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At-a-glance

Provincial and territorial congenital anomalies surveillance: a summary of surveillance programs across Canada

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Abstract

The Canadian Congenital Anomalies Surveillance Network was established in 2002 to address gaps in the national surveillance of congenital anomalies (CAs) and support the sustainability of high-quality, population-based, CA surveillance systems within provinces and territories. This paper highlights the methodologies of each local CA surveillance system, noting similarities and variabilities between each system, to contribute to enhanced national CA surveillance efforts.

Highlights

- The Canadian Congenital Anomalies Surveillance Network was established in 2002 under the umbrella of the Canadian Perinatal Surveillance System to support high-quality, population-based congenital anomalies surveillance systems in Canada. Each local congenital anomalies surveillance system covers diverse populations and geography, operates under different structures and has varying program maturity.
- Engagement of every jurisdiction is essential for sustaining local and national CA surveillance.
- Provincial and territorial CA surveillance systems are uniquely positioned to support public health priorities.

Introduction

Congenital anomalies (CAs) are the leading cause of infant deaths in Canada[1] and one of the most frequent causes worldwide.[2] Congenital anomalies surveillance systems were established globally after the thalidomide tragedy, including in Canada, with the national Canadian Congenital Anomalies Surveillance System (CCASS).[3,4]

However, gaps exist in the CCASS data and there are opportunities to address the limitations.[4] Historically, administrative health data ascertained from the Canadian Institute for Health Information (CIHI) Discharge Abstract Database (DAD) have been exclusively used for CCASS.[3,4] The CIHI-DAD comprises hospital discharge data for all provinces and territories, except for Quebec, and is used to identify cases with CAs.[5] The Public Health Agency of Canada (PHAC) developed linkage methodologies to follow up infant admissions that occur up to one year of age; however, this is not sufficient for complete ascertainment of CAs in Canada, as data may be incomplete.[6] There are limitations in the CIHI-DAD for stillbirths, elective termination of pregnancies for fetal anomalies (ETOPFA), environmental exposures, and individual risk factors, all of which also impact the completeness of the CCASS.

The Canadian Congenital Anomalies Surveillance Network was established in 2002, within the Canadian Perinatal Surveillance System. The goal of this network is to enhance CA surveillance data. Members include clinicians, academics and public health professionals from across Canada.

The *Action Plan to Protect Human Health from Environmental Contaminants,* announced by the Government of Canada in 2008, is a federal initiative designed to protect the health of Canadians from harmful environmental contaminants.[6] Under this action plan, PHAC, with support from the Canadian Congenital Anomalies Surveillance Network, works with provinces

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and territories to establish or enhance local CA surveillance systems to improve CA surveillance in Canada. This will address gaps in national CA surveillance, since local data are more complete and accurate.[7] The objective of this paper is to provide an overview of each provincial and territorial CA surveillance system that supports enhanced local and national surveillance activities.

Methods

The Canadian Congenital Anomalies Surveillance Network Data Publication Working Group conducted a survey based on the National Birth Defects Prevention Network's State Birth Defects Surveillance Program Directory.[8] This survey was modified to ascertain program level details across jurisdictions as shown in Table 1.

Every province and territory (British Columbia [BC], Alberta [AB], Saskatchewan [SK], Manitoba [MB], Ontario [ON], Quebec [QC], New Brunswick [NB], Prince Edward Island [PE], Nova Scotia [NS], Newfoundland and Labrador [NL], Yukon [YT], Northwest Territories [NT] and Nunavut [NU]) had opportunities to respond to the survey via email correspondence or through one-on-one interviews in May 2023. Only one representative from each jurisdiction was eligible to respond to the survey, with completion implying consent. Qualitative data were analyzed using thematic analysis and constant comparison methodology.[9]

Health Research Ethics Board (HREB) review and approval were not required, as it was considered a quality assurance project and fell within the scope of CA surveillance practice, and no identifiable registry data were accessed.[10]

Results

Representatives from nine provinces and three territories completed the survey, for a completion rate of 92%. The results of the survey provide an overview of the current state and activities of CA surveillance for each jurisdiction (Table 1).

