Children and Youth With Medical Complexity in Canada

Methodology Notes

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Abbreviations

ATC   Anatomical Therapeutic Chemical

CCI   Canadian Classification of Health Interventions

CIHI   Canadian Institute for Health Information

CVSD   Canadian Vital Statistics Death Database

DAD   Discharge Abstract Database

HCRS   Home Care Reporting System

HMDB   Hospital Morbidity Database

ICD-10-CA   International Statistical Classification of Diseases and Related Health
             Problems, 10th Revision, Canada

NACRS   National Ambulatory Care Reporting System

NPDB   National Physician Database

NPDUIS   National Prescription Drug Utilization Information System

PLPB   Patient-Level Physician Billing

RAI-HC   Resident Assessment Instrument–Home Care

Objectives

These methodology notes are intended to accompany the *Children and Youth With Medical Complexity in Canada* report, which aims to provide a better understanding of this particular landscape across Canada along with the differences across provinces and territories. The methodologies used for all analyses in the report, including analyses of health system resource use, medication use and transfers from pediatric to adult care, palliative care and home care, can be found in this document.

CIHI data sources

Discharge Abstract Database and Hospital Morbidity Database

The Discharge Abstract Database (DAD) captures administrative, clinical and demographic information on hospital discharges from facilities in all provinces and territories outside Quebec. Data from Quebec is submitted directly to the Canadian Institute for Health Information (CIHI) by the Ministère de la Santé et des Services sociaux du Québec. This data is appended to the DAD to create the Hospital Morbidity Database (HMDB). The DAD and HMDB use the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada (ICD-10-CA) and the Canadian Classification of Health Interventions (CCI) to code diagnoses and interventions.

National Ambulatory Care Reporting System

The National Ambulatory Care Reporting System (NACRS) captures information on client visits to hospitals and community-based ambulatory care. NACRS currently collects data on day surgeries, emergency department use and other ambulatory care visits; data varies by region. NACRS uses ICD-10-CA and CCI to code diagnoses and interventions.

Patient-Level Physician Billing

The Patient-Level Physician Billing (PLPB) data is derived from the National Physician Database (NPDB), which contains physicians' billing data (fee codes) that provincial and territorial Medicare programs submit to CIHI. The NPDB provides information on the demographic characteristic of physicians, physician payments and physicians' level of activity within Canada's health care systems. For each physician visit, the PLPB has additional visit information such as health care number, the reason for visit (International Classification of Diseases, Ninth Revision [ICD-9] codes), service billed for and location of service provided. CIHI currently collects PLPB data from Nova Scotia, Ontario, Manitoba, Saskatchewan and Alberta, although data up to 2017–2018 is available only from Nova Scotia, Ontario and Alberta.

National Prescription Drug Utilization Information System

The National Prescription Drug Utilization Information System (NPDUIS) contains drug claims–level data collected from publicly financed drug benefit programs in 10 Canadian provinces and territories. NPDUIS houses pan-Canadian information related to public program formularies, drug claims, policies and population statistics. NPDUIS does not include spending on drugs dispensed in hospitals or on prescriptions funded through cancer agencies and other special programs.

Home Care Reporting System

The Home Care Reporting System (HCRS) contains information from the Resident Assessment Instrument–Home Care (RAI-HC) developed by interRAI. The assessment instrument is designed for use with adults residing in in-home and community-based settings. Along with administrative, demographic and resource utilization data, the RAI-HC data collected from publicly funded home care programs is submitted to HCRS and made available across Canada to plan and monitor care, understand populations, improve quality and allocate resources.

Other data sources

Canadian Vital Statistics Death Database

The Canadian Vital Statistics Death Database (CVSD) is a census of all deaths occurring in Canada each year. Deaths are reported by provincial and territorial vital statistics registries to Statistics Canada, including demographic and cause of death information. Through an agreement with Statistics Canada, CIHI has access to a version of the CVSD for death records linked to the DAD, NACRS and the Ontario Mental Health Reporting System.

Annual population estimates

The annual population estimates from Statistics Canada present annual estimates of the total population and annual estimates by age and sex for Canada and the provinces and territories.

Family representatives

To supplement the data derived from CIHI and Statistics Canada, semi-structured qualitative interviews were carried out with a small number of parents of medically complex children and youth who were identified through conferences and/or through their previous engagement work.

These interviews focused on the following:

- The identification of challenges in care and gaps in health services for children and youth with medical complexity;
- Family experiences with all aspects of care (acute care, emergency department, palliative, home care) as well as services provided in schools; and
- Parents' reactions to research findings and relevance to their unique family situation.

Table 1 presents the coverage of the databases that were used in this study.

