

# Infant Mortality Report 2009-2011

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A Three Year Review of Infant Deaths in the Island  
Health Region

Infant Mortality Review Committee

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## Executive Summary

This report provides a summary of the infant deaths that occurred between 2009 and 2011 in the Island Health region and builds on findings and recommendations from previous reports in 2008, 2009 and 2010. It is intended to provide Island Health leadership with a better understanding as to why infants are dying, and what factors may be modifiable in order to prevent these deaths.

Island Health's Infant Mortality Review Committee (IMRC) has been reviewing infant deaths since its inception in 2007 when finding revealed higher rates of infant mortality in the Health Authority than the rest of the Province. In addition, the rate of infant deaths to infants of Aboriginal ancestry was higher than the rate of non-Aboriginal infants. The role of the committee is to analyze data and to try to determine the reasons for these high infant death rates, and develop recommendations and monitor activities to reduce infant mortality in Island Health.

From 2009 to 2011, there were 76 infant deaths in Island Health that met the IMRC review criteria; a rate of 3.95 infant deaths per 1,000 live births. The number of deaths continued to decrease, from 29 in 2009, to 24 in 2010 and 23 in 2011. Likewise the rate of infant deaths decreased 17.7 percent between 2009 and 2010, and 3.8 percent between 2010 and 2011. However, caution should be exercised when dealing with a small number of cases as an increase or decrease may indicate random variation rather than a significant change in rates.

The cause of death is summarized into four main categories: Extreme prematurity, Sudden Unexplained Death in Infancy (SUDI), Congenital abnormalities and unknown or other.

Extreme prematurity was the largest group with over half (39 cases) of the infant deaths falling into this category. While the cause of death was listed as extreme prematurity, the actual mechanism of premature delivery of a high risk infant varied and included Premature Rupture of Membranes (PROM), incompetent cervix, acute chorioamnionitis, possible placental abruption, and medical induction due to congenital anomalies. Cause of death included severe Respiratory Distress Syndrome, early acute hypoxic ischemic injury, or expected demise in the case of congenital malformations.

The second largest category was SUDI with twenty cases, all of which occurred in the Post Neonatal Period (28-364 days). The majority of these were term infants. In almost every case, potential sleep practice factors – sleep surfaces, sleep environments and sleep positions – were identified, and in many of the cases broader social complexities were also noted. Of the twenty SUDI deaths, 8 identified as Aboriginal, 10 as Caucasian and 2 as other or unknown.

Congenital anomalies were listed as the reported cause of death in seven of the cases from 2009 to 2011. These included renal agenesis, diaphragmatic hernia, hypertrophic cardiomyopathy, as well as anomalies related to Trisomy 18 and Trisomy 21. An additional 10 cases were listed as "Other" and included complications related to infectious disease, post-surgical complications, multiorgan failure, high grade glioma and cases where the cause of death was undetermined.

## Conclusions and Recommendations

As discussed in annual reports, infants of First Nations ethnicity were over-represented within the SUDI deaths. 27% of infant deaths were reported as First Nations/Aboriginal ethnicity, disproportionate to the 7% of the general population on Vancouver Island. Furthermore, young maternal age was also found to have an association, with an infant mortality rate of 9 infants per 1,000 live births – twice that of mothers aged 20 to 34. Similarly the IMRC has identified that Vancouver Island has a high teen mother rate. The association with young, maternal age should be contextualized within the social determinants that impact the optimal health of young mothers and their infants such as income, gender-based risks and disparities, stable housing and social support. Age and pregnancy status are not the risks, per se.

Infant Mortality review has identified 2 broad categories of concern: extreme prematurity and SUDI. These categories can form the approaches Island Health programs can take in efforts to reduce infant mortality. Strategies to reduce premature delivery center on access to prenatal care and maternal health surveillance. SUDI prevention includes specific measures regarding safe sleep practices (including surface, environments and positions) and awareness. Helping families and communities make informed choices, by offering resources and education can be accomplished by Island Health programs. Addressing the broad and pervasive nature of social complexities requires advocacy and changes to social policy in order to influence the determinants of health. Linking the knowledge developed by this committee with Health and Political leaders remains an indirect but important part of the committee's work.

In addition to being actively involved in IMRC meetings and reviews, members of the IMRC are involved in initiatives focused on reducing Infant Mortality. The Child Youth and Family Program has been hosting regional engagement sessions through 2013 with the goal of developing a network of care that will match services to need and support a seamless, accessible, responsive, safe, quality continuum of perinatal services and care across Island Health. In addition, culturally relevant safe sleep strategies have been developed in collaboration with First Nations communities and a research proposal to implement an Infant "sleeping box" program to infants and families born in the Cowichan Area was successfully submitted to the Children's Health Foundation of Vancouver Island and will be piloted in 2014.

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## 1. Introduction

Infant mortality refers to the death of a live born baby during the first year of life, and is normally expressed as a number of deaths per 1,000 live births in a specified population. Infant mortality is influenced by a multitude of factors including maternal health, quality of and access to medical care, and socioeconomic conditions and as such infant mortality rate is a commonly used measure of a population's health and wellbeing<sup>1</sup>. Reduction of child mortality (death under the age of 5), much of which is attributed to infant mortality, is one of the United Nations Millennium Development Goals. At a National and Provincial level the infant mortality rate has decreased from 7-8 per 1,000 down to 4-5 per 1,000 from 1990 to 2012<sup>2</sup>. While the infant mortality rate for the Island Health region has likewise shown a decreasing trend over time, it remains one of the highest in the province, and there continues to be a disparity with more than a quarter of infant deaths occurring among infants with maternal ethnicity identified as Aboriginal.

The Island Health Infant Mortality Review Committee has been reviewing cases of infant deaths in the health Authority since 2007 in response to findings that revealed higher rates of infant mortality in Island Health compared to other regional health authorities in the Province. The findings also showed that the Aboriginal population had an infant mortality rate 2-3 times higher than the non-Aboriginal population. While infant mortality rates among Aboriginal populations have been decreasing, the 2006-2010 figures indicate the rate remains twice as high as non-Aboriginal populations<sup>3</sup>. As a result of these findings, one of Island Health's performance measures is to eliminate the gap in infant mortality between First Nations and non-Aboriginal peoples. While there was no significant change in the proportion of infant deaths with Aboriginal ethnicity from 2009 to 2011, several initiatives, including development of a culturally relevant safe sleep guide for First Nations, have been implemented over the past year with the goal of decreasing the gap in future years.

The following report is a summary of the infant deaths that occurred in the Island Health region from 2009 to 2011. It is intended to inform the leadership of Island Health with the findings concerning the deaths occurring between 2009 and 2011, and with an update of the work of the Infant Mortality Review Committee.

This is the first report that has combined three years of data, rather than reporting over a one year period. While this allows for more robust comparisons, it should be noted that there is an issue of small numbers when breaking down infant deaths over specific years or across descriptive categories.

The infant mortality rate for Island Health for 2009-2011 was 3.95 per 1,000 live births; this is slightly lower than the 3-year rate reported by Vital Statistics for the Island Health region (4.26 per 1,000 live births – see section 2.1 for comparison of numbers reported by IMRC and Vital Statistics), and slightly higher than the Provincial 3-year rate of 3.63 per 1,000. A total of 76 infant deaths were reported for Island Health between 2009 and 2011.

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<sup>1</sup> Reidpath DD and Allotey P. Infant mortality rate as an indicator of population health. *J Epidemiol Community Health* 2003; 57:344-346.

<sup>2</sup> BC Vital Statistics and World Health Organization Global Health Observatory Data Repository.

<sup>3</sup> Provincial Health Officer. The Health and Well-being of the Aboriginal Population: Interim Update. Oct 2012; BC Ministry of Health, Office of the Provincial Health Officer.

## 1.1 Methodology

The Island Health Infant Mortality Review Committee (IMRC) works collaboratively with the British Columbia Coroners Service, and the Ministry of Children and Family Development. Using a database template developed by the IMRC in 2008, chart reviews of the infants that meet the IMRC criteria and their mothers were conducted (list of database fields can be seen in Appendix D). The work done by the Committee is mandated under the Health Authorities Act to plan, deliver, monitor, and report on health services and is a function of Island Health quality improvement with a purpose to provide recommendations based on aggregate data on modifiable risk factors to reduce infant mortality. This data was supplemented with data from BC Vital Statistics.

As in previous years, the Island Health Infant Mortality Review Committee used the following inclusion criteria for inclusion of cases into the review:

