

# Experiences of PrEP Use among People Recently Diagnosed with HIV: Oregon, 2016-2019

A Special Surveillance Report  
May 2020



# Executive Summary

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Pre-exposure prophylaxis (PrEP) is effective at blocking HIV transmission when used correctly and consistently. The Centers for Disease Control & Prevention's HIV Surveillance branch added a question about past PrEP use to HIV case report forms beginning in June 2016. Since then, Oregon surveillance staff have observed newly reported HIV cases who have affirmed recent PrEP use, raising questions about why PrEP was not effective at preventing HIV acquisition for these individuals. We conducted open-ended interviews with 16 people who were diagnosed with HIV between 2016-2019 and who reported using PrEP on the HIV case report. Participants provided insight into their experiences taking PrEP. All participants were male-identified MSM. Length of time taking PrEP ranged from 8 days – 3 years. Participants reported high levels of social support and few difficulties with adherence; experiences of PrEP stigma were rare. The most common reason participants stopped taking PrEP was that they could not afford it. Out-of-pocket costs were prohibitive for participants whose insurance did not fully cover PrEP and few reported using drug assistance programs. Changes in insurance coverage appeared to be a particularly dangerous time for PrEP users, as many reported lapses in insurance that caused them to discontinue PrEP use. Some reported seroconverting during these lapses in insurance. Participants said the two things that would have most helped them be successful on PrEP was help navigating systems to pay for PrEP and better and earlier information about PrEP availability and how to take it.

## Acknowledgments

This report was prepared on behalf of Oregon's HIV Prevention & Surveillance Program by Program Design & Evaluation Services, an interagency research and evaluation unit affiliated with Oregon Health Authority and Multnomah County Health Department. Doris Cordova, Lonnie Ferguson & Brie Kennedy collected the data. Julian Adanaque-Bugarin assisted with transcription and Spanish translation. Linda Drach analyzed the data and wrote this report.

Thanks to the 16 individuals who participated in interviews; these data will improve PrEP access in Oregon.

The final version of this report released 5/22/20.

This report was supported, in part, by cooperative agreement number NU62PS924543, funded by the Centers for Disease Control & Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention and Department of Health and Human Services.



# Contents

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Executive Summary.....	1
Acknowledgments.....	1
Background.....	3
PrEP Use in Oregon.....	3
Recent PrEP Use among People Newly Diagnosed with HIV.....	3
Specific Aims & Methods.....	4
Results.....	5
Sample.....	5
Response Rate.....	5
Participant Demographics.....	5
Key Themes.....	6
History of PrEP Use & Decision to Take It.....	6
Provider Interactions.....	6
Access to PrEP: Logistics, Costs, and Insurance.....	7
Taking Pills.....	8
Side Effects.....	9
Social Context.....	9
Sexual Experience.....	10
Why Participants Stopped Taking PrEP.....	10
What Might Have Helped Participants Stay on PrEP.....	11
Discussion.....	12
Conclusions.....	13
Recommendations.....	14
References.....	15
Appendix 1: Factors Related to HIV Seroconversion among Recent PrEP Users Questionnaire.....	18

# Background

Pre-exposure prophylaxis (PrEP) is effective at blocking HIV transmission when used correctly and consistently. Studies have shown that PrEP reduces the risk of getting HIV from sex by about 99% when taken daily. Among people who inject drugs, PrEP reduces the risk of getting HIV by at least 74% when taken daily.<sup>1</sup> PrEP is recommended for people who are concerned about their risk of HIV acquisition, which may include people in serodiscordant relationships, people having condomless anal or vaginal sex, and people who inject drugs. PrEP provides an added layer of protection against HIV acquisition along with condoms and other prevention strategies.

PrEP “failure” for biomedical reasons is rare – worldwide, there have been fewer than 10 cases of HIV seroconversion despite adequate serum drug levels.<sup>2,3</sup> Seroconversion for other reasons – including low PrEP adherence, PrEP discontinuation, PrEP contemplation without initiation, and PrEP refusal<sup>4</sup> – are far more common.

Peer-reviewed scientific literature and popular media, including online posts, identify various barriers and facilitators of PrEP use, such as access issues and individual and medical provider knowledge, attitudes and beliefs.<sup>5,6,7</sup> Stigma and shaming have been identified as a factor that may be related to low PrEP uptake among gay men, in particular,<sup>8-9</sup> while lack of knowledge about PrEP and low risk perception – even when sexual and/or drug use behaviors and networks might indicate a high probability of HIV exposure – may play a larger role among groups with low PrEP uptake, including women, Black men, and people who inject drugs.<sup>10,11,12</sup>

## PrEP Use in Oregon

Surveillance data related to current PrEP use in Oregon do not exist. Available data from the All Payers All Claims dataset indicate that PrEP prescriptions in Oregon have increased dramatically in recent years – from eight in 2012 to 571 in 2016 – but remain low overall. Like other parts of the United States, young people, women of all racial/ethnic groups and men of color remain under-represented among PrEP users in Oregon.

