

## ORIGINAL RESEARCH

# Access to HIV Pre-exposure Prophylaxis in Practice Settings: a Qualitative Study of Sexual and Gender Minority Adults' Perspectives

Christina J. Sun, PhD, MS<sup>1</sup>, Kirsten M. Anderson, MPH, MSW<sup>1</sup>, David Bangsberg, MD, MSc, MPH<sup>1</sup>, Kim Toevs, MPH<sup>2</sup>, Dayna Morrison, MPH<sup>3</sup>, Caitlin Wells, BA, BS<sup>4</sup>, Pete Clark, BA<sup>2</sup>, and Christina Nicolaidis, MD, MPH<sup>1,5,6</sup>

<sup>1</sup>Oregon Health & Science University-Portland State University School of Public Health, Portland, OR, USA; <sup>2</sup>Multnomah County Health Department, Portland, OR, USA; <sup>3</sup>Oregon AIDS Education and Training Center at Portland Veterans Affairs Research Foundation, Portland, OR, USA; <sup>4</sup>Cascade AIDS Project, Portland, OR, USA; <sup>5</sup>Portland State University School of Social Work, Portland, OR, USA; <sup>6</sup>Oregon Health & Science University School of Medicine, Portland, OR, USA.

**BACKGROUND:** Sexual and gender minority (SGM) populations remain at disproportionate risk of HIV infection. Despite the effectiveness of pre-exposure prophylaxis (PrEP) in preventing HIV, PrEP uptake has been slow.

**OBJECTIVE:** To identify barriers and facilitators of PrEP access by examining SGM patients' experiences with accessing health care systems and engaging with providers about PrEP in a variety of practice settings.

**DESIGN:** Semi-structured, individual, qualitative interviews.

**PARTICIPANTS:** Twenty-seven sexual and gender minority adults residing in Oregon.

**APPROACH:** Interviews were audio-recorded, transcribed, and analyzed using thematic analysis.

**KEY RESULTS:** We identified three main themes. Participants described the centrality of patient-provider relationships to positive experiences around PrEP, the necessity of personally advocating to access PrEP, and the experience of system-level barriers to PrEP access. Participants also made several suggestions to improve PrEP access including improving provider engagement with SGM patients, encouraging providers to initiate conversations about PrEP, and increasing awareness of medication financial support.

**CONCLUSIONS:** In order to reduce HIV disparities, improving PrEP access will require additional efforts by providers and resources across health care settings to reduce barriers. Interventions to improve provider education about PrEP and provider communication skills for discussing sexual health are needed. Additionally, there should be system-level improvements to increase coordination between patients, providers, pharmacies, and payers to facilitate PrEP access and uptake.

**KEY WORDS:** prevention; HIV/AIDS; qualitative research; patient preferences; doctor-patient relationships.

J Gen Intern Med 34(4):535–43

DOI: 10.1007/s11606-019-04850-w

© Society of General Internal Medicine 2019

## INTRODUCTION

Despite declines in new HIV infections in the United States (U.S.), sexual and gender minority (SGM) populations remain disproportionately affected by HIV.<sup>1</sup> Emtricitabine/tenofovir (Truvada™) as pre-exposure prophylaxis (PrEP) is an effective, safe, and important HIV prevention strategy.<sup>2–10</sup> However, only around 8% of the 1.1 million Americans who could benefit from PrEP are taking the medication.<sup>11</sup>

The sequential steps required to achieve protection with PrEP (i.e., PrEP care continuum) are a potential reason for slow uptake; multiple barriers need to be reduced.<sup>8, 12, 13</sup> Research among potential PrEP users identifies awareness and knowledge of PrEP, costs, side effects, PrEP stigma, beliefs about HIV, and access to health care as important factors impacting uptake of PrEP.<sup>14–21</sup> Findings from open-label trials and demonstration projects have been similar,<sup>22–24</sup> although research in these contexts has focused on adherence and sexual behavior changes rather than uptake.<sup>25–30</sup> Others have studied provider barriers to PrEP implementation, finding that provider education is an important aspect of PrEP access.<sup>22, 31–35</sup> Few studies have examined patient experiences outside of research settings, mainly exploring experiences within specific clinics and programs already designed to deliver PrEP.<sup>22, 27, 36–39</sup> While these findings are helpful for implementation, little is known about PrEP use in less controlled settings where providers may not be equipped to prescribe PrEP and potential PrEP users may not receive the same level of support. Furthermore, the U.S. Preventive Services Task Force's current draft recommendation statement on PrEP states that clinicians should provide PrEP for patients at high risk of acquiring HIV (Grade A)<sup>40</sup>, which in the future may result in increasing demands for PrEP in primary care settings. We sought to identify barriers and facilitators of PrEP access by examining SGM patient experiences of

Received June 14, 2018

Revised October 25, 2018

Accepted December 27, 2018

Published online February 4, 2019

accessing health care systems and engaging providers about PrEP in a variety of practice settings.

## METHODS

### Community-Academic Partnership

This project was identified as a community priority of the nPEP/PrEP stakeholder group: a collaboration between representatives from AIDS service organizations, local health departments, Oregon AIDS Education and Training Center, and universities. Partners jointly developed the interview guide and recruitment strategies, met to finalize themes, and generated and enacted dissemination plans to share research findings. The Portland State University Institutional Review Board approved this study.

