



Federico Pipitone
federico.pipitone@inserm.fr



Laszlo Blanquart
pole.prevention@accantess-t.com



PrEP in Motion

Back to PrEP à Porter?

Addressing lost to follow-up participants (LTFU) in a community-based multidisciplinary PrEP implementation strategy for transgender women in Paris

F. Pipitone, G. Girard, A. Faye, V. Isernia, F. Peralta, L. Cruz Villanueva, F. Ouvrard, B. Spire, M. Mora, L. Zimmermann, G. Rincón, C. Pignedoli, M. Cervantes, M. Auriche, A. Deprez, S. Le Gac, A. Benalycherif, R. Landman, L. Blanquart, L. Sagaon Teyssier, J. Ghosh



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26–31 July • Rio de Janeiro, Brazil

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Declaration of Interests Statement

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Consultant / Advisory Boards: None

Honoraria / Speaker Fees: None

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Summary

Main questions

What specific **access barriers** underlie discontinuation of a community-based PrEP program? Does stopping the program bring about a new **HIV risk** among former participants? If so, is **PrEP** still a viable **solution**?

Findings

PrEP-naïve participants, those with **low adherence**, or **non-French speakers** are most likely to disengage. Interviews offered deeper insights into aspects such as **geographical distance**, **risk re-evaluation**, **side effects**, **adherence**, **psychological distress**, and **appointment scheduling dissatisfaction**.

Why is it important?

Understanding HIV prevention journeys will allow **public health interventions** to be precisely tailored to the **evolving needs** of specific populations.



PrEP & PEP Focus Group, 2023, Paris, France





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Since 2010



Context

Systemic transphobia +
Racism +
Administrative delays in regularization +
Laws forbidding the purchase of sexual services =
Self-management of health / reduced or foregone medical care / retention issues



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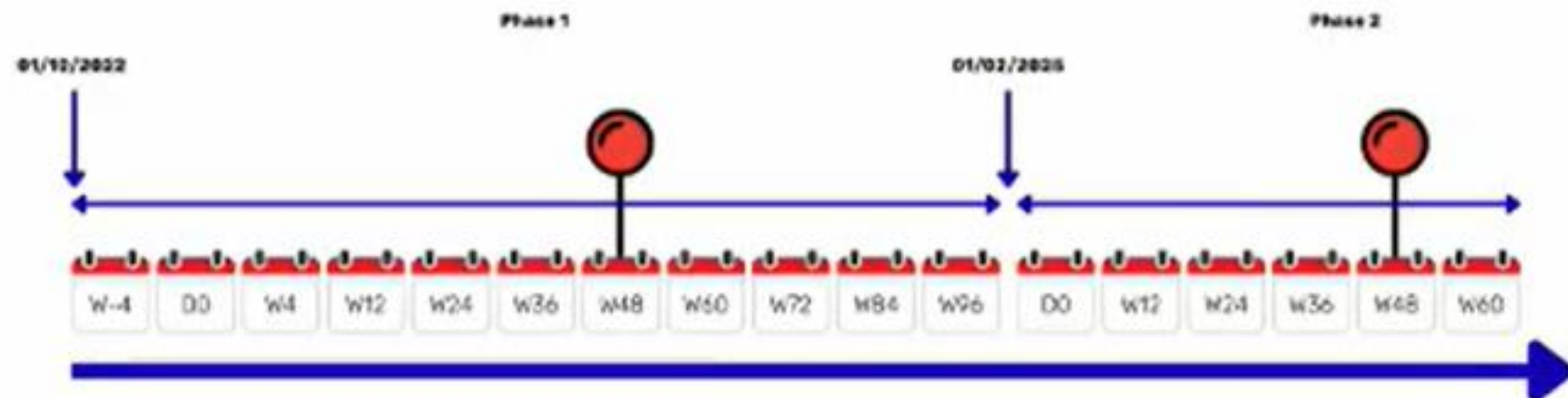
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ANRS – 0566 PrEP à Porter

Methodology: descriptive, single-arm, single-center, national, adaptive study (2 phases)



Phase 1 : Monitoring of a cohort of 101 transgender women receiving PrEP through the multidisciplinary outreach program, supplemented by focus groups and individual interviews, leading to the development of a new strategy.

