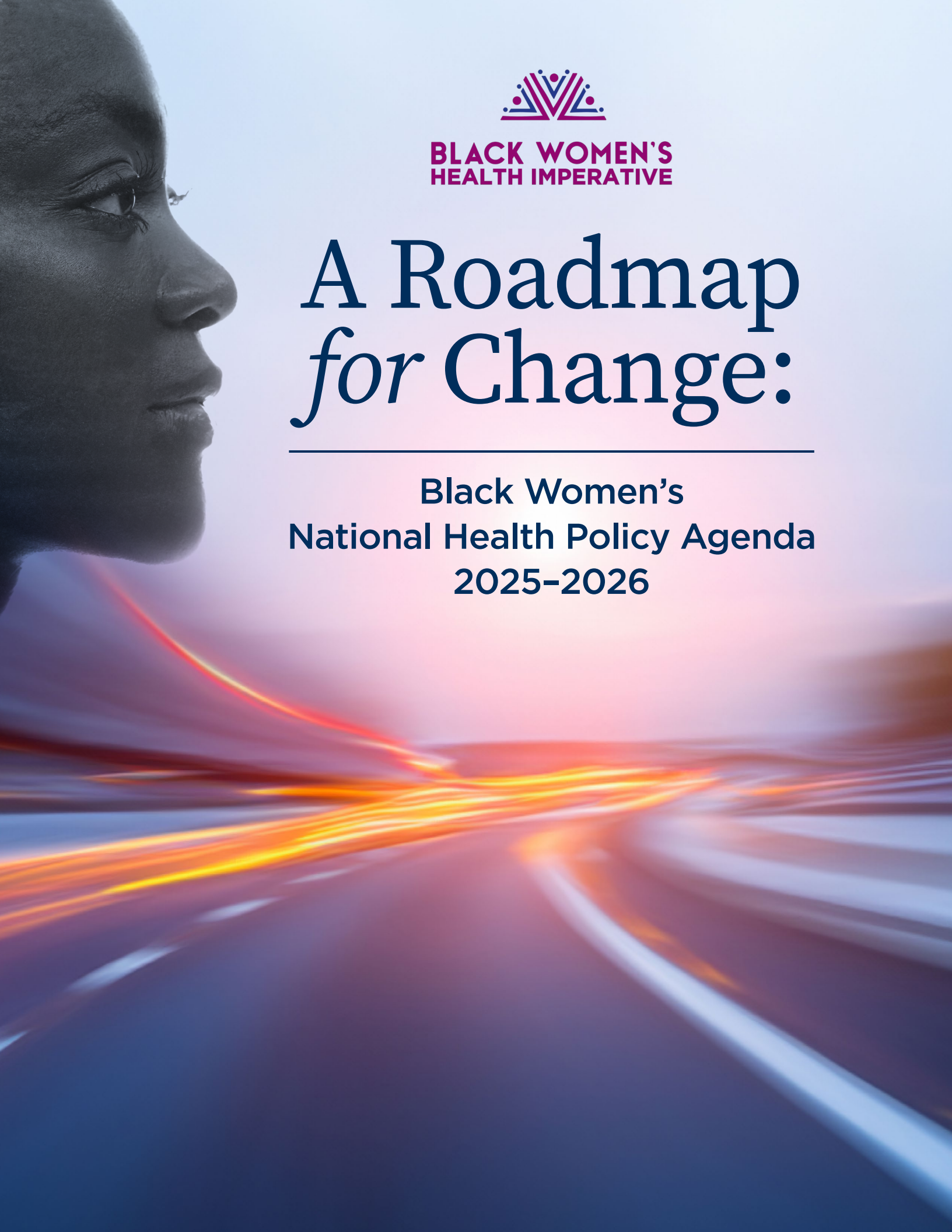

BLACK WOMEN'S HEALTH IMPERATIVE

A Roadmap *for* Change:

Black Women's National Health Policy Agenda 2025–2026

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BLACK WOMEN'S HEALTH IMPERATIVE

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President's Letter

Joy D. Calloway, MHSA, MBA
President & CEO
Black Women's Health Imperative

Dear Stakeholders,

I write to you at a turning point, not just for our nation, but for Black women and girls whose health, safety, and economic security hang in the balance.

Right now, federal workers face uncertainty about when their next paycheck will come. Medicaid has been gutted, eventually stripping essential coverage from millions of people, including hundreds of thousands of Black women and families who depend on it to survive. This year alone, more than 300,000 Black women lost their jobs, many from the very sectors that kept this country running during the pandemic. And while crucial health information has been scrubbed from government websites, the long-term implications of CDC and HHS rollbacks have weakened the very infrastructure meant to protect public health.

Meanwhile, artificial intelligence is reshaping healthcare, employment, and democracy itself—often without the ethical guardrails needed to protect our communities from bias and harm.

The state of our union is fragile. But our collective power? Sturdy. Robust. Unshakeable.

At the Black Women's Health Imperative, we know that moments like this demand both clarity and courage. For forty-two years, we have been solving the most critical health issues facing Black women and girls through innovative programs, transformative research, and life-saving policies. We do not wait for broken systems to fix themselves. We build new ones—rooted in equity, justice, and the knowing that when Black women are centered, everyone rises.

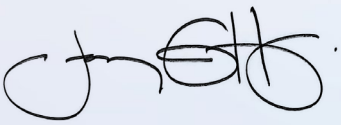
This year's National Health Policy Agenda reflects that commitment. It advances solutions that place Black women at the center of national conversations on health, economic security, and technology. Through our 5 policy pillars, we tackle Medicaid access, reproductive justice, maternal mortality, chronic disease, and the ethical use of AI in healthcare. And we call on policymakers not just to see us or hear us, but to act boldly, urgently, and in partnership to deliver lasting change.

As BWHI's new President and CEO, I stand on the shoulders of visionary women who refused to accept inequity as destiny. Byllye Avery gathered 2,000 women on the campus of Spelman College in 1983 and sparked a movement. That fire - for health equity for Black women and girls - still burns brightly. And it is our responsibility to carry it like a torch for this generation and the ones to come.

Black women deserve more than survival. We deserve safety, dignity, economic opportunity, and the full promise of this nation. The policies in this agenda are our blueprint for making that vision real.

I invite you, implore you, challenge you to join us. Read the agenda. Share it. Discuss it. Use it to advocate in your communities and at every level of government. And if you are in a position to shape policy, fund programs, or open doors—partner with us. Because the fight for Black women's health is the fight for justice itself.

With resolve and hope,



Joy D. Calloway, MHSA, MBA
President & CEO
Black Women's Health Imperative

Executive Summary

Black women's health is at a defining moment. Despite decades of progress in awareness, coverage, and advocacy, too many Black women and girls still face preventable barriers to care and health outcomes that expose the deep structural inequities embedded within our health system.

A Roadmap for Change: Black Women's National Health Policy Agenda 2025–2026 is both a roadmap for the future and a call to action for policymakers, advocates, and partners to demonstrate a greater commitment to advancing policies that center the experiences, rights, and wellbeing of Black women and girls at every stage of life.

Rooted in the Black Women's Health Imperative's legacy of policy, research, and community leadership, this agenda outlines a comprehensive vision for equitable policymaking and accountability in six key areas: Medicaid, Maternal Health, Reproductive Justice, HIV, Chronic and Rare Diseases, and Technology and Artificial Intelligence. Each area represents one piece of a larger fight to advance real health equity for Black women and girls.

Our policy priorities detailed in this Agenda focus on:

- Protecting and expanding Medicaid so Black women and families have continuous, affordable coverage across the lifespan.
- Improving maternal health outcomes by investing in workforce development, addressing chronic disease, and fully integrating doulas and midwives into care.
- Defending reproductive justice by safeguarding abortion access, ensuring contraceptive and menstrual equity, and expanding comprehensive sex education.
- Ending disparities in HIV prevention and care through equitable access to testing, PrEP, and supportive services that prioritize health and safety.
- Transforming how chronic and rare diseases are studied and treated through inclusive research, prevention, and treatment that see us fully.
- Ensuring equitable access to technology and AI while protecting communities from bias, data misuse, and environmental harm.

BWHI's work begins with research that captures the lived realities of Black women and girls and translates that evidence into action. Whether through our research studies on cancer screening and menopause or broader analyses of Black women's health, our findings reveal an undeniable truth: policy built without the data and experiences of Black women and girls cannot produce truly actualized justice.

To be clear: this agenda comes at a time of deep uncertainty. Across the country, rollbacks and funding cuts threaten the very programs that our communities rely on most. This document does not cover every issue where Black women are disproportionately experiencing harm – but it reflects the fights we must have now and the ones BWHI is most equipped to lead.

Still, this is about more than closing gaps, because Black women and girls deserve more than that. It is about building systems that allow us to live fully and freely. This agenda calls on policymakers, healthcare leaders, and technology developers to meet this moment with accountability, courage, and care. By advancing this agenda, we claim a future where Black women's health is central to our nation's wellbeing – where thriving in health and dignity is our everyday reality.

Black women's health experiences and outcomes have always told the truth about who this country values, listens to, and protects. We deserve more than survival. We deserve systems that do not only respond when we are already in crisis. This agenda envisions what is *possible* when we no longer have to piece together care from fragmented systems and when our choices can move beyond survival and pain toward wholeness and joy.

For us, health equity is not a far-fetched aspiration. It is our mandate. It is our imperative.

AUTHOR'S NOTE

We acknowledge the extensive history of scientific racism that erases, disregards, and misrepresents Black women, queer, and trans individuals.[1] While we use the term "women" throughout this agenda in order to be in alignment with the sources of the data referenced, we recognize that these data likely capture the experiences and outcomes of queer and trans individuals not provided the opportunity to self-identify. Additionally, while we present Black women's outcomes in comparison to white women, we reject the notion that white women represent the assumed baseline.[2] This practice is utilized in this policy agenda to highlight disparities, which is critical for exposing pervasive systemic inequities and shaping interventions that advance equitable health outcomes for Black women.

Research at BWHI

Women's Health Research

For decades, health research did not adequately include women, an issue recognized by the National Institutes of Health (NIH), which prompted the establishment of the Office of Research on Women's Health in the 1990s.[3] Despite the significant gains in the inclusion of women in the past 30 years, women's health remains significantly understudied.[4] There are many instances where women are still receiving treatment based on evidence, outcomes, and observations from research conducted entirely or mostly on men. Being underresearched leads to poor understanding of issues and treatment, which may put women at risk. Advancing women's health and health disparities research is essential to advancing science itself and improving women's overall health and outcomes.

To address the disparities in women's health, research must inform effective programs and policies that are responsive to the lived experiences of the people and communities that they serve. At BWHI, translating data collected from Black women and girls into actionable insights ensures that policy decisions are grounded in sound science, an approach that is especially critical in today's political climate. The rest of this section will detail the importance of conducting research at BWHI, the role of research in policy, and describe two studies conducted by BWHI where science is used to inform policy.

BWHI's Research Approach

The disparity in women's health research is even more evident in Black women, who continue to be inadequately represented in research while being overrepresented in disease.[5] As a result, women's health research results can not always be generally applied to Black women.[6] BWHI's approach to research focuses on collecting and analyzing data and using results to contribute to the organization's mission to solve critical health issues that Black women and girls face. With a focus on using culturally relevant and community-engaged methods, BWHI conducts research that reflects the lived experiences of Black women and girls in order to identify systemic barriers, provide education and awareness, and inform policies.

Partnerships with academic institutions, community organizations, healthcare providers, policymakers and our most important stakeholders- the voices of Black women- are central to BWHI's work. Working with partners allows BWHI to expand its reach and create solutions that are responsive to the needs of the community and also sustainable at a systems level.

The Role of Research in Policy

At BWHI, the integration of research and policy happens from the beginning. Research questions are informed by policy priorities and the evidence that is generated from the research is then used to inform legislation, shape guidelines, and support advocacy. Based on findings from research conducted at BWHI, the Policy and Research Team develops strategies to advance legislation, creates policy briefs and fact sheets, and collaborates closely with elected officials and movement partners.

CURRENT RESEARCH PROJECTS

Project Health Equity

The Research: Black women in Alabama and Georgia continue to experience higher breast and cervical cancer mortality rates despite similar incidence rates compared to White women.[7,8] These disparities are largely driven by systemic barriers, including limited access to early detection and high-quality care, as well as delays in follow-up after abnormal screenings.[9] Addressing these multi-level challenges requires coordinated efforts that integrate research, clinical services, and community engagement.[10]

Project Health Equity (PHE) is a partnership between the Black Women's Health Imperative (BWHI) and Hologic, along with the University of Alabama at Birmingham (UAB) and Morehouse School of Medicine (MSM). The goal of this study is to increase cancer screenings by identifying and addressing barriers to breast and cervical cancer care among Black women. The study includes:

- Outreach and enrollment through clinical and community channels.
- Patient navigation to reduce barriers to screening and follow-up.
- Data collection and analysis to measure impact and guide improvements.

