## **PrEP Retention**

#### Learning Community, May 17<sup>th</sup>

#### Welcome! Please introduce yourself in the chat ©



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### Welcome!

- Please introduce yourself in the chat!
- We're happy to have attendees here from the following clinics:
  - Bell Flower Clinic, Indianapolis, Indiana
  - Litoral Clinic, Migrant Health Center, Mayagüez, Puerto Rico
  - Mary Eliza Mahoney Health Center, Newark, New Jersey
  - Morrisania Clinic, Health & Hospitals, Bronx, New York
  - NYC Department of Health, NYC, New York
  - Take Care Down There Clinic, Columbus Public Health, Columbus, Ohio



## Group Agreements

- Keep cameras on, especially when talking
- All participants contribute to the discussion
- We're here to learn together
- Confidentiality: any patient information shared remains private



### **Clinics Share**

#### If you provide ongoing PrEP care:

What has been your clinic's experience with PrEP retention?

This can include your attempts to address retention, challenges, and/or successes in this area.

#### If you don't provide ongoing PrEP care, or are just starting PrEP:

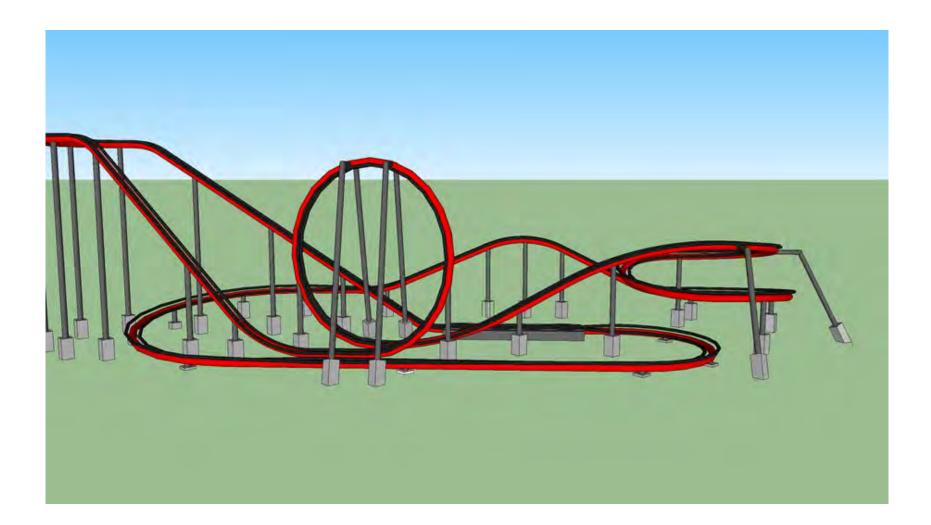
What concerns do you have related to PrEP retention?

If you don't provide ongoing PrEP care, do you conduct follow-up after the initial prescription?



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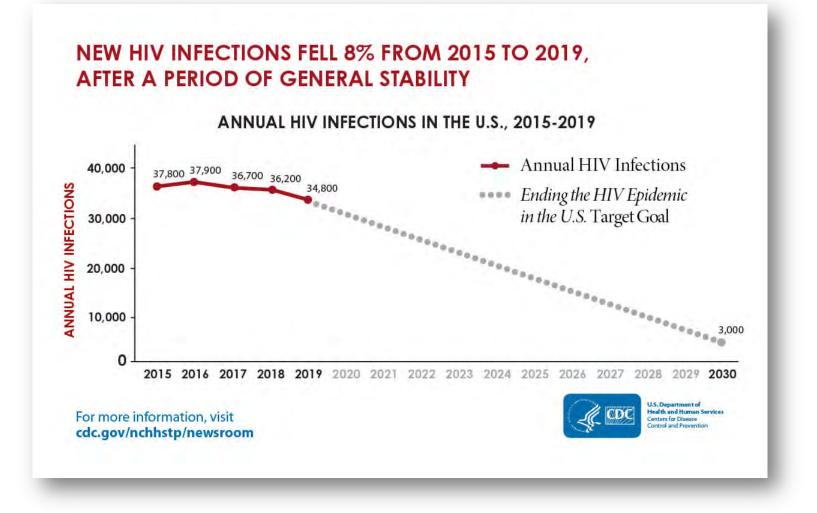
#### **PrEP** Retention





