

**Moving from Interprofessional Disarticulation  
to Transformative Dialogue and Action:**  
Examining a Transdisciplinary Process to Address Equitable Access to  
High Quality Maternity Care in North America

Saraswathi Vedam

Master of Science in Nursing, Yale University  
Doctor of Science (honoris causa), Amherst College

School of Public Health, Sydney Medical School  
University of Sydney

THIS THESIS IS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY  
UNIVERSITY OF SYDNEY, AUSTRALIA

## DECLARATION

### **Statement of Authentication**

This thesis is submitted to the University of Sydney in fulfilment of the requirement for the Degree of Doctor of Philosophy. I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged. The work presented in this thesis, is to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

**Signature:**

**Date: October 25, 2019**

## **Ethical Considerations & Financial Support**

Ethical approval for access to the data sources included in each of the included studies was obtained from the University of British Columbia (UBC) Ethics Board. I am a Professor of Midwifery at UBC, and Registered Midwife. I have no financial conflict of interest related to these studies. A 3 year operating grant (20R44645) from the Canadian Institute of Health Research supported all phases of the Canadian Birth Place study (UBC Behavioural Research Ethics Board approval H09-00381). The community based participatory phases of community engagement, study design, data collection, quantitative data analysis planning for The Changing Childbirth in British Columbia study (H12-02418 UBC ethics) was supported by grant UNR12-0701 from the Vancouver Foundation and the knowledge translation and manuscript development was supported by a Michael Smith Health Research Foundation Health Professional Investigator award #17020. The Access and Integration Maternity care Mapping Study (ethics exempt) was supported by multi-year grants from the Transforming Birth Fund (TBF) of the New Hampshire Charitable Foundation for community engagement, regulatory validation, data collection, analysis and knowledge translation. Some phases of that study had project support from the Foundation for the Advancement of Midwifery. Study design, content validation, data collection, data analysis and knowledge translation for The Giving Voice to Mothers study (UBC Ethics approval H15-01524) was also supported by TBF grants 111794, 105661, 100156, and 95835; and community engagement for member checking and knowledge translation planning was supported by a grant from Groundswell Foundation BJF21019. TBF grants also provided primary infrastructure support for the convening of all four Summits and for the development of this research program.

My work also was sustained within the financial security net of a tenured professor appointment at the University of British Columbia.

## **Collection of Output for Examination**

I formulated and initiated the research questions answered by this PhD thesis, gained ethics approval, and was the lead investigator for the research and knowledge translation projects that are included in this thesis. This included conceptualization, funding acquisition, investigation, methodology, project administration and supervision, and visualization. I was the sole author of Chapters 1, 2, 3, 4, and 7, and first author for each of the five papers included in Chapters 5 and 6. Within a community-based participatory research framework, I provided leadership and coordination for design and execution of the studies including recruitment, data collection, and analyses, and facilitating a transdisciplinary process to create an analysis plan and interpret the findings.

I drafted the manuscripts, solicited and reviewed co-author input, edited, finalized, and submitted the papers to peer-reviewed journals, and led all stages of revision and re-submission as necessary. Manuscripts 1-5 have contributing authors who were members of multi-disciplinary research teams, and, in keeping with the transdisciplinary engagement process, provided valuable insights and unique perspectives based on their roles and expertise with community health, health services, and policy. All manuscripts were submitted for publication in peer-reviewed journals within the period of this doctoral program. All co-authors for each manuscript approved the open source publications included in this thesis, and reprinting in accordance with Creative Commons Licensing agreements. Descriptions of their specific contributions are provided within the manuscripts as well as in Appendix A.

Saraswathi Vedam  
Date: 19 October, 2019

As supervisors for the candidature upon which this thesis is based, we can confirm that the authorship attribution statements above are correct.

Lesley Barclay AO PhD  
Date: 20 October 2019

Caroline Homer AO PhD  
Date: 20 October 2019

## **Dedication**

This thesis is dedicated to my father, K. Vedam, who was, and will remain for me, the real Dr. Vedam. He was the epitome of grace, humility, integrity, and rigour in the pursuit of truth through scientific enquiry. His academic career began at the vanguard of transdisciplinary imagination. He was a physicist and expert in optics, but his work in materials science was within one of the first transdisciplinary labs in the world. There he collaborated with chemists, biologists, and engineers to solve real world complex problems presented by more than one dimension. It turns out that ellipsometry leads to an understanding of internal and external structures, the movement of light, and the liquid-solid interface, which in turn inform the real world contributions of high-pressure optics and holography to medical imaging, rust and road safety. More importantly, my father was the best of listeners, cared deeply about the lived experience of others, and believed that peaceful engagement was the right and true path.

## Acknowledgements

I acknowledge and am grateful that I was able to complete this work as a guest on the traditional, ancestral, and unceded lands of the Coast Salish Nations including the x<sup>w</sup>məθkwəyəm (Musqueam), Skwxwú7mesh (Squamish), and Tsleil-waututh Nations in Canada; and the the Gadigal peoples of the Eora Nation in Australia.

Most doctoral dissertations are born because of the kindness, largesse, and collective understanding of the authors' community and research mentors; as my ideas evolved from more than 30 years of dialogue with service users and colleagues, my list for thanks is especially long. I describe the unique and essential contributions of my co-authors and collaborators within each manuscript, but several deserve special mention for this thesis.

First, I must thank Lesley Barclay, as she was the first to insist that I document the mystery of the Summit success through a doctoral program, and, making such an impossible idea attainable, she guided me through beginning to end with wisdom, grace, and so much patience. I am so grateful that Caroline Homer agreed to join Lesley as co-supervisor, as her insights and queries improved this work immeasurably. Both of them are the finest of midwifery researchers and mentors, always applying the highest of standards, and never losing focus on keeping the person at the centre of our work. Their encouragement is humbling.

None of these studies would have been possible without Kathrin Stoll, my partner in research for a decade. She has an uncanny ability to translate my vision into the concrete, and my life of enquiry benefits from her deep commitment to rigour, accuracy, and meaningful analyses. Melissa Cheyney and I are walking the same rare path of academic midwifery, exploring the complex worlds of community birth and interprofessional dialogue. She was my thinking partner before and through all of the Summits, and through all of these research projects. *Namaskarams* to those who put me on this path: my mother Nalini Vedam, who spent 60 years bringing people from different worlds together in her kitchen, and who let me go to the ends of the earth even as she prepared to depart the earth; Murray Enkin, who showed me that evidence for quality care exists; and Eugene Declercq and Holly Kennedy who study what they believe, and are not afraid to explain complex concepts. Gene never failed to respond to my most basic queries with sage advice and encouragement. His vote of confidence was key to my audacious pursuit of a research

life. Jennie Joseph, Katsi Cook, Monica McLemore, Indra Lucero, Tina Santoni, Pat Deibel, and Pandora Hardtman exemplify service for the greater good; their lives helped me to articulate the Third Reality. Timothy Fisher's openness to transdisciplinary discovery, more than anyone, made me believe that continued engagement was worth the effort.

Betsy McNamara of the Transforming Birth Fund, and the anonymous donor she represented, took a risk when they provided the financial backing for Home Birth Summit I. Over the next decade, even when it was hard to understand the way we proposed to address the wicked problem, they invested in the transdisciplinary imagination of the delegates. They held the space for this discovery, and trusted the circuitous and iterative process.

My team at the Birth Place Lab, from staff to trainees, and my practice partners, were endlessly supportive, often taking on more when I was less available. I am so grateful to Leah Houtman for her attention to detail as she copyedited the final version, making the final product look polished for submission. Chris Burman and Barasab Nicolescu were both so generous and helpful in their communications. Alma Torlakovic at the Higher Research Degree program office rescued me with her kind, warm, and clear assistance with navigating the submission process.

Finally, I am indebted to those at home who soothed me, waited for me, fed me, listened to me, made me sleep, but did not let me stop until I was done: my brother, Subramanyam Vedam; my dear friends, Courtney Broten, Aldabaran Tatum, and Laura Schummers; my daughters, Sophia, Lakshmi, Maya, and Zoë Miller-Vedam, who understands me so well that she could illuminate my thoughts by creating perfect graphics in a single day. Most importantly, my life partner, Jeff Miller, has never hesitated to be a champion of my dreams and pursuits, regardless of the time, resources, or attention that they inevitably draw from our life together.

## **Abstract**

Maternity providers in North America are in conflict about birth place, debating issues related to safety, autonomy, and quality of care. Very little is known about how birth place interacts with experience and outcomes of maternity care, or about how to resolve these differences among provider disciplines within established health care systems.

A multi-stakeholder group of leaders convened at a series of Home Birth Summits in the United States to delineate a Common Ground Agenda, including nine priority areas for action and research. The aim of this doctoral study was to examine how and why this transdisciplinary process generated new evidence and tools that can improve maternity services.

## **Methods**

I synthesized the results of four original research studies using a range of methodologies as appropriate to the study topic. In the Canadian Birth Place Study, I examine mixed methods data on provider attitudes to place of birth. In the Changing Childbirth in British Columbia (BC) and Giving Voice to Mothers studies, psychometric analysis cross-sectional survey data led to development of four new person-centered measures of experience of maternity care. In the Access and Integration Maternity Care Mapping Study, a Delphi study created a scoring system (MISS) to assess midwifery integration. Correlation and regression analyses elicit linkages between integration and key maternal-newborn outcomes. Finally, I triangulated results of these studies within the Taming Wicked Problems Framework, to elicit an underlying and contributory factor for effective transdisciplinary action.

## **Results**

Among maternity care providers (n=825), 84% of variance in attitudes to home birth was attributable to provider type alone. Women from diverse backgrounds (n=2051, 3586 pregnancies) reported reduced autonomy and respect when cared for by physicians and when



giving birth in institutional settings. Among women in the United States (US) (n=2700), disparities in experiences of care, including mistreatment, links to race, socioeconomic status, place of birth and type of provider. U.S. states with higher midwifery integration and greater access to home birth reported significantly fewer adverse maternal-newborn outcomes and significantly higher rates of physiologic birth.

## **Discussion**

The participatory approach and synthesis of outcomes of these studies was essential to understand and address inequities in experience and access to quality maternity health services in the US. Person-centered care emerged as a hidden common value that informed a transdisciplinary research process, and community-responsive knowledge translation outputs.

## **Conclusion**

Increasing knowledge among all types of providers about quality and safety of birth place, and person-centered care, could improve outcomes across birth settings. The Summit process of transdisciplinary engagement reduced interprofessional conflict and facilitated co-creation of evidence and tools that improve quality, safety, and accountability in North American maternity care.

## **Glossary**

AABC - American Association of Birth Centers

ACNM - American College of Nurse Midwives

ACOG - American College of Obstetricians and Gynecologists

AAP - American Academy of Pediatrics

CPM - Certified Professional Midwife

CNM - Certified Nurse Midwife

CM - Certified Midwife

LM - Licensed Midwife

MANA - Midwives Alliance of North America

NACPM - National Association of Certified Professional Midwives

RM - Registered Midwife

TBF - Transforming Birth Fund

## Table of Contents

DECLARATION .....	2
Statement of Authentication .....	2
Abstract .....	8
Methods .....	8
Results .....	8
Discussion .....	9
Conclusion.....	9
Glossary .....	10
CHAPTER 1: Introduction.....	15
1.1 Moving from Conflict to Collaboration: The Home Birth Summit Model .....	17
1.2 Research Question .....	18
1.3 Research Objectives .....	19
CHAPTER 2: Approach.....	22
2.1 Introduction .....	22
2.2 Addressing the Objectives.....	24
2.2.1 To Examine Maternity Provider Attitudes Related to Birth Place and Women’s Autonomy .....	24
2.2.2 To explore women’s experience of autonomy and respect in maternity care. ....	25
2.2.3 To Describe How Health Systems Variance Affects Access and Outcomes of Care in the U.S. ....	26
2.2.4 To Explain Why a Transdisciplinary, Multi-Stakeholder Process is an Effective Strategy to Improve Person-Centered Care .....	27
2.3 Relevant Methodologies.....	27
2.3.1 The Canadian Birth Place Study (Objective 1).....	28
2.3.2 The Changing Childbirth in BC Study (Objective 2, Manuscripts 1-3) .....	29
2.3.3 Giving Voice to Mothers (Objective 2, Manuscript 4).....	30
2.3.4 Access and Integration Maternity Care Mapping Study (Objective 4, Manuscript 5) .	31
2.4 Summary .....	31
CHAPTER 3: Background.....	32
3.1 Introduction .....	32
3.2 The impact of birth setting on autonomy and self-determination during childbirth .....	32
3.3 The debate on safety in North America.....	33

3.4 Examining Interprofessional Disarticulation: Provider Attitudes .....	35
3.4.1 Quantitative Survey Findings on Provider Attitudes.....	36
3.4.2 Qualitative focus group data on provider attitudes.....	37
3.4.3 Qualitative Findings.....	37
3.5 Health systems integration: comparing the context of care between Canada and the U.S.	39
3.6 Conclusion.....	40
CHAPTER 4: What is Known About How to Address This Type of Problem? .....	42
4.1 Introduction .....	42
4.2 Wicked Problems .....	42
4.3 Transdisciplinary Approaches to Addressing Wicked Problems .....	44
4.4 Person-Centered Measurement of the Lived Experience of Health Care.....	49
4.5 Community Based Participatory Action Research.....	51
4.6 The Future Search Model for Transdisciplinary Engagement .....	53
4.7 Future Search and the Home Birth Summits.....	54
4.7.1 Delegate Responsibilities.....	56
4.7.2 Trust Building.....	56
4.7.3 The Common Ground Agenda.....	58
4.7.4 Conclusion.....	60
CHAPTER 5: How Do Provider Attitudes Affect Experience and Quality of Care?.....	61
5.1 Introduction .....	61
5.2 The Need for Innovation in Measurement of Autonomy and Respect in Maternity Care ..	61
Manuscript 1: The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. ....	64
Manuscript 2: 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. ....	65
5.3 Changing Childbirth in BC.....	66
Manuscript 3: The Changing Childbirth in BC Study: examining autonomy in Canadian maternity care. ....	67
5.4 Equity, Safety, and Respect in U.S. Maternity Care .....	68
5.5 Giving Voice to Mothers Study.....	69
5.5.1 Survey Construction and Content Validation .....	69
5.5.2 Analysis .....	70

Manuscript 4: Giving Voice to Mothers: inequity and mistreatment during pregnancy and childbirth in the United States.....	72
5.6 Conclusion.....	73
CHAPTER 6: Health Systems Interactions with the Wicked Problem.....	74
6. 1. Introduction .....	74
6.2 Interprofessional Disarticulation, Access and Outcomes of Maternity Care .....	75
6.2.1 Licensure and Integration (Phase 1) .....	75
6.2.2 Changing Rates of Home Birth by State.....	76
6.2.3 Disaggregating Licensure From the Realities of Integration by State (Phase 2).....	77
6.2.4 Linking Provider Integration and Place of Birth to Maternal-Newborn Outcomes (Phase 3) .....	77
Manuscript 5: Mapping integration of midwives across the United States: Impact on access, equity, and outcomes.....	78
6.3 Mapping Equity in Maternity Care .....	79
6.4 Conclusions and Implications .....	80
CHAPTER 7: Discussion.....	81
7.1 Introduction .....	81
7.2 The Trajectory of Transdisciplinary Imagination.....	82
7.2.1 Taming the Wicked Problem of Home Birth.....	83
7.2.2 The Hidden Third Reality – Person-Centred Care .....	85
7.2.3 Summit II: Expanding the circle and defining the scope of the problems in each domain .....	91
7.2.4 Summit III: Advancing Equity through Voice, Policy, Practice & Research .....	94
7.3 The Future of Transdisciplinary Engagement Towards Equity, Safety and Respect.....	97
7.3.1 US Birth Summit IV: Health Equity.....	97
7.4 Lessons Learned from Applying Transdisciplinary Methodology.....	101
7.5 Limitations.....	102
7.6 Conclusions .....	104
Bibliography.....	106
APPENDIX A .....	120
Author Contributions.....	120
Manuscript 1 .....	120
Manuscript 2 .....	120

Manuscript 3 .....	120
Manuscript 4 .....	122
Manuscript 5: .....	122
APPENDIX B: .....	124
Dissemination and Implementation of scales.....	124
APPENDIX C .....	127
Innovative Knowledge Translation and Policy Implications: Actioning the Third Reality....	127
Access and Integration of Maternity Care Maps .....	127
Physician Attitudes to Midwives .....	128
Safety of home birth .....	128
Interprofessional Collaboration .....	129
Autonomy, Respect, and Person-Centered Care.....	129
Interprofessional Education .....	130

## CHAPTER 1: Introduction

Rates of planned home birth in the U.S. and Canada remained at less than 1% for several decades, but in the last five years trends in National Vital Records data showing a 75% increase in births at home suggest that women are increasing their interest in this option (MacDorman and Declercq 2016; Canadian Institute of Health Information 2015). Despite the emergence of high quality evidence supporting the safety and cost-effectiveness of midwife attended planned home birth (De Jonge et al. 2015; Olsen and Clausen 2012a; Janssen et al. 2009; Hutton, Reitsma, and Kaufman 2009; Schroeder et al. 2012; Janssen, Mitton, and Aghajanian 2015; Scarf et al. 2018; Cheyney et al. 2014; Homer et al. 2014; Hollowell et al. 2011), maternity providers in North America have been in conflict about birth at home and birth centers, debating issues related to safety, access, the value of obstetric intervention, and patient autonomy (Chervenak, McCullough, & Arabin, 2011; de Vries, Paruchuri, Lorenz, & Vedam, 2013; Zielinski, Ackerson, & Low, 2015).

Skilled birth attendants can assist a woman to assess her birth site options according to her health status, distance to specialist services, and other appropriate maternity care resources. Ideally, those providers offer care across all settings and are fully integrated into a network of maternity care services at all levels. However, in North America, there are very few regions where home birth providers are fully integrated as regulated health professionals into interprofessional care provider networks. Many state health systems in the Canada, United States and Mexico have historically restricted access to skilled attendants across birth settings and placed a high value on institutional birth (Kornelsen et al. 2010; Foster and Alonso 2018; Cheyney 2008; Vedam and Stoll 2008). These systems for organization of care have been influential in low and middle resource countries (European Court of Human Rights, 2014; European Court of Human Rights Strasbourg, 2014; Karlsen et al., 2011; Kruske, Young, Jenkinson, & Catchlove, 2013), without clear evidence of overall benefits to quality and safety for women and newborns (Miller et al., 2016; Scarf et al., 2018).

There are large differences in regional conditions for practice and/or in cultural expectations around place of birth. In Canada and the U.S., midwives are the only maternity care providers who currently offer choice of birthplace. In many regions, women who plan home births and their midwives encounter hostility and reprimand if care is transferred from home to hospital to access specialist care. Rights to choice and self-determination are core values in health care discourse (Groves, Sixth, & Conference, 2013), but provider attitudes can influence patient decisions and choices (Finsen, Storeheier, and Aasland 2008; Hall, Tomkinson, and Klein 2012; Allcock, Griffiths, and Penketh 2008), and experiences of care (Janssen, Henderson, and Vedam 2009; Cheyney 2008). They affect informed consent discussions with patients as well as having an impact on levels of comfort with collaboration between disciplines (Healy, Humphreys, and Kennedy 2016; Vedam et al. 2009, 2012).

In the U.S, the widely disparate regulatory and practice landscape for midwives is associated with divergent attitudes among health care leaders and policy makers about management of labour and birth in the community. When there are conflicting opinions about optimal care among health professionals and policy makers, patient access to care may be adversely affected (Healy, Humphreys, and Kennedy 2016; Barclay et al. 2016a; Cheyney 2008; Vedam et al. 2009, 2012). Thus, differences in access to options for birth place across regions may simply represent the results of a patient decision-making process that is driven by pre-existing provider philosophies and attitudes. Until recently, very little was known about how differences in provider attitudes are intertwined with choice of birth place, experience of maternity care, and maternal-newborn outcomes. Experience of care has been elevated as a core component of quality care (World Health Organization, 2016), but measures of provider-patient interactions are scarce. Even less has been studied about how to resolve these differences within the context of established multi-disciplinary care systems. Poor coordination of care across birth settings has been associated with adverse maternal and newborn outcomes (Guise and Segal 2008; Manojlovich et al. 2014). In both high, and low resource countries, these issues are persistent “wicked problems” (Brown, Harris, & Russel, 2010) in maternity care.



## **1.1 Moving from Conflict to Collaboration: The Home Birth Summit Model**

In October 2011, I convened an international, multidisciplinary group of leaders at a national Home Birth Summit to address their shared responsibility to provide high quality care to families that plan to give birth at home, even as they acknowledged their opposing views. Delegates from divergent stakeholder groups (midwifery, obstetrics, nursing, pediatrics, consumers, consumer advocates, hospital administrators, policymakers, legislators, researchers, ethicists, and public health and liability specialists) explored every facet of the existing system, and engaged in frank and productive conversations. All perspectives and viewpoints were considered valuable in this purposeful dialogue, where delegates explored facets of the existing maternity care system that contributed to both adverse and salutogenic outcomes, regardless of planned place of birth. Home Birth Summit delegates were able to inform, design, and influence a transdisciplinary change process, and/or commit to measurable steps within their stakeholder groups.

The first Summit, facilitated according to the Future Search process (Weisbord and Janoff 2000; Weisbord and Janoff 2007; Klein 2012) for multi-stakeholder engagement, was not a conference, rather a structured process for opposing factions to discover common ground. The process was entirely interactive: no speakers, no papers, rather a structured set of cross-sector dialogues based on a successful model used in high conflict zones across the world. By the close of this first Summit, the delegates arrived at nine Vision Statements and formed as many multi-disciplinary Task Forces to address this Common Ground Agenda. They committed to work together to maximise equitable access to licensed providers; facilitate patient engagement, autonomy, and informed decision-making; and strive towards effective interprofessional collaboration across birth settings. They ultimately described a vision for an integrated system of maternity care.

The Common Ground Vision Statements were considered so significant and so timely that they were read into [Congressional Record](#) by Congresswomen Lucille Roybal-Allard (157 Cong. Rec H7634 2011, Roybal-Allard 2011). Over the past decade, as Chair of the Steering

Council for the Summit, I coordinated the continued transdisciplinary research and knowledge translation activities generated by those nine Action Task Forces. I authored the yearly renewable grants from the Transforming Birth Fund from the New Hampshire Charitable Foundation that supported this work, constituting over one million U.S. dollars. The delegates presented this work at the 2013 Institute of Medicine Workshop on Birth Setting, and at three subsequent national Home Birth Summits. This process and strategy led to the expansion of evidence and quality improvement measures that met the needs of a range of stakeholders, including health professionals, policy makers, women and families.

This thesis explores the nature of the ‘wicked’ problems addressed by the Summits, and the resulting transdisciplinary research findings and strategies that can address these areas of conflict and disarticulation. I was principal investigator for several of these research projects. I link my findings on divergence in provider attitudes and philosophy of care to women’s autonomy and options for care, the degree of midwifery integration into state health care systems, and disparities in pregnancy and childbirth outcomes across birth settings. My studies examine how the nature of interactions between service users, service providers, and health systems modulate person-centred outcomes. These factors together could explain why a novel model for transdisciplinary engagement at the Home Birth Summits (see Chapter 7) was essential to address the “wicked” problems of inequity in access, equity, and quality in US maternity care.

## **1.2 Research Question**

In this thesis, I interrogated the research question: Can transdisciplinary engagement improve access, equity, and quality in maternity care? I address this question through a series of publications; the methodology is described below, and manuscripts are presented in Chapters 4 and 5.

### 1.3 Research Objectives

I sought to engage with four research objectives in the process of examining my overarching research question:

Objective 1. Examine maternity provider attitudes about birth place and women's autonomy.

Objective 2. Explore how type of provider and place of birth modulates the experience of autonomy and respect in maternity care across diverse cohorts.

Objective 3. Describe how health systems variance in access to providers affects access and outcomes of childbearing care the United States.

Objective 4. Explain why a transdisciplinary, multi-stakeholder process can be an innovative, evidence-based, and effective strategy to improve person-centered care in highly contentious and complex areas of health services.

To address these objectives, I review findings from the published literature and present findings from new investigations that I led via five new manuscripts. These studies examined the sources and impacts of divergent provider attitudes on place of birth, described development and application of novel person-centered measures of the lived experience of maternity care, and quantified the linkages between the level of integration of providers across birth settings and disparities in outcomes and experience of care in North America. I examined data describing women's divergent experiences of respect, autonomy, and choice of birth place within environments that displayed wide disparities in regulation and integration of midwives.

In Chapter 2, I describe the approach I take to addressing my research question, linking the objectives to each research study, describing the methodologies used for each study, and introducing the frameworks that informed the synthesis of the studies.

In Chapter 3, I present findings from the literature on the "wicked problem" of interprofessional disarticulation in maternity care, including findings from my previous cross-sectional, national Canadian Birth Place Study of attitudes among maternity care providers (n=825), which demonstrated that 84% of the variance in favourability to home birth was

attributable to provider type alone. Triangulation of quantitative survey and qualitative focus group data suggested that increasing knowledge among all types of providers about quality and safety of birth place, and skills that support interprofessional collaboration, could improve access and outcomes of care across birth settings.

Next, in Chapter 4, I explore the literature on how other disciplines have capitalized on transdisciplinary imagination to address wicked problems, and how patient-oriented outcomes and community-based participatory action research can inform effective solutions. I introduce the Taming Wicked Problems framework, which I apply to the synthesis of my findings. Finally, I describe the transdisciplinary process undertaken at the Home Birth Summits.

In Chapter 5, I present Manuscripts 1-4, which report on the community-led development (Manuscripts 1,2, and 4) and application (Manuscripts 3 and 4) of new quality measures in Canada and the U.S. These papers demonstrate how these unique measures can elicit the lived experience of interactions with providers when making maternity care decisions, including complex concepts like autonomy, respect and mistreatment. Manuscripts 3 and 4 explore the links between experiences of care, birth place, and type of provider. The participatory process and design of these tools emerged from priorities identified at Home Birth Summit I, and informed discussions at Summits III and IV.

In Manuscript 5, found within Chapter 6, I report on the process and results of a multi-year health systems evaluation that required transdisciplinary engagement of Summit delegates. The study included development of a 50-state regulatory database, definition of optimal midwifery integration and creation of a weighted scoring system that facilitated linkages to population-based outcomes. This study demonstrates the potential for transdisciplinarity to elucidate complex interactions between health systems and access to providers, options for birth care, quality and safety.

Finally, in Chapter 7, to understand how to explain and replicate effective models that promote interprofessional collaboration, I undertake a closer examination of the Home Birth Summit process to see how transdisciplinary engagement worked. I explain the relationship of

the Summit structure, strategy and process to the Taming Wicked Problems Framework and Methodology of Transdisciplinarity, including discovery of a “Hidden Third” reality (Nicolescu, 2014). I link this process to the collaborative generation of pragmatic tools that can transform quality of care, including maternal experience and well-being.

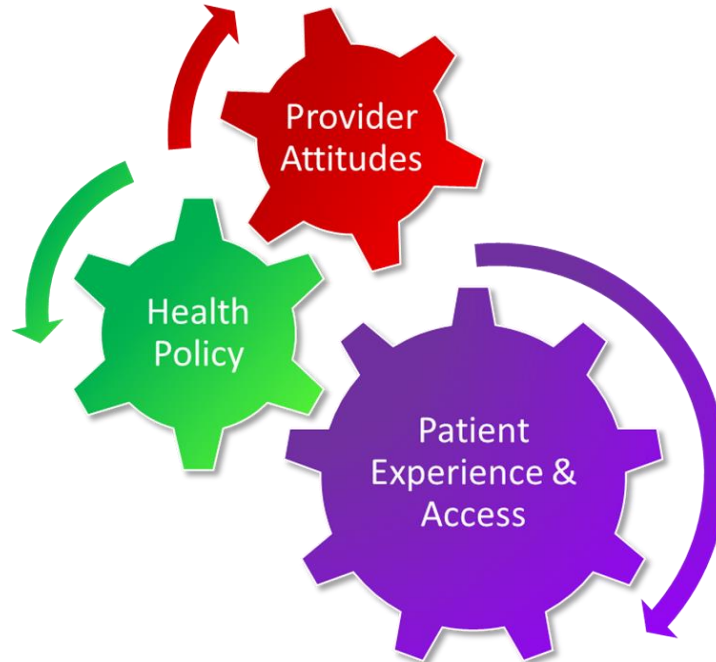
## **CHAPTER 2: Approach**

### **2.1 Introduction**

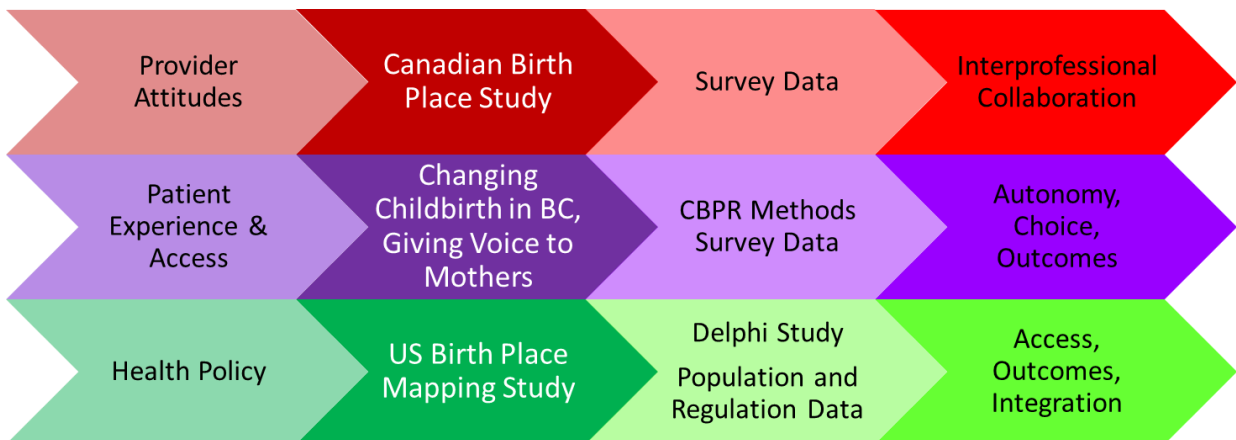
I designed this doctoral program to investigate and ultimately explain the impact of transdisciplinary engagement in research on addressing the complexities of improving equity, access, and quality in maternity service delivery. I synthesized findings of my research in three separate but intersecting arenas of influence: provider attitudes, patient autonomy and choice, and health systems conditions and constraints. Figure 1, below, illustrates the intersecting and cascading effects of provider relationships, on health systems and ultimately on person-centered outcomes, and why it was necessary to examine my research question from all three perspectives. The manuscripts further explicate these inextricable relationships.

The synthesis is based on original sources of data that both informed and were generated by the Summits. These studies utilized a range of methodologies that were appropriate to the study topic: a mixed methods investigation in the Canadian Birth Place Study; Delphi, regulatory and population-based outcomes analyses in the Access and Integration Maternity Care Mapping Study; and psychometric and survey data analyses from the critical participatory action research studies, Changing Childbirth in BC and Giving Voice to Mothers. Figure 2 names each data source, type of data available, and depicts the relevance of each source of data to my topic.

**Figure 1. Place of Birth: Policy, Practice, and Voice**



**Figure 2. Domains, Studies, Methodologies, Relevance of Data Analyses**



## 2.2 Addressing the Objectives

As described in Chapter 1, there are four objectives. The context and approach for each objective will be described in this next section. Table 1 displays the relationship between objectives and the studies.

Table 1: The relationship between the four objectives and the manuscripts

Objective	Manuscript	Methods	Summit Years	Chapter
1 Explore provider attitudes	<b>Canadian Birth Place Study</b> Triangulation to describe scope and nature of wicked problem	Mixed-methods: survey & focus groups	2011-2013	3
2 Understand links between provider, place, and experience, across diverse cohorts	<b>Changing Childbirth in BC</b> Manuscript 1-2: measure development Manuscript 3- BC provincial application	CBPR, Survey Psychometrics	2014-2017	5
2 Inequity in experience of care	<b>Giving Voice to Mothers</b> Manuscript 4 – U.S. national application	CBPR, Survey, Intersectional analysis	2015-2019	5
3 Examine Health systems effects & interactions	<b>Access and Integration Maternity Care Mapping Study</b> Manuscript 5	Delphi Population/Epi/Bivariate Regression	2013-2018	6
4 Examine Transdisciplinarity		Theoretical Framework	2011-2019	4
		Synthesis		7

### 2.2.1 To Examine Maternity Provider Attitudes Related to Birth Place and Women's Autonomy

My previous research, through the Canadian Birth Place Study (Vedam, Aaker, and Stoll 2010; Vedam et al. 2009b; Vedam, Stoll, et al. 2014; Vedam, Stoll, Schummers, Rogers, et al. 2014), suggests that divergence in attitudes to birth place across professional disciplines



contributes to interprofessional disarticulation and willingness to collaborate across settings for birth.

This study confirmed variations among provider beliefs about the normalcy of birth, the evidence on safety of home birth, comfort with interprofessional consultations during transfer, and risks of loss or liability from home birth. These findings on attitudes by provider type informed Summit I (2011) discussions and proceedings at Summits I and II (2011 and 2013). However, it was unclear how these provider attitudes interact with patient preferences, choice, access to or experience of care. During this doctoral program, I analyzed qualitative data from the Canadian Birth Place Study to elucidate provider motivation, interprofessional behaviours and opinions about service users choices. These findings are presented as background information in Chapter 3.

#### 2.2.2 To explore women's experience of autonomy and respect in maternity care.

In the Changing Childbirth in BC study, I worked with community members to explore preferences and experiences of maternity care, including the experience of decision-making. The participatory methods and initial findings of this study were informed by and informed the transdisciplinary discussions at Summit II and III. During my doctoral study, at the urging of delegates and study participants, I conducted and published the psychometric analysis and community based participatory approaches to development of two new instruments to measure autonomy and respect in maternity care. I then applied these tools in a mixed-effects modelling regression analysis of data from a geographically and socio-economically representative sample of women in British Columbia (n=3400 pregnancies).

The findings from this work are articulated in three manuscripts, included in Chapter 5:

- Vedam S, Stoll K, Rubashkin N, Martin K, Miller-Vedam Z, Hayes-Klein H, Jolicoeur G, the CCinBC Steering Council. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *Social Science and Medicine: Population Health*, 2017, 3: 201-210.

<http://dx.doi.org/10.1016/j.ssmph.2017.01.005>

- Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson, Jolicoeur G, the CCinBC Steering Council. 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. *PLOS ONE*, 2017,12(2): 1-17. <http://dx.doi.org/10.1371/journal.pone.0171804>
- Vedam S, Stoll K, McRae D, Martin R, MacRae L, Korchinski M, Jolicoeur G, CCinBC Steering Council. The Changing Childbirth in BC Study: examining autonomy in Canadian maternity care. *Patient Education and Counselling*, 2018, Nov 18: 1-12. <https://doi.org/10.1016/j.pec.2018.10.023>

Subsequently I undertook a national study, and developed a manuscript reporting on an analysis of health equity and differential access to respectful care. This study was only possible after the building of transdisciplinary trust, and years of effective collaboration with community stakeholders through the Summits. This resulted in the following publication that is located in Chapter 5:

- Vedam S, Stoll K, Khemet Taiwo T, Rubashkin N, Cheyney M, Strauss N, McLemore M, Cadena M, Nethery E, Rushton E, Schummers L, Declercq E. The GVM-U.S. Steering Council. Giving Voice to Mothers: inequity and mistreatment during pregnancy and childbirth in the United States. *Reproductive Health*, 2019, 16:77. <https://doi.org/10.1186/s12978-019-0729-2>

### 2.2.3 To Describe How Health Systems Variance Affects Access and Outcomes of Care

This paper describes a transdisciplinary research process that was undertaken to explore if variations in the regulatory landscape for midwives are linked to access to options for place of

birth and how the regulatory and interprofessional environment is associated with maternal and newborn outcomes. The paper is located in Chapter 6:

- Vedam S, Stoll K, MacDorman M, Declercq E, Cramer R, Cheyney M, et al. (2018) Mapping integration of midwives across the United States: Impact on access, equity, and outcomes. PLoS ONE 13(2): e0192523.  
<https://doi.org/10.1371/journal.pone.0192523>

#### 2.2.4 To Explain Why a Transdisciplinary, Multi-Stakeholder Process is an Effective Strategy to Improve Person-Centered Care

Finally, in Chapter 7, I synthesize my findings by tracing the trajectory of successful transdisciplinary engagement in four national Birth Summits held over a decade. This chapter explains why and how the Summit model succeeded in catalyzing effective transdisciplinary teams and sustained collaboration in this high conflict zone where previously the stark divergence in provider attitudes had prohibited even respectful dialogue. I describe the strategic and evidence based engagement of multiple stakeholders, the equity model and appreciative inquiry meeting model, and ongoing outcomes, with the context of the Taming Wicked Problems Framework, and best practices in transdisciplinary methodology and community based participatory research. The vision statements address previous areas of conflict and disarticulation across providers: autonomy, interprofessional education, collaboration, equity, physiologic birth, liability and licensure. I show how these emerged only because of the method of transdisciplinary engagement, and how that initial critical participatory process that included consumers, clinicians, and policy makers, lead to ongoing program of pragmatic, person-centered research, and development of community-responsive knowledge translation tools.

### **2.3 Relevant Methodologies**

Throughout my doctoral program I have employed, and learned to use, a variety of the most suitable methodologies in relation to the study design, conduct, analysis and knowledge translation of research. These include rigorous methods for survey construction and distribution,

community based participatory research, Delphi studies, health systems evaluation; psychometric, correlation, regression, and intersectional analyses. Because I addressed a complex, ‘wicked problem’ I needed to select and apply appropriate methods for the topic at hand. I detail these by study in this section.

### 2.3.1 The Canadian Birth Place Study (Objective 1)

The Canadian Birth Place Study involved five phases of a mixed methods study:

(1) expert review and construct validation of the existing instrument within a Canadian context; (2) administration of modified surveys to Canadian midwives and physicians, (3) analysis and dissemination of quantitative findings (4) focus groups with maternity providers and interviews of key informants, that provided qualitative data to clarify and elaborate findings of the quantitative survey and (5) triangulation of the qualitative and quantitative findings to describe sources of interprofessional disarticulation, and which identified and confirmed facilitators/ barriers to effective collaboration across birth settings. Quantitative findings from Phases 1-3, including psychometric testing of a multidisciplinary version of a Provider Attitudes to Planned Home Birth scale (PAPHB-m), and descriptive and bivariate findings were reported in previous publications (Vedam 2012, 2014) that provided background to this doctoral work but are not included as part of the thesis.

I also applied these data to examine divergence in attitudes to planned home birth within the single profession of midwifery. This North American cross-border comparison study, provided important background to this doctoral work. I linked findings from my 2007 survey of CNM members of the American College of Nurse-Midwives (n =1893); and 2) data from RM members of the Canadian Association of Midwives (n = 451) as captured by the Canadian Birth Place Study (S. Vedam, Stoll, Schummers, Rogers, & Paine, 2013). To compare the demographics, practice experience, and attitudes to home birth between these 2 types of North American midwives, I developed the Provider Attitudes to Planned Home Birth scale– international (PAPHB-i) (Schummers, Vedam, Fairbrother, Klein, & Kaczorowski, 2012) and used it as an outcome measure in descriptive and bivariate analyses (Vedam et al. 2013).

During my doctoral study, I analyzed the qualitative data from the Canadian Birth Place Study (Phase 4), and completed the triangulation Phase 5. I subjected the qualitative focus group data to systematic thematic analysis within an interpretative description framework based on work by Thorne which has been shown to be a pragmatic approach to analyze qualitative data arising from the applied health discipline research and that can enhance uptake and implementation by stakeholders (Thorne, Kirkham, & MacDonald-Emes, 1997). Though these qualitative findings are not presented in a manuscript as a component of my doctoral thesis, they have been presented at professional conferences (Vedam, Stoll, and Jolicouer 2016) and provided important background and insight into the characteristics of the intransigent ‘wicked problem’ that I address.

### 2.3.2 The Changing Childbirth in BC Study (Objective 2, Manuscripts 1-3)

This Canadian provincial, community-based participatory action research project, used an extensive content validation process including community consultations with 1300 women, literature review, and expert panel review, to develop with team guidance and support, four versions of a cross-sectional online survey (130 items) and focus group questions. We explored topics that have not previously been detailed including: women’s preferences for model of care; perceptions of reasons for intervention; access to midwifery care; and experiences of autonomy, respect, discrimination, or coercion, when participating in a clinical decision making process.

In the first phase of analysis the community-led Steering Council recommended the development and psychometric testing of two new scales that capture complex domains of patient experience. Psychometric analysis and testing confirmed reliability and validity of the instruments. The two scales, with Likert type responses, measure the degree of *Mothers Autonomy in Decision Making – MADM* (potential scores range from 7-42) and women’s experience of respectful maternity care – the *Mothers on Respect index - MORi* (range 0-7) (see Tables 2 & 3). Higher scores indicate that women had greater agency and received more respectful care.

For each pregnancy, women could report their experiences with up to three maternity care providers. In other words, women could contribute up to 9 rows of data. Mixed effects analysis controls for multiple observations from the same women, i.e. women reporting on multiple pregnancies and care providers. In the analysis, the random effects in the mixed-effects model included pregnancy (1, 2 or 3) nested within woman as women could answer for more than one provider per pregnancy.

### 2.3.3 Giving Voice to Mothers (Objective 2, Manuscript 4)

Using a community-based participatory action research model, I led a transdisciplinary team of delegates, clinicians, community based organization (CBO) leaders, and members of the target populations. Together we combined and adapted survey items from Listening to Mothers III, the Changing Childbirth in BC, and other instruments with validated items measuring experience of respect in maternity care to assess the experiences among women who planned home births in the United States, and women from communities of color. My team and I designed and conducted a formal expert content validation of the draft survey instrument. Community members from the target population rated each item on a quantitative scale for clarity, relevance, and importance. In addition to the previously validated Mothers Autonomy in Decision Making (MADM) and Mothers on Respect (MOR) index, community members requested the inclusion of metrics to capture institutional racism, non-consented care, mistreatment and factors associated with resilience in the face of challenging pregnancy experiences. In the analysis phases, the insights that the community partners brought informed a realistic coding rubric for the sociodemographic data, modelling for regression analyses (adjusting for differences in risk profile, ethnicity, multiple socioeconomic barriers, etc), using the MORi and MADM scale scores as an outcome measure. They also informed the development of culturally safe approaches to an intersectional analysis stratifying mistreatment by personal characteristics, models of care, and place of birth.

### 2.3.4 Access and Integration Maternity Care Mapping Study (Objective 4, Manuscript 5)

In order to explore the interactions between health systems constraints, provider attitudes, and patient experience, I led a multi-year mixed methods study in collaboration with a transdisciplinary team of regulatory, health systems, public health, consumer experience, epidemiology, anthropology, human rights law and medical ethics experts brought together at Summits 1-3). The 5 phases involved included:

- 1) development of a 50 state regulatory database,
- 2) a modified Delphi study to define and characterize the components of midwifery integration,
- 3) verification and validation of the ‘on the ground’ relevance, importance, and realities of integration through a 50 state survey of 90 regulatory and practice experts,
- 4) development of a weighted scoring system that could be used to calculate meaningful summary state integration scores (ranked by best conditions for patient access to quality care), and
- 5) correlation and regression analyses linking regulation and integration of midwives with place of birth; and also linking integration scores with national data on key maternal and newborn outcomes.

I also employed methodologies for innovative data display and knowledge translation to create interactive online maps, and “State Report Cards” to illustrate state-by-state access to regulated midwives, actual integration of midwives and impact of local interpretations of regulations. These were also important when reporting back to community members and policy makers visually, as they were easily understood by state regulators and others.

### **2.4 Summary**

In Chapters 1 and 2, I have described the reasons for asking my research question and my plan for understanding the potential a transdisciplinary process to address interprofessional conflict in maternity care. I introduced four studies that I conducted to explore the interrelationships between provider attitudes, patient experience, and health policy, linked them to the research objectives, and described the methodologies used in each investigation. In Chapter 3 and 4, I will review the literature that provides rationale for my approach.

## **CHAPTER 3: Background**

### **3.1 Introduction**

In Chapters 1 and 2, I presented my research question and objectives for this doctoral program, and described the approach and methodologies that I employed to address the complex problem that exists around place of birth in North America. In Chapter 3, I will review the literature that describes the nature of the conflict and disarticulation among service users, service providers, and health systems. I will present the evidence on preferences of place of birth among service users, and divergence in opinions and attitudes to place of birth among different types of maternity providers. By triangulating quantitative and qualitative findings from the Canadian Birth Place study, I will illustrate the relationships between patient autonomy and choice, provider attitudes, and health systems contexts.

### **3.2 The impact of birth setting on autonomy and self-determination during childbirth**

International investigators define “planned home birth” as the care of healthy pregnant women by skilled practitioners within a system that provides for referral to a hospital when necessary (Olsen & Clausen, 2012b). Rates of planned home birth vary across high resource countries, for example, 4-1.5% in North America, Japan, and Australia (MacDorman, Declercq, and Menacker 2011; Hilder, Zhichao, Parker, and Jahan 2014; Kataoka, Eto, and Iida 2013); 3.3% in New Zealand (New Zealand Ministry of Health, 2011), and 20% in the Netherlands (De Jonge et al., 2015). National guidelines for providers about what options should be offered also vary (National Institute for Health and Clinical Excellence (NICE) n.d.; Campbell et al. 2019; American College of Obstetricians and Gynecologists 2011; European Court of Human Rights 2014).

Women attribute their preference for planned home birth to a greater ability to control the environment and process of care (Boucher et al. 2009; Janssen, Henderson, and Vedam 2009; Cheyney 2008). They report that giving birth in their own setting changes the provider-patient dynamics, allows for inclusion of their family and community, and increases their privacy,



comfort, and sense of physical, cultural, and spiritual safety. The supportive and familiar environment facilitates the agency necessary to participate fully in decision making around options for care (Symon 2006; Declercq et al. 2013; Janssen, Henderson, and Vedam 2009; Blix 2011; Hildingsson, Rådestad, and Lindgren 2010; van Haaren-ten Haken et al. 2012; Boucher et al. 2009; Bailes and Jackson 2000). However, the ability to realize rights to autonomy and choice about place of birth assumes unrestricted access to high quality, skilled care across birth settings.

Divergent discipline-specific beliefs about risk and the sovereignty of patient autonomy can adversely affect interprofessional cooperation around access to options for care, including choice of birth place (Barclay et al., 2016; de Vries et al., 2013; Healy et al., 2016; Roome et al., 2016). When maternity providers situate choice of birth place at the center of interprofessional discussions, they often encounter ethical tensions around decision making, professional responsibility, and mutual interaction (Barclay et al. 2016; Chervenak et al. 2013; Kukla et al. 2009; Wendland 2007; Cheyney, Everson, and Burcher 2014; Nieuwenhuijze et al. 2014; McCourt et al. 2012).

### **3.3 The debate on safety in North America**

When patients and providers participate in an intentional birth place selection process, there is a skilled birth attendant, and, when necessary, transfer from home is to a receptive hospital environment, optimal outcomes can be achieved ( Cheyney, Bovbjerg, et al., 2014; De Jonge et al., 2015; Hollowell et al., 2011; Homer et al., 2014; Hutton et al., 2009; Janssen et al., 2015; Janssen, Saxell, et al., 2009; Olsen & Clausen, 2012a; Scarf et al., 2018; Schroeder et al., 2012). However, it is not possible to derive information on safety from a randomized controlled study, because very few women will consent to be randomized to birth site (Hendrix et al., 2009).

Since 2009, several large prospective cohort studies from Canada, the Netherlands, the UK and Australia have concluded that there were no significant differences in perinatal outcomes when comparing outcomes of births at home or birth centers to planned hospital births in a high resource country (Janssen 2009, de Jonge 2009, Hutton 2008, Hollowell et al., 2011, Scarf 2018).

Prior to the first Home Birth Summit in 2011, midwifery professional associations in the U.S. and Canada (American College of Nurse-Midwives, Canadian Association of Midwives, Midwives Alliance of North America, Royal College of Midwives, and National Association of Certified Professional Midwives), several consumer groups (Lamaze International, Childbirth Connection), and public health bodies (World Health Organization, American Public Health Association, American Association of Birth Centers) had issued policies and guidelines supporting the right of women to make an informed choice of birth place (Canadian Association of Midwives, 2001; Chamberlain & Patel, 1994; Governing Council of the American Public Health Association, 2001; Ministry of Health (Community Health and Culture), 1989; New Zealand College of Midwives, 2009; American College of Nurse-Midwives, 2003; World Health Organization, 1997). Most of these evidence-based guidelines note that planned home birth is associated with reduced interventions, increased maternal satisfaction, improved maternal outcomes, and cost-effectiveness.

In contrast, physician researchers were questioning the safety of home birth. In early 2010, the American Journal of Obstetrics and Gynecology published a meta-analysis by Wax and colleagues. These investigators concluded that "less medical intervention during planned home birth is associated with a tripling of the neonatal mortality rate." (Wax, Pinette, Cartin, & Blackstone, 2010, p. 1) Despite numerous questions about the quality of the American investigation (Michal, Janssen, Vedam, Hutton, & De Jonge, 2011), the American College of Obstetricians and Gynecologists published a guideline purporting support for informed choice but advising against birth outside a hospital (American College of Obstetricians and Gynecologists, 2011). In 2012, Chervenak and colleagues invoked the ethical concept of beneficence to suggest that planned home birth was so unsafe that provider had a responsibility to protect the unborn child by dissuading women from choosing home birth (Chervenak, McCullough, & Brent, 2012). The American Association of Pediatrics and the American Medical Association supported this stance (American Medical Association, 2013.; Lawrence et al. 2012). This sparked renewed debate among and within North American maternity

professional groups, and brought this discussion into the public sphere, including coverage by both the New York Times and the Washington Post.

In 2013, I collaborated with an ethics researcher to examine the links between the professions of investigators, and/or the professional association of the journal that published articles on home birth with the design of studies, interpretation of data, and direction of conclusions on safety of home birth. We found that the interpretation of these studies “coincide[d] almost perfectly with the profession of the first authors. Studies by midwives find no association between mortality and place of birth, while studies done by gynecologists/obstetricians find increased risk of perinatal/neonatal death associated with home birth.” (de Vries et al., 2013, p. 230). This suggests that provider attitudes are largely influential in how options for birth place are presented both to the public and to individuals.

### **3.4 Examining Interprofessional Disarticulation: Provider Attitudes**

Women and families are ill-served by interprofessional conflict and confusion about best practice in health care. Interprofessional teamwork is crucial to high-quality health care. Skillful collaboration across disciplines can reduce risk, particularly when care is transferred from low to high resource settings. For example, research indicates that fewer intrapartum neonatal and maternal deaths occur during critical obstetric events when professionals collaborate on decision making and when coordination of care is seamless (Cornthwaite, Edwards, and Siassakos 2013; Guise and Segal 2008). Poor communication, disagreement, and lack of clarity around provider roles have been identified as primary determinants of these adverse outcomes (Guise and Segel 2008; McCourt et al. 2012; Commission 2010; Cornthwaite, Edwards, and Siassakos 2013). Moreover, when patients perceive that interprofessional conflict is in play, their sense of safety is reduced (Manojlovich et al. 2014).

In the U.S., consumers and home birth providers frequently encounter a lack of receptivity, and even hostility, when transfer to acute care is warranted. This condition may delay timely transfer and significantly reduce continuity of care. Some models for effective

collaboration and communication exist in local maternity care systems, but there is no existing national venue to consider these problems and develop universal solutions (Vedam, Leeman, et al. 2014). In the United States the active debate on place of birth alongside increased public uptake of community-based birth (MacDorman, Declercq, and Menacker 2011) indicated the need for examination, constructive discussion and consensus-building around this issue. Moreover, recent national initiatives to address health care reform in the U.S. had highlighted the value of multidisciplinary collaboration when seeking innovative strategies to revise and improve systems for health care delivery (Petersen, 2006).

Differences in perspectives and philosophy among providers around place of birth have been described both by quantitative analyses (Vedam et al., 2012; Vedam, Stoll, White, Aaker, Schummers, et al., 2009), and qualitative analyses (Cheyney, 2008; Cheyney, Everson, et al., 2014); but until the Canadian Birth Place Study, the sources of conflict and controversy around place of birth had not been explored in depth. In the Canadian Birth Place Study, I examined the sources of these intra and interprofessional differences among midwives and physicians, and willingness to support choice of birth place and/or practice in community settings.

#### 3.4.1 Quantitative Survey Findings on Provider Attitudes

During the quantitative phase of the Canadian Birth Place study (2010-2011), Canadian obstetricians (n=835), registered midwives (n=759), and a random sample of family physicians (n=3000) were invited to complete a comprehensive survey that included information about their demographic profile, education and practice experiences with home birth (39 items), and 48 attitude items. Care provider type accounted for 84.2% (adjusted R<sup>2</sup>) of the variance in scores on a scale (PAPHB-m) measuring favourability attitudes towards planned home birth. Favourability scores among family physicians and obstetricians were significantly lower than midwives ( $p < 0.001$ ). Provider beliefs about the normalcy of birth, criteria for site selection, confidence in their ability to provide skilled emergency care, comfort with a familiar physical environment, and risks of loss or liability from home birth were aligned with the variance in attitudes by provider

type. Providers who agreed that “birth can only be described as normal in retrospect” had lower favourability scores (Vedam, Stoll, et al., 2014; Saraswathi Vedam et al., 2012).

#### 3.4.2 Qualitative focus group data on provider attitudes

During the period of my doctoral study, to further elucidate attitudes of physicians and midwives around place of birth within the interdisciplinary context, I conducted a qualitative analysis of 15 provider-specific focus groups across Canada. I sought to explain why and how provider attitudes are affected by practice experience, education, and exposure as delineated in the quantitative phase, and to describe the impact of financial factors, logistics of practice, and regulatory barriers related to scope of practice on attitudes and chosen site of practice among family physicians, midwives, and obstetricians. I explored the characteristics of interprofessional relationships as they interact with collaboration around home birth practice, seeking information on factors that may modify provider attitudes to planned home birth.

Focus groups (18) and interviews (5) took place in seven communities across Canada: Halifax, Montreal, Toronto, Regina, Comox, Nelson, and Vancouver. The focus groups were homogeneous to encourage open expression of conflicting professions-based perceptions of barriers to home birth, and they included physicians and midwives currently providing maternity care. Research sites were chosen to represent geographic diversity of the Canadian population and varying practice conditions including presence of regulated midwifery and percentage of births attended by family practitioners (from 60% in British Columbia to less than 20% in Ontario) (Hanvey, Levitt, Kaczorowski, et al., 2012). Rural settings were also included in the research sites in order to identify some of the issues that are unique to rural providers, rural geographies, and communities with diverse populations.

#### 3.4.3 Qualitative Findings

Obstetricians, midwives, and family physicians all spoke of negotiating divergence in philosophy, scope and practice. They discussed the impact of several factors on the nature of interprofessional relationships including experiences of consultation and collaboration during

transfer, knowledge of and exposure to each other's worlds, and their different philosophies of practice. Some participants attributed the degree of conflict or cooperation to modelling, and content of their health professional programs, but most agreed that personal relationships and exposure to individual practitioners was more powerful in shaping attitudes and willingness to collaborate. Trust and the time it takes to build trust was a key theme. Intraprofessional peer opinion reinforced negative stereotypes about each other. Health systems constraints including logistical, legal, and liability concerns adversely affected willingness to collaborate and were seen as insurmountable; but all providers noted that positive leadership by health systems and clinical leaders could transform the working environment. Considerable interest was expressed in the results of this study when it was presented at Summit III and as conference papers (Vedam S, 2015; Vedam, Klein, Stoll, Dharamsi, & The Canadian Birth Place Study Team, 2013).

The areas of greatest divergence emerged when discussing women's choice, perceptions of risk, and philosophy of practice. All providers believed that they supported physiologic birth, choice, and women centred care. Obstetricians and family physicians believed that women did not believe that physicians had their best interests in mind and could support them, and that midwives might reinforce negative opinions among clients. While midwives identified a difference between woman-directed vs woman-centered care, both midwives and doctors expressed a responsibility first to the woman vs peers. Pregnant women were framed by all professional groups as challenging to care for when their choices for care, including planned home birth and refusal of interventions, were outside community standard. Midwives perceived that they were often unfairly blamed for, or seen as being too tolerant of, non-adherence to recommendations. "Some MW [midwife] clients reject the standard of care in the community; OBs [obstetricians] don't appreciate if they get pulled into cases where women refuse all medical care". Overall the experience of transfer from home to hospital, regardless of maternal newborn outcomes, was most likely to increase a sense of vulnerability in both midwives and physicians, and adversely affect attitudes to planned home birth, and interprofessional collaboration.

### **3.5 Health systems integration: comparing the context of care between Canada and the U.S.**

There are some key differences in the organization of health care between the U.S. and Canada that presented challenges to advancing woman-centered care across North American birth settings. In Canada, all registered midwives are required by regulation to offer and attend planned home births (Canadian Association of Midwives, 2016). Canadian obstetric guidelines have increasingly evolved to recognize midwife-attended planned births in home and birth centers as a reasonable choice that all healthy term pregnant women should be offered (Campbell et al., 2019; Society of Obstetricians & Gynaecologists of Canada, 2011; Society of Obstetricians and Gynecologists of Canada, 2008). This evolution reflects a societal acknowledgment of rights to patient autonomy and person-centred approaches to care even when professional bodies disagree about the interpretation of the evidence (National Institute for Health and Clinical Excellence 2014; Campbell et al. 2019; Halpern 2009) .

As a group, Canadian midwives had so few differences in their favourable attitudes towards planned home birth, that it was not possible to evaluate or quantify factors that link to their favourable attitudes (Vedam, Stoll, Schummers, Fairbrother, et al. 2014). In contrast, U.S. Certified Nurse-Midwives (CNMs) display a range of favourability scores (Vedam et al. 2009a), that link to their level of clinical and educational exposure.

In 2014, prior to the commencement of the thesis, we linked data from 2 national surveys: 1) a 2007 survey of CNM members of the American College of Nurse-Midwives (n =1893); and 2) midwifery data from the Canadian Birth Place Study (n = 451) to compare the demographic and practice experience backgrounds that might explain the apparent differences in the range of attitudes to home birth (Vedam, Stoll, Schummers, Rogers, et al., 2014). By applying the Provider Attitudes to Planned Home Birth scale–international (PAPHB-i), we demonstrated that American Certified Nurse-Midwives (CNMs) have significantly less favorable attitudes towards home birth than Canadian registered midwives (RM). Descriptive and bivariate analyses demonstrated that while scope of practice, clinical competencies, and philosophy of maternity practice were similar between RMs and CNMs, CNMs were four times less likely to

have exposure to home birth education and practice; and those CNM participants that did provide care in the home expressed serious concerns about experiencing the disapproval of hospital-based peers.

In the U.S., while CNMs are licensed in all 50 states, less than 3% practice in homes or birth centers. Since the 1990's, planned home and birth center births have been primarily attended by Certified Professional Midwives (CPMs) who do not have access to hospital privileging, and in several states are not included in the panel of regulated and licensed providers (Cheyney et al. 2015). Overall CNM attitudes are more favourable than physician attitudes but their willingness to practice in the home align more with physicians than with CPMs. In the Canadian Birth Place study, the disagreement about the value and advisability of home birth was primarily between midwives and physicians, whereas, in the U.S., disparities in attitudes among available midwives and physicians towards the rights to choose place of birth and style of care are both *intraprofessional* and *interprofessional*. This disparate landscape for human health resource allocation means that service users in the U.S. have limited options for choice of birth place depending on the health care systems in their regions. Interprofessional disarticulation and conflict is associated with reduced access to safe systems for communication and delivery of care across settings in the U.S. throughout the childbearing year (Cheyney, Everson, and Burcher, 2014).

### **3.6 Conclusion**

In summary, when even when all types of providers accepted that planned home birth was embedded into the health care system, guardianship of normal birth and women-centered care was interpreted and implemented differently. Their knowledge of each other's roles and scopes of practice were intertwined with their attitudes, and attitudes to each other were intertwined with attitudes to choice of birth place. The degree of educational and clinical exposure to each other's practice affected their comfort, confidence, and willingness to work with each other to provide collaborative care. Visibility of optimal vs poor outcomes affected



favourability. They had very different understandings of the concepts of patient autonomy and risk. The nature of personal relationships, perceived power, and system leadership set the tone.

Differences in provider attitudes to birth place are a proxy for disparities in professional philosophies about patient autonomy, rights to self-determination, and the potential for risk in childbirth (Hall, Tomkinson, and Klein 2012; Healy, Humphreys, and Kennedy 2016a; Cheyney 2008; Barclay et al. 2016; Sandwick et al. 2018). These disarticulations affect the experience of care as well as maternal-newborn population health and well-being (Guise and Segal 2008; Reed, Sharman, and Inglis 2017). Service users from non-dominant and marginalized cultures are likely even more at risk when providers disagree and health systems constrain options or discourage interprofessional collaboration. (Reed et al., 2017; Sandwick et al., 2018). Most importantly, divergence in health professional attitudes and inability to collaborate are linked to critical delays in providing care, and adverse maternal and newborn outcomes, including psychological trauma (Guise and Segel 2008; McCourt et al. 2012; Commission 2010; Cornthwaite, Edwards, and Siassakos 2013; Polachek et al. 2015; Stramrood et al., n.d.; Riley et al. 2016).

## **CHAPTER 4: What is Known About How to Address This Type of Problem?**

### **4.1 Introduction**

In previous chapters, I described the scope, nature and impacts of the problem of disarticulation among providers, service users, and systems around planned home birth. This type of problem is often called a “wicked problem”. In Chapter 4, I will explain the characteristics of wicked problems that involve multiple stakeholders, and review the evidence on innovative ways to address these problems including transdisciplinary methods, community based participatory research and action, and person-centered approaches to health care. Then, I illustrate the relevance of these insights to the Home Birth Summits process and outcomes.

### **4.2 Wicked Problems**

The concept of “wicked problems” was coined in the context of urban planning (Rittel & Webber, 1973) and applies to many complex real world problems that involve multiple interacting systems and uncertainties. Wicked problems are embedded in societies and communities, and cannot be solved without investigators, decision-makers, and the victims of those problems exploring a range of options to effect change in that society. The sources of “wicked problems” are often contested, and they resist conventional ways to resolve them (Brown, Harris, and Russel 2010; Sharts-Hopko 2013; Burman, Aphane, and Mollel 2017) . Over the last decade, a community-university partnership in the Limpopo province, South Africa, have been developing a framework for building resilience to complex challenges that they call the Taming Wicked Problems Framework (Burman, Aphane, and Mollel 2017). They were inspired to this work as a result of a multi-stakeholder efforts to respond to the HIV AIDS epidemic in their community. Within the context of multi-faceted challenges of the HIV AIDS epidemic in South Africa, C.J. Durban summarizes the characteristics of wicked problems. They

“ are difficult to ‘identify and define’; have ‘no definitive solution that will resolve them’; solutions are ‘not correct or incorrect but rather they range from better to worse’; solutions ‘cannot be tested in the short term and are impossible to determine once and for all’; often attempts to solve a wicked problem ‘changes the problem but

does not necessarily alleviate it’; each wicked problem can ‘be explained in numerous ways, and one’s choice of explanation determines the solutions that will be generated’ – and whilst attempts to overcome wicked problems may change the dynamics of the situation, the efforts can sometimes generate unexpected outputs that are ‘potentially harmful’ (Burman 2018 adapted from Sharts-Hopko 2013:104).

Another feature of wicked problems is that they are typically non-linear, but rather reflexive, iterative, or circular so reinforce themselves. Bradbury and Vehrencamp (2014) suggest that to break these cycles of dysfunction we need to understand these interplays and system-level deficits before we can develop effective interventions. In addition, to change these systems, there needs to be a mechanism for exposing, understanding, and altering the hidden dynamics between the players (Coleman, Vallacher, Nowak, & Bui-Wrzosinska, 2007). This is especially germane when seeking improve maternal and newborn well-being and experience within the context of interprofessional disarticulation, divergence between priorities of communities and providers, and health systems barriers to access and/or equitable care.

Campbell and Cornish (2010) observe that wicked problems persist because they remain in the domain of “external experts” and solutions are “imposed on communities” and thus are not congruent with the needs, priorities, or lived realities of the populations experiencing the adverse events. This is true of unsolved complex problems in many fields, such as environmental and ecologic management, poverty and social disadvantage, or multi-generational and historical disenfranchisement of Indigenous populations. Strategic initiatives for these wicked problems require the input and expertise of different disciplines, but ultimately must be feasible and resonant within community realities (Chan et al. 2009; Browne 2017; Reed, Sharman & Inglis, 2017). Campbell and Cornish argue that ‘community involvement is a vital pre-condition for creating “health-enabling” social environments’ (2010, p.1570).

In 2018, in response to persistent global wicked problems facing women and girls’ reproductive health, the WHO published a Health and Human Rights report (High-Level Working Group., 2017) describing and transformative agenda based on the principles of equality,

inclusiveness, non-discrimination, participation and accountability. The authors recommend a shift from seeing people as passive recipients of health towards seeing them as active agents who are capable of making decisions about their own health care and who can inform sound policy implementation. However to do so they must have access to accurate, impartial and relevant information. To generate these data, the authors assert that community participation must move beyond consultation to “continuing dialogue between duty-bearers and rights-holders about their concerns and demands. For policies and interventions to be fully responsive to their needs and consistent with their rights, they should be designed and monitored in partnership” (p. 41) with communities. They suggest that a deliberate collaborative, multi-stakeholder process will expand and deepen the identification and descriptions of problems and thus strengthen the development of effective interventions beyond the purely biomedical approaches. They also note that the authentic inclusion of diverse voices in an equitable decision- making process can reduce mistrust, foster solidarity, and “reduce gaps between policy intent and policy acceptance.”

#### **4.3 Transdisciplinary Approaches to Addressing Wicked Problems**

In 2003, Dr. Michael C Lu, future director of the Maternal and Child Health (MCH) Bureau in the U.S. Department of Health and Human Services, published a landmark article suggesting that disparities across childbearing communities are linked to life course experiences, environmental exposures, and inequity in access to health services (Lu & Halfon, 2003). A decade later, he and others raised an alarm about a rising crisis in maternal newborn health outcomes (Halfon, Larson, Lu, Tullis, & Russ, 2014) where conventional approaches to this complex and multifaceted problem, were not stemming the tide. In 2014, Dr. Michael Lu, now head of MCH policy for the nation, introduced a road map for moving from isolated to collective impact, recommending multi-level cross-sector interventions to address life course research, practice, and policy in maternal and child health (Lu, 2014). He refers to a “whole person, whole family, whole community systems approach” to health policy reform first described by Kotelchuk and Fine in 2010 (Maternal and Child Health Bureau, 2010).

Recently a multidisciplinary team of researchers discussed a tilting at windmills approach of the activist educator, practitioner, or researcher who is concerned with effecting social policy reform (Sandwick et al., 2018). They contend that these issues are “wicked, entangle, and intractable, with myriad origins and mutations....and [indeed such] problems of capitalism, racism, sexism, xenophobia, and grotesque inequality gaps are unlikely to be ‘solved by a single policy intervention’” (p. 483). They suggest that unidimensional conceptions of the patient or community can mask a more intersectional view of structures and systems that interact with the lived experience of the service user. To expand our imagination for possible solutions they propose that multi-stakeholder teams elevate the community as the key informant or “expert” in a transdisciplinary strategic planning process. Because the “group” becomes relational and dynamic—rather than isolated and static—it is possible to envision novel solutions.

In 2011, this discourse on the value of transdisciplinary problem solving was already active in many fields including environmental and conservation science, education, materials science, and architecture (Brown et al., 2010). Entire *cross-disciplinary* academic fields had arisen and flourished as the new millennium entered: biophysics, human rights law, bioengineering, computer design, health management, etc. The terms and definitions are instructive and relate to the evolution of multi-stakeholder approaches to problem solving. *Multidisciplinary* activities draw upon insights from two or more disciplines that juxtaposes these insights and without seeking to integrating them (Szostak 2015). Similarly, *interdisciplinary studies* draw on the expertise of various disciplines to answer a question without defining a single, cohesive curricula or lines of enquiry. The National Academies of Sciences define interdisciplinary research (IDR) (2004) as investigations that “integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or area of research practice.”(p. 26)

*Transdisciplinary* research, education, or engagement, however, describes an ongoing process of discovery, involving stakeholders that are both inside and outside the “academy”

towards innovative, and unanticipated solutions. Basarab Nicolescu, quantum physicist, president, and founder of the International Center for Transdisciplinary Research and Studies (CIRET), explains four reproducible axioms that underpin a transdisciplinary process (Nicolescu, 2014; Torkar & McGregor, 2012):

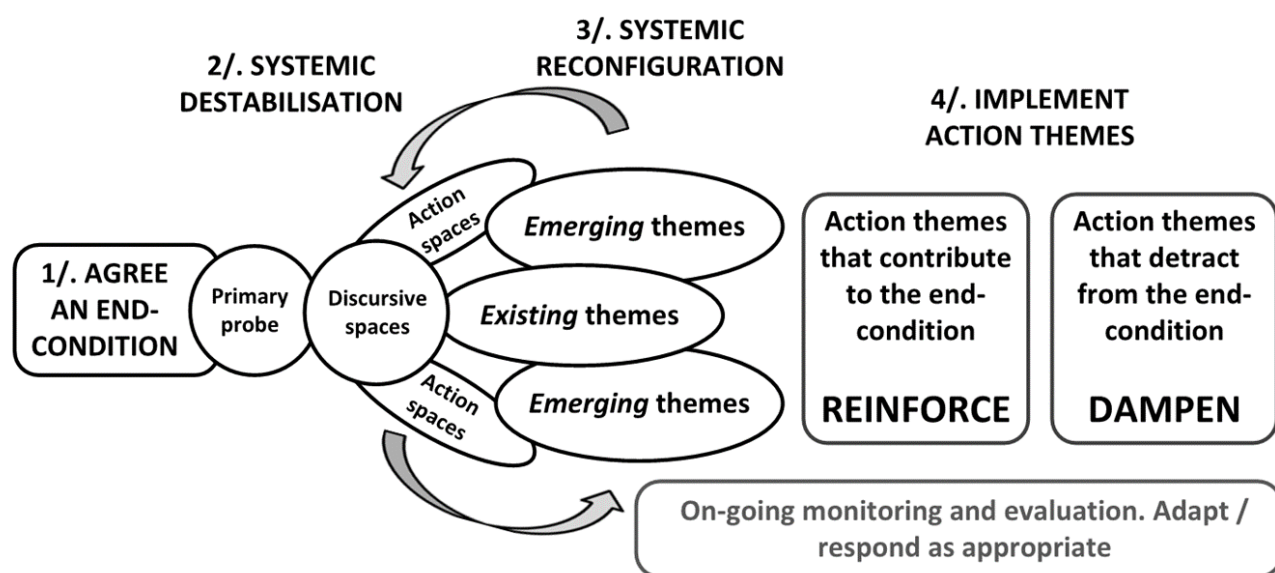
1. There are different levels of reality: an internal level of what we think, an external level of things and relationships, and a third level of reality that emerges only when we draw connections across such levels.
2. Understanding is stoked by discovery of ‘common ground’ around what different stakeholders think and want.
3. The critical goal is to comprehend the relationships that exist among and between the components of a system.
4. Since beliefs are infused with values, the transdisciplinary may often need to work actively to change values (adapted by Vedam from Nicolescu 2014).

*Interdisciplinary* initiatives may involve community or governmental stakeholders in their work but are concerned with the exploration of intersecting systems of thought, rather than actionable initiatives to address a social or cultural division. *Transdisciplinary* initiatives, however, are interested in pragmatic solutions based on new ways of thinking that are generated through engagement across disciplines, and especially with non-traditional partners (Szostak 2015). Nicolescu names this new knowledge the “Hidden Third” and suggests that it is only possible to discover this level of reality when exploring the space between factors inside complex systems, where the factors are inherently interdependent (Nicolescu, 2014). For example, in a multi-stakeholder process to explore access to high quality birth care across settings, the realities and priorities of providers, hospital systems, communities, women, and families are intersecting and overlapping even when they are divergent. If that “Hidden Third” emerges, discovering the common ground within those intersections holds the potential for envisioning a different future.

Burman designed a visual map (see Figure 3) to display the interplay and feedback system that emerges when an effective transdisciplinary process is active, that is called the ‘Taming Wicked Problems Framework’ (Burman, Aphane, and Mollel 2017). Like Nicolescu, he acknowledges the ‘discovery’ step where various disciplines must arrive together at a “Third” and new area of knowledge to arrive at a common ground agenda, that will neither be “random, nor entirely predictable” (p. 3). He also shows through the diagram that while there might be evidence-informed best practices to manage wicked problems like interprofessional conflict, they may not be enough to consistently avoid conflict; rather, sustained engagement will allow the system to evolve in an iterative fashion – producing new evidence that will feedback into the transdisciplinary process and catalyze novel and higher level initiatives.

Burman summarizes and synthesizes the literature to explain his model,

“...whilst it is not possible to produce replicable results that fit the criteria associated with evidence informed best practices, it is possible to manage them (Ramalingham 2013; Snowden & Boone 2007). The other aspects of complex systems that are relevant include (1) complex systems are made up of multiple agents that interact through feedback loops (Dunn et al. 2016); (2) agents are understood to mean any entity that influences the system (Sturmberg & Martin 2009); (3) the outcomes, or outputs, associated with complex systems emerge from the feedback interactions of the agents within the system (Shiell, Hawe & Gold 2008), and (4) the feedback processes that maintain the system are self-regulating (Pincus & Metten 2010), self-organising (Lee 1997) and self-sustaining... Emergence from a complex system is thus mediated by discrete and indeterminate interactions of the agents within the system.” (Burman 2018, p. 4)



**Figure 3.** The ‘Taming Wicked Problems Framework’. *Reproduced with permission from the author*

A coordinated transdisciplinary approach to wicked problems or interprofessional conflict in maternity care has been rare. In 2019, Dr Michael Lu predicted that the future of Maternal Child Health in the US would depend on our willingness to “work outside of our comfort zone in MCH, building collaborations across multiple sectors including education, housing, social services, economic and community development to address social determinants” (Lu 2019, 3). However, he notes that this will not occur spontaneously but will have to be an intentional transdisciplinary process. In 2011, shortly after the U.S. Birth Summit series first convened, Kania and Kramer (2011) described unprecedented success in troubled school districts when community leaders ‘abandoned their individual agendas’ to discover a shared approach to stimulating educational achievement. They termed this “collective impact” when there is “commitment of a group of important actors from different sectors to a common agenda for solving a specific social problem” (p. 36). They established five conditions for successful collaboration: a common agenda, shared measurement, coordinated and mutually reinforcing strategies, continuous communication, and backbone organization to achieve the greatest collective impact.



#### 4.4 Person-Centered Measurement of the Lived Experience of Health Care

Patient experience indicators are now collected at many US and Canadian hospitals, but they do not include patient-oriented measures of outcomes and experience of maternity care. In fact, experience of care has long been considered a “soft” outcome, and quality of care has been measured solely through externally observable data (Kennedy et al., 2018b). In maternity care, examples of key outcome metrics are rates of mortality, prematurity, blood loss, hypertension, operative delivery, and other biomedical metrics. The most value that institutions have assigned to the patient perspective has been to mount post care surveys of patient satisfaction. Unfortunately, satisfaction has been shown to be a poor discriminator of actual quality of health services and most tools used to measure satisfaction have not been tested for reliability or validity (Mpinga and Chastonay 2011; Sitzia 1999).

This poor state of health services evaluation is likely a result of a century of pursuit of objective, quantifiable evidence through scientific enquiry. Nicolescu questions this historical precedent, and proposes transdisciplinary methodology as a way to move beyond the limiting environment of traditional science, and elevate the perspective of the “Subject”:

“Modern science was ...founded on the idea...of a total separation between the knowing subject and Reality, which was assumed to be completely independent from the subject who observed it. Objectivity, set up as the supreme criterion of Truth, has one inevitable consequence: the transformation of the Subject into an Object. The death of the Subject is the price we pay for objective knowledge. The human being became an object—an object of the exploitation of man by man, an object of the experiments of ideologies, which are proclaimed scientific, an object of scientific studies to be dissected, formalized, and manipulated.” (Nicolescu, 2014, p. 186-187)

Nicolescu goes on to explain that in the transdisciplinary approach, the Subject, the Object, and the Hidden Third are interrelated. The new domain of reality that he calls “the Hidden Third” is a source of knowledge but, in turn can only be informed by the Subject who knows the reality, or the lived experience of care. He proposes that we must consider the human perspective to understand how to proceed when there is discontinuity between objective realities

of observers, because “no level of Reality constitutes a privileged place from which one is able to understand all the other levels of Reality.” (Nicolescu 2014, 192).

Patient-centered, or person-centered, or, in maternity, woman-centred models of care, prioritize the preferences of the service user, support informed decision-making, and enable the recipients to define the components of quality care. In maternity care, these features can increase access to respectful health care and build resilience in families with multiple forms of disadvantage. In fact, person-centered models of care have been linked to improved outcomes in underserved populations, as well as increased uptake of care, cost-savings, and reduced use of elective obstetric interventions, and reduced prematurity (McRae et al. 2018; Hickey et al. 2018). To address deficits in health service delivery, patient-centered care has become an international priority. Health care leaders, investigators and planners agree that optimal health care services should be focused on the service user, not the provider and administration (Janssen, Mitton, and Aghajanian 2015; McRae et al. 2016; Shaw et al. 2016; Wong et al. 2012).

Over the past decade, global health leaders have increasingly recognized the importance of involving the service user and patient partners in care planning, service delivery, and the identification of patient-oriented outcomes. More recently, there has been a shift towards evaluating patient experience as an indicator of quality, resulting in the call for development of new instruments that measure the impact of models of care on quality, safety and cost-effectiveness. In 2016, the WHO codified experience of care as a quality indicator in its own right. They established the Standards for Improving Quality of Maternal Newborn Care in Health Facilities (WHO, 2016), including standards calling for evidence based practices for routine care; effective communication and patient involvement in decision making; respect and preservation of dignity; provision of emotional support; and competent, motivated personnel to effect improvements in patient experience. To assess adherence to these standards new measures of person-centered care are necessary. In subsequent chapters, I will show how the Summit process led to the identification and generation of new metrics and instruments to assess quality of maternity care from the woman’s perspective.

