

# Black Cisgender Women's PrEP Knowledge, Attitudes, Preferences, and Experience in Chicago

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**Background:** Although black cisgender women in Chicago continue to disproportionately account for new HIV diagnoses, few are on pre-exposure prophylaxis (PrEP). We used concurrent mixed-methods to understand women's PrEP knowledge, attitudes, experience, and preferences in Chicago.

**Setting and Methods:** We surveyed 370 HIV(-) cisgender women visiting a sexually transmitted infection clinic (n = 120) or emergency department (n = 250). Two focus groups were conducted with PrEP-naïve women, and interviews were conducted with 7 PrEP-experienced women. Quantitative data were analyzed using descriptive statistics and multivariable logistic regression, and qualitative data using thematic analysis.

**Results:** Majority of women identified as black (83.0%) and had a regular source of health care (70.0%). In the past 6 months, 84.1% had vaginal or anal sex, most with inconsistent condom use (94.2%). Only 30.3% had heard of PrEP, but once explained, one-quarter considered starting PrEP, with protecting health (76.4%) and reducing HIV worry (58.1%) the most common reasons. Factors associated with considering PrEP included being Latina [adjusted odds ratio (aOR): 3.30, 95% confidence interval (CI): (1.21 to 8.99)], recent sexually transmitted infection [aOR: 2.39, 95% CI: (1.25 to 4.59)], and higher belief in PrEP effectiveness [aOR: 1.85, 95% CI: (1.22 to 2.82)]. Most (81.1%) had concerns about taking PrEP with side effects a common concern. Qualitative themes aligned with survey results, revealing a disconnection

from current PrEP marketing, need for community-level PrEP education/outreach, and importance of provider trust.

**Lessons Learned:** Despite significant PrEP implementation work in Chicago, less than one-third of women in our study had heard of PrEP. Once informed, PrEP attitudes and interest were positive. Translating these results into interventions reflecting women's preferences and barriers is critical to increase PrEP uptake by cisgender women in Chicago and elsewhere.

**Key Words:** PrEP, HIV prevention, cisgender women, mixed methods, PrEP access

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## INTRODUCTION

The widespread introduction of pre-exposure prophylaxis (PrEP) to prevent HIV has been an important step in efforts to end the HIV epidemic in the United States.<sup>1</sup> Although uptake in some populations has been growing, in the fourth quarter of 2017, the PrEP-to-need ratio for women (number of PrEP prescriptions divided by number of new HIV diagnoses) was less than a fourth of that of men (0.4 versus 2.1). This reflects a significant inequity in PrEP use among women compared with their need.<sup>2</sup> Black cisgender women in particular are underrepresented among PrEP users, although they accounted for 11.5% of all new HIV infections in 2017, and have a 14.6-fold higher risk of acquiring HIV infection compared with white women.<sup>3</sup> Work to date has found barriers along the PrEP care continuum for cisgender women, including difficulty identifying women who are the most likely to benefit from PrEP, low levels of PrEP knowledge, HIV and PrEP stigma, mistrust in the health care system, and self-reported barriers to PrEP initiation and adherence, such as substance abuse, intimate partner violence, and depression.<sup>4–11</sup>

Research into interventions to increase PrEP uptake and adherence in other disproportionately impacted groups, such as men of color who have sex with men and transgender women, is ongoing in many high burden areas in the United States.<sup>12,13</sup> Approaches have targeted multiple steps along the PrEP continuum to address a range of barriers from knowledge to access.<sup>13,14</sup> Despite ground-breaking work to increase PrEP awareness and uptake in Chicago, success in improving PrEP uptake among black cisgender women remains extremely low, with only 336 on PrEP in 2017.<sup>15,16</sup>

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We designed a mixed-methods study that examined PrEP knowledge, attitudes, preferences, and experiences among PrEP-naïve and PrEP-initiated cisgender women to identify preferred intervention and implementation strategies that can increase PrEP uptake.

## METHODS

### Cross-Sectional Survey Sample and Design

We recruited nonpregnant, adult HIV-negative cisgender PrEP-naïve women from the following 2 locations in Chicago: (1) a sexual health and sexually transmitted infection testing and treatment clinic [sexually transmitted infections (STI) clinic] run by the Chicago Department of Public Health located on the west side of Chicago and (2) the adult emergency department (ED) of an academic medical center located on the south side of Chicago. The neighborhoods served by these 2 sites are mostly people of color, with a high proportion of households living below the federal poverty line, and some of the highest HIV incidence rates in the city, including Washington Park and Chatham with rates of 55.8–88.7 per 100,000 in 2018.<sup>15</sup> Pregnant women were excluded because the recommendations and decisions regarding PrEP use during pregnancy could be quite different from those for nonpregnant women, and subanalyses would not have been possible given the sample size.

Women were recruited by the research team in the site waiting rooms, and eligibility determined through the initial survey questions. In the ED, we preferentially recruited women presenting with a chief complaint of STI-related symptoms and women who had a positive STI test in the previous 6 months. Eligible women completed a self-administered tablet-based survey through REDCap.<sup>17</sup> When available, we used published survey items on PrEP knowledge, attitudes, PrEP stigma,<sup>4</sup> and access preferences, and when not available, we used surveys from other studies noted in the acknowledgments. We also asked about preferred sources for PrEP information, preferred locations to initiate and refill PrEP, and potential barriers or support needs. As needed, questions were adapted for relevance to cisgender women and to accommodate survey length constraints (Table 1). Additional questions included sociodemographic factors, health care access, HIV-risk behaviors in the past 6 months (eg, sexual activity and condom use), perceived HIV risk (zero to very large), worry about getting HIV (none of the time to all of the time), and activities to protect against HIV.<sup>7,8,18,19</sup> PrEP eligibility was determined based on the 2017 US Public Health Services (USPHS) summary guidance criteria for PrEP described by Calabrese et al (see also Table 2).<sup>20,21</sup> After asking about PrEP knowledge, PrEP was explained to elicit attitudes and preferences.

