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It's Time to Eliminate Racism and Fragmentation in Women's Health Care

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Three overlapping public health crises have profound consequences for the health of women of color in the United States: 1) deeply rooted systemic racism, tragically exposed by police violence (Alang, McAlpine, McCreedy, & Hardeman, 2017); 2) the COVID-19 pandemic, which has much higher death rates for Black, Hispanic, and Native American populations (Artiga & Orgera, 2020; Centers for Disease Control and Prevention, 2020a); and 3) a tripled mortality rate from pregnancy-related conditions for Black and Native women compared with White women (McDormand, DeClercq, Cabral, & Morton, 2016). In 2020,

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these injustices converged to produce a public outcry and an inducement for policymakers to quickly focus on the stark racial inequities in women's health care.

The Intersection of Racial Inequities and Fragmentation in Women's Health Care

In 2017 and 2018, the three-to four-fold greater risk of pregnancy-related mortality among Black women came to the attention of mainstream America as a profound marker of racial injustice. But for every such death, there are an estimated 100 near misses or cases of severe maternal morbidity, and Black mothers carry a disproportionate burden of risk for 22 of the 25 indicators for severe maternal morbidity (Centers for Disease Control and Prevention, 2020b).

For Black women, the leading causes of pregnancy-related mortality are cardiomyopathy, hypertensive disorders of pregnancy, and hemorrhage (Howell, 2018). Black women develop these conditions and their precursors earlier, are more likely to have related complications during pregnancy, and are more likely to die from these morbidities in the postpartum year than their White counterparts (Beckie, 2017). Notably, one-third of maternal deaths occur between 1 week and 1 year postpartum—a period that marks the end of obstetric care and the absence of connection to primary care for almost one-half of women with pregnancy complications (Bennett et al., 2014). Stories and survey findings that underlie these statistics reveal the impact of wide gaps in care after birth and hospital discharge, and an epidemic of disrespect and failure to listen to the voices of Black women in maternity care settings (Vedam et al., 2019).

Chronic conditions with multifactorial causes, such as diabetes and hypertension, are also more prevalent among Black and Brown and Native women than White women across the life course (Johnson-Lawrence, Zajacova, & Sneed, 2017; Quinones et al., 2019). Exposures to adverse physical, social, and economic inequities and stereotype threats accumulate over the life course and across generations; and these threats manifest as physical stress, metabolic dysfunction, and mental health burdens (Bailey et al., 2017); Basuer et al., 2016.

The reproductive years provide a window into the underlying and future health of women and opportunities for prevention—opportunities too often missed. There is robust evidence that pregnancy complications, including gestational diabetes, hypertensive disorders of pregnancy, depression, and substance use disorder, are all associated with future chronic illness (Allalou et al., 2016; Kramer, Campbell, & Retnakaran, 2019; Rayanagoudar et al., 2016). Gestational diabetes presents a case in point. Up to 60% of women with gestational diabetes may go on to develop type 2 diabetes in the following decade, yet only 20%–55% receive the recommended follow-up testing and connection to primary care in the 1–3 years after pregnancy (Bernstein et al., 2017; Shah, Lipscombe, Feig, & Lowe, 2011; Stuart et al., 2018). Moreover, Black, Latina, and Native women are most likely to develop type 2 diabetes, yet least likely to receive follow-up care (Jones, Hernandez, Edmonds, & Ferranti, 2019; McCloskey, Bernstein, Winter, Iverson, & Lee-Parritz, 2014; McCloskety et al., 2019).

Fragmentation in women’s health care is a long-standing, intransigent problem with structural roots and elusive solutions (Clancy & Massion, 1992). Public investment in women when they are pregnant, through such policies as the “pregnancy option” for Medicaid eligibility, ends with the postpartum period and leaves women in the chasm between obstetrics and ongoing primary an preventive care.

Launching a National Initiative to Bridge the Chasms of Racism and Fragmentation

In 2017–2019, we implemented a national initiative called *Bridging the Chasm (BtC) between Pregnancy and Health over the Life Course*, funded by the Patient Centered Outcome Research Institute, National Institutes of Diabetes and Kidney Disease, and Office of Research on Women’s Health. Our mission was to bring together a network of patients, advocates, providers, researchers, policymakers, and health system innovators to co-create a national agenda. We launched the initiative in July 2018 with a conference that combined an analysis of the evidence, storytelling, and consensus-building events to decide upon the agenda’s key elements. We convened groups of BtC network members to flesh out each element of the agenda over the next year.

