

*Bridging the chasm between pregnancy and  
health over the life course (BtC)*



**Final Report:  
A National Agenda for Research and Action**

Funded by

PCORI (#6947-BUSPH)

Office of Research on Women's Health | NIDDK (5RO1DK107528)

## EXECUTIVE SUMMARY

### Introduction

Fragmentation in women's health care has been experienced and studied for years, and still many are frustrated that very little seems to change. As a society and health care system, we invest in people when they are pregnant to assure healthy infants. However, after the immediate postpartum period new mothers fall into a deep and wide chasm between reproductive health care and ongoing primary care and between what we know and what we do. Research tells us that pregnancy is a stress test for women's health; complications such as gestational diabetes and hypertensive disorders of pregnancy, signal significant risk for future chronic illness, and need intentional follow-up testing and care in the first year postpartum and beyond (Kim, 2014). Such follow up care can prevent complications in subsequent pregnancies as well as chronic conditions that go on to plague women and their families across their life course. Despite what we know about the ripple effects of pregnancy complications, health care outside of pregnancy remains, at best, the patchwork quilt that Clancy and Massion described in their classic commentary in 1992.

For people of color, the patchwork is particularly ragged. Pregnancy complications are more prevalent and the risk of severe maternal morbidity and death in the year after birth are far greater than for White women. Structural racism, social inequities, and gaps in resources in rural America, are all significant contributors to illness that accumulate over women's life course and come to bear on health during and long after pregnancy (Garcia and Sharif, 2015). The chasms in women's health care are complex: health system fragmentation; racial, social and gender injustice; and failure to translate what we know into what we do.

Complex problems call for innovative, collaborative, multi-pronged solutions that build upon, leverage different kinds of expertise, and elevate the voices of women and all pregnant and parenting people.

### Methods

The aims of this project were: 1) to engage and sustain a network of patients, advocates, providers, researchers, policy-makers, and health system innovators to bring their respective expertise to the task of creating an Agenda for Research and Action that could serve as the basis for major change in how we invest in women's health across the life span, social and racial/ethnic differences, geographies, sectors and domains of expertise; 2) to build sustainable momentum that can be harnessed going forward to implement the Agenda, one step at a time; and 3) to assure that the voices of women, especially women of color who carry the burden of disproportionate risk and sharp insights based on their lived experience, are front and center in the movement for change. Toward these ends we conducted a three-phase project over a two-year period:

In Phase 1 we recruited the BtC Stakeholder Engagement Leadership Council, consisting of community and advocacy organizations and academic partners whose mission aligned with BtC, to guide the project.

In Phase 2 we convened a pioneering Conference that engaged a dynamic network of diverse stakeholders to share expertise and stories, and co-create the outline for the *National Agenda for Research and Action*.

In Phase 3 we convened seven Working Groups (WGs) based on themes identified at the Conference, and created an on-line portal to serve as the communication hub for the ongoing work of BtC. Each WG, co-led by two members of the BtC Network, with volunteer representatives from all stakeholder groups, held five conference calls to create a problem statement, analyze evidence and professional and personal experience, and collectively decide upon strategic priorities to constitute the Agenda. WG topics include:

- 1) Advocate for policy changes to transform health care delivery;
- 2) Align research with women's lived experience over the life cycle;
- 3) Develop high touch models of care;
- 4) Eliminate disrespect, racism and all other implicit bias within health care;
- 5) Preserve the narrative: Use health data to bridge the chasm;

- 6) Promote investment in communities; and
- 7) Educate the public to heighten awareness of root causes.

## Results

The strategies selected by the BtC WGs are depicted in the Strategy Map on the following page. The blue lines indicate the cross-cutting nature of each of these strategies. Each WG analyzed both peer-reviewed and grey literature as well as generally available media articles and blogs as a basis for identifying possible strategies. Members deliberated on the merits of strategies for the Agenda based on four criteria: promotion of health equity, effectiveness, innovation, and feasibility. Participants balanced a sense of urgency in light of the current political landscape with a firm sense of the deep root causes of the problems, and selected foci for research and action that were on a continuum from practicable in the near to mid-term to aspirational in the longer term future.

## Conclusions

Since the inception of BtC, the public eye has turned to maternal health—the attention provoked by reports of the tragic facts and stories about black women dying in childbirth at three times the rate of white women, and the disrespect that too often follows women of color through their health care experiences. Key issues that percolated up during the BtC Conference and were fleshed out by BtC WGs are now receiving attention of policy-makers: implicit bias training for providers; Medicaid coverage up to 1 year postpartum for women who would otherwise lose coverage at 60 days; inclusion, reimbursement, and support of doulas and other community and peer health workers; the call for quality metrics in maternal health; and “pregnancy medical home” demonstration projects. These items included on current policy agendas at state and federal levels, remarkable for their breadth and accelerated pace, create a ‘policy window’ for the expanded scope of the BtC Agenda.

The time is ripe to leverage the co-created *BtC Agenda for Research and Action* and carry forward the work that most aligns with our individual and collective missions and with the constituents we know best. The work achieved by the BtC Conference participants and WGs can serve as the basis for a growing network of peers to adapt and disseminate the material and messages of the BtC report and advance the Agenda.

The report that follows provides a summary of the literature on each WG topic. As such it describes and justifies 3-5 strategies deemed most innovative, equity-promoting, effective, and feasible by each WG, and lays out potential stakeholders, existing initiatives/potential collaborations, and expected challenges to inform implementation of the Agenda. We also include an extensive bibliography for reference.

This report is a resource for advocates, researchers, clinicians, health system innovators, and policy-makers already committed to transforming maternity care and promoting birth equity in America. And it is a call for us all to push forward an Agenda that assures continuity, respect, and holism in the care of pregnant and parenting people across the chasm from pregnancy to the first year postpartum and beyond--across the life course.

**NOTE:** The work of BtC was completed in October, 2019. We have taken the time to gather and include extensive feedback on the initial report and are now completing the BtC final report in May 2020 in the midst of the global pandemic. COVID-19 is taking an enormous toll on communities of color in general and is changing access to health care and quality of that care for pregnant and parenting people in ways that are harmful in many cases and in others, helpful. As research and program resources are (understandably) focused on COVID-19 at this time, sparse attention is being paid to reproductive-aged women, pregnant and birthing people, and their ongoing needs. While this report does not address COVID-19 per se, the pandemic magnifies the importance of the strategies presented in this BtC National Agenda. We must keep our eyes on the prize as we work together, even as COVID-19 and its aftermath unfolds: policies and programs that support equity, dignity, and continuity in women’s health before, during and beyond the ‘perinatal’ window.

## Policy

1. Support federal and state legislation to extend Medicaid coverage to 12 months PP (auto-enrollment)
- 2a. Health systems innovations: Establish new models for comprehensive primary care (structural transformation)
- b. Fund innovative models for transition from maternity care to ongoing primary care after pregnancy
- c. Fund capacity for ACOs to address social determinants
- 3a. Design/promote quality metrics responsive to specific conditions, social determinants, women's experience (NCQ)
- b. Pay-for-performance: reward warm handoff to PC
- 4a. Incentivize multi-specialty entry to primary care
- b. Require accrediting bodies to assess competency in link of repro health with future health
- c. Expand early childhood home visiting to mothers PP yr.3

## Research

1. Work with NIH and other funders to develop RFAs to fund gaps: screening & tx after pregnancy complications, barriers to PP care, predisposing factors, info needs; give preference to mixed methods & CBPR
2. Evaluate impact of consistent, comprehensive care by provider type during extended PP period, including initiatives for PP Medical Home, name changes for complications to reflect risks, patient-facing IT
3. Negotiate with EPIC to develop/test a template for transfer of pregnancy history to primary care
4. Request supplements to existing longitudinal study of reproductive age women to add investigation of the impact of pregnancy complications on future health

## Preserving the Narrative

1. Develop a PP discharge template w/coded fields, risk info & *Mother's Health Book* (paper/app/electronic)
2. Support women to share their stories with providers and motivate providers to listen
3. Form inter-professional collaboration for CME about how women's childbirth/PP stories affect their lives

## Eliminate Disrespect and Racism

1. Develop anti-racism competency-based training (with women and their organizations); require for licensure and institutional accreditation
2. Develop new Patient-Report Experience Measure of implicit bias/ racism (JCAHO health equity indicator); use evaluate and track progress
3. Fund evaluation of education programs and their behavioral outcomes; tie to accreditation/licensure
4. Fund a national workforce development center to increase the #/% of Black health care providers

## High Touch Models of Care

1. Implement within ACOs/IDNs a flexible, collaborative team-based models of care for the PP year with warm handoff to a PC home for women with socially or medically complicated pregnancies
2. Develop training modules on the physiologic, psychologic and social dimensions of maternal health in the year after a pregnancy & integrate into each profession; design/conduct innovative team training
3. Develop/pilot a group model of maternal health care for the PP year geared to women's experience and follow-up of pregnancy complications
4. Create *Mom's Health Matters* in communities with a high burden of maternal morbidities & chronic illness

## Invest in Communities

1. Incentivize funders to allocate 2% of annual funding for capacity building/infrastructure to accompany grants to small CBO's.
2. Create a Center for CBO growth/ sustainability for women's health & development.
3. Support local agencies to create and gain paid seats at the tables of local and city/state agencies which determine policies that affect the social determinants of women's health.

## Bridging the Chasm

**Public Education**  
Strategies TBD  
based on cross-cutting priorities

# FINAL REPORT: BRIDGING THE CHASM (BtC)

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**Note:** The BtC was conceived and implemented as a ‘women’s health’ initiative. However, the issues addressed throughout this report are equally relevant to all individuals who may become pregnant; and it is important to recognize that transgender and non-binary people are too often invisible and inadequately tended to during pregnancy and beyond. Throughout this report, we primarily refer to “women” and “women’s health care” and “mothers” and “maternal health”, but also use the more inclusive language of “pregnant people” or “pregnant and parenting people” interchangeably.



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### To cite this report:

McCloskey, L. Bernstein J., and the BtC Collaborative. Final Report: A National Agenda for Research and Action. PCORI Final Report, May 2020. <https://www.pcori.org/research-results/2017/bridging-chasm-between-pregnancy-and-womens-health-over-life-course>

## Acknowledgements

An initiative as broad, sweeping and collaborative as *“Bridging the Chasm between Pregnancy and Women’s Health over the Life Course”* (BtC) requires the expertise and generosity of many. We aimed high – wishing to help shape the movement underway to change the face of health care for women in the U.S., most especially for women of color who are disproportionately burdened with maternal morbidities and mortality. As we had hoped, but more than we had ever imagined, people from many ‘walks of life’ stepped up with enormous amounts of time, energy, and ideas so that we could co-create the *“National Agenda for Research and Action to Bridge the Chasm”* presented here. To all we are indebted.



### Authors/The BtC Collaborative

Needless to say, the ideas, analyses and writing of this report could not have come to fruition without the contributions of each member of the seven Working Groups (WGs). As the BtC Collaborative we have created the Agenda for Research and Action to BtC, which can catalyze change and give all authors a sense of pride and a roadmap to turn strategies into reality and inspire others to join the effort.

**First and foremost**, this work could not have occurred at all and absolutely could not have thrived without the voices of people with lived experiences engaged every step of the way. Here we honor the patients, patient advocates, and those holding up community grassroots organizations and caregiving on the front lines. To the doulas, women who have lived with diabetes, other chronic conditions and pregnancy complications, and/or experienced birth trauma or loss, the maternal health advocates and organizers, and the leaders of small community-based organizations (CBOs) striving to sustain funding, we honor your work, thank you for your trust, time, and expertise. To those who participated in the BtC Conference with the expertise of “lived experience”, each noted in Appendix B, we extend our deep gratitude. For the WG phase of BtC, we are particularly indebted to Nneka Hall, Boston-based doula and infant low awareness advocate, who reached out to her colleagues in a vibrant community of doulas of color to invite them to participate. Nneka, Denise Bolds and Tamara Thompson gave their time and insights generously and kept ideas real and relevant. The Agenda is all the better for it. It is not easy to take time away from everyday tasks to share your experience for the greater good. It can be tiring. We hope BtC will bear fruits that make it worth the time and effort contributed to BtC, and help you carry your work forward with more support than ever.

### Funders

We wish to acknowledge the early funders of the BtC Conference- the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Office of Research on Women’s Health (ORWH). We offer special thanks to Dr. Andrew Bremer, our Project Officer for NIDDK (NIH RO1 DK107528). He recognized the value of a multi-stakeholder innovative conference to translate our research (and others’) into action. Likewise, Dr. Janine Clayton, Director of the ORWH, acknowledged the alignment of BtC with the mission and new strategic plan of her Office. She offered seed funding for the Conference, and generously served on the Stakeholder Leadership Council and as a keynote speaker for the Conference and as co-facilitator of the Research WG. Her multi-pronged support was invaluable to the initiative.

The lions’ share of the funding for the BtC Initiative came from PCORI (EAIN Eugene Washington 6947-BUSPH). Our two project officers, Yasmeen Long and Ivey Wohlfeld, have offered constant and thoughtful support over the course of the two year project. We are honored to have conducted the important work of BtC, supported all the way by their keen interest in the project and dedication to genuine patient-engagement.

### The Stakeholder Engagement Leadership Council (SELC)

The SELC members guided, prodded, and inspired us each step of the way-- from design of the Conference, engagement of patients, providers, policy-makers, advocates, and leaders in all facets of health care, to the big picture thinking needed to keep the Agenda grounded, real, and actionable. To all who joined us as leaders on this adventure- still not over- we are deeply honored and so very grateful for all we have learned from you along the way. Let’s keep it up together!

### BtC Conference Team

We knew that the Conference we envisioned to launch BtC, one that brought the arts and human stories to the task of systems change, required pioneers to make it happen. And so we invited our talented colleague/educator, actor/director, Chase Crossno, to design Day 1 activities and recruit a team of theatre artists and facilitators who shared her commitment to bring the spirit and tools of improvisational theatre and storytelling to projects of social and racial justice. They made miracles happen as participants began to know and trust each other, put aside any power differentials, and worked up the confidence to tell their BtC stories before diving into the deliberative task of Agenda-setting. We offer our special thanks to the remarkable team of actor/facilitators: Chase Crossno, Mia Anderson, Juliet Bowler, Jennifer Pamphile, Suzy Sarfaty, and Margie Zohn.

On Day 2 of the Conference we relied on facilitators and documentarians who carefully led or captured the process and results of each roundtable conversation, such that the 'bones' of the Agenda emerged by the end of the Conference. Big thanks to: Adriana Black, Katie Klucevsek, Natasha Lerner, Sarah Mart, Kyle Megrath, Erin Miller, Jennifer Pamphile, Nikki Spenser, Madeline Wachman, and Annette Yin. And of course, we are grateful to the Stakeholder Engagement Leadership Council members who also led roundtable discussions.

### **WG Staff**

We offer particular thanks to the team of student fellows, funded by the Center of Excellence in Maternal and Child Health Education, Science and Practice (HRSA/MCHB grant # T76MC00017), who served as research assistants and staff to each WG: Zendilli Depina, Ebosetale Eromosele, Bridgette Maynard, Ebere Oparaeke, and Brenna Burke- Weber. Each consistently lent their valuable time to literature reviews, coordination, and detailed documentation of many meetings over many months.

### **Project Coordination**

We owe a debt of gratitude for the impressive coordination skills of three talented project managers and coordinators—Myrita Craig who helped us get started, Annette Yim who shepherded us through the Conference, and Martina Xiomara Spain who has worked tirelessly and effectively this last year to keep us on track, participate in writing, and support us through many challenges. It is a pleasure to say a formal thank you here on behalf of all who participated in the BtC network.

### **Portal Designers**

After the Conference, we knew we needed a portal to serve a hub of network building and information sharing for the BtC Working Groups. We were delighted to work with Kirsten Peterson, Meredith Boginski and Claire Crawford, expert designers willing and able to work within our resource constraints. The portal they created ([www.bridging-the-chasm.com](http://www.bridging-the-chasm.com)) proved to be an ideal platform, and we are grateful for their foresight and technical prowess.

### **Graphic artist**

Finally, we want to acknowledge our colleague and most talented graphic artist, Megan Smith. At the outset of the project, Megan captured the essence of the BtC mission in a most beautiful image. We see a rich diversity of women crossing chasms of all kinds, held up by helping hands (if not systems), as they seek health and well-being across the life course. Thank you Megan; it meant a lot to us and to everyone who has participated in BtC to be guided by a colorful and meaningful image.

### **Key informants**

As questions arose in the working groups, members reached out broadly to colleagues and activists to get information 'on the ground.' We appreciate the generosity of those who contributed in this way. In particular we wish to thank Toni Hill, a direct entry midwife and founder/director of Blooming Moon Midwifery Services in Northern Mississippi, for spending her valuable time talking with us as a BtC key informant, sharing what it takes to sustain a grassroots birthing organization. Terry Mason, who is at the center of efforts to promote and certify CHWs, consulted on potential strategies for workforce development and team building; this contribution was key to the High Touch WG.

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# SELC: Meet BtC's founding organizations

## Boston University

Dept. of Community Health Sciences,  
School of Public Health

Dept. of OB/GYN,  
School of Medicine

Division of Women's Health,  
Dept. of Internal Medicine,  
School of Medicine

Dept. of MacroPractice,  
School of Social Work

## National Alliance for Hispanic Health

The National Alliance for Hispanic Health, whose members include individuals, not-for-profit organizations, and corporations, works to ensure that the best health for all incorporates the best of science, culture, and community. The goal of the Alliance is to close the gaps in three key areas: 1. research, services and policy; 2. scientific discovery and benefit for the individual and; 3. community services and medical practice.

## Office of Research on Women's Health

Office of Research on Women's Health is the first Public Health Service office dedicated specifically to promoting women's health research within and beyond the NIH scientific community. The ORWH crafts and implements the NIH Strategic Plan for Women's Health Research in partnership with NIH Institutes and Centers and co-funds research on the role of sex and gender on health.

## Black Women's Health Imperative

Black Women's Health Imperative's mission is to lead the effort to solve the most pressing health issues that affect Black women and girls in the U.S. Through investments in evidence-based strategies, they deliver bold new programs and advocate health-promoting policies to ensure Black women enjoy optimal health and well-being in a socially just society.

## DiabetesSisters

DiabetesSisters is a 501(c)(3) nonprofit organization whose mission is to improve the health and quality of life of women with diabetes, and to advocate on their behalf. They believe all women with diabetes should have access to a healthy support system that includes peers with diabetes to provide encouragement, empowerment, and education with the purpose of helping each woman reach her full potential in life. An empowered, informed woman with diabetes is a healthy woman with diabetes!

## Patient Centered Primary Care Collaborative

Patient Centered Primary Care Collaborative is a nonprofit multi-stakeholder membership organization dedicated to advancing an effective and efficient health system built on a strong foundation of primary care and the patient-centered medical home to achieve the "Quadruple Aim": better care, better health, lower costs, and greater joy for clinicians and staff in delivery of care.



## Bridging the Chasm between Pregnancy and Women's Health over the Life Course





# Meet the Members



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Health  
Sciences



**Judith Bernstein, PhD, Professor Emerita**

My public health career began 40 years ago as an applied anthropologist and educator of community health workers in Nepal. My work focuses on the disconnects between lives of women and health care systems meant to serve their needs across the life course. At BUSPH, I direct the Center for Excellence in Maternal and Child Health.

I have been a nurse and public health professional for the past 50 years, working with both inner city and rural communities to develop comprehensive integrated approaches to women's health. I use mixed methods to study women's access to preventive care.

Boston  
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Medicine



**Aviva Lee  
Parritz, MD**

I am a Maternal-Fetal Medicine specialist and Chair of the Department of Obstetrics and Gynecology, at Boston Medical Center, Boston University School of Medicine. My research interest is management of pre-gestational and gestational diabetes and its impact on maternal and neonatal outcomes. My achievements include sustained clinical collaborations between departments and across institutions, and patient-centered processes of care to decrease racial disparities in health care outcomes and perinatal mortality. models of care.



**Tracy Battaglia,  
MD, MPH**

I have 16 years of experience designing, implementing and evaluating community-engaged Patient Navigation programs to reduce delays across the continuum of cancer care. As Director for the Center of Excellence in Women's Health, and Director for Community Engagement of Boston University's Clinical and Translational Science Award, I have achieved national recognition for improving the health of vulnerable women at risk for delays in care through stakeholder partnerships. Since 2001, I have also served as Director of the Avon Breast Health Initiative at Boston Medical Center.

Boston  
University  
School of Social  
Work



**Linda Sprague  
Martinez, PhD**

I am an Associate Professor at the School of Social Work at Boston University where I teach courses in community planning, assessment and analysis. My research is focused on how assets can be recognized and leveraged by communities to improve living environments and health. I am specifically interested in examining community development strategies to tackle health inequities. Community engaged research approaches are central to my work. I have expertise in urban health; community, student and youth engaged research; photovoice; community assessment and mobilization; and qualitative research methods and analyses.

Patient  
Centered  
Primary Care  
Collaborative



**Ann Greiner, MS**

I serve as President and CEO of the Patient-Centered Primary Care Collaborative (PCPCC). In this role, I am responsible for leading the overall organizational strategy, managing a high-functioning internal team, and fostering multi-stakeholder strategic partnerships. At a critical time in U.S. health policy, I direct PCPCC's policy agenda, working across a diverse stakeholder group of more than 70 executive member organizations to advance an effective and efficient health care system built on the strong foundation of primary care and the patient-centered medical home (PCMH).

University of  
Oklahoma Health  
Sciences Center



**Emily Jones,  
PhD, RNC**

I am a nurse scientist at Zeigler College of Nursing who conducts type 2 diabetes and cardiovascular disease prevention-focused community-based participatory research in partnership with the Chickasaw Nation of Oklahoma. Specifically, I work with American Indian women who are diagnosed with gestational diabetes to identify and implement intervention approaches to reduce cardiometabolic risk factors and diabetes development in the postpartum period and subsequent years. I collaborate in team science to intervene at multiple points in the life course to promote optimal cardiometabolic health of mothers and offspring.



Office of  
Research on  
Women's Health



**Janine Austin Clayton, MD**

I was appointed Associate Director for Research on Women's Health and Director of the Office of Research on Women's Health at the NIH in 2012. I have strengthened NIH support for research on diseases, disorders, and conditions that affect women. I am the architect of NIH policy requiring scientists to consider sex as a biological variable across the research spectrum, a part of NIH's initiative to enhance reproducibility, rigor, and transparency. As co-chair of the NIH Working Group on Women in Biomedical Careers, I also lead NIH's efforts to advance women in science careers.

Black Women's  
Health  
Imperative



**Linda Goler Blount, MPH**

I joined Black Women's Health Imperative as President and CEO in 2014. I oversee strategic direction and am responsible for moving the organization forward in its mission to achieve health equity, reproductive and social justice for Black women across the lifespan. During more than 25 years working in private and non-profit sectors, I have provided innovative leadership that deploys an inter-disciplinary approach to large-scale challenges. Before joining the Imperative, I served as Vice President of Programmatic Impact for United Way of Greater Atlanta, where I led transformation in health, income, education and housing stability through place and population-based work.

National Alliance  
for Hispanic  
Health



**Athena K. Ramos,  
PhD, MBA, MS, CPM**

I am currently the Community Health Program Manager/Instructor for the Center for Reducing Health Disparities in the Department of Health Promotion at the University of Nebraska Medical Center (UNMC) in Omaha, Nebraska. I lead a Latino outreach and engagement team and serve as principal investigator for a number of community-based health and social research and education initiatives in areas such as immigrant health, community welcoming and integration, and rural community capacity-building. I am an experienced administrator, program manager, and researcher with proven ability to develop and implement health, social, and human service programs with culturally diverse populations. I have over 15 years of experience in health promotion, strategic thinking, community development, and public relations. I am grounded in community participatory methods and hope to improve Latino health and well-being.

DiabetesSisters



**Anna Norton, MS**

I am the CEO of DiabetesSisters. I was diagnosed with type 1 diabetes in 1993 and manage the disease with an insulin pump (since 2000) and CGM (since 2010). I've been involved with DiabetesSisters since 2011, serving as a committee member for the Weekend for Women Conference. I joined staff as Operations Manager in 2012, and today, I am honored to serve women with diabetes as CEO. I've spent many years in the non-profit world, raising funds for United Way, medical centers and universities, with over 15 years' experience in Annual Giving, Major Gifts, and Event Planning. I am also bilingual in English and Spanish. As a woman with diabetes, I am passionate about the work DiabetesSisters does - when I learned of this organization, I was eager to become involved and help make a difference in the lives of other women like me.

Boston  
University  
School of  
Medicine



**Suzanne Sarfaty, MD**

I have a 20 year history of program development for medical school administration and education. Initially, as Assistant Dean of Student Affairs and later Assistant Dean of Academic Affairs, I developed and implemented the Medical School Summer Research Program (MSSRP) and the Global Health Program, both in response to student request to have expanded extracurricular programming programs at BUSM. I have served as primary advisor/PI for the Outreach Van project, a service learning project that delivers weekly food, clothing, and medical care to the homeless of Boston. Advising students in a variety of capacities, I am dedicated and passionate about mentoring students. I initiated and lead Boston University's affiliation with the Alan Alda Center for Communicating Science.

Texas Christian  
University and  
UNTSC School  
of Medicine



**Chase Crossno,  
MPH**

I am the Assistant Artistic Director and an Assistant Professor, Community and Public Health at the TCU and UNTSC School of Medicine in Fort Worth, a new medical school program seeking accreditation to open in 2019. After receiving my undergraduate degrees in Theatre and Anthropology from the University of Texas at Austin, I spent two years in rural Namibia using theatre and art to engage and educate high school students and local communities. After receiving my MPH at Boston University in 2015, I continued to draw on my theater experience at the BU School of Public Health and Clinical and Translational Science Institute, working with physicians and researchers, training them to translate their research and scholarship in to meaningful information for the public.



## Chapter 1: Introduction



### Missed Opportunities to Prevent Chronic Illness after Pregnancy and Assure Wellness across the Life Course for all Women

*BtC applies multiple perspectives: health systems, gender, racial and birth justice, and translational science.*

“Bridging the Chasm” took root in a collective outrage about and call for an end to four tragic realities—all related to the state of maternal health care in America and the price paid by Black, Brown, Native people and Asian Americans (AAPI) and Pacific Islanders in risk, illness, and death. **All require building bridges across deep and rocky chasms. All raise important questions that have been experienced by women and recognized by advocates, researchers, even policy makers and health system leaders for decades, yet have not been adequately addressed, nor taken on as a whole (Howell, 2018).** The BtC network shares the desire and commitment to call out the realities, take on the hard questions and carve out a path forward for the sake of holism and equity in women’s health. Each of four tragic realities inspired and framed the BtC mission: to collaboratively create a National Agenda for Research and Action to BtC. Each raises tough questions and calls up a perspective to bring to the task.

- The health care system for women and all pregnant and parenting people is fragmented and full of gaping holes. The gaps leave many people—especially those already marginalized—vulnerable to preventable illness and death in the postpartum period and beyond. Quality of healthcare, from preconception through postpartum care, has been proposed as be a critical lever for addressing disparities; our task, however, is not only to assure a ‘culture of safety’ but to go beyond this construct to a ‘culture of equity’. **How can we create and evaluate innovative system reforms and public policies that increase investment in women’s health after the baby is born and bridge the chasm between reproductive and ongoing primary care for women? The question calls up a health system perspective.**
- Structural and interpersonal racism, as well as social inequities, are deeply embedded in history and baked into the social contract and health care system in America. Communities have inequitable resources to support families and allow mothers to sustain their own health and well-being. Every community has lots of assets, but women cannot easily change their diet and exercise while holding down multiple jobs to make a living wage; implicit bias is baked into health care, and institutional racism into housing policies and access to safe environments and healthy food. *Place matters, racism matters, and all social determinants of health play a large role in shaping health.* **How can we reform the way health care is delivered to recognize these realities and advocate for investments that go beyond changes in health care to bridge these divides?**

Given the systemic and longstanding racism that exists within health care, women of color do not trust health care system nor many providers. Routinely, women of color are disrespected and their concerns dismissed as they go through pregnancy, childbirth and the postpartum experience, a reality that contributes to dangerous and sometimes fatal gaps in care. **How can BtC contribute to the movement to change the power relations in health care and assure that the voices of women of color are listened to, respected, and become central in clinical decision-making? These questions call up a racial equity and birth justice perspective.**

- Patient voices are not at the center of the design of health services/systems nor research projects and policy-making meant to serve mothers and their needs. Without women with lived experience engaged in the processes of decision-making at all levels—clinical care, health systems innovation, research design, and policy-making—it is unlikely bridges across the chasm will be effective. **How can we assure that pregnant and parenting people are at the center of decision-making about how health care is designed and delivered, research is designed and policy is proposed, particularly in contexts where their power is often devalued? This question calls up a gender and gender identity perspective.**

- There is a wide gap between what we know about pregnancy as a stress test and window into women's health over the life course, and what we do about it. As discussed throughout this report, science well establishes the link between pregnancy and postpartum health and future cardiovascular, metabolic health and social well-being in the future. There are also myriad evidence-based prevention strategies to interrupt the path to chronic illness and compromised health and well-being over the life course; however, there is ample evidence to show that preventive testing and care in the extended postpartum period and beyond fall far below what would be expected based on the knowledge base. In the case of gestational diabetes and the trajectory to type2 diabetes, for example, we know a great deal about the disease process, how to treat it during pregnancy, and how to prevent or delay the onset diabetes and cardiovascular diseases. We know that as many as 60 percent of pregnant people with gestational diabetes develop type 2 diabetes in the decade after delivery, contributing to the national epidemic. We know about barriers to follow up testing and care. We make good but incremental attempts at interventions, mostly geared to changing individual behaviors, such as reminders for postpartum testing, educational websites, mobile apps. Many of these efforts are promising for some but miss the mark for people with social vulnerabilities. **How can BtC help to expedite the translation of science to practice in clinical and community settings? This question calls up a translational science perspective.**

### *Background and Significance*

Fragmentation in women's health care has been studied for years, and still many are frustrated that nothing seems to change. There is a deep divide between public investment in people when they are pregnant for the sake of healthy babies and the low level of support of mothers for the sake of their own health and well-being over time, especially in the years following childbirth. Prenatal care places a laser focus on maternal health, though largely pointed toward the health of the baby; postpartum care is uneven; and after that, pregnant people fall into the chasm between obstetrics and primary care. Research tells us that pregnancy is a stress test, and complications such as gestational diabetes and cardiovascular conditions and metabolic disorders raise red flags for future chronic illness (Allalou, et al., 2016; Ravangoudar, et al., 2016. In fact, sixty percent of women with gestational diabetes go on to develop type 2 diabetes (Kim, 2002) and have a twofold higher risk of cardiovascular events in the following decade (Kramer et al., 2019). But who is paying attention? Who is realigning strategies and priorities to effectively change the way systems, clinicians, and interventions work for all pregnant people over their life course? As Carolyn Clancy stated in her classic article in 1992, health care for women was and remains a patchwork quilt (Clancy, 1992).

For women of color, the patchwork is even more ragged; key pregnancy complications are more prevalent and as researchers, journalists and activists have powerfully demonstrated, pregnancy-associated mortality rates for Black women are intolerable. Mothers, daughters, sisters, and friends of color share stories of being dismissed, disrespected, and given sub-quality or improper care by providers. Such experiences occur across the spectrum of health care- from routine encounters to tragic life events, such as infant or maternal death or severe maternal morbidities. Researchers frequently point to differential treatment and implicit bias as one of the pathways that underlies the significant race-based inequities seen in maternal health outcomes (Mustillo, et al., 2004; Collins, et al., 2007; Dominguez, et al., 2008). Structural racism is a significant cause of illness that operates through features of the social environment that influence individual behavior, disease, and health status (Garcia and Sharif, 2015; Hardeman, et al., 2017)). In many rural areas as well as segregated urban areas of this country, resources are severely restricted; lack of access and disrespect are not just a 'third world' problem (Vedem, et al., 2019).

A distinct system of reproductive health care and related policies has grown up to assure that pregnancies are planned and infants are born healthy, with funding and specialty content designated for pregnancy, inter-conception care and contraception. Once the immediate postpartum period is over, however, new mothers typically find neither a bridge to primary care nor practices and policies to protect their ongoing health. For the majority, the opportunity to prevent or mitigate future illness is lost. Continued access to care is a low priority for mothers themselves, for clinicians, and for policy makers, despite how much is known about the ways that pregnancy complications, such as hypertensive disorders of pregnancy, gestational diabetes, depression and addiction, can progress into chronic conditions that have debilitating impacts on parents and their families over the life course.

## *Complex Problems Call for Innovative, Collaborative Solutions*

We evoke an image of a strong, sturdy bridge, with women walking across it before, during, after pregnancy and beyond. Building bridges requires many types of experts to ensure that it is strong. Engineers, architects, environmental and transportation specialists are all needed. In addition, people who will use the bridge-- walkers, drivers and community residents--are integral to the process of design. Complex problems in health care call for innovative, collaborative, multi-pronged system-wide solutions. Building bridges across the chasms in women's health care takes all of us: community leaders, patients, clinicians, researchers, advocates, policy-makers, and health system innovators. Some of us have been advocating for attention, and finally getting traction, to the high rates of black maternal mortality; others have promoted legislation to support people with postpartum depression, fought for respectful maternity care, or researched follow-up care after gestational diabetes or gestational hypertension. We have a lot to learn from each other.

Between 2018 and 2019, a dynamic, multi-expertise network of people with a shared commitment to co-create a *National Agenda* that would form the basis for change in how we invest in the health of pregnant people across the life span, across social and racial differences, across geographies, and across sectors and domains of expertise. We present here both the content of that Agenda and the process by which it was developed.

The process of knowledge creation and testing described in this report is rooted in the power of patient and community engagement, which recognizes other forms of expertise, but puts patient representatives at the forefront. We sought to avoid the trappings of academic control and academic 'speak' that can take over, even in patient-engaged research, if leadership is not intentionally shared, and pioneering methods are not implemented. The National Conference we held in our first year of funding to kick start the National Agenda had a pioneering format that was philosophically rooted in improvisational theatre and storytelling to inspire deep empathy and understanding across boundaries and transform power relationships. In the year following the Conference, seven working groups, with representatives from diverse experience and expertise in each, took the ideas and recommendations generated by the Conference participants, elaborated and consolidated them, and transformed them into a final product: a *National Agenda for Research and Action*. The entire project has been guided by a *Stakeholder Engagement Leadership Council*, with community, academic, and health care organizations represented. The findings and this report have been produced by all participants on an equal footing. We expect this approach will move us forward from describing the myriad problems to finding solutions that work.

## CHAPTER 2: METHODS



The aims of this project were to create a cross-disciplinary, multi-focal network of engaged stakeholders; describe the chasm between reproductive and preventive care for women across the life course; explore the root causes for this gap, its impact on women's health and its potential remedies; create the Agenda for Research and Action to BtC; sustain momentum, and build collective energy that could be used going forward to implement the strategies.

### Year 1 (2018): Leadership and Organization of the Bridge the Chasm (BtC) Conference

At the outset of the initiative, The BtC team formed the Stakeholder Engagement Leadership Council, with representatives from each BtC constituent group: national organizations with missions related to community and patient engagement, researchers, clinicians, policy analysts and advocates, and communication, and health system innovators. Representatives were affiliated with The Black Women's Health Imperative, DiabetesSisters, the Patient Centered Primary Care Collaborative, the National Alliance for Hispanic Health; Boston University Schools of Public Health, Social Work and Medicine, and a theater/communications expert at the School of Medicine, Texas Christian University and University of North Texas Health Science Center. The SELC created the invitation list, planned and implemented the Conference. Two agencies at the National Institutes of Health: the Office of Women's Health Research and the National Institute of Diabetes and Digestive and Kidney Diseases provided funding for the planning of the Conference, and an award from the Patient-Centered Outcomes Research Institute (PCORI) enabled us to execute the Conference (and entire BtC initiative), including the coverage of travel and lodging reimbursement to non-academic participants.



#### *Network Building and Conference Invitations*

All members of the SELC and the BtC team contributed lists of invitees based on their own network's reach, assuring balance across constituent groups. We sent invitations and self-returned stamped RSVP cards via 'snail mail', as well as email invitations to a total of 150 individuals. A total of 100 expressed interest in attending and 75 were ultimately able to attend (the number we had planned for and could support). As indicated on the list in Appendix A, attendees were well balanced among each constituent group: patients, advocates, researchers, policy-makers, and health system innovators.

*Pre-Conference training sessions:* Six actor-facilitators attended two 6-hour training rehearsals in preparation for Day 1 of the Conference. As part of their preparation, they read articles related to cultural humility and intersectionality and familiarized themselves with the activities and improvisational tools outlined in a facilitator's guide. The two rehearsal days consisted of practicing activities and dialoguing about their application to Conference content. Seven documentarians also trained in two pre-Conference sessions, learning their role as participant observers, capturing Conference proceedings and recording the details of each of the sessions on Day 2, including non-verbal interactions during roundtable discussions.

The study team prepared an annotated bibliography, summarizing key findings from literature related to gestational diabetes (GDM): Its epidemiology, risk for type 2 diabetes, follow-up testing and preventive counseling after GDM, and medical treatments, interventions, and emerging innovations for follow-up education and prevention. We posted the annotated bibliography and other pre-Conference information on a website to allow participants to prepare in advance. As part of network-building, each participant received a list of attendees and all who had expressed the wish to be part of the BtC network even if unable to attend the Conference.

### **Day 1: Use of improvisational theater techniques to build community and train participants in the art of focused storytelling, sharing their unique perspective on what 'bridging the chasm' means to them.**

The theatre-based methods used to launch the Conference on Day 1 were grounded in three frameworks: 1) theatre arts as a way to bring people together in shared humanity and fun; 2) cultural humility to promote the position of inquiry and understanding rather than expertise, placing members of stakeholder groups in mutually beneficial rather than hierarchical relationships; and 3) intersectionality to encourage individuals to understand their own and others' multiple

identities and how they interact to affect one's privilege and relations with others. These frameworks are reflected in the activities of Day 1; together they sought to diminish traditional power dynamics and allow for meaningful communication across stakeholder groups.

### *Keynote Panel*

Opening remarks from **Dr. Lois McCloskey** (BtC Director) and **Dr. Janine Austin Clayton** (Director, Office of Research on Women's Health from the National Institute of Health) and a panel of powerful keynote speakers set the intention of the Conference: to share knowledge, build community, and turn a mission to improve women's health into concrete strategies for change. **Linda Goler Blount**, CEO of the Black Women's Health Imperative, highlighted discrimination, inequity and challenges faced by women of color, and reminded us of the vibrant history of Black women as leaders. She focused on how to transform the narrative about Black women's health by keeping women at the center of the conversation and plans for change. **Dr. Phyllisa Deroze**, patient advocate for type 2 diabetes and Professor of American Literature, began her talk by telling her dual stories of being diagnosed with type 2 diabetes as an African American woman and her traumatic childbirth experience as an African American woman with type 2 diabetes. Her commitment is to activism and education of others through her blog site ([www.diagnosed-not-defeated](http://www.diagnosed-not-defeated)) and the organization, DiabetesSisters. She left us with a memorable quote: "I entered the childbirth experience a warrior; I left as a wounded soldier." **Dr. Haywood Brown**, Vice President of Diversity, Inclusion, and Equal Opportunity at University South Florida System and Past President of the American College of Obstetrics and Gynecology (ACOG), focused on the key elements of ACOG's recent initiative, Optimizing Postpartum Care, which redefines and expands postpartum care to build toward women's lifelong health. Lastly, **Dr. Neel Shah**, Assistant Professor of Obstetrics, Gynecology, and Reproductive Biology at Harvard Medical School and Director, Delivery Decisions Initiative of Ariadne Labs, synthesized the key messages of other panelists and challenged the audience to use the stories that they would be developing to promote disruption and innovation within health care.

*Improvitational Theatre and Storytelling Activities:* Participants then divided into six mixed groups of ten, each representing diverse areas of work and experience, and led by an actor-facilitator expert in improvisational theatre methods and interactive techniques. The groups were mixed at this stage in an effort to share perspectives across traditional roles and hierarchies. Theater helps to build connection to others and to content, bringing attention to nonverbal communication and encouraging participants to respond freely without self-consciousness. Thematic distilling techniques help participants to communicate complex concepts using conversational language, identifying main points, and explaining meaning and context. Storytelling evokes emotion, facilitates collective cohesion and enhances the likelihood of making personal connections while working together to create solutions. Each group practiced five different communications skills exercises:

*Building connection:* Activities for this initial workshop focused on the use of clear, vivid, conversational language to ensure successful exchange of ideas and information between audiences, and were grounded in self-reflection and co-learning to support participant appreciation for the importance of diversity in health research, policy and advocacy. These included the following *exercises*:

1. Understand how we learn facts and the importance of providing context;
2. Recognize the value of mistakes and risk-taking for connection and understanding across 'borders';
3. Take care of and be responsible for your audience as a leader/change agent;
4. Practice effective use of language, tone of voice, body language and eye contact to communicate with intention;
5. Notice the many roles one occupies in a given day and discover how to access the voices.