### Focus Groups and Key Informant Interviews Study Population and Design

We conducted 2 focus groups (FGs) with PrEP-naïve nonpregnant cisgender women aged 18 years or older ( $n = 16$ ). We performed key informant interviews (KIIs) with nonpregnant cisgender women aged 18 years or older who

had initiated PrEP. Our KII recruitment target was 10, but because of challenges identifying PrEP-experienced cisgender women, we were only able to complete interviews with 7. These participants were recruited through local community-based organizations that provided social and health services to women at risk of HIV and through clinical contacts of the study team.

The FG protocol was informed by a social ecological theory and designed to provide insights into survey responses and the multilevel factors that shape women's PrEP knowledge, attitudes, and preferences.<sup>22</sup> The KII protocol used a semistructured protocol to understand women's pathways to PrEP use, facilitators of and barriers to PrEP uptake and adherence, and recommendations to increase PrEP access and uptake for cisgender women.

The study was approved by the Institutional Review Boards at Northwestern University, University of Chicago, and the Chicago Department of Public Health. All individuals provided informed consent before participating in the study, and if eligible were compensated for their participation. All individuals were also given PrEP educational materials at the end of their study encounter.

## Data Analysis

### Quantitative

We created composite variables on perceived PrEP stigma (5 items) and effectiveness (3 items), both scored on a five-point *strongly agree* to *strongly disagree* scale, with higher scores representing better perceived effectiveness and lower stigma.<sup>7,18,23</sup> We also created summation variables for correct responses to STIs that PrEP protects against (6 questions, score 0–6) and HIV knowledge (9 questions, score 0–9).

We analyzed the data in SAS 9.3 (SAS Institute, Inc., Cary, NC), reporting descriptive statistics, and results of bivariate analyses (including  $\chi^2$  or Fisher exact tests and  $t$  tests). Factors significant at the  $P < 0.20$  level in bivariate analyses were included in multivariable logistic regression models for PrEP awareness and likelihood to start PrEP in the next 6 months. We also included variables a priori based on known associations from the literature.

### Qualitative

We developed an analytic codebook based on the FG and KII protocols, extant literature and field notes, and deidentified FG and KII transcripts in Dedoose for analysis.<sup>24</sup> After the initial codebook was created, 2 independent coders analyzed an FG transcript, and 2 additional independent coders analyzed a KII transcript. All coders then met to compare results, establish coding norms, and refine the codebook. We also used open coding to identify emergent themes and invoked a negative incident analysis to identify divergent statements.<sup>25</sup> Each coder then coded assigned transcripts independently, starting with broad coding and progressing to more focused coding. Codes were reviewed by a second coder with differences discussed until a consensus was reached by the coding team.<sup>26</sup>

**TABLE 1.** Survey Domains and Specific Areas and Illustrative Questions

Domains	Areas	Sample Questions With Sources
Sociodemographics and health care	Age, ethnicity, education, insurance, and usual source of care	
Health care utilization	Regular sources of care and HIV testing	What type of place best describes your regular health care provider? Health center Doctor's office HMO Pharmacy clinic Emergency department Somewhere else Do not want to respond
HIV risk	Sexual partners and practices, STIs, and IDU	With how many men did you have vaginal sex in the past 6 mo? <sup>19</sup> vaginal sex is where a man puts his penis into your vagina.  How frequently did you use a condom when you had vaginal sex in the past 6 mo? Always Most of the time Sometimes Never
HIV knowledge	Transmission and treatment	HIV can be transmitted in the following ways (check all that are true) Sex, sharing needles, pregnancy/childbirth, sharing a drinking glass, kissing on the cheek, or using public toilets
Self-perceived HIV risk	Risk and worry	There are medications which can cure HIV (true/false) I think my chances of getting infected with HIV are: zero, almost zero, small, moderate, large, and very large I worry about getting infected with HIV: none of the time, rarely, some of the time, a moderate amount of time, a lot of the time, or all of the time <sup>19</sup>
PrEP knowledge and experience	PrEP knowledge*, ever recommended to use, and ever used	5 point Likert scale: When on PrEP I do not need to use a condom PrEP is effective for preventing HIV if taken on a daily basis <sup>8</sup>
PrEP attitudes, interest, and willingness	PrEP stigma, <sup>4</sup> interest in using, and willingness to use	People who are on PrEP sleep around (5 point Likert scale)
Preferred sources of PrEP information	Usual source of health information and trusted sources for PrEP	What source(s) would you trust the most for information on PrEP (choose all that apply) Friend, family member, my PCP, another doctor or nurse, family planning clinic, another clinic or medical providers, internet search, social media, HIV prevention organization, or somewhere else

*(continued on next page)*

**TABLE 1.** (Continued) Survey Domains and Specific Areas and Illustrative Questions

Domains	Areas	Sample Questions With Sources
Preferences for PrEP access	Source of initial and follow-up PrEP	<p>If you were to start PrEP where would you prefer to have your first PrEP-related visit?</p> <p>My PCP, family planning clinic, STI clinic, pharmacy, or somewhere else</p> <p>What would be the most important factor in choosing where you would get PrEP?<sup>†</sup></p> <p>Cost of appointment</p> <p>Familiarity with clinic</p> <p>Anonymity</p> <p>Hours open</p> <p>Length of waiting time</p> <p>Easy to access clinic</p> <p>How welcoming they are</p> <p>Confidentiality</p>
Potential barriers to PrEP	Cost, confidentiality, and PrEP stigma	<p>If you were to decide to take PrEP, which of the following are concerns that you have related to taking PrEP? (choose all that apply)</p> <p>Side effects of PrEP</p> <p>PrEP may interact with a medication I am already taking</p> <p>PrEP may not protect me completely from HIV</p> <p>Having to take a pill once a day</p> <p>Might make me more likely to have sex without a condom</p> <p>My partner would be angry or think that I am not being faithful</p> <p>People will see me taking medication and think I have HIV</p> <p>Having to talk to a health care provider about my sex life</p> <p>I will not be able to afford the cost of medication</p> <p>I would not know where to go to get PrEP</p> <p>I am too busy with child care</p> <p>I want to become pregnant in the near future</p> <p>I have no concerns</p>
Support needs for PrEP	Cost, adherence, and disclosure	<p>If you were to take PrEP, what support do you think you would need?</p> <p>Help remembering to take the education every day</p> <p>Support telling my partner I am taking PrEP</p> <p>Support telling my family or friends I am taking PrEP</p> <p>Financial support to pay for the medications or medical visits</p> <p>Others</p> <p>I would not need support</p>

\*Schneider personal communication.