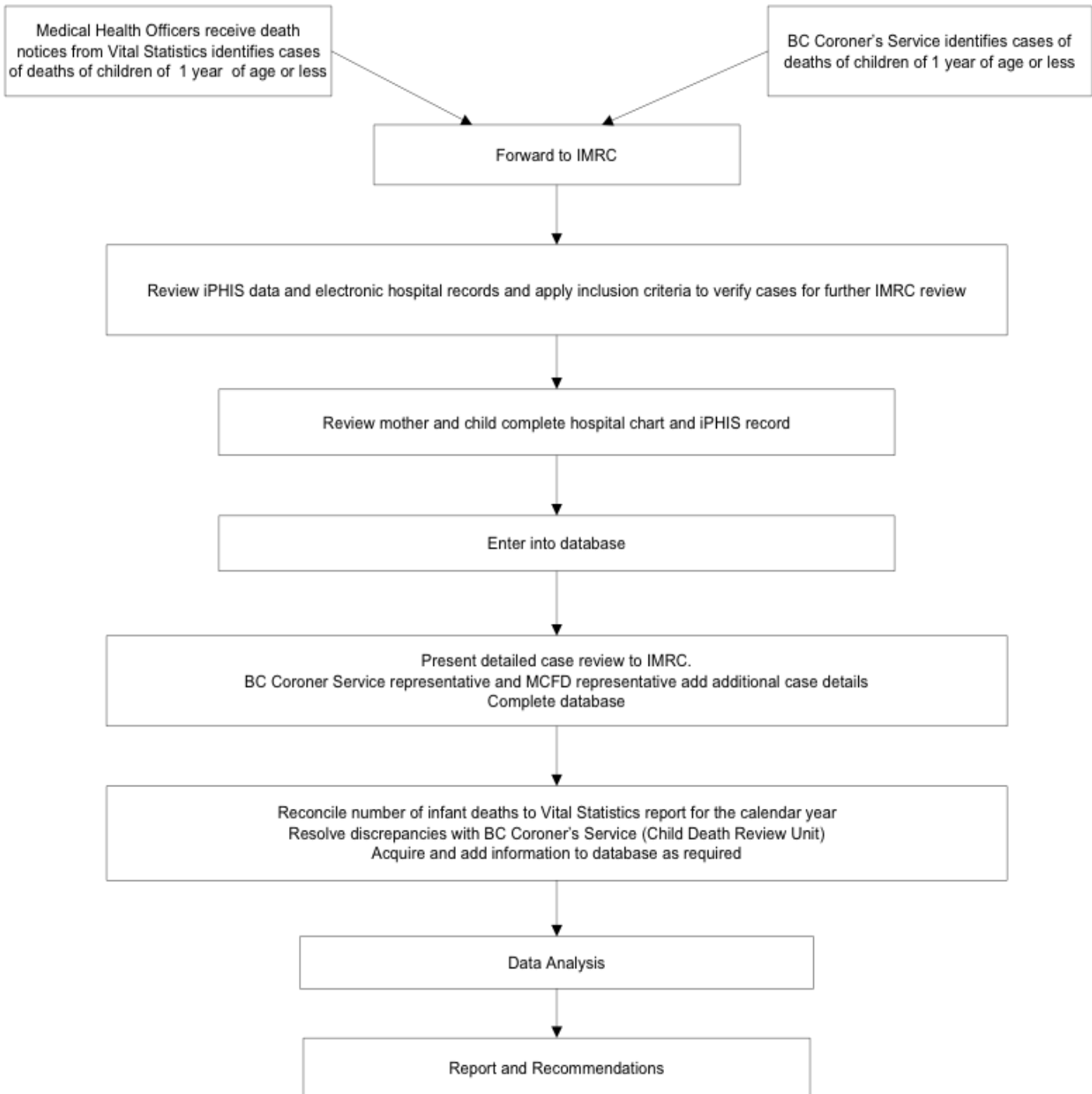
- Infant deaths are defined as the death of a child less than 12 months of age<sup>4</sup>.
- Infant mortality rates are calculated using the number of infant deaths divided by the total number of live births, multiplied by 1000.
- The *Vital Statistics Act* defines a live birth<sup>5</sup> as “The complete expulsion or extraction from its mother, irrespective of the duration of the pregnancy, of a product of conception in which, after the expulsion or extraction, there is:
  - a) Breathing;
  - b) Beating of the heart;
  - c) Pulsation of the umbilical cord; or
  - d) Unmistakable movement of voluntary muscle, whether or not the umbilical cord has been cut or the placenta attached.”
- The infant deaths studied were those whose maternal residence was within the Island Health boundary, whether they died on Vancouver Island or at BC Children’s and Women’s Hospital in Vancouver. Not included are infants who may have died on Vancouver Island but whose mother’s normal place of residence is outside of the Island Health boundary.
- For the purpose of the case review, stillbirths are not included, as stillbirths do not meet the definition of an infant death.

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<sup>4</sup> Conference Board of Canada, N.D.

<sup>5</sup> BC Vital Statistics. Glossary of Terms. <http://www.vs.gov.bc.ca/stats/annual/2007/pdf/glossary.pdf>

The following diagram provides an overview of the case review process conducted by the Island Health Infant Mortality Review Committee:





## 1.2 Glossary of Terms

For the purposes of this report, the following are commonly used terms and their definitions.

**Safe Sleeping Practices** – includes **sleep position** (back), **sleep environment** (firm surface, without pillows, comforters, quilts or bumper pads), and **sleep surfaces** (crib, cradle or bassinet next to bed).

**Aboriginal** – For purposes of this report, a baby is considered to be Aboriginal if the parent identifies the infant as having Aboriginal blood. It includes First Nations (status or non-status), Inuit and Métis infants.

**Infant death** – the death of a baby who is born alive (i.e. not a stillbirth) between the time of birth and an age of 365 days.

**Neonatal death** – the death of a baby less than 28 days after birth. Neonatal deaths are further divided as follows:

- Early neonatal death- death of children less than 7 days after birth
- Late neonatal death - death of children from 7 to 27 days after birth

**Post-neonatal death** – the death of a baby aged between 28 and 364 days.

**Extremely Preterm** – a baby who is born at a gestational age of less than 28 weeks.

**Very Preterm** – a baby who is born at a gestational age of 28 to less than 33 weeks.

**Late Preterm** – a baby who is born at a gestational age of 33 to less than 37 weeks.

**Full term** – a baby who is born at a gestational age of 37 to less than 42 weeks

**Sudden Infant Death Syndrome (SIDS)** – The sudden death of an infant, normally during sleep, where a full autopsy determines no anatomical cause of death and where no illness or external risk factors likely to contribute to a sudden infant death can be identified.

**Sudden Unexplained Death in Infancy (SUDI)** – The sudden death of an infant, normally during sleep, where a full autopsy determines no anatomical cause of death and where external risk factors that may contribute to infant death are present (E.g. placed prone to sleep, sleeping on adult bed) but their role in the death cannot be specifically determined.

It should be noted that experts remain divided on the issue of separating sudden infant deaths into the categories of SIDS and SUDI. The definitions above conform to that of the BC Coroners Service.

**Social Determinants of Health** – The social determinants of health influence the health of populations. They include income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; gender; and culture.

## 2. Results from the 2009-2011 Case Review of all Infant Deaths

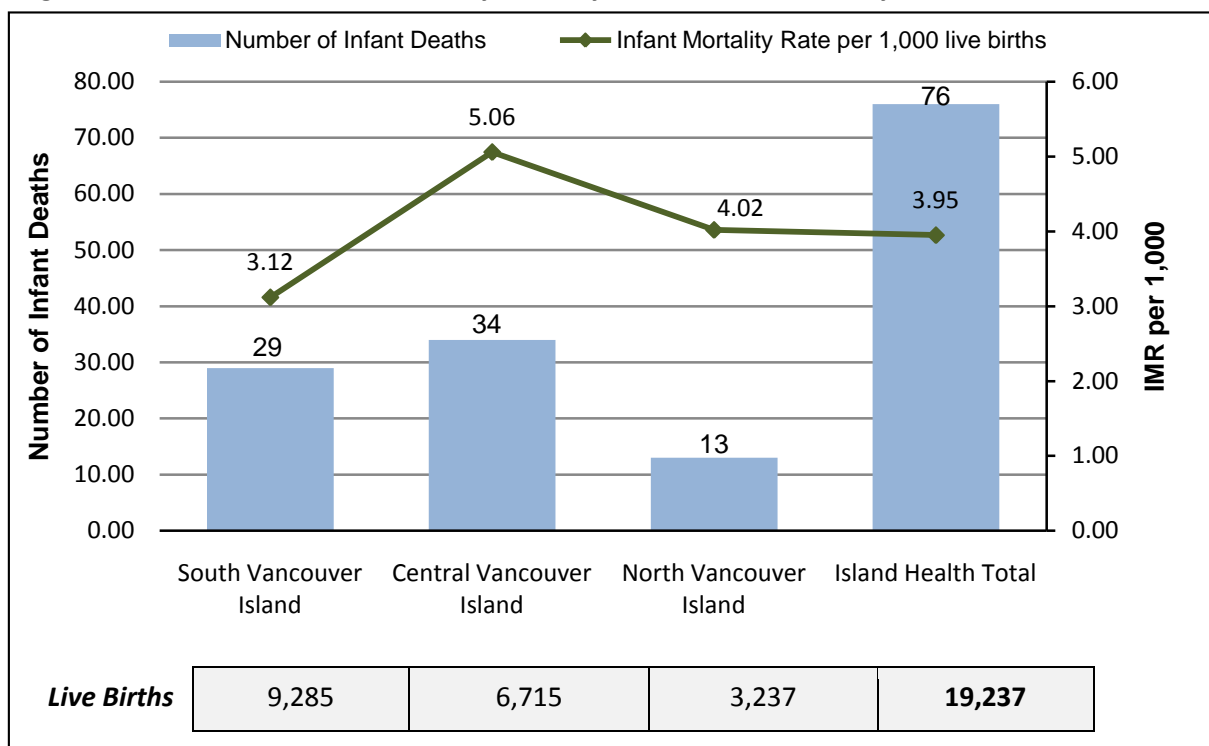
### 2.1. Geography

The IMRC uses the mother's place of residence from the hospital records to determine where infant deaths are occurring in the region and to learn if certain areas are experiencing higher rates of infant mortality than others. For the three year period from 2009 to 2011, the highest number and the highest rate of infant deaths is occurring in Central Vancouver Island HSDA with 34 deaths at a rate of 5.06 infant deaths per 1,000 live births. At the Local Health Area (LHA) level, the highest number of infant deaths is occurring in the Greater Victoria LHA; however, it also had the highest number of live births. The highest rate of infant mortality occurred in Qualicum LHA at 8.21 infant deaths per 1,000 live births. As can be seen in Table 1 below, there is a slight discrepancy between infant deaths reported by Vital Statistics for some areas compared to what was recorded in the Island Health charts.

**Table 1: Infant Mortality Rates by Island Health Local Health Area, 2009-2011**

	Island Health LHA	Live Births	Infant Deaths per 1,000 Live Births	Infant Deaths by HSDA	Vital Stats Reported
61	Greater Victoria	5,432	2.95	29	34
62	Sooke	2,392	3.76		
63	Saanich	1,195	1.67		
64	Gulf Islands	266	7.52		
65	Cowichan	1,599	5.63	34	31
66	Lake Cowichan	112	8.93		
67	Ladysmith	419	0.00		
68	Nanaimo	2,823	4.96		
69	Qualicum	731	8.21		
70	Alberni	1,031	3.88	13	14
71	Courtenay	1,563	5.76		
72	Campbell River	1,152	2.60		
84	Vancouver Island West	72	0.00		
85	Vancouver Island North	450	2.22		
<b>Island Health Total</b>		19,237	3.95	76	79

**Figure 1: Island Health Infant Mortality Rates by Health Service Delivery Areas, 2009-2011**



## 2.2. Ethnicity of Deceased Infant

Table 2 below identifies the listed ethnicity of the deceased infants. Five of the infant deaths from 2009 to 2011 were sets of twins so there are 71 mothers and fathers for 76 infant deaths. Ethnicity was known for 49 of the cases (61 percent) with the data on the remaining cases unknown or incomplete. Hospital records list ethnicity of an individual based on self-identification. For the purpose of this report, the maternal ethnicity determined the ethnicity of the infant. In all of the known cases of Aboriginal fathers, the mother was also listed as Aboriginal; however, in some of the cases where the mother was listed as “Aboriginal”, the ethnicity of the father was listed as “unknown.”