*Distilling stories:* After a lunch break for networking, participants re-convened in their mixed groups to dive deeply into narratives about pregnancy and women's health over the life course. Actor/facilitators used improvisational tools to hone skills necessary to distill a message. These activities included:

- |           |   |
|-----------|---|
| VTS       | Come to see oneself as one perspective among many – value the importance of perspective   |
| Castle    | Notice what perspective can do to how stories are received; practice listening with intention   |
| Picture   | Share (and hear) stories, drawn from data and/or experience, with vivid detail and evocative emotion  |
| Half-life | Find what matters most about your story, remove jargon, and bring the story hook to the surface; practice heightened listening and providing thoughtful feedback. |



*Creating and sharing stories:* In the final segment of Day 1, actor-facilitators supported participants to craft a 3 minute story, capturing their reason for being at the conference. Thirteen participants volunteered to share their story in the late afternoon session, granting written consent to be video-taped and to have their story posted on the BtC portal and to have it used (potentially) in written materials, without names or identifying details shared. Counting the key-note storyteller, there are 14 stories included on the BtC portal, six told by patient representatives, five by clinician/researchers, two by policy-makers or analysts, and one by a health system innovator. To set the stage, we asked the audience to: 1) listen, engage and connect; 2) notice patterns across stories as well as differences; 3) reflect individually and with each other on the meaning of what was being shared. As a whole the narratives exposed deep rifts between the needs and desires of women, and the health care they receive, the enduring impacts of disrespectful care, and the frustration of clinicians working in settings where women's experiences are devalued. Whether patients or providers, participants told their stories with palpable emotion, despite the years that had passed.

*Patient stories: Traumatic experiences as motivation for advocacy*

Seven of the storytellers shared their experience as patients. In all but one of these stories, women recounted ways their own wishes and experiences had been discounted and their autonomy breached. These included stories of symptoms that had been long overlooked despite begging for diagnosis, and stories of profound childbirth and postpartum traumas. We also heard about repeated pregnancies affected by GDM, with no follow up, no inquiries, no support.

***Stories of no voice, no choice***

For one woman it was a primary care appointment for knee pain that finally resulted in a casual diagnosis of type 2 diabetes: *"Well, it looks like you don't have arthritis, but you do have diabetes"*. For another it was the fifth pregnancy that finally led to diagnosis of GDM. One woman with a recent diagnosis of type 2 diabetes before her pregnancy described her desperate need to be normal during childbirth. Despite her deepest wish and *"an A1C better than yours"*, she was kept lying flat in labor, tethered to the bedrails because of the label in her chart: type 2 diabetes. Another participant told us that after 27 hours of labor and a postpartum hemorrhage, she was discharged with no resources and little attention to the traumatic stress disorder (PTSD) symptoms that she would likely experience postpartum. A year later she experienced a miscarriage in public. Again, she felt alone and more marginalized than she had ever been before. In her words, *"I am here (at the Conference) because I should not be here. I am here to represent African American women whose voices are otherwise not in the room."*

***Stories of long term consequences***

Storytellers shared with us that experiences of being dismissed or disrespected during childbirth - even if in ways invisible to others- left them feeling traumatized and distrustful for years to come. *"Always ask,"* one said, *"What is the walk like for someone who has suffered during childbirth?"* And she reminded us, *"All voices are important."* Another participant described years of infertility, her two prior miscarriages followed by traumatic postpartum events after her first live birth: sent home with a fever and fear, and re-admitted 12 hours later, feeling like she was fighting for her life, and confined to bed for five months. Remembering the moment tearfully, she said, *"I was unable to see the child I had waited four years to hold."* Three years later she was diagnosed with type 2 diabetes. She claims the experience is her motivation each day in her work as a registered dietician and diabetes advocate.

***Lessons Learned: empower, collaborate and prevent***

Patients' stories also included expressions of good fortune and motivation to be part of the change. One woman simply wanted to say, *"I'm here because the Diabetes Prevention Program (DPP) changed my life. I am testament to: education works. My participation in the DPP and in DiabetesSisters has kept me healthy without glucose abnormalities for many years."* Now caring in her home for a relative with complications of diabetes, she said, *"We need to empower, we need to collaborate, and we need to prevent type 2 diabetes among African American women."*

*Clinicians'/Researchers Stories: Challenges when trying to put patients first*

Five clinician/researchers told stories about early experiences of caring for patients that left indelible marks on their career paths. One provider's story went like this: 'A 43 year old woman with symptoms of a viral sore throat was sent home from the emergency room and four days later had an acute heart attack. No one asked her pregnancy history (four with GDM!)" She said she never forgot the lesson--as a clinician or as a researcher. "Always ask a woman's pregnancy history!" Another provider told her 'tale of two births'—both involving cesarean sections deemed medically necessary and culturally or personally intolerable. The first was a Hmong woman, who when told she needed a C-section, pleaded not to have surgery: "If you cut me open, the evil spirits will come in. I can always have another child. If the evil spirits enter me, I can never get them out." The storyteller prevailed on the health care team and respected the patient's wish to not be cut. The second tale did not end as well; a 17 year old African American woman was forced to have a court-ordered cesarean despite her refusal. The clinician felt frustrated, sad and helpless in a system stacked against the mother's wishes. In her words: "We must prioritize women's wishes. Trust them and they will trust us. Unless women trust us, they will not come."

Bringing this point home, a different provider recounted a late-session chaotic scene with a patient who had many big challenges: overweight, high blood pressure, glucose 'over the roof', and three kids, one of them a new baby. She was again 25 weeks pregnant. When the clinician began to inquire about how all of this could happen, the patient quickly let her know: "It's not that I didn't know or didn't want to come in for my glucose testing or to get help... I couldn't. My insurance ran out after my baby was a couple of months old." Stunned back into reality, the provider remembers her thoughts at that moment; she have stuck with her ever since. "My people (OB's) have failed my people (African American women)". "We need to get out of our silos; the period of pregnancy is just one snapshot in a woman's life. We cannot leave her there!"

One clinician/researcher reflected on the flip side of the coin. What happens when we DO ask women for their stories, their perspectives? Remembering an early research experience which engaged her with Native women, the storyteller asked an interviewee, "What was it like to have GDM three years ago? How did it make you feel about your health after pregnancy?" The woman's response was telling: "No one has ever asked me that before. I have to think about that." The clinician realized then that listening is, itself, an intervention. And that what we ask and what we do has to be designed in partnership with people we want to learn from. Another clinician, also reflecting on her hard-won lessons of what matters most, "We must find our empathy. Find our humanity. I've always wanted to move up in leadership so that I can be sure we can flip the way we do things. We don't heal; we cause harm. We have to do it differently- we have to get out of hospitals. Let's bring it back to the people."

Bringing it back home, a research scientist told a story from the birth of her first child when she was quite young. Recalling for us her estranged mother's attendance at her own child's birth at a difficult moment, she reflected, "It turns out that a moment of tragedy can change a life. It turns out that my commitment to women's health I learned from my mother in that moment."

### *Stories of Policymakers*

The stories of those most engaged in policy analysis and advocacy added a dimension to and reinforced the themes of patients and clinician/researchers. Reflecting on her early career, a policy expert recalled an initial 'ah ha' moment, realizing that women were not represented in clinical studies, on Congressional committees, or near the top of government health agencies. She made the decision to be part of that change, and in reflecting back, said, 'The reason we were successful over time is that we worked with so many partners. There is so much power in working together. And now we face challenging times, truly. We need to keep our sights high while defending our values. With allies we can still make a difference, get where we want to go.'

### *Lessons from storytelling*

The audience was deeply engaged. The storytelling session ended with shared tears of appreciation and a rich conversation about trauma and its enduring impacts on women over their life course. Together, the stories from diverse perspectives painted the picture of women, especially women of color, being devalued even as they are giving

birth to the next generation; of providers called to listen and honor the wishes, needs and voices of pregnant and postpartum people; yet systems with contradictory pressures, unprepared to elevate patients to the center of their own care. Science and policy- both with power to change the status quo- also fail too often to place women's voices, bodies, needs and wishes, at the center of design and decision-making.

The combined narrative offered a powerful platform for brainstorming and agenda-setting to 'bridge the chasm' during Day 2. As the final charge for Day 1, we asked participants to reflect on the stories they had heard, review research findings as presented in the annotated bibliography, and bring three innovative and/or important bridge building ideas for research and action to the next day's deliberations.

## **DAY 2: Translating stories into action**

Day 2 began with a brief check in and charge for Day and a charge by Dr. McCloskey. The personal, highly moving stories shared on Day 1 stayed with participants as we set out to generate ideas to disrupt the status quo in women's health care, particularly the chasms between maternity and primary and preventive care. The day was structured around two "World Café's" (roundtable discussions, guided by a facilitator with a discussion guide). World Café 1 in the morning aimed to generate a list of potential ways to 'bridge the chasm', generated through brainstorming based on insights from experience (Day 1) and data (annotated bibliography). In the afternoon, participants in World Café 2 self-selected their area of interest and explored innovation strategies by cluster.

### *World Café 1*

Mixed groups of patients, clinicians, advocates, researchers, policy experts and health system innovators, exchanged their ideas about potential solutions and clustered them into domains for action. Facilitators used flipcharts and large sticky notes to capture key ideas and to experiment with clustering them. The aim of the session was to generate a set of ideas with the potential to bridge the chasm(s), with prevention of progression of GDM to type 2 diabetes as a case in point. The charge to facilitators was to: 1) stimulate ideas that are fresh, and innovative and 2) combine the best of participants' varied expertise to build on top of what we already know. The challenge was to assure balance in the conversation: allow everyone to participate, keep the focus on bridges over the chasms, and allow conversation to extend beyond the GDM case as desired. Documentarians took detailed notes on all facets of the discussions.

### *Initial clustering of ideas and collaborative refinement*

During the lunch break, SELC members and facilitators collected the clusters of large sticky notes across groups and compared them. They consolidated the clustered ideas into 11 proposed content areas. After lunch, SELC members then led a discussion of the proposed content areas to make sure they made sense to group participants and to scan for any key ideas missing. A lively interaction ensued and the 11 areas were revised and/or renamed. The final 11 topics served as the basis for World Café 2 roundtables in the afternoon. The 11 topic areas and top three strategies within each were:

1. Develop models of care that bridge across the chasms created by a lack of fit between women's lived experiences and the existing structures and requirements of health care systems.
2. Manage women's health data to empower women with access to their own information, create continuity of information across the life cycle (linking maternal to infant health records, reproductive health to preventive health care) and educate non-OB providers about the importance of pregnancy complications and challenges for future health.
3. Promote disruption: Create a toxic environment for racism.
4. Keep social justice at the core of attempts to bridge the chasm.
5. Create upstream media campaign to address root causes.
6. Return resources to communities to assess and respond to the health needs of women.
7. Deliver information to women, create roadmap of education (GoodMoms).
8. Transform health care delivery via payment reform, quality measurement, coverage expansions and policy changes.
9. Decrease implicit bias, change patient-provider relationships.
10. Stay in touch with mothers postpartum and beyond.

11. Expand investment in research on women's health and intervention evaluation to address impact of pregnancy complications across life course.

### *World Café 2*

Participants self-selected into one of the 11 topics, each to be explored at a roundtable with an assigned facilitator and documentarian. The purpose of World Café 2 was to identify the three (or so) strategies that for each of these topics, reporting back to the group those that were deemed most promising based on consensus on: 1) innovation; 2) equity-promoting; 3) effectiveness; and 4) feasibility. Facilitators guided the groups to consider key considerations for each novel idea: stakeholders to engage, resources and existing initiatives, and key challenges and opportunities. The result was a set possible strategies within each of the 11 topic areas that were then to be further fleshed out during Year 2 to create a *National Agenda of Research and Action to BtC*.

The *Models of Care* group focused on bringing care to women, postpartum care innovation, and community-based follow-up. The *Health Data* group generated ideas related to data access, linkage across the reproductive years, and the development of evidence based guidelines fueled by data. In the *Promote Disruption* group there was discussion about organizational change, use of data and storytelling to drive progress, and accountability. *Keeping Justice at the Core* focused on social justice training for professionals, reframing discussions to resonate, and a culture of accountability. Ideas about an *Upstream Media Campaign* included a massive media campaign, propelled by key influencers, and partnered with community activists and local hospitals; and public health information made accessible for young people. *Return Resources to Communities* generated ideas about investment in communities, peer support mechanisms, and cross-sector collaborations. *Deliver Information to Women* explored resources and content for development of a roadmap for education. *Transform Health Care* group explored transformation via payment reform, measurement, and coverage expansion. The *Decrease Implicit Bias* group focused on autonomy and respect for U.S. midwives and doulas, reframing and de-medicalizing health care services, and bringing care to women, co-creating new modalities with them. *Staying in Touch Postpartum and Beyond* suggested leveraging everyone in a woman's medical village, collaborative care models (OB and pediatrics), and the development of woman-centered quality measures. In *Research and Evaluation*, there was discussion about how the topics that were generated in the morning could be integrated into research content and drive progress.

To close the Conference, we discussed the results of Café 2 and prepared for post-conference tasks and activities. We agreed to review the synthesis of conference proceedings and results, and to use the eleven topic areas as the initial outline of a *National Agenda for Research and Action to BtC*. We committed to form ongoing collaborations/working groups/partnerships to pursue ideas that were generated at the BtC Conference, and to finalize a National Agenda, to facilitate information sharing and communication through an on-line portal, and ultimately to disseminate the Agenda through a final report, peer-reviewed publications, and media/social media.

### **Year 2 (2019): Post-Conference Engagement, Building the BtC Network, and Selecting Strategies**

Activities for Year 2 were grounded in a collaborative and iterative process framework and designed to enhance the voices of key stakeholders in women's health. To build on the energy, enthusiasm and commitment generated by the BtC Conference, we reached out in the immediate post-Conference period to maintain engagement from those who attended, bring in invitees who declared interest but were not able to attend the event, and expand the network of stakeholders to include the breadth and depth of expertise needed to create the National Agenda for Research and Action to BtC. We did this in two ways--through an online portal and intensive outreach to potential partners across the country in five domains: patients and their advocates, clinicians, policy makers, health care innovators and researchers.

#### Post-Conference engagement and network building

We used a snowball recruitment approach over two months to identify experts and stakeholders whose work coincided with the BtC mission. Many new names came from the Conference participants and the SELC, and others were suggested in phone conversations with national leaders. In some cases we had introductions but in others we simply cold-called.

## The BtC Online Portal

In partnership with a web designer, we developed and launched the Bridging the Chasm portal (<http://bridging-the-chasm.com>) to serve as a central hub where stakeholders could communicate, share resources, build partnerships, and generate discussions and ideas from which a National Agenda for Research and Action could be derived. The portal had three important functions: 1) exchange information (announcements, resources, and extensive bibliographies by topic area); 2) build consensus (document exchange and commentary); and 3) generate products collectively (posting problem statements, literature summaries, and strategy ideas for review and development). The Portal also served as an archive for Conference products: programming, keynote speakers, and stories told on Day 1. Each participant had access to the emails of all members to promote networking and each WG had its own section to communicate and develop ideas and deliverables.

## Focusing the work: Consolidation of BtC Conference topics into WG topics

After the conclusion of the Conference, Drs. McCloskey and Bernstein took the lead in reviewing the notes and tear sheets from each of the Conference workshop topics in order to streamline the eleven topics that were generated into a smaller number of distinct working groups. The purpose of these WGs was to share and receive resources and information related to respective content areas, decide upon strategies to be prioritized within each topic area, and to consolidate them into the National Agenda. The proposed seven WG topics were reviewed and finalized by the SELC .

## WG topics

The seven final WG topics were:

1. Advocate for policy changes to transform health care delivery (includes quality/regulatory measures)
2. Align research with women's lived experience over the life cycle
3. Develop high touch models of care (includes roadmap for education)
4. Eliminate disrespect, racism, and all other implicit bias within health care (includes promote disruption)
5. Preserve the narrative: use health data to bridge the chasm
6. Promote investment in communities
7. Educate the public to heighten awareness of root causes.

## WG leadership and member enrollment

BtC team members (project directors, project manager and research fellows) staffed each of these WGs in collaboration with one or two facilitators and a Maternal and Child Health Research Fellow from Boston University. Facilitators were drawn from Boston University School of Medicine, Boston College, The University of North Texas Health Science Center and Texas Christian University, The University of Oklahoma Health Sciences Center, The University of San Diego, the National Institutes of Health's Office of Research on Women's Health, The Black Women's Health Imperative, March of Dimes, Ariadne Labs, The Rand Corporation, The National Birth Equity Collaborative, and the Resilient Sisterhood Project.

The role of the facilitators included close collaboration with the BtC team to complete deliverables and ensure productive and successful work group discussions. BtC staff provided support, including communicating with members between conference calls about tasks or ideas if unable to attend the calls; conducting literature reviews; transcribing meeting notes, and distributing them via the BtC Portal; arranging conference calls; and assisting with other tasks needed for the success of the WGs.

In order to encourage broad membership in the seven WGs, we recruited participants using a snowball method, beginning with participants at the BtC Conference, and actively reaching out to researchers, patients, providers, advocates, policy and health systems leaders, dedicated to improving women's health care. Our colleagues referred their contacts to BtC and urged participation from a variety of groups invested in women's health. Continuous enrollment on the BtC Portal had resulted in 182 registered Portal members. Of those registered, 87 individuals signed up WGs, and 70 became participating members of one or more WGs. . A full list of WG participants and their respective organizations can be found in Appendix B.



## Work plan

Each WG had a mission to address a unique thematic area but utilized a standardized process to develop their plank for the National Agenda. The BtC team created a work plan for the seven WGs consisting of a series of five conference calls over the span of five months. The BtC team scheduled a total of 35 conference calls which took place between March 30 and August 30, 2019. These conference calls led to the following deliverables from each WG:

1. A problem statement;
2. A synthesis of existing literature on the WG topic;
3. A menu of strategy options with rationale for the importance of each strategy;
4. Selection of 3 strategies and rationale for these strategies as the top priorities; and
5. A statement for each strategy that includes an evaluation of existing stakeholders and potential collaborators, related initiatives, supportive factors, challenges, and action steps for implementation.

WG participants were expected to provide thought leadership, creative idea generation and sharing, and some collaborative work in between conference calls. The diversity of WG members ensured that the collaborative process addressed a wide range of issues, perspectives and experiences.

## Strategy generation: The conference call process

On each of the five conference calls, WG facilitators were tasked with a specific goal, action steps to achieve the assigned goal, and materials to prepare for the subsequent conference call (see work plan below). The BtC team emphasized the importance of using an iterative and collaborative process when conducting WG discussions. This allowed for a diversity of experiences and ideas to be heard, WGs to re-visiting areas for discussion across calls. Drs. McCloskey and Bernstein were present for all calls, which allowed them to identify emerging cross-cutting issues.

## Strategy Selection, refinement and bundling

This iterative approach was critical to finalizing the strategies for each WG. Between Calls #3 and #4, WGs were tasked with selecting three strategies for exploration and recommendations. We quickly recognized that the WGs were in need of a more structured approach to assessing the strategies that came up during discussions. The BtC team decided to conduct a web-based (Qualtrix) survey among all WG members, asking them to review and give feedback on the menu of options created in Call #3. First, we asked members to assess the strategies as “High,” “Medium,” or “Low” based on the following criteria: innovative (a fresh approach to an existing strategy or entirely new strategy); effective (most likely to make a difference based on any available evidence and/or your expertise); equitable (most likely to promote health equity and not exacerbate inequities), and feasible (most able to be implemented and scaled up given current structures in place, evidence support, and popular and political will). Then we asked them to rank the strategies in order of importance, based on their best judgement. Respondents were also able to revise strategies or offer new options. The BtC team aggregated the results of each survey and prepared a worksheet for facilitators to use on Call #4.

During Call #4, facilitators led the discussion about the rationale and challenges of each strategy any new suggestions from WG members. Groups were able to review the survey results together and reach consensus regarding the resulting strategies. WG members were able to examine the results as a group and provide valuable input on the prioritization, language, and focus of the strategies.

After these discussions, BtC staff realized that an additional survey was needed to deepen and validate the outcomes of Call #4. The work group facilitators and BtC team further refined the options and bundled options by theme and sent a follow-up survey to aid in prioritizing the revised strategies and strategy bundles. The follow-up survey followed the same format as the initial survey and asked participants to evaluate each option using the four key criteria, and to rank the strategies or strategy bundles in order of importance using their best judgement. In many instances WG members decided to place the recommended strategies into bundles to allow for a more comprehensive multi-faceted Agenda. Scoring full bundles rather than each individual strategy was challenging, though in the end, useful.

Finally, the BtC team and co-facilitators synthesized the outcomes, themes, and strategies of the conference calls, surveys, and deliverables produced. The BtC team then hosted to conference calls with SELC members to discuss the emerging priorities, cross-cutting strategies, and best ways to convey the findings to diverse audiences.

## Workplan for WG Strategy Generation

*Call 1: Create a problem statement specific to each workgroup topic.*

- Define scope, layers, women's health care context
- Questions to consider: What's the current state of the issue? What makes this topic timely/important?
- Action Steps
  1. Draft problem statement and circulate to all members for review.
  2. Collect literature for review in next call and submit to Research Fellow within 2 weeks if possible.
  3. Collect resources to be posted on BtC portal.
  4. Submit to facilitators and fellow ideas for others to join WG to balance expertise.
  5. Preparation for Call #2: Review the background literature review for each topic.

*Call 2: Identify system-level strategies that have been attempted and evaluated or at least reported on.*

- Identify areas of the literature relevant to the problem you have laid out, using peer reviewed and grey literature, paying attention to what has promise and what has failed.
- Characterize gaps (areas not addressed or reported on to date).
- Action Step: Draft a synthesis of the evidence.
- Preparation for Call #3: Review strategies originally selected at BtC Conference.

*Call 3: Select strategies that rise to the top as most important and necessary at this time.*

- Create a menu of options from call 2 review (existing strategies that should be expanded, adapted, tailored to specific populations or areas of the problem).
- Evaluate the potential for impact of each of these strategies.
- Action Step: Draft a menu of options with rationale for why each is important.
- Preparation for Call #4: Select 3 strategies to put forward for discussion and consensus.

*Call 4: Select three strategies for exploration and recommendations.*

- Select strategies based on these criteria:
  1. Innovative
  2. Likely to make a difference in outcomes overall
  3. Likely to promote health equity (not exacerbate inequities)
  4. Feasible (consider structures in place for implementation, evidence, support, and political will)
- Action Step: Describe the rationale for selecting these strategies over others based on criteria (and other reasons that emerge as important).
- Preparation for Call #5: Think through the possible implementation issues for the 3 strategies you selected together in preparation for a group discussion to elaborate them.

*Call 5: For each strategy, identify potential stakeholders—networks and alliances. For each strategy identify critical action steps.*

- Note vested interests and potential collaborators
- Describe ongoing initiatives that may align with each strategy
- Describe known supportive factors, challenges and barriers
- Identify critical actions steps
- Action Step: Draft a statement for each strategy that evaluates existing stakeholders and potential collaborators, related initiatives, supportive factors, likely challenges, and critical action steps to implement each strategy.

Chapter 3: Overview of Selected Strategies



The strategies selected by the BtC WGs are graphed here in the Strategy Map on the following page, and detailed in the sections for each WG (see below). We have attempted to show the cross-cutting nature of each of these strategies with blue lines. Two guiding principles have been the driving force for strategy development: Effective, meaningful change can only happen if: 1) women’s participation is at the center, with full valuing of their voices and experience; and 2) change agents commit to eliminate the individual and structural forms of disrespect, racism, and unconscious bias that are historically and currently embedded in the social determinants of health and in health care. We offer these carefully debated and selected strategies for discussion as a first step toward actions to make meaningful improvements in women’s health care, particularly in the chasm between reproductive and primary care for women, and ultimately, in measures of health equity.

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Develop high touch models of care.....47

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Educate the public to heighten awareness of root causes.....76

## Policy

1. Support federal and state legislation to extend Medicaid coverage to 12 months PP (auto-enrollment)
- 2a. Health systems innovations: Establish new models for comprehensive primary care (structural transformation)
- b. Fund innovative models for transition from maternity care to ongoing primary care after pregnancy
- c. Fund capacity for ACOs to address social determinants
- 3a. Design/promote quality metrics responsive to specific conditions, social determinants, women's experience (NCQ)
- b. Pay-for-performance: reward warm handoff to PC
- 4a. Incentivize multi-specialty entry to primary care
- b. Require accrediting bodies to assess competency in link of repro health with future health
- c. Expand early childhood home visiting to mothers PP yr.3

## Research

1. Work with NIH and other funders to develop RFAs to fund gaps: screening & tx after pregnancy complications, barriers to PP care, predisposing factors, info needs; give preference to mixed methods & CBPR
2. Evaluate impact of consistent, comprehensive care by provider type during extended PP period, including initiatives for PP Medical Home, name changes for complications to reflect risks, patient-facing IT
3. Negotiate with EPIC to develop/test a template for transfer of pregnancy history to primary care
4. Request supplements to existing longitudinal study of reproductive age women to add investigation of the impact of pregnancy complications on future health

## Preserving the Narrative

1. Develop a PP discharge template w/coded fields, risk info & *Mother's Health Book* (paper/app/electronic)
2. Support women to share their stories with providers and motivate providers to listen
3. Form inter-professional collaboration for CME about how women's childbirth/PP stories affect their lives

## Eliminate Disrespect and Racism

1. Develop anti-racism competency-based training (with women and their organizations); require for licensure and institutional accreditation
2. Develop new Patient-Report Experience Measure of implicit bias/ racism (JCAHO health equity indicator); use evaluate and track progress
3. Fund evaluation of education programs and their behavioral outcomes; tie to accreditation/licensure
4. Fund a national workforce development center to increase the #/% of Black health care providers

## High Touch Models of Care

1. Implement within ACOs/IDNs a flexible, collaborative team-based models of care for the PP year with warm handoff to a PC home for women with socially or medically complicated pregnancies
2. Develop training modules on the physiologic, psychologic and social dimensions of maternal health in the year after a pregnancy & integrate into each profession; design/conduct innovative team training
3. Develop/pilot a group model of maternal health care for the PP year geared to women's experience and follow-up of pregnancy complications
4. Create *Mom's Health Matters* in communities with a high burden of maternal morbidities & chronic illness

## Invest in Communities

1. Incentivize funders to allocate 2% of annual funding for capacity building/infrastructure to accompany grants to small CBO's.
2. Create a Center for CBO growth/ sustainability for women's health & development.
3. Support local agencies to create and gain paid seats at the tables of local and city/state agencies which determine policies that affect the social determinants of women's health.

## Bridging the Chasm

**Public Education**  
Strategies TBD  
based on cross-cutting priorities





## Title: Advocate for Policy Changes to Transform Healthcare Delivery

### Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

*Advocate for policy changes to transform health care delivery via new payment mechanisms, quality measures, and coverage expansions.*

- Expand payment mechanisms to bundle additional services into intrapartum and postpartum fees to: 1) incentivize OB providers for warm-handoff to primary care/documentation; 2) add postpartum visits; 3) assure referrals and preventive measures, such as glucose tolerance testing after GDM; and 4) peer support groups and educational sessions, etc. Allow reimbursements to go beyond procedures to cover communication with patients and shared decision-making.
- Develop new quality measures/metrics to promote risk-based contracts specifically for the GDM to Type 2 diabetes transition and the path from hypertensive disorders of pregnancy to cardiovascular disease. Hold primary care providers accountable for follow-up after a pregnancy complication such as GDM or gestational hypertension.
- Expand public and private insurance coverage to support the postpartum period for a minimum of one year after birth, in the same way as pregnancy is currently supported. Such expansion should allow for a range of postpartum supports needed to shore up the health of new mothers. These include: group postpartum visits and peer support groups; glucose testing and blood pressure monitoring at home; doula care; telehealth for new mothers; nurse home visits; a family caregiver benefit for home healthcare of postpartum women.

### Problem Statement

A range of policy gaps hinder the underlying health, access to and quality of care for pregnant and parenting people. A key barrier is insufficient Medicaid coverage and the absence of any coverage for new mothers beyond 60 days postpartum, when follow-up of pregnancy complications and social determinants can reduce the risk of chronic illness. Maternal and child health (MCH) policy is typically more focused on improving neonatal and infant outcomes, and is less developed for addressing the significant needs in the postpartum period and across the life course. There has been a surge of state and federal legislation that includes promising strategies for bridging the chasm between high levels of care during pregnancy and low levels of support for new mothers. Examples include the expansion of Medicaid coverage to one year after birth and support of doula care in the postpartum period. Quality measures to promote postpartum attention to new mothers are currently only available for substance use disorder and postpartum depression, though others are being considered by the Task Force on Maternal Morbidity and Mortality of the National Quality Forum (NQF). Patient-centered medical homes (PCMHs) offer continuous, comprehensive and holistic care, especially for patients with chronic conditions, with good results, but have not been adapted to the challenges of continuity in maternal health care. Primary care reduces emergency department (ED) visits, but is underfunded and policies have not supported it as a critical bridge from maternity care to primary care across the life course. Political will for these and other policy changes is growing as a result of intensified attention to intolerable rates of maternal mortality among Black women. One-third of pregnancy-associated deaths occur between one week and one year postpartum, and well-publicized stories of prominent Black women have called out the harm done to them and to other women of color when they are not listened to, disrespected, and ignored during and after difficult pregnancy and birth experiences. The need to address gaping holes in the care of pregnant and parenting people, and to tackle root causes of Black women's heightened risk, has emerged as a national public health priority.

[Note: See review of the literature: Summary of Evidence (Chapter 4)]

### Recommended Strategies

After in depth conversations about myriad specific strategies--many of them inter-related--WG members decided it would be most useful to policy-makers and advocates to cluster strategies in four main 'buckets': Health insurance coverage, Health system innovations, Quality measurement and accountability, and Workforce capacity building.



## Strategy #1: Health Insurance Coverage

Description
Support federal and state legislation to extend Medicaid coverage to 12 months postpartum, including auto-enrollment.

### ***Rationale***

Continuous health insurance coverage plays a major role in keeping people healthy before, during and after pregnancy. Disrupted insurance hinders access to critical postpartum follow up of mothers' medical and mental health conditions that are associated with ongoing morbidity and pregnancy-related mortality. Medicaid is the largest payer of health care for pregnant and postpartum people in the U.S. (<https://www.cdc.gov/nchs/data/databriefs/db318.pdf>), covering about 43% of births annually, and is an important 'player' in the effort to assure continuity of coverage and care. Currently, for those who have Medicaid insurance under the "pregnancy – related services" category, the federal requirement extends coverage only to 60 days postpartum. This cut-off means that many women fall into a chasm of health un-insurance two months after they give birth. Extending Medicaid coverage to 12 months would require all states, not just those who have 'expanded' Medicaid, to cover mothers for up to one year postpartum, and to do so through 'auto enrollment' to assure seamless coverage.

### ***Medicaid Expansions: Evidence of Positive Impacts***

In 2014, with the passage of the Affordable Care Act (ACA), the "Medicaid Expansion" program in states where it was adopted, ensured coverage for millions more women of reproductive age, based on income eligibility regardless of pregnancy or postpartum status. Currently 33 states and the District of Columbia have accepted federal funding for expanded Medicaid, and it is under consideration in 3 more states. Medicaid expansions have had a clear positive impact on insurance coverage for women of reproductive age, lowering the rate of un-insurance by 13.2 percentage points (Wehby & Lu, 2017). With 17 states opting out of Medicaid expansion, about 2.5 million uninsured adults fall into the coverage gap, including pregnant people who lose coverage after 60 days postpartum due to failure to meet the eligibility requirements of their state's 'regular' Medicaid program. (The median eligibility level varies across states. In 2019, the range extended from 40 percent of federal poverty level (FPL) -- \$8532 per year for family of three--in non-expansion states to 138 percent of FPL - \$29,435 per year for family of three.) They earn too much to qualify for Medicaid and not enough to be eligible for the ACA marketplace premium subsidies. Most people in the coverage gap live in the South; and people of color make up a disproportionate share of the uncovered population (Johnston et al., 2018 Cole et al., 2018; National Partnership for Women and Families Fact Sheet, 2018, Garfield et al., 2019). Medicaid coverage appears to decrease delays in prenatal care (Daw, et al., 2017); and we can speculate that extended coverage will improve access to and use of follow up care in the postpartum year. A recent study adds weight to the argument. New mothers in a state without Medicaid expansion (Utah) were found to have greater loss of Medicaid insurance and fewer outpatient visits between one and six months postpartum, compared to counterparts in a state with expansion (Colorado). Strikingly, the effects were largest among women who experienced significant maternal morbidity at delivery (Gordon, Sommers, Wilson, & Trivedi, 2020). A recently presented study found that Medicaid expansion is also associated with maternal health outcomes. They found lower rates of maternal mortality, reflecting 1.6 fewer maternal deaths per 100,000 women, in states with Medicaid expansion compared to states without expansion—a finding the authors attribute to increased access to insurance prior to pregnancy, allowing pre-existing conditions to be addressed sooner (Rosenberg, 2019).

What we know about postpartum care drives the importance of this policy strategy home. Four out of ten Medicaid beneficiaries do not attend a postpartum visit 6-10 weeks after birth (Rodin, 2019). The first 100 days after delivery, known as the 'fourth trimester' is promoted as a critical window for continued postpartum surveillance by ACOG. The following 6-12 months are equally critical for mothers whose health during and immediately following pregnancy signal risk for severe morbidity, mortality, and ongoing chronic health conditions. In fact, one-third of pregnancy-related deaths occur between one week and one year, and 11 percent occur between 43 and 365 days; most are preventable

with careful attention to prior conditions (Petersen, et al., 2019). Cardiomyopathy, the leading cause of death between 43 and 365 days, is associated with hypertensive disorders of pregnancy (Behrens, et al., 2019). Careful follow-up and monitoring after the official postpartum period is often lacking, given the chasm between maternity and primary care (McCloskey, et al., 2019), and without insurance such care proves nearly impossible.

#### *Insurance is not Access*

It is important to remember that coverage does not equal access (Johnson et al, 2015); and as such, expanded coverage is an important necessary yet insufficient step to assure continuity of care during and beyond the first postpartum year. The extension of Medicaid coverage to one year postpartum must be accompanied by other strategies designed to fix the structural gaps in care between the official postpartum period and connection to ongoing primary care.

#### *Gathering Momentum*

There is federal and state-level momentum for this strategy. With the public's and policy-makers' eyes keenly focused on eliminating racial and ethnic disparities in maternal mortality, extending Medicaid coverage to one year postpartum is one key element of several comprehensive pieces of legislation now pending in Congress (see below). However, it must be joined by other strategies designed to fill the myriad structural gaps in women's health care, as articulated in Strategies #2-4.

### **Review of criteria for selection of strategy #1:**

#### Innovation: Medium

In the past year this strategy has gained momentum. While the strategy is one of many ways that the Centers for Medicare & Medicaid Services (CMS) is turning to innovations to improve maternity care, the good news is that it is more routine than innovative at this point in time.

#### Effectiveness: High

If inclusive of auto enrollment and universal at national level, the strategy will be highly effective at increasing coverage for preventive care in the first year after pregnancy. The strategy is necessary but not sufficient as an effective path to true access and utilization. The strategy also does not address ongoing preventive/primary care for women whose pregnancies signal risk for chronic illness.

#### Promotes Equity: High

By design, expanding coverage to all women who meet Medicaid income eligibility criteria, will promote equity. It is a necessary but insufficient step, however. To achieve true access, this strategy must be comprehensive and inclusive of the strategies aimed at eliminating racism and disrespect within health care (below).

#### Feasibility: Medium

Existing momentum in State legislatures and the U.S. Congress suggests high feasibility, but the sustainability and strengthening of bipartisan support is an unknown factor in an election year.

### **Components to Consider**

Stakeholders (vested interests and potential collaborators who should be at the table):

*Government:* Center for Medicare and Medicaid Services (CMS).

*Professional organizations:* ACOG and the Society for Maternal and Fetal Medicine (SMFM).

*Private, non-profit, advocacy organizations:* Association of Maternal and Child Health Programs (AMCHP); Community Catalyst; Families USA; National Partnership for Children and Families (NPCF); Institute for Medicaid Innovation (IMI).

#### Examples of existing initiatives

Federal legislative proposals that include extended Medicaid coverage to one year postpartum (as of January 2020):

HELPING MOMS ACT, HR 4996 [Rep. Kelly] <https://www.congress.gov/bill/116th-congress/house-bill/4996>

MOMMIES Act S. 1343 [Sen. Booker], H.R.2602 [Rep. Pressley] <https://www.congress.gov/bill/116th-congress/senate-bill/1343/text>

MOMS Act S. 3568 [Sen. Gillebrand] <https://www.congress.gov/bill/116th-congress/senate-bill/116/text>  
 MOMMA's Act S. 916 [Sen. Durbin], H.R. 1897 [Rep. Kelly] <https://www.congress.gov/bill/116th-congress/house-bill/1897/text>

State legislative proposals:

Texas House Bill 241 (in committee) [For related state – specific initiatives and practices see:

<https://www.kff.org/womens-health-policy/issue-brief/expanding-postpartum-medicaid-coverage/>];

California AB-577 Health care coverage: maternal mental health.(2019-2020) women covered for one year postpartum for pregnancy related mental health conditions. [See:

[https://leginfo.ca.gov/faces/billTextClient.xhtml?bill\\_id=201920200AB577.](https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201920200AB577.)]

#### Opportunities and known supportive factors

- Existing legislative initiatives (federal and state) represent enormous opportunities for achieving this strategy. Current bills are all part of packages that aim to address racial disparities in maternal mortality, issues that are garnering long overdue public and political attention. Many have garnered bipartisan support that can be strengthened and leveraged.
- Two major professional associations, ACOG and SMFM, have already called for the extension of Medicaid coverage to one year postpartum.
- Arguments focus on the coverage of women for up to one year—the end of the window for “pregnancy-related mortality”. In this timeframe, some goals of *Bridging the Chasm* can be advanced, namely post-pregnancy follow up of complications such as hypertensive disorders of pregnancy and gestational diabetes, and a warm hand off to a primary care provider (PCP).
- The legislative proposals open a window of opportunity to expand the period of coverage and broaden the argument to include prevention of chronic illnesses (e.g. Type 2 diabetes and cardiovascular disease), as well as the associated cost savings that such prevention would bring.

#### Challenges and barriers

- Any strategy built on the ACA has some risk going forward.
- Bi-partisan buy-in has been difficult for extending Medicaid, even in the context of maternal mortality prevention, due to the high perceived cost and lack of clear, current evidence regarding if/how these expenditures may lead to long-term cost savings.
- Auto enrollment may face fewer political barriers and could still be a plus.
- Some women in need are not included in this policy remedy: Women who are permanent residents or undocumented do not qualify. In some states pregnant women *are* eligible for Medicaid in the five years after becoming a legal permanent resident, but not all.

### **Strategy #2: Health System Innovations**

Description
<p>a. <u>Establish new models for comprehensive primary care (structural transformation)</u>. Through federal legislation, support “Women’s Health Homes” (WHHs) to provide structure for connectivity and integration in women’s health care before, during and after pregnancy for at least up to 3 years. Key elements of the model include:</p> <ul style="list-style-type: none"> <li>• continuity over time and between specialties and team-based care with community health workers on teams;</li> <li>• integration of physical, mental and social health;</li> <li>• quality metrics and system-level accountability;</li> <li>• systems focus on chronic illness and preventive care; accountability to specified populations;</li> <li>• culture of patient-centeredness[ Cross-cutting with High Touch WG].</li> </ul> <p>b. Center for Medicare and Medicaid Innovation (CMMI):  <u>Fund innovative models for transition</u> from maternity care to ongoing primary care after pregnancy, particularly for women with pregnancy complications.</p>

- transitional models, such as “Got Transition” (from adolescent to adult care) <https://www.gottransition.org/>;
  - payment models, such as extending existing bundled payment or creation of a new bundle for extended postpartum period (up to one year after delivery);
  - performance incentives built into the provider payment mechanism, e.g. adequate reimbursement for value-based care models, and pay for performance with reimbursement tagged specifically to procedures related to prevention of chronic illness.
- c. CMMI: Fund capacity for Accountable Care Organizations (ACOs) to address Social Determinants of Health (SDOH) for women of reproductive age, with distinct focus on women who experienced medically and/or socially complicated pregnancies, up to 3 years postpartum.

