Brain Health in Ontario

Forming an Integrated Approach



ONTARIO BRAIN INSTITUTE INSTITUTE



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About OBI:

The Ontario Brain Institute (OBI) is a provincially funded, not-for-profit research centre seeking to maximize the impact of neuroscience and establish Ontario as a world leader in brain research, commercialization and care. OBI creates convergent partnerships between researchers, clinicians, industry, patients, and their advocates to foster discovery and deliver innovative products and services that improve the lives of those living with brain disorders.

About ICES:

ICES is an independent, non-profit research institute whose legal status under Ontario's health information privacy law allows it to collect and analyze health care and demographic data, without consent, for health system evaluation and improvement.

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Foreword

We say it time and time again, the driving force of the Ontario Brain Institute (OBI) is improving the lives of those impacted by brain disorders. We do this by increasing awareness about brain health and sharing knowledge and resources as widely as possible. Yet, there is still so much to uncover in terms of our overall understanding of brain disorders and brain health.

Motivated by the national and global momentum for brain health improvement, we compiled a snapshot of the current state of brain health in Ontario. We contextualize this information in the real-world by consulting with community organizations and content experts. As a champion and advocate for brain health, we hope this report facilitates dialogue and unites the brain health community towards our shared goal of improving the brain health of Canadians. The report aims to increase brain disorder awareness, promote the adoption of cross-sector collaboration to tackle the needs of the brain health community, and inform program and resource planning, policy, and decision-making to support people with brain disorders.

Building on over a decade of brain health excellence, OBI is looking to advocate for brain health awareness to decision makers and focusin on making Ontario a world leader in brain research, commercialization, and care.

Our vision is that in the next 30 years: • there will be vast improvements to overall population health with brain disorders being diagnosed earlier, slowed, and even prevented • we will understand the molecular underpinnings

- of the brain disorders
- population-level screening will be routine through the discovery of risk factors and early,

1 in 3 Ontarians are living with a brain disorder

prevention-oriented interventions

- diagnoses will be made and even anticipated based on the molecular fingerprint of disease
- a new generation of disease-modifying drugs and technologies will have flooded the market
- treatment strategies employed to harness the brain's inherent plasticity will facilitate recovery from injury
- citizens will be empowered with knowledge and tools to be proactive in maintaining their brain health
- Ontario's policies related to brain health will inform and be informed by this transformation
 the impact of these advances on quality of life, cost of care, and impact on the economy cannot be overstated

As we take stock of the current state of 13 brain disorders in Ontario through the Brain Health in Ontario (BHIO) Project, we are proud to reflect on the progress we have collectively made in uniting Ontario's brain health community. OBI's team science and cross-disorder approach align with the global call to action by the World Health Organization to optimize brain health across the life course. OBI addresses brain health by focusing our efforts broadly on brain health and supporting advancements in all sectors working to improve the lives of people with brain disorders. OBI has accelerated scientific discoveries, invested in home-grown neurotechnology, and supported person-centered care in communities, and endeavours to build on these successes as we look to the future.

We remain motivated by our long-term goal to champion our collaborative approach to improve brain health in Ontario and around the globe.



Dr. Tom Mikkelsen, President & Scientific Director

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ICES and Data Partners

This study contracted ICES Data & Analytic Services (DAS) and used de-identified data from the ICES Data Repository, which is managed by ICES with support from its funders and partners: Canada's Strategy for Patient- Oriented Research (SPOR), the Ontario SPOR Support Unit, the Canadian Institutes of Health Research and the Government of Ontario. The opinions, results and conclusions reported are those of the authors. No endorsement by ICES or any of its funders or partners is intended or should be inferred.

Parts of this material are based on data and information compiled and provided by CIHI. However, the analyses, conclusions, opinions, and statements expressed herein are those of the author, and not necessarily those of CIHI.

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We acknowledge the contribution of the following content experts with whom we consulted with to better understand the brain disorder findings for clinical relevance, validity and robustness. They provided invaluable feedback that significantly improved the way in which we communicate and present the data.

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Parkinson Canada (Maria Marano, Lorena Araujo)

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(Peter Athanasopoulos, Tory Bowman)

Patient and Community Advisory Members

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Executive summary

Brain disorders are a leading cause of disability worldwide. In Canada, they have a greater impact on the number of years lived in less-than-ideal health than both heart disease and cancer. The cumulative burden of living in less-than-ideal health has tremendous impacts on individuals, families, society, and the economy.

Through the Brain Health in Ontario (BHIO) Project, health administrative data was used to obtain a snapshot of the current state of 13 brain disorders in Ontario, including prevalence, incidence, cost, and co-occurrence. These findings were shared with content experts and advocacy and community organizations to contextualize this information in the real-world.

Over a lifetime one in three Ontarians will develop a brain disorder. The direct healthcare system costs for people with brain disorders is two to over ten times higher than for the average Ontarian, highlighting the importance of risk

reduction and delaying the onset of age-related brain disorders like stroke or dementia.

Brain disorders can co-occur. One in six people with a brain disorder assessed in the BHIO Project have at least one of the other brain disorders assessed, and mental health and addictions related health service use is two to five times higher for people with brain disorders compared to the average Ontarian. Brain disorders' impact on mental health can affect other life areas such as a person's ability to maintain employment, physical health, financial health. and social health.

Knowing the economic and societal impact, it's time to think and act differently about brain disorders. We need to take a team science approach – sustained collaboration and integration between researchers, clinicians, industry, policy makers, and patients and their advocates will foster discovery and deliver

innovative products and services that improve the lives of those living with brain disorders. This integrated approach also extends to how we treat the brain. We need to move towards a one brain approach and look across brain disorders to identify common factors which will help us better diagnose, treat, and care for individuals. These goals are shared by other brain research organizations in Canada like the Brain Canada Foundation.

We recommend placing equal emphasis on knowledge creation, translation, and commercialization; all supported by an integrated and collaborative approach based on real world evidence that comes from data. This includes basic research into understanding the underlying biology of brain disorders and their risk factors, applied research focussed on treatments, interventions, technologies and educational tools, evaluation and implementation research of care

> Its time to think and act differently about brain disorders

programs and pathways, and lived experience led research questions.

With a unified approach, the Ontario and Canadian brain health community can work to fit research findings together in different ways to come up with new insights and potential lifechanging breakthroughs. Now is the time to push for strategies that optimize brain health through strong, strategic coordination and collaboration between stakeholders across public and private sectors. Together we can answer the outstanding question of how can we improve access to and connectedness of different levels of care for people with brain disorders?

Imagine what else could be possible if we worked together to remove the unnecessary barriers and created an environment that is conducive to facilitating ground-breaking discoveries in the field of brain science.

An intro to brain health

What is brain health?

The human brain is remarkable. It allows us to sense and interact with our surroundings, think, communicate and move. It has an amazing ability to adapt, is capable of self-repair and can outperform any supercomputer. Because of all the things our brains are capable of, maintaining optimal brain health benefits our general health, well-being, productivity and creativity throughout our lives. Indeed, brain health goes beyond the absence of disease embracing all functions controlled by the brain which allow a person to realize their full potential over the life course (Box 1).

Despite this exquisite function, there are a number of ways for the brain and related nervous system to become impaired. Neurological disorders, mental health challenges, and brain injuries all result in changes to and disruption of brain function, and are chronic, lifelong conditions that impact individuals and their families (Box 2). As such, it is informative to think about these conditions collectively as brain disorders. This broader grouping unifies an otherwise disparate group of injuries, diseases, and conditions, and brings added awareness and attention to the health consequences and care needs of those affected by all disorders of the brain.

Box 1. _____ Defining brain health

The World Health Organization defines brain health as "the state of brain functioning" across cognitive, sensory, social-emotional, behavioural and motor domains, allowing a person to realize their full potential over the life course, irrespective of the presence or absence of disorders." Mental health is an aspect of brain health, defined as "a state of well-being in which an individual realizes their own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to [their] community."

Brain health is determined by our continuous interactions between our physical health, our environment, our physical safety and financial security, our ability to learn and connect socially, and our access to quality health and social services, as well as our own individual context. These interactions lead to lifelong adaptation of brain structure and functioning. - World Health Organization, 2022

Box 2. _____ What is a brain disorder?

Brain disorders are linked to changes to and disruption of brain function, from age-related neurodegenerative diseases such as Alzheimer's and Parkinson's disease, to congenital disorders and other neurological disorders, to trauma and injury to the brain or spinal cord, and even mental illness like depression.

Tumours

Brain disorders* include:

Neurological conditions

Dementia Epilepsy Motor neuron disease Multiple sclerosis Parkinsonism disorders Stroke and Transient Ischemic

Attack (TIA)

Concussion Spinal Cord Injury Traumatic Brain Injury

Injuries

Attention deficit/ hyperactivity disorder (ADHD) Autism Spectrum Disorder (ASD) Cerebral Palsy Fetal Alcohol Spectrum Disorder (FASD)

* this list is not exhaustive.

Those disorders in italics were assessed using health administrative data through the Brain Health in Ontario Project.

> Maintaining good brain health benefits our general health, well-being, productivity and creativity across the entire life

Malignant Brain Tumour Non-malignant brain tumour

Congenital Conditions Down Syndrome Hydrocephalus Spina Bifida Other genetic conditions

Mental Health Conditions

Neurodevelopmental

Anxiety

disorder

Depression

Mood disorders

Schizophrenia

Obsessive compulsive

Substance use disorder

About brain disorders

Over a lifetime, 1 in 3 people will develop a brain disorder. In fact, nearly every person is impacted by a brain disorder with the appreciation that individuals with a brain disorder do not live in isolation. Not counted in this number is the impact on family and friends, caregivers, coworkers, and society who support and care for these individuals (Figure 1). Reflect on your connections, how many people do you know of impacted by a brain disorder? Collectively, brain disorders are a leading cause of disability worldwide. According to the Global Burden of Disease project, in Canada, brain disorders have the greatest impact on the number of years lived in less-than-ideal health (YLD, 23%), larger than heart disease (3%) or cancer (3%). Moreover, brain disorders represented 17% of the number of years of full health lost, second to cancer (19%) and above heart disease (11%; Figure 2; Institute for

One in three **have a brain disorder**



Figure 1: One in three people in Ontario are directly impacted by a brain disorder. These brain disorders range from highly prevalent disorders that impact more than 10% of the population like depression and brain injury (traumatic brain injury and concussion), those that impact 1 to 10% of the population, including ADHD, stroke and dementia, to disorders like cerebral palsy or parkinsonism which directly impact less than 1% of the population. Data was generated by combining health system data from 2019 (Brain Health in Ontario Project, those disorders in blue) with other prevalence estimates taken from Autism Ontario (2020), Morkem et al. (2020), Centre for ADHD Awareness Canada, and the Canadian Chronic Disease Surveillance System (2019).



Figure 2: According to the Global Burden of Disease Study brain disorders are a leading cause of disability in Canada. Brain disorders represent 17% of all years of full health lost (disability-adjusted life years; DALY) which counts both years of health lost due to disability (YLD) and years of life lost (YLL). When we look at YLD, 23% of the number of years lived in less-thanideal health are due to brain disorders. Brain disorders make up 15% of years lost due to deaths (YLL) (Institute for Health Metrics and Evaluation, 2020).

Health Metrics and Evaluation, 2020). Since people with brain disorders tend to live longer than those with heart disease or cancer, the cumulative burden of living in less-than-ideal health has tremendous impacts on individuals, families, society, and the economy. It is also worth noting that unlike other chronic diseases like heart disease, cancer, and diabetes, there is no established 'health index' for the brain. This creates barriers for routine screening, early diagnosis, and self-management which are known to decrease burden and improve treatment or management for other chronic diseases.

Notably, most brain disorders are not curable. Some treatments exist for certain brain disorders, but many individuals struggle to find treatments that effectively manage their disorder and symptoms. Considering the dramatic impact of brain disorders on quality of life, the growing prevalence, and costs associated with care, continued focus on brain research and approaches to care are urgently needed.

The Brain Health in Ontario Project

Through 2022, OBI, using data sets and analytic services available through ICES, launched the **Brain Health in Ontario (BHIO) Project** to raise awareness about the current landscape of brain health in Ontario.

Using health administrative data from 2019, we estimated (1) the number of people in Ontario with various brain disorders, (2) the associated direct cost of all publicly provided health care services used by individuals with brain disorders relative to the general Ontario population, and (3) the interrelationships among these brain disorders and mental health and addiction service use. We consulted with content experts and advocacy and community organizations to contextualize this information in the real-world. The 13 brain disorders assessed in BHIO include:

- cerebral palsy
- dementia (including Alzheimer's disease)
- epilepsy
- malignant brain tumour
- motor neuron disease
- multiple sclerosis
- non-malignant brain tumour
- parkinsonism
- schizophrenia
- spina bifida
- spinal cord injury
- stroke & transient ischemic attack
- traumatic brain injury & concussion

We present this evidence to inform program and resource planning, policy, and decision-making. For the complete methodology of the Brain Health in Ontario Project, see Appendix A. In addition to the report, online resources of this information is available on the BHIO webpage, located at <u>braininstitute.ca/brainhealth</u>. Users can read about the 13 brain disorders on an individual page built for each disorder analyzed. This presentation of information is designed for discovery and understanding of the societal impact of specific brain disorders, as well as for comparison with other conditions. Easily accessible infographics and chart packs for use in research, advocacy, decision making, and caregiving efforts are also available for download.

