

# How Children and Youth with Medical Complexity Use Hospital and Emergency Department Care across Canada

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## Abstract

Children and youth with medical complexity are a diverse group with uncommon diagnoses, a spectrum of needs and varying access to supports. Although this population represents a small proportion of all children, their unique needs lead to substantial use of healthcare services. With its first pan-Canadian report on children and youth with medical complexity, the Canadian Institute for Health Information examined how this population uses healthcare services. Key findings include the wide variation in the rate of medical complexity among children and youth across Canada. Children and youth with medical complexity were found to require a high proportion of hospital and emergency department care; however, their readmission rates were found to be lower than that of the general pediatric population.

## Introduction

Children and youth with medical complexity have a wide range of conditions. Most of these children and youth share four characteristics: complex chronic conditions, functional limitations, high healthcare utilization and a high need for caregiving (Berry et al. 2013; Cohen et al. 2011).

This study used Canadian Institute for Health Information's (CIHI) data to identify children and youth, newborn to 24 years old, who had at least one hospital stay or day surgery in 2015–2016. Children and youth were included in the study if they had a complex chronic condition or neurological impairment recorded in any hospital stay or day surgery between April 2010 and March 2016.

Building on previous literature (Cohen et al. 2012; Feudtner et al. 2014), these children and youth were grouped into four types of medical complexity:

- neurological impairment: a diverse group of constant and progressive health conditions that involve the central and peripheral nervous systems and result in functional and/or intellectual impairment
- single condition: a complex chronic condition that affects a single body system severely enough to require specialty pediatric care and often some time in hospital

- multiple conditions: complex chronic conditions that affect more than one body system
- neurological impairment with other condition(s): neurological impairment as well as other single or multiple conditions

## Key Findings

### Rate of medical complexity across Canada

This study identified 97,561 children and youth with medical complexity across Canada in 2015–2016. Most children and youth were younger than five years (38%) or older than 20 (23%). The sex distribution was relatively even (51% male).

The age-adjusted rate of medical complexity was 948 per 100,000 children and youth. This rate varied by province and territory (Figure 1), which could be due to differences in service availability (i.e., outpatient and community), the movement of patients across provincial or territorial boundaries and procedures for healthcare number registration of newborns.

