Decolonizing Birth Research: ***Indigenous researchers, clinicians, and communities measuring respect during childbearing***

WANDA PHILLIPS-BECK PHD, RN
RACHEL OLSON, PHD
SARASWATHI VEDAM PHD RM FACNM SCI D(HC)

FALL, 2023

2020

Background
The birthplace lab

Centering lived experiences in health services research

Respectful Maternity Care

Research and tools designed to help understand how service users experience care.

Birth Place and Provider

Research on the links between provider, place of birth, and health outcomes, and tools to support collaboration.

Person-Centered Decision Making

Online course for health care providers and tools to support dialogue and decisions.

www.birthplacelab.org

Participatory research process

“It doesn’t happen in Canada”

birth place lab

THE RESPECT STUDY

RESEARCH EXAMINING THE STORIES OF PREGNANCY AND CHILDBEARING IN CANADA TODAY

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Engaging Community in Transformative Research

birth place lab

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Complete the Survey Here

Time to complete

30-70 minutes

It is ok to answer a few questions, stop and return to the survey later (be sure to use the same device). You can also skip questions.

Why?

Your pregnancy or birth experience deserves to be counted.

Confidentiality

Voluntary and anonymous

Community Members choose the topics

- Access to models of birth care
- Place of birth
- Experiences with pregnancy & birth care
    - Decision-making
    - Respect, Autonomy
    - Racism, Mistreatment
    - Consent and Declining Procedures
- What builds Health and Well-Being
- Lead toward the development of person-centred measures of quality care

Mothers Autonomy in Decision-Making (MADM) Scale

Likert responses, Range of scores 7-42, internal reliability 0.96

(Vedam et al., PLOS One, 2017)

Please describe your experiences with decision making during your pregnancy, labor, and/or birth.
My doctor or midwife asked me how involved in decision making I wanted to be
My doctor or midwife told me that there are different options for my maternity care
My doctor or midwife explained the advantages/disadvantages of the maternity care options
My doctor or midwife helped me understand all the information
I was given enough time to thoroughly consider the different care options
I was able to choose what I considered to be the best care options
My doctor or midwife respected my choices

Mothers On Respect Index (MORI)

Range of scores 14-84; internal reliability 0.94
(Vedam et al., SSM Population Health, 2017)

A: Overall while making decisions about my pregnancy or birth care: (select or circle one answer for each statement)

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
I felt comfortable asking questions	1	2	3	4	5	6
I felt comfortable declining care that was offered	1	2	3	4	5	6
I felt comfortable accepting the options for care that my doctor or midwife recommended	1	2	3	4	5	6
I felt pushed into accepting the options my doctor or midwife suggested	6	5	4	3	2	1
I chose the care options that I received	1	2	3	4	5	6
My personal preferences were respected	1	2	3	4	5	6
My cultural preferences were respected	1	2	3	4	5	6
	SECTION A TOTAL SCORE:					

B: During my pregnancy I felt that I was treated poorly by my doctor or midwife because of: (select or circle one answer for each statement)

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
My race, ethnicity, cultural background or language*	6	5	4	3	2	1
My sexual orientation and / or gender identity*	6	5	4	3	2	1
My type of health insurance or lack of insurance*	6	5	4	3	2	1
A difference of opinion with my caregivers about the right care for myself or my baby*	6	5	4	3	2	1
ADD ALL SCORES IN SECTION B:	SECTION B TOTAL SCORE:					

C: During my pregnancy I held back from asking questions or discussing my concerns because: (select or circle one answer for each statement)

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
My doctor or midwife seemed rushed*	6	5	4	3	2	1
I wanted maternity care that differed from what my doctor or midwife recommended*	6	5	4	3	2	1
I thought my doctor or midwife might think I was being difficult*	6	5	4	3	2	1
ADD ALL SCORES IN SECTION C:	SECTION C TOTAL SCORE:					

