Ontario

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Spina Bifida

Brain Health in Ontario Project

ONTARIO BRAIN INSTITUTE
INSTITUT ONTARIEN DU CERVEAU

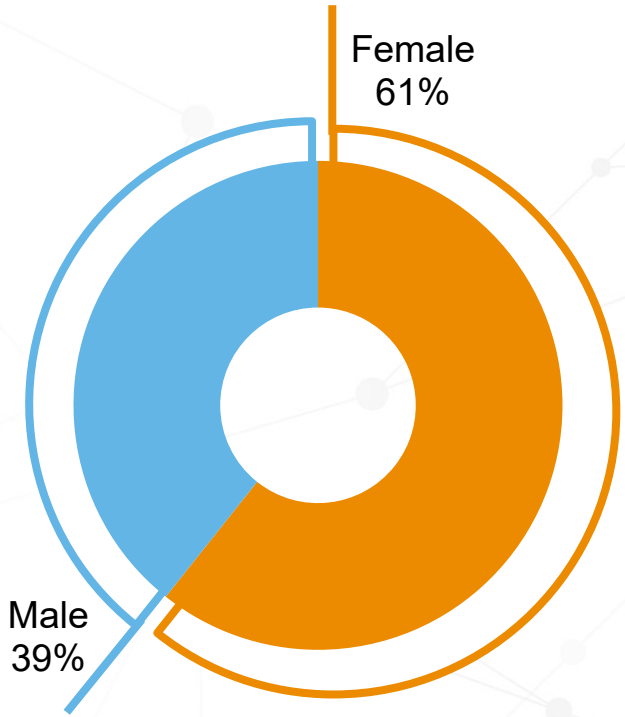
WELCOME TO BRAIN CENTRAL

Spina Bifida

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

- Children born with spina bifida can have a lesion on their spinal cord, making it vulnerable to injury and resulting in significant irreparable damage.
- Similar to spinal cord injury, the extent of damage from the lesion depends on where it occurs on the spinal cord, with higher lesions resulting in more damage.
- Three types of spina bifida are most common and range in severity. Myelomeningocele is the most severe where the spinal cord and the meninges (its protective covering) both push through the open part of the spine. Meningocele describes the situation when only the meninges push through the opening and typically no nerve damage occurs, although individuals may have minor disabilities. Spina bifida occulta is also referred to as ‘hidden’ because the protrusion is covered by skin and does not cause harm.
- There is no known cure for spina bifida. However, some forms of spina bifida are treatable with surgery soon after birth in order to prevent infection and further damage to the spinal cord. Fetal surgery prior to birth is also available for some forms of spina bifida. Individuals with spina bifida may require assistive devices to help with walking, and surgery may also be necessary to help manage ongoing complications.