Table 1   The coverage of the databases used in this study

Service	Data sources	Years	Provincial and/or territorial coverage
Acute care	DAD and HMDB	2010–2011 to 2018–2019	All provinces and territories
Day surgery	DAD and HMDB, NACRS	2010–2011 to 2018–2019	All provinces and territories
Emergency department	NACRS	2010–2011 to 2018–2019	Ontario, Alberta and Yukon
Specialty clinic visits	NACRS	2015–2016 to 2017–2018	Alberta
Medication	NPDUIS	2015–2016 to 2016–2017	Manitoba, Saskatchewan and British Columbia
Community physician visits	PLPB	2013–2014 to 2017–2018	Nova Scotia, Ontario and Alberta
Home care*	HCRS	2015–2016 to 2017–2018	Newfoundland and Labrador, Nova Scotia, Ontario, Manitoba, Alberta, British Columbia and Yukon
Death information	CVSD	2015 to 2017	All jurisdictions except Quebec and Yukon
Population estimates	Population estimates	2011, 2015 and 2018	All provinces and territories

Note
* Jurisdictions provide wholly or partially submitted data.

Project methods

1. Defining children and youth with medical complexity

Operational definition

A standard method of identifying children and youth with medical complexity does not exist. After consultation with the Children and Youth With Medical Complexity Expert Advisory Group, the cohort of children and youth was operationalized as follows. The cohort included all individuals who met the following criteria:

- Was a Canadian resident age 0 to 24;
- Had at least one hospital stay or day surgery in 2015–2016; and
- Had complex chronic conditions or neurological impairment that were captured in any hospital stay or day surgery from April 2010 to March 2016.

The first hospital stay or day surgery in 2015–2016 is the index hospitalization.

Complex chronic conditions and neurological impairment

CIHI adopted the diagnostic and procedural codes for defining complex chronic conditions and neurological impairment from Feudtner et al. (2014),[1] which only included physical conditions. Appendix A includes the ICD-10-CA and CCI codes that were included based on the Canadian coding standards.

Identifying different groups for children and youth with medical complexity

Consistent with previous literature,[2] children and youth were grouped into 1 of 4 types of medical complexity as follows:

- **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 only 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 1 body system.
- **Neurological impairment with other condition(s):** Neurological impairment as well as single or multiple conditions.

Aligning with previous research,[1] 10 categories of complex chronic conditions by body system were created (see Appendix A):

- Neurological impairment;
- Cardiovascular;
- Respiratory;
- Renal and urologic;
- Gastrointestinal;
- Hematologic and immunologic;
- Metabolic;
- Other congenital and genetic defects;
- Neoplasms; and
- Miscellaneous, not elsewhere classified.

Exclusion criteria

Neonatal cases were excluded from this study if they could not be assigned to any of the 4 types of medical complexity. Sensitivity analyses demonstrated that most neonatal conditions appeared to resolve within the first 2 years of life, meaning these children would not return to the hospital for the same condition.

Medical technology assistance

Medical technology assistance was defined as the reliance on a medical device to manage or treat a chronic illness, and maintain essential body functions necessary for sustaining life or overall functional status.[2] Examples include gastrostomy tubes or peripherally inserted central catheters. This definition does not include devices such as wheelchairs or communication aids.

To identify medical technology assistance in the cohort, the diagnostic and procedural codes included in Cohen et al. (2012)[2] were used as a starting point. Clinical experts reviewed codes used in a more recent study.[1] The current study adopted some of these in the final list of codes based on recommendations by clinical experts (see Appendix B).

Socio-demographic characteristics in the cohort

This study examined the socio-demographic characteristics of children and youth with medical complexity, including age at the index hospitalization, sex, province or territory of residence, neighbourhood income quintiles (income groups) and rural/remote or urban residence. Province or territory of residence, neighbourhood income quintile and rural/remote or urban residence were assigned based on the child's or youth's postal code at their index hospitalization using Statistics Canada's Postal Code Conversion File Plus.

2. Age-adjusted rate of medical complexity by jurisdiction

The in-hospital crude rates of medical complexity were calculated based on the province or territory of residence associated with the index hospitalization. These rates were age-standardized to the 2011 Canadian population according to Statistics Canada. The confidence intervals associated with the rates reflect the range of results for each province and territory, with wider confidence intervals reflecting less certainty in the rate.

3. Primary health care and specialty clinics

Primary health care was defined as a visit to a general practitioner or pediatrician, which took place in the community (see Appendix C). This analysis was based on data in the 2 years following the index hospitalization. There is no pan-Canadian standard for PLPB data, leading to notable variation in data elements and coding practices across provinces. For this reason, a high degree of caution should be used if comparing interprovincial results from the billing data.

For the specialty clinic analysis, Alberta was the only jurisdiction to submit full coverage clinic visit information to NACRS. These clinic visits included only publicly funded clinics and did not capture services paid for out of pocket.

4. Hospital stays

The analysis of hospital stays was based on acute care data in the 2 years following the index hospitalization. This study explored the proportion of children and youth with medical complexity with at least one hospital stay, as well as the average number of hospital stays and length of stay among those with at least one hospital stay. The analysis includes overall rates and rates by type of medical complexity.

