



Centering Lived Experience & Expertise:
Health equity and measurement

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ALIGNMNH

OPEN FORUM

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How do we enhance quality in research?



To have **credible, usable data**, we need to:

1. Ask the right questions
2. Ask the questions the right way
3. Ask the right people
4. Ask enough people



Person-Centered Research

- ❖ *Changing Childbirth in BC (N 3400)*
- ❖ *Giving Voice to Mothers -US (N 2700)*
- ❖ *The RESPCCT Study*
- ❖ *Decolonizing Birth Research*
- ❖ *Birth Includes Us (Queer and Trans people)*
- ❖ *RMC Measurement Registry*



Addressing Power & Building Trust

- **Steering Council of service users – DECISION MAKERS**
- **Multi-stakeholder research team**
 - All Provinces & International Experts
 - Service Users & NGOs that serve underrepresented populations
 - Clinicians and Professional Associations
 - Researchers from Indigenous health, public health, midwifery, obstetrics, family medicine, nursing, sociology, anthropology, mental health,
- **Design, Analysis and Interpretation Led by those with lived experience**
(eg IBPOC+;LGBTQ2S+; disabilities, etc)
- Integrated, continuous knowledge translation



Community Based Participatory Research:

Co-Creation of measures and metrics

- Literature Review based on service users priorities
 - Select, adapt or design new questions
- Community members rate questions for
relevance, clarity, and importance
- Ongoing community consultations
 - SC reviews all drafts, recruitment, and messaging
 - Beta and Pilot Testing by those with lived experience



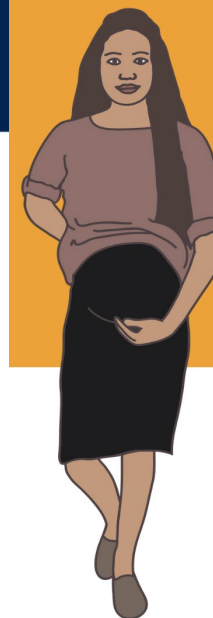
Your birth
experience
deserves to
be counted.

www.respcct.ca



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Person-centered measures of quality care

A decorative horizontal bar is positioned below the title. It features a gradient from dark blue on the left to a reddish-brown in the center, and back to dark blue on the right.

Mothers Autonomy in Decision-Making (MADM) Scale

(Scores 7-42, Cronbachs Alpha .96)

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

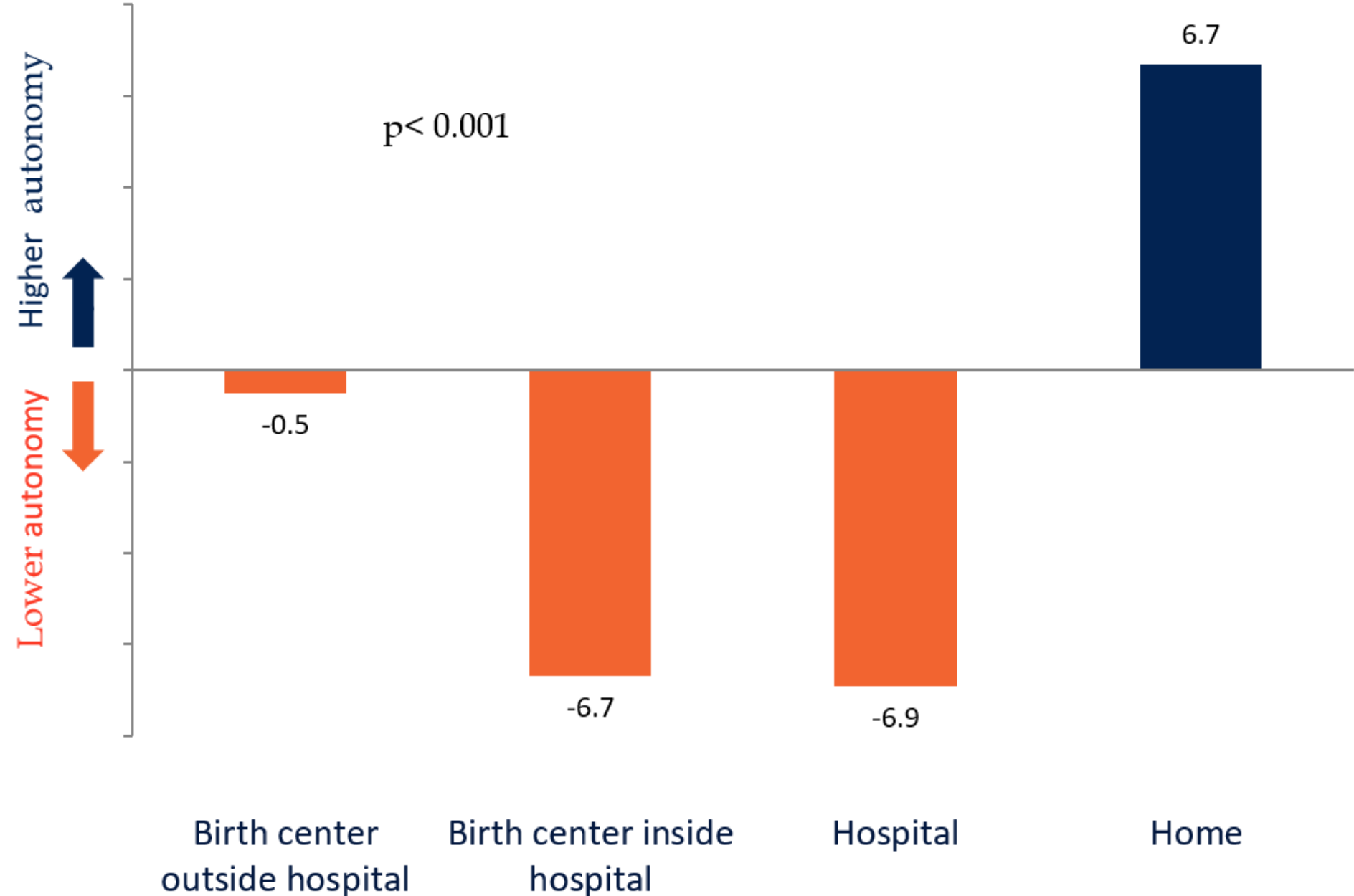
My doctor or midwife helped me understand all the information