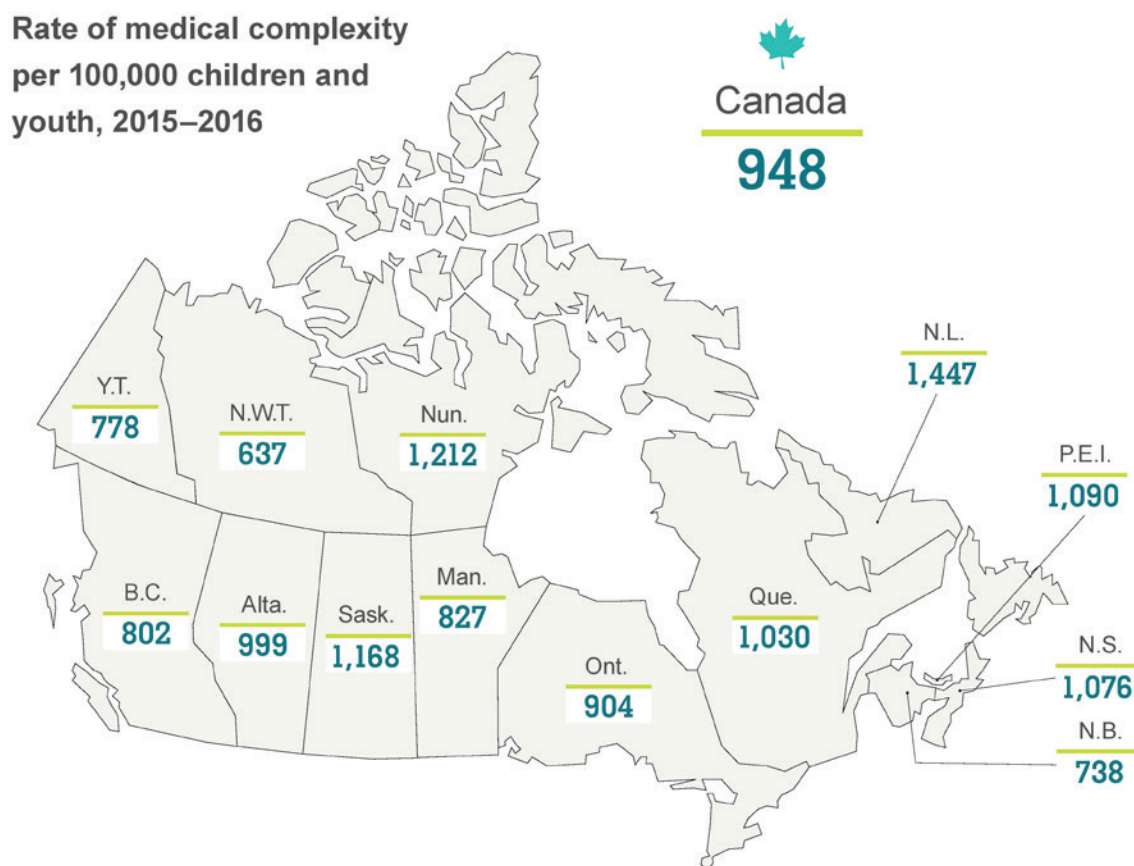
### Emergency department visits

In Ontario, Alberta and Yukon, these children and youth accounted for 17% of emergency department (ED) visits and 21% of the total costs for all children and youth. In these provinces, the total cost of ED care for these children and youth was more than \$15 million over two years. Two-thirds of children and youth with medical complexity had at least one ED visit (68%; Table 1).

### Hospital stays

Over two years, the hospital care cost associated with these children and youth was \$866 million. Compared with children and youth with other conditions, children and youth with medical complexity had longer stays in the hospital and accounted for a greater proportion of acute care costs (Figure 2). Children and youth with medical complexity were admitted to the hospital in the two years following their first hospital stay more frequently than those without medical complexity (36% and 15%, respectively).

**FIGURE 1.**  
**Age-adjusted rate of medical complexity per 100,000 children and youth, by province and territory, 2015–2016**



Sources: Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, CIHI; Population estimates, 2011 and 2015, Statistics Canada.

### Readmissions, high users and long stays in the hospital

The 30-day readmission rate after discharge from hospital was 5% over two years, which is lower than the readmission rate for the general pediatric population (6.9%) (CIHI n.d.). Approximately 1% of children and youth were high users (individuals with an average of three or more hospital stays and 30 days in the hospital per year). One in seven hospital stays among high users included an intensive care unit (ICU) stay. Long stays in the hospital (60 or more days) represented approximately 2% of hospital stays over two years, and most included an ICU stay (76%).

### Out-of-province and out-of-territory hospitalizations

In total, 3% of children and youth in this study were hospitalized outside their home province or territory for their first

hospital stay in 2015–2016. Compared with those in larger jurisdictions, more children and youth from Prince Edward Island, New Brunswick and the territories travelled out of jurisdiction for care.

### Palliative care in the hospital

Palliative care is an important component of care for patients and their families (Feudtner et al. 2015). Less than 1% of children and youth had palliative care in the hospital in 2015–2016. Infants were twice as likely to have palliative care, compared with children and youth aged one to 24 years. Approximately one-third of the children and youth who died in hospitals had a record of palliative care in the two years prior to their deaths (35%). In contrast, 66% of adults aged 19 and older who died in the hospital received palliative care in the last year of life (66%) (CIHI 2018).

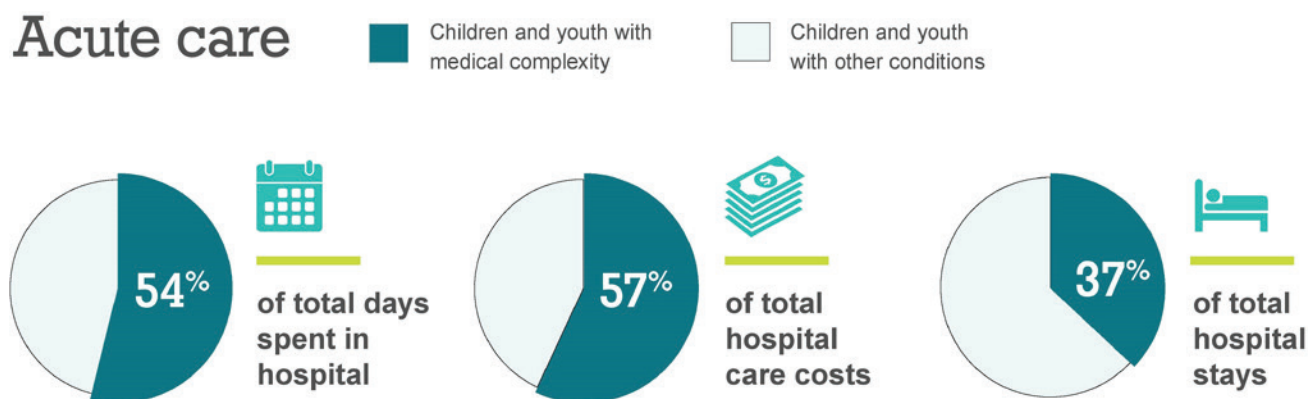
**TABLE 1.** Health system use among children and youth with medical complexity, by type of medical complexity, in the two years after the first hospital stay in 2015–2016