## 4.5 Community Based Participatory Action Research

To capture the perspective of services users when addressing wicked problems in health care, we need to employ novel methodologies. Conventional data collection instruments (medical records, lab tests, vital records, administrative data) cannot capture the context of care for the recipient or their response. Individuals are influenced by the societies and communities they live in and sometime norms, cultural values, and interpretation of health care experiences are informed by the collective community experience.

To examine wicked, complex problems, some researchers recommend mixed methods approaches, linking objective medical outcome data to quantitative and/or qualitative from surveying or interviewing service users. However, typically the observer or investigator generates the topics of enquiry in mixed methods (Gómez, 2014; Mertens, 2015). To better inform study topics and dissemination plans, some investigators have broadened the research team to include researchers from diverse disciplines, community members, and policymakers (Gómez, 2014; Mertens, 2015; Witteman et al., 2018). However, collaborations solely between academics and policymakers can be plagued by conflicts of interests, values and goals, including conflicts of time, language, and values (Choi et al., 2005; Greenhalgh & Russell, 2006; Nelson, 2013), which then can disturb the trust and confidence of clinicians and patients alike in the emergent recommendations.

A recent narrative review of 55 studies (Harrison et al., 2019) elicited four key conditions for successful patient engagement in research and health policy reform: respect (cited in 43% of studies), equitable power dynamics among stakeholders (n=21, 38%), trust between patients and researchers (n=17, 31%), and inclusion of a diversity of stakeholders (n=12, 22%). Other principles that were cited less often but important included collaborative decision-making, flexibility of the engagement process, and support from institutional/organizational leadership.

Community-based participatory research is led or co-led by service users; their expertise guides the methods for community engagement and data collection, interpretation of data, and they decide how to tell the story (Jagosh et al., 2015). The plan for collecting data in culturally

safe and congruent ways as defined by the communities. Some may prefer to participate via survey, others through talking circles, others through one on one conversations with trusted community leaders. Researchers can counteract negative or distrustful relationships by being conscious of social and cultural positions and power dynamics that exist across stakeholder groups (Mertens, 2014, 2015; Jagosh et al., 2015). In addition, community-led research processes reduce the phenomena of blaming the victim when addressing wicked problems (Mertens 2015). Jagosh and colleagues (2015) applied a realist methodology via interviews of 11 academic-community partnerships engaged in longitudinal studies to understand what leads to sustainability of relationships, research and the development of novel, actionable, effective solutions. They concluded that the establishment of trust and a continuing commitment to co-creation and sharing the leadership power amongst the stakeholders was key to “(a) sustaining collaborative efforts toward health improvement; (b) generating [unanticipated] spin-off projects; and (c) achieving systemic transformations” (p. 1).

These findings about community based participatory action research methodologies align with the principles, and unexpected discovery of new ways of thinking and doing, that Nicolescu (2014) suggests transdisciplinary methodologies achieve. Together the features of these methodologies may provide a foundation to understand why the US Home Birth Summits were able to address wicked problems in maternity care. The Summits engaged diverse stakeholder groups in a meeting model based on equity, trust building, and discovery of common ground, which led to an ever-expanding understanding of stakeholder realities and unanticipated, transformational activities. In the following chapters, I will examine and show how the US Birth Summits were a departure from business as usual. I will explicate the multi-year transdisciplinary process that informed and catalyzed discovery of a Hidden Third reality, person-centred care, which lived as a sacred shared value and guide for a strategic plan.

#### **4.6 The Future Search Model for Transdisciplinary Engagement**

The Future Search Network (FSN) is a non-profit agency that supports stakeholders from diverse, and often opposing, viewpoints to untangle complex social, economic, technological, and environmental issues and challenges (Weisbord 2004; Weisbord and Janoff 2000; Weisbord and Janoff 2007). Developed by Marvin Weisbord and Sandra Janoff, Future Search is a unique strategic planning method based on a set of principles that maximizes the capacity of meeting participants to engage in cooperative action for the common good. Without having to defend or sell their own agendas or give up cherished values, large diverse groups of people with a history of conflict and disarticulation engage in purposeful dialogue to “(1) validate a common mission, (2) take responsibility for action, and (3) develop commitment to implementation” (Weisbord and Janoff 2007). Future Search meetings use a highly-structured methodology, which encourages self-management, innovation, and responsibility for action by delegates before, during, and after the meeting. Through the formalized process for consensus building, constructive action agendas are articulated, including taking responsibility for what happens next. However, at the onset of the meeting there are no pre-set goals or objectives. The outcomes are determined entirely through a process that engages all stakeholders from all perspectives within an equity framework (Klein, 2012; Schweitz & Martens, 2005).

This meeting methodology has been successful in brokering lasting agreements and shared initiatives in highly volatile and polarized settings, around a variety of issues related to poverty, health care access, regional and ethnic conflict, and education in Africa, Asia, Australia, Europe, India, and North and South America (Klein, 2012; Schweitz & Martens, 2005). Notably, FSN facilitated a meeting in the Southern Sudan between child soldiers, their advocates, and army officials responsible for conscripting child soldiers to discuss the future of the children outside the context of political differences. Resulting from this meeting, 16,000 child soldiers were demobilized and multiple schools were established. Other projects successfully reduced the spread of HIV AIDS in South Africa, Senegal, Nigeria and Ghana, addressed the fate of street children in Iran, rebuilt an integrated education strategy across 40 communities across Indonesia;

focused on drug abuse and drug trafficking in the Maldives; improved adolescent reproductive health in Ethiopia and the Philippines; and developed women leaders in Siberia. In the U.S., Future Search has also worked with numerous public health agencies including the Center for Disease Control and INOVA Health Systems, health care providers, health care administrators, and communities across the United States to address issues of health inequality. These projects have included initiatives to reform welfare policy and to reduce infant mortality in disadvantaged regions, to reduce economic, racial, and ethnic disparities in health care, and redesign of the patient care process, policy, and local practice around hospital/community collaboration (Halton, 2011; Klein, 2012).

#### **4.7 Future Search and the Home Birth Summits**

In 2008, I participated in a multi-stakeholder, provincial consensus conference on cesarean reduction in British Columbia. I was impressed to witness respectful and intentional dialogue involving clinician leaders, consumers, researchers, policy makers, and ethics experts inform a pragmatic strategic plan. As Chair of the ACNM Home Birth Section, I had spent eight years presenting proposals to the Board of Directors on behalf of CNMs that attended home birth who were struggling with untenable regulatory and practice conditions, with minimal effects on interprofessional collaboration around place of birth. At the Annual General Meeting, that year I proposed to the Board that it was time to convene a multi-stakeholder consensus conference, and the Board ratified our proposal, placing the responsibility back on the Section for how to achieve such a goal.

After serious consideration of multiple meeting formats, I recruited consultants from Future Search to facilitate the first Home Birth Consensus Summit. With the support and participation of leaders of all of the major maternity professional national associations including the American College of Obstetricians and Gynecologists, the American College of Nurse Midwives, the Midwives Alliance of North America, the National Association of Certified Professional Midwives, Lamaze International, the American Academy of Pediatrics, and the American Academy of Family Physicians, as well as consumer advocacy organizations such as

Lamaze, Childbirth Connection, and Our Bodies Ourselves, I raised funds and convened a multidisciplinary Vision Team in March 2009 for an exploratory meeting at the University of California, San Francisco. At that meeting, Sandra Janoff, Future Search founder, guided us through an intentional consensus process to identify a frame that would draw various stakeholders to a Future Search meeting. We agreed that while there was no agreement on safety of home birth or women's right to choose place of birth, all could agree that rates of home birth were rising (Declercq et al. 2010; MacDorman, Menacker, and Declercq 2010; MacDorman, Declercq, and Menacker 2011), and we had a shared responsibility to care for families who choose home birth. Next the Vision Team identified 23 perspectives that were critical to inform dialogue on place of birth.

The evidence on the most effective use of the Future Search Process provides guidelines on both maximum total participants (56-81), and balance of delegates across stakeholder groups. Previous successful Future Search meetings have shown that each group can have a maximum of nine members across no more than nine groups, hence the Vision Team identified some stakeholder groups as containing more than one profession (M Weisbord & Janoff, 2007). The following nine stakeholder groups were identified:

- Home Birth Consumers (parents and potential parents considering this option)
- Consumer Representatives (including doulas, childbirth educators, childbirth and women's health care reform and information agencies)
- Home Birth Midwives (CPM, CNM, LM, traditional, etc.)
- Maternal-Child Health Collaborating Providers (including paediatrics, labor and delivery nursing, neonatal care providers, CNMs who facilitate access for hospital admission)
- Obstetricians and OB Family Practice Physicians
- Leaders with expertise in Health Care Models, Systems, and Hospital Administration
- Insurance (Liability and Payors)
- Health Policy, Legislators, Regulators, and Ethicists
- Public Health, Research, and Education

The Future Search model for co-creation requires narrowing the focus and keeping the eye on the goals of the meeting when identifying stakeholder groups, and when nominating

delegates. Delegate nomination was a meticulous, intentional, and an iterative process with many rounds of vetting, internally and externally. Delegates had to belong to one or more of the nine sectors, and had opportunities to contribute their perspective from any of these viewpoints.

The delegate invitee list was then refined over the following year through multiple rounds of consultations with the [Steering Council, and a Planning Committee](#) of members who represented each stakeholder. The key elements for invited delegates were that each had one or more of these qualities: *authority, resources, expertise, information, or need* with respect to the future of home birth in the United States. Hence, multidisciplinary subcommittees, chaired by the Vision Team members who were most familiar with certain stakeholder groups, determined the final invitation list, selecting from an extensive list of highly qualified individuals. The final delegate selection process focused on achieving first a balance of perspectives (pro, con, neutral) in the whole room, as well as balance of ethnicities, gender, age, geography across the country. Finally, delegates were prioritized for their known ability to engage in respectful dialogue regardless of their affiliations, or expressed stance on this subject.

#### 4.7.1 Delegate Responsibilities

Home Birth Summit delegates were positioned within their professional, personal networks, or government bodies to inform and influence a change process, and/or commit to measurable steps within their stakeholder groups. The delegates however did not represent any organization but rather attended as individuals. As many of the attendees wore more than one hat in their personal and professional lives, they only committed to sit and dialogue within their assigned stakeholder group for one exercise within the meeting. The rest of the meeting they were in "cross-functional" groups and could speak from their many perspectives.

#### 4.7.2 Trust Building

At the start of the Summit delegates were each assigned to a circle of chairs (no tables or microphones) where they represented a single stakeholder group, such that each of 8 circles had 9 stakeholders representing different perspectives, and thus were microcosms of the "whole system". Several of the delegates had never had a face-to-face conversation with someone from a





The delegates stayed in the same cross-functional circles throughout the process of priority setting, eliciting barriers and opportunities, and visioning the future. The circles were small enough to learn each other's styles, life stories, and unexpected competencies (from singing, summarizing, challenging with diplomacy, role playing, listening). They had two opportunities to sit with like-minded delegates in single stakeholder groups, but their task was serious: What is your group proud of? *and* What are you sorry about (take responsibility for) when you think of the past? What will your stakeholder group commit to for the future?

#### 4.7.3 The Common Ground Agenda

Following three days of robust, respectful, and thoughtful dialogue, delegates at the first Home Birth Consensus Summit crafted a [Common Ground Agenda](#) (See Figure 5) of nine priority areas for action. In particular, delegates discussed the importance of building a maternal health care system that puts our most marginalized populations at the center, with the goal of improving health care for all. Since 2011, delegates from nine stakeholder groups have worked together to identify and facilitate solutions to challenging issues in pregnancy and birth care. While the conversation began with home birth and the needs of 1% of the childbearing population, it became apparent that the themes were cross-cutting and relevant to all service users. The areas of most significant concern that emerged were *access to high quality care across communities in all regions of the country; inequities in health care delivery and outcomes; variations in experiences of respectful care; inequities in access to health professional education; the scarcity of person-centered quality measures; and related challenges related to midwifery licensure and regulation.*

Delegates developed nine action initiatives to facilitate continuity of care across birth settings, ensure universal data collection, enhance informed decision-making, improve patient engagement, and develop curricula for maternity health professional educational programs on home birth and effective interprofessional collaboration.

**Figure 5**

## Home Birth Consensus Summit



### *The Future of Home Birth in the United States: Addressing Shared Responsibility*

The following statements reflect the areas of consensus that were achieved by the individuals who participated in the Home Birth Consensus Summit at Airlie Center in Warrenton, Virginia from October 20-22, 2011. These statements do not represent the position of any organization or institution affiliated with those individuals.

**STATEMENT 1:** We uphold the autonomy of all childbearing women.

All childbearing women, in all maternity care settings, should receive respectful, woman-centered care. This care should include opportunities for a shared decision-making process to help each woman make the choices that are right for her. Shared decision making includes mutual sharing of information about benefits and harms of the range of care options, respect for the woman's autonomy to make decisions in accordance with her values and preferences, and freedom from coercion or punishment for her choices.

**STATEMENT 2:** We believe that collaboration within an integrated maternity care system is essential for optimal mother-baby outcomes. All women and families planning a home or birth center birth have a right to respectful, safe, and seamless consultation, referral, transport and transfer of care when necessary. When ongoing inter-professional dialogue and cooperation occur, everyone benefits.

**STATEMENT 3:** We are committed to an equitable maternity care system without disparities in access, delivery of care, or outcomes. This system provides culturally appropriate and affordable care in all settings, in a manner that is acceptable to all communities. We are committed to an equitable educational system without disparities in access to affordable, culturally appropriate, and acceptable maternity care provider education for all communities.

**STATEMENT 4:** It is our goal that all health professionals who provide maternity care in home and birth center settings have a license that is based on national certification that includes defined competencies and standards for education and practice.

**STATEMENT 5:** We believe that increased participation by consumers in multi-stakeholder initiatives is essential to improving maternity care, including the development of high quality home birth services within an integrated maternity care system.

**STATEMENT 6:** Effective communication and collaboration across all disciplines caring for mothers and babies are essential for optimal outcomes across all settings. To achieve this, we believe that all health professional students and practitioners who are involved in maternity and newborn care must learn about each other's disciplines, and about maternity and health care in all settings.

**STATEMENT 7:** We are committed to improving the current medical liability system, which fails to justly serve society, families, and health care providers and contributes to:

- inadequate resources to support birth injured children and mothers;
- unsustainable healthcare and litigation costs paid by all;
- a hostile healthcare work environment;
- inadequate access to home birth and birth center birth within an integrated health care system; and,
- restricted choices in pregnancy and birth.

**STATEMENT 8:** We envision a compulsory process for the collection of patient (individual) level data on key process and outcome measures in all birth settings. These data would be linked to other data systems, used to inform quality improvement, and would thus enhance the evidence basis for care.

**STATEMENT 9:** We recognize and affirm the value of physiologic birth for women, babies, families and society and the value of appropriate interventions based on the best available evidence to achieve optimal outcomes for mothers and babies.

---

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

#### 4.7.4 Conclusion

In Chapter 4, I defined the concept of a wicked problem, and illustrated how my research topic fits this definition. Transdisciplinary and community based approaches to addressing wicked problems, require sustained engagement for divergent stakeholders to build trust, discover commonality, and move to action. At the first Home Birth Summit, delegates discovered and delineated a vision, but the transdisciplinary process of transformation was still nascent.

Delegates re-convened for two additional national Home Birth Summits in April 2013, and September 2014. Progress in this area has required stakeholders with historically opposing views to collaborate throughout the development and implementation of innovative strategies for increasing access to high quality care for all communities, and across settings for birth. Over the past decade, as Chair of the Steering Council, I coordinated the multi-disciplinary work of 9 action Task Forces who prioritized the advancement of evidence-based policy, consumer engagement, curriculum development, interdisciplinary collaboration, regulatory reform, and data collection related to birth place.

One of the most important outcomes was that many of these multi-stakeholder Task Forces continued to meet monthly for years. Since 2011, the Summit delegates group I led, have collaborated on several high-profile research, policy, and knowledge translation initiatives which have the potential to transform maternity care in North America. Some helped us to understand the scope of the problem and others offered pragmatic policy solutions and tools.

In Chapters 5 and 6, I present original research that both informed, and were informed by this multi-year transdisciplinary process of discovery. In Chapter 6, I trace the attractors, detractors and Hidden Reality that emerged, and explain the reasons for success and continued engagement despite the emergence of more complex wicked problems.

## **CHAPTER 5: How Do Provider Attitudes Affect Experience and Quality of Care?**

### **5.1 Introduction**

Access to person-centred care, including the rights to respect and autonomy in patient-provider interactions emerged as an underpinning theme in discussions, debates, and action initiatives during all three Home Birth Summits (2011, 2013, 2014). However, measures of the lived experiences of patient-provider interactions during maternity care were not yet available. During the 3 years between Summits, I completed the Canadian Birth Place Study and published my findings about divergence in provider attitudes to home birth. Yet, very little was known about how differences in attitudes among multidisciplinary providers may have affected the experience of making decisions about choice of birth place or obstetric procedures. Person-centred measures of maternity care were still scarce.

The transdisciplinary dialogue at the Summits, and my previous research in this area, informed development of new measures of autonomy and respect, that in turn facilitated understanding among the stakeholders. The participatory process for development and application of these measures are presented in Manuscripts 1-4. In Chapter 5, I introduce each of the papers with a summary of context in which the research occurred and the participatory and transdisciplinary approaches used.

### **5.2 The Need for Innovation in Measurement of Autonomy and Respect in Maternity Care**

How people are treated during childbirth can affect the health and well-being of mother, child, and family. A traumatic birth and loss of autonomy can have serious adverse impacts on postnatal mental health and family relationships (Ross and McLean 2006; Beck 2017; Otley 2011; Greer, Lazenbatt, and Dunne 2014; Stramrood et al., n.d.). The clash in cultural beliefs among providers about maternity care options and risk has been associated with the choice to have an unattended home birth (freebirth), or an attended high-risk home birth, despite maternity care provider recommendations for a hospital birth (Kornelsen et al. 2010; Andrew Symon et al. 2010; Dahlen, Jackson and Stevens, 2011; Jackson, Dahlen and Schmied, 2012).

These women believe that they were put at unnecessary risk by maternity care providers as a result of medical errors, the overuse of interventions, and their inability to participate fully in decision-making. Deficits in care and communication contributed to traumatic births that impacted their mothering ability and future maternity care decisions.

In 2016, just after the start of my doctoral program, the World Health Organization (WHO) published eight standards for assessment of quality of maternal and newborn care including “the extent to which health care services provided to individuals and patient populations improve desired health outcomes and [are] safe, effective, timely, efficient, equitable and people-centred.” (World Health Organization (WHO), 2016, p. 14). Earlier, in 2015, Bohren and colleagues (2015) published findings from a systematic review of 65 studies on experience of care during childbirth across 34 countries and a variety of geographic and economic contexts. The investigators reported widespread disrespect and human rights violations experienced by women giving birth. Citing a wide range of definitions and descriptors of disrespect and abuse, they created a consistent typology for assessing prevalence of mistreatment: physical and verbal abuse, neglect, discrimination, denial of autonomy, health facility and human resource deficits, and absence of emotional support (Bohren et al., 2015). The WHO subsequently affirmed that the ability for self-determination, participation in decision-making, and freedom from discrimination, harm and mistreatment are health human rights (Vogel, Bohren, Tunçalp, Oladapo, & Gülmezoglu, 2016; World Health Organization, 2018), that should be evaluated at the service provision level.

During my doctoral program of study, spurred by the consumer delegate demand for person-centred metrics and accountability measures, I addressed these gaps by leading the development and validation of two new scales, the Mothers Autonomy in Decision Making (MADM) and the Mothers on Respect (MOR) index, (Manuscript 1 and 2). These scales were developed during the knowledge translation phase of a provincial, community based participatory action research project, Changing Childbirth in BC. In the interpretation phases of that study, service users in Canada from diverse socio-economic backgrounds and

geographic contexts, concurring with the consumer delegates in the United States, prioritized an analysis plan focusing on the data points around respectful care. Two manuscripts (1 and 2) describing the development and psychometric testing of instruments that measure experiences of autonomy and respect when in conversation with maternity providers follow.

**Manuscript 1: The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth.**

<http://dx.doi.org/10.1016/j.ssmph.2017.01.005>





## Article

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



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

<sup>a</sup> Birth Place Research Lab, Division of Midwifery, University of British Columbia, 5950 University Boulevard, Vancouver, BC, Canada V6T 1Z3

<sup>b</sup> School of Population and Public Health, University of British Columbia, 2206 East Mall, Vancouver, BC, Canada V6T 1Z3

<sup>c</sup> Department of Global Health Sciences, University of California San Francisco, Mission Hall Building, 550 – 16th Street, 3rd Floor, San Francisco, CA 94158, USA

<sup>d</sup> Department of Obstetrics and Gynecology, University of California San Francisco, Mission Hall Building, 550 – 16th Street, 3rd Floor, San Francisco, CA 94158, USA

<sup>e</sup> Human Rights in Childbirth, 6312 SW Capitol Highway St, 234 Portland, OR 97239, USA

<sup>f</sup> Midwives Association of British Columbia, 2-175 E. 15th Avenue, Vancouver, BC, Canada V5T 2P6

## ARTICLE INFO

## Keywords:

Childbirth  
Human rights  
Participatory research  
Psychometrics  
Scale development  
Respectful maternity care  
Survey research  
Provider–patient communication

## ABSTRACT

**Background:** Abuse of human rights in childbirth are documented in low, middle and high resource countries. A systematic review across 34 countries by the WHO Research Group on the Treatment of Women During Childbirth concluded that there is no consensus at a global level on how disrespectful maternity care is measured. In British Columbia, a community-led participatory action research team developed a survey tool that assesses women's experiences with maternity care, including disrespect and discrimination.

**Methods:** A cross-sectional survey was completed by women of childbearing age from diverse communities across British Columbia. Several items (31/130) assessed characteristics of their communication with care providers. We assessed the psychometric properties of two versions of a scale (7 and 14 items), among women who described experiences with a single maternity provider ( $n=2514$  experiences among 1672 women). We also calculated the proportion and selected characteristics of women who scored in the bottom 10th percentile (those who experienced the least respectful care).

**Results:** To demonstrate replicability, we report psychometric results separately for three samples of women (S1 and S2) ( $n=2271$ ), (S3,  $n=1613$ ). Analysis of item-to-total correlations and factor loadings indicated a single construct 14-item scale, which we named the Mothers on Respect index (MORi). Items in MORi assess the nature of respectful patient-provider interactions and their impact on a person's sense of comfort, behavior, and perceptions of racism or discrimination. The scale exhibited good internal consistency reliability. MORi-scores among these samples differed by socio-demographic profile, health status, experience with interventions and mode of birth, planned and actual place of birth, and type of provider.

**Conclusion:** The MOR index is a reliable, patient-informed quality and safety indicator that can be applied across jurisdictions to assess the nature of provider-patient relationships, and access to person-centered maternity care.

## Body

Reports of disrespectful maternity care are emerging worldwide, despite protections against abusive treatment of women in health care settings as outlined in formal international Conventions on human rights (United Nations Commission on the Status of Women, 2016; Oviedo, 1997). Bowser and Hill's groundbreaking landscape analysis

(Bowser & Hill, 2010) provides an evidence-based definition of disrespect and abuse in childbirth which includes seven domains: “physical abuse, non-consented care, non-confidential care, non-dignified care (including verbal abuse), discrimination based on specific attributes, abandonment or denial of care, detention in facilities”. Bohren and colleagues, from the WHO Research Group on the Treatment of Women During Childbirth (Bohren et al., 2015) con-

\* Corresponding author.

E-mail address: [saraswathi.vedam@ubc.ca](mailto:saraswathi.vedam@ubc.ca) (S. Vedam).

<sup>1</sup> Changing Childbirth in BC Steering Council, c/o Birth Place Lab at UBC Midwifery.

ducted a mixed methods systematic review of 65 studies across 34 countries and concluded that there is no consensus at a global level on how disrespectful maternity care is measured. Their review added the domains of “poor rapport between women and providers, including ineffective communication, lack of supportive care, and loss of autonomy”, to Bowser’s examples of abuse and disrespect in childbirth. Bohren et al.’s paper ends with an urgent call to develop “validated and reliable research tools to measure the mistreatment of women in childbirth.” (Bohren et al., 2015).

While others have begun to develop tools to measure disrespect and abuse in childbirth in low resource settings, no published instrument has been developed by service users, or validated via a large dataset of childbearing women. In this paper, we describe a person-centered research process to develop a new quality and safety instrument that measures respectful maternity care.

### 1.1. Disrespect and abuse in maternity care

Most of the emerging literature on respectful maternity care focuses on low-resource settings (Sheferaw, Mengesha, & Wase, 2016; Warren et al., 2013). However, women who give birth in hospitals in the United Kingdom, United States, and Australia have also reported poor care by staff, including unkind and coercive treatment, and the trivializing of physical complaints, preferences, and personal needs (Brown, 1994; Declercq, Sakala, Corry, Applebaum, & Herrlich, 2013; Fraser, 1999). In their qualitative study of women’s experiences of hospital-based birth, Baker et al. reported that over half of British women interviewed ( $n=24$ ) commented on the negative attitudes and behaviors of midwives. Care providers were described as offensive, harsh, judgmental, insensitive, threatening, and abrupt (Baker & Precilla, 2005). At times, care providers treated women like children and intimidated them, which resulted in feelings of anger, inferiority, and resentment.

Lukasse et al. (2015) studied 6923 pregnant women in six European countries. They found that one in five pregnant women had experienced some form of abuse (e.g. being degraded, black mailed, insulted, or abused physically and/or emotionally) when receiving health services over her lifetime; and a history of abuse in healthcare was associated with increased fear of birth during pregnancy. Very little is known about the maternity care experiences of Canadian women. Published studies and reports are either outdated (Public Health Agency of Canada, 2009), focus only on vulnerable populations (Varcoe et al., 2013) or do not assess important dimensions of quality of care, i.e. maternity care free from abuse and disrespect (Reis, Deller, Carr, & Smith, 2012).

The WHO bulletin by Freedman et al. (2014) proposes a definition of disrespect and abuse as “interactions or facility conditions that local consensus deems to be humiliating or undignified and those interactions or conditions that are experienced as or intended to be humiliating or undignified”. They construct this phrase after considering multiple domains, including “Behavior that by local consensus constitutes disrespect and abuse”, “subjective experience”, “intentionality”....a woman’s “lived experience” and ....”deeper dynamics of power”.

Freedman also makes a distinction between normalized disrespect and abuse that women consider disrespect and abuse but providers do not, and behavior that women consider normal or acceptable but others consider disrespect and abuse. Among survey respondents in the Listening to Mothers Study III ( $n=2400$ ), 30% of black and Hispanic primiparous women and 21% of white women who delivered in hospitals in the United States reported that they sometimes or always felt “treated poorly because of a difference of opinion with [their] caregivers about the right care for [herself or her] baby” (Declercq et al., 2013). In the same study, 25% of women who had experienced an induction of labor or a cesarean section felt pressured to accept those interventions, 59% of women who received episiotomies did not give consent at all, and 63% of women experiencing a primary Cesarean section and 47% of women who had a repeat CS reported that the

provider made the “final decision” about whether they would receive cesarean surgery (Declercq et al., 2013).

### 1.2. Loss of autonomy and maternal outcomes

The right to informed consent and refusal enshrines the human right to autonomy in most nations. The American Medical Association and the American College of Obstetricians and Gynecologists have affirmed that informed consent is a basic principle of law and ethics that physicians must honor (American Medical Association, 2006). In *Ternovszky v. Hungary*, the European Court of Human Rights recognized that women’s decisions about childbirth are an expression of personal autonomy and as such are protected by Article 8 Right to Private and Family life (European Court of Human Rights, 2014b). The ability to make those decisions, however, depends upon the woman having both adequate information and respect for her decision-making capacity.

The Baker study (Baker & Precilla, 2005) established that women had little control over the decision-making process during labor, had inadequate information about birth options, and received interventions that were contrary to their preferences (Baker & Precilla, 2005). In the Baker study, women desired more information about the benefits and risks of certain procedures. The study concluded that inadequate information and sense of loss of control both contributed to feelings of disrespect (Baker & Precilla, 2005).

Women’s reports of care indicate that interventions are routinely imposed on them without meaningful informed consent. These violations can range from securing consent on the basis of inaccurate information, coercion, or threats, to performing interventions in the absence of consent, either without telling or asking the patient before the intervention, or performing the intervention over the patient’s explicit non-consent, sometimes with violent force (Bowser & Hill, 2010). Poor treatment has been linked to postpartum depression, post-traumatic stress and fear of childbirth during subsequent pregnancies (Lukasse, Schroll, & Karro, 2015). Post-traumatic stress disorder (PTSD) can result from negative birth experiences, and is associated with lack of involvement in decision-making, perceptions of inadequate care and feeling powerless (Creedy, Shochet, & Horsfall, 2000; Soet, Brack, & Dilorio, 2003).

Hodnett (2002) conducted a systematic review of 137 studies of factors linked to women’s satisfaction with childbirth. She found that care provider attitudes and behaviours most strongly influenced women’s experiences, rather than women’s characteristics (e.g. socio-economic status, race), the physical environment and medical interventions. In the Changing Childbirth in BC participatory research project, 95% of women said it was “very important” or “important to lead decisions about their maternity care” and those who had low scores on the Mothers Autonomy in Decision Making (MADM) scale indicated inability to direct their care (Vedam et al., 2015, 2017). Research suggests that the fear of mistreatment and loss of autonomy during childbirth can be directly linked to women’s unwillingness to seek life-saving measures from skilled providers, thus reducing access to basic health human rights (Abuya et al., 2015; Bohren et al., 2015; Jackson, Dahlen, & Schmied, 2012). This current paper focuses on measuring the experience of respectful/disrespectful care as it is correlated with sense of autonomy in decision-making.

### 1.3. Measuring respectful care

Leading global health agencies are prioritizing person-centered, respectful maternity care (International Federation of Gynecology and Obstetrics, International Confederation of Midwives, White Ribbon Alliance, International Pediatric Association, & World Health Organization, 2015; National Institute for Health and Clinical Excellence, 2014; White Ribbon Alliance, 2015; World Health Organization, 2015). The World Health Organization Research Group

on the Treatment of Women During Childbirth hopes to address the scarcity of evidence on the incidence, scope and impacts of disrespectful care, and develop tools to assess the quality and safety implications of abuse of human rights in childbirth (Bohren et al., 2015).

In African hospital settings, there are reports of physical abuse, non-consented care, non-confidential care, non-dignified care, discrimination, abandonment, and detention in facilities, that present a major deterrent to seeking out maternity care at hospitals (Abuya et al., 2015; Okafor, Ugwu, & Obi, 2015; Warren et al., 2013). For example, Abuya et al. (2015) conducted exit interviews with 641 women who delivered at thirteen hospitals in Kenya. One in five women reported some experience of abuse or disrespect: 8.5% reported violations of confidentiality, 18% experienced non-dignified care, and 14% reported being abandoned or neglected. Four percent received care they did not consent to, 4% experienced physical abuse and 8% were detained at the hospital because of non-payment of fees. The prevalence of any disrespectful or abusive treatment during childbirth in a representative sample of new mothers from Tanzania was 19.5% when assessed via exit surveys before leaving the hospital and 28.2% at follow up (when a subsample of women was interviewed at home). The most common events that were reported were being ignored (14.2%), being shouted at (13.2%), and threats from hospital staff (11.5%). Five percent of women were slapped or pinched (Kruk, Kujawski, Mbaruku, Ramsey, Moyo, & Freedman, 2014). Women in Tanzania ( $n=1388$ ) who experienced abuse/disrespect during childbirth were half as likely to want to return to the same facility to deliver their next child (Kujawski, MbarukuLynn, Freedman, Ramsey, Moyo & Kruk, 2015).

To date quantitative instruments to measure the incidence and characteristics of respectful maternity care are scarce. Vogel et al. (2015) propose to use their qualitative data about experiences with disrespectful and abusive care to inform the development of a quantitative measure specific to maternity care. In Norway one quantitative measure, the NorAQ scale (Swahnberg et al., 2003) measures lifetime history of abuse. The scale includes three items that measure 'Abuse in Healthcare'. The scale has been used with obstetric patients in Norway (Swahnberg et al., 2007) but does not specifically assess abuse during pregnancy and childbirth.

More recently, Sheferaw et al. (2016) described the development and psychometric testing of a 15 item scale that assesses respectful maternity care along four dimensions: friendly care, abuse-free care, timely care and discrimination-free care. Items were generated inductively, via in depth interviews with 8 postpartum women, pilot tested with 40 women, subjected to expert review and tested for reliability and validity by interviewing 509 women within 7 days of being discharged from hospitals and health centers in Addis Ababa, Ethiopia. Highly relevant to the Ethiopian context, the scale focused on the overall experience of care by health workers in a low resource institutional setting. It included items that describe situations that are rarely reported in high resource countries, such as being slapped by a care provider or being shouted at for not following care providers' instructions. Moreover, while in the process of developing the Ethiopian RMC scale extensive input was sought from women, the women did not select the key topics or design the items. This RMC scale focuses primarily on women's experiences of provider behavior during labour and birth, not on their ability to exercise autonomy without discrimination as they sought to participate as decision leaders over the course of maternity care.

In summary, there are few existing validated instruments that can be used to measure the extent and impact of respectful/disrespectful maternity care as affected by patient-provider communication. None have been developed by service users, or are appropriate for use as a quality and safety indicator across jurisdictions and settings. Our Changing Childbirth in BC and Giving Voice to Mothers studies responded to these gaps through a person-centered research process. This paper describes the resulting development and validation of a new scale, the Mothers on Respect Index (MORI) that measures women's

experiences when interacting with primary maternity care providers.

## 1. Methods

In 2012, our team was funded by the Vancouver Foundation to conduct a provincial community-led participatory action research (CBPR) project entitled "Changing Childbirth in BC: Women exploring access to high quality maternity care." A diverse community of childbearing women worked alongside community partners (e.g. leaders from non-governmental service agencies) and university researchers to design a mixed-methods study of maternity care in British Columbia (BC). Recognizing diversity in their perspectives and lived experience, the group self-organized into four work groups to address the needs of immigrant and refugee women, formerly incarcerated women, women facing multiple social and economic barriers, as well as midwifery and physician service users from urban and rural settings.

A community consultation with 1333 women determined key areas for study, and preferred modes of data collection and survey distribution. Based on their recommendations, the team developed a cross-sectional online survey to assess *preferences for model of care, experiences of decision making and respectful care, and access to maternity care providers*. An extensive content validation process included a literature review, an expert panel review, and community specific modifications by work groups. The CBPR process resulted in creation of four population-specific versions of a one-hour online survey that collected data on socio-demographics, preferences for maternity care, the process of decision-making, access to maternity providers, and experiences of care during the childbearing cycle.

### 1.1. Item development

Our team included women from all the target populations, psychometric experts, clinicians with over 30 years of experience, psychologists and sociologists. All of them participated in literature review to identify items from existing surveys and scales (e.g. Listening to Mothers I, II, and III, Perceptions of Racism, AMDD) as well as in new item generation, and ongoing expert content validation of the survey as a whole.

To examine aspects of the provider-patient relationship, the community members prioritized items that measure experiences of comfort, coercion, discrimination and/or autonomy when in conversation with their maternity care providers. They selected items on childbirth care, respectful care, and decision making from the Listening to Mothers surveys (Declercq et al., 2013; Declercq, Sakala, Corry, Applebaum, & Risher, 2002; Declercq, Sakala, Corry, & Applebaum, 2006), adapted some validated items from other tools, and generated new items. Professional team members who were midwives, nurses, psychologists, physicians, and health care administrators, provided a few additional items (e.g., length of prenatal appointments, reasons for change of prenatal provider), but these were then further vetted and approved by the four community work groups.

Across all four versions of the final survey, there were 310 total items, including slightly different questions on branching pages for specific populations (e.g. modified items for pregnancies that ended in loss, past tense for multiparas, present tense for currently pregnant respondents), and population-specific items for each vulnerable group (ie. on incarceration or immigration). Individual respondents were presented with 130 common core items, 31 of which were about the decision making process and experiences of communication with providers. To determine if women's experiences with maternity care differed depending on socio-demographic characteristics, the survey also included questions about women's race/ethnicity, family income, immigration status, age and pregnancy complications and outcomes. Finally, women were asked who their primary maternity care provider during pregnancy was. Each item was automatically populated with the care provider type that the woman identified in response to the

statement: “The following answers describe my conversations or experiences with my: family doctor, obstetrician, midwife, health centre nurse or other.”

### 1.2. Sample

Following ethics approval from the University of British Columbia, the survey was distributed via professional organizations, social media, and posters in clinical offices throughout the province of British Columbia (BC). The cross-sectional survey was open to women of childbearing age and their family members in BC. Respondents ( $n=4082$ ) from diverse socio-economic and cultural backgrounds provided survey data, including 2323 women with past childbirth experiences.

The community felt strongly that survey participants should be able to describe their maternity care experiences for up to two previous pregnancies and/or during a current pregnancy. Women who were cared for by more than one type of provider during pregnancy were able to report on experiences with each type of provider (obstetrician, midwife, family physician, health centre nurse). Hence, for the purposes of scale development, to avoid confounding by multiple observations from one woman, we limited our psychometric analysis to maternity experiences of women with a single provider during pregnancy ( $n=2514$  experiences from 1672 women). We also excluded pregnancy experiences from other provinces and countries, and those where the primary care provider was a nurse or ‘other’ because they did not reflect the primary care provider model in Canada.

We report socio-demographic characteristics for study participants as they described themselves at the time of data collection. To demonstrate that findings are replicable, we report psychometric results separately for two samples (S1 and S2) ( $n=2271$  experiences). Sample 1 included 1596 experiences, and Sample 2 included 675 experiences from women who reported on previous pregnancies. We did not include experiences from a subset of the 1672 women who were pregnant at the time of data collection ( $n=243$  experiences) because some scale items asked about experiences during birth.

### 1.3. Data analysis

#### 1.3.1. The Mothers on Respect index (MORi)

The survey included 14 items that measured aspects of patient-provider communication (see Table 1). Items 1–7 had three response options, and items 8–14 had 4 response options. We list these response options and how they were harmonized below. Initially, we evaluated the psychometrics of seven items that measure a woman's comfort when engaging with her primary maternity care provider over the course of her pregnancy (see items 1–7, Table 1). We examined the correlation between each scale item and the sum of all of the other items, to ensure that each individual item contributes to the same construct, and estimated internal reliability with Cronbach's alpha. We examined the factor structure of the seven-item scale via unweighted least squares factor analysis (no rotation) for both samples of women (S1 and S2) who had completed pregnancies (see Table 2). We only created scale scores for women who completed all 7 items, i.e. 849 women in sample 1, and 373 in sample 2. Higher scores indicate more respectful interactions with care providers.

We also considered the number of eigenvalues  $> 1$  and screeplots (not shown here), when determining the factor structure of the scale. Factor loadings, item-to-total correlations, screeplots and number of Eigen values confirmed that all 7 items measure a single construct which we recognized as “respectful maternity care”. Because of the patient-driven development of the items, we named this scale the **Mothers on Respect index (MORi)**. Finally, we report the proportion and selected characteristics of women who scored in the bottom 10th percentile of the MORi, i.e. those who reported the least respectful care. For the purpose of analysis, women who checked one or more complications (from a pre-defined list) were grouped together.

**Table 1**  
MORi – scale items.

<b>Overall while making decisions during my pregnancy I felt:</b>	
1	Comfortable asking questions
2	Comfortable declining care that was offered
3	Comfortable accepting the options for care that my (midwife, doctor) recommended
4	Coerced into accepting the options my (midwife, doctor) suggested (reverse scored) <sup>a</sup>
5	I chose the care options that I received
6	My personal preferences were respected
7	My cultural preferences were respected
<b>During a prenatal visit I held back from asking questions or discussing my concerns:</b>	
8	Because my (midwife, doctor) seemed rushed (reverse scored)
9	Because I wanted maternity care that differed from what my (midwife, doctor) recommended (reverse scored)
10	Because I thought my (midwife, doctor) might think I was being difficult (reverse scored)
<b>When I had my baby I felt that I was treated poorly by my (midwife, doctor):</b>	
11	Because of my race, ethnicity, cultural background or language (reverse scored)
12	Because of my sexual orientation and/or gender identity (reverse scored)
13	Because of my health insurance (reverse scored)
14	Because of a difference in opinion with my caregivers about the right care for myself or my baby (reverse scored)

<sup>a</sup> This item was re-phrased when it was administered to the US sample. The word coerced was replaced with pushed.

#### 1.3.2. MORi – Canada

Once we determined that the construct being measured was “respectful maternity care”, the team recognized that 7 additional items in the CCinBC survey also measured women's impressions and behavior related to being heard and respected during maternity care. However, during the survey construction phase, the community reviewers had selected different response options for these items. Hence, to evaluate these items for inclusion in a 14-item index, we recoded them to align all response options with the Y/N/NA options. For items 8–10 we recoded responses ‘Yes, once’ or ‘Yes, more than once’ into Yes, and ‘No’ and ‘Never’ into No. For items 11–14, we recoded responses from women who answered ‘Never’ into ‘No’ and responses from women who answered ‘Sometimes’, ‘Usually’ or ‘Always’ into ‘Yes’. We then added these additional 7 items to the MOR-1 index, for a total of 14 items (see Table 1). These 7 additional items were reverse-scored. Again, we only created scale scores for women who completed all 14 items, i.e. 833 women in sample 1, and 366 in sample 2. In a second phase of analysis, we confirmed that again higher scores indicate more respectful care, but that the 14-item scale evaluates 3 different dimensions of respectful care. The results of psychometric testing for both scale versions are discussed below.

#### 1.3.3. MORi – USA

In the summer/fall of 2016, the first author collaborated with community leaders across the United States to adapt and formally content validate the survey instrument, through a similar community based participatory process, with women from communities of color and women who chose home birth (Vedam, Stoll, Jolicouer & Martin, 2016). The study, called Giving Voice to Mothers, collects information about maternity care experiences among a sample of women who gave birth within the past 5 years. The 14 item MORi scale with harmonized Likert response options, (ranging from 1 – strongly disagree to 6 – strongly agree) was embedded in this survey. Data collection for the US study will complete in December 2016. However, the high response rate to date provides a robust enough cohort to examine the reliability

**Table 2**  
Corrected item-to-total correlations and factor loadings for the 14 item MORi.

Items	Sample <sup>a</sup>	% who agreed with item	Corrected Item-to Total Correlations	Factor loadings
<b>Overall while making decisions during my pregnancy I felt:</b>				
1 Comfortable asking questions	S1	92.7	0.64	0.70
	S2	95.8	0.54	– <sup>b</sup>
	S3	94.4	0.79	0.82
2 Comfortable declining care that was offered	S1	82.6	0.59	0.62
	S2	92.1	0.62	– <sup>b</sup>
	S3	88.1	0.79	0.82
3 Comfortable accepting the options for care that my (midwife, doctor) recommended	S1	91.1	0.71	0.79
	S2	94.6	0.59	– <sup>b</sup>
	S3	92.6	0.82	0.85
4 Coerced into accepting the options my (midwife, doctor) suggested	S1	12.7	0.48	0.52
	S2	13.2	0.25	– <sup>b</sup>
	S3	20.5	0.63	0.64
5 I chose the care options that I received	S1	86.4	0.56	0.63
	S2	93.4	0.52	– <sup>b</sup>
	S3	89.7	0.77	0.80
6 My personal preferences were respected	S1	90.0	0.73	0.80
	S2	94.4	0.65	– <sup>b</sup>
	S3	90.9	0.84	0.87
7 My cultural preferences were respected	S1	97.1	0.59	0.68
	S2	98.0	0.50	– <sup>b</sup>
	S3	94.7	0.75	0.79
<b>During a prenatal visit I held back from asking questions or discussing my concerns:</b>				
8 Because my maternity care provider seemed rushed	S1	23.9	0.48	0.49
	S2	16.0	0.42	– <sup>b</sup>
	S3	12.5	0.68	0.69
9 Because I wanted maternity care that differed from what my maternity care provider recommended	S1	14.0	0.53	0.54
	S2	10.4	0.55	– <sup>b</sup>
	S3	11.2	0.79	0.81
10 Because I thought my maternity care provider might think you were being difficult	S1	18.7	0.55	0.57
	S2	10.6	0.51	– <sup>b</sup>
	S3	15.2	0.75	0.76
<b>When I had my baby I felt that I was treated poorly by my (midwife, doctor):</b>				
11 Because of my race, ethnicity, cultural background or language	S1	1.4	0.30	0.36
	S2	0.5	0.11	– <sup>b</sup>
	S3	2.4	0.53	0.57
12 Because of my sexual orientation and/or gender identity	S1	0.3	0.19	0.25
	S2	0	–	– <sup>b</sup>
	S3	0.9	0.47	0.69
13 Because of my health insurance	S1	0.5	0.18	0.23
	S2	0.5	0.13	– <sup>b</sup>
	S3	3.6	0.52	0.56
14 Because of a difference in opinion with your caregivers about the right care for yourself or your baby	S1	10.5	0.54	0.57
	S2	6.4	0.51	– <sup>b</sup>
	S3	11.2	0.72	0.76

<sup>a</sup> S1 refers to Canadian Sample 1; S2 refers to Canadian Sample 2 and S3 refers to the US sample.

<sup>b</sup> Factor analytic results cannot be displayed for sample 2 because of 0 variance for item 12.

and construct validity of the measure in a more racially diverse sample. The US sample ( $n=2357$  started surveys) included 58.3% Caucasian women, 11.2% Black women, 8.4% Hispanic/Latina women, 3.4% Native Alaskan, Native Hawaiian or other Pacific Islander women, and 18.7% of women who identified as Asian, African, other or biracial.

## 2. Results

### 2.1. Demographics

Participating women were 32.6 years old, on average. By linking postal codes to provincial data by health authority, we determined that our sample was closely matched to the socioeconomic, age, and geographic distribution profile of childbearing women in BC. Two-thirds of the 2514 care provider experiences reported were about care

by midwives (1723, 68.5%), and the rest about care by family physicians (500, 19.9%) and obstetricians (291, 11.6%). Nearly one in ten represented the experiences (243; 9.7%) of currently pregnant women.

Women were able to self-identify as recent immigrants or refugees, and/or describe multiple barriers (e.g. history of substance use, poverty, homelessness or incarceration). In total 75 (4.5%) women with these challenges completed the survey, and several more described their experiences during population-specific focus groups without completing the survey. Most women self-identified as White (92.5%), with the largest representation from minority groups being Chinese (1.6%) and First Nations, Inuit, or Métis (1.8%). Group socioeconomic characteristics included 8.2% women with family incomes < \$30,000 (CAD) and 10.2% with no post-secondary education.

The majority of the pregnancies were low risk; however, 10.2% of

women reported at least one medical or social risk factor (high blood pressure, diabetes, fetal growth problems, fetal status compromised, depression, lack of social support during pregnancy, or unstable housing). In addition, 18 women (1.1%) reported on experiences during twin pregnancies.

## 2.2. Item-to-total correlations and factor structure

Corrected item-to-total correlations for the 7 item MOR index exceeded 0.45 for all items in Sample 1, providing strong evidence that the scale is uni-dimensional, i.e. measures one underlying construct (Roberts & Yeager, 2004). Factor loadings for the MORi scale items ranged from 0.52 to 0.82 for Sample 1, and 0.21–0.76 for Sample 2 (see Table 2). For Sample 2, lower item-to-total correlations and factor loadings for item # 4 of the MOR index (“Overall while making decisions during my pregnancy/birth care I felt coerced into accepting the options my care provider suggested”) suggest that this item does not fit as well with the other scale items for women who had a previous pregnancy.

Corrected item-to-total correlations for the 14-item version of the scale ranged from 0.18 to 0.73 (S1). Factor analysis of the 14-item version of the scale revealed a three factor scale for Canadian sample 1, i.e. items 1–7 and 14 grouped together, as well as items 12 & 13 and items 8–10. Item 11 cross-loaded on factors 1 & 2. Evaluation of the items that loaded together reveal three logical domains that describe the participant's reactions to respectful/disrespectful care: sense of autonomy and comfort; modified behavior; and perceptions of discrimination. Because item 11 cross-loaded and 2 of the sub domains have less than 3 items (i.e. do not have the minimum number of items needed for a subscale), we elected to conceptualize the 14 item MORi as a unidimensional scale. Factor loadings for the Canadian and US samples are presented in Table 2. While a few lower factor loadings were observed with the Canadian sample (See MORi items 11–13), when administered to a more racially diverse sample of American women who gave birth in the last 5 years, we found factor loadings > .45 for MORi items, indicating a unidimensional scale. The harmonized response options and high relevance of some of the items to the US context (i.e. items about poor treatment as a result of race and health insurance status) likely explain differences in the Canadian and US factor analytic results.

## 2.3. Internal consistency reliability

In Canada, for the 7-item MOR index, Cronbach alphas were good for women in S1 (0.85) and S2 (0.76). Alpha could not be calculated for the subsample of currently pregnant women because of low response variance (i.e. almost all women choose ‘yes’ on all items). For the 14 item MOR index, Cronbach alphas were 0.85 (S1) and 0.80 (S2).

The Cronbach's alpha for the US sample ( $n=1613$ ) was 0.94. Corrected item to total correlations ranged from 0.43–0.84. The unweighted least squares factor analysis showed that 13 items loaded above 0.55 on factor 1 and one item loaded above 0.45. Although two Eigenvalues were above 1 and the scree plot indicated either a one or two factor solution, given the high factor loadings on one factor and the overall low loadings on the second factor (ranging from – 0.04 to 0.50) we confirmed the 14 item MORi index as single construct scale.

## 2.4. MORi scores among women in BC

Descriptive analysis using scores for individual items on the MOR index showed that, in British Columbia, most women reported that their personal and cultural preferences were respected, and that they were comfortable asking questions while making decisions during pregnancy and birth. Fewer were comfortable declining care that was offered, and approximately 1 in 10 reported feeling **coerced** into accepting options their care provider suggested. Poor treatment

“because of a difference in opinion with their caregivers about the right care for themselves or their baby” was reported by 10.5% of women in sample 1 and 6.4% of women in sample 2. The most common reason women “held back from asking questions or discussing concerns” was the perception that care providers were rushed. Women reported that they also held back their questions and concerns because of differences in opinion with their care providers, and fear that the care provider “might think [she] was being difficult.” (see Table 2).

Women with self-reported risk factors (high blood pressure, diabetes, compromised fetal status, depression, lack of social support, or unstable housing) were more likely to score in the bottom 10th percentile of the MOR index, compared to women with no reported risk factors. Women who reported one or more of these medical or social risk factors during pregnancy were four times as likely to have low MORi scores (19.8% versus 5.2%). Similarly, women who were recent immigrants or refugees, or had a history of substance use, incarceration, poverty and/or homelessness, were more likely to have very low MORi scores, (13.5% versus 6.3%), compared to women who reported no barriers. In this BC population, poor treatment from care providers because of sexual orientation, race or women's insurance status was very rare. The likelihood of scoring in the bottom 10th percentile was similar for women of color versus white women (see Table 3).

Women who planned a home birth and gave birth at home were unlikely to score in the bottom 10<sup>th</sup> percentile of MORi, and they were least likely to report overall experiences of disrespectful care. However, 16.2% of women who needed to be transferred to hospital from a planned home birth reported very low MORi scores and were much more likely to score in the bottom 10th percentile of the MORi scale compared to women who gave birth at home (0.5%) or those who planned a hospital birth (8.8%).

Women under the care of midwives were the least likely to have low MORi scores (see Table 3). Women who reported on their experiences with midwives were also less likely to have low MORi scores; 3.6% of midwifery clients, compared to 15.3 % of women who saw family physicians during pregnancy and 21.6 % of women who saw obstet-

**Table 3**  
MORi scores (7 item version), reported by selected indicators ( $n=1672$ ).

	<i>n</i> (%)	MORi scores 0–10th percentile <i>n</i> (%)
<b>Self-reported pregnancy complications</b>	170 (10.2)	19 (19.8)
Yes	1502 (89.8)	42 (5.2)
No		
<b>Place of birth<sup>a</sup></b>	928 (66.8)	41 (8.8)
Planned hospital birth, delivered at hospital	120 (8.6)	12 (16.2)
Planned home birth, delivered at hospital	308 (22.2)	1 (0.5)
Planned home birth, delivered at home		
<b>Primary maternity provider</b>	288 (17.2)	20 (15.3)
Family Physician	179 (10.7)	16 (21.6)
Obstetrician	1205 (72.1)	25 (3.6)
Midwives		
<b>Vulnerable status</b>	75 (4.5)	7 (13.5)
Yes	1597 (95.5)	54 (6.3)
No		
<b>Race/ethnicity</b>	1296 (93.0)	41 (5.6)
Self-identified as Caucasian	97 (7.0)	5 (7.9)
Self-identified as woman of color		
<b>CS</b>	97 (6.9)	18 (38.3)
Yes, pressured into decision	151 (10.7)	5 (6.9)
Yes, not pressured		
<b>Induction</b>	112 (7.9)	17 (27.9)
Yes, and pressured into it	113 (8.0)	4 (7.0)
Yes, and not pressured into it		

<sup>a</sup> Not all place of birth options are listed.

tricians. Higher scores among women who saw midwives persisted regardless of birth setting; 3.1% of women who planned a home birth with midwives reported disrespectful experiences and 4.4% who planned a hospital birth. In contrast, 22% of women who planned a hospital birth reported experiences of disrespect when describing encounters with physician providers.

### 3. Discussion

Measuring respectful care over the childbearing cycle requires thoughtful assessment of several domains. We have constructed a reliable and validated instrument that assess the culture of dialogue in maternity care. The MOR index is a straightforward tool to measure the experience of respect during discussions with providers about maternity care options. The index captures a complex set of effects and interactions related to three domains within the experience of respectful maternity care: 1. a woman's sense of autonomy and comfort when accepting or declining care options, 2. evidence of the woman modifying her behavior as a result of fear of anticipated disrespect, and 3. perceived differential treatment as a result of a non-modifiable socio-demographic factor. The significance of the first two domains is supported by findings of Lukasse et al. (2015) that loss of agency and poor treatment leads to fear. The third dimension, differential treatment based on race, ethnicity or personal characteristics, measures the occurrence of violations related to stigma and discrimination as described by both Bowser and Bohren (Bohren et al., 2015; Bowser & Hill, 2010).

In 2012, the USAID Maternal Child Health Integrated Program commissioned a comprehensive report on the state of “respectful maternity care” (RMC) across low and high resource countries (Reis et al., 2012). The authors concluded “safe motherhood must be expanded beyond the prevention of morbidity or mortality to encompass respect for women's basic human rights, including respect for women's autonomy, dignity, feelings, choices, and preferences.” The report identified key areas of disrespect and abuse in each country and described the major challenges to improving conditions for women in Canada as, “limited political will, institutional commitments, and plans to implement RMC, lack of accountability of doctors and their dominance over maternity care, and lack of specific training related to RMC for nurses, ob-gyns, anesthetists, and pediatricians”.

In our provincial study, Changing Childbirth in BC, a diverse community of childbearing women concurred with the USAID report and global researchers when they identified respectful care and the process of decision-making as core topics for study. They decided to include strongly worded items to evaluate the extent of coercive behaviors among providers. There was an overwhelming response from women and their family members from many socio-economic & cultural backgrounds across the province; 4082 respondents (including 392 from vulnerable populations) provided survey data and over 1100 women wanted to participate in focus groups, confirming the importance and currency of these topics.

While overall the MORi scores reflect a respectful environment in BC, over 10% of women reported that they felt **coerced** into accepting options for care, across provider groups. Women who were cared for by midwives and those who planned home births had overall higher scores, signifying respectful care.

Women from vulnerable populations were more likely to score in the bottom 10<sup>th</sup> percentile of the MORi scale. This finding is consistent with reports on reduced access to high quality health care experienced among recent immigrants, refugees, incarcerated, street-entrenched and homeless individuals (Thomson, Dykes, Singh, Cawley, & Dey, 2013). Fear of disrespectful behavior in institutions has been identified in both low and high resource countries as a major deterrent to seeking out essential maternity care at hospitals (Abuya et al., 2015; Jackson, Dahlen, & Schmied, 2012; Symon, Winter, Donnan, & Kirkham, 2010). The MOR index could inform quality improvement initiatives

aimed at increasing adherence and access to skilled attendants, and/or life-saving measures, for vulnerable populations.

#### 3.1. Measuring quality: shared decisions or disrespect?

Three of the MORi scale items that measure how a sense of respect affects patient behavior may provide some insight into differences in scores across providers. “Holding back their questions because of” a sense of time pressure implies that they were not able to adequately engage in a decision-making discussion with the provider. In the Canadian model of maternity care, the obstetrician is least likely to have the time during prenatal, labor or birth to develop a trusting relationship or engage in ongoing discussions about options for care. In contrast, Canadian midwives are mandated by regulatory language to initiate and engage clients in informed choice discussions. Accordingly, the time needed to revisit topics and facilitate the patient-directed evolution of a care plan is built into the payor model (fee per course of midwifery care). Family physicians may have limited time allotted to each prenatal visit but their model of care is inherently relationship-based, sometimes over several years. Family physicians also typically have a limited obstetric caseload, perhaps allowing them more time to be present with laboring patients. A focus on a shared decision making process is emerging in medical education and health institutions, and has been linked to evidence of quality care in midwife-led units (Ten Hoope-Bender et al., 2014; Sandall, Soltani, Gates, Shennan, & Devane, 2015).

Women who reported medical or social risk factors had lower MORi scores than women with no health concerns during pregnancy. This suggests that the experience of respect might interact with the need to engage in a decision making process with maternity providers. The MORi scores suggest that, in BC, women experienced disrespect when they had “differences of opinion around maternity care options” more commonly than discrimination based on non-modifiable characteristics (sexual orientation, race). Our findings also indicate that experiences of respectful care vary depending on how obstetric procedures are presented to women. Women who felt pressured into having an induction or Cesarean section were more likely to report disrespectful care, compared to women who had these procedures without an experience of pressure.

This finding is supported by the differences among women who had to change their planned place of birth. Transfer from home to hospital birth typically requires women to engage in a detailed decision making process around options for care. BC women had lower MORi scores when they had experienced transfer from home to hospital. Interestingly, women who had home births reported experiencing the most respectful care; they had the highest MORi scores of all women in both samples. This could be a compounding effect since only midwives attend home births in BC (and midwifery care was also associated with higher scores). The reduction in scores among women whose care was transferred across birth settings could reflect the multi-disciplinary nature of informed consent discussions or simply an increased need to engage in difficult conversations involving differences in opinions around the care plan (Vedam, Leeman, Cheyney, et al., 2014; Fox, Sheehan, & Homer, 2014; Cheyney, Everson, & Burcher, 2014).

Perceptions of disrespect may be dependent on woman's reactions to inherent provider-patient power dynamics, which are known to influence patient choices (Cheyney, 2008; Lindgren & Erlandsson, 2010; Lukasse 2012). A sense of disrespect may also be affected by a woman's self-image. In marginalized populations, women may not feel they can exercise their agency because of systematic erosion of self-confidence and self-worth. A woman's sense of disrespect can also be affected by institutionally sanctioned behaviors such as adhering to minimum standards for informed consent (signatures) instead of requiring a detailed informed decision making process, including adequate time to consider options, such as in the case of *Montgomery v. Lanarkshire Health Board* (United Kingdom

Supreme Court, 2015). The evidence suggests that the use of coercion and pressure significantly increases women's likelihood of receiving unnecessary surgeries. A 2014 study found that women who perceived pressure to have a Cesarean section were more than five times more likely to have one, more than six times more likely to have one with no medical basis, and nearly seven times more likely to have an unplanned cesarean (Jou, Kozhimannil, Johnson, & Sakala, 2015).

The items included in both versions of MORi address common priorities described in patient-oriented outcomes research about quality maternity care. (Canadian Institute for Health Research, 2016). Due to the simple nature of the questions may be easily applied in low, middle, and high resource settings. Shared-decision making has been associated with reducing the unnecessary obstetric interventions that occur in all regions (Sandall et al., 2015; Hodnett et al., 2012). Research on provider attitudes in Australia revealed that while doctors and midwives supported a pregnant woman's right to make autonomous decisions, these same providers believed that under certain circumstances a pregnant woman's autonomy could be overridden for the safety of the baby (Kruske, Young, Jenkinson, & Catchlove, 2013). It is at this interface where refusal of unnecessary care may also provoke disrespectful behavior and create conflict. Thus, the items of the MORi could be used to conduct baseline measurements and post-intervention effects of respectful care in quality initiatives aimed to reduce obstetric interventions.

### 3.1.1. Respect as a component of patient safety

Effective reform requires an understanding of the components of care that affect patient experience and concepts of safety. The MORi enlists the user in evaluating the process of decision making and its effects, and so could help to clarify and normalize expectations for respectful interactions within the patient-provider dynamic. The dimensions of respect that Freedman et al. (2014) describe as being important to women include “behavior that by local consensus constitutes disrespect and abuse”, “intentionality” and...a woman's “lived experience” of the “deeper dynamics of power”. Women in North America report that relationship-based care that provides ample time for shared decision-making, increases their sense of safety and self-determination, facilitates family involvement, and allows for greater cultural congruency (Cheyney, 2008; Lothian, 2013). MORi can measure differences between their expected and actual interactions during maternity care discussions with providers. Interestingly our community process of RMC scale development in a high resource country also elicited the same four domains that are important during labour and birth women in a low resource country (Sheferaw et al, 2016): friendly care, abuse-free care, timely care and discrimination-free care. However, MORi measures these dimensions specifically as they relate to women's experience of decision making over the course of pregnancy, childbirth and postpartum care.

Vulnerable populations may particularly benefit from a model that supports informed decision making and strong provider-patient relationships. (McRae et al., 2016; Scupholme, Paine, Lang, Kumar, & DeJoseph, 1994). Finally, efforts to reduce unnecessary cesarean section rates may be facilitated by applying the MORi as a simple quantitative measure to evaluate of informed consent and refusal conversations in obstetric practice.

While numerous professional organizations and health systems have endorsed respectful, person-centered care as a key component of safe care, to our knowledge no official body is actually using a validated tool to measure and follow respectful care over time in high or middle resource countries. If incorporated as a routine quality and safety measure at the antenatal clinic or hospital level, this tool could help clarify the confusion providers often exhibit over the conflict between patient rights and their own perceived professional responsibilities concerning pregnant persons (Kruske et al., 2013). As well, implementation of the MORi at the hospital level could support more women to make more informed decisions by comparing respectful treatment

across birth facilities.

### 3.2. Implications for human rights in childbirth

Abuses of human rights in childbirth are documented by several high profile legal cases in low, middle and high resource countries. A case brought before the Jharkhand High Court in India, Kalyani Meena v. Union of India & Ors, addressed the overwhelming number of preventable deaths of women who die either in pregnancy or childbirth as a result of human rights violations. In Konovalova v. Russia, the European Court of Human Rights upheld a woman's claim that her treatment during childbirth was inhuman and degrading, and violated her right to privacy (European Court of Human Rights, 2014a). In Dubska v. the Czech Republic, Ms. Dubska argues for access to home birth in response to mistreatment and abuse prevalent in Czech Hospitals, including “the arrogant, intimidating, disrespectful and patronizing behaviour on the part of the hospital staff and the lack of privacy” (European Court of Human Rights Strasbourg, 2014). A recent UK case, Montgomery v. Lanarkshire, emphasized the necessity of providing adequate information in order to ensure safe decision making consistent with the dignity of patients (United Kingdom Supreme Court, 2015). A 2005 US civil case, Meador v. Stahler and Gheridian, awarded damages for a medically unnecessary cesarean (Chalidze, 2009; Middlesex Superior Court, 1993). This judgment cited that her provider misrepresented medical risks, ignored her express wishes, and compelled her to agree to the procedure. Similarly, in 2014, in Rinat Dray v Staten Island University Hospital et al. (Supreme Court of the State of New York, 2014), Ms. Dray contends she was subjected to a forced cesarean section, and the supporting briefs detail dozens of U.S. women's accounts of similar abuses at the hands of birth care providers, including threats, bullying, belittling, coercion, and dehumanizing treatment.

Legal scholars and global health professionals cite both individual and community-level factors that normalize these behaviors among institutional staff. These include lack of standards and accountability, scarcity of legal and ethical recourses or sanctions, ineffective leadership, and lack of resources to support reform through evaluation and training of care providers (Chalidze, 2009). When seeking redress for violations of their rights, women could use MORi scores to quantify care received, and support petitions for rights to autonomy, self-determination, privacy and freedom from inhuman and degrading treatment. In both legal and practice settings, the tool can be used to assess and provide context for assessing individual complaints. If used to evaluate care on a population level, MORi scores have the potential to serve as a clear standard for care received in various settings, ultimately informing patient driven policy changes with respect to informed consent and access to options for care.

Finally, the mode of development through extensive community input from diverse service users allows them to define the most important aspects of care that protect their human rights. Our research directly addresses the expressed community concern about lack of access to a maternity care model that prioritizes relationship-based care, patient-led decision making, and respectful maternity care across disenfranchised communities. It also enhances the applicability of this tool to examinations of women's experiences of respectful maternity care across low, middle, and high resource countries. This method of community led, participatory research generates authentic patient-oriented outcomes (Canadian Institute for Health Research, 2016) and may assist in informing and health professional education and health systems policy.

## 4. Limitations

The binary response format (Yes, No) of our initial MORi scale resulted in low response variance. A six point Likert response format may be more effective at capturing nuanced reactions to complex



personal interactions. Accordingly, we administered the 14 item MORi scale with the harmonized 6 point Likert response format to a large sample of mothers from communities of color who have given birth within the past 5 years in the United States. The improved internal consistency reliability, and factor structure of the 14-item scale in this diverse population, suggests that the multi-dimensional scale is stable.

The 14 item MORi can be used to quantify women's sense of disrespect and dismissal especially when engaging in conversations with providers. It does not measure incidence or impact of other types of abusive behavior (shouting, scolding, slapping, coercive procedures) which have been noted widely in the global context, and are measured by Sheferaw's tool. Noting this deficit the community members in the Giving Voice to Mothers study added validated items with harmonized Likert type responses to their own survey. Preliminary results (Vedam, Stoll & Declercq, 2016) indicate significant differences among populations in the rate and severity of these experienced behaviours. It may be advisable to evaluate psychometric properties of an expanded MORi that includes those additional items.

Results from the subgroup analysis of women who scored in the bottom 10th percentile on the MORi should be interpreted with caution, for subgroups < 20 women. Participants were likely highly motivated as they voluntarily completed a long online survey, hence, their experiences may not be representative of the entire BC maternity population.

## 5. Conclusion

Our method of community led, participatory research generated authentic patient-directed items for inclusion in a new validated scale that assesses women's experience of respect and ability for self-determination in maternity care. The MOR index may assist institutions and individual providers to evaluate the psychosocial impact of informed consent processes, as well as patient perceptions of discrimination and poor treatment. MORi scores could be used as a concrete indicator to inform institutional quality improvement initiatives, and health systems policy reform. The MOR index could also be used by patients to evaluate provider-patient interactions with learners and thus inform health professional education curricula, in patient oriented outcomes maternity care research, and by clinicians who desire to engage patients in continuous quality improvement in their practice settings. Application of this new quality and safety indicator may improve access to a maternity care model that prioritizes relationship-based, person-centered care.

## Author contributions

Conceived and designed the study: SV KS GJ CCinBC SC. Gathered the data: SV KS GJ KM CCinBC SC. Analyzed the data: SV KS NR GJ KM CCinBC SC. Contributed materials/analysis tools: SV KS GJ KM NR HHK ZMV. Wrote the paper: SV KS NR ZMV HHK GJ KM. Reviewed/edited/approved: SV KS NR HHK ZMV KS GJ CCinBC SC.

## Acknowledgements

From 2012–2014, Vancouver Foundation provided an operating grant (UNR12-0701) which supported the design, data collection, and quantitative analysis phases of our provincial community-led participatory action research (CBPR) project entitled “*Changing Childbirth in BC: Women exploring access to high quality maternity care.*” We would like to thank our community partners including leaders of the Immigrant Services Society of BC, Midwives Association of British Columbia, Womenin2Healing, Access Midwifery, Strathcona Midwifery Collective, and Pomegranate Clinic, for their remarkable support of the diverse group of mothers as ongoing partners in the Steering Council. We are also grateful to academic colleagues from Public Health, Obstetrics, and Midwifery, and the Women's Health Research

Institute for providing training and support for the community members. We are in awe of the persistence and perseverance of work group leaders Lorna McRae, Mo Korchinski, Anna Tashlykova, Raquel Velasquez, and Nora Timmerman who liaised with community members. Thank you to Barbara Karlen, Research Coordinator, who continues to patiently support all aspects of community engagement and knowledge translation. Most of all we thank the women and families of British Columbia whose frankness and commitment to improving maternity care immeasurably contributed to the drafting and testing of a patient-responsive scale.

## References

- Abuya, T., Warren, C. E., Miller, N., Njuki, R., Ndwiga, C., Maranga, A., & Bellows, B. (2015). Exploring the prevalence of disrespect and abuse during childbirth in Kenya. *PLoS One*, *10*(4), e0123606. <http://dx.doi.org/10.1371/journal.pone.0123606>.
- American Medical Association (2006). Opinion 8.08 – Informed Consent. Retrieved on April 27, 2016 at (<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion808.page?>)
- Baker, S., & Precilla, Y. (2005). “I Felt as though I’d been in Jail”: Women’s Experiences of Maternity Care during Labour, Delivery and the Immediate Postpartum. *Feminism & ...*. Retrieved from (<http://fap.sagepub.com/content/15/3/315.short>)
- Bohren, M. A., Vogel, J. P., Hunter, E. C., Lutsiv, O., Makh, S. K., Souza, J. P., & Gülmezoglu, A. M. (2015). The mistreatment of women during childbirth in health facilities globally: A mixed-methods systematic review. *PLoS Medicine*, *12*(6). <http://dx.doi.org/10.1371/journal.pmed.1001847>.
- Bowser, D., & Hill, K. (2010). Exploring evidence for disrespect and abuse in facility-based childbirth report of a landscape analysis, 1–57. Retrieved from (<http://www.urc-chs.com/uploads/resourceFiles/Live/RespectfulCareatBirth9-20-101Final.pdf>)
- Brown, S. (1994). Missing voices: The experience of motherhood. Retrieved from ([https://scholar.google.ca/scholar?Q=Missing+Voices%3A+The+Experience+of+Motherhood+btnG=&hl=en&as\\_sdt=0%2C5#0](https://scholar.google.ca/scholar?Q=Missing+Voices%3A+The+Experience+of+Motherhood+btnG=&hl=en&as_sdt=0%2C5#0))
- Canadian Institute for Health Research (CIHR) (2016). *Canada's strategy for patient-oriented research: Patient engagement framework at a glance*. Retrieved on April 27, 2016 at ([http://www.cihr-irsc.gc.ca/e/documents/spor\\_panel-en.pdf](http://www.cihr-irsc.gc.ca/e/documents/spor_panel-en.pdf))
- Chalidze, L. (2009). Misinformed consent: Non-medical bases for American birth recommendations as a human rights issue. *New York Law School Law Review*, *54* N.Y.L.
- Cheyney, M. J., Everson, C., & Burcher, P. (2014). Homebirth transfers in the United States: Narratives of risk, fear, and mutual accommodation. *Qualitative Health Research*, *24*(4), 443–456.
- Cheyney, M. J. (2008). Homebirth as systems-challenging praxis: Knowledge, power, and intimacy in the birthplace. *Qualitative Health Research*, *18*(2), 254–267.
- Creedy, D., Shochet, I., & Horsfall, J. (2000). Childbirth and the development of acute trauma symptoms: Incidence and contributing factors. *Birth*. Retrieved from (<http://onlinelibrary.wiley.com/doi/http://dx.doi.org/10.1046/j.1523-536x.2000.00104.x/full>)
- Declercq, E. R., Sakala, C., Corry, M. P., Applebaum, S., & Herrlich, A. (2013). *Listening to Mothers: Pregnancy & Birth*. New York: Childbirth Connection, May 2013. Retrieved on April 28, 2016 at ([http://transform.childbirthconnection.org/wp-content/uploads/2013/06/LTM-III\\_Pregnancy-and-Birth.pdf](http://transform.childbirthconnection.org/wp-content/uploads/2013/06/LTM-III_Pregnancy-and-Birth.pdf))
- Declercq, E. R., Sakala, C., Corry, M. P., Applebaum, S., & Risher, P. (2002). *Listening to mothers: Report of the first national U.S. survey of women's childbearing experiences*. New York: Maternity Center Association.
- Declercq, E., Sakala, C., Corry, M. P., & Applebaum, S. (2006). *Listening to mothers II: Report of the second national U.S. survey of women's childbearing experiences: Executive summary (Vol. October)*. New York: Childbirth Connection.
- European Court of Human Rights (2014a). Case of Kononova vs. Russia. Retrieved from (<http://hudoc.echr.coe.int/app/conversion/pdf/?Library=ECHR&id=001-146773&filename=001-146773.pdf>)
- European Court of Human Rights (2014b). Case of Ternovszky v. Hungary. Retrieved from (<http://hudoc.echr.coe.int/app/conversion/pdf/?Library=ECHR&id=001-102254&filename=001-102254.pdf>)
- European Court of Human Rights Strasbourg (2014). Dubska and Krejzova v the Czech Republic. Retrieved from [http://hudoc.echr.coe.int/eng/?i=001-148632#{"itemid": "001-148632"}](http://hudoc.echr.coe.int/eng/?i=001-148632#{).
- Fraser, D. (1999). Women's perceptions of midwifery care: A longitudinal study to shape curriculum development. *Birth*. Retrieved from (<http://onlinelibrary.wiley.com/doi/10.1046/j.1523-536x.1999.00099.x.pdf>)
- Fox, D., Sheehan, A., & Homer, C. (2014). Experiences of women planning a home birth who require intrapartum transfer to hospital: A metasynthesis of the qualitative literature. *International Journal of Childbirth*, *4*(2), 103–119.
- Freedman, L. P., Ramsey, K., Abuya, T., Bellows, B., Ndwiga, C., Warren, C. E., Kujawski, S., Moyo, W., Kruk, M. E., & Mbaruku, G. (2014). Defining disrespect and abuse of women in childbirth: A research, policy and rights agenda. *Bull World Health Organ*, *92*(12), 915–917. <http://dx.doi.org/10.2471/BLT.14.137869>.
- Hodnett, E. D., Downe, S., & Walsh, D. (2012). Alternative versus conventional institutional settings for birth. *Cochrane Database of Systematic Reviews*(8). <http://dx.doi.org/10.1002/14651858.CD000012.pub4>.
- Hodnett, E. D. (2002). Pain and women's satisfaction with the experience of childbirth: A systematic review. *American Journal of Obstetrics and Gynecology*, *186*, S160–S172.