I was given enough time to thoroughly consider the different care options

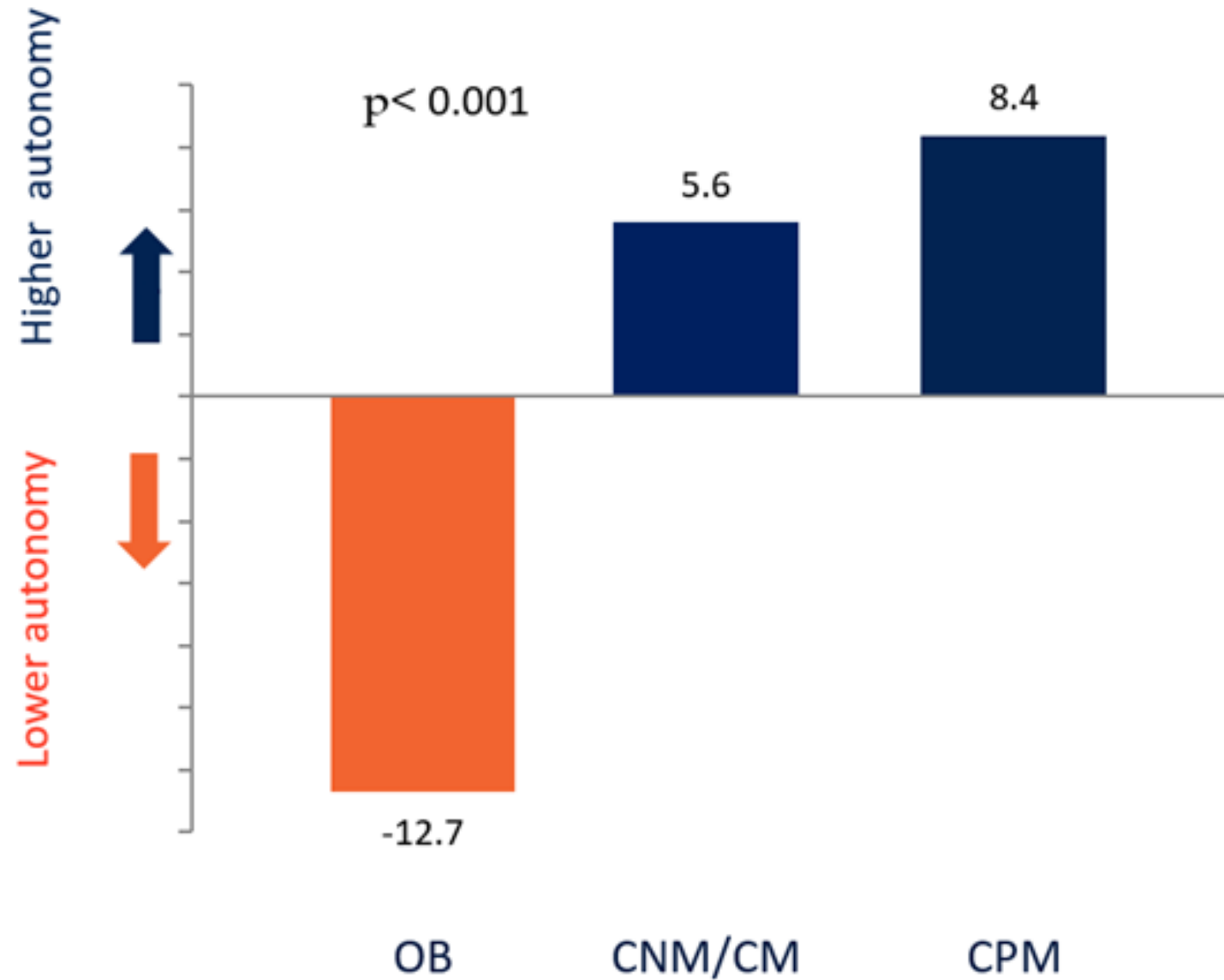
I was able to choose what I considered to be the best care options