Oregon’s Chime In study, which surveys a different population in the Portland metropolitan area each year, found in 2017 that about 1 in 5 HIV-negative MSM participants reported taking PrEP in the past 12 months. However, many discontinued PrEP for reasons that included not perceiving oneself as at risk, financial barriers, and access issues, like having to see a doctor to have prescriptions renewed. PrEP use among people who inject drugs (surveyed in 2018) and high-risk heterosexuals (surveyed in 2019) was extremely low.

## Recent PrEP Use among People Newly Diagnosed with HIV

The CDC HIV Surveillance branch added a question about past PrEP use to HIV case report forms beginning in June 2016. Since then, Oregon surveillance staff have observed newly reported HIV cases who have affirmed recent PrEP use, raising questions about why PrEP was not effective at preventing HIV acquisition for these individuals. In 2019-2020, the Oregon Health Authority’s HIV Prevention & Surveillance Program engaged Program Design & Evaluation Services, an interagency research & evaluation unit, to conduct a follow-up assessment with individuals diagnosed with HIV in Oregon whose case report indicated PrEP use.

## Specific Aims & Methods

The specific aims of this project were to gather descriptive epidemiological information on people newly diagnosed with HIV who reported taking PrEP and to use the information to improve PrEP services in Oregon.

All individuals who were diagnosed with HIV in Oregon between June 2016 – October 2019 and met the following criteria were eligible for this assessment:

- had recent PrEP use indicated on the HIV case report
- were at least 18 years old
- were not known to speak a language other than English or Spanish, and
- were aware of their HIV status.

Trained interviewers contacted all eligible participants by letter, inviting them to participate in a health study, and then followed up by phone one week after the letter was sent. All participants received at least 4 phone calls and 2 mailed letters inviting them to participate in the study.

All interviews were conducted by phone, in January - March 2020, using a semi-structured interview guide of 12 open-ended items and 3 close-ended, demographic items (Appendix 1). The guide was developed with stakeholder input from the Statewide Oregon PEP/PrEP Workgroup.

Participants gave verbal consent to participate. Each participant who completed an interview received a \$50 Mastercard gift card as a token of appreciation.

Interviews were recorded, with participant permission, and transcribed verbatim. Transcripts were exported to NVivo 11 for data management and analyzed using a general inductive approach to identify and code major and minor themes.<sup>13</sup>

# Results

## Sample

Of 723 HIV cases diagnosed during the designated time period, 40 (5.5%) replied “Yes” to the question on the HIV case report: “Have you ever taken PrEP for HIV prevention?”, 475 (65.7%) replied “No” and 215 (29.7%) had a missing response.

Among the 40 individuals who replied “Yes,” nine were excluded for the following reasons: two were under age 18, five were not diagnosed in Oregon, one spoke a language other than English or Spanish, and one had been diagnosed very recently and did not yet know his status. The remaining 31 individuals received a written letter inviting them to participate in the assessment. One was determined to be incarcerated for the duration of the study and was subsequently excluded.

According to HIV case report data contained in the Enhanced HIV/AIDS Reporting System (eHARS), the 30 individuals in the sample were all male; 29 reported sex with men (MSM) and 1 was listed as MSM/IDU. Seventy percent (n=21) were listed in eHARS as white, non-Latino, 23% (n=7) as Latino, 1 as Black/African American, and 1 as Multiracial. Ninety percent were from the Portland tri-county area, and the mean age was 37 years (range: 24 – 63).

## Response Rate

Sixteen of 30 eligible individuals (53%) completed interviews. Among those who did not participate, 12 did not respond to interview invitations and two refused.

Fifteen interviews were conducted in English and one in Spanish. Two interviews were not audiotaped; interviewers took notes and the summaries were coded for themes, but not quoted. Taped interviews averaged 16 minutes in length (range: 10 – 22 minutes), minus the introductions, consent, and arrangement of payment.

## Participant Demographics

There were no significant differences between respondents and non-respondents related to race, age, county of diagnosis, or year of diagnosis.

We asked the 16 participants three demographic questions: gender identity, sexual orientation, and race/ethnicity. All three questions offered more expansive response options than were available on the case report form.

All participants self-identified as male, which matched the eHARS data on sex. Sixty-three percent of participants (n=10) identified as gay, 3 identified as queer, 1 as bisexual, 1 as something else, and 1 as questioning.

We used an expanded list of the major OMB race and ethnic for self-reported race/ethnicity, including an open-ended response option. Four of the 16 participants reported different or more nuanced racial and ethnic information than what was provided in eHARS. Two individuals whom eHARS categorized as white offered additional racial classifications and two individuals who were listed as Latino in eHARS identified as both Latino and either “inter-racial” or white.

Five participants chose more than one racial or ethnic heritage (compared to one person who was listed as “multiracial” in eHARS); among the 11 who chose just one identity, 8 identified as white and 3 as Latino.

## Key Themes

Participants provided insight into their experiences taking PrEP from contemplation through discontinuation. Summarized results are reported by theme, with sample quotes presented in italics that illustrate the themes.

### History of PrEP Use & Decision to Take It

Fifteen of 16 participants reported taking PrEP. The one individual who did not take PrEP initiated the process but did not fill the prescription after receiving bills for labs he believed should have been covered by insurance; the individual tested positive while “fighting with the insurance company.” We include data from this individual even though he did not actually take PrEP because we felt his story offers a valuable perspective.

