# Engaging parents to create an enabling environment for young people's PrEP use

Supplementary content for family strengthening programmes that support youth sexual and reproductive health









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We would also like to acknowledge the adolescent girls and young women who are working towards the prevention of HIV in their communities throughout Africa and globally. Their calls for more engagement of their parents are the rationale for this module. The opinions and guidance of adolescent girls and young women in Kenya and Zimbabwe, presented in the findings, informed the activities described in the module.

The module is also informed by the collective knowledge and expertise of organisations such as LVCT Health in Kenya and PZAT in Zimbabwe that work tirelessly for the prevention of HIV throughout Africa. We hope this resource supports them in their work.

This module is a sister document to the <u>HIV Prevention Ambassador Training</u> <u>Package</u> and in some cases adapts content from that package, which is designed for youth, to make it relevant to the parents of young people. Although the HIV Prevention Ambassador Training Package is not an appropriate base curriculum for this module (appropriate base curricula are explored further in <u>Using this module</u>), co-located use of both resources may lead to improved PrEP-related outcomes. For example, this module teaches parents how to communicate positively with a child who is contemplating PrEP use, while the youth-focused HIV Prevention Ambassador Training Package helps young people bring up PrEP in conversation with their parents.

# **Acronyms and Abbreviations**

AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
F-TAF	Tenofovir Alafenamide and Emtricitabine
FTC	Emtricitabine
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
IUD	Intrauterine Device
LGBTQ	Lesbian, Gay, Bisexual, Transgender, or Queer/Questioning
MPT	Multipurpose Technology
OPTIONS	Optimizing Prevention Technology Introduction On Schedule
PEP	Post-exposure Prophylaxis
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PrEP	Pre-exposure Prophylaxis
PZAT	Pangaea Zimbabwe AIDS Trust
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
TDF	Tenofovir Disoproxil Fumarate
USAID	U.S. Agency for International Development
U=U	Undetectable Equals Untransmittable

# Terminology

#### Throughout this document, we will use the following terms:

- Adolescent girls and young women (AGYW), the population for whom this module was initially developed, but with the understanding that the module can be adapted (with adaptations described in the document) for adolescent boys and young men
- "Parents" to refer to parents, caregivers, and guardians (generally understood to be the persons responsible for the care and wellbeing of children within the home)
- "PrEP" refers to all antiretroviral (ARV)-based biomedical HIV prevention methods, including oral pre-exposure prophylaxis (PrEP) and the PrEP ring. When only one biomedical prevention method is referenced, that method will be named explicitly.
- "Oral PrEP" refers to PrEP taken orally.
- "PrEP ring" refers to the dapivirine ring.

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# Overview

This module is designed for use by HIV programmes that wish to introduce parents to PrEP as part of an effort to support young people's PrEP use, with an emphasis on PrEP use among AGYW. The module can introduce oral PrEP alone or with other prevention technologies, such as the PrEP ring. It was developed in response to both AGYW's and researchers' calls for interventions that engage parents in PrEP programming (Camlin, 2020; Koay, 2021; Makyao, 2018) and because parents have an important, but often unaddressed, role to play in young people's PrEP initiation and effective use. It contains the following:

- Instructions on <u>using this module</u>, including how to identify an appropriate base familystrengthening curriculum, how to select and adapt activities from the module, detailed instructions on how to prepare for implementation, and opportunities to incorporate local HIV Prevention Ambassadors into the training (thereby using the <u>HIV Prevention Training Package</u> and this module synergistically)
- A <u>session overview and instructions</u> that identify the needed materials, give time estimates for each activity, offer facilitation tips, and generally support the facilitator in implementing each selected activity
- **Further resources for facilitation**, including a certificate that participants can receive when they have completed the PrEP session, a pretest and post-test that can be used to assess participant knowledge, and handouts for participants to take home (these can also be enlarged to also function as posters)
- An <u>Essential Knowledge</u> component that facilitators can use to educate themselves on PrEP in order to implement the session and answer participant questions that go above and beyond the content covered
- A literature review on parents' role in AGYW's PrEP use
- **<u>Findings on how to introduce PrEP to parents</u>** generated through dialogues with facilitators and parent participants of existing family strengthening programmes and with AGYW who are and are not using PrEP

# Using this module

This module is designed to supplement existing curriculum-based interventions for parents of adolescents and young people. It is meant to achieve the following objectives:

- Parents will become familiar with PrEP and will be able to articulate information on how and why to use PrEP, who can use PrEP, and its side effects.
- Parents will be able to identify both possible benefits of their children's PrEP use and any concerns they have about PrEP.
- Parents will recognise the important role that they can play in facilitating their children's voluntary PrEP use.
- Parents will be able to describe strategies to support their children's voluntary PrEP initiation and effective use, including by supporting them directly and by challenging others' stigmatising attitudes.

Implementers of parent engagement activities who wish to add a supplementary session on PrEP to an existing family strengthening programme or those who wish to engage parents for the first time as part of a comprehensive PrEP programme should follow the steps below.

## Read the entire module.

Having a sense of why and how this module was developed, the essential information that facilitators will be asked to understand, and the activities that could be implemented will help you decide how to use what is shared here.

## Assess your existing family strengthening intervention to determine opportunities to supplement it with a session on PrEP or identify a family strengthening intervention to which a session on PrEP could be added.

This module is designed to supplement a base curriculum — for example, <u>Families Matter!</u>, <u>Sinovuyo Teens</u>, or <u>Talking Parents</u>, <u>Healthy Teens</u>. The base curriculum is necessary to introduce parents to basics related to positive parent/child relationships and their children's sexual and reproductive health (SRH). Topics that should be covered in the base curriculum include:<sup>1</sup>

- Ways to promote loving, warm, and affectionate relationships between parents and their adolescent children
- Parenting skills, including how to strengthen the parent-child relationship, how to improve communication, how to supervise children, how to use nonviolent discipline techniques, and how to create a safe environment for adolescents
  - Parents' role in educating their children about sexuality, including the information their children will need (such as knowledge of reproductive health and anatomy), how to identify one's own sexual values, and how to communicate with children on sex-related issues
  - Challenges young people face to their SRH, and the role of parents in keeping them safe
  - The changes young people go through, socially, physically, and emotionally, before and during puberty
  - The realities of adolescent sexual behaviour
  - Information on family planning, sexually transmitted infections (STIs), HIV, and AIDS and resources where both parents and their children can find out more or access services
  - Information on how to respond if a child experiences violence, including sexual violence, and contact information for crisis support services
  - The importance of protecting and promoting parental mental health

If the base curriculum already in use does not cover topics related to SRH and HIV prevention in depth but is otherwise relevant, the foundational knowledge sessions of the <u>HIV Prevention</u> <u>Ambassador Training Package</u> can be adapted for parents and used to fill this gap. In addition, if the base curriculum has already been fully implemented (i.e., all sessions for some parent groups are complete), this module can still be implemented as a supplement that builds on the skills already taught as well as a refresher on some of those skills, such as strong parent/ child communication.

<sup>1</sup> Many of these topics and additional components of effective parenting curricula are explored in more detail in UNICEF's Programming Guidance for Parenting of Adolescents, where it is also possible to find step-by-step guidance on assessing an existing programme for parents.

# Prepare specific PrEP information about your location and context.

The module is designed for global use. It does not provide information specific to any one context. We recommend identifying and providing to participants the following locally determined information as part of the session on PrEP:

- Information about PrEP methods available locally, including at the district/county level whenever possible
- Where parents can refer adolescents and young people to get PrEP preferably at a youthfriendly health clinic or health care center
- Generic brands available in your location (if possible, bring sample methods such as pills or the PrEP ring for participants to see)
- National guidelines for the use of available PrEP methods, including:
  - Who can access PrEP
  - Minimum age for PrEP use and age at which parental consent is required
  - Use during pregnancy
  - Guidance on what to do when considering no longer using PrEP
- Testing required before starting PrEP, such as testing for HIV and hepatitis B, and local laws relevant to HIV prevention, SRH, and PrEP, including:
  - Age of consent for STI screening and HIV testing

# Add PrEP services to your existing local referral directory.

Implementation of the base curriculum should include the distribution of a directory of locally available SRH service providers, counsellors, and crisis support for children who experience violence. The existing directory should provide information such as services offered, location, hours, and contact information for each organisation. This directory should be revised to include facilities that offer PrEP.

If a local referral directory is not available, use the <u>template in the HIV Prevention Ambassador</u> <u>Training Package</u> to create one. Make sure to include only organisations and individuals that provide quality, stigma-free services to youth. Once the directory is complete, make copies available to participants.

# Determine the activities in this module that are most relevant to your participant group.

The table below aligns each activity to its specific objective. If you must shorten the session due to time constraints and if the parents you are working with are already highly knowledgeable about all the forms of PrEP that are locally available and do not have misconceptions about their use, consider skipping activities 1 and 2. You may decide to give the pretest to determine individual participant knowledge before making this decision. If you can implement the module over several days, you may also consider conducting multiple shorter sessions.

ACTIVITY	TIME	OBJECTIVE	
Introduction	15 min	Participants will share their existing knowledge (via pretest) and become familiar with the session objectives and basic facts about PrEP.	
1. Four Corners	10 min	Participants will be able to differentiate between methods that can be used to prevent HIV.	
2. Guest speakers	25 min	Participants will be able to ask questions of local PrEP experts.	
3. Theatre	30 min	Participants will be able to identify the benefits of young people's PrEP use and any concerns they have about its use and to brainstorm responses to those concerns.	
4. Your child's dreams	20 min	Participants will discuss how PrEP use could help their children fulfil their dreams.	
5. Communicating with care	45 min	Participants will be able to identify opportunities to discuss PrEP with their children, practice communication skills that allow those discussions to strengthen parent-child relationships, and identify opportunities to support their children's PrEP use.	
6. What would you do?	25 min	Participants will be able to brainstorm strategies to counter PrEP stigma expressed by others in the family, community, or health facilities.	
7. Stating our intentions and closing	10 min	Participants will share an action that they plan to take in the immediate future to further inform themselves or otherwise support their children's PrEP use, now or in the future.	

If you choose to remove activities, it is preferable not to omit activities 2, 3, 5, 6, and 7 because they are the most important components, even for knowledgeable parents.

# Review the selected activities and identify any adaptations needed.

Depending on which of the answers below best describe your plans for using the PrEP session, the resources you have available to you, and the characteristics of your participants, you may need to adapt the training or change the way you facilitate. Review the statements below and determine which answer best describes your unique context, and then adapt or facilitate according to the recommendations.