- International Federation of Gynecology and Obstetrics, International Confederation of Midwives, White Ribbon Alliance, International Pediatric Association, & World Health Organization. Mother-baby friendly birthing facilities. *International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics* 128 2015 95–99 doi: 10.1016/j.ijgo.2014.10.013.
- Jackson, M., Dahlen, H., & Schmied, V. (2012). Birthing outside the system: Perceptions of risk amongst Australian women who have freebirths and high risk homebirths. *Midwifery*, 28(5), 561–567. <http://dx.doi.org/10.1016/j.midw.2011.11.002>.
- Jou, J., Kozhimannil, K. B., Johnson, P. J., & Sakala, C. (2015). Patient-perceived pressure from clinicians for labor induction and cesarean delivery: A Population-based survey of U.S. women. *Health Services Research*, 50(4), 961–981. <http://dx.doi.org/10.1111/1475-6773.12231>.
- Kruk, M., Kujawski, S., Mbaruku, G., Ramsey, K., Moyo, W., & Freedm (2014). Disrespectful and abusive treatment during facility delivery in Tanzania: A facility and community survey. *Health Policy and Planning*, 1–8. <http://dx.doi.org/10.1093/heapol/czu079>.
- Kruske, S., Young, K., Jenkinson, B., & Catchlove, A. (2013). Maternity care providers' perceptions of women's autonomy and the law. *BMC Pregnancy and Childbirth*, 13(1), 84. <http://dx.doi.org/10.1186/1471-2393-13-84>.
- Kujawski, S., MbarukuLynn, G., Freedman, L. P., Ramsey, K., Moyo, W., & Kruk, M. E. (2015). Association between disrespect and abuse during childbirth and women's confidence in health facilities in Tanzania. *Maternal and Child Health Journal*, 19(10), 2243–2250.
- Lindgren, H., & Erlandsson, K. (2010). Women's experiences of empowerment in a planned home birth: A Swedish population-based study. *Birth*, 37, 309–317.
- Lothian, J. A. (2013). Being safe: Making the decision to have a planned home birth in the United States. *Journal of Clinical Ethics*, 24(3), 266–275.
- Lukasse, M., Schroll, A., & Karro, H. (2015). Prevalence of experienced abuse in healthcare and associated obstetric characteristics in six European countries. *Acta Obstetrica et*. Retrieved from (<http://onlinelibrary.wiley.com/doi/10.1111/aogs.12593/pdf>).
- McRae, D. N., Muhajarine, N., Stoll, K., Mayhew, M., Vedam, S., Mpofu, D., & Janssen, P. (2016). Is model of care associated with infant birth outcomes among vulnerable women? A scoping review of midwifery-led versus physician-led care. *SSM – Population Health*, 2, 182–193.
- Middlesex Superior Court (1993). Meador v. Stahler and Gheridian. California.
- National Institute for Health and Clinical Excellence (2014). *Intrapartum care for healthy women and babies: Guidance and guidelines*. Retrieved on April 27, 2016 at (<https://www.nice.org.uk/guidance/cg190>)
- Okafor, I. I., Ugwu, E. O., & Obi, S. N. (2015). Disrespect and abuse during facility-based childbirth in a low-income country. *International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics*, 128(2), 110–113. <http://dx.doi.org/10.1016/j.ijgo.2014.08.015>.
- Oviedo (1997). Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: Convention on human rights and biomedicine. Council of Europe. Retrieved from (<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?DocumentId=090000168007cf98>)
- Public Health Agency of Canada. What Mothers Say: The Canadian Maternity Experiences Survey. Ottawa, 2009. <http://www.publichealth.gc.ca/mes>.
- Reis, V., Deller, B., Carr, C. & Smith, J. (2012). *Respectful maternity care country experiences*. USAID maternal child health integrated program. Retrieved on April 28, 2016 at ([https://www.k4health.org/sites/default/files/RMC%20Survey%20Report\\_0.pdf](https://www.k4health.org/sites/default/files/RMC%20Survey%20Report_0.pdf))
- Roberts, A. R., & Yeager, K. R. (2004). *Evidence-based practice manual: research and outcome measures in health and human services* (1st ed.). Oxford University Press.
- Sandall, J., Soltani, H., Gates, S., Shennan, A., & Devane, D. (2015). Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews*, 9. <http://dx.doi.org/10.1002/14651858.CD004667.pub4>.
- Scupholme, A., Paine, L. L., Lang, J. M., Kumar, S., & DeJoseph, J. F. (1994). Time associated with components of clinical services rendered by nurse-midwives: Sample data from phase II of nurse-midwifery care to vulnerable populations in the United States. *Journal of Nurse – Midwifery*, 39(1), 5–12.
- Sheferaw, E. D., Mengesha, T. Z., & Wase, S. B. (2016). Development of a tool to measure women's perception of respectful maternity care in public health facilities. *BMC Pregnancy and Childbirth*, 16(1), 67. <http://dx.doi.org/10.1186/s12884-016-0848-5>.
- Soet, J. E., Brack, G. A., & Dilorio, C. (2003). Prevalence and predictors of women's experience of psychological trauma during childbirth. *Birth*, 30(1), 36–46 (Retrieved from(<http://www.ncbi.nlm.nih.gov/pubmed/12581038>)).
- Supreme Court of the State of New York (2014). Dray v. Staten Island University Hospital. Retrieved on April 27, 2016 at (<https://iapps.courts.state.ny.us/fbem/DocumentDisplayServlet?DocumentId=o8epZVpMGIUuC/0zwmwfpq== & system=prod>)
- Swahnberg, I. M. K., & Wijma, B. (2003). The NorVold Abuse Questionnaire (NorAQ): Validation of new measures of emotional, physical, and sexual abuse, and abuse in the health care system among women. *European Journal of Public Health*, 13(4), 361–366. <http://dx.doi.org/10.1093/eurpub/13.4.361>.
- Swahnberg, K., Schei, B., Hilden, M., Halmesmaki, E., Sidenius, K., Steingrimsdottir, T., & Wijma, B. (2007). Patients' experiences of abuse in health care: A Nordic study on prevalence and associated factors in gynecological patients. *Acta Obstetrica et Gynecologica Scandinavica*, 86(3), 349–356. <http://dx.doi.org/10.1080/00016340601185368>.
- Symon, A., Winter, C., Donnan, P. T., & Kirkham, M. (2010). Examining autonomy's boundaries: A follow-up review of perinatal mortality cases in UK independent midwifery. *Birth*, 37(4), 280–287. <http://dx.doi.org/10.1111/j.1523-536X.2010.00422.x>.
- Ten Hoop-Bender, P., de Bernis, L., Campbell, J., Downe, S., Fauveau, V., Fogstad, H. et al. (2014). Improvement of maternal and newborn health through midwifery. *Lancet*, 384(9949), 1226–1235.
- Thomson, G., Dykes, F., Singh, G., Cawley, L., & Dey, P. (2013). A public health perspective of women's experiences of antenatal care: An exploration of insights from a community consultation. *Midwifery*, 29(3), 211–216. <http://dx.doi.org/10.1016/j.midw.2012.01.002>.
- United Kingdom Supreme Court (2015). Montgometry v Lanarkshire Health Board. Retrieved on April 27, 2016 at ([http://blogs.lexisnexis.co.uk/dr/wp-content/uploads/sites/2/2015/06/2015\\_2\\_All\\_ER\\_1031.pdf](http://blogs.lexisnexis.co.uk/dr/wp-content/uploads/sites/2/2015/06/2015_2_All_ER_1031.pdf))
- United Nations Commission on the Status of Women (2016). Convention on the elimination of all forms of discrimination against women. Retrieved March 30, 2016, from (<http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>)
- Vedam, S., Leeman, L., Cheyney, M., Fisher, T., Myers, S., Low, L., & Ruhl, C. (2014). Transfer from planned home birth to hospital: Improving interprofessional collaboration. *Journal of Midwifery and Women's Health*, 59(6), 624–634.
- Vedam, S., Stoll, K., DeClercq, E., et al. (2016). *Giving voice to mothers of colour*. International Normal Labour and Birth Research Conference, 11th session. University of Western Sydney, Australia
- Vedam, S., Stoll, K., Martin, K., Rubashkin, N., Partridge, S., Thordarson, Jolicoeur, G., & the CCinBC Steering Council. 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. PLOS ONE. January 2017 (in press).
- Vedam, S., Stoll, K., Jolicoeur, G., Partridge, S., Tashlykova, A., Korchinski, M., & Timmerman, N. (2015). *Measuring women's autonomy and experience of respectful maternity care*. XXI FIGO World Congress of Gynecology & Obstetrics, October 2015, Vancouver, BC.
- Vogel, J. P., Bohren, M. A., Tunçalp, Ö., Oladapo, O. T., Adanu, R. M., Baldé, M. D., & Gülmezoglu, M. A. (2015). How women are treated during facility-based childbirth: Development and validation of measurement tools in four countries – Phase 1 formative research study protocol. *Reproductive Health*, 12, 60. <http://dx.doi.org/10.1186/s12978-015-0047-2>.
- Warren, C., Njuki, R., Abuya, T., Ndwiiga, C., Maingi, G., Serwanga, J., & Bellows, B. (2013). Study protocol for promoting respectful maternity care initiative to assess, measure and design interventions to reduce disrespect and abuse during childbirth in Kenya. *BMC Pregnancy and Childbirth*, 13, 21. <http://dx.doi.org/10.1186/1471-2393-13-21>.
- White Ribbon Alliance (2015). Pulling back the curtain on disrespect and abuse: The movement to ensure respectful maternity care. Retrieved on April 4, 2016 at (<http://whiteribbonalliance.org/wp-content/uploads/2016/03/Policy-Brief-Pulling-Back-the-Curtain-on-DR.pdf>)
- World Health Organization (2015). *WHO | Prevention and elimination of disrespect and abuse during childbirth* Geneva, Switzerland: World Health Organization (Retrieved from([http://www.who.int/reproductivehealth/topics/maternal\\_perinatal/statement-childbirth/en/](http://www.who.int/reproductivehealth/topics/maternal_perinatal/statement-childbirth/en/))).

**Manuscript 2: 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.**

<http://dx.doi.org/10.1371/journal.pone.0171804>

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>1</sup>, Nicholas Rubashkin<sup>3</sup>, Sarah Partridge<sup>4</sup>, Dana Thordarson<sup>1</sup>, Ganga Jolicoeur<sup>5</sup>, the Changing Childbirth in BC Steering Council<sup>†</sup>

**1** Birth Place Research Lab, Division of Midwifery, University of British Columbia Vancouver, British Columbia, Canada, **2** School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada, **3** Department of Obstetrics and Gynecology, University of California San Francisco, San Francisco, California, United States of America, **4** Residency Program, Department of Family Practice, University of British Columbia, Vancouver, British Columbia, Canada, **5** Midwives Association of British Columbia, Vancouver, British Columbia, Canada

<sup>†</sup> A complete list of Steering Council members can be found in the Acknowledgments.

\* [vedam@midwifery.ubc.ca](mailto:vedam@midwifery.ubc.ca)



**OPEN ACCESS**

**Citation:** Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson D, et al. (2017) 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. PLoS ONE 12(2): e0171804. doi:10.1371/journal.pone.0171804

**Editor:** Saravana Kumar, University of South Australia, AUSTRALIA

**Received:** March 15, 2016

**Accepted:** January 26, 2017

**Published:** February 23, 2017

**Copyright:** © 2017 Vedam et al. This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

**Data Availability Statement:** De-identified data are hosted on DataVerse at <https://dx.doi.org/10.14288/1.0342356>. Future interested researchers may contact their institutional ethics review board or UBC Ethics Board to request access to confidential data: <https://ethics.research.ubc.ca/about-human-research-ethics/contact-us#ubc-breb>.

**Funding:** 1. Vancouver Foundation (NPO) <https://www.vancouverfoundation.ca/> This work was

## Abstract

Shared decision making (SDM) is core to person-centered care and is associated with improved health outcomes. Despite this, there are no validated scales measuring women's agency and ability to lead decision making during maternity care.

## Objective

To develop and validate a new instrument that assesses women's autonomy and role in decision making during maternity care.

## Design

Through a community-based participatory research process, service users designed, content validated, and administered a cross-sectional quantitative survey, including 31 items on the experience of decision-making.

## Setting and participants

Pregnancy experiences (n = 2514) were reported by 1672 women who saw a single type of primary maternity care provider in British Columbia. They described care by a midwife, family physician or obstetrician during 1, 2 or 3 maternity care cycles. We conducted psychometric testing in three separate samples.

## Main outcome measures

We assessed reliability, item-to-total correlations, and the factor structure of the The Mothers' Autonomy in Decision Making (MADM) scale. We report MADM scores by care provider

partially supported by operating grant #UNR12-0701 for the provincial community based participatory Changing Childbirth in BC study. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

**Competing interests:** The authors have declared that no competing interests exist.

type, length of prenatal appointments, preferences for role in decision-making, and satisfaction with experience of decision-making.

## Results

The MADM scale measures a single construct: autonomy in decision-making during maternity care. Cronbach alphas for the scale exceeded 0.90 for all samples and all provider groups. All item-to-total correlations were replicable across three samples and exceeded 0.7. Eigenvalue and scree plots exhibited a clear 90-degree angle, and factor analysis generated a one factor scale. MADM median scores were highest among women who were cared for by midwives, and 10 or more points lower for those who saw physicians. Increased time for prenatal appointments was associated with higher scale scores, and there were significant differences between providers with respect to average time spent in prenatal appointments. Midwifery care was associated with higher MADM scores, even during short prenatal appointments (<15 minutes). Among women who preferred to lead decisions around their care (90.8%), and who were dissatisfied with their experience of decision making, MADM scores were very low (median 14). Women with physician carers were consistently more likely to report dissatisfaction with their involvement in decision making.

## Discussion

The Mothers Autonomy in Decision Making (MADM) scale is a reliable instrument for assessment of the experience of decision making during maternity care. This new scale was developed and content validated by community members representing various populations of childbearing women in BC including women from vulnerable populations. MADM measures women's ability to lead decision making, whether they are given enough time to consider their options, and whether their choices are respected. Women who experienced midwifery care reported greater autonomy than women under physician care, when engaging in decision-making around maternity care options. Differences in models of care, professional education, regulatory standards, and compensation for prenatal visits between midwives and physicians likely affect the time available for these discussions and prioritization of a shared decision making process.

## Conclusion

The MADM scale reflects person-driven priorities, and reliably assesses interactions with maternity providers related to a person's ability to lead decision-making over the course of maternity care.

---

## Introduction

A move towards more person-centered care lies at the heart of global health care reform [1,2]. Indicators of person-centered care (including involvement in decision making) for acute care hospital patients are now collected on a national level in Canada [3]. A systematic review of 137 articles concluded that involvement in decision making, the quality of the provider-patient relationship, and the amount of support received from care providers are three main factors

that influence women's satisfaction with their birth experiences [4]. Shared decision making is considered a cornerstone of person-centered care and is associated with improved health outcomes [1,5–8], even when patients prefer not to participate in decision making. A more recent systematic review of 39 studies that examined the association between shared decision making and outcomes found that 54% of affective-cognitive outcomes (e.g. satisfaction with care), 37% of behavioural (e.g. diet, exercise, stress management) and 25% of health outcomes (e.g. symptom improvement, general health ratings) were positively and significantly associated with shared decision making. Decisional conflict was associated with shared decision making (SDM) in one of the studies [9].

Person-led decision making is especially important during pregnancy and birth, yet the inability to participate in decision making is commonly reported by childbearing women in English speaking countries [10]. In a qualitative study, Baker et al [11] reported that women felt that they were treated like children, were intimidated by care providers, had little control over the decision-making process, did not receive enough information about different options, and received interventions that were contrary to their preferences. Women had a desire to be better informed about why certain procedures were necessary and what the outcome might be. The authors concluded that this inadequate information provision and feeling of loss of control can be remedied by improved communication between care providers and childbearing women.

As a result, international health agencies emphasize the importance of respectful dialogue and service-user involvement in decision making during maternity care [12,13]. While several instruments have been developed to assess SDM in health care [9], or the quality of prenatal care received [14], none have focused on informed choice discussions between providers and during maternity care. Moreover, to our knowledge, none of the validated SDM scales were designed by service users. Caron-Flinterman noted that patients' experiential knowledge "contributes to the relevance and quality of biomedical research" [15].

In the Changing Childbirth in BC research project, a steering group of women of childbearing age from different cultural and socio-economic backgrounds engaged multiple stakeholders, as well as leaders from NGOs, researchers, and community agencies, to examine women's experiences with maternity care in British Columbia (BC). Together they designed a mixed-methods study to explore topics that have not previously been detailed—women's preferences for model of care; perceptions of reasons for intervention; access to midwifery care; and experiences of autonomy, respect, discrimination, or coercion, when participating in a shared decision making process. This paper describes the resulting development and testing of a new scale to assess women's autonomy and role in decision making throughout the course of pregnancy.

## Methods

The Vancouver Foundation funded our provincial, community-led participatory action project, and the research support necessary for development of this scale. The Steering Committee was composed of community members and leaders from Immigrant Services Society of British Columbia, Women in2 Healing, Midwives Association of British Columbia, Access Midwifery, Strathcona Midwifery Collective, clinicians and maternity care researchers from the Department of Family Practice at UBC, Children and Women's Hospital, and the Women's Health Research Institute. The core Steering Committee comprised 10 people at first, and expanded to 18 to include more women representing vulnerable populations.

The research team self-organized into four different work groups, adding some additional community members to each to ensure representation of the perspectives of the four sub-

populations: women marginalized by economic and social barriers to health, formerly incarcerated women, immigrant and refugee populations, and all other maternity service users.

The team used existing public e-lists and member databases to canvas the community about areas for study, and preferred modes of data collection. Through community consultations with 1300 women, the work groups agreed on key topics for study, a mixed-methods approach, recruitment strategies, and a timeline for data collection.

## Survey development

Following a broad literature review on their chosen topics, the team adapted or modified previously validated items, and generated new items to populate four versions of a cross-sectional online survey and focus group questions. After an extensive content validation process, including expert panel review by all Steering Committee members and all work group members, the final instrument included 130 core items that collected information on demographics, access to maternity care, preferences for model of care, maternal and newborn outcomes, knowledge of midwifery care, and experience of care including the process of decision-making.

Given the length of the survey we reduced the burden to participants by using an online platform with logic branching to ensure that participants only answered questions that related to their experience; by allowing skipping of any question, except the eligibility criteria; by making it optional for women with previous childbirth experiences to report on care during 1, 2 or 3 maternity care cycles; and by setting the survey save functions to allow respondents to complete the survey over more than one session.

The survey was edited for lay language (i.e. a grade 8 reading level), and then pilot tested with several women from the target populations. Final revisions were made, based on the feedback of women who pilot tested the survey. For instance, issues with survey logic branching were corrected at this stage and some items were reworded, to improve clarity.

**Measuring experiences of decision making in maternity care.** To construct the decision-making section of the survey, the community members reviewed several previously validated instruments and found that, while there were other tools surrounding shared decision making, there were no scales that measured the ability of the person to lead the decision making, or the degree to which their preferences were respected. Moreover, all of the published tools included a broad range on indicators of quality in prenatal care or were developed for general medical treatment options (e.g. for cancer or diabetes), and thus not always relevant to maternity care where decisions impact both mother and baby. Our community team members wanted a measure that did not pathologize pregnancy but could assess involvement in all types of decision making during the entire course of pregnancy. They also noted that none of the existing instruments measured the impact of time allowed for decision making. Hence, to respond to the stated community concerns, we adapted the language of previously validated tools and generated new items.

Of a total 31 items describing preferences for and experiences of decision making over the childbearing cycle, 14 items addressed the nature of communication with providers, and seven items specifically measured women's perception of their role and agency when participating in a shared decision making process (responses on a six-point Likert scale, range of scores 7–42). Higher scores indicate that women had greater agency and autonomy when engaging in an SDM process with a maternity care provider. Four of these items were adapted to the maternity care context from the previously validated 9-item Shared Decision Making Questionnaire [16] that had been administered to 2351 German primary medical care patients to describe their consultations about a specific health problem, illness or complaint. For example, the team changed 'My doctor told me there are different options for treating my medical

**Table 1. Scale items—Mothers Autonomy in Decision Making (MADM)<sup>1</sup>.**

Please describe your experiences when making decisions and choosing options for care during this pregnancy. ( <i>Auto-populated with provider type</i> )
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 and disadvantages of the maternity care options
My _____ helped me understand all the information
I was given enough time to thoroughly consider the different maternity care options
I was able to choose what I considered to be the best care options
My _____ respected that choice

<sup>1</sup>. Response options are (1) Completely disagree; (2) Strongly disagree; (3) Somewhat disagree; (4) Somewhat agree; (5) Strongly agree; (6) Completely agree

doi:10.1371/journal.pone.0171804.t001

condition' to 'My (*family physician/obstetrician/midwife*) told me that there are different options for my maternity care'.

The research team then designed three new items, reflecting the priorities identified by ongoing community consultation, to assess the ability of women to lead decision-making:

- 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 (*family physician/obstetrician/midwife*) respected that choice

Finally, most other instruments measure interactions between patients and a single type of provider, usually physicians. In contrast, respondents to the Changing Childbirth in BC survey could indicate that their responses referred to any of five types of maternity professionals (midwife, family physician, health centre nurse, obstetrician, or other) when they described their experience. See [Table 1](#) for a full list of scale items.

To assess the scale items within the context of their preferences for decision making, we asked women how important it is for them to lead the decisions about their pregnancy, birth and baby care. Response options included 'very important', 'important', 'somewhat important' and 'not important'. We also asked participants to rate whether they were satisfied or dissatisfied with their ability to participate in decision making in different periods over the course of care: 1) pregnancy, 2) labour and birth, 3) after the birth, 4) baby care or 5) none of the above.

## Data collection

Women of childbearing age across BC were recruited via email, community list-serves, NGO websites and social media outlets (i.e. convenience sampling). The survey was accessible online, and for women with barriers to this format, also via assisted data entry by a trained volunteer at the site of their care. Recruitment posters and postcards were printed and disseminated widely in community centers, grocery stores, and maternity shops; in midwife and family physician offices; and at BC Women and Children's Hospital, the largest referral maternity hospital in the province. To introduce the study to maternity care providers and to encourage recruitment, the first author also made presentations at a UBC Department of Family Practice meeting, and hospital department meetings in Richmond, Vancouver and Victoria, and at the provincial Annual General Meetings of the College of BC Midwives. Data was collected between January and June 2014.



The University of British Columbia (UBC) provided ethics approval for the Changing Childbirth in BC Study. Participants who clicked on the survey link were first taken to an informed consent page that explained the purpose of the study, and described the study team, potential impacts and consent procedures. Potential participants were informed that their participation in the study was entirely voluntary, that they could skip items, and that they could decide to leave the study at any time. Participants were further informed that by continuing on to fill out this survey, they consented to participate in the study. This consent procedure is standard for online surveys that are administered in British Columbia and was approved by the University Ethics Board.

## Sample

Women could report on their experiences during two previous pregnancies and the current pregnancy (if applicable). If women had more than one care provider during a single pregnancy, they had the option of describing their experiences with up to three different care providers. For the purposes of the current analysis, we excluded responses about childbirth experiences from outside of British Columbia and about health center nurses and “other” care providers from the dataset, to focus on the three types of primary maternity care providers available in BC (i.e. midwives, family physicians, or obstetricians). This resulted in a sample of 2051 women reporting on 3400 care provider experiences.

Of women who responded to the scale items on the survey ( $n = 2051$ ), the majority (88.6%) experienced their last pregnancy within 5 years of data collection. Only 47 women experienced their last pregnancy more than 10 years ago. By linking postal codes to provincial data by health authority, we determined that our sample was closely matched to the geographic distribution, and socioeconomic and age profile of childbearing women in BC. With respect to visible minorities our sample was under-represented. Women in the sample also reported higher education on average than the general population of Canada. Reported family incomes in our sample resembled incomes of families in British Columbia in 2014.

To avoid multiple observations from the same woman, we excluded 886 care provider experiences reported by 379 women who had multiple providers during a pregnancy. Sample characteristics are reported for the 1672 women who saw a single care provider during pregnancy. Socio-demographic data pertain to the time of data collection, not the time of the pregnancy experience (with the exception of the women who were pregnant at the time of data collection). To assess the psychometric properties of the scale items, we analyzed responses from two groups: care provider experiences during the course of 1 or 2 previous pregnancies ( $n = 2271$ ), and experiences of women who were pregnant at the time of data collection ( $n = 243$ ), for a total of 2514 care provider experiences. We report results separately for each pregnancy, to demonstrate that findings are replicable.

## Data analysis

We estimated internal consistency reliability with Cronbach's alpha. To examine how well each item contributes to the overall measurement of women's role in decision making, we generated corrected item- to-total correlations. High correlation coefficients represent ‘good items’ that should be included in the scale. In addition, when all corrected item- to- total correlations exceed 0.45 there is strong evidence of the uni-dimensionality of a scale [17]. We performed unweighted least squares factor analysis (no rotation), to examine the factor structure of the scales and to determine the construct validity of the new measure.

We created scale scores (i.e. the sum of the items) for women who responded to all seven scale items, i.e. women who missed any items or marked one or more items as ‘not applicable’

were not included. We report median scores because scale scores were not normally distributed. Median scores are reported for the full sample, and separately for women who saw midwives, family doctors and obstetricians. We calculated descriptive statistics for women who reported their preferences for and satisfaction with role in decision-making. The relationship between care provider type and dissatisfaction with involvement in decision making was assessed, using the Chi-square test. Finally, we examined the average length of prenatal appointments (< 15 minutes, 15–30 minutes, 31–60 minutes and > 60 minutes), in association with autonomy scores and stratified by care provider type.

## Results

Of the 2514 care provider experiences reported, 68.5% (n = 1723) related to midwifery care, 19.9% (n = 500) to care provided by family physicians, and 11.6% (n = 291) to obstetric care; 9.7% (n = 243) care provider experiences were submitted by women who were pregnant at the time of data collection.

The average age of women at the time of data collection was 32.6 years; 4.5% self-identified as vulnerable (i.e. women who arrived as immigrants or refugees in Canada within the last 5 years and/or women with a history of substance use, poverty, homelessness or incarceration). The majority of women identified as White (92.5%), 1.6% identified as Chinese, and 1.8% as First Nations, Inuit, or Métis. The remainder reported other ethnicities. Of the women surveyed, 8.2% reported family incomes < 30,000 and 37.4% reported incomes exceeding \$91,000. While most women had completed college or university, 10.1% reported high school as the highest level of education completed.

Eighteen women (1.1%) were expecting twins; 10.2% of women reported one or more medical or social risk factor during pregnancy (high blood pressure, diabetes, problems with baby's growth, problems with baby's health, depression, lack of social support during pregnancy, or housing difficulties).

The majority of women (90.8%) said it was *very important* or *important* that they lead decisions about their care. When asked whether they were satisfied with their ability to participate in decision making during pregnancy, labour and birth, and/or postpartum (including baby care), 6.2% of women were dissatisfied during pregnancy, 15.2% during labour and birth, 15.8% after the birth, 12.9% with baby care and 2.7% were not satisfied at any point during pregnancy. Women with physician carers were consistently more likely to report dissatisfaction with their involvement in decision making (see [Table 2](#)).

## Reliability and validity of MADM

Cronbach alphas, for the seven items that measured autonomy and role in decision making, exceeded 0.90 in each subsample (see [Table 3](#)). All corrected item-to-total correlations for the first pregnancy exceeded 0.7 and most exceeded 0.8. These findings could be replicated with

**Table 2. Dissatisfaction with decision-making experience, by care provider type.**

Women dissatisfied with experience of decision-making:	Family Physician	Obstetrician	Midwife	p
During pregnancy	47 (16.4)	35 (19.7)	21 (1.7)	< 0.001
During labour/birth	77 (29.4)	52 (32.3)	88 (8.8)	< 0.001
After birth	68 (26.0)	65 (40.4)	92 (9.2)	< 0.001
About newborn care	47 (17.9)	56 (34.8)	80 (8.0)	< 0.001
At any time	18 (6.9)	10 (6.2)	10 (1.0)	< 0.001

doi:10.1371/journal.pone.0171804.t002

**Table 3. Cronbach alphas for MADM scale, full sample and by care provider type.**

	Pregnancy 1	Pregnancy 2	Currently pregnant
MADM- All	0.96	0.97	0.96
MADM- MW	0.93	0.96	0.96
MADM-FP	0.95	0.95	--
MADM-OB	0.95	0.97	--

MW: midwife; FP: family physician; OB: obstetrician

--Alphas for sample sizes < 20 are not reported

doi:10.1371/journal.pone.0171804.t003

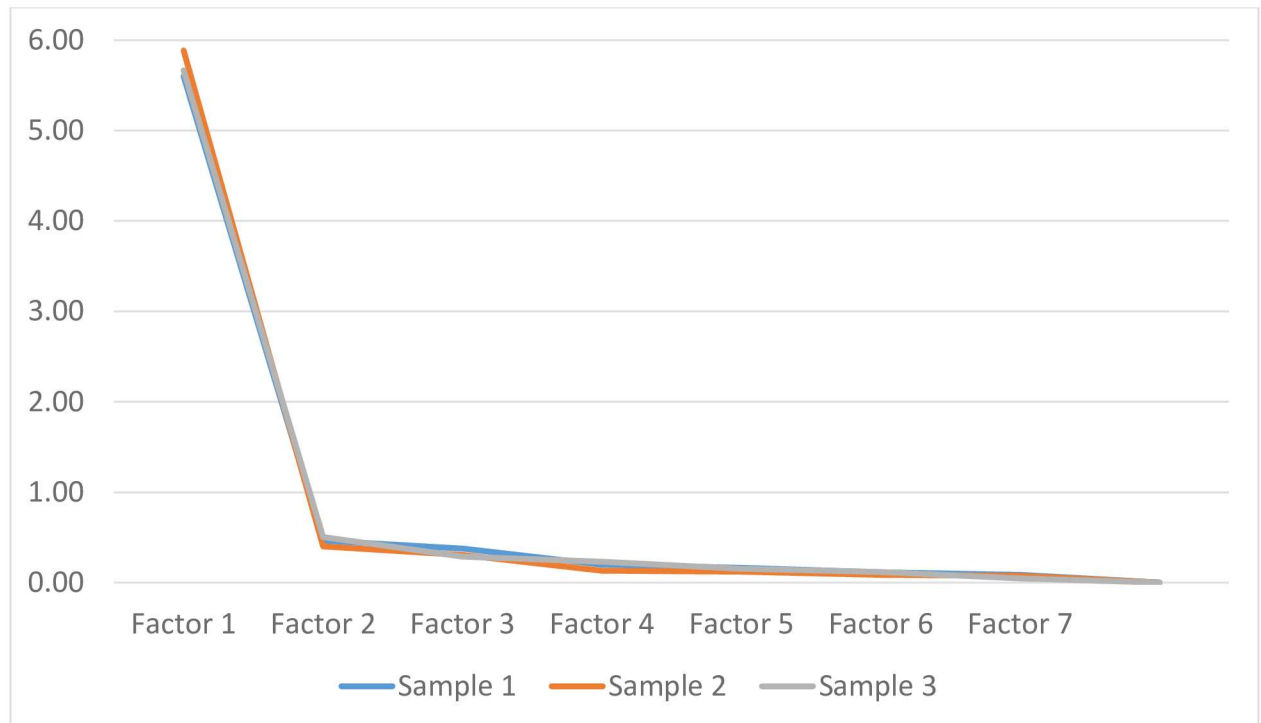
the second sample (i.e. women reporting experiences during a different pregnancy) and third sample (women who were pregnant at the time of data collection) (see Table 4). Because all seven items were highly correlated with the sum of all other items, we concluded that they formed a uni-dimensional scale, measuring autonomy in decision making. An examination of Eigenvalues, factor loadings and the scree plot of MADM items further supported the uni-dimensionality and construct validity of the scale. For each sample, one Eigenvalue was larger than 1, scree plots exhibited a clear 90 degree angle (see Fig 1), and the factor analysis generated one factor, with loadings ranging from 0.74–0.93 for sample 1, 0.76–0.95 for sample 2 and 0.79–0.93 for sample 3. To honor the participatory construction of the instrument, we named the scale Mothers' Autonomy in Decision Making (MADM).

**Table 4. Corrected item to total correlations and factor loadings of MADM items.**

Scale item		Corrected ITTC	Factor loadings
My _____ asked me how involved in decision making I wanted to be	P1	0.73	0.74
	P2	0.75	0.76
	CP	0.78	0.79
My _____ told me that there are different options for my maternity care	P1	0.86	0.88
	P2	0.91	0.93
	CP	0.85	0.87
My _____ explained the advantages/disadvantages of the maternity care options	P1	0.86	0.88
	P2	0.90	0.91
	CP	0.88	0.90
My _____ helped me understand all the information	P1	0.90	0.92
	P2	0.93	0.95
	CP	0.91	0.93
I was given enough time to thoroughly consider the different care options	P1	0.90	0.93
	P2	0.93	0.95
	CP	0.87	0.90
I was able to choose what I considered to be the best care options	P1	0.88	0.91
	P2	0.91	0.93
	CP	0.87	0.91
My _____ respected that choice	P1	0.84	0.87
	P2	0.87	0.89
	CP	0.85	0.89

Pregnancy 1 –P1; Pregnancy 2 –P2; Currently Pregnant—CP; ITTC- Item to total correlations

doi:10.1371/journal.pone.0171804.t004



**Fig 1. Scree plots for Samples 1, 2, and 3.** When examining construct validity indicators separately for physician and midwifery consumers in Sample 1, we found that factor loadings for women who were cared for by family physicians ranged from 0.73–0.88 (n = 264), 0.80–0.92 for women under the care of obstetricians (n = 150) and 0.64–0.91 for midwives (n = 927). For all care provider groups the scree plots showed one factor with an Eigenvalue above 5; all other Eigenvalues fell clearly below 1 (see Fig 2).

doi:10.1371/journal.pone.0171804.g001

### Median scale scores

MADM median scores were highest for midwifery clients (40.0 in pregnancy 1 and 41.0 in pregnancy 2 and among pregnant women), and 10 or more points lower for women who saw physicians during pregnancy (see Table 5). See Fig 3 for a graphic representation (box plots) of scale scores by provider type.

### Time and experience of autonomy

Increased time for prenatal appointments was associated with higher scale scores (see Table 6), and there were significant differences between providers with respect to average time spent in prenatal appointments (see Fig 4).

Midwifery care was associated with higher MADM scores, compared to physicians, even during short prenatal appointment (less than 15 minutes). For sample Pregnancy 1, women who saw midwives with appointment times of < 15 minutes had a median MADM score of 30, compared to a median MADM score of 23 among those who saw obstetricians, and 22 among women who saw family physicians during short appointments. We obtained similar findings for women who reported prenatal appointments that lasted between 15–30 minutes: those with midwives had median MADM scores of 39, and those cared for by OBs scored 34.5 and those with family physicians scored 33. Among the women who said it was ‘very important’ or ‘important’ to lead the decisions around their care (90.8%), and who were dissatisfied with their experience of decision making at any time during the maternity care cycle, MADM scores were very low (median 14).

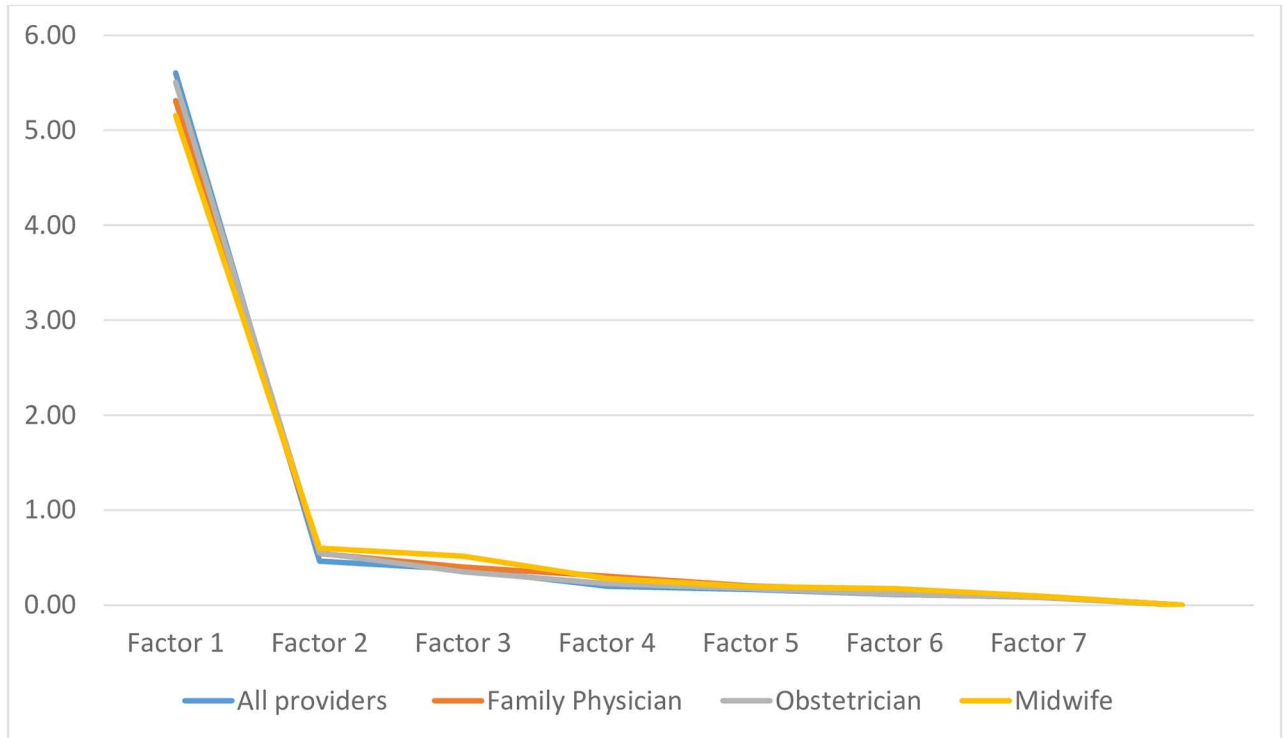


Fig 2. Scree plots by provider type (Sample 1).

doi:10.1371/journal.pone.0171804.g002

Table 5. MADM median scale scores, full sample and stratified by care provider.

	Pregnancy 1		Pregnancy 2		Currently Pregnant	
	n	Median	n	Median	n	Median
MADM-all	1344	38.0	571	40.0	190	40.5
MADM-MW	927	40.0	433	41.0	162	41.0
MADM-FP	266	29.0	93	30.0	17	--
MADM-OB	151	28.0	45	31.0	11	--

MW: midwife; FP: family physician; OB: obstetrician

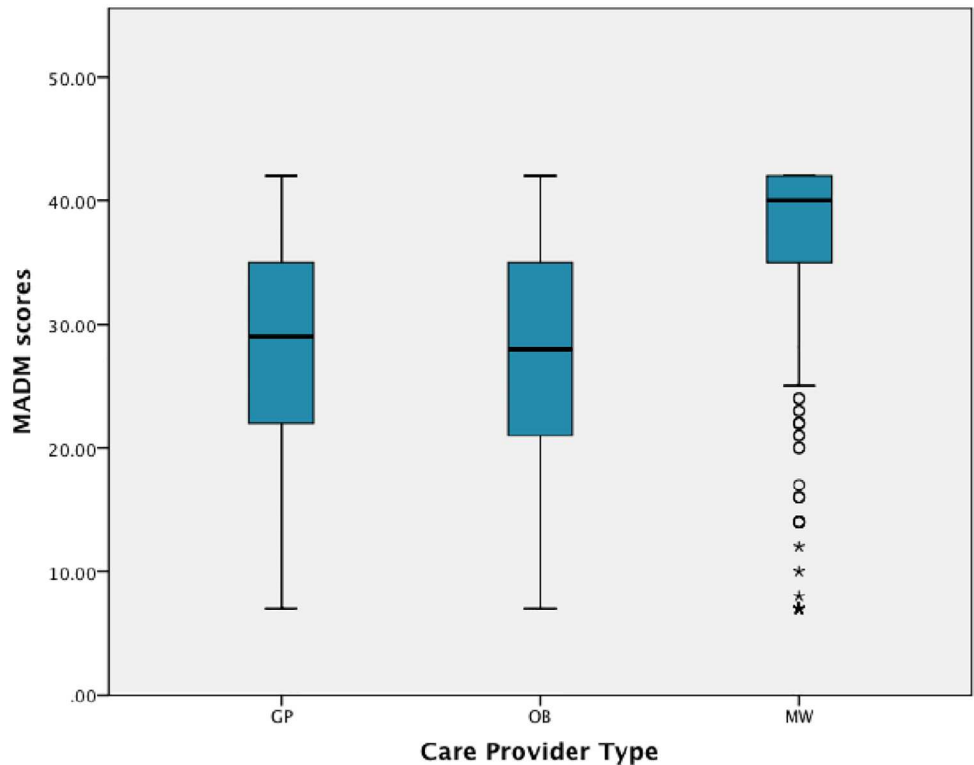
--Medians for sizes < 20 are not reported

Note: Some responses were excluded from this analysis because women did not complete all MADM scale items or checked 'not applicable' on one or more items: 252/1596 (15.8%) for sample 1, 104/675 (15.4%) for sample 2 and 53/243 (21.8%) for the women who were pregnant at the time of data collection

doi:10.1371/journal.pone.0171804.t005

## Discussion

We introduced a new scale to measure women's experiences with autonomy in decision making. The Mothers Autonomy in Decision Making (MADM) scale is a reliable instrument for assessment of experiences among women who are reflecting on past childbearing experiences as well as women who are currently pregnant. It is uni-dimensional and internally consistent. This new scale was developed and content validated by community members representing various populations of childbearing women in BC. Notably, it uniquely allows assessment of women's ability to *lead* decision making, whether they have enough time to consider their options, and whether providers respect women's choices.



**Fig 3. Box plot: MADM scores by care provider type (Sample 1 = 1344).** Median and interquartile range of MADM scores by care provider group for pregnancy 1 (n = 1344). The horizontal line inside each box represents the median score for each provider group, and the upper and lower boundaries of each box represent the upper and lower quartiles. The vertical lines represent the range of scores, excluding outliers, which are represented by open circles and asterisks.

doi:10.1371/journal.pone.0171804.g003

When women are encouraged by clinicians to have a key role in decision making, several benefits have been observed: increased satisfaction with the consultation process, reduction in options/procedures that are over-used, and increased sustainability of health systems [18]. However, a review of barriers and facilitators of shared decision-making among care providers revealed three salient factors: care provider motivation, the belief that outcomes are enhanced with shared decision making, and the perception that shared decision making has a positive impact on the clinical process [19]. Our study elicits some differences between types of providers with respect to the level of autonomy and involvement that women experienced.

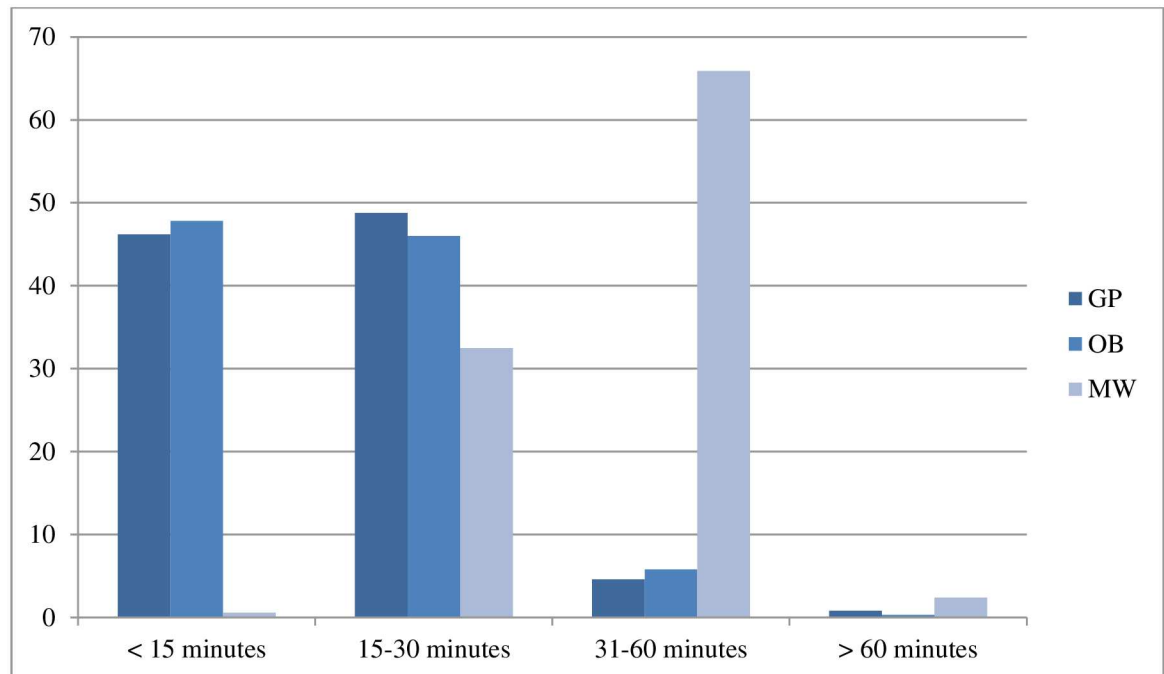
The importance of pregnant women’s autonomy and the aspiration to shared-decision making have been affirmed by statements from medical professional associations [20],

**Table 6. MADM median scale scores, by average length of prenatal appointments.**

	Pregnancy 1		Pregnancy 2		Currently Pregnant	
	n	Median	n	Median	n	Median
< 15 minutes	191	23.0	73	25.0	9	--
16–30 minutes	501	36.0	207	39.0	74	39.5
31–60 minutes	649	41.0	292	42.0	106	41.5
>60 minutes	25	41.0	5	--	11	--

-- Medians for sample sizes < 20 are not reported

doi:10.1371/journal.pone.0171804.t006



**Fig 4. Average prenatal appointment lengths, by care provider type (n = 1723).**

doi:10.1371/journal.pone.0171804.g004

including, the Institute of Medicine [21], the American College of Obstetricians and Gynecologists [22] the National Institute for Clinical Excellence [13], and the Society for Maternal Fetal Medicine [20]. However, contentious debates continue among professionals over the meaning of and limits to autonomy around issues like elective cesarean sections, genetic testing, and place of birth [23, 24]. More in-depth, obstetrician-driven explorations of the principles of autonomy, beneficence, and respectful care are emerging [25]. They are an important addition to the current approach to evidence-based obstetrics that has been criticized for an emphasis on risk measurement to the detriment of women's autonomy [23,25,26]. However, despite these efforts in the fields of medical ethics and anthropology, quantitative measures of women's autonomy are sorely lacking. Measures such as the MADM scale could be integrated into clinical trials to explore associations between obstetric interventions and autonomy, potentially implemented as a national quality measure, or even employed as a provider performance indicator—taking autonomy out of the theoretical realm of professional statements and placing it as a standard of practice.

In our sample, women who experienced midwifery care reported increased agency and autonomy in decision making, compared to women under physician care. Midwives have been recognized for prioritizing the importance of shared decision making, and women centered care [27,28]. However, shared decision-making requires taking the time and willingness to engage in evidence-based discussions with women about the pros and cons of different care options. Other instruments that assess the quality of prenatal care incorporate this important dimension, i.e. whether people have sufficient time to discuss their options and make decisions [14]. Current differences in models of care, health professional education, regulatory standards, and compensation for prenatal visits likely affect the time available for these discussions and the emphasis placed on the shared decision making process.

## A patient-driven health service priority

Our study results demonstrate that physicians are spending less time than midwives during prenatal visits, and that reduced time during prenatal appointments is associated with lower autonomy scores. These findings are especially significant in BC [29] where over the last decade, the birth rate is rising, there has been a reduction in the number of family physicians and obstetricians who provide maternity care, and midwives have been added to the register. Rural and remote areas are particularly affected, and many pregnant women travel long distances to urban centers to access care [30]. In addition, family physicians' mandate is to provide universal access to care for all types of people, from cradle to grave, despite a chronic physician shortage. Similarly, obstetricians-gynecologists must provide consultation and care for all women with complex gynecologic conditions and at-risk pregnancies, including referrals from family physicians and midwives. The need to ensure universal access to care in this provincial context may have fostered an environment where detailed discussions about options and preferences are sometimes deferred, or are a lower priority, because of time constraints.

Also, since the bulk of people that family physicians and obstetricians see in a session have some pathological medical condition, the physician's necessary emphasis on addressing medical comorbidities may leave little time to explore normal physiologic processes. In current medical practice, detailed discussions with medical patients about options and preferences are focused on conditions that require complex care planning (eg. chemotherapy, palliative care) [9]. In contrast, a "risk" focus for informed consent conversations has been attributed to modern obstetric care [31,32]. Unfortunately, discussions that center on evidence-based options to address potential pathology may inadvertently create a perceived "expert knowledge" imbalance between caregiver and the pregnant person, further undermining the person's sense of autonomy.

Because of widespread community-based advocacy for inclusion of midwifery within the BC maternity care system, midwifery care was introduced in 1998. Midwifery is now the fastest growing primary maternity profession in BC. Midwives in BC offer primary care to healthy pregnant women and their normal newborn babies from early pregnancy, through labour and birth, and up to three months postpartum. Following extensive community consultations in the 1990s, BC established a provincial midwifery model of practice which includes regulatory requirements that midwives provide, and demonstrate that they offer: 1) continuity of carer; 2) informed decision making; 3) women-centered care; and 4) choice of birthplace.

In our sample, midwives typically spent 30–60 minutes with women in each prenatal visit, whereas almost half of physicians spent less than 15 minutes. Women's sense of autonomy increased with more time for prenatal appointments. Notably, in BC the payor model for midwives acknowledges the additional time needed to establish relationship-based continuity of care and to engage in an informed decision making process. To ensure that caseloads are reasonable enough to both provide a living wage, and to ensure adequate face-to-face time per person, midwives are paid a single comprehensive fee for each course of care and are capped on the number of persons they can be compensated for annually. Family physicians and obstetricians, in contrast, are paid in a fee-for-service model that incentivizes higher caseloads and procedures, without addressing impacts on quality of relationships or person-led care.

At the same time, care providers vary in their attitudes towards medical management of birth and their comfort with letting go of control [24,33]. Some providers express the view that being in control is part of their job and a way to avoid medico-legal issues. Other providers value women's agency and shared decision making. Some care providers recounted how the evidence can easily be presented in a way that will maximize compliance with care providers'



preferred course of action. Other care providers believe that women like to defer to medical authority even after their care provider has engaged them in an informed choice discussion [33].

However, the majority of respondents in our study, regardless of type of care provider, indicated a preference for leading decision making. Women who were dissatisfied with their role in decision making during pregnancy, birth, and postpartum had very low MADM scores. These findings draw attention to the importance of asking women how important it is for them to lead decision around their care and under which circumstances they want to share decision making or defer to the recommendations of their care provider(s). Previous research with health care consumers in the UK found that a desire to be involved in decision making is context specific. Consumers felt that health professionals 'should seek involvement to the level that the consumer desires'. Consumers desired less involvement in emergency situations, because they expected health professionals to direct care, to the best of their professional expert knowledge [34].

Finally, medical students and residents must navigate these attitudes and preferences as they formulate their own approach to informed consent. Within the educational context, the value of deferring to women as "experts" about their own physiologic responses is not consistently emphasized. Care provider education could prepare both medical and midwifery trainees for the realities of person-centered practice. The scale is brief and easy to administer, making it ideal to capture the patient perspective on the performance of health professional learners on clinical education encounters.

## Strengths and limitations

Our scale development through a community-led participatory approach makes the MADM scale particularly relevant to person-centered care. The psychometric testing of the scale in a large geographically distributed provincial sample, with replication of results in two further samples, supports the reliability and construct validity of the scale. Internal consistency reliability of MADM was excellent for the full sample with a mix of care providers, and also across specific provider groups.

The convenience sampling frame (including recruitment via social media) is a limitation of this study, because it prevents us from calculating a response rate as it is unknown how many eligible participants were invited to the study/saw the advertisement. Furthermore, the accuracy of results might be impaired by recall bias. The chance of recall bias in this study is minimized because the majority of women who responded to the survey experienced their last pregnancy within 5 years of data collection (88.6%). Research suggests that women's recall of their birth experiences, even if asked 10–15 years after the event is very accurate, when compared to medical charts [35,36].

Finally, we note that while we had 4.5% participation from the target vulnerable groups, and 8.2% of women reported low family income (<30K), results may not be representative of the experiences of vulnerable populations in BC. Nonetheless, we used a participatory approach to design all survey items and to recruit survey respondents. One of the four work groups represented maternity care recipients in the province that did not self-identify as from a vulnerable group, but all four work groups agreed on a core set of items to be assessed in all populations, so that we could compare findings across groups. We partnered with NGOs serving vulnerable populations and paid participants an honorarium, offered food, chose convenient locations and had childcare on site, to reduce barriers to research participation. In addition, anticipating common barriers to participation from the 3 vulnerable populations, our primary method of data collection for those populations was via focus groups on the same

4 topic areas. Preliminary results of the qualitative data indicate that the themes strongly support our quantitative findings and the triangulated results will be reported elsewhere.

## Conclusion

We have created a reliable and valid scale that can evaluate the process of decision making in maternity care. The Mothers Autonomy in Decision Making (MADM) scale will be especially valuable in a field that has a scarcity of reliable tools to evaluate patient experience. The adaptation of previously validated items and generation of new items by community members strengthens the relevance of the scale to person-centered care.

In an era of increased demand and value for patient involvement and self-determination in health care, an instrument that allows women to quantify their ability to participate in decision making can inform quality assurance and improvement of health services and health professional education. Health care systems that prioritize person-led care may benefit from using the MADM scale to assess the agency accorded to service users when making decisions in different models of maternity care. Global applications may assist health policy makers to appraise evidence of respectful maternity care.

## Acknowledgments

We would like to acknowledge the staff and leadership of our community partners for their unwavering commitment to supporting this complex and diverse group of women to tell their stories. We are grateful to academic colleagues from several UBC Departments including Education, Family Practice, Public Health, Obstetrics, and Midwifery, and the Women's Health Research Institute for providing training and support for the community as they engage in all steps of the research process. The project would not have been possible without the persistence and perseverance of the members of the Steering Council, including work group leaders Lorna McRae, Mo Korchinski, Anna Tashlykova, Raquel Velasquez, and Nora Timmerman who liaised with community members. We thank Birth Place Lab Research Coordinator, Barbara Karlen, and our research assistant Nicolas Christofi, MD who volunteered his evenings to finalize this paper. We thank Sarah Munro for her comments about the manuscript and provision of valuable references. Most of all we thank the women and families of British Columbia whose frankness, acuity and personal expertise immeasurably improved the design and content of a client-responsive scale. Members of the CCinBC Steering Council: Cora Beitel, Jennifer Borins, Allison Campbell, Marijke De Zwager, Cathy Ellis, Karen Gelb, Jennifer Hetherington, Catriona Hippman, Nané Jordan, Mo Korchinski, Ruth Martin, Lorna McRae, Daphne McRae, Carmen Nunez, Martha Roberts, Kathy Sherrell, Anna Tashlykova, Nora Timmerman, Raquel Velasquez, Kim Williams.

## Author Contributions

**Conceptualization:** SV KS GJ.

**Data curation:** KS KM.

**Formal analysis:** SV KS DT KM SP GJ.

**Funding acquisition:** SV GJ.

**Investigation:** SV KS GJ KM.

**Methodology:** SV KS GJ.

**Project administration:** SV GJ KS KM BR.

**Resources:** SV KS GJ KM SP DT NR.

**Supervision:** SV.

**Validation:** SV KS KM SP.

**Visualization:** SV KS KM.

**Writing – original draft:** SV.

**Writing – review & editing:** SV KS GJ KM SP DT NR.

## References

1. Barry MJ, Edgman-Levitan S. Shared Decision Making—The Pinnacle of Patient-Centered Care. *New England Journal of Medicine* [Internet]. Massachusetts Medical Society; 2012 Feb 29; 366(9):780–1. Available from: <http://dx.doi.org/10.1056/NEJMp1109283>
2. CMA. Guidelines for Physicians in Interactions With Industry. Canadian Medical Association [Internet]. 2007;1–5. <http://policybase.cma.ca/dbtw-wpd/Policy/pdf/PD08-01.pdf>
3. Canadian Institute for Health Information: Patient Experience [Internet]. [cited 2015 Nov 2]. from: <https://www.cihi.ca/en/health-system-performance/quality-of-care-and-outcomes/patient-experience>
4. Hodnett ED. Pain and women's satisfaction with the experience of childbirth: A systematic review. *American Journal of Obstetrics & Gynecology*. 2002; 186(Suppl 5):S160–72.
5. Hack TF, Degner LF, Watson P, Sinha L. Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psycho-oncology* [Internet]. 2006 Jan [cited 2015 Nov 2]; 15(1):9–19. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15669023>
6. O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB et al. Decision aids for people facing health treatment or screening decisions. The Cochrane database of systematic reviews [Internet]. 2009 Jan [cited 2015 Nov 2]; (3):CD001431. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19588325>
7. Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. The Cochrane database of systematic reviews [Internet]. 2001 Jan [cited 2015 Nov 2]; (4):CD003267. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/11687181>
8. Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions [Internet]. The Cochrane database of systematic reviews. Chichester, UK: John Wiley & Sons, Ltd; 1996 [cited 2015 Oct 2]. CD007297 p. <http://www.ncbi.nlm.nih.gov/pubmed/20091628>
9. Shay LA, Lafata JE. Where Is the Evidence? A Systematic Review of Shared Decision Making and Patient Outcomes. *Medical Decision Making* [Internet]. 2014 Oct 28 [cited 2015 Oct 10]; 35(1):114–31. Available from: <http://mdm.sagepub.com/content/early/2014/10/28/0272989X14551638>
10. Reis V, Deller B, Carr CC, Smith J. Respectful Maternity Care [Internet]. United States Agency for International Development, Maternal and Child Health Integrated Program. 2012. Available from: [https://www.k4health.org/sites/default/files/RMCSurveyReport\\_0.pdf](https://www.k4health.org/sites/default/files/RMCSurveyReport_0.pdf)
11. Baker SR. "I Felt as though I'd been in Jail": Women's Experiences of Maternity Care during Labour, Delivery and the Immediate Postpartum. *Feminism & Psychology* [Internet]. 2005 Aug 1 [cited 2015 Sep 7]; 15(3):315–42. Available from: [http://www.researchgate.net/publication/236010785\\_I\\_felt\\_as\\_though\\_id\\_been\\_in\\_Jail\\_Womens\\_experiences\\_of\\_maternity\\_care\\_during\\_labour\\_delivery\\_and\\_the\\_immediate\\_postpartum](http://www.researchgate.net/publication/236010785_I_felt_as_though_id_been_in_Jail_Womens_experiences_of_maternity_care_during_labour_delivery_and_the_immediate_postpartum)
12. International Federation of Gynecology and Obstetrics, International Confederation of Midwives, White Ribbon Alliance, International Pediatric Association, World Health Organization. Mother-baby friendly birthing facilities. *International journal of gynaecology and obstetrics: the official organ of the International Federation of Gynaecology and Obstetrics* [Internet]. Elsevier; 2015 Feb 2 [cited 2015 Nov 3]; 128(2):95–9. Available from: <http://www.ijgo.org/article/S0020729214005451/fulltext>
13. Intrapartum care for healthy women and babies: Clinical guideline. National Institute for Health and Care Excellence [Internet]. NICE; 2014 [cited 2015 Nov 3]. <http://www.nice.org.uk/guidance/cg190>
14. Heaman MI, Sword WA, Akhtar-Danesh N, Bradford A, Tough S, Janssen PA, et al. Quality of prenatal care questionnaire: instrument development and testing. *BMC pregnancy and childbirth* 2014; 14(1):1.
15. Caron-Flinterman JF, Broerse JEW, Bunders JFG. The experiential knowledge of patients: a new resource for biomedical research? *Social science & medicine* (1982) [Internet]. 2005 Jun [cited 2015 Sep 19]; 60(11):2575–84. Available from: <http://www.sciencedirect.com/science/article/pii/S0277953604005702>

16. Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9): Development and psychometric properties in a primary care sample. *Patient Education and Counseling*. Elsevier Ireland Ltd; 2010 Jul; 80(1):94–9.
17. Roberts AR, Yeager KR. *Evidence-Based Practice Manual: Research and Outcome Measures in Health and Human Services*. 1st ed. Oxford University Press; 2004.
18. Légaré F, Turcotte S, Stacey D, Ratté S, Kryworuchko J, Graham ID. Patients' perceptions of sharing in decisions. *Patient*. 2012; 5(1):1–19.
19. Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Education and Counseling*. 2008 Dec; 73(3):526–35. doi: [10.1016/j.pec.2008.07.018](https://doi.org/10.1016/j.pec.2008.07.018) PMID: [18752915](https://pubmed.ncbi.nlm.nih.gov/18752915/)
20. Lawrence HC III, Copel JA, O'Keeffe DF, Bradford WC, Scarrow PK, Kennedy HP et al. Quality patient care in labor and delivery: a call to action. *American Journal of Obstetrics and Gynecology* [Internet]. Elsevier Inc.; 2012; 207(3):147–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22188236>
21. *Crossing the Quality Chasm* [Internet]. Washington, D.C.: National Academies Press; 2001 [cited 2015 Oct 31]. <http://www.nap.edu/read/10027/chapter/1>
22. *Statement of Policy: Global Women's Health and Rights* [Internet]. 2015. <http://www.acog.org/-/media/Statements-of-Policy/Public/2012GlobalWmHlthRights.pdf?dmc=1&ts=20151103T0013466542>
23. Kukla R, Kupperman M, Little M, Lyerly AD, Mitchell LM, Armstrong EM et al. Finding Autonomy in Birth. *Bioethics* [Internet]. 2009; 23(1):1–8. Available from: <http://doi.wiley.com/10.1111/j.1467-8519.2008.00677.x>
24. Cheyney M, Burcher P, Vedam S. A crusade against home birth. *Birth issues in perinatal care*. 2014; 41(1):1–4.
25. Lyerly AD. *A Good Birth: Finding the Positive and Profound in Your Childbirth Experience*. Avery; 2013.
26. Wendland CL. The Vanishing Mother: Cesarean Section and "Evidence-Based Obstetrics". *Medical Anthropology Quarterly*. 2007; 21(2):218–33. PMID: [17601085](https://pubmed.ncbi.nlm.nih.gov/17601085/)
27. ten Hoop-Bender P, de Bernis L, Campbell J, Downe S, Fauveau V, Fogstad H, et al. Improvement of maternal and newborn health through midwifery. *Lancet (London, England)* [Internet]. Elsevier; 2014 Sep 27 [cited 2015 Oct 17]; 384(9949):1226–35. Available from: <http://www.thelancet.com/article/S0140673614609302/fulltext>
28. Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. *The Cochrane database of systematic reviews* [Internet]. 2015 Sep 15 [cited 2015 Sep 16]; 9:CD004667. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26370160>
29. Harris SJ, Janssen PA, Saxell L, Carty EA, MacRae GS, Petersen KL. Effect of a collaborative interdisciplinary maternity care program on perinatal outcomes. *Canadian Medical Association Journal*. 2012; 184(17):1885–92. doi: [10.1503/cmaj.111753](https://doi.org/10.1503/cmaj.111753) PMID: [22966055](https://pubmed.ncbi.nlm.nih.gov/22966055/)
30. Grzybowski S, Stoll K, Kornelsen J. Distance matters: A population based study examining access to maternity services for rural women. *BMC Health Services Research*. 2011; 11(147):1–8.
31. Regan M, Mcelroy K. Women's Perceptions of Childbirth Risk and Place of Birth. *The Journal of Clinical Ethics*. 2013; 24(3):239–52. PMID: [24282851](https://pubmed.ncbi.nlm.nih.gov/24282851/)
32. Coxon K, Sandall J, Fulop NJ. To what extent are women free to choose where to give birth? How discourses of risk, blame and responsibility influence birth place decisions. 2014; Available from: <http://www.tandfonline.com/loi/chrs20>
33. Hall WA, Tomkinson J, Klein MC. Canadian care providers' and pregnant women's approaches to managing birth: minimizing risk while maximizing integrity. *Qualitative health research* [Internet]. 2012 May; 22(5):575–86. Available from: <http://qhr.sagepub.com/content/22/5/575.short>
34. Edwards A, Elwyn G, Smith C, Williams S, Thornton H. Consumers' views of quality in the consultation and their relevance to "shared decision-making" approaches. *Health Expectations* [Internet]. 2001 Dec 20 [cited 2015 Nov 2]; 4(3):151–61. Available from: <http://doi.wiley.com/10.1046/j.1369-6513.2001.00116.x>
35. Githens P, Glass C, Sloan F, Entman S. Maternal recall and medical records—an examination of events during pregnancy, childbirth, and early infancy. *Birth-Issues In Perinatal Care* 1993; 20 (3):136–141
36. Maternal Recall of Distant Pregnancy Events. *Journal of Clinical Epidemiology*; 51(5):399–405. PMID: [9619967](https://pubmed.ncbi.nlm.nih.gov/9619967/)

### 5.3 Changing Childbirth in BC

In 2014, I convened a steering group of women of childbearing age from different cultural and socio-economic backgrounds. Together we engaged multiple stakeholders from NGOs, the university, and community agencies to examine women's experiences with maternity care in British Columbia. The team self-organized into four work groups: 1) current and potential midwifery patients; 2) previously incarcerated women; 3) immigrant and refugee women 4) and women experiencing multiple social barriers. They designed a cross-sectional survey and focus group prompts to examine preferences, access, and experiences of care, and knowledge of midwifery. In the beginning of the decision making section in the survey, women selected a response for the following statement: "*The following answers describe my conversations or experiences with my family doctor, obstetrician, midwife, health centre nurse or other*". Subsequent questions were automatically populated with the correct care provider type. Women of childbearing age across BC were recruited via email, postcards, community list-serves, NGO websites, post-card, posters, and social media outlets.

Women (n=4087) from all socio-economic backgrounds provided survey data. Women also participated in 20 focus groups (n=203) to further explicate their responses. Bivariate analysis revealed that women believe that the most important factors in maternity care are having a respectful, supportive and trusting relationship with care provider(s); enough time to discuss options for care; and being unpressured during decision making. There were significant differences across midwives, family physicians, and obstetricians in the frequency of these experiences with coercive or disrespectful care ([2018 policy report](#)). Women who were pressured to accept the intervention had significantly lower MADM and MORi scores (Vedam, Stoll, and Martin 2017; Vedam, Stoll, and Rubashkin 2017). Mixed-effects analysis, published as part of analysis undertaken during my PhD (Manuscript 3), suggests that women's role in decision making differs significantly depending on their health status, recommended interventions, planned place of birth, and type of providers. These findings provide insight into several of aspirational goals of the Home Birth Summit Common Ground Agenda. The manuscript follows.

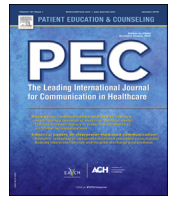
**Manuscript 3: The Changing Childbirth in BC Study: examining autonomy in Canadian maternity care.**

<https://doi.org/10.1016/j.pec.2018.10.023>



Contents lists available at ScienceDirect

## Patient Education and Counseling

journal homepage: [www.elsevier.com/locate/pateducou](http://www.elsevier.com/locate/pateducou)

## Patient-led decision making: Measuring autonomy and respect in Canadian maternity care



Saraswathi Vedam<sup>a,b,\*</sup>, Kathrin Stoll<sup>a</sup>, Daphne N. McRae<sup>c</sup>, Mo Korchinski<sup>d</sup>, Raquel Velasquez<sup>a</sup>, Jessie Wang<sup>a</sup>, Sarah Partridge<sup>a</sup>, Lorna McRae<sup>e</sup>, Ruth Elwood Martin<sup>d</sup>, Ganga Jolicoeur<sup>f</sup>, CCinBC Steering Committee<sup>a</sup>

<sup>a</sup> Birth Place Lab, Department of Family Practice and Midwifery, University of British Columbia, Vancouver, British Columbia, Canada

<sup>b</sup> School of Medicine, University of Sydney, Australia

<sup>c</sup> School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada

<sup>d</sup> Women In 2 Healing, Department of Family Practice, University of British Columbia, Vancouver, British Columbia, Canada

<sup>e</sup> Access Midwifery and Family Care, Victoria, British Columbia, Canada

<sup>f</sup> Midwives Association of British Columbia, Vancouver, British Columbia, Canada

## ARTICLE INFO

## Article history:

Received 9 February 2018

Received in revised form 23 September 2018

Accepted 26 October 2018

## Keywords:

Autonomy

Decision-making

Pregnancy

Patient-oriented

Participatory research

Respectful maternity care

Childbirth

Person-centered

Quality measure

## ABSTRACT

**Objective:** The **Changing Childbirth in British Columbia** study explored women's preferences and experiences of maternity care, including women's role in decision-making.

**Methods:** Following content validation by community members, we administered a cross-sectional online survey exploring novel topics, including drivers for interventions, and experiences of autonomy, respect, or mistreatment during maternity care. Using the *Mothers Autonomy in Decision-Making (MADM)* scale as an outcome measure in a mixed-effects analysis, we examined differential experiences by socio-demographic and prenatal risk profile, type of care provider, interventions received, and nature of communication with care providers.

**Results:** A geographically representative sample of Canadian women (n=2051) reported on 3400 pregnancies. Most women (95.2%) preferred to be the lead decision-maker during care. Patients of physicians had significantly lower autonomy (MADM) scores than midwifery clients as did women who felt pressured to accept interventions. Women who had a difference in opinion with their provider, and those who felt their provider seemed rushed reported the lowest MADM scores.

**Conclusion:** Women's autonomy is significantly altered by model of maternity care, the nature of interactions with care providers, and women's ability for self-determination.

**Practice Implications:** If health professionals acquire skills in person-centred decision-making experience of autonomy among pregnant women may improve.

© 2018 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## 1. Introduction

In 2012, the USAID Maternal Child Health Integrated Program examined the state of “respectful maternity care” worldwide and concluded that concepts of “safe motherhood must be expanded beyond the prevention of morbidity or mortality to encompass respect for women's basic human rights, including respect for women's autonomy, dignity, feelings, choices, and preferences” [1]. Patient-centered care prioritizes the needs of patients over those of

healthcare providers and administrations, and has been defined by Berwick as ‘the experience (to the extent the informed individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in healthcare (p. 560) [2]. The WHO sets out standards for high quality maternity care [3] that elevate experience of care outcomes as important health outcomes, and include the following: 1) Communication with women and their families is effective and responds to their needs and preferences, 2) women and newborns receive care with respect and preservation of their dignity and autonomy, and 3) every woman and her family are provided with emotional support that is sensitive to needs and strengthens the woman's capability.

Childbearing women value the opportunity to be full participants in care planning, including the ability to understand and

\* Corresponding author at: Birth Place Lab, Faculty of Medicine, University of British Columbia, E418 Shaughnessy Building, 4500 Oak Street, Vancouver, BC, V6H 3N1, Canada.

E-mail address: [saraswathi.vedam@ubc.ca](mailto:saraswathi.vedam@ubc.ca) (S. Vedam).

apply the best available evidence to their individual situations [4,5]. They report that having enough time to engage in decision-making increases their sense of safety and ability for self-determination [5,6]. While patient engagement increases demands on provider time in the short term, it can increase efficiency in the long term through improved patient adherence to the care plan [7–9]. On the other hand, the experience of mistreatment by providers (eg. non-consented care, loss of patient autonomy, or poor provider-patient communication) during pregnancy and childbirth has been linked to reduced adherence to care, psychosocial distress, and adverse maternal newborn health [10–13].

Retaining a sense of control over healthcare decisions is especially important for patients who experience difficulties accessing healthcare due to poverty, race, immigrant status, or other barriers [14,15]. When women experience poor treatment or trauma during pregnancy and birth, they can develop depression and post-traumatic stress disorder (PTSD) [16]. In the Canadian context, Aboriginal women report distress during pregnancy and childbirth due to lack of choice and racism, compounded by economic challenges. Distanced and dismissive health care providers contribute to feelings of having “no power, no choice, and no control” [14]. Immigrant women in Canada face similar barriers [15].

Patient-centered care was described in the 2014 British Columbia Ministry of Health’s strategic plan as a key priority for the provision of healthcare [17]; yet very little is known about how women, including disadvantaged women, experience maternity care in BC. In particular, no studies have used a validated measure to examine autonomy in decision-making during pregnancy and childbirth.

This paper reports on quantitative findings of the *Changing Childbirth in BC* study. The primary research questions were: Is autonomy and agency in decision-making during pregnancy and childbirth, as measured with the Mothers Autonomy in Decision-Making (MADM) scale, experienced differently depending on women’s socio-demographic and prenatal risk profile, type of prenatal care provider, nature of communication with care providers, and/or interventions received?

## 2. Methods

In 2013, a Vancouver Foundation grant supported our team to initiate the *Women taking Charge of Changing Childbirth in BC* study, a community-based participatory research project. We initially planned to support midwifery clients to evaluate their experience of the first 15 years of care by registered midwives in BC. Hence, the Midwives Association of BC (MABC) and the BC Women’s Hospital Foundation joined as community partners. However, two community consultations – one of maternity care service users (n = 1333) and one of service providers (midwives and family physicians) – mandated expansion of the sample definition to include populations who historically did not or could not access midwifery care. We then recruited service users with lived experience of care, and additional community partners who served special populations including: the Immigrant Services Society of BC, an NGO offering settlement services for immigrants and refugees; Women in2Healing, an NGO helping women transition after being incarcerated; and two clinics who serve women with a history of substance use, poverty and homelessness.

These service users, NGO leaders, clinicians, and researchers, formed a Steering Council that met over several months to select priority research questions, and identify data collection modalities (survey and focus groups). The resulting mixed-methods study was designed by women of childbearing age from different cultural and socioeconomic backgrounds for 4 target populations: 1) current

and potential midwifery consumers; 2) previously incarcerated women; 3) recent immigrants and refugees 4) and women experiencing multiple social vulnerabilities. In this paper we report on findings from the *Changing Childbirth in BC* online survey.

### 2.1. Survey development

Our multi-stakeholder Steering Council collaborated to develop and content validate a core set of 310 survey and focus group questions exploring access to, preferences for, and experiences of maternity care, including the process of decision-making. Details on women-led survey construction and content validation are published elsewhere [18,19]. The team then supplemented the core survey tool with items that capture unique aspects of care and potential barriers that are germane to disadvantaged communities. All versions were embedded into an online platform and beta and pilot-tested by community members from the target populations before distribution. The Behavioural Research Ethics Board at University of British Columbia approved the study (H12-02418).

### 2.2. Recruitment

The online survey was open to women who had experienced pregnancy while living in British Columbia, as well as women who were planning to become pregnant. Data collection took place between January and June 2014. We used a convenience and purposeful sampling frame, i.e. community partners recruited participants through social media channels, postcards and posters at clinics, and counselors and clinicians at NGOs that serve vulnerable populations recruited participants. In addition, we used snowballing and networking via community and neighborhood groups, e-mail lists, local pregnancy and parenting vendors, conferences and fairs. Participants could access the survey through a link, and could complete the survey on any device. Recruitment was robust, with over 4000 community members across all health authorities providing survey data in 2014 (see Fig. 1). Among survey respondents, 1100 women volunteered to provide more detailed information in follow-up focus groups. We trained 33 community members to lead 20 focus groups across the province (n = 133), prioritizing regions with the most demand, as well as in communities that had identified challenges to completing an online survey (eg. recent immigrants and refugees). Community focus group facilitators and participants received honoraria, and participants were also offered childcare, refreshments, and support for transportation.

### 2.3. Measurement

Initial analysis of survey data resulted in the development and validation of two scales that measure the degree of *Mothers’ Autonomy in Decision Making (MADM)* and women’s experience of respectful maternity care – the *Mothers on Respect index (MORi)* [18,19]. Both scales are reliable measures that have been applied in middle and high resource countries to assess the quality and safety of provider-patient relationships and person-centered maternity care [20,21]. The outcome measure for the current analysis is the MADM scale.

The 7-item MADM scale enables women to rate the degree to which maternity care providers facilitate patient involvement and agency by eliciting preferences for role in decision-making, by providing enough information about different care options, and by respecting women’s choices. Higher scores indicate that care providers supported autonomy in decision-making to a higher degree. For a list of scale items, see Table 1. The MADM scale



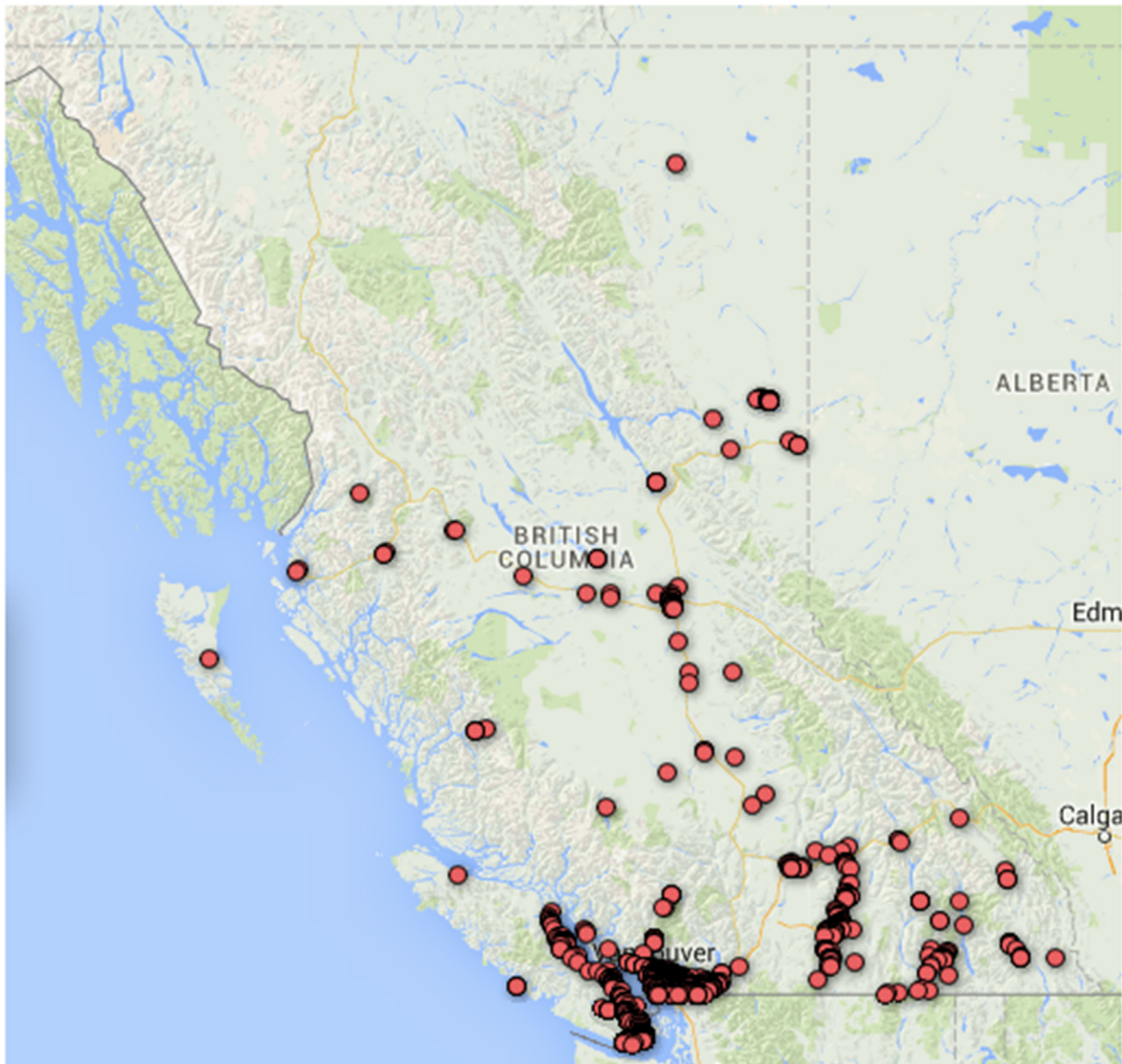


Fig. 1. Geographic location of survey respondents.

Table 1

Scale items – Mothers Autonomy in Decision Making (MADM) Please describe your experiences when making decisions and choosing options for care during this pregnancy.

My (provider) asked me how involved in decision making I wanted to be
My (provider) told me that there are different options for my maternity care
My (provider) explained the advantages/disadvantages of the maternity care options
My (provider) 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 (provider) respected that choice

Care provider type is automatically populated according to answer to prior item: The following section describes my experiences with a midwife, family physician or obstetrician.

Response options range from Completely disagree (1) to Completely agree (6).

showed very high internal consistency reliability across three samples of childbearing Canadian women (alphas ranged from 0.96–0.97). Examination of Eigenvalues, scree plots and factor analysis provided strong evidence that MADM measures one underlying construct. (18)

We compared MADM scores for women with different maternal characteristics to determine if autonomy in decision-making varies by patient attributes. Variables assessed included: vulnerable status (defined as one of the following: an immigrant or refugee, history of incarceration, homelessness, or substance use or identified as First Nations, Inuit or Metis); before tax household income of \$ 30,000 or less; race/ethnicity (divided into two groups: Women of Colour versus White women); and women without any post-secondary education.

We also examined potential variations in MADM scores by presence of medical or psycho-social risk factors (eg. high blood pressure, diabetes, depression, housing difficulties, no support

from family and friends, or problems with fetal or newborn health); as well as by type of provider; place of birth; or care provider behaviours that might be associated with patient autonomy, such as pressure to accept interventions. The latter were grouped as follows: 1) Women who did not have an induction/Cesarean section, but felt pressure from their provider to have an induction/Cesarean Section. 2) Women who had an induction/Cesarean section, and felt pressure to accept an induction/Cesarean Section. 3) Women who had an induction/Cesarean section, and did not feel pressure from a care provider to have these interventions.

#### 2.4. Sample

The focus of the current analysis are the 2051 women who experienced care by obstetricians, family physicians, or midwives while living in British Columbia. These women were invited to fill out all sections of the online survey: preferences; access; experiences with maternity care; and information about pregnancy (eg. singleton or twins), birth (eg. mode of delivery), postpartum; and socio-demographics. Some women skipped items, resulting in variable denominators for most analyses. See Sample Size flow chart in Fig. 2.

#### 2.5. Data analysis

We report means and frequencies to describe the socio-demographic and health profile of participants, rates of interventions, and their experiences with maternity care. We also provide descriptive statistics about women's preferences and

ability to engage in decision-making during pregnancy, labour, and birth.