Phase 2 : Follow-up of the cohort with the implementation of new preventive measures focused on the needs of the users.

Primary evaluation criterion: Comparative analysis of retention rates between W48 of Phase 1 and W48 of Phase 2.

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Objectives of the Sub-study on Lost to Follow Up

General objective: To assess **loss to follow-up** within a community-based PrEP program

Specific objective: To identify the **underlying reasons** for being **lost to follow-up**



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Methods

A mixed methods study:

Definition: Lost to follow up (LTFU) was defined as **missing the last two scheduled visits of Phase 1 (W84 and W96)**. Because data extraction does not capture recent visits for late-enrolled participants, this information is missing for a portion of them.

- **Quantitative data**

- On-paper surveys and medical records;
- **Multivariate logistic regression GEE (OR & 95%CI).**

- **Qualitative data**

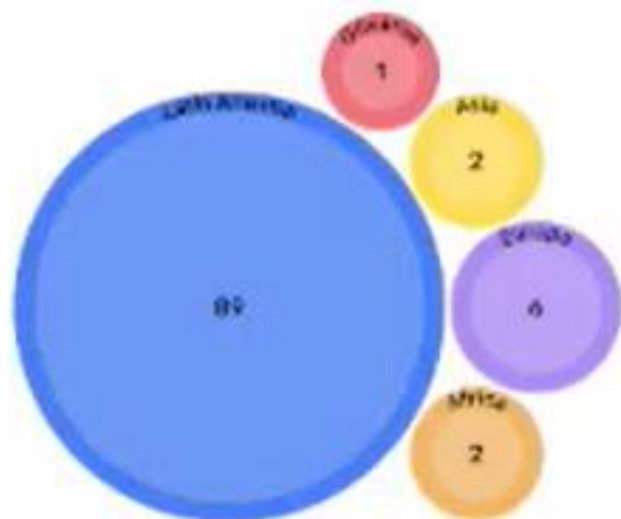
- In-person/phone interviews with 15 LTFU;
- Qualitative **thematic analysis.**



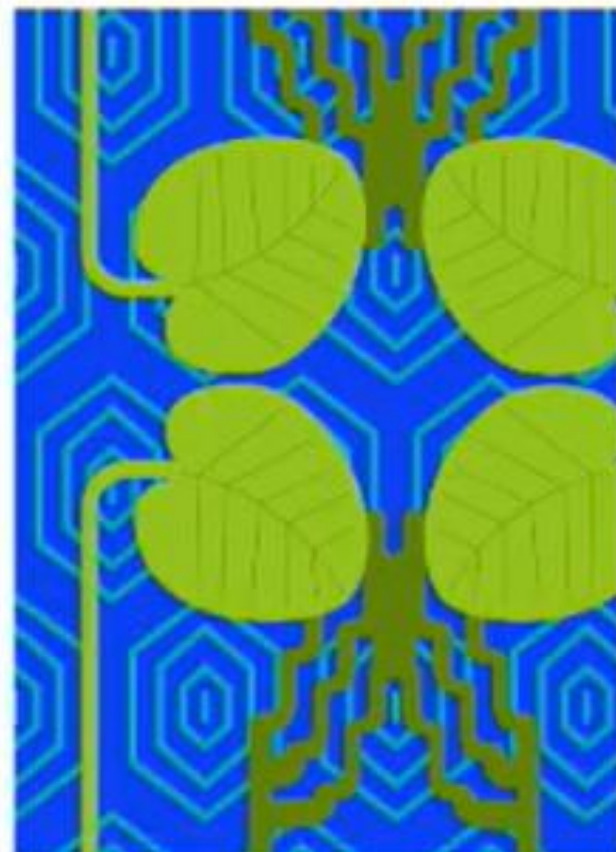
Socio-demographic Characteristics

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(n=101)



