

Infant Mortality and Morbidity Surveillance and Response in BC



Meeting Report

October 2, 2017



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1. Introduction

On October 2, 2017, Perinatal Services BC (PSBC) and the First Nations Health Authority (FNHA) hosted a stakeholder meeting to improve perinatal, maternal, and infant mortality and morbidity surveillance and response in BC. The meeting was planned and organized by a small working group that included representation from Regional Health Authorities, the Provincial Health Services Authority, First Nations Health Authority and the British Columbia Ministry of Health. At the meeting, 53 healthcare providers, administrators and researchers from across British Columbia and representatives from two national organizations came together for a full day of discussions. This report summarizes the content and recommendations of the meeting.

The meeting objectives were to:

- share current information about perinatal, maternal, and infant mortality rates and trends;
- explore provincial, national, and international good practice models for surveillance and response; and
- build a common vision for improving provincial and national surveillance and response and strengthen relationships to support action.

The morning was divided into two sets of presentations that covered:

- the current state of surveillance and response in BC, including maternal and neonatal mortality, BC Coroners Service report on infant mortality, and First Nations infant mortality; and
- 2. **models for improving surveillance and response**, including overviews of the Island Health Infant Mortality Review Committee, BC Patient Safety & Learning System, Canadian Perinatal Surveillance System at the Public Health Agency of Canada, and international models.

In the afternoon, participants were divided into working groups to discuss a number of questions in order to build a common vision for perinatal, maternal, and infant surveillance and response for the future.

This report includes summaries of the presentations and discussions and outlines recommendations for next steps.



2. Current State of Surveillance and Response in BC

The following are key points from each presentation during this session.

2.1 Maternal Mortality in BC

Presented by Petra Selke, Clinical Professor, Gynecology and Obstetrics, UBC

- 1. BC's maternal mortality ratio and pregnancy associated mortality compare favourably to those of other jurisdictions in North America and with the UK.
- 2. Causes of death are comparable, with cardiovascular disease being the major indirect cause of death.
- 3. Public health issues arising from the review are untreated epilepsy, inadequately treated mental health issues including depression, advanced maternal age, and obesity.

Complete ascertainment of deaths at the provincial level in BC is not currently possible. Areas for improvement include information sharing across health authorities and engagement with the BC Coroners Service. However, while under-reporting remains an issue, the surveillance of maternal deaths that is currently possible aligns with findings from other similar jurisdictions (such as the UK). This indicates that, while not perfect, our data from the Perinatal Data Registry and other administrative data sets is of good quality.

2.2 BC and Canadian Perspectives in Neonatal Morbidity and Mortality

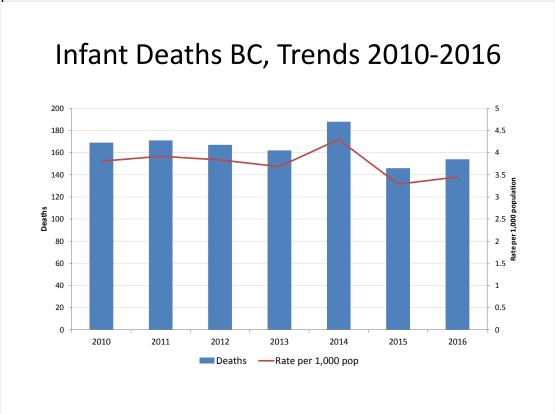
Presented by Deepak Manhas, Neonatologist, BC Women's Hospital

- 1. Advances in Neonatal medicine have led to increased survival of more premature babies. These babies are experiencing fewer health complications due to improvements in Neonatal Intensive Care, education, equipment, and research and implementation of best practices.
- 2. Areas for focused improvement for neonatal morbidity and mortality in BC include addressing issues of transportation and transfer to higher levels of neonatal intensive care, as well as supporting and engaging with marginalized populations.
- 3. Skin-to-skin mother baby care and breastfeeding are critical, mutually supportive interventions that improve outcomes and can be delivered in both high and low resource settings.

2.3 Infant Mortality in BC: Trends and Findings

Presented by Carla Springinotic, Child Death Review Coroner, BC Coroners Service

- 1. The BC Coroners Service is mandated to investigate and review all child deaths.
- 2. The rate of infant deaths in BC from 2010 to 2016 remains quite constant over the time period reviewed.