## Rationale

### ***Transform the structure of women’s health care to support comprehensive, integrated care (strategy #2a):***

The implementation of a *Women’s Health Home (WHH)* entails the kind of major structural transformation needed to ‘bridge the chasm’ between pregnancy and preventive care for women over the life course. While ambitious, it can be informed by two existing structures with track records and evidence: the *Patient-Centered Medical Home (PCMH)* and the *Medicaid Health Home State Plan Option (MHH)*. In addition, the *Maternity Care Home (MCH)*, sometimes called the *Pregnancy Home*, implemented under the CMS Strong Start Program to offer enhanced prenatal care to improve birth outcomes, can provide a point of reference. The table below shows the three models plus the proposed *WHH*, the target populations, who is responsible, and payment arrangements.

The *PCMH* has a long track record as a model of care in a wide variety of settings. The model is based on five key pillars: first contact, continuity over time, comprehensiveness (care for the whole person), coordination across specialties and caregivers within and across the health system, and patient centeredness. Generally speaking, *PCMHs* are situated in physician- or mid-level practitioner-led primary care practices. The ACA added additional elements: health information technology to link services, referral to community and social support services, patient and family support, and a focus on care transitions and appropriate follow up (Bodenheimer and Pham, 2010). Myriad published evaluations of the *PCMH* provide a strong foundation for adapting the model to women’s health care. A systematic review of 48 papers and reports show a trend toward positive findings with respect to overall utilization and cost savings, especially for those with complex chronic conditions who are in mature *PMCHs*. Results are mixed regarding impact of *PCMHs* on use of specialty care and quality of care received (Jabbapour et al., 2017; <https://www.pcpcc.org/resource/investing-primary-care-state-level-analysis>). The Veterans Administration (VA) is the only known system to implement *PCMHs* for women, offering care coordination across time and specialties and service integration with reported success (Clancy & Sharp, 2013). The VA success is a relevant and promising example for a *WHH*, yet other health care systems will need to pursue internal structures that mirror the scaffolding inherent in the VA system.

*The MHH*, authorized under the ACA, is designed for adults with chronic conditions. *MHHs* offer person-centered, team-based care coordination with a strong focus on behavioral health care, social supports and services, and consumer engagement. Some states are building health home models on a medical home framework by expanding links to a range of providers and increasing the breadth of available support services. [See <https://www.medicaid.gov/state-resource-center/medicaid-state-technical-assistance/health-home-information-resource-center/downloads/hh-overview-fact-sheet.pdf>.] Evaluation at five years for eleven sites points to reduced emergency department use and no increase in costs for the complex patient population served by a *MHH*; but as yet data are insufficient to draw conclusions about utilization and quality of primary and behavioral health care (Spillman & Evans, 2017).

*Maternity Care Homes (MCH)*, as designed under the CMS-funded Strong Start Program, offered enhanced prenatal and postpartum care, including psychosocial support, education and health promotion, but did not represent systems transformation nor address maternal health beyond 6-10 weeks postpartum. They were implemented as *PCMHs*, fared poorly with respect to Strong Start goals- lowering preterm birth and low birth weight – compared to the most successful comparison model, Birth Centers. *The MCH* is not an appropriate model upon which to base the proposed *WHH*.

The proposed *WHH*, designed for women whose pregnancy complications and social determinants forewarn future chronic illness, could build upon a blend of the *MHH* model, focused on team based coordination, social supports and services, and the *PCMH* model (focus on cross-specialty care, care across transitions, information technology (IT) to link services, and family engagement). To achieve the goals of “Bridging the Chasm”, the proposed new model must directly address equity. Distinct additional pillars to guide the new model are: 1) engagement of patients and community members in the design and local implementation of the model, and 2) inclusion of “community health doulas” and/or “community women’s health workers” as required members of the health care team (See High Touch WG Strategy # 1 and #2.)

	PCMH	Medicaid Health Home	Maternity/Pregnancy Care Home	Proposed Women’s Health Home
Target Population and Time Period	Any individual across life span	Patients with chronic conditions- as long as meet clinical criteria	Pregnant women at risk for preterm birth enrolled in Medicaid or CHIP (Strong Start) – one year after birth	Women with pregnancy complications (clinical and social) identified during pregnancy and up to three years after birth
Who determines care content?	NCQA	State Medicaid programs	Medicaid managed care organizations	Medicaid or ACO
Payer	Commercial or Medicaid	Medicaid	Medicaid	Medicaid and Private Insurers
Payment	Per member per month	Per member per month	Bundled payments	Per member per month

Source: <https://www.integration.samhsa.gov/integrated-care-models/health-homes>

### ***Create Innovative models for transition (strategy #2b)***

**CMS Innovation Waivers can be the funding mechanism for models that facilitate transition from maternity care to ongoing primary care, with a special (but not sole) focus on people whose pregnancies were complicated by medical, mental health, or social conditions.** The models can be informed by well-established systems designed to support transition from pediatric to adult care for children and youth with special needs and for all adolescents.

- Extend bundled payment or create new bundle for postpartum period between 6 weeks and 1 year postpartum.
- Build in performance incentives for institutions to establish WHHs and for providers to establish and follow best practices for team-based care.

Strategy #2b asserts that CMS Innovation Waivers can support the development and evaluation of new ways to standardize ‘warm’ handoffs from maternity to primary care. If tested in the Medicaid innovation context, such practices and protocols could become uniform ‘best practices’ in health systems, regardless of insurance. The mechanisms needed are already a customary part of pediatric practice, and lessons learned from the process of transitioning children with special needs to adult care can be a useful blueprint for transfer from obstetrics to primary care. Research identified three key lessons: 1) the transition must begin early (for BtC, that means during pregnancy); 2) providers on both side of the transition require training (for BtC training is especially important for primary care physicians who may lack specific knowledge of how to follow – up after pregnancy and other issues specific to reproductive-aged women); and 3) patients and their families must be prepared and engaged (in the case of ‘bridging the chasm’, families and support systems should be brought engaged to help promote the self-care of new mothers during the transition and beyond). (See <https://mchb.hrsa.gov/cshcn0910/core/pages/co6/co6tahc.html>).

An initiative of the National Alliance to Advance Adolescent Care (NAAAC), “Got Transition”, has developed tools for providers, patients and families, and advocates to support the transition of adolescents from pediatrics to adult care. The Alliance has disseminated tools for providers that define the core elements of health care transition, guidelines for engaging the adolescents in their own transition, and condition-specific tools for providers on both sides of the



transition. These are excellent models for a similar initiative to support the transition of new mothers to primary care. (See <https://www.gottransition.org/>).

### ***Incorporate social determinants perspective into women's health care (strategy #2c)***

**CMS Innovation Waivers can be used to fund innovative models for ACOs to address SDOH among pregnant and parenting people.** Many existing ACOs limit their approach to social determinants to screening and referrals for homelessness, food insecurity, unemployment, exposure to violence, adverse childhood experiences (ACEs), and other environmental risk factors. However, there are examples of ACOs that have taken on the issues more directly: granting prescriptions for food (from food bank), a housing program funded with ACO dollars, and partnering with community organizations to support prevention of domestic violence and sex trafficking. [See housing example in the *Flexible Services Program Guidance Document Companion Guide* (<https://www.chlpi.org/wp-content/uploads/2013/12/Flexible-Services-Guidance-Documents-Companion-Slides-vF.pdf>)]. The ACO mechanism is promising because it addresses both patient needs and cost reductions for ACO-enrolled patients with complex needs. Known models for addressing social determinants within ACOs include a Massachusetts Medicaid ACO certification that requires ACOs to stratify the population and perform needs assessments of social determinants. (See [https://www.mass.gov/files/documents/2019/01/17/ACO%20brief%20%232\\_1.pdf](https://www.mass.gov/files/documents/2019/01/17/ACO%20brief%20%232_1.pdf)), and a nutrition aid program at four hospitals within Advocate Health Care, an ACO in the Chicago area. The savings of \$3,800 per patient, or \$4.8 million in total were attributed to the nutrition program. (See: <https://revcycleintelligence.com/news/accountable-care-organization-saves-4.8m-with-nutrition-aid>.)

### **Review of criteria for selection of strategies #2a, #2b, #2c:**

#### Innovation: High-Medium

Each strategy within this bundle was deemed highly innovative, tempered only by the fact that two are adaptations of existing strategies in other contexts (#2a and #2b). While apparently a simple idea, the actual development of a systematic warm handoff between maternity and primary care for women with pregnancy complications would be highly innovative. Within #2c, there is great room for innovation at the state level, as demonstrated by states that have already initiated coverage for food and housing assistance through prescriptions.

#### Effectiveness: Medium

Expansion of existing medical home models to create a new type of health home for women would not solve all the challenges of the chasm we describe, but would go a long way toward improving access and continuity for women across life stages. Overall, mechanisms for innovations in health care delivery are the first step, but effectiveness also depends on the quality of implementation. Poor implementation could not only keep the status quo in place but could amplify inequities.

#### Equity: Medium

System transformations within CMS are likely to promote equity, though they take a long time to refine and disseminate to the point of impact on health outcomes. Attention to the social determinants of health is an important beginning, especially if screening is followed by allocation of funds to allow for innovative prescriptions for 'treatment' of social determinants and development of metrics to document such efforts.

#### Feasibility: low

See challenges.

### **Components to Consider**

#### Stakeholders: (vested interests and potential collaborators who should be at the table):

*Health insurers and health systems:* CMS; Blue Cross Blue Shield, United Health Group, Aetna; Health Care of American; United Health Care, Kaiser Permanente, and other large health systems.

*Professional Associations:* ACOG, SMFM, American College of Physicians (ACP), Society for General Internal Medicine (SGIM), American College of Nurse Midwives (ACNM), National Association of Certified Professional Midwives (NACPM); American Public Health Association (APHA), Association of Women's Health, Obstetric & Neonatal Nurses (AWOHNN).

*Government:* Health Resource Systems Administration (HRSA)/Maternal and Child Health Bureau (MCHB); Office of Women’s Health (OWH); Office of Research in Women’s Health (ORWH); National Institute of Child Health & Human Development (NICHD), Centers of Disease Control and Prevention (CDC) Division of Reproductive Health; state Departments of Public Health/Title V and other units dedicated to women’s health.

*Private non-profits and advocacy organizations:* Patient Centered Primary Care Collaborative (PCPCC); Core Quality Measures Collaborative (CQMC); National Alliance to Advance Adolescent Health (NAAA), Black Women’s Health Imperative (BWHI), Alliance for Hispanic Health (AHH); National Association of ACO’s (NAACO); Black Mamas Matter (BMM); National Birth Equity Coalition (NBEC); Every Mother Counts (EMC); March For Moms (MFM); doula certification organizations (DONA International, Childbirth and Postpartum Professional Association (CAPPA) and ICEA Birth Doula Certification Program); all grassroots doula organizations and others invested in birth justice in communities of color.

#### Examples of existing initiatives

As described above, for strategy 2a, the VA model of *PCMH* for women, and the existing *MHH* for adults with chronic illness (and their evaluations) For strategy 2b and c, “Got Transition” of the NAAAC; numerous state ACO innovations, as noted above.

#### Opportunities and known supportive factors

Existing policies and innovations lay the groundwork for these strategies. For example, the *MHH* is a promising platform for a *WHH*. However, requirements to enroll in a *MHH* would need to be modified to align with the need for long-term primary care for women, and the definition of chronic health conditions would need to be expanded to include complications of pregnancy known to give rise to chronic illness. The *WHH* could be a marketing strategy for large health systems and ACOs.

#### Challenges and barriers

This comprehensive strategy will face challenges structurally and politically, yet the impact potential is high.

- It will be challenging to implement these structural changes if the primary care workforce remains limited, as addressed in the final workforce-related strategies below.
- Reimbursement would have to follow/accompany the structural changes, as noted. Changes in structure and reimbursement mechanisms will have to be pursued in concert, which is an enormous challenge.
- The Center for Medicare and Medicaid Innovation (CMMI) has funding under the Affordable Care Act (ACA), and as such may be at risk if related aspects of the ACA are repealed or replaced. Without CMMI, states may need to apply for Section 1115 waivers. Making this a state by state process will reinforce existing variations and inequities between states.
- The effort requires collaboration among myriad stakeholders, as noted, presenting substantial challenges.

### ***Strategy #3: New Quality Measures to ‘Bridge the Chasm’***

Description
<p><b>Health Care Quality: Measurement and Accountability</b></p> <p>a. NQF/Healthcare Effectiveness Data &amp; Information Set (HEDIS): Design and promote quality measures related to “Bridging the Chasm” between childbirth and three years postpartum, with attention to specific conditions and follow-up (e.g. glucose tolerance testing, blood pressure monitoring), attention to social determinants (assessment, referral), the patient experience (e.g. being listened to, respected) For example:</p> <ul style="list-style-type: none"> <li>• Specific conditions: 1) GDM: glucose tolerance test within 1 year postpartum and results to the primary care provider (PCP), with ongoing follow up as per Guidelines from the American Diabetes Association (ADA) and ACOG, and 2) Hypertension: discharge with blood pressure cuff at discharge after delivery for all women with hypertensive disorder.</li> <li>• SDOH: Documented assessment of SDOH and meaningful links to community resources at key points of care.</li> </ul>



- Patient Experience: Patient reports of being listened to, respected at key points of care, including the transition from delivery to postpartum care to primary care.
  - Transition: See Strategy 3b below.
- b. Develop pay for performance policies to reward warm handoff between obstetric provider and PCP and documentation in medical record. [Crosscutting with Preserve the Narrative WG strategies.]

### Rationale

Quality measures are integral to our health care system. If they are meaningful they hold providers and health systems accountable to patients and the public. If they are overly focused on limited aspects of care that are just easy to measure (e.g. # of visits) or developed without inclusivity (i.e. neglect patient or community input), they are less meaningful and can even be counterproductive (Saver et al., 2015). Despite their flaws, in the era of value-driven care and value-based payment, quality measures are an important driver of health care practices and processes; their relationship to outcomes is not clear. This strategy calls for measures (a system of measures) that focus on continuity and equity across the chasm. It is the National Quality Forum (NQF) that convenes healthcare stakeholders to decide upon measures with scientific merit and practicability, and the National Committee for Quality Assurance (NCQA) that selects measures to incorporate in HEDIS (Healthcare Effectiveness Data Information System), which is the system for accountability and accreditation. Over the past two decades, the only maternal health measures in HEDIS have focused on prenatal care (timely initiation) and postpartum care (attendance at visit between 21 and 56 days after birth, now extended to 7-84 days). In the 1990's when HEDIS was developed, these were viewed as the best and most practicable measures, but they lack meaning as we seek to eliminate racial/ethnic disparities in infant and maternal morbidities and mortality. NCQF has recently added new measures that relate to maternal health and are promising yet challenging to measure: prenatal depression screening and follow up; postpartum depression screening and follow up; and follow up after high intensity care for substance use disorder.

### Strategy #3a

We call on NQF to engage multiple stakeholders (including Black, Brown, Native and AAPI women, clinicians, advocates) to develop maternal health measures that capture: 1) continuity/transition of care between Ob-Gyn and primary care in general and for specific conditions (e.g. hypertension, pre-eclampsia, GDM) and patients; 2) documentation of the transition from maternity to primary care, assessments of social determinants and referral; 3) extent to which women, especially women of color, feel listened to and respected throughout the prenatal period, childbirth, discharge planning, postpartum, and in the transition to primary care; and 4) the extent to which the health system/provider engages community members as advisors and partners. Together, these represent a system of measures that can reflect and drive continuity and respect in care for pregnant and parenting people for up to one to three years following. The systems approach to measures is in keeping with a strategic direction of NQF. (See [http://www.qualityforum.org/Story/M Measurement\\_Systems\\_White\\_Paper.aspx](http://www.qualityforum.org/Story/M Measurement_Systems_White_Paper.aspx).) A set of measures geared toward follow up of patients in 'the chasm' and for the following one to three years, could prevent deaths between one week and one year postpartum and could interrupt the trajectory to chronic illness among women who have warning signs during pregnancy.

While our strategy is ambitious, there is much in place that lends feasibility. Through an initiative supported by the Aetna Foundation, NQF is collaborating with a diverse group of experts to identify quality and payment innovations to systematically address social determinants of health, which, they acknowledge, can account for almost 60 percent of health outcomes (See NQF link above.) In addition, NQF announced in October 2019, a new two year initiative to solicit expert opinion and public input to create new quality measures that relate to maternal morbidity and mortality. It is a welcome initiative that aligns perfectly with "Bridging the Chasm" aims. Also highly relevant to our strategy recommendation is the pioneering effort by the NBEC and CMQC. Funded by ACOG, the organizations are gathering voices of women of color across the country and developing measures of patient experience in maternity care. Though developed for maternity care, the measures will be applicable and adaptable for women's care in the year postpartum and beyond. (See <https://www.cmqqc.org> and <https://www.birthequity.org>).

### Strategy #3b

The WG chose to separate the "warm handoff" to primary care providers as a specific 'pay for performance' measure. While it could also be a quality measure, WG members felt that it was an excellent measure by which to hold maternity and primary care providers accountable to the links they must build. Such 'handoffs' are a core piece of safe and

preventive care for women after complicated pregnancies. If they are institutionalized through payment and quality metrics, ‘warm handoffs’ can become the standard of care, at least insofar there is sufficient and appropriate primary care provider supply and capacity. (See strategy 4.)

### **Review of criteria for selection of strategies #3a, #3b:**

#### Innovation: High

In an environment where maternal health measures have been limited to counts of visits, the set of measures we recommend are highly innovative. They capture processes of continuity and transition, ongoing SDOH assessment and follow-up, and the experience of Black, Brown, AAPI and Native women in health care.

#### Effectiveness: Medium

The effectiveness of the measurement strategy is limited mainly by the need for data systems that allow for the data capture, storage, sharing, and security. Data on the follow-up of specific conditions (testing, discharge ‘tools’) will likely be the lowest hanging fruit, if available EMR systems. The ‘pay for performance’ incentive for the warm handoff could in fact be highly effective given the ‘teeth’ of payment incentives.

#### Equity: Medium

The SDOH and patient experience measures could begin to guide changes in care that then become institutionalized. ACO’s are a context in which such measures could be most easily incorporated and impact assessed.

#### Feasibility: Medium

The feasibility of measure development is high given NQF’s Task Force on Maternal Morbidity and Mortality, established after the WG completed its recommendations and ratings. However, it will take much longer to build the political and professional will for the “pay for performance” measure, with low or medium feasibility

### **Components to Consider**

Stakeholders: (vested interests and potential collaborators who should be at the table):

*Non-governmental health care metric organizations:* National Quality Forum (NQF), National Committee for Quality Assurance (NCQA), CDC-funded PQC’s.

*Community-based advocacy organizations:* National Birth Equity Collaborative (NBEC), the California Maternity Care Quality Collaborative (CMCQQ), National Partnership for Children and Families (NPCF).

*Professional Associations:* ACOG; Association of Women’s Health (AWH), AWOHNN, ACNM; National Association of Certified Professional Midwives (NACPW).

*Government:* Agency Health Care Research and Quality (AHRQ)

Ongoing initiatives. As described above, the NQF initiatives on SDOHs and maternal mortality and morbidity measures, and the ACOG-hosted NBEC and CMCQC project. Also, the CDC-funded Perinatal Quality Collaboratives (PQCs), which are state or multi-state networks of teams working to assess and improve the quality of care for mothers and newborns. <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc.htm>

Finally, the Quality Care for Moms and Babies Act (QCMBA) (H.R. 1551; Rep. Engel (D-NY16) Rep. Stivers (R-OH15), Sen Stabenow (D-MI) focuses on quality in maternity care. <https://www.congress.gov/bill/116th-congress/house-bill/1551/text>. The bill directs the Department of Health and Human Services to work with stakeholders to create a core set of maternity care quality measures for childbearing women and newborns, and the AHRQ to develop a Consumer Assessment of Health Care Providers and Systems.

#### Opportunities and known supportive factors

All of the initiatives noted above present significant windows of opportunity for us to advocate for extending the lens beyond maternity care to the first year after birth and (ultimately) beyond. The NQF initiative on maternal mortality and morbidity also presents the opportunity to recommend condition-specific follow-up measures “in the chasm” to protect the health of women in the one to three years after birth. The PQCs represent another existing platform that can be

leveraged to include quality concerns in the year after childbirth- both for the sake of maternal health (including future pregnancies), and newborn and child health. The QCMBA is also a great starting point as a legislative lever to elevate the importance of quality measures in the year following birth.

#### Challenges and barriers

Measures require health system informatics. All EMRs are slow at making additions or changes, which means some measures, especially those hardest to measure if not already part of the system, may take many years to implement. That said, changes in EPIC (the most commonly used software) can be made at the local level and even universally, but require advocacy and patience. Patient report measures may require a system of patient surveillance, which would require resources at each institution or from a central source.

### ***Strategy #4: Workforce Development/Capacity Building***

Description
<p>a. Implement incentives for physicians, nurses, advanced practice nurses, and PAs to enter primary care with multi-pronged approach:</p> <ul style="list-style-type: none"> <li>• Increase # training slots;</li> <li>• Build in loan repayment structure;</li> <li>• Build on existing structures, such as National Health Service Corps (multiple programs, including Indian Health Service), Armed Forces, state-based State Loan Repayment Assistance Programs (SLRP), and the Public Service Loan Forgiveness Program through the Department of Education, which requires ongoing employment at a 'qualified employer'.</li> </ul> <p>b. Require that accrediting bodies for all obstetrics/maternity care training programs and all primary care training programs (MDs, PAs, advanced practice nurses (APNs), certified nurse midwives (CNMs) require a credit unit on linking reproductive health care and primary care for women for licensure and re-licensure.</p> <p>c. Mandate that the Maternal Infant Early Childhood Home Visiting (MIECHV) provide training for home visitors to provide care focused on mothers' health and well-being for up to three years postpartum (in addition to infant and child-focused care).</p> <ul style="list-style-type: none"> <li>• Add funding, training of nurse-visitors, and performance indicators related to maternal health, with particular focus on follow-up care and for mothers who had/have conditions such as postpartum preeclampsia, depression, addiction, hypertension, and diabetes.</li> <li>• Expand support for doulas and community health worker reimbursement, extending the role of doulas across the reproductive continuum from pregnancy through the extended postpartum period. (See Strategy 4.)</li> </ul>

#### **Rationale**

##### ***Primary care professional workforce capacity (strategy #4a)***

Access to comprehensive, integrated primary care requires workforce capacity. If health care systems are to help people cross the chasm between pregnancy and chronic illness later in life, the demand for PCPs of all disciplines (physicians, physician assistants, nurse practitioners, certified nurse midwives) and supporting clinicians (nurses) will be greater than the existing workforce can handle. Shoring up the primary care professional workforce requires increasing FTE training slots in all of these roles, recruit caregivers who have experience and respect for the diverse communities, and train them with curricula focused on women's health over the life course, addressing SDOH and the impact of structural racism and unconscious bias in health systems and clinical practice, and engaging in cultural humility and anti-racist and anti-biased practices.

Increased funds through existing mechanisms, such as the National Health Service Corps to repay loans for health professionals, is more efficient than creating a new program. The Public Service Loan Forgiveness Program would cover existing, employed health care providers, even if caregivers had started to repay loans. A policy analysis from the National Institute for Health Care Reform (2011) describes the available options in some detail: (See: Carrier, E.R., Yee, T., Stark, L., 2011). Matching supply to demand: Addressing the U.S. Primary Care workforce shortage. National Institute

for Health Reform, 7, 1-7. Accessed 10/230/19 at <http://media.khi.org/news/documents/2012/10/24/PrimaryCareWorkforceShortage.pdf>.

### Summary of Health Reform Provisions to Increase Primary Care Capacity

POLICY	DESCRIPTION	POTENTIAL IMPACT
Payment Reform	Designated primary care practitioners receive a 10% Medicare bonus payment. Medicaid payment rates for specific primary care services provided by primary care physicians increased to at least equal Medicare levels.	Some modeling suggests higher payment rates can increase the quantity of primary care services provided; however a temporary increase may have less impact.
Care Delivery Reforms and Pilot Programs	Medicare Shared Savings/ACO program; community health teams to support patient-centered medical homes.	Health care organizations, such as ACOs, may encourage development of team-based primary care practices to increase capacity and improve efficiency.
Support Primary Care Training in Academic Settings	Awards grants to plan, develop and operate training programs in primary care; provides financial assistance to trainees and faculty; enhances faculty development in primary care and physician assistant programs.	Students recruited through targeted training programs are more likely to enter primary care in underserved areas. However such programs may require large investment with a relatively small yield. Also, if residency slots are fixed, increases in US graduates may merely displace international graduates, resulting in minimal impact on the net primary care workforce.
Creating New Primary Care Residency Programs (for physicians)	Redistributes residency positions in case of vacancies, and mandates 75% of new Medicare-supported residencies be in primary care, including internal medicine; academic medical centers or teaching hospitals may obtain grants for primary care residency programs.	Focusing on residency programs historically has a higher yield than creating academic training programs. Residents can also provide patient care and generate revenue for hospitals during their training.
Scholarships for Students Planning to Practice Primary Care	Grants to medical schools to recruit students likely to practice in rural areas; grants to train residents in preventive medicine specialties.	Students who are more likely to practice primary care, particularly in underserved areas, are also likely to face financial barriers to obtaining medical training; scholarships can address this barrier.
Loan Forgiveness and Direct Financial Incentives for Primary Care Practitioners	Increases annual and aggregate maximum on loans for nurses; increase in National Health Service Corps scholarships and loan forgiveness funding for primary care practitioners who practice in shortage areas.	Relative to scholarships, loan forgiveness has much lower dropout rates, higher retention and satisfaction.

Source: Carrier, Stark & Yee, 2011

Seen together, these options create a synergy for increasing the primary care workforce. The approaches must be applied across provider groups- physicians, nurse-practitioners, nurse-midwives. Certified nurse-midwives are currently licensed to practice independently in only 25 states; 19 states require CNMs to enter into a written agreement with a collaborating physician that specifies exactly what actions, interventions or therapies require the general or direct supervision of a physician, but in many rural areas there is no physician willing to enter into such an agreement; and 7 states allow CNMs to practice independently, but without prescriptive authority. CNMs in these states interested in gaining prescriptive authority must enter into a collaborative agreement to lawfully prescribe pharmacologic and non-pharmacologic therapies (primary care). Restrictions of this type are a major challenge to the expansion of CNMs into primary care practice (see <https://www.midwifeschooling.com/independent-practice-and-collaborative-agreement-states/>).

### ***Inclusion of non-clinical caregivers in primary care teams and training***

The models of care proposed in this report require holistic, multi-disciplinary and multi-racial, multi-cultural team members. The inclusion of non-clinical caregivers, including doulas, community health workers, patient navigators is crucial to the function of primary care teams and in this report, is addressed under “High Touch Models of Care” below.

Here we raise the importance of cross-training among all types and levels of clinical care providers and non-clinical providers. Such structures do not typically exist in professional or non-professional training programs, making it imperative to create new mechanisms and funding so that primary care teams can function with efficiency, respect, and patient-centeredness. Cross-training strategies are presented under “High Touch Models of Care” below.

#### ***Curriculum module linking reproductive care to primary care for licensing (strategy 4b)***

There is now a wealth of research supporting the linkage between reproductive care and health status in later life, and much of it links specific prodromal conditions in pregnancy with the burden of chronic illness, most specifically hypertensive disorders of pregnancy with the risk for cardiac disease, postpartum depression with an increased risk of chronic depression. The evidence is emerging for relapse in the postpartum period and death from overdose among women with opioid use disorder during pregnancy. Despite this evidence, health care professionals of all specialties demonstrate need for information if they are to accept referral to primary care as a priority for the postpartum agenda. There is much evidence to show that requiring modules for accreditation is an effective way to ensure that clinicians obtain necessary knowledge, although training evaluations do not generally go the next step and tie that increased knowledge to changes in practice behaviors (Kwant, 2015).

#### ***Home visiting workforce expansion (strategy #4c)***

We recognize that the literature on home visiting is mixed, but much of the variation appears to be tied to insufficient training and application of performance standards, and there is great potential for improvement in outcomes (Handler, 2019). Public health visitors are already in the home in many programs designed to assess short-term postpartum recovery, child wellness, and parenting skills. Training these visitors in a curriculum specific to the needs of women who find themselves ‘in the chasm’ needs to be instituted and evaluated. Dyadic care (mothers and babies seen simultaneously or in the same location) is being tested in outpatient clinic settings, most commonly to screen mothers for depression identified at a well-child visit (Silverstein, 2018; Caskey 2016; Srinivasan, 2018). The extension to the home that we propose here is crosscutting with the strategies proposed by the High Touch WG. The policy component consists of legislative funding and agency performance standards.

#### **Review of criteria for selection of strategies #4a, #4b, #4c:**

##### Innovation: Medium

Dyadic care is new, and the extension of home visiting to women’s health in the three years post-delivery is innovative. The strategies proposed to expand the primary care workforce are not new, but advocating for them in the context of prevention of chronic disease among women is a new strategy.

##### Effectiveness: Medium

To be effective, this approach would have to be implemented with attention to quality and outcomes measured to determine effectiveness.

##### Equity: Medium

Home visiting has primarily been used in low income, low resource communities, but if the focus is pregnancy complications, it would need to be applied universally to high risk women. A study of continuously insured women with gestational diabetes showed that despite insurance coverage, nearly half of the women who would have benefited from preventive care to delay early onset of Type 2 diabetes did not receive any follow-up (Bernstein et al, 2017).

##### Feasibility: Low

There have been concerted efforts to expand the primary care workforce with little success for two decades. Tying education to accreditation, licensure and re-licensure is a complicated and lengthy process. Home visiting is labor intensive and thus relatively expensive.

## ***Components to Consider***

### Stakeholders:

*Professional Associations:* ACP, AAFP, SGIM, Association of Women’s Health Nurse Practitioners (AWHNP), ACNM, American Academy of Physician Assistants (AAPA), AWOHNN, Association of Obstetric and Neonatal Nurses (AONN).

*Education:* ACGME, all primary care residency programs.

*Government:* National Health Service Corps (including Indian Health Service), Armed Forces, state-based State Loan Repayment Assistance Programs (SLRP), and the Public Service Loan Forgiveness Program through the Department of Education.

*Private, non-profits:* Patient Centered Primary Care Collaborative.

### Examples of existing initiatives:

Strategy 4a. See table above for existing mechanisms for funding to attract clinicians to primary care.

Strategy 4b. There are already modules required for Obstetrics—e.g. Hypertension in Pregnancy—that are identified by the Alliance for Innovation on Maternal Health (AIM) as effective interventions.

Strategy 4c. The Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program could be expanded to incorporate a maternal health focus, with relative ease.

### Opportunities and known supportive factors:

Mechanisms already exist that can be expanded, and building on an existing framework is usually a popular approach and less costly. The success of the National Health Service Corp (NHSC) points to the feasibility of primary care recruitment programs (See <http://clinicians.org/wp-content/uploads/2019/06/NHSC-2019-Fact-Sheet.pdf>)

Maternal and Child Health (MCH) programs within state agencies are familiar with the structure of home visiting programs, and increasingly recognize the value of promoting women’s health beyond pregnancy. The program is an excellent opportunity to bring together MCH and non-communicable disease units within state departments of public health, to mutual benefit.

### Challenges and barriers:

The proposed strategies require federal funding. Increasing the number of slots for International Medical Graduates (26% of U.S. physicians in practice) and non-citizen U.S. medical school graduates has potential, but was not chosen as a primary strategy for reasons of political feasibility.

## Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

- Centers for Medicare and Medicaid Innovation (CMMI) should direct funding to learning networks for pregnancy/delivery/postpartum care, and these networks must include patients.
- Target CDC funding and coordination to diabetes and other pregnancy complications, including evaluation of existing programs for cost effectiveness & scalability, implementation of interventions shown to work in other settings/fields, and critical examination of the applicability of other types of public health successes.
- Explore basic research in PP physiology/biology (1st PP year), best strategy for glucose testing innovations, what kind of information women want and need, and how best to access it; reassess predictive analytics for GDM that account for individual and community resilience as well as social predictors of health.
- Identify effective programs and lobby for funding.

## Problem statement

In our efforts to “Align Research with Women’s Lived Experience over the Life Cycle,” we recognize that patient voices must be front and center. There are multifaceted and overwhelming problems that women, clinicians, health care systems, and society encounter in bridging chasms in the care of women who experience pregnancy complications that indicate risk for women’s adverse future health outcomes. Two primary examples are the pregnancy complications of gestational diabetes mellitus (GDM) and hypertensive disorders of pregnancy (HDP). Significant care chasms exist between complicated pregnancies, the postpartum period, and beyond. In research, these problems fall into three broad categories reflecting current realities related to 1) the research agenda, 2) women’s health care design, and 3) an overall failure to prioritize prevention across the life course.

First, the research agenda must be multidisciplinary, more comprehensive, and inclusive of socioeconomic and cultural considerations impacting women’s health and health care following GDM and HDP. We must carry out longitudinal studies that include both mother and child. Current funding priorities are silo’ed, focusing on pregnancy through delivery and not on following women and their children post-pregnancy. Researchers struggle to obtain funding in part because programs and funding opportunities are often narrowly focused, and there is not an easy way for researchers and interested collaborators to connect them together. We call for a research agenda that leads to the creation of platforms that support multidisciplinary, multi-sector collaborations. Women in their reproductive years encounter many forces which affect them. We call for a culture of research that allows women to engage with researchers and others in an environment rich with supports; one in which all women’s voices are valued and heard, and online, social media, and non-concurrent means of contributions are maximized. In other words, research should serve both pressing and long term needs of women by providing evidence that can be turned into major policy changes that assure, for example, that black women do not have to fear dying after delivery and women with gestational complications do not have to endure an unnecessary burden of subsequent chronic illness (diabetes and heart disease).

Second, care design for women with GDM and HDP must integrate innovation (new models of care and new technologies) and account for women’s, their support persons’, and clinicians’ experiences. There is a need for improved funding for innovation in health care systems and health care technologies, and the implementation science that supports adoption of effective strategies. Innovations may include but not be limited to improvements in the electronic health record (EHR) to promote interoperability and the ability to ascertain relevant data and produce necessary flags and alerts for the care team. We call for funding and support for projects that promote the long-term integration of successful, sustainable interventions in real life practice.

In all of this, a clear priority should be to establish supports and mechanisms to make it feasible (and even a natural course of action) for women to engage in their own health and the health of their families. Women’s partners and support persons are critical in this regard, yet there is currently a lack of “on-ramp” for partners to be engaged. Thus, our solutions tend to be divorced from partners who are key players for change in women’s lives. We envision and call



for a culture in which women can prioritize their own health and balance those priorities with demands on their time and energy that are managed and shared with their family and other supporters and caregivers, others, organizations, and programs.

Lastly and crucially, research on prevention of cardiometabolic diseases must be a priority for women with GDM and HDP and their children across the life course. We will not bridge chasms without prioritizing and linking prevention in preconception, inter-conception, prenatal, postpartum, and primary care. These areas are presently silo'ed and disjointed and not viewed in the context of the social determinants of women's health, frequently resulting in a continuing cycle of poor health for many women and their children.

**[Note: See review of the literature: Summary of the Evidence (Chapter 4)]**

## Recommended Strategies

### ***Strategy #1: Potential RFA for patient-engaged intervention research***

Description
<ul style="list-style-type: none"> <li>a. Develop new funding sources dedicated to BtC (RFAs, cooperative grants, multi-source collaborations) in both public and private venues: federal agencies (NIH, including the MFMU Network, AHRQ, CMMI, MCHB), state agencies, and major foundations. For NIH, request that the RFA be reviewed by a special emphasis panel recruited for this purpose.</li> <li>b. Develop new funding streams to address gaps in screening and treatment after pregnancy complications, most specifically for gestational diabetes mellitus and hypertensive disorders of pregnancy with focus on innovations to reduce barriers to postpartum glucose testing and preventive treatment. Assure patient engagement in the process of development.</li> <li>c. Develop and test interventions, with patient engagement, to address the role of social, behavioral, and environmental factors responsible for ethnic, immigrant, racial and sociodemographic disparities in pregnancy complications.</li> <li>d. Conduct patient-engaged research to further define what kind of information related to BtC after pregnancy complications that diverse women want, need, and will find easy to use.</li> </ul>

#### ***Rationale:***

Intervention research that is tailored for culture and situation and sensitive and relevant to diverse populations of women is required to address the longer term implications of pregnancy complications.

#### ***Review of criteria for strategy selection:***

Innovation: Medium to High

The focus on calls for patient-engaged, interventional research that addresses the chasm between complicated pregnancies, the postpartum period, and future care of women is innovative. Calls with this specific, targeted focus do not currently exist in robust ways with major funders.

Effectiveness: High

Perceived likelihood of high effectiveness related to 1) researchers' interest in carrying out this kind of interventional research, based on our literature review, and the paucity of relevant current funding mechanisms and 2) the evidence that suggests this type of patient-engaged and patient-participatory research approach will yield equitable health outcomes.

Promotes equity: High

Strategy #3 (within the bundle), in particular, contains emphasis on approaches that will promote/produce equity in women's health outcomes.

Feasibility: Medium to High

Perceived likelihood that there would be significant response to such RFAs.

***Components to consider***Stakeholders: (vested interests and potential collaborators who should be at the table):

In identifying the stakeholders, we recognize that it's about action and not just territory. With that in mind, we would be seeking to form an alliance and bridge chasms between stakeholders of different types who may or may not perceive this strategy to be in their domain of interest. Potential stakeholders should include:

*Patient based or community based coalitions* invested in the research topic (e.g. Black Mamas Matter, National Birth Equity Coalition, National Alliance for Hispanic Health, Black Women's Health Initiative);

*Professionals* (Hospital associations, professional associations, OB/GYN care providers, primary care providers);

*Researchers* (e.g. university-based and free-standing such as RAND);

*Private foundations*, who often play a double role of funder and advocate (e.g., Preeclampsia Foundation, Kaiser, Robert Wood Johnson Foundation);

*State and federal funding agencies* (e.g., PCORI, NIH and specifically the ORWH and issue focused state-based grantors).

Examples of existing initiatives that may align with each strategy:

Recent attention and action related to the unacceptably high U.S. maternal mortality rates and the resulting funding initiatives may be synergistic with this bundle.

Opportunities and known supportive factors:

Many professional associations (ACOG, ACNM, American Hospital Association (AHA), ADA, etc.) have in recent years established guidelines pertaining to postpartum follow up among women with complications of pregnancy (GDM, HDP).

Challenges and barriers:

Historically, research funds are invested in follow up of the child, not the mother.

***Strategy #2: Evaluation of the Impact of Innovative Care Delivery (e.g., Women's Health Home Model)***

Description
<ul style="list-style-type: none"> <li>a. Research the impact of changing the common names/labelling of pregnancy related conditions to reduce their stigma and encompass their potential for lifelong impact (e.g. the misleading labeling for gestational diabetes and gestational hypertension, which suggest conditions that have no impact beyond pregnancy) and/or stigma (e.g. 'elderly primip', 'poor compliance', 'addicted mom').</li> <li>b. Test the effectiveness of a multi-pronged approach (e.g. group-based care at intervals throughout the postpartum year, enhanced by frequent in-person or patient-facing technology contacts) to engage women in their own care and facilitate care plans.</li> <li>c. Evaluate the impact of providing consistent, comprehensive care to women through an extended postpartum period, in women's health home models, by practitioner type, within states/regions that extend Medicaid to 12 months postpartum (cross-fertilized with WGs on Policy and High Touch Models).</li> </ul>

***Rationale:***

Evaluation of the impact of innovative, patient-engaged approaches to comprehensive postpartum care, both in-person and through patient-facing technology, provided through a medical home model for continuity and accessibility, is essential if the U.S. is to move the needle on maternal health equity following complications of pregnancy.

***Review of criteria for strategy selection:***Innovation: Medium to High

The majority perceived this bundle to be highly innovative though many expressed issues with feasibility. The innovation comes from promoting disruption in terms of the messaging regarding pregnancy complications and the realities of future risk for cardio-metabolic disease. There is also innovation embedded in patient-facing technology that engages women in their ongoing care. Further, application of the patient-centered primary care medical home model to postpartum women for an extended postpartum period is an innovative approach to caring for women across the life course.

Effectiveness: Medium to High

Perceived likelihood of effectiveness is related to innovative aspects above in this bundle.