Preliminary findings include the completion of 55 breast cancer and 38 cervical cancer screenings in Alabama as a result of the navigation services offered to participants in the study, demonstrating the impact of this unique partnership. Identified barriers to screening include insufficient healthcare communication around screening recommendations, out of pocket costs, insurance availability, and difficulties with appointment scheduling. As findings continue to emerge, the project will aim to inform institutional practices, shape policy, and guide the development of a research agenda focused on eliminating inequities in breast and cervical cancer outcomes.

The Policy: The United States Preventive Services Task Force (USPSTF)'s decision to update guidelines to begin breast cancer screening at age 40 is important for Black women who are more likely to be diagnosed at a younger age, are diagnosed with more aggressive forms, and have a 40% higher mortality rate than White women.[11] Previously, the recommendation was for women to make an individual decision with their clinician about screening between the ages of 40 and 50. For cervical cancer, evidence shows that Black women receive screening, but experience delays in follow-up care, thus contributing to higher mortality rates.

Findings from the PHE study, in addition to the updated USPSTF guidelines, highlight the need for policies that can close that gap between healthcare recommendations and access for Black women. Policy implications can include:

- Expanding Medicaid coverage and other safety-net programs for preventative services like breast and cervical cancer screening.
- Implementing policies that require care coordination, navigation, and funding so that women can promptly complete follow-up care after abnormal results.
- Increasing funding to expand access for screening in rural and underserved areas, including funding for mobile units and partnerships with federally qualified health centers (FQHCs).

Black Women's Perimenopause and Menopause Survey

The Research: During the menopausal transition, Black women often experience an earlier onset, longer duration, and more severe symptoms, such as hot flashes, which affect 79% of Black women compared to 65% of White women.[12] Black women are also less likely to seek medical care or utilize available resources for menopausal symptoms, though the reasons for this disparity are poorly understood.[13] Despite the prevalence of severe menopausal symptoms among Black women, there remains a significant gap in research addressing their unique experiences and barriers to care.[14] This study aims to fill this research gap by exploring the interplay of cultural, socioeconomic, and systemic factors that shape the menopausal experiences of Black women by:

- Exploring the lived experiences of Black women during the menopause transition.
- Identifying barriers to accessing menopausal care among Black women.

Preliminary findings from the survey show that overall, Black women are knowledgeable of the stages and management options for menopause, but less knowledgeable about all of its symptoms and what constitutes early menopause. While Black women report many sources of menopause information, they experience challenges because none of those sources are regarded as useful, demonstrating a need for a variety of resources and support on healthy aging and menopause.

The Policy: These findings provide the evidence to develop policy grounded in data and the lived experiences of Black women that can address gaps in access to information, culturally responsive care, and clinician training. Examples of potential implications include:

- Expanding insurance coverage for menopause-related care.
- Funding for provider training to address racial and cultural differences in symptoms.
- Inclusion of Black women in federally-funded research.

Next Steps

These are just two examples of how BWHI uses research to inform policy. BWHI remains committed to translating research into action by shaping evidence-based policies to ensure that Black women and girls are included and prioritized in national health conversations.

Our Policy Pillars

At BWHI, we know that the health, wellbeing, and advancement of Black women and girls depend on bold, comprehensive policies that address systemic inequities and create opportunities for us to thrive throughout all stages of our lives.

Guided by five interconnected pillars, BWHI's policy work focuses on key issue areas necessary to secure quality and affordable healthcare, strengthen families, ensure equitable governance, expand education and employment opportunities, and promote access to technology and artificial intelligence in safe and sustainable ways.[15] Together, these pillars provide a path forward for building a more healthy, just, and empowered future for Black women and girls.

Pillar I: Access to Quality and Affordable Healthcare

Access to quality and affordable healthcare is essential for improving overall health outcomes and reducing health disparities. This multifaceted pillar centers on the following key issue areas: sexual and reproductive health, rights, and justice, Medicaid and Medicare protection and expansion, HIV prevention and treatment, mental health services, women's health research, drug pricing, chronic disease prevention and management, and rare disease management. Every generation of Black women and girls deserve the opportunity to make decisions about their health based on evidence-based information in consultation with culturally competent healthcare providers.

Pillar II: Healthy Families and Children First

Healthy families and children are the foundation of a thriving society. This pillar emphasizes the importance of comprehensive policies that support maternal health and wellness, including maternal mental health, financial stability, housing, and nutrition/food security for families and children. By prioritizing these areas, we can ensure that all children have the opportunity to succeed and that families have the resources they need to thrive.

Pillar III: Equitable Governance and Relationships

If we truly strive to form a more perfect union, we must have equitable governance that is "of the people, by the people, and for the people." This pillar centers on the important role of building transformative relationships with lawmakers, policymakers, and coalition partners at the federal, state, and local levels to ensure that policy changes protect and promote the health and well-being of Black women and girls.

Pillar IV: Employment/Education Justice and Equity

Employment and education justice and equity are vital for ensuring that all individuals have access to fair opportunities and support systems. This pillar addresses the need for culturally tailored and comprehensive curricula for the training of health leaders. Competent comprehensive sex education, as well as the impacts of climate change on health, workplace protections for pregnant and postpartum workers, and protecting the mission of and funding for Historically Black Colleges and Universities (HBCUs). Ensuring justice and equity in these areas promotes a more inclusive and supportive society.

Pillar V: Technology Access and Artificial Intelligence (AI)

Access to technology and the ethical use of artificial intelligence (AI) are critical for ensuring that all individuals can participate in and benefit from the digital economy. This pillar addresses the need for equitable technology access, the ethical development and deployment of AI language models and the promotion of digital literacy and skills.

I. Medicaid

Overview

Medicaid is a critical pillar of our country's healthcare system and a cornerstone of healthcare access for Black women and girls. When Medicaid functions at its full capacity, it supports wellness at every stage – from preventive pediatric care to reproductive and maternal health, chronic disease management, and aging with dignity. When it's weakened, Black women and girls feel the consequences disproportionately. **The Black Women's Health Imperative (BWHI) is committed to protecting Medicaid from harmful restrictions on its core functions and advancing state and federal reforms that strengthen the program's capacity to meet Black women's health needs across the lifespan.**

The Medicaid Program

Medicaid is a joint federal and state government program established in 1965 by President Lyndon B. Johnson to provide health coverage to low-income individuals.[16] The federal government primarily serves to provide financial support and set required guidelines for Medicaid program operation, while each state government is responsible for determining eligibility, covered benefits, and provider payment methods.[17] Over the last 60 years, Medicaid has grown to fill critical gaps in the U.S. healthcare system by extending coverage to low-income families, pregnant women, people with disabilities, and people with long-term care needs.[18]

While Medicaid may sometimes supplement an individual's coverage, it is distinct from other forms of health insurance like Medicare, the Children's Health Insurance Program (CHIP), and private plans offered through the Affordable Care Act (ACA) marketplace. Each serves different populations: Medicare covers individuals aged 65 and older, people with certain disabilities, and people with End-Stage Renal Disease (ESRD) or Amyotrophic Lateral Sclerosis (ALS); CHIP serves children and teenagers up to age 19 who do not qualify for Medicaid and cannot afford private insurance; and the ACA marketplace is designed for people who cannot access affordable coverage through an employer, Medicare, or Medicaid.[19,20,21] Thus, Medicaid is an irreplaceable pillar of the U.S. healthcare system, serving low-income individuals and continually adapting to close gaps left by other programs.

Medicaid's Impact on Black Women and Girls

Medicaid's impact on the lives of Black women and girls cannot be overstated. One in four, approximately 3.3 million, Black women rely on Medicaid for healthcare coverage.[22] Additionally, 52% percent of Black girls under 18 are covered by Medicaid.[23] This emphasizes Medicaid's role as a vital safety net program, providing coverage for comprehensive healthcare services that would otherwise be unaffordable for many in our community. A particularly critical area of this essential coverage is labor and delivery services. Medicaid pays for 65% of births by Black

mothers, making it the largest payer for Black maternal healthcare.[24] Given its influence on how Black women and girls are born, give birth, and receive care throughout their lives, Medicaid is essential to supporting the health and well-being of our community.

The Medicaid Landscape: Essential Policies, Ongoing Limits, and Rising Threats

Medicaid programs across the U.S. have utilized, and are integrated into, several core provisions, including Medicaid expansion, the 340B Drug Pricing Program, pregnancy-based eligibility and coverage through the postpartum period, and reimbursement for doula and midwifery care, to expand access to care for millions. These policies bring us closer to a society where healthcare is accessible for all – not only those that can afford it.

Yet, even as these policies have fostered progress, numerous policies continue to limit access to care. Longstanding provisions like the Hyde Amendment restrict access to abortion services for Medicaid enrollees, and across the country, efforts to weaken key Medicaid protections are on the rise.

Because Medicaid covers such a significant portion of access to care for Black women and girls, any attempts to destabilize the program would cause the greatest harm to our communities. Below, we outline the Medicaid policies BWHI believes are necessary to ensure that Medicaid effectively serves all Black women and girls.

Medicaid Expansion

Medicaid expansion is one of the most significant healthcare reforms of the modern era that has dramatically improved access to care. The Affordable Care Act (ACA) gave states the authority to extend their Medicaid program eligibility to low-income individuals with incomes up to 138% of the Federal Policy Level ($21,597 in 2025).[25] Before the ACA, many low-income, nondisabled adults were excluded from Medicaid unless they were pregnant, parenting, caring for dependents, or fit into another narrowly defined eligibility group.[26]

To incentivize states to adopt Medicaid expansion, the federal government offers states a 90% federal matching rate towards the costs of covering expansion enrollees.[27] As a result, forty states and Washington D.C. have expanded their Medicaid programs.[28] Today, expansion enrollees make up about 24% of all Medicaid beneficiaries.[29] This growth is a striking depiction of how this policy has broadened healthcare coverage nationwide.

Unfortunately, most of the states that have not expanded Medicaid are located in the South, where 56% of the country's Black population resides.[30] In these states, nearly half of unsinured adults would become eligible if Medicaid expansion were adopted.[31] The decision to forgo expansion leaves far too many individuals, including Black women and girls who would otherwise qualify, without access to health insurance. It also prevents them from benefiting from the well-documented advantages of Medicaid expansion, including health improvements like higher rates of routine and preventive care, reduced rates of positive depression screenings, and earlier cancer diagnoses, as well as economic benefits like an average $1,140 reduction in medical debt per person, fewer evictions, and improved access to credit.[32]

Despite gains in coverage, Medicaid expansion states and enrollees continue to be targeted in federal proposals aimed at reducing access and spending. In fact, the recent 2025 reconciliation package, or H.R. 1, One Big Beautiful Bill Act, signed into law on July 4, 2025 imposes a series of harmful restrictions on expansion states specifically. These include:

- **Harsh work requirements for adults aged 19 to 64**. Roughly 20 million Medicaid expansion enrollees are at risk of losing coverage under these policies, even though evidence shows that work requirements do not increase employment.[33,34] Most adults with Medicaid already work full time.[35] Among those who do not, many are unable to work due to disability, caregiving responsibilities, or school, or have part time employment.[36] Work requirements would therefore fall hardest on Black women, who are more likely to be employed in low-wage, part-time jobs with fewer benefits, and who often shoulder caregiving responsibilities for loved ones.[37,38]
- **More frequent eligibility redeterminations.** These measures do little to prevent "fraud", but instead disproportionately cause eligible people to lose coverage.[39] Missed mail, administrative delays, or confusing paperwork are very simple, everyday examples of how an individual who otherwise continues to meet eligibility standards could be disenrolled from their Medicaid coverage.[40]
- **Mandatory copays up to $35 for certain services that were previously free or lower cost.** For low-income patients, even minimal increases in copays can deter use of healthcare services and lead to worse health outcomes.[41]
- **Permission for providers to turn away patients who cannot pay**. This policy fundamentally undermines Medicaid's role as a safety net by restricting when, where, and how patients who are already facing barriers to affordable care can access necessary services.
- **Limits on provider taxes**. States depend on provider taxes to finance their Medicaid programs.[42] By capping these tax rates, the federal government is essentially reducing state Medicaid funding and forcing unacceptable trade offs: cut services, cut coverage, or raise costs.[43] Each of these choices would severely impact Medicaid expansion enrollees.

