

Infant Mortality Report 2012-2014

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 2012 and 2014 in the Island Health region and builds on findings and recommendations from previous reports starting from 2008. 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 findings 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 2012 to 2014, there were 81 infant deaths in Island Health that met the IMRC review criteria; an estimated rate of 4.26 infant deaths per 1,000 live births. This represents an increase from the 2011-2013 rate of 3.62 per 1,000. The number of deaths had decreased from 23 in 2011 to 12 in 2012; however, the numbers increased again in 2013 and 2014 to a high of 34 and 35, respectively. While this increase is concerning, 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.

This report summarizes the cause of death into four main categories: extreme prematurity, Sudden Unexplained Death in Infancy (SUDI), congenital abnormalities and unknown or other.

Similar to what was seen in the 2011-2013 report, extreme prematurity was the largest category with 43% (35 cases) of infant deaths falling into this group. The mechanism of premature delivery of a high risk infant varied and included Premature Rupture of Membranes (PROM), severe intrauterine growth restriction (IUGR), acute chorioamnionitis, placental abruption, and incompetent cervix. Cause of death included complications related to extreme prematurity such as severe Respiratory Distress Syndrome and early acute hypoxic ischemic injury.

Congenital anomalies were listed as the reported cause of death in 21% (17) of cases from 2012-2014. These included diaphragmatic hernia, congenital heart defects, congenital neuromuscular disease, metabolic abnormalities, as well as Trisomy 13 and Trisomy 21 related anomalies.

The smallest category was SUDI with 15% (12) 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 twelve SUDI deaths, 6 identified as Aboriginal, 3 as Caucasian and 3 as other or unknown.

An additional 21% (17) of cases were listed as “Other” and included complications related to infectious disease, perinatal asphyxia, severe hyperbilirubinemia, and hypoxic events that may or may not have been related to prematurity of infant.

Conclusions and Recommendations

As discussed in previous reports, infants of First Nations ethnicity continue to be over-represented within infant deaths, and in particular among SUDI deaths. Aboriginal/First Nations/Metis peoples make up 6.6% of the general population within Island Health, but represent 26% percent of infant deaths and 50% of SUDI deaths. Infants born to young mothers are also at higher risk, with an infant mortality rate of 11.4 infants per 1,000 live births – 3 times the rate of mothers aged 20 to 34. This is of note as Vancouver Island also 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, but these associations rather point to a need to assess the accessibility and appropriateness of health and support services for young mothers.

The Infant Mortality Review Committee has identified two 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 hosted 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. IMRC members also participated in the Provincial Aboriginal Safe Sleep Working Group, developing culturally relevant safe sleep strategies in collaboration with First Nations communities. More recently, the Infant Baby Bed program – a pilot project initially funded by the Children’s Health Foundation of Vancouver Island and delivered through Island Health’s Public Health program – was started in the spring of 2015, providing all new mothers in the Cowichan Area with supplies and information in a container that can be converted into a baby bed. In 2016, through funding from the West Coast General Hospital (WCGH) Foundation and the WCGH Auxiliary, the program was expanded to the Port Alberni and West Coast communities.

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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 wellbeing¹. 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 following report is a summary of the infant deaths that occurred in the Island Health region from 2012 to 2014. It is intended to inform the leadership of Island Health with the findings concerning the deaths occurring in this period, and with an update of the work of the Infant Mortality Review Committee.

While aggregation of IMR data over a three year period 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 2012-2014 was 4.26 per 1,000 live births – about 12% higher than the provincial rate of 3.81 per 1,000. A total of 81 infant deaths were reported for Island Health between 2012 and 2014. The rate is higher than the previous 3 year period of 2011 to 2013, when the infant mortality rate was 3.62 deaths per 1,000 live births, and the total number of deaths was 69.

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 age².
- Infant mortality rates are calculated using the number of infant deaths divided by the total number of live births, multiplied by 1000.

