“Is That for Me?”: Challenging Assumptions of PrEP for Women

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SisterLove Inc
Atlanta GA/Johannesburg SA
SISTERLOVE, INC.

- FOUNDED JULY 1989
- METROPOLITAN ATLANTA, GA
  - 20 COUNTY AREA
- 13 FULL TIME, 4 PART TIME, 3 INTERNS,
  1 LAW/POLICY FELLOW
- SERVE OVER 5,000 WOMEN, MEN AND
  YOUTH PER YEAR
- 2+2 OFFICE LOCATIONS (USA & RSA)

“We are a big organization doing bigger things!”
MISSION

• SISTERLOVE IS ON A MISSION TO ERADICATE THE IMPACT OF HIV AND SEXUAL AND REPRODUCTIVE OPPRESSIONS UPON ALL WOMEN AND THEIR COMMUNITIES IN THE US AND AROUND THE WORLD.
SISTERLOVE PROGRAMS

- HEALTH, EDUCATION AND PREVENTION (HEAP)
- ADVOCACY & POLICY MOBILIZATION
- POSITIVE WOMEN’S LEADERSHIP
- COMMUNITY-BASED PREVENTION RESEARCH
- SISTERLOVE INTERNATIONAL/SOUTH AFRICA (SLISA)
RATES OF FEMALE ADULTS AND ADOLESCENTS LIVING WITH DIAGNOSED HIV INFECTION
YEAR-END 2014—UNITED STATES AND 6 DEPENDENT AREAS

N = 235,813 TOTAL RATE = 171.0

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data are based on address of residence as of December 31, 2014 (i.e., most recent known address).
### HIV IN U.S. BLACK WOMEN

<table>
<thead>
<tr>
<th>Location</th>
<th>Cases/100,000</th>
<th>Black Women cases/100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>170</td>
<td></td>
</tr>
<tr>
<td>New York State</td>
<td>446</td>
<td>1306</td>
</tr>
<tr>
<td>Maryland</td>
<td>434</td>
<td>983</td>
</tr>
<tr>
<td>Washington DC</td>
<td>1298</td>
<td>2413</td>
</tr>
<tr>
<td>Florida</td>
<td>28</td>
<td>1205</td>
</tr>
<tr>
<td>Urban Detroit</td>
<td>456</td>
<td>1063</td>
</tr>
</tbody>
</table>

Brown, Gina – NIH/OAR 2016
Note: Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data for the year 2015 are preliminary and based on 6 months reporting delay.

a Hispanics/Latinos can be of any race.
Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data for the year 2015 are preliminary and based on 6 months reporting delay.

a Hispanics/Latinos can be of any race.
People living in the South are more likely to be diagnosed with HIV over the course of their lifetime than other Americans, with the highest risk in Washington, DC (1 in 13) and the lowest risk in North Dakota (1 in 670)

AFRICAN AMERICANS HAVE THE HIGHEST LIFETIME RISK OF HIV DIAGNOSIS

- African Americans are the most affected ethnic group with a lifetime HIV risk of 1 in 20 for men (compared to 1 in 132 for whites) and 1 in 48 for women (compared to 1 in 880 for whites)\(^1\)
- African American MSM and Hispanic MSM have a 1 in 2 and 1 in 4 lifetime risk of HIV infection, respectively

## CDC: Numbers of Persons at Risk for HIV Remain High, But Percentages Vary by Population

Estimated percentages and numbers of adults with indications for PrEP, by transmission risk group, United States, 2015

