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Systems & Data Sources for Congenital Anomalies Surveillance in Canada - 2011

Province/Territory	Province/Territory	Earliest available data	Live births covered yearly	Province/Territory/ Nation-wide	Case definition				Surveillance Methods		Data Collected			Data use	Mandatory Reportable Cases (P/T Legislation) Yes/No
					Conditions	Pregnancy outcomes	Age	Coding	Data sources	Case ascertaiment	Infant/fetus information	Mother information	Father information		
AB	Alberta Congenital Anomalies Surveillance System (ACASS)	1980	~38,000-50,000	yes	all anomalies in ICD-9 Ch XIV and ICD-10 Ch XVII. Also congenital haematologic, metabolic, neuromuscular, endocrine, neoplastic and neurologic disorders as well as congenital infections if associated with anomalies	live births, some fetal deaths <20 wks, fetal deaths ≥20 wks, and elective terminations	up to 1 yr after delivery	RCPCH adaptation of ICD-10, ICD-9/10 (if not covered adequately in RCPCH), and McKusick Classification	hospital records, clinical genetics centres, pathology/autopsy reports, cytogenetic laboratories, newborn metabolic screening and vital stats	active and passive (medical records are reviewed when diagnosis is unclear or unconfirmed at time of ascertainment/reporting; letters are sent to physicians to clarify diagnoses and encourage reporting)	identification and demographic, birth weight, gestational age, birth defect diagnostic information	identification and demographic	identification and demographic	routine statistical monitoring, monitoring outbreaks and cluster investigation, epidemiological studies, data requests from clinics, special interest groups and health units/regions	no
BC	Health Status Registry (HSR)	1952	~45,000	yes	most congenital anomalies, some metabolic and genetic diseases, some handicapping conditions up to 19 yrs of age	live births, fetal deaths ≥20 wks	a person can be registered at any time, if registration requirements are met	ICD-9/10 and McKusick Classification	hospital records, hospital separation data, clinical genetics centres, and vital stats (birth/death certificates)	passive	identification and demographic	identification and demographic	identification and demographic	routine statistical monitoring, monitoring outbreaks and cluster investigation, epidemiological studies and identification of potential cases for other epidemiological studies, public health program evaluation	no
BC	Perinatal Data Registry, Perinatal Services BC	2000	~45,000	yes	all anomalies in ICD-10 Ch XVII	live births, fetal deaths ≥20 wks, elective terminations ≥20 wks, birth weight ≥500 grams	up to 28 days of life or 1 year if never discharged home	ICD-9/10	hospital records, hospital separation data, physician reports, prenatal diagnostic facilities, and vital stats (birth/death certificates)	passive	identification and demographic, birth weight, gestational age, birth defect diagnostic information, and results from certain tests and procedures	identification and demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors	no information collected	routine statistical monitoring	no
NB	New Brunswick Congenital Anomalies Surveillance Project	2000	~7,000	yes	all anomalies in ICD-10 Ch XVII	live births and fetal deaths ≥20 wks	up to 1 yr after delivery (most data gained on postnatal diagnosis at time of discharge)	ICD-10	hospital records and vital statistics (birth/death certificates)	passive	identification and demographic, birth weight, gestational age, birth defect diagnostic information	identification and demographic	no information collected	routine statistical monitoring	no
NL	Newfoundland and Labrador Provincial Perinatal Program (NLPPP)	2001	~5,000	no (85% coverage - 3 of 4 Regional Health Authorities)	all anomalies in ICD-10 Ch XVI	live births, fetal deaths ≥20 wks and elective terminations ≥20 wks	up to 28 days of age or discharge or death	ICD-10	hospital separation data, prenatal record, follow-up clinic and vital stats (birth/death certificates)	active and passive	identification and demographic, birth weight, gestational age, birth defect diagnostic information, and results from certain tests and procedures, and infant complications	identification and demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, maternal risk factors	identification and demographic	routine statistical monitoring/surveillance, epidemiological studies/applied health research, clinical review, quality assurance, program planning	no
NS	Surveillance for Congenital Anomalies in Nova Scotia (SCANS) (Atlee Perinatal Database (NSAPD) and the Fetal Anomaly Database (FAD) transitioning to SCANS starting 2011)	1980 (Atlee) 1992 (FAD)	~9,000	yes	all anomalies	live births, stillbirths (NSAPD); including elective terminations regardless of GA (FADB); both (SCANS)	up to 28 days of age or discharge or death (NSAPD, FADB); up to one year (SCANS)	NSAPD definitions (from 1980) with ICD-10-CA from 2003; FADB definitions; RCPCH adaptation of ICD-10 (with McKusick) in SCANS	medical chart (NSAPD); with prenatal diagnostic facilities, cytogenetic laboratories, maternal serum screening programs (FADB); with Vital Statistics, billings (SCANS)	passive (NSAPD); active (FADB and SCANS)	demographic, anthropometric, birth defect diagnostic information, results from certain tests and procedures, and infant complications (NSAPD); with karyotype, prenatal test results (FADB), with recommended variables (SCANS)	demographic, obstetric history, illnesses/conditions, prenatal care, pregnancy/delivery complications (NSAPD); maternal risk factors (FADB), with recommended variables (SCANS)	none (NSAPD); occupation (FADB); with ethnicity, consanguinity (SCANS)	epidemiological studies, clinical review (FADB); with routine statistical monitoring, program planning (NSAPD), with cluster investigation (SCANS)	no