My doctor or midwife respected my choices

Autonomy (MADM) scores by place of birth



MADM scores: Autonomy by prenatal provider



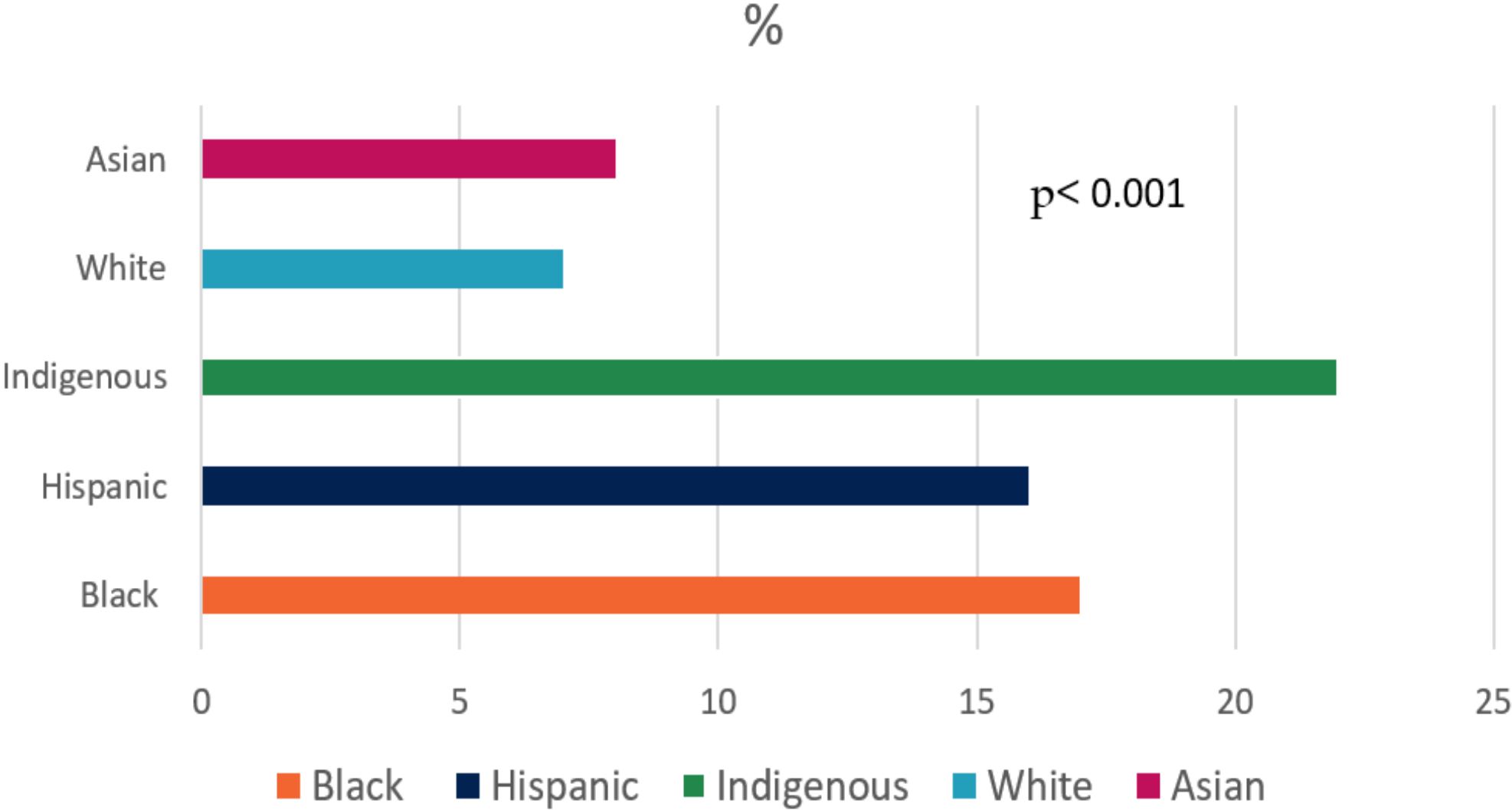
The Mothers On Respect (MOR) index

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



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:					

Mothers on Respect – Lowest MORi Scores 1-10th percentile



Measuring Mistreatment



Your private or **personal information was shared** without your consent (Y/N)

Your **physical privacy was violated**, for example being uncovered or having people in the delivery room without your consent (Y/N)

A healthcare provider **shouted at or scolded you** (Y/N)

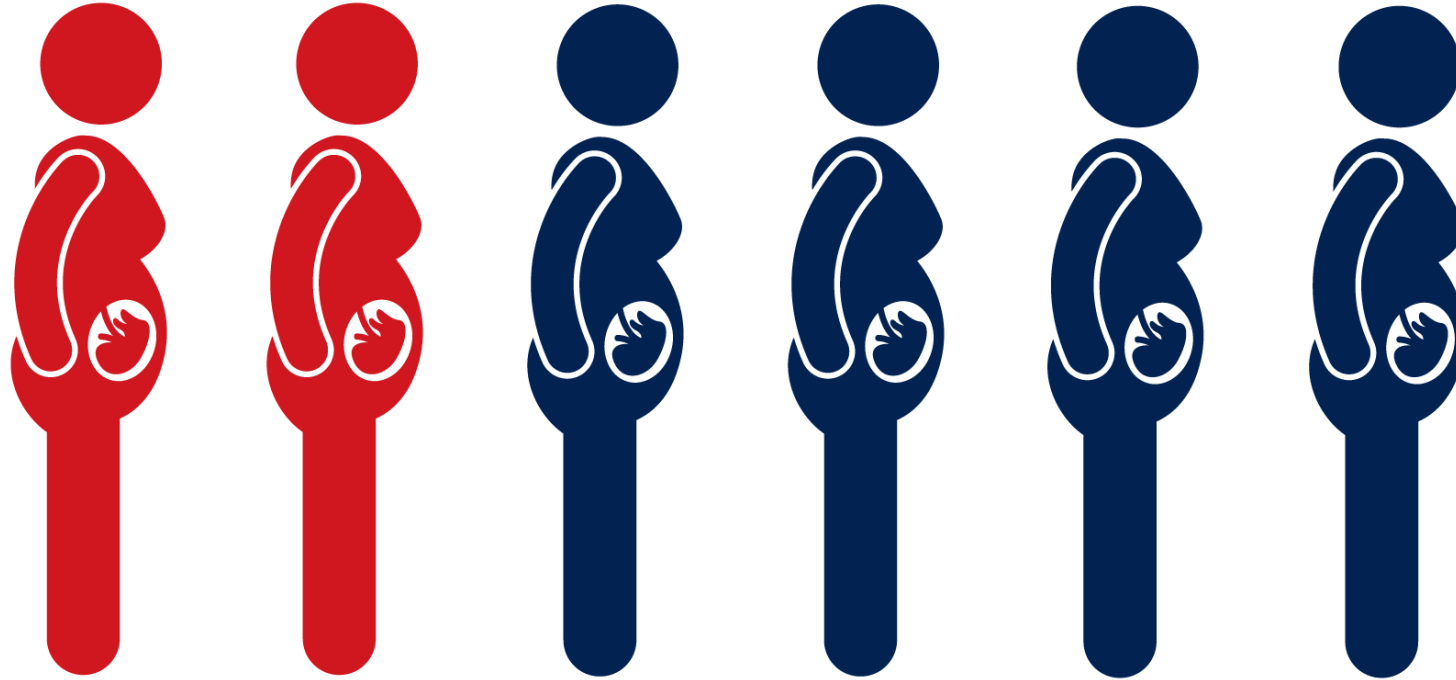
Healthcare providers **withheld treatment or forced you to accept treatment** that you did not want (Y/N)

Healthcare providers **ignored you, refused to help, or failed to respond** to requests for help in a reasonable amount of time. (Y/N)

You experienced **physical abuse** (aggressive physical contact, inappropriate sexual conduct, episiotomy without anesthesia) (Y/N)

Healthcare providers **threatened you** in any other way (Y/N)