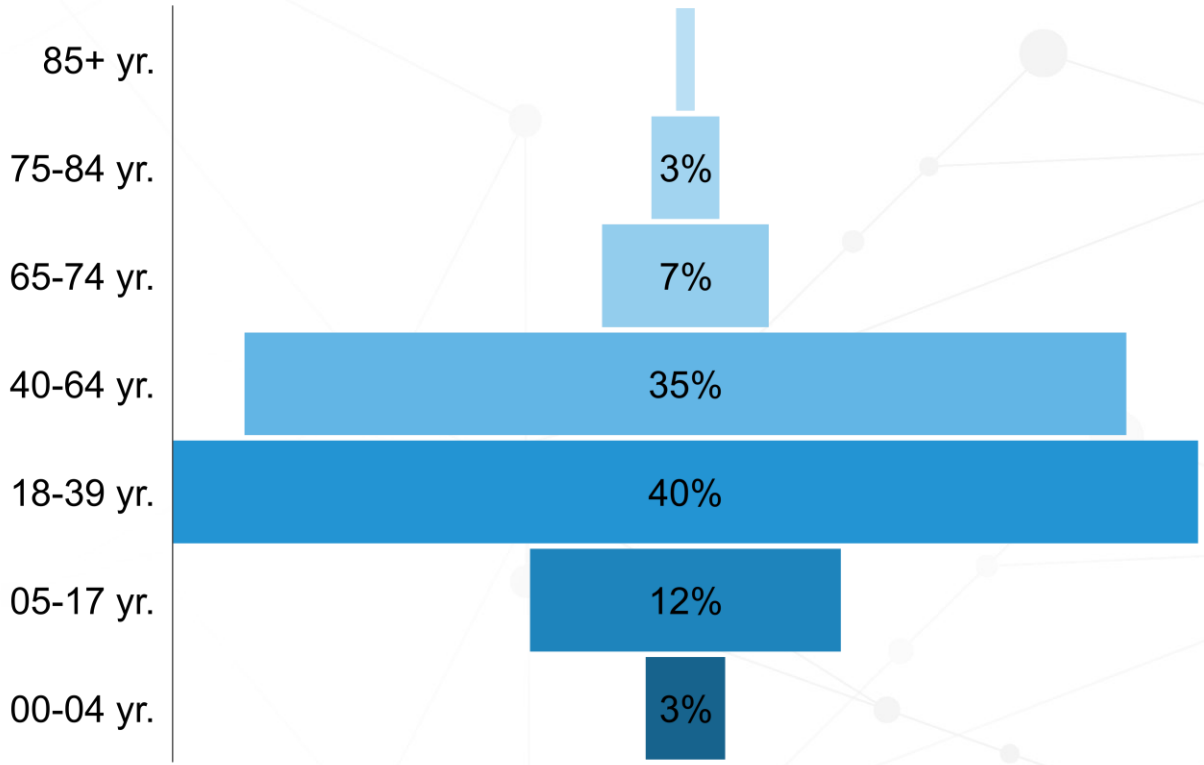
Demographics: Sex distribution



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

*Note, years represent the fiscal year. For example, 2019 is from April 1, 2019 to March 31, 2020.

Demographics: Age distribution



On April 1, 2019 the majority of people with spina bifida were between the ages of 18 and 39 years, with 90% of people being under the age of 65. The mean age of a person with spina bifida was 38 ± 19 years.

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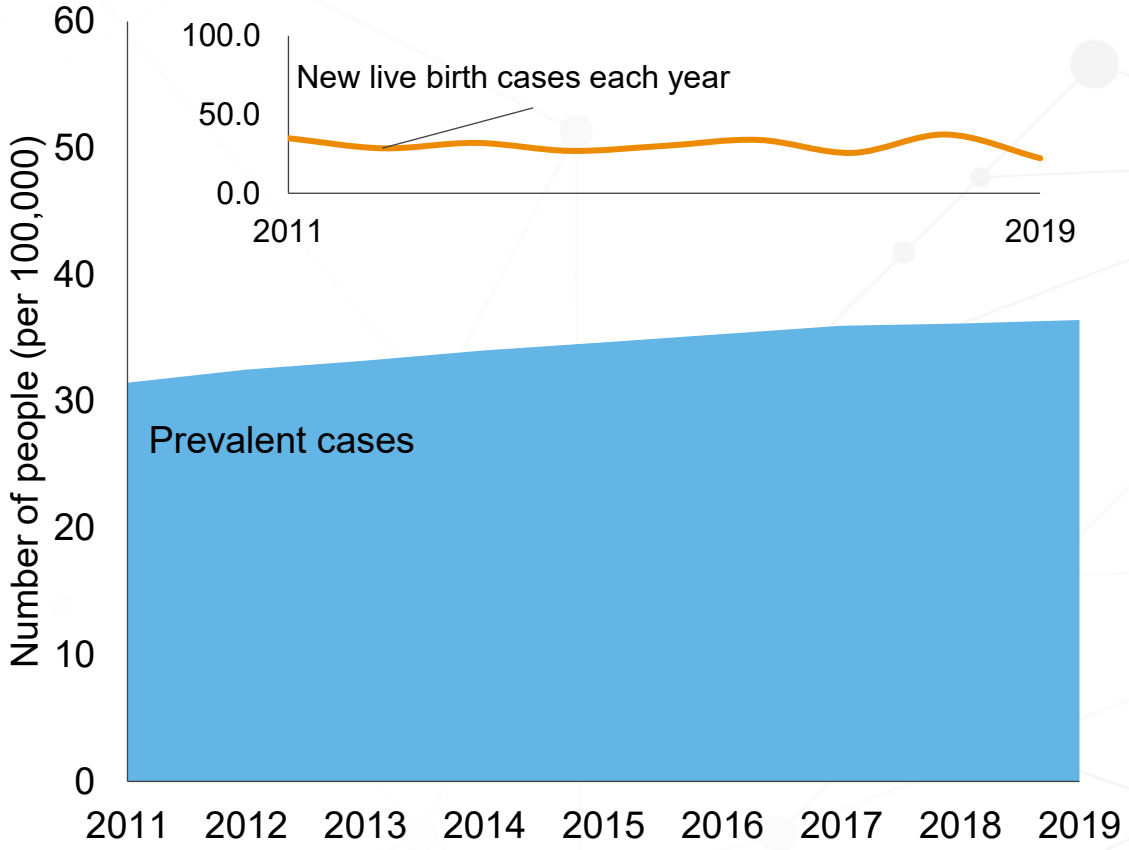
Prevalence and incidence over time



