

Infant Mortality Report 2017 to 2019

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

Infant Mortality Review Committee

April 2024

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Island Health's commitment to reconciliation

Before Canada and British Columbia were formed, Indigenous peoples lived in balance and interconnectedness with the land and water in which the necessities of life are provided. Healthy lands, healthy people. Island Health acknowledges and recognizes these homelands and the stewardship of Indigenous peoples of this land; it is with humility we continue to work toward building our relationship.

Island Health is committed to addressing racism, continuing our journey of cultural safety and humility and integrating Indigenous health and wellness practices. Large disparities persist in the health outcomes, and the social determinants of health, of Indigenous peoples. Island Health recognizes that these disparities are due to the ongoing impacts of colonization and intergenerational trauma. We acknowledge the findings and Calls to Actions of the Truth and Reconciliation Commission and are guided by them in our work as a Health Authority.

Executive Summary

This report provides a summary of the infant deaths that occurred between 2017 and 2019 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, ongoing colonial practices have resulted in racism, intergenerational trauma and significant harm to Indigenous peoples through mass relocation of land, loss of culture and language and the creation of the residential school systems. These practices have affected the burden of poverty, lack of housing, lack of education and poor access to healthcare services in Indigenous communities¹. These factors increase the likelihood of infant death and poor social determinants of health are directly associated with disparities between the infant mortality rate between Indigenous and non-Indigenous infants. One of the main goals of the IMRC is to strive to eliminate the disparity of Indigenous infant deaths to non-Indigenous infant deaths. 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.

¹ Public Health Agency of Canada. Key Health Inequalities in Canada: A National Portrait. Ottawa: Public Health Agency of Canada; 2018

From 2017 to 2019, there were 70 infant deaths in Island Health that met the IMRC review criteria; a rate of 3.8 infant deaths per 1,000 live births. This is in line with the 2016-2018 period rate of 3.8 per 1,000 live births. The number of infant deaths slightly decreased from 72 deaths to 70 over the three-year time period. It is important to note that 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 anomalies and unknown or other.

Similar to the 2016-2018 report, extreme prematurity was the largest cause of death category with 51% (36) 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), acute chorioamnionitis, infant affected by prolapsed cord, placental separation and incompetent cervix. Cause of death included complications related to extreme prematurity such as cardiac failure, perinatal asphyxia and coagulation defect.

Congenital anomalies were listed as the reported cause of death in 26% (18) of cases from 2017-2019. The anomalies included: Trisomy 13 (Patau syndrome) trisomy 18 (Edwards syndrome), trisomy 21 (Down syndrome), congenital heart malformations and other anomalies.

The smallest category was SUDI with 8% (6) of cases, with all the infant deaths occurring in the Post Neonatal Period (28-364 days). Two of these infants were born at term. In all cases, potential sleep practice factors – sleep surfaces, sleep environments and sleep positions – were identified as potential contributors, and in many of the cases broader social complexities were also noted.

An additional 21% (15) of cases were listed as “Other/unknown” and included complications related to infectious disease, perinatal asphyxia, and hypoxic events that may or may not have been related to prematurity of infant.

Conclusions and Recommendations

Infant mortality is known world-wide as a key indicator of child health and, more generally, of societal well-being. It is influenced by a multitude of factors, including not only the robustness of the health care system but also the economic, social and physical conditions of people identifying as women and their infants and of the communities in which they live. While the IMRC reviews and reports on all cases of infant death that meet the criteria, the recommendations over the years have been focused on those deaths that have a preventable component, or a modifiable risk factor.

In 2013, the IMRC created its first 3 year rolling report using 2009-2011 data. Since then, 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 2017-2019 review builds

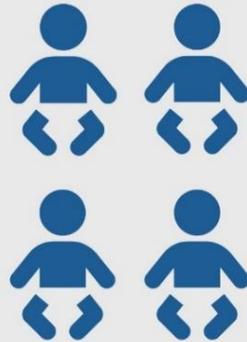
on the findings and recommendations of the previous reports which are centered on reducing preventable infant deaths related to unsafe sleep practices, quality improvement aimed at pre- and post-natal care and services to support optimal reproductive health. The committee recognizes the importance of community collaboration across all recommendations to continue to reduce the likelihood of infant mortality. The profile of infant deaths at Island Health has remained consistent since the previous 2016-2018 report and therefore, recommendations regarding Safe Sleep and the Baby Bed Program will continue as Committee priorities.



Island Health Infant Mortality

2017-2019

Rates



3.8 infant deaths per
1,000 live births

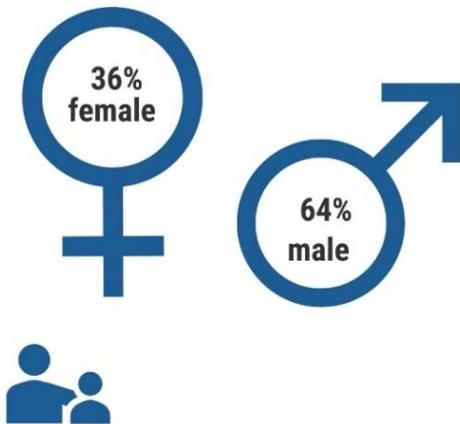


higher than the rate for BC
(3.4 per 1,000)

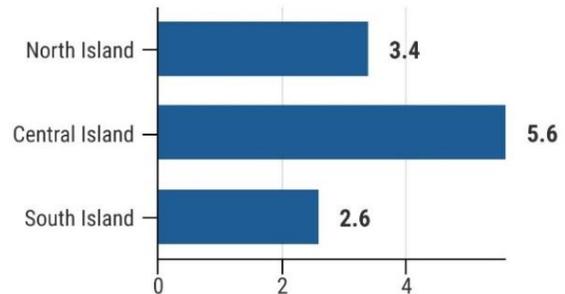


Same as the Island Health
rate for 2016-2018
(3.8 per 1,000)

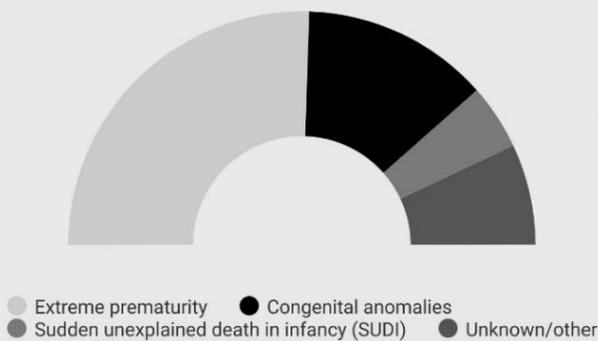
Demographics



Infant deaths per 1,000 live births



Causes



13%

of infant deaths had a sleep
related risk factor reported



30%

of infant deaths occurred in the
post neonatal period



65%

of infants were born prematurely; of
which 78% were born extremely pre-
term

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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 the birthing person's 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 wellbeing². The Island Health Infant Mortality Review Committee (IMRC) 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 were born to Island Health residents from 2017 to 2019. The intention of this review is 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 IMRC.

While aggregation of 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 2017-2019 was 3.8 per 1,000 live births – higher than the provincial rate (3.4 per 1,000 live births) for this time period. A total of 70 infant deaths were reported for Island Health between 2017 and 2019. The rate is the same as the previous 3-year period of 2016 to 2018 (3.8 deaths/1,000 live births), and similar to the total number of 72 infant deaths.

BC Guiding Framework for Public Health, the Ministry of Health has set a target of 2.5 infant deaths per 1,000 live births to be reached by 2023. This can be considered the ultimate target or benchmark. Island Health has set annual targets based on a 5.5% decline per year in order to meet the 2023 target. The current target for 2022/2023 is 3.32 per 1,000 live births. Island Health reports on the rate annually as a 5-year aggregate.

1.1 Methodology

The Island Health Infant Mortality Review Committee (IMRC) works collaboratively with the British Columbia Coroners Service (BCCS), the Ministry of Children and Family Development (MCFD), First Nation Health Authority (FNHA) and First Nation Health Director representatives from the three Traditional Families on Vancouver Island. Using a database template developed by the IMRC in 2008, chart reviews of the infants that meet the IMRC criteria and their birthing person were conducted (list of database fields can be seen in Appendix D. Database fields were updated in 2023, where 98 variables from the database were removed based on an evaluation of the data quality). 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.

² Reidpath DD and Allotey P. Infant mortality rate as an indicator of population health. *J Epidemiol Community Health* 2003; 57:344-346.