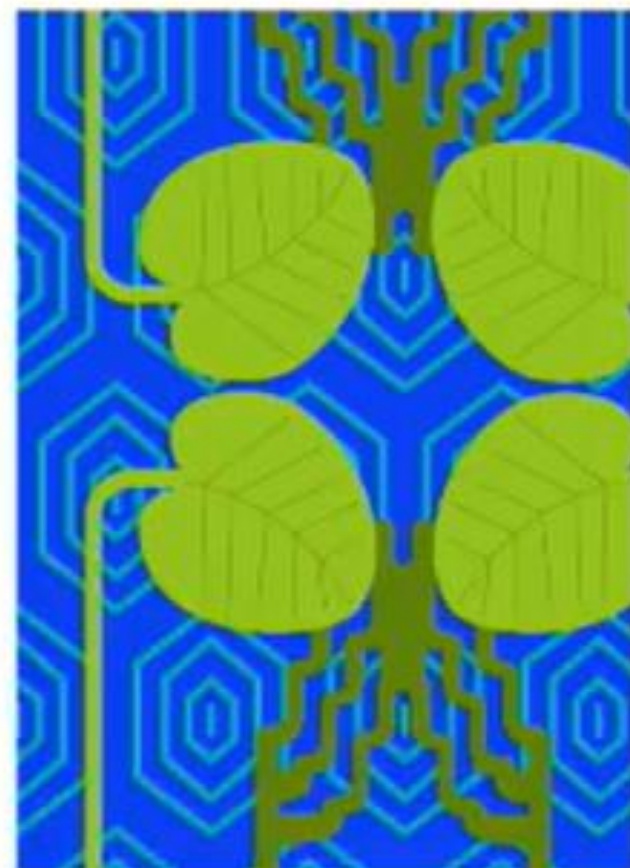
Participants of the study	N=101
Age	
Median	34 [29,40]
Country of origin, n	
Peru	67
Brazil	10
Ecuador	7
Colombia	4
France	3
Social security, n	
No social security	51
State Medical Assistance (AMN)	37
National health insurance card / Universal healthcare coverage	14
EPICES score >30, n	85
Sex work, n	92
Formal employment, n	9
Lifestyle habits, n	
Alcohol use (Regular or occasional)	78
Smoke	34
Substance use	64





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Baseline Characteristics (n=101)



Comorbidities	N = 101 n
History of STIs	76
Feminizing hormone therapy	38
Past surgical history	86
Gender-affirming surgery (vaginoplasty)	5
Feminizing surgery	70
Silicone Injection	67
Silicone complications	24

Participant wishes to benefit from:	N=101 n
Mental Health Hub	57
Social and administrative support	80
Legal Hub	45
Trans Social Action Fund	24

Group	N = 101 n
Already on PrEP at enrollment	60
PrEP initiation at enrollment	41



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Quantitative Results (n=101)

MULTIVARIABLE ANALYSIS — FIRTH PENALIZED LOGISTIC REGRESSION

The Firth penalized logistic regression model used **N = 800** visit-level observations to identify the factors below associated with this outcome.

Among the 101 participants, 52 attended the W84 and/or W96 appointments, 16 did not attend W84 and W96 (=LTFU), 26 participants did not reach weeks 84–96 due to late enrollment, and 7 people withdrew.



