



Monday, November 13, 2023 at 12:00 p.m. CT

Results From CFAR Pilot Awards Seminar

**PrEP Persistence, Risk, and Decision Making
and A Multilevel Approach to ARV Implementation Strategies for YBMSM**



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Persistence, Risk, and Decision-Making Among a PrEP Using Cohort: A Mixed- Methods Study

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Howard Brown
Health

Background



- Preventive-Effective Adherence: PrEP works if taken when potentially exposed to HIV
 - Different from life-long ART treatment
- Little information on decision-making around PrEP use in U.S.
 - How do people decide to start PrEP? Stop PrEP? How do people evaluate their HIV exposures?
 - Important for improving PrEP delivery and supporting persistence
- We used a mixed-methods approach to understand PrEP use among current users

PrEP Use Patterns Over Time

- 40% High Sustained
- 29% Declining
- 30% Short Use

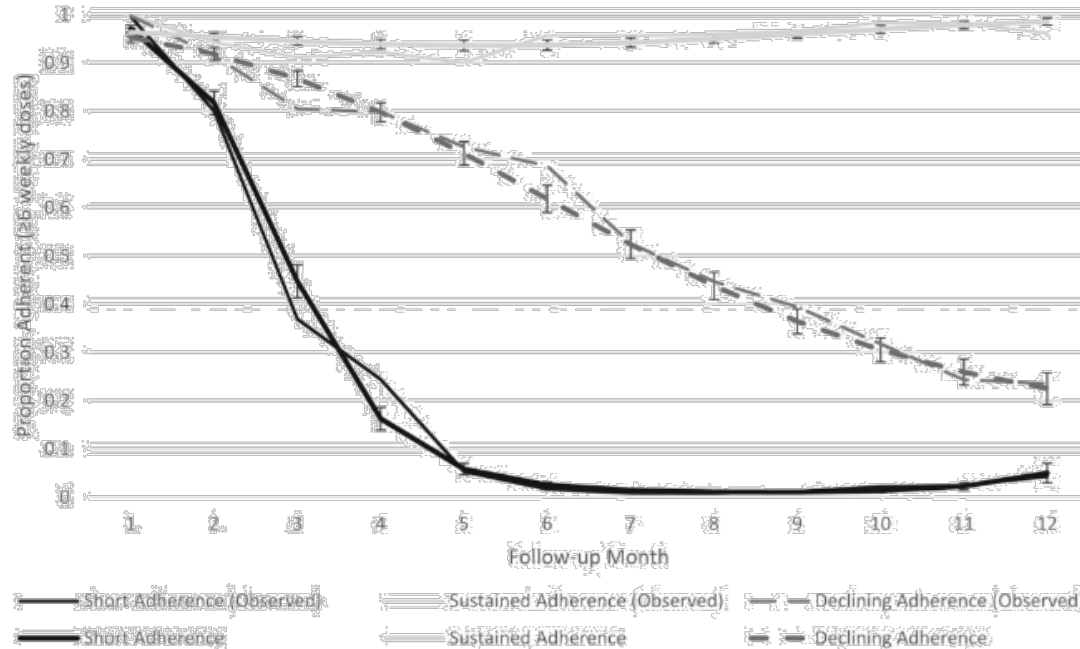
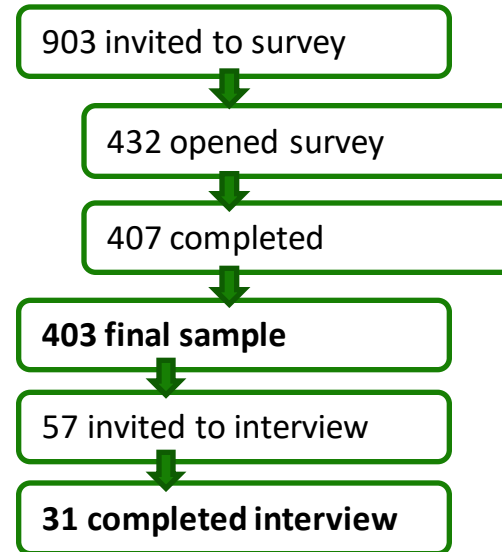


FIGURE 1. Observed and predicted adherence by assigned PrEP use trajectory (95% CI).

