Surveillance Advances

# Insights in public health surveillance for maternal and newborn health

January 30, 2024          12:00 – 1:00pm (CT) / 1:00 – 2:00pm (ET)

## Speakers

Dr. Ann Sprague          Project Advisor, Better Outcomes Registry and
                         Network (BORN) Ontario

Dr. Gillian Alton         Epidemiologist, BORN Ontario

Dr. Deshayne Fell         Adjunct Professor, School of Epidemiology and
                         Public Health, University of Ottawa
                         Affiliate Investigator, Children's Hospital of Eastern
                         Ontario (CHEO) Research Institute

National Collaborating Centre
for Infectious Diseases

Centre de collaboration nationale
des maladies infectieuses

Public Health          Agence de la santé
Agency of Canada       publique du Canada

# Land Acknowledgment: NCCID

The National Collaborating Centre for Infectious Diseases is hosted by the University of Manitoba, on the original lands of Anishinaabe, Cree, Oji-Cree, Dakota and Dene peoples, and on the homeland of the Métis Nation.

At NCCID, we strive to honor the lands and their original caretakers in our work. We acknowledge that we are on Treaty One land. We recognize that this and other treaties, have been implemented as part of the process of colonization intended to benefit some while harming others. We are committed to working with our partners towards reconciliation.
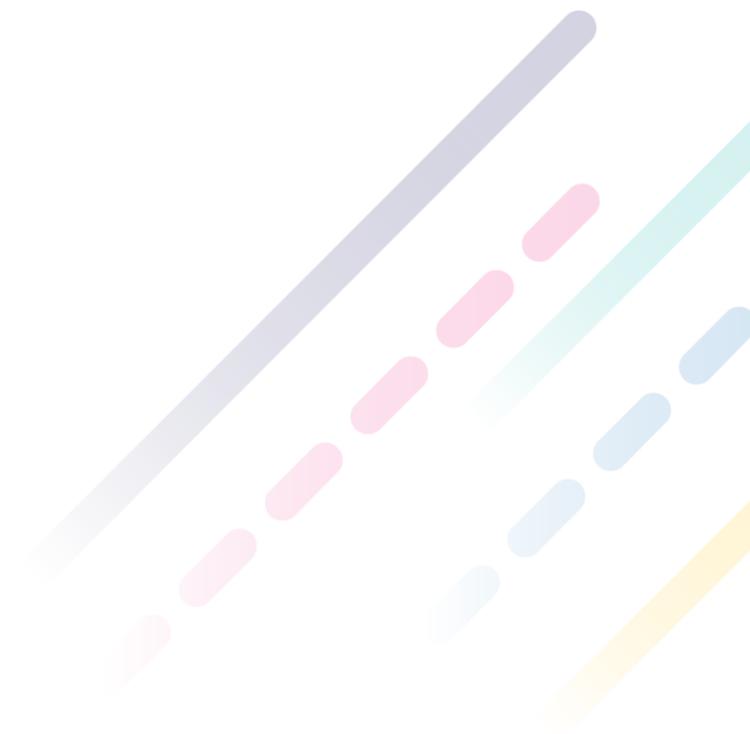
# Housekeeping

- Seminar recording and presentation slides will be available shortly after the seminar at the NCCID website: https://nccid.ca/

- If you have technical problems with Zoom, please email us at nccid@umanitoba.ca

- The chat box for participants has been disabled for this session. We will use the chat box to share additional information.

- Please use the Q&A tab to submit your questions for our speakers

- You can "like" other people's questions to push them up in priority

# Accreditation

Surveillance Advances is a self-approved group learning activity (Section 1) as defined by the Maintenance of Certification Program of the **Royal College of Physicians and Surgeons of Canada**.

The seminar series is also approved by the Council of Professional Experience for professional development hours for members of the **Canadian Institute of Public Health Inspectors**.

If you would like a letter of participation, please complete the survey which will be shared after the seminar.
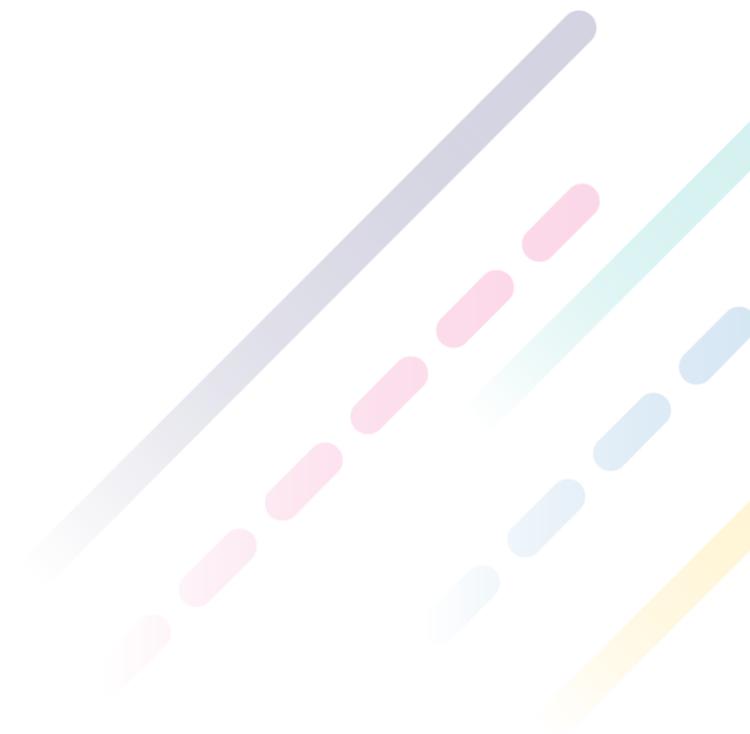
# Land Acknowledgment: PHAC

I would like to take this time to acknowledge the land that I live and work on is the traditional territory of the Wendat, the Anishnaabeg, Haudenosaunee, Métis, and the Mississaugas of the Credit First Nation.