#### The session will cover PrEP use by....

Your answer	Recommended adaptation/facilitation strategy		
Adolescent girls and young women	Most scenarios in the session focus on AGYW. You are unlikely to need to make revisions.		
Both adolescent boys and girls and young women and men	Because the scenarios/examples in the session focus on AGYW, you should either change the gender of some of the adolescents in the scenarios or add scenarios that will challenge parents to consider how they might support their sons to have conversations about, initiate, or continue to use PrEP.		

#### The session will be given to the parents of....

Your answer	Recommended adaptation/facilitation strategy
Preteens and very young adolescents (10-14)	Parents of this age group may feel that PrEP is not yet relevant to their children. Acknowledge that this may be the case, and that their children may not be eligible to use PrEP according to local guidelines. However, stress that having knowledge of PrEP before it is needed is far better than learning about it after it could have been of use. In addition, emphasise that participants can also educate other parents — not only their own children — about what they are learning. In this way, they can create healthier communities beyond their own households.
Adolescents and young people (ages 15–24)	Parents may feel that even though their child is eligible to use PrEP, it is not yet useful to or appropriate for them. Stress that parents may sometimes be surprised to learn what information would be useful to their children or their children's friends, and that having knowledge of PrEP before its needed is far better than learning about it after it could have been of use. In addition, emphasise that participants can also educate other parents — not only their own children — about what they are learning. In this way, they can create healthier communities beyond their own households.

#### This session will be given in a context in which....

Your answer	Recommended adaptation/facilitation strategy
Only oral PrEP is available	Activities are written to emphasise oral PrEP — the method of PrEP most widely available at the time this module was published — and include the PrEP ring. Whenever the PrEP ring is mentioned, please remove it from the activity.
Oral PrEP and the PrEP ring are both available	Activities are written to emphasise oral PrEP — the method of PrEP most widely available at the time this module was published — and include the PrEP ring. If more information on the PrEP ring is desired, please refer to the Essential Knowledge section.

#### We will have the following guests present during our session on PrEP....

N.	
Your answer	Recommended adaptation/facilitation strategy
A health care worker (HCW) familiar with PrEP	This person can be invited to attend either the guest speaker activity only or the entire session. If they are invited to attend the entire session, ensure that they understand that they are attending as a health care worker and do not need to disclose their personal parenting choices or preferences.
An HIV Prevention Ambassador	This person can be invited to attend either the guest speaker activity only or the entire session. The ambassador should be given information on what to expect before the session, including the ages and number of participants. The ambassador should be supported by the facilitator both before and throughout their time in front of the parent group. Before the session begins, the facilitator should ask the parents to consider each question before they ask it and avoid asking a question of the HIV Prevention Ambassador that they would not want asked of their own daughters. If questions arise that are inappropriate (e.g., "Did you begin to have sex with more partners after starting to take PrEP?"), the facilitator should intervene.
Both	Speak to both guest speakers about their roles, using the tips above, and ensure that the HCW understands the HIV Prevention Ambassador's training. This will help the HCW recognise the ambassador's expertise and legitimacy before they respond to questions together in front of the group.
Neither	If it is not possible to bring in someone who is knowledgeable about PrEP, consider showing a short video clip or providing materials from the local health facility. Participants can review these materials and present them to one another, highlighting what they find most interesting/surprising/confusing for additional discussion.

#### This session will be given to parents of young people who....

	Description of a description of the different sector of the
Your answer	Recommended adaptation/facilitation strategy
Openly identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ)	While gay, bisexual, and other men who have sex with men and transgender women are priority populations that may benefit from PrEP use, this training is not designed to identify or address their unique needs. <u>Parental acceptance of a young person's gender identity or sexual orientation is vital</u> to that young person's mental health and well-being. If parents mention that they have children who identify as LGBTQ, let them know that their emotional support of their children is invaluable, and that PrEP is available to their children. If possible, share the information of any local clinics that are known to be competent and friendly to LGBTQ youth, such as the <u>Wits RHI</u> <u>Trans Health Centre</u> in South Africa, and local groups that support the parents of LGBTQ youth, such as the <u>services available from GALZ</u> in Zimbabwe. Direct parents to locally adapted resources that provide information on parenting LGBTQ children, or to this webpage from <u>Healthy Children</u> that is promoted by the United States Centers for Disease Control and Prevention as part of their <u>Resources for LGBT Youth and Friends/Supporters</u> .
Do not openly identify as LGBTQ	Sexual orientation and gender identity can be contentious topics in some settings. Children may identify as LGBTQ but not share this information with their parents. If parents bring up questions or make comments about LGBTQ people, let parents know that children who are part of marginalised groups have a huge need for parental support and that skills such as open communication will be especially important when discussing topics such as gender identity and sexual orientation with their children. If there are locally available resources that parents can use to educate themselves, share these. If not, if questions arise, direct parents to resources such as this webpage from <u>Healthy Children</u> that is promoted by the U.S. Centers for Disease Control and Prevention as part of their <u>Resources for LGBT</u> <u>Youth and Friends/Supporters</u> .

#### Decide where to insert the activities you selected.

When possible, insert the session on PrEP described in this module near the end of the base curriculum. For example, if the base curriculum contains seven sessions, the PrEP session could be added just after session 5 or 6. That way most information and parenting skills will already have been covered, and participants will already be comfortable with each other. Inserting this supplemental session close to the end of the existing intervention is important because this module does not include icebreaker activities, which are necessary at the beginning of a new parent group. The supplemental PrEP session can also be implemented after the base curriculum has been completed.

# B Prepare the materials needed for the training, including any printouts.

The materials needed for the session on PrEP are similar to those that are likely already in use. Review the table below to identify any materials that may still need to be collected, based on the activities you plan to implement. The materials listed in the table should also be printed in advance.

When possible, parents should complete the pretest before the session on PrEP begins. If test completion occurs several days before the session, the information from the pretest can help the facilitator tailor the session to the participants' specific knowledge and existing attitudes towards PrEP.

# Finally, it is important to account for the need to translate any materials, particularly printed materials, to local languages.

ΑCTIVITY	MATERIALS	PRINTOUTS NEEDED	ANY OTHER PREPARATION
Introduction		• Copies of the pretest for each parent (or one copy for each pair, depending on whether each parent will complete the pretest alone)	• If the pretest is given before the session begins, instead of administering the pretest again, use the introduction to share an overview of the group's test results, emphasizing how those results will help shape the session
1. Four Corners	<ul> <li>4 sheets of A4 paper labeled with the following: "PEP", "PrEP", "Condoms", and "ART"</li> <li>Markers</li> <li>Sticky tack or tape</li> </ul>	<ul> <li>Essential Knowledge (1 copy) for facilitator reference</li> <li>Packet of take-home information (including)         <ul> <li>PrEP, PEP, and ART</li> <li>Expanding options to fit our lives.</li> <li>Oral PrEP: Answering your questions</li> <li>The PrEP Ring: Answering your questions</li> <li>Tips for Using Oral PrEP</li> <li>Tips for Using the PrEP Ring</li> </ul> </li> </ul>	• Hang A4 papers in four corners of the room
2. Guest speakers			<ul> <li>Prepare guest speakers per instructions in Step 6 of "Using this module"</li> </ul>
3. Theatre	<ul> <li>Markers</li> <li>Flip chart paper that includes a drawing of the box in Activity 3 instructions</li> </ul>	• Script (3 copies), one for each actor and one for the facilitator	<ul> <li>Identify, in advance, at least one and up to four participants willing to take part in a skit. Give them time to read the skit in advance.</li> </ul>
4. Your child's dreams			
5. Communicating with care	<ul> <li>Markers</li> <li>Flip chart paper with a written list of ways that youth want parents to support their PrEP use (see full list in Activity 5)</li> <li>Flip chart with written list of scenarios (see full list in Activity 5)</li> </ul>	• Images 1 to 4	

6. What would you do?	• Flip chart with the written list of scenarios (see Activity 6)	• Images 5 to 10	
7. Stating our intentions and closing		<ul> <li>Updated service directory</li> <li>Copies of the post- test for each parent (or one copy for each pair, depending on whether each participant will complete the pretest alone)</li> </ul>	

If a programme plans to use this supplementary session regularly, use pretest and post-test findings to tweak the activities depending on reoccurring gaps in knowledge or negative attitudes about PrEP, particularly those still demonstrated in the post-test.



# SESSION OVERVIEW

As part of a more comprehensive programme for parents of adolescents and young people, it is important that parents are informed about new HIV prevention methods, such as oral PrEP and the PrEP ring, that could positively affect the health of their children. Participants will learn about different locally available forms of PrEP, be able to clarify any misinformation they may have about PrEP, consider how PrEP may benefit their children now or in the future, and identify parents as an important component of their children's successful voluntary PrEP use. Then, they will build skills to communicate with their children about PrEP, support their children's PrEP initiation and longer-term use, and disrupt PrEP stigma.

By the end of this session:

- Parents will become familiar with PrEP and be able to articulate information on how and why to use PrEP, who can use PrEP, and its side effects.
- Parents will be able to identify both possible benefits of their children's PrEP use and any concerns they have about PrEP.
- Parents will recognise the important role that they can play in facilitating their children's voluntary PrEP use.
- Parents will be able to describe strategies to support their children's voluntary PrEP initiation and effective use, including by supporting them directly and by challenging others' stigmatising attitudes.

#### KEY MESSAGES

- There are multiple forms of pre-exposure prophylaxis, also called PrEP. The forms of PrEP available locally are [insert locally available options].
- PrEP prevents HIV transmission. It can be used with other HIV prevention methods, including condoms. The best methods for prevention are those that an individual can use effectively.
- PrEP is safe with limited side effects.
- Myths about PrEP harm young people who could benefit from using this HIV prevention option but may choose not to because misinformation results in fear and stigma.
- Parents have an important role to play in facilitating their children's knowledge of and access to HIV prevention methods, such as PrEP, that will keep them healthy.
- Now or in the future, parents can support their children's PrEP use in concrete ways. These include direct support to young people and challenging PrEP misconceptions and stigma from others.

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#### **INTRODUCTION (15 MIN)**

- 1. Introduce the session by referring to the session overview.
- 2. If you have not already asked parents to take the pretest, share copies of the pretest and give participants time to complete it. Let them know that the purpose of this exercise is to understand how their collective knowledge changes during the session and that they do not have to put their names on the test. Be clear that you do not anticipate that they will already have all of the answers and that they should simply do the best they can.
- **3.** Once the pretest has been completed, collect the tests and ask the group to come together for an initial conversation.
- **4.** Begin by asking participants what puts young people in our community at risk of HIV acquisition and what young people can do to limit that risk.
- 5. Mention that oral PrEP and the PrEP ring are two options that young people and others can use to lower the risk of HIV acquisition. Share the following key facts:
  - PrEP, which stands for pre-exposure prophylaxis, is an antiretroviral medication that prevents HIV. When someone uses PrEP, HIV cannot enter their cells. This means the virus cannot multiply and the person will not get HIV.
  - PrEP is highly effective when taken correctly. For oral PrEP, this means taking a pill daily. For the PrEP ring, this means replacing the ring every month.
  - When people take PrEP, they report feeling more confident and less worried about their health.
  - Evidence shows that people who use PrEP do not begin to have sex with more partners or use condoms less often.
  - PrEP has no impact on fertility and does not prevent pregnancy.
  - PrEP is a good option for many people, including those who:
    - Do not know the HIV status of their partner or whether their partner living with HIV has an undetectable viral load
    - Are not sure if their partner is monogamous
    - Struggle to talk to their partner or negotiate safer sex
    - Have unequal power within the relationship (for example, this may occur more often when there is a large age difference between partners)

#### **FACILITATION TIPS**

Read the pretest questions aloud and/or allow parents to work in pairs to modify this exercise for low-literacy parent groups.