Promotes equity: High

The patient engagement-focused approaches embedded in this bundle (patient facing technology and extended postpartum care through medical home model) have high potential to promote equitable health outcomes in diverse women. If implemented with an equity lens, they may directly address the needs of women of color, rural women and women living in poverty who have higher rates of chronic illness in later life. Without an equity lens that considers the intersection of race/ethnicity and income differentials, technological innovations will gravitate toward women higher educational levels and resources. The ubiquity of smart phones and familiarity with apps and messaging across populations may allow the dispersion of new approaches to maintaining contact, but will have to be done thoughtfully with local adaptations to reach all those who would benefit.

Feasibility: Medium

Developing consensus regarding changing common names/labelling of pregnancy and messaging related conditions would be a heavy lift with numerous stakeholders. Lastly, there would be some question of feasibility around developing consensus for who the key providers are in the medical home model.

***Components to consider:***Stakeholders (vested interests and potential collaborators who should be at the table):

*Patients and providers* are primary stakeholders for research in all three sub-areas.

*Provider Organizations*: The American Association of Medical Colleges (AAMC), the American Association of Colleges of Nursing (AACN), the National League for Nursing (NLN), ACNM and associations of other relevant disciplines (social workers, mental health workers, breastfeeding and lactation specialists, and doulas are important partners in prioritizing issues for research and disseminating results.

For testing the impact of changing common names, labelling, and messaging around “gestational” conditions (#2a):  
*Stakeholders who may not be the usual suspects in this area* (e.g. experts in design thinking, the media, and women’s

reproductive rights advocates and activists who could translated research on the impact of stigma into public opinion change.)

For both #2b (multi-pronged approaches ) and #2c (consistent, prolonged care within a women’s health home), *Employers , insurance payers (Medicaid and private insurance) and HMOs* are critical partners who could use research findings to offer evidence-based comprehensive models for postpartum care and wellness and prevention interventions as an added benefit for women with medical or social complications of pregnancy.

Examples of existing initiatives that may align with each strategy:

Ongoing state-led maternal health quality improvement projects , initiatives in progress to expand workforce capacity and services (Nurse Family Partnership; certification for doula programs, full licensure for CNMs, etc.) and federal legislation on the docket to improve maternal safety and postpartum care all urgently require research findings to support and evaluate proposed policy change.

Opportunities and known supportive factors:

Contemporary trends in promoting women-centered care; attention to unacceptable U.S. maternal mortality rates. NIH initiatives to encourage use of CBPR, NIH attention to pragmatic research with special review groups to evaluate real world interventions, and funding from PCORI all support the centrality of women’s role as experts in their own lives, an essential component for conduct of the research strategies bundled here.

Challenges and barriers:

Perceived likelihood of challenges and barriers related to changing labels because of historic emphasis on the medicalization of complications of pregnancy with little attention paid to the social, environmental and personal determinants impacting women’s health and lives both preceding and following complications of pregnancy. Historic lack of “life course” approach to women’s health with resulting, current models of care that are episodic in nature and do not prioritize prevention.

### **STRATEGY #3: Documentation**

Description
<ul style="list-style-type: none"> <li>a. Negotiate with EMR companies, such as EPIC, to develop and test a template for transfer of pregnancy history to primary care records that can be retrieved for future research. (cross-fertilized with WG on Preserve the Narrative)</li> <li>b. Advocate for a new claims code to permit administrative data research focused on post-delivery risks related to a history of pregnancy complications, specifically including depression, substance use disorder, hypertensive disorders of pregnancy, and gestational diabetes mellitus. (cross-fertilized with WG on Preserve the Narrative)</li> </ul>

**Rationale:**

Effective electronic health record documentation and preservation of the narrative following women’s complications of pregnancy will enable more focused, meaningful research to address women’s future health outcomes, needs, and health care approaches.

**Review of criteria for strategy selection:**

Innovation: Medium to High

Robust EHR/database capabilities to preserve the narrative and permit more focused post-delivery related research following complications of pregnancy do not currently exist.

Effectiveness: Medium to High

If created, such EHR capabilities would promote effective means of carrying out research focused on bridging the chasm between women's pregnancy and future health.

Promotes equity: Medium

This would potentially help us better understand diverse women's trajectories from pregnancy to future years given the widespread use of EPIC and similar EHRs across the U.S. Large data sets with their large, diverse samples provide ample possibilities for tracking effects across the life cycle and improvements in racial and ethnic inequities, but are only useful if women can be inked across different episodes of care and different settings in which they access care and if race and ethnicity are entered reliably and completely.

Feasibility: Medium

Concern: bottlenecks with extracting EPIC data in a uniform way and collecting like variables across institutions. May be challenging from a computer coding perspective. Would be costly and requires reimbursement mechanism if claim code is developed. Would require working closely with funders for the reimbursement code so that the diagnoses would be retrievable.

***Components to consider:***

Stakeholders (vested interests and potential collaborators who should be at the table):

*Creators and maintainers of large datasets* (information technology experts), ranging from EHRs such as EPIC to NIH's All of Us. These platforms could be used to interrogate areas of research interest.

*Funders and payers* are needed to develop reimbursement codes so diagnoses can be retrieved.

Examples of existing initiatives that may align with each strategy:

Initiatives focused on development of big data relevant to women's pregnancies and future health such as PRAMS, NIH's All of Us, state and federal WIC data, and ongoing initiatives focused on improving EHR technologies. Also consider women's health advocacy groups to tap into the power of peer-to-peer interactions that might help engage the large entities who create and maintain big data.

Opportunities and known supportive factors:

Current era of big data in which opportunities abound to advocate for processes to create documentation to preserve the narrative following complications of pregnancy in a way that leads to impactful research.

Challenges and barriers:

There may be challenges with extracting EMR data in a uniform way and collecting the same variables across institutions. Costs related to developing claim code.



## Title: Develop High Touch Models of Care

### Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

Develop “high touch” models of care that bridge across the chasm created by fragmentation and the mismatch between women’s lived experiences and the existing structures and requirements of health care systems.

- Engage women in extending and redesigning the postpartum period to address their ongoing needs and shift the focus of the health care system from baby to dyad (a dual goal that recognizes the importance of monitoring and maintaining health for women).
- Bring postpartum care to women at convenient, local, trusted sites instead of requiring women to negotiate challenges in order to get to care (e.g. home visits for postpartum glucose testing, church and community centers, with testing available in non-traditional settings such as supermarkets and pharmacies, hairdressers and work settings).
- Leverage all health care professionals into a woman’s ‘health care village’ as part of routine well-woman care that mirrors the simple, clear and comprehensive approach that is standard for well-child care.

### Problem statement

Our current system of maternal and women’s health care, which has remained unchanged for the past 50 plus years, is designed to deliver episodic, fragmented care in clinical settings and fails to place women and their lived experience at the center of care. The fragmentation is especially stark when considering women after their infants are born. Over 40% of women do not receive routine postpartum care, even when they are covered for this visit under Medicaid (ACOG, 2016; Rodin, 2019), and more than half of women with pregnancy complications so not receive follow-up medical care in primary care settings in the months and years following childbirth (Bennett, et. al., 2014). There is a distinct mismatch between what the health care system offers and what women need to surmount barriers for self-care and prevention of illness.

Increasingly, evidence points to the risks of such neglect: Increased likelihood of pregnancy-associated mortality and the onset of chronic illnesses, such as diabetes, hypertension, cardiovascular conditions, depression, and addiction relapse (ACOG, 2018). There is a distinct mismatch between what the health care system offers and what women need to surmount barriers for self-care and prevention of chronic illness over time.

The gaps are especially detrimental for women of color, whose health is significantly compromised by chronic stressors and distrust of the health care system, both born of their experience of racism. The Black Mamas Matter Alliance documents the extent of the problem, and sets the standard for holistic care of and for Black women (Muse, 2018; National Partnership for Women and Families, 2018; Sakala, 2020).

Innovative team-based models that combine clinical and community-based caregivers and engage patients as central players in their own health and health care are emerging, but even these models typically do not continue their ‘high touch’ and holistic approach to care beyond pregnancy and the immediate postpartum period. The current model of care must shift to be more consistent with pregnant and parenting people’s lived experiences, and build on a clear body of evidence that exposes the ties that bind women’s reproductive health to their health and illness over the course of their lives. Three interrelated themes have been identified by both women and their providers (Kennedy et al., 2018): 1) implementation of care models that enhance both well-being and safety; 2) optimizing physiological, psychological, and social processes in pregnancy, childbirth, and the postnatal period; and 3) development and validation of outcome measures that capture short and longer term well-being (Kennedy, et al., 2018). High touch models of care offer a pathway to address the challenges of fragmentation for all women and move determinedly toward equity for women of color.

[Note: See review of the literature: Summary of Evidence (Chapter 4)]

## Recommended Strategies

### ***Strategy 1: Collaborative, team based models of care***

Description
<p>Implement within ACOs and other integrated delivery networks (IDNs), flexible, collaborative team-based models of care that extend for at least one year beyond pregnancy and assure a warm handoff to a primary care home, with a particular focus on people whose pregnancies were complicated by social and/or clinical conditions. (Cross-cutting with “Eliminate Disrespect, Racism and Implicit Bias” and “Advocate for Policy Change” WGs)</p> <ol style="list-style-type: none"> <li>Incorporate multi-disciplinary clinicians (physicians, advanced practice nurses, midwives, social workers, therapists) and community-based caregivers, including doulas, community health workers (CHWs), peer navigators (PNs).</li> <li>Equip nurse-midwives (and nurse-midwifery model) to care for women ‘across the chasm’ and across reproductive years, with special attention to the needs of women whose pregnancies signaled risk for chronic illness based on pregnancy complications or substantial SDOH.</li> <li>Enhance existing education and certification mechanisms to equip team members for extended postpartum collaborative practice AND create innovative cross-training for collaborative teams. (Also see Strategy #2 below.)</li> <li>Expand Medicaid coverage and use CMS Innovation waivers to pilot funding mechanisms to reimburse comprehensive team based care in the postpartum year. (Also see “Advocate for Policy Changes” WG)</li> </ol>

### ***Strategy 2: Design and conduct innovative content and models of team training***

Description
<p>Create a cadre of cross-trained, community-based women’s health caregivers to be members of health care teams to ‘bridge the chasm’. Develop and evaluate training modules on the physiologic, psychologic, and social dimensions of maternal health in the year (+) after pregnancy, integrate the competencies into existing educational curricula for each component of the workforce, and design and conduct innovative models of team training.</p> <ol style="list-style-type: none"> <li>Develop modules to educate a cadre of community-based certified caregivers to assure key competencies needed to ‘bridge the chasm’. Competencies include (but are not limited to): serving as liaison between patient and clinical care team; informing and referring people with pregnancy complications and/or chronic conditions to appropriate tests and follow-up care; assisting with SDOHs, recognizing key warning signs of postpartum health risks; connecting to primary care.</li> <li>Incorporate the BtC competencies and resources within existing training programs and certification processes for doulas, CHWs, and patient navigators (PNs).</li> <li>Identify opportunities for cross-training of community-based caregivers (CHWs, doulas, PNs).</li> <li>Enhance competencies for Nurse-Midwifery and Advanced Practice Nursing Education Programs (including continuing education) to prepare for collaborative practice at the intersection of postpartum and primary care.</li> <li>Create and sustain Regional/National Training Centers, led by representatives of all the components of the newly expanded workforce, to design and conduct innovative, experiential team-based training for <i>maternal health collaborative care teams</i>, to equip them to work together to achieve high quality, respectful, multi-disciplinary care for women. Such training can be based upon existing models, e.g. simulation labs used to train teams in Emergency Departments, or take advantage of new opportunities within reformed health systems, such as ACO’s, and learn from innovations to address social predictors of health within the context of medical care delivery.</li> </ol>



## Rationale for Strategies #1 and #2

In 2014 the American College of Obstetrics and Gynecology (ACOG) convened *The Inter-professional Task Force on Collaborative Practice* (ACOG, 2014) in response to national policy changes, including passage of the ACA, to move providers and health systems toward a more seamless and value-based form of health care. The report defines what it would take to shift to a collaborative brand of maternity care that includes patients as full partners, with providers from multiple disciplines (i.e. Ob-Gyns, midwives, physician assistants, nurse managers/coordinators, dietitians/nutritionists, and social workers, with links to primary care physicians and/or advanced practice women's health nurse practitioners), all functioning to the full scope of their education, certification and practice. The Task Force recognized the value of non-traditional settings for health care (e.g. homeless shelters, churches, housing developments) as well as telehealth and mHealth modalities, but did not include community-based caregivers (certified or uncertified) as integral members of collaborative care teams. It is important to note, too, that the proposed model did not extend beyond the immediate postpartum period; it was not until 2018 that ACOG redesigned postpartum care to include a 4<sup>th</sup> trimester (up to six months), allowing for a more individualized, flexible transition to ongoing well-woman care. We propose here a model for development of an expanded workforce that includes a variety of community-based caregivers working in concert with a diverse panel of clinicians.

### *Community-based Caregivers as Key Team Members across the Chasm*

The value of caregivers who are community-based (i.e. have shared language, culture, race/ethnicity, and/or other shared social histories and identities with the patients they serve) has always been recognized by patients and communities. In the past five to ten years, the value of community-based caregivers has been increasingly recognized within health care systems, and their roles incorporated to varying extents in health care teams. The extent to which they are incorporated as full members of health care teams varies greatly. There is robust evidence, cited below, to support the recommendation that community-based caregivers with the high touch model of caregiving, can be effective bridge builders across the chasm.

Community Health Workers (CHWs) are the most widespread among front-line workers, and their role has been promoted within the ACA and by state health reform policies. Evaluations have found CHWs improve outcomes related to diabetes and hypertension self-management, and are cost effective in community-based cardiac care (see Summary of the Evidence, Chapter 4.). There is a strong and growing state-based and national movement to professionalize CHWs, create and apply standardized certification and training, and advocate for fair compensation (Mason, et al, 2011; WHO, 2018). However, CHWs are not typically trained or employed in maternal health. An evaluation of 31 CHW training packages showed a gap in integrated, comprehensive approaches and no topics that relate to the care of women after pregnancy (Tran, et al., 2014).

Patient Navigators (PNs), on the other hand, have grown up primarily through research-funded projects, largely related to cancer diagnosis and management. Breast cancer researchers, for example, established that PNs improve outcomes (rates of screening, follow-up, and timely treatment) among women from diverse racial/ethnic groups (Battaglia, et al., 2016). PNs also contribute to cost savings in the treatment of geriatric cancer patients (Paskett, 2017). While patient navigators are not typically employed in MCH settings, one non-randomized study found a PN program led to improved contraception uptake, depression screening, and vaccination (Yee, et al., 2018). Since PNs have most often been trained in the context of research studies; curricula are overall not standardized nor geared toward certification. PNs trained and working in oncology settings are in some places, an exception. It is also worth noting that in some health care settings, roles similar to those of PNs are undertaken by care coordinators.

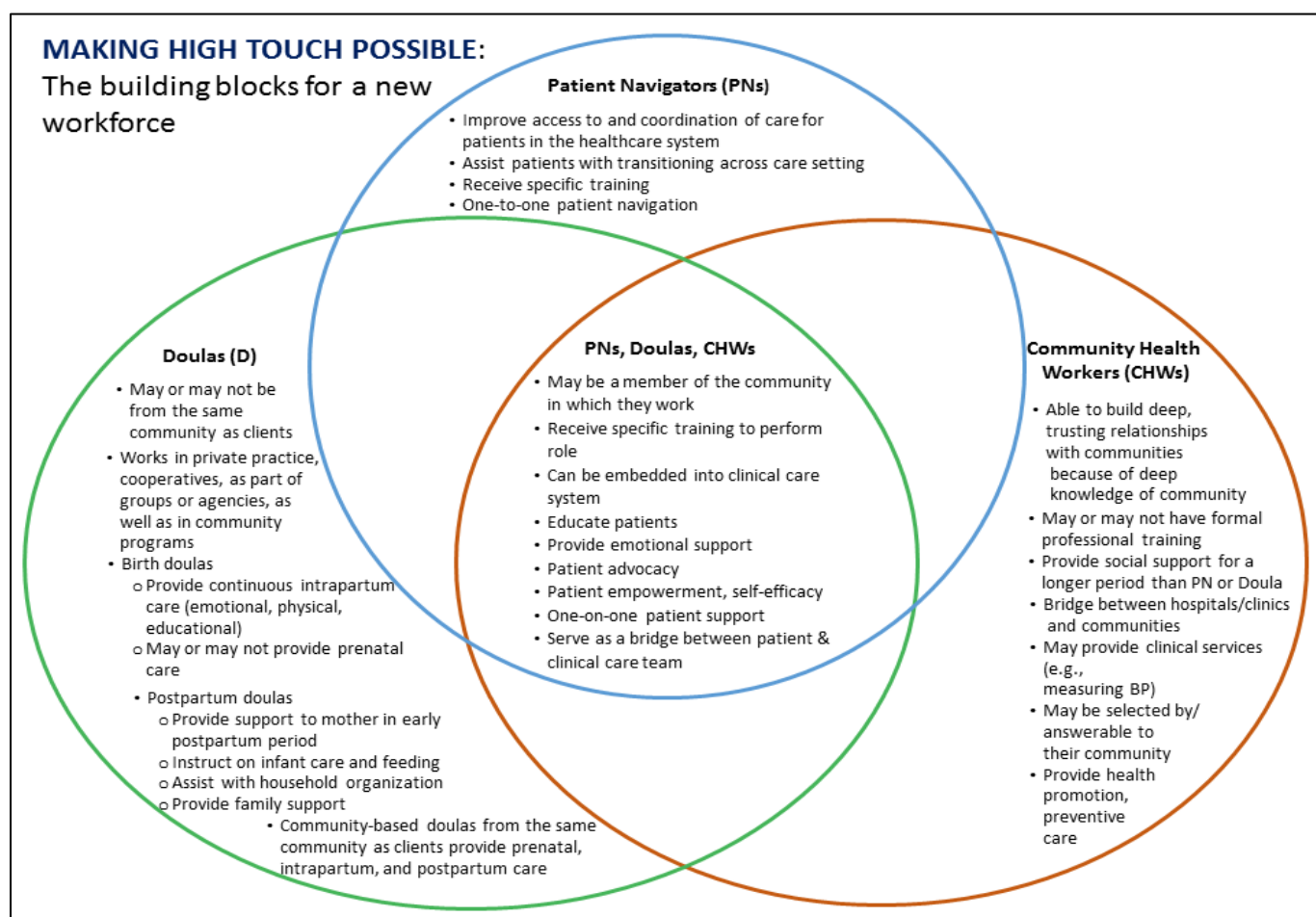
Doulas are widely recognized as community-rooted birth workers whose woman-centric, holistic approach to care is crucial for bringing equity to maternal health in the U.S. Doula care and support during pregnancy, childbirth, and in the immediate postpartum period is associated with improved overall satisfaction among mothers, reduced preterm birth and cesarean rates, increased breastfeeding initiation, improved parenting practices, increased mother-child interaction and reduced postpartum depression rates (see Summary of the Evidence, Chapter 4). In fact, there is a rapidly growing

movement within state legislatures and in Congress to require Medicaid and private insurers to make doula care a reimbursable component of maternity care, as documented by the Doula Medicaid Project

(<https://healthlaw.org/doulamedicaidproject/>).

Doulas' contribute to better birth outcomes and satisfaction through the strong emotional and social support they offer before, during and after birth, which can mitigate the impacts of stress and social disadvantage and discrimination (Gentry, et al., 2010). Impacts are greatest among women with Medicaid, bolstering the argument that doula care can also be cost effective. Typically doula care does not extend beyond the postpartum period, although some postpartum and full spectrum doulas offer care after the immediate postpartum period and across the life course, particularly during periods of transition. While they are not required to be licensed, most doulas are trained and certified through several recognized one-year programs (DONA International, the Centering Pregnancy and Parenting Association (CPPA); and the U.S. authority within the International Childbirth Education Association (ICEA), which can provide platforms for enhanced training for doulas who wish to work in health care settings and play a role in 'bridging the chasm.'

The Venn Diagram below depicts current unique and shared key features of the roles of PNs, CHWs, and doulas, as described in the literature. They have several features in common; most central to all is that, by design, the workers share language, culture, race, ethnicity, and/or other shared social histories and identities with the patients they serve, a characteristic that is sometimes labelled as 'peer'. As a whole, the diagram illustrates the breadth of the workforce that can be enlisted and trained to build a bridge across the chasm in women's health. The diagram points to aspects of each groups' expertise and training that can be leveraged as BtC competency-based modules are designed for doulas, CHWs and PNs.



Source: Diagram created by Dr. Stacey Klamman

### *Clinical providers as key team members across the chasm*

Currently, there is a clear, structural disconnect between maternity care providers, primary care providers, and patients after the immediate postpartum period (MacDonald, et al., 2007). Obstetric and primary care physicians are most often trained and practice in silos, without systems to connect them. The philosophy and training of nurse-midwives, on the other hand, is holistic, woman-centered, geared toward continuity (Kennedy, 2018), and linked to reductions in preterm birth (Sandall, et al., 2016) and increased postpartum visits (Alliman, et al., 2019). Nurse-midwives are ideally suited to play a key role as ‘bridges’ between reproductive and primary care. While some nurse-midwifery education programs may already emphasize lifelong health and health care, some curricula may have to be enhanced to cover the links between reproductive health complications with later risks for cardiovascular health and diabetes. However, policy barriers may stand in the way, and practice limits designed to protect existing areas of recognized expertise are not easy to modify. Although the federal government views midwives as well as obstetricians as primary care providers, the Institute of Medicine (1996) and the National Committee for Quality Assurance do not. Regulations in 18 states limit midwifery practice to pregnancy, birth, well-woman gynecology, and newborn care (Phillippi & Barger, 2015).

In addition, PCPs, if trained to do so, can proactively build the bridge between pregnancy and preventive care, especially for women following complicated pregnancies. In one such example, a transition clinic for postpartum women with hypertensive disorders of pregnancy successfully engaged the majority of postpartum women in home blood pressure monitoring, medication use, and the initiation of self-care (Celi, et al., 2019). The internists were reimbursed for care in the postpartum period (2-3 visits each on average). Similar innovations could be promoted among other primary care providers, including women’s health nurse practitioners.

### *Collaborative Team Training*

Training of collaborative teams requires innovation in the curricula of each discipline, as well as experiential inter-professional education (IPE) to elevate the importance of cohesive, patient-centered teams to assure safety, quality and satisfaction. Without effective team-based training, introduced early in the education of all profession, existing patterns of power, decision-making, and communication are likely to prevail, and the goals of truly collaborative care will fail. IPE training models are frequently used in emergency and family medicine residency programs (Achkar, et al., 2018).). Most typically, IPE is taken up to improve team collaboration and communication as a way to prevent medical errors and assure safety in in-patient or emergency department settings. However, we know of no IPE efforts within ACO’s, or IDN’s geared toward the more difficult task of training multi-disciplinary teams that include non-traditional care-givers in the context of patient-centered medical homes. An experiential, on-site model for IPE in maternity care is a key innovation for ‘bridging the chasm’.

### Innovative: Medium to High

While high touch models are well-established for pregnant and postpartum people, we found no evidence of their use for purposes of maternal health in the period following the official postpartum period. The cross-training of collaborative teams is also not a uniform component of the proposed high touch models of care.

### Effectiveness: High

As noted above, there is ample indirect evidence from a broad array of specialties and conditions that community-based health workers improve satisfaction and outcomes, and in some cases, cost effectiveness.

### Promotes equity: High

The evidence that CHWs, PNs and doulas can positively influence health outcomes is strongest in communities of color.

### Feasibility: Medium to High

Models of care that incorporate CHWs are already supported by state and federal policies and reimbursement structures (e.g. ACA Patient Centered Medical Homes and Medicaid Health Homes). The models include care coordination during pregnancy and the immediate postpartum period as well as adult chronic illness, making adaptation to a system that cares for women across ‘the chasm’ likely feasible.

### ***Components to consider:***

Stakeholders: (vested interests and potential collaborators who should be at the table):

*Professional organizations:* ACOG, ACP, SGIM, ADNM, NANPWH, AWOHNN, National Association of Clinical Social Workers (NACSW), National Association of Community Health Workers (NACHW), National Black Doula Association (NBD);

*Education/Certification:* American College of Graduate Medical Education; DONA International, Childbirth and Postpartum Professional Association, International Childbirth Education Association, National Center for Inter-professional Education;

*Advocacy organizations/Maternal Health:* National Birth Equity Coalition; Ancient Song Doula Services, Black Mamas Matter Alliance, Every Mother Counts, In Our Own Voice, March of Dimes, Moms Rising; Black Women's Health Imperative; HealthConnects One; SisterSong; DiabetesSisters; Pre-eclampsia Foundation, the National Partnership for Women and Families (NPWF);

*Community organizations/Community health and engagement:* WIN Network, Detroit; 100 Million Healthier Lives.

*Government:* HRSA/MCHB, Congress: Black Maternal Health Caucus (US House of Representatives).

Examples of existing initiatives: IMI (Maternal Models of Care to Improve Health Care Delivery and Outcomes in Medicaid); National Women's Law Project (NWLP) (Medicaid Doula Project; Northern New England Perinatal Quality Collaborative (NNEPQC) (protocols for transition to primary care); myriad state-based initiatives to promote doula care and CHWs; Institute for Health Improvement- Merck for Mothers; Ariadne Labs- Delivery Decisions Initiative.

[Note: See also legislation in WG: "Advocating for Policy Change".]

### Opportunities and known supportive factors:

Heightened awareness about the structural and interpersonal barriers to equitable, holistic, woman-centric maternity care in the U.S, has given rise to a gathering momentum for high touch models of care and training presented here. Most notably, the plethora of state and federal legislative initiatives that seek to tackle the unequal burden of severe morbidities and mortality shouldered by Black women (see Policy strategies) create a strong platform for action.

The training strategies we propose are also timely. At the state and national level, public health advocates and coalitions of doulas and CHWs - big and small, local and national-- are successfully promoting adoption of policies that assure they are valued and well-compensated members of the health care workforce. In turn, competencies and certification programs are being clarified and sharpened, presenting an opportunity to incorporate competencies related to 'bridging the chasm'. The parallel innovations in IPE occurring in graduate medical education programs also serve as an important platform for expansion to Ob-Gyn residency programs and the inclusion of non-traditional members of the workforce.

### Challenges and barriers

First and foremost, the current system is fragmented, provider training is silo'ed according to specialty, and EMRs are disconnected. A collaborative team is a necessary but is in itself an insufficient 'fix'. The team model needs an organizational structure that supports it; ACOs can be such a home but they vary greatly in size, resources, orientation, and leadership. The lack of clarity and uniformity in how the roles and competencies of PNs, CHWs and doulas are defined also poses a challenge to training that must build on existing education programs.

### ***Strategy #3: Develop and pilot a group model of maternal health care***

Description

Develop and pilot a group model of maternal health care to be offered during the full year postpartum, geared to women's experience, information and story-sharing, follow-up of pregnancy complications (e.g. gestational diabetes, hypertension disorders, maternal depression, substance use relapse, social stressors), that assures connection to a primary care home.

- a. Develop an in-person model based on lessons learned from *CenteringPregnancy*® and *CenteringParenting*® (Centering Healthcare Institute) <https://www.centeringhealthcare.org/> and the OB Nest Model (Mayo Clinic) <https://www.mayoclinichealthsystem.org/ob-nest>.
- b. Conduct feasibility studies regarding the best setting for group model extended postpartum care—obstetrics, pediatrics, primary care, or other location dependent on how services for women are organized.
- c. Investigate feasibility of virtual models to accommodate demanding schedules of new mothers, transportation and child care issues, and geographic distances for rural and some urban/peri-urban women.

### Rationale:

*Group prenatal care* (GPC), also known as *CenteringPregnancy* (based on the specific model developed by the Centering Healthcare Institute (ICH)), has gained traction in the past two decades as an alternative approach to health care for pregnant women. In this model, women are encouraged and supported as active participants in their health and healthcare, meeting together with an obstetric provider and co-facilitator every 2 weeks during pregnancy.

Three systematic reviews of GPC (Catling, et al., 2015; Carter, et al., 2017; Byerly & Haas, 2017) report mixed but promising results for key outcomes measured: low birth weight and preterm birth, psychosocial health of mothers, and satisfaction. A more recent matched cohort study, conducted in a diverse population (Cunningham, et al. 2019) found that GPC patients were about 67% less likely to have a preterm birth or low birthweight infant and the benefit was greatest for those with five or more group care visits. Those in group care also reported significantly higher satisfaction with their prenatal care. A cluster of studies provide evidence for the mental health value of GPC, with those at higher levels of stress or lower support benefitting most from group care. For example, GPC studies have documented an increased sense of community among military women (Kennedy, et al. 2009; 2011), increased self-esteem, reduced stress, social conflict, and postpartum depression (Ickovics, et al., 2011) among women receiving care in public hospitals, and higher maternal functioning postpartum among women at greater risk for psychosocial distress (Heberlein, et al., 2016).

GPC has been shown to offer benefit for women with high risk profiles: adolescents, African Americans, and low-income women (Byerley & Haas, 2018; Ickovics et al., 2016). Women with GDM (Schellinger, et al., 2017) and women with medication-assisted treatment for opioid use disorder (Sutter, et al., 2019) were more likely to receive follow-up care. Based on evidence on the value of group care for women with high risk profiles, a similar model could be effective for women 'in the chasm'.

*CenteringParenting*, a two-generation intervention, continues from *CenteringPregnancy*, after the baby's arrival. The group of parents, caregivers and children meet with their healthcare team for nine well-child visits over the first two years. Health assessments, immunizations and developmental screenings follow the American Academy of Pediatrics (AAP) Bright Futures nationally recognized guidelines. The longer group visit format allows the healthcare team to better observe the parent-child interactions, model behaviors and developmentally appropriate activities, and for the group to explore the topics that matter most. In addition to traditional health and safety topics, groups explore a variety of important socio-emotional concepts including attachment, serve & return interactions, stress management, mindfulness, relationships, family planning, community resources and positive parenting. Peer support and the relationships that develop through shared experiences reinforce parental efficacy and provide a foundation from which parents can better navigate the challenges of raising healthy families. Further, the format enables the group to address health disparities, Adverse Childhood Experiences (ACEs), toxic stress, social determinants of health and other critical social needs.



The evidence base for *CenteringParenting* is growing. There are a few feasibility and implementation studies (Bloomfield & Rising, 2013; Jones, 2018), with two small studies reporting results: higher satisfaction compared to usual care, and increased clinic attendance and immunization rate, and no difference in lead screening (Gullett, et al., 2019). Parents highly valued the camaraderie and chance to learn from other parents and the extra time with providers, and providers highly valued the more intensive interaction with parents. In addition, providers favored the group model because it allowed them to better address the SDOH.

The WG examined these increasingly promising results for GPC and first seeds of evidence on *CenteringParenting*, and concluded that the model, with its focus on social cohesion and support, self-care, and the shared monitoring of conditions that forewarn risk, has great potential to create a much-needed bridge for mothers during a vulnerable and isolating time.

There are no known examples or studies of virtual models of group care for pregnant or postpartum women. The WG felt that the time is right for a telemedicine innovation. Telemedicine in women's health is burgeoning and there is movement toward reimbursement policies that favor virtual health care (Fanberg & Waltzman, 2018).

#### Innovation: High

Although group models exist for pregnant people and parents, an in person group model of maternal health care that would extend throughout the entire postpartum year and include a focus on women's own health and self-care would be highly innovative. There is no existing organizational scaffolding for it, nor any 'routine' model of care with which to compare it. Likewise, a virtual group care for the extended postpartum period would be highly innovative.

#### Effectiveness: Medium

Ample evidence from *CenteringPregnancy* and *CenteringParenting* points to the likelihood that the model would be especially effective among people with high risk conditions (e.g. GDM, SUD) and among Black women who are at particular risk for severe maternal morbidity and maternal mortality.

#### Promotes equity: Medium to High

If such a model can be organized in a way that is accessible to women, particularly women of color and those with pregnancy complications, and is adapted to address key morbidities/follow-up that cause pregnancy-associated mortality and chronic illness over the life course, it is highly likely to promote equity.

#### Feasibility: Medium

Implementing a group model for maternal health would face considerable feasibility challenges, as there is currently no organizational scaffolding for it. We need feasibility studies to determine if pediatric, primary care or obstetric settings are most likely to incorporate such a model, and if new mothers would desire and find it possible as new mothers to attend group care (and if so, where and how often). In some ways, a telemedicine-based model (or hybrid model) may be more feasible than an in-person model. However, an internet-reliant model may place those without the resources for connectivity at a significant disadvantage.

#### **Components to Consider:**

Stakeholders: (vested interests and potential collaborators who should be at the table):

*Professional Associations:* ACOG, ACP, ACNM, SGIM, National Association of Nurse Practitioners in Women's Health (NANPWH), AWOHNN, National Association of Telemedicine (NAT)

#### Examples of existing initiatives:

Institute for Centering Healthcare-new initiatives; National Healthy Start Initiative (and local HSI projects) that include *Centering*, CMS Initiative to reimburse telemedicine; multi-site evaluation of South Carolina's *CenteringPregnancy*

Expansion (13-24 practices); *Centering Parenting* RCT; CRADLE RCT study at Greenville Health System; ongoing RCT of *CenteringParenting*.

#### Opportunities and Supporting Factors:

- As discussed, the research evidence in support of the group model of care is especially strong for higher risk women.
- This, in combination with the maternal health crisis for Black women, presents an ideal opportunity for the ICH to expand its models and partnerships, and for other models, such as the Mayo Clinic OB Nest model, to consider expansion for maternal health in full postpartum year.
- The increasing acceptance of telemedicine and reimbursement for it (at least in individual medical encounters).
- CMS policies that promote innovation also present timely opportunities for innovative models to in-person and virtual models.

#### Challenges and Barriers:

- Innovations do not diffuse quickly in existing health systems, especially when the innovation runs up against resistance from parties interested in maintaining the status quo. In the case of group care models, barriers within institutions can include the burden of scheduling, low turnout, preparation of class materials, and financial costs (need minimum enrollment to break even on revenue).
- To change how medical visits are conducted is to fundamentally change decades-old or deeply rooted traditional practice, and that is not easy, even when the content remains similar and only the delivery format that is changing.
- In the case of the group model well maternal health care, it is especially challenging because of the systemic chasm we have described. No one specialty- no one provider- is responsible to deliver the care beyond the immediate postpartum period or perhaps in the 4<sup>th</sup> trimester up to six months, as defined by ACOG.

### ***Strategy 4: Establish “Moms’ Health Matters” initiatives in communities where the burden of maternal morbidities and mortality and women’s chronic illnesses is high***

Description
<p>Establish “Moms’ Health Matters” initiatives in communities where the burden of maternal morbidities and mortality and women’s chronic illnesses is high, to facilitate the co-location of health information, resources, and referrals at sites where women already gather:</p> <ul style="list-style-type: none"> <li>• Clinical sites: Well-child care</li> <li>• Public agencies: WIC, TANF, Head Start</li> <li>• Community sites: Day care centers, faith based organizations, grocery or other stores, hair salons and barbershops, nail salons, women’s groups</li> </ul>

#### **Rationale:**

Reaching busy new parents with inquiries about their own health, and their ability to access information, resources, and referrals, requires meeting them where already they gather: at pediatric clinics, public agencies, workplaces, and in their own communities at faith-based events, child care sites, hair and nail salons, and food and retail stores. Public health promotion initiatives of various kinds have taken this approach with some promising results. The WG decided it was crucial to augment system-changing strategies with initiatives to reach women in places convenient to them with news important to them. Such news may include ‘big picture’ messages about the value of their own health, how to connect to resources for housing or food assistance, lactation consultation and available primary care providers; and it can include assessments and health reminders specific to them (e.g. blood pressure checks or testing after GDM). The assessments, information and referrals will be tailored to local realities (languages and health literacy, culture, and health resources), and CHWs, doulas, and people already at sites may be trained to be the connectors.

Such efforts will be most effective if coordinated by a local Alliance of community agencies and organizations with strong representation and leadership by people from communities most affected. One example of such an Alliance can be seen in the DHHS-funded Minority AIDS Initiative (MAI) of the early 2000's. The purpose of the MAI was to decrease HIV/AIDS in minority communities through strengthening local organizational capacity and assuring accessibility of preventive and treatment services in minority communities (see:

<https://www.kff.org/wp-content/uploads/2013/01/minority-aids-initiative-policy-brief.pdf>).

Although co-location was not a specific strategy for the MAI, the overall structure and objective is instructive for our aim to build community capacity to make maternal health information and services accessible to women of color [Note: Cross-fertilization with Invest in Communities WG].

This strategy can be informed by the experience of co-located services in the sites we recommend:

Well child visits: It is well known that mothers may delay or neglect their own health care, including postpartum visits, especially after the birth of a new child, even while faithfully taking their children to all well-child visits (Gregory, et al., 2020). Because even low-income mothers are in frequent contact with their children's providers during the first two years after birth, well-child visits present an ideal opportunity to talk to women about their own health needs (Wolf, et al., 2018). New mothers report a desire and willingness to receive postpartum health care for themselves (Verbeist, et al., 2016; Henderson, et al., 2016), even if not in the traditional postpartum visit, and a willingness to receive advice and referrals from their child's provider (Fagan, et al., 2009; Rosener, et al., 2016). There is growing evidence that the well-baby visit is a feasible and effective co-location for some maternal health services, namely contraceptive counseling (Kumaraswami, et al., 2018) and postpartum depression screening and referral (Liberto, 2012). Many states have passed legislation supporting perinatal depression initiatives, including Medicaid reimbursement for pediatricians to conduct depression screening and referral (Smith, et al., 2018)--a policy that has undoubtedly bolstered this particular co-location. Also supporting the efforts are broader calls in the pediatric community to shift the national discourse about adverse birth outcomes from the narrow focus on caring for mothers during pregnancy to a comprehensive investment in mothers' health before, during, and after pregnancy (Wise, 2008; Cheng & Kotelchuck, 2012). In summary, well-child visits present a potential venue for engaging women in conversations about their extended postpartum health and why and how they can gain the support they need, particularly after challenging pregnancies. While promising, pediatric providers can become overwhelmed with the already extensive and expanding scope of well-child visits.

Public Agencies, such as Head Start, WIC, SNAP, TANF: Lower-income women spend many hours interacting with public agencies, and these agencies and their staff also present an ideal opportunity to co-locate health information and referrals. Such efforts may be occurring locally, yet little is written about it. One such example comes from a randomized clinical trial of maternal depression screening and brief intervention (problem solving education) for mothers at Head Start sites (Silverstein, et al., 2017, 2018). Embedding mental health services into Head Start was shown to be a promising strategy especially for parents whose depression was persistent. Although more ambitious and treatment-focused than what we recommend for "Mom's Health Matters", the study results are encouraging: mothers can be engaged to address their own health concerns while interacting with a public program. There are many examples of co-location in rural areas, as described by "Rural health Information", although we do not know of evaluations. [See <https://www.ruralhealthinfo.org/toolkits/services-integration/2/co-location>.] The "multi-generational" or "two generational" approach, touted by the Aspen Institute, is a whole family approach to health information and services, and is an apt framework that can inform the "Mom's Health Matters" initiative. [See <https://www.ruralhealthinfo.org/toolkits/services-integration/2/multigenerational>; and <https://ascend.aspeninstitute.org/two-generation/guiding-principles/>.

Community – based sites such as hair and nail salons, faith-based organizations, and shops:

Faith-based organizations and beauty salons and barbershops are the community sites most frequently reported in the public health literature as places and partners for health promotion activities (Linnan, et al., 2015). The majority of (published) initiatives relate to general health, heart disease prevention, and cancer screening. There is strong evidence

that workers at these sites are eager health promotion “extenders”, though there is little evidence about effectiveness, owing to limited evaluation designs. Nonetheless, when health care system gaps exist as they do for women ‘in the chasm’, the WG members believe it is critical to take information and resources to places where mothers gather and engage as promotoras those with whom they interact and trust.

Innovative: High The creation of regional alliances, composed of community –based organizations and members, business owners, public agency officials, and women’s health and pediatric providers, to facilitate co-located health information, resources, and referrals is a novel idea.

Effective: Medium

Despite little evidence about effectiveness on health behavior change and outcomes, co-location is likely to be effective as a way to meet of this strategy—to reach women with information, resources and referrals.

Promotes Equity: Medium

Co-location efforts, guided by regional alliances made up of community members and organizations, are likely to promote equitable decision-making, with the promise of improving people’s access to health services ‘in the chasm’ and over the life course.