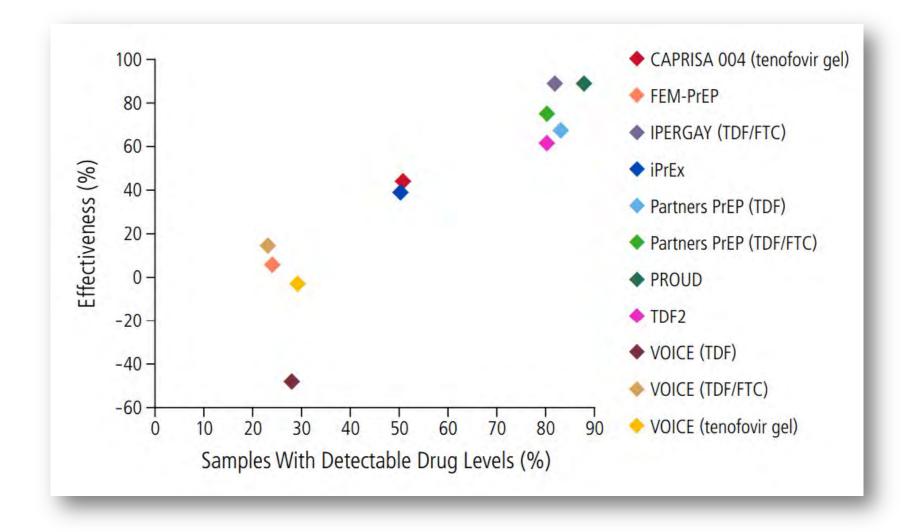
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### New Infections Are Not Falling As Quickly As Needed



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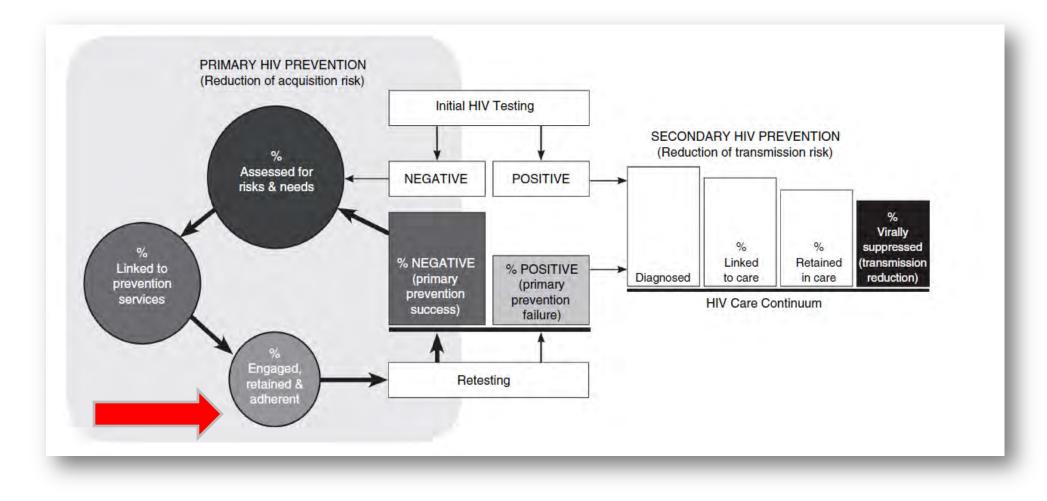
#### PrEP works...If you take it





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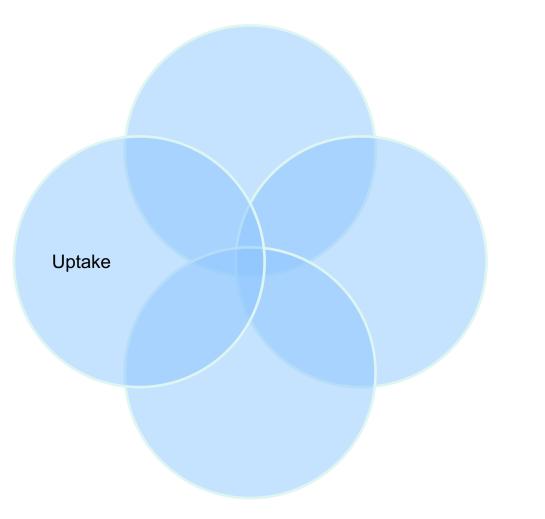
#### Keeping Patients Engaged Is the Largest Part of the Cascade



