UNSPOKEN:
Sexuality, Romance, and Reproductive Freedom for Women Living with HIV in the United States

*Findings from a National Survey*

A report by Positive Women’s Network – United States of America (PWN-USA)

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Dedication

Dedicated to the nearly 200 women living with HIV in the United States who generously and courageously shared their insights, experiences, wisdom, and perspectives in this research process, answering a series of deeply personal questions about their sexual, romantic and reproductive lives, dreams, and desires.

Also dedicated to the millions of women living with HIV globally who have fought for the right to live as whole, dignified human beings for more than three decades – and sometimes, died for it.

Special dedication to Cicely Bolden, a young woman in Dallas, Texas, who was brutally stabbed to death in September 2012. Her murderer, Larry Dunn, attempted to use Cicely’s HIV status as a defense for his actions. Our hearts and prayers remain with Cicely’s loved ones. Positive Women’s Network – USA is committed to creating a safer and more just world where women living with HIV are free from stigma, discrimination, and violence.
Thank you

This report would not have been possible without our stellar advisory team and contributors:

Michelle Anderson
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Christina Rodriguez
Marissa Smith
Evany Turk
Juanita Williams

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Findings from a National Survey of Women Living with HIV in the United States

A. Introduction

To better understand the current experiences of women living with HIV in the United States with respect to sexual and reproductive health, in their own words, Positive Women's Network – United States of America (PWN-USA) conducted a survey of US women living with HIV in August and September 2013. This survey was conducted among 179 women living with HIV in the United States. The purpose of the survey was to collect quantitative and qualitative data on sexual and reproductive health and rights as they are currently experienced by women living with HIV in the US, in order to recommend program planning, policy change, and further research to uphold the full rights of women living with HIV as sexual and reproductive beings. The survey explored the following key areas of interest: 1) Engagement in HIV care, including viral load; 2) women's self-perceptions of their bodies and sexuality; 3) sexual activity; 4) women's navigation of disclosure to romantic and sexual partners, 5) to what extent women understand and are being counseled on viral suppression as a prevention strategy, 6) efforts to prevent HIV transmission and 7) access to and utilization of SRH services. The survey was conducted by via a questionnaire, distributed online and on paper.

B. Background: Survey Planning Team and Process

1. SRHR Project Team. The Project Team described earlier in this paper in “Project Design” provided input into the development of the survey instrument as well as dissemination. The Project Team was comprised of a project coordinator and three subject matter experts: a literature review consultant, a technical advisor on policy, and a lead on survey design and implementation. All members of the Project Team were women openly living with HIV.

2. SRHR Advisory Group. In addition to the Project Team, PWN-USA convened a diverse six member advisory group composed of women living with HIV from across the nation to provide essential input and feedback to the SRHR Project Team during development of the survey tool and distribution process. Each member represented a region of the US. The advisory group served as pilot survey respondents, focus group members, recruiters and group facilitators. PWN-USA sought a diverse group of survey respondents and utilized the reach of Advisory Group members to ensure this diversity. The combined efforts of these two groups resulted in a consensus survey instrument and process which was sensitive to participant concerns and ensured participant confidentiality.

C. Participants

The total number of individuals, including women living with HIV, who attempted to complete the survey was 200. A total of 179 women living with HIV living in the United States (respondents) completed the 70 question survey. Of the total, 133 (74%) respondents completed the survey online and 46 respondents (26%) completed the survey in paper form. Respondents were offered a $20 incentive as appreciation for their time spent completing the survey.
D. Data Collected

The survey collected two forms of data: qualitative data, including participant comments and quantitative data, including metrics.

Both the online and paper survey collected the following data: 1) demographics, 2) HIV serostatus and care, 3) relationships, 4) sexual practices including disclosure of HIV serostatus, 5) sexual health and reproductive practices, 6) SRH services and access and 7) confidentiality. The table below provides a breakdown of the total number of questions asked for each section.

<table>
<thead>
<tr>
<th>Name and Number of Survey Sections</th>
<th>Total Number of Questions per Survey Section</th>
<th>Questions per Survey Section by Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Demographics</td>
<td>Total questions: 15</td>
<td>Questions #2 thru #16</td>
</tr>
<tr>
<td>2. HIV Serostatus and Care</td>
<td>Total questions: 8</td>
<td>Questions #17 thru #24</td>
</tr>
<tr>
<td>3. Relationships</td>
<td>Total questions: 9</td>
<td>Questions #25 thru #33</td>
</tr>
<tr>
<td>4. Sexual Practices</td>
<td>Total questions: 14</td>
<td>Questions #34 thru #48</td>
</tr>
<tr>
<td>5. Sexual Health Practices</td>
<td>Total questions: 10</td>
<td>Questions #49 thru #58</td>
</tr>
<tr>
<td>6. SRH Services &amp; Access</td>
<td>Total questions: 8</td>
<td>Questions #59 thru #66</td>
</tr>
<tr>
<td>7. Privacy, Confidentiality &amp; Disclosure</td>
<td>Total questions: 3</td>
<td>Questions #67 thru #69</td>
</tr>
</tbody>
</table>

E. Methods:

The 70-question survey instrument was accessible online and in paper form. For the online survey, outreach was conducted via email and social media, including listservs and social media of PWN-USA members and allies.

Participants were automatically screened out of the survey if ANY of the following conditions were met: i) did not complete consent form ii) identified gender as “male”, “not sure”, or “prefer not to respond” iii) did not currently reside in US iv) answered “What is your HIV status?” with “HIV-negative”, “not sure” or “prefer not to respond.”

For the paper survey, advisory group members were instructed to recruit women living with HIV 18 years or older from their geographic areas, inclusive of women who were postmenopausal. Advisory group members also supported participation of women living with HIV by conducting in-person and phone-based groups for women living with HIV who either did not have access or limited access to computer and online technology.
F. Survey Results:

Following are the survey results for the following areas: 1) demographics, 2) HIV serostatus and care, 3) relationships, 4) sexual practices including disclosure of HIV serostatus, 5) sexual health and reproductive practices, 6) SRH services and access and 7) confidentiality.

I. Demographics

- **Age:** Respondents ranged in age from 22 years old to 65 years old. Overall, the respondent sample was mature, with the paper survey respondents skewing slightly younger.
  - 41% of electronic survey respondents and 43% of paper survey respondents were of reproductive age (defined as 44 years or younger). The remainder were postmenopausal.

- **Gender:** 98% of respondents identified as female, 2% as transgender. 1 participant identified as intersex.

- **Sexual Orientation:** Heterosexual 80%, bisexual 9%, lesbian 5%, asexual 4%, queer 1%, pansexual 1%.

- **Race/Ethnicity (self report):**
  - 54% African American or Black
  - 30% Caucasian/White
  - 8% Hispanic or Latina
  - 4% African
  - 3.6% multi-racial or bi-racial
  - 1% Asian, Pacific Islander, Native American, and other

There was a marked disparity in self-reported race/ethnicity among respondents to the online survey and respondents to the paper survey. While 31.7% of online survey respondents identified as Caucasian or white, only 2% of paper survey respondents self-reported as Caucasian/white. In addition, 21% of paper survey respondents self-reported as Hispanic or Latina, while only 3% of online survey respondents self-reported as Hispanic/Latina. This may be indicative of disparities in technology access which impacted the electronic survey as well as the power and limitations of network-based outreach which impacted the paper survey results. Respondent rate for African American/Black for the online and paper surveys was similar, at 53.8% for online and 54.1% for paper surveys.

- **US Residence Status:**
  - 89% US citizens by birth (93.8% of respondents to online survey and 71% of paper survey respondents)
  - 4% documented immigrants
  - 1% naturalized US citizens
  - Paper survey respondents were more likely to report that they were living in the US with immigrant status
• **Education:**
  o Respondents were asked to report their highest level of formal education completed.
  o Online survey respondents tended to be more educated.
  o 39% of online respondents had a 2 or 4 year college degree, while 11% of paper survey respondents had a 2 or 4 year college degree.
  o 15% of online respondents had completed a graduate degree program, compared with 4% of paper survey respondents.
  o 12% of respondents overall had not completed high school: 6% of online survey respondents did not complete high school and nearly 30% of paper survey respondents had not completed high school.
  o 11% of paper survey respondents had completed a vocational, technical, or professional schooling program after high school, compared with 16.5% of online survey respondents.