<table>
<thead>
<tr>
<th>Transmission risk group</th>
<th>% with PrEP indication*</th>
<th>Estimated number</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men who have sex with men, aged 18-59 yrs†</td>
<td>24.7</td>
<td>492,000</td>
<td>212,000-772,000</td>
</tr>
<tr>
<td>Adults who inject drugs, aged ≥18 yrs§</td>
<td>18.5</td>
<td>115,000</td>
<td>45,000-185,000</td>
</tr>
<tr>
<td>Heterosexually active adults, aged 18-59 yrs¶</td>
<td>0.4</td>
<td>624,000</td>
<td>404,000-846,000</td>
</tr>
<tr>
<td>Men**</td>
<td>0.2</td>
<td>157,000</td>
<td>62,000-252,000</td>
</tr>
<tr>
<td>Women</td>
<td>0.6</td>
<td>468,000</td>
<td>274,000-662,000</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>1,232,000</td>
<td>661,000-1,803,000</td>
</tr>
</tbody>
</table>

CI = confidence interval.
*Percentage of all estimated persons in each transmission risk group and demographic subset with PrEP indications.
†Based on 2007–2012 National Health and Nutrition Examination Survey (NHANES) data, weighted as recommended using current population estimates. Risk factors used to define PrEP indications included two or more male sex partners and at least one of the following: any condomless sex or sexually transmitted infection diagnosis in past 12 months.
§Based on 2013 National Survey on Drug Use and Health. Risk factors used to define PrEP indications included injection of heroin, methamphetamine, stimulants, or cocaine, and injecting with a needle used by someone else before them.
¶Based on 2011–2013 National Survey of Family Growth and 2007–2012 NHANES data, weighted as recommended using current population estimates. Risk factors used to define PrEP indications included two or more opposite sex partners and at least one of the following: sex with an HIV positive partner; or any condomless sex in the last 4 weeks and sex with a male who injects drugs or bisexual male (females only) in last 12 months.
**The relative standard error for males was 30.09%.

WOMEN AND PREP

• AN ESTIMATED 468,000 WOMEN 15-49 YEARS OF AGE HAVE INDICATIONS FOR PREP USE

• AN UNKNOWN NUMBER OF UNINFECTED WOMEN IN HIV DISCORDANT COUPLES BECOME PREGNANT EACH YEAR

• ONLY 18,812 WOMEN HAVE INITIATED PREP, WITH 7,313 OF THOSE NEW STARTS BEING IN 2015

Only 4% of women at risk have started Truvada for PrEP
There is a discrepancy between the HIV epidemic in women and number of women using PrEP.

WHAT IS SEXUAL/REPRODUCTIVE OPPRESSION?

SEXUAL/REPRODUCTIVE OPPRESSION IS THE CONTROL AND EXPLOITATION OF WOMEN, GIRLS, AND INDIVIDUALS THROUGH OUR BODIES, SEXUALITY, LABOR, AND REPRODUCTION. -- ACRJ
CURRENT EXAMPLES OF REPRODUCTIVE OPPRESSION

• POPULATION CONTROL POLICIES, EITHER SUBTLE OR COVERT
• LIMITING ACCESS TO REPRODUCTIVE HEALTH INFORMATION AND SCIENTIFICALLY ACCURATE SEX EDUCATION INFORMATION
• RESTRICTING AND CRIMINALIZING IMMIGRANT FAMILIES
• INCARCERATING SUBSTANCE-ADDICTED MOTHERS FOR “FETAL ABUSE”
• FORCING OR COERCING USE OF DANGEROUS CONTRACEPTIVES ON VULNERABLE WOMEN
• FAMILY CAPS IN WELFARE POLICIES
• FORCED OR DENIED MARRIAGE INITIATIVES
• FEDERAL POLICIES AGAINST ABORTION INCLUDING FAMILY PLANNING RESTRICTIONS
SEXUAL & REPRODUCTIVE JUSTICE (SRJ)

• SEXUAL & REPRODUCTIVE JUSTICE EXISTS WHEN ALL PEOPLE HAVE THE SOCIAL, POLITICAL AND ECONOMIC POWER AND RESOURCES TO MAKE HEALTHY DECISIONS ABOUT OUR GENDER, BODIES, SEXUALITY, AND FAMILIES FOR OUR SELVES AND OUR COMMUNITIES
LOCATING HIV IN HUMAN RIGHTS & SRJ