Cultural Safety and Family Engagement

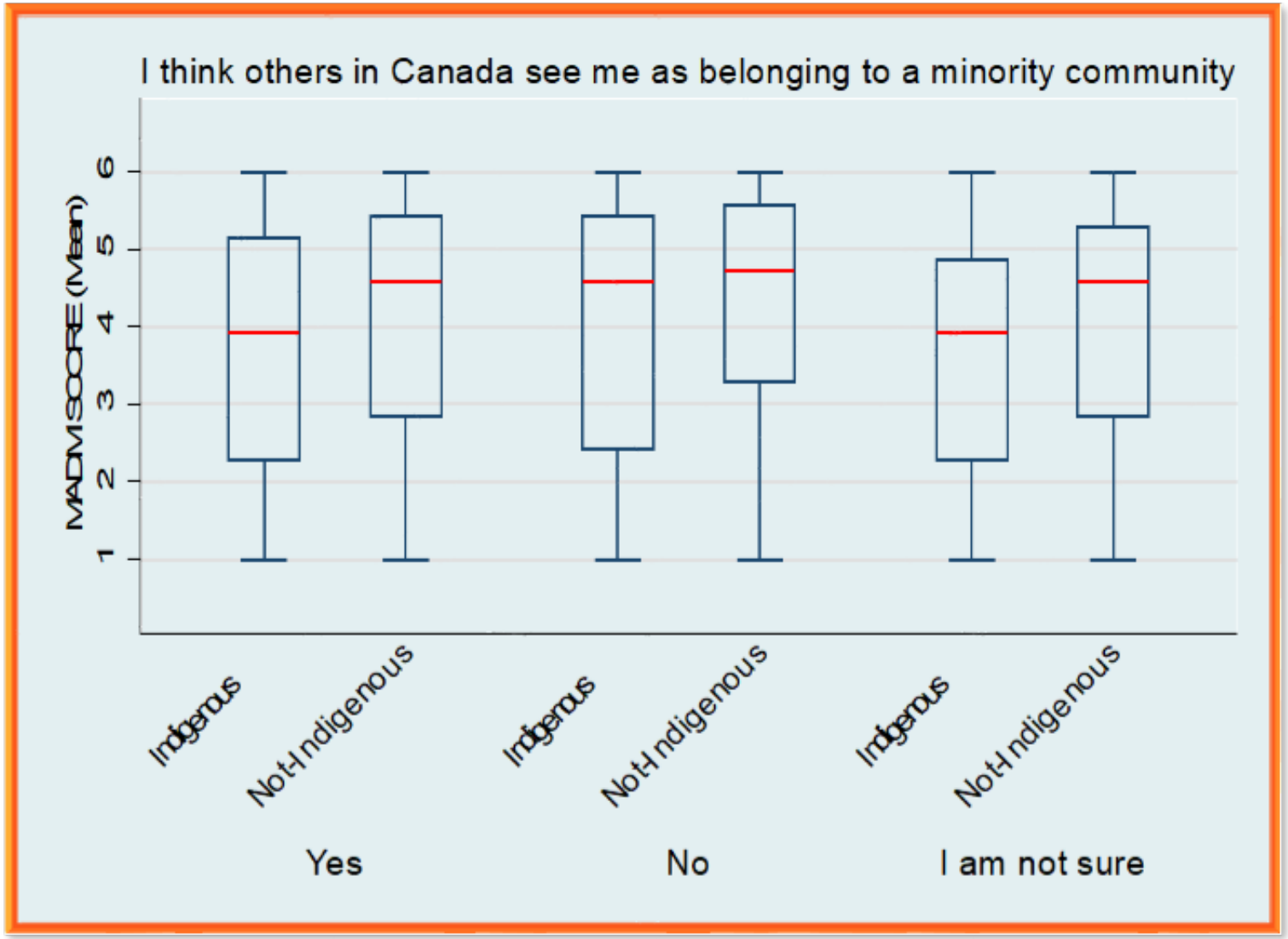
The health care team supported my cultural or family traditions