### Participants, Recruitment, and Eligibility

Participants were eligible for the study if they were 18 years or older; currently using PrEP, seeking PrEP, or had stopped using PrEP; and a resident of Oregon. AIDS service organizations; lesbian, gay, bisexual, transgender, and queer community centers; and local health departments recruited participants through word of mouth and print and social media flyers. Participants received \$15 for participation in the study and were incentivized to aid recruitment by receiving an additional \$5 if they recruited another person who completed the interview.

### Data Collection

After conducting practice interviews with community partners, two co-authors (CJS and KMA) conducted 27 individual, semi-structured interviews. Interview domains focused on knowledge and attitudes about PrEP; experiences seeking, obtaining, and adhering to PrEP; and changes resulting from PrEP use.

### Data Analysis

We conducted a thematic analysis using a data-driven inductive approach and constructivist paradigm (i.e., theorized participants' motivations, experiences, and meanings from what they said rather than making inferences about the sociocultural contexts and structural conditions that enabled individual accounts), following the six phases outlined by Braun and Clarke.<sup>41</sup> Coding was conducted at the semantic level and organized with Atlas.ti 7. Three co-authors (CJS, KMA, CN) independently read four transcripts and made notes for coding, then collectively developed a preliminary codebook with detailed descriptions of each code. Two co-authors (CJS and KMA) independently read and coded all transcripts, giving equal attention to each data item. During this process, they met to discuss and reconcile codes, add additional codes as necessary, and resolve discrepancies through consensus. After coding, three co-authors (CJS, KMA, CN) met to determine preliminary themes representing a patterned response, check each theme against other themes, and verify that themes were

grounded in the data. Diagramming was used to explore the relationship and connectedness between themes. The full team of academic and community partners met to refine and finalize themes, such that themes were coherent, specific enough to be distinct and general enough to describe patterns observed in multiple responses; name themes; and identify exemplar quotes to ensure the analysis and data matched.<sup>42</sup>

## RESULTS

### Description of Participants

Participants ( $N=27$ ) were 21 to 67 years old (mean 38.0; Table 1). Most participants identified as cisgender gay men. Nearly one-third of the sample identified as Latino or multi-racial. Income levels varied widely, but all participants had some college education. More than half of participants had private or employer-sponsored insurance. Most participants sought or received PrEP from primary care or infectious disease clinics.

### Themes

Participants expressed a range of experiences during interactions with providers and health care systems when seeking, obtaining, and using PrEP. Three overarching themes emerged: the centrality of patient-provider relationships, the necessity of individual advocacy to access PrEP, and the experience of system-level barriers to PrEP access.

### Patient-Provider Relationships Are Central to Positive Experiences Around PrEP

Participants described a connection between the quality of the provider relationship and PrEP counseling. Some participants described providers who had created a safe environment to facilitate discussions about sexual health and PrEP. One participant shared,

She [provider] was totally cool about everything and just no judgment whatsoever. Everything was very matter of fact, like, "Who do you have sex with?" and just very casual and she used correct pronouns for me. (P15)

Generally, providers who were knowledgeable and well-informed about PrEP were described as sex positive (having positive attitudes about sex and comfortable with patients' sexuality and sexual behaviors). Participants also shared that having open conversations with their providers about potential HIV risk and sexual health concerns strengthened the patient-provider relationship and comfort participants had with their providers. For example,

The doctor was really affirming, which was also mind-blowing because I've never actually had a doctor that

Table 1 Participant Characteristics

	<i>M</i> ± <i>SD</i> (range) <i>n</i> (%)
Age	38.0 ± 11.0 (21–67)
Gender	
Cisgender male	22 (81.5)
Transgender male	1 (3.7)
Transgender female	2 (7.4)
Genderqueer female	1 (3.7)
Queer	1 (3.7)
Sexual identity	
Gay/homosexual	20 (74.1)
Queer	2 (7.4)
Pansexual	2 (7.4)
Bisexual	2 (7.4)
Lesbian	1 (3.7)
Race	
White	19 (70.4)
Latino	5 (18.5)
Multiracial	3 (11.1)
Education	
Some college	9 (33.3)
Bachelor's degree	8 (29.6)
Any graduate school	10 (37.0)
Income	
\$0–9999	7 (25.9)
\$10,000–19,999	1 (3.7)
\$20,000–34,999	5 (18.5)
\$35,000–49,999	7 (25.9)
\$50,000–74,999	6 (22.2)
\$75,000–99,999	0
\$100,000+	1 (3.7)
Relationship status	
Single	15 (55.6)
Partnered	7 (25.9)
Married	4 (14.8)
Widowed	1 (3.7)
Geographic location	
Portland metropolitan area	20 (74.1)
Other urban area	5 (18.5)
Rural	2 (7.4)
Health care coverage	
Private/employer-sponsored insurance	12 (44.4)
Medicaid	9 (33.3)
Medicaid and private insurance	1 (3.7)
Medicare	1 (3.7)
Medicare and private insurance	2 (7.4)
Veterans Health Administration	1 (3.7)
Uninsured	1 (3.7)
Clinical setting	
Infectious disease	12 (44.4)
Primary care	12 (44.4)
Community-based sexual health	3 (11.1)

has talked to me about sex and risks, in my life... It was just an awesome experience.” (P14)

Having a provider who was knowledgeable about PrEP made participants more comfortable and willing to use PrEP. One participant reflected,

I think the conversation with my doctor was probably the greatest influence [in deciding to start PrEP]. (P20)

Participants stated they wanted to discuss and receive counseling about PrEP with their providers. As a participant shared,