During field testing, parents who were completely unfamiliar with PrEP found the pretest confusing. If parents are completely unfamiliar with PrEP, the facilitator may decide to skip the pretest. It will still be useful to complete the post test.

Participants may not have seen PrEP before. If possible, bring samples to show them what different methods look like, include all the forms of PrEP available in your community.

If the parents wish to further discuss whether the use of PrEP leads to behaviours such as reduced condom use, you can let them know that this has been studied and that researchers found that "there was no evidence that PrEP use was associated with risk compensation" (Fonner, 2016). In fact, in some studies, participants reported having fewer partners and using condoms more often after starting oral PrEP (Cassidy, 2021).

Because such a diverse group of people can benefit from PrEP, some of the parents in the group may also be interested in initiating PrEP. Make sure that parents know that you, as the facilitator, are also a resource to them if they have questions about their own PrEP use. Session

- Have partners that are abusive
- Have had an STI recently
- Ultimately, PrEP is for people who want to protect themselves from HIV in a way that they can control!
- People who use PrEP can start and stop as they wish. PrEP use is recommended when there is a possibility of HIV transmission. Because it can be difficult to know when an exposure may occur, it is useful for those who wish to stop taking PrEP to talk to a health care provider about other HIV prevention methods that may work for them.

#### **ACTIVITY 1: FOUR CORNERS (10 MIN)**

- 1. Explain that PrEP is often confused with other HIV prevention methods. In this activity, the group will have the chance to test their knowledge and learn something new.
- 2. Hand out the "packet" of six <u>handouts</u>. Direct participants to the PrEP, PEP, and ART tool. Share a few key facts from the handout and note that they will have the chance to review it further on their own when they take the packet home.
- **3.** Ask all participants to stand up in the middle of the room. Say that you will read a statement about one type of HIV prevention. The participants should go to the corner with the name of the type of prevention you are describing: condoms, antiretroviral therapy (ART), PrEP, or PEP.
  - a. This prevention method uses antiretroviral medication to create a shield around your cells to protect them from HIV. – PrEP
  - **b.** This prevention method is effective at preventing the transmission of most STIs; it also prevents pregnancy. Condoms
  - **c.** This prevention method can be used in emergencies if you have been exposed to HIV. PEP
  - **d.** This prevention method can be used by a person who is living with HIV to achieve an undetectable viral load, thereby protecting their sexual partner. – ART
  - e. This prevention method creates a barrier between the skin and body fluids that may contain HIV. Condoms
- **4.** After reading each statement and giving participants time to choose a corner, ask one person who chose the correct corner to explain their thinking. If the answer is PrEP, PEP, or ART, refer to the handout where participants can find more information. While the handout does not mention condoms, if questions come up on condom use, these can be asked of the guest speakers in the next session.
- 5. Once you have gone through all the statements, thank everyone for participating and ask them to return to their seats.

#### FACILITATION TIPS

Make sure to review the contents of the handout with parents in advance of the Four Corners activity. Do not assume existing knowledge of ART and PEP.

If participants are reluctant to participate, slow to pick a corner, or seem afraid to make a mistake, acknowledge that this is meant to be a game where we all learn together, and no one is expected to get each one right. You can also increase the fun to encourage participation and create more of a game-like atmosphere. For example, you can play music after reading each statement and ask that everyone run to the corner of their choice when the music stops.

When talking about pregnancy prevention in Statement B, stress that PrEP does not prevent pregnancy, an important issue for AGYW.

Pointing out where they can learn more in the handout can help facts "stick" in the participants' minds and gives them a resource to review later. However, if the group is low-literacy, pair participants so that no one feels lost when you and others refer to printed text.

Celebrate mistakes: If someone makes an incorrect choice, thank them for their bravery and congratulate the group on learning together. Our mistakes are some of our best teachers.

#### ACTIVITY 2: GUEST SPEAKERS (25 MIN)

- Let participants know that we are fortunate to be joined by guest speakers who are experts on PrEP and can answer the group's questions.
- 2. Ask each guest to introduce themselves, including how they interact with PrEP (e.g., a health care provider who prescribes oral PrEP or an HIV Prevention Ambassador who educates young people about oral PrEP and the PrEP ring).
- **3.** Break participants into pairs and ask each pair to come up with at least one question for the guest speakers.
- **4.** After two minutes, ask for a volunteer to share one of the questions their pair came up with.
- 5. After that question is answered, go to the next pair and ask if their question has already been answered or they have a new question. If they have a new question, ask them to share it.
- 6. Continue until all pairs are called upon.
- **7.** If there is time remaining, open up to additional questions by any participant.

#### **FACILITATION TIPS**

Make sure you talk to both the health care provider and the HIV Prevention Ambassador in advance so that they understand the audience and are prepared. Also speak with the participants regarding appropriate questions for youth speakers. If myths/ inaccuracies came up in the pretests or the previous discussions, you can raise these directly with the guest speakers during this activity.

If it is not possible to bring in an expert, document the questions and concerns of the group (these can still be generated in a pairs' brainstorming activity and recorded by the facilitator). Ask a health care worker and/or HIV Prevention Ambassador, depending on the question, for their responses between activities so you can share those answers during the next activity.

During field tests, many parents wanted to know how their adolescent children, both male and female, could learn more about PrEP. At the end of the guest speakers activity, ask the guest speaker(s) to comment on where both adolescents and parents can go to learn more.

#### ACTIVITY 3: THEATRE (30 MIN)

- Explain that now that everyone has basic information on PrEP, the group will hear a conversation between two women discussing PrEP. The skit will be acted out in two parts. After each part, the participants will be asked to think about what they heard being discussed. In particular, they will be asked to remember what the women said about the benefits of PrEP, their concerns about their children's PrEP use, and any responses to those concerns. Let participants know from the very beginning that some inaccurate information could be influencing the women's concerns and that the participants should be on the lookout for misinformation that needs to be corrected.
- 2. Have the two participants act out the skit through the first stopping point (see <u>Script</u> under Further Resources).
- 3. Clap for the participants and ask them to be seated.

#### **FACILITATION TIPS**

When choosing who will act out the skit, select participants who enjoy being dramatic and will get excited about participating in a small play. Make sure they are comfortable reading. If only one person wants to participate in the skit, the facilitator can play the other role. If there are two facilitators, they can each play a role. The same two people can participate in the second act, or two new people can be engaged. (If two new people are engaged, ensure that it is clear which role each person is playing in the skit.)

The skit currently refers to "woman 1" and "woman 2"; feel free to have the participants come up with character names to use in the skit. 4. On flip chart paper, write the following headings:

Why might a parent support their daughter's PrEP use?		
What concerns might they have about PrEP?	Why is this a concern?	Responses to those concerns
1.		1.
2.		2.
3.		3.

- 5. Ask the group to think about what they just heard. Why would a parent support their child's use of PrEP? Write down their responses under, "Why would a parent support their daughter's PrEP use?"
- 6. Now ask about the concerns that a parent could have about PrEP. List those that participants heard in the skit as well as any others they might have heard in their community. Once those concerns are listed, ask participants to think about why each issue might be a concern. They can use what they saw in the skit or what they believe might be true in their communities. Finally, ask them to recall how each concern was addressed in the skit or to come up with their own responses. Fill in the table as ideas are generated.
- **7.** Now, return to the skit and have the same two participants or two new participants continue through the end.
- 8. Once again, clap for the participants and ask them to be seated.
- 9. Return to the table, adding any new content to each area.
- 10. After the table has been completed, ask whether any of the concerns are important to discuss further. A concern may be selected because parents want to know more or because the group did not feel it was fully addressed in this activity. Star these outstanding concerns for further discussion with guest speakers (if they are still in attendance), immediate discussion within the group, or further research and report back by the facilitator.

If your group of parents includes many men, consider doing the skit as written but after it has been conducted, asking the group how the conversation might look different if it were between two men. For example, are there ways that men can sensitize one another about PrEP to support their daughters' PrEP use? Alternatively, the group may choose to discuss how the conversation between the women could be different if the women (or men) were discussing their sons' PrEP use. For example, how might parents talk to one another about supporting their sons' use of PrEP?

Letting participants know in advance that they may hear incorrect information in the skit helps them listen carefully and makes them more likely to remember accurate information (Schwarz, 2016).

If participants say that they themselves would not support their daughter's PrEP use, note that in this activity the emphasis is on recalling what was seen in the skit and thinking about situations in which other parents may support PrEP use.

An example of a concern, its "why", and responses to that concern that could be entered in the table is as follows:

Concern – Others will believe my daughter has many sexual partners

Why is this a concern – Her emotional well-being could be harmed by this gossip

Responses – Her physical wellbeing will be benefited by her PrEP use, and if I stand by her, she will know that I do not believe such gossip. This will help protect her emotional well-being. I could also help others understand the facts about PrEP, which could reduce such gossip and its effects on all PrEP users.

#### ACTIVITY 4: YOUR CHILD'S DREAMS (20 MIN)

- Remind parents of the father in the skit who wanted his daughter to become his business partner. Ask parents to break into groups of three, and then share with one another at least one dream that they have for their children's futures. If they know the dreams their children have for themselves, these can also be shared. Such dreams could be specific, such as "My child hopes to become the principal or headmaster of a secondary school," or more general, such as "I hope that one day my child will be a respected member in her community".
- 2. Once everyone has shared their dreams in the small group, ask a few people to share those dreams out loud with the larger group.
- **3.** Explain to participants that in this activity they are going to think about how PrEP might help our AGYW achieve the dreams we have for them and the dreams they have for themselves.
- **4.** Use the following dream as an example: "My child dreams of becoming a doctor". How could PrEP help someone achieve this dream?
  - If someone is protected from HIV, they often experience less stress. This leaves them with more energy and focus to devote to pursuits such as studying.
  - My child may become more interested in science and medicine by directly benefiting from new medical technologies such as PrEP.
- 5. Now, ask the groups to reconvene and discuss each of the dreams that were mentioned in their small group.
- 6. Walk around the room to hear how discussions are going. When the discussions seem to be ending, ask a few people to share with the larger group how PrEP might help their children achieve the dreams discussed.
- 7. Close by saying that we all have dreams for our children and that they also have big dreams for themselves. Using PrEP can be a way to remove barriers to achieving those dreams.

