

# Patient Experiences of Men Who Have Sex with Men Using Pre-Exposure Prophylaxis to Prevent HIV Infection

Sharon Parker, PhD,<sup>1,2</sup> Philip A. Chan, MD,<sup>2</sup> Catherine E. Oldenburg, MPH,<sup>3</sup>  
Michael Hoffmann,<sup>2</sup> Joanna Poceta,<sup>2</sup> Julia Harvey,<sup>4</sup> E. Karina Santamaria, MPH,<sup>4</sup> Rupa Patel, MD,<sup>5</sup>  
Kelly I. Sabatino,<sup>4</sup> and Amy Nunn, ScD<sup>2,4</sup>

*To the Editor:*

**I**N THE UNITED STATES (US), new HIV infections are increasingly concentrated among men who have sex with men (MSM). Although MSM represent only 4% of males in the US,<sup>1</sup> they account for 61% of all new infections.<sup>2</sup> Despite demonstrated efficacy of antiretroviral pre-exposure prophylaxis (PrEP) in reducing HIV acquisition, evaluation of PrEP uptake and use outside of research settings remains limited.<sup>3–5</sup> Commonly cited barriers to PrEP implementation include limited awareness about PrEP, concerns about side-effects, adherence, cost, access, low perceived risk of HIV acquisition, and stigma.<sup>2,4,6,7</sup> Whether and how these barriers affect PrEP uptake and PrEP clinical programs in real-world settings is unknown. Similarly, other than in efficacy trials that found that individuals on PrEP did not engage in higher risk behaviors after PrEP initiation, little is known about changes in sexual risk behaviors following PrEP initiation.<sup>8</sup>

To understand PrEP patients' experiences in real-world settings, we conducted in-depth qualitative interviews with MSM prescribed PrEP at an infectious diseases outpatient center in Providence, Rhode Island. Interviews explored overall experiences taking PrEP, sexual risk behaviors and decision-making, self-reported experiences with payers, and normative recommendations for how best to raise community awareness about PrEP. The study was approved by the Lifespan Institutional Review Board (IRB).

Study inclusion criteria included being HIV-negative and taking PrEP for at least 3 months. Interviews were structured to allow flexible responses and introduction of additional topics by both interviewer and participant. We conducted interviews until reaching saturation, when no additional information emerged. Each interview was digitally recorded, professionally transcribed, and de-identified. A grounded theory approach was used to interpret interview findings. Transcripts were coded using contextual themes, and our findings were organized in analytical memos. Results are presented here.

Table 1 summarizes demographic characteristics of participants. Table 2 summarizes the primary findings. Patients generally reported positive experiences with PrEP and experienced few adverse clinical outcomes. PrEP users generally reported consistent adherence patterns; however, these results should be interpreted with caution, given that self-reported adherence to PrEP may not always correlate with drug levels. Despite this challenge, our results are consistent with prior research suggesting that facilitators of medication adherence include establishing a daily routine, using a pill-box, receiving daily text message reminders, and setting alarms.<sup>9</sup>

PrEP medication costs were generally covered by insurance companies, including public and private payers. Most patients' insurance covered the majority of PrEP costs, but several patients reported high co-payments for PrEP and related clinical and laboratory services. Industry-sponsored patient assistance programs helped offset many, but not all, of these costs. Overall, out-of-pocket costs were inconvenient for a few patients but did not present insurmountable barriers for most participants.

Some patients reported that pre-authorization requests for PrEP payments and requirements that patients pick-up medications from a specialty pharmacy as minor obstacles, but they did not generally hinder patients from initiating or continuing to take PrEP. However, our staff spent considerable time navigating both industry and clinic-sponsored patient assistance programs to reduce patients' out-of-pocket costs. Other clinics may require additional staff resources to provide these important support services to PrEP clients.

Participants overwhelmingly reported no increases in number of sexual partners or decreases in condom use. It should be noted that nearly three-quarters of patients in our study engaged in condomless anal sex or concurrent sexual partnerships before initiating PrEP and maintained these behaviors while taking PrEP. Our findings echo those of another recent qualitative study that found that patients who

<sup>1</sup>Department of Social Work-Joint Master of Social Work, North Carolina Agricultural and Technical State University, Greensboro, North Carolina.

