

WOMEN AND HIV IN THE CURRENT US CLIMATE:

Opportunities and Challenges in Policy and Research



HIGHLIGHTS

- ▶ **The Women's Research Initiative on HIV/AIDS (WRI), a program established by The Well Project in 2003**, is a multidisciplinary and multisectoral effort dedicated to identifying gaps for women in HIV prevention, treatment, and cure research and policy. In April 2021, the WRI convened a virtual meeting to assess the current US policy landscape as it relates to women and HIV.
- ▶ **Strengthening racial justice movements and the devastating and ongoing COVID-19 pandemic have further exposed longstanding racial and gender inequities** throughout our society, highlighting the need for fundamental change. At the same time, the 2020 election and the new administration's efforts and commitments provide opportunities to fundamentally shift the landscape around women's health and HIV and forge new pathways toward meaningful progress.
- ▶ **An HIV research and policy response that effectively serves all women will work to dismantle systemic racism**, proactively and explicitly include everyone who identifies as a woman, and facilitate the engagement of women across the lifespan, including during pregnancy and breastfeeding.
- ▶ **In order to be successful, the HIV response must expand its focus beyond predominantly biomedical approaches** that singularly prioritize outcomes specifically related to medication-based interventions, such as viral suppression and pre-exposure prophylaxis (PrEP) uptake. Supporting women's health in all its complexity means promoting overall well-being through the development and adoption of holistic approaches (including biomedical, behavioral, and social/structural strategies) in research, policy, and programming.
- ▶ **The HIV epidemic will never end without comprehensively addressing the experiences and needs of women living with and vulnerable to HIV** (who are overwhelmingly Black women and other women of color) at every level of programming, research, and policy.

The Well Project and the WRI define "women" as anyone who identifies as such across the gender spectrum, including cis and trans women.

"In order to truly move the needle forward, we have to create space for new women research advocates. We can't keep calling on the same five women. We need to lift up the voices of the women who are doing the work in their communities - they have important things to say. Let's hand them the mic so we all can hear it!"

GINA BROWN, RSW, community engagement manager at the Southern AIDS Coalition, The Well Project's community advisory board chair.

BACKGROUND

The new administration, which has expressed a commitment to inclusion and progressive values, is poised to have a dramatic impact on the landscape of women's health and HIV. Concurrently, widespread uprisings for racial justice and the persistent COVID-19 pandemic are forcing a long-overdue reckoning with the pervasive and insidious effects of systemic injustice on health and quality of life for people in the US. These changes are expected to have an impact on policy and research initiatives pertaining to women living with or vulnerable to HIV.

The current administration has announced plans or taken action on a variety of fronts to address issues that impact women living with and vulnerable to HIV, including:

- Broadening **health care access**
 - Working to strengthen the Affordable Care Act (ACA), including:
 - Financial incentives for states that have not yet expanded Medicaid
 - Offering states the option of expanded postpartum Medicaid coverage (from 60 days to one year)
 - Expanding access to affordable insurance coverage through COVID-19 relief packages
 - Withdrawing waiver authorities for Medicaid work requirements
- Expanding **LGBTQ protections against discrimination**, including in health care
- Informing **non-citizens about their rights to access health care**
- Actively addressing **gender inequity**, including through the development of the White House Gender Policy Council, tasked with addressing gender-related concerns across a range of areas (such as health), both domestically and globally
- Using executive orders to **advance health care issues**, such as:
 - Reversing the global and domestic gag rules, which prohibited any funding for organizations that offer or provide information about abortion
 - Re-engaging with the World Health Organization
 - Committing to support for United Nations Population Fund (UNFPA)
 - Reviewing regressive ACA policies, such as work requirements

Events of 2020, particularly the COVID-19 pandemic and the multitude of murders of Black men and women by the police, have cast a bright light on systemic racism in the US, including its manifestation in health disparities and inequalities. Statistically, more severe COVID-19 illnesses and increased hospitalizations and deaths have occurred among Black, Latinx, and indigenous communities. There is also increasing acknowledgement of the particularly profound and detrimental impact the pandemic has had on women: from increased intimate partner violence, to higher burden of responsibility for childcare, to job loss, and beyond. Heightened attention to the issues of racial and gender inequality provides an opportunity to execute broad change and specifically address the shortcomings of the current HIV policy and research agendas as they apply to women in all their diversity.