Study Design

- Patients contacted by the PrEP retention team were invited to complete online survey
 - Patients who will run out of PrEP in next 30 days and don't have appointment
 - Ranked by gender/race/age
- Purposeful selection by race/gender/PrEP use to invite subset for interviews



Study Sample

	Surveys (n=403)	Interviews (n=31)
Median Age (IQR)	27 (25, 29)	28 (26, 29)
Age		
18-24	17.9% (72)	16.1% (5)
25-34	78.7% (317)	74.2% (23)
35-44	2.5% (10)	6.5% (2)
45+	1.0% (4)	3.2% (1)
Gender		
Cis Men	80.0% (322)	32.3% (10)
Cis Women	1.2% (5)	3.2% (1)
Trans Men	6.2% (25)	9.7% (3)
Trans Women	8.7% (35)	32.3% (10)
Non-Binary	3.0% (12)	19.4% (6)
Race/Ethnicity		
Black	18.4% (74)	13.5% (10)
White	50.4% (203)	29.0% (9)
Hispanic	22.6% (91)	32.3% (10)
Asian	4.0% (16)	6.5% (2)
Orientation		
Gay	57.3% (231)	29.0% (9)
Bi	10.7% (43)	16.1% (5)
Queer/Questioning/Other	30% (121)	45% (14)
Insurance		
Private	69.2% (279)	48.4% (15)
Public	14.6% (59)	25.8% (8)
SelfPay	15.9% (64)	25.8% (8)
Median Months since started PrEP (IQR)	26 (12, 41)	25 (11, 39)

Sample Characteristics

- Most still active PrEP users
 - Last PrEP 0.7 days on average
- 90% felt PrEP completely/almost completely protects from HIV
 - 90% felt confident that their use of PrEP protected them from HIV
- 53% had ever taken a break from PrEP
 - Of those, 51% due to lack of sex; 25% due to trusted relationship
- 95% take/took PrEP every day (2.5% event-driven or 2-1-1)

Health Behavior Models to Understand Decision Making

- Perceptions around HIV
- Knowledge about PrEP
- Perceptions of PrEP
- Reasons for PrEP use
- Community Norms
- Clinical Barriers & Facilitators



HIV & PrEP

- **Perceptions around HIV**
 - Not as Bad – but still stigma
 - “Community” as vulnerable
- **Knowledge about PrEP: Friends, Community, Providers**
 - *I heard through like a sexual partner that I had a while back. I was straight at that time and I was curious and I started messing around. And one thing that I heard is like HIV was very -- it was more, I guess the numbers were higher in like gay community or what, like in the gay culture. And so, I was always being extra careful. And, I had people saying about like PrEP, but I didn't know what it was. I just thought it was like, I don't know, like, I just didn't ask questions. I don't want to like, you know, be more involved. Until one time I remember I didn't use protected sex at that time. And that person is like, “Oh dude, you don't have to worry about it, I am on PrEP,” and I said, I was like, “What is that?” And he showed me, and like, we looked it up online. I thought it was too good to be true, like if there's a pill for not having HIV, why do people so -- it was just confusing. And so I didn't believe it. -Bisexual Hispanic Cis Man*
 - *Yeah, yeah. And I think the community one was like really the big deal for me. So I mean, as like a Latino man too like I just I mean, I know for me and I know for others too like if I hear somebody say that's like a credible leader in the community that like something is good then I'm more likely to believe it than if it's just science based, right? – Queer Hispanic Non-binary Participant*

