



Patient-Centered Measurement:  
Innovation Challenge Series

*Learning Collaborative 2018 Webinar*

*Thursday, February 8, 2018*

WELCOME

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David Andrews, Patient Advisor

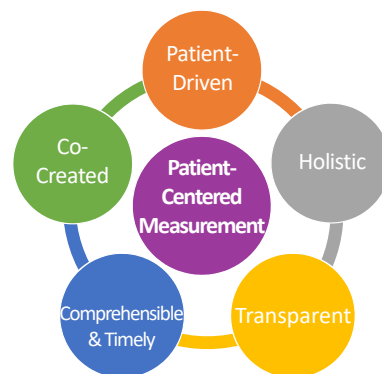
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## 2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

### Overview

- Share [Principles for Making Health Care Measurement Patient-Centered](#)
- Identify novel solutions through 2017 Innovation Challenge



Graphic courtesy of [American Institutes for Research](#).

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## 2017 Innovation Challenge

### *Winning Submissions*

- **Katharina Kovacs Burns, MSc, MHSA, PhD, Alberta Health Services**  
Explores a strategy to engage patient and family advisors in gathering and analyzing patient experience data in real-time
  
- **Saraswathi Vedam, RM, FACNM, SciD, MSFHR Health Professional Investigator, Birth Place Lab, University of British Columbia**  
Describes the development and validation of patient-designed measures of autonomy and respect, as well as patient-reported items that capture mistreatment in maternity care

## Today's Presenters

- Katharina Kovacs Burns, MSc, MHSA, PhD, [Alberta Health Services](#)
  
- Saraswathi Vedam, RM, FACNM, SciD, MSFHR Health Professional Investigator, [Birth Place Lab, University of British Columbia](#)



# Patient & Family Engagement in Measuring Patient Experience

A Unique Strategy for Real-time Data Collection to Guide Quality  
Improvement

Presenter: Katharina Kovacs Burns, MSc, MHSA, PhD  
Alberta Health Services & School of Public Health, University of Alberta

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## Acknowledgements

- Patient/Family Advisors & particularly Marian George
- Lynette Lutes ( Senior Program Officer, Quality & Healthcare Improvement)
- Clinical Quality Metric Staff – Tara Walsh (Executive Director), David Casey (Director), Maarit Cristall (Lead Analyst)
- Engagement and Patient Experience Staff – Deanna Picklyk (Director), Jennifer Rees (Lead Consultant EPE & Patient Family Advisory Group), & Collaborators/Advisors for project - Sarah Singh, Jessica Lamb Spence and Zone EPE Consultants (Sheila Smith, Chris Mayhew, Kait Cooper, Jason Gibson)
- Units at specific Hospital sites – patients & their families, staff and clinicians.

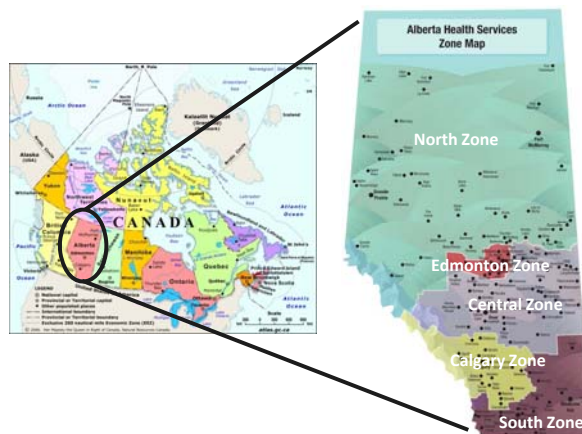
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## Overview

- Setting Context
- Our Patient-centred measurement challenge
- Our approach to addressing challenge
- Engagement of patients & families/caregivers
- Addressing Patient-driven priorities
- Challenges & surprises
- Lessons learned & applied
- Where we go from here....

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## Context - Alberta Health Services, Alberta, Canada



- ✓ Canada's 1<sup>st</sup> and largest province-wide, fully integrated health system.
- ✓ Delivers health services to >4.2 million people
- ✓ 110,000 Staff + 8,000 Medical Staff
- ✓ 14,000 volunteers including patients/families
- ✓ Programs & services offered at >650 facilities across Alberta

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## Patient-Centred Measurement Challenge

Units/Sites not having the capacity (i.e. human resources, time, finances or other supports) for gathering, analyzing and using 'real-time' patient\* experience data.

\* Patient = patients/clients/residents and their families or informal caregivers

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## How Challenge Affects Patients/Families/Caregivers

- Do not have 'real time' patient experience data including concerns/complaints collected on units/sites
- Gap in understanding what can or needs to change quickly with patient care on units/sites to improve patient/family experiences.
- Delays in staff/clinicians addressing common or specific patient experience concerns on unit
- If only HCAHPS or big data exists, staff/clinicians may not know
  - *about their data*
  - *have the time to search through this big data*
  - *which specific areas of care or practice are ranked by patients as needing improvements or changes*

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## Patient-Centred Measurement Challenge for Staff/Clinicians

Lots of Big Data/Data Sources:



>90% of staff say:

"I didn't know we had this data ..."

"I don't have time to dig through all of the data to find what I need for my unit!"



Most staff don't interpret or use big data .... e.g. for quality improvement.

Staff say "We need 'real-time' patient experience data ...."

but...  
"None of us on the units/sites have time to collect patient/family experience data in 'real-time'?"



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## Our Approach to Addressing Challenge

**Ideal but rare & unrealistic:**

have a dedicated staff person at each site to visit patients/families on units and gather their experiences regularly, analyze and report to colleagues for planning improvement strategies



**Proposed, promising strategy:**

Train and utilize volunteer Patient or Family Advisors to:

- Gather experiences directly and in 'real time' from patients and families/caregivers (e.g. health care provided & interactions with health care providers on hospital units)
- Assist in analysis of data & findings Pre-Post quality/practice improvement intervention

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## Proposed Work

- 10 month Pilot study – urban & rural mix of sites/units
- 4 objectives:
  - 1) develop a strategy with Patient/Family Advisors or Volunteers partnering with AHS site/unit staff to gather 'real-time' in-hospital patient/family experiences;
  - 2) determine overall experiences of Advisors/Volunteers during the pilot, including (a) effectiveness of their training, & (b) their specific work with site/unit staff pilots;
  - 3) determine site/unit staff perspectives & experiences with overall process, & having Advisors co-partner on pilots including suggested quality improvement interventions; and
  - 4) Using pilot results, conduct a feasibility assessment regarding expansion of the proposed strategy/approach across sites/units within AHS.

urban vs. rural areas



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## Previous or Current Patient Experience to Learn From

### Patient/Family Advisors

- Councils, Committees & initiatives related to patient experience

### Central Alberta, Canada

- Patient Experience Advisors engaged former patients/families in Patient Rounding with staff

### Unit specific example - Patient/Family volunteer

- worked with CQM and unit staff to design/select patient experience questions for online survey
- used iPad to gather & enter experiences from patients/families
- Involved in populating dashboard/poster for unit staff

### Sprint pilot

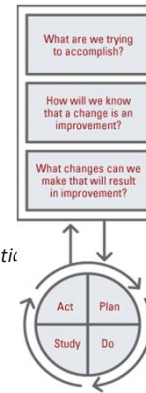
- utilizing an APP with Imogene survey to have patients on two acute care units rate their care experiences; dashboard for units to analyze their own data.

