Data Learnings for Rare Disease Analysis

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Introduction

Background

Rare diseases are often described as conditions affecting less than 1 in 2,000 people, although definitions vary.[1, 2] These diseases are often chronic, debilitating and even life-threatening. Many rare diseases do not currently have treatments.[1] However, the number of drugs for rare diseases approved for the Canadian market has increased over the past decade, which impacts our health systems and patient care.[3]

Innovative therapies for rare diseases are increasingly based on small and short-term clinical trials.[4] Collection and use of real-world evidence is 1 of the 4 pillars of the National Strategy for Drugs for Rare Diseases announced by Health Canada in March 2023.[5] This pillar points to the need to improve the evidence base around these therapies to support decision-making. The Canadian Institute for Health Information (CIHI) is supporting this pillar of the strategy with the use of CIHI data sets to provide context and information on drug use, patient care and other outcomes for patients with rare diseases.

Pan-Canadian data is particularly important for rare diseases and drugs for rare diseases due to the smaller numbers of people who have a particular rare condition. CIHI's pan-Canadian administrative health data is a valuable source of real-world data for the long-term evaluation, monitoring and tracking of drugs for rare diseases. The broad scope of data at CIHI can be used to support the evidence around drugs for rare diseases.

About this report

As part of CIHI's work to support the strategy, the feasibility of using CIHI data to analyze a small set of rare diseases was explored, while considering provincial and territorial stakeholder information needs. This generated insights about the use of CIHI data for analyses of drugs for rare diseases. This report shares these insights with an aim to

- Highlight key considerations to support those using or requesting CIHI data for analyses of rare diseases; and
- Explore opportunities to improve CIHI's ability to support analyses of drugs for rare diseases and to generate better information for decision-making in Canada.

Considerations when using CIHI data for rare disease analysis

CIHI's data holdings can be leveraged to produce actionable information to support decision-making. To explore the current uses and limitations of selected CIHI databases when conducting focused analyses of rare diseases, the following sections summarize key considerations under 3 main themes:

- Identifying patients with rare diseases in CIHI databases;
- How patients with rare diseases interact with the health care system; and
- How disease-specific factors can impact analysis.

Can we identify patients?

Patients with rare diseases can be identified based on recorded diagnosis information or through prescribed drug use. Both options have benefits and limitations, and there may be scenarios where it is more appropriate to use one approach over the other.

When neither disease-based nor treatment-based identification approaches are sufficient, the feasibility of using **a proxy** may be explored as an alternate method to identify patients with a rare disease. Proxies can be algorithms developed using a broader range of information, including patient demographics, symptoms, diagnosis information, procedure codes and/or medication patterns.

Identification based on diagnosis

***International Classification of Disease* (ICD) codes** are often used to record disease diagnoses in CIHI's databases. Some rare diseases have unique ICD codes, making it possible to identify patients with those conditions. However, not all rare diseases have unique codes and many are often grouped with other diseases.

The ability to identify specific rare diseases using ICD codes is impacted by the version of the classification system used for the data of interest. ICD-10-CA is currently the most widely used version in Canada; it includes unique codes for nearly 500 rare diseases.[6] Some administrative data reported in certain databases, such as the Patient-Level Physician Billing Repository, is coded using an earlier version, which has fewer unique ICD codes for rare diseases.

While ICD coding is the most common way to capture disease diagnoses, some CIHI databases capture information using predefined lists of diseases or health conditions (i.e., pick-lists). The conditions included in these lists can vary across databases and need to be assessed on a case-by-case basis to determine whether they can be used to identify the rare disease of interest.

Misdiagnosis is common for patients with rare diseases[7] and may occur more often in some health care settings than others. In some cases, it may be appropriate to identify a patient with a rare disease only after multiple health care visits have the recorded diagnosis.

Identification based on drug treatment

Prescription drug data captured in the National Prescription Drug Utilization Information System (NPDUIS) at CIHI may be used to identify patients with a rare disease.

Prescription drug data from NPDUIS can assist in identifying patients with a rare disease in situations where a drug is specific to a rare disease. When a drug is prescribed to treat multiple diseases or is used off-label for a rare disease, identifying patients with a particular rare disease through this approach is more challenging and may not be feasible.

Data coverage in NPDUIS is important to consider as it can impact whether patients who are receiving the treatment can be identified in the data. There can be differences in jurisdictional drug plan design and funding criteria for specific drugs, and in the availability of private claims data. Currently, NPDUIS contains claims-level data from most public drug programs in most Canadian jurisdictions, as well as claims data on privately funded drugs from 3 jurisdictions (Manitoba, Saskatchewan and British Columbia).