- Human Rights
- Sexual & Reproductive Justice
- HIV Research
- Prevention
- Care
- Treatment
- Advocacy
SEXUAL & REPRODUCTIVE JUSTICE FRAMEWORK

- Health Services Delivery
- Sexual & Reproductive Oppression
- Sexual & Reproductive Rights/ Legal Advocacy
- Organizing & Movement Building
SEXUAL & REPRODUCTIVE JUSTICE - CHALLENGES

- LACK OF INFORMATION, SCREENING, AND LINKAGE TO CARE
- DISCRIMINATION, BIAS, AND STIGMA IN HEALTH CARE SETTINGS
- SEX-NEGATIVITY – NEGATIVE BIAS TOWARD WOMEN'S SEXUALITY AND SEXUAL EXPRESSION
- INFORMED CONSENT IS NOT UPHELD
- FAMILY PLANNING OPTIONS ARE LIMITED OR WITHHELD
- INSUFFICIENT PROVIDER EXPERTISE AND INADEQUATE WOMEN-CENTERED RESEARCH
- AGENCY AND SELF-DETERMINATION ARE NOT RESPECTED
REPRODUCTIVE JUSTICE RESOURCES

- FROM ABORTION RIGHTS TO SOCIAL JUSTICE – HAMPSHIRE CIVIL LIBERTIES & PUBLIC POLICY [HTTP://CLPP.HAMPSHIRE.EDU/CONFERENCE/2015-CONFERENCE]
- ECHOING IDA [HTTP://STRONGFAMILIESTOMOVEMENT.ORG/ECHOING-IDA]
- IN OUR OWN VOICE [HTTP://WWW.BLACKRJ.ORG/]
- TRUST BLACK WOMEN [HTTP://WWW.TRUSTBLACKWOMEN.ORG]
- REPRODUCTIVE JUSTICE: A GLOBAL CONCERN
  - ARTICLE - [HTTP://SCHOLARSHIP.LAW.WM.EDU/CGI/VIEWCONTENT.CGI?ARTICLE=1367&CONTEXT=WMJOWL]
  - BOOK - [HTTP://WWW.AMAZON.COM/REPRODUCTIVE-JUSTICE-GLOBAL-CONCERN-PsyCHOLOGY/DP/0313393397]
PREP RESOURCES FOR PROVIDERS

REMS Materials
On this page, you’ll find downloadable resources for you and uninfected individuals. You will need Adobe Acrobat installed on your computer to view these resources. If you do not have it and would like to download it, please click here.

DEAR HEALTHCARE PROVIDER LETTER
Information for healthcare providers on the new TRUVADA indication for pre-exposure prophylaxis (PrEP)
Download ➔

TRAINING GUIDE FOR HEALTHCARE PROVIDERS
A comprehensive overview of TRUVADA for a PrEP indication
Download ➔

IMPORTANT SAFETY INFORMATION FOR HEALTHCARE PROVIDERS
Important safety information about TRUVADA for a PrEP indication
Download ➔

http://www.truvadapreprems.com

http://www.cdc.gov/hiv/risk/prep/

Towards an integrated primary and secondary HIV prevention continuum for the United States: a cyclical process model
STARSHIPPP

- STARSHIPPP – STRATEGIES FOR THOSE AT RISK SEEKING HIGH IMPACT PREVENTION & PREP
  - SCREEN, IDENTIFY & LINK TO CARE
  - HEALTHY LOVE PARTY PLUS
  - #PREPFLIX & CHILL
  - I DESIRE: CAMPAIGN TO HEAR WOMEN’S VOICES
  - POWAR WORKSHOPS (PREVENTION OPTIONS FOR WOMEN AT RISK)
  - US WOMEN & PREP WORKING GROUP

- ISTARSHIPPP – 5 HIGHLY IMPACTED DISTRICTS IN SOUTH AFRICA
THE US WOMEN & PREP WORKING GROUP

• THE US WOMEN AND PREP WORKING GROUP IS A NATIONWIDE NETWORK OF ADVOCATES, CLINICIANS, HEALTHWORKERS, RESEARCHERS, ACADEMICS, GOVERNMENT AND PHARMACEUTICAL INDUSTRY REPRESENTATIVES.