#### 2.5.1. Mixed-effects analysis

To examine factors that are related to women's experiences of autonomy and involvement in decision-making, we conceptualized the MADM scale score as the outcome variable in two Poisson mixed-effects regression models (to test the association between individual variables and MADM scores, and to examine incident rate ratios when all variables are entered into the model). Poisson regression was chosen because the MADM scores were skewed towards higher scores (i.e. negatively skewed). We used mixed-effects modeling because women could describe their maternity experiences in up to three pregnancies, and for up to three types of maternity care providers in each pregnancy. Mixed-effects analysis controls for multiple observations from the same women. The mixed effects models included socio-demographic factors (e.g. race, educational attainment), obstetric factors (e.g. presence of any social or medical prenatal risk factors), type of maternity care provider, and planned place of birth, and items assessing care provider behaviours that might be linked to perceptions of autonomy (see Table 2). We performed two rounds of analyses, first associating

MADM scores with individual factors, then determining which factors are most strongly associated with experiences of autonomy and decision-making, via hierarchical mixed-effects Poisson regression (i.e. when all factors are included in the model).

### 3. Results

Most women (93%) experienced their last pregnancy within 5 years of data collection. Participating women were 32.8 years of

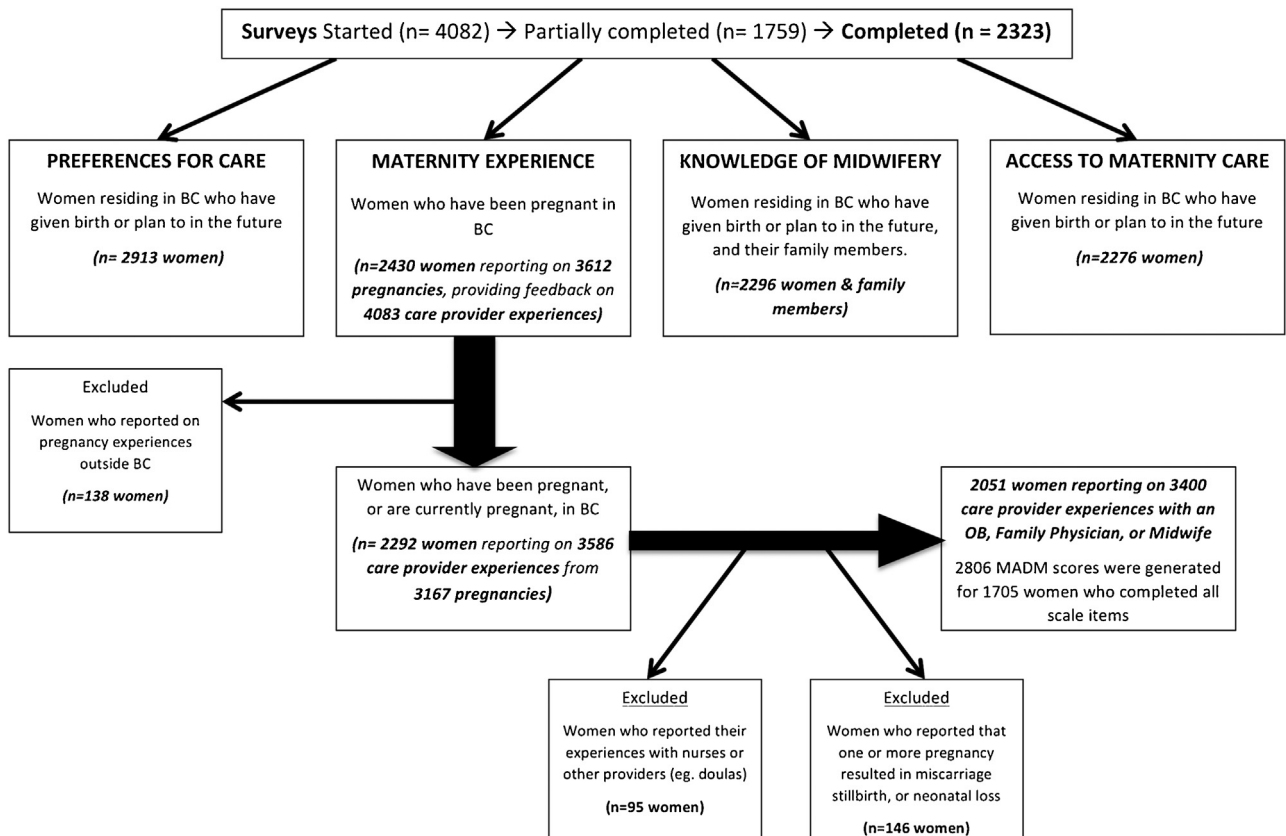


Fig. 2. Sample size flowchart.

**Table 2**  
Sample characteristics (n = 2051).

	n (%)
Vulnerable status	135 (8.2)
Family income < 30 k	119 (7.7)
Women of colour	119 (7.4)
No postsecondary education	163 (9.9)
Expecting twins	37 (1.8)
One or more medical/psycho-social risk factor during pregnancy	277 (13.5)
Number of providers during pregnancy	
Single provider	1672 (81.5)
Two or more provider	379 (18.5)
Woman was pregnant at time of data collection	303 (14.8)
MADM scale filled out in reference to:	
A midwife	2071 experiences
A family physician	772 experiences
An obstetrician	557 experiences
Place of birth	
Planned hospital birth and gave birth at hospital	1209 (69.8)
Planned home birth but was transferred to hospital for birth	140 (8.1)
Planned home birth and gave birth at home	337 (19.4)
Unplanned home birth	28 (1.6)
Other (e.g. woman gave birth in health center or en route to hospital etc.)	19 (0.9)
Held back questions more than once during prenatal visits because provider seemed rushed	181 (9.1)
Held back questions more than once during prenatal visits because wanted different care for self or baby	112 (5.6)
Held back questions more than once during prenatal visits because was worried about being difficult	126 (6.3)
Treated poorly because of race/ethnicity	18 (1.0)
Induction No/Pressure Yes	98 (5.6)
Induction Yes/Pressure Yes	179 (10.1)
Induction Yes/Pressure No	152 (8.6)
CS No/Pressure Yes	53 (3.0)
CS Yes/Pressure Yes	141 (8.0)
CS Yes/Pressure No	225 (12.7)

age (at time of data collection), on average, and self-identified as, Asian only (3.4%), First Nations, Inuit, or Metis only (1.4%), White only (90.9%) and other/biracial (4.3%). Of the 2051 women, 135 (8.2%) were from a vulnerable group, i.e. self-identified as an immigrant or refugee, First Nations, Inuit, or Metis, or had a history of incarceration, homelessness, or substance use. Group socioeconomic characteristics included 7.7% with family incomes < \$30,000 (CAD), and 9.9% with no post-secondary education or training.

The proportion of women who participated from different health authorities were representative of the geographic and socio-economic profile of childbearing women across the province, but the sample under-represented women of colour. See Fig. 1 for location of respondents, and Table 2 for additional sample characteristics.

### 3.1. Decision-making during maternity care

When asked who usually makes decisions about pregnancy, birth and infant care, 1262 (61.5%) women said that they make decisions together with their partner, 1210 (59.0%) said they are the sole decision makers, 3 (0.1%) said their partners take the lead, and 4 (0.2%) said parents/elders lead the decisions. Participants could check all options that apply to their situation. Almost all women had a strong preference for leading decisions around options for care (see Table 3). A little less than half also highly valued the input

**Table 3**  
Women's preferences for role in decision-making (n = 2051).

	n (%)
It is very important to me that I lead the decisions	1440 (70.2)
It is important to me that I lead the decisions about my pregnancy, birth and baby care	512 (25.0)
It is not important that that I lead the decisions	10 (0.5)
It is very important or important to me that my doctor or midwife guides the decisions	970 (47.3)

of their provider. Only 10 participants indicated that leading decisions was not important to them.

### 3.2. Interventions and procedures

One in five women (n = 368, 20.8%) had a Cesarean section. When asked who made the decision for the procedure, 66.9% of them reported that their care provider recommended the procedure. Overall, 332 (18.8%) women reported that their labours were induced. As a proportion of all women who provided data, 277 (15.8%) felt pressured to have their labor induced, 194 (11.1%) felt pressure from a healthcare provider to have a Cesarean section, and 120 women (or 6.8%) felt pressure to have epidural anesthesia.

Among the 332 women who did have an induction, 179 women (53.9%) felt pressured to accept the intervention. Of the 368 women who had a Cesarean, 141 (38.3%) reported feeling pressure to agree to surgery.

### 3.3. Women's autonomy in decision-making

We generated MADM scores for 1705 women who provided data on 2806 pregnancy experiences. Scores ranged from 7 to 42, with a median score of 39 (5th percentile: 15; 95th percentile: 42).

#### 3.3.1. Mixed effects models

When examining individual effects, factors that were linked to significantly lower MADM scores (i.e., less agency in decision-making) were: reporting a medical/social risk factor during pregnancy (4% lower MADM scores), having no post-secondary education (5% lower), expecting twins (7% lower), and receiving care from a family physician (27% lower), or obstetrician (26% lower). Scores were also significantly lower among women who held back questions because their care provider seemed rushed (44% lower), or because they had a difference in opinion with their care provider about the right care for themselves or their baby (48%

lower); or when they felt that their care provider might think that they were being difficult (44% lower). MADM scores were also much lower if women felt treated poorly because of their race/ethnicity (46% lower). Women who felt pressure from a care provider to accept a Cesarean section or induction had significantly lower MADM scores (13–18% lower), whereas women who had these interventions but were not pressured had significantly higher MADM scores (5–6% higher) (see Table 4).

When entering all factors into the model, the following factors were still significantly linked to lower MADM scores: receiving care from a physician compared to a midwife, holding back questions during prenatal appointments, and being pressured into interventions (see Table 4). Women who reported holding back questions more than once during prenatal visits because their provider seemed rushed exhibited the largest effect size, with MADM scores 24% lower compared to women who did not report this issue at all or who had this experience only once during pregnancy. Finally, those who reported that they experienced poor treatment from a care provider because of their race/ethnicity had MADM scores that were, on average, 16% lower and women who reported a difference in opinion about the right care for themselves or their baby had MADM scores that were 19% lower.

## 4. Discussion and conclusion

### 4.1. Discussion

We set out to determine if autonomy and agency in decision-making during pregnancy and birth differ depending on women's

socio-demographic and prenatal risk profile, type of care provider, nature of communication with care providers, or interventions received. Scores on the MADM scale were negatively skewed, meaning that autonomy in the whole sample was generally high. However, reduced autonomy was associated with having no postsecondary education, having medical or social risk factors during pregnancy or perceived racial discrimination from providers. Autonomy was noticeably lower among women who reported difficulties communicating with their care provider, such as having a difference in opinion with their care provider, not feeling comfortable to ask questions, or feeling pressured into interventions.

With respect to equity, our study elicited adverse effects of perceived discrimination on women's sense of autonomy in decision-making. Similarly, other researchers have documented that race and culture have the potential to negatively influence person-centred decision-making due to implicit bias and internalized racism [22,23].

Women expressed a strong desire for a model of maternity care that supports woman-led decision-making. However, they indicated that providers mostly led decisions around interventions. There were significant differences in MADM scores when different types of primary maternity providers cared for women; MADM scores were over 20% lower among women who saw physicians compared to women who saw midwives. There were no significant differences in MADM scores between midwife-led care at home and at the hospital, indicating consistent experiences with autonomy and decision-making among midwifery clients, irrespective of planned place of birth.

**Table 4**

Mixed effect models, showing association between maternal characteristics, experiences of care and MADM scores.

	n Individual models	Incident Rate Ratios and 95% Confidence Intervals (IRR) Individual models	p Individual models	All variables in model (n = 1934)
Vulnerable status	2766	1.00 (0.98–1.03)	0.826	IRR = 1.04 (1.01–1.08)
Family income < 30 k	2260	1.00 (0.97–1.03)	0.820	Not significant
Women of colour	2352	1.00 (0.98–1.03)	0.718	Not significant
No post-secondary education	2384	0.95 (0.93–0.97)	< 0.001	Not significant
Expecting twins	2778	0.93 (0.88–0.97)	0.002	Not significant
One or more medical or social risk factor during pregnancy	2778	0.96 (0.94–0.98)	< 0.001	Not significant
GP experience compared to MW-planned hospital birth	2778	0.73 (0.71–0.74)	< 0.001	IRR = 0.82 (0.80–0.84)
OB experience compared to MW-planned hospital birth	2778	0.74 (0.73–0.76)	< 0.001	IRR = 0.83 (0.81–0.85)
MW-planned home birth compared to MW-planned hospital birth	2778	1.00 (0.99–1.02)	0.374	Not significant
Held back questions more than once during prenatal visits because provider seemed rushed	2750	0.56 (0.55–0.58)	< 0.001	IRR = 0.76 (0.73–0.78)
Held back questions more than once during prenatal visits because wanted different care for self or baby	2739	0.52 (0.51–0.54)	< 0.001	IRR = 0.81 (0.77–0.85)
Held back questions more than once during prenatal visits because was worried about being difficult	2752	0.56 (0.55–0.58)	< 0.001	IRR = 0.85 (0.81–0.89)
Treated poorly because of race/ethnicity	2511	0.54 (0.50–0.59)	< 0.001	IRR = 0.84 (0.77–0.93)
Induction No/Pressure Yes	2525	0.82 (0.80–0.85)	< 0.001	IRR = 0.92 (0.93–0.98)
Induction Yes/Pressure Yes	2541	0.86 (0.84–0.88)	< 0.001	IRR = 0.95 (0.93–0.98)
Induction Yes/Pressure No	2533	1.05 (1.03–1.07)	< 0.001	Not significant
CS No/Pressure Yes	2524	0.82 (0.79–0.86)	< 0.001	IRR = 0.94 (0.89–0.98)
CS Yes/Pressure Yes	2538	0.87 (0.85–0.89)	< 0.001	Not significant
CS Yes/Pressure No	2535	1.06 (1.04–1.08)	< 0.001	IRR = 1.06 (1.03–1.09)

The random effects in the mixed-effects model included pregnancy (1, 2, or 3) and number of care providers (1, 2, or 3). In the mixed-effects analysis, we only included cases where all items of the 7-item scale were completed. Finally, we report incident rate ratios (IRR) and p-values for the relationship between MADM scores and each individual factor, as well as IRRs with a p-value of < 0.05 when all factors are added to the model.

#### 4.1.1. Associations between model of care, autonomy and choice

Our results align with findings from other studies on women's experience of autonomy and respect [24,25]. Even across populations which differ in demographics, and access to options for maternity care, women consistently rate having a trusting relationship with their care provider as one of most important traits of good care [26,27]. However, trust is disturbed when women are not given the opportunity to participate in decision-making.

Pregnant women in British Columbia can choose from three types of providers: obstetricians, midwives, and family physicians. Most women see physicians during pregnancy in BC; in 2015/2016, 22.5% received prenatal and/or birth care from midwives [28]. The midwifery model of care in BC may explain why MADM scores are higher among midwifery clients. The College of Midwives of British Columbia (CMBC) mandates “a time commitment from each midwife that enables her to develop a relationship with the woman during pregnancy”, “[encouragement for] women to participate actively in their care and to make choices about the services they will receive, . . . and comprehensive care . . . [to] promote the attainment of these desired experiences of care [29]. Informed decision-making requires detailed discussions with women about the pros and cons of different care options and the evidence basis for recommendations. Accordingly, the payor model for midwives in BC allows for considerably more face-to-face time than physician models for care delivery [18].

#### 4.1.2. Risk, preferences, and pressure in maternity care

A number of reported care provider behaviours and attitudes were also associated with less autonomy in decision-making: perceived discrimination by the care provider based on race/ethnicity, care providers who were too rushed to give women enough time to ask questions during prenatal appointments. Women who reported social or medical health risk factors had somewhat lower MADM scores, which might be a function of being presented with more challenging decisions. However, these associations were no longer significant when all factors were entered into the model, suggesting that women's autonomy and agency are affected more by interactions with care providers than risk status and other maternal characteristics.

In the current study, 1 in 7 felt pressure from a healthcare provider to be induced, and 1 in 10 reported feeling pressured into a Cesarean section. Results from a representative sample of women ages 18–45 who gave birth at hospitals in the US in 2011/2012 suggest very similar rates; 15.8% of women felt pressured to accept an induction, and 13.3% reported that a care provider pressured them to have a Cesarean section [30]. Women in our study who were pressured to accept the intervention had significantly lower scores on the MADM scale, whether or not they actually had the intervention, whereas having an intervention without experiencing pressure did not reduce a woman's sense of autonomy.

Concepts of safety, risk, and appropriate use of interventions differ across types of providers [31,32] as well as between women, maternity care providers, and hospital staff [33], further complicating conversations. For example, in a study that examined opinions among Australian doctors and midwives about a pregnant woman's right to make autonomous decisions, clinicians agreed that, under certain circumstances, it was acceptable to override a pregnant woman's autonomy when concerns were raised about safety for the baby [34]. Negotiating refusal of care and differences of opinion may create conflicts and ethical dilemmas and also provoke disrespectful behaviour.

Divergence in provider attitudes, leading to variance in models of practice, exerts a cascading and iterative effect on maternal experience of autonomy when choosing options for birth care, including choice of birth place and obstetric interventions. In 2012, Canadian investigators [35] conducted focus groups and

interviews with 9 pregnant women and 56 intrapartum care providers (family doctors, midwives, nurses, obstetricians, and doulas). Care providers differed in opinion on medical management of birth and in readiness to rescind control. While certain providers valued women's decision-making agency, others held the view that the provider has a medico-legal responsibility to retain control. Providers believed that the evidence can be presented in a way that promotes compliance with the provider's preferred course of action; others pointed to women's tendency to defer to medical authority even after having an informed choice conversation with the provider [35]. A more recent integrative review of the literature by Healy et al. [36] examined how perceptions of risk impact providers' willingness to facilitate options for care in labour even among low-risk women. The authors concluded providers' heightened sense of personal responsibility and fear of liability reduces their ability to allow consumers to lead decisions.

Our findings highlight the difficulties that patients encounter in a risk-adverse culture when they resist or decline interventions. [37,38] Most disturbing is the disconnect between women's expressed desire to lead decision-making and their reports that in the majority of cases providers are actually making the decisions for interventions. Clinicians describe the complexity of respecting a woman's choice when her desires are in conflict with evidence-based maternity care [39,40]. However, we concur with Barry and Edgman-Levitan (2012) who wrote, “. . . the most important attribute of patient-centered care is the active engagement of patients when fateful healthcare decisions must be made” [41].

#### 4.1.3. Strengths and limitations

From its inception, this project has been community-based and grounded in a participatory action research model. Our methodology allowed us to identify authentic person-centred priorities for maternity care, which in turn appeared to enhance recruitment of a large, geographically representative and socio-economically diverse sample of childbearing women who received care from all three types of available providers. However, the convenience sampling frame, and challenges with recruiting survey respondents from vulnerable populations, limit the generalizability of findings.

To address this issue, we convened nine focus groups of immigrant and refugee women, First Nations women, and women with a history of incarceration, substance use and/or homelessness. We designed semi-structured questions along the same domains that were included in the survey, i.e. preferences for care, experiences of care and access to care. Analysis of this data by community coders has been completed, and findings align with the quantitative results. In 2016, we also adapted the Canadian survey to the US context, to collect data on experience among communities of colour, in the Giving Voice to Mothers study (n = 2700). One in three women who responded self-identified with a visible minority and reported significantly more mistreatment, and loss of autonomy, than White women [42].

Another limitation of the study is that women without internet access may not have been able to participate. To mitigate this barrier, our NGO partners and midwifery clinics who served disadvantaged women provided computers to facilitate participation. Questions that appeared later in the survey (e.g. socio-demographic questions) had the highest number of missing responses, as some women did not complete the survey. This means that the mixed-effects models that included all factors were based on smaller sample sizes.

#### 4.2. Practice implications

Patient-centered models of primary healthcare, which emphasize strong patient-provider relationships, and offer services

focused on individual needs and circumstances, are more responsive to the needs of vulnerable populations [6]. Midwifery is a family-centered model of care that prioritizes informed decision-making, and is associated with increased satisfaction with care, cost savings, and reduced use of obstetric interventions [43–45]. Continued expansion of the midwifery model of care may improve patient experience.

A recent Delphi study engaged 71 international healthcare experts in a systematic process to define professional competencies that support patient-provider interactions when they engage in a decision-making process in maternity care. Important items included open and respectful communication between women and care professionals, provision of evidence-based and understandable information, and antenatal preparation for making unexpected decisions during the childbearing cycle [46]. The authors posit that the term shared decision-making does not imply an equal stake in the decisions, and that the goal is to support patients to retain their autonomy and congruence with their innate philosophies and preferences [46]. Other authors have emphasized that interprofessional shared decision-making that does not prioritize patient preferences can reduce patient autonomy and agency [36,37]. Requiring health professionals to acquire skills to facilitate person-centred decision-making is essential to increase experiences of autonomy for pregnant women [47].

## 5. Conclusion

The *Changing Childbirth in BC* study results confirm that pregnant women's experiences of autonomy and agency are significantly altered by model of maternity care, medical/social risk factors, educational status, and patient experience of provider behaviour. Our research addresses an expressed community concern about lack of access to a maternity care model that prioritizes patient-led decision-making. Person-centred approaches to maternity care delivery in Canada may improve quality and safety, as defined by women.

## Author contributions

SV: conception and design of the study, acquisition of data, analysis, interpretation of data, drafting the article and revising it critically, final approval

KS: conception and design of the study, analysis, interpretation of data, drafting the article and or revising it critically, final approval

DM: acquisition of data, analysis, interpretation of data, revising article critically, final approval

MK: conception and design of the study, acquisition of data, revising article critically, final approval

RV: conception, acquisition of data, revising article critically, final approval

JW: interpretation of data, drafting the article, revising article critically, final approval

SP: interpretation of data, analysis, revising article critically, final approval

LM: the conception and design of the study, revising article critically, final approval

RM: the conception and design of the study, acquisition of data, interpretation of data, revising article critically, final approval

GJ: the conception and design of the study, acquisition of data, interpretation of data, revising article critically, final approval

## Declarations of interest

None.

## Acknowledgments

We thank our community partners for their long-term commitment to the diverse group of women they serve. We are grateful to academic and clinician colleagues from several UBC Departments including Education, Family Practice, Public Health, Obstetrics, and Midwifery, and the Women's Health Research Institute, for assisting with recruitment, research training and support for the community. In particular, work group leaders Lorna McRae, Mo Korchinski, Anna Tashlykova, Raquel Velasquez, Cathryn Ellis, and Nora Timmerman recruited and liaised with community members. We thank Birth Place Lab Research Coordinators, Barbara Karlen and Karen Gelb, for their skillful coordination of our multi-stakeholder and transdisciplinary teams. Our student research assistants Kelsey Martin, Sabrina Afroz, and Kerri Blackburn supported the project over several semesters, formatting and editing knowledge translation materials over many years. This analysis was undertaken in partial fulfillment of the first author's doctoral program at University of Sydney, with stewardship and support from supervisors, Lesley Barclay and Caroline Homer. This work was supported by the Vancouver Foundation [grant numbers #UNR12-0701]; and a Michael Smith Foundation for Health Research - Health Professional Investigator award [grant number 17020]. Most of all we thank the women and families of British Columbia whose frankness, perseverance, and willingness to share their stories were both impressive and humbling.

## References

- [1] USAID, Maternal and Child Health Integrated Program. *Respectful Maternity Care: Country Experiences*, (2012).
- [2] D.M. Berwick, What "patient-Centered" Should Mean: Confessions of an Extremist, Vol. 28, *Health Affairs*, 2009.
- [3] World Health Organization (WHO), Standards for Improving Quality of Maternal and Newborn Care in Health Facilities [Internet] Available from: (2016). [http://www.who.int/maternal\\_child\\_adolescent/documents/improving-maternal-newborn-care-quality/en/](http://www.who.int/maternal_child_adolescent/documents/improving-maternal-newborn-care-quality/en/).
- [4] J. Lothian, Being safe: making the decision to have a planned home birth in the United States, *J. Clin. Ethics* 24 (2013) 266–275.
- [5] R.E. Gee, M.P. Corry, Patient engagement and shared decision making in maternity care, *Obstet. Gynecol.* 120 (2012) 995–997.
- [6] S.T. Wong, M.J. Lynam, K.B. Khan, L. Scott, C. Loock, The social paediatrics initiative: a RICHER model of primary health care for at risk children and their families, *BMC Pediatr.* [Internet]. 12 (2012) 158.
- [7] L. Trenaman, A. Selva, S. Desroches, K. Singh, J. Bissonnette, N. Bansback, et al., A measurement framework for adherence in patient decision aid trials applied in a systematic review subanalysis, *J. Clin. Epidemiol.* 77 (2016) 15–23.
- [8] K.J. McCaffery, R. Turner, P. Macaskill, S.D. Walter, S.F. Chan, L. Irwig, Determining the impact of informed choice: separating treatment effects from the effects of choice and selection in randomized trials, *Med. Decis. Making* 31 (2011) 229–236.
- [9] M. King, I. Nazareth, F. Lampe, P. Bower, M. Chandler, M. Morou, et al., Impact of participant and physician intervention preferences on randomized trials: a systematic review, *J. Am. Med. Assoc.* 293 (2005) 1089–1099.
- [10] S. Miller, A. Lalonde, The global epidemic of abuse and disrespect during childbirth: history, evidence, interventions, and FIGO's mother-baby friendly birthing facilities initiative, *Int. J. Gynecol. Obstet.* 131 (2015) 49–52.
- [11] S. McMahon, A. George, J. Chebet, I. Masha, R. Mpembeni, P. Winch, Experiences of and responses to disrespectful maternity care and abuse during childbirth: a qualitative study with women and men in Morogoro Region, Tanzania, *BMC Pregnancy Childbirth*. 14 (2014) 268.
- [12] A. Symon, C. Winter, P.T. Donnan, M. Kirkham, Examining autonomy's boundaries: a follow-up review of perinatal mortality cases in UK independent midwifery, *Birth* 37 (2010) 280–287.
- [13] H.G. Dahlen, M. Jackson, J. Stevens, Homebirth, freebirth and doulas: casualty and consequences of a broken maternity system, *Women Birth* 24 (2011) 47–50.
- [14] C. Varcoe, H. Brown, B. Calam, T. Harvey, M. Tallio, Help bring back the celebration of life: a community-based participatory study of rural Aboriginal women's maternity experiences and outcomes, *BMC Pregnancy Childbirth* [Internet] 13 (2013) 26. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23360168>.
- [15] G. Higginbottom, P. Postgradip, E. Studies, M. Ba, C. Research, A.S. Bell, et al., An Integrative Review of Experiences of Maternity Services for Immigrant Women in Canada, *Divers Equal Heal Care*, 9, Radcliffe Publishing, 2012, pp. 253–266.
- [16] J.E. Soet, G.A. Brack, C. Dilorio, Prevalence and predictors of women's experience of psychological trauma during childbirth, *Birth* 30 (March) (2003) 36–46. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12581038>.

- [17] British Columbia Ministry of Health. Setting Priorities for the B.C. Health System 2014. Available from: <http://www.health.gov.bc.ca/library/publications/year/2014/Setting-priorities-BC-Health-Feb14.pdf>.
- [18] S. Vedam, K. Stoll, K. Martin, N. Rubashkin, S. Partridge, D. Thordarson, et al., 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. Kumar S, editor, *PLoS One* 12 (2) (2017). e0171804. Available from: <http://dx.plos.org/10.1371/journal.pone.0171804>.
- [19] S. Vedam, K. Stoll, N. Rubashkin, K. Martin, Z. Miller-Vedam, H. Hayes-Klein, et al., The mothers on respect (MOR) index: measuring quality, safety, and human rights in childbirth, *SSM Popul. Heal.* [Internet] 14 (3) (2017) 201–210. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S2352827317300174>.
- [20] P. Baji, N. Rubashkin, I. Szebek, K. Stoll, S. Vedam, Informal cash payments for birth in Hungary: are women paying to secure a known provider, respect, or quality of care? *Soc. Sci. Med.* 189 (2017) 86–95. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0277953617304483>.
- [21] Vedam S, (Conference Paper) Stoll K, Monroe S, Jennie Joseph J, Paula Rojas P, Roberta Eaglehorse R, Strauss N DE et al. The Giving Voice to Mothers Study: Measuring Respectful Maternity Care in North America. (ICM conference, June 2017, Toronto). 2017.
- [22] D.R. Williams, R. Wyatt, Racial Bias in health care and health: challenges and opportunities, *J. Am. Med. Assoc.* 314 (2015) 555–556. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26262792>.
- [23] W.J. Hall, M.V. Chapman, K.M. Lee, Y.M. Merino, T.W. Thomas, B.K. Payne, et al., Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *105, Am. J. Public Health* 105 (2015) 60–76.
- [24] J. Sandall, H. Soltani, S. Gates, A. Shennan, D. Devane, Midwife-led continuity models versus other models of care for childbearing women, in: J. Sandall (Ed.), *Cochrane Database of Systematic Reviews* [Internet], John Wiley & Sons, Ltd, Chichester, UK, 2013, doi:<http://dx.doi.org/10.1002/14651858.CD004667.pub3> [cited 2017 Apr 2]. Available from: .
- [25] M.J. Renfrew, A. McFadden, M.H. Bastos, J. Campbell, A.A. Channon, N.F. Cheung, et al., Midwifery and quality care: findings from a new evidence-informed framework for maternal and newborn care, *Lancet* 384 (2014) 1129–1145. Available from: <http://www.sciencedirect.com/science/article/pii/S0140673614607893>.
- [26] J. Goberna-Tricas, M.R. Banús-Giménez, A. Palacio-Tauste, S. Linares-Sancho, Satisfaction with pregnancy and birth services: the quality of maternity care services as experienced by women, *Midwifery* 27 (2011) e231–e237.
- [27] L. Lewis, Y. Hauck, F. Ronchi, C. Crichton, L. Waller, Gaining insight into how women conceptualize satisfaction: western Australian women's perception of their maternity care experiences, *BMC Pregnancy Childbirth* 16 (2016) 29.
- [28] Perinatal Services of British Columbia. Perinatal Health Report: Deliveries in British Columbia 2015/2016. [Internet], (2018) . Available from: [http://www.perinatalservicesbc.ca/Documents/Data-Surveillance/Reports/PHR/2015\\_16/PHR\\_BC\\_2015\\_16.pdf](http://www.perinatalservicesbc.ca/Documents/Data-Surveillance/Reports/PHR/2015_16/PHR_BC_2015_16.pdf).
- [29] College of Midwives of BC. Midwifery Model of Practice [Internet], (2015) . Available from: <http://cmbc.bc.ca/wp-content/uploads/2015/12/11.05-Midwifery-Model-of-Practice.pdf>.
- [30] J. Jou, K.B. Kozhimannil, P.J. Johnson, C. Sakala, Patient-perceived pressure from clinicians for labor induction and cesarean delivery: a population-based survey of U.S. women, *Health Serv. Res.* [Internet] 50 (2015) 961–981. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25250981>.
- [31] S. Vedam, K. Stoll, L. Schummers, N. Fairbrother, M.C. Klein, D. Thordarson, et al., The Canadian birth place study: examining maternity care provider attitudes and interprofessional conflict around planned home birth, *BMC Pregnancy Childbirth* 14 (2014) 353. Available from: <http://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-14-353>.
- [32] R. de Vries, Y. Paruchuri, K. Lorenz, S. Vedam, Moral science: ethical argument and the production of knowledge about place of birth, *J. Clin. Ethics* 24 (2013) 225–238.
- [33] M. Cheyney, C. Everson, P. Burcher, Homebirth transfers in the United States: narratives of risk, fear, and mutual accommodation, *Qual. Health Res.* 24 (2014) 443–456. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24598774>.
- [34] S. Kruske, K. Young, B. Jenkinson, A. Catchlove, Maternity care providers' perceptions of women's autonomy and the law, *BMC Pregnancy Childbirth* 13 (2013) 84. Available from: <http://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-13-84>.
- [35] W.A. Hall, J. Tomkinson, M.C. Klein, Canadian care providers' and pregnant women's approaches to managing birth: minimizing risk while maximizing integrity, *Qual. Health Res.* 22 (2012) 575–586. Available from: <http://qhr.sagepub.com/content/22/5/575.short>.
- [36] S. Healy, E. Humphreys, C. Kennedy, Midwives' and obstetricians' perceptions of risk and its impact on clinical practice and decision-making in labour: an integrative review, *Women Birth* 29 (2016) 107–116.
- [37] L. Barclay, J. Kornelsen, J. Longman, S. Robin, S. Kruske, S. Kildea, et al., Reconceptualising risk: perceptions of risk in rural and remote maternity service planning, *Midwifery* [Internet] 38 (2016) 63–70. Available from: <http://www.sciencedirect.com.ezproxy.library.ubc.ca/science/article/pii/S0266613816300353>.
- [38] R.G. De Vries, Y. Paruchuri, K. Lorenz, S. Vedam, Moral science: ethical argument and the production of knowledge about place of birth, *J. Clin. Ethics* 24 (3) (2013).
- [39] K. Records, B.L. Wilson, Reflections on meeting women's childbirth expectations, *JOGNN* 40 (4) (2011) 394–398.
- [40] M. Müller-Engelmann, H. Keller, N. Donner-Banzhoff, T. Krones, Shared decision making in medicine: the influence of situational treatment factors, *Patient Educ. Couns.* 82 (2011) 240–246.
- [41] M.J. Barry, S. Edgman-Levitan, Shared decision making – the pinnacle of patient-centered care, *New Engl. J. Med.* [Internet]. *Massachusetts Med. Soc.* 29 (366(9)) (2012) 780–781, doi:<http://dx.doi.org/10.1056/NEJMp1109283>.
- [42] S. Vedam, K. Stoll, T. Khemet Taiwo, N. Rubashkin, M. Cheyney, N. Strauss, M. McLemore, M. Cadena, E. Nethery, E. Rushton Schummers L DE the Gv-USC. They threatened and bullied me: a participatory research study of mistreatment during pregnancy and childbirth in the United States (2018) (submitted Rev.).
- [43] P.A. Janssen, C. Mitton, J. Aghajanian, Costs of planned home vs. Hospital birth in British Columbia attended by registered midwives and physicians, *PLoS One* 10 (7) (2015). e0133524 <https://www.ncbi.nlm.nih.gov/pubmed/?term=Janssen+Mitton>.
- [44] P.A. Janssen, et al., Outcomes of planned hospital birth attended by midwives compared with physicians in British Columbia, *Birth* 34 (2007) 140–147.
- [45] B. O'Brien, B. Chalmers, D. Fell, M. Heaman, E.K. Darling, P. Herbert, The experience of pregnancy and birth with midwives: results from the Canadian maternity experiences survey, *Birth* 38 (September) (2011) 207–215.
- [46] M.J. Nieuwenhuijze, I. Korstjens, A. de Jonge, R. de Vries, A. Lagro-Janssen, On speaking terms: a Delphi study on shared decision-making in maternity care, *BMC Pregnancy Childbirth* [Internet] 14 (2014) 223. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25008286>.
- [47] S. Vedam, C. Broten, N. Jahng, L. Hamilton, J. Wang, Dialogue and Shared Decisions: An Interprofessional Course on Collaborative Leadership in Maternity Care, International Normal Labour and Birth Research Conference, June, Ann Arbor, Michigan, 2018.

## 5.4 Equity, Safety, and Respect in U.S. Maternity Care

In both high and low resource countries, pregnant people who are recent immigrants, Indigenous, and/or disenfranchised by their lower socioeconomic status, race/ethnicity, or social situation are at increased risk for poor health outcomes, and reduced access to high quality care (Warren et al. 2017; Abuya et al. 2015; Elder, Goddeeris, and Haider 2016; Howell et al. 2018; McRae et al. 2018; Watson and Downe 2017). In recent studies, people have described experiences of racism, mistreatment and neglect of professional ethics by health care providers (HCPs) in North America (Ceron et al., 2016). The distress and racism experienced by Aboriginal women including discrimination, loss of autonomy, loss of community, and dehumanizing interactions with care providers has been documented in Canada (Varcoe, Brown, Calam, Harvey, & Tallio, 2013). Wanda Phillips-Beck, Indigenous researcher, in a reaction to Browne's work on the experience of Indigenous people notes that, "experiences of disenfranchising interactions with providers and health systems [reflect] overlaying discourses, policies and practices, which are firmly entrenched in organizations and institutions, and in the dominant society through the media, public conversations, and everyday practices." (Browne 2017b; Phillips-Beck personal communication, August 2019). To date, there is very little information on the experience and impact of institutional bias and provider mistreatment in health care, and those few patient-centered measures that exist have not been evaluated, validated or endorsed as culturally safe, comprehensive in scope, and/or relevant to maternity care.

Researchers and health practitioners have addressed health status of marginalized populations within the context of broader contributors to social, economic and emotional wellbeing. These include the social determinants of health and the experience of racism in the healthcare system (Kyoon-Achan, Kinew, Phillips-Beck et al, in press). As the WHO has affirmed, freedom from discrimination, harm and mistreatment are not only health human rights, they are independent and important health outcomes (Allan & Smylie, 2015; High-Level Working Group., 2017) that should be measurable (Bohren et al., 2015). Despite these realities, to date, there are minimal health care metrics that can capture the complex lived experiences of



mistreatment during the core and formative life experiences of pregnancy and birth. Relevant indicators of institutional racism, intergenerational trauma trigger events, implicit bias, disrespect, could link these experiences to factors like birth environment, provider, or access to models of care that support or reduce resilience, well-being, and confidence. Delegates addressed this context of equity in maternity care by designing the Giving Voice to Mothers study.

## **5.5 Giving Voice to Mothers Study**

Using a community-based participatory action research model, three Home Birth Summit Task Forces (Research and Data, Ethics and Equity, and Consumer Engagement) designed a new mixed-methods study to assess experiences of maternity care among communities of colour and among women who planned to give birth at home. No previous study has collected the voices of these often marginalized women in the US, nor through a process where they have chosen and designed the items of importance such as experiences of loss of autonomy, institutional racism, refusal of care, discrimination, and factors that support resilience despite mistreatment.

The Giving Voice to Mothers study assessed how planned place of birth, model of care, and personal characteristics like socioeconomic status, race and ethnicity interact with experience of pregnancy and childbirth care. The survey captured information on the process of decision-making and autonomy when offered interventions, experiences with mistreatment, discrimination and/or disrespect, refusal of care, and non-consented care, as well as access to options for maternity care and providers of choice.

### **5.5.1 Survey Construction and Content Validation**

The study began with a several months of consultation with a multi-stakeholder Steering Council of community partner organizations, clinicians, consumer advocates, and perinatal researchers to select or adapt previously validated items, identify missing topics, and design new questions to populate into a draft online survey. Then, 31 mothers from 4 communities of color (Black, Latina, Asian, Indigenous), and women who had planned to give birth in homes and birth centers rated the *relevance, importance, and clarity* of each survey item and commented on ways

for differences in risk profile, ethnicity, multiple socioeconomic barriers, etc) using the MORi and MADM scale scores as an outcome measure. The manuscript follows.

**Manuscript 4: Giving Voice to Mothers: inequity and mistreatment during pregnancy and childbirth in the United States.**


. <https://doi.org/10.1186/s12978-019-0729-2>

RESEARCH

Open Access

# The Giving Voice to Mothers study: inequity and mistreatment during pregnancy and childbirth in the United States



Saraswathi Vedam<sup>1\*</sup> , Kathrin Stoll<sup>1</sup>, Tanya Khemet Taiwo<sup>2,3</sup>, Nicholas Rubashkin<sup>4</sup>, Melissa Cheyney<sup>5</sup>, Nan Strauss<sup>6</sup>, Monica McLemore<sup>7</sup>, Micaela Cadena<sup>8</sup>, Elizabeth Nethery<sup>9</sup>, Eleanor Rushton<sup>1</sup>, Laura Schummers<sup>10</sup>, Eugene Declercq<sup>11</sup> and the GvTM-US Steering Council

## Abstract

**Background:** Recently WHO researchers described seven dimensions of mistreatment in maternity care that have adverse impacts on quality and safety. Applying the WHO framework for quality care, service users partnered with NGOs, clinicians, and researchers, to design and conduct the Giving Voice to Mothers (GvTM)–US study.

**Methods:** Our multi-stakeholder team distributed an online cross-sectional survey to capture lived experiences of maternity care in diverse populations. Patient-designed items included indicators of verbal and physical abuse, autonomy, discrimination, failure to meet professional standards of care, poor rapport with providers, and poor conditions in the health system. We quantified the prevalence of mistreatment by race, socio-demographics, mode of birth, place of birth, and context of care, and describe the intersectional relationships between these variables.

**Results:** Of eligible participants ( $n = 2700$ ), 2138 completed all sections of the survey. One in six women (17.3%) reported experiencing one or more types of mistreatment such as: loss of autonomy; being shouted at, scolded, or threatened; and being ignored, refused, or receiving no response to requests for help. Context of care (e.g. mode of birth; transfer; difference of opinion) correlated with increased reports of mistreatment. Experiences of mistreatment differed significantly by place of birth: 5.1% of women who gave birth at home versus 28.1% of women who gave birth at the hospital. Factors associated with a lower likelihood of mistreatment included having a vaginal birth, a community birth, a midwife, and being white, multiparous, and older than 30 years. Rates of mistreatment for women of colour were consistently higher even when examining interactions between race and other maternal characteristics. For example, 27.2% of women of colour with low SES reported any mistreatment versus 18.7% of white women with low SES. Regardless of maternal race, having a partner who was Black also increased reported mistreatment.

**Conclusion:** This is the first study to use indicators developed by service users to describe mistreatment in childbirth in the US. Our findings suggest that mistreatment is experienced more frequently by women of colour, when birth occurs in hospitals, and among those with social, economic or health challenges. Mistreatment is exacerbated by unexpected obstetric interventions, and by patient-provider disagreements.

**Keywords:** Respectful maternity care, Mistreatment, Pregnancy, Childbirth, Race, Disrespect, Abuse, Participatory research, Hospital birth, Home birth, Health equity, Midwifery, Quality measure

\* Correspondence: [saraswathi.vedam@ubc.ca](mailto:saraswathi.vedam@ubc.ca)

<sup>1</sup>Birth Place Lab, Division of Midwifery, Faculty of Medicine, University of British Columbia, Vancouver (Canada), E416 Shaughnessy (Mailbox 80), 4500 Oak Street, Vancouver, BC V6H 3N1, Canada

Full list of author information is available at the end of the article



## Plain English summary

Global health experts agree that how people are treated during childbirth can affect the health and well-being of mother, child, and family, but very little is known about experiences of care among childbearing populations in the United States. In this study, community members worked with researchers to design a survey that would capture their lived experiences of care during pregnancy and childbirth, including seven types of mistreatment by health providers or health systems. We collected information across the country including from communities of colour, and women who planned to give birth at home or in a birthing center. Of the 2700 women who filled out the survey, one in six (17.3%) reported mistreatment. Among all participants, being shouted at or scolded by a health care provider was the most commonly reported type of mistreatment (8.5%), followed by “health care providers ignoring women, refusing their request for help, or failing to respond to requests for help in a reasonable amount of time” (7.8%). Some women reported violations of physical privacy (5.5%), and health care providers threatening to withhold treatment or forcing them to accept treatment they did not want (4.5%). Women of colour, women who gave birth in hospitals, and those who face social, economic, or health challenges reported higher rates of mistreatment. Rates were also increased in women who had unexpected events like cesareans or transfer from community to hospital care; and women who disagreed with a health care provider, about the right care for themselves or the baby, reported the highest rates of mistreatment.

## Background

High quality, respectful maternity care is a global priority [1]. In 2017, the World Health Organization (WHO) published eight standards for quality of maternal and newborn care that can be used to evaluate “the extent to which health care services provided to individuals and patient populations improve desired health outcomes and [are] safe, effective, timely, efficient, equitable and people-centred” [2]. Four of the standards emphasize care that demonstrates respect, dignity, emotional support, and a systemic commitment to a patient-led, informed decision-making process. The International Federation of Gynecologists and Obstetrics, the International Confederation of Midwives, the International Pediatric Association, and the White Ribbon Alliance have prioritized the WHO quality care standards, and protection of human rights in childbirth, as essential to optimizing birth outcomes [3].

Care provider actions and interactions are associated with women’s experience of trauma during birth, as indicated in an online survey ( $n = 748$ ) [4]. Qualitative

analysis identified four common themes: ‘prioritizing the care provider’s agenda’; ‘disregarding embodied knowledge’; ‘lies and threats’; and ‘violation’ [4]. A traumatic birth can have serious impact on postnatal mental health and family relationships. Short-term consequences of adverse experience of care include pain and suffering, and long-term consequences cited in the international literature include post-traumatic stress disorder, fear of birth, negative body image, and feelings of dehumanization [4–7]. In addition to these outcomes, fear of disrespect and abuse, and loss of autonomy have been cited as drivers for planned unattended home births, and reduce uptake of care, even among women with known risk factors [8]. Indeed, such mistreatment is itself an adverse outcome as it constitutes a violation of basic human rights [9].

Recognizing these serious health impacts, the World Health Organization (WHO) issued a statement in 2014 calling for further research on defining and measuring disrespect and abuse in public and private facilities worldwide [10, 11]; and urged health systems to protect and promote women’s rights to dignified and respectful care, in addition to ensuring universal access to timely, safe and effective clinical care [11]. While significant disparities in maternal and newborn outcomes are reported across populations in the United States (US) [12], very little is known about whether mistreatment is a component of these adverse outcomes. To understand experiences of childbirth care, especially among communities of color and those who choose to deliver in community settings, service users partnered with NGOs, clinicians, and researchers, to conduct the Giving Voice to Mothers (GVtM)–US study.

## Measuring mistreatment in high resource countries

To date, evaluations of respectful maternity care (RMC) have focused primarily on monitoring care during hospital births in low-resource settings [6, 13, 14]. However, childbearing women from high and middle resource countries have also reported negative experiences during hospital births, including being ignored, belittled or verbally humiliated by healthcare providers, having interventions forced upon them, and being separated from their babies without reason or explanation [7, 15–17]. For example, women from Slovakia who were interviewed ( $n = 15$ ) reported that care providers treated them as objects incapable of making decisions about their own care. Many of them did not consent to interventions such as episiotomies. Violations of their dignity, privacy, and confidentiality were common. Women said that care providers did not listen to them, doubted their perceptions and feelings, ignored their wishes, imposed their will on women, and made them feel guilty or like failures [17].

In high resource countries, pregnant people who are recent immigrants, Indigenous, and/or disenfranchised by their lower socioeconomic status, race/ethnicity, incarceration, substance dependence, or housing instability have been reported to be at increased risk for poor health outcomes, and reduced access to high quality care [18–22]. Few investigators have examined whether experiences of RMC differ by sociodemographic factors, but one U.S. national study identified racial disparities in the treatment of childbearing women in hospitals [23]. Among respondents, 30% of Black and Hispanic primiparous women and 21% of White women who delivered in hospitals in the US reported that they were “treated poorly because of a difference of opinion with [their] caregivers about the right care for [herself or her] baby” [23].

In 2015, the WHO Research Group on Treatment of Women During Childbirth conducted a systematic review of the literature on RMC [13]. Bohren and colleagues examined qualitative and quantitative evidence from 65 studies on the mistreatment of women during childbirth in health facilities across 34 countries, representing diverse geographical and economic settings. The investigators identified multiple examples of disrespect and human rights violations experienced by women giving birth, ranging from physical and verbal abuse, to a lack of supportive care, to neglect, discrimination, and denial of autonomy [13]. Noting wide inconsistencies in terminology and definitions of disrespect and abuse, the authors named the phenomenon “mistreatment” and delineated the phenomena across seven dimensions: physical abuse, sexual abuse, verbal abuse, stigma and discrimination, failure to meet professional standards of care, poor rapport between women and providers, and poor conditions and constraints presented by the health system [13]. They proposed that future investigators utilize this typology to inform studies that seek to understand the prevalence and impact of mistreatment across jurisdictions or populations, and/or to evaluate the success of interventions. Since 2015, numerous authors have responded to the Bohren typology, noting a lack of global evidence on the topic [24–27]. Some investigators have adapted the typology to qualitative studies of the prevalence and characteristics of mistreatment in low resource countries [14], but none to date have applied the typology to assess experience of care in high resource countries, and none have assessed the seven domains in a quantitative survey.

Notably, while the lived experience among study participants provided the descriptive data that informed the Bohren typology, none of the studies included in the systematic review used a patient-led approach to item development. Best practice in patient-oriented outcomes research would suggest that “mistreatment” as an

outcome may be best described and delineated by the recipients of care. Patient experience indicators of quality and safety are now routinely collected at institutions in other areas of medicine, yet patient-designed instruments that can assess the impact of experience of maternity care remain scarce.

In this paper, we introduce a set of patient-designed indicators of mistreatment that align with the typology proposed by Bohren et al., and are relevant to service users in high resource settings. We present results from a large national survey that utilized these items to examine how women in the US overall, and among key subgroups, report on mistreatment during pregnancy and childbirth. In addition, we examine the relationships between race and mistreatment in the context of factors that are frequently related to health inequity. The concept of intersectionality is rarely considered during design, analysis or interpretation of public health studies [28]; we aimed to address this gap in this study.

## Methods

In 2016, using a community-based participatory research process [29, 30], we convened a multi-stakeholder team to launch Giving Voice to Mothers (GVtM-US), a study of maternity care experiences of women who experienced pregnancy in the United States between 2010 and 2016. The only previous national study on experience of maternity care in the US was limited to women who planned hospital births, had limited information on differential experiences by race, and did not measure mistreatment [23]. Hence, our team, comprised of community members, clinicians, community health service leaders, and researchers designed a study on quality of maternity care as experienced by pregnant persons from 4 communities of colour (African American, Indigenous, Hispanic, and Asian) who gave birth in any location, as well as women who planned to give birth in homes and freestanding birth centers. The Behavioural Research Ethics Board at University of British Columbia approved the study (H15–01524). All participants reviewed an informed consent form before deciding whether they wanted to participate in the online survey.

## Survey development

The GVtM Steering Council recruited community agency leaders and service providers to adapt a survey instrument, developed by service users to study maternity care experiences in British Columbia, Canada [31–33], to the United States context. The validated instrument explored four domains including: preferences for care, interactions with care providers, role in decision-making, and access to care options. Following consultations with the communities they serve, the GVtM Steering Council identified, drafted, or adapted

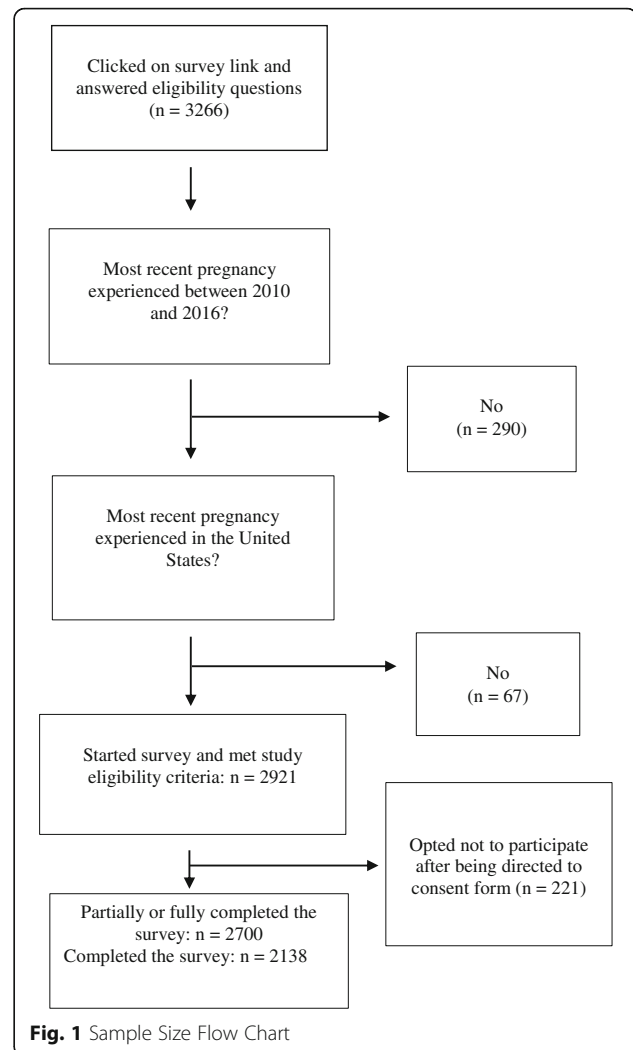
additional items from the literature that assess non-consensual care, disparities in access, social determinants, and institutional racism [34, 35]. Some items had been used to measure disrespect and abuse in low resource countries and were adapted for application to the US context [35].

The community agencies (NGOs) then recruited 57 women from the target populations to review the draft, and subsequently 31 community members, with representation from all target populations, served on an expert panel to formally content validate the adapted instrument. They rated each item on a 4-point ordinal scale for clarity, relevance, and importance and provided narrative commentary. We retained, revised, or discarded items based on best practice guidelines for content validation [36]. The community members strongly endorsed the inclusion of the previously validated quality measures, the Mothers Autonomy in Decision Making (MADM) scale [31] and the Mothers on Respect (MOR) index [32]. They also adapted the Perceptions of Racism (PR) scale [34] to be inclusive of all study populations. Community members suggested inclusion of additional novel items in the instrument such as “*When you experience problems, what helps you and your family survive, succeed and thrive?*” and, in cases of refusal of care, “*How did your doctor or midwife react?*” and “*Who stood up for you?*”. They provided detailed answer options that reflected their lived experience.

Most questions had pre-defined Likert response options, but the survey instrument also included several open-ended questions to allow participants to provide explanatory detail. The final GVtM survey instrument contained 218 items (the full list of survey items is available upon request via: <http://www.birthplacelab.org/contact-us/>), with 60 items measuring aspects of mistreatment. It was translated and back translated into a Spanish version, and both versions were mounted on an online platform that allowed for branching to questions adapted for participants who experienced pregnancy loss, and for those who were currently pregnant.

#### Inclusion criteria

Women who experienced at least one pregnancy in the United States between 2010 and 2016, including those currently pregnant, could participate. Of the 2700 women who completed or partially completed the survey, some participants skipped questions and others did not finish the survey, resulting in variable denominators for each section. Because we compare variables that appear across the entire survey, we restrict our analysis to the 2138 women who completed the survey. Details on sample delineation are in Fig. 1.



#### Recruitment

All partners participated in evidence-based strategies for recruitment of traditionally marginalized groups, including social networking and venue-based sampling [37–39]. We used strategies to ensure strong representation of women of colour, and women who planned a birth at home or at a freestanding birthing center. For example, we engaged agencies in study recruitment who serve these populations, and some held survey café events with computer access available, and/or trained peers, known as “data doulas” [40] to support participants with their own data entry. To achieve our goal of robust sampling from women of colour and those who chose home and birth center births, based on the rates of participation to date, halfway through the data collection period we closed the survey to women who identified as White and who gave birth in a hospital, but kept it open to other participants.

In New York State data collection was embedded in an established ongoing statewide maternity care evaluation project led by one of the NGO partners, Choices in Childbirth. The Steering Council recognized that this was likely to lead to oversampling from a single state; hence, they initially considered launching the study as a New York State pilot study to demonstrate feasibility and generate enough data to highlight need for national follow up. However, community members served by the distributed NGOs and clinicians on the team felt strongly that they wanted the GvTM study to be open to participants from rural, urban, and suburban contexts *across* the United States. They felt that social media recruitment had the greatest potential for securing comparative data from a wide range of service users. Hence, to respect an authentic, patient-oriented participatory research process, the survey was distributed nationally. The GvTM survey was open from March 2016–March 2017.

## Measurement

### Mistreatment

Content validation resulted in new patient-designed and patient-validated items to measure mistreatment in childbirth that align with the dimensions codified by Bohren (Table 1) [13]. Of note, the community members on the Steering Council and the women who participated during the expert content validation stage endorsed these items without knowledge of the Bohren systematic review in progress, yet their lived experience resonated with the typology. Specifically, the mistreatment items measure the following domains: physical abuse, sexual abuse, verbal abuse, neglect and abandonment, poor rapport between women and providers, loss of confidentiality, and lack of supportive care. Community members also elected to include the MADM (autonomy) and MOR (respect), and an adapted Perceptions of Racism scale [34] that measure other domains in the Bohren typology: stigma and discrimination, failure to meet professional standards of care, lack of informed consent, and loss of autonomy. Twenty-two additional survey items related to the typology and assessed RMC, such as care provider behaviors in response to refusal of care, and the respondent's overall sense of dignity, respect, and privacy during interactions with providers.

The focus of the current paper is application of mistreatment items that describe patient experience of provider behaviors. Subsequent reports will focus on analysis of data related to the mistreatment domains of autonomy and respect (eg. MADM, MOR, and PR scale scores), and non-consented care among the GvTM participants.

### Maternal/paternal race

Community members on the study team recommended that research that relies on US Census categories fails to

capture the lived experience of people who self-identify across more than one race, and/or experience the effects of visible minority race. Accordingly, the team designed a complex but respectful and realistic approach to collecting and coding this set of items. Respondents could self-identify and provide considerable detail about their identity, selecting multiple descriptors under 13 pre-defined categories. For analysis, we recoded this variable into mutually exclusive categories (see Additional file 1: Table S1). We used the same coding scheme for paternal race/ethnic identity (as identified by the woman), and also created four variables that describe combinations of maternal/paternal race, i.e. 1) woman white, partner white, 2) women black, partner black, 3) women white, partner black, 4) women black, partner white. Throughout this paper Indigenous includes participants who self-identify as Native American, Native Hawaiian or Pacific Islander, Alaska Native, or Indigenous to Mexico or South America.

### Low SES

We created a comprehensive composite index that measures low SES, taking into account family income below the federal poverty threshold (based on before tax family income and household size). In the low SES category, we also counted respondents who reported that their heat or electricity was turned off (during or in the year before pregnancy), inability to buy enough food or meet financial obligations; and respondents who reported receiving a housing subsidy, assistance from Indian Health Services or a state health plan, Temporary Assistance for Needy Families (TANF), food stamps, WIC food vouchers or money to buy food. We coded respondents with one or more of the indicators of low SES as 1; and respondents that did not report any of the indicators as 0.

### History of social risks

To distinguish those who may experience differential treatment because of social factors, we grouped together respondents who reported substance use (smoking, daily alcohol use during pregnancy, and/or drug dependence) during pregnancy, women with a history of incarceration (herself or partner), involvement of child or family services, and/or intimate partner violence. Women who reported one or more of the indicators of social risk were coded as 1; women did not report any social risk indicators were coded as 0. We also created composite indices that measure elevated pregnancy risks and newborn health problems. A description about how these indices were derived can be found in footnotes below the tables.

### Analysis

To describe the overall prevalence of mistreatment in the study population, we calculated the proportion of



**Table 1** GvTM items that align with WHO [63] typology of mistreatment

Bohren et al. – Third-Order Themes	Bohren et al. – Second -Order Themes	GvTM – US items and scales
Physical abuse	Use of force Physical restraint	"You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)"
Sexual abuse	Sexual abuse	
Verbal abuse	Harsh language Threats and blaming	"Health care providers (doctors, midwives, or nurses) shouted at or scolded you" "Health care providers threatened to withhold treatment or to force you to accept treatment you did not want" "Health care providers threatened you in any other way"
Stigma and discrimination	Discrimination based on socio-demographic characteristics	Mothers on Respect (MOR) Index (14 items) <sup>a</sup> <ul style="list-style-type: none"> <li>• Adapted 17-item Perceptions of Racism Scale</li> <li>• Four items that assess perceived discrimination from care providers or other disrespectful care provider behaviours, e.g. During my pregnancy I held back from asking questions or discussing my concerns because I felt discriminated against; During my pregnancy I held back from asking questions or discussing my concerns because my care provider used language I could not understand.</li> <li>• One item asking women how often they have felt treated unfairly because of their race, heritage or ethnic group</li> </ul>
Failure to meet professional standards of care	Lack of informed consent and confidentiality Physical examinations and procedures Neglect and abandonment	"Your private or personal information was shared without your consent" "Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)" "My doctor or midwife explained different options for care during my labour and birth." "My doctor or midwife asked me what I wanted to do before the following procedures were done: (episiotomy, continuous fetal monitoring, screening tests etc)." "Health care providers ignored you, refused your requests for help, or failed to respond to requests for help in a reasonable amount of time."
Poor rapport between women and providers	Ineffective communication Lack of supportive care Loss of autonomy	Mother Autonomy in Decision Making scale (MADM) (7 items) <sup>b</sup> <ul style="list-style-type: none"> <li>• Three items that ask women to rate the level of respect, dignity and privacy that their care provider showed during labour and/or birth</li> <li>• Five items about care that women declined, what they declined, why, how their care provider reacted and if anyone helped the woman maintain her wishes.</li> </ul>
Health system conditions and constraints	Lack of policies Facility culture	Adapted Perceptions of Racism Scale included items assessing treatment in medical offices and hospital wards

<sup>a</sup>Vedam S, Stoll K, Rubashkin N, et al. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *Social Science and Medicine: Population Health*. <https://doi.org/10.1016/j.ssmph.2017.01.005>

<sup>b</sup>Vedam S, Stoll K, Martin K, et al. 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. *PLOS ONE* <https://doi.org/10.1371/journal.pone.0171804>

women who experienced each of the seven types of mistreatment and what proportion experienced any mistreatment (i.e. any of the seven indicators). We report sociodemographic variables for all women who started the survey and met eligibility criteria ( $n = 2700$ ), as well as for all women who completed the last item on the survey ( $n = 2138$ ). Rates of mistreatment are stratified by maternal characteristics such as race, parity, age, immigrant status, SES, pregnancy health status, and social risks (history of substance use, incarceration and/or intimate partner violence); as well as context of care factors (induction, mode of birth, place of birth, type of provider, and disarticulation between their own preferences for care and their provider's recommendations).

We used logistic regression to quantify the relationship between mistreatment and the variables described above. To examine the relationship between mistreatment and maternal race/ethnicity, we calculated odds ratios comparing the odds of mistreatment among women of color to the odds among white women.

To elucidate the intersectional relationships between maternal race and other factors that are linked to mistreatment, we examined the relationship between race and mistreatment within categories of other sociodemographic and context of care variables. Within categories (e.g., nulliparous, age 17–25 years, place of birth), we calculated the prevalence of mistreatment among women of colour and white women separately.

Larger differences between groups indicate larger disparities in mistreatment by race.

To report illustrative details provided in open-ended text boxes, community and research team members verified the applicability and resonance of the Bohren framework and recommended that we include the voices of mothers by identifying exemplars based on the Bohren typology. Three team members independently reviewed the text boxes and came to consensus about representative quotes, which were then reviewed and approved by the community partners.

## Results

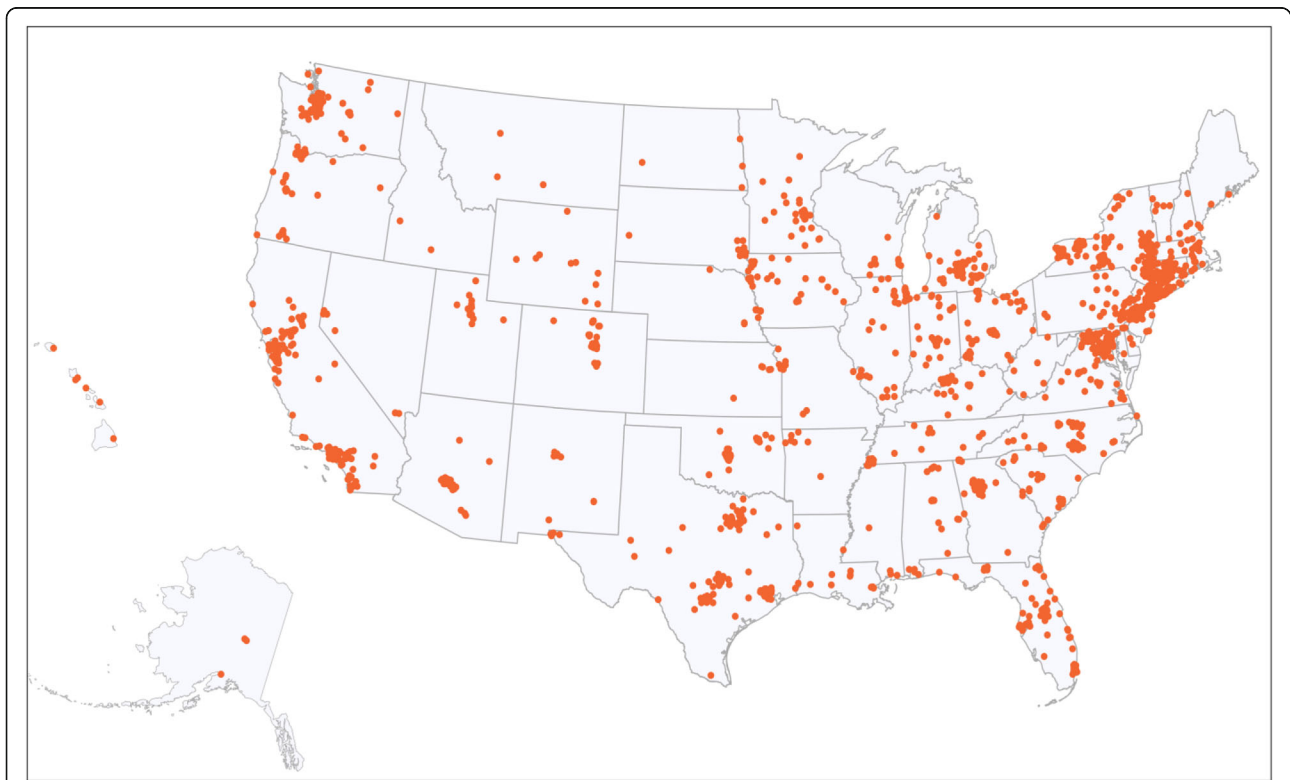
### Sample ( $n = 2138$ )

The majority of participants (64.5%) were between the ages of 25 and 35 when they gave birth; 13.5% were pregnant at the time of data collection. Most were born in the US (90%) and the majority completed post-secondary education. Participants from all 50 states completed the survey (see Fig. 2), and as expected, the largest proportion of responses were submitted by women from New York State (29.7%). One in three women across the whole sample reported family incomes less than \$50,000 per year. The majority of participants received prenatal care from midwives (71.1%), and half (49.6%) gave birth in their homes or a free-standing birth center. Fewer women of colour had

prenatal care by midwives (eg. 59.9%) compared to white women (76.5%), and fewer women of colour (38.2%) compared to white women (55.2%) gave birth in homes or birth centers. Close to 14% of women had a Cesarean birth (CB), with variation by race: 17.8% women of colour had a CB compared to 11.8% of White women. Additional file 1: Table S2 displays socio-demographic characteristics for the 2700 participants, the 2138 participants included in the analysis of mistreatment items. Sample characteristics for the 2138 women included in the mistreatment analysis closely resembled those of all women who started the survey ( $n = 2700$ ).

### How common is mistreatment?

One in six women (17.3%) in our sample experienced one or more types of mistreatment (Table 2). Being shouted at or scolded by a health care provider was the most commonly reported type of mistreatment (8.5%), followed by “health care providers ignoring women, refusing their request for help, or failing to respond to requests for help in a reasonable amount of time” (7.8%). Fewer women reported violation of physical privacy (5.5%), and health care providers threatening to withhold treatment or forcing them to accept treatment they did not want (4.5%). Very few women reported physical abuse, sharing of their personal information without consent, or healthcare providers threatening



**Fig. 2** Map of zip codes, representing maternal residence at time of pregnancy

**Table 2** Mistreatment by Care Providers in Childbirth (MCPC) Indicators ( $n = 2138$ )

Did you experience any of the following issues or behaviours during your care?	<i>n</i> (%)
Your private or personal information was shared without your consent	26 (1.2)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	117 (5.5)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	182 (8.5)
Health care providers threatened to withhold treatment or to force you to accept treatment you did not want	97 (4.5)
Health care providers threatened you in any other way	44 (2.1)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	166 (7.8)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, refusal to provide anesthesia for an episiotomy, etc.)	27 (1.3)
Any mistreatment (one or more of the above)	369 (17.3)

them in other ways (see Table 2). See Table 3 for quotes from the GVTM survey, illustrating mistreatment of US women.

### Mistreatment by sociodemographic factors

#### *Race, ethnicity and immigration status*

Indigenous women were the most likely to report experiencing at least one form of mistreatment by health-care providers (32.8%), followed by Hispanic (25.0%) and Black women (22.5%). Women who identified as White were least likely to report that they experienced any of the mistreatment indicators (14.1%). Differences in mistreatment by race were pronounced for some indicators. For example, twice as many Hispanic and Indigenous women as compared to White women reported that health care providers shouted at or scolded them. Likewise, Black women, Hispanic women, Asian, and Indigenous women were twice as likely as White women to report that a health care provider ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time (see Table 4).

Overall, White women with a White partner reported the least mistreatment (12.0%), followed by White women with a Black partner (17.0%) (see Additional file 1: Table S3). Bi-racial couples experienced less mistreatment when the woman was White as opposed to Black. However, for some indicators of mistreatment (eg., *Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time*) White women with a Black partner were twice as likely to report mistreatment when compared to White women with a White partner.

Women who were born in the US reported similar rates of mistreatment compared to women who were not born in the US, but had lived there for more than 5 years (see Additional file 1: Table S4). Recent immigrants were more likely to report mistreatment, although results should be interpreted with caution as the number of recent immigrants was small ( $n = 34$ ).

#### *Age and parity*

One in four women 24 or younger reported any mistreatment compared to one in seven women over 30 years old. Young women were also more likely to report physical abuse by providers compared to older women (Additional file 1: Table S5). Multiparous women reported lower rates of mistreatment on all indicators (see Additional file 1: Table S6), compared with women who were first-time mothers. Overall, first-time mothers were twice as likely to report mistreatment.

#### *Socioeconomic, social, and pregnancy risk status*

Women who reported low SES had similar rates of mistreatment on some of the indicators (e.g. sharing of personal information without consent) but were twice as likely to report being threatened or shouted at by HCPs, compared to women with moderate or high SES (Table 5). Women with pregnancy complications and women with social risks (i.e. a history of substance use, incarceration, and/or IPV) reported among the highest overall mistreatment rates among the subpopulations studied, with one in three reporting any mistreatment. These two groups were also more likely to report being shouted at or scolded and that their physical privacy was violated (Table 5).

#### Mistreatment by context of care

##### *Place of birth*

Table 6 shows higher rates of mistreatment in hospital settings (28.1%), including birth centers that are located inside hospitals (24.0%), than in community birth settings (home or freestanding birth center). Rates of mistreatment were similar between women who gave birth at home (5.1%) or in a freestanding birth center (7.0%). The likelihood of being ignored by care providers and/or providers refusing to help was three times more common among women who gave birth in hospital settings (12.6 and 10.8%), compared to those who delivered at home (2.3%) or in a freestanding birth center (2.5%). Violation of physical privacy was also three times more common in hospital settings. Being threatened by care

**Table 3** Quotes illustrating mistreatment of US women

*Before I switched to a birth center, one military midwife was disrespectful of our cultural needs and refused to accept them. When I mentioned my desires, I was belittled and made to feel incompetent.*

Hispanic woman who gave birth in California

*The doctor who refused to test me for an amniotic fluid leak and instead tested me for an STD test I had already received during the pregnancy. I believe his assumption that I was leaking something due to an STD rather than a pregnancy complication was due to race and put my life and my newborns life at risk - I went a week leaking fluid after I had went in to get it checked out. I worry that Doctor is still discriminating against other mothers and they are receiving negligent care as well.*

Black woman who gave birth in California

*I was told I was hurting my children and being selfish because I wanted to have a vaginal delivery. Both children were in head down birth position. I was forced into a cesarean by my OB.*

Indigenous woman who gave birth in Texas

*The doctor who performed my c-section was hateful, rude, rough and threatening.*

Indigenous woman who gave birth in Oklahoma

*[I was] forced to be in a hospital because of having Medicaid which led to many interventions and being bullied/talked down to until I agreed. This pregnancy we saved up for a midwife so I can have a home birth.*

Indigenous woman who gave birth in New York State

*The amount of times I felt coerced into decisions or was mocked or rushed. Overall it was a very dehumanizing and frustrating experience ... my original ob/gyn practice was rude and insulting to me and said that I risked having child protective services being called if I refused antibiotics due to being GBS positive.*

White woman who gave birth in NJ

*The forced episiotomy. The doctor didn't care, refused to give me medication because my episiotomy hurt, Nurse XX from XX told me to get over it and gave me lube & told me to do anal sex instead! That's the care we're getting in Southern California if you are not insured & have to rely on Medical insurance.*

Hispanic woman who gave birth in California

*When I refused to be induced-even after I was a couple days "overdue" I seriously started to feel like \*! was the problem. It was horrible.*

White woman who gave birth in Iowa at 24

*I hated being shouted at and lied to by the midwife.. I never dreamed that a woman would treat a laboring woman that way. She was abusive and downright mean. I was refused food and water for 26 hours. I wasn't allowed to move out of bed to walk around. I felt like I lost my autonomy over my own body. I had given up and I remember weeping when my son was born. I was at least glad he was safe. I felt like a child and I felt so unlike my usual self. These professionals broke my spirit.*

Hispanic woman who gave birth at a in hospital birth center inside a hospital in North Carolina

*The way I was treated during postpartum. If I was given adequate support with breastfeeding and actual education about it, I feel I would have been successful outright instead of struggling for months, and if I was not judged for being a younger mom, I would have felt safe and secure*

South Asian woman who gave birth in Nevada

*One nurse, whom we otherwise really liked, made comments generalizing about people by race (e.g., "you Asian women all tear during birth"). It wasn't done in a judgmental way but I would have preferred that she not say such things.*

East Asian woman

*I was offered WIC repeatedly though I explained that I did not qualify. I believe it was because I am Latina and my partner black that we were repeatedly offered WIC.*

Hispanic woman with Black partner in New York

providers or having treatment withheld/being forced to accept treatment was twice as likely in hospital settings, compared to community settings.

Women who were transferred from a community setting to a hospital, after the onset of labor, experienced high rates of mistreatment (34.6%). One in four reported being shouted at or scolded by a health care provider, one in ten were threatened, and one in seven were ignored (Table 6). Of the women who transferred to hospital from a home birth ( $n = 80$ ), 37 (46.3%) reported that they were treated poorly by health professionals during their transfer or afterwards because of their decision to have a home birth.

### Mode of delivery

Additional file 1: Table S7 shows much higher rates of mistreatment when women had unplanned Cesareans and instrumental vaginal births. Women who had a vaginal birth after caesarean (VBAC) reported low levels of mistreatment. Separating women who had a VBAC in a community birth setting versus in a hospital revealed that 1 in 3 women who had a VBAC in the hospital experienced mistreatment versus 6% of women who gave birth in the community.

### Newborn health problems

One in four women who reported that their newborn(s) had any health problems experienced one or more types of mistreatment. Women whose newborns had health problems were more likely to report that their private or personal information was shared without their consent and that providers ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time, compared to women whose newborns did not have health problems (see Additional file 1: Table S8).

### Disarticulation between provider and woman

We found higher rates of mistreatment when preferences for care did not align between women and providers: Any mistreatment was reported by 19.4% of women who declined care during pregnancy or birth, 37.9% of women who reported being pressured into one or more medical interventions or procedures, and 78.8% if they also had a difference in opinion with their care provider (see Additional file 1: Table S9).

### Demographic and other factors related to mistreatment

In bivariable logistic regression analyses (Table 7), we found that Black, Hispanic and Indigenous women, primiparas and women with elevated pregnancy risks were significantly more likely to report mistreatment, compared with White women. Younger women, women with a history of substance use, incarceration and/or

**Table 4** Mistreatment indicators, stratified by maternal race (n = 2138)

	Black n = 320 n (%)	Hispanic n = 188 n (%)	Indigenous n = 64 n (%)	Asian n = 90 n (%)	Women of colour n = 682 n (%)	White n = 1416 n (%)
Your private or personal information was shared without your consent	2 (0.6)	5 (2.7)	2 (3.1)	0 (0)	9 (1.3)	17 (1.2)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	27 (8.4)	12 (6.4)	6 (9.4)	7 (7.8)	52 (7.6)	62 (4.4)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	35 (10.9)	30 (16.0)	10 (15.6)	9 (10.0)	87 (12.8)	90 (6.4)
HCPs threatened to withhold treatment or to force you to accept treatment you did not want	21 (6.6)	11 (5.9)	7 (10.9)	6 (6.7)	45 (6.6)	51 (3.6)
Health care providers threatened you in any other way	6 (1.9)	8 (4.3)	3 (4.7)	1 (1.1)	18 (2.6)	26 (1.8)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	41 (12.8)	23 (12.2)	7 (10.9)	12 (13.3)	85 (12.5)	79 (5.6)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	6 (1.9)	4 (2.1)	0 (0)	1 (1.1)	11 (1.6)	16 (1.1)
Any mistreatment (one or more of the above)	72 (22.5)	47 (25.0)	21 (32.8)	19 (21.1)	162 (23.8)	199 (14.1)

interpersonal violence (IPV) and those of low socio-economic status also reported significantly increased odds of mistreatment compared with those that did not have these sociodemographic risk factors for mistreatment (see Table 7). Finally, context of care was linked to mistreatment. Women who had prenatal care from midwives were much less likely to report mistreatment compared to those who had prenatal care from physicians (OR 0.31, 95% CI 0.25–0.40), whereas an unplanned Cesarean or assisted

vaginal birth was linked to significantly increased odds of mistreatment compared to spontaneous vaginal delivery (OR 3.7, 95% CI 2.8–5.0). Women who gave birth at the hospital were 7 times as likely to report any mistreatment compared to women who gave birth in the community (OR 7.2, 95% CI 5.3–9.7). Women who reported a difference in opinion with their care provider had very high odds of mistreatment compared with those who did not report a difference in opinion (OR 22.7, 95% CI 13.9–36.9).

