebral palsy, epilepsy, multiple sclerosis, and spinal cord injury will grow in line with the growth of the population, so that incidence rates in 2031 will remain close to those seen in 2011 (Table 3-7). For conditions whose risk increases markedly with age, the incidence will increase beyond the rate of population growth. In particular, for Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism, the incidence rate will increase by almost 50%.

- For traumatic brain injury, the number of hospitalizations is expected to increase by 28% over the next 20 years unless better prevention strategies are implemented.

TABLE 3-7: Projected incidence, by select neurological condition, Canada, 2011, 2016, 2021, 2026, and 2031, Microsimulation Project **[10]**

| | PROJECTION YEAR | | | | |
| | 2011 | 2016 | 2021 | 2026 | 2031 |
	Number of incident cases* (rate per 100,000 population in projection year)†				
Alzheimer's disease and other dementias	59,600	66,700	77,500	93,200	110,700
	(360)	(370)	(410)	(460)	(530)
Brain injury (traumatic)‡	20,200	21,000	22,700	24,800	25,900
	(60)	(60)	(60)	(70)	(70)
Cerebral palsy	1,800	1,900	2,000	2,000	2,200
	(20)	(20)	(20)	(20)	(20)
Epilepsy	18,300	19,000	20,400	21,600	22,400
	(50)	(50)	(60)	(60)	(60)
Multiple sclerosis	4,100	4,400	4,300	4,300	4,800
	(15)	(16)	(15)	(14)	(15)
Parkinson's disease/ parkinsonism	10,400	11,900	14,000	16,000	18,600
	(60)	(60)	(70)	(80)	(90)
Spinal cord injury (traumatic)‡	1,400	1,600	1,700	1,600	1,700
	(4)	(5)	(5)	(4)	(5)

NOTES: Alzheimer's disease and other dementias and Parkinson's disease/parkinsonism projections were for a population age 40+ years. Multiple sclerosis projections were for a population age 20+ years. Traumatic spinal cord injury projections were for a population age 5+ years. Traumatic brain injury and epilepsy projections were for a population age 0+ years. Cerebral palsy projections were for a population age 0 to 20 years. * Data were rounded to the nearest hundred. † Data were rounded to the nearest ten (except for multiple sclerosis and traumatic spinal cord injury, which were rounded to the nearest unit). ‡ Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.

SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

• The number of deaths among Canadians with a neurological condition will increase, with the greatest impact seen in those living with Parkinson's disease/parkinsonism, where a 74% increase in the number of deaths is projected over time. The total number of deaths for those living with Alzheimer's disease and other dementias, which is already the highest of the modelled conditions in 2011, will increase by a further 70% by 2031 (Figure 3-6).

FIGURE 3-6: Projected number of deaths, by select neurological condition, Canada, 2011, 2016, 2021, 2026, and 2031, Microsimulation Project **[10]**
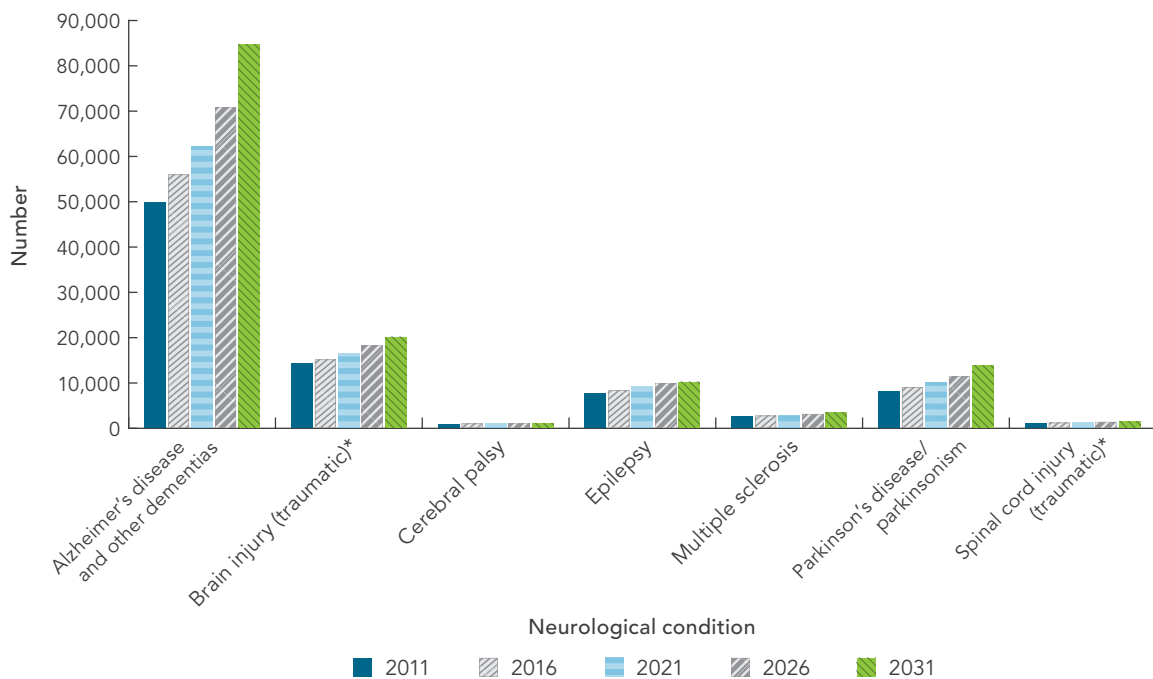
NOTES: * Traumatic brain and spinal cord injuries were based on hospitalized cases, and excluded injuries that did not present to hospital.
SOURCE: POHEM-Neurological (Statistics Canada and Public Health Agency of Canada).

3.5   Knowledge gaps

While several projects of this Study generated new findings that hold promise for the further determination of scope of neurological conditions in Canada, it was also demonstrated that for some conditions, different data sources produced incongruent results. This complexity calls for caution and careful consideration when selecting the most appropriate statistics to describe the burden of neurological conditions in Canada.

Regarding the scope of neurological conditions, the Study identified two main categories of gaps – gaps in research and gaps in infrastructure. Research gaps included the lack of data on:

• The identification of certain neurological conditions, such as multiple sclerosis or Parkinson's disease, at their earliest stages (noting that early symptoms are often non-specific, which makes it hard to reach a diagnosis, in addition to a tendency to use coding to describe symptoms rather than the diagnosis itself);

• Less prevalent conditions such as ALS, dystonia, and Huntington's disease, as well as other neurological conditions not targeted by the Study;

- Neurological conditions in populations typically excluded from participation in national population surveys;[47] and

- The extent of neurological conditions among children (including cerebral palsy, epilepsy, multiple sclerosis, brain injury, and stroke), and the persistence of these conditions into adulthood.

Gaps in infrastructure included the need for:

- Standardization of diagnostic codes (e.g. ICD-10-CA) used in physician billing claims and hospital data in all provinces and 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); and

- Complete data capture and reporting of benign brain tumours in existing provincial and territorial cancer registries.