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Factors associated with a HIGHER risk of LTFU aOR [95% CI]

- PrEP-naïve status **4.54 [2.93–7.03]**
- Low or unknown PrEP adherence **3.76 [2.28–6.20]**
- Not speaking French **2.37 [1.60–3.51]**



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Factors associated with a **LOWER** risk of LTFU aOR [95% CI]

- Gender-affirming-related surgery **0.34 [0.16–0.71]**
- Silicone injection history **0.46 [0.29–0.73]**
- Identified financial difficulties **0.39 [0.27–0.59]**
- Association-hospital (combined) follow-up **0.17 [0.09–0.34]**
- Willingness to use mental health services **0.26 [0.17–0.39]**
- Willingness to use social services **0.30 [0.18–0.49]**



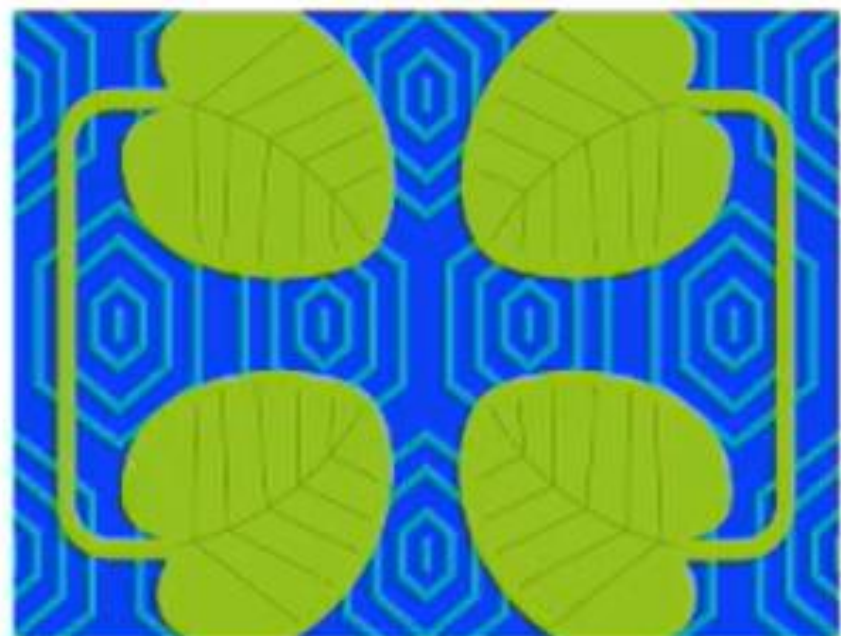
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Qualitative Results (n=15 LTFU)

Main reasons for stopping community-based PrEP care

- Geographical short-term/long-term **distance**;
- Subjective-based risk **reevaluation**;
- **Psychological** difficulties putting sexual health on stand-by;
- Feared/perceived **side effects**;
- Dissatisfaction with **appointment scheduling/communication**.

Taking PrEP elsewhere





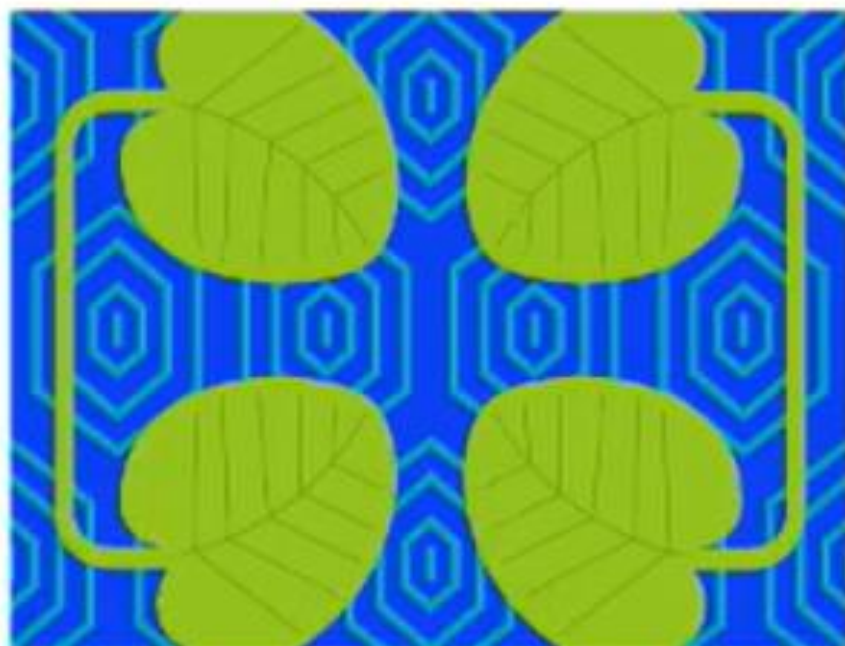
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For some participants adherence seemed to be a challenge throughout PrEP journey