**Table 2: Ethnicity of Deceased Infant, Island Health, 2009-2011**

Ethnicity	#	% of total cases
Caucasian	24	33.80%
Aboriginal	19	26.76%
Other*	6	8.45%
Unknown	22	30.99%
*Other includes: Mexican, Filipina, Vietnamese, Chinese, East Indian and Black (Cayman Islands)		

## 2.3 Maternal Age

The average age for the 71 mothers of the deceased infants was 28 years. The data reveals that the highest rate of infant deaths occurred to older mothers aged 35 years and older, at a rate of 8.72 deaths per 1,000 live births. The rate of infant deaths to teenage mothers ( $\leq 19$  years) is close behind at 8.59 deaths per 1,000 live births.

**Table 3: Infant Deaths by Maternal Age, Island Health, 2009-2011**

Age of Mother (years)	# of Infant Deaths	# of Live Births	Infant Mortality Rate per 1,000
$\leq 19$ (Teenage Mother)	7	815	8.59
20-34	52	14524	3.58
$\geq 35$ (Older Mother)	12	3898	8.72

## 2.4 Multiple Gestations

Twenty of the infant deaths in Island Health between 2009 and 2011 were twins, 5 of which were sets of twins where both infants died, while 10 of the deaths occurred to one of the twins in a set. In Vitro Fertilization or IVF was reported in recorded in 6 infant death cases, of which 5 resulted in multiples.

In the cases where both twins died in a set, the following complications were listed in the database:

- Incompetent cervix
- Monchorionic-diamniotic twins
- Unknown

The following pregnancy complications were listed for the other twin where only one infant in the set died:

- Incompetent cervix
- Dichorionic diamniotic twins, bleeding @5-6 wks
- Monchorionic-diamniotic twins
- 1 embryo transferred - split for mono-di twins
- Unknown

## 2.5 Alcohol and Substance Use during Pregnancy

Reported alcohol and substance use during pregnancy are captured on the Provincial Antenatal Record (Perinatal Services BC). The Antenatal Record is a tool developed to facilitate the assessment and documentation of important information about the woman’s health and pregnancy care in a structured and standardized manner. A number of the fields in the antenatal record are collected as part of a database for the British Columbia Perinatal Database Registry (BCPDR) to ultimately evaluate provincial perinatal outcomes, and to improve health care initiatives.<sup>6</sup> In some of the fields the data was incomplete or was not known.

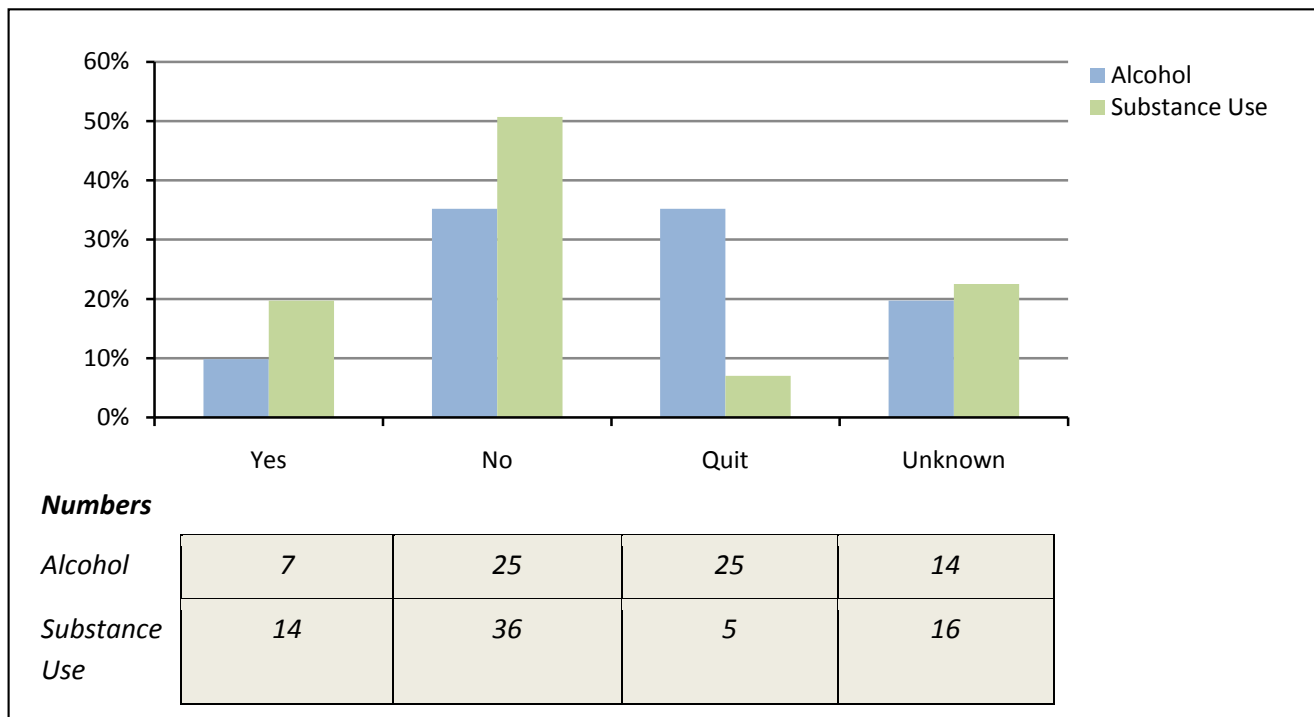
### 2.5.1 Alcohol Use during Pregnancy

The antenatal case reviews (N=71 mothers) noted the following: alcohol use during pregnancy was reported in seven of the cases, no alcohol use was reported in 25 of the cases, 25 cases noted cessation of alcohol use upon pregnancy diagnosis and 14 of the cases did not have information noted in the antenatal record.

### 2.5.2 Substance Use during Pregnancy

Of the 71 cases reviewed, 14 noted a history of illegal substance use in pregnancy. Where specified, marijuana use was most commonly noted, with a small number of records indicating cocaine and/or heroin use. Among the 16 unknown cases, 9 had no available data, while the rest had a history of substance use, but no information regarding current use.

**Figure 2: Proportion reporting Alcohol and Substance Use (Illicit Drugs) during Pregnancy**



<sup>6</sup>BCPHP- A Guide for Completion of the Antenatal Record part 1 and 2  
<http://www.perinataleservicesbc.ca/NR/rdonlyres/E1EA26B6-EF44-4677-A72D-5B6A3F1E75BB/0/FormGuidesAntenatalRecordPartlandII1582.pdf>

### 2.5.3 Tobacco Use during Pregnancy

Eighteen ( 25% ) of the 71 cases noted tobacco use in pregnancy. Cessation of tobacco during planning for or after pregnancy diagnosis occurred in 13 cases (18%), 26 (37%) cases report no tobacco use and in 14 cases it was unknown or the data was incomplete. Pre-pregnancy tobacco use averaged 14.0 cigarettes per day, while the average number of cigarettes smoked during pregnancy was 11.2 cigarettes per day. The range of use during pregnancy was broad, spanning 3-30 cigarettes a day. Exposure to second hand smoke during pregnancy was reported in 12 cases (see Table 6 below).

The overall rate of tobacco use during pregnancy in Island Health for 2008-2012 was 12.6 percent; compared to a provincial rate of 9.1 percent.<sup>7</sup>

**Table 4: Maternal Smoking, Island Health, 2009-2011**

Smoking Data	#
Reported Smoking During Pregnancy	18
Average Cigarettes a Day (pre-pregnancy)	14.0
Average Cigarettes a Day (during pregnancy)	11.2
Quit	13
Unknown	14
Known exposure to 2 <sup>nd</sup> hand smoke during pregnancy	12

## 2.6 Gestational Age and Birth weight of all 2009-2011 Cases

### 2.6.1 Gestational Age of Infants

The gestational age is the duration of pregnancy measured from the first day of the last normal menstrual period, and is expressed in completed days or completed weeks. The gestational age was reviewed for all infant deaths to determine whether the infant was pre-term (less than 37 weeks), term (37 to 41 weeks), or post-term (42 weeks or more).

Among all infant death cases from 2009-2011, there were 52 pre-term infants (68.4 percent), of which 38 were extremely pre-term (32 born at <24 weeks and 6 born at 25-27 weeks), 5 were very preterm (28 to <33 weeks) and 9 were late preterm (33 to <37 weeks). Among all live births, 7.3 percent of Island Health infants were born prematurely compared to 7.4 percent in BC in the three year period. In Island Health, the rate of preterm infant deaths was 36.7 per 1,000 preterm live births compared to a rate of 33.6 preterm infant deaths per 1,000 preterm live births in BC.<sup>8</sup> There were 23 infants (30%) that were full term at the time of their death and none of the infants were post-term. In one case, the gestational age was unknown.

<sup>7</sup> Perinatal Services BC – BC Perinatal Database Registry

<sup>8</sup> BC Vital Statistics, VISTA Database

**Table 5: Gestational Age of Deceased Infant, Island Health, 2009-2011**

Gestational Age of Deceased Infant	# of Infant Deaths	% of Infant Deaths	IMR by Gestational Age Group
Pre-Term (<37 weeks)	52	68.4%	36.7
Term (37-41 weeks)	23	30.3%	1.30
Post-Term (≥ 42 weeks)	0	0.0%	--
Unknown/ Not recorded	1	1.3%	--

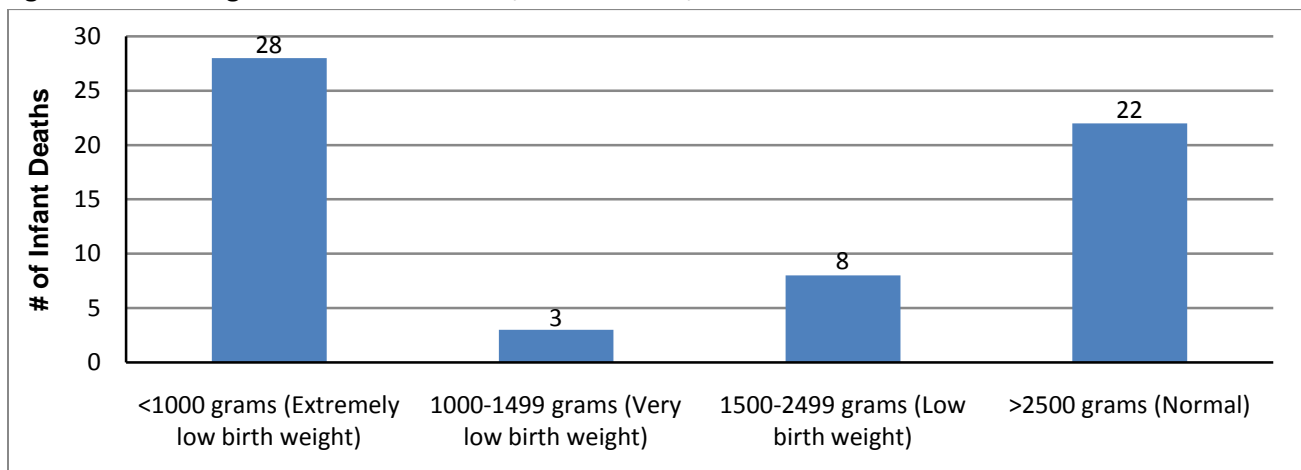
**Table 6: Deceased Infants with Extreme and Moderate Prematurity, Island Health, 2009-2011**