It is home to many First Nations, Métis, and Inuit peoples. I am grateful for the opportunity to share their home.
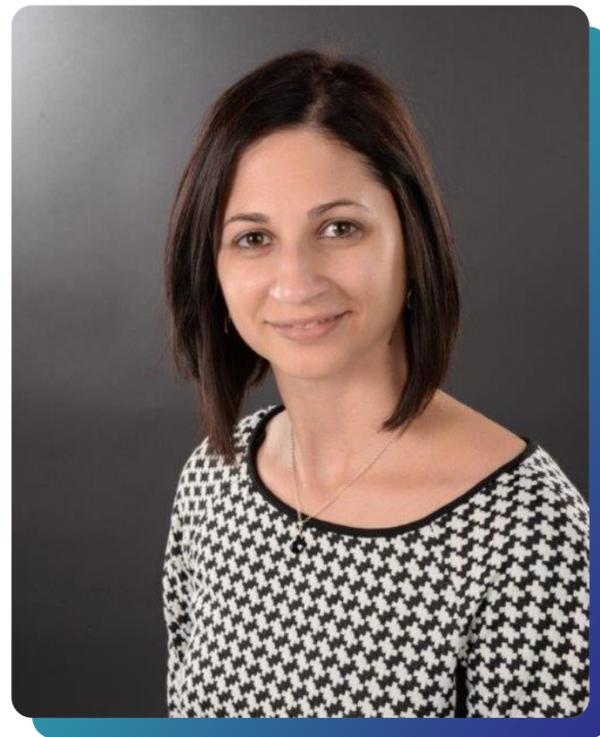
# Today's speakers

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# Maternal Newborn Surveillance in Ontario

Presented by:

**Dr. Ann Sprague**

**Dr. Gillian Alton**

**Dr. Deshayne Fell**

January 2024

# Disclosures

**Deshayne Fell**:

- In the past 2 years: I have received travel support from WHO and an honoraria from PATH

- I am now an employee of Pfizer, but my comments today represent my own personal opinions based on my research that was conducted when I was employed by the University of Ottawa

- I am not speaking as a representative of Pfizer and the research I will be presenting/discussing was not funded by Pfizer

**Gillian Alton & Ann Sprague**:

- No disclosures

# Objectives

- Provide an overview of Better Outcomes Registry and Network (BORN) Ontario

- Outline surveillance activities at BORN Ontario

- Discuss methodological issues associated with surveillance in the maternal newborn population

# What is the Better Outcomes Registry & Network (BORN) Ontario?

- BORN is a maternal-child **REGISTRY**: granted registry Status under the *Personal Health Information Privacy Act* (PHIPA) in Nov 2009

- Allows BORN to collect, use and disclose personal health information **without consent** for the purpose of "facilitating or improving the provision of health care".

This special authority requires BORN to develop and adhere to *rigorous privacy policies* and have them reviewed and *approved* by the Ontario Information and Privacy Commissioner.

BORN cannot collect data unless it meets one of the 7 purposes laid out in our Privacy & Security Policies.

# BORN Purposes

1) Identify individuals or settings where **appropriate care has not been received** and facilitate access to care and treatment for mothers, infants and children.

2) Facilitate **continuous improvement** of healthcare delivery tools to minimize adverse outcomes.

3) Determine where maternal and/or newborn **outcomes are clinically or statistically discrepant** with accepted norms and raise alerts where necessary.