• **Geography**
  o 25 states were represented
  o Regionally:
    - 39% of responses overall came from the Southern US (SC, TX, FL, GA, LA, TN, WV, VA, NC)
    - 21% came from the Midwest (MI, IL, OH, ID, IA)
    - 23% came from the Northeast and Mid-Atlantic region (DC, NY, NJ, PA, MD, CT, DE)
    - 14% came from the West Coast region (CA, WA)
    - 2% came from the Southwest (CO, AZ)
  o Within these, the majority of paper survey responses came from a handful of metropolitan areas: Atlanta, GA, Chicago, IL, Dallas, TX, San Diego, CA, and the New York City metro area, where recruiters were based.
  o Areas of residence:
    - 47% urban
    - 19% suburban
    - 17% rural
  o Paper survey respondents were slightly more likely to characterize their area of residence as urban, less likely to live in suburban or rural areas.

**Economics, Housing, Health Insurance and Employment Indicators**

• **Housing:**
  o 30% of respondents lived in subsidized housing
  o 27% renting at market price (unsubsidized)
  o 26% were homeowners
  o 10% shared housing
  o 2% homeless

• **Work Status:**
  Participants were asked whether they worked or volunteered, part time or full time.
  o Overall, we found that respondents were very active.
  o 62% of online respondents were working or volunteering part or full time and 54% of paper survey respondents were working or volunteering part time or full time.
  o Online survey respondents were more likely to be paid for their time and paper survey respondents were more likely to volunteer.
Nearly a third of paper respondents reported volunteering their time (30.4%), while 7.5% of online survey respondents reported volunteering their time.

The online sample was more likely to be employed. 37% were employed full time and 19% were employed part-time, compared with 13% and 11% respectively of the paper sample.

23% of respondents overall reported they were unable to work. The survey did not ask respondents to specify reasons for being unable to work.

- **Income:**
  It is clear that most survey respondents are living at the economic margins.
  - Nearly half of all respondents (47%) reported an annual income of under $20,000.
  - At least 29% of all respondents were earning $10,000 or less, well below the federal poverty level for a 1-person household.
  - 30% of paper survey respondents and 11% of online survey respondents reported an income of under $5000 per year.
  - Only one paper survey respondent reported an annual income over $50,000, compared with 15% of online survey respondents.
  - Just over a fifth of online survey respondents (21.5%) had an income of $40,000 or more.
  - Women with an annual income of $10,000 and less were more likely to live in subsidized housing.
  - Most women with an annual income of $50,000 or more owned their own home or apartment.
  - There was no discernible relationship between income and relationship status.

- **Health Insurance Coverage:**
  - 43% were on Medicaid. Over a third of women on Medicaid were also on Medicare.
  - 19% were on AIDS Drugs Assistance Program (ADAP)
  - 29% of online respondents had access to a private insurance plan provided by an employer, compared with 8% of paper survey respondents.
  - Only 1% of respondents had private insurance plans through other sources (school or coverage provided by a parent or guardian).
  - 4% of online survey respondents were paying for their own private insurance coverage.
  - 8% of paper survey respondents reported they did not have any health insurance coverage. All were in the South.
  - In contrast, only 5% of online survey respondents reported they did not have any health insurance coverage. The majority were in the South.
  - Immigrant women were likely to be on ADAP.

- **Access to Technology:**
  Access to technology differed greatly between online and paper survey respondents.
  - For online respondents, over 62.6% reported having a smart phone, 59% had a laptop, and 54.7% had internet service.
  - For paper survey respondents, 37% had access to a smart phone; 28% had a laptop and 26% had internet service.
• Childcare and Family Responsibilities:
  52% of paper survey respondents and 29% of online survey respondents reported having at least one child under the age of 18 in their homes. Many women reported having multiple children in their homes, some of whom were grandchildren.

II. HIV Diagnosis and Engagement in Care

• Diagnosis Timeframe:
  - 14% of respondents had been living with HIV for over 20 years.
  - Over half (51.1%) were diagnosed prior to 2001.
  - 13% had been diagnosed since 2010.

• Notification of Diagnosis:
  - All respondents were most likely to have learned of their diagnosis from a doctor (ob/gyn, family doctor, emergency room doctor) – 67% of paper survey respondents and 52% of online survey respondents.
  - About a fifth (22%) of online respondents learned of their diagnosis from the health department, compared with only 13% of paper survey respondents.
  - 11% of online survey respondents learned of their diagnosis from an AIDS service organization or community-based organization.
  - 6.5% of paper survey respondents were initially informed of their diagnosis by a family member, compared with less than 1% of online survey respondents.

![How did you find out about your HIV-positive status? (select one response)](chart)

Receiving HIV Care:

• 96% of respondents were currently in care
  - Receiving care at HIV-specific clinic: 42% of online respondents and 56.5% of paper respondents.
  - Receiving care from private physician: 28% of online respondents and 13% of paper respondents.
  - Receiving care from hospital-based clinic: 24% of online respondents and 26% of paper respondents.
• Receiving care at community health center: 9% of online respondents and 2% of paper respondents.

![Where do you receive your care? (select one response)](image)

![At the time of your last labs, what was your CD4 (T-cell) count? (select one response)](image)

- **Currently taking HIV medications:** 91% on HAART.
- **Suppressed Viral Load (SVL):** 80% had a SVL at the time of their last labs.
- **CD4 (T-cell) count:** 66% had CD4 counts above 500.
III. Relationships

Relationship Status:

38% of respondents identified themselves as being single, 31% stated they were currently married or had a significant other, and 28% described themselves as widowed, divorced, or separated.

- **In Relationship**: 58% currently describe themselves as being in a relationship and 40% described themselves as not being in a relationship.
- **Not in Relationship**: Of those not in relationships - 25% stated they could not find a suitable partner, 21% were no longer with partner and 20% preferred not to be in relationship.
- **Length of Relationship**: 59% had been in relationship with their current partner 3 years or more and, of this group, 38% were in relationship with the same person at the time of diagnosis with HIV.
- **Partner’s HIV Status**: 64% of respondent’s partners are HIV-negative.
- **Proximity to Partner**: 78% of respondents live with or in the same city/town as their partners.
- **Nature of Relationship**: 68% described their relationships as monogamous.
- **Relationship Satisfaction**: The majority of women who stated they were very satisfied with their relationship identified friendship as a fulfilling factor in their relationship (52%), while 45% who stated they were dissatisfied reported money as an issue – identifying as either financially responsible or financially dependent within the relationships.

IV. Sexual Practices

- **Change in Sexual Practices or Behaviors**: 75% reported a change in sexual practices or behaviors since being diagnosed as HIV-positive.
- **Quantity of Sex**: Nearly two thirds, or 63%, reported a decrease in the frequency of sex since being diagnosed HIV-positive.

<table>
<thead>
<tr>
<th>Has the QUANTITY of sex changed since your HIV-positive diagnosis? (select one response)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- I have more sex now than I used to</td>
</tr>
<tr>
<td>- I have less sex now than I used to</td>
</tr>
<tr>
<td>- The amount of sex I have is about the same</td>
</tr>
<tr>
<td>- Unable to compare - living with HIV since birth or childhood</td>
</tr>
<tr>
<td>- Not sure</td>
</tr>
<tr>
<td>- Prefer not to respond</td>
</tr>
<tr>
<td>- Other</td>
</tr>
</tbody>
</table>
• **Quality of Sex:** 32% reported no change in quality of sex, 26% reported that quality of sex is worse and 18% reported that quality of sex is better.

![How has the QUALITY of sex changed since your HIV-positive diagnosis?](image)

• **Partner Selectivity:** 68% reported being more selective about their sexual partner(s) and 33% reported being more selective about their romantic partner(s).