Data linkage across databases

Patients with rare diseases may be identifiable in some databases and not others due to differences in how diagnoses are reported. Data linkage can enable the identification of patients with rare diseases by leveraging information on diagnosis or drug use in other data holdings. For example, a patient cohort identified in the pharmaceutical data based on drug use for a rare disease with no specific ICD code can be linked to the hospital data to locate emergency department visits or hospital admissions for these patients.

Data linkage can also be performed to gather more fulsome information on a patient identified with a rare disease (in a single or in multiple data holdings).

Concepts in action

Huntington disease (HD) can be identified in CIHI's hospital data using an ICD-10-CA code and in long-term care data through a pick-list code. It cannot be identified directly in home care data (as that database's pick-list does not include HD) or in physician billing data (as that uses ICD-9-CA, which groups HD with other diseases).

In the ICD-10-CA classification, **Duchenne's muscular dystrophy (DMD)** is grouped under the same code as other muscular dystrophies, which prevents analysis specific to the rare disease using hospital and emergency department data. In addition, there is no DMD-specific drug treatment available in Canada (at the time of writing), which means it is also not feasible to identify patients in prescription drug data and link records across databases.

How do patients interact with the health care system?

Understanding how patients with different rare diseases access and use health care services, together with understanding what and how data is captured in CIHI's databases, will help determine the best starting point for identifying a rare disease cohort. When patient health care records are identifiable only in health care settings where care is less frequently sought, the data will not tell the full story and could be biased. For example, a cohort based on hospitalization data for patients with some rare diseases may represent only the most ill patients or those with end-stage disease.

The following table summarizes key considerations for the use of selected CIHI databases for rare disease analysis. An overview of these databases and links to related metadata can be found in the appendix.

Table Overview of selected CIHI databases for use in rare disease analysis

Health care setting and coverage	Overview
Acute care and emergency department • Databases – DAD, NACRS* • Coverage – Acute care: Pan-Canadian – Emergency department: Selected provinces/territories	Acute care (hospital inpatient) and emergency department use can represent necessary hospital treatment for severe episodes of illness and poor outcomes (e.g., severe infections, end of life). These databases may capture only a subset of the rare disease population, such as those who are the most ill, and would not be representative of the broader patient population due to most care occurring in the outpatient setting.
Outpatient clinics • Database – NACRS* • Coverage – Limited	Outpatient clinic visits in the hospital (when the patient is not admitted) can be a major source of care for those with rare diseases. These health care encounters could provide insights about routine care and health outcomes for patients with rare diseases. CIHI receives limited clinic data.
Home care • Databases – HCRS, IRRS-HC • Coverage – Selected provinces/territories	Publicly funded home care can support some people with rare diseases living in their own home or other supportive living environments. CIHI captures this data, which may provide insights about the specialized care needs of, health conditions of and clinical outcomes for people living with rare diseases.
Long-term care • Databases – CCRS, IRRS-LTCF • Coverage – Selected provinces/territories	In the community, it can be difficult to manage the care of those with rare diseases even with the support of home care services, and some patients move into more formal care settings such as long-term care. Long-term care data can provide information about care provision and health outcomes for those living with rare diseases in long-term care that is not captured in other settings.
Primary care • Database – PLPB Repository • Coverage – Selected provinces/territories†	CIHI's Patient-Level Physician Billing (PLPB) data can provide insights on the care provided to patients with rare diseases in the community and in clinics, based on physician services. Some clinics may have physicians on alternative payment plans (such as a salary), and if those physicians do not shadow bill for services delivered, those services are not captured in the data.
Pharmaceutical care • Database – NPDUIS • Coverage – Public claims: All provinces and 1 territory – Private claims: 3 provinces	NPDUIS contains claims-level prescription drug data from most public drug plans and some private plans filled through community pharmacies. Data on prescription drugs dispensed to patients can provide information about disease treatments, symptom management, complications and outcomes; in some cases, it can enable identification of patients with rare diseases through disease-specific treatments.

Notes

* NACRS contains data for hospital-based and community-based ambulatory care, including day surgery, outpatient and community-based clinics, and emergency departments.

† Coding used in community care data (billing codes, ICD version) is not standardized across provinces/territories.

For more details, see the appendix or CIHI's Data holdings web page.

Source

Canadian Institute for Health Information.