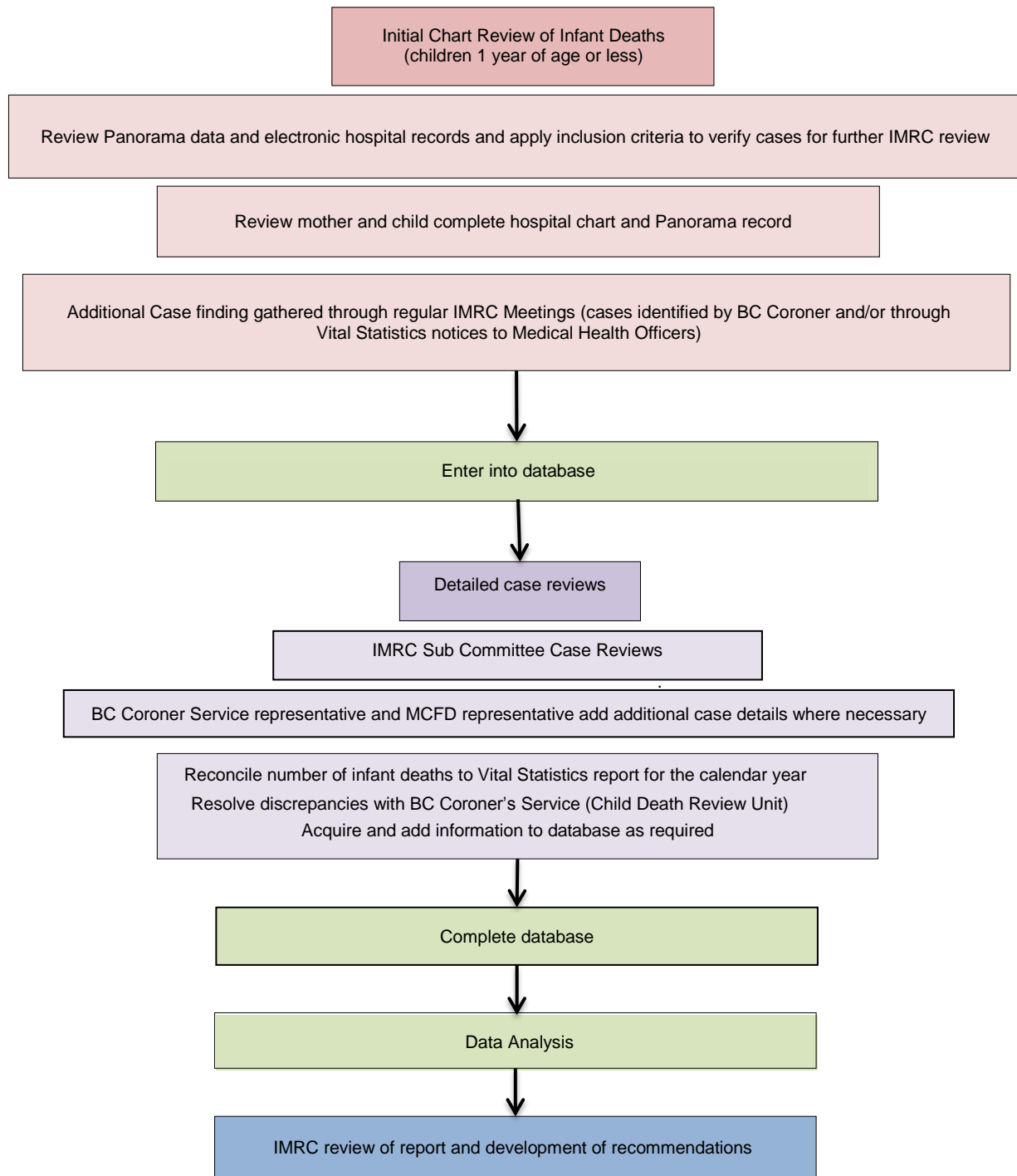
¹ Reidpath DD and Allotey P. Infant mortality rate as an indicator of population health. *J Epidemiol Community Health* 2003; 57:344-346.

² Conference Board of Canada, N.D.

- The *Vital Statistics Act* defines a live birth³ 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.

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

³ BC Vital Statistics. Glossary of Terms. <http://www.vs.gov.bc.ca/stats/annual/2007/pdf/glossary.pdf>



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 2012-2014 Case Review of all Infant Deaths

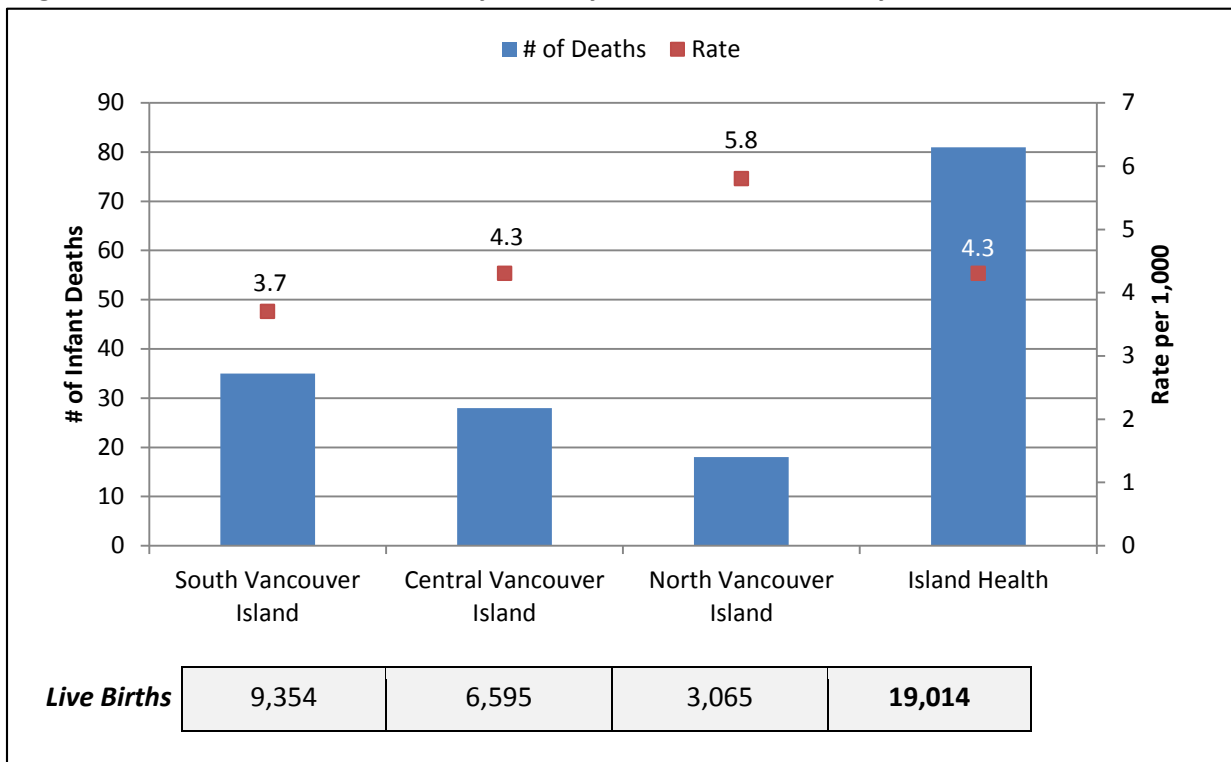
2.1. Geography

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. Overall for the three year period from 2012 to 2014, Island Health had an infant mortality rate of **4.26 deaths per 1,000 live births**. This is about 12% higher than the provincial rate of 3.81 per 1,000 for same period. The greatest number of deaths occurred in the Greater Victoria LHA, while the highest rate was in Vancouver Island West. It should be noted that only one death occurred in that region during the three year period. While the South Island HSDA had the highest number of deaths (N=35; rate=3.7 per 1,000), the infant mortality rate was higher in North Island (5.8 per 1,000 live births) and Central Island (4.3 per 1,000). As can be seen in Table 1 below, there is a slight discrepancy between infant deaths reported by Vital Statistics for some HSDAs compared to what was recorded in the Island Health charts.