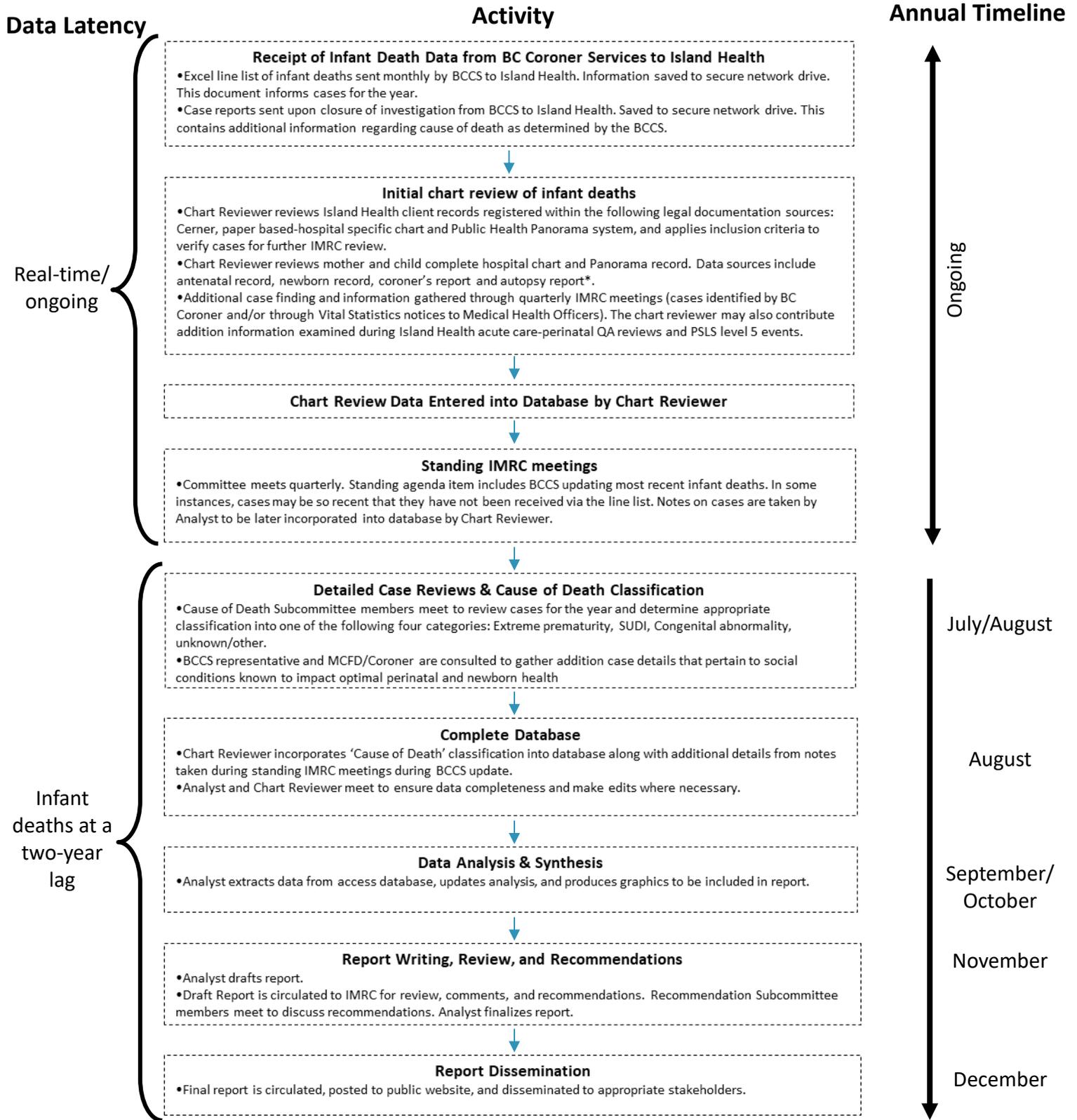
As in previous years, the Island Health IMRC used the following inclusion criteria for inclusion of cases into the review:

- Infant deaths are defined as the death of a child less than 12 months of age³.
- The *Vital Statistics Act* defines a live birth⁴ 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 where the residence of the birthing person was within the Island Health boundary, whether they died on Vancouver Island or at BC Children’s and Women’s Hospital in Vancouver or elsewhere. Not included are infants who may have died on Vancouver Island but the normal place of residence of the birthing person 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.
- Infant mortality rates are calculated using the number of infant deaths divided by the total number of live births, multiplied by 1000.

³ Conference Board of Canada, N.D.

⁴ 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.

British Columbia Perinatal Data Registry- the British Columbia Perinatal Data Registry (BCPDR) contains data abstracted from obstetrical and neonatal medical records on nearly all births in the province from over 60 hospitals as well as births occurring at home attended by BC registered midwives. The BCPDR also collects data on the birthing person's postpartum readmissions up to 42 days post-delivery and baby transfers and readmissions up to 28 days after birth.

Birthing person: Someone who gives birth, regardless of their gender identity, which may be female, male, non-binary or other⁵.

Antenatal Record- the Antenatal Record is a tool developed to facilitate the assessment and documentation of important information about the birthing person'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.

Gestational Age- 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.

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).

Indigenous – The term 'Indigenous' encompasses First Nations, Métis and Inuit people, either collectively or separately, and is a preferred term in international usage, e.g., the 'U.N. Declaration on the Rights of Indigenous Peoples.' In its derivation from international movements, it is associated more with activism than government policy and so has emerged, for many, as the preferred term⁶. An umbrella term for self-identified descendants of pre-colonial/pre-settler societies. In Canada these include the First Nations, Inuit and Métis peoples as separate peoples with unique heritages, economic and political systems, languages, cultural practices and spiritual beliefs. While the collective term has offered a sense of solidarity among some Indigenous communities, the term should not serve to erase the distinct histories, languages, cultural practices, and sovereignty of the more than fifty nations that lived in Canada prior to European colonization⁷). For purposes of this report, a baby is considered to be Indigenous if the parent or caregiver identifies the infant as First Nations (status or non-status), Inuit and Métis infants. Antenatal records for the birthing person's and health records for the non-birthing parent are used to identify the infant as Indigenous. In some cases, Indigenous ancestry of an infant was available from BC Coroner Service and was incorporated into the database for analysis if the birthing person's ancestry was missing.

⁵ National Institute for Children's Health Quality (2021). Retrieved from: <https://nichq.org/insight/exploring-nonbinary-approach-health>

⁶ UBC. (2023). Equity and inclusion glossary of terms. Retrieved from <https://equity.ubc.ca/resources/equity-inclusion-glossary-of-terms-2/>

⁷ Rainbow Health Ontario. (2023). *Glossary*. Retrieved from <https://www.rainbowhealthontario.ca/news-publications/glossary/>

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 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.

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.

Coroner Categories of Death:

Natural Causes: A death primarily resulting from a disease of the body and not resulting secondarily from injuries or abnormal environmental factors.

Accident: A death due to unintentional or unexpected injury. It includes death resulting from complications reasonable attributed to the accident.

Homicide: A death due to injury intentionally inflicted by action of another person. Homicide is a neutral term that does not imply fault or blame.

Undetermined causes: deaths that (because of insufficient evidence or inability to otherwise determine) cannot be reasonably categorized as natural or injury deaths. This includes some sudden infant deaths and fatalities due to other unknown or undetermined causes.

2. Results from the 2017-2019 Case Review of all Infant Deaths

2.1. Geography

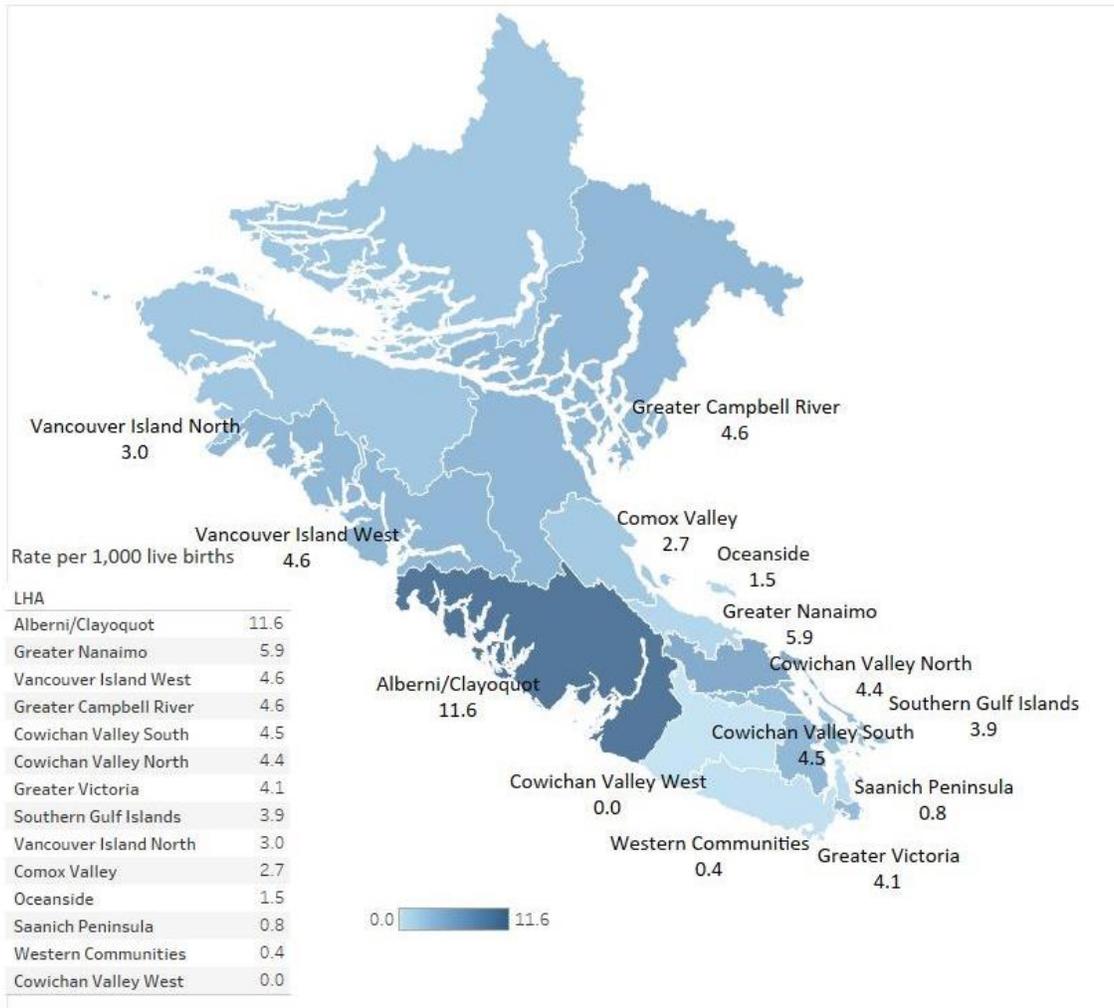
The IMRC uses the birthing person or caregiver’s place of residence from the hospital records to determine where infant deaths are occurring in the region and to learn if certain areas are experiencing higher rates of infant mortality than others. Overall, for the three-year period from 2017 to 2019, Island Health had an infant mortality rate of 3.8 deaths per 1,000 live births. This is higher than the provincial rate (3.4 per 1,000

live births) for the same time period. There were 21 infant deaths in Island Health in 2017, 27 in 2018 and 22 in 2019. The greatest number of deaths for the combined three-year period occurred in the Greater Victoria Local Health Area (LHA), while the highest rate was in Alberni/Clayoquot (11.6 per 1,000 live births). The number of deaths in the Greater Victoria LHA could be inflated as a result of the birthing person or caregiver's giving a temporary address if they are required to travel to Victoria for the birth, as Victoria General Hospital (VGH) offers specialized perinatal services for Island residents.

