

Interrogating the Intersection of HIV and Women's Sexual and Reproductive Health

HIGHLIGHTS

- ▶ **The Women's Research Initiative on HIV/AIDS (WRI)**, a program of The Well Project, is a multidisciplinary and multisectoral effort dedicated to identifying gaps for women in HIV prevention, treatment, and cure research and policy. In October 2021, the WRI convened a meeting to identify best practices, gaps, and barriers in research at the intersection of HIV and women's sexual and reproductive health.
 - While some aspects of this discussion may apply to women globally, this meeting was focused on US women.
- ▶ **Research and policy around this topic must be grounded in its historical context**, including the ways in which women have been marginalized and Black people (Black women in particular) and other people of color have been abused by the medical establishment.
- ▶ Despite playing a fundamental role in women's health and well-being, **sexual and reproductive health remains disconnected from HIV prevention, care, research, and policy**, which has contributed to failures in reaching and serving women.
- ▶ Appropriate, relevant, and holistic sexual and reproductive health care for women living with and vulnerable to HIV **must acknowledge and address women's lives in all of their complexities** (including race, socioeconomics, gender identity, motherhood/care provision, geography, etc.).
- ▶ To optimize reproductive and sexual health among women living with HIV, HIV treatment success must no longer be measured exclusively by viral suppression. Rather, **metrics of treatment success, including those driving federal strategies, must center the well-being of women living with HIV**, including their sexual health and pleasure.
- ▶ HIV prevention efforts require **an urgent reframing of the language of "risk" around vulnerability to HIV and shifting to a framework that prioritizes resilience and strength** in order to be successful among women.

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

"Sexual and reproductive health, rights, and justice must center Black women. To quote Ayanna Pressley, 'the people closest to the pain should be closest to the power.' Proximity is critical when it comes to research, policy, and community engagement."

DAZON DIXON DIALLO, MPH, DHL,
SisterLove

CONTEXTUALIZING WOMEN'S SEXUAL AND REPRODUCTIVE HEALTH: A CALL TO ACTION

While the sexual and reproductive health needs of women have long been under-addressed in health care generally, within the broad category of women, some have historically been particularly marginalized, including Black women and other women of color, poor women, and women with disabilities.

There is no denying that racism in the US has been pervasive throughout the medical system, including subjecting Black people to medical experiments in the name of "advancing science." One prominent example is Dr. J. Marion Sims, considered by many to be the "father of gynecology," who experimented on enslaved women without their consent and without the use of anesthesia. This case (and countless other examples) illustrates the degree to which much of the health care system in the US is built upon abuse that continues to have implications for the sexual and reproductive health care of Black women and other women of color today.

While learning about and acknowledging history is an important first step, we also must address the *ongoing* unjust power dynamics (including white supremacy, patriarchy, and structural racism) that perpetuate reproductive oppression in sexual and reproductive health research, policy, and care. In order to do so, the WRI asserts that:

- Endeavors to improve sexual and reproductive health care must center women, particularly Black women and other women of color, who historically have been the most marginalized
- Efforts must be undertaken to ensure that women are able to achieve full bodily autonomy and make the best decisions for their health
 - These efforts must acknowledge that many existing policies and legislative priorities disproportionately target and impact Black women and other women of color and women of lower socioeconomic status (e.g., state-level abortion bans)
- Women must be supported in developing their capacity to understand research paradigms, protocols, and frameworks to facilitate their ability to contribute to the HIV research process and to fully benefit from research outcomes

LANGUAGE MATTERS

Language plays a fundamental role in all HIV and sexual and reproductive health programming.

Whether intentional or not, the use of stigmatizing language can reinforce the multiple forms of oppression and discrimination that women living with and vulnerable to HIV may experience based on their gender, race, sexual identity, socioeconomic status, or other factors. Employing appropriate and sensitive language requires many to revisit unacknowledged linguistic assumptions and habits. Examples include "birth control" and "family planning," both of which connote negative efforts to manage fertility in some communities; potential replacements include "contraception" and "fertility decision-making."

Language must be inclusive around gender and sexual identity and reject heteronormative and cis-normative conventions (e.g., assumptions about women's sexual experiences with male partners and specific sexual behaviors that may be irrelevant to their lives).

Because women historically have been underrepresented in the HIV response, The Well Project and the WRI unapologetically focus on women across the gender spectrum, including cis and trans women living with and vulnerable to HIV. When appropriate, we also strive to be inclusive of broader gender identities, including transgender men, non-binary individuals, and others who could benefit from our resources and information. Our language choices throughout this document reflect this approach, primarily referencing "women" but also using more inclusive language as appropriate, such as "lactating people" and "breast/chestfeeding."

GAPS IN RESEARCH AMONG WOMEN LIVING WITH HIV

As HIV is most commonly sexually transmitted, it is surprising how much remains unknown about the intersection between HIV and women's sexual and reproductive health. In order to redress this, this intersection needs to be contextualized within the broad landscape of women's lives.