Mistreatment by population



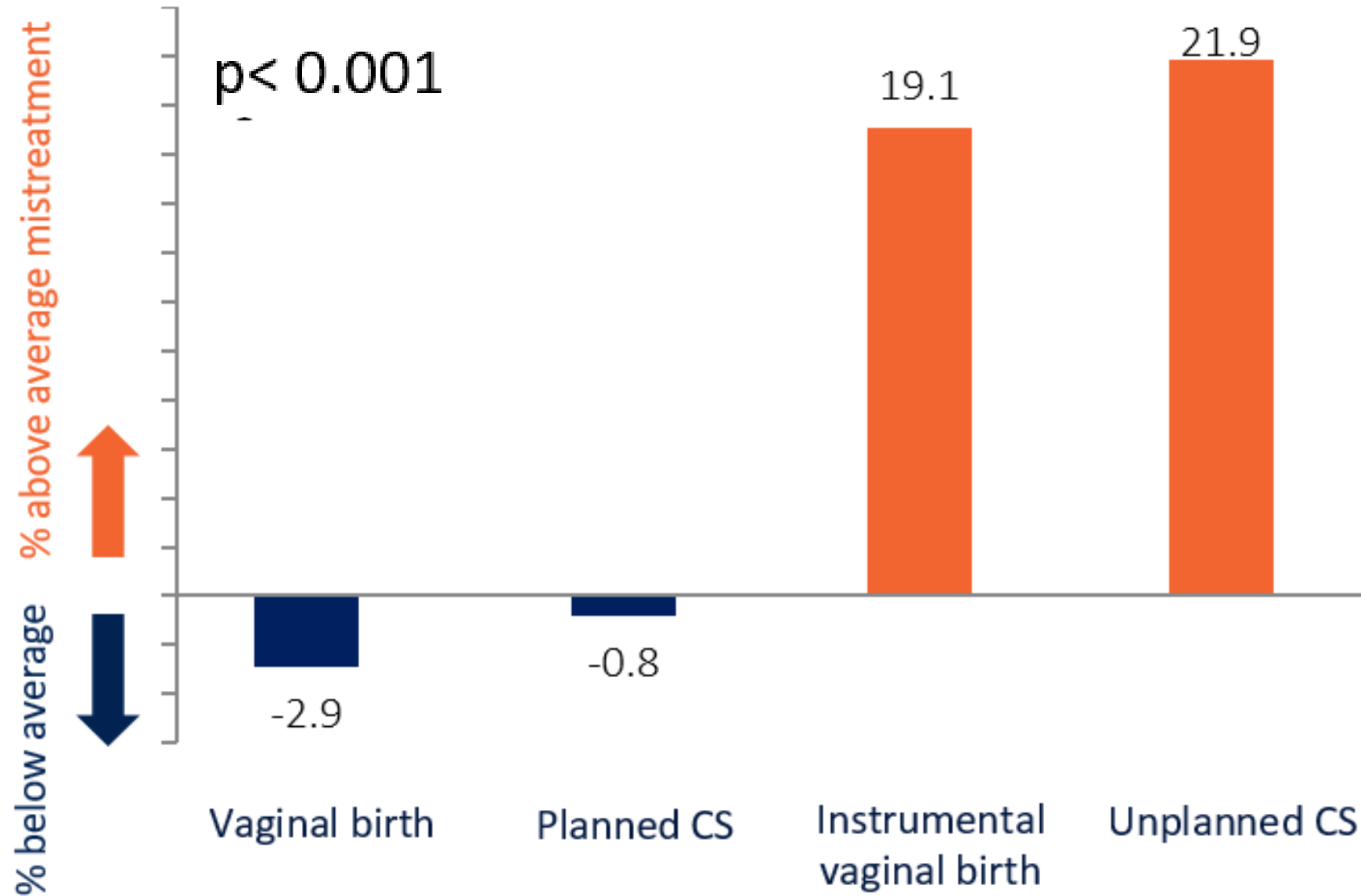
1 in 3 in LMICs, and BIPOC communities
Lancet 2019, Reproductive Health 2019

1 in 6 experienced mistreatment in full sample

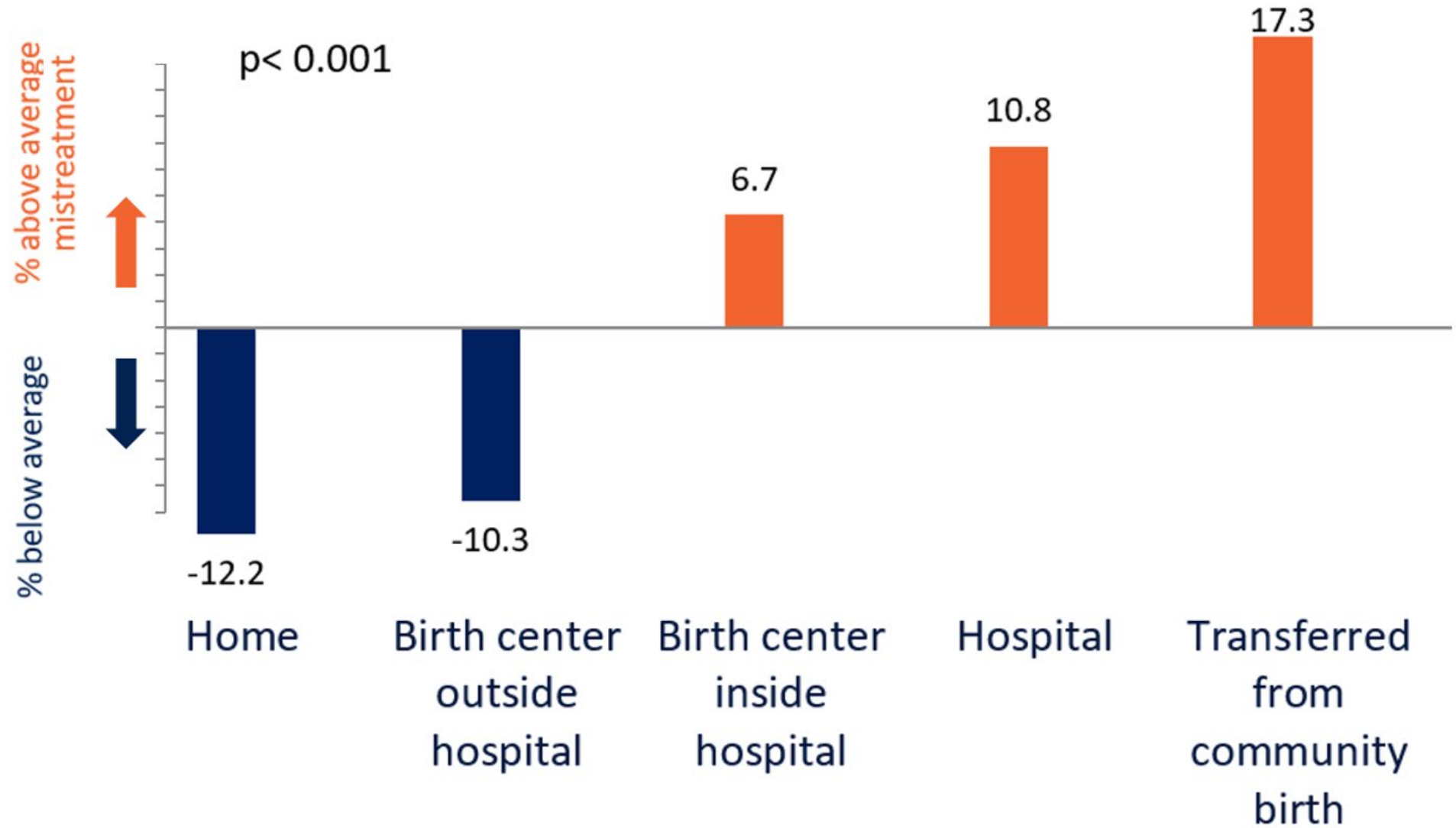
At any time during your recent labor or birth did you
DECLINE care
offered to you or your baby?