Table 1: Infant Mortality Rates by Island Health Local Health Area, 2012-2014

LHA	LHA Name	Island Health Case Review			Vital Statistics
		Live Births	Rate per 1,000 live births	Infant Deaths by HSDA	Infant Deaths by HSDA
61	Greater Victoria	5,515	4.71	35	38
62	Sooke	2,550	2.35		
63	Saanich	1,152	1.74		
64	Gulf Islands	231	4.33		
65	Cowichan	1,594	1.88	28	24
66	Lake Cowichan	128	7.81		
67	Ladysmith	443	6.77		
68	Nanaimo	2,745	5.10		
69	Qualicum	683	1.46		
70	Alberni	887	6.76		
71	Courtenay	1,535	3.91	18	16
72	Campbell River	1,153	7.81		
84	Vancouver Island West	45	22.22		
85	Vancouver Island North	360	5.56		
Island Health		19,014	4.26	81	78

Figure 1: Island Health Infant Mortality Rates by Health Service Delivery Areas, 2012-2014



2.2. Ethnicity of Deceased Infant

Table 2 below identifies the listed ethnicity of the deceased infants based on the maternal ethnicity or nationality as listed on the antenatal record. There were four sets of twins and one set of triplets so there are 75 mothers and fathers for 81 infant deaths. Ethnicity was known for 56 of the mothers (75 percent) with the data on the remaining cases listed as “unknown” or “incomplete”. In the period of 2012 to 2014, 19 of the 75 mothers (25%) and 21 of the 81 infant deaths (26%) were listed as Aboriginal. While it is clear Aboriginal infants are over-represented among infant deaths, it is not possible at this time to calculate the Aboriginal-specific infant mortality rate as information on live births to Aboriginal women was not available.

Table 2: Ethnicity of Deceased Infant, Island Health, 2012-2014

Ethnicity	#	% of total cases
Caucasian	26	32%
Aboriginal (includes First Nations and Metis)	21	26%
Other	9	11%
Unknown	25	31%

2.3 Maternal Age

The average age for the 75 mothers of the deceased infants was 29.2 years. The data reveals that in the period of 2012 to 2014, the highest rate of infant deaths occurred among young mothers (11.4 per 1,000), while mothers 35 and over had the lowest rate of infant deaths (3.2 per 1,000).

Table 3: Infant Deaths by Maternal Age, Island Health, 2012-2014

Age of Mother (years)	# of Infant Deaths	# of Live Births	Infant Mortality Rate per 1,000
≤ 19 (Younger Mothers)	7	616	11.4
20-34	55	14,359	3.8
≥ 35 (Older Mothers)	13	4,046	3.2

2.4 Multiple Gestations

Thirteen of the infant deaths in Island Health between 2012 and 2014 were twins, including 4 sets of twins where both infants died, and 5 cases where death occurred to one twin in a set. There was one set of triplets where all three infants were deceased. In Vitro Fertilization or IVF was recorded in 5 infant death cases, of which 3 resulted in multiples (twins).

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. In many of the fields the data was incomplete or was not known.