<sup>†</sup>Adapted from the World Health Organization Health System Responsiveness domains.<sup>28</sup>  
IDU, injection drug use; PCP, primary care provider.

## RESULTS

### Quantitative Results

We surveyed 370 women between April and August 2018, 120 (32.4%) from the STI clinic and 250 (67.6%) from the ED (Table 2). The median age was 28 years (range 18–57 years), and most (83.0%) identified as black, with one half (58.9%) having at least some college education (Table 2). Three-quarters (71.3%) had a regular source of health care (83.0% doctor's office or health center), and 61.9% had health insurance. Most (84.1%) reported vaginal or anal sex in the past 6 months, with low rates of consistent condom use (14.5% for vaginal sex and 19.2% for anal sex). Respondents reported low rates of partners known to be a high risk of HIV infection, transactional sex, or injection drug use. One-third had sex with >1 partner, and 11.6% reported testing positive for a bacterial STI in the previous 6 months. HIV knowledge was very high (median score of 7 of the 9), although 20% believed there was a cure for HIV, and 11.4% reported that HIV can be transmitted by using public toilets.

More than one-third of women met the USPHS summary guidance criteria for PrEP.<sup>21</sup> These women were more likely to report higher levels of worry of acquiring HIV than women not meeting these criteria [46.3% versus 11.7%, respectively ( $P < 0.0001$ )] and a self-assessed risk of getting HIV [moderate or higher: 15.8% versus 6.2%, ( $P < 0.0001$ )] (see Appendix, Supplemental Digital Content, <http://links.lww.com/QAI/B465>). Only 30.3% of surveyed women had heard of PrEP before the survey; with the most common source of knowledge from an advertisement (35.7%). Only 29.4% of PrEP-aware women reported hearing about PrEP from a medical provider. Few factors were associated with PrEP awareness (Table 3), and in the multivariable analysis, only knowing someone on PrEP [adjusted odds ratio (aOR) 14.33 95% confidence interval (CI): (2.82 to 72.87)] was predictive of pre-existing PrEP knowledge.

Once PrEP was explained, PrEP attitudes were relatively positive as follows: a median PrEP stigma score of 3.2 of the 5 (5 represents the lowest stigma) and a median belief in PrEP effectiveness 3.8 of the 5 (5 represents the highest effectiveness) (Table 4). About a third (28.4%) considered starting PrEP in the next 6 months, with protecting health (76.8%) and reducing HIV worry (58.1%) the most common reasons (Table 4). More women who met the USPHS summary guidance criteria for PrEP considered starting PrEP than women who did not meet the criteria (40.9% versus 22.4% respectively,  $P = 0.002$ ) (see Appendix, Supplemental Digital Content, <http://links.lww.com/QAI/B465>). A number of factors were associated with considering starting PrEP in bivariate analysis, with being Latina [aOR 3.30, 95% CI: (1.2 to 8.99)], recently having an STI [aOR 2.39, 95% CI: (1.25 to 4.59)], and a higher belief in PrEP effectiveness [aOR 1.85, 95% CI: (1.22 to 2.82)] remaining significant in the multivariable model (Table 5).

Women noted that if they were to decide to take PrEP, most preferred to start PrEP in their usual source of medical care (64.3%), followed by a STI clinic (12.2%) or a family planning clinic (8.4%) (Table 4). Preferred places for regular PrEP care follow-up were slightly different, although the usual source of care remained most common (56.8%),

followed by a pharmacy (18.6%), STI clinic (12.2%), and family planning clinic (5.1%). The top reasons influencing where women would want to receive PrEP included cost (23.5%), familiarity with the clinic (22.2%), confidentiality (22.7%), and ease of access (13.8%).

Most women (80.7%) reported concerns about taking PrEP that included side effects (68.4%), incomplete HIV protection (25.4%), cost (24.3%), and drug interactions (23.2%). Almost three-quarters (72.2%) said they would need some form of support around using PrEP, including financial support (34.6%), disclosure to partners and/or family (25.4%), and adherence (29.5%) (Table 4).

### Qualitative Results

Among the 16 FG participants, 14 (87.5%) were African American, with a mean age of 44 years (range 26–62 years). Among the 7 key informants (KIs), 6 (85.7%) were African American with a mean age of 46.7 years. At the time of the KIIs, 6 of the participants were using PrEP (duration of use ranging from 1 to 18 months), and one participant had discontinued PrEP after 2 weeks because of side effects.

Qualitative themes from FGs with PrEP-naive women generally aligned with survey results and provided contextual information not identified in the survey, including problems with current PrEP screening and advertising. KII findings identified multiple pathways to PrEP use that have relevance for improving PrEP uptake among cisgender women. Both data sources yielded recommendations for PrEP interventions for cisgender women vulnerable to HIV.