Gestational Age of Deceased Infant	# of Infant Deaths
Extremely Preterm (< 24 Weeks)	32
Extremely Preterm (25-27 Weeks)	6
Very Preterm (28 to < 33 Weeks)	5
Late Preterm (33 to <37 Weeks)	9

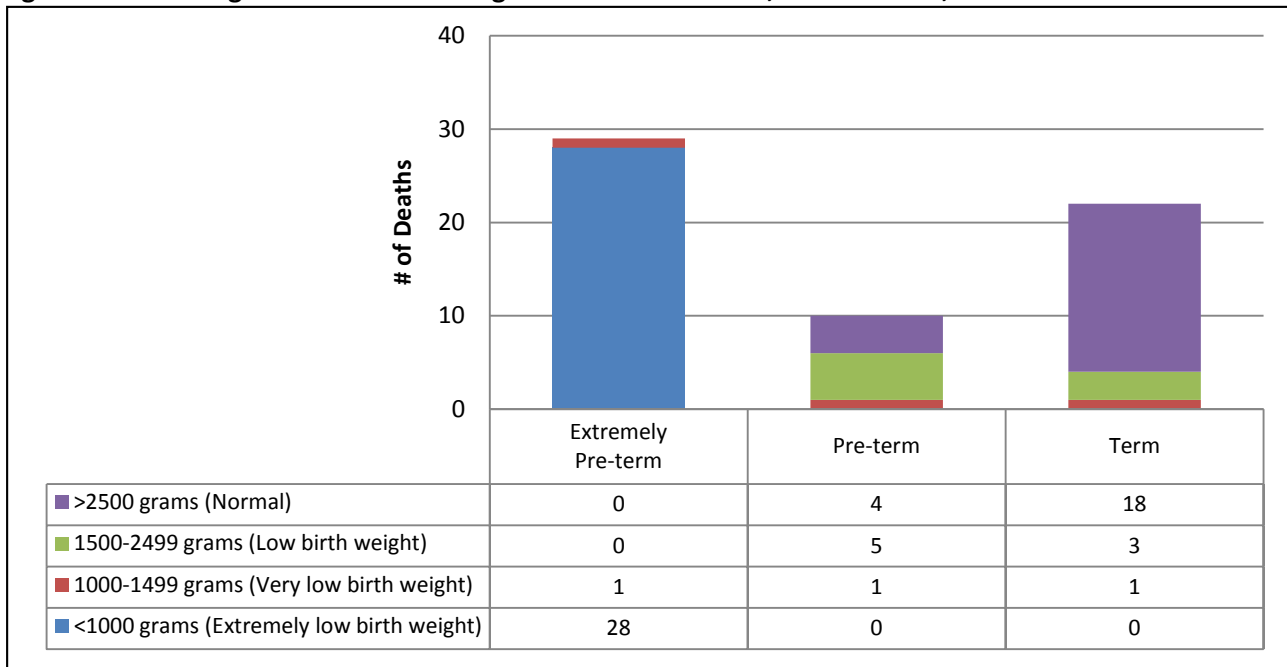
### 2.6.2 Birth weight of Deceased Infants

The birth weight of the deceased infants was known in 61 cases between 2009 and 2011. Of these cases, 22 were normal birth weight (>2500 grams) and 39 were low birth weight (≤2499 grams). The low birth weight infants can be further broken out into extremely low birth weight (<1000 grams), very low birth weight (1000-1499 grams) and low birth weight (1500-2499 grams). Extremely low birth weight reflects either extreme prematurity (the majority of cases) or severity of processes which affect fetal growth. It is an acknowledged significant risk factor for poor outcome in NICU populations. There was one infant born at term that was very low birth weight (1000-1499 grams), three infants were low birth weight and born at term while the remaining 18 term infants were of normal birth weight.

**Figure 3: Birth weight of Deceased Infants, Island Health, 2009-2011**



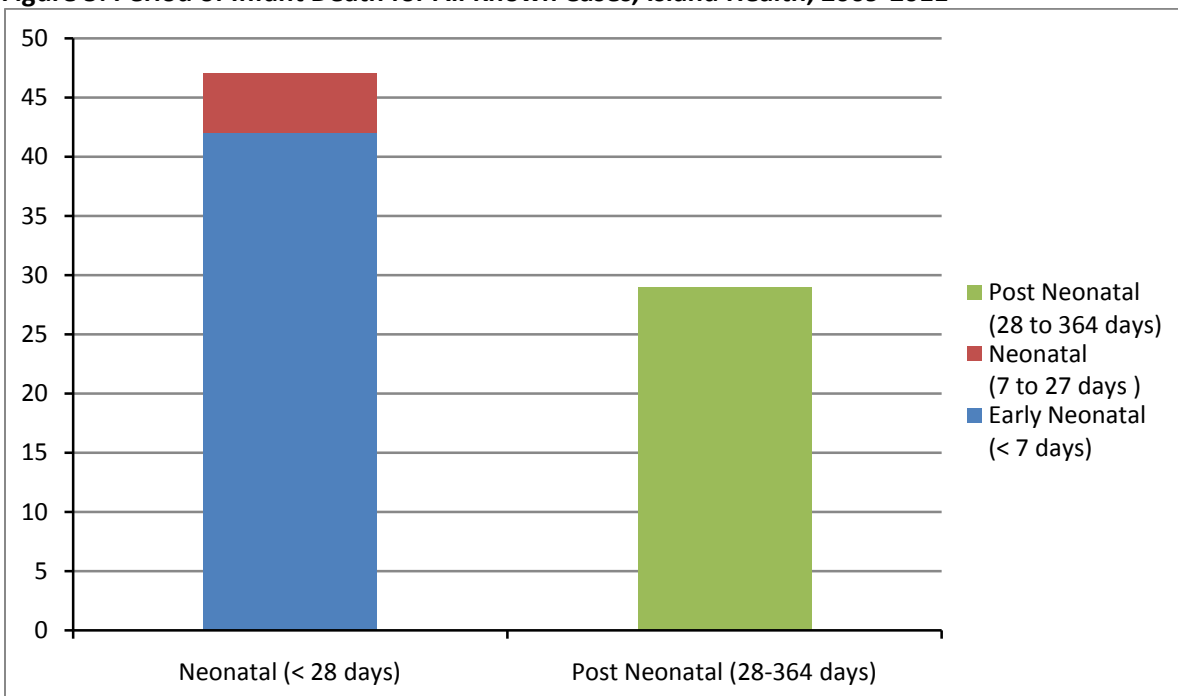
**Figure 4: Birth Weight and Gestational Age of Deceased Infants, Island Health, 2009-2011**



### 2.6.3 Period of Infant Death

The majority (62%) of infant deaths in 2009-2011 occurred in the Neonatal period (< 28 Days) compared to the Post Neonatal period (28-364 Days after birth). There were 47 infant deaths in the Neonatal period, of which 42 occurred in the early neonatal period (< 7 days after birth) while 5 deaths occurred between 7-27 days after birth.

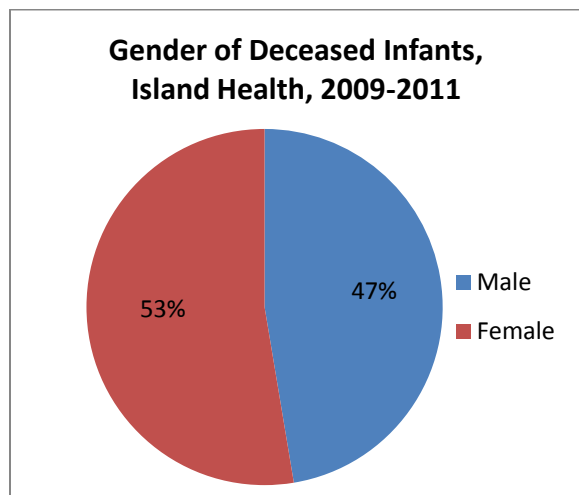
**Figure 5: Period of Infant Death for All Known Cases, Island Health, 2009-2011**





## 2.7 Gender of the Deceased Infant

In 2009-2011, 53 percent of the infants were female (40/76) and 47 percent of the infants were males (36/76).



## 2.8 Carnitine Palmitoyl Transferase 1 or CPT1

Carnitine palmitoyl transferase I or CPT1 is an enzyme in the body that is important in converting fat to energy<sup>9</sup>. A common variant (P479L), which might predispose to low blood sugar in some cases, is being investigated to determine how common it is and whether it plays a role in infant mortality in Aboriginal infants of BC. More than 20% of Aboriginal infants on Vancouver Island are born with two copies of the variant but the presence of the variant is likely higher in some communities than others. A total of ten infants had test results recorded for CPT1. Of these, the P479L variant was not found in 5 cases. Four of the remaining five were heterozygous (one copy) for the variant, while one was homozygous suggesting that the variant did not play a major role in the deaths reviewed for this report. Further study is underway to determine whether there are associated health risks when infants are born with 2 copies of the variant.

## 2.9 Prenatal Care

Prenatal care (also known as antenatal care) is a continuum inclusive of primary and acute care and public health. It affords the opportunity to offer health screening, education and referrals that aim to optimize the perinatal health outcomes of the mother and her infant.

Typically, primary maternity care in the antenatal period is conducted monthly for the first two trimesters (weeks 1 to 28), every two weeks from weeks 28 to 36 of pregnancy, and weekly after week 36.

Perinatal Services BC (PSBC) requests that primary health care providers provides a copy of the Antenatal record to the mother and faxes it to the intended hospital of birth at 20 weeks and 36 weeks gestation. Primarily, sharing of this information is to ensure that the hospital can plan care with and for the woman. Also, it may inform care if the woman unexpectedly requires acute maternity care services early in the antenatal period,

<sup>9</sup> Definition of CPT1 from [http://www.hss.state.ak.us/dph/wcfh/metabolic/downloads/cpt1\\_brochure.pdf](http://www.hss.state.ak.us/dph/wcfh/metabolic/downloads/cpt1_brochure.pdf)

Between 2009 and 2011, the completeness of the Antenatal record varied considerably from provider to provider. The information that was available was entered into the database.