30-day overall readmission rate: This indicator measures the urgent readmissions within 30 days of discharge for episodes of care. Please note that this measure includes newborns while a similar indicator in CIHI's Your Health System web tool does not.

High users: High users were defined as children and youth who had an average of 3 or more hospital stays (episodes of care) and a cumulative length of stay of 30 or more days per year.

Long stays in hospital: Long stays in hospital were defined as 60 or more consecutive days in a single hospital stay.

Out-of-province or out-of-territory hospital stays: This analysis was based on index hospitalizations only. Out-of-province or out-of-territory hospital stays were defined as hospitalization records with a facility jurisdiction that differed from the province or territory associated with the child's health care number. Children and youth without a valid health care number were excluded from this analysis. Quebec facilities did not report the province or territory associated with a person's health care number to CIHI's HMDB. Therefore, it was impossible to track the number of out-of-province or out-of-territory cases with hospital stays in Quebec.

Costs of hospital care: Hospital care costs were calculated based on resource intensity weights from CIHI's case-mix grouping methodologies and the cost per standard hospital stay at the provincial or territorial level. This cost per standard stay represents the average cost of 1 person receiving services in a hospital within that specific province or territory.

5.   Emergency department visits

The emergency department analysis was based on data in the 2 years following the index hospitalization. This study explored the proportion of children and youth with medical complexity with at least 1 emergency department visit in 2 years, as well as the average number of visits among those with at least 1 visit. The analysis includes overall rates and rates by type of medical complexity.

Costs in emergency departments: The emergency department costs were calculated based on resource intensity weight from CIHI's Comprehensive Ambulatory Classification System and the cost per standard hospital stay at the jurisdiction level.

6.   End of life

The proportion of children and youth who died within 2 years of the index hospitalization was calculated based on vital statistics data from Statistics Canada.

The location of death was categorized as in hospital, within another health care facility, at home, or another location or unknown location. The location of death was reported for children and youth who died within 2 years of the index hospitalization, including the date of the index hospitalization discharge.

7.   Palliative care

Palliative care, also called end-of-life or comfort care, is a type of health care for individuals and families facing a life-threatening illness. Palliative care helps people achieve the best possible quality of life right up until the end of life, but does not necessarily focus solely on end-of-life care. This analysis excluded those residing in Quebec or those with a health care number from Quebec.

Palliative care in hospital: Children and youth with medical complexity admitted to hospital in 2015–2016 were designated as palliative if they had any of the following on record:

- A diagnostic code for palliative care (code Z51.5);
- The main patient service of palliative care;
- A palliative medicine intervention; and/or
- A palliative medicine service provider.

The palliative designation in hospital care could not be captured in Quebec due to differences in palliative care coding practices.

Physicians providing palliative care: Palliative care claims were identified using PLPB data based on fee service codes for each province (see Appendix D).

The physician specialty was defined based on the most commonly submitted claims for palliative care among children and youth with medical complexity. This analysis did not restrict billing claims by setting or service location.

8. Medication use

Drugs were classified using the 2019 version of the Anatomical Therapeutic Chemical (ATC) classification system from the World Health Organization classification system. The ATC classification system divides drugs into different groups according to the organ or system on which they act and their chemical, pharmacological and therapeutic properties. Drugs were classified into groups at 5 different levels, including 14 main groups (first level), therapeutic subgroup (second level), pharmacological subgroup (third level), chemical subgroup (fourth level) and chemical substance subgroup (fifth level). ATC levels 2 and 4 were used in these analyses.

CIHI's NPDUIS database contains information on drug claims (public and non-adjudicated) that were dispensed in community pharmacies.

The number of unique drug classes (ATC level 4) used by children and youth with medical complexity was counted for 1 year following their index hospitalization. This number does not necessarily reflect the number of drug classes used at one time. The proportions of children and youth with 5 or more and 10 or more drug classes were calculated by dividing those numbers by the total number of children and youth with medical complexity.

2 measures determined which types of drugs were most common. The **rate of use** was calculated by dividing the number of children and youth who had at least one claim for the drug class (ATC level 4) by the total number of children and youth with medical complexity.

The proportion of total claims was calculated by dividing the number of claims for a given therapeutic subgroup (ATC level 2) by the total number of claims from children and youth with medical complexity. The proportion of total claims was ranked to determine the most commonly claimed medications.

9. Home care

Analyses used the first assessment for home care in the 2 years following a child's or youth's index hospitalization. Since the sample size for children and youth with medical complexity who received home care and were also included in CIHI's HCRS was limited, this analysis included all provinces and territories with full or partial coverage in HCRS.

Caregiver distress: Caregivers of individuals receiving publicly funded home care services were identified as "distressed" if they experienced feelings of distress, anger or depression or were unable to continue in their caring activities. Identification is based on a clinical assessment conducted by a trained health professional.

Cognitive impairment and activities of daily living impairment: Embedded within each interRAI instrument are various scales and indices that can be used to evaluate an individual's current clinical status. These scales have been carefully researched to ensure that they are comparable to industry gold standard measures.