The amount of time participants reported taking PrEP varied from 8 days to 3 years, with a median duration of 10.5 months.

Nearly all participants said they viewed PrEP as part of basic preventive health care for gay men. Only one participant reported a specific situational reason for initiating PrEP – he said his HIV positive partner requested that he start the medication. Most people said they knew about PrEP from advertising, information they received through “word of mouth,” or conversations with friends:

*I guess I heard about it just from friends. There is a lot of advertising: ‘If you are gay, go on PrEP.’ I think that’s how [I learned about it], just word of mouth and advertising. #525*

*As a gay man, I paid attention to details of, you know, of sexual health and tried to pay attention to that. I first learned about PrEP probably 2 years before I started taking it. #507*

*I guess just being part of the gay community – I think it’s hard to not know about it, to be honest. It was around. I always knew about it. It seemed like ‘Why wouldn’t you do it?’ I meant to go on it a lot earlier than I did. #514*

### Provider Interactions

As gatekeepers for PrEP prescriptions, medical personnel are key players in increased use of PrEP.

Participants reported a wide range of interactions with their doctors related to PrEP, from active encouragement to ignorance to “some pushback.”

Six people said their doctors were the ones to initiate conversations about PrEP:

*I think I first heard about PrEP from my doctor. Well, actually, I probably saw an advertisement online, but then it was something that my doctor talked to me about and helped me decide it was probably a good idea to start taking. #522*

*[Clinic staff] were the ones that were really pushing me to get on PrEP. I did come with my own questions and curiosities, but they were the ones that really helped me to make the decision to hop on that medication. #518*

Nine respondents indicated that they approached their doctors about PrEP with mixed results, depending on the provider.

*I first learned about PrEP probably 2 years before I started taking it. I printed off some information and took that into my primary care doctor to propose to him that it might be a good thing for me to begin taking. He took some time to review that, probably 2 or 3 weeks or so... He knew nothing about PrEP at that time... If I put myself on the scale of 1 to 10, for knowledge about PrEP, I felt I was probably a 6 or 7 range as a patient. My doctor was probably in a 2 range. #507*

*I approached my doctor about it... I was very apprehensive about going to my doctor who is [a member of a conservative religion] and just saying ‘hey, you know I’d like to be on PrEP and here’s why.’ And so, I did approach my doctor and he couldn’t have been more understanding. He knew what I was talking about and it was a positive experience to be put on it. #526*

*I talked to my doctor about it. I told him I was gay and that I was interested in possibly dating again. I had met someone that I was interested in and I thought we would probably go down that road at some point, so he prescribed it for me, and talked to me a little bit about it. We did some testing prior to see if I was a good candidate for the prescription and we moved forward with it. #525*

Two participants who tested positive on initial or early lab testing for PrEP clearly describe missed opportunities by medical staff:

*[My first doctor] never recommended PrEP, he never told me that this pill existed. Because of this, I didn't take it and continued having sexual relations... My sister recommended [a different clinic]; the doctor that saw me was an HIV specialist. He asked me a lot of questions... I told him it had been six months [since I tested for HIV]. He asked me if I wanted to take a test to confirm my status, I said yes. That was when he recommended this Truvada pill that was preventative... He asked me if I had any problems with starting on it right away... and he called the pharmacy so that they would have it ready for me. ...If I had talked more with my previous doctor about HIV, maybe things would have been different. But there's no going back now. #524*

*I would've started it earlier if someone had suggested it or my doctor had brought up that option. #514*

### Access to PrEP: Logistics, Costs, and Insurance

The fifteen participants who started taking PrEP described the logistics of getting Truvada after receiving their prescriptions as “easy,” “effortless,” and “pretty routine.”

*Oh, it was really easy. You know, before I had left my doctor's appointment... they already had the prescription sent down to their pharmacy and I was able to pick it up within that hour and the refills were very easy to get after that, as well. #518*

Two people mentioned having to make special arrangements with a commercial pharmacy that did not normally stock Truvada, but they both described this as a minor inconvenience, not a barrier:

*That process of picking up the medication from the pharmacy was good. The pharmacy had to pre-order it because that wasn't something they normally had in the office, but they were really communicative. #507*

Experiences with paying for PrEP were not as universally positive. Seven people described seamless processes paying for their prescriptions. These participants were covered by either the Oregon Health Plan, the Veteran's Administration, or an employer-covered private health plan.

*Medicaid was fantastic in covering the entire cost of it, so I was really appreciative of that. It wasn't even really an inconvenience. #526*

However, more participants reported difficulties with insurance plans that wouldn't pay for PrEP or required high out-of-pocket costs:

*I was paying for health coverage out of pocket, and the cost of PrEP, as I did some brief shopping around was not something I could afford out of pocket at that time. #507*

*I think the number one thing that made it difficult is the price. God, it's \$3,000! That's just crazy. That is definitely like a deterrent. #522*

*Yeah, [cost] was a big influence [on why I stopped taking PrEP] because I don't make so much money. Truvada was totally out of pocket. It was the main thing that made me stop taking it. #528*

Eight participants described significant barriers due to losing their health insurance, changing insurance plans, or experiencing a lapse in coverage. Seven of these reported terminating their PrEP use because they could no longer afford it; one was unable to start. Two reported getting back on PrEP as soon as they could, only to discover they had seroconverted in the interim while they had a lapse of coverage.

