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OAD0507: "I will not lower my voice": Experiences from trans and gender-diverse communities

PrEP experiences and challenges among transgender women in the United States and Puerto Rico in the era of PrEP choice: findings from the ENCORE cohort

Presented on behalf of co-authors: Tonia Poteat, Asa Radix, Chris Beyrer, Jason Schneider, Marissa Miller, Vani Vannappagari, Leigh Ragone, Adrienne Guignard, Annemiek de Ruiter, Sari Reisner, Andrea Wirtz, and the ENCORE Study Group

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Thank you to the trans women who have generously shared their time, experiences, and bodies for the purposes of this research, and the advancement of science.

And to the many trans and gender diverse colleagues, collaborators, advocates, and community members who continue to put themselves forward, despite the risks, to continue this critical work.



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Summary

What is your main question?

- What are the experiences of trans women who use PrEP in the United States and Puerto Rico?
- What are the reasons for choosing one PrEP method over another? Do these challenges and reasons differ by race, ethnicity, and/or age?

What did you find?

- 18% of our sample had used PrEP (last 6 months), 95% of whom only had experience with daily, oral PrEP
- Respondents rated their experience using PrEP positively, which was consistent across PrEP methods and sociodemographic characteristics
- Black and Latina trans women, and women ages 18-29 were more likely to report stigma related to their PrEP use
- Reasons for PrEP method choice also differed by race, ethnicity, and age

Why is it important?

- Transgender women generally reported positive PrEP experiences, but motivations and challenges differed by sociodemographics.
- Shared decision-making tools and interventions that address individual experiences and motivations may support effective PrEP use among populations most burdened by the HIV epidemic.



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Background

HIV prevalence and incidence among trans women are high¹⁻⁴

- Highest prevalence of all priority populations in the US epidemic (19-44%)
- HIV incidence has increased in recent years and is disproportionately concentrated among Black, Latina, and young trans women

PrEP engagement has been sub-optimal^{5,6}

- Prior to June 2025, there were two FDA-approved PrEP options for trans women in the US: oral TDF/TAF PrEP and long-acting cabotegravir
- **20% of trans women** who may benefit are **using PrEP effectively**
- **Low PrEP initiation rates** (6.5 initiations/100-person-years among PrEP eligible trans women) and **high discontinuation rates** (37.5 discontinuations/100 person-years among trans women using PrEP)

With expanding PrEP options, more data are needed on PrEP experiences, challenges, and motivations for PrEP choice



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encore ✨

Enhanced Cohort methods for HIV Research and Epidemiology (R01AI172092, mPI: Wirtz, Reisner)

- Nationwide, community co-led, observational cohort study
- Primary study aim: evaluate HIV incidence, risk factors, and syndemic conditions among transgender women in the US
- N=2,506 transgender women not living with HIV in all 50 US states, the District of Columbia, and Puerto Rico enrolled from April 2023 to December 2024
- Hybrid, hub-supported digital cohort model
 - Biannual study visits (survey and HIV test) can be completed remotely or with in-person support available in 10 Ending the HIV Epidemic (EHE) priority jurisdictions
 - Survey including more than 10 domains completed from any web-enabled device
 - Self-collected sample (either DBS or oral fluid) for HIV testing at central lab
- All study materials and procedures available in English and Spanish
- Recruitment via community partners, dating apps, and machine-learning based ad services



Statistical Analysis

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- All analyses restricted to participants who self-reported taking PrEP in prior 6 months
- Descriptive statistics to characterize:
 - **Self-rated PrEP experience**
 - “On a scale of 0-100, zero being negative to 100 being positive, how would you rate your experience overall using [oral/long-acting injectable*] PrEP?”
 - **Challenges taking PrEP**
 - “What challenges, if any, have you experienced taking [oral/long-acting injectable] PrEP? Select all that apply”
 - **Reasons for PrEP method selection**
 - “Why have you decided to use [oral PrEP (pills)/long-acting injectable PrEP] instead of [injectable PrEP/oral PrEP]? Select all that apply”
- Challenges and reasons were tailored for each method as appropriate (e.g., remembering to take daily pill was only included as a challenge for oral PrEP users)
- Participants who had used both methods (prior 6 mo) were asked to rate experiences and report challenges for both methods
- We assessed for differences by PrEP method, race, ethnicity, and age (using Chi-square, Fisher’s exact, Kruskal–Wallis, and t-tests as appropriate)

*Note: “Injectable PrEP” refers to long-acting cabotegravir



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Results: Sample Characteristics

Ever PrEP use

- 24% (591/2506)

Analytic sample: Prior 6-month PrEP use

- 18% (441/2,506)

PrEP methods prior 6 months*

- 94% oral PrEP only (415/441)
- 3% long-acting injectable PrEP only (15/441)
- 2% both methods (9/441)