It was recognized that the copy of the Antenatal Record on the hospital chart was not necessarily reflective of all prenatal visits that took place. For example if the mother entered hospital between 20 and 36 weeks significant information on prenatal visits could be missing. In most of the cases the number of visits was recorded; however, there was not a great deal of supporting documentation regarding the actual nature of the visit or issues identified.

### 3. Reported Cause of Death

The IMRC groups infant deaths into four main categories:

- Extreme prematurity
- Sudden Unexplained Death in Infancy (SUDI)
- Congenital Abnormalities
- Unknown or Other

Extreme prematurity is further broken down into three sub-categories: 1) intent to treat – those that died in neonatal ICU; 2) extreme premature infants categorized as live births but with perinatal complications leading to early demise (includes infants born with extreme prematurity and no intent to treat, infants assessed to be extremely high risk for poor outcome resulting in early withdrawal of care or where treatment was deemed to be futile); and 3) those that were mid-term terminations (MTT) for congenital reasons or twin-to-twin transfusions (TTT).

During the case review process, the IMRC reviews the hospital charts, autopsy reports and Coroner’s data to determine the circumstance around the death including contributing factors, as well as the most likely cause of death. The following table illustrates the cause of death for the 2009-2011 cases.

**Table 11: Cause of Infant Death, Island Health Region, 2009-2011**

Cause of Death	Number	Sub-category		Percent of sub-category	Overall Percentage
<b>SUDI</b>	20				<b>26.3%</b>
<b>Extreme Prematurity or Complications of Perinatal Disease*</b>	38	<i>Intent to treat</i>	7	18%	<b>50.0%</b>
		<i>No intent to treat</i>	21	55%	
		<i>MTT/TTT</i>	10	26%	
<b>Congenital Anomalies</b>	8				<b>10.5%</b>
<b>Unknown or Other</b>	10				<b>13.2%</b>

\*Infants in this category are not necessarily in the Extreme Preterm (<28 weeks) gestational age category.

### ***3.1 Extreme Prematurity***

Cause of death due to extreme prematurity accounted for half of the cases (50%). Over one quarter (10/38) of these deaths were due to mid-term termination (5 for congenital abnormalities) or induction for twin-to-twin transfusion. Among the remaining 28, the mechanism of death varied and included:

- Premature rupture of Membranes (PROM) due to incompetent cervix
- Acute Chorioamnionitis
- Placental abruption
- Early acute hypoxic ischemic injury.

Seven of these premature births (18%) had some level of clinical intervention with infant death occurring >1 day after birth.

### ***3.2 Sudden Unexplained Death in Infancy (SUDI)***

SUDI was reported as the cause of death in 20 of the cases between 2009 and 2011. All of the SUDI deaths occurred in the Post Neonatal Period (28 to 364 days) and most of the infants reached term, although four of were moderately premature (33-36 weeks). In almost every case, unsafe sleeping practices appeared to be a factor, while at least 12 of the cases had social concerns noted in the records.

In 9 of the 20 SUDI cases, tobacco use during pregnancy was reported, and in one additional case, second hand smoke exposure was noted. In 6 additional cases tobacco use was reported prior to the current pregnancy.

Of the 20 SUDI deaths, 8 were identified as Aboriginal, 10 as Caucasian, and 2 as other/unknown ethnicity.

### ***3.3 Congenital Anomalies***

Congenital anomalies were the reported cause of death in 7 of the cases between 2009 and 2011, although an additional 5 categorized as Extreme Prematurity with mid-term termination were due to congenital anomalies. These cases included renal agenesis, Trisomy 18, Trisomy 21, pulmonary hypoplasia, hypertrophic cardiomyopathy and diaphragmatic hernia.

### ***3.4 Unknown or Other***

Eleven of the infant deaths between 2009 and 2011 did not fit under the preceding categories. These included post-surgical complications, infection-related complications, multiorgan failure, high grade glioma and unknown/undetermined causes of death.

## **4. IMRC Activities**

Many of the IMRC members actively participate in other committees, or are engaged in other projects and initiatives around the Island and in the Province. Appendix B provides a summary of these initiatives and identifies who was involved, when it took place and a description of each initiative. Many of the activities relate to recommendations in the previous reports pertaining to the creation of a clear, preventative strategy

for Safe Sleep, and supporting socially and culturally sensitive messaging about sleep conditions for infants and support for families in general but also for those identified 'at risk.'

Members of the committee have also been involved in genetic research regarding CPT1 and ensuring that the messages about feeding infants and children when they are ill are included in discussions and planning with Aboriginal communities.

A full list of the recommendations from the 2008, 2009 and 2010 reports and the progress made on corresponding initiatives can be found in Appendix B.

## 5. Summary and Recommendations

### 5.1 Sudden Unexpected Death in Infancy

When an infant dies in the context of an unsafe sleeping situation, the committee universally feels this is an inherently preventable loss. It is in this context that infant mortality is strongly related to many of the social determinants of health. Social determinants of health such as gender, poverty, ethnicity<sup>10</sup>, age, violence, unstable housing, geography and low educational attainment impact infants, children and pregnant women.<sup>11</sup> Some, especially poverty, housing and education, are of course well beyond the mandate of Island Health. However, we can use the resources and central position of the Health Authority to develop program initiatives and messages which can help parents of all backgrounds understand risks and make safe sleep choices for their babies.

Recommendations include:

- Facilitate the connection between parents and parenting resources available in their communities.
- Ensure that those resources, whether public health (Island Health), First Nations HA, private physicians can evaluate parents' needs and deliver information and tools to allow them to make healthy and safe choices. Identify, using data from IMRC review work, and additional reviews as necessary, regions and communities of particular risk and potential for more focused intervention.
- Work with health care providers to identify families and infants at risk, in a way which compliments programs such as the Nurse Family Partnership.
- Continue to support and evaluate approaches for primary prevention, including dissemination of information, such as "Baby's Own Bed," and the more concrete approach of the Sleeping Box program.

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<sup>10</sup> As defined by Statistics Canada, ethnicity refers to the ethnic or cultural origin of a person's ancestors (Statistics Canada, 2007).

<sup>11</sup> Salmon. Aboriginal mothering, FASD prevention and the contestations of neoliberal citizenship. *Critical Public Health* 2011; 21(2):165-78.

## 5.2 Perinatal Care

Quality improvement aimed at pre and post natal care and services supports optimal reproductive health and the prevention of disabilities through enhancing the health of women during pregnancy, birthing and the postpartum period<sup>12</sup>. Facilitating clients' engagement with prenatal care is dependent on understanding what those clients value as quality care. Otherwise, the time limited opportunity to promote health and identify health risks early on is compromised<sup>13</sup>. Examining maternal child health indicators such as the number of antenatal visits, gestational age at birth, preterm birth and low birth weight help to inform a better understanding of how to impact infant mortality rates.

Recommendations regarding quality improvement activities that are relevant to impacting the incidence of infant mortality include:

- Perform a jurisdictional review of access to primary maternity care across Island Health. The purpose of which is to identify accessibility gaps and strengths. Accessibility should be broadly defined to include both local primary maternity care service availability and women's experiences of safety in care.
- Explore a regional approach to complex care planning for women with health complications that may precipitate preterm birth.
- Work with the Chief Medical Health Officer to update the 2008 Island Health report on Women's Health in order to inform public health based interventions known to prevent preterm birth.
- Continue Public Health Nursing program and service planning to intentionally engage in a client focused, care relationship with priority populations of perinatal women.

## 5.3 Other Risk Factors

Specific potential risk factors, including CPT-1 variants, require ongoing consideration and integration with the Provincial working group on this disorder to further understand risk and prevention within at risk First Nations Populations and communities.

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<sup>12</sup> British Columbia Ministry of Health (2008). *Evidence Review: Reproductive Health* British Columbia: Population Health and Wellness, Ministry of Health.

<sup>13</sup> Sword et al. Women's and care providers' perspectives of quality prenatal care: a qualitative descriptive study. *BMC Pregnancy and Childbirth*. 2012; 12:29.

## Appendix A – Infant Mortality Review Committee Members

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Listed in alphabetical order (last name)

Dr. Laura Arbour, Geneticist  
Clinic Lead- Medical Genetics, Department of Laboratory Medicine  
Island Health  
and UBC Medical Genetics

Matt Brown  
Regional Coroner, Vancouver Island Region  
BC Coroners Service

Dr. Richard Crow  
Executive Medical Director, Population & Community Health  
and Adult Mental Health & Addictions Services,  
Island Health

Dr. Jerome Dansereau  
Physician - Director, Perinatology Services  
Island Health

Dr. Charmaine Enns  
Medical Health Officer – North Island,  
Island Health

Dr. Adele Harrison  
Medical Director, Quality and Patient Safety  
Island Health

Edith Imber  
Project Coordinator Quality Initiatives  
Child Youth and Family Health and Public Health,  
Island Health

Adele Lambert  
Coroner, Vancouver Island Region  
BC Coroners Service

***Continued on following page...***

Erin O'Sullivan  
Leader, Perinatal Program Development  
Island Health

Melanie Rusch  
Manager, Population Health and Epidemiology  
Planning and Community Engagement  
Island Health

Dr. Brian Sinclair (IMRC Chair)  
Medical Program Director, Child Youth and Family Programs,  
Island Health

Dr. Richard S. Stanwick  
Chief Medical Health Officer,  
Island Health

Jan Tatlock  
Community Program Services Director,  
Child Youth and Family and Public Health,  
Island Health

Jani Urquhart  
Planning Analyst  
Planning and Community Engagement and Population Health,  
Island Health

Tom Weber  
Executive Director of Service,  
Ministry of Children and Family Development  
Central/North Vancouver Island