Table 2 describes the outcome scales of home care assessment, along with their score ranges.

Table 2   Outcome scales of home care assessment

Outcome scale	Description	Score range
Activities of Daily Living (ADL) Self-Performance Hierarchy Scale	This scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss: 1) early loss — personal hygiene; 2) middle loss — toileting and locomotion; and 3) late loss — eating.	• 0 to 6, with higher scores indicating greater decline in ADL performance • This study used a score of 6 to define difficulties in ADL performance.
Cognitive Performance Scale	This scale describes the cognitive status of a patient, combining information on memory impairment, level of consciousness and executive function.	• 0 to 6, with higher scores indicating more severe cognitive impairment • This study used scores of 5 or 6 to define cognitive impairment.

Informal care: Informal caregivers provide help for instrumental and personal activities of daily living. The average number of hours of care provided by caregivers in the 7 days prior to assessment was calculated.

There were limitations on the home care analysis. Home care assessments (and outcome scales) are not designed for children and youth. Also, the database includes only publicly funded home care.

10. Transfer from pediatric to adult care

Consistent with previous literature,[3] the 18th birthday was defined as the transfer point, and this analysis included all youth with medical complexity who turned 18 in 2015–2016 and did not die before their 20th birthday. This study compared the use of hospital care, emergency departments and community physician visits in the 2-year period before and after transfer. Quebec was excluded from this analysis as Quebec did not report birthdates. Details for the identification of community physician visits, including general practitioner, pediatrician and community specialist visits, can be found in Appendix C.

Appendix A: Diagnostic and procedural codes to define medical complexity, by body system

The tables in this appendix contain diagnostic and procedural codes that define medical complexity by body system:

- Neurological impairment (Table A1);

- Cardiovascular conditions (Table A2);

- Respiratory conditions (Table A3);

- Renal and urologic conditions (Table A4);

- Gastrointestinal conditions (Table A5);

- Hematologic and immunologic conditions (Table A6);

- Metabolic conditions (Table A7);

- Congenital conditions (Table A8);

- Neoplasms (Table A9); and

- Miscellaneous conditions not classified elsewhere (Table A10).

Table A1   Neurological impairment — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Brain and spinal cord malformations	Q00–Q07, G90.1	n/a
Mental retardation	F71–F73	n/a
CNS degeneration and diseases	E75.0, E75.1, E75.2, E75.4, F84.2, G11.1–G11.4, G11.8, G11.9, G12.0–G12.2, G12.8, G12.9, G31.00, G31.02, G31.8, G32.8, G93.8, G93.9, G94, G91.1, G31.9, G25.3, G95.1, G95.8, G90.9, Q85.1	n/a
Infantile cerebral palsy	G80.–	n/a
Epilepsy	G40.1–, G40.2–, G40.3–, G40.4–, G40.81, G40.91	n/a
Other CNS disorders	G37.1, G37.2, G37.8, G81.99, G82.5–, G83.5, G83.9, G93.1, G93.5, R40.20	1.AN.87.^^

Subcategory	ICD-10-CA codes	CCI codes
Occlusion of cerebral arteries	I63.3, I63.5	n/a
Muscular dystrophies and myopathies	G71.–, G72.–	n/a
Movement diseases	G10.–, G20.–, G21.0, G21.1, G21.8, G23.0– G23.2, G23.8, G24.0, G24.8, G25.3–G25.5, G25.8, G25.9, G80.3	n/a
Devices	T85.0, T85.1, T85.7, Z98.2, Z45.8	1.AC.50.^^, 1.AC.52.MB-SJ, 1.AC.52.DA-SJ, 1.AC.52.ME-SJ, 1.AC.52.GN-SJ, 1.AC.52.MF-SJ, 1.AC.52.GI-SJ, 1.AC.52.MJ-SJ, 1.AC.52.MP-SJ, 1.AC.52.GK-SJ, 1.AC.52.MQ-SJ, 1.AC.52.GJ-SJ, 1.AP.52.ME-SJ, 1.AP.52.MF-SJ, 1.AP.52.MJ-SJ, 1.AP.52.MQ-SJ, 1.AC.54.ME-SJ, 1.AC.54.MF-SJ, 1.AC.54.MJ-SJ, 1.AC.54.MP-SJ, 1.AC.54.MQ-SJ, 1.AC.54.HA-TS, 1.AE.53.^^-JA, 1.AN.53.^^-JA, 1.AJ.53.SE-JA, 1.BA.53.SZ-DV, 1.AX.52.MB-TS, 1.AX.52.HA-TS, 1.AX.52.ME-SJ, 1.AX.52.MQ-SJ, 1.AX.53.DA-DV, 1.AX.53.LA-DV, 1.AX.54.LA-DV, 1.BX.09.^^, 1.BX.53.LA-DV, 1.BB.53.^^

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.
CNS: Central nervous system.