All local systems report on births occurring within their mother's place of residence. However, two have the capacity to report on out-of-province births. All include live births and stillbirths in their case definition, with half routinely ascertaining early ETOPFAs (i.e. delivered < 20 weeks gestational age). Two additional provinces (ON and NL) have limited ascertainment for early ETOPFAs. One year after delivery is the case ascertainment limit for most jurisdictions, except for NT (18 years), QC (13 years), ON (discharge from a neonatal intensive care unit) and YT (at birth).

Every system is population-based, with seven using a hybrid method of ascertainment. For instance, they passively receive case notifications and actively ascertain cases using additional data sources such as health records to contribute to completeness and accuracy of CAs within their jurisdiction. The remaining five rely on passive methods. All jurisdictions use multiple data sources, while nine out of 12 verify cases using additional clinical data (e.g. pediatric cardiology).

The reporting of CAs is mandated with supporting legislation in only two jurisdictions (BC and NT). While all programs have undergone privacy and/or ethical reviews, 10 out of 12 have completed a full privacy impact assessment. Three-quarters (9/12) share de-identified record–level data with PHAC, while the remaining share aggregate data. Funding from PHAC helps support 11 out of 12 systems, and 8 out of 12 receive provincial/territorial and/or in-kind supports.

Discussion

The Public Health Agency of Canada, with the support of the Canadian Congenital Anomalies Surveillance Network, has actively engaged each province and territory to establish or enhance local CA surveillance to strengthen national surveillance efforts under the *Action Plan to Protect Human Health from Environmental Contaminants*.[6] Each jurisdiction began at a different stage, with some already operating CA surveillance systems, and others needing to be established or revamped. As highlighted in Table 1, each program is unique and incorporates local diverse populations and geography.

The ascertainment and reporting of out-of-province cases are substantially limited. Provinces and territories report a wide range in the percentage of deliveries that occur outside of their jurisdiction—anywhere from less than 1% up to 75% (data not shown). Due to existing local case definitions and the lack of interjurisdictional data sharing agreements, births or deliveries outside of the mother's place of residence with CAs are missed. Thus, it is difficult to report on the true burden of CAs. This supports the need for inter-provincial and -territorial data sharing agreements to enhance local surveillance efforts.

The ascertainment of ETOPFAs significantly improves data quality (i.e. completeness), particularly when those less than 20 weeks gestational age are included. Many pregnancies with lethal or severe anomalies (e.g. anencephaly) are terminated early and are not included in most passive systems.[11,12] Two-thirds of local systems include at least limited data for early ETOPFAs, which provides more accurate estimates, particularly for more severe CAs, compared to those that do not include early ETOPFAs. It is also important to distinguish spontaneous stillbirths from ETOPFA at or greater than 20 weeks gestational age. The current definition of stillbirths needs updating to reflect this key distinction, as it has a significant impact on CA and stillbirth surveillance efforts.[13] Nine jurisdictions have the capacity to distinguish spontaneous stillbirths from ETOPFA at or greater than 20 weeks gestational age (data not shown).

All local systems use multiple data sources, including some with clinical data, to contribute to the verification of cases. The capacity to use both passive and active components for CA surveillance, and to verify data using multiple data sources, increases confidence in data quality. This differs from CCASS, which is a passive system that has historically primarily used one health administrative data source for reporting[6] and research.[14,15] Administrative health data are not collected for the purpose of CA surveillance; thus, there are data quality limitations. A previous comparison of CCASS with a provincial CA surveillance system showed that although there was satisfactory agreement between the two systems for some major anomalies, there was often an overestimation of anomalies in CCASS due to a lack of validation and issues with classification and coding.[16] This limitation was also reported when comparing administrative health datasets with dedicated local CA surveillance systems.[17,18] Although hybrid case ascertainment is more resource intensive, it results in more complete and accurate data. This is particularly relevant for rare anomalies and jurisdictions with lower population numbers, as the misclassification and coding of cases can significantly impact prevalence.