- **Reproductive health care for women living with HIV:** More than four decades into the HIV epidemic, it remains the case that the information and tools to support reproductive health decision-making among women living with HIV is often not grounded in or based on up-to-date science. This results in multilevel barriers that impede women's ability to make evidence-informed choices and access relevant resources. Because clinical research is rarely conducted among pregnant and lactating people, there remain huge knowledge gaps about how HIV treatment and prevention work among a significant sub-set of women living with and vulnerable to HIV. In addition, there is a particular lack of research on breast/chestfeeding for women living with HIV in high-resource settings.
- **Looking beyond cisgender and heterosexual women:** While there remains a dearth of knowledge around and consideration for the sexual and reproductive health of women living with HIV, even deeper gaps exist for women who do not identify as heterosexual and/or cisgender. For example, while we lack data about transgender women's lived experiences around HIV prevention and care, we also know far too little about their needs, priorities, aspirations, and strengths *beyond* HIV. There is also minimal understanding of the aspirations, goals, needs, successes, and experiences around sexual and reproductive health among lesbian, bisexual, and queer women living with HIV.
- **Sexuality, sex, and pleasure:** Sexual agency, pleasure, justice, and well-being for women living with HIV are rarely studied and as a result, providers lack informed practice guidance on these topics. An opportunity exists to examine the links between HIV and sexual justice and pleasure through a lens that moves beyond vulnerability to a holistic approach that addresses the complexity of women's lives, including their resilience, agency, and pleasure-seeking.
- **Trauma and violence against women:** Unfortunately, women living with HIV continue to experience disproportionate rates of sexual assault, intimate partner violence, and other traumas compared to the general population of women. The failure of sexual and reproductive health services to sufficiently include provisions for trauma-informed spaces and training for providers contributes to their inability to serve the broad range of women's experiences and needs.

PREVENTING HIV AMONG WOMEN AND REFRAMING "RISK"

HIV prevention approaches typically utilize a framework that centers an individual's "risk" as the basis for assessing their likelihood of acquiring HIV. This framework is utilized by providers, individuals, and other decision-makers to determine who would most benefit from prevention approaches. It has failed

Policy Challenges

The policy landscape surrounding and affecting the sexual and reproductive health of women is complex, multilayered, and varies significantly by state. While the current federal administration has demonstrated an increased commitment to addressing and supporting women's sexual and reproductive health, significant activity at the state level has worked to undermine these advances (recent examples include anti-transgender legislation and abortion bans). Federal HIV policy efforts, including the *Ending the HIV Epidemic (EHE)* initiative and the *National HIV/AIDS Strategy (NHAS)*, have insufficiently recognized the importance of sexual and reproductive health, especially among women living with HIV.

in efforts to prevent HIV among women, partially because individual behavior is rarely the driver of a woman's likelihood of acquiring HIV. For example, while US Black women are not more likely than white women to engage in sexual behaviors that increase their risk of acquiring HIV, they are 14 times more likely to acquire HIV than white women. And yet providers rarely consider forces outside women's control (including systemic racism, poverty, geography, partner behavior and vulnerability, etc.) when assessing their "risk," nor do they encourage women to do so. Furthermore, studies have demonstrated that many women see HIV acquisition as a relatively minor concern relative to other pressing issues in their lives, such as economic and housing stability. Thus, they may eschew prevention interventions, such as pre-exposure prophylaxis (PrEP), from which they could benefit.

Replacing the current personal risk framework with a focus on the interconnected forces that shape women's vulnerability to HIV – in effect moving away from "risk perception" to "HIV relevance" – could help both providers and women better assess whether HIV prevention services are appropriate for them. Furthermore, integrating HIV prevention into broader sexual and reproductive health and wellness efforts has the potential to normalize it and thus significantly broaden access and reduce stigma.

Beyond concerns related to the ways risk has been construed, there are significant psychosocial and structural barriers to women's uptake and persistent use of effective HIV prevention options, particularly PrEP. These include:

- **Stigma** related to taking HIV medications
- **Concerns about side effects and interactions**, specifically with regard to contraception and hormones
- Problematic mixed messages around **efficacy**, as a result of persistent underrepresentation of US women in trials of novel HIV prevention modalities
- The **frequency of provider visits**, which, although required for the administration of PrEP, often feel unachievable in the context of women's complex lives
- **Daily adherence**, as event-driven approaches have not been tested in cisgender women

Finally, a lack of integrated trauma-informed, behavioral health, and sexual and reproductive health services

"We talk about women's inaccurate risk perception as an individual-level factor, when what places women at risk is not their individual-level behavior. What would it mean to 'perceive' my risk due to epidemiological factors that are driven by systemic racism? Can empowering women to recognize the ways systemic racism increases their vulnerability to HIV motivate them toward HIV prevention?"

SARIT GOLUB, PHD, MPH, Hunter College

Normalizing HIV Care

HIV has long been siloed from other aspects of health and in particular from women's health. Historically, this served an important purpose: "exceptionalizing" the condition was the only way to drive attention and funding, as mainstream health movements were unwilling to incorporate HIV into their agendas. While this strategy was successful in developing systems that provide care and access to treatment, segregation from other health care is stigmatizing and has been especially damaging for women. Four decades into the epidemic, women's health institutions must better integrate HIV services and gender-affirming care. Normalizing HIV care within the women's health community will facilitate an inclusive and well-informed approach to care provision and prevention.

