Brain Disorders in Ontario:

Prevalence, Incidence and Costs from Health Administrative Data

July 2015

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About the Organizations Involved in this Report

The Institute for Clinical Evaluative Sciences

The Institute for Clinical Evaluative Sciences (ICES) is an independent, non-profit organization that uses population-based health information to produce knowledge on a broad range of health care issues. ICES' unbiased evidence provides measures of health system performance, a clearer understanding of the shifting health care needs of Ontarians, and a stimulus for discussion of practical solutions to optimize scarce resources.

Key to ICES' work is its ability to link population-based health information, at the patient level, in a way that ensures the privacy and confidentiality of personal health information. Linked databases reflecting 13 million of 34 million Canadians allow researchers to follow patient populations through diagnosis and treatment, and to evaluate outcomes.

ICES receives core funding from the Ontario Ministry of Health and Long-Term Care. In addition, ICES scientists and staff compete for peer-reviewed grants from federal funding agencies, such as the Canadian Institutes of Health Research, and project-specific funds from provincial and national organizations. ICES knowledge is highly regarded in Canada and abroad, and is widely used by government, hospitals, planners, and practitioners to make decisions about health care delivery and to develop policy.

The Ontario Brain Institute

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.

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List of Exhibits

List of Abbreviations

DAD: Discharge Abstract Database

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, 4th Edition

ICD-9: International Classification of Diseases, 9th Revision

ICD-10: International Classification of Diseases, 10th Revision

ICES: Institute for Clinical Evaluative Sciences

LHIN: Local Health Integration Network

MOHLTC: Ministry of Health and Long-Term Care

NACRS: National Ambulatory Care Reporting System

NPHSNC: National Population Health Study of Neurological Conditions

OBI: Ontario Brain Institute

OCR: Ontario Cancer Registry

ODB: Ontario Drug Benefit claims database

OHIP: Ontario Health Insurance Plan database

OMHRS: Ontario Mental Health Reporting System

Introduction

Motivation

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. Despite this exquisite function, there are a number of ways for the brain and related nervous system to become impaired. The inherent intricacy of the interconnected systems leads to complexity in resulting brain disorders, which manifest in various forms and may differ in occurrence and severity over the life course. The various conditions – age-related neurodegenerative diseases such as Alzheimer's and Parkinson's disease, congenital disorders, other neurological disorders, trauma and injury to the brain or spinal cord, and mental illnesses like schizophrenia – all result in changes to and disruption of brain function. As such, it may be informative to consider 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 and spinal cord.

Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data was conceived and developed through a collaboration involving the Ontario Brain Institute (OBI) and the Institute for Clinical and Evaluative Sciences (ICES) to address knowledge gaps and provide insights into brain disorders in Ontario. The report was created with the following objectives:

- To estimate the prevalence and incidence of brain disorders from population-based health administrative data;
- To provide an overview of costs associated with all publically provided health care services used by individuals with brain disorders;
- To present evidence to inform program and resource planning, policy and decision-making regarding brain disorders in the Ontario health system.

According to a recent estimate, one in three individuals will directly experience some type of brain disorder in their lifetime,[1] and this does not take into account the impact on family and friends, caregivers, co-workers, and society as a whole. Brain disorders represent a wide range of neurological and mental health conditions that tend to be under-recognized for various reasons, including poor detection, diagnosis or misdiagnosis within primary and acute care, and a lack of sufficient contact between individuals and the health system due to real or perceived societal stigmas. Often, the reasons underlying poor recognition (and treatment) of these conditions vary by brain disorder.

Despite the challenges in recognition and reporting, brain disorders represent an emerging public health concern for the developed and developing worlds.[2] Considering the chronic nature of brain disorders, affected individuals often require lifelong treatment, management and care. This becomes an even greater concern as aging populations live longer and the prevalence and co-occurrence of chronic conditions increases. As of 2010, the global burden of brain disorders was estimated to account for 10.4% of disability-adjusted life years, up from 7.3% in 1990,[2] and this collective burden now exceeds other chronic conditions, including cancer and cardiovascular disease.[3] While these estimates provide important information and indicate an increasing global awareness about brain disorders, an assessment of their current impact across Canada and in individual provinces is lacking.

Although informative, previous systematic reviews and meta-analyses of the prevalence and incidence of neurological conditions have noted several limitations in the data sources, methodological approach and scope of published studies, including the relative absence of recent Canadian data.[4,5] In addition, individual studies tend to focus on single or small groupings of disorders and do not capture the totality of the number of individuals living with brain disorders and associated treatment costs. To date, there have also been two public reports that have profiled the epidemiology and impact of brain disorders in Canada, one national and one provincial. *The Burden of Neurological Diseases, Disorders and Injuries in Canada,* released in 2007, highlighted the significant disability, health system use and costs associated with

11 neurological conditions.[6] However, absent from this national report were region-specific estimates of the prevalence and economic impact of these conditions. The 2012 publication *Opening Eyes, Opening Minds: The Ontario Burden of Mental Illness and Addictions Report* estimated the disease burden and mortality associated with nine prevalent mental illnesses and addictions in Ontario, but did not address the broader array of brain disorders or provide information on the economic impact of these conditions.[7]

Given the restrictions of previous research in this area, there was a clear need to provide an Ontario-specific, population-based assessment of the prevalence and incidence of brain disorders as well as the associated costs related to health system interaction by individuals with these disorders. This report is an important first step in ensuring that affected individuals and their family caregivers receive the services and care they require, and that the health system continues to build the capacity to meet their needs, now and in the future. Through this OBI-ICES collaboration, the data holdings and health services research expertise of ICES were utilized and enhanced with input from clinical content experts and the knowledge translation team of OBI.

This report was also informed by *Mapping Connections: An Understanding of Neurological Conditions in Canada*, the recent overview of the National Population Health Study of Neurological Conditions (NPHSNC).[5] The NPHSNC was a federally funded, Canada-wide research initiative involving a unique partnership between the Government of Canada (through the Public Health Agency of Canada and Health Canada) and Neurological Health Charities Canada, a collective of 24 organizations representing individuals and families living with neurological conditions.[5] Detailed results from the NPHSNC studies are now appearing in the research literature. Through sharing of information, this report builds on these existing investments to provide an objective and comprehensive view of the current landscape of brain disorders in Ontario.

This report focuses on 13 brain disorders: benign brain tumour, primary malignant brain tumour, cerebral palsy, dementia (including Alzheimer's disease), epilepsy, motor neuron disease, multiple sclerosis, parkinsonism (including Parkinson's disease), schizophrenia, spina bifida, spinal cord injury, stroke and transient ischemic attack, and traumatic brain injury. While it is by no means exhaustive, this list represents several common brain disorders whose incidence, prevalence and cost may be reasonably estimated with health administrative data. As a group, these brain disorders demonstrate the breadth and diversity of conditions affecting Ontarians. Additional efforts will be required to expand the current scope of inquiry to the various brain disorders not captured in this report, including other mental illnesses and neurological and neurodevelopmental disorders.

Overview

The report is divided into three main sections: Methods, Findings and Concluding Considerations. The Methods section (Chapter 2) outlines the algorithms used to identify the brain disorders in the health administrative data. This section also describes the analyses for estimating prevalence and incidence, and outlines the calculations for the costs associated with health system use. The Findings (Chapters 3 through 15) present the estimated prevalence, incidence and costs associated with health system use for each of the 13 brain disorders. In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. The reasons for this are explained in more detail in Chapter 2. It is important to note that only individuals who have made contact with the health system *and received a diagnosis or drug therapy related to their documented brain disorder* are included in the estimates.

The findings presented in this report provide an objective baseline assessment of brain disorders in Ontario, including the following:

- Number and proportion of persons with the selected brain disorder by sex, age group, rural or urban residence, and neighbourhood income quintile as of 2010/11;

- Age- and sex-adjusted prevalence and incidence of the selected brain disorder in Ontario and by Local Health Integration Network from 2004/05 to 2010/11 (see **Exhibit 1.0** for a map depicting LHIN boundaries);

- Crude prevalence of the selected brain disorder by sex and age group from 2004/05 to 2010/11;

- Distribution of the costs associated with one year of health system use for persons with the selected brain disorder, by age group; and

- Proportion of costs associated with one year of health system use for persons with the selected brain disorder, by type of health care service and age group.

In addition, each chapter contains a simple clinical overview of the associated brain disorder. Also, to include the perspectives of individuals with these conditions and their families, OBI engaged its partner organizations to contribute short remarks highlighting some of the challenges of living with brain disorders.

The final section (Chapter 16) highlights the demographic, prevalence, incidence and cost patterns observed across the brain disorders. It also discusses the report's strengths, limitations and caveats, as well as next steps.

EXHIBIT 1.0 Map of Local Health Integration Networks in Ontario

CHAPTER 2

Methods

Overview

This chapter outlines the definitions and diagnostic codes used to identify the 13 brain disorders in the linked health administrative data. To address the report's objectives and provide comparable data consistently across brain disorders, a common approach was required. This chapter describes the methods used to calculate prevalence and incidence as well as the calculation of costs associated with health system use. These costs were calculated based on using a health care service funded by the Ontario Ministry of Health and Long-Term Care (MOHLTC), regardless of the underlying reason for treatment (i.e., costs were not necessarily directly related to the treatment or management of a brain disorder).

Brain Disorder Definitions

Diagnostic codes and algorithms for identifying individuals with the relevant brain disorders in the health administrative data were identified through several channels:

- communications with Public Health Agency of Canada staff and expert advisors, including Catherine Pelletier and Asako Bienek of the Canadian Chronic Disease Surveillance System Neurological Conditions Working Group, Dr. Christina Bancej of the Working Group on Health and Economic Modelling of Neurological Conditions, and Jocelyn Rouleau of the Maternal and Infant Health Section;
- consultation with ICES scientists and other health services researchers;[9-14] and
- a search of the English-language peer-reviewed literature.[4,8,15]

The identified brain disorders and corresponding algorithms are listed in **Exhibit 2.1**. Where possible, these definitions were based on previously validated or commonly used algorithms.[9-14,16] Brain disorders such as autism spectrum disorders, depression, and drug and alcohol addictions were not included in this report out of concerns about the ability of health administrative data to capture these disorders accurately and/or because the available algorithms had not been validated.

A Note on Interpreting the Prevalence and Incidence Estimates in this Report

Increasingly, it is recognized that health administrative data can play a role in disease surveillance. Recent work funded under the Public Health Agency of Canada's National Population Health Study of Neurological Conditions[5] illustrates that it is feasible to estimate both prevalence and incidence of several neurological conditions using health administrative data sources. The large number of persons covered in these data holdings improves the precision and generalizability of estimates, particularly among older populations who are known to have regular health system contact. The longitudinal aspect of health administrative data is also appealing for reporting prevalence and incidence as, depending on the jurisdiction, many years of data and longitudinal time trends are available.

However, these data are not collected for research purposes and are therefore not without limitations. In particular, 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 report are a starting point for establishing regular measurement and reporting on brain disorders across the province over time.

EXHIBIT 2.1 Brain disorders featured in the report and their related algorithms

Brain Disorder	Algorithm[a]	Evidence Grade[b]	Reference	Algorithm Measure of Performance (with 95% Confidence Intervals)	Age Restriction
Brain tumour, benign	1 hospitalization record	III	Clinical and health administrative data expertise	Not available	None
Brain tumour, primary malignant	1 cancer registry record with histologic confirmation	I	Validated algorithm[16]	Not available	None
Cerebral palsy	1 hospitalization record or 1 physician claim record	II	Accepted algorithm[c]	Not available	None
Dementia (including Alzheimer's disease)	*For individuals younger than 66 years:* 1 hospitalization record or 3 physician claim records at least 30 days apart in a 2-year period *For individuals 66 years and older:* 1 hospitalization record or 3 physician claim records at least 30 days apart in a 2-year period or 1 prescription drug reimbursement record	I	Accepted algorithm[13,d]	Sensitivity: 79.3 (72.9–85.8) Specificity: 99.1 (98.8–99.4) PPV: 80.4 (74.0–86.8) NPV: 99.0 (98.7–99.4)	40 years and older
Epilepsy	*For individuals younger than 20 years:* 3 physician claim records at least 30 days apart in a 2-year period *For individuals 20 years and older:* 1 hospitalization record or 3 physician claim records at least 30 days apart in a 2-year period	I	Validated algorithm[12,d]	Sensitivity: 73.7 (64.8–82.5) Specificity: 99.8 (99.6–99.9) PPV: 79.5 (71.1–88.0) NPV: 99.7 (99.5–99.8)	None
Motor neuron disease	1 hospitalization record or 1 physician claim record	II	Accepted algorithm[c]	Not available	None
Multiple sclerosis	1 hospitalization record or 5 physician claim records in a 2-year period	I	Validated algorithm[14,d]	Sensitivity: 84.2 (79.7–88.8) Specificity: 100.0 (99.9–100.0) PPV: 86.0 (81.6–90.3) NPV: 99.9 (99.9–100.0)	20 years and older
Parkinsonism (including Parkinson's disease)	1 hospitalization record or 2 physician claim records at least 30 days apart in a 1-year period	I	Validated algorithm[10,d]	Sensitivity: 71.9 (66.1–77.7) Specificity: 99.9 (99.9–99.9) PPV: 73.8 (68.0–79.5) NPV: 99.9 (99.9–99.9)	40 years and older
Schizophrenia	1 hospitalization record or 2 physician claim records in a 2-year period	II	Accepted algorithm[9]	Not available	7 years and older
Spina bifida	1 hospitalization record	II	Accepted algorithm[e]	Not available	None
Spinal cord injury	1 hospitalization record	II	Accepted algorithm[c]	Not available	None
Stroke and transient ischemic attack	1 hospitalization record	I	Validated algorithm[11,d] adapted to clinical expert feedback	Sensitivity: 36.9 (27.6–46.2) Specificity: 99.8 (99.7–99.9) PPV: 80.9 (69.6–92.1) NPV: 98.7 (98.4–99.0)	None
Traumatic brain injury	1 hospitalization record or 1 emergency department visit record	II	Accepted algorithm[c]	Not available	None

[a]Each algorithm has its own sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV), and these are provided where known.
[b]**Grade I:** the algorithm has been previously validated for Ontario health administrative data and meets generally accepted standards for predictive value and specificity (note: sensitivity can be variable). **Grade II:** the algorithm has not been validated for Ontario health administrative data but has been used in previous Canadian research studies and/or is accepted in the research community. **Grade III:** the algorithm has not been validated for Ontario health administrative data but has been developed with input from clinical experts.
[c]Written communication with Dr. Christina Bancej, Working Group on Health and Economic Modelling of Neurological Conditions, Public Health Agency of Canada, April 2013
[d]Written communication with Catherine Pelletier and Asako Bienek, Canadian Chronic Disease Surveillance System for Neurological Conditions Working Group, Public Health Agency of Canada, April 2013
[e]Written communication with Jocelyn Rouleau, Maternal Health and Infant Section, Public Health Agency of Canada, June 2013

Data Sources

The analyses in this report relied on information from 12 population-based, linked health administrative databases. A brief description of each data source and its use in the report is provided in **Exhibit 2.2**. All data are held at ICES and were linked via unique encoded identifiers. All analyses were conducted in the secure environment of ICES following provincial privacy standards.

EXHIBIT 2.2 Health administrative data sources

Data, Source, Years Reported	Description	Health Care Service	Used for Demographic Characteristics, Prevalence and Incidence	Used for Costs Associated with Health System Use
Client Agency Program Enrollment Tables, Ontario Ministry of Health and Long-Term Care, 2009–2010	Data regarding patient enrollment with physicians practicing under an Ontario family practice model.	Physicians and other health care professionals		✓
Continuing Care Reporting System, Canadian Institute for Health Information, 2009–2010	Population-based resident information for over 600 publicly funded residential care homes with 24-hour nursing care, and all patients staying in a designated complex continuing care bed who are typically deemed to be in a non-acute state but still require treatment in an institution.	Long-term care, complex continuing care		✓
Discharge Abstract Database, Canadian Institute for Health Information, 1995–2010	Administrative, clinical and demographic data on all hospital discharges in Ontario. Disease diagnosis captured using the ICD coding scheme, either as the diagnosis responsible for admission or as a comorbidity.	Hospital care	✓	✓
Home Care Database, Ontario Association of Community Care Access Centres, 2009–2010	Data of all publicly funded home care services in Ontario, including nursing care, physiotherapy, social work and homemaking services.	Home care		✓
National Ambulatory Care Reporting System, Canadian Institute for Health Information, July 2001–2010	Captures all emergency department visits in Ontario, including the disease diagnosis responsible for the visit or as a comorbidity using the ICD coding scheme.	Hospital care	✓	✓
National Rehabilitation Reporting System, Canadian Institute for Health Information, 2009–2010	Data from participating, specialized rehabilitation facilities or from general hospitals with rehabilitation units, programs or designated rehabilitation beds across Ontario.	Inpatient rehabilitation		✓
Ontario Cancer Registry, Cancer Care Ontario, 1995–2010	Data of all new cancer diagnoses and cancer deaths in Ontario since 1964, except for non-melanoma skin cancer. The registry uses multiple sources such as pathology reports, patient records, hospital discharge records and death records from the Registrar General of Ontario. Cancer diagnoses are captured using the ICD coding scheme.	Cancer registry	✓	
Ontario Drug Benefits Database, Ontario Ministry of Health and Long-Term Care, 1995–2010	Drug reimbursement data for individuals 65 years or older, those receiving social assistance from Ontario Works or the Ontario Disability Support Program, residents of long-term care homes or homes for special care, recipients of services under the Home Care Program, individuals enrolled in the Trillium Drug Program, and individuals covered under the Special Drugs Program.	Prescription drugs	✓	✓
Ontario Health Insurance Plan Claims Database, Ontario Ministry of Health and Long-Term Care, 1995–2010	Claims data from inpatient, outpatient and long-term care settings for physicians in Ontario. Disease diagnosis is captured as the diagnosis responsible for the claim using the ICD coding scheme. Other data include claims for select services that are publicly funded provided by other health care professionals, such as midwives, oral surgeons, chiropractors, optometrists and physiotherapists; and diagnostic test and laboratory service billings.	Physicians and other health care professionals	✓	✓
Ontario Mental Health Reporting System, Canadian Institute for Health Information, October 2005–2010	Data on all adult-designated inpatient mental health beds in Ontario. Mental health diagnoses are captured using the DSM coding scheme while non-mental health comorbidities are captured using the ICD coding scheme.	Hospital care	✓	✓
Ontario Population Estimates Tables, Ontario Ministry of Health and Long-Term Care, 2004–2010	The tables provide estimates for the Ontario population by census division. The estimates are based on Census information from Statistics Canada and adjusted with data from other sources.	N/A	✓	
Registered Persons Database, Ontario Ministry of Health and Long-Term Care, 1995–2010	Demographic information such as age, sex, health insurance eligibility and death information for anyone who has received Ontario health care coverage. It contains postal code information that is linkable to other geographic information such as rural or urban residence, neighbourhood income quintile and Local Health Integration Network.	N/A	✓	✓

Abbreviations: ICD, International Classification of Diseases; DSM, Diagnostic and Statistical Manual of Mental Disorders.

Brain Disorder Algorithms

The algorithms used to identify individuals with each brain disorder are presented in **Exhibit 2.1**. 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. All algorithms were scrutinized by clinical content experts for each brain disorder. **Exhibit 2.1** outlines the number of data sources used, the frequency of records required and any age restrictions applied for each brain disorder. As noted previously, the 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.

The statistical performance of the algorithms used in this report varies by brain disorder, and this performance (sensitivity, specificity, positive predictive value, negative predictive value) has been reported in **Exhibit 2.1**, where known. When looking at the results, the algorithm's validity and performance should always be considered. To help guide this process, **Exhibit 2.1** also grades the evidence supporting each disease case definition:

- **Grade I** – the algorithm has been previously validated for Ontario health administrative data and meets generally accepted standards for predictive value and specificity (note: sensitivity can be variable);
- **Grade II** – the algorithm has not been validated for Ontario health administrative data but has been used in previous Canadian research studies and/or is accepted in the research community;
- **Grade III** – the algorithm has not been validated for Ontario health administrative data but has been developed with input from clinical experts.

Time Frame

Estimates for prevalence, incidence and cost of brain disorders are reported from April 1, 2004 to March 31, 2011. For the report's findings to be robust, a lengthy accrual period (the amount of time required to accumulate prevalence for individuals with one or more pre-existing brain disorders) was required in order to obtain stable estimates. The accrual period spanned nine years, from April 1, 1995 to March 31, 2004. Following the accrual period, the algorithms continued to identify new individuals with brain disorders until March 31, 2011. All data sources used to identify brain disorders were available throughout the study period with two exceptions. Data for emergency department records (from the National Ambulatory Care Reporting System) and mental health–designated beds (from the Ontario Mental Health Reporting System) were not available until July 2000 and October 2005, respectively. Individuals with a brain disorder who did not come into contact with the health system and have their diagnosis recorded during the study period are not captured in our analyses.

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 (see **Exhibit 2.1**) in order to improve algorithm performance or because identification of some disorders is not feasible in younger populations. For example, schizophrenia is not typically diagnosed in children younger than 7 years.[17] 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).

Brain Disorder Evaluation

For each brain disorder, one or more clinical content experts (listed in the Acknowledgements) reviewed the results for general consistency with published findings. Further, a health economist reviewed the costing methodology, as well as the cost-related findings presented for each disorder.

Some of the brain disorders examined are relatively rare. In analyses where the brain disorder populations were separated into even smaller groups (for example, by age category), counts of less than 6 were either suppressed to reduce re-identification risk or combined with an adjacent category.

Demographic characteristics

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, 2010. Sex (male/female), age groups in years, rural or urban residence, and neighbourhood income quintile were 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 (18–64 years) and older adults (65+ years) were also presented where applicable. If known, the rurality of an individual's residency was based on Statistics Canada 2006 Census data for community size and reported as either rural (less than 10,000 inhabitants) or urban (at least 10,000 inhabitants).[18] The income quintile of a person's neighbourhood was based on geographic and income information available in the census.[18] Within larger geographic regions, each dissemination area (a unit of geographic aggregation) was ranked based on the average neighbourhood income per person-equivalent (a measure based on household income, in dollars, adjusted for household size) and then divided into fifths to create community-specific income quintiles where 1 was the lowest-income quintile and 5 was the highest. Rural or urban residence status and neighbourhood income quintile were missing for less than 1% of each brain disorder cohort.

Prevalence

Prevalence for each brain disorder was determined on April 1 of each year from 2004 through 2010. 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.[19] For brain disorders with age restrictions, the total population consisted only of individuals within the appropriate age range. **Exhibit 2.3** illustrates the prevalence calculation (using 2006/07 as an example). For comparability between years, prevalence estimates were standardized by age and sex to the 2006 Census population.[20] Accrual of persons with brain disorders started on April 1, 1995, and was carried over to future years unless the persons died, left Ontario or lost health insurance eligibility. Age-specific and sex-specific prevalence estimates for each brain disorder were calculated by age group in 2004 and 2010 with no adjustments made. Ontario is divided into 14 Local Health Integration Networks (LHINs) which are responsible for health care planning, integration and funding (see **Exhibit 1.0** for a map depicting LHIN boundaries). For each LHIN, age- and sex-adjusted prevalence estimates for each brain disorder in 2004 and 2010 were calculated and standardized to the 2006 Census population.

Incidence

Incidence for each brain disorder was determined annually from 2004 to 2010. Incidence was calculated as the number of persons with a newly identified brain disorder accrued between April 1 and March 31 of the

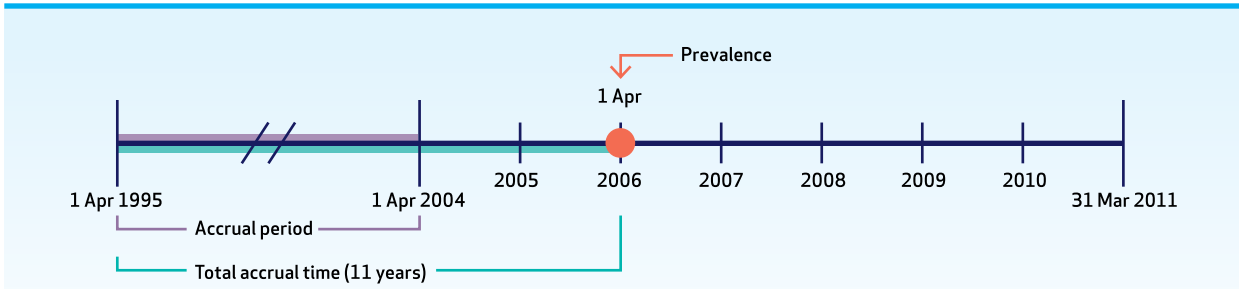
*Brain disorders with age restrictions had fewer age groups (e.g., dementia was captured only for persons aged 40 years and older, so the first age group was 40–64 years), or had age groups that were truncated based on the age cutoff (e.g., multiple sclerosis was captured only for persons 20 years and older, so the first age group was 20–39 years instead of 18–39 years).

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. **Exhibit 2.4** illustrates the incidence calculation (using 2008/09 as an example). 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 2006 Census population.

Refinements in Prevalence and Incidence Estimates

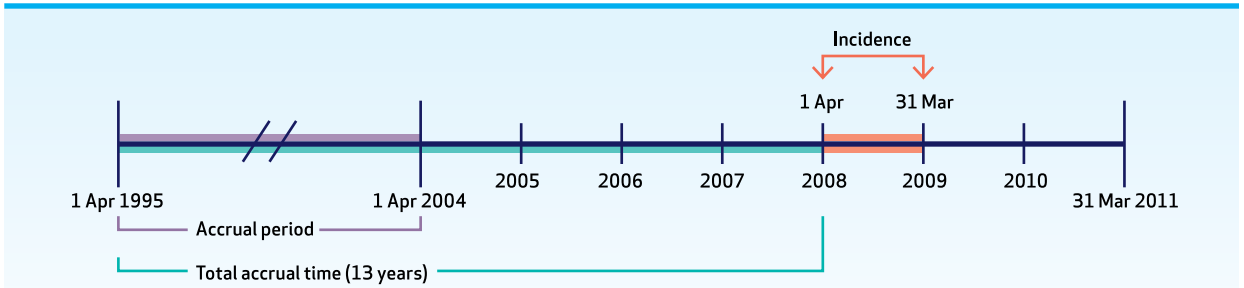
Because of their diversity, not all brain disorders could be estimated in the same way. While cerebral palsy is a developmental disorder that most commonly occurs during pregnancy, the prevalence for children 5 years and younger was estimated instead of incidence or newborn prevalence because diagnosis can be delayed or go unrecognized until 5 years of age. Multiple sclerosis can occur in persons aged 50 years and older (known as late-onset multiple sclerosis), but to limit false positives, incidence was only captured for those aged 20–64 years. Because spina bifida is a congenital developmental disorder, live birth prevalence was

EXHIBIT 2.3 Timeline depicting yearly prevalence calculation (2006/07 example)



Prevalence in 2006/07 (the orange marker) was calculated by identifying all individuals with a brain disorder up to April 1, 2006. To be eligible as a case, an individual had to be alive and residing in Ontario with valid provincial health coverage on April 1, 2006.

EXHIBIT 2.4 Timeline depicting yearly incidence calculation (2008/09 example)



Incidence in 2008/09 (the orange bar) was calculated by identifying all individuals with a newly identified brain disorder. Cases identified prior to 2008 (teal and purple bars) are not part of the susceptible population.

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.

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. This report provides estimates of these direct costs paid by the Ontario Ministry of Health and Long-Term Care; see **Exhibit 2.5** for a full list of costs included. These costs were calculated using Ontario health administrative data for a continuum of health care services categorized into seven types: complex continuing care, long-term care, home care services, hospital care, physician and other health care professional services, prescription drugs and rehabilitation services (see **Exhibit 2.2** for data sources used). The methods used to estimate these costs are summarized in **Appendix B** and reported in detail elsewhere.[21]

EXHIBIT 2.5 Types of health care services and their constituent costs

Category	Constituent Costs[a]	Excluded Costs[b]
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 services or support from informal caregivers
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 clinics and renal dialysis clinics, ambulatory care costs were not captured. Examples of ambulatory care services not captured are outpatient physiotherapy programs and diagnostic tests and imaging services.
Long-term care	• Long-term care	• Only the government-funded portion of long-term care was considered. Out-of-pocket costs for long-term care accommodations were not included.
Physician and other health care professional services	• 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 billings not included in the Ontario Health Insurance Plan Claims Database were not captured. • Billings from non-physician health care professionals were limited to specific groups of individuals. Services provided by the majority of non-physician health care professionals are paid for out-of-pocket and/or by third-party insurers; these were not captured.
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 captured for the majority of individuals younger than 65 years because they are paid for out-of-pocket and/or by third-party insurers. Drugs dispensed during acute inpatient stays were captured as hospital care costs.
Rehabilitation services	• Inpatient rehabilitation services	• Outpatient rehabilitation programs were not captured.

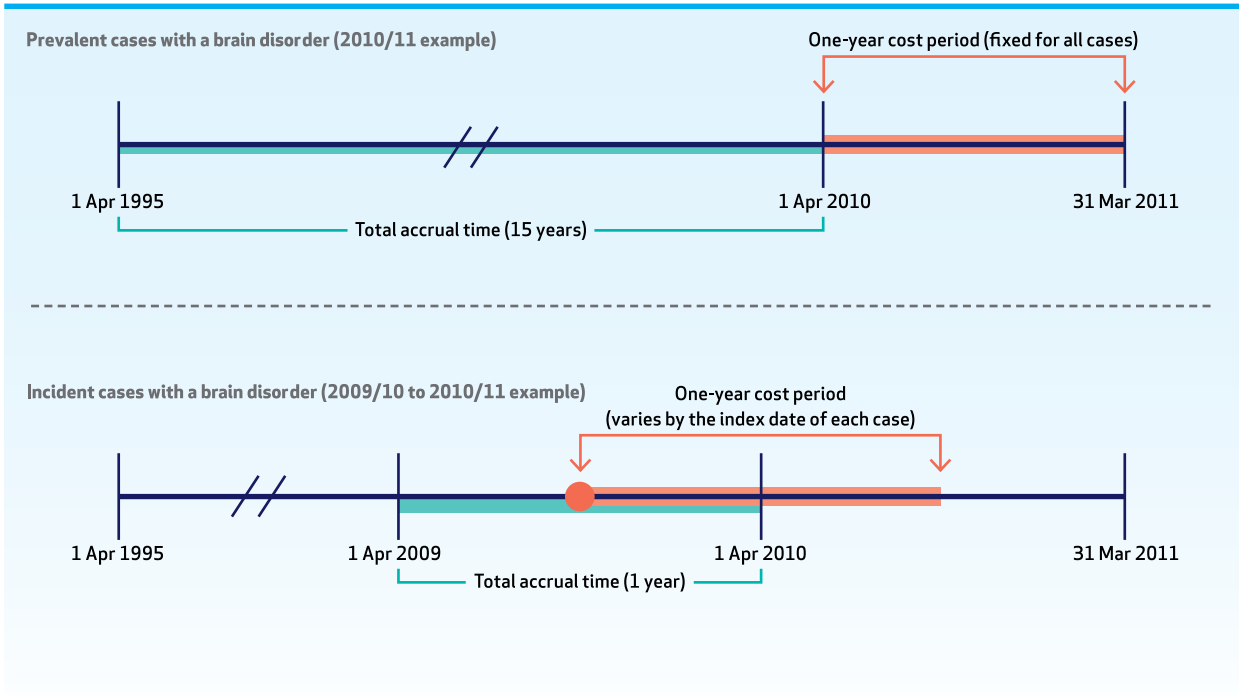
[a] These costs are for services funded by the Ontario Ministry of Health and Long-Term Care. Not captured are costs paid by the individual, his or her family, third-party insurers or other private payers. Also not captured are indirect costs such as those associated with productivity loss and informal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

The costs associated with health system use were calculated for two groups of individuals (**Exhibit 2.6**). The first group, to be referred to as *prevalent cases*, is all persons with each brain disorder identified as of April 1, 2010. Prevalent cases were followed from April 1, 2010 to March 31, 2011 to calculate their costs associated with one year of health system use. The second group, to be referred to as *incident cases*, consists of persons with a brain disorder that was newly identified between April 1, 2009 and March 31, 2010. Incident cases were followed for one year from their incidence (index) date to estimate their costs associated with one year of health system use.

The distribution of the costs associated with health system use was presented for prevalent and incident cases with a brain disorder. The mean, median and interquartile range were provided for the entire group and by age group. For prevalent and incident cases with a brain disorder, the costs were also examined by type of health care service. For prevalent cases with a brain disorder, the costs were further broken down into those younger than 65 years and those 65 years and older.

The prevalence, incidence and cost data tables used to construct the exhibits presented in Chapters 3 to 15 are available upon request. **Appendix C** includes a list of available supplementary data.

EXHIBIT 2.6 Timelines depicting one-year health system cost accrual for prevalent and incident cases with a brain disorder



A Note on Interpreting the Cost Estimates Included in this Report

There are two important caveats regarding the cost calculations in this report.

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 report.

Second, this report *does not capture all possible costs associated with brain disorders.* Specifically, the report only captures costs from the perspective of the Ontario Ministry of Health and Long-Term Care (MOHLTC); 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 costs captured represent the majority (85%) of costs attributable to individual persons* from the perspective of the MOHLTC. 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.[21]

Examples of the sorts of costs that are not included in this report because they are not considered from the perspective of the MOHLTC 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 third-party 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 report's cost calculations. For these brain disorders, the report presents an accurate description of costs to the Ontario Ministry of Health and Long-Term Care 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.

The costing methodology employed[21] has been successfully used in other projects.[22-25] A summary of the methodology is provided in **Appendix B.**

*Dr. Walter Wodchis, email communication, January 8, 2015.

"I wish people would understand that a brain tumour may not be a death sentence. We never know what our bodies will throw at us. It's part of life's dance, of how well we cope with what we've been given."

– Connie

CHAPTER 3

Brain Tumour, Benign

Overview

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. Benign brain tumours grow slowly and do not invade surrounding tissues. While benign brain tumours are noncancerous, 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.

While 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 benign brain tumours.

Data Quality

Benign brain tumour was studied using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with benign brain tumour were determined.

When looking at the results for benign brain tumour, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for benign brain tumour is considered grade III (the algorithm has not been validated using Ontario health administrative data but has been developed with input from clinical experts).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 3.1 Number and proportion of persons with benign brain tumour, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, females accounted for 69.1% of the 5,684 Ontarians identified with benign brain tumour.
- The mean age of a person with benign brain tumour was 62.7 years.
- Among persons with benign brain tumour, 44.1% were between the ages of 40–64 years. The majority of persons with benign brain tumour (91.5%) were older than 40 years.
- Among persons with benign brain tumour, 11.1% lived in a rural setting.
- Persons with benign brain tumour were evenly distributed across neighbourhood income quintiles with 19.7% and 19.6% living in neighbourhoods with the lowest and highest incomes, respectively.

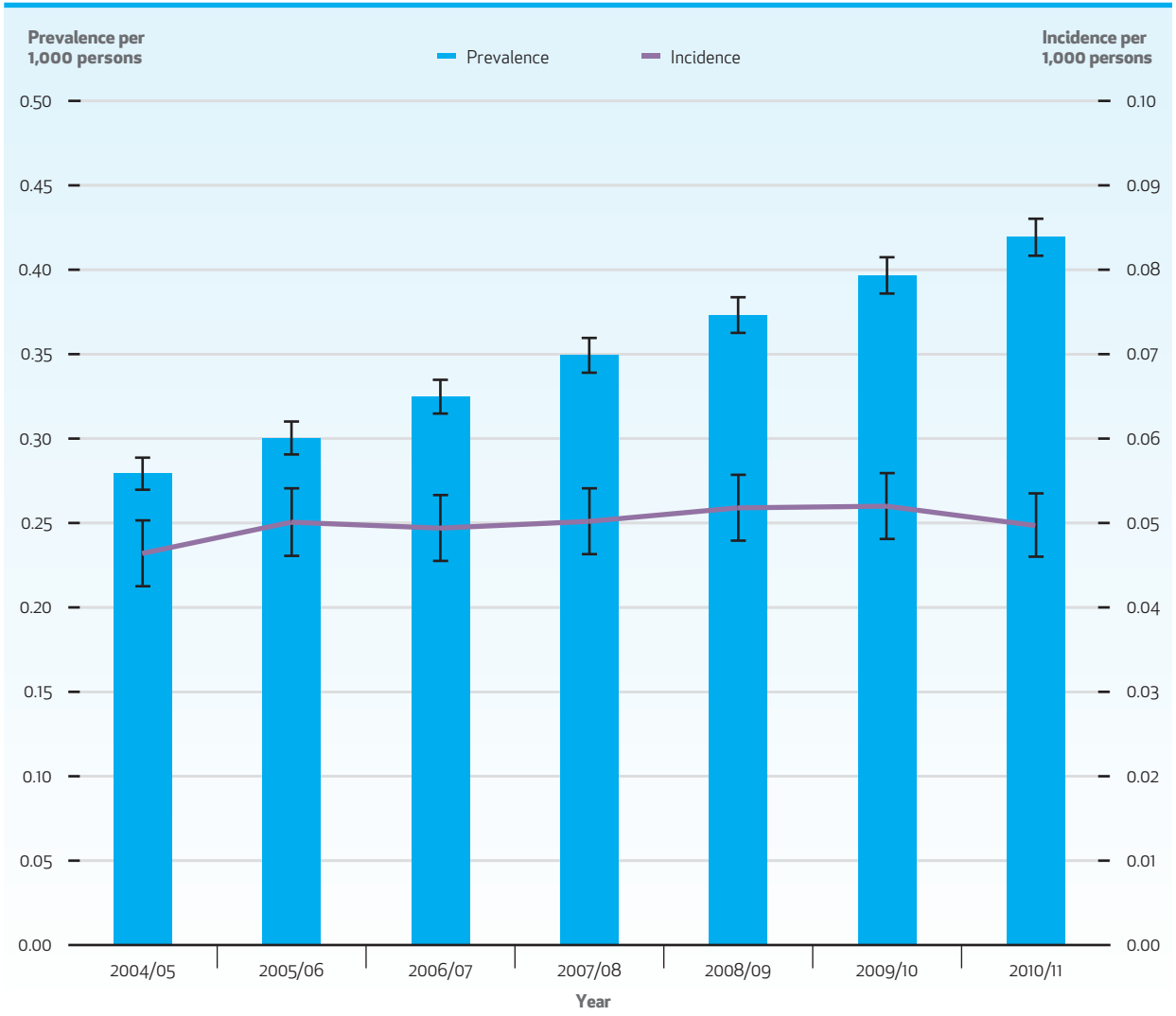
Characteristic	Cohort
Ontario, n	5,684
Sex, n (%)	
Female	3,929 (69.1)
Male	1,755 (30.9)
Age distribution, years	
Mean ± standard deviation	62.7 ± 17.0
Median (interquartile range)	63 (52–76)
Age group, years, n (%)	
0–4	9 (0.2)
5–17	73 (1.3)
18–39	403 (7.1)
40–64	2,505 (44.1)
65–74	1,150 (20.2)
75–84	1,056 (18.6)
85+	488 (8.6)
Children 0–17	82 (1.4)
Adults 18–64	2,908 (51.2)
Older adults 65+	2,694 (47.4)
Residence, n (%)	
Rural	631 (11.1)
Urban	5,047 (88.8)
Income quintile, n (%)	
1 (lowest)	1,119 (19.7)
2	1,154 (20.3)
3	1,139 (20.0)
4	1,138 (20.0)
5 (highest)	1,113 (19.6)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 3.2 Age- and sex-adjusted* prevalence and incidence of benign brain tumour per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians identified as having benign brain tumour increased from 3,344 to 5,684.
- The age- and sex-adjusted prevalence of benign brain tumour per 1,000 persons increased from 0.28 in 2004/05 to 0.42 in 2010/11.
- Between 2004/05 and 2010/11, the total number of Ontarians newly identified as having benign brain tumour increased from 555 to 673.
- The age- and sex-adjusted incidence of benign brain tumour per 1,000 persons stayed constant at 0.05 in 2004/05 and 2010/11.



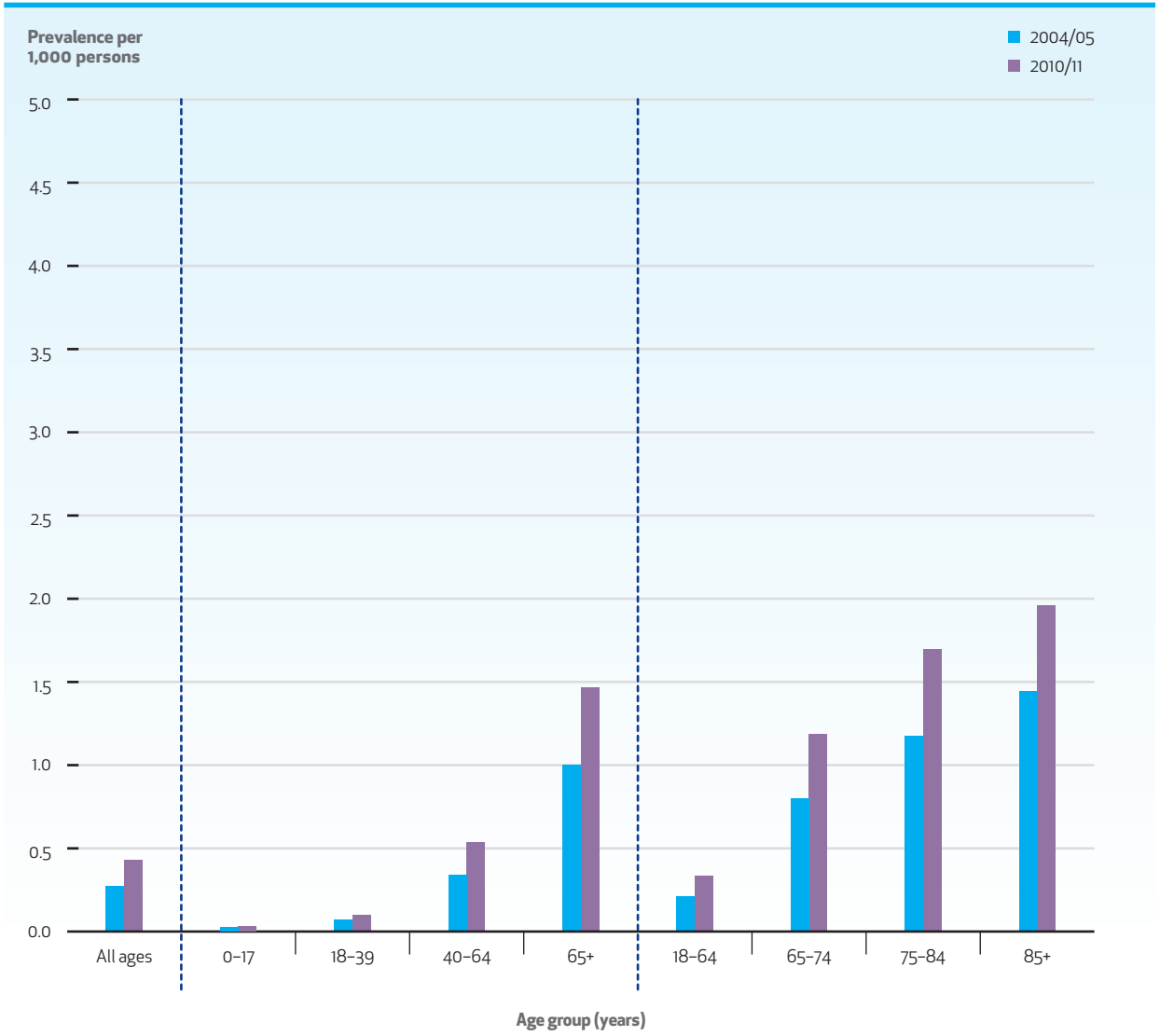
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 3.3A Crude prevalence of benign brain tumour per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of benign brain tumour for individuals aged 0–17 years, 18–64 years and 65 years and older was 0.03 per 1,000, 0.34 per 1,000 and 1.46 per 1,000, respectively.

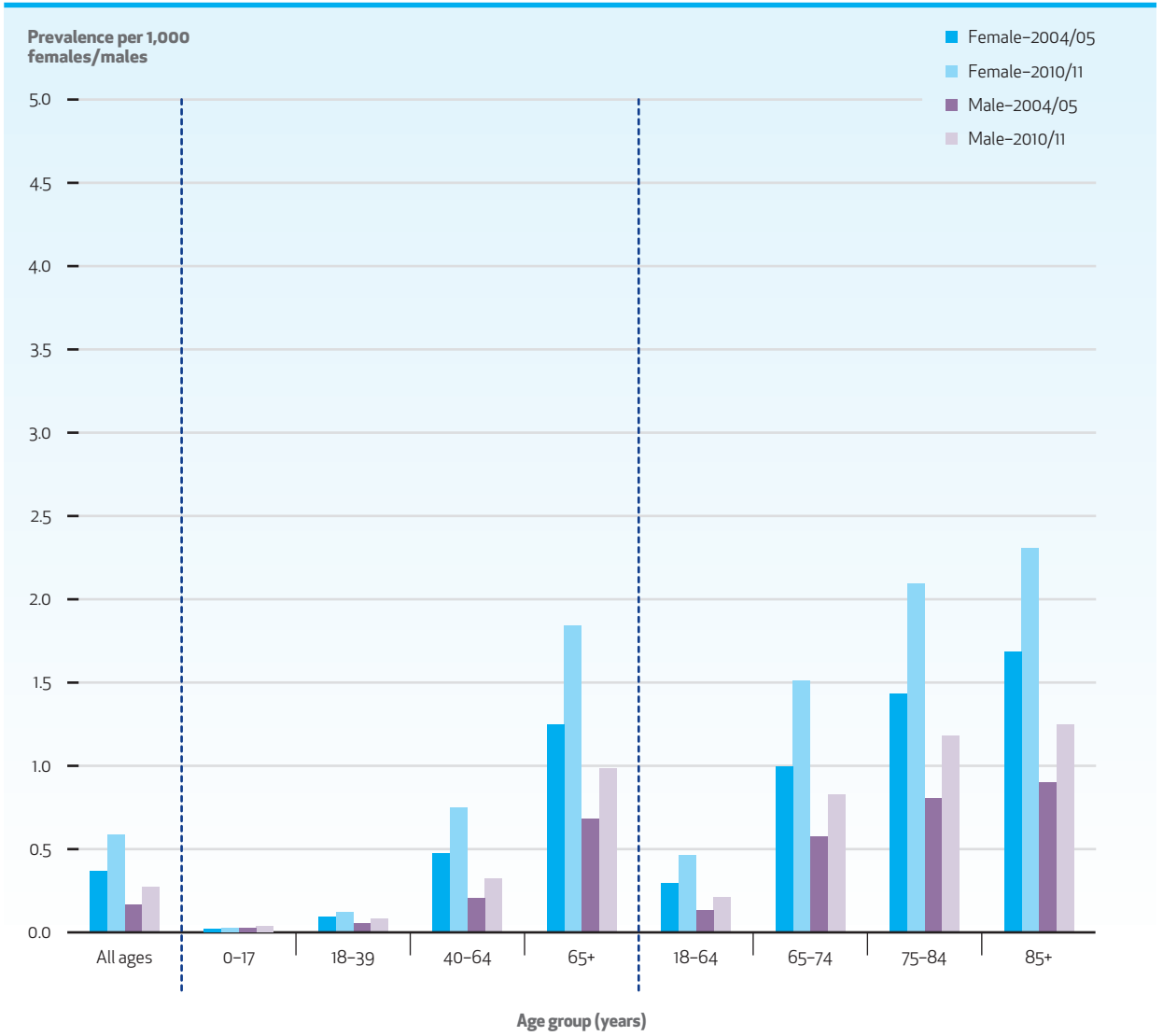


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 3.3B Crude prevalence of benign brain tumour per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of benign brain tumour was greater for females (0.59 per 1,000) than males (0.27 per 1,000).
- Between 2004/05 and 2010/11, the crude prevalence of benign brain tumour among females rose from 0.37 to 0.59 per 1,000 females and among males, rose from 0.17 to 0.27 per 1,000 males.

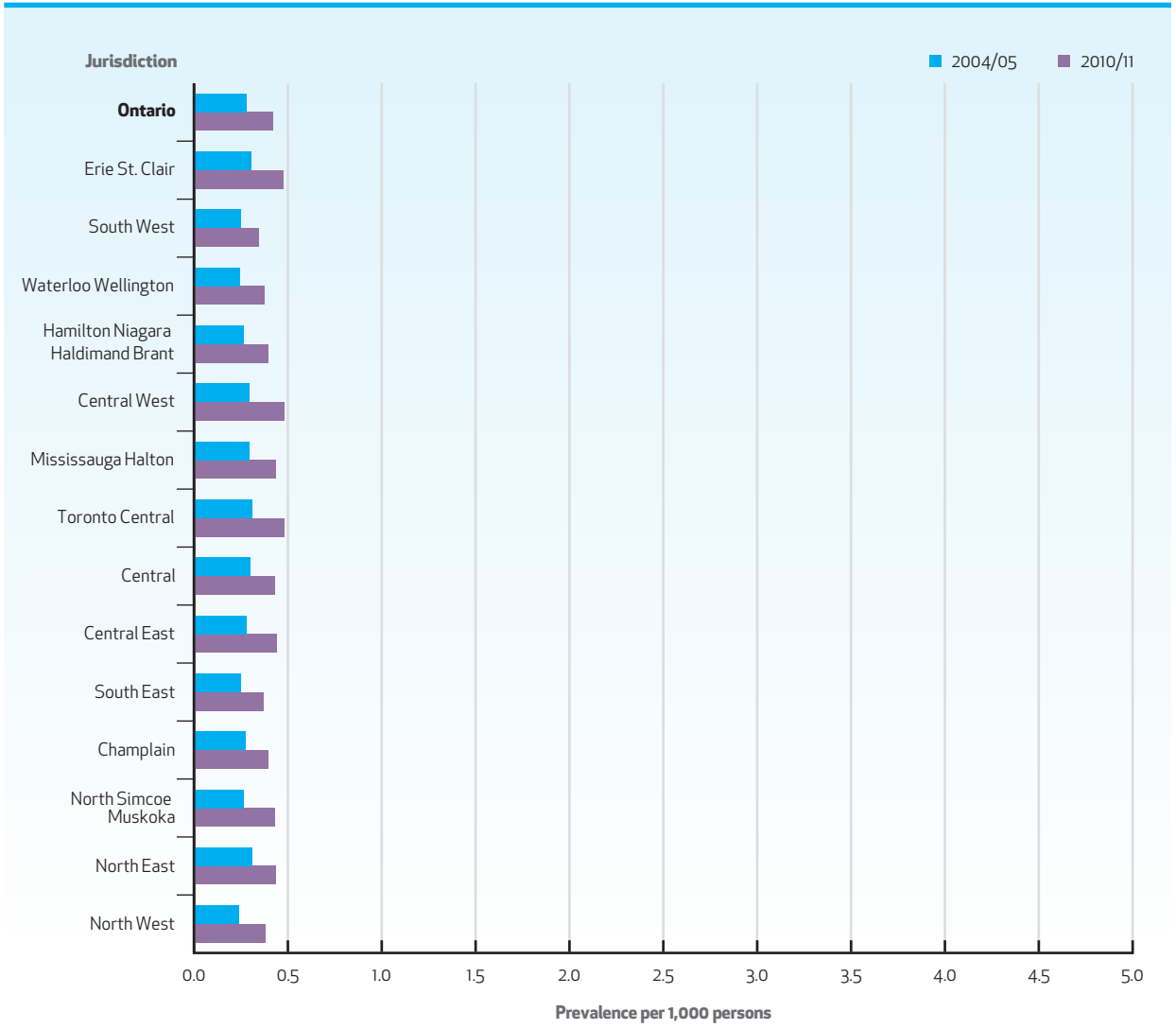


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 3.4 Age- and sex-adjusted* prevalence of benign brain tumour per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of benign brain tumour increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 1.4-fold variation in the age- and sex-adjusted prevalence of benign brain tumour in 2010/11, which was greater than the 1.3-fold variation in 2004/05.
- In 2010/11, the Toronto Central, Central West and Erie St. Clair LHINs had the three highest age- and sex-adjusted prevalence estimates of benign brain tumour with all at approximately 0.48 per 1,000 persons.
- In 2010/11, the South West, South East and Waterloo-Wellington LHINs had the three lowest age- and sex-adjusted prevalence estimates of benign brain tumour at 0.35, 0.37 and 0.37 per 1,000, respectively.



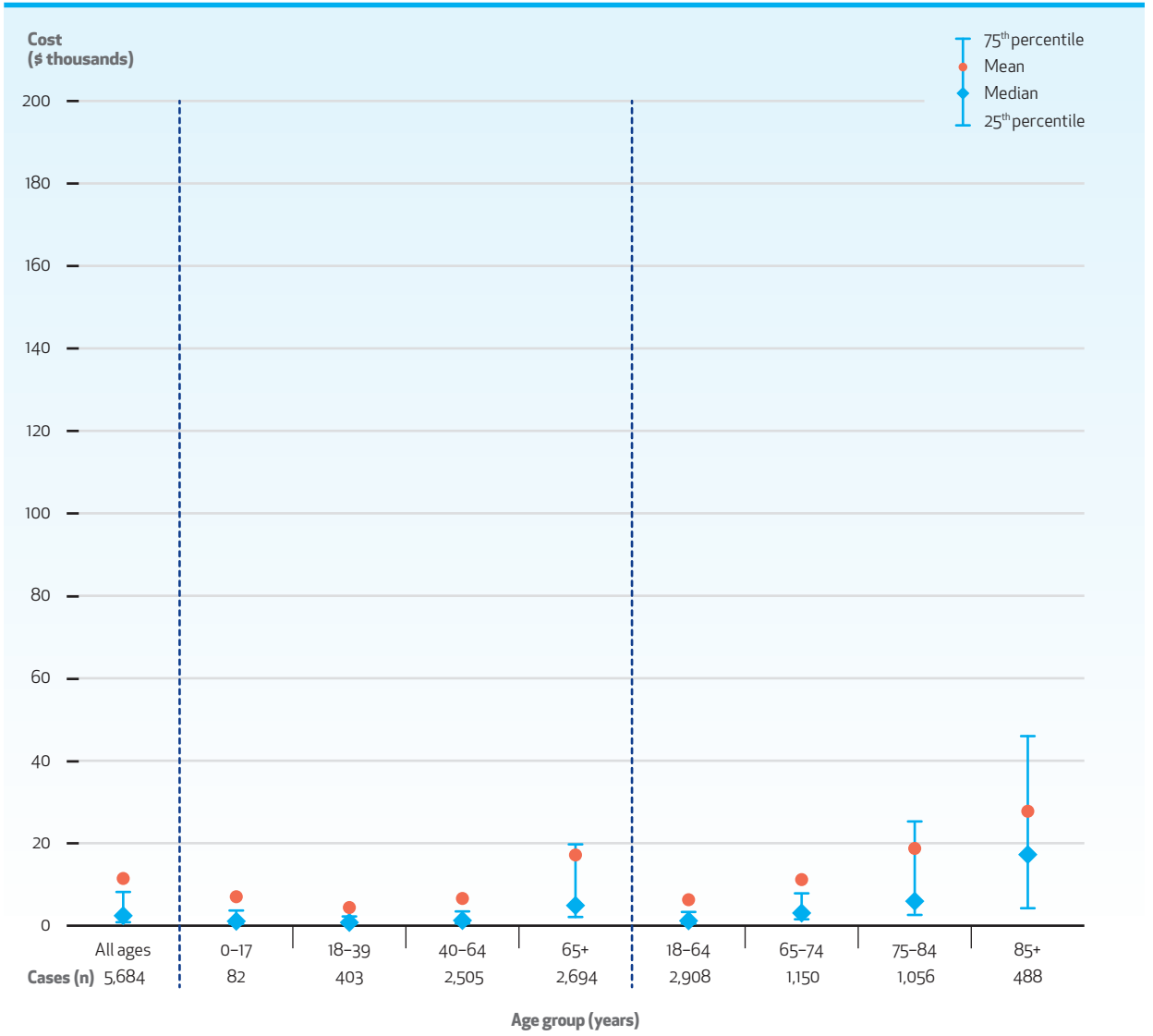
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population

EXHIBIT 3.5A Distribution of costs* associated with one year† of health system use for prevalent cases with benign brain tumour, by age group, in Ontario, 2010/11

Key Findings

- The mean cost associated with one year of health system use by prevalent cases with benign brain tumour was $11,436 (median $2,404). The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $837 to $8,174.
- Among prevalent cases with benign brain tumour, the median cost associated with one year of health system use generally increased with age, and was highest in persons aged 85 years and older ($17,234).

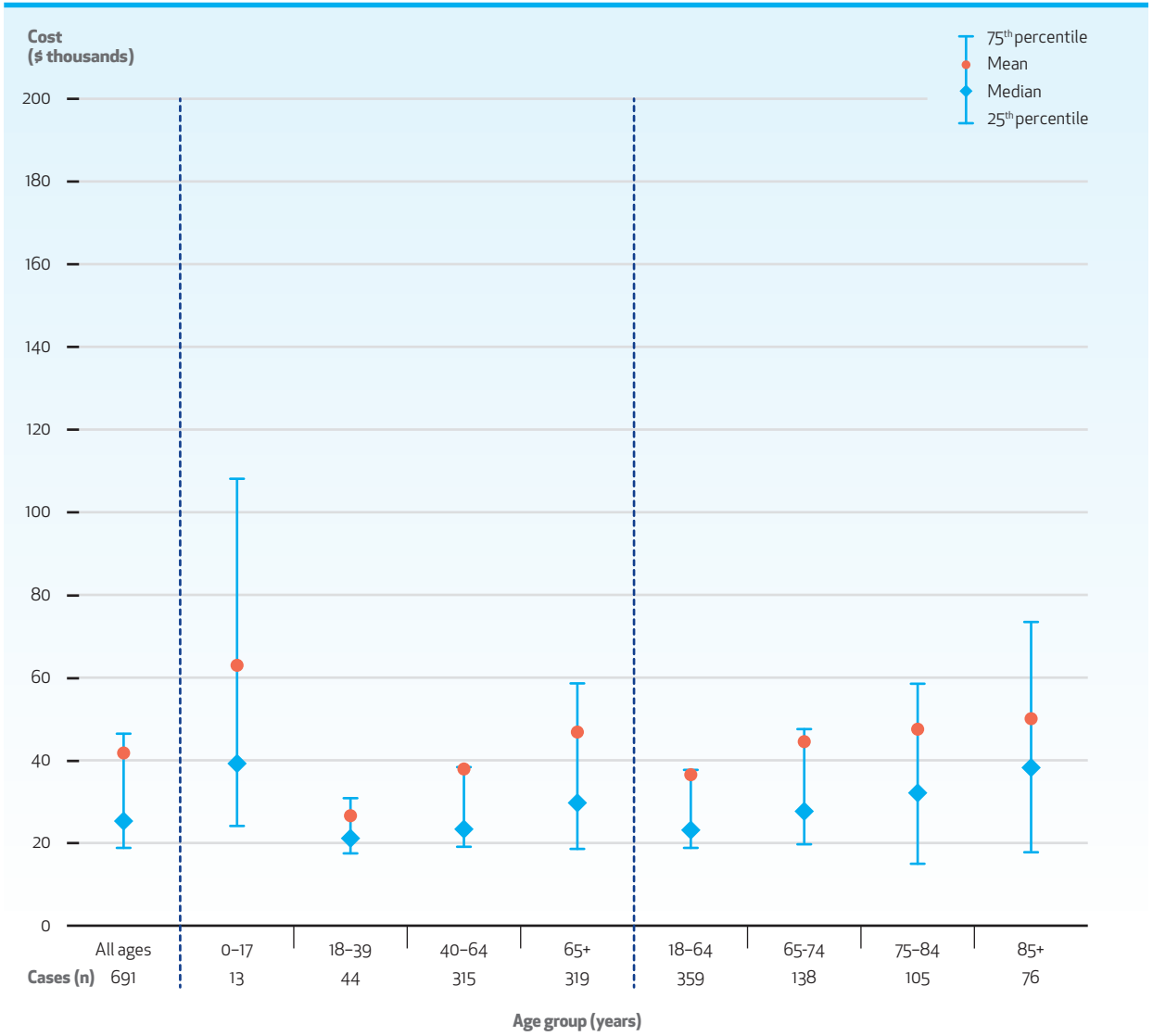


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 3.5B Distribution of costs* associated with one year† of health system use for incident cases with benign brain tumour, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- For incident cases with benign brain tumour, the mean and median costs associated with one year of health system use were $41,779 and $25,309, respectively. The interquartile range of costs extended from $18,814 to $46,437.
- Among incident cases with benign brain tumour, individuals aged 0–17 years had the highest median cost ($39,227) associated with one year of health system use.

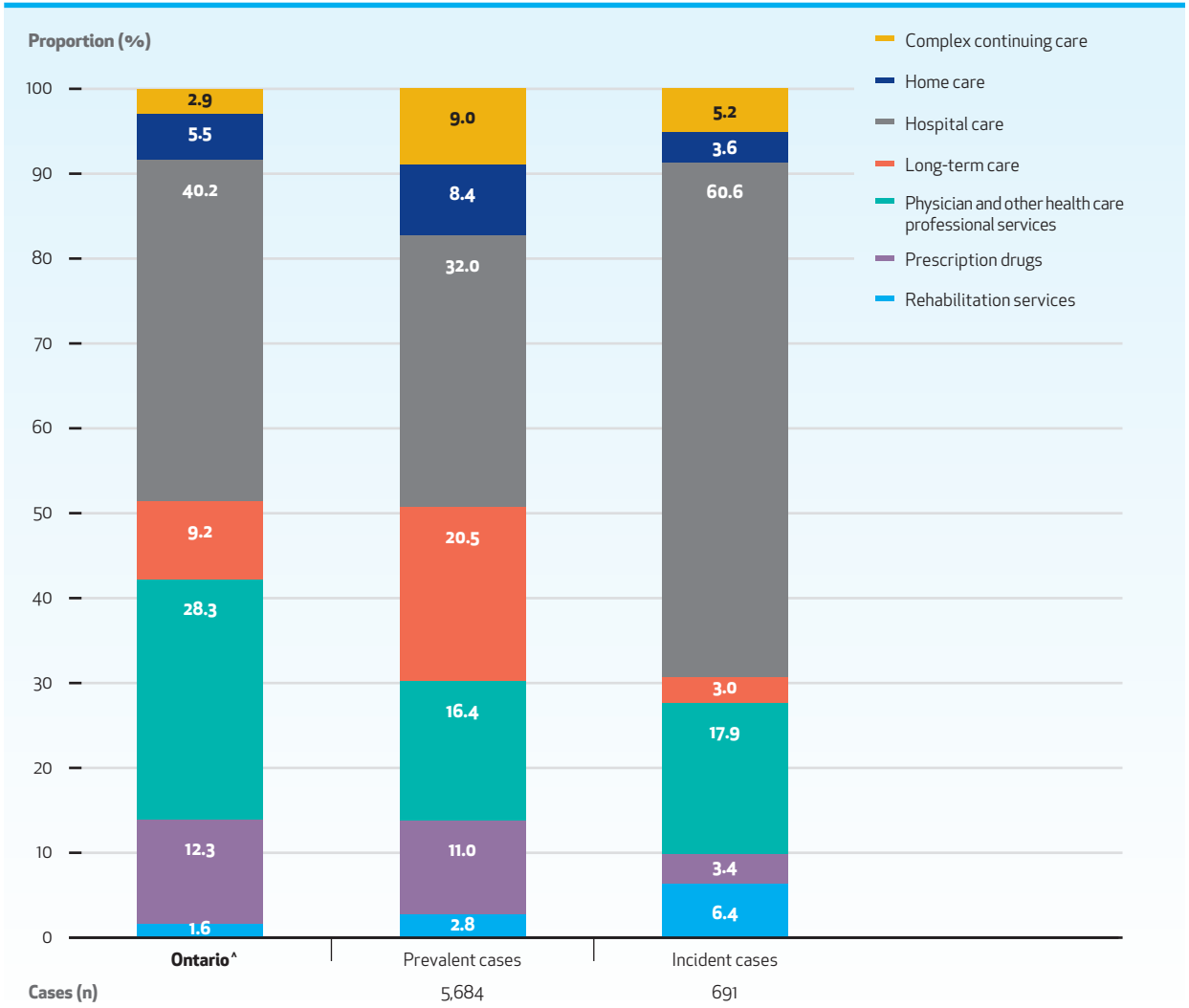


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 3.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with benign brain tumour, by type of health care service

Key Findings

- Among prevalent cases with benign brain tumour, the majority of the costs associated with health system use were attributable to hospital care (32.0%), long-term care (20.5%), and physician and other health care professional services (16.4%).
- Among incident cases with benign brain tumour, the majority of the costs associated with one year of health system use were attributable to hospital care (60.6%), physician and other health professional care services (17.9%) and rehabilitation services (6.4%).