I think what I would've wanted was a conversation about the commitment. I just want it laid all out for me

like, “This is what you'd be committing to. This is the cost that would be involved and these are the possible risks.” (P12)

More commonly, participants described negative relationships that interfered with PrEP access. They felt providers demonstrated discomfort with sexuality and PrEP by not taking sexual histories, not offering PrEP to participants who met prescribing criteria, using inappropriate or offensive language, and not offering risk reduction or PrEP adherence counseling. Participants identified these interactions as barriers to disclosing important information related to HIV risk. One participant shared,

I was apprehensive about asking him [about PrEP] because I don't think that he knew that I was gay when I was going for testing because I'd get tested every six months. He always seemed like it wasn't necessary, like it was a hassle, so I was a little worried about talking to him about it. (P13)

Some participants attributed these strained relationships and poor patient-provider communication to providers' discomfort with their gender identity, sexual identity, or sexual behavior. A participant reflected,

I felt like he totally slut shamed me... I really couldn't believe the way that he treated me. And it was so clearly linked to when he noticed that I was a PrEP user, aka, when he noticed I was a gay man. (P3)

Another participant said,

I think my trans status sort of threw the doctor for a loop. She almost didn't seem to know quite how to handle it. (P24)

It was also mentioned that participants whose providers were not aware of their gender identity, sexual identity, or sexual behavior would have additional challenges accessing PrEP:

It might be really hard for a person in the closet to ask for PrEP—you first have to come out to your doctor then you have to convince the doctor that PrEP's a good thing, too. (P1)

Because of these experiences with provider discomfort and bias, some participants described difficulties trusting medical providers and systems. For example,

When things go wrong, I start questioning, “Is that going to go wrong because they just made a mistake or is it wrong because they don't give a fuck about me?” (P15)

Finally, participants noted that they wanted their providers to initiate conversations about PrEP. As this participant reflected,

I just wish doctors were more open about discussing it, even bringing it up with their patients. I was a little surprised when my primary doctor had never mentioned [PrEP]. (P7)

Another participant suggested that PrEP should be addressed during routine exams, saying,

[Discussing PrEP] would've been such a casual conversation to have at that point when I go in for a yearly wellness exam. (P9)

### Individual Patient Advocacy Is Required to Access PrEP

Participants shared difficulties engaging with the health care system and their individual advocacy to acquire PrEP. For instance, one participant reflected,

If I hadn't been my own advocate and so confident in what I was wanting to do, I could have easily given up. (P13)

Advocacy for PrEP occurred in multiple forms. When participants met with providers who lacked awareness or knowledge of PrEP, participants educated providers about PrEP, prescribing guidelines, and other clinical resources. One participant described,

Because of insurance I've had three different providers. And each one of them didn't know about PrEP. So the first one I had to take the guidelines with me so that he would actually prescribe it to me. And then the second one and the third one when I told them I was on Truvada they both asked me if I was HIV positive. (P4)

After educating providers, several participants felt that their providers questioned them in uncomfortable ways or with inappropriate skepticism about meeting prescribing criteria and medication adherence. For example,

I had to talk quite a bit about why I want to be on Truvada, what I thought it was for, what I knew about it, what I knew it didn't protect against and I pretty much had to convince them that I was adult enough to be on it. (P5)

One participant, a transgender man, described that his provider did not seem to understand why he might be a good candidate for PrEP, and needed to be convinced:

The doctor seemed to think that the type of sex that I was having didn't really warrant going on PrEP. I told her, "Well, I'm a man who has sex with men who I know for a fact have sex with other men, and I have multiple partners, so I am pretty interested in it." (P24)

Finally, prescribing guidelines state that multiple laboratory tests should be done before and during use to identify contraindications. However, participants noted that these tests did not always occur, as described:

[My doctor has] never given me a blood test. He's never tested my liver, and he didn't test to see whether or not I was positive before putting me on. (P2)

After filling a prescription, the impetus remained on patients to manage follow-up labs. One noted, "I still do my own testing. I still have to remind him [provider] when I have to check my kidneys and things like that." (P4)

### Patients Experience Many Systemic Barriers to PrEP Use

Participants reported seeking PrEP through different practice settings and with providers of various specialties (e.g., infectious disease, primary care, nurse practitioner, naturopathic doctor) and described many systemic barriers. These barriers were related to the speed and ease of processes, actual and perceived costs, pharmacies, and follow-up care.

The PrEP continuum was extended when participants had to visit multiple doctors or return to the same doctor more than once for a prescription. One participant described,

I told him about the medication... I never heard back. So I contacted him again... I still didn't hear back. I think it was the third appointment where I went in and kind of demanded that something get done. (P13)

Participants who lived in rural areas had difficulty finding doctors who would prescribe PrEP and often had to travel long distances for PrEP access: "If you're in the rural areas they don't have any specialists, so you have to go out of your way." (P1) Even in urban areas, several participants had difficulty connecting to a provider because some health systems only allowed certain providers to prescribe PrEP or did not have a clear policy for whom should prescribe PrEP: "She [primary care provider {PCP}] wanted him [infectious disease doctor] to prescribe it, and he wanted her to prescribe it." (P6) For participants who did not currently have a regular provider, initiating care with a provider often resulted in a delay. One participant described, "I called the local doctor group and said, 'I want a doctor' and they told me it was about four months wait." (P5)