## Appendix B – Previous IMRC Report Recommendations and Progress of Activities

2008 Annual Report	<p><b>1. Focus attention and efforts on the following two categories as most readily modifiable risk factors for infant mortality. This will include:</b></p> <p><b>a. Sleep-related deaths</b> – Island Health and partners will use a variety of evidence- informed strategies to reduce the number of sleep-related deaths occurring in Island Health;</p> <p><b>b. Deaths related to CPT1-</b> Follow the best genetic/ public health guidance on fever and acute illness as it relates to CPT1. Also, ensure that the messages about feeding infants and children frequently when they are ill be included in the discussions and planning with Aboriginal communities (see page 15).</p>	
	<i>Actions</i>	<i>Progress</i>
	<p><b>a. Sleep-related deaths</b></p> <ul style="list-style-type: none"> <li>- Supporting and strengthening the Island Health Medical Health Officer’s team in working with Island communities to deliver safe sleep messages. All Island Aboriginal communities must be included in this work wherever opportunities exist. <i>(Lead: Dr. Charmaine Enns)</i></li> <li>- Supporting effective education for all new parents with consistent guidelines and tools for primary care providers, prenatal educators, community, and hospital staff. Provide particular educational emphasis on the importance of safe sleep practice for at-risk populations such as teen mothers, families with premature infants and those at social risk. <i>(Lead: Erin O’Sullivan and Michele Fryer)</i></li> <li>-</li> </ul>	<p>Members of the IMRC engaged with the Provincial Safe Sleep Working Group as well as with community partners on safe sleep initiatives.</p> <p><b>Activities completed in 2009:</b></p> <ul style="list-style-type: none"> <li>- Island Health Brochures and Fridge magnets on Safe Sleep Practices and B.O.B. for Aboriginal Communities</li> <li>- MCFD Brochure on Safe Sleeping for Babies</li> </ul> <p><b>Activities ongoing from 2008-2012:</b></p> <ul style="list-style-type: none"> <li>- Community and/or organization presentations on “How to reduce infant mortality through safe sleep practices” (partnership w/ USMA/MCFD, FN communities, health providers, CYF, day care operators, family medicine residents)</li> </ul>
	<p><b>b. Deaths related to CPT1</b></p> <ul style="list-style-type: none"> <li>- Members of the committee have also been involved in genetic research regarding CPT1 and ensuring that the messages about feeding infants and children when they are ill are included in discussions and planning with Aboriginal communities. <i>(Lead: Dr. Laura Arbour and Dr. Charmaine Enns)</i></li> </ul>	<p><b>Activities completed in 2011:</b></p> <ul style="list-style-type: none"> <li>- Provincial CTP1 Working group struck to work on public health messages, parent info and guidelines for health care professionals.</li> </ul>



**2. Island Health will continue to endorse the infrastructure of collaboration/ partnership of the Infant Mortality Review Committee to improve the methods of data collection and exchange and the quality of the information collected.**

<i>Actions</i>	<i>Progress</i>
<ul style="list-style-type: none"> <li>- This includes a formal information sharing agreement between Island Health, the BC Coroner’s Office, and the Ministry of Children and Family Development. <i>(Leads: Michele Fryer and Edith Imber)</i></li> </ul>	<p>IMRC continues to collaborate with the BC Coroners Service and the Ministry of Children and Family Development in information sharing and in developing these reports.</p>

1. ***Extreme Prematurity: Prevention strategies around effective and accessible prenatal care are required to identify and modify risks for premature labor and delivery. These risks include young age, multiple gestations, and complications of twin or multiple pregnancies.***  
 In this category, all deaths were in hospital, and were directly related to the complications of extreme prematurity or complex congenital risk factors. All deaths occurred at less than 28 weeks gestation, with a significant number at or less than 24 weeks. The latter is often considered the lower limit of effective viability. If at delivery an infant of less than 24 weeks draws breath, it is still considered a live birth, but often no specific resuscitation is provided. The underlying risk factors for extreme prematurity are multi-factorial and complex.

<i>Actions</i>	<i>Progress</i>
<ul style="list-style-type: none"> <li>- The Infant Mortality Review Committee plans to obtain a more detailed understanding of the lives of the mothers and families in which this occurs.</li> <li>- Consideration should be given to reduction in post discharge risks (discharge planning) for complex infants cared for in NICU.</li> </ul>	

**2. Sudden Unexpected Death in Infancy: A clear preventative strategy for “Safe Sleep” for infants needs to be in place. This must begin during the prenatal period, early in postnatal care (pre-discharge) and be aligned with Government initiatives for post natal care and follow up by Public Health. The committee’s work has also identified that SUDI cases are often associated with poverty, and housing conditions, especially in Aboriginal families. This reflects that it may not be the infant’s ethnic background per se that is the risk, but the living conditions of the family that is the determinant of risk.**

SUDI deaths account for the second highest number of deaths in the 2009 case review. Eight of the nine deaths were associated with unsafe sleep conditions on review by the Coroner. In addition these deaths were frequently associated with poor social determinants of health such as poverty or poor housing conditions. Three (3) of the infants in this review were identified as Aboriginal. In 3 SUDI cases, the families were known to or had been involved with MCFD.

Actions	Progress
<ul style="list-style-type: none"> <li>- Develop clear preventative strategy for “Safe Sleep” for infants.</li> <li>- We must support socially and culturally sensitive messaging about sleep conditions for infants and support for families in general but also for those identified ‘at risk.’</li> <li>- Issues of housing and broader social determinants of health may be beyond the defined scope of this committee’s work, but remains a central point of emphasis to be brought forward.</li> </ul>	<p>Members of the IMRC engaged with the Provincial Safe Sleep Working Group as well as with community partners on safe sleep initiatives.</p> <p><b>Activities ongoing from 2008-2012:</b></p> <ul style="list-style-type: none"> <li>- Community and/or organization presentations on “How to reduce infant mortality through safe sleep practices” (partnership w/ USMA/MCFD, FN communities, health providers, CYF, day care operators, family medicine residents)</li> </ul>
<p><b>3. <u>CPT1 as a possible risk factor for infant mortality: Definitive risk for infant mortality with the common CPT1 variant has not been established.</u></b></p> <p>Preliminary studies in BC have suggested a 1% risk for sudden unexpected death for those with two copies of the variant, which is higher than expected and deserving of exploration. Although an association with sudden death on Vancouver Island has been detected in one study it remains unclear whether other risk factors contributed to the deaths and the role of the variant in the deaths remains speculative.</p>	<p><b>Activities completed in 2011:</b></p> <ul style="list-style-type: none"> <li>- Provincial CTP1 Working group struck to work on public health messages, parent info and guidelines for health care professionals.</li> </ul> <p><b>Activities completed in 2012:</b></p> <ul style="list-style-type: none"> <li>- Two papers on CPT1 published by committee members ( Collins et al., BMC Pediatr. 2012 Dec 12;12(1):190, and Sinclair et al., Pediatrics. 2012 Nov;130(5):e1162-9).</li> </ul>
<ul style="list-style-type: none"> <li>- Careful assessment of the variant in the context of other infant mortality risk factors for cases on Vancouver Island needs to be carried out.</li> <li>- Further research is also needed to understand if this common variant is affecting the health of First Nations infants and children negatively.</li> </ul>	

**4. Barriers to Data Collection: In upcoming years, the Island Health IMRC will continue to collaborate with the BC Coroners Service and the Ministry of Children and Family Development in information sharing and in developing these reports. In addition, the IMRC will review its data sources and the mechanism of how this information flows to the Committee.**

In conducting this review, several gaps were identified in the gathering of data. Many charts had incomplete data. For instance, providers often failed to fill in the “ethnicity” of the patient. Weight of the mother was often not listed, or if it was listed, height was not measured so a Body Mass Index (BMI) could not be calculated. Other fields in the pre-natal record were frequently left blank, leading to inconsistencies in the data. As a result many of these fields were not analyzed in this review. The solution to this problem is not readily apparent, as it is difficult to change the habits of providers (particularly physicians). A strategy may be to mount an effort to educate health care providers on the importance of providing as complete a history as possible, including obtaining heights, and an accurate history of previous drug use, and ethnicity. Testing for CPT1 is carried out at Provincial Health Services Authority (PHSA) labs and the results are not necessarily available in the hospital records. An improved process to ensure that CPT1 results are incorporated into the patient record is desirable.

<i>Actions</i>	<i>Progress</i>
<ul style="list-style-type: none"> <li>- Continued collaboration with BC Coroners Service and MCFD.</li> <li>- Review of data sources and mechanisms of information flow.</li> <li>- Future policies to address the most prevalent risk factors in infant mortality can be evaluated with continued surveillance of infant mortality rates on Vancouver Island with future reviews.</li> </ul>	<p>The committee has refined the data review process to improve the flow of information between the Coroner, MCFD and the Health Authority which has enhanced the quality of the data. The database has also provided the IMRC with a central repository for managing and analyzing the data.</p>

**1. Island Health should make a commitment to ongoing health promotion and surveillance for infant mortality on Vancouver Island.**

Infant mortality is an important indicator for many reasons. It reflects maternal health, access to and quality of medical care, the socio-economic determinants of health, and public health practice. It is also an indicator of societal wellbeing and will reveal the inequities experienced by sub-populations within a society. Therefore, the work of the Infant Mortality Review Committee in surveillance and review of all infant deaths within Island Health, including the provision and tracking of subsequent recommendations from that review needs to be considered as foundational and sustained by the Health Authority.

Actions	Progress
<ul style="list-style-type: none"> <li>- Commitment to IMRC work – including provision and tracking of subsequent recommendations from review</li> </ul>	

**2. In future years, the IMRC should create a rolling report that covers a minimum of three years of aggregate data when reporting infant deaths. The aggregate reporting will help to stabilize small numbers in the data and give a clearer picture of trends in infant deaths in the Health Authority. This rolling report will also allow the IMRC to provide finer level of detail in the case review as greater numbers mask identification.**

In 2010, there were 24 infant deaths in Island Health that met the IMRC criteria. This is a decrease of 5 infant deaths from 2009 and a 17.7 percent decrease in the rate from 4.53 to 3.73 infant deaths per 1,000 live births. However caution should be exercised when dealing with a small number of cases as an increase or decrease may indicate random variation rather than a significant change in rates.

Actions	Progress
<ul style="list-style-type: none"> <li>- Create a rolling report that covers a minimum of three years of aggregate data when reporting infant deaths.</li> </ul>	<p>The 2009-2011 infant deaths were combined into one report for the subsequent reporting period.</p>

**3. The IMRC should seek to participate in and inform any multi-year, multi-agency strategies conducted by the Health Authority and the Province.**

Extreme prematurity was the leading cause of death in 2010 for infants under one year of age in Island Health. This is an increase from 11 cases in 2009 (38 percent) to 14 cases in 2010 (58.3 percent). In the 2009 report, the IMRC made recommendations to identify and modify risks for premature labor and delivery, including strategies pertaining to prenatal care. The IMRC acknowledges that this is a multi-year, multi-agency strategy that is in part addressed in the Perinatal Redesign led by the Ministry of Health.