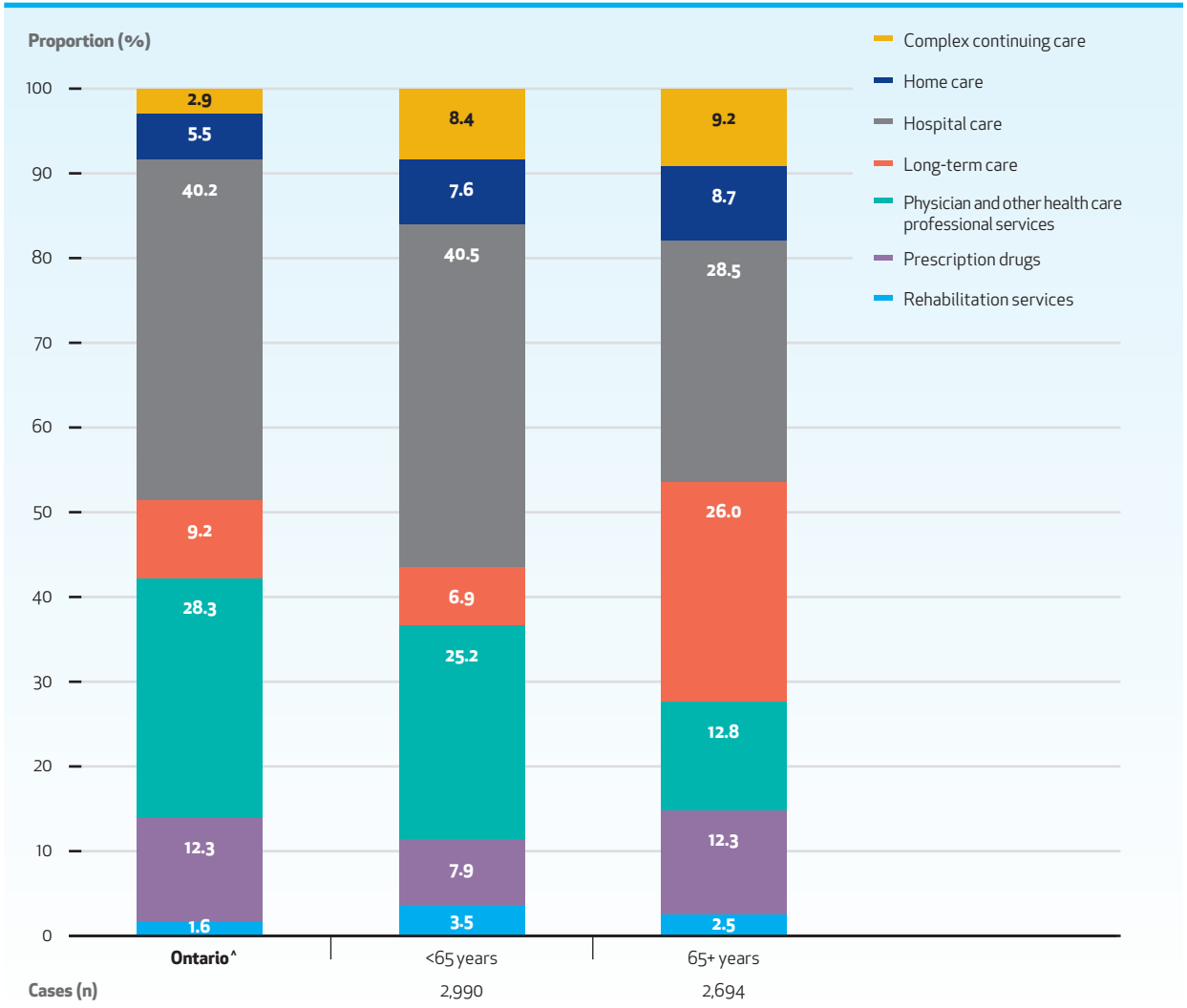


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 3.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with benign brain tumour, by age group and type of health care service

Key Findings

- Among prevalent cases with benign brain tumour who were younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (40.5%), physician and other health care professionals (25.2%) and complex continuing care (8.4%).
- Among prevalent cases with benign brain tumour aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (28.5%), long-term care (26.0%) and physician and other health care professional services (12.8%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 4

Brain Tumour, Primary Malignant

"I think what the world needs to know about life with a brain tumour is that it is a lifelong journey that affects not only the patient but also the family. After treatments and surgery, it changes your lifestyle, and with knowledge, your peer groups and great friends by your side, every step is more bearable. We need to know we have the support when we feel we don't have the strength to keep going. Support is the greatest thing anyone can do for the survivor and families."

– Brain Tumour Foundation of Canada program participant and brain tumour survivor

Overview

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.

Data Quality

Primary malignant brain tumour was assessed using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with primary malignant brain tumour were determined.

When looking at the results for primary malignant brain tumour, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for primary malignant brain tumour is considered grade I (the algorithm for Ontario health administrative data has been previously validated, and the algorithm meets generally accepted standards for predictive value and specificity [note: sensitivity can be variable]).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 4.1 Number and proportion of persons with primary malignant brain tumour, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 54.2% of the 3,115 Ontarians identified with primary malignant brain tumour.
- The mean age of a person with primary malignant brain tumour was 42.5 years.
- Among persons with primary malignant brain tumour, the majority (42.0%) were aged 40–64 years.
- Among persons with primary malignant brain tumour, 11.4% lived in a rural setting.
- Persons with primary malignant brain tumour were not evenly distributed across neighbourhoods by income quintile; 17.6% lived in the lowest-income neighbourhoods and 21.4% lived in the highest.

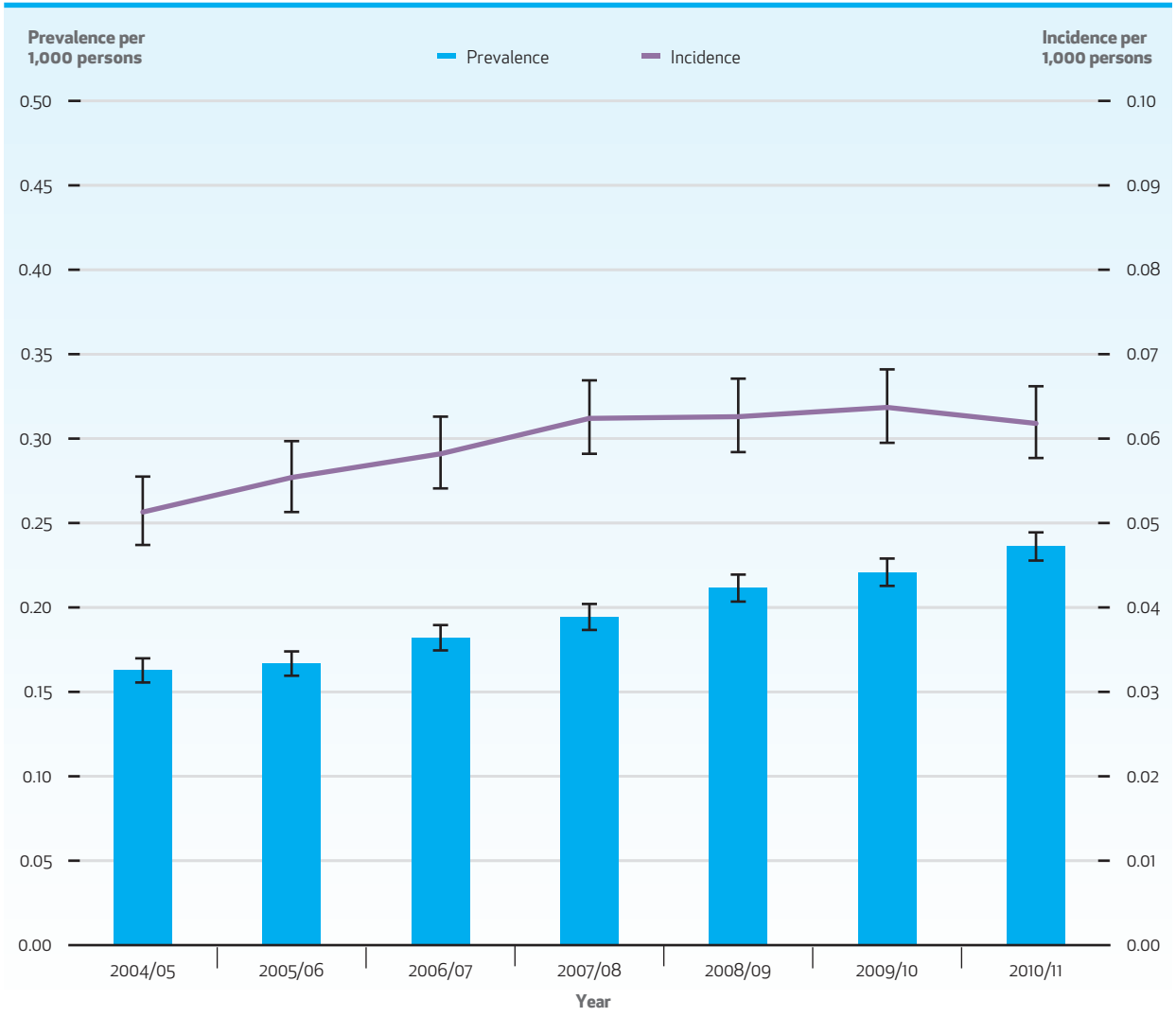
Characteristic	Cohort
Ontario, n	3,115
Sex, n (%)	
Female	1,427 (45.8)
Male	1,688 (54.2)
Age distribution, years	
Mean ± standard deviation	42.5 ± 20.6
Median (interquartile range)	44 (25–57)
Age group, years, n (%)	
0–4	49 (1.6)
5–17	433 (13.9)
18–39	864 (27.7)
40–64	1,309 (42.0)
65–74	268 (8.6)
75+	192 (6.2)
Children 0–17	482 (15.5)
Adults 18–64	2,173 (69.8)
Older adults 65+	460 (14.8)
Residence, n (%)	
Rural	355 (11.4)
Urban	2,759 (88.6)
Income quintile, n (%)	
1 (lowest)	548 (17.6)
2	597 (19.2)
3	603 (19.4)
4	688 (22.1)
5 (highest)	668 (21.4)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 4.2 Age- and sex-adjusted* prevalence and incidence of primary malignant brain tumour per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with primary malignant brain tumour increased from 2,001 to 3,115.
- The age- and sex-adjusted prevalence of primary malignant brain tumour per 1,000 persons increased from 0.16 in 2004/05 to 0.24 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified primary malignant brain tumour increased from 626 to 831.
- The age- and sex-adjusted incidence of primary malignant brain tumour per 1,000 increased from 0.051 in 2004/05 to 0.062 in 2010/11.



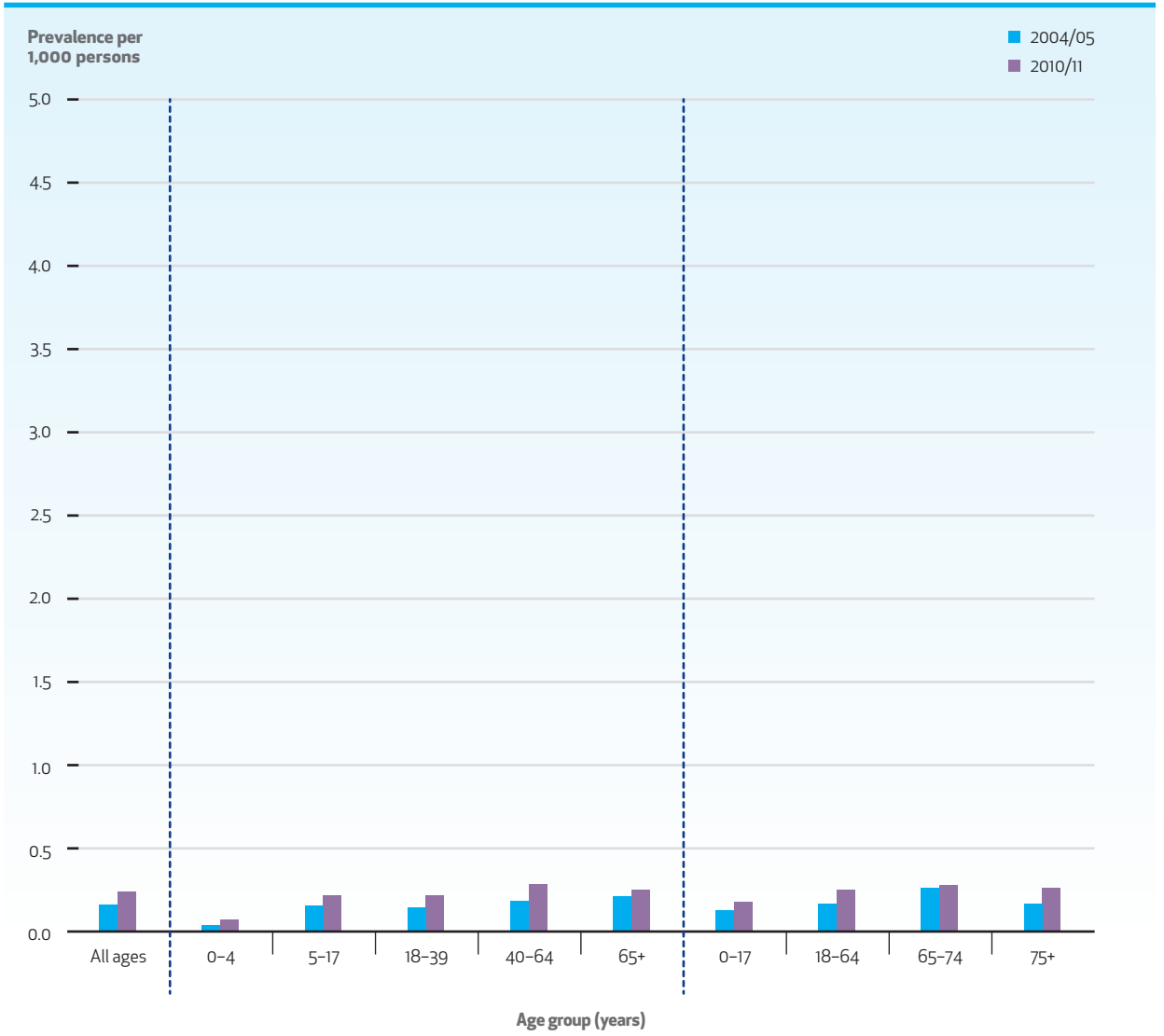
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 4.3A Crude prevalence of primary malignant brain tumour per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of primary malignant brain tumour for individuals aged 0–17 years, 18–64 years, and 65 years and older was 0.18, 0.25 and 0.25 per 1,000, respectively.

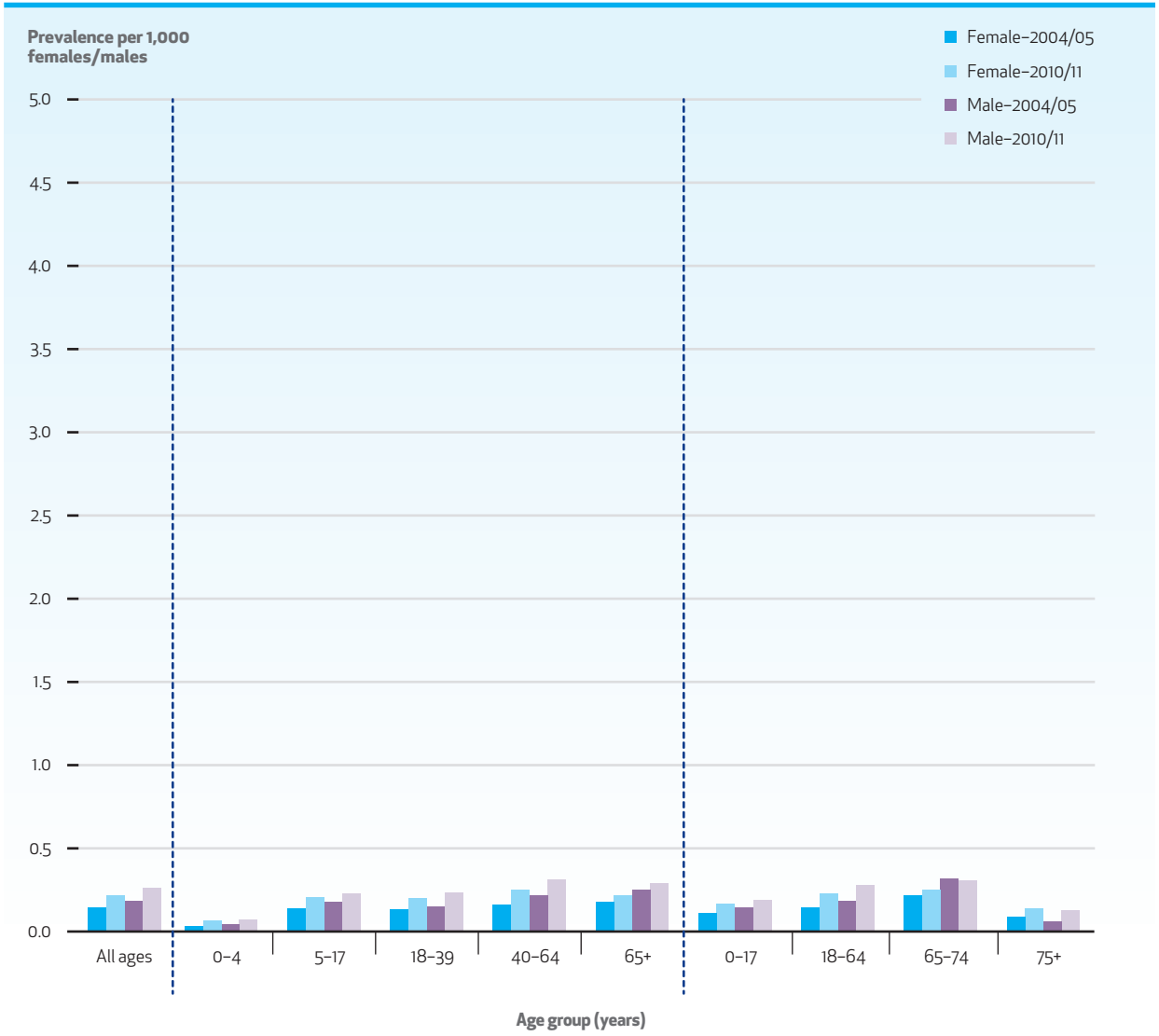


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 4.3B Crude prevalence of primary malignant brain tumour per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of primary malignant brain tumour was greater for males (0.26 per 1,000) than females (0.21 per 1,000).
- Among females, the crude prevalence of primary malignant brain tumour rose from 0.14 to 0.21 per 1,000 between 2004/05 and 2010/11
- Among males, the crude prevalence of primary malignant brain tumour rose from 0.18 to 0.26 per 1,000 between 2004/05 and 2010/11.

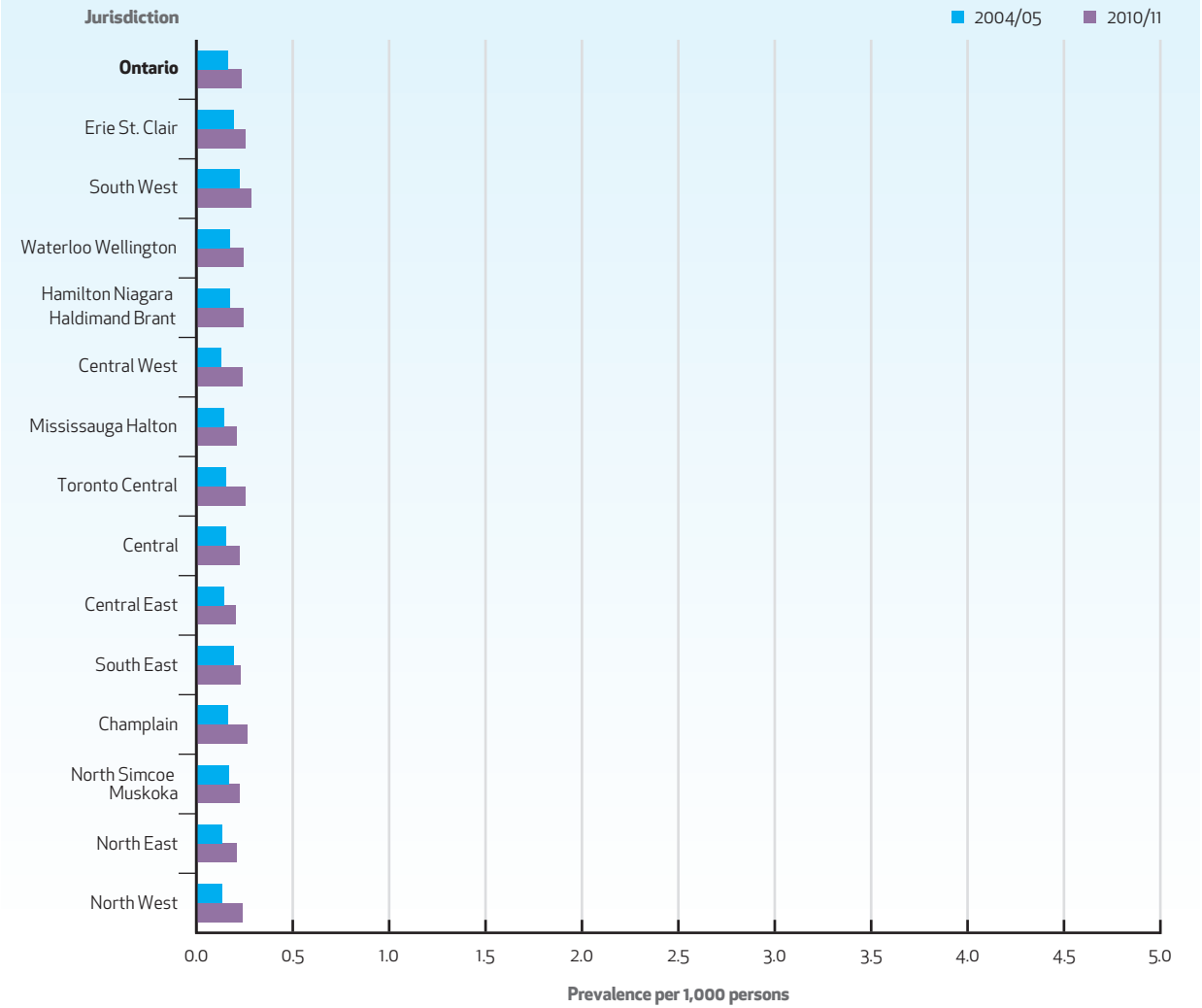


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 4.4 Age- and sex-adjusted* prevalence of primary malignant brain tumour per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of primary malignant brain tumour increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 1.4-fold variation in the age- and sex-adjusted prevalence of primary malignant brain tumour in 2010/11, which was less than the 1.7-fold variation in 2004/05.
- In 2010/11, the South West, Champlain and Erie St. Clair LHINs had the three highest age- and sex-adjusted prevalence estimates of primary malignant brain tumour (0.28, 0.26 and 0.26 per 1,000 persons, respectively).
- In 2010/11, the lowest age- and sex-adjusted primary malignant brain tumour prevalence was 0.21 per 1,000 persons, which was shared by the Central East, Mississauga Halton and North East LHINs.



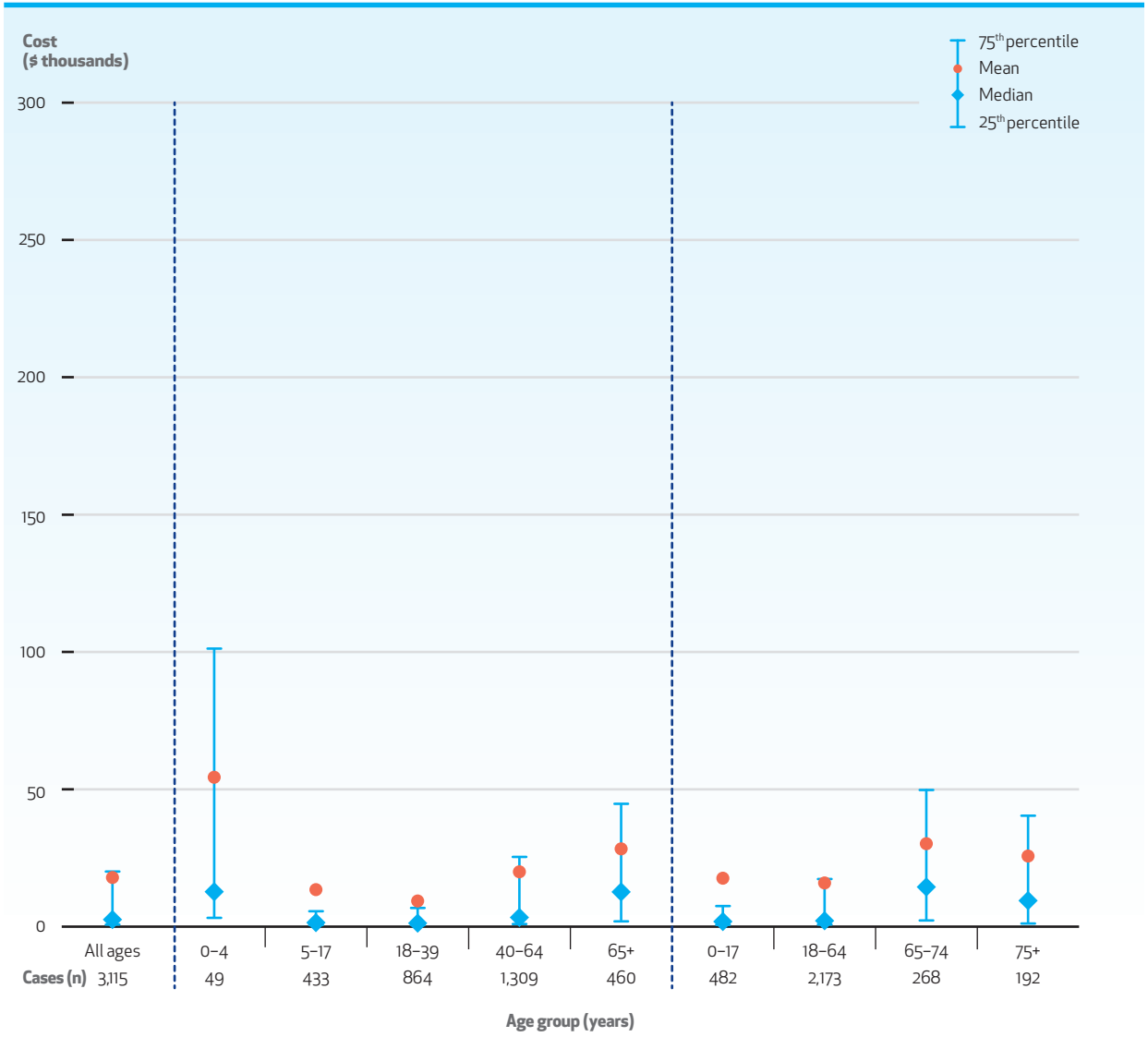
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 4.5A Distribution of costs* associated with one year† of health system use for prevalent cases with primary malignant brain tumour, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with primary malignant brain tumour were $17,880 and $2,562, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $756 to $20,069.
- Among prevalent cases with primary malignant brain tumour, the median cost associated with one year of health system use was highest among persons 65 years and older ($12,628), and more specifically among persons aged 65–74 years ($14,428).

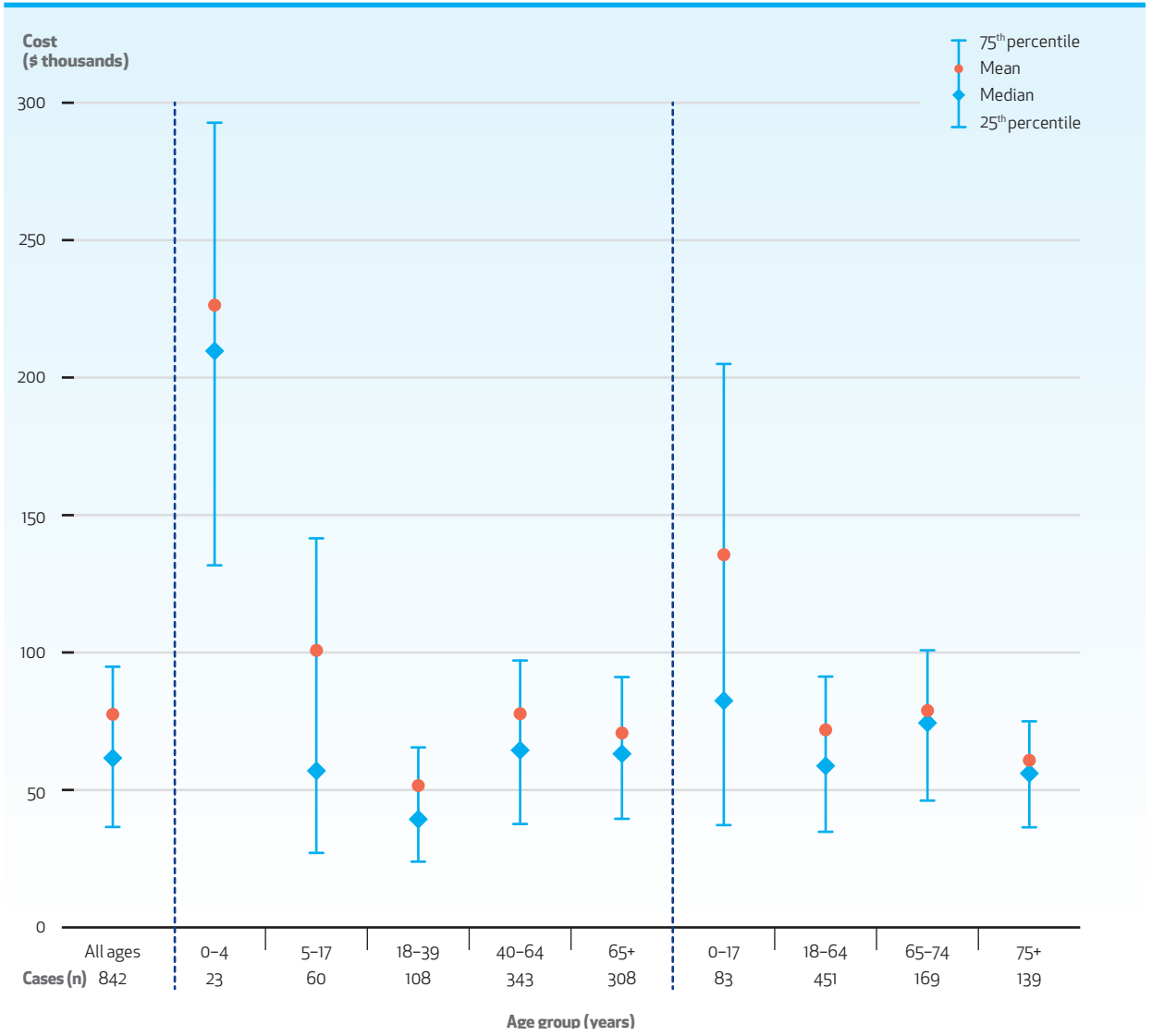


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 4.5B Distribution of costs* associated with one year† of health system use for incident cases with primary malignant brain tumour, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with primary malignant brain tumour were $77,509 and $61,586, respectively. The interquartile range of costs extended from $36,528 to $94,831.
- Among incident cases with primary malignant brain tumour, the median cost associated with one year of health system use was highest among persons aged 0–17 years ($82,440), and more specifically, among persons aged 0–4 years ($209,676).

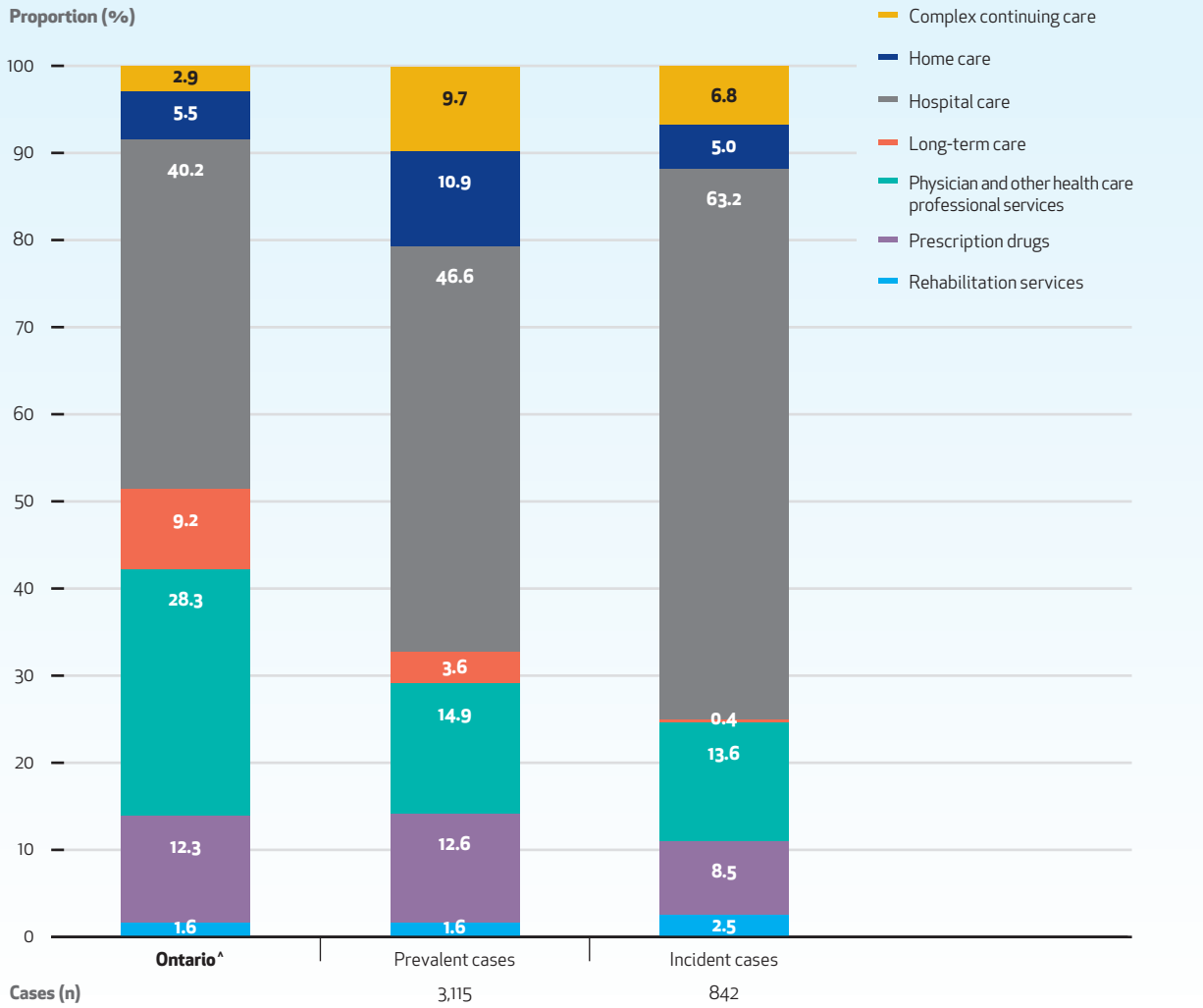


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 4.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with primary malignant brain tumour, by type of health care service

Key Findings

- Among prevalent cases with primary malignant brain tumour, the majority of the costs associated with health system use were attributable to hospital care (46.6%), physician and other health care professional services (14.9%) and prescription drugs (12.6%).
- Among incident cases with primary malignant brain tumour, the majority of the costs associated with health system use were attributable to hospital care (63.2%), physician and other health care professional services (13.6%) and prescription drugs (8.5%).

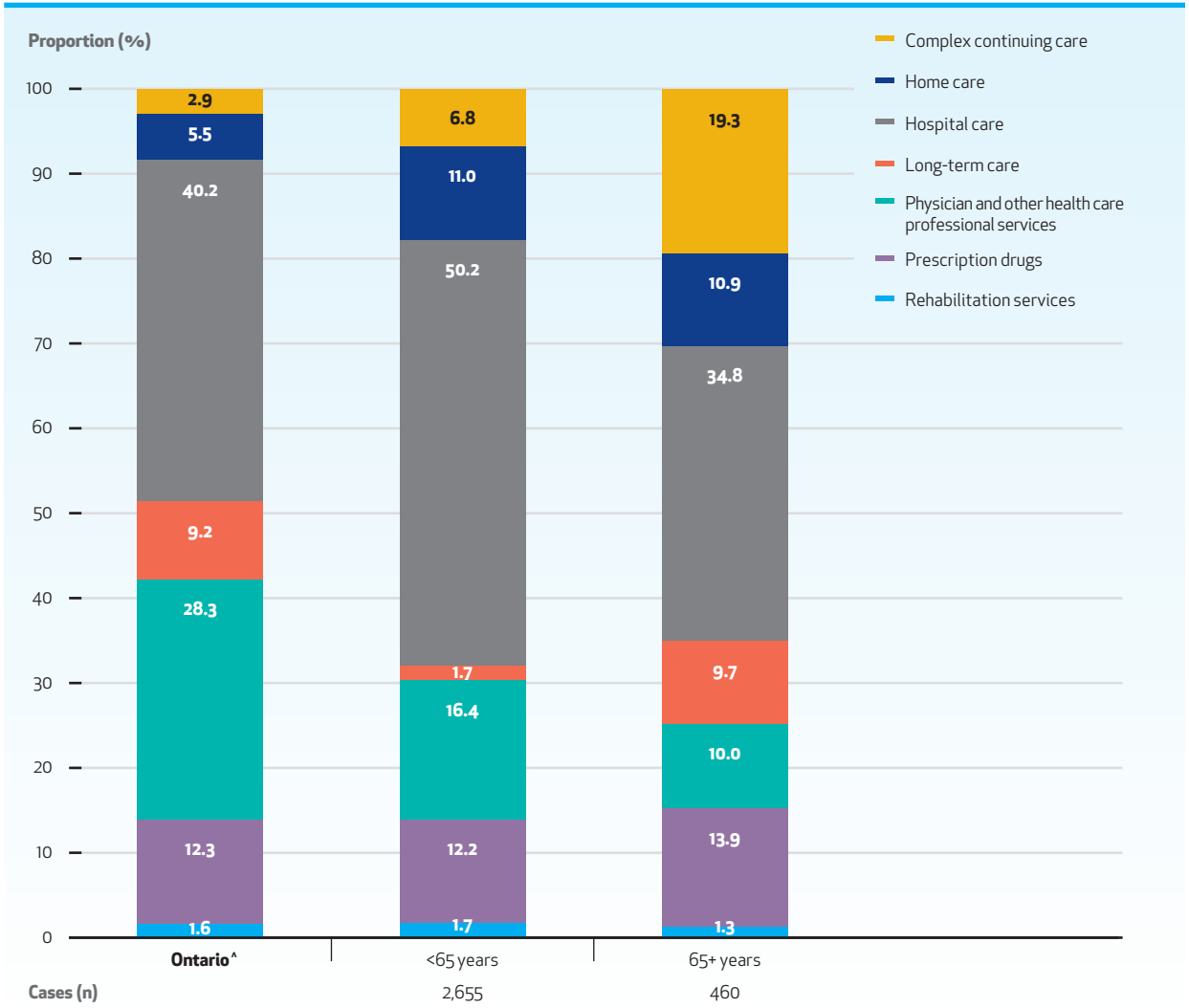


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 4.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with primary malignant brain tumour, by age group and type of health care service

Key Findings

- Among prevalent cases with primary malignant brain tumour younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (50.2%), physician and other health care professional services (16.4%) and prescription drugs (12.2%).
- Among prevalent cases with primary malignant brain tumour aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (34.8%), complex continuing care (19.3%) and prescription drugs (13.9%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 5

Cerebral Palsy

"I wish people understood that cerebral palsy is only a condition and does not make us different from other people. It is something that may make it hard for you to understand me, but not something that makes it hard for me to understand you."

– A client of the Ontario Federation for Cerebral Palsy

"The biggest challenges about living with cerebral palsy are people's attitudes towards disability and inclusion."

– A client of the Ontario Federation for Cerebral Palsy

Overview

Cerebral palsy describes a motor 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.

Data Quality

Cerebral palsy was studied using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence and the costs associated with health system use of persons with cerebral palsy were determined. Cerebral palsy is a developmental disorder that most commonly occurs during pregnancy, but diagnosis can be delayed or go unrecognized until five years of age. Therefore, rather than estimating incidence or newborn prevalence, prevalence was estimated for children five years and younger.

When looking at the results for cerebral palsy, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for cerebral palsy is considered grade II (the algorithm for Ontario health administrative data has not been validated but has been used in previous Canadian research studies and/or is accepted in the research community).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 5.1 Number and proportion of persons with cerebral palsy, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 52.8% of the 34,126 Ontarians identified with cerebral palsy.
- The mean age of a person with cerebral palsy was 30.3 years.
- Among persons with cerebral palsy, 36.0% were aged 17 years or younger and 92.2% were younger than 65 years.
- Among persons with cerebral palsy, 12.1% lived in a rural setting.
- The percentage of individuals with cerebral palsy living in neighbourhoods of differing income quintiles varied between 18.0% (the highest neighbourhood income quintile) and 22.5% (the lowest).

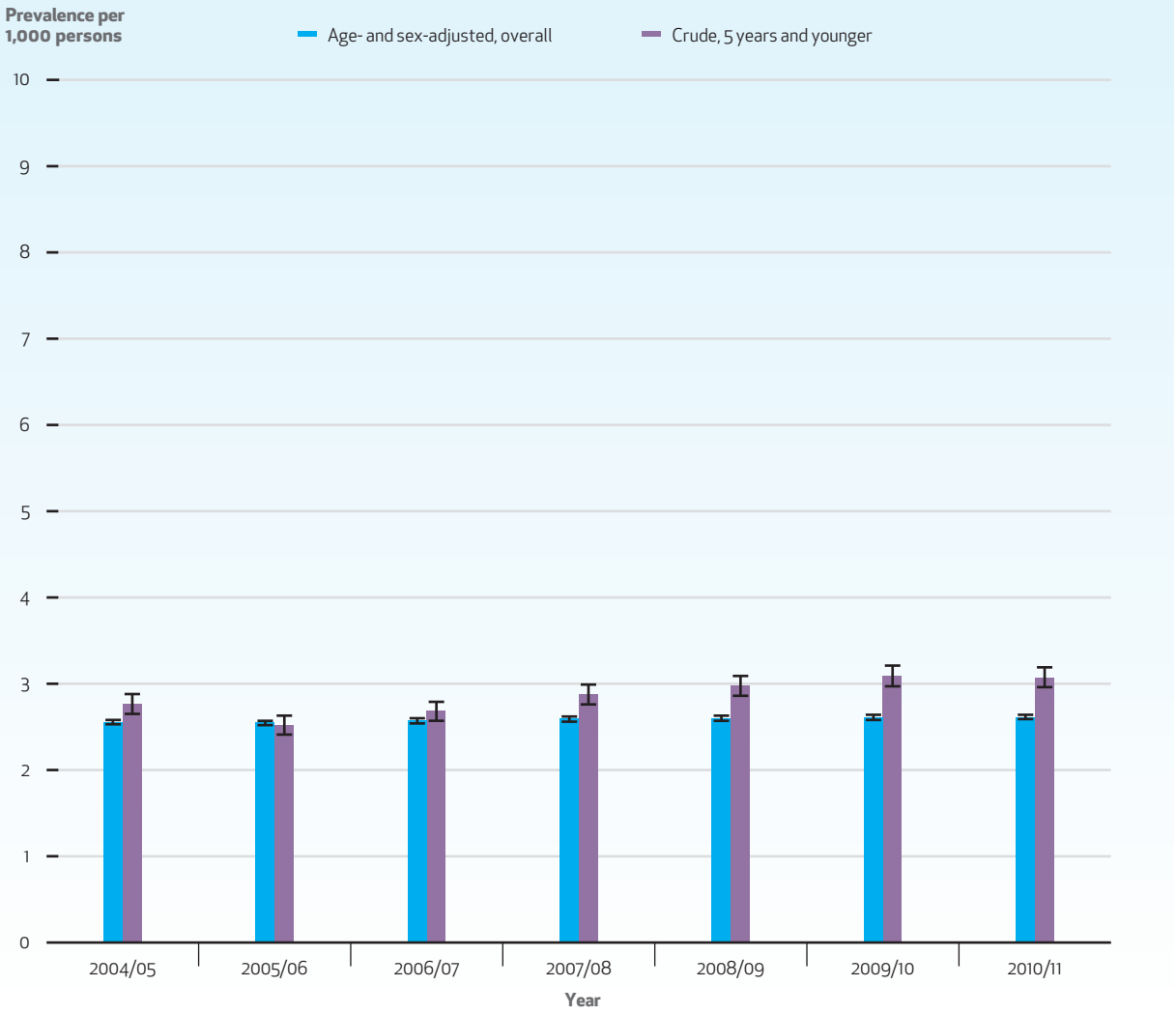
Characteristic	Cohort
Ontario, n	34,126
Sex, n (%)	
Female	16,097 (47.2)
Male	18,029 (52.8)
Age distribution, years	
Mean ± standard deviation	30.3 ± 21.1
Median (interquartile range)	24 (13–46)
Age group, years, n (%)	
0–4	2,633 (7.7)
5–17	9,641 (28.3)
18–39	10,757 (31.5)
40–64	8,437 (24.7)
65–74	1,446 (4.2)
75–84	873 (2.6)
85+	339 (1.0)
Children 0–17	12,274 (36.0)
Adults 18–64	19,194 (56.2)
Older adults 65+	2,658 (7.8)
Residence, n (%)	
Rural	4,129 (12.1)
Urban	29,963 (87.8)
Income quintile, n (%)	
1 (lowest)	7,678 (22.5)
2	6,961 (20.4)
3	6,518 (19.1)
4	6,655 (19.5)
5 (highest)	6,143 (18.0)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 5.2 Age- and sex-adjusted* prevalence (overall) and crude prevalence (persons 5 years and younger) of cerebral palsy per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians identified with cerebral palsy increased from 32,029 to 34,126.
- The age- and sex-adjusted prevalence of cerebral palsy per 1,000 persons was approximately 2.6 from 2004/05 to 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with cerebral palsy aged 5 years and younger increased from 2,282 to 2,633.
- The crude prevalence of cerebral palsy per 1,000 persons aged 5 years and younger increased from 2.8 to 3.1 between 2004/05 and 2010/11.



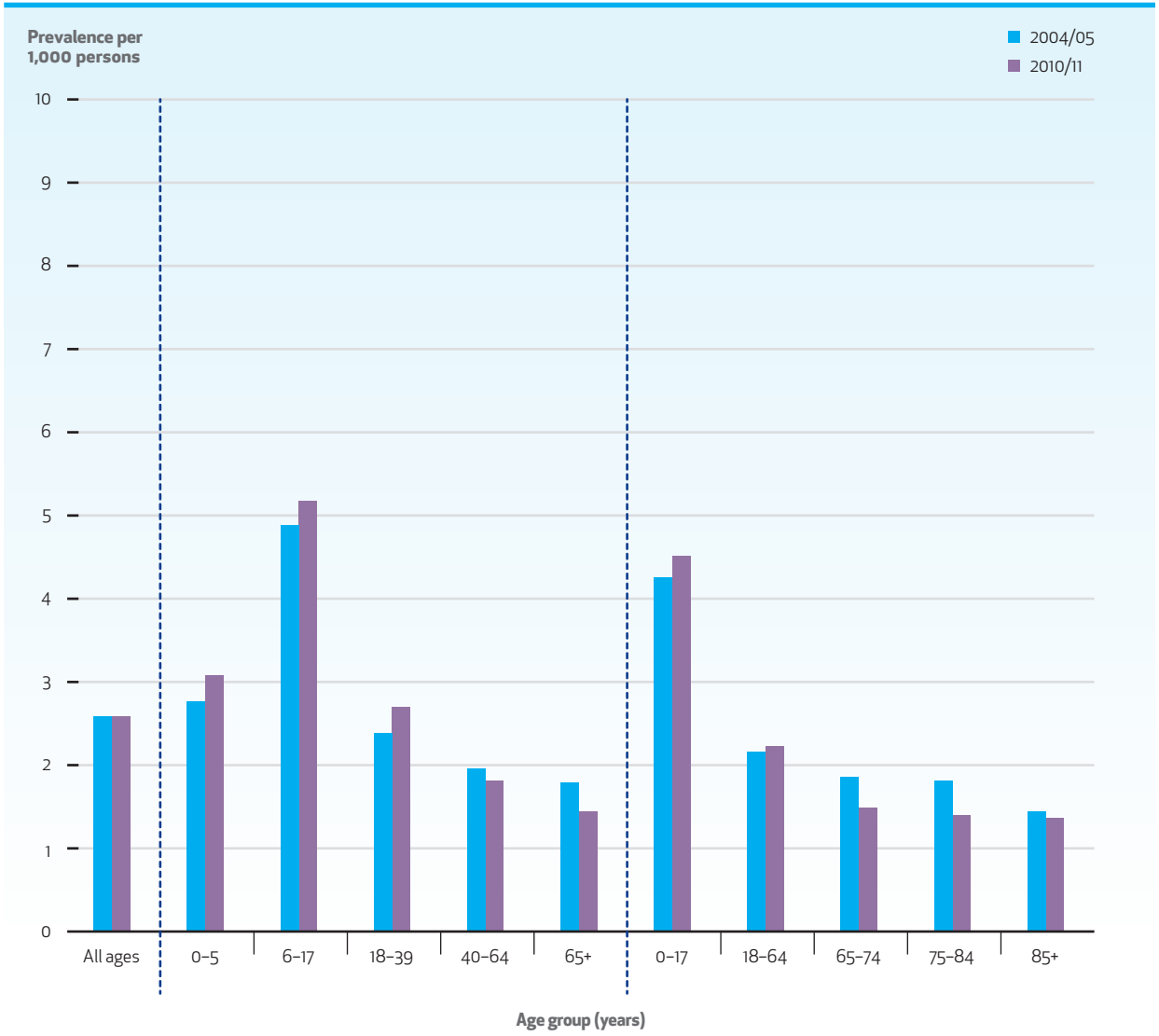
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 5.3A Crude prevalence of cerebral palsy per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of cerebral palsy for persons aged 0–17 years, 18–64 years, and 65 years and older was 4.5, 2.2 and 1.4 per 1,000, respectively.

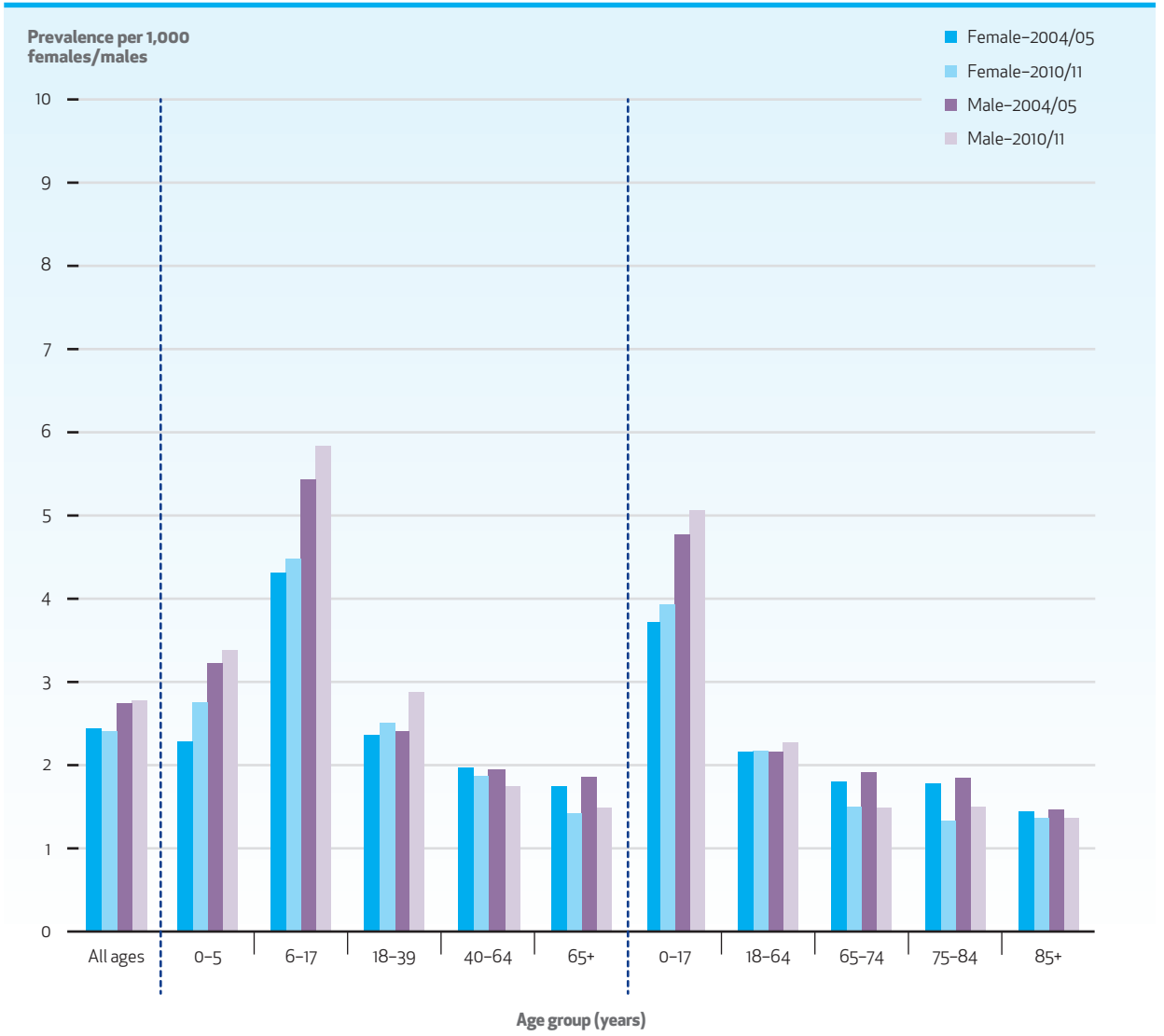


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 5.3B Crude prevalence of cerebral palsy per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of cerebral palsy was greater for males (2.8 per 1,000) than females (2.4 per 1,000).
- Between 2004/05 and 2010/11, the crude prevalence of cerebral palsy among females remained unchanged at 2.4 per 1,000 females.
- The crude prevalence of cerebral palsy among males remained similar between 2004/05 (2.7 per 1,000) and 2010/11 (2.8 per 1,000).

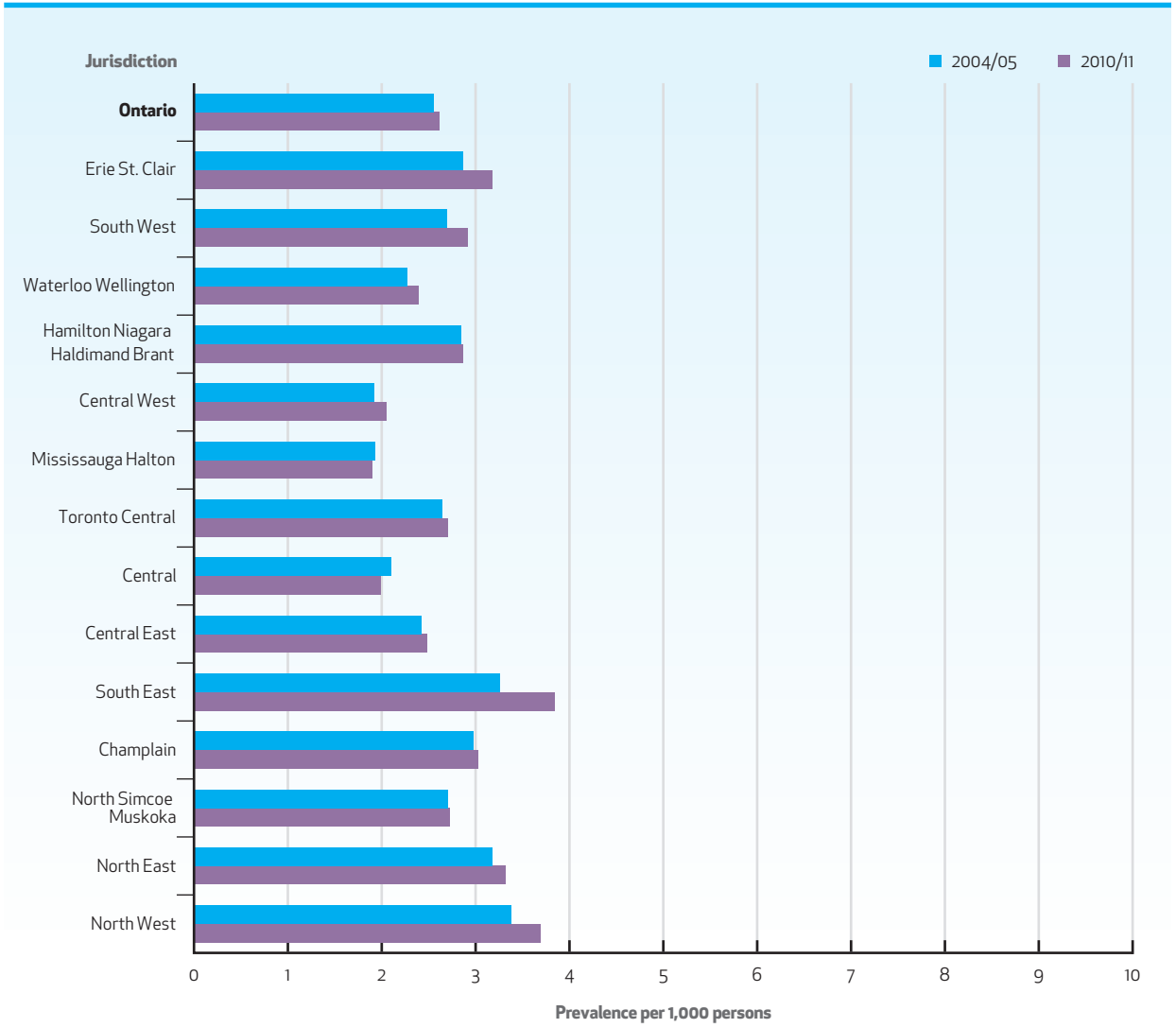


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 5.4 Age- and sex-adjusted* prevalence of cerebral palsy per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- In 2010/11, there was a two-fold variation in the age- and sex-adjusted prevalence of cerebral palsy across the Local Health Integration Networks (LHINs), which was more than the 1.8-fold variation in 2004/05.
- In 2010/11, the South East, North West and North East LHINs had the three highest age- and sex-adjusted prevalence estimates of cerebral palsy (3.8, 3.7 and 3.3 per 1,000 persons, respectively).
- In 2010/11, the Mississauga Halton, Central and Central West LHINs had the three lowest age- and sex-adjusted prevalence estimates of cerebral palsy (1.9, 2.0 and 2.1 per 1,000 persons, respectively).
- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of cerebral palsy increased across all LHINs with the exception of the Mississauga Halton and Central LHINs.



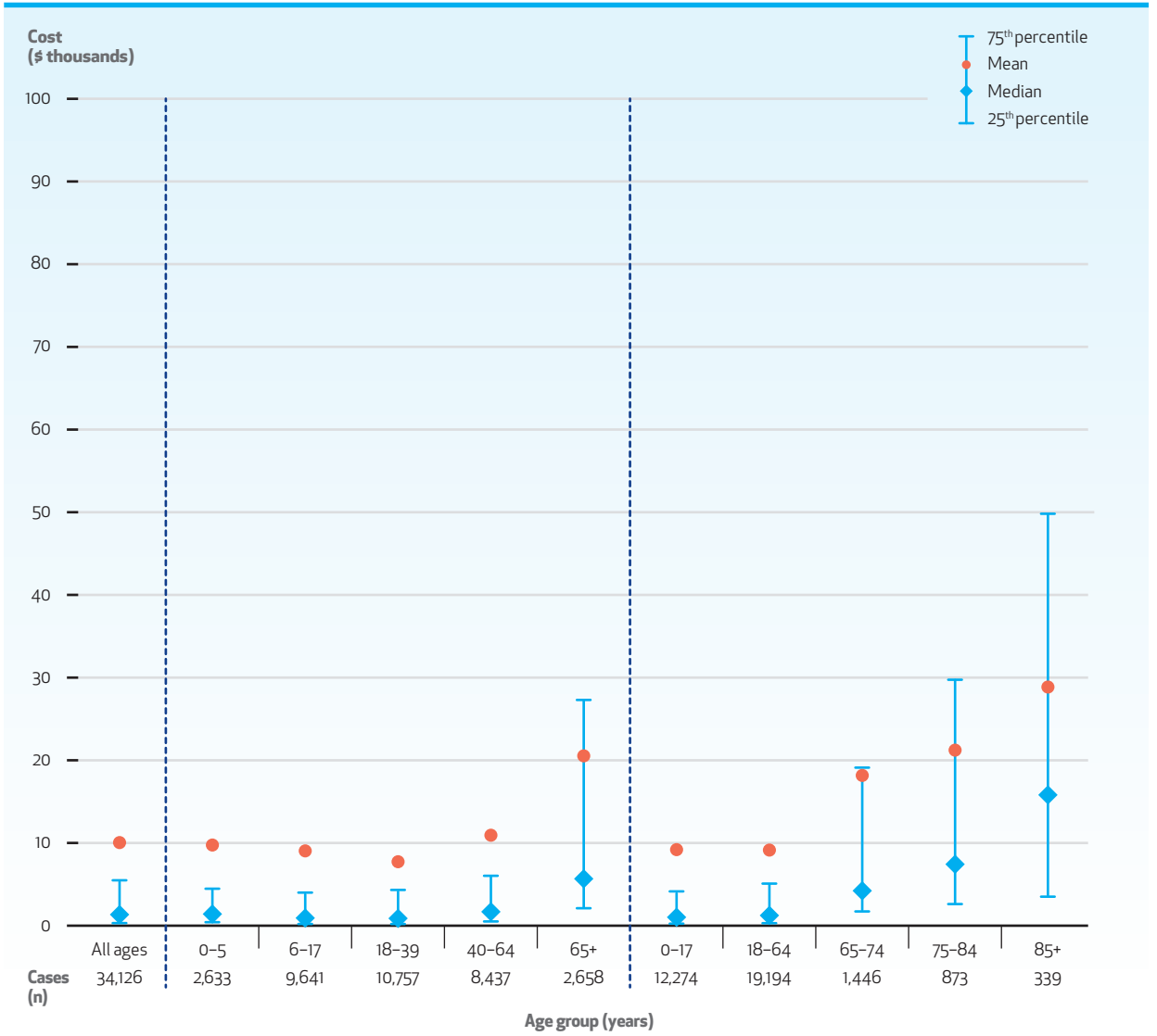
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 5.5 Distribution of costs* associated with one year† of health system use for prevalent cases with cerebral palsy, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with cerebral palsy were $10,047 and $1,340, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $314 to $5,488.
- The mean and median costs associated with one year of health system use among prevalent cases with cerebral palsy aged 5 years and younger were $9,751 and $1,408, respectively. The interquartile range of costs extended from $422 to $4,472.
- Among prevalent cases with cerebral palsy, the median cost associated with one year of health system use was similar in persons younger than 65 years, but beyond this, increased with increasing age. Persons 85 years and older had the highest median cost ($15,810).

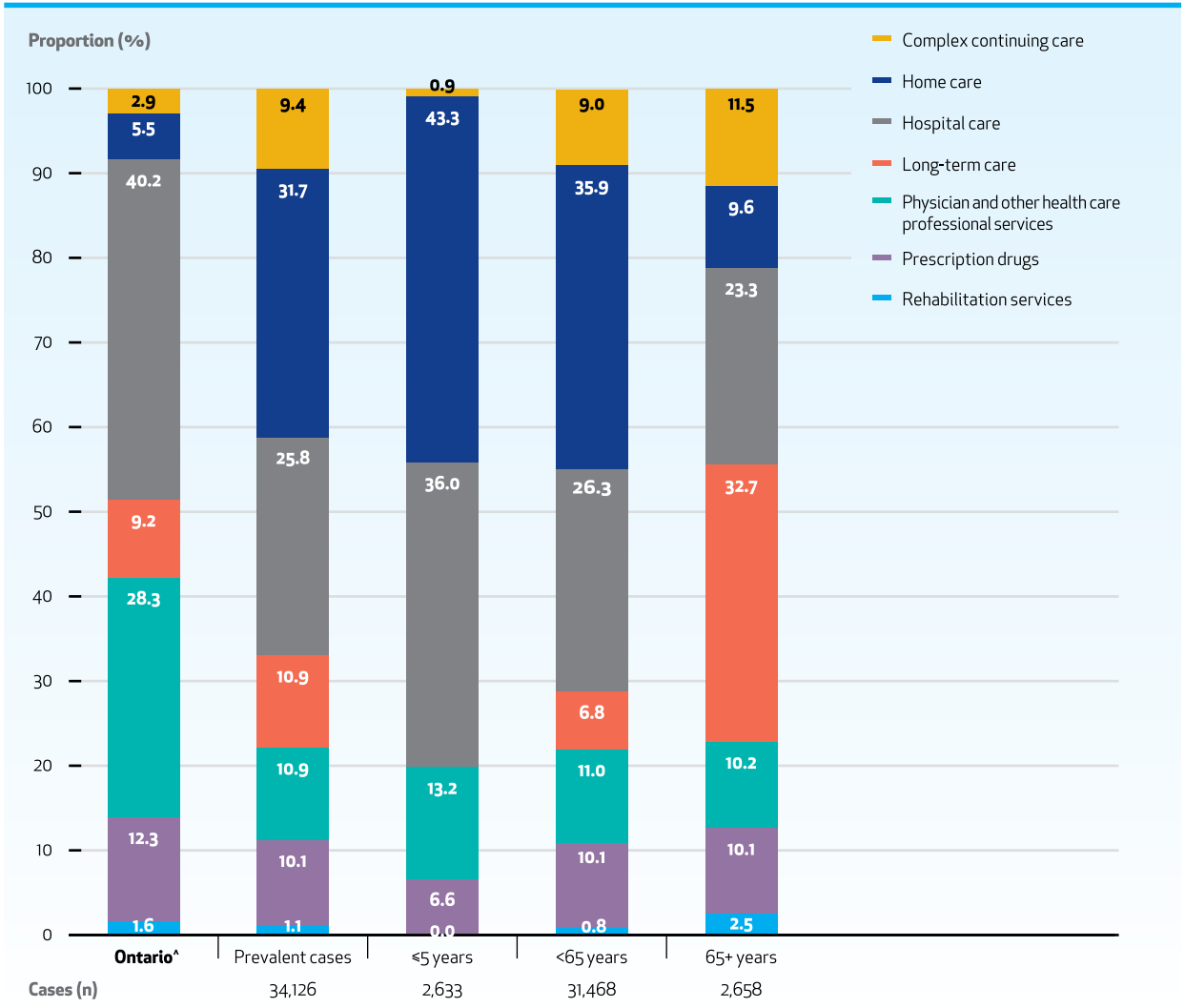


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 5.6 Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with cerebral palsy, by age group and type of health care service

Key Findings

- Among prevalent cases with cerebral palsy, the majority of the costs associated with health system use were attributable to home care (31.7%), hospital care (25.8%), long-term care (10.9%) and physician and other health care professional services (10.9%).
- Among children with cerebral palsy aged 5 years and younger, the majority of the costs associated with health system use were attributable to home care (43.3%), hospital care (36.0%) and physician and other health care professional services (13.2%).
- Among prevalent cases with cerebral palsy aged younger than 65 years, the majority of the costs associated with health system use were attributable to home care (35.9%), hospital care (26.3%) and physician and other health care professional services (11.0%).
- Among prevalent cases with cerebral palsy aged 65 years and older, the majority of the costs associated with health system use were attributable to long-term care (32.7%), hospital care (23.3%) and complex continuing care (11.5%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 6

Dementia

(including Alzheimer's Disease)

"When I think of dementia and what it entails, I think of a 'living loss.' Suddenly it seemed my mother was not the mother I had known my entire life."

– Christine

"The biggest challenge has been as soon as people heard my diagnosis, they changed their attitudes towards me. It's like suddenly my opinion didn't matter anymore. People now look to my spouse for answers."

– A participant in the Alzheimer Society of Ontario's early-stage dementia support program

Overview

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.

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 (where the problem arises from cerebrovascular disease), Parkinson's disease and Lewy body dementia, fronto-temporal degenerations like Pick's disease, 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. 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.

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. The agents currently available for Alzheimer's disease can provide modest benefits for some of the symptoms of this condition, but these drugs do not prevent progression of the illness, not everyone responds, and side effects can occur. Dementia can have a profound impact on the quality of life of the person with the condition and his or her 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.

Data Quality

Dementia (including Alzheimer's disease) was assessed using health administrative data for the population of Ontario aged 40 years and older. Descriptive characteristics, prevalence, incidence and costs associated with health system use of persons with dementia were determined. The majority of dementia occurs in persons 65 years and older, so additional prevalence and incidence estimates were presented for this age group. However, estimates were presented for ages 66 years and older instead of 65 years and older because a one-year period was required to accurately ascertain insurance claims data for persons using prescription drugs that are only available starting at age 65 years.

