



# BLACK WOMEN **VOTE**

## NATIONAL HEALTH POLICY AGENDA

2020 - 2021



**BLACK WOMEN'S**  
HEALTH IMPERATIVE

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October 2020

Dear Supporters,

For Black women, 2020 has been a difficult year. Day after day, we have carried the burden of trying to survive a pandemic while also trying to survive being Black in America. The physical, mental, emotional, and economic toll is immense—and all too familiar.

Black women have navigated danger in America for centuries. Our humanity, our safety, and our rights are devalued in the workplace, doctor's offices, classrooms, and our own neighborhoods. As the brutal and reckless police murder of Breonna Taylor demonstrated, we are not protected even when asleep in our own homes. The need for change in every system, from education to housing to health care, is urgent.

In response, the Black Women's Health Imperative (BWHI) has updated our ***Black Women Vote: National Health Policy Agenda*** for 2020 to include a fifth pillar, *Social Justice*. This new section addresses the issues of police violence, sexual assault, and incarceration. The 2018 agenda's four pillars focus on *Access to Quality and Affordable Health Care*, *Equitable Responses to Public Health Emergencies*, *Sufficient Diversity in Clinical Research*, and *Increased Funding to Support Historically Black Colleges and Universities*. Under each pillar, the Agenda includes a thorough yet non-exhaustive list of the most pressing health issues facing Black women today, with concrete policy recommendations to help move toward real solutions.

This Policy Agenda serves to mobilize Black women, who have historically stood at the forefront of social movements, to advocate for ourselves and our communities. With it, BWHI aims to empower Black women with a blueprint for change and deliver a call to action for policymakers, practitioners, academics, and community leaders.

Black women are at our most powerful when we exercise our voices and our passion through civic engagement and political action. With our very well-being at stake in the current political climate, it is time to do what we have always done: be the heroes of our own story. As the legacies of US Representative John Lewis and Supreme Court Justice Ruth Bader Ginsburg demonstrate, justice does not come easily. We must organize, mobilize, and fight for it.

Black women deserve a just and equitable future. Join us in creating one.

Sincerely,

A handwritten signature in black ink that reads "Linda Goler Blount". The signature is fluid and cursive, with the first name "Linda" being the most prominent.

Linda Goler Blount  
President and CEO



# Executive Summary

The health crisis faced by Black women and girls has spiraled. Policymakers, health care providers, and community-based organizations must pay close attention to the adverse effects of disparate funding, underrepresented research, unhealthy conditions, and social attitudes about the well-being of Black women. The Black Women's Health Imperative (BWHI) presents ***Black Women Vote: National Health Policy Agenda***, a foundational policy blueprint to be executed by Black women. It offers evidence to both policymakers and practitioners as to why the health and wellness of more than 21 million Black women matters in the United States.

For 35 years, BWHI has been the only national organization dedicated solely to improving the health and wellness of Black women and girls physically, emotionally, and financially. BWHI advances and promotes Black women's health through three focus areas: Wellness Programs; Policy and Advocacy; and Research Translation.

In the areas of policy and advocacy, BWHI evaluates and develops national and state public policies to address the most critical issues facing Black women's health.

These include:

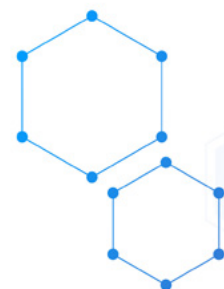
- Reproductive health and justice
- Maternal mortality and morbidity
- Cardiovascular disease and hypertension
- Breast, lung, colorectal, and cervical cancer
- Diabetes
- HIV/AIDS
- Mental health

## What is the National Health Policy Agenda for Black Women?

The National Health Policy Agenda for Black Women has been created to help inform and support partnerships with policymakers and other stakeholders on the critical health policy issues that impact and improve the well-being of Black women. This Agenda also provides an opportunity for voters to engage in substantive policy discussions—particularly around key health policy issues impacting Black women and girls—and to seek meaningful solutions.

In 2018 and 2020, Black women demonstrated their political power. A record-breaking 603 Black women ran for elected office in 2018. BWHI's policy agenda provides a roadmap to measure candidates' overall support of issues that disproportionately impact Black women. It is a tool to hold lawmakers accountable at a time when many of our public policies and programs are under attack.

The Agenda also serves as a pathway for key decision-makers who are being tasked with taking action on behalf of their constituencies. This targeted policy approach will ensure that Black women's health outcomes from birth to death are not treated as secondary to those of other women in our country.





## Why is the Agenda Needed?

Over the years, the federal government has decreased investments in the care of women of color in general and for Black women specifically. The reduction in both the policy and funding focus on women's health has accelerated over the past four years; reductions, in turn, affect health care coverage and reimbursement, public health and emergency response management, clinical research, and even the sustainability of Historically Black Colleges and Universities (HBCUs).

The Affordable Care and Patient Protection Act (ACA) has consistently been undermined and targeted for repeal without a sufficient replacement under the administration of the 45th president. This targeted repeal is being pushed despite notable improvements in health care through the ACA, including a significant decrease in the number of uninsured and underinsured Americans and an increase in access to preventive screening services. Certain legislators continue to work toward its repeal, and the administration has sought to undermine the program in multiple ways. Black women will disproportionately suffer from new insurance rules, since new insurance products will not need to offer meaningful coverage and can charge the beneficiary more based on age and gender. These new insurance programs are also intended

to draw healthier and younger individuals away from the national health exchanges, increasing the costs for those who have benefited from ACA programs. State and federal legislators have sought to weaken the protections for preexisting conditions and essential health benefits, providing a very stark reminder of what is at stake.

Attacks on Medicaid have had a negative impact on Black women's health. A lifesaving provider of health care for low-income individuals and families, Medicaid is targeted for spending cuts, new work requirements, and coverage changes. Many mothers, elderly people, and people with disabilities wonder who these public servants are serving with their legislative and regulatory efforts to dismantle Medicaid.

BWHI seeks to empower our supporters to advocate on both the local and national levels through the dissemination and execution of the Agenda, which can be adapted and expanded upon to include state-level policy, especially for community-based organizations looking to engage and mobilize their bases around specific policies that impact Black women's and girls' health.



*Image courtesy Phelan Marc Media*

# The Five Pillars of the National Health Policy Agenda for Black Women

BWHI hopes that the Agenda will help guide the work toward ensuring that all Black women and girls are able to live happier, longer, and healthier lives. To address the growing disparities in health equity for Black women and girls, the Agenda rests upon five pillars.

## **Pillar I: Access to Quality and Affordable Health Care**

*Black women are disproportionately subject to disparities in reproductive and maternal health outcomes, cancer deaths, and chronic disease diagnoses and outcomes—largely due to gaps in access to quality and innovative care.*

This first pillar asserts that Black women's health outcomes depend on the *accessibility, availability, and affordability of quality care*. Access to quality affordable care will allow health care providers to detect and treat health issues more effectively in Black women, which can potentially lead to a reduction and, hopefully, elimination of health disparities impacting Black women.

BWHI seeks to generate and leverage evidence that strongly supports prioritizing Black women and girls on the following policy and community-level issues:

- A. Affordable Care and Patient Protection Act (ACA, a.k.a. “Obamacare”)
- B. Medicaid and Medicare
- C. Access to Affordable Medicine and Biosimilars
- D. Access to High-Quality Maternal and Infant Health Resources
- E. Reproductive Health, Rights, and Justice
  - 1. Title X Family Planning
  - 2. Access to Affordable Contraceptives
  - 3. Access to Safe and Legal Abortion
  - 4. Comprehensive Sex Education
  - 5. Endometriosis
  - 6. Uterine Fibroids
  - 7. Menstrual Equity
  - 8. Infertility and Surrogacy Disparities
  - 9. Menopause
  - 10. Toxins in Beauty and Menstrual Care Products
- F. Access to Cancer Prevention, Screening, and Treatment Services
- G. Cardiovascular Health
- H. Diabetes
- I. Obesity
- J. HIV/AIDS
- K. Mental Health
- L. Rare Disease
- M. Epilepsy

*In each of these areas, BWHI advocates for targeted funding and programs to address the disproportionate, and often grave, consequences for Black women and girls. BWHI also urges policymakers and health care practitioners to be more proactive in increasing the life expectancies and quality of life for these women and their families.*

## **Pillar II: Equitable Responses to Public Health Emergencies**

Health equity can mean many things to different populations and organizations. To BWHI, it means eliminating, in and among communities, health disparities that are based on race, education, income, or other environmental and social determinants.

World and national public health emergencies devastate entire communities, especially low-income communities of color. These afflictions can come from water contamination (like in Flint, Michigan); opioid dependence; the COVID-19 pandemic of 2020; extreme weather and hurricanes; wildfires; outbreaks of measles and other infectious diseases; and mass casualty events through gun violence. Black women and their children suffer adverse health outcomes when the conditions of their environment are not sufficiently addressed. Black women across the country are organizing and spearheading efforts to raise awareness in our communities about the impacts of environmental racism.

- A. Covid-19
  - 1. Chronic Disease and COVID-19
  - 2. Heart Disease
  - 3. Access to Care
  - 4. Economics (jobs and housing)
  - 5. Childcare
  - 6. Mental Health
  - 7. Vaccines and Clinical Trials
- B. Environmental Health and Environmental Justice
  - 1. Access to Clean Water
  - 2. Climate Change and Pregnancy
- C. Tobacco
- D. Opioid Crisis
- E. Gun Violence
- F. Incarceration and Money Bail

*Consequently, the Agenda advocates for direct funding and intervention to take on core areas as they relate to Black women and girls: access to clean water; opioid crisis; COVID-19; gun violence; incarceration and money bail; tobacco; and climate change and pregnancy.*

### **Pillar III: Sufficient Diversity in Clinical Trials and Health Care Delivery Systems**

Black women are vastly underrepresented in clinical research and trials. Increased diversity among people in clinical trials helps researchers improve treatments for diseases that disproportionately affect Black women and ensure the safety and effectiveness of new therapies for everyone. Historical racism, discrimination, and exploitation in medical research against Black women has led to distrust in research trials and therefore a reticence to join them. Federal preventive screening guidelines are based on evidence that too often includes few or no Black women, resulting in clinical guidance that may be inaccurate for diseases with a disproportionate impact on Black women, such as cervical and breast cancers. Recruiting diverse researchers and physicians to care for Black women, their families, and their communities will increase cultural competency, community trust, and overall well-being. Increasing the reach of telehealth and artificial intelligence for Black women will help reduce disparities.

*The Agenda outlines a plan for appropriate identification of diversity in clinical research, health care workforce, and health care technology.*

### **Pillar V: Social Justice**

Despite facing disproportionate rates of violence, long-standing stereotypes have created a status quo that invalidates and often ignores Black women's humanity, pain, and trauma. As a result, they are often denied safety and justice. As long as laws are written in ways that allow for injustice, archaic and oppressive policies and practices will continue to harm Black women.

*To address the need for systemic change, the Agenda advocates for policy reform across three critical issues affecting the health of Black women and girls: police violence; sexual assault; and incarceration.*

### **Pillar IV: Increased Funding to Support HBCUs**

Black women comprise the vast majority of the student population at Historically Black Colleges and Universities (HBCUs) earning bachelor's and master's degrees. HBCUs need additional funding to ensure that Black women's educational endeavors and opportunities for economic advancement are supported. The sustained funding will help HBCUs build capacity, leadership, and culturally and linguistically relevant approaches to issues affecting college-aged Black women, such as reproductive and sexual health education and responses to intimate partner violence and sexual assault.

As part of the Agenda, BWHI emphasizes our *My Sister's Keeper*<sup>7</sup> program, which mobilizes young, Black, college-aged women to join the reproductive justice movement, creates awareness of the importance of sexual and reproductive health across the lifespan, and builds a network of student leaders who will grow into civic and political leaders to advocate on behalf of reproductive justice policy matters.

*The Agenda also provides guidance so that HBCUs ensure their medical schools are part of the national dialogue on resolving health disparities in the United States.*

### **A Way Forward**

BWHI is excited to release this second edition of its legislative Agenda. Based on these five pillars; the nation will now have a blueprint for how to solve health inequities for Black women and girls.



# BLACK WOMEN VOTE:

## National Health Policy Agenda





# Pillar I. Access to Quality and Affordable Health Care: Areas of High Priority for Black Women's Health

## A. Affordable Care and Patient Protection Act (ACA)

Despite its imperfections, the ACA has successfully made health insurance more accessible, secure, reliable, and affordable for millions of Americans, including a large number of Black women. Black, Hispanic, and white adults have all made historic insurance coverage gains under the ACA. The uninsured rate for Black adults dropped from 24.4 percent in 2013 to 14.4 percent in 2018.<sup>2</sup> The ACA requires coverage of preexisting conditions and essential health benefits. It has allowed people to access routine health care treatment and checkups with a primary care physician. Access to women's preventive services with no copay helps address Black women's disproportionate risk of conditions that qualify as preexisting conditions—including diabetes, hypertension, obesity, cancer, and HIV/AIDS—by expanding their ability to access timely counseling, screening, and treatment. Before passage of the ACA, people of color accounted for 54 percent of those uninsured in the United States. Black women and other women of color, who already face systemic barriers to accessing health care, were greatly impacted by this horrific lack of access to care. Before passage of the ACA, about 19 percent of the nonelderly US population was uninsured.<sup>3</sup> About 20 percent of African Americans were uninsured.

Black women between the ages of 15 and 44<sup>4</sup> face the greatest disparities in health care coverage. Insurance is especially critical for women during their reproductive years. Health care access, often preconditioned on having insurance, is necessary for women to be able to participate in routine exams as well as to have access to birth control if they want to prevent pregnancy. Low-income Black women are less likely to have health insurance than low-income white women.

The Essential Health Benefits requirement under the ACA covering prenatal and maternity care helps ensure the health and safety of Black mothers and their families. Section 1557 of the ACA also protects Black women's health by prohibiting discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities. The law covers individuals with preexisting conditions at the same rate as healthy people, which allows Black women to remain covered without fear of high medical debt, one of the leading causes of bankruptcy.

The administration of the 45th president has pressed the Supreme Court to overturn the ACA. If the Court agrees to do so, it would signify the permanent end of Obamacare coverage for 23 million Americans who would then become uninsured.<sup>5</sup> The administration has stated it will repeal and replace the ACA; however, no alternative plans have been introduced. Dissolving the ACA during a global pandemic that has infected eight million Americans would take decades to rectify.<sup>6</sup>

**ACA Policy Recommendations:** BWHI supports and recommends preserving and improving upon the Affordable Care Act to ensure millions of Americans retain access to affordable, quality health care, and thus fervently opposes all repeal-and-replace efforts. BWHI opposes the development of insurance products that are exempt from the ACA insurance requirements and that would result in coverage that is both costly and meaningless. BWHI supports retaining investments in minority health clinics to combat health disparities and ensure access to essential health care services.

BWHI also supports and recommends preventive health care legislation such as introduced in the 116th Congress, the purpose of which was to improve specialty training for treating low-income individuals and women of color and to require the Department of Health and Human Services to conduct research to better understand and address the health care needs of women across the country.



*Image courtesy istock.com/FG Trade*

## B. Medicaid and Medicare

Medicaid provides essential coverage and access to comprehensive health care services for Black women, especially those who are low income. In fact, nearly one-third (31 percent)<sup>7</sup> of Black women of reproductive age are enrolled in the Medicaid program. Medicaid covers a wide range of reproductive health care services, including family planning; sexually transmitted infection testing and treatment; and pregnancy-related care, including prenatal services, childbirth, and postpartum care. Medicaid finances 43 percent of all births in the United States.<sup>8</sup> In addition to receiving family planning and maternity care benefits, Black women can also use Medicaid's long-term care services that support them as they age, which includes access to mental health services, management of chronic disease, and disability care. As Black women age, Medicare as a federal health care safety net becomes even more essential.

Thirty-eight states and D.C. have adopted Medicaid expansion.<sup>9</sup> Medicaid expansion allows for the federal government to use its funding to help prospective Medicaid recipients purchase private insurance in health insurance exchanges. Research says that Medicaid expansion has improved access to care among low-income populations. Expanding Medicaid will increase state spending, but the expansion simultaneously reduces the amount spent on traditional forms of Medicaid. Expansion also allows for some states to cut additional costs outside of Medicaid.<sup>10</sup> Data confirm that states that have expanded Medicaid have been in a much better position to address COVID-19 amid the current economic recession. Around four million uninsured adults would be eligible for Medicaid coverage if the remaining states chose to expand their programs as well.

Furthermore, Medicaid expansions have demonstrated improved maternal health outcomes, specifically for Black women. The Centers for Medicare & Medicaid Services (CMS) estimates that 50 to 60 percent of births in rural communities are financed by Medicaid.<sup>11</sup> These programs benefit all women but are especially critical to rural areas and can facilitate better outcomes for women residing in these areas.

**Medicaid & Medicare Policy Recommendations:** BWHI supports and recommends Medicaid expansion in all 50 states; the protection of Medicaid as a safety net program with no harmful waivers such as work requirements, premiums, or time limits; and expanded coverage and reimbursements for services that help reduce racial disparities, such as postpartum care and doula services to reduce the high rate of maternal deaths. BWHI opposes any efforts to exclude trusted providers of family planning services.



## C. Access to Affordable Medicine and Biosimilars

A biosimilar is a medicine that is highly similar to a previously approved reference biologic (medicine derived from living organisms such as blood and tissues) currently on the market, but it usually is a more affordable option for many patients who rely on biologic treatments. The Food and Drug Administration (FDA) has granted approval to biosimilars that treat several conditions. Biosimilar medicines offer solutions that provide greater access to these advanced therapies for patients. As biosimilars become more widely available in the United States, they expand therapeutic options, enhancing the likelihood that patients will be able to begin treatment. An analysis by Avalere Health for the Biosimilars Council shows that 1.2 million US patients could gain access to biologics by 2025 as the result of biosimilar availability.<sup>12</sup>

These data also suggest that women, lower income people, and elderly individuals would disproportionately benefit from access to biosimilar medicines, which can greatly improve health outcomes for Black women. For example, after analyzing records from almost 800,000 Medicare beneficiaries, researchers found that Black psoriasis patients on Medicare may be less likely to receive biologic treatment, and that economic and geographic factors play a part in access to biologics. Researchers found that patients who did not have a Medicare Part D low-income subsidy—which offers assistance to people who qualify in paying for prescription drug costs—were 70 percent less likely to use biologics. In addition, Black patients were approximately 70 percent less likely, compared with white patients, to be on biologics.<sup>13</sup>

**Affordable Medicine Policy Recommendations:** BWHI supports and recommends access to affordable lifesaving drugs, including biosimilars, and policies that give biosimilars an opportunity to compete in the market and expand patient access to critical medicines.



