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Building a National Health Data System for Perinatal Opioid Exposure: A Collaborative Approach

PHO Rounds

Andi Camden & Ashley Smoke
Wednesday October 29, 2025



PHO Disclosure

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Disclosures

Conflicts of Interest



This project is supported by funding from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

Andi Camden – none to disclose

Ashley Smoke – member of several advisory groups, receives payment for consulting activities

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Learning Objectives

- 1 Describe the role of the Canadian Perinatal Opioid Project in strengthening surveillance of perinatal opioid exposure, including the project's key goals and outcomes.
- 2 Summarize engagement strategies used in the Canadian Perinatal Opioid Project.
- 3 Locate and use surveillance data featured on the Canadian Perinatal Opioid Project dashboard in their public health practice.

Background

Increasing opioid use and toxicity



Need for the Project

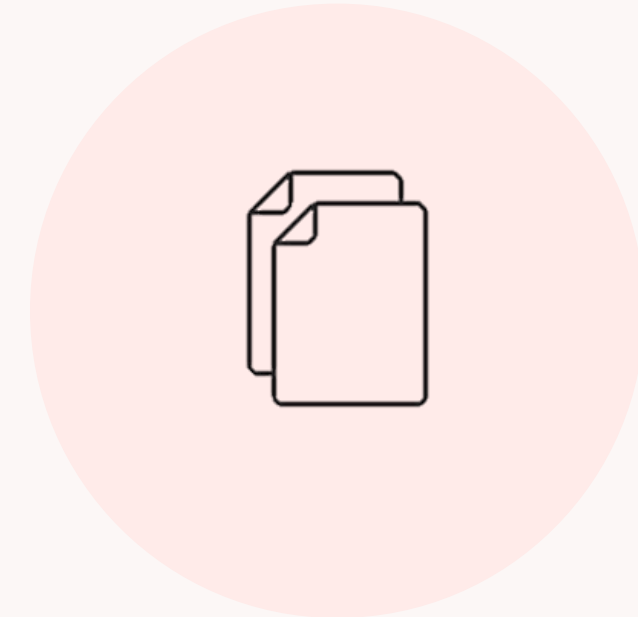
Knowledge Gaps



information



surveillance



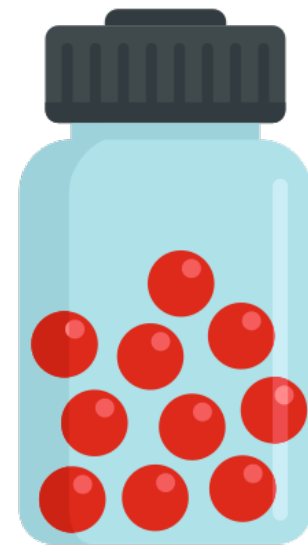
guidelines

Neonatal Abstinence Syndrome

Surveillance Indicator

45%

ICD-10



Canadian Perinatal Opioid Project

Objectives



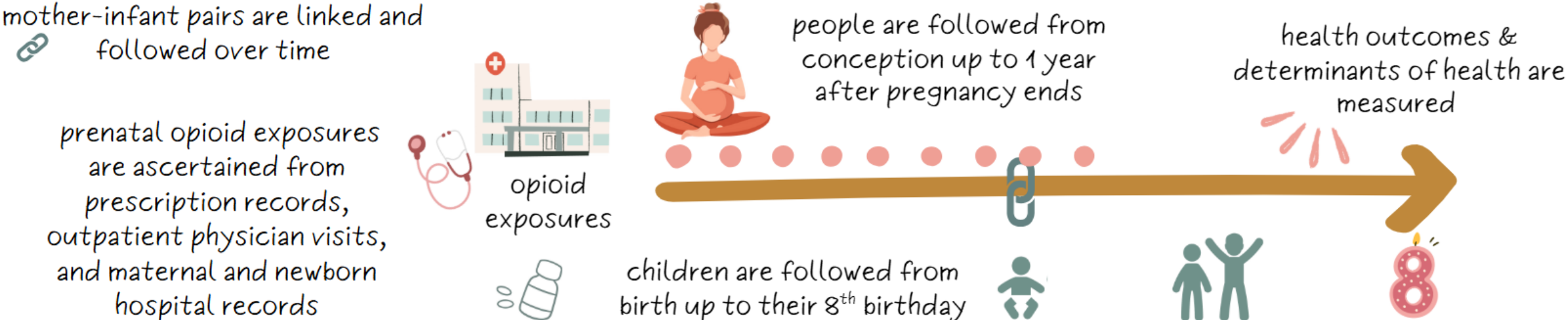
SURVEILLANCE

Develop a national surveillance system to monitor perinatal opioid use and investigate the impact of perinatal opioid use on maternal and child health in Canada