Perceptions of PrEP

- *Oh, good. I would say now versus then with -- when PrEP first started it was very much like slut-shaming, it was very much like blue pill --. It was very much like childish just like blue pill, derogatory terms, and I never understood it. And now it's not a thing. People have grown, thankfully, so.* -Hispanic Trans Woman
- *Most people are interested especially like my straight friends, whenever I tell them like, "I'm taking an HIV prevention medication." They're like, "I didn't even know something like that exist." And then I kind of explained a little bit about it and they're like, "That's actually really cool." But most of my gay and bisexual friends they're aware of it and, or are on it themselves or interested in getting on it.* -Bisexual Black Cis Man
- *To be honest, I've never wanted to be...I was like, wow, like this is something that I wanted to protect myself, take care of my health, but I felt like, how would I say, like I don't want to like say it in a mean way, but I felt like that was just an excuse for me to have just unprotected sex and not care about my health, because it was like, oh, STDs, you can get a shot and that will go away.*– Bisexual Hispanic Cis Man

Reasons for PrEP Use: Relationships, Pleasure, Health, Anxiety

- *I guess the peace of mind. But also, I don't personally think that HIV or like contracting AIDS makes me less of a person or bad person. There's nothing wrong with having HIV, but I guess I just want to take care of my machine. I want to just take care of my body.* - Hispanic Trans Woman
- *Ease of mind, really. I think when I first started taking it, it was really sexually liberating and kind of, it was definitely eye-opening to see what it was like to engage in sexual activity without this specter of HIV infection hang over. And it allowed for more focus on the experience and pleasure in a way that I don't think I had experienced before. So that was pretty revolutionary I would say in terms of my own sexual development experiences.* -Queer White Non-binary Participant
- *Not really, but it really reduced the panicking feeling because you asked me why I took this at the very beginning, right. It really worked, like mentally it worked. I was really freaking out. There was a time I cuddled with a stranger and I was freaking out. I just went to the emergency room to ask for PEP and the nurse just refused to give me that medicine because she thinks I'm fine. So right now I think that it was ridiculous, but that's exactly how I felt at that time. PrEP how does that say, eliminate my, like how do you say, scare to HIV.* – Gay Asian Cis Man