Actions	Progress
<ul style="list-style-type: none"> <li>- Seek to participate and inform any multi-year, multi-agency strategies</li> </ul>	<p><b>Activities ongoing from 2012</b></p> <ul style="list-style-type: none"> <li>- <b>Right from the Start</b> program to provide universal as well as enhanced services for childbearing families from pregnancy up to two years of age begun in fall of 2012</li> </ul> <p><b>Activities ongoing from 2013</b></p> <ul style="list-style-type: none"> <li>- <b>Complex Care Planning and Support</b> model begun at VGH in 2013 including perinatal risk assessment and care planning and pregnancy support and planning care teams.</li> </ul>

**4. Continuing the recommendations in the 2009 report, members of the IMRC should continue to liaise and work with the Provincial Safe Sleep Working Group as well as with community partners on safe sleep initiatives. IMRC should work to ensure families receive consistent messaging on safe sleep from both the acute care and public health service providers in Island Health.**

The number of SUDI deaths has decreased from 9 cases in 2009 (31 percent) to 4 cases in 2010 (16.7 percent). This decrease may just indicate a natural variation in the numbers between the two years. However, it should be noted that members of the IMRC have spent considerable efforts in Safe Sleep initiatives.

- Continued work with Provincial Safe Sleep Working Group and Community Partners on safe sleep initiatives.
- Work to ensure consistent messaging on safe sleep from both acute care and public health service providers in Island Health.

**Activities completed in 2011:**

- Provincial Aboriginal Safe Sleep Working Group struck in 2011 to design, deliver and evaluate a safe sleep training initiative for Aboriginal and First Nations peoples.

**Activities completed in 2012:**

- Provincial Safe Sleep guidelines adopted as regional standards within Island Health: posted on intranet for use in acute care settings, included in neonatal guidelines and posted on Public Health Sharepoint for PHN use.
- Provincial Safe Sleep parent resources – distributed via acute and community perinatal services.
- Safe Sleep Education – provided to licensed daycare operators at Island Health facilities.

**5. Data Collection: The IMRC continues to deal with challenges associated with incomplete data when conducting chart reviews. However, the committee has refined the data review process to improve the flow of information between the Coroner, MCFD and the Health Authority which has enhanced the quality of the data. The database has also provided the IMRC with a central repository for managing and analyzing the data. It is anticipated that over the coming years that the database will provide a much more detailed picture of infant mortality in the region. However, improvements can still be made to improve the data collection and review process.**

- Continued review of data collection, entry and analysis to determine areas for quality improvement.

## Appendix C – Data Fields and Definitions

Data for Mothers collected from antenatal record	
Infant_Death_date	Infant's date of death (day/month/year)
Mother_Personal Health No	Mother's Personal Health Number (10 digits, no spaces)
Mother_MRN	Mother's Medical Record Number
Mother_firstname	Mother's given name
Mother_lastname	Mother's surname
Mother_Date of Birth	Mother's Date of Birth (dd/mm/yy)
Residence	City or Town (i.e. Victoria, Sidney, Parksville etc)
Mother_ethnicity	Mother's ethnicity
Paternal_ethnicity	Father's ethnicity
Mother_Aboriginal	Is the mother aboriginal (First Nations, Metis, Inuit etc.)? (Yes, No, Unknown, N/A or blank)
Mother_reserve	Does the mother live on reserve? (Yes, No, Unknown, N/A or blank)
Marital Status	Mother's marital status ( Single, Married, Common-law, Divorced, Separated, Widowed, Other)
Employment_status	Is the mother employed? (Yes, No, Unknown)
Medications	Is the mother taking any kind of medication? (Enter "No", "Unknown" or if yes, list types)
EDD_confirmed	Confirmed estimated date of delivery (as per section 4)
Ultrasound_weeks	If ultrasound was performed, enter gestational day and weeks of infant (Antenatal record)
PresPregnancy_IVF	InVitro fertilization present during pregnancy? Enter "No" or if "yes", specify treatment (Antenatal record)
PresPregnancy_Complication	Enter "No" or if "yes", specify complication (Antenatal record)
Mat_Preexist_condition	Does the mother have any disease or pre-existing condition? Enter "No" or if "yes", specify (Antenatal record)
Mat_hist_STIs_infections	Has the mother had STIs or infections? Enter "No" or if "yes", specify complication (Antenatal record)
Mat_HX of mental illness	Does the mother have any history of mental illness? Enter "No" or if "yes", specify complication (Antenatal record)
Mat_Mental_illness_type	List illnesses selected (Anxiety-1; Depression-2; Bipolar-3; PP Depression-4; Unknown-5; Other-6; N/A-7) If more than one selected, enter semi-colon between selection (e.g. 4;5)
Mat_issues_other	Does the mother have any history of other issues or pre-existing conditions? Enter "No" or if "yes", specify complication (Antenatal record)
Mat_diet_concerns	Indicate diet concerns (per Antenatal record) Enter 'N/A' if no answer or not applicable



Mat_folic acid	Indicate folic acid concerns (per Antenatal record) Enter 'N/A' if no answer or not applicable
OTC_drugs	Indicate OTC drug/ vitamin concerns (per Antenatal record) Enter 'N/A' if no answer or not applicable
Alcohol	Does the mother drink alcohol? (Select "Yes," "Never," or "Quit" as per the Antenatal record)
Pregnancy_alcohol	During pregnancy (current), how many drinks per week? (per antenatal form)
TWEAK_Score	Score between 0-7 to determine alcohol dependency (< 3 - too low to be considered a problem; 3-7- Patient has a problem)
Substance Use_Type	Does the mother use substances? (Enter type of substance or No, or 'N/A' as per antenatal sheet)
Smoking	Does the mother smoke? (Select "Yes", "Never" or "Quit" as per the antenatal record)
Pre_Pregnancy_smoking	Before pregnancy, how much did the mother smoke (cigarettes/ day) (select '0' if not applicable)
Pregnancy_smoking	During pregnancy (current), how much does the mother smoke (cigarettes/ day)? (select '0' if not applicable)
Secondhand_smoke_expos	Was the mother exposed to 2nd hand smoke? Enter either "No" or if yes, indicate comment
Financial_housing_issues	Did the mother have any financial or housing issues? Describe support system in place. Indicate comments as per antenatal record.
IPV_Issues	Did the mother have any issues with Inter Partner Violence? Indicate comments as per antenatal record
Blood_Pressure_result	Enter result of blood pressure test
Mother_PP_BMI	Mother's pre-pregnancy BMI (body mass index) (if blank, enter '0')
Phys_swabs_cervix	Indicate results from antenatal record relating to Swabs/ cervix cytology (if blank, enter N/A)
Summary_comments	Any additional comments listed in section 11 of antenatal record
Mother Rh factor	Mother's Rh Factor (Rh positive, Rh negative or Unknown)
STS_results	Serology Testing for Syphilis. Indicate negative or positive
HIV Test_results	Results of the HIV test? Enter "yes", "no" or "declined"
HBsAg_results	What was the results of the HBsAg test? Enter either positive or negative
Other_test_results	Document other tests conducted (e.g. Hep C, TSH, Varicella etc.)
Gest_diabetes_results	Enter results from gest. diabetes screen. Enter positive or negative
GBS_results	Enter results from Group B Strep screen. Enter either positive or negative
EPDS_Score	Score of Edinburgh Postnatal Depression Scale (28-32 weeks). Enter score as per antenatal record.
EPDS_Follow-up	Is follow-up care required for the EPDS Scale? Enter "yes", "no" or "n/a"

Potential_concerns	Indicate any concerns related to lifestyle, pregnancy, labour or birth, postpartum, or newborn (as per section 15 of antenatal record)
Amniocentesis_Performed	Was amniocentesis performed?

<b>Data for Infants collected from antenatal record, labor and delivery summary, newborn record, autopsy</b>	
Mother_PHN	Mother's Personal Health Number
Mother_Last_Name	Mother's Last Name
Infant_MRN	Infant's Medical Record Number
Infant_DoD	Infant's Date of Death (day/month/year)
Mat_Gravida	Total number of prior plus pregnancies regardless of gestational age, type, time or method of termination/ outcome
Mat_Term	Total number of previous pregnancies with birth occurring at >= 37 weeks gestation
Mat_Preterm	Total number of previous pregnancies with birth occurring between 20-36 weeks gestation
Mat_Abortion_spontaneous	Total number of previous spontaneous terminations of pregnancies ending prior to 20 completed weeks gestation, weighing < 500g
Mat_Abortion_induced	Total number of previous induced terminations of pregnancies ending prior to 20 weeks gestation, weighing < 500g
Mat_Living	Total number of children the woman has given birth to, and are presenting living
Gravida_health	Present health of other children (as indicated on antenatal record)
Prenatal_StartDate	Date of 1st prenatal visit (as per antenatal record)
Total_Prenatal_visits	Total number of prenatal visits
Comments_Prenatal	Any comments (prompts etc) from prenatal visits (as per antenatal record)
Kotelchuck_Index	Kotelchuck Index Score
Location_Death	Place of death (Hospital, Community, or Other)
Mother's Hospital ID	Mother's Hospital ID Number
Newborn Hospital ID	Newborn's Hospital ID Number
Birth_Quantity	Is the infant a singleton, twin, or triplet (as per birth and labour summary)
Labour_Status	What is the status of the labour (select from drop down list as per birth and labour summary)
Intrapartum_liquor	Was the intrapartum liquor meconium, bloody, or N/A? (As per birth and labour summary)
Date of Delivery	Actual Date of delivery
Time of Delivery	Actual Time of delivery