*I was no longer insured and just the process of health navigating [by myself] at that time made it a bit discouraging to continue being on PrEP. #516*

*I had a lapse in my insurance and was unable to continue taking the PrEP medication... During that time, I had already kind of progressed into being more sexually open with people. And I was really trying to, I guess, ration the end of my last prescription, because I kind of knew I would be going without it for a little while... When I was getting towards the end of that prescription, I had a little bit of desperation... there was definitely some networking amongst friends to see if anyone had any extra PrEP pills that they might be able to part with... #518*

*I had insurance through my work and that made it easy to afford and made the whole process very simple. But then when I switched jobs, I lost one insurance and I was switching over to another and the process just kind of fell apart for me. #522*

*It was quite easy for the first number of years. Then, there was that snafu that came out of nowhere, relating to the [Gilead] subsidy ending, and it had something to do with my switch from a Silver to a Bronze healthcare plan through Obamacare... I went to Walgreens [and] they said it was going to be \$3,000 a month, I said, 'That's not possible, so I'm not going to do that.' ... I had a gap of about two to three weeks without any [PrEP] coverage... I believe that's when I become positive. #520*

Few participants talked about drug assistance programs. Four mentioned getting some assistance from Gilead and one said a pharmacist told him about Gilead's program, but he felt too overwhelmed at that point to learn more about the application process. Only one person mentioned using PrEP navigation services:

*I was talking with CAP and they were going to help me get on PrEP again, and we were going back and forth... I had a challenge to get it because they needed proof of income and insurance, which I didn't have insurance at the time. But then I got converted to HIV positive and I no longer needed PrEP, I needed a different type of medication. #502*

## Taking Pills

All participants reported using — or intending to use — a daily PrEP schedule, and most said they had no difficulty adhering to it. For example:

*I incorporated [PrEP] into my morning getting up, getting ready routine. I was really consistent in taking that within a 2-hour window in the morning — every morning, taking that pretty consistently. To my best knowledge, I didn't have any missed doses during the time that I was on PrEP. #507*

Only two individuals reported difficulty maintaining a daily schedule:

*I was taking it off and on, which is bad... I really didn't follow the directions ...it was like when I was at the peak of my sexual activity, that's when I would just like take it... I feel like I was taking it as if it was the Plan B — like women do for an abortion. #504*

*What got me in trouble is that I was a kind of fair-weathered taker. And I would take it for about three months while I was sexually active, and if I wasn't sexually active, I would stop using. And that's kind of the problem that I had, I tried to take it every day. But I just was very lackadaisical with the regimen. So, I did not take it as prescribed, I would just kind of take it intermittently, until I finally ran out of Truvada medication. #526*

## Side Effects

Seven participants reported side effects from PrEP. Four reported gastrointestinal issues, like stomach pain, stomach upset, and/or diarrhea. One person reported insomnia, one reported headache, and one reported elevated liver enzymes. Two individuals quit taking PrEP because of these side effects, including the individual with elevated liver enzymes and one of the individuals with GI issues — the latter reported that the stomach pain continued after he discontinued PrEP. Finally, one participant discontinued PrEP because he and his doctor were concerned about potential effects on his kidneys, given his specific medical situation.

## Social Context

Participants talked about several social dimensions of PrEP use: community knowledge and norms, social support, and stigma.

Ten participants commented on LGBTQ community awareness and positive norms related to PrEP, including both the informal communication that occurs between friends and the sponsored communication of advertising and health promotion seen at bathhouses, testing venues, and through social media and hook-up apps.

*It was almost kind of like a badge of honor if you were on PrEP...On social apps, a lot of gay men are kind of like — before you even ask them if they want to hook up — they say ‘oh, I’m negative and on PrEP.’ So, it is kind of like a gateway, or just kind of a statement that is made all the time. #526*

*I came into contact with opinions, but they were usually kind of positive. Everyone seemed to feel that [PrEP] was liberating them from the confines of just the community at large and that kind of slut shaming that goes along with that label of being promiscuous... My circle of friends was kind of joyous. #516*

*In the gay community, getting on PrEP is a “sign of respect.” Because it shows you are “getting tested” and using PrEP as “protection.” #508 (full transcript unavailable, quotations indicate verbatim text)*

Several people commented that they have seen a noticeable increase in PrEP messaging in the past few years.

*I am on Grindr and other gay-targeted apps. I definitely see a lot of programs around Oregon Reminders and other HIV testing and/or PrEP ads that are coming on there. So, I feel that the presence of that communication now is more than it was 3-4 years ago. There has definitely been some headway or improvement during that time. #507*

*I think moving forward into 2020, there’s been a lot more talk, a lot more information out there to reach the populations for this medication. #516*

All participants who shared information about their PrEP use with friends and family reported positive feedback. Four participants said they didn’t tell anyone because they consider medical information personal and are “*not influenced by friends or families about my own health situation.*” No one reported negative reactions from friends or family about their PrEP use.