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## Pilot Project Specific Steps/Methods

- Pilot recruitment (i.e. rural & urban units/sites & patient advisors)
- Orientation/Training
- Co-design Action Plan (Pre-post improvement intervention patient experience measurement), outcomes, deliverables & timeline
- Implementation steps:
  - *Co-design of patient experience data collection measures/tool*
  - *iPad with Select Survey tool online*
  - *Data collection by Advisor/Volunteer (Real-time, pre-improvement intervention)*
- Real-time data analysis – use of dashboard/poster presentation
- Staff huddle discussion of results
- Co-design of improvement strategy
- Follow-up patient experience data (Post-improvement intervention)
- Determine overall experiences of Advisors/Volunteers & Staff/Clinicians



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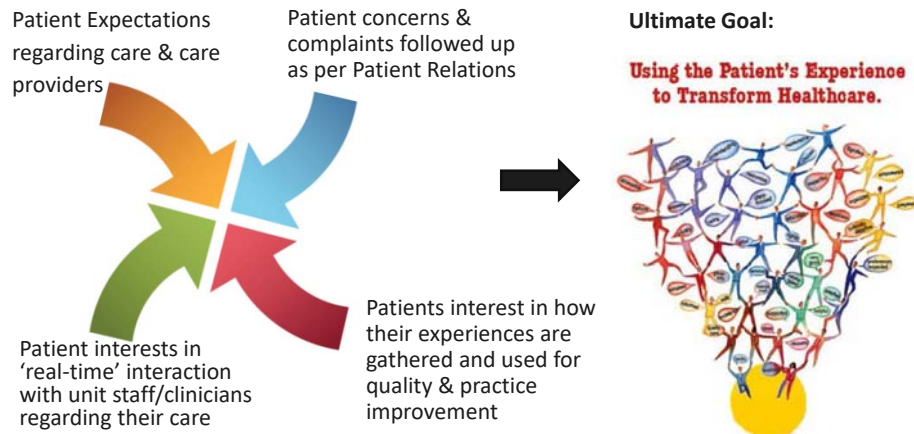
## Engagement of patients & families/caregivers in Proposed Pilot

- Patients/Families partner with staff/clinicians with goal to:
- evaluate & improve healthcare delivery & patient experiences/outcomes
- Co-design/develop project & patient experience tools
- Gather, analyze and interpret real-time experience data
- Identify real-time improvement strategies
- Follow-up on 'what difference' improvement strategies had on experiences

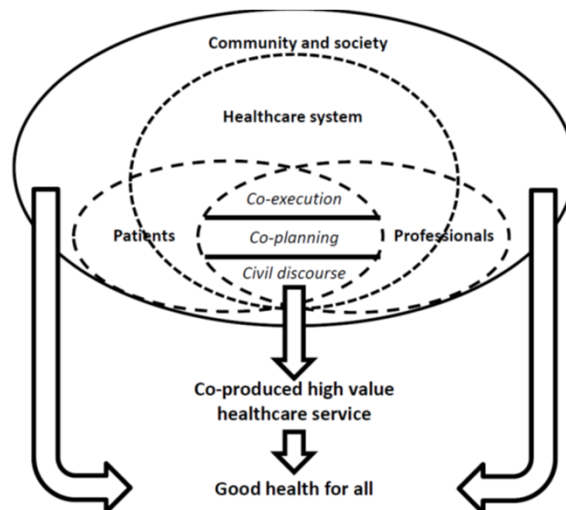


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## What Patient-Driven Patient Experience Priorities will be addressed:



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Kaplan & Batalden, The New World of Co-producing Health & Healthcare, WIHI. 2016.

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## Challenges & surprises

### Challenges: Unknowns

- Advisors/Volunteers ongoing interest
- Staff/Clinician perceptions/experiences
- Feasibility & Sustainability



Aim BIG



Test small

(Cynosure Health, 2012)








### Surprises

- The huge initial interest by Patient/Family Advisors and Volunteers
- Unit Staff identifying this need & opportunity for real-time 'fast' data



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## Lessons learned & applied

- 
 Patient experience measurement is of interest to not only patients/families but also staff/clinicians, and organizational leaders.
- 
 Gathering 'real-time' patient experience data requires innovative approaches
- 
 Patient/Family Advisors or Volunteers are 'keen' to play a role
- 
 Patient/Family Advisors or Volunteers as co-designers of initiatives does not automatically feel 'normal' or 'comfortable' for everyone involved
- 
 Be prepared to spend time for orientation, training and discussion
- 
 Be prepared to make adjustments along the way.....
- 
 Gathering of experiences of Patient/Family Advisors or Volunteers is equally as important as gathering patient and family experiences

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## *Whose Agenda and Whose Destiny?*

*Enhancing Quality, Validity, and Reliability via*  
**PERSON-Centered research**

*NQF Webinar, Vedam et al., 2018*

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## Goals & Objectives

- To examine patient-oriented outcomes in maternity care
  - *To explore the benefits (and challenges) of community-based participatory research*
  - *To describe the development of 2 new measures of respectful maternity care*
  - *To report results of application of these scales across diverse populations*

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## Our transdisciplinary teams

*Kathrin Stoll, PhD*

*Nicholas Rubashkin, MD, PhD Cand.*

*Ruth Martin, MD*

*Kelsey Martin, SMIII*

*Ganga Jolicouer, ED, MABC*

*Mo Korchinski*

*Raquel Velasquez*

*CCinBC Steering Committee*

### ***Childbearing Families in BC and US***

*Shafia Monroe, Paula Rojas, Jacqueline Left Hand Bull, Jennie Joseph, Claudia Booker,  
Marinah Farrell, Zsakeba Henderson, Nan Strauss, Melissa Cheyney, Eugene DeClercq*

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***There are no conflict of interests from any of  
the authors to disclose***

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## Person-Centered Outcomes Research