Table A2 Cardiovascular conditions — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Heart and great vessel malformations	Q20.–, Q21.2, Q21.3, Q21.4 Q25.1–Q25.9, Q26.–, Q28.2, Q28.3, Q28.9	1.LD.84.^^, 1.IN.84.^^, 1.LA.84.^^, 1.IF.83.^^
Endocardium diseases	I34.0, I34.8, I36.0, I36.8, I37.0, I37.8	n/a
Cardiomyopathies	I42.–, I43.–, I51.5	n/a
Conduction disorders	I44.–, I45.–, I47.–, I48.–, I49.0–	n/a
Dysrhythmias	I49.1–I49.5, I49.8, I49.9, R00.1	n/a
Other conditions	I27.0, I27.1, I27.2, I27.8, I27.9, I50.9, I51.7, I42.8, I63.1, I63.2, Z95.1	n/a

Subcategory	ICD-10-CA codes	CCI codes
Devices	T82.0, T82.1, T82.2, T82.5, T82.6, T82.7–, Z95.0–, Z95.2, Z95.3, Z95.8, Z45.0, Z45.00, Z45.01, Z45.08, Z95.9	1.HZ.53.^^, 1.IS.53.GR-LF, 1.IS.53.HN-LF, 1.HZ.34.^^, 1.HP.53.^^, 1.ID.53.^^-QL, 1.KA.53.^^-QL, 1.IC.53.^^QL, 1.HP.54.^^, 1.HP.83.LA, 1.HZ.37.JA-NN, 1.HB.53.LA-JA, 1.HD.53.GR-JA, 1.HB.54.LA-JA, 1.HD.54.GR-JA, 1.YY.54.LA-GX, 1.YY.84.LA, 1.HB.53.LA-JA, 1.HD.53.GR-JA, 1.YY.53.LA-GX, 1.YY.54.LA-NJ, 1.YY.54.LA-FR, 1.YY.54.LA-FS, 1.YY.54.LA-FU, 1.YY.54.LA-GX, 1.YY.54.LA-NM, 2.HZ.07.NK, 2.HZ.07.NL, 2.HZ.07.NM, 2.HZ.07.NR, 1.JD.53.LA-JA
Transplantation	T86.200, T86.201, Z94.1	1.HZ.85.^^

Notes

ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A3   Respiratory conditions — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Respiratory malformations	Q30–Q34, P28.0	n/a
Chronic respiratory diseases	G47.31, I26.9, J84.1, J96.0–, J96.1–, Z90.2–	n/a
Cystic fibrosis	E84.–	n/a
Other	n/a	1.GE.89.^^, 1.GE.91.^^, 1.GR.87.^^, 1.GR.89.^^, 1.GR.91.^^, 1.GT.87.^^, 1.GT.89.^^, 1.GT.91.^^, 1.GR.58.^^, 1.GT.58.^^
Devices	J95.00–J95.03, J95.08, Z43.0, Z93.0, Z99.0, T85.6, Z99.1	1.GJ.77.LA, 1.GJ.77.QB, 2.GJ.70.BA, 2.GM.70.BA, 1.GJ.50.CA-NG, 1.GJ.50.CA-TS, 1.BJ.09.HA-DV, 1.BJ.09.JH-ED, 1.BJ.53.LA-DV, 1.GJ.54.^^
Transplantation	T86.800, T86.801, Z94.2	1.GT.85.^^, 1.GR.85.^^, 1.HY.85.LA-XX-K

Notes

ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A4   Renal and urologic conditions — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Congenital anomalies	Q60–Q64	n/a
Chronic renal failure	N18.–	n/a
Other	Z90.5, Z90.6	1.PC.58.^^, 1.PC.89.^^, 1.PC.91.^^, 1.PG.87.^^, 1.PG.89.^^, 1.PG.76.^^, 1.PM.89.^^, 1.PM.91.^^, 1.PM.92.^^
Chronic bladder diseases	G83.4, N31.2, N31.9	n/a
Devices	T85.7, Z93.5, Z93.6, Z91.1, Z99.2, Z43.5, Z43.6, Z46.6	1.KY.76.^^, 1.KY.80.^^, 1.PZ.21.HQ-BR, 1.PZ.21.HQ-BS, 1.PZ.21.HP-D4, 1.PE.50.^^, 1.PE.57.DT-^^, 1.PE.52.HH, 1.PG.52.^^, 1.PG.77.LA, 1.PG.80.^^, 1.PG.76.^^, 1.PM.77.^^, 1.PM.82.^^, 1.PV.80.^^, 1.IS.53.HN-LF, 1.IS.53.LA-LF, 1.PG.35.BA-D1, 1.PG.35.BA-D2, 1.PG.35.BA-D3, 1.PE.54.^^, 1.PG.54.^^, 1.PM.54.^^
Transplantation	T86.100, T86.101, Z94.0	1.PC.83.LA, 1.PC.85.^^

