



W O M E N ' S
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O N H I V / A I D S

**WOMEN'S RESEARCH
INITIATIVE ON HIV/AIDS**

Calistoga, CA

April 25-28, 2013

2013 MEETING SUMMARY

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EXECUTIVE SUMMARY

The Women's Research Initiative on HIV/AIDS (WRI) is dedicated to elevating, enhancing, and expediting research on women and HIV. The 2013 WRI meeting focused on *creating enduring engagement of women in HIV research and care* and addressed the importance of enduring engagement of women across the research spectrum. Using a modified "treatment cascade" as a framework, the meeting highlighted the reasons for gaps in women's HIV care and treatment and identified successful strategies to address them.

The Treatment Cascade

Great strides have been made in HIV care in the United States, but despite these efforts, only a quarter of people living with HIV have undetectable virus. The treatment cascade illustrates the challenges we continue to face across the HIV spectrum, from identifying people living with HIV through managing their disease:

- 85 percent of women living with HIV have been diagnosed (15 percent of women do not know they are infected)
- 70 percent of HIV-positive women have been linked to care
- 41 percent of HIV-positive women have been retained in care (more than half of all HIV-positive women are not)
- Only 36 percent of HIV-positive women have been prescribed ART
- A mere quarter of all HIV-positive women (26 percent) are virologically suppressed

WRI 2013 used the cascade as a framework to guide a discussion around the challenges and opportunities at each point across the HIV disease spectrum (testing, linkage to care, engagement in care, adherence). These discussions were held around expert presentations that brought together data on women along the cascade that had never before been assembled or presented. The group discussed barriers, shared successes, and brainstormed how to improve outcomes at each step in the cascade. The WRI concurred that the cascade is a very useful framework, though its linear and static nature do not always reflect the complexities and nuances of women's lives.

The WRI's Take on Women and the Cascade

The discussion around the cascade began with two presentations that laid the groundwork for the realities facing women as they approach the spectrum of HIV care. The first was a personal perspective from a long-time HIV-positive woman treatment activist and the second, a review of a Chicago-based research study called "Health, Hardship and Renewal," examined how HIV-positive women's post-diagnosis economic resources helped them manage their health, medically and socially. These interactive discussions helped identify the challenges that women face and highlight potential opportunities to help them successfully navigate their experience living with and treating HIV disease.

Testing

The WRI then proceeded to address the first point on the cascade: HIV testing and diagnosis. Fifteen percent of HIV-positive women are undiagnosed and the question remains, how do we reach women who have not been tested for HIV? The presentation included a review of epidemiological data that highlighted racial and geographic differences in prevalence among women as well as access to testing. It also became clear that while prenatal HIV testing has been effective in reaching many women, it too frequently is the only point of intervention – we must capitalize on additional opportunities.

The group discussed a number of challenges in HIV testing among women:

- State informed consent and pretest counseling laws
- Inadequate provider training/education in HIV testing and counseling
- HIV stigma and discrimination
- Women may:
 - Not access health care until they become pregnant or experience symptoms
 - Not believe they or their partner is at risk
 - Have experienced violence or fear violence
 - Put family responsibilities above self-preservation and health needs
- Lack of research on how best to reach women at risk and with undiagnosed HIV infection
 - Most studies on HIV testing don't focus on women outside the context of pregnancy

This presentation prompted a robust discussion about the role of providers in HIV testing among women and the importance of educating providers about stigma, the need for routine testing, and HIV in general, in order to ensure that all women have access to HIV testing and are able to make an informed choice about being tested. The group strongly advocated that providers be held accountable and measured on their “success” in testing women in an effort to ensure that HIV testing becomes a routine part of women’s health care.

Linkage to care

Seventy percent of HIV-positive women have been linked into care, which means that nearly a third of HIV-positive women have not. A case study from San Francisco General Hospital elucidated a number of successful strategies to link women into care, including the provision of next-day appointments, post-test counseling and education, partner/family notification, links to primary care, and referrals to research for newly diagnosed patients. The team provides initial medical appointments, management of acute medical issues, appointment reminders, follow up on missed visits, and psycho-social stabilization. Team members are trained to address trauma, stigma and social isolation, culture/race/gender, immigration status, and poverty.

The discussion sparked by the presentation addressed the importance of peer educators and/or system navigators to assist individuals newly diagnosed with HIV in getting linked to care. The group also recommended the use of technology as well as provider training and measurability as useful tactics to enhance linkage to care.