Similarly, participants in this study did not share stories of PrEP stigma that included the name-calling and branding seen in the media and literature. However, one participant who placed himself outside of the mainstream LGBTQ community experienced the HIV stigma that is sometimes connected to PrEP use:

*I left my Truvada next to my night lamp. [A friend] read it and googled it and said it was for HIV positive people. And I told him it was to prevent it. I was in the middle of a rumor and somebody said I had HIV. There was not enough information because some medications, the first thing you read when someone googles, it says: ‘HIV treatment,’ so people freak out. #528*

Another participant shared a story about internalized HIV stigma that may have affected his decision to discontinue PrEP:

*I guess I kind of felt like some people do: that if you get HIV, your life is*

*basically over. It's really messed up, it affects everything. So, I just didn't want, I felt like [HIV] was something that these nasty people got, and I just wasn't that person. Anyway, I thought that maybe I should [start taking PrEP]. And then later I thought, why am I doing this? #525*

## Sexual Experience

The most common theme related to how PrEP changed participants' sexual experience, shared by nine participants, was that it decreased anxiety and promoted "peace of mind."

*It made it more enjoyable ... Knowing for a fact that I was still able to take care of myself and put the worry behind my mind and know as long as I take my daily medicine, even if the condom does break, I'm still in a sense taking care of myself and planning for the worst. #517*

*There was a little less anxiety in sleeping with anonymous partners, although it didn't completely wipe out all of my concerns...definitely a little more peace of mind in just having a little more open and free sex. #518*

Most participants said that they didn't have more sex or different types of sex after starting PrEP, but some worried less about serosorting.

*It definitely changed who I would have sex with... It really helped me push forward and eliminate that stigma for individuals who are HIV positive, undetectable. So, it did give me that sense of control of not having to fully sort through who I engage with in sexual intimacy. But as far as [condom] use, that would still be used, but it did relieve that scare or that sense of exposure, to a manageable chronic disease, during the moment. #516*

*I'm not sure that it affected the frequency of sex so much, but definitely in anticipating sex, worrying about whether they were positive or negative, that became much less of an issue for me. #520*

Similarly, most participants reported no change in their condom use related to PrEP. Some specifically mentioned that they continued to use condoms for STD prevention. Only two participants said that they stopped using condoms or "didn't worry" about not using condoms while on PrEP:

*I felt more confident about not using condoms. And I probably felt like I could have sex more frequently and that there wasn't so much of a risk. You know, I was aware that PrEP doesn't prevent other STD's. But I think that in the LGBT community, HIV is kind of the one that everyone has to watch out for. I definitely felt more liberated sexually. #522*

*I was constantly looking for people who were on PrEP, as well, so that we didn't have to resort to using a condom. And so that's kind of how it changed my sex life ... It really gave me that permission and that go-ahead to have unprotected sex. #526*

## Why Participants Stopped Taking PrEP

The most common reason participants stopped taking PrEP was that they could not afford it. Eight participants said cost was the primary reason or the only reason they discontinued PrEP (or, in the case of one participant, why he never started it). A ninth participant said both cost and risk perception played equal roles: he felt he couldn't justify paying \$50/month out-of-pocket once his perceived risk had decreased.

*Had I not lost my insurance and had just been able to afford the prescription out of pocket, I never would have stopped taking it. #518*

Among the remaining seven participants for whom cost was not a factor, three stopped because of actual or potential side effects, two cited lifestyle changes (including a combination of moving, changing jobs, a lost prescription bottle, substance use, and a perception of decreased risk), and two heard about PrEP too late – they had already seroconverted.

A total of six participants discovered they were HIV positive while doing lab testing for PrEP. One individual tested HIV positive during initial lab testing, one during a four-month follow-up lab, three during testing to get back on PrEP after a lapse, and one while waiting to resolve bills he accrued trying to initiate PrEP.

## What Might Have Helped Participants Stay on PrEP

Responses to the question “Looking back, what kind of things might have helped you have a better experience with PrEP or helped you to stay on PrEP?” fell into two main categories: better information on navigating the system, especially insurance and drug assistance programs, and better, more timely information about PrEP and how to take it.

Only one participant used the term ‘patient navigation,’ but many described a need for medical personnel, pharmacists, or “someone” to provide more tangible help accessing drug assistance programs, assessing health insurance options, and solving problems related to out-of-pocket costs or other barriers.

*If there is anything that would have made my experience more successful on PrEP, I would have to say it would be, my doctor’s office being more aware and informed of those details... knowing that financial assistance was available. #507*

*I don’t know if this is even a realistic thing to imagine, but a little bit more advocacy or concern on the part of my primary care physician to make sure that my insurance plan covered it and to prevent the sudden stop in coverage that I ended up experiencing. I don’t know if doctor’s offices particularly get involved with that. #520*

*Gilead has that program that subsidizes Truvada. I really think that needs to be offered a lot more freely. #526*

*Not to blame them, but if the pharmacist had been more informed about the ways that I could get help — maybe a bit knowledgeable of resources. Just in general, if those resources were more accessible — maybe in the clinics that prescribe PrEP. I think it would have been a little bit less overwhelming and I would have felt like I had people I could turn to. #522*

Other participants said that they needed to be introduced to the idea of taking PrEP earlier and would have benefited from more specific information about how PrEP works and how to take it effectively.