- 3. The majority of deaths (39%) were among infants under 28 days of age, followed by deaths among youth 15-18 years (23%).
- 4. The leading causes of deaths in infants under 12 months are perinatal causes (such as preterm labour, premature rupture of membranes, and infection), followed by congenital and chromosomal anomalies, undetermined causes of sudden infant death (sleep related deaths, suffocation), and other deaths (accidental, homicide, cancers, infections/sepsis).

2.4 Our Babies' Health & Wellness: Closing the Gap in First Nations Infant Mortality Rates *Presented by Shannon McDonald, Deputy Chief Medical Officer, FNHA*

- 1. The First Nations infant mortality rate in BC is 2.3 times higher than the rate for non-First Nations residents. (Note that this data does not include non-status indigenous people or Métis.)
- Together with communities, the First Nations Health Authority has identified the following key issues, environments, and contexts associated with infant mortality:
 - low birth weight/prematurity;
 - exposure to poverty;
 - barriers to accessing prenatal care;
 - unsafe sleep environments;
 - exposure to substances;
 - comparatively high level of teenage pregnancy.



The disproportionately high infant mortality rates among status First Nations suggest that the social determinants of health (housing, income, education etc.) are underlying drivers of infant mortality.

3. FNHA has developed and continues to implement recommendations focused on working in partnership with various organizations in health, social services, and education sectors. An example of an innovative program is the "Honouring Our Babies" safer sleep cards and education programs that takes a pragmatic, family-centered and culturally safe approach to reducing infant sleep related deaths.

2.5 Discussion

The following is a summary of the discussion that followed the presentations.

Causes of Maternal Mortality

Interest in expanding the ascertainment period of pregnancy related deaths to the extended postpartum period of one year was expressed, as we are likely missing complications of pregnancy that manifest in severe health issues lasting longer than the puerperium. In addition, there was interest in including non-obstetric causes of death to capture maternal mental health (including postpartum depression and related suicide) and homicide by intimate partners.

Identification of Indigenous Identity

Identification of Indigenous Identity was an important discussion point, with the suggestion of adopting the BC Government's Standard for Aboriginal Administrative Data (a set of questions used for the collection of data specific to Indigenous people) across all data collection processes. It was noted that the First Nations Client File does not include non-status, Métis, or Inuit populations; the Standard for Aboriginal Administrative Data (approved by the BC government in 2004) would capture these populations. Interior Health Authority has been using the Data Standard 2011 and the BC Coroners Service has been using the Data Standard since 2016.



3. Models for Improving Surveillance and Response

The following are key points from each presentation during this session.

3.1 Island Health Infant Mortality Review Committee: Process and Outcomes *Presented by Charmaine Enns, Medical Health Officer, Island Health*

- 1. Island Health formed the Infant Mortality Review Committee (IMRC) in 2007 as a response to higher rates of infant mortality in Island Health compared to the provincial rate. The IMRC is responsible for monitoring and analysis of infant deaths making recommendations and reporting to stakeholders.
- 2. Case inclusion is infants under 12 months of age who meet the Vital Statistics Act definition of live birth and maternal residence within Island Health. The IMRC database contains information on the infant, mother, and environment (e.g. social determinants).
- Since the establishment of the IMRC, infant related deaths in Island Health have declined—however, the increasing numbers of very premature infants and their greater mortality rates constitute an increasing proportion of these deaths, leading to more stable overall rates.
- 4. A key factor of success of the IMRC has been the composition of the committee: the individuals at the table are able to make decisions to change care delivery and exert influence over the contexts of women's, infants and families lives.
- 5. The case review methodology highlights the importance of qualitative, contextual data in understanding, and thus contributing to preventing future, infant deaths.

3.2 BC Patient Safety & Learning System

Presented by Annemarie Taylor, Executive Director, BC Patient Safety & Learning System (PSLS)

- PSLS is a province-wide, web-based safety event reporting system that includes all health authorities, across the continuum of care. All health authority staff and maternity care providers can report.
- 2. There are 10,000 to 12,000 patient safety event and hazard reports each month.
- 3. The maternity care category includes delivery complication; fetal complication; neonatal complication; maternal complication; and other.
- 4. Some of the opportunities to leverage the data included in the PSLS to improve maternal and neonatal morbidity surveillance may include: changes to the taxonomy of the PSLS to ensure capture of the most relevant data; specialty forms to facilitate and streamline reporting; dashboards for monitoring; and mechanisms for sharing data across the province such as notifications, blog stories, and lessons learned.