Taken together, these restrictions undermine the progress Medicaid expansion has achieved, put millions of low-income individuals at risk of losing access to coverage and care, and create disincentives for states that have not yet expanded to do so. For states that already have, the new requirements make it harder to maintain these coverage gains. For Black women and girls, these changes will deepen inequities in access to care and chip away at the central purpose of Medicaid expansion: reducing barriers to care for those most in need.

Medicaid expansion states and enrollees continue to be targeted in federal proposals aimed at reducing access and spending.

POLICY RECOMMENDATIONS

- **Repeal work requirements and additional eligibility redeterminations.** These measures are associated with coverage loss due to administrative churn and procedural disenrollments, rather than actual ineligibility.[44] In addition to being confusing for enrollees, these reporting requirements are complex and costly for states to implement, while failing to achieve stated goals of increasing employment and reducing fraud.[45]
- **Reinstate state flexibility to use provider taxes**. Provider taxes are a core financing tool for Medicaid. Allowing states to set and use provider tax rates ensures reliable, stable funding and protects access to essential care for expansion enrollees.
- **Remove financial barriers to care, including higher copays and provider refusal of patients who cannot pay.** Medicaid has existed as a critical safety-net program for 50 years. Policies that limit access based on ability to pay would not only betray the program's core purpose, but also push millions of vulnerable patients out of care, with significant health and financial repercussions.

Medicaid's 340B Drug Pricing Program

The 340B Drug Pricing Program was established by Congress in 1992 to protect safety-net hospitals and the low-income communities they serve from rising drug prices.[46,47] By allowing eligible entities to purchase medications at reduced prices, the program was intended to lower prescription costs for patients so that covered entities could use these savings to expand access to comprehensive, essential services like dental care, mental health support, HIV treatment, and more.[48] Today, there are over 40,000 covered entities in the program, and they have purchased over $66 billion in outpatient drugs in 2023 alone.[49]

While 340B was well intended, its benefits have not consistently reached the patients it was created to help. Disproportionate Share Hospitals (DSHs), which serve a higher percentage of low-income patients and receive funding from the Centers for Medicare and Medicaid Services to help cover the cost of care for uninsured patients, receive 80% of the 340B program's money.[50,51] However, unlike other covered entities such as federally qualified health centers and Ryan White clinics, DSHs are not required to reinvest those savings into the communities they serve.[52] Most 340B hospitals also are not obligated to pass on medication discounts or financial assistance to patients, allowing them to charge full price and keep the profit.[53] In many cases, these hospitals provide minimal free or discounted care and instead, use aggressive billing practices to collect medical debt from patients.[54] The lack of consistent reporting standards across 340B-covered entities, particularly for the entities that profit the most, undermines the program's intended impact of improving healthcare access for medically underserved communities.

The prioritization of profit over patients in the operations of 340B-covered entities leaves low-income, uninsured patients vulnerable and without recourse. Despite repeated reporting, the discrepancies in savings that covered entities receive versus what patients actually see remains alarmingly normalized. According to the Government Accountability Office (GAO)'s review of 55 covered entities, only 30 provide discounts to low-income, uninsured patients at some or all of their contract pharmacies, and of those, only 23 pass the full discounts to patients. [55] Compounding this problem, there are no standardized patient protections or clear definitions of who qualifies as a "patient", which makes accountability even more difficult.[56] For example, community clinics can only purchase 340B drugs for patients who receive care from a narrowly defined set of services, but hospitals are not restricted in the same way.[57] This has raised concerns that some 340B hospitals may use the program's benefits to serve wealthier communities and increase their revenue, instead of keeping the focus on underserved patient populations.[58,59]

Without reform, low-income, unsinured patients will continue to accumulate medical debt, struggle to afford essential medications, and face difficulties adhering to care plans.[60,61,62] For Black women specifically, who rely heavily on services provided at Ryan White HIV clinics and federally qualified health centers, abuses of the program by hospitals not held to the same accountability and transparency in reporting standards significantly limit the care and resources they should receive.[63,64] This ongoing misalignment effectively prices out the patients the program was designed to protect – a troubling trend already pervasive across changes to Medicaid in 2025 and that must not be repeated in the 340B drug pricing program.

POLICY RECOMMENDATIONS

- **Reform hospital eligibility to prioritize providers that serve large numbers of low-income, underinsured, and uninsured patients.** This ensures that 340B program funds are directed toward the communities they were designed to serve, instead of being diverted to higher-income areas or patient populations.
- **Require all 340B entities to report revenue and use of savings to standardize transparency and accountability.** Building on the reporting practices of entities already held to these standards, all hospitals who provide access to care for 340B enrollees should be required to demonstrate concrete community impact, including showing how dollars are supporting care support to low income /underinsured communities and routine audits should ensure that program resources are being used to benefit low-income, uninsured patients.
- **Establish sliding scale pricing for patients and set minimum charity care standards for 340B entities.**[65] These measures guarantee that hospitals provide adequate charity care while making medications truly affordable through sliding scale pricing. Patients should also be clearly informed of these benefits both at clinics and at pharmacy counters.

Black women are over three times more likely to die from pregnancy-related complications than White women, and over 60% of pregnancy-related deaths occur during the postpartum period – most between 42 and 365 days after delivery. [331,332]

Pregnancy-based Medicaid Eligibility and Postpartum Coverage

Pregnancy is a common entry point into Medicaid coverage, particularly for women of reproductive age.[66] Under federal law, states are required to provide pregnancy-based Medicaid coverage to eligible individuals through 60 days postpartum.[67] Today, almost every state – including Washington, DC – has adopted the new option to extend Medicaid postpartum coverage to 12 months, except for Wisconsin.[68]

While states' adoption of the 12-month postpartum coverage Medicaid extension is relatively recent, early evidence of benefits is compelling. In Texas, for example, women with extended coverage used twice as many postpartum services, 10 times as many contraceptive services, and three times the number of mental health and substance use disorder services.[69] They also experienced fewer short interpregnancy intervals, which are associated with poor maternal and infant health outcomes.[70,71] Early research also shows that continuous coverage allows more time to address the leading causes of pregnancy-related deaths, including hypertensive disorders, diabetes, and other chronic conditions more common among Medicaid enrollees, and mental health conditions.[72]

The stakes for establishing 12 month postpartum coverage as a national standard are particularly high for Black women. Black women are over three times more likely to die from pregnancy-related complications than White women, and over 60% of pregnancy-related deaths occur during the postpartum period – most between 42 and 365 days after delivery. [73,74] These facts highlight the lifesaving potential of Medicaid coverage beyond 60 days. Over four in five pregnancy-related deaths are preventable, meaning timely postpartum care could lead to earlier interventions and healthier outcomes.[75] And with one in eight Black women uninsured, continued access to Medicaid after childbirth is a meaningful, though temporary, step to closing persistent gaps in maternal health outcomes and health coverage.[76]

POLICY RECOMMENDATION

- **Protect pregnancy-based Medicaid eligibility and the 12-month postpartum coverage option as a permanent, national standard.** Although nearly every state has adopted the 12-month option, it is important to establish this care as a federal guarantee. Under a federal requirement, states could still retain flexibility in how they implement the benefits, but this national standard would ensure that no state walks back coverage and that postpartum women everywhere have continuous access to care.

Medicaid Reimbursement for Doulas and Midwives

Doulas and midwives play an important role in improving maternal health outcomes and birthing experiences. Doulas are nonclinical birth workers who offer valuable advocacy, physical comfort, emotional support, and information before, during, and after birth.[77] Midwives, who are trained clinical providers, deliver comprehensive care throughout the perinatal period, often offering a low-intervention alternative to traditional obstetric care.[78] Both types of care have been linked to lower rates of maternal and infant complications and cesarean births, as well as higher rates of breastfeeding and overall satisfaction among birthing people.[79]

Even with this evidence, Medicaid reimbursement for doulas and midwives is inconsistent. Currently, 23 states reimburse doulas, with most others exploring and finalizing pathways to do so.[80] For midwifery care, only 19 states reimburse both certified nurse midwives (CNMs) and other trained, licensed midwives, while 32 states reimburse only CNMs.[81] Cost and lack of coverage are among the greatest barriers to accessing doula and midwifery care, both for patients and for the sustainability of these workforces.[82]

This fragmented coverage has severe consequences. Entire categories of qualified birth and support providers are underutilized at a time when maternal health deserts and obstetric racism are worsening across the country.[83,84,85,86] More than 2.2 million women of reproductive age live in maternal health deserts, and between 2020 and 2022, 2.8 million women were impacted by reductions in maternal care across the country.[87] Additionally, one in six Black babies are born in areas with limited or no maternal healthcare access.[88] When able to access services, 54% to 78% of Black women in a focus group reported experiences of obstetric racism and discrimination, ranging from neglect to overt violence or disrespect.[89] These realities drive many Black women to seek doula support and highlight the need to improve midwifery access.[90,91] Yet, outdated reimbursement practices prevent both midwives and doulas from providing the consistent care they are trained for, leaving Black women, who already face the highest risks of harm, complications, and death, without care that could be life-changing or lifesaving.[92]

The lack of cohesive integration of midwives, in particular, is the direct result of a long history of deliberate exclusion.[93] Black midwives were once the backbone of maternal care in America, but were systematically pushed out as male physicians sought to professionalize obstetrics and falsely portray midwives as unsafe and unqualified.[94] That legacy endures and can be seen in the lack of reimbursement and integration into today's healthcare system, despite overwhelming evidence of midwives' safety and effectiveness.[95] Doula care, by contrast, has gained more acceptance in recent years, in part because it is viewed as complementary to physician-led care rather

than replacing it. To be clear, this is not to suggest that doula reimbursement has been without its own challenges, but the difference does reveal additional resistance from advocates of physician-led obstetric care to share the role of primary maternal care providers with midwives. The growing recognition of the value of doulas is a positive and important development. At the same time, it points to an uneven approach to support for the maternal health workforce: support roles are welcomed, but midwives, who could ease the strain on hospitals and increase access to care, are still undervalued.

To create a sustainable, patient-centered maternal healthcare system, both midwives and doulas must be equitably reimbursed and fully integrated as accessible and affordable options for pregnant people. Black women deserve nothing less than the full range of birthing options – not only to survive pregnancy and childbirth, but to also experience them with safety, dignity, and joy. Expanding reimbursement will save lives, strengthen the workforce, and transform what birth looks and feels like in this country.

POLICY RECOMMENDATIONS

- **Expand equitable Medicaid reimbursement for doula services.**
  This will remove the financial burden for pregnant women enrolled in Medicaid, helping them gain access to the advocacy, emotional support, and guidance of a doula throughout pregnancy, childbirth, and the postpartum period.
- **Expand equitable Medicaid reimbursement for all licensed midwives, not just CNMs.**
  Doing so strengthens the maternal healthcare workforce, broadens access to safe, low-intervention care for pregnant women enrolled in Medicaid, and helps reduce maternal health disparities, particularly for Black women.

Hyde Amendment

The Hyde Amendment is a federal provision that prohibits the use of federal funds to be used to pay for abortion services under Medicaid, except in cases of rape, incest, or when the life of the mother is at risk.[96,97] It has been attached to annual Congressional spending bills since 1976.[98]

While 16 states provide funding for abortion for their Medicaid enrollees, 34 other states, and Washington, DC do not.[99] This leaves 7.8 million women of reproductive age (15-49) enrolled in Medicaid without abortion coverage, half of which are women of color.[100] Because Medicaid primarily serves low-income individuals, lack of abortion coverage forces many of these women to take on additional financial burdens, including out-of-pocket travel costs, to access care.[101]

These restrictions have significant implications for maternal health, economic stability, and family wellbeing, particularly for Black women. The broader consequences of limited abortion access are discussed in greater detail in the ***Abortion Access*** section of this policy agenda.

POLICY RECOMMENDATIONS

- **Remove the Hyde Amendment from future spending bills.**
  Repealing this restriction would allow Medicaid, and other federal health insurance programs, to cover abortion care and reduce financial and logistical barriers for low-income women.
- **Pass the Equal Access to Abortion Coverage in Health Insurance (EACH) Act.**
  This bill would require federal health insurance programs, including Medicaid, to cover abortion services. With this in place, the 7.8 million women of reproductive age enrolled in Medicaid would have greater financial means to access abortion.