When looking at the results for dementia, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for dementia is considered grade I (the algorithm for Ontario health administrative data has been previously validated, and the algorithm meets generally accepted standards for predictive value and specificity [note: sensitivity can be variable]).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 6.1 Number and proportion of persons with dementia (including Alzheimer's disease), by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, females accounted for 64.3% of the 135,756 Ontarians identified with dementia.
- The mean age of a person with dementia was 81.5 years.
- Among persons with dementia, a larger proportion were distributed among the older age groups, with 41.7% being aged 85 years and older.
- Among persons with dementia, 12.2% lived in a rural setting.
- The distribution of persons with dementia across neighbourhood income quintiles showed a slightly higher proportion at the lowest income quintile (21.9%) compared with those at the highest (18.9%).

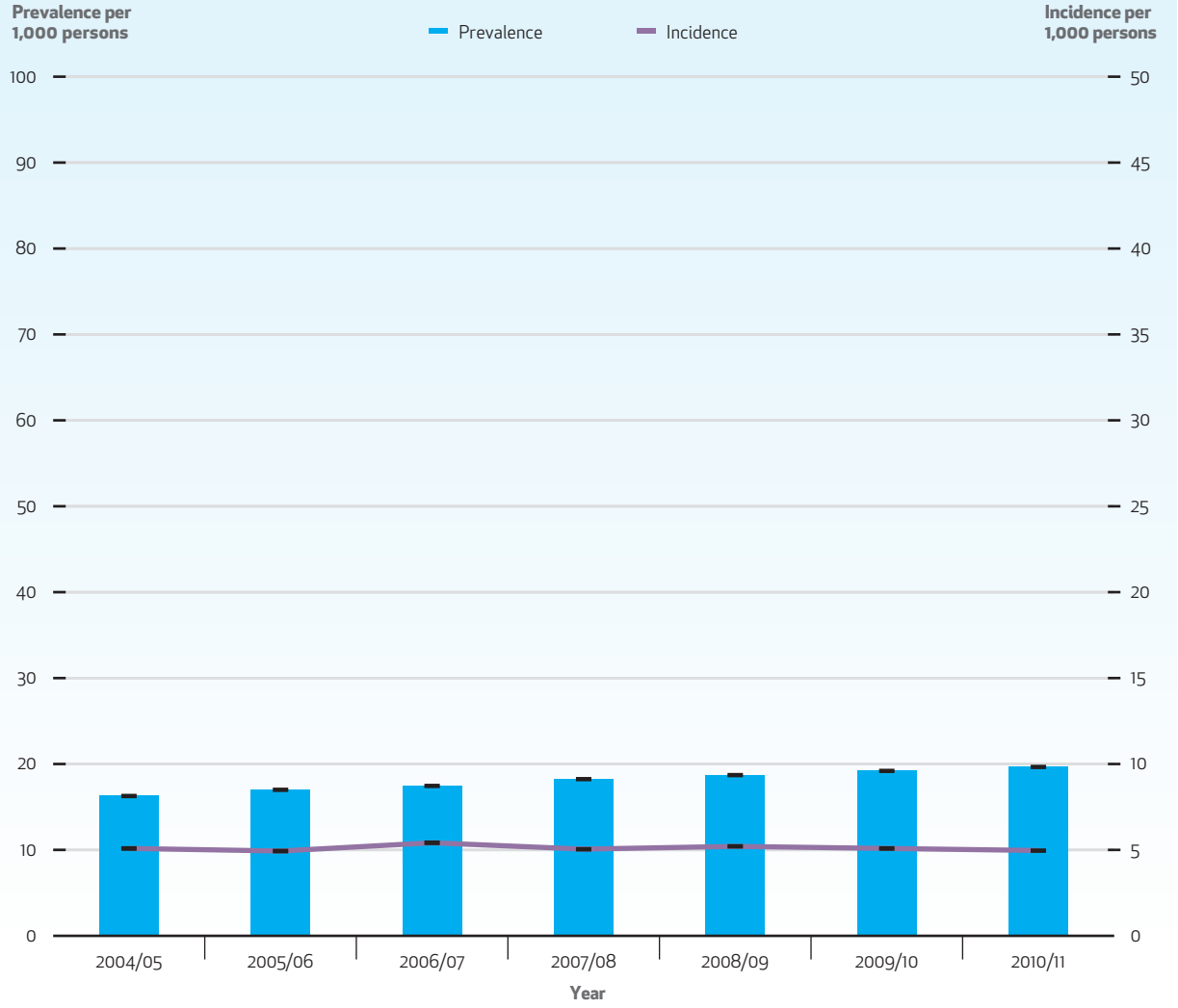
Characteristic	Cohort
Ontario, n	135,756
Sex, n (%)	
Female	87,268 (64.3)
Male	48,488 (35.7)
Age distribution, years	
Mean ± standard deviation	81.5 ± 9.4
Median (interquartile range)	83 (77–88)
Age group, years, n (%)	
40–65	8,817 (6.5)
66–74	16,429 (12.1)
75–84	53,929 (39.7)
85+	56,581 (41.7)
Adults 40–65	8,817 (6.5)
Older adults 66+	126,939 (93.5)
Residence, n (%)	
Rural	16,507 (12.2)
Urban	119,186 (87.8)
Income quintile, n (%)	
1 (lowest)	29,671 (21.9)
2	26,817 (19.8)
3	26,176 (19.3)
4	26,679 (19.7)
5 (highest)	25,714 (18.9)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 6.2A Age- and sex-adjusted* prevalence and incidence of dementia (including Alzheimer's disease) per 1,000 persons aged 40 years and older, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the total number of Ontarians aged 40 years and older with dementia increased from 90,821 to 135,756.
- The age- and sex-adjusted prevalence of dementia per 1,000 persons aged 40 years and older increased from 16.3 in 2004/05 to 19.7 in 2010/11.
- The total number of Ontarians 40 years and older with newly identified dementia increased from 26,326 in 2004/05 to 30,848 in 2010/11.
- The age- and sex-adjusted incidence of dementia per 1,000 persons aged 40 years and older decreased slightly from 5.1 in 2004/05 to 5.0 in 2010/11.



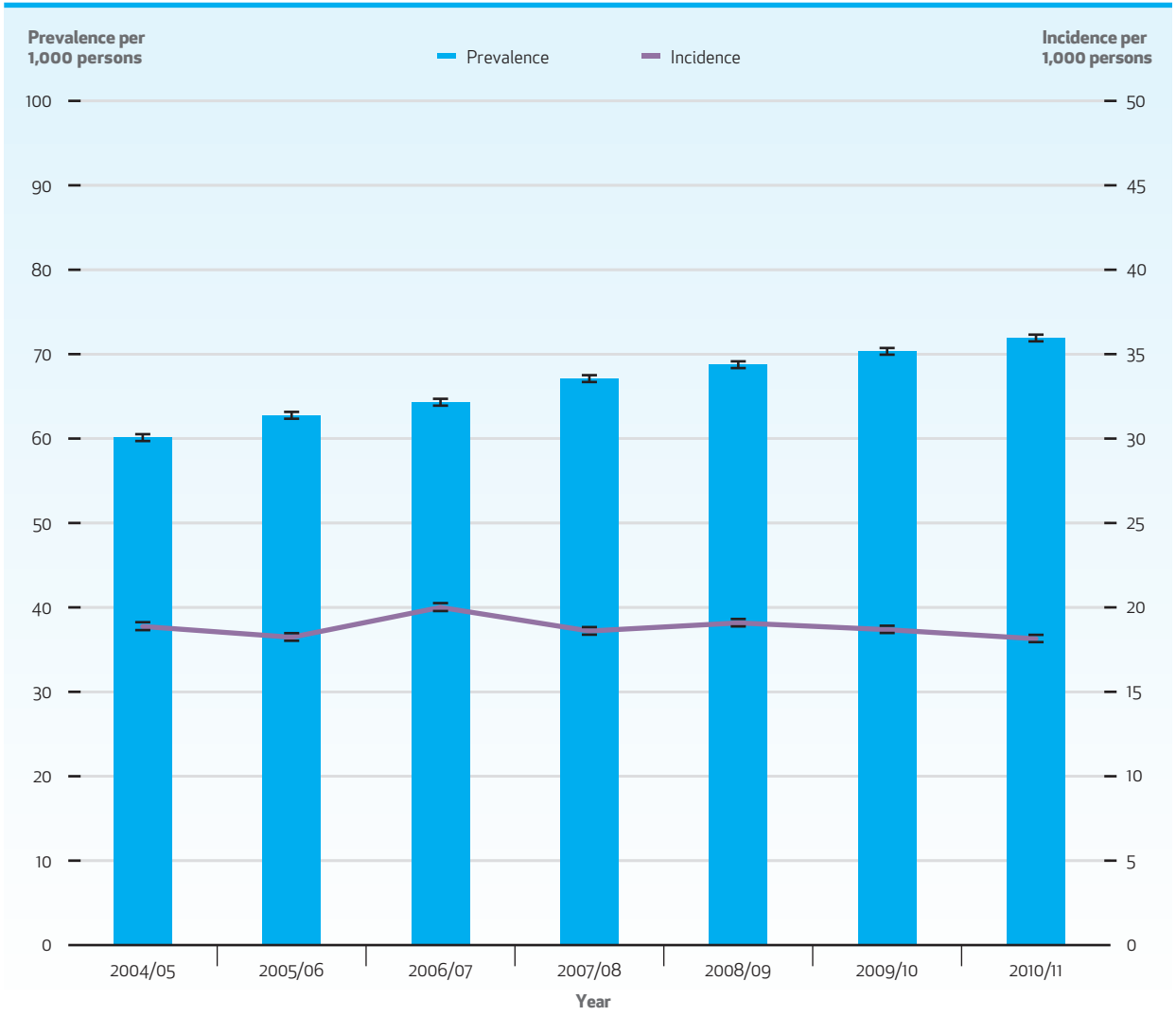
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 6.2B Age- and sex-adjusted* prevalence and incidence of dementia (including Alzheimer's disease) per 1,000 persons aged 66 years and older, in Ontario, 2004/05 to 2010/11

Key Findings

- The total number of Ontarians aged 66 years and older with dementia increased from 85,277 in 2004/05 to 126,939 in 2010/11.
- The age- and sex-adjusted prevalence of dementia per 1,000 persons aged 66 years and older increased from 60.1 in 2004/05 to 72.0 in 2010/11.
- The number of Ontarians aged 66 years and older with newly identified dementia was 24,766 in 2004/05 and 28,651 in 2010/11.
- The age- and sex-adjusted incidence of dementia per 1,000 persons aged 66 years and older decreased slightly from 18.9 in 2004/05 to 18.1 in 2010/11.



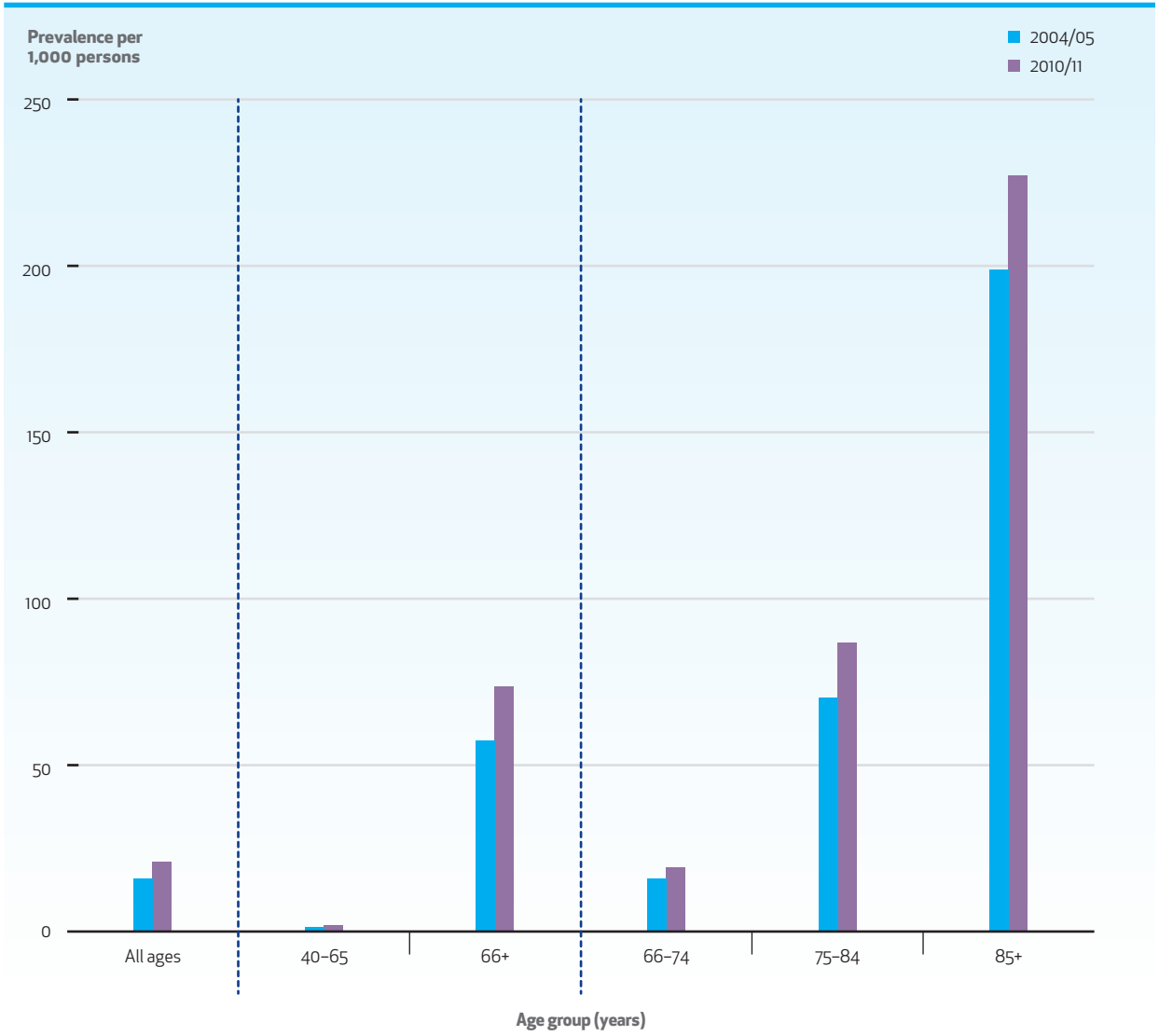
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 6.3A Crude prevalence of dementia (including Alzheimer's disease) per 1,000 persons aged 40 years and older, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of dementia for individuals aged 66–74 years, 75–84 years and 85 years and older was 19.3, 86.7 and 227.2 per 1,000, respectively.

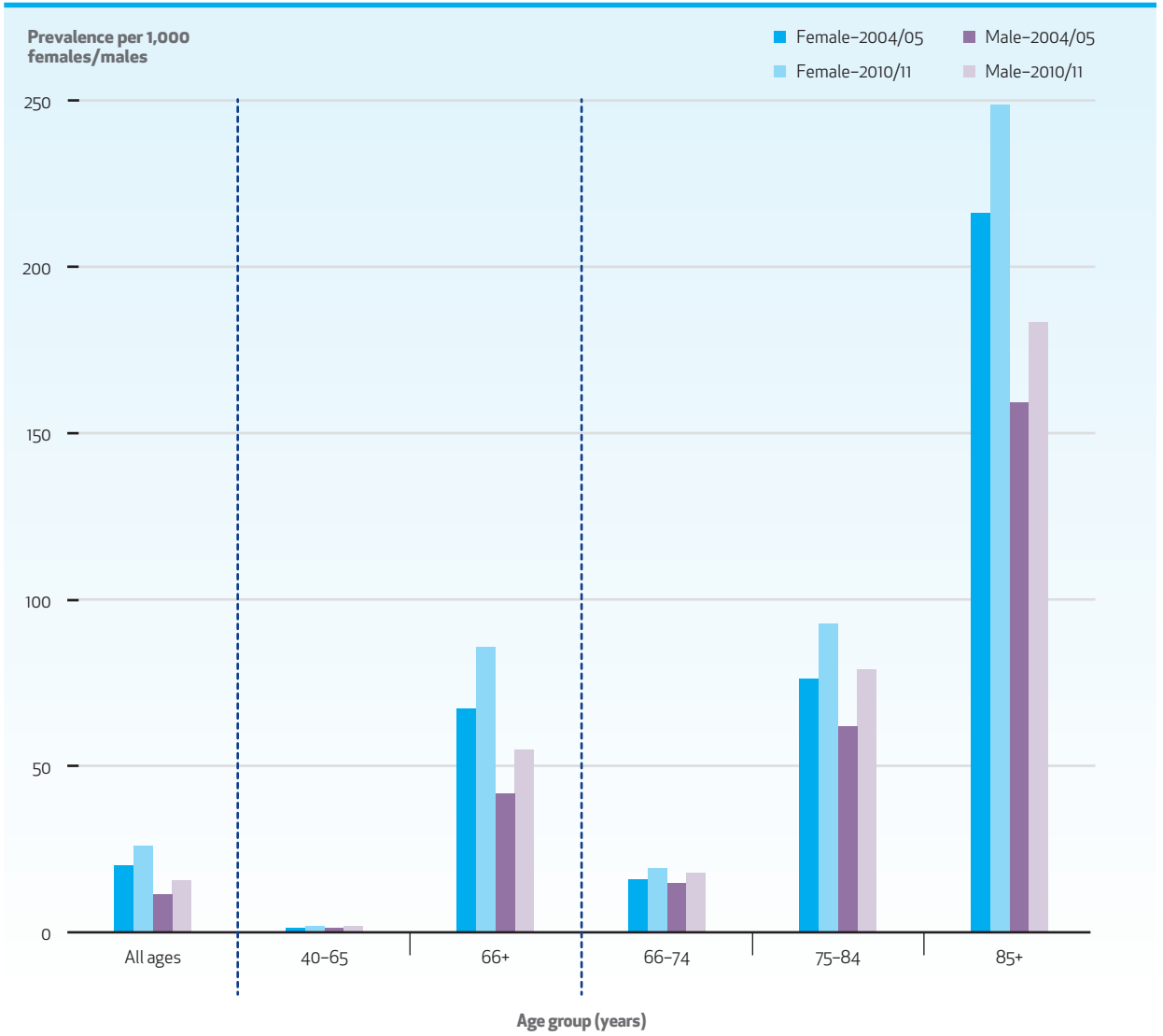


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 6.3B Crude prevalence of dementia (including Alzheimer's disease) per 1,000 females and 1,000 males aged 40 years and older, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of dementia was greater for females (25.8 per 1,000) than males (15.5 per 1,000).
- Between 2004/05 and 2010/11, the crude prevalence of dementia among females aged 40 years and older increased from 20.0 to 25.8 per 1,000. In the same period, the crude prevalence of dementia among females aged 66 years and older increased from 67.1 to 85.6 per 1,000.
- Comparing 2004/05 and 2010/11, the crude prevalence of dementia among males aged 40 years and older increased from 11.3 to 15.5 per 1,000. In the same period, the crude prevalence of dementia among males aged 66 years and older increased from 41.7 to 54.7 per 1,000.

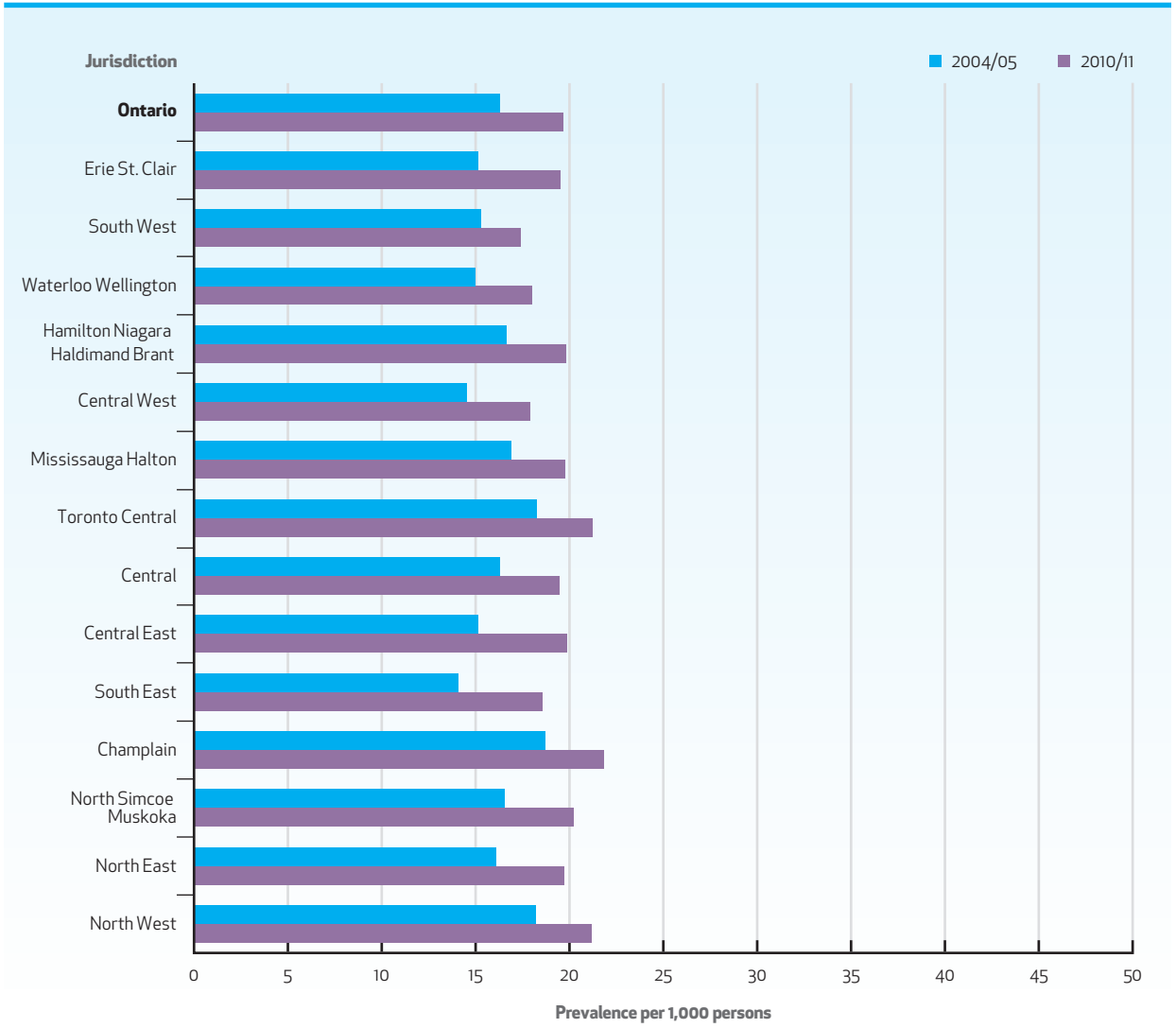


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 6.4 Age- and sex-adjusted* prevalence of dementia (including Alzheimer's disease) per 1,000 persons aged 40 years and older, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of dementia increased across all Local Health Integration Networks (LHINs).
- In 2004/05 and 2010/11, there was a 1.3-fold variation in the age- and sex-adjusted prevalence of dementia across the LHINs.
- In 2010/11, the Champlain, Toronto Central and North West LHINs had the three highest age- and sex-adjusted prevalence estimates of dementia (21.8, 21.2 and 21.2 per 1,000 persons aged 40 years and older, respectively).
- In 2010/11, the South West, Central West and Waterloo Wellington LHINs had the three lowest age- and sex-adjusted prevalence estimates of dementia, (17.4, 17.9 and 18.0 per 1,000 persons aged 40 years and older, respectively).



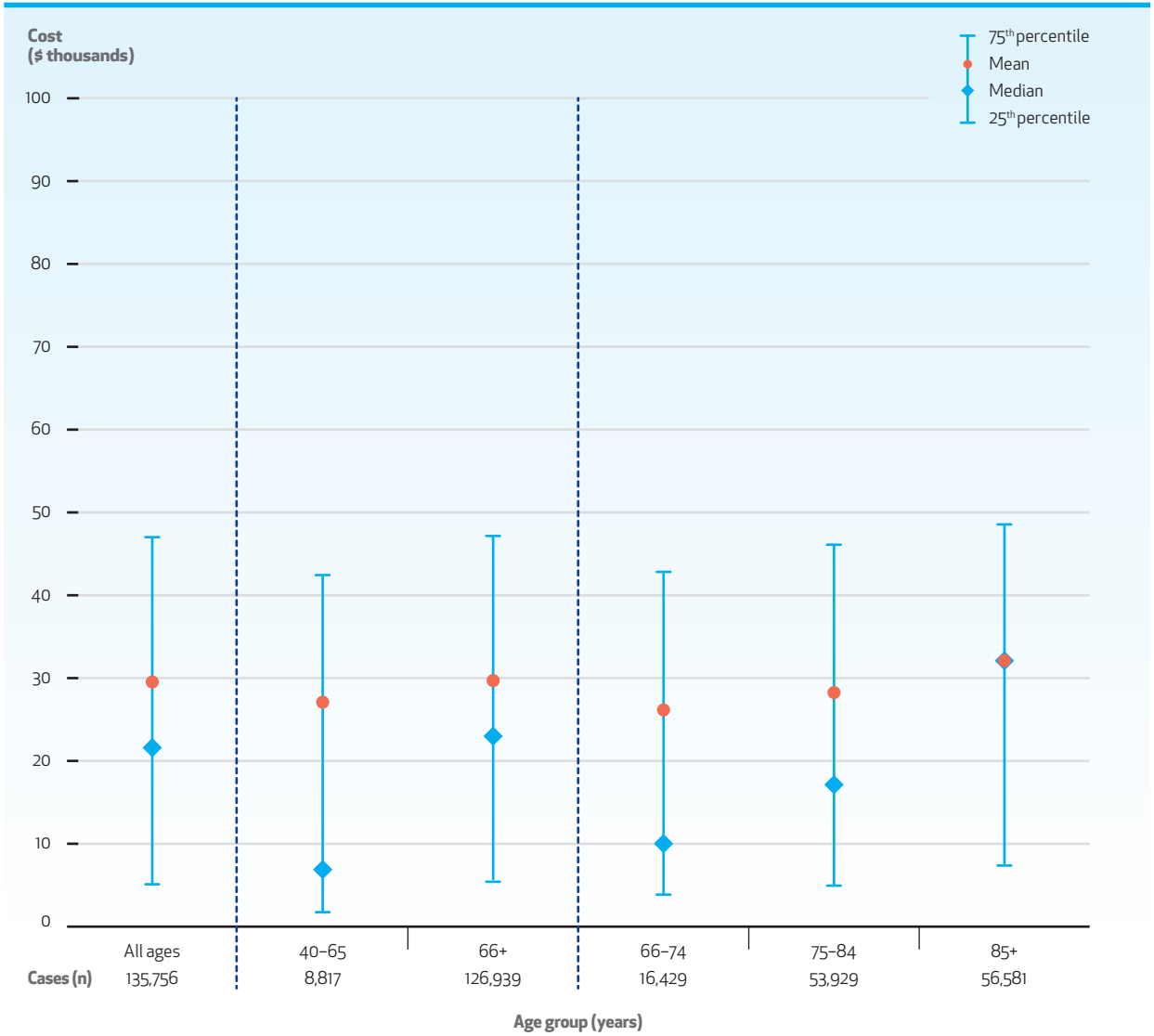
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 6.5A Distribution of costs* associated with one year† of health system use for prevalent cases with dementia (including Alzheimer's disease), by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with dementia were $29,524 and $21,588, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $5,112 to $47,013.
- Among prevalent cases with dementia, the median cost associated with one year of health system use increased by age with the highest median cost found among persons aged 85 years and older ($32,088).

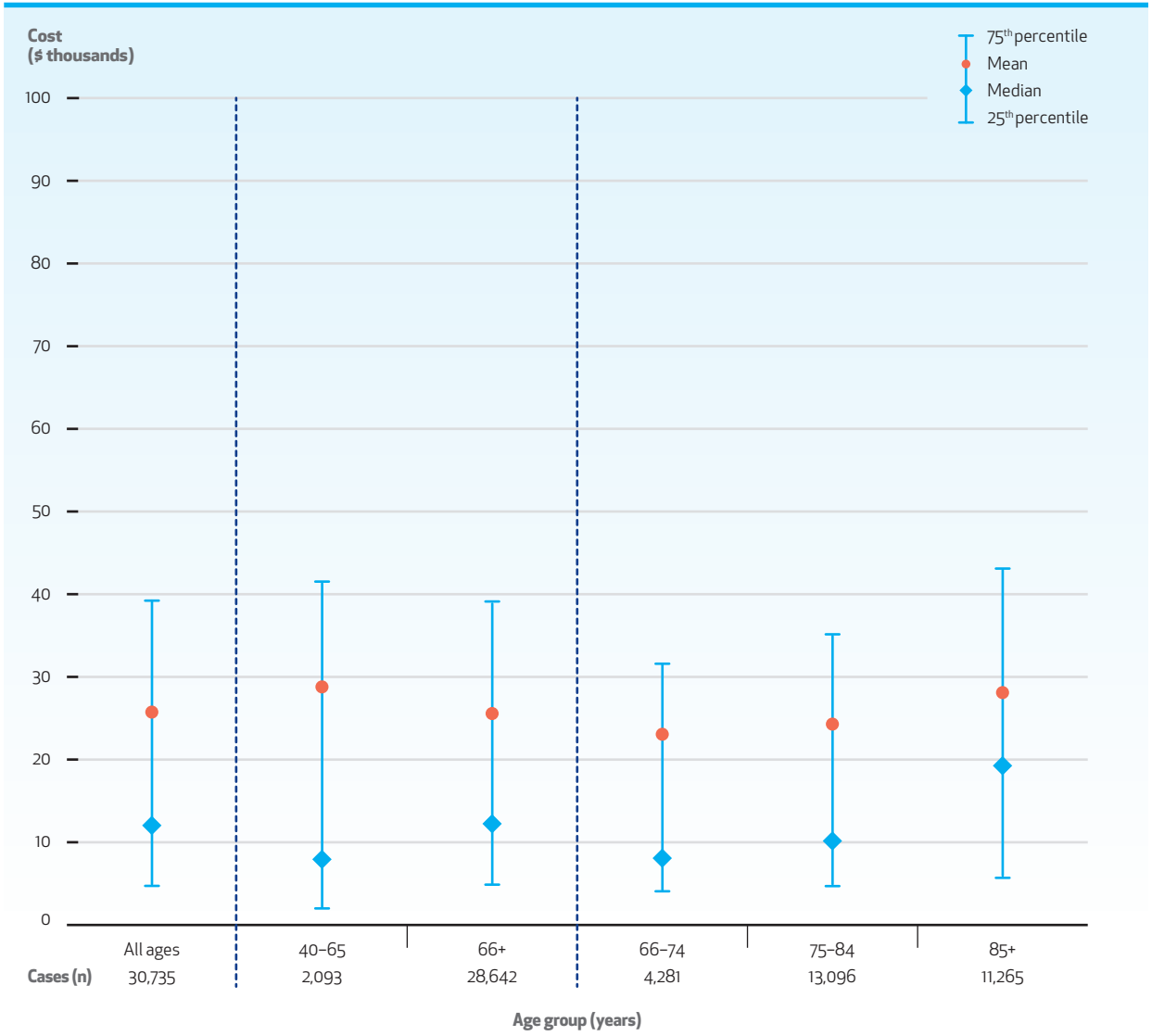


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 6.5B Distribution of costs* associated with one year† of health system use for incident cases with dementia (including Alzheimer's disease), by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with dementia were $25,743 and $12,035, respectively. The interquartile range of costs extended from $4,728 to $39,223.
- Among incident cases with dementia, the median cost associated with one year of health system use increased by age, with the highest median cost found among persons aged 85 years and older ($19,259).

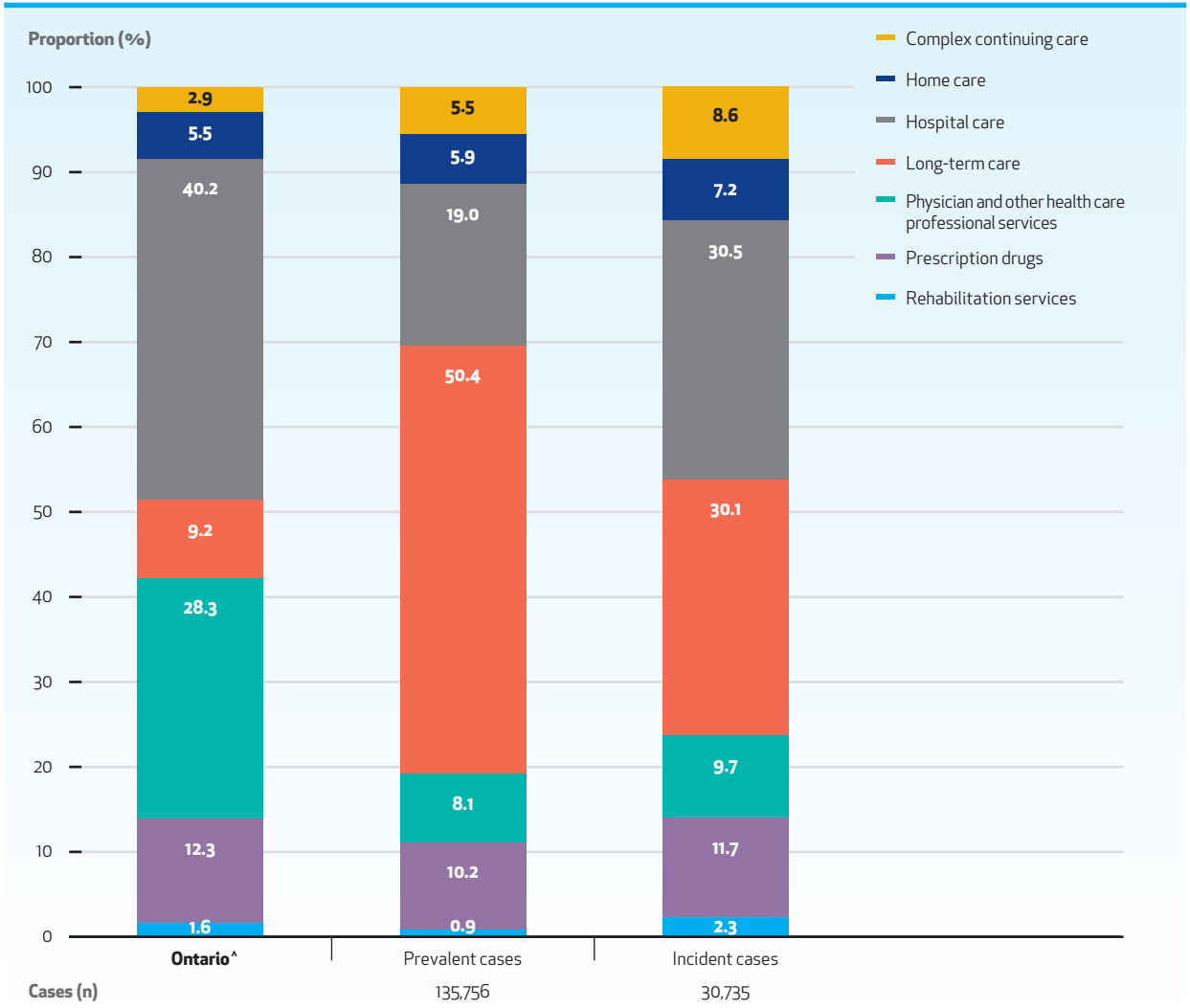


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 6.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with dementia (including Alzheimer's disease), by type of health care service

Key Findings

- Among prevalent cases with dementia, the majority of the costs associated with health system use were attributable to long-term care (50.4%), hospital care (19.0%) and prescription drugs (10.2%).
- Among incident cases with dementia, the majority of the costs associated with health system use were attributable to hospital care (30.5%), long-term care (30.1%) and prescription drugs (11.7%).

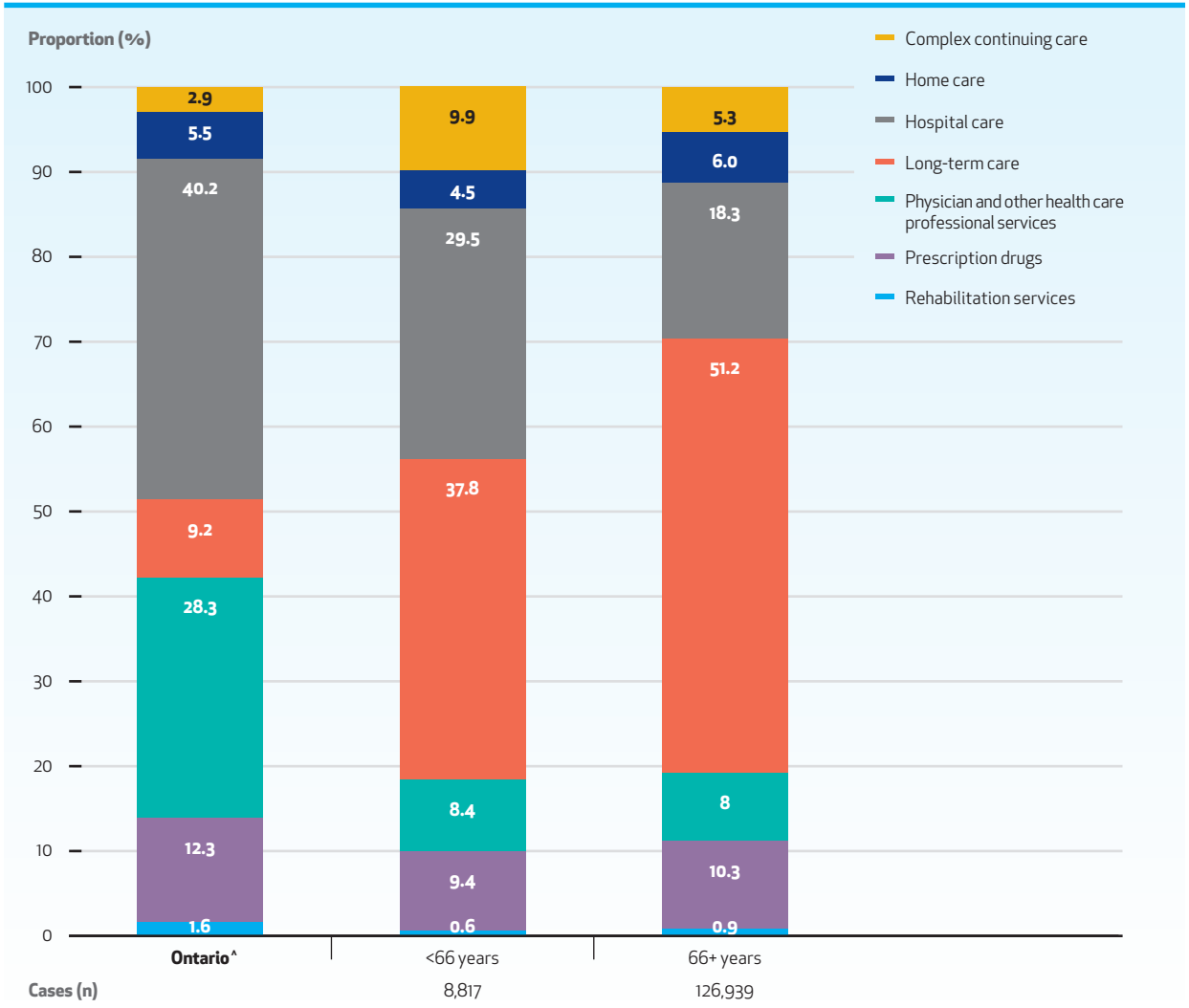


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 6.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with dementia (including Alzheimer's disease), by age group and type of health care service

Key Findings

- Among prevalent cases with dementia aged younger than 66 years, the majority of the costs associated with health system use were attributable to long-term care (37.8%), hospital care (29.5%) and complex continuing care (9.9%).
- Among prevalent cases with dementia aged 66 years and older, the majority of the costs associated with health system use were attributable to long-term care (51.2%), hospital care (18.3%) and prescription drugs (10.3%)



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 7

Epilepsy

"I had always dreamed of babysitting my grandchildren and taking them to the park, but I can't even hold my newborn granddaughter."

"School was a huge challenge. I struggled to understand what was being taught, and when I finally understood, it was wiped away with a seizure."

– Clients of Epilepsy Ontario

Overview

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, depending on the part of the brain involved, can 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 anxious to experiencing tonic-clonic seizures, which are characterized by loss of consciousness and severe muscle contractions. 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.

Data Quality

Epilepsy was assessed using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with epilepsy were determined.

When looking at the results for epilepsy, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for epilepsy is considered grade I (the algorithm for Ontario health administrative data has been previously validated, and the algorithm meets generally accepted standards for predictive value and specificity [note: sensitivity can be variable]).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 7.1 Number and proportion of persons with epilepsy, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April, 1, 2010, males accounted for 51.1% of the 89,867 Ontarians identified with epilepsy.
- The mean age of a person with epilepsy was 41.5 years.
- The majority of persons with epilepsy were younger than 65 years, with 16.1% aged 0–17 years and 69.1% aged 18–64 years.
- Among persons with epilepsy, 12.6% lived in a rural setting.
- Persons with epilepsy were not evenly distributed across neighbourhoods by income quintile: 23.6% lived in the lowest-income neighbourhoods and 17.3% lived in the highest-income neighbourhoods.

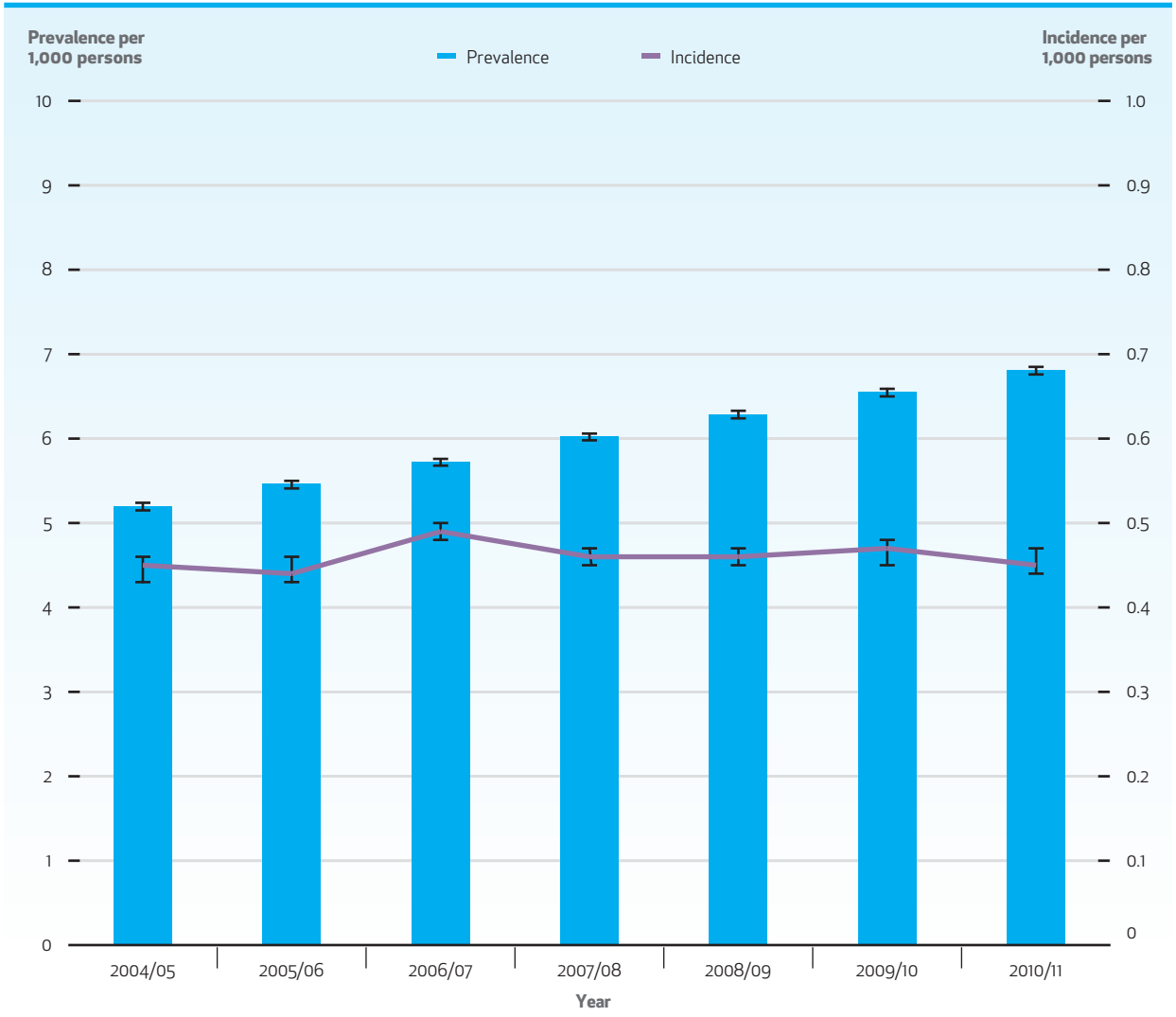
Characteristic	Cohort
Ontario, n	89,867
Sex, n (%)	
Female	43,952 (48.9)
Male	45,915 (51.1)
Age distribution, years	
Mean ± standard deviation	41.5 ± 21.2
Median (interquartile range)	42 (24–57)
Age group, years, n (%)	
0–4	1,488 (1.7)
5–17	12,994 (14.5)
18–39	26,948 (30.0)
40–64	35,145 (39.1)
65–74	6,871 (7.6)
75–84	4,728 (5.3)
85+	1,693 (1.9)
Children 0–17	14,482 (16.1)
Adults 18–64	62,093 (69.1)
Older adults 65+	13,292 (14.8)
Residence, n (%)	
Rural	11,293 (12.6)
Urban	78,539 (87.4)
Income quintile, n (%)	
1 (lowest)	21,165 (23.6)
2	18,631 (20.7)
3	17,127 (19.1)
4	17,032 (19.0)
5 (highest)	15,520 (17.3)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 7.2 Age- and sex-adjusted* prevalence and incidence of epilepsy per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with epilepsy increased from 63,898 to 89, 867.
- The age- and sex-adjusted prevalence of epilepsy per 1,000 persons increased from 5.2 in 2004/05 to 6.8 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified epilepsy increased slightly from 5,510 to 5,981.
- The age- and sex-adjusted incidence of epilepsy per 1,000 persons was unchanged at 0.45 in 2004/05 and 2010/11.



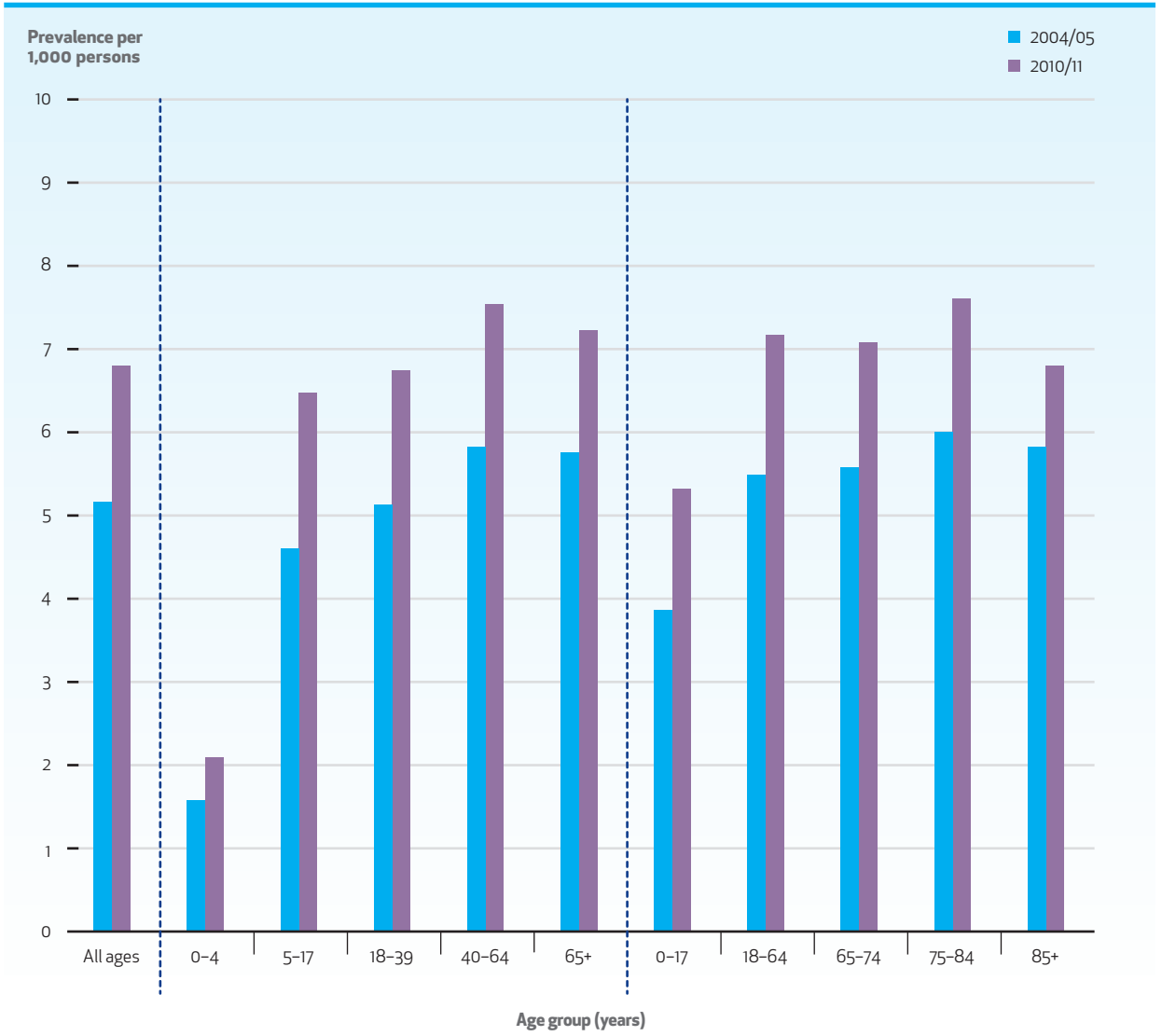
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 7.3A Crude prevalence of epilepsy per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of epilepsy for individuals aged 0–17 years, 18–64 years, and 65 years and older was 5.3, 7.2 and 7.2 per 1,000, respectively.

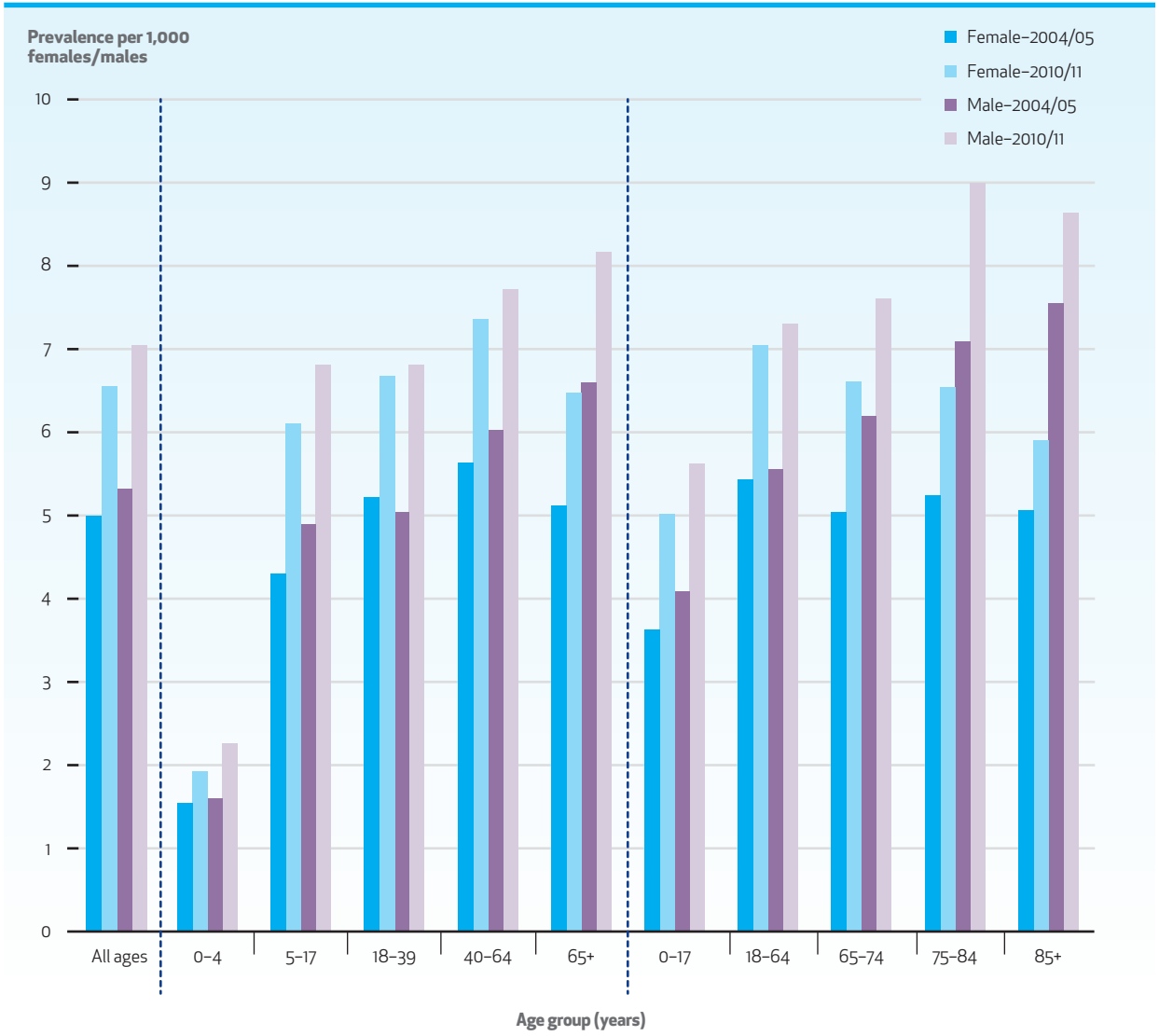


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 7.3B Crude prevalence of epilepsy per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of epilepsy was greater for males (7.0 per 1,000) than females (6.6 per 1,000).
- From 2004/05 to 2010/11, the crude prevalence of epilepsy among females rose from 5.0 to 6.6 per 1,000 females.
- From 2004/05 to 2010/11, the crude prevalence of epilepsy among males rose from 5.3 to 7.0 per 1,000 males.

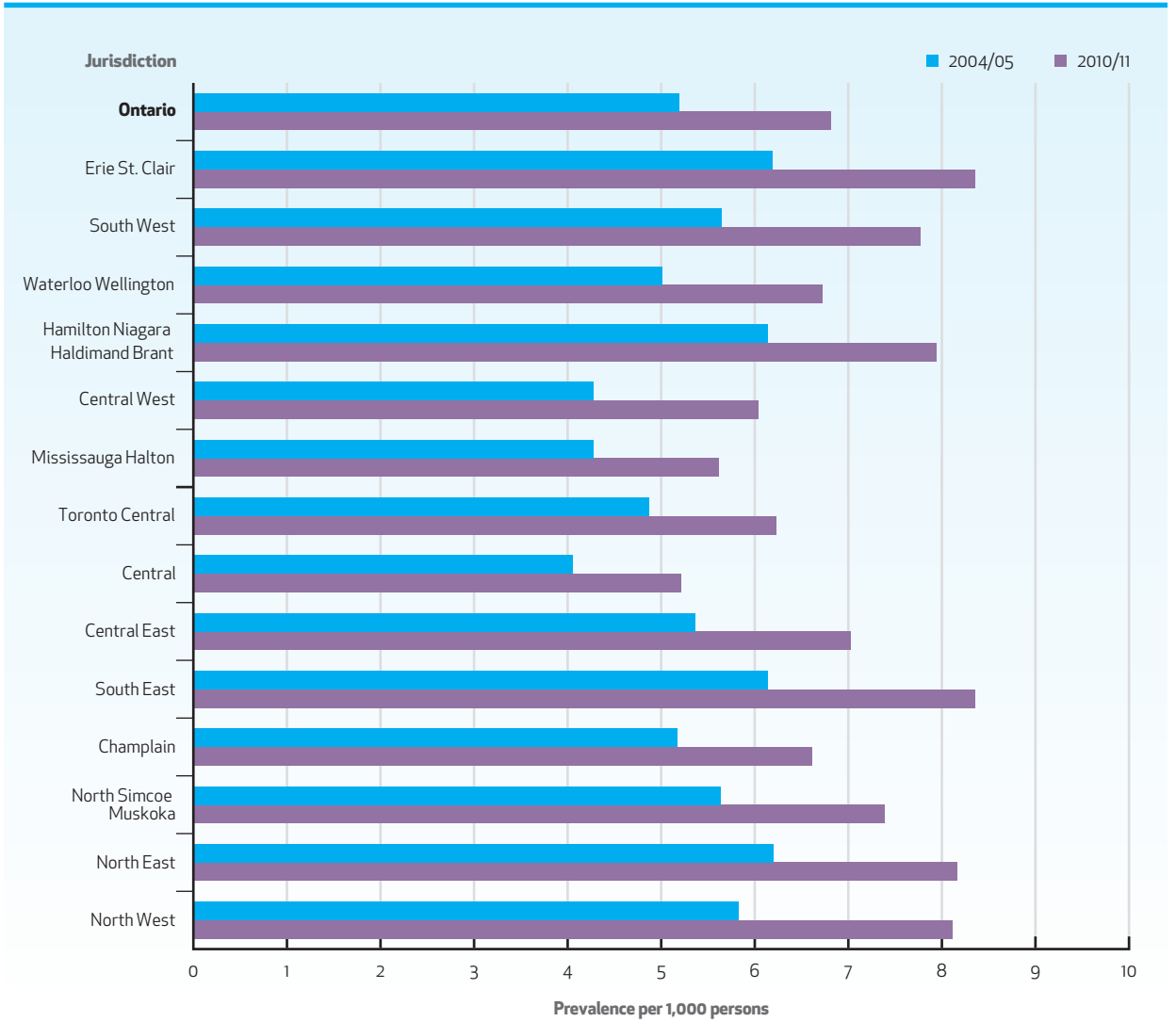


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 7.4 Age- and sex-adjusted* prevalence of epilepsy per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of epilepsy increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 1.6-fold variation in the age- and sex-adjusted prevalence of epilepsy in 2010/11, which was greater than the 1.5-fold variation in 2004/05.
- In 2010/11, the Erie St. Clair, South East and North East LHINs had the three highest age- and sex-adjusted prevalence estimates of epilepsy: 8.4, 8.4 and 8.2 per 1,000 persons, respectively.
- In 2010/11, the Central, Mississauga Halton and Central West LHINs had the three lowest age- and sex-adjusted prevalence estimates of epilepsy: 5.2, 5.6 and 6.0 per 1,000 persons, respectively.



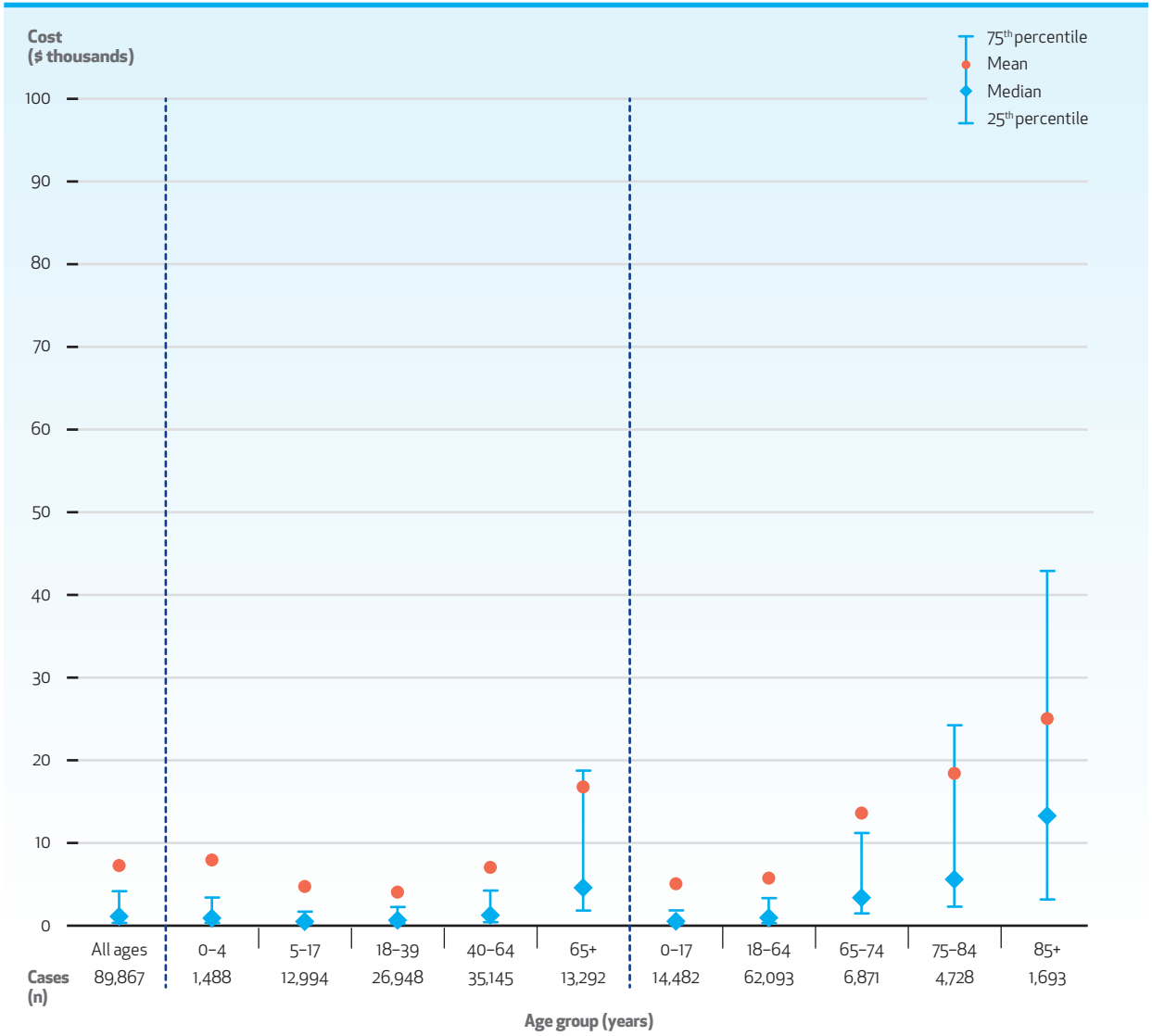
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 7.5A Distribution of costs* associated with one year† of health system use for prevalent cases with epilepsy, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with epilepsy were $7,283 and $1,124, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $338 to $4,171.
- Among prevalent cases with epilepsy, the median cost associated with one year of health system use generally increased with age. The median costs were highest for those aged 85 years and older ($13,293).

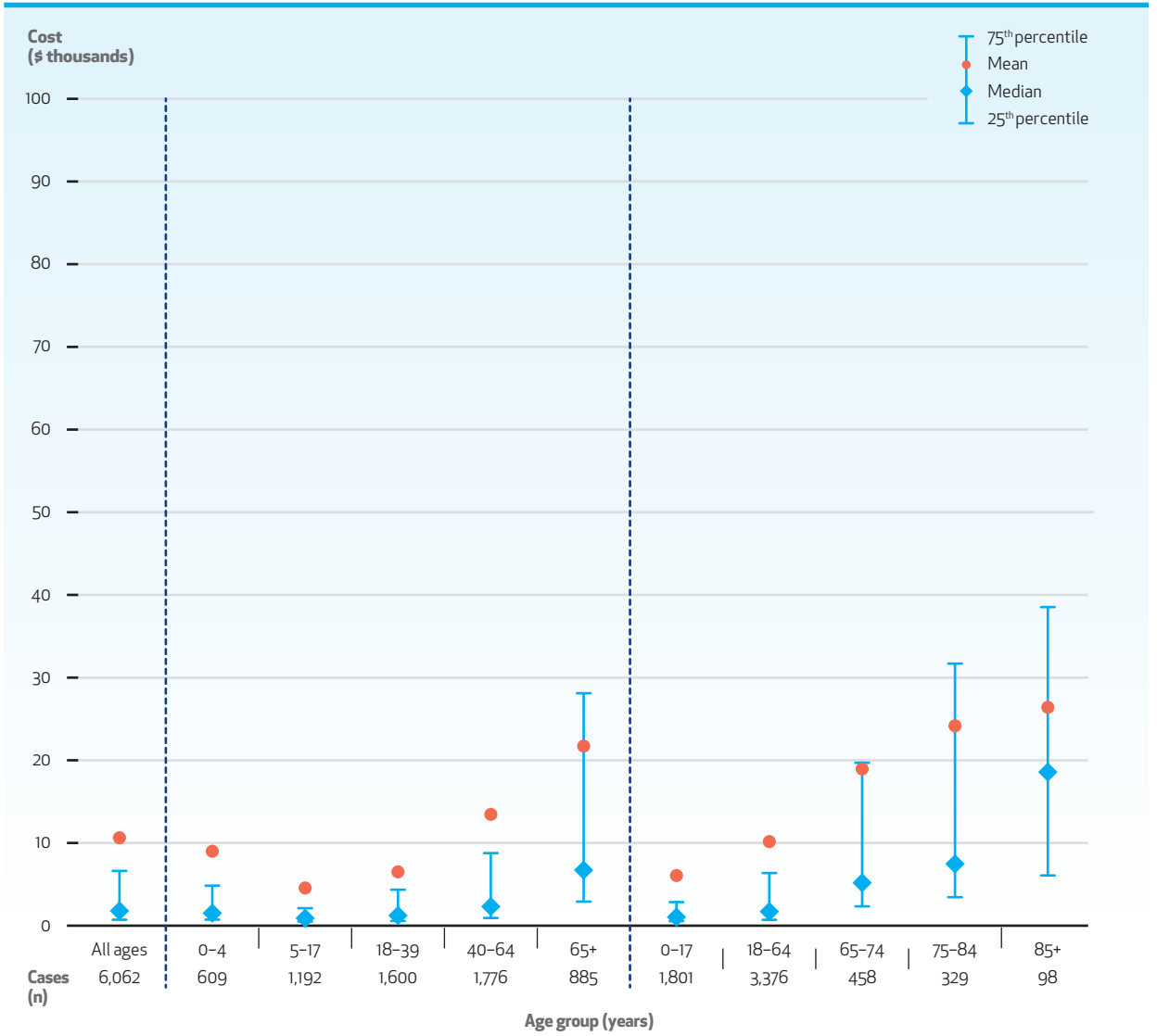


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 7.5B Distribution of costs* associated with one year† of health system use for incident cases with epilepsy, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with epilepsy were $10,631 and $1,790, respectively. The interquartile range of costs extended from $722 to $6,624.
- Among incident cases with epilepsy, the median cost associated with one year of health system use generally increased by age with the highest median cost occurring in those aged 85 years and older ($18,572).