I was allowed to practice cultural rituals in the facility

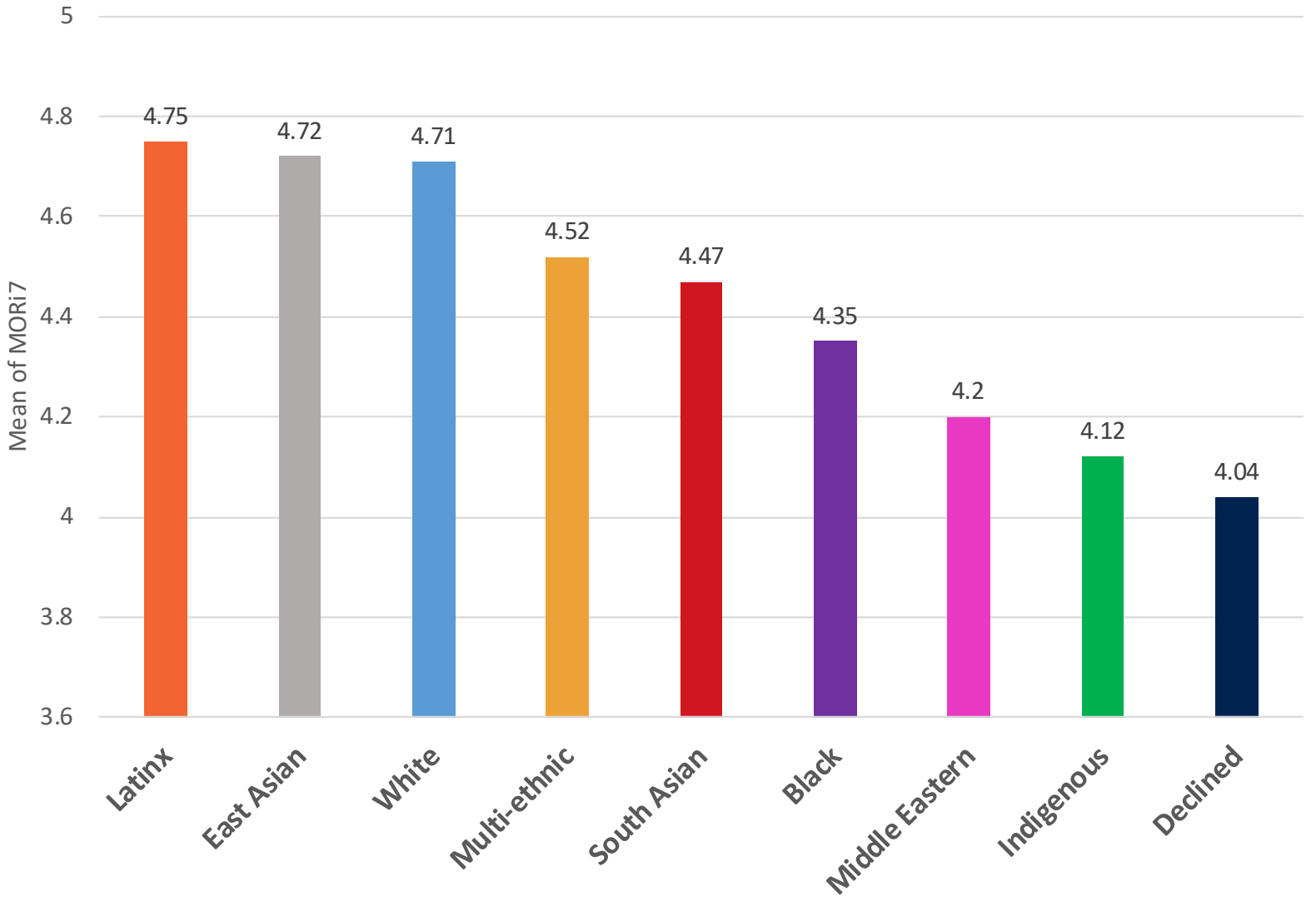
I was able to have exactly the people I wanted with me during labor and birth.

Finding a midwife or doctor who shared my heritage, race, ethnic or cultural background was important to me