Findings from the Study were highly valuable in providing researchers and the Agency the tools and evidence to consider when developing national surveillance of neurological conditions in Canada.

3.6   Key themes

In this chapter, various data sources were explored for their utility and suitability in examining the epidemiology of neurological conditions in Canada. It was noted that:

- The Study has produced many new estimates of the prevalence and incidence of neurological conditions in Canada which were not previously available. For many neurological conditions, estimates derived from administrative data, self-report survey, and EMRs conform to estimates based on meta-analyses of international studies. However, primarily for technical reasons, additional studies will be necessary to obtain reliable prevalence estimates for ALS, muscular dystrophy, spinal cord injury, and traumatic brain injury in Canada.

- When the estimates of prevalence and incidence from different sources differ significantly, they need to be interpreted with caution and the differences must be carefully balanced and critically appraised.

- Estimates of prevalence and incidence compiled periodically and systematically from health administrative data can be used to trace the course of neurological conditions over time, as well as across provinces and territories.

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[47] For example, the CCHS covers the population age 12 years and older living in private dwellings in the ten provinces and the three territories, but does not include individuals living on reserves and other Aboriginal settlements in the provinces, full-time members of the Canadian Forces, the institutionalized population, and individuals living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James. The CCHS covers 90% of private households in the Yukon, 97% in the Northwest Territories, and 92% in Nunavut. All together, these exclusions represent less than 3% of the target population. In addition to these exclusions, the SLNCC did not include residents of the territories. The Aboriginal Peoples Survey, also managed by Statistics Canada, aims at identifying the needs of First Nations individuals living off reserve, Métis, and Inuit, and focuses on social and health issues. The First Nations Regional Health Survey, managed by the First Nations Information Governance Centre, collects health and well-being information from on reserve and northern First Nations individuals. However, currently neither survey collects information on neurological conditions.

- The expansion of the evolving surveillance system for neurological conditions in Canada has been enhanced by the determination of the best sources of epidemiological data for certain neurological conditions and by the validation of algorithms for use with administrative data.

- Detailed guidelines and a toolkit for the development and maintenance of registries that can contribute to the surveillance of neurological conditions are now available.

- Neurological conditions are the primary diagnoses of more than half of Canadians in continuing care (home care programs and long-term care facilities). Therefore, to determine the prevalence of severely debilitating neurological conditions in Canada, data from both the community and long-term care facilities are necessary to obtain a more comprehensive picture.

Microsimulation modelling of seven neurological conditions projects that by 2031:

- Traumatic brain injury, Alzheimer's disease and other dementias, and epilepsy will continue to be the most prevalent of the modelled conditions.

- In a population age 65 years and older, the number of Canadians living with each of the modelled neurological conditions will more than double.

- The number of new cases of cerebral palsy, epilepsy, multiple sclerosis, and spinal cord injury will rise with the growth of the population.

- The number of Canadians receiving a new diagnosis of Alzheimer's disease and other dementias or Parkinson's disease/parkinsonism will close to double.

- The number of Canadians hospitalized with a brain injury will increase by 28%.

4. RISK FACTORS FOR NEUROLOGICAL CONDITIONS

Given the spectrum of impacts caused by neurological conditions on individuals (Chapter 1), the extent and costs of their care needs (Chapter 2), as well as the number of Canadians potentially affected by these conditions (Chapter 3), the prevention and early detection of neurological conditions are important strategies for alleviating their burden at the individual, community, and health care levels. Two projects of the Study were devoted to identifying and outlining the biological, lifestyle, socioeconomic, environmental, psychosocial, and genetic factors that are potentially associated with the development and progression of 14 neurological conditions [13][14]. The project teams reviewed several thousand articles, applied predetermined criteria to select systematic reviews, meta-analyses, and observational studies, and analyzed them using a process of qualitative synthesis.

Risk factors for disease progression were exceedingly difficult to identify [14], as it was often impossible to disentangle risk factors for onset from determinants of progression or rate of progression. To do so would require repeated observations over time, beginning with or before the earliest manifestations of the condition and continuing until its advanced stages, and for some conditions, even after the death of the individual.

4.1 Potential modifiable risk factors for the onset of neurological conditions are being identified

Associations identified by the Onset Risk Factors Project [13] that could be modified by available interventions were particularly relevant, as they offer the potential for the prevention or mitigation of neurological conditions. For example, the synthesis of the literature confirmed that some cardiovascular risk factors, such as smoking and diabetes, are not only associated with the development of stroke but also with Alzheimer's disease and other dementias. Brain injury, a neurological condition in itself, was also identified as a risk factor for Alzheimer's disease and other dementias in men, and for epilepsy in both sexes. In turn, addressing falls in the aging population would help reduce risks associated with the development of traumatic brain and spinal cord injuries. The synthesis of the literature performed by this project team also corroborated that environmental risk factors, such as vitamin D deficiency, were associated with multiple sclerosis and that exposure to pesticides was associated with Alzheimer's disease and other dementias, ALS, brain tumours, and Parkinson's disease. It was further noted that complications of pregnancy and delivery were associated with several neurological conditions in children.

Identifying potential factors in the prevention of neurological conditions is encouraging, but when reviewing these results, it is important to understand that the presence of a factor associated with a condition does not necessarily imply that it is the cause of the condition, and conversely, its absence would not guarantee that an individual would not develop the condition. Furthermore, some of the associations identified by this project may only occur in a small percentage of the cases of a specific neurological condition, or may only apply to specific populations. These findings may be useful to future researchers seeking to determine population attributable risks. The Onset Risk Factors Project [13] research team recognized the need to assess both the clinical and public health significance of these risk factors; that is, if a risk factor is only associated with a small proportion of cases of a rare neurological condition, the impact of an intervention would be smaller from a public health perspective than if the risk factor is associated with a large proportion of cases of a common neurological condition. The Onset Risk Factors Project [13] team is currently applying these considerations to their project.[48]

The existing information on risk factors will eventually be expanded by other projects of the Study. For instance, the Canadian Longitudinal Study on Aging: Neurological Conditions Initiative (CLSA-NCI) Project [5] aims to incorporate in its study a long-term assessment of risk and predictive lifestyle factors for epilepsy, dementia, Parkinson's disease, and brain injury. In addition, existing data sources, such as those of the EMR and interRAI Projects [6][8], could be developed further to yield additional insights into the lifestyle, socioeconomic, and environmental factors that constitute risks for specific neurological conditions. Eventual incorporation of risk factor dynamics into the seven microsimulation models would improve the precision of model projections and would allow for the evaluation of various outcomes obtained using different interventions [10]. Finally, expanding existing disease or patient registries, which was an objective of the Cerebral Palsy Registry Project [4], will improve study power in the identification of risk factors for low prevalence neurological conditions. This information may eventually assist Canadians in the reduction of their risk at the individual level, and may lead to strategies for the prevention and early detection of neurological conditions.