*Image courtesy istock.com/skhoward*



## D. Access to High-Quality Maternal and Infant Health Resources

Black maternal and infant health is in crisis. Black women are three to four times more likely to die from complications of pregnancy or childbirth than white women.<sup>14</sup> There are also devastating racial disparities in infant mortality for Black women. According to maternal health research studies, Black infants in America are now more than twice as likely to die as white infants—a racial disparity that is actually wider now than it was in 1850, 15 years before the end of slavery.<sup>15</sup> This racial disparity persists regardless of age, socioeconomic status, education, and other factors. In fact, a Black woman with an advanced degree is more likely to lose her infant than a white woman with less than an eighth-grade education.<sup>16</sup>

The crisis of maternal mortality for Black women also persists across class lines. The United States is the only developed country in the world with rising rates of maternal mortality. According to the Centers for Disease Control and Prevention (CDC), more than 60 percent of pregnancy related deaths in America are preventable.<sup>17</sup> For every woman who dies in childbirth, 70 others experience a “near miss” case of severe maternal morbidity that may lead to lifelong conditions, plaguing women’s health.<sup>18</sup> Black women are also twice as likely to lose their babies to premature death; causes include insurance coverage gaps and social determinants of health.<sup>19</sup> The prevailing reason is linked to racism and implicit bias in medicine.

Black women are disproportionately impacted by risk factors related to pregnancy, such as hypertension or gestational diabetes, but these factors are made worse by the compounded stress of racial discrimination, lower quality health care, climate change, and COVID-19. Marginalized areas, often home to communities of color, are characterized as housing communities with more multistory, densely populated buildings less likely to have air conditioning, which is costly to run, or access to clean water to keep hydrated. A recent study examined the long-term impact in 108 US cities of “redlining”—a racially discriminatory practice begun in the 1930s by which banks and real estate companies refused or limited loans, mortgages, and other investments within specific geographic areas, especially Black inner-city neighborhoods. This study found temperatures in formerly redlined areas, still usually home to communities of color, are often as much as 13°F warmer than in non-redlined areas.<sup>20</sup> Hotter temperatures exacerbate existing maternal health disparities.

Medicaid programs play an integral role in maternal services, particularly within Black households. Currently, Medicaid covers nearly half of all births in the United States.<sup>21</sup> Research indicates Medicaid expansion under the Affordable Care Act to be an effective method of decreasing maternal mortality in America. States that expanded Medicaid coverage between 2014 and 2016 significantly improved health outcomes for mothers and babies during childbirth.<sup>22</sup>

## Maternal Health Partnerships

To address the impact of racism in our country’s maternal health care system, the Black Women’s Health Imperative is partnering with key stakeholders in the nursing, patient advocacy, policy and research communities to develop a patient-centered, values-based implicit bias curriculum that incorporates the lived experiences of Black women to improve provider awareness of this critical barrier to care.

This important body of work will review the science, interventions, and current policies related to implicit bias and racism in maternal health care; gather and integrate stories from Black women and their significant others and families whose lives have been impacted by maternal mortality and morbidity; Improve provider awareness of the adverse effects of implicit and institutional bias; and set a strategy for addressing structural racism and systems of care delivery, which are barriers to promoting and improving maternal health at the national and state levels. These recommendations will be included in a major patient-centered, evidence-based suite of advocacy tools and research interventions that will provide tangible solutions for achieving optimal maternal health care for Black women by Black women.

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*Image courtesy istock.com/electravk*

Research supports that implicit bias negatively impacts Black patients' medical care. One study finds that white medical students rated Black patients' pain lower than that of their white counterparts. Additionally, providers' recommendations for Black patients were found to be less accurate. Another study, in New York City, found that Black, college-educated women were more likely to suffer life-threatening complications during childbirth than women of other races with less education.<sup>23</sup>

**Maternal & Infant Health Policy Recommendations:** BWHI supports and recommends access to quality health insurance and programs that protect women's health throughout their lifetime and that foster healthy pregnancy and postpartum outcomes for Black women and their babies. Programs identifying and treating social disparities and other conditions that increase maternal mortality risks are needed for hypertension, diabetes, and obesity. Providers should be trained in patient-centered practice and culturally sensitive care. Medical and family leave policies need improvement. Young parents and caregivers need support. At the national level, funding is needed for comprehensive data collection and reporting on maternal morbidity and mortality across the country, including state-level maternal mortality data. Critically, we call for funding and support for robust accountability measures for when institutions fail Black women, including state maternal mortality review teams that assess all pregnancy-associated deaths in order to identify commonalities and potential solutions. BWHI stands with the Black Maternal Health Caucus, which is organized around the goals of elevating awareness of the Black maternal health crisis within Congress and advancing policy solutions to improve maternal health outcomes and end disparities.

BWHI supports legislation that addresses social determinants of health and funds community-based organizations working to improve maternal health outcomes for Black women. BWHI supports growing and diversifying the perinatal care workforce to ensure that every mom in America receives maternity care and support from people she can trust. We need investment in digital tools like telehealth to improve maternal health outcomes in underserved areas, and we need investment in innovative payment models to incentivize high-quality maternity care and continuity of health insurance coverage from pregnancy through labor and delivery, up to one year postpartum.

Long-term needs include adopting different approaches to diversifying medical professions for physicians and other clinicians.<sup>24</sup> Racial minorities often face greater barriers to their entrance to medical school. The cost of a medical education is sometimes a huge deterrent for prospective students. Diversifying the medical professions will require a concentrated effort that pours resources into Black communities while defraying medical costs for middle- and low-income students.





Image courtesy Adobe stock/Paolese

## E. Reproductive Health, Rights, and Justice

Black women, regardless of age, income, or education, should have access to the full range of reproductive health services—including access to affordable contraceptives and safe, legal abortion—free from discriminatory barriers. BWHI recognizes, however, that the legal right to reproductive health services is not sufficient without also addressing the social, political, and economic inequalities that affect Black women's ability to access the services. Reproductive justice—the human right for women and girls to control their bodies, their sexuality, their gender identity, their work, and their reproduction—is critical to affirming and retaining the dignity of Black women.

In this section, BWHI points out disparities affecting Black women and recommends policies in the areas of Title X family planning, contraceptives, safe and legal abortion, comprehensive sex education, endometriosis, uterine fibroids, menstrual equity, infertility and surrogacy disparity, menopause, and toxins in beauty and menstrual products.

**Reproductive Health Policy Recommendations:** Along with specific recommendations in each of the following topics, BWHI recommends policies that address the social determinants of health—such as access to housing, education, and jobs—as crucial to achieving reproductive justice.



## Title X Family Planning

The Title X Family Planning Program is the only federal funding stream dedicated solely to reproductive health services for low-income women in the United States. The program provides funding to clinics and health care organizations so that they can provide free or low-cost HIV/STI screenings, breast and cervical cancer screenings, and contraceptives counseling. Recently, there has been a trend from policymakers to propose rules that would redefine eligibility for Title X funding, prohibiting (“gagging”) doctors, nurses, and other providers from referring Title X patients to abortion services in an ultimate attempt to defund Title X clinics and other abortion service providers. Defunding Title X clinics by attacking the Title X family planning program would have dire consequences for Black women, many of whom rely on these clinics and other community health centers as their primary source of care.

**Title X Policy Recommendations:** BWHI supports and recommends the preservation of women’s preventive services coverage under Title X by fully funding eligible Title X program providers regardless of abortion practices or beliefs.

## Access to Affordable Contraceptives

Access to affordable contraceptive care is critical to the health and well-being of Black women. Contraceptives can be very expensive, particularly the most effective long-acting reversible methods, and are often much less accessible to those without health insurance. Structural racism, gender discrimination, and economic standing all hinder Black women’s autonomy in family planning.

Currently, 30 states and D.C. require insurance plans to cover contraceptives. Lack of insurance coverage, as well as lack of accessibility to gynecological care, may prevent Black women from receiving the full range of contraceptive options available. Some forms of birth control help alleviate gynecological conditions that disproportionately impact Black women, including ovarian cancer and uterine fibroids. Effective contraceptives allow Black women to create a family in their own time, grow the families they have, or not have children at all. Unintended pregnancy is one of the main contributors to college dropout rates.<sup>25</sup> Access to affordable and highly effective methods of contraception helps women in their teens and 20s effectively and safely prevent unplanned pregnancies, thus ensuring that Black women can continue their education and cultivate their budding careers.

In mid-2020, the presidential administration implemented two federal regulations that extend religious and moral exemptions from the ACA’s contraceptive coverage benefit to employers, schools, individuals, and insurers.<sup>26</sup> Before the ACA, contraceptives were inaccessible to many Black women because of cost. This change undermining the ACA’s intent creates yet another barrier to affordable contraceptive care for Black women.

**Affordable Contraceptives Policy Recommendations:** BWHI recommends access to affordable, highly effective contraceptives through the maintenance of the ACA’s contraceptive coverage benefit with no religious or moral exemptions. BWHI also recommends improved patient education to increase Black women’s understanding of contraceptive use so that they are able to make the best decisions for their bodies. BWHI supports meaningful legislation intended to enhance contraceptive options for all women, such as bills introduced in previous Congresses like the Affordability Is Access Act,<sup>27</sup> the Access to Birth Control Act,<sup>28</sup> and the Protect Access to Birth Control Act.<sup>29</sup>

## Access to Safe and Legal Abortion

Policies that restrict access to safe and legal abortions disproportionately affect Black women, particularly those who are low income. Black women are often targeted by anti-abortion campaigns that use thinly veiled racism and sexism to shame those who use abortion services. Black women remain the focus of anti-abortion rhetoric despite the fact that they account for only 39 percent of all legal abortions; white women comprise 51 percent.<sup>30</sup> Abortion, at any point during pregnancy, is a complex and personal decision that women have the right to make for themselves with the care and guidance of a medical provider. Abortion clinics, in particular, are important to women of low economic backgrounds and those without health insurance. The same facilities that provide abortions are also safe spaces where many women seek prenatal support, sex education, and pregnancy care. Abortion clinics are essential, particularly to those who reside in rural areas.

Advocates must help policy makers recognize that abortion bans do not stop women from having abortions. Instead, these barriers to care make it more dangerous and expensive for women to terminate their pregnancies. Abortion bans are especially devastating for maintaining the reproductive health of Black women.

The American South currently exemplifies the detrimental effect of abortion bans, as states like Alabama and Mississippi close facilities in the region. There are three clinics available for service in Alabama,<sup>31</sup> while only one remains open for the entire state of Mississippi.<sup>32</sup> By closing these facilities, lawmakers prevent women from receiving critical health care services that they are otherwise unable to afford. Combined with low access to contraceptives, these bans amount to forced pregnancy.

In May 2019, Missouri legislators passed the Missouri Stands for the Unborn Act.<sup>33</sup> This anti-abortion policy banned procedures after eight weeks into a woman's pregnancy. Missouri's law had the potential to prohibit more than two-thirds of patients from obtaining abortions within the state.

The Supreme Court in June 2020 struck down Louisiana's abortion restrictions as unconstitutional in the case *Medical Services v. Russo*.<sup>34</sup> The case was brought by the Center for Reproductive Rights on behalf of abortion providers. States have used various tactics to interfere with access to safe and legal abortions. Some of these measures include biased counseling, mandatory ultrasounds, and unnecessary waiting periods. States have also employed measures that ban abortions at specific weeks of pregnancy.

**Safe and Legal Abortion Policy Recommendations:** BWHI supports and advocates equitable access to abortion. BWHI calls for legislation to reverse the Hyde Amendment to ensure affordable abortion coverage and care for every woman. Regardless of income, comprehensive health insurance must be available.

BWHI strongly supports the constitutional rights guaranteed by *Roe v. Wade* and lobbies to protect a woman's ability to determine whether to end a pregnancy and to protect a health care provider's ability to provide reproductive health care services, including abortion. BWHI applauds states that are moving to codify a woman's right to choose abortion.



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## Comprehensive Sex Education

Black youth deserve medically accurate information about sex that allows them to make healthy decisions about their bodies. Comprehensive sex education—as opposed to abstinence-only education—is effective at helping young people adopt healthy sexual behaviors. Sex education is a lifelong process that exceeds the time of one’s adolescence. In addition to understanding one’s development and reproductive health, individuals should be encouraged to explore interpersonal relationships, intimacy, body image, and gender identification.

Federal funding for pregnancy prevention and sex education courses serves approximately 2 percent of the teenage population in America.<sup>35</sup> In addition to inequitable allocation of funds, many states refuse to accept support for sex education, often citing moral and religious beliefs. Black teens, in particular, are often unable to obtain the information needed to promote healthy sexual experiences. Comprehensive sex education is most effective in reducing reproductive health disparities among teens and young adults.<sup>36</sup> Culturally competent sex education courses are critical for marginalized communities of color, especially Black women, whose sexually transmitted infections (STIs) are less likely than white women’s to be detected early. Black women are more vulnerable to infection of the sexually transmitted viruses chlamydia, syphilis, and gonorrhea. In a recent CDC study, Black women were 5 times more likely to contract chlamydia than their white counterparts,<sup>37</sup> 7.6 times more likely to get gonorrhea,<sup>38</sup> and 5.2 more times likely to have syphilis.<sup>39</sup> Sex education courses must include medically accurate information, discourage gender or racial stereotypes, create safe spaces for survivors of sexual abuse or assault, provide support to sexually active youth, be sensitive to pregnant or parenting youth, and reassure those with varying gender identities or sexual orientations.



*Image courtesy istock.com/SDI Productions*

**Sex Education Policy Recommendations:** BWHI supports legislation and policies that encourage health education programs and provide lifesaving information about sex-related topics, including HIV. BWHI supports and recommends comprehensive sex education and re-introduction of Rep. Barbara Lee’s (CA-13) Real Education for Healthy Youth Act, which would eliminate federal funding for harmful sexual risk avoidance education programs, instead reprogramming the funding to support the new comprehensive grant program.

BWHI also recommends funding teacher training on sex education and providing grants for comprehensive sex education to public or private entities that focus on adolescent health and education or have experience with training sex educators. BWHI further recommends that programs be required, rather than merely encouraged, to promote inclusiveness of LGBTQ youth in the funded sex education programs. BWHI is opposed to federal funding of programs that are insensitive and unresponsive to the needs of LGBTQ youth.



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## Endometriosis

Endometriosis is a condition that occurs when the tissue that normally grows inside of the uterus, called endometrium, grows outside of the uterus in the pelvis. Once in the pelvis, the endometrial tissue causes inflammation and scarring as it attaches to the pelvic organs such as fallopian tubes, ovaries, bladder, and the bowel. This scarring and inflammation cause pelvic pain, painful periods, and infertility. Quality of life can be significantly impacted. Approximately 10 percent of American women are affected by endometriosis, and it is cited as the single most common cause of chronic pelvic pain in women.<sup>40</sup>

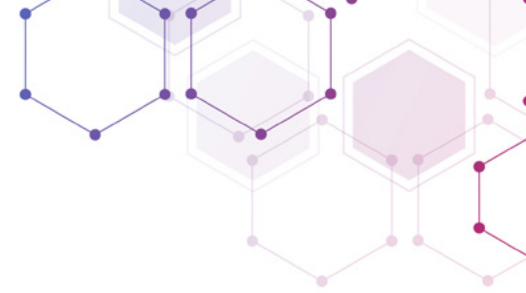
Endometriosis is another condition that has a unique effect on Black women. Although it is difficult to pinpoint the endometriosis incidence rate among Black women,<sup>41</sup> endometriosis affects 1 in 10 women of all races during their reproductive years.<sup>42</sup> Researchers found the likelihood of diagnosis of endometriosis appears to differ among various racial and ethnic groups and that endometriosis is less likely to be diagnosed in Black women and more likely to be diagnosed in Asian women, when compared with white women. However, the clinical presentation of the women included in these studies does seem to impact this trend. Namely, when comparing Black and white women and when endometriosis was diagnosed surgically or through self-report, Black women were less likely to have a diagnosis of endometriosis. In fact, Black women are only about half as likely to be diagnosed with endometriosis compared to white women, according to a systematic review and meta-analysis.<sup>43</sup>

The cause of endometriosis remains unknown. Due to numerous factors, such as the racial empathy gap and lack of awareness of endometriosis, providers sometimes dismiss Black women's chronic pelvic pain or presume it to be due to other conditions like uterine fibroid tumors or pelvic inflammatory disease.<sup>44 45 46</sup>

Black women have not been included in research studies on endometriosis at rates proportional to the population. Thus, doctors misdiagnose the condition even when

endometriosis symptoms are present.<sup>47</sup> Also, it is commonly known that Black women are often not listened to or believed when presenting with manifestations of intense and chronic pain, often suffering for years without a proper diagnosis.<sup>48</sup> Health care providers must strive to provide culturally sensitive care to women whom they treat, recognizing that women of different ethnicities may present with different symptomatology.

**Endometriosis Policy Recommendations:** More conversations are needed about Black women and endometriosis. Women should not feel ashamed of this condition. It's important to challenge racial stereotypes regarding endometriosis and Black women. BWHI supports culturally competent training for health care providers to improve their approach in providing services and treating diseases in Black women. These reproductive health issues carry stigma. It is important that health care providers understand how these issues are perceived by individuals in the patient's community.



## Uterine Fibroids

Uterine fibroids, a common and significant health problem, affect an estimated 26 million women between the ages of 15 and 50, across all racial backgrounds and socioeconomic levels in the United States.<sup>49</sup> While normally benign, uterine fibroids can vary in size from a half-inch nodule to clusters of more than seven inches in diameter.

Unlike with endometriosis, it is clear that Black women are disproportionately burdened by uterine fibroids. Black women suffer from uterine fibroids at two to three times the rate of white women;<sup>50</sup> 80 percent of Black women will have them during their lifetime. Black women are also more likely to suffer from uterine fibroids at an earlier age and with greater levels of pain than women of other races,<sup>51</sup> and they are more likely to undergo hysterectomy at some point for treatment.<sup>52</sup> Around 25 percent of Black women will suffer from fibroids by the age of 25.

Genetic elements play a role in the prevalence of fibroids among Black women but some studies have suggested that lifetime accumulation of stress may trigger fibroids. In the Black Women's Health Study, a causal relationship was found between racial discrimination and uterine fibroid tumors.<sup>53</sup> Vitamin D deficiency for those with darker skin has also been linked to fibroids in Black women.<sup>54</sup> More research on treatment alternatives for fibroids and improved access of Black women for alternatives for fibroid treatment, including medication and minimal surgical options, are needed.

Although uterine fibroids are the most common gynecological condition affecting women, many suffer for years before seeking care. Reasons include that many adolescent girls and women are unaware of what uterine fibroids are, believing that symptoms like heavy menstrual bleeding lasting more than a week, pelvic and lower abdominal pain, anemia, and frequent urination during periods are normal. Providers also need to better understand the condition and its symptoms to adequately provide treatment options to their patients. Generally, despite the widespread prevalence, there is a lack of awareness and prioritization of uterine fibroids as an important women's issue.

The physical, emotional, and societal costs are astounding: 200,000 hysterectomies are performed each year primarily to remove uterine fibroids. Severe fibroid symptoms can be disabling, and women with uterine fibroids are more likely to experience infertility, miscarriages, and difficulties during pregnancy and childbirth. Uterine fibroids are associated with low-birth-weight babies and infant mortality. The direct annual costs to the U.S. health care system are estimated to be as high as \$9.4 billion. Pain, stress, and other physical and emotional symptoms of uterine fibroids may interfere with a woman's ability to work or work productively, thus impacting her quality of life, and the ability to care for her family. This cost has been estimated to be as high as \$7.76 billion annually.

Much more research and education are critical to reducing the burden of uterine fibroids in the United States.