![Since my HIV-positive diagnosis, I am .... (select all that apply)](image)

• **Current Sexual Activity:** 42% reported having sex on a regular/consistent basis with one partner, another 38% reported having sex with self, 14% are not having sex because they cannot find a partner, and 11% are not having sex because they do not want to disclose HIV status. 10.4% reported they hook up regularly with someone they know and 4% reported regular hookups with more than one partner.
• **Talking with My Partner:** Over 80% respondents talk to their partner(s) about HIV transmission risk, sexually transmitted infections (STIs) and use of barrier methods.

![Bar Graph showing talk to partner](image)

- HIV transmission risk
- Sexually Transmitted Infections (STIs)
- Contraception/birth control
- Use of barrier methods, i.e. condoms, dental dams and/or finger cots

- **Knowledgeable about Barrier Methods:** 97% are knowledgeable about latex male condoms, 93% are knowledgeable about non latex male condoms, 84% are knowledgeable about female condoms, 79% are knowledgeable about dental dams and 64% are knowledgeable about finger cots.

- **Use of Barriers:** 46% reported they always use barriers. 18% reported they never use barriers, over half of those stated they had an agreement with their partners not to use barriers. 9% stated they sometimes used barriers, or “it depends on the partner”. 26% stated that barriers were not relevant because they were not currently sexually active.

![Pie Chart showing use of barriers](image)

- We always use barriers because it is important to me
- We always use barriers because it is important to both of us
- We always use barriers because it is important to my partner
- We sometimes use barriers
- We never use barriers because I don’t like them
- We never barriers because my partner does not like them

• **Access to Male and Female Condoms:** Respondents get their male and females condoms from ASO/CBO (72%), health department (63%), community events (46%) and stores (43%).
• **Pre-Sex Disclosure of HIV Status:** 60% reported they always disclose their HIV status before having sex, 10% stated they disclose sometimes and 2% reported that they never disclose.

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Do you disclose your HIV status before having sex? (select one response)

- Yes, always
- No, never
- Sometimes
- Not applicable because I have only one partner who already knows
- Not sure
- Prefer not to respond

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• **HIV Status of Sexual Partner(s):** For 42% of respondents, HIV status of their sexual partner was unimportant. However, 18% reported a willingness to be sexually involved only with HIV-positive partner(s). Another 14% reported they would only consider being sexually involved with HIV-negative partner(s).

• **Importance of HIV Status for Romantic Partner(s):** For 52% of respondents, HIV status was not a factor in romantic partnerships. However, 15% were only willing to consider HIV-positive romantic partner(s) and another 12% were only willing to consider HIV-negative romantic partner(s).

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Is HIV status important to you in considering romantic/intimate (long-term or life) relationships? (select one response)

- Yes, I will only consider a romantic/intimate relationship with HIV-negative partners
- Yes, I will only consider a romantic/intimate relationship with HIV-positive partners
- No, HIV status is not a factor for me when considering a romantic/intimate relationship
- Not sure
- Prefer not to respond
- Other
V. Body Image

Approximately 75% reported a change in sexual practices or behaviors and 63% reported a decrease in frequency of sex since being diagnosed as HIV-positive. This change may be a result of feelings around body image and perceptions about being a sexually desirable woman. When asked how HIV has affected their body image, a quarter (25%) of respondents reported that they were currently accepting of their bodies. However, of the group who are currently accepting, respondents were split in how they had felt about body image immediately following diagnosis.

Half (12.5%) of respondent comments reported no change or were celebratory about how they felt about their body image (“I am very happy with my body. HIV has not affected the way I feel about my body”) and half (12.5%) of respondents acknowledged that, although they initially experienced a negative view of their body, they grew to appreciate their body once again as they learned to accept their HIV diagnosis (“At first I felt dirty and ashamed. However, over the years I have come to terms with my diagnosis and accept my situation, which allows me to feel better about my body”).

Another 12.5% of total respondents indicated experiencing an awareness of their body and how it might be changing as a result of HIV but this group was not specific as to how they felt about these changes (“I'm more health conscious now and I'm more aware of my physical appearance”). Conversely, 62.5% of respondents reported experiencing moderate to severely negative changes in body image. This latter group expressed that the HIV, in particularly the impact of the anti-retroviral therapy, made them anxious, more fearful and self-deprecating about their bodies. One respondent offered this comment about how the medications made her feel about her body, “I was very secure about my body before my diagnosis. After the diagnosis and the long term medication effects, not so much because of the side effects of the medications, that is the body changes have made me a little insecure.” Another respondent expressed absolute devastation from the effects HIV has had on her body, “There is an invisible big black X from head to toe. I am diseased and am unworthy of feeling good about my body again.” Some respondents described isolating themselves as a coping strategy – specifically mentioning coping with poor body image by not thinking about it, or by gaining weight to avoid being asked out. Other stated that they regained appreciation of their bodies through others, especially a significant partner, which can also be understood as a coping mechanism.

Use of Barrier Methods and HIV Status of Sexual Partners

- 31% reported always using barriers “because it is important to both of us”
- 18% reported not being engaged in sexual activity
- 13.5% reported always using barriers because “it is important to me”
- 11% respondents stated that they do not use barriers, “because we have agreed not to use them”
- About 8% of respondents stated they “sometimes” use barriers, or that it depends on the partner
- Another 5% stated that they do not use barriers because their partners do not like barriers

VI. Sexual and Reproductive Healthcare

- Present gynecological (or "female") problems: 78% responded they do not have gynecological (or "female") problems which would interfere with sexual experiences or ability to have sex.
- Experienced Sexual Dysfunction: Within the last 12 months, 50% have not experienced any symptoms while 30% have experienced low sexual desire (e.g., lack of interest in sex, poor libido, etc.), 20% difficulty achieving orgasm and 19% experience non-arousal.
• **Experienced sexually transmitted infection after HIV diagnosis:** 68% responded no while 29% responded yes.

• **Experienced non-consensual sex:** The majority of respondents 69% had experienced nonconsensual sex. 29% reported they had never been sexually violated. 34% of respondents were younger than 13 years old when they first experienced nonconsensual sex.

• **Fertility Desire:** 39% of respondents do want to have children, 26% had had a surgical procedure that interferes with having a child and 29% are menopausal or post-menopausal.

• **Information from Provider:** 27% of respondents who do want children want information from their provider about which HIV medication regimen is a good choice when considering pregnancy.

• **Experienced intimate partner violence (IPV):** The majority of respondents (72%) had experienced IPV.
Sexual and Reproductive Health Information and Choices

- **Obtaining SRH Information:** Online respondents get their SRH information from the following primary sources - 76% from an HIV specialist, 47% from the internet, 42% from support groups and 29% from magazines/books. Paper survey respondents also relied on HIV specialists for SRH information from an HIV specialist (57%) and support groups (45%), but were much less likely to get SRH information from the internet (20%).

- **Treatment as Prevention/Suppressed Viral Load:** 50% of respondents agreed that HIV transmission can be reduced dramatically where the HIV positive partner has a suppressed viral load.

- **Provider Education:** 46% reported that their provider had informed them about the relationship between suppressed viral load and transmission risk.
Sexual and Reproductive Health Services & Access

- **SRH Access** (in order of importance with a rating of 70% or higher except the last two responses which rated under 45% and 35% respectfully): Prevention and treatment of reproductive tract infections and sexually transmitted infections; early diagnosis and treatment for breast and cervical cancer; sexual and reproductive health throughout the ages; family planning services, including contraceptives; prevention and management of gender-based violence; menopause; prevention and appropriate treatment of sub-fertility and infertility; and SRH assessment.

- **Provider Service Offerings**: The most (over 50% in descending order) - Breast examination, pap smear, pelvic examination, mammogram, STI screening and hormonal therapy. The least 5 (under 50% in descending order) - screening for menopause, adoption services, abortion services, fertility services, emergency contraception pill, reproductive services and family planning services.

- **Utilization of SRH Services** (in descending order): Pap smear, breast examination, pelvic
examination, mammogram, STI screening, family planning services, screening for menopause, hormonal therapy, SRH assessment, reproductive services, abortion services, adoption services, fertility services and emergency contraception.