<sup>2</sup>Warren Alpert Medical School of Brown University and The Miriam Hospital, Providence, Rhode Island.

<sup>3</sup>Department of Epidemiology, Harvard School of Public Health, Boston, Massachusetts.

<sup>4</sup>Department of Behavioral and Social Sciences, Brown University School of Public Health, Providence, Rhode Island.

<sup>5</sup>Division of Infectious Diseases, Washington University in St. Louis, St. Louis, Missouri.

TABLE 1. SOCIODEMOGRAPHIC, BEHAVIORAL, AND CLINICAL INFORMATION FOR PrEP PROGRAM PARTICIPANTS

	N = 24
Age (mean, SD)	33.2 (10.5)
Race and ethnicity	
White/Caucasian	18 (75%)
African American/black	1 (4%)
Asian	0 (0%)
Hispanic or Latino/a	6 (25%)
Other	5 (21%)
Education (highest level completed)	
Elementary school	1 (4%)
High school	5 (21%)
College	14 (58%)
Graduate school	4 (17%)
Annual income (mean)	\$54,429
Insurance	
None	2 (8%)
Private insurance	18 (75%)
Medicaid	4 (17%)
Prior authorization needed	2 (8%)
Participated in drug manufacturer's patient assistance program	2 (8%)
Co-payment for medication a barrier	1 (4%)
Sexual risk behaviors	
Men who have sex with men (MSM)	24 (100%)
Men who have sex with women (MSW)	1 (4%)
Women who have sex with men (WSM)	0 (0%)
Condomless anal sex with another man (MSM)—past 3 months	17 (71%)
Anal sex with HIV positive man (MSM)—past 3 months	7 (29%)
Substance use	
Alcohol use	16 (67%)
Injection drug use—ever	2 (8%)
Methamphetamine use—past 3 months	1 (4%)
Popper (amyl nitrate) use—past 3 months	6 (25%)
Referral source	
HIV/STD clinic	10 (42%)
Another outpatient physician	6 (25%)
Research study	3 (12%)
PEP program	1 (4%)
Other community referral	4 (17%)

STD, sexually transmitted disease; PEP, post-exposure prophylaxis.

already engaged in risk reduction strategies did not abandon them after commencing PrEP.<sup>8</sup>

Larger quantitative studies have demonstrated that PrEP users generally did not increase their risk behaviors and in some cases actually decreased their risk behaviors after initiating PrEP.<sup>3,5</sup> However, clinical trials, particularly those intended to demonstrate efficacy, are not ideally suited for studying behavioral changes following implementation of a new intervention, including for PrEP. For example, participants in the initial PrEP efficacy trials did not know which arm they had been randomized to (PrEP or placebo), and participants received frequent behavioral counseling.

Given the risk behaviors of our patient populations before and after PrEP and the fact that only a very small fraction of participants attributed their decision to no longer use con-

doms to PrEP, our study suggests that sexual decision-making and behavioral risk compensation remain complex and warrant continued attention by researchers and practitioners. However, the overwhelming majority of our patients did not use condoms at every sexual encounter *before* or *after* commencing PrEP. Most importantly, most of our highest-risk participants preferred not to use condoms and did not use other HIV prevention methods; for these patients, PrEP provides an important HIV prevention method that can dramatically reduce HIV acquisition risks.

In addition, many individuals expressed interest and preference for intermittent PrEP use. Many patients noted that they might change PrEP use if their relationship status or risk-taking behaviors changed. Notably, several patients increased HIV and other sexually transmitted diseases (STD) screening. PrEP may therefore promote earlier detection of HIV and other STDs; this is a noteworthy positive spillover effect of expanding PrEP use.