About OBI's position and this paper

The objective of this paper is to facilitate dialogue and rally brain health organizations towards the shared goal of improving the brain health of Canadians by using Ontario as a proxy for the impact of brain disorders in Canada, and the OBI model as an example of the efficacy of cross stakeholder, multi- and inter-disciplinary collaboration and coordination. This paper is intended to be used as a tool to:

- provide current information on the landscape of brain disorders in Ontario.
- advocate for brain health awareness.
- promote the need for collaborative efforts towards brain research (OBI's team science approach and cross-disorder approach).
- facilitate dialogue on Ontario's opportunity to lead the way in advancing research on brain health and care for those with brain disorders.

The target audience for this paper is organizations focused on brain health, policymakers, and health officials. The paper may also be helpful for clinicians, researchers, and persons with lived experiences and their care partners.

Insights from the Brain Health in Ontario Project

The Brain Health in Ontario Project was developed to address knowledge gaps in the prevalence, incidence, cost, and co-occurrence among brain disorders and to contextualize this information in real world by talking with content experts and advocacy and community organizations.

We present this evidence to inform program and resource planning, policy, and decisionmaking regarding brain disorders and the Ontario healthcare system. Optimizing brain health creates positive social and economic impacts, all of which contribute to greater well-being and helps to advance society.

As of 2019. 2.45 million Ontarians have one of the 13 brain disorders assessed in the BHIO Project (Box 2, italics text; Figure 3), with nearly 158,000 people newly identified in 2019 alone. However, this is an underestimate of the total picture of brain health since other highly prevalent disorders like autism spectrum disorder, ADHD, depression, and anxiety were not possible to measure from health system administrative data. Moreover, we can only capture those individuals who directly interact with the healthcare system. Not counted are individuals who do not see a physician or seek medical care, whose diagnosis or therapy related to their brain disorder is not recorded, who have less severe

disorders or are in earlier stages and may be missed, and those who rely on community-based supports.

Brain disorders are a growing economic concern

Brain disorders occur across age and sex and are affected by many determinants at various stages of life (Box 1). Likewise, the healthcare system accommodates people differently because of age, sex, and their changing needs during disorder progression (see Figure 1–13: E within Appendix B). The majority of people (58%) living with a brain disorder are in their prime working years which can negatively impact productivity and







Figure 4: Brain disorders affect people across age and sex. Pediatric (0-17 years), adult (18 - 64 years), senior (65+ years).

economic output (Figure 4). The chronic nature of brain disorders means that affected individuals often require lifelong treatment, management, and care. This becomes an even greater concern for our aging population as people live longer and the prevalence and co-occurrence of chronic conditions increases. All these factors affect health system planning – knowing with whom and when costs are highest helps to inform what aspects of the healthcare system to focus on for improvements and change. For example, across disorders hospital care cost is high in the first year of a brain disorder. What does this mean about knowledge, awareness, and access to seek primary care first?





Improving care and support for people living with brain disorders can yield a productive economic benefit. For example, direct healthcare system costs for the treatment of people with brain disorders are higher than for the average Ontarian, ranging from two times more per person for traumatic brain injury and concussion to over ten times more per person for dementia and motor neuron diseases like ALS (see Figure 1-13: D within Appendix B). In fact, costs borne by the Ontario healthcare system on an annual basis for a single brain disorder range from

tens of millions to billions depending on the prevalence of the disorder and cost of treatment (i.e., physician services, hospital, long-term care, drugs, and others) (Figure 5). In total, this represents a significant portion of the Ontario health budget. Since first-year costs are higher than subsequent-year costs (see Figure 1-13: D within Appendix B), delaying onset of agerelated brain disorders like stroke or dementia, or preventing other disorders like concussion, by even one year can save costs - highlighting the importance of risk reduction.



Figure 5: Relative total direct cost of the 13 different brain disorders to the Ontario healthcare system for 2019. Dementia, stroke, and brain injury have the highest total cost.

Delaying onset of age-related brain disorders like stroke or dementia, or preventing other disorders like concussion, by even one year can save costs - highlighting the importance of risk reduction.

Importantly, these costs only reflect direct expenditure by the healthcare system so the true societal cost is vastly underestimated. Not included are costs related to additional supports covered by private insurance, the Ontario Disability Support Program, or services paid for out of pocket like occupational therapy, physical therapy, psychotherapy, and equipment, to name a few (see Appendix A for limitations and considerations). Additionally, these costs do not account for informal caregiving provided to individuals by family members or friends. These uncounted costs are significant for many disorders including dementia and epilepsy.

The high costs to the healthcare system shows the importance and value of better incorporating community care into the traditional healthcare pathway. Community-led organizations focus on short- and long-term change to improve

the well-being of people with brain disorders by working directly with their community. As non-profits, their funding is provided through grants or fundraising efforts, with the goal of providing services that are accessible. Many such organizations are small in scale and focus on the local community – allowing for closer connections and an improved understanding of needs. This means they are better equipped to provide local and accessible care. The work of community organizations involves a combination of community empowerment, advocacy, and program-delivery. Programs include those that provide education, disorder management training, and social support to help reduce the load on the healthcare system. However, funding constraints are an issue frequently faced by community organizations which directly impacts their ability to provide the support and care needed by their communities.

The chronic nature of brain disorders means that affected individuals often require lifelong treatment, management, and care



Brain disorders do not occur in isolation

The interrelationship between brain disorders has also become more evident from new research findings, feedback from patients, and analysis of healthcare system data.

Patient and family partners in OBI's Integrated Discovery Programs (IDPs) tell us about their experience with co-occurrence of brain conditions such as epilepsy and depression, or ADHD and autism. They also tell us about the shared challenges across brain disorders, like sleep in children with cerebral palsy, epilepsy, and autism. Researchers in the IDPs are uncovering clues about the biology that connects brain disorders including shared genetic risk factors across neurodevelopmental conditions, and the emergence of dementia across neurodegenerative diseases like Alzheimer's disease and Parkinson's disease. The Brain Health in Ontario Project shows that one in six people with a brain disorder have at least one other brain disorder - a huge overlap in occurrence. Of the disorders assessed, dementia, stroke, TBI, epilepsy, schizophrenia, and parkinsonism are the top co-occurring brain disorders. (Figure 6, Figure 1-13: F within Appendix B). The fact that cooccurrence is recognized through experience, research, and healthcare system data support the idea of common underlying biology across brain disorders. This knowledge can guide research questions, promote program development that addresses this complexity, and encourage individuals living with a brain disorder, their families and healthcare professionals to look at ways to manage co-occurrence by recognizing symptoms early and seeking appropriate treatment sooner.



Top co-occurring brain disorder pairs			
Disorder 1	Disorder 2		
Dementia	Stroke & TIA		
Dementia	TBI & Concussion		
TBI & Concussion	Stroke & TIA		
Dementia	Parkinsonism		
Epilepsy	TBI & Concussion		
TBI & Concussion	Schizophrenia		
Epilepsy	Stroke & TIA		
Epilepsy	Dementia		
Dementia	Schizophrenia		
Epilepsy	Cerebral Palsy		

Figure 6: 15% or one sixth of people with a brain disorder assessed in the BHIO Project have at least one other co-occurring brain disorder. Those brain disorders that represent 5% or more of co-occurrences are listed alongside the purple column on the left. The most common co-occurring disorder pairs are in the chart on the right.



Figure 7: Mental health and addictions related health service use is higher for people with brain disorders, ranging from 2.3 times more outpatient visits to 5.3 times more hospitalizations.

Mental health is a key aspect of brain health

Over the last few years, greater attention has been paid to the importance of mental health and the need for more mental health supports and services for those in need. The BHIO Project found that visits for mental health challenges occur across brain disorders. This relationship was unsurprising to many content experts and community organization representatives. Using healthcare system administrative data, we found mental health and addictions related health service use was, on average, two to five times higher for people with brain disorders compared to the average Ontarian (Figure 7). For some disorders, these numbers are much higher. Take Parkinson's disease for example: these individuals are hospitalized for mental health and addictions related services twelve times more and use emergency department services six times more than the general Ontario population (see Figure 8: G within Appendix B). Knowing the increase in

mental health and addiction challenges in people with brain disorders, primary care could focus on monitoring mental health more closely in these populations to combat the large hospitalization and emergency department use.

Given this overlap in brain disorders and mental health challenges, it is unsurprising that mental health conditions are rooted in changes to brain function – mental health is an important aspect of brain health. Community organization representatives noted that social isolation and stigma are two factors common across brain disorders that can affect mental health, and lead to impacts in other life areas such as a person's ability to maintain employment. Indeed, living with a brain disorder affects other areas of health including physical health, the ability to take medications, mental health, financial health, and social health (Box 3).

Box 3. Optimizing brain health

Optimizing brain health not only reduces the prevalence and burden of neurological disorders, but also improve mental and physical health overall and create positive social and economic impacts, all of which contribute to greater well-being and help advance society, irrespective of the presence or absence of disorders.

- World Health Organization, 2022

New knowledge means new questions

Through consultations with content experts and advocacy and community organization representatives on the BHIO Project data, several questions emerged regarding how to better support people with brain disorders. In reviewing the questions below, note that they have a common thread: How can we improve the access to and connectedness of different levels of care for people with brain disorders?

- How can we increase knowledge of when to seek primary care and its role, including for mental health and addictions?
- How can we increase access to primary care for people with brain disorders?

• Do primary care professionals need to have a better awareness and understanding of brain disorders?

- How does access to primary care, and drug and OHIP coverage affect hospital and specialist care costs?
- How can we reduce hospital care costs in the first year? What can we put in place at the primary and community care levels?
- How can we better incorporate community care into the care pathway?
- Can we explore how healthcare costs change as a brain disorder progresses to inform what services need to be focused on and when? • How can we promote a 'one brain' or a 'whole person' approach to care?

Box 4. One Brain approach Box 4. _____

One Brain approach – where the brain is a single, complex system with commonalities across neurological disorders, mental illnesses, and brain injuries, rather than as a collection of siloed diseases. The One Brain approach means that every discovery has the potential to have an impact across a spectrum of brain diseases and disorders, as well as on our understanding of brain functioning. Looking at the brain as one system encourages collaboration, knowledge sharing, and rich, and varied multidisciplinary teams all working together to advance brain research and magnify the potential for impact.

- Brain Canada Foundation, 2022

It's time to think and act differently about brain disorders

Healthcare administrative data provides us with a starting point to explore the impact of brain disorders. The overlap in brain disorders emphasize the importance of a cross-disorder (i.e., one brain) approach (Box 4). We need to look across brain disorders and identify common factors which will help us better diagnose, treat, and care for individuals. The sheer complexity of brain disorders means this will require multi- and inter-disciplinary collaboration across sectors to bring all stakeholders together under this common societal goal. Given the costs coupled with the burden of living in less-than-ideal health. brain health is an enormous societal

challenge that requires pan-Canadian efforts to address.

The good news is, because different brain disorders have things in common, new knowledge on one disorder, for example Parkinson's disease or stroke, can benefit other disorders, like dementia. OBI has supported this idea over the last decade with our team science approach, fostering collaboration between researchers, clinicians, industry, patients, and their advocates.

An integrated approach to brain health

OBI's team science approach

OBI has supported the team science approach over the last decade. OBI has and continues to build and nurture collaboration between researchers, clinicians, industry, patients, and their advocates to foster discovery and deliver innovative products and services that improve the lives of those living with brain disorders.

At OBI we believe that partnership will lead us to answers in brain health. With an integrated approach, the Ontario and Canadian brain health community can work to fit research findings together in different ways and allow researchers to come up with new insights and potential lifechanging breakthroughs.

In the past decade, OBI has delivered on our commitment to lay the foundation for Ontario to become a world leader in brain health research. commercialization. and care. OBI has seen the success of the team science approach at a provincial scale through our Integrated Discovery Programs (IDPs) and cross-stakeholder partnerships (Box 5). United with our provincial partners, OBI has effectively changed neuroscience research activities in Ontario to pan-provincial collaborative networks of interdisciplinary scientists. We have supported the generation of new healthcare interventions for people living with brain disorders, creation of new neuroscience focused companies, and developed significant value in commercial activity, training, and employment in this sector. Brain health is a complex problem and requires coordination across partners, sectors, and regions. Consider the examples of our team science approach below and the potential impact of this approach more widespread.