4) Enable health care providers to improve care by providing information & tools to **compare their outcomes and performance** with peers and/or benchmarks.
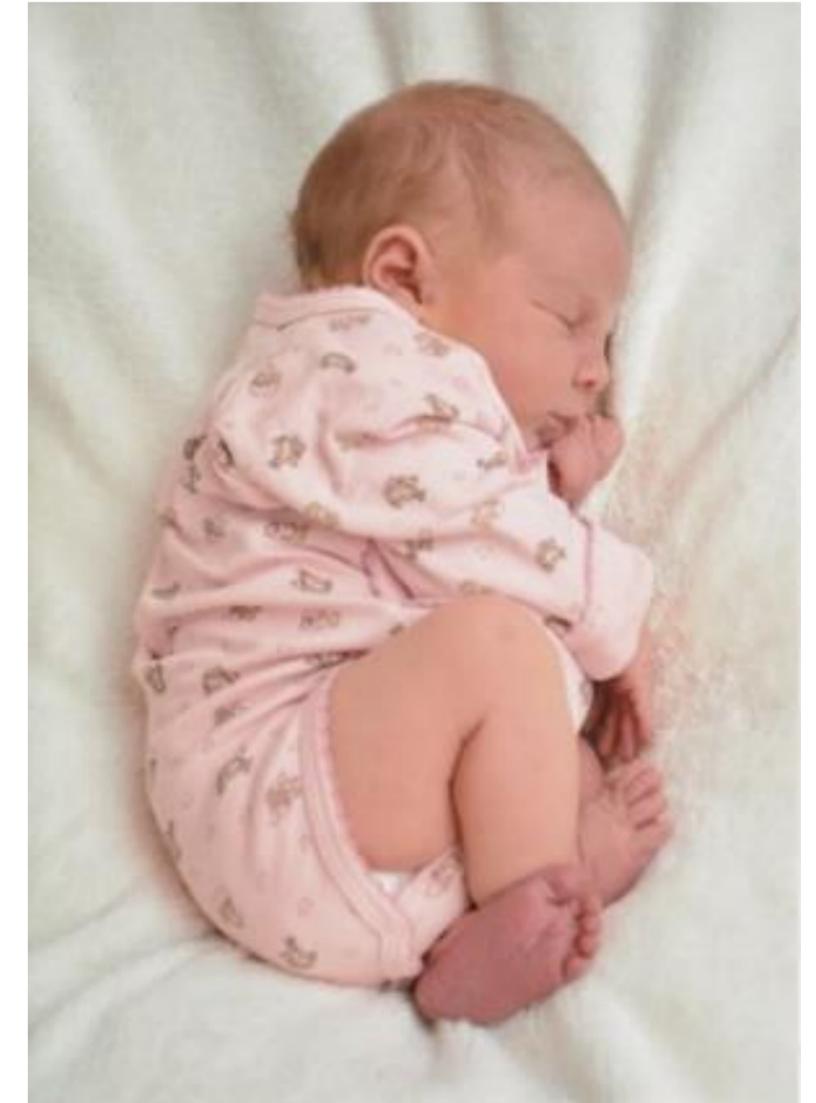
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# BORN Purposes (continued)

5) Identify areas where **best practice evidence needs implementation** (knowledge translation strategies) to improve the quality and efficiency of care for mothers, infants and children.

**6)** **Create reports** that can be used to provide the Ministry of Health and Long-Term Care, Local Health Integration Networks and Public Heath Units with comprehensive and timely information for mothers, babies and children.

7) Facilitate the provision of health care to a pregnant person and/or baby through the **pre-population of personal health information used by or between health information custodians within the circle of care** of a pregnancy and/or resulting delivery (including post-partum care and newborn care).