**Table 5** Mistreatment, stratified by SES, and elevated pregnancy/social risk (n = 2138)

	Low SES		Elevated pregnancy risks		Elevated social risks	
	Yes (n = 743) n (%)	No (n = 1395) n (%)	Yes (n = 441) <sup>a</sup> n (%)	No (n = 1697) n (%)	Yes (n = 176) <sup>b</sup> n (%)	No (n = 1962) n (%)
Your private or personal information was shared without your consent	12 (1.6)	14 (1.0)	10 (2.3)	16 (0.9)	5 (2.8)	21 (1.1)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	47 (6.3)	70 (5.0)	37 (8.4)	80 (4.7)	23 (13.1)	94 (4.8)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	89 (12.0)	93 (6.7)	68 (15.5)	114 (6.7)	27 (15.3)	155 (7.9)
Health care providers threatened to withhold treatment or to force you to accept treatment you did not want	48 (6.5)	49 (3.5)	34 (7.7)	63 (3.7)	17 (9.7)	80 (4.1)
Health care providers threatened you in any other way	19 (2.6)	25 (1.8)	13 (2.9)	31 (1.8)	5 (2.8)	39 (2.0)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	78 (10.5)	88 (6.3)	53 (12.0)	113 (6.7)	23 (13.1)	143 (7.3)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	19 (2.6)	8 (0.6)	10 (2.3)	17 (1.0)	6 (3.4)	21 (1.1)
Any mistreatment (one or more of the above)	160 (21.5)	209 (15.0)	123 (27.9)	246 (14.5)	53 (30.1)	316 (16.1)

<sup>a</sup>Elevated pregnancy risk status: Women were grouped as having pregnancy risk factors if they reported a pre-pregnancy BMI of 40 or higher, were carrying twins, or reported that they experienced high blood pressure, gestational diabetes or other health complications during pregnancy (including breech baby, problems with baby's growth/health, preterm labour, but not preterm birth)

<sup>b</sup>History of social risks: To distinguish those who may experience differential treatment because of social factors, we grouped together women who reported substance use (smoking or daily alcohol use during pregnancy, and/or drug dependence during pregnancy), women with a history of incarceration (herself or partner), involvement of child or family services, and/or reported intimate partner violence

**Table 6** Mistreatment, stratified by actual place of birth (*n* = 1954)

	Hospital ( <i>n</i> = 759)	Birth Centre Inside Hospital ( <i>n</i> = 167)	Birth Centre Outside Hospital ( <i>n</i> = 157)	Home ( <i>n</i> = 871)	Transferred to hospital from community ( <i>n</i> = 107)
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Your private or personal information was shared without your consent	9 (1.2)	5 (3.0)	1 (0.6)	7 (0.8)	0 (0)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	78 (10.3)	15 (9.0)	1 (0.6)	7 (0.8)	13 (12.1)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	98 (12.9)	18 (10.8)	4 (2.5)	19 (2.2)	28 (26.2)
Health care providers threatened to withhold treatment or to force you to accept treatment you did not want	50 (6.6)	7 (4.2)	5 (3.2)	16 (1.8)	10 (9.3)
Health care providers threatened you in any other way	19 (2.5)	4 (2.4)	4 (2.5)	6 (0.7)	9 (8.4)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	96 (12.6)	18 (10.8)	4 (2.5)	20 (2.3)	19 (17.8)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	16 (2.1)	3 (1.8)	1 (0.6)	1 (0.1)	4 (3.7)
Any mistreatment (one or more of the above)	213 (28.1)	40 (24.0)	11 (7.0)	44 (5.1)	37 (34.6)

**Table 7** Crude odds ratios estimating associations between maternal characteristics and any mistreatment (*n* = 2138)

	<i>n</i>	OR	95% CI	
		Logistic Regression	Lower bound	Upper bound
<b>SOCIO-DEMOGRAPHICS</b>				
Maternal Race: Black (reference category: white)	2098	1.77	1.31	2.40
Maternal Race: Hispanic (reference category: white)	2098	2.04	1.42	2.93
Maternal Race: Asian (reference category: white)	2098	1.64	0.97	2.77
Maternal Race: Indigenous (reference category: white)	2098	2.98	1.73	5.13
Maternal Race: Women of colour (reference category: white women)	2098	1.91	1.51	2.41
Age: 17 to 25 years (reference category: 31–39)	1956	1.71	1.08	2.69
Age: 26–30 years (reference category: 31–39)	1956	1.15	0.88	1.49
Age: Over 40 (reference category: 31–39)	1956	1.04	0.62	1.74
Nulli/primiparity (reference category: multiparity)	2135	2.50	1.99	3.14
Low SES - Yes (reference category: no)	2138	1.56	1.24	1.96
<b>MEDICAL OR SOCIAL FACTORS</b>				
Elevated pregnancy risk - Yes (reference category: no)	2138	2.28	1.78	2.92
History of substance use, incarceration and/or IPV (social risk)- Yes (reference category: no)	2138	2.24	1.59	3.17
<b>CONTEXT OF CARE</b>				
Prenatal midwifery care (reference group: prenatal physician care)	2076	0.31	0.25	0.40
Actual place of birth hospital or alongside birthing center (reference group: community birth)	2119	7.17	5.31	9.68
Mode of birth unplanned Cesarean or operative vaginal delivery (reference group: planned Cesarean or spontaneous vaginal birth)	2129	3.72	2.79	4.97
Difference in opinion with care provider (reference group: no difference in opinion with care provider)	2138	22.69	13.94	36.92

### Intersection between race, other maternal characteristics, and context of care

When examining the intersection of race and the maternal characteristics, rates of mistreatment among women of colour who were young, nulliparous or primiparous, or had low SES, social risk factors, or pregnancy complications were higher than for white women who reported the same conditions or experiences. For example, among those who had pregnancy complications, mistreatment was reported by 37.0% women of colour versus 22.1% white women. Similarly, women of colour with low SES reported higher rates of mistreatment than white women with low SES (26.9% versus 17.7%). Regardless of race, among women who had a difference in opinion with their care provider, the majority (83.0% of women of colour, 76.4% of white women) reported one or more types of mistreatment (Table 8).

Place of birth and operative birth appear to have similar modification effects for both women of color and white women. Giving birth at home or in a freestanding birth center was associated with lower rates of mistreatment across racial groups, when compared to rates of mistreatment among women who gave birth in hospitals. For example, among women of colour who gave birth in the community, 6.6% reported any mistreatment, compared to 33.9% who gave birth at hospitals.

### Discussion

In the Giving Voice to Mothers study, service users of maternity care in the US described mistreatment across categories that closely align with the WHO (Bohren) typology that was derived from global evidence on the phenomena. In this study of care in a high resource country, physical abuse was uncommon, but verbal abuse and failure to respond to requests for

help were the most common types of reported mistreatment; rights to information and autonomy were apparently disregarded; and difference of opinion with care providers had a strong association with reported mistreatment. While the overall rates of mistreatment are lower in our US sample than recent studies report in low resource settings [5], they are still unacceptably high for a high resource country given a cultural emphasis on autonomy, gender equity, human rights, better working conditions for providers, and resources for training.

Protective factors, in terms of mistreatment were: being White, having a vaginal birth, giving birth at home or in a freestanding birth center, having a midwife as the primary prenatal provider, and having a baby after 30 years of age. Being multiparous was also protective, which may suggest that prior experience helps patients avoid disrespectful treatment, or conversely that disrespectful treatment is normalized by prior experiences among certain populations. Importantly, more than half of our sample planned community births, and they experienced very low rates of mistreatment when compared to those who gave birth in hospital. Since less than 2% of all childbearing women in the US give birth in community settings [41], the rate of mistreatment (30%) among women in our sample who gave birth in a hospital, is likely a better estimate of the true rate of mistreatment during childbirth among US women.

### Patient-led measurement of health equity

In 2017 the National Quality Forum (NQF) convened a multi-stakeholder group of experts to develop a shared agenda to achieve health equity [42]. The team

**Table 8** Intersection between mistreatment, race and additional variables (n = 2138)

Intersectional Factor	n	n (%) who report any mistreatment	
		Women of colour (n = 162)	White women (n = 199)
<b>Sociodemographics</b>			
Nulliparity	811	92/282 (32.6)	114/529 (21.6)
Age 17–25 years	116	17/55 (30.9)	11/61 (18.0)
Low SES	726	83/309 (26.9)	74/417 (17.7)
<b>Medical or Social Factors</b>			
Elevated pregnancy risk	434	60/162 (37.0)	60/272 (22.1)
Social risk	172	30/66 (45.5)	21/106 (19.8)
<b>Context of care</b>			
Prenatal midwifery care	1120	63/393 (16.0)	107/1057 (10.1)
Actual place of birth: hospital or in-hospital birthing centre	1013	137/404 (33.9)	146/609 (24.0)
Actual place of birth: home or freestanding birthing centre	1009	17/258 (6.6)	38/751 (5.1)
Unplanned Caesarean or operative vaginal birth	235	43/105 (41.0)	48/130 (36.9)
Difference in opinion with care provider	102	39/47 (83.0)	42/55 (76.4)

highlighted four priority areas for action: identify and prioritize areas to reduce health disparities, invest in the development and application of person-centered health equity performance measures, incentivize the reduction of health disparities, and implement evidence-based interventions to reduce disparities.

Our Giving Voice to Mothers study has addressed this mandate through the patient-led development and validation of unique items that can be used to measure disrespect, abuse, and discrimination during maternity care. Using these items, we were able to show that some populations experienced significantly higher rates of mistreatment, such as women of color, young women, and those who reported economic, social or health risks. All women who self-identified as Black, Indigenous, Hispanic, or Asian reported higher than average experiences of mistreatment. Regardless of their own race, having a partner who was Black also increased their risk of mistreatment.

The types and recipients of mistreatment identified by participants in the GVtM study are consistent with patient-oriented research evidence from a recent qualitative study [43] in California. McLemore and colleagues [43] explored pregnancy-related healthcare experiences through focus groups of women of color from three urban areas in California. The study included English and Spanish speaking women, age 18 or greater with social and/or medical risk factors for preterm birth. Based on the data collected from 54 women in two focus groups, the authors identified five themes: 1) disrespect during healthcare encounters; 2) stressful interactions with all levels of staff; 3) unmet information needs; 4) inconsistent social support; and 5) care that affected confidence in parenting and newborn care. Focus group participants provided examples of each of the seven types of mistreatment that we measured. Participants discussed sharing of personal information, violation of physical privacy and being “yelled at” by a physician. Half of the participants discussed being pressured or threatened, with the most common type of threat being, “if you do not comply or do this, your baby will die or you will have a bad outcome.” Similarly, coercive language reported by participants in our GVtM study frequently referred to the potential loss of the baby.

#### **Mistreatment, inequity, and access to high quality care**

In high resource countries, pregnant people who experience discrimination due to lower socioeconomic status, race/ethnicity, or housing instability, are especially at risk for poor health outcomes [20]. For, example, a European team reviewed published evidence on discrimination against Romani women in maternity care in Europe [21]. Results revealed that many Romani women encounter barriers to accessing maternity care. Even when

they were able to access care, they experienced discriminatory mistreatment on the basis of their ethnicity, economic status, place of residence or language. The grey literature revealed some health professionals held underlying negative beliefs about Romani women [21].

Similarly, much has been written about how implicit bias by healthcare provider links to disparities in access to and quality of care [44]. Growing evidence suggests that differential quality of care in North America contributes to racial and ethnic disparities in obstetric and perinatal outcomes [18, 20, 45–47] and that access to high quality of care in obstetrics varies widely by jurisdiction and type of provider [48]. In our study Indigenous women were the most likely to report mistreatment among the racial groups, closely followed by African American and Hispanic women. Indigenous men and women in Central America report barriers to accessing healthcare and abusive treatment and neglect of professional ethics from HCPs [49]. Canadian research has documented the distress and racism experienced by Aboriginal women including discrimination, loss of autonomy and dehumanizing interactions with care providers [50].

Vedam et al. [32] found that in British Columbia, women from vulnerable populations (i.e. recent immigrants or refugees, women with a history of incarceration and/or substance use, homelessness or poverty), women with pregnancy complications, those who have birth at hospital (versus home) and women who experienced pressure to have interventions were more likely to score very low on the MOR index, a scale that measures respectful maternity care [32]. Our intersectional analysis underscores that the negative impacts of race and social vulnerability are intertwined and cumulative, that those who are already at risk for the worst outcomes, also experience higher levels of mistreatment. Given that the burden of disparities borne by these populations has shown little improvement in recent decades, understanding the presence of mistreatment in childbirth may aid our efforts to comprehend underlying causes, and inform our efforts to eliminate them.

#### **The context of care**

We also elicited differential treatment when women's choices and opinions about “the right care” for themselves or their baby did not align with providers. Those who were transferred to hospital from the community, women who reported being pressured into interventions, and those who had a difference of opinion with their health care provider reported higher rates of mistreatment. Differential rates of mistreatment may be associated with differences by race in level of patient autonomy and/or pressure to accept interventions from providers, which in itself constitutes mistreatment. The



relationships between differences of opinion, interventions, and mistreatment require further study to elucidate the temporal nature of these associations. In qualitative study, researchers in New England interviewed 50 white women and 32 women of color the day after they gave birth at a tertiary care facility [51]. Women of color reported more pressure to accept epidural anesthesia and were also more likely to experience failure in their pain medication and report that providers ignored their pain and anxiety.

Higher rates of mistreatment among those who have unplanned cesarean births warrants a closer examination, given country-level disparities in overuse and underuse of obstetric interventions [1], as well as the confounding reality that proportionately more women of colour in our sample, as in the general US population, had cesareans. Multiple authors have examined racial differences in both primary cesarean and VBAC rates and found women of colour have an increased risk of cesarean delivery after adjusting for sociodemographic and clinical risk factors [52–55]. Additionally, women with private health insurance have a lower predicted probability of having a cesarean section for clinical indications than do women with public health insurance [56].

The significant number of respondents that reported “being ignored” or that “providers failed to respond to their requests for help” is a disturbing finding in a high resource setting, especially in light of recent data that links delayed response to clinical signs to maternal mortality. The California Department of Public Health (CDPH), the California Maternal Quality Care Collaborative (CMQCC) and the Public Health Institute (PHI) recently released data from a statewide examination of maternal deaths from 2002 to 2007 [57]. The report identified that healthcare provider factors were the most common type of contributor to maternal deaths, averaging 2.5 factors per case and present among 269 cases or 81% of maternal deaths in that time period. The most common provider factor was delayed response to clinical warning signs, followed by ineffective care [57].

Finally, place of birth appears to have a modulating effect on experiences of mistreatment. Women from all race and ethnic backgrounds who gave birth at home or in birth centers reported far fewer examples of all seven types of disrespect and abuse. This is especially poignant in light of the finding that women who needed to transfer to hospital from a planned community birth, ostensibly to access a safe environment to respond to emerging complications, experienced very high rates of mistreatment. Whether these differences are a result of the change in locus of control and loss of cultural safety that all people feel in their own environments [58], or the effects of structural racism, societal norms, and

implicit bias that exist in institutional cultures, remains to be explored.

### Implications

Bohren and colleagues argue that instances of mistreatment constitute violations of people’s human rights. [13] Several respondents in our study provided descriptions about how mistreatment violated these basic principles. Amnesty International identified the inappropriate, disrespectful, and discriminatory treatment of pregnant and childbearing people in the United States as constituting a human rights violation and documented incidents of women, particularly women of colour, being abandoned, ignored, threatened, coerced, shouted at, and otherwise mistreated [59]. Violations of human rights in childbirth tend to be more severe in countries where women have limited options in terms of where, how and with whom they can give birth. Authors of the WHO Research Group [60] argue that, to prevent mistreatment, health care providers need to first consider how they can meet women’s socio-cultural, emotional and psychological needs.

A recent publication on addressing racial disparities in the management of hypertension discussed how performance measures can be used to incentivize self-monitoring programs, and the development of pragmatic, effective interventions to improve health equity [61]. The authors describe a multi-strategy approach that takes into account the complex interactions between social determinants of health, societal drivers of inequity, payment models, and cultural competency education for health professionals. They refer to the five domains of health equity measurement described in the NQF report: first, building collaborations to address factors that maintain racial and ethnic disparities; second, creating a culture of equity and individualized care and routine training around issues of structural racism and intersectionality of multiple drivers of disadvantage; third, moving to the development of multidisciplinary teams, and fourth, addressing issues of access to high quality care across communities and settings for care. The final domain focusses on the equitable application of evidence-based interventions that are responsive to patient reported outcomes and priorities [61].

With respect to mistreatment, dignity, and freedom from human rights abuses in maternity care, this last priority is dependent on the health systems ability to monitor and describe patient experience with reliable indicators. Our patient-driven performance measures can target the key components of mistreatment to address by jurisdiction, and identify settings where quality improvement related to respectful maternity care is most needed, as well service users most at risk for differential treatment. Abuya and colleagues [19] have suggested several intervention and implementation activities to

eliminate mistreatment of women in low resource countries. Many of these strategies are also relevant in the US context, such as training for care providers in promoting respectful care including values clarification and attitude transformation (VCAT), training on VCAT based on providers' and clients' rights and obligations, and revision of professional ethics and practices. The authors also recommend strengthening facility quality improvement systems for monitoring, reporting, addressing, and resolving disrespect and abuse cases. Mentorship and on-the-job role-modeling by identified champions within the facility as part of routine continuous professional education has been shown to shift team culture. At the same time civic education about patient rights and avenues for redress may be needed to ensure accountability even in high resource countries.

### Strengths and limitations

Strengths of the study include the large sample size that allows for the best estimate to date of the frequencies and types of mistreatment occurring among diverse subpopulations among childbearing people in the US. Importantly, the Giving Voice to Mothers study provides the first complete set of patient-designed and validated quantitative indicators, across all domains of the Bohren typology, that can be used to describe prevalence and characteristics of mistreatment in maternity care across all settings. This study also provides the first published estimates of associations between social factors like race/ethnicity, and modulating effects of planned place of birth or interventions, and rates and forms of mistreatment as identified by patients themselves.

A primary limitation of the study is that the sample is voluntary and not population-based, as there is currently no data collection system designed to capture and describe experiences of birth care for all pregnant people in the United States. Rather we sampled for diversity, oversampling from communities that are often under-represented in national studies on experience of care, such as Black and Indigenous women, and those planning to give birth at home or in a birth center. Compared to the characteristics of women who gave birth in the United States in 2016, women in our study had similar proportions of previous births, but were more educated, older, and more likely to have been born in the United States [62]. With respect to racial representativeness, we report data from a similar proportion of black women and more Indigenous women; 14.0% of US births in 2016 (CDC) were women who identified as 'black' compared to 15.4% in this study; 1% are identified as Indigenous in the US vs 3% in our sample [62]. Overall, our samples of women from Hispanic, Asian, and other communities of color were lower than the national reported rates. Of note, 24% of the US births in

2016 had a mother identified as "Hispanic origin" compared to roughly 10% in the current study.

Notably, patient reports of improved experience of care in homes and birth centers are repeatedly cited in the global literature. Since 50% of our sample were reporting on community births (when the representative rate would have been 2%), the logical expectation would that the entire sample is skewed towards much *less* mistreatment than the general population. Because women with very positive or very negative experiences are often more motivated to participate in studies that invite them to share their stories, we anticipate that we have lower representation from women who had more routine or simply "satisfactory" experiences that might not be characterized as either particularly empowering nor traumatizing. To mitigate bias introduced because communities of color tended to describe worse experiences and community birthers more positive ones, we stratified results by race and place of birth.

In general, the GVTM sample might have a 'higher' SES population than is representative of the US childbearing population which, given our findings, we anticipate would decrease rates of reported mistreatment, and potentially underestimate mistreatment in the US population at large. The large proportion of community birth also accounts for the higher socioeconomic status – since without universal health care, community birth is often not accessible by low SES service users. Since even in this more privileged population the overall rates of mistreatment were at 17%, and significantly higher for those who planned and delivered in hospitals, our findings highlight the need for further investigations in this understudied area.

Regional variation in outcomes and access to high quality care across the United States have been described in the literature [48], and our national sample is not representative of the lived experience of many subgroups including undocumented immigrants, incarcerated pregnant parents, and families located in rural settings with limited options for maternity care. With respect to generalizability in the international context, women and people have different interpretations of consent and power. Hence, while standardizing indicators through these typologies is helpful, it will not change that each person will have their own sense of bodily/self autonomy and human rights, placed within the cultural context of each environment. Finally, not all people giving birth identify as women and/or mothers, and mistreatment as associated with gender identity, sexuality and parenting status are areas where further study is needed.

Nonetheless, that higher rates of mistreatment so clearly track along marginalized groups, and with women whose choices in care differ from their providers' recommendations, suggests that regardless of any sampling issues

invariably contained in this study, there is much work yet to be done in the United States, as no level of mistreatment of a childbearing person is acceptable.

## Conclusion

The Giving Voice to Mothers- US study led to development of several new patient-designed indicators of mistreatment in maternity care. They use lay language to capture lived experience from the service user's perspective, and can be used to quantify the nature and frequency of occurrence of different types of disrespect and abuse. They are aligned closely with global definitions of the domains of mistreatment, and thus are relevant across high, middle, and low resource countries.

Application of these measures elicited disparities in experience of maternity care across communities of color and birth settings in the United States. With some translation and adaptation, these indicators could be implemented in patient-reported outcomes research globally. In the United States, these indicators could be incorporated as performance measures to incentivize expansion of programs to address settings, practices, and institutional cultures that lead to persistent disparities in maternity care.

## Additional file

**Additional file 1: Table S1.** Self-identified maternal and paternal race ( $n = 2700$ ). **Table S2.** Socio-demographic characteristics of samples, compared to national statistics. **Table S3.** Mistreatment, stratified by self-identified race of woman and partner. **Table S4.** Mistreatment, stratified by immigration status. **Table S5.** Mistreatment, stratified by maternal age at birth. **Table S6** Mistreatment, stratified by parity. **Table S7.** Mistreatment, stratified by labour induction and mode of birth. **Table S8.** Mistreatment, stratified by newborn health problems. **Table S9.** Mistreatment indicators, stratified by disarticulation between women and providers.

## Abbreviations

CA-PAMR: California Pregnancy-Associated Mortality Review; CDPH: California Department of Public Health; CI: Confidence Interval; CMQCC: California Maternal Quality Care Collaborative; GvtM - US: Giving Voice to Mothers-United States; HCP: Healthcare provider; IPV: Intimate Partner Violence; MADM: Mother's Autonomy in Decision-Making Scale; MORi: Mothers on Respect Index; NGO: Non-governmental organization; NQF: National Quality Forum; PHI: Public Health Institute; PR: Perceptions of Racism; RMC: Respectful maternity care; SES: Socio-economic status; VBAC: Vaginal Birth after Cesarean; WHO: World Health Organization

## Acknowledgments

This paper would not have been possible without the long term commitment and participation of these members of the GvtM US Steering Council: Shafia Monroe, Paula Rojas, Marimah Farrell, Jacqueline Left Hand Bull, Roberta Eaglehorse, Claudia Booker, Vanessa Calderi, Michelle Goodwin, Zsakeba Henderson, Jennie Joseph.

Community organizations involved in study design, recruitment, and knowledge translation include: Choices in Childbirth, Every Mother Counts, the International Center for Traditional Childbearing, Mamas of Color Rising, Oregon Intertribal Breastfeeding Coalition, Phoenix Midwife, Mama Sana/Vibrant Woman, Mountain Midwifery Center, and Easy Access Women's Health Clinic (Commonsense Childbirth).

We would also like to thank research assistants who supported content validation, survey administration, data, manuscript formatting, and citation management, Richelle Powers, Norah Macy, Jessie Wang, Sabrina Afroz and Julie. Finally, the participatory process and knowledge translation activities have greatly benefitted from countless hours and expertise provided by Lynsey Hamilton, Ian Allison, Aldabaran Tatum, and Barbara Karlen.

## Funding

This project was funded by the New Hampshire Charitable Foundation Transforming Birth Fund.

## Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Authors' contributions

SV conceived the study and oversaw all aspects of the work, including community engagement, survey design, data collection and analysis. SV drafted and edited the paper, KS performed the data analysis, and drafted/edited the paper, TKT & NR, MC, NS, MMcL, MC, LS, ED advised on statistical analysis, drafted sections of the paper, helped to interpret data, revised, provided language for and/or edited the manuscript. NS was also involved in content validation. EN contributed to data analysis and interpretation and ER participated actively in survey development and coordinating the content validation. All authors read and approved the final manuscript.

## Ethics approval and consent to participate

The Behavioural Research Ethics Board at University of British Columbia approved the study (H15-01524).

All invited participants reviewed an informed consent form before deciding whether they wanted to participate in the online survey.

## Consent for publication

The consent form clarified that study results would be reported in the form of de-identified aggregate statistics and/or de-identified quotes. For participants or community partners who wish to participate in preparation of analysis or publications, the de-identified dataset (without open-ended comments) is available from the corresponding author on reasonable request and completion of a data sharing agreement.

## Competing interests

The authors declare that they have no competing interests.

## Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## Author details

<sup>1</sup>Birth Place Lab, Division of Midwifery, Faculty of Medicine, University of British Columbia, Vancouver (Canada), E416 Shaughnessy (Mailbox 80), 4500 Oak Street, Vancouver, BC V6H 3N1, Canada. <sup>2</sup>University of California Davis School of Medicine, Sacramento, California, USA. <sup>3</sup>Department of Midwifery, Bastyr University, Seattle, WA, USA. <sup>4</sup>Department of Obstetrics and Gynecology, University of California San Francisco and the Institute for Global Health Sciences, California, USA. <sup>5</sup>Department of Anthropology, Oregon State University, Corvallis, Oregon, USA. <sup>6</sup>Every Mother Counts, New York City, USA. <sup>7</sup>Department of Family Health Care Nursing and ANSIRH Bixby Center for Global Reproductive Health, University of California, San Francisco, USA. <sup>8</sup>Young Women United, Albuquerque, New Mexico, USA. <sup>9</sup>School of Population & Public Health, Faculty of Medicine, University of British Columbia, Vancouver, Canada. <sup>10</sup>Department of Family Practice, Faculty of Medicine, University of British Columbia, Vancouver, Canada. <sup>11</sup>School of Public Health, Boston University, Massachusetts, Boston, USA.

Received: 4 January 2019 Accepted: 30 April 2019

Published online: 11 June 2019

## References

- Miller S, Abalos E, Chamillard M, Ciapponi A, Colaci D, Comandé D, et al. Beyond too little, too late and too much, too soon: a pathway towards

- evidence-based, respectful maternity care worldwide. *Lancet*. 2016;388:2176–92.
2. World Health Organization (WHO). Standards for improving quality of maternal and newborn care in Health Facilities [Internet]. 2016. Available from: [http://www.who.int/maternal\\_child\\_adolescent/documents/improving-maternal-newborn-care-quality/en/](http://www.who.int/maternal_child_adolescent/documents/improving-maternal-newborn-care-quality/en/)
  3. The Partnership for Maternal Newborn & child health. Professional associations affirm commitment to improving quality of maternal and newborn health care [Internet]. FIGO news, WHO news. 2017. Available from: <http://www.who.int/pmnch/media/events/2017/ililongwe/en/index1.html>
  4. Reed R, Sharman R, Inglis C. Women's descriptions of childbirth trauma relating to care provider actions and interactions. *BMC Pregnancy Childbirth*. 2017;17(1).
  5. Hameed W, Avan BI. Women's experiences of mistreatment during childbirth: a comparative view of home- and facility-based births in Pakistan. *PLoS One*. 2018;13(3):e0194601.
  6. McMahon S, George A, Chebet J, Moshia I, Mpembeni R, Winch P. Experiences of and responses to disrespectful maternity care and abuse during childbirth; a qualitative study with women and men in Morogoro region, Tanzania. *BMC Pregnancy Childbirth*. 2014;14(1):268.
  7. Baker S, Choi P, Henshaw C. 'I Felt as though I'd been in Jail': Women's Experiences of Maternity Care during Labour, Delivery and the Immediate Postpartum. *Feminism & Psychology*. 2005;15(3):315–42.
  8. Kane S, Rial M, Kok M, Matera A, Dieleman M, Broerse JEW. Too afraid to go: fears of dignity violations as reasons for non-use of maternal health services in South Sudan. *Reprod Health*. 2018;15(1).
  9. Khosla R, Zampas C, Vogel JP, Bohren MA, Roseman M, Erdman JN. International human rights and the mistreatment of women during childbirth. *Health Hum Rights*. 2016;18(2):131.
  10. Freedman LP, Kruk ME. Disrespect and abuse of women in childbirth: challenging the global quality and accountability agendas. *Lancet*. 2014;384(9948):e42–4.
  11. World Health Organization (WHO). Prevention and elimination of disrespect and abuse during facility-based childbirth [internet]. Geneva, Switzerland: WHO Statement; 2015 [cited 2016 Apr 4]. Available from: [https://apps.who.int/iris/bitstream/handle/10665/134588/WHO\\_RHR\\_14.23\\_eng.pdf;jsessionid=5EAC99EB257C701EF9FC086FD19D5FE7?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/134588/WHO_RHR_14.23_eng.pdf;jsessionid=5EAC99EB257C701EF9FC086FD19D5FE7?sequence=1)
  12. Rosenthal L, Lobel M. Explaining racial disparities in adverse birth outcomes: unique sources of stress for black American women. *Soc Sci Med*. 2011;72(6):977–83.
  13. Bohren MA, Vogel JP, Hunter EC, Lutsiv O, Makh SK, Souza JP, et al. The mistreatment of women during childbirth in health facilities globally: a mixed-methods systematic review. *PLoS Med* [Internet]. 2015 [cited 2016 Mar 22];12(6):e1001847; discussion e1001847. Available from: <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001847>
  14. Warren CE, Njue R, Ndwigwa C, Abuya T. Manifestations and drivers of mistreatment of women during childbirth in Kenya: implications for measurement and developing interventions. *BMC Pregnancy and Childbirth*. 2017;17(1):102.
  15. Beck CT. A secondary analysis of mistreatment of women during childbirth in health care facilities. *J Obstet Gynecol Neonatal Nurs*. 2018;47(1).
  16. Ravaldi C, Skoko E, Battisti A, Cericco M, Vannacci A. Abuse and disrespect in childbirth assistance in Italy: a community-based survey. *Eur J Obstet Gynecol Reprod Biol*. 2018;224:208–9.
  17. Babiaková K, Debreceniiová J, Hlinčíková M, Kříšková Z, Sekulová M, Šumšalová S. Women mothers bodies: women's human rights in obstetric care in healthcare facilities in Slovakia. *Občan, demokracia a zodpovednosť*. 2015.
  18. Howell EA, Zeitlin J. Quality of care and disparities in obstetrics. *Obstet Gynecol Clin N Am*. 2017;44(1):13–25.
  19. Abuya T, Ndwigwa C, Ritter J, Kanya L, Bellows B, Binkin N, et al. The effect of a multi-component intervention on disrespect and abuse during childbirth in Kenya. *BMC Pregnancy and Childbirth*. 2015;15(1).
  20. Elder TE, Goddeeris JH, Haider SJ. Racial and ethnic infant mortality gaps and the role of socio-economic status. *Labour Econ*. 2016;43:42–54.
  21. Watson HL, Downe S. Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review. *Reprod Health*. 2017;14(1).
  22. McRae DN, Janssen PA, Vedam S, Mayhew M, Mpofu D, Teucher U, et al. Reduced prevalence of small-for-gestational-age and preterm birth for women of low socioeconomic position: a population-based cohort study comparing antenatal midwifery and physician models of care. *BMJ Open*. 2018;8(10):e022220.
  23. Declercq ER, Sakala C, Corry MP, Applebaum S, Herrlich A. Major survey findings of listening to mothers (SM) III: new mothers speak out. *J Perinat Educ*. 2014;23(1):17–24.
  24. Bond S, You X. Mistreatment of women during pregnancy and birth impedes global efforts to improve access, quality, and safety of maternity care. *J Midwifery Womens Health*. 2015;60(6):785.
  25. DeVoe JE, Wallace LS, Fryer GE. Measuring patients' perceptions of communication with healthcare providers: do differences in demographic and socioeconomic characteristics matter? *Health Expect*. 2009;12(1):70–80.
  26. Downe S, Finlayson K, Tuncalp O, Metin Gülmezoglu A. What matters to women: a systematic scoping review to identify the processes and outcomes of antenatal care provision that are important to healthy pregnant women. *BJOG An Int J Obstet Gynaecol*. 2016;123(4):529–39.
  27. Freedman LP, Ramsey K, Abuya T, Bellows B, Ndwigwa C, Warren CE, et al. Defining disrespect and abuse of women in childbirth: a research, policy and rights agenda. *Bull World Health Organ*. 2014;92(12):915–7.
  28. Bowleg L. The problem with the phrase women and minorities: intersectionality-an important theoretical framework for public health. *Am J Public Health*. 2012;102(7):1267–73.
  29. Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream. *Circulation*. 2009;119(19):2633–42.
  30. Israel BA. *Methods for community-based participatory research for health*. San Francisco, CA: Jossey-Bass; 2013. p3-37.
  31. Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson D, et al. 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. Kumar S, editor. *PLoS One* [Internet]. 2017 [cited 2017 Aug 14];12(2):e0171804. Available from: <http://dx.plos.org/10.1371/journal.pone.0171804>
  32. Vedam S, Stoll K, Rubashkin N, Martin K, Miller-Vedam Z, Hayes-Klein H, et al. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *SSM - Popul Heal* [Internet]. 2017 Dec [cited 2017 Aug 14];3:201–210. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S2352827317300174>.
  33. Mortel M, Mehta SD. Systematic Review of the Efficacy of Herbal Galactagogues. *J Hum Lact*. 2013;29(2):154–62.
  34. Green NL. Development of the perceptions of racism scale. *J Nurs Scholarsh*. 1995;27(2):141–6.
  35. Kruk ME, Kujawski S, Mbaruku G, Ramsey K, Moyo W, Freedman LP. Disrespectful and abusive treatment during facility delivery in Tanzania: a facility and community survey. *Health Policy Plan*. 2018;33(1):e26–33.
  36. Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health*. 2006;29(5):489–97.
  37. Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Methodol*. 2014;14:1–29.
  38. Merli MG, Verdery A, Mouw T, Li J. Sampling migrants from their social networks: the demography and social organization of Chinese migrants in Dar Es Salaam, Tanzania. *Migr Stud*. 2016;4(2):182–214.
  39. Schicker RS, Hiruy N, Melak B, Gelaye W, Bezabih B, Stephenson R, et al. A venue-based survey of malaria, anemia and mobility patterns among migrant farm workers in Amhara region, Ethiopia. *PLoS One*. 2015;10(11):e0143829.
  40. Cheyney M, Bovbjerg M, Everson C, Gordon W, Hannibal D, Vedam S. Development and validation of a national data registry for midwife-led births: the midwives alliance of North America statistics project 2.0 dataset. *J Midwifery Women's Heal*. 2014;59(1):8–16.
  41. MacDorman MF, Declercq E. Trends and characteristics of United States out-of-hospital births 2004–2014: new information on risk status and access to care. *Birth*. 2016;43(2):116–124.
  42. A roadmap for promoting health equity and eliminating disparities: the four I's for health equity: final report [Internet]. A roadmap for promoting health equity and eliminating disparities: the four I's for health equity: final report. National Quality Forum; 2017 Sep. Available from: <https://www.qualityforum.org>

- [org/Publications/2017/09/A\\_Roadmap\\_for\\_Promoting\\_Health\\_Equity\\_and\\_Eliminating\\_Disparities\\_The\\_Four\\_I\\_s\\_for\\_Health\\_Equity.aspx](http://org/Publications/2017/09/A_Roadmap_for_Promoting_Health_Equity_and_Eliminating_Disparities_The_Four_I_s_for_Health_Equity.aspx).
43. McLemore MR, Altman MR, Cooper N, Williams S, Rand L, Franck L. Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. *Soc Sci Med*. 2018;201:127–35.
  44. The Joint Commission. Implicit bias in health care. *Quick Saf*. 2016.
  45. Bryant AS, Worjloh A, Caughey AB, Washington AE. Racial/ethnic disparities in obstetric outcomes and care: prevalence and determinants. *Am J Obstet Gynecol*. 2010;202(4):335–43.
  46. Krieger N, Gruskin S, Singh N, Kiang MV, Chen JT, Waterman PD, et al. Reproductive justice & preventable deaths: state funding, family planning, abortion, and infant mortality, US 1980–2010. *SSM - Popul Heal*. 2016;2:277–93.
  47. Wong CA, Gachupin FC, Holman RC, Maccorman MF, Cheek JE, Holve S, et al. American Indian and Alaska native infant and pediatric mortality, United States, 1999–2009. *Am J Public Health*. 2014;104(S3).
  48. Vedam S, Stoll K, MacDorman M, Declercq E, Cramer R, Cheyney M, et al. Mapping integration of midwives across the United States: impact on access, equity, and outcomes. *PLoS One*. 2018;13(2):e0192523.
  49. Ceron A, Ruano AL, Sanchez S, Chew AS, Diaz D, Hernandez A, et al. Abuse and discrimination towards indigenous people in public health care facilities: experiences from rural Guatemala. *Int J Equity Health*. 2016;15(1):77.
  50. Varcoe C, Brown H, Calam B, Harvey T, Tallio M. Help bring back the celebration of life: a community-based participatory study of rural aboriginal women's maternity experiences and outcomes. *BMC Pregnancy Childbirth* 2013;13(1):26. Available here: <https://doi.org/10.1186/1471-2393-13-26>
  51. Morris T, Schulman M. Race inequality in epidural use and regional anesthesia failure in labor and birth: an examination of women's experience. *Sex Reprod Healthc*. 2014;5(4):188–94.
  52. Min CJ, Ehrenthal DB, Strobino DM. Investigating racial differences in risk factors for primary cesarean delivery. *Am J Obstet Gynecol*. 2015;212(6).
  53. Huesch M, Doctor JN. Factors Associated With Increased Cesarean Risk Among African American Women: Evidence From California, 2010. *American Journal of Public Health*. 2015;105(5):956–62.
  54. Washington S, Caughey AB, Cheng YW, Bryant AS. Racial and ethnic differences in indication for primary cesarean delivery at term: experience at one U.S. institution. *Birth*. 2012;39(2):128–34.
  55. Yee LM, Costantine MM, Rice MM, Bailit J, Reddy UM, Wapner RJ, et al. Racial and ethnic differences in utilization of labor management strategies intended to reduce cesarean delivery rates. *Obstet Gynecol*. 2017;130(6):1285–94.
  56. Morris T, Meredith O, Schulman M, Morton CH. Race, insurance status, and nulliparous, term, singleton, vertex cesarean indication: a case study of a New England tertiary hospital. *Women's Heal Issues*. 2016;26(3):329–335.
  57. California Maternal Quality Care Collaborative. California Pregnancy-Associated Mortality Review (CA-PAMR): Report from 2002 and 2007 Maternal death reviews [internet]. 2018. Available from: <https://www.cmqcc.org/resource/california-pregnancy-associated-mortality-review-ca-pamr-report-2002-and-2007-maternal>
  58. Cheyney M, Everson C, Burcher P. Homebirth transfers in the United States: narratives of risk, fear, and mutual accommodation. *Qual Health Res*. 2014;24(2):443–56.
  59. Amnesty International. Deadly Delivery The Maternal Health Care Crisis in the USA. 2011[cited 2017 Apr 3]; Available from: <http://www.amnestyusa.org/sites/default/files/deadlydeliveryoneyear.pdf>.
  60. Vogel JP, Bohren MA, Tunçalp O, Oladapo OT, Gülmezoglu AM. Promoting respect and preventing mistreatment during childbirth. *BJOG*. 2016;123(5):671–4.
  61. Anderson AC, O'Rourke E, Chin MH, Ponce NA, Bernheim SM, Burstin H. Promoting health equity and eliminating disparities through performance measurement and payment. *Health Aff*. 2018;37(3):371–7.
  62. Martin, Joyce A. MPH, Hamilton BE, Osterman MJ, Driscoll AK, Drake P. Births : final data for 2017 [internet]. *National Vital Statistics Reports*. CDC; 2018 [cited 2018 Dec 15]. Available from: <https://stacks.cdc.gov/view/cdc/60432>.
  63. Bohren MA, Vogel JP, Hunter EC, Lutsiv O, Makh SK, Souza JP, et al. The mistreatment of women during childbirth in health facilities globally: a mixed-methods systematic review. *Jewkes R, editor. PLoS Med [Internet]*. 2015 [cited 2017 Sep 3];12(6):e1001847. Available from: <http://dx.plos.org/10.1371/journal.pmed.1001847>.

**Ready to submit your research? Choose BMC and benefit from:**

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

**At BMC, research is always in progress.**

Learn more [biomedcentral.com/submissions](http://biomedcentral.com/submissions)



## 5.6 Conclusion

In Chapter 5, I describe the person-centred development of 2 new scales and 7 validated indicators that document the lived experience of maternity care. The impetus to prioritize their development emerged from discussions that began at Home Birth Summit I (2011) and continued through Summit III (2014). They were essential to examine and further a shared understanding of person-centred care, and the accountability and attention to experience of care that service users desire. These tools were then available for use as quality measures and in research to inform the understanding of the impact of patient-provider conflict and interprofessional disarticulation during maternity care.

Following the evolving mandate of the Common Ground Agenda, I led a transdisciplinary team of delegates (Autonomy, Consumer, Equity, and Research Task Forces), as we utilized these measures in the Giving Voice to Mothers study to describe disparities in experience of care that align with known disparities in maternal-newborn outcomes across sub-populations. Simultaneously, three of the delegate Task Forces (Regulation, Consumer, and Research) tackled the need to elucidate the complex context of care across the United States. In Chapter 6, I describe a transdisciplinary study to examine the intersections between patient experience, access to different types of care providers across the health system, and associated outcomes.

## CHAPTER 6: Health Systems Interactions with the Wicked Problem

### 6. 1. Introduction

At Home Birth Summit III (HBS) held in September 2014, having built a level of trust through collaboration on Task Forces, the Planning Committee decided to address one of the detracting spaces: disagreement about the evidence on safety of planned home birth. A team of over 20 highly respected American and international place of birth researchers (including Marian MacDorman, Eugene Declercq, Ank de Jonge, Jette Clausen, Jennifer Holloway, and Patti Janssen) met at the Summit with the goal of designing a US Birth Place program of research. Before assessing the safety of planned home birth, they recommended a study to describe existing conditions for interprofessional practice, maternal newborn outcomes across populations, models of care, and access to care across birth settings. Without understanding the experience and context for care in different regions, it is difficult to make an accurate evaluation of contributors to adverse or optimal outcomes.

A 2014 Lancet series (ten Hoope-Bender, 2014) concluded that improving maternal and child health through integration of midwifery should be a global priority; yet access to midwifery in all settings is inconsistent across the US. The Access and Integration Maternity Care (AIMM) Mapping Study was the first step of a strategic plan to address these gaps developed at Home Birth Summit III (HBS 2014). As principal investigator, nominated and supported by the experts from the Summit, I convened a transdisciplinary team of researchers, clinicians, consumers, and legal experts from two HBS Task Forces to collect and link data from 3 sources that, taken together, describe the state of midwifery integration and access to home birth in the United States.

In Chapter 6, I provide context for the AIMM study and why it required a multi-year, multi-stakeholder engagement of delegates. Manuscript 5 describes the methods and findings of the study. To examine the intersections between midwifery integration in the United States and outcome of maternity care, I led a multi-disciplinary team in this 5 year, 3 Phase study of the

associations of the regulatory environment and publicly available vital statistics data. During my doctoral program, I completed the analysis, and interpretation of data, and knowledge translation phases of this study.

## **6.2 Interprofessional Disarticulation, Access and Outcomes of Maternity Care**

In many North American jurisdictions, there are significant regulatory, logistic, financial, and legislative barriers to provision of home birth services. These restrictions may exist in part as a consequence of attitudes and beliefs that are particular to the professional culture and/or significant deficiencies in resources and networks of professional healthcare providers essential to providing safe home birth. In 2014 in the US, although Certified nurse-midwives (CNMs) were licensed in all 50 states, 98% of them only offered hospital birth. Certified professional midwives (CPMs) offered care in birth centers and homes but could only practice legally in 26 states. Physicians had largely ceased attending births at home. Both public and private payors frequently decline to cover costs incurred by a planned home birth. The malpractice environment and regional differences in malpractice legislation also likely contribute significantly to variations in availability of home birth options. All of these conditions contribute to further disarticulation across providers and inconsistencies access to an integrated system of maternity care across settings.

### 6.2.1 Licensure and Integration (Phase 1)

In 2013, following Summit II, the Foundation for Advancement of Midwifery funded the development of the Home Birth Summit Regulation and Licensure Database, a state-by-state record of the regulatory conditions for midwifery practice (and by extension, women's access to physiologic birth and choice of birth place). Delegates from the Regulation and Licensure Task Force collaborated with the Consumer Engagement Task Force and delegate regulatory and legal expert consultants to populate a database with publicly available state regulatory data, and develop a preliminary scoring system to highlight barriers that affect integration of midwives into local maternity care systems.



In Phase 1 of the AIMM study, the Regulation and Licensure and Consumer Task Forces collaborated to develop the HBS Midwifery Regulation and Licensure Database, which described regulatory conditions for midwifery practice across all 50 states, and assigned scores according to the existence of barriers and/or optimal conditions for integration of midwives. The database was subdivided into 3 sections showing the regulatory status of CPMs, CNMs and CMs in each state, with approximately 40 items in each category. The database lists and scores: types of requirements for certification, composition of regulatory boards/agencies, scopes of practice, medication authority, autonomous practice vs. collaborative practice agreement requirements, and other indicators of the current regulatory landscape for every type of midwife in each of state.

Once complete these multi-stakeholder Task Forces presented it at Home Birth Summit III, many of them feeling discouraged by the incredibly disparate context for regulatory conditions, language, and oversight across 50 states. They saw the reality as a barrier or detractor to the Common Ground Agenda. In contrast, the international research experts at Summit III believed that this regulatory database could be used to examine associations between the regulatory environment and perinatal outcomes. They convened to design the AIMM study.

#### 6.2.2 Changing Rates of Home Birth by State

Members of the HBS Research and Data Task Force regularly monitor and publish data on the changing birth rates in each state. However, it was difficult to track these trends according to planned place of birth or type of provider because most state birth certificate forms do not identify hospital births that were transferred from planned home births, nor do they reliably capture attendant credentials, or the state of integration of midwives who attend home births. Nonetheless, it was clear that overall consumer interest in planned home birth was rising rapidly. Whether this is an indicator of increasing availability of integrated providers or simply a symptom of lack of choice and autonomy in hospitals is unknown.

### 6.2.3 Disaggregating Licensure From the Realities of Integration by State (Phase 2)

In Phase 2, when examining the regulatory data, the consumer, clinician, and legal advocate Summit delegates understood that there were discrepancies between publicly available information about midwifery regulation and licensure, and the realities of how statutes are interpreted or actioned. Hence, the transdisciplinary teams realized they had to validate the data that informs the scoring system so that it describes the actual context of practice. Hence, in 2015 and early 2016, we focused on verifying the ‘on the ground’ relevance, importance, and realities of integration through a 50 state survey of 90 regulatory and practice experts. The expert survey included over 100 questions about the state of midwifery integration. This information allowed for a realistic comparison of the level of integration of maternity care providers, and legal status of midwives, on a state-by-state basis. Subsequently, the epidemiologists on the team collated CDC data on indicators of physiologic birth for each state (e.g. rates of spontaneous vaginal births, induction of labour, vaginal birth after Cesarean rates, and changing rates by place of birth). In the final stage of Phase 2, we developed an algorithm for an integration score for each type of midwife (for each state), and calculated integration scores (by type of midwife) for each state.

### 6.2.4 Linking Provider Integration and Place of Birth to Maternal-Newborn Outcomes (Phase 3)

Effects of changing rates of chosen birth place on maternal and fetal outcomes were also unclear. Members of our research team created a US Birth Certificate Comparison Database, which compares maternal-newborn outcomes that are collected on birth certificates in each of the 50 states, and lists key perinatal outcomes collected in each state. In Phase 3 of the AIMM study, this Database allowed us to select and compare items that all states collect that represent key maternal and fetal outcomes (C-sections vs vaginal births, inductions, neonatal complications).

The open source manuscript reporting on the methods and results of the AIMM study follows. All supporting and supplementary files, including the data sources and regulatory database are available from the publisher. In addition, [State Report Cards](#), and a set [of interactive data maps](#) are available on my Birth Place Lab website.

**Manuscript 5: Mapping integration of midwives across the United States: Impact on access, equity, and outcomes.**

<https://doi.org/10.1371/journal.pone.0192523>

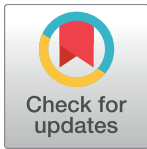
RESEARCH ARTICLE

# Mapping integration of midwives across the United States: Impact on access, equity, and outcomes

Saraswathi Vedam<sup>1,2\*</sup>, Kathrin Stoll<sup>1</sup>, Marian MacDorman<sup>3</sup>, Eugene Declercq<sup>4</sup>, Renee Cramer<sup>5</sup>, Melissa Cheyney<sup>6</sup>, Timothy Fisher<sup>7</sup>, Emma Butt<sup>1</sup>, Y. Tony Yang<sup>8</sup>, Holly Powell Kennedy<sup>9</sup>

**1** Birth Place Lab, Department of Family Practice, Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada, **2** University of Sydney, School of Medicine, Sydney, Australia, **3** Maryland Population Research Center, University of Maryland, College Park, Maryland, United States of America, **4** School of Public Health, Boston University, Boston, Massachusetts, United States of America, **5** Law, Politics and Society, Drake University, Des Moines, Iowa, United States of America, **6** Department of Anthropology, Oregon State University College of Liberal Arts, Corvallis, Oregon, United States of America, **7** Department of Obstetrics and Gynecology, Geisel School of Medicine, Dartmouth University, Lebanon, New Hampshire, United States of America, **8** Health Administration and Policy, George Mason University, Fairfax, Virginia, United States of America, **9** Department of Midwifery, Yale School of Nursing, Orange, Connecticut, United States of America

\* [saraswathi.vedam@ubc.ca](mailto:saraswathi.vedam@ubc.ca)



**OPEN ACCESS**

**Citation:** Vedam S, Stoll K, MacDorman M, Declercq E, Cramer R, Cheyney M, et al. (2018) Mapping integration of midwives across the United States: Impact on access, equity, and outcomes. *PLoS ONE* 13(2): e0192523. <https://doi.org/10.1371/journal.pone.0192523>

**Editor:** Dongmei Li, University of Rochester, UNITED STATES

**Received:** June 27, 2017

**Accepted:** January 16, 2018

**Published:** February 21, 2018

**Copyright:** © 2018 Vedam et al. This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

**Data Availability Statement:** Data are available from the UBC Abacus Dataverse Network: <https://dx.doi.org/10.14288/1.0363296>. AIMM Report Card data and corresponding data maps are available at <http://www.birthplacelab.org/how-does-your-state-rank> and <http://birthplacelab.org/maps>.

**Funding:** This work was made possible by a grant from the Transforming Birth Fund of the New Hampshire Charitable Foundation <https://www.nhcf.org/> and with infrastructure support by the

## Abstract

Poor coordination of care across providers and birth settings has been associated with adverse maternal-newborn outcomes. Research suggests that integration of midwives into regional health systems is a key determinant of optimal maternal-newborn outcomes, yet, to date, the characteristics of an integrated system have not been described, nor linked to health disparities.

## Methods

Our multidisciplinary team examined published regulatory data to inform a 50-state database describing the environment for midwifery practice and interprofessional collaboration. Items (110) detailed differences across jurisdictions in scope of practice, autonomy, governance, and prescriptive authority; as well as restrictions that can affect patient safety, quality, and access to maternity providers across birth settings. A nationwide survey of state regulatory experts (n = 92) verified the ‘on the ground’ relevance, importance, and realities of local interpretation of these state laws. Using a modified Delphi process, we selected 50/110 key items to include in a weighted, composite Midwifery Integration Scoring (MISS) system. Higher scores indicate greater integration of midwives across all settings. We ranked states by MISS scores; and, using reliable indicators in the CDC-Vital Statistics Database, we calculated correlation coefficients between MISS scores and maternal-newborn outcomes by state, as well as state density of midwives and place of birth. We conducted hierarchical linear regression analysis to control for confounding effects of race.

## Results

MISS scores ranged from lowest at 17 (North Carolina) to highest at 61 (Washington), out of 100 points. Higher MISS scores were associated with significantly higher rates of spontaneous

University of British Columbia. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

**Competing interests:** The authors have declared that no competing interests exist.

vaginal delivery, vaginal birth after cesarean, and breastfeeding, and significantly lower rates of cesarean, preterm birth, low birth weight infants, and neonatal death. MISS scores also correlated with density of midwives and access to care across birth settings. Significant differences in newborn outcomes accounted for by MISS scores persisted after controlling for proportion of African American births in each state.

## Conclusion

The MISS scoring system assesses the level of integration of midwives and evaluates regional access to high quality maternity care. In the United States, higher MISS Scores were associated with significantly higher rates of physiologic birth, less obstetric interventions, and fewer adverse neonatal outcomes.

## Introduction

The Lancet Series on Midwifery (2014) concluded that “national investment in midwives and in their work environment, education, regulation, and management . . . is crucial to the achievement of national and international goals and targets in reproductive, maternal, newborn, and child health” [1]. In countries where midwives are integrated into the health care system, the benefits of midwifery care are well-documented [2]. Global health experts recommend scaling up midwifery to improve maternal and newborn outcomes, reduce rates of unnecessary interventions, and realize cost savings [3,4]. However, access to midwifery care in the United States (US) is markedly lower than in most other “Organisation for Economic Co-operation and Development” (OECD) countries, with approximately 10% of US births attended by midwives compared to 50–75% in other high-resource countries [5]. In addition to low density of midwives per state, all midwives are not universally licensed to practice or integrated into regional health care systems. American midwives face multiple challenges to practice, including numerous regulatory barriers and inability to secure third party reimbursement [6]. As a result, women in many states cannot access midwives because of legal or payor restrictions [7,8].

Regulation has been identified by the International Confederation of Midwives as one of the pillars of a strong midwifery profession [9]. Regulation refers to a set of criteria and processes arising from the legislation that describes the scope of midwifery practice (activities which midwives are educated for, competent in, and authorized to perform, consistent with the ICM Definition of the Midwife) [9]. On a global scale, maternal and perinatal outcomes are better in jurisdictions where midwives are regulated and have the legislative authority to practice to their full scope across birth settings, including collaborating with or referring to other health professionals [2]. To date, it has been difficult to examine the impact of variations in midwifery regulation and integration across the United States on perinatal outcomes or on consumer access to maternity care. To address these gaps, a panel of maternity care and health policy experts who were delegates to the Home Birth Summit III [HBS] in 2014 (<http://www.homebirthsummit.org/>) designed **The Access and Integration Maternity Care Mapping (AIMM) Study**. The aim of this transdisciplinary, national research project was to examine the impact of state regulatory environments on access to midwives and association with perinatal outcomes across populations in the United States.

## Why does integration matter?

There are very few jurisdictions in the United States (US) where all types of midwives, irrespective of practice site, are fully integrated as regulated health professionals into interprofessional

care provider networks. However, interprofessional teamwork is essential to the provision of high-quality maternity care [10]. For example, research indicates that, when professionals collaborate on decision-making and when coordination of care is seamless, fewer intrapartum neonatal and maternal deaths occur during critical obstetric events [11]. Poor communication, disagreement, and lack of clarity around provider roles are identified as primary determinants of these adverse outcomes [10–12]. Beliefs about risk, beneficence, non-maleficence and patient autonomy are often discipline-specific and divergent [13,14]. Rates of intervention, and labour management options that facilitate normal, physiologic birth are known to differ by type of provider [15], by birth setting [16,17], and by provider education. When differences around defining risk and responsibility exist among providers, interprofessional cooperation and access to options for care are reduced [18–20]. Moreover, when patients perceive interprofessional conflict, the culture of safety is diminished [21–23].

Conversely, collaboration among health professionals can improve safety and quality, particularly when care is transferred from low to high resource settings [10]. For example, when a woman plans to give birth in a community setting (home or birth center) she benefits when her midwife can facilitate access to specialized hospital personnel, equipment, or medications when necessary. The ability of midwives to function autonomously to their full scope of practice in community settings, in collaboration with other members of the health system, can enhance cost-effectiveness of maternity care [24,25]. Regardless of birth setting, midwife-led care has been linked to significantly improved perinatal outcomes, and maternal experience, in both healthy and at-risk populations [26–28]. In the US, current evidence suggests that scope of practice laws, as well as other aspects of state policy and regulation, may be reducing the maternity care workforce and access to services [26]. An integrated maternity care system facilitates the full exercise of scope of practice, autonomy, self-regulation, and collaboration across disciplines.

### The diverse context for American midwifery practice

Over 15 years ago, the American Public Health Association issued a position statement, calling for increased access and integration of midwifery services in the United States. [29](29) Yet, consistent U.S. standards for regulation, scope of practice, and access to reimbursement for midwives are still lacking, resulting in a fragmented system of care.

There are three professional designations for midwives in the United States: Certified Nurse-Midwife (CNM), Certified Midwife (CM) and Certified Professional Midwife (CPM). CNMs/CMs obtain their basic education in midwifery through university-based nursing programs and obtain a master's degree. Both CMs and CPMs are direct-entry midwives without a prior nursing credential. CPMs have a median of three years of education before attending deliveries as a primary midwife; half gain certification via portfolio review, 40% graduate from an accredited school and others report blended education pathways [7]. CNMs can obtain licensure in all 50 states and DC, and their scope includes well-woman gynecology and primary care, as well as maternity care. They are prepared for practice in any birth setting, but they almost exclusively practice in hospitals [6,30]. CMs are currently licensed in 5 states, and are prepared for an identical scope of practice and settings for care as CNMs. CPMs can currently obtain licensure in 30 states. They provide antepartum, intrapartum, and postpartum/newborn care in community based settings, but typically cannot obtain hospital practice privileges and often have difficulty establishing reliable systems for referral and collaborative care. [7,31]

Wide variations in state regulatory conditions for midwifery practice, especially with respect to birth place, have created an environment of interprofessional hostility in some

jurisdictions and interprofessional cooperation in others. Given the emerging evidence on the adverse impact of interprofessional disarticulation on maternal experience and outcomes [31,32], it is important to understand the connections between different regulatory environments and differences in health outcomes, especially when significant disparities exist across populations. Differences in adverse perinatal outcomes between Caucasian women and women of colors are well-documented [33–36], and persist even when controlling for socioeconomic status and access to quality prenatal care [33,37]. There is a dearth of information about whether health disparities can be attributed to differences in health insurance coverage, or access to providers, or quality of care [36,38,39].

In 2015, 89.8% of US births were attended by physicians, 8.5% by CNMs/CMs, 0.8% by other midwives (including CPMs), and 0.8% by other providers [40]. In 2014, methods of payment varied by place of birth: 44.2% of hospital births were paid for by Medicaid, 48.0% by private insurance, 3.4% were self-pay, and 4.4% via other sources. In contrast, 16.4% of community births (birth center or home) were paid for by Medicaid, 29.4% by private insurance, 50.0% through self-pay and 4.2% via other sources. Most community births are attended by midwives and half are not covered by insurance [41]. The regulatory environment for payors has been shown to significantly impact the extent of midwifery practice in a state and autonomy of midwives [42].

Such systems-level deficits may have significant, negative impacts on the health and well-being of maternal-newborn populations. Rates of obstetric interventions are on the rise in the United States and adverse maternal and newborn outcomes are high, compared to other OECD countries [43]. Black Americans experience substantially higher rates of maternal and neonatal mortality, preterm birth, and low birth weight [33,34,44]. However, one study found that in states where CNMs have greater professional autonomy (i.e. physician supervision not required), there were lower rates of surgical birth, preterm birth and low birth weight, even when adjusted for maternal age, parity, race, education, marital status, cigarette use and prenatal care utilization [26].

In the **Access and Integration Maternity Care Mapping (AIMM) Study**, we went beyond CNM autonomy to create an evidence-based scoring system to rank the level of integration of all types of midwives into health systems. We then examined the relationships between state Midwifery Integration Scores, density of midwives, access to midwives across practice settings, rates of obstetric interventions, and maternal and newborn outcomes.

## Methods

We convened a multi-disciplinary Task Force with expertise in maternity services research, public health, midwifery, obstetrics, epidemiology, consumer advocacy, and/or roles in midwifery regulation, legislation, and law. They identified the key variables needed to populate a database of published regulatory data across all 50 states and the District of Columbia, detailing rules regarding scope of practice, and requirements for licensure of CNMs, CPMs, and CMs and practice across birth settings. We then employed a formal, process (see **Table 1**), modeled on the Delphi method [45,46], best practices for transdisciplinary research, and legal epidemiology [47], to identify and validate the most important items for inclusion in a composite measure of midwifery integration.

### Round 1 –Concept generation

The Task Force self-organized into two teams, one with regulatory, law, and consumer access expertise, and another with expertise in public health, legal anthropology, and perinatal epidemiology research methods, including instrument development. Both teams included

**Table 1. Development of an evidence-based Midwifery Integration Scoring System (MISS).**

<p><b>Delphi Round 1 –Concept generation</b></p> <ul style="list-style-type: none"> <li>• HBS Regulation and Licensure Task Force (Team 1) reviews source documents and identifies 7 domains of midwifery integration</li> <li>• Database populated with state regulations on scope of practice and restrictions</li> <li>• Team 1 agrees by consensus on 110 key items describing midwifery regulation</li> </ul>
<p><b>Delphi Round 2 –Expert content validation</b></p> <ul style="list-style-type: none"> <li>• HBS Research and Data Task Force (Team 2) defines optimal regulatory conditions that support patient access and collaborative practice–informed by a review of the evidence, and consultation with Team 1</li> <li>• Database and rubrics translated into format to allow for a ranked composite scoring and comparison across states</li> <li>• State regulatory content experts (N = 92, 1-2/state) review items and scoring rubrics for accuracy and relevance to local implementation of the law</li> <li>• Team 2 harmonizes data and adapts scoring rubrics to reflect state realities</li> <li>• Final scoring system reviewed and confirmed by consensus among Teams 1 and 2, and national midwifery regulators and clinical leaders</li> </ul>
<p><b>Delphi Round 3 –Development and application of composite measure</b></p> <ul style="list-style-type: none"> <li>• Team 2 selects 50 key indicators of midwifery integration indicating level of autonomy, ability to practice to full scope, and collaboration across birth settings.</li> <li>• Teams 1 and 2 convene to rank order answer options in each of the 50 items (higher scores indicated more favourable access and practice conditions)</li> <li>• Team 1 develops a weighted scoring system based on patient safety and quality. Item level scores are weighted and summed for a total optimal score of 100.</li> <li>• MISS tool generates State Integration Scores (range = 17 to 61 across the US).</li> <li>• Density of midwives (per 1000 state births) and access to midwives across settings (home, birth center, hospital) correlated to MISS scores and outcomes.</li> <li>• Correlation and regression analyses link state MISS scores to selected perinatal outcomes that are reliably reported by CDC Vital Statistics</li> </ul>
<p><b>Delphi Round 4 –Development of the AIMM report card</b></p> <ul style="list-style-type: none"> <li>• Teams 1 and 2 meet to reach consensus on interpretation and key messages</li> <li>• Creation of Interactive AIMM Maps: <ul style="list-style-type: none"> <li>◦ MISS scores categorized into four quartiles (very low, low, moderate, high)<sup>1</sup></li> <li>◦ Perinatal outcomes linked to MISS scores and displayed by highest and lowest quartiles</li> <li>◦ 4 base maps to display: level of integration, density, proportion of midwife-attended births in 3 settings, and proportion of black births by state</li> </ul> </li> </ul>

**1:** We categorized MISS scores and outcomes into four equal categories: Values between the 1-24<sup>th</sup> percentile, the 25<sup>th</sup>-49<sup>th</sup> percentile, the 50<sup>th</sup> to 74<sup>th</sup> percentile and the 75<sup>th</sup> to 100<sup>th</sup> percentile.

<https://doi.org/10.1371/journal.pone.0192523.t001>

clinicians, and consumers. Over three rounds of drafts, edits, and consensus-based discussions, Team 1 identified seven relevant domains that were important to identify in state regulations on midwifery. Four domains describe midwifery practice: scope of practice, provider autonomy, governance, access to referral and medications; and three domains describe patient safety, quality, and access to maternity providers across birth setting. The team identified 110 indicators that differentiate the regulatory environment by domain for each type of midwife (CM, CPM, or CNM), and assigned numeric values to describe the diverse conditions, permissions, or restrictions delineated in the state laws (see [Table 2](#)).

We then widened the consultant pool to include experts from national regulatory, legal, payor, professional and perinatal surveillance bodies. These policy leaders noted that the statutory language does not always accurately represent the realities of how rules and laws are interpreted and implemented. Language used in rule-making may be interpreted in more or less restrictive ways, and some rules are not actionable given infrastructure constraints and systems-level limitations. For example, in one state, CPMs have statutory authority to access emergency medications for the management of complications, such as maternal hemorrhage; however, pharmacists in that state are restricted from furnishing these medications to



**Table 2. Sample midwifery integration indicators and weighted scores.**

---

**Are CPM/CNM/CMs regulated?**

- 0 = Prohibited
- 1 = Allowed by previous judicial opinion or not mentioned/not prosecuted to date
- 2 = Unregulated but allowed by statutory permission
- 4 = Licensed

---

**Are there statutory limitations/restrictions to site of practice for licensed CPM/CNM/CMs?**

- 0 = Yes
- 1 = Lack of access to hospital privileging or physician referral/signer
- 2 = No

---

**Consultation/referral required by law for certain conditions?**

- 0 = Unregulated state
- 1 = Required (R) but difficult to access when needed
- 2 = Not required (NR) but difficult to access when initiated by midwife
- 3 = R or NR but easily accessed when initiated by CPM/CNM/CM

---

**Evidence-informed, validated quality assurance (QA)/quality improvement (QI) state system for all sites (home, hospital, birth centers)**

- 0 = Hospital only
- 1 = Hospital and birth center only
- 4 = Home/hospital/birth center

---

**Is Medicaid reimbursement available for CPM/CNM/CMs?**

- 0 = No
- 2 = Yes, but challenges with reimbursement including birth site
- 3 = Yes

---

**Do CPM/CNM/CMs have prescription-writing authority?**

- 0 = Prohibited or not authorized
- 1 = Allowed only by physician
- 2 = Limited list of medications allowed
- 3 = Comprehensive list of medications allowed
- 4 = Prescription-writing authority

---

<https://doi.org/10.1371/journal.pone.0192523.t002>

practitioners who are not affiliated with hospitals. Because CPMs cannot gain access to hospital privileges, they must find alternate ways to exercise their authority to carry these lifesaving medications.

## Round 2 –Expert content validation

Hence, to verify the realities of implementation of the law within each state, Team 2 identified and recruited state and national regulatory experts (n = 92) to complete an online survey. Participants included 75 state-specific regulatory board representatives; the presidents, regional and chapter chairs for state midwifery associations, state legislative and policy chairs for the American College of Nurse Midwives (ACNM) and National Association of Certified Professional Midwives (NACPM). They evaluated the connections and discordances between theory and practice for each of the identified indicators within the state regulatory environment. In poorly integrated states our national experts (ACNM, NACPM legislative directors) referred us to local midwifery or consumer experts who could reliably speak to ‘on the ground’ conditions. When two state experts disagreed on an indicator or experts did not know the answer, we further consulted with 17 state or national regulators, to resolve discrepancies.

We harmonized expert responses with our regulatory database through a systematic line-by-line comparison. We validated and/or deferred to the statutory language when there were no discrepancies between statutes and local interpretation or implementation. When state experts provided evidence of local interpretation that differed from the apparent intent of laws or rules, we added or adapted response options to reflect the realities of midwifery practice, consumer access, and/or the interprofessional environment.

### Round 3—Development and application of composite measure

A final Delphi process (see [Table 1](#)), involving both multidisciplinary teams, led to selection of 50/110 indicators of midwifery integration, and the development of a weighted Midwifery Integration Scoring System (MISS) (50 items, maximum summary score 100) that quantifies the potential impact on patient access to high-quality maternity care across birth settings. Both teams reviewed the 110 items and only retained those that were deemed, by consensus, important or very important to the assessment of midwifery integration. In some cases, 2–3 items were combined into one stem query, and response options expanded. Some items were excluded because team members felt that the items were not directly pertinent to midwifery integration. For example, one item (Does informed consent language in statute and/or regulations allow for informed refusal by client?) was excluded because the item relates more to human rights issue rather than quantifying the level of midwifery integration. To create the weighting system, using a scale of 0 (not important), 1 (somewhat important), 2 (important), 3 (very important), 4 (essential), the teams assessed each item for its potential impact on patient access to high-quality maternity care. They assigned higher item-level scores to indicators of greater integration, more interprofessional collaboration, and/or wider consumer access across birth settings. The final list of items describe the range of possible options for scope of practice, regulatory body, prescriptive authority, requirements for physician supervision, access to Medicaid, etc. that vary in both statutory language and implementation across states. See [S1 Table](#) for a full list of the indicators and scoring system.

### Ranking states by MISS scores and outcomes

We used the MISS composite summary scores to rank states by degree of integration. Then, using the 2014 CDC-Vital Statistics Database, we calculated Spearman's rho correlation coefficients between the continuous MISS integration scores and selected maternal-newborn outcomes in each state. We used Spearman's rho because the MISS scores were normally distributed as indicated by the Shapiro-Wilk Test (0.960,  $p = 0.08$ ), but the outcomes data were not. We selected indicators that represent cost-effectiveness and quality in perinatal care (e.g. rates of spontaneous vaginal birth, exclusive breastfeeding, cesarean, induction, VBAC, pre-term birth, low birth weight, neonatal mortality) [43,48], and were available and reliable in the CDCs Vital Statistics database [47]. Finally, based on data from the Area Health Resource File, and Centers for Medicare and Medicaid Services, we calculated correlations between MISS scores; state density of midwives (per 1000 births); and consumer access to midwives across birth settings, defined as the proportion of all births at 1) hospital, 2) home and 3) birth centers for two categories of midwives a) CNMs/CMs and b) CPMs and other direct entry midwives as reported on the birth certificates for each state.

In addition, we calculated the correlations between 1) CM and 2) CPM licensure and perinatal outcomes, to examine the differential effects of licensure versus integration scores by state for all outcomes. We also identified states with the highest increases in community births (at home and birth centers) over the past 8 years and examined correlations with MISS scores.

Finally, appreciating the complex nature of health disparities, to understand the relative importance of midwifery integration on perinatal outcomes, we conducted hierarchical linear regression modelling, to control for the proportion of Non-Hispanic Black births in each state, when examining the relationship of MISS scores with rates of five outcomes: caesarean, pre-term birth, neonatal death, low birth weight, and breastfeeding at birth.

## Results

State MISS scores ranged from 17 in North Carolina to 61 in Washington State, with notable regional variation (see [Figs 1 and 2](#)). Higher MISS integration scores were correlated to a

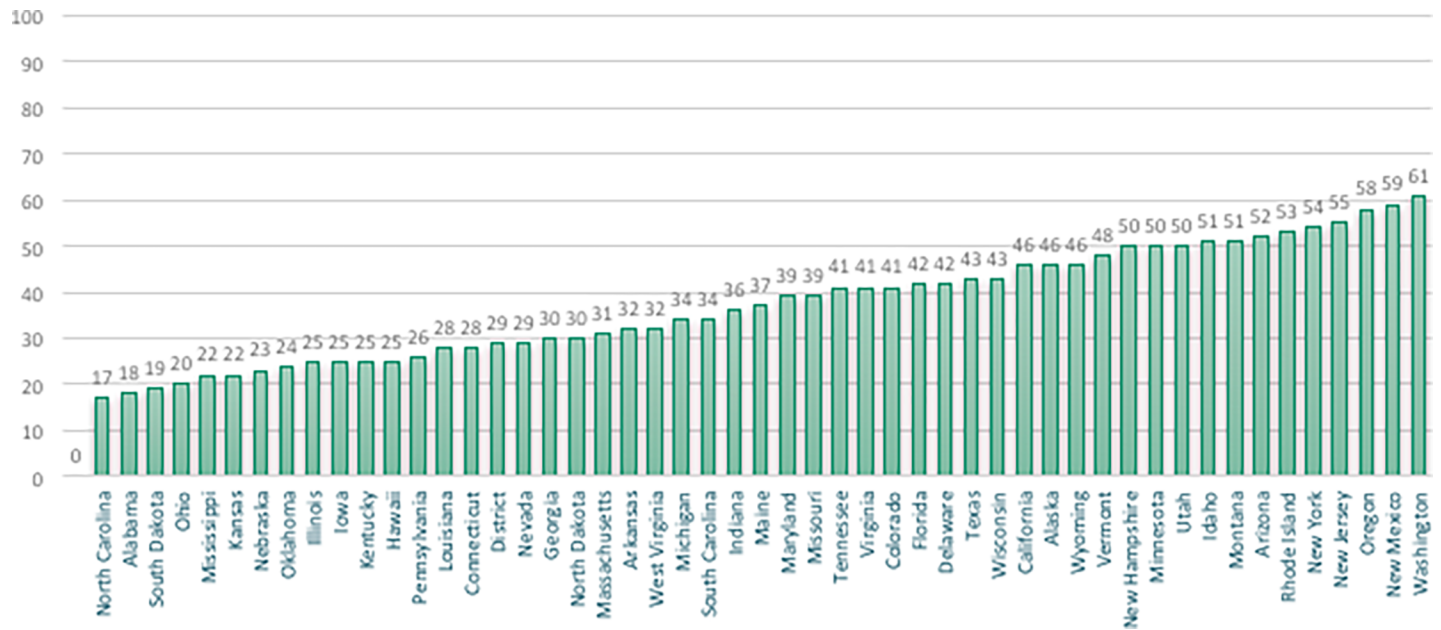


Fig 1. Rank-ordered integration scores for 50 states and Washington, DC (2014–2015).

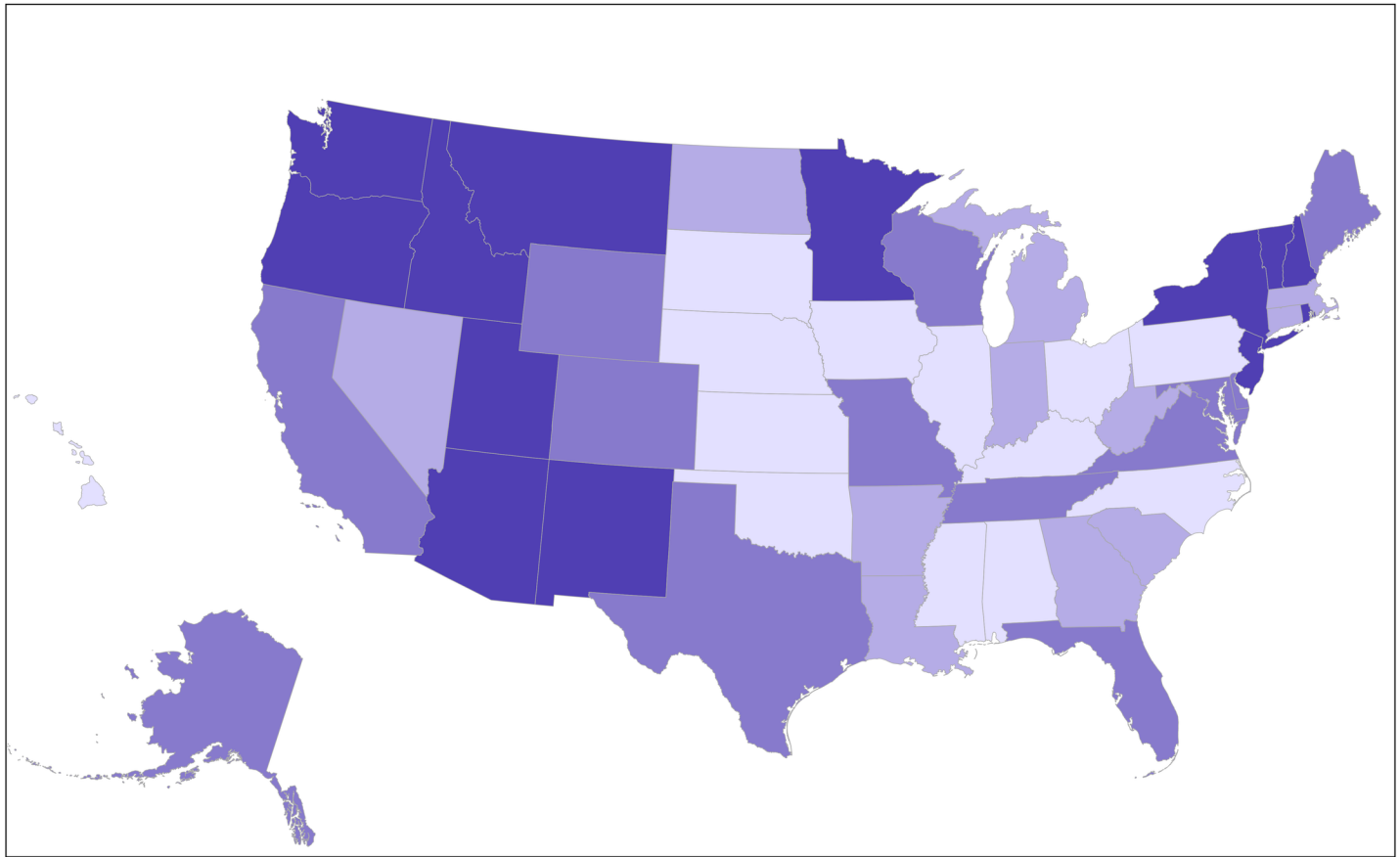
<https://doi.org/10.1371/journal.pone.0192523.g001>

higher density of midwives per state and higher proportion of midwife-attended births across settings (see Table 3). Higher MISS scores, and improved access to midwives in all settings, were associated with significantly higher rates of spontaneous vaginal delivery, vaginal birth after cesarean (VBAC), and breastfeeding at birth and at six months; and significantly lower rates of cesarean section (CS), preterm (PTB), and low birth weight (LBW) infants (see Table 4). Higher MISS scores were correlated strongly with lower rates of neonatal mortality (see S1 Fig) and race-specific neonatal mortality (see S2 Table).

Between 2004 and 2014, community birth rates increased significantly ( $p < 0.05$ ) in all states, except Vermont, Rhode Island, Oklahoma, Maine and DC. The average increase over the time period was 72%. [41] The states with the largest increases were Montana, Oregon, Washington, Utah and Wyoming. States with higher MISS scores had significantly higher rates of community births in 2014 ( $r_s = 0.445$ ,  $p = 0.01$ ) and significantly larger increases in community birth rates from 2004–2014 ( $r_s = 0.328$ ,  $p = 0.02$ ).

Our regulatory data described conditions for 2014–2015, when CPMs had regulatory authority to practice in 27 states and CMs in 5 states. CPM licensure significantly correlated to access to midwifery care in community settings ( $r_s = 0.440$ ,  $p = 0.001$ ). Licensure alone was not synonymous with integration, and did not confer the same benefits on outcomes or interventions (see S4 Table).

