Workshop Report

Title: Expanding Access to HIV Prevention with Long-Acting Injectable PrEP

Organized by: Sankalp Rehabilitation Trust and Durbar Mahila Samanwaya Committee (DMSC)

Supported by: Third World Network (TWN)

Date: 17.06.2025

Venue: ICMARD, Ultodanga

Agenda of the Workshop:

Community Briefing on HIV PrEP and Lenacapavir Access

Objectives of the Workshop:

1. To build community understanding of PrEP as a key HIV prevention tool.
2. To identify and discuss challenges in accessing and using PrEP.
3. To minimize the gap between PrEP science and high-risk community populations.

Background:

Expanding HIV Prevention with Long-Acting Injectable PrEP - The Case for Lenacapavir in India

Despite substantial progress in the global AIDS response, the fight against HIV is currently at a crossroads. An estimated 1.3 million new HIV infections still occur every year globally, with 55% of them concentrated among key populations and their partners - especially sex workers, people who use drugs (PWID), adolescent girls, adult women, gender diverse and LGBTQI+ individuals.

Traditional HIV prevention tools - condoms, counselling, and regular HIV testing - must now be combined with new strategies like Pre-Exposure Prophylaxis (PrEP).

India represents a diverse landscape of communities with varying vulnerabilities to HIV. The present moment offers a critical opportunity to introduce newer, more effective tools for prevention, provided access and policy hurdles are effectively addressed.

Resource Persons:

Leena Menghaney

A lawyer, she has worked for decades on legal and advocacy issues related to HIV and access to affordable treatment. She has contributed to the HIV/AIDS Bill in India and has extensive experience

with Medecins Sans Frontieres (Doctors Without Borders) working on patent barriers to life-saving medicines.

Eldred Tellis

Founding Director of Sankalp Rehabilitation Trust, with over four decades of experience working with injecting drug users and HIV prevention. An Ashoka Fellow and Red Ribbon Award winner, he has led national-level work in harm reduction and drug policy reforms.

Key Discussion Points:

1. **HIV Prevention as Public Health Priority:**
   Framing PrEP access not just as a medical but a human rights issue.
2. **Prevention > Treatment:**
   Emphasis was placed on investing in prevention tools like PrEP, which can ultimately reduce the long-term costs and burden of treatment (ART for 12 months equals the cost of 2 Lenacapavir doses yearly).
3. **Injectable PrEP - Lenacapavir: Scientific Efficacy & Access Barriers:**
   a. 100% protection in trials among cisgender women.
   b. 99% risk reduction in gender-diverse and high-risk groups.
   c. Under clinical trial for drug user
   d. Currently unavailable in India.
4. The **initial dose of lenacapavir for HIV-1 treatment or PrEP** consists of lenacapavir injections and tablets, followed by 2 lenacapavir injections every 6 months (twice a year) thereafter.
5. **Most common Side Effects:**
   Noted side effects include injection site reactions (a lump or bump, itching, redness, at the injection site.
6. **Lack of Availability in India:**
   a. The global rollout is slow.
   b. Government hesitation due to behavioural concerns (reduced condom use).
7. **Need for Community Representation:**
   a. Demanded inclusion of sex workers, TG, MSM, and PWID in any NACO/SACS discussions.
   b. Highlighted importance of sharing lived experiences in shaping HIV policy.
8. **Questioning NACO's Stance:**

a. Participants raised concerns about why PrEP is not being approved despite similar annual costs to ART if produced in India as a generic.

9. **Right to Life:**
    a. Affirmed that every individual, regardless of identity, deserves access to life-saving prevention.
10. **CRG Meetings at WBSAP&CS:**
    a. Emphasized the need for community representation in meetings.
11. **Policy Advocacy:**
    a. Encourage lobbying MPs and MLAs to initiate national-level discussions on PrEP inclusion.
12. **Drug Pricing & Patent Barriers:**
    a. Dissected how Indian pharma monopolies could block access to countries who issued a compulsory license for importing generic from India when faced with inflate drug prices from Gilead, the US pharma corporation.
    b. Advocated for strengthening patent oppositions and open licensing to reduce costs and increase access.

On Access & Affordability:

- Urgent need to break pharmaceutical monopolies.
- Push for broader licensing to enable generic production and reduce costs.
- Government must prioritize prevention alongside treatment.

Scientific Breakthrough: Lenacapavir (LEN)

Lenacapavir is a twice-yearly injectable PrEP and a major innovation, especially for individuals unable to adhere to daily oral PrEP.