TABLE 1
Overview of provincial and territorial congenital anomalies registry and surveillance programs in Canada

Program characteristics	Province/territory[a]											
	BC	AB	MB	ON	QC	NB	PE	NS	NL	YT	NT	NU
First year of available data	1952	1980	2010	2012	2008	2015	2016	1988	2012	2001	2011	2010
Population reported[b]	BC residents at time of delivery and BC delivery	AB residents at time of delivery and AB delivery	MB residents at time of delivery and MB delivery	ON residents at time of delivery and ON delivery	QC residents at time of delivery and QC delivery	NB residents at time of delivery and NB delivery	PE residents at time of delivery and PE delivery	NS residents at time of delivery and NS delivery	NL residents at time of delivery and NL delivery	YT residents at time of delivery	NT residents at time of delivery	NU residents and NU delivery
Case definition												
LB+SB	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
ETOPFA < 20 weeks GA[c]	✓	✓	X	Limited ascertainment	X	✓	✓	✓	Limited ascertainment	X	✓	X
Spontaneous abortion	X	✓	X	X	X	X	Limited ascertainment	✓	✓	X	X	X
Ascertainment limit	1 year	1 year	1 year	Until NICU discharge	13 years	1 year	1 year	1 year	1 year	At birth	18 years	1 year
Total births/year (LB+SB)	≈ 43 700	≈ 50 000	≈ 17 542	≈ 140 000	≈ 80 000	≈ 6200	≈ 1350	≈ 8000	≈ 3800	≈ 425	≈ 590	≈ 810
Population-based system	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Collection methods	Hybrid	Hybrid	Passive	Passive	Passive	Hybrid	Passive	Hybrid	Hybrid	Passive	Hybrid	Hybrid
Legal/privacy considerations												
Reporting of CA mandated	✓	X	X	X	X	X	X	X	X	X	✓	X
PIA required	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	X
Type of data shared with PHAC	Aggregate	Aggregate	De-identified record level	De-identified record level	Aggregate	De-identified record level	De-identified record level	De-identified record level	De-identified record level	De-identified record level	De-identified record level	De-identified record level

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TABLE 1 (continued)
Overview of provincial and territorial congenital anomalies registry and surveillance programs in Canada

Program characteristics	Province/territory[a]											
	BC	AB	MB	ON	QC	NB	PE	NS	NL	YT	NT	NU
Type of funding												
CA surveillance system supported by PHAC funding	✓	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Provincial funding and/or in-kind support	In-kind support from the Provincial Advisory Committee, and the Office of the Public Health Officer	Supported by Alberta Health Services and in-kind support from Alberta Health	In-kind support	BORN funding	X	PerinatalNB resources	In-kind support	In-kind support from IWK Health	Provincially funded	X	X	X
Data sources used for routine ascertainment and verification												
Discharge abstract[d]	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓	✓
Vital events (LB, SB, deaths)	✓	✓	X	X	✓	X	✓	✓	✓	X	✓	✓
Physician billing claims	Limited ascertainment	X	✓	X	X	X	X	✓	X	✓	X	✓
Perinatal database	✓	X	X	✓	X	✓	X	✓	✓	X	X	X
Clinical genetics and/or cytogenetics data	✓	✓	X	✓	X	X	X	X	✓	X	X	X

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TABLE 1 (continued)
Overview of provincial and territorial congenital anomalies registry and surveillance programs in Canada

Program characteristics	Province/territory[a]											
	BC	AB	MB	ON	QC	NB	PE	NS	NL	YT	NT	NU
Other data[e]	Imaging data, pediatric cardiology clinic at BC Children's Hospital	Congenital Anomaly Reporting Form, Newborn screening, pathology reports, provincial electronic clinical information system	None	BORN Information System includes pregnancy, birth and neonatal outcomes	None	Hospital chart review, and MFM chart review, which includes genetics and autopsy results if requested by physician	National Ambulatory Care Reporting System, RIS/PACS DI System, and Cerner Clinical Information System	Fetal Anomaly Database, IWK Cardiology Database, Medical Services Insurance Claims, DAD for anomaly-related admissions up to 1 year	Outpatient clinics, reports from: x-ray, echocardio-graph, autopsy, maternal fetal assessment unit, genetics	LB with a defect flagged by maternity care providers at discharge. Child with a birth defect flagged by pediatricians, Q and O-35 ICD-10 codes flagged in 3M at Whitehorse General Hospital NACRS	NT Congenital Anomalies Reporting Form; health insurance	None
Multiple data sources used for verification	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Capacity for chart review	✓	✓	X	X	X	✓	X	X	✓	X	✓	✓
Confirmation of common aneuploidies with cytogenetics	✓	✓	X	✓	X	✓	X	X	✓	X	X	X

Source: Survey conducted in 2023 by the Canadian Congenital Anomalies Surveillance Network Data Publication Working Group.