Box 5. The work OBI supports

Integrated Discovery Programs (IDPs):

Over the last 10 years, OBI has facilitated the creation of six large cross-sector, interdisciplinary programs. These pan-Ontario programs take a different approach to research that spans many disciplines and brings together a diverse group of stakeholders including researchers, clinicians, industry partners, and patients and their advocates. The programs collect various types of data, including genetic, molecular, imaging and behavioural, which are standardized and stored on OBI's state-of-the-art informatics platform, Brain-CODE. Brain-CODE is a database designed to store, manage, and analyze many different types of data. By establishing a common approach to how data are collected, standardized assessments allow data to be shared across the province. The IDPs have generated more than 12 million clinical data points from over 21,000 participants. With in-depth information on individuals with a specific disorder, researchers are taking a new look at the root causes among diverse disorders. This approach is part of a province-wide system where clinical and research data are gathered and kept in a comparable format, allowing for research and discovery within and between disorders. The approach is hypothesis-driven, yet allows exploratory, curiosity-driven research.

- CP-NET: The Childhood Cerebral Palsy Integrated Neuroscience Discovery Network
- CAN-BIND: The Canadian Biomarker Integration Network in Depression
- EpLink: The Epilepsy Research Program of the Ontario Brain Institute
- CONNECT: Concussion Ontario Network: Neuroinformatics to Enhance Clinical Care and Translation
- ONDRI: Ontario Neurodegenerative Disease Research Initiative
- POND Network: Province of Ontario Neurodevelopmental Disorders Network

Programming for community groups:

The Growing Expertise in Evaluation and Knowledge Translation (GEEK) program provides funding, evaluation expertise, and support to community-led programs and services for people living with brain disorders. GEEK supports the sustainability, scale and/or spread of these programs, to improve the quality and quantity of evidence-based care in the community. Since 2018, we have supported 12 programs:

- Ontario Brain Injury Association (OBIA): Brief Intensive Case Management Acquired Brain Injury
- Christian Horizons: Educational Pathway to Employment

Box 5. _____ The work OBI supports (continued)

- Kids Can Fly: Peer-Administered CBT-Informed Support for Postpartum Depression
- Alzheimer's Society of Ontario: UFirst! For Care Partners
- Surrey Place: The Aging & IDD Education Program an extension of the MMW Clinic
- Sunnybrook Health Sciences Centre: Family Navigation Project
- Vista Centre Brain Injury Services: Acquired Brain Injury Transition Program
- Epilepsy Ontario: Epilepsy-specific Mental Health Program in Ontario (UPLIFT)
- Health Nexus Santé: The Indigenous Brain Story
- March of Dimes Canada: Living with Stroke Virtual Delivery in Community Settings
- Epilepsy Toronto: Functional Seizure Program
- JIAS (Jewish Immigrant Aid Services) Toronto: Mental Health Supportive Initiatives for Vulnerable Refugee Newcomers Program

Supporting companies:

OBI promotes the commercialization of early stage neurotechnologies through an effective neurotech ecosystem, having supported 42 devices, 13 therapeutics, and 44 software/informatics companies since 2010. The Neurotech Entrepreneurship to Validate Emerging Innovations (NERVE; formally known as ONtrepreneurs) program is Canada's single largest award that catalyzes early stage entrepreneurs to commercialize brain-related technologies by accessing funding and support to launch or grow their neurotechnology ventures. The Neurotech Early Research and Development (NERD) program provides milestone-based investment to support product development. The program helps to de-risk investments in neurotechnologies by bridging the funding gap between research grants and private capital. View the full list of companies <u>here</u>.

Sharing knowledge:

Through the OBI network, over 300 knowledge products, such as guidelines, webinars, podcasts, and toolkits, have been created and over one million people have been reached, most notably through public-facing initiatives such OBI's public talks and engagement on our website.

SUCCESSES OF A TEAM SCIENCE APPROACH AT THE PROVINCIAL LEVEL

1. Breakthrough research:

Supporting translational research programs carried out by the OBI's IDPs creates better treatments and care in partnership with patients.

- The pan-Ontario POND identified common biological underpinnings across different neurodevelopmental disorders and are now further probing the relationship between sex and neurodevelopment by studying sex hormones.
 This type of research requires a large scale of data, only possible through provincial and national partnerships.
- A multi-year study conducted by CP-NET, found that 33% youth diagnosed with cerebral palsy, had symptoms of depression and 31% of the participants had symptoms of anxiety. These results shed light on how the brain changes through the teenage years and into adulthood and will help researchers and care providers better understand the disorder's trajectory.
 New biomarkers predicting treatment response
- New biomarkers predicting treatment response in people living depression were identified by CAN-BIND. These include brain wave signatures identified by EEG and a micro-RNAs.

2. Learning healthcare system:

OBI promoted open science and accelerated research in brain health with eleven data releases to date, four of which are significant clinical data releases. These newly accessible clinical datasets were created to amplify discovery and innovation in the areas of neurodevelopmental disorders, neurodegenerative disorders, concussion, and depression, and have been cleaned, standardized, and curated to protect sensitive patient information. Moreover, research data from 3,000 study participants are now matched with their health system ID, allowing for data linkages that enable scientists to identify and prioritize research questions and make use of real-world information. OBI is working with each of its IDPs to create partnerships with frontline service organizations, for example MINT Memory Clinics and Project ECHO, where discovery from the clinical research program is immediately applied into the local care setting.

3. Patient centred:

OBI has over 300 patient partnership activities. OBI partnered with EpLink and POND to develop research priorities driven by people with lived experience. These priority setting partnerships resulted in the creation of the top 10 research priorities for epilepsy and neurodevelopmental disorders. Read more <u>here.</u> Moreover, each of the IDPs OBI supports have Patient Advisory Committees with members having lived experience, being a care partner, or a community organization representative. In addition to research, OBI runs programming to support community-based organizations working directly with people with brain disorders and their care partners.

4. Investing in neurotechnology:

OBI is growing a globally competitive neurotechnology cluster by training highly qualified personnel and working with partners across Canada to create a seamless pipeline of support for Ontario companies through our NERVE and NERD programs. The result to date is the growth of 90+ portfolio companies who have collectively secured over \$200 million in follow-on investment into Ontario and brought 20 new products to market.

5. Connected care:

By partnering with companies and community groups OBI helps bring new products to market or programs to people with brain disorders and their care partners.

• By connecting research with community-based care, mothers with postpartum depression are able to receive evidence-based cognitive behavioural therapy that was developed in a clinic and delivered by a community agency, <u>Kids Can Fly</u>, from recovered peers. Read more about the 1-day program <u>here.</u>

• <u>Mobio</u>, an OBI portfolio company, developed and commercialised an AI-powered digital theragnostic platform that delivers clinically validated psychotherapy programmes personalised to every patient using digital biomarkers. They recently partnered with Green Shield Canada to launch a 6-month pilot to make the mindfulness app available to Green Shield's customers and also partnered with Loblaws Inc to make their mindfulness app available on the PC Health app.

• The Epilepsy Ottawa Novela study, or EONS

project, brought together <u>Epilepsy Ottawa</u> and <u>Novela Neurotechnologies</u> to test new seizure tracking technology developed by Novela, an OBI portfolio company. The study was rolled out with 50 adult at-home patient partners recruited by Epilepsy Ottawa to determine if the Neureka® epilepsy monitor can improve the quality of life of those living with epilepsy.

OBI's one brain approach

Knowing how interconnected brain disorders are, and how essential our brains are for living a good life, when we think of the brain and how to tackle brain disorders, we need to take a one brain approach – looking across brain disorders and brain functions (Box 4). While we do need to study brain disorders more wholistically, it is important to remember both across and within there is a spectrum and no one size fits all solution.

OBI supports IDPs that look across brain disorders. For example, ONDRI set out to examine both differences and similarities between neurodegenerative diseases such as: Alzheimer's disease, mild cognitive impairment, Parkinson's disease, vascular cognitive impairment, frontotemporal dementia, and amyotrophic lateral sclerosis – one of the first studies of its kind, aimed at breaking down traditional clinical diagnostic silos. A new understanding of disordered sleep in children came about through the integration and collaboration of researchers focused on epilepsy (Ep-Link), cerebral palsy (CP-NET), and neurodevelopmental disorders (POND). The mental health and wellbeing of adolescents and

adults with cerebral palsy was studied in CP-NET's MyStory project, finding depression and anxiety in about one third of people with cerebral palsy studied (Gorter et al., 2022). Ep-Link and CANBIND explored the relationship between epilepsy and depression and anxiety through their recent joint report Epilepsy, Depression & Anxiety: What do we know?

Reflecting on community programs that support people with brain health challenges and their caregivers, there are common needs across the different groups. For example, the twelve community-based programs OBI has supported over the last four years (Box 4) broadly fall into four program-types: System navigation,



education and skill development, interventional programing, and social support. This tells us that regardless of diagnosis, there is a large overlap in the types of care needed to allow a person to realize their full potential over the life course. By continuing to support research and programs that address brain health more broadly, we can identify those factors which will help us better diagnose, treat, and care for individuals.

Opportunity & recommendations

Despite the advancements in brain research since the 1990's there is still much to understand. Currently, care focuses on improving quality of life to reduce the number of years people with brain disorders live in less-than-ideal health. Considering the dramatic impact of brain disorders on the quality of life of these individuals, the growing prevalence, and costs associated with care, continued investment in brain research and approaches to care are urgently needed. Driving forward brain health research is the only hope and path to treatments and cures.

The team science and one brain approaches to answering questions about brain health is gaining momentum globally, evidenced by the release of the World Health Organization's framework for brain health optimization: "By addressing brain health determinants at the individual and societal level, we can optimize brain structure and function across the life course leading to enhanced well-being, improved health, and social and economic benefits." (World Health Organization, 2022). The World Health Organization's call to action points out the necessity for united effort: "Strategies to optimize brain health require multisectoral and interdisciplinary collaboration that involve all sectors of human society with integrated, person-centred approaches focused on promotion, prevention, timely diagnosis, treatment and care, as well as the active engagement of persons with lived experience." (World Health Organization, 2022)

Indeed, there are mounting global and national calls to action to address brain health. The Economist Impact programme, *The value of action: mitigating the global impact of neurological disorders*, compiled data from ten brain disorders across eleven countries to demonstrate the global impact of brain disorders, outline the gaps in current policies, and determine the value of taking concrete action to address brain health. For example, they noted policy interventions aimed to reduce caregiver burden and help people with brain disorders live full active lives will limit the economic and social costs felt by society, benefiting both those directly affected and wider society (The Economist Group, 2022). The Neurological Health Charities of Canada (NHCC) looks to address the patchwork approach to neurological health in Canada by implementing a National Neurological Strategy. Their framework focuses on six areas including strengthening government leadership through policies and programs for people with brain disorders; improving accessibility to early diagnosis, treatment, and care; workforce capacity building; reducing stigma and discrimination; strengthening health information systems; and fostering strategic approaches to research (NHCC 2022). They and others have partnered with the Canadian Brain Research Strategy (CBRS) who are recommending the Canadian government establish a distinctly Canadian brain research initiative that is collaborative, transdisciplinary, and open (CBRS, 2022).

We have national momentum for brain health, with the efforts put forth for creating dementia, autism, concussion, and mental health national strategies, and the added focus on mental health through the COVID-19 pandemic. We need to continue this push. Driving forward brain health research is the only hope and path to treatments and cures.

Driving brain research forward: Recommendations

We must drive forward brain health research paths that are rooted in equity, diversity, and inclusivity and connect research discovery, patient care, and commercialization:

• Basic research to identify biomarkers and the underlying biology and interconnectedness of brain disorders, and their risk factors • Applied research for tools, technologies, prevention strategies, and interventions/ treatments to better assess, monitor, and care for people with brain disorders

• Evaluation of care programs, policies, practices, and pathways for people with brain disorders

• Implementation research for tools, technologies, interventions, and care practices • Identification of strategies and educational

tools to promote brain health and resilience • Research on the impact of brain disorders in

the provinces and territories

• Lived experience led research questions

Now is Ontario and Canada's time to push for strategies and research paths that optimize brain health through strong, strategic coordination and collaboration between stakeholders across public and private sectors. We need a national strategy for targeted investment in brain and mental health. Imagine what else could be possible if we worked together to remove the unnecessary barriers and created an environment that is conducive to facilitating ground-breaking discoveries in the field of brain science.

To learn more about the Brain Health in Ontario Project, including methodology and a snapshot of the individual disorders examined, please see Appendix A through C, or visit www.braininstitute.ca/brainhealth. If you would like to learn more about the data, please contact BHIO@braininstitute.ca.

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Appendix A: methodology and considerations

Methodology

To address the project's objectives and provide comparable data consistently across brain disorders, a common approach was required. Years are reported by the fiscal year calendar. For example, the year 2011 represents the dates between April 1, 2011 – March 31, 2012.

Demographic Profile

A demographic profile was constructed for each brain disorder based on all individuals with that condition who were alive and residing in Ontario on April 1, 2019. Sex (male/female) and age groups in years are described. Summary statistics, including the mean (standard deviation) and median (interquartile range), were reported for age. Additionally, the number and proportion of individuals with a brain disorder were reported according to the following age groups: 0–4 years, 5–17 years, 18–39 years, 40–64 years, 65–74 years, 75–84 years and 85+ years. Specific age groups describing newborns (<1 year), children (0–17 years), adults (18/20/40–64 years) and older adults (65+ years) were also presented where applicable.

