



Will and Should Women in the U.S. Use PrEP? Findings from a Focus Group Study of At-risk HIV-negative Women in Oakland, Memphis, San Diego, and Washington, DC

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Background

- In 2009, 23% of new HIV infections in the U.S. were among women
- Women of color, particularly African-American women are disproportionately at risk of and affected by HIV. In 2009:
 - Black women= 57% new HIV infections/13% of population >13
 - Latinas = 16% new HIV infections/14% of population >13
 - Whites = 21% new HIV infections/67% of population >13
- In 2009, the rate of new HIV infections among Black women was 15 times that of white women and 3 times that of Latinas
- Over 1/3 of new infections among Black women and Latinas in 2009 were among those aged 13-29 (CDC 2011).

- Clearly, more effective HIV prevention strategies for women are needed.

- Recent clinical trials have generated excitement about the potential for PrEP to be one of these ; but none of the efficacy trials included U.S. women.
- Little is known about knowledge, attitudes, and likelihood of using PrEP among U.S. women, even as FDA has just approved its use for “adults.”

Methods

- Formative, qualitative, community-based and participatory research
- Focus group study with 92 HIV-negative women in 4 cities: Oakland, CA; Memphis, TN; San Diego, CA; Washington, DC
- Two FG held in each city
- Defined as “at risk” by virtue of social networks, sex and drug-related risk practices, SES
- Recruitment by local women-serving CBOs; FG led by trained, local facilitators
- \$50 incentive (provided in cash or credit card)
- Questionnaire with demographic & behavioral information
- Qualitative FG discussions on basic understanding of PrEP, attitudes about administration and uptake, incentives and barriers to use, targeting and marketing
- Sessions recorded and transcribed (Spanish transcript translated to English); transcripts analyzed for themes and potential site differences

