Centering Lived Experience & Expertise:

Health equity and measurement

SARASWATHI VEDAM PHD,RM,CNM,FACNM

ADVANCING MATERNAL HEALTH EQUITY AND REDUCING MATERNAL MORTALITY

NASEM

JUNE 7, 2021

No conflicts to declare

Funding Sources:

- Transforming Birth Fund, New Hampshire Charitable Foundation
- Michael Smith Foundation Health Professional Investigator Award
- Groundswell Fund
- Canadian Institute of Health Research

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How do we enhance quality in health equity research?

To have credible, usable data, we need to:

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

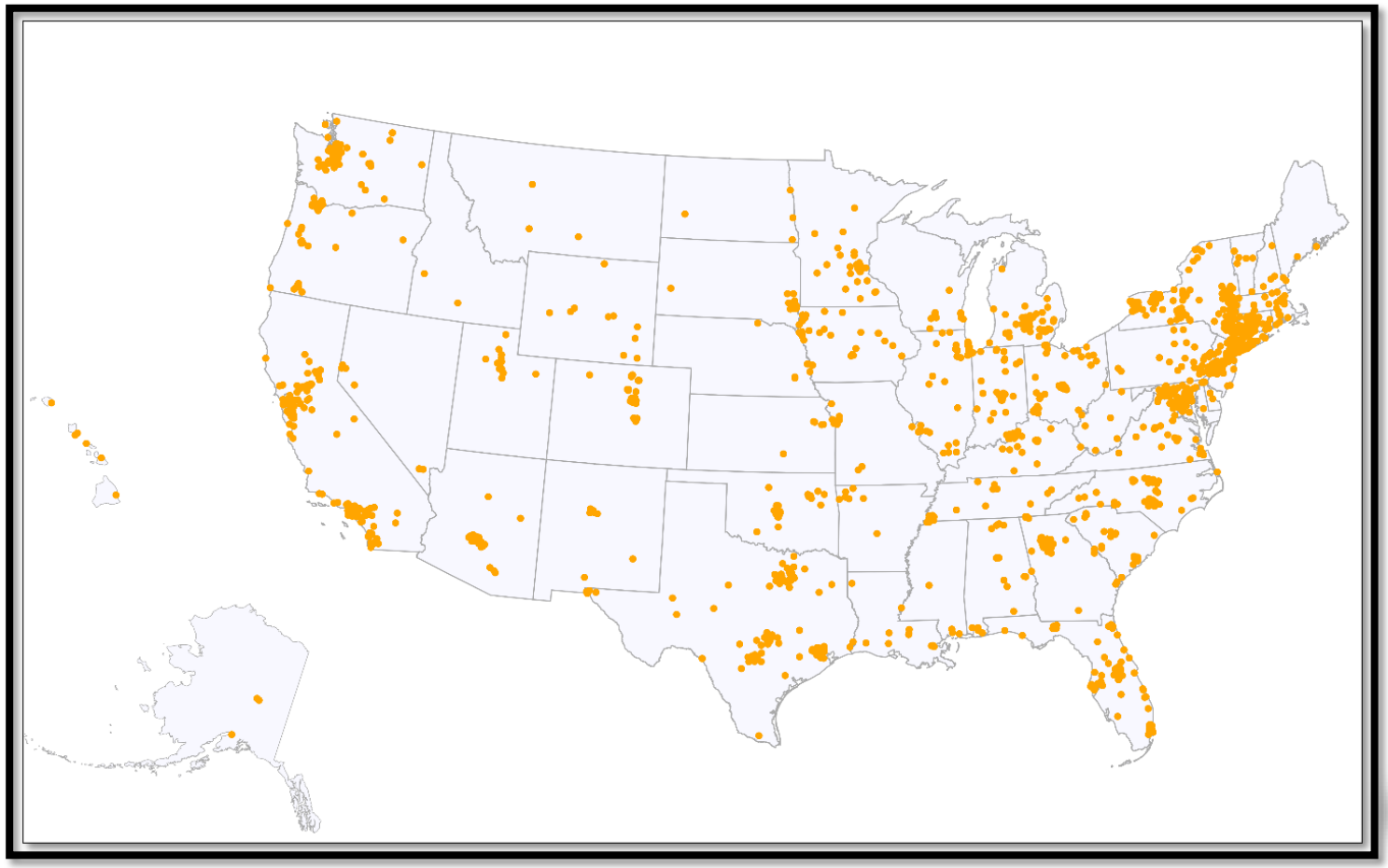
Equity Action Themes:

Measurement, Accountability, Health Professional Education, Representation, and Workforce Development

Community Participatory Action Research

Giving Voice to Mothers

N 2700



Supported by: Transforming Birth Fund, New Hampshire Charitable Foundation; Groundswell Fund; and Michael Smith Foundation for Health Research

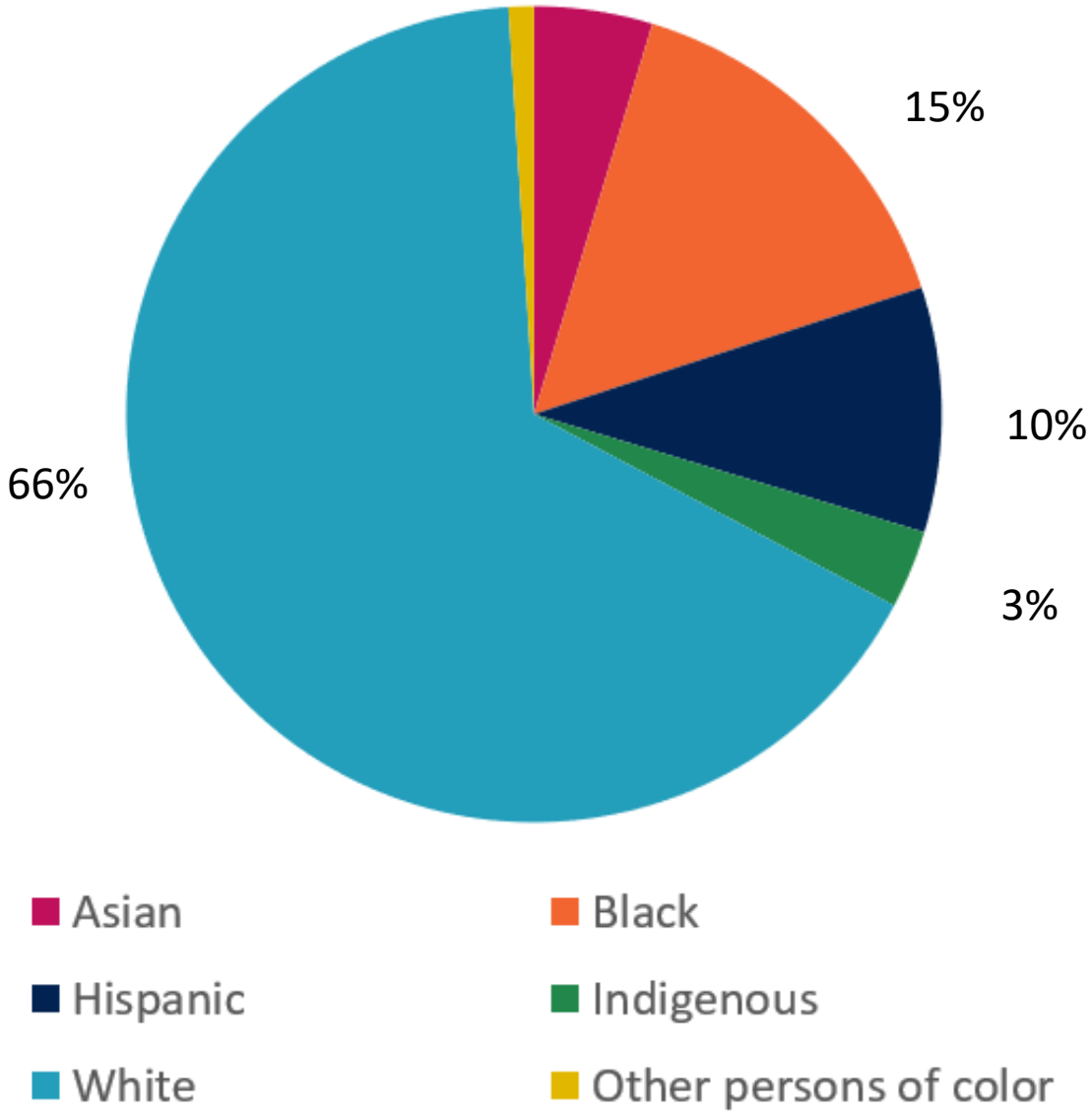
Community Members chose the topics

- Access to models of care
- Experiences with pregnancy & birth care
  - Decision-making
  - Respect, Autonomy
  - Racism, Mistreatment
  - Consent & Non-Consent
- What builds Health and Well-Being