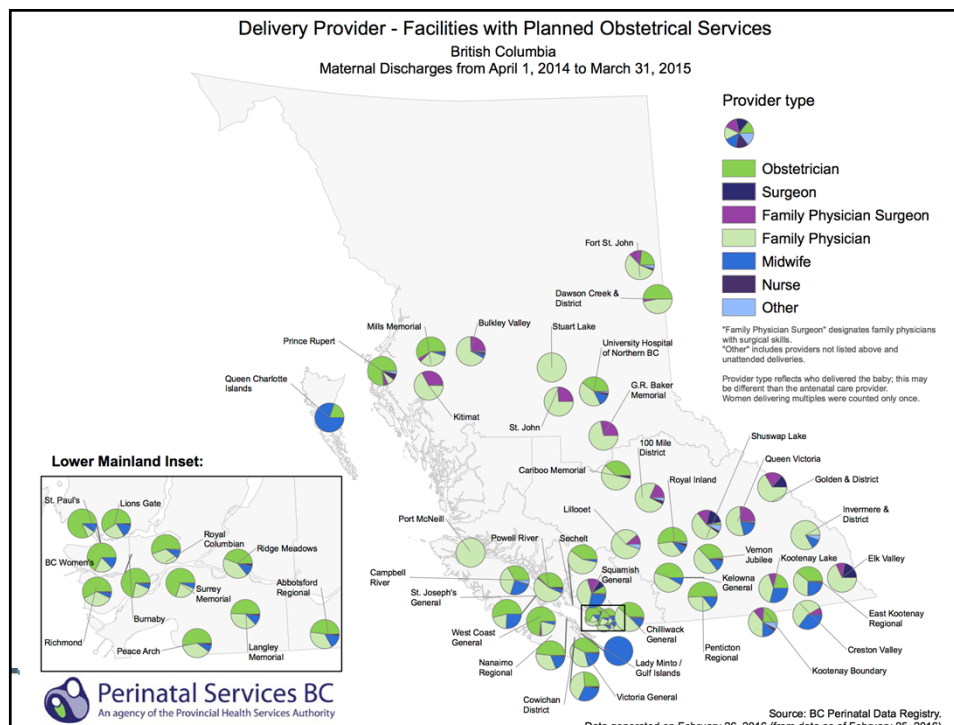
### *The Participatory Process*

Stakeholders engaged in:

- Formulating research **questions**;
- Defining essential characteristics of study **participants**,
- Identifying and **selecting outcomes** that the population of interest notices and cares about (e.g., survival, function, symptoms, quality of life).
- Choosing **methods of data collection**, leading recruitment, monitoring study conduct and progress;
- Partners in **analysis, interpretation**, key messages
- Designing/suggesting plans for **dissemination** and implementation activities
- Ongoing training, education, **capacity building**

*PCORI Institute/CBPR*

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## Changing Childbirth In BC

- Community-based participatory design
  - *Consultation with 1333 women to identify issues*
- Community Partners included:
  - BC Women's Foundation
  - Women in 2 Healing
  - Midwives Association of BC
  - Immigrant Services Society
  - UBC Family Medicine & Midwifery
  - School of Population and Public Health
  - Women's Health Research Institute
  - Strathcona Midwifery Collective
  - Access Midwifery
  - Pomegranate

*Vancouver Foundation*

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## The Community

**Steering group** of women of childbearing age from different cultural and socio-economic backgrounds



**Four working groups:**

- Current/potential maternity clients
- Women who have been incarcerated
- Immigrant and refugee women
- Woman who have experienced homelessness, poverty and/or other barriers

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## Study Topics

- Access to care
- Preferences for care
- Experiences with maternity care
  - *Decision-making*
- Knowledge of midwifery

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## Mixed Methods

- Online quantitative survey (130 items)
  - *Developed and content validated by the community*
  - *Informed by the literature*
- Print survey in group settings as needed (8-10 women)
- Focus groups (20) and key interviews
  - *Honoraria childcare & meals provided (vulnerable)*
  - *Consent forms in lay language*
  - *Regional Facilitators training and support*

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## Listening to Mothers

### Listening to Mothers<sup>III</sup> Pregnancy and Birth



Report of the Third National U.S. Survey of Women's Childbearing Experiences



Eugene R. Declercq  
Carol Sakala  
Mouwun P. Conry  
Sandra Applebaum  
Ariel Herlich  
May 2013

### Listening to Mothers<sup>III</sup> New Mothers Speak Out



Report of National Surveys of Women's Childbearing Experiences  
Conducted October - December 2012 and January - April 2013



Eugene R. Declercq  
Carol Sakala  
Mouwun P. Conry  
Sandra Applebaum  
Ariel Herlich  
June 2013

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## Shared Decision Making vs. Women-Led Decision Making?

### Assessment

#### The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample

Levente Kriston<sup>a</sup>, Isabelle Scholl<sup>a</sup>, Lars Hölzel<sup>b</sup>, Daniela Simon<sup>b</sup>, Andreas Loh<sup>c</sup>, Martin Härter<sup>a,b,\*</sup>

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#### ABSTRACT

**Objective:** To develop and psychometrically test a brief patient-report instrument for measuring Shared Decision Making (SDM) in clinical encounters.

**Methods:** We revised an existing instrument (Shared Decision Making Questionnaire; SDM-Q), including the generation of new items and changing the response format. A 9-item version (SDM-Q-9) was developed and tested in a German primary care sample of 2351 patients via face validity ratings, investigation of acceptance, as well as factor and reliability analysis. Findings were cross-validated in a randomly selected subsample.

**Results:** The SDM-Q-9 showed face validity and high acceptance. Factor analysis revealed a clearly one-dimensional nature of the underlying construct. Both item difficulties and discrimination indices proved to be appropriate. Internal consistency yielded a Cronbach's  $\alpha$  of 0.938 in the test sample.

**Conclusion:** The SDM-Q-9 is a reliable and well accepted instrument. Generalizability of the findings is limited by the elderly sample living in rural areas of Germany. While the current results are promising, further testing of criterion validity and administration in other populations is necessary.

**Practice implications:** The SDM-Q-9 can be used in studies investigating the effectiveness of interventions aimed at the implementation of SDM and as a quality indicator in health services assessments.

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**The 9-item Shared Decision Making Questionnaire (SDM-Q-9)**

*[Example]* Please indicate which health complaint/problem/illness the consultation was about:

*[Example]* Please indicate which decision was made:

Nine statements related to the decision-making in your consultation are listed below. For each statement please indicate how much you agree or disagree.