• WE WORK TO:

  • ENSURE THAT COMMUNITIES, HEALTH CARE PROVIDERS AND INSTITUTIONS LOCALLY AND NATIONALLY ARE INFORMED ABOUT PREP

  • MOBILIZE ADVOCACY WITH WOMEN’S VOICES IN ORDER TO SUCCESSFULLY INFLUENCE PUBLIC POLICY AND FUNDING DECISIONS WITH REGARD TO PREP AND OTHER BIOMEDICAL PREVENTION OPTIONS FOR WOMEN
THE ADVOCACY

- Sexual & Reproductive Health & Rights
- Service Delivery & Advocacy
- Women’s Power to Prevent HIV in Women’s Hands
- Global Advocacy for Appropriate Research & Development
- Cooperation and Collaboration among domestic and international partners
THE WORKING GROUP

• LEADERSHIP TEAM (5) AND GROUP MEMBERS (100+)

• FACE-TO-FACE & TELECONFERENCE MEETINGS

• WEBINARS, RESEARCH, & COMMUNICATIONS

• TRANSGENDER PERSONS AFFINITY GROUP
THE PURPOSE OF THE WORKING GROUP

- NATIONAL COMMUNITY REPRESENTING WOMEN’S VOICES
- INQUIRY, ADVOCACY & ACCOUNTABILITY
- ENSURE WOMEN’S SAFETY, EFFICACY AND ACCESSIBILITY IN PREP RESEARCH & ROLLOUT
- EDUCATE AND ENGAGE COMMUNITY IN PREP DISCOURSE AND INFORMATION DISSEMINATION
- MOBILIZE A DIVERSITY OF WOMEN’S HIV AND HEALTH ADVOCATES, RESEARCHERS AND POLICY MAKERS IN PREP AND OTHER BMPO FOR WOMEN
US WOMEN & PREP WORKING GROUP SURVEY – MARCH 2017

- PREP AVAILABILITY AND ACCESS FOR WOMEN
- FUNDING FOR PREP SERVICES
- FACTORS INFLUENCING SLOW UPTAKE OF PREP FOR WOMEN
- PRIORITIES OF THE US WOMEN & PREP WORKING GROUP
ADVANCING THE AVAILABILITY & ACCESSIBILITY FOR WOMEN IN THE US

- Expand Dept of Health conversation to include women in Prep services
- Prep education during HIV testing/counseling
- SHIPP study
- Grantmaking to support Prep integration for women
- Prescribe and provide Prep
- Training held at multiple clinical sites
- Making Prep info available online and in adaptable resources
- Continue to research Prep and women through trials
- Developing and distributing positions on policy and administration
WHAT ARE THE IMPENDING FACTORS FOR SLOW UPTAKE AMONG WOMEN.

• CHALLENGE FOR PROVIDERS AND WOMEN WITH REGARD TO ASSESSING RISK

• MEDIA COVERAGE AND SOCIAL MARKETING OF PREP FOCUS PRIMARILY ON GAY MENT

• UNCLEAR HOW MUCH WOMEN SEE THEMSELVES IN COVERAGE OF IMPLEMENTATION AND RESEARCH

• LACK OF UNDERSTANDING THAT PREP NEEDS TO BE IN PLACE WHERE WOMEN AND GIRLS GO FOR CARE – FP & STI CLINICS

• LACK OF KNOWLEDGE AMONG WOMEN

• WHO PAYS AND FOR HOW LONG

• MYTHS AND MISINFORMATION IN CIRCULATION
NAH, I DON’T THINK SO...

