

**NLCHI Stillbirth System
Data Users Guide
March 2014 v.1.1**

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Stillbirth Data User Guide 2014

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Table of Contents

	Page
1. NLCHI Stillbirth System - Introduction	
1.1 Overview	1
1.2 Purpose of Dataset	1
1.3 Population Reference Coverage	1
1.4 Reporting Period	1
1.5 Years Available	1
1.6 Management Responsibility	1
2. Description of Dataset	
2.1 Description	2
2.2 Data Dictionary/Elements.....	2
2.3 Reference Materials	2
3. Data Source(s)	
3.1 Origin of Data	2
3.2 Flow of data.....	3
3.3 Data Collection and Processing Time Lines	3
4. Data Quality Processes	
4.1 Edit and Correction Process.....	3
4.2 Maintenance Procedure	4
5. Significant Data Quality History	
5.1 Methodological/Revision Changes	5
6. Data Quality Limitations	
6.1 Contributors Impact on Data Quality	5
7. Data Access, Storage, Retrieval and Privacy	
7.1 Access.....	5
7.2 Storage and Retrieval	5
7.3 Privacy	6
8. Comparisons to Other Holdings	
8.1 Centre Holdings.....	6
8.2 Other Holdings	6
Appendix 1 - Data Dictionary.....	7
Appendix 2- Copy of Registration of Stillbirth Form.....	12
Appendix 3 - Glossary	13

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1. Introduction

1.1 Overview

This document has been prepared to inform users of the NLCHI Stillbirth System about the data, the system, and known data quality issues which may impact the use or interpretation of the data.

This document is reviewed annually and revised as needed to ensure it remains current and useful. Feedback from readers is welcomed. Suggestions for future updates can be sent to:

Manager Clinical Standards and Information
Newfoundland and Labrador Centre for Health Information
70 O'Leary Avenue
St. John's, NL A1B 2C7
Phone 709 752-6014

1.2 Purpose of Dataset

This dataset is used primarily for research regarding stillbirths which occur within the province of Newfoundland & Labrador and to provide aggregate statistical information. It is also used to cross reference other datasets for quality assurance and verification purposes.

The Research and Evaluation Department (R&E) at the Centre provides stillbirth statistical information and reports to government agencies, health care managers, clinicians, etc. to assist in making evidence-based decisions.

1.3 Population Reference Coverage

Under the Vital Statistics Act (2009) all stillbirths occurring within the province of Newfoundland and Labrador must be reported to Vital Statistics within 5 days of delivery. All health care facilities and midwives in private practice in Newfoundland and Labrador submit Registration of Stillbirth (RSB) forms to Vital Statistics in compliance with the Act.

1.4 Reporting Period

The reporting period for Stillbirths is the calendar year, January 1st to December 31st.

1.5 Years Available

Data is available for the years 1992-2013.

1.6 Management Responsibility

The Manager Clinical Standards and Information is responsible for managing the NLCHI Stillbirth System, ensuring the system is of the highest quality attainable and available to stakeholders for use.

The NLCHI Live Birth/Mortality Systems Advisory Committee is comprised of internal and external stakeholders. This committee's mandate is to advise the Manager Clinical Standards and Information on stakeholder information needs, data collection, and other relevant issues. One of the committee's

responsibilities is to perform an annual review of the RSB form and make recommendations regarding data collection requirements.

2. Description of Dataset

2.1 Description

This dataset contains demographic, administrative and clinical data related to all stillbirths that occur in the province, both resident and non-resident. NLCHI's Stillbirth System is populated with data from 1992 to 2013.

There are 61 data elements which include information about the infant, mother and other parent.

The Registration of Stillbirth (RBS) form contains multiple sections. Responsibility for completion of the sections varies as noted in the table below:

Section	Responsibility for Completion
Registration	Vital Statistics
Infant	Health Care Professional
Birth Mother	Health Care Professional
Other Parent	Health Care Professional
Informant	Health Care Professional/Funeral Home
Health History	Health Care Professional
Medical Certification	Health Care Professional
Disposition-Funeral Home	Funeral Home
Office Use	Vital Statistics

Data are retained in a longitudinal file to facilitate efficient retrieval and creation of statistical data reports and research. The longitudinal file is updated annually with previous year's data.