Co-Creation of measures and metrics

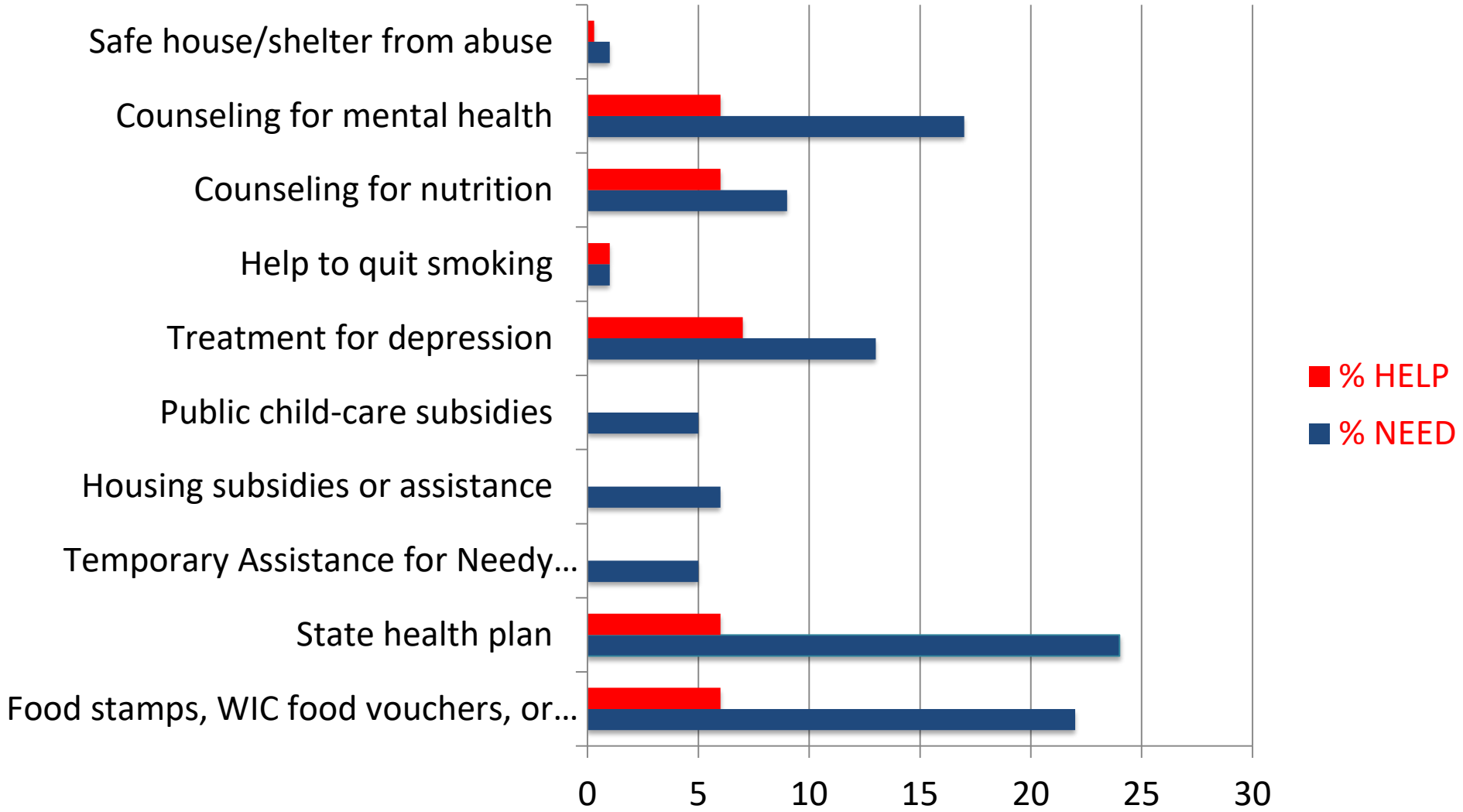
- Literature Review based on service users priorities
  - Select, adapt or design new questions
- Community members rate questions for relevance, clarity, and importance
- Ongoing community consultations
  - SC reviews all drafts, recruitment, and messaging
  - Beta and Pilot Testing by those with lived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

N2700, 34% Communities of Color



During your pregnancy, did you feel you needed the following ?

During your care did your doctor or midwife help you to get ?



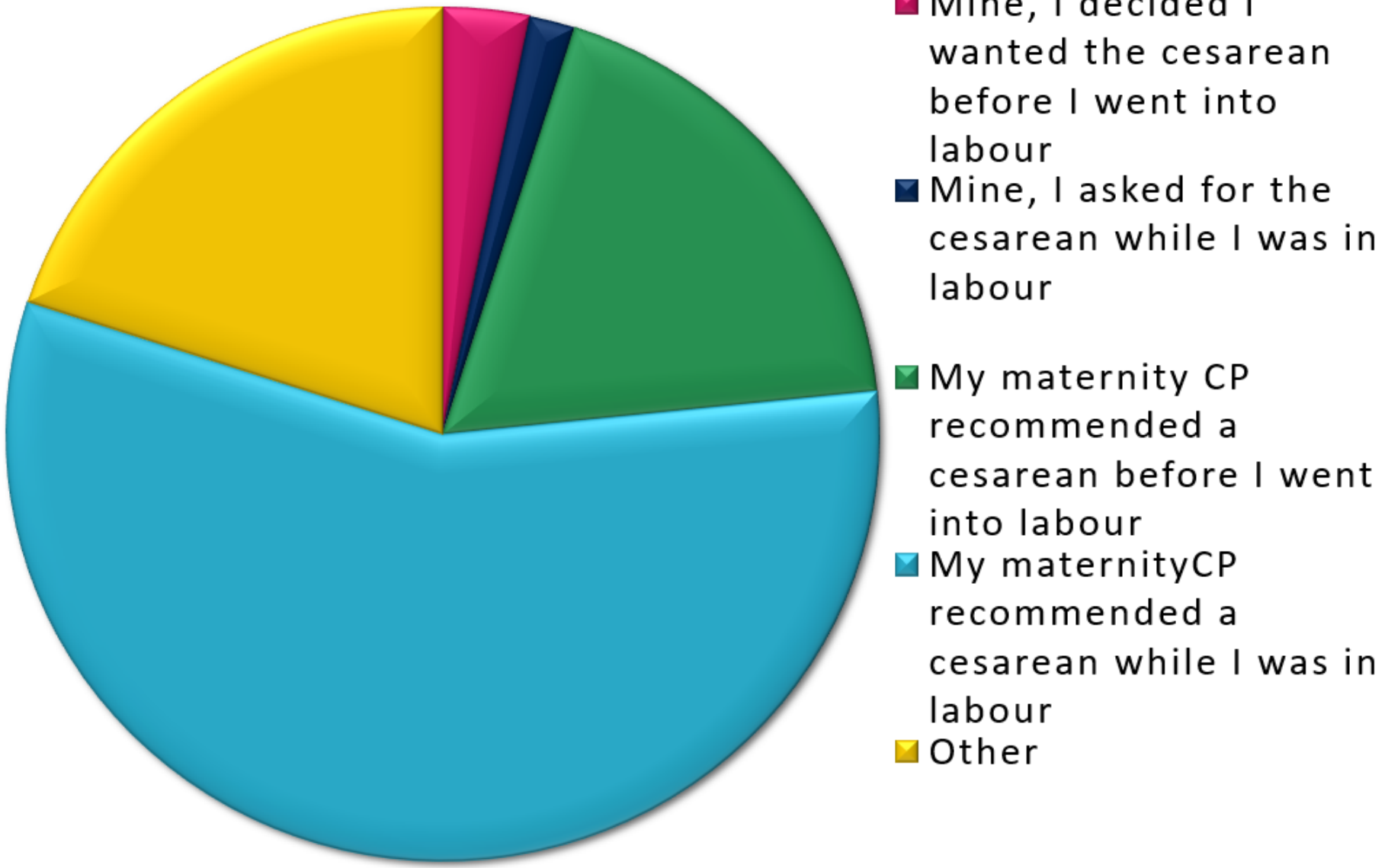
Unmet needs for services during pregnancy, by race

		BLACK		LATINA		ASIAN		INDIGENOUS	
UNMET NEEDS	OVERALL RATE	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR	95 % CI
Depression	6%	**1.97**	**1.29-3.02**	1.58	0.92-2.71	1.73	0.84-3.54	**3.10**	**1.53-6.25**
Mental Health	9%	**2.50**	**1.80-3.48**	1.49	0.94-2.34	1.61	0.88-2.94	**2.85**	**1.55-5.24**

Decision Making

- **91% said “It is very important to me that I lead decisions”**
- **Only 1% felt it was not important to lead decisions**

Who made the decision to have a CS ?