3.3 Overview of Public Health Agency of Canada/ Canadian Perinatal Surveillance System Maternal Health Surveillance Activities

Presented by Susie Dzakpasu, Epidemiologist, Public Health Agency of Canada (PHAC)

- 1. PHAC's Canadian Perinatal Surveillance System has a mandate to contribute to improved health for pregnant women, mothers, and infants in Canada through ongoing monitoring and reporting on perinatal health determinants and outcomes.
- Severe maternal morbidity (SMM) is defined as disease-specific, intervention specific, and organ dysfunction-based. Rates are calculated using the Canadian Institute for Health Information (CIHI) Discharge Abstract Database and are based on province/territory of occurrence (not province/territory of residence). Data includes all provinces except Quebec.¹



- 3. PHAC has transitioned from maternal mortality to pregnancy-related mortality, which includes obstetric and non-obstetric death of women up to one year following birth or termination. PHAC is also transitioning from using vital statistics data to hospitalization data, which are more comprehensive and timely.
- 4. General strengths of data include representation of 98% of births from participating provinces and timeliness. General limitations are the

¹ The data sharing agreement between Quebec and CIHI does not permit CIHI to share Quebec data with third parties. PHAC is working with Quebec's ministry of health to incorporate the province's data directly.

- exclusion of Quebec (which accounts for 20% of Canadian births), exclusion of deaths outside hospitals, and limited data on maternal risk factors (e.g. pre-pregnancy weight, ethnicity, socioeconomic status).
- 5. PHAC is revising SMM diagnoses/procedures, expanding SMM population to include prenatal and postpartum events and terminations, and engaging with Quebec to include their data.
- 6. Regarding maternal mortality, PHAC is developing methods for deriving cause of death from diagnostic/procedure codes and proposing standardized province/territory pregnancy-related death certificate questions.

3.4 Eliminating Preventable Maternal Morbidity and Mortality in Canada

Presented by Jennifer Blake, CEO, Society of Obstetricians and Gyneacologists of Canada (SOGC)

- 1. There are gaps in the existing data surveillance process in Canada, including data access, coverage, timeliness, and completeness. In addition, there are no standardized definitions, indicators, processes, or reporting among provinces/territories.
- 2. Canada does not have a national enquiry process and has not set targets for maternal mortality reduction.
- 3. The UK and US have systems that include standardized definitions and review processes. These include capturing both direct and indirect causes of death, attention to case finding, and an implementation strategy for recommendations.
- 4. To respond to the complexity of contributing health system factors, eliminate preventable maternal death, and develop a system that will support the prevention of severe morbidity, Canada needs to implement a national, standardized system that includes:
 - standard definitions and indicators;
 - standard data collection processes;
 - · consistent denominators for analyzing/reporting; and
 - data sharing across jurisdictions.
- 5. SOGC is currently reviewing activities in provinces/territories, gathering partners and stakeholders, working with PHAC and planning a national workshop.





4. Future Surveillance and Response

Participants were divided into working groups to discuss the following questions to begin generating a common vision for perinatal, maternal, and infant surveillance and response for the future:

- 1. Regarding local, provincial, and national data sources and surveillance, what are the gaps? How can we link data more effectively? What is our vision for surveillance in the future?
- 2. How are we utilizing existing data and surveillance to improve clinical policy and practice? What are we doing well? What are the gaps? Are we feeding the information back to healthcare providers and communities (engagement and communication)? Does PSLS have a role here and are we utilizing it fully? What is our vision for response?

4.1 Strengths of Existing System

Working groups agreed there was a breadth of clinical resources and expertise in BC, including passionate healthcare providers. There are existing provincial databases (Perinatal Data Registry of PSBC, Vital Statistics, Coroners Service and PSLS) that capture and provide mortality and morbidity information. There is knowledge sharing through the Provincial Perinatal and Maternal Mortality and Morbidity Review Committee (the provincial section 51 committee chaired by PSBC) and health authority quality and safety councils, as well as facility-based maternal and neonatal processes for reviewing critical incidents and deaths.

4.2 Current Gaps

Working groups identified the following gaps and potential solutions to closing those gaps.

Improving Data Quality and Relevance

Standardization

All working groups identified the need to develop standard definitions and to collect and apply them using the same methodology criteria. or Ideally, this standardization would occur at the national level. A corollary discussion identified the importance of minimum. identifying а clinically relevant data set and focusing energy on improving data quality and availability.