Many participants reported that their primary care physicians, pharmacists, and other health care providers had limited knowledge about PrEP. Several recent articles suggest that many practitioners are not knowledgeable about PrEP.<sup>10</sup> Some research suggests that primary care providers believe PrEP should be offered by infectious disease (ID) specialists, while other studies have found that ID specialists believe that PrEP provision is more suitable for primary care settings.<sup>11,12</sup> Educating the broader medical community about this novel HIV prevention technology may help expand PrEP awareness and access, increase PrEP referrals to knowledgeable providers, and retain patients in care.

This study has several limitations. The study sample was limited to participants enrolled in PrEP care; information could not be captured for patients lost to PrEP follow-up. It is conceivable that patients who were not retained in PrEP care had different experiences than patients retained in care. Additionally, approximately 75% of patients had private insurance. Average co-payments for monthly medications varied widely and ranged from \$0 to \$200; co-payments ranged from \$0 to \$50 for clinical services, depending on insurance carrier. Other patients with different insurance coverage might have different experiences paying for PrEP.

Further, because many of our patients were middle-class, White MSM, our findings may not be generalizable to other populations including women, transgender populations, or MSM from other racial groups or socioeconomic strata.

This study is among the first to explore experiences of patients taking PrEP in real-world settings. We were able to overcome many of the commonly perceived barriers to providing PrEP, including paying for medications, billing insurance companies for PrEP, and utilizing patient assistance programs to fill gaps in insurance coverage. In general, patients reported adhering to medications, experiencing minimal side effects, and not increasing risk-taking behaviors. Perhaps most importantly, PrEP was highly acceptable and was the only HIV prevention method used by many of our participants engaged in condomless anal receptive sex, many of whom also had concurrent sexual partners.

Our findings from a PrEP implementation program serving high-risk MSM suggest that PrEP programs are indeed scalable interventions, enhance HIV and STD screening for populations at high risk that might not otherwise use prevention methods, and are particularly important and highly

TABLE 2. PATIENT EXPERIENCES WITH PrEP

<i>Theme</i>	<i>Participant quotes</i>
Patients self-reported high rates of medication adherence	It's only one pill so it's not that bad. I would just take one pill every night before I'd go to sleep, and that was it. I set a little reminder on my phone so I didn't forget it. At first I didn't feel comfortable taking a pill every single day. But right now I don't mind. It's not really a big deal.
Patients experienced few obstacles paying for PrEP and PrEP-related services	We have a card [government-issued flexible spending debit card] that we use to pay for co-pays. As far as I know, the insurance company pays for it. They haven't raised any flags or asked any questions. I went to Walgreens and [the pharmacist] said that [the drug manufacturer] has a co-pay program, which I had never heard of. Basically, I didn't have to pay my co-pay anymore. The co-pay was sent to the drug manufacturer. So that entire \$70 was paid by them. She gave me the number. It took maybe fifteen, twenty minutes.... very, very simple.
Many patients engaged in high risk behavior before PrEP and continued behaviors after commencing PrEP (few reported increases in high risk behaviors)	I don't know that it's changed dramatically. A lot of my sex life depends on how busy me and my partner are. The first few months that I was on PrEP I thought I was going to be having a lot of sex. But really I think I had about four partners, which is not an unusual amount for me. I don't have as many partners. I've gone from 60 or more partners to around 30 or 35. I'm in an open relationship, me and my partner, we like to try different things ... we like to play. I've been with the same person for a few years now and we just like doing it, so I do see myself on it [for life], especially with the risks that are out there.
Most patients did not use condoms before commencing PrEP	We have explored other options. Condoms are still not a realistic option for us. I mean, I can lie to myself and say I'm going to wear those, but it's not going to happen. My partner count went down, but with the exclusive partners that I do have ... it does tend to be unprotected sex.
PrEP promoted increased frequency of HIV and STD screening	So now every 3 months, I'll know my status. I'm kind of locked in to come and get tested, which is a nice thing because before, someone would have to twist my arm and drag me in [to get tested]. When I started coming here, I was getting tested (for HIV and STDs) every 6 months. Now I get tested every 3 months.
Patients expressed interest in intermittent PrEP	Ultimately, I'm looking for a relationship and I feel like PrEP is definitely a temporary thing until I'm in a relationship. My thought was that I would take PrEP until I hopefully find a relationship where I don't have risk of exposure. For the foreseeable future I plan on staying on it. If there are any other options in the future I'd like to explore those options ... I'm always up for hearing what's the next thing. I would trade it for something better, if it were ever available.
Patients offered suggestions for enhancing community awareness about PrEP and PrEP uptake	I think social media would be a great tool.... why not take advantage of it. Every month there's a Bareback sex party that's internationally promoted across the world. One of them happens in Providence. It would be perfect to have a [PrEP awareness] station. Have PrEP go mainstream. Buses have advertisements all the time. You have every walk of life on that bus. Somebody's going to see it and think ... maybe I should go get tested or I know somebody who should, why don't I refer them to what I seen on the bus at a bus stop, get the public aware and knowing about it no matter what.
Patients suggested community-based physicians needed more information about PrEP	I am surprised by the number of physicians who don't know what PrEP is. I think if the physician community doesn't know, you can't possibly expect the regular, non-medical people to know. When I go to a doctor's office, they said to me ... is this drug for your heart? When [my primary care doctor] found out I was on Truvada he asked me "Why are you on Truvada? You're not positive." I said, "It's a preventive medication." ... It was one of those things where he didn't even know.

