**CHOICE** Collaboration for HIV Prevention Options to Control the Epidemic

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## BACKGROUND

An incredible tool for HIV prevention — pre-exposure prophylaxis (PrEP) — continues to be underutilized among adolescent cisgender girls and young women (AGYW).<sup>1,2</sup> One group with an important role to play in creating an enabling environment for AGYW's PrEP use is their parents, stakeholders who can act as a significant barrier or facilitator of their daughters' PrEP use.<sup>3</sup> This is particularly true when young women live with their parents. 4 When parents don't understand what PrEP is, they may reject PrEP because they believe it is an HIV treatment or that it would lead to HIV acquisition.4,5

Yet, many parents are interested in and supportive of PrEP for their children once they understand what it is.<sup>6,7</sup> And, although it is an individual's choice to use PrEP, many young women decide to disclose their use to their parents for reasons such as fear of inadvertent disclosure or simply because they want their parents to be informed.<sup>4,8</sup> Furthermore, in some locations, parental consent is required for PrEP use by individuals younger than 18.9

If parents do accept or support their daughter's PrEP use, it is important that they have the skills to demonstrate this support.<sup>4</sup> Young women decide whom to tell, or not tell, based in part on perceptions of acceptance. In some cases, parents may not be against PrEP use, but the perception that a parent is unsupportive can lead PrEP users to hide or discontinue their PrEP use.<sup>5</sup>

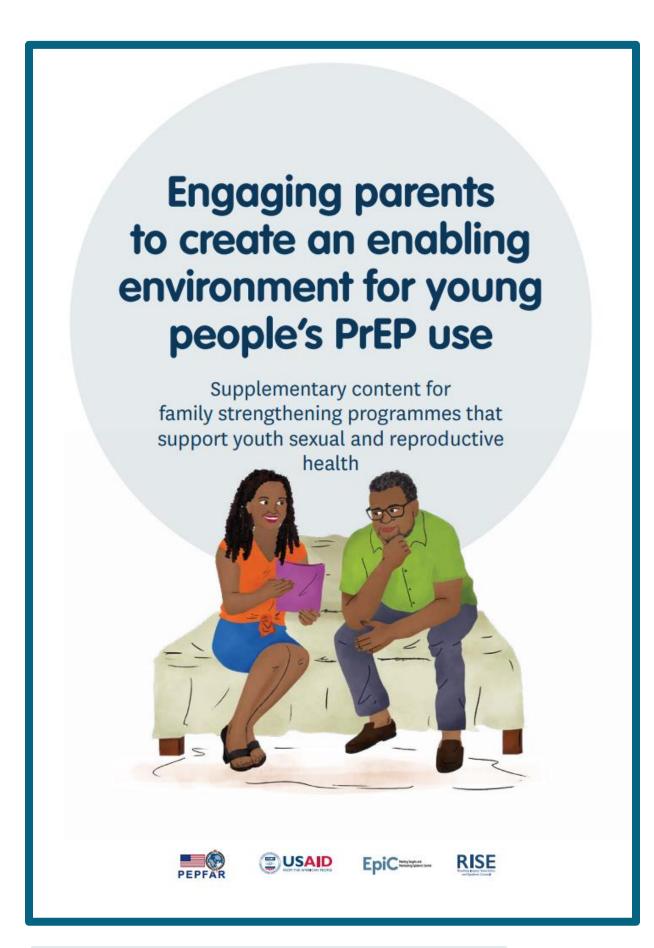
Given parents' potentially huge impact on PrEP use and calls for their engagement from AGYW, parents, and researchers,<sup>3,10</sup> the CHOICE collaboration funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID) developed a module that can be layered onto existing family strengthening curricula to build parental knowledge about and support for AGYW's PrEP use.

\*The module is also relevant to other caregivers; "parents" is used as shorthand for those parenting AGYW.

