

# Tapping into the Unheard Voices of End-Users to Effectively Deliver Pre-Exposure Prophylaxis (PrEP)\* for Adolescent Girls and Young Women

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\*OPTIONS refers to PrEP as the product category (inclusive of all formulations of ARV-based HIV prevention), and refers to specific products by formulation designation and/or name (e.g. oral PrEP/TDF-FTC, topical PrEP/dapivirine ring, injectable PrEP/cabotegravir, etc).

## BACKGROUND

- In 2015, the World Health Organization (WHO) recommended providing oral pre-exposure prophylaxis (oral PrEP) as an additional prevention choice for all persons at substantial risk of HIV infection (suggested as when HIV incidence is around 3 per 100 person years or greater). In sub-Saharan Africa, the population at substantial risk includes adolescent girls and young women.
- In addition, recent results from two efficacy trials have provided evidence for the potential of a new ARV-based prevention or PrEP product – the dapivirine vaginal ring. Open label and additional studies are ongoing and/or planned to further understand its effectiveness and safety in adolescent and young women.
- As countries plan for the study and roll out of these products, the voices of young women themselves are often not a part of the dialogue.
- The OPTIONS Consortium and the WHO convened two workshops at AIDS 2016 that offered a forum for oral PrEP and vaginal ring users from a variety of countries in Africa to share thoughts and recommendations for effectively delivering ARV-based prevention products for young women.

## METHODS

**Workshop One** was conducted with the WHO within the AIDS 2016 scientific program, encouraging dialogue through facilitated panel discussions. It began with an invitation for participants to record hopes and challenges for oral PrEP via Post-It Notes. Participants then placed them on flip-charts around the room.

**Panel 1** focused on the experiences of adolescent girls and young women.

**Panel 2** solicited lessons learned from key population groups (female sex workers, MSM, and transgender people).

**Panel 3** allowed policy-makers to reflect on issues raised and to share country-level experiences.

**Workshop Two** was conducted within the AIDS 2016 Global Village. It focused on the use of oral PrEP and the dapivirine ring, promoting dialogue among panelists who had used the methods and attendees through facilitated discussions.

**Panel 1** provided an update on evidence and implementation timeline for oral PrEP evidence and the dapivirine vaginal ring

**Panel 2** highlighted experiences of young participants in the vaginal ring and oral PrEP demonstration studies, a user of oral PrEP in the private sector and young women who would be potential future users, followed by moderated discussion.



Fig 1: Trial participants from the dapivirine ring study share their experiences, Durban July 2016. Credit: FHI360

## RESULTS



Fig 2: Various ARV-based HIV prevention products being designed for women. Credit: MTN

### Hopes and Challenges for Oral PrEP

Findings from the Post-It note exercise included:

- Hopes:** increasing empowerment and user choice; reducing infection; increasing access for those wanting to use it – adolescent girls <18 years of age, those living in rural areas, and members of other key population groups.
- Challenges:** discrimination; adherence; side effects; lack of monetary or political support for full-scale oral PrEP programs at the country-level.

### Adolescent Girls and Young Women at Risk Want PrEP

- Adolescent girls and young women at risk of HIV infection desire options for PrEP, including access to oral PrEP and the vaginal ring.
- These products offer young women tools for greater control in their sexual lives, and protection for those in compromising relationships or circumstances, including those at risk for sexual violence.
- Implementation needs to acknowledge that one size does not fit all
- “Getting the messaging right,” e.g. presenting PrEP in a positive way, and for use by anyone at substantial risk, not only for key population groups was seen as critically important.

### Effective Delivery of Oral PrEP is Challenging

- Side effects caused some users to stop oral PrEP use, especially during the first two weeks.
- Others raised concerns about the large pill size, feeling judged or criticized by health care workers, and fears of being discovered using oral PrEP
- There is a need for healthcare workers to sensitively address issues of gender-based violence, gender-identity and sexual orientation.
- Media and marketing were seen to be critical in ensuring that neither PrEP, nor groups that might use PrEP, are further stigmatized.

### Legal and Policy Frameworks Can Work Against PrEP Roll-out

- Concerns were raised about offering forms of PrEP for high-risk groups in countries where sex work is illegal, parental consent is required for those under 18, and where laws are punitive for priority populations (e.g. MSM).
- Participants expressed dismay about programs that target sex workers while simultaneously criminalizing their livelihoods.
- The importance of ongoing advocacy for PrEP products was highlighted, especially amidst concerns about the capacity of young women to effectively use and adhere to ARV-based PrEP products.

### More Real World Experience is Needed

- The gathering and dissemination of “real use” evidence will be critical to wide-scale acceptability of PrEP.
- Surveillance has shown the use of tenofovir-based regimens for HIV treatment to be safe; however potential long-term side-effects of oral PrEP among uninfected individuals (regarding bone-density and kidney function) concern policy-makers and have deterred some potential users.
- There is a strong need for program and policy-makers to engage with adolescent girls and young women about their experiences using PrEP to ensure products, programs and services meet their needs.

### Key messages from both workshops include:

- Adolescent girls and young women are not the same. They require different things, and they will access them in different ways
- Programs need to embrace the notion that young and adolescent women are sexual beings with the capacity to make informed and effective prevention decisions.
- Adherence poses challenges, however motivated users with the right support are able to implement unique and effective solutions.

Fig 2: Participants of the SHAZI HUB youth drop-in center in Zimbabwe learn about ARV-based prevention through participatory life skills sessions. Credit: Pangaea Global AIDS



## CONCLUSIONS

These workshops elevated the voices of actual and potential end-users of PrEP products, specifically oral PrEP and the vaginal ring, into discussions about how to most effectively deliver these methods. Although significant investments are being made in the study and rollout of oral PrEP and the ring, identifying and reaching young women with these products will not be simple. Understanding and responding to the needs and concerns of current and future users will be vital to ensure young women have access to effective, new HIV prevention products.

### PrEP

*Is not perfect  
Is not easy  
Is not for everyone  
Is not for always  
Will not end HIV on its own*

***But...we won't end the epidemic without it***

*Mitchell Warren- AVAC and Workshop Facilitator*

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