RESEARCH

Using this surveillance system, our objectives are to:

1. Describe the epidemiology of perinatal opioid use in Canada
2. Describe SDOH of people with perinatal opioid use
3. Examine adverse maternal and child health outcomes
4. Investigate long-term developmental health outcomes
5. Investigate long-term vision and eye health among children



Canadian Perinatal Opioid Project

Provincial Partners



Open access Protocol

BMJ Open Canadian perinatal opioid project: a protocol for a national health data system

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Lauren E Kelly, ^{8,9} Hong Lu, ² Alexandra Lucchese, ¹ Amy Metcalfe, ¹⁰
Nazeem Muhajarine ^{1,11,12} Nathan C Nickel, ^{13,14} Isobel Sharpe, ²
Astrid Guttman ^{1,2,15}

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Engagement Activities

1

PEER RESEARCHERS
with living experience of pregnancy/parenting, and opioids

2

COLLABORATORS
Provincial and national organizations (e.g., SOGC, CPS, CCSA, Health Nexus)

3

ADVISORY GROUPS
8 people with lived/living experience (PWLLE)
18 knowledge users (KU)

4

CONSENSUS METHODS
Surveillance indicators determined using DELPHI methods

7

KNOWLEDGE TRANSLATION
Website
Dashboard
Infographics
Publications
Reports
Conferences

6

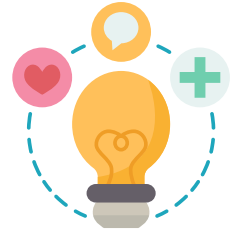
RESEARCH
Engagement throughout the research process

5

STORYTELLING
Highlighting the people (and their strengths) behind the numbers



Peer Researchers



Builds trust/
relationship
building

Participant
recruitment

Facilitates
advisory group
meetings

Data collection
(e.g., interviews)

Unique insights

Validation

Purpose

Impact

Advisory Groups

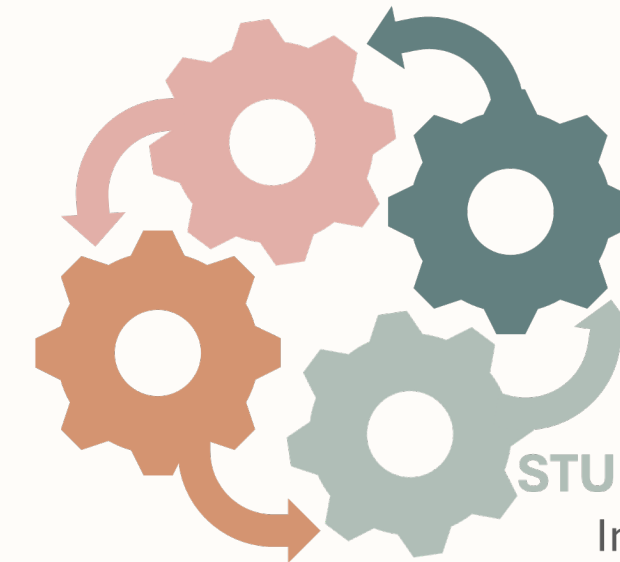
Integrated Engagement

- Type of engagement
- Internal criteria
- Who to invite?
- What's the role?
- Where?
- How long?
- How much?
- Removing equity barriers (e.g., childcare, disability accommodations, online)
- How to find participants
- Peer researcher



