



Key Learnings Memo:

Listening Session with Black Women HIV Advocates

November 2-3, 2022



The purpose of this document is to provide the Gilead team with a summary of key learnings from the November 2-3, 2022, *Listening Session with Black Women HIV Advocates*.

Impact of HIV Among Black Women

- According to the Centers for Disease Control and Prevention, **Black women continue to be diagnosed with HIV at disproportionately high rates** relative to white and Hispanic/ Latina women.¹
- Per the Center for HIV Law and Policy, **1 in 32 Black women will be diagnosed with HIV in their lifetime.**²
- Despite recent progress that has seen new HIV diagnoses decrease by 21% from 2010 to 2016, **Black women still accounted for 6 in 10 new HIV infections among women in 2016.**³
- As of 2019, **Black women accounted for 54% of new HIV diagnoses** among women in the United States, despite comprising only 13% of women in the United States.^{4**}
- Among Transgender people, **Black Transgender women have the highest rate of new HIV diagnoses.** Black Transgender women also have the highest HIV prevalence among trans women.⁵
- While the U.S. Ending the HIV Epidemic Plan aims to have at least 50% of PrEP eligible people be prescribed PrEP by 2025, the **CDC estimated that only 10% of PrEP eligible women were prescribed PrEP in the United States in 2019.**^{6 **^}
- In 2019, 8% of PrEP eligible Black people were prescribed PrEP, while 63% of PrEP eligible White people were prescribed PrEP.^{7 **^}

** Based on sex assigned at birth.

^Among people age 16 and older.

REFERENCES:

¹ https://www.cdc.gov/mmwr/volumes/68/wr/mm6818a3.htm?s_cid=mm6818a3_w

² https://www.hivlawandpolicy.org/issues/racial-justice?qt-related_content_issues=1#:~:text=At%20some%20point%20in%20their,quality%20of%20medical%20care%20received

³ <https://www.nbcnews.com/health/womens-health/hiv-hits-black-women-hardest-cdc-report-says-n1003891>

⁴ <https://www.cdc.gov/hiv/group/gender/women/diagnoses.html>

⁵ <https://www.sfaf.org/collections/beta/high-rates-of-undiagnosed-infection-among-black-trans-women/>

⁶ <https://www.cdc.gov/hiv/group/gender/women/prep-coverage.html>

⁷ <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-vol-26-no-2.pdf>

Addressing the unmet needs of people living with or impacted by HIV is part of Gilead's mission to end the epidemic for everyone, everywhere. We believe everyone should have access to the same healthcare, regardless of their background, and seek to support underserved communities that experience obstacles to quality care, including Black women.

Gilead has supported the health of Black women for many years by fighting for greater access to healthcare services, reducing disparities in care, advancing education, and helping community-based organizations expand their work. Since 2017, Gilead has provided more than **\$35,800,000 in philanthropic support*** for U.S. based Black women-led and Black women-serving organizations, with 78% of these funds distributed to organizations working to end HIV. To protect and progress this work, we must identify new and improved ways to strengthen Gilead's engagement with this community and set specific goals for measurable outcomes.

Gilead hosted a listening session with Black women leaders in the HIV response to provide the company with specific feedback and recommendations, based on previous and potential efforts, which are summarized in this memo. Gilead will use these key learnings to help:

- **Develop a community engagement and health equity strategy** for Black women
- **Identify areas where Gilead could increase involvement** with Black women
- **Establish clear priorities for the provision of financial resources** for organizations serving Black women

The listening session was attended by nine Black women HIV advocates from across the United States and representatives from Gilead's Office of the General Counsel, Public Affairs, HIV Sales, HIV Franchise Marketing, and Inclusion & Diversity teams. Attendees engaged in in-depth discussions and provided insight to Gilead around key topics (noted below) to help develop a comprehensive strategy for Black women.

“We are all HIV Possible.”

-Tatyana Moaton, Ph.D., MBA-HRM

**This figure represents funding for Black women-led organizations and Black women-serving organizations, respectively. It is inclusive of HIV and Oncology centric initiatives focused on prevention, education, training, awareness campaigns, nonprofit capacity building, convenings, and other community programming.*

Advisor Attendees:

Linda Goler Blount, MPH, President & CEO, Black Women's Health Imperative

Tori Cooper, Director of Community Engagement for the Transgender Justice Initiative, HRC

Dázon Dixon Diallo, DHL, MPH, Founder & President, SisterLove, Inc.

Linda H. Scruggs, MHS, LPC, Co-Executive Director, Ribbon and Project Director, HIV Age Positively Organizing Center

Linda M. Dixon, Esq., Health Law Director, Mississippi Center for Justice

June Gipson, Ph.D., EdS, President & CEO, My Brother's Keeper, Inc.

Jackie Hendricks, Founder, Jackie Hendricks Ministries

Tatyana Moaton, Ph.D., MBA-HRM, Senior Capacity Building Specialist, San Francisco Community Health Center

Monica Johnson, Founder and CEO, HEROES, Inc.