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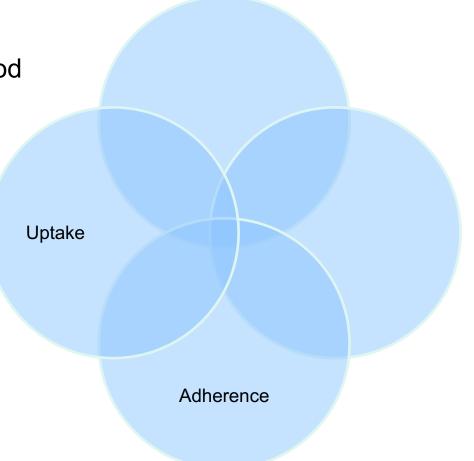
• **PrEP Uptake** – Number of patients who start PrEP





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- **PrEP Uptake** Number of patients who start PrEP
- **PrEP Adherence** Frequency of daily use over a period of time

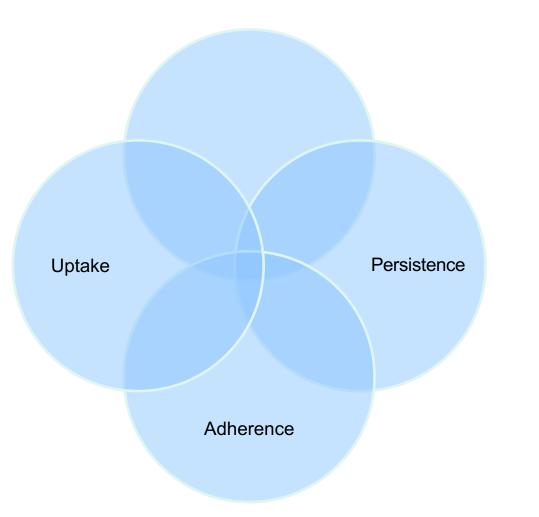






- PrEP Uptake Number of patients who start PrEP
- **PrEP Adherence** Frequency of use over a period of time
- **PrEP Persistence** Duration of continued use over a period of time

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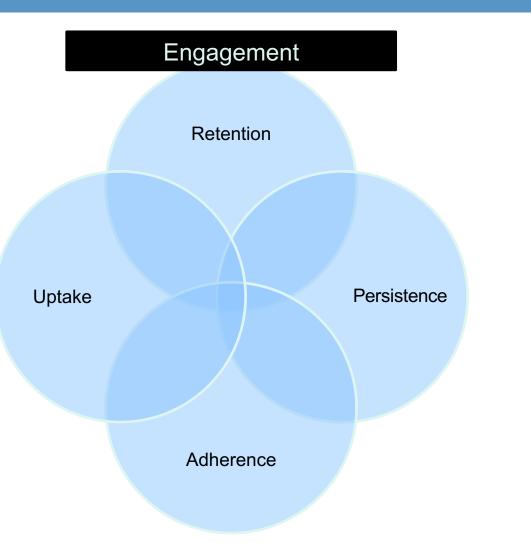
- PrEP Uptake Number of patients who start PrEP
- **PrEP Adherence** Frequency of daily use over a period of time
- **PrEP Persistence** Duration of continued use over a period of time
- PrEP Retention Duration of time coming to clinic regularly

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	Retention
Uptake	Persistence
	Adherence



- PrEP Uptake Number of patients who start PrEP
- **PrEP Adherence** Frequency of daily use over a period of time
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### Why Focus on Retention?

- Retention provides opportunities for
  - Preventive Care
  - Sexual health needs assessment and development of a sexual health plan
  - Sexually transmitted disease and HIV screening
  - Prescriptions for PEP and/or PrEP





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### **PrEP** is Different

#### **Reasons to Start PrEP**

- MD Recommendations
- Self-perceived risk
- Peers
- Advertising
- Other

#### **Reasons to Stop PrEP**

- Self-perceived risk
- Cost
- Side effects
- Peers
- Other





COLUMBIA VAGELOS COLLEGE OF PHYSICIANS AND SURGEONS Rowe K, Theodore DA, Zucker J, Cohensedgh O, LaSota E, Carnevale C, Cohall A, Olender S, Gordon P, Sobieszczyk ME. Lost2PrEP: Understanding Reasons for Pre-Exposure Prophylaxis and Sexual Health Care Disengagement Among Men Who Have Sex with Men Attending a Sexual Health Clinic at a Large Urban Academic Medical Center in New York City. AIDS Patient Care STDS. 2022 Apr;36(4):153-158. doi: 10.1089/apc.2022.0004. PMID: 35438522; PMCID: PMC9057871.