- 1128/2108 (53.5 %) responded **yes** : 51.5 % of colour , 54.4 % White
- White women more likely to report that their care provider accepted their decision to decline care.
- **Women of colour 2x more likely :**
 - ➡ care providers **performed the procedure against their will.**
 - ➡ providers **kept asking them** until they agreed, or
 - ➡ midwife, doctor or a family member asked to convince them.

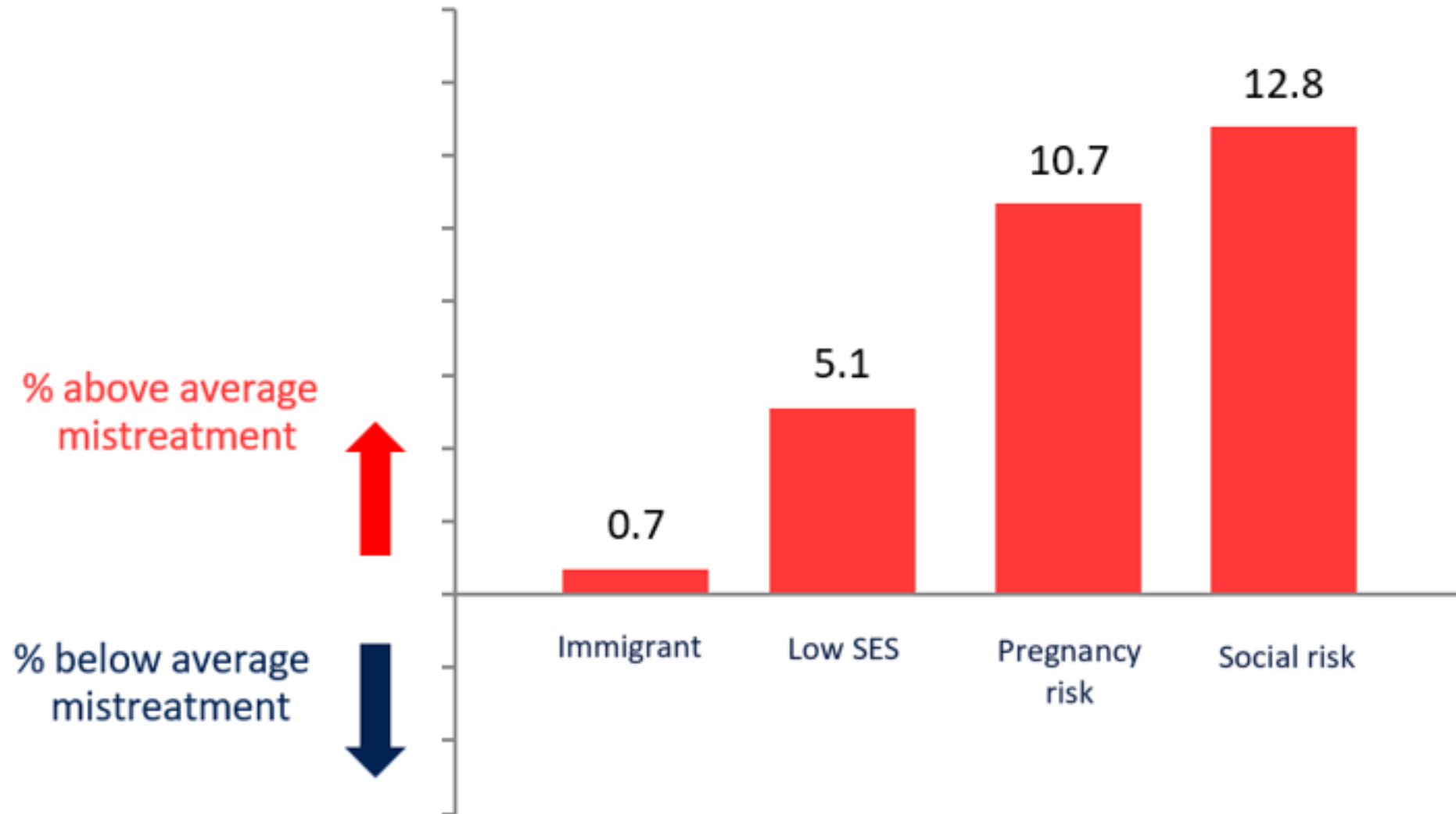
Rate of mistreatment by mode of birth



Rate of mistreatment by place of birth



What is linked to mistreatment?



Engaging Community in Transformative Research



THE

RESPCOT

STUDY

RESEARCH EXAMINING THE STORIES OF PREGNANCY AND CHILDBEARING IN CANADA TODAY



What are the best Indicators of Respectful Maternity Care in high and middle resource countries?

- ❖ Global scan for validated items
 - ❖ Person-centred, and patient-designed items prioritized
- ❖ **Delphi Process**: transdisciplinary, heterogeneous panel
- ❖ Formal Quantitative Rating: **importance, relevance, clarity**
- ❖ **210 Final Items**: consensus & sorted by domains
- ❖ Ease of applicability to regional context

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Respectful Maternity Care Measurement Registry

Click on a domain below to see the available items.

[Autonomy](#)[Responsiveness of Healthcare Providers](#)[Choice of Evidence-Based Care Options](#)[Cultural Safety and Family Engagement](#)[Health System Conditions and Constraints \(Human Resources\)](#)[Health System Conditions and Constraints \(Physical\)](#)[Information and Consent](#)[MORi](#)[Non-Verbal Communication](#)[Patient Reactions to Experiences of Care](#)[Physical Exams and Procedures](#)[Physical Mistreatment](#)[Privacy and Confidentiality](#)[Stigma and Discrimination](#)[Supportive Behaviours of Healthcare providers](#)[Verbal Communication](#)[Verbal Mistreatment](#)

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

Verbal Mistreatment

Did you feel the doctors, nurses, or other health providers shouted at you, scolded, insulted, threatened, or talked to you rudely?