DISSEMINATION
Sharing findings, co-creation of accessible communications

RESEARCH PRIORITIES
Asking important questions



RECOMMENDATIONS
Meaningful and appropriate

STUDY FINDINGS
Interpretation

1

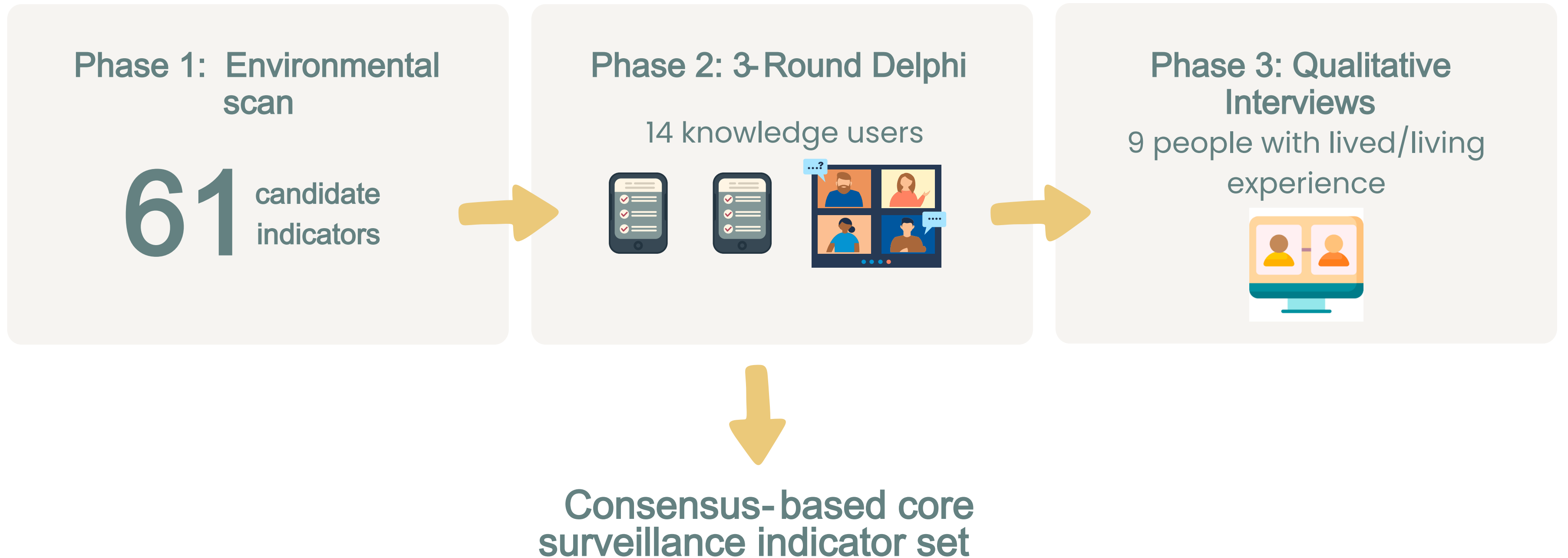
people with lived experience

2

knowledge users

Consensus Methods

Population health Indicators



Phase 3: Interviews with PWLLE

Qualitative Themes



Navigating Pain & Opioid Use in Pregnancy

Structural Vulnerabilities & Perinatal Health

Power Imbalances, Mistrust, & Need for Trauma-Informed Care

Reclaiming Power through Advocacy, & Peer-Support

“When it comes to any kind of hospital care, but especially for substance users that are pregnant, there needs to be a person with lived experience like a patient advocate that has gone through the system, has substance use history has you know dealt with CAS, knows how to advocate for their patient.” (P103)

“...my son he has ADHD and ODD, he’s not on the spectrum he was tested, but my goodness, he has behavioural kind of stuff and he’s 14 so I’m always wondering if it was related. I always have these kinds of questions of if methadone was related to behavioural stuff.” (P106)