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

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

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

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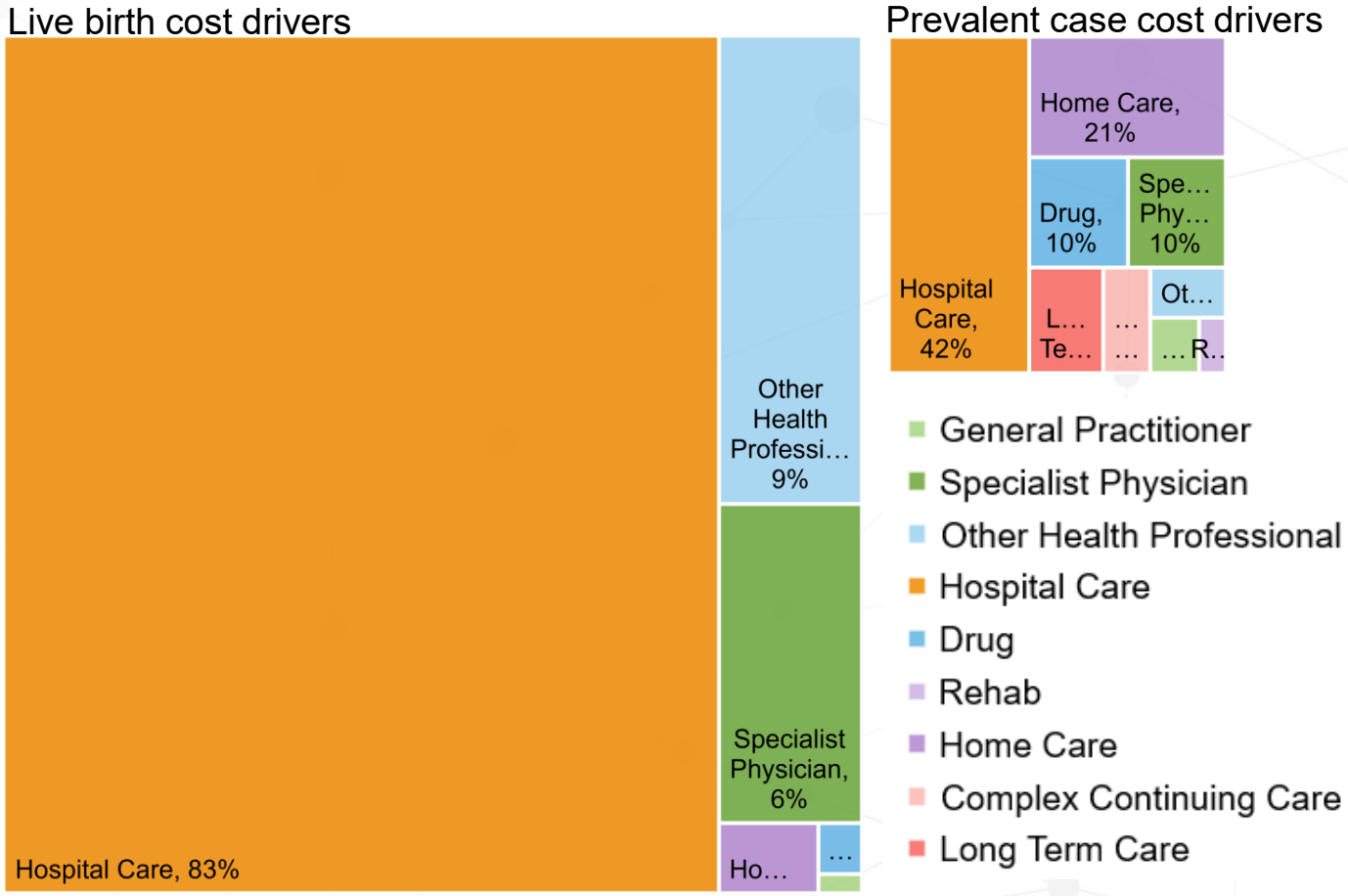
Cost Drivers: Live birth prevalent vs. prevalent