Feasibility: High

There is strong evidence that engaging pediatric providers, faith-based organizations and public agencies in health promotion activities is feasible. At the same time, pediatric providers in particular will face enormous challenges if too much of maternal care is folded into their already packed agendas for well-child visits.

## **Components to Consider**

Stakeholders: (vested interests and potential collaborators who should be at the table):

*Government:* DHHS (funders of regional health promotion), state DPHs, WIC sites, TANF offices, Headstart, Early Intervention (EI), SNAP

*Professional Associations:* AAP, National Association of Pediatric Nurse Practitioners (NAPNAP)

*Non-governmental/non-profit community agencies:* churches, mosques, temples, other faith-based organizations; Black business owner organizations, other neighborhood business organizations; cosmetology licensing/certification boards, faith-based organizations and councils

Examples of existing Initiatives: Perinatal depression screening initiatives in well child clinics (AZ, CA, ME, NH, MA, NC and other states); nutrition – based health information and referrals often co-located at WIC sites.

Opportunities and Supporting Factors: Opportunities will vary by region and local context.

Overall, the existence of widespread perinatal depression screening in pediatric offices (and its support in state legislation) presents an opening for other maternal health initiatives that are co-located in pediatric offices. Likewise, the prior example of a DHHS-funded regionalized council charged with coordinating health promotion activities and building local HIV service capacity, is a supporting factor. Certification and licensure programs in cosmetology may present an opening for added module on women’s health that could be seen as a welcome opportunity for some students.

Challenges and Barriers: Challenges will vary according to the sites and the contexts. In general, for the well-baby visit co-location, pediatric providers may feel resistant to accepting more responsibility for maternal health, no matter how straightforward. For the public agencies, bureaucratic processes can act as barriers since the co-location require space and staff involvement. Finally, training such a diverse set of workers is at the heart of the promise of this strategy and will require substantial resources.

***Strategy #5: Fund innovative digital technologies to connect women to each other, to clinicians and community-based caregivers, and to information and resources in the year+ following birth.***

Description
Innovative digital technologies could be geared to specific pregnancy complications and social stressor and appropriate follow-up as well as more general health and well-being, and facilitate connection to a primary care home in the postpartum year and beyond.

**Rationale**

Digital technologies are playing an increasingly visible and important role in women's health globally and in the U.S. Web-based programs, SMS interventions and mHealth apps have proliferated and evidence is extremely promising, though still emerging. A web-based program for women with GDM was linked to a decrease in postpartum weight gain retention (Nicklas, et al., 2014), and another maternal health follow-up program to increased postpartum visits (Himes, et al., 2017). Numerous on-line support groups are effective in providing emotional and informational support to women with or at risk for postpartum depression (Lee, et al., 2015). Most promising is the two-fold finding of an evaluation of a smartphone program that allows women to monitor their blood pressure at home (postpartum) and automates the data collection and reminders (Hirshberg, et al., 2019). The program was found to be more successful than usual care and to eliminate racial disparities.

These and now emerging digital technologies open new avenues for connecting women to each other, to providers, and to information in the chasm between pregnancy and their ongoing health. They should be seen as augmenting and not substituting for systems change.

Innovation: High

Many pieces exist that will be helpful to the health of women 'in the chasm', but the innovation will be in the design of a seamless technology that brings together the multi-pronged needs and desires of women from vastly different backgrounds and levels of literacy (information, interaction with providers, shared information across providers, contact with doulas or CHWs, self-monitoring, etc.)

Effective: Medium

Digital technologies can only be effective in the context of having a health care home that extends beyond pregnancy.

Promotes Equity: Low

The larger digital divide presents a significant barrier to true equity in the application and impact of digital solutions.

Feasibility: Medium to High

Requires investment and partnership between business/tech firms and clinicians, women, public health practitioners and researchers.

**Components to Consider:**

Stakeholders: (vested interests and potential collaborators who should be at the table):

*Private companies:* Tech companies, both large corporations such as Google, Apple, Microsoft, Android, and venture capital start-ups with specific innovations;

*Patients* who can advise on needs;

*Health care providers and health care institutions* who will purchase and use the software.



#### Examples of existing initiatives:

MAHMEE <https://www.npr.org/sections/health-shots/2019/08/18/749454254/this-app-aims-to-save-new-moms-lives>.

In California, a recent partnership between [Wildflower Health](#), [Care1st Health Plan](#) and the [California Health Care Foundation](#) (CHCF) will use Wildflower's mobile health platform to help Medi-Cal families receive better information about pregnancy and birth. [See <https://stateofreform.com/featured/2018/11/collaboration-brings-maternal-health-education-to-new-mobile-health-apps/>.]

Existing innovations have great potential for adaptation/expansion to fill the chasm. Recovery Solutions (HRS), for example, offers a turnkey telehealth platform that reduces hospital readmissions and improve outcomes for high-risk chronically ill patients. The company provides tablets loaded with software that allows real-time communication via text, video, or voice chat, integration with wireless Bluetooth devices (stethoscopes, pulse oximeters, blood pressure monitors, thermometers, and scales) for remote monitoring of vitals, plus educational videos and guidance on diet and medications for 30 diseases. Adaptation to gestational complications would increase the company's range and market, and offer continuity of care following gestational diabetes or gestational hypertension.

The George Institute for Global Health, with offices in Australia, England, India and China, has developed the SMARThealth (Systematic Medical Appraisal and Referral and Treatment) system and is adapting it for use in the extended postpartum period. Rural community health workers in India are being trained to identify women who had GDM or HTN during pregnancy, and help them manage their care postpartum to avoid future heart disease, stroke and diabetes. The app is a prototype that could be adapted for use throughout the world, including in the U.S. in urban and rural areas where CHWs and doulas are the frontline "high touch" trusted members of the health care team. [See <https://www.georgeinstitute.org.uk/projects/smarthealth-pregnancy-improving-womens-life-long-health-in-rural-india>.]

#### Opportunities and Supporting Factors:

As new mobile technologies with great relevance to "Bridging the Chasm" emerge, they represent potential platforms for added features. Chief among them is MAHMEE, designed to keep women connected to their providers, each other, and to critical health information in the extended postpartum period. MAHMEE could be an ideal platform for continued monitoring and follow up after GDM and hypertension beyond the first postpartum year.

#### Challenges and Barriers:

At the same time as these positive results are emerging, the Pew Foundation reports that the digital divide persists in the U.S., reminding us that web-based programs and smartphone apps will not be able to fill maternal health gaps for everyone. Despite great advances, in households with income lower than \$30,000, 30% do not own a smartphone, 44% lack a computer, and 46% lack broadband access. [See <https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/>].



## Title: Eliminate Disrespect, Racism and All Implicit Bias within Health Care

### Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

- Change patient/provider relationships and embed social justice training into professional education—this is everyone's work, not the work solely of minorities or advocates;
- Craft and share stories and use cultural exchanges and immersion experiences and data metrics to reframe discussions so they resonate;
- Develop leadership and mentorship in this area to leverage the power to share perspectives; and
- Promote disruption: Create a toxic environment for bigots through leadership/mentorship, reframing through data and storytelling, and continuous quality improvement for accountability.

### Problem statement

Mothers, daughters, sisters, and friends of color share stories of being dismissed, disrespected, and given sub-quality or improper care by providers. Such experiences occur across the spectrum of health care—from routine encounters to tragic life events, such as infant or maternal death or 'near misses'—and have increasingly been brought to light in the popular media. In addition, researchers frequently point to differential treatment and implicit bias as one of the pathways that underlie the significant race-based inequities seen in maternal health outcomes.

Black women are more than three times as likely to die in pregnancy as White/Hispanic women, and have a 55% higher rate of death from endometrial cancer (Eichelberger, et al., 2016). Although prevalence of intra-partum complications is not different between Black and White women, case fatality rates for preeclampsia, eclampsia, abruptio placentae, placenta previa, and postpartum hemorrhage are significantly higher among Black women (Tucker, et al., 2007). Further, Black women and other women of color are less likely than their White counterparts to receive recommended follow-up care after pregnancy complications, such as GDM (Shah, et al., 2011; McCloskey, et al., 2014); and lack of follow-up of pregnancy complications in the immediate postpartum period and beyond increases the substantial risk for GDM-linked diabetes (Bernstein, et al., 2017; McCloskey, et al., 2018) and gestational hypertension-linked hypertension (Behrens, et al., 2017) in the decade following delivery.

Preterm birth and low birth weight are associated with mothers' reports of racial discrimination- findings that point to the impact of chronic stress on birth outcomes (Mustillo, et al., 2004; Collins, et al., 2007; Dominguez, et al., 2008). In the U.S., infants born to Black mothers are twice as likely to die in the first year of life as those born to White mothers (10.97 vs. 4.67 (Murphy, et al., 2018). Black women have lower quality cancer screening and poorer follow-up of abnormal results, and are 20% less likely to receive chemotherapy when needed, which explains in part their significantly lower cervical cancer survival rate compared to White women? (58% vs. 69%). Eichelberger states the underlying problem: "Race is a social construct and the overwhelming statistics we present are attributable to a broken racist system, not a broken group of women" (2016). Structural racism is a significant cause of illness that operates through features of the social environment that influence individual behavior, disease, and health status (Garcia & Sharif, 2015).

The Joint Commission Report on implicit bias in health care finds that there is extensive evidence that unconscious biases can lead to differential treatment of patients by race, gender, weight, age, language, income and insurance status, resulting in overuse and underuse problems that have an impact on patient safety (2016). In a survey of 2700 women, one out of six reported experiencing bias and mistreatment during pregnancy, with rates higher for women of color (27.2% vs. 18.7% for white women with low SES (Vedam, 2019). Bias was characterized as: physical or verbal abuse, loss of autonomy, discrimination, failure to meet professional standards of care, poor rapport with providers, and poor conditions within the health system. McLemore et al (2018) interviewed 54 women of color who were at high risk for preterm birth about their health care experiences. Participants described disrespect during healthcare encounters, including experiences of racism and discrimination; stressful interactions with all levels of staff; unmet information needs; and inconsistent social support. Atenasio & Hardeman (2019) suggest that the likelihood of mistreatment is greatest when women of color are 'uncooperative', ie exert autonomy by declining procedures.

Initiatives suggested by Vedem et al. include: “diversifying the health care workforce, mandating anti-racism and implicit bias training for everyone who interacts with childbearing families, increasing access to doulas and midwives, and raising public awareness of their human rights.” Several measurement tools now available for measuring ‘respectful maternity care’ in global settings (Sheferaw et al., 2016; Taavoni et al., 2018; Bohren et al., 2018) can be adapted and used as benchmarks for progress in efforts to eliminate implicit bias and explicit discrimination, and domains of respectful breastfeeding care have been defined for the US as a basis for developing a breastfeeding-specific tool (Ateva, 2019). The National Birth Equity Coalition (NBEC), the Alliance for Innovation on Maternal Health (AIM) and the California Maternal Quality Care Collaborative have formed a coalition (Mothers Voices Driving Birth Equity) to develop a PREM (Patient-reported Experience Measure) that is specifically focused on improving quality of and accountability for the birth experiences of Black women.

When women are not met with supportive and socially-informed care, when institutions work to avoid liability rather than make profound changes to prioritize women’s health, women are left traumatized – or worse – by a health system meant to care for them. Embedded discrimination – racism, sexism, classism, and other forms of oppression within today’s medical system – makes quality care a privilege and not a right for many women forcing many to seek alternative treatment options or not receive care at all (Press, et al., 2008). Women deserve to feel safe and fully supported in their transition after birth – for themselves and their future health, not just for the health of their babies. They deserve to be met with providers deeply concerned with their voices and stories. They deserve institutions that make concerted efforts to reimagine and transform care to meet the needs and experiences of patients.

Disparities and inequities are not inevitable. The medical and public health literature of the last decade has amply described outcomes associated with disrespect, implicit bias and racism; the time is now ripe to engage people who have experienced such care in the creating and testing effective educational, policy and program interventions. It is time to hold institutions accountable.

**[Note: Review of Literature: See Summary of the Evidence, Chapter 4.]**

## Recommended Strategies

### ***Strategy #1: Require competency-based training for accreditation to eliminate disrespect, institutional and interpersonal bias***

Description
<p>Require for accreditation that all medical, nursing and other clinical training programs incorporate competency-based training and assessment aimed at the elimination of disrespect and institutional and interpersonal bias within clinical practice through regulatory bodies such as Accreditation Council for Graduate Medical Education (ACGME), Accreditation Commission for Education in Nursing (ACEN), the Commission on Collegiate Nursing Education (CCNE) and others. This educational curriculum must meet high quality standards. Specifically:</p> <ol style="list-style-type: none"> <li>Engage patients in design and implementation of the curriculum;</li> <li>Avoid the one-off workshop by being longitudinally embedded in health care training and delivery;</li> <li>Address directly the historic/structural roots of racism in clinical practice; and</li> <li>Incorporate innovative methods and best practices that strengthen empathy, knowledge and understanding (drawing from narrative medicine, theater, film and visual arts)</li> </ol>

#### ***Rationale:***

It is imperative to recast interpersonal racism in health care as malpractice, and expose and disrupt institutional racism. Further, it is imperative to eliminate all forms of bias in the care of transgender and non-binary pregnant and parenting people.

### ***Review of criteria for strategy selection:***

#### Innovation: High

AMA GME cultural competency modules merely scratch the surface of unconscious bias and do not delve more deeply into the centrality of racism in health care. This new strategy for transformative education, in contrast, addresses both institutional and interpersonal racism. The call for patient engagement in curriculum development enhances the likelihood that education will result in positive changes in the patient-provider relationship.

#### Effectiveness: Medium to High

In the U.S. there have been attempts to do this—in some periods of time better than others, with mixed success (see literature summary table). Effectiveness would depend on a concerted, national effort involving the major stakeholders—most importantly women of color and advocacy organizations-- with broad dissemination and longitudinal format, accompanied by evaluation and tracking of specific outcomes.

#### Promotes equity: High

Although there is potential for backlash from requiring this curriculum, it is likely to provoke examination of self and institutional behaviors and structures. Increased consciousness may improve provider-patient relations and contribute to institutional change. Without the requirement ‘with teeth’ it is unlikely such training will occur in the places it is most needed.

#### Feasibility: Medium

The concept is promising but requires other entities (professional accrediting organizations) to fundamentally change their practices without receiving substantial financial supports.

### ***Components to consider:***

#### Stakeholders (vested interests and potential collaborators who should be at the table):

For example, supporters of the Kamala Harris bill to promote implicit bias training (and more) include ACNM, ACOG, SMFM, AMCHP, BMMA, Black Women Birthing Justice, Black Women’s Health Imperative, Center for Reproductive Rights, Children’s Hospital of Philadelphia, Commonsense Childbirth - National Perinatal Task Force, EMC, In Our Own Voice: National Black Women’s Reproductive Justice Agenda, March of Dimes, National Association to Advance Black Birth, National Birth Equity Collaborative, National Black Midwives Alliance, National Health Law Program, NPWF, National Partnership for Women & Families, National WIC Association, National Women’s Law Center, Planned Parenthood Federation of America, WomenHeart, and 1,000 Days.

*Progressive legislators*: e.g., authors of bills in progress that include expansion of the definition of the postpartum period and efforts to expand access to continuing health care and resources.

*Advocacy organizations*: e.g., Reproductive Justice organizations, including NBEC, SisterSong, BMMA, EMC; organizations representing women’s health over life course, such as Diabetes Sisters, Pre-eclampsia Foundation; organizations representing transgender and non-binary pregnant and parenting people, such as Family Equality Council and National Center for Transgender Equality;

*Public Agencies*: e.g., CMS, State Title V agencies working on Diversity, Equity and Inclusion issues;

*Professional Organizations*: e.g., ACOG, PCC, ACP, American Medical Association (AMA), APHA, AMCHP, AHA, MQCC, American Bar Association (ABA) (malpractice issues); health care worker unions, such as 1199, media organizations

willing to volunteer time to develop training materials and philanthropic foundations willing to fund media development or distribution of materials;

*Insurers* (private and Medicaid) and regional health care providers (e.g., Kaiser).

Examples of existing initiatives that may align with each strategy:

ACGME already has a roundtable around this topic. ACOG has engaged with the California Maternal Health Quality Improvement Project, the National Birth Equity Coalition, First Place Lab and others.

The Maternal Care Act, sponsored by Kamala Harris, is pending (<https://www.harris.senate.gov/news/press-releases/harris-reintroduces-legislation-addressing-black-maternal-mortality-crisis>), as is an effort in California to mandate implicit bias training

(<https://www.beckershospitalreview.com/hospital-physician-relationships/california-to-mandate-implicit-bias-training-as-part-of-continuing-medical-education.html>).

Opportunities and known supportive factors:

- Accreditation bodies are already starting to consider such a strategy.
- Media attention to the overrepresentation of Black women in maternal mortality has raised public awareness of gaps in access, gaps in care, acts of bias and racism in health care, and the difficulty women have in getting their voices heard by providers and health care delivery institutions.
- If it is done well, it appeals to both head and heart and balances both.
- For institutions, training using a standardized curriculum with demonstrated progress in culture change may enhance job satisfaction and count toward community benefit requirements, and it could address poor scores on patient satisfaction that weigh heavily with hospitals (e.g. the Press-Ganey instrument with question about disrespect currently under development).
- For professional training programs, an effective curriculum may reduce eventual burnout, protect against malpractice suits, increase efficiency and improve health outcomes through respectful patient/provider communication and decision sharing.

Challenges and barriers:

- The impact of competency modules is unclear. DEI (diversity, equity and inclusion) training abounds, but is rarely robust—we need a public outcry to make it so. Getting institutions to change their ‘academic’ behaviors feels like climbing a mountain.
- The culture of medicine with its de-emphasis of communication and focus on test scores and procedure performance does not lend itself easily to this type of learning. Resistance to change within ACGME, ACEN, etc. is a barrier, and also getting training programs and institutional settings to make room in their established curricula and new hire modules. The focus of much current training is on individual responses, obscuring structural racism. A culture shift is necessary to allow difficult conversations to be de-emotionalized.
- Widespread ignorance among health care workers and administrators of the historic and present effects of racism in health care, and limited will to do something effective about it.
- Over time, the curriculum will need positive and negative reinforcement, harnessing existing policy levers and new ones under development.

***Strategy #2: Develop a quality measure to capture patient experience of implicit bias/racism within maternity and postpartum care.***



Description
<p>Develop a patient reported quality measure (PREM) that captures patient experience of implicit bias/racism within maternity and postpartum care.</p> <p>Use this PREM as an evaluation tool for an institution to measure its progress toward health equity and accreditation (JCAHO).</p> <p>This strategy grows from and applies work by a coalition of the National Birth Equity Coalition (NBEC), the Alliance for Innovation on Maternal Health (AIM), the California Maternal Quality Care Collaborative, and ACOG. It applies existing Birthplace Lab tools for measuring respectful maternity care (<a href="https://www.birthplacelab.org/tools/">https://www.birthplacelab.org/tools/</a>), as recognized by the National Quality Forum. [CROSS-CUTTING WITH POLICY WG].</p>

### ***Rationale:***

We need to capture and know with certainty how patients and their families perceive and experience their care particularly in regards to any implicit bias, racism, disrespect or discrimination, and its perceived impact on their health. For BtC we are concerned with the experiences during maternity care and in the extended postpartum period.

### ***Review of criteria for strategy selection:***

Innovation: Medium to high

The innovation lies in the specificity of the measure that are being/can be developed through extensive conversations with women of color, and the possibility of capturing women's own narratives about their experiences in health care institutions and with providers in 'real time'.

Effectiveness: High

Hospitals pay serious attention to patient satisfaction surveys, and respond to all measures considered by JCAHO. Serial testing points can be used for continuous quality improvement.

Promotes equity: High

This strategy challenges complacency and requires a cultural change to hold both individuals and institutions accountable through monitoring women's self-reported experiences of racism, disrespect, disregard, and discriminatory treatment that persists within health care.

Feasibility: Medium to High

This strategy builds on work already in progress, with established objectives defined by CMQCC:

- 1) Develop a community informed theoretical model in collaboration with Black birthing people based on learning from focus group interviews;
- 2) Map existing theoretical constructs in the literature onto the constructs identified from Black mothers and through the ongoing work of advocacy organizations to inform the co-creation and co-testing of a PREM of respect, mistreatment, and discrimination;

On the other hand, measure development is especially tricky and demanding when the object of measurement is perception attached to actions. The process can be costly, and requires as yet undetermined financial support. Frameworks are available, but not well operationalized in the specific context of health care.

### ***Components to consider:***

Stakeholders (vested interests and potential collaborators who should be at the table):

*Advocacy organizations for reproductive justice*, e.g. advocates willing to expand definitions and outcomes to include a focus on women in the postpartum year (e.g. SisterSong);

*Advocacy organizations representing women who experience interpersonal and structural racism* (e.g. BWHI, BMMA, MfM, and others);

*Advocacy organizations working specifically to bridge the chasm* (e.g. Diabetes Sisters and the Pre-eclampsia Foundation; media experts willing to volunteer time to develop training materials and philanthropic foundations willing to fund media development or distribution of materials);

*Professional organizations:* (e.g., ACOG, PCP, ACP, AMA, APHA, AHA, MQCC, ABA and other professional organizations, health care workers' unions);

*Insurers* (private and Medicaid) and *regional health care delivery organizations* (e.g. Kaiser);

*Licensing and accreditation bodies:* ACGME, ACEN, ACME, JAHCO;

*Quality measurement/improvement organizations:* (e.g., Maternal Quality Care Collaboratives and the National Birth Equity Collaborative; the National Quality Forum and the NCQA; State Title 5 Agencies working on DEI (diversity, equity and inclusion) curricula; the American Hospital Association).

Examples of existing initiatives that may align with each strategy:

The organizations mentioned above have begun the work to develop a measure that covers pregnancy and delivery; a measure that applies to women's efforts to bridge the chasm can be developed either as an extension of existing efforts or a complementary process. The Council on Patient Safety in Women's Health Care, Alliance for Innovation on Maternal Health Care (AIM) has released a health equity bundle.

Opportunities and known supportive factors:

- Evaluations of respectful maternity care have been conducted in low-resource settings, but very little has been done until recently to investigate whether disrespect is an important component of documented disparities in health outcomes in the U.S. The study of inequity and mistreatment during pregnancy and childbirth in the U.S. (Vadem et al., 2019) focuses on maternity care, and presents a typology of mistreatment that can form the basis of its extension into the postpartum year as women navigate the chasm between pregnancy and their future health.
- Collaborative work between the NBEC, AIM, the CMCQC, funded by ACOG, has laid out the vision and the tasks: "Co-creation and testing of best practices that lead to improved listening, shared decision making and trust between Black mothers, clinicians, and health systems."
- Congressional attention has turned to the quality of maternity care. The Quality Care for Moms and Babies Act (QCMBA) (H.R. 1551; Rep. Engel (D-NY16) Rep. Stivers (R-OH15), Sen Stabenow (D-MI) <https://www.congress.gov/bill/116th-congress/house-bill/1551/text> directs the Department of Health and Human Services to work with stakeholders to create a core set of maternity care quality measures for childbearing women and newborns, and the AHRQ to develop a Consumer Assessment of Health Care Providers and Systems.

Challenges and barriers:

Endorsed performance measures can be used to track and quantify health care processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality care, but they require a rigorous process of development and testing that is lengthy and complex.

### **STRATEGY #3: Fund evaluation of anti-racism training**

Description
Fund evaluation of education programs to establish impacts on clinicians' behaviors over time and tie the results to accreditation of training programs.

#### **Rationale:**

A strong evaluation process is an essential companion for anti-racism curriculum development and deployment. Proof of effectiveness is the first necessary step toward inclusion in standards for accreditation.

#### **Review of criteria for strategy selection:**

##### Innovation: High

Training programs in health care institutions are currently fragmented and rarely evaluated except for participant satisfaction, even though effectiveness of a general one-shot program without follow-up or measurable outcomes is known to be very low. Funding for evaluation of behavioral change outcomes with measurement of institutional change over time is essential for changing the culture of health care delivery.

##### Effectiveness: High

Funding for evaluation would highlight best practices and greatly enhance the likelihood of sustained implementation.

##### Promotes equity: Medium

Funding for evaluation does not guarantee that change will occur as a result of training.

##### Feasibility: Low

Health care organizations would have to devote considerable time and effort to monitor and report outcomes, and might encounter pushback from staff in making this a priority activity. Buy-in from the major accreditation organizations is essential to reinforce the training process but is unlikely to happen soon enough to have the necessary impact.

#### **Components to consider:**

##### Stakeholders (vested interests and potential collaborators who should be at the table):

Stakeholders for this strategy would include all of those mentioned in strategy #2, but with a bigger role for professional organizations and accrediting authorities.

##### Examples of existing initiatives:

Ongoing advocacy and legislative and agency work under strategy #2 (development of metrics) lays the basis for obtaining funding for evaluation of the impact of training programs that address implicit bias, racism, disrespect or discrimination, and perceived impacts on patient health.

##### Opportunities and known supportive factors:

The media campaign to highlight the problem of Black maternal mortality and a decade of efforts to expose social determinants of health have laid a foundation for new efforts to address inequities. The health care conditions that result from structural racism are expensive across all of society, not just to the patients who experience them, so there is a basis for uniting unlikely groups of advocates (concerned with effects on lives) with large organizations such as insurers that seek to protect profits.

##### Challenges and barriers:

Competing priorities tend to result in one-off, limited attempts to address small parts of problems (stopgaps), because the effort to change the culture of health care that is required here is much more monumental.

## **Strategy #4: Increase the number of Black clinicians providing care across the chasm**

Description
Fund a national workforce development center to increase the proportion of Black physicians, nurses, certified nurse-midwives, advance practice nurses in the fields of Ob-Gyn, Family Practice and Primary Care.

### ***Rationale:***

This is an effective mechanism to increase the pool of Black clinicians in these fields.

### ***Review of criteria for strategy selection:***

#### Innovation: High

There is a need for a central body to consolidate findings from innovative experiments and identify best practices.

#### Effectiveness: High

This strategy would take advantage of considerable ferment and action in the field—high demand for new workforce roles and high attention to addressing disparities in maternal mortality and morbidity and the increased burden of chronic conditions across the life cycle.

#### Promotes equity: High

Putting funding and technical and educational expertise behind this priority would make it much more likely to succeed in addressing inequity.

#### Feasibility: Medium

This strategy would require rethinking traditional approaches to workforce development—always difficult but certainly possible.

### **Components to consider:**

#### Stakeholders (vested interests and potential collaborators who should be at the table):

Entities that should be front and center include:

*Black Professional organizations* (e.g., The National Medical Association, the Association of Black Women Physicians, the National Black Nurses Association, the Association of Black Cardiologists, and the Society of Black Academic Surgeons (SBAS)).

*Advocacy and professional organizations* listed for other strategies in this bundle.

*Health workforce development organizations and agencies* (federal and state level).

#### Examples of existing initiatives that may align with each strategy:

Partner with medical schools and college and high school enrichment programs, HBCUs, HRSA, NACCHO's Workforce Development Center, etc. Successful approaches should build on the lessons of the ACGME 3000 by 2000 Initiative.

#### Opportunities and known supportive factors:

Shortages in primary care providers and nursing have been exposed and demand solutions. There is an extensive literature to support the importance of concordance (race, ethnicity, culture and experience) as a factor in access to health care providers and satisfaction with encounters. As increased awareness about the crisis of Black maternal health has risen, Congress has begun to act.

#### Challenges and barriers:

The primary challenge would be competing priorities for funding. Collaboration among different professional and new model workforce groupings would be essential but is sometimes difficult to achieve, since some traditional 'territories' of authority might shrink and others might expand. The Center would have to embrace the health care team concept wholeheartedly.



## Title: Preserve the Narrative: Using Health Data to Bridge the Chasm

### Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

Manage women's health data to empower women with access to their own information, create continuity across the life cycle (linking maternal to infant health records, reproductive health to preventive health care) and educate non-OB providers about the importance of pregnancy complications and challenges for future health.

- Access: Give women an easy way to carry health information/data from doctor to doctor and empower them through written capture of their own history and plan and effective discharge planning.
- Continuity: Enter the prenatal problem list into the primary care problem list and birth history as a required item (hard stop) in electronic medical records, advocate for a universal electronic health record, and create enforceable standards and meaningful use rules for data management.
- Education: Emphasize continuity of care across specialties (relevance of obstetric history to future health) in medical school and resident training, and include the impact of prenatal experiences on future health risks in guidelines from key health care associations (AHA, ADA, ACOG, and the U.S. Preventive Services Task Force).

### Problem statement

Improving the flow of information over time and communication between providers and patients and within and across health data systems raises complex challenges: time constraints in medical encounters, the absence of appreciation for the patient's story, and complicated technical difficulties with transmitting information medical specialties and between electronic health records formats. On the technical side, there are not reliable electronic 'highways' that connect health records across specialties, time and illness episodes. Providers are not trained to listen and patients are not supported to speak up about their experience, perceptions and preferences. As we discuss above, distrust by women of color of health care providers and systems erodes honest and open exchanges during medical encounters.

In the past decade, electronic medical records (EMRs) have improved capture of medical detail (Reed et al, 2013; Byron, 2013; Haskew et al, 2015) but at the cost of additional burdens for providers and reduced time for meaningful patient-provider communication (Haskew, 2015). In addition, detailed electronic record formats can contribute to medical error through incomplete information capture. Alert fatigue is a significant problem (Anker et al., 2017; Bachman et al, 2017; Johnson et al., 2017). Moreover, EHRs present a significant barrier to transfer of information from one specialty to another (e.g. back and forth between obstetrics and primary care), and from one health care system to another, when women seek care from different health care institutions.

Epic, the most widely used EMR system in the U.S., is based upon a problem-list format for organizing information, which is a strength for information cataloging, but has inherent risks for interpreting, synthesizing and helping patients. As Dr. Robert Wachter points out, the risk of the Epic format is that providers may forget that 'patients are more than the sum of their problems'. And in that, he laments, is the danger of losing the all-important clinical synthesis. Dr. Suzanne Koven, primary care physician and writer in residence at Massachusetts General Hospital, summarizes the issue at stake: "Epic is not well-suited to communicating a patients' complex experience or a physicians' interpretation of that experience as it evolves over time, which is to say: Epic is not built to tell a story." (Koven S. *As hospitals go digital, human stories get left behind*. STAT. April 18, 2019) [www.statnews.com/2016/04/06/electronic-medical-records-patients](http://www.statnews.com/2016/04/06/electronic-medical-records-patients).

The "Preserve the Narrative" WG assessed ways to capture the patient narrative of key events and experiences in pregnancy and childbirth as a matter of record, contributing to and complementing the clinician's synthesis and leading to higher quality and continuity of care.

**Review of Literature: See Summary of the Evidence, Chapter 4.**

## Recommended Strategies

### *Strategy #1: Medical Record Reforms*

Description
<ol style="list-style-type: none"> <li>Develop an electronic record postpartum discharge template with coded fields (i.e., not free text), including specifics about patient risks, key information to be communicated to the PCP, and when and how to prepare for next pregnancy. The discharge template would be populated in the EMR and could be given to the patients.</li> <li>Develop methods to store key information related to a patient's pregnancy and childbirth, any complications, and important follow-up needs and information. This may include development of a hard copy "Mothers' Health Book", a smartphone app or a data card with a QR code that would be readable by all health providers.</li> <li>Create structure and support for women to write or narrate significant experiences during pregnancy and childbirth, focused on what they see as most important to their health and well-being going forward.</li> </ol>

**Rationale:** Currently, the "problem list" in the discharge record is not saved in the EMR that advances to the mother's next providers. For example, a record of key pregnancy events, including medical complications as well as personal circumstances that are likely to impact health going forward, are lost to future primary care providers and even future maternity care providers. Storing and making accessible to mothers and future providers, key pregnancy and childbirth-related information in the EMR, is critical to the goal of bridging the chasm and preventing morbidity and mortality in the year after childbirth and preventing chronic illness over the life course. Mothers playing a role in documenting their own experience can have an enormous impact on creating mutual respect and trust in the provider-patient relationship and empowering people to care well for themselves.

Innovation: Medium to High

Although using the EMR to communicate patient information is not in and of itself innovative, recommending a uniform discharge template that would have embedded coded fields and be searchable or transferred to a problem list for use by other specialties IS innovative. Offering women opportunities to narrate or write the events, experiences of pregnancy and childbirth they feel to be most important, is highly innovative (and challenging). The existing initiative, "OurNotes" is the only known somewhat related current initiative.

Women are motivated to maintain records of their pregnancies and outcomes and it may be that a low technology solution of producing a simple pregnancy diary, either in paper or electronic format like a QR code, may be the best way for women to monitor their own health and have a way to communicate important information to providers after birth, between pregnancies, and going forward- until EMR interoperability becomes a reliable reality.

Effectiveness: High

Given the ubiquitous use of EMRs, a strategy that focuses on 'flagging' complications of pregnancy for 'watch' would be effective; however the WG feels there is sufficient 'alert' fatigue among providers that it could lead to less rather than more attention (Ancker et al., 2017; Backman, Bayliss, Moore, & Litchfield, 2017; Johnson, Hagadorn, & Sink, 2017). The effectiveness of patient-held records has not been well studied in high resource countries, and there is little or no information about whether these records are/would be carried, especially in light of the trend toward more QR codes being transferred to a mobile device or embedded on a chip care.

Promotes Equity: High to Low (It depends how implemented)

Improving information in the EMR would impact all women; therefore, promotion of equity would be high. If a system of a mother-held health card were to be promoted as a universal system, it also would promote equity; however, if it were at increased cost to the patient it could contribute to further to inequities.



Incorporating women's self-narrated or written stories in the EMR could promote equity since its intent is to promote listening to women's voices. On the flip side, however, it could place too much burden on women at a time that is already overwhelming and in a context that may not feel safe. If the stories are to be told to providers in person, with women initiating the conversation, those who have experienced personal and systemic racism or disrespect will be less likely to be willing to share, especially if they have no choice of providers in the system and they already feel vulnerable. Women may worry that telling their story would jeopardize their care. The strategy would have to be entirely voluntary and ideally, would be implemented in context of a future provider after the pregnancy / childbirth experience.

Feasibility: Medium to High

The strategy for either a recommended postpartum template or patient held maternal record is promising, but requires the collaboration of interdisciplinary groups, such as ACOG, Association of Women's Health, Obstetric & Neonatal Nurses (AWHONN), ACNM, AFP, and ACP. The first three groups of maternal health providers have a track record of developing and promulgating guidelines and safety bundles together (Bernstein et al., 2017; D'Alton et al., 2016; Lagrew et al., 2018; AWHONN, 2012), yet there is no track record of similar collaborations between obstetric and primary care providers. If the 'Mother's Health Book' were to be digital on a smartphone app or a data card with a QR code, readable by all health providers, questions of privacy and ownership would have to be carefully resolved.

Feasibility is a greater concern for mothers' adding notes or telling her story in her own medical record, but as one member put it, "It doesn't mean we shouldn't try." Supporting women to add their story would require a trusted person or other resources, and there may be a great deal of reluctance, distrust, and feelings of overwhelm. There are many questions about this approach currently but that method of communication (writing or recording into the EMR) may be one that is less daunting to women if they are able to take their time in privacy.

## ***Strategy #2: Birth Stories in Community Settings and Social Media Platforms***

Description
Support storytelling venues for mothers to create and share stories of pregnancy and childbirth, focused on what matters most to their health and well-being (Cross-cutting with PROMOTE COMMUNITY INVESTMENT WG)

**Rationale:** As described, medical records and public health research identify variables that influence maternal health outcomes. Neither captures the lived experience and full stories of pregnancy and childbirth, nor their profound impacts on women's health going forward, both physically and mentally. The experiences inside and outside the walls of health care, the experiences that are uplifting and inspirational, and those that are traumatic and damaging for years to come are all valuable to tell and to hear. . The stories can promote self-care and healing for individuals, empower women to talk to providers about their stories, and mobilize advocates to seek policy changes in institutions and legislatures.

Innovation: Medium to High

This is a highly innovative strategy if implemented in a community-driven context or intentional social media context, with aims to empower mothers and activate for policy or other types of changes in communities. It is likely the strategy would rely on private funding and be based in community organizations.

Effectiveness: Medium

Uncertainty around the effectiveness of this strategy stems from the broad nature of this approach. Without details how this would be done e.g. broad public education versus within particular communities or community-based projects, the panel found it hard to estimate the effectiveness.

Promotes Equity: Medium to High

Community-based or social media-based storytelling venues can strengthen equity through collective ownership and action. The WG raised the question and concern for ownership and privacy: Once told and shared, who owns the stories? How can women be assured the stories would not be used or exploited without their knowledge or permission.

Feasibility: Low to Medium

Again, the strategy would require community organization support and investment from funders. It is a programmatic strategy that is feasible, once envisioned, funded, and taken on by a community organization or coalition.

### **Strategy #3: Health Professional Education**

Description
<p>Develop an inter-professional collaboration committed to supporting and developing continuing medical education about the importance of women's pregnancy and childbirth stories and how childbirth and postpartum experiences affect their health. Products of this could be:</p> <ol style="list-style-type: none"> <li>a joint statement from organizations (e.g. ACOG, AWHONN, ACNM) similar to those on safety bundles;</li> <li>CME- developed activity online or in print and encouraged to be part of certification renewal for ACOG, ACNM, family practice physicians and internists</li> </ol>

**Rationale:** Currently non-obstetric providers may not know the importance of pregnancy events on women's health, e.g. GDM increasing the risk of Type 2 diabetes and heart disease. Additionally, many providers are not aware of risk factors for or the actual experience women have with childbirth trauma.

Innovation: Medium to High

This strategy will be most innovative if medical education initiatives on this topic include outcome-based evaluation that demonstrates auditable change in clinical practice

Effectiveness: Medium to High

There was general support for the effectiveness of this approach. Even if it were solely a joint statement made previously among obstetric providers, the publicity that such a statement could garner may be important for spreading awareness among women and providers.

Promotes Equity: Medium to High

This strategy has the potential to promote health equity, particularly if women's narratives related to childbirth and postpartum as well as life events and circumstances related to social determinates of health. The fact that CME is nearly universally required for continuing certification and credentialing means this strategy has the potential to reach a wide range of providers if they can all be brought to the table.

Feasibility: Medium to High

This model has already been tested with the promulgation of safety bundles, for example, but not with CME specifically. The strategy requires resources to bring the needed certification groups together to develop a plan and potentially develop materials which could be shared by all in their individual certification processes.

#### **For all three strategies:**

Stakeholders:

*Professional Organizations:* American Academy of Family Practice (AAFP), AAP, ACNM, ACOG, ACOOG, ACP, AWHONN, SMFM, SGIM, and licensing boards all the major professional groups.

*Electronic medical record vendors* (e.g. Epic, Cerner)

*Advocacy organizations:* BBMA, EMC, NBEC, and Open Notes advocates

*Government entities:* e.g., Office of the National Coordinator for Health IT (ONC) which promotes national health information technology (HIT) infrastructure and oversee its development.

Examples of existing initiatives that may align with these strategies:

"Open Notes" is a movement to spread the availability of open medical visit notes and study the effects of sharing notes (Mafi, 2017). The movement is based on the premise that ready access to one's own medical records (including notes) is empowering for patients, families and caregivers to feel more in control of health care decisions and improve quality

and safety in health care. Relevant to “Preserving the Narrative” is a recent (2015) offshoot of “Open Notes” called “Our Notes”, funded by the Commonwealth Fund of New York. The “OurNotes Initiative” promotes active patient engagement in health and illness by inviting patients to contribute to their own electronic health records (see: <https://www.opennotes.org/news/the-next-step-for-opennotes-is-ournotes/>).

Women’s narratives: ACOG Listening sessions; <https://blog.everymothercounts.org/telling-your-birth-story-matters-77118094fc8e>;

Transfer of information from obstetrics to other specialties: Bridges program in New York City for perinatal risk assessment at discharge

Storytelling: [http://www.oprah.com/omagazine/storytelling-organizations\\_1](http://www.oprah.com/omagazine/storytelling-organizations_1)

#### Challenges and Barriers:

The biggest challenge for all three strategies is making the issue of preserving the narrative enough of a priority to devote some time and resources toward it.



## Title: Promote Investment in Communities

### Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

- Invest in patient advocacy work: Establish peer support mechanisms, mentoring, and online resources for advocating for change, recruit broadly, and train women to share their stories.
- Enhance cross-sector collaborations—reach out to funders, payers, insurance providers, faith-based organizations as a driver for community solutions, local health care centers and hospitals, and the business community.
- Think about all dimensions of health (access to healthy foods, childcare, exercise etc.) and sustainable goals for lifestyle prevention.
- Target community benefit provisions to ensure that institutions divert funds to communities.

