



**FOSTERING  
HIV INNOVATION  
THROUGH  
COMMUNITY  
ENGAGEMENT**



The “**Community Voices & Preparedness for New Treatment Innovations**” project, spearheaded by the International Treatment Preparedness Coalition (ITPC), is a pivotal initiative seeking to facilitate a constructive dialogue between HIV treatment innovators and communities living with HIV.

The continuous challenge of persistent HIV transmissions and difficulties in achieving viral suppression among certain vulnerable groups underscores the critical need for ongoing innovation in treatment modalities.

At the forefront of these efforts, long-acting injectables (LAIs) are on the path to unlocking improvements in both prevention and treatment.

This report provides a high-level summary of three community dialogues conducted at the end of 2023 in Botswana, Eswatini, and South Africa by ITPC in partnership with BONELA, Dream Alive, and NACOSA respectively. The dialogues emphasize the role of community leaders in shaping the narrative around LAIs and the broader HIV treatment landscape.





# MAJOR FINDINGS

Findings are organized by knowledge gaps, concerns, readiness issues, and opportunities related to LAIs, offering an exploration of the diverse viewpoints expressed by community leaders.

## Knowledge gaps

- Community leaders revealed substantial knowledge gaps in understanding HIV and LAIs. A knowledge quiz administered in the three countries highlighted inconsistencies and limited awareness across various aspects of HIV prevention and treatment, including LAIs.
- Participants in South Africa demonstrated a higher familiarity with LAIs, while those in Eswatini showed the least awareness. The discussions unveiled a diverse understanding of HIV treatment goals, emphasizing factors like efficacy, efficiency, acceptability, accessibility, and affordability.
- Participants displayed gaps in fundamental HIV knowledge, such as naming HIV drugs, understanding ARV (antiretroviral) classes, and connecting information about the HIV life cycle with ARV classification. Preferences for simplified identifiers (e.g. using pill colors or nicknames) were expressed due to the complexity of terms.
- Limited knowledge about the effectiveness of pre-exposure prophylaxis (PrEP) and LAIs for prevention indicated the need for more education.





## Concerns

- Participants expressed concerns about potential side effects, safety issues, and the frequency of injections associated with LAIs. Questions arose about the overall safety profile, potential forgetting of clinic visits, and the impact of frequent injections on individuals.
- Notable apprehension about needles (trypanophobia), particularly among South African men, raised concerns about the likelihood of individuals returning for bi-monthly injections.
- Despite recognizing the convenience of LAIs, skepticism persisted regarding their effectiveness when administered every two months.
- Challenges related to transitioning from daily pills to injectables were highlighted, including scheduling difficulties, potential drug resistance, injection-site injuries, and concerns about reverting to pill regimens if injectables proved unsuitable.
- Participants considered the influence of cost on their country's decision to provide LAIs, emphasizing potential human rights and non-discrimination issues. Concerns were raised about the willingness or hesitance to pay extra for access.



## Readiness gaps

- Readiness gaps encompassed healthcare provider training, resource challenges, security risks, infrastructure limitations, and access difficulties. Participants expressed concerns about the lack of information regarding specific ARVs used in LAIs.
- Valid concerns were raised about challenges associated with administering injectables, including long queues at clinics and the need for efficient systems to prevent missed appointments, especially for those traveling out of town.
- Each country presented unique challenges. In Botswana, concerns included accessibility, timely delivery, stockouts, storage space, and limited regimen options. Eswatini raised concerns about potential implications for condom use and eligibility criteria. South Africa had concerns about knowledge gaps and the applicability of injectables in the elderly.



## Opportunities

- Participants recognized LAIs' potential to decongest healthcare facilities, reduce waiting times, and encourage attendance, contributing to a more efficient healthcare system.
- LAIs were discussed as a means to improve the quality of life, particularly for women facing challenges with tablet adherence during experiences like gender-based violence.
- LAIs were considered a solution to address treatment pill fatigue, limiting daily pill intake. Coupled with a two-month visit schedule, this addressed adherence challenges.
- Participants identified LAIs as another focal point for mobilizing resources and escalating advocacy for widespread rollout and HIV-related education.



# ROLE OF COMMUNITY IN LAI IMPLEMENTATION

Community leaders uniformly acknowledged the vital role of community-based organizations as equal partners in national processes related to LAIs. Participating organizations were recognized for complementing government efforts, reaching vulnerable populations in remote areas, and enhancing education and awareness.

Additionally, the discussion revealed expectations from policymakers and providers, focusing on HIV education, stigma-free care, community representation, and inclusive problem-solving. Community leaders explored demographic nuances among LAI beneficiaries and expressed expectations for support, information, and active community engagement in decision-making processes.

Recommendations for community engagement include community leaders' crucial role in building confidence, actively seeking information from health authorities, being involved in clinical trials, advocating for access strategies, and supporting local manufacturing.

Collaborative efforts through National AIDS Structures, revitalizing existing steering community advisory boards, mainstream dissemination of LAI information, and consistent feedback to diverse constituencies were identified as key strategies.

The community also stressed the importance of post-rollout monitoring, addressing stigma and discrimination, and prioritizing comprehensive treatment education for informed decision-making and community engagement.





# CONCLUSION

The participants in the dialogue actively engaged in discussions on LAI implementation, highlighting the crucial role of community perspectives in shaping innovative HIV treatment. ITPC appreciates their valuable contributions, emphasizing a community-centered approach. Inspired by this engagement, ITPC plans to create tailored educational materials aligned with community needs and to give regular updates on progress and access. ITPC commits to utilizing these insights in its role on the Steering Committee of the HIV Long-Acting Treatment Coordination Platform.

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## Acknowledgments

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