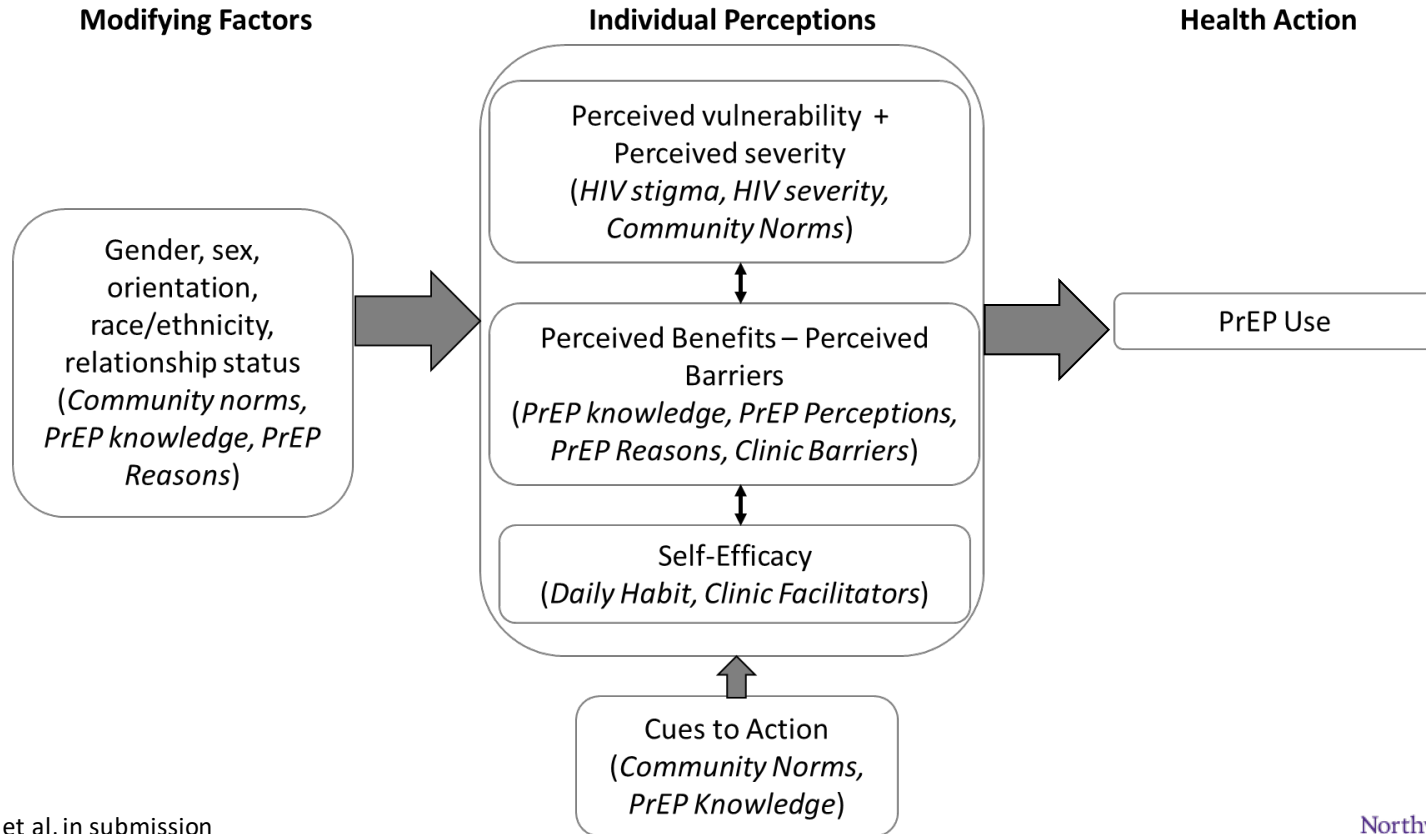
Community Norms

For a lot of us, it feels like driving with insurance. It feels like it's legal, like it should be required. Not everybody does it, but that's how it is in my community. Almost everybody does it. –White Trans Woman

- **Clinical Barriers & Facilitators**

- Complicated Processes, Insurance Barriers, Lack of Provider Knowledge or Culturally Awareness
- Reminders, Easy Refills

Health Belief Model



Community Norms

Descriptive Norms

(HIV vulnerability, PrEP knowledge, PrEP perceptions, Community norms)

Injunctive Norms

(PrEP knowledge, Community norms, Clinical barriers/facilitators, Daily habit)

Conclusions

- Using health models can identify leverage points for decision making
--> Developing better messaging/interventions