### PrEP Awareness and Knowledge Among PrEP-Naive Women

Analysis of FG data indicated that less than a third had heard of PrEP before the screening for the FG eligibility. Of these, a few had seen a citywide PrEP marketing campaign (PrEP4Love),<sup>16</sup> one woman knew someone on PrEP through her social network, and another woman had been offered PrEP at a local program for women with substance abuse and/or criminal legal system histories. Women were surprised to learn that PrEP had received the FDA approval in 2012, and expressed anger and confusion that they had not been educated about PrEP given the impact of HIV on their communities, their engagement in routine HIV-testing, and their use of multiple health, social, and research systems focused on HIV/AIDS. As one woman stated: “*I just want to know, is there a place that we can go and get the information about PrEP, is (there someone) that's administering the pill or whatever? Because, like I said, every six months. They're going down there, and why are you not telling me about this?*”

In expressing their anger, some women reported feeling like information about PrEP had been kept secret, pointing to a sense of medical and governmental mistrust. As noted by one woman:

*“Why is it secret if it's important for the community? Is it a game to the government? ...we actually have the medication to prevent it. But guess what? We're not advertising... it's not*

**TABLE 2.** Sociodemographic, Health Care, and Perceived and Reported HIV Risk (N = 370)

Variable	Mean (IQR)
Age	28 (23–35)
	<b>Number (Percentage)</b>
Variables	
Site	
STI clinic	120 (32.4%)
ED	250 (67.6%)
Which side of Chicago do you live in	
South side	258 (69.7%)
West side	69 (18.6%)
Others	41 (11.1%)
Missing	2 (0.5%)
African American*	307 (83.0%)
Hispanic or Latina	
Yes	43 (11.6%)
Missing	2 (0.5%)
Minority race or ethnicity	353 (95.4%)
Highest level education	
> High school or GED	147 (39.7%)
Missing	5 (1.4%)
Health insurance	
Yes	229 (61.9%)
Do not know	45 (12.2%)
Missing	36 (9.7%)
Reported regular health care provider	259 (70.0%)
If regular provider noted	
Doctor's office	148 (57.1%)
Health center	57 (22.0%)
Emergency department	12 (4.6%)
Health maintenance organization	10 (3.8%)
Ever tested for HIV	
Yes	321 (86.7%)
Missing	2 (0.5%)
Sex in the past 6 mo	
Vaginal sex	310 (83.8%)
Anal sex	52 (14.1%)
Either anal or vaginal sex	311 (84.1%)
Sex with more than one partner in the past 6 mo	130 (35.1%)
If sex in the past 6 mo, always use condoms	
Vaginal sex	45 (14.5%)
Anal sex	10 (19.2%)
Bacterial STI in the past 6 mo (chlamydia, gonorrhea, and syphilis)*	43 (11.6%)
Exchange sex for money, housing, drugs, or gifts in the past 6 mo	
Yes	6 (1.6%)
Missing	9 (2.4%)
Eligible for PrEP by USPHS summary guidance†	139 (37.6%)
HIV perceived risk	
Moderate or higher	36 (9.7%)
Missing	6 (1.6%)
Worry about getting HIV	
Some, moderate, or all the time	111 (30.0%)

**TABLE 2.** (Continued) Sociodemographic, Health Care, and Perceived and Reported HIV Risk (N = 370)

	Number (Percentage)
Missing	5 (1.4%)
HIV prevention behaviors	
Nothing	113 (30.5%)
Abstinence	51 (13.8%)
Not sharing needles	34 (9.2%)
Injection drug use: shared injection equipment. <sup>20</sup> ( <a href="https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf">https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf</a> ).	
*These variables have had missing results automatically converted to No from REDCap.	
†Any of the following: Sexual: HIV-positive sexual partner, recent bacterial STI, high number of sex partners in the past 6 months, history of inconsistent or no condom use in the past 6 months, commercial sex work, and in high HIV prevalence area or network.	
IQR, interquartile range.	

*on TV on an everyday basis... But you'll hear all these [other] commercial things...It's like—okay, that's cute. But, you know, herpes don't kill you; HIV does."*

Similarly, another woman felt like low-income communities were having information intentionally hidden from them:

*"I feel like there are, probably, certain communities that know about it; it just depends on what community you're in. So, the poverty communities, nine times out ten, they're not going to tell you anything. Figure it out the best way you can. Because the population is already high, as far as they say, so why not go ahead and knock some of these folks off. More funerals."*

Even among the women who had heard of PrEP, most were uncertain about how it worked or if it was relevant to them. For example, one of the women who reported seeing a PrEP4Love advertisement indicated that the campaign seemed to target men, not women. Women who were PrEP-naïve reported overall high levels of openness to PrEP, with several reporting that they were going to talk with their provider about PrEP. One woman described talking to her provider at her next visit:

*"I'll go pull out my phone, and say, 'I'm glad you got some time because I'm paying right now to see me. So, give me a second, let me go on Google, and pull everything out, and now you do have the information PrEP, we're going to sit here, we're going to get this knowledge together, and I want you to put me on this pill, so I can protect myself.'"*

Despite mistrust in the health care system, in general women trusted their individual health care providers and reported being open to receiving information from their primary care providers, gynecologists, case managers, psychiatrists, and HIV testers. Women underscored the importance of having a trusted health provider introduce

**TABLE 3.** Factors in Bivariate and Multivariate Analysis Associated With Hearing About PrEP Before the Study

Variable	P	OR (95% CI) (N = 364)	aOR (95% CI) (N = 359)
African American*	0.41		
Yes		1.30 (0.70 to 2.41)	1.39 (0.61 to 3.17)
No		Referent	Referent
Hispanic or Latina*	0.26		
Yes		0.65 (0.31 to 1.37)	0.65 (0.24 to 1.76)
No		Referent	Referent
Site*	0.78		
STI clinic		1.07 (0.67 to 1.72)	Referent
ED		Referent	0.78 (0.45 to 1.33)
Regular health care provider*	0.23		
Yes		1.36 (0.82 to 2.25)	1.50 (0.87 to 2.60)
No		Referent	Referent
Highest level of education*	0.56		
> High school or GED		1.15 (0.73 to 1.81)	1.31 (0.80 to 2.67)
≤ High school or GED		Referent	Referent
Condomless vaginal or anal sex*	0.80		
Yes		1.14 (0.42 to 3.11)	1.26 (0.87 to 2.60)
No		Referent	Referent
Exchange sex	0.073		
Yes		4.69 (0.85 to 26.00)	4.74 (0.74 to 30.52)
No		Referent	Referent
Know someone on PrEP	0.0006		
Yes		10.92 (2.32 to 51.42)	<b>14.33 (2.82 to 72.87)**</b>
No		Referent	Referent
Age (per 1 year increase)	0.93		
		1.00 (0.97 to 1.03)	0.99 (0.96 to 1.02)

\*Entered a priori into a multivariate model.  
\*\*P = 0.0013.