4.2 Genetic factors for the onset of neurological conditions are being identified

Certain neurological conditions targeted by the Study are caused by mutations of single genes that can be identified by highly predictive genetic tests. In conditions such as dystonia, Huntington's disease, and muscular dystrophy, the recognition of such genes as risk factors has considerable prognostic value. Certain autosomal dominant forms of Alzheimer's disease can be caused by mutations of the genes for amyloid precursor protein, presenilin 1 (PSEN1), or presenilin 2 (PSEN2). Moreover, approximately 10% of Parkinson's disease cases are attributable to mutations of single genes, either dominant (SNCA, LRRK2) or autosomal

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[48] Please visit the NHCC (www.mybrainmatters.ca) and the Agency (www.phac-aspc.gc.ca) websites, or contact the Project Investigator (see Appendix 1) for more information about results stemming from the risk factor projects.

recessive (Parkin, PINK1, DJ-1). Familial ALS makes up 5% of all ALS patients.[49] A mutation in SOD1 (Cu/Zn superoxide dismutase) was found in 20% of familial ALS cases; other mutations (e.g. FUS, TARDBP and C9ORF72) were also identified.[50]

Other neurological conditions result from the interplay of one or more susceptibility genes and toxic or environmental factors (that are often unidentified). Examples include sporadic Alzheimer's disease (APOE e4 allele and other genes), ALS (ATAXIN-2 and others), epilepsy (genes for voltage-gated or ligand-gated ion channels),[51] multiple sclerosis (HLA-DRB1*1501 allele and unidentified genes suspected on the basis of familial studies), and Parkinson's disease (at least 19 identified susceptibility genes).[52] Because of the lack of accuracy (due to inadequate sensitivity and/or specificity), susceptibility gene testing is currently not recommended in these cases to assess the risk of developing neurological conditions. However, susceptibility genes are of great interest because some may provide insights into the mechanisms that lead to these complex disorders.

4.3   Knowledge gaps

Clear and comprehensive evidence on risk factors for the onset and progression of neurological conditions are not yet available. In general, data on risk factors for neurological conditions are lacking or deficient regarding:

- The 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; and

- 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.

Steps have been taken to improve the availability of data and information on risk factors for neurological conditions in the future.

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4.4   Key themes

Regarding this component of the Study, which provided preliminary findings on risk factors for certain neurological conditions, it was noted that:

- The statistical analysis of risk factors for the onset of neurological conditions is a step in the process of identifying associations that are potentially amenable to prevention.

- Risk factors for disease progression require detailed and expensive longitudinal studies of 'at risk' and affected individuals throughout the course of the conditions, from their earliest to most advanced stages.

- There are substantial methodological challenges involved in the identification of risk factors related to disease causality. Such challenges include difficulty in demonstrating temporal relationships and in proving biological plausibility. In many instances, the appropriate studies have yet to be conducted.

- There is a complex interplay among genetic, epigenetic, and environmental factors that needs to be recognized when assessing risks for individuals and their family members.

IN CONCLUSION

This Study supported the collaboration of experts, researchers, health professionals, and stakeholders in the shared objective of a better understanding of the burden of neurological conditions in Canada. As a result, considerable data and information were produced that speak to the diverse impacts that neurological conditions have on Canadians living with these conditions, as well as on their families, communities, and the health care system. It was found that some Canadians diagnosed with a condition affecting their brain, spinal cord, or peripheral nervous system were able to manage their condition and were living in the community with or without support. Others had a neurological condition that was so disabling that they required continuing care or lived in a long-term care facility. Despite the range of impacts caused by these neurological conditions, many commonalities were also found, highlighting the validity of examining such a breadth of conditions under one Study.

> **The Study is a wonderful step forward – a multilayered initiative to gain a better understanding for the future of patients and the health care system.**
>
> *– Individual living with a neurological condition*

Understanding the impacts of these neurological conditions on Canadians in turn supported an understanding of the often extensive and complex health needs of those affected. The Study pointed to important gaps in the access to, and provision of, appropriate care for those living with a neurological condition, particularly for those with the most disabling conditions. Encouragingly, the Study also identified better ways to meet and manage these health needs.

It was recognized that an improved appreciation of the overall scope of neurological conditions in Canada was necessary to better meet the needs of those living with these conditions. Study projects used a variety of epidemiological methods to produce new estimates of the prevalence and incidence of neurological conditions among Canadians. Some data sources were better equipped to identify certain neurological conditions than others. These findings have provided substantial evidence to support the future direction of national surveillance of neurological conditions in Canada.

In addition, specific projects of the Study gathered evidence on factors associated with the onset of neurological conditions. As work continues to strengthen this evidence base, Canadians will benefit from these insights on how to support their neurological health.

This Study of neurological conditions was the largest of its kind ever to be undertaken in Canada and was successful in many respects. However, certain limitations should be noted. A decision was made at the onset of the Study to focus on the 14 neurological conditions that were most prevalent in Canada. Even so, due to small sample sizes in some projects,

insufficient reportable data were obtained pertaining to the impacts or extent of the less common neurological conditions such as ALS or Huntington's disease. Also, not all the data and information obtained from the Study projects were pan-Canadian, resulting in the need for caution when trying to extrapolate these findings to Canada as a whole or to other provinces and territories. Gaps were identified in each chapter that emphasized issues that were either faced by Study projects or identified during the consolidation of Study findings. In addition to these gaps, this Study was not able to address all topics of importance to those living with or affected by a neurological condition, such as sexual health or end of life care. Future studies may be able to address these and other limitations identified by the Study.

This report endeavoured to tell the story of Canadians living with a neurological condition – its range of impacts, gaps and successes in health service provision, the scope of the burden at a national level, and potential targets for prevention at the individual and population levels. This report, however, only highlights a few key findings distilled from the depth of information amassed during the administration of the Study, and serves as a small window into the bigger world explored in this process. For more information on the findings from the Study, its 13 projects, three national surveys, seven microsimulation models, or the hundreds of researchers, committee members, and other individuals involved, we encourage you to visit the NHCC (www.mybrainmatters.ca) and Agency (www.phac-aspc.gc.ca/cd-mc/nc-mn/ns-en-eng.php) websites.

Sincere appreciation and admiration is owed to all who played a role in this Study. Those who have eagerly waited for this information are to be thanked for their patience and support. Although this report signals an end to the Study itself, it will continue to catalyze new and important work, including further publications based on findings from Study projects, the establishment of ongoing surveillance at the national level, and the development of registries, protocols, and toolkits. The Study also helped to increase general awareness of neurological conditions among public health care program and policy makers. This work has provided, and will continue to provide, evidence for those seeking to address neurological conditions in Canada.

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APPENDIX 1 – Components of the National Population Health Study of Neurological Conditions

Each project and survey in this report may be mentioned by its reference number or short title. Table A-1 (below) indicates which neurological conditions and focus areas were explored by each project and survey, while their main objectives are highlighted in the list that follows. Brief descriptions, materials, and publications from these projects and surveys are also available on the NHCC (www.mybrainmatters.ca/en/national-population-health-study-neurological-conditions) and Agency (www.phac-aspc.gc.ca/cd-mc/nc-mn/fnd-fin-eng.php#fnd-fin-02) websites.

