

## **Women's HIV Research Collaborative (WHRC) Statement of Urgency**

In recognition of the continued disproportionate impact of HIV infection on women living in the United States, the HANC Legacy Project convened a Consultation on HIV Research and Women on June 11<sup>th</sup> and 12<sup>th</sup>, 2010 to discuss issues, concerns and opportunities for future HIV research with women. Consultation participants included twenty-three women with an expansive range of experience working in and living with various aspects of the fight against HIV. The in-depth review of current needs and priorities included all aspects of HIV research, including behavioral and clinical HIV prevention and therapy. It also reflected key concerns such as sensitivity to culture, quality of life, and the changing needs of women across the lifespan. While the focus of the consultation was HIV research with women living in the United States, members of the consultation were acutely aware of HIV research being conducted outside of the United States and the impact international research could potentially have on United States' HIV epidemic.

By the end of the consultation, attendees decided to partner with HANC Legacy to provide guidance and support to the DAIDS research networks as the networks strive to improve HIV research with women in the United States. The consultation attendees developed the following set of priorities related to HIV research with women in the United States:

- 1. Epidemiological data must continue to drive research priorities.** Awareness of the impact that HIV has had on women in the United States has been heightened through the use of epidemiological data from the Centers for Disease Control and Prevention. The CDC guidance mandates prioritizing HIV prevention efforts for those populations who are most burdened by infection. Given the disproportionate rate of HIV infection among Black and Latina women, the consultation attendees placed an emphasis on those populations. The group also, however, recognizes that gender inequalities and community –level structural barriers may place all women at risk for HIV infection. They therefore seek to increase knowledge about the factors that may increase research participation among all women and to assure that HIV research continues to expand to address the needs of women across their lifespan.
- 2. HIV treatment research for women continues to be an urgent priority.** Prior to the availability of HIV treatment women were 10% less likely than men to die from AIDS defined illnesses. In today's HIV treatment era, however, women are 20% more likely than men to die from AIDS<sup>1</sup>. While research has answered key questions and has provided specific strategies and treatments to reduce mother-to-child transmission, research must now seek to gain greater insight into gender disparities in treatment successes.
- 3. There is a critical need for research that seeks to understand the relationship between women's reproductive health, gender and economic inequalities and HIV prevention and treatment.** United States' health policies and programs that are designed to reduce the risk of HIV and other sexually-transmitted infections must be improved to explicitly address overall economic disempowerment among women, as well as disparities in poverty among ethnic populations. Research

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<sup>1</sup> Woldemichael, G., Christiansen, D., Thomas, S., Benbow, N. Demographic Characteristics and survival with AIDS: Health Disparities in Chicago, 1993-2001. American Journal of Public Health, 2009; 99: 118-123.

is needed that will help provide the data necessary to make those improvements. Studies show that economically marginalized women in the United States report a greater likelihood of initiating sexual interactions due to economic considerations than do women in more stable financial situations. Economic inequities linked to gender and/or ethnic differences have been shown to contribute to rising HIV incidence among women in the United States and around the world<sup>2</sup>. Structural interventions that can mitigate those factors must therefore be explored by future HIV prevention research.

Women’s participation in the exchange of sex for money or commodities has also been shown to be linked to economic disparities, inadequate access to substance use treatment and inadequate resources to provide treatment services that address prior abuse histories. Sex work is viewed as a driver of the HIV epidemic in the United States. If we are to curb the growth of HIV among women who are working in the sex trade industry specific research protocols must be designed to respond to the prevention and linkage to healthcare realities of women who are engaged in that profession.

4. **There is a critical need for increased involvement of women in the design and implementation of research.** It is understood that HIV prevention and treatment research must include growing numbers of adolescent and adult women. Low retention rates for women in HIV research studies are believed to be influenced by study designs intended for men, but were later altered to accommodate women. Increased involvement of women at all levels of research design, development and implementation is recommended as one means of building greater gender, economic and cultural competency. Those efforts must include diverse levels of community engagement of women ranging from Community Advisory Board (CAB) and research subject participation to support for mentoring of female behavioral and clinical researchers.
5. **There is a critical need for research involving men who report primarily having sex with women (MSW).** The majority of HIV positive women report being infected through heterosexual intercourse or through intravenous drug use. Few studies have focused on the prevention and linkage to healthcare needs of men who primarily identify as having sex with women. Data from these studies will be critical in designing effective prevention interventions for MSW and their partners.