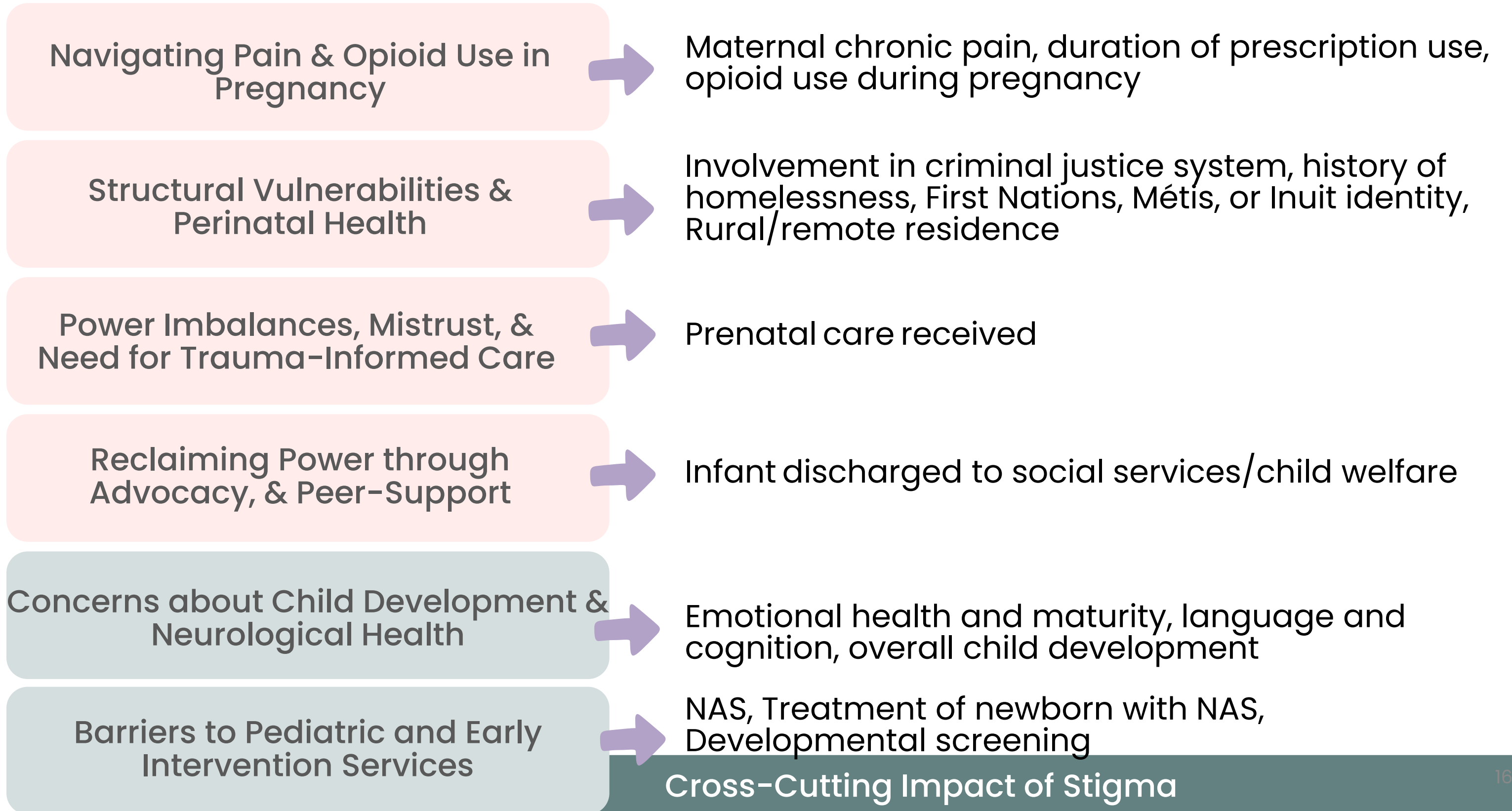
Concerns about Child Development & Neurological Health

Barriers to Pediatric and Early Intervention Services

Cross-Cutting Impact of Stigma

Phase 3: Interviews with PWLLE

Mapping Indicators



Phase 2: Maternal Health Indicators

Opioid Use/Treatment

- Fatal opioid toxicity (100%)
- Type of opioid use (92%)
- Non-fatal opioid toxicity (92%)
- Duration of Rx opioid use (86%)
- During pregnancy (100%)
- By trimester of pregnancy (92%)
- 1 year after pregnancy end (92%)

Other Rx Use

- Benzodiazepines (92%)
- Stimulants (83%)
- Mental health medications* (79%)

No data available

* Indicators suggested by knowledge users at the end of Round 1

Pregnancy

- Prenatal care (100%)
- Pregnancy outcome (92%)
- Gestational weeks (82%)
- Gestational hypertension* (77%)

Socio-demographics

- Homelessness (92%)
- Regular PCP (92%)
- Proximity to perinatal opioid use supports* (86%)
- First Nations, Métis, or Inuit Identity (83%)
- Maternal age (75%)
- Maternal age at first birth (75%)
- Immigrant to Canada (75%)
- Inv. in criminal justice system (75%)
- Rural/remote residence (71%)