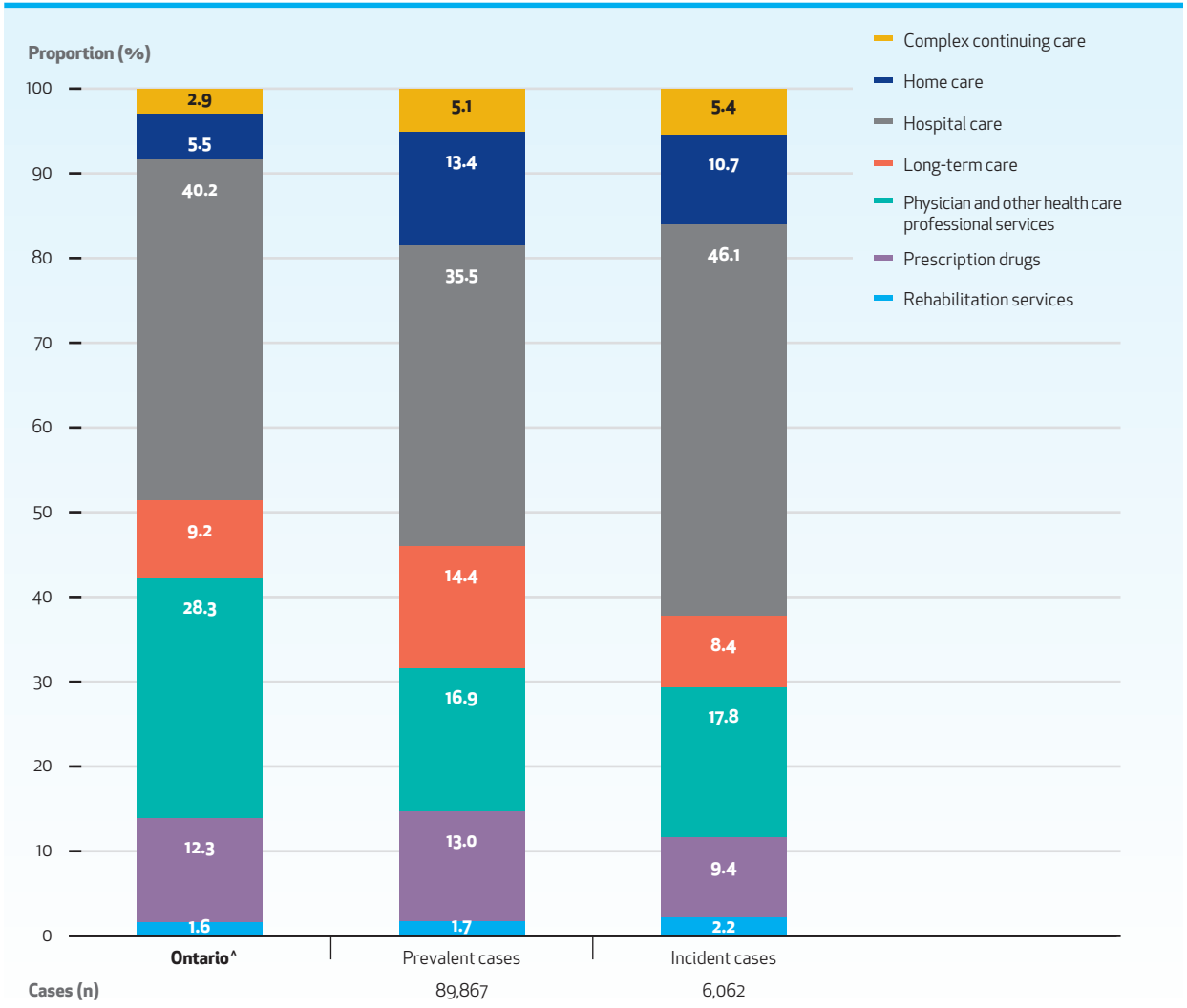


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 7.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with epilepsy, by type of health care service

Key Findings

- Among prevalent cases with epilepsy, the majority of the costs associated with health system use were attributable to hospital care (35.5%), physician and other health care professional services (16.9%) and long-term care (14.4%).
- Among incident cases with epilepsy, the majority of the costs associated with health system use were attributable to hospital care (46.1%), physician and other health care professional services (17.8%) and home care (10.7%).

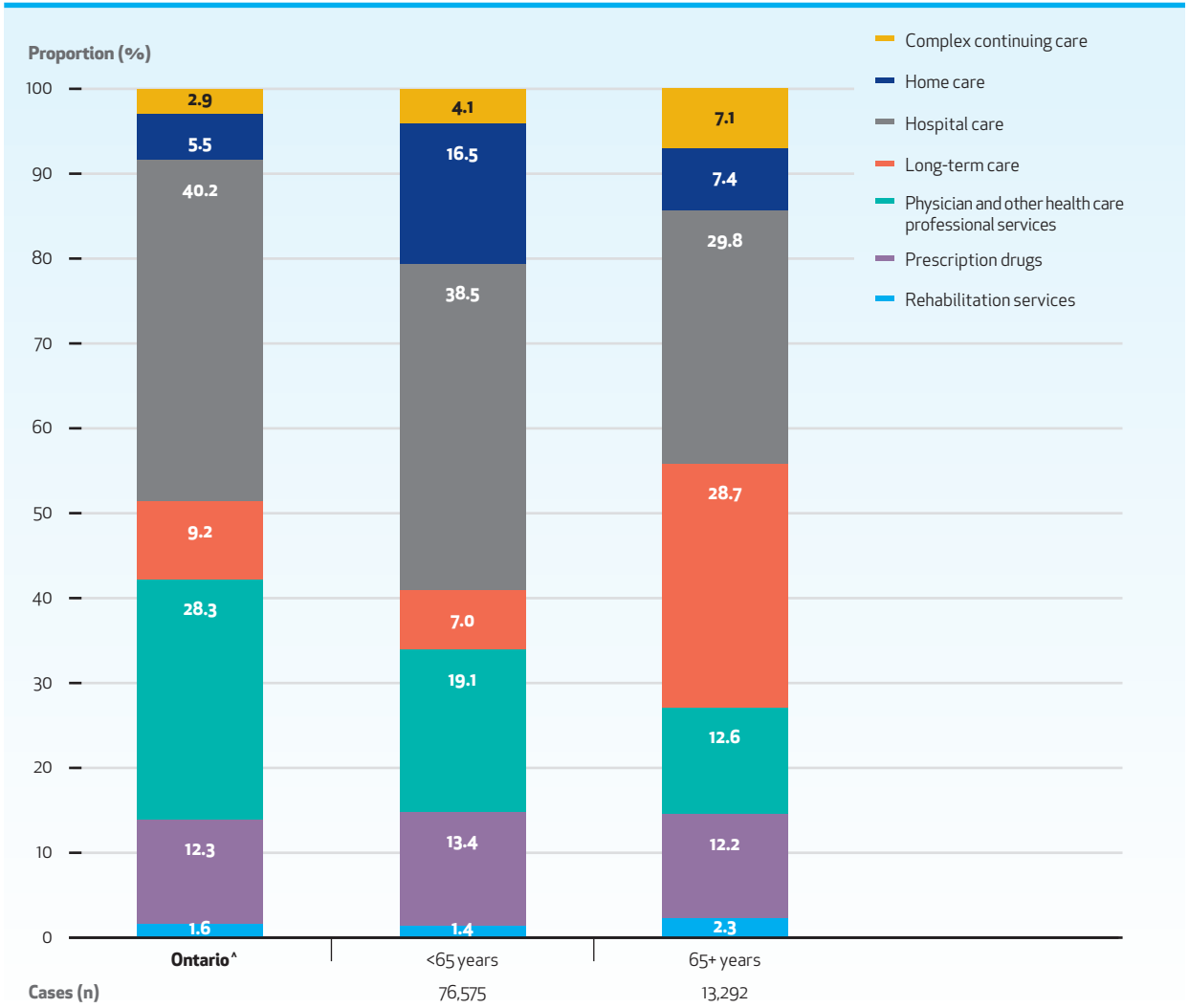


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 7.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with epilepsy, by age group and type of health care service

Key Findings

- Among prevalent cases with epilepsy aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (38.5%), physician and other health care professional services (19.1%) and home care (16.5%).
- Among prevalent cases with epilepsy aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (29.8%), long-term care (28.7%) and physician and other health care professional services (12.6%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 8

Motor Neuron Disease

"The biggest challenge about living with ALS [amyotrophic lateral sclerosis] is the continual change and loss of ability to perform seemingly simple tasks. People see the changes in people with ALS whereby they are not able to walk or support themselves anymore, but it is the loss of the ability to perform simple day-to-day tasks (brushing your teeth, feeding yourself or responding to email) that challenges both ALS patients and caregivers."

– Denise Alexander, 44

Overview

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 (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 typically presents in those between 40 and 70 years of age. Amyotrophic lateral sclerosis causes progressive weakness of the muscles in the mouth, throat, arms and legs. Affected persons may also develop cognitive difficulties or dementia. Amyotrophic lateral sclerosis is associated with premature mortality, with death often occurring within three to five years of symptom onset. While 5% of amyotrophic lateral sclerosis cases are hereditary, the definitive cause of the disease remains unknown for the other 95% cases. Amyotrophic lateral sclerosis has no cure, and effective treatment for motor neuron disease remains elusive. Currently, only one drug has been approved for the treatment of amyotrophic lateral sclerosis, 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 amyotrophic lateral sclerosis is supportive care (respiratory care, medical symptom management, rehabilitative therapy, lifestyle modification and palliative care). Persons with amyotrophic lateral sclerosis can benefit from an interprofessional team approach to health care. Expertise among the care providers pertaining to the many dimensions of living with amyotrophic lateral sclerosis – 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.

Data Quality

Motor neuron disease was assessed using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with motor neuron disease were determined.

When looking at the results for motor neuron disease, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for motor neuron disease is considered grade II (the algorithm for Ontario health administrative data has not been validated but has been used in previous Canadian research studies and/or is accepted in the research community).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 8.1 Number and proportion of persons with motor neuron disease, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 50.9% of the 997 Ontarians identified with motor neuron disease.
- The mean age of a person with motor neuron disease was 58.2 years.
- Among persons with motor neuron disease, 45.3% were aged 18–64 years and 46.8% were aged 65 years and older, and only a small proportion of those identified were aged 17 years or younger (7.8%).
- Among persons with motor neuron disease, 12.7% lived in a rural setting.
- Approximately 16.8% of persons with motor neuron disease lived in middle income neighbourhoods compared to 21.2% and 23.0% of persons with motor neuron disease living in the lowest and highest income neighbourhoods, respectively.

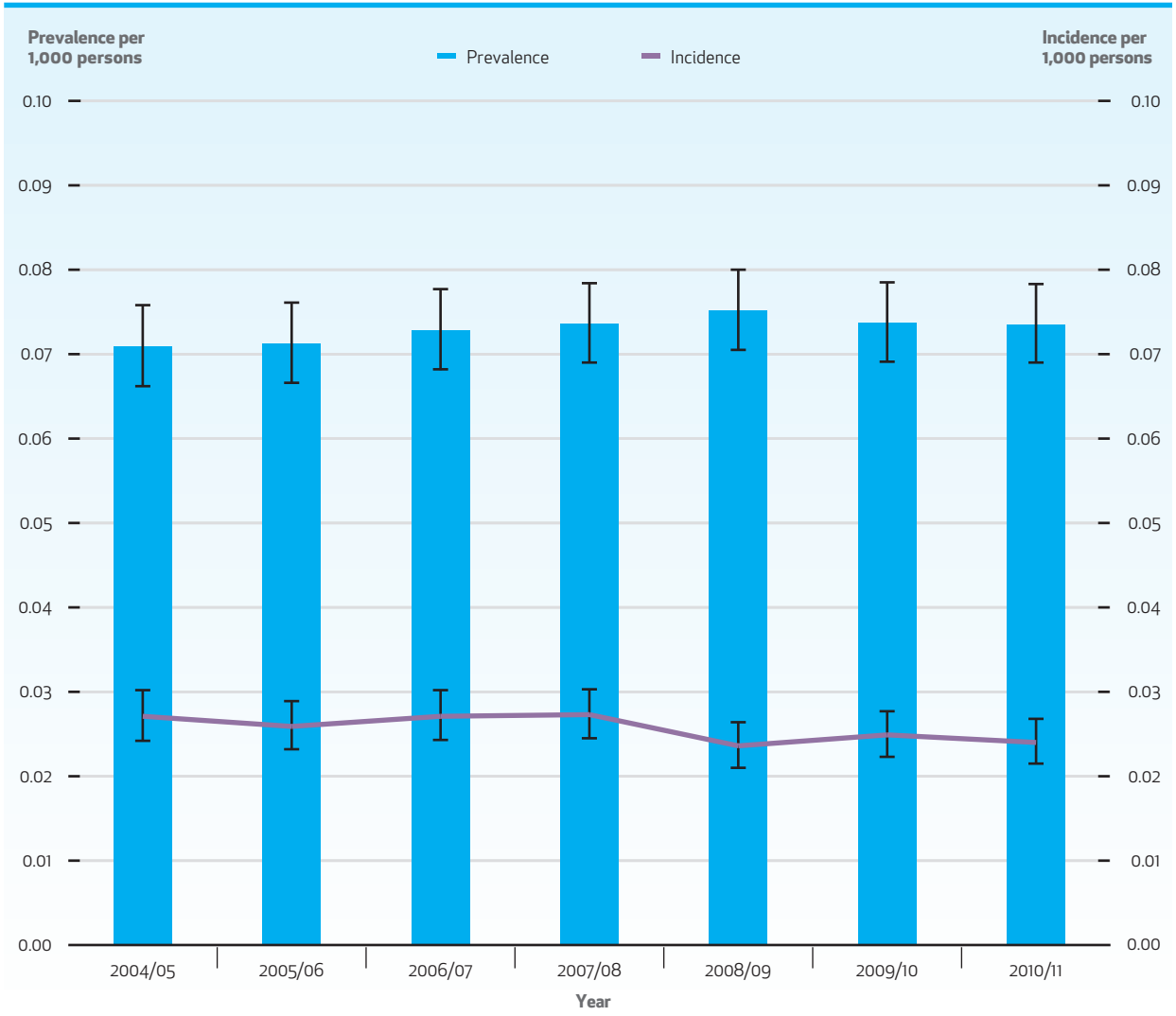
Characteristic	Cohort
Ontario, n	997
Sex, n (%)	
Female	490 (49.1)
Male	507 (50.9)
Age distribution, years	
Mean ± standard deviation	58.2 ± 22.1
Median (interquartile range)	63 (46–74)
Age group, years, n (%)	
18–39	110 (11.0)
40–64	342 (34.3)
65–74	219 (22.0)
75–84	181 (18.2)
85+	67 (6.7)
Children 0–17	78 (7.8)
Adults 18–64	452 (45.3)
Older adults 65+	467 (46.8)
Residence, n (%)	
Rural	127 (12.7)
Urban	870 (87.3)
Income quintile, n (%)	
1 (lowest)	211 (21.2)
2	220 (22.1)
3	167 (16.8)
4	168 (16.9)
5 (highest)	229 (23.0)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 8.2 Age- and sex-adjusted* prevalence and incidence of motor neuron disease per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with motor neuron disease increased from 858 to 997.
- The age- and sex-adjusted prevalence of motor neuron disease per 1,000 persons in 2004/05 and in 2010/11 was similar (0.071 and 0.074, respectively).
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified motor neuron disease was relatively unchanged at 327 and 331, respectively.
- The age- and sex-adjusted incidence of motor neuron disease was similar in 2004/05 and 2010/11 at 0.027 and 0.024 per 1,000 persons, respectively.



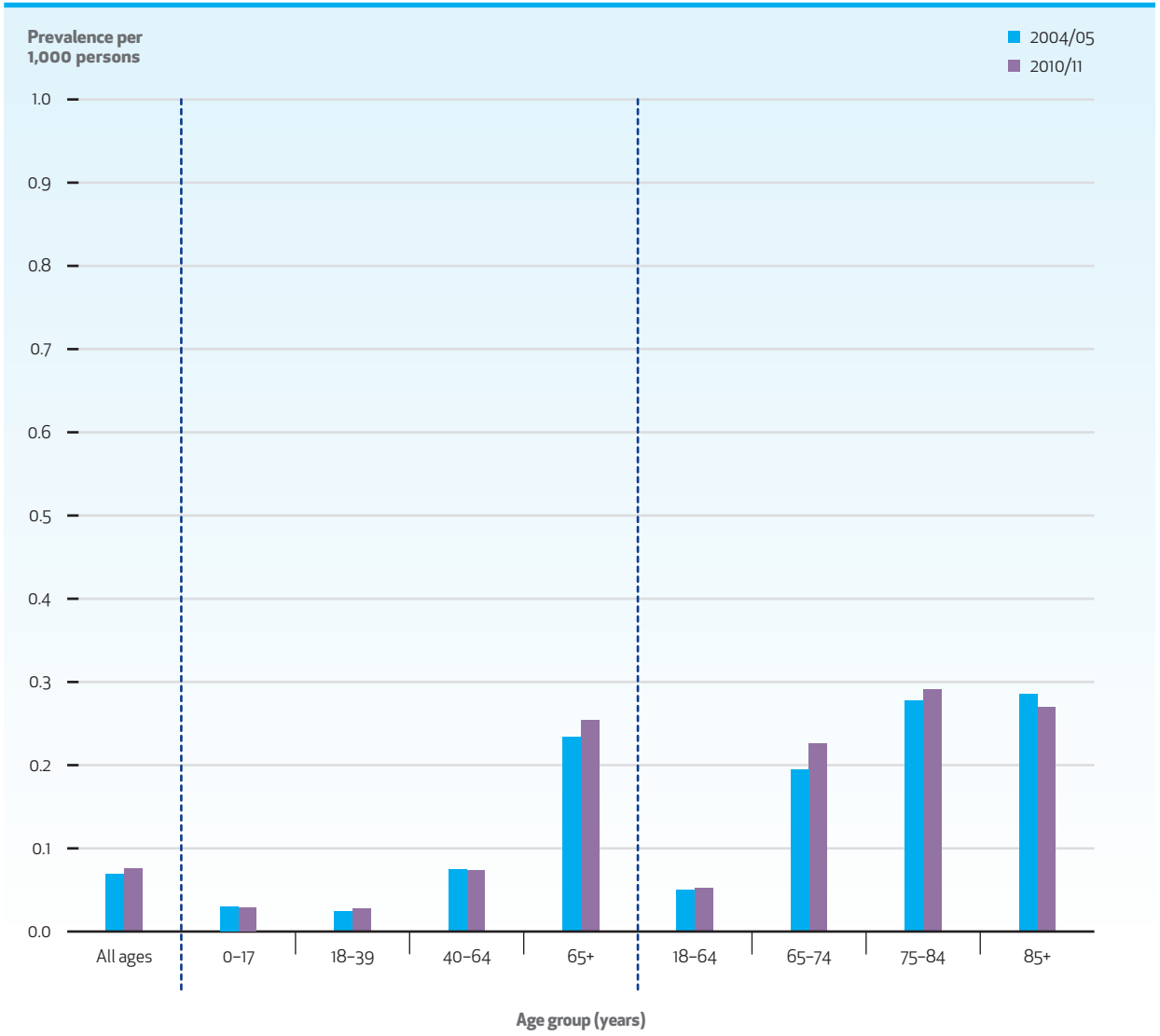
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 8.3A Crude prevalence of motor neuron disease per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of motor neuron disease for persons aged 0–17 years, 18–64 years, and 65 years and older was 0.029, 0.052, and 0.254 per 1,000, respectively.

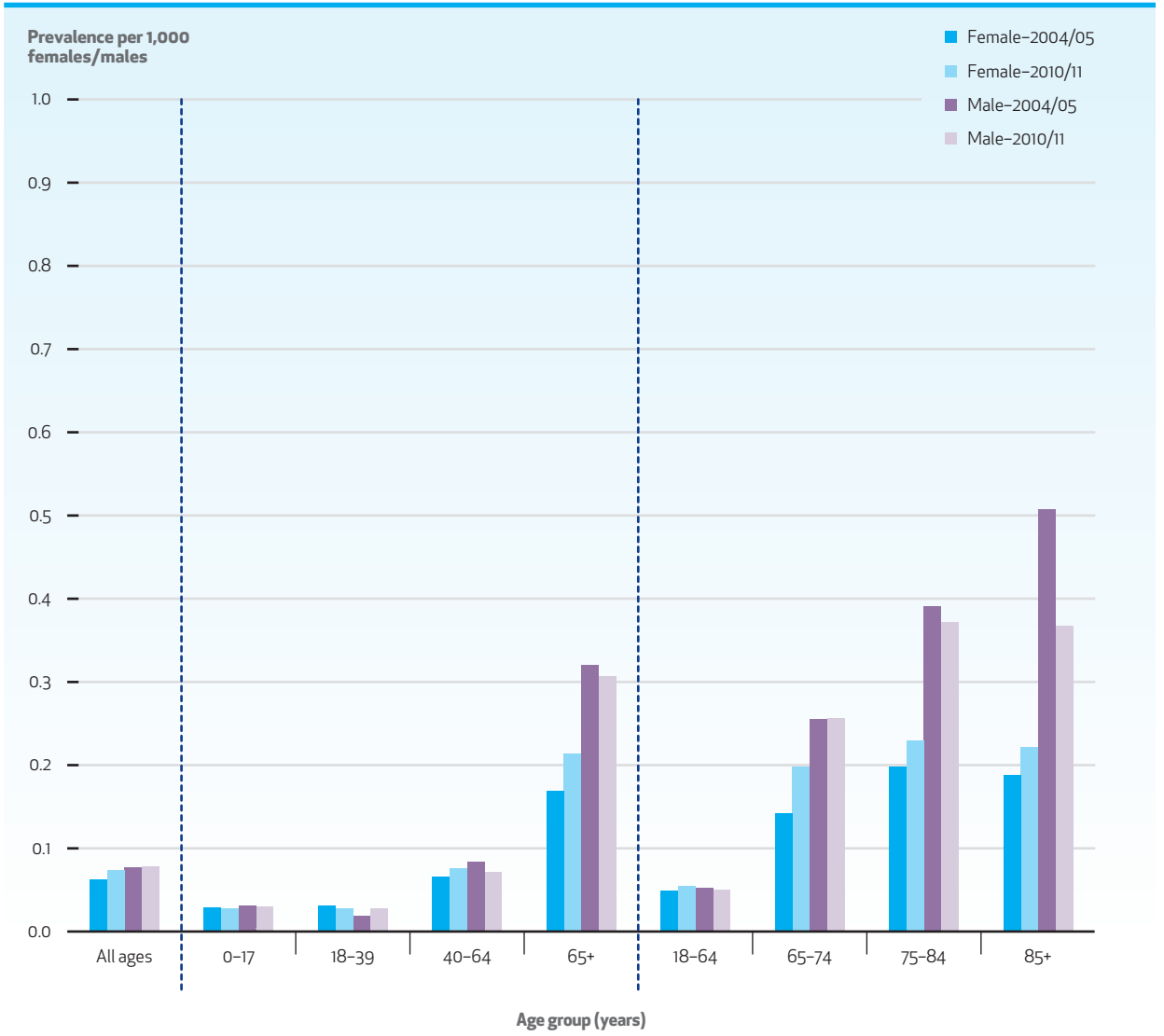


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 8.3B Crude prevalence of motor neuron disease per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of motor neuron disease was slightly greater for males (0.078 per 1,000) than females (0.073 per 1,000).
- Among females, the crude prevalence of motor neuron disease increased from 0.062 to 0.073 per 1,000 between 2004/05 and 2010/11
- Among males, the crude prevalence of motor neuron disease went unchanged between 2004/05 and 2010/11 (at 0.077 and 0.078 per 1,000, respectively).



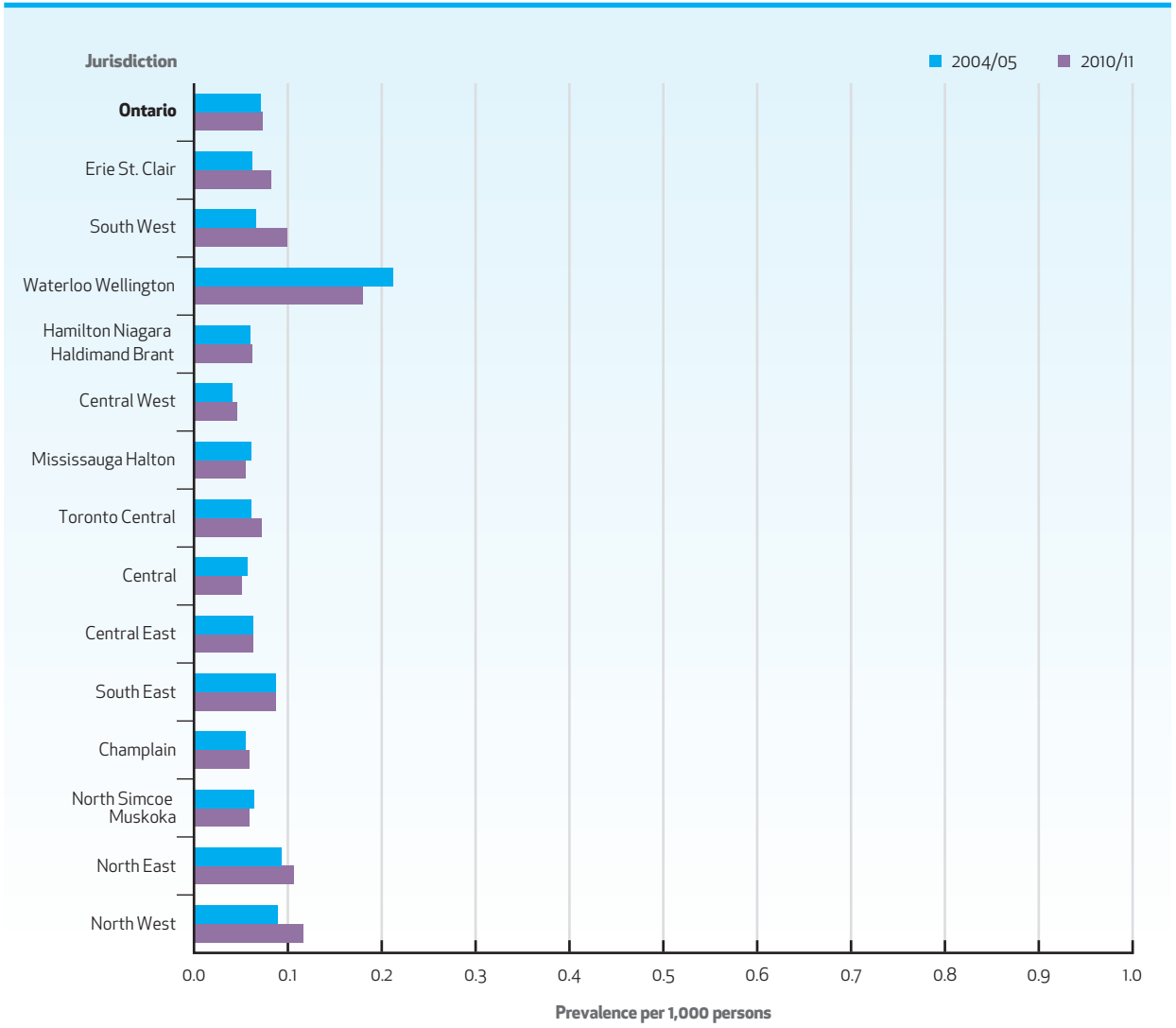
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 8.4 Age- and sex-adjusted* prevalence of motor neuron disease per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of motor neuron disease increased across all Local Health Integration Networks (LHINs), except for the Waterloo Wellington, Mississauga Halton, Central and North Simcoe Muskoka LHINs.
- Across the LHINs, there was a 4.0-fold variation in the age- and sex-adjusted prevalence of motor neuron disease in 2010/11, which was less than the 5.3-fold variation in 2004/05.
- In 2010/11, the Waterloo Wellington LHIN had the highest age- and sex-adjusted prevalence of motor neuron disease (0.18 per 1,000 persons), followed by the North West and North East LHINs (0.12 and 0.11 per 1,000 persons, respectively).
- Conversely, the Central West, Central and Mississauga Halton LHINs had the three lowest age- and sex-adjusted prevalence estimates of motor neuron disease in 2010/11 at 0.045, 0.051 and 0.055 per 1,000, respectively.

Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

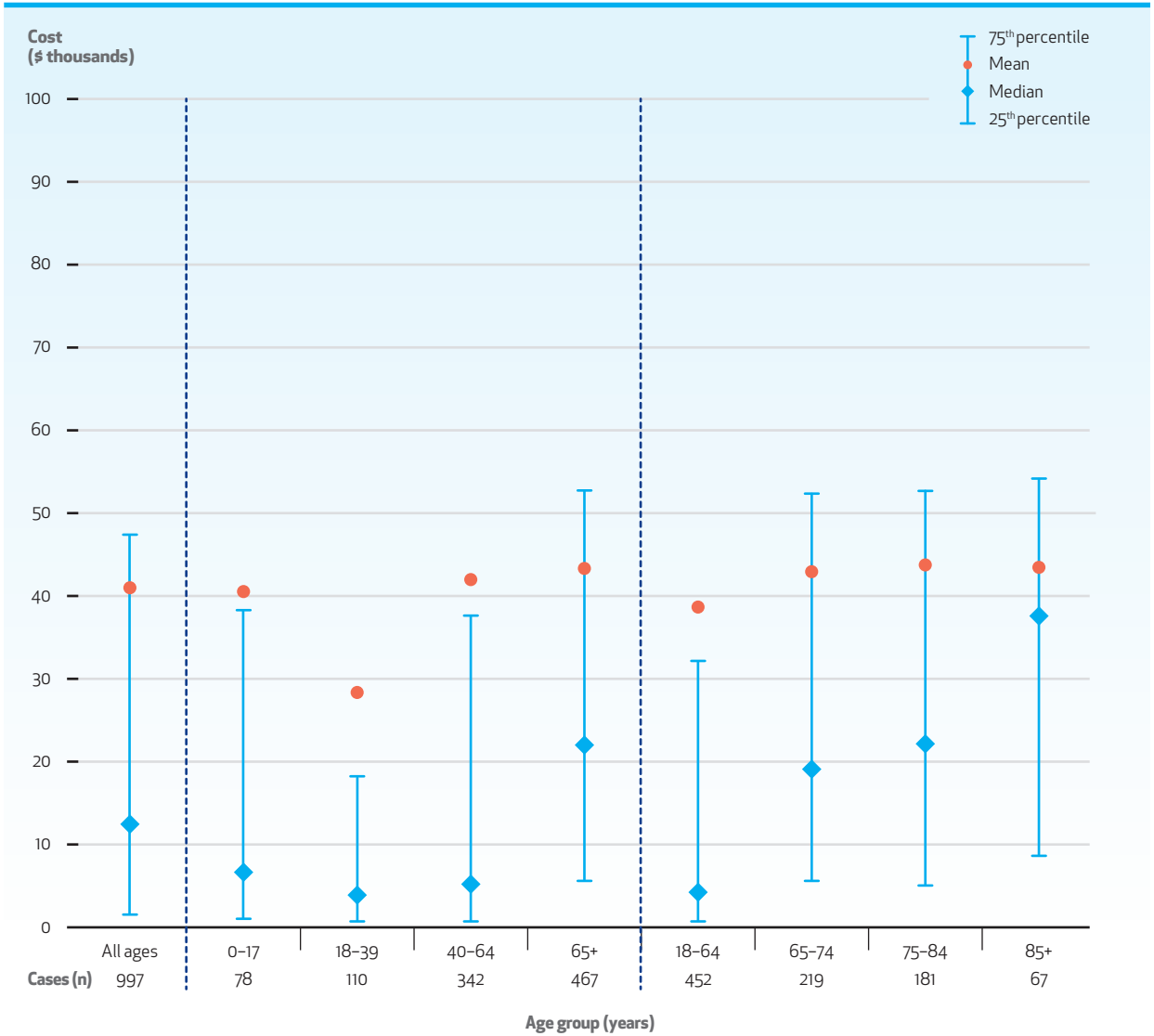


*Adjusted to the 2006 Census population.

EXHIBIT 8.5A Distribution of costs* associated with one year† of health system use for prevalent cases with motor neuron disease, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with motor neuron disease were $41,001 and $12,467, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $1,540 to $47,401.
- Among prevalent cases with motor neuron disease, the median cost associated with one year of health system use generally increased with age. The highest median cost was among those aged 85 years and older ($37,595).

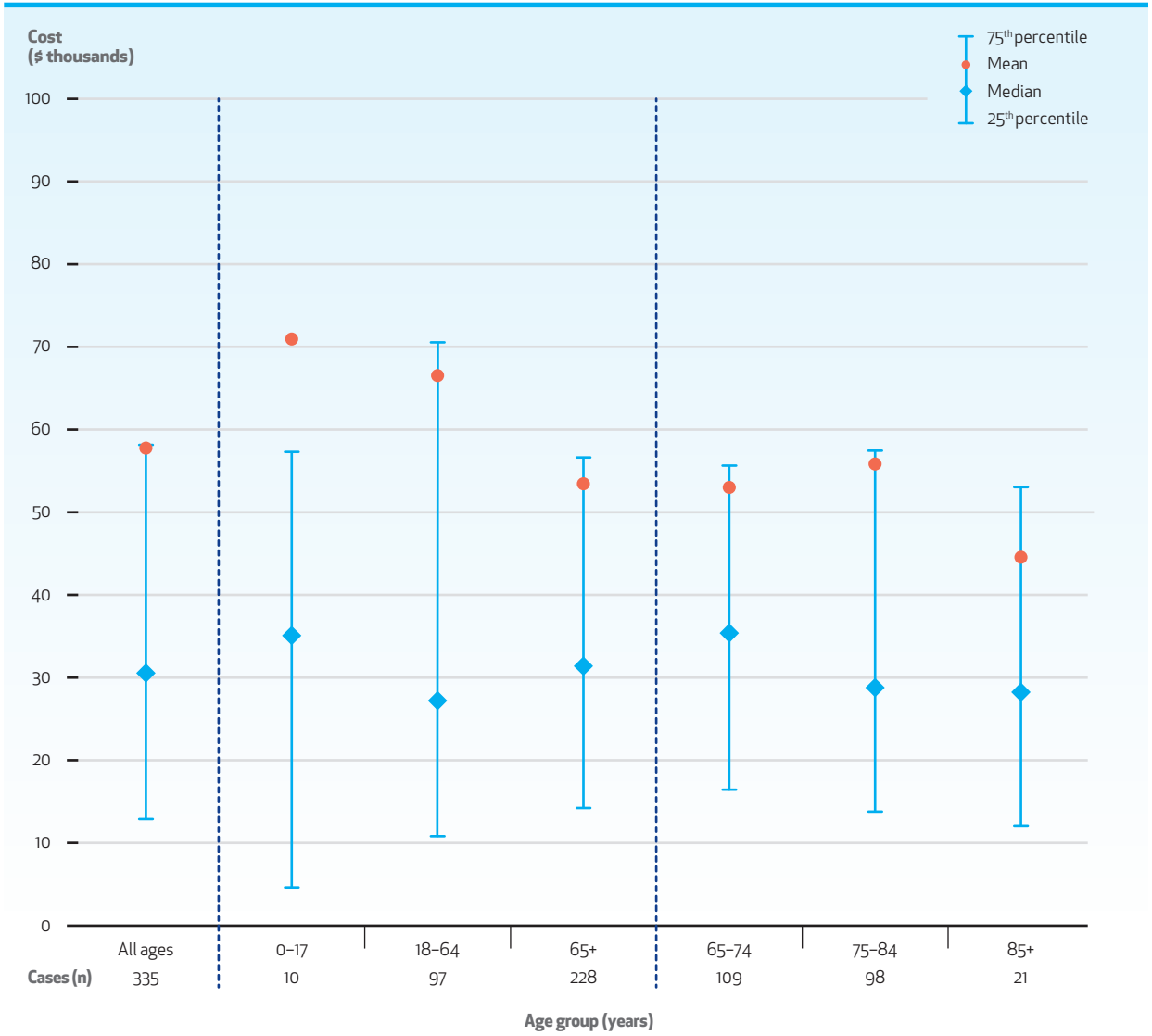


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 8.5B Distribution of costs* associated with one year† of health system use for incident cases with motor neuron disease, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- Among incident cases with motor neuron disease, the mean and median costs associated with one year of health system use were $57,742 and $30,537, respectively. The interquartile range of costs extended from $12,889 to $58,143.
- Among incident cases with motor neuron disease, the median cost associated with one year of health system use varied across age groups, ranging from $27,203 for persons aged 18–64 years to $35,378 for those aged 65–74 years.

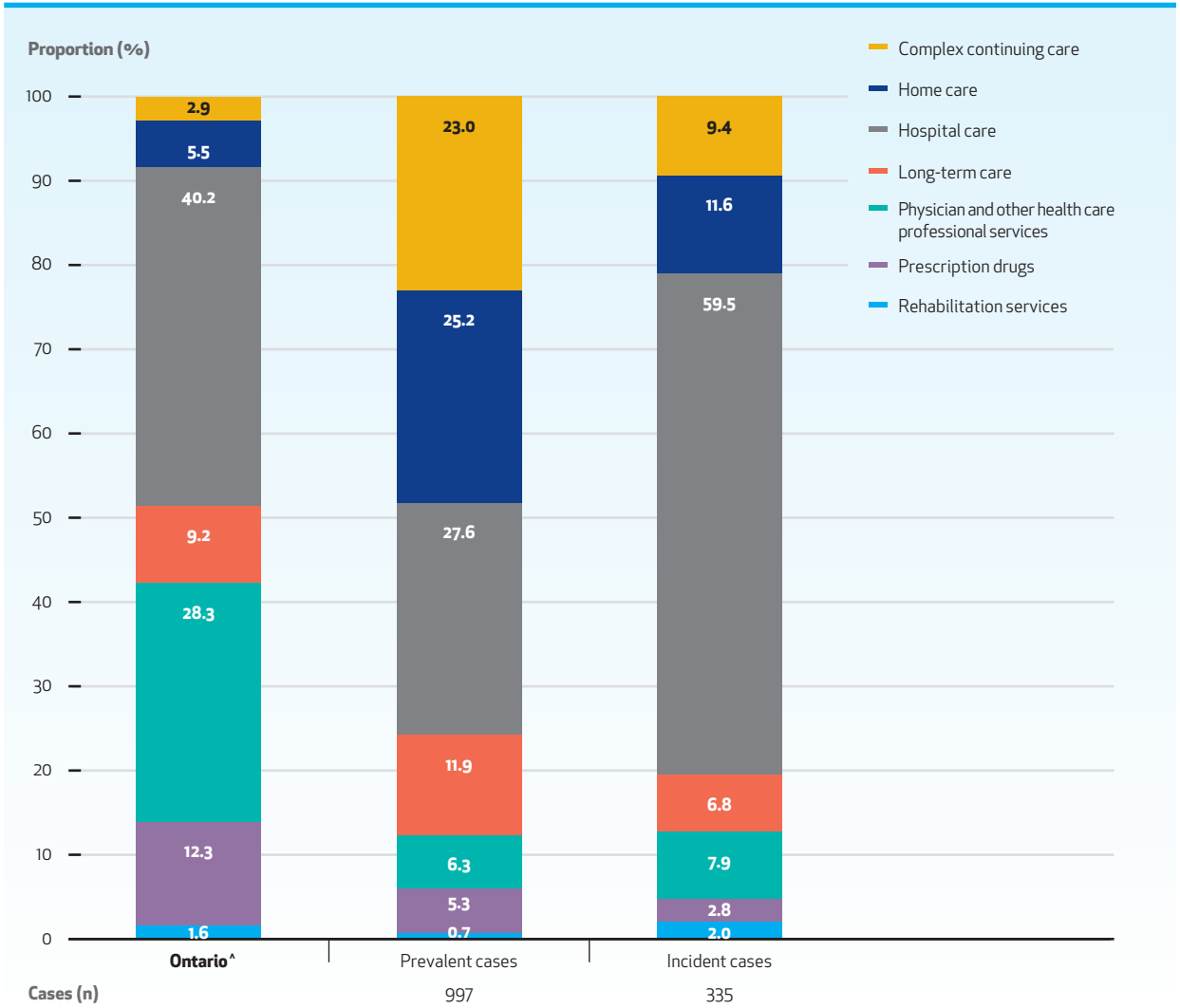


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 8.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with motor neuron disease, by type of health care service

Key Findings

- Among prevalent cases with motor neuron disease, the majority of the costs associated with health system use were attributable to hospital care (27.6%), home care (25.2%) and complex continuing care (23.0%).
- Among incident cases with motor neuron disease, the majority of the costs associated with health system use were attributable to hospital care (59.5%), home care (11.6%) and complex continuing care (9.4%).

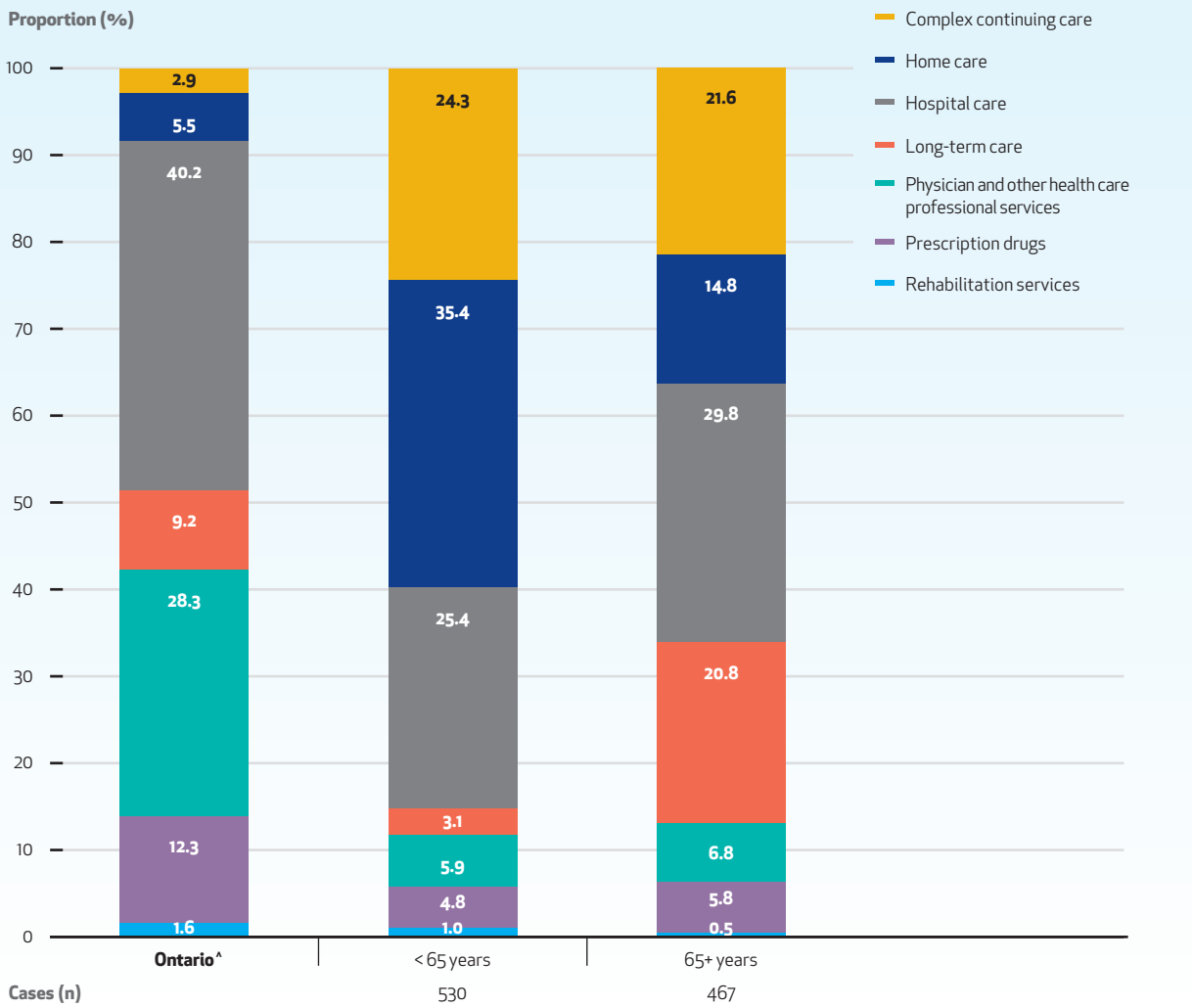


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 8.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with motor neuron disease, by age group and type of health care service

Key Findings

- Among prevalent cases with motor neuron disease aged younger than 65 years, the majority of the costs associated with health system use were attributable to home care (35.4%), hospital care (25.4%) and complex continuing care (24.3%).
- Among prevalent cases with motor neuron disease aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (29.8%), complex continuing care (21.6%) and long-term care (20.8%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 9

Multiple Sclerosis

"I wish people understood that MS is a disease that may become unmanageable. I face increasing challenges day to day, and I'm concerned about living independently and caring for myself. I worry about money and access to quality health care. These things are critical for me to better manage my disease."

– A respondent to the *Listening to People Affected by MS* online survey

Overview

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 fibres (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 non-traumatic cause of disability in young adults. Most affected individuals present with symptoms between the ages of 20 and 40 years. Women are affected three times as often as men. The disease is variable from one person to another, and the ability to predict outcomes is limited. Most affected individuals present with an initially relapsing-remitting course. Symptoms are stable between relapses, but most individuals will develop gradual disability progression (secondary progressive multiple sclerosis). About 15% of persons have a gradual progression of disability from onset (primary progressive multiple sclerosis). Ultimately, most patients experience a constellation of symptoms, including weakness, sensory symptoms, bowel and bladder dysfunction, fatigue, spasticity, pain and cognitive impairment. 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.

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.

Data Quality

Multiple sclerosis was assessed using health administrative data for the Ontario population aged 20 years and older. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with multiple sclerosis were determined. Multiple sclerosis can occur in those aged 50 years and older (known as late-onset multiple sclerosis), but to limit false positives, incidence was captured only for those aged 20–64 years.

When looking at the results for multiple sclerosis, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for multiple sclerosis is considered grade I (the algorithm for Ontario health administrative data has been previously validated, and the algorithm meets generally accepted standards for predictive value and specificity [note: sensitivity can be variable]).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 9.1 Number and proportion of persons with multiple sclerosis, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, females accounted for 72.6% of the 22,760 Ontarians identified with multiple sclerosis.
- The mean age of a person with multiple sclerosis was 51.2 years.
- Among persons with multiple sclerosis, the highest proportion (65.3%) was attributed to those aged 40–64 years.
- Among persons with multiple sclerosis, 13.1% lived in a rural setting.
- The distribution of persons with multiple sclerosis increased slightly across neighbourhood income quintiles, with 19.0% living in the lowest-income neighbourhoods and 21.4% living in the highest-income neighbourhoods.

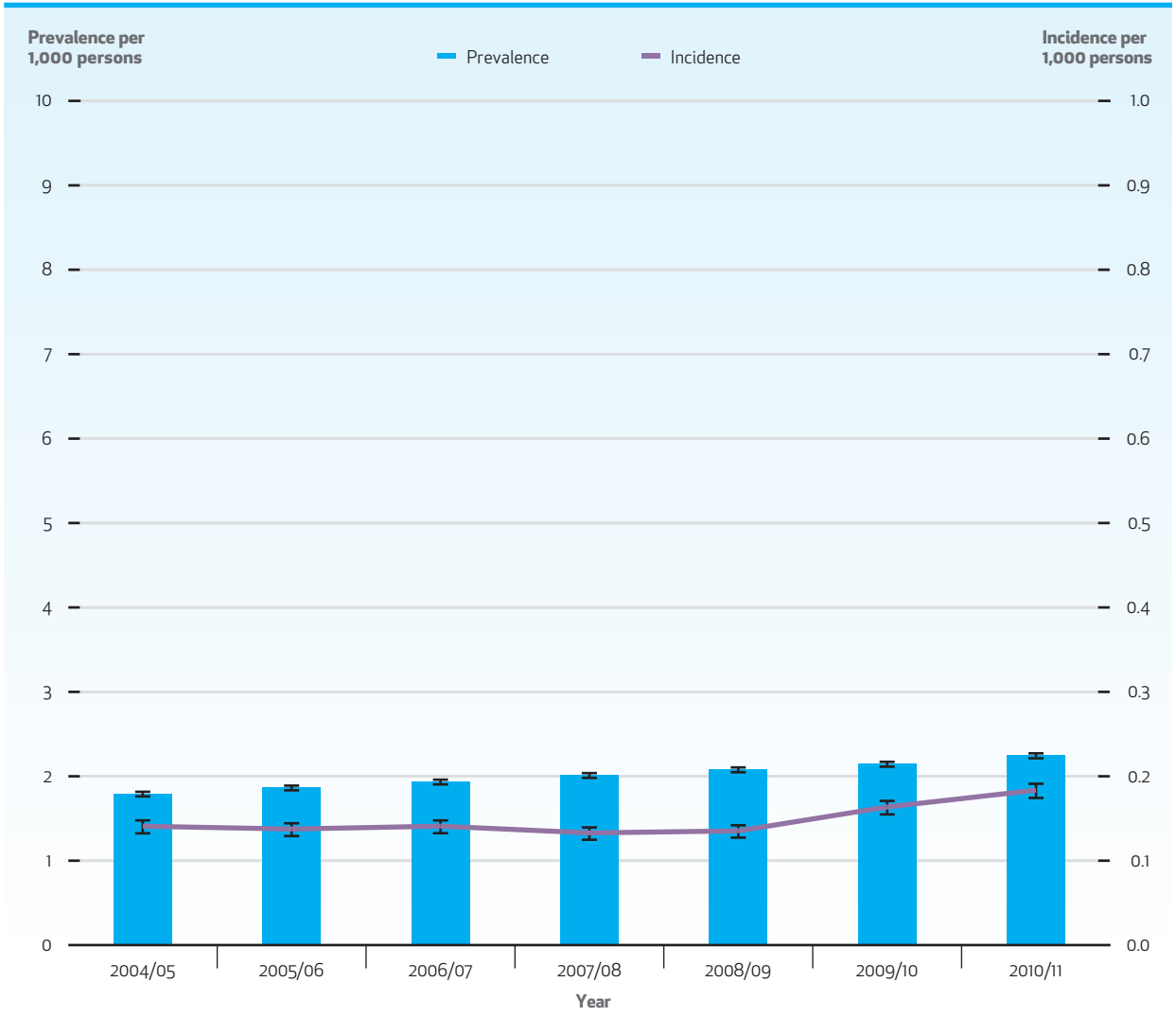
Characteristic	Cohort
Ontario, n	22,760
Sex, n (%)	
Female	16,529 (72.6)
Male	6,231 (27.4)
Age distribution, years	
Mean ± standard deviation	51.2 ± 13.2
Median (interquartile range)	51 (42–60)
Age group, years, n (%)	
20–39	4,375 (19.2)
40–64	14,867 (65.3)
65–74	2,400 (10.5)
75–84	922 (4.1)
85+	196 (0.9)
Adults 20–64	19,242 (84.5)
Older adults 65+	3,518 (15.5)
Residence, n (%)	
Rural	2,975 (13.1)
Urban	19,773 (86.9)
Income quintile, n (%)	
1 (lowest)	4,315 (19.0)
2	4,310 (18.9)
3	4,324 (19.0)
4	4,856 (21.3)
5 (highest)	4,865 (21.4)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 9.2 Age- and sex-adjusted* prevalence and incidence of multiple sclerosis per 1,000 persons aged 20 years and older, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with multiple sclerosis increased from 16,412 to 22,760.
- The age- and sex-adjusted prevalence of multiple sclerosis per 1,000 persons aged 20 years and older increased from 1.8 in 2004/05 to 2.2 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified multiple sclerosis aged 20–64 years increased from 1,296 to 1,830.
- The age- and sex-adjusted incidence of multiple sclerosis per 1,000 persons aged 20–64 years increased from 0.14 in 2004/05 to 0.18 in 2010/11.



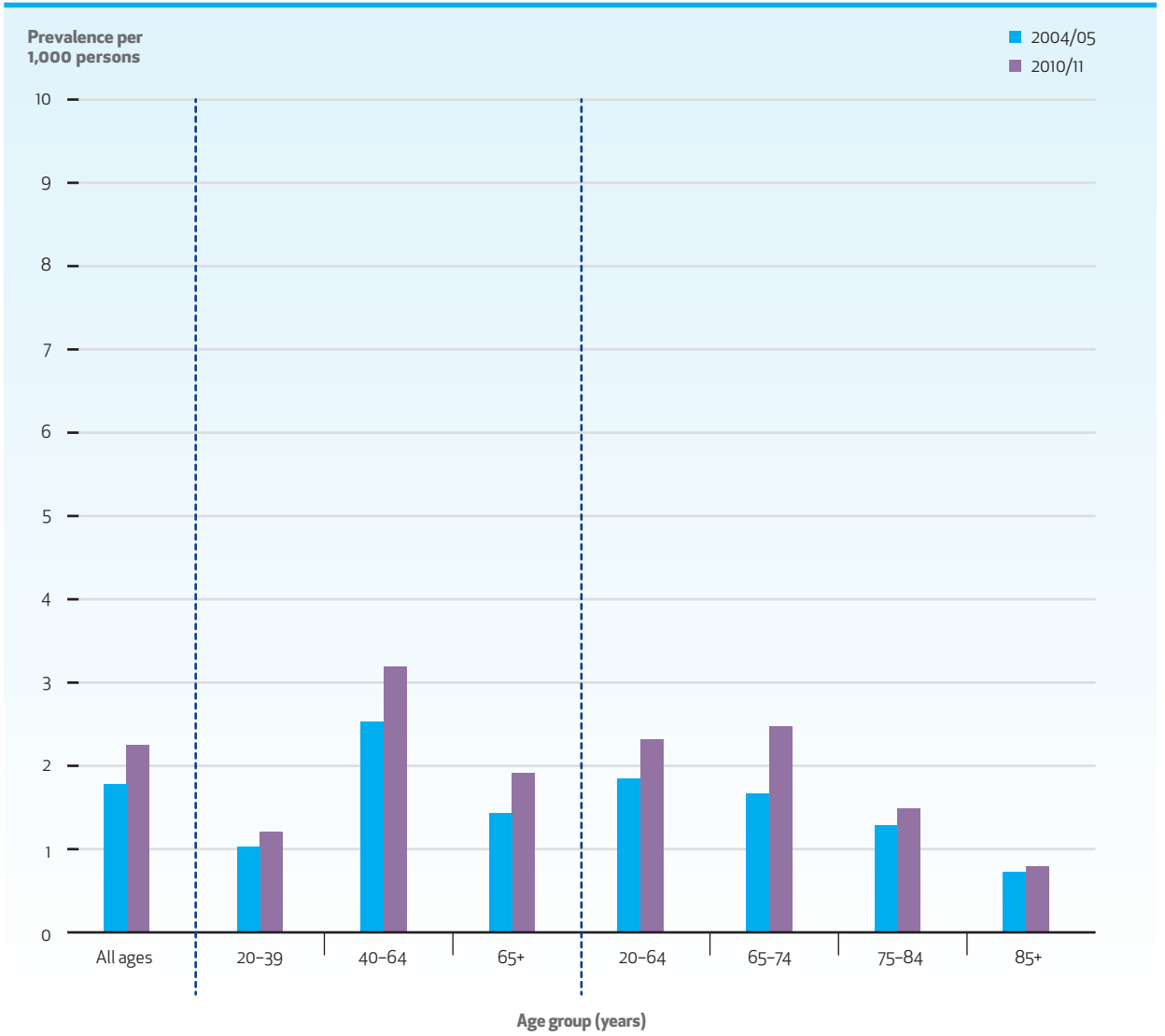
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 9.3A Crude prevalence of multiple sclerosis per 1,000 persons aged 20 years and older, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of multiple sclerosis increased and then decreased across age groups. The crude prevalence for individuals aged 20–39 years, 40–64 years and 65 years and older was 1.2, 3.2 and 1.9 per 1,000, respectively.

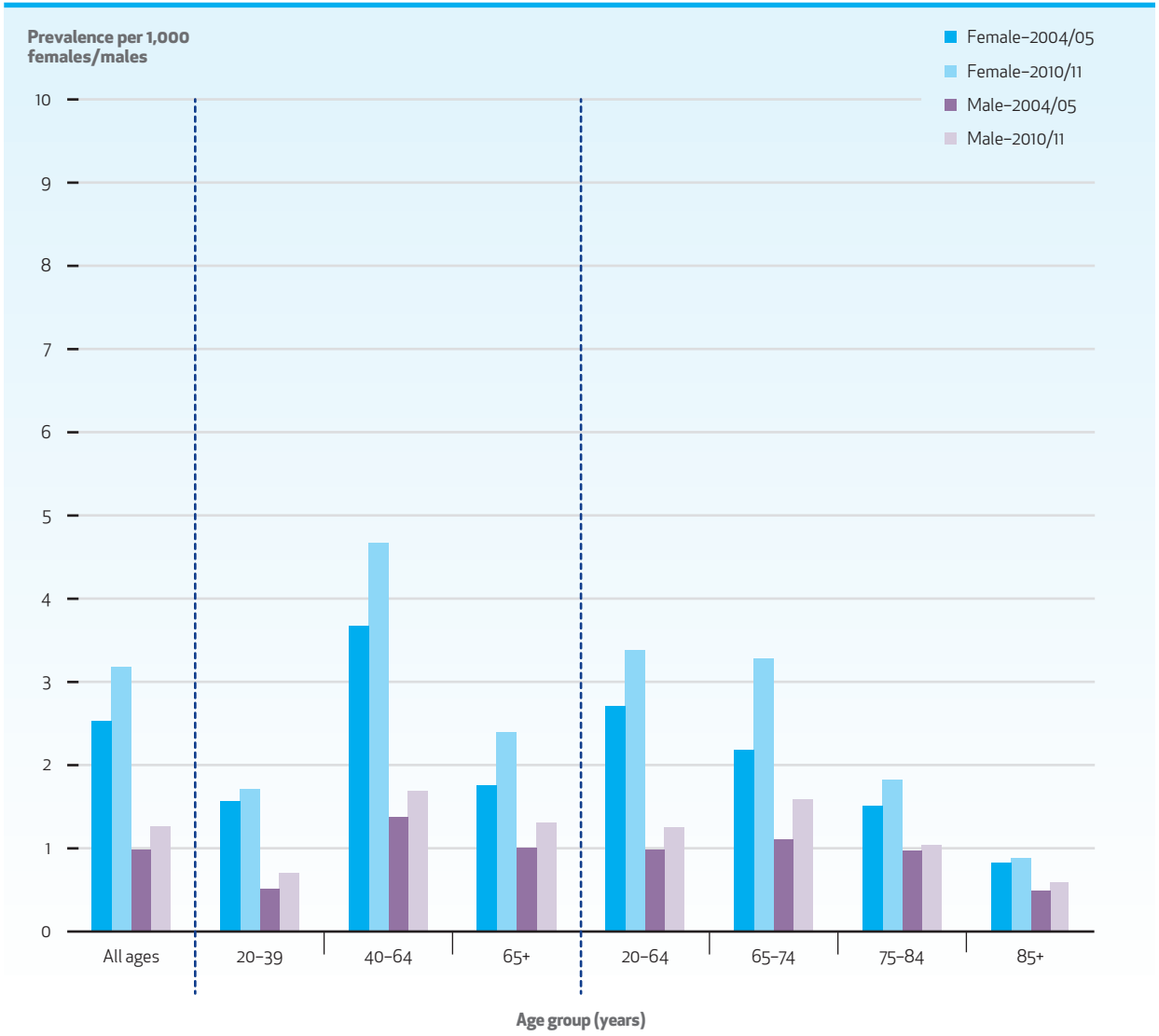


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 9.3B Crude prevalence of multiple sclerosis per 1,000 females and 1,000 males aged 20 years and older, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of multiple sclerosis was greater for females (3.2 per 1,000) than males (1.3 per 1,000).
- Between 2004/05 and 2010/11, the crude prevalence of multiple sclerosis among females aged 20 years and older rose from 2.5 to 3.2 per 1,000.
- Among males aged 20 years and older, the crude prevalence of multiple sclerosis rose from 0.98 to 1.3 per 1,000 between 2004/05 and 2010/11.

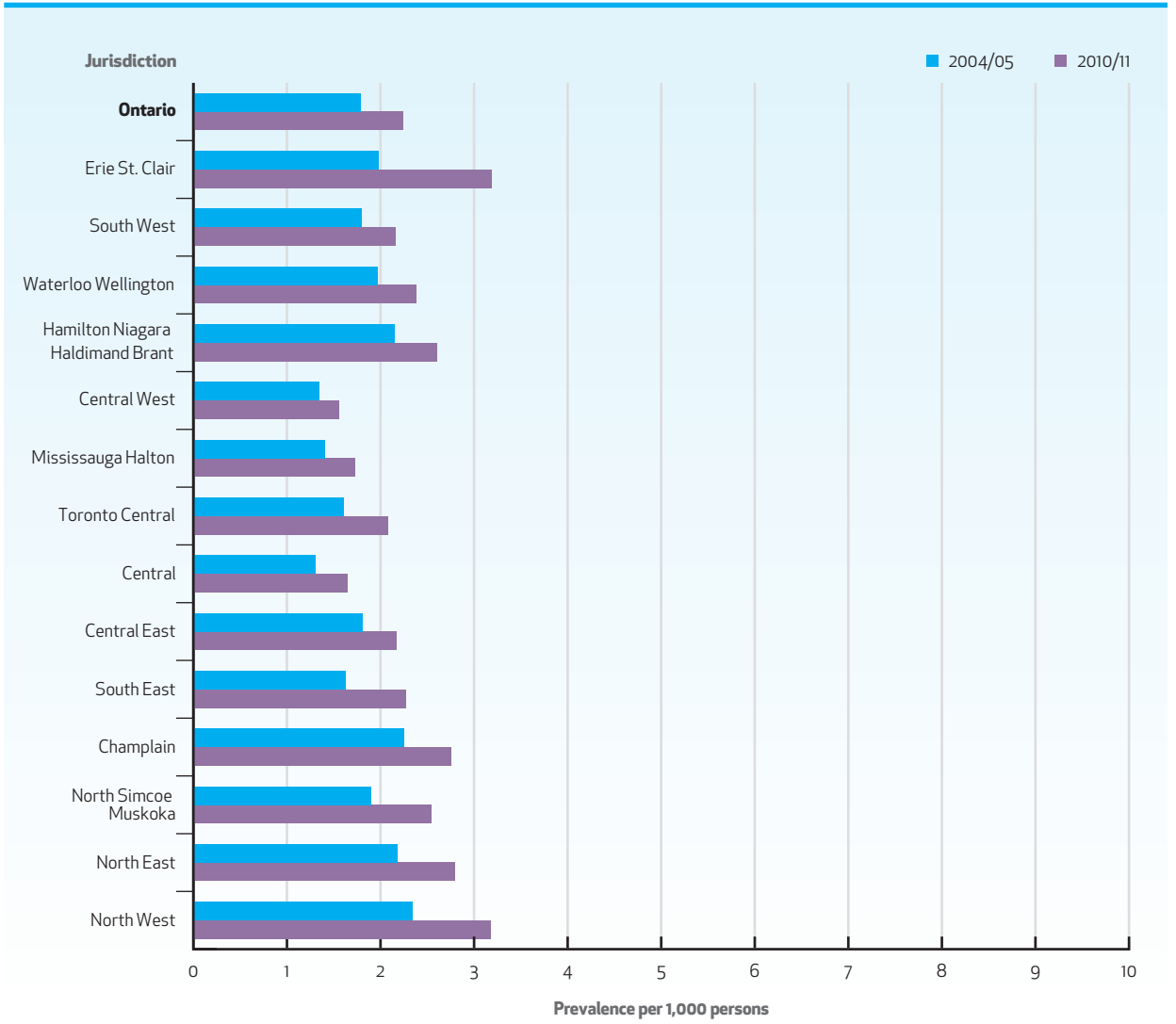


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 9.4 Age- and sex-adjusted* prevalence of multiple sclerosis per 1,000 persons aged 20 years and older, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of multiple sclerosis increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 2.0-fold variation in the age- and sex-adjusted prevalence of multiple sclerosis in 2010/11, which was greater than the 1.8-fold variation in 2004/05.
- In 2010/11, the age- and sex-adjusted prevalence of multiple sclerosis was highest for the Erie St. Clair, North West and North East LHINs (3.2, 3.2 and 2.8 per 1,000 persons aged 20 years and older, respectively).
- Conversely, the age- and sex-adjusted prevalence of multiple sclerosis in 2010/11 was lowest for the Central West, Central and Mississauga Halton LHINs (1.6, 1.6 and 1.7 per 1,000 persons aged 20 years and older, respectively).