acceptable interventions for reducing HIV acquisition among high-risk, HIV-negative MSM.

### Acknowledgments

The study was supported by an implementation grant from Gilead Sciences, Inc. Philip A. Chan is supported by Grant 1K23AI096923 and Amy Nunn is supported by Grant K01AA020228 from the National Institutes of Health. Additional support was provided by Grants R25DA037190, T37MD008655, R25MH083620, and T32DA013911 from the NIH.

SP, PAC, and AN led the writing of this article including study design and data analysis. CO, MH, JP, JH, KS, and KIS contributed to the analysis and drafting of the article. All authors read and approved the final article.

### Author Disclosure Statement

Philip A. Chan, Amy Nunn, and Leandro Mena have received grant support from Gilead Sciences, Inc. Amy Nunn has received consulting fees from Mylan, Inc.

### References

- Oster AM, Sternberg M, Lansky A, et al. Population size estimates for men who have sex with men and persons who inject drugs. *J Urban Health* 2015;92:733–743.
- Krakower DS, Mimiaga MJ, Rosenberger JG, et al. Limited awareness and low immediate uptake of pre-exposure prophylaxis among men who have sex with men using an internet social networking site. *PLoS One* 2012;7:e33119.
- Grant RM, Lama JR, Anderson PL, et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. *N Engl J Med* 2010;363:2587–2599.
- Liu A, Cohen S, Follansbee S, et al. Early experiences implementing pre-exposure prophylaxis (PrEP) for HIV prevention in San Francisco. *PLoS Med* 2014 Mar 4;11(3): e1001613. doi: 10.1371/journal.pmed.1001613.eCollection 2014.
- Marcus JL, Glidden DV, Mayer KH, et al. No evidence of sexual risk compensation in the iPrEx trial of daily oral HIV preexposure prophylaxis. *PLoS One* 2013;8: e81997.
- 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: 195–216.
- 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;27:248–254.
- Hojilla CJ, Koester K, 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* 2015. DOI: 10.1007/s10461-015-1055-5.
- Liu AY, Hessol NA, Vittinghoff E, et al. Medication adherence among men who have sex with men at risk for HIV infection in the United States: Implications for pre-exposure prophylaxis implementation. *AIDS Patient Care STDS* 2014;28:622–627.
- Krakower D, Mayer KH. Engaging healthcare providers to implement HIV pre-exposure prophylaxis. *Curr Opin HIV AIDS* 2012;7:593–599.
- 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;18:1712–1721.
- 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:e40603.

Address correspondence to:

*Amy Nunn, ScD  
Assistant Professor of Public Health and Medicine  
Brown University School of Public Health  
Warren Alpert Medical School of Brown University  
121 S. Main Street, 8<sup>th</sup> Floor  
Providence, RI 02903*

*E-mail: Amy\_Nunn@brown.edu*