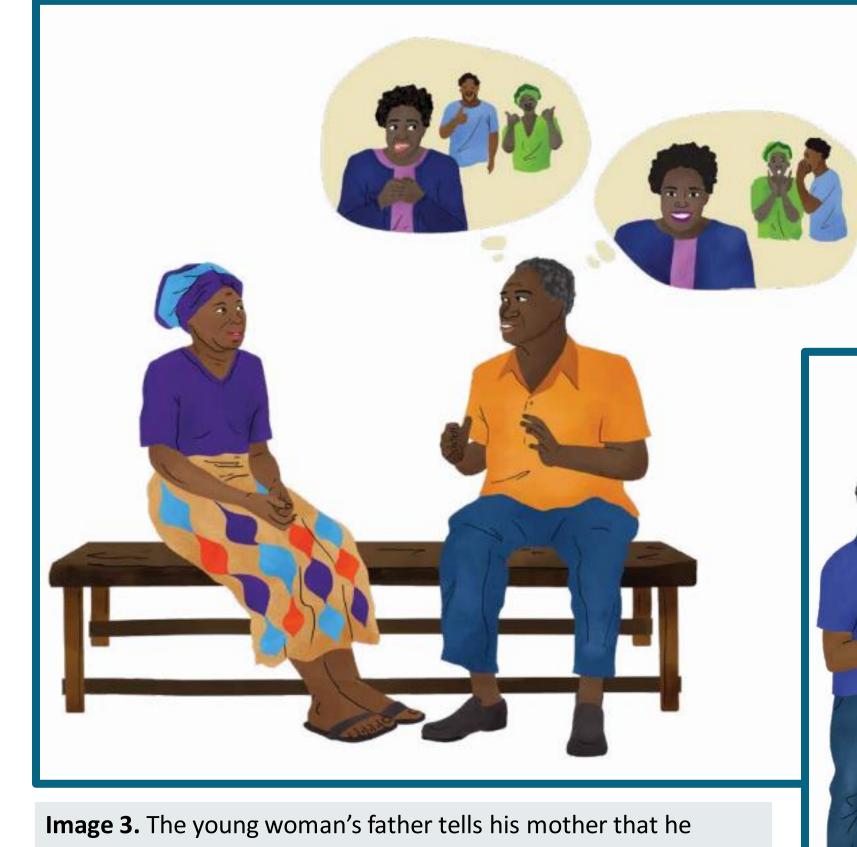
## DESCRIPTION

The module, Engaging Parents to Create an Enabling Environment for Young People's PrEP Use (Image 1), contains five main sections.

- 1. Using this Module guides the user on how to make the most use of the module's contents, including how to select an appropriate base curriculum and how to adapt the session to different contexts. (For example, some programs may operate in locations where only oral PrEP is available; others may also offer the PrEP ring).
- 2. Session Content describes the seven-activity session, designed to be implemented in 2.5 hours either consecutively or over several meetings (Image 2). This section links to implementation guidance, materials for implementation (such as scripts and images), and "tips and tricks" that facilitators can use in challenging situations. A third section covers essential knowledge about PrEP methods and combination prevention, oral PrEP, and the PrEP ring. The last two sections summarize a literature review on the need to engage parents in PrEP programming and findings from field dialogues implemented in Kenya and Zimbabwe to inform the module.
- 3. Essential Knowledge provides key information about PrEP methods and combination prevention, oral PrEP, and the PrEP ring.
- 4. Literature Review summarizes existing literature on the need to engage parents in PrEP programming
- 5. Field Dialogue Findings describes learning from field dialogues implemented in Kenya and Zimbabwe to inform the module