PrEP. However, despite the overall openness toward PrEP, some FG women indicated that they would not take PrEP because it did not align with their current circumstances or risk perceptions. However, other women reported that PrEP would reduce their worry about HIV infection. In particular, they noted concerns and risks associated with their male partners' infidelity, "if you gonna lie to me and ain't going tell the truth about what you out here messing around with these different women—and you catch something, I'm trying to protect myself...". For these women, protection against HIV with PrEP use reduces worry about infection from nonmonogamous partners.

Paralleling survey findings, the primary concerns about taking PrEP were side effects, stigma, and having the finances to cover PrEP. Women were also concerned about PrEP interacting with other medications or exacerbating preexisting

**TABLE 4.** PrEP Knowledge, Attitudes, and Preferences After PrEP Explained to Survey Participants

Categorical Variables	Number (Percentage)
Heard of PrEP	112 (30.3%)
If yes, top sources of PrEP information	
Advertisement	40 (35.7%)
Medical provider	33 (29.5%)
Friends	18 (16.1%)
HIV-testing counselor or outreach worker	14 (12.5%)
Online	7 (6.25%)
Know someone on PrEP	11 (3.0%)
Might/probably/definitely will take PrEP in next 6 mo	105 (28.4%)
What might be reasons you would take PrEP	
Protect my health	284 (76.8%)
Reduce my worry about HIV infection	215 (58.1%)
Because my doctor or nurse told me to	77 (20.8%)
Having a baby with someone HIV(+)	67 (18.1%)
Top preferred sources of PrEP information	
Regular primary care provider	182 (49.2%)
Other health care providers	131 (35.4%)
HIV prevention program	133 (35.9%)
Family planning clinic	104 (28.1%)
Internet search	83 (22.4%)
Top preferred sources to start PrEP	
Regular source of health care	238 (64.3%)
STI clinic	60 (16.2%)
Family planning clinic	31 (8.4%)
Pharmacy	12 (3.2%)
Any support needed to take PrEP	264 (71.4%)
Most common support needed to take PrEP	
Financial support	128 (34.6%)
Adherence support	109 (29.5%)
Disclosure to partner or family	95 (25.4%)
None	103 (27.8%)
Most common concerns about taking PrEP	
Concerns about PrEP side effects	253 (68.4%)
Concerns about having to take a pill once a day	289 (78.1%)
All correct knowledge about PrEP protection against STIs	281 (76.0%)

Continuous variables	Median (IQR) and N
Average PrEP stigma score (range 0–5) (N = 358)	3.2 (3–3.6)
Average PrEP effectiveness score (range 0–5) (N = 358)	4 (3.3–4.3)
HIV knowledge score (range 0–9) (N = 364)	7 (6–8)

\*Missing responses were counted as a negative response.

conditions. Among women of childbearing age, a major concern was how PrEP would affect fetal development. One woman asked: "if you're pregnant...does it affect the baby or anything in that way? I would like to know that information..." Additional concerns identified by women included stigma and how to handle disclosure to romantic and sexual partners.

**TABLE 5.** Factors in Bivariate and Multivariate Analysis Associated With Being Likely to Start PrEP in the Next 6 months

Variables	P	OR (95% CI), N = 355	aOR (95% CI), N = 353
African American*	0.06		
Yes		0.58 (0.33 to 1.04)	1.50 (0.60 to 3.74)
No		Referent	Referent
Hispanic or Latina*	0.0008		
Yes		2.94 (1.54 to 5.62)	<b>3.30 (1.21 to 8.99)</b>
No		Referent	Referent
Site	<0.0001		
STI		2.70 (1.68 to 4.33)	0.41 (0.16 to 1.04)
ED		Referent	Referent
Regular health care provider*	0.85		
Yes		0.95 (0.58 to 1.57)	<b>1.95 (1.00 to 3.80)</b>
No (referent)		Referent	Referent
Highest level of education*	0.54		
> high school or GED		0.86 (0.54 to 1.37)	0.72 (0.39 to 1.32)
≤ high school or GED		Referent	Referent
Health insurance*	0.06		
Yes		0.64 (0.40 to 1.02)	0.76 (0.42 to 1.39)
No		Referent	Referent
Residence	0.02		
South side		Referent	Referent
West side		1.97 (1.12 to 3.46)	0.40 (0.14 to 1.11)
Others		1.99 (0.99 to 3.99)	0.47 (0.15 to 1.45)
Any STI in the past 6 mo	<0.0001		
Yes		2.93 (1.69 to 5.06)	<b>2.39 (1.25 to 4.59)***</b>
No		Referent	Referent
Abstinence to prevent HIV	0.11		
Yes		0.56 (0.27 to 1.16)	0.49 (0.21 to 1.16)
No		Referent	Referent
Not sharing needles to prevent HIV	0.02		
Yes		2.29 (1.10 to 4.79)	1.82 (0.74 to 4.50)
No		Referent	Referent
PrEP information from HIV prevention organization	0.04		
Yes		1.64 (1.03 to 2.62)	1.14 (0.65 to 1.99)
No		Referent	Referent
PrEP information from somewhere else	0.14		
Yes		1.78 (0.82 to 3.86)	0.86 (0.33 to 2.26)
No		Referent	Referent
Concerns about side effects of PrEP	0.02		