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[1]   Kim Reimer

Title:	Neurological Conditions in British Columbia
Short title:	BC Administrative Data Project
Project objectives:	(1) To provide population-level estimates of incidence, prevalence, comorbidity, mortality, health care service utilization, and health care costs for selected neurological conditions in British Columbia;
	(2) To perform an extensive review of the diagnostic codes used to identify neurological conditions over time, through the consideration of alternative case definitions and through the comparison of findings with other sources, including surveys and published data.

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[2]   Catherine Pelletier, Asako Bienek, Dr. Sulan Dai, Jay Onysko, and Chris Waters

Title:	Expansion of the Canadian Chronic Disease Surveillance System for National Surveillance of Neurological Conditions
Short title:	CCDSS Expansion Project
Project objectives:	(1) Among the 15 neurological conditions assessed, to determine which conditions can be appropriately tracked at the national level using health administrative databases;
	(2) To develop case definitions for Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, parkinsonism, and stroke to track national prevalence and incidence, and eventually all-cause mortality, comorbidities, and use of health care services among Canadians living with these conditions.
Online resources:	www.phac-aspc.gc.ca/surveillance-eng.php

[3] Claudia Lagacé, Asako Bienek, Catherine Pelletier, Ming-Dong Wang, Dr. Sulan Dai, Dr. Christina Bancej, Dr. Catherine Dickson, and Jay Onysko

Title:	Findings from the Canadian Community Health Survey (2010–2011)
Short title:	CCHS 2010–2011 Project
Project objectives:	(1) To provide community-based prevalence estimates for neurological conditions by age and sex;
	(2) To examine the prevalence of neurological conditions by selected sociodemographic variables.
Online resources:	Annual Component (CCHS) 2010 and 2011

www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SurvId=50653&InstaId=81424&SDDS=3226

www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SurvId=50653&InstaId=114112&SDDS=3226

Chronic Disease Infobase data cubes
www.infobase.phac-aspc.gc.ca

[4] Dr. Michael Shevell and Dr. Maryam Oskoui

Title:	Expansion of a Canadian Multi-Regional Population-Based Cerebral Palsy Registry
Short title:	Cerebral Palsy Registry Project
Project objectives:	(1) To extend the existing cerebral palsy registry to additional regions and provinces, specifically Southern Alberta, British Columbia, Nova Scotia, and Newfoundland and Labrador;
	(2) To identify risk factors associated with cerebral palsy;
	(3) To acquire additional information on health service delivery to young children with cerebral palsy in order to identify any potential service gaps and regional disparities.
Online resources:	www.mabmackay.ca/modules/pages/index.php?id=115&langue=en&menu=7&sousmenu=64

[5] Dr. Christina Wolfson and Dr. Parminder Raina

Title:	Canadian Longitudinal Study on Aging: Neurological Conditions Initiative (CLSA-NCI)
Short title:	CLSA-NCI Project
Project objectives:	(1) To design a comprehensive assessment of four neurological conditions (Alzheimer's disease and other dementias, brain injury, epilepsy, Parkinson's disease) within the CLSA to estimate the prevalence and incidence of these conditions;
	(2) To assess the impact of the four neurological conditions on health, the social care system and families using both individual level data and linkage with administrative databases;
	(3) To develop CLSA sub-studies to examine the risk and prognostic factors of the targeted neurological conditions and conduct a subset of these studies within the timeframe of the Study.
Online resources:	www.clsa-elcv.ca

[6]   Dr. Neil Drummond and Dr. Richard Birtwhistle

Title:	Canadian Primary Care Sentinel Surveillance Network – Neurodegenerative Conditions
Short title:	EMR Project
Project objectives:	(1) To develop an efficient, effective, dynamic, valid, longitudinal chronic disease database that is relevant at local, regional, provincial and national levels, with particular reference to three neurological conditions (Alzheimer's disease and other dementias, epilepsy, parkinsonism);
	(2) To study the epidemiology of Alzheimer's disease and other dementias, epilepsy and parkinsonism in Canada;
	(3) To study the clinical care of people with Alzheimer's disease and other dementias, epilepsy, and parkinsonism in primary care settings.
Online resources:	www.rcsssp.ca/

[7]   Dr. Susan Jaglal

Title:	Use and Gaps in Health and Community-Based Services for Neurological Populations: A Systems Analysis
Short title:	Health Services Project
Project objectives:	(1) To identify health and community-based service needs and gaps and exemplary programs in the peer-reviewed and grey literature for individuals living with neurological conditions;
	(2) To explore from the perspective of service providers, the health and community-based service needs and gaps in the Canadian context taking into account different geographic regions (Atlantic Canada, Quebec, Ontario, Western Canada, Northern Canada), urban and rural, and community and institutional settings;
	(3) To describe the availability, access, use, coordination and integration of health and community services and perceived needs and gaps among service providers across the continuum of care and across the lifespan, by the variables listed above;
	(4) To identify opportunities and successes that can be leveraged across the regions and nationally to formulate key recommendations to help governments and stakeholders better plan programs and health services.

[8] Dr. John Hirdes, Dr. Colleen Maxwell, and Dr. Nathalie Jetté

Title:	Innovations in Data, Evidence and Applications for Persons with Neurological Conditions (ideas PNC)
Short title:	interRAI Project
Project objectives:	(1) To estimate the prevalence of 10 neurological conditions across the continuum of care in at least four Canadian provinces;
	(2) To examine the costs of care associated with neurological conditions including both formal and informal sources;
	(3) To examine the experience of informal caregivers providing support, including the extent and type of care provided, to different populations with neurological conditions in different care settings;
	(4) To develop a detailed clinical profile of persons with at least one of the 10 targeted neurological conditions in different care settings;
	(5) To evaluate the applicability of current planning approaches used in various service settings to persons with neurological conditions and provide recommendations on how to improve care planning protocols to meet current best practices identified in the neurological literature;
	(6) To examine access to, and utilization of, health and social services by persons with neurological conditions to identify service gaps where the needs of this population may not be met;
	(7) To identify approaches for performance measurement for organizations serving persons with neurological conditions.
Online resources:	www.interraicanada.uwaterloo.ca/iPNC/

[9] Dr. Joan Versnel and Dr. Tanya Packer

Title:	The Everyday Experience of Living with and Managing a Neurological Condition (LINC)
Short title:	LINC Project
Project objectives:	(1) To describe the impact of neurological conditions on the everyday life experiences of individuals, families, caregivers and communities;
	(2) To examine the complex inter-dependence between adults with a neurological condition and their families;
	(3) To describe the ability of health, social and community services and agencies in supporting individuals and families to self-manage life with a neurological condition.
Online resources:	www.ccmrg.ca/linc/