2.2 Data Dictionary/Elements

Data elements on the RSB form are those identified by the Live Birth/Mortality Systems Advisory Committee as required data by one or more of the stakeholders. Of all the elements on the RSB form, a minimum data set is entered into the dataset. The Stillbirth System Data Dictionary (Appendix 1) contains the list of data elements, element details and the reference year.

2.3 Reference Materials

Reference materials available from the Data Quality and Standards Department include:

- Copies of the RSB form(s), 1977-2013.
- The Guide to the Completion of Registration of Death and Registration of Stillbirth. This document is produced by Vital Statistics as a reference document for those responsible for completing the registration form.
- List of edits.

3. Data Source(s)

3.1 Origin of Data

Data originates at the facility where the birth has taken place. For stillbirths that occur at home or enroute to a hospital, the forms are completed by either a midwife or the hospital attending the infant immediately after birth.

3.2 Flow of Data

After RSB forms are completed at the facility where the birth occurs, the original and the Centre's copy are sent to Vital Statistics. When attended by a midwife, the midwife is responsible for sending the original and the Centre's copy to Vital Statistics. In the case of stillbirths that occur enroute to hospital the RSB is completed by the facility attending to the infant; the original and the Centre's copy are sent to Vital Statistics. Vital Statistics adds administrative data before forwarding the Centre's copy to Data Quality and Standards Department.

Health Information Management (HIM) analysts at the Centre, assign the medical codes. Medical codes are based upon the ICD-10-CA/CCI as of January 1, 2003. Prior to 2003, ICD-9/CCI classification system was used. The forms are forwarded to the data entry operator for demographic coding and data entry. The demographic coding includes Standard Geographical Code (SGC) and institution code for location of birth.

DQS staff complete an edit process at year-end prior to closure of the annual file. Once closed, the file is added to the longitudinal dataset and is ready for use by stakeholders.

The mortality data is de-identified post editing process before it is made available to researchers. Access to identifiable information is only provided when absolutely necessary.

3.3 Data Collection and Processing Time Lines

- Daily: facilities are legally required to report stillbirths to Vital Statistics within 5 days of delivery.
- Monthly: Vital Statistics completes the administrative section of the form and forwards a copy to the Centre.
- Annually: RSB forms are usually received by the Centre prior to the end of January for the previous calendar year.
- March 31, YYYY: the annual cycle of social and medical coding, data entry and corrections for the previous data year is scheduled for completion.
- April 1, YYYY: the stillbirth longitudinal file is scheduled to be updated with the previous calendar year data and made available for use.

4. Data Quality Processes

4.1 Edit and Correction Process

The NLCHI Stillbirth System contains a series of edit checks which have been designed to automatically flag data elements that are incomplete, illegible or contain incorrect data.

Corrections and/or clarifications are completed through contacting staff within the Health Records Department of the applicable hospital.

Internal edits are processed annually and consist of logic and derived fields. These include steps such as, sorting facilities within the applicable regional health authority and reviewing the appropriateness of the mother's age.

Adjustments to element values may be required during the edit process. For example, changing the previous year to current year, to calculate mother's age at date of delivery. This type of adjustment ensures accuracy when sorting data into age categories.

After all edits are completed a validation of MCP numbers is performed.

The correction process is scheduled to be completed by March 1st for the previous year's data.

4.2 Maintenance Procedure

The Live Birth/Mortality Advisory Committee members are responsible for bringing forward issues or concerns from their respective organizations, providing expertise, seeking input from their organizations and circulating decisions made by the committee.

This is a dynamic dataset therefore users should be aware of past data element changes and that changes are likely to occur in the future. Due to these ongoing changes, data elements have been added, revised or classified as inactive. Data elements that are deemed inactive are no longer entered into the dataset. However for historical purposes these data elements and their values remain in the dataset (for the applicable years).

Whenever it is discovered that Vital Statistics inadvertently omitted a form or a health care facility failed to report a stillbirth, these revisions are retrospectively added to the longitudinal file.

When corrections are required after the year-end file is closed, the revisions are made and the changes documented, including the rationale for the changes.

The revised stillbirth dataset is renamed, assigning a new version number and date to ensure accurate identification of the most recent data.

In 2008, data entry screens were redesigned and standardized to assist with data quality on input. For example, the date of birth format validation as mm/dd/yyyy was implemented.

End users of stillbirth data may identify data quality issues. When an issue is reported to DQS staff, corrective and/or preventative action is taken.