#### **PrEP Is Different**



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### Why Focus on Retention?

#### At Re-engagement

- 73% of patients had no healthcare contact during their gap in care
- 20% of participants had gonorrhea or chlamydia diagnosed at one or more sites
- 11% of patients required PEP

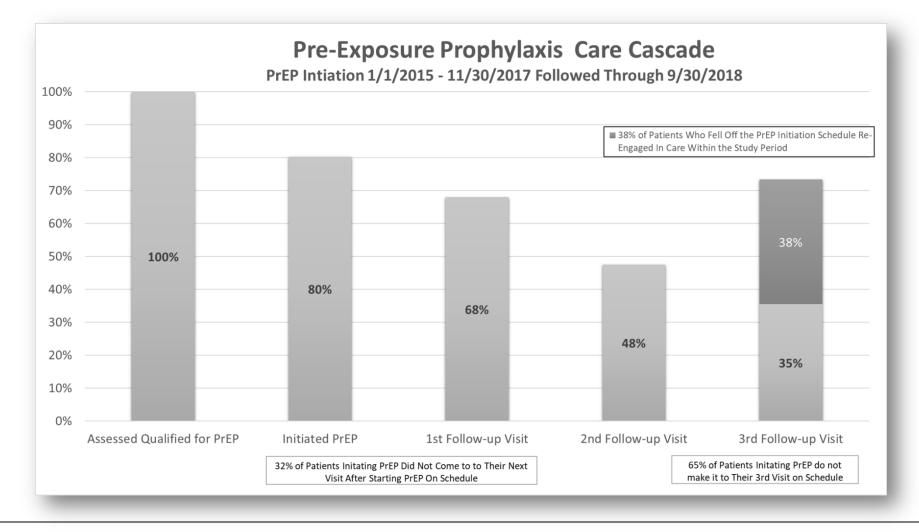




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Bartram L, Zucker J, LaSota E, Carnevale C, Richards P, Perez E, Mori K, Mgbako O, Olender S, Cohall A, Gordon P, Sobieszczyk M. "Rates of Neisseria gonorrhea and Chlamydia trachomatis among individuals returning to comprehensive HIV pre-exposure prophylaxis (PrEP) care". Adherence 2020 - 15th International Conference on HIV Treatment and Prevention Adherence. Nov 2020. Online.

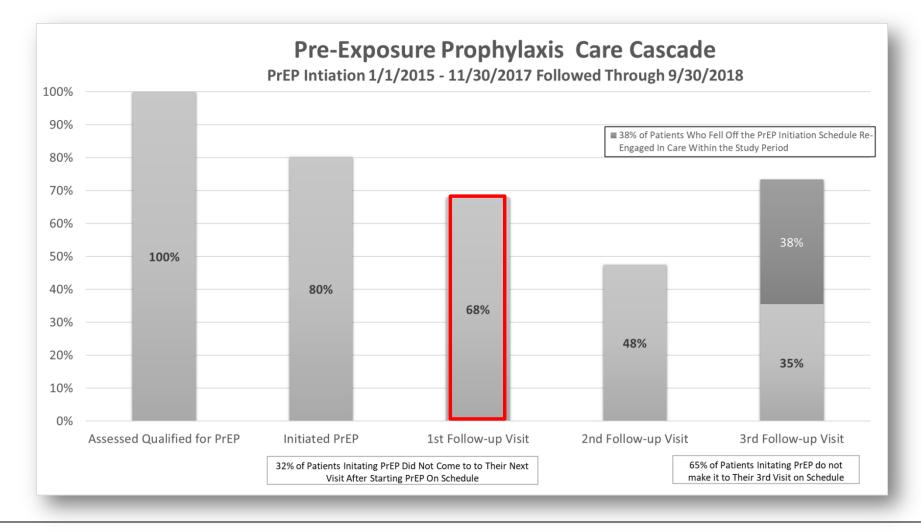


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Zucker J, Carnevale C, Richards P, Slowikowski J, Borsa A, Gottlieb F, Vakkur I, Hyden C, Olender S, Cohall A, Gordon P, Sobieszczyk ME. Predictors of Disengagement in Care for Individuals Receiving Pre-exposure Prophylaxis (PrEP). J Acquir Immune Defic Syndr. 2019 Aug 1;81(4):e104-e108. doi: 10.1097/QAI.00000000002054. PMID: 30985557; PMCID: PMC6594905.