**TABLE 5.** (Continued) Factors in Bivariate and Multivariate Analysis Associated With Being Likely to Start PrEP in the Next 6 months

Variables	P	OR (95% CI), N = 355	aOR (95% CI), N = 353
Yes		1.86 (1.09 to 3.20)	1.37 (0.71 to 2.64)
No		Referent	Referent
Concerns taking a pill once a day	0.01		
Yes		1.94 (1.15 to 3.26)	1.65 (0.86 to 3.15)
No		Referent	Referent
Need support to use PrEP	0.04		
Yes		1.78 (1.02 to 3.10)	1.16 (0.6 to 2.25)
No		Referent	Referent
No. of vaginal sex partners	0.013		
None		1.65 (0.74 to 3.65)	1.04 (0.38 to 2.84)
One		2.83 (1.26 to 6.32)	0.97 (0.52 to 1.83)
More than one		Referent	Referent
Condomless vaginal or anal sex*	0.22		
Yes		0.46 (0.13 to 1.63)	0.54 (0.14 to 2.05)
No		Referent	Referent
Correct knowledge about PrEP protection against STIs*	0.94		
All correct		0.97 (0.56 to 1.70)	0.66 (0.33 to 1.33)
Not all correct		Referent	Referent
Age (per 1 year increase)*	0.02		
HIV perceived risk per one-point increase)*	0.0003	1.44 (1.18 to 1.76)	1.19 (0.90 to 1.60)
Worry about getting HIV (per one-point increase)*	<0.0001	1.39 (1.20 to 1.61)	1.21 (0.99 to 1.47)
Summary of HIV knowledge (per one-point increase)*	0.36	1.10 (0.90 to 1.34)	0.94 (0.73 to 1.22)
Average of stigma (per one-point increase continuous)*	0.05	1.49 (1.00 to 2.22)	1.31 (0.80 to 2.13)
Average of PrEP effectiveness (per one-point increase)*	<0.0001	2.17 (1.53 to 3.07)	<b>1.85 (1.22 to 2.82)**</b>

\*Missing responses were counted as negative response.

\*\* $P < 0.05$  \*\*\* $P < 0.01$ .

Among the women who had initiated PrEP, most had done so after a possible exposure to HIV, with exposures occurring in both ongoing and casual relationships (ie, partner infidelity, condom failure, and condomless sex) or sexual assault. Four accessed PrEP through a county health clinic (2 heard about PrEP from HIV screening and PrEP project staff, one from a friend referral, and one from a partner referral), 2 accessed PrEP through a community health center (both had established care at the center), and one accessed PrEP through a research study.

For many KIs, PrEP initiation was rapid and few discussed needing additional time to consider PrEP uptake.

Specifically, 2 initiations were immediate and 3 initiations were within 1 month of requesting or being offered PrEP with minor lags due to scheduling clinic appointments. Most participants received same-day prescriptions. For these women, taking PrEP was a form of empowerment that enabled them to protect themselves independent of others' actions: "...for protecting me, everybody else needs to protect them, and I don't have to be part of it." In contrast to the women in the FG, these women were told about PrEP from clinical providers when seeking HIV testing or birth control. Similar to the survey results, after starting PrEP, women identified side effects as a primary barrier to staying on PrEP.

In both KII and FG, women provided suggestions for how to increase PrEP uptake. In both groups, women who had seen PrEP advertisements reported that these marketing efforts were not impactful because they were not perceived as targeting women or their communities. Women's top 3 recommendations for interventions to improve PrEP uptake included targeted advertising in public health settings; sharing information about PrEP through social networks, community events, and support groups; and increasing PrEP-related communication from medical providers. Women reported it was especially important to have trusted community ambassadors share information to overcome medical/pharmaceutical distrust, as illustrated by the advice offered to the research team by one of the KII women: "*Basically, you're gonna have to get a lot of more African American women to get out here and advocate for you all. Because if it's coming from you all (the interviewer), only thing they're—gonna take a look at is the dollar sign behind it. I'm gonna be honest with you...you all need to get some more African-American women that are actually from the street that's tired of the street — and have them advocate for you all.*"

The KIs offered a number of options to support disclosure of PrEP use, such as talking to a health care provider, to have accurate facts about PrEP before disclosing medication use with others, and enlisting peers to support PrEP discussions. They also discussed communication strategies that could be useful, such as appropriate timing of disclosure in relationships and the ability to assess the recipient's comfort level with the discussion. Participants also noted the importance of developing self-efficacy to "own what you're doing." FG participants also noted the need for communication skills and PrEP information to prepare for disclosure, including needs for age appropriate information to be able to discuss with children, partners, and other family members. "*I'd try to explain to my seven-year-old as best as a seven year old can comprehend that mommy's taking something to make her better. And I'd explain to him how important health is and why.*"

KIs did not discuss interventions to support PrEP adherence directly, but strategies emerged from participants' accounts of their adherence. These strategies included routinizing daily pill taking, such as taking PrEP with other medications or at mealtimes, and adherence aides, such as pill boxes and cell phone reminders. FG participants did express the need to ensure medication privacy in shared living spaces (eg, discreet storage, packaging, etc.) to prevent any unplanned disclosure and the need for packaging to aid in

adherence. Desired support for adherence to PrEP-specific medical visits was also mentioned, including easier access to health providers, travel assistance when needed, and combining PrEP visits with other health care visits.