The infant mortality rate in the Central, North and South Island Health Service Delivery Areas (HSDA) remained stable compared to the previous reporting period (2016-2018). Central Island Health Service Delivery Area (HSDA) had the highest number of deaths during the 2017 to 2019 time period and the highest infant mortality rate (5.6 per 1,000 live births) and is above the Island Health rate (3.8 per 1,000 live births). North Island Health Service Delivery Areas (HSDA) had the second highest infant mortality rate (3.4 per 1,000 live births), followed by South Island Health Service Delivery Areas (HSDA)(2.6 per 1,000 live births) and are both below the Island Health rate (3.8 per 1,000 live births) (Figure 1).

There is a slight discrepancy between infant deaths reported by Vital Statistics for South Island and Central Island compared to what was recorded in the Island Health charts (Table 1).

Map 1: Infant Mortality Rates per LHA, Island Health, 2017-2019



Note: Data is combined for Vancouver Island West & Greater Campbell River

Table 1: Infant Mortality Rates (LHA) & Counts (HSDA), 2017-2019

	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
SOUTH	411 (Previously 61)	Greater Victoria	5,109	4.1	24	25
	412 (62)	Western Communities	2,507	0.4		
	413 (63)	Saanich Peninsula	1,210	0.8		
	414 (64)	Southern Gulf Islands	258	3.9		
CENTRAL	421 (65)	Cowichan Valley South	1,559	4.5	36	37
	422 (66)	Cowichan Valley West	146	0.0		
	423 (67)	Cowichan Valley North	452	4.4		
	424 (68)	Greater Nanaimo	2,691	5.9		
	425 (69)	Oceanside	689	1.5		

	426 (70)	Alberni/Clayoquot	864	11.6		
NORTH	431 (71)	Comox Valley	1,495	2.7	10	10
	423 & 433 (72 & 84)	Greater Campbell River and Vancouver Island West	1,096	4.6		
	(434) 85	Vancouver Island North	328	3.0		
	Island Health		18,404	3.8	70	72

Figure 1: Infant Mortality Rates per Health Service Delivery Area, Island Health, 2009-11 to 2017-19

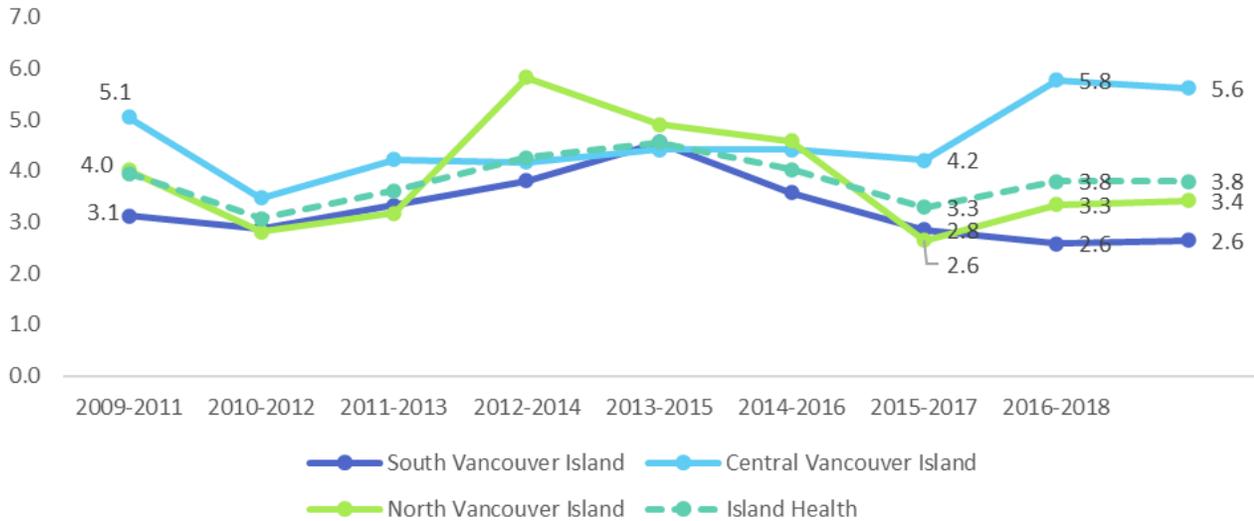


Table 2: Infant deaths, live births & mortality rates per Health Service Delivery Area, 2009-11 to 2017-19

South	2009-2011	2010-2012	2011-2013	2012-2014	2013-2015	2014-2016	2015-2017	2016-2018	2017-2019
Deaths	29	27	31	36	43	34	27	24	24
Live Births	9,270	9,363	9,305	9,437	9,443	9,511	9,485	9,282	9,084
Rate/1,000	3.1	2.9	3.3	3.8	4.6	3.6	2.8	2.6	2.6
Central	2009-2011	2010-2012	2011-2013	2012-2014	2013-2015	2014-2016	2015-2017	2016-2018	2017-2019
Deaths	34	23	28	27	29	29	28	38	36
Live Births	6,724	6,623	6,632	6,481	6,559	6,574	6,646	6,585	6,401
Rate/1,000	5.1	3.5	4.2	4.2	4.4	4.4	4.2	5.8	5.6
North	2009-2011	2010-2012	2011-2013	2012-2014	2013-2015	2014-2016	2015-2017	2016-2018	2017-2019
Deaths	13	9	10	18	15	14	8	10	10
Live Births	3,235	3,192	3,151	3,090	3,053	3,053	3,019	2,990	2,919
Rate/1,000	4.0	2.8	3.2	5.8	4.9	4.6	2.6	3.3	3.4
Island Health	2009-2011	2010-2012	2011-2013	2012-2014	2013-2015	2014-2016	2015-2017	2016-2018	2017-2019
Deaths	76	59	69	81	87	77	63	72	70
Live Births	19,229	19,178	19,088	19,008	19,055	19,138	19,150	18,853	18,404
Rate/1,000	4.0	3.1	3.6	4.3	4.6	4.0	3.3	3.8	3.8

2.2. Ethnicity/Race of Deceased Infant

Table 3 identifies the listed ethnicity of the deceased infants based on the birthing person’s self-reported ethnicity or race as listed on the antenatal record or health records. From 2017-2019, the database includes 68 pairs of parents for 70 infant deaths, as there were deaths in two sets of twins in this reporting period. Ethnicity is known for 41 of the birthing persons (59%) with the data on the remaining cases listed as “unknown” or “incomplete”. In some cases, ethnicity of an infant was available from BCCS and was incorporated into the database for analysis if the birthing person’s ethnicity was missing. From 2017-2019, 21 of the 41 infants with known ethnicity (51%) were white, 12 (29%) infants were listed as Indigenous, 8 (20%) were from underrepresented populations and 29 (41% of total) were unknown ethnicities. The proportion of infants’ deaths where the infant was identified as Indigenous has shown an encouraging downward trend since the 2014 to 2016 reporting period but significant work remains to continue a reduction in this trend (Figure 2). With 8% of the Island Health population identifying as Indigenous, Indigenous infants are over-represented among infant deaths. Unfortunately, it is not possible at this time to calculate the Indigenous-specific infant mortality rate as information on live births to Indigenous birthing people are not available.

Table 3: Ethnicity/Race of Deceased Infant, Case Count & Proportion, Island Health, 2017-2019

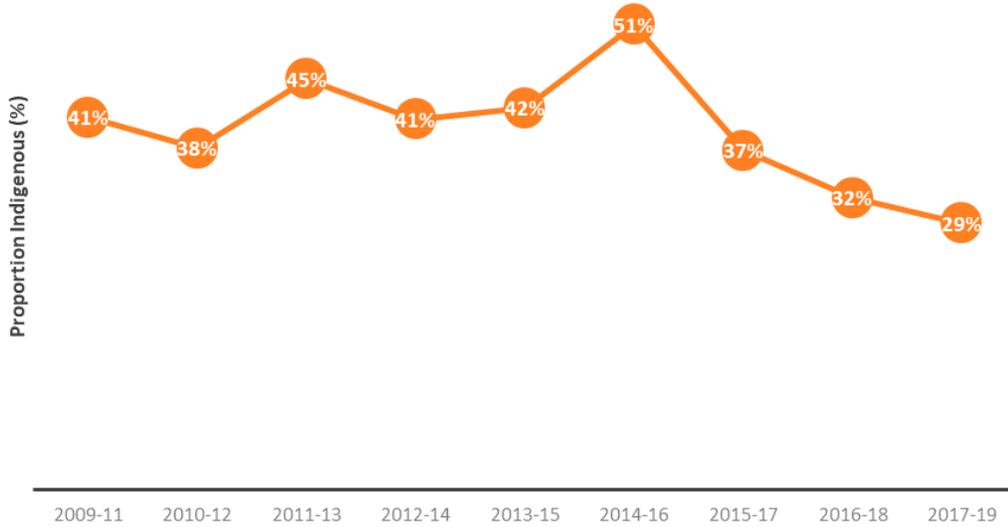
Ethnicity	Number of infant deaths	% of total cases (where ethnicity is known, N=41)
White ^a	21	51%
Indigenous (includes First Nations and Metis) ^b	12	29%
Underrepresented populations	8	20%
Unknown ^c	29	41% of total (N=70)

^aEthnicity/race is displayed in this table in ascending order based on number of infant deaths, where unknown is excluded

^bPersonal ethnicity/race that is unknown on antenatal or health records or incomplete

^cIndigenous ethnicity from antenatal or health records, BCCS may be incomplete. Limitations to these data sources include potential non self-identifying data, missing, incomplete or lagged data.