- **Family Planning Clinic:** 83% respondents have not visited a family planning clinic since being diagnosed.
- **Provider SRH Discussion:** 51% yes and 42% no in terms of provider talking to them about “being sexually healthy”.
- **Discussion of Sexual Health (SH) Issues:** Respondents who experience SH issues speak with (in descending order) their provider, other WLHIV, partner, support group members, friends, family and online.
- **Respondent SRH Discussions with Providers (in descending order):** Was helpful, asked additional questions, offered helpful advice, performed an examination, and encouraged additional screening for undiagnosed ailments

**VII. Privacy, Confidentiality & Disclosure**

- **Confidentiality of SRH Information:** 70% are confident that sexual health information will remain confident.
- **Violation of Confidentiality Pertaining to SH Information:** 74% report no violations while 15% report such a violation.
- **HIV Criminalization Documentation:** 18% reported they had been asked to sign such a document.

Have you ever been asked to sign a document informing you of specific HIV criminalization laws related to nondisclosure, transmission of HIV and/or pregnancy? (select one response)

- Yes
- No
- Not sure
G. Analysis of Survey Findings

Demographics

Results from the survey indicated that some characteristics of the respondent group are generally mirror characteristics of the general population of women living with HIV in the US. These demographics include age, gender, sexual orientation and geography.

For example, in terms of sexual orientation, the majority of respondents (80%) identified as heterosexual, which is consistent with CDC findings that the majority of women (84%) acquire HIV through heterosexual sex (CDC 2013). However, it should also be noted that although the survey results indicate that the majority of respondent identified as heterosexual there is a range of sexual and gender expression, identity and orientation among respondents.

On the other hand, there were other characteristics for which the respondent population percentage skewed differently than the average of the general population of women living with HIV in the US. These demographics included race/ethnicity, gender identity, education, housing, employment, health insurance coverage, technology, childcare responsibilities, and annual income. Respondents were less likely to be Latina, more likely to be Caucasian, and less likely to be transgender than national averages. Respondents were overall more likely to have access to technology and to have higher incomes than the national average for women living with HIV.

Please see table below for an example of how PWN-USA survey respondent race/ethnicity compared with known race/ethnicity data for Black, Latina and white women living with HIV in the United States.

Table B
Comparison of Survey Respondents with Surveillance Data for Women Living in the United States

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Data Sources</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CDC 2010</td>
<td>PWN SRHR Survey 2013 (Online)</td>
<td>PWN SRHR Survey 2013 (Paper)</td>
</tr>
<tr>
<td>Black</td>
<td>60%</td>
<td>55%</td>
<td>57%</td>
</tr>
<tr>
<td>Latina</td>
<td>19%</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>18%</td>
<td>31%</td>
<td>2%</td>
</tr>
</tbody>
</table>
The results from geographic location are roughly reflective of geographical distribution - by state and region - of women living with HIV in the US. Data collected from women residing in 25 states in total was obtained from the survey. The table below illustrates response rate on PWN-USA’s survey in ten states where women are heavily impacted by HIV.

**Table C**
Number of Survey Respondents in Relationship to the Top Ten States with Highest Numbers of Women and Girls Diagnosed with HIV in the United States

<table>
<thead>
<tr>
<th>Top Ten States</th>
<th>State Ranking by Rate</th>
<th>Survey Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PWN Survey 2013 (Online)</td>
<td>SRHR</td>
</tr>
<tr>
<td>1. New York</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>2. Florida</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>3. Texas</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>4. California</td>
<td>2</td>
<td>3</td>
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<td>5. New Jersey</td>
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<td>6. Maryland</td>
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<td>8. Georgia</td>
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<td>9. North Carolina</td>
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<td>10. Illinois</td>
<td>6</td>
<td>2</td>
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</table>

It should be noted that outside of these ten states where women bear a high burden of the HIV epidemic described above, South Carolina and Michigan topped Pennsylvania as respondent sources from the states listed in the table.

Over half (52%) of paper survey respondents and 29% of online survey respondents reported having at least one child under the age of 18 in their homes. The survey did not ask about other family responsibilities such as caring for parents, grandparents, relatives, and in-laws. However it is important to understand this aspect of HIV-positive women’s lives in order to more fully comprehend challenges and opportunities women may deal with in light of engagement in care.

**HIV Status and Engagement in Care**

Diagnosis was viewed in five-year increments beginning with the year 1983, the start of the AIDS epidemic, and ending with the current year 2013, the 30th year of the AIDS epidemic. The results show that 40% of the respondents were diagnosed HIV positive between 1991-2000 and 34% were diagnosed between 2001-2010. 12% reported receiving an HIV diagnosis within the last three years – 2011 to 2013.

An overwhelming majority (96%) of survey respondents are in care. The majority of respondents receive their care from an HIV specialist located at an HIV clinic. Other respondents receive their care from private physicians and hospital-based clinics. In terms of the HIV Continuum of Care, results for respondents are skewing higher than the national averages for people living with HIV (PLHIV) and women living with HIV (WLHIV). See table below for a comparison.
Table D
Comparison of Stages of Care for PLHIV, WLHIV and Survey Respondents

<table>
<thead>
<tr>
<th>Source</th>
<th>HIV Continuum of Care Categories</th>
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<tbody>
<tr>
<td></td>
<td>Retained in Care</td>
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<tr>
<td>PLWHA CDC (2012)</td>
<td>37%</td>
</tr>
<tr>
<td>WLHIV CDC (2012)</td>
<td>41%</td>
</tr>
<tr>
<td>Women* PWN-USA (2013)</td>
<td>96%</td>
</tr>
</tbody>
</table>

*Self-reported

Relationships

The majority of respondents (58%) are in a self-described romantic or intimate relationship with one primary partner. Of this group, 78% of respondents cohabit with or live in the same city/town as their partners. Over two-thirds (68%) of respondents in relationship view their relationships as being monogamous and 64% of respondents identified their partners as being HIV-negative. Additionally, 52% of respondents reported being very satisfied with their relationship while 45% stated they are dissatisfied. The respondents who stated they were dissatisfied were most likely to state that they are either financially responsible or financially dependent in the relationship. Meanwhile, 40% of the respondents did not describe themselves as being a romantic or intimate relationship. Of those respondents who do not have relationships, 25% indicated that they can't find a suitable partner, 21% are no longer with their partner (widowed, separated or divorce) and 20% prefer not to be in relationship at this point of time in their lives.

Change in Sexual Practices and Behaviors

Three-quarters of respondents reported that their sexual practices and/or behaviors had changed since their diagnosis. When invited to elaborate on changes to sexual practices and behaviors, common responses followed these themes:

(i) Use protection more frequently: “started using protection”, “always use condoms, wear it or keep moving”

(ii) Reduction in number of partners: “less open to sexual and romantic partnerships”, “more cautious emotionally”, “prior to HIV I was more casual sexually”, “careful on who I sleep with” “very careful about who I get involved with”

(iii) Low perceptions of body image or attractiveness: “too unattractive to attract a partner”

(iv) Fear of sex: “I have so much fear of sex that I have not been able to be social or consider dating or having sex”, “I can't relax and enjoy sex at all – I’m too afraid I will infect my partner although we remain protected”

Sexual Practices
Women living with HIV are sexually active. Despite body image and desirability challenges, lack of partner availability, and fear of transmitting HIV, 46% of respondents reported having sex on a regular/consistent basis with one or more partners, and another 38% respondents reported sexually pleasuring themselves.

This finding is consistent with research that shows that people living with HIV in the United States remain sexually active after being diagnosed HIV-positive (Northeast AETC, 2013).

Respondents report regularly communicating with partners about HIV transmission risk, sexually transmitted infections (STIs) and use of barrier methods, which is also consistent with attempts by people living with HIV in general to “reduce the risk of sexual HIV transmission by modifying their sexual practices.” Condom use among respondents is higher than condom use among the general PLHIV population and WLHIV population.