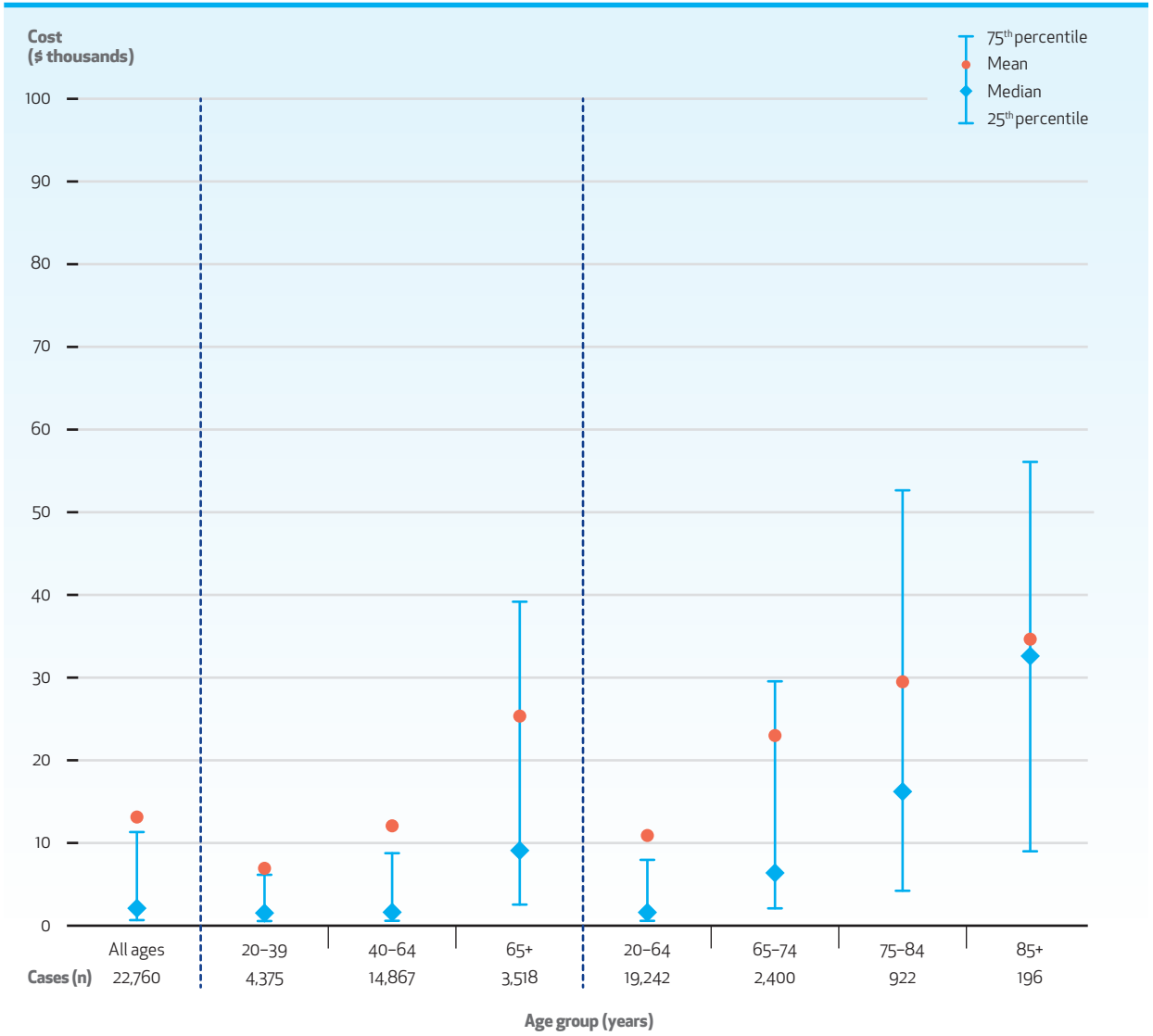
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 9.5A Distribution of costs* associated with one year† of health system use for prevalent cases with multiple sclerosis, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with multiple sclerosis were $13,135 and $2,104, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $674 to $11,322.
- Among prevalent cases with multiple sclerosis, the median cost associated with one year of health system use increased with age to $32,606 among persons aged 85 years and older.

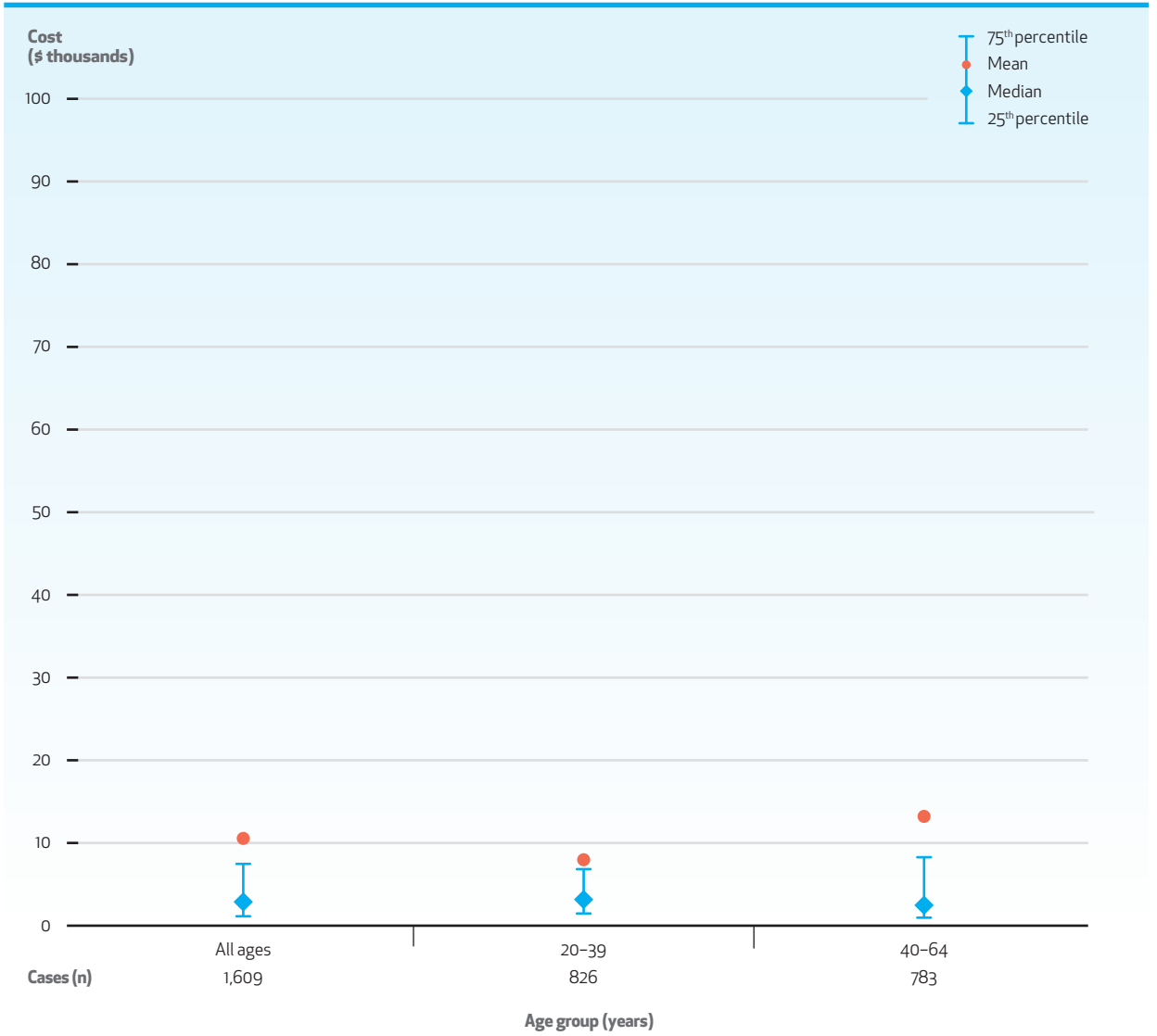


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 9.5B Distribution of costs* associated with one year† of health system use for incident cases with multiple sclerosis, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with multiple sclerosis were $10,563 and $2,884, respectively. The interquartile range of costs extended from $1,138 to $7,473.
- Among incident cases with multiple sclerosis, the median cost associated with one year of health system use was lower among those aged 40–64 years ($2,482) compared to those aged 20–39 years ($3,174).

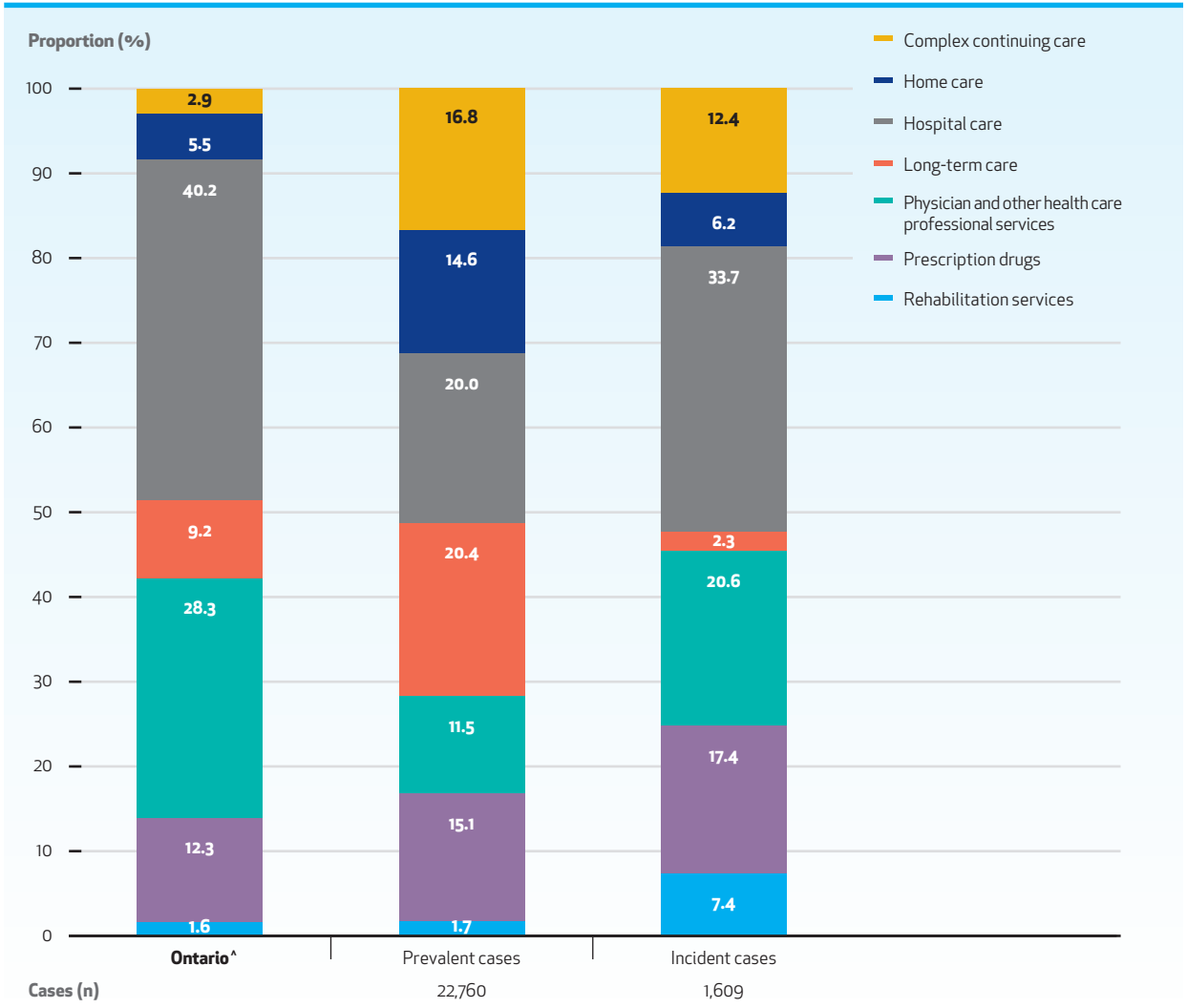


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 9.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with multiple sclerosis, by type of health care service

Key Findings

- Among prevalent cases with multiple sclerosis, the majority of the costs associated with health system use were attributable to long-term care (20.4%), hospital care (20.0%), and complex continuing care (16.8%).
- Among incident cases with multiple sclerosis, the majority of the costs associated with health system use were attributable to hospital care (33.7%), physician and other health care professional services (20.6%) and prescription drugs (17.4%).

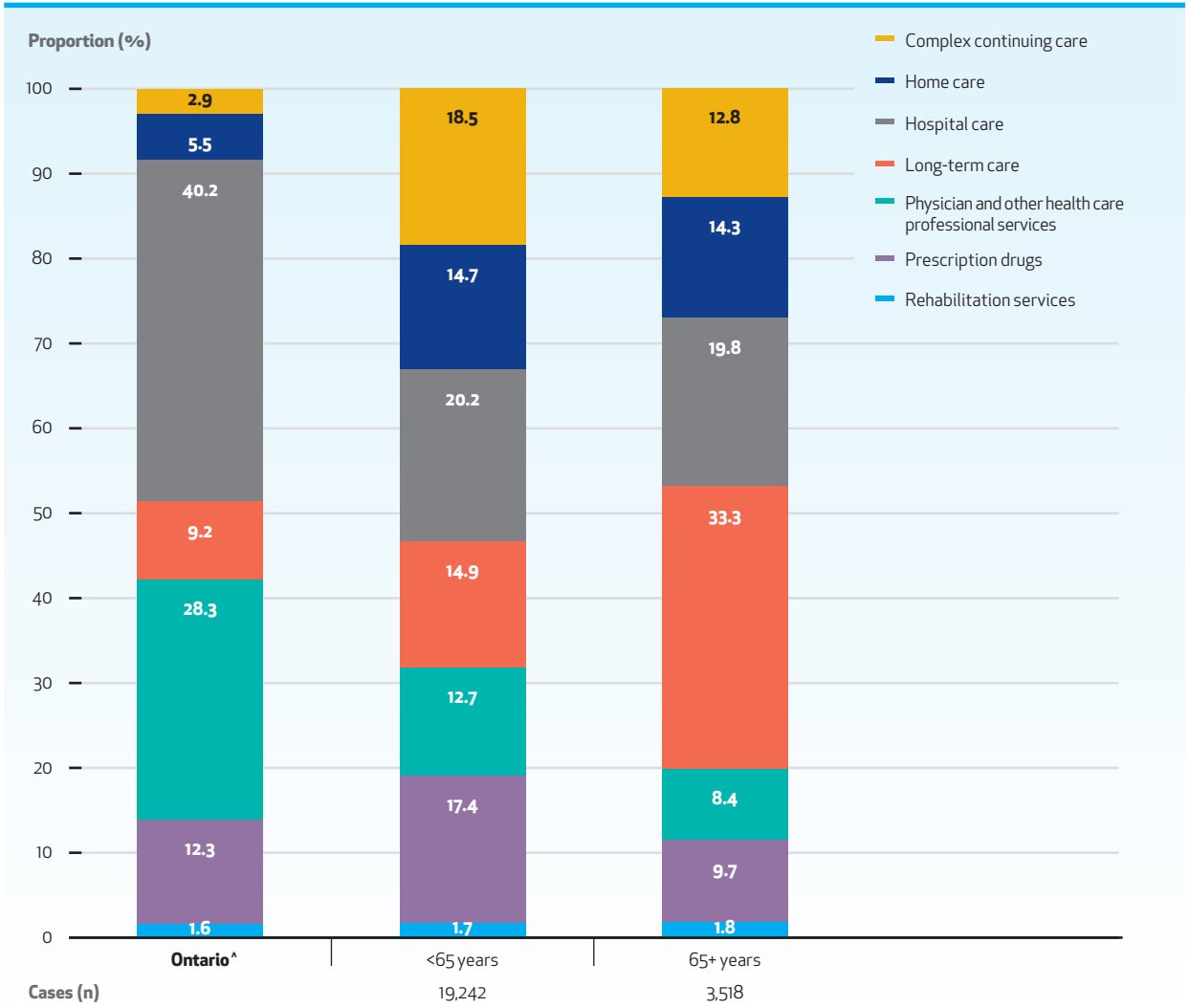


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 9.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with multiple sclerosis, by age group and type of health care service

Key Findings

- Among prevalent cases with multiple sclerosis aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (20.2%), complex continuing care (18.5%) and prescription drugs (17.4%).
- Among prevalent cases with multiple sclerosis aged 65 years and older, the majority of the costs associated with health system use were attributable to long-term care (33.3%), hospital care (19.8%) and home care (14.3%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 10

Parkinsonism

(including Parkinson's Disease)

"I wish people understood that Parkinson's disease is more than just shaking. This is a disease that picks away at your life, both physically and mentally. My mind has not left me, but my body is turning against me."

– A person living with young-onset Parkinson's disease since 2005

"It's important not to make any assumptions about what someone's Parkinson's is doing to them. Every case is different. Some people with Parkinson's will regress very quickly, whereas with other people, 20 years could go by and they wouldn't be appreciably different than when they were diagnosed."

– Andy Barrie

Overview

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. Among persons with Parkinson's disease, there is evidence of 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. Parkinsonism also causes unintentional movement in the form of tremor, which in the hand can resemble the rolling of a pill or small object when the hand is at rest. 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.

Data Quality

Parkinsonism (including Parkinson's disease) was assessed using health administrative data for the Ontario population aged 40 years and older. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with parkinsonism were determined. The majority of parkinsonism occurs in persons 65 years and older, so additional prevalence and incidence estimates were presented for this age group.

When looking at the results for parkinsonism, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for parkinsonism is considered grade I (the algorithm for Ontario health administrative data has been previously validated and meets generally accepted standards for predictive value and specificity [note: sensitivity can be variable]).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 10.1 Number and proportion of persons with parkinsonism (including Parkinson's disease), by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 53.8% of the 28,191 Ontarians identified with parkinsonism.
- The mean age of a person with parkinsonism was 74.6 years.
- Among persons with parkinsonism, the majority (82.1%) were 65 years and older.
- Among persons with parkinsonism, 11.9% lived in a rural setting.
- There was a slight income gradient with 19.2% of persons with parkinsonism in the lowest income quintile and 21.3% in the highest income quintile.

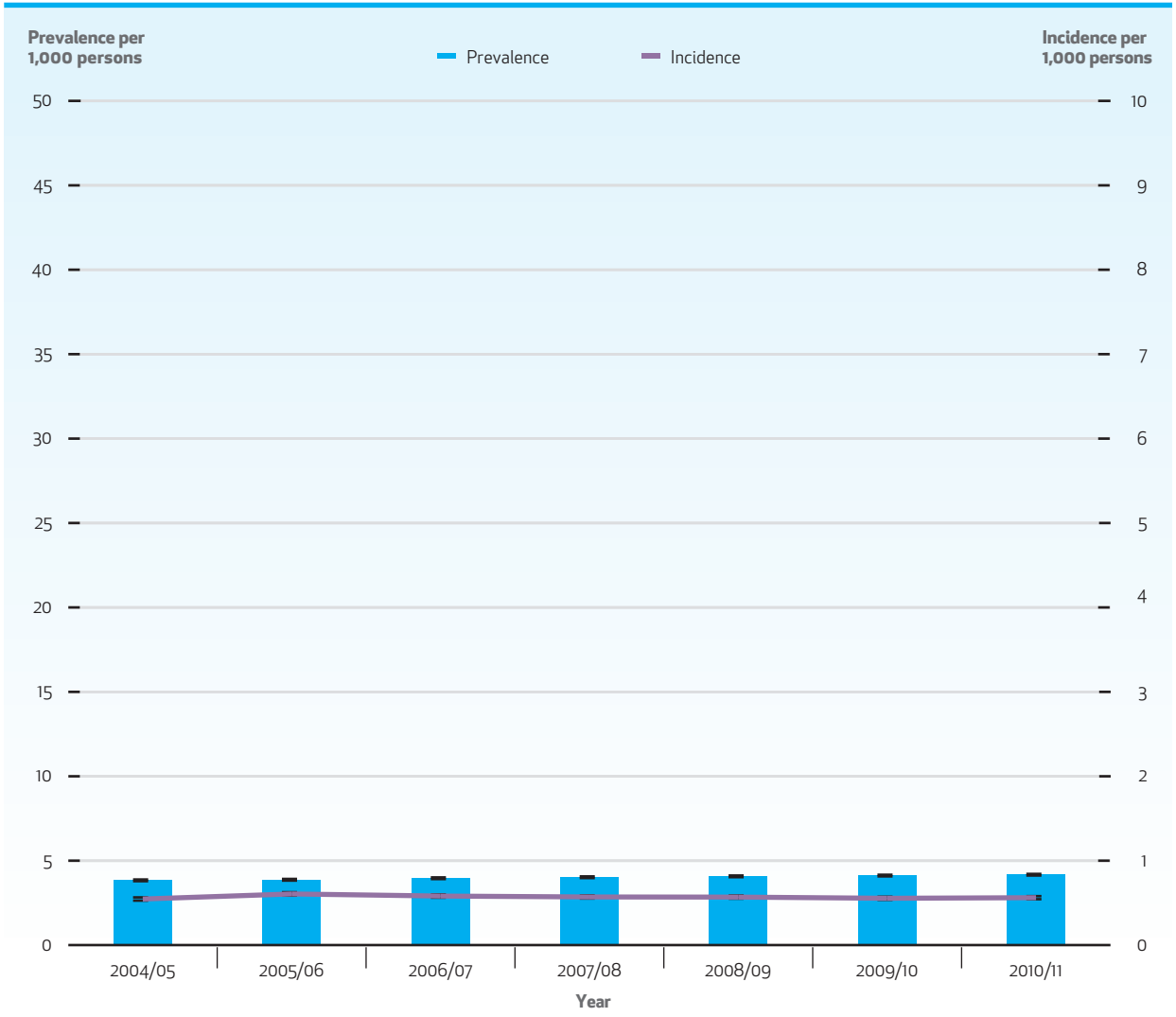
Characteristic	Cohort
Ontario, n	28,191
Sex, n (%)	
Female	13,029 (46.2)
Male	15,162 (53.8)
Age distribution, years	
Mean ± standard deviation	74.6 ± 10.6
Median (interquartile range)	76 (68–82)
Age group, years, n (%)	
40–64	5,048 (17.9)
65–74	7,235 (25.7)
75–84	10,973 (38.9)
85+	4,935 (17.5)
Adults 40–64	5,048 (17.9)
Older adults 65+	23,143 (82.1)
Residence, n (%)	
Rural	3,365 (11.9)
Urban	24,808 (88.0)
Income quintile, n (%)	
1 (lowest)	5,407 (19.2)
2	5,481 (19.4)
3	5,471 (19.4)
4	5,715 (20.3)
5 (highest)	5,992 (21.3)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 10.2A Age- and sex-adjusted* prevalence and incidence of parkinsonism (including Parkinson's disease) per 1,000 persons aged 40 years and older, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with parkinsonism who were aged 40 years and older increased from 22,089 to 28,191.
- The age- and sex-adjusted prevalence of parkinsonism per 1,000 persons aged 40 years and older increased from 3.8 in 2004/05 to 4.2 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified parkinsonism who were aged 40 years and older increased from 3,128 to 3,726.
- The age- and sex-adjusted incidence of parkinsonism per 1,000 persons aged 40 years and older was similar in 2004/05 (0.55) and 2010/11 (0.56).



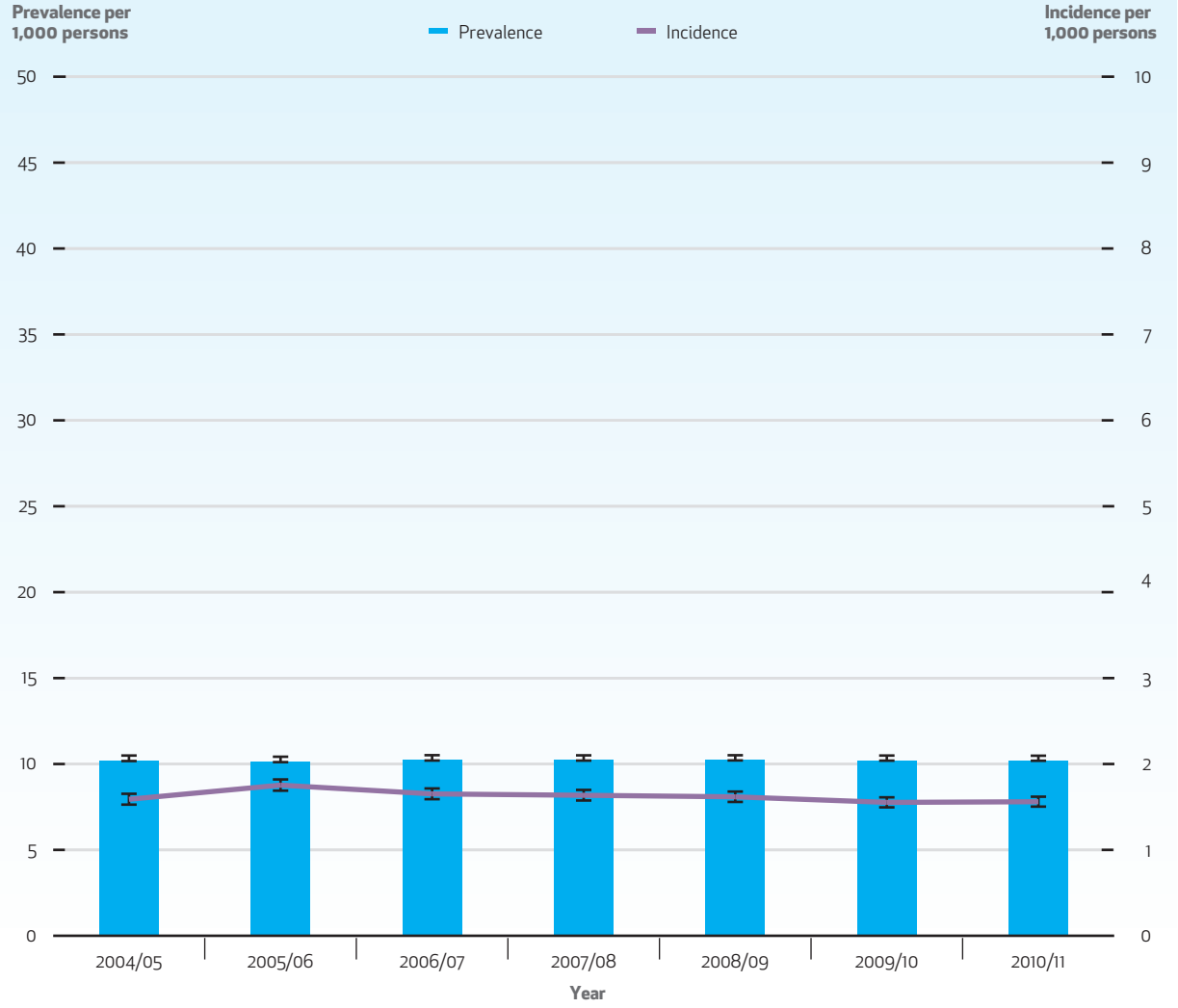
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 10.2B Age- and sex-adjusted* prevalence and incidence of parkinsonism (including Parkinson's disease) per 1,000 persons aged 65 years and older, in Ontario, 2004/05 to 2010/11

Key Findings

- The number of Ontarians aged 65 years and older with parkinsonism increased from 16,140 to 19,275 between 2004/05 and 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians aged 65 years and older with newly identified parkinsonism increased from 2,476 to 2,844.
- The age- and sex-adjusted prevalence of parkinsonism per 1,000 persons aged 65 years and older went unchanged at 10.3 in 2004/05 and 2010/11.
- Similarly, the age- and sex-adjusted incidence of parkinsonism per 1,000 persons aged 65 years and older went unchanged at 1.6 in 2004/05 and 2010/11.



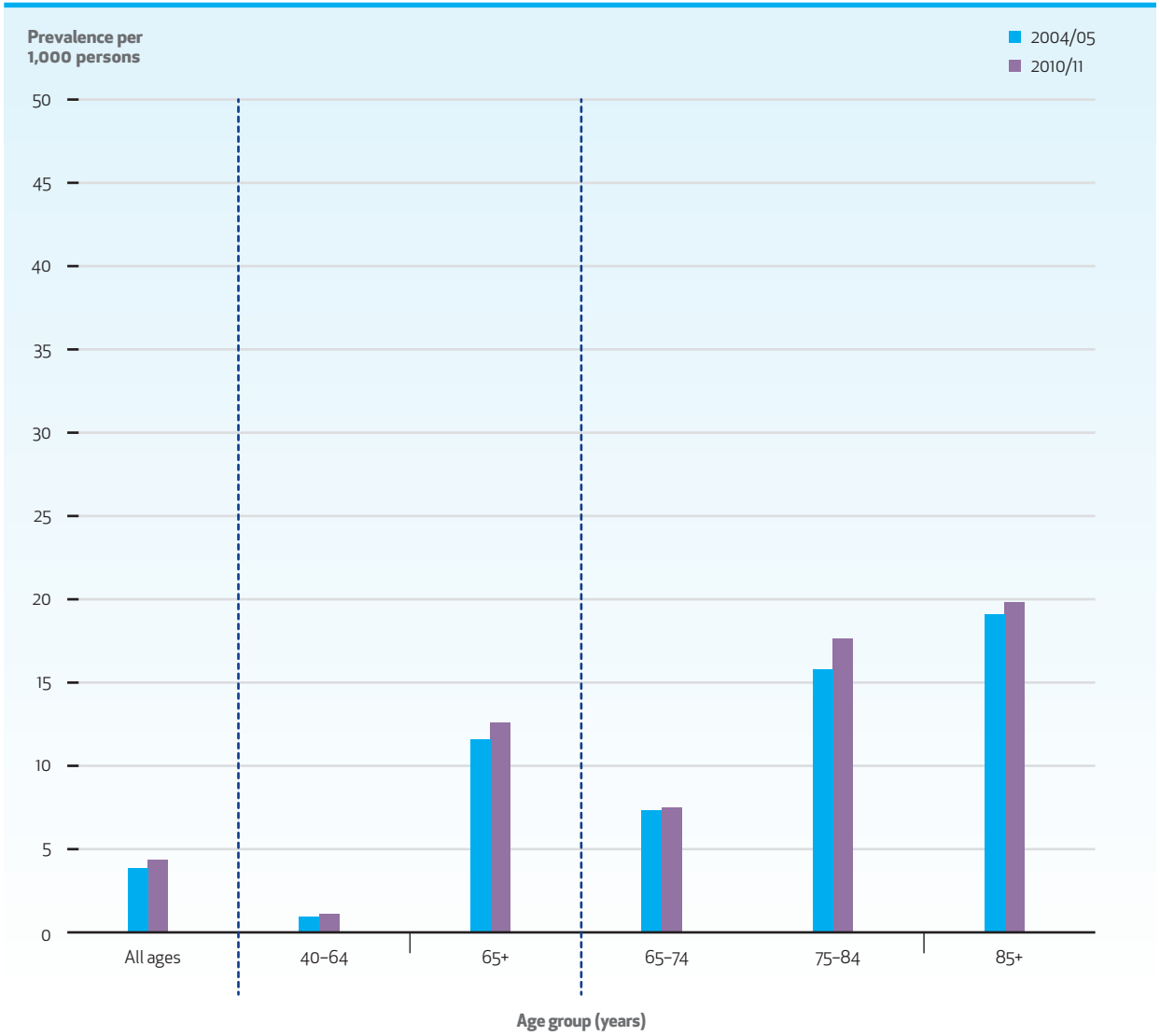
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 10.3A Crude prevalence of parkinsonism (including Parkinson's disease) per 1,000 persons aged 40 years and older, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of parkinsonism for individuals aged 40–64 years, 65 years and older, and 85 years and older was 1.1, 12.6, and 19.8 per 1,000, respectively.

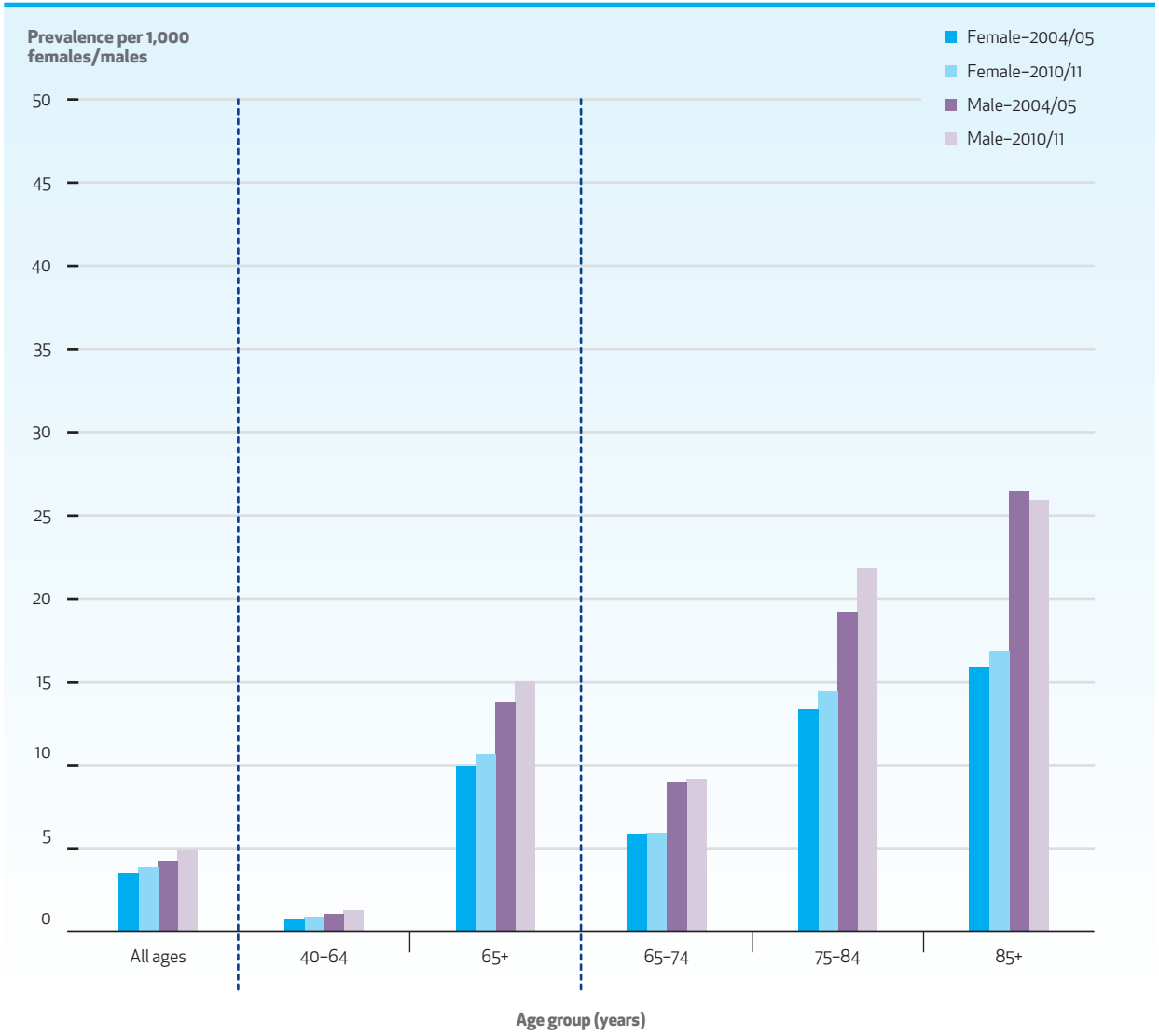


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 10.3B Crude prevalence of parkinsonism (including Parkinson's disease) per 1,000 females and 1,000 males aged 40 years and older, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of parkinsonism was greater for males (4.9 per 1,000) compared to females (3.9 per 1,000).
- Between 2004/05 and 2010/11, the crude prevalence of parkinsonism among females increased from 3.5 to 3.9 per 1,000 females aged 40 years and older.
- Comparing 2004/05 to 2010/11, the crude prevalence of parkinsonism among males increased from 4.2 to 4.9 per 1,000 males aged 40 years and older.

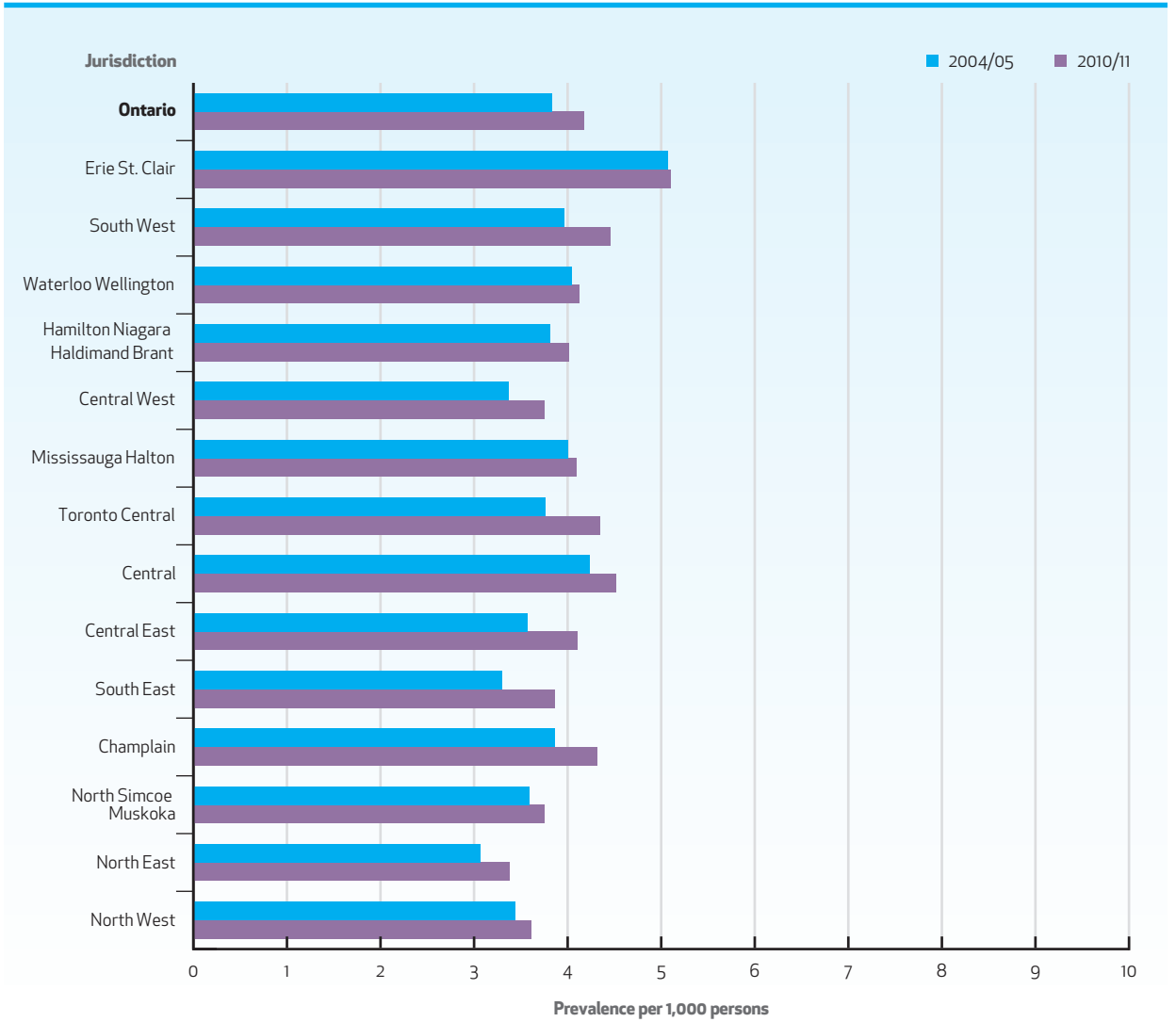


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 10.4 Age- and sex-adjusted* prevalence of parkinsonism (including Parkinson's disease) per 1,000 persons aged 40 years and older, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of parkinsonism increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 1.5-fold variation in the age- and sex-adjusted prevalence of parkinsonism in 2010/11, which was less than the 1.7-fold variation in 2004/05.
- In 2010/11, the highest age- and sex-adjusted prevalence of parkinsonism was observed in the Erie St. Clair, Central and South West LHINs, at 5.1, 4.5 and 4.5 per 1,000 persons, respectively.
- In 2010/11, the age- and sex-adjusted prevalence of parkinsonism was lowest in the North East, North West and Central West LHINs (3.4, 3.6 and 3.7 per 1,000 persons aged 40 years and older, respectively).



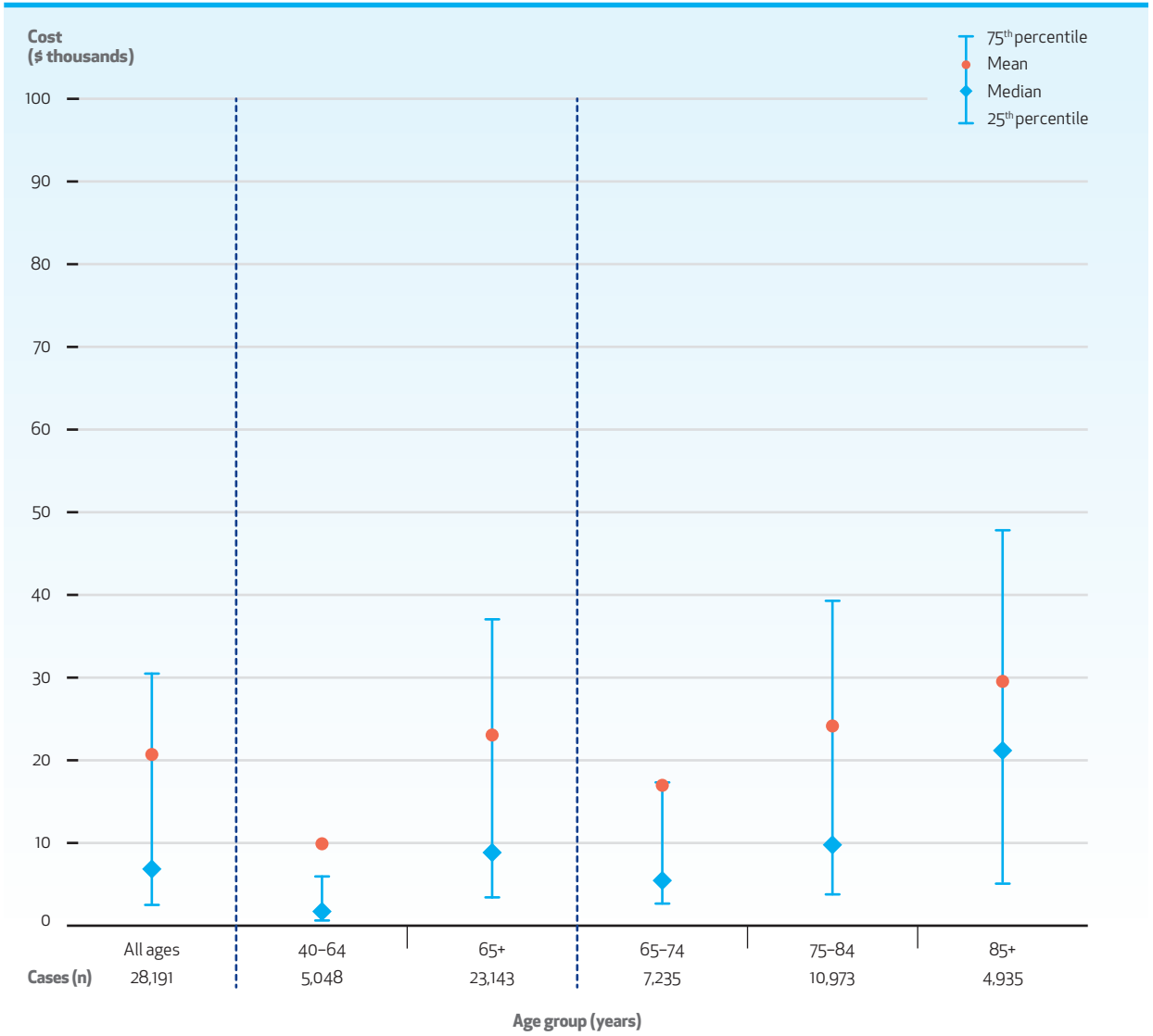
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 10.5A Distribution of costs* associated with one year† of health system use for prevalent cases with parkinsonism (including Parkinson's disease), by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with parkinsonism were $20,689 and $6,841, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $2,512 to $30,483.
- Among prevalent cases with parkinsonism, the median cost associated with one year of health system use increased by age with persons aged 85 years and older having the highest median cost associated with one year of health system use ($21,695).

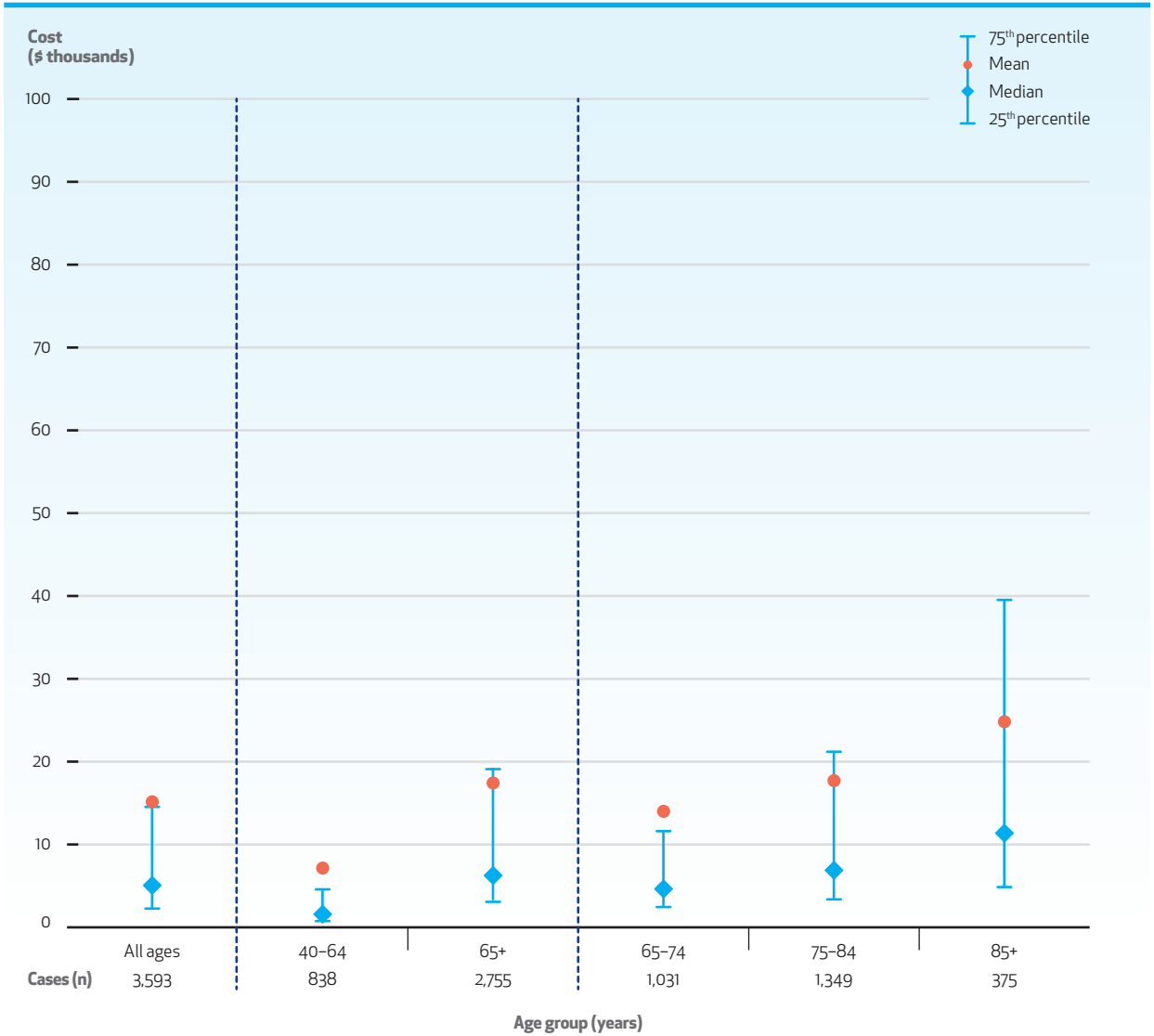


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 10.5B Distribution of costs* associated with one year† of health system use for incident cases with parkinsonism (including Parkinson's disease), by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- Among incident cases with parkinsonism, the mean and median costs associated with one year of health system use were $15,155 and $5,064 respectively. The interquartile range of costs extended from $2,265 to $14,542.
- Among incident cases with parkinsonism, the median cost associated with one year of health system use increased across age groups and was highest among persons aged 85 years and older ($11,372).

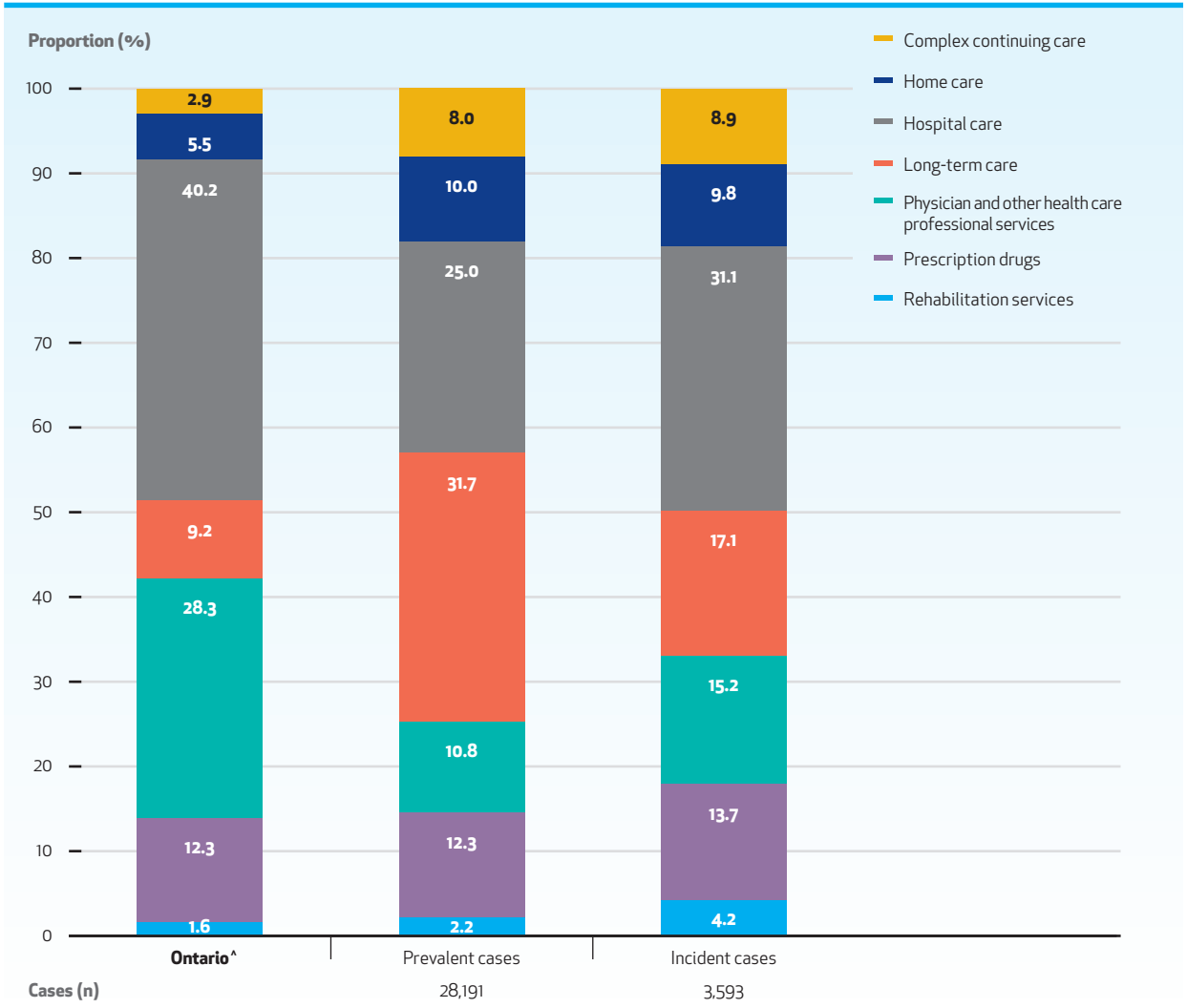


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 10.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with parkinsonism (including Parkinson's disease), by type of health care service

Key Findings

- Among prevalent cases with parkinsonism, the majority of the costs associated with health system use were attributable to long-term care (31.7%), hospital care (25.0%) and prescription drugs (12.3%).
- Among incident cases with parkinsonism, the majority of the costs associated with health system use were attributable to hospital care (31.1%), long-term care (17.1%) and physician and other health care professional services (15.2%).

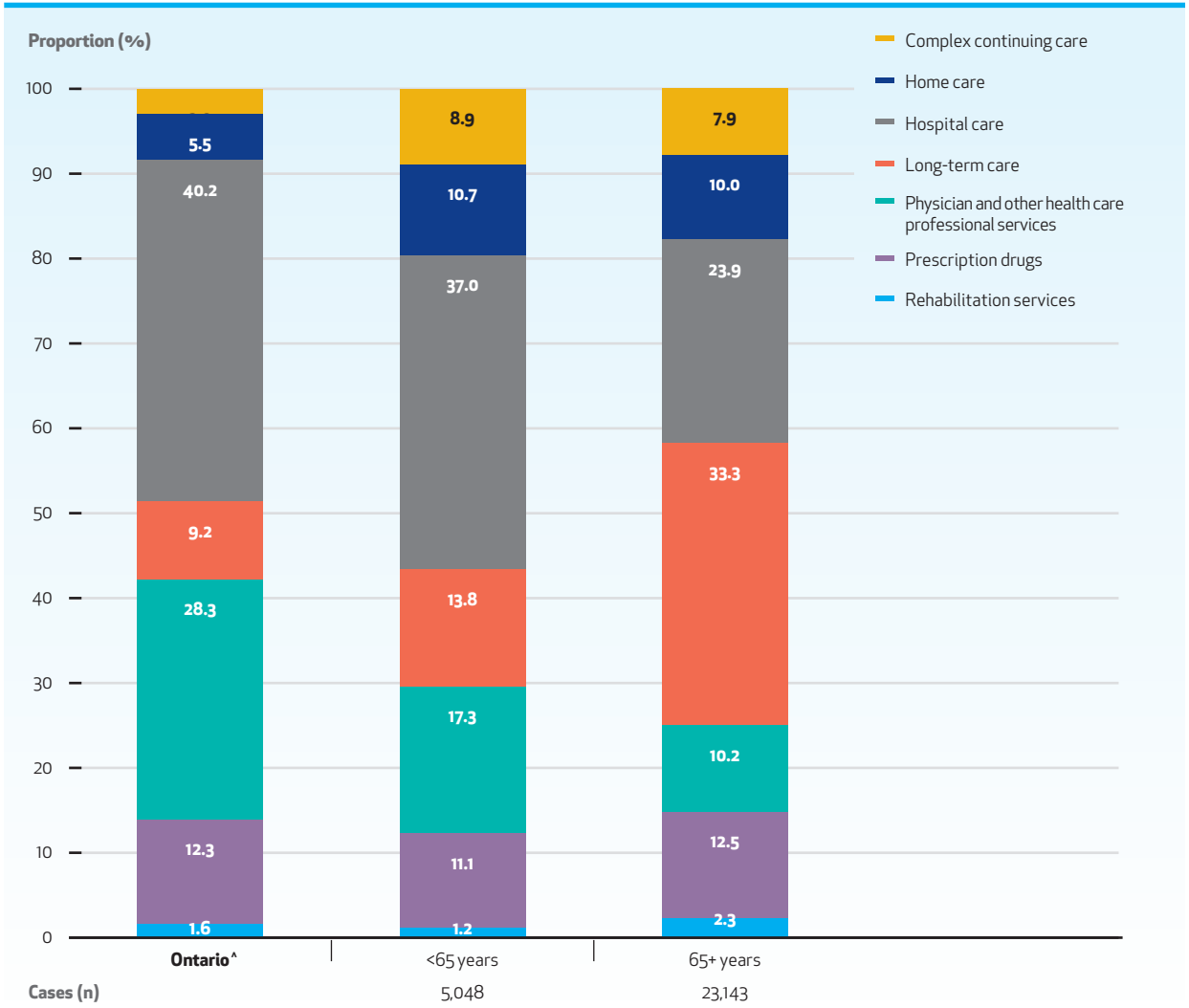


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 10.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with parkinsonism (including Parkinson's disease), by age group and type of health care service

Key Findings

- Among prevalent cases with parkinsonism aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (37.0%), physician and other health care professional services (17.3%) and long-term care (13.8%).
- Among prevalent cases with parkinsonism aged 65 years and older, the majority of the costs associated with health system use were attributable to long-term care (33.3%), hospital care (23.9%) and prescription drugs (12.5%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 11

Schizophrenia

"When someone gets schizophrenia, they will be ill for the rest of their life, but the illness can be treated and people can have a regular life. Instead of it being seen as an ending, it can be a beginning."

– Jesse Bigelow

"Sometimes I wish people would understand that people with schizophrenia aren't indifferent or incapable. They just need time to understand their symptoms and find balance mentally, spiritually, physically and emotionally."

– Marie Asuncion

"Schizophrenia shouldn't involve stigma or self-blame."

– Christine Walter

Overview

Schizophrenia 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 and affect/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 his or her thoughts have become disorganized. Schizophrenia is both chronic and episodic in nature, worsening and improving by varying degrees. With each cycle, despite temporary improvement, residual symptoms increase and capacity for normal functioning typically declines. 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.

Data Quality

Schizophrenia was assessed using health administrative data for the Ontario population aged 7 years and older. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with schizophrenia were determined. Findings in this chapter are presented from 2007/08 onwards instead of 2004/05 because estimates of schizophrenia improved after the Ontario Mental Health Reporting System was introduced (in October 2005) and adopted by all Ontario institutions (in 2006).

When looking at the results for schizophrenia, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for schizophrenia is considered grade II (the algorithm for Ontario health administrative data has not been validated but has been used in previous Canadian research studies and/or is accepted in the research community).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 11.1 Number and proportion of persons with schizophrenia, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 54.1% of the 119,571 Ontarians identified with schizophrenia.
- The mean age of a person with schizophrenia was 48.1 years.
- Among persons with schizophrenia, 31.2% were aged 18–39 and 52.4% were aged 40–64.
- Among persons with schizophrenia, 8.7% lived in a rural setting.
- There was a considerable income gradient, with 33.6% of persons with schizophrenia in the lowest income quintile versus 12.4% in the highest income quintile.

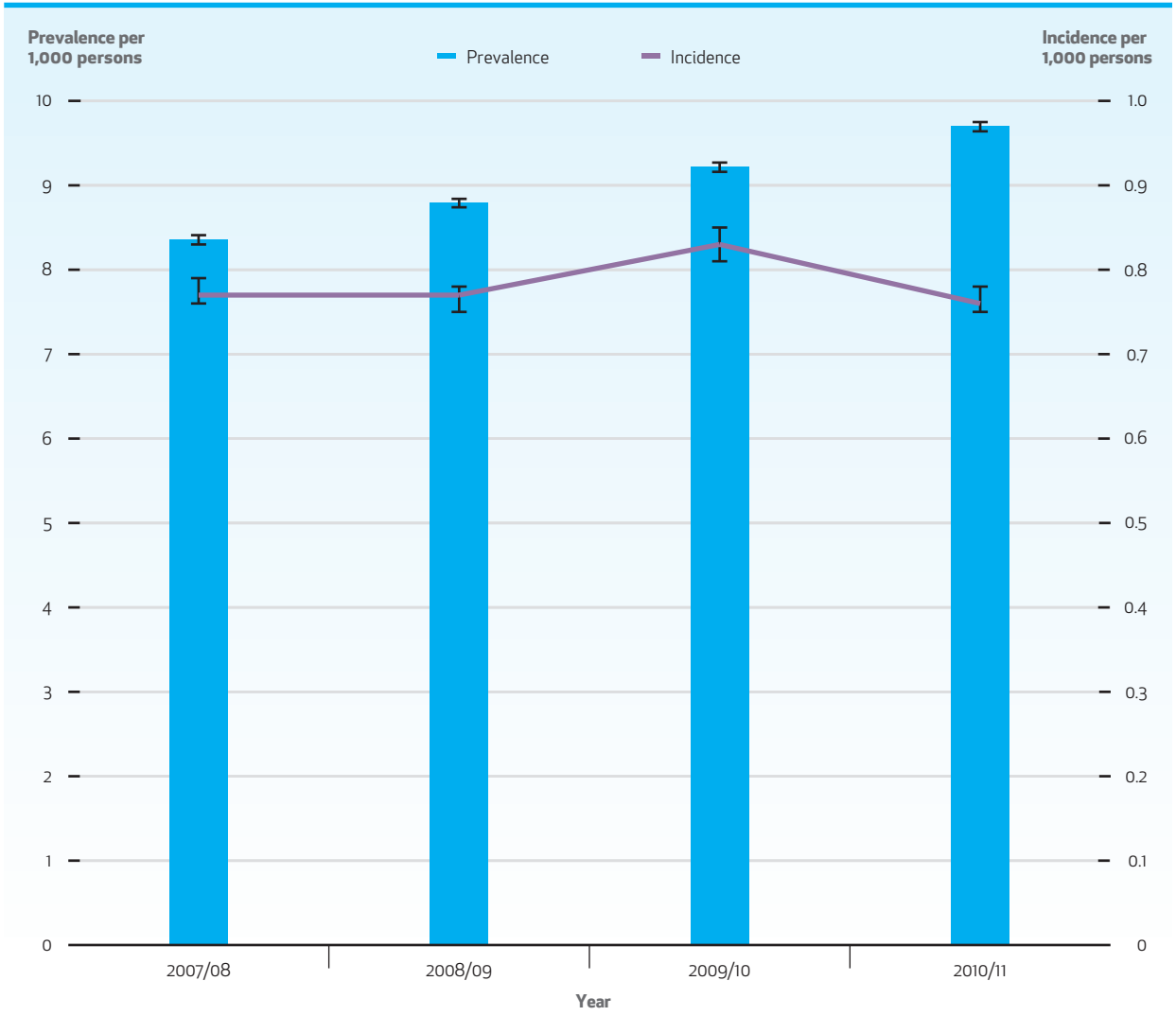
Characteristic	Cohort
Ontario, n	119,571
Sex, n (%)	
Female	54,941 (45.9)
Male	64,630 (54.1)
Age distribution, years	
Mean ± standard deviation	48.1 ± 16.4
Median (interquartile range)	48 (36–58)
Age group, years, n (%)	
7–17	832 (0.7)
18–25	9,099 (7.6)
26–39	28,254 (23.6)
40–64	62,617 (52.4)
65–74	10,226 (8.6)
75–84	6,072 (5.1)
85+	2,471 (2.1)
Children 7–17	832 (0.7)
Adults 18–64	99,970 (83.6)
Older adults 65+	18,769 (15.7)
Residence, n (%)	
Rural	10,393 (8.7)
Urban	109,115 (91.3)
Income quintile, n (%)	
1 (lowest)	40,120 (33.6)
2	25,849 (21.6)
3	19,985 (16.7)
4	17,819 (14.9)
5 (highest)	14,869 (12.4)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 11.2 Age- and sex-adjusted* prevalence and incidence of schizophrenia per 1,000 persons aged 7 years and older, in Ontario, 2007/08 to 2010/11

Key Findings

- Between 2007/08 and 2010/11, the number of Ontarians with schizophrenia increased from 98,413 to 119,571.
- The age- and sex-adjusted prevalence of schizophrenia per 1,000 persons aged 7 years and older increased from 8.4 in 2007/08 to 9.7 in 2010/11.
- Between 2007/08 and 2010/11, the number of Ontarians with newly identified schizophrenia increased from 9,045 to 9,262.
- The age- and sex-adjusted incidence of schizophrenia per 1,000 persons aged 7 years and older went unchanged from 0.77 in 2007/08 to 0.76 in 2010/11.



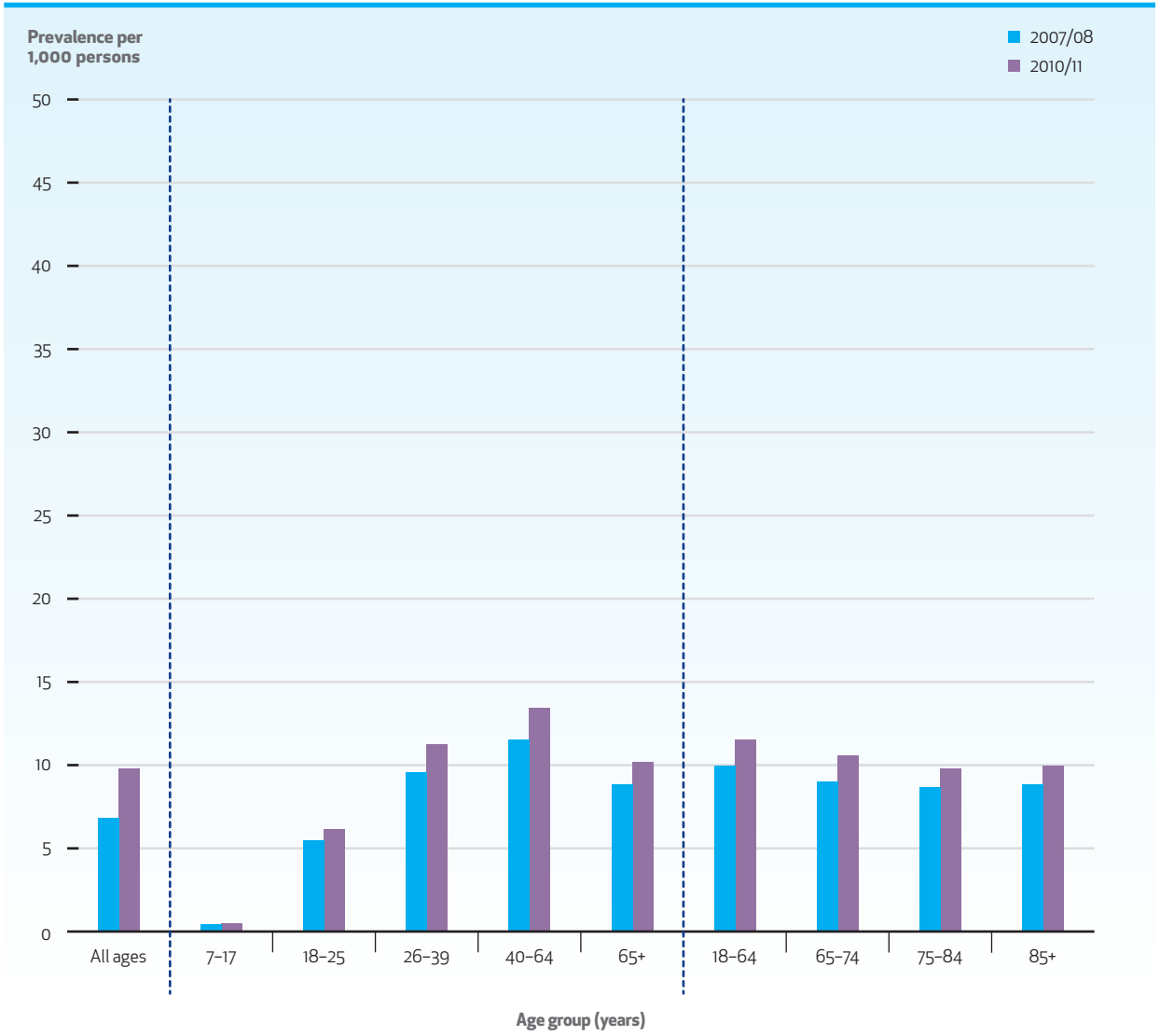
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 11.3A Crude prevalence of schizophrenia per 1,000 persons aged 7 years and older, by age group, in Ontario, 2007/08 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of schizophrenia for persons aged 7–17 years, 18–64 years and 65 years and older was 0.48, 11.5 and 10.2 per 1,000, respectively.