5. Significant Data Quality History

5.1 Methodological/Revision Changes

It is believed that the data elements collected and entered into the dataset had not been updated since the mid 1980s. From 1992 to 2002 there is little documentation available to identify revision history.

From 1991 to 1999 Vital Statistics began its registration numbering sequence with 1001. Since 2000 the numbering sequence was changed to begin with number 1.

Prior to 1990 Statistics Canada assigned code 12 to represent Newfoundland and Labrador; in June 1990 the code was changed to 10.

Since 2003, the RSB form has undergone significant changes to data elements collected and the minimum dataset entered into the NLCHI Stillbirth System.

The following versions of Statistics Canada SGC codes were used for social coding:

- 1991 to 2007 SGC version 1991
- 2007 to 2009 SGC version 2001
- 2007 to 2011 SGC version 2006
- 2012 to 2013 SGC version 2011

6. Data Quality Limitations

6.1. Contributors Impact on Data Quality

Whenever it is discovered that Vital Statistics inadvertently omitted a form, or a health care facility failed to report a birth, revisions are retrospectively added to the longitudinal file.

Historically, the only reference source available to assist with quality assurance activities was the Vital Statistics paper form, which is also the source of origin. Since 2009, DQS staff have been authorized to access the provincial Client Registry and the MCP Beneficiary Registration Database to cross reference key administrative and demographic data elements to improve data quality.

The Centre does not challenge submissions, consequently fields with unknown values are accepted; therefore some data elements may have a higher than expected 'unknown' result.

Due to significant investments in quality assurance processes in recent years, the file years from 2003 onward are more accurate and complete than those of previous years.

7. Data Access, Storage, Retrieval and Privacy

7.1 Access

Authorized users are allowed access and privileges as required to perform their duties as approved by their director/manager.

External users will be required to use the Centre's secure Managed File Transfer system (MFT) in order to receive private and confidential information. To gain access to MFT, the user must complete a MFT application form, provide by the

Information Protection Team. Access will be granted upon approval of the application.

7.2 Storage and Retrieval

Source documents used to create the dataset are kept indefinitely until such time as the Centre implements a new retention policy.

The electronic dataset is maintained indefinitely and is stored on a secure server at the Centre.

The Stillbirth System data has a standardized naming convention to provide easy identification and prompt retrieval of data. The naming convention rules can be found in Appendix 5.

7.3 Privacy and Confidentiality Responsibilities

The Centre's Secondary Uses Committee reviews applications for the use of record level stillbirth data for research and data quality purposes. A strong component of this committee is adherence to privacy and confidentiality legislation.

It is the responsibility of all users of stillbirth data to ensure complete confidentiality of the information and comply with all conditions to the data disclosure.

Researchers are granted access to de-identification data only, unless their research specifically requires identifiable data.

8. Comparisons to Other Holdings

8.1 Centre Holdings

Comparability across the years in the stillbirth system and with other Centre datasets is possible using static elements such as the mother's MCP number. In Clinical Database Management System (CDMS) the mother's MCP number provides access to other identifiers such as chart number that can be used to link to the infant.

8.2 Other Holdings

Comparability between Statistics Canada and Vital Statistics stillbirth databases is possible using the registration number.

Appendix 1 Stillbirth System Data Dictionary

Variable Name	Label	Value/Example	Type	Length	Applicable Year(S)	Comments
reg_num	Registration Number	Year-Province-Accession Number YYYY/NL/1234... 10=Newfoundland and Labrador	Numeric	8	1992 – 2013	
year	Year of Death	YYYY	Numeric	8	1992 – 2013	
deadname	Name of Deceased	Surname, Given Name(s)	String	40	1992 – 2013	
i_sex	Sex	1 = Male 2 = Female	Numeric	8	1992 – 2013	
i_locbir	Locality of Stillbirth	1 = Hospital 2 = Private Home 3 = Other Healthcare Facility 4 = Unknown 5 = Other	Numeric	8	1992 – 2013	
i_locoth	If Other, specify		String	15	1992 – 2013	
i_hospit	Hospital -Other Health Care Facility	Hospital Code	String	3	1992 – 2013	
facility	Hospital -Other Health Care Facility	Facility Name	String	45	1992 – 2013	This is a derived variable from i_hosp
momname	Name of Mother	Surname, Given Name(s)	String	40	1992 – 2013	
maiden_surname	Mother's Maiden Name	Surname, Given Name(s)	String	40	1992 – 2013	
mcp_validated	Mother's MCP	Mother's MCP was checked by NLCHI and is valid	Numeric	12	1992 – 2013	
m_dob_derived	Mother's Date of Birth	Mother's date of birth derived from validated mcp	Numeric	20	1992 – 2013	
m_age_derived	Mother's age	Mother's age at time of delivery	Numeric	8	1992 – 2013	Derived from derived dob and date of sb
m_hadd	Mother's Home Address	Mother's home address	String	8	1992 – 2013	Community Code Only
sgc_sb	SGC Code	Standard Geographical Classification	Numeric	8	1992 – 2009	Derived from m_hadd
m_pcode	Postal Code	Mother's postal code	String	6	1992 – 2013	