[10] Dr. Christina Bancej, Dr. Rochelle Garner, Dr. Philippe Fines, Dr. Douglas Manuel, Anna J. Zycki, Dr. Ronald Wall, Trang Nguyen, and Julie Bernier

Title:	National Population Health Study of Neurological Conditions Microsimulation Component: Health and Economic Modelling of Neurological Conditions
Short title:	Microsimulation Project
Project objectives:	(1) To build microsimulation models of seven groups of neurological conditions and injuries (Alzheimer's disease and other dementias, cerebral palsy, epilepsy, multiple sclerosis, Parkinson's disease/parkinsonism, hospitalized traumatic brain injury, hospitalized traumatic spinal cord injury), expanding on the Statistics Canada Population Health Model (POHEM) platform and to apply these models to project the future burden, both in terms of dollars and impact on health, of key neurological conditions over the next five, 10, 15, and 20 years under status quo assumptions.
Online resources:	www.statcan.gc.ca/microsimulation/health-sante/health-sante-eng.htm

[11] Dr. Carrie Bourassa

Title:	Understanding from Within: Developing Community-Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal People (Native Women's Association of Canada)
Short title:	NWAC Project
Project objectives:	(1) To improve the understanding of how Aboriginal Canadians conceptualize neurological conditions and the impact on their families and communities;
	(2) To determine risk and protective factors for neurological conditions among the participants of this study;
	(3) To assess the needed resources and supports to provide culturally appropriate care.
Online resources:	www.nwac.ca/research/neurological-conditions

[12] Dr. Karen Tu, Dr. Liisa Jaakkimainen, and Dr. Debra Butt

Title:	Validation of Administrative Data Algorithms to Determine Population Prevalence and Incidence of Alzheimer's Disease and Other Dementias, Multiple Sclerosis, Epilepsy and Parkinson's Disease (Parkinsonism)
Short title:	ON Administrative Data Validation Project
Project objectives:	(1) To perform an administrative data validation using coding algorithms based on case ascertainment for epilepsy, multiple sclerosis, Alzheimer's disease and other dementias and Parkinson's disease.[53] Validated administrative data algorithms for each of these conditions will provide new opportunities to examine their prevalence and incidence among patients.
Online resources:	www.ices.on.ca/Research/Research-programs/Primary-Care-and-Population-Health/EMRALD.aspx

[13] Dr. Daniel Krewski

Title:	Systematic Review of Factors Influencing the Onset of Neurological Conditions
Short title:	Onset Risk Factors Project
Project objectives:	(1) To conduct a comprehensive, systematic literature review for the development of each of the priority neurological conditions with respect to a wide range of risk factors, including biological, lifestyle, socioeconomic, environmental, and psychosocial factors, and comorbidity (such as stroke or mental illness) and possible mechanisms of action;
	(2) To assess and summarize the available evidence on the determinants of neurological conditions, and describe the strengths and weaknesses of the current scientific literature.

[14] Dr. Daniel Krewski

Title:	Systematic Review of Factors Influencing the Progression of Neurological Conditions
Short title:	Progression Risk Factors Project
Project objectives:	(1) To conduct a comprehensive, systematic literature review for the progression of each of the priority neurological conditions with respect to a wide range of risk factors, including biological, lifestyle, socioeconomic, environmental, and psychosocial factors, and comorbidity (such as stroke or mental illness) and possible mechanisms of action;
	(2) To assess and summarize the available evidence on the determinants of neurological conditions, and describe the strengths and weaknesses of the current scientific literature.

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[53] Because of limitations in physician billing data, administrative data validation was adjusted to identify patients with dementia overall and parkinsonism, rather than Alzheimer's disease and Parkinson's disease.

[15] Dr. Lawrence Korngut, Dr. Nathalie Jetté, and Dr. Tamara Pringsheim

Title:	Neurological Registry Best Practice Guidelines and Implementation Toolkit
Short title:	**Registry Guidelines Project**
Project objectives:	(1) To create comprehensive guidelines through consensus building for the development and implementation of registries of neurological conditions in Canada;
	(2) To create a toolkit for the development and implementation of neurological condition registries in Canada.
Online resources:	www.canadianregistrynetwork.org/

[16] Claudia Lagacé, Asako Bienek, Catherine Pelletier, Ming-Dong Wang, Dr. Sulan Dai, Dr. Christina Bancej, Dr. Catherine Dickson, and Jay Onysko

Title:	Survey on Living with Neurological Conditions in Canada (2011–2012)
Short title:	**SLNCC 2011–2012 Project**
Project objectives:	(1) To describe the characteristics of individuals with a neurological condition;
	(2) To describe the general physical and mental well-being of Canadians with a neurological condition;
	(3) To describe comorbid chronic conditions among Canadians living with a neurological condition;
	(4) To describe the impact of neurological conditions on quality of life.
Online resources:	www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5182

[17] Claudia Lagacé, Asako Bienek, Catherine Pelletier, Ming-Dong Wang, Dr. Sulan Dai, Dr. Christina Bancej, Dr. Catherine Dickson, and Jay Onysko

Title:	Survey of Neurological Conditions in Institutions in Canada (2011–2012)
Short title:	**SNCIC 2011–2012 Project**
Project objectives:	(1) To provide prevalence estimates of neurological conditions in long-term care facilities.
Online resources:	www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5187

[18] Dr. Nathalie Jetté and Dr. Tamara Pringsheim

Title:	Understanding the Epidemiology of Neurological Conditions and Building the Methodological Foundation for Surveillance
Short title:	**Systematic Reviews Project**
Project objectives:	(1) To perform systematic reviews of the incidence and prevalence of all priority neurological conditions identified by the Agency;
	(2) To summarize and make recommendations on the best ascertainment sources for surveillance for each of the neurological conditions of interest;
	(3) To develop an inventory of existing neurological registries in Canada and other developed countries.

TABLE A-1: Neurological conditions and focus areas considered by each project and survey of the National Population Health Study of Neurological Conditions

	PROJECT AND SURVEY NUMBER																	
	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[11]	[12]	[13]	[14]	[15]	[16]	[17]	[18]
NEUROLOGICAL CONDITIONS																		
All conditions (no differentiation)	•						•		•	•	•				•	•	•	•
Alzheimer's disease and other dementias	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•
Amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease)	•	•	•					•	•	•		•	•	•		•	•	•
Brain injury (traumatic)	•	•	•			•		•		•		•	•	•		•	•	•
Brain tumour	•	•	•					•				•	•	•		•	•	•
Cerebral palsy	•	•	•	•				•		•		•	•	•		•	•	•
Dystonia	•	•	•									•	•			•	•	•
Epilepsy	•	•	•		•	•		•		•		•	•	•		•	•	•
Huntington's disease	•	•	•			•		•				•	•	•		•	•	•
Hydrocephalus	•	•	•									•	•	•		•	•	•
Migraine	•	•	•												•	•	•	•
Multiple sclerosis	•	•	•					•		•		•	•	•		•	•	•
Muscular dystrophy	•	•	•					•				•	•	•		•	•	•
Parkinson's disease	•	•	•		•	•		•		•		•	•	•		•	•	•
Spina bifida	•	•	•										•	•		•	•	•
Spinal cord injury (traumatic)	•	•						•		•					•	•	•	•
Spinal cord tumour			•													•	•	
Stroke		•	•											•		•	•	•
Tourette syndrome		•	•										•	•		•		•
FOCUS AREAS																		
Impacts	•	•								•	•				•			
Health services	•	•		•				•	•	•	•							
Scope	•	•	•	•	•	•		•	•	•		•		•		•		•
Risk factors				•							•		•	•				

APPENDIX 2 – Glossary

Algorithm:
A step-by-step procedure for calculations based on a determined set of operations and rules (see Case definition).