Concepts in action

Many people with **HD** will be admitted to long-term care once they reach mid- to late-stage disease.[8] Only a subset of patients will be hospitalized or visit the emergency department, typically for infections, falls or psychiatric issues. Outpatient and community care are important for this population, but HD cannot be identified directly in CIHI's home care databases or in physician billing data for provinces/ territories that use ICD-9-CA.

While all patients with **cystic fibrosis (CF)** receive care through specialist CF clinics, only a small proportion of CF patients are hospitalized each year, typically for antibiotic treatment.[9, 10] Many patients take Trikafta, a drug to treat CF, and claims for this drug are well captured in NPDUIS. Patients also take other routine medications to manage disease symptoms and may take medications to treat specific acute conditions.

Data coverage

While CIHI collects comparable, pan-Canadian data on multiple aspects of Canada's health systems, it is important to note that the availability of data varies across health care settings and across jurisdictions, which can impact analysis (view a summary of the data available by year and jurisdiction). Without sufficient data for the health care setting in which patients frequently seek care, the analysis might not be feasible or it may be a challenge to create a cohort that is representative. In particular, patients with rare diseases often receive care through specialist outpatient clinics as well as in primary care, where there are gaps in coverage.

How do disease characteristics impact analysis?

There are thousands of rare diseases, with some estimates placing the number between 6,000 and 8,000.[1] Each rare disease affects a small number of patients, and rare diseases as a group are diverse and present in a wide variety of symptoms. Understanding disease-specific characteristics allows for the evaluation of how well the available data supports the analytical objectives for a specific rare disease.

Disease prevalence and expected patient volumes

Sufficient patient volumes are required to conduct meaningful analysis and protect the privacy of individuals when reporting findings. Patient volumes may be too small for analysis of very rare diseases due to the low prevalence of the condition or gaps in data coverage and collection across health care databases.

Where volumes are small, it may be necessary to aggregate multiple years of data to identify enough patients to ensure confidence in results and to enable public reporting. If aggregating data over time, it's important to be aware of any changes to database coverage, classification systems, clinical practice and treatments that may have occurred.

Concepts in action

Spinal muscular atrophy (SMA) has an estimated prevalence of approximately 1 to 2 per 100,000 individuals, or an incidence of around 1 in 11,000 live births.[11, 12] To conduct an analysis on SMA, 17 years of data were aggregated to provide sufficient patient volumes. Several versions of the ICD classification system (ICD-9, ICD-9-CA and ICD-10-CA) were used over this period. Since these versions capture diagnoses differently, mapping codes was required.

Fibrodysplasia ossificans progressiva is an ultra-rare disease with approximately 900 cases globally and only 20 known patients in Canada.[13, 14] The number of patients with this rare disease expected in CIHI's data is too small to analyze and report on.

Disease onset and progression

In some analyses, disease onset or date of diagnosis may be the desired point from which to track patients (e.g., to explore the natural history of a rare disease). A proxy for disease onset in CIHI data may be the first visit to a doctor's office or the first hospitalization with the diagnosis code, depending on the disease. It may also be possible to identify patients who have died from a disease and look retrospectively at their pathway through the health care system.

Rare diseases that progress slowly may require many years of data to monitor certain outcomes. The time period may exceed the CIHI data available or introduce some uncertainty, making it difficult to evaluate particular outcomes.

Outcomes

Due to the diverse nature of rare diseases, the outcomes that are important to assess for each rare disease will vary. To determine whether the analytical objectives of a project can be met, it is necessary to determine which outcomes should be monitored and how or whether they are captured in CIHI's databases. Here are some examples of outcomes that can be explored using CIHI's data:

Inpatient hospitalization and emergency department use: CIHI has high-quality pan-Canadian hospital data that supports monitoring trends in hospital use for patients with rare diseases. This data can provide insights on how many times patients are admitted or readmitted to hospital, the primary and additional diagnoses associated with each hospital stay, procedures performed and lengths of stay, as well as emergency department use for patients in selected provinces.

Prescription drug treatment: For some analyses, the use of or change in use of prescription drugs may be an important outcome to track to gain insights into a patient's health status. For example, a reduction of antibiotic use to treat acute infections in patients with CF may indicate an improvement in their health status and/or outcomes.

Mortality: Death can be an important outcome measure for some rare diseases (e.g., rapidly progressing diseases like some forms of SMA or rare cancers). Deaths can be identified in CIHI's data when the death occurs in hospital or long-term care. For some specific analyses, CIHI can also leverage Statistics Canada's Vital Statistics death records for individuals with past hospital records (e.g., DAD, NACRS).