Prevalence

Prevalence for each brain disorder was determined on April 1 of each year from 2011 through 2019. Prevalence was calculated as the number of persons with a brain disorder on April 1 of a given year divided by the total mid-year population of Ontario measured as of July 1 of a given year. For brain disorders with age restrictions, the total population consisted only of individuals within the appropriate age range. For comparability between years, prevalence estimates were standardized by age and sex to the 2011 Census population for years 2011 – 2015, and 2015 Census population for year 2016 – 2019. Accrual of persons with brain disorders started on April 1, 1988 or April 1, 1991 depending on database availability, and was carried over to future years unless the persons died, left Ontario or lost health insurance eligibility.

Incidence

Incidence for each brain disorder was determined annually from 2011 to 2019. Incidence was calculated as the number of persons with a newly identified brain disorder accrued between April 1 and March 31 of the following year divided by the susceptible population. The susceptible population was counted as the total mid-year Ontario population minus those who already had the brain disorder. The 'index date' was used to define the date of incidence. As mentioned previously, this date may not be the true clinical diagnosis date of the disorder. For brain disorders with age restrictions, the susceptible population consisted only of individuals in the appropriate age range. The accrual period identified individuals with a pre-existing brain disorder so they would not be mistakenly counted as having a newly identified brain disorder in later years. For comparability between years, incidence was standardized by age and sex to the 2011 and 2015 Census population. The maximum followup date was March 31, 2020.

Costs Associated with Health System Use

There are many costs associated with health system use when a person receives care and treatment for their brain disorder or other coexisting health conditions. We provide a comparison of these direct costs paid by the Ontario Ministry of Health for a person with a brain disorder. These costs were calculated using Ontario health administrative data for a continuum of health care services categorized into seven types: complex continuing care, longterm care, home care services, hospital care, physician and other health care professional services covered by OHIP, prescription drugs and rehabilitation services. Costs included within the categories are described in Table 1 below.

We also provide and estimated cost comparison range for a person with a brain disorder compared to the average Ontarian. We calculated the mean 1-year cost of an incident case based on the 2019 incident case cohort by looking at the costs accrued up to 365 days from diagnosis date with a maximum follow-up date of March 31, 2020. The mean 1-year cost of a prevalent case was based on the 2019 prevalent case cohort using a one-year period, from April 1, 2019 to March 31, 2020. A general Ontario cohort was created, and costs calculated for a one-year period, from April 1, 2019 to March 31, 2020. While these data are not age and sex matched, cost comparisons were made between the disorder-specific relevant age groups of children (0–17 years), adults (18/20/40–64 years) and older adults (65+ years) described above.

Further description of costs calculation can be found in the original report Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data published in 2015, found here.

Co-occurring brain disorders

Brain disorders do not always occur independently, and across those we looked at there are co-occurrences. To determine the degree to which certain brain disorders might co-occur, we identified the frequency of cooccurrence for each brain disorder by looking at the number of people within a given disorder cohort that also appear in one, two, or three or more brain disorder cohorts. We also looked at which brain disorders most often co-occur by identifying the proportion of individuals who appear in every other brain disorder cohort.

Mental Health and Addictions Service Use

Health service use for mental health and addictions related reasons was estimated using three Health Service Use Indicators related to rates of visits: (1) Rates of mental health and addictions—related outpatient visits, (2) Rates of mental health and addictions—related emergency department visits, and (3) Rates of mental health and addictions—related hospitalizations. Detailed definitions of visits can be found in the 2021 Mental Health and Addictions System Performance in Ontario Scorecard technical appendix, found here.

Health service use by persons with a brain disorder who were alive and eligible on April 1, 2019 were standardized to the 2015 census population and compared to the Ontario population alive and eligible April 1, 2019 (from Registered Persons Database).

Table 1: Types of health care services and their constituent costs

Category	Constituent Costs ^a	Excluded Costs ^ь
Complex continuing care	Inpatient complex continuing care services	
Home care	• Includes community health services, homemaking services, personal care and support services, and services provided by visiting health professionals (e.g., nurses, physiotherapists, social workers)	• Does not include private home care se
Hospital care	 Inpatient hospitalization Inpatient mental health hospitalization Same-day surgeries Emergency department visits Renal dialysis clinic visits Cancer care clinic visits 	 With the exception of cancer care clin costs were not captured. Examples of physiotherapy programs and diagnost
Long-term care	• Long-term care	 Only the government-funded portion costs for long-term care accommodat
Prescription drugs	 Prescription drug claims for Ontario Drug Benefit Program members. This covers all individuals 65 years or older, and persons younger than 65 years who are receiving assistance from either Ontario Works or the Ontario Disability Support Program; receiving coverage from the Trillium Drug Program or the Special Drugs Program; receiving home care services; or living in long-term care homes 	 Prescription drug costs were not capt years because they are paid for out-of dispensed during acute inpatient stays
Physician and other health care professional services. Broken down into three categories: General practitioner, Specialist, and other health care professional service billings	 Physician billings, including shadow billing Capitation fees Other health care professional billings (e.g., optometrists, physiotherapists, nurse practitioners) for eligible groups, which includes individuals 65 years and older, those with specific chronic diseases, and those receiving social assistance from either Ontario Works or the Ontario Disability Support Program Diagnostic test and laboratory service billings 	 Diagnostic test and laboratory service Plan Claims Database were not captu Billings from non-physician health car individuals. Services provided by the n paid for out-of-pocket and/or by third
Rehabilitation services	Inpatient rehabilitation services	Outpatient rehabilitation programs we

• These costs are for services funded by the Ontario Ministry of Health and Long-Term Care. Not captured are costs paid by the individual, his or her family, third-party insurers or other private payers. Also not captured are indirect costs such as those associated with productivity loss and informal caregiving.

^{**b**} This is not an exhaustive list.

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- nics and renal dialysis clinics, ambulatory care f ambulatory care services not captured are outpatient tic tests and imaging services
- of long-term care was considered. Out-of-pocket tions were not included
- tured for the majority of individuals younger than 65 of-pocket and/or by third-party insurers. Drugs ys were captured as hospital care costs
- e billings not included in the Ontario Health Insurance ured
- re professionals were limited to specific groups of majority of non-physician health care professionals are
- rd-party insurers; these were not captured

ere not captured

General considerations

Brain Disorder Algorithms

The algorithms used to identify individuals with each brain disorder are presented in Appendix C: Codes and Conditions. Each algorithm had been either (a) previously validated against another gold standard data source (such as an electronic medical record) or (b) previously developed or employed by experts with clinical and health administrative data experience. Health administrative data, with the exception of cancer registry records, do not contain a brain disorder diagnosis date. Rather, the data indicate a physician-specified reason for the health care service encounter or a physician-prescribed drug for reimbursement from the Ontario government. Thus, individuals identified by an algorithm can be thought of as being physician-diagnosed. However, it should be noted that although the reason stated in the data oftentimes agrees with an individual's clinical diagnosis, in other situations, the reason provided is not an actual diagnosis. Rather, the stated reason could be a clinical suspicion of the disorder or a negative

test result. It is also common for an individual to present with several health problems, but not have all of them captured through diagnostic codes for a specific health encounter. These difficulties are handled with algorithms featuring time sequencing and repetition, which improves the identification of true positives and true negatives; however, the algorithms are not perfect.

Inclusion and Exclusion Criteria

For each brain disorder, the 'index date' was the earliest health system encounter with a relevant diagnostic code, drug code or entry in the cancer registry. For algorithms requiring a series of health system encounters of the same type (e.g., the dementia algorithm requiring three physician claims records at least 30 days apart in a two-year period), the date of the most recent encounter in that series was used to determine the index date. Individuals' age and sex had to be known on the index date in order for them to be included. In addition, individuals had to be Ontario residents and covered by Ontario health insurance at the time. The Ontario Health Insurance Plan's Registered Persons Database was used to confirm these inclusion criteria. Persons residing in Ontario but not eligible for provincial health insurance coverage (including refugee claimants, tourists and international students or individuals covered by other programs, such as Canadian Armed Forces personnel and federal inmates) were not counted. Further, some brain disorder algorithms had age restrictions in order to improve algorithm performance or because identification of some disorders is not feasible in younger populations. Individuals with multiple brain disorders are eligible to be counted as long as they meet the criteria (i.e., the conditions are not mutually exclusive).

Co-occurring brain disorders

The methodology used to identify co-occurrence among brain disorders is only possible amongst the disorders assess in this project. Notably, several major brain disorders are missing, including but not limited to neurodevelopmental disorders, ADHD, anxiety, depression, mood disorders, and substance use disorders.

To estimate the co-occurrence of mental health issues and substance use among people with a brain disorder, we compared visit rates for these reasons between people with a brain disorder and the Ontario census population. Visit reasons in this analysis include: substance-related and addictive disorders, schizophrenia spectrum and other psychotic disorders, mood disorders, anxiety disorders, deliberate self-harm, trauma and stressor-related disorders, obsessivecompulsive disorder and related disorders, and personality disorders.

Disorder specific considerations

Cerebral palsy

Cerebral Palsy is a developmental disorder that most commonly occurs during pregnancy, the prevalence for children 5 years and younger was estimated instead of incidence or newborn prevalence because diagnosis can be delayed or go unrecognized until 5 years of age.

Spina Bifida

Because spina bifida is a congenital developmental disorder, live birth prevalence was estimated instead of incidence. Yearly live birth prevalence was calculated by dividing the number of individuals born with spina bifida by the newborn population of that year.

Limitations

The data collected for the purposes of this project are not collected for research purposes and are therefore not without limitations.

The availability, reliability and validity of diagnoses and drug claims in the data are subject to administrative rules governing service provision, as well as financial incentives associated with payment for services. Not only must an individual make health system contact, but a diagnosis or drug therapy related to his or her brain disorder must also be recorded. This requirement will introduce bias into estimates as healthier individuals with less health system contact or those with less severe disorders or at earlier stages may be missed. With the exception of cancer, information on disease severity, stage or subtype is not typically available in health administrative data, and date of onset is difficult to calculate. In addition to potentially underestimating prevalence among individuals with less severe brain disorders, the lack of refinement in diagnostic codes (i.e., the number of ICD digits available across jurisdictions) typically precludes the identification of disorder subtype. Currently, there is a wide variety of algorithms in use across Canada, and there is variability in the databases that are included, the time periods for brain disorder accrual, the number of encounters required and the temporal sequence of those claims. Consistency of measurement across jurisdictions can be challenging given that different provinces have different health administrative data holdings and different rules/incentives/restrictions for health insurance administration, payment and coverage. Despite the above caveats, the estimates of prevalence and incidence included in this project

are a starting point for establishing regular measurement and reporting on brain disorders across the province over time.

There are two important caveats regarding the cost calculations data. First, the costs associated with health system use include all health system contact, not only services related to the care or treatment of an individual brain disorder. For example, if an individual had surgery for a heart condition or received a drug therapy for arthritis in the relevant time period, these costs were counted in the analyses. In other words, it is not possible to draw conclusions regarding the specific costs attributable to a given brain disorder from the data presented in this project. Second, this project does not capture all possible costs associated with brain disorders. Specifically, the project only captures costs from the perspective of the Ontario Ministry of Health (MOH); it does not capture services that are paid for privately (i.e., payments to third-party insurance companies and other out-of-pocket payments for services) by an individual or his or her family, services paid for by other provincial ministries, or informal costs, such as when family members or friends serve as caregivers. The most significant missing attributable costs are those associated with ambulatory care in acute care hospitals. Examples of missing ambulatory care services include specialist clinics, imaging clinics and outpatient rehabilitation clinics. Examples of the sorts of costs that are not included in this project because they are not considered from the

perspective of the MOH are private home care, over-the-counter drugs and health products, and equipment and supplies to support mobility. Although these are important components of the overall cost profile of individuals with brain disorders, it is simply not feasible to capture such costs using existing health administrative data. An important example of these data limitations is the relative absence of prescription drug costs for the majority of individuals younger than 65 years, as these costs are typically covered by thirdparty insurers. This exception is important to note when considering the overall cost analyses and the breakdown of costs by sector as there will be certain brain disorders, such as epilepsy, where drugs are an important component of care in younger populations but not captured in the project's cost calculations. For these brain disorders, the project presents an accurate description of costs to the MOH but not to society more broadly. Prescription drug data were available for selected younger individuals receiving assistance from Ontario Works (a social assistance program for those in temporary financial need) or the Ontario Disability Support Program (a social assistance program for individuals with disabilities who are in financial need); receiving coverage from the Trillium Drug Program or the Special Drugs Program; receiving home care services; or living in long-term care homes.