#### **FACILITATION TIPS**

If a question is raised about how much parents' dreams should dictate children's decisions especially in the case of opposing dreams — it is important for parents to understand that children have their own agency. Parents' dreams for their children may demonstrate their love but are not more important than their children's dreams for themselves. At the same time, parents may not know what their children aspire to do and may feel more comfortable sharing their personal dreams for their children. Both types of dreams are fine in this activity.

When facilitating this activity, it's important to acknowledge that people living with HIV can still achieve their goals and dreams. Individuals living with HIV can live healthy and productive lives by knowing their status and adhering to treatment.

#### **ACTIVITY 5: COMMUNICATING WITH CARE (45 MIN)**

- 1. Remind participants that parents have an important role to play in their children's health. This means being able to talk to their children about making healthy choices, which could include using PrEP. Communicating with their children in a healthy and positive manner is one way that parents can demonstrate care for their children.
- Ask participants to think back to previous sessions or their own experiences of positive and negative communication with their children. Ask for and write down some characteristics of each type of communication.
  - For example, negative communication could involve yelling, accusations, judgment, and refusing to listen.
  - For example, positive communication could use open body language and nonjudgmental questions to show concern and respect for your child and curiosity about their perspectives.
- **3.** Note that there are many ways, including communication, to support young people's PrEP use. Share and review flip chart paper with the following information. Let participants know that this list was generated by young people.

Youth say that parents could help them by:

- **a.** Listening to their thoughts and helping them decide if any form of PrEP is a good option for them
- b. Not judging them for choosing to use PrEP
- c. Providing them with PrEP information
- **d.** Helping them identify a clinic that provides PrEP and providing them with transport money to get to the clinic or offering to go with them
- e. Reminding them to use PrEP, if they choose to do so
- **f.** Helping them handle any side effects, including by providing regular meals
- 4. Explain to participants that in this activity they will be using what they already know about positive and negative communication and incorporating what they have learned about how parents can support young people's PrEP use. The facilitator will lead the group through two examples and then give small groups time to do their own.
- 5. Write up the first scenario: "A father finds a PrEP pamphlet in his daughter's bedroom". Display the "negative communication image 1" and ask the group to describe what they see. They may say that they see judgment, accusations, and anger from the father, as well as fear from the daughter. Now show the "positive communication image 1" and ask the group to share their thoughts. For the positive image, does the group see the father demonstrating any positive communication skills?

#### **FACILITATION TIPS**

If there is time, participants can brainstorm ways to expand the list of parent supports for AGYW PrEP use. When sharing items from this list, the facilitator should let the participants know the list was generated by AGYW.

If participants are reluctant to say they would support their children's PrEP use, remind them that the skills they learn here may not be used immediately but could be useful in the future.

Think about the number of men and women in the participant group and change the sex of the caregiver in the scenarios as needed to make the scenarios more representative of the percentage of men and women in the group. For example, if the group is 50% men, a scenario that currently describes a mother/aunt should be changed to describe a father/uncle. Have a scenario of at least one person of each gender, even if 100% of the group is women or men.

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For example, they may say that he seems curious and open. Finally, ask if they see any signs of the support that young people report wanting. For this image, they may say that they see the father listening (a) and not judging, (b).

- 6. Now, write up the second scenario: "A mother learns that her daughter is taking PrEP". Display the "negative communication image 2" and ask what the group believes is happening and what signs of negative communication they are witnessing. This may include destruction of the pills, yelling, judgement, and sadness and frustration from the daughter. Now display the "positive communication image 2" and ask what signs of positive communication they see. This could include curiosity, nonjudgmental listening, and openness to learning new information. Finally, ask if they see any of the specific support that young people want for their PrEP use. In this case, this could include listening (a) and not judging (b).
- 7. Now, divide the participants into four groups. Point to the four additional scenarios on the flip chart paper. Ask the groups to create two "living pictures" (people posed as if in a drawing) where they demonstrate negative communication, and then positive communication, about one of the scenarios. For example, group 3 would create a negative living picture and a positive living picture for scenario 3. Ask that at least one of the group members not be included in the living pictures. This person will be the narrator who explains what the living picture is demonstrating.

The flip chart should read:

- 1) An adolescent girl's aunt believes that her niece is having sex.
- 2) A father sees that his daughter has used his phone to look for a clinic that provides family planning and PrEP.
- 3) A mother learns that her daughter has been to an SRH clinic without her knowledge.
- 4) A mother learns that her daughter has stopped using PrEP.
- 5. Ask the groups to come back together and for the first group to present on scenario 1 to the larger group. Begin with the negative living picture. While some of the group members form the living picture, the narrator should explain what is happening, including the types of negative communication on display. Next, ask the first group to present their positive living picture. This time the narrator should explain the types of positive communication, along with any actions to support PrEP use (a-f, above), being demonstrated.
- 6. Call on the next group to present and continue until everyone has shared their living pictures.

- After each group completes their negative and positive living pictures, applaud the presenters and ask a few participants to share something that stood out to them.
- 8. End by sharing that this activity shows us that our bodies can communicate quite a lot, even without words, so it is important for parents to think about not only what they say, but also what their body language is communicating. At the same time, it also shows us that sometimes the most important thing to do is to listen nonjudgmentally. When it is hard to know how to support a young person's PrEP use, listening with an open mind and heart is always a good option.

#### ACTIVITY 6: WHAT WOULD YOU DO? (25 MIN)

- Let participants know that young people do not only want direct help from their parents. They also want indirect help. For example, they want their parents to be able to reduce misconceptions or negative perceptions about PrEP among their parents' peers and in their communities.
- Explain that in this activity you will read a scenario. The groups that worked together during the last activity will remain together, but this time instead of creating a living picture, they will brainstorm a solution.

3. Reveal **image 5** and read the caption out loud: A father wants his daughter to be protected from HIV, but when he tries to bring it up, his own mother says that this will bring shame on the family because neighbours will assume the girl

is promiscuous. What can he do?

solution. Ask participants to explain

(verbally, not through drawing) whether

this solution could work and what could

4. Show **image 6** with the proposed







6. Show **image 8** with the proposed solution. Ask participants to explain (verbally, not through drawing) whether this solution could work and what could be done to improve it.

If it is possible to give prizes to winning groups (even if the prize is something like having the winning group choose the next energiser), this can encourage healthy competition and participation.

Images that include written text in English may need to be subtitled.

When printing the images, make sure they are large enough for the full group to see from their seats. Or, print multiple images so that smaller groups (such as individuals sitting near one another or at the same table) can have their own copies of the images.

#### **FACILITATION TIPS**





- 7. Show **image 9** and read the caption out loud: A mother's sister-in-law shames the woman for allowing her daughter to use PrEP, saying that she will become infertile. Her husband sees this occur and wants to correct her and defend his family's choices. What could he do?
- 8. Show **image 10** with the proposed solution. Ask participants to explain (verbally, not through drawing) whether this solution could work and what could be done to improve it.
- **9.** Finally, read two more challenges aloud. These challenges do not include an image. They are:
  - a) A mother wants her husband to support their daughter's PrEP use, but he has been unsupportive in the past. What can she do?
  - b) A local religious leader preaches that offering PrEP at the nearby clinic will encourage young people to sin. What could parents of young people in the community do?
- **10.** Ask each small group (from the previous activity) to come up with a solution to each scenario. When they share their solutions, write each one under the relevant challenge.
- Once all solutions are listed, ask each participant to vote for the solution that best addresses Challenge A and which one best addresses Challenge B. Congratulate the winning groups.
- **12.** Finally, ask participants if they would feel prepared to engage in such conversations and, if not, what would help them feel more prepared?

If there is time, or instead of using the final two scenarios (without images) provided, ask the participants to describe a situation where someone stigmatises PrEP use. This should be a situation they believe is likely to occur in their community. Then, ask the group to brainstorm responses to this participantgenerated scenario.

#### ACTIVITY 7: STATING OUR INTENTIONS AND CLOSING (10 MIN)

- 1. Thank everyone for their participation and energy throughout the day.
- 2. Ask participants to complete the post-test, allowing it to be completed in pairs as needed to accommodate literacy-related barriers. Let participants know that they can choose to put their names on the post-tests or leave this information off. If they want to know how they scored individually, they will need to include their names.
- **3.** Let the participants know that you will close by asking everyone to share one intention they now have related to their children's use of PrEP.
- **4.** After everyone shares their intentions, share your own. It could be related to researching any unanswered questions the group raised during the session.
- 5. End by saying that parents are important models and guides in their children's lives. Their children look up to them not only for answers, but for support. They can help their children make choices that keep them healthy and safe, including staying HIV-free. If they want to learn more about PrEP or speak further to an expert, they can talk to a health care worker.
- 6. Pass out the service directory, including links to national websites, with information on where PrEP can be found locally. Ask if there are any final questions.

#### **FACILITATION TIPS**

If you will see the parents again after this session, you can share the group's post-test results in a subsequent meeting, highlighting and correcting any continuing gaps in knowledge. If you will not see the parents again, let them know that you are happy to score individual post-tests immediately following the session so that they can have access to their results.

Intentions do not need to be big commitments. Here are some examples: "I will educate myself on PrEP," "I will ask my daughter if she has heard of PrEP," or "I will ask my doctor if they provide PrEP".

If you all will gather again after this session, let participants know that the next time you see them, you will ask each person if they made progress toward completing their intention. If not, ask if there is any help that you could provide to move them forward.

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# Essential knowledge

# PrEP Methods and Combination Prevention

# **COMBINATION PREVENTION BASICS**

## What is **PrEP**?

In recent years, there has been important progress in expanding HIV prevention options, including methods using medications called antiretrovirals (ARVs) for HIV-negative people. These methods are sometimes known as PrEP. In this manual, we use the term "PrEP" or "PrEP methods" to talk about all of the HIV prevention methods that use ARVs to protect a person from HIV before they are exposed. PrEP stands for pre-exposure prophylaxis. This means:

Pre	Exposure	Prophylaxis
Before	Coming into contact with HIV	Medication to prevent an infection from happening

ARVs are a type of medication that stops HIV from making copies of itself and spreading to other cells. There are six classes (types) of ARVs; each attacks HIV at different points in its life cycle. Within each type, there are many specific drugs. Drugs from multiple types of ARVs are often combined to attack different parts of the virus at the same time. ARVs are used in PrEP, PEP, and ART (see "PrEP, PEP, and ART – what's the difference?" below for more detail).