There was consensus on the value of standardization, however caution was also expressed about focusing too much on getting the quantitative data "perfect" instead of good enough. The importance of the qualitative data for context and shaping response was emphasized.

Ethnicity

Ethnicity for the whole population, including self-identification as a First Nations, Métis, Inuit or Indigenous person, was identified as a significant data gap that participants agreed should be addressed. For all, identifying ethnicity needs to be done in a culturally safe way, with both healthcare providers and communities understanding why the information is being collected and how it will be used. This will require concerted efforts to educate healthcare providers and also to engage and dialogue with communities. Identified opportunities include expanding the universal application of the Government



Standard for Aboriginal Administrative Data. A meaningful discussion regarding OCAP standards (ownership, control, access, and possession principles about data collection and use) is required as part of community dialogue.

Social Determinants of Health

All working groups discussed the importance of collecting data about the social determinants of health. Areas that were highlighted included substance use (tobacco, alcohol, pharmaceuticals, cannabis and other illicit substances); socioeconomic status including education, housing and food security; and experience of intimate partner violence. As this data may be seen as sensitive, and as some health care providers may be reluctant or not fully appreciate the clinical importance of these determinants for maternal and infant outcomes, self-reporting of socioeconomic variables including ethnicity as part of intake/medical history taking may be a viable option



Timeliness

Timeliness is related to perception of clinical relevance. Investment in providing data to drive practice change back to clinicians in a more timely fashion was identified as important. This will involve aggregation (for rare events such as maternal deaths) and a focus on "near misses" (severe adverse events) for quality improvement.

Integrated System

Feedback loops need to exist in the health system to identify deaths that occur in hospital and in the community and communicate about those deaths across the system. These loops should incorporate all of the providers/administrators across the continuum of care that touched that woman/baby.

There was some discussion about the need to link provincial databases (e.g. PSBC, PSLS, MCFD) and link acute care systems (e.g. Cerner) to public health (e.g. Panorama) and community (e.g. PARIS) systems. There also needs to be better integration with national and international surveillance systems. It was also recognized that "elegant" systems solutions can improve healthcare provider engagement and improve data quality.

Sharing Data

The need to appropriately and rigorously apply the relevant privacy legislation while simultaneously overcoming unnecessary barriers to data sharing to improve patient care was clearly stated. All working groups agreed there were challenges in accessing data.

Privacy and information sharing agreements are needed to facilitate systematic and complete data sharing. One of the critical opportunities identified is to "roll-up" reviews of maternal and neonatal deaths, and the lessons learned, for sharing across the province and across the nation. Specific suggestions included circulating an annual report for providers and developing and disseminating recommendations based on adverse cases and rare events. There was also a suggestion to include positive examples of practice changes that had improved outcomes when reviewing lessons learned. In addition, reviews done at the hospital level should be aggregated for provincial and national learning.



Supporting Health Care Providers and Communities

One group discussed that maternal and infant deaths are deeply felt by providers, family members and communities. It was suggested that there is a gap in emotional support for personal reflection and grieving, particularly for healthcare providers.

4.3 Opportunities for Future Work

There was discussion about educating healthcare providers on the value of the data collected—why the data are required and how the data will be used. This would improve knowledge translation and ultimately promote participation, supporting data quality. There were also suggestions to explore or expand on the role of PSLS to develop focused reporting for providers as a quality improvement vehicle.

There was interest in further exploring effective models for systematic review and reporting, such as the UK Confidential Enquiry into Maternal and Child Health (CEMACH), the US CDC system, and PNSN (Pesquisa Nacional de Saúde e Nutrição (the National Study of Health and Nutrition)— a nationally representative survey in Brazil).

There were some suggestions to learn from the global perspective—for example, using virtual methods to collect data in communities with limited resources and exploring the use of telehealth to improve data collection and to support mortality and morbidity review and response in rural and remote communities in BC.

There is opportunity for community and stakeholder engagement, particularly in First Nations communities. One group identified the *Truth and Reconciliation Commission's Call to Action #19* to establish measurable goals in consultation with Indigenous peoples to close gaps in health outcomes between Indigenous and non-Indigenous communities as an important commitment and a resource for improving maternal, perinatal and infant mortality and morbidity surveillance and response in British Columbia.