Appendix B: Brain Health in Ontario Project 13 disorders data

1. Cerebral palsy

Cerebral palsy describes a motor neuron disorder that arises as a result of an injury to the developing brain. Cerebral palsy is characterized by dysfunction in movement and posture that limits activities. The injury can occur before, during or after birth (usually before two years of age). There are many risk factors for cerebral palsy including being born prematurely, having a stroke, and being exposed to infections. Cerebral palsy is a chronic condition

The consensus definition of cerebral palsy includes motor impairment and the frequent co-occurrence of other challenges. These include seizures, as well as impairments in cognitive ability and senses (impaired vision, hearing and abnormal pain), which can contribute to the overall health burden on the child and family. The symptoms of cerebral palsy vary greatly in type and severity.

Early diagnosis of cerebral palsy is crucial as although the brain injury underlying cerebral

palsy does not change over time, related health complications can cause further harm. Drugs and surgery can lessen muscle stiffness and help with musculoskeletal abnormalities; in addition, physiotherapy can play a critical role in helping to maximize motor function.

Individuals with cerebral palsy engage with an interprofessional health team including developmental paediatricians, neurologists, surgeons, physical and occupational therapists, speech-language pathologists, social workers, special education teachers and many others to assist in overcoming everyday hurdles.

Cerebral palsy is not a barrier to living a full and satisfying life. Rather, challenges are often a result of external factors such as inaccessible buildings and transportation, negative societal attitudes, and exclusion from education, recreation, and employment opportunities.



Demographics: Age distribution

igure 1–B: On April 1,	
2019 the majority of people	85+ yr.
vith cerebral palsy were	75–84 yr.
between the ages of 18	10 61.00
and 39 years, with 89% of	40-64 yr.
people being under the age	18–39 yr.
of 65. The mean age of a	05–17 vr
person with cerebral palsy	<u> </u>
vas 35 ± 21 years.	00-04 yr.



Figure 1-A: On April 1, 2019 males accounted for 53% of the 46.732 Ontarians identified with cerebral



Prevalence and incidence over time



Figure 1-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with cerebral palsy are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 0.07 to 0.05 per 1000 people and prevalence increased from 2.91 to 3.19 per 1000 people.

In total, the number of people with cerebral palsy increased from 38,743 in 2011 to 46,732 people in 2019.

Cost Drivers: Incident vs. prevalent





Prevalent case cost drivers



by total box size. The largest cost driver of incident cases was attributable to hospital care (45%), while home care (31%) and hospital care (26%) had the highest costs for prevalent years) compared to the average Ontarian.





Cost Drivers vary by age and sex for prevalent cases

Figure 1-E: Overall, health care costs (in Canadian dollars, 2019) for people with cerebral palsy are higher for the pediatric (0 – 17 years) population compared to adults (18 – 64 years) and are also higher for females than males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst pediatric individuals, home care accounts for the largest cost driver at 53% of all costs, while home care and hospital care drives costs in the adult population at 28% and 27% respectively. Home care is the largest cost driver in both females and males representing 30% and 32% of the health care costs respectively.



Figure 1-F: Of those individuals who were identified as having cerebral palsy between 2011 and 2019, 43% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Epilepsy was the top co-occurring brain disorder, with 16% of those with cerebral palsy also having epilepsy, followed by 14% with a traumatic brain injury or concussion, and 4% having had a stroke.

Mental health and addictions service use



- People with cerebral palsy
- Ontario population
- Figure 1-G: Of those individuals who were identified as having cerebral palsy in 2019, their visit rates for mental health and addictions related services were between 1.6X to 2.2X greater than the general Ontario population, depending on visit type.

2. Dementia

As individuals age, they may see a decline in one or more areas of their thinking, such as memory or decision-making. Changes of this nature seen with normal aging are mild and do not have a significant impact on the ability to live independently. However, if the decline interferes with independence in everyday activities and cannot be explained by another mental disorder like a depression or a delirium (acute confusional state), it is characteristic of a disorder called dementia. In addition to its cognitive and functional manifestations, dementia can be associated with changes in mood and behaviour.

Dementia arises from changes in the structure and function of people's brains. Although there is a growing understanding of dementia and its causes, there is much to learn. Dementia is more common after the age of 65 and affects both men and women. Primarily because women in general live longer than men, there are more women with dementia.

There are many possible causes of dementia. The most common is a condition called Alzheimer's disease, which accounts for approximately six in 10 cases of dementia. Other causes include vascular dementia, Parkinson's disease and Lewy body dementia, fronto-temporal degenerations, traumatic brain injuries, and excessive consumption of alcohol. It is not unusual in older persons with a dementia to find more than one underlying cause.

Doing things like protecting the head from injury, avoiding excessive alcohol intake, following a heart-healthy diet, and living an active physical, mental and social life can decrease a person's risk of developing a dementia. A healthy lifestyle may ward off dementia just as it does other conditions. Because dementia often progresses over time, it is important to ensure early on that advance planning is done. Options for drug treatment of the more common causes of dementia are limited.

Dementia can have a profound impact on the quality of life of the person with the condition and their primary caregiver, who is often a spouse or other family member. Over time, services typically have to be mobilized to support dementia sufferers, with many of them eventually having to move into a care facility.

Demographics: Sex distribution





Demographics: Age distribution

Figure 2-B:	85+ yr.
On April 1, 2019 the	
majority of people with	75 81.00
dementia were over 85	70-04 yi.
years of age, with 92% of	
people being over the age	65–74 yr.
of 65. The mean age of a	
person with dementia was	40–64 vr
82 ± 10 years.	

Figure 2-A: On April 1, 2019 females accounted for 61% of the 196,052 Ontarians identified with dementia.



Prevalence and incidence over time



Figure 2-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with dementia are depicted in orange and blue, respectively. Between 2011 and 2018, incidence decreased from 5.48 to 4.72 per 1000 people and prevalence changed from 23.86 to per 25.16 per 1000 people.

In total, the number of people with dementia increased from 157,168 in 2011 to 194,548 people in 2018 (not shown: 196,052 people in 2019).

Cost Drivers: Incident vs. prevalent





Prevalent case cost drivers



Figure 2-D: In 2019, the average total cost to the health system for an Ontarian with dementia was 1.3X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (46%), while long term care (49%) had the highest cost for prevalent cases.

The average total health care costs for a person with dementia (prevalent case) for 1 year are 4X higher for seniors (65+ years) and 15X higher for adults representing the early onset population (40 - 64 years) compared to the average Ontarian.



Cost Drivers vary by age and sex for prevalent cases

Figure 2-E: Overall, health care costs (in Canadian dollars, 2019) for people with dementia are higher for the senior (65+ years) population compared to adults (40 - 64 years) and are also higher for females than males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst seniors, long term care accounts for the largest cost driver at 50% of all costs, while long term care and hospital care drives costs in the adult population at 38% and 31% respectively. Long term care is the largest cost driver in both females and males representing 55% and 39% of the health care costs respectively.

Co-occurring brain disorders



Figure 2-F: Of those individuals who were identified as having dementia between 2011 and 2019, 48% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Stroke, including transient ischemic attack, was the top co-occurring brain disorder, with 23% of those with dementia also having had a stroke, followed by 11% with a traumatic brain injury or concussion, and 6% having parkinsonism.

Mental health and addictions service use



People with dementia

Ontario population

Figure 2-G: Of those individuals who were identified as having dementia in 2019, their visit rates for mental health and addictions related services were between 3.3X to 5.7X greater than the general Ontario population, depending on visit type.

3. Epilepsy

Epilepsy, sometimes referred to as a "seizure disorder," is a common brain disorder characterized by recurrent seizures. A seizure is a burst of uncontrolled electrical activity in the brain which may cause a disruption in sensation or behaviour. Since many different brain regions may be involved in the development and spreading of seizures, the experience and clinical presentation of epilepsy can take various forms – from feeling anxiety to a loss of consciousness and severe muscle contractions (called tonic– clonic seizures).

Seizures can be provoked by a number of factors including chemical imbalance, head trauma, and illness, while other factors such as stress and fatigue can trigger seizures. Susceptibility to seizures varies between individuals and is also influenced by genetic and environmental factors.

While seizures are often unpredictable, some individuals retain awareness at the onset of, or even throughout, their seizure. Manifestations at the beginning of a seizure, such as a sense of déjà vu, a distortion of reality, a foul smell or a "rising sensation" (typically referred to as an aura) may precede the loss of awareness or consciousness. In some cases, seizures can be lessened by drug, lifestyle and/or surgical intervention. However, some cases of epilepsy are uncontrollable, or "intractable." Intractable epilepsy is severe and may result in physical harm to the body, compromised quality of life and shortened lifespan. Further, persons with intractable epilepsy may be limited in terms of suitable opportunities for education and employment, which undoubtedly impairs quality of life.

Severe seizures, especially those involving unusual movement or behaviour, can appear to be dramatic and may be frightening to some, adding to the misconception that epilepsy is an unpredictable and violent disorder. Additionally, the stigma associated with epilepsy often means that persons who experience seizures face consequences in daily life above and beyond those which are a direct result of the condition.



Demographics: Age distribution

Figure 3-B:	85+ yr.
On April 1, 2019 the	75–84 yr.
majority of people with	65–74 vr
epilepsy were between the	
ages of 40 and 64 years,	40–64 yr.
with 76% of people being	18–39 yr.
under the age of 65. The	05 17.vr
mean age of a person with	00-17 yi.
epilepsy was 48 ± 16 years.	00–04 yı



Prevalence and incidence over time



Figure 3-C-a: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of adult (18+) Ontarians with epilepsy are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 0.58 to 0.60 per 1000 people and prevalence increased from 8.69 to 9.82 per 1000 people.

The number of adults with epilepsy increased from 91,494 in 2011 to 116,957 people in 2019.



Figure 3–C–b: The incidence and prevalence of pediatric (<18) Ontarians with epilepsy are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 0.13 to 0.14 per 1000 people and prevalence increased from 5.52 to 6.16 per 1000 people.

The number of youth with epilepsy increased from 15,236 in 2011 to 17,051 people in 2019.

Cost Drivers: Incident vs. prevalent





Prevalent case cost drivers



Figure 3-D: In 2019, the average total cost to the health system for an Ontarian with epilepsy was 2.3X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (57%). Hospital care was also the largest cost driver of prevalent cases (37%), followed by long term care (15%).

The average total health care costs for a person with epilepsy (prevalent case) for 1 year are 8X higher for pediatric individuals (<18), 5X higher for adults (18 - 64), and 2X higher for seniors (65+) compared to the average Ontarian.



Figure 3-E: Overall, health care costs (in Canadian dollars, 2019) for people with epilepsy are highest for seniors, followed by adults then pediatric individuals. Costs are similar for females than males. The cost drivers, those services that drive health care costs, vary depending on age and sex.

Amongst pediatric individuals, home care accounts for the largest cost driver at 46% of all costs, while hospital care drives costs in the adult and senior population at 42% and 32% respectively.

Hospital care is the largest cost driver in both males and females representing 39% and 34% of the health care costs respectively.



Figure 3-F: Of those individuals who were identified as having epilepsy between 2011 and 2019, 51% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Traumatic brain injury and concussion was the top co-occurring brain disorder, with 17% of those with epilepsy also having a brain injury, followed by 11% having had a stroke, and 10% having had dementia.

Mental health and addictions service use





The most common co-occurring brain disorders are:

%	11%	10%	
c brain or ssion	Stroke	Dementia	

- People with epilepsy
- Ontario population

Figure 3-G: Of those individuals who were identified as having epilepsy in 2019, their visit rates for mental health and addictions related services were between 1.9X to 5.1X greater than the general Ontario population, depending on visit type and age group.

4. Malignant brain tumour

Malignant brain tumours are cancerous growths in the brain and are classified as either primary or secondary brain tumours.

Primary tumours originate in cells of the brain, while secondary tumours originate in other types of cells that travel to the brain. Primary malignant brain tumours grow rapidly and can invade surrounding structures and tissues. Some types of primary malignant brain tumours may spread to other central nervous system sites. Secondary malignant brain tumours, also known as brain metastases, arise from a site outside the brain. An example is lung cancer that has spread to the brain. These types of cancers may also spread to other body organs.

While some tumours can be surgically removed, surgery is not always an option due to the location of the tumour in the brain. In these cases, chemotherapy or radiation may be used to treat the malignant brain tumour.



Demographics: Age distribution

85 . vr

Figure 4-B:

On April 1, 2019 the majority	0J+ yi.
of people with a malignant	75–84 yr.
brain tumour were between	65–74 yr.
the ages of 40 and 64 years,	40-64 vr
with 80% of people being	10 0 i yi.
under the age of 65. The	18–39 yr.
mean age of a person with	05–17 vr.
malignant brain tumour was	,
47 ± 20 years.	00–04 y





Prevalence and incidence over time



Figure 4–C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with a malignant brain tumour are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 7.85 to 7.21 per 100,000 people and prevalence increased from 38.97 to 41.59 per 100,000 people.

In total, the number of people with malignant brain tumour increased from 5,156 in 2011 to 6,103 people in 2019.

Cost Drivers: Incident vs. prevalent

Incident case cost drivers



Prevalent case cost drivers



Figure 4–D: In 2019, the average total cost to the health system for an Ontarian with a malignant brain tumour was 5.1X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of both incident and prevalent cases was attributable to hospital care at 67% and 45% respectively.