**Uterine Fibroids Policy Recommendations:** BWHI supports and recommends legislation improving research and education on uterine fibroids, as well as research into treatment alternatives for fibroids. Building on the Black Women's Health Study, BWHI supports increased funding and research of the effects of stress and racism on reproductive health. BWHI supports improving screening methods for patients, such as the inclusion of questions about pelvic pain. BWHI supports investment in new and innovative technologies to measure pain and provide alternatives to surgical solutions.





## Menstrual Equity

Period poverty is the inability to afford adequate products for menstruation. Period poverty is often associated with developing nations, but for many women in the United States, this issue persists and is a reality. Poor, homeless, incarcerated, and detained women are often unable to buy menstrual supplies; Black women comprise the majority of these groups. A gynecological survey in St. Louis found that 64 percent of low-income participants had been unable to afford sanitary products at some point in the last year. Twenty-one percent of respondents shared that they were unable to do so on a monthly basis. Nearly half of those surveyed admitted to having to choose between menstruation products and food.

Menstrual equity is recognized as the affordability, accessibility, and safety of menstrual products. The concept further expands to education and reproductive care. Menstrual equity focuses on making sure that women have the support they need and the ability to choose how they want to care for their menstrual health. Importantly, menstrual equity seeks to end the stigma around periods that prevents legislators, medical care providers, and educators from prioritizing menstrual health. This movement serves to ensure that low-income women, public school students, incarcerated women, and shelter residents are provided and have unfettered access to menstrual products.

One key strategy to achieve this goal is to abolish the tampon tax. The tampon tax creates an unfair and discriminatory burden on women because it levies additional taxes on menstrual products. This tax is synonymous to a regular sales tax. According to ACLU, these products are not tax exempt because the states fail to recognize them in the category of necessity. The increasing costs of menstrual products are financially burdensome for many women, creating a lack of access that has caused many girls and women to miss school or work. Some women resort to less hygienic sanitation methods, which can cause health problems.

On March 27, 2020, Congress passed the Coronavirus Aid, Relief, and Economic Security (CARES) Act (H.R. 748). This legislative package was created to help Americans manage and overcome the debilitating financial burdens of the pandemic. Embedded within the Act in a section titled *Inclusion of Certain Over-the-Counter Medical Products as Qualified Medical Expenses* is a provision that money spent on menstrual products—defined as tampons, pads, liners, cups, sponges, or similar products used for menstruation—counts as expenses incurred for medical care. As a result of its new designation as a medical care item, individuals can use their tax-preferred savings accounts, including Health Savings Accounts (HSAs) or Flexible Spending Accounts (FSAs), to purchase these essential menstrual products.

**Menstrual Equity Policy Recommendations:** BWHI stands behind efforts to foster menstrual equity through legislation similar to two bills introduced in the 116th Congress that would have provided menstrual hygiene products for homeless individuals and increased the affordability of menstrual hygiene products for individuals with limited access. Future legislation should consider free menstrual hygiene products to students, low-income individuals, homeless individuals, people who are incarcerated, and people in public federal buildings.



Image courtesy Phelan Marc Media



### Positive Periods

The Black Women's Health Imperative (BWHI) launched the Positive Period! Campaign in October 2019, understanding that reproductive justice and gender justice is inextricable to Black women's health. The Positive Period! Campaign provided 2,000 menstrual cups for women and girls in Kigali, Rwanda and Atlanta, Georgia, a first step toward addressing inequities. BWHI has now decided to transform Positive Period into a program instead of a yearly campaign, expanding the number of communities it will reach through menstrual product distribution and menstrual education. BWHI will continue to build awareness about menstrual product insecurity in the United States and abroad. One of the organization's goals is to engage in public education to raise awareness and reduce stigma. Actions like these will catalyze a movement for change in which menstrual health care will not be treated as luxury, allowing affordability, access, and safety.

### Infertility and Surrogacy Disparities

Infertility, defined as difficulty achieving and sustaining pregnancies, affects roughly 12 percent of all women up until the age of 44.<sup>55</sup> Compared to white women, Black women are almost twice as likely to experience infertility. Furthermore, Black women are less likely to seek out infertility medical assistance for conception—approximately 8 percent of Black women between the ages of 25 and 44 seek medical help to get pregnant, compared to 15 percent of white women.<sup>56</sup> Barriers to infertility medical services include the high costs of infertility treatment and pregnancy medical assistance. Even with access to infertility treatments, Black women still do not seek these treatments.

Surrogacy has also been a solution for infertility. As noted in CDC data, from 1999 to 2006, gestational carriers resulted in 13,380 deliveries and 18,400 infant births.<sup>57</sup> The overall number of Black parents choosing surrogacy still remains low, and this may be connected once again to socioeconomic factors, because surrogacy carries an average cost of \$80,000 to \$100,000.<sup>58</sup>

**Infertility Policy Recommendations:** BWHI supports the principles of the Access to Infertility Treatment and Care Act, which has been introduced in the 115th and 116th Congresses. These bills sought to require health insurance coverage for infertility treatment.



## Menopause

Much of what we know about how we experience menopause comes from the largest ongoing study of women and menopause, the Study of Women's Health Across the Nation (SWAN), which began in 1996.<sup>59</sup> It's a multi-site, longitudinal, epidemiologic study focused on the physical, biological, psychological, and social changes during menopause.

Menopause is the time when menstrual periods stop permanently, meaning a woman has not had any bleeding, including spotting, for 12 months in a row, at which time a woman can no longer get pregnant. Menopause is a normal part of a woman's life, and through the years has euphemistically been referred to as the "change of life". Sixty million women in the United States are in menopause. However, most medical schools spend zero hours on the subject. Menopause does not happen all at once. As the body transitions to menopause over several years, one may have symptoms such as vaginal dryness, mood swings, memory problems, depression, problems sleeping, weight gain, changing feelings about sex, and irregular periods. The transition time leading up to a woman's last period is known as perimenopause. The timeframe and severity of symptoms of both perimenopause and menopause vary by individual.

However, SWAN has shown that Black and Latina women fare differently than their white counterparts. While the median age in the US for reaching menopause is 52, for Black and Latina women it's 49. After menopause, for example, one of the most common discomforts is hot flashes, characterized by sudden feelings of warmth that spread over the upper body, often with blushing and sweating. Even there, the differences are stark. White women experience hot flashes for around 6.5 years after their final period, while for Latinas it's 8.9 years, and for Black women it's 10 years.

A later and shorter menopause transition isn't just more comfortable; it is also a marker of aging and health. After menopause, ovaries make extremely low levels of the hormones estrogen and progesterone. These low hormone levels can raise the risk for other health problems. The timing of menopause is linked to the risk for heart disease, stroke, osteoporosis, bone fracture, and overall life expectancy. Later and shorter menopause is better for all of these. Estrogen has a lot of protective qualities, so having it in the system longer is generally better for women's health, though it is unfortunately also linked with greater risk for breast and ovarian cancer.

In most cases, menopause is a natural process, and many symptoms will eventually go away over time. However, there are treatments that can relieve ongoing symptoms, based on individual situations. Pros and cons should be thoroughly discussed with a physician. Common therapies include hormone replacement therapy (HRT), topical hormone therapy, nonhormone medications, and osteoporosis medications.

**Menopause Policy Recommendations:** BWHI advocates for legislation that supports research into menopause, particularly in regard to its impact, early onset, and heightened symptoms experienced by Black women. Research is also needed to understand the correlation between the timing of menopause and the risk for heart disease, stroke, osteoporosis, bone fracture, and overall life expectancy. Further investigations into whether environmental factors, like stress, accelerate menopause will provide a significant opportunity for Black women to moderate and make lifestyle choices to facilitate their health through the latter half of their lives.



*Image courtesy 1stock.com/adamkaz*

### Toxins in Beauty and Menstrual Care Products

The high levels of harmful chemicals and other toxic ingredients in beauty and menstrual care products marketed specifically to Black women and other women of color is an issue of environmental justice. Studies show that women of color are being exposed to higher levels of toxic chemicals from beauty products in comparison to white women.<sup>60</sup> One in 12 beauty products marketed to Black women contains harmful ingredients.<sup>61</sup> Harmful ingredients such as steroids, mercury, and even excessive levels of estrogen are used in skin-lightening face creams, hair relaxers, and straighteners. Douching products are often marketed to Black women, but these products may contain harmful chemicals such as Diethyl phthalate (DEP), which can cause congenital disabilities in the unborn.

Menstrual care products such as tampons and menstrual pads have been found to contain harmful ingredients. New independent-product testing results reveal undisclosed toxic chemicals in tampons, including carbon disulfide, methylene chloride, toluene, and xylene. Testing of tampons and menstrual pads has found pesticide residue, parabens, and phthalates linked to hormone disruption; antibacterial chemicals such as triclosan; and various carcinogens including styrene and chloroform. Given the fact that tampons are used by up to 70 percent of menstruating women in the US, more regulation of menstrual products is needed.<sup>62</sup> Tampons, pads, and menstrual cups are considered “medical devices” by the FDA but are not subject to ingredient labeling. As a result, a full list of ingredients used in these products rarely is disclosed publicly.<sup>63</sup> This lack of transparency and disclosure is harmful to Black women as they continue to consume these products without adequate protection.

**Toxins Policy Recommendations:** BWHI supports and recommends mandatory testing and disclosure of ingredients in beauty and menstrual care products; updating federal standards governing the safety of personal care products; policies that increase the affordability of alternatives to tampons and pads; and training for health professionals to counsel patients about the potential risks of exposure to hidden chemicals in their beauty and menstrual care products.



## F. Access to Cancer Prevention, Screening, and Treatment Services

Black women bear a disproportionate burden of cancer compared with other groups. NIH data show that African Americans have the highest mortality rate of any racial or ethnic group for all cancers combined and for most major cancers.<sup>64</sup> Black people have the highest death rates and shortest survival rates for any ethnic/racial group in the United States.<sup>65</sup> Cancer disparities in incidence and death rates for Black women are exacerbated for low-income women because of the prevalence of environmental factors that increase cancer risk. These environmental factors can include lack of access to healthy foods, limited opportunity for physical activity, and targeted campaigns by tobacco and fast food companies.

The causes of cancer disparities are complex and consist of several systemic factors related to social, economic, cultural, environmental, and health care barriers; reducing these disparities is not an easy fix. Unequal access to quality cancer prevention, early detection, and treatment are particular factors that increase Black women's cancer burden; in fact, the mortality rates for some of these cancers are the worst in states in which Medicaid and public health programs are poorly funded and provide the least coverage. BWHI aims to continue to spread awareness, translate cancer research, and promote effective policy and systems change to eliminate these disparities. The four cancers that follow are focus points due to the availability of evidence-based strategies and solutions.



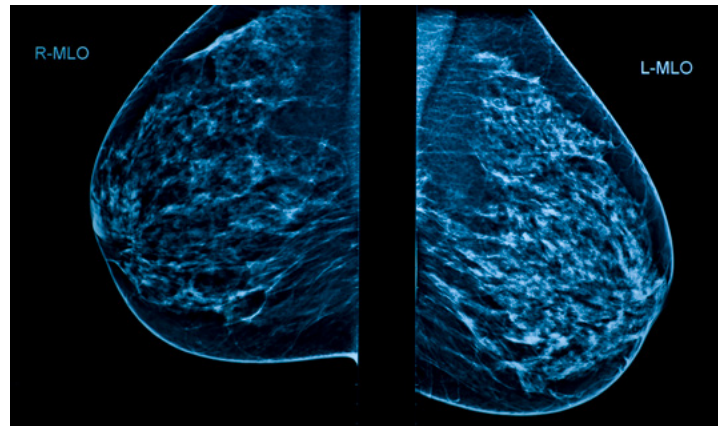
*Image courtesy istock.com/kali9*

## Breast Cancer

Breast cancer is the most commonly diagnosed cancer among Black women.<sup>66</sup> Currently, Black women's breast cancer death rates are 40 percent higher than for white women.<sup>67</sup> Breast cancer incidence rates are also higher among Black women under age 45 than white women. The median age of diagnosis is 59 for Black women, compared to 63 for white women, with a greater percentage being diagnosed in their 40s and younger.<sup>68</sup>

As a result of increased detection by screening mammography, breast cancer incidence rates among white women and Black women have converged. Early and increased breast cancer screenings have been effective strategies to address breast cancer disparities. However, due to the COVID-19 pandemic, progress in this area may be derailed. National Cancer Institute data suggest 10,000 more people in the US may die from breast cancer or colorectal cancer due to delayed screenings during the coronavirus pandemic. While the incidence rates for white women have stabilized, the rates continue to increase, albeit slowly, in Black women. Racial disparities in breast cancer mortality often are attributed to the prevalence of obesity in Black women.<sup>69</sup> However, these disparities are just as likely caused by systemic issues related to poverty, access to screening, quality of diagnosis and treatment, and provider bias.

Studies have shown that breast tissue density is one of the strongest predictors of risk for breast cancer, and that the risk of cancer for women with dense breast tissue, many of whom are women of color, is much greater.<sup>70</sup> In particular, Black women tend to have more dense breast tissue, which limits the sensitivity of a 2D screening mammography, thus requiring improved screening technologies such as early detection and screening by appropriate methods. Studies have shown that 3D mammography appears to be more effective at detecting lesions in dense breast tissue than 2D mammography.<sup>71</sup> Even though screening mammography rates for Black and white women are about the same, cancers are detected later in Black women, who are more likely to die from breast cancer than white women; this suggests a need for more access to 3D screening technology. In addition, these issues were not given the attention they deserve in the 2015 federal preventive screening guidelines for mammography, which proposed raising the age for screening mammography from age 40 to age 50 and failed to include 3D mammography in its recommendation for an A or B grade. Thankfully, this guideline changed and has been placed in a moratorium through the Protecting Access to Lifesaving Screenings (PALS) Act, legislation for which BWHI was a leader in developing and passing.



*Image courtesy istock.com/yumiyum*

**Breast Cancer Policy Recommendations:** BWHI supports and recommends the elimination of annual deductibles, copayments, and coinsurance payments (“cost-sharing”) for all screening mammograms, including those provided to women more frequently than current federal screening guidelines, such as annual mammograms for women starting at age 40. BWHI also supports the elimination of cost-sharing for diagnostic imaging for breast cancer, including diagnostic mammograms, breast ultrasounds, and breast MRIs. BWHI supports the full coverage of 3D mammography without copays, coinsurance, or deductibles. Black women in need of screenings beyond standard mammograms should not have to pay any additional out-of-pocket expenses for these screening and diagnostic tests.

## Colorectal Cancer

Colorectal cancer is the third-leading cause of cancer death among US women. However, Black women have the highest incidence and death rates from colorectal cancer as compared to women of other race and ethnicities. Compared to white women, colorectal cancer rates are 19% higher in Black women.<sup>72</sup>

These numbers are exacerbated by disproportionate burden in access to care, including less screening of Black women compared with white women. Screening both prevents cancer by finding and removing precancerous lesions and prevents cancer death by early detection of cancerous lesions that can be treated successfully. Quality treatment and follow-up care is key to reducing the colorectal cancer burden for Black women.

**Colorectal Cancer Policy Recommendations:** BWHI supports and recommends increased access to screening tests that detect and remove adenomatous polyps that lead to colorectal cancer, funding for culturally relevant public education on the importance of colorectal cancer screening targeting Black women and prevention strategies for colorectal cancer, and on policies that ensure that Black women receive the recommended surgical treatment and adjuvant chemotherapy for colorectal cancer.

## Lung Cancer

Lung cancer is the leading cause of cancer deaths for Black women, with related death rates currently at 34.4/100,000. The data show that while Black women are less likely to smoke than white women, they are about as likely to develop lung cancer and die from lung cancer as white women.<sup>73</sup> The exact cause of this disparity is not clear; however, researchers believe it is interaction of biological, environmental, political, and cultural factors. Cancer experts note the importance of curbing smoking before it starts, especially for Black teen girls, and increasing the availability of smoking cessation services for current smokers. These methods have been shown to prevent lung cancer and lung cancer deaths. Because people who begin smoking at younger ages are more likely to become regular smokers, it is imperative that programs intervene early. Studies have shown that there are more inducements to start and continue smoking in lower-income neighborhoods and in neighborhoods with more Black residents, particularly due to targeted marketing by tobacco companies.<sup>74</sup> Although tobacco is not the only cause of lung cancer, it does contribute to 80 to 90 percent of lung cancer deaths.<sup>75</sup> Lung cancer screening is now recommended for high-risk individuals, but it can be prohibitively expensive. Therefore, smoking cessation, especially in the teen years, is key for decreasing lung cancer in Black women and girls. Tobacco is discussed further in Pillar 2.

**Lung Cancer Policy Recommendations:** BWHI advocates for legislation that raises awareness and emphasizes the importance of early screening to increase the odds of early detection and diagnosis of lung cancer. BWHI supports more research into the prevention and treatment of lung cancer in women. The development, funding, and promotion of smoking cessation programs to combat the targeted tobacco marketing campaigns in Black communities will assist in decreasing the prevalence of lung cancer among Black women.





*Image courtesy istock.com/FatCamera*

## Cervical Cancer

The vast majority of cervical cancer cases are caused by specific types of the Human Papillomavirus (HPV), the most common sexually transmitted infection in the United States. The HPV vaccine protects against nine types of HPV, including HPV types 16 and 18, which together cause approximately 80 percent of cervical cancer cases. The HPV vaccine is recommended for children ages 9-11 and all adults up until age 45.


Cervical cancer used to be a leading cause of cancer death for women in the United States. Around 4,000 women die each year in the United States from cervical cancer, a highly preventable and treatable disease. With preventive services, including the HPV vaccine, and routine screening, including regular Pap tests which can detect precancerous changes in the cervix, it is now a much more preventable and treatable cancer. When caught early, the five-year survival rate for cervical cancer is higher than 90 percent.

Prevention and cancer screening, with regular pap testing, are the best approaches to protecting women from cervical cancer and to ensuring early detection and life-saving treatment. Many deaths from cervical cancer could be avoided if cancer screening rates increased among women at risk. Deaths from these cancers occur disproportionately among women who are uninsured or underinsured.

Black women have a higher risk of late-stage diagnosis and cervical cancer mortality and they are more likely to die from the disease than any other racial or ethnic group. Black women are more than one-and-a-half times as likely to die from cervical cancer as white women in the United States. In Alabama—which has the highest rates of cervical cancer mortality of any US state—they are almost twice as likely to die from cervical cancer as white women.

Of the 4,115 people who died of cervical cancer in the United States in 2014, 796 were black. This means that almost one in five women who died from cervical cancer were Black, a troubling figure considering that the population of American Americans in the United States is 13 percent.

Human Rights Watch research in 2017 and 2018 in Alabama found that low-income and Black women in the state face significant barriers to preventing cervical cancer, including a lack of practicing gynecologists in rural areas; difficulty securing transportation to travel to appointments, including critical follow-up appointments after abnormal screening results; a lack of access to information on methods of preventing cervical cancer, including the HPV vaccine and the importance of routine screenings; distrust in the health care system stemming from a history of structural racism embedded in the medical field; and a lack of access to consistent health care coverage to connect women to diagnostic services and follow-up care.



Addressing the barriers to treatment and care that impact Black women, including lack of access to information and reproductive health care services, can greatly reduce cervical cancer mortality rates.