**BORN Information System (BIS) Data In - Data Out**

If you contribute data, you can retrieve data
If you don't contribute, BORN has to retrieve it for you
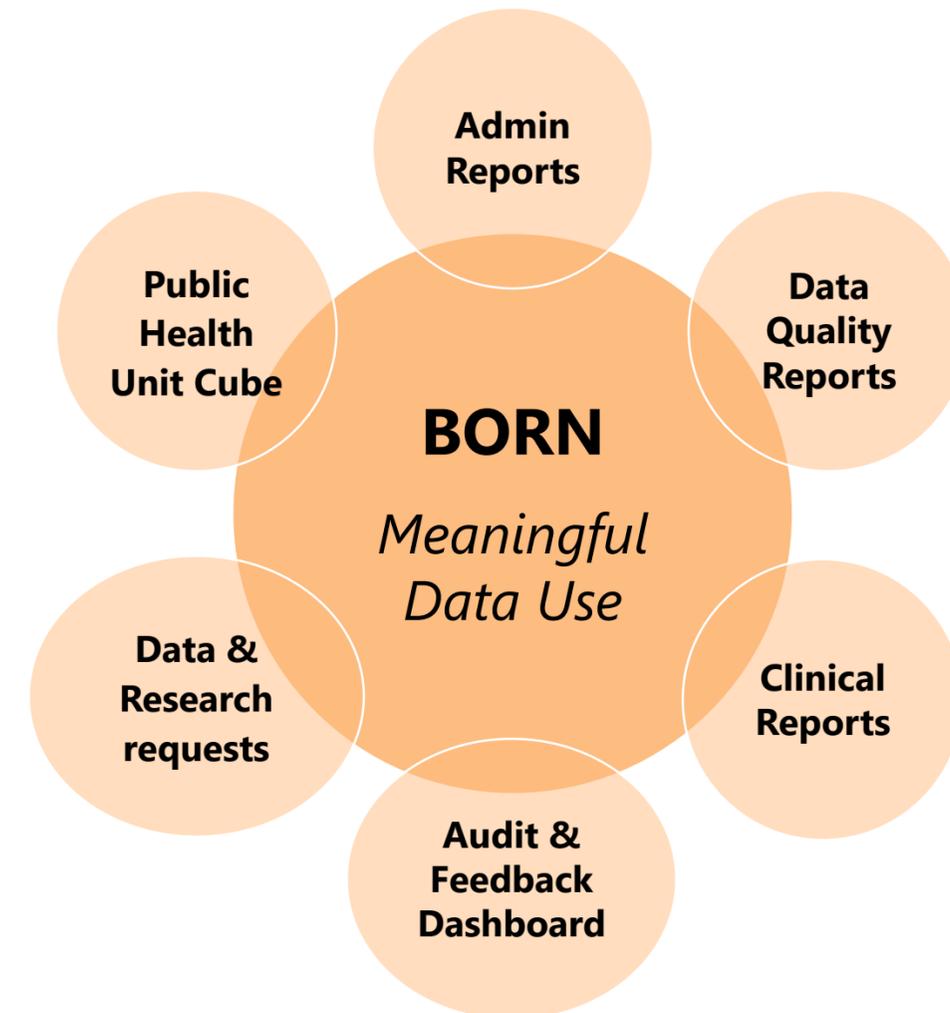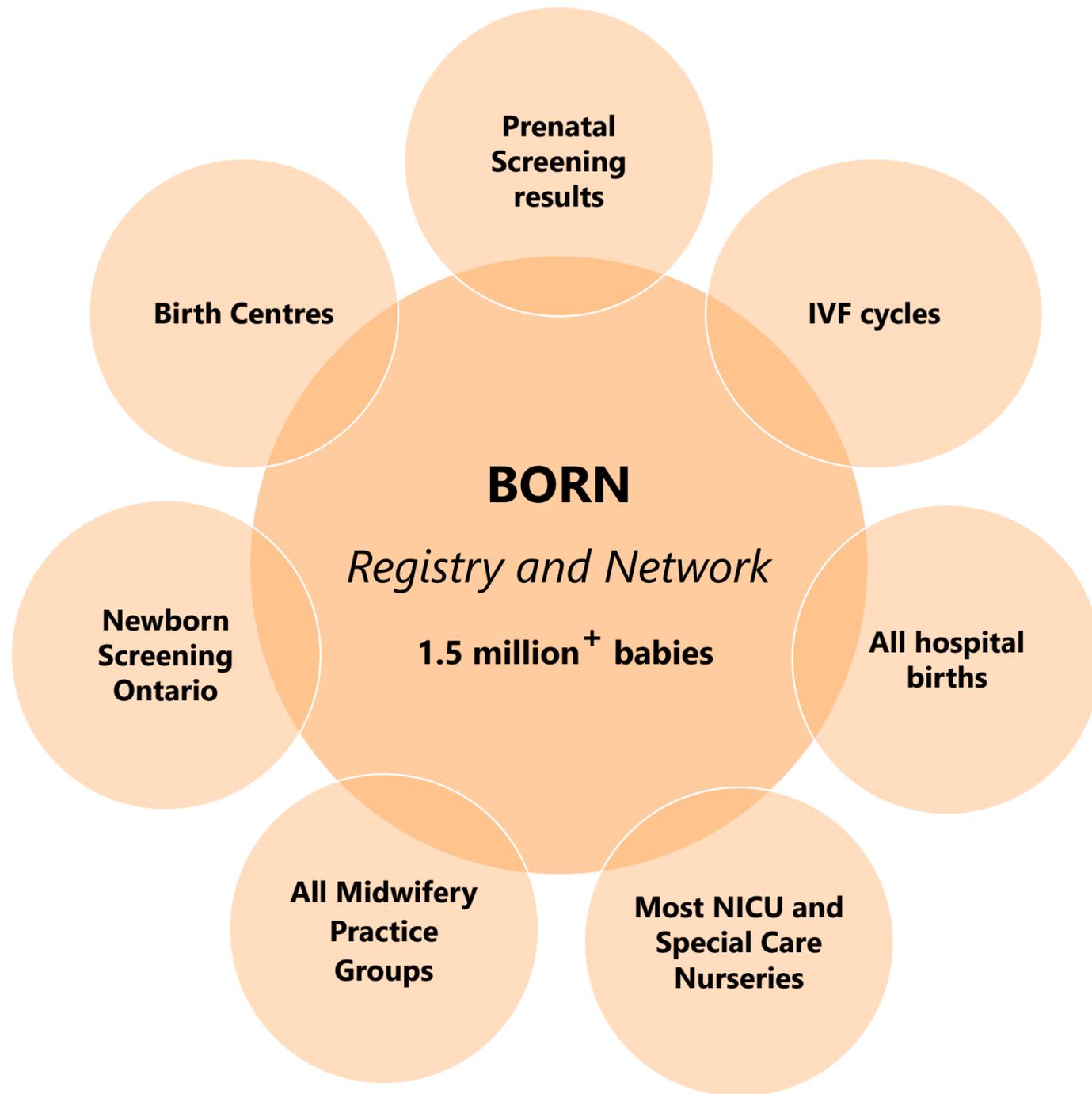
Manual entry or electronic capture from HIS and labs. Ongoing DQ processes

13

# Surveillance - Collaboration is Key!

- 1 data source may not be enough

- Often involves complex probabilistic and deterministic data linkages
  - A lot of data sharing agreements

- Who has the best data and the point in time that is most meaningful?

- What is the surveillance meant to convey? Who can help spread the word?

- A concrete example – COVID-19
  - Ontario Ministry of Health (MOH) had PCR testing results in CCM
  - COVAX-ON had vaccination info (dosage, date, time)
  - BORN Information System had maternal-newborn outcomes in near-real time
  - → Only by linking all of these could the full picture be established and communicated to the public, health care providers, funders, governments

# Surveillance in Pregnancy - Tricky!

- In best cases, pregnancy lasts 39+ weeks. However, exposures at different periods can have differing effects

- Need special consideration of:

  - Enough time to adequately study outcomes

    - Length of pregnancy vs. study/grant time period

    - Normal data lags in registry

  - Methodological considerations

    - Time varying exposures

    - Fixed cohort bias

# Ongoing Surveillance at BORN

- Clinical outcomes
    - Live dashboard for all hospitals contributing data – 6 KPIs with benchmarks and signals (red, yellow, green)
    - Newborn Screening – missed screen alerts
    - Prenatal Screening – nuchal translucency quality assurance, surveillance of positive and negative tests to tweak algorithms
    - Maternal Mortality – linking datasets to measure and report and compare MM rates
    - Infant Mortality – linking datasets to measure and report and compare MM rates

# Maternal Mortality Surveillance

- In developed countries, much MM is preventable.