Optimizing engagement in care

This point in the cascade is typically referred to as “retained in care,” but the WRI agreed to use a phrase that more actively represents the role that women play in managing this stage of their care: “engagement.” There is a significant drop off at this point in the cascade, with only 41 percent of women engaged in care. The presentation described clinically appropriate approaches and tools to engage women in care and highlighted the impact that engaging women can have on their health outcomes. The group discussed the barriers posed by physician constraints, including time and resource restrictions—e.g., the “15 minute” appointment—and brainstormed about the role that other clinical team members (PAs, RNs, peer educators) can play in keeping women engaged in their care.

The group discussed a number of additional ways to affect women’s engagement in their care, including targeting medical education, improving health literacy, and providing culturally competent care and high-quality case management. The WRI also recommended leveraging knowledge gained from successful models of care, both disease-specific (diabetes and obstetrics), and institution-specific (the VA system, Kaiser Permanente).

Supporting adherence

The final point on the cascade measures the proportion of individuals who are virologically suppressed – this currently represents just over a quarter of all HIV-positive women. To unpack those numbers, the WRI engaged in a discussion around adherence, including why women are adherent to treatment and why they may not be, the factors influencing adherence and models to positively impact adherence. Members of the group shared their experiences and successes and postulated how those learnings could be more broadly applied. The group discussed the need to distinguish between barriers to adherence and reasons for not taking pills, to address attitudes toward health and wellness in general, and to provide women with multiple options of long-acting ART.

The WRI concluded that there is a need for novel evaluative measures around non-adherence, research into effective adherence interventions, better understanding of pill taking over the long term, and improved patient support and patient empowerment tools.

Realities and Implications of the Affordable Care Act and Other Policy Changes

It became evident at the WRI 2013 that the shifting policy landscape is a vital consideration for any recommendations related to women and the HIV treatment cascade moving forward. A policy discussion framed around the Affordable Care Act (ACA), Ryan White, and the National HIV/AIDS Strategy (NHAS) helped to elucidate how to optimally affect steps along the cascade for women.

The discussion focused on the policy opportunities along each point of the cascade, as well as currently unanswered questions and highlighted the potential transformative effect of the ACA in bringing undiagnosed women into care. The WRI concluded that the ACA in particular presents a number of opportunities and challenges:

- The prioritization of community health centers means that many women will receive care from providers who are not HIV specialists – creating opportunities for provider education and the integration of women’s health services and HIV
- Preventive services will be covered for women, including HIV screening, but we need to ensure that women are aware of this and know how to access these services
- Plans will require measurement – it remains to be determined how to best leverage and utilize those measurements in order to optimize outcomes among HIV-positive women
- Many policymakers are uninformed about HIV – providing an opportunity to educate them about what is possible with HIV today

Conclusion

As a body, the WRI is uniquely qualified to review what we know and what remains unknown about women across the treatment cascade. The WRI 2013 assembled never-before presented data, knowledge, and experience on the barriers and opportunities to treatment success for HIV-positive women. The transdisciplinary nature of the group allowed for a holistic examination of the multitude of factors affecting women getting tested for HIV, being linked into care, being engaged in their care, adhering to treatment, and achieving optimal health and well-being outcomes. As a next step, the WRI will develop and submit for publication a manuscript describing the opportunities and challenges for women at points of intervention along the treatment cascade especially in the context of upcoming policy changes.

Further, because personal commitment is such an integral component of the WRI experience, at the end of the meeting, participants articulated how they will use the knowledge gathered at the meeting in their own work over the coming year (please see page 11 for a full list)

Importantly, the WRI 2013 concluded that the treatment cascade is an important tool, allowing for the identification of vital intervention points along the treatment spectrum. However, it is limited in its utility by its linear nature. The realities and complexities of women’s lives are rarely so linear, and while a woman may achieve viral suppression at one point in her treatment experience, at another point in the future she may be unable to adhere to or access treatment, or she may disengage from care. Optimizing care for HIV-positive women requires consideration of these realities, and successful interventions must plan for them. Furthermore, the treatment cascade utilizes virological suppression as the final “success” measure for treatment, but the WRI concluded that success is much more complex than a viral measurement. To ensure that we are truly optimizing women’s care—and their overall health and well-being—the treatment spectrum must consider the context of women’s lives and how to help them succeed in ways that extend beyond the management of HIV disease.