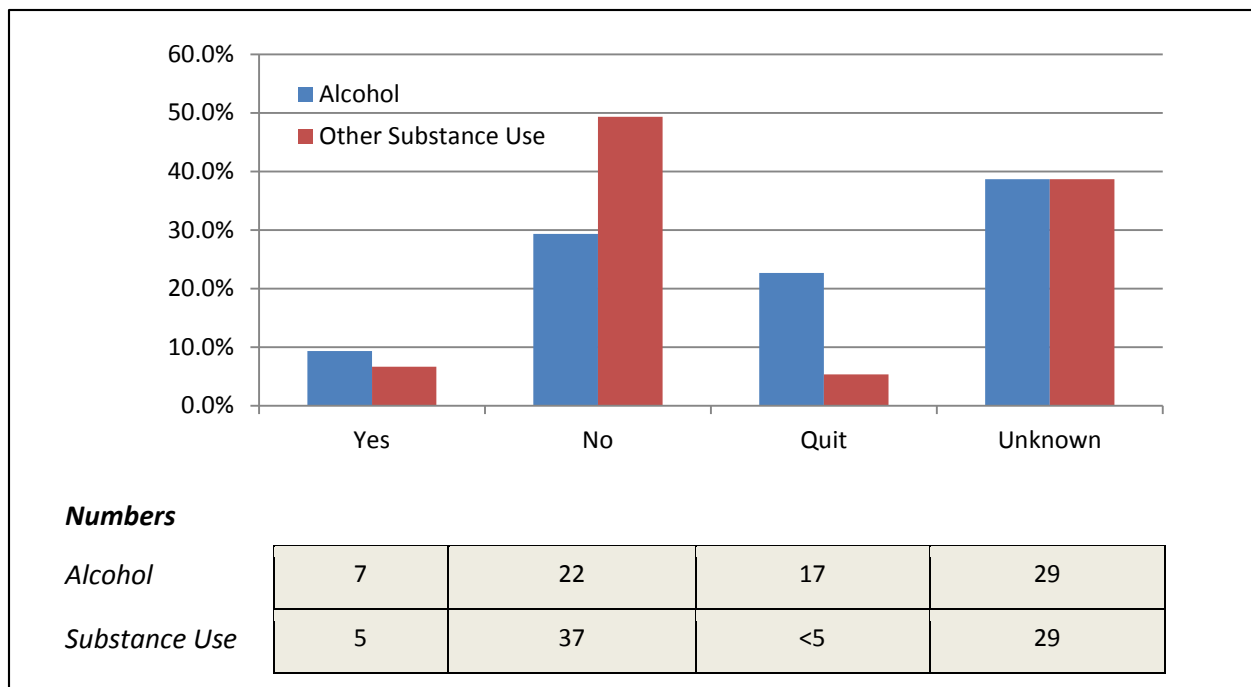
2.5.1 Alcohol Use during Pregnancy

The antenatal case reviews (N=75 mothers) noted the following: alcohol use during pregnancy was reported in 7 of the cases, no alcohol use was reported in 22 of the cases, 17 cases noted cessation of alcohol use upon pregnancy diagnosis and 29 of the cases did not have information noted in the antenatal record.

2.5.2 Substance Use during Pregnancy

In 5 of the 75 cases some form of substance during pregnancy was noted, the majority being marijuana use. Among the remaining 70 cases, less than 5 indicated cessation of use at pregnancy diagnosis, 33 cases indicated no substance use, less than 5 had a history of substance use noted and 29 cases were unknown or left blank.

Figure 2: Proportion reporting Alcohol and Substance Use (Illicit Drugs) during Pregnancy, 2012-2014



2.5.3 Tobacco Use during Pregnancy

Tobacco use during pregnancy was indicated in 16 cases (21 percent of mothers), 10 cases indicated cessation of use and 40 indicated no tobacco use during pregnancy. In 13 cases it was unknown or the data was incomplete. Among those who continued to smoke during pregnancy, pre-pregnancy tobacco use averaged 11.75 cigarettes per day, while the average number of cigarettes smoked during pregnancy was 5.88 cigarettes per day. The range of use during pregnancy was broad, spanning 1 to 20 cigarettes a day. Exposure to second hand smoke during pregnancy was reported in 14 cases, with a small number of these cases noting that a partner smoked outside the house (see Table 4 below).

The overall rate of tobacco use during pregnancy in Island Health for all deliveries in 2012-2014 was 11 percent; compared to a provincial rate of 7.6 percent.⁴

Table 4: Maternal Smoking, Island Health, 2012-2014

Smoking Data	#
Reported Smoking During Pregnancy	16
Average Cigarettes a Day (pre-pregnancy)	7.9
Average Cigarettes a Day (during pregnancy)	3.3
Quit	10
Unknown	13
Known exposure to 2 nd hand smoke during pregnancy	13

⁴ Perinatal Services BC – BC Perinatal Database Registry

2.6 Gestational Age and Birth weight of all 2012-2014 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 2012-2014, there were 53 pre-term infants (65%), of which 34 were extremely pre-term (<27 weeks), 10 were very preterm (28 to <33 weeks) and 9 were late preterm (33 to <37 weeks). In 2012-14, there were 76.2 preterm births per 1,000 live births in BC – similar to the Island Health rate of 80.0 per 1,000. The rate of preterm infant deaths in Island Health for the same time period was 34.8 per 1,000 preterm live births, slightly higher than the provincial rate of 30.9 preterm infant deaths per 1,000 preterm live births. Among Island Health cases, an additional 27 infants (33.3%) were born full term.

Table 5: Gestational Age of Deceased Infant, Island Health, 2012-2014

Gestational Age of Deceased Infant	# of Infant Deaths	% of Infant Deaths
Pre-Term (<37 weeks)	53	65.4
Term (37-41 weeks)	27	33.3

Table 6: Deceased Infants with Extreme and Moderate Prematurity, Island Health, 2012-2014

Gestational Age of Deceased Infant	# of Infant Deaths	% of Infant Deaths
Extremely Preterm (< 27 Weeks)	34	42.0
Very Preterm (28 to < 33 Weeks)	10	12.3
Late Preterm (33 to <37 Weeks)	9	11.1

2.6.2 Birth weight of Deceased Infants

Among the 81 cases for 2012-2014, birthweight was recorded for 73 infants. Of these, 27 (37%) were normal birth weight (>2500 grams) and 46 (63%) 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). Of the 46 low birth weight cases, 33 were extremely low birth weight, 3 were very low birth weight, and 10 were low birth weight.