1. My doctor made clear that a decision needs to be made.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
2. My doctor wanted to know exactly how I want to be involved in making the decision.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
3. My doctor told me that there are different options for treating my medical condition.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
4. My doctor precisely explained the advantages and disadvantages of the treatment options.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
5. My doctor helped me understand all the information.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
6. My doctor asked me which treatment option I prefer.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
7. My doctor and I thoroughly weighed the different treatment options.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
8. My doctor and I selected a treatment option together.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
9. My doctor and I reached an agreement on how to proceed.	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree

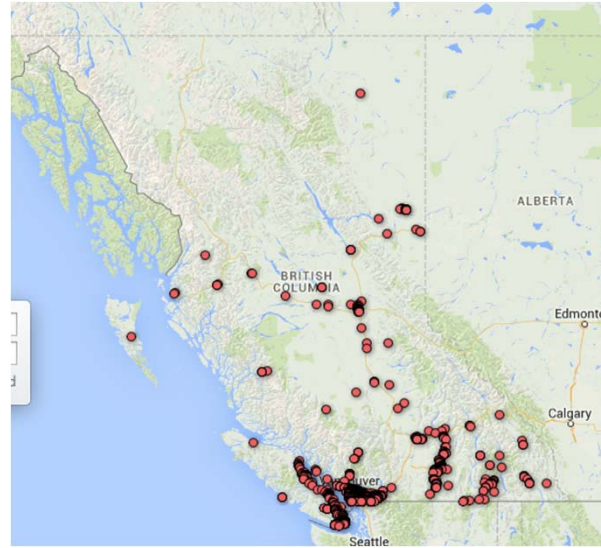
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## Patient-Led Decision Making

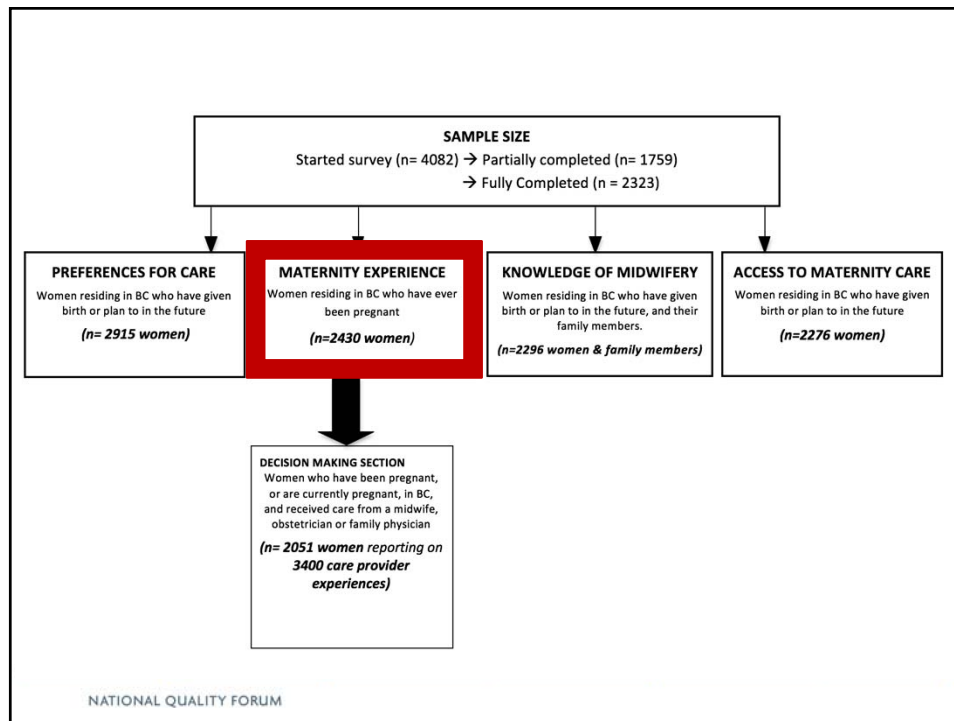
Please describe your experiences when making decisions and choosing options for care during this pregnancy.	Completely Disagree - Completely Agree	N/A
My ____ asked me how involved in decision making I wanted to be	○ ○ ○ ○ ○ ○ ○	○
My ____ told me that there are different options for my maternity care	○ ○ ○ ○ ○ ○ ○	○
My ____ explained the advantages/disadvan. of the maternity care options	○ ○ ○ ○ ○ ○ ○	○
My ____ 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 ____ respected that choice	○ ○ ○ ○ ○ ○ ○	○

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## Survey Respondent Map



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## Preferences For Care

Percent of women who answered 'very important' to the following: (n = 2915)

What is most important to you for your maternity and newborn care?	Full sample n=2915	Vulnerable n=392
Choice of birthplace (home or hospital)	66.4	70.9
Having only one provider care for me	24.0	24.4
Having no more than 4 providers care for me	53.8	52.1
I lead the decisions about my pregnancy, birth and baby care	69.3	76.0
My doctor or midwife guides the decisions	11.8	10.1
Having support people of my choice present for labour and birth	80.4	82.5
Having a provider who has expertise with natural methods for pain relief	58.4	60.4
Having a provider who has expertise with high-risk pregnancies	26.4	31.7
Having access to medicines for pain relief	19.9	32.6
Knowing the doctor/midwife who will care for me during my birth	71.7	59.3
Not being separated from my baby after birth	89.9	76.1
Being able to choose a planned caesarean	7.4	10.1
Having a pain-free birth	9.2	18.3
Being cared for by my own family doctor	7.9	21.3
Staying in my community for pregnancy and birth	60.1	64.6
Having a provider who will do newborn care/breastfeeding support at my home	62.1	66.7
Having enough time to ask questions and discuss my options	86.4	79.9
Having a trusting relationship with my care provider	89.7	82.5
Having a care provider who speaks my language	79.9	67.8

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## Major factors' in deciding which MCP to choose (n = 2922)

	Full sample n=2922	Vulnerable n=267
Provided my prenatal care in a previous pregnancy	37.2	32.2
Had provided my well-woman (gyn) care	12.1	10.5
Was recommended by a health professional	24.0	27.9
Is highly rated on websites with information about specific care providers	16.7	19.4
Was a good match for what I value and want	87.7	83.9
Attends births at a hospital I like	48.0	44.4
Is female/included female providers	54.6	61.8
Was assigned to me as my maternity care provider	13.3	16.5

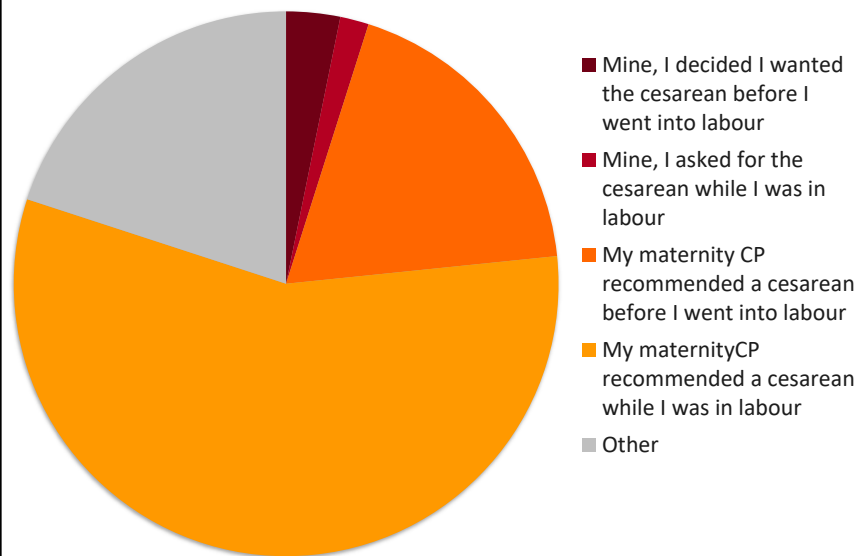
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## Preferences For Care – Leading Decisions

n=2915	
	n (%)
It is very important or important to me that I lead the decisions about my pregnancy, birth and baby care	2766 (95.0)
It is very important to me that I lead the decisions	2018 (69.3)
It is very important or important to me that my doctor or midwife guides the decisions	1392 (47.8)
It is not very important to me that that I lead the decisions	11 (0.4)

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## Who made the decision to have a CS ?