### Problem statement

Community-based organizations (CBOs) are best situated to support women across the gap between their pregnancies and their ongoing health. Such organizations are close (geographically and/or experientially) to women and their everyday lives, and they most often create models of care and caregiving with the full participation of those they seek to support. However, community-based organizations, particularly those of small or moderate size, are at an enormous disadvantage in competing for limited financial resources. Both public and private funding streams are limited, often come with strings attached, require data or evidence that are out of reach, are geared toward larger, well-established organizations, and fail to cover costs of infrastructure building. Up against such odds, it is extremely challenging for CBOs to thrive and grow into the future. As a result, the vibrancy and connectivity offered by community-placed and community-run organizations- in this case, those run by, for and with women- can be lost.

While collaborative partnerships among small organizations offer some promise, it also generally means not getting enough dollars to actually do the work that has been promised (“getting the crumbs, not a chunk of the pie”). If community organizations partner with large institutions, the approach that is often taken consists of throwing money at the problem, causing confusion and infighting over distribution of resources, and ultimate- out of necessity- grass roots groups may find themselves adapting in ways that change who they are in the effort to achieve sustainability. Further a low resource situation can degenerate into taking advantage of the altruism of community staff, who are expected to volunteer overtime and accept low salaries because of their commitment to address a significant problem. The result: high turnover and staff burnout.

The vicious cycle continues. Grass roots organizations often operate in crisis mode and simply cannot spare the staff or do not have the experience to find the right funding proposals and meet their requirements. These sustainability problems are compounded by absence of financing for infrastructure building. Competition is fierce for existing funding streams that support community-based initiatives (e.g. state block grant funds, small foundation grants, or corporate philanthropies), and awards are usually small and insufficient to meet goals of selected projects. In addition, funding may be distributed unfairly (i.e. based on the overall prevalence of a problem rather than community-specific needs). All of these conditions imperil the survival of the very organizations that have the best chance to address inequities and improve women’s health across the life cycle.

#### [Note: See Review of Literature: Summary of the Evidence (Chapter 4)]

Our scan of the peer-review and gray literature did not find results that would meaningfully inform the recommendations of the “Invest in Communities WG”. Thus, we conducted web-based scans to help us describe the current ‘state of the state’ of corporate philanthropic and foundation funding priorities as they are related to our two main questions: 1) To what extent do they invest in small community-based organizations, and 2) to what extent do they invest in women’s health and well – being or in initiatives that align with the BtC mission? We did not scan public funding sources. [See Chapter 4 for details of the search strategy and findings.]

1. **Grant-making and corporate philanthropy from pharmaceuticals, and fortune 500 companies to grassroots organization.**

We reviewed funding priorities of an extensive list of Fortune 500 companies, most generous pharmaceuticals companies, insurance companies and biotech organizations. Many of these organizations or companies stated that they offered community investment and support grants; however, their criteria for corporate philanthropy focused on STEM initiatives, employee matching services and grants, and disease specific topics. Organizations that related to grants related to community investments were more likely to fund larger organizations than small grassroots ones. Additionally, companies that invest in women's health and well-being only support non-governmental organizations that work abroad or outside the United States.

Two pharmaceuticals stand out as potential funders of women's health initiatives related to the BtC mission: *AstraZeneca* corporation grants and *Merck*, through its *Merck for Mothers* program and its Diabetes program. In both instances, the topical areas are relevant, though current awards go to much larger organizations or academic/clinical institutions. Small grassroots organizations would be best positioned to partner with other larger and more robust organizations, which highlights the core dilemma: the absence of sizeable funding sources that would allow their community-rooted efforts to grow and be sustained.

## 2. Grant-making from national, state, regional and city level healthcare foundations.

We selected key health foundations at the local, regional and state levels as examples to assess the extent to which their funding priorities and awards might support small community based organizations (CBOs) and/or support initiatives that align with the BtC mission. Overall, large national foundations focus on broad themes related to access to health, the healthcare system and insurance (e.g. Commonwealth Foundation, Kaiser Family Foundation) or health equity, social determinants, and healthy communities (e.g. Robert Wood Johnson Foundation, W.K. Kellogg Foundation). Women's health and well-being per se are not areas of focus, though could be (and are) funded under the broader themes. Small grassroots organizations are best positioned to receive funds from national foundations as members of multi-sectoral collaborations under "healthy communities" grants in their geographic area. Likewise, regional and local foundations are focused on specific communities, and in some cases do make award small CBOs, but with small amounts of money (e.g. "All things Chelsea" grants of the Community Health Foundation for Southeast Michigan- \$5000 to \$25,000). We identified one local foundation, the Boston Foundation, which specifically awards general operating support grants (from \$25,000 to \$150,000) to small CBOs. They do so through their "Open Door" grant program, which seeks to fund innovative ideas to solve community challenges. Such operating support grants are rare.

## Recommended Strategies

The WG made two overarching strategy recommendations—the first focused on funders and the second on the organizations themselves.

### Strategy #1: Incentivize private and public funders

Description
Incentivize private and public funders to allocate 2 percent of annual expenditures for capacity building and infrastructure development when they award grants that include partnerships with small community-based organizations. ["Small" defined as annual budget < \$1 million]

### Strategy #2: Create a Center for Growth and Sustainability of Small Community-based Organizations.

Description
The Center will serve as a hub of technical assistance to grassroots organizations whose mission is focused on women's health and well-being over the life course. Areas of technical assistance deemed necessary to allow small CBOs to thrive include: <ol style="list-style-type: none"> <li>Leadership and management development</li> <li>Governance and board development</li> <li>501c3 process consultation</li> </ol>

- d. Financial management and operations
- e. Donor relations, fundraising, grant writing
- f. Program development, budgeting, and monitoring and evaluation
- g. Communications, including use of film and social media to increase visibility and better positioned for funding
- h. Assuring community engagement
- i. Advocacy strategies for policy change related to organization's mission
- j. Strategic partnering with cross-sectoral CBOs to create sustained partnerships for innovative grant making in women's health
- k. Identifying local legal and business resources for pro bono services as needed
- l. Gaining paid seats at the table of local public and private agencies that are engaged in planning that affects the social determinants of women's health.

### **Rationale:**

The WG members gathered their wealth of experience directing or consulting to CBOs and our shared knowledge of the current funding environment, and laid out two broad strategies that, they believed, could lead to a fundamental shift in how grassroots organizations can sustain themselves. They did not consider radically different business models, as this ambitious agenda would have required far more expertise and time.

Each of the two strategies are aspirational yet pragmatic. The first strategy requires finding policy levers that could incentivize funders to devote a portion (2%) of their community-placed awards to go toward the infrastructure/operating budgets of local grassroots organizations. State legislatures or city/county/town councils could mandate such allocations, though we know of no such policies. More likely is the uptake of such a policy/practice within funding organizations, such as hospital community benefit programs, corporate philanthropy or health foundations. The second strategy requires a funder with a vision. Beyond that, it is a straightforward strategy—the establishment of a Technical Assistance Center for CBOs, in this case specifically focused on women's well-being over the life course. If funded, it would go a long way toward enabling community leaders of women's health organizations to be building bridges for and with women across the chasm.

Innovative: Medium. There are other centers that provide support to non-profits, but none that we know that are focused on women's health organizations and none that have the broad scope described in Strategy #2.

Effective: Medium. If implemented the TA center and incentives would go a long way to allow small CBOs to enjoy the kind of stability they need to thrive, yet many of the same fundamental challenges will remain for small organizations.

Promotes Equity: High. The strategies would put small grassroots organizations on a more level playing field and grant them the opportunity to be 'real' players in local planning and decision making and access to funds.

Feasible: Medium. Strategy #1 requires moral leadership and vision on the part of funders (and/or legislators), though regulating the incentives is more challenging.

### **Stakeholders:**

*Private:* Leaders of corporate philanthropy, hospital community benefit organizations, healthcare foundations, city and state legislators, esp. women's caucuses, community development corporations, National CBO Network (and other such associations), Association of Maternal and Child Health Programs.

*Public:* HRSA/Bureau of Maternal and Child Health (MCHB), Healthy Start Initiative (also at local level), Title V (also at state level).



## Title: Public Education Campaigns that Heighten Awareness of Root Causes

### Tasks set by attendees at the Bridge the Chasm Conference (July, 2018):

- Create a national public education campaign to highlight how and why complicated pregnancies may lead to long-term health implications, emphasizing disparities in maternal morbidity/ mortality and the root causes.
- Start by informing young women.
- Start with the women themselves in co-creating changes in policy and systems innovations, and involve their communities.
- Connect patient stories and case studies with data to propel action, guarding against appropriation of stories without compensation or respect, and find the best cultural messengers.
- Re-evaluate existing health messages critically for hierarchical approach, one size does not fit all, and internalized sexism.

### Problem statement

For too long, pregnancy has been the sole focus of public health campaigns concerning women's health. Pregnancy is compartmentalized, isolated from the developmental cycle of women's health, and often treated as a disease or defined by its potential for health risks and concern for the babies' health. Health messages primarily focus on the importance of women taking care of themselves in order to have a healthy baby, but after delivery, where are the messages that help women validate their experiences and make their own health a priority, so their needs and goals don't get lost in the process of conceiving, birthing and nurturing families? Underlying many health messages directed at Black, Brown, AAPI and Native women, particularly related to their bodies and reproductive lives, reinforce old stereotypes and stigmas rooted in the histories of enslavement and other oppressions. The consequences are sweeping; young women of color may not understand their own bodies, sexual health, and the physical and emotional dimensions of pregnancy and its impact on their own health.

The lack of holistic, woman-centric messages in the public sphere calls for a public health education and awareness campaign that elevates the health and dignity of women, especially women of color, validates their experiences, and calls on society, communities, and individuals to value the health of women even after children are born. It is time to take down the top-down messages that stigmatize and blame women, especially pregnant women, instill fear, and fail to honor women because of and beyond their role as mothers. Let's send mothers the message, "You matter, your health matters, even after the baby is born!" Pervasive messages about immunizing our children and attending well-child visits can be matched by equally powerful messages that call us all to invest in the health of mothers after birth and across the years when chronic illness becomes a risk.

### Review of Literature: See Summary of the Evidence, Chapter 4.

We conducted a review of peer-reviewed literature that evaluates public health education campaigns, covering a broad array of public health issues relevant to women, children, families, and youth: drunk driving, tobacco and drug use, child physical abuse, nutrition, and breast cancer. We then gathered reports and commentaries (gray literature) on key public health education campaigns, including teen contraceptive use and pregnancy, black women's health, the impact of social media, and drug use, and reviewed for key 'lessons learned'.

We found that most campaigns have not been evaluated in a format that would show actual causal effects on the desired outcomes. From descriptions, the characteristics that appear to be associated with success include: the engagement of community members and partnerships in the design of the campaign, avoiding shame/blame, messages focused on empowerment rather than risk and fear, and wide dissemination in multiple venues. [Please see a summary of the review in Chapter 4.]

## Recommended Strategies

The WG advanced the conversation that had taken place at the Conference, highlighting the deeply embedded narratives that pervade public education about women's health and must be replaced. To support the goals of "Bridging the Chasm", the fundamental public narrative must first shift. We must first elevate and celebrate the inherent dignity and value of women, before and beyond their role as reproducers and caretakers, and second, highlight how the experience of pregnancy and childbirth can launch a lifetime of health care and self-care. These messages can be tricky and warrant the thoughtful expertise of women in communities as well as professionals in mass communications. They have different implications for women of color and white women and for women in different cultural and social communities. They also have different implications and must take on different forms depending on the specific goals, as reflected in the other six WG's of "Bridging the Chasm". If the intent is to eliminate disrespect and racism in health care, for example, the messages must be specifically geared to the health care workforce and institutions. If the intent is to change Medicaid policies, a sharpened message about the importance of granting health insurance for mothers (as we do children) beyond the first weeks and months after pregnancy, must be crafted for public policy-makers as well as the general public. And if the intent, on the other hand, is to call out the importance of specific health-related actions women can take to care for themselves, these messages must be carefully, creatively, designed with the expertise of women themselves (from different communities) and of mass communications professionals.

There are examples we can build on. ACOG's "Every Mom, Every Time" campaign has come with a simple slogan and a button for clinicians to wear that has promise as one small step toward change. See <https://sales.acog.org/Every-Mom-Every-Time-Pin-P936.aspx>. This effort addresses women's needs in the extended postpartum period, and it has possibilities for creating a culture shift toward listening to women's voices.

In recognition of the fact that public education campaigns that heighten awareness of root causes must be developed within the context of each other WG, this WG did not develop specific recommendations. Rather, they put forward the call for such campaigns to accompany the work of those who carry forward the agenda of each WG. These are principles that can animate the public education campaigns that become part of advancing the BtC Agenda:

- Women's stories and experience at the center of design, at the table from the start
- The health and well-being of women as non-pregnant persons, as focal point
- Women of color celebrated not stigmatized
- Blame/shame and sexism eliminated
- Institutional responsibility to end disrespect and racism present in messages
- Policies highlighted in education campaigns (not just behavior change)
- Patient and community power, not risk, at center



In summary, the work of developing public education outreach begins now as the Bridging the Chasm network/community reaches out to disseminate what we have learned, and engage others to put strategies into practice.



## Chapter 4: Review of Literature

### Summary of Evidence

We began our literature search with an investigation of the state of health care delivery for women of reproductive age, the root causes of inequity in health care, and research on clinical conditions that put women at high risk for chronic illness in later life and the likelihood of receiving preventive care for those conditions. Those topics were a necessary foundation for the work of creating a national agenda to bridge the chasm between pregnancy and women's health over the life course, but we decided to report elsewhere on these findings, in order to keep the focus on the specifics of bridge building.

In the following pages we have assembled both peer reviewed (observational and randomized, controlled trials) and gray literature (magazine articles, blogs and websites describing local efforts to close the gap), arranged here by Working group topic and by type of source within topic. Criteria for selection included currency (last 10 years) except for classic articles, and potential for application to conditions in the U.S. TOPIC

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## ADVOCATE FOR POLICY CHANGES TO TRANSFORM HEALTH CARE DELIVERY

### SUMMARY OF EVIDENCE

**Background and Significance:** See WG: Advocate for Policy Changes to Transform Healthcare Delivery, problem statement (p. 27)

Domains of Action	Publication Type	Findings	Conclusion
<p><i>Medicaid policies</i></p> <p>1. Work requirements</p> <p>2. Eligibility &amp; coverage</p> <p>3. Impact of ACA Medicaid expansion: Who is covered and who is not</p> <p>4. Impact of increased enrollment</p>	<p>1. Commentary and 1 state (ARK) evaluation (Huberfield, 2019, Ku and Brantley, 2019, Somers et al. 2019)</p> <p>2. 2011–2015 American Community Survey of 3,137,989 low-educated adults aged 19–64 years (Wehby &amp; Lyu, 2017)</p> <p>3. National data analyses by state policy of the impacts of the Affordable Care Act's Medicaid Expansion on women of reproductive age (Johnston et al., 2019; Cole et al., 2018; Nat. Partnership for Women and Families Fact Sheet, 2018; Garfield et al., 2019)</p> <p>4. Kaiser Family Foundation Policy Brief Fact Sheet, 2019; Palanker et al, 2016; Spillman &amp; Evans, (2017)</p>	<p>1. Medicaid work requirements in the nine states could cause 600,000 to 800,000 adults to lose coverage. Results from first year in Arkansas show 18000 adults have been terminated from Medicaid due to non-compliance, and no increase in the number employed.</p> <p>2. ACA Medicaid expansions decreased un-insurance among low-income women of reproductive age by 13.2 percentage points. Effects were stronger for younger women and white women. About 6.7 million working women (aged 18-64) -- about 1 in 10 across the United States have health insurance through Medicaid.</p> <p>3. More than 2.3 million working women ages 18–64 (2013-2015) gained Medicaid coverage- 54% growth nationally. Medicaid expansion was associated with an 11.44-percentage-point decline in the share of CHC patients who were uninsured. In 2017, 19.9% of Latina women are still uninsured, 13.7% of Black women, 8.9% of Asian women, and 8.0% of White women. 2.5 million uninsured adults fall into the coverage gap that results from state decisions not to expand Medicaid. They earn too much to qualify for Medicaid, but not enough to be eligible for the ACA marketplace premium tax credits. Most people in the coverage gap live in the South. State decisions not to expand their programs disproportionately affected people of color, particularly Black Americans.</p> <p>4. Women on Medicaid are less likely than uninsured women to report that they delayed or went without care due to cost</p>	<p>1. Work requirements negatively impact the health of Medicaid-eligible women.</p> <p>2. ACA Medicaid expansions increased coverage in 2015 across the entire population of low-educated adults and have reduced age disparities in coverage. There is still a need for interventions that target eligible young and Hispanic adults.</p> <p>3. Medicaid expansion effects were variable across states, but largely successful in opening some doors to access to health care for women of reproductive age. Racial/ethnic disparities in insurance coverage persist, and the gaps are greatest in the South, where many states did not opt for expansion.</p> <p>4. Although access to care is a big arena and insurance is only one component; Medicaid expansions have been successful in increasing the potential for access. Effects on utilization are yet</p>

on care utilization		(compared to low-income women on private insurance). Of the six exclusions that limit access, maintenance rx, fetal reduction, genetic testing, preventive services not covered by law, and treatment of self-inflicted conditions apply to BtC issues. Medicaid Health Home reduced ED visits with no increase in federal costs for complex patients.	to be determined, and early analyses of effects on outcomes are mixed (Brown et al., 2019).
<i>Other policy impacts</i>	<p>1. Analysis of over 2 million women enrolled in employer based plans (2008-2015) to assess impact of eliminating out-of-pocket costs on women's use of preventive care visits and LARC's, accounting for baseline costs (Dalton, Carlos et al, 2018)</p> <p>2. Study of impact of New Jersey state policies to identify and treat PPD among Medicaid-covered women (Kozhimannil et al, 2011).</p> <p>3. PP home visiting (Handler et al., 2019)</p> <p>4. Trans-generational clinic approaches (Curry et al., 2004)</p>	<p>1. The association between eliminating out-of-pocket costs and use of preventive services differs according to baseline costs. Women whose out-of-pocket costs were low or moderate to begin with, were more likely to use a preventive service when those costs were eliminated. However, women whose baseline costs were high had lower utilization rates even after their out-of-pocket costs were eliminated. All effects were relatively small (e.g. OR 1.05). The impact of <u>no</u> out-of-pocket costs on likelihood of a LARC placement was stronger and consistent.</p> <p>2. The legislation had no measureable effect on initiation of treatment after childbirth or f/u care among those with continuous coverage.</p> <p>3. Data suggest that universal postpartum nurse home visiting has appeal as a postpartum women's health strategy. The data also suggest that the success of such a strategy likely depends on: the value women, families, and community stakeholders attach to the program; the appeal of its universality and the support for home visiting by nurses in particular; the processes adopted by the hospitals and agencies implementing the program; strategies for engaging women after leaving the hospital; and, the initial and ongoing</p>	<p>1. The impact of reducing out of pocket expense on use of preventive services appears to be less effective for women with high baseline costs vs. women with lower baseline costs.</p> <p>2. Overall, less than 7% of women initiated mental health care in the 6 months following delivery. Among those who did, most received medication and outpatient services.</p> <p>3. " Universal early postpartum home visiting is not a substitute for a woman's visit with a medical provider; however, it should be viewed not only as an early childhood program but an important strategy for improving the delivery of postpartum care for women."</p>

		<p>marketing of the program, which ultimately may affect women's willingness to participate.</p> <p>4. A pediatric clinic smoking cessation intervention has long-term effects in a socioeconomically disadvantaged sample of women smokers</p>	<p>4. Results encourage implementation of evidence-based clinical guidelines and reimbursement for addressing women's needs for smoking cessation in pediatric practice.</p>
<i>Legislation</i>	<p>1. Federal Legislation to Improve Maternal Health: Summary and Status (AMCHP, June 3, 2019)</p> <p>MOMMIES (Booker)</p> <p>MOMMA's (Kelly, Durbin)</p> <p>QCMBA (Engel, Stivers)</p> <p>CARE (Harris, Adams)</p> <p>MOMS (Gillebrand)</p> <p>Helping MOMS Act (Kelly)</p> <p>Maternal Health Quality Improvement Act (MHQIA) (Engel, Eliot)</p> <p>2. The Lower Health Care Cost Act of 2019 (Title IV), Bipartisan Discussion Draft, May 23, 2019)</p>	<p>1. Six bills re: maternal health introduced in 116<sup>th</sup> Congress. Key measures across bills include:</p> <ul style="list-style-type: none"> <li>* Medicaid and CHIPS extended to one year PP (MOMMA's, MOMMIES, Helping MOMS Act);</li> <li>* Directs AHRQ to develop and use Consumer Assessment of HC Providers and Systems Maternity Survey (QCMBA);</li> <li>* USDHHS directed to work with relevant providers, specialties, consumer to identify core set of maternity care quality measures (QCMBA);</li> <li>* Authorizes funding for implicit bias training in medical education (MOMMA's, CARE, MHQIA);</li> <li>* Authorizes Pregnancy Medical Homes or other Integrated Care Programs (CARE);</li> <li>* Requires guidance and reports to increase access to doula services (MOMMIES);</li> <li>* Increases Medicaid payment to Medicare PC rates (MOMMIES);</li> <li>* Authorizes funding for AIM and (MOMS)</li> <li>* Authorizes grants to support rural obstetric collaborative networks and demonstration projects to improve training of obstetric providers in rural areas.</li> </ul> <p>2. Aims to deliver better health care outcomes and better health care experiences at lower costs. Reported out of Committees for Senate and House consideration on June 26, 2019.</p> <p>Title IV: Improving Public Health includes 4 sections relevant to BtC:</p> <p><i>Sec 405:</i> Modernizes PH data system. Enhances interoperability of PH data systems with health information technology.</p> <p><i>Section 406.</i> Innovation for maternal health. Directs HHS to establish grant program to improve maternal health care</p>	<p>1. Several of these bills' provisions were included in the "Lowering Health Costs Act", which increases their likelihood of passage (see below) in current Congress.</p>



	<p>3. State measures: NJ bundle example</p>	<p>quality and eliminate preventable maternal morbidity and mortality..  <i>Section 407</i> Training for health care providers. Establishes HHS grant program for training of HC professionals to prevent discrimination, implicit bias.  <i>Section 408</i> Study on training to reduce and prevent discrimination. Requires HHS to contract with research organization to make recommendations for best practices associated with training for health care professionals to prevent discrimination (pnc., labor, birthing, PP care)  <i>Section 410.</i> Integrated services for pregnant and PP women. Authorizes HHS to award grants to states for innovative, evidence-informed programs for integrated services to pregnant and PP women (Pregnancy Medical Homes)- <i>new language added after comment period that extends timeframe to 1 year PP.</i></p> <p>This bundle includes: coverage of doula care under Medicaid (A1662); requirement for patient safety bundles for hospital licensing (A4930); requiring facilities to set standards and collect data using California model (A4930); expansion of episode of care bundle to include the PP period &amp; beyond (A4932); survey (A3933); Medicaid coverage to 1 yr pp (A3934); ban on c-section by choice (A4935); fund development of a decision making tool for clinical care (A4936); mental health funding (A4937); develop interconception care resources (A4939); develop standardized perinatal care curriculum for CHWs (A4940); public health campaign (A4941); adopt standards for respectful care similar to NYC (A219).</p>	
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	<p>Fund (Jabbapour, De Marchis et al, 2017).</p> <p><i>Primary Care Shortage and Failing System:</i></p> <p>4. Commentaries (Haq et al, 2019; Cook &amp; March, 2018; Bodenheimer and Pham 2010).</p> <p>5. Position Paper of the American College of Physicians, 2018</p> <p>6. Brousseau &amp; Matteson, 2016; BRFSS 2011 data.</p>	<p>3. Systematic review of 45 peer-reviewed papers and government reports and evaluations of PCMHs shows <i>decrease in overall cost, with a more positive trend for more mature PCMHs and for those patients with more complex medical conditions. Data on utilization overall positive but mixed</i>—studies show increase in PCP use but inconsistent on whether this leads to change in specialty services or ER use. <b>Effects on quality are mixed but, excluding one outlier, were either positively correlated with PCMH or showed no difference in quality measures</b> from control. All the studies that examined the <b>patient experience showed positive outcomes</b>. Differences in utilization and quality relate largely to differences in study design and measures.</p> <p>4. US health policies are inadequate to recruit, train, distribute, and retain an adequate primary care workforce to address the needs of the population. Primary care business model set up to fail with huge panel sizes and growing complexity of chronic care and documentation needs. Need macro and micro level ‘fixes.’  <i>Macro:</i> attract more medical students into primary care by narrowing the primary care–specialty income gap; improve primary care physicians’ work lives; and third, reallocate Medicare graduate medical education funds toward primary care training. NP training programs could also be expanded.  <i>Micro:</i> Keep panel sizes the same and create primary care teams in which tasks not requiring high-level medical skills would be delegated to other team members.</p> <p>5. American College of Physicians’ position paper asserts that internists are well-suited to provide high quality women’s health care and require appropriate training on issues specific to women, including team-based care for complex issues. ACP notes that risk factors related to chronic disease (such as diabetes, high cholesterol, and cardiovascular disease) are becoming more prevalent in women of reproductive age, that women in this age group also have unique mental health</p>	<p>patient experience. Also promising for quality and decreased utilization, though less consistent. Since most positive findings relate to cost savings and patient experience for those with complex medical conditions and in mature PCMHs , application to women after complicated pregnancies is promising (latter conclusion ours’).</p> <p>4. Need focused policy agenda to situate primary care physicians as cornerstone of equitable care - will increase access, improve outcomes, and decrease healthcare spending.</p> <p>5. ACP’s position paper is a solid foundation for recommending further training for internists in women’s care after complicated pregnancies, although this is not specifically addressed in the paper.</p>
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	<p>7. Commentary. (Ogur et al, 2019; Schottenfeld, et al., 2016).</p> <p>8. Patient Centered Primary Care Collaborative, 2019: Analysis of primary care spending by states</p> <p>9. Cost of transformation among Primary Care Practices (Martself et al., 2013 )</p> <p>10. Medicaid Health Home for chronic conditions (CMS CMS Findings Fact Sheet, 2019)</p>	<p>needs, such as postpartum or peri-menopausal depression, and that women are at particular risk for under- or episodic insurance coverage.</p> <p>6. Women with a prior pregnancy are not more likely to be engaged with the healthcare system for preventive care than women who have not been pregnant</p> <p>7. Fixing primary care requires working together to create a system in which physicians can effectively lead interdisciplinary teams in providing high-value and equitable health care to the populations they serve. This means training a cohort of young physicians who see themselves as change agents and who embrace and advance the mission of primary care. This requires solving systems that overburden primary care providers.</p> <p>8. Findings: Lack of agreement about how to measure primary care investment; Between 2011-2016, spending on primary care was low; it varied considerably state to state; Primary care spending was associated with fewer emergency department visits but not with patient satisfaction; Regulatory efforts in ten states showed increased momentum.</p> <p>9. One time transformation median cost: \$30,991 per practice (range, \$7694 to \$117,810). Median ongoing yearly costs of \$147,573 per practice (range, \$83,829 to \$346,603). Care management activities accounted for over 60% of practices’ transformation-associated costs.</p> <p>10. Claims-based rates did not take into account beneficiary’s factors such as mental illness and lack of stable housing that may be associated with higher need than is reflected in medical claims, leading to inadequate reimbursements. Positive outcomes include reduced hospitalizations and emergency department use and Medicaid spending.</p>	<p>6. Lack of transition to primary care after pregnancy is a lost opportunity.</p> <p>7. Recommendations: 1) Support PCP with multidisciplinary teams to deal with the multitude of contextual factors that create poor health and complicate care 2) Train PCP differently so they see complex patients as deeply in need of their care and thus more rewarding to work with, and see systems obstacles as opportunities to innovate.</p> <p>8. Primary care spending at the state and national level can heighten visibility of how payers value primary care over time</p> <p>9. Costs of turning a practice into a medical home can vary widely, so financial obstacles can be dependent on individual practices and be burdensome for small or independent practices. Tailored subsidies or transformation plans could be helpful.</p> <p>10. Health outcomes are related to the risk profile of patient population (if patients are mostly high risk, can have more incidence of negative health outcomes comparatively). Challenges to implementation: lower enrollment at start, staff turnover, patient engagement, meeting data-reporting requirements.</p>
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<p>ACO's</p>	<p>1.Hacker &amp; Walker, 2013: Commentary</p> <p>2.Dolin, 2013: Commentary</p>	<p>1.Need to address challenges of overlap between panel composition and community health indicators in order to assess results</p> <p>2. All new models of care (including ACO's and medical homes) are looking for the most cost-effective and efficient way to manage the health of large populations</p>	<p>1.Recommendation: Collaboration-- link ACO's with public health system to improve patient health</p> <p>2.Recommendations: Engagement strategies to close gaps: multi-modal communication, customized contact, web-based interactive programs, financial incentives</p>
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## DEVELOP HIGH TOUCH MODELS OF CARE

### SUMMARY OF EVIDENCE

**Background and Significance:** See WG: Develop High Touch Models of Care problem statement (p.47)

Strategies	Evidence based:	Evaluated but not tested:	Conclusion
<i>Community Health Workers</i>	<ol style="list-style-type: none"> <li>1. CHW interventions increase screening rates, (Englstat, et al., 2005; Gibbons, et al., 2007; Wells, et al., 2011).</li> <li>2. CHW interventions increase transition to primary care after hospitalization (Kangovi, et al., 2014)</li> <li>3. CHWs improve outcomes related to diabetes and (Kennedy et al., 2018) hypertension self-management (Liebman, et al., 2008; Norris, 2006; Kim, et al., 2016; Brownstein, et al., 2007; Shah et al, 2013; <a href="#">Viswanathan, et al., 2009</a>; Allen, et al., 2011).</li> <li>4. CHWs are cost effective, i.e. deliver positive return on investment (Mason, et al., 2011; Kim, et al., 2016; Johnson, et al., 2011; Allen, et al., 2014; Dennison, et al., 2014).</li> </ol>	<ol style="list-style-type: none"> <li>1. An evaluation of 31 CHW training packages showed a gap in integrated, comprehensive approaches and no topics that cover future risks associated with pregnancy complications or indications for follow-up post-pregnancy (Tran, et al., 2014).</li> <li>2. The WIN network offers a comprehensive model of Community CHW support, navigation, education for women and families in Detroit <a href="https://www.winnetworkdetroit.org/">https://www.winnetworkdetroit.org/</a>.</li> </ol>	<p>1-3. There is ample indirect evidence to support the effectiveness of interventions by CHWs as a component of high touch efforts to bridge the chasm.</p> <p>4. Cost-effectiveness has been demonstrated for cardiac care in community health centers.</p>
<i>Peer support interventions</i>	<ol style="list-style-type: none"> <li>1. Peer support interventions help to reduce depressive symptoms (Gjerdingen, et al., 2013; Pfieffer, et al., 2011).</li> <li>2. Mothers account positive impact of peer support on emotional wellbeing (McLeish &amp; Redshaw, 2011), specifically for socially-marginalized women (McLeish &amp; Redshaw, 2011).</li> <li>3. Mixed reviews about the effectiveness of telephone-based peer-support interventions (Gjerdingen, et al., 2013; Dennis, et al., 2009).</li> </ol>		<p>Provided proper training and considerations for mothers' specific needs, peer-support interventions indicate benefits for mothers experiencing postpartum depressive symptoms.</p>
<i>Provider interventions</i>	<ol style="list-style-type: none"> <li>1. Clear disconnect in information provided amongst maternity care providers, PCPs, and patients (MacDonald, et al., 2007).</li> <li>2. Visiting nurse programs have been beneficial to mothers in the immediate PP period,</li> </ol>		<p>Provider models may prove more successful if consideration is taken for the barriers and specific needs that mothers have in the postpartum period.</p>



	<p>particularly amongst women at high risk for PPD (Shaw, et al., 2006), but have not focused on mother's well-being or connection to follow-up care (Olds, et al., 2000, 2004, 2007).</p> <ol style="list-style-type: none"> <li>3. Mothers are willing to contact providers and seek support in the immediate PP period (Corrigan, et al., 2015), but barriers exist that make accessing support difficult (Hadfield and Wittkowski, 2017; Hoedjes, et al. 2012).</li> <li>4. Assessments of birth should assess life challenges rather than childcare abilities alone (Corrigan, et al., 2015).</li> <li>5. Staff training, pt. education, advice and discharge call recommending PCP improve PP transition to PCP by 20-309% (Matthews, 2016; Ohuabuna, 2013).</li> <li>6. The Northern New England Perinatal Quality Collaborative creates protocols for transition to primary care and performs case reviews (Campbell, 2018).</li> <li>7. Postpartum transition clinic for women at risk for or diagnosed with HTN (Celi, et al., 2019).</li> <li>8. Midwifery model of care: Midwife-led continuity of care in childbirth is associated with improved birth outcomes for women and newborns as evidenced by lower preterm births, stillbirths, unnecessary labor interventions, and patient satisfaction (Sandall et al., 2016). In addition, midwifery led models of care at US birth centers were associated with a 32% increase in attendance at follow-up postpartum visits (85.5%) compared to the national average of 54% (Alliman, et al., 2019) and led to reductions in preterm birth (Sandall, et al., Cochrane review, 2016).</li> </ol>	<p>Although the federal government views midwives and obstetricians as primary care providers, the Institute of Medicine and the National Committee for Quality Assurance do not. Yet, in 2010, the IOM report on The Future of Nursing recommended that advanced practice nurses practice to their fullest education and training. However regulations in 18 states limit midwifery practice to pregnancy, birth, well-woman gynecology, and newborn care (Phillippi &amp; Barger, 2015).</p>	<p>Documentation systems need to be in place with review and feedback.</p> <p>Data suggest that universal postpartum nurse home visiting has appeal as a postpartum women's health strategy. The success of such a strategy likely depends on: the value women, families, and community stakeholders attach to the program; the appeal of its universality; the processes adopted by the hospitals and agencies implementing the program; strategies for engaging women after leaving the hospital; and, the initial and ongoing marketing of the program, which ultimately may affect women's willingness to participate.</p> <p>Transition to primary care for high risk women has promise for increasing access to targeted care and increasing patient self-monitoring; provider salary was sustainable through insurance reimbursement.</p> <p>The midwifery model of care, if expanded to allow primary care to follow delivery, may provide an important avenue for bridging the gap between delivery and care over the life cycle.</p>
<i>Navigator interventions*</i>	<ol style="list-style-type: none"> <li>1. Navigator activities improve screening rates (Christie, 2008) and time to treatment for cancer (Battaglia, et al., 2016; Freund, et al., 2014; Ali-Faisal, 2017).</li> </ol>	<p>A review of interventions across the spectrum of women's health care (McKenney, et al., 2018) found numerous health inequities in access to health services, the process of</p>	<p>The patient navigator model has been most thoroughly assessed in cancer settings, where they show improvements in outcomes with cost-savings. There is one promisingly positive observational</p>

	<p>2. Utilization of services was improved among low income minorities (Christie, 2008; Ko, et al., 2016) and across all race/ethnicity, language and insurance status (Battaglia, 2016).</p> <p>3. In one non-randomized study, a postpartum navigation program was associated with improved retention in routine postpartum care and frequency of contraception uptake, depression screening, and vaccination (Yee, et al., 2017).</p> <p>4. Post-colonoscopy navigation (Jandorf, et al., 2012) and navigation for geriatric cancer patients (Paskett, 2016) are associated with cost savings.</p>	<p>care, and health outcomes. Authors conclude that providing patient-centered support to address barriers to care (patient navigation) may be ideally suited to help ameliorate these inequities, and identified a need for research that goes beyond patient satisfaction to establish the effects of navigator services on outcomes.</p>	<p>study of navigation in the postpartum period (Yee, et al., 2017), with a RCT in progress.</p>
<i>Virtual interventions</i>	<p>1. Web-based programs are linked to decrease in PP weight gain retention (Nicklas et al., 2014).</p> <p>2. Online support groups are effective in providing emotional and informational support to women experiencing PPD or PP mood disorders (Evans, 2012; Danaher, 2013; Lee et al., 2015).</p> <p>3. Tech-based interventions improve maternal follow-up to postpartum visits (Himes, et al., 2017).</p> <p>4. Home blood pressure monitoring with automated data collection/reminder was more successful than usual care (Hirshberg, et al., 2018) and removed racial disparities (Hirshberg et al., 2019).</p> <p>5. Text messages reduce preterm births (Siwicki, 2019).</p>	<p>Medicaid reimbursement for telehealth is possible but challenging (Fanberg &amp; Waltzman, 2018).</p>	<p>Tech-based interventions show promise of providing supportive spaces, reminders to follow-up, and accessible information for PP women.</p>
<i>Doula model</i>	<p>1. Doula support during pregnancy and delivery improves mother's overall satisfaction with the birth experience, c/s rate, labor duration, and other delivery-related outcomes (Bohren, et al., 2017; Fortier et al., 2015; Campbell et al., 2006), breastfeeding initiation (Narvaez, 2018), parenting practices and mother-child interaction (Hans, et al., 2013). Improvements in pregnancy and delivery outcomes appear to</p>	<p>1. A model for postpartum doula certification (DONA) is described but not specifically tested.  <a href="https://www.dona.org/become-a-doula/birth-doula-certification/">https://www.dona.org/become-a-doula/birth-doula-certification/</a></p> <p>2. PP doula scope of practice (<a href="http://www.cappa.net/postpartum-doula">http://www.cappa.net/postpartum-doula</a>)</p>	<p>Doula care has not been widely tested beyond the immediate postpartum period, but shows promise for BtC based on its proven effectiveness in the prenatal and intrapartum periods.</p>

	<p>be strongest for low income, high risk women (e.g. Medicaid enrollees).</p> <p>3. Continuous support appears to be a critical factor (Lunda, et al., 2018).</p> <p>4. The pathway for these improvements is the ability of doula care during pregnancy to mitigate the consequences of social determinants of health (Gentry, et al., 2010).</p> <p>5. Doula care has only been minimally tested beyond the immediate postpartum period, with positive results in addressing PPD (Gjerdingen, et al., 2013).</p> <p>6. Focus groups with community doulas suggest the need for expanded training, particularly in resources and services (Low, 2006).</p> <p>7. Doula services may be cost-effective in light of findings related to reduced preterm birth and caesarean (Kozhimannil, et al., 2016).</p>		
<i>Centering Model</i>	<p>1. 3 systematic reviews of CenteringPregnancy (Catling, et al., 2015; Carter, et al, 2017; Byerly &amp; Haas, 2017) suggest improvements in low birth weight and preterm birth, psychosocial health of mothers, and satisfaction. The birth outcomes are confirmed by Cunningham, et al., 2019). Group care results in higher maternal functioning (Heberlein, et al., 2016) increased f/u for women with diabetes (Schillinger, et al. 2017; Mazzoni, et al., 2015) and greater use of medication assisted treatment for opioid use disorder (Sutter, et al., 2019). Military women benefitted from a greater sense of community (Kennedy, et al., 2009, 2011), and weight gain trajectories were normalized (Magriples, et al., 2015).</p> <p>2. Group prenatal care resulted in equal or improved perinatal outcomes at no added cost. (Ickovics, et al., 2007) and was acceptable to staff (Kania, et al., 2017).</p> <p>3. In a retrospective cohort study, a centering model consisting of ten 2-hour sessions</p>		<p>Participation in group care may improve the rate of preterm birth and other associated complications, compared with traditional care, especially among black women; these differences resulted in major cost-savings.</p>

	<p>significantly reduced the rate of pre-term birth among low risk women matched for pre-pregnancy risk level. (Pickelshimer, et al., 2012). LBW and newborn ICU stay and costs were also reduced in a Medicaid population in S. Carolina (Gareau, et al., 2016).</p> <p>4. There are only a few feasibility studies of <i>CenteringParenting</i> ((Bloomfield &amp; Rising, 2013; Jones, 2014), and one small outcomes study reporting higher satisfaction compared to usual care, and increased clinic attendance and immunization rate, but no difference in lead screening (Gullett, et al., 2019).</p>		
<i>Collaborative care</i>	<p>1. Long history in obstetrics, family medicine and emergency medicine: (IOM, 2010; Avery, et al., 2010; Achkar, et al., 2018).</p> <p>2. Evidence of safety, quality, satisfaction (DeJoy, 2011).</p>		
<i>System-wide high touch interventions</i>		<p>Siwicki, 2018: The Parkland Center for Clinical Innovation Preterm Birth Prevention Program is a comprehensive program combining: risk prediction, provider notification, risk-driven, tailored patient education via digital technology, and workflow redesign to improve birth outcomes and reduce the rate of preterm birth. The Prediction Model leverages machine learning and data from claims, eligibility, EHR and community data (demographic, clinical and socioeconomic data) to predict the risk for preterm delivery.</p>	<p>Experiments are ongoing, but reports are limited to the process of implementation. Evidence of outcomes, if positive, will support policy changes to enable reimbursement and sustainability.</p>
<i>Co-location in familiar venues</i>	<p><u>Well-child visits</u>: New mothers report a desire to receive postpartum care, even if not in the traditional postpartum visit (Verbeist, et al., 2016; Henderson, et al., 2016), and a willingness to receive advice and referrals from their child's provider (Fagan, et al., 2009; Rosener, et al., 2016). There is growing</p>	<p>Cheng &amp; Kotelchuck (2016) describe the need to shift to a model of comprehensive investment in women's health before, during and after pregnancy.</p>	