Focus Group Sites

WORLD
Oakland, CA

Christie's Place
San Diego, CA

The Women's
Collective
Washington, DC

Choices
Memphis, TN

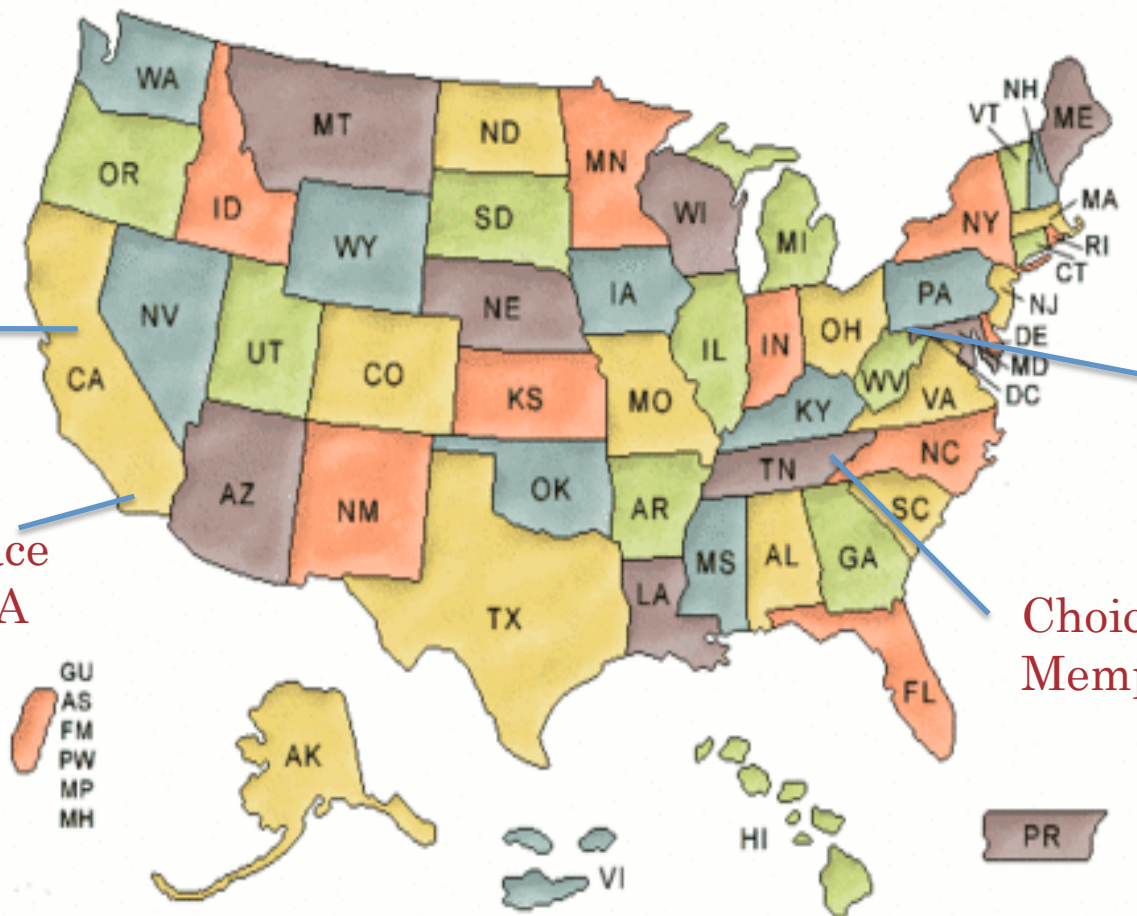


Table 1

Demographic Characteristics	Number (%)*
Age:	
<i>18-30 years</i>	22 (24)
<i>31-50 years</i>	50 (55)
Race/Ethnicity:	
<i>Black/African American</i>	62 (69)
<i>Latina/Hispanic</i>	17 (19)
<i>White</i>	6 (7)
Marital/Relationship Status:	
<i>Married/Cohabiting</i>	30 (33)
<i>Single</i>	25 (28)
Employment Status:	
<i>Employed</i>	45 (50)
<i>Unemployed</i>	43 (48)
Education:	
<i>At Least Some College</i>	54 (59)
<i>High School or GED</i>	26 (29)
Income: <i>\$20,000 per year or less</i>	62 (69)
Housing Status: <i>Stably Housed</i>	75 (83)
* Out of total completing question	

Table 2

Behavioral Characteristics	Number (%)*
Have Multiple Partners	8 (9)
Ever Had HIV Test	81 (91)
Know HIV Status	74 (83)
HIV/STI Prevention Methods Ever Used:	
<i>Male Condom</i>	77 (86)
<i>Monogamy</i>	46 (51)
<i>Abstinence</i>	40 (44)
<i>Female Condom</i>	18 (20)
Contraception Methods Ever Used:	
<i>Male Condom</i>	71 (84)
<i>Oral (Birth Control Pill)</i>	62 (73)
<i>Abstinence</i>	35 (41)
<i>Female Condom</i>	19 (22)
Perceives Self at Risk of Getting HIV Within the Next Year	24 (27)
* Out of total completing question	

FG Questions & Discussion Topics

- Basic concepts: HIV transmission and PrEP
- Ever heard of PrEP?
- For which women might PrEP be most helpful?
- Perceived barriers to uptake among women
- Best sources of information about PrEP
- Will PrEP encourage more women to get HIV test?
- Comfort with asking medical provider for PrEP
- Potential impact of PrEP on woman's sex life, including use of condoms
- Desired level of efficacy of PrEP
- Key considerations for women re: taking PrEP

Findings: For Which Women Would PrEP be Helpful?

- Prostitutes, sex workers, “promiscuous” women (those with >1 sex partner)
- Young women
- Women with experience of sexual violence
- All women (b/c “you don’t know what your partner is up to”)
- Drug-using women
- Older women (b/c “they are having sex, too”)
- Those with HIV+ partners (sero-discordant)
- Women in and out of prison or who welcome back men who have been in prison
- Police officers, health care workers, and others with occupational exposure
- African American and Hispanic/Latina women

Young Women

P: “So its kind of almost like when you put ‘em on the pill, you put ‘em PrEP, you know what I’m sayin’ ‘cause *obviously* teen pregnancies still there, so they *are* having unprotected sex and this is no matter HOW you pound it into them, they’re still choosing to have unprotected sex so its kind of like a double thing that you would do. . .as a parent especially. . . I put her on the pill, might as well put her on PrEP too at 12, 13, you know.” (FG 8 MEM)

P: “Only reason I disagree with that is because you know sometimes when we’re growin’ up. . .you tell, you give a young woman something and tell her this is to prevent something, she might be a little more promiscuous, to say I can’t get it ‘cause I’ve already taken a pill that’s gonna not. . .”

P: “especially this generation right now.” (FG 4 OAK)

Every Woman

P: “I think it should be on the market for everybody you know, I think if it was FDA approved”.