Costs served as a barrier to uptake, either because participants could not afford PrEP or had heard PrEP was expensive. One participant noted, “Part of the reason why I waited so long was I didn’t have the money to be able to afford the drug.” (P23) Similarly, another participant shared, “The prescription was sitting around for a while since I couldn’t cover the copay.” (P16) It was common for participants to report that they had heard from others that the biggest problem in accessing PrEP was the cost. One participant, who was uninsured, described pursuing PrEP and determining that cost would prevent him from accessing the medication:

I’m going to have to incur that cost, which is just daunting and scary. Is a cost going to stop me from doing this thing? And it looks like it is. (P9)

To reduce the burden associated with cost, some participants described applying for and receiving financial support from the manufacturer. Often, they had learned about it through PrEP-focused patient navigators. However, participants reported difficulty accessing the manufacturer’s program. Some PrEP users sought to increase awareness of the manufacturer’s financial support by discussing it with friends. As one participant shared, “As soon as I learn that someone is on PrEP, I’ll talk to them, ‘Oh my god, are you getting reimbursed?’ They’re like, ‘What is that?’ So, maybe there is more we can do to help spread the word.” (P17)

Additional difficulties related to cost and access arose when trying to fill PrEP prescriptions at pharmacies. Some participants encountered problems when trying to pay for the medication using insurance; others had challenges applying the manufacturer’s financial support. One participant reflected,

If I didn’t have credit cards I would not be able to afford it [PrEP] because my pharmacy doesn’t do the copay card. You have to do a reimbursement that takes about a month to a month and a half to get it. (P11)

Other participants experienced interruptions in medication because their pharmacies did not stock PrEP and they had to wait several days for refills. Several PrEP users tried to avoid these problems by receiving refills by mail. For some, this approach was ideal, but others experienced problems due to strict delivery requirements: “The fact that they have to ship it to me is very inconvenient because then I either need to have it shipped to my work because that’s where I am during the day or stay home because UPS won’t leave anything at the door of your apartment.” (P5)

Finally, follow-up care varied widely among participants, including the frequency, content, and delivery mode. Most participants reported receiving regular HIV testing. However, in many cases, participants were primarily responsible for ensuring that testing was done. Some participants attended in-person visits every three to six months, while others never had a follow-up visit. Some described receiving little

counseling about PrEP from their providers, while other providers consistently offered risk reduction and condom use counseling at every visit. Participant responses to counseling were mixed; some reported feeling supported while others were not interested. One participant who responded positively to risk reduction counseling shared, “He reminds me how important condoms are. I say, ‘That’s really great information and I agree with you 100%. With any new partners I always use condoms.’” (P5) However, the same participant said he would not be interested in adherence counseling because “I feel that that’s really something the person taking Truvada should be responsible for.” (P5) Another participant who did not receive adherence and risk reduction counseling said, “I’d like them to offer it so I’d know they’re offering it to other people, but I don’t need it myself.” (P6)

Many patients reported receiving follow-up care by phone or email, which was generally described as more convenient than in-person, while still sufficient to ask questions and bring up concerns. A number of participants suggested that follow-up care would be easier if they received reminders when they were due. One participant described, “It would be awesome if it was like a text message that said, ‘If you’re taking your pills, you have two weeks left. We’ve already booked your test, go into any [clinic] and have your blood drawn. Thanks so much.’” (P17)

## DISCUSSION

In this study, we explored patient experiences seeking and using PrEP to prevent HIV in practice settings. Participants identified relationships with their providers, self-advocacy, and systemic barriers as key elements to accessing and using PrEP. Participants also made suggestions including improving provider engagement with SGM patients, encouraging providers to initiate conversations about PrEP, and increasing awareness of financial assistance.

Our study contributes to the existing literature by examining experiences of PrEP access and use outside of clinical trials and open-label projects during which PrEP is provided for free with regular monitoring. Studying PrEP experiences in practice settings, we were able to examine issues related to patient-provider relationships, medication costs, and coordination between patients, providers, pharmacies, and payers.

In our study, participants received PrEP from infectious disease, primary care, and community-based sexual health clinics. There is on-going discussion about the role of different types of providers in prescribing PrEP, particularly PCPs and infectious disease specialists.<sup>43-47</sup> PCPs are a preferred source of PrEP for many patients,<sup>48, 49</sup> and increased trust in a PCP is associated with increased PrEP willingness.<sup>50</sup> This corroborates our finding that many participants felt more comfortable discussing sensitive topics with a provider they already knew and trusted. Additionally, it was typically easier and faster for participants to receive PrEP from a PCP, as long as that

provider was knowledgeable about PrEP. However, many PCPs lack the knowledge to be comfortable and effective in prescribing and managing PrEP, including providing follow-up care, as observed in our study and previous research.<sup>47, 51–53</sup>

Several participants in this study accessed PrEP through community-based sexual health clinics, and all described positive experiences. Fewer reports have examined the provision of PrEP in this context. These clinics may represent an additional opportunity to increase PrEP access. Providers at community-based sexual health clinics, including STD clinics, already serve populations at increased risk for HIV and may engage patients with culturally competent and non-judgmental discussions about their sexual health. Some previous studies have described successful PrEP implementation through STD clinics.<sup>22, 36, 49</sup> Further research is needed to understand patients' preferences and experiences in accessing PrEP at STD clinics and the role of provider and organizational factors.

It is possible that negative experiences with providers such as those reported by several of our participants could deter patients from further engaging with providers and become a barrier to accessing other health care. Several participants in our sample feared that negative PrEP-seeking experiences might be related to provider discrimination. Increased perception of stigma is associated with decreased utilization of medical care among SGM populations.<sup>54, 55</sup> In contrast, when providers are able to engage positively with patients seeking PrEP, this interaction can

be an avenue to encourage preventative care among patients who have lower health care-seeking behaviors.