Alternate level of care:
Care provided in an acute care hospital for patients deemed well enough by their care team to be cared for elsewhere. Patients receiving this level of care are usually awaiting transfer to a long-term care facility or some other form of supported living.

Alzheimer's disease and other dementias:
Alzheimer's disease is a degenerative disease of the brain with characteristic pathological features and is the most common form of dementia. Dementia is a syndrome characterized by loss of memory, the ability to think, as well as changes in mood, behaviour and ability to communicate. Other common types of dementia include vascular dementia, frontotemporal dementia, or Lewy body dementia, each with distinct clinical and pathological features. In this report, the term 'other dementias' includes these forms as well as instances of dementia not classified by type.

Amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease):
A disease that causes progressive muscle weakness and paralysis due to the degeneration of the upper and lower motor neurons in the brain and spinal cord.

Anterior horn cell disease:
A classification of diseases associated with the anterior horn cells located in the spinal cord. Includes ALS.

Brain injury (traumatic):
An injury of the brain due to trauma (most often caused by vehicle crashes, falls, or sports activities) that can result in effects that range from mild and transient symptoms of concussion to profound and permanent impairments of neurological function.

Brain tumour:
Classified either as primary (if it arises from cells within or surrounding the brain) or secondary (if due to metastasis originating from tumours in other parts of the body). Primary brain tumours can be benign or malignant. Depending on their location and size, brain tumours can cause a variety of neurological problems including seizures, headaches, or focal neurological symptoms and signs such as weakness, clumsiness, and impaired vision, sensation, or speech.

Caregivers (informal and formal):
As used throughout the Study and its projects, informal care refers to care provided by family, friends, and neighbours, while formal care refers to health care workers.

Case definition:
In a health surveillance context, the criteria that must be met by an individual to be identified as having a specific condition. More complex case definitions usually include an algorithm that specifies, for example, how many codes, from what data source, and within what time period are required to meet the case definition (e.g. one hospital admission or three or more physician codes for a particular condition during a two-year period).

Cerebral palsy:

A non-progressive but not unchanging disorder that affects the ability to move or maintain balance and posture that is caused by an insult to, or an anomaly of, the developing brain.

Comorbidity:

Traditionally referred to as diseases, disorders, or conditions that occurred at the same time as another disorder but were not related to it causally or as a complication. As understanding of the biology of specific diseases has advanced, the meaning of some associations has changed. For example, mood disorders, once considered a comorbidity of Parkinson's disease (as well as several other neurological conditions), are now interpreted as a possible early manifestation of this condition.[54,55] In this report, the term is used in both its traditional sense (e.g. the SLNCC 2011–2012 Project [16]) as well as more broadly as 'other diagnoses' recorded in databases along with targeted neurological conditions (e.g. the BC Administrative Data Project [1]).

Confidence interval:

A statistical measurement of the reliability of an estimate. Narrow confidence intervals indicate greater reliability than those that are wide. The 95% confidence intervals indicate the ranges of values that are likely to include the true value 19 times out of 20.

Continuing care:

Health, social, and support services, which may include respite and palliative care, offered on a prolonged basis through home care programs or in long-term care facilities such as nursing homes.

Direct costs:

Monetary valuation of resources associated with health care paid for by public or private health insurance or by individuals and their families.

Dystonia:

A movement disorder that causes muscles to contract involuntarily, forcing all or part of the body into repetitive, often twisting movements. Dystonia may be generalized (affecting multiple muscle groups) or focal (affecting only a single body area).

Electronic medical record:

A digital version of a paper chart containing the complete patient's medical history from one practice, mostly used by health care providers for diagnosis and treatment.[56]

Epilepsy:

A neurological disorder in which sudden bursts of electrical activity in the brain produce 'seizures' that can vary in frequency and form as a brief stare, an unusual movement of the body, a change in awareness, or a generalized convulsion. Most seizures last a few seconds or a few minutes.

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54 Schuurman AG, Van den Akker M, Ensinck KT, Metsemakers JF, Knottnerus JA, Leentjens AF, et al. Increased risk of Parkinson's disease after depression: A retrospective cohort study. Neurology. 2002 May;58(10):1501-504.

55 Leentjens AF, Van den Akker M, Metsemakers JF, Lousberg R, Verhey FR. Higher incidence of depression preceding the onset of Parkinson's disease: A register study. Mov. Disord. 2003 Apr;18(4):414-18.

56 Office of the National Coordinator for Health Information Technology. What is an Electronic Medical Record (EMR)? [Internet]. Washington (DC): Office of the National Coordinator for Health Information Technology; [cited 2014 Mar 26]. Available from: www.healthit.gov/providers-professionals/electronic-medical-records-emr.

Episodic:
Condition or symptom that presents irregularly or on occasion and can be categorized as separate events.

Estimate:
An approximation of the true value of a characteristic of a population. As used in this report, estimates derived from a sample of the entire population currently represent the best available information.

Health administrative data:
Collections of information on the delivery of health care services. In Canada, health care databases of the provincial and territorial governments collect and store information relevant to the administration of universal medical care insurance. The main sources of health administrative data pertain to hospital services, physician billings, and prescription drugs. Depending on how data concerning specific health conditions are captured, they can also be used for surveillance purposes, such as estimating disease prevalence and incidence.

Health Utilities Index score:
A measure of health-related quality of life, the Health Utilities Index – Mark 3 (HUI-3) is comprised of eight attributes: cognition, mobility, dexterity, speech, vision, hearing, emotion, and pain and discomfort. HUI-3 scores fall between a minimum value of -0.36 (worse than dead), through to 0.0 (dead), to a maximum value of 1.0 (full health). Disability categories in this report were derived from the HUI-3, with scores lower than 0.7 representing 'severe disability'.

Huntington's disease:
An inherited disorder that causes cells in specific parts of the brain to degenerate. Symptoms include emotional turmoil (depression, apathy, obsessive behaviour), loss of mental function (inability to focus, think and recall, or make decisions), or physical deterioration (weight loss, involuntary movements, diminished coordination, inability to walk, talk, or swallow).