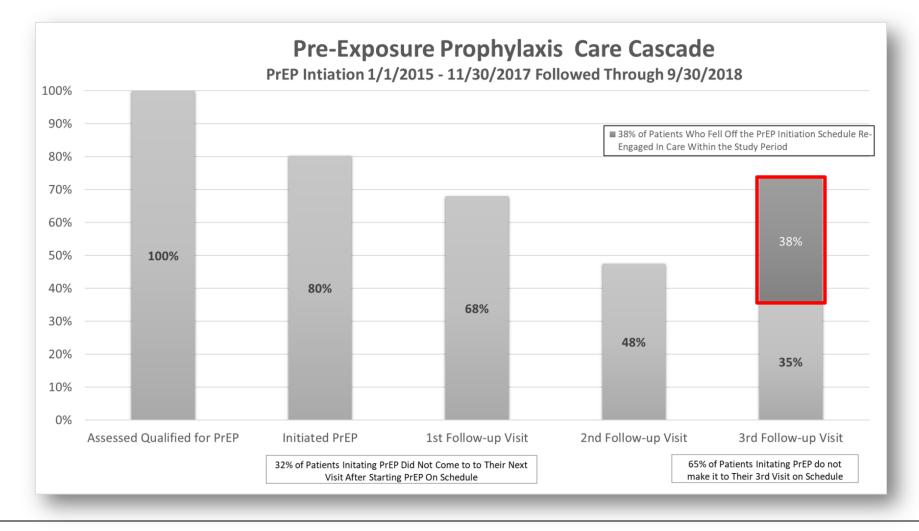


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#### n = 78,100% 100 90 n = 55, 80 71% n = 45,70 58% n = 38.60 Percent 49% 50 n = 24, 40 31% 30 20 10 0 **Eligible for PrEP** Started PrEP Retained in care Retained in care Retained in care at 30 days at 90 days at 180 days

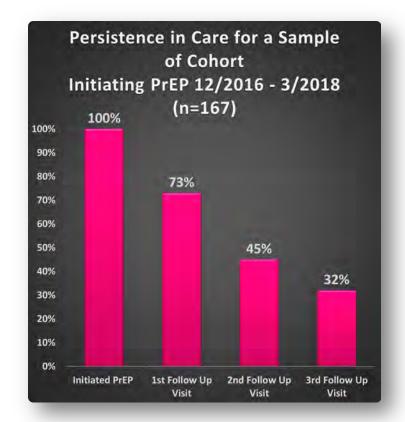
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Women

#### **Adolescents**





Carnevale C, Zucker J, Richards P, Molina E, Rojas H, Arache A, Simpson B, Dominguez J, Borsa A, Perez E, Mero J, Keith S, Sobieszczyk ME, Gordon P, Cohall A. "PrEP initiation amongst adolescents ages 16-24 at a Major Urban Medical Center in New York City." Adherence 2019 - 14th International Conference on HIV Treatment and Prevention Adherence. Jun 18, 2019. Miami Beach, Florida.

Theodore DA, Zucker J, Carnevale C, Grant W, Adan M, Borsa A, Richards P, Olender S, Cohall A, Gordon P, Sobieszczyk ME. Pre-exposure Prophylaxis Use Among Predominantly African American and Hispanic Women at Risk for HIV Acquisition in New York City. J Assoc Nurses AIDS Care. 2020 Jan-Feb;31(1):110-114. doi: 10.1097/JNC.00000000000147. PMID: 31789687; PMCID: PMC7380512.