II. Maternal Health

Overview

Maternal health is a key indicator of the health and wellness of a country's population. Despite spending $3,700 more per person than any other high-income country, the United States has the highest maternal mortality rate compared with other high-income countries.[102,103] Adverse maternal health outcomes are particularly pronounced among Black pregnant and postpartum people who are two to three times more likely to experience a pregnancy-related death or pregnancy-related complication than their white counterparts.[104] Our work is guided by a vision in which all Black pregnant, postpartum, and parenting people – including non-binary and genderqueer people – experience safe, affirming, and joyful pregnancy and birth experiences and outcomes. **The Black Women's Health Imperative (BWHI) is committed to continuing its legacy in fortifying Black women's maternal wellness and eliminating inequities in maternal health, including in addressing maternal mortality, maternal morbidity, maternal mental health, cardiovascular conditions, and infertility.**

Advancing Black Maternal Health Equity

In the last 10 years, Black women-led community-based organizations – with support from values-aligned partners – have sounded the alarm, raised awareness, and engaged in strategic coalition-building to address racial inequities in Black maternal and perinatal health.[105] This advocacy has led to several notable successes, including congressional funding for maternal mortality review committees (MMRCs) to identify factors, including racism and discrimination, contributing to pregnancy-related deaths; media campaigns on urgent maternal warning signs; and resources to support healthcare professionals and Black pregnant and postpartum people have effective and respectful conversations that have the potential to save lives.

Despite these advancements, Black women continue to experience a greater risk of death or injury around the time of pregnancy. In 2024, the provisional maternal mortality rate for non-Hispanic Black women was 50.5 per 100,000 live births, over 2.5 times the maternal mortality rate for all women (19.3 deaths per 100,000 live births).[106] Maternal mortality review committees attribute cardiovascular and hypertensive disorders (e.g., eclampsia, pre-eclampsia, and cardiomyopathy) as leading causes of maternal deaths among non-Hispanic Black women. MMRCs acknowledge the role of chronic stress, including from structural and interpersonal racism and discrimination.[107]

BWHI's maternal health portfolio consist of four areas of focus – representing where we believe we can have the greatest impact optimizing Black maternal health and wellness:

1) Access to quality and affordable maternal healthcare
2) Perinatal workforce development and retention
3) Chronic disease prevention and management
4) Maternal health across the life spectrum

Nearly one in four Black women experience mistreatment in childbirth, which is among the highest prevalence of mistreatment of all racial groups.[333]

Access to Quality and Affordable Maternal Healthcare

Medicaid finances over 40% of all births in the United States.[108] Recent advancements in healthcare financing has led to the extension of Medicaid coverage to 12 months postpartum in 49 states and Washington, DC.[109] The passage of the American Rescue Plan Act of 2021 was a critical legislative win to increase access to maternal healthcare, as nearly 30% of pregnancy-related deaths occur 43-365 days postpartum, and relative to white women a greater proportion of Black women experience a pregnancy-related death during the same period.[110,111] Even with the extension of Medicaid services, 1 in 10 women of reproductive age are uninsured. Efforts to expand Medicaid coverage include reducing income requirements to ease eligibility into the program. States that have expanded Medicaid coverage increase health insurance coverage before pregnancy and prenatal care initiation, and reduce avoidance of care due to costs.[112,113]

Expanding access to maternal healthcare also necessitates improving the quality of care delivered. The World Health Organization characterizes high-quality care as safe, effective, timely, efficient, equitable, and people-centered.[114] Nearly one in four Black women experience mistreatment in childbirth, which is among the highest prevalence of mistreatment of all racial groups.[115] Black women often report being ignored and experiencing providers refusing their requests for help. Dismissing Black pregnant and postpartum people not only increases their risk of adverse mental and emotional health outcomes, but also places them at risk of injury and other pregnancy-related complications. These data are particularly alarming considering that listening to Black pregnant and postpartum people express their symptoms and taking action to address them, can save their lives. Recent efforts in the United States have adopted respectful maternity care metrics, and patient-reported experience measures to capture quality of care provided to Black women.[116] For example, Birthing Cultural Rigor developed the patient-reported experience measure (PREM) of Obstetric Racism™ to quantify exposure to obstetric racism in hospital quality improvement projects. The Irth App was developed to document and provide consumer reviews of Black birthing peoples' experiences with healthcare providers and healthcare systems, aimed to support informed patient decision-making and provide anti-racism accountability metrics for healthcare systems.[117,118,119]

POLICY RECOMMENDATIONS

- **Pass the Momnibus Act**, which provides a comprehensive approach to ending maternal health disparities by improving the quality of maternal healthcare and data, investing in social supports, expanding maternal mental healthcare, and more.[120]
- **Strengthen and expand Medicaid access** for maternal healthcare at federal and state levels.
- **Expand the implementation of national performance measures** focused on measuring quality of maternal healthcare.

Perinatal Workforce Development and Retention

Studies demonstrate not only that Black women desire to receive healthcare from providers who look like them, but also that Black women experience improved health outcomes when they receive healthcare services from Black providers.[121] Black patients with Black providers for their prenatal or maternity care, have significantly greater odds of receiving postpartum care within 12 weeks after childbirth, as compared to patients who received care from a non-Black provider.[122] Perinatal care workers, including doulas, lactation counselors, and community health workers, provide critical information, resources, and touchpoints with healthcare practitioners and healthcare services.[123] As rates of cesarean sections and other medical interventions are greater among Black women, there has been a paradigm shift in reclaiming traditional birthing practices including birthing in stand-alone birth centers as well as receiving care and support from midwives and doulas.[124,125] As one participant shared in a qualitative analysis,

"The first midwives, the first wet nurses, that's Black women. We revolutionized mother and baby care, and then thanks to a lot of things in America, we lost some of that. I feel like we are regaining that now."[126]

While the demand for midwives and doulas and out-of-hospital births has increased, limitations in health insurance coverage restrict many Black patients from actualizing their desired care plans.[127] As of 2024, only eight states require doula coverage for private insurance plans and 18 states and Washington, DC have implemented Medicaid coverage for doula support.[128] Black doulas experience challenges with burnout and a lack of support navigating bureaucratic reimbursement processes that do not adequately compensate them for their services.[129] Additionally, aspiring midwives must navigate complex variations in state licensure and regulations that impact their scopes of practice. While Certified Nurse-Midwives (CNMs) are licensed in all 50 states and Washington, DC, fewer states recognize and contain licensure for Certified Professional Midwives (CPMs) and Certified Midwives (CMs). Black midwifery students also experience financial and clinical preceptor mentorship barriers to completing midwifery training requirements.[130]

POLICY RECOMMENDATION

- **Pass the Perinatal Workforce Act**, to expand research and access to a diversified perinatal workforce, including midwives and doulas, and advance respectful maternity care delivery models.

To ensure that Black pregnant people have the autonomy to make the best decisions for their health and their families, abortion must not only be legalized, but decriminalized...

Chronic Disease Prevention and Management

Cardiovascular and hypertensive disorders (e.g., eclampsia, pre-eclampsia, cardiomyopathy) represent the leading causes of maternal deaths among non-Hispanic Black women. This is particularly concerning considering that studies indicate temporal increases in the prevalence of hypertensive disorders of pregnancy (e.g., gestational hypertension, eclampsia, and pre-eclampsia), chronic hypertension, and diabetes (e.g., pre-gestational diabetes, and diabetes) among all women, with non-Hispanic Black women experiencing the highest overall prevalence.[131] Over two-thirds of pregnancy-related deaths attributed to cardiovascular conditions are preventable. Scholars attribute the increased risk of hypertensive and cardiovascular conditions among Black pregnant and postpartum people to a range of factors including chronic stress induced by structural and interpersonal racism and discrimination.[132]

POLICY RECOMMENDATION

Invest in Black-led community-based organizations that center Black pregnant and postpartum people, facilitate continuity of care, and address social determinants of health.

Maternal Health Across the Life Spectrum

Relative to women who deliver in their 20s and early 30s, pregnant people 35 years and older experience elevated risk of pregnancy complications, including pregnancy loss and pregnancy-related deaths.[133] Stillbirth rates are nearly 30% higher for women ≥35 years than for women <35 years, and two times higher among non-Hispanic Black women relative to non-Hispanic white women. Inequities in pregnancy loss are particularly concerning as reproduction, and specifically abortion are increasingly criminalized, restricting access to reproductive healthcare and placing women at elevated risk for maternal deaths. Further, women who deliver over the age of 40 years have the highest rate of pregnancy-related deaths (76.5 per 100,000 live births) followed by women 35-39 years (28.7 per 100,000 live births), relative to all other age groups.[134] For Black pregnant people, 17-34% of the increase in severe maternal morbidity is attributed to an increase in maternal age.[135] To ensure that Black pregnant people have the autonomy to make the best decisions for their health and their families, abortion must not only be legalized, but decriminalized, to protect pregnant people and their healthcare providers from criminalization.

In 2023, the percentages of births in the U.S. to individuals over 40 (4.1%) surpassed births to adolescents, 10-19 years of age (4.0%).[136] Black individuals in particular are experiencing motherhood in their mid-30s to mid-40s, due to investments in education, prioritizing career advancement, striving for financial stability, and due to social dynamics surrounding partnerships and dating. Additionally, Black women have a greater prevalence of infertility and reproductive health conditions that increase the risk of infertility (e.g., diminished ovarian reserve, pelvic inflammatory disease, fibroids).[137,138,139,140] In 2012, the American Society of Reproductive Medicine lifted the experimental designation of oocyte cryopreservation, approving the use for non-medical indications, and ushering in a surge in egg freezing utilization. The total number of oocyte cryopreservation cycles performed in 2016 was 8,828, compared to 2,925 cycles completed in 2012. Despite experiencing a greater prevalence of infertility and reproductive health conditions that increase the risk of infertility, only 7.1% of oocyte cryopreservation cycles are performed among Black women.[141]

POLICY RECOMMENDATIONS

- **Decriminalization abortion** and other forms of pregnancy loss (e.g., stillbirth).
- **Pass the Access to Fertility Treatment and Care Act**, to expand health insurance coverage and access to infertility treatments and fertility preservation.

III. Reproductive Justice

Overview

Reproductive justice – the human right to maintain personal bodily autonomy, have children, not have children, and parent children in safe and sustainable communities – is vital not only for the health of Black women and girls, but also for our full self-determination.[142] To truly actualize reproductive justice, Black women and girls must have the freedom and resources necessary to make informed decisions about their sexual and reproductive lives. **The Black Women's Health Imperative (BWHI) advances reproductive justice by fighting for abortion access, contraceptive equity, comprehensive sex education, and menstrual equity – knowing that these rights are foundational to how Black women and girls can be present and empowered in every other area of life.**

Abortion Access

Abortion is a safe, common, and effective medical procedure used to terminate a pregnancy.[144] In the United States, one in four women will have an abortion.[145] Women must be able to access abortion for any reason, and this decision is often influenced by multiple factors ranging from financial preparedness and concerns about future opportunities, to health risks and partner-related reasons.[146,147] Denying access to abortion can profoundly affect a woman's life and the lives of those who depend on her. Compared to women who receive abortions, women denied abortions face a higher risk of life-threatening complications during childbirth, are more likely to stay connected to violent partners, and experience long-term financial insecurity and household poverty.[148] They are also more likely to raise children alone and in poverty, which can negatively impact child development.[149]

For Black women, restrictions on abortion disproportionately worsen maternal mortality rates, labor market participation, and educational outcomes.[150] Research shows that legalizing abortion reduces maternal mortality among Black women by 30% to 40%, while a nationwide ban could increase it by over 20%.[151,152] Beyond direct health impacts, Black women's common role as primary breadwinners in their families means that being denied an abortion and the resulting setbacks to education and earnings can amplify the negative consequences described above.[153] Nearly 60% of Black women aged 25 to 54 live in the 26 states with total bans or restrictions on abortion access.[154] In these circumstances, Black women are often less able to travel for an abortion.[155] This reality shows that for Black women, choice alone is not enough – practical, equitable access to abortion is essential.

Abortion access in the United States has become a complicated patchwork of laws that are highly dependent on factors such as geography, income, and insurance status. As of 2024, 18 states completely ban abortion, 8 states impose restrictions on access, and the remaining 25 states protect abortion to some degree.[156] Because of the Hyde Amendment, federal funds, including those that finance Medicaid, cannot be used to cover abortion outside of cases of rape, incest, or life endangerment.[157] The Affordable Care Act (ACA) reinforces these restrictions, applying the same limitations to ACA marketplace plans generally.[158] Taken together, this means that where a person lives, how much they make, and what type of insurance they have can determine whether or not abortion is out of their reach.