"I continue to be struck by how the metrics used to track the efficacy of care for people living with HIV are almost entirely focused on the virus and transmissibility and not on the health and mortality of people living with HIV. Most of my patients who die have an undetectable viral load, and their deaths are caused by preventable things related to unaddressed trauma like crack use, lung disease, depression, suicide, violence, and on and on."

EDWARD MACHTINGER, MD, professor of medicine, director of the Women's HIV Program at the University of California at San Francisco

THE CURRENT ADMINISTRATION IS:

- Addressing the COVID-19 pandemic and its disproportionate impact on the economic stability of Black and other communities of color
- Acknowledging and endeavoring to address systemic racism and institutionalized white supremacy
- Elevating the important role of science and evidence-based practices in policy and decision making
- Demonstrating understanding of intersectionality and its impact on equity
- Increasing diverse representation in health staffing across agencies at the federal level

CHALLENGES

- The impact of systemic racism, including on federal agencies, the US health care system, and overall treatment of people living with HIV
 - The need to build capacity to address these effects, including a cohesive, multisectoral discourse on and approach to dismantling structural racism
- A lack of data on sex and gender identity and the imprecise classification and stratification of sex and gender data at the federal level [e.g. trans people being categorized as the wrong gender in data collection; using “women” (assumed to be cisgender) and “heterosexual women” interchangeably]
- A lack of thoughtful and targeted communication about shifting policies with people living with HIV and other HIV community members, resulting in inaccurate perceptions of what services may be available to them (e.g., access to health care and reproductive services, impact of changes around immigration law)
- The persistence of research frameworks (e.g., clinical trial protocols) that exclude participants due to pregnancy, potential for pregnancy, and lactation
- Enduring issues in federal HIV policy and programming [including both the End the HIV Epidemic (EHE) and the HIV National Strategic Plan], such as:
 - A lack of inclusion of people living with HIV in their focus, structures, and policies
 - The valorization of biomedical outcomes in both HIV treatment and prevention, (e.g., achieving viral suppression and taking PrEP as prescribed) to the exclusion of behavioral and social outcomes (e.g., attention to quality of life and health equity/inequity)
 - A lack of attention to sexual and reproductive health and justice, which are fundamental in the lives of women and all people living with and vulnerable to HIV
- State-level legislation that runs counter to the federal administration’s philosophy and policies (e.g., anti-trans legislation, barriers to sexual and reproductive health care)
- The perpetuation of outdated and scientifically unsound HIV criminalization laws at the state level, including but not limited to the concerning dichotomy of molecular HIV surveillance as both a factor contributing to HIV criminalization and a pillar of the federal HIV response

“It’s really important that the federal HIV response show leadership on issues like systemic racism and hateful state legislation against trans communities, and acknowledge that, in a discriminatory environment, it is literally impossible to end an epidemic that primarily is harming Black and brown, queer, and trans communities.”

NAINA KHANNA, co-executive director of PWN-USA

RECOMMENDATIONS: ADVANCING THE RESEARCH AND POLICY AGENDA

In order to advance a research and policy agenda on women and HIV that ensures access and equity for all US women, the HIV community (including policy-making bodies, federal stakeholders, research institutions, large and small community organizations, and others) must contend with the ingrained societal issues challenging the nation as a whole. Participants in the WRI 2021 virtual meeting identified a number of gaps that need to be addressed and committed to helping advance these efforts through multidisciplinary and multisectoral collaboration.