While the mainstream women's health community has many improvements to make, so too does the HIV community, which continues to under-fund priorities around women and under-address them in research (including clinical trial enrollment).

contributes to ongoing HIV vulnerability for women. Movement toward the provision of holistic care, coupled with supportive services to address broader issues of poverty, housing instability, and food insecurity, is necessary.

RECOMMENDATIONS

Based on the challenges outlined above, the WRI identified a number of recommendations related to education, advocacy, research, and policy that advance sexual and reproductive health for women living with and vulnerable to HIV. These will serve to ensure that all women have the access they need to comprehensive information and services around sexual and reproductive health. The WRI is committed to working collectively with all relevant stakeholders, including WRI members, to advance these efforts.

“We need to stop talking about risk. If you’re doing “this” or “that”—these are judgment terms. We need to treat HIV like a health condition and advocate for women to have the authority and agency about our own bodies so that we can make the best decisions for us.”

GINA BROWN, RSW, Southern AIDS Coalition

Education, Advocacy, and Awareness

- Determine a path to move beyond the language of “risk” when communicating with women living with and vulnerable to HIV, shifting the conversation to a resilience and strength framework; to include the development of education and advocacy efforts that:
 - Increase awareness of the factors that elevate women’s exposure to HIV
 - Encourage the integration of HIV testing and prevention into wellness visits
 - Position sex positively
- Develop and execute a novel media/education campaign providing information about the intersection of HIV and sexual and reproductive health to a broad audience that includes women living with and vulnerable to HIV, providers, policymakers, and researchers
- Undertake efforts to center the needs, perspectives, contributions, and leadership of women living with HIV in all efforts designed to serve them
 - Formalize a process by which women living with HIV can be identified and recommended for seats at decision-making tables
- Develop pathways and mentorship opportunities encouraging women, especially Black women and other women of color, to lead HIV research, policy and care

Research and Policy

- Undertake efforts across the landscape of HIV research and policy to ensure integration of sexual and reproductive health into broader health care efforts for women living with and vulnerable to HIV
 - Engage with federal policymakers to ensure that HIV policy (including the NHAS, EHE, and other efforts) addresses the sexual and reproductive health needs of women living with HIV
 - Pursue efforts to improve inclusion of pregnant and lactating people in HIV clinical trials
 - Develop innovative approaches to integrate sexual and reproductive health into community-based service delivery models
- Recognizing that viral load is only one measurement of health for women living with HIV, develop, validate, and disseminate to researchers and policymakers measurements of resilience/quality of life with specific application for women living with HIV
 - Feature all aspects of life that are relevant (many of which have historically not been valued/included), e.g., sexual pleasure, bodily autonomy, reproductive freedom, mental health, experiences with violence

- Increase research efforts around the genital tract microbiome and its interaction with HIV, the interaction of HIV with related comorbidities prevalent among women, and multi-purpose prevention technologies
- Incorporate training on sexual and reproductive health (including efforts that highlight the intersections with HIV prevention and care) in CME/CE programming that is required to renew medical licenses
- Pursue efforts to collaborate with medical schools to ensure the early integration of sexual and reproductive health into physician training around HIV
- Address enduring gaps in HIV research and policy around breast/chest feeding by developing and implementing a comprehensive research agenda
- Disrupt the policing of women’s bodies by pursuing decriminalization efforts, including the repeal of policies that criminalize women living with HIV who want to breast/chestfeed their children
- Undertake efforts to elevate and fully fund community-based research that prioritizes the involvement of the populations it aims to serve in the design and implementation of studies
 - Explore funding mechanisms that require academic researchers to engage in equitable budgeting with community-based partners

“How can we create policies and structures that ensure HIV efforts address the needs and survival of women instead of focusing narrowly on the virus? Women served by HIV programs are FAR more likely to die from overdose, suicide, lung disease, and an array of preventable illnesses rather than HIV. How can we resource and require HIV programs to be accountable to address the preventable causes of illness and death in the communities they serve?”

EDWARD MACHTINGER, MD,
Women’s HIV Program at the University of California at San Francisco

CONCLUSION

The fall WRI 2021 undertook efforts to better understand the intersection of HIV and women’s sexual and reproductive health, elucidating gaps and challenges in research and policy. To make gains in this arena, it is imperative that HIV policy and care center the sexual and reproductive health needs of women living with HIV, including their rights around sexual agency and pleasure and reproductive decision-making. There exists an opportunity for researchers, providers, and policymakers to reframe HIV prevention around the potential for it to act as a lever for increased sexual agency, autonomy, and liberation. It is also vital that women living with and vulnerable to HIV be better integrated into HIV-focused research and policy development.

All of these efforts and interventions must be situated in an anti-racist, feminist, queer- and trans-affirming framework. These actions must also acknowledge the continuing impact of systemic racism and historic mistreatment of women, especially Black women and other women of color, and women who do not identify as cisgender and/or heterosexual.

To access current and past WRI meeting information and reports, [please click here.](#)

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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.