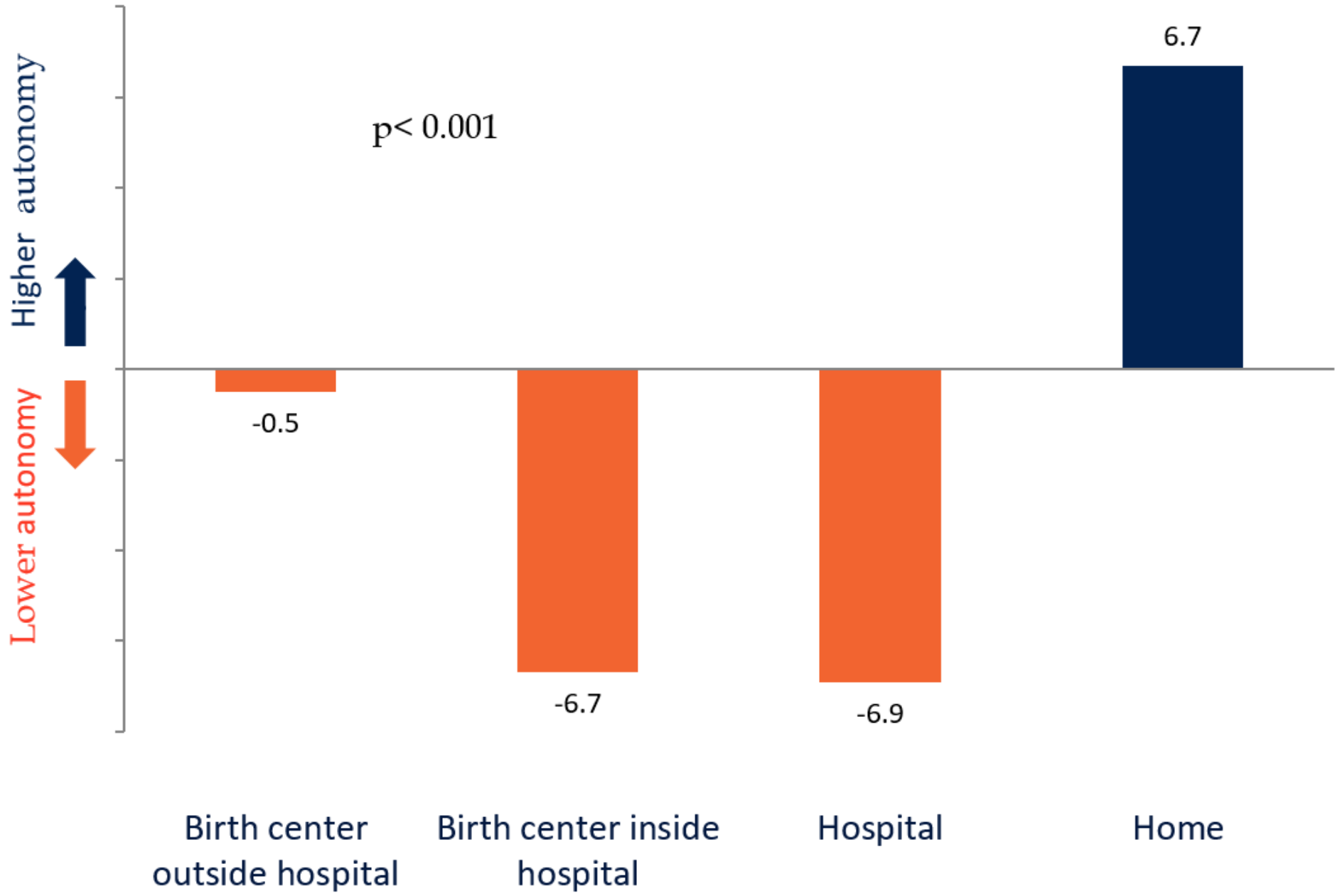
Mothers Autonomy in Decision-Making (MADM) Scale

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

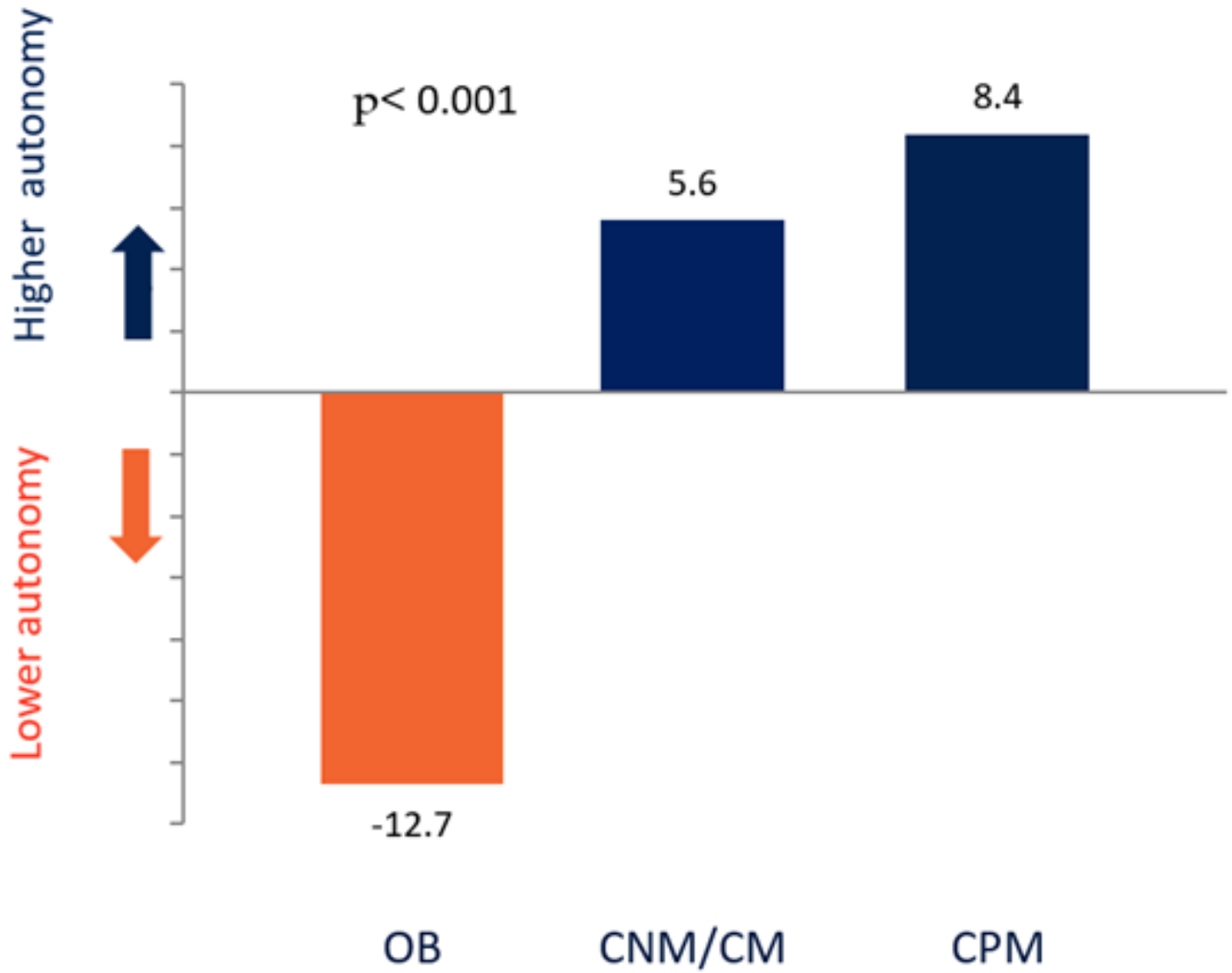
(Vedam et al., PLOS One, 2017)