Figure 3: Birth weight of Deceased Infants, Island Health, 2012-2014

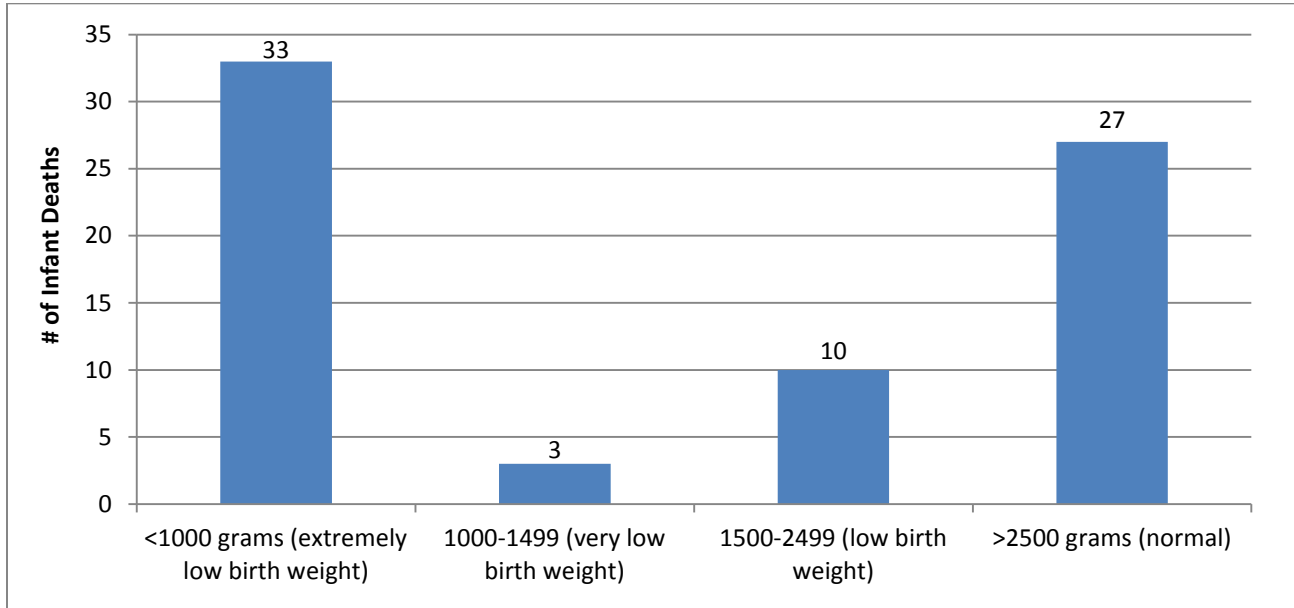
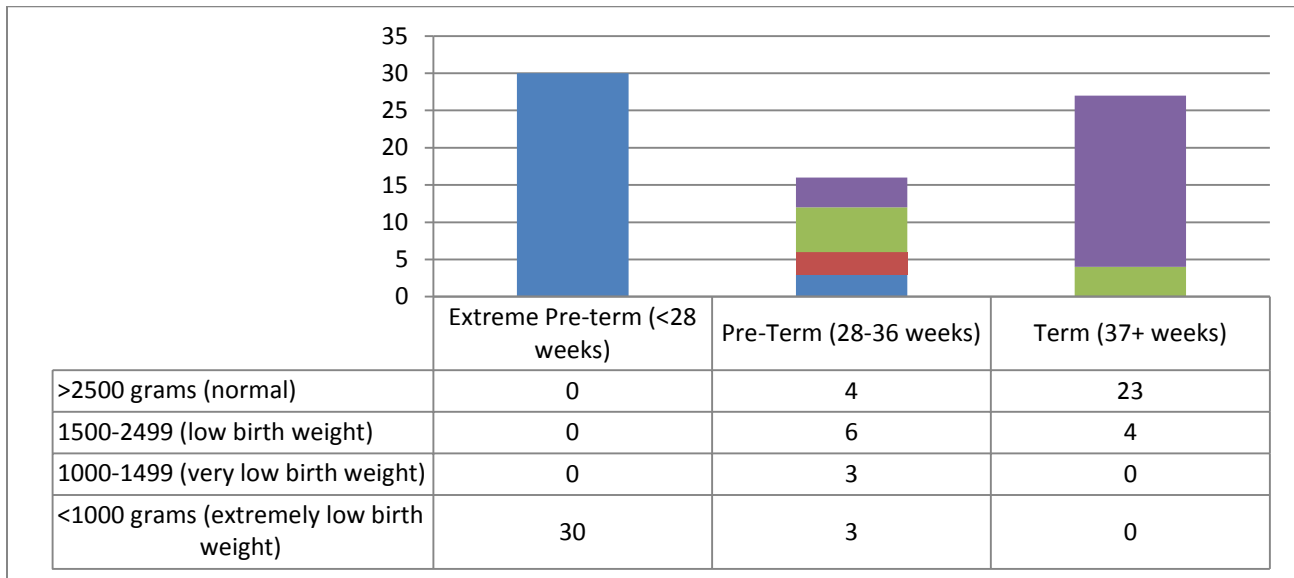


Figure 4 illustrates that 23 of the infants that were normal birth weight (>2500 grams) were born at Term or Post-term (≥ 37 weeks), while 4 were considered normal birth weight but were Pre-Term (28-36 weeks). There were 30 infants who were both Extremely Pre-Term (< 28 weeks) and extremely low birth weight (<1000 grams). There were 6 infants who were Pre-Term and low birth weight (1500-2499 grams), 3 that were Pre-Term and very low birth weight (1000-1400 grams) and 3 that were Pre-Term and extremely low birth weight (<1000g).