Figure 2: Infant Deaths, Proportion identified as Indigenous*, Island Health, 2009-2011 to 2017-2019



*Note:

- Excluded cases where ethnicity is unknown.
- From 2014 to 2019, an additional data source was used to identify the ethnicity of infants. This may have resulted in higher proportion of those known to be Indigenous compared to the previous years.

2.3 Birthing Person’s Age

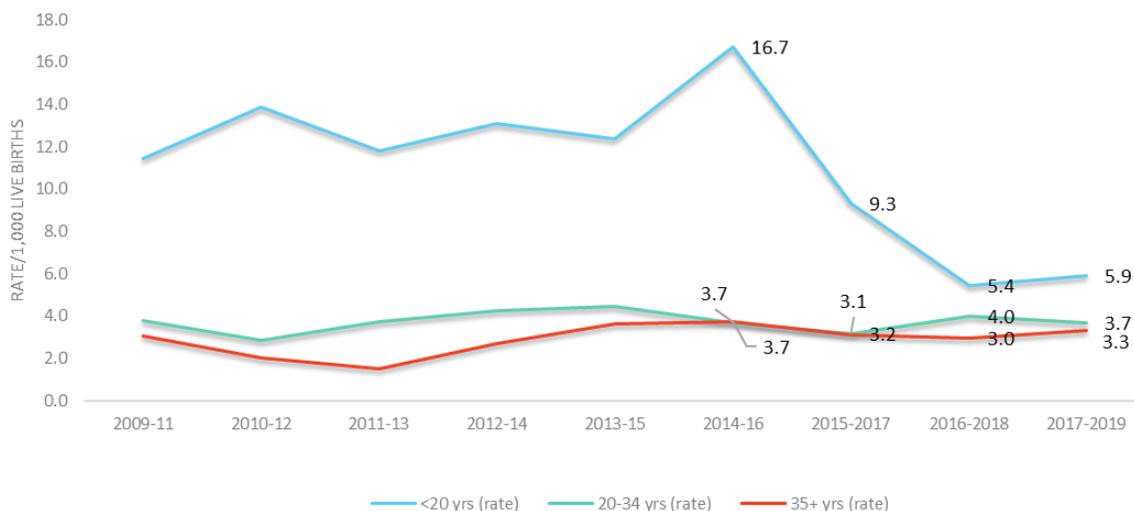
The average age of the birthing persons of the deceased infants is approximately 30 years with a median age of 31. The data reveals that in the period of 2017 to 2019, the highest rate of infant deaths occurred among young (< 20 years of age) birthing people (Table 4). This is consistent across reporting periods (Figure 2); however, the rate among younger birthing people has been decreasing since the 2014-2016 period which has since stabilized since the last reporting period (2016-18). The decline in infant mortality rates in birthing people below 20 years of age coincides with a decrease in live births in this age group during this timeframe.

Table 4: Birthing Person’s Age of Deceased Infants, Case Count & Rate per 1,000 live births, Island Health, 2017-2019

Age of Birthing Person (years)	Number of infant deaths	Number of Live Births	Infant Mortality Rate per 1,000
<20 (Younger birthing people)	2	339	5.9
20-34	49	13,260	3.7
≥ 35 (Older birthing people)	16	4,804	3.3

*3 birthing parents with unknown age

Figure 3: Birthing Person’s Age of Deceased Infant, Rate per 1,000 live births, Island Health, 2009-11 to 2017-19



2.4 Multiple Gestations

10 of the infant deaths in Island Health between 2017 and 2019 were twins. In 6 instances only one twin died while the other one survived. There were two instances where both twins died. Out of the 10 twin deaths, seven of these deaths occurred in the neonatal period. Six infants who were multiples had a cause of death classified as “extreme prematurity.”

2.5 Gestational Age and Birthweight of all 2017-2019 Cases

2.6.1 Gestational Age of Infants

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 deaths from 2017-2019, there were 55 infants (79%) with documented gestational age. Of these infants, 46 were classified as pre-term infants (84%), of which 35 (76% of 46) were extremely pre-term (<28 weeks), 5 were very preterm (28 to <33 weeks) and 6 were late preterm (33 to <37 weeks) (Table 6). In 2017 to 2019 time period, there were 91.4 pre-term births per 1,000 live births in Island Health, higher than the provincial rate of 79 per 1,000. Among Island Health cases, an additional 9 infants (16%) were born full term. The rate of pre-term infant deaths for 2017 to 2019 is 27.4 deaths per 1,000 pre-term live births compared to 0.5 deaths per 1,000 term live births (Table 5). The rate of pre-term infant deaths has seen an overall decreasing trend since 2013-15 but has been increasing since the 2015-2017 period (Figure 3).

Table 5: Gestational Age of Deceased Infants, Case Count, Proportion & Rate per 1,000 live births
Island Health, 2017-2019

Gestational Age of Deceased Infant	Number of infant deaths	% of Infant Deaths (when gestational age is known, N=55)	# of Live Births (in category)	Rate per 1,000 live births
Pre-Term (<37 weeks)	46	84%	1,678	27.4
Term (37-41 weeks)	9	16%	16,622	0.5

Of all the infant deaths from 2017 to 2019, over three quarters were born prematurely, of which 76% were born extremely premature (<28 weeks).

Figure 4: Gestational Age of Deceased Infant, Rate per 1,000 live births, Island Health, 2009-11 to 2017-19

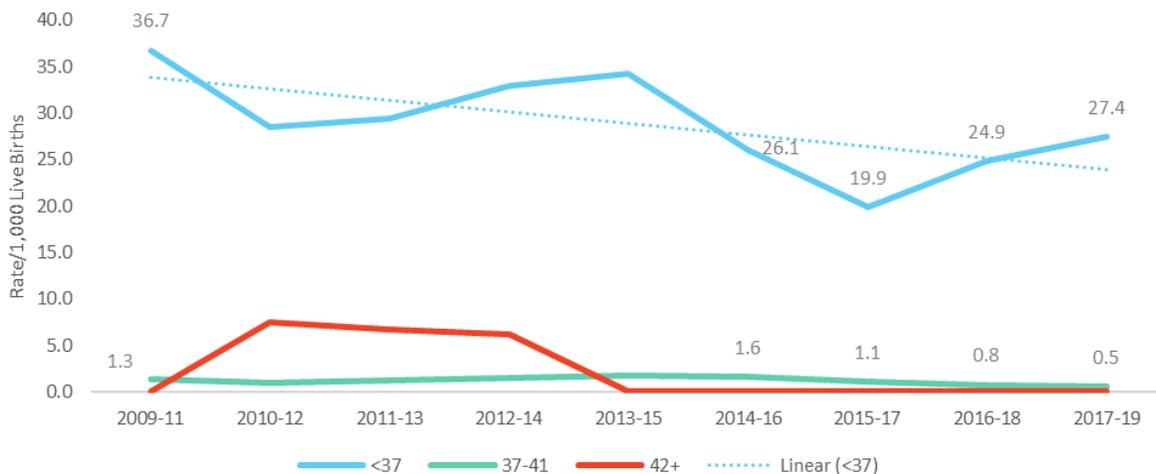


Table 6: Deceased Infants with Extreme and Moderate Prematurity, Case Count & Proportion, Island Health, 2017-2019

Gestational Age of Deceased Infant	Number of infant deaths (N=46 born pre-term)	% of Infant Deaths (N=55 gestational age known)
Extremely Preterm (< 28 Weeks)	35	64%
Very Preterm (28 to < 33 Weeks)	5	9%
Late Preterm (33 to <37 Weeks)	6	11%

2.6.2 Birthweight of Deceased Infants

Among the 70 infant deaths in 2017-2019, birthweight was recorded for 49 (70%) infants. Of these infants with known birthweight, 14 (29%) were normal birthweight (>2500 grams) and 35 (71%) were low birthweight (\leq 2499 grams). The rate of deaths to low birthweight infants is 33.5 deaths per 1,000 low birthweight births compared to 0.8 deaths per 1,000 normal birthweight births (Table 7). This is likely due to

the high rate of premature deaths. The low birthweight infant deaths can be further broken out into extremely low birthweight (<1000 grams), very low birthweight (1000-1499 grams) and low birthweight (1500-2499 grams). Of the 35 low birthweight cases, 24(34%) were extremely low birthweight, 7(10%) were very low birthweight, and 4(6%) were low birthweight (Figure 5).