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

Autonomy (MADM) scores by place of birth



MADM scores: Autonomy by prenatal provider



The Mothers On Respect (MOR) index

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

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

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

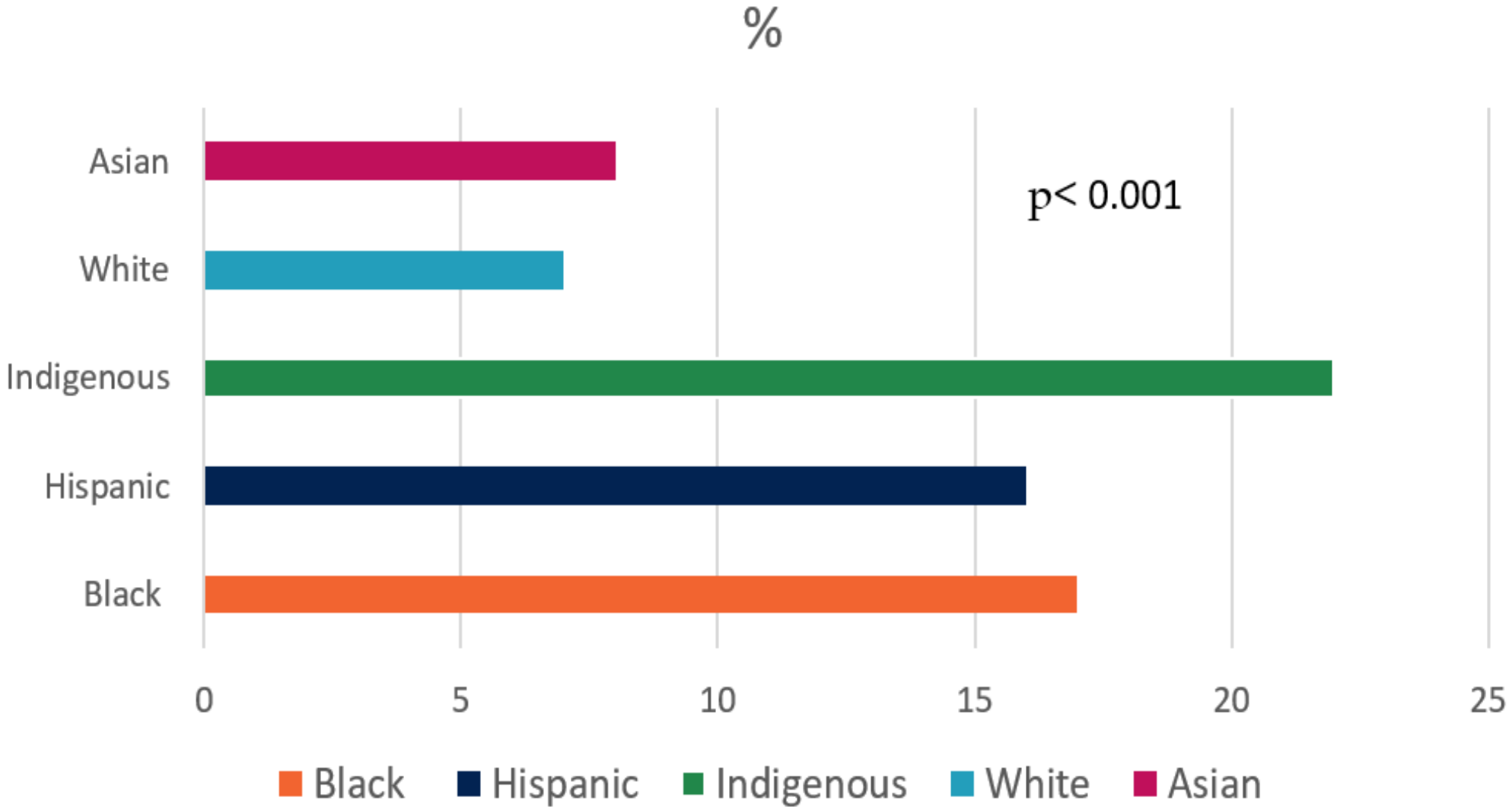
B: During my pregnancy I felt that I was treated poorly by my doctor or midwife because of: (select or circle one answer for each statement)

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

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

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

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



Autonomy and Respect, by Provider Type and Place of Birth

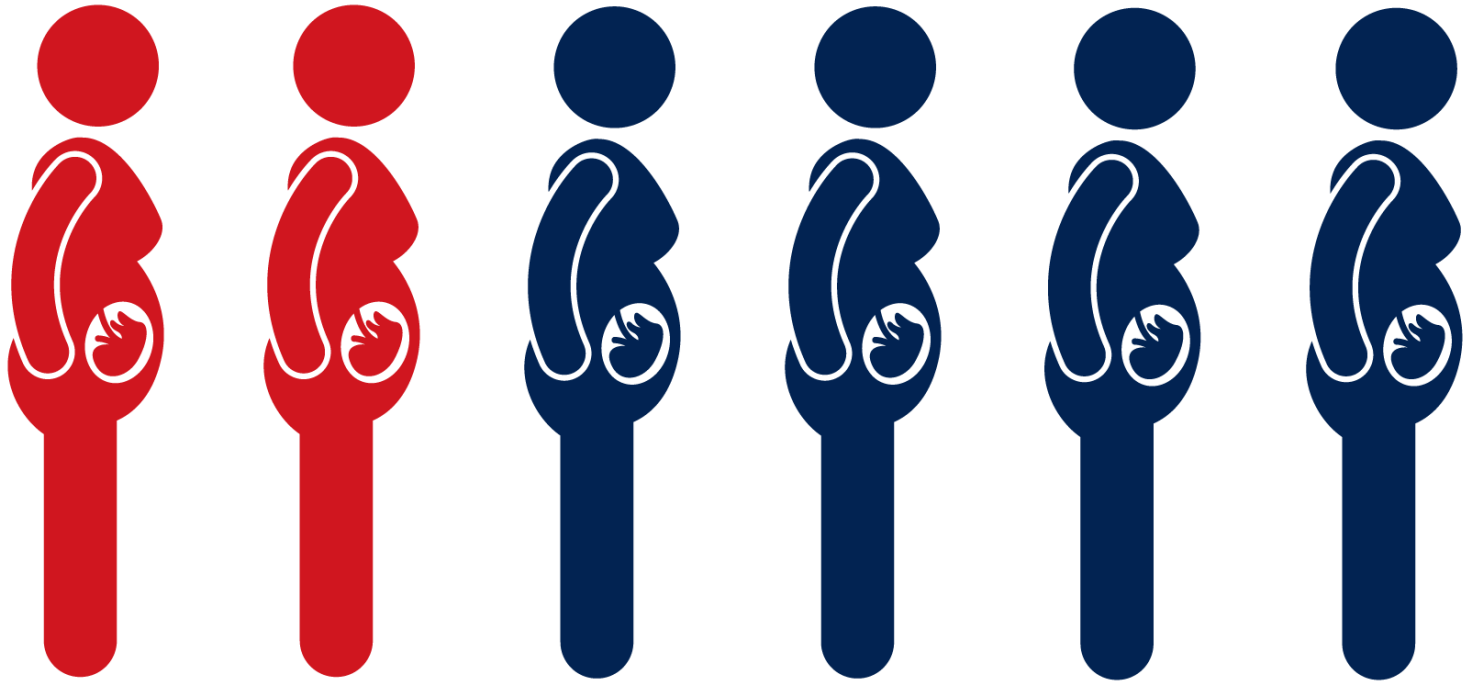
	OR	95% CI
MADM - VERY HIGH AUTONOMY (reference: moderate or low autonomy) n= 1763		
MW, community birth	5.35	3.92-7.29
MW, hospital birth/HBC	1.77	1.16-2.70
DC, hospital birth/HBC (reference)	1	
MORI – VERY HIGH RESPECT (reference: moderate or low respect) n=1676		
MW, community birth	5.57	4.10-7.56
MW, hospital birth/HBC	0.93	0.58-1.50
DC, hospital birth/HBC (reference)	1	

