

To PrEP or Not to PrEP

Perspectives from US iPrEx Open Label Extension (OLE) Participants

IAPAC Adherence 2014

Abstract 440

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Disclosures

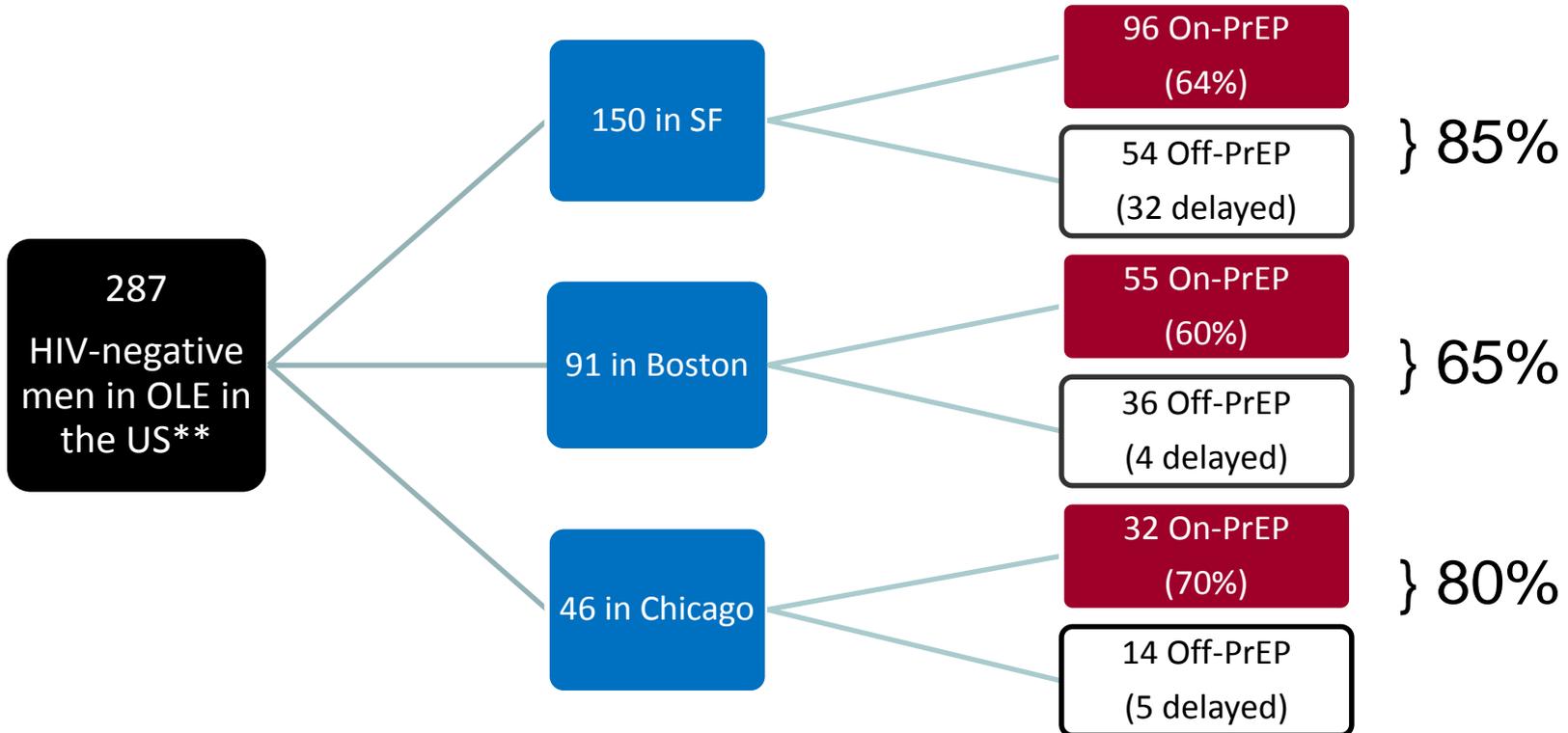
- **Gilead Sciences donated all study product for the iPrEx Open Label Extension study.**
- **The interviews conducted before July 16, 2012 (all San Francisco, 5 Chicago interviews) reflect perceptions of Truvada for PrEP prior to it being approved by the FDA for a prevention indication.**