*I had to go to [my doctor] about it and that was a poignant decision that I made: I’m going to go talk to her about this. I didn’t know how...it was a weird conversation to have with your primary care doctor. A lot of them don’t bring up sex...I think if it was more a part of the conversation earlier, I would’ve been on it earlier than I was. #514*

*I think we need more information, but we don’t need those huge sheets that they make. We need something more simple. #528*

*I run into ... the misconception that if you take Truvada one day, you are protected from Truvada that day. I mean, I had partners who would give Truvada out at orgies, or sex parties. It’s like, ‘dude, that’s not how it works, you know?’ I think that for Truvada to be effective in reducing HIV, there needs to be a more explicit understanding of how it works. #526*

*I really didn’t ask many questions – which now, I feel like I should have asked a lot more questions. #504*

## Discussion

Sixteen individuals newly diagnosed with HIV between 2016-2019 shared information about their experiences taking PrEP (or trying to take PrEP) prior to seroconversion. All participants were men who had sex with men; most identified as gay or queer and considered themselves part of the LGBTQ community. Unlike much of the literature on barriers to PrEP use among MSM, this specific subset of individuals reported positive community norms and social support around PrEP and reported little to no stigma related to their PrEP use.

Many participants reported interactions with medical providers that could have been better. Several shared stories that showed missed opportunities – providers who did not offer PrEP, did not know about PrEP when the patient approached them, or were not able to offer information and referrals about financial assistance to support participants' PrEP use. Oregon's AIDS Education and Training Center (AETC) has been conducting public health detailing with medical providers to address these gaps in knowledge, but this work only began in earnest in 2018. This work could be scaled up, particularly among primary care providers, who generally know less about PrEP than HIV specialists, but are more likely to encounter individuals who could benefit from PrEP.<sup>14</sup>

The most common reason participants stopped taking PrEP was that they could not afford it. Out-of-pocket costs were prohibitive for participants whose insurance did not fully cover PrEP and few reported using drug assistance programs. Changes in insurance coverage appeared to be a particularly dangerous time for PrEP users, as many reported lapses in insurance that caused them to discontinue PrEP use. Some reported seroconverting during these lapses in insurance. These findings were consistent with one study using open-ended data from a national on-line survey of 1,000 gay and bisexual men, which found that 80% of individuals who discontinued PrEP did so either because of cost or a change in risk.<sup>15</sup>

Participants said the two things that would have most helped them be successful on PrEP was help navigating systems to pay for PrEP and better and earlier information about taking PrEP.

Our sample was homogenous, but an accurate representation of the population taking PrEP in Oregon during 2016-2019: PrEP uptake has been low in Oregon overall, but particularly among groups other than urban MSM. According to a recent systematic review and meta-analysis of

published studies, PrEP use has been twice as high among MSM as non-MSM nationwide. Rates appear to be low but growing among Latinos, transgender women, and Black/African Americans, and remain stagnant among youth.<sup>16</sup>

Oregon's version of the National HIV Behavioral Surveillance Project, Chime In, found that awareness of PrEP was low among people who inject drugs (surveyed in 2018) and high-risk heterosexuals (surveyed in 2019); PrEP use among these groups was almost nonexistent. Because Chime In is only conducted in the Portland metropolitan area and the three sample populations do not include transgender people, no local data on PrEP knowledge, attitudes, or use in Oregon's rural communities or among transgender individuals is currently available.

From national literature, we know that the primary reason for low PrEP uptake among all groups is "self-risk underestimation;" that is, not believing oneself to be at risk for HIV despite behavior that presents opportunities for transmission.<sup>17</sup> Low risk perception as a driver for deciding against PrEP use has been documented among women,<sup>10,18</sup> Black/African Americans,<sup>11</sup> people who inject drugs,<sup>12</sup> and young MSM.<sup>19</sup>

Additional barriers exist. Fears of stereotyping/stigma and medical mistrust have been documented among cisgender women,<sup>20</sup> transgender women,<sup>21</sup> and Black/African Americans.<sup>22</sup> Concerns about side effects and drug interactions between PrEP and gender-affirming hormone therapy may constitute additional, unique barriers for transgender people.<sup>23,24</sup> Finally, people who are less likely to use PrEP (both in Oregon and nationally) generally have less access to social determinants of health, such as income, education, and health insurance – additional hurdles to address in increasing PrEP uptake and supporting health equity.

This assessment has limitations. The overall number of participants was small, and we don't know how the experiences of non-participants compares to the individuals we interviewed. For example,

nonparticipants may have had more difficulty taking PrEP or may have had other reasons for discontinuing PrEP that they didn't want to discuss. Also, as discussed, our sample consisted entirely of MSM. Participants included white, Latino, and multiracial individuals, but no Black men participated.