Similar to our findings, participants in other real-world studies found cost to be a challenge for patients. In a primary care clinic, both perceived cost and actual cost were important barriers to PrEP access, with knowledge about payment assistance programs being particularly vital to continuing PrEP if one's health insurance or financial situation changed.<sup>38</sup> While few participants in a PrEP program at one STD clinic encountered payment issues, clinic staff dedicated considerable time to helping navigate medication assistance programs.<sup>37</sup> It appears that support in obtaining payment assistance is critical to PrEP uptake and retention.<sup>37, 38, 56</sup>

Findings from this study should be considered in light of several limitations. Most participants were white cisgender gay men; however, this proportion mirrors the state's HIV epidemiology. We found that transgender and genderqueer participants reported experiences that were more difficult due to gender identity-related discrimination but were not thematically different than the experiences of cisgender participants. The experiences of cisgender women and heterosexual adults may differ. It is also possible that participants in this study had more negative experiences than those not in the study. Only one participant was uninsured; those without insurance are likely to face challenges in accessing PrEP. Additionally, all participants had at least some college education. Potential PrEP users with a different educational background may face additional barriers. Most participants resided in a single urban

**Table 2 Recommendations for Providers**

Interview findings	Examples of communication techniques to address finding
Need for providers to engage in open, non-judgmental conversations about sexuality and sexual history	Providers should take a sexual history for all patients. Be careful to avoid expressing surprise or judgment through body language and facial expressions. Avoid assumptions and use non-gendered language. For instance, ask, "Who are your sexual partners?" and "What sexual activities do you participate in? What body parts do you use?" At follow-up visits, ask, "Have there been any changes in your sexual history?" Then, ask specific questions about a few of the patient's previous answers to confirm.
Lack of provider knowledge about PrEP and need for patients to educate providers	Providers should utilize clinical resources and engage in continuing education to learn about PrEP prescribing. One key resource is the clinical practice guidelines issued by the Centers for Disease Control and Prevention (CDC). <sup>8</sup> Additional information for providers, including resources for continuing education about PrEP, can be found on the CDC's website ( <a href="https://www.cdc.gov/hiv/risk/prep/index.html">https://www.cdc.gov/hiv/risk/prep/index.html</a> ) and from the AIDS Education & Training Center ( <a href="https://aidsetc.org/topic/pre-exposure-prophylaxis">https://aidsetc.org/topic/pre-exposure-prophylaxis</a> ). If the patient requests PrEP but the provider is unable to prescribe, identify other local providers who are able to prescribe. The PrEP Locator created by Emory University and powered by the CDC's National Prevention Information Network service provider database is one resource to find such providers ( <a href="https://preplocator.org/">https://preplocator.org/</a> ).
Few providers initiate conversations about PrEP	Make the introduction of PrEP general. For instance, say, "PrEP is something that I like to talk to all my patients about. Do you know what PrEP is?" If no, give a brief description. If the patient expresses interest about PrEP: "I am glad you are interested in PrEP, and I am happy to discuss this with you. Do you have any questions first, before getting into the details?" Then, if the person meets the indications for PrEP: "Based on the sexual history we discussed, PrEP seems like it might be a good fit for you." If PrEP is not indicated for the patient at this time, let them know that it is available if their sexual practices change in the future.
Concern about cost and lack of information about payment assistance options	Let patients know that PrEP can be affordable for most people. Give patients information about medication assistance programs, especially financial support available through the manufacturer ( <a href="https://www.gileadadvancingaccess.com">https://www.gileadadvancingaccess.com</a> ). If the clinic or health system has patient navigators, resource referral specialists, or other staff who can assist in applying for payment assistance, refer patients to these staff. If not, local AIDS service organizations may be able to assist patients to apply for insurance or PrEP financial assistance.

area. Participants in other cities or rural areas may have different PrEP access experiences. For instance, at the time of interviews, Medicaid programs in the Portland metropolitan area fully cover PrEP, but this policy is not true for all of Oregon.

Despite these limitations, our study has several important implications. Providers can use these findings to provide responsive, patient-centered care. Patients want providers who are non-judgmental and comfortable having conversations about sexual health and sexuality (see Table 2 for examples of communication techniques). Ensuring that providers are taking complete sexual histories in a culturally appropriate way is a key step to increase PrEP access. Additionally, participants want providers to be knowledgeable about PrEP and discuss its effectiveness, side effects, and other considerations. Providers, especially PCPs, should be educated about PrEP so that they can counsel patients about PrEP, accurately follow prescribing guidelines, and reduce the risk of undetected and untreated complications. Providers have endorsed the suggestion of increased PrEP training.<sup>47</sup> PCPs should also be encouraged to initiate conversations with their patients about PrEP, as our research agrees with previous studies showing that patients bear the burden of introducing this topic.<sup>47, 57</sup> Crucial next steps include developing and testing interventions to improve patient-provider relationships, especially around sexual health.