Concepts in action

Amyotrophic lateral sclerosis (ALS) patients often experience rapid disease progression, with an average life expectancy of 2 to 5 years following diagnosis,[15] so it could be feasible to track mortality as an outcome through the data.

HD in adults appears later in life[16] and is diagnosed in outpatient settings. CIHI has limited data for indicating diagnoses in an outpatient setting, so the approach relies on later stages of disease, such as when the patients are admitted to long-term care, and works backward to understand the care pathways.

Opportunities to enhance analysis for rare diseases at CIHI

The strengths of CIHI's data for rare disease analysis lie in its pan-Canadian data foundation and the ability to bring together data from different health care settings to generate information about health care use, treatments and health outcomes.

The feasibility of conducting rare disease analyses is currently impacted by differences in database coverage, gaps in data on the care received by patients in the outpatient setting and the ability to identify patients with rare diseases.

To enhance CIHI's ability to support the analytical priorities for drugs for rare diseases, there are opportunities to

- Improve the capture of rare disease diagnoses in the data through ICD-11;
- Improve the capture of drugs for rare diseases through data advancement to include drugs dispensed in hospitals, cancer drugs and more privately funded claims;
- Collaborate with rare disease data partners to leverage other data sources, including rare disease registries and newborn screening data; and
- Improve the coverage of data about care provided in specialist outpatient clinics and primary health care settings.

Improve the capture of rare disease diagnoses in the data through the implementation of ICD-11: ICD-10 captures only about 8% of the estimated 6,000+ different rare diseases.[17] The new version of the ICD classification system, ICD-11, captures around 5,500 rare diseases, which will better support the identification of patients with rare diseases.[18]

Improve the capture of drugs for rare diseases by consolidating data into a pan-Canadian prescription drug information system that encompasses "All Drugs, All People": A strong prescription drug data foundation is needed to support diverse health system analytics, including the evidence base to make decisions around drugs for rare diseases. CIHI currently holds data on drugs for rare diseases that are covered by public drug plans in some jurisdictions. Consolidating pan-Canadian prescription drug data into 1 modernized information system will ensure that more data on drugs for rare diseases is captured at CIHI, improving the ability to evaluate these drug products in the real-world setting and identify patients with rare diseases within the data through disease-specific treatments.

Collaborate with rare disease data partners: While CIHI's databases are a rich source of pan-Canadian administrative health data, data collection is not targeted to provide insights on patients with rare diseases. There is an opportunity to leverage external data sources that contain additional information about patients with rare diseases, such as rare disease registries and newborn screening programs.

- **Rare disease registries** can contain valuable diagnostic, treatment, clinical and specific outcomes data that is not currently available in CIHI's data holdings. There is significant potential for this data to support the evaluation of drugs for rare diseases and improve the information available to support decision-making.
- **Newborn screening programs** in the provinces and territories can support early diagnosis and management of treatable rare diseases. Newborn screening data could support the identification of rare disease patients and provide insights on the proportion of patients with a rare disease that is captured in CIHI's data.

Improve the coverage of data in outpatient health care settings: Most rare disease care and monitoring is conducted in outpatient settings. A lack of data on the care of patients with rare diseases in outpatient settings is a significant gap in understanding patients' journeys and outcomes and in identifying representative patient populations.

- **Specialist outpatient clinics** play a significant role in the diagnosis and management of many rare diseases (e.g., CF clinics). Expanding the collection of outpatient clinic data could better enable the identification of patients with rare disease diagnoses and provide insights into routine care, types of services accessed, monitoring, interventions and outcomes that do not require admission to hospital.

- **Primary care** is often the first point of contact a person has with a health system, and information captured in this setting could provide additional insights into the care received by rare disease patients in the outpatient setting and support patient-focused analysis across the continuum of care.
  - **Physician billing data** can provide some information about services provided by physicians. Improvements in patient-level data coverage and more diagnosis information can facilitate more insights on the care received by patients with rare diseases in the primary care setting.
  - **Electronic medical record (EMR) data** can contain detailed information about the reason for a visit, observations, interventions, lab and imaging tests, referrals and prescribed medications.[19] As EMR data develops, it is anticipated to provide additional insights on the care of patients with rare diseases, including important information about diagnosis, progression and outcomes. Records of patients with rare diseases identified in EMR data could also potentially be linked with other data, such as prescription drug and hospital data, to provide greater insights on health care utilization.