Delivery_Type	Is the delivery a SVD- Spontaneous Vaginal Delivery, or CS, Repeat CS, or VBAC? (indicate as per B & L summary)
Delivery_Assist	Was the delivery assisted? If so, indicate type of method of assistance (select from dd list as per B & L summary)
Delivery_CS	Was the delivery by CS? Indicate primary or repeat (select from dd list as per B & L summary)
Cord_Abnormalities	Any abnormalities or complications with the umbilical cord (as per B & L summary)
Sex_newborn	Sex of newborn according to labour and birth summary
Age_Newborn	Gestational Age of the newborn in weeks (from Antenatal History)
Status_Infant	Status of newborn- either alive or stillbirth (as per B & L summary)
Newborn_Apgar_1 min	Apgar Total Score at 1 minute
Newborn_Apgar_5 min	Apgar Total Score at 5 minutes
Newborn_Apgar_10 min	Apgar Total Score at 1 minute at 10 minutes
Amniotic Fluid__newborn	Amniotic Fluid during Transition to 1 hour of age (Select Clear, Meconium, Bloody, or Unknown)
Heart rate_newborn	What is the newborn's heart rate at transition to 1 hour of age?
Respirations_newborn	Respirations at transition to 1 hour
Eval_Development_BW	Birthweight (grams) at evaluation of development
Eval_Development_Length	Length (cm) at evaluation of development
Eval_Development_HC	Head circumference (cm) at evaluation of development
Development_assess	Was the newborn Preterm, Term, Postterm, SGA, AGA, or LGA?
GenAppearance_Comments	Comments re: the general appearance of the newborn (from newborn record)
PhysExam_Comments	Comments from the Physical exam- summary of newborn record exam
CPT1_Screen	Enter results from the CPT1 Screen (positive or negative, with comments)
Hearing_Screen_Date	Date of the hearing screening (from part 2 of the newborn record)
Hearing_Screen_Result	Results from the hearing screening (from part 2 of the newborn record)
Metabolic_Screen_Date	Date of the metabolic screening (from part 2 of the newborn record)
Metabolic_Bilirubin	If "Yes: indicate Age (h) that the Bilirubin screen was conducted. If "No", enter 0 (from part 2 of the newborn record)
Prophylaxis_HBsAg_ind	Was the HBsAg Prophylaxis indicated? (from part 2 of the newborn record)
Prophylaxis_HIV_ind	Was the HIV Prophylaxis indicated? (from part 2 of the newborn record)
Prophylaxis_GroupB_Strep	Group B Strep Intrapartum Prophylaxis conducted? (from the newborn record)
Nutrition_Date	Date of Newborn Nutrition Screen
Nutrition_Type	What type of nutrition was initiated? (Select from list as per newborn record)

ProblemList_Date	Date of the Problem list from part 2 of the newborn record
ACoRN_Sequence	Was ACoRN (Acute, Care of at Risk Newborns) sequence initiated? (Select from list as per newborn record)
ACoRN_Narrative	Indicate narrative notes (comments) from Problem List in part 2 of newborn record
ProgressNotes_Date	Date of Progress Notes
Progress_Notes	Indicate narrative notes (comments) from Progress Notes in part 2 of newborn record
Discharge_Age	Indicate Newborn Age at discharge (hours) Select from list as per newborn record
Discharge_Loss%	Percentage of weight loss of the newborn at discharge
Discharge_Gen_appear	General appearance of the newborn at discharge
Discharge_Status	Status of newborn at discharge- indicate comments from part 2 of newborn record
Autopsy_Date	Date of Autopsy
Autopsy_Time	Time of Autopsy
Autopsy_Place	Place of Autopsy (Name of Hospital or Lab)
Autopsy_Summary	Summary of the findings as described in the autopsy report.
Autopsy_Diagnosis	Indicate Diagnosis as described in the autopsy report.
Cause_Of_Death	Indicate cause of death of infant, as described in the autopsy report

<b>Postpartum Data for Mothers and Infants from Newborn Record, Autopsy, Coroner's Report</b>	
Postpartum Unique_ID	Postpartum Unique ID
Mother's Last Name	Mother's Last Name
Mother's PHN	Mother's 10 digit personal health number
Discharge_Nutrition	Newborn nutrition at discharge (as per part 2 of newborn record)
Discharge_Problems	Problems at discharge requiring follow-up (as per part 2 of newborn record)
Discharge_Location	Location where newborn was discharged (home, MCFD, etc) (as per part 2 of newborn record)
Discharge_Follow_up	Has a follow-up been recommended for the newborn? (as per part 2 of newborn record)
Neonatal_Death	Was this a neonatal death?
Autopsy_consented	Was an autopsy consented? (as per part 2 of newborn record) **
Coroner_Report	Was a Coroner's Report completed?
Coroner_Case.	Coroner's Case Number (BC Coroner's Service Infant Death Investigation Protocol)
Place_of_Death_township	Name of City or Town where incident occurred

Date_of_Death	Date of death as per BC Coroner's Report
Time_of_Death	Time of death as per BC Coroner's Report
Premise_of_Death	Premise of death as per Coroner's Report (e.g. private residence, foster home, daycare)
Deceased_Name	First and Last Name of deceased
Deceased_Age_days	Age of deceased infant (days)
Deceased_Ethnicity	Ethnicity of Deceased
Deceased_onreserve	Does the deceased live on reserve?
Adults_Present	No. of adults present at time of death as per BC Coroner's Report
Children_Present	No. of children present at time of death as per BC Coroner's Report
No_other_fatalities	No. of other fatalities in this incident as per BC Coroner's Report. Enter '0' if N/A
Primary_Caregiver_relation	Relationship of Primary care giver to infant (mother, father, aunt etc)
Infant_LivingWith	Who was the infant living with at the time of death?
No_household	Total number of people living in household
No_non-relatives_household	Total number of non-relatives (non-immediate) living in household
Supervisor of Infant	Who was responsible for supervision at time of incident (relationship to infant)
Contributing_factors_death	Contributing factors to death (Coroner's Report)
MCFD_Involvement	Was there Ministry of Childrens and Family Development involvement? Known to MCFD? etc. (As per BC Coroner's Report)
Autopsy Performed?	Was an autopsy performed? (As per BC Coroner's Report)
Death_circumstance	Circumstance of death (As per BC Coroner's Report)
Cause of Death	Cause of Death (As per BC Coroner's Report)
Significant_Medical_Conditions	Other Significant Medical Conditions contributing to death (As per BC Coroner's Report)
Hospitalizations_post	No. of hospitalizations since birth (As per BC Coroner's Report)
Home_visit	Was there Post-natal Public Health home visit? (As per BC Coroner's Report)
No_Siblings	Number of Siblings of deceased infant
Recent Medical Event	Recent Medical Event occuring in the last 72 hours before death
Date_Phys_Visit	Date of last visit to Physician
Medical_Event_details	Details of recent medical event or procedure (As per BC Coroner's Report)
Medical_Event_Date	Date of Medical Incident or procedure (As per BC Coroner's Report)
Medication Prescribed	Was medication prescribed to treat recent medical event? (As per BC Coroner's Report)
OTC_Medication	Was an over the counter medication given to treat a recent medical event?

Concerns_Medical Treatment	Indicate any concerns from the child's last medical treatment (As per BC Coroner's Report)
Previous Diagnosis_Allergies	Did the Infant have any previously diagnosed allergies? (Indicate "Unknown", "No", or if Yes, describe)
Congenital_Anomalies	Did the infant have any congenital anomalies? If yes, describe.
Hist_Respiratory	Did the Infant have any history of respiratory issues? (Indicate "Unknown", "N/A", "No", or if Yes, describe)
PD_Seizures	Did the Infant have any history of seizures or convulsions? (Indicate "Unknown", "N/A", "No", or if Yes, describe)
Other_Factors	Other concerns, factors or circumstances that might have impacted the infant (not yet identified)
In-house_Illness	Was there anyone in the house living with an illness? Indicate "Unknown", "N/A", "No", or if Yes, describe)
Condition_Infant_deceased	Status of Infant when found
Condition_Scene	What was the condition of the scene of death? (as listed in look-up)
Caregiver_Behaviour	List all items that the caregiver is currently using (e.g. OTC Medication, Prescription Medication, Herbal Remedies, Cigarettes, Alcohol, other)
Caregiver_Smoking	Does the caregiver smoke? If yes, enter # of cigarettes is the caregiver using a day? If no, enter "0"
Caregiver_Alcohol	If using alcohol, what is the daily consumption? (drinks per day) If no, enter "0"
Scene_Hazards	List all environmental hazards at the scene of death- enter "N/A" if not applicable. (e.g. none, 2nd hand smoke, recent renovations, dampness mold, toxic gases, etc.)
Evidence_Overlay/wedging/pallor	Is there evidence of overlay, Pressure Pallor, or Wedging? Specify which and details. Indicate N/A if not applicable
Caregiver_Testimony	Did the caregiver notice anything unusual or different about the infant in the last 24 hours? (As per BC Coroner's Report)
Date_Last_Alive	Date and time that the child was last seen alive (As per BC Coroner's Report)
Sleeping_Practice_issue	Is sleeping situation considered an issue or factor in the death?
Infant_Last_placed	Where was the infant last placed? Indicate specific Location (crib, chair, adult bed etc)
Infant_Last_checked	Where was the infant last known alive? Indicate specific Location (crib, chair, adult bed etc)
Infant_Last_Found	Where was the infant found? Indicate specific Location (crib, chair, adult bed etc)
Infant_Placed_position	Position in which infant was last placed (side, back, front etc) (as per BC Coroner's Report)
Bedding_List	List all types of bedding/ items/ pillows in the bed with the infant (as per BC Coroner's Report) separate list with semi-colon
Objects_Face	List all types of objects by the face, nose or mouth of the infant? as per BC Coroner's

	Report) separate list with semi-colon
Sleep_Additional	Was anyone sleeping with the infant? (as per BC Coroner's Report)
Sleep_Additional_Person	What was the relation of the person sleeping with the infant to the infant? (as per BC Coroner's Report)
Appearance_comments	What was the appearance of the deceased (bruises, rash, scratches, secretions, etc.) Describe and specify location. Enter "N/A" if not Applicable
Infant_General_Dietary	List all foods and/or liquids that are included in infant's regular diet? List all that apply (as per BC Coroner's Report) separate list with semi-colon
Infant_Last_Dietary	List all foods and/or liquids that were fed the infant in the last 24 hours before death? List all that apply (as per BC Coroner's Report) separate list with semi-colon
History of Abuse	Is there history of abuse in the family? If yes, select type of abuse
Abuse_Related	Was the death a result of abuse? If yes, indicate type of abuse (e.g.head trauma, blunt trauma, bruising, fractures, burn/ scald, drowning, suffocation/ strangulation etc)
Vehicular_Related	Was the death the result of a vehicular incident? If yes, list all contributing factors to injury (Infant seat, Vehicle type, Stolen vehicle, licensed driver, incident type etc)
Fire or Burn	Was the death the result of a fire or burning? If yes, list all contributing factors to injury. (Source of fire, type of structure, working smoke detector)
Fall_Related	Was the death the result of a fall? If yes, list all contributing factors to injury (Place, Barriers present, Fell onto, distance of fall)
Drowning_Related	Was the death the result of a drowning? If yes, list all contributing factors to injury (Place, Activity of carer, H2O temp, Private or public pool, lifeguard present etc)
Poisoning/ Drug_Related	Was the death the result of poisoning or drug intoxication? If yes, list all contributing factors (Type of drug, Prescribed to, Source of CO)
Additional_Comments	Any Additional Comments attributed to the deceased infant?