Celebrating a decade of impact, BWHI's My Sister's Keeper (MSK) Program equips young Black women with the tools, confidence, and community to lead in advancing reproductive justice and advocating for their own health and wellness.[143]

To address these gaps in coverage for abortions needed for reasons outside of rape, incest, or life endangerment, some states provide their own funds to cover abortion through Medicaid or include abortion as a covered benefit in their ACA marketplace plans.[159,160] Even with these efforts, millions of Black women are excluded. About 3.3 million Black women are enrolled in Medicaid, and 30 states and Washington, DC do not provide their own funds for abortion outside of these cases.[161,162] About 12% of Black women are enrolled in the individual marketplace (mostly ACA marketplace plans), and 25 states prohibit plans sold on state marketplaces from covering abortion.[163,164] These coverage exclusions show that even where abortion is legal, affordability remains a major barrier – especially for Black women.

In addition to geographic and coverage barriers, there have been unrelenting attacks on medication abortion access. Medication abortion, which accounts for over 60% of abortions, has been subjected to increased review and scrutiny in an attempt to remove regulatory approval, and 28 states impose some type of restriction on it.[165,166] Mifepristone, a safe and effective medication used as part of a two-drug regimen for medication abortion, has been the center of various attempts of legal overreach to limit access by imposing restrictions that are not science-based.[167] This is particularly significant because Mifepristone has been proven safe and effective when prescribed through telehealth visits, allowing patients to end their pregnancies privately and safely at home.[168] Restricting access would not only strip away this option, but also reverse progress made reaching patients in reproductive healthcare deserts through telemedicine.[169]

Another critical area of concern for abortion access for Black women is the provision of emergency abortion services. In June 2025, (Emergency Medical Treatment and Labor Act) EMTALA guidance that clarified hospitals' obligations to provide emergency abortion care when a patient's life or health is at risk was rescinded.[170] Clear emergency protocols save lives; ambiguity puts patients at risk. Without explicit protections, patients in need of emergency abortion services may be denied lifesaving care – a reality already in place in states with abortion bans.[171] This further endangers Black women, who face disproportionately high rates of pregnancy complications and maternal mortality, and for whom timely access to emergency abortion services may be a matter of survival.

POLICY RECOMMENDATIONS

- **Pass the Equal Access to Abortion Coverage in Health Insurance (EACH) Act.**
  This bill would require federal health facilities and insurance programs, including Medicaid, Medicare, and the ACA marketplace, to cover and provide access to abortion services, effectively eliminating the patchwork of restrictions that leave millions of Black women without abortion coverage across the country.
- **Pass the Abortion Justice Act.**
  This bill would establish a fundamental right to abortion, protect patients and providers from criminalization, require health insurance plans to cover abortion services, and create a grant program to increase access to abortion services. By addressing legal rights, affordability, and provider availability together, this bill creates a comprehensive framework for improving access to abortion.
- **Remove the Hyde Amendment from future spending bills.**
  Repealing this restriction would allow Medicaid and other federal health insurance programs to cover abortion care. This would significantly reduce financial and logistical barriers for low-income women, particularly the one in four Black women covered by Medicaid.
- **Protect medication abortion.**
  Congress can, and should, safeguard access to Mifepristone and other medication abortion. This protection is critical for patients who need abortion services, especially to maintain access for patients who rely on telehealth, and for the integrity of FDA approvals to remain rooted in science, not politics.
- **Codify EMTALA protections for emergency abortion care.**
  Federal law must explicitly affirm providers' obligations, including the protections outlined in the recently rescinded EMTALA guidance, to render stabilizing, lifesaving abortion care when a patient's life or health is at risk. No state abortion ban should be permitted to preempt the provision of emergency medical treatment.

BWHI's Opill Access Fund helps Black women protect their reproductive health through no-cost access to Opill®, ongoing support, and a commitment to making birth control available when life gets hard.[186]

Contraceptive Equity

Contraceptive use among Black women in the United States carries a painful history of forced and coerced sterilization and reproductive control.[172] This legacy makes it all the more important for Black women to be empowered to make our *own* decisions regarding contraceptive use, and to be able to access them freely and safely if we choose to.

Contraceptive equity is a critical element of reproductive justice. Contraceptives not only help women decide if and when to become pregnant, but also help manage reproductive health conditions such as endometriosis, fibroids, and polycystic ovarian syndrome (PCOS) that affect many Black women.[173,174,175] Despite these benefits, access to contraceptives is far from equitable.[176] Nineteen million women of reproductive age live in counties with little to no health centers that offer the full range of contraceptive options.[177] Additionally, four in ten Black women aged 18 to 44, and nearly half of Black mothers with children under 18, cannot afford to spend more than $10 on birth control.[178] While the Food and Drug Administration (FDA) recently approved over-the-counter (OTC) contraception, access is still limited.[179] Many states do not require insurance coverage of OTC contraceptives, meaning they may still be financially out of reach for many women.[180]

Current attacks on contraceptive access are threatening to reverse decades of progress in reproductive health in ways that disproportionately harm Black women. Efforts to roll back contraceptive access have taken the form of both legal challenges and state-level restrictions.[181] Laws and lawsuits have targeted emergency contraception, OTC contraception, and intrauterine devices (IUDs), often by spreading disinformation that these methods cause abortion.[182] For example, a law passed in Indiana and a bill proposed in Oklahoma falsely asserted that IUDs and emergency contraception induced abortion.[183] The Indiana law goes further by restricting Medicaid coverage, limiting the contraceptive options available to low-income patients.[184] At the federal level, there were also attempts to weaken health insurance mandates for contraception and allow religious employers to deny contraceptive coverage without following the established exemption process, though these rules were struck down by a judge.[185]

When considered together, these policies have compounding effects: Black women, who already experience higher rates of unintended pregnancy, maternal mortality, reproductive health conditions, and financial barriers to care, are left with less tools to manage their health and plan their futures. True contraceptive equity requires that Black women have affordable, unbiased, and informed access to the full range of contraceptive options without coercion.

POLICY RECOMMENDATIONS

- **Pass the Right to Contraception Act.** This bill would protect the right of individuals to seek, obtain, and use contraceptives, and the right of healthcare providers to provide contraceptive services and information. This would safeguard contraceptive access from state-level rollbacks and disinformation, and protect Black women from political barriers to care.
- **Expand coverage of all FDA-approved contraception, including over-the-counter (OTC) contraception, without cost sharing.** Requiring health insurance plans like Medicaid and ACA plans to cover all contraceptive options as preventive care would eliminate financial barriers that keep contraceptives out of reach for many women. Coverage of newly approved OTC contraceptives is especially important because it expands access, convenience, and privacy. However, without insurance coverage, these options will remain unaffordable for those who need them most.

Comprehensive Sex Education

The right to make informed decisions begins with access to complete, accurate information. Black girls and LGBTQ+ youth deserve comprehensive and up-to-date sex education that goes beyond abstinence-only messaging to include topics like consent, intimate partner violence, physical and emotional safety, sexual orientation, and more.

Black youth have suffered from sex education programs that miss key aspects of the realities of their lives. Over the past 20 years, Black teens have been five to sixteen times more likely than White teens to contract chlamydia, syphilis, and gonorrhea.[187] They are also nearly five times more likely than Latino youth, and seventeen times more likely than White youth, to be diagnosed with HIV.[188] While teen pregnancy rates have declined overall, Black teen birth rates remain double those of White teens.[189] But pregnancy and disease prevention in sex education is not enough. Research shows that only 40% of Black teenage girls reported that their first time having sex was wanted.[190] There are clearly deep, dangerous gaps in teaching about consent, autonomy, and protection from coercion that must also be addressed.

Comprehensive sex education also requires the inclusion and affirmation of Black LGBTQ+ youth. Only 10 states require LGBTQ+ topics to be included in sex education curricula, and six Southern states – where much of the United States' Black population resides – either prohibit educators from discussing LGBTQ+ topics or require that they teach them in a negative manner.[191,192] This is particularly harmful for Black LGBTQ+ youth because they are left to navigate how to build safe, healthy relationships without the basic guidance and support their non-LGBTQ+ peers may receive.[193] At the same time, they face the layered stigmas of racism, homophobia, or transphobia.[194] As a result, Black LGBTQ+ youth are more exposed to bullying, isolation, and violence, and face higher risks of mental health challenges.[195,196,197] Inclusive sex education curricula are not only vital for positive sexual health outcomes among Black LGBTQ+ youth, but also for stronger feelings of belonging in important settings like school.[198]

These disparities highlight the urgent need for more honest, inclusive, and critical sex education conversations. Black parents overwhelmingly support sex education that covers a wide range of topics, including preventing sexual abuse, respecting each other as equals, and teaching about sexual orientation.[199] Research also shows that culturally-responsive, comprehensive sex education goes far beyond delaying initiation of sexual activity.[200] Its positive effects include increasing condom and contraceptive use, improving knowledge about the body and healthy relationships, and decreasing risk-taking behaviors.[201] These benefits are amplified when the curriculum explicitly acknowledges gender and power, and when parents, teachers, and youth-friendly service professionals are involved.[202] Ultimately, the push for comprehensive sex education is just as much about preventing unsafe sexual behavior as it is about teaching and equipping Black girls and LGBTQ+ youth, and every young person they interact with, with the information they need to maintain safe, dignified, healthy social relationships.

POLICY RECOMMENDATION

- **Pass the Real Education and Access for Healthy Youth Act.**
  This bill would bolster federal grant support for sex education and sexual health services for young people aged 10 through 29. It prioritizes evidence-based, medically accurate, and inclusive information, while prohibiting the use of these funds for abstinence-only or otherwise inaccurate programs. With a specific focus on organizations and healthcare entities that are eligible for the 340B-drug pricing safety net program, this bill also represents a critical step to address gaps and mis-education for Black girls and LGBTQ+ youth in vulnerable communities.[203]

BWHI's Positive Period Program is ending the shame around menstruation and building a new culture of knowledge, equity, and pride through advocacy, education, and community engagement.[215]

Menstrual Equity

Menstrual equity is the principle that, in an equitable and inclusive society, everyone who menstruates should have access to safe, affordable menstrual products.[204] Without this access, individuals are not fully able to work, study, or participate in daily life, which makes menstrual equity a matter of collective concern.[205] This proves true for Black women and girls, who are more vulnerable to period poverty and menstrual hygiene challenges across the United States.[206] Nearly one in four Black women report struggling to afford menstrual products, while two in five report having to use a menstrual product for longer than recommended and, at times, relying on substitutes like paper towels instead.[207]

Menstrual inequity impacts Black women and girls as well as low income women in a myriad of ways. For students, these challenges directly affect classroom performance and participation. Black girls who do not have adequate access to menstrual products often experience feelings of shame and embarrassment, difficulty focusing on school, falling behind academically, and missing school and work.[208,209] In fact, high school girls miss an average of two to three days of school per month because of lack of access, which compounds existing racial and gender inequities in education.[210,211] For Black women, one study found that nearly half of Black respondents experienced period poverty, with disruptions extending across mental health, daily activities, work, sports, school, and sexual and personal relationships.[212]

Low income women, in particular, cannot afford to miss work without risking their financial stability, and the recurring cost of menstrual products creates an ongoing economic burden. Over just 10 years of menstruation, women can expect to spend nearly $2,000 on tampons or pads.[213] These costs can be even higher for women who have complex menstrual needs. No woman should be forced to choose between menstrual products, food, or other necessities.

The health consequences of inadequate access to safe, affordable menstrual products are of equal concern. Prolonged use of menstrual products beyond what is recommended or use of makeshift substitutes can increase the risk of vaginal and urinary tract infections, severe reproductive health conditions, and toxic shock syndrome.[214] Black women already face disparities in maternal and reproductive health. Thus, it is important that Black women and girls have consistent access to menstrual products from an early age, to prevent downstream health complications, promote positive reproductive and overall health, and fully engage in school, employment, and community life.

POLICY RECOMMENDATIONS

- **Pass the Menstrual Equity for All Act.** This bill would expand access to menstrual products through Medicaid, Temporary Assistance for Needy Families (TANF), and federal grant programs; require large employers, correctional facilities, and public federal buildings to provide free menstrual products; and prohibit state and local taxes on menstrual products.
- **Follow state examples of menstrual equity laws.** Several states demonstrate how feasible it is to make menstrual products widely available for their residents and offer a roadmap for action at the state and federal levels. For example: **California** requires all state buildings, public schools with grades 3 through 12, California State Universities, and California Community Colleges to stock free menstrual products, and exempts menstrual products from sales and use taxes. **Virginia** requires free menstrual products in public schools and eliminated its sales tax on menstrual products.