Communications with Partner - Disclosure of HIV Status and Barrier Methods

In terms of pre-sex communications, 60% always disclose their HIV status before having sex, 10% stated they disclose sometimes and 2% never disclose. The remainder stated that disclosure was not applicable because they either have one partner, who already knows, or because they are not sexually active at this time. In addition, over 80% respondents reported talking to their partner(s) about HIV transmission risk, sexually transmitted infections (STIs) and use of barrier methods. This may be because a high percentage of respondents report they are aware and knowledgeable about barrier methods to reduce transmission of HIV, from 64% reporting understanding of how to use finger cots to 93% reporting comfort with using male condoms.

Interestingly, although there may be little correlation between the two questions, 42% responded that HIV status of their sexual partners was not important to them, while 18% are only interested in being sexually involved with HIV-positive partner(s) and another 14% are only interested in being sexually involved with HIV-negative partner(s).

Sexual Function

Within the last 12 months, 50% have not experienced any symptoms which would interfere with sex, although 50% have experienced low sexual desire (e.g., lack of interest in sex, poor libido, etc.), difficulty achieving orgasm, and/or non-arousal. While the survey did not specifically ask respondents experiencing sexual dysfunction why this might be so, responses to the question pertaining to gynecological (or "female") problems indicate that 78% of respondents do not have gynecological (or "female") problems which would interfere with sexual experiences or ability to have sex.

Experiences of Non-Consensual Sex and Intimate Partner Violence

Over two-thirds of respondents (69%) had experienced nonconsensual sex. More than a third of respondents (34%) had experienced nonconsensual sex when they were younger than 13 years old. For many respondents, sexual abuse and violence continued throughout their lifetimes.

Only 29% of online respondents and 22% of paper respondents reported they had never experienced nonconsensual sex. Some respondents reported they were “not sure”.

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Nearly three-quarters of respondents (72%) reported having experienced intimate partner violence (IPV) or domestic violence (DV) at some time in their lives. For many women, IPV started young. About a third reported at least one experience of IPV or DV before the age of 25.

One respondent commented that “when not being raped physically I was being blackmailed.”

**Fertility Desires, Intentions and Decision-making**

In terms of childbearing, 39% of respondents do want to have children, 26% had a surgical procedure that interferes with having a child and another 29% are menopausal or post-menopausal. Respondents who are interested in having children indicated that they receive fertility planning information from a variety of sources. Most respondents who do want children desire information from their provider about HIV medication.

**Sexual and Reproductive Health Information**

Respondents indicated that they get their SRH information from a variety of sources: 76% from a HIV specialist, 47% from the internet, 42% from support groups and 29% from magazines/books. Although 76% of respondents indicated they get sexual health information from HIV specialists, less than half (46%) reported being informed by a health care provider about the importance of having a suppressed viral load (SVL), especially in the context of a sexual relationship where having a SVL can dramatically reduce HIV transmission. This finding correlates with the percentage of responses to the question pertaining to providers having discussions with respondents about “being sexually healthy”: 51% of respondents indicate that their providers do talk to them about “being sexually healthy” while another 42% responded no in terms of provider talking to them about “being sexually healthy”.

**Utilization of SRH Services**

The majority of respondents have utilized the following SH services: Pap smear, breast examination, pelvic examination, mammogram, STI screening, family planning services, screening for menopause, hormonal therapy, SRH assessment, reproductive services, adoption services, fertility services and emergency contraception. These results correlate with provider service offerings. An interesting finding indicates that the majority of reproductive services utilized by respondents are pap smear, breast examination, pelvic examination, mammogram, and STI screening while the least used SRH services are family planning services, screening for menopause, hormonal therapy, SRH assessment, reproductive services, abortion services, adoption services, fertility services and emergency contraception. This finding may correlate with the fact that 60% of respondents were born between the years 1960-1979, spanning between ages 34 and 53. Additionally, respondents indicate that at least 26% of respondents had a surgical procedure that interferes with having a child and another 29% are menopausal or post-menopausal. These findings may also account why the majority of respondents (83%) have not visited a family planning clinic since being diagnosed.

**Confidentiality**

The majority of respondents feel relatively confident that their sexual reproductive and health
information will remain confidential. At issue is whether or not the continuance of HIV criminalization laws will change this.
Discussion

As previously described, the HIV epidemic among women in the US is characterized by severe racial, ethnic and socioeconomic disparities. Respondents to PWN-USA's survey reflected some of these disparities, with women of color representing 71% of respondents, and 54% of respondents identifying as African American or Black.

Although PWN-USA’s respondent sample tended to be less poor, presumably slightly older, and more engaged in care than national averages, responses provide a window into understanding the lives, realities and desires of women living with HIV today. As women living with HIV have become healthier, and ceased to perceive HIV as a death sentence, women living with HIV are living in the present and making plans for the future – including attending school, participating in community activities, entering or re-entering the workforce, and taking on family responsibilities that may include parenting.

These themes are borne out by responses to the PWN-USA survey. 14% of survey respondents had been living with HIV for over 20 years and over half (51%) of respondents had been diagnosed with HIV for over 10 years, a testament to increased longevity of people living with HIV. The majority of respondents with an income of $50,000 or more owned their own home or apartment, demonstrating that women living with HIV are making long term plans and investments in their own futures when they have the financial flexibility to do so.

Family responsibilities, including but not limited to childbearing and child-rearing, play an increasingly important role in the lives of women living with HIV. Over 40% of our sample was women of reproductive age, and regardless of age, over half of paper survey respondents and nearly a third of online survey respondents reported having at least one child under the age of 18 in their homes. Many women reported several children, including grandchildren, in their homes.

Disparities between paper and online survey respondents make it clear that women living with HIV who tend to have access to technology, including the internet, have a different set of privileges than women who do not, and the reasons for this are complex. Over 62.6% of online respondents reported having a smart phone, 59% had a laptop, and 54.7% had internet service. Internet access and technology literacy may play an important role in women’s ability to access medical and legal information, to enter or re-engage with the workforce, and to make informed decisions about their lives and futures.

As seen in the survey results, there was a marked disparity in formal education, employment, housing status, and health insurance types between online survey takers and paper survey takers. Among online respondents, 39% had a 2 or 4-year college degree. Of PWN-USA’s overall sample, 12% had not completed high school; while nearly a third (30%) of paper survey respondents had not completed high school, only 6% of online survey respondents had not completed high school. Of online survey respondents, 37% were employed full time and 19% were employed part-time, compared with 13% and 11% respectively of the paper sample.

Findings from the HIV Cost Services and Utilization Study (HCSUS), conducted in the mid 1990’s, demonstrated that women living with HIV were more likely to be living in extreme poverty, compared with HIV-positive men (64% of WLHIV compared with 41% of MLHIV had annual incomes of $10,000 or less). Nearly twenty years later, in PWN-USA’s study, 29% of respondents reported annual incomes of $10,000 or less. The limitations of a survey administered largely online are clear:

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respondents are more likely to be employed, to have more money, more access, more education, greater social mobility, and more privilege overall than national averages of women living with HIV. Understood in this context, PWN-USA’s findings relevant to economics and financial security are alarming. Nearly half of all respondents (47%) reported an annual income of under $20,000, and nearly a third of paper respondents (30%) and 11% of online survey respondents reported an income of under $5,000 per year. Income eligibility requirements to access benefits such as Medicaid, ADAP, and housing and other services may force women to keep their incomes low in order to get medications, stay in care, and provide for their dependents. 43% of respondents were on Medicaid, and only 8% of paper respondents and 29% of online respondents had access to private insurance plans provided by employers or family members.

As a point of reference, the federal poverty level for an individual in 2013 is $11,430. For a woman taking care of one or two children, the federal poverty level for a family of two or three is $15,510 or $19,530 respectively. Many of the respondents came from urban areas with a relatively higher cost of living and are likely economically challenged to ensure their own well-being, let alone the well-being of others they may be responsible for. PWN-USA’s survey results also show a high level of dissatisfaction with financial contributions by partners towards living expenses and, in fact, this was the area in which women living with HIV reported the greatest dissatisfaction with their relationships. These findings suggest that women living with HIV may be financially supporting their partners to some extent on their own limited incomes.