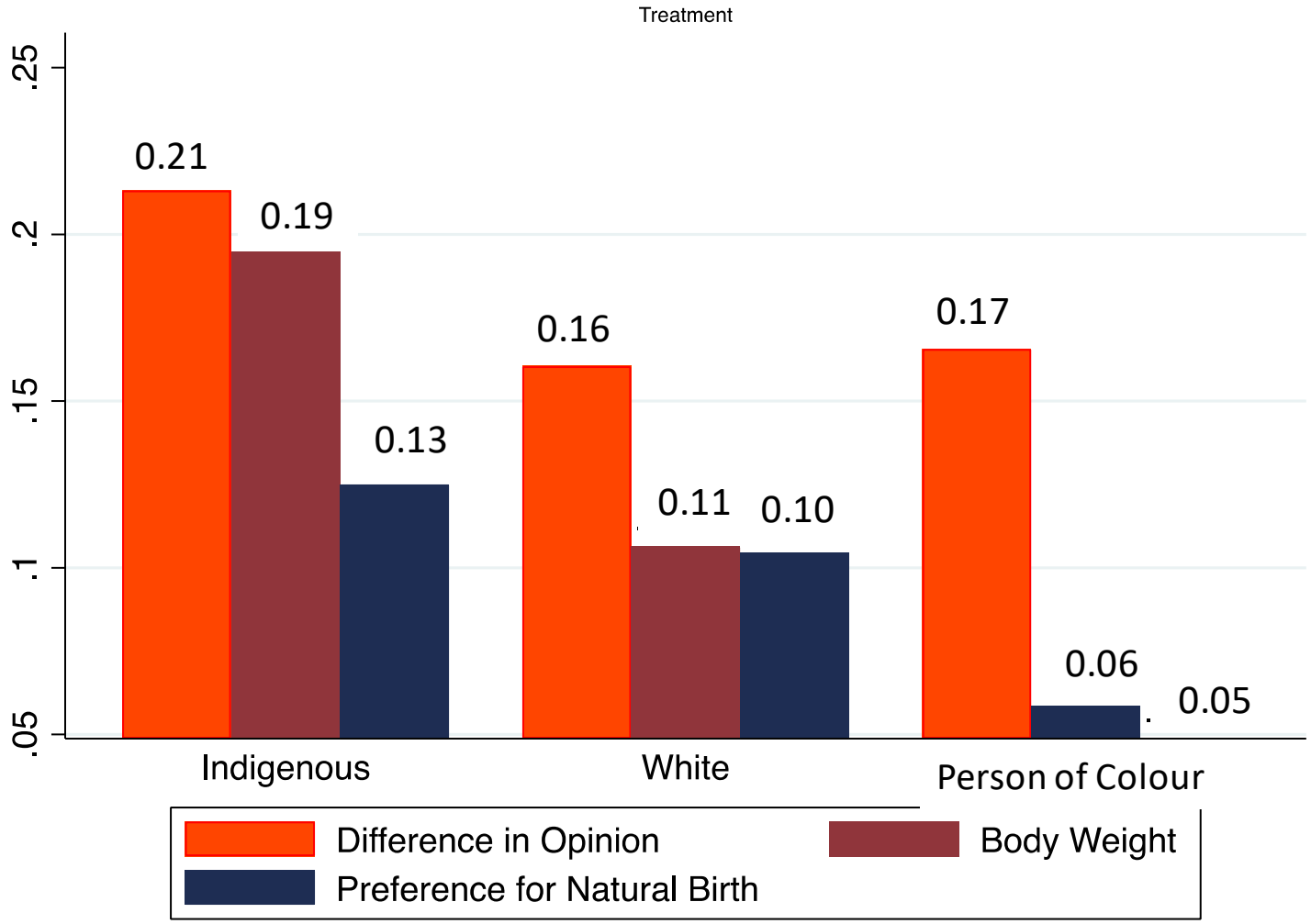
Autonomy by Indigeneity



Respect by Race/Ethnicity



Treated Poorly - IBPOC



Measuring Mistreatment

My private or **personal information was shared** without my consent (Y/N)
My **physical privacy was violated**, for example being uncovered or having people in the delivery room without my consent (Y/N)
A healthcare provider **shouted at or scolded me** (Y/N)
Healthcare providers **withheld treatment or forced me to accept treatment** that I did not want (Y/N)
Healthcare providers **ignored me, refused to help, or failed to respond** to requests for help in a reasonable amount of time. (Y/N)
I experienced **physical abuse** (aggressive physical contact, inappropriate sexual conduct, episiotomy without anesthesia) (Y/N)
Healthcare providers **threatened me** in other ways (Y/N)

Decolonizing Birth Research - Objectives

1. To determine and develop culturally safe ways to measure the lived experiences of and factors associated with respect, disrespect, racism, implicit bias, and mistreatment during health care in Indigenous communities.

2.To co-develop a roadmap for Indigenous communities to lead maternity care research that promotes autonomy and cultural safety, and decolonizes birth research

FIRST NATIONS HEALTH AND SOCIAL SECRETARIAT OF MANITOBA

Addressing Power & Building Trust

- **Steering Council of Indigenous Peoples**
  - **Service users with Lived Experience**
  - Knowledge Keepers and Elders
  - Community Engagement Coordinator from the Nation
  - Indigenous Researchers from nursing, sociology, anthropology
  - National Indigenous Council of Midwives (NICM) as key partner
- **Design, Analysis and Interpretation co-Led by Indigenous researchers and local knowledge keepers**
- Integrated, continuous KT – with ongoing and iterative community consultations

Applying OCAP™ principles

- Ownership and Control starts with Funding models
  - Redesign of funding streams and transfer of funds
  - BC Support Unit grant to 3 Co-PIs – two Indigenous researchers and one settler immigrant with an academic position
  - Existing mechanisms: Fiscal agent at UBC to disburse funds
  - Decolonized process: Ownership resides with the Indigenous leads

Relationships and Community-led research

- Identify Communities where Indigenous Leads have pre-existing and long-standing trusting relationships
- Firelight and Dr. Phillips-Beck identify Community Leads – Engagement Coordinator
- Recruit and Indigenous Research Fellow to support (capacity building)
- Firelight staff drafted research guides with culturally safe options for data collection and training guides.
- Communities decide their own preferred methodologies