### PrEP Retention is A Challenge For Everyone

#### RESEARCH ARTICLE

#### Patterns and clinical consequences of discontinuing HIV preexposure prophylaxis during primary care

Douglas Krakower<sup>1,2,34</sup> (6), Kevin M Maloney<sup>4</sup>, Victoria E Powell<sup>1</sup>, Ken Levine<sup>2</sup>, Chris Grasso<sup>2</sup>, Kathy Melbourne<sup>5</sup>, Julia L Marcus<sup>2,3</sup> and Kenneth H Mayer<sup>1,2</sup>

Corresponding author: Douglas Knowers, Division of Infectious Discases, Bish Isniel Deacroses Medical Center, 110 Francis SL WILMOB, Suile GB, Bosson, Massachnetts, USA, Tel. +1 (617)-632-0758. (discloseed/biblinc.hanaped.edu)

#### Abstract

Introduction: Discontinuations of HIV preexposure prophylaxis (PEP) by at risk individuals could decrease the effectiveness. of PrEP. Our objective was to characterize patterns of, reasons for, and clinical outcomes associated with PrEP discontinuations in primary care.

Methods: We conducted medical chart reviews for patients prescribed PrEP during 2011 to 2014 at a Boston community health centre specializing in healthcare for sexual and gender minorities. Patients were followed through 2015. We character ized patients' sociodemographics, relationship status, behavioural health conditions, patterns of and reasons for PrEP discontinuations, and HIV seroconversions. Cox proportional hazards models were used to assess patient factors associated with PrEP

and 73% were non-Hispanic white; 40% were in used PrEP continuously (60%), had 1 or more most often due to a decrease in HIV risk percent Of the 7 (1.1%) PrEP patients diagnosed with seroconverted after discontinuations. In a mult disorders, and insurance status, those who we 2.2, 95% CI 1.6 to 3.1 for ages 25 to 29 to 3.4, vs. cisgender men), and who had more likely to have discontinuations. Conclusions: Discontinuations of PrEP among patients who were younger, ident occurred after discontinuations of PrEP, Keywords: HIV; PrEP; primary care; disc

Received 4 September 2018; Accepted 18 January Copyright © 2019 The Authors. Journal of the Inters This is an open access article under the terms of I provided the private work is properly clied.

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#### Table 2, Reasons for and patterns of HIV preexposure prophylaxis discontinuation events

Reasons for discontinuation	First discontinuation (N = 239) n (%)	Second discontinuation (N = 51) n (%)	Third discontinuation (N = 10) n (%)	Fourth discontinuation (N = 2) n (%)	Total discontinuations (N = 302) n (%)
Decrease in ) IIV risk perception	84 (35.2)	13 (25.5)	1 (10,0)	1 (500)	99 (32.8)
ion-adherence to care plan"	34 (14.2)	11 (21.6)	2 (20.0)	1 (50.0)	48 (15.9)
Not documented	27 (11.3)	12 (23.5)	3 (30.0)	1.00	42 (13.9)
insutance barrier	290 (12.6)	6 (11.6)	1 (10.0)	2	37 (12.3)
Medication Intolerance	1/1 (5.9)	3 (5.9)			17 (5.6)
ass to follow-up	13 (5.4)	-	1 (10.0)		14 (4.6)
Other	12 (5.0)	3 (5.9)	-		15 (5:0)
Medication related toxicities	9 (3.8)	-	-	2	9 (3,0)
Financial barrier	7 (2.9)	-	1.000	-	7 (2.3)
Patient preference <sup>b</sup>	6 (2.5)	3 (5.9)	1 (10.0)	-	10 (3.3)
HIV seroconversion <sup>e</sup>	2 (0.8)	-	1000	-	2 (0.7)
Transler of care with intent to discontinue <sup>d</sup>	1 (0.4)	-	1 (10,0)	-	2 (07)



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### **Common Barriers to PrEP Retention**

- Provider Attitudes
- PrEP Is Not Right For Me

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• Side Effects

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• Insurance/Medication Payment barriers





### **Provider Attitudes**

- Sexuality is normal
- Offer resources and support
  - Sex positive messaging
  - Harm reduction approaches
  - Emphasizing benefits—rather than risks
- Provider "development"
  - Recognizing your own feelings about sexuality
  - How comfortable are you with the conversation
  - Separate your own values to effectively provide advice