*data on PrEP method was not reported for 2 participants

Factor	n (%)
N	441
Age, median (IQR)	33 (27, 42)
Race/ethnicity	
Non-Hispanic White	249 (56.5%)
Non-Hispanic Black	48 (10.9%)
Hispanic White	26 (5.9%)
Hispanic Black	9 (2.0%)
Non-Hispanic and more than one race or another race	52 (11.8%)
Hispanic and more than one race or another race	54 (12.2%)
Unknown	3 (0.7%)
Health insurance	
Uninsured	38 (8.6%)
Public insurance	186 (42.2%)
Private insurance	209 (47.4%)
Unknown	8 (1.8%)
Census region	
West	122 (27.8%)
Midwest	98 (22.3%)
Northeast	79 (18.0%)
South	140 (31.9%)



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A majority had positive experience with PrEP

Self-rated PrEP experiences (0-100 scale):

Daily Oral (n=424)

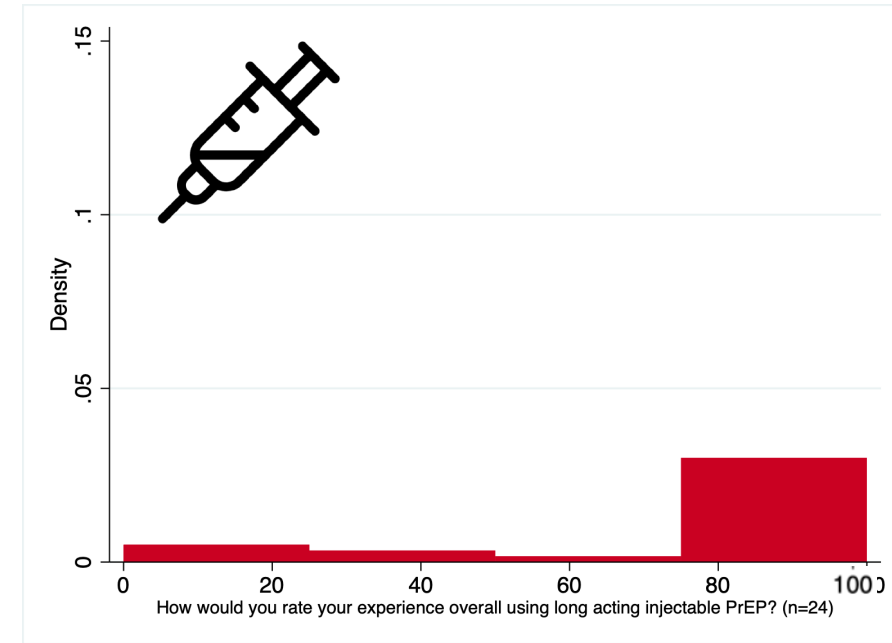
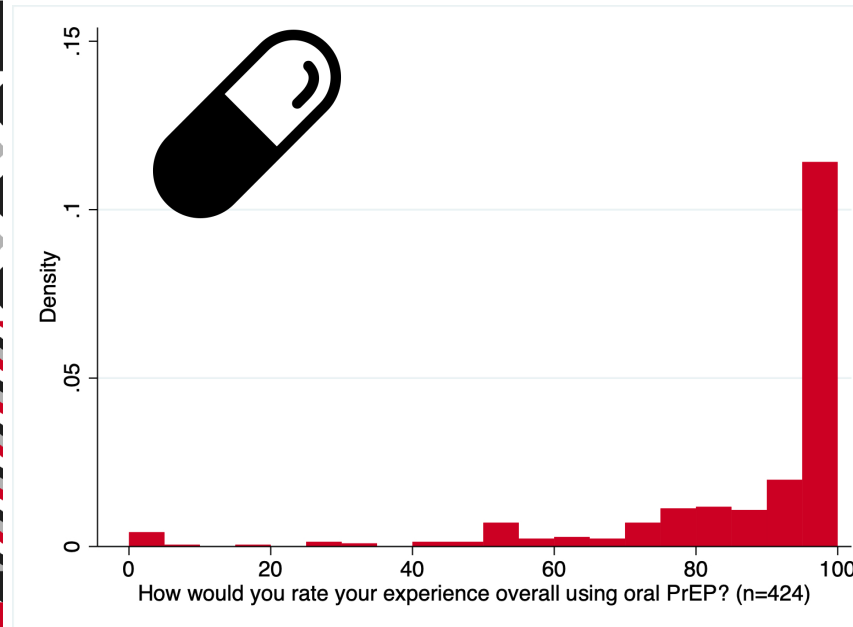
- Mean (sd): 88 (21)
- Median (IQR): 100 (82-100)

93% rated their experience positively*

LAI (n=24)

- Mean (sd): 78 (35)
- Median (IQR): 100 (70-100)