Background

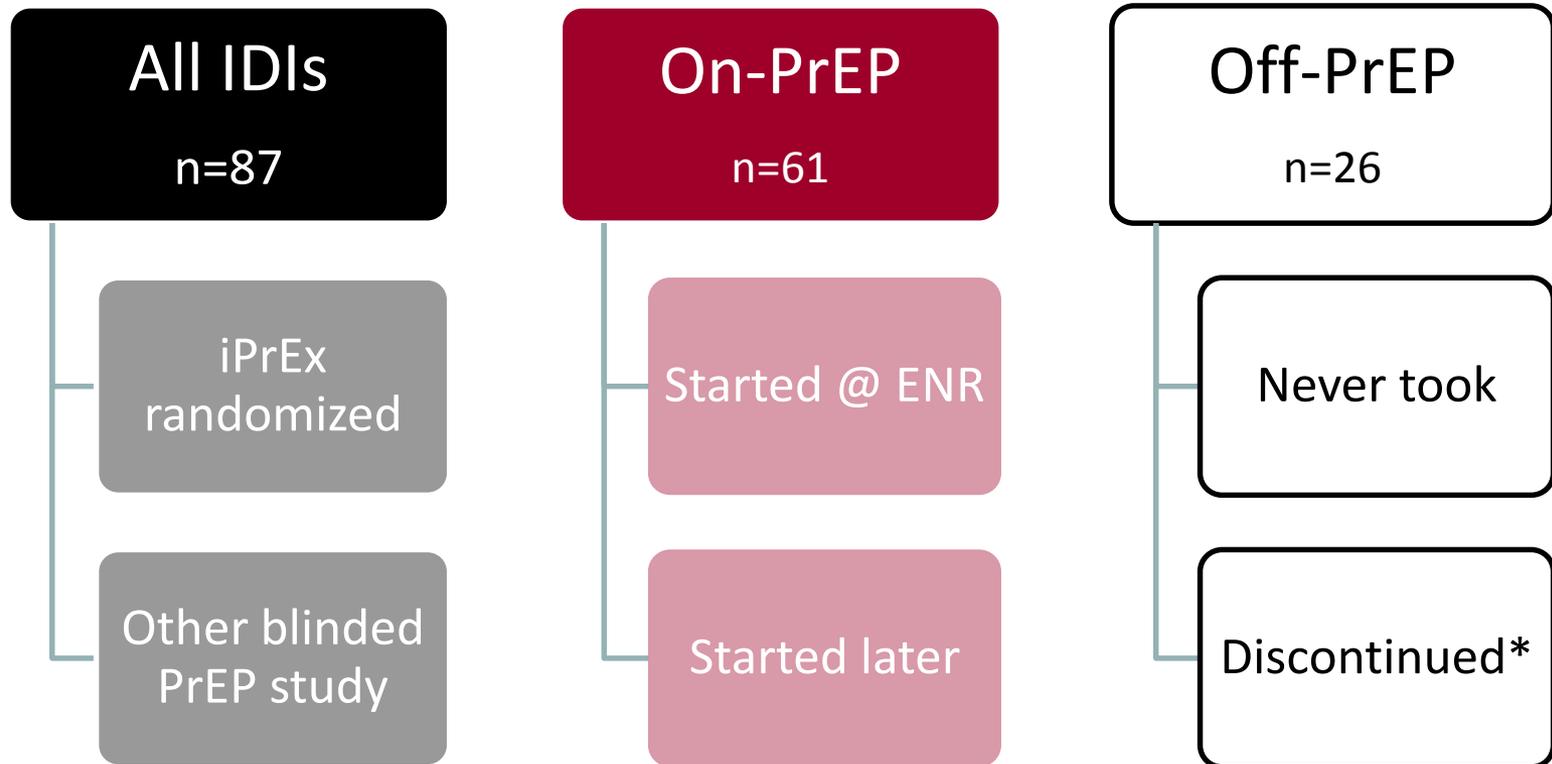
- **iPrEx OLE launched in June 2011**
- **During OLE, MSM and TGW who had previously participated in iPrEx or other blinded PrEP trials in the US were offered study participation; HIV-negative participants were given the option to take open label PrEP or not**
- **If the participant enrolled off-PrEP, they could elect to begin up to 48 weeks after enrollment**
- **Uptake of PrEP in OLE was 70% at enrollment; 76% in follow-up**
- **A subset of US-based participants was purposefully-selected for in-depth-interviews (IDIs) on OLE study experiences**