In action

Pharmaceutical Data and Information Roadmap: CIHI has initiated a 5-year Pharmaceutical Roadmap, an initiative that aims to develop a comprehensive and modernized pharmaceutical data management system. This will consolidate pan-Canadian prescription drug data (public, private, hospital, cancer) and expand the data foundation to "All Drugs, All People," which improves data for drugs for rare diseases.[20]

Linkage to rare disease registry data: In support of the National Strategy for Drugs for Rare Diseases, CIHI is assessing the feasibility of linking rare disease registry data to administrative health data; the goal is to understand the challenges, risks and value add to creating comprehensive information about rare disease populations and treatment outcomes. This work is being done in partnership with a pan-Canadian rare disease registry.

Conclusion

CIHI's pan-Canadian clinical and administrative health data is a valuable resource to support the evidence base around drugs for rare diseases. To inform the use of CIHI's data for this purpose, this report has outlined key considerations when using CIHI's data for analysis of rare diseases and highlighted opportunities to address current limitations and enhance analysis.

The opportunities highlighted focus on improving the ability to identify rare disease patients in the data, capture more of the patient care journey through the health system and track meaningful outcomes. Certain opportunities are already underway at CIHI, while others require further exploration.

As CIHI continues to support the National Strategy for Drugs for Rare Diseases, we will work with health system partners to support information needs and identify opportunities to enhance analysis. Data advancement initiatives and access to other sources of data for drugs for rare diseases will become increasingly important for the generation and use of real-world evidence for health system decision-making for rare diseases in Canada.

Related resources

- *Pan-Canadian Prescription Drug Data Landscape, March 2024*
- Government of Canada improves access to affordable and effective drugs for rare diseases
- Canada's Drug Agency: Drugs for rare diseases

Appendix: Overview of selected CIHI databases

Database	Overview
Discharge Abstract Database (DAD)	The DAD captures administrative, clinical and demographic information on hospital discharges (including deaths, sign-outs and transfers). Some provinces and territories also use the DAD to capture day surgery.
National Ambulatory Care Reporting System (NACRS)	NACRS contains data on hospital-based and community-based ambulatory care: • Day surgery • Outpatient and community-based clinics • Emergency departments
Continuing Care Reporting System (CCRS)*	CCRS contains demographic, clinical, functional and resource utilization information on individuals receiving continuing care services in hospitals or long-term care homes in Canada.
Home Care Reporting System (HCRS)*	HCRS contains demographic, clinical, functional and resource utilization information on clients served by publicly funded home care programs in Canada.
Integrated interRAI Reporting System (IRRS)	IRRS was launched in 2019–2020. IRRS manages information captured with interRAI's integrated suite of assessments at multiple points throughout a person's encounter with an organization and across organizations and health care sectors. It houses comprehensive health information (demographic, administrative and clinical) from different care settings in a single reporting system.
Patient-Level Physician Billing (PLPB) Repository	PLPB data captures administrative information on physician claims for publicly insured medical services funded through provincial and territorial medical care plans.
National Prescription Drug Utilization Information System (NPDUIS)	NPDUIS contains pan-Canadian prescription claims-level data, focusing primarily on publicly financed drug benefit programs. The database also contains supporting information for additional context: • Formulary and drug product information • Information on policies of public drug plans in Canada

Database	Overview
Primary health care (PHC) electronic medical record (EMR) data	PHC EMR data from the Alliance for Healthier Communities was collected from 73 Community Health Centres (CHCs) in Ontario, sourced from the Alliance's Business Intelligence Reporting Tool. CIHI and Alliance member CHCs signed a data-sharing agreement in 2020 permitting CIHI to receive an annual data file on an ongoing basis. The acquisition and use of personal health information in relation to this data source supports the following purposes: • To illustrate the patient's journey through certain aspects of the care continuum, including aspects not captured by administrative data; • To explore the quality and comparability of data across data holdings, which is essential for data integration and improvement; • To evaluate fitness of the linked data for proof-of-concept analytics; • To demonstrate the value of structured and linkable PHC EMR data; and • To provide insights into the quality of CIHI's existing data (e.g., how well chronic diseases or virtual care is captured in the DAD, NACRS, NPDUIS and the PLPB Repository).

Note

* CIHI is moving to IRRS for long-term care (IRRS-LTCF) and home care (IRRS-HC) data. CIHI will decommission the previous reporting systems for home care (HCRS and HCRS-CA) by March 2025, and the reporting system for long-term care (CCRS) by March 2026.

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