Gilead Attendees:**Office of the General Counsel**

Deborah Telman, Executive Vice President, Corporate Affairs and General Counsel

Public Affairs

Alex Kalomparis, Senior Vice President, Public Affairs

Jane Stafford, Executive Director, Public Affairs

Shanell McGoy, Senior Director, Public Affairs

Darwin Thompson, Director, Public Affairs

Shannon Weber, Director, Public Affairs

Anique Graham, Senior Manager, Public Affairs

Inclusion & Diversity

Perika Sampson, Global Head of Inclusion & Diversity

HIV Marketing

Frank Conway, Executive Director, Marketing, HIV Franchise

HIV Sales

Anita Lowe, Executive Director, Sales, HIV Prevention



TOPIC 1: ASSESS AND ARTICULATE SPECIFIC CHALLENGES TO BE ADDRESSED, BASED ON CURRENT DATA AND NEEDS OF BLACK WOMEN

Summary of Responses

Current Data Does Not Reflect the Community

- Current public health data is not fully representative of Black women, especially across different economic backgrounds. Critical segments of this community are not being engaged.
- When looking at data from a US perspective, some may not see Black women as a priority audience, but HIV is a critical health emergency for Black women globally.
- Black women's lived experiences are informative and can provide helpful data on the real-time impact of the HIV epidemic.
- Subject-matter experts are likely to cosign on their experiences and can provide insight into areas of planned research.

Lived Experiences of Black Women are not Elevated

- Black women's stories need to be validated and heard, elevating stories of resilience to give others hope and a success model for thriving with HIV.
- For example, facilitating a qualitative study analyzing the lived experiences of Black women living with HIV via case studies.

Black Women are not Prioritized or Centered

- People prioritize what they value. If decision-makers don't understand the value proposition for HIV prevention for Black women then progress can't be made.
- There is very limited funding uniquely and specifically for Black women, and this funding is often limited to one year. Multi-year funding is critical to the success of programs.
- Where are the resources dedicated to, and the sustainability for, Black woman-led and serving organizations?
- In playing "oppression Olympics," or only targeting the traditional groups, Black women are being left behind.
- There must be an intersectional approach (re: Kimberlé Crenshaw) that takes into consideration all elements of Black women's lives: how race, class, gender, and other characteristics factor into providing holistic care for Black women.

Racism, Patriarchy and the Social and Structural Determinants of Health

- Black women's lives, well-being, and bodies are not valued, particularly in areas in the US South. Black women and Black Transwomen are often made to feel invisible.
- Black women are left to advocate for themselves and don't receive the same level of support as they provide others.
- "We can't keep putting the burden of change on the backs of Black women." - Linda Goler Blount, MPH

- White supremacy and patriarchy cause Black women to be “the oppressed of the oppressed”. If we change the landscape and condition of HIV for Black women, the floor will be raised and all other groups would benefit.
- Black women are deeply impacted by social and structural determinants of health. Racism and oppression are causing physical and mental harm to Black women, and there are structural barriers in place limiting pathways to well-being.
- There is a lack of care and understanding among medical professionals, limiting the opportunities for Black women to receive quality care.
- We need to have a conversation about equity before equality, including changing policies and addressing conscious bias as part of structural interventions.

Lack of Support for Prevention Resources

- There is a lack of investment in prevention resources and education for Black women and Black Transwomen.
- A well-resourced campaign dedicated to making HIV prevention a household term for Black women would go a long way toward both behavior and policy change.
- “They care about us when we get sick,” but not before.
- Stigma is a critical issue and creates barriers to maintaining health.
- Medicaid expansion to assist with providing these resources is critical for women’s health care, and Black women’s health care.
- Whatever strategies are developed need to be unique and responsive to Black women’s needs.



TOPIC 2: IDENTIFY INDIVIDUAL AND COMMUNITY SOLUTIONS, INCLUDING LIFE SKILLS, SUPPORTIVE SERVICES, ECONOMIC DEVELOPMENT

Summary of Responses

Center Black Women and Embrace their Intersectionality

- Black women live intersectional lives and are more than just their status.
- Black women tackle heart disease, diabetes, and other circumstances in addition to living with HIV.
- We need many studies to address community-based intersections; what does it mean to center black women, and how do we support black women-led spaces?
- We need to convene groups of Black women with multiple intersections to help with connecting the dots and ask, “how can Black women show up in this research?”.
- We need to acknowledge intersectionality and take a holistic approach to engage Black women.

Training, Education, and Career Pipelines

- We need to establish or support effective leadership development programs for Black women, to set them up for success with education and career pipelines.

Policy, Advocacy, and Legal Aid

- There are existing coverage gaps in health care. While Medicaid and CHIP are the largest providers, access to health insurance is across the board.
- We need to prioritize legal support for those living with HIV, as they experience significant discrimination and may not understand their rights.
- Advocacy and lawmaker education are critical pieces for advancing this work, along with strategic policy changes.