Key Data:

- 100% protection among cisgender women in trials.
- 96% risk reduction in gender-diverse and other high-risk groups.
- Ongoing clinical trial (PURPOSE 4) focused on PWID.

Policy Momentum:

- US FDA approved LEN for PrEP on June 18, 2025.
- WHO is set to release global PrEP guidelines at the International AIDS Conference in Kigali, July 2025.

Barriers to Access

Pricing & Patents:

- LEN could be manufactured for $40 per person annually.
- Gilead holds multiple overlapping patents, potentially blocking affordable generics.

Challenges in India:

- Need for increased legal action against patent monopolies.
- Push for domestic production to serve both Indian and excluded middle income country HIV programmes and markets.
- Gilead's pricing remains undisclosed, which obstructs planning for large-scale rollout.

Story Shared by Eldred Tellis:

Eldred narrated his experience of moving courts for justice and shared the first legal case he was involved in - a doctor from Nagaland, deeply committed to serving his community. Unbeknownst to him, he was living with HIV. While working at a hospital, he donated blood for a patient in need. The hospital authorities discovered his HIV-positive status during routine screening but chose not to inform him directly. Instead, word of his condition spread from the hospital to his village through informal channels.

The news became public in the village, and soon he faced severe discrimination. He was denied entry back into his own village and ostracized by the very people he had once served. Shockingly, he learned about his HIV status not from a medical professional or the hospital, but from the villagers themselves. Feeling betrayed and dehumanized, he decided to seek justice and filed a case against the hospital. However, the initial verdict was deeply unjust - he was denied justice, with the judgment falsely asserting that people living with HIV were not eligible for marriage.

This deeply disturbing experience caught the attention of Eldred, who decided to challenge the verdict by filing an appeal. In the subsequent proceedings, the case turned in the doctor's favor. It was a significant victory - not just for him, but for all people living with HIV in India. This landmark moment became the catalyst for the birth of **Sankalp Rehabilitation Trust**, which began as a movement to fight for the dignity, rights and justice of people living with HIV.

Eldred also shared other experiences, particularly about the plight of injecting drug users in Manipur. In one such account, he described how desperate parents, unable to manage their children's addiction, would bribe jail authorities to take them in - hoping that confinement would somehow serve as care or rehabilitation. These stories underscored the deep stigma, lack of support systems, and urgent need for compassionate, rights-based responses to addiction and HIV.

Remarks by JD TI, WBSAP&CS:

- Acknowledged the efficacy of Lenacapavir for High-Risk Populations.
- Raised NACO's concerns that PrEP may reduce condom use, increasing STI risks (syphilis, gonorrhoea).
- Reiterated that condoms remain essential in combination prevention.
- Assured that the matter will be brought up in upcoming district, state, and national-level meetings.

Plan of Action:

1. **Collective Mobilization to Break Drug Monopoly:**
   Support Sankalp and Leena Menghaney in advocacy efforts across states, bringing together TG, MSM, Sex Workers, PWID and other stakeholders as one united community.
2. **Advocacy Letters to NACO:**
   - Each organization (including DMSC) to send formal communication to NACO requesting the inclusion of Lenacapavir in national HIV prevention programs.
   - Letters will highlight its relevance and effectiveness for specific communities.
3. **Strategic Engagement:**
   - Publish counter-narratives addressing government concerns over condom substitution.
   - Point out the real-world challenges like condom supply chain disruption and unavailability of Hepatitis B vaccines in India over the past 1.5 years.
4. **State-Level Advocacy Tour:**
   - Sankalp will lead statewise visits to HIV stakeholder organizations to strengthen the advocacy network and build grassroots support for injectable PrEP.

Closing Remarks:

The workshop concluded with a powerful address by Ms. Bishakha Laskar, Secretary of DMSC, who emphasized the immense importance of injectable PrEP in enhancing HIV prevention among sex workers and other high risk community people. She also expressed gratitude to Sankalp Rehabilitation Trust, Leena Menghaney and Eldred Tellis for their insightful contributions and reaffirmed DMSC's commitment to supporting the movement for accessible, affordable and community-centered HIV prevention tools.

Conclusion:

The training workshop marked the beginning of a crucial movement to ensure that Long-Acting Injectable PrEP becomes accessible in India. With an intersectional, rights-based and science-backed approach, community members and allies committed to a united advocacy front to ensure no one is left behind in the fight against HIV.


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