Finally, eHARS data may undercount the number of people recently diagnosed with HIV who had taken PrEP; this was a new data element in 2016 and we found a large proportion of missing data. The eHARS data also reveal some limitations in fully and accurately describing patient demographics, as evidenced by the more nuanced picture that emerged when participants were offered expanded demographic choices related to racial and ethnic identity, sexual orientation, and gender identity.

## Conclusions

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Based on findings from this small study, barriers to successful PrEP use among PrEP users with greatest access (e.g., urban MSM) included cost, insurance difficulties, and challenging encounters with medical providers – issues that are complex, but which can be addressed through policy and systems change.

More information is needed about PrEP knowledge, attitudes, and experiences of the full range of people who could benefit from PrEP – including women, youth, people of color, transgender people, people who inject drugs, and people living in rural and frontier areas of Oregon.

Based on Chime In data and the scientific literature, lack of knowledge and low risk perception – despite behaviors that present opportunities for HIV acquisition – are factors likely to be driving low PrEP uptake among all groups except urban MSM. Additional efforts to increase PrEP use among under-represented groups and promote health equity in Oregon must include education, social marketing, and community engagement, in addition to policy and systems change that promote equal access to social determinants of health.

# Recommendations

Participants said the two things that would have most helped them be successful on PrEP were help navigating systems to pay for PrEP and better and earlier information about PrEP availability and how to take it. In addition, we found that out-of-pocket costs and insurance changes created barriers to getting and staying on PrEP. Addressing the following areas may help increase PrEP usage in Oregon:

## Patient Navigation

- Evaluate and expand PrEP navigation and consumer education services in Oregon.
- Ensure that navigation messaging includes: (1) simple, clear messaging about what PrEP is, how it is used, and what to do to get help paying for it, (2) the importance of planning for insurance changes or lapses, and of seeking help early if changes are anticipated, and (3) risk assessments for discontinuing PrEP.
- Expand messaging to Oregon's medical community about PrEP to increase PrEP prescribing and avoid missed opportunities. This message should include information on the availability of PrEP navigation services in order to increase the overall knowledge and uptake of PrEP navigation services.
- Continue and possibly scale up public health detailing, particularly among primary care providers, who generally know less about PrEP than HIV specialists, but are more likely to encounter individuals who could benefit from PrEP.

## Increasing PrEP Awareness, Promoting Equity

- Ensure that all PrEP messaging is value-neutral and does not reinforce or perpetuate PrEP stigma. Dubov et al<sup>8</sup> recommend that public health messaging about PrEP emphasize two things: (1) the importance of PrEP for people who are sexually active regardless of number of partners or types of behavior and (2) PrEP as additional protection against HIV along with condoms and other prevention strategies.
- Ensure that PrEP messaging and education reaches beyond urban MSM to other communities who could benefit from PrEP but may not perceive themselves to be at risk. These include women, men of color, transgender people, people who inject drugs, rural people, and youth.
- Explore non-traditional methods of providing PrEP, including telePrEP,<sup>25</sup> home-based PrEP,<sup>26</sup> and long-acting injectable PrEP (when available).

## Insurance and Out-of-Pocket Costs

- Ensure the maximum usage of all available payer sources (including insurance and patient/drug assistance programs) to reduce gaps in PrEP coverage.

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# Appendix 1: Factors Related to HIV Seroconversion among Recent PrEP Users Questionnaire

## I. Interview Script/Protocol

Hello. May I speak with <name of participant>?

Hi, my name is <interviewer> and I work for the Oregon Public Health Division. I'm calling to see if you might be interested in participating in a paid interview about a health-related topic. We sent you an official letter about this project <last week>.

Before I tell you more about the project, I want to make sure I'm talking to the right person, so I can protect your privacy. Can I confirm your full name and date of birth?

\_\_\_/\_\_\_/\_\_\_ (Confirm you are talking with the correct person; If not, thank & discontinue. If yes, initial date of birth and proceed.)

Thank you. We are following up with people who have been diagnosed with HIV about their experiences with pre-exposure prophylaxis or PrEP, the pill to prevent HIV. We are trying to make PrEP easier for people to get and take, and it's helpful to hear from people who have experiences taking PrEP. I'm hoping you would be willing to talk with me for about 20 minutes on the phone—either now or at a time that's convenient for you. If you decide you want to do the interview, we will send you a \$50 Mastercard gift card afterwards as a small way to say thank you for your time.

If you agree to talk with me, everything you tell me will be confidential. We will use an ID number, not your name, to record any information you give me in the interview. Talking with me is completely voluntary and you don't have to answer any of the questions I ask if you don't want. You can also end the interview at any time. Also, please know that whether you do this interview or not, it won't affect any services you might get from the State of Oregon like insurance or food stamps—this is not connected with any of those things.

If you have any questions or concerns about the interview, I can give you the number of Josh Ferrer, who is the manager in charge of this project. (971-673-0149)

Would you be interested in talking with me? YES NO (thank you)

Would now be a good time or should we schedule another time?

Interviewer initial here to indicate informed consent given: \_\_\_\_\_

SCHEDULED FOR: \_\_\_\_\_

## II. PrEP Use Before Seroconversion Study Questionnaire

### Introduction

Thank you so much for agreeing to talk with me about your experiences using PrEP. We want to learn more about what that's like for people and what kinds of support people may need to make PrEP easier to use.