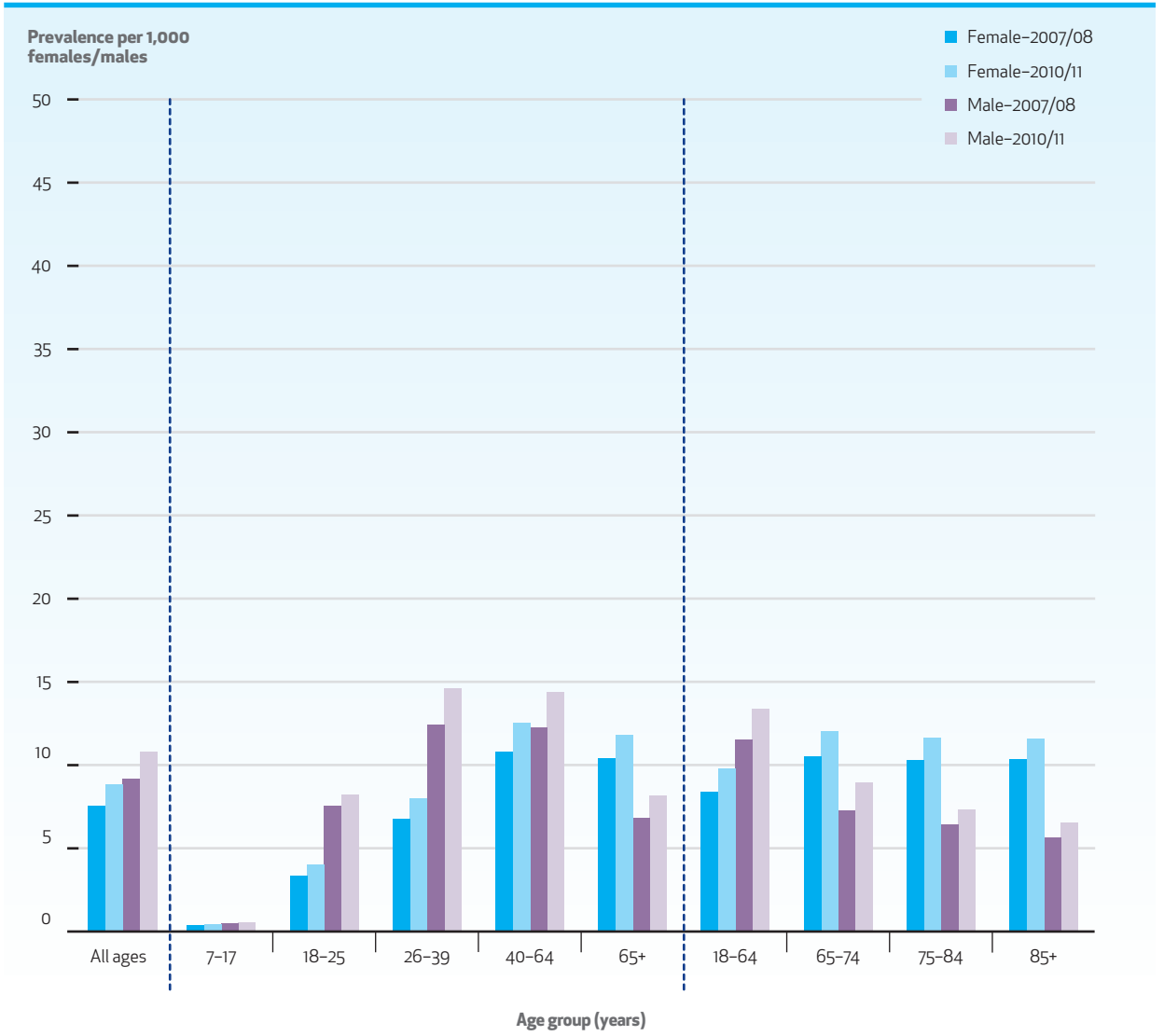


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 11.3B Crude prevalence of schizophrenia per 1,000 females and 1,000 males aged 7 years and older, by age group, in Ontario, 2007/08 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of schizophrenia per 1,000 persons aged 7 years and older was greater for males (10.8) than females (8.8).
- Among females aged 7 years and older, the crude prevalence of schizophrenia rose from 7.5 to 8.8 per 1,000 between 2007/08 and 2010/11.
- Among males aged 7 years and older, the crude prevalence of schizophrenia increased from 9.2 to 10.8 per 1,000 between 2007/08 and 2010/11.



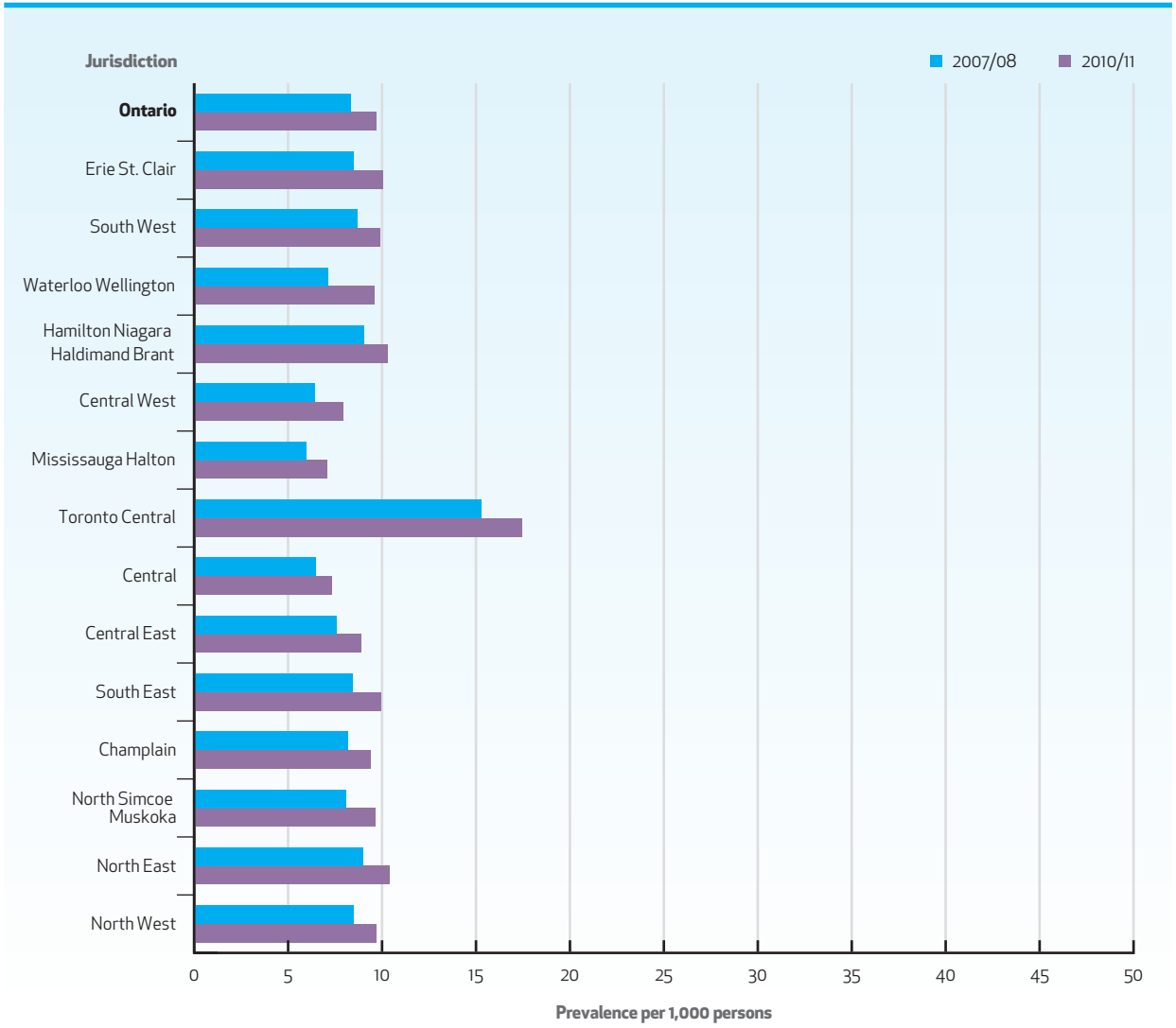
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 11.4 Age- and sex-adjusted* prevalence of schizophrenia per 1,000 persons aged 7 years and older, in Ontario and by Local Health Integration Network, 2007/08 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of schizophrenia increased across all Local Health Integration Networks (LHINs).
- Across all LHINs, there was a 2.5-fold variation in the age- and sex-adjusted prevalence of schizophrenia in 2010/11, which was similar to the 2.6-fold variation seen in 2007/08.
- Excluding the Toronto Central LHIN, there was a 1.5-fold variation in the age- and sex-adjusted prevalence of schizophrenia across the LHINs in 2007/08 and 2010/11.
- In 2010/11, the age- and sex-adjusted prevalence of schizophrenia per 1,000 persons aged 7 years and older was highest for the Toronto Central LHIN (17.4), followed by the North East and Hamilton Niagara Haldimand Brant LHINs (10.4 and 10.3, respectively).
- In 2010/11, the age- and sex-adjusted prevalence of schizophrenia per 1,000 persons aged 7 years and older was lowest for the Mississauga Halton, Central and Central West LHINs (7.1, 7.3 and 7.9, respectively).

Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

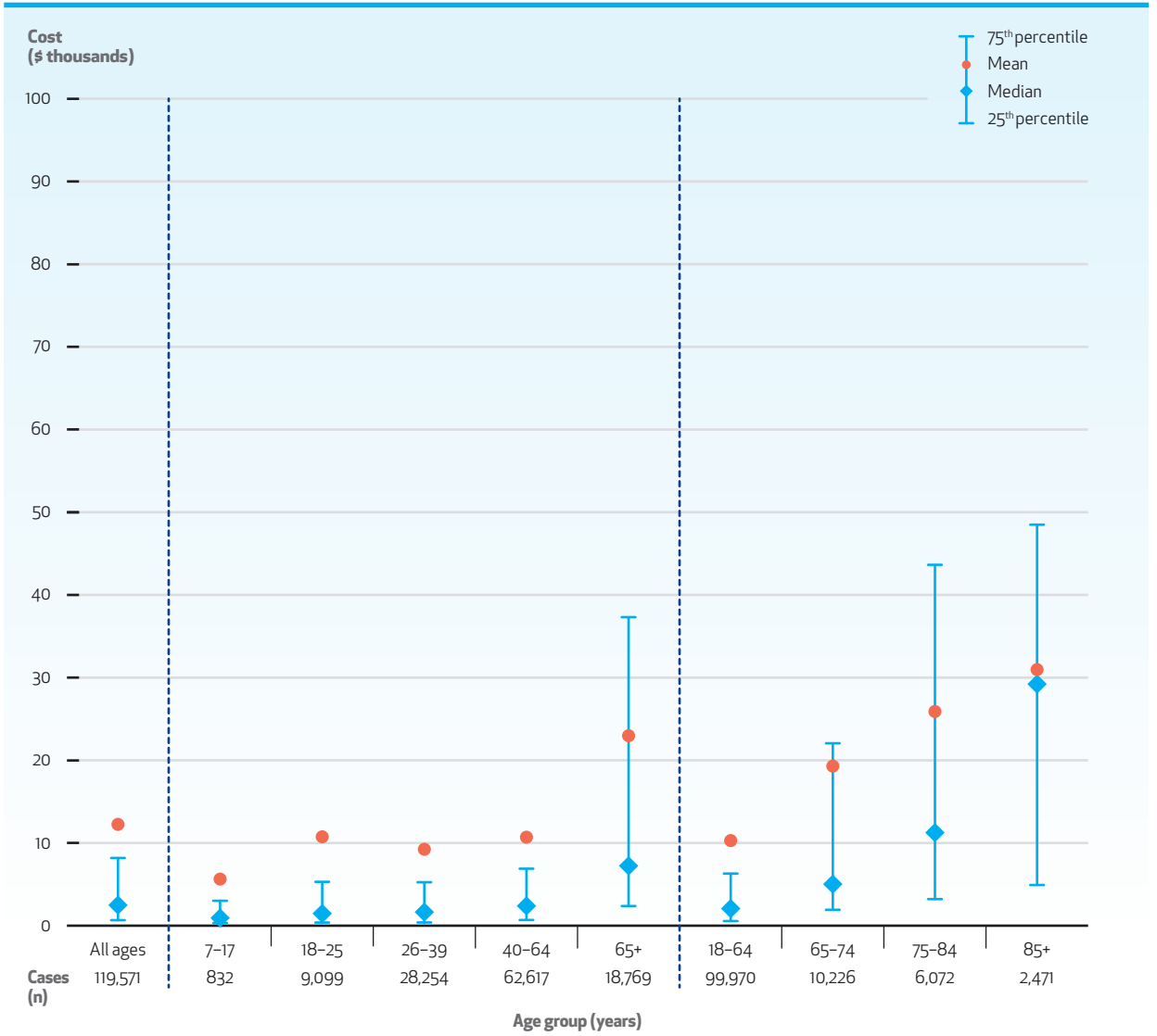


*Adjusted to the 2006 Census population.

EXHIBIT 11.5A Distribution of costs* associated with one year† of health system use for prevalent cases with schizophrenia, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with schizophrenia were $12,252 and $2,490, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $668 to $8,185.
- Among prevalent cases with schizophrenia, the median cost associated with one year of health system use increased with age, from $935 among persons aged 7–17 years to $29,223 among those aged 85 years and older.

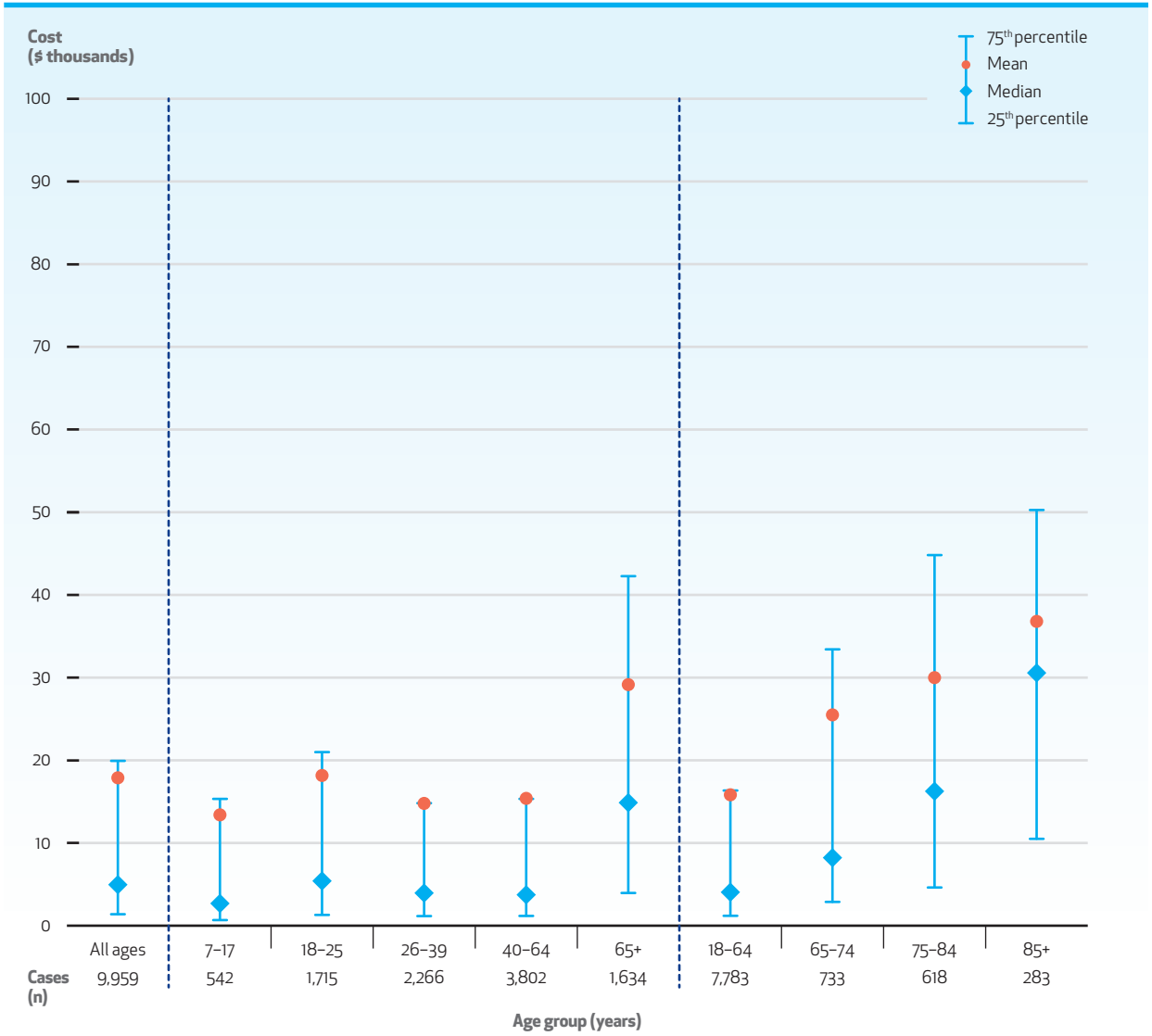


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 11.5B Distribution of costs* associated with one year† of health system use for incident cases with schizophrenia, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with schizophrenia were $17,871 and $4,948, respectively. The interquartile range of costs extended from $1,385 to $19,931.
- Among incident cases with schizophrenia, the median cost associated with one year of health system use generally increased with age, from $2,678 among persons aged 7–17 years to $30,558 among those aged 85 years and older.

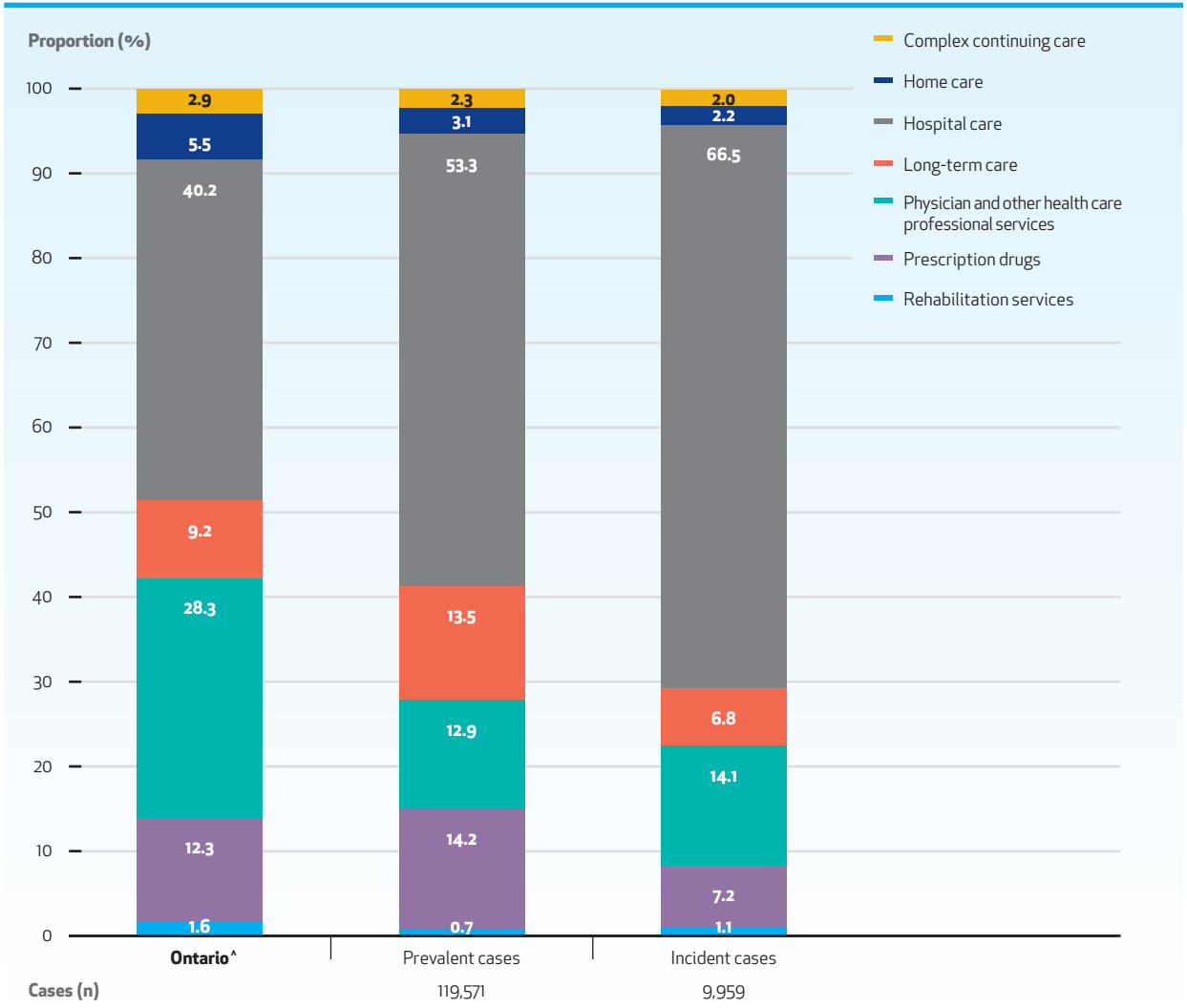


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 11.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with schizophrenia, by type of health care service

Key Findings

- Among prevalent cases with schizophrenia, the majority of the costs associated with health system use were attributable to hospital care (53.3%), prescription drugs (14.2%) and long-term care (13.5%).
- Among incident cases with schizophrenia, the majority of the costs associated with health system use were attributable to hospital care (66.5%), physician and other health care professional services (14.1%) and prescription drugs (7.2%).

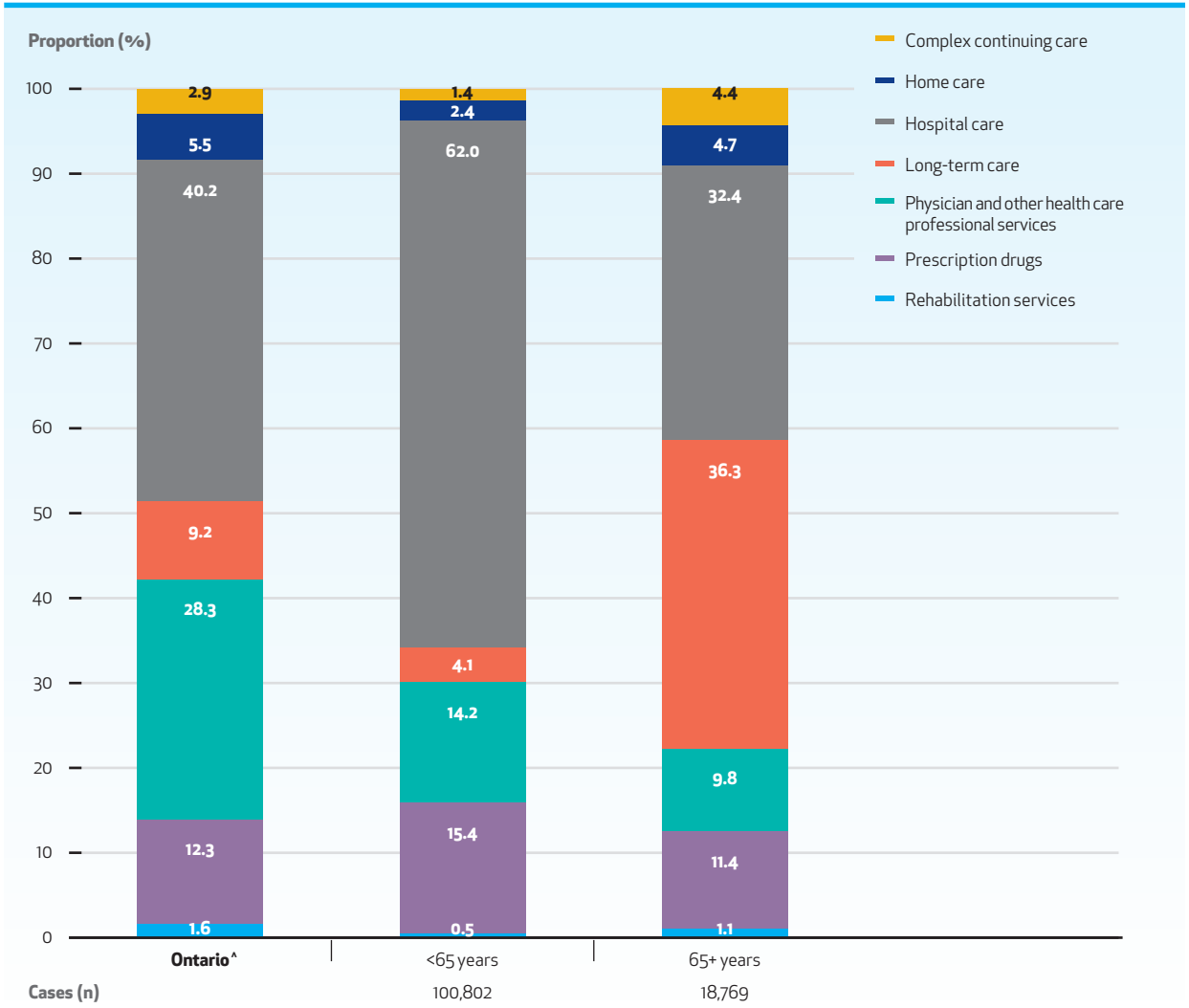


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 11.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with schizophrenia, by age group and type of health care service

Key Findings

- Among prevalent cases with schizophrenia aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (62.0%), prescription drugs (15.4%) and physician and other health care professional services (14.2%).
- Among prevalent cases with schizophrenia aged 65 years and older, the majority of the costs associated with health system use were attributable to long-term care (36.3%), hospital care (32.4%) and prescription drugs (11.4%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 12

Spina Bifida

"Living with spina bifida, I always knew that I would need to use my brain and imagination to get ahead and achieve all my goals. If I were born able-bodied, I would have probably barely finished high school, gone to work in the mines and spent my life doing a job I hated to make ends meet. Instead, I have a job with deep meaning to me, and I spend a good deal of my time pursuing my passion for creating art."

– Steve

"The biggest challenge about living with spina bifida as an adult is accessing appropriate health care in a timely manner. Our conditions don't magically disappear when we turn 18! We require the same monitoring through a multidisciplinary clinic – similar to what is available in most pediatric health care hospitals and treatment centres."

– Shauna

Overview

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.

Data Quality

Spina bifida was assessed using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence and the costs associated with health system use of persons with spina bifida were determined. The live-birth prevalence was estimated instead of incidence because spina bifida is a developmental congenital disorder.

When looking at the results for spina bifida, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for spina bifida is considered grade II (the algorithm for Ontario health administrative data has not been validated but has been used in previous Canadian research studies and/or is accepted in the research community).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 12.1 Number and proportion of persons with spina bifida, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, females accounted for 60.6% of the 3,469 Ontarians identified with spina bifida.
- The mean age of a person with spina bifida was 32.2 years.
- Among persons with spina bifida, 26.5% were aged 0–17 years and 67.5% were aged 18–64 years.
- Among persons with spina bifida, 14.2% lived in a rural setting.
- Persons with spina bifida were not evenly distributed across neighbourhoods of different income quintiles; approximately 24.3% lived in the lowest-income neighbourhoods compared to 18.1% who lived in the highest-income neighborhoods.

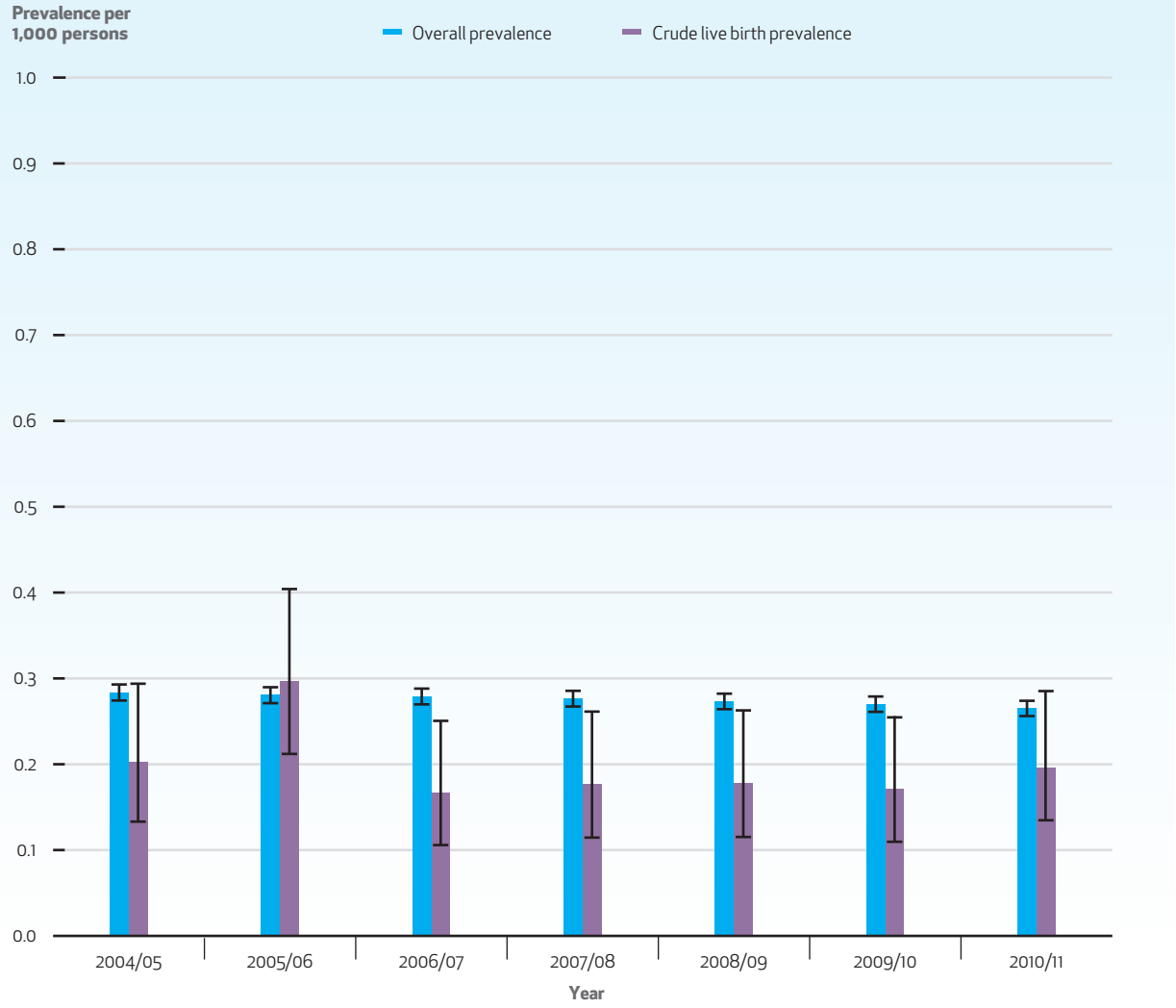
Characteristic	Cohort
Ontario, n	3,469
Sex, n (%)	
Female	2,101 (60.6)
Male	1,368 (39.4)
Age distribution, years	
Mean ± standard deviation	32.2 ± 18.9
Median (interquartile range)	30 (17–45)
Age group, years, n (%)	
0–4	150 (4.3)
5–17	770 (22.2)
18–39	1,401 (40.4)
40–64	941 (27.1)
65–74	135 (3.9)
75+	72 (2.1)
Newborns 0–1	27 (0.8)
Children 0–17	920 (26.5)
Adults 18–64	2,342 (67.5)
Older adults 65+	207 (6.0)
Residence, n (%)	
Rural	493 (14.2)
Urban	2,976 (85.8)
Income quintile, n (%)	
1 (lowest)	843 (24.3)
2	722 (20.8)
3	642 (18.5)
4	617 (17.8)
5 (highest)	628 (18.1)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 12.2 Age- and sex-adjusted* overall prevalence and crude live birth prevalence of spina bifida per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with spina bifida decreased from 3,567 to 3,469.
- The age- and sex-adjusted overall prevalence of spina bifida per 1,000 persons decreased from 0.28 in 2004/05 to 0.26 in 2010/11.
- In 2004/05 and 2010/11, the number of Ontario newborns identified with spina bifida was 27.
- The crude live birth prevalence of spina bifida per 1,000 persons remained constant at approximately 0.20 in 2004/05 and 2010/11.



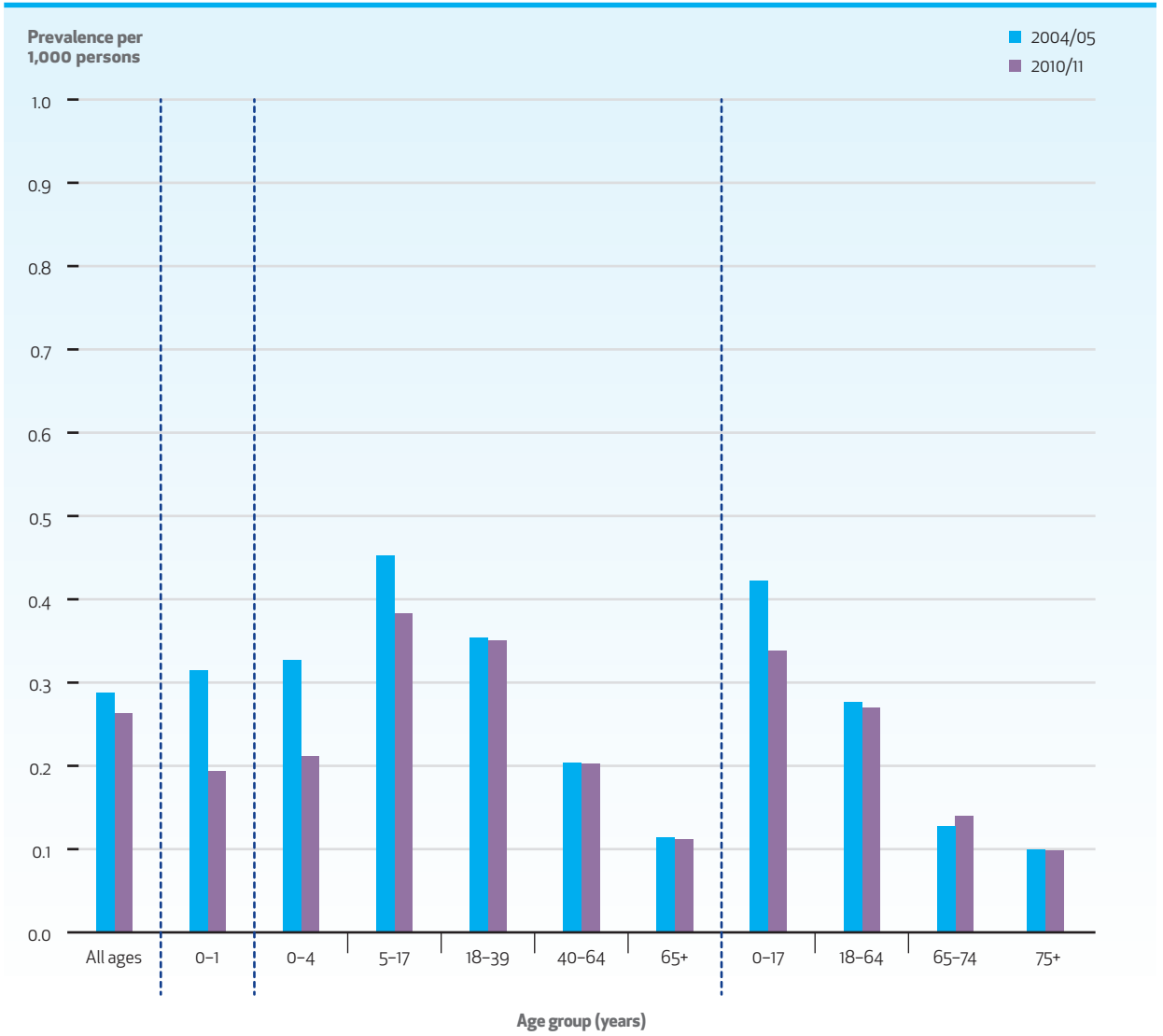
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 12.3A Crude prevalence of spina bifida per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of spina bifida for persons aged 0–17 years, 18–64 years and 65 years and older was 0.34, 0.27 and 0.11 per 1,000, respectively.

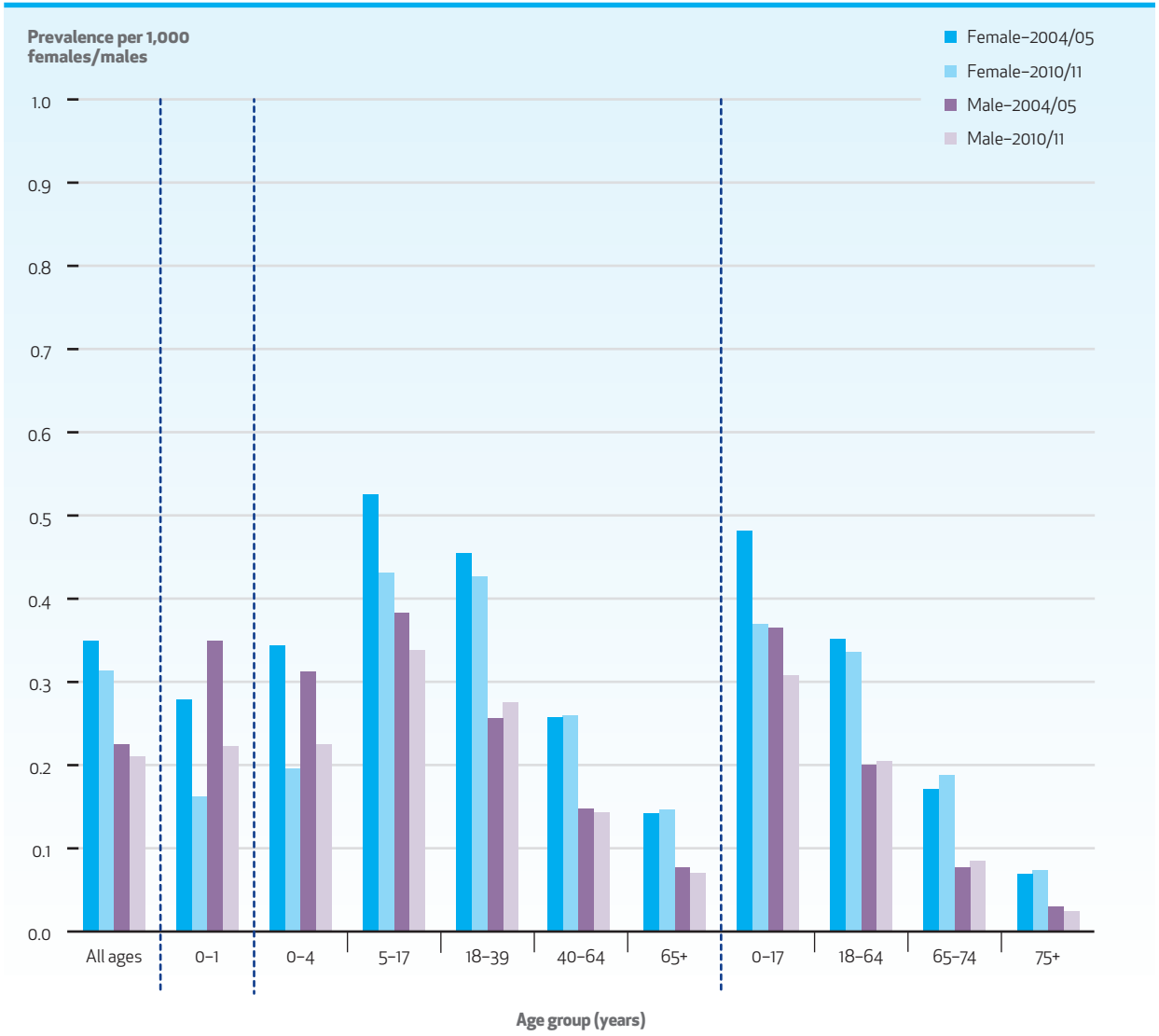


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 12.3B Crude prevalence of spina bifida per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of spina bifida was greater for females (0.31 per 1,000) than males (0.21 per 1,000).
- Among females, the crude prevalence of spina bifida per 1,000 decreased from 0.35 to 0.31 between 2004/05 and 2010/11.
- Among males, the crude prevalence of spina bifida per 1,000 decreased from 0.23 to 0.21 between 2004/05 to 2010/11.

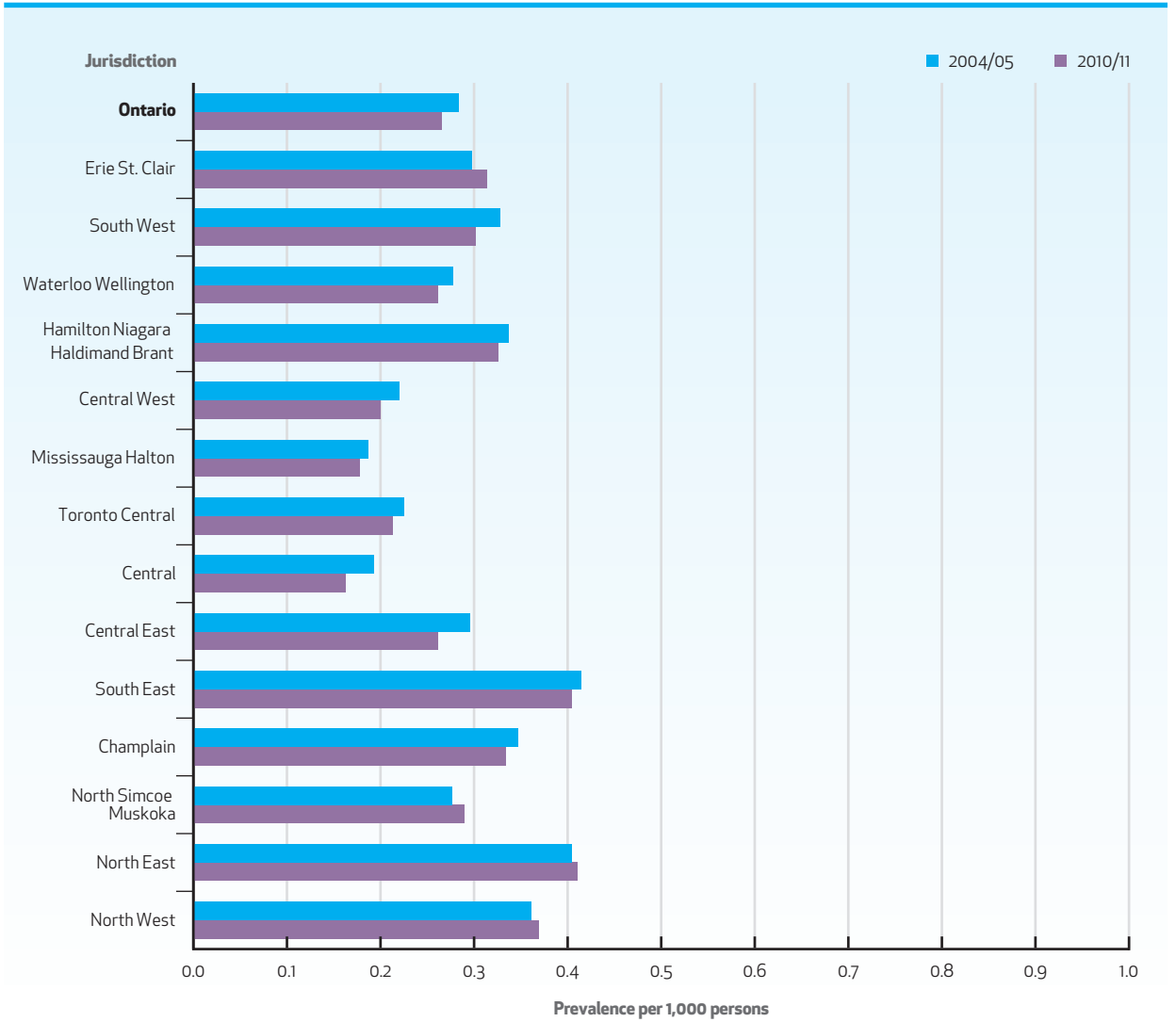


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 12.4 Age- and sex-adjusted* prevalence of spina bifida per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of spina bifida decreased in most of the Local Health Integration Networks (LHINs), the exceptions being the Erie St. Clair, North Simcoe Muskoka, North East and North West LHINs.
- Across the LHINs, there was a 2.5-fold variation in the age- and sex-adjusted prevalence of spina bifida in 2010/11, which was greater than the 2.2-fold variation in 2004/05.
- In 2010/11, the prevalence of spina bifida was highest for the North East, South East and North West LHINs (0.41, 0.40 and 0.37 per 1,000 persons, respectively).
- In 2010/11, the prevalence of spina bifida was lowest for the Central, Mississauga Halton and Central West LHINs (0.16, 0.18 and 0.20 per 1,000 persons, respectively).



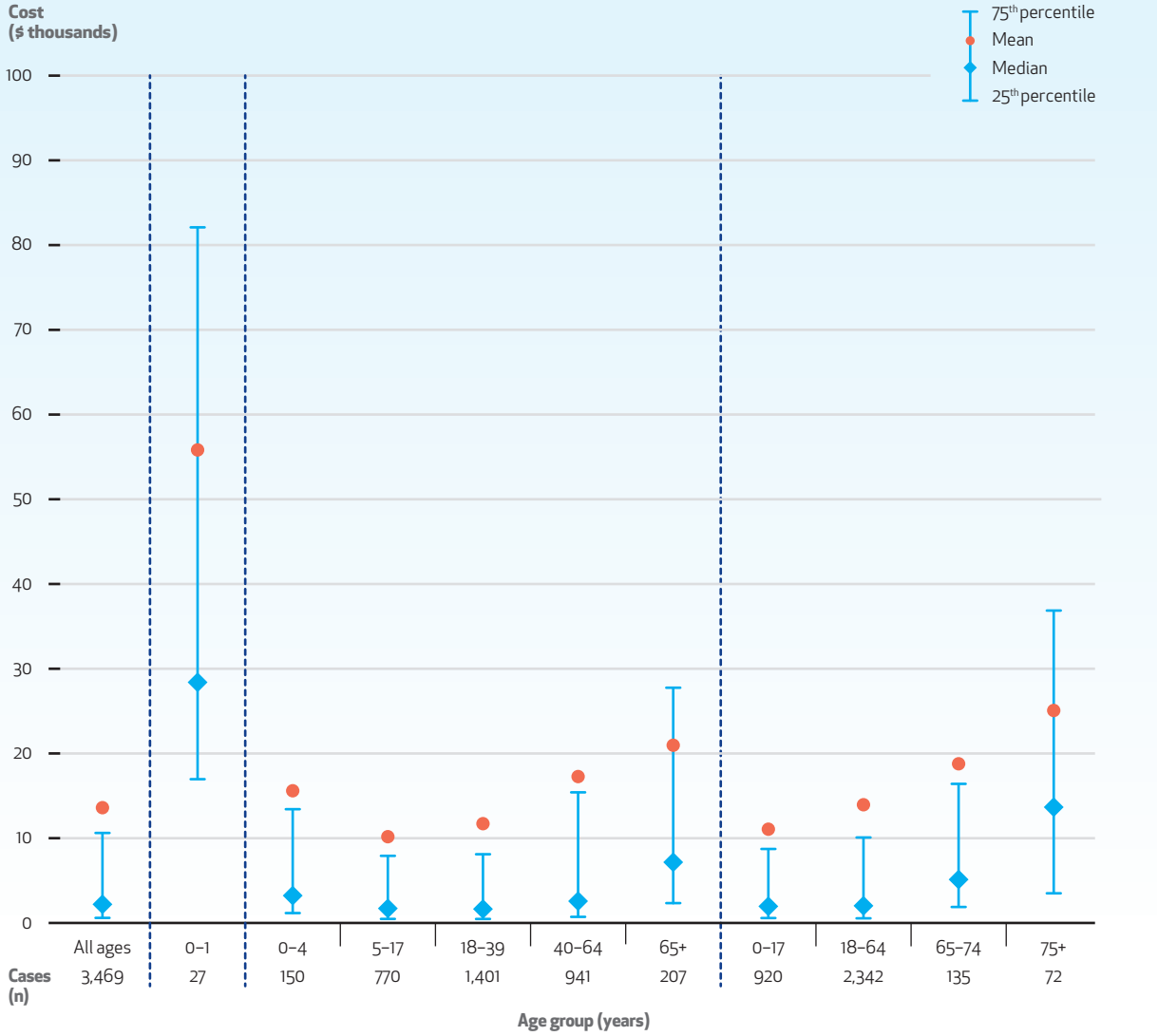
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 12.5 Distribution of costs* associated with one year† of health system use for prevalent cases with spina bifida, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with spina bifida were $13,589 and $2,185, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $598 to $10,621.
- The mean and median costs associated with one year of health system use among newborns with spina bifida were $55,807 and $28,384, respectively. The interquartile range of costs extended from $16,966 to $82,089.
- Among prevalent cases with spina bifida, the median cost associated with one year of health system use decreased then increased with age. The median cost associated with one year of health system use was highest among newborns ($28,384).

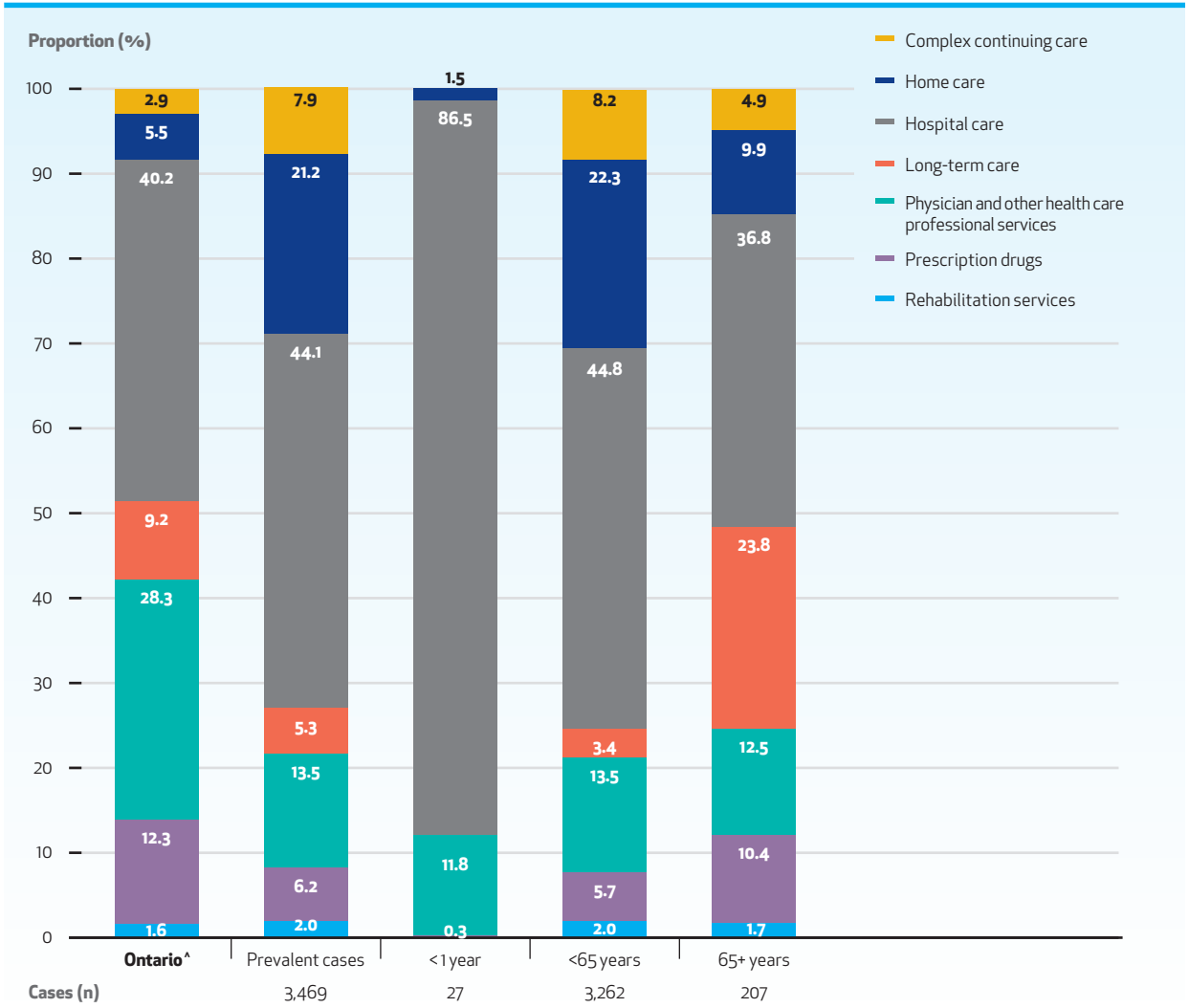


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 12.6 Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with spina bifida, by age group and type of health care service

Key Findings

- Among prevalent cases with spina bifida, the majority of the costs associated with health system use were attributable to hospital care (44.1%), home care (21.2%), and physician and health care professional services (13.5%).
- Among newborns with spina bifida, the majority of the costs associated with health system use were attributable to hospital care (86.5%).
- Among prevalent cases with spina bifida aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (44.8%), home care (22.3%) and physician and other health care professional services (13.5%).
- Among prevalent cases with spina bifida aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (36.8%), long-term care (23.8%) and physician and other health care professional services (12.5%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

"I wish people understood that sustaining a spinal cord injury changes how you do things, but doesn't need to take away from a wonderful, quality life in which you can still dream and achieve great things. You can still do most things, just in a new or different way."

– Christine Selinger, Educator, Spinal Cord Injury Ontario

CHAPTER 13

Spinal Cord Injury

Overview

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 skill-building activity.

Data Quality

Spinal cord injury was assessed using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with spinal cord injury were determined.

When looking at the results for spinal cord injury, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for spinal cord injury is considered grade II (the algorithm for Ontario health administrative data has not been validated but has been used in previous Canadian research studies and/or is accepted in the research community).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 13.1 Number and proportion of persons with spinal cord injury, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 72.3% of the 4,944 Ontarians identified with spinal cord injury.
- The mean age of a person with spinal cord injury was 49.4 years.
- The majority of persons with spinal cord injury (79.0%) were aged 18–64 years.
- Among persons with spinal cord injury, 18.7% lived in a rural setting.
- Among persons with spinal cord injury, a slightly greater proportion lived in neighbourhoods belonging to the lowest income quintile as opposed to the highest income quintile (20.8% versus 18.8%).

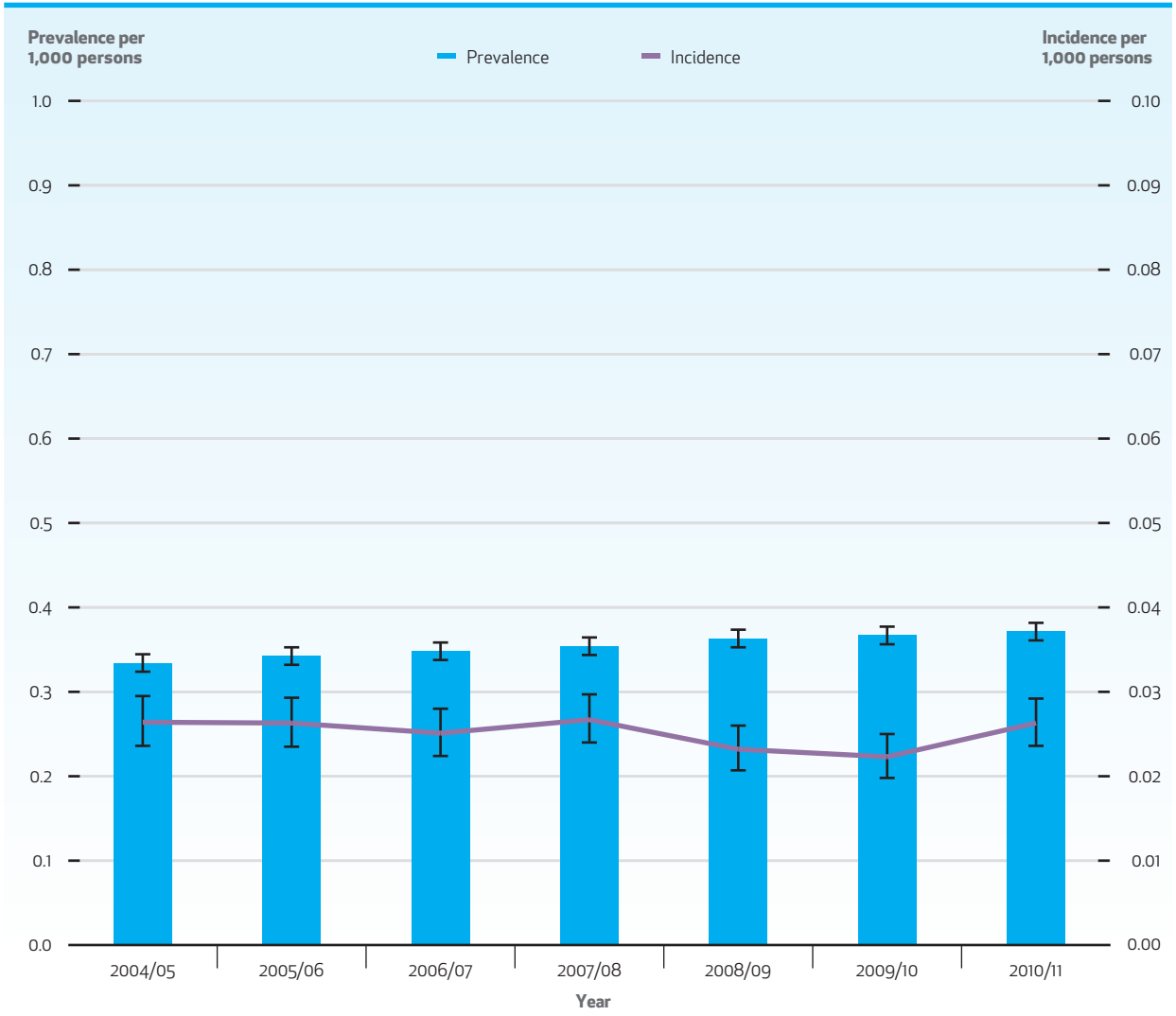
Characteristic	Cohort
Ontario, n	4,944
Sex, n (%)	
Female	1,371 (27.7)
Male	3,573 (72.3)
Age distribution, years	
Mean ± standard deviation	49.4 ± 17.2
Median (interquartile range)	49 (36–61)
Age group, years, n (%)	
0–17	82 (1.7)
18–39	1,439 (29.1)
40–64	2,468 (49.9)
65–74	517 (10.5)
75–84	311 (6.3)
85+	127 (2.6)
Children 0–17	82 (1.7)
Adults 18–64	3,907 (79.0)
Older adults 65+	955 (19.3)
Residence, n (%)	
Rural	924 (18.7)
Urban	4,019 (81.3)
Income quintile, n (%)	
1 (lowest)	1,027 (20.8)
2	1,043 (21.1)
3	952 (19.3)
4	959 (19.4)
5 (highest)	928 (18.8)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 13.2 Age- and sex-adjusted* prevalence and incidence of spinal cord injury per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with spinal cord injury increased from 4,055 to 4,944.
- The age- and sex-adjusted prevalence of spinal cord injury per 1,000 persons increased from 0.33 in 2004/05 to 0.37 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified spinal cord injury increased slightly from 320 to 353.
- The age- and sex-adjusted incidence of spinal cord injury per 1,000 was relatively unchanged at 0.026 in 2004/05 and 2010/11.



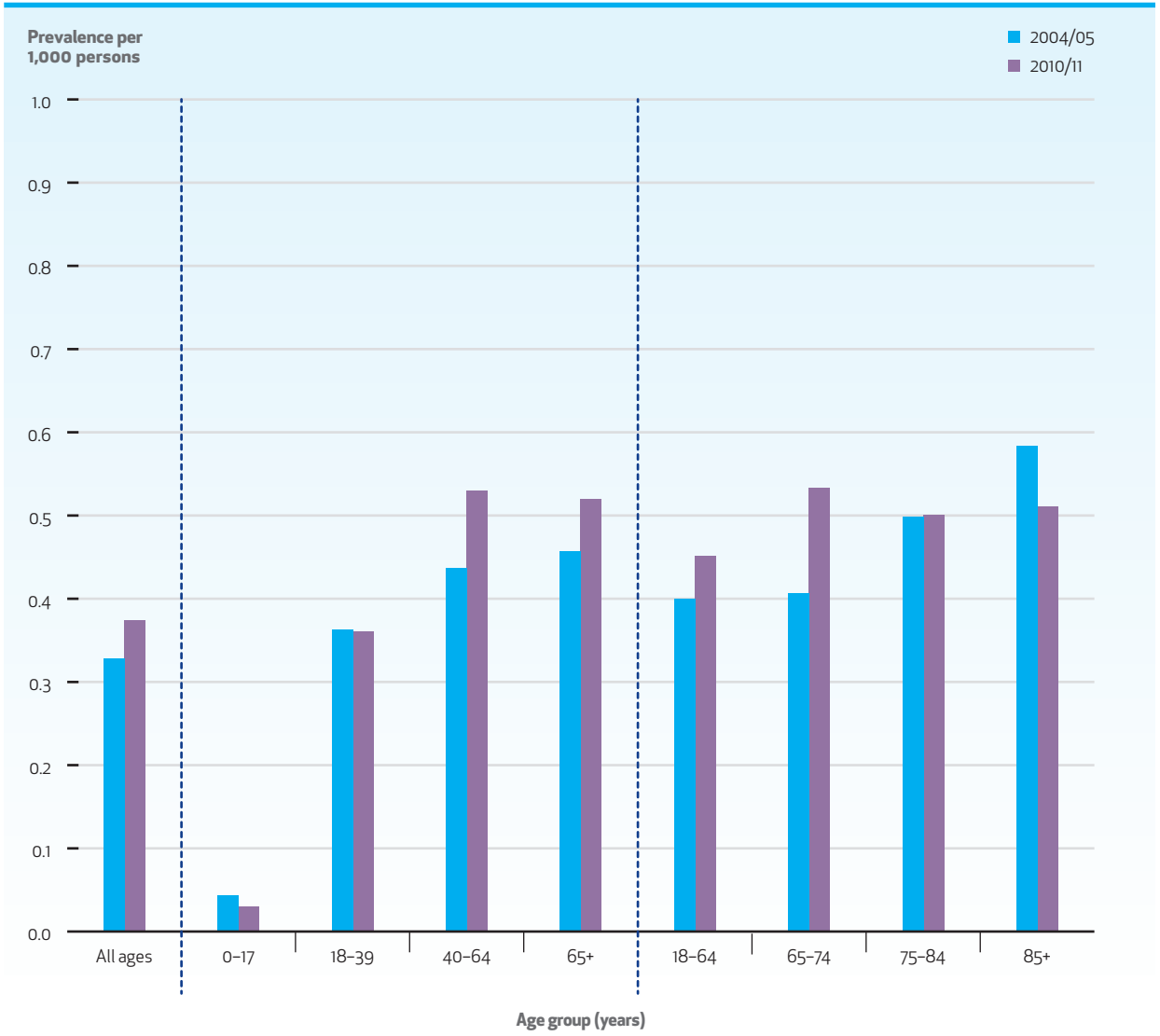
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 13.3A Crude prevalence of spinal cord injury per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of spinal cord injury for persons aged 0–17 years, 18–64 years and 65 years and older was 0.03, 0.45 and 0.52 per 1,000, respectively.

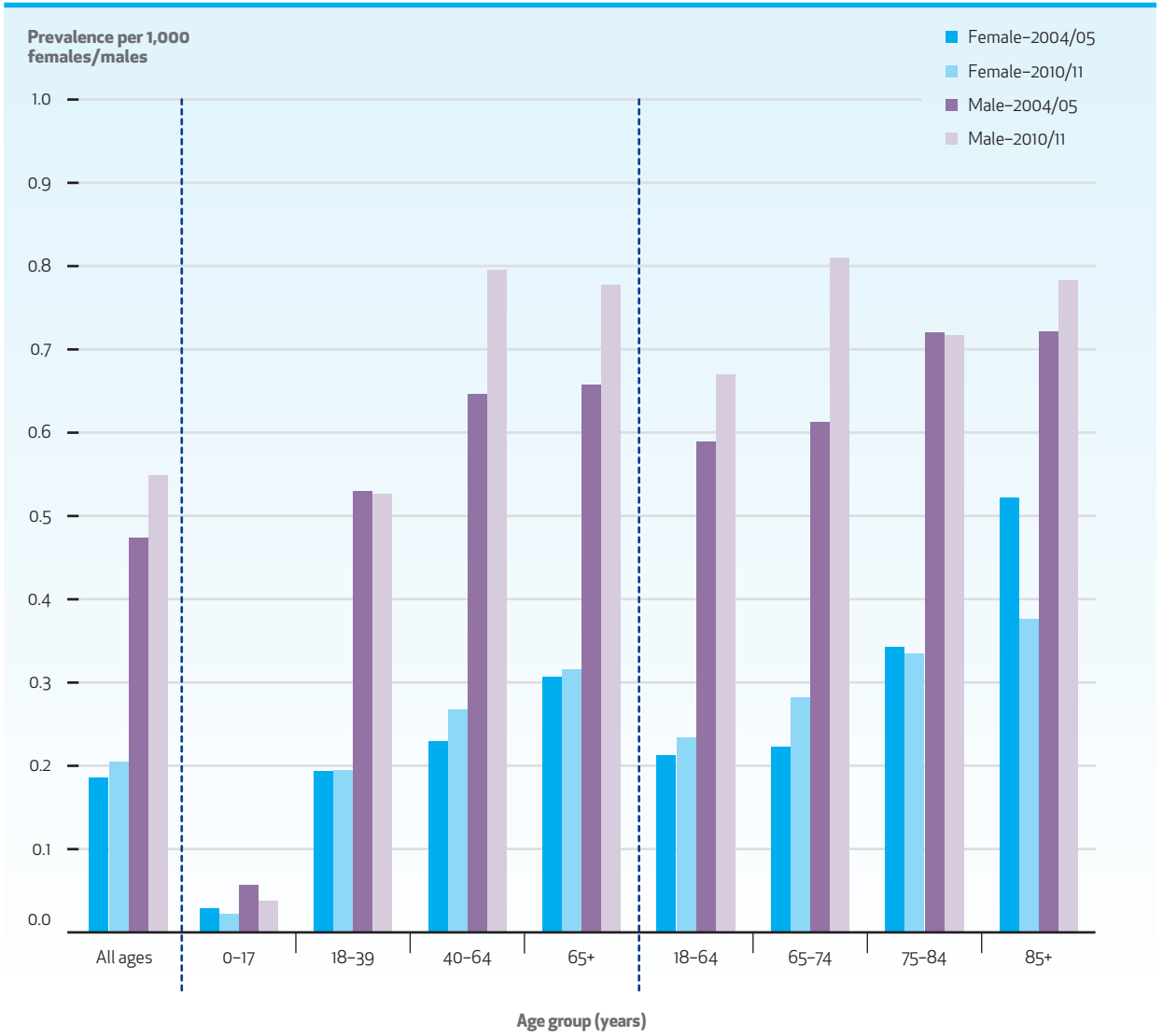


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 13.3B Crude prevalence of spinal cord injury per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of spinal cord injury was greater for males (0.55 per 1,000) than females (0.20 per 1,000).
- Among females, the crude prevalence of spinal cord injury per 1,000 increased slightly from 0.19 to 0.20 between 2004/05 and 2010/11.
- Among males, the crude prevalence of spinal cord injury per 1,000 increased from 0.47 to 0.55 between 2004/05 and 2010/11.