Cervical cancer screening has been a major success for all women. However, Black women are dying from cervical cancer at more than two times the rate of white women. Moreover, Black women are more likely to be diagnosed at later stages with more aggressive forms of cervical cancer than any other racial group.<sup>76</sup> Cervical cancer is entirely preventable through regular cancer screening and is highly treatable if found early. The HPV vaccine prevents almost all cervical cancer, as well as other HPV-related cancers. Black women need access to prevention (HPV vaccine), early detection (Pap and HPV testing), and quality treatment.

In 2017, the US Preventive Services Task Force (USPSTF) proposed dropping co-testing (Pap test plus HPV test) from its draft federal guidelines for cervical cancer screening. The draft guidelines were based on evidence gathered largely from white women in studies mostly based in Europe, so it is no surprise the preventive health needs of Black women failed to be recognized within them. BWHI voiced its opposition to these draft guidelines and supported a legislative effort to place a moratorium on this change. Fortunately, the USPSTF heard the concerns from the clinical and patient groups and gave an A grade to its final recommendation for co-testing.

However, in 2020, the American Cancer Society (ACS) released new guidelines against continued routine use of the Pap test, instead suggesting that women ages 25-65 undergo primary HPV testing every five years. Additionally, the guidelines remove a recommendation to screen women under age 25 altogether. These changes represent a departure from established current clinical practice and screening guidelines from other professional societies like the American College of Obstetricians and Gynecologists (ACOG).

Co-testing, with the Pap test and HPV test together, is more sensitive than a Pap test alone.<sup>77</sup> According to the American Society for Clinical Pathology and American Society of Cytopathology, eliminating co-testing could, as a result of the absence of Pap testing, exacerbate the disparities in cervical cancer screening and detection in already underserved and vulnerable populations.<sup>78</sup> Screening with the HPV test alone, as the ACS recommends, could miss a cancer diagnosis in 20 percent of women.<sup>79</sup>

**Cervical Cancer Policy Recommendations:** BWHI supports and recommends increased access to the HPV vaccine, as well as more outreach and public education to increase vaccination and screening of vulnerable, hard-to-reach populations. BWHI rejects the ACS guidelines. Black women have significantly higher rates of cervical cancer; limiting screening will further widen the disparities gap. BWHI supports the development of HPV vaccines that target the HPV subtypes most common in Black women. BWHI supports co-testing—combining the Pap test and HPV test—as the preferred screening option and standard of care, as well as increased access to appropriate follow-up and treatment for those with abnormal screening results. The recent JAMA study on HPV testing reiterated that HPV testing is more sensitive than Pap testing in finding cervical cancer, but that neither test alone finds as many cancers as both tests do together; therefore, co-testing must be maintained to provide women the most complete screening available.

Legislation should increase understanding of the barriers that women of color face in accessing reproductive health care services and information, including cervical cancer preventive and diagnostic services. It should also address these barriers and provide women of color with information and access to preventive services and timely follow-up treatment to lower risk of cervical cancer incidences and mortality. BWHI calls for legislation that increases federal funding for early detection programs, implements implicit bias and cultural competency trainings with providers, determines the effectiveness of innovative interventions to improve screening, studies the efficacy of self-screening HPV tests, and includes Black women in clinical trials.



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## G. Cardiovascular Health

Heart disease is the number-one killer of Black women, with cancer and stroke as other leading causes of death. According to the American Heart Association, among African American women ages 20 and older, nearly half (48.3%) already have cardiovascular disease (CVD).<sup>80</sup> CVD kills nearly 50,000 Black women annually, but only one in five Black women believes she is personally at risk.<sup>81</sup> Major risk factors for heart disease include diabetes, smoking, elevated blood pressure, high blood cholesterol, physical inactivity, obesity, and a family history of heart disease—factors that all disproportionately impact Black women. Research also shows that prolonged exposure to stress, as from coping with perceived racism, may produce higher cortisol reactivity. In Black women, cortisol—a stress hormone—can lead to higher rates of obesity,<sup>82</sup> which increases the risk of heart disease and other chronic illnesses. Efforts to improve the heart health of Black women should be a top policy priority. Black women, specifically, are 60 percent more likely to have high blood pressure and 20 percent more likely to die from heart-related complications.<sup>83</sup>

**Cardiovascular Health Policy Recommendations:** BWHI supports and recommends increased access to preventive care and affordable cardiovascular medicines and medical devices, increased funds for public health campaigns that educate Black women about their risk of heart disease, funding for culturally tailored and appropriate programs to assist in managing stress and promoting smoking cessation, and the increased representation of Black women in trials for medicines that improve cardiovascular health. BWHI also supports legislative efforts that recognize the impact of improving prevention, detection, and treatment modalities for Black women with cardiovascular disease and diabetes.



## H. Diabetes

Compared to the general population, Black people are disproportionately affected by type 2 diabetes.<sup>84</sup> For Black women, the risk is great: They are two to four times more likely than white women to have the disease. Type 2 diabetes affects one in every four Black women ages 55 and older, and is listed as the fourth leading cause of death for all ages. Diabetes is also widespread, affecting nearly 12 percent of all Black women ages 20 and older.<sup>85</sup> As Black women age, the risk of developing type 2 diabetes increases. While Black women ages 20 and older only account for 13 percent of the total female population in the United States, they represent 15 percent of all diabetes cases.<sup>86</sup> Black women are especially at risk due to high rates of obesity, lack of physical activity, and stress. Many health care providers do not screen for prediabetes, so Black women who are at risk for Type 2 diabetes are oftentimes not aware it can be prevented.

While Black women are less likely to develop gestational diabetes during pregnancy, those Black women who do receive this diagnosis have nearly 10 times greater risk of developing type 2 diabetes later (among all race and ethnic groups). Gestational diabetes places women at higher risk for future health issues, and even the child is at increased risk of developing type 2 diabetes. One of the risks for gestational diabetes is polycystic ovary syndrome, and between 5 percent and 10 percent of women of reproductive age (18–44) are affected.<sup>87</sup>

### COVID-19 and Diabetes

The American Diabetes Association (ADA) reports that people with diabetes are not more likely to get COVID-19 than the general population. People with diabetes face the problem of having worse outcomes—not a greater chance of contracting the virus. Coronavirus surveillance data show that people with diabetes have much higher rates of serious complications and death than people without diabetes—and that generally the more health conditions someone has (for example, diabetes and heart disease), the higher their chance of getting serious complications from COVID-19. While the death toll is likely to rise as the virus continues to spread, the death rate—the number of people who die from the virus as a percentage of the total number of people who contract the virus—will decrease as health care providers get better at detecting and treating the virus.<sup>88</sup>

People with diabetes do face a higher chance of experiencing serious complications from COVID-19. The risk of getting extremely sick from COVID-19 is likely to be lower when diabetes is well managed. In general, people with diabetes are more likely to experience severe symptoms and complications when infected with a virus. When people with diabetes do not manage their fluctuating blood sugar levels, they are generally at risk for several diabetes-related complications. Having heart disease or other complications in addition to diabetes could worsen the chance of getting seriously ill from COVID-19, like other viral infections, because with diabetes, the body's ability to fight off an infection is compromised.<sup>89</sup> Viral infections can also increase inflammation in people with diabetes. This is caused by above-target blood sugar levels, and both this and the inflammation could contribute to more severe complications.<sup>90</sup>



**Angela F. Ford, PhD, MSW**  
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Chief Program Officer  
Change Your Lifestyle. Change Your Life.  
*Image courtesy Phelan Marc Media*



### **BWHI Community-Based Program: Change Your Lifestyle. Change Your Life. (CYL<sup>2</sup>)**

CYL<sup>2</sup> is the branded National Diabetes Prevention Program (National DPP) offered by BWHI. The National DPP is based on more than a decade of research that proved how individuals at risk for getting type 2 diabetes could reduce those risks—thereby delaying the onset of the disease—by losing 5 percent of their weight and maintaining 150 minutes of physical activity weekly. CYL<sup>2</sup> is a year-long group-based program using trained lifestyle coaches to teach participants how to make healthier food choices, increase physical activity, and manage stress. These positive lifestyle changes also help them avoid hypertension, heart disease, and numerous other chronic conditions.

BWHI was one of the original six grantees awarded a five-year cooperative agreement with the Centers for Disease Control and Prevention (CDC) under DP12-1212, Preventing Type 2 Diabetes Among High Risk, to scale the newly launched program in 2012 in California, Indiana, Maryland, Michigan, and Tennessee. In 2017, BWHI was awarded a second cooperative agreement under DP17-1705, scaling the National Diabetes Prevention Program in Underserved Areas. CYL<sup>2</sup> is being delivered in very rural counties of Alabama, Louisiana, and Mississippi, all counties where the program did not exist but that are part of the CDC-designated Diabetes Belt. BWHI is also working with two former DP12-1212 partners to expand the program in rural underserved counties. Currently, CYL<sup>2</sup> is delivered in nine states (the eight above plus Texas). Under DP17-1705, BWHI will work with partners to increase the awareness of prediabetes, increase clinician screenings and detection for prediabetes, apply best practices to retain participants, and engage public and private payers to sustain the program. The BWHI provider network, EDGE (Educate, Deliver, Guide, Empower), was formally launched in 2017 to serve as a resource for diabetes prevention in communities of color.

**Diabetes Policy Recommendations:** BWHI supports adding prediabetes (diabetes prevention) screenings to the annual well-woman visit; increased clinician screening, detection, and referral of adults with prediabetes to evidence-based lifestyle programs; increased funding for awareness programming and public education initiatives about the prevalence of prediabetes and how to prevent type 2 diabetes; and increased benefit coverage for diabetes prevention and continued insurance coverage of preventive screening for gestational diabetes. BWHI supports and recommends creating a reimbursement model that more adequately covers the cost to deliver the evidence-based prevention programs to individuals who are most at risk for getting type 2 diabetes and recommends creating policies that ensure adequate representation of Black women in clinical trials, especially those relating to diabetes.

The evidence-based Medicare Diabetes Prevention Program (MDPP) expanded model aims to prevent progression to type 2 diabetes in individuals with an indication of prediabetes. The majority of services furnished under the MDPP expanded model are currently required to be furnished in person, except for limited virtual make-up sessions. Because of the COVID-19 pandemic, Medicare has suspended some restrictions with implementing MDPP. These temporary changes include:

- Increase the number of virtual make-up sessions that can be offered by MDPP suppliers.
- Allow MDPP suppliers that have the capability to deliver certain sessions virtually.
- Waive the once-per-lifetime benefit and allow MDPP beneficiaries whose sessions were suspended to resume sessions or start over.

Although some of these MDPP restrictions have been relaxed for the COVID-19 pandemic, BWHI recommends permanent abolishment of these restrictions so that more Black women can benefit from MDPP and other evidence-based life-saving programs.

## I. Obesity

Obesity has become a serious health crisis in the United States, with 42 percent of Americans being obese.<sup>91</sup> For Black women, who have the highest rates of obesity or being overweight nationwide, this crisis is particularly acute. About four out of five African American women are overweight or obese, according to the US Department of Health and Human Services Office of Minority Health.<sup>92</sup> The COVID-19 pandemic is further exacerbating these troubling health disparities. According to a 2020 CDC publication, having obesity also increases the risk of severe illness from COVID-19.<sup>93</sup>

Making the relevant lifestyle changes to prevent Black women from becoming obese and overweight will also prevent other serious conditions, including diabetes, high blood pressure, high cholesterol, and cardiovascular disease.



*Image courtesy Phelan Marc Media*



Defined as a body mass index (BMI) of 30 or above, obesity has an integral role in people's daily functions and quality of life. Those who are overweight and obese are more likely to have high blood pressure and high cholesterol. Obesity with these conditions serves as a precursor to poor health outcomes related to cardiovascular disease risk, diabetes, kidney disease, and some cancers. Long-standing obesity can be debilitating and lead to certain types of arthritis and increase risk for developing brain diseases, such as Alzheimer's and stroke. According to the *State of Obesity 2020* report published by Trust for America's Health, the US adult obesity rate stands at 42.4 percent, the first time the national rate has passed the 40 percent mark and further evidence of the country's obesity crisis. The national adult obesity rate has increased by 26 percent since 2008.<sup>94</sup> This report further highlights the prevalence of obesity among racial and ethnic minority populations and the impacts of social determinants of health on obesity. Poverty and discrimination contribute to higher obesity rates in Black and Hispanic people. Black adults have the highest level of obesity nationally at 49.6 percent; that rate is driven in large part by an adult obesity rate among Black women of 56.9 percent. Latinx adults have an obesity rate of 44.8 percent. The obesity rate for white adults is 42.2 percent, and Asian adults have an overall 17.4 percent obesity rate. Obesity rates are greatest in southern states with high minority populations: Alabama; Arkansas; Indiana; Kansas; Kentucky; Louisiana; Michigan; Mississippi; Oklahoma; South Carolina; Tennessee; and West Virginia.

Outcome data from the COVID-19 pandemic show Black people have increased risk of death due to coronavirus. While advanced age has been the most prevalent predictor of adverse coronavirus disease outcomes and mortality, increased BMI also has been cited to be a major contributor, especially in adults under 65 years old. Additionally, people with obesity are three times more likely to be hospitalized with COVID-19 if they have hypertension or diabetes. The stay-at-home and shelter-in-place policies enacted by many states and workplaces impacted eating habits and physical activity. Because of increased risks of morbidity and death in Black and Hispanic populations with COVID-19, addressing obesity is a public health priority.

Obese individuals are more likely to suffer from high blood pressure, increased levels of blood fat, diabetes, and LDL cholesterol. Each of these conditions serves as a risk factor for heart disease and stroke. Research shows that African Americans are 20 percent less likely to engage in physical activity than whites.<sup>95</sup> Black women, in particular, are more likely to gain weight at earlier ages than white women.<sup>96</sup>

Obesity affects Black women more than any other group in America. Hypertension, often associated with one's weight, develops at a younger age in Black women and can lead to various forms of cardiovascular disease.<sup>97</sup> Generally, African Americans have higher cardiovascular and renal damage at any level of blood pressure compared to whites.<sup>98</sup>

BWHI encourages exercise and a balanced diet to combat obesity in Black women. Science often looks to us as those who are most affected by this condition. However, it is critical to point out that much of the data surrounding BMI is prejudicial and does not take into account the differences between fat and muscle. BMI is not representative of all body types and particularly excludes women with curvier figures—often Black women. Relying on this chart, doctors maintain that Black women have higher rates of obesity than any other group in the United States.

**Obesity Policy Recommendations:** BWHI supports policy solutions that prevent obesity by expanding access to nutrition support programs and creating more opportunities for people to be physically active. BWHI supports expanding Medicare coverage of intensive behavioral therapy for obesity, particularly as provided by allied health professionals. Currently, such therapy is covered only if provided by a primary care practitioner. It is imperative that organizations, health care experts, policymakers, corporations, and communities work together to address this obesity epidemic among Black women through education, awareness, and culturally sensitive interventions.

## J. HIV/AIDS

The Black community has been disproportionately affected by HIV/AIDS since the beginning of the epidemic, and that disparity has increased over time.<sup>99</sup> Black women have the highest rate of new HIV diagnoses among all women (about 4,114, or 58 percent, in 2018).<sup>100</sup> The rate of new diagnoses among Black women (26.2) is 15 times the rate among white women and nearly five times the rate among Latinas.<sup>101</sup> Several complex factors contribute to this disproportionate HIV/AIDS burden, including poverty, lack of access to health care, higher rates of some sexually transmitted infections, lack of awareness of HIV status, and stigma.<sup>102</sup> Black women also are most likely to have been infected through heterosexual transmission, the most common transmission route for women overall.<sup>103</sup>

These racial disparities are particularly alarming considering the efficacy of pre-exposure prophylaxis (PrEP). When taken daily, PrEP has been shown to reduce the risk of HIV infection from sex and from injection drug use by more than 90 and 70 percent, respectively.<sup>104</sup> While two-thirds of people who could potentially benefit from PrEP are Black or Latino, in 2015 they accounted for the smallest percentage of prescriptions to date.<sup>105</sup>

Nevertheless, even with new HIV diagnoses continuing to occur disproportionately among Black women, data show a 40 percent decrease in new diagnoses for Black women between 2008 and 2015.<sup>106</sup> This is encouraging news as BWHI continues to advocate for policy solutions to prevent HIV.

HIV testing remains a critical tool in the fight for Black women's health. Most Americans have never had any form of HIV testing despite CDC recommendations that every person from the age of 13 to 64 should be tested. In its analysis of 2016-2017 national survey data, the CDC found that less than 40 percent of persons age 13-64 have been tested for HIV in their lifetimes. In addition, less than 30 percent of people most at risk for HIV have been tested in the last year.

One in 48 Black women in the United States will contract HIV in her lifetime. From 2009 to 2014, 84 percent of transgender individuals diagnosed with HIV were transgender women.<sup>107</sup> This high rate may be attributed to the fact that there are several prevention challenges that may impact the health outcomes for transgender women. Many transgender people face stigma, discrimination, social rejection, and exclusion that prevent them from fully participating in society, including accessing health care.<sup>108</sup> Health care providers' lack of knowledge about transgender issues can be a barrier for transgender people who receive an HIV diagnosis and are seeking quality treatment and care services.<sup>109</sup> In total, these issues affect the health and well-being of transgender people, placing them at increased risk for HIV.

As of 2020, 37 states have laws that criminalize HIV exposure.<sup>110</sup> Many of these laws are unnecessarily harsh in nature and have penalties that include incarceration; these policies appear to stem from hysteria and homophobia. Policies on HIV should also take into account the stigma and prejudice that is still often associated with HIV. Public policies and laws around the disease's transmission should be evidence based and nondiscriminatory in nature.

**HIV/AIDS Policy Recommendations:** BWHI supports and recommends increased access to preventive services for sexual and reproductive health, and funding for HIV prevention efforts, including public education about the benefits of PrEP and access to PrEP prescriptions.



### **BWHI Community-Based Program: On Our Own Terms**

BWHI launched “On Our Own Terms” (OOOT), a national strategy to improve sexual health and HIV outcomes for Black women, in December of 2017. The strategy is supporting collaborations, solutions, and policies guided by the lived realities of Black women related to HIV, reproductive health, and overall wellness. Through OOOT, BWHI is creating a national network of Black women's and other organizations to strengthen community assets, deliver innovative solutions, and make a lasting impact on the health and wellness of Black women and other women of color.



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## K. Mental Health

Racial disparities in mental health are at their worst when it comes to mental health care services. Black Americans often receive poorer quality of care and lack access to culturally competent care; only one third have access to the mental health care they need. In addition, Black adults are more likely than their white counterparts to report persistent symptoms of emotional distress, sadness, hopelessness, and feeling as if everything is an effort. Black women, in particular, use mental health services irregularly, due in part to lack of proximity to services, lack of insurance coverage, mental health stigma, and distrust of mental health professionals based on historic and present discrimination and bias.<sup>111</sup> This distrust may be a result of the way physician-patient communication differs for Black Americans and white Americans. One study found that physicians were 23 percent more verbally dominant and that they engaged in 33 percent less patient-centered communication with Black patients than with white patients.<sup>112</sup> Recruiting diverse researchers and physicians to care for Black women, their families, and their communities will increase cultural competency, community trust, and overall well-being.