- Traditionally defined as death up to 42 days post delivery, but UK group has demonstrated the importance of looking out to 1 year post delivery to pick up many mental health and substance use issues that can be tied to pregnancy and birth

- In ON, the Coroner reviews most maternal deaths, but don't always know if someone has been pregnant within the last year.
    - This group issues reports with recommendations, but currently not a robust KT strategy or feedback loop
    - BORN working with coroner's group to try and improve surveillance
    - Ultimate goal to facilitate and improve care and prevent maternal deaths

# Maternal Mortality Surveillance (continued)

- BORN Group currently analyzing 20 years of linked CIHI DAD, CIHI NACRS and BIS data on maternal deaths

- Interdisciplinary group (OB, MFM, Nursing, MW, Anesthesia, Public Health, Fertility, Epidemiologists from BORN and PHAC, Neonatologist, Internal medicine, data analyst, SOGC science lead)

- Reviewing all diagnosis codes, intervention codes and birth and death information for each person who died.

- Will determine most likely cause of death, whether it was obstetric related and discuss preventability

- This project is first step: much more to do.

# Infectious Disease Surveillance at BORN

| Disease | Illness, Vaccination and Medications |
|---|---|
| 2009 H1N1 | All |
| COVID-19 | Illness and vaccination |
| RSV | Not yet. Advocacy work ongoing |
| Syphilis and congenital syphilis | Illness available but not robust. Partnering with pan-Canadian group |
| Group B streptococcus | On the horizon |
| CMV | Newborn Screening ON recently added this to their panel so surveillance is possible |

# Enhanced pandemic surveillance:
## 2009 H1N1 Pandemic

**In 2 months, we:**

- Obtained a letter of support from the CMOH and distributed to all maternity hospitals (~106 sites)

- Worked with surveillance experts and care providers to develop paper-based questions (only 3 questions were possible)

- Worked with the database vendor to add new data collection fields

- Through regional coordinators, worked with hospitals to develop tools to assist with data collection

- Developed communication strategy, including hosting province-wide webinar to train care providers and coders how to collect and code the data

# Enhanced pandemic surveillance: 2009 H1N1 Pandemic

**1**
## H1N1 Influenza Vaccination During Pregnancy and Fetal and Neonatal Outcomes

Deshayne B. Fell, MSc, Ann E. Sprague, PhD, Ning Liu, MSc, Abdool S. Yasseen III, MSc, Shi-Wu Wen, PhD, Graeme Smith, MD, PhD, and Mark C. Walker, MD, MSc, for Better Outcomes Registry & Network (BORN) Ontario

**2**
QUANTITATIVE RESEARCH
## Vaccination Patterns in Pregnant Women During the 2009 H1N1 Influenza Pandemic: A Population-based Study in Ontario, Canada

Ning Liu, MB, MSc,[1] Ann E. Sprague, RN, PhD,[2,3] Abdool S. Yasseen III, MSc,[3] Deshayne B. Fell, MSc,[2,3] Shi-Wu Wen, MD, PhD,[3,4] Graeme N. Smith, MD, PhD,[5] Mark C. Walker, MD, MSc[2-4]

**3**
## Infant outcomes among pregnant women who used oseltamivir for treatment of influenza during the H1N1 epidemic

Hai-yan Xie, MSc; Abdool S. Yasseen III, MSc; Ri-hua Xie, PhD; Deshayne B. Fell, MSc; Ann E. Sprague, PhD; Ning Liu, MSc; Graeme N. Smith, PhD; Mark C. Walker, MD; Shi Wu Wen, PhD

**4**
RESEARCH ARTICLE
## Infant Respiratory Outcomes Associated with Prenatal Exposure to Maternal 2009 A/H1N1 Influenza Vaccination

Deshayne B. Fell[1], Kumanan Wilson[2,3,4]*, Robin Ducharme[3,4], Steven Hawken[3,4,5], Ann E. Sprague[1], Jeffrey C. Kwong[3,6,7,8], Graeme Smith[9], Shi Wu Wen[4,10], Mark C. Walker[1,4,10,11]

**5**
## Health outcomes of young children born to mothers who received 2009 pandemic H1N1 influenza vaccination during pregnancy: retrospective cohort study

Laura K Walsh,[1,2] Jessy Donelle,[3] Linda Dodds,[4] Steven Hawken,[2,3,5] Kumanan Wilson,[2,3,5] Eric I Benchimol,[2,3,6] Pranesh Chakraborty,[2,6] Astrid Guttmann,[3,7,8] Jeffrey C Kwong,[3,7,9,10] Noni E MacDonald,[4] Justin R Ortiz,[11] Ann E Sprague,[1,2,6] Karina A Top,[4] Mark C Walker,[1,2,5] Shi Wu Wen,[2,5] Deshayne B Fell[2,3,6]