Women living with HIV demonstrate high levels of internalized stigma, which emerges immediately following an HIV diagnosis, and may be related to body image and self-esteem issues. This internalized stigma may play out in sexual as well as reproductive choices, and interactions with partners as well as providers. Judgmental attitudes documented in the literature by WLHIV towards other WLHIV choosing to conceive or parent further demonstrate this internalized stigma.

Nearly two-thirds (62.5%) of respondents reported experiencing moderate to severely negative changes in body image and frequently using words like “dirty”, “unattractive”, “diseased”, “ugly”, “unwanted” to describe themselves. Similar to themes described in studies by Siegel et al.¹ and Hackl et al.² some PWN-USA respondents described isolating themselves as a coping strategy – specifically mentioning dealing with poor body image by not thinking about it, or by gaining weight to avoid being noticed. “I don’t feel as pretty as I used to. I let myself gain weight to avoid being asked out,” reported one PWN-USA survey respondent.

Although a quarter of respondents report they are now comfortable with their bodies, half of that 25% reported negative self-perceptions of body image immediately following diagnosis. Their hard work to claim, or re-claim, a positive self-image in light of their diagnosis can be seen in these statements.

“In the beginning I felt dirty, like poison. In the almost 18 years since my diagnosis I have slowly regained some of my confidence as a beautiful human being.”

“At first I felt dirty and ashamed. However, over the years I have come to terms with my diagnosis and accept my situation, which allows me to feel better about my body.”

“Crazy as it sounds, it’s been “freeing”... I’ve had to learn true self-care.”

“I hated the person I saw in the mirror. I have since began exercising which gives me more energy and feel better about my appearance”
Women living with HIV also report high levels of fear and anxiety about sex, and although 96% of respondents were currently in medical care, many (54%) have not been adequately counseled on the relationship between suppressed viral load and reduced likelihood of transmission. As Siegel et al. found, respondents reported being worried and anxious about sex and not being able to enjoy sex even when using condoms, because of their fear of infecting partners. Despite the fact that over 80% of respondents had suppressed viral loads, and most are using condoms, many PWN-USA respondents still felt high levels of stress, worry, or anxiety associated with possible HIV transmission and/or re-infection by a partner took away from pleasure and ease during sex.

A large majority of respondents (91%) were currently on HAART, and respondents shared that HIV medications are a source of stress and anxiety when it comes to body image and sex. Side effects from long-term anti-retroviral therapy made them anxious, more fearful and self-deprecating about their bodies.

Some women who had been infected sexually reported that the trauma of diagnosis itself had affected their feelings about sex.

“I have lost a lot of desire to have sex because that is how I became infected.”

“I feel like that is what got me into this health issue”

“I waited until I was 26 to have sex and have led a pretty uneventful sex life in comparison to other people I know, only to find out that I contracted the virus just months after losing my virginity... When I was diagnosed, I felt dirty and wouldn’t let my boyfriend near me. I didn’t see why he would want to have sex with me and when we finally did, I was in constant fear and did not enjoy it. I have come to realize that the initial fears and negative feelings toward sex weren’t really about sex but rather a lack of self-acceptance and denial about the diagnosis. I still have a difficult time. It’s like there was a light switch that was turned off and has been hidden since my diagnosis that has left me believing that I don’t have a right to have or really enjoy sex.”

Many women who reported currently being celibate had not been sexually active since their diagnosis. For some women, sex was correlated with risk or with the partner who infected them.

“I do not want to be intimate with no one. I hated men at one time because I felt like it was their fault. My ex-husband gave me the disease so all men were cheaters and I didn’t want any intimacy at all. But I have let go of all the anger and opened up my heart, mind and soul.”

“HIV has changed everything about my sex life... [Since my partner passed] I feel dirty and I feel like no man would ever want to touch me. I just avoid it and do not date at all since he passed, I don’t feel sexy at all, I don’t feel like any man could ever be physical with me without thinking about the virus.”

“There is a big black X- saying, ’Do not have sex with this woman; she has been X’d from physical pleasure. Forever.”

Nearly two-thirds (63%) of PWN-USA’s respondents reported a decrease in the frequency of sex being diagnosed HIV-positive. Consistent with Bova et al.’s findings, however, the majority of respondents to PWN-USA’s survey reported currently being sexually active, independently of time since diagnosis. PWN-USA’s findings were also similar with Bova et al.’s with respect to women describing the
quality of sex and intimacy experiences. Bova et al. found that half of participants reported that the quality of the sexual activity had stayed the same (31%) or improved (21%) since an HIV diagnosis. PWN-USA found that 32% reported no change in quality of sex, 18% reported that the quality of sex was better, and 26% percent reported that the quality of sex was worse.

The majority of women living with HIV-- at all phases of disease progression-- are having sex, and most report having one consistent partner. Most respondents (68%) described themselves as being in monogamous relationships, and 64% of respondents reported that their partners were HIV-negative. Women who described themselves as single were slightly more likely to report they were regularly having sex with one partner than women who reported being in relationships or married (30.2% compared with 28.3% and 24.5% respectively). There was no clear correlation between time since diagnosis and current sexual activity. 14% of PWN-USA’s respondents stated they were not currently having sex because they could not find a partner.

Many women (75%) reported changes in sexual behavior and practices since their diagnosis. These included increased condom use - 75% of sexually active respondents reported they “always” or “sometimes” use condoms with their partners. Separately, some respondents discussed changes to perceptions around sex and sexual partners in a positive light:

“It has made me pay more attention to how a man handles me in bed.” “It makes me more cautious, but I’ve learned what I like and what I don’t like from sex positive workshops.”

Several respondents described the ways in which HIV diagnosis forced them to examine or reassess sexuality and relationships.

“At first I felt unworthy. I took 4 years away from any kind of sexual relationship so I could work on my self-esteem. A year ago I came to terms with the idea that I am worthy of love and sex.”

In addition, over two-thirds of respondents (68%) reported being more selective about their sexual partners since their diagnosis. Over a quarter (28%) of women who reported that they are currently in a relationship (spouse or partner) were in relationship with the same person at their time of diagnosis with HIV.

Within relationships where a woman is living with HIV and her partner is not, stress on the relationships associated with an HIV diagnosis is not well understood and there is limited, if any, support available for WLHIV and their partners in terms of services available or peer support networks. PWN-USA’s survey did not ask questions about this. However, respondents alluded to relationship tension in some of their comments about sex: “I have a lot of anxiety about exposing my husband but don’t feel able to express it for fear of pushing him away.”
Unmet Sexual and Reproductive Health Counseling Needs

In general, women living with HIV report that they rely on their providers, particularly HIV specialists, for guidance on SRH issues. Further, when they do discuss SRH issues with providers, trends show that WLHIV report providers are “helpful,” “ask additional questions,” “offer helpful advice,” and “encourage additional screening.” However, findings among survey respondents indicate that providers may be focusing on secondary prevention and screening for gynecological health issues at the expense of discussing sexual health more generally, including women’s reproductive or family planning desires.

Despite the fact that women living with HIV are sexually active, and that 29% of respondents indicated they had been diagnosed with a sexually transmitted infection after HIV diagnosis, nearly half (42%) of survey respondents reported that their providers had not talked to them about “being sexually healthy.” Further, although 39% of PWN-USA’s respondents reported desiring children in the future, when asked about SRH services offered by providers, women were least likely to report being offered reproductive services, fertility treatment, adoption support, and family planning services including abortion, oral contraception, and emergency contraception.

Because of the triggering nature of the question and the impersonality of the research design, PWN-USA’s survey did not explore women’s history of unwanted pregnancy or choices to terminate pregnancy post-diagnosis; however this is an area that warrants further research. It should be noted that a number of respondents reported having received their initial HIV diagnosis during pregnancy or childbirth.