The health worker or other staff threatened that if you did not comply, you or your baby would have poor outcome

Healthcare provider(s) threatened to give treatment I did not want*

The health worker or other staff threatened to withhold care from you or your baby

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The health worker or other staff threatened that if you did not comply, you or your baby would have poor outcome

Source for Original Item

Bohren, M. A., Vogel, J. P., Fawole, B., Maya, E. T., Maung, T. M., Baldé, M. D., ... Tunçalp, Ö. (2018). Methodological development of tools to measure how women are treated during facility-based childbirth in four countries: labor observation and community survey. *BMC Medical Research Methodology*, 18(1). <https://doi.org/10.1186/s12874-018-0603-x>

Item as Adapted for RESPCCT Study

Health care providers told me that my baby/babies would have a poor outcome if I did not follow their advice.

Stigma and Discrimination

Intersectional Discrimination Index (Scheim & Bauer, 9 items) -Alpha = 0.90 (n= 2834)

These questions are about experiences related to **who you are**. This includes both how you describe yourself and how others might describe you. For example, your skin color, ancestry, nationality, religion, gender, sexuality, age, weight, disability or mental health issue, and income.

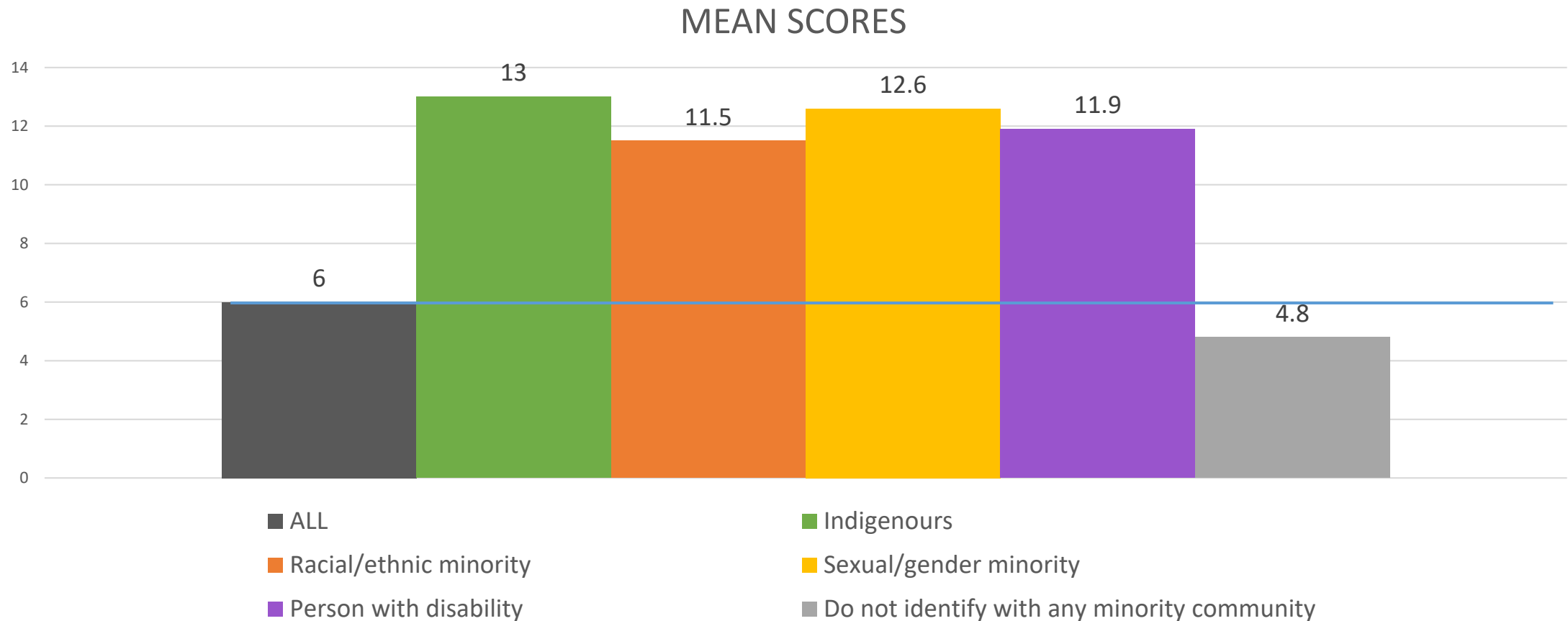
Because of who you are, have you...

	Never	Yes, but not in the past year	Yes, once or twice in the past year	Yes, many times in the past year
1. Heard, saw, or read others joking or laughing about you (or people like you)				
2. Been treated as if you are unfriendly, unhelpful, or rude				
3. Been called names or heard/saw your identity used as an insult				
4. Been treated as if others are afraid of you				
5. Been stared or pointed at in public				
6. Been told that you should think, act, or look more like others				
7. Heard that you or people like you don't belong				
8. Asked inappropriate, offensive, or overly personal questions				
9. Been treated as if you are less smart or capable than others				

Fig. 2. Intersectional day-to-day discrimination Index (InDI-D)—final version.

Intersectional Discrimination Index

(range 0-27; higher scores indicate more discrimination)



Co-Creation of anti-oppression health systems

Reducing bias and increasing validity of research findings:

- Working with communities so that the **right information**, reaches the **right people**, in the **right way**.
- **Cognitive congruence**: Prioritize indicators designed by service users and that measure characteristics they deem important and relevant
- Strive to ensure that the stories entrusted to us are able to **catalyze tangible, pragmatic solutions**.

Person-centered outcomes research on high quality care
for all childbearing families.



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.

Salutogenic Approach to Birth Research

What makes people healthy?

- Measure **undisturbed birth rates** alongside **caesarean rates**
- Measure **upright spontaneous births** alongside **vacuum and forceps assisted** deliveries
- Measure **midwife** and **doula attended births** alongside **epidural rates**
- Measure **respect** and **disrespect** alongside models of care
- Measure the impact of **place of birth** on optimal outcomes
- Measure **racism** and **anti-racism** in health care

Tracking mistreatment, abuse, and violence during COVID-19



Elephant circle is a birth justice organization inspired by elephants who give birth within a circle of support. Without such a circle people experience mistreatment. A pandemic exacerbates failures in wrap-around support.