The average total health care costs for a person with a malignant brain tumour (prevalent case) for 1 year are 6X higher compared to the average Ontarian.





Cost Drivers vary by age and sex for prevalent cases

Figure 4-E: Overall, health care costs (in Canadian dollars, 2019) for people with a malignant brain tumour are higher for the senior (65+ years) population compared to adults (18 – 64 years) and are similar for females than males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults and seniors, hospital care accounts for the largest cost driver at 47% and 35% of all costs respectively. Hospital care is also the largest cost driver in females and males representing 42% and 48% of the health care costs respectively.



Figure 4-F: Of those individuals who were identified as having a malignant brain tumour between 2011 and 2019, 55% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Epilepsy was the top co-occurring brain disorder, with 22% of those with a malignant brain tumour also having epilepsy, followed by 12% having had a stroke and 11% a traumatic brain injury or concussion.

Mental health and addictions service use





- People with a malignant brain tumour
- Ontario population
- Figure 4-G: Of those individuals who were identified as having a malignant brain tumour in 2019, their visit rates for mental health and addictions related services were similar to the general Ontario population, with the rates ranging from 0.9X to 1.4X the general Ontario population depending on visit type.

5. Motor Neuron Disease

Motor neuron disease is a category of disorders characterized by degeneration of motor neurons that results in progressive weakness and deterioration in swallowing, speech and breathing. Two common forms of motor neuron disease are spinal muscular atrophy and amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease).

Spinal muscular atrophy is a hereditary disease which affects individuals as young as six months of age. A loss of lower motor neurons creates weakness in skeletal muscles of the torso, upper arms and upper legs.

Amyotrophic lateral sclerosis (ALS) typically presents in those between 40 and 70 years of age. ALS causes progressive weakness of the muscles in the mouth, throat, arms and legs. Affected persons may also develop cognitive difficulties or dementia.

ALS is associated with premature mortality, with death often occurring within three to five years of symptom onset. While 5% of ALS cases are hereditary, the definitive cause of the disease remains unknown for the other 95% cases. ALS has no cure, and effective treatment for motor neuron disease remains elusive. Currently, only one drug has been approved for the treatment of ALS, and it has only modest effectiveness – it can only slow the progression of the disease and extend the lifespan by a few months. Without a cure or viable drug therapies, the best available treatment for persons with ALS is supportive care (respiratory care, medical symptom management, rehabilitative therapy, lifestyle modification and palliative care).

Persons with ALS can benefit from an interprofessional team approach to health care. Expertise among the care providers pertaining to the many dimensions of living with ALS – including expertise in nutrition, breathing, communication, exercise and physical activity, occupational therapy, social work, interpersonal relationships, and legal counselling especially in addressing end-of-life decisions – can assist in promoting the best possible quality of life for the affected person.

Demographics: Sex distribution



Demographics: Age distribution

Figure 5–B:

On April 1, 2019 the majority	0J+ yi.
of people with a mater pouron	75–84 yr.
or people with a motor neuron	,
disease were between the	65–74 yr.
ages of 40 and 64 years, with	10_61 vr
55% of people being under the	40-04 yi
age of 65. The mean age of a	18–39 yr.
person with a motor neuron	05–17 yr.
disease was 57 ± 22 years.	,
	00-04 y

85.

Figure 5-A: On April 1, 2019 males accounted for 53% of the 1,174 Ontarians identified with a motor neuron disease.



Prevalence and incidence over time



Figure 5-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with a motor neuron disease are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 2.93 to 2.03 per 100,000 people and prevalence decreased from 8.66 to 7.83 per 100,000 people.

In total, the number of people with a motor neuron disease changed from 1,144 in 2011 to 1,174 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 5-D: In 2019, the average total cost to the health system for an Ontarian with a motor neuron disease was 1.3X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (49%), while home care (27%) and hospital care (22%) had the highest costs for prevalent cases.

The average total health care costs for a person with a motor neuron disease (prevalent case) for 1 year are 24X higher for adults (18 – 64) and 5X higher for seniors (65+) compared to the average Ontarian.

Cost Drivers vary by age and sex for prevalent cases



Figure 5-E: Overall, health care costs (in Canadian dollars, 2019) for people with a motor neuron disease are higher for the senior (65+ years) population compared to adults (18 - 64 years) and are also higher for males than females. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, home care accounts for the largest cost driver at 34% of all costs, while hospital care and complex continuing care drives costs in the adult population at 26% each. Home care is the largest cost driver in both females and males representing 26% and 28% of the health care costs respectively.

Co-occurring brain disorders



Figure 5-F: Of those individuals who were identified as having a motor neuron disease between 2011 and 2019, 58% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Dementia was the top co-occurring brain disorder, with 18% of those with a motor neuron disease also having dementia, followed by 12% with cerebral palsy, and 11% having had a stroke.

Mental health and addictions service use



- People with motor neuron disease
- Ontario population
- Figure 5-G: Of those individuals who were identified as having a motor neuron disease in 2019, their visit rates for mental health and addictions related services were between 1.3X to 3.0X greater than the general Ontario population, depending on visit type.

6. Multiple sclerosis

Multiple sclerosis is considered to be an immune-mediated disease of the central nervous system. The disease affects the protective covering of the nerve (myelin) and damages the nerve fibers (axons). The result may be a wide variety of symptoms, depending on what parts of the central nervous system are affected.

The cause of multiple sclerosis remains unknown. However, it is considered to be a complex disease in which one or more environmental factors act together in a genetically susceptible individual to cause disease. The genetic factors most consistently associated with multiple sclerosis involve the HLA allele. Environmental factors of particular interest include Epstein–Barr virus infection, vitamin D insufficiency, smoking and obesity.

Multiple sclerosis is the most common nontraumatic cause of disability in young adults. Most affected individuals present with symptoms between the ages of 20 and 40 years. Women are affected nearly three times as often as men. The disease is variable from one person to another, and the ability to predict outcomes is limited. Most patients experience a constellation of symptoms, including weakness, sensory symptoms, bowel and bladder dysfunction, fatigue, spasticity, pain and cognitive impairment.

Treatment involves treatment of acute relapses, use of disease-modifying therapies and chronic symptom management. While there have been major advancements in disease-modifying medications that reduce the risk of relapses and delay progression in relapsing forms of multiple sclerosis, there are currently no approved disease-modifying therapies for primary progressive multiple sclerosis.

Multiple sclerosis adversely affects employment and social relationships, and burdens the affected individual, his or her family, the health care system and society. Quality of life is lower in persons with multiple sclerosis compared to the general population and persons with other chronic diseases.





Demographics: Age distribution

Figure 6–B:

On April 1, 2019 the majority	85+ yr
of people with multiple	75_84 vr
clerosis were between the	75-0- yi
ages of 40 and 64 years, with	65_74 vr
77% of people being under the	05 / F yi
age of 65. The mean age of a	40 <u>-</u> 64 vr
person with multiple sclerosis	-0-0+ yi
vas 54 ± 14 years.	20–39 vr
)

Figure 6-A: On April 1, 2019 females accounted for 72% of the 31,470 Ontarians identified with multiple sclerosis.



Prevalence and incidence over time



Figure 6-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with multiple sclerosis are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 12.84 to 13.21 per 100,000 people and prevalence increased from 243.03 to 273.86 per 100,000 people.

In total, the number of people with multiple sclerosis increased from 24,843 in 2011 to 31,470 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 6-D: In 2019, the average total cost to the health system for an Ontarian with multiple sclerosis was 1.3X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (37%), while hospital care (22%) and long term care (20%) had the highest costs for prevalent cases.

The average total health care costs for a person with multiple sclerosis (prevalent case) for 1 year are 5X higher for adults and 2X higher for seniors compared to the average Ontarian.



Cost Drivers vary by age and sex for prevalent cases

Figure 6-E: Overall, health care costs (in Canadian dollars, 2019) for people with multiple sclerosis are higher for senior (65+ years) population compared to adults (20 - 64 years) and are also higher for males than females. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, drugs and hospital care account for the largest cost drivers at 25% and 22% of all costs respectively, while in seniors long term care and hospital care account for the largest cost drivers at 30% and 22% respectively. Hospital care is the largest cost driver in males representing 25% health care costs while long term care and hospital care drive female costs at 21% each.



Figure 6–F: Of those individuals who were identified as having multiple sclerosis between 2011 and 2019, 32% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Traumatic brain injury or concussion was the top co-occurring brain disorder, with 10% of those with brain injury also having multiple sclerosis, followed by 8% having had a stroke, and 7% having dementia.

Mental health and addictions service use



- People with motor multiple sclerosis
- Ontario population
- Figure 6-G: Of those individuals who were identified as having multiple sclerosis in 2019, their visit rates for mental health and addictions related services were between 1.9X to 2.5X greater than the general Ontario population, depending on visit type.

7. Non-malignant Brain Tumor

A brain tumour is a mass of abnormal cells in or around the brain. The cause of most brain tumours is unknown. Several factors may be associated with an increased risk of developing a brain tumour, including radiation exposure, a family history of brain tumours, and advancing age.

Non-malignant brain tumours grow slowly and do not invade surrounding tissues.

While non-malignant brain tumours are noncancerous (benign), their impact on brain function is nonetheless serious and may cause significant neurological symptoms, including behavioural and cognitive changes, dizziness, headaches, seizures, paralysis and even death.

Although some tumours can be surgically removed, surgery is not always an option due to the location of the tumour in the brain. In many cases, radiation is used to treat non-malignant brain tumours.

Demographics: Sex distribution



Demographics: Age distribution

Figure 7-B:

On April 1, 2019 the majority	95 vr
of people with a non-	00+ yi.
malignant brain tumour were	75–84 yr.
petween the ages of 40 and	65–74 yr.
64 years, with 54% of people	40–64 yr.
peing over the age of 65. The	10 20 1
mean age of a person with a	10-39 yr.
non-malignant brain tumour	05–17 yr.
was 65 ± 16 years.	00-04 yr.

Figure 7-A:

On April 1, 2019 females accounted for 70% of the 9,798 Ontarians identified with a non-malignant brain tumour.



Prevalence and incidence over time



Figure 7-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with a non-malignant brain tumour are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 5.68 to 4.98 per 100,000 people and prevalence increased from 52.38 to 64.79 per 100,000 people.

In total, the number of people with a non-malignant brain tumour increased from 6,928 in 2011 to 9,798 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 7-D: In 2019, the average total cost to the health system for an Ontarian with a non-malignant brain tumour was 3.9X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (57%), while hospital care (34%) and long term care (20%) had the highest costs for prevalent cases.

The average total health care costs for a person with a non-malignant brain tumour (prevalent case) for 1 year are 5X higher for pediatric individuals (0 – 17 years), 4X higher for adults (18 - 64 years) and 2X higher for seniors (65+ years) compared to the average Ontarian.





Figure 7-E: Overall, health care costs (in Canadian dollars, 2019) for people with a nonmalignant brain tumour are higher for the senior (65+ years) population compared to adults (18 - 64 years) and are also higher for males than females. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, hospital care accounts for the largest cost driver at 43% of all costs, while hospital care and long term care drives costs in the senior population at 31% and 24% respectively. Hospital care is the largest cost driver in both females and males representing 31% and 40% of the health care costs respectively.

Co-occurring brain disorders



Figure 7-F: Of those individuals who were identified as having a non-malignant brain tumour between 2011 and 2019, 60% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Stroke was the top co-occurring brain disorder, with 15% of those with a non-malignant brain tumour also having had a stroke or transient ischemic attack, followed by 15% having epilepsy and 13% having dementia.

Mental health and addictions service use



The most common co-occurring brain disorders are:



- People with non-malignant brain tumour
- Ontario population
- Figure 7-G: Of those individuals who were identified as having a non-malignant brain tumour in 2019, their visit rates for mental health and addictions related services were between 1.5X to 1.7X greater than the general Ontario population, depending on visit type.

8. Parkinsonism

Parkinsonism describes a cluster of symptoms including tremor, rigidity (stiffness), akinesia or bradykinesia (loss or slowness of voluntary movement) and postural instability (tendency to fall). Parkinsonism typically affects persons aged 50 years and older. The most common cause of parkinsonism is Parkinson's disease. Other causes include other brain disorders, toxins, medications and inherited disorders. These various causes lead to parkinsonism through changes in a region of the brain called the basal ganglia, where evidence suggests a loss of dopamine–producing neurons in the substantia nigra part of the basal ganglia.

An individual with parkinsonism will experience difficulty with initiation and completion of movement, with fine motor skills and with walking. Other difficulties include effects on swallowing, volume of voice, blinking and initiation of spontaneous facial expressions. Symptoms not related to motor function include cognitive impairment, mood disturbance including depression, anxiety and apathy, constipation and bladder disturbance, pain related to rigidity, and disordered sleep – all of which greatly hamper quality of life. In patients with onset before the age of 65, parkinsonism may lead to premature retirement or necessitate disability leave. Parkinsonism also impairs the ability to communicate and interact with the surrounding environment, which often instills a sense of isolation among affected persons. Dopamine replacement medications can help some of the symptoms of parkinsonism, especially in Parkinson's disease, but these effects are usually transient and there are no cures.