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## Changing Childbirth in BC: Scale Development

- Community wanted to explore factors potentially associated with **Autonomy** and **Respect** in provider relationships
- Closer look at relevant scale items
- Included in analysis (N1672/2514 pregs):
  - *Women who had ever been pregnant in British Columbia and received care from a midwife, family doctor or obstetrician*

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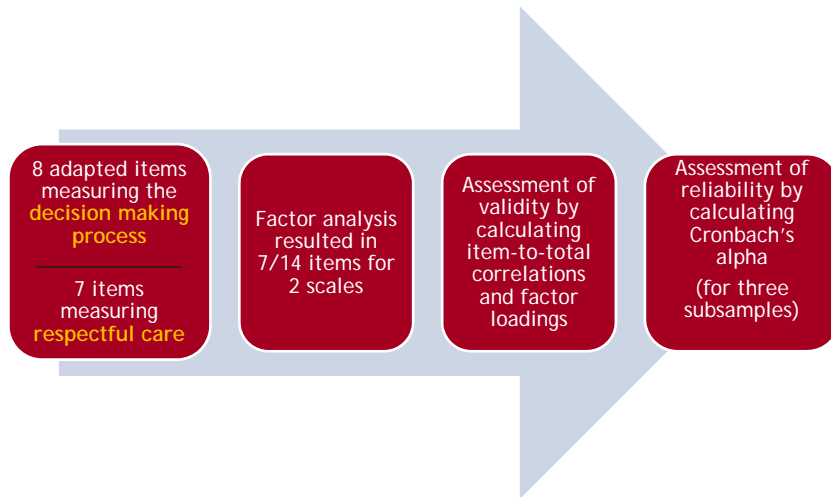
## Mothers On Respect: The (MOR) index

- Range 0-7, higher scores – more respectful maternity care
- Sum of the following (Yes/No) items:

Overall while making decisions during my pregnancy/birth care I felt:	No	Yes	NA
Comfortable asking questions	<input type="radio"/>	<input type="radio"/>	
Comfortable declining care that was offered	<input type="radio"/>	<input type="radio"/>	
Comfortable accepting the options for care that my ____ recommended	<input type="radio"/>	<input type="radio"/>	
Coerced into accepting the options my __ suggested (reverse scored)	<input type="radio"/>	<input type="radio"/>	
I chose the care options that I received	<input type="radio"/>	<input type="radio"/>	
My personal preferences were respected	<input type="radio"/>	<input type="radio"/>	
My cultural preferences were respected	<input type="radio"/>	<input type="radio"/>	

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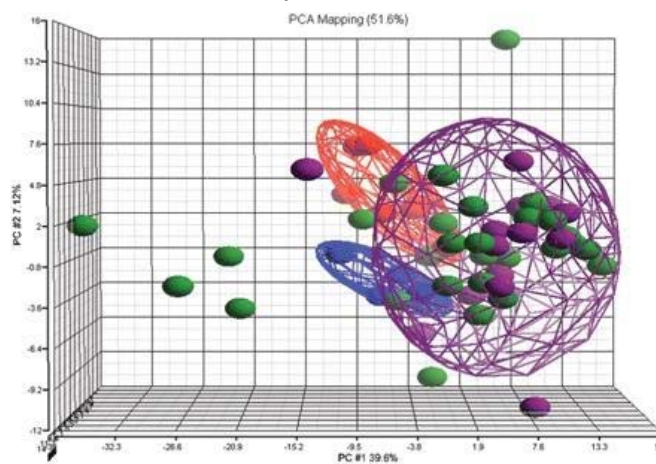
## Scale development and psychometric evaluation



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## Scale development

### ■ Construct Validity

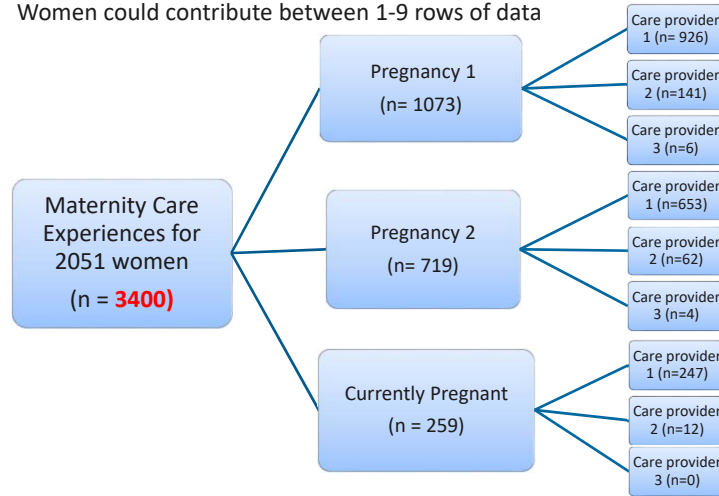


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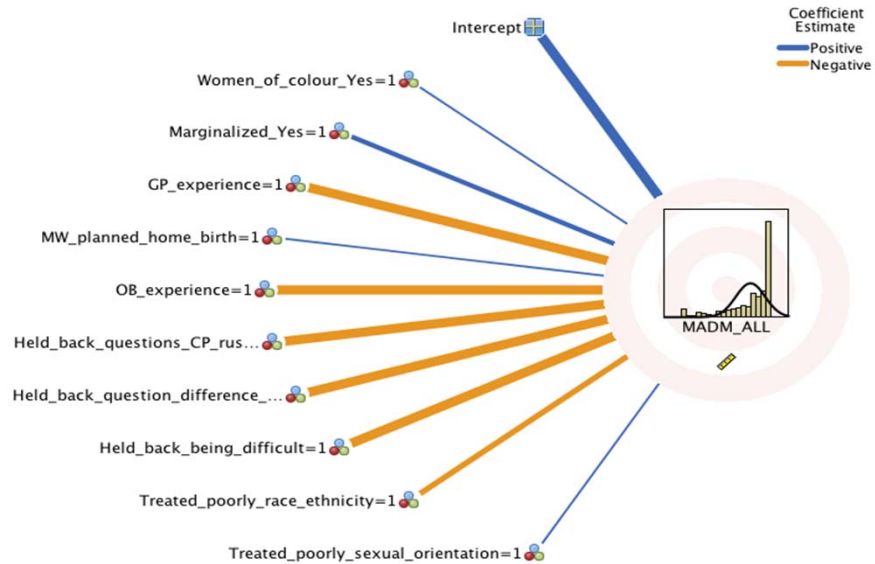
## Mixed Effects Analysis:

- ▶ Control for possible effect of one woman reporting on a number of different pregnancies and care providers
- ▶ Women could contribute between 1-9 rows of data

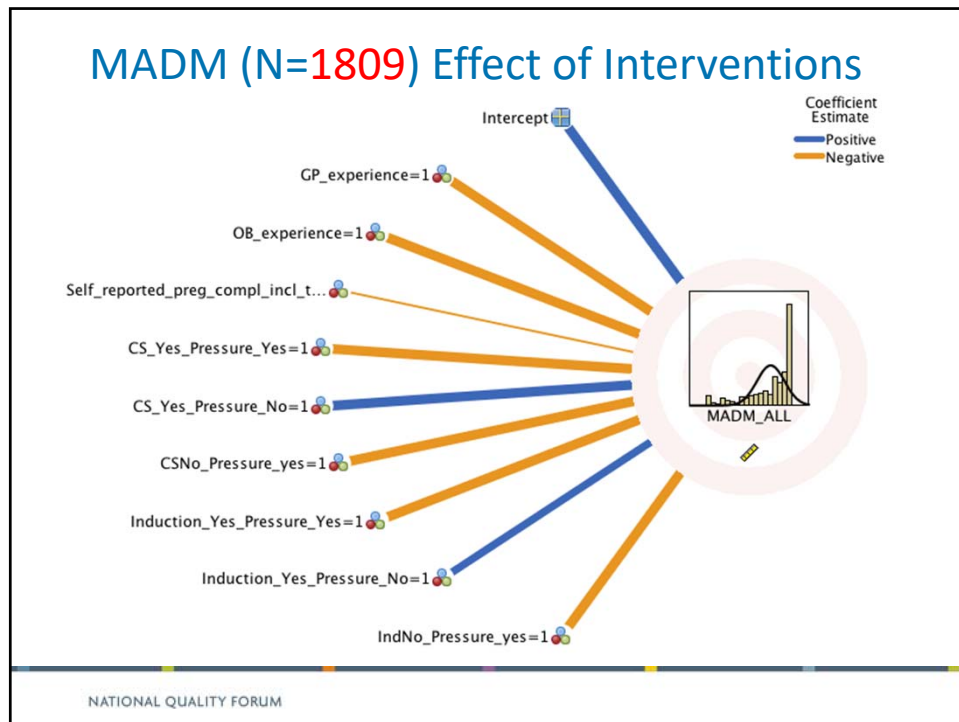


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## MADM (n=2325) – Experience of Discussion



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### Difference of Opinion with providers

*Women held back their questions if they wanted different care because they were worried about poor treatment*

**Lower MADM and MORi scores**

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## Feeling Pressured



Regardless of provider type  
or actual care

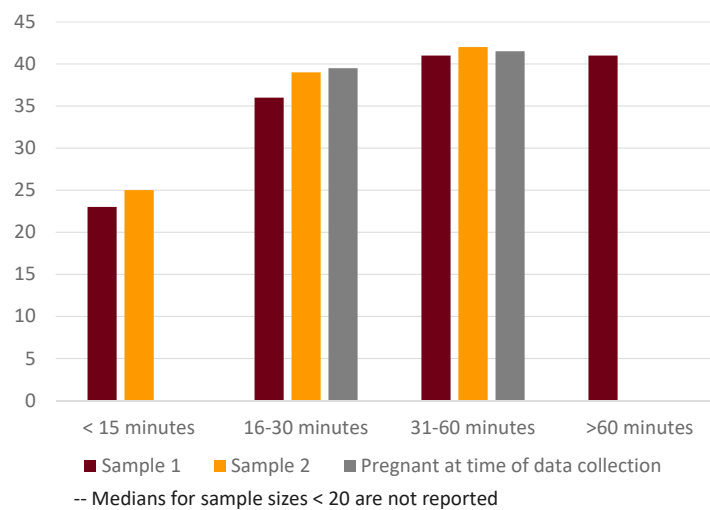
**Pressure =**

↓ *Respect*

↓ *Autonomy*

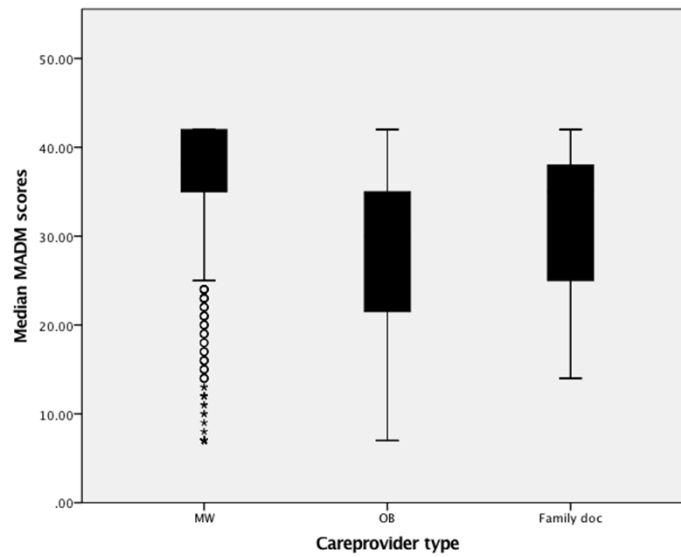
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## MADM median scale scores, stratified by average length of prenatal appointments.



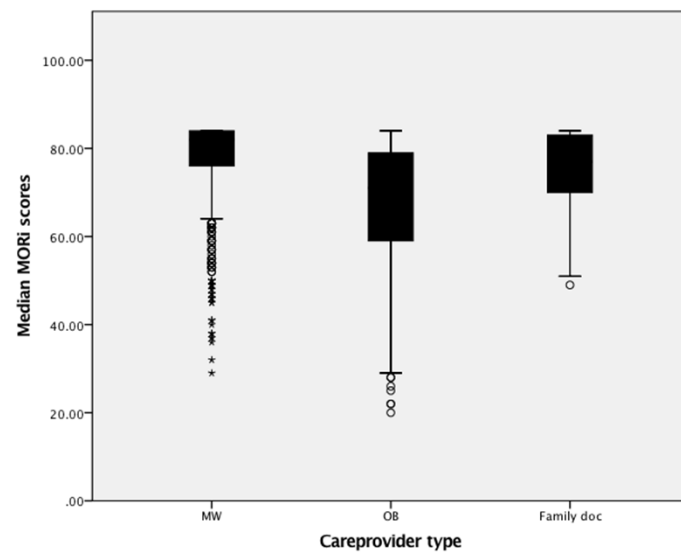
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## MADM scores, by provider type