Figure 5: Birthweight of Deceased Infants, Case Count, Island Health, 2017-2019

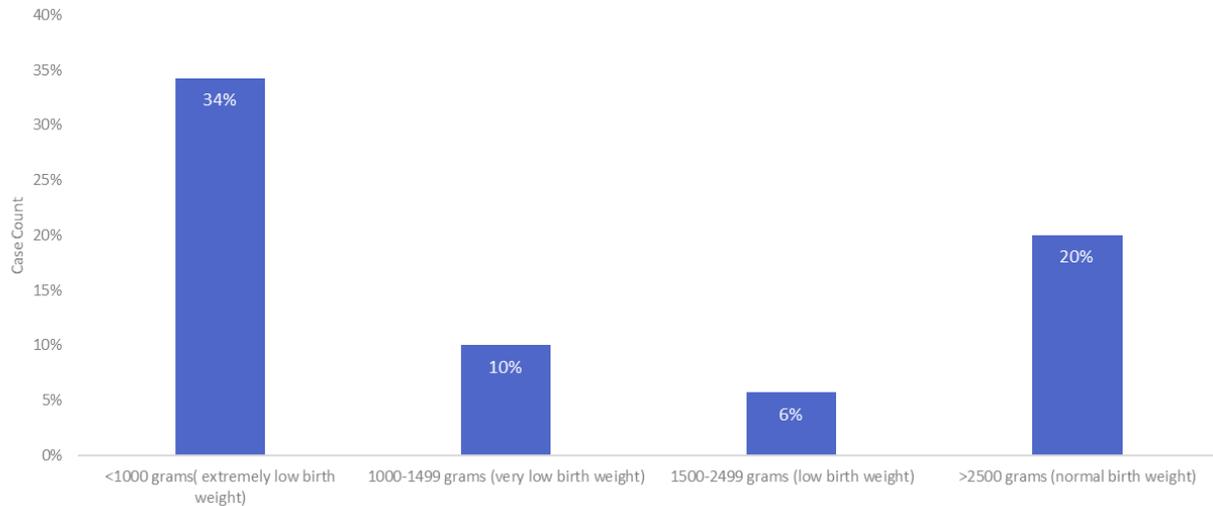


Table 7: Birthweight of Deceased Infants, Case Count & Rate per 1,000 live births, Island Health, 2017-2019

Birthweight of Deceased Infant	# of Infant Deaths	# of Live Births (in category)	Rate per 1,000 live births
Low birth weight (<2500 grams)	35	1,044	33.5
Normal birth weight (>2500 grams)	14	17,345	0.80

Figure 5 (below) illustrates the age of gestation and infant weight at birth. Not surprisingly, infants born prior to 37 weeks (pre-term) gestation tend to experience lower birthweights compared to infants born at term. Seventy-eight percent of infants considered extremely pre-term (<28 weeks) were born weighing less than 1,000 grams (extremely low). Sixty three percent of infants born pre-term (28 to <33 weeks) were born with either a low, very low or extremely low birthweight while 100% of infants born at term were born at a normal birthweight.

Figure 5: Birthweight and Gestational Age of Deceased Infants for Known Cases, Island Health, 2017-2019



2.6.3 Period of Infant Death

The majority (63%) of infant deaths in 2017-2019 occurred in the Neonatal period, early neonatal and late neonatal combined (< 28 Days) (Figure 6). This represents a total of 51 infant deaths, of which 44 occurred in the early neonatal period (< 7 days after birth) and 7 occurred between 7-27 (late neonatal) days after birth. In 2008 to 2009 when the Infant Mortality Review Committee was initially formed, the proportion of post-neonatal deaths was much higher, representing 58 percent of cases. This has dropped to 27% of cases in 2017 to 2019. Figure 6 illustrates the proportion of neonatal and post-neonatal infant deaths for the 2017 to 2019 time period while figure 7 illustrates the rate of neonatal and post-neonatal infant deaths per 1,000 live births. Figure 8 illustrates the cause of death in the infant deaths during the postnatal period.

Figure 6: Period of Infant Death (days since birth), Proportion, Island Health, 2017-2019

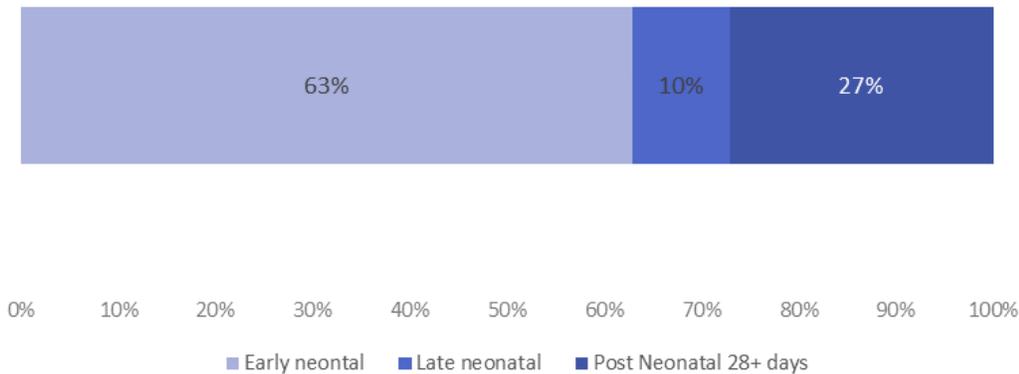


Figure 7: Period of Infant Death (days since birth), Rate per 1,000 live births, Island Health, 2017-2019

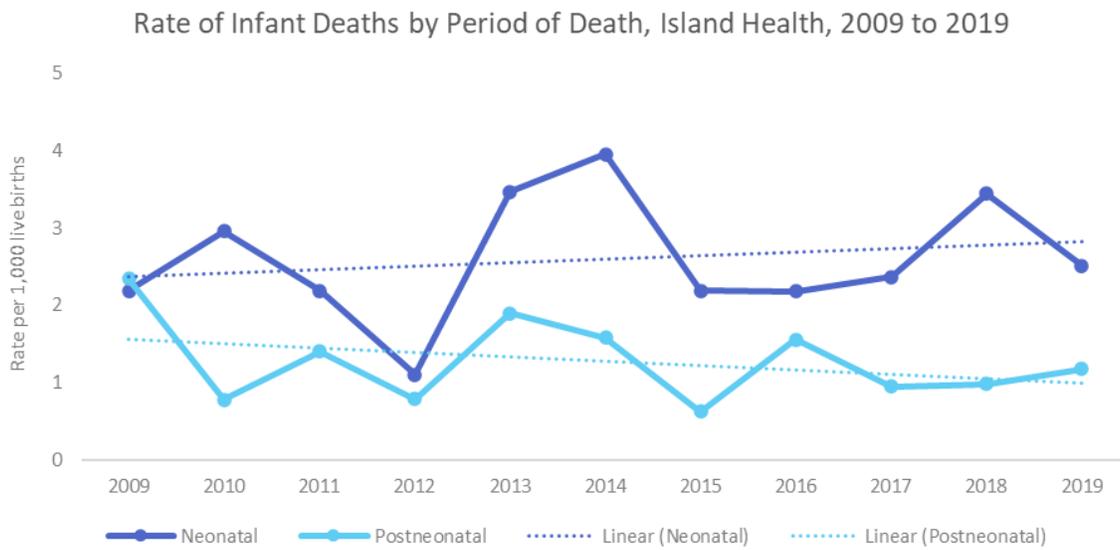
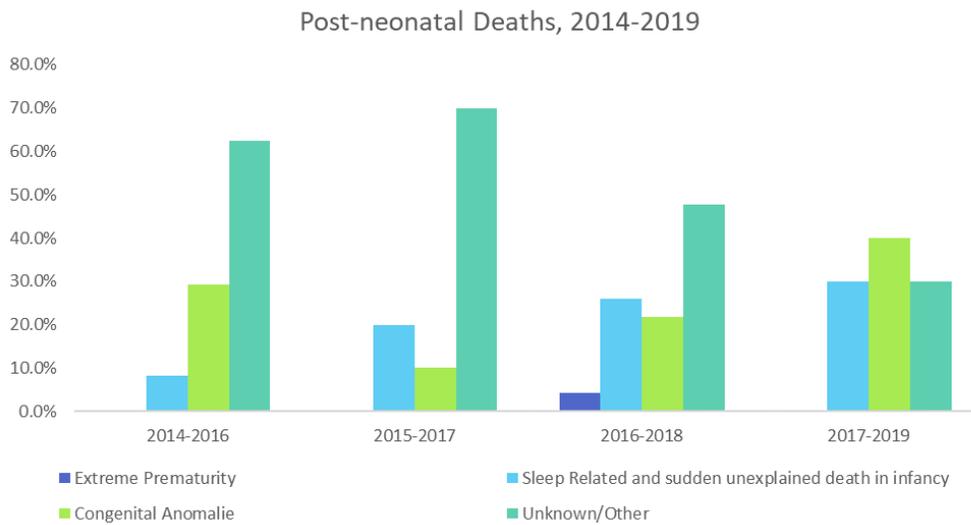


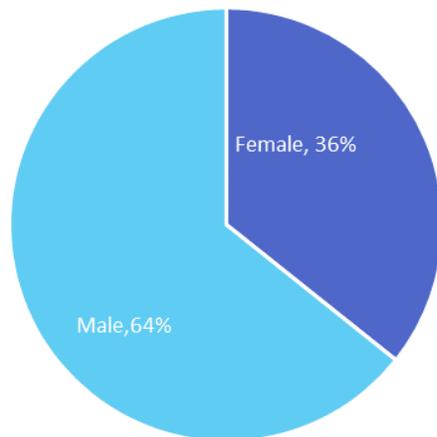
Figure 8: Post Neonatal Deaths by Cause of Death, Proportion, Island Health, 2014-2016 to 2017-2019



2.6 Sex of the Deceased Infant

In 2017-2019, 64% of the deceased infants were male (41/69) and 36% of the infants were female (28/69) (Figure 9). Three cases were missing information on the sex of the infant.