*Cost drivers examined include: Hospital care, home care, general practitioner, specialist physician, other health professional, drug cost, rehab, complex continuing care, and long term care.

Cost Drivers: Incident vs. prevalent

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

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

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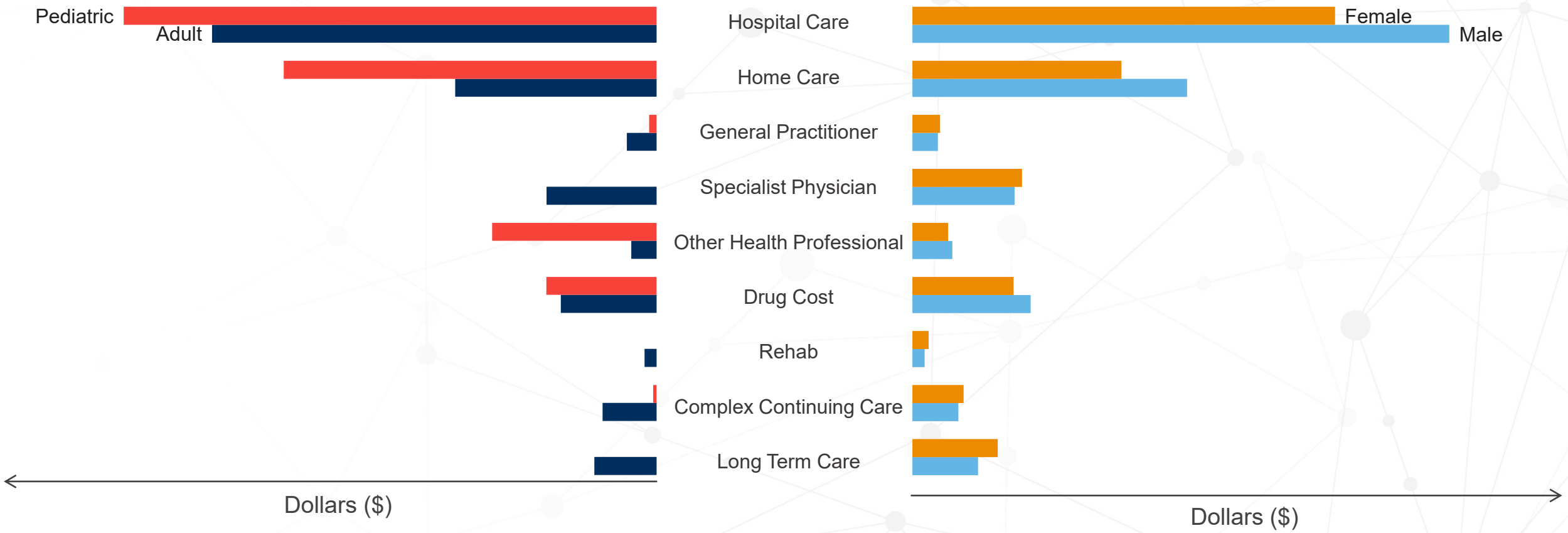
*Cost drivers examined include: Hospital care, home care, general practitioner, specialist physician, other health professional, drug cost, rehab, complex continuing care, and long term care.