IV. HIV

Overview

The human immunodeficiency virus (HIV) epidemic has been a public health issue for Black women and girls for decades.[216] Persistent disparities in transmission, treatment, and outcomes are driven by avoidable gaps in prevention, healthcare access, and support services – not personal failures. **The Black Women's Health Imperative (BWHI) calls for bold, strategic investments in prevention, access to treatment, and integrated care systems to reduce new HIV cases among Black women and girls, and ensure that those living with HIV can lead longer, healthier lives with the support they deserve.**

About HIV

HIV is a virus that attacks the body's immune system and increases vulnerability to other infections and diseases.[217] It is primarily acquired through contact with certain bodily fluids from a person with HIV, including blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids, and breast milk.[218] The most common modes of transmission are condomless sex and blood-to-blood contact, including through injection drug use.[219] Once an individual acquires HIV, they have it for life.[220] Without treatment, HIV can lead to acquired immunodeficiency syndrome (AIDS).[221] However, antiretroviral therapy (ART) treatment taken consistently as prescribed can reduce the amount of HIV in the blood to undetectable levels, make the virus untransmittable through sex, and allow people with HIV to live long and healthy lives.[222] This evidence-based consensus is summarized in the U=U campaign – Undetectable = Untransmittable – which underlines the importance of treatment access, adherence, and stigma reduction.[223]

HIV Among Black Women

Black women have been disproportionately affected by HIV since the beginning of the HIV epidemic.[224] In 2022, Black women accounted for 50% of all new HIV diagnoses among women – a rate 10 times higher than among White women and three times higher than among Latinas.[225] Black women also represent the largest group of women living with HIV.[226] The rate of AIDS among Black women is 18 times higher than the rate in White women.[227] Black transgender women also face alarming disparities, making up nearly 50% of all new diagnoses among transgender women in 2019.[228]

These disparities are driven by multiple, overlapping factors, including limited access to healthcare and testing, higher rates of poverty, greater HIV-related stigma, and residence in communities with higher prevalence of HIV and sexually transmitted infections (STIs).[229,230] They are not influenced by differences in high-risk behavior. In fact, Black women are no more likely to have condomless sex, multiple sexual partners, or use more drugs than women of other races. [231]

Despite these disturbing statistics, there has been some progress. From 2010 to 2022, the rate of new HIV diagnoses among Black women declined by 39%.[232] However, this progress has slowed, as this number decreased by only 1% from 2018 to 2022.[233] These trends show that HIV prevention strategies have had some positive effect, but further targeted, sustained efforts are needed to aptly address the persistent gap facing Black women.

BWHI's policy approach to addressing HIV among Black women has focused on four key areas: (1) combatting stigma; (2) preventing future transmissions; (3) improving access to comprehensive treatment; and (4) providing essential support, beyond medical treatment, that focuses on the wellbeing of Black women living with HIV and AIDS.[234] These priority areas are integrated into the policy solutions outlined below.

Expand Opt-Out Hiv Testing and Invest in Stigma Reduction

Knowing one's HIV status is the foundation of prevention, but stigma and misconceptions about risk keep many people from seeking routine HIV testing.[235] Since 2006, the Centers for Disease Control (CDC) has recommended that healthcare providers adopt an "opt-out" approach, where HIV testing is offered as part of routine care and testing unless a patient declines.[236] This model keeps HIV testing voluntary but normalizes it, reducing fear, judgement, and stigma often associated with asking for an HIV test.

Expanding opt-out HIV testing is particularly important for Black cisgender and transgender women, most of whom live in the South – the region with the highest level of discomfort and stigma towards people with HIV in the country.[237] Southern states are also more likely to enforce HIV criminalization laws, which reinforce stigma at the structural level.[238] At the community level, Black cisgender women report losing relationships and social support after disclosing their HIV status, while Black transgender women experience compounded rejection and discrimination.[239] These intersecting factors make it harder to seek testing, share results, and stay engaged in care. Expanding opt-out testing is a necessary step to normalize HIV screening, reduce stigma, and ensure earlier detection and connection to treatment. Luckily, programs like the Black Women First Initiative have demonstrated successful strategies for reducing stigma and improving outcomes for Black cisgender and transgender women living with HIV, offering a strong model for how to encourage more women to know their status, understand their risk, and engage in care.[240,241]

POLICY RECOMMENDATIONS

- **Expand opt-out HIV testing in all healthcare settings.** Normalizing HIV testing as part of routine care reduces stigma, increases early detection, and helps ensure that Black cisgender and transgender women begin treatment sooner.
- **Bolster and expand funding for Black Women First Initiative and similar programs that decrease stigma and improve care for Black cisgender and transgender women with HIV.** Programs like these have proven to be effective in reducing stigma and improving health outcomes through culturally responsive, community-based models that should be replicated nationwide.

Increase Prep Access and Awareness

To improve HIV prevention, preexposure prophylaxis (PrEP) must be accessible, understood, and trusted by Black women, adolescent girls, and Black transgender women. PrEP is a highly effective medication for preventing HIV that can reduce the risk of sexually acquired HIV by up to 99%.[242] Yet, despite the disproportionately high rates of HIV among Black women and adolescent girls, awareness and uptake of PrEP among Black women and adolescent girls is critically low.[243] Less than 20% of Black women are aware of PrEP, and just 1% have been prescribed it.[244] While there is limited data on PrEP uptake among Black transgender women, one study shows that only 18% of Black and Latinx transgender women aware of PrEP had ever taken it.[245] This gap can be attributed to both provider-side and patient-side barriers. Providers may lack training or feel uncomfortable initiating conversations about PrEP, while Black women and adolescent girls may have concerns about cost, confidentiality (especially while on a parent's insurance), mistrust or curiosity about the novelty of PrEP, limited understanding of PrEP's relevance to their lives, or stigma tied to accusations of promiscuity or infidelity.[246] Ensuring that both providers and patients are educated about PrEP, and that PrEP is affordable and appropriately prescribed, will be critical to reducing HIV transmission rates among Black women and adolescent girls.

POLICY RECOMMENDATIONS

- **Pass the PrEP Access and Coverage Act.**
  This bill would require private and public health insurance programs to cover HIV prevention drugs like PrEP without cost-sharing or preauthorization, and invest in PrEP outreach to high-risk populations.
- **Protect the U.S. Preventative Services Task Force (USPSTF)'s authority to require coverage of recommended preventive services.**
  The integrity of the USPSTF is under attack. Safeguarding USPSTF's ability to issue preventive service recommendations grounded in evidence, not political interference, protects mandated health insurance coverage of essential interventions like PrEP.

Address the Connection Between HIV and Intimate Partner Violence (IPV)

Intimate partner violence (IPV) is often both a risk factor for HIV transmission and a barrier to care. Women living with HIV are more likely to experience IPV, and women exposed to violent relationships are four times more likely to contract STIs, including HIV.[247] IPV can limit a woman's ability to access healthcare, like HIV testing, treatment, and prevention, due to controlling behavior from a violent partner, financial dependency, lack of privacy, and feelings of shame.[248] It also makes it more difficult to negotiate condom use or safely decline sex.[249] Fear of being accused of promiscuity or infidelity can also lead to violence following requests for the violent partner to get tested for STIs or discuss HIV prevention.

PrEP can be lifesaving for women at risk of IPV-related HIV exposure. However, research shows that women experiencing severe psychological IPV are more likely to be embarrassed to initiate a PrEP discussion with a healthcare provider or domestic violence advocate.[250] Women who experience physical IPV and IPV-specific medical mistrust are also less likely to accept a PrEP recommendation from a domestic violence advocate.[251]

Four in ten Black women experience physical violence from an intimate partner at some point in their lives.[252] Over half of all transgender and non-binary people, including Black transgender women, experience IPV.[253] Coupled with disproportionately high HIV rates and low PrEP awareness and uptake, this data underscores the urgent need for research and interventions that address the intersection of IPV and HIV among Black cisgender and transgender women.

POLICY RECOMMENDATIONS

- **Increase CDC, Health Resources and Services Administration (HRSA), and National Institutes of Health (NIH) funding for research and community-based interventions to improve access to HIV prevention and treatment for women experiencing IPV.**
  Investing in this research will strengthen prevention and treatment approaches specifically for women experiencing IPV, who face uniquely challenging barriers to care.
- **Expand IPV risk screening and safety planning within HIV clinics.**
  Integrating IPV screening directly into HIV care helps identify women who are at risk, connect them to safety resources, and improve health outcomes.

When integrated care is affordable, accessible, sustained, and grounded in trusted community partnerships, it addresses the unique challenges Black women face everyday.

Invest in Integrated Care Systems

Effective HIV care requires more than just medication, especially for Black women living with HIV.[254] Integrated care systems that combine HIV treatment with wraparound services like mental health support, substance use treatment, housing assistance, and food security can improve health outcomes and long-term retention in care.[255] When integrated care is affordable, accessible, sustained, and grounded in trusted community partnerships, it addresses the unique challenges Black women face, especially those complicated by HIV stigma, discrimination, and systemic barriers to care.[256] These programs go beyond supporting medical needs by also improving overall wellbeing, enabling Black women to live healthier lives on their own terms.

Although federal HIV funding has grown over time, intentional, targeted investments are still required to close disparities and maximize impact for Black women.[257,258] This would include creating disparities-focused funding opportunities specifically designed for high-vulnerability groups like Black women; increased funding for the Ryan White HIV/AIDS Program, which offers exemplary models of integrated care; strengthening the 340B Drug Pricing Program, which keeps HIV medications affordable; and expansion of housing and community programs that care for the whole person.[259,260]

End HIV Criminalization Laws

HIV criminalization is a damaging remnant of the early HIV epidemic that continues to punish people living with HIV – especially Black women. Thirty-two states still have laws that criminalize HIV by imposing criminal penalties for alleged or perceived exposure, nondisclosure, or transmission.[261] These laws apply even when there is no intent to harm, no actual transmission, or the person is virally suppressed.[262] Most of these laws were enacted during the early HIV epidemic, when little was understood about the virus.[263] Today, we know better: these laws do not prevent transmission, but instead drive stigma and fear, discourage testing and early prevention, and compromise patient-provider trust.[264]

Black people are more likely to be arrested and convicted of HIV-related offenses, and Black women face some of the most harmful enforcement.[265,266] These laws can be used as tools of control against women in abusive relationships, can complicate custody battles and pregnancies, and are used to overtarget sex workers.[267] For Black trans women specifically, HIV criminalization reinforces harmful stereotypes and transphobia, and deepens profiling, stigma, and discrimination.[268]

The goal should be ending HIV and not punishing people, especially Black women, for living with it. That will not happen until these outdated laws are repealed.

POLICY RECOMMENDATIONS

- **Increase funding within the existing HIV care infrastructure.**
  Strengthening programs including the Ryan White HIV/AIDS Program, 340B Drug Pricing Program, and community-based services supports stable, accessible care and support for people living with HIV.
- **Utilize Medicaid waivers and state-level reimbursement mechanisms to fund wraparound services**.
  Expanding coverage for housing, transportation, and other essential supports through innovative care models allows women to stay engaged in and compliant with HIV care and treatment.

POLICY RECOMMENDATIONS

- **Repeal state-level HIV criminalization laws.**
  HIV criminalization laws are outdated, scientifically inaccurate, and detrimental to the health and safety of Black cisgender and transgender women. Repealing these laws is critical to reducing stigma, strengthening patient-provider trust, and aligning health policy with science.
- **Pass the Repeal Existing Policies that Encourage and Allow Legal (REPEAL) HIV Discrimination Act.**
  This bill would mandate a federal review of laws that criminalize HIV, develop best practices for reform, and track states' progress in modernizing or repealing these discriminatory laws.

V. Chronic and Rare Diseases

Chronic Disease Overview

Diabetes and obesity are chronic conditions that are among the most significant drivers of poor health in the United States.[269] Black women experience the highest prevalence and most severe consequences of both diseases.[270,271] **The Black Women's Health Imperative (BWHI) recognizes the urgent need to address diabetes and obesity in our community and advocates for a comprehensive, tailored approach to chronic disease care that reflects both the complexity of these conditions and the unique needs of Black women and girls.**

Diabetes

Diabetes is a public health issue that disproportionately impacts Black women. Black women are nearly 1.5 times more likely to be diagnosed with diabetes and face a 1.5 times higher risk of dying from the disease.[272] Diabetes often leads to additional health complications, including heart disease, kidney disease, and vision loss.[273] It also intersects with maternal health by exacerbating pregnancy complications such as gestational diabetes and preeclampsia, which in turn can increase maternal morbidity and mortality among Black women.[274] These disparities are influenced by multiple factors, including limited access to high-quality, affordable healthcare, barriers to regular preventive care, higher rates of food insecurity, and chronic stress.[275]

Obesity

Obesity is a public health challenge and key driver of chronic disease for Black women and girls. Black girls aged six to eleven and those in high school are over 1.5 times more likely to be obese compared to their peers.[276] Among adults, about 60% of Black women are obese – a rate that is 70% higher than that of White women.[277] Like disparities in diabetes, the higher rates of obesity among Black women and girls are shaped by more than individual behaviors. Social determinants of health, such as limited access to safe spaces for physical activity, targeted advertising for unhealthy food, lack of affordable healthy food options, and chronic stress all contribute to the high obesity prevalence.[278] These data highlight the importance of early intervention to mitigate lifelong health challenges for Black girls and show that policy solutions must go beyond individual responsibility to address the systemic barriers that lead to these outcomes.