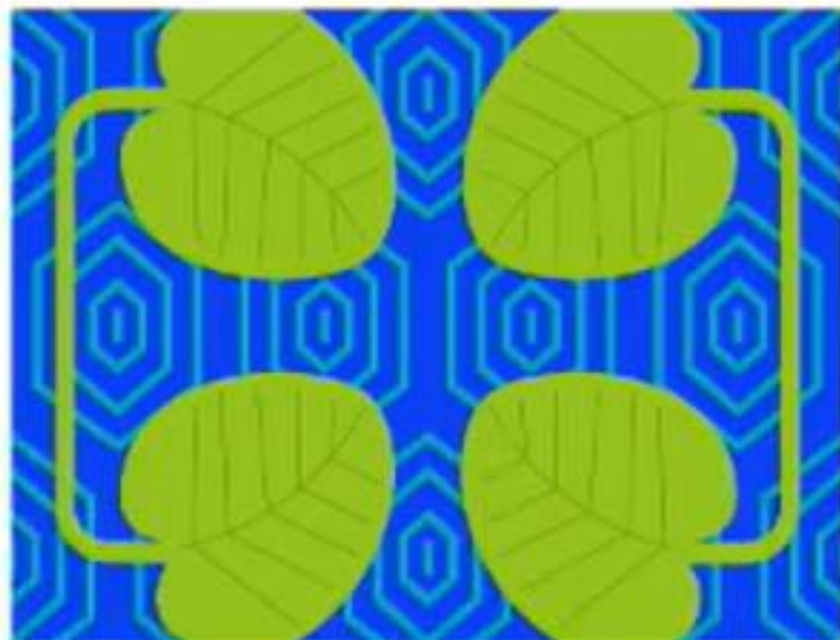
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Nonetheless, all LTFU emphasized the importance of community-mediator outreach



Qualitative Results (n=15 LTFU)

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9/15 perceived themselves to still be at risk of contracting HIV



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- Among them, 7 people are willing to get back to the program and are motivated by:
 - Online PrEP appointment;
 - Combining PrEP with feminizing hormone therapy;
 - On demand PrEP scheme.



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- 2 individuals do not want to restart PrEP even though they recognized an ongoing risk of HIV infection from client pressure in sex-work:
 - 1 is because of sex work reduction;
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 - Both do not know about Post-exposure prophylaxis (PEP).



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Irrespective of the reason of stopping the program, several participants have heard about long-acting injectable PrEP and would love to know more about it.



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At least half of the participants continue to visit Acceptess-T's offices to access other programs



Among these LTFU, two people continue taking PrEP without doctor follow-up:

**1 On-demand PrEP;
1 ineffective use of PrEP
("PEP-like" PrEP).**

Conclusion



- Among the 101 participants, at W96, we have at least 16 participants who are considered LTFU.
- PrEP-naïve individuals, non-French speakers, and those with low adherence are particularly vulnerable to disengagement. This disengagement also stems from a combination of structural barriers and personal challenges. Actual lost to follow-up participants can be brought back with:
 - An intensified follow-up strategy;
 - Innovations in PrEP and new multidisciplinary activities tailored to specific needs;
 - Better synergies between the different services of the community-based organization.
- **Potential post-discontinuation HIV seroconversions may be prevented by implementing re-engagement protocols for individuals lost to follow-up, diversifying PrEP service delivery and formats, and combining community-based medical care with peer navigation.**