Study Population



**6 HIV-positive men; 2 in Boston, 4 in SF

Participant Sampling



*Participants who took PrEP and discontinued were asked some questions from the On-PrEP interview guide

Methods

- IDIs were conducted off-site by a researcher not affiliated with the study site(s)
- SF: April-May 2012; Chicago: July 2012; Boston: August 2012
- Interviewer utilized (2) IRB-approved interview guides (on-PrEP and off-PrEP) consisting of open-ended questions designed to elicit information on study experiences (e.g., motivations to participate in OLE and to take or not take PrEP)
- Interviews were digitally recorded, transcribed verbatim, coded (using Atlas.ti & Dedoose), and analyzed using Framework Analysis

Purpose

We describe reasons to take or not take PrEP and how PrEP did or did not fit into the lives of participants in San Francisco (SF), Boston, and Chicago.

Characteristics of Study Sample

	SF (n=29)	Boston (n=28)	Chicago (n=30)	Total (n=87)
Age (median, range)	47, 25-65	48, 26-61	22, 21-25	34, 21-65
Race/Ethnicity (%)				
White	62%	68%	7%	45%
Black	21%	21%	67%	37%
Latino	10%	11%	23 %	15%
Other	7%	0 %	3%	3%
Use of PrEP (%)				
On-PrEP	69%	68%	73%	70%
Off-PrEP	31%	32%	27%	30%

Findings: Summary

- Chicago participants were younger and more likely to be Black or Latino
- Most on-PrEP IDI-participants chose to take PrEP for an “extra layer of protection”
- Some also experienced “fringe benefits” to taking PrEP that were unexpected
- Off-PrEP participants expressed myriad reasons not to take PrEP, including:
 - prior experiences with or concerns about side effects
 - change in relationship status
 - utilizing other safer-sex strategies or
 - (less often) having medical issues precluding use of PrEP

Findings: On-PrEP

Participants definitely viewed themselves as being at risk of acquiring HIV.

A lot of my friends are HIV positive and it seemed like a good thing to do to help stem [the] epidemic...Also, I do sex work and I do sleep with people who are HIV positive so I do, you know, end up drinking and having sex with others...I don't necessarily seek out bareback sex or anything, but, you know, the legitimate need for- I have a, I have a higher, a higher general exposure rate.

-San Francisco, White, 29, 16 April 2012

Staying negative and stopping the spread of HIV was very important to them.

It's not something I do all the time, but it happens, it has happened, you know. It's happened in various points of my life, when I've been down or something like that. That said, you know for me risky sex is... you know, you hook up and people want to have sex without condoms, it's just what happens today. This is a reality. And sometimes that person is me, and sometimes it's the other person.

-Boston, Latino, 26, 14 August 2012

Findings: On-PrEP

PrEP was viewed as an extra layer of protection when having sex, such as in the event of condom non-use or malfunction.