Gradilla, Niles, Strauss et al. (2020) APHA Conference

Measuring Mistreatment

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

Mistreatment by population

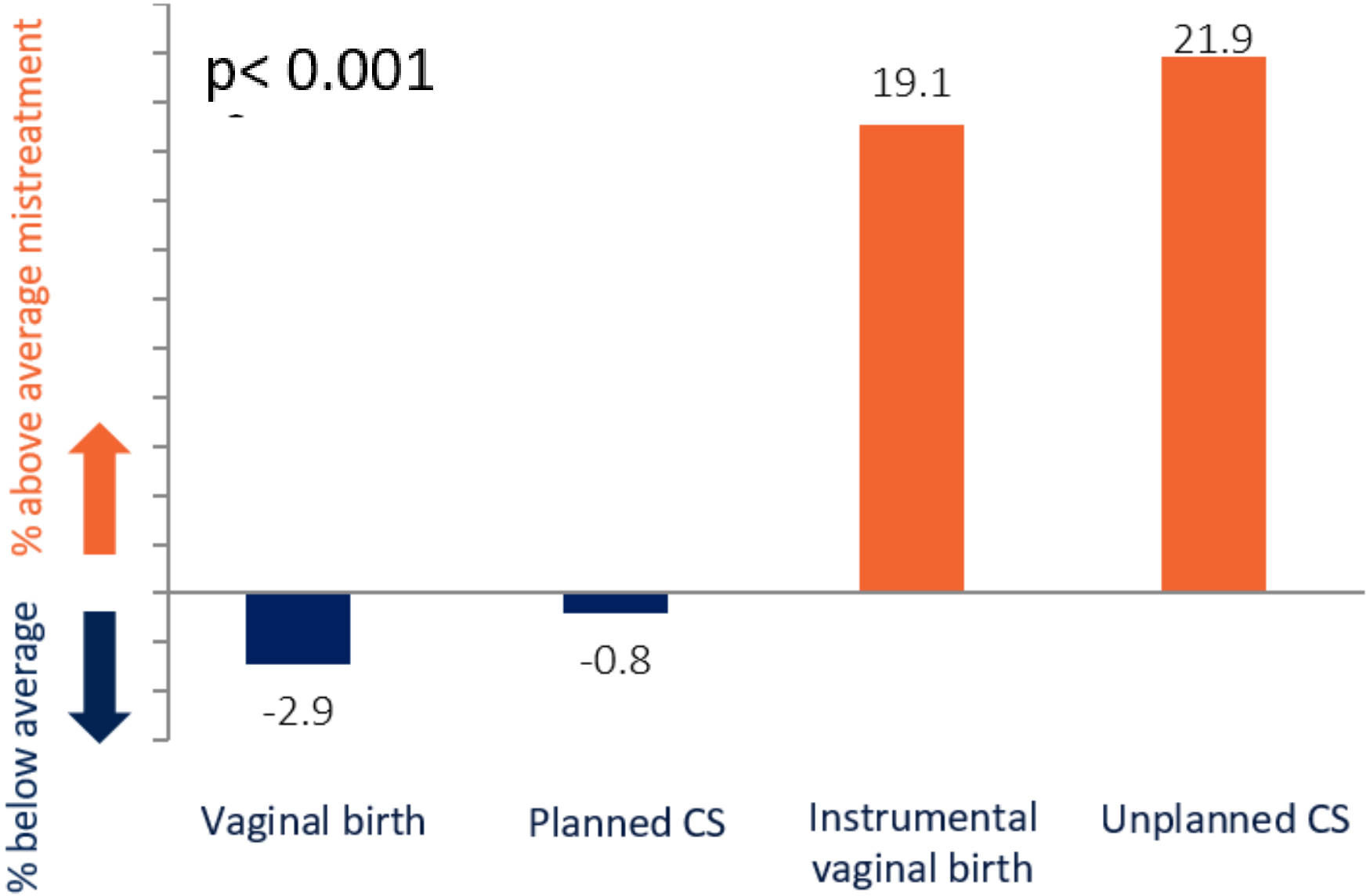


I in 3 in LMICs, and BIPOC communities

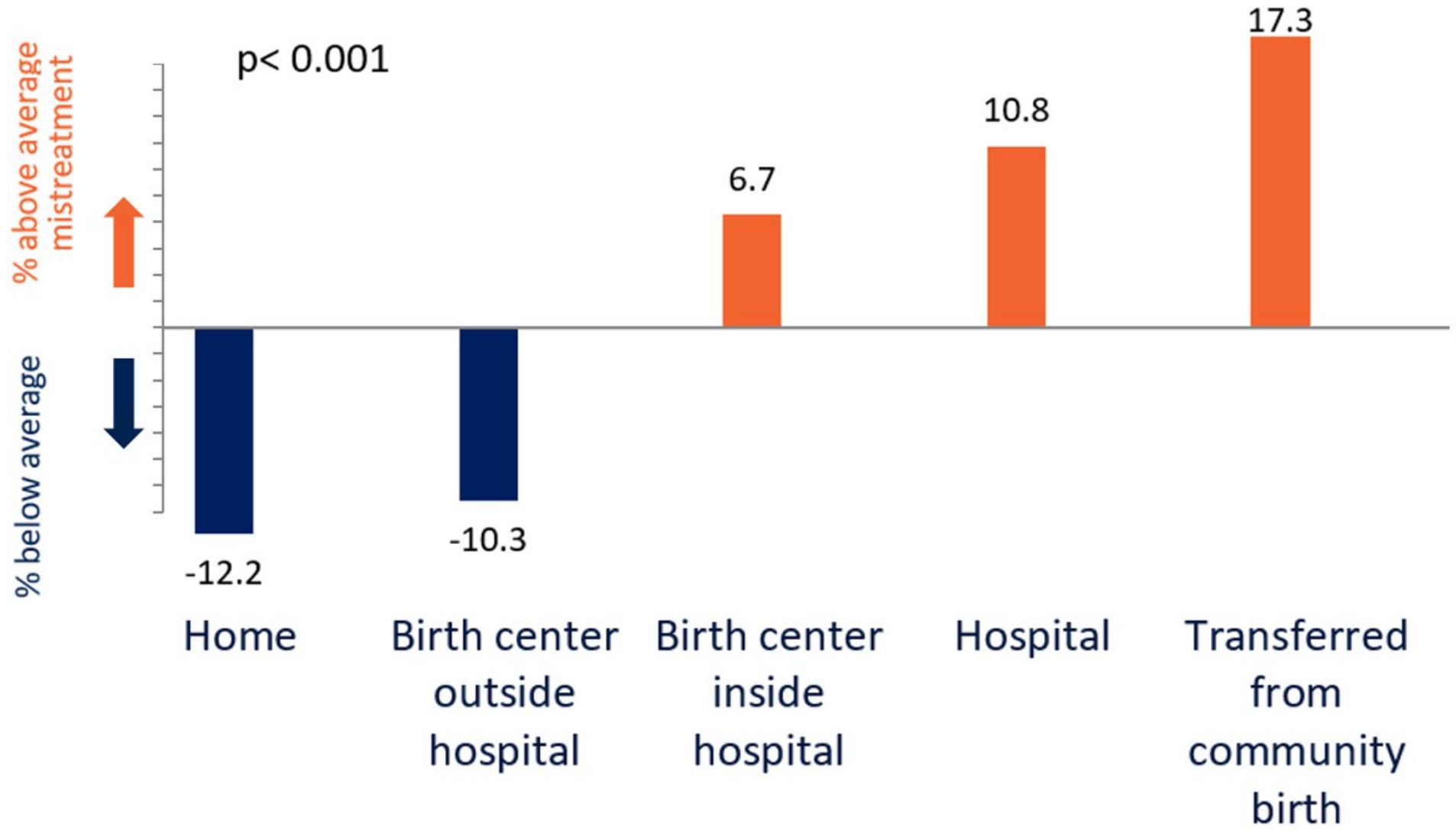
Lancet 2019, Reproductive Health 2019

1 in 6 (17%) experienced mistreatment in full sample

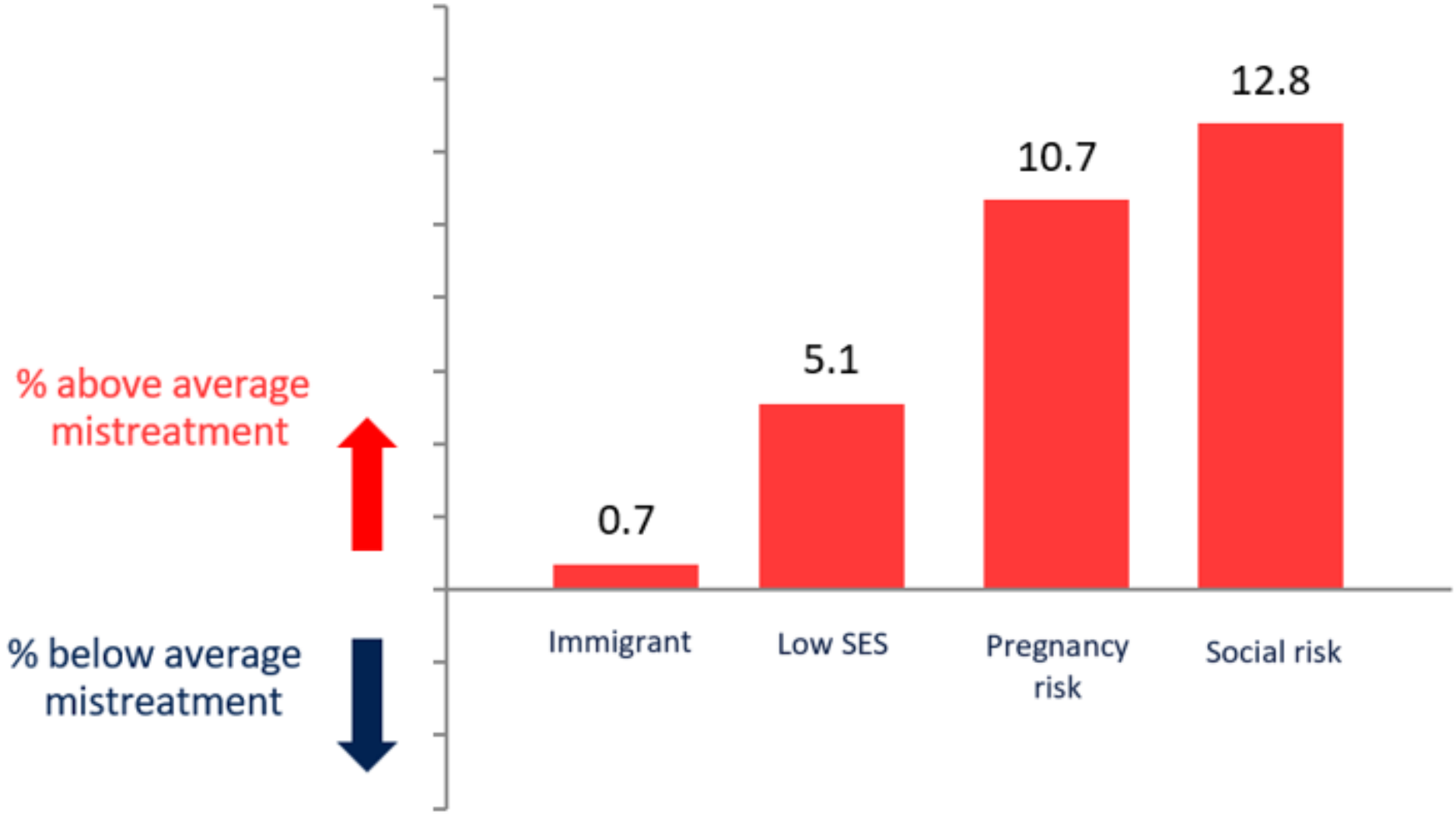
Rate of mistreatment by mode of birth



Rate of mistreatment by place of birth



What is linked to mistreatment?

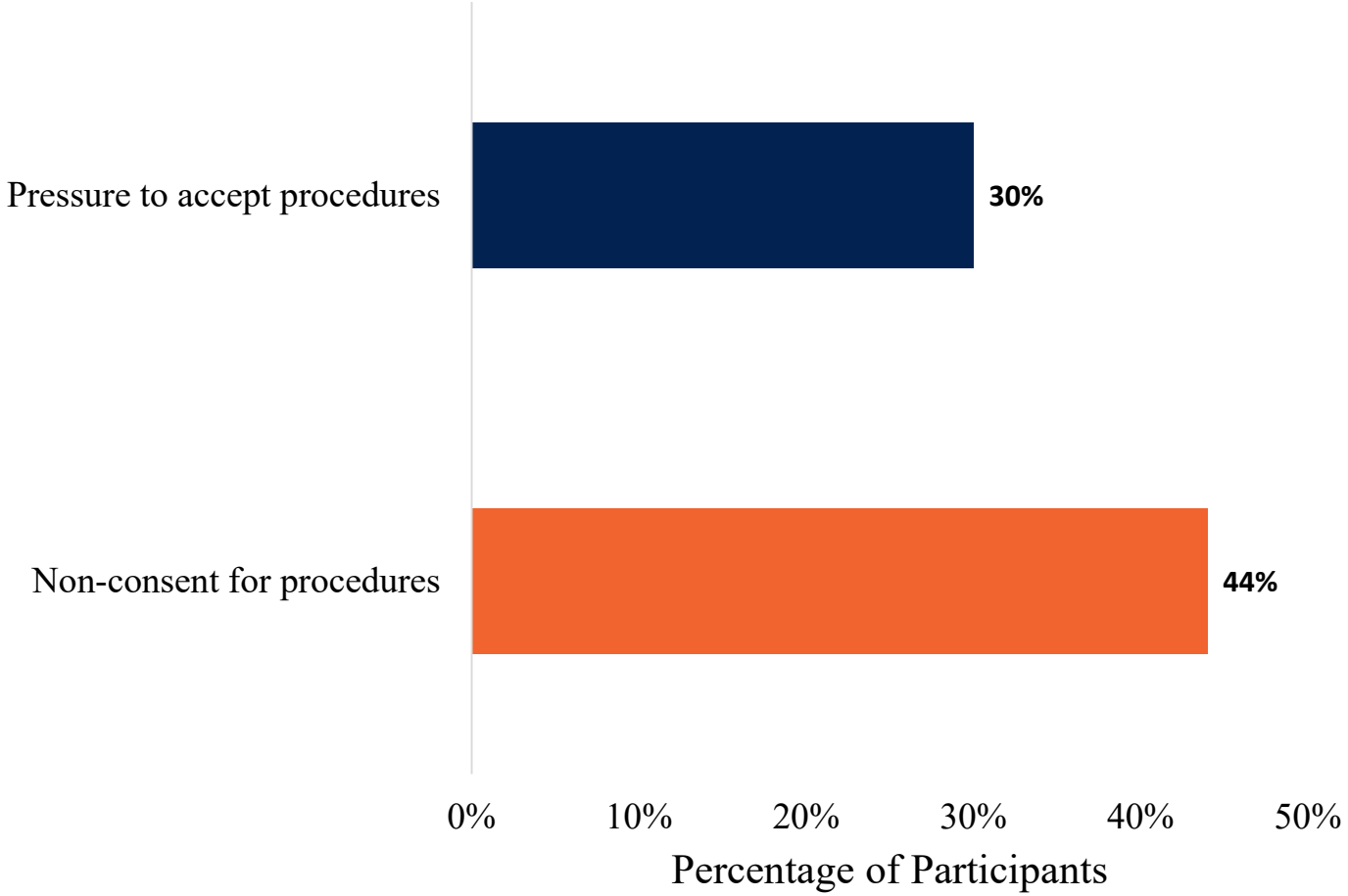


Intersection between mistreatment, race and additional socio-demographic and context of care variables (n= 2138)

	n (%) who report any mistreatment	
RACE + SOCIODEMOGRAPHICS	**Women of colour**	**White women**
Race	162 (23.8)	199 (14.1)
Race + Nulliparity	94 (32.6)	114 (21.6)
Race + Age 17-25 years	17 (30.9)	11 (18.0)
Race + Low SES	83 (26.9)	74 (17.7)
Race + Pregnancy complications	60 (37.0)	60 (22.1)
Race + Social risk	30 (45.5)	21 (19.8)
RACE + CONTEXT OF CARE	**Women of colour**	**White women**
Race + Prenatal midwifery care	63 (16.0)	107 (10.1)
Race + Actual place of birth hospital or in-hospital birthing centre	137 (33.9)	146 (24.0)
Race + Actual place of birth home or freestanding BC	17 (6.6)	38 (5.1)
Race + Unplanned Caesarean or operative vaginal birth	43 (41.0)	48 (36.9)
Race + Difference in opinion with care provider	39 (83.0)	42 (76.4)

Experience of Non-Consent and Pressure during Perinatal Care in the U.S. (n=1635, 51% POC, 54% White)