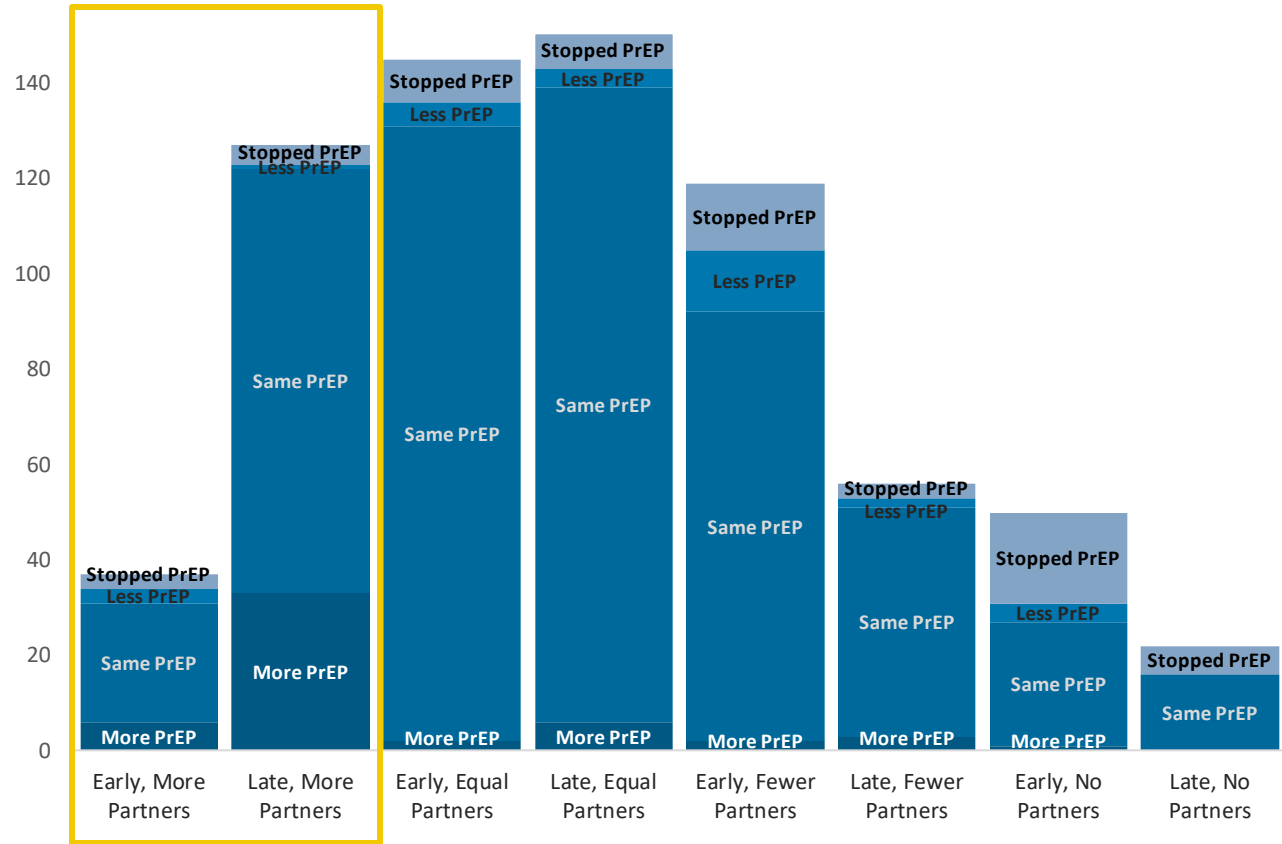
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