Health Conditions

- Mental illness (100%)
- Perinatal alcohol use (100%)
- Perinatal drug use (100%)
- Death (100%)
- Substance use disorder (92%)
- Chronic medical conditions (82%)
- Disability (82%)
- Chronic pain (75%)

Psychosocial

- Abuse/violence* (93%)
- Trafficking victimization* (86%)
- Trauma* (86%)
- Suicidal behaviour* (79%)
- Access to support from family/friends* (71%)

Phase 2: Child Health Indicators

Newborn

- Discharged to social services/child welfare (100%)
- Birthweight (92%)
- Treatment of newborn with NAS (83%)
- Length of hospital stay (75%)
- Admission to the NICU (75%)
- Opioid withdrawal symptoms (75%)

<2 years

- Regular primary care provider (100%)
- Well-child visits (83%)
- Enhanced 18-month well-child visits (75%)
- Developmental screening (75%)

5-6 years

- Child development overall (100%)
- Emotional health & maturity (83%)
- Language & cognitive (83%)
- Physical health & well-being (75%)
- Social competence (75%)
- Communication skills & knowledge (75%)

<8 years

- Attendance in school* (86%)
- Adverse childhood experiences* (79%)
- Anxiety (75%)
- ADHD (75%)
- Death (75%)
- Fetal alcohol syndrome (75%)
- Mood/affective disorder (75%)
- Eating-related concerns* (71%)

No data available

Storytelling

GOALS

- 1) highlight the stories and people behind the numbers
- 2) break stigma



Infographics & Social Media

#ENDOVERDOSE

1 in 4

deaths in pregnancy or within 1 year of pregnancy involved OPIOIDS in 2020 in Ontario

source: doi: 10.23889/ijpds.v9i5.2810

interested in learning more? [click here!](#)

31 AUGUST 2025 |  International Overdose Awareness Day



Pregnancy, Opioid Toxicity & Death

1 in 20

pregnant people in Ontario take opioids for pain, treatment for opioid use disorder, or non-medical reasons

Fatal and non-fatal drug toxicity ratios are at a crisis point among those who are pregnant and newly parenting in Ontario. This trend is happening amongst reports that overdose and drug toxicity is decreasing; overdose prevention and harm reduction services are being scaled back, and provincial policies are being implemented that increase the criminalization and isolation of people living in poverty who use drugs.