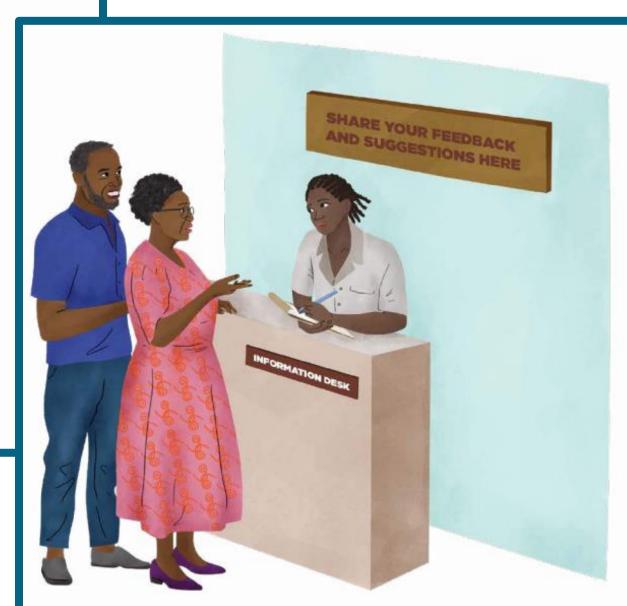


**Image 1.** Cover Page



would rather his daughter be healthy and let people say what they will, than for his daughter's health to be unprotected and the neighbors be happy.

**Image 2.** The adolescent girls' parents go to the clinic to report that a provider shamed their daughter when she asked about PrEP. The daughter is now too embarrassed to return for regular medical care. The parents ask what can be done so that this does not happen to other adolescents.



## LESSONS LEARNED

During field dialogues to shape the module, groups of parents (38 participants), facilitators (21 participants) and AGYW not using PrEP (26 participants) shared priority topics (Figure 1) that were then integrated into the module. The topics that were of most interest across respondent groups — who should use oral PrEP, how safe is oral PrEP, why should AGYW in our community use PrEP, and how does oral PrEP work are covered in detail. Parents' top concerns, as described by parents themselves or by AGYW and facilitators of family strengthening programs, also informed the module. In particular, the module addresses the misconceptions that using PrEP will increase sexual activity, increase AGYW's number of sexual partners, or make users infertile. Importantly, the module also supports parents to identify their own values related to their daughters' PrEP use, stand up to stigma that may come from others (Image 2), and even talk to their friends and family to build broader support for PrEP.

Field dialogue participants also brought up gendered dynamics related to parents' comfort engaging their daughters on issues of sexual and reproductive health, where mothers are more likely to engage directly, and fathers may not feel as comfortable in this role. These dynamics are accommodated in the module. Case studies and instructions to facilitators are provided to help fathers identify a role for themselves in supporting their daughters' choices related to HIV prevention, whether they do so directly (e.g., talking to their daughters) or indirectly (e.g., by supporting their daughters' choices with other family members) (Image 3).

The module performed well in field tests. Parents (147) and family strengthening facilitators (57) from Zimbabwe and Kenya participated. Pre-and post-test results showed that PrEP knowledge doubled: average knowledge scores rose from 33 percent to 68 percent. In addition, there was a dramatic increase in parents saying they would support their children's PrEP use, from 40 percent to 60 percent. Qualitative feedback suggested that participants would also share information with other adults in their social networks.