<Review elements of consent if interview script read a different day... “Just to remind you...”>

### Permission to Audio Tape

I'd like to audiotape this call, with your permission, to make sure I understand everything you say. If you decide that's OK, we will transcribe what you say from the tape—making sure anything that might identify you or another person is taken out—and then erase the tape. The written summary would not include your name or anything that could identify you. Is it OK with you if I tape this call?

YES *(begin recording. tell participant that you have started recording. Remind them that you will strike any identifying information that they mention, like names, from the transcript, but encourage them to avoid identifying themselves or others, whenever possible.)*

NO *(say OK, and tell the participant you will continue the interview without recording)*

### Verify PrEP Use Status

- 1. OK, just to verify: have you ever taken PrEP (pre-exposure prophylaxis, also known as Truvada), the pill that helps prevent HIV infection?**

YES

NO *(thank and discontinue interview)*

DON'T KNOW *(thank and discontinue interview)*

- 2. When did you start taking PrEP? (month and year?)**

- 3. And when did you stop taking it? (month and year?)**

### Decision to Take PrEP

I'd like to learn a little bit about your decision to take PrEP and your experiences taking it.

- 4. How did you first hear about PrEP? (PROMPT, AS NEEDED: What kinds of things had you heard about it? Did you know other people taking it?)**

- 5. What made you interested in taking PrEP?**

## Experience Using PrEP

- 6. How was the experience of getting your PrEP prescriptions? (PROMPT, AS NEEDED):**
  - Did you approach your doctor for PrEP or did your doctor talk to you about it?
  - Did you use PrEP Navigation services? (e.g., get help from a person at an agency whose job it is to help people think through their options related to PrEP)
  - How easy or difficult was it to get the prescription filled?
  - How was your experience with follow-up labs/medical visits?
  
- 7. How did you pay for PrEP? Were there any issues that made it difficult to afford? (e.g., insurance, out-of-pocket costs, pharmacy drug assistance programs (DAP))**
  
- 8. Tell me a little more about how you used PrEP—for example, did you take it daily or use a less than daily schedule? (PROMPT, as needed):**
  - If less than daily, how many days a week (on average) do you think you took PrEP?
  - Some people use PrEP just around the times they have sex but not at other times; was this true for you?
  - Some people only take PrEP when they travel or vacation, but not when they are at home; was this true for you?
  - Did you have any difficulties following the schedule for taking PrEP that was either recommended by your doctor or that you originally intended to follow?
  
- 9. Did you experience side effects? (if yes) Tell me a little about that.**
  
- 10. How did taking PrEP change your sexual experience—related to condom use, choice of partners, or other issues around sex? (e.g., decreased anxiety, sense of control, ways of hooking up, types of sex)**
  
- 11. Did you have any experiences with friends, family, or partners that made it either easier or more difficult to take PrEP? (PROMPT: for example, people’s reactions to learning that you were taking PrEP or other people’s opinions or stereotypes about PrEP use)**

## Reasons for Discontinuing PrEP

### 12. What influenced your decision to stop taking PrEP?

12b. **Thanks for sharing that. So, it sounds like the main reasons you stopped taking PrEP were:**  
<SUMMARIZE PARTICIPANT ANSWER AND CHECK BOXES BELOW.>

- didn't think your risk was high enough anymore/risk changed/change in partners
- had only intended to have "seasonal" or temporary PREP use (e.g., while having sex or vacationing)
- cost
- general social stigma/negative stereotypes
- specific peer, partner, or family reactions
- access to medications or labs
- access to prescribing medical provider
- difficult interactions with medical provider/provider poorly informed
- side effects
- adherence difficulties/didn't want to take a daily pill
- transportation/housing/structural barriers
- other life priorities/life chaos/hierarchy of needs
- personal barriers like depression, anxiety, substance abuse
- didn't stop taking it
- other:

**Did I get that right? Anything else?**

**13. So, the main reason we are doing these interviews is to learn more about the kinds of things that help people get and take PrEP and the kinds of things that make it hard to take PrEP. Looking back, what kind of things might have helped you have a better experience with PrEP or helped you to stay on PrEP?**

**14. Would you be willing to answer 3 quick demographic questions?****a. What is your gender identity?**

- Male
- Female
- Transgender
- Non-binary or nonconforming or genderqueer
- Something else: \_\_\_\_\_
- Don't know/refused

**b. What is your sexual orientation?**

- Gay
- Lesbian
- Bisexual
- Straight or heterosexual
- Queer
- Something else: \_\_\_\_\_
- Questioning/don't know/refused

**c. How do you identify your race, ethnicity, tribal affiliation, or ancestry? (choose all that apply)**

- American Indian/Alaska Native
- Asian
- Black or African American
- Hispanic/Latino/Latinx
- Middle Eastern/North African
- Native Hawaiian or Pacific Islander
- White
- Something else: \_\_\_\_\_
- Don't know/refused

**That's my last question. Is there anything else you want to talk about or do you have any questions for me?**  
ARRANGE FOR PAYMENT OF INCENTIVE. PROVIDE ANY REFERRALS NEEDED.