## PrEP, PEP, and ART — what's the difference?

It is important that parents and guardians understand the differences between PrEP, PEP, and ART, including when each can be taken and whom they are for, so they can explain these differences to others. Sometimes the same ARVs are used for PrEP, PEP, and ART.

Parents and guardians should understand that PrEP, PEP, and ART must be used as prescribed and cannot be interchanged. It is also important to be able to explain that unlike ART, PrEP and PEP are **only** for people who are HIV negative. The differences between PrEP, PEP, and ART are summarised below.

- **PrEP (pre-exposure prophylaxis)** is for **HIV-negative** people to use **before** they are exposed to HIV. The ARVs used in PrEP work by preventing the virus from entering or replicating in the body.
- **PEP (post-exposure prophylaxis)** is for **HIV-negative** people to use immediately **after** being exposed to HIV. The ARVs used in PEP work by stopping the virus from multiplying and spreading to new cells. If taken early (within 72 hours of being exposed to HIV), PEP can isolate the virus to a few cells. When these cells die (which they do naturally), so does the virus. PEP is a combination of three ARVs. WHO recommends tenofovir combined with either lamivudine (3TC) or emtricitabine (FTC) and ritonavir-boosted lopinavir (LPV/r) or ritonavir-boosted atazanavir (ATV/r) for PEP. You take them once or twice a day, depending on which drugs are prescribed, for a month.
- **ART (antiretroviral therapy)** is for **people living with HIV.** The ARVs used in ART slow down or stop the virus from multiplying and spreading to new cells. ART does not cure HIV, because the virus remains in the infected cells. By the time someone starts ART, HIV has usually infected too many cells

for it to die off naturally (as it does with PEP). However, if ART is taken every day, it can reduce the level of HIV so much that standard blood tests cannot detect it. This stops HIV from progressing to AIDS. When somebody has undetectable levels of HIV (known as an undetectable viral load, or UVL for short) there is not enough of the virus in their blood to transmit HIV to their sexual partners. This preventive effect is being promoted as U=U (undetectable equals untransmissible). Someone can find out if their viral load is undetectable by going to a facility that does viral load testing. However, they need to keep taking ART as prescribed to keep their viral load undetectable.

Refer to the <u>PrEP, PEP, and ART Tool</u> for a summary on how PrEP, PEP, and ART differ, including whom they are for, how they work, when they are used, and how effective they are.

#### What are the ways to use PrEP?

Because different AGYW have different HIV prevention needs and product preferences, and because AGYW's needs and preferences may change over their lifespan, researchers are always looking for new HIV prevention methods. Often people associate the term "PrEP" with the oral PrEP. However, now PrEP should be thought of as a category of ever-expanding ARV-based HIV prevention methods in development and being approved for use. Current PrEP methods approved for use or in development include:

- **Oral PrEP** a pill that contains ARVs that greatly reduce the chances of getting HIV when taken every day. Most oral PrEP pills contain a combination of two ARVs tenofovir disoproxil fumarate (TDF) and emtricitabine (FTC) although in some countries, different combinations are in use. A new form of oral PrEP, combining tenofovir alafenamide and emtricitabine (F-TAF), has recently been approved for men who have sex with men in some countries. Researchers are also developing a new form of oral PrEP called islatravir, which would only have to be taken once a month. Oral PrEP was the first PrEP method approved for use across the globe. You can learn more about oral PrEP in Oral PrEP Essential Knowledge.
- **Vaginal ring** a silicone ring that is inserted into the vagina and worn continuously over one month to slowly release the ARV dapivirine. Referred to as 'PrEP ring' or 'the ring' in this module, it has been shown to reduce the risk of HIV with no safety concerns with long-term use and has recently been approved for use in some countries. Other rings are being developed that could be used for multiple months in a row without removal, as well as rings that use other ARVs, such as tenofovir. Dapivirine is used only in the ring and is not found in other HIV prevention or treatment products. You can find more about the ring in **PrEP Ring Essential Knowledge**.
- **Injectable PrEP** different types of PrEP injections are being developed and tested to see if they work to prevent HIV. A long-acting PrEP injection containing cabotegravir (CAB PrEP) has been shown to be highly effective in preventing HIV and could provide long-term protection. Injectable PrEP has not yet been approved for use. This training does not currently focus on injectable PrEP; more information will be added once injectable PrEP is recommended for use by the WHO.
- **Multipurpose technologies (MPTs)** these products combine HIV prevention with contraception and will one day help AGYW meet more SRH needs with a single product. MPTs in development include a daily dual-prevention pill containing both PrEP and a contraceptive and a multipurpose ring containing levonorgestrel for contraception and dapivirine for HIV prevention. No MPT for HIV prevention has been approved for use. This training does not currently focus on MPTs; more information will be added as MPTs are recommended for use by the World Health Organization (WHO).

The time span from initial product development to rollout into the community is long. ARV-based HIV prevention methods must go through many years of testing. They must also gain approval from regulators, including national ministries of health. Check the <u>Useful Resources in the Ambassador</u> <u>Toolkit</u> to get details on which new methods may be approved or available in your location.

The table below provides a quick summary of some of the key attributes AGYW will consider when comparing different PrEP methods and condom use. The remaining sections will go into more detail on the two PrEP methods currently available on the market, oral PrEP and the ring. Remember that no method can provide protection if it is not used correctly and consistently.

	Attributes/ Method	Condoms	Oral PrEP	PrEP Ring	Injectable
C	How it's used	On-demand for sex; placed on the penis (male/external condom) or in the vagina/rectum (female/internal condom)	Pill taken daily	Vaginal ring replaced each month	Injection given every 2 months
ŤŦ	Site of action	Vaginal/anal area depending on type of sex (localised)	Whole body (systemic)	Vaginal area (localised)	Whole body (systemic)
ð	Role of male partner use	Male partner consent required	Woman initiated; use can be private	Woman initiated; use can be private	Woman initiated; use can be private
đ	How effective for HIV prevention	Over 90%, when used correctly (with lubricant)	Over 90%, when used correctly and consistently	Over 50%, when used correctly and consistently	Over 99%, when used correctly and consistently
¥.	Protection against STIs and pregnancy	Yes, if used correctly each and every time one has sex	NO *	NO *	NO *
•	Availability	Widely available	Available in most countries (check local guidelines)	Available in some countries (check local guidelines)	Not yet available; not yet approved

\*These methods should always be used in combination with a condom and a reliable method of contraception if possible. Future MPTs in the form of a pill or ring will be able to protect against HIV and pregnancy.

## What is combination prevention?

The term combination prevention often refers to programmes that implement different types of interventions aimed at reducing HIV transmission within a community or group of people.

In this training module, the term refers to someone using multiple prevention methods, such as condoms, STI screening and treatment, and PrEP, to maximise protection from HIV and other unwanted sexual health outcomes.

PrEP methods are designed to contribute to the existing package of HIV prevention options — including abstinence, condoms, STI screening and treatment, and having fewer sexual partners — not replace them. Each method has its benefits and challenges, and the best approach — or combination of approaches — varies by individual and relationship. Parents and guardians can help AGYW determine what method is best for them by helping them think through their needs for protection from HIV, STIs, and pregnancy.

## Who is PrEP for?

WHO recommends PrEP for populations with a high prevalence of HIV — including AGYW who have unique vulnerabilities to HIV in many communities — as an additional prevention option alongside other HIV prevention methods. However, determining who is most vulnerable to HIV can be complicated. Research shows that AGYW often think they are less vulnerable to HIV than they actually are. A person's vulnerability is influenced by environmental factors, such as the prevalence of HIV in their community;

social factors, such as gender norms and inequality; and behavioural factors, such as the sexual activities they engage in, including having unprotected sex with multiple partners.

AGYW in sub-Saharan Africa are a priority population for PrEP because of their disproportionate vulnerability to HIV. Overall, it is very unlikely that AGYW who are not vulnerable to HIV will try to get PrEP. Therefore, it is important to promote PrEP use as an option for all sexually active AGYW who want to protect themselves from HIV, regardless of how vulnerable they think they are.

PrEP can give AGYW more power and control over their sexual health and their ability to protect themselves against HIV acquisition, especially AGYW who find other HIV prevention methods difficult to use. While the final decision to use PrEP should be made by AGYW in conversation with their health care providers, the following information may be useful when identifying which AGYW would benefit from using a PrEP method as part of their combination HIV prevention strategy. AGYW may be vulnerable to HIV if they:

- Are in a sexual relationships where they do not use condoms every time they have sex and:
  - They do not know the HIV status of their partner
  - They do not have confidence that their partner is monogamous
  - They are not able to talk to their partner about sex or negotiate safer sex
  - They, or their partner, has recently had an STI
  - Their partner has HIV and is on treatment but is not confident they have an undetectable viral load
  - They are in a transactional sexual relationship
  - Their partner is violent or controlling
  - Their partner is much older than they are
  - They want to protect themselves from HIV in a way they do not have to discuss with their partner
- Have multiple sex partners
- Use alcohol and drugs before having sex
- Inject drugs and do not always use new equipment (only oral PrEP is suitable)

PrEP might also be suitable for AGYW who are experiencing repeated sexual violence. It is important that AGYW experiencing sexual violence are aware of and can access PrEP if they want to. However, messaging should not focus on sexual violence as a reason why AGYW would use PrEP, because this could create stigma for girls and women who choose to use it for other reasons. It is important to empower AGYW and support them to make a choice to use PrEP to protect their health.

Not all PrEP methods provide the same amount of protection from HIV or protection from all the ways someone may be exposed to HIV, and each has different side effects and special considerations for use that are important to remember when choosing between methods. More information on each available PrEP method can be found throughout this section.

#### How to choose the right HIV prevention options

Parents and guardians should support AGYW to choose their HIV prevention options based on accurate information, their relationships and lifestyle, fears, their own personal preferences, and other circumstances that may influence their decision. HIV prevention choices and PrEP method preferences vary from person to person and also change over time. The following sections will equip parents and guardians with essential knowledge about available PrEP methods and important decision-making strategies to help AGYW know about and decide if any PrEP methods are right for them as part of a personal HIV prevention strategy.

# **GETTING PrEP**

Before anyone can start using PrEP, they will need to see a health care provider who can counsel and test them for HIV, prescribe it, and then conduct regular HIV tests. This requirement can be a barrier to PrEP use for AGYW. For example, they may be concerned about:

- Being judged by the health care provider
- Receiving a positive HIV test result
- Having to discuss their sex lives
- Being seen attending the service by their parents, partner, or other people
- The health care provider breaking their confidentiality and telling others they are using PrEP

Parents and guardians can support AGYW to get PrEP by:

- Telling them about the process so they know what to expect
- Offering to accompany them to talk to a health care provider or visit a service location to get PrEP
- Giving them information about youth-friendly services in their area where they can get PrEP
- Talking through any concerns they might have, such as getting an HIV test
- Otherwise supporting AGYW to see a health care provider, such as by making an appointment or helping them identify transport options
- Sharing a link to a national or local online service directory or online health service booking platform (which includes PrEP service providers)

Depending on the PrEP method that an adolescent girl or young woman chooses, there may be different tests she will need before starting PrEP use. More information on the requirements is contained in the essential knowledge for each method. It is important to check local guidelines or ask a health care provider what the requirements are for each method in your area to ensure that you are able to provide accurate, up-to-date information to training participants.