**6**
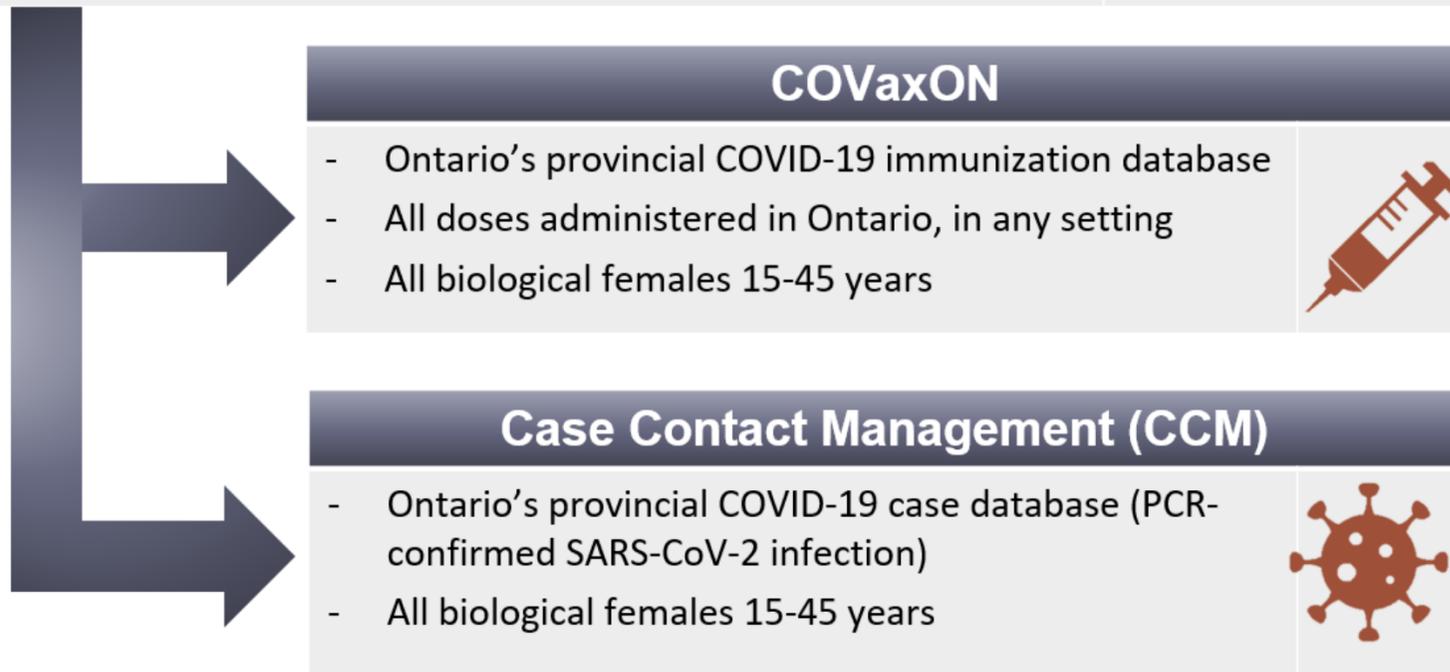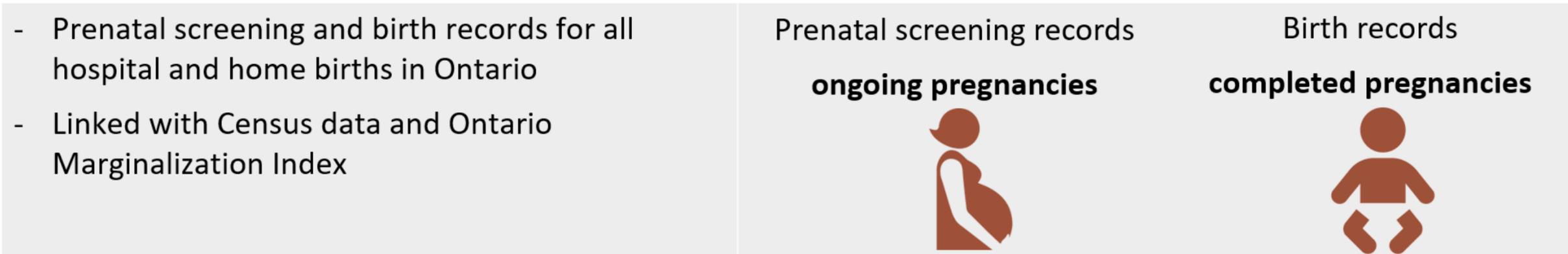*Outcomes in children up to 10 years of age → ongoing*

21

Numerous early challenges for **COVID-19 disease surveillance** in pregnancy:
- Early on, there was no easy way to get linkable data about an emerging disease
- Permissions/agreements/contracts for obtaining/sharing data difficult
- Alignment with national and international data collection
- → Initial solution was a **case report form (CRF)** completed for pregnant people with COVID-19 admitted to hospital

Eventually, COVID-19 disease and vaccination surveillance evolved to a hybrid approach: **CRF + linkage with CCM + linkage with COVAX-ON**, also with challenges:
- Multiple live databases being linked in near-real time
- Data changes and edits from month-to-month
- Missing key data elements for linking and matching
- Pregnancy flag in databases often missing (massively under-documented)
- Lags in data availability (particularly due to length of pregnancy)
- Changes in testing protocols