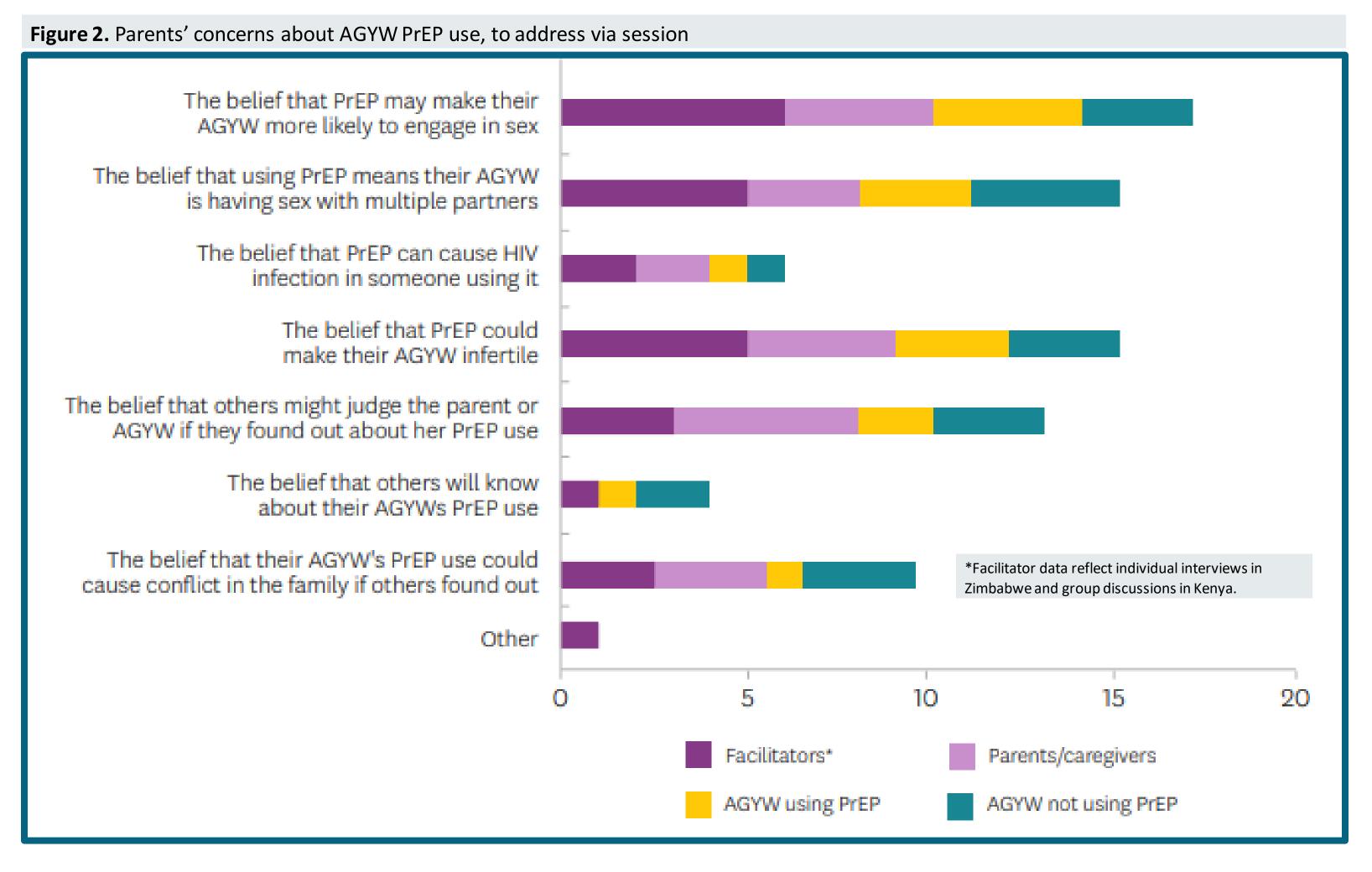


Figure 1. Topics identified as priorities for session inclusion in dialogues with facilitators, parents, and AGYW Who should use oral PrEP? Why should AGYW in the community use PrEP? How does oral PrEP work? How does one use oral PrEP? How could an AGYW access oral PrEP? How safe is oral PrEP/ what are side effects? How effective is oral PrEP? How long should AGYW use PrEP? How can a caregiver talk to their child about PrEP? How can a caregiver support their AGYW to start or stay on PrEP? How to increase support among others for their AGYW to use PrEP? \*Unit of measurement is number of dialogues. Facilitator dialogue data reflects individual interviews How to address others' stigmatizing in Zimbabwe and group discussions in Kenya. All other attitudes toward oral PrEP? dialogues occurred with groups. Other Parents/caregivers AGYW using PrEP AGYW not using PrEP

## CONCLUSIONS / NEXT STEPS

Parents can be an invaluable resource in making PrEP an accessible reality for AGYW. Contributors to Engaging Parents to Create an Enabling Environment for Young People's PrEP are currently partnering with AGYW HIV programming across Africa to scale up the module, including through the Maximizing Options to Advance Informed Choice for HIV Prevention (MOSAIC) project, which is funded by PEPFAR through USAID.