In an accompanying article elsewhere in this issue, we describe the consensus-building process, the content of the agenda with a rationale for each selected strategy, and a road map of the path forward (BtC Collaborative, 2021). Here, we present the context for selecting these strategies and some examples of avenues for action.

Context for Action: Gathering of Political Will

We launched the project as the maternal mortality crisis was coming into public view. As the project concluded, the crisis garnered significant political attention that resulted in policy and research action. In 2019, at least eight bills that directly addressed racial disparities in maternal health were filed in the U.S. House of Representatives. This came on the heels of the bipartisan passage and presidential signing of the Preventing Maternal Deaths Act of 2018, which authorizes the Centers for Disease Control and Prevention to support state and tribal maternal mortality reviews. In 2021, policymakers are setting their sights on extending Medicaid coverage to the first year postpartum for women eligible through the pregnancy option.

In 2020, the National Institutes of Health (NIH) and private funders centered new funding initiatives on maternal mortality and morbidities and on strategic plans to address the links between pregnancy and women’s health over a life span. For example, the National Institute of Child Health and Human Development (2020) Strategic Plan highlights funding for research on pregnancy-related conditions that contribute to maternal morbidity and mortality, including the long-term health of women and their children (NIH National Institute of Child Health and Human Development Strategic Plan, 2020), and the 2019–2023 Strategic Plan of the Office of Research on Women’s Health (NIH Office of Women’s Health, 2019) that addresses the intersection of biological, social, and life course factors with disease prevention.

Across racial lines, a large proportion of the public increasingly acknowledges and calls for remedies to address the effects of racism on American life. This changing landscape creates a significant opportunity to elevate the issues of racism and fragmentation in women's health care and to press for substantive policy changes in both public and private spheres.

The Path Forward

The multiplank BtC agenda is based on evidence from science and the lived experience of members of the BtC collaborative as women, as community caregivers, and as clinicians, researchers, policy advocates, and health system innovators. The six working groups were: 1) eliminate racism and all forms of bias in health care, 2) invest in communities, 3) transform the structure/model of care, 4) enact policy scaffolding for the transformation, 5) preserve women's narratives in data systems, and 6) align research with women's lived experience.

The first plank sets forth strategies to eliminate racism and systemic bias at the interpersonal and institutional levels within health care systems by proposing mandatory, longitudinal, accreditation-backed health professions training programs that target institutional policies rather than focusing only on individual beliefs and behaviors. Discrimination by race, gender, weight, age, language, income, and insurance status results in overuse and underuse of services, affects patient safety (Cooper & Roter, 2003), and can create physiologic inflammation that contributes to chronic illness (Slopen et al., 2010; Sullivan et al., 2019). Tackling disrespect and racism within maternal health care is a prerequisite to other meaningful structural changes.

The second plank calls for devoting resources to community-based organizations headed by and for women of color. Community-based organizations (CBOs) are integral and well-situated to partner with women, advocates, policymakers, and researchers to find solutions that support women across the chasm. However, grassroots community organizations are often side-lined and at a disadvantage when competing against larger organizations for funds. The federal government can strengthen the capacity of small and moderate-sized CBOs (e.g., by creating a tax break for funders who allocate a percentage of their annual expenditures to CBO infrastructure costs). Private foundations can pool resources to fund a National Center for CBO Capacity Building to provide technical support to grassroots organizations owned or managed by women of color whose mission relates to women's well-being over the life course. Substantial investment in community organizations run by and for women of color sets the foundation for health system reforms that require community and patient engagement.