	<p>evidence that the well-baby visit is a feasible, effective co-location for some maternal health services, namely contraceptive counseling (Kumaraswami, et al., 2018), and postpartum depression screening and referral (Olsen, et al., 2005, 2006; Freeman, et al., 2005; Liberto, 2012). Many states will reimburse pediatricians for maternal depression screening and referral (Smith, et al., 2018), but silo'ed specialties and reimbursement issues present real challenges</p> <p><u>Public agencies:</u> Screening for brief intervention was offered to mothers at HeadStart (Silverstein, et al., 2017, 2018).</p> <p><u>Community-based sites:</u></p> <p>Faith-based organizations and beauty salons and barbershops are the community sites most frequently reported in the public health literature as places and partners for health promotion activities (Linnan, et al., 2015; Campbell, et al., 2007; Dehaven, et al., 2004).</p>		
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## ELIMINATE DISRESPECT, RACISM AND ALL IMPLICIT BIAS IN HEALTH CARE

### SUMMARY OF EVIDENCE

**Background and Significance:** See WG: Eliminate Disrespect, Racism and All Implicit Bias in Health Care, problem statement (p. 60)

Discrimination/bias affect dx and tx	Evidence Based	Commentaries, Description	Conclusion
<p>1. <i>Pain</i></p> <p>2. <i>Cardiac disease</i></p> <p>3. <i>Stroke</i></p>	<p>Women of color were more likely to experience failure in their pain medication and were less likely to have their pain and anxiety taken seriously by doctors, and more likely to be pressured to accept epidural anaesthesia (Morris &amp; Shulman, 2014). African American, White and Hispanic patients experience similar levels of chronic pain with similar medical conditions (Edwards, 2005), but Hispanics and Blacks receive fewer pain prescriptions (Pletcher et al., 2008; Rust et al., 2004; Hampton et al., 2015; Drwecki et al., 2011). African Americans are more likely to report disability, lower quality of life, and discrimination (Ezenwa, 2012). Physician decisions are shaped by false beliefs about racial differences (Hoffman, 2016). Classic study of gender and race bias in physician decision making for cardiac conditions (Shulman et al, 1999). Women with GDM and preeclampsia have 26% and 31% (resp.) increased 10yr cardio disease risk but providers are less likely to discuss cardiovascular disease with women; African Americans are less likely to be referred for cardiac catheterization when presenting with chest pain, and are at higher risk of heart failure than whites, but are less likely to be aware of risk (American College of Cardiology, 2018)</p>	<p>Mothers Voices Driving Equity: Podcast (<a href="https://blog.ncqa.org/podcast/inside-health-care-episode-19-dr-joia-crear-perry-maternity-health-equity/">https://blog.ncqa.org/podcast/inside-health-care-episode-19-dr-joia-crear-perry-maternity-health-equity/</a>)</p>	<p>Race and gender bias in delivering services affects health outcomes.</p>



<p><i>4. Maternal morbidity/mortality</i></p>	<p>The likelihood of treatment for whites vs. blacks increases with pro-white bias (Green et al, 2007)</p> <p>Howell (2017), Chen, et al. (2019), and Saddiqi, et al. (2017) all document large disparities in maternal morbidity and mortality for women of color (Black, Brown, Native and AAPI), with the largest burden borne by Black women (4 times that of White women).</p>		
<p><i>Intervention strategies</i></p>	<p>1. Small changes in implicit bias among medical students achieved with structured curriculum van Ryn et al., 2015)</p> <p>2. Exposure to positive role models has a weak effect on reduction of bias (Joy-Gaba &amp; Nosek, 2010)</p> <p>3. Delivery and payment design reduce disparities in postpartum care (Howell, et al., 2017).</p> <p>4. Patient navigators reduce disparities in postpartum care (Yee, et al., 2017).</p>	<p><b>1. Respectful Medical Care</b>, conceptualized as</p> <ul style="list-style-type: none"> <li>- freedom from harm and mistreatment</li> <li>- right to privacy and confidentiality</li> <li>- preserving women's dignity</li> <li>- prospective information and informed consent</li> <li>- continuous access to family/community support</li> <li>- quality of physical environment and resources</li> <li>- providing equitable maternity care</li> <li>- engaging with effective communication</li> <li>- respecting women's choices that strengthen their capabilities to give birth</li> <li>- availability of competent, motivated resources</li> <li>- provision of efficient and effective care</li> <li>- continuity of care (Shakibazadeh, 2017)</li> </ul> <p><b>2. Medical education may be a valuable tool in reducing racial bias within institutions</b> (Drwecki, 2010); Four recommendations: 1) increase self-awareness, 2) create an inclusive learning environment, 3) create learning opportunities for positive interaction, and 4) develop empathetic skills to decrease implicit bias (Boscardin et al., 2015; ACOG committee opinion, 2015)</p> <p><b>3. Cannot tackle the black-white gap without political will;</b> must increase demand for comprehensive care; need leadership and creativity to build partnerships; have to change the public discourse (Lu, 2010);</p> <p><b>4. White Coats for Black Lives (AMA J Ethics, 2015): Use physician privilege for social change.</b></p>	<p>Educational strategies to reduce implicit bias have been designed and implemented, but there have been only a few rigorous trials, and these show weak effects.</p>

		<p>a) aggressively recruit, support, and promote Black, Latino, and Native American people in medicine to ensure physician workforce reflects U.S. diversity;</p> <p>b) hospitals and practices must take action to eliminate the significant impact of implicit racial biases on care of patients of color;</p> <p>c) physicians should join community members in advocating for single-payer health care system to eliminate cost-associated barriers to care;</p> <p>d) health care workers need to recognize that their responsibility to their patients is more than physical exams, prescriptions, surgical interventions; must also recognize socioeconomic and environmental factors, like structural racism, that directly affect health.</p> <p><b>5. Conversations about race must be navigated with critical dialogue, accepting responsibility, and rectifying errors (Tsai J et al., 2018). Steps include:</b></p> <ol style="list-style-type: none"> <li>1. Reinforce that race has limited genetic explanation while engaging learners and health professionals in addressing patient barriers to health</li> <li>2. Engage colleagues in conversations about bias</li> <li>3. Address your language (and the language of others)</li> <li>4. Develop teaching service policies around informed consent and pain management</li> <li>5. Strive for cultural humility, not competence</li> </ol>	
<i>Measurement tools</i>	<p>1. A postpartum survey tool to measure disrespect in maternity care has been validated in Ghana, Guinea, Myanmar and Nigeria (Bohren et al., 2018), a 15 item scale is available for Ethiopia (Sheferaw, 2018), and a 20 item scale for Iran (Taavoni, 2018).</p> <p>2. Ateva et al (2019) identifies factors associated with respect that affect breastfeeding rates:</p> <p>Freedom from harm &amp; ill-treatment; information &amp; informed consent; companionship; privacy; dignity and respect; equitable care; health status</p>		

## PRESERVE THE NARRATIVE -- USE HEALTH DATA TO BRIDGE THE CHASM

### SUMMARY OF EVIDENCE

**Background and Significance:** See WG: Preserve the Narrative, problem statement (p.68)

Strategies	Evidence based:	Commentaries:	Conclusion
<i>EHR based interventions</i>	<ol style="list-style-type: none"> <li>1. Patient survey indicates that ability to access records is an important component of patient satisfaction (BlackBook Research, 2018; Patel et al, 2018).</li> <li>2. Women's access to their records saves time for providers, adds value to their experience, and increases quality of health care outcomes (Simineirio et al, 2014; Wittie et al, 2015).</li> <li>3. Patients appreciate ability to add information to the EHR system through smartphone or web based applications (Forster et al, 2015; Chang et al, 2015).</li> </ol>	<ol style="list-style-type: none"> <li>1. UK trial raises questions about balancing security against utility (Pagliari 2007)</li> <li>2. Structured documentation (e.g. checkboxes can meaningful use requirements) compromise the essence of the patient's story ( McCartney, 2013; Koven, 2016).</li> <li>3. There is potential to integrate social barriers to care into EMR systems (CDC; AHA, 2018; Robezneiks, 2019)</li> <li>4. Cedars-Sinai has launched Mahmee, a fully integrated technical platform that connects over 1,000 providers (clinical and support services); initial results show 200% increase in breastfeeding and 60% reduction in neonatal jaundice admissions (Jaramillo, 2019).</li> </ol>	<p>Patient access to their EHR information increases satisfaction and quality of care, but may also limit patient-provider communication or information exchange "outside the box." The highly defined structure and discrete variables of EMR don't accommodate the range of human experience. Patients' ability to write in their EMR record needs to be explored as a possible solution.</p>
<i>Electronic Portal Use</i>	<ol style="list-style-type: none"> <li>1. Portal benefits are seen for providers, including administrative efficiencies, improved responsiveness to patient's needs, more effective care, decrease use of health services, and cost savings (Emont, 2011).</li> <li>2. Portal benefits are seen for patients, including quick and easy access to personal and general health care and better ability to recall appointments (Forster et al, 2015; Ukoha, et al., 2018), and users of Kaiser Permanent's oPAP were more likely to close gaps of care (particularly cancer screening tests) (Henry et al., 2016). Patients have positive attitudes towards the portal, but also have a lack of</li> </ol>	<ol style="list-style-type: none"> <li>1. Portal use is universal. It can be used by all ages (Clain, 2015) and practice size is not a driver (Clain, 2015; Friedman, 2015). Additionally, despite unique challenges occurring for rural and underserved patients, overall tools for engagement, including the ability to have direct contact between patients and providers, is effective in increasing engagement from patients in rural and underserved areas (HealthIT.gov, n.d.)</li> <li>2. For portals to be effective, teamwork between providers, portal venders, and patients is necessary (Gruessner, 2015).</li> </ol>	<p>Electronic portal use is beneficial to both providers and patients universally, especially when looking at preventative care. Effectiveness of these portals takes teamwork between providers, patients, and the vendors themselves, particularly in order to improve adoption of and engagement in electronic portals. Portals function best when patients can report, not just receive information.</p>

	<p>awareness and/or motivation to use the portal (Goel et al., 2011).</p> <p>3. Engagement and adoption can be affected by patient characteristics (Ukoha, et al., 2019), practice leadership focus, staff engagement, activation of features, marketing practices, and incentives (Wald, 2010). Kaiser Permanent's tool, oPAP appeared to be effective in increasing engagement with preventive healthcare (Henry et al., 2016).</p>	<p>3. Patients see the value in tracking health outcomes, and patient-reported outcomes improve shared decision-making and engagement (Lavelle et al, 2016).</p> <p>4. Kaiser Permanent's Online Personal Action Plan (oPAP tool) is encouraging in terms of development of patient-enabled health-management tools (Kaiser Permanente, 2016).</p>	
<i>Improve People to People Communication</i>	<p>Provider to Provider</p> <p>1. A Modified Bedside Handoff Tool eliminated unnecessary and time-consuming discussion for providers. However, further observation and reinforcement is needed to increase compliance further. (Wollenhaup et al, 2017)</p> <p>Patient to Provider</p> <p>1. Narrative medicine (NM) showed an increase in empathy scores of providers after participating, and that most providers have a positive attitude towards NM; however, there were gender differences. Women showed increase in empathy immediately and then plateau'ed, while men showed gradual increases in empathy over time (Chen et al. 2017)</p> <p>2. Patients feeling not listened to and inconsistencies in information given from providers were identified as two main themes among women's views in continuity of information during and after pregnancy. In order to improve on this, patients recognized and identified that providers' sharing information about the women would be beneficial, alongside being able to meet with professionals at the same time and midwives/health visitors having the same training (Olander et al., 2019)</p>	<p>Provider to Provider</p> <p>1. Systematic partnerships between OBGYNs and PCPs could assure transition of care that is necessary for disease detection, prevention, and long-term care; for example, it could meet the needs of a postpartum patient with GDM and reduce risk of developing Type 2 DM and related complications for others in the population (Martinez et al, 2017).</p> <p>2. To optimize postpartum care, a woman-centered and individualized, patient-tailored postpartum care plan should be discussed during pregnancy and should include contact with a maternal care provider within 3 weeks, counseling on pregnancy complications and chronic medical conditions (ACOG Committee Opinion, 2018)</p> <p>3. Mothers who suffer a loss (miscarriage, stillbirth, neonatal death) should also follow-up with an OBGYN or obstetric provider (ACOG Committee Opinion, 2018)</p> <p>4. Optimizing care will require policy changes in the scope of ongoing postpartum care, facilitated by reimbursement (ACOG Committee Opinion, 2018).</p>	<p>Improving people to people communication includes focusing on provider to provider and patient to provider communication. Among providers, partnerships between Ob-Gyns and PCPs are important and can assure more quality of care, particularly with transition of care. Additionally, giving providers the tools, such as a bedside handoff tool, can allow them to efficiently share necessary information. Sharing information allows patients to feel listened to, and helps providers share information with patients. Optimization of postpartum care requires care to be tailored to each individual patient and centered on their experiences and stories. Between patients and providers, patient-generated health data allows patients to have control over their health care and provides space for them to tell their story. This act of storytelling is seen in the use of narrative medicine, which uses storytelling as a form of evidence that can be used to increase patients and provider communication, understanding, and relationship.</p>

Provider to Patient

1. Education of providers would be more innovative and effective if it were linked to some sort of auditable change in clinical practice (Bloom, 2005; Cervero & Gaines, 2015).

Patient to Provider

1. Patient-generated Health Data (PGHD) is data created, recorded, or gathered by patients (or family members, caregivers) to help address health and health concerns, PGHD can supplement data that already exists, fill in information gaps, provide a more comprehensive picture of ongoing patient health, rather than at one point in time, can provide info on how patients are doing between visits, provide info on preventative care and chronic care management, and improve patient safety (Office of the National Coordinator for Health Information Technology, 2015; National Learning Consortium, 2014).

2. Patient-doctor conversation is the “single most powerful tool in medicine” -Dr. Danielle Ofri (ASH Clinical News, 2018) and narratives, or patient stories, and storytelling can be enhance the doctor-patient relationship while also be used as a clinical tool to (ASH Clinical News, 2018; Luu, 2018; Gray, 2009).

3. Narrative Medicine (NM) is the study of literary texts (reading and writing) to enrich medical training and practice. NM promotes storytelling and bridges the gap between providers and patients (Fogel, 2018). There are four genres of narrative based medicine: patient stories, physicians stories, narratives about physician-patient encounters, and grand stories (meta-narratives) (Kalitzkus and Matthiessen, 2009)

## PROMOTE INVESTMENT IN COMMUNITIES

### REVIEW OF GRANT OPPORTUNITIES FOR COMMUNITY BASED ORGANIZATIONS

**Background and Significance:** See WG: Promote Investment in Communities, problem statement (p.73)

#### NATIONAL, STATE, REGIONAL AND CITY LEVEL HEALTHCARE FOUNDATIONS

This review describes the extent to which healthcare foundations, represented by selected examples, align with or might support the ability of community based organizations (CBOs), particularly small CBOs, to address the BtC mission.

##### National Level examples

##### 1. The [Jewish Healthcare Foundation](#) (JHF)

The JHF awards grants to improve health outcomes for elderly, poor, and disabled residents in and beyond the Pittsburgh region. They focus their efforts on improving healthcare quality, cost, and efficiency for their target population. The Foundation funds proposals that reflect its mission and priorities: Aging & Long-term Care, Jewish Community, Professional Education & Workforce, Public Health, and Quality & Safety. The JHF does not fund organizations outside western Pennsylvania, capital needs and general operations. This suggests that the organization might not support capacity building activities.

The JHF has an operating arm called the Women's Health Activist Movement Global (WHAMglobal) which consists of a network of advocates and experts. Their goal is to improve equity, leadership, healthcare delivery and outcomes. The WHAM mission is to identify the root causes of maternal mortality and provide support and care for moms and families through the entirety of their care. WHAM's mission aligns with the BtC's goals and objectives. However, WHAM is not a grant-making organization; it is partnered and funded by the JHF and Heinz foundation. They provide the health care services themselves.

##### 2. [Kaiser Foundation](#) (KF)

The KFF funding priorities (2017-2019) include: Access to care, healthy eating active living, and behavioral health. The KF has eight major funding areas: Northern and Southern California, Colorado, Georgia, Hawaii, Mid-Atlantic (DMV region), Washington and Northwestern region of the U.S. The following Kaiser locations have grant making institutions.

*KF Washington:* their funding priorities are:

- a) Advancing health equity
- b) Increasing access to health care and coverage for people who are uninsured and underinsured
- c) Promoting healthy weight, physical activity and access to healthy food
- d) Supporting mental health and access to mental health care
- e) Strengthening economic and educational opportunities for underserved population

*KF Mid-Atlantic region* (District of Columbia, Maryland and Northern Virginia): addresses three prioritized areas of need as identified by their community health needs assessment. The prioritized areas include: socio-economic security, health care access, and mental health and wellness. KF funds organizations that fit with their community health goals. They have two grant rounds, one in spring and the other in fall.

Potential for grassroots: The KFF announced an initiative to create equitable access to grant resources and encourages application from non-traditional and traditional organizations including new, small, grassroots organizations. Their goal is help small grassroots grow and thrive.

*Kaiser Permanente (KP) Hawaii* provides funds for organizations that provide health services in Hawaii. Their funding priorities include:

- a) Community Health Initiatives that promote wellness and healthy eating
- b) Safety Net Partnerships that work closely with community clinics, health departments, and public hospitals to develop the infrastructure required to deliver quality health care.



- c) Care and Coverage for people participating in Medicaid and Charity Care programs.
- d) Education of medical practitioners, consumers and policy makers on how to deliver better health for all.

*KP Georgia* provides funding to NGOs and government organizations that improve access to health care, inform health policy. They support the implementation of programs that align with their funding priorities and support the health Georgia residents. Funding priorities include: 1) Promote prevention strategies that advance good health and 2) Provide treatment for prevalent chronic conditions that adversely impact underserved people living in the Kaiser Permanente of Georgia service area.

*KP Colorado* has notable partnerships with CBOs in the Colorado region. They work with their partners in the community to address health disparities and public health issues in communities that suffer from underinvestment. *KP Colorado* has strict grant making guidelines (such as regular evaluation of their partnerships within the community) and their proposals/grant making are by invitation only.

*KP Southern California* funds regional grants are by invitation only, unsolicited letters of intent (LOI) or proposals are no longer accepted. Grants are made to pre-identified organizations. Grant investments are primarily focused on addressing specific community needs identified through KP hospitals' Community Health Needs Assessments.

*KP North California* provides individual grants, and multi-year grants to support community initiatives in the Northern California region. Organizations that align with their community health goals are invited to apply for funding or may receive formal RFP. Their funding areas include:

- a) Access to care and coverage
- b) Healthy Eating Active Living
- c) Mental health and wellness
- d) Community and family safety

### 3) The [Robert Wood Johnson Foundation](#) (RWJF)

The RWJF provides a large amount of funding to universities and organizations in Massachusetts, such as Commonwealth Alliance, Community Catalyst, Mt. Auburn Associates, Harvard T. Chan School of Public Health, Boston University School of Public Health, University of Massachusetts, etc., and other health centers and universities across the U.S. Their major focus areas and topics include:

- a) Healthy Communities
  - i) Built Environment and Health
  - ii) Disease Prevention and Health Promotion
  - iii) Health Disparities
  - iv) Social Determinants of Health
- b) Healthy Children, Healthy Weight
  - i) Child and Family Well-Being
  - ii) Childhood Obesity
  - iii) Early Childhood
- c) Health Leadership
  - i) Health Leadership Development
  - ii) Nurses and Nursing
- d) Health Systems
  - i) Health Care Coverage and Access
  - ii) Health Care Quality and Value
  - iii) Public and Community Health

### Findings

The RWJF has an extensive list of grantees. Criteria used appear to be: 1) State: Massachusetts, 2) Year: 2001 - 2019, 3) Award amount: less than \$100,000 and pages 1-9. Grassroots organizations are not present or identified on the RWJF grant database. The following might suggest possible reasons for this finding:

- 1) The grassroots organization might have been partnered with larger organizations.

2) Grantees which include grassroots organizations might be present in other states.

4) The W.K. [Kellogg Family Foundation \(WKKFF\)](#)

The WKKFF's premise support capacity building and grassroots organizations. Their website states they favor proposals from organizations that:

- seek start-up costs for creative new strategies;
- identify on-going means for being self-sustaining;
- promote prevention of social problems;
- demonstrate inter-agency cooperation; and
- empower targeted populations to meet their own needs more effectively.

The WKKFF's funding priorities include: Thriving Children, Working Families and Equitable communities. The WKKFF does not fund events and capital requests, such as the purchase or renovation of buildings, vehicles or technology. A review of the Kellogg grant database identified grants awarded to state and community foundations/organizations that operated in Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Virginia and West Virginia.

5) The Commonwealth Foundation Grants Program (CFGP) and [Commonwealth Fund](#) (CF)

The CFG funds non-profit civil society organizations in the Americas, Africa, Asia, Pacific, and Europe. They are international and provide funding to countries which are Commonwealth members. However, the CF operates in the U.S. The mission of the CF is to promote a high-performing health care systems that achieve better access, improved quality, and greater efficiency, particularly for society's most vulnerable, including low-income people, the uninsured, and people of color.

The CF supports independent research on health care issues and makes grants to improve health care practice and policy. Their priority areas include advancing Medicare; controlling healthcare costs; federal and state health policy; health care coverage and access; healthcare delivery system reform; international health policy; and practice innovations tracking health system performance.

Previous grantees include healthcare organizations such as Harvard Pilgrim Health Care, AARP Foundation, Academy Health Alliance for health policy, American Medical Informatics Association, Beth Israel Deaconess Medical Center, Boston College Trustees, Brigham and Women's Hospital, Brown University Catalyst for payment reform, Center for excellence in healthcare journalism, Center for health care strategies, Corporation for supportive housing. Small grassroots organizations were not identified as previous grantees.

## Regional Level

1) [REACH Healthcare Foundation \(REACH\)](#)

REACH allocates the majority of its grant making to three outcomes in the Kansas and Missouri region: access to quality, affordable health coverage and health care for uninsured and underserved populations. The foundation also invests in capacity building to strengthen the management, operations and governance of nonprofit organizations engaged in health improvement. REACH supports small organizations by giving small funds, and larger sums to community health foundations. REACH focus areas/outcomes include:

- a) Enroll all eligible people in the health insurance marketplace or existing public health insurance programs.
- b) Close the coverage gap through expanded eligibility/availability of Medicaid and other publicly funded insurance options.
- c) Strengthen the capacity of the safety net and community to provide high quality, integrated care for consumers with no or inadequate health insurance coverage.
- d) Support the Kansas and Missouri policy agendas to improve access to health coverage and strengthen the health care safety net.

## 2) [Community Health Foundation for Southeast Michigan](#) (CHFSM)

The CHFSM interests range from arts and culture to the environment, and health and human services. Their general recommendation for grant seekers is to read their guidelines, call the CHFSM to talk about their proposal and if it aligns with their goal of enhancing the quality of life in S.E. Michigan. The CHFSM has targeted funds to support specific fields of interest, beyond their general grant making. These funds include

- a) The Chelsea foundation supports “all things Chelsea” that address their communities pressing needs. The foundation, awards grants to strengthen Chelsea and benefit its residents. Grant awards typically range from \$5,000 to \$25,000.
- b) The Community Foundation for Livingston County promotes public well-being and quality of life in Livingston County.
- c) The Detroit Auto Dealers (DADA) supports nonprofit organizations in Wayne, Oakland, Macomb, Washtenaw, St. Clair, Monroe and Livingston counties, with a primary focus on charitable organizations and activities that assist children and youth.
- d) The HOPE Fund (Helping Others through Partnerships and Education) was created to strengthen organizations and projects that support lesbian, gay, bisexual and transgender individuals and families, through targeted grant making, projects and technical assistance.
- e) The Ralph C. Wilson, Jr. Legacy Funds provides funding for caregivers, design & access, youth sports, and Grosse pointe community assets.
- f) The Youth Leadership which supports programs that give young people a voice in their communities and help them gain leadership experience

### State Level

#### 1) The [California Endowment](#) (CE)

The CE funds a number of initiatives ranging from strengthening safety nets for families struggling with poverty to diversifying the health care workforce. Their goal is to expand access to affordable, quality health care for underserved individuals and communities and to promote fundamental improvements in the health status of all Californians. The CE awards single and multi-year grants and Direct Charitable Activity (DCA) contracts. However, their funding opportunities are by invitation only and they do not accept unsolicited proposals or letters of intent. The CE has a General Operating Support Grants, in addition to their Project Grants and Program Support Grants, indicating that they might support capacity building initiatives. Their funding priorities include:

- a) Increasing access to quality health care and improving the capacity of community-based primary care health delivery and prevention.
- b) Addressing the lack of opportunity and health and wellness of youth.
- c) Improving neighborhood conditions in distressed and unstable communities.

In addition to the funding priorities, the CE invests in three “bolds areas”, which reflect their beliefs of making California a healthier place and a model for a nation free from social inequality and racial injustice. These areas include:

- i) People Power: developing young and adult leaders to work inter-generationally to raise up the voices of marginalized communities and promote greater civic activism as essential building blocks for an inclusive, equitably prosperous state.
- ii) Reimagining Institutions: transforming public institutions to become significant investors in, and champions of, racial and social equity, and in the healthy development and success of young people for generations to come.
- iii) A 21st century “Health for All” system: ensuring prevention, community wellness, and access to quality health care for ALL Californians.

Finally, the CE has several initiatives, such as [Building Healthy Communities](#), [Youth in Action](#), [Prevention](#) which involve keeping Californians healthy, [Schools](#), and thriving [Neighborhoods](#). These are not grant-making initiatives, they are programs in-place to improve the health and wellness of California residents. The CE partners with communities and sites to implement these programs.

## 2) [Colorado Health Foundation](#) (CHF)

The CHF funds projects that advance opportunities to pursue good health and achieve health equity for Colorado residents. Their four focus areas are: a) Maintaining healthy bodies, b) Nurture health minds, c) Strengthen community health, and d) Champion health equity. The strengthening communities involves partnering with communities to identify and tackle health-related challenges, and investing in quality food, affordable housing, and promoting health equity. The Colorado foundation grants provides support for projects, general operating expenses and capacity building.

### City Level

#### 1) The [Brandywine Health Foundation](#) (BHF)

The BHF is located in Coatesville, Pennsylvania, their goal is to improve the health and well-being of people who live and work in the greater Coatesville area. The BHF fosters community partnerships, and grant-making which supports capacity building, promotes health equity, healthy youth, and a healthy community. Their annual grant cycle occurs in the fall season. Their focus areas include:

- a) Health Equity involves:
  - Advancing access to primary, behavioral and reproductive health services by providing grants to nonprofit healthcare providers serving the Greater Coatesville community that improve access to care for underserved residents.
  - Providing grants to nonprofit healthcare providers to reduce health disparities in maternal and prenatal health outcomes among women of color.
  - Providing program grants to nonprofit healthcare providers to increase culturally appropriate resources related to healthy eating, nutrition, physical activity, stress reduction, mental health stigma.
- b) Healthy Youth empowers youth (age 12-24) in the community to achieve and maintain a healthy lifestyle, cultivate leadership skills and experience, and achieve their goals for the future.
- c) Healthy Community to improve community conditions that help impact the health of everyone in Greater Coatesville.

The BHF works with an existing network of safety net providers, community and health organizations serving the uninsured and underinsured in the Greater Coatesville Area, some of their grants are by invitation only. The BHF has a new grant making fund for the FY 2020 -2023, which includes:

- a) Community Well-Being Fund is a general operating grant, applicants can apply for small general operating grant over a two-year period.
- b) Collaborative Innovation Fund provides fewer and larger sized grants over a two-year period that focuses on the foundation's priorities 1 and 2; funding equity, health and well-being initiatives. This grant application requires organizational partnerships; at least one non-profit partner and one civic, faith-based and/or grass roots community partner.
- c) Collective Impact Fund is a planning grant which will provide an opportunity for a second phase which includes a two-year implementation grant. The planning grant focuses on incorporating Collective Impact Approaches, a proven practice to bring groups and community together to use all the skills around the table to address community social, health and economic problems.

#### 2) The [Boston Foundation](#).

The BF grantees range from small grassroots organization to large community organizations and universities that operate in the Greater Boston Area. Their foundation major impact areas are:

- a) [Arts and Culture](#): involves building a creative culture that honors all voices and artistic expressions, and gives all Bostonians the opportunity to experience diverse art.
- b) [Education](#): ensures that all Greater Boston residents can access the education and training they will need to succeed in our regional economy.
- c) [Health and Wellness](#): promotes and advances health equity, where everyone has the opportunity to attain their best health regardless of their identity or socioeconomic status.
- d) [Neighborhood and Housing](#): ensures that all residents of Greater Boston have a safe, affordable and decent home in healthy, thriving neighborhoods.
- e) [Job and Economic development](#): providing access to family-sustaining careers and stimulate the growth of generational wealth within historically marginalized populations.
- f) [Non-profit effectiveness](#): Accelerate social change by strengthening Greater Boston nonprofit organizations and leaders

In addition to the impact areas grants, the BF has open door grants and special funds. The BF has [special funds](#) which were created in partnership with other donors to address specific issues and pressing needs in the community. The *open door grants* were created for organizations that serve and build power in communities historically excluded from institutional philanthropy and those whose leadership reflects the communities they serve. New and existing nonprofit organizations in the Greater Boston that do not have the same strategy, goals or approaches as the foundation's five impact areas are encouraged to apply for this grant. The goal of the *Open Door Grants* is to test new ideas and innovations that address the challenges and opportunities in the community. The BF has two types of grants that support general operating funds and projects.

- The general operating support grants vary in size and duration, and range from \$25,000 to \$150,000 per year, and may be awarded for up to five years. They also have smaller general operating support or project support (including capacity-building projects), ranging from \$10,000 to \$50,000. They may be renewed for up to two years in a row.
- Project support grants: supports specific projects or programs that are aligned with the five impact areas or Nonprofit Effectiveness strategy. Awards range from \$25,000 to \$100,000 often one-year awards, but in certain cases may be awarded as multi-year grants.

### **Grant-making and corporate philanthropy from pharmaceuticals, and fortune 500 companies to grassroots organizations**

#### **Purpose of Summary:**

Our goal was to identify corporate philanthropy and grant-making from pharmaceutical companies, biotech, insurance companies and fortune 500 companies that could support BtC's mission and provide funding to small grassroots organization for women's health initiatives.

#### **Findings**

We reviewed an extensive list of fortune 500 companies, most generous pharmaceuticals companies, insurance companies and biotech organizations. Many of these organizations or companies stated that they offered community investment and support grants, however, their criteria for corporate philanthropy focused on STEM initiatives, employee matching services and grants, and disease specific topics. Organizations that offered grants related to BtC concepts were more likely to fund larger organizations compared to small grassroots organization. Additionally, the companies that provided funding to support women's health initiatives, only supported non-governmental organizations that work abroad or outside the United States.

The following offered community related grants:

#### **Fortune 500 companies**

- 1) [The Walmart Foundation](#): gives local community grants from \$250 to \$5000. The local grants are designed to address the unique needs of the communities where a Walmart is located. However, their strengthening community grants involve access to healthier food, disaster preparedness and relief, local giving, diversity, equity and inclusion, veteran benefits, etc.

- 2) [Bank of America](#): has a philanthropic investments grants to help move individuals and communities forward through workforce development and education, community development and basic needs.
  - The first focusses on the needs of individuals and families by investing in workforce development & education and basic needs.
  - The second focusses on the needs of the community by addressing economic development and social progress by investing in affordable housing, revitalization, arts, and the environment.

#### Pharmaceuticals

- 1) [The Novartis Corporation](#): has a philanthropic grants for non-profit organizations that is dedicated to enhancing the quality of life, recognize the interests of our employees (employee matching grants), and addressing significant social issues related to health, education and civic engagement in the communities where Novartis operates. The philanthropic grants support programs that focus on underserved populations promoting health and disease state awareness, science, math and technology education, and civic and community development initiatives.
- 2) [The JAZZ foundation](#): provides funding to non-profit organizations that support awareness, focus on treatment of diseases in our therapeutic areas of focus; support the patient journey; support the improvement of communities in which our employees live and work; or otherwise support our corporate strategy and initiatives.
- 3) [The Boehringer Ingelheim Cares Foundation](#): supports programs that align with its goals to improve access to healthcare for those in need and enhance science and math education while strengthening the communities in which we live and work. Connecticut is the geographic focus of programs the Foundation supports.
- 4) [AstraZeneca US corporations grants](#): AstraZeneca's charitable giving supports organizations in the US that are aligned with its priorities of advancing patient health in its core therapeutic areas, health and science innovation and community investment. Applications for US Corporate Contributions are accepted year-round by invitation-only. Unsolicited applications are accepted in July. Additionally, AstraZeneca supports capacity building and mission support.
  - Astrazeneca core therapeutic areas include: programs and initiatives that help educate and support patients managing cardiovascular disease, diabetes, inflammation and infection, respiratory diseases, cancer, and conditions we're addressing through neuroscience (including mental health).
  - Health & Science Innovation: Programs and initiatives that innovatively address the challenges to healthcare across the US.
  - [Community Investment](#): Smaller, community-focused programs that help fill a gap to improve health and healthcare and help empower patients to manage their own health better.

Additionally AstraZeneca has an RFP for diabetes grant, however, only healthcare professionals (such as Cardiologists, Endocrinologists, Primary Care Physicians, NPs, PAs, and nurses) or related organizations are eligible to apply for funding.

- 5) [Merck](#): has a variety of large diabetes grants, however the MSD partners with eight large organizations and the grants/funding go to them.

The bridging the gap diabetes program: through grants to eight organizations, the Merck foundation is supporting evidence-based, multi-sector approaches to promote sustainable improvements in the delivery of diabetes care.

- [Alameda County Public Health Department](#) (Oakland, California)
- [Clearwater Valley Hospital and St. Mary's Hospitals and Clinics](#) (Orofino, Idaho)
- [La Clínica del Pueblo](#) (Washington, DC)
- [Marshall University](#) (Huntington, West Virginia)
- [Minneapolis Health Department](#) (Minneapolis, Minnesota)
- [Providence Health and Services](#) (Portland, Oregon)
- [Trenton Health Team](#) (Trenton, New Jersey)
- [Western Maryland Health System](#) (Cumberland, Maryland)

Additionally, the Merck foundation has a diabetes prevention grant; however, the funding goes to the YMCA Diabetes Prevention Program. Merck also has a neighborhood of choice community grant that focuses on community investment in the following areas: art, education, civic, environment, and human health services. The community grant provides financial support and shares the expertise of their employees through grant and volunteer programs that address critical health and selected social issues in 105 communities where the company has a presence. Boston will be eligible for this because Merck has a presence [here](#).

#### 6) Merck and Maternal health (Merck for Mothers)

Merck for Mothers, known as MSD for Mothers outside of the United States and Canada, is a 10-year \$500 million initiative focused on improving the health and well-being of mothers during pregnancy and childbirth. In 2012, they launched the Global Giving Program, their corporate grants initiative through which their offices around the world to support eligible nonprofits working to improve maternal health. The grants are only available to NGO's that operate outside the U.S.



## Public Education to Heighten Awareness of Root Causes

### Summary of the Evidence

**Background and Significance:** See WG: Public Education to Heighten Awareness, problem statement (p.76)

Strategies	Evaluations/Trials	Reports/Descriptions	Conclusions
<i>Campaigns targeting:</i> 1. <i>Alcohol impaired driving and crashes</i>	Meta-analysis showed some differences after multimedia intervention, but no impact on injury or fatalities (Yadav & Kobayashi, 2015). Campaigns may affect knowledge but there was no demonstrated effect on consumption (Young et al., 2018).	1. <i>Teen Pregnancy: Milwaukee United Way</i> Claims reduction of teen pregnancy by 56%. <a href="https://milwaukeeenns.org/2015/01/29/teen-pregnancy-campaign-turns-heads-resonates-with-youth/">https://milwaukeeenns.org/2015/01/29/teen-pregnancy-campaign-turns-heads-resonates-with-youth/</a>	Most campaigns have not been evaluated in a format that would show associations between content/format and changes in behaviors, perceptions, or outcomes. However, characteristics that appear to be associated with success as measured include: community partnerships and building; avoiding shame/blame; focused, widely disseminated messages; focus on empowerment, not risk.
2. <i>Smoking</i>	For youth, campaigns that focus on prohibition (e.g. Philip Morris “Don’t Smoke!”) increase smoking initiation, while campaigns targeted to youth rebelliousness (e.g. “Truth”) reduce smoking rates (Farrelly et al., 2002).	2. <i>Women of color require spaces where they can seek care that is catered to them:</i> a) Black Women’s Health Imperative website, Twitter, Instagram, Youtube, LinkedIn used to create community based on real needs and preferences; comprehensive, changing content. <a href="https://www.bwhi.org/">https://www.bwhi.org/</a>	
3. <i>Child physical abuse</i>	Systematic review showed mixed results from multi-faceted, multimedia interventions. Studies lack program theory descriptions and a clear review of targeted risk factor. The evidence is insufficient to support the intervention (Poole et al., 2014).	b) Black Mamas Matter Alliance: creates a campaign that is used to increase awareness, activism, and community building; partners with organizations and sponsors that have similar interests & goals <a href="https://blackmamasmatter.org/about/">https://blackmamasmatter.org/about/</a>	
3. <i>Drug use</i>	Cochrane review finds that 4 studies showed positive results and 2 demonstrated iatrogenic effects, suggesting need for caution. The paucity and inconsistency of available evidence does not permit general conclusions as to whether mass-media interventions are effective in preventing use of or intention to use illicit drugs (Allara et al., 2015).	3) <i>Campaigns that respond to or try to undo the effects of using media to shame and blame:</i> <a href="https://www.change.org/p/candie-s-foundation-stop-shaming-young-parents-2">https://www.change.org/p/candie-s-foundation-stop-shaming-young-parents-2</a> and <a href="http://www.noteenshame.com/about">http://www.noteenshame.com/about</a> Small effects from fear at too high a cost: <a href="https://www.npr.org/sections/health-shots/2015/11/02/453960470/scaring-people-can-make-them-healthier-but-it-can-backfire-too">https://www.npr.org/sections/health-shots/2015/11/02/453960470/scaring-people-can-make-them-healthier-but-it-can-backfire-too</a>	
4. <i>Marijuana use</i>	The “Above the Influence” campaign predicted lower marijuana use by the final wave of data collection. Students responded better to print material while community favored multimedia (Slater et al., 2011)		
5. <i>Nutrition</i>	Review: Social media campaigns have positive effect on food choices, but it is difficult to measure the additive benefits of the social media component in complex interventions (Klassen et al., 2018).	4) <i>Campaigns that exaggerate risks/ consequences:</i> DARE increased drug use in high risk teens.	

<p>6. Breast cancer</p>	<p>CDC: Radio messages increased mammography utilization among African American women (Hall et al., 2015).</p>	<p><a href="https://www.vox.com/2014/9/1/5998571/why-anti-drug-campaigns-like-dare-fail">https://www.vox.com/2014/9/1/5998571/why-anti-drug-campaigns-like-dare-fail</a></p> <p>5) Empowerment based programs succeed Power to decide increased teen contraception use: <a href="https://powertodecide.org/what-we-do/information/why-it-matters">https://powertodecide.org/what-we-do/information/why-it-matters</a></p>	
<p><i>Listening to Mothers</i></p> <p><i>Modalities:</i></p> <p>1. Campaign timing</p> <p>2. Texts and MHealth</p>	<p>Targeting of public service ads during key cultural and sports events increases engagement and retention of material (Hair et al., 2017)</p> <p>Are you listening? 'Every mom. Every time.' is ACOG's public awareness campaign created to educate and encourage providers to help eliminate preventable maternal mortality.</p> <p>Review: smartphone applications are acceptable to adolescents and may improve health (L'Engle et al., 2018)</p>	<p><a href="https://sales.acog.org/Every-Mom-Every-Time-Pin-P936.aspx">https://sales.acog.org/Every-Mom-Every-Time-Pin-P936.aspx</a></p>	

## Chapter 5: Discussion



BtC is the first known national initiative to form a national network of diverse stakeholders to tackle the multi-layered and longstanding challenge in women's health care that has perplexed patients, providers, and health systems for decades--the absence of a continued health care path for pregnant and parenting people after birth, once the immediate postpartum period is over. The BtC mission is ambitious yet 'just the beginning' of a movement that is underway in many sectors--

from birth equity organizations and maternal health coalitions to NIH researchers and health system designers. BtC sought first to collaboratively produce *a National Agenda for Research and Action to BtC*; and second, to inspire partnerships across the country to advocate for and implement aspects of the Agenda that align with existing aims and activities. The Agenda could only have been created, and going forward can only be achieved, by collaboratives of people with lived experience, community caregivers and advocates, clinicians, researchers, policy-makers, and health system innovators who brought a vast array of expertise to the task.