Some described the experience of using PrEP as reducing previous anxiety, giving the participant greater “peace of mind.”

*...I don't feel that any of those steps that can make that situation more likely, but just in the end where you wake up, F*** what did I do? It's not as bad, it's not; you don't have this guilt-ridden thing. You're not sweating for two weeks before you get a test at Magnet. You can breathe a little easier knowing all right; it's not quite as bad.*

- San Francisco, Latino, 28, 30 April 2012

...We all have our slips sometimes where we're, like, engaged in sex and stuff like that and either we're intoxicated or we just feel a certain way about a person, you know, we really don't take, you know, the safest route all the time. But I make sure I take my pill, like, everyday or especially the times where I go out and have sex, whether I'm protected or not. So, because all the time... I'm not protected all the time.. I guess that makes me feel comfortable in a way...so that helps.

- Chicago, Black, 21, 20 July 2012



Findings: On-PrEP

The experience of taking PrEP often also came with some unexpected “fringe benefits.” Some participants felt empowered to consider relationships with partners they had previously excluded.

Others found the addition of a routine contributed to stability in other parts of their lives.

...After he disclosed his status to me that was almost like the big hurdle for me. I was trying to figure out like how exactly can I get around it?...how exactly could I get around to having sex with him and being confident and okay and comfortable? And then I realized an opportunity like this, you know, how PrEP is like, “Ah, here is the opportunity to do so.”

-Chicago, Black, 24, 16 July 2012

...it's [PrEP is] helping me. 'Cause, normally I'm late for things. I forget a lot of things. But, just remembering this one little important thing, it's helped me remember a whole bunch of other important things.

-Chicago, Asian, 24, 18 July 2012

Findings: Off-PrEP

Some participants chose to participate off-PrEP so they could continue to help the study. They reported that their relationship status or behavior had changed.

It's been a long time since I decided to take part in the project. I got involved with the study because I feel like the medicine will actually be of some good for people that's had unprotected sex. I'm not one of those people so I decided not to... have the pill.

- Chicago, Black, 25, 17 July 2012

... Well, so my circumstances have changed a little since when I first entered the study, the first half of it. I've been living with the same guy for two and a half years now and we're both negative. And...there's no sex outside of the house...and it just doesn't seem worthwhile to take the active drug. Especially since when I was on the study pill...there was [once] when my liver enzyme function tests went up and so that was scary and, and it wasn't because of the drug. I was on placebo but still, like why bother doing that when I know I'm not having any kind of exposure?

-San Francisco, Asian, 27, 13 April 2012

Findings: Off-PrEP

Other off-PrEP participants were nervous about or had experienced side effects previously, either in the randomized phase, or while on-PrEP earlier in OLE.

Interestingly, more IDI participants reported *fear* of side effects than actually reported *having* side effects.

I mean I tried to do [to take PrEP] as much as I could. Towards the end it was a lot more difficult 'cause the symptoms (side effects) were just continuous. So it was not easy to sort of take it and have a social life or a sex life. To be honest with you.

- Boston, Latino, 26, 14 August 2012

Well, when they did the unblinding of the study, it turned out that I had been on the placebo and, so I simply decided since I hadn't been taking it...I just kind of opted for that. That, that's like number one. If it's bad for my liver, I don't wanna take that stuff. I think that's the answer. If it's, if there's any side effects, especially, I mean, I'm healthy right now...I feel really good and I am healthy and so I don't, I don't want to take something that's gonna give me side effects.

-San Francisco, Black, 47, 12 April 2012

Conclusions & Implications

- In-depth interview participants expressed a range of factors influencing their decisions to take PrEP
- Accurate information regarding safety and tolerability of PrEP, as well as tools to help with accurate personal risk assessment, may assist in the decision to take PrEP
- Understanding and supporting motivations to use PrEP will be critical to its success as an HIV prevention intervention

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Thank you.



Questions?

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