## DISCUSSION

In our study in Chicago, we found low PrEP awareness and knowledge among cisgender women despite one-third of the survey sample meeting PrEP criteria and significant public health work to increase availability of and community education around PrEP.<sup>16</sup> However, once PrEP was explained, most of the women reported positive attitudes toward PrEP, with almost one-third of survey respondents interested in starting PrEP in the near future. In addition, these women had clear preferences of where they would like to receive PrEP information and PrEP care, and what type of support they would need to overcome barriers at the individual, partner, and health system levels. Seventy percent of women had a regular source of care, largely physician offices or health centers, which were also the most common place where they wanted to receive information and start PrEP.

The low levels of PrEP knowledge were consistent with a number of other studies of cisgender women.<sup>7,9</sup> Among the women surveyed, the only factor associated with PrEP awareness before the study was knowing someone who was taking PrEP. Information preferences, once informed about PrEP, also highlighted the potential role of leveraging social networks to expand PrEP uptake, a strategy that has been used to increase PrEP among black men who have sex with men.<sup>14</sup> The AIDS Foundation of Chicago also had initiated a social marketing campaign explicitly targeted to women of color (SpreadTingle) <https://www.aidschicago.org/page/news/all-news/viiv-healthcare-and-afc-partner-to-improve-womens-health>.

One recurrent finding in the quantitative and qualitative results was the importance of having a trusted health care provider as the preferred source of PrEP information, as well as using women's usual source of health care to access PrEP. These results were consistent across both quantitative and qualitative data, despite the fact that survey respondents were accessing care at different care sites (STI clinic or ED) rather than their regular source of care. Use of EDs and STI clinics by patients who have access to primary care has been previously described and also highlights the opportunity for providers in urgent or other episodic care sites to discuss an HIV risk and PrEP and be knowledgeable about referral options for women who express interest.<sup>27</sup> The preference for PrEP access at regular sources of care emphasizes the importance of health system responsiveness (familiarity, feeling welcomed, confidentiality, and access-financial and otherwise), a factor previously found important for adherence in people living with HIV in other settings.<sup>28</sup> In general, distrust of the medical system has previously been identified as a significant barrier to PrEP uptake and HIV care adherence among black women.<sup>11,29</sup> Although system change, including addressing structural barriers and intrinsic and extrinsic bias, is needed to overcome this barrier, results from our study suggest that leveraging already trusted

members of the medical community is an important facilitator. However, this work will also need to include building the capacity of trusted primary care providers to integrate PrEP into routine care.<sup>30</sup> Models of integration of HIV and primary care and other chronic care models offer strategies that can be adapted to provide the identified support needs for these women to start and remain on PrEP.<sup>31</sup>

Potential barriers and needed support identified in both quantitative and qualitative findings included concerns about side effects, drug interactions, disclosure, financial challenges, and incomplete HIV protection as well as remembering to take a daily pill. These findings are consistent with previous PrEP research as well as earlier findings for HIV-positive women and antiretroviral therapy.<sup>4,9</sup>

The relatively lower PrEP stigma is in contrast with some other studies, although our population differed in care sites and demographics. Calabrese et al<sup>4</sup> studied PrEP stigma among women attending Planned Parenthood clinics, finding both negative PrEP-user stereotypes and expected external disapproval if started, both associated with less interest in starting PrEP. The high interest in PrEP once made aware of the medication was consistent with a number of studies as well as the anger about not being informed about PrEP despite routinely accessing medical care and HIV prevention services.<sup>8,9</sup>

Our study had a number of limitations. The survey sample was composed of women accessing medical care for sexual health or urgent care needs, and may not represent the knowledge and attitudes of women attending routine primary care visits, those seeking care in reproductive health clinics or women not seeking care at all. All data were obtained through a self-report and may thus be subject to social desirability bias. In addition, a number of the questions and scales we used have only been validated in other populations, such as men who have sex with men, and work is needed to ensure that the psychometrics are valid among cisgender women, particularly black women. Because of limited resources, we could not also interview providers, but that is part of an ongoing follow-on study being led by some of the authors. Finally, our findings are based on cross-sectional data and cannot be used to make causal inferences on women's PrEP knowledge, attitudes, and experiences.

Despite these limitations, our study is one of the first to use mixed-methods and include both PrEP-experienced and PrEP-naïve women, adding to the growing literature on how to improve the PrEP care continuum among black and other cisgender women. The women offered concrete suggestions on how to improve PrEP-related messaging and the resources needed to help women understand, initiate, and remain on PrEP. Research is needed on how to build on these suggestions to develop and scale-up culturally and gender-relevant interventions to improve cisgender women's awareness and knowledge and uptake of PrEP. Settings for such interventions should leverage the trust of already established health care providers, or community-based organizations and social networks. These results have been shared with the broader community, including women and service providers, and work has started to better understand how to design effective strategies to increase PrEP access across the

continuum to contribute to the local Getting to Zero efforts and the national work to End the HIV Epidemic.