<sup>3</sup>Jackson-Gibson M, Ezema AU, Orero W, Were I, Ohiomoba RO, Mbullo PO, et al. Facilitators and barriers to HIV pre-exposure prophylaxis (PrEP) uptake through a community-based intervention strategy among adolescent girls and young women in Seme Sub-County, Kisumu, Kenya. BMC Public Health. 2021;21(1):1284. Available from: <a href="https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-021-11335-1">https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-021-11335-1</a>. Subscription required. Subscription required. <sup>5</sup>Giovenco D, Gill K, Fynn L, Duyver M, O'Rourke S, van der Straten A, et al. Experiences of oral pre-exposure prophylaxis (PrEP) use disclosure among South African adolescent girls and young women and its perceived impact on adherence. PLoS One. 2021;16(3):e0248307. Available from: <a href="https://www.doi.org/10.1371/journal.pone.0248307">https://www.doi.org/10.1371/journal.pone.0248307</a>

<sup>6</sup>Kidman R, Nachman S, Kohler H-P. Interest in HIV pre-exposure prophylaxis (PrEP) among adolescents and their caregivers in Malawi. AIDS Care. 2020;32(Suppl 2):23-31. Available from: https://www.tandfonline.com/doi/abs/10.1080/09540121.2020.1742861?journalCode=caic20. Subscription required. <sup>7</sup>Hill S, Johnson J, Washington L, Rahman F, Simpson T, Elopre L. Caregiver support as novel strategy to improve adolescent and young adult adherence to PrEP in Deep South. J Adolesc Health. 2020;66(2 Suppl):S125–6. Available from: https://doi.org/10.1016/j.jadohealth.2019.11.251. Subscription required.

8Camlin CS, Koss CA, Getahun M, Owino L, Itiakorit H, Akatukwasa C, et al. Understanding demand for PrEP and early experiences of PrEP among young adults in rural Kenya and Uganda: a qualitative study. AIDS Behav. 2020;24(7):2149–62. Available from: https://www.doi.org/10.1007/s10461-020-02780-x. Subscription required.

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<sup>&</sup>lt;sup>1</sup>Celum CL, Delany-Moretlwe S, Baeten JM, van der Straten A, Hosek S, Bukusi EA, et al. HIV pre-exposure prophylaxis for adolescent girls and young women in Africa: from efficacy trials to delivery. J Int AIDS Soc. 2019;22(S4):e25298. Available from: https://onlinelibrary.wiley.com/doi/10.1002/jia2.25298

<sup>&</sup>lt;sup>2</sup>Green K, Vu Hoang MC, Vu Ngoc B, Nguyen Tan T, Tran Thi T, Bac Si G, et al. Low PrEP uptake but good retention among transgender women: preliminary results from real-world PrEP roll-out in Vietnam. 10<sup>th</sup> IAS Conference on HIV Science. Mexico City, Mexico. 21–24 July 2019. Available from: <a href="http://programme.ias2019.org/Abstract/Abstract/Abstract/3495">http://programme.ias2019.org/Abstract/Abstract/Abstract/Abstract/Abstract/Abstract/3495</a>

<sup>&</sup>lt;sup>9</sup>Taggart T, Bond KT, Ritchwood TD, Smith JC. Getting youth PrEPared: adolescent consent laws and implications for the availability of PrEP among youth in countries outside of the United States. J Int AIDS Soc. 2019;22(7):e25363. Available from: <a href="https://onlinelibrary.wiley.com/doi/10.1002/jia2.25363">https://onlinelibrary.wiley.com/doi/10.1002/jia2.25363</a>.

10 Skovdal M, Magoge-Mandizvidza P, Dzamatira F, Mazwera R, Nyamukapa C, Thomas R, e al. Improving access to pre-exposure prophylaxis for adolescent girls and young women: recommendations from health providers in eastern Zimbabwe. BMD Infect Dis. 2022;22(1):399. Available from: <a href="https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-022-07376-5">https://onlinelibrary.wiley.com/doi/10.1002/jia2.25363</a>.