You are

- ☐ A nurse
- ☐ A doula
- ☐ A doctor
- ☐ A midwife
- ☐ A birthing person
- ☐ Other

Did you witness or experience the mistreatment directly?

- ☐ Yes
 - ☐ No
-

<https://www.elephantcircle.net/report-violations>

Do you identify as Black or Indigenous?

- ☐ Yes
- ☐ No
- ☐ I identify as a person of color, but not Black or Indigenous



What did the mistreatment include? (Check all that apply)

- ☐ Physical abuse
- ☐ Verbal abuse
- ☐ Sexual Abuse
- ☐ Stigma and discrimination
- ☐ Failure to meet professional standards of care
- ☐ Poor rapport, ineffective communication, lack of respect, lack of privacy
- ☐ Health system conditions and constraints

Describe what happened in as much detail as you would like:

Your answer _____

When did this occur?

Date

yyyy-mm-dd _____

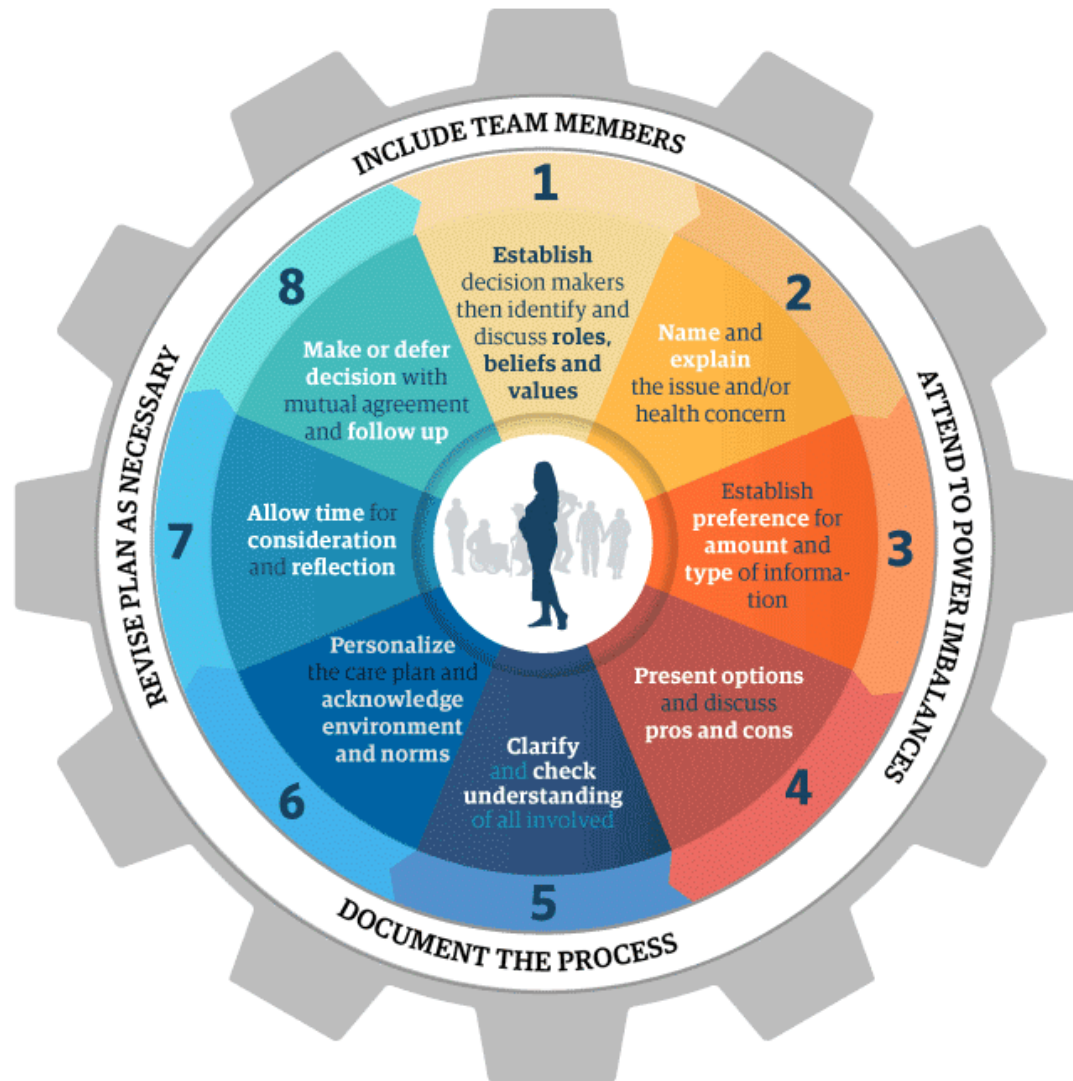
Where did this occur? (Please include country, state, postal code, and facility name if applicable)

Your answer _____

Your answer _____

<https://www.elephantcircle.net/report-violations>

Person-Centred Decision Making



Clarify who will be included and what their roles will be in the decision making process. Ask about their beliefs and values.

Clearly identify and explain the problem that is the main focus for the decision.

Assess the person's preferred approach to receiving information to assist decision making including depth of information, health literacy.

Discuss the literature, clinical guidelines, and research surrounding the topics, or know where to find this information.

Check in with the person to ensure comprehension and ensure that any questions are responded to.

Facilitate interpretation of options, benefits, and risks within their context and values. Discuss the environment and the feasibility of their preferred option.

Check in to identify personal needs for time to reflect or consider options. Allow for consultation with family or others, reviewing of resources, and additional queries that arise.

Make a clear decision or defer the decision explicitly. A follow up plan should be set regardless of whether decision was made or deferred.

INCLUDE TEAM MEMBERS	ATTEND TO POWER IMBALANCES	DOCUMENT THE PROCESS	REVISE PLAN AS NECESSARY
Take an inter-professional approach by including every member of the team.	Verbally create a safe environment and invite contribution from everyone. Avoid making assumptions.	Document the information exchange each and every time one of the eight elements are addressed.	Be open to revising the plan when conditions or patient preferences evolve or change.

WHAT YOU CAN DO DURING A VIOLATION



**Delay and try to
buy time.**



**Document what is
happening.**



**Restate your needs
and wishes aloud.**



**Make eye contact or
hold someone's hand.**



**Get more
information.**



**Focus on what you
have the power to do.**

BIRTH RIGHTS

A resource for every day people to defend
human rights during labor and birth

▶▶ bit.ly/BIRTHRIGHTSRESOURCE



National Advocates
for Pregnant Women



BIRTH RIGHTS BAR ASSOCIATION

HOW TO SAY: “WHAT HAPPENED TO ME WAS NOT OKAY”



Talk about what happened.