Figure 9: Sex of Deceased Infants, Island Health 2017-2019



2.7 Carnitine Palmitoyl Transferase 1 or CPT1

Carnitine palmitoyltransferase I or CPT1A is an enzyme in the body that is important in converting fat to energy⁸. A variant (P479L), common in some Indigenous groups including First Nations of BC, might predispose an infant to having low blood sugar⁹ in some cases, and may also predispose to infection^{10,11}, both possibly increasing the chance of infant mortality in First Nations infants of BC. More than 20 percent of First Nations 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. The last study of the association of the P479L variant and infant deaths in BC was carried out on data from 1999-2009 (Sinclair et al 2012). There has been no update since that time, therefore the current relevance is unknown.

In the current report, of the 70 infant deaths from 2017-2019, no results were available for the CPT1A P479L variant, therefore no added information can be provided regarding risk. However, there is reasonable evidence to suggest that safe sleep (see below) practices, and well baby feeding practices (see [First Nations Person Resource](#)) may reduce the risk for infant death associated with the CPT1A variant. It is recommended that persons of all First Nations infants in the Island Health region be counselled in that regard.

2.8 Sleep-Related Risk Factors

There are several known risk factors that increase the likelihood of a possible sleep-related death with the likelihood increasing as additional risk factors occur. These factors include placing an infant to sleep on its

⁸ Definition of CPTI from http://www.hss.state.ak.us/dph/wcfh/metabolic/downloads/cpt1_brochure.pdf

⁹ Collins S, Hildes Ripstein GE, Thompson JR, Edmunds S, Miners, A, Rockman Greenberg C, Arbour L. Neonatal hypoglycemia and the CPT1A p.P479L variant in term newborns: a retrospective cohort study of Inuit newborns from Kivalliq Nunavut. *Paediatr Child Health*, 2020 Apr 3;26(4):218-227. doi: 10.1093/pch/pxaa039. eCollection 2021 Jul

¹⁰ Collins SA, Edmunds S, Akearok GH, Thompson JR, Erickson AC, Hildes-Ripstein E, Miners A, Somerville M, Goldfarb DM, Rockman-Greenberg C, Arbour L. Association of the CPT1A p. P479L Metabolic Gene Variant with Childhood Respiratory and Other Infectious Illness in Nunavut. *Frontiers in pediatrics*. 2021 Jul 6;9:685.

¹¹ Sinclair GB, Collins S, Popescu O, McFadden D, Abour L, Vallance HD. Carnitine palmitoyltransferase I and sudden unexpected infant death in British Columbia First Nations. *Pediatrics* 2012 Nov;130(5):e1162-9. doi: 10.1542/peds.2011-2924.

abdomen (prone) or side, bed sharing with another person, put to sleep on a soft surface such as, adult beds, daybeds and couches, exposure to tobacco smoke either prenatally or during infancy and overheating through swaddling or excess clothing and layers.

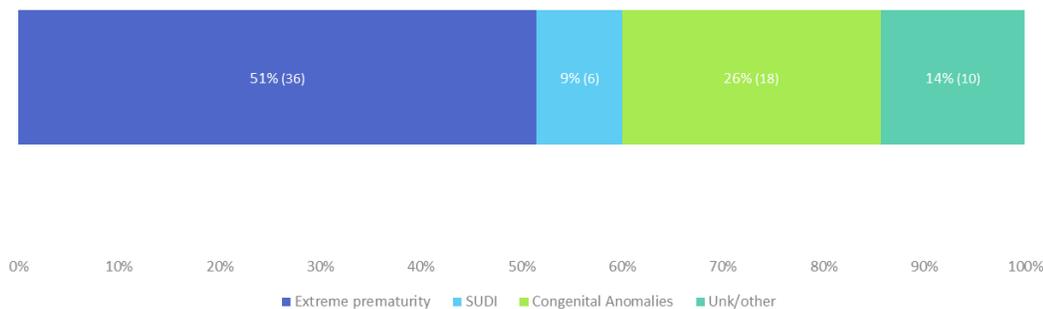
From 2017 - 2019, 9 of the 70 (13%) infant deaths had sleep related risk factors reported which included sleeping in prone or side-lying, bed sharing with an adult, and sleeping on soft surfaces with blankets. It is important to note that determining a single cause of death can sometimes be challenging due to more than one factor possibly contributing to cause of death. In section three of this report, the number of infant deaths reported as sleep-related/sudden unexplained death in infancy (SUDI) as the cause of death is lower than those reported in this section. This is likely due to the challenge of determining cause of death as mentioned above; however, it is important to acknowledge all infant deaths where sleep-related risks were present as sleep-related deaths are preventable with safe sleeping practices¹².

3. Reported Cause of Death

During the case review process, the IMRC reviews the antenatal records, 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)
- Sleep Related/ Sudden Unexplained Death in Infancy (SUDI)
- Congenital Anomalies
- Unknown or Other

Figure 10: Infant Deaths by Cause of Death, Proportion, Island Health, 2017-2019



There are often multiple factors contributing to the death of an infant and while the cases have been categorized into the following four categories for the purposes of reporting, cases could fall into more than

¹² Protective sleep related factors are an infant sleeping on its back, an infant sleeping in its own uncluttered sleep space such as a crib or bassinet, sleeping in the same room as persons, breastfeeding and pacifier use.

one category for cause of death. For example, there are some instances where extreme prematurity was listed as the cause of death; however, it was a mid-trimester termination based on a known congenital anomaly or other health issue. Similarly, there are cases that have been categorized as congenital anomaly as the cause of death; however, the infant might have been extremely premature at the time of the death.

3.1 Extreme Prematurity

Cause of death due to extreme prematurity was listed for 36 of the cases (51%) in 2017 – 2019 (Figure 10), similar to the previous reporting period of 2015-2017 (49%). 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 deaths that were classified as being due to extreme prematurity (69%) fell into the second category (no intent to treat). Please note, data on intention to treat was incomplete for 2019 cases.

3.2 Sleep-Related and Sudden Unexplained Death in Infancy (SUDI)

SUDI was reported as the cause of death in 6 (9%) of the cases in the period of 2017 – 2019 (Figure 10). In the majority of these cases accidental suffocation and asphyxiation in bed was noted. All six of these cases had sleep-related risk factors reported at time of death. All six of the SUDI cases occurred in the post neonatal period (>28 days after birth) and two of these infants were born at term (37 to 41 weeks gestation).

3.3 Congenital Anomalies

The cause of death was listed as a result of congenital anomalies for 18 (26%) of the infant deaths in 2017-2019 (Figure 10). Trisomy 13 (Patau syndrome) trisomy 18 (Edwards syndrome), trisomy 21 (Down syndrome), congenital heart malformations and other anomalies.

3.4 Unknown or Other

There were 10 (14%) infant death cases between 2017-2019 (Figure 10) that did not fit under the preceding categories and therefore were listed as “Other” for the reported cause of death. Of the “Other” cases, cause of death included complications from infection, perinatal asphyxia and hypoxic injury possibly associated with prematurity, and several cases with ill-defined and unspecified causes of mortality.

4. Summary and Recommendations

The IMRC reviews and reports on all known infant deaths within the Island Health region that meet the case criteria; however, the recommendations over the years have been focused on those deaths that have a preventable component, or a modifiable risk factor. The profile of infant deaths at Island Health has remained consistent since the previous 2013-2015 report and therefore, the following recommendations regarding safe sleep and universal baby bed program will continue as Committee priorities. The third recommendation regarding the health of people identifying as women is new as of this report.

- 1) Promote Safe Sleep Practices

- Consistent application of best practice knowledge related to Infant Safe Sleep within acute care settings, Public health, FNHA, MCFD and Primary Care. All healthcare providers need to be supported in access to knowledge exchange specific to safe sleep best practices.
- Health care providers to identify families and infants 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 advocate for a universal Baby Bed Program.
- Persons need to be connected to the appropriate resources to support healthy and safe decision making. It is the responsibility of the care providers to employ client centered and best practice approaches to engaging with persons; with intent to mutually work towards securing access to supports and resources that can mitigate the impact of the social conditions of risk.
- IMRC members to work with Island Health communications to develop infographic for public dissemination illustrating key data regarding sleep-related infant deaths with information on best practices for safe sleep.

2) Normalize Universal Baby Bed Program

- Island Health should embed and normalize universal baby bed program.
- Promote baby bed program as a part of healthy infancy. The baby bed program recognizes the importance of safe sleep practices and connection to a Public Health Nurse (PHN) or Family Support Worker (FSW). The program enables safer sleep practices through the promotion of family health. Areas of focus include: exclusive breastfeeding, tobacco cessation and supporting new persons to engage with community supports and resources within their communities.

3) Be strategic on advancing the Health and Wellness of People identifying as women

With the understanding that the health of people identifying as women is significant with or without their ability to reproduce the IMRC supports a holistic approach of health promotion and service that supports people identifying as women in achieving their best health across the age continuum. That said, the IMRC has specific recommendations relating to reproduction and pregnancy:

- Engage with the Provincial direction to develop a Maternity Care Strategy, pre-conception through post-partum; using momentum to better understand system barriers to access safe and comprehensive perinatal care across Island Health communities and inform improvement decisions using IMRC data.
- IMRC should work with stakeholders to conduct a review of the Ministry of Health's Women's Health Strategy with an eye to optimizing birthing people 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, culturally safe care relationship with priority populations of perinatal people.