BWHI's Change Your Lifestyle. Change Your Life. (CYL²)™ program is the first CDC-approved culturally tailored lifestyle change curriculum designed to prevent or manage type 2 diabetes among Black women.[285]

The Connection Between Obesity, Diabetes, and Black Women's Health

Obesity is the strongest predictor of type 2 diabetes.[279] This creates a cycle for Black women and girls where higher rates of obesity increase the likelihood of developing diabetes, heart disease, kidney disease, and pregnancy-related complications. If left unmanaged, this cycle of chronic disease can begin as early as childhood and persist throughout a woman's life.

Beyond pregnancy complications, there are important reproductive health considerations for women with obesity and diabetes, including concerns about irregular menstruation and fertility challenges.[280] Insulin resistance, a central component of diabetes, can disrupt hormone balance and contribute to reproductive health conditions like polycystic ovary syndrome (PCOS).[281] With high rates of related reproductive health issues among Black women, this adds another layer to why lifestyle changes and policy reform around diabetes care are crucial within this community.[282,283]

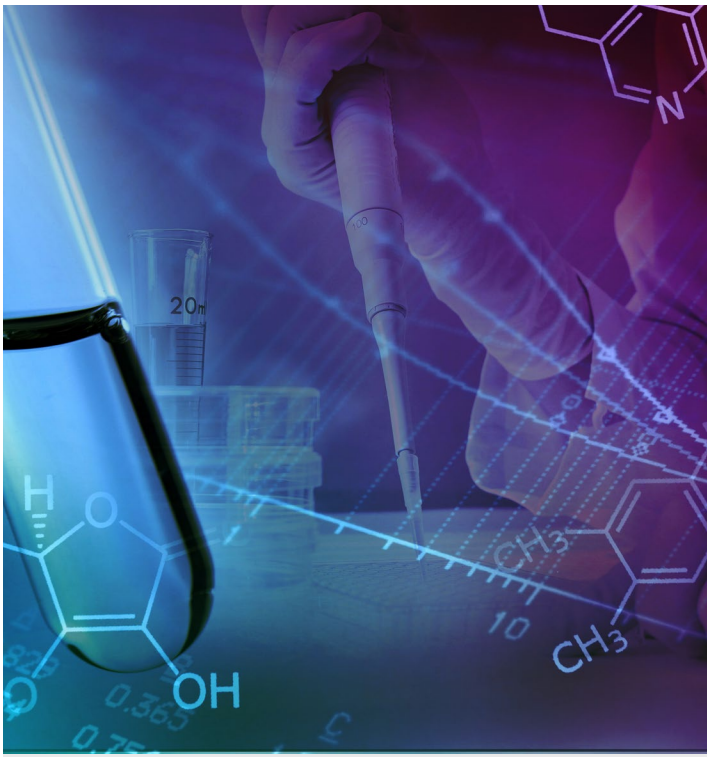
Black women and girls do not have to have lives dictated by diabetes and obesity. With early intervention, improved access to comprehensive and affordable nutrition, weight, and diabetes care, and greater investments in healthier environments, Black women and girls can reduce the risk of developing these conditions and manage them more effectively. Every Black woman and girl deserves this opportunity to live a healthy life.

POLICY RECOMMENDATIONS

- **Expand access to culturally tailored nutrition and lifestyle programs.**
  Invest in community-based programs that provide nutrition education, lifestyle change resources, and physical activity guidance for Black women. When these interventions are culturally relevant, they lead to higher rates of engagement, adherence, and improved health outcomes.[284]
- **Increase health insurance coverage for diabetes prevention, obesity management, and medications.**
  It is essential that health insurance covers services such as nutrition therapy, weight management programs, and diabetes prevention programs. This coverage should also extend to FDA-approved anti-obesity and type 2 diabetes medications so that patients have the full range of clinically effective tools to manage their health.
- **Expand access to behavioral and mental health treatment.**
  Health insurance programs should cover behavioral therapy and support programs that focus on lifestyle modification, stress management, and emotional wellbeing. Integrating behavioral health into chronic disease management not only improves adherence, but also addresses the emotional and mental health factors influencing eating behaviors and weight management. These interventions are particularly vital for Black women, who are more likely to experience the negative health effects of chronic stress.

'Things are not well with me. And the one thing I know I can do when I come home is cook me a pot of food and sit down in front of the TV and eat it. And you can't take that away from me until you're ready to give me something in its place,' a program participant said. So that made me start to think that there was some other piece to this health puzzle that had been missing, that it's not just about giving information; people need something else.

— Excerpt from *The Black Women's Health Book* chapter titled, "Breathing Life into Ourselves: The Evolution of the National Black Women's Health Project" by Byllye Y. Avery, Founder of the Black Women's Health Imperative



Rare Diseases and the Rare Disease Diversity Coalition™ Overview

A rare disease is a condition that affects less than 200,000 people in the United States.[286] While there are an estimated 10,000 known rare diseases, together they impact more than 30 million Americans.[287] Patients from historically marginalized populations are disproportionately affected, often facing delayed diagnoses, limited access to appropriate care, and misinterpretation of their symptoms and lived experiences by providers.[288] These inequities are further compounded by the relative lack of research funding for rare diseases that disproportionately affect communities of color.[289]

In 2020, the Black Women's Health Imperative launched The Rare Disease Diversity Coalition, or RDDC™, to address the extraordinary challenges faced by historically marginalized populations with rare diseases. RDDC™ works to reduce racial disparities in the rare disease community; identify and advocate for evidence-based solutions that alleviate the burden of rare diseases on historically marginalized populations; and to help achieve greater equality within the rare disease community.

Since its inception, RDDC™ has served as both a convener and an advocate, bringing together patients, experts, and stakeholders, while advocating for federal regulatory and legislative priorities that expand equitable access to diagnosis, treatment, and care for patients with rare diseases.

Federal Regulatory Policy Priorities

To improve the standard of care for historically marginalized populations with rare diseases, clinical trial protocols must evolve. RDDC™ believes that federal regulatory policies, such as FDA guidance on decentralized clinical trials (DCTs), are necessary tools to advance this change.

Requiring Diversity Action Plans in Decentralized Clinical Trials

Diversity action plans play a critical role in ensuring that clinical trial sponsors take consistent, intentional steps to improve racial representation in DCTs.[290] By including more study participants from historically marginalized populations, sponsors can strengthen the reliability of trial data and ensure that safety and efficacy outcomes reflect the diversity of the patients who will ultimately use the drug or medical product. While the Food and Drug Administration (FDA) has issued draft guidance on diversity action plans for clinical trials, there is still a need for additional guidance to address the unique structure and implementation process of DCTs. Because decentralized and hybrid models rely heavily on technology and remote participation, they present both new opportunities to expand access, and unique challenges that must be considered when designing diversity action plans.

POLICY RECOMMENDATION

Require DCT sponsors to develop and implement diversity action plans as part of their trial responsibilities.

The FDA should require DCT sponsors to develop and implement diversity action plans. These plans should include strategies that are tailored to the unique structure of DCTs and address barriers like digital health literacy, broadband availability, language access, and accessibility for people with disabilities. The FDA should also issue specific guidance on diversity action plans for DCTs. By expanding on existing guidance, the FDA would help DCT sponsors consistently and effectively apply best practices to advance enrollment and retention of participants from historically marginalized populations within their trial structures.

Engaging Patient Experiences in Decentralized Clinical Trial Development

In DCTs, patients often have greater responsibilities compared to traditional trials. Understanding their ability and willingness to meet these responsibilities is essential for trial success and diverse participation. Patient perspectives provide clinical insight into disease impact, treatment priorities, and the practical barriers patients may face, including lack of reliable access to technology, in-person trial locations, and quality healthcare. This is especially important for patients with rare diseases who may have additional challenges navigating trial requirements. Incorporating patient experiences into trial design helps sponsors ensure that study protocols, technologies, and endpoints reflect real-world patient needs and ultimately foster stronger engagement and retention.

POLICY RECOMMENDATION

Require DCT sponsors to meaningfully engage patients and incorporate their experiences into decentralized trial design. The FDA should require DCT sponsors to engage patients and incorporate their experiences into trial design as part of its broader guidance on diversity and patient engagement. Doing so would ensure that DCTs are developed with special attention to accessibility, disease burden, and patient priorities, thereby improving trial relevance, strengthening recruitment and retention, and advancing equity in clinical research.

Addressing Barriers to Patient Use of Digital Healthcare Technologies

A core feature of DCTs is the use of digital health technologies, which can broaden participation and improve data collection. These tools range from wellness applications to advanced medical devices. However, without careful consideration of patient barriers, use of digital health technologies risks excluding individuals from lower socioeconomic groups or underserved populations. Many patients – particularly those with rare diseases – may lack reliable broadband, access to necessary devices, or the training to effectively use these technologies. These barriers undermine equitable participation and can limit the generalizability of trial findings.

POLICY RECOMMENDATION

Require DCT sponsors to address potential barriers to patient use of digital health technologies. The FDA should specifically require DCT sponsors to guarantee availability of digital health technologies for all participants and provide training and resources for participants with limited technology proficiency, broadband access, or device availability. The FDA should also encourage sponsors to establish clear protocols for instances of technological failure or unavailability and to assess additional barriers faced by rural and low-income populations. Embedding these requirements into FDA guidance would help DCTs more effectively expand participation and reduce inequities in clinical research.

Partnering with Community-Based Organizations to Recruit Diverse Participants in Clinical Trials

Comprehensive recruitment strategies are essential for ensuring diverse participation in clinical trials. While the FDA's draft guidance acknowledges the importance of partnerships, it should go further by explicitly recommending that sponsors collaborate with community-based, faith-based, nonprofit, and patient advocacy organizations. These groups often serve as trusted messengers within diverse communities, maintain longstanding local connections, and can act as hubs for recruitment, education, and training necessary for DCT participation. Such partnerships not only strengthen enrollment, but also support the long-term viability of DCTs.

RDDC™'s 2022-2023 Diversity, Equity, and Inclusion Efforts in Rare Disease Organizations Survey (DEI Survey) conducted with Upequity highlighted the importance of these approaches. The survey examined how rare disease organizations engage in outreach, education, and support for patients of color, and resulted in recommendations to improve diversity in clinical trial recruitment. These recommendations emphasize practical, patient-centered strategies that can be applied broadly across the clinical trial landscape.

POLICY RECOMMENDATIONS

- **Update FDA draft guidance to encourage DCT sponsors to partner with trusted community and advocacy organizations to recruit diverse participants.**
  The FDA should also incorporate additional related strategies into its guidance to sponsors to strengthen recruitment efforts, expand outreach to diverse communities, and advance equity in clinical research, including:
- **Posting clinical trial information** on advocacy organizations' websites, social media, and other public-facing platforms.
- **Creating a guide that explains clinical trials** and participation in plain language.
- **Providing opportunities for families**, including those affected by rare diseases, to learn more about trials through community forums.
- **Sharing trial information** across multiple communication channels – not just social media.
- **Implementing targeted recruitment strategies** to reach historically marginalized populations.

Federal Legislative Priorities

In addition to recommending improvements to FDA guidance, RDDC™ tracks and advocates for federal legislation that reduces participation barriers and promotes equity in clinical trials.

Policies that encourage enrollment of patients with rare diseases in clinical trials and studies of off-label drugs.

Increasing trial participation is especially important for patients with rare diseases from historically marginalized populations, who are often excluded from clinical research and experience challenges accessing emerging therapies.

- **H.R. 3521 - Clinical Trial Modernization Act**
  This bill would expand access to clinical trials by funding community-based outreach, modernizing trial design, and reducing barriers to participation.
- **H.R. 6094 - Providing Realistic Opportunity To Equal and Comparable Treatment (PROTECT) for Rare Act**
  This bill would require coverage of certain drugs used to treat rare diseases under Medicaid, private health insurance, and the Medicare prescription drug benefit.

Funding to advance the study and treatment of rare disease and its impact on diverse populations.

Federal research funding must reflect the needs of rare disease patients across racial and ethnic groups to ensure that treatments and discoveries are equitable and inclusive.