Hydrocephalus:
A neurological condition in which excess cerebrospinal fluid accumulates in the brain cavities (ventricles). Hydrocephalus can be congenital (due to abnormalities of the developing brain), acquired (due to complications of intracranial haemorrhage, meningitis, head injury, or brain tumour), or idiopathic (due to an unknown cause). Depending on several factors (age of onset, rapidity of development, and severity) hydrocephalus can damage brain structures and cause neurological symptoms, including cognitive impairment or gait disorder.

Incidence:
The number of new cases of a disease or condition occurring in a given time period in a population at risk. Incidence can be expressed as an incidence proportion (the number of new cases within a specified time period divided by the size of the population initially at risk) or an incidence rate (the number of new cases per population in a given time period, expressed as new cases per number of person-years).

Indirect costs:
Monetary valuation of economic production and productivity lost due to sickness, disability, or premature death.

International Classification of Diseases (ICD):
A health care classification system that assigns diagnostic codes to diseases. The tenth revision of the ICD, known as ICD-10 (ICD-10-CA in Canada), is currently used to code data on hospital separations (discharge, transfers, and death) in all provinces and territories of Canada. The ICD-9 is still used as the basis for physician billing codes in many Canadian provinces and territories.

Meta-analysis:
The statistical synthesis of data from several studies that address a similar question.

Microsimulation
To project the future trajectory of the population, microsimulation models mathematically simulate the life course of representative (synthetic) persons from their birth to their death through exposure to multiple risks to health, development and progression of chronic diseases, and impairment of health. The models project health and economic outcomes useful for planning and policy decision-making: incidence and prevalence, health-related quality of life, survival, cost of health care, production lost to working-age disability, and death.

Migraine:
A type of recurrent throbbing headache that is often associated with nausea and even vomiting, sensitivity to light and sound, and, in about a third of those affected, visual or sensory auras.

Multiple sclerosis:
An autoimmune disease characterized by disseminated patches of demyelination (called plaques) in the brain and spinal cord. Multiple sclerosis is unpredictable, affecting vision, hearing, speech, memory, balance, and mobility, often in a pattern of relapses and remissions.

Muscular dystrophy:
A group of genetically transmitted diseases characterized by progressive weakness and wasting of the muscles that control voluntary body movement. Different types of muscular dystrophy have distinct patterns of muscle involvement, age of onset, rate of progression, and type of inheritance. Even among individuals with a specific type of muscular dystrophy, symptoms and severity can be quite variable.

Parkinson's disease:
A neurodegenerative disease resulting from the progressive loss of brain cells that produce dopamine, a chemical that carries signals between nerves in the brain. The four main features are: rigidity or stiffness of the arms, legs, or neck; tremor (usually of the hands); bradykinesia (slowness and reduction of movement); and postural instability (loss of balance). The terms parkinsonism or parkinsonian syndrome are used to describe the motor features (rigidity, tremor, bradykinesia, or postural instability) whether they are due to Parkinson's disease, other brain diseases, or the side effects of certain medications.

Patient registry:
A systematic collection of data related to patients with a specific diagnosis or condition that serves a predetermined purpose. For example, patient registries can provide epidemiological data that help assess disease burden or evaluate therapeutic measures.

Prevalence:
The frequency of a disease or condition in a population, expressed as the proportion of the population that has the disease or condition. Prevalence provides a measure of the burden of the disease in the population.

Progressive:
Disease or condition that shows deterioration or worsening over time.

Qualitative synthesis:
Systematic but non-statistical analysis (as opposed to a meta-analysis) of results and findings from qualitative or quantitative studies identified through a systematic review of the literature.

Range (of data):
The difference between the largest and smallest value in a set of observations.

Relative risk and population attributable risk:
Relative risk is a measure of the contribution of a risk factor to the development of a disease. It is calculated as the ratio of disease incidence in those 'exposed' to the risk factor to the disease incidence among those 'not exposed' to the risk factor. The population attributable risk takes into account both the relative risk and the prevalence of the risk factor. This is important because a high relative risk may indicate that a factor is devastating when it occurs, yet its occurrence may be so infrequent that its broader impact on population health may be relatively minimal.

Rett syndrome:
A rare genetic developmental disorder of the brain that occurs almost exclusively in girls. Girls with Rett syndrome usually develop normally until six to 18 months of age, whereupon their development slows and there is a regression of communication skills, loss of hand dexterity, slowing of the normal rate of head growth, and the appearance of stereotyped hand movements and gait disturbances. Other problems may include seizures, disorganized breathing patterns, or excessive irritability.

Risks and risk factors:
Risk is the chance that an event will occur, and is usually expressed as a proportion or frequency with a value between 0 (no risk) and 1 (definite risk). As used in relation to health and disease, a risk factor is a variable (e.g. a behaviour, condition, or exposure) that affects the risk of disease occurrence.

Spina bifida:
A spectrum of developmental disorders in which there is a defective closure of the neural tube during the first four weeks of pregnancy. This neural tube defect results in varying degrees of paralysis of the lower limbs and impairment of bladder or bowel function.

Spinal cord injury:
Damage to any part of the spinal cord. Depending on the level of the spinal cord that is injured and the severity of the lesion, the arms and legs (quadriplegia) or legs (paraplegia) may be affected by weakness, paralysis, or loss of sensation. Bladder, bowel and sexual function are often affected as well. Spinal cord injuries are most frequently caused by vehicular crashes, falls, or sport/recreational activities.

Static:

Disease or condition that remains stable or shows little change.

Stroke:

A sudden loss of brain function caused by an interruption of the flow of blood to the brain (ischemic stroke) or the rupture of blood vessels in the brain (haemorrhagic stroke). The effects of a stroke depend on where the brain was injured, as well as how much damage occurred. A stroke can result in one-sided arm and leg weakness, known as hemiplegia, or can cause other impairments of movement, coordination, vision, speech, memory, or in the capacity to think.

Surveillance:

As used in public health, surveillance is the ongoing systematic collection, analysis, and interpretation of data on population health that is used to plan, implement, and evaluate public health practice.[57]

Systematic review:

A critical assessment and evaluation of a set of research studies that address a particular clinical issue. A systematic review may also include a quantitative pooling of data, called a meta-analysis.[58]

Tourette syndrome:

A neurological disorder characterized by tics, which are involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. The onset of symptoms is usually before the age of 18 years, with the appearance of facial tics (rapid eye blinking or mouth twitches), involuntary sounds (such as throat clearing and sniffing), or tics of the limbs. Symptoms often lessen in early adulthood.

[57] WHO: Health Topics: Public Health Surveillance [Internet]. Geneva (CH): World Health Organization; 2014 [cited 2014 Jan 22]. Available from: www.who.int/topics/public_health_surveillance/en/.

[58] AHRQ: Glossary of terms [Internet]. Rockville (MD): Agency of Healthcare Research and Quality, U.S. Department of Health and Human Services, [cited 2013 Sep 24]. Available from: www.effectivehealthcare.ahrq.gov/index.cfm/glossary-of-terms/?termid=70&pageaction=showterm.