The two-year initiative began with a pioneering conference, and culminated in the co-produced *Agenda* presented in this report. While initiated within the walls of a university and funded by NIH and PCORI, BtC quickly became the project of the network of individuals and organizations with longstanding investment in and commitment to end the four tragic realities that lie at the heart of the BtC mission. The SELC drove the planning and the work was powered by the national network, consisting of all Conference participants (listed in Appendix A) and all WG members (authors listed in the front of the report). The broad outlines/categories of the Agenda emerged from the Conference, which brought 80 diverse stakeholders together to review evidence, share personal and professional stories, and reach consensus about the range of strategies that could disrupt the current status of maternal health care in America, especially bridging the chasm between pregnancy and women's health over the life course. The foundation was laid for the next step: the formation of WGs to flesh out the planks of the Agenda that had been identified at the Conference. As described, each WG conducted rigorous analysis of evidence and existing initiatives, shared insights from lived experience and best practices, and came to consensus through discussion and surveys of priorities on the 3-5 highest priority strategies (or cluster of strategies). Along the way, tough questions continued to surface and became grist for the mill of shared decision-making.

The four tragic realities that inspired and framed the Conference, as outlined in the Introduction (Chapter 1), continued to be the heart of the seven distinct but cross-cutting WG's charged with producing the planks of the National Agenda.

- **The health care system for women and all pregnant and parenting people is fragmented and fraught with gaping holes that leave many people--especially those already marginalized--vulnerable to preventable illness and death in the postpartum period and beyond.** Two WGs ("Develop High Touch Models of Care" and "Advocate for Policy Changes to Transform Health Care Delivery") addressed this reality and related questions. How can we create and evaluate innovative models of care, system reforms, and public policies that increase investment in women's health after the baby is born and bridge the chasm between reproductive and ongoing primary care for women? Who is supposed to care for women 'in the chasm' and how can systems be reformed to create a seamless connection between maternity care and primary care providers and services? How can training of obstetric and primary care providers be strengthened to allow for seamless care of women that takes into account reproductive histories and experiences? How can inter-professional teams of caregivers be trained together and supported to work together in the delivery of holistic care for women after the postpartum period? How can Medicaid insurance and benefit policies support the bridge across the chasm?

Integrating findings of two WGs (Policy and High Touch) whose recommendations were inter-dependent, the two strategies deemed most innovative, likely to promote equity, effective, and feasible were:

- Expand Medicaid coverage from 60 days to one year postpartum for eligible women, with auto enrollment (Policy);
  - Use CMS/ CMMI mechanism to fund innovative models of ‘women’s health home’ and ‘transition’ care that carries people across the chasm after the postpartum period is over (Policy, High Touch).
- **Structural and interpersonal racism, as well as social inequities, are deeply embedded in history and in the social contract and health care system in America.** Place matters, racism matters, and all social determinants of health play a large role in shaping health. How can ACO’s and other health systems partner with and support CBOs to help them address the SDOHs effectively, meaningfully? Given the systemic and longstanding racism that exists within health care, women of color do not trust the health care system nor many providers. Routinely, they are disrespected and their concerns dismissed as they go through pregnancy, childbirth and the postpartum experience, a reality that contributes to dangerous and sometimes fatal gaps in care. How can BtC support the movement to change the power relations in health care and assure that mothers’ lived experience is listened to, respected, and becomes central in health care decision-making?

Integrating findings of three WGs whose findings address structural and interpersonal racism and social inequities in complementary ways, three complementary strategies deemed innovative, equity-promoting, effective, and feasible were:

- Establish (and evaluate) “Mom’s Health Matters” initiatives in communities where burden of maternal morbidities and women’s chronic illnesses is high (High Touch Models of Care WG, Research WG);
  - Create a Center for Growth and Sustainability of Small CBO’s, focused on leadership, communications, community engagement, advocacy strategies, and gaining seats at the table of local public and private agencies that are engaged in planning that affects SDOHs (Promote Community Investment WG);
  - Require for accreditation that all medical, nursing and other clinical training programs incorporate competency-based training and assessment aimed at the elimination of disrespect and institutional and interpersonal bias within clinical practice through regulatory bodies (Eliminate Disrespect and Racism WG).
- **Patient voices are not at the center of the design of health services/systems, research, nor policy meant to serve mothers and their needs.** Without women with lived experience engaged in the processes of decision-making when health systems innovate, researchers write proposals, and policy-makers create legislation, it is unlikely the bridges across the chasm will be effective. How can we assure that pregnant and parenting people are at the center of decision-making about how health care is designed and delivered, research is designed, and legislation is proposed, particularly in contexts where their power is often devalued? How can patient engagement in research be authentic and adequately supported within the constraints of funding? How can legislative bodies build in patient and advocate engagement throughout the process of policy-making? In what ways can health systems engage patients consistently and meaningfully when decisions are made about how services will be delivered?

Integrating findings of three WGs whose findings address patient engagement directly, the complementary strategies deemed innovative, equity-promoting, effective, and feasible were:

- Engage patients in the design and implementation of curriculum for competency-based training to eliminate disrespect and racism in health care (Eliminate disrespect and racism WG);

- Conduct patient-engaged research to further define what kind of information related to BtC after pregnancy complications women from diverse communities want, need, and will find easy to use (Research WG);
  - Place women's voices and stories at the center of a BtC public education campaign (Public Education Campaigns WG).
- **There is a wide gap between what we know about pregnancy as a stress test and window into women's health over the life course, and what we do about it.** As discussed throughout this report, science well establishes the link between pregnancy health and future cardiovascular, metabolic health and social well-being of women across the life course. Despite evidence-based prevention strategies, follow-up and monitoring after pregnancy complications is poor.

The entire BtC Agenda is intended as a resource and impetus for translating evidence and lived experience into action on multiple fronts: policy (to transform health care delivery and payment reform), research (to align with women's lived experience over the life course), innovation in health care models (high touch and team-based models), health care professions training (to eliminate disrespect and racism); health data systems (to preserve women's narratives across time and providers); community development (building capacity of CBO's); and public education (to heighten awareness of root causes of maternal health racial inequities).

*Doors open for implementation: The public eye turned to maternal health as BtC launched and came to fruition.*

When BtC was funded in 2017, the consciousness of the American public had not yet woken to the tragic facts about and stories of Black maternal health: that Black women die in childbirth at three times the rate of White women; that the disrespect shown all too often to Black, Brown Native and AAPI mothers in maternity care settings sometimes meets fatal ends; that the overall maternal mortality rate in the U.S. surpasses that of all other high-resource countries and is rising.

As we concluded the project in 2019, it was and remains a different world. Facts and women's voices and stories matter. And they are everywhere. The lived experience of Black women and the impact on their health and the health of their mothers and daughters is now headline news in mainstream media. Maternity care is under scrutiny. Public and private funders are stepping up. ACOG called for a "fourth trimester" to extend obstetric care to new mothers and launched a national campaign (with buttons): "*I'm Listening. Every Woman. Every Time.*" And the momentum has fueled political action.

Policy-makers are filing and passing bills in State Houses and in the U.S. Congress to take on the 'maternal health crisis.' In 2019 at least eight bills that directly address racial disparities in maternal health were filed in the U.S. House of Representatives on the heels of the bipartisan passage of a bill that supported maternal mortality reviews and increased numbers of providers in rural areas in 2018. The NIH and private funders have centered new funding initiatives on maternal mortality and morbidities, opening the door to BtC recommendations for research. Most notably, the NICHD 2020 Strategic Plan highlights funding for research on "pregnancy-related conditions that contribute to maternal morbidity and mortality, stillbirth, preterm birth, and the long-term health of women and their children."

*The changed landscape creates a policy window for BtC to make a contribution, expanding the national agenda.*

For BtC the dramatic change in the maternal health landscape offers enormous opportunity as well as challenges. As the *National Agenda* demonstrates, many of the issues that percolated up during the BtC Conference and were fleshed out by WGs are now receiving the attention of policymakers. As discussed in Chapter 3 (Policy WG), examples in the national policy arena include legislation that would mandate implicit bias training for providers; Medicaid up to 1 year postpartum for women who would otherwise lose coverage at 60 days; inclusion of and reimbursement for doula care; the call for quality metrics in maternal health; and "pregnancy medical home"

demonstration projects. The national legislative agenda, even if much of it is pending, is remarkable for its breadth and accelerated pace and creates a ‘policy window’ far more hopeful for future implementation than we had assumed at the start of the initiative. While the impetus for legislative proposals is the prevention of maternal and pregnancy-associated mortality and the racial gap in these outcomes, the significance of supporting women beyond the immediate postpartum period in ways that can prevent chronic illness over her life course, is not front and center on the national policy radar screen. That is to say, maternal morbidities, such as gestational diabetes, pre-eclampsia and hypertension, often neglected beyond and between pregnancies, contribute to maternal death within a year, can rise up in a future pregnancy, and are warning signs for cardiovascular disease and type 2 diabetes throughout a woman’s life. The chasm between 56 days postpartum (last postpartum visit as measured in HEDIS) and 365 days (last day when a death is counted as “pregnancy-associated”) is the chasm, we argue, that must be crossed with a sturdy bridge to a primary care or family health care home, to ongoing care for women much like that offered to children, and to the conditions that make self-care possible. With the momentum surrounding maternal mortality and morbidities, there is now a strong platform and animated public discourse that can boost the BtC Agenda.

### **The process: Did it work?**

#### *Racial equity and patient engagement the driving force behind the BtC conference and Agenda*

Two guiding principles were the driving force behind the BtC process for the Conference and the Agenda Development by WGs: eliminating disrespect and racism in health care and systems, and engaging patients (and grassroots community organizations) every step of the way. While one WG was devoted to racism in the health care system, racial equity is a thread that ran through the work of all groups, as it must be. Patient engagement was at the heart of the design of the conference and WGs, both through the planning role played by the SELC community-based organization members (Black Women’s Health Imperative, DiabetesSisters) and the broad representation of birth justice organizations, patient representatives and advocates throughout the process.

Interestingly, the two principles and the imperative that they be sustained in the final product of a BtC Agenda bubbled up early and powerfully at the Conference. The stories shared on Day 1 exposed deep rifts in the capacity of the health care system to meet the needs of women and the frustration and distress of clinicians working in conditions where experiences of women are devalued. Many of these stories were about ways in which patients of color were disrespected and their autonomy breached in encounters with providers, and the profound impact these events had on their lives going forward. All of this prepared participants for deeper engagement with strategy generation on Day 2. As a result, racial equity, patient engagement in all strategy design (at the Conference and in all settings) were key threads across all roundtable discussion, regardless of topic.

During Year 2 patient representatives and advocates remained as key players in WGs. Several patient representatives who participated in the conference also lent their expertise in Year 2 and other patient and community advocates also joined WGs. The BtC network included several leaders in the vibrant community of doulas of color from across the United States; all played significant roles in WGs, often grounding conversations in the realities of their clients and their own lived experience. For example, in the High Touch WG, clinicians and policymakers were inspired about the potential for doulas to support women to tell their stories of pregnancy and birth to primary care providers. One community doula leader voiced concern and reticence. She said, “maybe,” but questioned the assumption that the role would be well-received, urging members to consider that doulas choose their status because of attachment to the birth process, and it may not be so easy to shift their interest to prevention of chronic disease. “Furthermore”, she said, “if you want them to be in the position of communicating patients’ needs to providers and being the in-between broker, how are they going to get the status and training to do that? It’s too much to put on their shoulders.” The WG stopped in its tracks and did not formulate a recommendation that placed extra responsibility on doulas or doula training.

It is also important to note how much diverse members of WGs learned from each other along the way. Many reported to be surprised to find out how many seeds of future solutions are happening already at the local level despite challenges at the federal level. For example, from a doula member we learned of the advocacy achievements

of the “Wisconsin Doulas of Color Collective,” lending even greater strength to the people at the table. From a policy advocate we learned about the packages of laws recently passed in New Jersey and California, lending ideas for the Agenda. From a healthy system innovator, we learned about the WIN Network, a woman-inspired neighborhood network that helps patients get the health care they need in collaboration with several large health systems in Detroit.

**The ideas contained in the BtC Agenda were collaboratively generated and vetted within the structure of each WG. As such, the authorship of the Agenda is shared among all WG members, as is the authorship of this report.**

***The BtC Agenda: Cross-cutting and sequential, aspirational and practicable***

The multi-pronged Agenda clearly demonstrates three lessons learned as we look toward next steps and implementation.

**First, building the bridges across multiple chasms is a complex task that cuts across research, health system innovation, policy, community investment and public education.** It is not surprising that the strategies discussed in one WG were considered from a different angle in another. As a team of WG facilitators, the SELC and the BU team met at the end of the project, and everyone agreed that the relationships among strategic WG areas are important to analyze and emphasize so that those among us who wish to implement given strategies can collaborate and draw on the strengths of evidence and arguments from many angles. The Strategy Map at the beginning of Chapter 3 gives a visual picture of how very interrelated the strategies that emerged from different WG’s are.

**Second and relatedly, the Agenda as a whole can and should be viewed as a pyramid of action,** with elements already in place as the foundation of specific desired strategic actions, the coalition building advocacy required as a next step, and at the top, the ultimate strategic outcomes desired. The figure below represents one such pyramid as an example, showing the current, and near future actions for six selected recommendations.

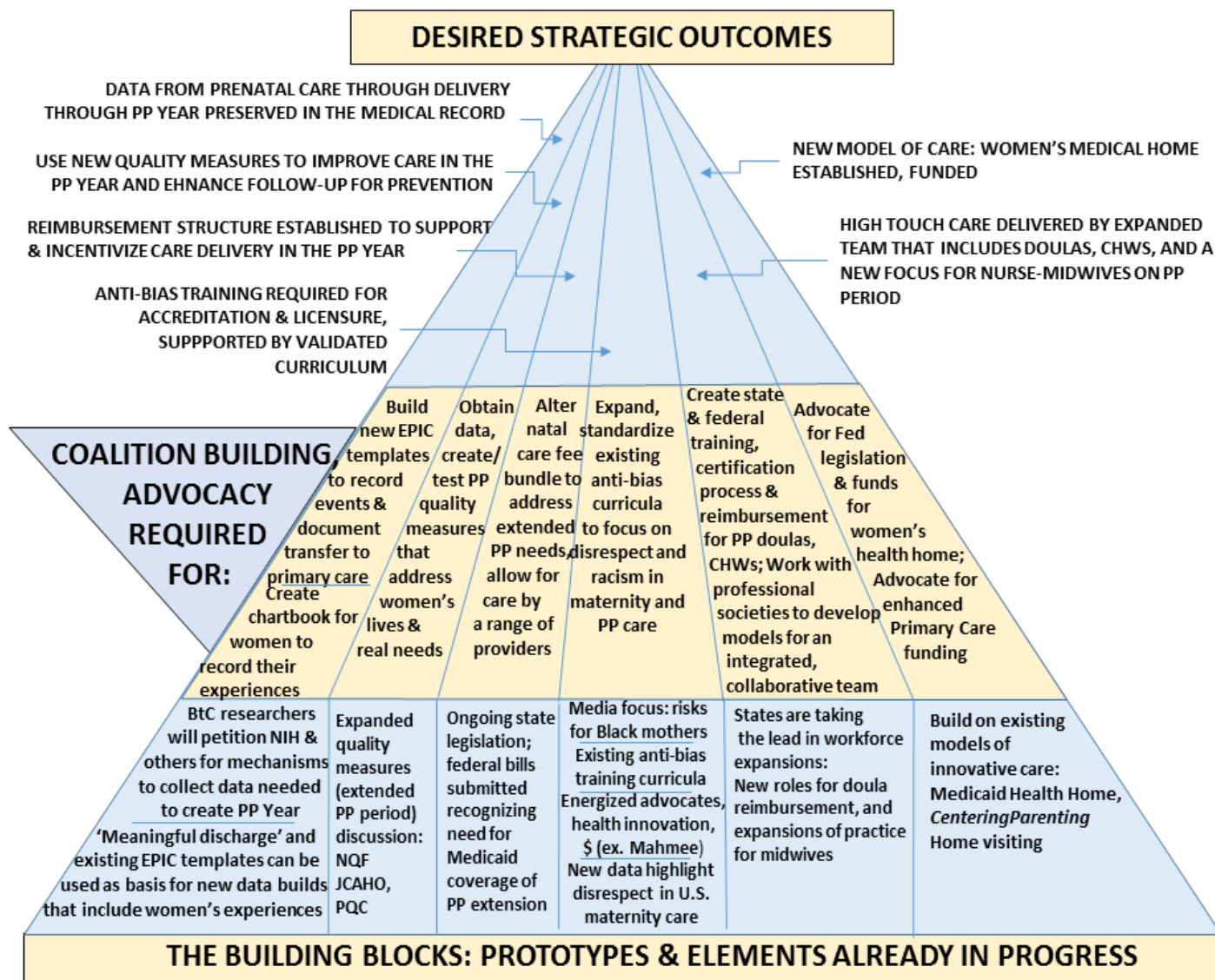
We highlight here one example of strategies that are cross-cutting and require intentional collaboration to build on and leverage actions among ‘sectors’ to achieve a desired outcome: (WG that made recommendation). To achieve the systems transformation we are calling the “Women’s Health Home” requires that we:

- Create the “High Touch Model of Care” that incorporates women’s health doulas and CHWs as valued members of multi-disciplinary clinical teams, ready to care for women ‘in the chasm’ - at least up to 1 year postpartum (High Touch);
- Enact legislation that reimburses doulas at a fair wage and promotes their inclusion on health care teams (Policy);
- Engage doula educators in deciding how new curricula can be added to current training and certification as desired (High Touch);
- Enact legislation to require Medicaid coverage to 1 year postpartum with auto enrollment (Policy);
- Design experiential cross-training modules for all members of collaborative teams, including anti-racism/implicit bias training (Eliminate Disrespect, High Touch);
- Work with NQF to develop quality measures that reflect collaborative team performance/quality (Policy);
- Negotiate with EPIC to develop/test a template for transfer of pregnancy history to primary care (Preserve the Narrative);
- Work with community based organizations and advocates to create fora to support pregnant and parenting people to share experiences of pregnancy, birth and postpartum – identifying ways (and tools) to assure that key elements of stories are central in health care encounters going forward (Preserve the Narrative, Promote Investment in Community);
- Advocate with CMS to use CMMI mechanism to support innovation, adaptation of current Medicaid Health Home model to a Women’s Health Home, with elements specific to women with medical and social complications during pregnancy (Policy and High Touch);
- Incentivize multi-specialty entry to primary care and require accrediting bodies to adopt competency to link reproductive care and primary care (Policy);



- Fund capacity for ACO's to address social determinants and 'host' Women's Health Homes (Policy)
- Work with NCQA to accredit the "Women's Health Home" (Policy);
- Develop and test interventions, with patient engagement, to address racial inequities in pregnancy complications (Research).

Each WG, balancing a sense of urgency in light of the current political landscape with the firm sense of deep root causes of the problems being addressed, included strategies that they deemed practicable in the near future and those that are longer-term, and some even aspirational.



Finally, we must all work to our strengths to turn the recommendations into action. The National Agenda for Research and Action to BtC presents an ambitious, far-reaching blueprint to address four key challenges in maternal health in America: the absence of a health care path for women that connects reproductive and primary care; structural racism and social inequities that shape wide disparities between the health and health care experiences of women of color and White women; and the gap between what we know and what we do to meet the needs of women's health over the life course. This report includes the recommendations, evidence, and resources for researchers, patients and patient advocates, policy-makers and health system designers to coalesce and drive the needed change. The BtC Agenda has come to fruition just as the momentum for what could be meaningful transformation in the system of care for mothers and women intensifies. **The time is ripe for all of us to leverage the co-produced Agenda to achieve what we set out to do:** continue existing and form new partnerships that strengthen our capacities to put an end to the four tragic realities that brought us together. Each according to our individual and collective missions and with the stakeholders we know best.

The figure below portrays the BtC Agenda by constituency group to help organize our future efforts.



# Bridging the Chasm (BtC) between Pregnancy Complications and Women's Health over the Life Course:

## A National Agenda for Research & Action

Findings from seven work groups:

Policy, Research, Preserve the Narrative, Eliminate Disrespect, High Touch Models of Care, Invest in Communities, & Public Education

What each constituency can do:

### Government & State/Federal Agencies

- Pass federal & state legislation:
  - 1) to extend Medicaid coverage to 12 months pp (auto-enrollment)
  - 2) to promote women's medical homes for continuity/integrated care pre-pregnancy - pp year
- Workforce development: Incentivize entry to primary care, home visiting for PP mothers & team-based care
- Actively support inclusion of CBOs in state and local planning
- Co-locate information & resources for PP year at sites where women gather & train staff to refer
- Fund a national workforce development center to increase the #/% of Black health care providers

### Researchers & Funders

- Develop RFAs to fund knowledge gaps
- Evaluate new models of care
- Develop/test template for discharge to PC
- Study long term impact of women's pregnancy complications on their future health

### Foundations

- Fund & grow CBOs for BtC work
- Allocate \$ for infrastructure support (training & resources)

### Health Care Organizations

- Require anti-racism training/assessment
- Develop flexible PP year models of support & wrap-around care (doulas, CHWs, navigators)
- Negotiate with EPIC to develop/test a template for transfer of pregnancy history to primary care
- Implement a *Mother's Health Book* for personal record keeping and a PP discharge template
- Support women to share their stories with providers and motivate providers to listen
- Promote a centering model of care for the PP year, especially after pregnancy complications

### Professional Organizations

- Develop guidelines for integrated care in the PP year
- Educate members about developing research that ties pregnancy complications to future health outcomes
- Collaborate to associate new quality metrics with outcomes that can be tied to accreditation
- Require anti-racism training for licensure & renewal

### Business

- Corporations can create woman-friendly practices & policies for the postpartum year (flexible hours, paid family leave, etc.)

### Quality Measure Developers

- Design/promote metrics & 'pay for performance' for warm handoff to primary care with documentation

### Advocacy Organizations & CBOs

- Advocate for state/federal legislation to extend PP period to 1 year with coverage/support
- Lobby state/local agencies for participation in planning process
- Testify at legislative hearings to highlight the impact of pregnancy experiences on future health
- Lead anti-racism education efforts

### Educators

- Form inter-professional collaboration for CME to connect pregnancy experiences with future health
- Develop & implement anti-racism training/assessment
- Create innovative technologies to connect women to each other, to providers, to resources

### Media Experts

- PSAs to enhance value of women's health to society
- Create an anti-racism campaign
- Develop CBO fundraising videos demonstrating accomplishments to enhance fundability

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## **ELIMINATE DISRESPECT, RACISM AND ALL OTHER IMPLICIT BIAS WITHIN HEALTH CARE**

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## **PRESERVE THE NARRATIVE: USE HEALTH DATA TO BRIDGE THE CHASM**

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## APPENDIX

## Appendix A. List of BtC Conference Participants

Adrienne Adams	Patient Representative, Black Women's Health Imperative
Chenelle Norman Adebisi, MPH	Harvard Medical School, Center for Primary Care
Jill Ashton	MA Commission on the Status of Women
Mary Barger, PhD, MPH, BSN, CNM	University of San Diego, Hahn School of Nursing
Wendy Bennett, MD, MPH	Johns Hopkins University School of Medicine, Dept. of Medicine and Johns Hopkins Bloomberg School of Public Health, Depts. of Epidemiology and Population, Family and Reproductive Health Institute for Healthcare Improvement
Quin Bottom-Johnson	March for Moms
Ginger Breedlove, PhD, CNM	NIDDK, National Institutes of Health (NIH)
Andrew Bremer, MD, PhD	University of South Florida System, ACOG
Haywood L. Brown, MD	Patient Representative, Black Women's Health Imperative
Annette Brown	Harvard Medical School, Dept. of OB-GYN, ACOG
Allison Bryant, MD, MPH	Patient Representative, DiabetesSisters
Cindy Campaniello	Patient Representative, Women in Control, Boston University
Diane Carter	Tufts University School of Medicine, Dept. of OB-GYN
Patrick Catalano, MD	University of Pittsburgh School of Medicine, Dept. of OB-GYN and School of Public Health, Dept. of Epidemiology
Janet Catov, PhD, MS	Patient Representative, Black Women's Health Imperative
Gera Christian	National Institutes of Health, Office of Research on Women
Janine Clayton, MD	Patient Representative, Type2Musings.com
Corinna Cornejo	Texas Christian University and University of North Texas Health Science Center, School of Medicine
Chase Crossno, MPH	YWBoston
Fatima Dainkeh, MPH	Boston University, Clinical Research Education Office of Human Research Affairs, Clinical & Translational Science Institute
Karla Damus, PhD, MSPH, MN, RN, FAAN	CMS, Division of Quality and Health Outcomes
Lekeisha Daniel-Robinson, MSPH	Boston University School of Public Health, Dept. of Community Health Sciences
Gene Declercq, PhD	Network for Excellence in Health Innovation
Susan Dentzer	Patient Representative, <a href="http://www.diabetesnotdefeated.com">www.diabetesnotdefeated.com</a> , <a href="http://Blackdiabeticinfo.com">Blackdiabeticinfo.com</a>
Phyllisa Deroze, PhD	MA Department of Public Health, Dept. of Family Health and Nutrition
Karin Downs, RN, MPH	University of Chicago School of Medicine
Annie Dude, MD, PhD	Patient Representative, Black Women's Health Imperative
Deborah Fair	Network for Excellence in Health Innovation
Valerie Fleishman, MBA	American Association of Diabetes Educators
Angela Forfia	MA Commission on the Status of Women
Liz Friedman	Black Women's Health Imperative
Linda Goler Blount, MPH	Primary Care Collaborative
Ann Greiner, MS	Ariadne Labs
Susan Gullo, RN	Wake Forest School of Medicine, Dept. of Endocrinology and Metabolism
Kristen G. Hairston, MD, MPH	Boston University School of Medicine, Dept. of Family Medicine
Brian Jack, MD	

Emily Jones, PhD, RNC-OB, FAHA, FPCNA	University of Oklahoma Health Sciences Center, Zeigler School of Nursing
Susan Kaufman, MS	Community Care Cooperative
Sarah A. Keim, PhD, MA, MS	Ohio State University College of Medicine, College of Public Health, Nationwide Children's Hospital
Shin Y. Kim, MPH	Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health,
Christina LaChance, MPH	U.S. Department of Health and Human Services, Health Resources and Services Administration, Office of Women's Health
Ana Langer, MD	Harvard T.H. Chan School of Public Health, Maternal Health Task Force
Monica Le, MD, MPH	MassHealth, University of Massachusetts School of Medicine
Aviva Lee-Parritz, MD	Boston University School of Medicine, Dept. of OB-GYN
Natasha Lerner, MPA	Boston University School of Public Health, Center of Excellence in MCH Education, Science, and Practice
Monica Mallampalli, PhD, MSc	HealthyWomen
Susan Manning, MD	Massachusetts Dept. Public Health, Bureau of Family Health and Nutrition
Sarah Mart, MS, MPH	DiabetesSisters
Shailja Mathur, MS, Med, RD	Rutgers University Cooperative Extension, Dept. of Community and Family Health Sciences
Leah Mayne	Patient Representative, Black Women's Health Imperative
Timoria McQueen Saba	Patient Advocate, <a href="http://www.Timoriaqueen.com">www.Timoriaqueen.com</a>
Kyle Megrath, MA	Boston University Center of Excellence in Women's Health
Erin Miller, MPH	Boston University School of Public Health
Suzanne E. Mitchell, MD	Boston University School of Medicine, Dept. of Family Medicine
Suzi Montasir, MPH	YMCA
Christine Morton, PhD	Stanford University
Jacinda Nicklas, MD, MPH/MSPH	University of Colorado School of Medicine at Denver, Dept. of Medicine
Michelle Owens-Gary, PhD	Center for Disease Control, Division of Diabetes Translation
Jennifer Pamphile	Boston University Center of Excellence in Women's Health
Athena Ramos, PhD, MBA, MS, CPM	National Hispanic Health Alliance, Rural Futures, University of Nebraska Medical Center
Sue Rericha	Patient Representative, DiabetesSisters, Diabetes Daily
Janet Rich-Edwards, ScD	Harvard University Chan School of Public Health, Dept. of Epidemiology
Amber Rucker	Ariadne Labs
Darshak Sanghavi, MD	Optum Labs
Suzanne C. Sarfaty, MD	Boston University School of Medicine, Dept. of Medicine, Global Health Programs
Ellen Seely, MD	Harvard Medical School, Dept. of Medicine, Brigham and Women's Hospital
Neel Shah, MD, MPP, FACOG	Harvard Medical School, Dept. of OB-GYN, Ariadne Labs
Georgia Simpson, MS	U.S. Dept. of Health and Human Services, Office of Minority Health
Nikki Spencer, MSW, MPH	Boston University Center of Excellence in Women's Health
Linda Sprague Martinez, PhD	Boston University School of Social Work
Suzanne Theberge, MPH	National Quality Forum
Lois Uttley, MPP	Community Catalyst



Madi Wachman, MSW, MPH

Elynor Walcott

Jasminn Winters

Susan Wood, PhD

Priscilla Woodson

Tina Yarrington, MD

Lynn M. Yee, MD, MPH

Laurie Zephyrin, MD, MPH, MBA

Chloe A. Zera, MD, MPH

Boston University, Center for Innovation in Social Work and Health

Patient Representative, Women in Control, Boston University

Patient Representative, Black Women's Health Imperative

The Milkin Institute School of Public Health-George Washington University, Jacob's Institute of Women's Health and Dept. of Health Policy and Management

Patient Representative, Black Women's Health Imperative

Boston University School of Medicine, Dept. of OB-GYN

Northwestern University Feinberg School of Medicine, Dept. of OB-GYN

New York University School of Medicine, Veteran's Health Administration

Beth Israel Deaconess Medical Center, Dept. of OB-GYN, Harvard Medical School

## Appendix B. List of WG Participants, by group

### WG: Advocate for Policy Changes to transform health care delivery

#### Co: Leaders

Chloe	Bird	The Rand Corporation
Cassie	Ryan	Boston College School of Nursing

#### Staff::

Bridgette	Maynard	Boston University School of Public Health
Martina	Spain	Boston University School of Public Health

#### Members:

Judith	Bernstein	Boston University School of Public Health
Ann	Celi	Brigham and Women's Hospital
Ann	Greiner	Patient Centered Primary Care Collaborative
Amy	Haddad	Association of MCH Programs
Arden	Handler	University of Illinois at Chicago
Irene	Headen	Drexel University School of Public Health
Kay	Johnson	Johnson Group Consulting
Shondra	McCage	Chickasaw Nation Department of Health
Lois	McCloskey	Boston University School of Public Health
Alyson	Northrup	Association of MCH Programs
Athena	Ramos	National Hispanic Health Alliance, Rural Futures, University of Nebraska Medical Center
Elena	Rios	National Hispanic Medical Association
Suzanne	Theberge	National Quality Forum
Chloe	Zera	Beth Israel Deaconess Medical Center

### WG: Align Research with women's lived experience over the life cycle

#### Co-Leaders:

Emily	Jones	University of Oklahoma Health Sciences Center
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#### Advisor:

Janine	Clayton	NIH Office of Research on Women's Health
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#### Staff:

Martina	Spain	Boston University School of Public Health
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#### Members:

Ndidiamaka	Amutah-Onukagha	Tufts University School of Medicine
Judith	Bernstein	Boston University School of Public Health
Ann	Celi	Brigham and Women's Hospital, Harvard Medical School
Karla	Damus	Boston University
Alissa	Dangel	Tufts Medical Center
Annie	Dude	University of Chicago
Joyce	Edmonds	Boston College School of Nursing
Erin	Ferranti	Emory University School of Nursing
Teri	Hernandez	University of Colorado at Denver, School of Nursing
Cassandra	Marshall	University of California, Berkeley School of Public Health
Lois	McCloskey	Boston University School of Public Health
Jacinda	Nicklas	University of Colorado, Denver
Joan	Rosen Bloch	Drexel University College of Nursing & Health Professions
Ellen	Seely	Brigham and Women's Hospital, Harvard Medical School

Lynn                      Yee                      Northwestern University

### **WG: Develop High Touch Models of Care**

#### Co-Leaders:

Sue                      Gullo                      Ariadne Labs

Tina                      Yarrington                      Boston University School of Medicine

#### Staff:

Ebere                      Oparaeké                      Boston University School of Public Health

#### Advisor:

Christine                      Lachance                      HRSA, Office of Women's Health

#### Members:

Jodi                      Anthony                      Mathematica Inc.

Judith                      Bernstein                      Boston University School of Public Health

Ann                      Celi                      Brigham and Women's Hospital and Harvard Medical School

Mary                      Fitzmaurice                      Centering Healthcare Institute

Christina                      Gebel                      March of Dimes, Massachusetts

Lisa                      Heelan-Fancher                      University of Massachusetts, Boston

Stacey                      Klamán                      University of North Carolina at Chapel Hill

Monica                      Mallampalli                      HealthyWomen

Lois                      McCloskey                      Boston University School of Public Health

Suzanne                      Mitchell                      Boston University School of Medicine

Rose                      Molina                      Beth Israel Deaconess Medical Center / Dimock Community Health Center

Madi                      Wachman                      Center for Innovation in Social Work & Health, Boston University

Chloe                      Zera                      Beth Israel Deaconess Hospital and Harvard Medical School

### **WG: Eliminate Disrespect, Racism, and All Implicit Bias Within Health Care**

Co-Leaders:                      University of North Texas HSC and Texas Christian University School

Chase                      Crossno                      of Medicine

Joia                      Crear Perry                      National Birth Equity Collaborative

#### Staff:

Brenna                      Burke-Weber                      Boston University School of Public Health

Ebere                      Oparaeké                      Boston University School of Public Health

#### Members:

Candice                      Belanoff                      Boston University School of Public Health

Judith                      Bernstein                      Boston University School of Public Health

Denise                      Bolds                      Bold Doula

Breanna                      Chachere                      Boston Medical Center, Perinatal Neonatal Quality Improvement Network

Colette                      Dieujuste                      Simmons University School of Nursing

Nneka                      Hall                      Quietly United in Loss Together (QUILT)

NeKeshia                      Jones                      Health Resources in Action

Lois                      McCloskey                      Boston University School of Public Health

Christine                      Morton                      Lamaze International

Joan                      Rosen Bloch                      Drexel University School of Public Health

### **WG: Preserve the Narrative: Using Health Data to Bridge the Chasm**

**Co-Leaders:**

Mary	Barger	University of San Diego School of Nursing
Suzanne	Sarfaty	Boston University School of Medicine
<b>Staff:</b>		
Brenna	Burke-Weber	Boston University School of Public Health
<b>Members:</b>		
Trude	Bennett	University of North Carolina School of Public Health
Joan	Rosen Bloch	Drexel University School of Nursing
Judith	Bernstein	Boston University School of Public Health
Rebecca	Carter	Tulane University School of Public Health
Daniel	Enquobahrie	University of Washington School of Public Health
Barbara	Lund	Fresenius Medical Care
Lois	McCloskey	Boston University School of Public Health
Randiesa	Spire	iCare Connect Healthcare, Inc
Vivienne	Souter	University of Washington School of Public Health, ACOG

**WG: Promote Investment in Communities**

Lilly	Marcelin	Resilient Sisterhood Project
Eboasetale	Eromosele	Boston University School of Public Health
Candice	Belanoff	Boston University School of Public Health
Judith	Bernstein	Boston University School of Public Health
Breanna	Chachere	Boston Medical Center, Perinatal Neonatal Quality Improvement Network
Alba	Cruz-Davis	Regis College School of Health Sciences and Health Administration
Nneka	Hall	Quietly United in Loss Together (QUILT)
Lois	McCloskey	Boston University School of Public Health
Anna	Norton	DiabetesSisters
Sue	Rericha	Diabetes Daily
Tamara	Thompson	Mother Earth Doula Care

**WG: Public Education to Heighten Awareness of Root Causes****Co-Leaders:**

Linda	Goler Blount	Black Women's Health Imperative
Christina	Gebel	March of Dimes, Massachusetts
<b>Staff:</b>		
Zendilli	Depina	Boston University School of Public Health
<b>Members:</b>		
Judith	Bernstein	Boston University School of Public Health
Denise	Bolds	Bold Doula
Ann	Celi	Brigham and Women's Hospital, Harvard School of Medicine
Joia	Crear Perry	National Birth Equity Collaborative
Phyllisa	Deroze	BlackDiabeticInfo.com, DiabetesnotDefeated.com
Nneka	Hall	Quietly United in Loss Together (QUILT)
Lois	McCloskey	Boston University School of Public Health
Suzi	Montasir	YMCA
Randiesa	Spire	iCare Connect Healthcare, Inc

**Appendix C. Acronyms**

## ACRONYMS

AAPI	Asian Americans and Pacific Islanders
ABA	American Bar Association
ACA	Affordable Care Act
ACGME	Accreditation Council for Graduate Medical Education
ACNM	American College of Nurse-Midwives
ACO	Accountable Care Organization
ACOG	American College of Obstetricians and Gynecologists
ADA	American Diabetes Association
AHA	American Hospital Association
ACP	American College of Physicians
AMA	American Medical Association
AMCHP	Association of Maternal and Child Health Programs
APHA	American Public Health Association
APN	Advanced Practice Nurse
AWHONN	Association of Women’s Health, Obstetric & Neonatal Nurses
BtC	Bridging the Chasm
CBO	Community Based Organizations
CDC	Centers for Disease Control and Prevention
CHW	Community Health Worker
CMMI	Center for Medicare and Medicaid Innovation
CMQACC	California Maternal Quality Care Collaborative
CMS	Centers for Medicare & Medicaid Services
CNM	Certified Nurse-Midwife
DEI	Diversity, Equity, and Inclusion
ED	Emergency Department
EHR	Electronic Health Record
EMC	Every Mother Counts
EMR	Electronic Medical Record
GDM	Gestational Diabetes Mellitus
HCA	Healthcare Associates

HDP	Hypertensive disorders in pregnancy
HEDIS	Healthcare Effectiveness Data and Information Set
HRSA	Health Resources and Services Administration
ICEA	International Childbirth Education Association
IDN	Integrated Delivery Network
IMI	Institute for Medicaid Innovation
IPE	Inter-Professional Education
MCH	Maternity Care Home
MCH	Maternal and Child Health
MCHB	Maternal and Child Health Bureau
MHH	Medicaid Home Health State Plan Option
MIECHV	Maternal, Infant, and Early Childhood Home Visiting
NAAAC	National Alliance to Advance Adolescent Care
NAACO	National Association of Accountable Care organizations
NBEC	National Birth Equity Collaborative
NCQA	National Committee for Quality Assurance
NICHD	National Institute of Child Health and Human Development
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIH	National Institutes of Health
NPCS	National partnership for Children and Families
NQF	National Quality Forum
OB	Obstetrics
ORWH	Office of Research on Women's Health
OWH	Office of Women's Health
PA	Physician Assistant
PC	Primary Care
PCMH	Primary Care Medical Home
PCMH	Patient-Centered Medical Home
PCORI	Patient-Centered Outcomes Research Institute
PCPCC	Patient-Centered Primary Care Collaborative
PN	Practical Nurse
PP	Postpartum

PPACA	Patient Protection and Affordable Care Act
PQC	Perinatal Quality Collaboratives
PRAMS	National Institutes of Health
PREM	Patient Reported Quality Measure
QCMBA	Quality Care for Moms and Babies Act
RCT	Randomized Controlled Trial
SDOH	Social Determinants of Health
SGIM	Society of General Internal Medicine
SMFM	Society for Maternal Fetal Medicine
USPSTF	U.S. Preventive Services Task Force
VA	Veterans Affairs
WG	Working Group
WHH	Women's Health Home