



## **Recommended Data Variables for Congenital Anomalies Surveillance in Canadian Provinces & Territories**

To promote the development and enhancement of surveillance systems for congenital anomalies in Canadian provinces and territories, the Canadian Congenital Anomaly Surveillance Network (CCASN) specified three objectives: (1) to identify sources of ascertainment, and data available from these sources, in each jurisdiction; (2) to determine the minimal data necessary for: (a) linkage between the sources and (b) provincial/territorial-level surveillance; and, (3) to identify data additional to the minimal set that would enhance the value of the system in service planning and research.

In relation to the second and third objectives, the Demographic and Risk Indicators Working Group of the CCASN reviewed existing practices and recommendations for data collection from surveillance systems in Canada, the United States and Europe, and relevant scientific literature identified from an environmental scan. Key issues included:

- enabling linkage of multiple sources of ascertainment, as this has been shown to be crucially important in maximizing comparability of data over time within and between jurisdictions;
- collection of information on the diagnosis and information relevant to the interpretation of the diagnosis (such as sex, birth weight, gestation, plurality and contact information for responsible party); and,
- the ability to conduct surveillance by time, place and maternal characteristics.

For each variable, the group considered both the importance of the variable and the feasibility of collecting the data. The resulting list of variables is organized into two categories:

1. Minimum data variables deemed necessary to meet provincial/territorial program objectives (Table 1); and
2. Recommended data variables which can enhance the capacity of the system (Table 2).

**Table 1. Minimum Data Variables for Congenital Anomalies Surveillance in Canadian Provinces and Territories**

No.	Data Variable Name	Data Format	Data Usage
<b>Personal Identification and Administrative Information</b>			
<b>Infant/Fetus</b>			
1	Personal (unique) health number (PHN)	Char 9 or other	Unique ID for linkage
2	Birth registration number (BRN)	Char 11	Unique ID in Vital Stat
3	Date of birth/termination	mm/dd/yyyy	Linkage and age calculation
4	Place of birth	Text	Analysis and reporting
5	Hospital ID of birth	Char 12	Linkage and identification
6	Death registration number (DRN)	Char 11	Unique ID in Vital Stat
7	Date of death	mm/dd/yyyy	Linkage and survival analysis
8	Place of death	Text	Analysis and reporting
9	Live/stillbirth or termination flag	Char 2	Linkage and analysis
10	Sex	Char 1	Linkage and analysis
11	Family name	Char 50	Linkage and identification
12	First name	Char 40	Linkage and identification
13	Middle name	Char 50	Linkage and identification
<b>Mother</b>			
14	Personal health number (PHN)	Char 9 or other	Unique ID for linkage
15	Date of birth	mm/dd/yyyy	Linkage and age calculation
16	Family name	Char 50	Linkage and identification
17	Maiden name	Char 50	Linkage and identification
18	First name	Char 40	Linkage and identification
19	Middle name	Char 50	Linkage and identification
20	Residence postal code at delivery	Char 7	Linkage and analysis
21	Residence standard geographic code	Char 7	Linkage and analysis
22	Residence health region	Char 2	Linkage and analysis
<b>Case Ascertainment and Reporting</b>			
23	Source of report	Char 7	Analysis and reporting
24	Name/code of reporting agency	Text	Analysis and reporting
25	Single or multiple anomalies	Char 1	Analysis and reporting
26	Syndrome flag	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
27	Diagnostic code(s) (ICD-10-CA, ICD-9-CM)	Char 7	Analysis and reporting
28	ICD version indicator	09 vs. 10	Analysis and reporting
29	Baby's birth weight (g)	Numeric	Analysis and reporting
30	Gestational age (weeks)	Numeric	Analysis and reporting
31	Plurality (singleton, twins, ...)	Char 2	Analysis and reporting
32	Date of reporting	mm/dd/yyyy	Analysis and reporting
<b>Contact Information</b>			
33	Name of responsible party (physician...)	text	
34	Mailing address of responsible party	text	
35	Tel and fax number of responsible party	Numeric	
36	Email address of responsible party	text	

**Table 2. Recommended Data Variables for Enhanced Congenital Anomalies Surveillance in Canadian Provinces and Territories**