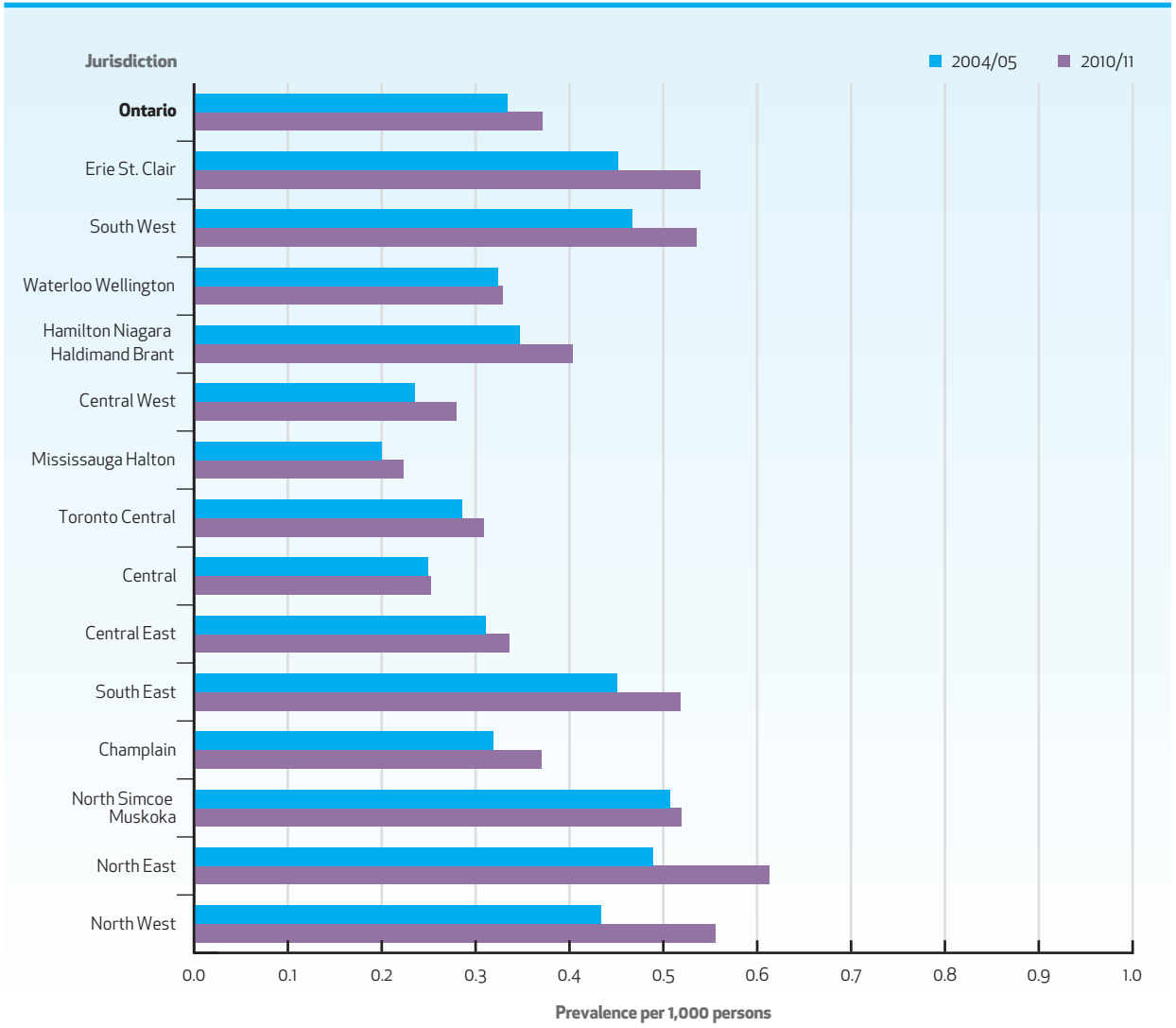


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 13.4 Age- and sex-adjusted* prevalence of spinal cord injury per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of spinal cord injury increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 2.7-fold variation in the age- and sex-adjusted prevalence of spinal cord injury in 2010/11, which was greater than the 2.5-fold variation in 2004/05.
- In 2010/11, the highest age- and sex-adjusted prevalence of spinal cord injury was for the North East, North West and Erie St. Clair LHINs (0.61, 0.56 and 0.54 per 1,000 persons, respectively).
- In 2010/11, the lowest age- and sex-adjusted prevalence of spinal cord injury was for the Mississauga Halton, Central and Central West LHINs (0.22, 0.25 and 0.28 per 1,000 persons, respectively).



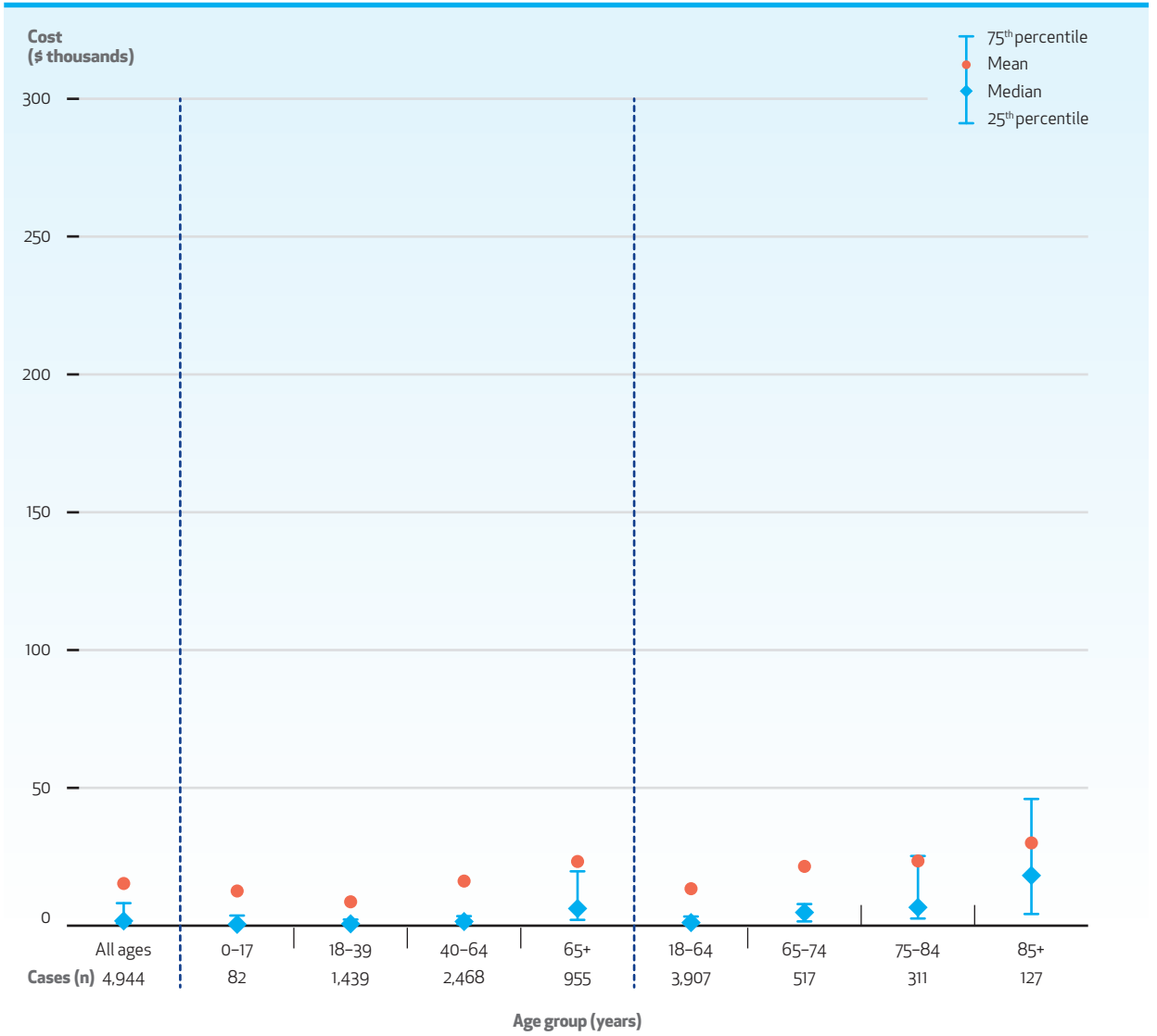
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 13.5A Distribution of costs* associated with one year† of health system use for prevalent cases with spinal cord injury, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with spinal cord injury were $15,307 and $1,719, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $346 to $10,005.
- Among prevalent cases with spinal cord injury, the median cost associated with one year of health system use increased by age, with the highest cost found among persons aged 85 years and older ($18,206).

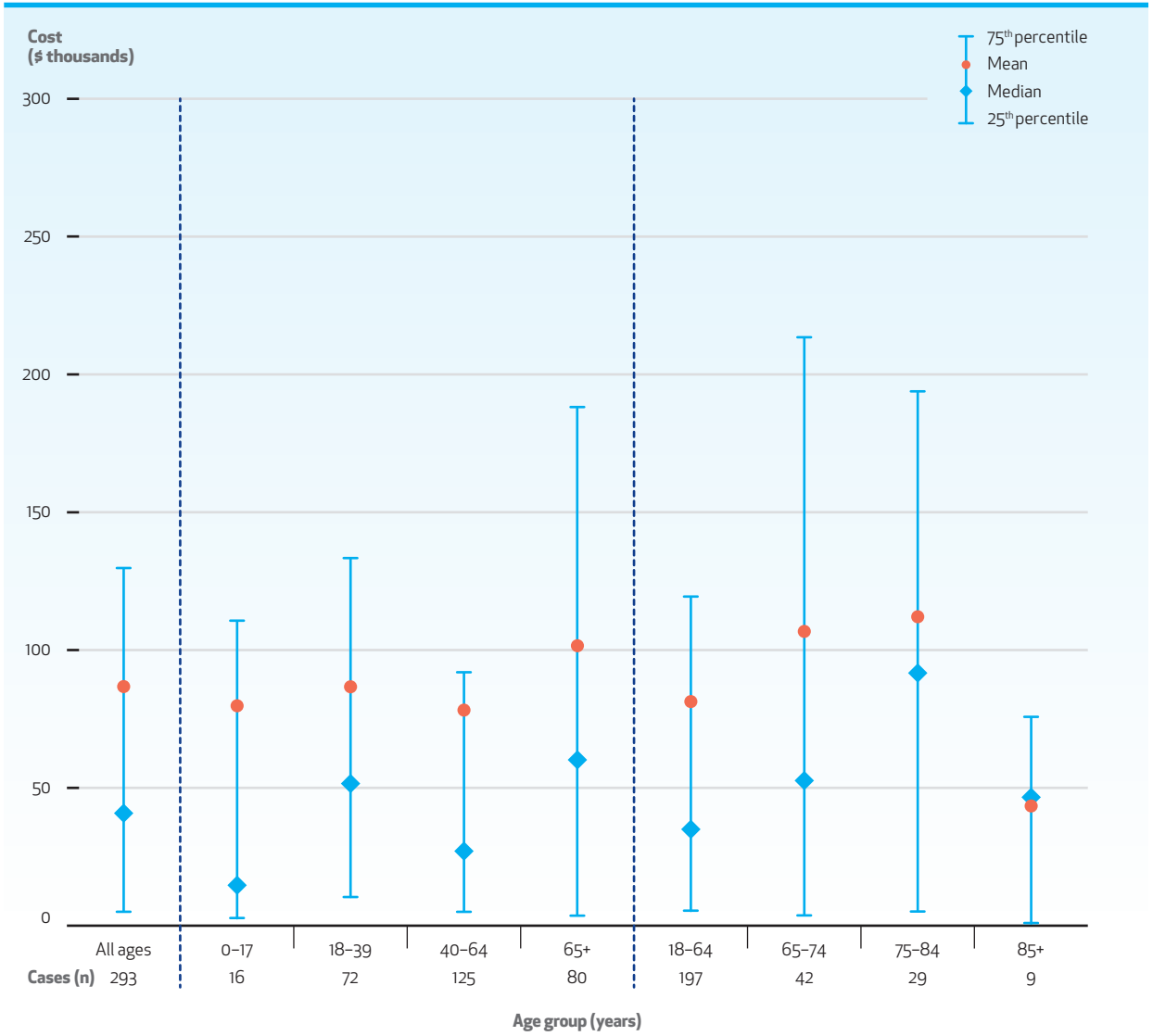


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 13.5B Distribution of costs* associated with one year† of health system use for incident cases with spinal cord injury, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with spinal cord injury were $86,688 and $40,735, respectively. The interquartile range of costs extended from $5,050 to $129,756.
- Among incident cases with spinal cord injury, the median cost associated with one year of health system use varied from $14,609 among persons aged 0–17 years to $91,603 among those aged 75–84 years.

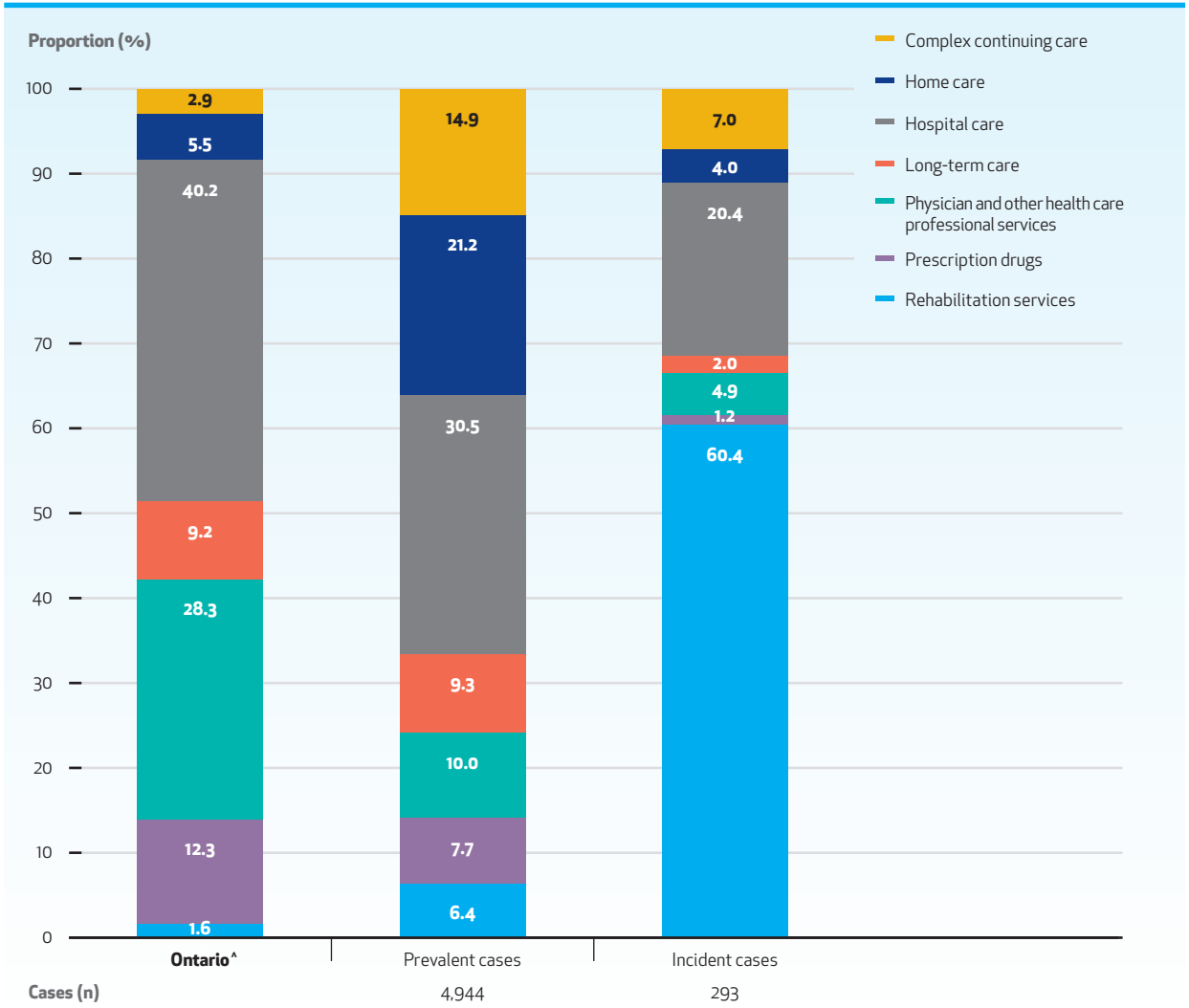


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 13.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with spinal cord injury, by type of health care service

Key Findings

- Among prevalent cases with spinal cord injury, the majority of the costs associated with health system use were attributable to hospital care (30.5%), home care (21.2%) and complex continuing care (14.9%).
- Among incident cases with spinal cord injury, the majority of the costs associated with health system use were attributable to rehabilitation services (60.4%), hospital care (20.4%) and complex continuing care (7.0%).

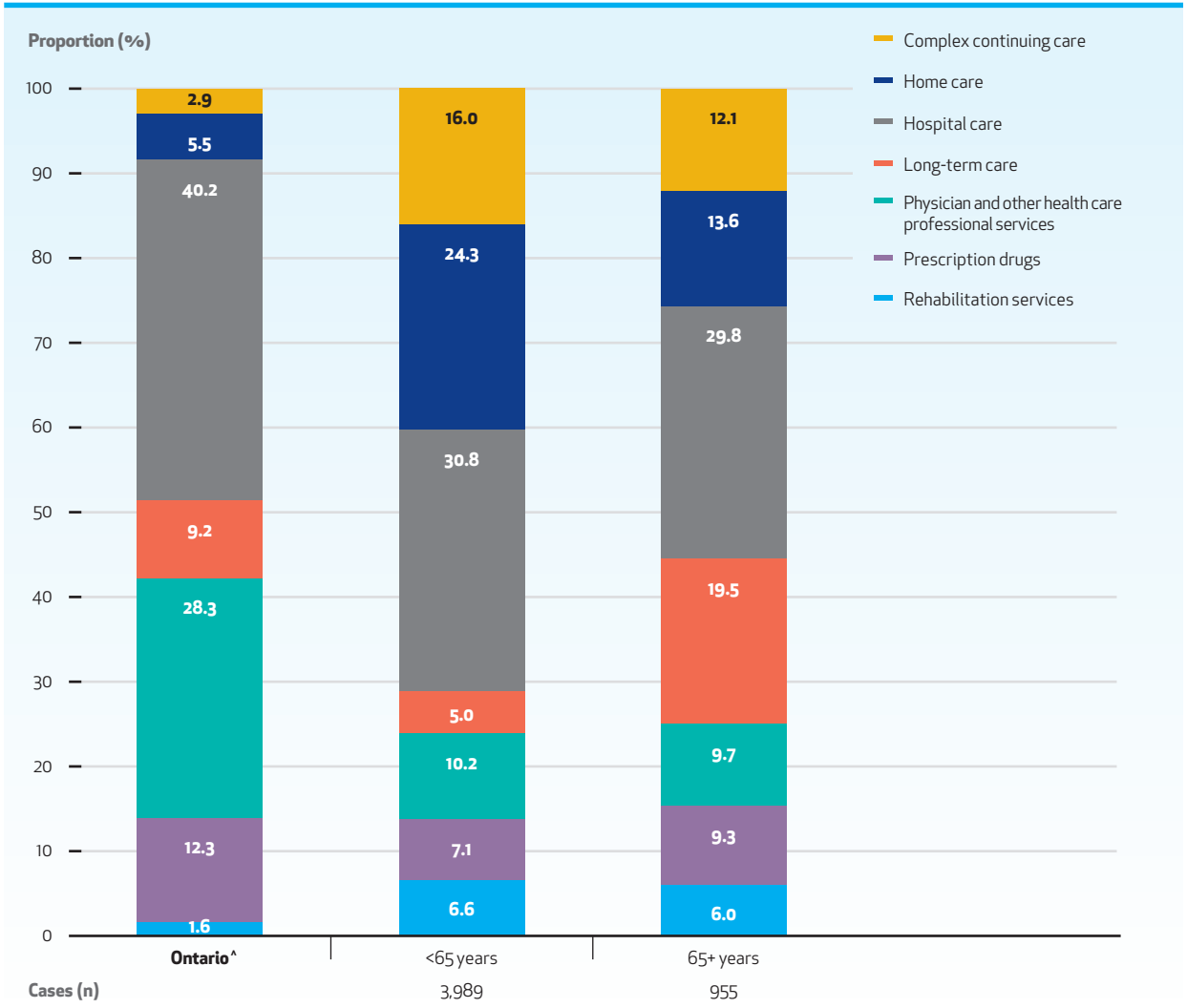


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 13.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with spinal cord injury, by age group and type of health care service

Key Findings

- Among prevalent cases with spinal cord injury aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (30.8%), home care (24.3%) and complex continuing care (16.0%).
- Among prevalent cases with spinal cord injury aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (29.8%), long-term care (19.5%) and home care (13.6%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

"I wish people understood that stroke is difficult. People automatically assume my intelligence is diminished because I speak slowly.

The biggest challenge about being a stroke survivor is learning to speak again. The second time is more challenging."

– Jeff Blanchard

CHAPTER 14

Stroke and Transient Ischemic Attack

Overview

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% of all strokes) and hemorrhagic (15% of all strokes). 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 (e.g., problems with speech, memory and concentration), 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).

"An ounce of prevention is worth a pound of cure." 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.

Data Quality

Stroke and transient ischemic attack were assessed using health administrative data for the entire population of Ontario. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with stroke and/or transient ischemic attack were determined.

When looking at the results for stroke and/or transient ischemic attack, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for stroke and/or transient ischemic attack is considered grade I (the algorithm for Ontario health administrative data has been previously validated, and the algorithm meets generally accepted standards for predictive value and specificity [note: sensitivity can be variable]).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 14.1 Number and proportion of individuals with stroke and/or transient ischemic attack, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 51.4% of the 94,174 Ontarians identified with stroke and/or transient ischemic attack.
- The mean age of a person with stroke and/or transient ischemic attack was 72.6 years; 73.9% of persons with stroke and/or transient ischemic attack were aged 65 years and older.
- Among persons with stroke and/or transient ischemic attack, 15.1% lived in a rural setting.
- Persons with stroke and/or transient ischemic attack were more likely to live in neighbourhoods belonging to the lowest income quintile (22.4%) compared to the highest income quintile (17.7%).

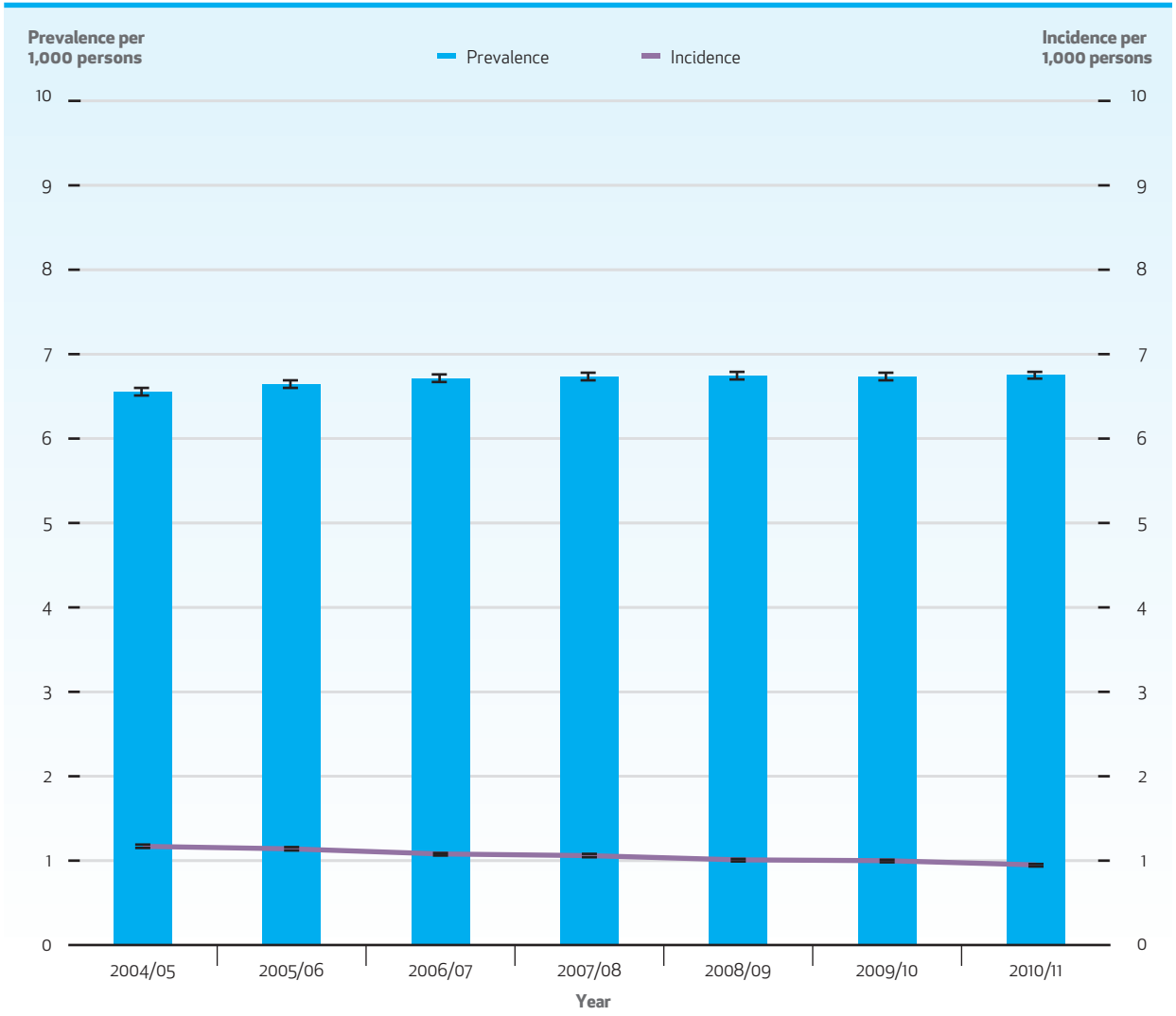
Characteristic	Cohort
Ontario, n	94,174
Sex, n (%)	
Female	45,806 (48.6)
Male	48,368 (51.4)
Age distribution, years	
Mean ± standard deviation	72.6 ± 14.3
Median (interquartile range)	75 (64–83)
Age group, years, n (%)	
0–4	82 (0.1)
5–17	358 (0.4)
18–39	1,717 (1.8)
40–64	22,388 (23.8)
65–74	21,084 (22.4)
75–84	29,324 (31.1)
85+	19,221 (20.4)
Children 0–17	440 (0.5)
Adults 18–64	24,105 (25.6)
Older adults 65+	69,629 (73.9)
Residence, n (%)	
Rural	14,199 (15.1)
Urban	79,941 (84.9)
Income quintile, n (%)	
1 (lowest)	21,051 (22.4)
2	19,764 (21.0)
3	18,394 (19.5)
4	17,836 (18.9)
5 (highest)	16,659 (17.7)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 14.2 Age- and sex-adjusted* prevalence and incidence of stroke and/or transient ischemic attack per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with stroke and/or transient ischemic attack increased from 77,752 to 94,174.
- The age- and sex-adjusted prevalence of stroke and/or transient ischemic attack per 1,000 persons increased slightly from 6.6 in 2004/05 to 6.8 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified stroke and/or transient ischemic attack decreased from 13,345 to 12,749.
- The age- and sex-adjusted incidence of stroke and/or transient ischemic attack per 1,000 persons decreased from 1.2 in 2004/05 to 1.0 in 2010/11.



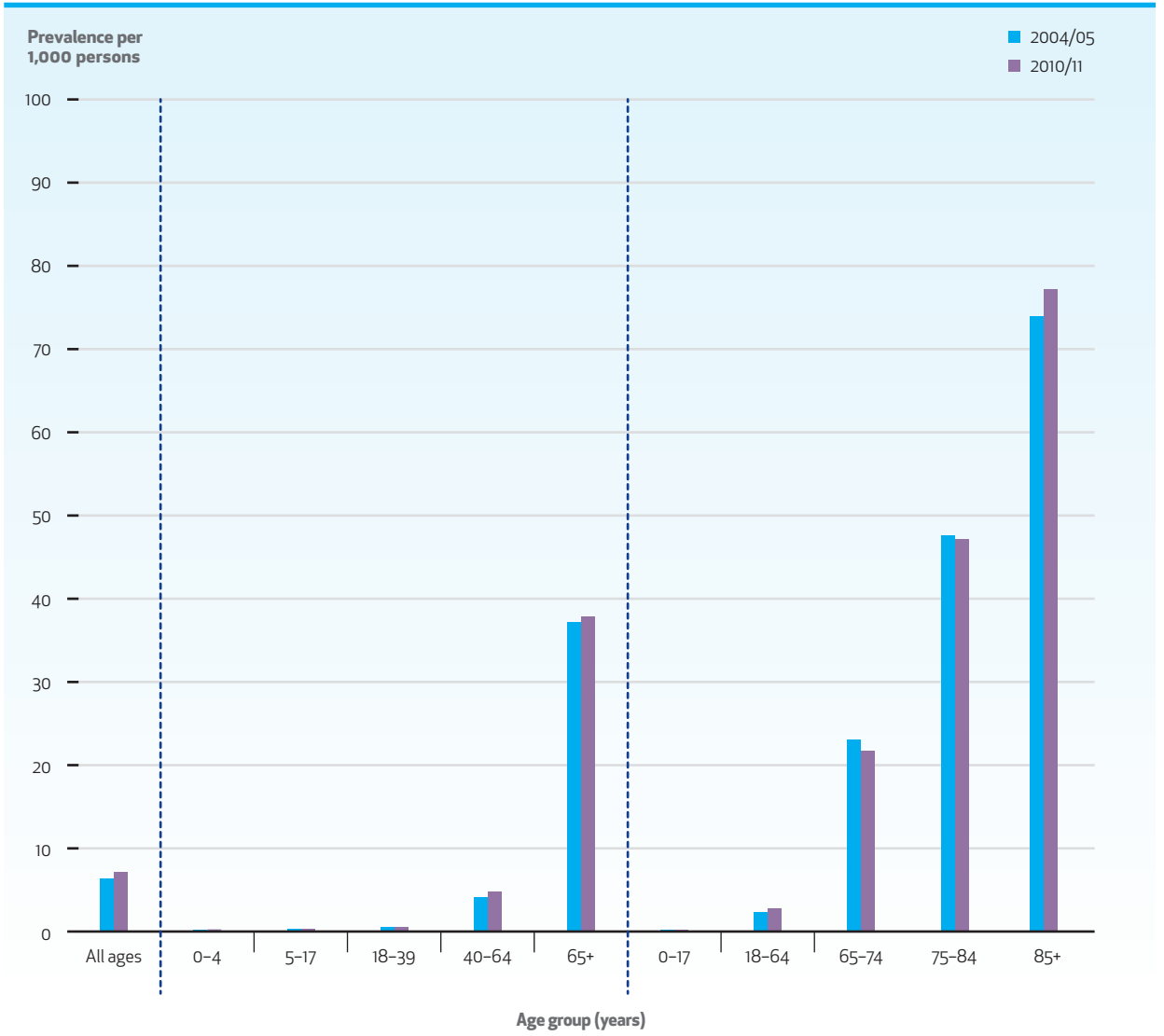
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 14.3A Crude prevalence of stroke and/or transient ischemic attack per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of stroke and/or transient ischemic attack for persons aged 0–17 years, 18–64 years and 65 years and older was 0.2, 2.8 and 37.8 per 1,000, respectively.

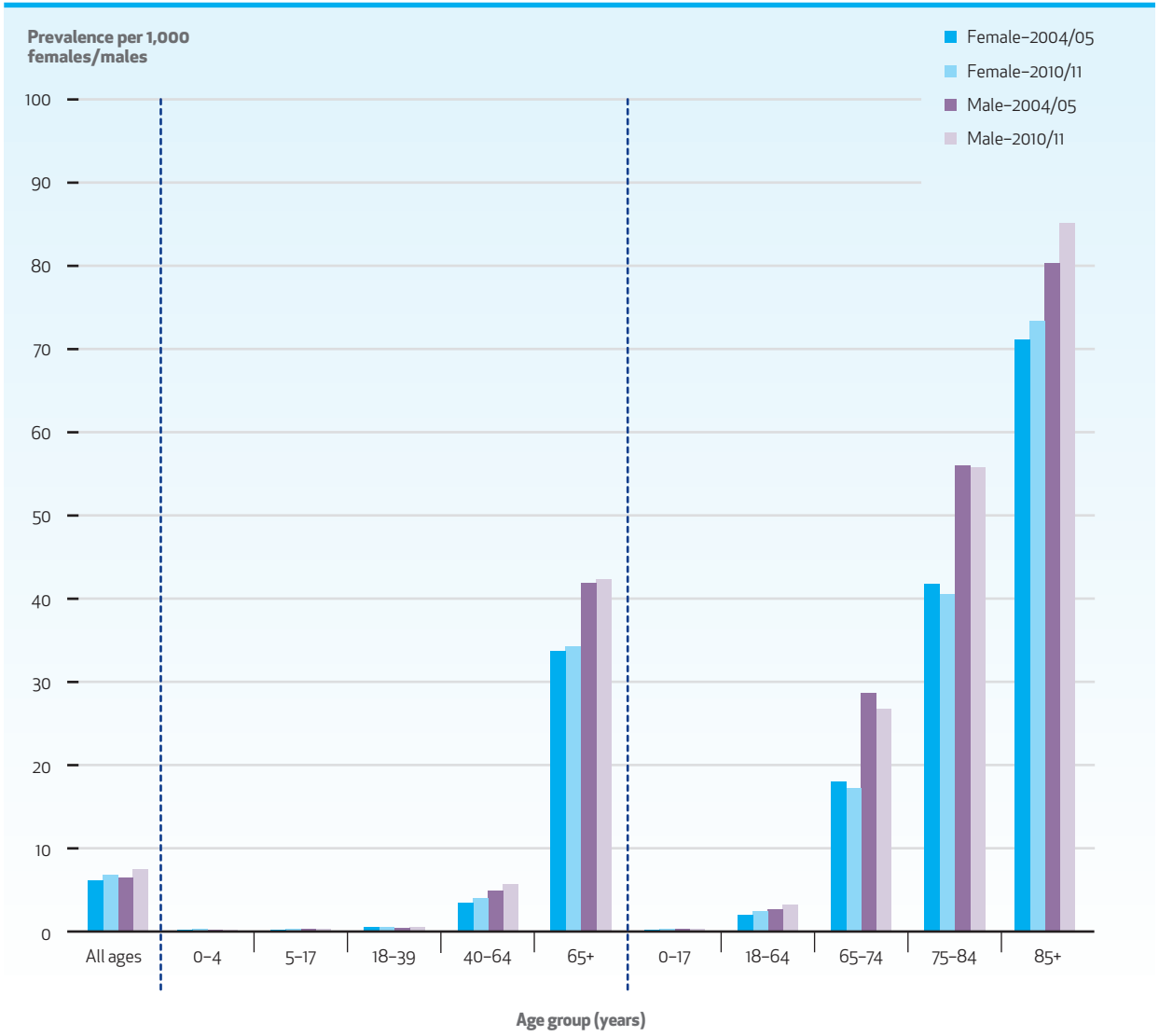


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 14.3B Crude prevalence of stroke and/or transient ischemic attack per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of stroke and/or transient ischemic attack was greater for males (7.4 per 1,000) than females (6.8 per 1,000).
- Among females, the crude prevalence of stroke and/or transient ischemic attack per 1,000 increased from 6.1 to 6.8 between 2004/05 and 2010/11.
- Among males, the crude prevalence of stroke and/or transient ischemic attack per 1,000 increased from 6.5 to 7.4 between 2004/05 and 2010/11.

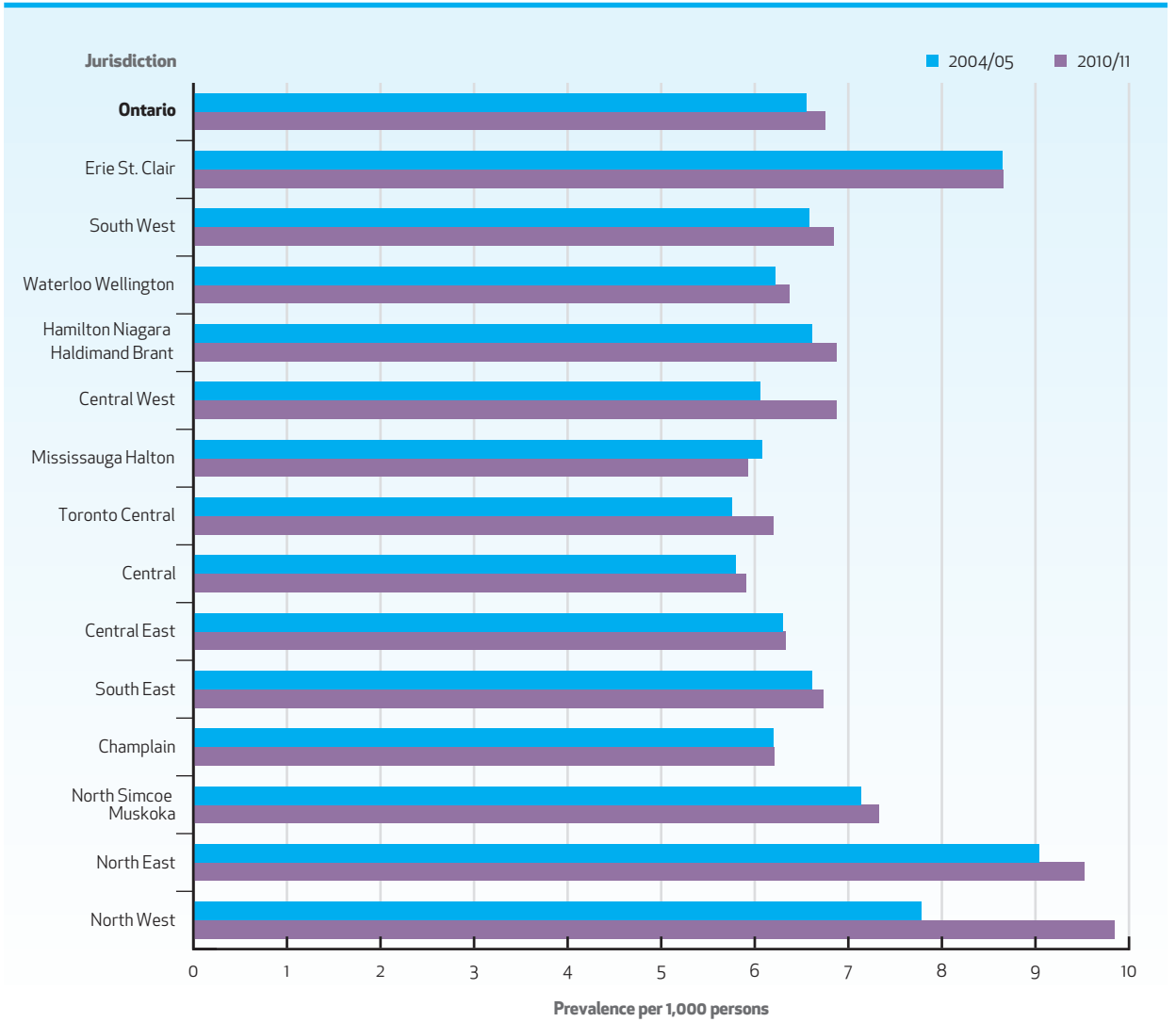


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 14.4 Age- and sex-adjusted* prevalence of stroke and/or transient ischemic attack per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of stroke and/or transient ischemic attack increased across all Local Health Integration Networks (LHINs) with the exception of the Erie St. Clair and Mississauga Halton LHINs.
- Across the LHINs, there was a 1.7-fold variation in the age- and sex-adjusted prevalence of stroke and/or transient ischemic attack in 2010/11, which was greater than the 1.6-fold variation in 2004/05.
- In 2010/11, the North West, North East and Erie St. Clair LHINs had the three highest age- and sex-adjusted prevalence estimates of stroke and/or transient ischemic attack (9.8, 9.5 and 8.7 per 1,000 persons, respectively).
- In 2010/11, the Central, Mississauga Halton and Toronto Central LHINs had the three lowest age- and sex-adjusted prevalence estimates of stroke and/or transient ischemic attack (5.9, 5.9 and 6.2 per 1,000 persons, respectively).



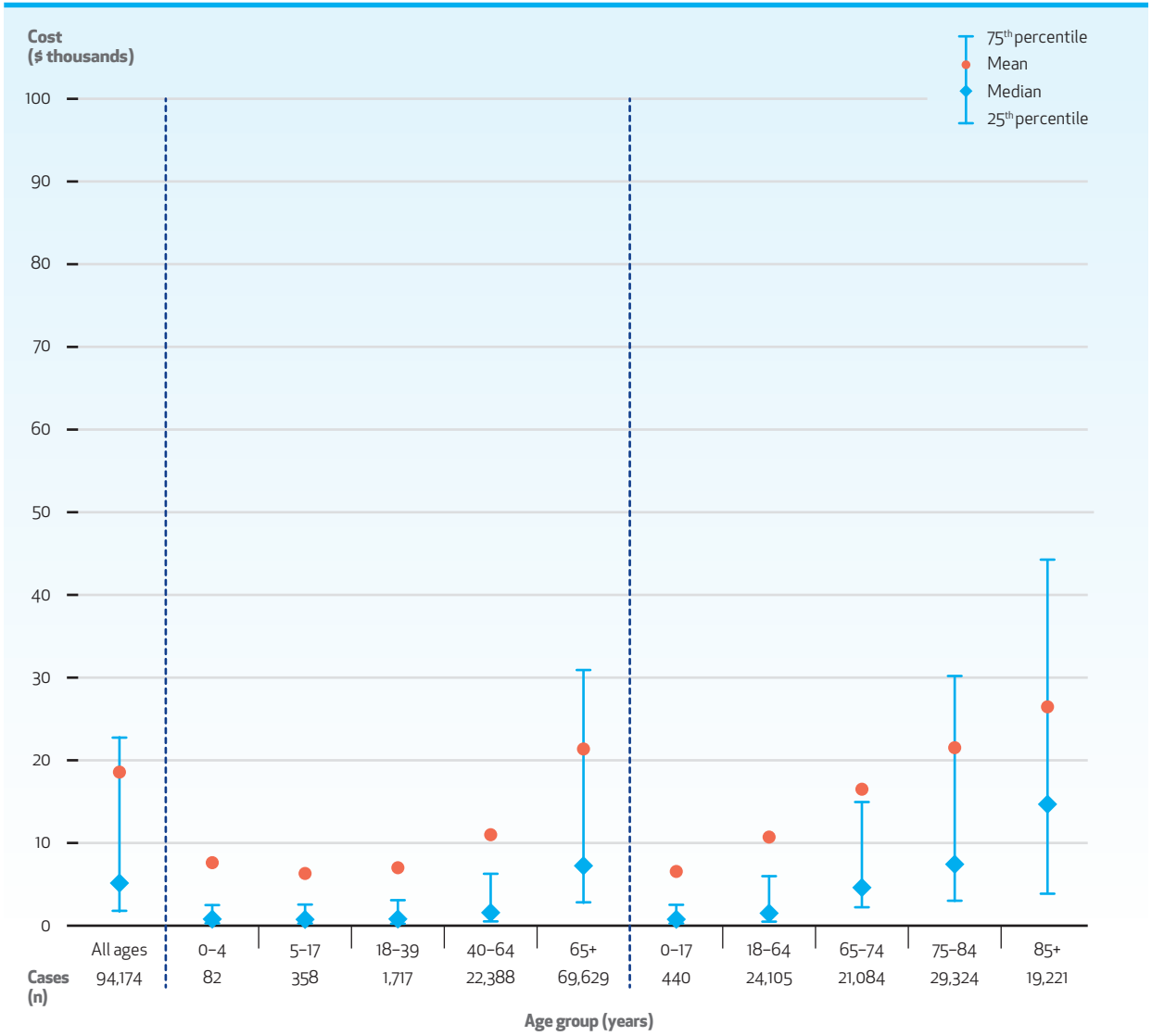
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 14.5A Distribution of costs* associated with one year† of health system use for prevalent cases with stroke and/or transient ischemic attack, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with stroke and/or transient ischemic attack were $18,572 and $5,151, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $1,798 to $22,743.
- Among prevalent cases with stroke and/or transient ischemic attack, the median cost associated with one year of health system use generally increased with age. The age group with the highest median cost associated with one year of health system use was persons aged 85 years and older ($14,688).

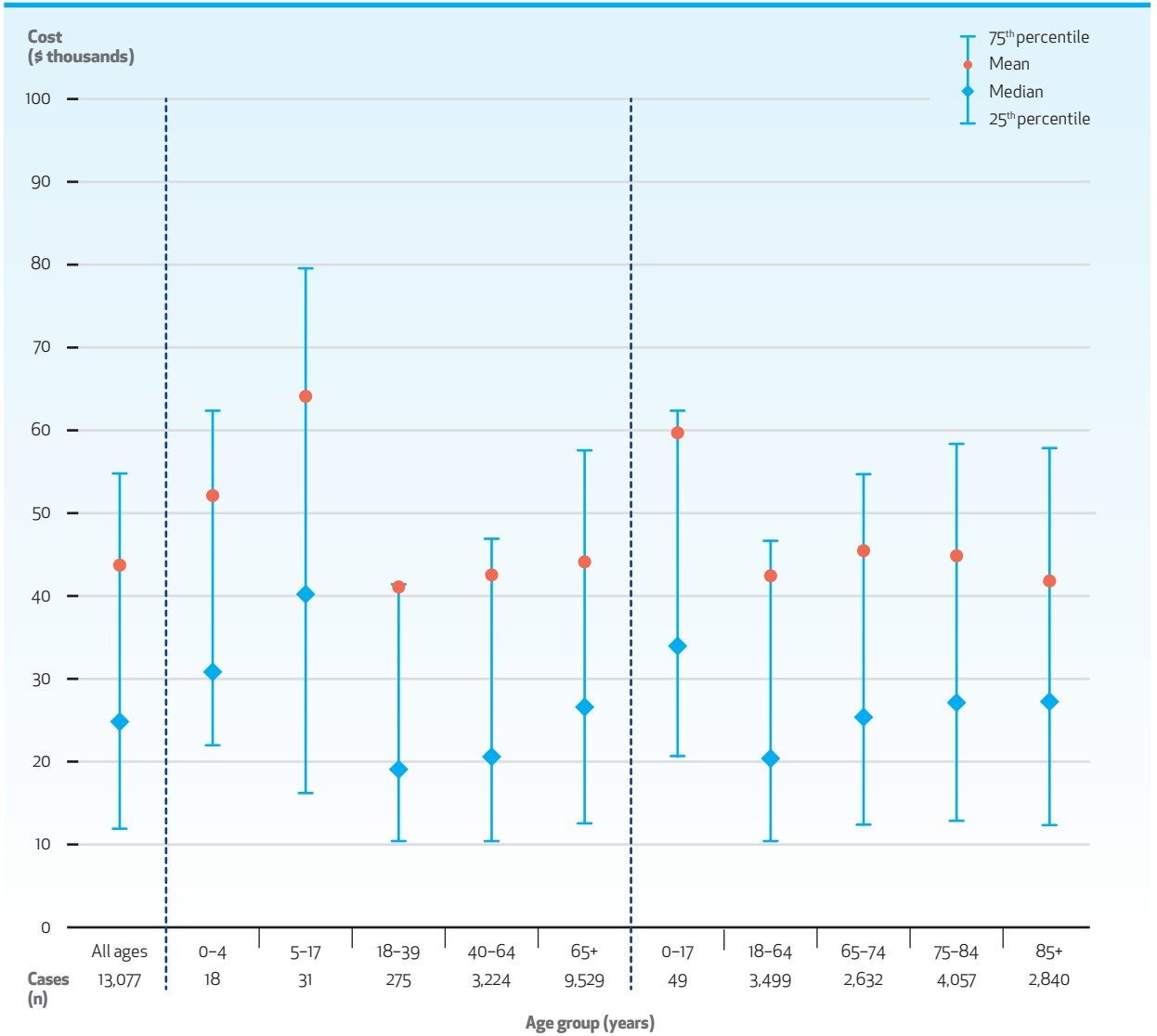


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 14.5B Distribution of costs* associated with one year† of health system use for prevalent cases with stroke and/or transient ischemic attack, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with stroke and/or transient ischemic attack were $43,711 and $24,811, respectively. The interquartile range of costs extended from $11,906 to $54,789.
- Among incident cases with a stroke and/or transient ischemic attack, the median cost associated with one year of health system use was higher in younger age groups compared to older age groups. The highest median cost associated with one year of health use was found in persons aged 5–17 years ($40,204).

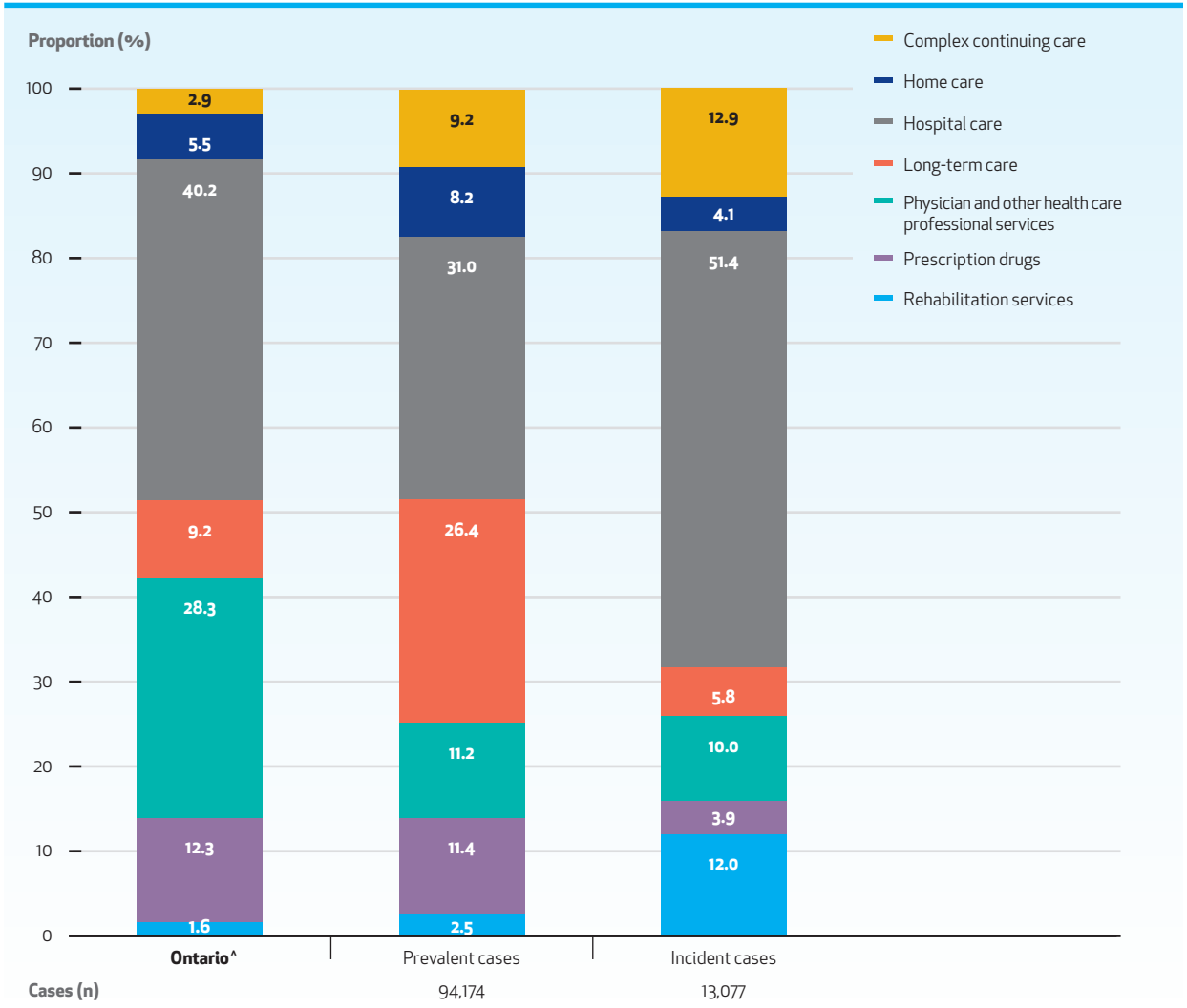


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 14.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with stroke and/or transient ischemic attack, by type of health care service

Key Findings

- Among prevalent cases with stroke and/or transient ischemic attack, the majority of the costs associated with health system use were attributable to hospital care (31.0%), long-term care (26.4%), and prescription drugs (11.4%).
- Among incident cases with a stroke and/or transient ischemic attack, the majority of the costs associated with health system use were attributable to hospital care (51.4%), complex continuing care (12.9%) and rehabilitation services (12.0%).

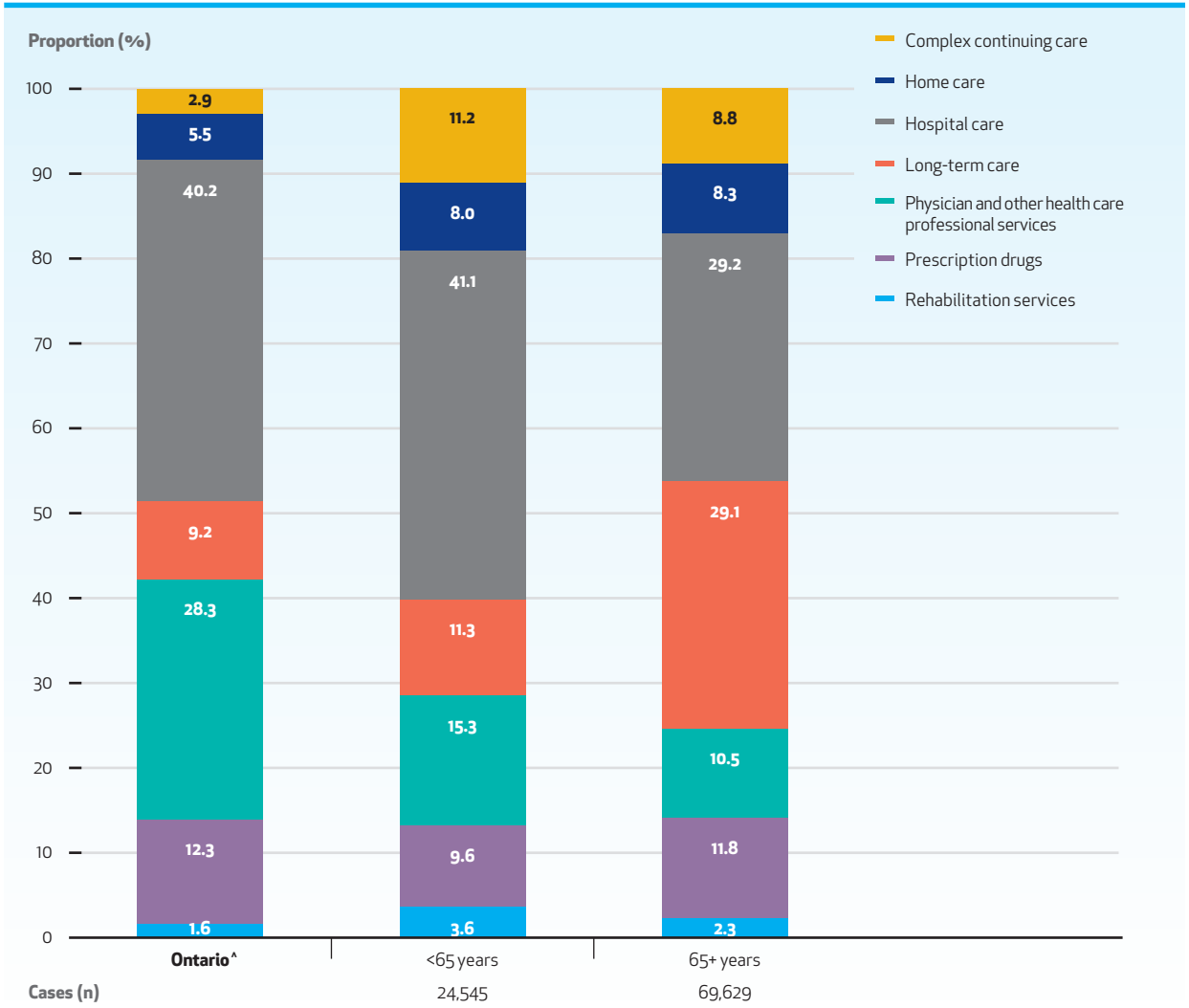


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 14.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with stroke and/or transient ischemic attack, by age group and type of health care service

Key Findings

- Among prevalent cases with stroke and/or transient ischemic attack aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (41.1%), physician and other health care professional services (15.3%), and long-term care (11.3%).
- Among prevalent cases with stroke and/or transient ischemic attack aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (29.2%), long-term care (29.1%) and prescription drugs (11.8%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

CHAPTER 15

Traumatic Brain Injury

"I wish people understood that a brain injury is a real physical and emotional impairment that affects my life in profound ways.

The biggest challenge about living with a brain injury has been the fact that my life has been totally turned inside out. Nothing is the same anymore. I no longer work. My friends are not the same. I am not the same person I was, and most importantly, my family dynamics are not the same. I am starting life all over again as a new person."

– A client of the Ontario Brain Injury Association

Overview

Traumatic brain injury 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 (including 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.

Data Quality

Traumatic brain injury was assessed using health administrative data for the entire Ontario population. Descriptive characteristics, prevalence, incidence and the costs associated with health system use of persons with traumatic brain injury were determined.

When looking at the results for traumatic brain injury, the validity and performance of the algorithm used to detect individuals should always be considered. **Exhibit 2.1** grades the evidence supporting each disease case definition from validated (grade I) to clinical input (grade III). The algorithm for traumatic brain injury is considered grade II (the algorithm for Ontario health administrative data has not been validated but has been used in previous Canadian research studies and/or is accepted in the research community).

Further details regarding the methodology of the presented findings can be found in **Chapter 2**.

EXHIBIT 15.1 Number and proportion of persons with traumatic brain injury, by sex, age group, rural or urban residence, and neighbourhood income quintile, in Ontario, April 1, 2010

Key Findings

- On April 1, 2010, males accounted for 62.0% of the 227,605 Ontarians identified with traumatic brain injury.
- The mean age of a person with traumatic brain injury was 33.9 years.
- Among persons with traumatic brain injury, 24.5% were aged 5–17 years and 40.3% were aged 18–39 years.
- Among persons with traumatic brain injury, 16.3% lived in a rural setting.
- Persons with traumatic brain injury were evenly distributed across neighbourhood income quintiles, with 20.6% and 19.7% living in neighbourhoods of the lowest and highest incomes, respectively.

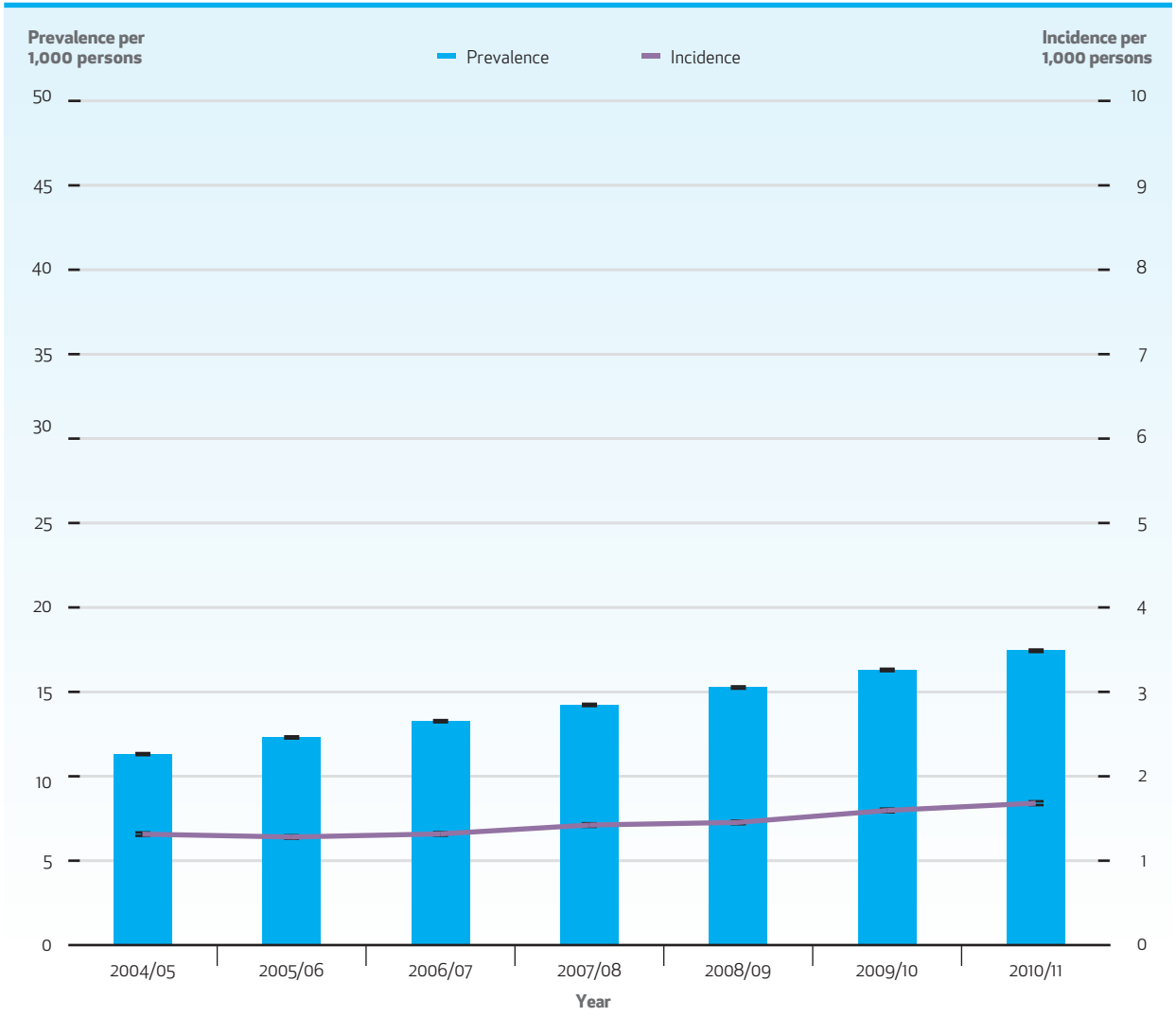
Characteristic	Cohort
Ontario, n	227,605
Sex, n (%)	
Female	86,466 (38.0)
Male	141,139 (62.0)
Age distribution, years	
Mean ± standard deviation	33.9 ± 21.3
Median (interquartile range)	27 (17–48)
Age group, years, n (%)	
0–4	2,342 (1.0)
5–17	55,761 (24.5)
18–39	91,789 (40.3)
40–64	52,553 (23.1)
65–74	10,720 (4.7)
75–84	8,972 (3.9)
85+	5,468 (2.4)
Children 0–17	58,103 (25.5)
Adults 18–64	144,342 (63.4)
Older adults 65+	25,160 (11.1)
Residence, n (%)	
Rural	37,009 (16.3)
Urban	190,508 (83.7)
Income quintile, n (%)	
1 (lowest)	46,919 (20.6)
2	44,319 (19.5)
3	43,945 (19.3)
4	46,421 (20.4)
5 (highest)	44,732 (19.7)

Note: Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 15.2 Age- and sex-adjusted* prevalence and incidence of traumatic brain injury per 1,000 persons, in Ontario, 2004/05 to 2010/11

Key Findings

- Between 2004/05 and 2010/11, the number of Ontarians with traumatic brain injury increased from 142,140 to 227,605.
- The age- and sex-adjusted prevalence of traumatic brain injury per 1,000 persons increased from 11.3 in 2004/05 to 17.4 in 2010/11.
- Between 2004/05 and 2010/11, the number of Ontarians with newly identified traumatic brain injury increased from 16,219 to 21,653.
- The age- and sex-adjusted incidence of traumatic brain injury per 1,000 persons increased from 1.3 in 2004/05 to 1.7 in 2010/11.



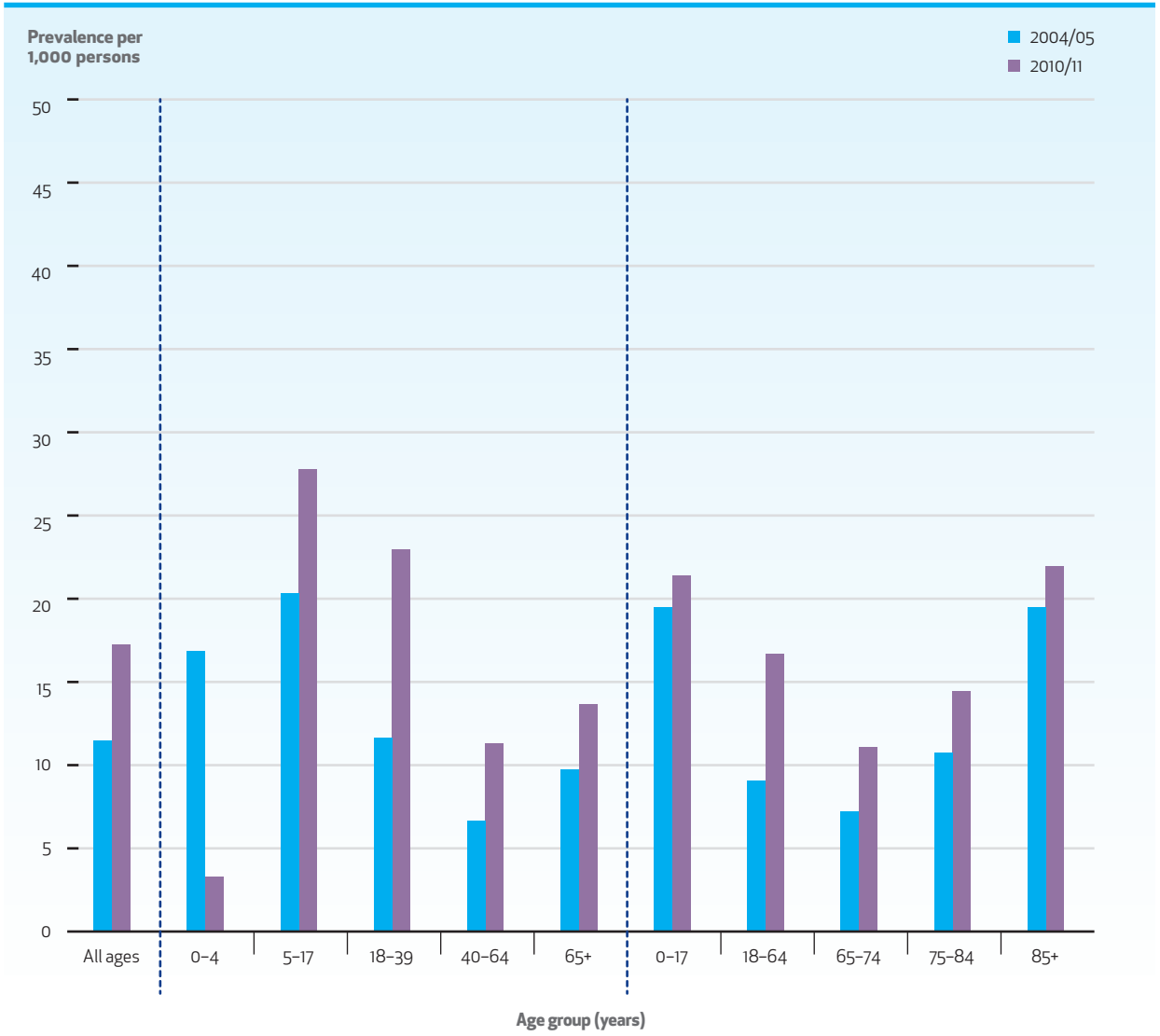
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.
Error bars indicate 95% confidence intervals.