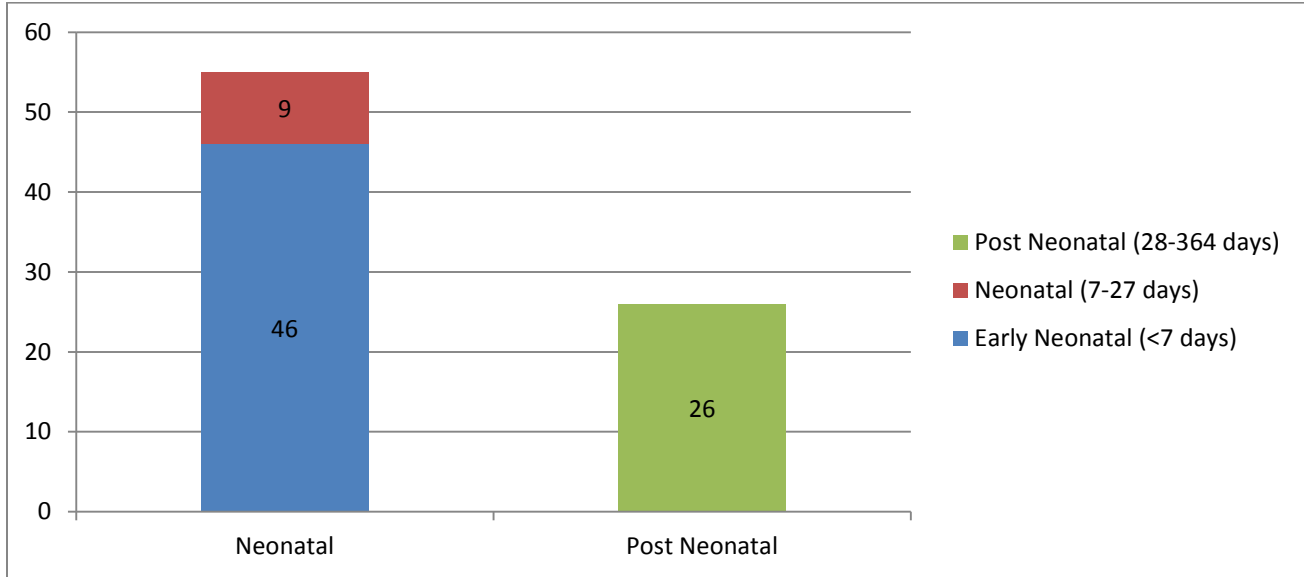
Figure 4: Birth Weight and Gestational Age of Deceased Infants, Island Health, 2012-2014



2.6.3 Period of Infant Death

The majority (68%) of infant deaths in 2012-2014 occurred in the Neonatal period (< 28 Days). This represents a total of 55 infant deaths, of which 46 occurred in the early neonatal period (< 7 days after birth) and 9 occurred between 7-27 days after birth. In 2008-09 when the Infant Mortality Review Committee was initially formed, the proportion of post-neonatal deaths was much higher, representing 58% of cases. This has dropped to 32% of cases in 2012-14.

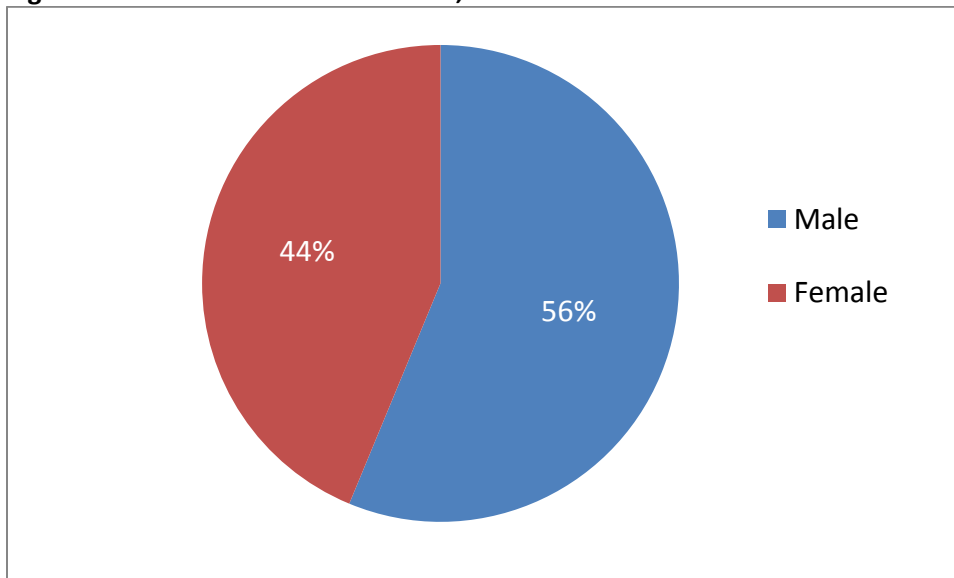
Figure 5: Period of Infant Death for All Known Cases, Island Health, 2012-2014



2.7 Gender of the Deceased Infant

In 2012-2014, 56 percent of the infants were male (45/80) and 44 percent of the infants were female (35/80). One case was missing information on gender of infant.

Figure 6: Gender of Deceased Infants, Island Health 2012-2014



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 energy⁵. 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 four infants in among the 2012-2014 infant deaths had test results recorded for CPT1. Of these, there was 1 case recorded as heterozygous (one copy) for the variant, while three were recorded as homozygous for the P479L variant. The remaining cases were listed as either “Not Applicable, Not screened, or Unknown”. These results need to be interpreted with caution as very few infants are testing and the information is not representative.

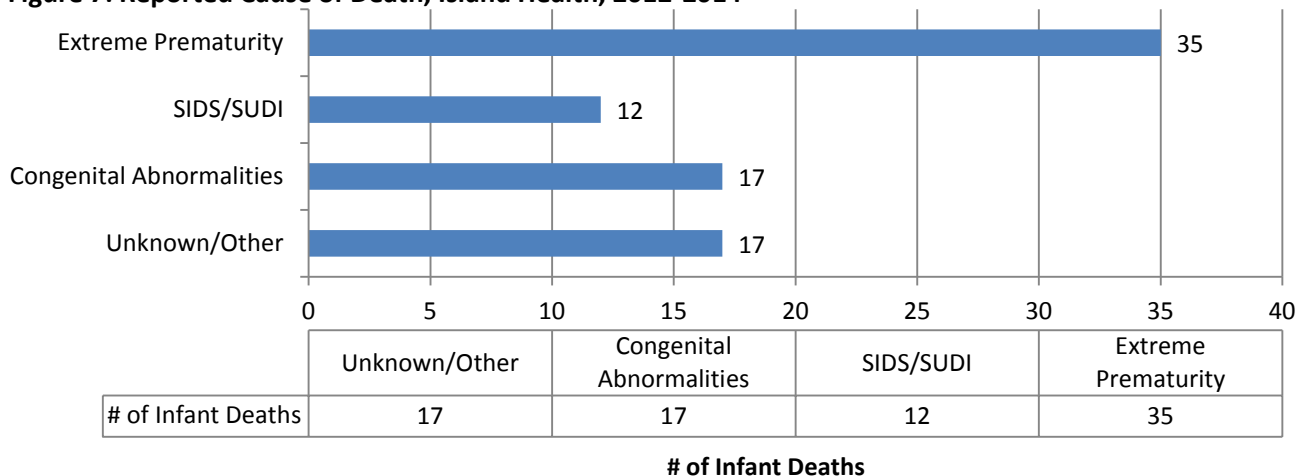
3. Reported Cause of Death

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 IMRC groups infant deaths into four main categories:

- Extreme prematurity (Intent to Treat, No Intent to Treat and Mid-trimester Termination, see section 3.1 below)
- Sudden Unexplained Death in Infancy (SUDI)
- Congenital Abnormalities
- Unknown or Other

The following figure illustrates the cause of death for the 2012-2014 cases.

Figure 7: Reported Cause of Death, Island Health, 2012-2014



⁵ Definition of CPTI from http://www.hss.state.ak.us/dph/wcfh/metabolic/downloads/cpt1_brochure.pdf

3.1 Extreme Prematurity

Similar to the period of 2011-2013, cause of death due to extreme prematurity was listed for 35 of the cases (43%) in 2012 to 2014. 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). The majority of cases (86%) fell into the second category (no intent to treat); while 2 cases had some level of intervention initiated and 3 cases were MTT or TTT.

3.2 Sudden Unexplained Death in Infancy (SUDI)

SUDI was reported as the cause of death in 12 (15%) of the cases in the period of 2012 to 2014. The majority of these cases were either indicated as positional/accidental asphyxia, or included indication of a sleep-related risk factor. Only one case was undetermined with no apparent sleep-related risk factors.

All of the SUDI cases occurred in the Post-Natal period (>28 days after birth). The gestational ages of the infants were known in 11 of the cases with the majority (73%) being born at Term.

Half (6) of the SUDI cases were reported as being Aboriginal, 3 were listed as Caucasian and 3 were unknown.

3.3 Congenital Anomalies

The cause of death was listed as a result of congenital abnormalities for seventeen (21%) of the infant deaths in 2012-2014. The abnormalities included: congenital diaphragmatic hernia, congenital neuromuscular disease, Noonan's syndrome, congenital cardiomyopathy and other cardiac anomalies, Trisomy 13, congenital nephrotic syndrome, and other metabolic abnormalities.

3.4 Unknown or Other

There were seventeen (21%) infant death cases between 2012-2014 that did not fit under the preceding categories and therefore were listed as "Unknown or Other" for the reported cause of death. All of the cases had a known cause of death, with the exception of one case that died at BC Children's Hospital for which there was limited information in the charts. Of the 16 known "Other" cases, cause of death included complications from infection, perinatal asphyxia and hypoxic injury possibly associated with prematurity, and one case of homicide.

4. Summary and Recommendations

Since its inception in 2007, the IMRC has been developing recommendations and leading activities to reduce infant death in the Island Health region. The recommendations over the years have been focused on those deaths that have a preventable component, or a modifiable risk factor. More recently, the committee has conducted aggregate reporting in 3 year rolling reports such as this in order to stabilize small numbers in the data and give a clearer picture of trends in infant deaths in the Health Authority. The 2012-2014 review resulted in a general profile of infant deaths that is similar to the previous 2011-2013 report. Therefore, the committee remains focused on the recommendations from the previous report which are centered on reducing preventable infant deaths related to unsafe sleep, and quality improvement aimed at pre and post-natal care and services to support optimal reproductive health. In brief, these recommendations are:

1) Sudden Unexpected Death in Infancy

- Facilitate the connection between parents and parenting resources available in their communities.
- Ensure that those resources, whether public health (Island Health), First Nations HA, or private physicians, can evaluate parents' needs and deliver information and tools that support the family 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 who may benefit from an offer of more intensive services via family support programs, and/or Public Health family visitation services such as the Nurse Family Partnership or the Mother's Story.
- 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 Baby Bed program.

Unsafe sleep remains a concern across the Island. The Baby Bed program has been successful in its initial implementation and has even been expanded to additional communities; however, funding remains a challenge for broader implementation and sustainability.

2) Perinatal Care

- 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.
- Work with the Chief Medical Health Officer to conduct a review of the Ministry of Health's Women's Health Strategy with an eye to optimizing childbearing women's health and the health of their infants. Use this review to inform an update to the 2008 Island Health report on Women's Health.

- Continue Public Health Nursing program and service planning to intentionally engage in a client-focused care relationship with priority populations of perinatal women.
- Perform in-depth case review of extreme premature cases to better understand underlying factors and proportion of cases that are preventable and/or predictable in order to inform future recommendations regarding primary (e.g. diet, folic acid) and secondary prevention efforts. Combine these in-depth reviews with analysis using cumulative IMRC database (2009-2014) to inform a special report on infant mortality related to prematurity.

With respect to perinatal care, some of the work above is ongoing (e.g. regional approach to complex care planning, client-focused care with priority populations), while other recommendations have not been implemented.

5. 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, supporting socially and culturally sensitive messaging about sleep conditions for infants and ensuring 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 previous reports and the progress made on corresponding initiatives can be found in Appendix B.

Appendix A – Infant Mortality Review Committee Members

Listed in alphabetical order (last name)

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

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

Dr. Shannon MacDonald
Senior Medical Officer, Vancouver Island Region
First Nations Health Authority

Erin O’Sullivan
Leader, Perinatal Program Development
Island Health

Continued on following page...