Importantly, ambivalence by WLHIV about perceiving themselves as sexual and reproductive beings may negatively impact patient-provider communication. Research findings show that women living with HIV—not providers—are more likely to initiate conversations about fertility, and women whose desires and intentions are congruent are more likely to have these conversations. Women living with HIV who are ambivalent toward pregnancy are especially vulnerable to having unmet reproductive counseling needs, because nuanced discussion related to preventing unintended pregnancies, HIV prevention that does not prevent pregnancy, choices that can protect women and their partners during conception, and learning to cope with indecision regarding childbearing are likely to be missed.

Violence and Abuse

As demonstrated in the literature and by PWN-USA’s survey findings, violence and abuse at all stages of life are prevalent among women living with HIV. Only 29% of respondents reported they had never experienced nonconsensual sex. Over a third of respondents (34.1%) first experienced nonconsensual sex before the age of 13, and nearly a fifth (19.8%) experienced nonconsensual sex before the age of 18. The survey did not ask about other forms of childhood sexual abuse (CSA).

Only a quarter of survey respondents reported they had never experienced intimate partner violence (IPV) or domestic violence (DV). The survey did not specifically ask whether respondents had experienced IPV or DV following HIV diagnosis. Findings show that women who had experienced nonconsensual sex at a young age were likely to also have experienced IPV at a young age. For example, 63.2% of women who had been sexually assaulted before the age of 13 experienced IPV or DV between the ages of 13 and 17. Women who experienced IPV at a young age were also likely to experience IPV later. For example, over half of women who experienced IPV between the ages of 18 and 24 also experienced IPV between the ages of 25 and 34. The chart below shows how patterns of abuse persisted among respondents who experienced IPV early in life.
These findings suggest that given a history of violence, abuse, and trauma, compounded by body image and self-esteem issues resulting from HIV diagnosis, as well as negative perceptions of sex and sexuality, women living with HIV may face challenges securing and navigating healthy and fulfilling intimate relationships. In addition, data shows that rates of post-traumatic stress disorder (PTSD) and complex post-traumatic stress disorder (C-PTSD) are high among women living with HIV in the United States – at 30%, a rate 6 times higher than the general population. The survey did not ask whether respondents had been screened for intimate partner violence or history of trauma and this is an area that requires further inquiry and intervention.
Recommendations: A Way Forward

Much work is needed to achieve sexual and reproductive health and rights for women living with HIV in the United States. The following comprise initial recommendations from the authors. It is the hope of PWN-USA that this report will serve as a catalyst to further dialogue, research efforts, and advocacy towards dignity for all people living with HIV.

**Meaningful Involvement is Necessary**

Women living with HIV must play a vital role in the design and development of research studies, program and service delivery design, lead in education efforts and in holding decision-makers accountable for developing policies which support and uphold sexual and reproductive health and rights for all people living with HIV.

When decisions are made that impact SRHR of women living with HIV, networks representing WLHIV must be consulted and involved. To achieve this, ongoing support is needed for local, national and international efforts that build capacity of women living with HIV and their communities to engage, mobilize and ensure that policies which impact their health and rights are appropriate in the context of HIV.

**Addressing Stigma, Discrimination and Misperceptions about HIV**

To achieve sexual and reproductive rights for women living with HIV it is necessary to address the social, political and institutional context of WLHIV's lives. In particular, stigma, institutionalized discrimination, and misperceptions about HIV transmission and what it means to be living with an HIV diagnosis must be addressed. HIV criminalization laws and statutes should be eliminated. In addition, any sentence where HIV diagnosis was used as a sentence enhancement or as a factor in determining sentence length or severity should be reviewed. Judges and law enforcement officials should receive trainings designed to improve understanding of HIV medical information and transmission routes, and to reduce stigma and discrimination.

It is also important to correct and proactively address inaccurate media portrayals of life with HIV, especially as they relate to inaccurate portrayals of transmission risk, sex, sexuality and reproductive capacity post-diagnosis, and ability of PLHIV to parent.

**Research and Provider Training for Young and Mature WLHIV is Especially Needed**

Based on our assessment, there is striking limited data and research on a number of relevant areas of interest related to sexual and reproductive health and rights for women living with HIV in the United States, including the specific needs of young WLHIV and mature WLHIV.

There is a specific lack of available data on young PLHIV and perinatally infected WLHIV entering adolescence/adulthood. The literature reviewed revealed scarce research on gynecological health habits, self-perception, intimate partnerships, and sexual health experiences of adolescents and young women living with HIV.
While studies typically were designed to evaluate women ranging from 18 to 69 years of age, the vast majority of research reviewed, as indicated by the sample mean and median age, centered on mature women—women ranging from 40 to 50 years old. Many studies failed entirely to capture information on young adult women transitioning from adolescence to adulthood, particularly from 18-21 years old and none of the literature assessed specifically identified study participants living with HIV since birth or childhood. Study design remained a critical factor for determining “who” was eligible for each study and perhaps due in part to ethics in child research requiring consent, much of the literature solely focuses on women 18 years of age and over rather than minors.

As young people born with HIV enter the tumultuous period of adolescence, adulthood, and early sexual activity, research is needed to understand clinical factors that may affect sex, sexuality and reproductive options, as well as the potential psycho-social, emotional, and behavioral effects of an HIV diagnosis prior to becoming sexually active. Specific research is needed to understand how people living with HIV prior to becoming sexually active experience and understand their sexuality, their intimate partnership needs, and how this may influence romantic and sexual relationship choices, physical and mental health and quality of life.

In addition, the sexual and reproductive health and rights of mature women living with HIV are often entirely overlooked. Once a woman living with HIV is no longer perceived as a potential risk to an unborn fetus, interest in her SRH seems to disappear. Clinical research is required to determine how the progression of HIV physically impacts women who are menopausal or post-menopausal. Literature shows that women living with HIV tend to begin menopause early, and under-report symptoms of menopause to their providers, likely due to assumptions that symptoms are related to HIV disease progression or other ongoing health concerns, rather than menopause. Thus it is imperative that providers are trained to ask questions about menopause of their mature HIV-positive women clients. Mature WLHIV are also sexually active and have needs for intimate partnership. Available surveillance data indicates that women are sexually active well into their 70’s and 80’s. Like their younger counter parts, mature women require affirming and age appropriate SRHR services and protections.

**Factors Influencing Engagement in SRH Care**

Limited research is available assessing attempts to improve quality of SRH care by addressing factors that may influence WLHIV’s engagement in SRH care. Furthermore, much of the literature on reproductive health places a questionable onus on women in regards to gynecological screening rates rather than provider behavior, clinic policies, and insurance access which may impact care and adherence.

Data shows that factors including provider-patient communication, provider’s understanding of health guidelines for WLHIV, and provider accessibility may all play a key role in the engagement of WLHIV in care. As PWN-USA’s survey results demonstrated, women living with HIV rely heavily upon providers for guidance when it comes to making decisions about sexual and reproductive health. Thus, provider bias and provider communications skills may play a critical role in determining the extent to which WLHIV identify their concerns and communicate and realize their desires with respect to body image, sexuality, and reproductive decision-making.

However, we were not able to identify studies in the literature that focused on evaluating interventions at the point of provider-patient communication on SRH issues, or increases in knowledge and
understanding of their own sexual and reproductive health by women living with HIV as a result of provider education.

In addition, little information is available on how well HIV primary care clinics perform cervical cancer and breast cancer screenings over an extended period of time.

**Improving Programs and Service Delivery**

Regardless of specialty, HIV and SRH providers should be held to the highest standard to provide medically accurate and nonjudgmental information, about sexual and reproductive options for WLHIV, including counseling on viral suppression as one aspect of risk reduction for women in serodifferent relationships and WLHIV exploring conception. PWN-USA’s finding that over half of the respondent sample did not recall being counseled about viral suppression as an aspect of transmission risk reduction is troubling and indicates that, over three decades into the HIV epidemic, despite data showing that viral suppression may be excellent strategy to reduce horizontal and vertical transmission, providers are either inadequately informed about this revolutionary scientific development or are fundamentally uncomfortable having nuanced conversations about risk reduction with their clients and patients – at an enormous cost to health, decision-making, dignity and quality of life. This may also reflect a deeply held stigmatizing attitude towards women living with HIV as sexual and reproductive beings. A more robust analysis of how effectively PLHIV in the United States have been counseled on viral suppression as a risk reduction strategy is needed, with data disaggregated by race, ethnicity, gender, point of care, provider type, geography and other factors. Concurrently, it is necessary that providers receive training to counsel WLHIV about their sexual health, sexual choices, and reproductive options in a way that is informative, compassionate and nonjudgmental.