FIRST NATIONS HEALTH AND SOCIAL SECRETARIAT OF MANITOBA

The role of the CPAR (settler) researcher

- BPL Support staff and trainee activities:
  - Using templates from the Indigenous researchers adapt Community Agreements and Consent Forms
  - Draft Community Lead role descriptions
  - Draft Ethics applications
  - Gather Elder and Council approvals
  - Provide training materials
  - Record community meetings, conduct literature reviews as directed
  - Track Community Engagement
  - Document the process

Decolonizing and respectful process included: (Based on Phillips-Beck, 2020 Decolonizing research elements

- Engage community early – these include determining community readiness and negotiating agreements
- Seeking appropriate approvals by communities
- Respecting community specific protocols and practices
- Work with community to create job descriptions and roles and descriptions
- Assess training needs and develop orientation and training
- Co-creation of data collection methods and tools (sharing circles, workshops, etc.
- Ongoing communication, regular check-in meetings and supervision/direction when needed
- This included determining the best way to continue communicate and give back to community

Decolonizing Birth Research
Indigenous researchers, clinicians, and communities
measuring respect during childbearing

Declaration of Informed Consent and Permission to Use Information

I (name) _____on this day (complete date) _____, give permission for the researchers from the Firelight Group or the Birth Place Lab at UBC and to interview me for the *Decolonizing Birth Research Project*.

I understand that the Firelight Group and the Birth Place Lab at UBC are hosting this study and that the goal for this study is to improve the childbearing experiences of Indigenous people who live in remote or rural areas, young parents, and those who experience multiple life challenges (such as incarceration, relocation, substance use, housing instability and/or poverty). Funded by the BC Support Unit for People and Patient-Oriented Research, this project (SPOR-PCM) will use wise practices to develop a ways to measure experiences of respect, disrespect, racism and/or mistreatment among Indigenous families during pregnancy and childbirth.

The team will also work with my community to co-develop a roadmap for Indigenous communities to lead or

ROAD MAP – Principles of Respectful Maternity Care Research

1. Community Knows What They Need
2. Prepare the Researcher
3. Plan for Long-Term Relationships with Community
4. Invest in Indigenous Researchers
5. Cultural Centering for research
6. Honor and Foster Resilience/autonomy in community
7. Inclusive Data Translation.

Each of these domains require specific action/considerations

Community Knows What They Need

- Community dictates what research is needed
- Includes the voices of ALL community members
- Elder/knowledge Keeper involvement

Prepare the Researcher

- Understand the historical, sociocultural, political, and economic context of the community
  - Responsibility of researchers to their participants

Plan for Long-term Relationships with Community

- research is a relationship not a project
- Be in community with the people

Invest in Indigenous Researchers

- long-term, fair, and prompt financial renumeration
- fosters social justice and health equity
- provides cultural safety
- fosters relationships, reciprocity, and respect

Cultural Centering

- Includes; language, land, spirituality, cultural practices etc.
- Respects spirituality
- Views Indigenous methodologies and pedagogy as equal or higher value to scientific data
- Elder/ Knowledge keeper involvement

Honor and Foster Resilience

- Strength based research
- ensures informed consent
- decolonizes researcher
- Balances power

Inclusive Data Translation

- OCAP Principles
- Beyond OCAP - Indigenous leads involved in all aspects of data disemmination including written paper
- acknowledgement of Indigenous leads contributions to the project and KT in paper
- Community dictates how data is used

Next steps:

- Improving the health of Indigenous, Black, Latinx, immigrant, unhoused, disable, and other marginalized childbearing communities is still ongoing and a future endeavor for the Birthplace lab and research community.
- The patient care measures indexes we have introduced have proven useful in these populations in the RESPECCT study, but Nation-based indicators are also needed.
- Collaboration with organizations such as the First Nation Health and Social Secretariat and Indigenous Scholars are central to this work.

Structural and systems-level disruption

"..Such a powerful shift would promote reproductive rights aligned with Human Rights standards such as right to culture, right to health, right to security, and right to justice. Strengthening Indigenous women's capabilities through respect, equity, and empowerment requires the democratization, production and intergenerational transfer of reproductive health knowledge at local levels, within Indigenous communities, translated through Indigenous languages and worldviews, situated within the kinship and cultural bodies of the individual and her clan/First Nation."

Elder Katsi Cook
Mohawk Nation
Founder, Konon:kwe Council