Variable Name	Label	Value/Example	Type	Length	Applicable Year(S)	Comments
hth_auth	Regional Health Authority		Numeric	8	1992 – 2013	Derived from sgc_sb
m_marsta	Mother's Marital Status	1=Never Married 2=Legally Married & Not Separated 3=Legally Married but Separated 4=Divorced 5=Widowed 6=Unknown	Numeric	8	1992 – 2013	
Laparent	Living Arrangements	1=Living together as a couple 2=Not living together as a couple 3=Unknown	Numeric	8	1992 – 2013	
m_edu	Mother's Education	1=Has not Graduated High School 2=Graduated High School 3=Beyond High School 4=College/University 5=Unknown	Numeric	8	1992 – 2013	
Medterm	Was death due to Medical Termination of Pregnancy	1=Yes 2=No	Numeric	8	2009-2013	
pr_week	Duration of Pregnancy (weeks)		Numeric	8	1992 – 2013	
pr_day	Duration of Pregnancy (days)		Numeric	8	1992 – 2013	
num_sb	Number of Stillborn in this event		Numeric	8	1992 – 2013	
num_born	Total number of children in this event	1=Singleton 2=Twin 3=Triplet 4=Quadruplet 5=Quintuplet	Numeric	8	1992 – 2013	
live_ev	Total number of <u>liveborn</u> children ever to this mother		Numeric	8	1992 – 2013	

Variable Name	Label	Value/Example	Type	Length	Applicable Year(S)	Comments
still_ev	Total number of <u>stillborn</u> children ever to this mother		Numeric	8	1992 – 2013	
ch_total	Total number of children ever born to this mother (live + still)		Numeric	8	1992 – 2013	Automatically calculated upon entry of number of live + still
fetaldem	Did fetal demise occur...?	1=Before Labour 2=During Labour 3=During Operative Procedure 4=Other 5=Before Hospital Admission	Numeric	8	1992 – 2013	Value '5' no longer a selection on Registration of Stillbirth form.
fetal_ot	If Other, specify	Specify when Other fetal demise occurred	String	100	1992 – 2009	
labor_induced	Was labour induced?	1=Yes 2=No	Numeric	8	1992-2013	
sb_date	Date of stillbirth	(mm/dd/yyyy)	Date	20	1992 – 2013	
Season	Season when stillbirth occurred	1=Winter (Dec - Feb) 2=Spring (Mar - May) 3=Summer (June - Aug) 4=Fall (Sept – Nov)	Numeric	8	1992 – 2013	This is a derived variable from sb_date
Weight	Birth weight (grams)		Numeric	8	1992 – 2013	
icd10_a	Immediate Cause of Stillbirth	Fetal disease or condition directly leading to stillbirth (ICD-10 Code)	String	6	1992 – 2013	
ctypea	Cause a Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
icd10_b	Antecedent Cause of Stillbirth	Fetal and/or maternal conditions, giving rise to the immediate cause of stillbirth (ICD-10 Code)	String	6	1992 – 2013	
ctypeb	Cause b Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
icd10_c	Antecedent Cause of Stillbirth	Fetal and/or maternal conditions, giving rise to the immediate cause of stillbirth (ICD-10 Code)	String	8	1992 – 2013	
ctypec	Cause c Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	