Health system use	Total	Type of medical complexity			
		Neurological impairment	Single condition	Multiple conditions	Neurological impairment with other condition(s)
Hospital stays (Canada)					
Proportion with at least one hospital stay	36%	32%	28%	59%	61%
Average number of hospital stays	2.5	2.0	1.9	3.4	3.3
Average length of stay (days)	21	13	15	33	29
ED visits (Ontario, Alberta and Yukon)					
Proportion with at least one visit	68%	67%	65%	77%	79%
Average number of visits	4.3	4.0	3.9	5.2	5.5

The average number of hospital stays and length of stay were calculated for children and youth with at least one acute hospital stay. The average number of ED visits was calculated for children and youth with at least one ED visit in Ontario, Alberta and Yukon. The analysis period begins with the child's or youth's first hospital stay in 2015–2016 and ends after two years of follow-up.

Sources: Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, CIHI; Population estimates, 2011 and 2015, Statistics Canada.

**FIGURE 2.** Hospital care for children and youth



Source: Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018.

**Conclusion**

This study offered a population-based overview to understand how children and youth with medical complexity use hospital and ED care across Canada. These children and youth represent less than 1% of the pediatric population, and their extensive medical needs correspond to a high proportion of hospital care.

Both families and service providers strive to reduce hospital stays for these children and youth as much as possible. Experts advocate for enhanced care delivery in hospitals and communities, which includes care coordination, integration

and specialty clinics, to empower both families and service providers to promote proactive care rather than reactive care for children and youth with medical complexity (CAPHC 2018). **HQ**

**Additional Findings**

These findings and others – as well as more information on data, terminology and methods – are described in detail in the report *Children and Youth with Medical Complexity in Canada* (available free of charge) at <https://www.cihi.ca/en/children-and-youth-with-medical-complexity-in-canada>.

## References

- Berry, J.G., R.K. Agrawal, E. Cohen and D.Z. Kuo. 2013, June 25. The Landscape of Medical Care for Children with Medical Complexity. Retrieved January 28, 2021. <<https://www.childrenshospitals.org/issues-and-advocacy/children-with-medical-complexity/issue-briefs-and-reports/the-landscape-of-medical-care-for-children-with-medical-complexity>>.
- Canadian Association of Paediatric Health Centres (CAPHC). 2018, April. *CAPHC Guideline for the Management of Medically Complex Children and Youth through the Continuum of Care*. Retrieved January 28, 2021. <<https://ken.caphc.org/xwiki/bin/view/Management+of+Medically+Complex+Children+and+Youth+Across+the+Continuum+of+Care/>>.
- Canadian Institute for Health Information (CIHI) (n.d.). Your Health System: Pediatric Patients Readmitted to Hospital Details for Ontario. Retrieved January 28, 2021. <<https://yourhealthsystem.cihi.ca/hsp/indepth>>.
- Canadian Institute for Health Information (CIHI). 2018. *Access to Palliative Care in Canada*. Retrieved January 28, 2021. <<https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>>.
- Cohen, E., D.Z. Kuo, R. Agrawal, J.G. Berry, S.K.M. Bhagat, T.D. Simon et al. 2011. Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics* 127(3): 529–38. doi:10.1542/peds.2010-0910.
- Cohen, E., J.G. Berry, X. Camacho, G. Anderson, W. Wodchis and A. Guttman. 2012. Patterns and Costs of Health Care Use of Children with Medical Complexity. *Pediatrics* 130(6): e1463–70. doi:10.1542/peds.2012-0175.
- Feudtner, C., J.A. Feinstein, W. Zhong, M. Hall and D. Dai. 2014. Pediatric Complex Chronic Conditions Classification System Version 2: Updated for ICD-10 and Complex Medical Technology Dependence and Transplantation. *BMC Pediatrics* 14(1): 199. doi:10.1186/1471-2431-14-199.
- Feudtner, C., W. Zhong, J. Faerber, D. Dai and J. Feinstein. 2015. Appendix F – Pediatric End-of-Life and Palliative Care: Epidemiology and Health Service Use. In Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine, eds., *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life*. The National Academies Press.
- Statistics Canada. n.d. Table 17-10-0005-01. Population Estimates on July 1st, by Age and Sex. doi: 10.25318/1710000501-eng.

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