

Surveillance Systems and Data Sources for Congenital Anomalies in Canada

Name	Province	Earliest available data	Live births covered yearly	Province-wide	Case definition				Surveillance Methods		Data Collected			Data use
					Conditions	Pregnancy outcomes	Age	Coding	Data sources	Case ascertainment	Infant/fetus information	Mother information	Father information	
Alberta Congenital Anomalies Surveillance System (ACASS)	AB	1980	36,000-38,000	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	Royal College of Paediatrics and Child Health-RCPC (formerly British Paediatric Association-BPA) Classification of Diseases, ICD-9/10 (if not covered adequately in RCPC), 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 measurements (weight, gest. 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
Health Status Registry (HSR)	BC	1952	~40,000	Yes	most congenital anomalies, some metabolic and genetic diseases, some handicapping conditions up to 19 yrs of age	live births, fetal deaths =20 wks, and elective terminations =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)	active and 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
British Columbia Reproductive Care Program (BCRCP)	BC	2000	~40,000	Yes	all anomalies in ICD-10 Ch XVII	live births, fetal deaths =20 wks and elective terminations =20 wks		ICD-9/10	hospital records, hospital separation data, physician reports, prenatal diagnostic facilities, and vital stats (birth/death certificates)	passive	identification and demographic, birth measurements (weight, gest. age), birth defect diagnostic info, and some tests and procedures	identification and demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, maternal risk factors	no info collected	routine statistical monitoring
Manitoba Maternal Serum Screening Program (MMSSP)	MB	1985	<14,000	No (limited to women undergoing prenatal screening or ~70% of total)	major birth defects	live births, fetal deaths – stillbirths, spontaneous abortions (<20 wks, fetal deaths =20 wks), and elective terminations	most data gained on postnatal discharge diagnosis	ICD-9/10	hospital records, hospital separation data, prenatal diagnostic facilities, cytogenetic laboratories and clinical genetics centres	active and passive (medical records are reviewed where they relate to conditions detectable by MSS, e.g., NTD, Down syndrome)	identification and demographic, birth measurements (weight, gest. age), birth defect diagnostic info, tests and procedures, and infant complications	identification and demographic, gravidity/parity, illnesses/conditions, prenatal diagnostic info and pregnancy/delivery complications	no info collected	epidemiological studies and identification of potential cases for other epidemiological studies, public health program evaluation
Newfoundland and Provincial Medical Genetics Program	NF	1976	~4,800	Yes	neural tube defects	live births, fetal death <20 wks gestation, fetal deaths =20 wks, elective terminations <20 wks and elective terminations =20 wks	up to 2 yrs after delivery	ICD-9/10	hospital records, prenatal diagnostic facilities, clinical genetics centres, maternal serum screening programs, and vital stats (birth/death certificates)	active and passive	demographic, birth measurements (weight, gest. age), and birth defect diagnostic info	demographic, gravidity/parity, illnesses/conditions, prenatal diagnostic info, pregnancy/delivery complications, family history	no info collected	routine statistical monitoring and epidemiological studies
Nova Scotia Atlee Perinatal Database and the Fetal Anomaly Database	NS	1980 (Atlee) 1992 (FAD)	9,000-10,000	Yes	major and minor anomalies in infants >20 wks or >500 grs (Atlee), major and minor anomalies identified antenatally, after birth or death (FAD)	live births, fetal death <20 wks (if an anomaly is identified prior to stillbirth), fetal deaths =20 wks, induced deliveries for fetal anomaly	up to 28 dys of age or discharge or death	NS system developed by experienced specialists. Atlee is incorporating ICD-10 to facilitate national comparisons. The FAD utilizes unique codes developed by experienced specialists.	hospital records, physician reports, prenatal diagnostic facilities, cytogenetic laboratories, maternal serum screening programs, and vital stats (birth/death certificates)	active for both databases (based on inclusion criteria)	demographic, birth measurements (weight, gest. age), birth defect diagnostic info, tests and procedures, and infant complications	demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, maternal risk factors	known occupational risk factors/exposures and family history	routine statistical monitoring, monitoring outbreaks and cluster investigation, epidemiological studies, program planning, clinical review. The FAD is primarily used for surveillance and research.
Niday Perinatal Database	ON	2004	~100,000	No (85% of provincial births)	neural tube defects, other CNS anomalies, cleft lip, cleft palate, Down syndrome, cardiovascular, GI, musculoskeletal, renal and respiratory anomalies	live births and fetal deaths =20 wks	at time of discharge	Niday database definitions	hospital records	active	demographic, birth measurements (weight, gest. age), birth defect diagnostic info, tests and procedures, and infant complications	demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications and maternal risk factors	no info collected	routine statistical monitoring
Ontario Maternal Serum Screening Program	ON	1993	~70,000	No (limited to women undergoing prenatal screening)	trisomy 18 and 21, open neural tube defects, also receive data on other cytogenetic and ultrasound abnormalities	live births, fetal deaths =20 wks, and elective terminations =20 wks	within a few dys of birth (diagnosis must be made at time of hospital admission record filing)	ICD-9/10, karyotypic results, ultrasound findings	hospital records, physician reports, prenatal diagnostic facilities, clinical genetics centres, cytogenetic laboratories, maternal serum screening programs	active and passive	identification and demographic, birth measurements (weight, gest. age), birth defect diagnostic info, tests and procedures, and infant complications	identification and demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, maternal risk factors, family history	no info collected	routine statistical monitoring, monitoring outbreaks and cluster investigation, epidemiological studies, public health program evaluation
PEI Reproductive Care Program	PEI	1990	~1,400	Yes	all anomalies in ICD-9 Ch XIV and ICD-10 Ch XVII	live births and fetal deaths =20 wks	usually within a few dys of birth, but follow-up can be longer if diagnosis is uncertain at discharge	ICD-9/10	hospital records and prenatal records	active	demographic, birth measurements (weight, gest. age), birth defect diagnostic info, tests and procedures, and infant complications	demographic, gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, maternal risk factors, family history	no info collected	routine statistical monitoring and identification of potential cases for other epidemiological studies
MED-ECHO	QC	1989	~71,000	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-9/10	hospital admission/separation data	passive	demographic, birth defect diagnostic info	no info collected	no info collected	routine statistical monitoring, epidemiological studies
Canadian Congenital Anomalies Surveillance System (CCASS)	AB BC MB NB NL NS NU NWT ON PEI QC SK YK	1973	~330,000	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-9/10	hospital admission/separation data	passive	demographic, birth defect diagnostic info	no info collected	no info collected	routine statistical monitoring, epidemiological studies, data requests