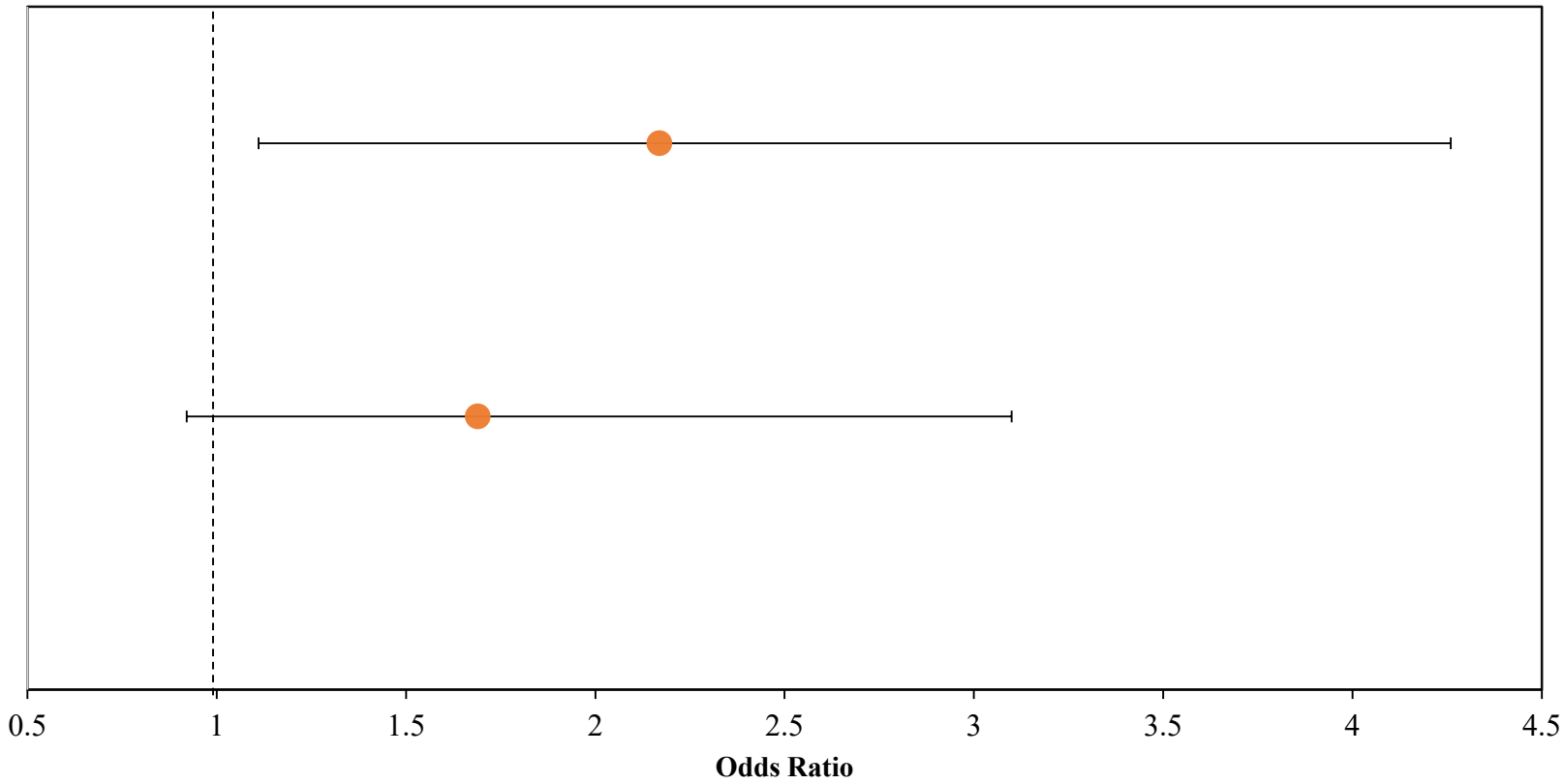
Capacity building: Trainees and Mentors



- Mean scores for both outcomes were **significantly higher for BIPOC** ($p < 0.001$)
- **BIPOC identity explained 39% of variance in non-consent**, 27% in pressure ($p<0.001$)
- Higher mean pressure scores were **associated with induced and operative vaginal or surgical births** compared to SVB and facility-based vs. community births.

Logan et al. (2021)

Patient-reported Autonomy and Mistreatment amongst Black Birthing People in Southeastern U.S. (n= 382)



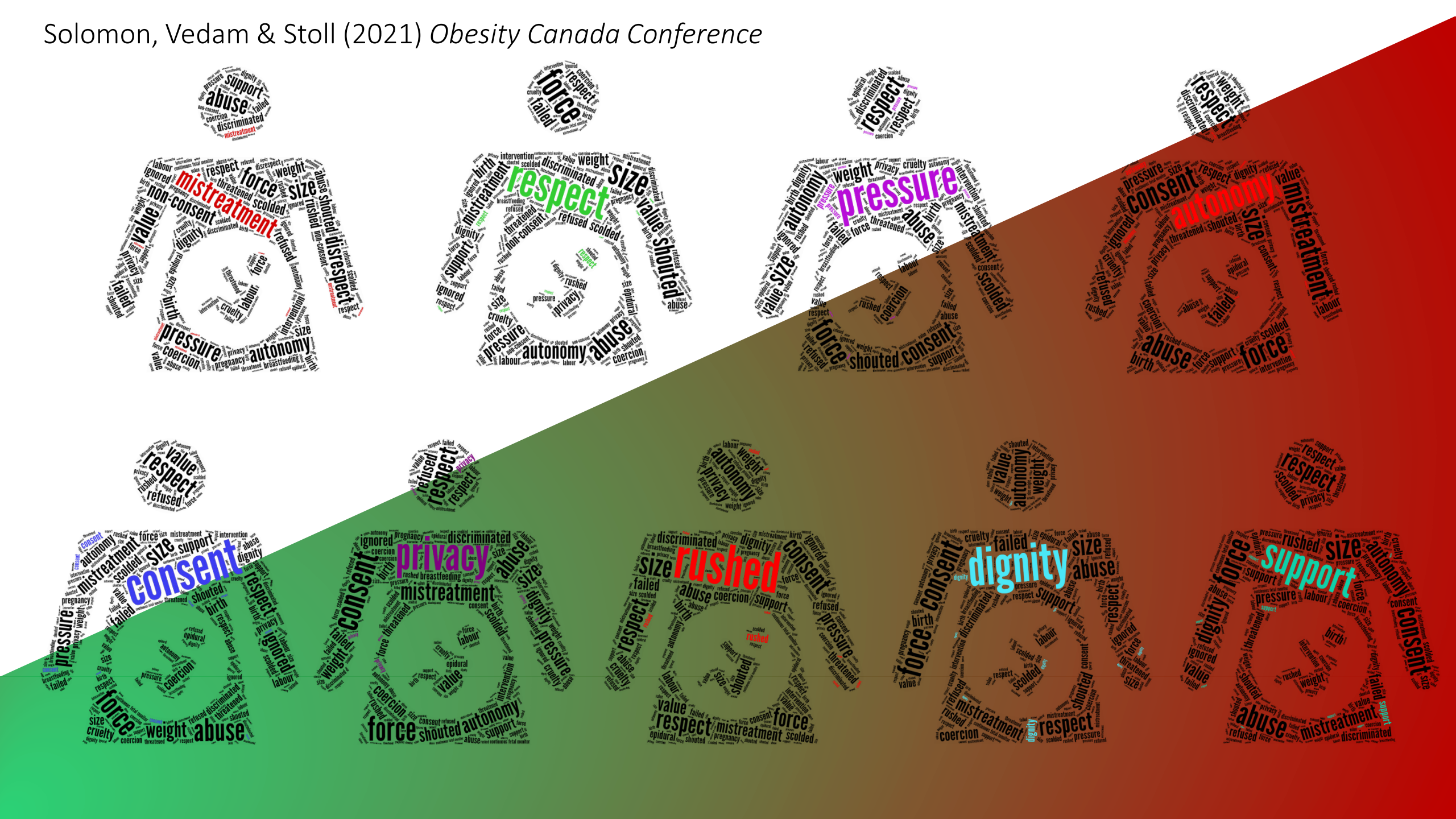
OR, (95% CI)

2.17 (1.11-4.26)

1.69 (0.92-3.10)

Julian, Stoll & Vedam (2020) *APHA Conference*

Solomon, Vedam & Stoll (2021) *Obesity Canada Conference*



Why Does it Matter: Mistreatment and risk of mortality

The California Pregnancy-Associated Mortality Review (CA-PAMR):