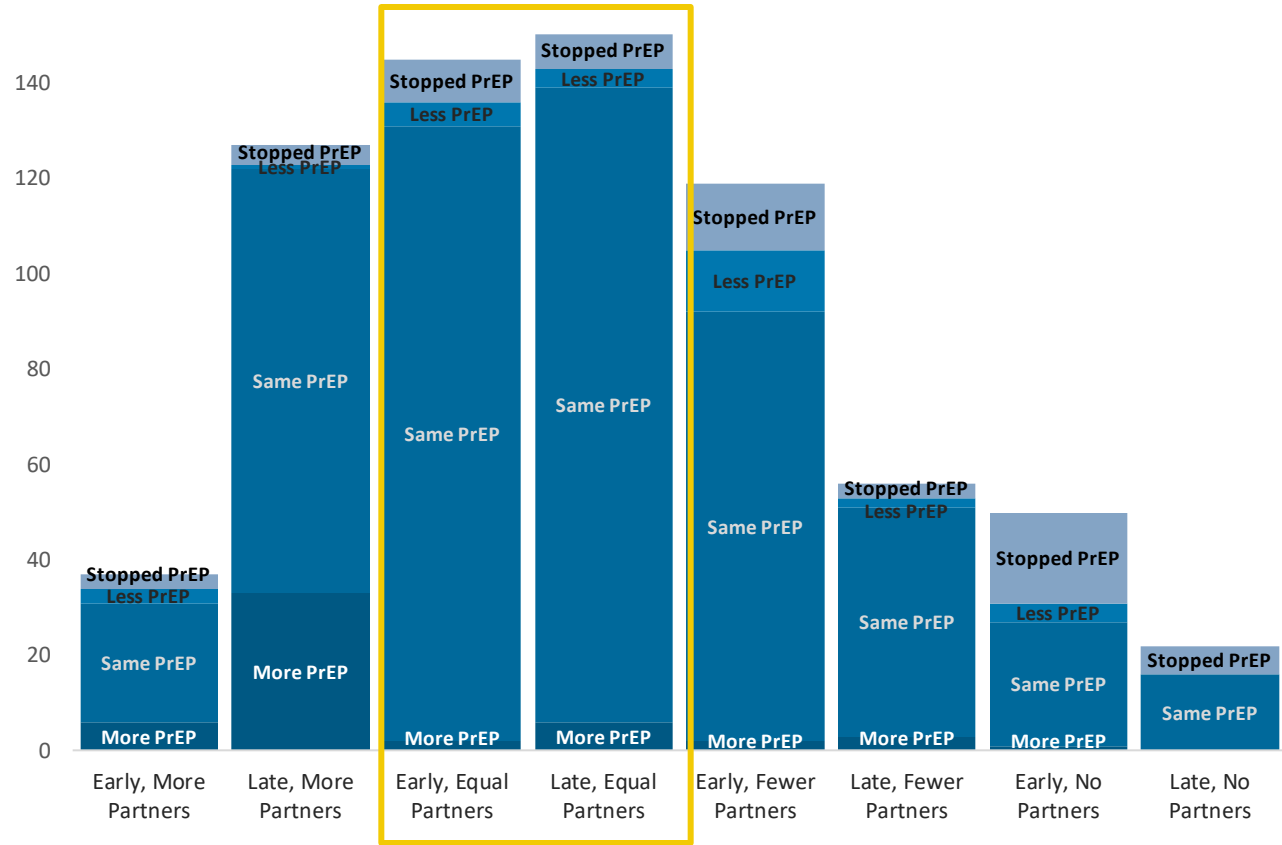
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In a Pandemic