Variable Name	Label	Value/Example	Type	Length	Applicable Year(S)	Comments
icd10_d	Antecedent Cause of Stillbirth	Fetal and/or maternal conditions, giving rise to the immediate cause of stillbirth (ICD-10 Code)	String	6	1992 – 2013	
ctyped	Cause d Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
icd10_e	Antecedent Cause of Stillbirth	Fetal and/or maternal conditions, giving rise to the immediate cause of stillbirth (ICD-10 Code)	String	6	1992 – 2013	
ctypee	Cause e Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
icd10_f	Antecedent Cause of Stillbirth	Fetal and/or maternal conditions, giving rise to the immediate cause of stillbirth (ICD-10 Code)	String	6	1992 – 2013	
ctypef	Cause f Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
icd10_g	Antecedent Cause of Stillbirth	Fetal and/or maternal conditions, giving rise to the immediate cause of stillbirth (ICD-10 Code)	String	6	1992 – 2013	
ctypeg	Cause g Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
oth_con1	Other Condition	Other significant condition(s) of fetus or mother which may have contributed to the stillbirth but were not related to the immediate cause of stillbirth (ICD-10 Code)	String	8	1992 – 2013	
octype1	Other Condition 1 Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
oth_con2	Other Condition	Other significant condition(s) of fetus or mother which may have contributed to the stillbirth but were not related to the immediate cause of stillbirth (ICD-10 Code)	String	8	1992 – 2013	
octype2	Other Condition 2 Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
oth_con3	Other Condition	Other significant condition(s) of fetus or mother which may have contributed to the stillbirth but were not related to the immediate cause of stillbirth (ICD-10 Code)	String	8	1992 – 2013	

Variable Name	Label	Value/Example	Type	Length	Applicable Year(S)	Comments
octype3	Other Condition 3 Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
oth_con4	Other Condition	Other significant condition(s) of fetus or mother which may have contributed to the stillbirth but were not related to the immediate cause of stillbirth (ICD-10 Code)	String	8	1992 – 2013	
octype4	Other Condition 4 Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
oth_con5	Other Condition	Other significant condition(s) of fetus or mother which may have contributed to the stillbirth but were not related to the immediate cause of stillbirth (ICD-10 Code)	String	8	1992 – 2013	
octype5	Other Condition 5 Type	1=Fetal Condition 2=Maternal Condition	Numeric	8	1992 – 2013	
autopsy	Autopsy Y/N?	1=Yes 2=No	Numeric	8	1992 – 2013	
disposit	Disposition	1=Burial 2=Cremation 3=Unknown 4=Other	Numeric	8	1992 – 2013	
disp_oth	If Other, specify		String	8	1992 – 2013	

Appendix 2 Copy of the Registration of Stillbirth Form



Government of Newfoundland and Labrador
Service NL, Vital Statistics Division

REGISTRATION OF STILLBIRTH

1. Registration Number: 10

Department Use Only

Vital Statistics Division
Government Service Centre
6 Meave Place, P.O. Box 8700
St. John's, NL, Canada A1B 4J6
T (709) 722-3205 F (709) 722-0846

Privacy Notice
Personal information contained on this form is collected under the authority of the *Vital Statistics Act 2009* and will be used to register the stillbirth and provide extracts or search notices for administrative, statistical, research, medical and law enforcement purposes.
If you have any questions about the collection or use of this information, please contact a Vital Statistics Client Representative at the following location: →

**THIS IS A PERMANENT LEGAL RECORD. PLEASE PRINT PLAINLY AND COMPLETE ALL ITEMS.
THIS RECORD MUST BE COMPLETED AND FILED WITH THE REGISTRAR GENERAL.**

INFANT

2. Surname: _____ Given Name(s) (if any): _____

3. Sex: M F Unknown Other

4. Locality of Stillbirth: Hospital Private Home Other Health Care Facility Other (specify) _____ Unknown

5. Hospital / Other Health Care Facility Name: _____ Hospital Code: _____ Postal Code: _____

BIRTH MOTHER

7. Current Surname: _____ Maiden Surname: _____ All Given Name(s): _____ 8. Health Care Number: _____

9. Chart #: _____ 10. SIN: _____ 11. Date of Birth: _____ 13. Birthplace (Town / Prov. / Country): _____

14. Usual Home Address (not P.O. Box) (City/Town/Prov/Country): _____ SGC code: _____ Postal Code: _____

15. Complete Mailing Address (if different from above): _____ Postal Code: _____

16. Legal Marital Status: Never Married Legally Married and not separated Legally Married but Separated Divorced Widowed Unknown