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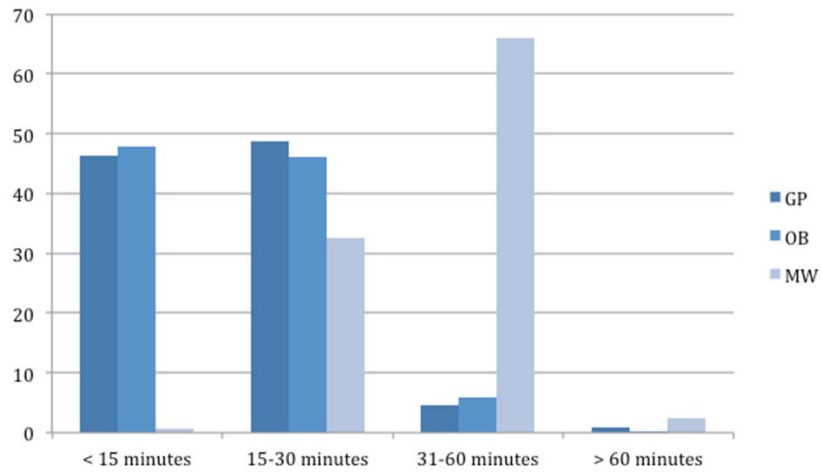
## MORi scores, by provider type



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## Average length of prenatal appointments.

Figure 2: Average length of prenatal appointments, by care provider type (n=1723)



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## Women Need Time



Higher MADM scores  
with more

TIME to process  
information

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ELSEVIER

RESEARCH ARTICLE

## The Mother's Autonomy in Decision Making (MADM) scale: Patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care

Saraswathi Vedam<sup>1,\*</sup>, Kathrin Stoll<sup>1,2</sup>, Kelsey Martin<sup>3</sup>, Nicholas Rubashkin<sup>3</sup>, Sarah Partridge<sup>4</sup>, Dana Thordarson<sup>1</sup>, Ganga Jolicoeur<sup>2</sup>, the Changing Childbirth in BC Steering Council<sup>5</sup>

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\* A complete list of Steering Council members can be found in the Acknowledgments.  
\* [vedam@midwifery.ubc.ca](mailto:vedam@midwifery.ubc.ca)

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Article

The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth

Saraswathi Vedam<sup>a,c</sup>, Kathrin Stoll<sup>a</sup>, Nicholas Rubashkin<sup>a,d</sup>, Kelsey Martin<sup>a</sup>, Zoe Miller-Vedam<sup>a</sup>, Hermine Hayes-Klein<sup>a</sup>, Ganga Jolicoeur<sup>a</sup>, the CCinBC Steering Council<sup>1</sup>

OPEN ACCESS

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ELSEVIER

**Social Science & Medicine**


Volume 189, September 2017, Pages 86–95

**Informal cash payments for birth in Hungary: Are women paying to secure a known provider, respect, or quality of care?**

Petra Baji<sup>a, b, c, d, e</sup>, Nicholas Rubashkin<sup>c, d, e</sup>, Imre Szezik<sup>a</sup>, Kathrin Stoll<sup>f</sup>, Saraswathi Vedam<sup>f, g</sup>

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## MOTHERS AUTONOMY IN DECISION MAKING: THE MADM SCALE

Please tell us about your discussions with your doctor or midwife about your options for care (for example: prenatal testing, starting your labour, medications, where to give birth, newborn care, whether to have a cesarean, etc.)

My answers describe my conversations or experiences with a:

☐ Family doctor  
☐ Obstetrician/OB-GYN doctor

☐ Midwife  
☐ Not applicable, did not have a doctor or midwife

**KEY**

**Level of Autonomy**  
(by quartiles)


Total Score	Indication of Respect
7 - 15	Very Low Patient Autonomy
16 - 24	Low Patient Autonomy
25 - 33	Moderate Patient Autonomy
34 - 42	High Patient Autonomy

**Please describe your experiences with decision making during your pregnancy, labour and/or birth.** (select one option for each)

	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My doctor or midwife asked me how involved in decision making I wanted to be.	1	2	3	4	5	6
My doctor or midwife told me that there are different options for my maternity care.	1	2	3	4	5	6
My doctor or midwife explained the advantages/disadvantages of the maternity care options.	1	2	3	4	5	6
My doctor or midwife helped me understand all the information.	1	2	3	4	5	6
I was given enough time to thoroughly consider the different care options.	1	2	3	4	5	6
I was able to choose what I considered to be the best care options.	1	2	3	4	5	6
My doctor or midwife respected my choices.	1	2	3	4	5	6
<b>SUM OF ALL CIRCLED ITEMS = TOTAL SCORE:</b>						

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### MOR: MOTHERS ON RESPECT INDEX

Please tell us about your discussions with your doctor or midwife about your options for care (for example: prenatal testing, starting your labour, medications, where to give birth, newborn care, whether to have a cesarean, etc.)

My answers describe my conversations or experiences with a:

☐ Family doctor  
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☐ Midwife  
☐ Not applicable, did not have a doctor or midwife.

#### Scoring Table

Enter total score section A	
Enter total score section B	
Enter total score section C	
A + B + C = TOTAL SCORE	

The range of scores is 14-84, with higher score indicating more respectful care.

#### KEY

Level of Respect Experienced (by quartiles)

Total Score	Indication of Respect
14 - 31	Very Low Respect
32 - 49	Low Respect
50 - 66	Moderate Respect
67 - 84	High Respect

#### 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:**

#### 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:**



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## GIVING VOICE TO MOTHERS

What do **YOU** think is most important for your pregnancy care?

PLEASE CONSIDER SHARING YOUR STORY

[www.voicesofmothers.org](http://www.voicesofmothers.org)

Questions? Please contact Barbara at 404.875.2000 ext. 5879 or [barbara.karlen@ubc.ca](mailto:barbara.karlen@ubc.ca)




## DANDO VOZ A LAS MADRES

¿Qué considera usted lo más importante para **SU** cuidado materno?