No.	Data Variable Name	Data Format	Data Usage
<b>Personal Identification and Administrative Information</b>			
37	Baby's name change flag	Char 1	Linkage and identification
38	Adopted name (AKN)	Text	Linkage and identification
39	Mother's hospital chart ID	Char 12	Linkage and identification
40	Mother's mailing address at birth or termination	Text	Linkage and identification
41	Mother's place/country of birth	Text	Analysis and reporting
42	Marital status of mother	Char 2	Analysis and reporting
43	Immigrant from other country (mother)	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
44	Mother's ethnicity	Char 2	Linkage and analysis
45	Father's date of birth	mm/dd/yyyy	Linkage and age calculation
46	Father's ethnicity	Char 2	Linkage and analysis
<b>Diagnostic Information</b>			
<b>Infant/Fetus</b>			
47	Text description of birth defect	Text	Analysis and reporting
48	Birth length (cm)	Numeric	Analysis and reporting
49	Weight centile	Numeric	Analysis and reporting
50	Head circumference (cm)	Numeric	Analysis and reporting
51	Apgar score	Numeric	Analysis and reporting
52	Birth order	Numeric	Analysis and reporting
53	Cytogenetic analyses performed	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
54	Diagnostic tests and procedures performed	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
55	Autopsy performed	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
56	Date of diagnosis or test(s)	mm/dd/yyyy	Analysis and reporting
<b>Mother</b>			
57	Medical record number(s)	Char 12	Linkage and identification
58	Receiving prenatal care flag	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
59	Participate prenatal class flag	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
60	Number of prenatal visits	Numeric	Analysis and reporting
61	Date of last menstrual period (LMP)	mm/dd/yyyy	Analysis and age calculation
62	Number of ultrasounds: <input type="checkbox"/> 1st trimester <input type="checkbox"/> 2nd trimester	<input type="checkbox"/> 0 <input type="checkbox"/> 1-2 <input type="checkbox"/> 3-4 <input type="checkbox"/> 5+ <input type="checkbox"/> 0 <input type="checkbox"/> 1-2 <input type="checkbox"/> 3-4 <input type="checkbox"/> 5+	
63	Mother's pre-pregnancy weight (kg)	Numeric	Analysis and reporting
64	Mother's height (cm)	Numeric	Analysis and reporting
65	Number of pregnancies (including current pregnancy)	Numeric	Analysis and reporting
66	Parity	Numeric	Analysis and reporting
67	Number of pregnancy losses in <input type="checkbox"/> Stillbirth <input type="checkbox"/> Spontaneous abortion <input type="checkbox"/> Induced abortion	Numeric Numeric Numeric	Analysis and reporting Analysis and reporting Analysis and reporting
68	Maternal conditions: <input type="checkbox"/> Chronic hypertension <input type="checkbox"/> Pre-pregnancy diabetes <input type="checkbox"/> Maternal obesity <input type="checkbox"/> Pre-pregnancy heart disease <input type="checkbox"/> Pre-pregnancy renal disease <input type="checkbox"/> Blood-borne pathogens <input type="checkbox"/> Other (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> HIV/AIDS <input type="checkbox"/> HBV <input type="checkbox"/> HCV <input type="checkbox"/> Other Text	Analysis and reporting



No.	Data Variable Name	Data Format	Data Usage
69	Pregnancy complications: <input type="checkbox"/> Pre-eclampsia <input type="checkbox"/> Pregnancy-induced hypertension <input type="checkbox"/> Gestational diabetes <input type="checkbox"/> Prenatal bleeding <input type="checkbox"/> Premature rupture of membranes <input type="checkbox"/> Pregnancy infections <input type="checkbox"/> Other (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Syphilis <input type="checkbox"/> Rubella <input type="checkbox"/> TB <input type="checkbox"/> Other Text	Analysis and reporting
70	Mode of delivery (vaginal vs. cesarean)	<input type="checkbox"/> Vag. <input type="checkbox"/> CD Text	Analysis and reporting
71	Complications of delivery: <input type="checkbox"/> Prolonged labour <input type="checkbox"/> Shoulder dystocia <input type="checkbox"/> Forceps delivery <input type="checkbox"/> Birth asphyxia <input type="checkbox"/> Other (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No Text	Analysis and reporting
72	Prenatal screening: <input type="checkbox"/> Down syndrome <input type="checkbox"/> Neural tube defects (NTDs) <input type="checkbox"/> Congenital metabolic disorders <input type="checkbox"/> Other defects (specify) <input type="checkbox"/> Other screening (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No Text Text	Analysis and reporting
<b>Parental Social Class and Socio-economic Information</b>			
73	Mother's education: <input type="checkbox"/> Highest university degree <input type="checkbox"/> Highest college degree <input type="checkbox"/> Trade certificate or diploma <input type="checkbox"/> Completed high school <input type="checkbox"/> Less than grade 12	Text Text <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
74	Mother on social-family welfare flag	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
75	Mother on health care subsidy flag	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
76	Mother's occupation at conception	Text	Analysis and reporting
77	Father's occupation at conception	Text	Analysis and reporting
<b>Parental Risk or Protective Factors</b>			
78	Maternal alcohol use prior/during pregnancy	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
79	Prescription drug use during pregnancy	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
80	Non-prescription drug use prior/during pregnancy	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
81	Maternal smoking prior/during pregnancy	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
82	Other maternal exposure: <input type="checkbox"/> Environmental hazards <input type="checkbox"/> Occupational hazards <input type="checkbox"/> Radiations <input type="checkbox"/> Medications <input type="checkbox"/> Other (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No Text	Analysis and reporting Analysis and reporting Analysis and reporting Analysis and reporting Analysis and reporting
83	Family history of malformations	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
84	Family history of genetic diseases	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting
85	Use of folic acid at conception	<input type="checkbox"/> Yes <input type="checkbox"/> No	Analysis and reporting

**Notes:**

1. Coding for missing values should be added to all variables; code "9" for character variables and "." for numeric variables.
2. Personal Health Number, Inpatient Chart Number and other medical record numbers may vary by province/territory, thus data from each jurisdiction may need to be analyzed separately.
3. Data on use of alcohol, drug, and smoking are self-reported and may be under-reported; some variables are collected for administrative purposes. Caution in interpretation should always be exercised.
4. Coding standards should be developed for all variables. Statistics Canada's data classification and coding may be used as a reference.