• WANTED ADDITION INFORMATION ABOUT PREP TO READ OVER
• WANTED TO KNOW WHY THEY HAD NOT HEARD OF IT UNTIL APPOINTMENT FOR HIV TESTING, SO THEY CONCLUDED THE MEDICATION WAS TOO NEW ON THE MARKET
• DECIDED THEY WOULD USE CONDOMS MORE OFTEN
• DID NOT WANT TO TAKE A MEDICATION DAILY FOR PREVENTION

• DID NOT HAVE HEALTH INSURANCE AND DID NOT WANT TO PAY MONEY FOR HIV PREVENTION
• WANTED TO TALK TO FAMILY AND FRIENDS
• DID NOT FEEL THEY COULD BE ADHERENT TO PREP BASED ON THEIR PILL TAKING HISTORY
• DID NOT FEEL THEIR SEXUAL BEHAVIOR WAS “RISKY” OR SUBSTANTIAL ENOUGH FOR DAILY MEDICATION.
THE DEBATES

- ADHERENCE: OLDER VS YOUNGER WOMEN
- DELIVERY SYSTEM: PILL A DAY VS TOPICAL VS INJECTABLE VS, VS, VS
- TIME TO PROTECTION: 7 VS 10 DAYS
- HEALTHCARE APPROACHES: WOMEN ONLY VS PARTNERS
- PREGNANCY: PRECONCEPTION PLANNING VS CONTRACEPTION ONLY
- SERO-DISCORDANCY – APPROACH TO PREGNANCY OUTCOMES (SPERM WASH/IN VITRO OR PREP/VIRAL SUPPRESSION
- RESEARCH IS CONCLUSIVE VS NO, IT IS NOT!
PREP ADVOCACY PARTNERSHIPS

- AVAC PXROAR AND www.prepwatch.org
- BLACK TREATMENT ADVOCATES NETWORK
- WOMEN ‘S HIV RESEARCH COLLABORATIVE
- WOMEN’S RESEARCH INITIATIVE (THE WELL PROJECT)
- HPTN WOMEN-AT-RISK SUBCOMMITTEE
- IRMA/MY PREP EXPERIENCE (PREP STORIES)
- PROJECT INFORM
- FB - PREP FACTS: RETHINKING HIV PREVENTION & SEX
- CONSORTIUM OF PREP PROJECTS FUNDED BY GILEAD SCIENCES
- HIVE – www.hiveonline.org
- FB - PREP FACTS: WOMEN’S SEXUALITY & HIV PREVENTION
PREVENTION IN WOMEN’S HANDS
PREP IN WOMEN’S VOICES
MORE PREP RESOURCES

- **PREP SUPPORT HOTLINE FOR CLINICIANS:**
  1-855-448-7737 (1-855-HIV-PREP)

- **TO CONTACT THE US WOMEN AND PREP WORKING GROUP:**
  USWOMENPREPWORKINGGROUP@GMAIL.COM

- **FOR A GREAT BOOKLET ON WOMEN AND PREP, GO TO**
  HTTP://WWW.PROJECTINFORM.ORG/PDF/PREP_WOMEN.PDF

- **OTHER WEBSITES:**
  - HTTP://WWW.SISTERLOVE.ORG/US-WOMEN-PREP-WORKING-GROUP/
  - WWW.PREPWATCH.ORG
  - HTTP://WWW.HIVEONLINE.ORG/FOR-YOU/
  - MYPREPEXPERIENCE.BLOGSPOT.COM
  - WWW.PREPFAC'TS.ORG
  - FB – PREP FACTS: WOMEN’S SEXUALITY & HIV PREVENTION
Save the Date
July 19 – 21, 2018
Amsterdam

A Summit at the Intersections of HIV, Sexual & Reproductive Health & Justice Among Pan-African and Diasporan Women of African Descent
THANK YOU!
CONTACT ME AND FOLLOW US!

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