

Living Labs PrEP Adherence Study

Insights and Recommendations



In 2020, PATH Living Labs conducted a study in Kisumu and Homabay counties to delve into the determinants of preference, persistence, and factors affecting Adolescent Girls and Young Women (AGYW) in adhering to Pre-Exposure Prophylaxis (PrEP) for HIV prevention. The study embraced a comprehensive conceptual framework encompassing community, interpersonal, and individual factors.

Study Objectives:

The study aimed to achieve several objectives:

1. Measure PrEP adherence through self-report, return visits, and biomarkers.
2. Identify motivations for taking and continuing PrEP, including discussions on challenges and reasons for discontinuation.
3. Explore care experiences by comparing PrEP delivery through safe spaces and health facilities.
4. Identify determinants of persistence and adherence at individual, interpersonal, and community levels.
5. Evaluate the level of HIV risk among AGYW on PrEP.
6. Examine healthcare providers' attitudes toward AGYW reproductive health services and HIV prevention.

Study Design:

The study followed a prospective mixed-methods approach, employing a longitudinal design with two data collection time points. This included qualitative and quantitative data collection through interviews and biological sampling.

Key Study Findings:

- Many AGYW self-reported PrEP adherence, but blood samples indicated otherwise.
- Reasons for discontinuing PrEP included stock-outs, lifestyle changes, concerns about privacy, and social pressures.
- AGYW's experiences of intimate partner violence and mild depression were notable.

PATH Living Labs PrEP Adherence Study Follow-Up: Further Insights and Recommendations

In 2022, as a continuation of the initial study, PATH Living Labs conducted a follow-up investigation in Homabay County. This follow-up aimed to gain deeper insights into the perspectives, motivations,

challenges, and potential solutions related to Pre-Exposure Prophylaxis (PrEP) adherence among Adolescent Girls and Young Women (AGYW).

Study Objectives:

The follow-up study sought to achieve the following objectives:

- Gain a comprehensive understanding of AGYW's perspectives on PrEP usage, adherence, and discontinuation.
- Explore the motivations driving AGYW to initiate and persist with PrEP, as well as the factors leading to its discontinuation.
- Identify any changes in AGYW's perceptions and experiences related to PrEP since the initial study.
- Collect feedback on the concepts proposed during the initial study's co-creation sessions and assess their feasibility and impact.

Study Design:

Employing a qualitative research approach, the follow-up study utilized focus group discussions and in-depth interviews to gather data. The participants were AGYW who had previously taken part in the initial study, as well as those who had discontinued PrEP.

Key Study Findings:

1. **Changing Perceptions:** AGYW exhibited evolving perceptions of PrEP. Some regarded it more positively due to increased awareness, while others still expressed concerns about side effects and stigma.
2. **Motivations for Adherence:** The desire to stay HIV-negative, health provider recommendations, and support from peers were prominent motivators for adherence.
3. **Challenges to Adherence:** Privacy concerns, stock-outs, and difficulties integrating daily pill-taking into routines remained challenges.
4. **Concept Feedback:** The concepts generated during the initial study, such as "Special Clinic Days" and "Tuelimishwe" forums, were generally well-received, with participants emphasizing their potential to enhance PrEP uptake and adherence.

AGYW and Service Provider Co-Creation Insights:


Based on the follow-up study, additional insights were gained from AGYW and service providers:

1. **Personalized Support:** AGYW expressed the need for personalized counseling and guidance to address individual concerns and challenges.
2. **Community Champions:** Participants recommended the identification and training of community champions to provide information and support for PrEP users.
3. **Provider Training:** Healthcare providers highlighted the importance of continuous training to equip them with up-to-date information about PrEP.

Reinforced Concepts:

1. **Special Clinic Days:** The concept of designated days for PrEP services was reinforced as a practical way to provide focused support and foster a sense of community among AGYW.

Special Clinic Days



POV/NEED

AGYWs on PrEP face a lot of challenges in their journey. They lack and therefore need to hide their PrEP. Most partners don't understand the importance of PrEP, and AGYWs are often at risk of GBV. They feel judged by the community because they think that they are on HAART. They dread their refill days as they often feel targeted at the facilities because they have to queue at the CCC with HIV+ patients. Sometimes, they opt to go to facilities that are far where people don't know them to get their refills.

It is not much easier for HCP as the facilities do not have lab equipment to perform liver and kidney tests for them to be able to properly monitor their clients' health.

There is need for an intervention to improve the PrEP experience for both the AGYWs and the HCP.

HMW
HMW create an environment where a girl is able to take PrEP everyday to prevent HIV infection?

Solution

"maybe these girls need their own special clinic"

-HCP Homabay County


Special clinic days is a concept in which AGYWs are given their own special days to go to the facilities to get comprehensive PrEP services such as enrollment, testing and refill. The environment during these days is made friendly to the AGYWs, from nurses' attitudes, the language to the ambience of the clinic with nice music that the AGYWs can enjoy while they wait for their turn to be served. These are days in which the AGYWs do not have to queue together with HIV+ patients and they can be free to mingle with each other and learn from one another. These are safe days for AGYWs free from fear of being judged or intimidated by other members of the community.

On these days, the AGYWs may also have the added benefit of getting health talks from the healthcare providers and receiving screening services that they may not be able to get when they are at the safe spaces. On these days the AGYWs will be using their own special clinic cards that are attractive and different from the ones that known HIV+ patients use. These special clinic days would encourage and increase the number of AGYWs coming to facilities- AGYWs who would otherwise fall to attend clinics due to stigmatization and intimidation. The HCPs will in turn draw satisfaction from rendering services to this group that need special care. The HCPs would be motivated and would look forward to such days to serve this group.

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2. "Tuelimishwe" Forums: The idea of community sensitization events gained further traction, indicating its potential to raise awareness and knowledge about PrEP.

Tuelimishwe Forums



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HMW
HMW strengthen PrEP system to foster adoption and effective adherence of the drug by AGYWs?

Solution

"we should empower the community and show them that there are many options of HIV prevention and HIV management"

-HCP Homabay County

Tuelimishwe forums is a concept in which sensitization forums are organized in the community for the purpose of educating them about PrEP in a bid to reduce the myths and misconception about PrEP and reduce stigma and discrimination of AGYWs.

Awareness would be created through social media platforms, church and youth meetings etc. These meetings would be held in schools, churches, health facilities and in community barazas. AGYWs are free to choose where their sensitization talks can be conducted, whether it is in the facility or safe space.

Some features of the forms will be:

- PrEP Sensitization Campaigns
- Talks done by qualified HCP
- Done periodically e.g., quarterly, twice a month, weekly etc.
- Conducted at facilities, social halls, schools etc

Potential barriers include:

- Rigidity of the community on issues about HIV infection
- Lack of proper funding
- Difficulty to break existing myths and misconceptions about PrEP

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Conclusion

The follow-up study by PATH Living Labs provided deeper insights into the evolving perspectives of AGYW on PrEP adherence, reaffirming the significance of personalized support and community-based interventions. It reinforced the concepts generated earlier, such as "Special Clinic Days" and "Tuelimishwe" forums, and introduced new ideas, collectively contributing to an enriched understanding of how to enhance PrEP uptake, persistence, and overall effectiveness among AGYW. Notably, it is important to highlight that while these concepts show promise, they have not been implemented yet, leaving ample room for future implementation, and testing to gauge their actual impact on PrEP adherence and the well-being of AGYW.