**Integration of Services**

The literature shows that consolidating and bundling HIV primary care with gynecology care improves SRH care for women, and PWN-USA’s survey findings demonstrated that WLHIV who are in medical care are not generally accessing family planning clinics. Thus, it is imperative that sexual and reproductive health care services are well-integrated with HIV care and services, in both clinical and community settings. This recommendation is well-documented in the literature. Tello, et al. recommended structural and clinic system changes including integration of HIV and SRH care. In addition, as detailed in Barroso et al., service integration and coordination is necessary, and those staffing HIV and reproductive health services should be adequately trained to provide integrated services as well as referrals with compassion and respect for individual rights.

Corollary factors which may impact and influence SRHR for women living with HIV should also be accounted for in SRH/HIV service integration goals. The high prevalence of violence and trauma among women living with HIV indicates it is necessary to improve screening for factors which influence SRHR of WLHIV, including screening for physical and emotional violence, intimate partner violence (IPV), sexual coercion and forced sex. Women living with HIV suffer from high rates of PTSD, complex PTSD, and the downstream effects, which may include coping mechanisms that impact SRHR, for example, by putting women at risk for staying in violent and abuse relationships. Clinical and community based care settings should focus on screening for PTSD as well as IPV and implementing interventions that help women heal from trauma and leave abusive relationships. Such screenings should be linked with intervention, including but not limited to meaningful referrals for legal, housing, domestic violence shelters, substance use recovery programs and medical services, as well as interventions that reduce PTSD-
related symptoms and help women heal from the emotional, mental and physical long-term effects of trauma.

Issues pertaining to SRHR are deeply personal for WLHIV, as for most people, and correlate with cultural values and personal history. Culturally relevant SRH services for WLHIV can strongly facilitate provider-patient communication about sex, sexuality, intimate partnership and relationship desires, decision-making as it pertains to family planning, and current and past trauma or violence. However, cultural relevance in SRH services for WLHIV is frequently lacking and should be an emphasis in designing future programs. In addition, the use of interdisciplinary care teams, including teams which provide psychosocial support and integrate peer role models, has great potential for improving SRHR for WLHIV.

Increase Prevention Options and Access to Tools

Failure to offer WLHIV options to control family planning may result in unplanned pregnancies which in turn can lead to a decreasing sense of personal agency over events in a woman's life. The literature shows that up to 80% of pregnancies among WLHIV in the US may be unplanned, and a significant number are also unwanted. In addition, there is little discussion in the literature of the trauma that may result from termination of pregnancy by WLHIV, let alone the complex trauma that a woman may experience if she is diagnosed with HIV during pregnancy, particularly if she was encouraged or coerced to terminate the pregnancy. It is not unlikely that such experiences could influence future engagement in medical care and services – however, we were not able to find literature addressing this issue.

To uphold their sexual and reproductive rights, women living with HIV need access to a range of options for pregnancy prevention and for prevention of HIV transmission. Further research and development is needed to develop long-acting biomedical HIV prevention options that can be used by male partners of WLHIV attempting to conceive naturally.

WLHIV's sexual pleasure continues to be negatively impacted by fears related to transmission and challenges related to negotiating male condom use. Providers should counsel WLHIV on, and ensure accessibility of, birth control options other than male condoms. This includes scaling up availability and improving affordability of female condoms, ensuring that WLHIV are counseled about oral contraception, birth control injections, intra-uterine devices, and other forms of family planning which do not depend on negotiation with male partners.

HIV clinics and HIV specialty medical associations should expand partnerships with healthcare providers in the field of sexual and reproductive health through the American Society of Reproductive Medicine and similar professional organizations to ensure that issues that are critical to the sexual and reproductive health and rights of women living with HIV are included in policies and clinical practice.

Understanding Resilience Factors – Self Esteem and Economic Survival

Loving yourself when society has chosen to discard you because you no longer appear to serve a socially defined purpose is itself an act of revolution. Body image, self esteem, and internalized stigma continue to present major challenges for women living with HIV and are likely to impact ability to realize their sexual and reproductive rights, including choosing healthy relationships and engagement in sexual and reproductive health care. However, some women have overcome these obstacles. There are rich lessons to be learned from the resilience of women who have healed to become accepting and celebratory of their bodies, and sexuality.
More research is needed to understand how internalized stigma, feelings of WLHIV about their own sexuality, bodies, partnership and reproductive capacity intersect with women's agency in relationships, including relationships characterized by violence. Women's considerations for economic survival frequently involve sexual and romantic partners and further research is needed to understand how this may operate for women living with HIV. For example, specific research is needed to understand how women's willingness to support partners financially may intersect with HIV-positive women's perceptions about their self-worth, sexuality, and value as partners or spouses.

**Federal Policies and Guidance Should Reflect a Commitment to SRHR of WLHIV**

The implementation of the Affordable Care Act (ACA) may provide many opportunities to improve SRHR for WLHIV. Expanded access to healthcare for low-income communities and for individuals with chronic health conditions represents a major step towards greater coverage. Within Medicaid programs, coordinated and family-centered care models may provide better co-location of services at one point of care. In addition, the ACA provides opportunities for integration of SRH/HIV and integration with factors that suggest corollary risk. For example, screening for sexually transmitted infections, cervical cancer, mammograms, and intimate partner violence will all be covered without copays as preventive care measures for women. Realizing these promises for WLHIV has the potential to greatly improve SRHR for WLHIV, however, many challenges remain. Restrictions on copays for birth control, for example, may continue under ACA implementation, forcing WLHIV to continue negotiating condom use with their male partners as a family planning method.

Specifically, the National HIV/AIDS Strategy should be updated with goals and metrics that focus on improving SRHR for WLHIV. Examples of such metrics could include: increased rates of recommended second Pap smear screening for newly diagnosed women; increased rates of screening for IPV among WLHIV in care; and goals to improve PTSD symptoms among WLHIV who suffer from PTSD.

Because women's SRHR is inextricably linked with socio-economic status, including factors as diverse as access to employment and healthcare options that employment may confer, as well as financial flexibility within relationships, expanding employment opportunities for WLHIV should be a priority.

**Ongoing Advocacy will be Needed**

Ongoing advocacy and mobilization will be needed to inform and monitor existing strategies and policies issued at the Federal level including the Ryan White Care Act, Medicaid and Medicare, The Affordable Care Act and the National AIDS Strategy. In addition, advocacy efforts should focus on monitoring guidance documents from federal agencies to ensure that issues specific to the SRHR of WLHIV have been considered.

State-run programs including ADAP, Medicaid, and health exchanges and formularies in the Affordable Care Act should be monitored to ensure that the sexual and reproductive rights of women living with HIV are considered when developing and rolling out state programming. In addition, policies and guidance pertaining to assisted reproductive technology (ART) should be closely monitored for their potential impact on WLHIV.

Health care workers should be monitored to ensure they are well trained on legislation, policies and professional standards on human rights (such as criminalization and disclosure) and
patient care and improve their capacity to promote confidentiality, informed consent, gender equality, and a non-discriminatory and stigma-free environment for women living with HIV.

Advocacy that focuses generally creating a facilitative social and legal environment for women, girls, people living with HIV, and/or sexual minorities is critical to upholding the SRHR of WLHIV.

Finally, partnerships, collaborations, and coalition building between HIV and reproductive justice movements are necessary to ensure vibrant advocacy and ongoing monitoring of the sexual and reproductive rights of women living with HIV.
References


3 Bova C, Durante, A. Sexual Functioning among HIV-infected women. AIDS Patient Care and STDs. 2003 February;17(2): 75-83.