APPENDIX 3 – Acronyms

ALC	Alternate level of care
ALS	Amyotrophic lateral sclerosis
BC	British Columbia
CBANHC	Canadian Brain and Nerve Health Coalition
CCDSS	Canadian Chronic Disease Surveillance System
CCHS	Canadian Community Health Survey
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes of Health Research
CLSA	Canadian Longitudinal Study on Aging
CLSA-NCI	Canadian Longitudinal Study on Aging: Neurological Conditions Initiative
CNSF	Canadian Neurological Sciences Federation
EMR	Electronic medical record
CPCSSN	Canadian Primary Care Sentinel Surveillance Network
HUI-3	Health Utilities Index – Mark 3
ICD	International Classification of Diseases
LINC	The Everyday Experience of Living with and Managing a Neurological Condition
MAPLe	Method for Assigning Priority Level
NHCC	Neurological Health Charities Canada
NWAC	Native Women's Association of Canada
ON	Ontario
POHEM	Population Health Model
SLNCC	Survey on Living with Neurological Conditions in Canada
SNCIC	Survey of Neurological Conditions in Institutions in Canada
WHO	World Health Organization

APPENDIX 4 – National Population Health Study of Neurological Conditions: Implementation Committee

1. Celina Rayonne Chavannes, MBA
   Director, Research Initiatives,
   Neurological Health Charities Canada
   Co-chair, Implementation Committee

2. Sulan Dai, MD, PhD
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   Agency of Canada

3. Frances Gardiner, RN
   Program Officer, Chronic Disease
   Surveillance Division, Public Health
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4. Nathalie Gendron, PhD
   Assistant Director, Institute of
   Neurosciences, Mental Health
   and Addiction, Canadian Institutes
   of Health Research

5. Joyce Gordon
   President and *Chief Executive Officer*,
   Parkinson Society Canada
   Chair, Neurological Health
   Charities Canada

6. Deanna Groetzinger, MA
   Vice-President, Government Relations
   and Policy, Multiple Sclerosis Society
   of Canada

7. Deanna Huggett, MSc
   Senior Policy Analyst, Continuing Care
   Unit, Health Canada

8. Susan Latter, MRT(R), MSCS
   Stakeholder Representative

9. Suzanne Nurse, PhD
   Volunteer, Canadian Epilepsy Alliance

10. Jay Onysko, MA
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    Agency of Canada
    Co-Chair, Implementation Committee

11. Nalini Sen, MA
    Director, Research Program, Alzheimer
    Society of Canada

12. David Taylor, PhD
    Director of Research, ALS Canada

13. Stacey Thompson, BSc
    Project Coordinator, Neurological Health
    Charities Canada
    Secretariat, Implementation Committee

APPENDIX 5 – National Population Health Study of Neurological Conditions: Scientific Advisory Committee

1. Garth M. Bray, MD
   Professor Emeritus, Departments of Medicine and of Neurology and Neurosurgery, McGill University
   Expertise: Clinical neurology, laboratory investigation of neuronal responses to injury
   Chair, Scientific Advisory Committee

2. Celina Rayonne Chavannes, MBA
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3. Katharina (Kathy) Kovacs Burns, PhD
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4. Ian McDowell, PhD
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5. Thomas J. Murray, MD
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6. Scott B. Patten, MD, PhD
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7. Louise Pelletier, MD, MPH, FRCPC
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8. Peter Rosenbaum, MD, FRCPC
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   Canada Research Chair, Childhood Disability
   Co-founder, CanChild Centre for Childhood Disability Research
   Expertise: Childhood disability

9. Christopher A. Shaw, PhD
   Professor, Department of Ophthalmology and Visual Sciences, University of British Columbia
   Expertise: Genetic and environmental risk factors for neurological conditions

APPENDIX 6 – National Population Health Study of Neurological Conditions: Synthesis Panel

1. Garth M. Bray, MD
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3. Lesley K. Fellows, MD, DPhil
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4. Ian D. Graham, PhD
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   Senior Scientist, Centre for Practice-Changing Research, Ottawa Hospital Research Institute
   Expertise: Clinical epidemiology

5. Colleen Harris, RN, MN
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6. Carley Hay, MHSc
   Senior Specialist, Chronic Disease Management and Prevention Unit, Ontario Ministry of Health and Long-Term Care
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7. David Hogan, MD
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8. Katharina (Kathy) Kovacs Burns, PhD
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15. Christopher A. Shaw, PhD
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factors for neurological conditions

16. Jonathan Stoessl, MD
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Expertise: Parkinson's disease

17. Robyn Tamblyn, PhD
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Occupational Health, McGill University
Scientific Director, Clinical and
Health Informatics Research Group,
McGill University
Scientific Director, Institute of Health
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determinants of prescription drug use,
interventions to improve drug safety

18. Charles Tator, MD, PhD
Professor of Neurosurgery, University
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Founding Director, ThinkFirst Canada
Expertise: Brain and spinal cord injuries,
laboratory investigation of spinal
cord injury

19. Terry Lynn Young, PhD
Associate Professor, Discipline of Genetics,
Memorial University of Newfoundland
Expertise: Genetics of hearing loss,
pediatric epilepsy

APPENDIX 7 – National Population Health Study of Neurological Conditions: Stakeholder Engagement Panel

1. Patti Bryant
   Chair, Dravet.ca
   Secretary/Treasurer, Newfoundland and Labrador Health Libraries Association
   Coordinator, Document Delivery, Health Sciences Library, Memorial University of Newfoundland
   Director, Dravet.org
   Treasurer, Epilepsy Newfoundland and Labrador

2. Larry Chambers, PhD, FACE, HonFFPH
   Scientific Advisor, Alzheimer Society of Canada

3. Christine Crosbie, BA
   Public Relations and Strategic Communications Professional

4. Yazmine Laroche, BA
   Associate Deputy Minister, Transport Infrastructure and Communities, Infrastructure Canada

5. Robert Lester, MD
   Retired, Executive Vice President, Medical and Academic Affairs
   Retired, Chief Medical Executive, Sunnybrook Health Sciences Centre

6. Shannon MacDonald, BA
   Vice President, Public Affairs and Partnerships, Canada's Research-Based Pharmaceutical Companies (Rx&D)

7. Doug Martens, BSc (Pharm)
   Retired, Regional Manager, Pharmacy Program, Winnipeg Regional Health Authority
   Volunteer, Parkinson Society Manitoba and Parkinson Society Canada

8. Suzanne McKenna
   Intake/System Navigator for Acquired Brain Injury, Champlain Community Care Access Centre

9. Judy Murray, MSc
   Coordinator, District Stroke Centre, Mackenzie Health

10. Jay Onysko, MA
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11. James Orr, BA, LLB
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12. Peter Rosenbaum, MD, FRCPC
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    Co-founder, CanChild Centre for Childhood Disability Research

13. David Simmonds
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