Participants acknowledged that BC had the interest, expertise, commitment, and energy to be a leader in Canada for improving perinatal mortality and morbidity surveillance and contributing to the development of a nationally integrated system.



5. Recommendations for Next Steps

Based on working group discussions, it is clear that the vision for a local, regional, provincial, and national surveillance system includes standardization of definitions, improved data quality and promotion of timely, relevant data and information sharing to drive quality improvement, prevent future mortality and morbidity and improve health outcomes for the perinatal and infant population.

The following were identified as priorities for maternal, perinatal and infant mortality and morbidity response in British Columbia:

- develop standardized definitions, indicators, and processes;
- determine a minimum data set, including ethnicity and indicators of socioeconomic status:
- 3. overcome barriers to data access and use:
- share lessons learned at the local level at provincial and national tables to promote quality improvement, and move towards an integrated surveillance and response system at the regional, provincial, and national levels.



This report will be brought to the BC Provincial Perinatal and Maternal Morbidity and Mortality Review Committee, chaired by Perinatal Services BC and with representation from all of the Health Authorities, to review and to inform their work plan.

A key next step will be to engage actively with PHAC and SOGC to participate in the creation of national standardized definitions for maternal, perinatal, infant time periods, as well as to establish a minimum uniform data set. PSBC will support this work, and report back regularly to the Provincial Perinatal and Maternal Morbidity and Mortality Review Committee, as well as the Perinatal Services BC Steering Committee on a regular basis.

The provincial BC Safety & Learning System will explore with PSBC opportunities to create a customized perinatal reporter form, fields to increase ease of reporting, and a customized perinatal dashboard to enhance learning and timely data sharing. This data, and facilitating use of the data, may offer opportunities to understand perinatal patient safety issues and "near misses" and take action to improve patient safety and quality of care for this population.

Perinatal Services BC is in the process of improving and enhancing the Perinatal Database Registry (PDR) which will be rolled out in 2018. The re-developed PDR will collect and abstract self-identified ethnicity, making it available for public health surveillance purposes. Different methods of applying the Aboriginal Data Standard, as well as attempting to enhance collection of self-identified ethnicity and other socioeconomic indicators may be explored through pilot projects moving forward.

6. Conclusion

The key strengths of British Columbian system have led to good provincial perinatal outcomes and will be integral for future improvements. These include the breadth of clinical resources and expertise; the existence and use of provincial wide surveillance databases, generating high quality data; and the knowledge sharing taking place across the province. Younger premature babies are surviving at greater rates due to medical advances and skills of BC providers; and BC's maternal mortality rates are favourable compared across North America and the UK.

This meeting was a chance for stakeholders from across the province and nation to identify key areas for enhancement, and to present innovative solutions for improving data and outcomes. Some examples include: expanding the length of surveillance and the type of data being gathered; the use of qualitative, contextual data to understand and prevent future mortality; and pragmatic, family-centered, and culturally safe approaches to communicating with families about infant sleep-related deaths.

Although provincial trends are encouraging, significant disparities exist in outcomes for certain populations. High First Nations mortality rates highlight the need to gather quality data on social determinants of health and ethnicity for the whole population, including First Nations, Métis, Inuit and Indigenous people. Furthermore, as stressed by participants, the collection of this data and the use of this data for strategic interventions must be approached in a culturally safe way.

In order to improve data quality and outcomes across the province, the participants identified strategic priorities including: the need for greater standardization of definitions, indicators, and processes; data gathering on ethnicity and social determinants of health; addressing barriers to data access and use; and enhancing knowledge translation in order to move towards a system of surveillance and response that is integrated at regional, provincial and national levels.

As highlighted in this report, work is already underway to address several of the gaps identified, including the gathering of data on ethnicity. The presentations, discussions, and priorities from this meeting will inform the strategic work plan of the BC Provincial Perinatal and Maternal Morbidity and Mortality Review Committee and collaborations with PHAC, SCOG and BC PSLS. By focusing on these key priorities, learning from existing effective models of systematic review and reporting, and encouraging community and stakeholder engagement, British Columbia can become a leader in Canada for improving perinatal mortality and morbidity surveillance and health outcomes for the perinatal and infant population.