P: “I would, I would take the pill”

P: “I would take it too.” (FG 1, WDC)

P: “I think everyone should pretty much. . .I mean, as far as me being young. I just turned 21 and I know a lot people that’s pretty much my age or younger that’s pretty out here and some other people that’s like. . .it could benefit everybody, like pretty much everybody, ‘cause like my mother said you pretty much don’t know whose doin’ what. . .you don’t know if your partner is faithful to you, and then you pretty much don’t deserve that from anybody, so it’s like everybody should, I think everybody could benefit from it, just like anybody can catch a disease, I think everybody could benefit.” (FG 2, WDC)

P:” I say any woman because, like, if you meet someone you don’t know their background you don’t know if they gonna tell you the truth or not. . . “

P: “and they might not know either”

P: “I would go with any woman, too because even if. . . you’ve heard married too, ‘cause you never know what their husband’s doing. . . “
(FG 4, OAK)

Findings: Barriers to Uptake of PrEP

- Lack of information
- Cost
- Side Effects
- Availability
- Providers (lack of conversation about sex and HIV)
- Mistrust of medical system and government (especially among African American women)
- Aversion to pill-taking; inability to take a pill a day
- Being “in the moment”
- Newness of drug
- Individual chooses not to
- Confidentiality
- Denial (of HIV risk)
- Resistance among churches/ faith-based community
- Bad transportation system
- Stigma

Cost: Who Should Pay for PrEP?

P: “I think it should be paid for across the board. . . .insurance, med-Cal, government as prevention. They’re saving more money. . . .”

P: “You’re talking about an underserved community. . . so if you’re talkin’ about an underserved community than you have to understand that there are no funds attached. . . .”

P: “. . . so if you’re talking in that community than you have to make it available to them. If not, than don’t even bring it up to them. . . .”

P: “. . . no teases! ‘Cause that’s like a tease and that’s not necessary.”

P: “Bottom line is that it’d be great because they are targeting our community, let’s be real. We already say that up front that you’re looking at our community. We have to be realistic about you know, just the socio economics of our community. The underserved, you know with the finance it has to be made available, it has to be FREE. . . .” (FG 3, OAK)

P: “It depends on which insurances will cover it. For example, will Medi-Cal cover it or not? If Medi-Cal covers it, all the better because so many people do not have the financial means to cover these costs, and many do not even have Medi-Cal now.” (FG 5 SD)

Side Effects

F: So let me read you what the side effects are, the official side effects that could be common: Abnormal skin sensations, so feeling like your skin is crawling, back pain, cough, diarrhea, getting dizzy, having gas, headache, indigestion, joint pain, nausea, sinus damage, strange dreams, loss of appetite, sweating, tired, having trouble sleeping, weight loss and skin discoloration.

P: “That sounds like HIV.” (FG 4, OAK)

F: Other than how well it works, what other thing do you think is most important to women when as they’re deciding to use this?

P: “Side effects”

P: “Side effects”

P: “Interaction with other medication” (FG 4 OAK)

P: “How accessible is it”

P: “How does it make you feel, side effects”

P: “Is it gonna make me gain weight?”

P: “Will it interfere with medications I’m already on?” (FG 7 MEM)

Mistrust of Government and Medical System

P: “I think right now there’s a lack of trust, ‘cause you look at the hormone replacement situation where everybody was told to take these hormone pills and now its come out it may cause cancer, so I think that people are very cautious when it comes to government issued anything. . .”

P: “. . . you think about how, as minority people we been experimented on, you know, look at Tuskegee situation, so it’s like there’s not a lot of trust and then you think about finance, is it gonna be free? . . .”

P: “. . . I just don’t know, it has to work. . . you know ‘cause there’s not a lot of trust, with us, in medical science in terms of whether or not we trust what they giving us is not genocide. . .” (FG 3, OAK)

P: “Thing about the Gardasil, even with that. . . that message hasn’t gotten to the people that need it the most. When they came in, they came in wrong and they came in the poor neighborhoods and you know we have suspicious (*group agreement, yeah!*) Comin’ at us like this and wanting us to take a pill. . .you gotta explain why.” (FG 8 MEM)

Findings: Facilitators of PrEP Uptake: Information Sources and Marketing

- Peer-to-peer; friend-to-friend
- Doctors: OB-GYNs, other providers
- CBOs and family planning organizations
- Schools
- Social Media; Mass Media (tv & magazines)
- Flyers distributed where people gather (e.g., casino, beauty shops, bingo games, etc.)