Dr. Gustavo Pelligra
Physician
Island Health

Melanie Rusch
Manager, Population Health and Epidemiology, Planning
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
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>1. Focus attention and efforts on the following two categories as most readily modifiable risk factors for infant mortality. This will include:</p> <p>a. Sleep-related deaths – 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. Deaths related to CPT1- 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>	
	Actions	Progress
	<p>a. Sleep-related deaths</p> <ul style="list-style-type: none"> - 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> - 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> - 	<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>Activities completed in 2009:</p> <ul style="list-style-type: none"> - Island Health Brochures and Fridge magnets on Safe Sleep Practices and B.O.B. for Aboriginal Communities - MCFD Brochure on Safe Sleeping for Babies <p>Activities ongoing from 2008-2012:</p> <ul style="list-style-type: none"> - 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)
	<p>b. Deaths related to CPT1</p> <ul style="list-style-type: none"> - 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> 	<p>Activities completed in 2011:</p> <ul style="list-style-type: none"> - Provincial CTP1 Working group struck to work on public health messages, parent info and guidelines for health care professionals.

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"> - 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> 	<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"> - The Infant Mortality Review Committee plans to obtain a more detailed understanding of the lives of the mothers and families in which this occurs. - Consideration should be given to reduction in post discharge risks (discharge planning) for complex infants cared for in NICU. 	

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"> - Develop clear preventative strategy for “Safe Sleep” for infants. - 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.’ - 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. 	<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>Activities ongoing from 2008-2012:</p> <ul style="list-style-type: none"> - 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)

3. CPT1 as a possible risk factor for infant mortality: Definitive risk for infant mortality with the common CPT1 variant has not been established.

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.

<ul style="list-style-type: none"> - Careful assessment of the variant in the context of other infant mortality risk factors for cases on Vancouver Island needs to be carried out. - Further research is also needed to understand if this common variant is affecting the health of First Nations infants and children negatively. 	<p>Activities completed in 2011:</p> <ul style="list-style-type: none"> - Provincial CTP1 Working group struck to work on public health messages, parent info and guidelines for health care professionals. <p>Activities completed in 2012:</p> <ul style="list-style-type: none"> - 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).
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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"> - Continued collaboration with BC Coroners Service and MCFD. - Review of data sources and mechanisms of information flow. - 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. 	<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"> - Commitment to IMRC work – including provision and tracking of subsequent recommendations from review 	

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"> - Create a rolling report that covers a minimum of three years of aggregate data when reporting infant deaths. 	<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.

<i>Actions</i>	<i>Progress</i>
<ul style="list-style-type: none"> - Seek to participate and inform any multi-year, multi-agency strategies 	<p>Activities ongoing from 2012</p> <ul style="list-style-type: none"> - Right from the Start 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 <p>Activities ongoing from 2013</p> <ul style="list-style-type: none"> - Complex Care Planning and Support model begun at VGH in 2013 including perinatal risk assessment and care planning and pregnancy support and planning care teams.

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.

Activities completed in 2013:

- Provincial Aboriginal Safe Sleep Working Group completed in 2013. Developed and posted the “Honouring our Babies: Safe Sleep Toolkit” on the FNHA website. Available at: <http://www.fnha.ca/about/news-and-events/news/new-safe-infant-sleep-toolkit-honouring-our-babies-safe-sleep-cards-and-guide>

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.

Activities ongoing from 2014:

- Review of access data base including assessment and summary of data entry issues and suggestions for reducing number of fields, reducing text entry requirements and improving data validation processes

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. While contributing factors can be complex, the Health Authority can support strategies to develop programs and messages which can help parents of all backgrounds understand risks and make safe sleep choices for their babies.*

Actions

- Facilitate the connection between parents and parenting resources available in their communities AND ensure that those resources, whether Island Health, FNHA, or 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 Baby Bed program

Progress

Activities ongoing from 2014:

- Grant submitted to Children’s Health Foundation Vancouver Island for Baby Bed pilot project in 2014.
- Launch of Baby Bed pilot project in Cowichan Valley region in Spring 2015; provision of supplies and information for all new mother’s in a container that can be converted into a baby bed.

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. Facilitating clients' engagement with prenatal care is dependent on understanding what those clients value as quality care.

- 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.

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. While contributing factors can be complex, the Health Authority can support strategies to develop programs and messages which can help parents of all backgrounds understand risks and make safe sleep choices for their babies.

Actions	Progress
<ul style="list-style-type: none"> - Continue to support recommendations from 2009-2011 report. 	<p>Activities ongoing from 2014:</p> <ul style="list-style-type: none"> - Through funding from the Children’s Health Foundation of Vancouver Island, the Baby Bed program has continued in the Cowichan region, and with funding from the West Coast General Hospital (WCGH) Foundation and the WCGH Auxiliary, the program was expanded to Port Alberni and the West Coast in 2016; funding from the Nanaimo Regional General Hospital Auxiliary has been received to support expansion of the program in the Nanaimo region in 2017/18.

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. Facilitating clients’ engagement with prenatal care is dependent on understanding what those clients value as quality care.

<ul style="list-style-type: none"> - Continue to support recommendations from 2009-2011 report. - Perform in-depth case review of extreme premature cases to better understand underlying factors and proportion of cases that are preventable and/or predictable in order to inform future recommendations regarding primary (e.g. diet, folic acid) and secondary prevention efforts. Combine these in-depth reviews with analysis using cumulative IMRC database (2009-2014) to inform a special report on infant mortality related to prematurity. 	
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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?

Data for Infants collected from antenatal record, labor and delivery summary, newborn record, autopsy	
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

Postpartum Data for Mothers and Infants from Newborn Record, Autopsy, Coroner's Report	
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?