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)

Authors

Project Directors and Lead Authors: Lois McCloskey and Judith Bernstein

Ndidimaka Amutah-Onukagha, Tufts University School of Medicine
Jodi Anthony, Mathematica
Mary Barger, University of San Diego, Hahn School of Nursing
Candice Belanoff, Boston University School of Public Health
Trude Bennett, University of North Carolina Gillings School of Global Public Health
Chloe Bird, The Rand Corporation
Denise Bolds, Bold Doula
Brenna, Burke-Weber, Boston University School of Public Health
Rebecca Carter, Tulane University School of Public Health
Ann Celi, Brigham and Women's Hospital, Harvard Medical School
Breanna Chachere, Boston Medical Center, Perinatal Quality Improvement Network
Joia Crear-Perry, National Birth Equity Collaborative
Chase Crossno, University of North Texas Health Sciences Center/Texas Christian University School of Medicine
Alba Cruz-Davis, Regis College School of Health Sciences
Karla Damus, Boston University Medical Campus, Office of Human Research Affairs
Alissa Dangel, Tufts Medical Center
Zendilli Depina, Boston University School of Public Health
Phyllisa Deroze, Black Diabetic Info.com, DiabetesnotDefeated.com
Colette Dieujuste, Simmons University School of Nursing
Annie Dude, University of Chicago School of Medicine
Joyce Edmonds, Boston College Connell School of Nursing
Daniel Enquobahrie, University of Washington School of Public Health
Ebosetale Eromosele, Boston University School of Public Health
Erin Ferranti, Emory University N. H. Woodruff School of Nursing
Mary Fitzmaurice, Centering Healthcare Institute
Christina Gebel, March of Dimes, Massachusetts
Linda Goler Blount, Black Women's Health Imperative
Ann Greiner, Primary Care Collaborative
Sue Gullo, Ariadne Labs
Amy Haddad, Association of MCH Programs
Nneka Hall, Quietly United in Loss Together (QUILT)
Arden Handler, University of Illinois at Chicago School of Public Health
Irene Headen, Drexel University Dornsife School of Public Health
Lisa Heelan-Fancher, University of Massachusetts, Boston School of Nursing
Teri Hernandez, University of Colorado School of Nursing
Kay Johnson, Johnson Group Consulting
Emily Jones, University of Oklahoma Health Sciences Center, Ziegler College of Nursing
NeKeshia Jones, Health Resources in Action
Stacey Klaman, University of North Carolina Gillings School of Global Public Health
Barbara Lund, Frenesius Medical Care
Monica Mallampalli, HealthyWomen
Lilly Marcelin, Resilient Sisterhood Project
Cassondra Marshall, University of California, Berkeley School of Public Health
Bridgette Maynard, Boston University School of Public Health
Shondra McCage, Chicksaw Nation Department of Health
Suzanne Mitchell, Boston University School of Medicine
Rose Molina, Beth Israel Deaconess Medical Center / The Dimock Center
Suzi Montasir, YMCA
Jacinda Nicklas, University of Colorado School of Medicine
Alyson Northrup, Association of MCH Programs
Anna Norton, DiabetesSisters
Ebere Oparaeke, Boston University School of Public Health
Athena Ramos, University of Nebraska Medical Center
Sue Rericha, Diabetes Daily
Elena Rios, National Hispanic Medical Association
Joan Rosen Bloch, Drexel University College of Nursing and Health Sciences
Cassie Ryan, Boston College Connell School of Nursing
Suzanne Sarfaty, Boston University School of Medicine
Ellen Seely, Brigham and Women's Hospital, Harvard Medical School
Vivienne Souter, University of Washington School of Public Health, ACOG
Martina Spain, Boston University School of Public Health
Randiesa Spires, iCare Connect Healthcare, Inc.
Suzanne Theberge, National Quality Forum
Tamara Thompson, Mother Earth Doula Care
Madi Wachman, Boston University Center for Innovation in Social Work and Health
Tina Yarrington, Boston University School of Medicine
Lynn M. Yee, Northwestern University, Feinberg School of Medicine
Chloe Zera, Beth Israel Deaconess Medical Center, Harvard Medical School

Working Group Advisors:
Janine Clayton, NIH Office of Research in Women's Health
Christine LaChance, HRSA Office of Women's Health

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

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 (2017-18) we formed the BtC Stakeholder Engagement Leadership Council SELC), consisting of community and advocacy organizations and academic partners whose mission aligned with BtC, to guide the project.
In Phase 2 (July 2018) 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 (2019) 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 are 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 draft 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 and quality of care for pregnant and parenting people--in ways that are too often harmful and backward-looking, in some ways helpful and forward-looking. As research and program resources are (understandably) focused on COVID-19 at this time, sparce attention is being paid to reproductive-aged women, pregnant and birthing people, and their ongoing needs beyond birth and the postpartum period. While this report does not address COVID-19 per se, the pandemic magnifies the importance of the strategies presented in the *National Agenda for Research and Action to BtC.* We must keep our eyes on the prize as we move the Agenda forward, even as COVID-19 and its aftermath unfolds: policies and programs that support equity, dignity, and continuity in health care for women and all pregnant and parenting people 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

Bridging the Chasm

Public Education
Strategies TBD based on cross-cutting priorities

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.