### **Common Barriers to PrEP**

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## PrEP Is Not Right For Me

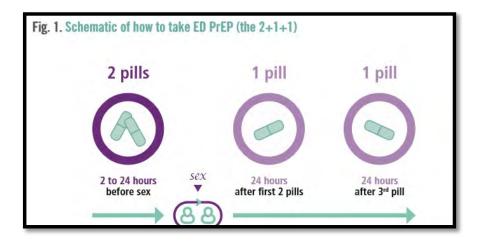
- Provider Attitudes
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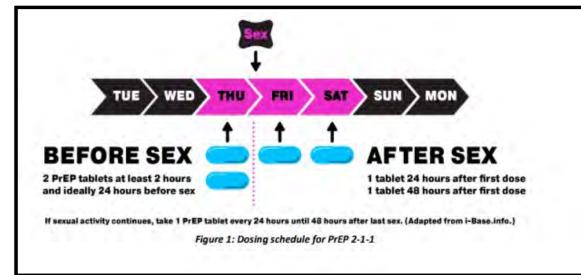
- "I don't really have enough sex to need to take PrEP anymore"
  - On-Demand
- "I heard on the news that PrEP was bad for my kidneys"
  - TAF
- "I just hate (or can't) swallow pills
  - Injectable Cabotegravir



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## **On-Demand (Great For Starts and Stops)**





- Only for men who have sex with men
  - Contraindicated for cisgender women, transgender women, and transgender men having vaginal/frontal sex
- Infrequent sex
- Able to plan for sex at least 2 hours in advance
- Contraindicated in Hepatitis B infection



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## PrEP Is Not Right For Me

• Provider Attitudes

• Prevention care is about more than just pills

- PrEP Is Not Right For Me
- Side Effects
- Insurance/Medication Payment barriers



### **Common Barriers to PrEP Retention**

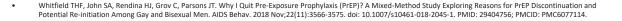
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### Side Effects

GI

#### • Self-limited

- Nausea
- Abdominal cramping
- Vomiting
- Provide counseling up front!

#### Renal

- Acute Kidney Injury
  - Discontinue and re-check in 2 weeks
  - May restart if CrCl >60 in one month
  - Also consider switch now that we are in the era of choice
    - Don't forget about PrEP Choice!



## **Common Barriers to PrEP Retention**

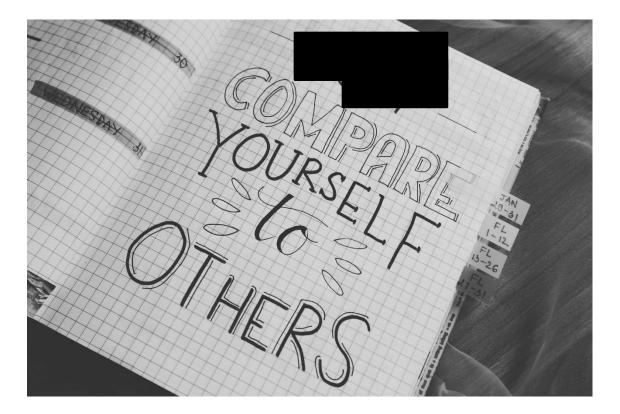
- Provider Attitudes
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- Insurance plans change
- Patients lose insurance
- Patients' benefits "lapse"
- Patient assistance programs expire
- Weird things happen!



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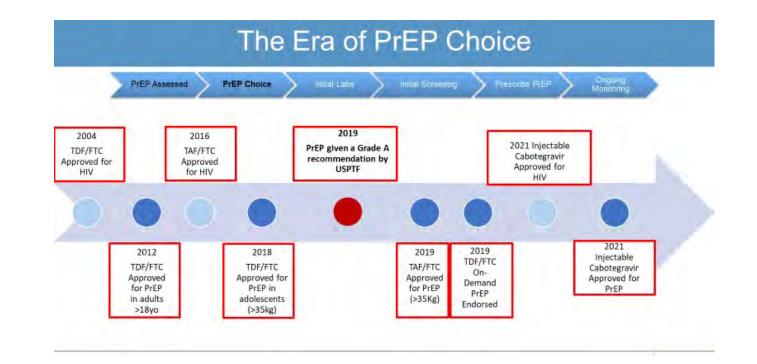
#### **Retention Strategies**