Additionally, providers and social and health service organizations could do more to connect potential PrEP patients to health care systems. Providing support to improve affordability (e.g., assistance to enroll in health insurance, insurance subsidy programs, and medication support programs); identifying providers experienced in PrEP care; and letting patients know what to expect in conversations with doctors would ease the process of accessing PrEP. It appears that PrEP-focused or PrEP-knowledgeable patient navigators are helping fulfill this role in practice settings across the county and future research could better understand their impacts in improving uptake.<sup>58</sup>

On a systems level, there are several opportunities for improvement. Health care clinics can routinize PrEP prescribing, including implementing measures in electronic health record systems to identify potential PrEP candidates and cue for lab orders and follow-up care. Improved coordination between pharmacies, insurance companies, and the manufacturer's financial support program may help patients reduce cost barriers and interruptions in PrEP access. Further research could explore other pharmacy-related improvements, such as enlisting pharmacists as an additional source of PrEP counseling.<sup>59</sup>

Improving patient-provider relationships, increasing provider knowledge of PrEP, and removing systemic barriers are key elements to improve successful PrEP access and use among SGM communities that are disproportionately affected by HIV. Reducing HIV disparities with PrEP will require additional efforts by providers and health care systems to ensure that PrEP is reaching those who need it.

**Acknowledgments:** We thank the participants and the nPEP/PrEP stakeholder group, particularly Miguel D. Carreon, FNP-C, DNP, for their insights and expertise that greatly assisted the research.

**Corresponding Author:** Christina J. Sun, PhD, MS; Oregon Health & Science University-Portland State University School of Public Health, 506 SW Mill St, Suite 450H, Portland, OR 97201, USA (e-mail: christina.sun@pdx.edu).

**Funding Information** This project was supported by Oregon AIDS Education and Training Center at Portland Veterans Affairs Research Foundation and grant number K12HS022981 from the Agency for Healthcare Research and Quality.

#### Compliance with Ethical Standards:

The Portland State University Institutional Review Board approved this study.

**Conflict of Interest:** The authors declare that they do not have a conflict of interest.

**Disclaimer:** The content is solely the responsibility of the authors and does not necessarily represent the official views of the Oregon AIDS Education and Training Center at Portland Veterans Affairs Research Foundation and Agency for Healthcare Research and Quality.

**Publisher's Note:** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## REFERENCES

- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2010–2015. *HIV Surveill Suppl Rep.* 2018;23(1).
- Gilead. U.S. Food and Drug Administration approves Gilead's Truvada® for reducing the risk of acquiring HIV. Available at: <https://www.gilead.com/news/press-releases/2012/7/us-food-and-drug-administration-approves-gileads-truvada-for-reducing-the-risk-of-acquiring-hiv>. Accessed November 13, 2018.
- Fonner VA, Dalglish SL, Kennedy CE, et al. Effectiveness and safety of oral HIV preexposure prophylaxis for all populations. *AIDS.* 2016;30(12):1973–1983.
- Grant R, Lama JR, Anderson PL, et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. *N Engl J Med.* 2010;363(27):2587–2599.
- Grohskopf LA, Chillag KL, Gvetadze R, et al. Randomized trial of clinical safety of daily oral tenofovir disoproxil fumarate among HIV-uninfected men who have sex with men in the United States. *J Acquir Immune Defic Syndr.* 2013;64(1):79–86.
- McCormack S, Dunn DT, Desai M, et al. Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): effectiveness results from the pilot phase of a pragmatic open-label randomised trial. *Lancet.* 2016;387(10013):53–60.
- Spinner CD, Boesecke C, Zink A, et al. HIV pre-exposure prophylaxis (PrEP): a review of current knowledge of oral systemic HIV PrEP in humans. *Infection.* 2016;44(2):151–158.
- Centers for Disease Control and Prevention. Preexposure prophylaxis for the prevention of HIV infection in the United States – 2017 update: a clinical practice guideline. Available at: <https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf>. Accessed November 13, 2018.
- Volk JE, Marcus JL, Phengrasamy T, et al. No new HIV infections with increasing use of HIV preexposure prophylaxis in a clinical practice setting. *Clin Infect Dis.* 2015;61(10):1601–1603.
- Okwundu CI, Uthman OA, Okoromah CAN. Antiretroviral pre-exposure prophylaxis (PrEP) for preventing HIV in high-risk individuals. *Cochrane Database Syst Rev.* 2012;(7):CD007189.
- National Center for HIV/AIDS Viral Hepatitis STD and TB Prevention. HIV prevention pill not reaching most Americans who could benefit – especially people of color. Available at: <https://www.cdc.gov/nchhstp/>