Research demonstrates that Black and African American individuals with mental health conditions, especially those with psychosis, are more likely to be placed in jail or prison than their racial and ethnic counterparts.<sup>113</sup>

LGBT youth are more likely to experience bullying, violence victimization, sexual assault, and other threats to their health and well-being.<sup>114</sup> Previous studies have found that transgender students also face these challenges and more. Many face rejection and discrimination from peers and school staff, at home, and in their communities. These young people, who include Black cis and trans girls, have even higher rates of persistent sadness and suicidal ideation.<sup>115</sup>

It is essential for Black women to have access to mental health professionals who look like them and can empathize with their stories. Culturally competent mental health professionals are critical to understanding the weight and impact of Strong Black Woman Syndrome and other stigmas surrounding Black mental health so that Black women are well supported.

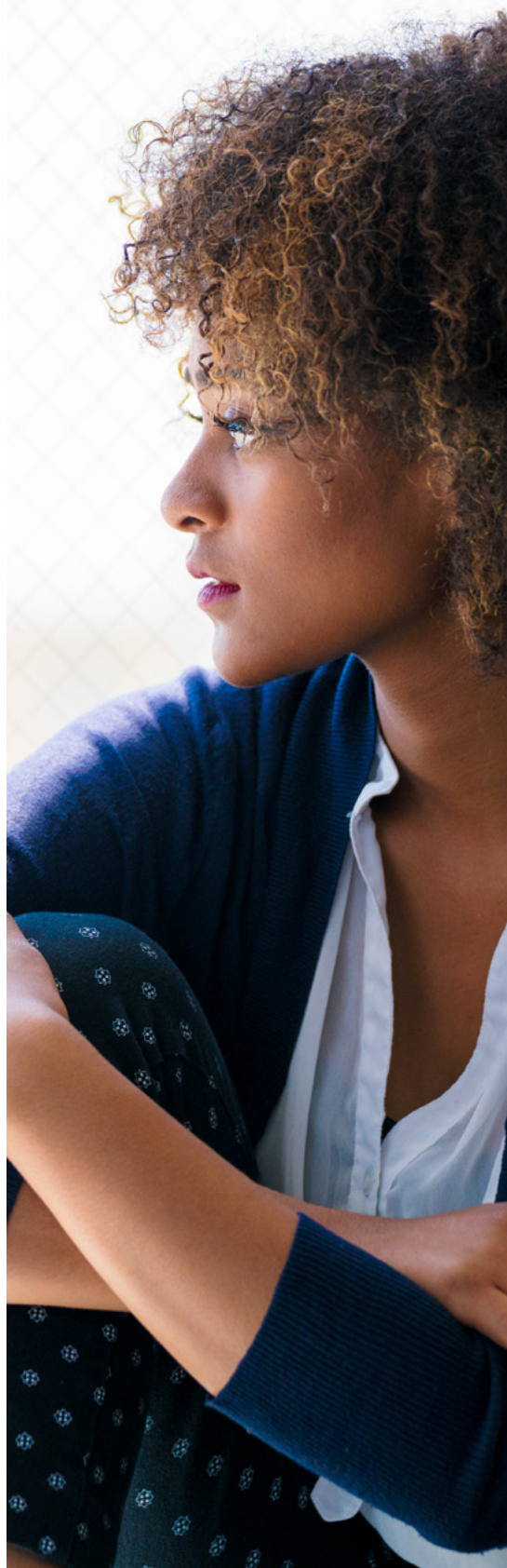


## Chronic Stress

Black women above the age of 18 were almost twice as likely as Black men to have serious psychological distress. According to the National Institute of Mental Health (NIMH), the continued strain of routine stress can lead to serious health problems, such as high blood pressure, depression, and some cancers. Black women's stress levels may also make them more prone to autoimmune disorders like lupus; gynecological problems such as incompetent cervix; and, as they age, neurological problems such as Alzheimer's disease. We know that stress is real, but we also know we need to learn to manage it. It is inarguable that all women endure stress in this society. However, Black women in particular, and women of color in general, face not only the stresses of sexism and classism but also the stresses of racism. Coping with chronic stress without support likely leads to finding solutions in unhealthy behaviors such as excessive drinking, drug use, or self-medicating through food. Most would say that this is not the way to live, yet many Black women are living it every day. Together, we must turn the tide.

**Mental Health Policy Recommendations:** BWHI supports and recommends increased access to mental health services. According to Mental Health America, behavioral health prevention is most effective in the community.<sup>116</sup> Increased access could be facilitated by covered community-based prevention. These prevention services can take place in many settings—schools, homes, local health agencies, and other community-based facilities. Innovative reimbursement models could support the cost of these preventive services with long-term benefits for the community. Through alignment with Mental Health America (MHA), BWHI further recommends promoting positive school climates and assessing social-emotional learning in schools. These actions build on the MHA's recommendation to build on early identification and intervention for those at risk for mental concerns, which BWHI supports. BWHI supports, for those in need, integrated treatment of mental health within the health care system and insurer reimbursements to ensure mental health treatment is covered under insurance plans with little or no out-of-pocket costs.

Furthermore, BWHI recommends modernizing the mental health workforce by increasing diversity, equity, and inclusion in the mental health profession through minority pipeline programs and cultural competence training. BWHI further recommends an in-depth look at racism in the mental health care delivery system and prioritizing mental health services, not prisons.



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## L. Rare Disease

The National Institutes of Health (NIH) defines rare disease as a condition that affects fewer than 200,000 people in the United States. This definition was created by Congress in the Orphan Drug Act of 1983. Rare diseases became known as orphan diseases, because drug companies were not interested in adopting them to develop treatments. The Orphan Drug Act created financial incentives to encourage companies to develop new drugs for rare diseases. The rare disease definition was needed to establish which conditions would qualify for the new incentive programs.<sup>117</sup>

Some rare diseases cause disability and impede people from working. Often, people require specialized health care and services to meet the challenges of living with rare conditions. Like other chronic conditions, health disparities are present among people living with rare diseases. Barriers to care may include care costs—affordability, coverage, and other social challenges. Because small populations are impacted by rare disease, robust research activities and funding may not exist for rare conditions. When compared to common chronic disease, other challenges with rare disease are vast. Some of these challenges include inadequate insurance coverage of diagnostic testing, lack of or no genetic information for a disease, lack of or no clinician knowledge or awareness of rare diseases and lack of patient awareness of previous incidence in family history.

Testing and screening for rare diseases are often delayed because clinicians lack knowledge about them. Delays in testing and screening lead to delays in proper diagnosis, management, and treatment of rare disease.

Rare disease experts are few and far between across the United States. Federally funded research might not even exist for a condition. Only 10 percent of rare diseases have an FDA approved therapy. Accessing these therapies can be limited and prohibited due to high costs.

Some rare diseases occur more often in Black people and other ethnic minority populations. Additionally, these populations are affected by social determinants of health and disparities that contribute to poor health outcomes associated with rare diseases. For example, in a review examining race and health outcomes of patients with a rare disease known as pulmonary arterial hypertension, results showed minorities are likely to be at higher risk of poor outcomes due to lack of access to proper health care and limited resources to assist them in living with the disease.

## RARE FACTS:

An estimated 30 million Americans have a rare disease. It can take an average of five years and consultations with over seven clinicians to reach an accurate diagnosis for a rare disease. Only ten percent of rare diseases have a treatment approved by the FDA.

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Some well known rare conditions—sickle cell anemia, sarcoidosis, and lupus, as well as lesser-known diseases like thalassemia and hereditary ATTR (hATTR) amyloidosis—occur at a higher frequency in African Americans than they do in other populations.<sup>118</sup> Although some rare diseases can occur across populations, racial and ethnic minorities experience disparities and poor health outcomes related to these rare diseases.<sup>119</sup> For example, although lupus occurs across populations, significant disparities exist in risk of disease development, severity of symptoms, and mortality. Black and Hispanic women are likely to face greater barriers to screening, diagnosis, and treatment of rare diseases, like lupus, due to a variety of cultural, socioeconomic, and environmental factors.

BWHI recognizes the challenges of people of color living with rare diseases. Often, racial and ethnic minorities living with rare diseases are isolated and not engage with organizations that can support them. Rare disease organizations exist to engage and support their respective rare disease communities. Many rare diseases patient groups would like to engage communities of color. However, these groups have not yet been successful in their outreach to

these communities. BWHI would like to understand how to move the needle in these areas and better understand any challenges diverse populations are having accessing care and getting a diagnosis. Thus, BWHI established a Rare Disease Diversity Coalition to educate the broader health care community on how to mitigate the social determinants of diagnosis and treatment of rare disease; increase the pace of accurate diagnosing of rare diseases in diverse populations; work with government agencies at HHS (e.g., FDA, NIH, AHRQ), NCQA, public and commercial insurers, and diversity and rare disease health groups to ensure that national health policies and regulations reflect population prevalence; develop a strategy to support patient organizations in engaging diverse groups; and ensure that research protocols, clinical guidelines, and standards of care reflect ethnic differences and response.

**Rare Disease Policy Recommendations:** BWHI recommends and supports the protections of the Affordable Care Act, including preventing insurance companies from discriminating against individuals who have rare disease. These protections include (1) guaranteed issue of insurance to all patients, regardless of health status, during annual open enrollment periods, special enrollment periods, and renewal periods; (2) prohibition on discriminatory benefit exclusions or limitations aimed at individuals or groups of individuals with expensive preexisting conditions; (3) community rating that guarantees patients are not charged higher premiums because of their health status, including if they have a gap in coverage; and (4) Medicaid expansion and removing Medicaid per capita caps. Insurance should cover telehealth visits for people with rare conditions to obtain access to experts.

BWHI recommends and supports increasing the tax credit rate for clinical testing expenses for rare diseases or conditions from 25 percent to 50 percent and requiring CDC to complete a study and report on enhancing and expanding the infrastructure to track the epidemiology of rare diseases or conditions. Furthermore, BWHI recommends extending newborn screening programs through the CDC and NIH.



## Sickle Cell Disease

In the United States, approximately 100,000 people have sickle cell disease (SCD) and two million people have the genetic trait.<sup>120</sup> SCD affects the oxygen-carrying red blood cells. While normal red blood cells with HbS are round with a doughnut-like indentation to carry oxygen, the HbS gene causes the red blood cells to become abnormally crescent-shaped and rigid. Sickled red blood cells get caught in the body's smaller blood vessels, blocking normal blood flow and causing severe pain and damage to the delicate tissues of the lungs, eyes, spleen, kidneys, and liver. People with one copy of the HbS gene are carriers of the sickle cell trait and may experience some symptoms. People with two copies of the gene develop sickle cell anemia, which can be deadly. In the United States, Black people are the majority of people with SCD; about 1 in 13 Black children are born with the sickle cell trait and about 1 in every 365 Black children are born with SCD.<sup>121</sup> Yet Black children are among the least likely to be included in SCD-related clinical trials.

The COVID-19 pandemic lends additional challenges for people with SCD. Challenges related to the social determinants of health may place people with SCD at higher risk for development of severe disease if infected with severe acute respiratory syndrome coronavirus 2 (SAR-CoV-2), the causative agent of COVID-19.<sup>122</sup> In 2020, a study was conducted in which 178 people with SCD in the United States were recorded in a registry as having both SCD and coronavirus disease. Of the 178 people in this study, 122 (69%) were hospitalized and 13 (7%) died. This study demonstrates the exacerbation of COVID-19 severity among SCD patients.<sup>123</sup> Additional preventative practices are needed to protect people with SCD from becoming infected with coronavirus.

People with SCD have additional health concerns and complications that present challenges accessing the health care system. Data from a multicenter longitudinal study (2005–2018) show people with sickle cell trait and SCD have faster decline in their kidney function.<sup>124</sup> This decline is further exacerbated in people with SCD who also have other chronic diseases such as diabetes and hypertension. The additive effects of these diseases can accelerate the development of end-stage kidney disease.



Image courtesy Michele Hyndman, Esq.

### Michele Hyndman, Esq.

Michele has been living with Sickle Cell since birth. However, despite various challenges, this highly educated and accomplished lawyer and tax consultant has used her illness as a driver to push towards greatness in everything she does. Michele has lived across this country and overseas, working for prestigious organizations and matriculated from the best colleges and universities in the world. She earned her L.L.M. in taxation from Georgetown University Law Center and her Bachelors of Arts in Mathematics- Economics from Columbia University. Michele also freely gives of her time, educating young women on hotel acquisition. She sits on on the Sickle Cell Disease Steering Committee for the Black Women's Health Imperative and is active in many other organizations.

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Promising results from gene therapy show that a cure for SCD may be possible. Researchers at NIH have been working on tackling new gene therapy opportunities for people with SCD. This new gene and improved viral vector—a virus-based vehicle that delivers therapeutic genes for use in gene therapy for SCD—was up to 10 times more efficient at incorporating corrective genes into bone marrow stem cells than conventional vectors currently used. This development could make gene therapy for SCD much more effective and pave the way to wider use of it as a curative approach for the painful, life-threatening blood disorder.<sup>125</sup>

**Sickle Cell Disease Policy Recommendations:** BWHI supports and recommends the consideration of legislation supporting sickle cell disease research, surveillance, prevention, and treatment, as well as continued coverage of sickle cell treatment under Medicaid and Medicare. BWHI supports the collection of data on the prevalence and distribution of SCD, funding for SCD public health initiatives to improve access to care and health outcomes, targeted inclusion of Black people with SCD in clinical trials, and increased support for health agencies to identify and evaluate strategies for prevention and treatment of SCD complications. Additionally, BWHI recommends ending funding disparities in SCD research. Federal research funding for SCD as compared to cystic fibrosis (CF) was similar between 2008–2018.<sup>126</sup> However, SCD is three times more prevalent than CF. BWHI seeks parity in federal research funding for diseases that impact Black women.

## M. Epilepsy

Epilepsy is a brain disorder characterized by recurring seizures. Because of the numerous types of seizures and epilepsies, this brain disease is often unrecognized by the public and misdiagnosed and undertreated by health care professionals. Although mischaracterized as a rare disease, epilepsy is a chronic disease. As with other chronic diseases, people of color, particularly Black people, have poor health outcomes related to epilepsy. According to the CDC, 3.4 million people in the United States are living with active epilepsy, representing 1.2 percent of the US population.<sup>127</sup> Based on US Census data and these CDC estimates, nearly 526,085 African Americans are living with active epilepsy.<sup>128</sup> Epilepsy requires multiple approaches to address the needs of people living with epilepsy and their families. Women, especially Black women, face additional challenges living with this disease. According to the Epilepsy Foundation, Black people with epilepsy are more likely to be diagnosed in an emergency room than white people, develop epilepsy over a lifetime, and develop status epilepticus—seizures lasting over five minutes or recurrent seizures without recovery between seizures.<sup>129</sup> Moreover, Black people with epilepsy living in rural communities have challenges in accessing health care providers with expertise in treating epilepsy.<sup>130</sup> Often, older antiseizure medications with many side effects are prescribed. Such older medications can affect a developing fetus in a woman of childbearing age.

Black women are more likely to die from a seizure compared to white women.<sup>131</sup> Additionally, hormonal changes in women with epilepsy can impact seizure control. Women with epilepsy are at higher risk for having weak bones and cardiovascular disease.<sup>132</sup> Because Black women have many of these conditions without epilepsy, aggressive steps should be taken to heighten awareness about epilepsy and to control seizure in Black women.

Despite progress in epilepsy education and awareness, people living with epilepsy and their families continue to be stigmatized and discriminated against in many settings. Epilepsy can be a barrier to employment opportunities, educational and personal fulfillment, and justice within legal systems. These discriminatory practices are compounded by race and ethnicity. The Epilepsy Foundation has reported many cases received through its full-time helpline involving racial discrimination for people living with epilepsy.<sup>133</sup>



Image courtesy Epilepsy Foundation

### Veronica Crowe, MPA

Epilepsy Advocate  
Manager of Philanthropic Giving  
Epilepsy Foundation

“I experienced my first tonic-clonic seizure at 13 and was diagnosed at 14. After learning about the symptoms, my mother realized I had been having seizures for years. Challenges in the workplace can include coworkers who don’t know what to do when I had a seizure in the office. Black women can be of service to one another by learning seizure first aid, symptoms, and triggers. Participating in epilepsy awareness events and donating to programs are more ways to offer support.”

**Epilepsy Policy Recommendations:** BWHI recommends and supports developing community-based programs for people with epilepsy, eradicating stigma and discrimination related to epilepsy, and protecting access to medications and treatments to control seizures. BWHI supports access to quality, affordable, physician-directed, and patient-centered care for people with epilepsy. This will require protections for people with preexisting conditions.

Cannabis has been reported to control certain types of seizures. Currently, there is one cannabis-based FDA approved treatment for certain pediatric epilepsies. However, there is no current FDA-approved cannabis therapy for adults. Legislation has been proposed to develop a national cannabis research agenda that addresses key questions and gaps in evidence in therapeutic treatment for neurological diseases, like epilepsy, cancers, and alternatives to opioid analgesics for acute pain.



# BLACK WOMEN VOTE:

## National Health Policy Agenda



*Image courtesy Waikinya Clanton*

## Pillar II. Equitable Responses to Public Health Emergencies

Health equity can mean different things to different populations and organizations. To BWHI, it means eliminating, in and among communities, health disparities based on race, education, income, or other environmental and social determinants. Public health emergencies often exacerbate disparities. In this section, we describe several crisis situations for Black women.

### A. COVID-19

SARS-CoV-2, the novel coronavirus that causes COVID-19 and the source of the global pandemic, has devastated many families and communities across the world. From January to October 2020 in the United States, nearly nine million people were diagnosed with COVID-19 and nearly 225,000 deaths were attributed to this coronavirus during this timeframe.<sup>134</sup> In the United States, a disproportionate number of people infected with this coronavirus—and those who die from COVID-19—are people of color. The CDC reports that a history of systemic health and social inequities have put racial and ethnic minority groups at an elevated risk of contracting COVID-19 or experiencing severe illness, regardless of age.<sup>135</sup> Black people represent 13 percent of the US population yet account for 25 percent of all people hospitalized with COVID-19. Black people are four times more likely to die from the disease compared to white individuals.<sup>137</sup> CDC data suggest the prevalence of chronic diseases, such as diabetes, cardiovascular disease, and other underlying chronic health conditions, also contributes to disparities in health outcomes related to COVID-19.

#### ***Chronic Disease and COVID-19***

Prior to the COVID-19 pandemic, compared to their composition of the US population, Black people were disproportionately diagnosed and impacted by certain common chronic diseases—cardiovascular disease (heart disease), diabetes, obesity, and some cancers. US Census data show that people living in counties with above-average Black populations are three times as likely to die of COVID-19 as those in above-average white counties.<sup>138</sup> The burden of chronic disease and related health disparities coupled with resulting poor health outcomes place Black people at elevated risk for death from COVID-19. Black people are experiencing a pandemic within a pandemic and are dying in unprecedented numbers because of COVID-19.

#### ***Heart Disease***

Cardiovascular disease (CVD), particularly serious heart conditions—heart failure, coronary artery disease, cardiomyopathies, and pulmonary hypertension—increases risk of severe illness from COVID-19. Additionally, hypertension and stroke may increase risk of severe illness from COVID-19.<sup>139</sup> Each year, approximately 50,000 Black women die from CVD. This health disparity is alarming. CVD affects one in every two Black women compared to one in three white women. Almost half of Black women over age 20 have CVD.<sup>140</sup> Education and awareness about CVD risk and COVID-19 could empower Black women to decrease their CVD risk in the age of COVID-19.