Many symptoms of parkinsonism cause complications leading to hospitalization – among them, pneumonia and other infections and fall-related injuries. Further, individuals with parkinsonism may develop significant cognitive impairment and psychiatric changes including hallucinations leading to nursing home placement. Persons with advanced parkinsonism require caregiver help and may become completely dependent for all activities of self-care.





Demographics: Age distribution

Figure 8–B:

On April 1, 2019 the majority	85+ yr
of people with parkinsonism	75_84 vr
were between the ages of 75	75-0- yi
and 84 years, with 81% of	65–74 vr
people being over the age of	0.971.91
65. The mean age of a person	40_64 v
with parkinsonism was 74 \pm	-0-0- yi
12 years.	20-39 vi

Figure 8-A:

On April 1, 2019 males accounted for 56% of the 44,503 Ontarians identified with parkinsonism.



Prevalence and incidence over time



Figure 8-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with parkinsonism are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 46.78 to 49.11 per 100,000 people and prevalence increased from 346.20 to 366.05 per 100,000 people.

In total, the number of people with parkinsonism increased from 35,157 in 2011 to 44,503 people in 2019.

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Cost Drivers: Incident vs. prevalent

Incident case cost drivers



Prevalent case cost drivers



Figure 8-D: In 2019, the average total cost to the health system for an Ontarian with parkinsonism was approximately equal for an incident case and a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (44%), while long term care (30%) and hospital care (27%) had the highest costs for prevalent cases.

The average total health care costs for a person with parkinsonism (prevalent case) for 1 year are 7X higher for adults and 3X higher for seniors compared to the average Ontarian.





Figure 8-E: Overall, health care costs (in Canadian dollars, 2019) for people with parkinsonism are higher for the senior (65+ years) population compared to adults (20 - 64 years) and are also similar for females and males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst senior, long care accounts for the largest cost driver at 32% of all costs, while hospital care drives costs in the adult population at 40% of all costs. Long term care is the largest cost driver in females at 36% and hospital care drives costs in males at 31% of the health care costs.

Co-occurring brain disorders



Figure 8-F: Of those individuals who were identified as having parkinsonism between 2011 and 2019, 62% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Dementia was the top co-occurring brain disorder, with 42% of those with parkinsonism also having dementia, followed by 8% having had a stroke, and 6% having a traumatic brain injury or concussion.

Mental health and addictions service use



People with parkinsonism Ontario population

Figure 8-G: Of those individuals who were identified as having parkinsonism in 2019, their visit rates for mental health and addictions related services were between 3.3X to 11.8X greater than the general Ontario population, depending on visit type.

9. Spina bifida

Spina bifida is a neurological disorder occurring as a result of impaired growth of the neural tube during embryonic development (neural tube is the term for the brain and spinal cord during the embryonic phase of development); this results in varying degrees of damage to the spinal cord and brain. The exact cause of spina bifida is not currently known.

Children born with spina bifida can have a lesion on their spinal cord, making it vulnerable to injury and resulting in significant irreparable damage.

Similar to spinal cord injury, the extent of damage from the lesion depends on where it occurs on the spinal cord, with higher lesions resulting in more damage.

Three types of spina bifida are most common and range in severity. Myelomeningocele is the most severe where the spinal cord and the meninges (its protective covering) both push through the open part of the spine. Meningocele describes the situation when only the meninges push through the opening and typically no nerve damage occurs, although individuals may have minor disabilities. Spina bifida occulta is also referred to as 'hidden' because the protrusion is covered by skin and does not cause harm. There is no known cure for spina bifida. However, some forms of spina bifida are treatable with surgery soon after birth in order to prevent infection and further damage to the spinal cord. Fetal surgery prior to birth is also available for some forms of spina bifida. Individuals with spina bifida may require assistive devices to help with walking, and surgery may also be necessary to help manage ongoing complications.

Demographics: Sex distribution



Demographics: Age distribution

Figure 9-B:

On April 1, 2019 the majority	
of people with spina bifida	85+ yr.
vere between the ages of 18	75–84 yr.
nd 39 years, with 90% of	65–74 yr.
people being under the age of	40-64 yr
5. The mean age of a person	10 20
vith spina bifida was 38 ±	10-39 yr.
9 years.	05–17 yr.
	00-04 yr

Figure 9-A:

On April 1, 2019 females accounted for 61% of the 5,333 Ontarians identified with spina bifida.



Prevalence and incidence over time



Figure 9-C: Live birth prevalence is the number of new people born with the disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The live birth prevalence and prevalence of Ontarians with spina bifida are depicted in orange and blue, respectively. Between 2011 and 2019, live birth prevalence changed from 34.88 to 22.24 per 100,000 people and prevalence increased from 31.48 to 36.43 per 100,000 people.

In total, the number of people with spina bifida increased from 4,189 in 2011 to 5,333 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 9-D: In 2019, the average total cost to the health system for an Ontarian with spina bifida was 5.8X more at birth than for a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of live birth cases was attributable to hospital care (83%), while hospital care (42%) and home care (21%) had the highest costs for prevalent cases.

The average total health care costs for a person with spina bifida (prevalent case) for 1 year are 6X higher for adults (18 – 64 years) and 18X higher for pediatric individuals (0 – 17 years) compared to the average Ontarian.





Figure 9-E: Overall, health care costs (in Canadian dollars, 2019) for people with spina bifida are higher for the pediatric (0 – 17 years) population compared to adults (18 – 64 years) and are also higher for males than females. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst both pediatric individuals and adults, hospital care accounts for the largest cost driver at 45% and 43% of all costs respectively. Hospital care is the largest cost driver in both females and males representing 40% and 44% of the health care costs respectively.



Figure 9-F: Of those individuals who were identified as having spina bifida between 2011 and 2019, 44% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Cerebral palsy was the top co-occurring brain disorder, with 15% of those with spina bifida also having cerebral palsy, followed by 13% with a traumatic brain injury or concussion, and 5% having epilepsy.

Mental health and addictions service use



People with spina bifida

Ontario population

Figure 9-G: Of those individuals who were identified as having spina bifida in 2019, their visit rates for mental health and addictions related services were between 1.5X to 2.5X greater than the general Ontario population, depending on visit type.

10. Schizophrenia

Schizophrenia (including schizophrenia spectrum and schizoaffective disorders) is a complex brain disorder that affects one's ability to differentiate between what is and is not reality. Symptoms of schizophrenia are considered either positive or negative.

The positive symptoms include the occurrence of delusions (false beliefs that are not amenable to change even in light of conflicting evidence, such as beliefs that one is going to be harmed, for example), hallucinations (elaborate sensory experiences such as hearing voices or seeing things that are not real), skewed perceptions (such as abnormalities in spatial awareness and sense of self) and disorganized thinking or behaviour.

The negative symptoms affect aspects of cognition, expression of emotion, and motivation and include declines in attention, memory and deficits of normal emotional responses.

Schizophrenia typically presents in individuals between 16 and 30 years of age. Early on, schizophrenia may resemble a general anxiety or depression, with increasing difficulty with attention, relaxation, and sleep. A person may withdraw from social settings and usual activity, which can be upsetting and problematic for friends, family, and employers.

When schizophrenia reaches an active, or psychotic, stage, the person may begin to behave erratically in response to having unusual beliefs or perceptions, or because their thoughts have become disorganized.

Schizophrenia is both chronic and episodic in nature, worsening and improving by varying degrees. Many individuals with schizophrenia grow estranged from family and have difficulty holding consistent employment.

There is no known cure for schizophrenia, and the ebb and flow of the severity of symptoms makes treatment complex. Treatment involves using a combined approach of medication and psychosocial interventions. The positive symptoms can often be controlled with medication. The negative symptoms, however, are more persistent, difficult to treat, and often have the greatest impact on quality of life and disability.

Demographics: Sex distribution



Demographics: Age distribution

Figure 10–B:

On April 1, 2019 the majority	85+ yr.
of people with schizophrenia	75–84 yr
were between the ages of 40	6E 74
and 64 years, with 81% of	65-74 yr
people being under the age of	40-64 yı
65. The mean age of a person	18_39 vr
with schizophrenia was 50 \pm	10 J) yi
16 years.	05–17 yr

Figure 10-A:

On April 1, 2019 males accounted for 57% of the 129,540 Ontarians identified with schizophrenia.



Prevalence and incidence over time



Figure 10-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with schizophrenia are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 0.47 to 0.41 per 1000 people and prevalence increased from 7.81 to 8.84 per 1000 people.

In total, the number of people with schizophrenia increased from 102,928 in 2011 to 129,540 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 10-D: In 2019, the average total cost to the health system for an Ontarian with schizophrenia was 1.6X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of both incident and prevalent cases was attributable to hospital care at 67% and 52% of all costs respectively.

The average total health care costs for a person with schizophrenia (prevalent case) for 1 year are 7X higher for adults (18 - 64) and 3X higher for seniors (65+) compared to the average Ontarian.



Cost Drivers vary by age and sex for prevalent cases

Figure 10-E: Overall, health care costs (in Canadian dollars, 2019) for people with schizophrenia are higher for seniors (65+ years) compared to adults (18 - 64 years) and are similar for females and males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, hospital care accounts for the largest cost driver at 59% of all costs, while hospital care and long term care drives costs in the seniors at 36% and 32% respectively. Hospital care is the largest cost driver in both females and males representing 45% and 58% of the health care costs respectively.

Co-occurring brain disorders

People with schizophrenia alone



Figure 10-F: Of those individuals who were identified as having schizophrenia between 2011 and 2019, 33% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Traumatic brain injury or concussion was the top co-occurring brain disorder, with 13% of those with schizophrenia also having brain injury, followed by 10% with dementia, and 4% with epilepsy.

Mental health and addictions service use



- People with schizophrenia
- Ontario population
- Figure 10-G: Of those individuals who were identified as having schizophrenia in 2019, their visit rates for mental health and addictions related services were between 8.4X to 50.3X greater than the general Ontario population, depending on visit type.

11. Traumatic Spinal Cord Injury

A spinal cord injury is an injury to any part of the spinal cord. The spinal cord is responsible for delivering nerve impulses (communication) between the brain and the rest of the body. Damage to the spinal cord can result in weakness or altered sensation (touch, pain, temperature) in areas of the body below the affected level of the spinal cord. It can also be associated with bowel and/or bladder dysfunction.

An injury to the spinal cord can be either partial or complete. With a partial injury to the spinal cord, some communication can still take place between the brain and the rest of the body via the spinal cord. In this case there is only a partial disruption to neurological function (e.g., motor or sensory function). In cases of complete injury, the transmission of information is completely cut off to the parts of the body below the area of injury.

The site of injury on the spinal cord determines how much of the body is affected such that the higher the injury on the spinal cord, the more parts of the body affected. For example, a neck injury can damage the cervical area of the spinal cord, which can affect the arms and legs and lead to quadriplegia. An injury lower down on the spinal cord can leave someone with paraplegia, where the legs are affected but the arms are spared.

Individuals with spinal cord injuries may experience a variety of complications including chronic pain, breathing difficulties and dysfunction of the bladder and bowel. The advances in emergency care can help minimize spinal cord damage, while intensive rehabilitation can help to restore some movement and sensation. Rehabilitation programs typically involve a combination of physical therapy and skillbuilding activity.



Demographics: Age distribution

Figure 11–B:

On April 1, 2019 the majority	85+ yr
of people with a spinal cord	75_84 vr
njury were between the ages	7 J=0 + yi.
of 40 and 64 years, with 65%	65–74 vr
of people being under the	0.571.91
age of 65. The mean age of	40-64 vr
a person with a spinal cord	чо-оч уі.
njury was 58 ± 16 years.	18–39 yr.

Figure 11-A:

On April 1, 2019 males accounted for 70% of the 6,518 Ontarians identified with spinal cord injury.



Prevalence and incidence over time



Figure 11-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with a spinal cord injury are depicted in orange and blue, respectively. Between 2011 and 2019, incidence increased from 2.97 to 4.35 per 100,000 people and prevalence increased from 46.86 to 54.82 per 100,000 people.

In total, the number of people with a spinal cord injury increased from 4,910 in 2011 to 6,518 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 11-D: In 2019, the average total cost to the health system for an Ontarian with a spinal cord injury was 6.1X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (50%) followed by rehab (24%), while hospital care (35%) followed by home care (18%) had the highest costs for prevalent cases.

The average total health care costs for a person with a spinal cord injury (prevalent case) for 1 year are 8X higher for adults and 2X higher for seniors compared to the average Ontarian.





Figure 11-E: Overall, health care costs (in Canadian dollars, 2019) for people with a spinal cord injury are higher for seniors(65+ years) compared to adults (18 - 64 years) and are also similar for females and males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, hospital care accounts for the largest cost driver at 40% of all costs, while hospital care and long term care drives costs in the senior population at 30% and 16% respectively. Hospital care is the largest cost driver in both females and males representing 30% and 38% of the health care costs respectively.