## Adherence, effective use, and persistence

When it comes to treatment for HIV and other illnesses, **adherence to treatment** — which means taking it correctly — is a big deal. In order to manage HIV and live positively, people living with HIV must try to adhere to their medicine at all times. However, because AGYW can choose to use PrEP when they are vulnerable to HIV and stop using it if they do not need it, the word adherence is less helpful when talking about optimal use of PrEP methods. We suggest using the terms **continuation or effective use** to talk about the use of PrEP during the entire time a person is vulnerable to HIV and using the word **persistence** to talk about overcoming barriers to continued PrEP use.



# **Oral PrEP**

## **ORAL PREP BASICS**

## What is oral PrEP?

Oral PrEP is a pill containing ARV medication that can be taken by HIV-negative people once a day to protect them from getting HIV.

## Who is oral PrEP for?

As of 2021, oral PrEP has been approved in many countries for men and women, including trans men and women. It is also approved for young people who weigh 35kg or more — about the weight of an average 11-year-old — in some countries, such as the United States. The use of oral PrEP "on-demand" has also been recommended by WHO for men who have sex with men.

In some countries, oral PrEP was first promoted for specific groups, such as men who have sex with men and sex workers, who are often especially vulnerable to HIV. Because of this, oral PrEP is often viewed as an HIV prevention method that is only used by these individuals. While these are also priority populations for oral PrEP use, thinking about oral PrEP this way is a major barrier for AGYW who do not identify with these groups.

Presenting oral PrEP as an option for only the most vulnerable groups may contribute to the stigma surrounding it. Research shows that rebranding oral PrEP as an option for all people who need, want, and can use PrEP, including AGYW who want to take control of their health and protect themselves from HIV, makes oral PrEP more appealing. This approach will also help to normalise oral PrEP use among AGYW.

Oral PrEP provides protection from HIV during unprotected vaginal and anal sex and for people who use injection drugs because it is systemic, which means it is dispersed throughout the body. Therefore, oral PrEP is a good option for AGYW who have unprotected vaginal or anal sex.

## How does oral PrEP work?

When HIV enters the body of an HIV-negative person who is **not** taking oral PrEP or using other HIV prevention methods, it attacks and enters immune system cells known as CD4 cells. HIV then makes copies of itself in these cells and spreads to other cells. Oral PrEP puts a shield around CD4 cells to prevent HIV from getting in and multiplying itself. If the virus cannot multiply, it simply dies within the body.

The most common brand of oral PrEP is Truvada, which is a combination of two ARVs called tenofovir and emtricitabine. There are also generic versions of oral PrEP. This means that the drug is made by a different company and will have a different brand name, but the ingredients are the same, and it works just as well! (Refer to your country national guidelines for information on other regimens approved for oral PrEP.)

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The combination of ARVs in oral PrEP protects the cells from HIV **before** it takes over cells and starts multiplying. Other types of ARVs, like those used in PEP and ART, can be used to prevent the spread of HIV **after** it has already infected cells.

## How effective is oral PrEP?

When oral PrEP is taken every day, the amount of ARVs in the body builds up and reduces HIV vulnerability by more than 90%. Most people will be protected after they have been taking oral PrEP for seven days. It is important that anyone who begins taking oral PrEP speaks to their health care provider about how long they need to take the medication before it reaches maximum effectiveness. Also, for maximum HIV protection, it is important to use oral PrEP in combination with condoms whenever possible.

## Does oral PrEP protect against other STIs and pregnancy?

Oral PrEP does **not** protect against other STIs or pregnancy, which is why it is recommended to use condoms and contraception in combination with oral PrEP.

# Does oral PrEP provide protection against HIV when having anal sex? What about oral sex?

Because oral PrEP is systemic, meaning the ARVs are present throughout the body, oral PrEP does provide protection during anal and oral intercourse. A male condom (with water-based lubricant when possible) should also be used for protection from STIs when having anal sex.

# **GETTING ORAL PrEP**

Many countries have included oral PrEP in national HIV prevention guidelines, allowing it to be provided at health clinics and other provider platforms, such as mobile and community-based services. Review local guidelines so that you are able to provide accurate and up-to-date information about oral PrEP to training participants. If possible, it is a good idea to talk to a community partner who knows the status of oral PrEP availability in your community or invite them to the training.

To get oral PrEP, AGYW will need to have a negative HIV test, not have signs of acute HIV infection, and not have had recent possible exposure to HIV (and therefore need PEP vs a PrEP method). AGYW may additionally need to get testing for hepatitis B and kidney function to make sure it is safe to start oral PrEP. AGYW may be able to receive three months' worth of oral PrEP at a time and see their health care provider quarterly for HIV tests or do self-testing, or they may need to visit their provider more frequently, depending on local guidelines. Remember to check your most up-to-date local guidelines!

# TAKING ORAL PrEP

## How is oral PrEP taken?

Oral PrEP is a pill that is taken daily. It can be taken with or without food. Taking the pill at the same time each day can make remembering to take it easier.

Although oral PrEP may still be effective for some populations when taken intermittently, it has to be taken **every** day to be effective for AGYW. If it is not taken daily, the ARV levels in the user will not be high enough to prevent HIV. It is important to emphasise this point, because studies show that AGYW may struggle with daily use of oral PrEP.

#### Are there any side effects?

Taking oral PrEP is similar to taking any other medication. Some people experience side effects, but for most people, they are minor and go away within a few weeks.

About one in 10 people who use oral PrEP will experience minor side effects, such as:

- Headache
- Weight loss
- Nausea
- Vomiting
- Abdominal discomfort

These side effects usually lessen with time or with a change in the time of day when the pill is taken. If AGYW are experiencing side effects, it is important for parents and guardians to support them to talk to a health care provider. In addition, parents and guardians can encourage oral PrEP users not to give up on taking the medication if they experience side effects. They can also offer moral support in dealing with these side effects.

If concerns about kidney or liver problems come up in conversations with peers or in the community, parents and guardians can say these are very rare side effects. If oral PrEP is affecting a person's kidneys or liver, the health care provider will most likely tell them to stop taking it. In most cases, the problem will resolve over time.

It is important to highlight that oral PrEP does not affect fertility. This is a common myth.

# Does oral PrEP interact with other medications, drugs, or alcohol?

Oral PrEP does not interact with contraceptives or other medications, drugs, or alcohol.

#### How is oral PrEP stored?

Oral PrEP should be kept in a cool, dry place, away from children, and in a tightly closed container.

#### What are the barriers to daily use?

AGYW can struggle with taking oral PrEP every day for a number of reasons, including:

- Fearing that if people find out they are taking oral PrEP, people will think they are living with HIV or discriminate against them
- Fearing that if their parents find out they are on oral PrEP, it will reveal they are sexually active
- Feeling the need to hide oral PrEP from their family and/or partner, making it difficult to take it regularly
- Finding it difficult to swallow the pill because it is larger than other pills they may be used to taking
- Getting tired of taking it every day

- Underestimating their vulnerability to HIV (research shows that people who think they need HIV protection are more likely to adhere to oral PrEP)
- Low awareness of and support for oral PrEP in the community, from parents and partners, and among other AGYW/their peers
- A poor understanding of how oral PrEP works
- Barriers to using health services, including repeat HIV testing and returning for oral PrEP refills
- A lack of support for daily use and managing side effects
- Changes in routine, such as being away from home

# How can parents and guardians support AGYW to use oral PrEP daily?

People use a variety of strategies to help them remember to take oral PrEP every day. Strategies will depend on an individual's situation, resources, and social networks. Strategies that parents and guardians could suggest to AGYW to take oral PrEP daily include:

- Taking the pill at the same time every day. Some AGYW report that they appreciate a reminder from their parents and guardians to take their pill.
- Incorporating the pill into their daily activities, for example, as part of their morning routine or when a favourite TV show comes on
- Setting a phone alarm
- Encouraging trusted partners, family members, or friends to remind them.
- Using daily pill boxes
- Keeping pills in a place that is easy to find
- Trying not to run out of oral PrEP completely by keeping a back-up supply
- Keeping their appointments with health care providers
- Practicing different ways of taking the pill to make it easier to swallow, such as placing the pill on their tongue, taking a sip of water, and bending their head forward before swallowing. If someone is still unable to swallow the pill, it is better to cut it in half and take both halves than to not take it at all. The pill should not be crushed.

People sometimes forget or skip a pill. If a person misses a pill, she can take it as soon as she remembers and continue to take it daily as before. It is safe to occasionally take two pills in one day.

If an adolescent girl or young woman is not sure whether she took her pill on a certain day, it is okay to take another pill. If she takes oral PrEP daily, she will still have high levels of protection if she occasionally misses a pill. If she usually misses more than one pill per week, she should think about other ways to help her take oral PrEP every day.

#### **STAYING ON ORAL PREP**

Oral PrEP can be used during periods in AGYWs' lives when they are vulnerable to HIV, and it can be stopped when their circumstances change. It is not a lifelong medication.

If an adolescent girl or young woman no longer feels vulnerable to HIV or wants to stop using oral PrEP for other reasons, she should speak to a health care provider.

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# How can parents and guardians support AGYW to stay on oral PrEP?

While AGYW may be enthusiastic when they first start taking oral PrEP, they may find it difficult to keep using it over time. Parents and guardians can support AGYW to keep taking oral PrEP by:

- Speaking with them to answer questions and address concerns
- Checking in with them regularly to see how they are doing and what challenges they are experiencing
- Supporting them with any side effects they are experiencing
- Suggesting that they find an oral PrEP buddy (someone who reminds them to take the pill and offers moral support) and supporting them to meet with that buddy
- Referring them to support groups for oral PrEP users, available through social media, virtual chat groups, and in person
- Suggesting they get oral PrEP refills through outreach services
- Recognising milestones (like having a "family celebration" for each month of successful oral PrEP use)

#### MYTHS AND FACTS ABOUT ORAL PREP

There are many myths about PrEP methods in general. These myths are listed in the PrEP Methods and Combination Prevention sections. Here are some common myths and facts specific to oral PrEP.