OVERVIEW OF THE WRI

Critical questions about HIV/AIDS in women remain unanswered, despite the fact that women incur more than half of all new HIV infections globally. Until these questions are addressed, we are limited in our ability to design and implement effective prevention and treatment intervention strategies. This limitation will result in further HIV infections and related deaths among women.

In 2003, the Women's Research Initiative on HIV/AIDS (WRI) was established to elevate, enhance, and expedite HIV treatment and prevention research on women and girls and identify gaps in clinical care and research. The annual WRI meeting brings together national HIV/AIDS thought leaders who represent clinical care, research, academia, advocacy, the government, the pharmaceutical industry, and women living with HIV. This expert, trans-disciplinary think tank has undertaken a number of efforts that have directly impacted the progress and direction of HIV research, including:

- Creating fellowships in academic and government institutions
- Influencing NIH's HIV plan for women and girls
- Fostering collaboration between clinical trial networks
- Conducting analysis of ARV drug labels
- Establishing ongoing dialogue with the FDA that influenced a meta-analysis of women-specific data across ARV studies
- Acting as a resource informing the development of notable studies, including the GRACE Study and the Women Living Positively Survey
- Researching models for comprehensive care centers

The WRI includes 30 current members who serve in staggered three-year terms to maintain the momentum and deliverables from this experience-rich think tank. An executive committee provides oversight and guidance for the annual meeting and related activities. For a full list of WRI attendees and invited speakers for 2013, please see page 13. For a full list of WRI members and past participants, please visit www.womensresearchinitiative.org.

WRI 2013 MEETING APPROACH

The 2013 WRI meeting focused on creating enduring engagement of women in HIV research and care. This focus was established by the WRI executive committee, which developed and planned the 2013 meeting.

In an effort to identify key opportunities to enhance women's engagement in HIV and associated care, WRI members and participants addressed a number of imperative questions:

- What are the biological/clinical/behavioral/social factors that affect engagement (and outcomes) of women in research and care?
 - Is the research base sufficient to answer this question?
 - If not, what more do we need to know?
- How do we impact the constraints or address triggers along the treatment cascade?
 - What research needs to be done?
 - What policy changes need to be made?
- What does positive engagement look like?
 - What are specific examples of strategies that help women remain engaged in treatment and care?
- How do we engage women in research related to each of the gaps identified in the cascade (testing and diagnosis, linkage to care, ongoing engagement in treatment and care, adherence)?
- How can we reframe “retention” as “enduring engagement”?
- What can each of us personally do in our work environment to advance the ideas generated at this WRI meeting?

To highlight the most critical and relevant research and intervention efforts, invited experts presented their work on key topics across the treatment cascade (testing, linkage to care, engagement in care, adherence). These presentations provided the basis for provocative discourse and engagement. These talks:

- *Applied the treatment cascade to women's real lives:* Heidi Nass, JD, a long-time treatment activist and HIV peer-educator delved into the real-life experiences of women at risk and infected with HIV and closely examined the multitude of factors that potentially impact a woman's experience with HIV treatment. These factors included institutional sexism, racism, and ageism; stigma; HIV criminalization; mainstream gaps in knowledge around HIV; HIV discrimination; sense of self-esteem and self-worth; and trauma and post-traumatic stress disorder.
- *Grounded the treatment cascade in the day-to-day lives of HIV-positive women:* Celeste Watkins-Hayes, PhD, Northwestern University provided an overview on her Chicago “Health, Hardship and Renewal” study. She examined how HIV-positive women's post-diagnosis economic resources (and the social contexts, relationships, and experiences that undergird their use) help them manage their health, medically and socially. Celeste's presentation provoked discussion around the impact of class and institutional ties, economic stability and mobility, and social isolation among HIV-positive women.