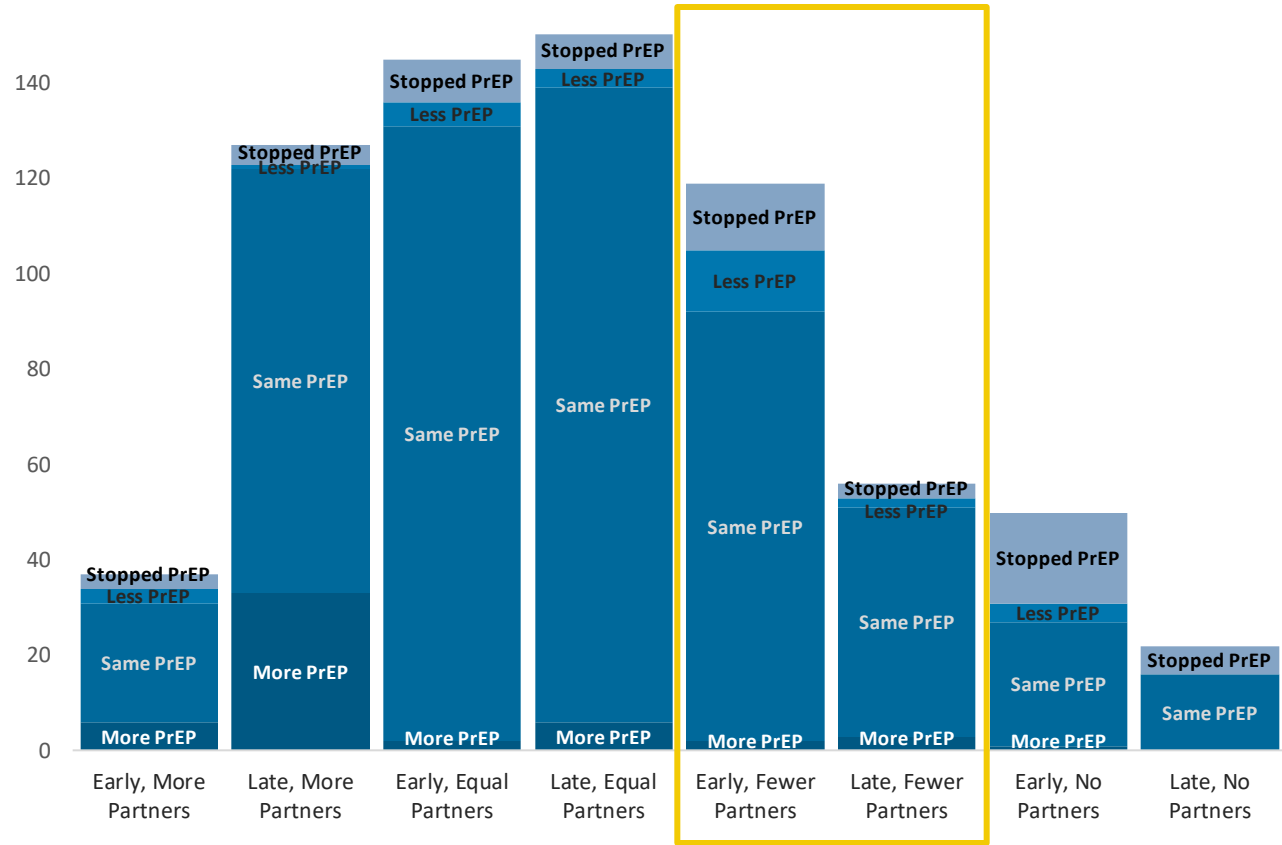
Decision Making During COVID



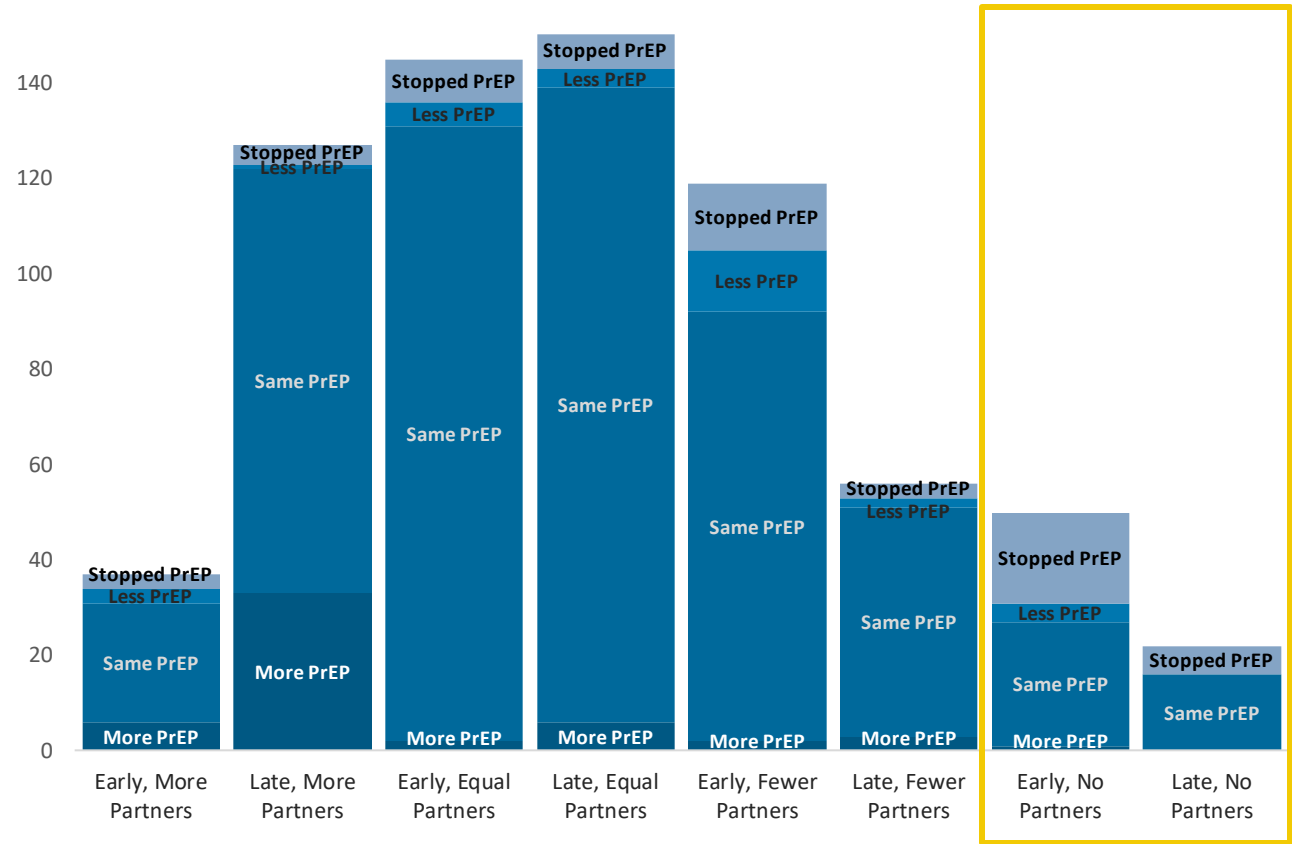
Decision Making During COVID



Decision Making During COVID



Decision Making During COVID



Decision Making During COVID

- Impact of COVID-19 on Sexual Experiences
 - Sexual Experiences
 - COVID-19 Concerns
- Impact of COVID-19 on PrEP use & STI Testing
 - Prevention-Effective Adherence
 - Maintaining PrEP use & STI Testing



Impact of COVID-19 on Sexual Experiences

And it's also a thing where because of the way that COVID impacted staying in touch with people, the network of people I'm in contact with has shrunk a little bit since before COVID began. And there are venues like, there's a local kink club that I go to for example that, they haven't fully reopened again yet. And so that's a place that I had a lot of connections with friends and things and that I would do play semi-regularly at, that I haven't been to in a while because of that.

-White bisexual trans woman

Because it's like, you know, when you can't really go outside as much, you're in the house so much more. And when you're in the house so much more and you don't have anyone living with you or anyone to talk to as much, it makes it easier to like get on a dating app and be like hey come over.

-Black trans woman

Impact of COVID-19 on Sexual Experiences

Well during COVID-19, I didn't hook up with anybody, like no random people other than the one person who is now my partner, but as far as sexually during COVID-19, I didn't hook up with anyone. But as far as dating and meeting people, there definitely was a factor but all of the dates that I went on were outdoor and tried to be as safe as possible.

–Black bisexual cis man

I have to say that I don't really think about opting out because I am vaccinated. I do wear my masks where I need to be wearing my mask. I mean, technically, you can get COVID now everywhere. So it's like, I'm like at this point, for me, if the other person feels like they're okay and they don't have any symptoms of it, like, for me, I treat it like another sexual disease as well like, you don't have any symptoms, I don't have any symptoms, we are both clean, we both been tested. We protect ourselves at this point. We can't hide for long.