17. Living Arrangements of Birth Parents: Living Together as a Couple Not Living Together as a Couple Unknown

19. Education: Has not Graduated High School Graduated High School Beyond High School College or University Degree (including Trade) Unknown

OTHER PARENT

23. Date of Birth: _____

INFORMANT

HEALTH HISTORY

27. Was this death due to a medical termination of pregnancy? Yes No

28. Duration of Pregnancy (weeks): _____ (days): _____ 29. Num. of stillborn in this event: _____

30. Total children in this event (including live & stillborn): Single birth Twin Triplet Quadruplet Quintuplet

31. Num. of children ever born to this Mother including this event: _____ Liveborn: _____ Stillborn: _____

33. Did Fetal Demise Occur ... Before Labour During Labour During Operative Procedures Other (specify) _____

34. Labour Induced: Yes No

MEDICAL CERTIFICATION - See Instructions On Reverse

36. Date of Stillbirth: _____ 37. Weight (grams): _____

39. Cause of Stillbirth: (Please Print) Check whether fetal or maternal

	Fetal (✓)	Maternal (✓)
PART I Immediate cause: Fetal disease or condition directly leading to stillbirth		
a) _____ (due to or as a consequence of) list only one diagnosis per line		
b) _____ (due to or as a consequence of) list only one diagnosis per line		
c) _____ (due to or as a consequence of) list only one diagnosis per line		
d) _____ (due to or as a consequence of) list only one diagnosis per line		
PART II Other significant conditions of fetus or mother which may have contributed to the stillbirth but were not related to the immediate cause (a) above.		
_____ list only one diagnosis per line		
_____ list only one diagnosis per line		
_____ list only one diagnosis per line		

40. Autopsy: a) Yes No b) If yes does the certified cause of death take into account information obtained at the time of autopsy? Yes No c) Further information expected on cause/nature of stillbirth? Yes No Unknown

41. Designation: Last Attending Physician Medical examiner Other (specify) _____
I certify that the above named person died on the date and from the causes stated herein.

42. Print name and address of last attending physician or medical examiner.

Signature: _____ Date certified: _____

DISPOSITION - FUNERAL HOME

Office Use

9-2300-84.1 2012-10-01

DISTRIBUTION: 2 White copies (Original) - Vital Statistics (via Funeral Home) Pink - Health Care Facility Goldenrod - Vital Statistics (via health care facility)

PLEASE PRESS FIRMLY - MULTIPLE COPY FORM

Appendix 3 Glossary

Client Registry

The Newfoundland and Labrador Client Registry System (the “Client Registry”) is a provincial information system containing demographic information on all individuals accessing the health and community services system in Newfoundland and Labrador (“clients”). The Client Registry is a fundamental component of the province’s vision for an integrated Electronic Health Record (“EHR”) for all residents of the province.

Hospital Code

This code identifies a Newfoundland and Labrador health care facility. A hospital code in the Stillbirth System consists of four characters, starting with an alpha followed by three numbers.

MCP Number

A 12 digit number issued to residents of the province by Newfoundland and Labrador Medical Care Plan.

Medical Coding

International Classification of Diseases and Related Health Problems, Tenth Revision, Canada (ICD-10-CA), this system consists of codes to classify diseases and health problems.

Canadian Classification of Health Interventions (CCI) is a national standard for classifying health care procedures. CCI is the companion classification system to ICD-10-CA.

Secondary Uses Committee

This Committee provides advice to the Chief Information Officer, who is accountable for the approval of new uses and disclosures of personal health information. Membership includes expertise in research, data quality and privacy information management.

Geographic Coding

This is a code that identifies a place of residence. The Standard Geographical Classification (SGC) is Statistics Canada's official classification of geographic areas in Canada. The SGC provides unique numeric codes for three types of geographic areas: provinces and territories, census divisions (counties, regional municipalities), and census subdivisions (municipalities).

Stillbirth

The complete expulsion or extraction from the mother of a fetus of at least 500 grams or more in weight or at least 20 weeks gestation in which, after the expulsion or extraction, there is no breathing, beating of the heart, pulsation of the umbilical cord or unmistakable movement of voluntary muscle.

Vital Statistics Division

The Newfoundland and Labrador Vital Statistics Division registers all vital events – births, adoptions, marriages and deaths and provides certificates regarding some of these vital events to the public.