#### ***Access to Care***

People with underlying health conditions are at greater risk of complications, even death, if they contract COVID-19. Similar to increased risk for contracting COVID-19 faced by racial and ethnic minority communities, these populations have additional barriers accessing health care during the COVID-19 pandemic. Accessing preventive care, services, and screenings is foundational to maintaining good health. However, COVID-19 has exacerbated negative health trends connected to accessing routine screenings, preventive and specialty care, follow-up medical appointments, immunizations, and other health promotion services. As health systems and hospitals reassign doctors and nurses to handle COVID-19 patients, other departments within hospitals and clinics, such as maternity wards and family health clinics, are significantly understaffed and restrict outside visitors. These barriers to care can facilitate COVID-19 infections and exacerbations of existing health conditions and chronic disease. Findings from a study conducted in Philadelphia on prevalence of COVID-19 among pregnant women revealed pregnant Black and Hispanic women are five times more likely to be exposed to the coronavirus.<sup>141</sup>





Image courtesy istock.com/Aja Koska

### ***Economics (jobs and housing)***

Black and Hispanic workers face significantly higher economic and health insecurity during this pandemic than white workers. COVID-19-related job and wage loss has hit Black and Latino people the hardest. There are primarily three categories of workers impacted by the pandemic: those who lost their jobs; those who are deemed essential workers; and those who can continue work from the comfort of their homes. Black and Latino Americans are overrepresented in low-wage jobs that offer the least flexibility and increase their risk for exposure to coronavirus.<sup>142</sup> According to the Pew Research Center, months into the COVID-19 pandemic, 61 percent of Hispanic Americans and 44 percent of Black Americans reported someone in their household experienced job or wage loss due to the coronavirus outbreak, compared with 38 percent of white adults.<sup>143</sup> Black women are nearly twice as likely as white men to say that they'd been laid off, furloughed, or had their hours or pay reduced because of the COVID-19 pandemic. The pandemic is a severe economic burden on Black women.<sup>144</sup> A survey by Leanin.org found "Women—especially women of color, particularly Black women—are more concerned about being able to pay for basic needs such as rent/mortgage, health care, or groceries for themselves or their families in the next few months."<sup>145</sup> The economic devastation due to COVID-19 is widespread across all populations. However, Black workers are less likely to weather such a storm because of fewer earners in their families, lower incomes, and lower liquid wealth than white workers. Programs are needed to protect earnings and wages of Black people during and after the coronavirus pandemic.

### ***Childcare***

Prior to the COVID-19 pandemic, 13 million working parents relied on the childcare industry to care for their children while they worked and did their jobs. Although the Office of Child Care within the Administration for Families and Children oversees and supports low-income working families by improving access to affordable, high-quality early care and afterschool programs, childcare licensing and regulations vary state to state. The COVID-19 pandemic has illuminated decades of ignored gaps within the childcare industry. There have been several warnings of a childcare crisis that would develop as a result of the public health crisis, especially due to the fact that little attention was paid to this industry by policymakers. The lack of childcare most affects those who work low-income jobs or are single parents. COVID-19 has illuminated the discord between economic opportunity and the costs of childcare.

Ninety-three percent of childcare workers are women, and half of childcare businesses are minority owned. Forty-five percent of women working in childcare are Black, Asian, or Latino. Due to the pandemic, the childcare sector closed 60 percent of its programs. Although there has been a slight rebound in programs reopening, this industry is still down roughly 237,000 workers from 2019. Some projections have suggested that the industry could permanently lose half its programs. Since the pandemic, two in every five childcare providers reported they would shut down for good without federal funding support.<sup>146</sup> If childcare programs do not receive government intervention or support, millions of working Americans, particularly Black women, will be unable to return to work due to the lack of childcare.<sup>147</sup>





## ***Mental Health***

Public health interventions to control the spread of COVID-19 have been challenging. Interventions such as social distancing can make people feel isolated and lonely and can increase anxiety.<sup>148</sup> These actions are necessary to reduce coronavirus infections, but they can be used as tools to heighten discrimination and racist practices. A recent Pew Research Center study revealed roughly 4 in 10 Black and Asian adults say people have acted as if they were uncomfortable around them because of their race or ethnicity since the beginning of the coronavirus outbreak, and they equally believe that other people may be suspicious of them if they wear masks out in public.<sup>149</sup> Whether practicing measures to prevent COVID-19 infections or attending to routine daily activities, Leanin.org reported that women are more likely than men to be experiencing symptoms of stress and burnout during the COVID-19 pandemic.<sup>150</sup> Twenty-five percent of women have had physical symptoms of severe anxiety, such as a racing heartbeat, compared to just 11 percent of men. Women are also about 50 percent more likely than men to feel that they have more to do than they can possibly handle. Results from the Leanin.org study revealed more than three-quarters of Black women and Latinas (76% and 79%, respectively) are spending three or more hours per day on housework, compared to just over half (55%) of white women.<sup>151</sup> Black women are the cornerstone of their communities; they take care of children and extended family members. They take care of their partners. They're usually holding a lot of different responsibilities at once, including being more frequent breadwinners than women of other races. Still, many times their voices and experiences are lost in the wilderness. Addressing mental health needs and coping with stress in a healthy way will strengthen Black women, the people they care about, and their community.

## ***Vaccines and Clinical Trials***

For decades, vaccines have been developed and used as a preventative therapy to control the spread of infections and viral diseases. Traditionally, vaccine development is an exceedingly long process involving various phases and clinical trials. Although lack of diversity in clinical trial participation is not a new phenomenon, the COVID-19 pandemic has shown disparities related to clinical trial enrollment for new therapies and vaccine development used to manage and treat diseases. Importantly, fast-tracking clinical trials to evaluate drugs and vaccines for COVID-19 may fail in evaluating the safety and efficacy of vaccines in a variety of racial and ethnic populations, particularly Black and Hispanic people—the very populations most impacted by this disease.

Longstanding and justifiable distrust with the US health care system, human research studies, and clinical trials exist among Black people. Historically, the US medical and health care systems have marginalized Black people through racist and biased health care encounters, withholding of curative therapies for diseases, and lack of inclusion in the disease management processes. Black and Hispanic people have benefited less from medical and curative advancements. Issues and challenges related to Black enrollment in COVID-19 vaccine clinical trials must recognize the inclusionary shortcomings of the clinical trial process. Because of the devastating impact of COVID-19 on Black communities, Black people should be at the forefront and vigorously sought out for enrollment in clinical trials.

**COVID-19 Policy Recommendations:** The COVID-19 pandemic highlights challenges and barriers that exist in the broken US health care, public health, education, political, and judicial systems. Many of the systematic defects are well recognized by racial and ethnic minority populations, particularly Black women and their families, who have to navigate these fractured systems daily to survive. Although the CARES Act attempted to address and serve as a safety net for many gaps within these systems, Black women did not fully receive the benefits from this Act.<sup>152</sup> To mitigate some of these concerns, BWHI recommends passing the Health Economic Recovery Omnibus Emergency Solutions (HEROES) Act to expand resources and benefits to Black communities impacted by COVID-19. BWHI recommends and supports key areas of this Act, such as direct payments to individuals, expansion of paid sick days along with family and medical leave and unemployment compensation; expansion of paycheck protection programs; pandemic premium pay for essential workers; tax credits and deductions; extending housing assistance; and requiring employers to develop and implement effective infection disease exposure plans, including mask-wearing and handwashing protocols.

## B. Environmental Health and Environmental Justice

### Access to Clean Water

The climate crisis and aging water systems across the country present a danger that disrupts our lives and endangers our health. Water and the Black experience are linked and fraught. For generations, our arrival, punishment, freedom, and sustenance in this country have involved a very complicated relationship with water.

According to analysis of data from the National Health Examination Surveys from 1988 to 2014, Black children are twice as likely as white children and three times as likely as Mexican American children to have elevated levels of lead in their blood.<sup>145</sup> While the health crisis around lead contamination in Flint grabbed headlines, many communities nationwide are facing similar challenges. Small and rural communities that rely on private wells or whose water systems lack the resources to deal with polluted sources may be hit the hardest.



Image courtesy AdobeStock/Riccardo Niels Mayer

Clean, safe, affordable water is essential. However, it is not accessible to everyone. Segregation, discriminatory land use, and unfair zoning policies have forced many low-income and communities of color into low-lying flood zones and “vulnerability zones.” These zones, for example, are located near industrial facilities that manufacture chemicals, treat wastewater, produce bleach, generate electric power, refine petroleum, or produce pulp and paper. Too often, due to industrial pollution, the water these communities rely on becomes contaminated.

BWHI is concerned about how contaminated water impacts the health of pregnant mothers and children. In Michigan, Pennsylvania, New Jersey, and other states, the deteriorating municipal water infrastructure is having devastating effects on Black women and children. Bottle-fed infants, who consume mostly formula mixed with tap water, can ingest high levels of lead that could lead to developmental delays.<sup>153</sup> When a woman is exposed to lead and other metals in water during pregnancy, she is more likely to miscarry or deliver a preterm baby. Black children are three times more likely than white children to have highly elevated blood lead levels. Environmental toxicants in water can also impact development in other ways. For example, exposure to many types of pesticides found in drinking water have been linked to spontaneous abortions and birth defects in offspring.<sup>154</sup>

A vital solution to safeguard water and the environment and to protect the public’s health is to demand that state and federal governments maintain and enforce sound environmental policies. Since 2017, the administration of the 45th president has rolled back nearly 100 environmental safeguards that keep Americans healthy and safe. Federal actions demolished safeguards of the Clean Water Act. During this three-year period, weakened federal water policies have failed Black communities.

**Policy Recommendations:** BWHI supports and recommends stronger environmental protections. *Increase our investment:* Congress must significantly increase federal funding for our nation’s water infrastructure by funding existing sources and developing new and innovative sources. *Support natural infrastructure:* Increase green space in low-income neighborhoods and communities of color, which have traditionally not enjoyed equal access to green space and its benefits compared to areas with wealthier populations. *Ensure affordability for all:* Increase funding for federal water infrastructure in a way that ensures low-income households can afford water services. BWHI further supports promoting affordability at the local level by encouraging states and water utilities to adopt low-income customer assistance programs and equitable rate structures.

## Climate Change and Pregnancy

A study recently published by the JAMA Network examines the outcomes of 33 million pregnancies to determine the correlation between heat exposure and birth complications in America.<sup>155</sup> Results from this study indicated that higher rates of heat exposure contributed to premature birth, low birth weights, and stillbirths amongst women. For Black women, pregnancy outcomes are exacerbated by climate change. Heat exposure plays a detrimental role in one's ability to have a healthy birthing experience.

Marginalized communities are more likely to be in urban neighborhoods that are referred to as “heat islands.”<sup>156</sup> These areas are significantly warmer than rural and suburban communities. Additionally, Black women are more likely to live closer to power plants that release toxic air into the environment of nearby communities. Black women are also less likely to live in buildings that have air conditioning. Thus, Black women are disproportionately affected by the harrowing effects of climate change.

Residents of Philadelphia who live in communities of color experience temperatures that average around 20 degrees warmer than those living in predominantly white neighborhoods—believed to result from lack of trees and burning concrete. Heat exposure specifically contributes to premature births because it causes dehydration and the premature rupturing of membranes. These determinants sometimes cause damage to the placenta; in the worst of cases, stillbirth results.

**Climate Change & Pregnancy Policy Recommendations:** BWHI supports legislation that fights to mitigate climate change and highlights the direct effect this crisis has on women of color. The Environmental Justice for All Act (H.R. 5986 in the 116th Congress) is an example of legislation that supported this goal by attempting to restore environmental justice and civil rights to disenfranchised communities.



Image courtesy istock.com/RuslanDashinsky



## C. Tobacco

Black women smoke tobacco at similar, and sometimes lower, rates than other racial and ethnic groups in America. Yet, somehow African American women are disproportionately affected by tobacco usage. Black women are more likely to die from tobacco-related causes and more likely to be exposed to secondhand smoke.<sup>157</sup> Experts believe that socioeconomic and metabolic characteristics are to blame for varying outcomes between Black smokers and others.

For decades, the tobacco industry has focused its attention on Black people.<sup>158</sup> Their advertising has made a concerted effort in targeting predominantly Black communities. Menthol cigarettes remain a prominent example of these tactics, which raises major health equity concerns considering the chemical compound makes cigarettes easier to smoke and harder to quit.<sup>159</sup> Nearly 90 percent of African American smokers use menthol cigarettes.<sup>160</sup> Approximately 45,000 Black Americans die as a result of smoking-related diseases each year.<sup>161</sup>

Research supports that smoking tobacco damages genetic material found in egg and sperm cells.<sup>162</sup> <sup>163</sup> Miscarriage and birth-defect rates are more frequent amongst the babies of women who smoke. Black children and adults are more likely to be exposed to secondhand smoke than any other racial or ethnic group.<sup>164</sup> Secondhand smoke increases the risk of infertility, ectopic pregnancy, spontaneous abortion, and stillbirth.<sup>165</sup> These damaging effects and death tolls are more prominent among Black women.



*Image courtesy istock.com/GoodLifeStudio*

Compared with women who are nonsmokers, women who smoke cigarettes have greater risks of reproductive health problems, many forms of gynecologic cancer and other types of cancer, coronary and vascular disease, chronic obstructive lung disease (COPD), and osteoporosis.<sup>166</sup> Similarly, compared to nonsmokers, e-cigarette users without a history of smoking are 74 percent more likely to have asthma. E-cigarette users with a history of smoking are three times more likely to have COPD.<sup>167</sup> Lung cancer is the second most common cancer not only in African American men, but also women, and it is the leading cause of cancer death. African Americans have the highest rates of tobacco-related cancer among racial and ethnic groups and are more likely to die because of the disease.

**Policy Recommendations:** BWHI supports and recommends increased lung cancer prevention efforts that are accessible and culturally appropriate for Black women and girls, including the expansion of teen education programs and smoking cessation services. BWHI supports increased access to affordable screening for individuals at high risk due to its potential to dramatically improve lung cancer survival rates by finding the disease at an earlier, more treatable stage. BWHI also supports funding for more research into the unique ways social determinants such as poverty and environmental stress impact Black women and contribute to high rates of lung cancer. BWHI supports prohibiting the sale of flavored tobacco products, including menthol cigarettes.

BWHI supports and recommends legislation that bolsters lung health and curtails youth tobacco use. Legislative requirements should be enacted: requiring cigarette packages to carry color labeling depicting negative health consequences of smoking; including e-cigarettes in FDA regulation of tobacco products; prohibiting online retail sale of tobacco products, including e-cigarettes; prohibiting added flavors in tobacco products, including e-cigarettes; supporting public education regarding tobacco regulation, the harms associated with tobacco use, and grants on tobacco cessation; outreach to medically underserved communities for tobacco use prevention and cessation; excise taxes on nicotine that has been extracted, concentrated, or synthesized; specialized funding for underserved communities, especially in cessation of menthol-flavored tobacco products; and other measures shown to be useful for preventing tobacco use.

## SEE-US program

Black Women's Health Imperative (BWHI) is launching the SEE-US program (Socially/Emotionally Empowered-Unapologetically Smoke-Free) to educate, train, and mobilize Black women on Historically Black College and University (HBCU) campuses in the fight against smoking and vaping. The program will be supported with a one-million-dollar grant from the Robert Wood Johnson Foundation. This program was created in direct response to the predatory marketing tactics of the tobacco/vaping industry in targeting young Black women and to raise awareness that smoking-related illnesses are the number one cause of death in the Black community, surpassing all other causes of death, including AIDS, diabetes, cancer, and heart disease.

The SEE-US program will build the anti-tobacco, anti-vaping advocacy skills and leadership capacity of female students attending seven HBCUs that are in the heart of tobacco country. The schools chosen for this program include: Tuskegee University, Alabama State University, Southern University, Dillard University, Tennessee State University, Mississippi Valley State University, and Jackson State University. Through the program, Black women student leaders will undergo a virtual training program where they will learn advocacy and mobilization strategies, as well as how to counteract smoking as a coping mechanism.



*Image courtesy AdobeStock/fizkes*

## D. Opioid Crisis

Although the current opioid crisis has largely been painted as an overprescription issue for rural, white America, its devastating impact is widespread in the lives of Black women and their families all over the country. In the District of Columbia, between 2014 and 2017, opioid overdose deaths among Black people more than tripled.<sup>168</sup> During a similar time period, nationally, the drug death rate was rising most steeply among Black communities. The CDC reports that deaths rose by 41 percent in 2016 among Black people in urban counties.<sup>169</sup> Fentanyl and Carfentanil—synthetic drugs more potent than heroin—are at the center of this epidemic for Black communities. Black patients have historically been less likely to be prescribed pain narcotics due to racist beliefs around pain tolerance and the likelihood of substance abuse. As a result, Black communities missed the initial surge in opioid use but are feeling the effects now. In order to address this crisis, all aspects of health and addiction must be addressed, including the ways in which over-policing and incarceration impacts drug addiction. It must be treated as the urgent public health crisis it is—with compassion—as opposed to moral judgment, for all who live with this chronic disease.

**Policy Recommendations:** BWHL supports and recommends funding for minority-led organization programs, initiatives, and awareness campaigns that debunk myths and fight stigma about the opioid crisis in Black communities; continued coverage of Suboxone treatment by Medicaid and Medicare; additional appropriations bill for CDC, Substance Abuse and Mental Health Services (SAMHSA), and Health Resources and Services Administration (HRSA) to address opioids and incorporate a strong enforcement strategy for opioid-related public health initiatives; and maintenance of the Office of National Drug Control Policy.

Furthermore, BWHL recommends more training opportunities for medical residents to address an anticipated physician shortage to combat the ongoing opioid crisis. BWHL also recommends innovative policies such as Medicare-supported graduate medical education positions in hospitals with approved residency programs in addiction medicine, addiction psychiatry, or pain management.





## E. Gun Violence

Gun violence is a public health issue that disproportionately affects Black women. Based on a 2015 study from the Violence Policy Center on homicide data, Black women are more than 13 times as likely to be murdered by a man they know than by a stranger.<sup>170</sup> A gun was the weapon used in 58 percent of homicides, and 88 percent of murders were not related to another felony crime.<sup>171</sup> Black women's lives are cut short much too often; this phenomenon is linked directly to easy gun access in America. These statistics also include gun violence perpetrated by police officers against Black women, although those numbers are much more difficult to quantify because of data and reporting issues.

Black women between the ages of 18 and 34 are more likely to die from gun violence by an intimate partner than any other group of women in the United States.<sup>172</sup> Black women are almost three times more likely to be shot and killed than white women in their same age group.<sup>173</sup> In addition to the dangers of physical violence, Black women who grow up in violent neighborhoods may also suffer mental trauma that stems from their experiences. Research supports that nearly one-third of Black women in poor violent communities suffer from PTSD-related symptoms. In 2020, the murder of Breonna Taylor has heightened awareness about underreported homicides of Black women by police. As with many cases of this nature, the officers responsible for Taylor's death remain uncharged. Black women are about 1.4 times more likely to be killed by police than are white women.<sup>174</sup>

**Policy Recommendations:** Several studies have concluded that high rates of gun ownership correlate with more gun violence, whether it is homicides, suicides, or domestic violence. In an effort to prevent more violence against Black women, BWHI supports and recommends federal policies that include common sense restrictions on the ownership and purchase of guns.