COMPARTA SU HISTORIA CON NOSOTROS

[www.voicesofmothers.org](http://www.voicesofmothers.org)

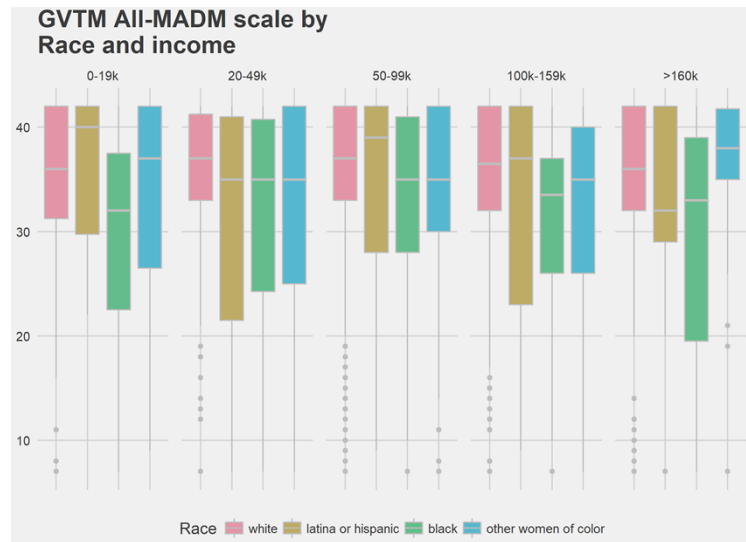
¿Preguntas? Por favor, póngase en contacto con Barbara al: 404.875.2000 ext. 5879 escriba a: [barbara.karlen@ubc.ca](mailto:barbara.karlen@ubc.ca)





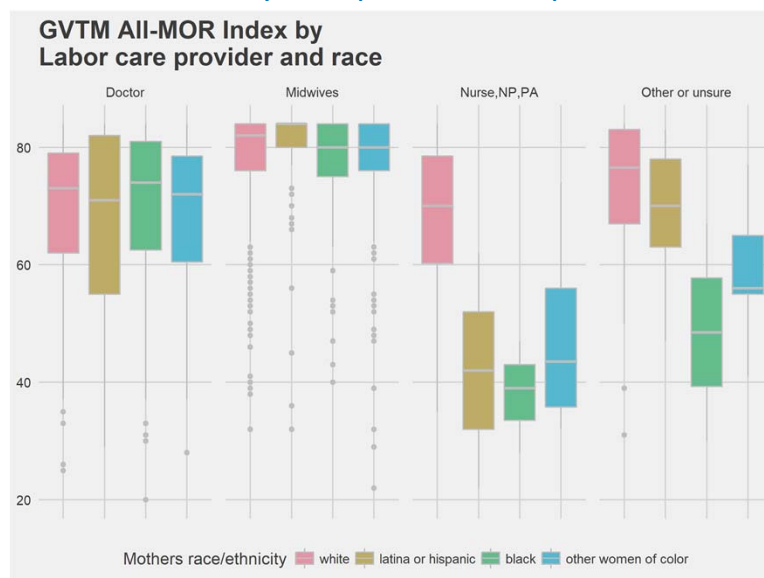

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## MADM during pregnancy and birth, stratified by race and income



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## MORi, stratified by intrapartum care provider and race



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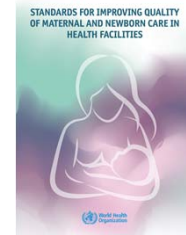


## Respectful Maternity Care and Quality of Care

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2016 WHO “Standards for improving quality of maternal and newborn care in health facilities”

1. Evidence-based practices for routine care and management of complications;
2. Actionable information systems;
3. Functioning referral systems;
4. **Effective communication;**
5. **Respect and preservation of dignity;**
6. **Emotional support;**
7. **Competent, motivated personnel; and**
8. Availability of essential physical resources.



World Health Organization (2016) Standards for Improving Quality of Maternal and Newborn Care in Health Facilities.



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## What Influences Quality?

(Simkin 2002)

- Systematic review of 137 studies
  1. *Involvement in decision making*
  2. *Quality of the provider-patient relationship*
  3. *Amount of support received from care providers*
  4. *Whether their expectations met reality*

How to evaluate these in practice?



*Develop reliable and valid scales that measure women's experiences with **respectful care** and **decision making** during pregnancy and birth*

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## Challenges with Implementation of RMC

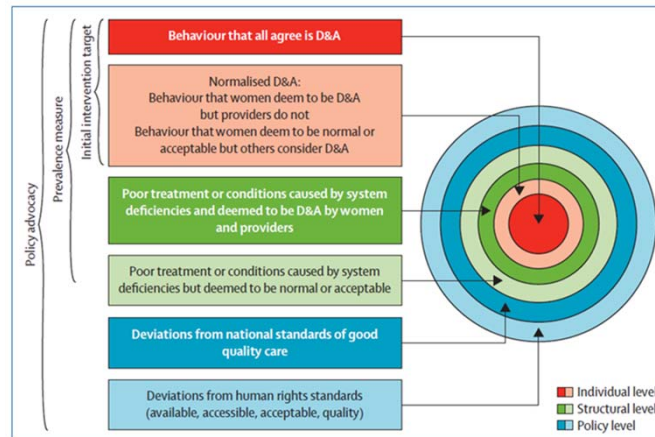


Figure: Definition of disrespectful and abusive treatment (D&A) of women in childbirth

Freedman et al. (2014). Defining Disrespect and Abuse of Women in Childbirth: A Research, Policy and rights Agenda. *Bulletin of the World Health Organization* 1;92(12): 915-7



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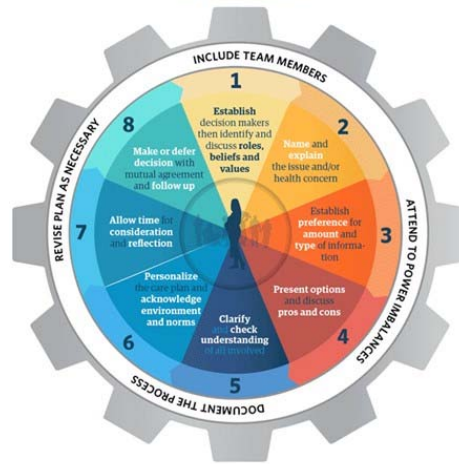
## Our plan to bring evidence to practice

- Pilot Studies
- Messaging
- NQF and PROMIS item banks
- Interprofessional Education
- Giving Voice to Mothers - Canada

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Dialogue and Shared Decision: Advancing Person-Centered Care  
*An interprofessional course for health professionals*

Shared Decision Making  
 Key Elements



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## Audience Question & Answer

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## Wrap Up & Announcements

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### 2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

#### *Focus on Patient-Centered Healthcare Measurement*

- Register to learn from other 2017 Innovation Challenge winners...
  - [March 1, 2018 at 1pm ET](#)
- Watch previous webinars in this series
  - [February 23, 2018](#)
  - [September 25, 2017](#)
  - [August 30, 2017](#)
- Register for [NQF's Annual Conference](#), March 12-13 in Washington, DC, for a special session, **NQF Measure Incubator™—Past, Present, and Future**
- To learn more, please contact NQF at [incubator@qualityforum.org](mailto:incubator@qualityforum.org)
- Share your ideas with us [#ptvoice](#) [#ptcenteredmeasures](#)

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