- *Discussed strategies to engage women in HIV testing and diagnosis:* Jen Kates, PhD, Kaiser Family Foundation grounded the group in background about factors that contribute to women's HIV risk (including age, race, geography), rates of testing among women, why women are tested (and why they may not be), barriers to testing and diagnosis, and potential opportunities to improve HIV testing among women, including the National HIV/AIDS Strategy, the new Empowered media campaign, CDC's High Impact Prevention approach, federally funded community health centers and family planning centers, and the Affordable Care Act.
- *Described strategies to link women into care:* Diane Jones, RN, San Francisco General Hospital described the success of their Positive Health Program, which aimed to link individuals not yet in care. The program strategies specifically addressed women with a variety of risk factors such as homelessness, marginal housing, incarceration, drug use, mental illness, and unstable immigration status. Diane described the approach of the program, including the services offered to newly diagnosed patients and the training provided to staff.
- *Addressed strategies to optimize the engagement of women in care and treatment:* Carol Golin, MD, University of North Carolina presented a talk that explored ways to engage HIV-positive women in care, identified clinically appropriate approaches, discussed the impact on outcomes of engaging women living with HIV in their care, and described effective and currently available tools. She concluded her talk with thoughts about how to move forward, including setting priorities, matching care to values, and addressing the changing context of healthcare.
- *Delved into strategies to support adherence for women:* Rivet Amico, PhD, University of Connecticut began her talk by describing reasons for adherence and non-adherence and similarities and differences between HIV-positive men and women. She addressed the roles of trauma, depression, pregnancy intention, and social support in adherence among women. She also described models of adherence and packaged evidence-based interventions, provided recommendations on how to "build your own intervention," and concluded with a vigorous discussion about how to best support adherence among women living with HIV.

Following these presentations, the WRI broke up into smaller groups to brainstorm opportunities and challenges and facilitate knowledge-sharing across disciplines and institutions.

The 2013 meeting also included a panel discussion focused on the Affordable Care Act (ACA) and Ryan White funding. The panel featured experts on the topic, including Grant Colfax, MD, White House Office of National AIDS Policy, Jen Kates, PhD, Kaiser Family Foundation, and Andrea Weddle, MSW, HIVMA. The panel addressed the following questions, provoking an engaged discussion among the larger group:

- What are the opportunities afforded by, and how do we capitalize on the implementation of ACA, Ryan White, and the National HIV/AIDS Strategy (NHAS) to optimally affect the treatment cascade for women?
- What don't we know about how the ACA and Ryan White will look in the immediate future?
- What opportunities does the cascade framework provide to affect the impact of the ACA, Ryan White, NHAS and other impending policy developments at the federal and state level with respect to optimal care, treatment, and health and wellbeing outcomes for women with HIV?
- How does work around women and HIV become better aligned and synergistic with other policy goals and efforts related to women's equality, such as reproductive and sexual health, women's health generally, and violence against women?

Based on the discussions emerging from WRI 2013, the group agreed that the WRI is uniquely positioned to develop and submit a manuscript describing the opportunities and challenges for women at points of intervention along the treatment cascade especially in the context of upcoming policy changes. A working group has been assembled to plan and execute that project.

MEMBER COMMITMENTS FOR 2013

Because personal commitment is such an integral component of WRI participation, at the end of each meeting, participants are asked to articulate how they will use the knowledge gathered at the meeting in their own work over the coming year. Below is a summary of the post-WRI commitments:

Research

- Conduct gendered analyses of ongoing work
- Develop gender-specific behavior risk models
- Generate health renewal data focused on women living with HIV and how they navigate inequality
- Advance research into long-acting ARVs
- Prioritize social and behavioral issues related to women and HIV in research
- Expand thinking around potential collaborations for WIHS study
- Continue to work with IAS and IAVI to encourage research participation by women in ART and cure research
- Rethink how to conduct a poverty reduction program through the lens of the cascade
- Continue the work of a successful stigma intervention study

Policy

- Get involved in state level policy decisions and affect change at the state level
- Lend voices to social justice efforts
- Work at the city-level to ensure that clinics are informing patients about medical exchanges coming with the Affordable Care Act
- Utilize a gender lens in working to achieve the goals of the National HIV/AIDS Strategy
- Synthesize efforts of federal groups working to achieve gender equality

Patient care

- Reinvigorate commitment to patients
- Look at successes screening women and getting them into care and determine how to implement them on a broader scale
- Continue fight to bring homeless populations into care
- Ensure routine testing in our clinics
- Develop grant for decision-making tool that will save time for providers
- Make sure women know about *A Girl Like Me*; provide them with other tools to address their experiences with stigma
- Brainstorm how to integrate social and behavioral efforts into the clinic setting

Advocacy

- Complete 30 years of living with HIV
- Bring more young women under 30 to the table (especially those perinatally exposed)
- Communicate WRI 2013 meeting takeaways broadly to other community members
- Educate the HIV community about the Affordable Care Act
- Present the information shared at WRI 2013 at academic/scientific meetings

Medical Education

- Work with medical colleges to ensure that they address issues around HIV stigma in their curricula
- Think creatively about how to influence medical education on HIV screening

WRI 2013 MEETING PARTICIPANTS (*2013 executive committee members)

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