мутнѕ	FACTS
Oral PrEP can protect someone only if they are having anal sex.	Oral PrEP targets HIV. It is effective no matter how the virus is transmitted.
If a person takes oral PrEP and tests positive for HIV, then ART will not work; oral PrEP leads to ART resistance.	✓ The risk of developing HIV drug resistance with the use of oral PrEP is very small (<0.1%), especially if a client takes their pill every day and gets tested for HIV regularly.
Y Oral PrEP has terrible side effects.	All medication causes side effects in some people. About one in 10 people experience minor side effects when they first start using oral PrEP (such as headaches, weight loss, nausea, vomiting, and abdominal cramps). These side effects will usually go away in a few weeks. If a PrEP user experiences side effects, they should talk to a health care provider.
Oral PrEP will make a person infertile.	This is not true. It has been proven that oral PrEP has no effect on fertility (a person's ability to get pregnant or impregnate others).

мутнѕ	FACTS
• Oral PrEP reduces a person's sex drive.	There is no interaction between oral PrEP and a person's libido (sex drive). However, other factors may affect sexual pleasure, sex drive, or sexual performance, such as anxiety, alcohol consumption, or a lack of arousal.
X Oral PrEP reduces the effectiveness of contraception.	✓ Oral PrEP has no effect on any methods of contraception.
Oral PrEP interferes with other HIV prevention methods such as condoms and lubricants.	Oral PrEP has no impact on the effectiveness of condoms and lubricants. Oral PrEP complements other prevention efforts but does not protect against STIs or pregnancy, so correct and consistent use of condoms (with water-based lubricants when possible) strengthens prevention.
Because the oral PrEP pill is so big, it is okay to crush it or break it in half.	✓ It is definitely not advisable to crush the tablet. It is also not advisable to break it in half, because the dosage may be compromised (i.e., some of the pill may be lost). Some health care providers say that if the pill is not swallowable (some people just cannot swallow a large pill), it is better to cut it in half (without losing any of the pill) than not to take it at all. However, many pharmacists advise against this.
People can share oral PrEP pills with others.	Most definitely not! Anyone who wants to use oral PrEP must get tested for HIV and talk with a health care provider to make sure it is okay for them to use it.

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# **PrEP** Ring

#### **Prep RING BASICS**

#### What is the ring?

The dapivirine vaginal ring (we refer to it as 'the ring') is a method of PrEP that is inserted into the vagina to protect against acquiring HIV. The ring is made from a flexible silicone that is easy to bend and contains an antiretroviral (ARV) drug called dapivirine that is slowly released in the vagina. The ring needs to be removed and replaced with a new ring every month.

#### Who is the ring for?

The ring is an HIV prevention option for people who want protection from HIV during vaginal sex. It was recommended by WHO in early 2021 for women who are unable or unwilling to use oral PrEP, or in situations where oral PrEP is not available, in combination with other safer sexual practices. It can be offered as an additional choice for women as part of combination HIV prevention.

A nonprofit called the International Partnership for Microbicides developed the ring and is seeking approval of the ring in several countries in Africa. It is expected that countries that approve the ring would do so for women ages 18 and older, although it is possible that some could approve it for adolescent girls (i.e., those under age 18). The age will depend on the evidence generated in ongoing studies, and ages may vary by country. In this document, any references to ring use by minors apply only to those countries that have also approved the ring for those under 18.

AGYW need to make an informed decision about which HIV prevention methods they choose. A variety of factors may influence someone's choice — for example, although oral PrEP is more effective when taken daily, perhaps someone does not have access to oral PrEP or faces challenges taking a pill every day.

Because the ring can provide protection from HIV only during vaginal sex, condoms (and water-based lubricant when possible) should also be used during anal sex. For AGYW who regularly engage in anal sex, other PrEP options, such as oral PrEP, should be considered. The ring is also not recommended for AGYW who may be exposed to HIV through injecting drugs.

#### How does the ring work?

The ring slowly releases an ARV called dapivirine into the vagina. Dapivirine works by preventing HIV from making copies of itself inside the body. If the virus cannot multiply, there will not be enough of the virus for the user to get HIV. When the ring is in the vagina, it releases enough dapivirine to block HIV from multiplying. Dapivirine doesn't stay in the vagina for very long if the ring is removed, which is why it is so important to keep the ring in place continuously. After an explanation or demonstration, it is easy for a ring user to insert and remove the ring with her clean fingers.

When the ring is worn throughout the month without being removed, it can reduce HIV vulnerability from exposure through vaginal sex by about 50%. We will learn more about how well the ring can work as it is rolled out in the real world.

The ring will be most effective when it is kept in place continuously, and then immediately replaced with a new ring every month if one is still exposed to HIV. It does not need to be removed for cleaning or during menses.

The ring must be in place for 24 hours before it can provide maximum protection from HIV. A backup form of HIV protection, for example a condom or abstaining from sex, should be used for the first 24 hours after ring insertion. The ring cannot provide protection if it is not in place!

The ring releases dapivirine in the vagina, and very little dapivirine is absorbed into the rest of the body.

#### Does the ring protect against other STIs and pregnancy?

No, like oral PrEP, the ring provides protection only against HIV, not pregnancy or STIs. Therefore, reliable contraception and condoms (with water-based lubricant, if possible) should be used to prevent unintended pregnancy and STIs.

#### Does the ring provide protection against HIV during anal sex?

The ring does not provide protection from HIV during anal sex. It is designed specifically for vaginal intercourse and should never be inserted rectally.

#### Will male partners be able to feel the ring during sex? Will it be safe for male partners?

The ring does not harm the male partner or have any effect on the penis. It also does not provide HIV protection for the male partner.

Most people do not feel the ring during sex. Because it is possible to use the ring without informing male partners, some AGYW who wish to keep their PrEP use private may choose the ring. However, AGYW who use the ring should be prepared to respond if a sexual partner who is not aware of the woman's ring use feels "something" during foreplay. If a sexual partner feels the ring during sex, it is important to check whether the ring is properly placed.

Parents and guardians can help AGYW disclose ring use to their partners (if they choose to do so) by giving them complete and correct information about the ring and how it works.

#### Are there any side effects?

Using the ring is like using any other medication. Some people will have side effects, which are usually minor to moderate and go away after a few days without ring removal. Although they are uncommon, possible side effects from the ring include urinary tract infections, discomfort of the vagina and/or area outside the vagina (vulva), changes in vaginal wetness or odour, increased itching, or pain in the lower part of the belly. No safety concerns were seen with long-term use of the ring. If a user experiences vaginal changes while using the ring, it is important that she visit her health care provider to make sure these are not symptoms of an STI.

#### Will the ring make AGYW less fertile?

The ring has no impact on hormones and has no effect on fertility. The ring does not cause STIs or cervical cancer. Because the ring does not prevent pregnancy, anyone using the ring who does not want to become pregnant should also use contraception.

#### Are there any other health concerns about using the ring?

In studies, no safety concerns were seen during long-term use among women who used the ring for two years or more. There is no evidence that the ring increases the risk or severity of STIs; however, because the ring does not prevent other STIs, a condom should also be used. Testing and treatment for STIs can be done while using the ring.

#### Is it possible to use the ring while pregnant?

Information from multiple studies has not shown any safety concerns to ring users or their infants as a result of brief use of the ring in early and late pregnancy. A small study of breastmilk among ring users who had weaned their infants showed no safety concerns and indicated that only very small amounts of dapivirine got into breastmilk. Studies to confirm the safety of the ring during all stages of pregnancy and breastfeeding are ongoing.

#### Does the ring need to be taken out to be cleaned?

The ring does not need to be removed or cleaned during the month. The ring should be kept in place all the time and does not interfere with daily activities such as bathing, sex, and menses. However, if a ring user does remove the ring to clean it, she should use only clean water to rinse it, and then reinsert the ring immediately. Douching, or washing inside the vagina, is not recommended at any time — including when the ring is in use. The vagina is self-cleaning and douching may interrupt this natural process.

#### What about wearing it during menses?

The ring will not have any impact on the timing, frequency, or volume of blood during menses; it does not block menstrual flow. It is okay to use the ring and tampons or the menstrual cup (or the "moon cup") at the same time. Menstrual bleeding may change the colour of the ring, but this is okay and will not change the ring's ability to protect the user from HIV. If menstrual changes occur, parents can support their AGYW to speak to a provider about possible causes, such as contraception.

#### What about wearing it during pregnancy or while breastfeeding?

Studies about brief use of the ring early and late in pregnancy have shown no safety concerns to the mother or baby. A small study of mothers who weaned their infants but were still producing milk showed no safety concerns to the mother and only very small amounts of dapivirine got into breastmilk. Studies to explore the safety of the ring during all stages of pregnancy and breastfeeding are ongoing.

#### Are there other ways to use the ring?

The ring has only one purpose: to protect against acquiring HIV. It is designed to be used in one way only: by inserting it in the vagina and keeping it in place for one month.

#### **GETTING THE PrEP RING**

In countries that approve the ring, it will be introduced in different ways and on different timelines. After the ring is approved in a country, other steps will still be needed before the ring could be available in health clinics or through other platforms. In addition, it will most likely be provided at specific clinics first and gradually rolled out to others, so getting the ring will be an evolving process. Review local guidelines so that you can provide accurate, up-to-date information about the ring to training participants. If possible, it is a good idea to talk to a community partner who knows the status of ring rollout in your community or invite them to the training.

Each country that approves the ring will develop its own clinical guidelines. It is likely that countries will require a negative HIV test and confirmation that the new user does not have signs of acute HIV infection or a recent possible exposure to HIV (and therefore need PEP instead of a PrEP method). It may be possible to receive up to three months' worth of rings at a time and have HIV tests quarterly. Negative HIV tests will be needed to continue using the ring. Similarly, some countries may also require regular pregnancy testing. Remember to check your most up-to-date local guidelines!

#### **USING THE PREP RING**

#### How is the ring used?

The ring is one size fits all. It is easy to insert. An adolescent girl or young woman can insert the ring herself or, if she wants help, her health care provider can insert the ring for her or check its placement inside the vagina. It sits in the vagina, just below the cervix. Like a tampon, the ring cannot move past the cervix or get "lost", and it does not dissolve or change size in the body. The ring is able to stay in place because its shape is firm enough to "hug" the sides of the vagina and not slip out. Parents and guardians should be familiar with how to insert and remove the ring so that they can answer questions and guide AGYW who are thinking about using the ring. The rings will come packaged in a box either individually or as a set of three, depending on how many can be supplied at one time. Each individual ring will be in a sealed, foil pouch that must be carefully torn or cut open (similar to a condom wrapper).

#### How long can the ring be used?

The ring may not work to prevent HIV if it is not replaced every month, so AGYW should not use the same ring for more than one month. Only one ring should be worn at a time.

Parents and guardians can support AGYW to continue using the ring month after month as long as that is their chosen HIV prevention method. There is no problem with using the ring as an HIV prevention method over the long term.