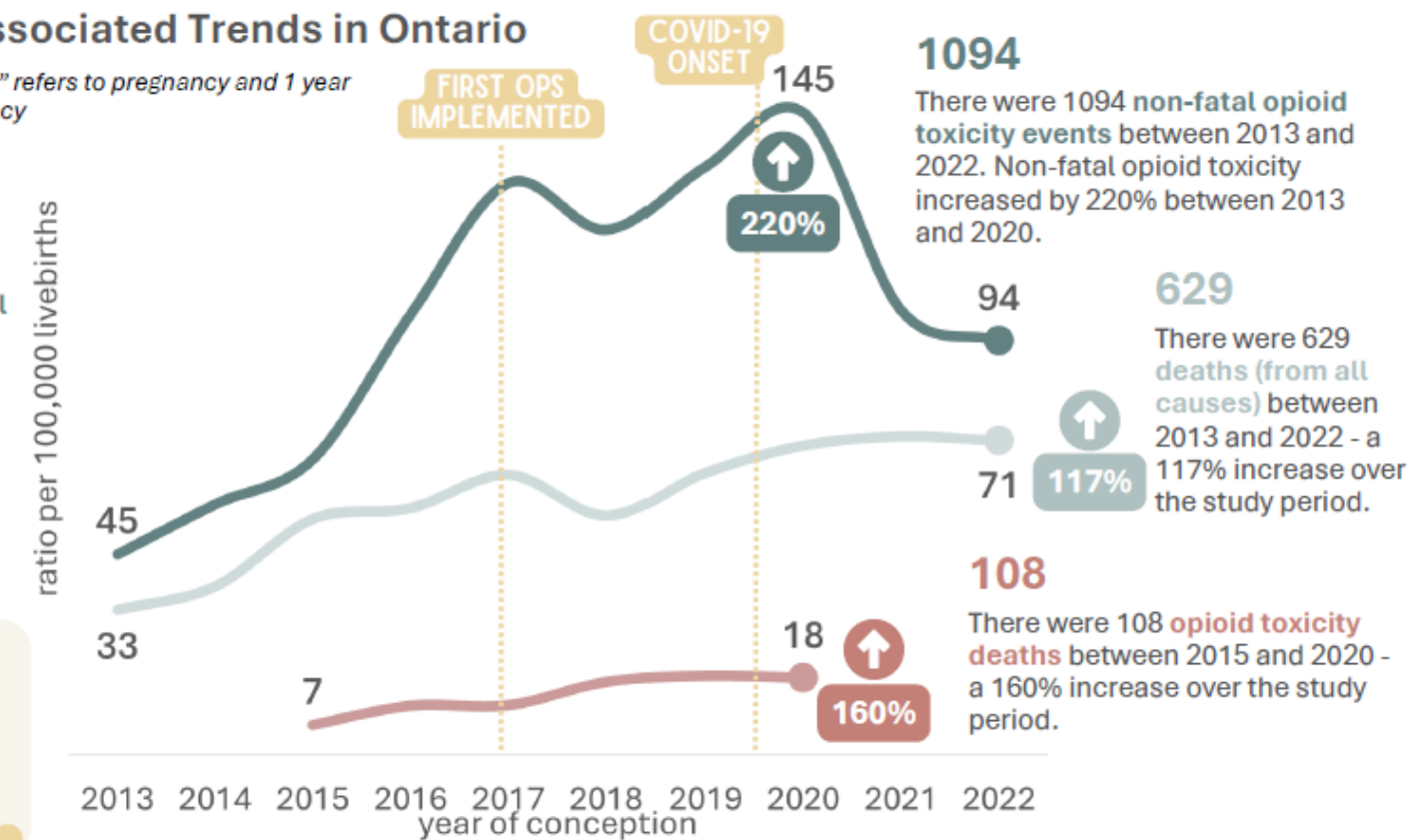
Fatal opioid toxicity ratios increased by 160% from 2015-2020 and non-fatal opioid toxicity ratios increased by 220% from 2013-2020 and remain disproportionately high. For many people who use drugs, pregnancy and early parenting are burdened with stigma, surveillance, and discrimination which can perpetuate isolation, trauma and heightened overdose risk. Child apprehension is a lifelong trauma and disproportionately impacts Black & Indigenous families.

Pregnancy-Associated Trends in Ontario

"pregnancy-associated" refers to pregnancy and 1 year after the end of pregnancy

Ontario data shows increases in pregnancy-associated[†] non-fatal and fatal opioid toxicity as well as deaths[‡] (from all causes) since 2013.

It's like being a pwud [person who uses drugs] they forget you deserve care during your pregnancy.



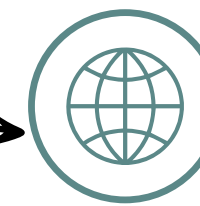
1094
There were 1094 non-fatal opioid toxicity events between 2013 and 2022. Non-fatal opioid toxicity increased by 220% between 2013 and 2020.

629
There were 629 deaths (from all causes) between 2013 and 2022 - a 117% increase over the study period.

108
There were 108 opioid toxicity deaths between 2015 and 2020 - a 160% increase over the study period.

Source: Camden et al. International Journal of Population Data Science. 2024 Sep 10;9(5), N=1,555,370 pregnancies. OPS, Overdose Prevention Site
 Note: Opioid toxicity deaths in pregnancy were not captured in administrative health data.

Dashboard



www.CPOProject.ca

- Overview
- Types of Opioids
- Maternal Factors
- Trends
- Maps
- Timing
- Duration



Canadian Perinatal Opioid Project

WELCOME TO THE DASHBOARD

click through the different dashboards!

This dashboard was created to start measuring opioid use during and after pregnancy in Canada. There is a critical need for information on the health impacts of the opioid epidemic on pregnant people, parents, and their children. Information generated from the Canadian Perinatal Opioid Project (CPOP) will inform supports to improve the health and well-being of pregnant people and parents who take opioids and their children.