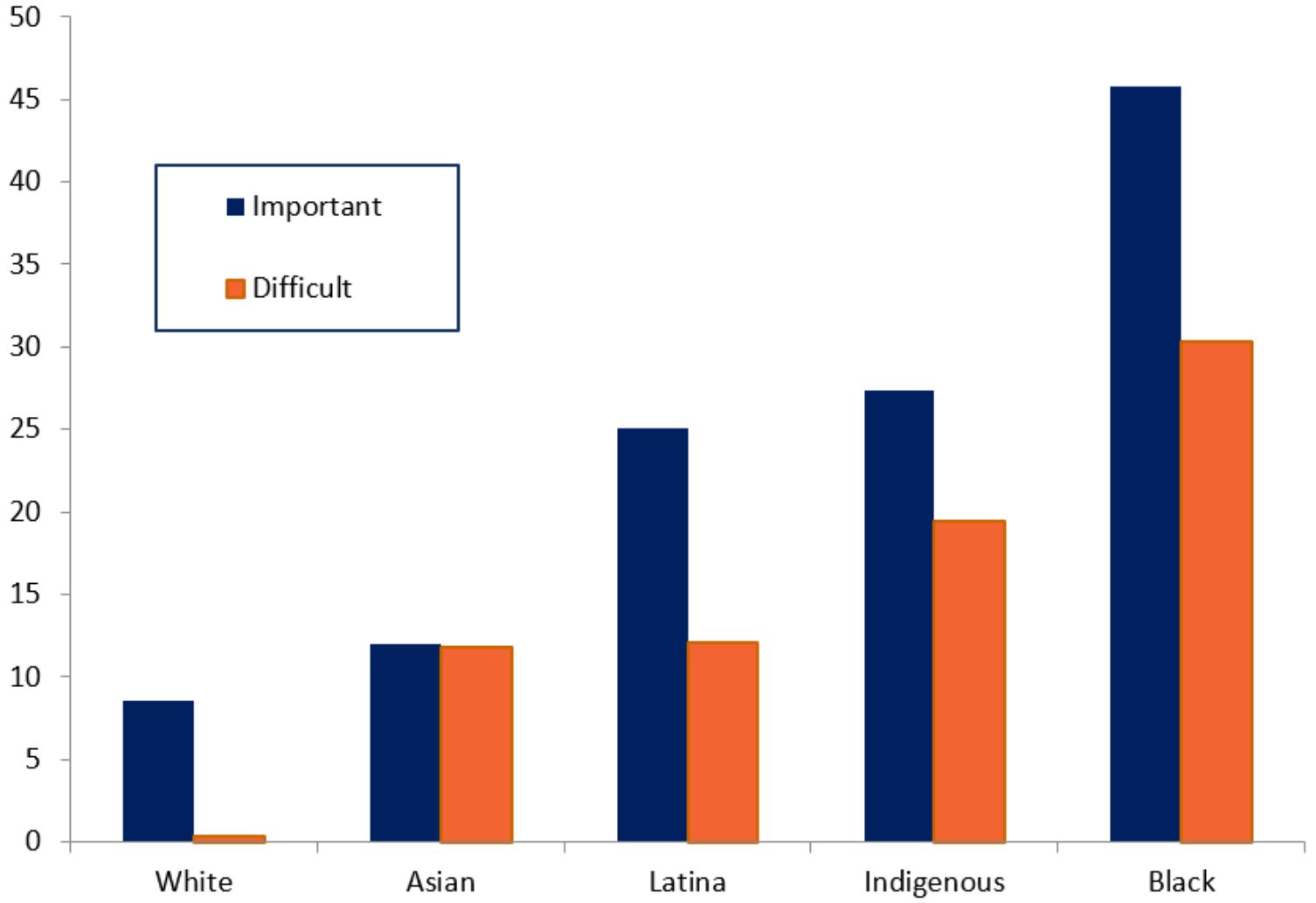
- Significant # of respondents reported "being ignored" or that "providers failed to respond to their requests for help
- **Healthcare provider factors** - most common contributor to maternal deaths,
- 81% of maternal deaths in that time period.

The most common provider factor was delayed response to clinical warning signs, followed by ineffective care.

When you experience problems, what helps you and your family survive, succeed and thrive? (n=2138)

- Immediate Family: 89.0 %
- Friends: 77.4 %
- Extended Family: 49.3%
- Faith Community: 31.6 %
- Work colleagues: 23.5 %
- Health clinics/healthcare providers: 11.8 %
- Elders in my community: 6.3 %
- Cultural group: 5.6 %
- Government agencies: 4.7 %
- Sports clubs: 2.0 %
- Neighborhood association: 2.0 %

Finding a midwife or doctor who shared my heritage, race, ethnic or cultural background was:
1) important, 2) difficult



Impact of Culturally-Centered Care in Community Birth Centers

	Clients in Culturally-Centered Model (Roots)	Clients in Community Birth Settings (GVtM Study)	
Autonomy (MADM) Score (Median)	36	32	(p<0.001)
Respect (MORi) Score (Median)	78	75	(p=0.011)

Almanza et al. (2021)


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[1]*, Kathrin Stoll[1,2], Kelsey Martin[1], Nicholas Rubashkin[3], Sarah Partridge[4], Dana Thordarson[1], Ganga Jolicoeur[5], the Changing Childbirth in BC Steering Council[¶]


RESEARCH ARTICLE Open Access

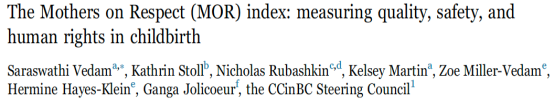
The Canadian birth place study: examining maternity care provider attitudes and interprofessional conflict around planned home birth

Saraswathi Vedam[1*], Kathrin Stoll[1], Laura Schummers[2], Nichole Fairbrother[3], Michael C Klein[4], Dana Thordarson[1], Jude Kornelsen[5], Shafik Dharamsi[6], Judy Rogers[7], Robert Liston[8] and Janusz Kaczorowski[9]


RESEARCH Open Access

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

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


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

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

Tool	Number of times requested	# of countries applied	Translation available in following languages:
Mother's Autonomy in Decision making Scale (MADM)	212	43	Spanish, French, Inuktitut, Arabic, Punjabi, Chinese (simplified), Chinese (traditional), German, Icelandic, Dutch, Polish, Turkish
Provider Attitudes towards Planned Home Birth scale (PAPHB)	97	5	Chinese (simplified
Mistreatment index	135	(120 global citations since 2019)	Spanish, German, Icelandic, Dutch, French, Punjabi, Chinese (simplified), Chinese (traditional), Arabic
Mothers on Respect Index (MORi)	254	46	Spanish, French, Inuktitut, Arabic, Punjabi, Chinese (simplified), Chinese (traditional), German, Icelandic, Dutch, Polish

GVtM: Early career scholar manuscripts in progress:

Dr. Nicholas Rubashkin, *University of California San Francisco*
- Race, decision-making, and VBAC

Dr. Katelyn Yoder, *University of California San Francisco*
- Community to hospital transfer experiences

Dr. Brittany Chambers & **Safyer McKenzie** MSc, *University of California San Francisco*
- Nativity and mistreatment, perceptions of racism

Dr. Zoë, Julian, *University of Alabama,* **Dr. Paulomi Niles,** *New York University*
- Mistreatment, autonomy, and respect as experienced by Black birthing people in Southern U.S.

Flor de Abril Cameron MPH, PhD(c), *Center for Research on Health Care Data, Pittsburgh*
- Experiences of Latinx service users

Alice Story MPH JM PhD(c), *University of Louisville*
- Factors influencing mode of delivery and perinatal outcomes by race

Dr. Jennifer Vanderlaan, *University of Nevada*
- Race, childbirth education, and delivery outcomes

Salutogenic Approach to Birth Research

birth place lab

What makes people healthy?

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

Your birth experience deserves to be counted.

www.respcct.ca

THE RESPCT STUDY
RESEARCH EXAMINING THE STORIES OF PREGNANCY AND CHILDBEARING IN CANADA TODAY

birth place lab

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The Birth Place Lab

www.birthplacelab.org

Centering lived experiences in health services research

Respectful Maternity Care

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

Birth Place and Provider

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

Person-Centered Decision Making

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

References

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Gradilla M, Niles P, Strauss N, Vedam S & Stoll K. (2020). CALL THE MIDWIFE: INFLUENCE OF PROVIDER TYPE AND PLACE OF BIRTH ON EXPERIENCE OF MATERNITY CARE. APHA Conference October 27, 2020:

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