EXHIBIT 15.3A Crude prevalence of traumatic brain injury per 1,000 persons, by age group, in Ontario, 2004/05 and 2010/11

Key Finding

- In 2010/11, the crude prevalence of traumatic brain injury for individuals aged 0–17 years, 18–64 years and 65 years and older was 21.4, 16.7 and 13.7 per 1,000, respectively.

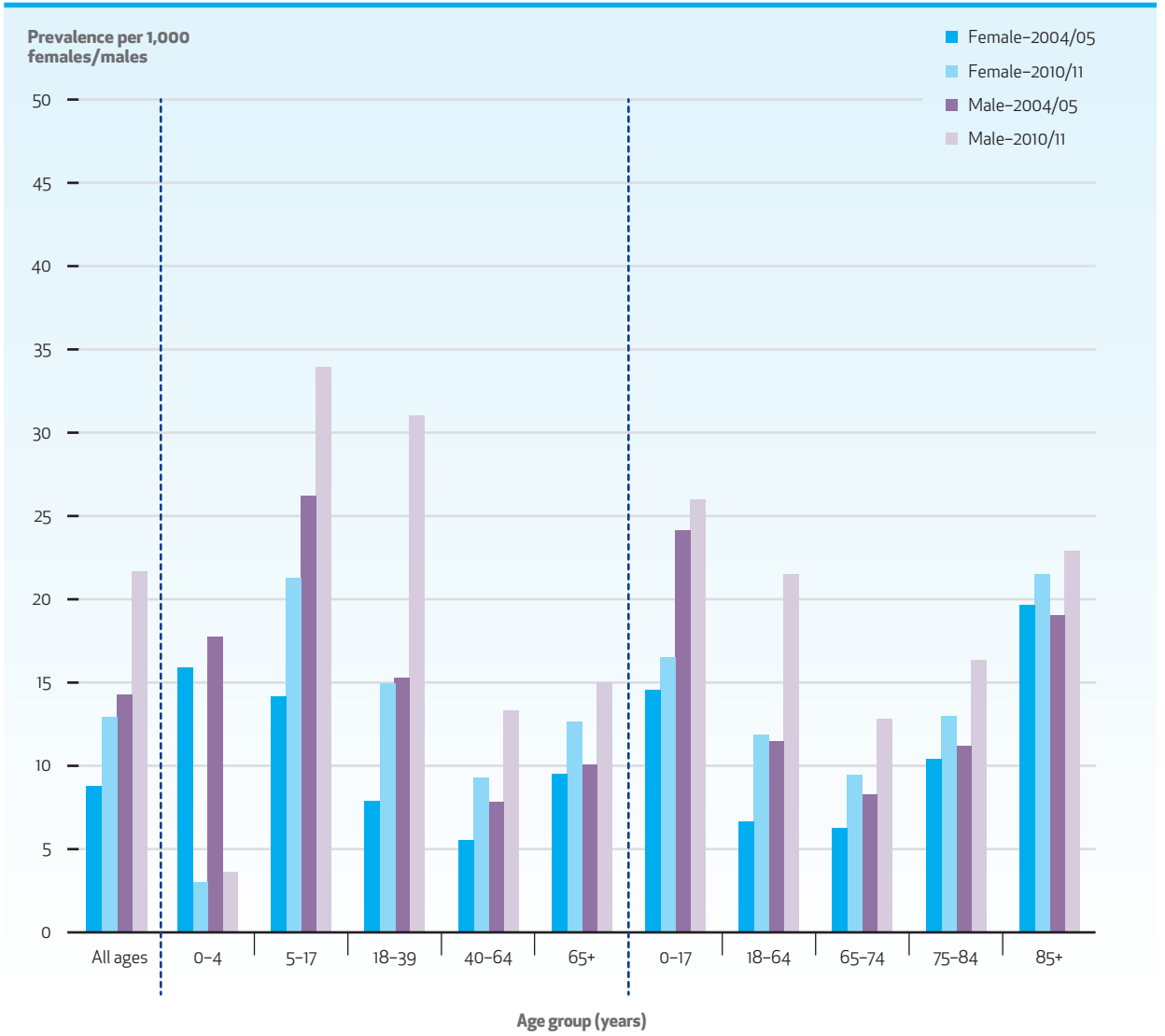


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 15.3B Crude prevalence of traumatic brain injury per 1,000 females and 1,000 males, by age group, in Ontario, 2004/05 and 2010/11

Key Findings

- In 2010/11, the crude prevalence of traumatic brain injury was greater for males (21.7 per 1,000) than females (12.9 per 1,000).
- Between 2004/05 and 2010/11, the crude prevalence of traumatic brain injury per 1,000 females rose from 8.8 to 12.9.
- Comparing 2010/11 to 2004/05, the crude prevalence of traumatic brain injury per 1,000 males rose from 14.2 to 21.7.

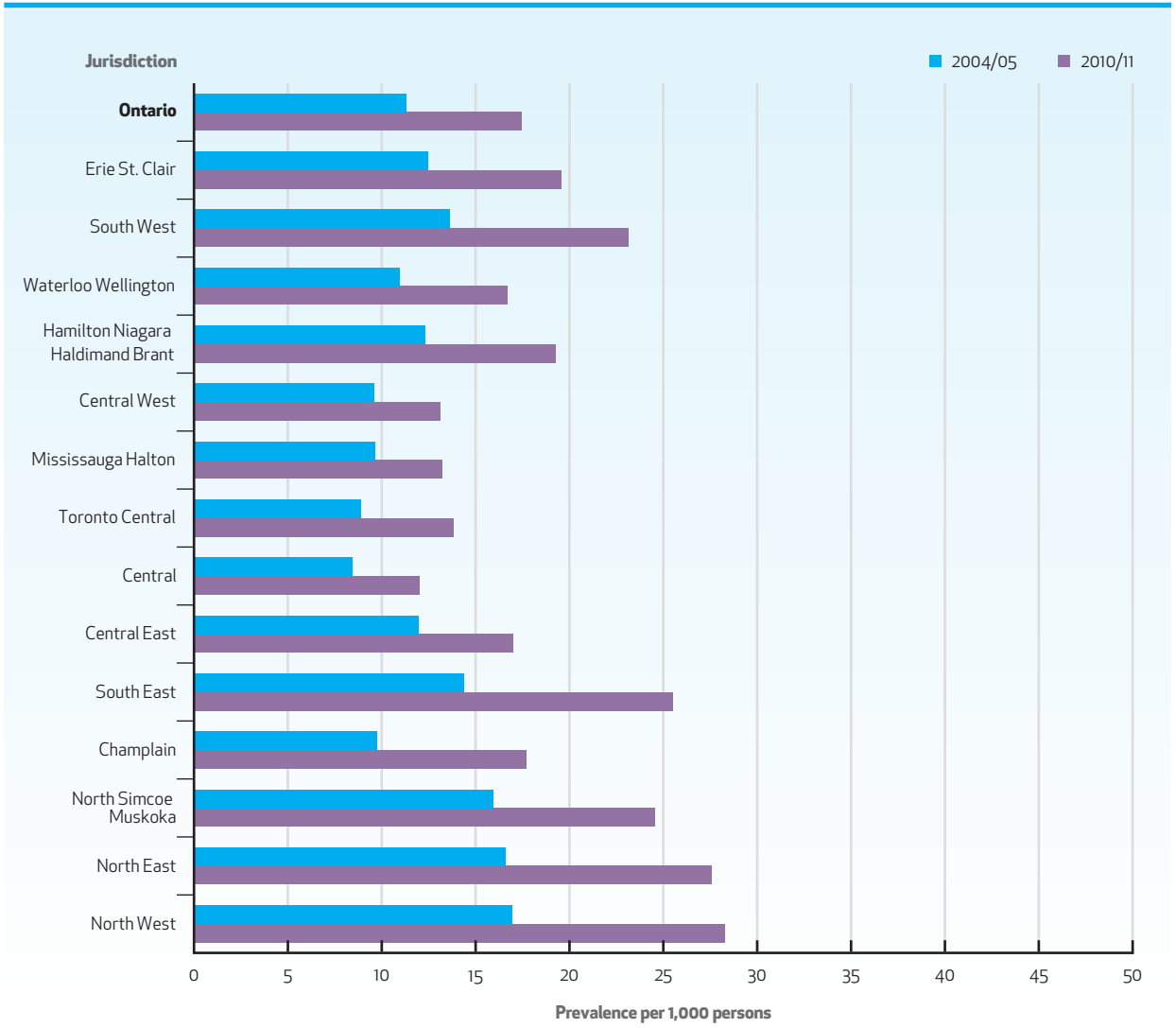


Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

EXHIBIT 15.4 Age- and sex-adjusted* prevalence of traumatic brain injury per 1,000 persons, in Ontario and by Local Health Integration Network, 2004/05 and 2010/11

Key Findings

- From 2004/05 to 2010/11, the age- and sex-adjusted prevalence of traumatic brain injury increased across all Local Health Integration Networks (LHINs).
- Across the LHINs, there was a 2.4-fold variation in the age- and sex-adjusted prevalence of traumatic brain injury in 2010/11, which was greater than the 2-fold variation in 2004/05.
- In 2010/11, the age- and sex-adjusted prevalence of traumatic brain injury was 28.3, 27.6 and 25.5 per 1,000 persons for the North West, North East and South East LHINs, respectively – the highest among the 14 LHINs.
- In 2010/11, the age- and sex-adjusted prevalence of traumatic brain injury was lowest for the Central, Central West and Mississauga Halton LHINs (12.0, 13.1 and 13.2 per 1,000 persons, respectively).



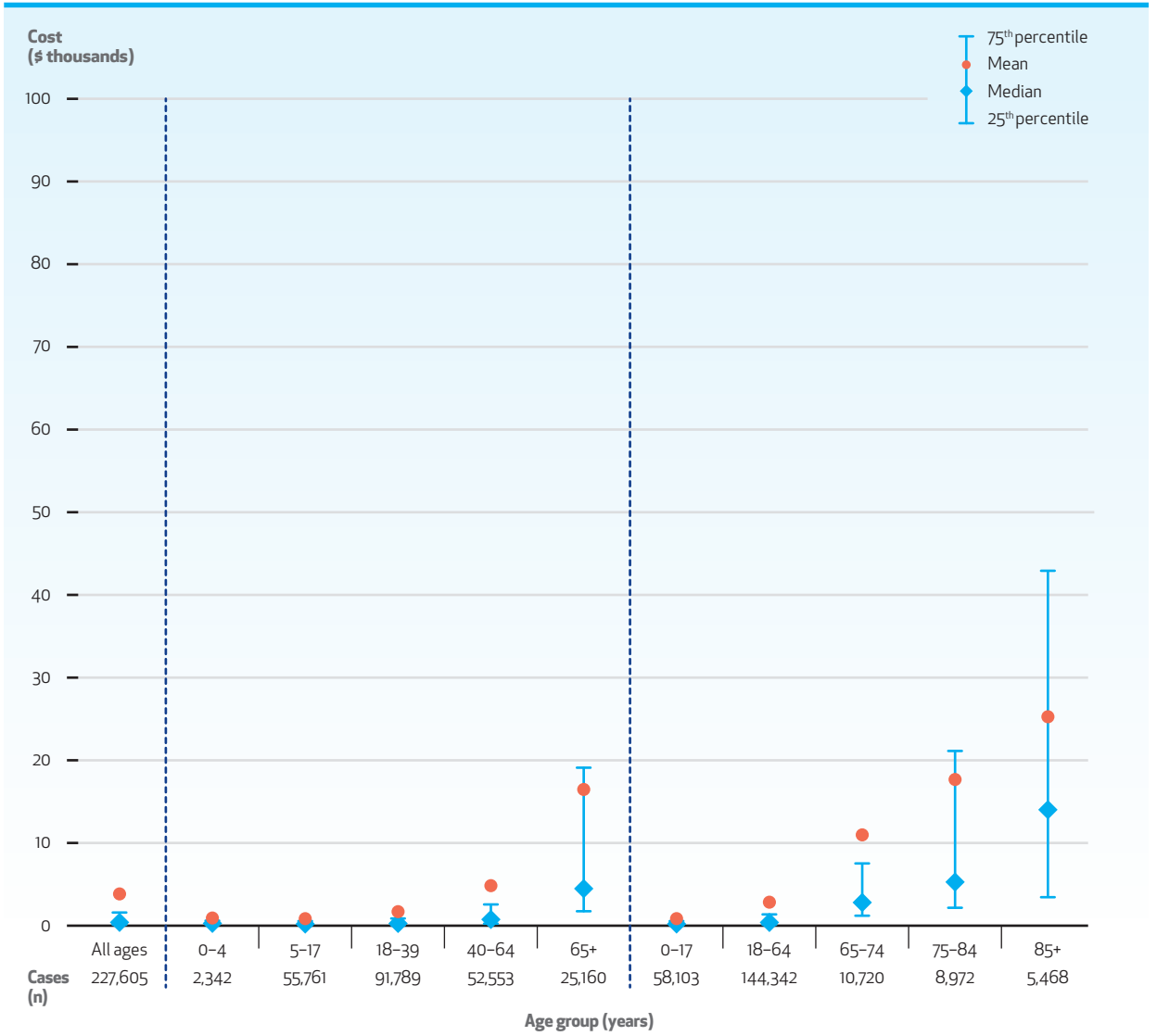
Note: In general, the estimates of prevalence and incidence based on health administrative data should be viewed conservatively. Consult Exhibit 2.1 for the evidence grade for the algorithm used to identify cases for this brain disorder.

*Adjusted to the 2006 Census population.

EXHIBIT 15.5A Distribution of costs* associated with one year† of health system use for prevalent cases with traumatic brain injury, by age group, in Ontario, 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among prevalent cases with traumatic brain injury were $3,854 and $415, respectively. The interquartile range of costs (from the 25th to 75th percentiles of the cost distribution across individuals) extended from $115 to $1,591.
- Among prevalent cases with traumatic brain injury, the median cost associated with one year of health system use generally increased with age, from $296 among persons aged 0–4 years to $14,033 among persons aged 85 years and older.

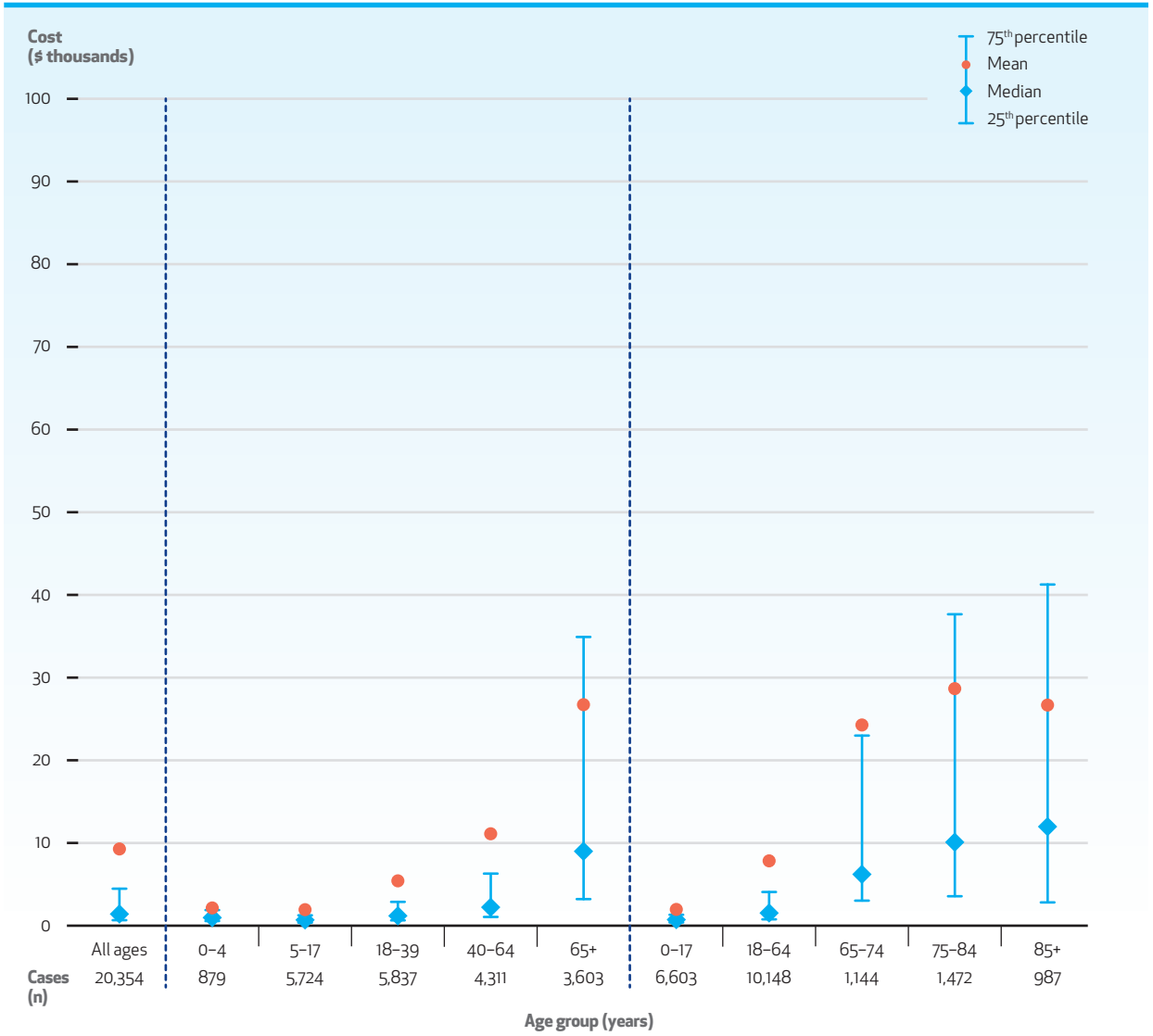


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010.

EXHIBIT 15.5B Distribution of costs* associated with one year† of health system use for incident cases with traumatic brain injury, by age group, in Ontario, 2009/10 to 2010/11

Key Findings

- The mean and median costs associated with one year of health system use among incident cases with traumatic brain injury were $9,277 and $1,408, respectively. The interquartile range of costs extended from $664 to $4,473.
- Among incident cases with traumatic brain injury, the median cost associated with one year of health system use generally increased across age groups from $970 among persons aged 0–4 years to $11,977 among persons aged 85 years and older.

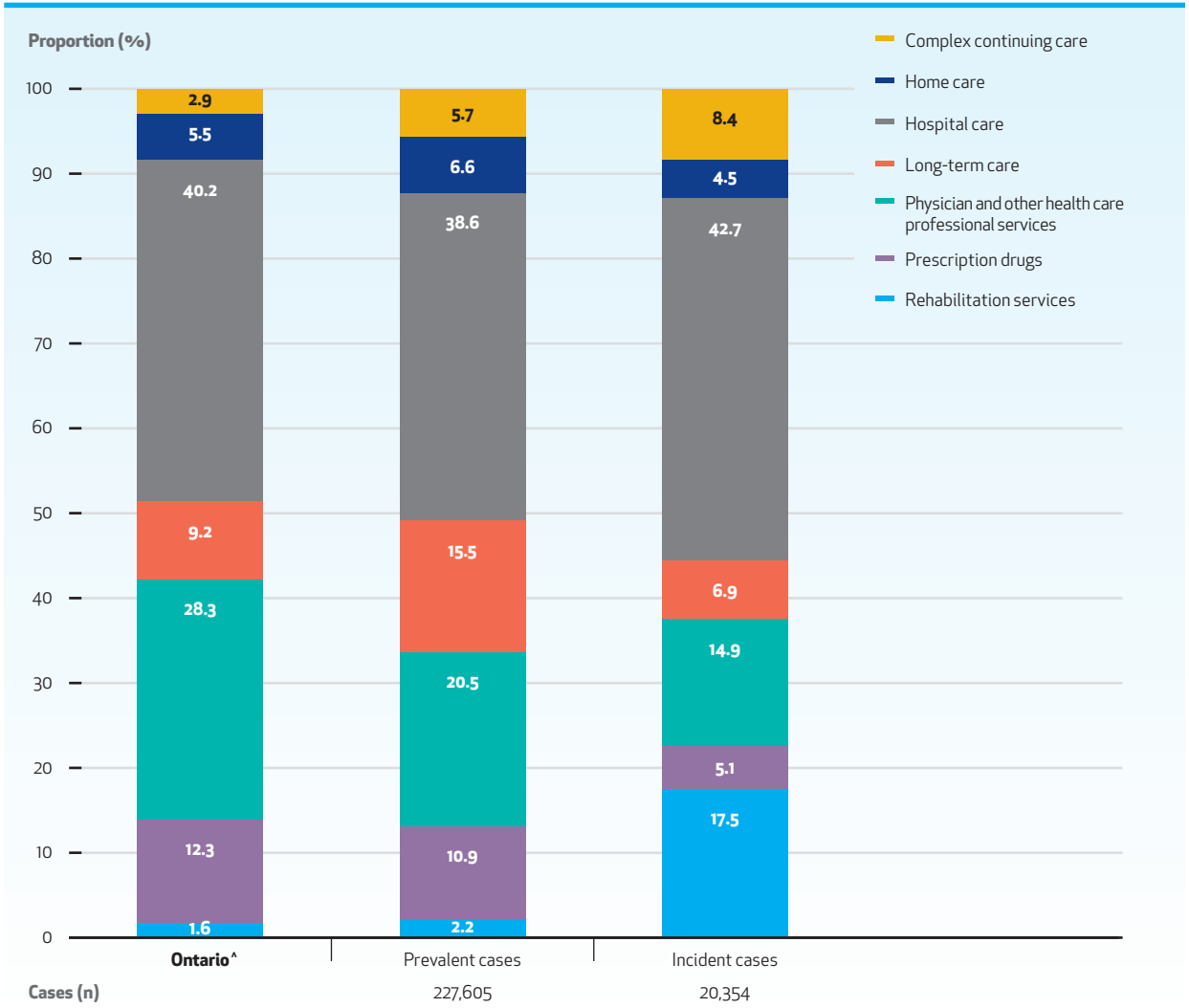


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.

EXHIBIT 15.6A Proportion of costs* associated with one year† of health system use in Ontario and for prevalent and incident cases with traumatic brain injury, by type of health care service

Key Findings

- Among prevalent cases with traumatic brain injury, the majority of the costs associated with health system use were attributable to hospital care (38.6%), physician and other health care professional services (20.5%) and long-term care (15.5%).
- Among incident cases with traumatic brain injury, the majority of the costs associated with health system use were attributable to hospital care (42.7%), rehabilitation services (17.5%) and physician and other health care professional services (14.9%).

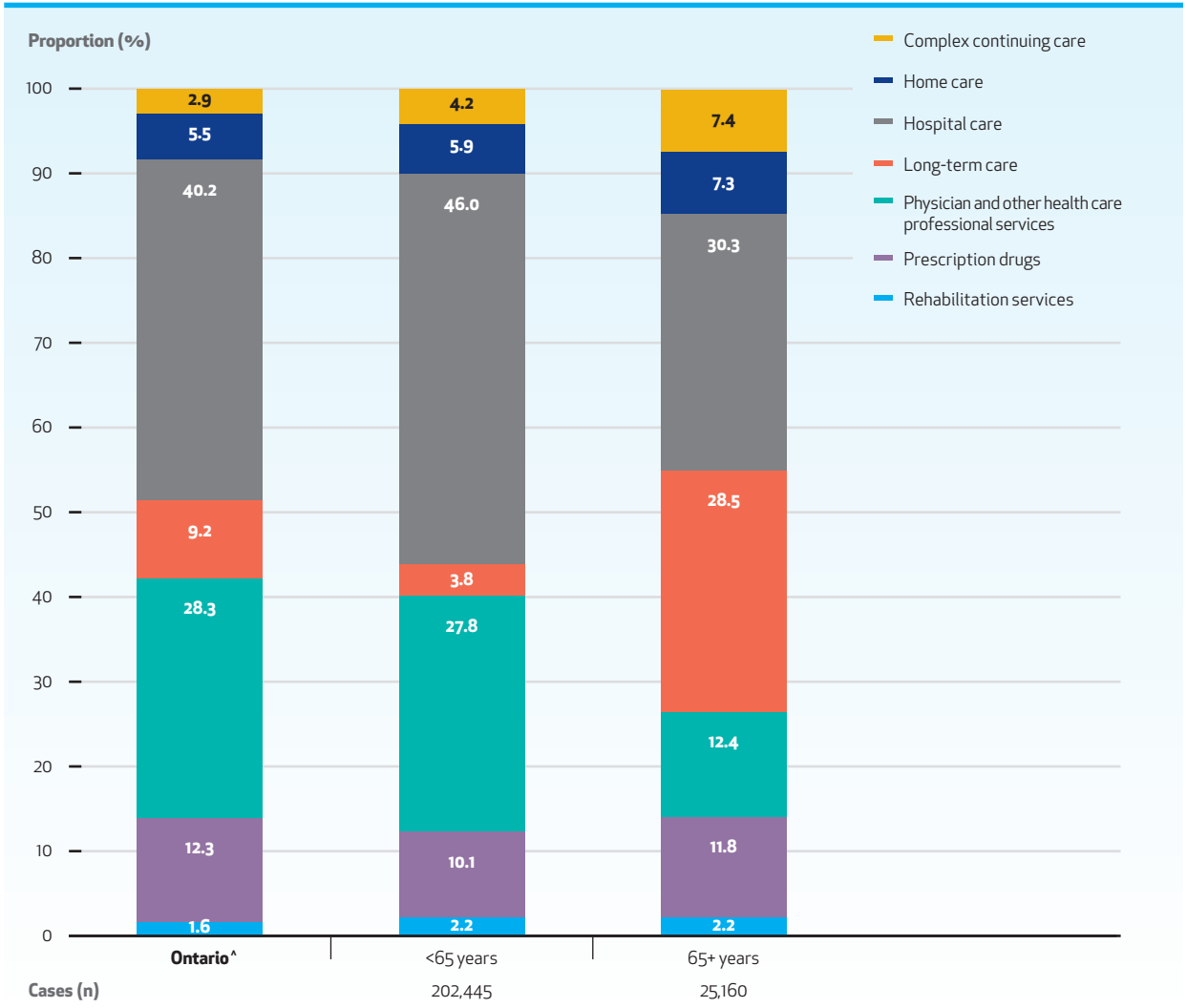


*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

EXHIBIT 15.6B Proportion of costs* associated with one year† of health system use in Ontario and for prevalent cases with traumatic brain injury, by age group and type of health care service

Key Findings

- Among prevalent cases with traumatic brain injury aged younger than 65 years, the majority of the costs associated with health system use were attributable to hospital care (46.0%), physician and other health care professional services (27.8%) and prescription drugs (10.1%).
- Among prevalent cases with traumatic brain injury aged 65 years and older, the majority of the costs associated with health system use were attributable to hospital care (30.3%), long-term care (28.5%) and physician and other health care professional services (12.4%).



*Costs consisted of all health service encounters of a person, not just encounters specific to this brain disorder. Only direct health system costs paid by the Ontario Ministry of Health and Long-Term Care were captured. The health system costs consist of complex continuing care, home care, hospital care, long-term care (for persons aged 18 years and older), physician and other health care professional services, prescription drugs (for select groups younger than 64 years and for all persons 65 years and older) and rehabilitation services.
†Costs for prevalent cases were measured for a one-year period from April 1, 2010. Costs for incident cases were measured for a one-year period from the date (between April 1, 2009 and March 31, 2010) that the individual became a case.
^Ontario refers to everyone with a valid Ontario health card, including those who may not be currently residing in Ontario.

Concluding Considerations

Summary

Individual brain disorders vary by their cause(s), symptoms, severity and occurrence during the life course, making each one unique. All brain disorders, however, share some commonalities: they pose long-term challenges to a person's health and quality of life and have a significant impact on other people, including care providers and family and friends who double as support group and caregivers.

To ensure appropriate care and supports for those affected by brain disorders, a current and comprehensive profile of the disorders, as well as an understanding of their collective importance, is essential. This report provides a current profile of the number of individuals affected by brain disorders, as well as changes in those numbers over time, as an important first step in understanding the overall impact of these conditions on the population.

This report builds on prior studies[4-15] and presents the results in a consistent and standardized manner to illustrate the collective scale and impact of brain disorders in the province. This report offers evidence based on health administrative data to inform priority-setting, planning and decision-making in the Ontario health system and is a starting point for subsequent research capturing the broader scope and impact of brain disorders.

Patterns Observed Across Brain Disorders

The 13 brain disorders featured in this report are benign brain tumour, primary malignant brain tumour, cerebral palsy, dementia (including Alzheimer's disease), epilepsy, motor neuron disease, multiple sclerosis, parkinsonism (including Parkinson's disease), schizophrenia, spina bifida, spinal cord injury, stroke and/or transient ischemic attack, and traumatic brain injury. While an in-depth discussion of each of these brain disorders is beyond the scope of this report, several themes are worth noting.

Patterns in Demographics

The demographic characteristics of each brain disorder population serve as a reminder of the distinctiveness of each condition. The size of the population affected ranged by orders of magnitude, from thousands of individuals in Ontario (benign brain tumour, primary malignant brain tumour, motor neuron disease, spina bifida and spinal cord injury) to hundreds of thousands of individuals (dementia, schizophrenia, stroke and/or transient ischemic attack, and traumatic brain injury). For some brain disorders (cerebral palsy and spina bifida), persons affected were younger, while other conditions (parkinsonism and dementia) were predominant in older persons. These age distributions reinforce the impact of brain disorders across the life course. Sex differences varied by condition with benign brain tumour, dementia (including Alzheimer's disease), multiple sclerosis and spina bifida being most common in women; primary malignant brain tumour, cerebral palsy, epilepsy, motor neuron disease, parkinsonism (including Parkinson's disease), schizophrenia, spinal cord injury, stroke and/or transient ischemic attack, and traumatic brain injury were most common in men. Specific age and sex combinations were also common (older women with dementia, younger men with schizophrenia). Within each brain disorder population, the proportion of individuals who lived in a rural setting varied from less than 10% (schizophrenia, 8.7%) to more than 15% (stroke and/or transient ischemic attack, 15.1%; traumatic brain injury, 16.3%; spinal cord injury, 18.7%). While informative, these geographic descriptors must be interpreted cautiously. For example, brain disorders may be more common in some regions due to the geographic distribution of disease risk factors. Alternatively, individuals may have moved to specific areas of the province to access treatment or specialized services.

For selected brain disorders (epilepsy, motor neuron disease, schizophrenia and spina bifida), there was variation in where individuals lived with at least a 5% absolute difference between neighbourhoods of different income levels, while for other disorders, individuals were relatively evenly distributed across neighbourhoods of all income levels. More research is required to determine if there are underlying factors prompting these findings. Broadly, the patterns in demographic characteristics across brain disorders

suggest that while policy solutions to support individuals will not be universal, there are common clusters of conditions and characteristics that are important to consider when targeting resources.

Patterns in Prevalence and Incidence

In general, across brain disorders the prevalence estimates based on health administrative data increased between 2004/05 and 2010/11. Three exceptions were motor neuron disease and cerebral palsy, which exhibited stable prevalence over time, and spina bifida, which showed decreasing prevalence over time. More than half of the brain disorders assessed had either a stable incidence over time (benign brain tumour, epilepsy, motor neuron disease, parkinsonism, schizophrenia, and spinal cord injury) or a decreasing incidence across years (dementia, and stroke and/or transient ischemic attack). After accounting for incidence trends, there are several factors that might contribute to increases in prevalence over time: improved clinical care and management leading to longer survival times, changes in diagnostic criteria and/or coding in administrative data, earlier diagnosis and/or detection from better clinical recognition, diagnostic testing advancements, and earlier screening. Some brain disorders did appear to have an increasing incidence over time (primary malignant brain tumour, cerebral palsy, multiple sclerosis, schizophrenia and traumatic brain injury). While this trend may indicate true increases in disease incidence, other contributing factors might include earlier diagnosis and/or detection, as well as methodological limitations (as previously described) that result from using health administrative data. Further study is needed to better understand and contextualize these findings.

The age- and sex-specific prevalence estimates provide more in-depth findings for each condition. Some brain disorders were more prevalent among females (benign brain tumour, dementia, multiple sclerosis and spina bifida) while others were more prevalent among males (primary malignant brain tumour, cerebral palsy, epilepsy, parkinsonism, schizophrenia, spinal cord injury, stroke and/or transient ischemic attack, and traumatic brain injury). Only motor neuron disease was found to have similar prevalence estimates for both sexes.

Age-specific prevalence estimates by disorder emphasize important differences across age groups. The prevalence of both cerebral palsy and spina bifida were greater among younger persons, whereas among older persons, other brain disorders (benign brain tumour, dementia, motor neuron disease, parkinsonism, and stroke and/or transient ischemic attack) were more prevalent. Further, some brain disorders exhibited more complex trends. Primary malignant brain tumour, epilepsy and spinal cord injury had age-specific prevalence estimates that plateaued in adulthood, while multiple sclerosis and schizophrenia had estimates that peaked at this stage of life. The age-specific prevalence pattern of traumatic brain injury featured two peaks – one among young adults and a second among seniors. It is worth noting that care and social needs for some brain disorders may change and become more complex as individuals 'age with their condition.' So even though prevalence peaks earlier in the life course for some brain disorders, they must be regarded as chronic, lifelong conditions, and as individuals with these conditions age, they will require special considerations to meet their needs. These findings are important to the design of targeted approaches to clinical interventions and capacity planning.

Another finding important for planning purposes is the regional variation in prevalence estimates within brain disorders across Ontario. Across the 14 Local Health Integration Networks, age- and sex-adjusted prevalence estimates in 2010/11 varied from 1.3-fold (for dementia) to 4.0-fold (for motor neuron disease). There are many factors that may contribute to regional variation in disorder prevalence, including differences in the characteristics and susceptibility of underlying populations, environmental factors, disparities in access to services which might delay or prevent brain disorder diagnosis, and geographical drift (movement) to urban areas.[26]

Patterns in Costs Associated with Health System Use

For each brain disorder, the costs associated with one year of health system use were estimated for prevalent and incident cases. These associated costs were not specific to the brain disorder, rather they were the costs associated with using the health system for any medical reason. The reported costs

captured a spectrum of health service sectors and settings: complex continuing care, home care, hospital care, long-term care physician and other health care professional services, prescription drugs and rehabilitation services. Across brain disorders, the median cost associated with one year of health system use ranged from $415 (for traumatic brain injury) to $21,588 (for dementia) per prevalent case with a brain disorder. The median cost associated with one year of health system use ranged from $1,408 (for traumatic brain injury) to $61,586 (for primary malignant brain tumour) per incident case with a brain disorder. Within brain disorders, the median cost associated with one year of health system use for incident cases was often greater than the costs among prevalent cases (e.g., as observed for benign brain tumour, primary malignant brain tumour, epilepsy, motor neuron disease, multiple sclerosis, schizophrenia, spinal cord injury, stroke and/or transient ischemic attack, and traumatic brain injury). These additional costs may reflect further clinical work and diagnostic assessment required to evaluate the type and severity of the brain disorder in the year after diagnosis. This might entail using services that include specialist consultation, diagnostic imaging, biopsy or laboratory tests. The additional costs may also be attributable to the immediate care and therapy necessary to treat the disorder such as prescription drugs, surgery and rehabilitation services. For the other brain disorders (dementia and parkinsonism), the median costs associated with one year of health system use were higher among prevalent cases compared to incident cases. These higher costs may be attributable to increased health system use to manage the disorder's progression, increasing severity, and clinical complexity resulting from comorbidities and/or end-of-life care.

Trends in the median cost associated with one year of health system use were observed by age group. Among prevalent cases with a brain disorder, the most common trend was an increase in costs as individuals aged. This was observed in the dementia, multiple sclerosis, parkinsonism, schizophrenia, and spinal cord injury populations. Another common trend was a slightly higher median cost among children (0–17 years) compared to adults (18–64 years), but overall, there was a general increase in costs as individuals aged. This trend was observed in the benign brain tumour, cerebral palsy, epilepsy, motor neuron disease, stroke and/or transient ischemic attack, and traumatic brain injury populations. One explanation for increasing costs with age is more health care services are utilized to treat the disorder's progression, severity, complications and/or sequelae; however, given that *all* health care services were assessed and not just those related to brain disorders, this trend could also be explained as costs rising with age. Other brain disorders (primary malignant brain tumour and spina bifida) showed a more complex pattern: costs were high among younger age groups, decreased in the intermediate age groups, and then increased greatly in later life. These multifaceted trends reinforce the changing needs of persons with brain disorders over the life course. Similar patterns were seen in the mean cost associated with one year of health system use for incident cases with a brain disorder.

A consistent trend across all disorders was that the mean cost associated with one year of health system use was consistently greater than the *median* cost – health system use and costs are known to follow a skewed distribution among individuals.[25] The median cost associated with health system use for prevalent cases with a brain disorder ranged from $415 (for traumatic brain injury) to $21,588 (for dementia) as compared to the mean cost, which ranged from $3,854 (for traumatic brain injury) to $41,001 (for motor neuron disease). This trend was similar for incident cases with a brain disorder.

When examining per-person costs associated with health system use, an important consideration is the total number of cases with each brain disorder. Some disorders have high per-person costs, but if the disorder is rare, such as motor neuron disease, the direct cost to the Ontario Ministry of Health and Long-Term Care might be lower than for a highly prevalent disorder with relatively lower per-person costs, such as traumatic brain injury. This consideration also holds when looking at the per-person costs of a brain disorder by age group. For brain disorders that have per-person costs that increase with age (dementia, multiple sclerosis, parkinsonism, schizophrenia and spinal cord injury), the total cost among older age groups will vary depending on the distribution of age within the conditions.

Examining costs associated with one year of health system use by type of health care service (complex continuing care, home care, hospital care, long-term care, physician and other health care professional services, prescription drugs and

rehabilitation services) provides additional information for these comparisons. Among the prevalent population of each brain disorder, hospital care was the highest contributor to costs for more than half of the disorders (benign brain tumour, primary malignant brain tumour, epilepsy, motor neuron disease, schizophrenia, spina bifida, spinal cord injury, stroke and/or transient ischemic attack, and traumatic brain injury); for other brain disorders, long-term care (dementia, multiple sclerosis and parkinsonism) and home care (cerebral palsy) accounted for the greatest proportion of costs. For those incident cases with a brain disorder, the cost of hospital care accounted for the greatest share of the costs in all brain disorders with the exception of spinal cord injury, for which rehabilitation services accounted for the greatest share.

The cost associated with one year of health system use by type of health care service also varied by age group among prevalent cases when comparing those younger than 65 years with those 65 years and older. For those younger than 65 years, hospital care was the health service contributing the highest costs for some disorders (e.g., benign brain tumour, primary malignant brain tumour, epilepsy, multiple sclerosis, parkinsonism, schizophrenia, spina bifida, spinal cord injury, stroke and/or transient ischemic attack, and traumatic brain injury); for other brain disorders, home care (cerebral palsy and motor neuron disease) and long-term care (dementia) accounted for the greatest proportion of costs. For those 65 years and older, hospital care costs were the highest contributing group in the majority of brain disorders (benign brain tumour, primary malignant brain tumour, epilepsy, motor neuron disease, spina bifida, stroke and/or transient ischemic attack, and traumatic brain injury); for other brain disorders, long-term care (cerebral palsy, dementia, multiple sclerosis, parkinsonism, schizophrenia) and rehabilitation services (spinal cord injury) contributed the highest proportion of costs.

Next Steps

This report provides a foundation for future research into brain disorders in Ontario. The analyses conducted for this report can be replicated in future years to continue to monitor trends in brain disorders. This report, and others like it,[5-7] can be used to inform public health initiatives; clinical management; and regional planning for health, social, education and other programming relevant to brain disorders. In fact, a broader surveillance system could be developed to include other measures important to individuals, such as life expectancy, disease burden through quality-adjusted life years or disability-adjusted life years, and quality-of-life measures.

The report also generates several relevant questions warranting further expansion of methods and more detailed exploration of individual brain disorders. Additional work is required to ensure and improve the validity of existing algorithms. In addition, more sophisticated attributable disease costing would allow for the analysis of costs specific to each brain disorder. Building on the increasing availability of administrative and clinical data sources (and linkage capability), future studies may contribute to an improved understanding of the etiology, progression and health system impact of various brain disorders. Because many of these disorders are chronic, this approach would allow researchers and policy-makers to understand how the care and social needs of those affected change and/or increase in complexity as they 'age with their condition.' The impact of novel health care service programs and modifications to existing health care delivery methods on management of the disorder can also be studied.

Many types of data currently exist that would further the population-based study of brain disorders. Links between the health administrative data used in this report and data from other sources, such as electronic medical records, laboratory tests, genomic information and education data, would improve the breadth and depth of our knowledge. Such rich data sources may allow for a more comprehensive examination of the epidemiology and health and social system impact of other brain disorders not examined in this report, including autism, bipolar disorder, depression, Down syndrome, drug and alcohol addictions, Huntington's disease and muscular dystrophy.

Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data provides an overview of 13 neurological conditions and mental health challenges affecting Ontarians. The report provides a much-needed update of population-based characteristics, prevalence and incidence estimates

for these disorders. In addition, the report provides an overview of the costs associated with health system use by individuals with brain disorders from the payer perspective of the Ontario Ministry of Health and Long-Term Care. The findings provide broad trends for each brain disorder. Beyond the connections made through the data, new partnerships were born. This report brought together the Ontario Brain Institute and the Institute for Clinical Evaluative Sciences, two organizations dedicated to improving the health of Ontarians. Ongoing encouragement of this sort of partnership is important as we work toward providing comprehensive, integrated care for persons with brain disorders.

Appendices

APPENDIX A Diagnostic Codes Used in Algorithms to Identify Brain Disorders

All codes, including their subcodes, were searched for by the algorithm.

Brain Disorder	Data Source	Type	Code	Description
Brain tumour, benign	DAD	ICD-9	225.0	Benign neoplasm brain
			225.2	Benign neoplasm of cerebral meninges
		ICD-10	D32.0	Benign neoplasm of cerebral meninges
			D32.9	Benign neoplasm of meninges, unspecified
			D33.0	Benign neoplasm of brain, supratentorial
			D33.1	Benign neoplasm of brain, infratentorial
			D33.2	Benign neoplasm of brain, unspecified
Brain tumour, primary malignant	OCR	ICD-9	191	Primary malignant neoplasm of brain
			192.1	Primary malignant neoplasm of cerebral meninges
Cerebral palsy	DAD	ICD-9	343	Infantile cerebral palsy
		ICD-10	G80	Infantile cerebral palsy
	OHIP	ICD-9	343	Cerebral palsy
Dementia (including Alzheimer's disease)	DAD	ICD-9	46.1	Creutzfeldt-Jakob disease
			290.0	Senile dementia, uncomplicated
			290.1	Presenile dementia
			290.2	Senile dementia with delusional or depressive features
			290.3	Senile dementia with delirium
			290.4	Vascular dementia
			294	Persistent mental disorders due to conditions classified elsewhere
			331.0	Alzheimer's disease
			331.1	Frontotemporal dementia
			331.5	Idiopathic normal pressure hydrocephalus
			331.82	Dementia with Lewy bodies
		ICD-10	F00	Dementia in Alzheimer's disease
			F01	Vascular dementia
			F02	Dementia in other diseases classified elsewhere
			F03	Unspecified dementia
			G30	Alzheimer's disease
	ODB	Drug class, drug name	Cholinesterase inhibitors	Donepezil
				Galantamine
				Memantine

Brain Disorder	Data Source	Type	Code	Description
Dementia (including Alzheimer's disease) con't	ODB	Drug class, drug name	Cholinesterase inhibitors	Rivastigmine
				Tacrine
	OHIP	ICD-9	290	Dementias
			331	Other cerebral degenerations
Epilepsy	DAD	ICD-9	345.0	Generalized nonconvulsive epilepsy
			345.1	Generalized convulsive epilepsy
			345.4	Localization-related (focal) (partial) epilepsy and epileptic syndromes with complex partial seizures
			345.5	Localization-related (focal) (partial) epilepsy and epileptic syndromes with simple partial seizures
			345.6	Infantile spasms
			345.7	Epilepsia partialis continua
			345.8	Other forms of epilepsy and recurrent seizures
			345.9	Epilepsy unspecified
		ICD-10	G40	Epilepsy and recurrent seizures
	OHIP	ICD-9	345	Epilepsy and recurrent seizures
Motor neuron disease	DAD	ICD-9	335	Anterior horn cell disease
		ICD-10	G12	Spinal muscular atrophy and related syndromes
	OHIP	ICD-9	335	Anterior horn cell disease
Multiple sclerosis	DAD	ICD-9	340	Multiple sclerosis
		ICD-10	G35	Multiple sclerosis
	OHIP	ICD-9	340	Multiple sclerosis
Parkinsonism (including Parkinson's disease)	DAD	ICD-9	332.0	Paralysis agitans
			332.1	Secondary parkinsonism
		ICD-10	F02.3	Dementia in Parkinson's disease
			G20	Parkinson's disease
			G21.0	Primary malignant neuroleptic syndrome
			G21.1	Other drug-induced secondary parkinsonism
			G21.2	Secondary parkinsonism due to other external agents
			G21.3	Postencephalitic parkinsonism
			G21.4	Vascular parkinsonism
			G21.8	Other secondary parkinsonism
			G21.9	Secondary parkinsonism, unspecified
			G22	Parkinsonism in diseases classified elsewhere
	OHIP	ICD-9	332	Parkinson's disease
Schizophrenia	DAD	ICD-9	295	Schizophrenic disorders
		ICD-10	F20	Schizophrenia
			F25	Schizoaffective disorders

Brain Disorder	Data Source	Type	Code	Description
Schizophrenia con't	OHIP	ICD-9	295	Schizophrenia
	OMHRS	DSM-IV	295	Schizophrenic disorders
Spina bifida	DAD	ICD-9	741	Spina bifida
		ICD-10	Q05	Spina bifida
			Q07.0	Arnold-Chiari syndrome
Spinal cord injury	DAD	ICD-9	806	Fracture of vertebral column with spinal cord injury
			907.2	Late effect of spinal cord injury
			952	Spinal cord injury without evidence of spinal bone injury
		ICD-10	S14.0	Concussion and oedema of cervical spinal cord
			S14.1	Other and unspecified injuries of cervical spinal cord
			S24.0	Concussion and oedema of thoracic spinal cord
			S24.1	Other and unspecified injuries of thoracic spinal cord
			S34.0	Concussion and oedema of lumbar and sacral spinal cord
			S34.1	Other and unspecified injury of lumbar and sacral spinal cord
			S34.3	Injury of cauda equina
			T06.0	Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
			T06.1	Injuries of nerves and spinal cord involving other multiple body regions
			T91.3	Sequelae of injury of spinal cord
Stroke and/or transient ischemic attack	DAD	ICD-9	362.30	Retinal vascular occlusion, unspecified
			430	Subarachnoid hemorrhage
			431	Intracerebral hemorrhage
			433.01	Occlusion and stenosis of basilar artery with cerebral infarction
			433.11	Occlusion and stenosis of carotid artery with cerebral infarction
			433.21	Occlusion and stenosis of vertebral artery with cerebral infarction
			433.31	Occlusion and stenosis of multiple and bilateral precerebral arteries with cerebral infarction
			433.81	Occlusion and stenosis of other specified precerebral artery with cerebral infarction
			433.91	Occlusion and stenosis of unspecified precerebral artery with cerebral infarction
			434	Occlusion of cerebral arteries
			435	Transient cerebral ischemia
			436	Acute, but ill-defined, cerebrovascular disease
			G45.0	Vertebro-basilar artery syndrome
			G45.1	Carotid artery syndrome (hemispheric)
			G45.2	Multiple and bilateral precerebral artery syndromes
			G45.3	Amaurosis fugax

Brain Disorder	Data Source	Type	Code	Description
Stroke and/or transient ischemic attack con't	DAD	ICD-9	G45.8	Other transient cerebral ischemic attacks and related syndromes
			G45.9	Transient cerebral ischemic attack, unspecified
			H34.0	Transient retinal artery occlusion
		ICD-10	H34.1	Central retinal artery occlusion
			I60	Nontraumatic subarachnoid haemorrhage
			I61	Nontraumatic intracerebral hemorrhage
			I63.0	Cerebral infarction due to thrombosis of precerebral arteries
			I63.1	Cerebral infarction due to embolism of precerebral arteries
			I63.2	Cerebral infarction due to unspecified occlusion or stenosis of precerebral arteries
			I63.3	Cerebral infarction due to thrombosis of cerebral arteries
			I63.4	Cerebral infarction due to embolism of cerebral arteries
			I63.5	Cerebral infarction due to unspecified occlusion or stenosis of cerebral arteries
			I63.8	Other cerebral infarction
			I63.9	Cerebral infarction, unspecified
			I64	Stroke, not specified as haemorrhage or infarction
Traumatic brain injury	DAD	ICD-9	310.2	Postconcussional syndrome
			800.1	Closed fracture of vault of skull with cerebral laceration and contusion
			800.3	Closed fracture of vault of skull with other and unspecified intracranial hemorrhage
			801.1	Closed fracture of base of skull with cerebral laceration and contusion
			801.3	Closed fracture of base of skull with other and unspecified intracranial hemorrhage
			802.6	Closed fracture of orbital floor (blow-out)
			802.7	Open fracture of orbital floor (blow-out)
			803.1	Other closed skull fracture with cerebral laceration and contusion
			803.3	Closed skull fracture with other and unspecified intracranial hemorrhage
			804.1	Closed fractures involving skull or face with other bones with cerebral laceration and contusion
			804.3	Closed fractures involving skull or face with other bones, with other and unspecified intracranial hemorrhage
			850	Concussion
			851	Cerebral laceration and contusion
			852	Subarachnoid, subdural, extradural hemorrhage, following injury
		ICD-10	853	Other and unspecified intracranial hemorrhage following injury
			854	Intracranial injury of other and unspecified nature
			907.0	Late effect of intracranial injury without mention of skull fracture
			907.1	Late effect of injury to cranial nerve
			925	Crushing injury of face scalp and neck
			F07.2	Postconcussional syndrome
			S02.0	Fracture of vault of skull

Brain Disorder	Data Source	Type	Code	Description
Traumatic brain injury con't	DAD	ICD-10	S02.1	Fracture of base of skull
			S02.3	Fracture of orbital floor
			S02.7	Multiple fractures involving skull and facial bones
			S02.8	Fractures of other skull and facial bones
			S02.9	Fracture of skull and facial bones, part unspecified
			S06	Intracranial injury
			S07	Crushing injury of skull
			T02.0	Fractures involving head with neck
			T06.0	Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
			T90.5	Sequelae of intracranial injury
	NACRS	ICD-9	310.2	Postconcussional syndrome
			800.1	Closed fracture of vault of skull with cerebral laceration and contusion
			800.3	Closed fracture of vault of skull with other and unspecified intracranial hemorrhage
			801.1	Closed fracture of base of skull with cerebral laceration and contusion
			801.3	Closed fracture of base of skull with other and unspecified intracranial hemorrhage
			802.6	Closed fracture of orbital floor (blow-out)
			802.7	Open fracture of orbital floor (blow-out)
			803.1	Other closed skull fracture with cerebral laceration and contusion
			803.3	Closed skull fracture with other and unspecified intracranial hemorrhage
			804.1	Closed fractures involving skull or face with other bones with cerebral laceration and contusion
			804.3	Closed fractures involving skull or face with other bones, with other and unspecified intracranial hemorrhage
			850	Concussion
			851	Cerebral laceration and contusion
			852	Subarachnoid, subdural, extradural hemorrhage, following injury
			853	Other and unspecified intracranial hemorrhage following injury
			854	Intracranial injury of other and unspecified nature
			907.0	Late effect of intracranial injury without mention of skull fracture
			907.1	Late effect of injury to cranial nerve
			925	Crushing injury of face scalp and neck
		ICD-10	F07.2	Postconcussional syndrome
			S02.0	Fracture of vault of skull
			S02.1	Fracture of base of skull
			S02.3	Fracture of orbital floor
			S02.7	Multiple fractures involving skull and facial bones
			S02.8	Fractures of other skull and facial bones
			S02.9	Fracture of skull and facial bones, part unspecified

Brain Disorder	Data Source	Type	Code	Description
Traumatic brain injury con't	NACRS	ICD-10	S06	Intracranial injury
			S07	Crushing injury of skull
			T02.0	Fractures involving head with neck
			T06.0	Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
			T90.5	Sequelae of intracranial injury

Abbreviations: ICD-9, *International Classification of Diseases, 9th Revision*; ICD-10, *International Classification of Diseases, 10th Revision*; DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition; DAD, Discharge Abstract Data, which contains hospitalization records; OHIP, Ontario Health Insurance Plan database, which contains physician claims records; ODB, Ontario Drug Benefit claims database, which contains prescription drug claims records; OCR stands for Ontario Cancer Registry, which contains cancer registry records; OMHRS, Ontario Mental Health Reporting System, which contains mental health hospitalization records; NACRS, National Ambulatory Care Reporting System, which contains emergency department visit records.

APPENDIX B Costing Methodology

Overview

The costs associated with health system use were calculated for 15 types of costs, including:

- complex continuing care
- home care
- inpatient hospitalization
- inpatient mental health
- same-day surgeries
- emergency department visits
- renal dialysis clinic visits
- cancer care clinic visits
- long-term care
- physician billings (including shadow billings)
- capitation fees
- other health care professional billings
- diagnostic test and laboratory service billings
- prescription drugs
- rehabilitation services

These cost types were grouped into the following seven health services categories:

- complex continuing care
- home care
- hospital care
- long-term care
- physician and other health care professional services
- prescription drugs
- rehabilitation services

The methodology for calculating each cost type is summarized below by health service category. The complete details for the costing methodology used in this report can be found in *Guidelines on Person-Level Costing Using Administrative Databases in Ontario*.[21]

Complex Continuing Care

Complex continuing care costs are calculated from the product of a person's Case Mix Index weight, their length of stay and the year-specific cost per Resource Utilization Group-weighted patient day. The Case Mix Index weight is a relative per diem cost of a particular person relative to the average per diem cost of care of reference resident. The Case Mix Index weight is based on the Resource Utilization Group III methodology, which classifies persons into one of 44 groups based on clinical diagnosis, physical and cognitive abilities, as well as services and treatments received. A person's Case Mix Index is calculated every quarter when he or she is reassessed. The year-specific Resource Utilization Group–weighted patient day is calculated by dividing Ontario's total complex continuing care costs in a year by the total provincial Case Mix Index weighted patient days from the same year.

Home Care

Home care costs consist of a case management fee plus the costs associated with delivering eligible home care services. The eligible home care services are community health services, homemaking services, personal care and support services, and visiting health professional services (e.g., nurses, physiotherapists, social workers). A person's year-specific personal case management fee is calculated by dividing the total Ontario case management cost in a year by the total number of home care clients in the same year. Services are provided on a per-visit basis or a per-hour basis. For services provided on a

per-visit basis, the total cost is calculated by multiplying the total number of service visits by a year-specific service visit cost. For services provided on a per-hour basis, the total cost is calculated by multiplying the total number of service hours by a year-specific service hour cost. The cost of each service visit or service hour is based on the Ontario-averaged cost of providing the service.

Hospital Care

Hospital care costs were calculated for costs associated with inpatient hospitalizations, inpatient mental health treatment, same-day surgeries, emergency department visits, renal dialysis clinic visits and cancer care clinic visits.

Inpatient Hospitalization

Inpatient hospitalization costs are calculated from the product of a Resource Intensity Weight assigned to a person's inpatient hospitalization and the year-specific cost per weighted case. Resource Intensity Weights represent the relative level of resources a particular person uses during his or her inpatient hospitalization relative to the average inpatient hospitalization resource use of a reference patient. The Resource Intensity Weight is based on the Case Mix Group methodology, which categorizes groups of persons based on gender, and similar clinical and resource utilization patterns. Resource Intensity Weights specific to a person are calculated by adjusting the base Resource Intensity Weight on length of stay, comorbidity level and interventions received. The year-specific cost per weighted case is calculated by dividing Ontario's total inpatient hospitalization costs in a year by the total provincial inpatient hospitalization Resource Intensity Weights from the same year.

Inpatient Mental Health

Inpatient mental health costs are calculated from the product of a person's Case Mix Index, his or her length of hospitalization and the year-specific cost per weighted patient day. The Case Mix Index weight is the relative per diem cost of a particular person compared to the average inpatient mental health per diem cost of a reference patient. The Case Mix Index weight is based on the System for Classification of In-Patient Psychiatry methodology, which classifies persons into one of 49 groups, defined first by mental health disorder and second by other clinical variables such as aggression, depression and suicidality. The amount of resources used depends on the phase of the hospitalization, so different Case Mix Index weights are calculated for the admission phase (days 1–5), the acute phase (days 6–730) and the long-term phase (day 731 and beyond). A person's Case Mix Index is calculated quarterly when he or she is reassessed. The year-specific cost per weighted patient day is calculated by dividing Ontario's total mental health inpatient costs in a year by the total provincial Case Mix Index weighted patient days from the same year. It should be noted that some inpatients seeking mental health care are treated via inpatient hospitalization instead of inpatient mental health. In these situations, a person's cost is based on Resource Intensity Weights and Ontario Case Costing Initiative costs associated with the Case Mix Group category MCC 19 – Mental Diseases and Disorders.

Same-Day Surgeries

Same-day surgery costs are calculated from the product of a Resource Intensity Weight assigned to a person's same-day surgery and the year-specific cost per weighted case. Resource Intensity Weights represent the relative level of resources a particular person uses during his or her same-day surgery relative to the average same-day surgery resource use of a reference patient. The Resource Intensity Weight is based on the Comprehensive Ambulatory Classification System methodology, which categorizes groups of persons based on their main problem, the interventions received, and their age and sex. The year-specific cost per weighted case is calculated by dividing Ontario's total same-day surgery costs by the total provincial same-day surgery Resource Intensity Weights from the same year.

Emergency Department Visits

Emergency department visit costs are calculated from the product of a Resource Intensity Weight assigned to a person's emergency department visit and the year-specific cost per weighted case. Resource Intensity Weights represent the relative level of resources a particular person uses during his or her emergency department visit relative to the average emergency department visit resource use of a reference patient. The Resource Intensity Weight is based on the Comprehensive Ambulatory Classification System methodology, which categorizes groups of persons based on their main problem, the interventions received and their age and sex. The year-specific cost per weighted case is calculated by dividing Ontario's total emergency department visit costs by the total provincial emergency department visit Resource Intensity Weights from the same year.

Renal Dialysis Clinic Visits

Renal dialysis clinic visit costs are calculated from the product of a Resource Intensity Weight assigned to a person's renal dialysis clinic visit and the year-specific cost per weighted case. Resource Intensity Weights represent the relative level of resources a particular person uses during his or her renal dialysis clinic visit relative to the average renal dialysis clinic visit resource use of a reference patient. The Resource Intensity Weight is based on the Comprehensive Ambulatory Classification System methodology, which categorizes groups of persons based on their main problem, the interventions received, and their age and sex. The year-specific cost per weighted case is calculated by dividing Ontario's total renal dialysis clinic visit costs by the total provincial renal dialysis clinic visit Resource Intensity Weights from the same year.

Cancer Care Clinic Visits

Cancer care clinic visit costs are calculated from the product of a Resource Intensity Weight assigned to a person's cancer care clinic visit and the year-specific cost per weighted case. Resource Intensity Weights represent the relative level of resources a particular person uses during his or her cancer care clinic visit relative to the average cancer care clinic visit resource use of a reference patient. The Resource Intensity Weights is based on the Comprehensive Ambulatory Classification System methodology, which categorizes groups of persons based on their main problem, the interventions received, and their age and sex. The year-specific cost per weighted case is calculated by dividing Ontario's total cancer care clinic visit costs by the total provincial cancer care clinic visit Resource Intensity Weights from the same year.

Long-Term Care

Long-term care costs are calculated from the product of a resident's per diem long-term care funding and their length of stay. The per diem long-term care funding is calculated by summing the resident's per diem nursing and personal care costs, program and support services costs, raw food costs, and other accommodation costs. The other accommodation costs are adjusted by a resident's ability to pay the resident basic co-payment. Calculation of the nursing and personal care cost is year-dependent. Prior to April 2010, each long term care facility's average resident case-mix was calculated using the Alberta Resident Classification System, which was then used to calculate per diem long-term care funding. From April 2010 and beyond, the nursing and personal care costs are weighted by Case Mix Index. The Case Mix Index represents the relative per diem cost of care for a particular resident relative to the average per diem cost of care of a reference resident. The Case Mix Index is based on the Resource Utilization Groups II methodology, which classifies patients into one of 34 groups based on their care needs, types of treatment received, and specific conditions or diagnoses. A person's Case Mix Index is calculated every quarter when he or she is reassessed.

Physician and Other Health Care Professional Services

Physician and other health care professional service costs consist of physician billings (including shadow billings), capitation fees, other health care professional billings, and diagnostic test and laboratory service billings.

Physician Billings (Including Shadow Billings)

The majority of physician and other health care professional service costs are derived from physician billings (including shadow billings). For persons whose physicians are on a fee-for-service payment system, their physician billings costs are calculated by totaling the billing cost of each service used. The billing cost of each service is calculated by multiplying the service's year-specific fees by the number of times the service is used in the same year. These billings include the physician component to analyzing and interpreting test results, as well as any subsequent follow-up visits in regards to the test. For persons whose physician are on capitation models, salary, or other alternative payments plans, their shadow billing costs are calculated by totaling the shadow billing cost of each service used. The shadow billing cost of each service is calculated by multiplying the service's year-specific fees by the number of times the service is used in the same year.

Capitation Fees

Capitation fees are assigned to persons whose physician belongs to a primary care patient enrolment model. This fee is calculated monthly based on the physician's care model at month's end. All capitation fees consist of a base Comprehensive Care Capitation payment adjusted by an age-sex multiplier. The base payment and multiplier depend on the physician's type of primary care patient enrolment model. There are two types of models: capitation-based blended models (e.g., Family Health Network and Family Health Organization) and fee-for-service–based blended models (e.g., the Comprehensive Care Model and the Family Health Group). Capitation-based blended models provide a capitation payment for a predefined basket of primary care services, adjusted by age and sex. For persons 65 years and older, an additional premium is added because the basket of care services is different. A 10% shadow billing premium for a basket of services and a 100% premium for out-of-basket services are captured as physician billings. Fee-for-service–based blended models are primarily paid using fee-for-service, but there is also a small monthly capitation fee for rostered patients, adjusted for age and sex. As well, Family Health Group physicians receive a comprehensive care premium equal to 10% of the fee schedule.

Other Health Care Professional Billings

Billing costs for other health care professionals (e.g., nurse practitioners, physiotherapists, optometrists and chiropractors) are covered by the Ontario Health Insurance Plan when care is provided to certain groups of persons (persons 65 years and older, those with specific chronic diseases, and those in specific government assistance programs). The billing cost of each service is calculated by multiplying the service's year-specific fees by the number of times the service is used in the same year. It should be noted that out-of-pocket costs and costs reimbursed by third-party insurers are not included; these represent the majority of the non-physician health care professional costs incurred by a person.

Diagnostic Test and Laboratory Service Billings

Diagnostic test and laboratory service billings consist of a physician component and a laboratory component. The physician component consists of services such as specimen collection, result analysis and interpretation, and patient follow-up. The laboratory component is a technical component of tests performed at Independent Health Facilities captured in the OHIP billings data (denoted by codes J and L). It should be noted there is no reliable way of estimating costs associated with laboratory tests not captured in the OHIP billings data as most laboratories and test clinics are privately owned and paid under global budgets.

Prescription Drugs

Prescription drug costs consist of all prescription drug costs paid by the Ministry of Health and Long-Term Care to pharmacies; this includes the cost of the medication and dispensing fees. All prescription drugs claimed under the Ontario Drug Benefit Program are captured. This program covers all persons 65 years and older, and persons younger than 65 years who are either (a) 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 persons with disabilities who are in financial need); (b) receiving coverage from the Trillium Drug Program or the Special Drugs Program; (c) receiving home care services; or (d) living in long-term care homes. Prescription drugs paid for out-of-pocket and/or by third-party insurers are not included in these costs, which means complete prescription drug utilization costs are not available for the majority of persons younger than 65 years.

Rehabilitation Services

Rehabilitation services costs are calculated from the product of a person's Rehabilitation Cost Weight and the year-specific cost per weighted case. The Rehabilitation Cost Weight is the relative resource use of a particular person compared to the average rehabilitation service resource use of a reference patient. The Rehabilitation Cost Weight is based on the Rehabilitation Patient Group case mix classification methodology, which classifies persons based on age, length of stay and level of disability as determined by the Functional Independence Measure motor score and cognitive score, both measured upon admission. Persons who have a short-term stay (defined as less than three days) or long-term stay (definition based on a person's Rehabilitation Patient Group) are considered outliers and have a modified Rehabilitation Cost Weight. The year-specific cost per weighted case is calculated by dividing Ontario's total inpatient rehabilitation costs in a year by the total provincial Rehabilitation Cost Weight for the same year.

APPENDIX C List of Supplementary Data

For each brain disorder featured in this report, the following data tables are available upon request. Please email the request to **ahrq@ices.on.ca.**

- Number and crude and age- and sex-adjusted prevalence per 1,000 persons (with 95% confidence intervals), in Ontario, 2004/05 to 2010/11
- Number and crude and age- and sex-adjusted incidence per 1,000 persons (with 95% confidence intervals), in Ontario, 2004/05 to 2010/11
- Number and crude prevalence per 1,000 persons (with 95% confidence intervals), by sex and age group, in Ontario, 2004/05 and 2010/11
- Number and crude and age- and sex-adjusted prevalence per 1,000 persons (with 95% confidence intervals), by Local Health Integration Network, in Ontario, 2004/05 and 2010/11
- Descriptive statistics (mean, median, quartile 1 and quartile 3) of the costs associated with one year of health system use for prevalent cases with a brain disorder, by age group, in Ontario, 2010/11
- Descriptive statistics (mean, median, quartile 1 and quartile 3) of the costs associated with one year of health system use for incident cases with a brain disorder, by age group, in Ontario, 2009/10 to 2010/11

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