Address Stigma, and Social and Structural Determinants of Health

- Comprehensive care for Black women living with HIV includes addressing the social determinants of health—access to services, transportation, education, and environment. Eliminating the challenges and barriers that come with neighborhood segregation (access to quality care locally).
- In the HIV epidemic, white men are typically prioritized and have certain privileges that Black women do not. There is a need to analyze: what equity is, how equity is reached, and how does our healthcare approach (including equitable medications) help Black women?
- Racism is felt across the United States, but it has specific repercussions in the “Bible Belt” or Southern US. There are different types of barriers for those receiving care, including socioeconomic factors (for example, access to transportation) as well as culture-related issues such as pervasive stigma.
- There is a need for culturally and socially responsive education in medical schools so that Black women receiving care are embraced with holistic, culturally-competent services.

Provide Funding and Other Resources

- Black women-led and Black women-serving organizations need multi-year funding opportunities.
- Funding is necessary to promote and support health equity. One of the advisors, Tori Cooper, shared an example of providing thousands of dollars of out-of-pocket money for rideshare services such as Uber and Lyft and other day-to-day support for community members.
- Most Black women led organizations are using the personal financial resources of leadership to serve their community and deliver programs.
- A potential approach could be non-traditional funding through RFAs or RFPs to support community organizations or initiatives. This grantmaking should be viewed as an investment in important life-saving ideas that need to be developed.

- It takes a great deal of time, energy, and human resources to write a grant. Black women have the experience, expertise, and capability to serve their community best, but due to gaps in understanding and time spent on renegotiations with funders there are barriers to receiving very necessary funding. We need "Black women friendly philanthropy".
- Even though Black women-led organizations have proven themselves through their work and service, external socio-political forces often limit their access to funding or support, intending to keep the work and impact of Black-serving organizations limited.
- There is a Public Health entrepreneurial spirit, and "seed money" is necessary to grow projects and implement new ideas.

Meet people where they are and connect in familiar ways

- Our approach to engaging Black women and promoting healing should incorporate mental health, faith, and affirmation of lived experiences.
- Part of the strategy should bridge arts and culture to reach people where they are living their lives. This can include a multitude of platforms like social media, local media, and engaging community voices and influencers to amplify key messages. For example, creating an event like a Black Women's Arts & Film Festival with a focus on health and centers of "Blackness".

Listen, Learn, and Trust

- We need to bring the voices of Black women leaders into this space, as they are speaking up for their communities.
- We also need to ensure Black women of varying economic and social backgrounds are being engaged and heard, not just Black women with greater access and privilege.
- "Our communities know their needs best, and deserve a seat at the table in conversations around scientific development."

Peer Support and Community Centered Programming

- Peer involvement helps women know that there are support systems. Through support groups, and other peer-to-peer work, we need to empower the community with an open space for Black women.
- We want to connect people in the community to those with similar stories and who understand where the services are, helping people to navigate a fractured system.
- It's crucial to encourage one another through community-centered programming: e.g., community health workers, Healthy Sexual[®] education resources, patient navigation models, etc.
- How do we help drive the work and the research? Connect with the National Institutes of Health, get people connected outside of their professional network, and get them to attend conferences.
- An example is to implement some sort of large-scale, recurring summit geared toward Black women's health.



OPPORTUNITIES FOR GILEAD:

Storytelling, Public Education, and Outreach

- Create a large-scale public campaign focused on Black women’s health as it relates to HIV.
- Use social media, local and national news articles, Black woman-centric community events, influencers, and other delivery channels to amplify key messages and connect with target audiences (Black women and decision-makers).
- Elevate the stories of Black women who are living and thriving with HIV.
- Invest in culturally-responsive prevention messaging that is relevant to regions and communities (e.g., public transportation, Black media/social media).
- Use storytelling as a tool to reduce stigma, and counter myths and misinformation about HIV.

Grantmaking and Financial Support

Support of Both Traditional and Innovative Community Programs for and by Black Women

- Support health social innovation and “Dream Maker” opportunities for Black woman-led and serving organizations; seeding new or creative projects related to HIV and Black women.
- Philanthropic investment to support Black women-centric initiatives focused on community education and/or HIV testing and prevention.
- Support peer-led community health programs including peer support groups.
- Support capacity building and training for leaders of Black woman-serving organizations.

Talent Development

- Support organizations that provide professional development for Black women in community-health leadership roles.
- Partner with organizations to support Black

women-centric career pipelines into the health field, including:

- o initiatives and organizations that provide Black women with the training and education required to work in health care and public health
- o organizations that support Black women to become clinical investigators.

Research, White Papers, and Improving Data

- Support a study analyzing the lived experiences of Black women living with HIV.
- Continue to invest in efforts to improve clinical trial diversity.
- Partner with organizations that help to ensure that Black women have knowledge of the relevant research, therapeutics, and progress on cures.
- Support for a Black Women’s Clinical Think Tank.

Convening Community

- Host or sponsor a National Black Women’s Health Summit.
- Create safe and sacred spaces for Black women to convene and discuss lived experiences, gain hope, and be connected to resources.
- Use culturally-relevant community events and channels to promote well-being. Themes can include:
 - o Faith and spirituality
 - o Music and art
- Meet Black women in communities and spaces where they already are, such as “sisterhood communities” that are created by Black women for Black women.
- Show up in spaces where providers and decision-makers convene (trainings, conferences).