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## REFERENCES

1. CDC. *High-Impact HIV Prevention CDC's Approach to Reducing HIV Infections in the United States*. 2012. Available at: [http://www.cdc.gov/hiv/strategy/dhap/pdf/nhas\\_booklet.pdf](http://www.cdc.gov/hiv/strategy/dhap/pdf/nhas_booklet.pdf). Accessed February 1, 2012.
2. Siegler AJ, Mouhanna F, Giler RM, et al. The prevalence of pre-exposure prophylaxis use and the pre-exposure prophylaxis-to-need ratio in the fourth quarter of 2017, United States. *Ann Epidemiol*. 2018;28:841–849.
3. Centers for Disease Control. *HIV Surveillance Report, 2017; Vol. 29*. Available at: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>. Accessed August 5, 2019.
4. Calabrese SK, Dovidio JF, Tekeste M, et al. HIV Pre-exposure prophylaxis stigma as a multidimensional barrier to uptake among women who attend planned parenthood. *J Acquir Immune Defic Syndr*. 2018;79:46–53.
5. Auerbach JD, Kinsky S, Brown G, et al. Knowledge, attitudes, and likelihood of pre-exposure prophylaxis (PrEP) use among US women at risk of acquiring HIV. *AIDS Patient Care STDS*. 2015;29:102–110.
6. Aaron E, Blum C, Seidman D, et al. Optimizing delivery of HIV preexposure prophylaxis for women in the United States. *AIDS Patient Care STDS*. 2018;32:16–23.
7. Koren DE, Nichols JS, Simoncini GM. HIV pre-exposure prophylaxis and women: survey of the knowledge, attitudes, and beliefs in an urban obstetrics/gynecology clinic. *AIDS Patient Care STDS*. 2018;32:490–494.
8. Rutledge R, Madden L, Ogbuagu O, et al. HIV Risk perception and eligibility for pre-exposure prophylaxis in women involved in the criminal justice system. *AIDS Care*. 2018;30:1282–1289.
9. Flash C, Dale S, Krakower DS. Pre-exposure prophylaxis for HIV prevention in women: current perspectives. *Int J Womens Heal*. 2017;9:391–401.
10. Chapman Lambert C, Marrazzo J, Amico KR, et al. PrEParing women to prevent HIV: an integrated theoretical framework to PrEP Black women in the United States. *J Assoc Nurses AIDS Care*. 2018;29:835–848.
11. Tekeste M, Hull S, Dovidio JF, et al. Differences in medical mistrust between Black and white women: implications for patient-provider communication about PrEP. *AIDS Behav*. 2019;23:1737–1748.
12. Liu AY, Vittinghoff E, von Felten P, et al. Randomized controlled trial of a mobile health intervention to promote retention and adherence to preexposure prophylaxis among young people at risk for human immunodeficiency virus: the EPIC study. *Clin Infect Dis*. 2019;68:2010–2017.
13. Remy L, Enriquez M. Behavioral interventions to enhance PrEP uptake among black men who have sex with men. *J Assoc Nurses AIDS Care*. 2019;30:151–163.
14. Young L, Schumm P, Alon L, et al. PrEP Chicago: a randomized controlled peer change agent intervention to promote the adoption of pre-exposure prophylaxis for HIV prevention among young Black men who have sex with men. *Clin Trials*. 2018;15:44–52.
15. CDPH. *HIV/STI Surveillance Reports*. 2018. Available at: [https://www.chicago.gov/content/dam/city/depts/cdph/infectious\\_disease/STI\\_HIV\\_AIDS/HIVSTI\\_SURVEILLANCE\\_REPORT\\_2018\\_1272018.pdf](https://www.chicago.gov/content/dam/city/depts/cdph/infectious_disease/STI_HIV_AIDS/HIVSTI_SURVEILLANCE_REPORT_2018_1272018.pdf). Accessed January 2, 2020.
16. Dehlin JM, Stillwagon R, Pickett J, et al. #PrEP4Love: an evaluation of a sex-positive HIV prevention campaign. *JMIR Public Heal Surveill*. 2019;5:e12822.

17. Harris PA, Taylor R, Thielke R, et al. Research Electronic Data Capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* 2009;42:377–381.
18. Mustanski B, Ryan DT, Hayford C, et al. Geographic and individual associations with PrEP stigma: results from the RADAR cohort of diverse young men who have sex with men and transgender women. *AIDS Behav.* 2018;22:3044–3056.
19. Napper LE, Fisher DG, Reynolds GL. Development of the perceived risk of HIV scale. *AIDS Behav.* 2012;16:1075–1083.
20. Prevention C for DC. *US Public Health Service: Preexposure Prophylaxis for the Prevention of HIV Infection in the United States—2017 Update: A Clinical Practice Guideline.* 2017. Available at: <https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf>. Accessed September 15, 2019.
21. Calabrese SK, Willie TC, Galvao RW, et al. Current US guidelines for prescribing HIV pre-exposure prophylaxis (PrEP) disqualify many women who are at risk and motivated to use PrEP. *J Acquir Immune Defic Syndr.* 2019;81:1.
22. Baral S, Logie C, Grosso A, et al. Modified Social Ecological Model: a tool to visually represent the risks and risk contexts of HIV epidemics. *BMC Public Health.* 2013;13:482.
23. Shrestha R, Karki P, Altice FL, et al. Measuring acceptability and preferences for implementation of pre-exposure prophylaxis (PrEP) using conjoint analysis: an application to primary HIV prevention among high risk drug users. *AIDS Behav.* 2018;22:1228–1238.
24. Lieber E, Weisner T, Taylor J. *Dedoose Software.* California, CA: Sociocultural Research Consultants; 2011.
25. Padgett D. *Qualitative Methods in Social Work Research: Challenges and Rewards.* Thousand Oaks, CA: Sage Publications; 1998.
26. Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook.* Los Angeles, CA: SAGE Publications; 2014.
27. Coster JE, Turner JK, Bradbury D, et al. Why do people choose emergency and urgent care services? A rapid Review utilizing a systematic literature search and narrative synthesis. *Acad Emerg Med.* 2017;24:1137–1149.
28. Poles G, Li M, Siril H, et al. Factors associated with different patterns of nonadherence to HIV care in Dar es Salaam, Tanzania. *J Int Assoc Provid AIDS Care.* 2014;13:78–84.
29. Saha S, Jacobs EA, Moore RD, et al. Trust in physicians and racial disparities in HIV care. *AIDS Patient Care STDS.* 2010;24:415–420.
30. Petroll AE, Walsh JL, Owczarzak JL, et al. PrEP awareness, familiarity, comfort, and prescribing experience among US primary care providers and HIV specialists. *AIDS Behav.* 2017;21:1256–1267.
31. U.S. Department of Health and Human Services. *Integrating HIV Care, Treatment & Prevention Services into Primary Care—A Toolkit for Health Centers.* Rockville, MD; 2017. Available at: <https://bphc.hrsa.gov/sites/default/files/bphc/qualityimprovement/pdf/p4c-toolkit-2018.pdf#zoom=125>. Accessed December 15, 2019.