-Hispanic gay cis man

Impact of COVID-19 on PrEP use & STI Testing

Things got less scary or a little bit more. The summer of 2020, I think I started going on some dates and things like that. But I think if I remember correctly, I believe when everything went down I stopped taking PrEP as well, just because I knew I wasn't going to be engaging in sexual activity.

–White queer non-binary

Well, it lessened my sexual activity because I was able to see fewer people and conscientiously sort of made that choice that I thought it was safer to not see any people, right? So in terms of PrEP use, I considered taking a break at the beginning and then just, sort of, it didn't, because it just seemed easier to continue rather than stop. I wasn't having difficulty remembering to take pills. It wasn't hard to get a prescription. The prescription was free, so I just sort of kept doing it.

-White non-binary

I've had it [STI testing] faithfully every month. No matter how many partners I mess around with no, you're going to see me every month. You're going to see me every month in here.

-Black gay cis man

Impact of COVID-19 on PrEP use & STI Testing

Just scheduling, attending not so much. And just with everything right now, everyone's really tight with COVID. I believe my next follow-up appointment isn't until next year... So things are definitely really spaced out.

–Hispanic

No, at least in Illinois with the lockdown that happened for like two and a half months, at that time none of my friends group had gotten tested since the last time because of the medical clinics were shut down and there were no real STIs to be spread a week from my network of people.

-Hispanic trans woman

Conclusions

- COVID-19 impacted sexual behaviors
 - Mostly inhibiting but lots of variation
- By & large, patients made testing/PrEP decisions in accordance with their sexual behaviors
 - Availability of services may have been limited, especially earlier in the pandemic