Co-occurring brain disorders



Figure 11-F: Of those individuals who were identified as having a spinal cord injury between 2011 and 2019, 47% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Traumatic brain injury or concussion was the top co-occurring brain disorder, with 22% of those with a spinal cord injury also having a brain injury, followed by 10% having had a stroke, and 8% having dementia.

Mental health and addictions service use



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- People with spinal cord injury
- Ontario population

Figure 11-G: Of those individuals who were identified as having a spinal cord injury in 2019, their visit rates for mental health and addictions related services were between 1.8X to 5.1X greater than the general Ontario population, depending on visit type.

12. Stroke and transient ischemic attack (TIA)

A stroke is a sudden brain injury caused by the interruption of blood flow to or sudden bleeding into a part of the brain. Broadly, there are two types of strokes: ischemic (85%) and hemorrhagic (15%).

An ischemic stroke is caused by interruption in blood flow due to sudden blockage of a brain artery. A hemorrhagic stroke is caused by rupture of a brain artery leading to bleeding into the brain or into the spaces around the brain. Interruption of normal blood flow prevents the brain from receiving adequate nutrients (e.g., glucose and oxygen) necessary for survival. Bleeding into the brain causes compression and damage from swelling. Stroke results in permanent death of one region of the brain – it is a form of permanent brain damage.

The effects of a stroke depend on the location and severity of damage. Most commonly, a stroke is associated with weakness on one side of body, difficulty with speech or understanding speech and loss of vision. Stroke can also result in cognitive difficulty, loss of sensation or imbalance.

A transient ischemic attack is the mildest form of ischemic stroke. It is a short-lived stroke lasting typically less than 30 minutes. A transient ischemic attack is often a warning sign for a future major ischemic stroke.

A stroke can be a life-altering event, or a fatal event. In Canada, approximately one in six patients with stroke will die in the first 30 days. Stroke survivors may face great limitation in ability, necessitating alternate methods and assistance for carrying out everyday activities. It is common for older adults who have suffered stroke to require long-term care. However, almost every stroke survivor can recover some function. Treatments for acute ischemic stroke vary, but include: clot-busting drugs or advanced endovascular treatment in appropriately selected patients. In order to improve functional recovery, patients may be offered physiotherapy, occupational therapy, speech-language therapy and adjusted living (in the case of paralysis).

The best treatment for stroke is prevention. The likelihood of having a stroke can be greatly reduced by controlling blood pressure. Other modifiable risk factors for stroke include smoking, high alcohol intake, poor diet, high cholesterol and substance abuse. It is important to concurrently maximize physical activity, healthy diet and good sleeping habits.





Demographics: Age distribution

Figure 12–B:

On April 1, 2019 98% of	85+ yr
people having had a stoke or	75_84 yr
TIA were over the age of 40.	75-0 - yi.
The mean age of a person who	65–74 vr
has had a stoke or TIA in the	J
Jast was 72 ± 14 years.	40-64 yr.
	20–39 yr.

Figure 12-A:

On April 1, 2019 males accounted for 50% of the 367,858 Ontarians identified with stroke or TIA.



Prevalence and incidence over time



Figure 12-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with stoke or TIA are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 1.3 to 1.34 per 1000 people and prevalence increased from 29.06 to 30.64 per 1000 people.

In total, the number of people with stroke or TIA increased from 295,149 in 2011 to 367,858 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 12–D: In 2019, the average total cost to the health system for an Ontarian with stroke or TIA was 3X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (49%) followed by rehab (17%), while hospital care (33%) and long term care (22%) had the highest costs for prevalent cases.

The average total health care costs for a person with stroke or TIA (prevalent case) for 1 year are 5X higher for adults and 2X higher for seniors compared to the average Ontarian.



Cost Drivers vary by age and sex for prevalent cases

Figure 12-E: Overall, health care costs (in Canadian dollars, 2019) for people with a stroke or TIA are higher for the senior (65+ years) population compared to adults (20 - 64 years) and are also higher for females than males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, hospital care accounts for the largest cost driver at 42% of all costs, while hospital care and long term care drives costs in the senior population at 31% and 25% respectively. Hospital care is the largest cost driver in both females and males representing 29% and 37% of the health care costs respectively.

Co-occurring brain disorders



Figure 12-F: Of those individuals who were identified as having a stroke or TIA between 2011 and 2019, 41% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Dementia was the top co-occurring brain disorder, with 24% of those with stroke or TIA also having dementia, followed by 10% with a traumatic brain injury or concussion, and 4% with epilepsy.

Mental health and addictions service use





People with stroke or TIA

Ontario population

Figure 12-G: Of those individuals who were identified as having a stroke or TIA in 2019, their visit rates for mental health and addictions related services were between 1.9X to 3.6X greater than the general Ontario population, depending on visit type.

13. Traumatic Brain Injury including Concussion

Traumatic brain injury (TBI) is a form of acquired brain injury where there is disruption of brain function due to a traumatic event. This can occur when the head is struck or strikes an object, or undergoes rapid acceleration and deceleration movements. Traumatic brain injury is usually classified as mild which includes concussion. moderate or severe.

There are many causes of traumatic brain injury (e.g., falls, sport-related injuries, motor vehicle accidents). It occurs among persons of all ages but some individuals are more susceptible than others, in particular children, teenagers and seniors.

Males are at a greater risk than females. Traumatic brain injury can occur as a single isolated event, but it can also occur repeatedly especially in certain sports (e.g., boxing, hockey, football).

The symptoms of traumatic brain injury depend on the location and extent of the damage to the brain. While loss of consciousness may result from traumatic brain injury, it is a common misconception that loss of consciousness must occur to have traumatic brain injury.

A person with mild traumatic brain injury may experience head pain, disorientation, dizziness, nausea and vomiting. There may be visual problems, sleep disruption, mood changes or lapses in memory. The same symptoms are amplified in moderate traumatic brain injury. Severe traumatic brain injury involves additional disorders of consciousness, weakness, seizures, coma, and even death. The long-term consequences of the injury may be apparent immediately or not until long after the event.

The best treatment for traumatic brain injury is prevention. While much research has gone into studying treatments for traumatic brain injury, no specific treatment exists. Instead, the management of traumatic brain injury focuses on supportive care, rehabilitation and helping the individual adapt to the injury. The impact on a person's quality of life and the whole family varies depending on the extent and severity of the injury.



Demographics: Age distribution

Figure 13–B:

On April 1, 2019 the majority	0.5
of people with a TBI or	85+ yr.
concussion were between the	75–84 yr.
ages of 18 and 39 years, with	65–74 yr.
87% of people being under	40-64 vr
the age of 65. The mean age	10.00
of a person with a TBI or	18–39 yr.
concussion was 37 ± 21 years.	05–17 yr.
	00-04 yr

Figure 13–A:

On April 1, 2019 males accounted for 55% of the 1,475,726 Ontarians identified with a TBI or concussion.



Prevalence and incidence over time



Figure 13-C: Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with a TBI or concussion are depicted in orange and blue, respectively. Between 2011 and 2019, incidence increased from 4.89 to 7.28 per 1000 people and prevalence increased from 71.49 to 100.45 per 1000 people.

In total, the number of people with a TBI or concussion increased from 949,761 in 2011 to 1,475,726 people in 2019.

Cost Drivers: Incident vs. prevalent



Prevalent case cost drivers



Figure 13-D: In 2019, the average total cost to the health system for an Ontarian with a TBI or concussion was 1.8X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident and prevalent cases was attributable to hospital care at 49% and 38% of all health care costs respectively.

The average total health care costs for a person with a TBI or concussion (prevalent case) for 1 year are 1.4X higher for adults and 2X higher for seniors compared to the average Ontarian.



Cost Drivers vary by age and sex for prevalent cases

Figure 13-E: Overall, health care costs (in Canadian dollars, 2019) for people with a TBI or concussion are higher for the senior population (65+ years) compared to adults (18 – 64 years) and are higher for females than males. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults and seniors, hospital care accounts for the largest cost driver at 43% and 32% of all costs respectively. Hospital care is also the largest cost driver in both females and males representing 34% and 41% of the health care costs respectively.



Figure 13-F: Of those individuals who were identified as having a TBI or concussion between 2011 and 2019, 12% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Dementia was the top co-occurring brain disorder, with 4% of those with a brain injury also having dementia, followed by 3% having had a stroke, and 2% with epilepsy.

Mental health and addictions service use



People with traumatic brain injury or concussion Ontario population

Figure 13-G: Of those individuals who were identified as having a TBI or concussion in 2019, their visit rates for mental health and addictions related services were between 1.8X to 2.7X greater than the general Ontario population, depending on visit type.

Appendix C: codes and conditions

Brain disorders featured in the report and their related algorithms

Brain Disorder	Evidence Grade	Reference	Algorithm	ICD-09 (CM) Codes	ICD-10 Codes	OHIP Dx Codes	ODB Drugs Name	OMHRS Codes	Age Restriction
Brain tumor, non- malignant (benign)	111	Clinical and health administrative data expertise	1 hospitalization record	225.0, 225.2	D32.0, D32.9, D33.0, D33.1, D33.2	N/A	N/A	N/A	None
Brain tumor, primary malignant	1	Validated algorithm	l cancer registry record with histologic confirmation	OCR: ICD (curr_topog_cd) = C71	N/A	N/A	N/A	N/A	None
Cerebral palsy	II	Accepted algorithm	1 hospitalization record or 1 physician claim record	343	G80	343	N/A	N/A	For incidence: Birth to 20 years of age. after 20 years: incidence = 0
Dementia (including Alzheimer's disease)	1	Accepted/validated algorithm	1 hospitalization record or 3 physician claim records at least 30 days apart in a 2-year period or 1 prescription drug reimbursement record	46.1, 290.0, 290.1, 290.2, 290.3, 290.4, 294, 331.0, 331.1, 331.5,	F00, F01, F02, F03, G30		Cholinesterase inhibitors = Donepezil, Galantamine, Memantine, Rivastigmine, Tacrine	N/A	40 years and older
Epilepsy	1	Validated algorithm	For individuals <18 years: 3 physician claim records at least 30 days apart in a 2-year period For individuals 18 years and older: 1 hospitalization record or 3 physician claim records at least 30 days apart in a 2-year period	345.0, 345.1, 345.4, 345.5, 345.6, 345.7, 345.8, 345.9	G40.x	345	N/A	N/A	None

Brain Disorder	Evidence Grade	Reference	Algorithm	ICD-09 (CM) Codes	ICD-10 Codes	OHIP Dx Codes	ODB Drugs Name	OMHRS Codes	Age Restriction
Motor neuron disease	II	Accepted algorithm ^c	l hospitalization record or l physician claim record	335	G12	335	N/A	N/A	None
Multiple sclerosis	1	Validated algorithm	1 hospitalization record or 5 physician claim records in a 2-year period	340	G35	340	N/A	N/A	20 years and older
Parkinsonism (including Parkinson's disease)	I	Validated algorithm	1 hospitalization record or 2 physician claim records at least 30 days apart in a 1-year period	332.0, 332.1	F02.3, G20, G21.0, G21.1, G21.2, G21.3, G21.4, G21.8, G21.9, G22	332	N/A	N/A	20 years and older
Schizophrenia	11	Accepted algorithm	1 hospitalization record or 3 physician claim records in a 3-year period	295	F20, F25	295	Cholinesterase inhibitors = Donepezil, Galantamine, Memantine, Rivastigmine, Tacrine	DSM-IV= 295	None
Spina bifida	11	Accepted algorithm ^e	1 hospitalization record	741	Q05, Q07.0	N/A	N/A	N/A	None
Spinal cord injury	II	Accepted algorithm ^c	1 hospitalization record	806, 907.2, 952	S14.0, S14.1, S24.0, S24.1, S34.0, S34.1, S34.3, T06.0, T06.1	N/A	N/A	N/A	18 years and older
Stroke and transient ischemic attack	1	Validated algorithmd adapted to clinical expert feedback	Incidence: 1 hospitalization record Prevalence: 1 hospitalization record or 2 physician claim records in a 1-year period	362.3, 430, 431, 434.0, 434.1, 434.9, 435.0, 435.1, 435.2, 435.3, 435.8, 435.9, 436	G45.0, G45.1, G45.2, G45.3, G45.8, G45.9, H34.0, H34.1, I60, I61 (except I61.7), I63.0, I63.1, I63.2, I63.3, I63.4, I63.5, I63.8, I63.9, I64	435, 436, 432	N/A	N/A	20 years and older
Traumatic brain injury	11	Accepted algorithm ^c	1 hospitalization record	3102, 8001, 8003, 8011, 8013, 8026, 8027, 8031, 8033, 8041, 8043, 850, 851, 852, 853, 854, 9071, 925	F072, S020, S021, S023, S027, S028, S029, S06, S07, T020, T060, T905	850, 854	N/A	N/A	None

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- Written communication with Catherine
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 Disease Surveillance System for Neurological
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- Written communication with Jocelyn Rouleau, Maternal Health and Infant Section, Public Health Agency of Canada, June 2013







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