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A5   Gastrointestinal conditions — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Congenital anomalies	Q39.0–Q39.4 Q41–Q45	n/a
Chronic liver disease and cirrhosis	K73.– , K74.–, K75.4, K76.0–K76.3, K76.5, K76.8	n/a
Inflammatory bowel diseases	K50.–, K51.–	n/a
Other	I82.0, K55.1, K56.2, K59.3, Z98.0, Z90.3, Z90.4	1.FJ.87.^^, 1.FJ.91.^^, 1.NA.89.^^, 1.NF.89.^^, 1.NK.87.^^, 1.NM.89.^^, 1.OA.58.^^, 1.OA.87.^^, 1.OJ.89.^^, 1.OK.91.^^, 1.SY.84.^^

Subcategory	ICD-10-CA codes	CCI codes
Devices	K91.62, K91.61, Z93.1–Z93.4, Z43.1–Z43.4 Z46.8	1.NA.77.^^, 1.NA.52.CA-NR, 1.NA.52.CA-TS, 1.NA.52.LP-TS, 1.NK.76.DQ, 1.NK.76.RJ, 1.NK.76.DR, 1.NK.76.SK, 1.NK.76.DS, 1.NK.76.SL, 1.NF.53.^^, 2.NF.70.^^, 1.NF.78.SH, 1.NF.78.SJ, 1.NF.78.DQ, 1.NF.78.DO, 1.NF.76.DQ, 1.NF.76.RJ, 1.NM.77^^, 1.NK.77.^^, 1.NK.53.^^, 1.NK.54.^^, 1.OW.80.^^, 1.OW.50.^^, 1.OW.35.^^, 1.NF.54.^^
Transplantation	T86.400, T86.401, T86.880, T86.881, Z94.4, Z94.81, Z94.82	1.NK.85.LA-XX-K, 1.NP.85.LA-XX-K, 1.OA.85.^^, 1.OJ.85.^^, 1.OK.85.^^, 1.OJ.83.^^

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A6 Hematologic and immunologic conditions — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Hereditary anemias	D55–D58	n/a
Aplastic anemias	D60, D61 D71	n/a
Hereditary immunodeficiency	D80–D89 D72.0, M30.3, M35.9	n/a
Coagulation or hemorrhagic conditions	D66, D68.2, D69.30, D69.4	n/a
Leukopenia	D70.0	n/a
Hemophagocytic syndromes	D76.1–D76.3	n/a
Sarcoidosis	D86.9	n/a
Acquired immunodeficiency	B24	n/a
Polyarteritis nodosa and related conditions	M30.0, M31.0, M31.1, M31.3, M31.4, M31.6	n/a
Diffuse diseases of connective tissue	M32.9, M33.9, M34.0, M34.1, M34.9	n/a
Other	n/a	1.OB.89.^^
Transplantation	n/a	1.WY.19.^^, 1.LZ.19.HH-U7-A, 1.LZ.19.HH-U7-J, 1.LZ.19.HH-U8-A, 1.LZ.19.HH-U8-J, 1.OB.85.GQ-XX-P

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A7   Metabolic conditions — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Amino acid metabolism	E70.0, E70.2, E70.3, E70.8, E71.0–E71.3 E72.0–E72.4 E72.8, E72.9	n/a
Carbohydrate metabolism	E74.–	n/a
Lipid metabolism	E75.– , E77.0, E77.1, E78.–, E88.1, E88.88	n/a
Storage disorders	E76.0–E76.3 E85	n/a
Other metabolic disorders	E79.1, E79.8, E80.4–E80.7, E83.0, E83.1, E83.3, E83.4, D84.1, E88.–, H49.8	n/a
Endocrine disorders	E00.9, E22.2, E23.0, E23.2, E23.3, E23.7, E24.0, E24.2, E24.3, E24.8, E24.9, E25.0, E25.8, E25.9, E26.8	1.FU.89.^^, 1.FV.89.^^, 1.PB.89.^^, 1.AF.59.^^, 1.AF.87.^^, 1.QM.89.^^, 1.QM.91.^^, 1.RB.89.^^, 1.RD.89.^^, 1.RM.89.^^, 1.RM.91.^^
Devices	Z96.4	1.YY.53.LA-QK, 1.AX.53.LA-QK, 1.OA.53.LA-QK, 1.YS.53.LA-QK

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A8   Congenital conditions — Diagnostic codes

Subcategory	ICD-10-CA codes
Chromosomal anomalies	Q90.9, Q91.3, Q91.4, Q91.7, Q92.8, Q93.–, Q95.0, Q96.9, Q97.–, Q98.–, Q99.8, Q99.9
Bone and joint anomalies	E34.3, M41.0, M41.2, M41.39, M41.8, M41.9, M43.3, M96.5, Q72.2, Q75.0, Q75.2, Q75.9, Q76.0–Q76.2, Q76.4–Q76.7, Q77.–, Q78.0–Q78.4
Diaphragm and abdominal wall anomalies	K44.9, Q79.0–Q79.5, Q79.9
Other congenital anomalies	Q81.–, Q87.1–Q87.3, Q87.4, Q87.8, Q89.7, Q89.9, Q99.2

Note
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.