79% rated their experience positively*



No significant differences by age, race, ethnicity, education, insurance, or region

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*positively is defined as score of 50+/100



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Reasons for PrEP method choice

“Why have you decided to use [oral PrEP (pills)/long-acting injectable PrEP] instead of [injectable PrEP/oral PrEP]? Select all that apply”

Daily oral (N=415)



- 35% Using pills before LAI FDA-approval
- 32% Healthcare provider recommendation
- 31% Unaware of long-acting injection option
- 24% Oral PrEP seems to be simpler to start and continue to use than injectable PrEP
- 17% Dislike injections
- 12% Oral PrEP seemed more appropriate for level of risk
- 7% Feel more confident that pills will protect against HIV
- 5% Worry that effectiveness of the injection decreases over time
- 2% Concerned about injections in a location with gluteal (butt) implants or other augmentation

Long-acting injection (N=24)



- 79% Prefer frequency of injections every 2 months over daily pills
- 38% Dislike pills
- 21% Healthcare provider recommendation
- 17% Feel more confident that injections will protect against HIV
- 13% Injectable PrEP seemed more appropriate for level of risk



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Reasons for PrEP method choice



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Sociodemographic differences in PrEP Method Choice

Black trans women who chose **oral PrEP**:

- More commonly cited concern that effectiveness of LAI PrEP would decrease over time (10% compared to 4%; $p=0.044$)
- Less commonly reported healthcare provider recommendation (19% compared to 35%; $p=0.011$)

Black trans women who chose **LAI PrEP** more commonly reported:

- Feeling more confident that injections will protect against HIV (50% compared to 6%; $p=0.011$)
- LAI PrEP seemed more appropriate for level of risk (50% compared to 0%; $p=0.010$)

Latina trans women who chose **oral PrEP**:

- More commonly reported feeling more confidence that pills will protect against HIV (18% compared to 4%; $p<0.001$)

Trans women ages 18-29 who chose **oral PrEP** more commonly cited the following reasons for their choice:

- Oral PrEP seems simpler to start and continue to use (31% compared to 19%; $p=0.007$)
- Dislike injections (24% compared to 14%; $p=0.007$)
- Feel more confident that pills will protect against HIV (11% compared to 5%; $p=0.036$)



Challenges by PrEP Method

"What challenges, if any, have you experienced taking [oral/long-acting injectable] PrEP? Select all that apply"

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Daily oral (n=424)

- 28% Difficult to remember to take pills daily
- 25% Side effects
- 22% People think you have a lot of sex partners
- 22% No challenges
- 21% Don't like the clinical visits/testing required
- 21% Does not protect against STI
- 20% People think you have HIV
- 19% Worry about interactions with hormones
- 19% Dislike taking pills regularly
- 17% Sex partner(s) don't want to use condoms because of PrEP use
- 13% Cost of the pills or associated clinical visits
- 10% Feels excessive for level of HIV risk
- 4% Partner(s) did not want you to use it or did not like you using it



Long-acting injection (n=24)

- 38% Side effects and/or pain at injection site
- 33% Don't like the clinical visits/testing required
- 29% No challenges
- 21% People think you have a lot of sex partners
- 17% Cost of injections or clinical visits
- 13% People think you have HIV
- 8% Worry about interactions with hormones
- 8% Sex partner(s) don't want to use condoms because of PrEP use
- 8% Feels excessive for level of HIV risk
- 8% Does not protect against STI
- 8% Dislike injections
- 8% Pausing/stopping injections is too complicated
- 0% Partner(s) did not want you to use it or did not like you using it
- 0% Complications with gluteal implants/augmentation
- 0% the oral lead-in was too complicated



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Daily oral (n=424)

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- 25% Side effects
- 22% People think you have a lot of sex partners
- **22% No challenges**
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- 21% Does not protect against STI
- 20% People think you have a lot of sex partners
- 19% Worry about interactions with hormones
- 19% Dislike taking pills regularly
- 17% Sex partner(s) don't like you using it because of PrEP use
- 13% Cost of the pills or associated clinical visits
- 10% Feels excessive for level of HIV risk
- 4% Partner(s) did not want you to use it or did not like you using it



Long-acting injection (n=24)

- 38% Side effects and/or pain at injection site
- 33% Don't like the clinical visits/testing required
- **29% No challenges**
- 21% People think you have a lot of sex partners
- 17% Cost of injections or clinical visits
- 13% People think you have HIV
- 8% Dislike injections
- 8% Pausing/stopping injections is too complicated
- 0% Partner(s) did not want you to use it or did not like you using it
- 0% Complications with gluteal implants/augmentation
- 0% the oral lead-in was too complicated

Roughly a quarter of users reported no challenges with PrEP use



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Daily oral (n=424)