MISS scores were significantly lower in states with a higher proportion of non-Hispanic Black births ( $r_s = -0.370$ ;  $p = 0.007$ ). Access to midwives across settings and density of midwives were also significantly lower in states with a higher proportion of black births ( $r_s = -0.375$ ,  $p = 0.007$  and  $r_s = -0.298$ ,  $p = 0.04$ ). To determine the amount of variance that is accounted for by integration of midwives, when taking into account disparities in neonatal mortality by race, we undertook further analysis. Differences in the percent of Non-Hispanic black birth across states accounted for 38.5% of the differences in neonatal mortality scores, and MISS scores explained another 11.6% of variance (see Table 5). This change was significant ( $p = 0.002$ ) meaning that the level of integration can explain differences in neonatal



**Fig 2. Map of midwifery integration across the United States.** Levels of integration displayed by quartiles of MISS scores. Deeper shades of purple represent higher integration and lighter shades represent lower integration of midwives.

<https://doi.org/10.1371/journal.pone.0192523.g002>

mortality rates, above and beyond the percent of black births. These two factors, state-level percent of black births and level of midwifery integration, can predict half of the variance (50.1%) in neonatal mortality rates. MISS scores also explained significant additional variance in rates of preterm birth and breastfeeding at birth scores (see Table 5). Integration scores did not add significant explanatory power to disparities in cesarean and low birth weight rates.

**Table 3. Significant correlations between MISS scores, and density and access to midwives by setting, United States, 2014.**

State-level	Correlation coefficient
Density of CNMs/CMs (per 1000 births)	0.495**
Density of CPMs (per 1000 births)	0.459**
Proportion of midwife-attended births all locations	0.431**
Proportion of midwife-led births in community settings	0.509**

\*\*Correlation is significant at the 0.01 level (2-tailed).

Notes: Midwifery density was determined separately for CNMs/CMs and for CPMs by dividing the number of midwives in each category in each state by the total number of births in each state and multiplying by 1000.

Consumer access to midwives across birth settings was defined as the proportion of all births documented at 1) hospital, 2) home and 3) birth centers for a) CNMs/CMs and b) CPMs and other direct entry midwives as reported on the birth certificates for each state.

<https://doi.org/10.1371/journal.pone.0192523.t003>

**Table 4. Significant correlations between midwifery care, MISS scores, and birth outcomes, United States, 2014.**

%	% of births attended by all types of midwives, hospital only	% of births attended by all types of midwives in community birth settings	Midwifery Integration State Scores
Spontaneous Vaginal Birth <sup>1</sup>	0.556**	0.435**	0.402**
Vaginal birth <sup>1</sup> after Cesarean <sup>2</sup>	0.483**	0.528**	0.330*
Induction <sup>3</sup>	-0.350*	-0.084	-0.275
Preterm birth <sup>4</sup>	-0.556**	-0.455**	-0.480**
Low birth weight <sup>5</sup>	-0.299*	-0.388**	-0.353*
Cesarean section <sup>2</sup>	-0.375**	-0.627**	-0.278*
Neonatal mortality rate <sup>6</sup>	-0.247	-0.364**	-0.545**
Breastfeeding at birth	0.474**	0.593**	0.584**
Breastfeeding <sup>7</sup> at 6 months	0.524**	0.533**	0.378**

\*\*Correlation is significant at the 0.01 level (2-tailed).

\*Correlation is significant at the 0.05 level (2-tailed).

<sup>1</sup> a vaginal birth without prior induction.

<sup>2</sup> all types of Cesarean sections.

<sup>3</sup> all types of inductions.

<sup>4</sup> births before 37 weeks gestation.

<sup>5</sup> babies weighing less than 2500 grams at birth.

<sup>6</sup> babies that died within 27 days of birth per 1000 births in the year 2013.

<sup>7</sup> exclusive breastfeeding.

Source: Authors, analysis of MISS scores, and data from CDCs Vital Statistics database (2014), 2013/ 2014 National Immunization Surveys and Area Health Resource File. Data for breastfeeding at 6 months is for the year 2012 and was obtained from the 2013 and 2014 National Immunization Surveys: [https://www.cdc.gov/breastfeeding/data/nis\\_data/rates-any-exclusive-bf-state-2012.htm](https://www.cdc.gov/breastfeeding/data/nis_data/rates-any-exclusive-bf-state-2012.htm).

<https://doi.org/10.1371/journal.pone.0192523.t004>

## Discussion

Our analyses showed that a state regulatory environment that supported greater integration of midwives into the health system was associated with a greater number of midwives and

**Table 5. Results from linear regression analysis, showing variations in outcomes that can be explained by % black births and MISS scores.**

	Outcome	Variance explained by % black birth (R2)	Additional variance explained by MISS integration scores (R2)	Total variance explained
<b>Model 1</b>	Neonatal death	0.385	0.116*	0.501
<b>Model 2</b>	Cesarean section	0.427	0.006	0.433
<b>Model 3</b>	Preterm birth	0.371	0.081*	0.452
<b>Model 4</b>	Low Birth Weight	0.552	0.018	0.570
<b>Model 5</b>	Exclusive breastfeeding at birth	0.425	0.107*	0.532

\*R square change significant (< 0.05).

Regression specifications: Hierarchical linear regression. The proportion of black births was entered in block 1 of the model and integration scores in the second block; outcomes were: Neonatal death, preterm birth, low birth weight, CS and breastfeeding at birth. For each model we found that the relationship between standardized predicted values and standardized residuals was linear and that the observed standardized residuals were normally distributed. A p value < 0.05 was deemed as significant.

<https://doi.org/10.1371/journal.pone.0192523.t005>

midwife-attended births in a state. This greater integration was significantly associated with higher rates of spontaneous vaginal birth, VBAC and breastfeeding at birth and at six months, as well as lower rates of obstetric interventions, preterm birth, low birth weight infants, and neonatal death. These findings are especially significant in the light of increased costs to any health care system associated with high cesarean and preterm birth rates, and low breastfeeding rates. This is a pathognomonic example of the current global public health focus on, “too much too soon, too little too late” [48].

While the associations illustrated do not imply causation, the MISS scores nonetheless can be a tool for generating testable hypotheses on the effects of midwifery integration on key outcomes. The observed relationships may help us identify states where childbearing women are at increased risk for poor outcomes and experience reduced access to high quality maternity care due to poor integration of midwives across birth sites (e.g. North Carolina, Alabama).

Model states (i.e. states with the highest MISS scores) can inform mechanisms to enhance integration of midwives in other states. However, it is important to note that no state enjoys regulatory conditions that are optimal to support quality and safety for families during pregnancy, birth and the postpartum period. The most integrated states now achieve scores that represent less than two thirds (61/100) of condition requirements for a fully integrated system for care.

### Can integration of midwives reduce health disparities?

African American mothers, in particular, are affected by adverse maternal and newborn outcomes; they experience a two to four times higher risk than White women for both maternal and infant mortality [44,49]. Some policy makers and public health experts attribute this to concomitant disparities among African Americans in wages, housing, and safe environments. Other researchers have proposed that outcomes such as LBW are due, in part or wholly, to experiences of discrimination across the life span of African-American mothers [50,51]. Giscombe and Lobel [52] hypothesized that racism functions as a severe stress trigger, and have explored biologic explanations for how stress influences adverse neonatal outcomes.

Nonetheless, Rossen et al. [53] describe considerable variation in county-level and race-specific infant mortality rates between black and white mothers. They suggest that this variation might be partly a result of contributing factors that are common to both white and black infants, including differential access to specialized care, perinatal regionalization, and overall patterns in health care delivery. Since data suggest that institutional racism is a contributing factor, place of birth, or model of maternity care, may also modulate these outcomes [41]. A recent population-level analysis in Canada described associations between midwifery care of at-risk populations and significantly reduced incidence of pre-term birth, low birth weight, and other adverse outcomes [54]. In our study, lower MISS scores were associated with significantly higher rates of neonatal mortality among Hispanic, black and white babies when examining race-specific outcomes. Density of midwives and access to midwives across birth settings were also significantly lower in states where more black babies are born. The additional variance explained when MISS scores were added to the equations suggests that, with greater integration of midwives in these states, the associated reduced rates of neonatal mortality, preterm birth, and increased breastfeeding success could confer important long term health benefits [55,56] for African American mothers.

### Does midwifery integration affect outcomes across birth settings?

Some investigators have suggested that poor neonatal outcomes may rise with increased access to midwives who attend home and birth center births [57,58]. In our state-by-state

comparison, however, the best outcomes for mothers and babies occur in states where all types of midwives are regulated and integrated into the health care system regardless of birth setting.

Nonetheless, significant interprofessional conflict persists around recommendations for safe birth care. For example, despite the emergence of high quality prospective observational studies supporting the safety and cost-effectiveness of planned home birth [16,24], leading maternity providers in North America have been in conflict about birth at home and birth centers, debating issues related to safety, access, the value of obstetric intervention, and patient autonomy [57–59]. These debates are reflected in widely varying state regulatory environments that may, in turn, influence conditions for maternity practice and public access to choice of birth place. Differences in community birth rates across regions may simply represent the influence of pre-existing provider philosophies and attitudes [60], which in turn affect informed consent discussions with patients as well as comfort with collaboration across disciplines [20].

Rates of planned home and birth center birth in the US and Canada remained at less than 1% for several decades, but current data suggest that American women are increasing their interest in this option [41]. Midwives are the only maternity care providers who currently offer choice of birth setting. However, because not all types of American midwives can legally practice in all birth settings, choice of birth place is functionally quite limited for a majority of US women. In some regions, women who plan to deliver at home or in a birth center, will (along with their midwives) encounter hostility, judgment, and, reprimand when they transfer across birth settings [31,61]. Person-centred maternity care should define quality and safety within a multi-faceted context that includes patient choice, access, experience, and cost-effectiveness.

### **Policy implications: Improving access to high quality maternity care**

Our ranking system highlights discrepancies in integration and related outcomes and could inspire political will, and guide legislative reform. The Midwifery Integration Scoring System can help to identify states where childbearing women and newborns might benefit from improved integration of midwives. In communities where access to *any* maternity provider is scarce [62], our findings suggest that expanding access to midwifery care may be an important part of the solution to both public health and human health resource challenges. All three types of midwives share a model of maternity care that has been associated with optimal outcomes and cost-effectiveness [1,63] by prioritizing person-centered care; promoting of normal, physiologic birth; judicious evidence-based use of obstetric interventions and procedures; and collaborating with and/or referring to obstetric specialists when indicated [7,64]. Our results align with this evidence suggesting that increased reliance on midwives could reduce the costly overuse of obstetric interventions, reduce rates of preterm birth and neonatal loss, and improve breastfeeding and vaginal birth rates, thereby helping to address serious maternal-newborn health deficits in the United States.

The US precedent of health systems restricting access to qualified attendants across birth settings, and placing high value on institutional birth, has been very influential in low and middle resource countries. [65,66] Unfortunately, the system of incentivizing institutional birth and physician management of healthy pregnancies has exacerbated the gaps between demand and available health human resources both in the US and in low resource settings. [66,67] Skilled midwives can assist a woman to assess her birth site options according to her health status and facilitate access to appropriate resources. Ideally, they would practice in a legal environment that allows them to practice to full scope, and collaborate seamlessly with other health professionals, across birth settings.

To enable midwives to work autonomously within their full scope of practice, the International Confederation of Midwives has identified standards for regulatory mechanisms that

protect the public by ensuring that midwives provide high quality midwifery care to every woman and baby [68]. Based on these ICM Standards, the US Midwifery Education, Regulation and Association (USMERA) workgroup has described Principles for Model Midwifery Legislation [69] that include many of the same components that comprise the MISS scores. If applied to state regulatory reform, they could contribute to state scores that are closer to the ideal (i.e. 100).

A recent Lancet analysis of maternal health policy revealed that countries with a sustained 20-year decrease in maternal mortality had increased country-wide access to health care through targeted investment in midwifery services. [4] In countries like India, Mozambique, Uganda, and Nepal skilled birth attendants are scarce in all settings and the consequences are disastrous—“too little too late” [48]. In high resource countries that are experiencing the phenomena of “too much, too soon”, expanding availability of midwives across health systems also has important implications for quality, safety, and cost-effectiveness [43,48].

## Limitations and opportunities

While this analysis represents a significant step forward, it has some limitations. We are using aggregated state measures and hence potentially subject to the ecological fallacy of making inferences concerning individual behavior, based on group data [70]. However, our goal is to measure systems of care at the state level rather than the relationship between individual providers and specific neonatal outcomes. We cannot conclude that a more integrated system of midwifery directly causes improved outcomes. It may simply reflect a state culture of better interprofessional cooperation that affects patterns of practice. Variations in access to *any* maternity care at the local level may have more impact on outcomes, and data derived from Area Resource maps on provider availability may be more informative. Functional levels of integration may vary by the interpretation of statutes by providers or referral institutions at the local level.

Our analysis captured relationships as relevant to the regulatory environment in the US in 2014–2016. As regulatory and practice conditions change, MISS scores will also change, so ongoing revisions of the source database will be necessary. Our team plans to partner with NACPM, ACNM, and regulatory boards to tri-annually update the data-informed AIMM maps.

Our findings could inform site selection for a national prospective cohort study, such that studies of midwifery outcomes can be restricted to states with high MISS scores or can control for level of integration. Cohort studies that take into account the level of midwifery integration could inform state regulatory language that supports increasing access to high quality care across settings and jurisdictions.

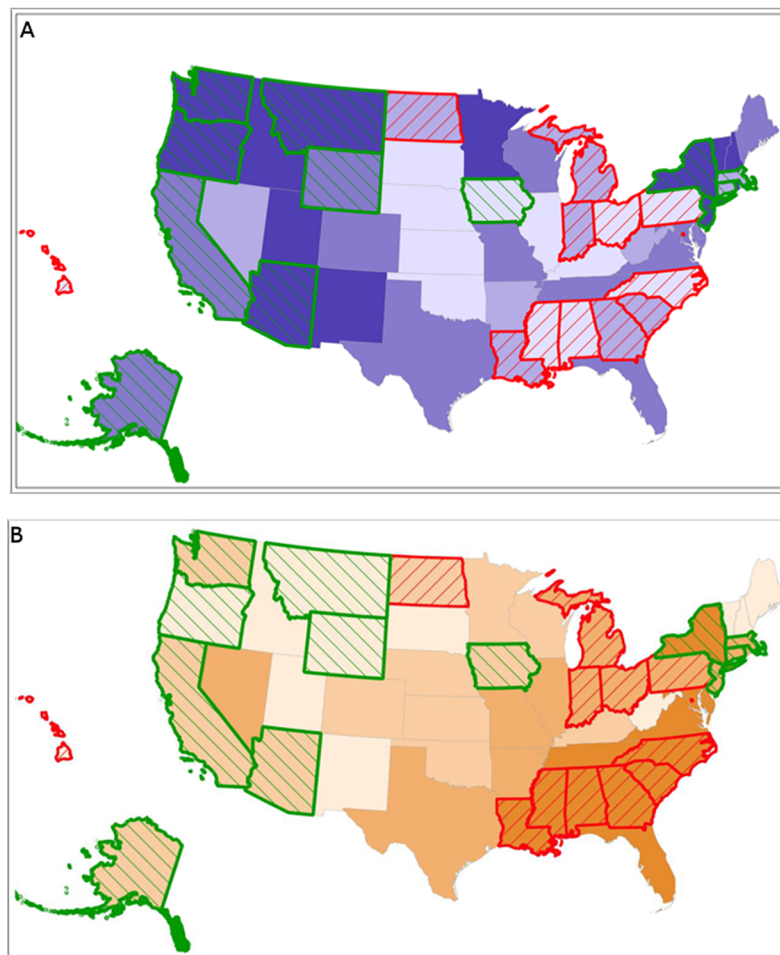
Finally, the MISS scoring system is based on evidence-based metrics that are relevant to midwifery regulation and practice globally. This composite scoring system could be adapted to country-level realities where items describe the domains according to the available maternity providers and regional conditions for practice, restrictions, and state of collaboration. It is likely that other high resource countries would achieve scores that represent a more fully integrated system, consistent with their reported improved outcomes.

The 2014 Lancet Series on Midwifery, in collaboration with the WHO, identified the top 11 research priorities needed to improve quality maternal and newborn care. [71] Global experts recognized that it is critical to ask “different questions” if we are to understand which outcomes are most important to track and which factors most contribute to those essential outcomes. To fully understand the relationships between health systems, model of care, access to care, and childbearing outcomes, more investigations on the impacts of the regulatory environment at the local, regional, and country level is needed.



### The AIMM Report Card

To make our findings more accessible to policy makers and consumers, Team 2 worked closely with a GIS specialist to create the AIMM “Report Card”, a visual representation of the data via a series of color-coded, interactive maps. The maps illustrate the range of midwifery integration across the United States by quartiles, as well as density and access to midwives in different settings. The AIMM Report Card displays how integration, access, and density of midwives link to outcomes by distinguishing states that are in the highest and lowest quartiles for indicators of optimal health according to global health agencies (e.g. WHO-recommended rates for cesarean). For example (see Fig 3A & 3B), on each map, upon selection of outcomes, green outlines appear for states that report the highest rates of spontaneous vaginal birth, vaginal birth after cesarean (VBAC), and breastfeeding. Red outlines appear for states in the highest quartile for rates of cesarean, induction, neonatal mortality, prematurity, and low birth weight infants.



**Fig 3. Base maps showing integration and percent of black births with neonatal mortality quartiles highlighted.** 3A: Levels of integration displayed by quartiles of MISS scores. Deeper shades of purple represent higher integration and lighter shades represent lower integration of midwives. Green outlines show where rates of neonatal mortality are lowest and red outlines show where rates are highest. 3B: Percent of black births per state by quartiles. Deeper shades of orange represent a higher proportion of black births and lighter shades represent a lower proportion of black births. Green outlines show where rates of neonatal mortality are lowest and red outlines show where rates are highest.

<https://doi.org/10.1371/journal.pone.0192523.g003>

The maps also show race-specific outcomes by MISS scores, and display outcomes by the proportion of Black women giving birth in each state. **Fig 3A** displays that, in most states where black women give birth, they do not have access to midwives who are well integrated into the system. These states also report the highest rates of neonatal mortality. New York State is a notable exception, reporting a high density of black births, among the lowest rates of neonatal mortality in the country, and a MISS score in the highest quartile.

Through the AIMM Report Card, the viewer can visualize how perinatal outcomes, interventions, and access to choice of birth place differ in states where midwives are well integrated, compared to states where disarticulations exist. Similarly, pop-up bar and pie graphs display state-level data for the proportion of women giving birth by settings, proportion of births attended by midwives that are covered by Medicaid, and state level rates of perinatal outcomes.

The data maps are available at <http://birthplacelab.org/maps>. State-specific report cards can be viewed at <http://www.birthplacelab.org/how-does-your-state-rank>.

These tools may be valuable to advocates, policy makers and other key stakeholders who seek to identify regions with reduced access to collaborative practice and options for maternity care.

## Conclusions

The Midwifery Integration Scoring System (MISS) is a powerful new tool to track the impact of the regulatory environment on patient access to health care, as well as choice of provider and birth place. The Access and Integration Maternity care (AIMM) Maps illustrate effective health human resource allocation in maternity care, based on population-level health outcomes data. Higher MISS Scores were associated with significantly more access to midwives, significantly higher rates of physiologic birth outcomes, lower rates of obstetric interventions, and fewer adverse neonatal outcomes. Race is associated with significant differences among states in neonatal outcomes; and the level of integration of midwives accounts for additional differences that persist after controlling for African American births. Our findings can inform health policy to improve regional access to high quality maternity care across populations and birth settings.

## Supporting information

**S1 Table. Midwifery Integration Scoring System (MISS) indicators.**  
(DOCX)

**S2 Table. Association between MISS scores and state-level, race-specific neonatal death rates.**  
(DOCX)

**S3 Table. Correlations between licensure, outcomes, and interventions.**  
(DOCX)

**S1 Fig. Scatter plot showing relationship between integration scores and neonatal death (2013).**  
(DOCX)

## Acknowledgments

We collaborated with many wise advisors over five years in this project including state and national experts on midwifery regulation and policy, including Ida Darragh, Cara Kinzelman,

Mary Lawlor; lawyers, Rebecca Spence and Tara Gaston who led the identification of relevant statutory data; and experts on perinatal epidemiology, interprofessional collaboration, maternity care workforce, health disparities, and person-centred outcomes research, especially Zsakeba Henderson, Lisa Kane Low, Nicholas Rubashkin, Caroline Homer, and Lesley Barclay. We could not have completed this work without the keen attention to detail, and hours of data management provided by Eleanor Rushton, Kari Bengston, and Nicole Zickler; research coordination by Barbara Karlen; and remarkable knowledge translation to accessible, interactive data maps by Alex Annejohn, Elizabeth Nethery, Jeanette McCullough, Ian Allison, and Lynsey Hamilton.

## Author Contributions

**Conceptualization:** Saraswathi Vedam, Marian MacDorman, Eugene Declercq, Melissa Cheyney, Timothy Fisher.

**Data curation:** Kathrin Stoll, Marian MacDorman, Emma Butt.

**Formal analysis:** Kathrin Stoll.

**Funding acquisition:** Saraswathi Vedam, Kathrin Stoll.

**Investigation:** Saraswathi Vedam, Kathrin Stoll, Marian MacDorman, Emma Butt.

**Methodology:** Saraswathi Vedam, Holly Powell Kennedy.

**Project administration:** Saraswathi Vedam.

**Resources:** Marian MacDorman, Renee Cramer, Melissa Cheyney, Timothy Fisher.

**Supervision:** Saraswathi Vedam, Marian MacDorman, Eugene Declercq, Holly Powell Kennedy.

**Validation:** Marian MacDorman, Eugene Declercq, Renee Cramer, Melissa Cheyney, Timothy Fisher, Emma Butt, Y. Tony Yang.

**Visualization:** Saraswathi Vedam, Kathrin Stoll.

**Writing – original draft:** Saraswathi Vedam, Kathrin Stoll.

**Writing – review & editing:** Saraswathi Vedam, Kathrin Stoll, Marian MacDorman, Eugene Declercq, Renee Cramer, Melissa Cheyney, Timothy Fisher, Emma Butt, Y. Tony Yang, Holly Powell Kennedy.

## References

1. Ten Hoop-Bender P, De Bernis L, Campbell J, Downe S, Fauveau V, Fogstad H, et al. Improvement of maternal and newborn health through midwifery. *Lancet*. 2014;
2. Renfrew MJ, McFadden A, Bastos MH, Campbell J, Channon AA, Cheung NF, et al. Midwifery and quality care: findings from a new evidence-informed framework for maternal and newborn care. *Lancet* [Internet]. 2014 [cited 2017 Apr 3]; 384(9948):1129–45. Available from: <http://www.sciencedirect.com/science/article/pii/S0140673614607893> [https://doi.org/10.1016/S0140-6736\(14\)60789-3](https://doi.org/10.1016/S0140-6736(14)60789-3) PMID: 24965816
3. Homer CSE, Friberg IK, Dias MAB, Ten Hoop-Bender P, Sandall J, Speciale AM, et al. The projected effect of scaling up midwifery. Vol. 384, *The Lancet*. 2014. p. 1146–57.
4. Van Lerberghe W, Matthews Z, Achadi E, Ancona C, Campbell J, Channon A, et al. Country experience with strengthening of health systems and deployment of midwives in countries with high maternal mortality. *Lancet*. 2014; 384(9949):1215–25. [https://doi.org/10.1016/S0140-6736\(14\)60919-3](https://doi.org/10.1016/S0140-6736(14)60919-3) PMID: 24965819
5. Goodman S. Piercing the veil: The marginalization of midwives in the United States. *Soc Sci Med*. 2007; 65(3):610–21. <https://doi.org/10.1016/j.socscimed.2007.03.052> PMID: 17475381

6. Walker D, Lannen B, Rossie D. Midwifery practice and education: Current challenges and opportunities. *Online J Issues Nurs*. 2014; 19(2):9.
7. Cheyney M, Olsen C, Bovbjerg M, Everson C, Darragh I, Potter B. Practitioner and Practice Characteristics of Certified Professional Midwives in the United States: Results of the 2011 North American Registry of Midwives Survey. *J Midwifery Women's Heal*. 2015; 60(5):534–45.
8. Phillippi JC. Women's perceptions of access to prenatal care in the United States: a literature review. *J Midwifery Womens Health* [Internet]. 2009; 54(3):219–25. Available from: <http://www.sciencedirect.com/science/article/pii/S152695230900004X> <https://doi.org/10.1016/j.jmwh.2009.01.002> PMID: 19410214
9. Castro Lopes S, Nove A, ten Hoop-Bender P, de Bernis L, Bokosi M, Moyo NT, et al. A descriptive analysis of midwifery education, regulation and association in 73 countries: the baseline for a post-2015 pathway. *Hum Resour Health* [Internet]. 2016; 14(1):1–12. Available from: <http://dx.doi.org/10.1186/s12960-016-0134-7>
10. Guise J, Segel S. Teamwork in obstetric critical care. *Best Pr Res Cl Ob*. 2008; 22(5):937–51.
11. Cornthwaite K, Edwards S, Siassakos D. Reducing risk in maternity by optimising teamwork and leadership: An evidence-based approach to save mothers and babies. *est Pract Res Clin Obstet Gynaecol*. 2013; 27(4):571–81.
12. Commission TJ. Preventing Maternal Death [Internet]. 2010. Available from: [http://www.jointcommission.org/assets/1/18/sea\\_44.pdf](http://www.jointcommission.org/assets/1/18/sea_44.pdf)
13. Roome S, Hartz D, Tracy S, Welsh AW. Why such differing stances? A review of position statements on home birth from professional colleges. Vol. 123, *BJOG: An International Journal of Obstetrics and Gynaecology*. 2016. p. 376–82.
14. Kotaska A. Informed consent and refusal in obstetrics: A practical ethical guide. *Birth* [Internet]. 2017; Available from: <https://dx.doi.org/10.1111/birt.12281>
15. Johantgen M, Fountain L, Zangaro G, Newhouse R, Stanik-Hutt J, White K. Comparison of labor and delivery care provided by certified nurse-midwives and physicians: A systematic review, 1990 to 2008. *Women's Heal Issues*. 2012;
16. Olsen O, Clausen JA. Planned hospital birth versus planned home birth. *Cochrane database Syst Rev* [Internet]. 2012; 9(9):CD000352. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4238062&tool=pmcentrez&rendertype=abstract>
17. Hollowell J, Puddicombe D, Rowe R, Linsell L, Hardy P, Stewart M, et al. The Birthplace national prospective cohort study: perinatal and maternal outcomes by planned place of birth Birthplace in England research programme. Final report part 4 on behalf of the Birthplace in England Collaborative Group. 2011;
18. Barclay L, Kornelsen J, Longman J, Robin S, Kruske S, Kildea S, et al. Reconceptualising risk: Perceptions of risk in rural and remote maternity service planning. *Midwifery*. 2016; 38:63–70. <https://doi.org/10.1016/j.midw.2016.04.007> PMID: 27162166
19. Coxon K, Homer C, Bisits A, Sandall J, Bick D. Reconceptualising risk in childbirth. Vol. 38, *Midwifery*. 2016. p. 1–5. <https://doi.org/10.1016/j.midw.2016.05.012> PMID: 27313002
20. Healy S, Humphreys E, Kennedy C. Midwives' and obstetricians' perceptions of risk and its impact on clinical practice and decision-making in labour: An integrative review. *Women and Birth*. 2016; 29(2):107–16. <https://doi.org/10.1016/j.wombi.2015.08.010> PMID: 26363668
21. Manojlovich M, Kerr M, Davies B, Squires J, Mallick R, Rodger GL. Achieving a climate for patient safety by focusing on relationships. *Int J Qual Heal Care*. 2014; 26(6):579–84.
22. Waldman R, Kennedy HP, Kendig S. Collaboration in Maternity Care: Possibilities and Challenges. Vol. 39, *Obstetrics and Gynecology Clinics of North America*. 2012. p. 435–44. <https://doi.org/10.1016/j.ogc.2012.05.011> PMID: 22963702
23. Cheyney M, Everson C, Burcher P. Homebirth transfers in the United States: narratives of risk, fear, and mutual accommodation. *Qual Health Res* [Internet]. 2014; 24(4):443–56. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24598774> <https://doi.org/10.1177/1049732314524028> PMID: 24598774
24. Janssen PA, Mitton C, Aghajanian J. Costs of planned home vs. Hospital birth in British Columbia attended by registered midwives and physicians. *PLoS One*. 2015;
25. Schroeder E, Petrou S, Patel N, Hollowell J, Puddicombe D, Redshaw M, et al. Cost effectiveness of alternative planned places of birth in woman at low risk of complications: evidence from the Birthplace in England national prospective cohort study. *BMJ*. 2012 Jan; 344:e2292. <https://doi.org/10.1136/bmj.e2292> PMID: 22517916

26. Yang YT, Attanasio LB, Kozhimannil KB. State Scope of Practice Laws, Nurse-Midwifery Workforce, and Childbirth Procedures and Outcomes. *Women's Heal Issues* [Internet]. 2016 May [cited 2017 Apr 2]; 26(3):262–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26965196>
27. Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. In: Sandall J, editor. *Cochrane Database of Systematic Reviews* [Internet]. Chichester, UK: John Wiley & Sons, Ltd; 2013 [cited 2017 Apr 2]. Available from: <http://doi.wiley.com/10.1002/14651858.CD004667.pub3>
28. McRae DN, Muhajarine N, Stoll K, Mayhew M, Vedam S, Mpofu D, et al. Is model of care associated with infant birth outcomes among vulnerable women? A scoping review of midwifery-led versus physician-led care. *SSM—Popul Heal*. 2016; 2:182–93.
29. American Public Health Association. Increasing access to out-of-hospital maternity care services through state-regulated and nationally-certified direct-entry midwives [Internet]. Vol. August, 20. Washington, D.C.: American Public Health Association; 2001. Available from: <http://www.apha.org/advocacy/policy/policysearch/default.htm?id=242>
30. Vedam S, Aaker J, Stoll K. Assessing Certified Nurse-Midwives' Attitudes Towards Planned Home Birth. *J Midwifery Women's Heal*. 2010; 55(2).
31. Cheyney M, Everson C, Burcher P. Homebirth transfers in the United States: Narratives of risk, fear, and mutual accommodation. *Qual Health Res*. 2014; 24(2):443–56.
32. Romijn A, de Bruijne MC, Teunissen PW, de Groot CJM, Wagner C. Complex social intervention for multidisciplinary teams to improve patient referrals in obstetrical care: protocol for a stepped wedge study design. *BMJ Open* [Internet]. 2016 Jul 14 [cited 2017 May 10]; 6(7):e011443. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27417199> <https://doi.org/10.1136/bmjopen-2016-011443> PMID: 27417199
33. Elder TE, Goddeeris JH, Haider SJ. Racial and ethnic infant mortality gaps and the role of socio-economic status. *Labour Econ*. 2016; 43. <https://doi.org/10.1016/j.labeco.2016.04.001> PMID: 27695196
34. MacDorman MF. Race and Ethnic Disparities in Fetal Mortality, Preterm Birth, and Infant Mortality in the United States: An Overview. *Semin Perinatol* [Internet]. 2011 Aug [cited 2017 Apr 3]; 35(4):200–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21798400> <https://doi.org/10.1053/j.semperi.2011.02.017> PMID: 21798400
35. Dimes M of. Racial and Ethnic Disparities in Birth Outcomes [Internet]. [cited 2017 Apr 3]. Available from: [http://www.marchofdimes.org/materials/March-of-Dimes-Racial-and-Ethnic-Disparities\\_feb-27-2015.pdf](http://www.marchofdimes.org/materials/March-of-Dimes-Racial-and-Ethnic-Disparities_feb-27-2015.pdf)
36. California Maternal Quality Care Collaborative. Racial Disparities [Internet]. [cited 2017 Apr 3]. Available from: <https://www.cmqcc.org/focus-areas/maternal-mortality/racial-disparities>
37. Rosenthal L, Lobel M. Explaining racial disparities in adverse birth outcomes: Unique sources of stress for Black American women. *Soc Sci Med*. 2011; 72(6):977–83. <https://doi.org/10.1016/j.socscimed.2011.01.013> PMID: 21345565
38. Bailey ZD, Krieger N, Ag nor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *Lancet* [Internet]. 2017 [cited 2017 Apr 15]; 389(10077):1453–63. Available from: <http://www.sciencedirect.com.ezproxy.library.ubc.ca/science/article/pii/S014067361730569X> [https://doi.org/10.1016/S0140-6736\(17\)30569-X](https://doi.org/10.1016/S0140-6736(17)30569-X) PMID: 28402827
39. Diers D. Finding Midwifery in Administrative Data Systems. *J Midwifery Women's Heal*. 2007; 52(2):98–105.
40. Martin JA, Hamilton BE, Osterman MJ, Driscoll AK, Mathews TJ. National Vital Statistics Reports, Volume 66, Number 1, January 5, 2017. 2015 [cited 2017 May 10];66(1). Available from: [https://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66\\_01.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66_01.pdf) PMID: 28135188
41. MacDorman MF, Declercq E. Trends and Characteristics of United States Out-of-Hospital Births 2004–2014: New Information on Risk Status and Access to Care. *Birth* [Internet]. 2016 Jun [cited 2017 Apr 15]; 43(2):116–24. Available from: <http://doi.wiley.com/10.1111/birt.12228> <https://doi.org/10.1111/birt.12228> PMID: 26991514
42. Declercq ER, Paine LL, Simmes DR, DeJoseph JF. State regulation, payment policies, and nurse-midwife services. *Health Aff*. 1998;
43. Shaw D, Guise J, Shah N, Others L, Others M, Others A, et al. Drivers of maternity care in high income countries: can health systems support woman-centred care? *Lancet* [Internet]. 2016; 388(10057):2282–95. Available from: [https://doi.org/10.1016/S0140-6736\(16\)31527-6](https://doi.org/10.1016/S0140-6736(16)31527-6) PMID: 27642026
44. MacDorman MF, Declercq E, Thoma ME. Trends in Maternal Mortality by Sociodemographic Characteristics and Cause of Death in 27 States and the District of Columbia. *Obstet Gynecol* [Internet]. 2017 Apr [cited 2017 Apr 15];1. Available from: <http://insights.ovid.com/crossref?an=00006250-900000000-98440>

45. Engels TCE, Powell Kennedy H. Enhancing a Delphi study on family-focused prevention. *Technol Forecast Soc Change*. 2007; 74(4):433–51.
46. Kennedy HP, Cheyney M, Lawlor M, Myers S, Schuiling K, Tanner T, et al. The Development of a Consensus Statement on Normal Physiologic Birth: A Modified Delphi Study. *J Midwifery Womens Health* [Internet]. 2015 Mar [cited 2017 Apr 16]; 60(2):140–5. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25782847> <https://doi.org/10.1111/jmwh.12254> PMID: 25782847
47. Burris S, Ashe M, Levin D, Penn M, Larkin M. A Transdisciplinary Approach to Public Health Law: The Emerging Practice of Legal Epidemiology. *Annu Rev Public Health* [Internet]. 2016 Mar 18 [cited 2017 May 10]; 37(1):135–48. Available from: <http://www.annualreviews.org/doi/10.1146/annurev-publhealth-032315-021841>
48. Miller S, Abalos E, Chamillard M, Ciapponi A, Colaci D, Comand D, et al. Beyond too little, too late and too much, too soon: a pathway towards evidence-based, respectful maternity care worldwide. Vol. 388, *The Lancet*. 2016. p. 2176–92.
49. Mathews TJ, Maccormack MF, Thoma ME. National Vital Statistics Reports Infant Mortality Statistics From the 2013 Period Linked Birth / Infant Death Data Set. *Natl Vital Stat Reports*. 2015; 64(9):2000–13.
50. Ward TCS, Mazul M, Ngui EM, Bridgewater FD, Harley AE. “You learn to go last”: Perceptions of prenatal care experiences among African-American women with limited incomes. *Matern Child Health J*. 2013;
51. Giurgescu C, McFarlin BL, Lomax J, Craddock C, Albrecht A. Racial discrimination and the Black-White Gap in adverse birth outcomes: A review. *Journal of Midwifery and Women’s Health*. 2011.
52. Giscombé CL, Lobel M. Explaining disproportionately high rates of adverse birth outcomes among African Americans: the impact of stress, racism, and related factors in pregnancy. *Psychol Bull*. 2005; 131(5):662–83. <https://doi.org/10.1037/0033-2909.131.5.662> PMID: 16187853
53. Rossen LM, Khan D, Schoendorf KC. Mapping Geographic Variation in Infant Mortality and Related Black–White Disparities in the US. *Epidemiology* [Internet]. 2016 Sep [cited 2017 Apr 2]; 27(5):690–6. Available from: <http://insights.ovid.com/crossref?an=00001648-201609000-00014> <https://doi.org/10.1097/EDE.0000000000000509> PMID: 27196804
54. McRae DN, Muhajarine N, Vedam S, Mayhew M, Mpofo D, Teucher U, Janssen PA. Saskatoon S. Antenatal Midwifery Care: Reducing Prevalence of Small-for-Gestational-Age Birth and Preterm Birth for Women of Low Socioeconomic Position. *Dep Community Heal Epidemiol Student Resid Res Day, Univ Saskatchewan, Saskatoon*. 2017;Feb 10.
55. Huesch M, Doctor JN. Factors Associated With Increased Cesarean Risk Among African American Women: Evidence From California, 2010. [cited 2017 May 10]; Available from: <http://search.proquest.com.ezproxy.library.ubc.ca/docview/1674426508/fulltextPDF/C46302C7A02C40BEPQ/1?accountid=14656>
56. Bartick MC, Jegier BJ, Green BD, Schwarz EB, Reinhold AG, Stuebe AM. Disparities in Breastfeeding: Impact on Maternal and Child Health Outcomes and Costs. *J Pediatr* [Internet]. 2017 [cited 2017 May 10]; 181:49–55.e6. Available from: <http://www.sciencedirect.com.ezproxy.library.ubc.ca/science/article/pii/S0022347616310964> <https://doi.org/10.1016/j.jpeds.2016.10.028> PMID: 27837954
57. Vries RG De, Paruchuri Y, Lorenz K, De Vries RG, Paruchuri Y, Lorenz K, et al. Moral Science: Ethical Argument and the Production of Knowledge about Place of Birth. *J Clin Ethics*. 2013; 24(3):225–38. PMID: 24282850
58. Cheyney M, Burcher P, Vedam S. A crusade against home birth. *Birth issues Perinat care*. 2014; 41(1):1–4.
59. Vedam S. In search of a common agenda for planned home birth in the United States. *J Perinat Educ*. 2012; 21(2):67–71. <https://doi.org/10.1891/1058-1243.21.2.67> PMID: 23449994
60. Vedam S, Stoll K, Schummers L, Fairbrother N, Klein MC, Thordarson D, et al. The Canadian birth place study: examining maternity care provider attitudes and interprofessional conflict around planned home birth. *BMC Pregnancy Childbirth* [Internet]. 2014 Jan 28 [cited 2016 Jan 5]; 14(1):353. Available from: <http://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-14-353>
61. Vedam S, Leeman L, Cheyney M, Fisher TJ, Myers S, Low LK, et al. Transfer from planned home birth to hospital: Improving interprofessional collaboration. *J Midwifery Women’s Heal*. 2014; epub ahead (6):624–34.
62. Kozhimannil KB, Casey MM, Hung P, Prasad S, Moscovice IS. Location of childbirth for rural women: Implications for maternal levels of care. *Am J Obstet Gynecol*. 2016; 214(5):661.e6–61.e10.
63. Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. *Cochrane database Syst Rev* [Internet]. 2015 Sep; 9:CD004667. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26370160>

64. Phillippi JC, Avery MD. The 2012 American college of nurse-midwives core competencies for basic midwifery practice: History and revision. *J Midwifery Women's Heal*. 2014; 59(1):82–90.
65. European Court of Human Rights Strasbourg. Dubska and Krejzova v the Czech Republic [Internet]. 2014. Available from: <http://hudoc.echr.coe.int/eng/?i=001-148632#%7B%22itemid%22:%5B%22001-148632%22%7D>
66. Randive B, Diwan V, De Costa A. India's Conditional Cash Transfer Programme (the JSY) to Promote Institutional Birth: Is There an Association between Institutional Birth Proportion and Maternal Mortality? *PLoS One*. 2013; 8(6).
67. Shaw D, Guise JM, Shah N, Gemzell-Danielsson K, Joseph KS, Levy B, et al. Drivers of maternity care in high-income countries: can health systems support woman-centred care? *The Lancet*. 2016.
68. International Confederation of Midwives. Global Standards for Midwifery Regulation. Regulation. 2011. p. 1–24.
69. Kennedy H.P., Myers-Ciecko J.A., Carr K.C., Breedlove G., Bailey T., Farrell M., Lawlor M., Daniels E., Darragh I. United States model midwifery legislation & regulation: a Delphi study. *J Midwifery Women's Heal*.
70. Subramanian S V., Jones K, Kaddour A, Krieger N. Revisiting Robinson: The perils of individualistic and ecologic fallacy. *Int J Epidemiol*. 2009; 38(2):342–60. <https://doi.org/10.1093/ije/dyn359> PMID: 19179348
71. Kennedy HP, Yoshida S, Costello A, Declercq E, Dias MA, Duff E, et al. Asking different questions: research priorities to improve the quality of care for every woman, every child. Vol. 4, *The Lancet Global Health*. 2016. p. e777–9. [https://doi.org/10.1016/S2214-109X\(16\)30183-8](https://doi.org/10.1016/S2214-109X(16)30183-8) PMID: 27663682

### 6.3 Mapping Equity in Maternity Care

Since Home Birth Summit III, the reality that women of color in the US experience more adverse perinatal outcomes and higher rates of interventions compared to Caucasian women (MacDorman 2011; Alhusen et al. 2016; Yee et al. 2017; Washington et al. 2012; Jou et al. 2015; Bryant et al. 2010) became increasingly apparent. The prevalence of adverse outcomes among marginalized populations vary state by state and may reflect a lack of access to a coordinated system of care across birth settings and maternity care providers.

The Access and Integration Maternity Care Mapping study resulted in an evidence-based MISS scoring system to rate regulatory conditions by state and availability of midwives across birth settings. To illustrate regional disparities and make the results immediately available to the consumer delegates, we reported results via a set of interactive data maps. These maps visually highlighted sharply disparate outcomes by region, and illustrated lack of access to an integrated health system in states with the highest rates of births to Black Americans.

In 2018, our transdisciplinary team linked MISS scores to rates of physiologic birth by state, and person-centered data from the Giving Voice to Mothers study that assessed quality of maternity care as experienced by women of color (Vedam et al., 2018). We compared states using bivariate and regression analysis with the Mothers Autonomy in Decision Making (MADM) scale, the Mothers on Respect index (MORi), and an adapted Perceptions of Racism (PR) scale as outcome measures. Of the total sample (N3275), 37.3% were women of colour (Black, Hispanic, Native, other). In states with low integration scores, women of colour had significantly lower MADM scores and 20.5% were not satisfied with their role in decision-making. Women with low MORi scores reported increased pressure by health professionals to accept interventions. Women who experienced midwifery care reported lower interventions and greater sense of autonomy in decision-making; but experiences of discrimination and disrespect were significantly increased among women of colour regardless of type of provider or birth setting.



## 6.4 Conclusions and Implications

Chapter 6 described a multi-faceted research and knowledge translation project that required several transdisciplinary teams of legal, research, clinician, and consumer experts to understand the deficits in person-centred care by state systems for maternal health care. In the process, we confirmed that communities of colors in the US experience less respectful maternity care, and reduced access to options for physiologic birth care. Data suggest that both type of provider and place of birth significantly modulate outcomes and access, and institutional racism is a contributing factor. These findings and the expanded public discourse about person-centred care and inequity in experiences of high quality care, including respect, lay the groundwork for the agenda for Summit IV, held in 2019. By this time the committed delegate list and Task Force membership included some who had participated in all 3 previous Summits, and some who had endorsed the Common Ground Agenda at Summit III in 2014. Many of them had developed trusting relationships, and had used their authority, information, expertise, networks or resources to recruit new partners.

In Chapter 7, I will elucidate how and why transdisciplinarity, participatory methods, and a person-centered approach to problem solving, dismantled conflict and “tamed” the wicked problem of access to quality maternity care across birth place, but, along the way, also began a new transdisciplinary process to address the even more complex, wicked problem of inequity in maternal newborn care.

## CHAPTER 7: Discussion

*Reasonable degrees of conflict can lead to the generation of ideas as well as foster team cohesion. It can “lead to a sharpening of critical issues” and catalyze important changes that benefit the organization (Haraway 2005).*

### 7.1 Introduction

The goal of this doctoral thesis was to explore if transdisciplinary engagement can improve access, equity, and quality in maternity care. In Chapter 7, I will analyze how and why an innovative model of conflict transformation used over a series of national Home Birth Summits successfully reduced interprofessional disarticulation in a highly contentious area of health services – place of birth.

Johan Vincent Galtung, Norwegian sociologist and mathematician, was founder of the academic discipline of peace and conflict studies. In his landmark publication for the United Nations Disaster Management Training Programme he notes that “conflicts are generally not solved, resolved, or dissolved. Parties, goals, and incompatibilities are usually still there ..... however, through conflict transformation the conflict as it was.....and a sense of being blocked/stuck, recedes into the background.” What remains is the capacity to handle conflict, autonomously, non-violently, and creatively, with everyone’s participation. (Galtung, 2010, p. 31:2)

Conflict resolution implies that the problem is solved, and conflict management seeks to contain conflict, but conflict transformation is a process of addressing underlying sources of conflict (attitudes, behaviours, and problems), seeking mutual interests, continual evolution of relationships, and reshaping discourses to move away from harmful conflict (Galtung, 2010). The conflict transformation processes that help explain the ongoing impact of the Home Birth Summits were based on a transdisciplinary methodology (Nicolescu, 2014) and reframed the issues within a ‘Taming Wicked Problems Framework’ (Burman, Aphane, and Mollel 2017). By describing the trajectory and processes of these Summits and action initiatives undertaken,

within this framework, I will illustrate how the transdisciplinary methodology led to successful multi-stakeholder engagement, and ongoing imaginative, pragmatic, and community-responsive outputs.

## **7.2 The Trajectory of Transdisciplinary Imagination**

My long-engaged experience of maternity care and interprofessional conflict led to my proposing the first Home Birth Summit. In Chapter 3, I presented global evidence from multiple sectors that establishes that it was not enough for collaboration to occur within and across the silos of clinicians, health institutions, and health policy makers, without the intentional and ongoing engagement and co-creation of solutions with women and families.

Several researchers (Healy, Humphreys, and Kennedy 2016; Hunter et al. 2008; Hall, Tomkinson, and Klein 2012; McLemore et al. 2018) have examined patient-provider dynamics and power relationships when perinatal care decision making occurs within the context of an interprofessional, collaborative clinical care model. In pregnancy and childbearing care, concepts of safety, risk, and appropriate use of interventions differ across types of providers, and also between women, maternity care providers, and hospital staff, further complicating conversations when transfer to an institution occurs. When disarticulation between race or culture occurs, a woman may feel that she would have been “safer” if she had stayed home (Dahlen, Jackson, and Stevens 2011; McLemore et al. 2018; Symon et al. 2010).

Clinicians report the complexity of respecting a woman’s choice when her desires are in conflict with evidence-based maternity care (Records & Wilson, 2011). However, patient safety and quality literature consistently address the impact of provider–patient relationships, and communication among all stakeholders, on health outcomes. Women value the opportunity to be full participants in care planning via a shared decision making process when applying the best available evidence (Nieuwenhuijze and Kane Low 2013). While all profess to have the goal of quality care and valuing patient choice and autonomy, the realities of the different philosophies of care and practice between midwives and physicians impede the actualization of person-centred care (Hall, Tomkinson, and Klein 2012; Healy, Humphreys, and Kennedy 2016;

Daemers et al. 2017). This is especially true when place of birth or conceptions of risk are involved (Barclay et al., 2016; Cheyney, Everson, & Burcher, 2014; Downe, Finlayson, Tuncalp, & Gulmezoglu, 2016; Downe, Finlayson, & Fleming, 2010; Downe, Walsh, & Gyte, 2008). For the most part, midwives acquiesce, some accept conflict, and a few act independently to support patient autonomy or their own personal philosophies (Daemers et al. 2017; Hall, Tomkinson, and Klein 2012). Consequently, if interprofessional conflict persists, the people that these maternity professionals collaborate to serve feel confused, abandoned, betrayed, or threatened. On the other hand, if an integrated system with positive relationships exist across midwives and doctors, the women report feeling relieved, elated, empowered and undisturbed in the course of pregnancy and childbearing (Nieuwenhuijze et al. 2014).

#### 7.2.1 Taming the Wicked Problem of Home Birth

At the Home Birth Summits, we addressed a complex, wicked problem, that before meeting was “difficult to define”, had no definitive solution, and had resisted previous attempts for resolution by various stakeholders working within their silos (Brown, Harris, and Russel 2010; Sharts-Hopko 2013; Burman 2018). As the mind-map displayed in Chapter 4, the problem was not only non-linear, but the components were reflexive and often reinforced each other (Bradbury & Vehrencamp, 2014; Brown et al., 2010). Previous attempts to address the problem through exclusion (licensure, reimbursement, hospital privileges), or collaborating within service silos (hospital based CNMs vs home based CPMs) left many service users without access, safety, or quality. The problems persisted because the solutions remained in the purview of service providers, health administrators, and policy makers as experts with differing priorities and realities. This state of affairs can be understood through Nicolescu’s description of transdisciplinary knowledge (epistemology). The Object of concern was a narrow, allopathic definition of safety, and the Subject, the service user, was only useful as the recipient of care solutions (Nicolescu 2014). Each of nine stakeholder groups had their own line of thought, or “reality” and their own agendas.

By engaging in an intentional transdisciplinary process all stakeholder groups were exposed to other ways of thinking and were able to both discover “common ground” and discover that “Third Reality” (Nicolescu, 2014 ) when they explored the interconnections between their worldviews. The mutual appreciation for each other’s perspectives emerged from devices like the mindmap or skits that visioned a perfectly integrated future system, and facilitated the understanding of the relationships that existed among and between the components of the whole system (Nicolescu, 2014). They then were able to begin to emerge from the complex problem by identifying common themes and applying the Third Reality to discrete activities, in stepwise fashion from most pressing and achievable, to increasingly complex, involving more stakeholders, and more sustained engagement across sectors and communities.

The Common Ground Statements, organized by themes, served as what Burman (2018) terms in the Taming Wicked Problems Framework, the “Agree - End Condition” which led to logical action spaces. Responding to a shared priority and recognition of a key source conflict: transfer from home to hospital, the initiatives began with clinician leaders from different disciplines collaborating with lawyers, liability specialists, consumers and consumer advocates to develop the Best Practice Guidelines for Transfer from Home to Hospital (see Appendix B). This first collaboration was so successful that the group went on to develop implementation tools and eventually approached the more complex task of addressing antepartum collaboration in the community. This success feedback loop informed the work of other Task Forces, and each subsequent activity engaged new and ever widening circle of transdisciplinary stakeholders. They envisioned and collaborated on still more complex multi-year projects like the national Access and Integration Maternity care Mapping (AIMM) Study and the national, participatory Giving Voice to Mothers study of experience of care among communities of color and those who chose home birth.

### 7.2.2 The Hidden Third Reality – Person-Centred Care

As Nicolescu, Kania, Kramer, Campbell and Cornish (Nicolescu 2014; Kania and Kramer 2011; Campbell et al. 2013; Campbell and Cornish 2010) all explain, involvement of an equal number of community members was key to the discovery of a Third Reality. Without their presence and participation, the stakeholders could have remained entrenched in their separate but parallel realities. However, because they were authentically and respectfully engaged, and adequate space and time was allotted to trust building, community members (childbearing women and families) participated in the process of co-creating a common ground agenda. Nicolescu describes why this was so important to the discovery of a new Reality. He explains that traditional approaches to science and evidence creation only consider Objective realities, without considering the perspective or inherent knowledge that the Subject holds.

“ The transdisciplinary notion of levels of Reality leads also to a new vision of Personhood, based on the inclusion of the Hidden Third. The unification of the Subject is performed by the action of the Hidden Third, which transforms knowledge into *understanding*. Understanding” means fusion of knowledge and being. In the transdisciplinary approach, the Hidden Third appears as the source of knowledge but, in its turn, needs the Subject in order to know the world: the Subject, the Object, and the Hidden Third are interrelated. The human person appears as an interface between the Hidden Third and the world. The erasing of the Hidden Third in knowledge signifies a one-dimensional human being, reduced to its cells, neurons, quarks and elementary particles.” (Nicolescu 2014, 196)

However, transdisciplinarity is concerned with the Subject-Object interaction. (Nicolescu 2014). Hence, by engaging in ongoing transdisciplinary process, where community voices, or the subjects, were heard, the Hidden Third Reality that emerged organically was the person-centred approach to problem solving in each theme. I contend that this component both underpins the Common Ground Agenda that delegates created, and informs each of the ensuing action initiatives. In fact, the various stakeholders elevated the Third Reality to be the guiding principle

for action initiatives -- keeping the service user's perspective, priorities, and experience of care as the deciding factors when our various disciplines disagreed or had divergent philosophies as we moved forward to actioning the agenda. Every ensuing activity - research, quality assessment, or implementation - has used the *person-centred lens* to guide the work. The MISS Scoring system weighted the regulatory condition according to its level of impact on access to care for the pregnant woman. The Best Practice Transfer and Collaboration guidelines enshrined patient preference, rights to choice, and patient debriefs as core components. The Dialogue and Decisions course teaches the steps to person-centred decision making and course activities are illustrated through simulation cases; and the participatory studies have both developed and embedded patient-designed and person-centred measures of autonomy, respect and mistreatment.

At the same time, our transdisciplinary process has preserved and enlisted discipline specific talents or expertise while actioning the Common Ground Agenda. For example, it has been possible to elevate the discourse on scaling up midwifery services and philosophy of care within the context of person-centred care and increasing access. We also capitalized on existing functional systems in medical and institutional systems for quality monitoring, interprofessional communication, and development of health professional curricula.

Figures 3 and 6 illustrate the relationship between the Taming Wicked Problems Framework, transdisciplinarity, the Hidden Third Reality, and Home Birth Summit I. The *End-Condition* was the Common Ground; the *primary probe*, or *Hidden Third Reality*, person-centred care; and the *discursive spaces* were the transdisciplinary Task Forces. Each *action space* is identified by the name/focus of each Task Force, and each Task Force is identified with a unique colour. The Task Forces that conceived or carried out the initiatives or "*existing or emerging themes*" are identified by colour. When more than one Task Force collaborated to complete the work, the theme is shaded with all relevant colours.

Initially the Research, Regulation and Licensure, and Collaboration Task Forces were able to identify concrete goals and actions responding to the issues that required only the modest trust that had been established to agree to meet and continue their discourse. Hence in Figure 6,

illustrating Summit 1 outcomes, they appear closest to the action themes. Notably several members of the Consumer Engagement group joined the Regulation and Licensure group to inform a 50 state database on regulatory conditions affecting access to midwifery care. Other Task Forces met and created various strategic agendas and identified small scale projects or projects (like interprofessional course development) that required funding and broad external stakeholder engagement, but they did not have concrete output until after Summit II.



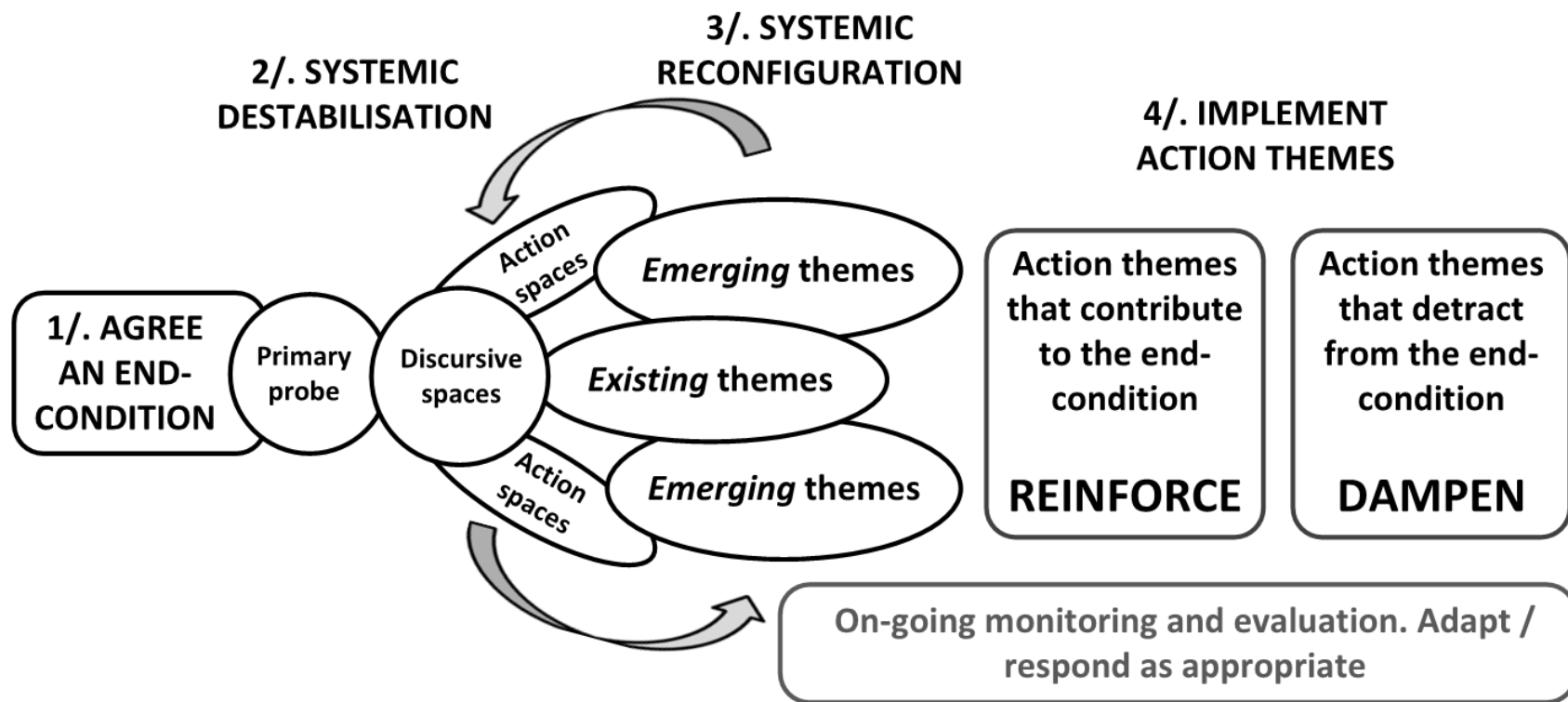
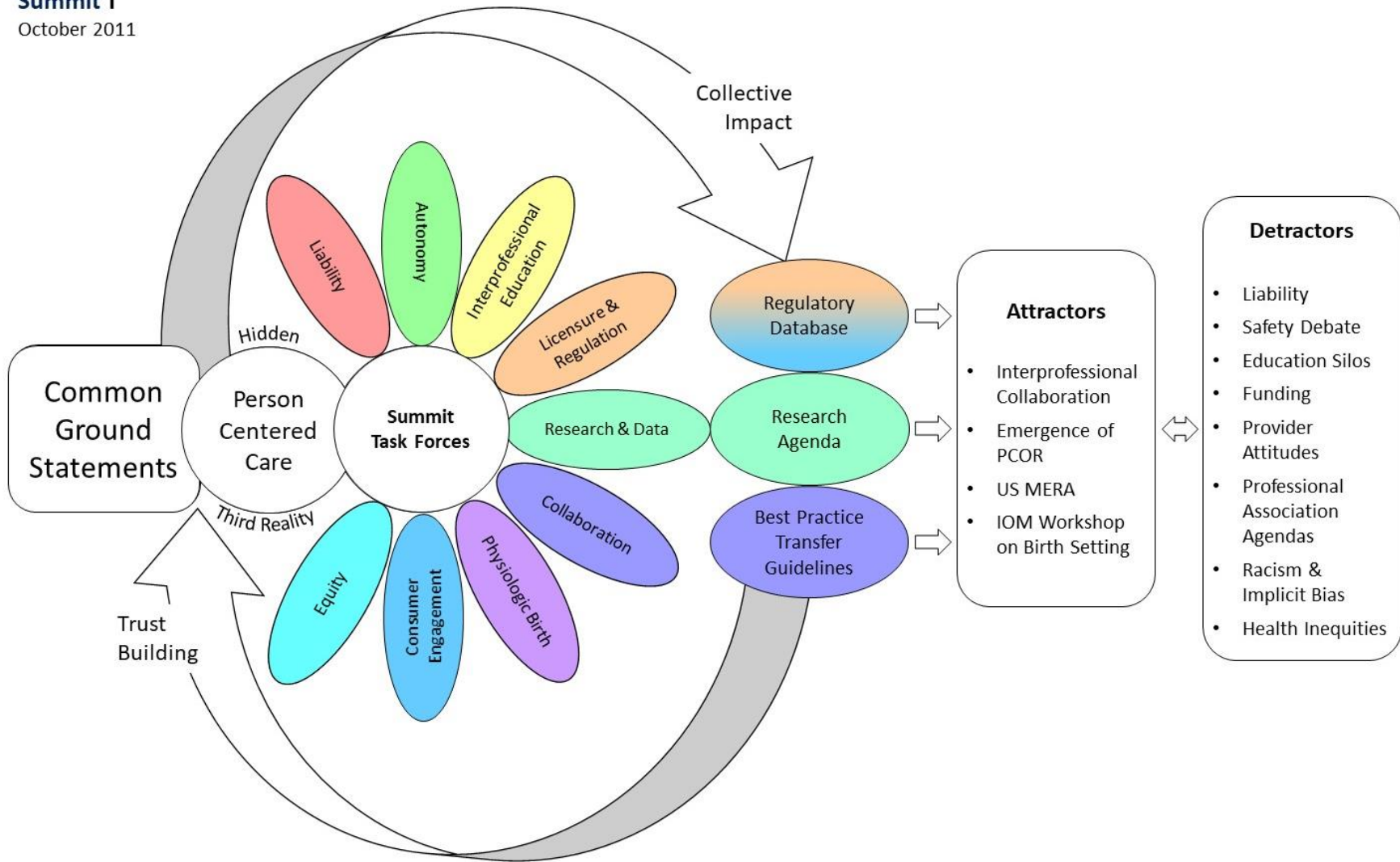


Fig. 3 Taming Wicked Problems

**Summit I**  
October 2011



**Legend:** Each Summit Task Force is represented by a single colour .  
The Action Themes are colour-coded to display the Task Forces that participated in each activity.

Vedam & Miller-Vedam 2019

Fig. 6 Home Birth Summit I

Of course, there was still tension because of traditional power structures where medical knowledge is elevated above the lived experience. I think this relates to Nicolescu's treatise on the tensions inherent in reversing the trend of the "subject" being turned into an "object". However, it not necessary to have or expect all stakeholders to embrace identical levels of understanding of the Third Reality. It is only important to remain in dialogue, and remain curious to keep the momentum towards ongoing reflexive practice and transformation. In fact, even as we co-created the Common Ground Agenda some of the stakeholders rushed to produce a Context and Scope document:

"In creating these statements relating to maternity care and birth place in the United States, we acknowledge the complexity inherent in each topic of concern, as well as some disagreement about how to best achieve or demonstrate these principles. While all agreed that there is great value and need for further work in these areas, action plans that flow from these principles may be carried out by individuals or in newly formed, multi-stakeholder **Task Forces** according to their own, or shared, values and priorities.

Summary statements such as these can be interpreted differently by different readers. Therefore, although there was both unanimity and consensus about the topics addressed, there was not necessarily unanimity as to all of the specific words chosen to create the statements. For example, words such as "autonomy", "independence", and "collaboration" may have different implications for practitioners, policy makers, and consumers. In addition to clinicians, consumers, health professional educators, insurers, lawyers, ethicists, administrators, and policy makers, the participants included researchers with expertise in epidemiology, public health, sociology, medical anthropology, legal, health policy and clinical research.

However, the goal of this summit was not to examine, debate, or form a consensus statement regarding the evidence published regarding safety or maternal-newborn outcomes of planned home birth. Rather, the goal was to discover areas of common ground among these diverse stakeholders, when considering the future of home birth in the United States. By addressing our shared responsibility, we were able to identify

several important and relevant topics that may benefit from ongoing multidisciplinary engagement. Hence, these **Common Ground Principles** are intended to provide a foundation for continued dialogue and collaboration across sectors, as we work together towards a common goal of improving maternal and newborn care for families choosing home birth.” (published by delegates on website, [Home Birth Summit](#)).

### 7.2.3 Summit II: Expanding the circle and defining the scope of the problems in each domain

During the second Summit in 2013, the original delegates met to review their progress on the *Common Ground Agenda*, as well as the outcomes of the Institute of Medicine (IOM) Symposium on Birth Setting (notably, the IOM had invited many of our delegates to serve on their expert panel). At Summit II, new leaders with particular expertise in each of the nine priority areas (patient autonomy, consumer engagement, interprofessional collaboration, regulation & licensure, interprofessional education, liability, physiologic birth, research, and health equity) were invited to join the delegate Task Forces. Each multi-disciplinary Task Force reported on their action agendas and had time to meet face-to-face to workshop their ideas. The delegates considered previous discussions around issues of heightened controversy and concern including equity, ethics, and evidence.

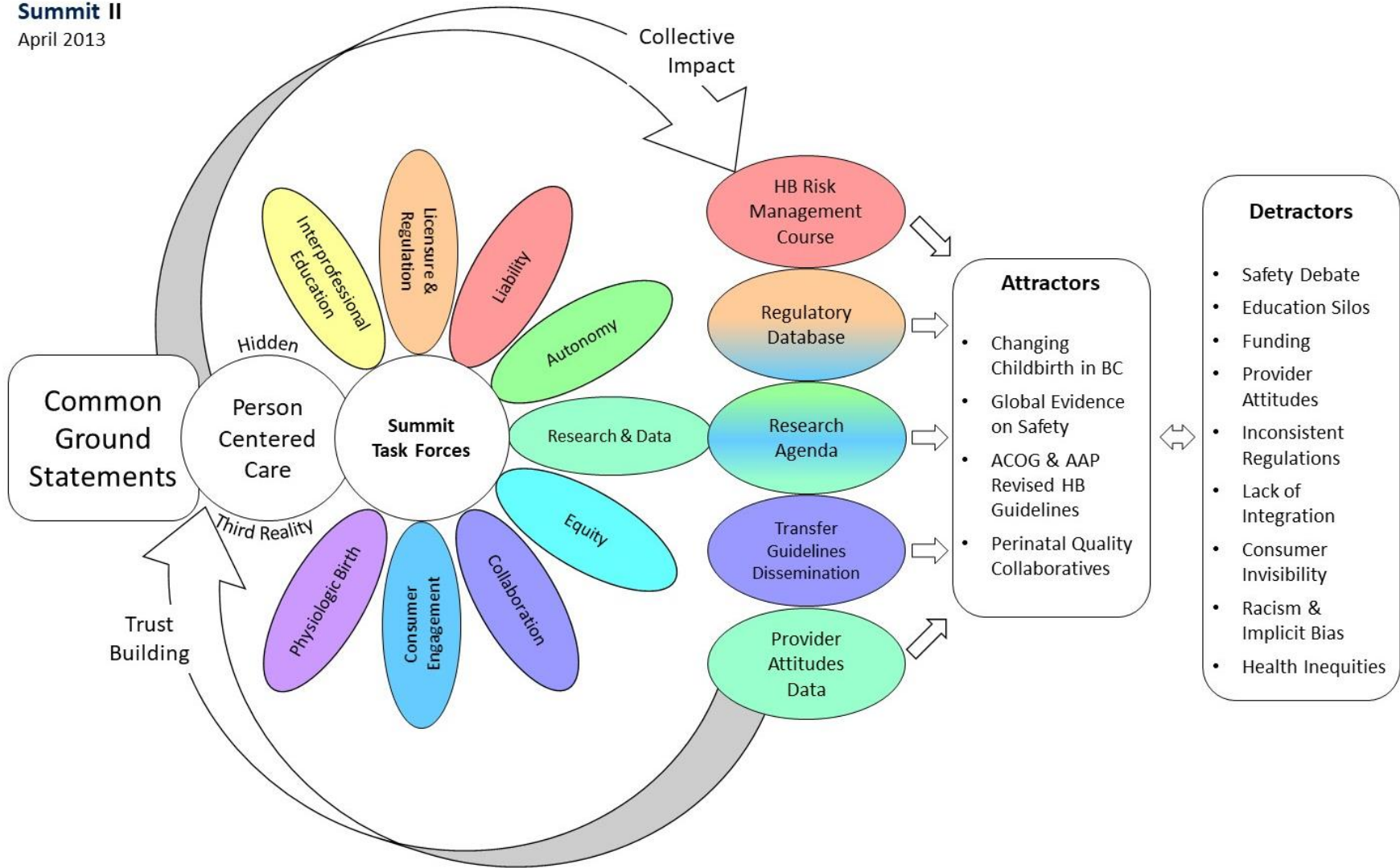
Soon after Summit I, the USAID Maternal Child Health Integrated Program (Reis, 2012) issued a comprehensive report on the state of “respectful maternity care” (RMC) across low and high resource countries. The authors concluded that “safe motherhood must be expanded beyond the prevention of morbidity or mortality to encompass respect for women’s basic human rights, including respect for women’s autonomy, dignity, feelings, choices, and preferences.” (p.v) The study identified key areas of disrespect and abuse in each country, and described the major challenges to improving conditions for women in North America as, “limited political will, institutional commitments, and plans to implement RMC”, “lack of accountability of doctors and their dominance over maternity care”, and “lack of specific training related to RMC for nurses, ob-gyns, anesthetists, and pediatricians.” (USAID 2012, 16-18).

During Summit II, it became clear that the Equity Task Force could not action their agenda without the commitment to RMC and equitable access from all of the disciplines making up the Task Forces. There was a moment of heightened tension when those remaining on the Equity Task Force challenged delegates in other Task Forces to attend to issues of inequity and race based disparities in access and outcomes. Delegates engaged in deep discussions and committed to hold the most disenfranchised and marginalized at the center of their work plans. They also decided that all future Summit agendas should be placed within an equity framework.

In addition, in the interim between Summits I and II, the context for intraprofessional and interprofessional collaboration was changing. The US Midwifery Education and Regulation Alliance (USMERA) formed and began working on model legislation and core common standards for midwifery education (Kennedy et al., 2018a). ACOG, AAP, ACNM, and NACPM had established new formal commitments to intraprofessional and interprofessional collaboration.

Figure 7 illustrates the expansion of the emerging themes and action initiatives after Summit II, within the Taming Wicked Problems Framework. The emerging global focus on person-centered care, and the human rights related to pregnancy and childbirth gave delegates renewed energy and commitment to pursuing the Common Ground Agenda. As we worked toward Summit III, we began to focus on more complex initiatives related to equity, autonomy, and reducing provider anxiety.

**Summit II**  
April 2013



**Legend:** Each Summit Task Force is represented by a single colour .  
The Action Themes are colour-coded to display the Task Forces that participated in each activity.

Fig. 7 Homebirth Summit II

#### 7.2.4 Summit III: Advancing Equity through Voice, Policy, Practice & Research

In fall of 2014, Summit III convened in Seattle, Washington. New thought leaders from the consumer, ethics, health planning, liability, and health disparities perspectives served as delegates. Discussions focussed on sharing the tangible evidence of concrete steps towards the [Common Ground Vision](#) and impacts on health systems. Noting the equity frame, delegates from consumer stakeholder groups reminded the organizers that the agenda, itself, should highlight the expertise, priorities, and experience of women and families. Accordingly, the Task Forces reported on community-based participatory research projects examining experience of maternity care; Best Practice Guidelines for Transfer from Home to Hospital; and development of a national State Midwifery Regulation database. The Summit III agenda was designed to provide a series of interactive, strategic planning sessions with multi-stakeholder discussions centered around the following themes:

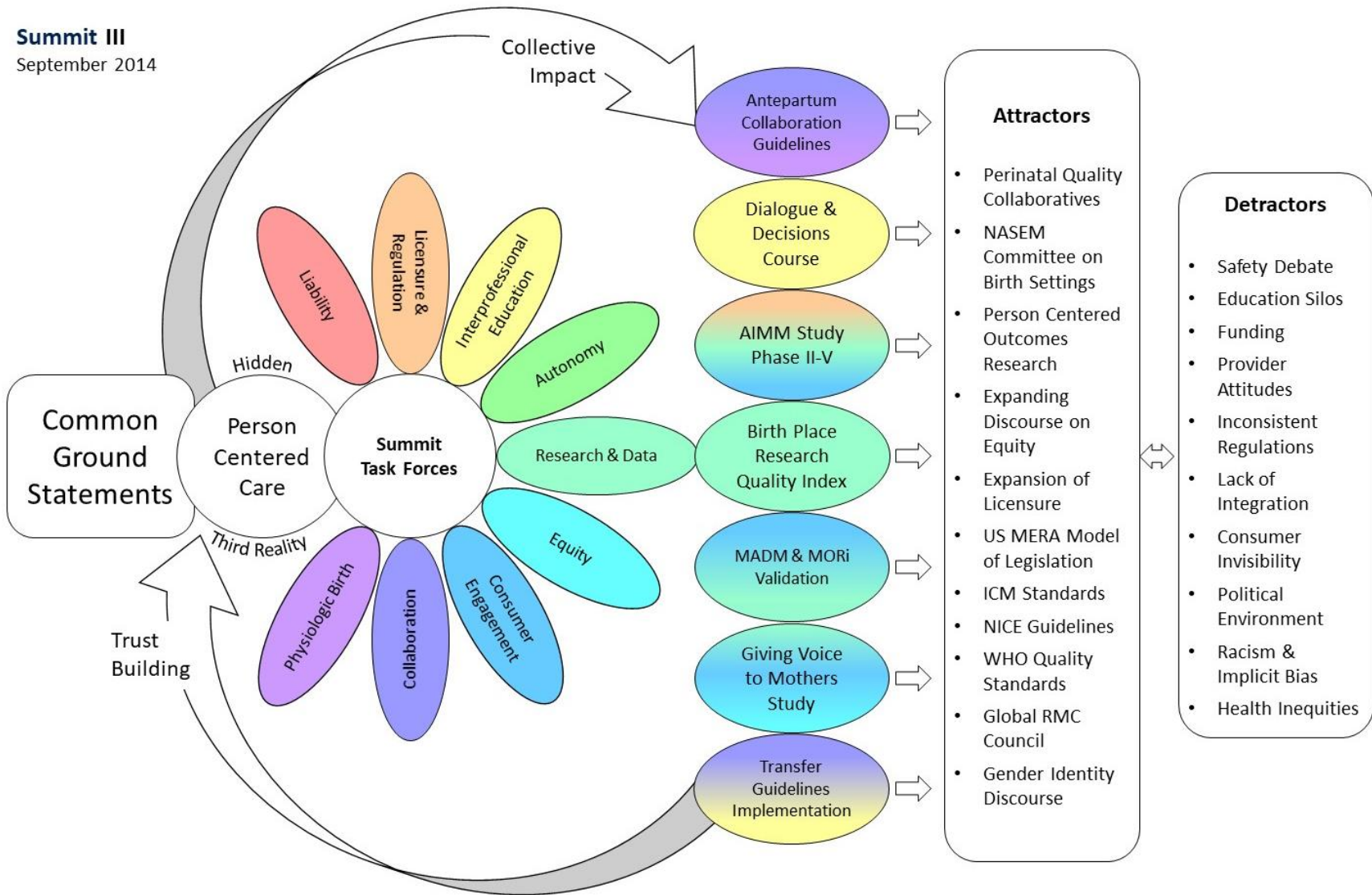
- Ethics of Home Birth & Informed Decision Making
- Voices of Women: Emerging Research on Equity, Access, & Experience
- Person-Centered competencies for Clinicians to Manage Risk & Reduce Liability
- Prioritizing Physiologic Birth
- Best Practices Across Birth Settings: Collaboration, Regulation, & Education
- Developing a National Research Agenda on Birth Place

Over the next 5 years, these conversations, new transdisciplinary alliances, and research informed the expansion of evidence-based policy, curriculum and clinical guidelines; regulatory and liability resources; and wide dissemination of novel quality and safety measures (See Appendix B, C). Since the first Home Birth Summit in 2011, there has been a shift in the national and global context to have more attractors than detractors (see Figures 6-8), and some of this shift can be attributable to the individual and collective work of the delegates. Some of the initiatives were carried forth by small transdisciplinary teams that emerged from the Summits, and others required the input and expertise of various Task Forces at different stages. This is illustrated by the multi-color coding of the action themes in each Figure. In addition, the

engagement and leadership of active Task Forces shifted as trust and comfort with transdisciplinarity grew, and more challenging aspects of the wicked problem seemed surmountable. Figures 7 and 8 display this evolution of the Summit transdisciplinary engagement and impacts within the Taming Wicked Problems framework.



**Summit III**  
September 2014



**Legend:** Each Summit Task Force is represented by a single colour.  
The Action Themes are colour-coded to display the Task Forces that participated in each activity.

Vedam & Miller-Vedam 2019

Fig. 8 Homebirth Summit III

## **7.3 The Future of Transdisciplinary Engagement Towards Equity, Safety and Respect**

### 7.3.1 US Birth Summit IV: Health Equity

Since the first Summit in 2011, a crisis in United States maternity care has become more visible and solutions more urgent. The general public, doctors, midwives, nurses, policymakers, clinicians, health policymakers are increasingly aware of shocking health disparities in outcomes for mothers and babies across communities. Newborn and maternal mortality, preterm birth, and poor pregnancy outcomes are highest in African American and Indigenous populations and persist even when taking into consideration socio-economic status (Alhusen et al., 2016; Browne, 2017b; Giurgescu, McFarlin, Lomax, Craddock, & Albrecht, 2011; Hilmert et al., 2014; Mendez, Hogan, & Culhane, 2014). The lack of equitable access to high quality maternity care has been linked to a shortage of providers in rural and disadvantaged communities, poor coordination of services, institutional racism, and, most importantly, the inability of the most at-risk patients to contribute meaningfully to the conversation and be heard (McLemore et al., 2018). The third Summit crystallized the priority action plan including a research agenda, and collaborative development of pragmatic tools to support ongoing quality improvement and accountability of health systems.