Write your narrative.



Give direct feedback.



File a formal complaint.



Work the system, be creative.



Contact a State representative.



Contact the media.



Take direct action.



File a lawsuit.

BIRTH RIGHTS

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▶▶ bit.ly/BIRTHRIGHTSRESOURCE



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BIRTH RIGHTS BAR ASSOCIATION



Welcome to the Quality Perinatal Services Hub (QPS HUB)

Where safe, respectful and unconditional loving care uplifts the experience of pregnancy and child birth.



INTRODUCTION TO QUALITY PERINATAL SERVICES (QPS) HUB

This map was created as an open-sourced repository of information – templates, protocols, guidelines - for rapid reorganization and allocation of workforce and establishment of auxiliary perinatal units, where necessary, to safely triage care, limit further viral contamination and protect the human rights and dignity of the birthing experience during the global crisis.

HOW TO USE THE QPS HUB



In partnership with



Introduction

Glossary

by Subject

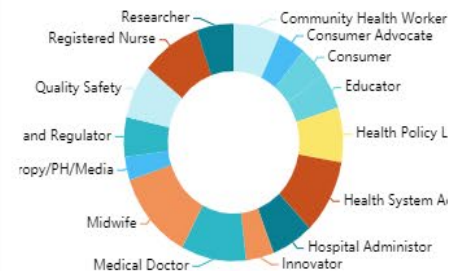
by Stakeholders

Available Resources

Accountability and Rights

COVID-19 Community Response

Resources by Stakeholder



Filter by Subjects

by Stakeholder

- Strategic Policy
- Communications
- Operations
- Clinical Workforce
- Community Services
- Legal/Rights
- Training
- Research

Filtered
363

Know your rights, report abuse !

Know your rights in your country

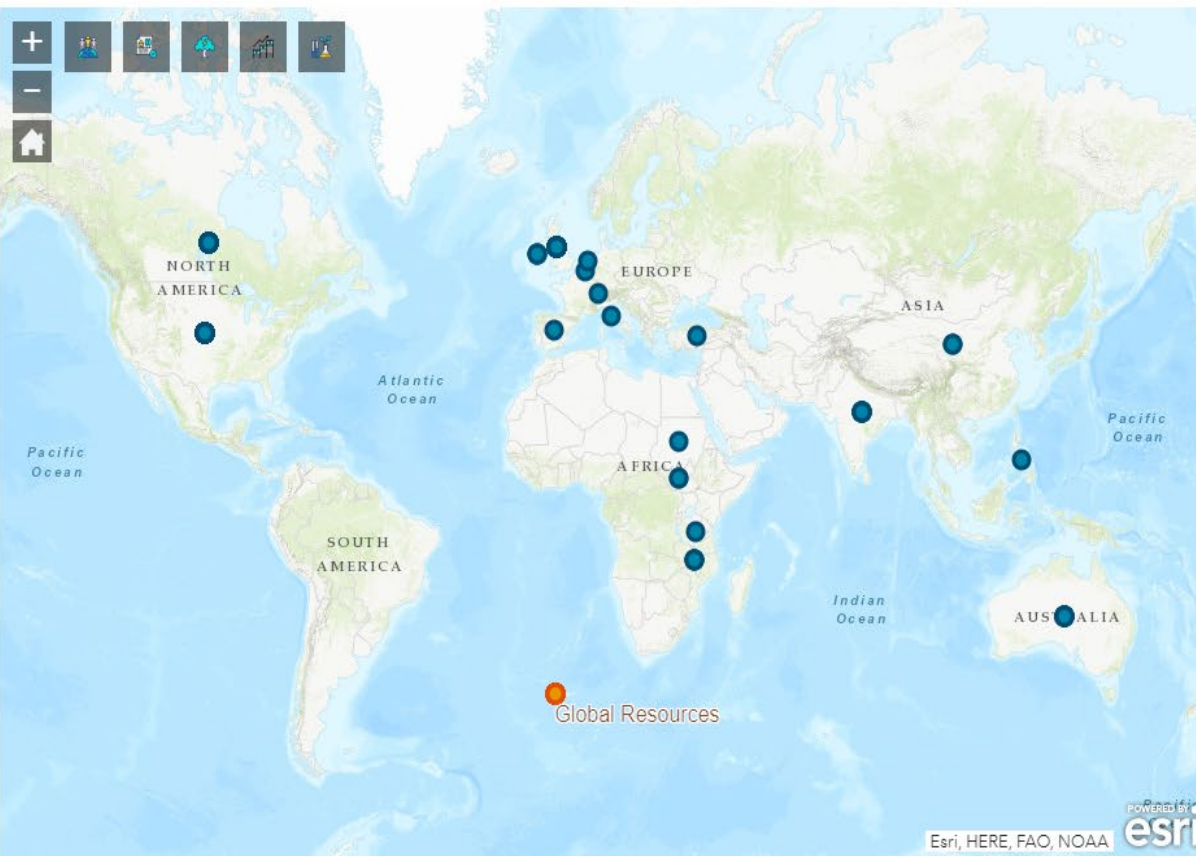
Is your practice up to UN Standard?

Report Abuse

Care in the Communities

Set Up a Rapid Response Birth Unit

Midwifery Care



ADD A RESOURCE

Source (Web Page)

Upload a file (max 10 MB)

Contact information

SHARE YOUR TH...

How user-friendly is the QPS HUB?

What type of user are you?

Share your thoughts with us

(i.e. additional resource or feature you would like on

Arts-Based Knowledge
Translation:
What Do they Want?

**What
Happened
To Me**

**Using Our Stories
to Improve Birth
in BC**

**A play inspired by
conversations with families
about pregnancy and childbirth
in British Columbia**

The Changing Childbirth in BC Study invites you to a performance inspired by the thousands of stories families shared about their experiences of pregnancy and birth. Afterwards, join us for a Talk Back session! Bring your ideas on how to improve health care for parents and babies in BC.

Saturday, February 29
Vancouver, BC

&

Saturday, March 14
Burnaby, BC

For FREE tickets:



www.birthplacelab.org/ccinbc



MIDWIVES ASSOCIATION
of BRITISH COLUMBIA



UBC THEATRE & FILM