Table A9   Neoplasms — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Neoplasms	C00–C97, D01–D09, D36.7, D10–D36, D37–D48, Q85.0	1.^^.35.^^.M^
Transplantation	T86.000, T86.001, Z94.80, Z94.83	n/a

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Table A10   Miscellaneous conditions not classified elsewhere — Diagnostic and procedural codes

Subcategory	ICD-10-CA codes	CCI codes
Devices	T84.09, T84.8, T84.19, T84.4, T84.59, T84.69, T84.7, T87.09–, T87.19, T87.2–, Y83.1, Y83.3, Z99.8	1.SC.75.^^, 1.SA.75.^^
Transplantation	T86.88–, T86.9	n/a

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.
n/a: Not applicable.

Appendix B: Diagnostic and procedural codes to identify medical technology assistance

Table B1   Diagnostic and procedural codes for medical technology assistance

ICD-10-CA codes	CCI codes
K91.61, K91.62, T82.1, T82.5, T82.7, T82.700, T82.701, T82.79, T84.4, T84.7, T84.8, T85.6, T85.7, Y83.3, Z43.4, Z46.6, Z93.4, Z95.2, Z95.8, Z99.1, J95.00, J95.01, J95.02, J95.03, J95.08, J95.09, K91.49, K91.41, K91.42, K91.40, T82.3, T82.4, T85.0, T85.1, Z43.0, Z43.1, Z43.2, Z43.3, Z43.5, Z43.6, Z45.9, Z46.5, Z49.1, Z49.2, Z93.0, Z93.1, Z93.2, Z93.3, Z93.5, Z93.6, Z95.0, Z96.4, Z98.2, Z99.2	1.AC.52.ME-SJ, 1.AC.54.ME-SJ, 1.IS.53.GR-LF, 1.IS.53.HN-LF, 1.IS.53.LA-LF, 1.NF.53.BT-QB, 1.NF.53.BT-TS, 1.NF.53.CA-TS, 1.NF.53.DA-QB, 1.NF.53.DA-TS, 1.NF.53.HA-TS, 1.NF.53.LA-QB, 1.NF.53.LA-TS, 1.NF.78.DQ, 1.NK.53.BT-TS, 1.NK.53.CA-TS, 1.NK.53.HA-TS, 1.NK.54.HA-QB, 1.NK.54.HA-TS, 1.PE.50.DA-BJ, 1.PZ.21.HQ-BS, 1.SC.75.PF-NW-A, 1.SC.75.PF-NW-K, 1.SC.75.PF-NW-Q, 2.GJ.70.BA

1.GJ.54.CA-NR, 1.GJ.54.JA-NG, 1.GJ.54.JA-TS, 1.GJ.54.JA-TW, 1.GJ.54.JA-TU, 1.GJ.77.LA, 1.GJ.77.LA-LG, 1.GJ.77-QB, 1.HB.53.LA-JA, 1.HD.53.GR-JA, 1.HZ.53.GR-FS, 1.HZ.53.GR-NK, 1.HZ.53.GR-NM, 1.HZ.53.GR-NN, 1.HZ.53.GR-NL, 1.HZ.53.LA-FS, 1.HZ.53.LA-NK, 1.HZ.53.LA-NL, 1.HZ.53.LA-NM, 1.HZ.53.LA-NN, 1.HZ.53.QA-NK, 1.HZ.53.QA-NL, 1.HZ.53.QA-NM, 1.HZ.54.LA-NJ, 1.KY.76.LA, 1.NF.54.HA-QB, 1.NF.54.HA-TS, 1.NF.54.JA-TS, 1.NK.53.DA-TS, 1.NK.53.LA-TS, 1.NK.77.EM, 1.NK.77.EN, 1.NK.77.RQ, 1.NK.77.RR, 1.NK.77.RR-XX-G, 1.NM.77.EP, 1.NM.77.EP-XX-G, 1.NM.77-RS, 1.NM.77.RS-XX-G, 1.OW.35.CA-D1, 1.OW.35.CA-D2, 1.OW.35.CA-D3, 1.OW.35.HA-D1, 1.PE.52.HH, 1.PE.54.BA-NR, 1.PE.54.DA-NR, 1.PE.54.JA-TS, 1.PE.54.LA-NR, 1.PV.80.LA, 1.PZ.21.HP-D4, 1.PZ.21.HQ.BR

1.AA.52.HA, 1.AN52.DA, 1.AB.52.DA, 1.AP.52.MJ-SJ, 1.AC.52.MF-SJ, 1.AP.52.MF-SJ, 1.AC.52.MQ-SJ, 1.AP.52.MQ-SJ, 1.AC.52.ME-SJ, 1.AP.52.ME-SJ, 1.AC.52.SE-SJ, 1.AC.52.MP-SJ, 1.AC.54.JA-TS, 1.AP.54.MQ-SJ, 1.AP.54.MJ-SJ, 1.AP.54.MF-SJ, 1.AP.54.ME-SJ, 1.AC.54.MQ-SJ