# Enhanced pandemic surveillance:
## COVID-19 Pandemic

- Prenatal screening and birth records for all hospital and home births in Ontario
- Linked with Census data and Ontario Marginalization Index

Prenatal screening records
**ongoing pregnancies**

Birth records
**completed pregnancies**

### COVaxON
- Ontario's provincial COVID-19 immunization database
- All doses administered in Ontario, in any setting
- All biological females 15-45 years

### Case Contact Management (CCM)
- Ontario's provincial COVID-19 case database (PCR-confirmed SARS-CoV-2 infection)
- All biological females 15-45 years

- Prenatal screening records (transferred weekly to the registry) and available birth records to identify ongoing and new pregnancies and births in near 'real-time'

- Monthly linkages with updates of the Public Health CCM Solution and COVaxON, provided by the Ministry of Health, to obtain information on COVID-19 infection and vaccination in pregnancy

# COVID-19 Disease During Pregnancy

**1**

COVID-19 Numbers to Know

**How are the Data Collected?**

In March 2020, BORN created a special **case-report form** to capture information about COVID-19 in pregnancy. Participating organizations, including hospitals and midwifery practice groups, complete this PDF-fillable case-report form and securely transfer it to BORN. Data from the forms are then linked to other data at BORN.

Note that data are not complete; due to data limitations, the information below does not include all births in the province.

**Preliminary Data**

Notes                                    +

Time Frame: March 1, 2020 - July 31, 2021...

| 2179 | 191 | 37 |
|---|---|---|
| Pregnant individuals in Ontario had COVID-19 (cumulative total) | Pregnant individuals in Ontario had a COVID-19 related hospitalization | Pregnant individuals in Ontario with COVID-19 were admitted to the ICU |

| 1651 | 12.2 | 16.1 |
|---|---|---|
| Pregnant individuals in Ontario with COVID-19 had a live birth | Percent of babies born to individuals with COVID-19 were preterm | Percent of babies born to individuals with COVID-19 were admitted to the NICU |

**2**

## Maternal-Newborn Health System Changes and Outcomes in Ontario, Canada, During Wave 1 of the COVID-19 Pandemic—A Retrospective Study

Nicole F. Roberts, MSc;[1] Ann E. Sprague, RN, PhD;[1,2] Monica Taljaard, PhD;[3,4] Deshayne B. Fell, PhD;[2,4] Joel G. Ray, MD, MSc;[5] Modupe Tunde-Byass, MD;[6,7] Anne Biringer, MD, CCFP;[8] Jon F.R Barrett, MBBch, MD;[9] Faiza Khurshid, MBBS, MD;[10] Sanober Diaz, MSc;[11] Kara Bellai-Dussault, MSc;[1,2] Dana-Marie Radke, RN;[1] Lise M. Bisnaire, PhD;[1,2] Christine M. Armour, MD, MSc;[1,2,12] Ian C. Joiner, MPA;[1] Mark C. Walker, MD, MSc[1,3,13,14,15]

N.F. Roberts

[1]Better Outcomes Registry & Network (BORN) Ontario, Ottawa, ON
[2]Children's Hospital of Eastern Ontario (CHEO) Research Institute, Ottawa, ON
[3]Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, ON

**3**

## Association of SARS-CoV-2 Infection During Pregnancy With Maternal and Perinatal Outcomes

Elisabeth McClymont, PhD, [1,2] Arianne Y. Albert, PhD, [3] Gillian D. Alton, PhD, [4,5] Isabelle Boucoiran, MD, [6,7] Eliana Castillo, MD, [8] Deshayne B. Fell, PhD, [5,9] Verena Kuret, MD, [8] Vanessa Poliquin, MD, [10] Tiffany Reeve, MSc, [3] Heather Scott, MD, [11] Ann E. Sprague, PhD, [4,5] George Carson, MD, [12] Krista Cassell, MD, [11] Joan Crane, MD, [13,14] Chelsea Elwood, MD, [1,3] Chloe Joynt, MD, [15] Phil Murphy, MS, [13,14] Lynn Murphy-Kaulbeck, MD, [16] Sarah Saunders, MD, [17] Prakesh Shah, MD, [18] John W. Snelgrove, MD, [19] Julie van Schalkwyk, MD, [1] Mark H. Yudin, MD, [19] and Deborah Money, MD [1,3], for the CANCOVID-Preg Team

# COVID-19 Vaccination During Pregnancy



**1** REPORT #7 (FINAL REPORT)
COVID-19 VACCINATION DURING PREGNANCY IN ONTARIO
December 14, 2020 to December 31, 2022

**2** Original Investigation

March 24, 2022

**Association of COVID-19 Vaccination in Pregnancy With Adverse Peripartum Outcomes**

Deshayne B. Fell, PhD[1,2]; Tavleen Dhinsa, MSc[2,3]; Gillian D. Alton, PhD[2,3]; et al

**3** RESEARCH

OPEN ACCESS

Check for updates

**Risk of preterm birth, small for gestational age at birth, and stillbirth after covid-19 vaccination during pregnancy: population based retrospective cohort study**