- **H.R. 4714/S. 2345 - Pediatricians Accelerate Childhood Therapies Act**
  This bill would require the National Institutes of Health (NIH) to create research award opportunities for pediatric scientists and physician scientists focusing on basic, clinical, translational, or pediatric pharmacological research.
- **S. 2333 - Pandemic and All-Hazards Preparedness and Response Act**
  This bill reauthorizes federal programs to prepare for public health emergencies and address drug and device shortages with a specific provision for those used for patients with rare diseases.
- **H.R. 1750 - Health Equity and Rare Disease (HEARD) Act of 2025**
  This bill would establish grants and initiatives under the Department of Health and Human Services (HHS) to address rare diseases in racial and ethnic minority populations. It would also require HHS to report to Congress on treatment barriers for Medicare beneficiaries of color and strategies for research and development of treatments of rare diseases that disproportionately affect minority populations.

Long-term telehealth solutions to improve and equalize access to specialized medical providers for rare disease patients.

Telehealth access is essential for patients with rare diseases – particularly those in rural and underserved areas who often have long travel distances for healthcare appointments and limited access to the specialists they need.

- **H.R. 1843/S. 1001 - Telehealth Expansion Act of 2023**
  This bill would permanently remove the requirement for deductibles for telehealth appointments from individuals enrolled in high deductible health plans.
- **H.R. 3440/S. 1636 - Protecting Rural Telehealth Access Act**
  This bill would expand Medicare coverage of telehealth services by removing geographical restrictions on patient location, allowing federally qualified health centers and rural health clinics to serve as the provider location, and extending coverage of audio-only services for evaluation, management, and behavioral health.

Improved access to newborn screening and genetic testing, which can lead to early detection.

Early detection of rare diseases through newborn screening and genetic testing is critical to reducing disparities in diagnosis and ensuring timely, equitable access to life-saving interventions.

- **H.R. 5864 - Expanded Genetic Screening Act**
  This bill would require state Medicaid programs to cover noninvasive prenatal genetic screening for pregnant women.
- **H.R. 4731/S. 2386 - Access to Infertility Treatment and Care Act**
  This bill would require health insurance programs to provide coverage for infertility treatments, including assisted reproductive technology services, without cost sharing.

Policies that support Medicare Dependent Hospitals (MDHs) that support rural communities.

Strengthening rural hospitals is critical to protecting access to specialized care and resources for rare disease patients in rural and underserved regions.

- **S. 1110 - Rural Hospital Support Act**
  This bill would permanently extend payment adjustments for Medicare-dependent hospitals (MDHs) and low-volume hospitals to ensure stable funding for rural hospitals.
- **H.R. 6430 - Assistance for Rural Community Hospitals (ARCH) Act**
  This bill would provide financial relief and extend payment adjustments for rural hospitals, including MDHs, to preserve access to care in rural areas.

VI. Technology Access and Artificial Intelligence (AI)

Overview

Artificial intelligence (AI) and emerging technologies are rapidly transforming how healthcare is delivered across the country. Innovations like telehealth, medical wearables, and reproductive health tracking apps carry the promise of expanding timely access to healthcare and addressing geographic, cost, and provider availability barriers that often drive negative healthcare experiences and outcomes. At the same time, they require deliberate attention and strong guardrails to ensure they do not deepen health inequities or create new avenues of harm for Black women and girls.

This brief represents an initial exploration into how AI and emerging technologies intersect with the health of Black women and girls in five key areas, and offers considerations for policymakers, researchers, and advocates. **The Black Women's Health Imperative (BWHI) is laying the groundwork for research, policy, and advocacy to ensure that today's technological innovations expand healthcare access in ways that protect our health, rights, and communities – and do not leave Black women and girls behind.**

Equitable Access to Tech-Enabled Care

The COVID-19 pandemic forced the U.S. healthcare system to accelerate the widespread adoption of telehealth, remote monitoring, and digital health tools.[291] Five years later, evidence shows how these innovations have also left gaps behind, particularly for Black communities.[292] The promise of tech-enabled care lies in its ability to expand access to providers, support self-management of health data, and reduce travel and wait-time burdens.[293,294] Yet, these advantages are not equitably experienced by those without stable internet access, digital devices, or the training needed to use them effectively.[295]

Research shows that only about 68% of Black adults have broadband internet access, compared to 83% of White adults.[296] This digital divide persists even when controlling for income: in neighborhoods with majority Black populations, broadband access is 10-15% lower than comparable White neighborhoods.[297] In some parts of the rural South, nearly 40% of Black households lack broadband access compared to 23% of White households.[298] These barriers mean that the most basic benefits of tech-enabled care are out of reach of the Black communities who could gain the most.

Stable digital access could transform healthcare engagement and delivery for Black women. Black women are more likely to hold jobs without paid time off, carry greater childcare responsibilities, and live farther from healthcare facilities, all of which make telehealth and remote monitoring critically important.[299,300] Medical wearables and related devices also support management of long-term health indicators tied to chronic conditions such as hypertension and diabetes, which disproportionately affect Black women.[301] These benefits will only become reality if Black women can reliably connect to virtual care platforms, afford devices to help track their health, and receive training to use them effectively and confidently. Otherwise, the technologies currently redefining the healthcare system's standard of care are doing so in ways that will leave too many people behind.

POLICY CONSIDERATIONS

- **Expand access to broadband internet** and literacy programs, and improve affordability of medical wearable devices.
- **Explore partnerships between healthcare providers** and rural and medically under-resourced areas via telehealth and other digital interventions.

Tech-Facilitated Reproductive Surveillance

Digital health tools such as fertility and period-tracking apps have become essential for women seeking to better understand their reproductive health.[302] These technologies help users track their menstrual cycles, manage symptoms, plan or prevent pregnancy, and learn more about their overall reproductive wellbeing.[303] Yet, these tools that offer autonomy and empowerment can also expose women to serious risk if their data are collected, sold, or distributed without their consent.[304]

In recent years, several cases have shown the dangers of weak privacy protections. A California jury recently found that Flo, a period-tracking app, violated the state's wiretap law by intentionally allowing Google and Meta to eavesdrop on in-app communications for nearly three years.[305] Additionally, in 2023, the U.S. data broker industry generated over $350 billion from selling personal information – often without users' knowledge – including reproductive health data.[306] Public records show that 25 data brokers in California sell reproductive health information.[307] Together, these findings illustrate an alarming trend: reproductive health data are being used as commercial assets rather than the produced health information.

This issue is of particular urgency for Black women. Black women are more likely to experience conditions like uterine fibroids, endometriosis, and infertility, where reproductive tracking tools can be highly beneficial.[308] Yet, Black women are also disproportionately criminalized for pregnancy outcomes like miscarriages, stillbirths, and substance use during pregnancy.[309] In states with laws that criminalize these outcomes, data from health apps could be weaponized against users, reinforcing the racialized use of surveillance for punishment.[310]

Technology should be a tool of empowerment, not exploitation or control. Protecting reproductive health data is a matter of privacy, autonomy, and justice.

POLICY CONSIDERATIONS

- **Expand privacy protections for reproductive health data**, such as by extending HIPAA protections to cover reproductive data collected outside of clinical settings and prohibiting the use, sale, or distribution of reproductive data for external purposes.
- **Establish clear data transparency standards** for companies to disclose how reproductive data is used and protected.

Algorithmic Harm and Data Misuse

Algorithms are becoming increasingly integrated into healthcare systems to support patient risk stratification, care management, appointment scheduling, and clinical decisions.[311] However, algorithms are only as fair as the data used to train them.[312] Research shows that many of these systems have been trained with data that underrepresent Black patients or do not capture the contextual determinants shaping their health.[313]

For example, one widely-used hospital algorithm that helped determine which patients should receive additional care management used past healthcare spending as an indicator for medical need.[314] Because Black patients have historically spent less money in the healthcare system, the algorithm systematically underestimated their needs.[315] When researchers recalibrated the system to account for this bias, the percentage of eligible Black patients rose from 17.7% to 46.5%.[316]

Algorithmic bias also shapes patient experiences in other ways. Automated scheduling systems that deprioritize patients characterized by a higher no-show risk can worsen access for those already facing barriers.[317] These patients are then scheduled in with or right after overbooked slots, leaving these patients with worse experiences.[318] In one study, Black patients visiting a clinic that used this predictive scheduling software waited 30% longer for appointments than non-Black patients.[319] These disparities show that caution is required to ensure that even seemingly neutral data points do not reinforce existing disparities.

To prevent these harms, algorithmic programs used in healthcare systems must be trained on representative data that reflect the full reality of Black patients' lives. This includes consideration of social determinants of health and access gaps. Equally important are mechanisms of redress and accountability for patients harmed by algorithmic misjudgments. As predictive models become more common in healthcare, there is an opportunity to use these tools to close longstanding gaps in care and lessen the impact of the country's most urgent healthcare challenges.

POLICY CONSIDERATIONS

- **Explore independent review** and redress mechanisms for algorithmic bias and harm.
- **Invest in community-engaged research** that builds more representative datasets to improve algorithmic fairness.

AI raises questions about the balance between digital tools and traditional healthcare providers, safety, bias, and accountability.

Environmental Harm of AI Expansion

The rapid expansion of AI infrastructure comes at a significant environmental cost, with both direct and indirect impacts on community health. Data centers – the facilities used to train and operate AI– are projected to consume 12% of the country's total energy by 2028, representing a 550% increase from last year.[320,321] By comparison, a single AI search uses anywhere from 10 to 30 times more energy than a regular internet search.[322]

These energy-intensive operations contribute to air pollution, heat pollution, and strain on local water resources.[323] Alarmingly, the siting of data centers and facilities that support AI development often harm predominantly Black communities the most, compounding a long history of environmental racism.[324] For example, historically Black communities in cities like Memphis, Tennessee are facing air poisoning caused by gas-powered generators by an AI company.[325] In southwest Memphis, residents already face a higher burden of toxic air exposure, and cancer risk is four times higher than the national average.[326]

Black communities have borne the health consequences of environmental racism for far too long. Black individuals are 40% more likely than White individuals to have asthma, and Black children are eight times more likely than White children to die from asthma-related complications.[327] More broadly, Black individuals are more likely to die from causes related to air pollution and to experience limited access to clean water.[328,329] Research also shows that Black mothers are disproportionately affected by air pollution, which is linked to adverse pregnancy outcomes like preterm birth, low birth weight, small-for-gestational-age fetuses and infants, and stillbirths.[330]

Without careful oversight and regulation, the continued growth of AI threatens to worsen these disparities in Black communities. AI expansion is not only a technology policy issue – it is also an environmental justice issue. Ensuring that these facilities do not exacerbate existing harms requires careful environmental review, thoughtful regulations, and meaningful engagement with the communities where AI infrastructure is being built.

POLICY CONSIDERATIONS

- **Examine how to improve environmental and health equity** assessments in AI infrastructure planning.
- **Improve community engagement** and require community benefit agreements during AI infrastructure planning.
- **Develop and incentivize environmentally sustainable solutions** for AI expansion.

Looking Ahead: AI and Black Women's Health

AI is increasingly becoming a first point of contact for individual health questions and concerns – from symptom checkers and therapy chatbots to AI responses in search engines. For Black women and girls, AI at its most accurate and culturally informed capacity could help bridge access gaps by providing on-demand health information, virtual mental health support, and real-time guidance for everyday health concerns. It could also help support preventive care by helping individuals track their health data like symptoms and early signs of chronic conditions. Yet, AI raises questions about the balance between digital tools and traditional healthcare providers, safety, bias, and accountability. Can AI tools meet the unique needs of Black women when they are still trained on data that fails to capture their experiences? What happens if AI is used as a substitute for traditional care and provides harmful or misleading advice? In the context of mental health, especially for youth, how can the benefits of AI for personal and emotional support be leveraged while ensuring that signs of crises or emergencies are recognized and acted on?

As AI advances, it must be a tool that expands access to trustworthy information, improves healthcare delivery, and promotes the overall health and wellbeing of all communities, especially Black women and girls.

Conclusion

This policy agenda began with a simple truth: Black women's health experiences and outcomes are a measure of this country's commitment to equity. Every policy goal within these pages is part of a greater vision of a future where Black women and girls can live fully, freely, and without the weight of preventable harm. *A Roadmap for Change: Black Women's National Health Policy Agenda 2025–2026* responds to the urgency of this moment with solutions that must come first — and with a blueprint for what is possible when Black women's health is recognized as essential to our nation's wellbeing.

The work ahead will not be easy, but it is necessary, and BWHI is ready. This policy agenda calls for courage from policymakers, accountability from systems, and collaboration across communities. We do this work so that one day, we may look back and see that Black women's health is no longer a test for our nation's values, but a testament to its progress, and a reflection of the health, dignity, and opportunity that every Black woman and girl deserves.

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