1.AC.54.MP-SJ, 1.AC.54.MJ-SJ, 1.AC.54.MF-SJ, 1.AX.52.ME-SJ, 1.AX.52.MB-SJ, 1.AX.52.MQ-SJ, 1.AX.53.DA-FT, 1.AX.53.LA-FT, 1.AX.11.HA-P1, 1.AW.09.HA-X7, 1.AX.13.HA-C2, 1.AX.13.GP-C2, 1.AX.11.HA-P2, 1.AX.53.DA-DV, 1.AX.53.LA-DV, 1.AX.80.HA-U9, 1.AX.54.HA-SJ, 1.AX.55.LA-SJ, 1.AX.53.DA-PL, 1.AX.53.LA-PL, 1.BG.11.HA-P1, 1.BG.11.HA-P2, 1.AZ.94.LA

1.GJ.77.HA, 1.GJ.82, 1.GJ.53.BA-EM, 1.GJ.53.HA-EM, 1.GJ.53.LA-EM, 1.GJ.53.LA-PM

1.OT.53, 1.PC.82.LA, 1.PE.52.HA, 1.PV.50.BA-BJ, 1.PV.50.BA-BM, 1.PV.50.BA-BP, 1.PV.57.BA-AM, 1.PV.57.BA-GX, 1.PV.57.LA-GX, 1.PV.59.BA-AG, 1.PV.59.BA-AS, 1.PV.59.BA-AT, 1.PV.59.BA-AZ, 1.PV.59.BA-GX, 1.PV.59.BA-X7, 1.PV.59.LA-GX, 1.PV.80.DA, 2.PV.70.BA, 2.PV.70.DA

1.NF.56.DA, 1.NF.56.LA, 1.NF.52.HA-TS, 1.NF.53.BA-TS, 1.NF.80.DA, 1.OW.12.ZZ, 1.OW.35.HA-D3, 1.OW.35.HA-D2, 1.NA.54.JA-HG, 1.NP.54.JA-TS, 1.NF.54.JA-HG, 1.NA.54.JA-TS, 1.NA.54.JA-NR

1.PM.52.BA-TS, 1.PM.52.BT, 1.PM.52.CA-TS, 1.PM.52.HA, 1.PM.52.HH-TS, 1.PM.52.JA, 1.PM.52.LA-TS, 1.PV.50.BA-BJ, 1.PV.50.BA-BM, 1.PV.50.BA-BP, 1.NP.73.BA, 1.NP.73.DA, 1.NP.73.JH, 1.NP.73.LA

1.AX.53.LA-QK, 1.OA.53.LA-QK, 1.SY.53.LA-QK, 1.ZZ.35.CA-N3, 1.ZZ.35.HA-N3, 1.ZZ.35.YA-N3 |

Notes
ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada.
CCI: Canadian Classification of Health Interventions.

Appendix C: Defining community physician visits

Table C1   Identification of community physician visits

Province	Physician type	Physician specialty codes	Care in the community codes
Nova Scotia	General practitioner	000	• facility_type = blank, 'OFFICE,' 'LODGE' or 'CORRECTIONAL CENTRE'
	Pediatrician	012	
	Community specialist	Any code other than 000 or 012, and care in the community	
Ontario	General practitioner	000	Either of the following: • facility_type = 'OFF,' 'HOP,' 'HOM,' 'HRP,' 'IHF,' 'OTN,' 'PDF' or 'RTF'
	Pediatrician	026	
	Community specialist	Any code other than 000 or 026, and care in the community	• facility_type = blank and facility_code = blank
Alberta	General practitioner	185	Any of the following: • facility_type = 'ACT' and func_center = 'CLNC' or 'D/N'
	Pediatrician	360	• facility_type = blank and func_center = blank (indicates home visit)
	Community specialist	Any code other than 185 or 360, and care in the community	• facility_type = 'OFFC,' 'CACC,' 'MLHL,' 'DMHL,' 'CRCT' or 'DIAG'

Note
Primary health care includes only general practitioners and pediatricians.

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Appendix D: Fee codes to identify physician claims for palliative care

Table D1   Fee codes to identify palliative care, by province

Province	Fee service codes
Nova Scotia	03.09C, 03.03C
Ontario	A945, C945, K023, G512, G511, B966, B998, B997, C882, C982, W882, W982, W872, W972, K700
Alberta	03.05I, 03.05T, 03.05U

References

1. Feudtner C, et al. Pediatric complex chronic conditions classification system version 2: Updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatrics*. 2014.

2. Cohen E, et al. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012.

3. Cohen E, et al. Health care use during transfer to adult care among youth with chronic conditions. *Pediatrics*. 2016.