The third plank calls for core structural change to address women's longitudinal health needs and reimagine health systems and models of care to assure continuity, holism, and equity. To strengthen continuity, the agenda calls for primary care residencies to require educational units on the follow-up of pregnancy complications and obstetrical residencies to require referral to primary care as an essential component of postpartum care. To ensure holism and equity, comprehensive, collaborative, team-based models of care can be extended to the full postpartum year and supported by innovative cross-training curricula. These teams should be inclusive of nurse-midwives (Johantgen et al., 2012), doulas (Bohren, Hofmeyr, Sakala, Fukuzawa, & Cuthbert, 2017), and community health workers trained in maternal health (Kangovi et al., 2014)—all essential, woman-centric caregivers whose effectiveness and value is well documented. In addition, group models of care and patient-centered medical homes have a strong evidence base (Carter et al., 2016; Chuang et al., 2017; Jabbapour, DeMarchis, Bazemore, & Grundy, 2017). These approaches can be adapted and offer a strong bridge across the chasm to primary care.

The fourth plank addresses the public policies needed to extend and support high-touch models of care through the first postpartum year and beyond. The Centers for Medicare and Medicaid Services can play a vital role in ensuring coverage and incentivizing continuous comprehensive care. Legislation can require automatic, continuous enrollment in Medicaid through the postpartum year, and the Centers for Medicare and Medicaid Services can use its program authority to expand benefits, such as doula care, and support linkage to primary care after pregnancy through pay-for-performance policies. The National Quality Forum can hold systems accountable for follow-up of pregnancy complications by developing new postpartum quality measures, such as glucose tolerance tests for women with gestational diabetes, blood pressure cuffs at discharge after pregnancy-related hypertension, and patients' reports of the presence or absence of respectful care.

The fifth plank proposes strategies to preserve women's narratives—their stories of significant experiences during pregnancy—and their medical data through innovations in data systems. Improving the flow of information and communication between patients and providers and within and across specialties and health data systems raises complex challenges: time constraints, the absence of appreciation for the patient's story, and a lack of electronic "highways" to connect health records across specialties and illness episodes. Solutions are both technical (e.g., electronic medical record solutions, including the development of a postpartum discharge template with coded fields) and interpersonal (e.g., inviting women to read clinical notes and to record brief stories to inform providers about important issues that might have been missed) (Leveille et al., 2020). New digital technologies (web- and mHealth-based) that place in women's hands the tools needed to follow their own health needs after pregnancy can augment electronic medical record systems change.

Finally, a reimagined research and evaluation agenda can generate evidence of the efficacy and impact on equity of the models of care, policies, and data systems within the BtC agenda. Specifically, the Agenda calls on the NIH, Health Resources & Services Administration, and private foundations to create funding streams to support longitudinal, holistic, culturally based, and racially just research, centered on women's lived experience. The agenda calls on funders to promote new approaches to patient- and community-engaged research, outcomes during the full postpartum year, and mentor and fund women of color to lead the research.

Legislative Momentum on Enacting the BtC Agenda

Most of the myriad legislative proposals pending in state-houses and the U.S. Congress address the maternal mortality and severe morbidity crisis. Although they do not speak to the critical absence of continuity and integration between obstetrics and primary care for women between pregnancies and beyond, they do set the stage for the BtC agenda and offer policy levers.

For example, the Black Momnibus Act (HR 6142) offers several avenues for incorporating the BtC agenda. Funds directed to innovative approaches to prenatal and postpartum care promoted in this act, such as group care, could be used to target mothers with a history of chronic illnesses. Support for implicit bias training in maternity care settings could cover institutional as well as interpersonal racism, be tied to health professions program accreditation, and be expanded to primary care settings.

Two other 2019 bills—the Maternal Health Quality Improvement Act and the Helping Medicaid offer Maternity Services (MOMS) Act—would extend Medicaid coverage for new mothers for 1 year after pregnancy, authorize public health programs such as the perinatal quality collaboratives, improve care for women in rural areas, and support provider training in implicit bias and culturally competent care.

These and other legislative proposals offer a platform upon which the primary goal of the BtC agenda—the inclusion of care and coverage for women across the chasm and assurance of a primary care home—can be added. This policy expansion, essential for reducing maternal deaths and severe morbidities, would also prevent chronic illness and promote well-being across a woman's life course while also addressing racism and fragmentation in women's health care that underlies the U.S. maternal mortality crisis. Our country's current intersecting crises—systemic racism, COVID-19 racial inequities, and rising and disproportionate maternal mortality/morbidity—offer an unprecedented opportunity to achieve what has so far proved elusive.

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