Centering Women Living with HIV: *Disrupt and re-invent the notion of community engagement by elevating and professionalizing the lived experiences of women living with and vulnerable to HIV, ensuring their contributions are meaningful and visible*

- Improve/expand institutional mentorship that supports the advancement of women (particularly Black women and other women of color and women living with HIV) across fields and sectors, including in the federal government and large AIDS service organizations, as well as in smaller grassroots entities
- Promote a pipeline of women living with HIV who are interested in expanding their advocacy work through placements in advisory boards, consulting roles, media efforts, etc.
- Build quality health and mortality metrics and accountability into program and service evaluation criteria, including aspects such as trauma, violence, depression and isolation scores, and consistency and quality of sexual and reproductive health care
- Develop a more nuanced approach to the way women's "risk" of acquiring HIV is conveyed, measured, and evaluated (including the use of language)

"We need more institutional mentorship in order to improve the process by which women living with HIV get invited to the relevant 'tables.' As leaders, we need to think about those entry points as welcoming spaces for newcomers that we are bringing into these conversations."

CELESTE WATKINS-HAYES, PH.D., *Jean E. Fairfax Collegiate professor of public policy and professor of sociology at the University of Michigan*

Funding: *Work with policymakers, academia, and industry to ensure HIV funding infrastructure addresses the needs of women living with and vulnerable to HIV*

- Conduct evaluation to measure percentage of all funding that focuses on women and goes to women-led HIV organizations
- Expand federal funding (and amend reporting expectations) beyond large HIV and direct-service organizations to smaller grassroots advocacy groups and organizations that deliver holistic HIV programming
- Expand community partnerships with universities that are funding community-based research and programming around equity

HIV Research: *Ensure that the HIV research agenda adequately and holistically serves women living with and vulnerable to HIV*

- Elevate new research paradigms that creatively and proactively ensure the inclusion of US women and disproportionately affected populations in HIV prevention and treatment studies
- Develop and reward protocols that are inclusive of people who are pregnant, may become pregnant, or are lactating
- Ensure that relevant research protocols reflect the input of and approval of women living with HIV

- Advance and amplify community-based participatory research and other research models that reflect the needs of the communities most affected by the study findings
- Reconceive the ways in which gender identity is documented, reported, and described in HIV research to ensure accuracy and inclusivity and to address existing inconsistencies and inaccuracies in federal reporting (e.g., the development of recommendations for consistent data collection among trans people)

HIV Policy: Pursue an inclusive HIV policy agenda that serves the people most affected by HIV, by creating policies that:

- Ensure that anti-racism efforts among the HIV community are led by Black and other communities of color
- Mandate evaluation criteria and metrics to measure progress on eliminating systemic racism at the institutional level across the HIV field, including in research settings (e.g., hiring, capacity building, anti-racist workplace policies, study criteria)
- Prioritize sexual and reproductive health care and rights for women living with and vulnerable to HIV
- Coordinate HIV community participation in the development of agency implementation plans for the HIV National Strategic Plan
- Promote policy agendas that have already been developed by groups in consultation with people living with HIV (e.g., PWN-USA, WRI)

CONCLUSION

The virtual WRI 2021 sought to elucidate the potential impact of the current administration’s policy and research priorities, recent racial justice movements, and the COVID-19 pandemic on women living with and vulnerable to HIV, and to identify a series of recommendations to address the needs of women, with a specific lens on race, gender, and equity. While women living with and vulnerable to HIV have been underserved and underprioritized in HIV programming, policy, and research throughout the epidemic’s four decades, the current landscape provides unique opportunities for transformation and progress.

The challenges of 2020 have led to widespread acknowledgment of racial and gender inequities and a commitment to change across institutions and organizations, including those involved in the HIV response (though these challenges have been apparent for many years, particularly to those affected by and advocating to dismantle them). It is incumbent upon stakeholders committed to advancing and improving care for women living with and vulnerable to HIV to engage in an unflinching examination of our institutions and practices and work to make our underlying systems more equitable. If we do not center the needs and leadership of women living with and vulnerable to HIV, particularly Black women and other women of color, our efforts to end the HIV epidemic will never succeed.

ABOUT THE WELL PROJECT AND THE WRI

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. Its program, The Women’s Research Initiative on HIV/AIDS (WRI), is a multidisciplinary and multisectoral effort dedicated to identifying gaps for women in HIV prevention, treatment, and cure research and policy. For more information, please visit www.thewellproject.org.