**HANC Legacy Consultation on HIV Research and Women Attendees:**

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|---------------------------|--|---|
| • Sarah Alexander, BA     | Associate Director for Communications      | HVTN  |
| • Lois Bates, BA          | Trans Health Program Coordinator           | Howard Brown Health Center                                |
| • Allegra Cermak, MA      | Community Advisory Board (CAB) Coordinator | AIDS Clinical Trials Group (ACTG)                         |
| • Anne Davis, BA          | Research Recruiter /CAB Representative     | University of Pittsburgh Microbicide Trials Network (MTN) |
| • Dázon Dixon Diallo, MPH | Executive Director                         | SisterLove Inc.   |

<sup>2</sup> Dunkle, K., Wingwood, G., Camp, C., DeClimente, R., Economically motivated relationships and transactional sex among unmarried African American and White women: Results from a U.S. national telephone survey. Public Health Reports 2010;125 (Supplement 4):90-100.

<ul style="list-style-type: none"> <li>• Stephanie Deyo</li> </ul>	<p>CAB Representative</p>	<p>National HIV Vaccine Research Initiative (NVHREI Partner) International Maternal- Pediatric-Adolescent AIDS Clinical Trials (IMPAACT) ACTG IMPAACT Lincoln University National Institute of Allergy and Infectious Diseases (NIAID)</p>
<ul style="list-style-type: none"> <li>• Morenike Giwa, BA</li> <li>• Robin Hogan, Ed.D</li> <li>• Tamara Lewis-Johnson, MBA, MPH</li> </ul>	<p>Community Advocate/CAB Representative Associate Professor Women's Health Program Manager</p>	
<ul style="list-style-type: none"> <li>• Georgette King, MPA</li> </ul>	<p>Senior Community Engagement Officer</p>	<p>HIV Prevention Trials Network (HPTN)</p>
<ul style="list-style-type: none"> <li>• Stacey Little, PhD</li> </ul>	<p>Project Director</p>	<p>Academy for Education and Development</p>
<ul style="list-style-type: none"> <li>• Stacey Long, JD</li> <li>• Jonathan Lucas, MPH</li> <li>• Sheila Matthew</li> <li>• Joy Mbajah, MA</li> </ul>	<p>Federal Legislative Director Community Program Manager Regional CAB Chair Prevention Manager</p>	<p>The Task Force HPTN &amp; MTN University of Florida (IMPAACT) National Alliance of State &amp; Territorial AIDS Directors (NASTAD)</p>
<ul style="list-style-type: none"> <li>• Kate Miller, MS</li> </ul>	<p>Paralegal</p>	<p>AIDS Legal Council HIV Vaccine Trials Network (HVTN) Project Wish (Chicago)</p>
<ul style="list-style-type: none"> <li>• Lisa Noguchi, MSN</li> </ul>	<p>CAB Representative Co-Chair Network Liaison</p>	<p>Global CAB MTN/Washington, DC Operations</p>
<ul style="list-style-type: none"> <li>• Kimberly Parker PhD, MPH, MA</li> <li>• Borris B. Powell, MHS</li> <li>• Claire Rappoport, MA</li> </ul>	<p>Assistant Professor Community Engagement Officer Community Liaison</p>	<p>Texas Women's University Legacy Project International Network for Strategic Initiatives in Global HIV Trials (INSIGHT)</p>
<ul style="list-style-type: none"> <li>• Jeffrey Schouten, MD, JD</li> </ul>	<p>Director</p>	<p>HIV AIDS Network Collaboration (HANC)</p>
<ul style="list-style-type: none"> <li>• Claire Schuster</li> <li>• Vallerie Wagner, MS</li> <li>• Steven Wakefield</li> <li>• Lisa-Diane White, BS</li> </ul>	<p>Network Community Coordinator Director of Education Director of Community Relations Director of Programs CAB Representative</p>	<p>IMPAACT AIDS Project Los Angeles HVTN SisterLove Inc. HPTN</p>