NU	Nutaqqavut Surveillance System (NSS)	2010	~750	yes	all anomalies in ICD-10 Ch XVII, inborn errors of metabolism and hereditary muscle and blood disorders	all, except early terminations	up to preschool (age 4)	ICD-9/10	hospital records, hospital discharge forms, prenatal records, well-child visit forms, birth defect reporting form, laboratory database, summary records from out-of-territory hospitals	active and passive	demographic, birth weight, gestational age, prenatal ultrasound, congenital anomalies diagnostic info, developmental delay, developmental conditions, hearing loss	demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, maternal nutrition/food security, maternal exposures	ethnicity, congenital anomalies, occupation, education level	routine statistical monitoring, program planning, clinical review, surveillance and research	no
NWT	NWT Congenital Anomalies Surveillance System	2011	~680 (average annual births between 2000-2007)	yes	all anomalies on ICD-10 Q16.0	live births and fetal deaths ≥20 wks	up to 19 years after delivery	ICD-10 Q16.0	hospital records, pathology reports, newborn metabolic screening and vital stats	active and passive	identification and demographic, birth weight, gestational age, birth defect diagnostic information	identification and demographic	identification and demographic	routine statistical monitoring, epidemiological studies, data requests	yes
ON	Better Outcomes Registry & Network (BORN) Ontario	1993-2008 (Please refer to the BORN Ontario info page for more information)	~140,000	yes	neural tube defects, other CNS anomalies, cleft lip, cleft palate, Down syndrome, cardiovascular, GI, musculoskeletal, renal and respiratory anomalies, trisomy 18 and 21, data on other cytogenetic and ultrasound abnormalities, inborn errors of metabolism, CF	live births and fetal deaths ≥20 wks, and terminations for fetal anomalies following prenatal diagnosis	prenatal up to within a few days of birth, planning to expand up to 1 year of age	ICD-10-CA and database-specific codes	1. Ontario Maternal Multiple Marker Screening Program (OMMMS) 2. Fetal Alert Network (FAN) 3. Niday Perinatal Database 4. Newborn Screeing Ontario 5. Ontario Midwifery Program •Planning to have data from: paediatric cardiology, genetic clinics, paediatric hospitals, vital stats	active and passive	identification and demographic, birth weight, gestational age, birth defect diagnostic information, results from certain tests and procedures, and infant complications	identification and demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications and maternal risk factors, family history, maternal age at delivery	no information collected	routine statistical monitoring	no
PEI	PEI Reproductive Care Program	1990	~1,400 - 1,500	yes	all anomalies in ICD-9 Ch XIV and ICD-10 Ch XVII	live births and fetal deaths ≥20 wks and ≥ 500 grams	to initial discharge from hospital and readmission to hospital up to and including 28 days of age	ICD-9/10	hospital records and prenatal records	active	identification and demographic, birth weight, gestational age, birth defect diagnostic information, and results from certain tests and procedures, and infant complications	demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors	age, employment status	routine statistical monitoring and identification of potential cases for other epidemiological studies	no

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QC	Quebec Congenital Anomalies Surveillance System	1989	~ 88,000	yes	all anomalies in ICD-9 Ch XIV and ICD-10 Ch XVII	live births and fetal deaths ≥20 wks	up to 1 yr after delivery	ICD-10	numerator: hospital data records for infants < 1 year old (Med-Echo) and stillbirths (Vital Stats); denominator: live births and stillbirths data from Vital Stats	passive	demographic, birth defect diagnostic information	no information collected	no information collected	routine statistical monitoring, epidemiological studies	no
YK	Congenital Anomalies Surveillance Yukon (CASY)	mid-2011	~385	yes	all anomalies in ICD-10 Ch XVII, inborn errors of metabolism and hereditary muscle and blood disorders	live births, fetal deaths ≥20 wks, elective terminations ≥20 wks, all elective terminations due to a congenital anomaly	up to 1 year of age	ICD-10	discharge summaries, reporting from health care professionals in territory	active	demographic, some perinatal, malformation and testing data	demographic, some perinatal, exposures, testing and family history data	limited demographic and family history data	routine statistical monitoring, program planning, clinical review, surveillance and research	no
CANADA	Canadian Congenital Anomalies Surveillance System (CCASS) Hospitalisation Data (source: CIHI)	1973	~370,000	all Provinces and Territories	all anomalies in ICD-9 Ch XIV and ICD-10 Ch XVII	live births and fetal deaths ≥20 wks	up to 1 yr after delivery before 2001 and 30 days since 2001 (except QC and AB still 1 year)	ICD-9/10	hospital admission/separation data	passive	demographic, birth defect diagnostic information	no information collected	no information collected	routine epidemiological monitoring of trends, reports, studies, data requests	n/a
	Canadian Congenital Anomalies Surveillance System (CCASS) Congenital Anomalies Surveillance Enhancement Initiative	2011	~162,135	NB, NS, NU, ON, SK, YK	all anomalies in ICD-10 Ch XVII	live births, stillbirths ≥20 wks and terminations of pregnancies	up to 1 year of age	ICD-10	provincial and territorial congenital anomalies surveillance program data	active and passive	demographic, birth weight, gestational age, birth defect diagnostic information	date of birth, place of residence	no information collected	routine epidemiological monitoring of trends, reporting, studies, data requests	n/a