Cost Drivers vary by age and sex for prevalent cases



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Cost Drivers vary by age and sex for prevalent cases

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

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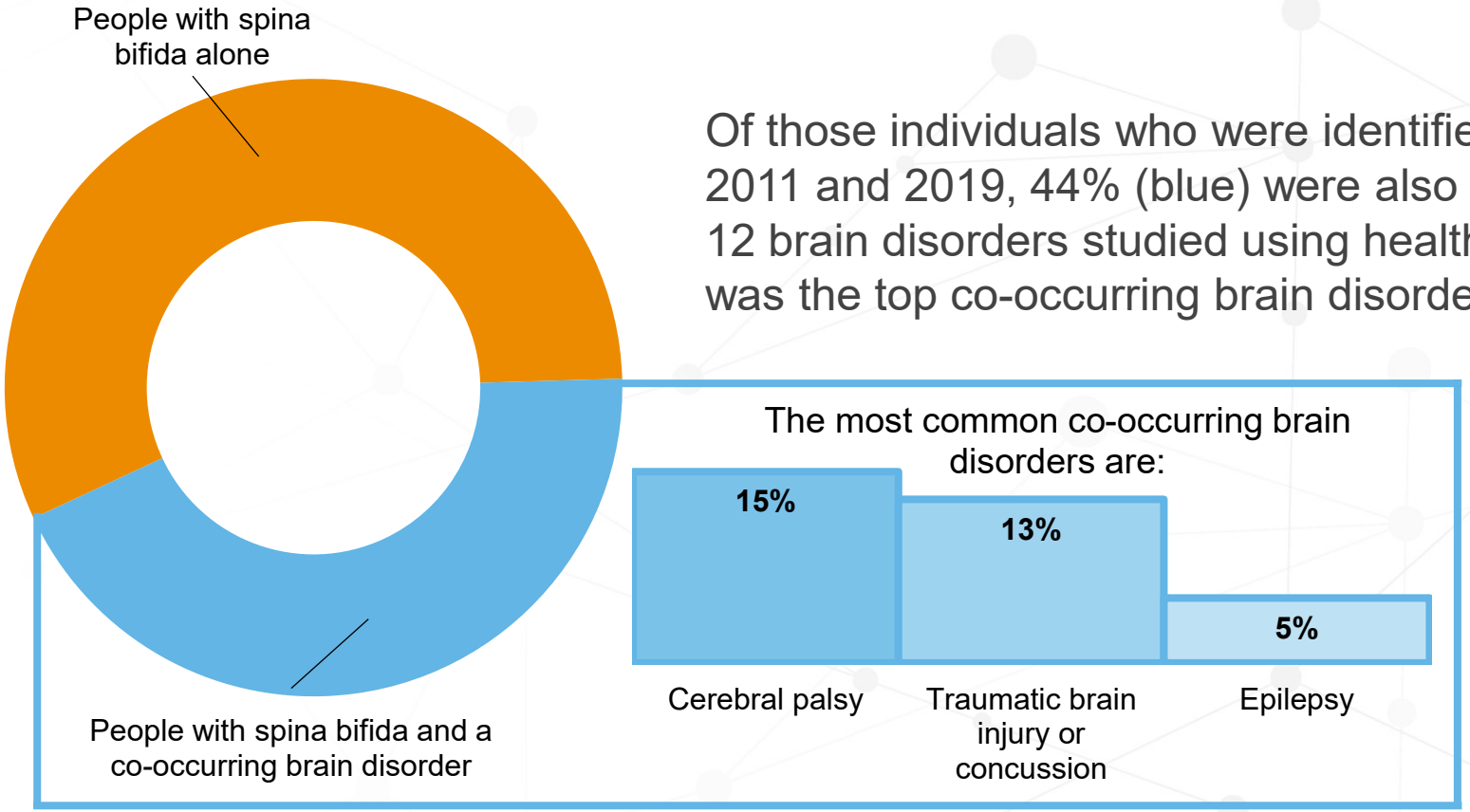
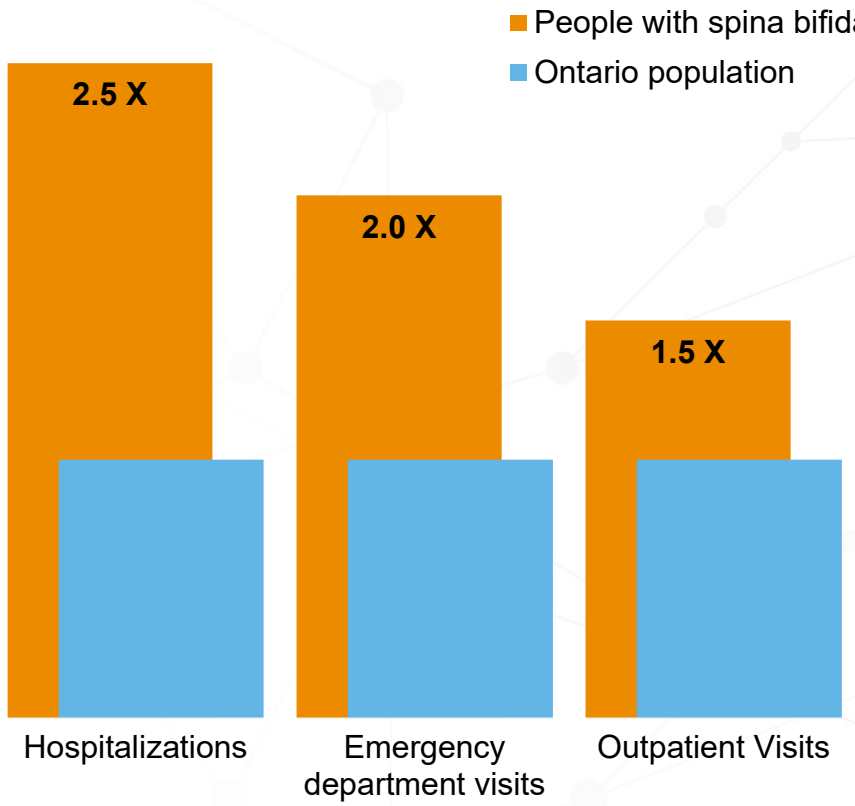
Co-occurring brain disorders



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

*Note, years represent the fiscal year. For example, 2019 is from April 1, 2019 to March 31, 2020.
*Note, other brain disorders studied include: non-malignant brain tumour, benign brain tumour, dementia (incl. Alzheimer's disease), epilepsy, motor neuron disease, multiple sclerosis, parkinsonism, schizophrenia, spina bifida, spinal cord injury, stroke, and traumatic brain injury & concussion.

Mental Health and addictions service use



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

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Additional study information

Brain Disorder	Evidence Grade	Reference	Algorithm	ICD-09 (CM) codes	ICD-10 codes	OHIP Dx codes	ODB drugs name	OMHRS codes	Age Restriction
Spina bifida	II	Accepted algorithm	1 hospitalization record	741	Q05, Q07.0	N/A	N/A	N/A	None

Brain health in Ontario project main page: www.braininstitute.ca/BrainHealth
Methods and Considerations: www.braininstitute.ca/brainhealth-methodology

Publication information