In concert with the National Medical Association, BWHI further recommends declaring a public health emergency in cities faced with the epidemic of gun violence. BWHI supports federal funds for this declaration. Although there is an ongoing COVID-19 pandemic, Black people and other communities of color cannot ignore the chronic epidemic of gun violence across the United States.

## F. Incarceration and Money Bail

Across the United States today, around 450,000 people—approximately 70 percent of all incarcerated people—sit in jail because they cannot pay bail,<sup>175</sup> not because they have been convicted of a crime. Black women are commonly held in jail with high bail amounts for minor offenses, and the jails then fail to provide adequate care, leading to a devastating impact on Black women's physical and mental health. Sandra Bland died in a Waller County, Texas jail in 2015 after a traffic stop and a bail amount of \$515 that her friends and family could not afford to pay. The same month of Sandra's arrest, five other Black women died in jails around the country while waiting to post bail—most on minor shoplifting charges. Several cases involved jail officials failing to provide medical care.<sup>176</sup> Furthermore, jails and prisons sometimes shackle Black women during childbirth. Black women are separated from their children and have basic reproductive health needs ignored.

Money bail is incredibly lucrative for insurance companies and private bail agents at a profit of \$1.4 to \$2.4 billion a year.<sup>177</sup> These payments are overwhelmingly paid by Black people. In Maryland's poorest communities, for example, for-profit bond premiums cost families more than \$250 million, not including interest or fees, over five years.<sup>178</sup> The fundamentally unfair system continues to prey on poor communities of color, especially women, who comprise the fastest-growing jail population.<sup>179</sup> Addressing the ways in which the criminal justice system disproportionately impacts Black women is a crucial step toward improving Black women's health overall.

**Policy Recommendations:** BWHI supports and recommends ending money bail; ending the policy of shackling incarcerated pregnant women; legislation that requires investigation into the for-profit bail industry; ongoing oversight; and investment into alternatives to money bail, such as avoiding detention through citations, pre- or post-charge diversion, earlier hearings, and automated phone and text messages.

# BLACK WOMEN VOTE:

## National Health Policy Agenda



*Image courtesy Dr. Latonya Washington*



## Pillar III. Sufficient Diversity in Clinical Trials and Health Care Delivery Systems

Black people navigate a health care delivery system that doesn't reflect their lives. Black participation in clinical trials is very low. Black health care providers are underrepresented in the health care workforce. And technology advances are not reaching Black women to the extent they should.

### A. Diversity in Clinical Trials

Black women are vastly underrepresented in clinical research and trials. For example, cardiovascular disease and cancer both disproportionately affect Black Americans; however, a 2015–16 report by the FDA revealed only 2.5 percent Black participants in clinical trials for cardiovascular disease and 2.74 percent participants in oncology.<sup>180</sup> Increased clinical trial diversity helps researchers improve treatments for diseases that disproportionately affect Black women. One of the key reasons we need Black women in clinical trials is to ensure that the discoveries, treatments, interventions, and prevention strategies will be applicable to this population. To create the most effective treatments, it is paramount to understand the diseases that affect Black women and how certain drugs metabolize in Black women. Fewer than 5 percent of NIH-funded researchers are Black.<sup>181</sup> As a result, the unique genetic, biological, and societal conditions experienced by Black women are not accounted for when developing drugs, vaccines, and treatments for many diseases and medical conditions. Other barriers may influence participation in clinical research among the Black community, such as issues of trust due to historical experimentation and exploitation. Such experimentation includes, among others, the experiments of J. Marion Sims on enslaved women; the exploitation of Henrietta Lacks, whose cells were produced in her name and without her knowledge or consent to develop a series of groundbreaking treatments for polio and in vitro fertilization; and the Tuskegee study, which studied how syphilis progressed in Black men and continued for decades after effective treatments had been identified.

Racial, ethnic, and gender diversity in clinical trial participation helps to ensure that drugs and vaccines work for everyone. Some therapeutics might not be effective in certain populations.

#### **Vaccines**

Clinical researchers in government, academia, and the private sector have documented differences in clinical trial and vaccine outcomes based on race and gender. Research has found that although not completely understood, people of different races and ethnicities can respond differently to drugs or therapies. The rush to find a vaccine for COVID-19 has exposed many existing gaps and the lack of diversity in clinical trials. Black Americans make up 14 percent of the U.S. population but on average 5 percent of clinical trial participants. Participation by Hispanics in clinical trials is even more abysmal. Hispanics account for 18 percent of the population; on average only 1 percent participate in clinical trials. The pressure and competition among pharmaceutical companies to produce an effective COVID-19 vaccine quickly during a pandemic could sideline efforts to ensure diversity among the ongoing clinical trial participants.

During 2020, the Food and Drug Administration (FDA) released new guidance for COVID-19 treatment and prevention that strongly encourages the inclusion of diverse populations in clinical vaccine development, including racial and ethnic minorities, elderly people, and those with underlying medical problems as well as pregnant women.<sup>182</sup>



### **BWHI Research: All of Us Research Program**

BWHI has joined 44 other national community groups and health care provider associations for the All of Us Research Program, part of the National Institutes of Health (NIH). The program is an effort to engage one million or more volunteers across the country to build one of the largest, most diverse datasets of its kind for health research. BWHI is helping to educate Black women and their families about the benefits of participation in this landmark project to accelerate breakthroughs in precision medicine. BWHI will be conducting a variety of activities as part of its involvement in the program, including holding community events, gathering public input, training program ambassadors, leading social media campaigns, and developing additional messaging that speaks to historical discrimination and the value of participation for Black women and girls.





Image courtesy Dr. Latonya Washington

However, this new FDA guideline does not require drug makers and researchers to meet these goals of inclusion, and the federal government poured billions of dollars into fast tracking more than a half dozen leading candidates for SARS-COV-2 vaccines. Yet the pharmaceutical companies, receiving federal dollars, are not required to publicly disclose their demographic goals for these COVID-19 clinical trials.

**Diversity in Clinical Trials Policy Recommendations:** BWHI supports and recommends focused research around Black women to better understand health disparities, including higher incidence and mortality rates from chronic conditions and increased funding and support for research focused on prevention and treatment for COVID-19, ovarian, breast, and cervical cancers. BWHI also supports funding for research that incorporates Black women's experiences into maternal health research and clinical trials to fully understand how the women respond to interpersonal and environmental stressors during pregnancy and childbirth.

BWHI further recommends increasing diversity of all clinical trial participants. Clinical researchers and companies that receive federal funds for vaccine development should be required to disclose the composition, race, ethnicity, and gender of clinical trial participants. If not enough Black people and other minorities are enrolled in clinical trials reflective of their burden of a disease, the FDA panel experts who monitor these trials should force a delay in release of new therapies until there are sufficient numbers of minority participants.

## B. Diversity in the Health Care Workforce

People of color, including Black women, are underrepresented in the American health care workforce. The Affordable Care Act (ACA) established a number of initiatives to address this issue, but the initiatives are in constant threat of losing funding. For example, the National Health Care Workforce Commission has yet to meet because Congress has not authorized its funding. The funds for these initiatives were intended for the training of culturally diverse health care paraprofessionals, such as home health aides; scholarships and loan forgiveness; community health teams that allow providers to diversify their own care teams; and the development of cultural competency curricula for training the health care workforce. Without adequate funding and authorization from Congress, these initiatives will not be able to fulfill their purpose of providing quality care for communities of color.

BWHI and other stakeholders, such as the National Medical Association (NMA) and the Association of American Medical Colleges (AAMC), continue to be concerned about the dwindling numbers of Black students entering medical school. Black enrollment, particularly of Black men, in US medical schools has been low. NMA and AAMC have partnered to address this national crisis. According to AAMC, since 2014, there has been only a slight increase in the enrollment of Black men in medical school, from 2.4 percent of medical students during 2014-2015 to 2.9 percent in the 2019-2020 academic year.<sup>183</sup> Medical schools and health and education organizations have increased their focus on addressing this issue. Black low enrollment and graduation from medical and other health professional schools can have impacts on the US health care system for decades. Though international medical graduates have addressed some gaps in access to care by Black people and other racial and ethnic populations, these graduates face additional challenges that impact their ability to practice in the United States.

International medical graduates entering US residency programs are very important to the diversity of the health care workforce. The current administration has proposed policies that could delay or even deny visas for noncitizen international medical graduates, many of whom come from countries in Africa and Latin America.

Delays or denials of H-1B visas for noncitizen international medical graduates can have a serious downstream impact on patients' access to care in both the immediate and near future. Community health centers, federally qualified health centers, and teaching hospitals rely on these medical residents to provide care to thousands of patients each year. Efforts must be in place to ensure the United States has a fair and efficient immigration system that strengthens American health care and advances the nation's health security.<sup>184</sup>

If the policy of denying visas is not reversed in the near future, patients will face treatment delays and gaps in care due to the lack of medical care providers, particularly in rural and urban areas that serve Black women. A policy of delaying or denying visas for continued medical training will contribute to a longer-term shortage of physicians, ultimately resulting in Black women having fewer options for life-saving care.

#### **Diversity in the Health Care Workforce Policy**

**Recommendations:** BWHI supports and recommends expanding multifaceted partnerships and funding for the health care workforce that is representative of diverse communities and increases diverse leadership of health professionals in educational institutions and hospitals; including culturally competent training into the licensure and accreditation training of physicians, nurses, and other health professionals; having diversity report cards for hospitals related to health care outcomes and ethnicity; advocating for the Health Equity and Accountability Act; maintaining the Office of Minority Health (OMH), Office of Women's Health (OWH), and National Institute on Minority Health and Health Disparities (NIMHD); increasing efforts to diversify the workforce to include Black clinical researchers, diversifying the disease research being funded, and increasing the pipeline of researchers with a focus on health disparities; expediting the process for H-1B visas for noncitizen international medical graduates; increasing funding to the Health Resources and Services Administration, CDC, and NIH for diversity in clinical trials; and providing cultural competency training for health professionals generally.



#### **Project TEACH: Partnering to Address Cancer-Focused Clinical Research Diversity**

Black women are vastly underrepresented in clinical research and trials. An analysis of data from the FDA indicates that in trials for 24 of the 31 cancer drugs approved since 2015, fewer than 5 percent of study patients were Black. Without more diverse participation, researchers cannot be confident that new precision treatments will be effective for all patients. In response to this need, BWHI, Friends of Cancer Research, and Stand Up To Cancer are partnering to support an innovative program, called Project TEACH (Trained Empowered Advocates for Community Health (Healing)). Project TEACH empowers Black women to participate in and effectively engage with researchers and clinicians in cancer-focused clinical research by:

- Organizing a core cadre of 100 trained Empowered Patient Partners (EPPs) to help build a suite of patient empowerment tools;
- Culturally adapting a pre-existing cancer patient engagement and advocacy curriculum;
- Educating and empowering EPPs on the fundamentals of patient-centered outcomes research (PCOR, comparative effectiveness research (CER), and collaborating with cancer researchers; and
- Creating a supplemental training program for researchers and clinicians on the appropriate recruitment and respectful treatment of Black women in cancer-focused PCOR and CER.

By educating and training this group of EPPs in the principles of clinical research, Project TEACH will empower Black women with the tools necessary to impact their own and future cancer treatment options. Project TEACH is supported by a funding award through the Eugene Washington PCORI Engagement Awards (Engagement Awards) program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI).

TEACH web: [www.teachforblackwomen.org](http://www.teachforblackwomen.org)

## C. Diversity in Health Care Technology

The health care industry is in dire need of more professionals of color who are leveraging technology to benefit the health and wellness of individuals across our nation, including the health and wellness of Black women. These professionals could create more inclusive technology and solutions to the health disparities Black women disproportionately face, such as the advent of 3D technology and its impact on breast cancer disparities.

Tech investment funding should support diversity, including Black women entrepreneurs and other women of color creating startup companies. As a Fast Company study pointed out, only 5 percent of venture funding went to women in 2015 and 1 percent went to African Americans.<sup>185</sup> We need policy solutions that can eliminate the bias and discrimination rife within the tech industry and within tech funding decisions.

**Technology Policy Recommendations:** BWHI supports and recommends enhanced access to technology programs; initiatives that increase the number of Black women in tech and startups with investment funding; and efforts that help build networks of Black women in tech, including those eligible for board positions.

## Artificial Intelligence

Artificial intelligence (AI), robotics, and related technologies are increasingly prevalent in business and society and are beginning to be applied more broadly to health care. These technologies have the potential to transform many aspects of patient care, as well as administrative processes within provider, payer, and pharmaceutical organizations.<sup>186</sup> Numerous research studies show AI can perform as well as or better than humans at key health care tasks, such as diagnosing disease.<sup>187</sup> AI can diagnose skin cancers like dermatologists, seizures like neurologists, and diabetic eye diseases like ophthalmologists. Additionally, some AI systems can reliably handle big health data to make efficient and sound decisions to improve clinical decision making as well as prioritizing administrative tasks.<sup>188</sup> Health care systems and providers are embracing AI to aid in comprehensive disease management of patients and developing more improved health care plans to allow patients to better manage and comply with treatments.<sup>189</sup>

The advantages of AI in health care will most likely pose a graver threat to millions of Americans by developing new and exacerbating existing health care disparities and inequities. Although these advances in AI are exciting, many racial and ethnic minority populations may not benefit from them. In 2019, a multi-university research study led by the University of Chicago found that health care algorithms used in AI carry the same racial, socioeconomic, or gender-based biases that they were developed to remove.<sup>190</sup> This study analyzed a software program that determines who gets access to high-risk health care management programs and found that the program consistently lets healthier whites into the program ahead of Black patients who are less healthy. “Because of the structural inequalities in our health care system, Black people at a given level of health end up generating lower costs than whites. As a result, Black patients were much sicker at a given level of the algorithm’s predicted risk.”<sup>191</sup> AI algorithms rely on large datasets. Research’s lack of inclusion of patients from particular backgrounds, such as Black women and minorities, could ultimately lead to misdiagnosis by AI systems.

**Artificial Intelligence Policy Recommendations:** BWHI supports and recommends advancement of AI with a health equity lens focused on eliminating health disparities and poor health outcomes of chronic conditions impacting Black women; inclusion of Black women in clinical trials research; and routine audits into algorithm developers’ workflows to avoid biases in AI systems.



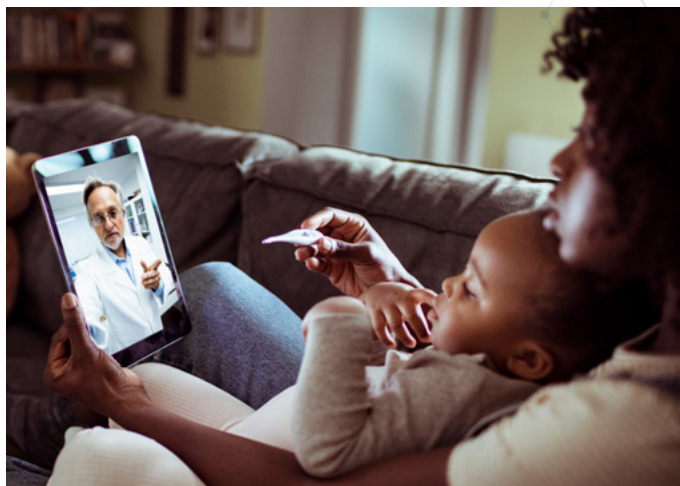
## Overbooked and Overlooked: Machine Learning and Racial Bias in Medical Appointment Scheduling

Racial bias in electronic health records systems' patient scheduling algorithms may contribute to an already inequitable health care experience by overbooking Black patients. Santa Clara University data scientist Michele Samorani led an interdisciplinary team of data scientists, public health expert Linda Goler Blount of BWHI, and a business ethicist in the first study to measure and address racial disparities in appointment scheduling.

Machine learning uses mathematical formulas to optimize the provider's schedule and eliminate provider overtime and idle periods. Patients for whom the algorithm predicts a high no-show probability are double-booked to reduce the impact of no-shows on clinic operations. The study found that Black patients were more likely to be overbooked than white.

In response, the authors developed an algorithm that completely eliminates racial disparity in scheduling with no significant increase in cost when compared to the traditional predictive overbooking framework.

Overbooked and Overlooked reviewed several models to seek solutions that could level the playing field for patients. The report suggests that there are ways that scheduling can be a win-win for systems and the patients they serve, and they should be explored.<sup>192</sup>



*Image courtesy istock.com/Geber86*

## Telehealth

Telehealth approaches to care can leverage access to care for Black women. According to the Health Resources and Services Administration (HRSA), telehealth is defined as the use of electronic information and telecommunications technologies to support long-distance clinical care, patient and professional health-related education, public health, and health administration. It allows the use of technologies—videoconferencing, internet, imaging, streaming media, wired, and wireless communications. Since its inception, telehealth has not been readily accessible to many vulnerable populations, including Black women. Although telehealth is vital to address systemic racism, Black women and other vulnerable people are being left behind by the telehealth revolution.<sup>193</sup>

The lack of access to technology, digital literacy, and reliable internet coverage disproportionately affects the elderly, communities of color, and low-SES communities. Especially with communities of color experiencing disproportionately higher and more severe cases of COVID-19, these barriers prevent the opportunity for early diagnosis and treatment.<sup>194</sup>

**Telehealth Policy Recommendations:** BWHI supports and recommends opportunities to facilitate Black women and their families' access to technologies that improve their ability to participate in the telehealth enterprise. To lessen the burden of COVID-19 on Black women, BWHI supports policy recommendations and programs for expanding access to telehealth services, rural health clinics, and federally qualified health centers; flexibilities and expanded funding for telehealth programs such as HRSA's \$11.5 million award through Telehealth Resources Centers; and telehealth for Medicaid substance use disorder services.

BWHI further recommends research on the use of telehealth during the COVID-19 pandemic. This research would provide insight into costs, use, and health outcomes related to racial and geographic disparities. BWHI recommends legislation to help rare disease patients get access to specialized care; health care laws should allow temporary reciprocity across the country for health care providers in good standing and with a valid license to practice medicine. BWHI supports legislation to reduce the barriers associated with state licensure, which is critically important to ensuring rare disease patients are able to access their out-of-state health care providers via telehealth services during the COVID-19 pandemic.

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*Image courtesy Camille Simpson*

## Pillar IV. Increased Funding to Support HBCUs

### A. Funding for Historically Black Colleges and Universities

Historically Black Colleges and Universities (HBCU) have a profound impact on the health and well-being of Black women, especially Black college-aged women. Black women comprise 65 percent of the student population at HBCUs earning bachelor's and master's degrees; these women go on to earn advanced degrees, become doctors and researchers, and contribute their expertise and lived experience to the health care field. They dream up solutions to health policy dilemmas, create new health treatments, and innovate technology for the 21st century.

In fact, HBCUs significantly contribute to the creation of Black science degree holders: agriculture (51.6%) of Black degree holders earned degrees at HBCUs; biology (42.2%); computer science (35%); physical science (43%); and social science (23.2%). Forty percent of Black members of Congress, 50 percent of Black lawyers, and 80 percent of Black judges graduated from HBCUs.<sup>195</sup> HBCUs need additional funding to ensure that Black women's educational endeavors and opportunities for economic advancement are supported. The sustained funding will help HBCUs continue to offer all students, regardless of race, an opportunity to develop their skills and talents and to strengthen the pipeline of students who go on to do work that improves health outcomes for Black women.