PAN-CANADIAN SUMMARY

% of pregnancies with POE	total # of pregnancies with POE	total # of pregnancies
4.1%	65,386	1,602,553

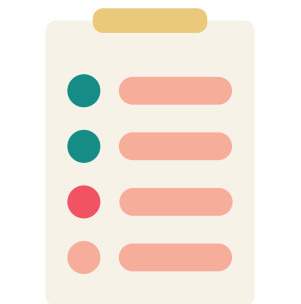
Prevalence of Prenatal Opioid Exposure by Province, 2013-2023 (combined)



Prevalence of Prenatal Opioid Exposure by Province, 2013-2023



Tasks



prenatal opioid exposure (POE) = any maternal prescription opioid record, opioid-related hospital visit, or physician care for opioid agonist therapy in pregnancy, or newborn with a diagnosis of neonatal abstinence syndrome

Indigenous Health

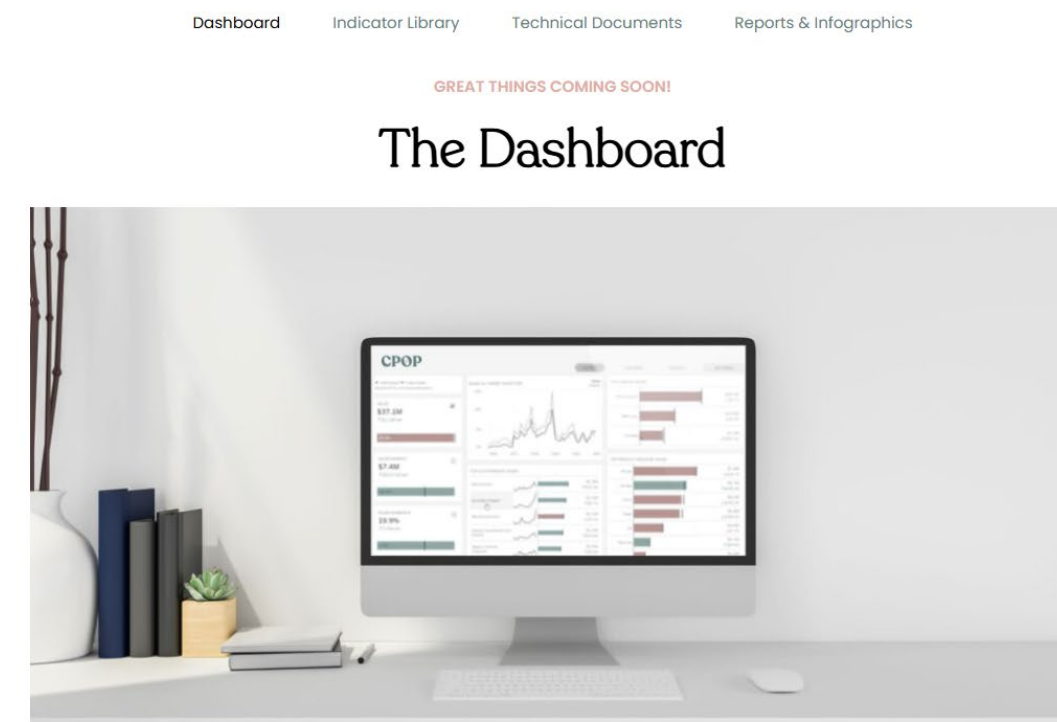
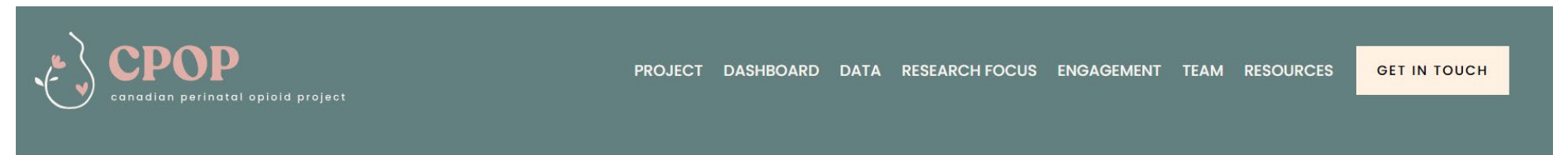
engaging with First Nation, Inuit,
and Métis communities



Source: The Indigenous Primary Health Care Council (IPHCC)

Next Steps

- Stay tuned! Dashboard launches on our project website in November
- Get in touch with indicator/
infographic suggestions
- andi.camden@sickkids.ca



www.CPOProject.ca

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Thank you!

Questions? Please reach out to Andi andi.camden@sickkids.ca