- newsroom/2018/croi-2018-PrEP-press-release.html. Accessed November 13, 2018.
12. **Kelley CF, Kahle E, Siegler A**, et al. Applying a PrEP continuum of care for men who have sex with men in Atlanta, Georgia. *Clin Infect Dis*. 2015;61(10):1590–1597.
  13. **Parsons JT, Rendina HJ, Lassiter JM, Whit THF, Starks TJ, Grov C**. Uptake of HIV pre-exposure prophylaxis (PrEP) in a national cohort of gay and bisexual men in the United States. *J Acquir Immune Defic Syndr*. 2017;74(3):285–292.
  14. **Brooks RA, Kaplan RL, Lieber E, Landovitz RJ, Lee S-J, Leibowitz AA**. Motivators, concerns, and barriers to adoption of pre-exposure prophylaxis for HIV prevention among gay and bisexual men in HIV serodiscordant male relationships. *AIDS Care*. 2011;23(9):1136–1145.
  15. **Galindo GR, Walker JJ, Hazelton P**, et al. Community member perspectives from transgender women and men who have sex with men on pre-exposure prophylaxis as an HIV prevention strategy: implications for implementation. *Implement Sci*. 2012;7(1):116.
  16. **Saber P, Gamarel KE, Neilands TB**, et al. Ambiguity, ambivalence, and apprehensions of taking HIV-1 pre-exposure prophylaxis among male couples in San Francisco: a mixed methods study. *PLoS One*. 2012;7(11):e50061.
  17. **Thomann M, Grosso A, Zapata R, Chiasson MA**. “WTF is PrEP?”: attitudes towards pre-exposure prophylaxis among men who have sex with men and transgender women in New York City. *Cult Health Sex*. 2018;20(7):772–786.
  18. **Young I, McDaid L**. How acceptable are antiretrovirals for the prevention of sexually transmitted HIV?: a review of research on the acceptability of oral pre-exposure prophylaxis and treatment as prevention. *AIDS Behav*. 2014;18(2):195–216.
  19. **Bauermeister JA, Meanley S, Pingel E, Soler JH, Harper GW**. PrEP awareness and perceived barriers among single young men who have sex with men in the United States. *Curr HIV Res*. 2013;11(7):520–527.
  20. **Hannaford A, Lipshie-Williams M, Starrels JL**, et al. The use of online posts to identify barriers to and facilitators of HIV pre-exposure prophylaxis (PrEP) among men who have sex with men: a comparison to a systematic review of the peer-reviewed literature. *AIDS Behav*. 2018;22(4):1080–1095.
  21. **Golub SA, Gamarel KE, Rendina HJ, Surace A, Lelutiu-Weinberger CL**. From efficacy to effectiveness: facilitators and barriers to PrEP acceptability and motivations for adherence among MSM and transgender women in New York City. *AIDS Patient Care STDS*. 2013;27(4):248–254.
  22. **Liu A, Cohen S, Follansbee S**, et al. Early experiences implementing pre-exposure prophylaxis (PrEP) for HIV prevention in San Francisco. *PLoS Med*. 2014;11(3):e1001613.
  23. **Grace D, Jollimore J, MacPherson P, Strang MJP, Tan DHS**. The pre-exposure prophylaxis-stigma paradox: learning from Canada’s first wave of PrEP users. *AIDS Patient Care STDS*. 2018;32(1):24–30.
  24. **Gilmore HJ, Liu A, Koester KA**, et al. Participant experiences and facilitators and barriers to pill use among men who have sex with men in the iPrEx pre-exposure prophylaxis trial in San Francisco. *AIDS Patient Care STDS*. 2013;27(10):560–566.
  25. **Hosek SG, Rudy B, Landovitz R**, et al. An HIV preexposure prophylaxis demonstration project and safety study for young MSM. *J Acquir Immune Defic Syndr*. 2017;74(1):21–29.
  26. **Carlo Hojilla J, Koester KA, Cohen SE**, et al. Sexual behavior, risk compensation, and HIV prevention strategies among participants in the San Francisco PrEP demonstration project: a qualitative analysis of counseling notes. *AIDS Behav*. 2016;20(7):1461–1469.
  27. **Liu AY, Cohen SE, Vittinghoff E**, et al. Preexposure prophylaxis for HIV infection integrated with municipal- and community-based sexual health services. *JAMA Intern Med*. 2016;176(1):75–84.
  28. **Koester K, Amico RK, Gilmore H**, et al. Risk, safety and sex among male PrEP users: time for a new understanding. *Cult Health Sex*. 2017;19(12):1301–1313.
  29. **Sagaon-Teyssier L, Suzan-Monti M, Demoulin B**, et al. Uptake of PrEP and condom and sexual risk behavior among MSM during the ANRS IPERGAY trial. *AIDS Care*. 2016;28(Suppl 1):48–55.
  30. **Amico KR, Mehrotra M, Avelino-Silva VI**, et al. Self-reported recent PrEP dosing and drug detection in an open label PrEP study. *AIDS Behav*. 2016;20(7):1535–1540.
  31. **Pinto RM, Berringer KR, Melendez R, Mmeje O**. Improving PrEP implementation through multilevel interventions: a synthesis of the literature. *AIDS Behav*. 2018;22(11):3681–3691.
  32. **Calabrese SK, Magnus M, Mayer KH**, et al. “Support your client at the space that they’re in”: HIV pre-exposure prophylaxis (PrEP) prescriber’s perspectives on PrEP-related risk compensation. *AIDS Patient Care STDS*. 2017;31(4):196–204.
  33. **Patel RR, Chan PA, Harrison LC**, et al. Missed opportunities to prescribe HIV pre-exposure prophylaxis by primary care providers in Saint Louis, Missouri. *LGBT Heal*. 2018;5(4):250–256.
  34. **Mullins TLK, Lally M, Zimet G, Kahn JA**. Clinician attitudes toward CDC interim pre-exposure prophylaxis (PrEP) guidance and operationalizing PrEP for adolescents. *AIDS Patient Care STDS*. 2015;29(4):193–203.
  35. **White JM, Mimiaga MJ, Krakower DS, Mayer KH**. Evolution of Massachusetts physician attitudes, knowledge, and experience regarding the use of antiretrovirals for HIV prevention. *AIDS Patient Care STDS*. 2012;26(7):395–405.
  36. **Marcus JL, Volk JE, Pinder J**, et al. Successful implementation of HIV pre-exposure prophylaxis: lessons learned from three clinical settings. *Curr HIV/AIDS Rep*. 2016;13(2):116–124.
  37. **Parker S, Chan PA, Oldenburg CE**, et al. Patient experiences of men who have sex with men using pre-exposure prophylaxis to prevent HIV infection. *AIDS Patient Care STDS*. 2015;29(12):639–642.
  38. **Arnold T, Brinkley-Rubinstein L, Chan PA**, et al. Social, structural, behavioral and clinical factors influencing retention in Pre-Exposure Prophylaxis (PrEP) care in Mississippi. *PLoS One*. 2017;12(2):e0172354.
  39. **Chan PA, Glynn TR, Oldenburg CE**, et al. Implementation of pre-exposure prophylaxis for HIV prevention among men who have sex with men at a New England sexually transmitted diseases clinic. *Sex Transm Dis*. 2016;43(11):717–723.
  40. U.S. Preventive Services Task Force. Draft recommendation statement: Prevention of human immunodeficiency virus (HIV) infection: pre-exposure prophylaxis. Available from: <https://www.uspreventiveservices-taskforce.org/Page/Document/draft-recommendation-statement/prevention-of-human-immunodeficiency-virus-hiv-infection-pre-exposure-prophylaxis>. Accessed January 30, 2019.
  41. **Braun V, Clarke V**. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
  42. **Nowell LS, Norris JM, White DE, Moules NJ**. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods*. 2017;16(1):1–13.
  43. **Hoffman S, Guidry JA, Collier KL**, et al. A clinical home for preexposure prophylaxis: diverse health care providers’ perspectives on the “purview paradox.” *J Int Assoc Provid AIDS Care*. 2016;15(1):59–65.
  44. **Krakower D, Ware N, Mitty JA, Maloney K, Mayer KH**. HIV providers’ perceived barriers and facilitators to implementing pre-exposure prophylaxis in care settings: a qualitative study. *AIDS Behav*. 2014;18(9):1712–1721.
  45. **Arnold EA, Hazelton P, Lane T**, et al. A qualitative study of provider thoughts on implementing pre-exposure prophylaxis (PrEP) in clinical settings to prevent HIV infection. *PLoS One*. 2012;7(7):e40603.
  46. **Krakower DS, Maloney KM, Grasso C, Melbourne K, Mayer KH**. Primary care clinicians’ experiences prescribing HIV pre-exposure prophylaxis at a specialized community health centre in Boston: lessons from early adopters. *J Int AIDS Soc*. 2016;19(1):21165.
  47. **Krakower DS, Ware NC, Maloney KM, Wilson IB, Wong JB, Mayer KH**. Differing experiences with pre-exposure prophylaxis in Boston among lesbian, gay, bisexual, and transgender specialists and generalists in primary care: implications for scale-up. *AIDS Patient Care STDS*. 2017;31(7):297–304.
  48. **Underhill K, Morrow KM, Collieran CM**, et al. Access to healthcare, HIV/STI testing, and preferred pre-exposure prophylaxis providers among men who have sex with men and men who engage in street-based sex work in the U.S. *PLoS One*. 2014;9(11):e112425.
  49. **Bien CH, Patel VV, Blackstock OJ, Felsen UR**. Reaching key populations: PrEP uptake in an urban health care system in the Bronx, New York. *AIDS Behav*. 2017;21(5):1309–1314.
  50. **Braksmajer A, Fedor TM, Chen SR**, et al. Willingness to take prep for HIV prevention: the combined effects of race/ethnicity and provider trust. *AIDS Educ Prev*. 2018;30(1):1–12.
  51. **Blackstock OJ, Moore BA, Berkenblit G V**, et al. A cross-sectional online survey of HIV pre-exposure prophylaxis adoption among primary care physicians. *J Gen Intern Med*. 2017;32(1):62–70.
  52. **Petroll AE, Walsh JL, Owczarzak JL, McAuliffe TL, Bogart LM, Kelly JA**. PrEP awareness, familiarity, comfort, and prescribing experience among U.S. primary care providers and HIV specialists. *AIDS Behav*. 2017;21(5):1256–1267.
  53. **Blumenthal J, Jain S, Krakower D**, et al. Knowledge is power!: increased provider knowledge scores regarding pre-exposure