Since Summit III, many historically marginalized populations have worked in collaboration with health systems partners to create community-led health agencies, innovative service delivery models, data-driven quality measures and pragmatic tools to support accountability of health systems, with a focus on equity. Summit IV signaled a new, and more troubling version of the “Third Reality” that our transdisciplinary work has been focused on for a decade. The first two Summits built and refined a Common Agenda and, through a structured formal consensus process, agreed upon the scope and nature of the problem facing people and providers. However, neither the most disenfranchised (Indigenous and Black service users), nor their community health workers and advocates were present at previous Summits and, hence unable to contribute to modifying the Agenda to anticipate the next level of reality that we are facing. Trust built across stakeholders at the first Summits, along with the framework for

engagement, opened a space to engage with new community experts, quality and safety experts, and policy makers. Yet, even with transdisciplinarity, when the stakeholders do not share an understanding of the lived experience and consequences of racism, we cannot discover common ground without emotional intelligence, culture and race-matched leadership, curiosity, and humility. We have now stepped into a more complex web of wicked problems laid upon mistrust born of multigenerational exclusion and trauma.

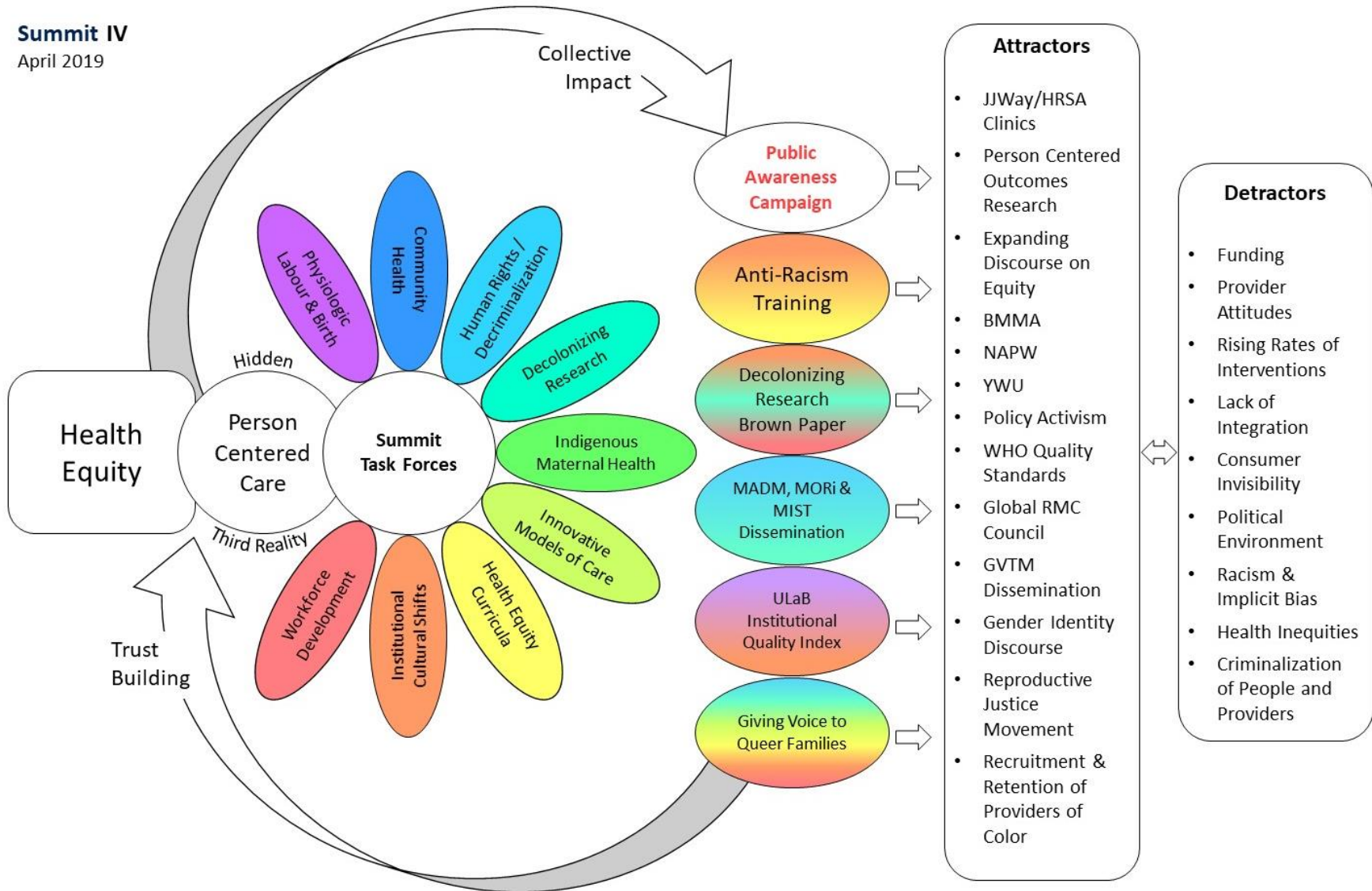
Nonetheless, inequities in birth outcomes are finally accepted as the result of different experiential and environmental exposures that affect development and cumulative allostatic load over the life course. To address these expanding and intersecting wicked problems of inequity, racism, and privilege in childbearing, we will need systems integration not only within healthcare but also across multiple sectors—where community, education, and economic conditions are attended to across the life course, including and especially when families are forming. This will require the transition of the existing legislative, disciplinary, and service provision silos to an integrated system of distributed services, co-generation of knowledge across sectors, and a commitment to community-responsive models of care (Lu, 2019). It may be possible to eliminate disparities if we embrace an ongoing transdisciplinary approach that keeps the person at the center of every conversation, elevates the expertise of the Subject and Community, and is not afraid to embrace the insights of a Third reality.

Figure 9 illustrates the new transdisciplinary *discursive spaces*, *action spaces* and *emerging themes* that emanated from Summit IV. To address an even more complex wicked problem, health inequity in maternity care across regional health systems, it was essential to recruit a panel of delegates that constituted representation from communities of color from various regions and perspectives, including patients, providers, or policy makers. They in turn identified health equity as the new sought after End-Condition, as elevated by the results of previous Summits' transdisciplinary research, and endorsed the focus on the Hidden Third Reality – person-centred care. While some of the previous themes re-emerged (such as health professional education, and access to physiologic birth), they are now focused on equitable

access to professional programs, development of health equity curricula, and racial disparities in rates of obstetric interventions. Delegates explored a concrete agenda to decolonize research processes, and elevate metrics of the lived experience of inequity. Other new action spaces address health systems conditions that are germane to transforming inequity in maternity care (eg workforce development, institutional culture shifts, and decriminalization). Interestingly, focussing on the interaction between the three domains of patient experience, provider attitudes, and health systems is still relevant. In addition, as the colour coding illustrates, initiatives aimed at this complex, wicked problem will require both transdisciplinary involvement and collaboration across Task Forces. At the same time, the external environment appears ripe for transformation, as there are many more attractors than potential detractors in place now.

Fig. 9 Birth Summit IV

**Summit IV**  
April 2019



**Legend:** Each Summit Task Force is represented by a single colour.  
The Action Themes are colour-coded to display the Task Forces that participated in each activity.

## 7.4 Lessons Learned from Applying Transdisciplinary Methodology

The situation in the U.S. mirrors the most pressing problems in pregnancy and birth care that global experts have identified in low resource countries. Recently the Lancet published a series on maternal health and on midwifery (Campbell et al. 2016; Koblinsky et al. 2016; ten Hoope-Bender et al. 2014). They both highlighted the urgent need to expand access to models that prioritize person-centered care and greater collaboration across the health professions. Similar priorities were identified by the World Health Organization in their most recent Standards for Improving Quality of Maternal and Newborn Care in Health Facilities (World Health Organization, 2016). The Sustainable Development Goals (SDG Targets 5.5 And 16.7) (United Nations, 2017) clearly endorse a person-centred approach to research, practice, and policy development.

“Ensure stakeholder participation in priority-setting, policy and programme design, implementation, monitoring and evaluation, and in accountability mechanisms. This can be achieved by establishing and/or strengthening transparent participation and social dialogue or multistakeholder mechanisms at community, subnational and national levels and ensuring that participation outcomes inform subnational, national and global policies and programmes related to women’s, children’s and adolescents” (“Maternal Health An Executive Summary for The Lancet’s Series’, Ceschia and Horton, 2016).

The Home Birth Summit 2011 [Common Ground Vision](#) articulates how we can achieve high quality, respectful care for all childbearing families in the United States. Some of the participating health professional organizations formed the Alliance for Innovation on Maternal Health (AIM) Council on Patient Safety to support and equip state and hospital systems, birth facilities, and maternity care providers in the US with tools and guidelines that may improve quality of care. However, as documented by the [Access and Integration Mapping Study](#) that the delegates published in February 2018, the progress has been significant in some regions of the country and slow in others.

While some health professional organizations have included a patient partner in conversations when identifying priority actions, an equitable model to elevate the patient voice has been notably missing in US maternity care reform. Unlike the UK and Australia, currently most provider organizations, regulatory, and health policy boards in the US do not have consumer representative members. In those organizations and regulatory bodies that do have consumer/public member participation, these representatives often serve within an isolated environment without any training or support. This is not ideal for the development of best policy around access to high quality maternity care or enhancing awareness of patient-driven outcomes. However, consumer representation in health policy is now well recognized by the federal government, and actively encouraged.

## **7.5 Limitations**

At all three Summits, delegates had frank discussions about the barriers to quality and safety in maternity care. However, to date, responsible maternity care providers in North America have not arrived at an agreement about appropriate settings for birth, and birth at home is not yet accepted generally. We established that provider attitudes and behavior exerts a cascading and iterative effect on women's experience of and choice of options for care. Together the delegates engaged in a multi-year transdisciplinary series of initiatives that in some domains resulted in measurable improvements in communication and collaboration across service users, service providers and health systems. For example, there has been widespread implementation of Best Practice Guidelines for Transfer, development and dissemination of a risk management course on birth place, and an interprofessional course on person-centred decision making. However, in other domains, such as loss of autonomy, physiologic birth, mistreatment, and racism, the Summits have led only to greater attention to dysfunction and lack of person-centred care.

As confirmed by the studies included in this thesis, both uptake of the Common Ground Agenda and implementation of the Summit outcomes and products, continues to vary greatly by jurisdiction and state, and by type of provider. Women with completed pregnancies who planned home births reported greater autonomy and a greater sense of respect when interacting with their care providers than those who planned hospital births. However, if their care was transferred from home to hospital their experience of respect and autonomy plummeted. Women's reports of discrimination and poor treatment were increased when they had differences of opinion with their providers about recommended care, and pressure to accept interventions was significantly associated with lower scores on MORi and MADM scales. One out of six women experienced some form of mistreatment over the course of childbearing. (Vedam, Stoll, and Martin 2017; Vedam, Stoll, and Rubashkin, 2017; Vedam, Stoll, McRae, et al., 2019; Vedam, Stoll, Taiwo, et al., 2019). These negative experiences were compounded when interprofessional conflict around their choices for care, including planned place of birth, existed. Women with midwife providers reported greater autonomy and respect, and less mistreatment.

In addition, wide variations in state regulatory conditions for midwifery practice, especially with respect to birth place (Vedam 2018), have created an environment of interprofessional hostility in some jurisdictions and interprofessional cooperation in others. The Access and Integration Maternity care Mapping Study analyzed and explicated these pathways by creating an evidence based scoring system for level of integration of providers across birth settings, reporting on state-by-state differences in integration, and linking integration scores to population based outcomes (Vedam 2018). Transdisciplinary engagement may need to occur at the local and regional level before conditions change enough to support person-centred care, autonomy, and respect.

While the Home Birth Summits produced some lasting and trusting cross-disciplinary relationships the face to face nature of the process used may have limited meaning for those "outside the circle". The leadership that delegates have displayed at



national venues (eg Institute of Medicine Workshop on Birth Setting, National Academies of Sciences, Congress) or via publications and professional associations (eg. Delegates who led changes in ACOG and AAP statements on home birth), may not have resonance or uptake at the local and regional level.

It is clear from the outputs and uptake of the information and tools on person-centred care, best practices, and quality (as defined by the service user) that the delegates generated (see Appendix C), that the Summits have contributed to measurable progress. Yet, it is simultaneously clear that these advances may not be apparent or accessible to those in historically disenfranchised communities. Both Burman and Galtung (Burman, Aphane, and Mollel 2017; Galtung 2010) note that not all wicked problems or conflicts are solvable, and persistent detractors may impede or delay progress.

In addition, there are some limitations specific to each of the studies that are described in each of the manuscripts.

## **7.6 Conclusions**

In summary, my doctoral program research informed and was informed by the transdisciplinary methodology of three national Home Birth Summits in the United States. The Home Birth Summits brought a cross-section of the maternity care system into one room to discuss improved integration of services for all women and families in the US across birth sites. Delegates were a multidisciplinary group of leaders who have a passion for quality in maternity care and a commitment to work together to improve safety for women and babies across birth settings. (Vedam, [www.homebirthsummit.org](http://www.homebirthsummit.org))

The community based participatory action methodology that we used for the Changing Childbirth in BC, Giving Voice to Mothers, and AIMM studies aligned with the multi-stakeholder, transdisciplinary best practice principles of engagement: collaborative decision making; attention to power dynamics; flexibility; and support from organizational leadership. We maintained this approach as we worked across disciplines

through and between the Summits (Gómez, 2014; Harrison et al., 2019; Jagosh et al., 2015; Mertens, 2015).

The model for transdisciplinary engagement at the Summits elevated the voices of service users, ensuring equity in representation and participation. Maternity care consumers bring important perspectives and skills that can inform the work of clinicians, researchers, and health planners to build effective and sustainable solutions. Placed within the context of patient-reported outcomes, and respectful maternity care, the multi-stakeholder, transdisciplinary approach we took was both a logical and evidence-based method to address interprofessional conflict and improve quality and safety in North American maternity care.

Though poorly understood by all of the stakeholders in 2011 at the original Summit, over nearly a decade of sustained engagement, this concept of person-centred care, informed and inspired knowledge generation, enhanced collaboration reducing disarticulation, and led to ongoing pragmatic, action initiatives (see Appendix C). These appear to be contributing to “taming” the wicked problem of inequitable access to high quality care across birth settings in North America.

## Bibliography

- Abuya, T., Warren, C. E., Miller, N., Njuki, R., Ndwiga, C., Maranga, A., Mbehero, F., Njeru, A., Bellows, B. (2015). Exploring the prevalence of disrespect and abuse during childbirth in Kenya. *PLoS One*, 10(4), e0123606. <https://doi.org/10.1371/journal.pone.0123606>
- Alhusen, J. L., Bower, K. M., Epstein, E., & Sharps, P. (2016). Racial Discrimination and Adverse Birth Outcomes: An Integrative Review. *Journal of Midwifery & Women's Health*, 61(6), 707–720. <https://doi.org/10.1111/jmwh.12490>
- Allan, B., & Smylie, J. (2015). First Peoples , second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. *Wellesley Institute*. Toronto. Retrieved from <http://www.welllivinghouse.com/wp-content/uploads/2016/03/Full-Report-FPSCT-Updated.pdf>
- Allcock, A., Griffiths, A., & Penketh, R. (2008). The effects of the attending obstetrician's anxiety trait and the corresponding obstetric intervention rates. *Journal of Obstetrics and Gynaecology*, 28(4), 390–393.
- American College of Nurse-Midwives. Criteria for Provision of Home Birth Services (2003). *J Midwifery Womens Health*. 48(4):299-301.
- American College of Nurse-Midwives. Criteria for Provision of Home Birth Services (2016). *J Midwifery Womens Health*. 2016 Jan-Feb; 61(1):127-33. doi: 10.1111/jmwh.12431.
- American College of Obstetricians and Gynecologists. (2011). ACOG Committee Opinion No. 476: planned home birth. *Obstet Gynecol*, 117(2 Pt 1):425-8.
- American Medical Association. (2008). Resolution 205: Home Deliveries. Retrieved August 2019 from: [https://www.ftc.gov/system/files/documents/public\\_comments/2014/03/00041-88892.pdf](https://www.ftc.gov/system/files/documents/public_comments/2014/03/00041-88892.pdf).
- Bailes, A., & Jackson, M. E. (2000). Shared responsibility in home birth practice: Collaborating with clients. *Journal of Midwifery & Women's Health*, 45(6), 537–543.
- Barclay, L., Kornelsen, J., Longman, J., Robin, S., Kruske, S., Kildea, S., Pilcher, J., Martin, T., Grzybowski, S., Donoghue, D., Rolfe, M., Morgan, G. (2016a). Reconceptualising risk: Perceptions of risk in rural and remote maternity service planning. *Midwifery*, 38, 63–70. <https://doi.org/10.1016/j.midw.2016.04.007>.
- Beck, C. T. (2018). A Secondary Analysis of Mistreatment of Women During Childbirth in Health Care Facilities. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 47(1), 94–104. <https://doi.org/10.1016/j.jogn.2016.08.015>.
- Blix, E. (2011). Avoiding disturbance: Midwifery practice in home birth settings in Norway. *Midwifery*, 27(5), 687–692. <https://doi.org/10.1016/j.midw.2009.09.008>.
- Bohren, M. A., Vogel, J. P., Hunter, E. C., Lutsiv, O., Makh, S. K., Souza, J. P., Aguiar, C., Coneglian, F.S., Luiz, A., Diniz, A., Tunçalp, O., Javadi, D., Oladapo, O.T., Khosla, R., Hindin, M.J., Gülmezoglu, A. M. (2015). The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review. *PLOS Medicine*, 12(6), e1001847. <https://doi.org/10.1371/journal.pmed.1001847>
- Boucher, D., Bennett, C., MacFarlin, B., & Freeze, R. (2009). Staying home to give birth: Why women in the United States choose home birth. *Journal of Midwifery & Women's Health*, 54(2), 119–126.

- Bradbury, J. W., & Vehrencamp, S. L. (2014). Complexity and behavioral ecology. *Behavioral Ecology*, 25(3), 435-442. <https://doi.org/10.1093/beheco/aru014>
- Brown, V., Harris, J., & Russel, J. (2010). *Tackling Wicked Problems Through the Transdisciplinary Imagination*. Washington, D.C.: Earthscan.
- Browne, A. J. (2017). Moving beyond description: Closing the health equity gap by redressing racism impacting Indigenous populations. *Social Science and Medicine*, 184, 23-26. . <https://doi.org/10.1016/j.socscimed.2017.04.045>
- Bryant, A. S., Worjolah, A., Caughey, A. B., & Washington, A. E. (2010). Racial/ethnic disparities in obstetric outcomes and care: prevalence and determinants. *American Journal of Obstetrics and Gynecology*, 202(4), 335-343. <https://doi.org/10.1016/j.ajog.2009.10.864>
- Burman, C J, Aphane, M. A., & Mollel, N. M. (2017). The Taming Wicked Problems Framework: Reflections in the Making. *Journal for New Generation Sciences*, 15(1), 51-73.
- Burman, Christopher J. (2018). The Taming Wicked Problems Framework: A plausible biosocial contribution to ‘ending AIDS by 2030.’ *The Journal for Transdisciplinary Research in Southern Africa*, 14(1), 1-12. <https://doi.org/10.4102/td.v14i1.401>
- Campbell, C., & Cornish, F. (2010). Towards a “fourth generation” of approaches to HIV/AIDS management: creating contexts for effective community mobilisation. *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, 22(2), 1569-1579. <https://doi.org/10.1080/09540121.2010.525812>
- Campbell, J., Buchan, J., Cometto, G., David, B., Dussault, G., Fogstad, H., ... Tangcharoensathien, V. (2013). Human resources for health and universal health coverage: fostering equity and effective coverage. *Bulletin of the World Health Organization*, 91(11), 853–863. <https://doi.org/10.2471/BLT.13.118729>
- Campbell, K., Carson, G., Azzam, H., & Hutton, E. (2019). No. 372-Statement on Planned Homebirth. *Journal of Obstetrics and Gynaecology Canada*, 41(2), 223–227. <https://doi.org/10.1016/j.jogc.2018.08.008>
- Campbell, O. M. R., Calvert, C., Testa, A., Strehlow, M., Benova, L., Keyes, E., Donnay, F., Macleod, D., Gabrysch, S., Rong, L., Ronsmans, C., Sadruddin, S., Koblinsky, M., Bailey, P. (2016). The scale, scope, coverage, and capability of childbirth care. *The Lancet*, 388(10056). [https://doi.org/10.1016/S0140-6736\(16\)31528-8](https://doi.org/10.1016/S0140-6736(16)31528-8)
- Canadian Association of Midwives. (2016). Midwifery Across Canada. Retrieved August 2016 from <https://canadianmidwives.org/midwifery-across-canada/#1454379739099-d5eba39e-3d2e>
- Canadian Association of Midwives. (2001). Position Statement on Home Birth. Retrieved September 2019 from [http://www.canadianmidwives.org/DATA/DOCUMENT/PSHomeBirth\\_ENG200103.pdf](http://www.canadianmidwives.org/DATA/DOCUMENT/PSHomeBirth_ENG200103.pdf)
- Canadian Institute of Health Information. (2015). Health Indicators Interactive Tool. Retrieved November 9, 2017, from <https://yourhealthsystem.cihi.ca/epub/>
- Ceron, A., Ruano, A. L., Sanchez, S., Chew, A. S., Diaz, D., Hernandez, A., & Flores, W. (2016). Abuse and discrimination towards indigenous people in public health care facilities: experiences from rural Guatemala. *International Journal for Equity in Health*, 15(77). <https://doi.org/10.1186/s12939-016-0367-z>

- Ceschia, A., & Horton, R. (2016). Maternal health: time for a radical reappraisal. *The Lancet*, 388, 10056, 2064-2066. [https://doi.org/10.1016/S0140-6736\(16\)31534-3](https://doi.org/10.1016/S0140-6736(16)31534-3)
- Chamberlain, G., & Patel, N. (1994). *The future of maternity services*. London, UK.: Royal College of Obstetricians and Gynaecologists.
- Chan, Y., Lam, G.L.T. & Cheng, H.C.H. (2009). Community Capacity Building as a Strategy of Family Violence Prevention in a Problem-Stricken Community: a Theoretical Formulation. *J Fam Viol* (2009) 24: 559. <https://doi-org.ezproxy.library.ubc.ca/10.1007/s10896-009-9254-3>
- Chervenak, F. A., McCullough, L. B., & Brent, R. L. (2012). The professional responsibility model of physician leadership. *American Journal of Obstetrics and Gynecology*, 208(2), 97–101.
- Chervenak, F. A., McCullough, L. B., Brent, R., Levene, M., & Arabin, B. (2013). Planned home birth: the professional responsibility response. *American Journal of Obstetrics & Gynecology*, 208(1), 31–38.
- Cheyney, M. (2008). Homebirth as systems-challenging praxis: Knowledge, power, and intimacy in the birthplace. *Qualitative Health Research*, 18(2), 254–267.
- Cheyney, M, Everson, C., & Burcher, P. (2014). Homebirth transfers in the United States: Narratives of risk, fear, and mutual accommodation. *Qualitative Health Research*, 24(2), 443–456.
- Cheyney, Melissa, Bovbjerg, M., Everson, C., Gordon, W., Hannibal, D., & Vedam, S. (2014). Outcomes of care for 16,924 planned home births in the United States: The midwives alliance of North America statistics project, 2004 to 2009. *Journal of Midwifery and Women's Health*, 59(1), 17–27. <https://doi.org/10.1111/jmwh.12172>
- Cheyney, Melissa, Everson, C., & Burcher, P. (2014). Homebirth transfers in the United States: narratives of risk, fear, and mutual accommodation. *Qualitative Health Research*, 24(4), 443–456. <https://doi.org/10.1177/1049732314524028>
- Choi, B. C. K., Pang, T., Lin, V., Puska, P., Sherman, G., Goddard, M., Ackland, M.J., Sainsbury, P., Stachenko, S., Morrison, H., Clotney, C. (2005, August). Can scientists and policy makers work together? *Journal of Epidemiology and Community Health*, 59, 632-637. <https://doi.org/10.1136/jech.2004.031765>
- Coleman, P. T., Vallacher, R. R., Nowak, A., & Bui-Wrzosinska, L. (2007). Intractable Conflict as an Attractor A Dynamical Systems Approach to Conflict Escalation and Intractability. *American Behavioral Scientist*, 50, 1454–1475. <https://doi.org/10.1177/0002764207302463>
- The Joint Commission. (2010). *Preventing Maternal Death*. Retrieved September 2019 from [http://www.jointcommission.org/assets/1/18/sea\\_44.pdf](http://www.jointcommission.org/assets/1/18/sea_44.pdf)
- Cornthwaite, K., Edwards, S., & Siassakos, D. (2013). Reducing risk in maternity by optimising teamwork and leadership: An evidence-based approach to save mothers and babies. *Est Practice & Research Clinical Obstetrics & Gynaecology*, 27(4), 571–581.
- Daemers, D. O. A., van Limbeek, E. B. M., Wijnen, H. A. A., Nieuwenhuijze, M. J., & de Vries, R. G. (2017). Factors influencing the clinical decision-making of midwives: A qualitative study. *BMC Pregnancy and Childbirth*, 17(1). <https://doi.org/10.1186/s12884-017-1511-5>
- Dahlen, H. G., Jackson, M., & Stevens, J. (2011). Homebirth, freebirth and doulas: Casualty and consequences of a broken maternity system. *Women and Birth*, 24(1), 47-50. <https://doi.org/10.1016/j.wombi.2010.11.002>

- De Jonge, A., Geerts, C. C., Van Der Goes, B. Y., Mol, B. W., Buitendijk, S. E., & Nijhuis, J. G. (2015). Perinatal mortality and morbidity up to 28 days after birth among 743 070 low-risk planned home and hospital births: A cohort study based on three merged national perinatal databases. *BJOG: An International Journal of Obstetrics and Gynaecology*, *122*(5), 720-728. <https://doi.org/10.1111/1471-0528.13084>
- de Vries, R., Paruchuri, Y., Lorenz, K., & Vedam, S. (2013). Moral science: Ethical argument and the production of knowledge about place of birth. *Journal of Clinical Ethics*, *24*(3), 225–238.
- Declercq, E., MacDorman, M., Menacker, F., & Stotland, N. (2010). Characteristics of planned and unplanned home births in 19 states. *Obstetrics & Gynecology*, *116*(1), 93–99.
- Declercq, E. R., Sakala, C., Corry, M. P., Applebaum, S., & Herrlich, A. (2014). Major Survey Findings of Listening to Mothers III: Pregnancy and Birth. *J Perinat Educ*. 2014 Winter; *23*(1): 9–16. doi: [10.1891/1058-1243.23.1.9](https://doi.org/10.1891/1058-1243.23.1.9)
- Downe, S., Finlayson, K., Tuncalp, & Metin Gulmezoglu, A. (2016). What matters to women: A systematic scoping review to identify the processes and outcomes of antenatal care provision that are important to healthy pregnant women. *BJOG: An International Journal of Obstetrics and Gynaecology*, *123*(4), 529–539. <https://doi.org/10.1111/1471-0528.13819>
- Downe, Soo, Finlayson, K., & Fleming, A. (2010). Creating a collaborative culture in maternity care. *Journal of Midwifery and Women's Health*, *55*(3), 250–254. <https://doi.org/10.1016/j.jmwh.2010.01.004>
- Downe, Soo, Walsh, D., & Gyte, G. (2008). Is maternity care evidence based or interpretation driven? Place of birth as an exemplar. *Midwifery*, *24*(3), 247–249. <https://doi.org/10.1016/j.midw.2008.07.001>
- Elder, T. E., Goddeeris, J. H., & Haider, S. J. (2016). Racial and ethnic infant mortality gaps and the role of socio-economic status. *Labour Economics*, *43*, 42-54. <https://doi.org/10.1016/j.labeco.2016.04.001>
- European Court of Human Rights. Case of Ternovszky v. Hungary (2014). *Ternovszky v Hungary*, No. 67545/09, (ECHR 2010-XII).
- European Court of Human Rights Strasbourg. *Dubská and Krejzová v the Czech Republic*. Applications Nos 28859/11 and 28473/12. (ECHR 2014-XII).
- Finsen, V., Storeheier, A. H., & Aasland, O. G. (2008). Cesarean section: Norwegian women do as obstetricians do - not as obstetricians say. *Birth*, *35*(2), 117–120.
- Foster, J., & Alonso, C. (2018). Contemporary Issues in the Training, Practice, and Implementation of Midwifery for Indigenous Women in Mexico. In Schwartz, D. (eds) *Maternal Death and Pregnancy-Related Morbidity Among Indigenous Women of Mexico and Central America. Global Maternal and Child Health (Medical, Anthropological, and Public Health Perspectives)*. (pp. 313-326). New York: Springer Publishing Co. [https://doi.org/10.1007/978-3-319-71538-4\\_16](https://doi.org/10.1007/978-3-319-71538-4_16)
- Galtung, J. (2010). Peace Studies and Conflict Resolution: The Need for Transdisciplinarity. *Transcultural Psychiatry*, *47*(1), 20-32. <https://doi.org/10.1177/1363461510362041>
- Giurgescu, C., McFarlin, B. L., Lomax, J., Craddock, C., & Albrecht, A. (2011). Racial discrimination and the Black-White Gap in adverse birth outcomes: A review. *Journal of Midwifery and Women's Health*, *56*(4), 362-370. <https://doi.org/10.1111/j.1542-2011.2011.00034.x>
- Gómez, A. (2014). New Developments in Mixed Methods With Vulnerable Groups. *Journal of Mixed Methods Research*, *8*(3), 317–320. <https://doi.org/10.1177/1558689814527879>

- Governing Council of the American Public Health Association. (2001). Policy statement no.20013: Increasing access to out-of-hospital maternity care services through state-regulated and nationally-certified direct-entry midwives. Washington, D.C. Retrieved August 2019 from <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/09/11/29/increasing-access-to-out-of-hospital-maternity-care-services-through-regulated-direct-entry-midwives>.
- Greenhalgh, T., & Russell, J. (2006). Reframing evidence synthesis as rhetorical action in the policy making drama. *Healthcare Policy = Politiques de Sante*, 1(2), 34–42. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19305651>
- Greer, J., Lazenbatt, A., & Dunne, L. (2014). ‘Fear of childbirth’ and ways of coping for pregnant women and their partners during the birthing process: a salutogenic analysis. *Evidence Based Midwifery*, 12(3), 95–100.
- Mezzich, J.E., Appleyard, J.A., Botbol, M., Ghebrehiwet, T., Groves, J., Salloum, I., van Dulmen, S. (2013). The Sixth Geneva Conference and Person-centered Health, *The International Journal of Person Centered Medicine*, 3(2), 99–105.
- Guise, J. M., & Segel, S. (2008). Teamwork in obstetric critical care. *Best Practice and Research: Clinical Obstetrics and Gynaecology*, 22(5), 937-951. <https://doi.org/10.1016/j.bpobgyn.2008.06.010>
- Halfon, N., Larson, K., Lu, M., Tullis, E., & Russ, S. (2014). Lifecourse health development: Past, present and future. *Maternal and Child Health Journal*, 18(2), 344-365. <https://doi.org/10.1007/s10995-013-1346-2>
- Hall, W. A., Tomkinson, J., & Klein, M. C. (2012). Canadian Care Providers’ and Pregnant Women’s Approaches to Managing Birth: Minimizing Risk While Maximizing Integrity. *Qualitative Health Research*, 22, 575–586. <https://doi.org/10.1177/1049732311424292>
- Hall, W. A., Tomkinson, J., & Klein, M. C. (2012). Canadian Care Providers’ and Pregnant Women’s Approaches to Managing Birth Minimizing Risk While Maximizing Integrity. *Qualitative Health Research*, 22(5), 575–586.
- Halpern, S. (2009). SOGC Joint Policy Statement on Normal Childbirth. *Journal of Obstetrics and Gynaecology Canada*, 31(7), 602. [https://doi.org/10.1016/S1701-2163\(16\)34236-0](https://doi.org/10.1016/S1701-2163(16)34236-0)
- Hanvey, L., Levitt, C., Kaczorowski, J., Chalmers, B.H. (2012). Canadian Hospitals Maternity Policies and Practices Survey. *Public Health Agency of Canada*. Ottawa.
- Haraway, D.L., Haraway, W. M. I. (2005). Analysis of the effect of conflict-management and resolution training on employee stress at a healthcare organization. *Hospital Topics: Research and Perspectives on Healthcare*, 83(4), 11-17. <https://doi.org/10.3200/HTPS.83.4.11-18>
- Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C.,.... Weiss, R. (2019, June 1). Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. *Health Expectations*, 22 (3), 307-316. Blackwell Publishing Ltd. <https://doi.org/10.1111/hex.12873>
- Healy, S., Humphreys, E., & Kennedy, C. (2016). Midwives’ and obstetricians’ perceptions of risk and its impact on clinical practice and decision-making in labour: An integrative review. *Women and Birth*, 29(2), 107–116. <https://doi.org/10.1016/j.wombi.2015.08.010>

- Hendrix, M., Van Horck, M., Moreta, D., Nieman, F., Nieuwenhuijze, M., Severens, J., & Nijhuis, J. (2009). Why women do not accept randomisation for place of birth: Feasibility of a RCT in the Netherlands. *BJOG: An International Journal of Obstetrics and Gynaecology*, *116* (4),537-544. <https://doi.org/10.1111/j.1471-0528.2008.02103.x>
- Hickey, S., Roe, Y., Gao, Y., Nelson, C., Carson, A., Currie, J., ... Kildea, S. (2018). The Indigenous Birthing in an Urban Setting study: the IBUS study : A prospective birth cohort study comparing different models of care for women having Aboriginal and Torres Strait Islander babies at two major maternity hospitals in urban South East Quee. *BMC Pregnancy and Childbirth*, *18* (431). <https://doi.org/10.1186/s12884-018-2067-8>
- High-Level Working Group Health and Human Rights Working Group. (2017). Leading the Realization of Human Rights to Health and Through Health. WHO:Geneva. Retrieved from <https://apps.who.int/iris/bitstream/handle/10665/255540/9789241512459-eng.pdf>
- Hilder L, Zhichao Z, Parker M, Jahan S, C. G. (2014). Australia's mothers and babies 2012. *Perinatal statistics series*. Perinatal statistics series no. 28. Cat. no. PER 59.
- Hildingsson, I., Rådestad, I., & Lindgren, H. (2010). Birth preferences that deviate from the norm in Sweden: planned home birth versus planned cesarean section. *Birth*, *288*-295. <https://doi.org/10.1111/j.1523-536X.2010.00423.x>
- Hilmert, C. J., Dominguez, T. P., Schetter, C. D., Srinivas, S. K., Glynn, L. M., Hobel, C. J., & Sandman, C. a. (2014). Lifetime racism and blood pressure changes during pregnancy: implications for fetal growth. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *33*(1), 43–51. <https://doi.org/10.1037/a0031160>
- Hollowell, J., Puddicombe, D., Rowe, R., Linsell, L., Hardy, P., Stewart, M., ... Brocklehurst, P. (2011). The Birthplace national prospective cohort study: perinatal and maternal outcomes by planned place of birth Birthplace in England research programme. *Final report part 4 on behalf of the Birthplace in England Collaborative Group*. Southampton: HMSO.
- Homer, C. S. E., Thornton, C., Scarf, V. L., Ellwood, D. A., Oats, J. J. N., Foureur, M. J., ... Dahlen, H. G. (2014). Birthplace in New South Wales, Australia: An analysis of perinatal outcomes using routinely collected data. *BMC Pregnancy and Childbirth*, *14*,206. <https://doi.org/10.1186/1471-2393-14-206>
- Howell, E. A., Brown, H., Brumley, J., Bryant, A. S., Caughey, A. B., Cornell, A. M., ... Grobman, W. A. (2018). Reduction of Peripartum Racial and Ethnic Disparities: A Conceptual Framework and Maternal Safety Consensus Bundle. *JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *47*(3), 275–289. <https://doi.org/10.1016/j.jogn.2018.03.004>
- Hunter, B., Berg, M., Lundgren, I., Olafsdottir, O.A., & Kirkham, M. (2008). Relationships: The hidden threads in the tapestry of maternity care. *Midwifery*, *24*(2), 132–137. <https://doi.org/10.1016/j.midw.2008.02.003>
- Hutton, E. K., Reitsma, A. H., & Kaufman, K. (2009). Outcomes Associated with Planned Home and Planned Hospital Births in Low-Risk Women Attended by Midwives in: A Retrospective Cohort Study. *BIRTH*, *36*(3), 180-189.
- Jackson, M., Dahlen, H., & Schmied, V. (2012). Birthing outside the system: Perceptions of risk amongst Australian women who have freebirths and high risk homebirths. *Midwifery*, *28*, 561-567. <https://doi.org/10.1016/j.midw.2011.11.002>



- Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., ... Pluye, P. (2015). A realist evaluation of community-based participatory research: Partnership synergy, trust building and related ripple effects. *BMC Public Health*, *15*(1). <https://doi.org/10.1186/s12889-015-1949-1>
- Janssen, P.A., Henderson, A. D., & Vedam, S. (2009). The experience of planned home birth: Views of the first 500 women. *Birth*, *36*(4), 297–304. <https://doi.org/10.1111/j.1523-536X.2009.00357.x>
- Janssen, Patricia A., Mitton, C., & Aghajanian, J. (2015). Costs of planned home vs. Hospital birth in British Columbia attended by registered midwives and physicians. *PLoS ONE*, *10*(7): e0133524. <https://doi.org/10.1371/journal.pone.0133524>
- Janssen, Patricia A., Saxell, L., Page, L. A., Klein, M. C., Liston, R. M., & Lee, S. K. (2009). Outcomes of planned home birth with registered midwife versus planned hospital birth with midwife or physician. *CMAJ*, *181*(6–7), 377–383. <https://doi.org/10.1503/cmaj.081869>
- Jou, J., Kozhimannil, K. B., Johnson, P. J., & Sakala, C. (2015). Patient-Perceived Pressure from Clinicians for Labor Induction and Cesarean Delivery: A Population-Based Survey of U.S. Women. *Health Services Research*, *50*(4), 961–981. <https://doi.org/10.1111/1475-6773.12231>
- Kabengele Mpinga, E., & Chastonay, P. (2011). Patient Satisfaction Studies and the Monitoring of the Right to Health: Some Thoughts Based on a Review of the Literature. *Global Journal of Health Science*, *3*(1). <https://doi.org/10.5539/gjhs.v3n1p64>
- Kania, J., & Kramer, M. (2011). Collective Impact. *Stanford Social Innovation Review*, Winter, 36-41. Retrieved from [www.ssireview.org](http://www.ssireview.org)
- Karlsen, S., Say, L., Souza, J. P., Hogue, C. J., Calles, D. L., Gülmezoglu, A. M., & Raine, R. (2011). The relationship between maternal education and mortality among women giving birth in health care institutions: Analysis of the cross sectional WHO Global Survey on Maternal and Perinatal Health. *BMC Public Health*, *11*. <https://doi.org/10.1186/1471-2458-11-606>
- Kataoka, Y., Eto, H., & Iida, M. (2013). Outcomes of independent midwifery attended births in birth centres and home births: A retrospective cohort study in Japan. *Midwifery*, *29*, 965-972. <https://doi.org/10.1016/j.midw.2012.12.020>
- Kennedy, H. P., Myers-Ciecko, J. A., Carr, K. C., Breedlove, G., Bailey, T., Farrell, M. V., ... Darragh, I. (2018a). United States Model Midwifery Legislation and Regulation: Development of a Consensus Document. *Journal of Midwifery and Women's Health*. <https://doi.org/10.1111/jmwh.12727>
- Kennedy, H. P., Dahlen, H.G., Downe, S., Foureur, M.J., Homer, C. E, Jefford, E. J.,McFadden, A, Michel-Schuldt, M., Sandall, J., Soltani, H., Speciale, A.M., Stevens, J., Vedam, S., Renfrew, M.J. (2018b). Asking different questions: a call to action to improve the quality of care for every woman, every child. *Birth* *45*(3): 222-231 <https://doi.org/10.1111/birt.12361>
- Klein, R. (2012). Future Search: Getting the Whole System in the Room for Vision, Commitment, and Action Marvin Weisbord and Sandra Janoff. San Francisco, CA: Berrett-Koehler Publishers, 2010.. *Journal of Product Innovation Management*. [https://doi.org/10.1111/j.1540-5885.2011.00899\\_2.x](https://doi.org/10.1111/j.1540-5885.2011.00899_2.x)
- Koblinsky, M., Moyer, C. A., Calvert, C., Campbell, J., Campbell, O. M. R., Feigl, A. B., ... Langer, A. (2016). Quality maternity care for every woman, everywhere: a call to action. Maternal Health Series, 6. *The Lancet*, *1-14*. [https://doi.org/10.1016/S0140-6736\(16\)31333-2](https://doi.org/10.1016/S0140-6736(16)31333-2)

- Kornelsen, J., Kotaska, A., Waterfall, P., Willie, L., & Wilson, D. (2010). The geography of belonging: The experience of birthing at home for First Nations women. *Health and Place*, 16, 638-645. <https://doi.org/10.1016/j.healthplace.2010.02.001>
- Kruske, S., Young, K., Jenkinson, B., & Catchlove, A. (2013). Maternity care providers' perceptions of women's autonomy and the law. *BMC Pregnancy and Childbirth*, 13(1), 84. <https://doi.org/10.1186/1471-2393-13-84>
- Kukla, R., Kuppermann, M., Little, M., Lyerly, A. D., Mitchell, L. M., Armstrong, E. M., & Harris, L. (2009). Finding autonomy in birth. *Bioethics*, 23(1), 1-8. <https://doi.org/10.1111/j.1467-8519.2008.00677.x>
- Lu, M. C. (2014). Improving maternal and child health across the life course: Where do we go from here? *Maternal and Child Health Journal*, 18, 339-343. <https://doi.org/10.1007/s10995-013-1400-0>
- Lu, M. C. (2019, January 15). The Future of Maternal and Child Health. *Maternal and Child Health Journal*, 23, 1-7. Springer New York LLC. <https://doi.org/10.1007/s10995-018-2643-6>
- Lu, M. C., & Halfon, N. (2003). Racial and Ethnic Disparities in Birth Outcomes: A Life-Course Perspective. *Maternal and Child Health Journal*, 7(1), 13-30. <https://doi.org/10.1023/A:1022537516969>
- MacDorman, M., Declercq, E., & Menacker, F. (2011). Trends and characteristics of home births in the United States by race and ethnicity, 1990-2006. *Birth*, 38(1), 1-7.
- MacDorman, M F, Menacker, F., & Declercq, E. (2010). Trends and characteristics of home and other out-of-hospital births in the United States, 1990-2006. *National Vital Statistics Reports*, 58(11), 1-16.
- MacDorman, Marian F. (2011). Race and Ethnic Disparities in Fetal Mortality, Preterm Birth, and Infant Mortality in the United States: An Overview. *Seminars in Perinatology*, 35(4), 200-208. <https://doi.org/10.1053/j.semperi.2011.02.017>
- MacDorman, Marian F., & Declercq, E. (2016). Trends and Characteristics of United States Out-of-Hospital Births 2004-2014: New Information on Risk Status and Access to Care. *Birth*, 43(2), 116-124. <https://doi.org/10.1111/birt.12228>
- MacDorman, Marian F., Declercq, E., & Menacker, F. (2011). Trends and Characteristics of Home Births in the United States by Race and Ethnicity, 1990-2006. *Birth*, 38 (1), 17-23. <https://doi.org/10.1111/j.1523-536X.2010.00444.x>
- Manojlovich, M., Kerr, M., Davies, B., Squires, J., Mallick, R., & Rodger, G. L. (2014). Achieving a climate for patient safety by focusing on relationships. *International Journal for Quality in Health Care*, 26(6), 579-584. <https://doi.org/10.1093/intqhc/mzu068>
- Maternal and Child Health Bureau. (2010). Rethinking MCH: The Life Course Model as an Organizing Framework. *U.S. Department of Health and Human Services*. Retrieved July 2019 from <https://www.hrsa.gov/sites/default/files/ourstories/mchb75th/images/rethinkingmch.pdf>
- McDougall, L., Oona M R Campbell, O.M.R., & Graham, W. (2-16) Maternal Health: An Executive Summary for The Lancet's Series. *The Lancet*, 1-8.
- McCourt, C., Rayment, J., Rance, S., & Sandall, J. (2012). Organisational strategies and midwives' readiness to provide care for out of hospital births: An analysis from the Birthplace organisational case studies. *Midwifery*, 28, 636-645. <https://doi.org/10.1016/j.midw.2012.07.004>

- McLemore, M. R., Altman, M. R., Cooper, N., Williams, S., Rand, L., & Franck, L. (2018). Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. *Social Science and Medicine*, 201, 27-135. <https://doi.org/10.1016/j.socscimed.2018.02.013>
- McRae, D.N., Muhajarine, N., Stoll, K., Mayhew, M., Vedam, S., Mpofu, D., & Janssen, P. A. (2016). Is model of care associated with infant birth outcomes among vulnerable women? A scoping review of midwifery-led versus physician-led care. *SSM - Population Health*, 2, 182–193. <https://doi.org/10.1016/j.ssmph.2016.01.007>
- McRae, Daphne N., Janssen, P. A., Vedam, S., Mayhew, M., Mpofu, D., Teucher, U., & Muhajarine, N. (2018). Reduced prevalence of small-for-gestational-age and preterm birth for women of low socioeconomic position: A population-based cohort study comparing antenatal midwifery and physician models of care. *BMJ Open*, 8(10), e022220. <https://doi.org/10.1136/bmjopen-2018-022220>
- Mendez, D. D., Hogan, V. K., & Culhane, J. F. (2014). Institutional racism, neighborhood factors, stress, and preterm birth. *Ethnicity & Health*, 19(5), 479–499. <https://doi.org/10.1080/13557858.2013.846300>
- Mertens, D. M. (2015, January 12). Mixed Methods and Wicked Problems. *Journal of Mixed Methods Research*, 9(1), 3–6. <https://doi.org/10.1177/1558689814562944>
- Michal, C. A., Janssen, P. A., Vedam, S., Hutton, E. K., & De Jonge, A. (2011, April 1). Planned home vs hospital birth: a meta-analysis gone wrong. *Medscape OB-GYN Womens Health*. Retrieved from <http://www.medscape.com/viewarticle/739987>
- Miller, S., Abalos, E., Chamillard, M., Ciapponi, A., Colaci, D., Comande, D., ... Althabe, F. (2016). Beyond too little, too late and too much, too soon: a pathway towards evidence-based, respectful maternity care worldwide. *Maternal Health*, 2. *The Lancet*, 388, 2176–92. [https://doi.org/10.1016/S0140-6736\(16\)31472-6](https://doi.org/10.1016/S0140-6736(16)31472-6)
- Ministry of Health (Community Health and Culture).(1989). Government Position on the Kloosterman Advisory Committee. The Hague: SDU.
- National Academy of Sciences, N. A. of E. and I. of M. (2004). *Facilitating Interdisciplinary Research*. Washington, D.C.: National Academies Press. Retrieved from <https://doi.org/10.17226/11153>
- National Institute for Health and Clinical Excellence (NICE). (2014). Intrapartum care for healthy women and babies: Guidance and guidelines. *NICE*. Retrieved from <https://www.nice.org.uk/guidance/cg190>
- Nelson, G. (2013). Community Psychology and Transformative Policy Change in the Neo-liberal Era. *American Journal of Community Psychology*, 52(3–4), 211–223. <https://doi.org/10.1007/s10464-013-9591-5>
- New Zealand College of Midwives. (2009). Consensus statement: Normal birth. Retrieved from <http://www.midwife.org.nz/quality-practice/consensus-statements-and-guidelines>
- New Zealand Ministry of Health. (2011). Maternity Tables 2011, Home Births. Retrieved from <https://www.health.govt.nz/publication/maternity-tables-2011#home>
- Nicolescu, B. (2014). Methodology of transdisciplinarity. *World Futures*, 70(3–4), 186–199. <https://doi.org/10.1080/02604027.2014.934631>
- Nieuwenhuijze, M. J., Korstjens, I., de Jonge, A., de Vries, R., & Lagro-Janssen, A. (2014). On speaking terms: a Delphi study on shared decision-making in maternity care. *BMC Pregnancy and Childbirth*, 14(1), 223. <https://doi.org/10.1186/1471-2393-14-223>

- Nieuwenhuijze, N., & Kane Low, L. (2013). Facilitating Women's Choice in Maternity Care. *Journal of Clinical Ethics*, 24(3), 276-282.
- Olsen, O., & Clausen, J. A. (2012). Planned hospital birth versus planned home birth. *Cochrane Database Syst Rev*, September 12, CD000352. <https://doi.org/10.1002/14651858.CD000352.pub2>
- Otley, H. (2011). Fear of childbirth: Understanding the causes, impact and treatment. *British Journal of Midwifery*, 19(4), 215–220. <https://doi.org/10.12968/bjom.2011.19.4.215>
- Petersen, W.E., Medves, J.M., Davies, B.,L., Graham, I.D. Multidisciplinary Collaborative Primary Maternity Care in Canada: easier said than done. (2006). The Multidisciplinary Collaborative Primary Maternity Care Model. *JOGC*, 29(11), 880-886.
- Records, K., & Wilson, B. L. (2011). Reflections on meeting women's childbirth expectations. *JOGNN*, 40(4), 394–398. <https://doi.org/10.1111/j.1552-6909.2011.01269.x>
- Reis, V., Deller, B., Carr, C., Smith, J. USAID, & Maternal and Child Health Integrated Program. (2012, November). Respectful Maternity Care: Country Experiences, Survey Report. *Maternal and Child Health Integrated Program, USAID*.
- Reed, R., Sharman, R., & Inglis, C. (2017). Women's descriptions of childbirth trauma relating to care provider actions and interactions. *BMC Pregnancy and Childbirth*, 17(21), 1-10. <https://doi.org/10.1186/s12884-016-1197-0>
- Riley, W., Begun, J. W., Meredith, L., Miller, K. K., Connolly, K., Price, R., ... Davis, S. (2016). Integrated Approach to Reduce Perinatal Adverse Events: Standardized Processes, Interdisciplinary Teamwork Training, and Performance Feedback. *Health Services Research*, 51(S3), 2431-2452.. <https://doi.org/10.1111/1475-6773.12592>
- Rittel, H. W. J., & Webber, M. M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, 4(2), 155–169. <https://doi.org/10.1007/BF01405730>
- Ross, L., & McLean, L. (2006). Anxiety disorders during pregnancy and the postpartum period: A systematic review. *Journal of Clinical Psychiatry*, 67(8), 1285–1298.
- Roome, S., Hartz, D., Tracy, S., Welch, A.W. (2016) Why such differing stances? A review of position statements on home birth from professional colleges, *BJOG*, 123 (3), 376-382.
- Roybal-Allard, L. (2011). *Congresswoman Roybal-Allard Speaks on the Home Birth Consensus Summit - YouTube*. YouTube.com. Retrieved from <https://www.youtube.com/watch?v=Nd7yn1wwkiU>
- Sandwick, T., Fine, M., Greene, A. C., Stoudt, B. G., Torre, M. E., & Patel, L. (2018). Promise and Provocation: Humble Reflections on Critical Participatory Action Research for Social Policy. *Urban Education*, 53(4), 473–502. <https://doi.org/10.1177/0042085918763513>
- Scarf, V. L., Rossiter, C., Vedam, S., Dahlen, H. G., Ellwood, D., Forster, D., ... Homer, C. S. E. (2018). Maternal and perinatal outcomes by planned place of birth among women with low-risk pregnancies in high-income countries: A systematic review and meta-analysis. *Midwifery*, 62, 240-255. <https://doi.org/10.1016/j.midw.2018.03.024>
- Schroeder, E., Petrou, S., Patel, N., Hollowell, J., Puddicombe, D., Redshaw, M., & Brocklehurst, P. (2012). Cost effectiveness of alternative planned places of birth in woman at low risk of complications: evidence from the Birthplace in England national prospective cohort study. *BMJ (Clinical Research Ed.)*, 344, e2292. <https://doi.org/10.1136/bmj.e2292>

- Schummers, L., Vedam, S., Fairbrother, N., Klein, M., & Kaczorowski, J. (2012). The Canadian birth place study: Development and validation of a survey instrument, and administration to multi-disciplinary maternity care providers. *Canadian Journal of Midwifery Research and Practice*, 11(1), 35–45.
- Schweitz, R., & Martens, K. (Eds.). (2005). *Future Search in school district change: Connection, community, and results*. Lanham, MD: Rowman & Littlefield Education.
- Sharts-Hopko, N. C. (2013). Tackling complex problems, building evidence for practice, and educating doctoral nursing students to manage the tension. *Nursing Outlook*, 61(2), 102–108. <https://doi.org/10.1016/j.outlook.2012.11.007>
- Shaw, D., Guise, J. M., Shah, N., Gemzell-Danielsson, K., Joseph, K. S., Levy, B., ... Main, E. K. (2016). Drivers of maternity care in high-income countries: can health systems support woman-centred care? *Maternal Health Series, 4. The Lancet, 1-14*. [https://doi.org/10.1016/S0140-6736\(16\)31527-6](https://doi.org/10.1016/S0140-6736(16)31527-6)
- Shlomi Polachek, I., Dulitzky, M., Margolis-Dorfman, L., & Simchen, M. J. (2015). A simple model for prediction postpartum PTSD in high-risk pregnancies. *Archives of Women's Mental Health*, 19, 3, 483–490. <https://doi.org/10.1007/s00737-015-0582-4>
- Sitzia, J. (1999). How valid and reliable are patient satisfaction data? An analysis of 195 studies. *International Journal for Quality in Health Care*, 11(4), 319–328. <https://doi.org/10.1093/intqhc/11.4.319>
- Society of Obstetricians & Gynaecologists of Canada. (2007). *A national birthing strategy for Canada*. Retrieved from <http://www.sogc.org/projects/pdf/BirthingStrategyVersionnbJune2107.pdf>
- Society of Obstetricians & Gynaecologists of Canada. (2011). *SOGC Position Statement - UBC Media Release - Trio of studies on attitudes of women, obstetricians, and family physicians on use of technology in childbirth*. Ottawa, ON: SOGC.
- Society of Obstetricians and Gynaecologists of Canada, College of Family Physicians of Canada, & Society of Rural Physicians of Canada. (2003). Number of births to maintain competence: Joint policy statement 113. Retrieved from <http://sogc.org/wp-content/uploads/2013/01/113E-JPS-April2002.pdf>
- SOGC (2009) Policy Statement on Midwifery. *J Obstet Gynaecol Can* 2009;31(7):662
- Stramrood, C. A. I., Paarlberg, K. M., Huis In 't Veld, T., Berger, L. W. A. R., Vingerhoets, J. J. M., Schultz, W.C.M., Van Pampus, M. G. (2011). Posttraumatic stress following childbirth in homelike-and hospital settings. *Journal of Psychosomatic Obstetrics and Gynecology*, 32, 88-97. <https://doi.org/10.3109/0167482X.2011.569801>
- Symon, A. (2006). Risk and choice in maternity care: an international perspective. *Edinburgh: Churchill Livingstone*.
- Symon, A, Winter, C., Donnan, P. T., & Kirham, M. (2010). Examining autonomy's boundaries: A follow-up review of perinatal mortality cases in UK independent midwifery. *Birth*, 37(4), 280–287. <https://doi.org/10.1111/j.1523-536X.2010.00422.x>
- ten Hoope-Bender, P., de Bernis, L., Campbell, J., Downe, S., Fauveau, V., Fogstad, H., ... Van Lerberghe, W. (2014). Improvement of maternal and newborn health through midwifery. *Lancet (London, England)*, 384(9949), 1226–1235. [https://doi.org/10.1016/S0140-6736\(14\)60930-2](https://doi.org/10.1016/S0140-6736(14)60930-2)

- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive Description: A Noncategorical Qualitative Alternative for Developing Nursing Knowledge. *Research in Nursing and Health* 20: 169–177. [https://doi.org/10.1002/\(SICI\)1098-240X\(199704\)20:2<169::AID-NUR9>3.0.CO;2-I](https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I)
- Torkar, G., & McGregor, S. L. T. (2012, March). Reframing the conception of nature conservation management by transdisciplinary methodology: From stakeholders to stakeholders. *Journal for Nature Conservation*, 20(2), 65-71. <https://doi.org/10.1016/j.jnc.2011.10.002>
- United Nations. (2017). The Sustainable Development Goals Report. *United Nations Publications*. Retrieved from <https://doi.org/10.18356/3405d09f-en>
- van Haaren-ten Haken, T., Hendrix, M., Nieuwehuijze, M., Bude, L., De Vries, R., & Nijhuis, J. (2012). Preferred place of birth: Characteristics and motives of low-risk nulliparous women in the Netherlands. *Midwifery*, 28(5), 609–618.
- Varcoe, C., Brown, H., Calam, B., Harvey, T., & Tallio, M. (2013). Help bring back the celebration of life: A community-based participatory study of rural Aboriginal women’s maternity experiences and outcomes. *BMC Pregnancy and Childbirth*, 13(1), 26. <https://doi.org/10.1186/1471-2393-13-26>
- Vedam, S., Aaker, J., & Stoll, K. (2010). Assessing Certified Nurse-Midwives’ Attitudes Towards Planned Home Birth. *Journal of Midwifery and Women’s Health*, 55(2), 133-142. <https://doi.org/10.1016/j.jmwh.2009.05.003>
- Vedam, S., Klein, M. C., Stoll, K., Dharamsi, S., & The Canadian Birth Place Study Team. (2013). Midwives and physicians: Explaining conflict and controversy around home birth. In *Family Medicine Forum*. Vancouver, BC.
- Vedam, S., Leeman, L., Cheyney, M., Fisher, T. J., Myers, S., Low, L. K., & Ruhl, C. (2014). Transfer from planned home birth to hospital: Improving interprofessional collaboration. *Journal of Midwifery and Women’s Health*, 6, 624–634. <https://doi.org/10.1111/jmwh.12251>
- Vedam, S., Schummers, L., Stoll, K., Rogers, J., Klein, M. C., Fairbrother, N., ... Kaczorowski, J. (2012). The Canadian birth place study: Describing maternity practice and providers’ exposure to home birth. *Midwifery*, 28(5), 600–8. <https://doi.org/10.1016/j.midw.2012.06.011>
- Vedam, S., Stoll, K. (2015). Access across birth settings: Understanding conflict and controversy among maternity providers. Canadian Public Health Association Annual Meeting. Vancouver, BC.
- Vedam, S., & Stoll, K. (2008). An analysis of barriers towards planned homebirths among North-American maternity care providers. In *8th Annual Conference of the Canadian Association of Midwives; November 13*, Canadian Association of Midwives Annual Meeting, Quebec City.
- Vedam, S., Stoll, K., Jolicouer, G., & Changing Childbirth in BC Steering Council. (2016). Provider Attitudes and Birth Place: Negotiating Divergence in Philosophy, Scope and Practice. In *International Normal Labour and Birth Research Conference*, Sydney, NSW.
- Vedam S, Stoll K, Khemet Taiwo T, Rubashkin N, Cheyney M, Strauss N, McLemore M, Cadena M, Nethery E, Rushton E, Schummers L, D. E. the Gv.-U. S. C. (2018). Mapping access to respectful care: the AIMM and Giving Voices Studies. In *ACNM Annual General Meeting*. Savannah, GA.
- Vedam, S., Stoll, K., Martin, K., Rubashkin, N., Partridge, S., Thordarson, D., & Jolicouer, G. (2017). 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. *PLoS ONE*, 12(2), 1-17. <https://doi.org/10.1371/journal.pone.0171804>

- Vedam S, Stoll K, MacDorman M, Declercq E, Cramer R, Cheyney M, Butt E et al. Mapping integration of midwives across the United States: Impact on access, equity, and outcomes. (2018). PLoS ONE. 13(2): e0192523. <https://doi.org/10.1371/journal.pone.0192523>
- Vedam, S., Stoll, K., McRae, D. N., Korchinski, M., Velasquez, R., Wang, J., ... Jolicoeur, G. (2018). Patient-led decision making: Measuring autonomy and respect in Canadian maternity care. *Patient Education and Counseling*, November, 1-12. <https://doi.org/10.1016/j.pec.2018.10.023>
- Vedam, S., Stoll, K., Rubashkin, N., Martin, K., Miller-Vedam, Z., Hayes-Klein, H., & Jolicoeur, G. (2017). The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *SSM - Population Health*, 3, 201–210. <https://doi.org/10.1016/j.ssmph.2017.01.005>
- Vedam, S., Stoll, K., Schummers, L., Fairbrother, N., Klein, M. C., Thordarson, D., ... Kaczorowski, J. (2014). The Canadian birth place study: examining maternity care provider attitudes and interprofessional conflict around planned home birth. *BMC Pregnancy and Childbirth*, 14(1), 353. <https://doi.org/10.1186/1471-2393-14-353>
- Vedam, S., Stoll, K., Schummers, L., Rogers, J., & Paine, L. L. (2014). Home birth in North America: Attitudes and practice of US certified nurse-midwives and Canadian registered midwives. *Journal of Midwifery and Women's Health*, 59(2), 141–152. <https://doi.org/10.1111/jmwh.12076>
- Vedam, S., Stoll, K., Schummers, L., Fairbrother, N., Klein, M. ., Thordarson, D., ... Kaczorowski, J. (2014). The Canadian birth place study: Examining maternity care provider attitudes and interprofessional conflict around planned home birth. *BMC Pregnancy and Childbirth*, 14(1), 353. <https://doi.org/10.1186/1471-2393-14-353>
- Vedam, S., Stoll, K., Taiwo, T. K., Rubashkin, N., Cheyney, M., Strauss, N., ... Declercq, E. (2019). The Giving Voice to Mothers study: Inequity and mistreatment during pregnancy and childbirth in the United States. *Reproductive Health*, 16, 77. <https://doi.org/10.1186/s12978-019-0729-2>
- Vedam, S., Stoll, K., White, S., Aaker, J., & Schummers, L. (2009). Nurse-midwives' experiences with planned home birth: Impact on attitudes and practice. *Birth*, 36(4), 274–282. <https://doi.org/10.1111/j.1523-536X.2009.00354.x>
- Warren, C. E., Njue, R., Ndwiga, C., & Abuya, T. (2017). Manifestations and drivers of mistreatment of women during childbirth in Kenya: Implications for measurement and developing interventions. *BMC Pregnancy and Childbirth*, 17(102), 1-14. <https://doi.org/10.1186/s12884-017-1288-6>
- Washington, S., Caughey, A. B., Cheng, Y. W., & Bryant, A. S. (2012). Racial and Ethnic Differences in Indication for Primary Cesarean Delivery at Term: Experience at One U.S. Institution. *Birth*, 39(2), 128-134. <https://doi.org/10.1111/j.1523-536X.2012.00530.x>
- Watson, H. L., & Downe, S. (2017). Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review. *Reproductive Health*, 14(1), 1-16. <https://doi.org/10.1186/s12978-016-0263-4>
- Wax, J. R., Lucas, F. L., Lamont, M., Pinette, M. G., Cartin, A., & Blackstone, J. (2010). Maternal and newborn outcomes in planned home birth vs planned hospital births: A metaanalysis. *American Journal of Obstetrics and Gynecology*, 203 (3), 243.e1–243.e8. <https://doi.org/10.1016/j.ajog.2010.05.028>
- Weisbord, M. (2004). *Productive workplaces revisited: Dignity, meaning and community in the 21st century*. San Francisco, CA: Jossey-Bass/Wiley.

- Weisbord, M., & Janoff, S. (2000). *Future Search: An action guide to finding common ground in organizations & communities*. San Francisco, CA: Berrett-Koehler Publishers, Inc.
- Weisbord, M., & Janoff, S. (2007). *Don't just do something, stand there!: Ten principles for leading meetings that matter*. San Francisco, CA: Berrett-Koehler Publishers, Inc.
- Weisbord, Marvin, & Janoff, S. (2007). Get the Whole System in the Room. *Journal for Quality and Participation*, 30(3),4-8.
- Wendland, C. (2007). The Vanishing Mother: Cesarean Section and “Evidence-Based Obstetrics.” *Medical Anthropology Quarterly*, 21(2), 218–233. <https://doi.org/10.1525/MAQ.2007.21.2.218>
- Witteman, H. O., Chipenda Dansokho, S., Colquhoun, H., Fagerlin, A., Giguere, A. M. C., Glouberman, S. et al. Volk, R. J. (2018). Twelve Lessons Learned for Effective Research Partnerships Between Patients, Caregivers, Clinicians, Academic Researchers, and Other Stakeholders. *Journal of General Internal Medicine*, 33(4), 558–562. <https://doi.org/10.1007/s11606-017-4269-6>
- Wong, S. T., Lynam, M. J., Khan, K. B., Scott, L., & Loock, C. (2012). The social paediatrics initiative: a RICHER model of primary health care for at risk children and their families. *BMC Pediatrics*, 12(1), 692. <https://doi.org/10.1186/1471-2431-12-158>
- WHO Technical Working Group.(1997). *Care in normal birth: A practical guide*. Geneva: WHO Safe Motherhood. *Birth*, 24(2), 121-12.
- World Health Organization (WHO). (2016). Standards for Improving Quality of Maternal and Newborn Care in Health Facilities. *WHO Document Production Services*, Geneva, Switzerland. Retrieved from [http://www.who.int/maternal\\_child\\_adolescent/documents/improving-maternal-newborn-care-quality/en/](http://www.who.int/maternal_child_adolescent/documents/improving-maternal-newborn-care-quality/en/)
- Yee, L. M., Costantine, M. M., Rice, M. M., Bailit, J., Reddy, U. M., Wapner, R. J., ... Tolosa, J. E. (2017). Racial and ethnic differences in utilization of labor management strategies intended to reduce cesarean delivery rates. In *Obstetrics and Gynecology*, 130(6), 1285–1294 <https://doi.org/10.1097/AOG.0000000000002343>



## APPENDIX A

### Author Contributions

#### Manuscript 1

Vedam S, Stoll K, Rubashkin N, Martin K, Miller-Vedam Z, Hayes-Klein H, Jolicoeur G, and the CCinBC Steering Council. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *Social Science and Medicine: Population Health*, 2017, 3: 201-210. <http://dx.doi.org/10.1016/j.ssmph.2017.01.005>

#### Author contributions

Conceived and designed the study: SV KS GJ CCinBC SC. Gathered the data: SV KS GJ KM CCinBC SC. Analyzed the data: SV KS NR GJ KM CCinBC SC. Contributed materials/analysis tools: SV KS GJ KM NR HHK ZMV. Wrote the paper: SV KS NR ZMV HHK GJ KM. Reviewed/edited/approved: SV KS NR HHK ZMV KS GJ CCinBC SC.

All authors read and approved the final manuscript.

Affiliations listed in manuscript.

---

#### Manuscript 2

Vedam S, Martin K, Rubashkin N, Partirdge S, Thordarson D, Jolicoeur G, and the CCinBC Steering Council. 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. *PLOS ONE*, 2017,12(2): 1-17. <http://dx.doi.org/10.1371/journal.pone.0171804>

#### Author Contributions

Conceptualization: SV KS GJ. Data curation: KS KM. Formal analysis: SV KS DT KM SP GJ. Funding acquisition: SV GJ. Investigation: SV KS GJ KM. Methodology: SV KS GJ. Project administration: SV GJ KS KM BR. Resources: SV KS GJ KM SP DT NR. Supervision: SV. Validation: SV KS KM SP. Visualization: SV KS KM. Writing – original draft: SV. Writing – review & editing: SV KS GJ KM SP DT NR.

All authors read and approved the final manuscript.

Affiliations listed in manuscript.

---

### Manuscript 3

Vedam S, McRae D, Korchinski M, Velasquez R, Wang J, Partridge S, McRae L, Martin R, Jolicoeur G, and then CCinBC Steering Council. The Changing Childbirth in BC Study: examining autonomy in Canadian maternity care. *Patient Education and Counselling*, 2018, Nov 18: 1-12. <https://doi.org/10.1016/j.pec.2018.10.023>

### Author Contributions

SV: conception and design of the study, acquisition of data, analysis, interpretation of data, drafting the article and revising it critically, final approval

KS: conception and design of the study, analysis, interpretation of data, drafting the article and or revising it critically, final approval

DM: acquisition of data, analysis, interpretation of data, revising article critically, final approval

MK: conception and design of the study, acquisition of data, revising article critically, final approval

RV: conception, acquisition of data, revising article critically, final approval

JW: interpretation of data, drafting the article, revising article critically, final approval

SP: interpretation of data, analysis, revising article critically, final approval

LM: the conception and design of the study, revising article critically, final approval

RM: the conception and design of the study, acquisition of data, interpretation of data, revising article critically, final approval

GJ: the conception and design of the study, acquisition of data, interpretation of data, revising article critically, final approval

All authors read and approved the final manuscript.

Affiliations listed in manuscript.

---

#### Manuscript 4

Vedam S, Stoll K, Taiwo TK, Rubashkin N, Cheyney M, Strauss N, McLemore M, Cadena M, Nethery E, Rushton E, Schummers L, Declercq E, and the GVtM-US Steering Council. Giving Voice to Mothers: inequity and mistreatment during pregnancy and childbirth in the United States. *Reproductive Health*, 2019, 16:77. <https://doi.org/10.1186/s12978-019-0729-2>

#### Author Contributions

SV Conceived the study and oversaw all aspects of the work, including community engagement, survey design, data collection and methods for analysis. Drafted, edited, and finalized the paper, submitted paper and managed and drafted all revisions and responses to editor and reviewers.

KV Participated in data analysis, and drafted/edited sections of the paper, assisted with revisions and responses to reviewers.

T K T, N R, MCh, NS, M McL, MC, LS, and ED advised on statistical analysis, drafted sections of the paper, helped to interpret data, revised, provided language for and/or edited the manuscript.

NS was also involved in item generation and content validation. EN contributed to data analysis and interpretation and ER participated actively in survey development and coordinating the content validation.

All authors read and approved the final manuscript.

Affiliations listed in manuscript.

---

#### Manuscript 5:

Vedam S, Stoll K, MacDorman M, Declercq E, Cramer R, Cheyney M, Fisher T, Butt E, Young YT, and Kennedy HP. (2018) Mapping integration of midwives across the United States: Impact on access, equity, and outcomes. *PLoS ONE*, 2019, 13(2): e0192523. <https://doi.org/10.1371/journal.pone.0192523>

#### Author Contributions

SV Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing

KS Data curation, Formal analysis, Funding acquisition, Investigation, Visualization, Writing – original draft, Writing – review & editing

MMcD Conceptualization, Data curation, Investigation, Resources, Supervision, Validation, Writing – review & editing

ED Conceptualization, Supervision, Validation, Writing – review & editing

RC Resources, Validation, Writing – review & editing

MC Conceptualization, Resources, Validation, Writing – review & editing

TF Conceptualization, Resources, Validation, Writing – review & editing

EB Data curation, Investigation, Validation, Writing – review & editing

YTY Validation, Writing – review & editing

HPK Methodology, Supervision, Writing – review & editing

All authors read and approved the final manuscript.

Affiliations listed in manuscript.

## APPENDIX B:

### Dissemination and Implementation of scales

Scale	Requested by	Country
Provider Attitudes towards Planned Home Birth Scale (PAPHB) – CN	Rosain Stennett The UWI School of Nursing, The University of the West Indies, Jamaica	Jamaica
PAPHB-CN	Lital Goldberg, MD (family physician), MPH Clalit Health Services, Israel	Israel
PAPHB-CN	Sandra Healy, PhD Student, Department of Nursing and Midwifery University of Limerick	Ireland
PAPHB- CN	Nasrin Javid, MMedSci, RM PhD student Centre for Midwifery, Child and Family Health, Faculty of Health   University of Technology Sydney	Australia
Provider Attitudes towards Planned Home Birth (USA)	Marjorie Greenfield, Obstetrics <a href="http://onlinelibrary.wiley.com/doi/10.1111/birt.12232/full">http://onlinelibrary.wiley.com/doi/10.1111/birt.12232/full</a>	USA
MADM	Meryem Kübra Şentürk Master student at Marmara University Faculty of Health Sciences, Division of Nursing, Department of Obstetrics and Gynecology Nursing, Başibüyük Mah. Maltepe Başibüyük Yolu Sk. /İstanbul TURKEY	Turkey
MADM	Petra Baji, Semmelweis University, Budapest (Department of Health Economics)	Hungary
MADM / MORi	Hannah Dahlen, Western Sydney University Department of Midwifery	Australia
MORi	Roonak Shahoei, PhD, Associate Professor School of Nursing & Midwifery, Kurdistan University of Medical Sciences(KUMS), Sanandaj, Iran	Iran
Mistreatment items/MADM/MORi	Reem Alghamdi, Queen’s University Belfast, School of Nursing & Midwifery	Ireland
MADM/MORi	Emma Swift, University of Iceland Midwifery	Iceland
MADM/MORi	Lilian L.Peters PhD Epidemiologist   postdoctoral researcher   Department of General Practice & Elderly Care Medicine   Section Midwifery Science   University Medical Center Groningen   The Netherlands Esther Feijen, Midwifery Science, AMU, Amsterdam	Netherlands
MADM/MORi	Marzia Lazzerini Paediatrician, DTMH, MSc, PhD	Italy

## Plain English summary

Global health experts agree that how people are treated during childbirth can affect the health and well-being of mother, child, and family, but very little is known about experiences of care among childbearing populations in the United States. In this study, community members worked with researchers to design a survey that would capture their lived experiences of care during pregnancy and childbirth, including seven types of mistreatment by health providers or health systems. We collected information across the country including from communities of colour, and women who planned to give birth at home or in a birthing center. Of the 2700 women who filled out the survey, one in six (17.3%) reported mistreatment. Among all participants, being shouted at or scolded by a health care provider was the most commonly reported type of mistreatment (8.5%), followed by “health care providers ignoring women, refusing their request for help, or failing to respond to requests for help in a reasonable amount of time” (7.8%). Some women reported violations of physical privacy (5.5%), and health care providers threatening to withhold treatment or forcing them to accept treatment they did not want (4.5%). Women of colour, women who gave birth in hospitals, and those who face social, economic, or health challenges reported higher rates of mistreatment. Rates were also increased in women who had unexpected events like cesareans or transfer from community to hospital care; and women who disagreed with a health care provider, about the right care for themselves or the baby, reported the highest rates of mistreatment.

## Background

High quality, respectful maternity care is a global priority [1]. In 2017, the World Health Organization (WHO) published eight standards for quality of maternal and newborn care that can be used to evaluate “the extent to which health care services provided to individuals and patient populations improve desired health outcomes and [are] safe, effective, timely, efficient, equitable and people-centred” [2]. Four of the standards emphasize care that demonstrates respect, dignity, emotional support, and a systemic commitment to a patient-led, informed decision-making process. The International Federation of Gynecologists and Obstetrics, the International Confederation of Midwives, the International Pediatric Association, and the White Ribbon Alliance have prioritized the WHO quality care standards, and protection of human rights in childbirth, as essential to optimizing birth outcomes [3].

Care provider actions and interactions are associated with women’s experience of trauma during birth, as indicated in an online survey ( $n = 748$ ) [4]. Qualitative

analysis identified four common themes: ‘prioritizing the care provider’s agenda’; ‘disregarding embodied knowledge’; ‘lies and threats’; and ‘violation’ [4]. A traumatic birth can have serious impact on postnatal mental health and family relationships. Short-term consequences of adverse experience of care include pain and suffering, and long-term consequences cited in the international literature include post-traumatic stress disorder, fear of birth, negative body image, and feelings of dehumanization [4–7]. In addition to these outcomes, fear of disrespect and abuse, and loss of autonomy have been cited as drivers for planned unattended home births, and reduce uptake of care, even among women with known risk factors [8]. Indeed, such mistreatment is itself an adverse outcome as it constitutes a violation of basic human rights [9].

Recognizing these serious health impacts, the World Health Organization (WHO) issued a statement in 2014 calling for further research on defining and measuring disrespect and abuse in public and private facilities worldwide [10, 11]; and urged health systems to protect and promote women’s rights to dignified and respectful care, in addition to ensuring universal access to timely, safe and effective clinical care [11]. While significant disparities in maternal and newborn outcomes are reported across populations in the United States (US) [12], very little is known about whether mistreatment is a component of these adverse outcomes. To understand experiences of childbirth care, especially among communities of color and those who choose to deliver in community settings, service users partnered with NGOs, clinicians, and researchers, to conduct the Giving Voice to Mothers (GVtM)–US study.

## Measuring mistreatment in high resource countries

To date, evaluations of respectful maternity care (RMC) have focused primarily on monitoring care during hospital births in low-resource settings [6, 13, 14]. However, childbearing women from high and middle resource countries have also reported negative experiences during hospital births, including being ignored, belittled or verbally humiliated by healthcare providers, having interventions forced upon them, and being separated from their babies without reason or explanation [7, 15–17]. For example, women from Slovakia who were interviewed ( $n = 15$ ) reported that care providers treated them as objects incapable of making decisions about their own care. Many of them did not consent to interventions such as episiotomies. Violations of their dignity, privacy, and confidentiality were common. Women said that care providers did not listen to them, doubted their perceptions and feelings, ignored their wishes, imposed their will on women, and made them feel guilty or like failures [17].

In high resource countries, pregnant people who are recent immigrants, Indigenous, and/or disenfranchised by their lower socioeconomic status, race/ethnicity, incarceration, substance dependence, or housing instability have been reported to be at increased risk for poor health outcomes, and reduced access to high quality care [18–22]. Few investigators have examined whether experiences of RMC differ by sociodemographic factors, but one U.S. national study identified racial disparities in the treatment of childbearing women in hospitals [23]. Among respondents, 30% of Black and Hispanic primiparous women and 21% of White women who delivered in hospitals in the US reported that they were “treated poorly because of a difference of opinion with [their] caregivers about the right care for [herself or her] baby” [23].

In 2015, the WHO Research Group on Treatment of Women During Childbirth conducted a systematic review of the literature on RMC [13]. Bohren and colleagues examined qualitative and quantitative evidence from 65 studies on the mistreatment of women during childbirth in health facilities across 34 countries, representing diverse geographical and economic settings. The investigators identified multiple examples of disrespect and human rights violations experienced by women giving birth, ranging from physical and verbal abuse, to a lack of supportive care, to neglect, discrimination, and denial of autonomy [13]. Noting wide inconsistencies in terminology and definitions of disrespect and abuse, the authors named the phenomenon “mistreatment” and delineated the phenomena across seven dimensions: physical abuse, sexual abuse, verbal abuse, stigma and discrimination, failure to meet professional standards of care, poor rapport between women and providers, and poor conditions and constraints presented by the health system [13]. They proposed that future investigators utilize this typology to inform studies that seek to understand the prevalence and impact of mistreatment across jurisdictions or populations, and/or to evaluate the success of interventions. Since 2015, numerous authors have responded to the Bohren typology, noting a lack of global evidence on the topic [24–27]. Some investigators have adapted the typology to qualitative studies of the prevalence and characteristics of mistreatment in low resource countries [14], but none to date have applied the typology to assess experience of care in high resource countries, and none have assessed the seven domains in a quantitative survey.