4) Reduce extreme premature births

IMRC to 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 (2009-2019) to inform a special report on infant mortality related to prematurity.

5) Application of Indigenous Data Standard for All Deliveries (as defined by the Government Standard for Aboriginal Administrative Data)

The purpose of the IMRC is "To contribute to the decrease in all infant mortality and the elimination of IMR disparity amongst population groups, through: 1) Monitoring and analysis of infant deaths; and 2) Recommendations and reporting to various stakeholders." The IMRC is acutely aware that within Island Health there is a disparity in the rate of infant deaths for Indigenous infants compared to non-Indigenous infants. Yet, there is no consistent way or method of collecting if an infant is identified as Indigenous.

- In the absence of an Indigenous Patient Identifier, it is not yet possible to calculate the Indigenous-specific infant mortality rate and the current Island Health IMRC reporting of Indigenous specific infant mortality will under represent the true rate.
- The application and use of the Indigenous Data Standard must be preceded by an implementation plan that includes training to staff on how to ask Indigenous identity questions in a culturally safe manner.

In addition to the above recommendations, the Island Health IMRC supports three recommendations made by the BC Coroners Service, Death Review Panel Report examining deaths among infants (2013-2018) released November 19, 2019. Full report available [here](#).

- Expand low-barrier and culturally safe public health services to vulnerable families from birth to one year postpartum
- Improve continuity of care and service coordination
- Determine the need for a provincial approach for Infant Mortality Review

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.

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 safe 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 CPT1A and are encouraging distribution of information providing advice to all First Nations children for feeding infants and children when they are ill. It is encouraged that this information is included in discussions and planning with Indigenous communities. A guide to preventing low blood sugar in healthy First Nations babies and young children can be found [here](#).

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

Current as of October 2023

Listed in alphabetical order (last name)

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

Dr. Hayley Bos
Perinatologist- Director Maternity
Island Health

Dean Campbell
Review Coroner, Child Death Review Unit,
BC Coroners Service, Ministry of Public Safety and Solicitor General

Vanessa Charlong
Nuu-Chah-Nulth Representative, First Nations
Health Director Association,
Health Director, Hupacasath First Nation

Shannon Cross
Leader, Quality Initiatives CYF,
Island Health

Rose Dumont
Coast Salish First Nation Health Authority Representative

Kathy Easton
Director, Public Health
Island Health

Dr. Charmaine Enns (IMRC Chair)
Medical Health Officer – North Island
Island Health

Dr. Réka Gustafson
VP Population and Public Health and Chief Medical Health Officer
Island Health

Dr. Jennifer Kask
Physician
Island Health

Gillian Kozinka
Director, Child Youth Strategy,
Island Health

Dr. Unjali Malhotra
Medical Director, Women's Health
First Nation Health Authority

Brennan MacDonald
Regional Director-Vancouver Island
First Nations Health Authority

Carolyn Maxwell
Director,
BC Coroner's Service

Cara McLean
Epidemiologist, Population Health Assessment, Surveillance & Epidemiology
Island Health

Pamela Miller
Executive Director for Ministry of Children and Family Development

Jenny Nijhoff
Regional Manager Public Health Perinatal Program
Island Health

Erin O'Sullivan
Leader, Perinatal Program Development

Island Health

Dr. Sarah O'Connor
Physician, Island Health

Dr. Gustavo Pelligra
Physician - Section Head, Neonatology, Physician
Island Health

Angela Reid
Manager, Population Health Assessment, Surveillance & Epidemiology
Island Health

Hanna Scrivens
Regional Manager for Maternal Child and Family Health,
First Nation Health Authority

Kim Roberts
Health Director
Ligwilda'xw Health Society

Dr. Aisling Young
Physician, Pediatric Cardiology
Island Health

Appendix B – Previous IMRC Report Recommendations and Progress of Activities

Recommendations (from Previous Reports- year in brackets)	Progress
Sleep-related deaths and SUDI	
<p>Island Health and partners will use a variety of evidence- informed strategies to reduce the number of sleep-related deaths occurring in Island Health (2008 IMRC Report)</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 Indigenous communities must be included in this work wherever opportunities exist. (2008 IMRC Report) - Supporting effective education for all new persons 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 parents, families with premature infants and those at social risk. (2008 IMRC Report) <p>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 postnatal 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 Indigenous 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. (2009 IMRC Report)</p> <ul style="list-style-type: none"> - Develop clear preventative strategy for “Safe Sleep” for infants. - We must support socially and culturally safe messaging about sleep conditions for infants and support for families in general but also for those identified ‘at risk.’ 	<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><u>Safe Sleep Promotion:</u></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 Indigenous Communities - MCFD Brochure on Safe Sleeping for Babies <p>Activities 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). - Provincial Safe Sleep person resources – distributed via acute and community perinatal services. - Safe Sleep Education – provided to licensed daycare operators and Island Health facilities. - 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. <p><u>Provincial Aboriginal Safe Sleep Working Group (2011-2013):</u></p> <ul style="list-style-type: none"> - Provincial Aboriginal Safe Sleep Working Group struck in 2011 to design, deliver and evaluate a safe sleep training initiative for Indigenous and First Nations peoples. - Developed and posted the “Honouring our Babies: Safe Sleep Toolkit” on the FNHA website. Available at: http://www.fnha.ca/about/news-and-

- 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.

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 (2010 IMRC Report)

Facilitate the connection between persons and personing resources available in their communities AND ensure that those resources, whether Island Health, FNHA, or private physicians, can evaluate persons’ 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 (2009-2011 IMRC Report)

Work with health care providers to identify families and infants at risk, in a way which compliments programs such as the Nurse Family Partnership (2009-2011 IMRC Report)

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 (2009-2011 IMRC Report)

[events/news/new-safe-infant-sleep-toolkit-honouring-our-babies-safe-sleep-cards-and-guide](#)

Provincial Safe Sleep Working Group (2016-2017)

- Provincial working group formed for the purpose of a harm reduction approach for health providers regarding safe sleep. Guidelines to be posted – date TBD.
- Perinatal Services BC convened a provincial working group in November 2016 for the purpose of “developing a practice support tool to assist and facilitate health care professionals in applying PSBC’s Safe Sleep Environment Guideline to practice and to have health focused discussions with families about safer infant sleep.” These materials took a harm reduction approach to infant safe sleep. The working group was also asked to provide input and feedback into a ‘refresh’ of the Ministry of Health’s “Every Sleep Counts!” materials. Island Health was represented on this working group.

The Safer Infant Sleep: Practice Support Tool and companion person resource were completed in August 2017 and updated in 2023 and can be found at: [Safer Infant Sleep | Perinatal Services BC \(psbchealthhub.ca\)](#)

Baby Bed Project:

- **2014-15** grant received from Children’s Health Foundation Vancouver Island (CHFVI) for Baby Bed pilot in Cowichan Valley started in spring 2015. Baby Beds provided to all birthing person’s in 3rd trimester to 3 months postpartum during 1:1 interaction with PHN and included bed, supplies, and safe sleep information.
- **2016-2018** West Coast General Hospital (WCGH) Foundation and the WCGH Auxiliary provided funding to expand the Baby Bed program to Port Alberni and the West Coast
- **2017-18** CHFVI, Nanaimo and Campbell River Hospital Auxiliaries provided funding to expand the program to Nanaimo, Mt Waddington, Comox Valley and Campbell River.

	<ul style="list-style-type: none"> - Fall 2017- spring 2018, with free beds from Baby Box Co (from US), Baby Bed Program expanded throughout Island Health. The universal program ended in Spring 2018 except in communities with charitable funding and a beds were made available to families by PHNs on an as needed basis. - In 2017, a Provincial Baby Bed project and evaluation was explored with MOH to expand the pilot to additional HAs but not implemented due to the short partnership with Baby Box Co. - 2019-2022 CHFVI funded 3 year expansion of universal program to Centre and Northern Vancouver Island. - 2020-2022 implement evaluation plan for universal program. - 2021 the program funding was cut short after 1 year due to limited Public Health capacity to manage the pandemic and projects. The universal Baby Bed program was placed on hold in April 2021 until such time as Public Health has capacity to resume the model program. Inventory in health units is being distributed on an ad hoc basis to families in need. - 2023- Baby beds offered throughout Island Health
<p>Deaths related to CPT1</p>	
<p>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 Indigenous communities (2008 IMRC Report)</p> <p>Careful assessment of the variant in the context of other infant mortality risk factors for cases on Vancouver Island needs to be carried out (2009 IMRC report)</p> <p>Further research is also needed to understand if this common variant is affecting the health of First Nations infants and children negatively (2009 IMRC Report)</p>	<p>Activities completed in 2011:</p> <ul style="list-style-type: none"> – Provincial CTP1 Working group struck to work on public health messages, person info and guidelines for health care professionals. – First Nation person Resource: <i>Preventing low blood sugar in health First nation babies</i>. Link: https://www.divisionsbc.ca/CMSMedia/Divisions/DivisionCatalog-victoria/News/Family%20brochure.pdf <p>Activities completed in 2012:</p> <p>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).</p> <p>Activities completed since 2015:</p>