- prophylaxis (PrEP) are associated with higher rates of PrEP prescription and future intent to prescribe PrEP. *AIDS Behav.* 2015;19(5):802–810.
54. **Whitehead J, Shaver J, Stephenson R.** Outness, stigma, and primary health care utilization among rural LGBT populations. *PLoS One.* 2016;11(1):e0146139.
55. Institute of Medicine. *The health of lesbian, gay, bisexual, and transgender people: building a foundation for better understanding.* Washington, D.C.: The National Academies Press; 2011.
56. **Chan PA, Mena L, Patel R,** et al. Retention in care outcomes for HIV pre-exposure prophylaxis implementation programmes among men who have sex with men in three U.S. cities. *J Int AIDS Soc.* 2016;19(1):20903.
57. **Adams LM, Balderson BH, Brown K, Bush SE, Packett BJ.** Who starts the conversation and who receives preexposure prophylaxis (PrEP)?: a brief online survey of medical providers' PrEP practices. *Heal Educ Behav.* 2018;45(5):723–729.
58. National Minority AIDS Council. National HIV and PrEP Navigation Landscape Assessment. Available from: <http://www.nmac.org/wp-content/uploads/2017/11/National-HIV-and-PrEP-Navigation-Landscape-Assessment-Report.pdf>. Accessed November 13, 2018.
59. **Bruno C, Saberi P.** Pharmacists as providers of HIV pre-exposure prophylaxis. *Int J Clin Pharm.* 2012;34(6):803–806.