**HBCU Funding Policy Recommendations:** BWHI supports and recommends increased funding for Historically Black Colleges and Universities (HBCU) and minority-serving institutions in the appropriations budget through expanded HBCU partnerships with federal agencies; renewed funding for the White House Initiative on HBCUs; continued programming from the HBCU Congressional Caucus; building of partnerships with HBCU medical schools; increased HBCU medical school recruitment for Black students and ensuring that Black health professionals including OB/GYNs are trained to provide care for Black women with cultural competence; increased support and funding for graduate medical exchange programs, such as sending Black medical students to Escuela Latinoamericana de Medicina in Cuba for a diverse, affordable graduate medical education; and funding to support all educational efforts to improve the delivery of culturally effective care and to ensure that Black women receive timely, accurate, and high-quality diagnoses and treatments for all conditions.

In addition, BWHI supports the Coronavirus Aid Relief and Economic Security (CARES)<sup>196</sup> Act, which provides emergency assistance for individuals, families, and businesses affected by the coronavirus pandemic. The Act provides 1.5 billion dollars worth of funding to HBCUs that were affected by sudden shutdowns in the wake of the outbreak. More than 75 percent<sup>197</sup> of HBCU students rely on Pell Grants to pay for their education. The remaining balance is often paid using PLUS loans borrowed by parents. The pandemic affected financial aid for many students. Some schools were unable to continue to provide auxiliary services, including dining areas and residence halls. Students were forced to evacuate their campuses all across America. In the worst of scenarios, homeless students and international students had nowhere to go.





### BWHI POLICY INITIATIVE: My Sister's Keeper Program (MSK)



My Sister's Keeper  
A BWHI PROGRAM

My Sister's Keeper (MSK) is a signature BWHI program created to empower young Black women on college campuses—with special emphasis on HBCUs and in communities—to advocate for and contribute to their own health and well-being as well as that of other Black women. Through skills training and leadership development, young Black women are versed in understanding and applying the tenets of reproductive rights and reproductive justice; sharing lived experiences through authentic storytelling; training and engaging women in policy basics, advocacy, base-building, and mobilization; understanding and employing strategies for emotional wellness/self-care; and creating anti-racism and anti-sexism strategies to apply in the fight for reproductive justice. MSK focus areas include sexual and reproductive health, rights, and justice; mental and emotional health; menstrual insecurity and stigma; gender discrimination and violence; anti-racism and allyship; and anti-tobacco, smoking, and vaping. MSK chapters are led by students.

*Image courtesy MSK*

## B. Black Girls and School Discipline Policies

Black school-age girls are punished disproportionately in comparison to their white classmates. The Department of Education found that Black girls are over five times more likely than white girls to be suspended at least once from school, seven times more likely to receive multiple out-of-school suspensions than white girls, and three times more likely to receive referrals to law enforcement. Black girls in New York City between elementary and middle school age were about 11 times more likely to be suspended than their white peers in 2017, according to a report from Education Trust-New York, a research and advocacy group. In Iowa, Black girls were nine times more likely to be arrested at school than white girls.

**School Discipline Policy Recommendations:** BWHI recommends policies and resources to support young Black school-age girls. Furthermore, BWHI promotes culturally competent educational policies and the enforcement of fair disciplinary actions for all students, including policies that reduce suspension and expulsion among students, specifically students of color, who are disciplined at alarmingly disproportionate rates.

To meet the needs of students, BWHI supports policy and legislation to reallocate funds previously used for sworn police officers toward student support positions such as school-based social workers, psychologists, restorative justice practitioners, or other mental or behavioral health professionals, as school system budgets support. BWHI recommends that school boards create time and funding for school staff to learn and apply alternatives to exclusionary school discipline. Additionally, BWHI encourages and supports school boards to listen to Black families' stories about multigenerational experiences with school discipline and school police, letting them lead the way to a more inclusive, loving education community for Black children.

Additionally, BWHI advocates for increased funding for teaching grants that would increase opportunities for individuals of color seeking opportunities in teaching professions.

## C. Gender-Based Violence Against Black Women on Campus

Sexual and relationship violence are serious public health problems with dire consequences for women. Sexual and relationship violence include a “continuum of behaviors and actions that includes but is not limited to sexual or gender-based harassment, sexual coercion, sexual abuse, stalking, sexual assault, rape, dating violence, and domestic violence.”<sup>198</sup> Sexual assault occurs when a person is unable to or does not consent to sexual activity. The CDC reports that about one in five women (22%) experiences an attempted or complete sexual assault during their college years.<sup>199</sup> Black women are particularly vulnerable to sexual and relationship violence because of systemic racism and sexism, both on their college campuses and within society at large. About four out of every 10 Black women (43.7%) have been or will be the victim of rape, physical violence, or stalking by an intimate partner in her lifetime.<sup>200</sup> In Black communities, sexual and relationship violence within the community often are tied to risk factors such as lack of adequate access to employment, quality education, stable housing, affordable contraceptives, and a living wage.



*Image courtesy istock.com/FatCamera*

### Sexual Assault on Campus

Sexual assault on HBCU campuses is a looming threat in the lives of young Black women. As many as 9.7 percent of Black women undergraduates at an HBCU report experiencing sexual assault.<sup>201</sup> This percentage is less than those reported at predominantly white institutions, but reporting is low across all campuses. The Department of Justice’s (DOJ) Office on Violence Against Women is facing large cuts to its funding. This office administers grants to the important “Reduce Sexual Assault, Domestic Violence, Dating Violence, and Stalking on Campus Program”. Without this funding, HBCUs and other institutions of higher education will struggle to respond to instances of sexual assault, domestic violence, and other forms of gendered violence in the way that justice requires. These institutions also will lack technical support to continue their programs.

Sexual assault prevention funding has been diverted to support more criminalization of immigration and border security efforts during the past few years. This can have a negative impact on Black women at HBCUs who already are at risk of having their cases mishandled due to complex factors of funding, political will, and interpretations of Title IX.

**Gender Violence on Campus Policy Recommendations:** BWHI supports and recommends the reauthorization of funding for the Violence Against Women Act, the Family Violence Prevention and Services Act, and the Victims of Crimes Act, along with anti-gender-discrimination policy and campus sexual violence policy enforcement such as Title IX of the Education Amendments Act of 1972 on college campuses. BWHI calls for ensuring that school officials and staff have training and skills on crisis interventions that identify and address young victims of physical abuse, sexual abuse, and sexual exploitation; funding for advocacy programs and support services for victims of domestic violence or intimate partner violence to reduce the stigma attached to seeking help; ensuring that survivors of physical abuse, sexual abuse, and sexual exploitation have access to sexual and reproductive health care including preventive care, mental health services, and abortion services; and establishing DOJ training for all law enforcement officials to focus on and address crisis interventions, mediation, de-escalation tactics, implicit bias, community relations, and appropriate engagement with Black women experiencing trauma.





*Image courtesy istock.com/FatCamera*



## D. Implicit Bias

Implicit bias refers to attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious way, making them difficult to control.<sup>202</sup> According to the Kirwan Institute for the Study of Race and Ethnicity at the Ohio State University, biases can be favorable and unfavorable assessments activated involuntarily and without an individual's awareness or intentional control.<sup>203</sup> The Perception Institute describes implicit bias as attitudes toward people or associated stereotypes about them without conscious knowledge.<sup>204</sup> The organization Racial Equity Tools suggests years of exposure to structural and cultural racialization and privilege have embedded stereotypes and biases in our individual psyches and broader culture.

People tend to hold implicit bias that favors their own ingroup, such as race, ethnicity, and gender. These implicit biases creep beyond social interactions and into professional settings and systems, including health care, education, and judicial. In health care, implicit biases can have detrimental effects on patients, particularly women of color.

Research studies have extensively documented implicit racial biases in several social and health care settings. The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) reported racism, bias, and disrespectful care contribute to the death of many Black women during pregnancy, birth, and postpartum periods. Approximately 700 women die each year due to pregnancy-related complications. Oftentimes, these preventable maternal deaths are underpinned by implicit and racial biases in the health delivery systems. Health care providers must be trained in implicit bias and cultural competency to mitigate these health outcomes. In partnership with AWHONN, BWHI seeks to change the perception and behaviors of providers related to racism and implicit bias, and their effect on maternal morbidity and mortality.

Implicit treatment biases have been observed in the management of chronic conditions such as pain management. Studies have shown that racial bias can affect how doctors assess and treat pain. In 2012, an analysis of 20 years of published research in the United States found that Black patients reporting pain were 22 percent less likely than white patients to get pain medication from their doctors. The gap was largest when the cause of the pain, such as back pain, was not immediately apparent.

Often, people with sickle cell disease (SCD) in crisis experience bias in treatment of their pain. Pain from SCD crisis is often undertreated. In part, this reflects racial and gender biases. Because the ischemic changes in SCD crisis can't be seen (unlike gangrene, for example, which is obvious), health care workers underestimate the person's pain. Too often, these patients are treated as drug seekers. Undertreatment is fueled, too, by federal insurance payers focusing increased attention on physician prescribing practices of narcotics. Regulations make prescribing adequate pain medications for chronic diseases cumbersome. Patients, in turn, are subjected to humiliating drug screens to make sure that they are taking the narcotics and not selling them.

**Implicit Bias Policy Recommendations:** Through its partnership with AWHONN, the BWHI recommends and supports patient-centered, values-based implicit bias training that incorporates the lived experiences of Black women during their pregnancy, birth, and postpartum care. Furthermore, BWHI recommends scientific review of interventions and policies related to implicit bias and racism in maternal care and delivery of health services to women of color. BWHI supports legislation expanding access to preventive, lifesaving women's health screening at safety net providers like Planned Parenthood and training of health care providers to enhance their ability to treat low-income women and women of color.

# BLACK WOMEN VOTE:

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*Image courtesy istock.com/LeoPatrizi*

## Pillar V. Social Justice

Every day in America, Black women live under the intersecting threats of racism and misogyny. Despite facing disproportionate rates of violence, long-standing stereotypes have created a status quo that invalidates and often ignores Black women's humanity, pain, and trauma. As a result, they are often denied safety and justice—including by the very systems that are supposed to offer protection and care.

Social justice is the movement toward everyone's rights being respected and protected. These protections should exist regardless of race, class, or gender. Equity guides access to opportunities. Although pursuit of social justice has been the hallmark of many recent societal movements and conscious protests to address discrimination, racism, sexism, and persistent injustices, some voices, particularly those of Black women, are often ignored.

Researchers at the University of Michigan reported that Blackness is associated with masculinity and leads to errors when categorizing Black women's gender or recognizing Black women's faces.<sup>205</sup> Because of this strong association of Black women to masculinity, Black women endure more social injustices than their white counterparts. Black women and girls are more associated with threat and danger than are white women and girls. Feminist movements that focus only on issues that predominantly affect white women, without addressing racialized sexism, ignore the needs of Black women, who face higher rates of police abuses, including sexual violence.<sup>206</sup> Research studies have found that Black women experience much higher rates of domestic and sexual abuse from partners than white women, and Black women are less likely to report this violence than white women.

Social injustices Black women endure extend beyond encounters with the judicial system. A study of Black women in Los Angeles showed that inequities in education, housing, health care access, and wages challenge the capacity of Black women to fully exert leadership. The Black women in this study struggled through a widening gender gap, as well as a racial wage gap. Black women represented 14 percent of low-wage workers, which is higher than all white male and female low-wage workers combined. The study revealed a \$5,000 wage gap between Black women who hold managerial positions and work professional roles compared to their white counterparts. The study concluded these are oppressive economic obstacles that limit professional and social mobility of Black women.<sup>207</sup> Historically, Black women have been hardest hit by economic and social crises, and the COVID-19 pandemic has not been any different.

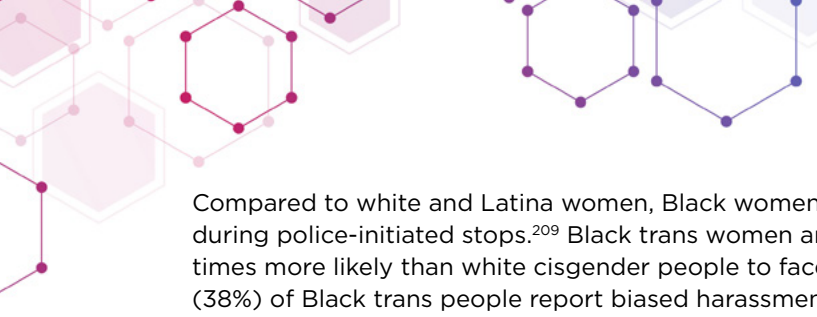
Social justice is a matter of life and death. Inequities in health arise because of the systemic circumstances many Black women face. Social and economic policies have a determining impact on health and wealth outcomes of Black women. Social injustices must be addressed at all levels of government and throughout all systems so that Black women and their families have opportunities to live their fullest potential.

There is an urgent need to remove the structural barriers to safety. As long as laws are written in ways that allow for injustice, archaic and oppressive policies and practices will continue to harm Black women. To address the need for systemic change, the Agenda advocates for policy reform across three critical issues affecting the health of Black women and girls: police violence; sexual assault; and incarceration.

### A. Police Violence

Black women are the invisible victims of police violence. The national conversation on policing practices and misconduct overwhelmingly centers Black men's experiences, often overlooking the trauma that Black women experience at the hands of police.<sup>208</sup> It is why George Floyd, Michael Brown, and Eric Garner are household names while Michelle Cusseaux, Natasha McKenna, and Aiyana Stanley-Jones are not. Despite this erasure, data show that, similar to Black men, Black women also experience police violence disproportionately.





Compared to white and Latina women, Black women are three times as likely to experience use of force during police-initiated stops.<sup>209</sup> Black trans women are at even higher risk, with trans people of color six times more likely than white cisgender people to face physical violence from police.<sup>210</sup> More than a third (38%) of Black trans people report biased harassment by police, and 15 percent report experiencing police assault.<sup>211</sup> Police also shoot Black women fatally at higher rates than women of other races, accounting for 20 percent of women overall and 28 percent of unarmed women killed this way.<sup>212</sup> Black girls experience more of the same, often within the school system, where they are criminalized more frequently than non-Black girls and constitute nearly half of arrests.<sup>213 214</sup>

Over the last two decades, research has also shown alarming trends in sexual violence committed by police. In 2010, a study found that sexual misconduct by police was the second-most reported complaint behind excessive force, and later analysis uncovered that a police officer was caught in an act of sexual misconduct every five days from 2005 to 2015.<sup>215</sup> Black women are predominantly the target of this type of violence.<sup>216</sup>

Although police violence is very real for Black women and girls, justice for that violence is rarely served. In most cases, officers who commit violent acts are never charged.<sup>217</sup> That must change, especially because a dangerous combination of factors—including stereotyping,<sup>218</sup> over-policing,<sup>219</sup> the militarization of law enforcement, and the “blue wall of silence” that protects police from accountability<sup>220</sup>—will only continue to increase the risk of unchecked police violence against Black women and girls.

**Police Violence Policy Recommendations:** BWHI supports and recommends several policy solutions to police violence, including the redistribution of excessive police funding to social services programming; national implementation of civilian police review boards; removal of police officers from public schools; an end to the Pentagon’s 1033 program, which allows law enforcement agencies to access heavy-duty, military-grade hardware; and an end to qualified immunity.

## B. Sexual Assault

Standing at the intersection of racism and misogyny, Black women are frequently victims of sexual violence. One in five are survivors of rape, and nearly 40 percent will experience sexual violence other than rape in their lifetime.<sup>221</sup> These numbers are likely higher, but for every Black woman who reports rape or assault, at least 15 do not.<sup>222</sup> For many, this violence begins during youth. In fact, nearly 60 percent of Black girls experience sexual violence before the age of 18.<sup>223</sup>

Sexual violence is an issue for Black women out in the world, at work, and at home. Forty percent of sex trafficking victims are Black women, a disproportionately high number considering this demographic only accounts for 13 percent of the US population.<sup>224</sup> Across industries, Black women experience the highest rates of workplace sexual harassment in comparison to all other non-Black women.<sup>225</sup> Even at home where they should be safest, Black women are at risk. They experience intimate partner violence at nearly three times the rate of women of other races,<sup>226</sup> but are less likely to have access to the necessary social and structural supports needed to address the physical and mental health consequences of this trauma.<sup>227</sup>

The high incidence of sexual violence against Black women is a reflection of both the long-standing hypersexualization of this population and the systemic racism that invalidates Black trauma. The harmful stereotypes about Black women as promiscuous create a justification for perpetrators of sexual violence, and the criminal justice system’s failure to see Black women as victims signals that there is less concern and fewer consequences for their assault.<sup>228 229 230</sup>

**Sexual Assault Policy Recommendations:** BWHI supports expanding of the statute of limitations on rape and sexual assault cases to give victims more time to report; expedited testing of the rape kit backlog; and legislation that eases the reporting process for victims and closes loopholes that make it difficult to hold perpetrators accountable. Additionally, BWHI recommends mandated trauma-informed training on sexual violence for those in the criminal justice system (e.g., police officers, district attorneys, judges); increased coordination between law enforcement and hospitals collecting medical evidence; and state or federally funded health services for victims of sexual violence.



Image courtesy istock.com/martin-dm

## C. Incarceration

Since 2000, the rate of imprisonment has steadily declined for Black women, who still face disproportionate rates of incarceration. Black women are imprisoned at twice the rate of white women and account for 44 percent of all incarcerated women.<sup>231</sup> Similarly, Black girls between the ages of 12 and 17 are 3.5 times as likely to be incarcerated as their white counterparts.<sup>232</sup> While imprisoned, Black women face substandard conditions and inhumane treatment.

Health services, including mental health and gynecological and obstetric care, are often inadequate. For example, while some facilities offer free menstrual hygiene products, they are irregularly allocated, the quality is second-rate, and the amount provided is usually insufficient, creating a monthly nightmare for the many who cannot afford to purchase their own products. Further, many of the processes and procedures of the criminal justice system are not trauma-informed. Nearly 90 percent of incarcerated women have experienced sexual violence, yet procedures such as cavity searches, pat downs, and shackling remain common.<sup>233</sup> For Black trans women, who are often placed in men's facilities, gender-affirming care is often non-existent, and sexual violence is frequent.<sup>234</sup>

Pre- and post-natal care in detention facilities is also lacking. Prior to labor and delivery, many states do not require medical exams or offer health counseling for pregnant inmates, and the general negligence of correctional procedures places undue stress on expectant mothers.<sup>235</sup> The consequences are stark: in some states, one in five prison pregnancies results in miscarriage, and in others the pre-term birth rate for incarcerated women exceeds the national average.<sup>236</sup> Further, while federal law now prohibits shackling of pregnant women, that law does not extend to state and county prisons, where an overwhelming majority (85%) of incarcerated women are housed. Following birth, it is common for many inmates to be rushed back to detention without the opportunity to bond with or care for their newborns.<sup>237</sup>

All of these systemic failures have long-term consequences for the women incarcerated, as well as their children and families, and must be addressed immediately.

**Incarceration Policy Recommendations:** BWHI advocates for more equitable sentencing; adequate, high-quality health care for incarcerated women; and placement of trans women in women's detention facilities as well as gender-affirming care for inmates. BWHI opposes shackling in all jails and prisons.

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