Appendix I: Participants

Perinatal Services BC

Tamil Kendall, Interim Provincial Executive Director*
Sayrin Lalji, Medical Advisor, Maternity; Chair PPMMMRC*
Kenny Der Manager, Clinical Data Integrity, Privacy, and Access Lubna Ekramoddoullah, Communications Officer
Karen Kuhlman, Program Assistant
Colin Sue, Business Solutions Analyst

First Nations Health Authority

Shannon McDonald, Deputy Chief Medical Officer, CMO Office (Presenter)
Ashraf Mohammed, Director, Health Surveillance, Community Health and Wellness Services
Deepthi Jayatilaka, Director, Community Programs Supports, Community Health & Wellness
Services

Lily Zhou, Epidemiologist, Community Health and Wellness Services Lucy Barney, Perinatal Care & Early Childhood Development Specialist, Community Health & Wellness Services (also Provincial Lead, Aboriginal, PSBC)

BC Association of Aboriginal Friendship Centres

Jeannette MacInnis, Manager of Health and Ending Violence Initiatives

BC Coroner's Service

Carla Springinotic, Child Death Review Coroner, Child Death Review Unit (Presenter)*

BC Ministry of Children and Family Development

Emily Horton, Executive Director, Provincial Office for the Early Years Alex Scheiber, Deputy Director of Child Welfare

BC Ministry of Health

Daniele Behn Smith, Aboriginal Health Physician Advisor Xibiao Ye, Director of Epidemiology Glenys Webster, Manager, Public Health Surveillance and Early Childhood Health Keren Massey, Senior Policy Analyst, Congenital Anomaly Surveillance Planning Michelle Barros Pinheiro, Policy Analyst, Women's and Maternal Health*

BC Patient Safety & Learning System

Annemarie Taylor, Executive Director, BC Patient Safety & Learning System (Presenter) Tammy Simpson, Provincial Coordinator

BC Pediatric Society

Stephanie Stevenson, Executive Director

BC Women's Hospital and Heath Centre

Deepak Manhas, Neonatologist (Presenter)*

Dorothy Shaw, Vice-President, Medical Affairs, PHSA (Panel Chair)

Fraser Health

Kirsten Grabowska, Maternal Fetal Medicine specialist, Obstetrician/Gynecologist* Michelle Urbina-Beggs, Clinical Nurse Specialist, Population Public Health Hamze Jomaa, Consultant, Quality Improvement & Patient Safety, MICY Pgm

General Practice Services Committee

Shelley Ross, Co-chair, GPSC; Chair, Maternity Care Working Group

Interior Health

Sue Pollock, Medical Health Officer*
Penny Liao-Lussier, Manager, Maternal Child Health, Population Health
Denise Chapple, Pediatrician
Bimal Chhetri, Public Health Epidemiologist
Shiraz Moola, Obstetrician/Gynecologist*

Island Health

Charmaine Enns, Medical Health Officer (Presenter)
Jan Tatlock, Director, Public Health
Deborah Chaplain, Director, Child, Youth and Family Services
Hayley Bos, Medical Director, Maternity Care
Maritia Gully, Manager, Population Health Assesment and Epidimiology
Diane Sawchuck, Research Liaison Officer

Midwives Association of British Columbia

Alix Bacon, President

Northern Health

Sandra Allison, Chief Medical Health Officer, Public Health Kari Harder, Public Health Epidemiologist

Provincial Health Services Authority

Joanne Wooldridge, Director, Maternal Newborn Surgical Services (reporting to regional Perinatal Coordinating Committee, PHSA Acute Perinatal Program)

Drona Rasali, Director, Population Health Surveillance and Epidemiology, BCCDC Kate Smolina, Director, BC Observatory for Population and Public Health, BCCDC Scott MacRae, Clinical Consultant, Women & Family Health, Performance Measurement and Reporting

Public Health Agency of Canada

Susie Dzakpasu, Epidemiologist (Presenter)

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Chantal Nelson, Senior Epidemiologist, Maternal & Infant Health & Congenital Anomalies Surveillance, Centre for Chronic Disease Prevention

Society of Obstetricians and Gynaecologists of Canada

Jennifer Blake, Chief Executive Officer (Presenter)

Tsawout First Nation

Eydie Pelkey, Tsawout First Nation Elder

University of British Columbia

Petra Selke, Clinical Professor, Gynecology and Obstetrics (Presenter)*
Jan Christilaw, Clinical Professor of Obstetrics and Gynecology (Panel Chair)*
Patti Janssen, Professor, School of Population and Public Health
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Vancouver Coastal Health

Réka Gustafson, Medical Health Officer, Maternal Child Sara Forsting, Regional Epidimiologist

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