Abbreviations: CA, congenital anomalies; DAD, Discharge Abstract Database; DI, diagnostic imaging; ETOPFA, elective termination of pregnancies for fetal anomalies; GA, gestational age; IWK, Izaak Walton Killam Hospital for Children; LB, live birth; MED-ECHO, maintenance et exploitation des données pour l'étude de la clientèle hospitalière; MFM, maternal fetal medicine; NACRS, National Ambulatory Care Reporting System; NICU, neonatal intensive care unit; PBD, physician billing database; PHAC, Public Health Agency of Canada; PACS, Picture Archiving and Communications System; PIA, privacy impact assessment; RIS, radiology information system; SB, stillbirth.

[a] Province/territory registry/surveillance program: AB, Alberta Congenital Anomalies Surveillance System (ACASS); BC, Enhanced British Columbia Congenital Anomalies Surveillance System (BCCASS); MB, Manitoba Congenital Anomalies Surveillance System (MCASS); NB, PerinatalNB; NL, Perinatal Program Newfoundland and Labrador/Newfoundland and Labrador Health Services (NLCASS); NS, Surveillance of Congenital Anomalies in Nova Scotia (SCANS); NT, NWT Congenital Anomalies Registry; NU, Nunavut Congenital Anomalies Surveillance System; ON, Better Outcomes Registry & Network Ontario (BORN Ontario); PE, Congenital Anomaly Surveillance (PEICANS); QC, Système de surveillance des anomalies congénitales au Québec; YT, Congenital Anomalies Support Yukon. No current information from Saskatchewan was provided.

[b] For NT and YT, residency determines population reporting, no matter where delivery occurred.

[c] For NL, limited ascertainment only if specified in notes of anomalies.

[d] QC uses MED-ECHO.

[e] 3M is a health record management software that includes ICD-10 codes.

Many local programs collaborate with and are supported by experts in a variety of specialties (e.g. maternal fetal medicine, genetics) and their provincial or territorial advisory group (where they exist). Local CA surveillance systems are better positioned to respond to cluster investigations, program planning and resource allocation and to support local interests and needs than a national level system.

Dedicated PHAC funding has provided opportunities for most local systems to establish or enhance CA surveillance within their jurisdiction and contribute to national CA surveillance activities. Funding from health authorities, provincial and territorial governments, and in-kind supports also contribute to local CA surveillance activities. For some programs, dedicated provincial or territorial funding is essential to support operations and sustainability over time.

Strengths and limitations

Almost all provinces and territories completed the survey and reflect the status of CA surveillance across Canada. Representatives from Saskatchewan were invited to participate; however, they were not able to provide any current information. Engagement with provinces and territories, the Canadian Congenital Anomalies Surveillance Network and PHAC contribute to a strengthened CCASS.

Addressing the diversity of each province and territory with a relatively short survey was challenging, and highlights the need for continued engagement and standardization across the country.

Conclusion

The engagement and investment to date from PHAC, provincial and territorial governments, and health authorities have been essential to sustain local and national CA surveillance, as were the efforts and dedication of the Congenital Anomalies Surveillance Network. While national CA surveillance can be reliable in smaller countries, such reliability and accuracy are challenging to achieve in geographically larger countries, highlighting the need for local systems to strengthen national surveillance in Canada.[3,7] To further enhance CA surveillance in Canada, interjurisdictional data sharing agreements are required.

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Conflicts of interest

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Authors' contributions and statement

CN, CC, QM, KJ, KD, LR, MJ, TB, YN—conceptualization.

CC, QM, KJ, KD, LR, MJ, TB, YN—analysis.

CN, CC, QM, KJ, KD, LR, MJ, TB, YN—writing—original draft.

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