	<p>Posted: <i>Medical Guideline: Prevention and Management of Hypoglycaemia in First Nations Infants and Young Children Including Screening for CPT1a Variant in Infants and Young Children who Present with Ketotic and Hypoketotic Hypoglycemia.</i></p> <p>Link: http://www.childhealthbc.ca/sites/default/files/FINAL%20April%205%202016%20Medical%20guideline%20prevention%20and%20management%20of%20hypoglycaemia%20in%20First%20Nations%20infants_0.pdf</p>
<p>Extreme Prematurity</p>	
<p>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. The underlying risk factors for extreme prematurity are multi-factorial and complex (2009 IMRC Report).</p> <ul style="list-style-type: none"> - The Infant Mortality Review Committee plans to obtain a more detailed understanding of the lives of the birthing person’s 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. <p>The IMRC should seek to participate in and inform any multi-year, multi-agency strategies conducted by the Health Authority and the Province (2010 IMRC Report)</p> <p>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</p>	<p>Activities ongoing from 2012</p> <ul style="list-style-type: none"> - <i>Right from the Start</i> 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"> - <i>Complex Care Planning and Support</i> model begun at VGH in 2013 including perinatal risk assessment and care planning and pregnancy support and planning care teams. <p>Since 2015:</p> <ul style="list-style-type: none"> - Permanent 0.5 FTE in place. Referral criteria established; including early referral to coordinator. Directly working with Maternal Fetal Medicine (MFM) Physician team. This includes regional referrals and may also contribute to the second recommendation in the Perinatal Care section. <p>Activities ongoing from 2018</p> <ul style="list-style-type: none"> - <i>Prevention of Preterm Birth Pathway Project</i> initiated by Dr. Kirsten Duckitt and Dr Jennifer Kask and funded by the Campbell River Medical Staff Engagement Initiative Society. With these funds, clinicians in Northern Vancouver Island were engaged and provided education with the aim of reducing preterm birth in October 2018. Aims included identifying risk factors for preterm birth so evidence based interventions could be instituted early and then managing people identifying as women

<p>special report on infant mortality related to prematurity (2011-2013 IMRC Report).</p>	<p>presenting in suspected preterm labour in a coordinated way according to Island Health policies. The intervention was repeated in Campbell River including health care providers from Gold River and the Comox Valley in April 2019 and was presented at the Quality Forum in Vancouver in February 2020. The Project was chosen in the first iteration of spread projects in Island Health in 2020; in 2021-2022 spread to Cowichan and then to West Coast (Port Alberni January 2023, Tofino March 2023.)</p>
<p>Perinatal Care</p>	
<ul style="list-style-type: none"> - 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 people identifying as women’s experiences of safety in care (2009-2011 IMRC Report). - Explore a regional approach to complex care planning for people identifying as women with health complications that may precipitate preterm birth (2009-2011 IMRC Report). - 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 (2009-2011 IMRC Report). - Continue Public Health Nursing program and service planning to intentionally engage in a client focused, care relationship with priority populations of perinatal people (2009-2011 IMRC Report). 	<ul style="list-style-type: none"> - <i>(Complementary to Extreme Prematurity- Recommendation 1)</i> Implementation of the Mother’s Story Approach to care is complete. This paradigm shift intentionally shifts away from a medical model to an intentional relational model of nursing care. This guides the provision of family visitation services to prenatal and postpartum people who may be considered vulnerable to poorer prenatal health outcomes due to higher exposure to social conditions of risk. - Continued partnership with the NTC Nursing Program to grow the approach with Island Health PHNS and NTC Community Nurses. - Process evaluation to be initiated in January 2018 - Hired Regional PH Perinatal Manager who has drafted a program plan for 2024-25 to revise and revitalize PHN enhanced program based on the Mother’s story approach to care and other universal best practices emerging from PSBC and across the Province.
<p>Committee Structure – Partnerships and Collaboration</p>	
<p>Island Health will continue to endorse the infrastructure of collaboration/ partnership of the Infant Mortality Review Committee</p>	<ul style="list-style-type: none"> - IMRC continues to collaborate with the BC Coroners Service and the Ministry of Children and Family Development in information sharing and in

<p>to improve the methods of data collection and exchange and the quality of the information collected (2008 IMRC report)</p> <p>The IMRC should seek to participate in and inform any multi-year, multi-agency strategies conducted by the Health Authority and the Province (2010 IMRC report).</p>	<p>developing these reports. This includes a formal information sharing agreement between Island Health, the BC Coroner’s Office, and the Ministry of Children and Family Development.</p> <ul style="list-style-type: none"> – In 2017, Island Health signed an Integrated Sharing Protocol (ISP) with BC Coroner’s Office to formalize the data sharing of infant deaths between the Health Authority and the Coroner’s Office. <p>Activities ongoing from 2012</p> <ul style="list-style-type: none"> - <i>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.</i> - 2023-24 Post pandemic review of all PH Nursing services and re-connection to communities and community partners. - 2024 – Working group formed to review and update RFTS program - 2024 – PHN multidisciplinary Advisory circle forming (including PPH and Indigenous Health leaders, patient partners and Knowledge Keeper representation) to offer perspective and advise on PH Perinatal programming. <p>Activities ongoing from 2013</p> <ul style="list-style-type: none"> - <i>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.</i> - 2023 – Development of Perinatal, Newborn and Women’s health C.A.R.E networks (CEC &OEC)
<p>Commitment to Surveillance and Health Promotion</p>	
<p>Island Health should make a commitment to ongoing health promotion and surveillance for infant mortality on Vancouver Island. 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</p>	<ul style="list-style-type: none"> – 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 (2009)

considered as foundational and sustained by the Health Authority (2010 IMRC report)

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 (2009 IMR report).

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 (2010 IMRC report).

Continued review of data collection, entry and analysis to determine areas for quality improvement in data collection and review process (2010 IMRC Report).

- Production of Annual Reports up to 2011, at which point the IMRC started the aggregate three year rolling reports.
- The 2009-2011 infant deaths were combined into one report for the subsequent reporting period, and since then, there have been three year rolling reports on an annual basis.
- Review of access database including assessment and summary of data entry issues and suggestions for reducing number of fields, reducing text entry requirements and improving data validation processes
- In 2017, Island Health signed an Integrated Sharing Protocol (ISP) with BC Coroner's Office to formalize the data sharing of infant deaths between the Health Authority and the Coroner's Office.
- IMRC surveillance system in the early stages of evaluation by epidemiologist from the Canadian Field Epi Program.

Appendix C – Data Fields and Definitions

Data for Birthing Person's collected from antenatal record (Variables updated September 2023)	
Infant_Death_date	Infant's date of death (day/month/year)
Mother_Personal Health No	Birthing person's Personal Health Number (10 digits, no spaces)
Mother_MRN	Birthing person's Medical Record Number
Mother_firstname	Birthing person's given name
Mother_lastname	Birthing person's surname
Mother_Date of Birth	Birthing Person's Date of Birth (dd/mm/yy)
Residence	City or Town (i.e. Victoria, Sidney, Parksville etc)
Mother_ethnicity	Birthing Person's ethnicity
Paternal_ethnicity	Non-birthing ethnicity
Mother_Aboriginal	Is the birthing person Indigenous (First Nations, Metis, Inuit etc.)? (Yes, No, Unknown, N/A or blank)
Mother_reserve	Does the birthing person live on reserve? (Yes, No, Unknown, N/A or blank)
Medications	Is the birthing person 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 birthing person have any disease or pre-existing condition? Enter "No" or if "yes", specify (Antenatal record)
Mat_hist_STIs_infections	Has the birthing person had STIs or infections? Enter "No" or if "yes", specify complication (Antenatal record)
Mat_HX of mental illness	Does the birthing person 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 birthing person 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 birthing person 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)
Substance Use_Type	Does the birthing person use substances? (Enter type of substance or No, or 'N/A' as per antenatal sheet)
Smoking	Does the birthing person smoke? (Select "Yes", "Never" or "Quit" as per the antenatal record)
Pre_Pregnancy_smoking	Before pregnancy, how much did the birthing person smoke (cigarettes/ day) (select '0' if not applicable)
Pregnancy_smoking	During pregnancy (current), how much does the birthing person smoke (cigarettes/ day)? (select '0' if not applicable)
Secondhand_smoke_expos	Was the birthing person exposed to 2nd hand smoke? Enter either "No" or if yes, indicate comment
Financial_housing_issues	Did the birthing person have any financial or housing issues? Describe support system in place. Indicate comments as per antenatal record.
IPV_Issues	Did the birthing person 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	Birthing person'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	Birthing person'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
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
Potential_concerns	Indicate any concerns related to lifestyle, pregnancy, labour or birth, postpartum, or newborn (as per section 15 of antenatal record)

Data for Infants collected from antenatal record, labor and delivery summary, newborn record, autopsy	
Mother_PHN	Birthing person's Personal Health Number

Mother_Last_Name	Birth person'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
Mother's Hospital ID	Birth person'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)
Sex_newborn	Sex of newborn according to labour and birth summary
Age_Newborn	Gestational Age of the newborn in weeks (from Antenatal History)
Amniotic Fluid__newborn	Amniotic Fluid during Transition to 1 hour of age (Select Clear, Meconium, Bloody, or Unknown)
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?
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_Result	Results from the hearing 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)
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
ProgressNotes_Date	Date of Progress Notes
Progress_Notes	Indicate narrative notes (comments) from Progress Notes in part 2 of newborn record
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 Birthing person's and Infants from Newborn Record, Autopsy, Coroner's Report	
Postpartum Unique_ID	Postpartum Unique ID
Mother's Last Name	Birthing Person's Last Name
Mother's PHN	Birthing person'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)
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
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 (parent, 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)
Home_visit	Was there Post-natal Public Health home visit? (As per BC Coroner's Report)
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)
Congenital_Anomalies	Did the infant have any congenital anomalies? If yes, describe.
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
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)
Additional_Comments	Any Additional Comments attributed to the deceased infant?