Centering Lived Experience & Expertise:
Health equity and measurement

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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
GOAL: PERSON-CENTRED CARE

1. 2017-19: create a team
2. 2017-19: seek funding
3. 2017-19: co-create survey
4. 2019-20: recruit participants
5. 2019-20: explore findings
6. 2021-23: identify key messages
7. 2021-23: create tools for sharing
8. 2021-23: tell the story

community
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
Person-centered measures of quality care
Mothers Autonomy in Decision-Making (MADM) Scale
(Scores 7-42, Cronbachs Alpha .96)

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

Vedam et al., PLOS 2017
Autonomy (MADM) scores by place of birth

- Birth center outside hospital: -6.7
- Birth center inside hospital: -6.9
- Hospital: -0.5
- Home: 6.7

p<0.001
MADM scores: Autonomy by prenatal provider

- OB: -12.7
- CNM/CM: 5.6
- CPM: 8.4

p < 0.001
## The Mothers On Respect (MOR) index

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

<table>
<thead>
<tr>
<th>Section A: Overall while making decisions about my pregnancy or birth care: (select or circle one answer for each statement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>I felt comfortable asking questions</td>
</tr>
<tr>
<td>I felt comfortable declining care that was offered</td>
</tr>
<tr>
<td>I felt comfortable accepting the options for care that my doctor or midwife recommended</td>
</tr>
<tr>
<td>I felt pushed into accepting the options my doctor or midwife suggested</td>
</tr>
<tr>
<td>I chose the care options that I received</td>
</tr>
<tr>
<td>My personal preferences were respected</td>
</tr>
<tr>
<td>My cultural preferences were respected</td>
</tr>
</tbody>
</table>

### SECTION A TOTAL SCORE: 

<table>
<thead>
<tr>
<th>Section 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)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>My race, ethnicity, cultural background or language*</td>
</tr>
<tr>
<td>My sexual orientation and / or gender identity*</td>
</tr>
<tr>
<td>My type of health insurance or lack of insurance*</td>
</tr>
<tr>
<td>A difference of opinion with my caregivers about the right care for myself or my baby*</td>
</tr>
</tbody>
</table>

### ADD ALL SCORES IN SECTION B: 

<table>
<thead>
<tr>
<th>Section B TOTAL SCORE:</th>
</tr>
</thead>
<tbody>
<tr>
<td>SECTION C TOTAL SCORE:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section C: During my pregnancy I held back from asking questions or discussing my concerns because: (select or circle one answer for each statement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>My doctor or midwife seemed rushed*</td>
</tr>
<tr>
<td>I wanted maternity care that differed from what my doctor or midwife recommended*</td>
</tr>
<tr>
<td>I thought my doctor or midwife might think I was being difficult*</td>
</tr>
</tbody>
</table>

### ADD ALL SCORES IN SECTION C: 

18
Mothers on Respect – Lowest MORi Scores
1-10\textsuperscript{th} percentile

\[
p< 0.001
\]
## Measuring Mistreatment

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your private or <strong>personal information was shared</strong> without your consent (Y/N)</td>
<td></td>
</tr>
<tr>
<td>Your <strong>physical privacy was violated</strong>, for example being uncovered or having people in the delivery room without your consent (Y/N)</td>
<td></td>
</tr>
<tr>
<td>A healthcare provider <strong>shouted at or scolded you</strong> (Y/N)</td>
<td></td>
</tr>
<tr>
<td>Healthcare providers <strong>withheld treatment or forced you to accept treatment</strong> that you did not want (Y/N)</td>
<td></td>
</tr>
<tr>
<td>Healthcare providers <strong>ignored you, refused to help, or failed to respond</strong> to requests for help in a reasonable amount of time. (Y/N)</td>
<td></td>
</tr>
<tr>
<td>You experienced <strong>physical abuse</strong> (aggressive physical contact, inappropriate sexual conduct, episiotomy without anesthesia) (Y/N)</td>
<td></td>
</tr>
<tr>
<td>Healthcare providers <strong>threatened you</strong> in any other way (Y/N)</td>
<td></td>
</tr>
</tbody>
</table>
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

% above average mistreatment

Vaginal birth: -2.9
Planned CS: -0.8
Instrumental vaginal birth: 19.1
Unplanned CS: 21.9

p < 0.001
Rate of mistreatment by place of birth

p < 0.001

-12.2  -10.3  6.7  10.8  17.3

Home  Birth center outside hospital  Birth center inside hospital  Hospital  Transferred from community birth

% above average mistreatment

% below average
What is linked to mistreatment?
Engaging Community in Transformative Research
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
Respectful Maternity Care Measurement Registry

Click on a domain below to see the available items.

<table>
<thead>
<tr>
<th>Autonomy</th>
<th>Responsiveness of Healthcare Providers</th>
<th>Choice of Evidence-Based Care Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural Safety and Family Engagement</td>
<td>Health System Conditions and Constraints (Human Resources)</td>
<td></td>
</tr>
<tr>
<td>Health System Conditions and Constraints (Physical)</td>
<td>Information and Consent</td>
<td>MORi</td>
</tr>
<tr>
<td>Non-Verbal Communication</td>
<td>Patient Reactions to Experiences of Care</td>
<td>Physical Exams and Procedures</td>
</tr>
<tr>
<td>Physical Mistreatment</td>
<td>Privacy and Confidentiality</td>
<td>Stigma and Discrimination</td>
</tr>
<tr>
<td>Supportive Behaviours of Healthcare providers</td>
<td>Verbal Communication</td>
<td>Verbal Mistreatment</td>
</tr>
</tbody>
</table>
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
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

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...

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

**Fig. 2.** Intersectional day-to-day discrimination Index (InDI-D)—final version.
Intersectional Discrimination Index
(range 0-27; higher scores indicate more discrimination)

MEAN SCORES

- ALL: 13
- Indigenours: 11.5
- Racial/ethnic minority: 12.6
- Sexual/gender minority: 11.9
- Person with disability: 4.8
- Do not identify with any minority community: 6
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 deeply 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.

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
Person-Centred Decision Making

1. Establish decision makers then identify and discuss roles, beliefs and values.
2. Name and explain the issue and/or health concern.
3. Establish preference for amount and type of information.
4. Present options and discuss pros and cons.
5. Clarify understanding of all involved.
6. Personalize the care plan and acknowledge environment and norms.
7. Allow time for consideration and reflection.
8. Make or defer decision with mutual agreement and follow up.

INCLUDE TEAM MEMBERS

ATTEND TO POWER IMBALANCES

DOCUMENT THE PROCESS

REVISE PLAN AS NECESSARY

- 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 topic, or know where to find this information.
- Check in with the person to ensure comprehension and ensure that any questions are answered.
- 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.
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
<table>
<thead>
<tr>
<th>Action</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk about what happened.</td>
<td>Write your narrative.</td>
</tr>
<tr>
<td>File a formal complaint.</td>
<td>Work the system, be creative.</td>
</tr>
<tr>
<td>Contact the media.</td>
<td>Take direct action.</td>
</tr>
<tr>
<td>Give direct feedback.</td>
<td>Contact a State representative.</td>
</tr>
<tr>
<td></td>
<td>File a lawsuit.</td>
</tr>
</tbody>
</table>

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


[BRBA](http://www.brba.org)
[National Advocates for Pregnant Women](http://www.napw.org)
What Do they Want?

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

Arts-Based Knowledge Translation: What Do they Want?