Notably, while the lived experience among study participants provided the descriptive data that informed the Bohren typology, none of the studies included in the systematic review used a patient-led approach to item development. Best practice in patient-oriented outcomes research would suggest that “mistreatment” as an

outcome may be best described and delineated by the recipients of care. Patient experience indicators of quality and safety are now routinely collected at institutions in other areas of medicine, yet patient-designed instruments that can assess the impact of experience of maternity care remain scarce.

In this paper, we introduce a set of patient-designed indicators of mistreatment that align with the typology proposed by Bohren et al., and are relevant to service users in high resource settings. We present results from a large national survey that utilized these items to examine how women in the US overall, and among key subgroups, report on mistreatment during pregnancy and childbirth. In addition, we examine the relationships between race and mistreatment in the context of factors that are frequently related to health inequity. The concept of intersectionality is rarely considered during design, analysis or interpretation of public health studies [28]; we aimed to address this gap in this study.

## Methods

In 2016, using a community-based participatory research process [29, 30], we convened a multi-stakeholder team to launch Giving Voice to Mothers (GVtM-US), a study of maternity care experiences of women who experienced pregnancy in the United States between 2010 and 2016. The only previous national study on experience of maternity care in the US was limited to women who planned hospital births, had limited information on differential experiences by race, and did not measure mistreatment [23]. Hence, our team, comprised of community members, clinicians, community health service leaders, and researchers designed a study on quality of maternity care as experienced by pregnant persons from 4 communities of colour (African American, Indigenous, Hispanic, and Asian) who gave birth in any location, as well as women who planned to give birth in homes and freestanding birth centers. The Behavioural Research Ethics Board at University of British Columbia approved the study (H15–01524). All participants reviewed an informed consent form before deciding whether they wanted to participate in the online survey.

## Survey development

The GVtM Steering Council recruited community agency leaders and service providers to adapt a survey instrument, developed by service users to study maternity care experiences in British Columbia, Canada [31–33], to the United States context. The validated instrument explored four domains including: preferences for care, interactions with care providers, role in decision-making, and access to care options. Following consultations with the communities they serve, the GVtM Steering Council identified, drafted, or adapted

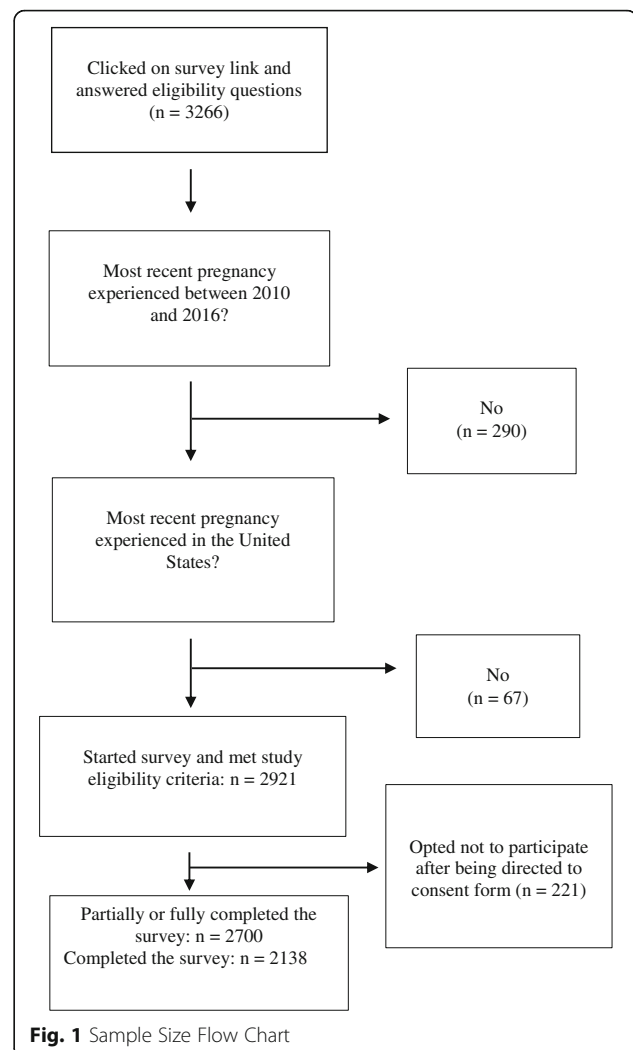
additional items from the literature that assess non-consensual care, disparities in access, social determinants, and institutional racism [34, 35]. Some items had been used to measure disrespect and abuse in low resource countries and were adapted for application to the US context [35].

The community agencies (NGOs) then recruited 57 women from the target populations to review the draft, and subsequently 31 community members, with representation from all target populations, served on an expert panel to formally content validate the adapted instrument. They rated each item on a 4-point ordinal scale for clarity, relevance, and importance and provided narrative commentary. We retained, revised, or discarded items based on best practice guidelines for content validation [36]. The community members strongly endorsed the inclusion of the previously validated quality measures, the Mothers Autonomy in Decision Making (MADM) scale [31] and the Mothers on Respect (MOR) index [32]. They also adapted the Perceptions of Racism (PR) scale [34] to be inclusive of all study populations. Community members suggested inclusion of additional novel items in the instrument such as “*When you experience problems, what helps you and your family survive, succeed and thrive?*” and, in cases of refusal of care, “*How did your doctor or midwife react?*” and “*Who stood up for you?*”. They provided detailed answer options that reflected their lived experience.

Most questions had pre-defined Likert response options, but the survey instrument also included several open-ended questions to allow participants to provide explanatory detail. The final GVtM survey instrument contained 218 items (the full list of survey items is available upon request via: <http://www.birthplacelab.org/contact-us/>), with 60 items measuring aspects of mistreatment. It was translated and back translated into a Spanish version, and both versions were mounted on an online platform that allowed for branching to questions adapted for participants who experienced pregnancy loss, and for those who were currently pregnant.

#### Inclusion criteria

Women who experienced at least one pregnancy in the United States between 2010 and 2016, including those currently pregnant, could participate. Of the 2700 women who completed or partially completed the survey, some participants skipped questions and others did not finish the survey, resulting in variable denominators for each section. Because we compare variables that appear across the entire survey, we restrict our analysis to the 2138 women who completed the survey. Details on sample delineation are in Fig. 1.



#### Recruitment

All partners participated in evidence-based strategies for recruitment of traditionally marginalized groups, including social networking and venue-based sampling [37–39]. We used strategies to ensure strong representation of women of colour, and women who planned a birth at home or at a freestanding birthing center. For example, we engaged agencies in study recruitment who serve these populations, and some held survey café events with computer access available, and/or trained peers, known as “data doulas” [40] to support participants with their own data entry. To achieve our goal of robust sampling from women of colour and those who chose home and birth center births, based on the rates of participation to date, halfway through the data collection period we closed the survey to women who identified as White and who gave birth in a hospital, but kept it open to other participants.



In New York State data collection was embedded in an established ongoing statewide maternity care evaluation project led by one of the NGO partners, Choices in Childbirth. The Steering Council recognized that this was likely to lead to oversampling from a single state; hence, they initially considered launching the study as a New York State pilot study to demonstrate feasibility and generate enough data to highlight need for national follow up. However, community members served by the distributed NGOs and clinicians on the team felt strongly that they wanted the GvTM study to be open to participants from rural, urban, and suburban contexts *across* the United States. They felt that social media recruitment had the greatest potential for securing comparative data from a wide range of service users. Hence, to respect an authentic, patient-oriented participatory research process, the survey was distributed nationally. The GvTM survey was open from March 2016–March 2017.

## Measurement

### Mistreatment

Content validation resulted in new patient-designed and patient-validated items to measure mistreatment in childbirth that align with the dimensions codified by Bohren (Table 1) [13]. Of note, the community members on the Steering Council and the women who participated during the expert content validation stage endorsed these items without knowledge of the Bohren systematic review in progress, yet their lived experience resonated with the typology. Specifically, the mistreatment items measure the following domains: physical abuse, sexual abuse, verbal abuse, neglect and abandonment, poor rapport between women and providers, loss of confidentiality, and lack of supportive care. Community members also elected to include the MADM (autonomy) and MOR (respect), and an adapted Perceptions of Racism scale [34] that measure other domains in the Bohren typology: stigma and discrimination, failure to meet professional standards of care, lack of informed consent, and loss of autonomy. Twenty-two additional survey items related to the typology and assessed RMC, such as care provider behaviors in response to refusal of care, and the respondent's overall sense of dignity, respect, and privacy during interactions with providers.

The focus of the current paper is application of mistreatment items that describe patient experience of provider behaviors. Subsequent reports will focus on analysis of data related to the mistreatment domains of autonomy and respect (eg. MADM, MOR, and PR scale scores), and non-consented care among the GvTM participants.

### Maternal/paternal race

Community members on the study team recommended that research that relies on US Census categories fails to

capture the lived experience of people who self-identify across more than one race, and/or experience the effects of visible minority race. Accordingly, the team designed a complex but respectful and realistic approach to collecting and coding this set of items. Respondents could self-identify and provide considerable detail about their identity, selecting multiple descriptors under 13 pre-defined categories. For analysis, we recoded this variable into mutually exclusive categories (see Additional file 1: Table S1). We used the same coding scheme for paternal race/ethnic identity (as identified by the woman), and also created four variables that describe combinations of maternal/paternal race, i.e. 1) woman white, partner white, 2) women black, partner black, 3) women white, partner black, 4) women black, partner white. Throughout this paper Indigenous includes participants who self-identify as Native American, Native Hawaiian or Pacific Islander, Alaska Native, or Indigenous to Mexico or South America.

### Low SES

We created a comprehensive composite index that measures low SES, taking into account family income below the federal poverty threshold (based on before tax family income and household size). In the low SES category, we also counted respondents who reported that their heat or electricity was turned off (during or in the year before pregnancy), inability to buy enough food or meet financial obligations; and respondents who reported receiving a housing subsidy, assistance from Indian Health Services or a state health plan, Temporary Assistance for Needy Families (TANF), food stamps, WIC food vouchers or money to buy food. We coded respondents with one or more of the indicators of low SES as 1; and respondents that did not report any of the indicators as 0.

### History of social risks

To distinguish those who may experience differential treatment because of social factors, we grouped together respondents who reported substance use (smoking, daily alcohol use during pregnancy, and/or drug dependence) during pregnancy, women with a history of incarceration (herself or partner), involvement of child or family services, and/or intimate partner violence. Women who reported one or more of the indicators of social risk were coded as 1; women did not report any social risk indicators were coded as 0. We also created composite indices that measure elevated pregnancy risks and newborn health problems. A description about how these indices were derived can be found in footnotes below the tables.

### Analysis

To describe the overall prevalence of mistreatment in the study population, we calculated the proportion of

**Table 1** GvTM items that align with WHO [63] typology of mistreatment

Bohren et al. – Third-Order Themes	Bohren et al. – Second -Order Themes	GvTM – US items and scales
Physical abuse	Use of force Physical restraint	"You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)"
Sexual abuse	Sexual abuse	
Verbal abuse	Harsh language Threats and blaming	"Health care providers (doctors, midwives, or nurses) shouted at or scolded you" "Health care providers threatened to withhold treatment or to force you to accept treatment you did not want" "Health care providers threatened you in any other way"
Stigma and discrimination	Discrimination based on socio-demographic characteristics	Mothers on Respect (MOR) Index (14 items) <sup>a</sup> <ul style="list-style-type: none"> <li>• Adapted 17-item Perceptions of Racism Scale</li> <li>• Four items that assess perceived discrimination from care providers or other disrespectful care provider behaviours, e.g. During my pregnancy I held back from asking questions or discussing my concerns because I felt discriminated against; During my pregnancy I held back from asking questions or discussing my concerns because my care provider used language I could not understand.</li> <li>• One item asking women how often they have felt treated unfairly because of their race, heritage or ethnic group</li> </ul>
Failure to meet professional standards of care	Lack of informed consent and confidentiality Physical examinations and procedures Neglect and abandonment	"Your private or personal information was shared without your consent" "Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)" "My doctor or midwife explained different options for care during my labour and birth." "My doctor or midwife asked me what I wanted to do before the following procedures were done: (episiotomy, continuous fetal monitoring, screening tests etc)." "Health care providers ignored you, refused your requests for help, or failed to respond to requests for help in a reasonable amount of time."
Poor rapport between women and providers	Ineffective communication Lack of supportive care Loss of autonomy	Mother Autonomy in Decision Making scale (MADM) (7 items) <sup>b</sup> <ul style="list-style-type: none"> <li>• Three items that ask women to rate the level of respect, dignity and privacy that their care provider showed during labour and/or birth</li> <li>• Five items about care that women declined, what they declined, why, how their care provider reacted and if anyone helped the woman maintain her wishes.</li> </ul>
Health system conditions and constraints	Lack of policies Facility culture	Adapted Perceptions of Racism Scale included items assessing treatment in medical offices and hospital wards

<sup>a</sup>Vedam S, Stoll K, Rubashkin N, et al. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *Social Science and Medicine: Population Health*. <https://doi.org/10.1016/j.ssmph.2017.01.005>

<sup>b</sup>Vedam S, Stoll K, Martin K, et al. 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. *PLOS ONE* <https://doi.org/10.1371/journal.pone.0171804>

women who experienced each of the seven types of mistreatment and what proportion experienced any mistreatment (i.e. any of the seven indicators). We report sociodemographic variables for all women who started the survey and met eligibility criteria ( $n = 2700$ ), as well as for all women who completed the last item on the survey ( $n = 2138$ ). Rates of mistreatment are stratified by maternal characteristics such as race, parity, age, immigrant status, SES, pregnancy health status, and social risks (history of substance use, incarceration and/or intimate partner violence); as well as context of care factors (induction, mode of birth, place of birth, type of provider, and disarticulation between their own preferences for care and their provider's recommendations).

We used logistic regression to quantify the relationship between mistreatment and the variables described above. To examine the relationship between mistreatment and maternal race/ethnicity, we calculated odds ratios comparing the odds of mistreatment among women of color to the odds among white women.

To elucidate the intersectional relationships between maternal race and other factors that are linked to mistreatment, we examined the relationship between race and mistreatment within categories of other sociodemographic and context of care variables. Within categories (e.g., nulliparous, age 17–25 years, place of birth), we calculated the prevalence of mistreatment among women of colour and white women separately.

Larger differences between groups indicate larger disparities in mistreatment by race.

To report illustrative details provided in open-ended text boxes, community and research team members verified the applicability and resonance of the Bohren framework and recommended that we include the voices of mothers by identifying exemplars based on the Bohren typology. Three team members independently reviewed the text boxes and came to consensus about representative quotes, which were then reviewed and approved by the community partners.

## Results

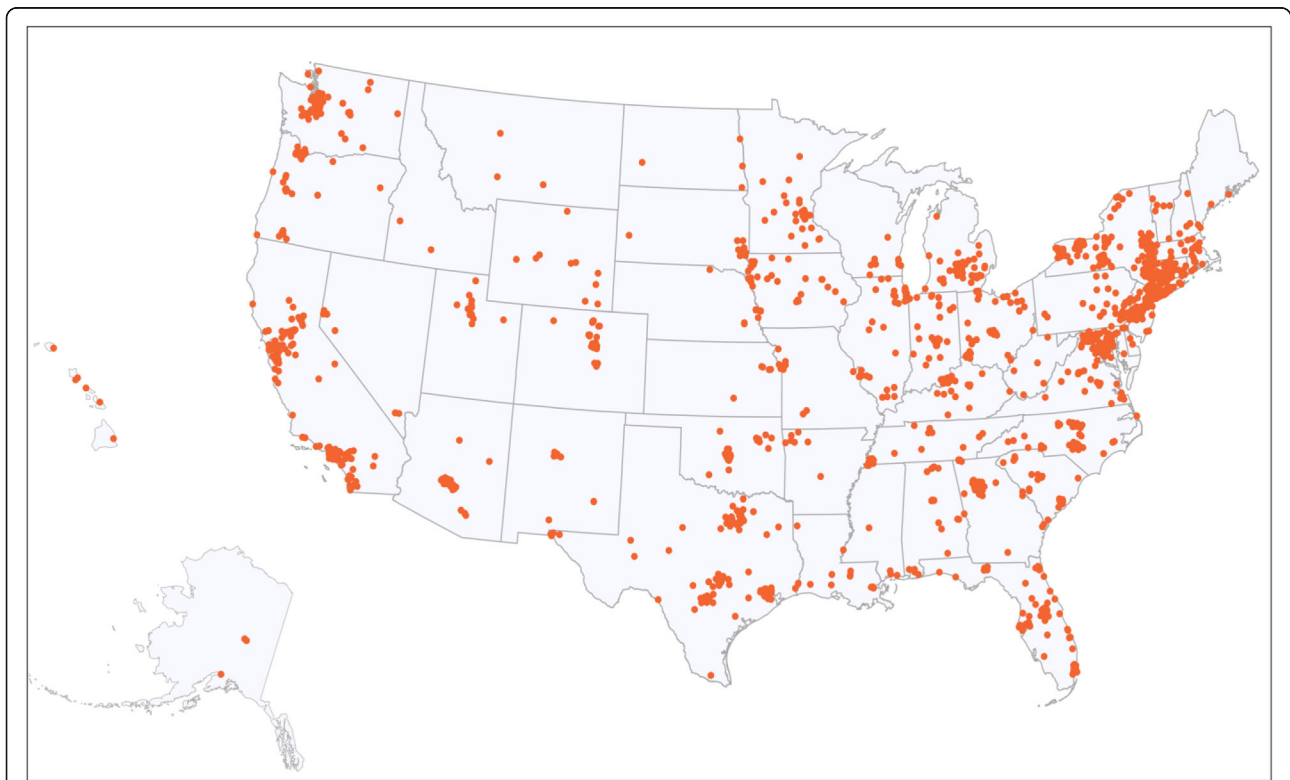
### Sample ( $n = 2138$ )

The majority of participants (64.5%) were between the ages of 25 and 35 when they gave birth; 13.5% were pregnant at the time of data collection. Most were born in the US (90%) and the majority completed post-secondary education. Participants from all 50 states completed the survey (see Fig. 2), and as expected, the largest proportion of responses were submitted by women from New York State (29.7%). One in three women across the whole sample reported family incomes less than \$50,000 per year. The majority of participants received prenatal care from midwives (71.1%), and half (49.6%) gave birth in their homes or a free-standing birth center. Fewer women of colour had

prenatal care by midwives (eg. 59.9%) compared to white women (76.5%), and fewer women of colour (38.2%) compared to white women (55.2%) gave birth in homes or birth centers. Close to 14% of women had a Cesarean birth (CB), with variation by race: 17.8% women of colour had a CB compared to 11.8% of White women. Additional file 1: Table S2 displays socio-demographic characteristics for the 2700 participants, the 2138 participants included in the analysis of mistreatment items. Sample characteristics for the 2138 women included in the mistreatment analysis closely resembled those of all women who started the survey ( $n = 2700$ ).

### How common is mistreatment?

One in six women (17.3%) in our sample experienced one or more types of mistreatment (Table 2). Being shouted at or scolded by a health care provider was the most commonly reported type of mistreatment (8.5%), followed by “health care providers ignoring women, refusing their request for help, or failing to respond to requests for help in a reasonable amount of time” (7.8%). Fewer women reported violation of physical privacy (5.5%), and health care providers threatening to withhold treatment or forcing them to accept treatment they did not want (4.5%). Very few women reported physical abuse, sharing of their personal information without consent, or healthcare providers threatening



**Fig. 2** Map of zip codes, representing maternal residence at time of pregnancy

**Table 2** Mistreatment by Care Providers in Childbirth (MCPC) Indicators ( $n = 2138$ )

Did you experience any of the following issues or behaviours during your care?	<i>n</i> (%)
Your private or personal information was shared without your consent	26 (1.2)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	117 (5.5)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	182 (8.5)
Health care providers threatened to withhold treatment or to force you to accept treatment you did not want	97 (4.5)
Health care providers threatened you in any other way	44 (2.1)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	166 (7.8)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, refusal to provide anesthesia for an episiotomy, etc.)	27 (1.3)
Any mistreatment (one or more of the above)	369 (17.3)

them in other ways (see Table 2). See Table 3 for quotes from the GVTM survey, illustrating mistreatment of US women.

### Mistreatment by sociodemographic factors

#### *Race, ethnicity and immigration status*

Indigenous women were the most likely to report experiencing at least one form of mistreatment by health-care providers (32.8%), followed by Hispanic (25.0%) and Black women (22.5%). Women who identified as White were least likely to report that they experienced any of the mistreatment indicators (14.1%). Differences in mistreatment by race were pronounced for some indicators. For example, twice as many Hispanic and Indigenous women as compared to White women reported that health care providers shouted at or scolded them. Likewise, Black women, Hispanic women, Asian, and Indigenous women were twice as likely as White women to report that a health care provider ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time (see Table 4).

Overall, White women with a White partner reported the least mistreatment (12.0%), followed by White women with a Black partner (17.0%) (see Additional file 1: Table S3). Bi-racial couples experienced less mistreatment when the woman was White as opposed to Black. However, for some indicators of mistreatment (eg., *Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time*) White women with a Black partner were twice as likely to report mistreatment when compared to White women with a White partner.

Women who were born in the US reported similar rates of mistreatment compared to women who were not born in the US, but had lived there for more than 5 years (see Additional file 1: Table S4). Recent immigrants were more likely to report mistreatment, although results should be interpreted with caution as the number of recent immigrants was small ( $n = 34$ ).

#### *Age and parity*

One in four women 24 or younger reported any mistreatment compared to one in seven women over 30 years old. Young women were also more likely to report physical abuse by providers compared to older women (Additional file 1: Table S5). Multiparous women reported lower rates of mistreatment on all indicators (see Additional file 1: Table S6), compared with women who were first-time mothers. Overall, first-time mothers were twice as likely to report mistreatment.

#### *Socioeconomic, social, and pregnancy risk status*

Women who reported low SES had similar rates of mistreatment on some of the indicators (e.g. sharing of personal information without consent) but were twice as likely to report being threatened or shouted at by HCPs, compared to women with moderate or high SES (Table 5). Women with pregnancy complications and women with social risks (i.e. a history of substance use, incarceration, and/or IPV) reported among the highest overall mistreatment rates among the subpopulations studied, with one in three reporting any mistreatment. These two groups were also more likely to report being shouted at or scolded and that their physical privacy was violated (Table 5).

#### Mistreatment by context of care

##### *Place of birth*

Table 6 shows higher rates of mistreatment in hospital settings (28.1%), including birth centers that are located inside hospitals (24.0%), than in community birth settings (home or freestanding birth center). Rates of mistreatment were similar between women who gave birth at home (5.1%) or in a freestanding birth center (7.0%). The likelihood of being ignored by care providers and/or providers refusing to help was three times more common among women who gave birth in hospital settings (12.6 and 10.8%), compared to those who delivered at home (2.3%) or in a freestanding birth center (2.5%). Violation of physical privacy was also three times more common in hospital settings. Being threatened by care

**Table 3** Quotes illustrating mistreatment of US women

*Before I switched to a birth center, one military midwife was disrespectful of our cultural needs and refused to accept them. When I mentioned my desires, I was belittled and made to feel incompetent.*

Hispanic woman who gave birth in California

*The doctor who refused to test me for an amniotic fluid leak and instead tested me for an STD test I had already received during the pregnancy. I believe his assumption that I was leaking something due to an STD rather than a pregnancy complication was due to race and put my life and my newborns life at risk - I went a week leaking fluid after I had went in to get it checked out. I worry that Doctor is still discriminating against other mothers and they are receiving negligent care as well.*

Black woman who gave birth in California

*I was told I was hurting my children and being selfish because I wanted to have a vaginal delivery. Both children were in head down birth position. I was forced into a cesarean by my OB.*

Indigenous woman who gave birth in Texas

*The doctor who performed my c-section was hateful, rude, rough and threatening.*

Indigenous woman who gave birth in Oklahoma

*[I was] forced to be in a hospital because of having Medicaid which led to many interventions and being bullied/talked down to until I agreed. This pregnancy we saved up for a midwife so I can have a home birth.*

Indigenous woman who gave birth in New York State

*The amount of times I felt coerced into decisions or was mocked or rushed. Overall it was a very dehumanizing and frustrating experience ... my original ob/gyn practice was rude and insulting to me and said that I risked having child protective services being called if I refused antibiotics due to being GBS positive.*

White woman who gave birth in NJ

*The forced episiotomy. The doctor didn't care, refused to give me medication because my episiotomy hurt, Nurse XX from XX told me to get over it and gave me lube & told me to do anal sex instead! That's the care we're getting in Southern California if you are not insured & have to rely on Medical insurance.*

Hispanic woman who gave birth in California

*When I refused to be induced-even after I was a couple days "overdue" I seriously started to feel like \*! was the problem. It was horrible.*

White woman who gave birth in Iowa at 24

*I hated being shouted at and lied to by the midwife.. I never dreamed that a woman would treat a laboring woman that way. She was abusive and downright mean. I was refused food and water for 26 hours. I wasn't allowed to move out of bed to walk around. I felt like I lost my autonomy over my own body. I had given up and I remember weeping when my son was born. I was at least glad he was safe. I felt like a child and I felt so unlike my usual self. These professionals broke my spirit.*

Hispanic woman who gave birth at a in hospital birth center inside a hospital in North Carolina

*The way I was treated during postpartum. If I was given adequate support with breastfeeding and actual education about it, I feel I would have been successful outright instead of struggling for months, and if I was not judged for being a younger mom, I would have felt safe and secure*

South Asian woman who gave birth in Nevada

*One nurse, whom we otherwise really liked, made comments generalizing about people by race (e.g., "you Asian women all tear during birth"). It wasn't done in a judgmental way but I would have preferred that she not say such things.*

East Asian woman

*I was offered WIC repeatedly though I explained that I did not qualify. I believe it was because I am Latina and my partner black that we were repeatedly offered WIC.*

Hispanic woman with Black partner in New York

providers or having treatment withheld/being forced to accept treatment was twice as likely in hospital settings, compared to community settings.

Women who were transferred from a community setting to a hospital, after the onset of labor, experienced high rates of mistreatment (34.6%). One in four reported being shouted at or scolded by a health care provider, one in ten were threatened, and one in seven were ignored (Table 6). Of the women who transferred to hospital from a home birth ( $n = 80$ ), 37 (46.3%) reported that they were treated poorly by health professionals during their transfer or afterwards because of their decision to have a home birth.

### Mode of delivery

Additional file 1: Table S7 shows much higher rates of mistreatment when women had unplanned Cesareans and instrumental vaginal births. Women who had a vaginal birth after caesarean (VBAC) reported low levels of mistreatment. Separating women who had a VBAC in a community birth setting versus in a hospital revealed that 1 in 3 women who had a VBAC in the hospital experienced mistreatment versus 6% of women who gave birth in the community.

### Newborn health problems

One in four women who reported that their newborn(s) had any health problems experienced one or more types of mistreatment. Women whose newborns had health problems were more likely to report that their private or personal information was shared without their consent and that providers ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time, compared to women whose newborns did not have health problems (see Additional file 1: Table S8).

### Disarticulation between provider and woman

We found higher rates of mistreatment when preferences for care did not align between women and providers: Any mistreatment was reported by 19.4% of women who declined care during pregnancy or birth, 37.9% of women who reported being pressured into one or more medical interventions or procedures, and 78.8% if they also had a difference in opinion with their care provider (see Additional file 1: Table S9).

### Demographic and other factors related to mistreatment

In bivariable logistic regression analyses (Table 7), we found that Black, Hispanic and Indigenous women, primiparas and women with elevated pregnancy risks were significantly more likely to report mistreatment, compared with White women. Younger women, women with a history of substance use, incarceration and/or

**Table 4** Mistreatment indicators, stratified by maternal race (n = 2138)

	Black n = 320 n (%)	Hispanic n = 188 n (%)	Indigenous n = 64 n (%)	Asian n = 90 n (%)	Women of colour n = 682 n (%)	White n = 1416 n (%)
Your private or personal information was shared without your consent	2 (0.6)	5 (2.7)	2 (3.1)	0 (0)	9 (1.3)	17 (1.2)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	27 (8.4)	12 (6.4)	6 (9.4)	7 (7.8)	52 (7.6)	62 (4.4)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	35 (10.9)	30 (16.0)	10 (15.6)	9 (10.0)	87 (12.8)	90 (6.4)
HCPs threatened to withhold treatment or to force you to accept treatment you did not want	21 (6.6)	11 (5.9)	7 (10.9)	6 (6.7)	45 (6.6)	51 (3.6)
Health care providers threatened you in any other way	6 (1.9)	8 (4.3)	3 (4.7)	1 (1.1)	18 (2.6)	26 (1.8)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	41 (12.8)	23 (12.2)	7 (10.9)	12 (13.3)	85 (12.5)	79 (5.6)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	6 (1.9)	4 (2.1)	0 (0)	1 (1.1)	11 (1.6)	16 (1.1)
Any mistreatment (one or more of the above)	72 (22.5)	47 (25.0)	21 (32.8)	19 (21.1)	162 (23.8)	199 (14.1)

interpersonal violence (IPV) and those of low socio-economic status also reported significantly increased odds of mistreatment compared with those that did not have these sociodemographic risk factors for mistreatment (see Table 7). Finally, context of care was linked to mistreatment. Women who had prenatal care from midwives were much less likely to report mistreatment compared to those who had prenatal care from physicians (OR 0.31, 95% CI 0.25–0.40), whereas an unplanned Cesarean or assisted

vaginal birth was linked to significantly increased odds of mistreatment compared to spontaneous vaginal delivery (OR 3.7, 95% CI 2.8–5.0). Women who gave birth at the hospital were 7 times as likely to report any mistreatment compared to women who gave birth in the community (OR 7.2, 95% CI 5.3–9.7). Women who reported a difference in opinion with their care provider had very high odds of mistreatment compared with those who did not report a difference in opinion (OR 22.7, 95% CI 13.9–36.9).

**Table 5** Mistreatment, stratified by SES, and elevated pregnancy/social risk (n = 2138)

	Low SES		Elevated pregnancy risks		Elevated social risks	
	Yes (n = 743) n (%)	No (n = 1395) n (%)	Yes (n = 441) <sup>a</sup> n (%)	No (n = 1697) n (%)	Yes (n = 176) <sup>b</sup> n (%)	No (n = 1962) n (%)
Your private or personal information was shared without your consent	12 (1.6)	14 (1.0)	10 (2.3)	16 (0.9)	5 (2.8)	21 (1.1)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	47 (6.3)	70 (5.0)	37 (8.4)	80 (4.7)	23 (13.1)	94 (4.8)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	89 (12.0)	93 (6.7)	68 (15.5)	114 (6.7)	27 (15.3)	155 (7.9)
Health care providers threatened to withhold treatment or to force you to accept treatment you did not want	48 (6.5)	49 (3.5)	34 (7.7)	63 (3.7)	17 (9.7)	80 (4.1)
Health care providers threatened you in any other way	19 (2.6)	25 (1.8)	13 (2.9)	31 (1.8)	5 (2.8)	39 (2.0)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	78 (10.5)	88 (6.3)	53 (12.0)	113 (6.7)	23 (13.1)	143 (7.3)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	19 (2.6)	8 (0.6)	10 (2.3)	17 (1.0)	6 (3.4)	21 (1.1)
Any mistreatment (one or more of the above)	160 (21.5)	209 (15.0)	123 (27.9)	246 (14.5)	53 (30.1)	316 (16.1)

<sup>a</sup>Elevated pregnancy risk status: Women were grouped as having pregnancy risk factors if they reported a pre-pregnancy BMI of 40 or higher, were carrying twins, or reported that they experienced high blood pressure, gestational diabetes or other health complications during pregnancy (including breech baby, problems with baby's growth/health, preterm labour, but not preterm birth)

<sup>b</sup>History of social risks: To distinguish those who may experience differential treatment because of social factors, we grouped together women who reported substance use (smoking or daily alcohol use during pregnancy, and/or drug dependence during pregnancy), women with a history of incarceration (herself or partner), involvement of child or family services, and/or reported intimate partner violence

**Table 6** Mistreatment, stratified by actual place of birth (*n* = 1954)

	Hospital ( <i>n</i> = 759)	Birth Centre Inside Hospital ( <i>n</i> = 167)	Birth Centre Outside Hospital ( <i>n</i> = 157)	Home ( <i>n</i> = 871)	Transferred to hospital from community ( <i>n</i> = 107)
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Your private or personal information was shared without your consent	9 (1.2)	5 (3.0)	1 (0.6)	7 (0.8)	0 (0)
Your physical privacy was violated (i.e., being uncovered or having people in the delivery room without your consent)	78 (10.3)	15 (9.0)	1 (0.6)	7 (0.8)	13 (12.1)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	98 (12.9)	18 (10.8)	4 (2.5)	19 (2.2)	28 (26.2)
Health care providers threatened to withhold treatment or to force you to accept treatment you did not want	50 (6.6)	7 (4.2)	5 (3.2)	16 (1.8)	10 (9.3)
Health care providers threatened you in any other way	19 (2.5)	4 (2.4)	4 (2.5)	6 (0.7)	9 (8.4)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	96 (12.6)	18 (10.8)	4 (2.5)	20 (2.3)	19 (17.8)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	16 (2.1)	3 (1.8)	1 (0.6)	1 (0.1)	4 (3.7)
Any mistreatment (one or more of the above)	213 (28.1)	40 (24.0)	11 (7.0)	44 (5.1)	37 (34.6)

**Table 7** Crude odds ratios estimating associations between maternal characteristics and any mistreatment (*n* = 2138)

	<i>n</i>	OR	95% CI	
		Logistic Regression	Lower bound	Upper bound
<b>SOCIO-DEMOGRAPHICS</b>				
Maternal Race: Black (reference category: white)	2098	1.77	1.31	2.40
Maternal Race: Hispanic (reference category: white)	2098	2.04	1.42	2.93
Maternal Race: Asian (reference category: white)	2098	1.64	0.97	2.77
Maternal Race: Indigenous (reference category: white)	2098	2.98	1.73	5.13
Maternal Race: Women of colour (reference category: white women)	2098	1.91	1.51	2.41
Age: 17 to 25 years (reference category: 31–39)	1956	1.71	1.08	2.69
Age: 26–30 years (reference category: 31–39)	1956	1.15	0.88	1.49
Age: Over 40 (reference category: 31–39)	1956	1.04	0.62	1.74
Nulli/primiparity (reference category: multiparity)	2135	2.50	1.99	3.14
Low SES - Yes (reference category: no)	2138	1.56	1.24	1.96
<b>MEDICAL OR SOCIAL FACTORS</b>				
Elevated pregnancy risk - Yes (reference category: no)	2138	2.28	1.78	2.92
History of substance use, incarceration and/or IPV (social risk)- Yes (reference category: no)	2138	2.24	1.59	3.17
<b>CONTEXT OF CARE</b>				
Prenatal midwifery care (reference group: prenatal physician care)	2076	0.31	0.25	0.40
Actual place of birth hospital or alongside birthing center (reference group: community birth)	2119	7.17	5.31	9.68
Mode of birth unplanned Cesarean or operative vaginal delivery (reference group: planned Cesarean or spontaneous vaginal birth)	2129	3.72	2.79	4.97
Difference in opinion with care provider (reference group: no difference in opinion with care provider)	2138	22.69	13.94	36.92

### Intersection between race, other maternal characteristics, and context of care

When examining the intersection of race and the maternal characteristics, rates of mistreatment among women of colour who were young, nulliparous or primiparous, or had low SES, social risk factors, or pregnancy complications were higher than for white women who reported the same conditions or experiences. For example, among those who had pregnancy complications, mistreatment was reported by 37.0% women of colour versus 22.1% white women. Similarly, women of colour with low SES reported higher rates of mistreatment than white women with low SES (26.9% versus 17.7%). Regardless of race, among women who had a difference in opinion with their care provider, the majority (83.0% of women of colour, 76.4% of white women) reported one or more types of mistreatment (Table 8).

Place of birth and operative birth appear to have similar modification effects for both women of color and white women. Giving birth at home or in a freestanding birth center was associated with lower rates of mistreatment across racial groups, when compared to rates of mistreatment among women who gave birth in hospitals. For example, among women of colour who gave birth in the community, 6.6% reported any mistreatment, compared to 33.9% who gave birth at hospitals.

### Discussion

In the Giving Voice to Mothers study, service users of maternity care in the US described mistreatment across categories that closely align with the WHO (Bohren) typology that was derived from global evidence on the phenomena. In this study of care in a high resource country, physical abuse was uncommon, but verbal abuse and failure to respond to requests for

help were the most common types of reported mistreatment; rights to information and autonomy were apparently disregarded; and difference of opinion with care providers had a strong association with reported mistreatment. While the overall rates of mistreatment are lower in our US sample than recent studies report in low resource settings [5], they are still unacceptably high for a high resource country given a cultural emphasis on autonomy, gender equity, human rights, better working conditions for providers, and resources for training.

Protective factors, in terms of mistreatment were: being White, having a vaginal birth, giving birth at home or in a freestanding birth center, having a midwife as the primary prenatal provider, and having a baby after 30 years of age. Being multiparous was also protective, which may suggest that prior experience helps patients avoid disrespectful treatment, or conversely that disrespectful treatment is normalized by prior experiences among certain populations. Importantly, more than half of our sample planned community births, and they experienced very low rates of mistreatment when compared to those who gave birth in hospital. Since less than 2% of all childbearing women in the US give birth in community settings [41], the rate of mistreatment (30%) among women in our sample who gave birth in a hospital, is likely a better estimate of the true rate of mistreatment during childbirth among US women.

### Patient-led measurement of health equity

In 2017 the National Quality Forum (NQF) convened a multi-stakeholder group of experts to develop a shared agenda to achieve health equity [42]. The team

**Table 8** Intersection between mistreatment, race and additional variables (n = 2138)

Intersectional Factor	n	n (%) who report any mistreatment	
		Women of colour (n = 162)	White women (n = 199)
<b>Sociodemographics</b>			
Nulliparity	811	92/282 (32.6)	114/529 (21.6)
Age 17–25 years	116	17/55 (30.9)	11/61 (18.0)
Low SES	726	83/309 (26.9)	74/417 (17.7)
<b>Medical or Social Factors</b>			
Elevated pregnancy risk	434	60/162 (37.0)	60/272 (22.1)
Social risk	172	30/66 (45.5)	21/106 (19.8)
<b>Context of care</b>			
Prenatal midwifery care	1120	63/393 (16.0)	107/1057 (10.1)
Actual place of birth: hospital or in-hospital birthing centre	1013	137/404 (33.9)	146/609 (24.0)
Actual place of birth: home or freestanding birthing centre	1009	17/258 (6.6)	38/751 (5.1)
Unplanned Caesarean or operative vaginal birth	235	43/105 (41.0)	48/130 (36.9)
Difference in opinion with care provider	102	39/47 (83.0)	42/55 (76.4)



highlighted four priority areas for action: identify and prioritize areas to reduce health disparities, invest in the development and application of person-centered health equity performance measures, incentivize the reduction of health disparities, and implement evidence-based interventions to reduce disparities.

Our Giving Voice to Mothers study has addressed this mandate through the patient-led development and validation of unique items that can be used to measure disrespect, abuse, and discrimination during maternity care. Using these items, we were able to show that some populations experienced significantly higher rates of mistreatment, such as women of color, young women, and those who reported economic, social or health risks. All women who self-identified as Black, Indigenous, Hispanic, or Asian reported higher than average experiences of mistreatment. Regardless of their own race, having a partner who was Black also increased their risk of mistreatment.

The types and recipients of mistreatment identified by participants in the GVtM study are consistent with patient-oriented research evidence from a recent qualitative study [43] in California. McLemore and colleagues [43] explored pregnancy-related healthcare experiences through focus groups of women of color from three urban areas in California. The study included English and Spanish speaking women, age 18 or greater with social and/or medical risk factors for preterm birth. Based on the data collected from 54 women in two focus groups, the authors identified five themes: 1) disrespect during healthcare encounters; 2) stressful interactions with all levels of staff; 3) unmet information needs; 4) inconsistent social support; and 5) care that affected confidence in parenting and newborn care. Focus group participants provided examples of each of the seven types of mistreatment that we measured. Participants discussed sharing of personal information, violation of physical privacy and being “yelled at” by a physician. Half of the participants discussed being pressured or threatened, with the most common type of threat being, “if you do not comply or do this, your baby will die or you will have a bad outcome.” Similarly, coercive language reported by participants in our GVtM study frequently referred to the potential loss of the baby.

#### **Mistreatment, inequity, and access to high quality care**

In high resource countries, pregnant people who experience discrimination due to lower socioeconomic status, race/ethnicity, or housing instability, are especially at risk for poor health outcomes [20]. For, example, a European team reviewed published evidence on discrimination against Romani women in maternity care in Europe [21]. Results revealed that many Romani women encounter barriers to accessing maternity care. Even when

they were able to access care, they experienced discriminatory mistreatment on the basis of their ethnicity, economic status, place of residence or language. The grey literature revealed some health professionals held underlying negative beliefs about Romani women [21].

Similarly, much has been written about how implicit bias by healthcare provider links to disparities in access to and quality of care [44]. Growing evidence suggests that differential quality of care in North America contributes to racial and ethnic disparities in obstetric and perinatal outcomes [18, 20, 45–47] and that access to high quality of care in obstetrics varies widely by jurisdiction and type of provider [48]. In our study Indigenous women were the most likely to report mistreatment among the racial groups, closely followed by African American and Hispanic women. Indigenous men and women in Central America report barriers to accessing healthcare and abusive treatment and neglect of professional ethics from HCPs [49]. Canadian research has documented the distress and racism experienced by Aboriginal women including discrimination, loss of autonomy and dehumanizing interactions with care providers [50].

Vedam et al. [32] found that in British Columbia, women from vulnerable populations (i.e. recent immigrants or refugees, women with a history of incarceration and/or substance use, homelessness or poverty), women with pregnancy complications, those who have birth at hospital (versus home) and women who experienced pressure to have interventions were more likely to score very low on the MOR index, a scale that measures respectful maternity care [32]. Our intersectional analysis underscores that the negative impacts of race and social vulnerability are intertwined and cumulative, that those who are already at risk for the worst outcomes, also experience higher levels of mistreatment. Given that the burden of disparities borne by these populations has shown little improvement in recent decades, understanding the presence of mistreatment in childbirth may aid our efforts to comprehend underlying causes, and inform our efforts to eliminate them.

#### **The context of care**

We also elicited differential treatment when women's choices and opinions about “the right care” for themselves or their baby did not align with providers. Those who were transferred to hospital from the community, women who reported being pressured into interventions, and those who had a difference of opinion with their health care provider reported higher rates of mistreatment. Differential rates of mistreatment may be associated with differences by race in level of patient autonomy and/or pressure to accept interventions from providers, which in itself constitutes mistreatment. The

relationships between differences of opinion, interventions, and mistreatment require further study to elucidate the temporal nature of these associations. In qualitative study, researchers in New England interviewed 50 white women and 32 women of color the day after they gave birth at a tertiary care facility [51]. Women of color reported more pressure to accept epidural anesthesia and were also more likely to experience failure in their pain medication and report that providers ignored their pain and anxiety.

Higher rates of mistreatment among those who have unplanned cesarean births warrants a closer examination, given country-level disparities in overuse and underuse of obstetric interventions [1], as well as the confounding reality that proportionately more women of colour in our sample, as in the general US population, had cesareans. Multiple authors have examined racial differences in both primary cesarean and VBAC rates and found women of colour have an increased risk of cesarean delivery after adjusting for sociodemographic and clinical risk factors [52–55]. Additionally, women with private health insurance have a lower predicted probability of having a cesarean section for clinical indications than do women with public health insurance [56].

The significant number of respondents that reported “being ignored” or that “providers failed to respond to their requests for help” is a disturbing finding in a high resource setting, especially in light of recent data that links delayed response to clinical signs to maternal mortality. The California Department of Public Health (CDPH), the California Maternal Quality Care Collaborative (CMQCC) and the Public Health Institute (PHI) recently released data from a statewide examination of maternal deaths from 2002 to 2007 [57]. The report identified that healthcare provider factors were the most common type of contributor to maternal deaths, averaging 2.5 factors per case and present among 269 cases or 81% of maternal deaths in that time period. The most common provider factor was delayed response to clinical warning signs, followed by ineffective care [57].

Finally, place of birth appears to have a modulating effect on experiences of mistreatment. Women from all race and ethnic backgrounds who gave birth at home or in birth centers reported far fewer examples of all seven types of disrespect and abuse. This is especially poignant in light of the finding that women who needed to transfer to hospital from a planned community birth, ostensibly to access a safe environment to respond to emerging complications, experienced very high rates of mistreatment. Whether these differences are a result of the change in locus of control and loss of cultural safety that all people feel in their own environments [58], or the effects of structural racism, societal norms, and

implicit bias that exist in institutional cultures, remains to be explored.

### Implications

Bohren and colleagues argue that instances of mistreatment constitute violations of people’s human rights. [13] Several respondents in our study provided descriptions about how mistreatment violated these basic principles. Amnesty International identified the inappropriate, disrespectful, and discriminatory treatment of pregnant and childbearing people in the United States as constituting a human rights violation and documented incidents of women, particularly women of colour, being abandoned, ignored, threatened, coerced, shouted at, and otherwise mistreated [59]. Violations of human rights in childbirth tend to be more severe in countries where women have limited options in terms of where, how and with whom they can give birth. Authors of the WHO Research Group [60] argue that, to prevent mistreatment, health care providers need to first consider how they can meet women’s socio-cultural, emotional and psychological needs.

A recent publication on addressing racial disparities in the management of hypertension discussed how performance measures can be used to incentivize self-monitoring programs, and the development of pragmatic, effective interventions to improve health equity [61]. The authors describe a multi-strategy approach that takes into account the complex interactions between social determinants of health, societal drivers of inequity, payment models, and cultural competency education for health professionals. They refer to the five domains of health equity measurement described in the NQF report: first, building collaborations to address factors that maintain racial and ethnic disparities; second, creating a culture of equity and individualized care and routine training around issues of structural racism and intersectionality of multiple drivers of disadvantage; third, moving to the development of multidisciplinary teams, and fourth, addressing issues of access to high quality care across communities and settings for care. The final domain focusses on the equitable application of evidence-based interventions that are responsive to patient reported outcomes and priorities [61].

With respect to mistreatment, dignity, and freedom from human rights abuses in maternity care, this last priority is dependent on the health systems ability to monitor and describe patient experience with reliable indicators. Our patient-driven performance measures can target the key components of mistreatment to address by jurisdiction, and identify settings where quality improvement related to respectful maternity care is most needed, as well service users most at risk for differential treatment. Abuya and colleagues [19] have suggested several intervention and implementation activities to

eliminate mistreatment of women in low resource countries. Many of these strategies are also relevant in the US context, such as training for care providers in promoting respectful care including values clarification and attitude transformation (VCAT), training on VCAT based on providers' and clients' rights and obligations, and revision of professional ethics and practices. The authors also recommend strengthening facility quality improvement systems for monitoring, reporting, addressing, and resolving disrespect and abuse cases. Mentorship and on-the-job role-modeling by identified champions within the facility as part of routine continuous professional education has been shown to shift team culture. At the same time civic education about patient rights and avenues for redress may be needed to ensure accountability even in high resource countries.

### Strengths and limitations

Strengths of the study include the large sample size that allows for the best estimate to date of the frequencies and types of mistreatment occurring among diverse subpopulations among childbearing people in the US. Importantly, the Giving Voice to Mothers study provides the first complete set of patient-designed and validated quantitative indicators, across all domains of the Bohren typology, that can be used to describe prevalence and characteristics of mistreatment in maternity care across all settings. This study also provides the first published estimates of associations between social factors like race/ethnicity, and modulating effects of planned place of birth or interventions, and rates and forms of mistreatment as identified by patients themselves.

A primary limitation of the study is that the sample is voluntary and not population-based, as there is currently no data collection system designed to capture and describe experiences of birth care for all pregnant people in the United States. Rather we sampled for diversity, oversampling from communities that are often under-represented in national studies on experience of care, such as Black and Indigenous women, and those planning to give birth at home or in a birth center. Compared to the characteristics of women who gave birth in the United States in 2016, women in our study had similar proportions of previous births, but were more educated, older, and more likely to have been born in the United States [62]. With respect to racial representativeness, we report data from a similar proportion of black women and more Indigenous women; 14.0% of US births in 2016 (CDC) were women who identified as 'black' compared to 15.4% in this study; 1% are identified as Indigenous in the US vs 3% in our sample [62]. Overall, our samples of women from Hispanic, Asian, and other communities of color were lower than the national reported rates. Of note, 24% of the US births in

2016 had a mother identified as "Hispanic origin" compared to roughly 10% in the current study.

Notably, patient reports of improved experience of care in homes and birth centers are repeatedly cited in the global literature. Since 50% of our sample were reporting on community births (when the representative rate would have been 2%), the logical expectation would be that the entire sample is skewed towards much *less* mistreatment than the general population. Because women with very positive or very negative experiences are often more motivated to participate in studies that invite them to share their stories, we anticipate that we have lower representation from women who had more routine or simply "satisfactory" experiences that might not be characterized as either particularly empowering nor traumatizing. To mitigate bias introduced because communities of color tended to describe worse experiences and community birthers more positive ones, we stratified results by race and place of birth.

In general, the GVTM sample might have a 'higher' SES population than is representative of the US childbearing population which, given our findings, we anticipate would decrease rates of reported mistreatment, and potentially underestimate mistreatment in the US population at large. The large proportion of community birth also accounts for the higher socioeconomic status – since without universal health care, community birth is often not accessible by low SES service users. Since even in this more privileged population the overall rates of mistreatment were at 17%, and significantly higher for those who planned and delivered in hospitals, our findings highlight the need for further investigations in this understudied area.

Regional variation in outcomes and access to high quality care across the United States have been described in the literature [48], and our national sample is not representative of the lived experience of many subgroups including undocumented immigrants, incarcerated pregnant parents, and families located in rural settings with limited options for maternity care. With respect to generalizability in the international context, women and people have different interpretations of consent and power. Hence, while standardizing indicators through these typologies is helpful, it will not change that each person will have their own sense of bodily/self autonomy and human rights, placed within the cultural context of each environment. Finally, not all people giving birth identify as women and/or mothers, and mistreatment as associated with gender identity, sexuality and parenting status are areas where further study is needed.

Nonetheless, that higher rates of mistreatment so clearly track along marginalized groups, and with women whose choices in care differ from their providers' recommendations, suggests that regardless of any sampling issues

invariably contained in this study, there is much work yet to be done in the United States, as no level of mistreatment of a childbearing person is acceptable.

## Conclusion

The Giving Voice to Mothers- US study led to development of several new patient-designed indicators of mistreatment in maternity care. They use lay language to capture lived experience from the service user's perspective, and can be used to quantify the nature and frequency of occurrence of different types of disrespect and abuse. They are aligned closely with global definitions of the domains of mistreatment, and thus are relevant across high, middle, and low resource countries.

Application of these measures elicited disparities in experience of maternity care across communities of color and birth settings in the United States. With some translation and adaptation, these indicators could be implemented in patient-reported outcomes research globally. In the United States, these indicators could be incorporated as performance measures to incentivize expansion of programs to address settings, practices, and institutional cultures that lead to persistent disparities in maternity care.

## Additional file

**Additional file 1: Table S1.** Self-identified maternal and paternal race ( $n = 2700$ ). **Table S2.** Socio-demographic characteristics of samples, compared to national statistics. **Table S3.** Mistreatment, stratified by self-identified race of woman and partner. **Table S4.** Mistreatment, stratified by immigration status. **Table S5.** Mistreatment, stratified by maternal age at birth. **Table S6.** Mistreatment, stratified by parity. **Table S7.** Mistreatment, stratified by labour induction and mode of birth. **Table S8.** Mistreatment, stratified by newborn health problems. **Table S9.** Mistreatment indicators, stratified by disarticulation between women and providers.

## Abbreviations

CA-PAMR: California Pregnancy-Associated Mortality Review; CDPH: California Department of Public Health; CI: Confidence Interval; CMQCC: California Maternal Quality Care Collaborative; GvtM - US: Giving Voice to Mothers-United States; HCP: Healthcare provider; IPV: Intimate Partner Violence; MADM: Mother's Autonomy in Decision-Making Scale; MORi: Mothers on Respect Index; NGO: Non-governmental organization; NQF: National Quality Forum; PHI: Public Health Institute; PR: Perceptions of Racism; RMC: Respectful maternity care; SES: Socio-economic status; VBAC: Vaginal Birth after Cesarean; WHO: World Health Organization

## Acknowledgments

This paper would not have been possible without the long term commitment and participation of these members of the GvtM US Steering Council: Shafia Monroe, Paula Rojas, Mariah Farrell, Jacqueline Left Hand Bull, Roberta Eaglehorse, Claudia Booker, Vanessa Calderi, Michelle Goodwin, Zsakeba Henderson, Jennie Joseph.

Community organizations involved in study design, recruitment, and knowledge translation include: Choices in Childbirth, Every Mother Counts, the International Center for Traditional Childbearing, Mamas of Color Rising, Oregon Intertribal Breastfeeding Coalition, Phoenix Midwife, Mama Sana/Vibrant Woman, Mountain Midwifery Center, and Easy Access Women's Health Clinic (Commonsense Childbirth).

We would also like to thank research assistants who supported content validation, survey administration, data, manuscript formatting, and citation management, Richelle Powers, Norah Macy, Jessie Wang, Sabrina Afroz and Julie. Finally, the participatory process and knowledge translation activities have greatly benefitted from countless hours and expertise provided by Lynsey Hamilton, Ian Allison, Aldabaran Tatum, and Barbara Karlen.

## Funding

This project was funded by the New Hampshire Charitable Foundation Transforming Birth Fund.

## Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Authors' contributions

SV conceived the study and oversaw all aspects of the work, including community engagement, survey design, data collection and analysis. SV drafted and edited the paper, KS performed the data analysis, and drafted/edited the paper, TKT & NR, MC, NS, MMcL, MC, LS, ED advised on statistical analysis, drafted sections of the paper, helped to interpret data, revised, provided language for and/or edited the manuscript. NS was also involved in content validation. EN contributed to data analysis and interpretation and ER participated actively in survey development and coordinating the content validation. All authors read and approved the final manuscript.

## Ethics approval and consent to participate

The Behavioural Research Ethics Board at University of British Columbia approved the study (H15-01524).

All invited participants reviewed an informed consent form before deciding whether they wanted to participate in the online survey.

## Consent for publication

The consent form clarified that study results would be reported in the form of de-identified aggregate statistics and/or de-identified quotes. For participants or community partners who wish to participate in preparation of analysis or publications, the de-identified dataset (without open-ended comments) is available from the corresponding author on reasonable request and completion of a data sharing agreement.

## Competing interests

The authors declare that they have no competing interests.

## Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## Author details

<sup>1</sup>Birth Place Lab, Division of Midwifery, Faculty of Medicine, University of British Columbia, Vancouver (Canada), E416 Shaughnessy (Mailbox 80), 4500 Oak Street, Vancouver, BC V6H 3N1, Canada. <sup>2</sup>University of California Davis School of Medicine, Sacramento, California, USA. <sup>3</sup>Department of Midwifery, Bastyr University, Seattle, WA, USA. <sup>4</sup>Department of Obstetrics and Gynecology, University of California San Francisco and the Institute for Global Health Sciences, California, USA. <sup>5</sup>Department of Anthropology, Oregon State University, Corvallis, Oregon, USA. <sup>6</sup>Every Mother Counts, New York City, USA. <sup>7</sup>Department of Family Health Care Nursing and ANSIRH Bixby Center for Global Reproductive Health, University of California, San Francisco, USA. <sup>8</sup>Young Women United, Albuquerque, New Mexico, USA. <sup>9</sup>School of Population & Public Health, Faculty of Medicine, University of British Columbia, Vancouver, Canada. <sup>10</sup>Department of Family Practice, Faculty of Medicine, University of British Columbia, Vancouver, Canada. <sup>11</sup>School of Public Health, Boston University, Massachusetts, Boston, USA.

Received: 4 January 2019 Accepted: 30 April 2019

Published online: 11 June 2019

## References

- Miller S, Abalos E, Chamillard M, Ciapponi A, Colaci D, Comandé D, et al. Beyond too little, too late and too much, too soon: a pathway towards

- evidence-based, respectful maternity care worldwide. *Lancet*. 2016;388:2176–92.
2. World Health Organization (WHO). Standards for improving quality of maternal and newborn care in Health Facilities [Internet]. 2016. Available from: [http://www.who.int/maternal\\_child\\_adolescent/documents/improving-maternal-newborn-care-quality/en/](http://www.who.int/maternal_child_adolescent/documents/improving-maternal-newborn-care-quality/en/)
  3. The Partnership for Maternal Newborn & child health. Professional associations affirm commitment to improving quality of maternal and newborn health care [Internet]. FIGO news, WHO news. 2017. Available from: <http://www.who.int/pmnch/media/events/2017/ililongwe/en/index1.html>
  4. Reed R, Sharman R, Inglis C. Women's descriptions of childbirth trauma relating to care provider actions and interactions. *BMC Pregnancy Childbirth*. 2017;17(1).
  5. Hameed W, Avan BI. Women's experiences of mistreatment during childbirth: a comparative view of home- and facility-based births in Pakistan. *PLoS One*. 2018;13(3):e0194601.
  6. McMahon S, George A, Chebet J, Moshia I, Mpembeni R, Winch P. Experiences of and responses to disrespectful maternity care and abuse during childbirth; a qualitative study with women and men in Morogoro region, Tanzania. *BMC Pregnancy Childbirth*. 2014;14(1):268.
  7. Baker S, Choi P, Henshaw C. 'I Felt as though I'd been in Jail': Women's Experiences of Maternity Care during Labour, Delivery and the Immediate Postpartum. *Feminism & Psychology*. 2005;15(3):315–42.
  8. Kane S, Rial M, Kok M, Matera A, Dieleman M, Broerse JEW. Too afraid to go: fears of dignity violations as reasons for non-use of maternal health services in South Sudan. *Reprod Health*. 2018;15(1).
  9. Khosla R, Zampas C, Vogel JP, Bohren MA, Roseman M, Erdman JN. International human rights and the mistreatment of women during childbirth. *Health Hum Rights*. 2016;18(2):131.
  10. Freedman LP, Kruk ME. Disrespect and abuse of women in childbirth: challenging the global quality and accountability agendas. *Lancet*. 2014;384(9948):e42–4.
  11. World Health Organization (WHO). Prevention and elimination of disrespect and abuse during facility-based childbirth [internet]. Geneva, Switzerland: WHO Statement; 2015 [cited 2016 Apr 4]. Available from: [https://apps.who.int/iris/bitstream/handle/10665/134588/WHO\\_RHR\\_14.23\\_eng.pdf;jsessionid=5EAC99EB257C701EF9FC086FD19D5FE7?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/134588/WHO_RHR_14.23_eng.pdf;jsessionid=5EAC99EB257C701EF9FC086FD19D5FE7?sequence=1)
  12. Rosenthal L, Lobel M. Explaining racial disparities in adverse birth outcomes: unique sources of stress for black American women. *Soc Sci Med*. 2011;72(6):977–83.
  13. Bohren MA, Vogel JP, Hunter EC, Lutsiv O, Makh SK, Souza JP, et al. The mistreatment of women during childbirth in health facilities globally: a mixed-methods systematic review. *PLoS Med* [Internet]. 2015 [cited 2016 Mar 22];12(6):e1001847; discussion e1001847. Available from: <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001847>
  14. Warren CE, Njue R, Ndwiga C, Abuya T. Manifestations and drivers of mistreatment of women during childbirth in Kenya: implications for measurement and developing interventions. *BMC Pregnancy and Childbirth*. 2017;17(1):102.
  15. Beck CT. A secondary analysis of mistreatment of women during childbirth in health care facilities. *J Obstet Gynecol Neonatal Nurs*. 2018;47(1).
  16. Ravalđi C, Skoko E, Battisti A, Cerizzo M, Vannacci A. Abuse and disrespect in childbirth assistance in Italy: a community-based survey. *Eur J Obstet Gynecol Reprod Biol*. 2018;224:208–9.
  17. Babiaková K, Debrecenióvá J, Hlinčíková M, Krišková Z, Sekulová M, Šumšalová S. Women mothers bodies: women's human rights in obstetric care in healthcare facilities in Slovakia. *Občan, demokracia a zodpovednosť*. 2015.
  18. Howell EA, Zeitlin J. Quality of care and disparities in obstetrics. *Obstet Gynecol Clin N Am*. 2017;44(1):13–25.
  19. Abuya T, Ndwiga C, Ritter J, Kanya L, Bellows B, Binkin N, et al. The effect of a multi-component intervention on disrespect and abuse during childbirth in Kenya. *BMC Pregnancy and Childbirth*. 2015;15(1).
  20. Elder TE, Goddeeris JH, Haider SJ. Racial and ethnic infant mortality gaps and the role of socio-economic status. *Labour Econ*. 2016;43:42–54.
  21. Watson HL, Downe S. Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review. *Reprod Health*. 2017;14(1).
  22. McRae DN, Janssen PA, Vedam S, Mayhew M, Mpofu D, Teucher U, et al. Reduced prevalence of small-for-gestational-age and preterm birth for women of low socioeconomic position: a population-based cohort study comparing antenatal midwifery and physician models of care. *BMJ Open*. 2018;8(10):e022220.
  23. Declercq ER, Sakala C, Corry MP, Applebaum S, Herrlich A. Major survey findings of listening to mothers (SM) III: new mothers speak out. *J Perinat Educ*. 2014;23(1):17–24.
  24. Bond S, You X. Mistreatment of women during pregnancy and birth impedes global efforts to improve access, quality, and safety of maternity care. *J Midwifery Womens Health*. 2015;60(6):785.
  25. DeVoe JE, Wallace LS, Fryer GE. Measuring patients' perceptions of communication with healthcare providers: do differences in demographic and socioeconomic characteristics matter? *Health Expect*. 2009;12(1):70–80.
  26. Downe S, Finlayson K, Tuncalp O, Metin Gülmezoglu A. What matters to women: a systematic scoping review to identify the processes and outcomes of antenatal care provision that are important to healthy pregnant women. *BJOG An Int J Obstet Gynaecol*. 2016;123(4):529–39.
  27. Freedman LP, Ramsey K, Abuya T, Bellows B, Ndwiga C, Warren CE, et al. Defining disrespect and abuse of women in childbirth: a research, policy and rights agenda. *Bull World Health Organ*. 2014;92(12):915–7.
  28. Bowleg L. The problem with the phrase women and minorities: intersectionality-an important theoretical framework for public health. *Am J Public Health*. 2012;102(7):1267–73.
  29. Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream. *Circulation*. 2009;119(19):2633–42.
  30. Israel BA. *Methods for community-based participatory research for health*. San Francisco, CA: Jossey-Bass; 2013. p3-37.
  31. Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson D, et al. 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. Kumar S, editor. *PLoS One* [Internet]. 2017 [cited 2017 Aug 14];12(2):e0171804. Available from: <http://dx.plos.org/10.1371/journal.pone.0171804>
  32. Vedam S, Stoll K, Rubashkin N, Martin K, Miller-Vedam Z, Hayes-Klein H, et al. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *SSM - Popul Heal* [Internet]. 2017 Dec [cited 2017 Aug 14];3:201–210. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S2352827317300174>.
  33. Mortel M, Mehta SD. Systematic Review of the Efficacy of Herbal Galactagogues. *J Hum Lact*. 2013;29(2):154–62.
  34. Green NL. Development of the perceptions of racism scale. *J Nurs Scholarsh*. 1995;27(2):141–6.
  35. Kruk ME, Kujawski S, Mbaruku G, Ramsey K, Moyo W, Freedman LP. Disrespectful and abusive treatment during facility delivery in Tanzania: a facility and community survey. *Health Policy Plan*. 2018;33(1):e26–33.
  36. Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health*. 2006;29(5):489–97.
  37. Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Methodol*. 2014;14:1–29.
  38. Merli MG, Verdery A, Mouw T, Li J. Sampling migrants from their social networks: the demography and social organization of Chinese migrants in Dar Es Salaam, Tanzania. *Migr Stud*. 2016;4(2):182–214.
  39. Schicker RS, Hiruy N, Melak B, Gelaye W, Bezabih B, Stephenson R, et al. A venue-based survey of malaria, anemia and mobility patterns among migrant farm workers in Amhara region, Ethiopia. *PLoS One*. 2015;10(11):e0143829.
  40. Cheyney M, Bovbjerg M, Everson C, Gordon W, Hannibal D, Vedam S. Development and validation of a national data registry for midwife-led births: the midwives alliance of North America statistics project 2.0 dataset. *J Midwifery Women's Heal*. 2014;59(1):8–16.
  41. MacDorman MF, Declercq E. Trends and characteristics of United States out-of-hospital births 2004–2014: new information on risk status and access to care. *Birth*. 2016;43(2):116–124.
  42. A roadmap for promoting health equity and eliminating disparities: the four I's for health equity: final report [Internet]. A roadmap for promoting health equity and eliminating disparities: the four I's for health equity: final report. National Quality Forum; 2017 Sep. Available from: <https://www.qualityforum.org>

[org/Publications/2017/09/A\\_Roadmap\\_for\\_Promoting\\_Health\\_Equity\\_and\\_Eliminating\\_Disparities\\_The\\_Four\\_I\\_s\\_for\\_Health\\_Equity.aspx](https://www.reproductivehealth.org/Publications/2017/09/A_Roadmap_for_Promoting_Health_Equity_and_Eliminating_Disparities_The_Four_I_s_for_Health_Equity.aspx).

43. McLemore MR, Altman MR, Cooper N, Williams S, Rand L, Franck L. Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. *Soc Sci Med*. 2018;201:127–35.
44. The Joint Commission. Implicit bias in health care. *Quick Saf*. 2016.
45. Bryant AS, Worjloh A, Caughey AB, Washington AE. Racial/ethnic disparities in obstetric outcomes and care: prevalence and determinants. *Am J Obstet Gynecol*. 2010;202(4):335–43.
46. Krieger N, Gruskin S, Singh N, Kiang MV, Chen JT, Waterman PD, et al. Reproductive justice & preventable deaths: state funding, family planning, abortion, and infant mortality, US 1980–2010. *SSM - Popul Heal*. 2016;2:277–93.
47. Wong CA, Gachupin FC, Holman RC, Maccorman MF, Cheek JE, Holve S, et al. American Indian and Alaska native infant and pediatric mortality, United States, 1999–2009. *Am J Public Health*. 2014;104(S3).
48. Vedam S, Stoll K, MacDorman M, Declercq E, Cramer R, Cheyney M, et al. Mapping integration of midwives across the United States: impact on access, equity, and outcomes. *PLoS One*. 2018;13(2):e0192523.
49. Ceron A, Ruano AL, Sanchez S, Chew AS, Diaz D, Hernandez A, et al. Abuse and discrimination towards indigenous people in public health care facilities: experiences from rural Guatemala. *Int J Equity Health*. 2016;15(1):77.
50. Varcoe C, Brown H, Calam B, Harvey T, Tallio M. Help bring back the celebration of life: a community-based participatory study of rural aboriginal women's maternity experiences and outcomes. *BMC Pregnancy Childbirth* 2013;13(1):26. Available here: <https://doi.org/10.1186/1471-2393-13-26>
51. Morris T, Schulman M. Race inequality in epidural use and regional anesthesia failure in labor and birth: an examination of women's experience. *Sex Reprod Healthc*. 2014;5(4):188–94.
52. Min CJ, Ehrenthal DB, Strobino DM. Investigating racial differences in risk factors for primary cesarean delivery. *Am J Obstet Gynecol*. 2015;212(6).
53. Huesch M, Doctor JN. Factors Associated With Increased Cesarean Risk Among African American Women: Evidence From California, 2010. *American Journal of Public Health*. 2015;105(5):956–62.
54. Washington S, Caughey AB, Cheng YW, Bryant AS. Racial and ethnic differences in indication for primary cesarean delivery at term: experience at one U.S. institution. *Birth*. 2012;39(2):128–34.
55. Yee LM, Costantine MM, Rice MM, Bailit J, Reddy UM, Wapner RJ, et al. Racial and ethnic differences in utilization of labor management strategies intended to reduce cesarean delivery rates. *Obstet Gynecol*. 2017;130(6):1285–94.
56. Morris T, Meredith O, Schulman M, Morton CH. Race, insurance status, and nulliparous, term, singleton, vertex cesarean indication: a case study of a New England tertiary hospital. *Women's Heal Issues*. 2016;26(3):329–335.
57. California Maternal Quality Care Collaborative. California Pregnancy-Associated Mortality Review (CA-PAMR): Report from 2002 and 2007 Maternal death reviews [internet]. 2018. Available from: <https://www.cmqcc.org/resource/california-pregnancy-associated-mortality-review-ca-pamr-report-2002-and-2007-maternal>
58. Cheyney M, Everson C, Burcher P. Homebirth transfers in the United States: narratives of risk, fear, and mutual accommodation. *Qual Health Res*. 2014;24(2):443–56.
59. Amnesty International. Deadly Delivery The Maternal Health Care Crisis in the USA. 2011[cited 2017 Apr 3]; Available from: <http://www.amnestyusa.org/sites/default/files/deadlydeliveryoneyear.pdf>.
60. Vogel JP, Bohren MA, Tunçalp O, Oladapo OT, Gülmezoglu AM. Promoting respect and preventing mistreatment during childbirth. *BJOG*. 2016;123(5):671–4.
61. Anderson AC, O'Rourke E, Chin MH, Ponce NA, Bernheim SM, Burstin H. Promoting health equity and eliminating disparities through performance measurement and payment. *Health Aff*. 2018;37(3):371–7.
62. Martin, Joyce A. MPH, Hamilton BE, Osterman MJ, Driscoll AK, Drake P. Births : final data for 2017 [internet]. *National Vital Statistics Reports*. CDC; 2018 [cited 2018 Dec 15]. Available from: <https://stacks.cdc.gov/view/cdc/60432>.
63. Bohren MA, Vogel JP, Hunter EC, Lutsiv O, Makh SK, Souza JP, et al. The mistreatment of women during childbirth in health facilities globally: a mixed-methods systematic review. *Jewkes R, editor. PLoS Med [Internet]*. 2015 [cited 2017 Sep 3];12(6):e1001847. Available from: <http://dx.plos.org/10.1371/journal.pmed.1001847>.

**Ready to submit your research? Choose BMC and benefit from:**

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

**At BMC, research is always in progress.**

Learn more [biomedcentral.com/submissions](https://biomedcentral.com/submissions)



	WHO Collaborating Centre for Maternal and Child Health (director) Institute for Maternal and Child Health IRCCS Burlo Garofolo	
GVTM – US survey	Nora Kropp, Birth India	India
MADM/Mori	Lee K. Roosevelt, PhD, MPH, CNM Clinical Assistant Professor School of Nursing University of Michigan ~ Ann Arbor	USA
MADM/MORi	Marit van der Pijl, MSc   Midwifery Science, MF-G102d   Location VUmc	Netherlands
MADM	Ioanna Koliandri Doctoral student at the Cyprus University of Technology in the Department of Nursing, School of Health Science.	Cyprus
Mori	Duygu MURAT ÖZTÜRK, PhD Amasya Üniversitesi Sağlık Bilimleri Fakültesi, Ebelik Bölümü, Amasya University Faculty of Health Sciences, Midwifery Department	Turkey
PAPHB-I	Chie Taniguchi, RN, CNM, PhD (Professor) Kanagawa University of Human Services Faculty of Health & Social Services School of Nursing	Japan
MADM	Cynthia Opie, Cluster Lead Strengthening Hospital Responses to Family Violence Initiative, Echuca Regional Health	Australia
MADM MORi	Jennifer R Stevens Midwifery Consultant UNFPA, Bangladesh Boston University	Bangladesh
MADM	Safella Lutfatul Jannah/ Master Student International Nurse-Midwifery Master of Science Program National Taipei University of Nursing and Health Sciences (NTUNHS)	Taiwan
MADM / MORi/mistreatment	Claudia Limmer Midwifery Research and Education Unit Department of Obstetrics, Gynaecology & Reproductive Medicine Hannover Medical School (MHH)	Germany
MORi	Brittany Chambers, Assistant Professor, Department of Epidemiology and Statistics, UCSF	USA

MADM	Jing Wang, head nurse in obstetrics department Shandong Maternal and Child Health Hospital,China	China
MADM/MORi	Chie Taniguchi, RN, CNM, PhD (Professor) Kanagawa University of Human Services Faculty of Health & Social Services School of Nursing	Japan
MORi	Mgr. Bc. Eva Urbanová, PhD. odborná asistentka	Slovakia



## APPENDIX C

### Actioning the Third Reality:

#### Innovative Knowledge Translation and Policy Outputs

The Home Birth Summits and ongoing transdisciplinary engagement led to several tangible tools, measures and metrics that are being used widely to improve access to high quality care. The following is a brief introduction to those resources with links to the tools and/or manuscripts that describe them.

##### Access to High Quality Maternity Care across Health Systems

The AIMM Study provided an unprecedented opportunity to better explore and understand if the rising rates of reported home births are linked to greater access to high quality care across settings, and if the status of integration of providers can be linked to outcomes. Our team created a series of tools to help consumers, clinicians, and policymakers to understand and utilize the data.

We present the results of our analyses through 4 interactive maps:

- a map of the that displays the United States by **access to regulated midwives**,
- a map showing actual **integration of midwives** and impact of local interpretations of regulations according to 4 color-coded categories
- a map that illustrates **rates of birth place** (home, birth center, hospital) for each state,
- a map displaying **rates of physiologic birth** for each state.

The Maps are hosted on my Birth Place Lab website in an open access format <https://www.birthplacelab.org/mapping-collaboration-across-birth-settings/>. Our established networks with transdisciplinary clinician leaders and organizations will facilitate updating the data-informed maps as conditions change. By making these data maps interact visually with each other, we illustrate the correlations between perinatal outcomes and choice of birth place in states where providers and care are well integrated, compared to states where disarticulation exists. To further explicate the implications of my findings, the maps were supplemented with 50 state report cards highlighting ‘model states’ (i.e., highest rates of integration of providers across birth settings). <https://www.birthplacelab.org/how-does-your-state-rank/>

Findings on provider attitudes and patient experiences from the Canadian Birth Place Study, Changing Childbirth in BC, and Giving Voice to Mothers inform the interpretation and recommendations. We also created a data linkage template so that the data can be updated to reflect changes in regional conditions, and can be analyzed and reported on a triennial basis.

### Physician Attitudes to Midwives

Given that attitudes to home births are linked to exposure and education, and midwives are the only professionals who attend home births in the United States and Canada, I theorized that attitudes to midwives were similarly affected by exposure and education. Using a transdisciplinary approach, I supervised two family physicians residents to adapt the PAPHB scale to a scale that measures attitudes to midwives, and apply it to a cohort of trainees.

- Publication: Lefebvre K, Wild J, Stoll K, **Vedam S**. Through the resident lens: examining knowledge and attitudes about midwifery among physician trainees. *Journal of Interprofessional Care*, 2018.  
<https://www.tandfonline.com/doi/full/10.1080/13561820.2018.1543258>

### Safety of home birth

Since attitudes to planned home birth are subject to beliefs about the evidence on safety, in the absence of any reliable standards to assess the quality of research on place of birth, I collaborated with colleagues at the University of Technology Sydney to develop and test a critical appraisal tool that could defuse debate based on pre-existing attitudes. Using a transdisciplinary, Delphi process with an international expert panel of midwives, physicians, epidemiologists, and public health researchers, we developed and tested a composite index with an embedded weighed scoring system to assist clinicians, and policy makers to interpret and incorporate into their informed choice discussions with service users. The manuscript and tool can be accessed on my Birth Place Lab website or through this link.

### [The Birth Place Research Quality Index \(ResQu\)](#)

- Publication: Vedam S, Rossiter C, Homer, Scarf V, Stoll K. The ResQu Index: a new instrument to appraise the quality of birth place research. *PLOS ONE*, 2017. 12(1): 1-19.  
<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0182991>

## Interprofessional Collaboration

The transdisciplinary Task Forces that emerged from the Home Birth Summit have continued to collaborate to create pragmatic tools to de-escalate conflict and support the culture of safety for families who were considering their options for birth place or who were planning to give birth at home.

- **[Best Practice Guidelines: Transfer from Planned Home Birth to Hospital](#)** and **Best Practice Guidelines for Collaboration between Community Midwives and Specialist Providers** as well as tools to support the implementation of the guidelines at hospitals and with individual practitioners. The *Best Practice Guidelines: Transfer from Planned Home Birth to Hospital* have been endorsed by 44 professional organizations and 215 individuals. The implementation tools include maternal and infant transfer forms are designed to facilitate the safe and respectful transfer of care from a planned home birth to a hospital. They have been downloaded by consumers, consumer organizations, clinicians, educators, health administrators, and policy makers over 6100 times and one organization has shared them with over 500 students in their Home Birth Transfer skills course.

## Autonomy, Respect, and Person-Centered Care

- A series of novel patient-designed and collaboratively developed and validated instruments to improve the evaluation of quality of maternity care including:
  - **[Mothers Autonomy in Decision Making Scale \(MADM\)](#)**
  - **[Mothers on Respect Index \(MORi\)](#)**
  - **[Provider Attitudes to Planned Home Birth Scale \(PAPHB\)](#)**
  - **[The Birth Place Research Quality Index \(ResQu\)](#)**
- These tools are all freely available for download from [the Birth Place Lab website](#) and have been used by researchers and clinicians internationally. The novel domains of patient experience captured by the MADM and MORi measures, as well as the

community-led development process, were recognized by the 2017 National Quality Forum innovation prize.

- In 2018, the Birth Place Lab at University of British Columbia which I lead, received an implementation grant from the inaugural American Institutes for Research “Small-Scale Pilots to Implement Principles of Patient-Centered Measurement” fund, through the Robert Wood Johnson Foundation. Again reference to website address This grant supports the patient-led implementation of our autonomy and respect quality measures of patient experience (MADM and MORi) at 5 sites nationally. Our partners at these sites are all engaged in women’s health delivery and advocacy, and serve diverse communities. All sites have identified a Lead Patient Partner to organize transdisciplinary working groups comprised of patient partners remunerated), clinicians, and hospital administrators to design and implement locally relevant and feasible pilots.

#### Interprofessional Education

- **Dialogue and Shared Decisions:** [Advancing Person-Centered Care](#) is an innovative online course for health professions. Through five interactive modules medical, midwifery, nursing, and genetic counselling trainees acquire key interprofessional competencies to work effectively and respectfully with each other and with patients. Module content focuses on *Person-Centered Decision Making, Place of Birth, Respectful Communication, Conflict Transformation, and Collaborative Leadership*. This course was designed by the Interprofessional Education Task Force formed at Summit I and developed by a transdisciplinary team of faculty and students at the University of British Columbia. It is now being adapted to the US context by delegates and partners who engaged in Summit III .