- PrEP Choice
- Extended availability
- Extended clinic hours
- Walk-in capacity
- Peer/personalized relationship
- Emphasis on pleasure, sex positivity
- Medication and visit navigation
- Routine integration
- Text Messaging



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### **PrEP Choice Considerations**

	How do you take it?	Frequency	Visit Interval	Approved for	Cost	"Tail"
TDF/FTC	Oral	Daily or On-Demand*	Q3 months	Everyone	\$	
TAF/FTC	Oral	Daily	Q3 months	Men and transgender women at sexual risk	\$\$\$	
Cabotegravir - LA	Injectable	4 weeks then Q2 months	Q2 months	Everyone at sexual risk	\$\$\$\$	Х



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"Providers may hold negative biases towards patients with multiple sex partners"

"Providers express concern that prescribing PrEP would encourage riskier sexual behavior"



Carnevale C, Zucker J, Richards P, Molina E, Rojas H, Arache A, Simpson B, Dominguez J, Borsa A, Perez E, Mero J, Keith S, Sobieszczyk ME, Gordon P, Cohall A. "PrEP initiation amongst adolescents ages 16-24 at a Major Urban Medical Center in New York City." Adherence 2019 - 14th International Conference on HIV Treatment and Prevention Adherence. Jun 18, 2019. Miami Beach, Florida.

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- Patients have concerns about
  - Cost
  - Insurance barriers
  - Side effects
  - Making appointments every 3 months
  - Pill taking



- PrEP Choice
- Extended availability
- Extended clinic hours
- Walk-in capacity
- Peer/personalized relationship
- Emphasis on pleasure, sex positivity
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- Routine integration
- Text Messaging

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#### Examples

- Brushing your teeth
- With morning coffee
- Before bed



• Rosenberg MJ, Waugh MS, Meehan TE. Use and misuse of oral contraceptives: risk indicators for poor pill taking and discontinuation. Contraception. 1995 May;51(5):283-8. doi: 10.1016/0010-7824(95)00074-k. PMID: 7628201.

## **PrEP Retention is Challenging**

#### **Common Barriers**

- Provider Attitudes
- PrEP Is Not Right For Me
- Side Effects
- Insurance/Medication Payment barriers

#### **PrEP Retention Strategies**

- PrEP Choice
- Extended availability
- Extended clinic hours
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- Routine integration



## Discussion



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### Quick Evaluation

- 1. How would you rate the value of today's discussion?
- 2. The level of the brief lecture was:
- 3. Attending the learning community is a good use of my time.
- 4. I felt comfortable contributing during the LC session.
- 5. As a result of today's session, are there any changes you would make in your practice?
- 6. Since the last LC, has your clinic made (or is in the process of making) any clinical practice changes related to HIV prevention services?





# What other topics would you be interested in hearing about at the LC? Please share in the chat!



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### Next Learning Community Session

Date: July 19, 2022

12-1pm EST

**Topic**: Choosing daily vs. on-demand PrEP

Presenter: Kerri Carnevale, DNP, MPH, AAHIVS



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### In the meantime...

#### Look out for our June newsletter!

Feedback? Anything you want to see? Questions for a clinician? Let us know!

#### **HIV PREVENTION** LEARNING COMMUNITY





#### **April Newsletter**

#### STI AWARENESS WEEK

It's STI Awareness Week! This year STI Awareness Week takes place from April 10 -16th. It provides an opportunity to spread awareness about STI prevention, testing, and care, while also reducing STI stigma.

The CDC has three different campaigns for 2022, all with their own toolkits and resources. Learn more about each at the links below:

- 1. Get Yourself Tested
- 2. Talk. Test. Treat.
- 3. Prepare Before You're There

What campaign will you choose to focus on this STI Awareness Week?

#### MARCH LC RECAP

March's LC focused on updated CDC PrEP guidelines. The 2021 guidelines include a number of changes that Dr. Jason Zucker reviewed during our last LC.

What were some of those key changes?

- 1. Inform all sexually active adults and adolescents about PrEP
- 2. Updates around PrEP modalities such as same-day PrEP, 2-1-1 dosing, and tele-PrFP
- 3. Cabotegravir (CAB) injections for PrEP 4. HIV laboratory tests

What guestions do you have about implementing the new PrEP guidelines? We're here to help.

NYC PTC: www.nycptc.org - National Network of PTCs: www.nnptc.org



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