Deshayne B Fell,[1,2] Sheryll Dimanlig-Cruz,[2,3] Annette K Regan,[4,5] Siri E Håberg,[6] Christopher A Gravel,[2,7] Laura Oakley,[6,8] Gillian D Alton,[1,3] Eszter Török,[1,3] Tavleen Dhinsa,[3] Prakesh S Shah,[9,10,11,12] Kumanan Wilson,[13,14,15] Ann E Sprague,[1,3] Darine El-Chaâr,[2,13,16] Mark C Walker,[1,2,3,13,16] Jon Barrett,[17] Nannette Okun,[18] Sarah A Buchan,[19,20] Jeffrey C Kwong,[19,20,21,22] Sarah E Wilson,[19,20] Sandra I Dunn,[3,23] Shannon E MacDonald,[24,25,26] Shelley D Dougan[1,3]

**4** **Temporal trends and determinants of COVID-19 vaccine series initiation after recent pregnancy**

Eszter Török, Tavleen Dhinsa, Sheryll Dimanlig-Cruz, Gillian D. Alton, Ann E. Sprague, Sandra I. Dunn, Prakesh S. Shah, Darine El-Chaâr, Annette K. Regan, Kumanan Wilson, Sarah A. Buchan, Jeffrey C. Kwong, Siri E. Håberg, Christopher A. Gravel, Nannette Okun, Mark C. Walker, Shannon E. MacDonald, Sarah E. Wilson, Jon Barrett & Deshayne B. Fell

**5** **Pregnancy, fetal, and neonatal outcomes after a first booster dose of covid-19 vaccine during pregnancy in Ontario, Canada: population based, retrospective cohort study**

Deshayne B Fell,[1,2] Sheryll Dimanlig-Cruz,[2,3,4] Eszter Török,[2,3] Siri E Håberg,[5] Annette K Regan,[6,7] Jay S Kaufman,[8] Robert W Platt,[8] Christopher A Gravel,[1,8] Liam Bruce,[3] Prakesh S Shah,[9,10,11,12] Kumanan Wilson,[4,13,14] Ann E Sprague,[2,3] Gillian D Alton,[2,3] Tavleen Dhinsa,[2,3] Darine El-Chaâr,[14,15] Sarah A Buchan,[16,17,18] Jeffrey C Kwong,[16,17,18,19] Sarah E Wilson,[16,17,18] Sandra I Dunn,[2,3,20] Shannon E MacDonald,[21,22,23] Jon Barrett,[24] Nannette Okun,[25] Mark C Walker[1,2,3,4,15]

# Pandemic Surveillance - Learnings

- Innovation has improved from H1N1 → COVID-19
  - H1N1 exclusively paper-based data collection → COVID-19 mostly database linkages
  - Data processing lags were long during H1N1 → COVID-19 used real-time data

| Strengths of current-state ID/vaccination surveillance capacity for maternal-newborn population | Ongoing challenges for ID/vaccination surveillance in maternal-newborn population |
|---|---|
| • <u>Comprehensive</u> pregnancy information available in BORN Ontario registry & administrative databases<br>• <u>Timely</u> data in BORN Ontario registry and many health administrative databases<br>• <u>Follow-up</u> of mothers and infants is possible in our health administrative databases<br>• <u>Coverage</u> of the full pregnancy population<br>• <u>Linkages</u> between databases to identify the pregnant population are well-established | • Pregnancy losses before 20 weeks are not routinely ascertained<br>• Administrative databases, alone, have limited information on baseline and clinical characteristics<br>• Reliable and complete source of vaccination data during pregnancy may be lacking in some P/Ts<br>• Very difficult to share data across P/Ts<br>• Capacity / human resource issues |

# Syphilis Surveillance – On the horizon

- Canadian rates of syphilis have been increasing drastically and disproportionately among women, leading to increasing rates of congenital syphilis.

- The rate of congenital syphilis ranges from 0-1 cases per year in some Maritime provinces, up to 315 cases per 100 000 in Manitoba. The overall Canadian rate of congenital syphilis is estimated at 26.1 per 100 000, which is significantly higher than the European rate of 1.9 per 100 000.

- The limited surveillance data available at present constrain our ability to inform best intervention strategies for the prenatal population.

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# RSV Surveillance

- Vaccine licensed for use in pregnancy by Health Canada in January 2024.
  - NACI recommendation pending
- Given to mother to prevent RSV in newborns (major cause of hospitalization, morbidity and mortality)
- Needs further population level surveillance
- Dependent on finding a reliable data source – not yet publically funded so no registry and no easy data sources
- Advocacy work to do – right partners, right message!

# What is Surveillance Success?

- Meaningful information that can help to impact change (facilitate or improve care)
  - Inform decision makers and funders
  - Inform those who receive care
  - Inform care providers
- Communicating the information – right message, right format, right time
- Partnerships – no one person/group has the ability to do all of this

# More Information on BORN

General Info:

- www.bornontario.ca

Data Requests:

- https://www.bornontario.ca/en/data/requesting-data.aspx

Surveillance Outcomes for COVID-19:

- https://www.bornontario.ca/en/whats-happening/covid-19-vaccination-during-pregnancy-in-ontario.aspx?_mid_=105528

# Questions?

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# Closing Remarks

# Thank You!

## Join us on Tuesday, February 27, 2024 (1:00-2:00pm ET) for the next seminar!

Please complete our **survey** that will be shared shortly after the seminar. Scan the QR code.

Seminar recording and presentation slides will be posted on https://nccid.ca/ within two weeks.

Visit https://nccid.ca/surveillance-advances-seminar-series/ for more information about the Surveillance Advances seminar series.