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- **22% People think you have a lot of sex partners**
- 22% No challenges
- **21% Don't like the clinical visits/testing required**
- 21% Does not protect against STI
- 20% People think you have a lot of sex partners
- 19% Worry about interaction with other medications
- 19% Dislike taking pills regularly
- 17% Sex partner(s) don't want to use condoms because of PrEP use
- 13% Cost of the pills or associated clinical visits
- 10% Feels excessive for level of HIV risk
- 4% Partner(s) did not want you to use it or did not like you using it

Top 3 most commonly reported challenges were similar across methods



Long-acting injection (n=24)

- **38% Side effects and/or pain at injection site**
- **33% Don't like the clinical visits/testing required**
- 29% No challenges
- **21% People think you have a lot of sex partners**
- 17% Cost of injections or clinical visits
- 13% People think you have HIV
- 13% Complications with hormones
- 13% Sex partner(s) don't want to use condoms
- 13% Feels excessive for level of HIV risk
- 13% Does not protect against STI
- 8% Dislike injections
- 8% Pausing/stopping injections is too complicated
- 0% Partner(s) did not want you to use it or did not like you using it
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Challenges by PrEP Method

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Daily oral (n=424)

- 28% Difficult to remember to take pills
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- **22% People think you have a lot of sex partners**
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- 13% Cost of the pills or associated clinical visits
- 10% Feels excessive for level of HIV risk
- **4% Partner(s) did not want you to use it or did not like you using it**

Stigma and partnership challenges were reported somewhat less frequently among LAI users



- 33% Don't like the clinical visits/testing required at injection site
- 29% No challenges
- **21% People think you have a lot of sex partners**
- 17% Cost of injections or clinical visits
- **13% People think you have HIV**
- 8% Worry about interactions with hormones
- **8% Sex partner(s) don't want to use condoms because of PrEP use**
- 8% Feels excessive for level of HIV risk
- 8% Does not protect against STI
- 8% Dislike injections
- 8% Pausing/stopping injections is too complicated
- **0% Partner(s) did not want you to use it or did not like you using it**
- 0% Complications with gluteal implants/augmentation
- 0% the oral lead-in was too complicated



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Challenges by PrEP Method

Daily oral (n=424)

- 28% Difficult to remember to take pills daily
- 25% Side effects
- 22% People think you have a lot of sex partners
- **Other LAI-specific challenges were not reported or were infrequent**
- 17% Sex partner(s) don't want to use condoms because of PrEP use
- 13% Cost of the pills or associated clinical visits
- 10% Feels excessive for level of HIV risk
- 4% Partner(s) did not want you to use it or did not like you using it

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Long-acting injection (n=24)

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- 21% People think you have a lot of sex partners
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- **8% Dislike injections**
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- **8% Feels excessive for level of HIV risk**
- **8% Does not protect against STI**
- **8% Dislike injections**
- 8% Pausing/stopping injections is too complicated
- 0% Partner(s) did not want you to use it or did not like you using it
- 0% Complications with gluteal implants/augmentation
- 0% the oral lead-in was too complicated

Other challenges



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Sociodemographic differences in PrEP challenges

Black trans women were significantly more likely to report:

- Other people think they have HIV due to PrEP use (28% vs 18%; $p=0.041$)
- Less likely to report:
 - PrEP method feels excessive for level of HIV risk (3% vs 12%; $p=0.018$)
 - Don't like clinical visits/testing required to stay on PrEP (9% vs 24%; $p=0.005$)

Latina trans women were significantly more likely to report:

- At least one PrEP challenge (85% vs 75%; $p=0.037$)
- Other people think they have a lot of sex partners due to PrEP use (38% vs 18%; $p<0.001$)
- Other people think they have HIV due to PrEP use (27% vs 17%; $p=0.038$)
- Partner(s) did not want them to use PrEP or did not like that they were using it (8% vs 3%; $p=0.046$)

Sociodemographic differences in PrEP challenges

Trans women ages 18-29 were significantly more likely to report:

- Sex partner(s) do(es) not want to use condoms because of PrEP (22% vs 14%; $p=0.05$)
- For those on oral PrEP, difficulty remembering to take pills daily (37% vs 23%; $p=0.002$)
- For those using LAI PrEP, other people think they have a lot of different sex partners (57% vs 6%; $p=0.014$) and other people think they have HIV (43% vs 0%; $p=0.017$)



Conclusions

Trans women rated their PrEP experiences positively

Challenges and motivations for PrEP method selection differed by sociodemographics

- Black and Latina trans women, and trans women ages 18-29 were more likely to report stigma related to their PrEP use
- Reasons for PrEP method selection also differed by race, ethnicity, and age

Decision support tools and interventions that address *individual experiences* and *motivations* may support effective PrEP use among populations most burdened by the HIV epidemic



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ENCORE Participants

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