Sources of Information/Marketing

P: “I would say. . . like Choices, Planned Parenthood, places like clinics that service those individuals, without judgment where they’re trusted and comfortable coming in to. It would be great if the school nurses would even touch on it. I would be happy if they would touch on birth control. . . . So you know, although we’re in the bible belt, there are places where the school systems are more liberal so utilizing the school system to get the information out cause that is where most of our kids spend the majority of their time. So, getting school nurses on board.”

P: “Also the colleges, I mean we need PrEP, although I’m not a big fan. . . .of using PrEP . . . just because of adherence issues, but to reach that community. I think like college campuses, student health centers, they will talk to you about those things and they’ll test you for HIV and everything else but that will be a good way to reach some of those younger people too, college campuses, boy and girls club.” (FG 8 Mem)

P: “Another issue could be the targeting of it, cause if you target it strictly towards AA women, we gonna think again. We gonna think it’s a government thing, “why us?” So, be careful how you target.”
(FG 7 MEM)

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Other Issues & Considerations

- Efficacy Level
- Condom use & “risk compensation”
- PrEP and HIV testing
- Impact of PrEP on sex life
- Stealth factor in taking PrEP
- General issues of frank talk about sex
- PrEP vs. PEP

Efficacy Level

P: “We would love to see 100%, but even at 42 – 67% it is an advantage. It’s something good and we also know that it isn’t going to stay there. We know that the doctors and others are studying for further down the line.”

P: “...a lot. It means a lot. Even 10% is better than nothing.”

F: What about 75%?

[Group murmuring in agreeable tone]

F: 90%?

P: “Why not just 100%?”

P: “As long as it gets approved before I become HiV positive then it’s okay.” (FG 5 SD)

P: “I guess working here has scared me so much to the point, where, even if I’m not sexually active. .. I’m taking my pill. I make sure I have condoms on me at all times. I probably have 10 in my purse right now. Haven’t had sex in a long time but I wanna be prepared! So if I have a pill that might help, you know. I have a 50% OF NOT getting HIV, ahhh, that’s even better. I’m probably halfway safe with my pills. ..I’m probably halfway safe from HIV. . . ok, I have my condoms so I probably safe most of the time.” (FG 8 Mem)

PrEP and Condom Use

F: *The other question is do you think if either the woman or the male partner is using PrEP that a condom would also be used as well?*

P: “I’d still be using condoms.”

P: “You can still be getting’ other things.”

(Lots of group chatter in agreement that they’d still use a condom)

P: “Them on the down low.”

P: “Cause you don’t know what they doin’, you just don’t know.” (FG 1 WDC)

P: “One comes to consider, nothing is certain. It’s not for sure that he is taking care of himself, it’s not certain whether or not he gives us HIV, so it’s better to use it [condom] to have some prevention because we really don’t have the certainty as to whether they are going to give it to us or not. Like she’s saying, we don’t know if he is giving us something, and suddenly he slips...” (FG 5 SD)

P: “After we get through puttin’ on the condom”S” (*emphasis on the “s” as in multiple condoms*) on and takin all the pills you supposed to take before you have sex you gonna be dry, asleep and tired!” (FG 3 OAK)

Site Differences

- Washington, DC—convey mistrust of government, health care system, men
- Oakland, CA—convey mistrust of government, health care system, men
- Memphis, TN—older group, some service providers; mention role of church, rural communities, HIV as class issue
- San Diego, CA—many in serodiscordant couples; more sanguine about behavior of men

Conclusions

- Most U.S. women at risk of HIV infection (and those who work with them) are unaware of PrEP.
- US women are highly diverse; and their opinions about PrEP are highly nuanced.
- But, with a demonstrated high level of efficacy, with correct and complete information from trusted sources, and with an assured way of paying for it, PrEP is viewed as an option that should be available to all kinds of women who are having sex, whether or not they perceive themselves to be at risk of HIV infection.
- Condoms should still be promoted and encouraged for STI prevention, but it is likely many women will opt not to use them or have male partners use them.
- Cost, efficacy level, and side effects are the most critical concerns U.S. women express about PrEP.
- More research is necessary.

Acknowledgements

- Participants
- Sites
 - The Women’s Collective, Washington, DC
 - Hosts: Farah Nageer-Kantor, June Pollydore, Myra Witherspoon
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 - WORLD, Oakland, CA
 - Host/Facilitator: Naina Khanna
 - Christie’s Place, San Diego, CA
 - Hosts: Liz Brosnan & Shannon Hansen
 - Facilitator: Rosario Rios
 - Choices, Memphis, TN
 - Host/Facilitator: Jennifer Marshall