# What if an adolescent girl or young woman wants to stop using the ring?

AGYW should be empowered to use HIV prevention methods during times when they feel vulnerable to HIV. PrEP methods do not have to be used for someone's whole life! A user can remove the ring herself when she wants to stop using it. Once the ring has been removed, she is no longer protected. Parents and guardians can help AGYW who want to stop using the ring — and switch to a different HIV prevention method such as oral PrEP, if they choose — by giving them information and linking them to a health care provider, if needed.

# What about stopping the ring and switching to another PrEP method?

Parents and guardians can help an adolescent girl or young women switch to another PrEP method by making sure she sees a health care provider to get the right testing for and access to the PrEP method before she stops using the ring, so that she can begin using the new method as soon as she removes the ring. It is important to be aware of how long it takes to be protected after starting the new method, so extra precaution should be taken during this time, such as using condoms (with lubricant when possible).

#### Can the ring and oral PrEP be used at the same time?

The safety and effectiveness of using oral PrEP and the ring at the same time has not yet been studied. Based on what is known about oral PrEP and the ring, it is not likely that there are safety concerns about using both products at once. However, more information is needed about whether using both products at the same time is safe, and it is not known if using both products provides more protection from HIV. It is best for AGYW to choose the HIV prevention method that works best for them, so that they can use it correctly and consistently.

#### What happens if the ring comes out accidentally?

While it is not likely, the ring may come out accidentally, for example, during menstruation, during a bowel movement, when removing a tampon, or if not inserted correctly. If this happens in a clean environment (such as in bed or in the user's underwear) and the ring does not touch anything dirty (for example, the toilet or dirty ground), then the ring can be rinsed with clean water and immediately re-inserted. If it touches something dirty, or if the woman is not sure, then she should discard it and re-insert a new ring as per instructions.

#### How is the ring disposed of when finished?

Used rings should be placed in the foil wrapper (either its original or the empty one of the new ring), tissue, or toilet paper and disposed in a trash/rubbish bin that is kept away from children and animals. DO NOT throw rings in a flushing toilet or burn them. Hands should be washed after handling the used ring. When it is time to replace the ring, it is important to get the new ring before the old one is thrown away to make sure that a ring is in place at all times.

#### How is the ring stored?

If they are not being worn (for example, when someone has a three-month supply), rings should always be stored in a clean, cool, dry place, not in direct sunlight, and away from children and animals. Extra rings should be kept in the unopened foil packaging until used, to make sure they stay clean. If the ring is removed from its foil package and not used right away, the ring should be placed back in the foil package and stored in a clean bag or wrapped in a tissue. Ideally, the ring should always be kept inserted to provide maximum protection against HIV acquisition. Women can also store unused rings (still in the foil packaging) in a small purse or toiletry bag.

# Does the ring interact with other medications, drugs, or alcohol?

Only small amounts of dapivirine are released from the ring, so interactions with medication or other chemicals such as alcohol are unlikely. AGYW should be reminded to keep safe when drinking or using drugs and, if having sex, to make sure to use condoms to protect against other STIs and pregnancy.

#### Can contraception be used when using the ring?

The ring does not prevent pregnancy, so it is important for AGYW who do not want to become pregnant to use contraception as well. The ring can be used with most types of contraception, such as an intrauterine device (IUD), oral or injectable contraceptives, or female condoms, with no complications. The IUD is placed up in the uterus past the cervix and away from vagina where the ring sits. Female condoms sit below the ring in the vagina.

However, the dapivirine ring should NOT be used with other vaginal rings, such as the contraceptives NuvaRing® or Annovera.

#### Can condoms be used when using the ring?

Yes, the ring can be used with either male or female condoms.

#### What are the barriers to consistent use?

The ring is most effective when it is left in the vagina continuously for a month, and then taken out and immediately replaced with a new ring.

Barriers to using the ring vary from person to person, and may include:

- Discomfort with inserting the ring into the vagina, concern about inserting it correctly, or anxiety about the ring coming out
- Trouble inserting the ring into the vagina on their own, for example, those with longer fingernail styles or who have limited mobility
- Discomfort from side effects, such as urinary tract infection, discomfort in the vagina, vaginal itchiness, or pelvic pain, and lack of support to manage these side effects
- Concerns about hygiene when wearing the ring during menses or having it inserted without cleaning it for a month
- Underestimating the likelihood they could acquire HIV (research shows that people who think they need an HIV prevention method are more likely to consistently use their chosen method)
- Concerns about or beliefs that male partners may not support their partners using HIV prevention methods or that male partners might think the ring would interfere with sex
- · Concern about others finding out that they are using the ring and judging them for having sex
- Low awareness of and support for the ring in the community, from parents or partners, or among other AGYW
- · Low understanding of how the ring works
- Barriers to regular visits to a health facility to obtain ring refills

# How can parents and guardians support AGYW to use the ring consistently?

Women use a variety of strategies to help them use the ring consistently. The strategies and support needed will depend on an individual's situation, resources, and social networks. Support that parents and guardians could provide to help AGYW use the ring consistently include:

- Using models or animations to demonstrate how to insert the ring correctly and to remove and reinsert it if the ring's position in the vagina is causing discomfort
- Reinforcing that the ring can be worn comfortably without disrupting daily activities and should not be removed during sex, menses, or any other activities
- Helping with ways to remember to replace the ring each month, which could be reminders on a phone or in a diary or a note in a place where it will be seen each day, such as on a mirror
- Helping AGYW access information on available HIV prevention options, choose the methods that work best for them, or change their method or personal HIV prevention plan if needed
- Providing information to key stakeholders, community influencers, and males and helping to sensitise people about the ring
- Encouraging AGYW to keep appointments with health care providers
- Correcting myths and incorrect information about the ring in their communities

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#### **STAYING ON THE PREP RING**

The ring can be used during periods in AGYWs' lives when they may be likely to acquire HIV, and it can be stopped if their circumstances change or if they would like to try another prevention method. Ring use is not a lifelong commitment.

If a user wishes to stop using the ring, they can remove it. After the ring is removed, dapivirine does not stay in the body for long, so it is important to discuss other HIV prevention and SRH needs and options with a health care provider.

#### How can parents and guardians support AGYW to stay on the ring?

Some AGYW may be enthusiastic when they first start using the ring, and then face challenges to continuing to use it over time. Parents and guardians can support AGYW to keep using the ring by:

- Texting with them to answer questions and address concerns
- Checking in with them regularly to see how they are doing and what challenges they are experiencing
- Supporting them through any side effects they are experiencing
- Helping them find a ring buddy (someone who reminds them to replace it every month and offers moral support)
- Creating or referring them to support groups for ring users, including in-person and virtual groups using social media
- Suggesting they get ring refills through outreach services, if the ring is approved in their country
- Recognising milestones (such as having a special "family celebration" after three months of ring use)
- Reassuring AGYW that there are no safety concerns about long-term use of the ring and linking them to health providers if they have more questions

#### **MYTHS ABOUT THE PrEP RING**

МҮТНЅ	FACTS
X The ring can protect someone no matter how they are exposed to HIV.	The ring is only effective against HIV transmission during receptive vaginal sex because the medication is released only into the vagina. The ring does not protect against exposure from anal sex, oral sex, or injection drug use.
If a person uses the ring and tests positive for HIV, then ART will not work; the ring leads to ART resistance.	So far, there is no evidence that the ring increases resistance to HIV treatment medication. This is an important topic, and the ring's developer will continue to study it.
X The ring has terrible side effects.	✓ All medication can cause side effects in some people. With the ring, some people experience minor to moderate side effects when they first start using it (urinary tract infections, discomfort of the vagina and/or area outside the vagina [vulva], changes in vaginal wetness or odour, increased itching, or pain in the lower part of the belly). These side effects usually do not last long, and most women continue to use the ring without having to remove it. However, anyone using an HIV prevention product should talk to their health care provider if they experience health changes to make sure they can be tested and treated for STIS.
The ring will make a person infertile.	This is not true. The ring has no effect on fertility (a person's ability to get pregnant).
X The ring causes STIs.	The ring does not affect the likelihood of getting an STI. However, the ring does not protect against other STIs, so condoms should be worn with the ring to prevent STIs.
X The ring causes cervical cancer.	The ring does not cause cervical cancer or any other type of cancer.
X The ring will affect sex.	The ring should be kept in during sex. It does not change a person's libido (sex drive). Most women and their male partners say that they could not feel the ring during sex and that it did not affect their sexual pleasure. In fact, some women report that the ring increased sexual pleasure.
X The ring reduces the effectiveness of contraception.	The ring has no effect on contraception, but it should not be used at the same time as contraceptive vaginal rings such as Nuvaring or Annovera.

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MYTHS	FACTS
The ring interferes with other HIV prevention methods such as condoms and lubricants.	The ring has no impact on the effectiveness of male or female condoms and lubricants. The ring complements other prevention efforts, but it does not protect against STIs or pregnancy, so using the ring with correct and consistent use of condoms (with water-based lubricants when possible) strengthens protection.
X The ring will get lost in my vagina or stretch it out.	The ring, like a tampon, stays in the vagina and is blocked by the cervix from moving higher up in the body. The ring is flexible and hugs to the size of the women's vagina; it does not change the size or shape of the vagina.
The ring will get dirty if left it in all month without cleaning.	The ring is designed to stay in the vagina for a whole month without needing to be removed to be cleaned, even after sex or during menstruation. When the ring is removed after one month, a woman may see some stains, but this is normal! Staining can happen when natural body fluids come into contact with the ring, but they have no effect on the ring's effectiveness or the health of the vagina.
<b>X</b> People can share rings with others.	Most definitely not! Rings should not be shared. Anyone who wants to use the ring must get tested for HIV and see a health care provider to make sure it is okay for them to use it.

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# Further resources for facilitation

#### PRETEST AND POST-TEST

#### **True or False**

The statements below are about oral PrEP. Some are incorrect and some are correct. Please put a check mark ( ) in the box next to each correct statement.

- □ Oral PrEP protects against pregnancy.
- □ Oral PrEP protects against sexually transmitted infections other than HIV.
- □ If someone is taking oral PrEP, they do not need to use condoms.
- Gender inequality and violence make it more difficult for adolescent girls and young women to protect themselves from HIV.
- □ Oral PrEP is for people who are HIV negative.
- □ Oral PrEP has no effect on fertility.
- □ Oral PrEP is very safe when taken correctly.
- □ Oral PrEP has limited side effects.
- □ Oral PrEP is very effective against HIV infection when used correctly.
- □ Oral PrEP needs to be taken every day to be effective.
- □ The PrEP ring should be replaced every month.
- □ Once you start taking oral PrEP, you must take it for the rest of your life.
- Everyone using oral PrEP plans to have many sexual partners.
- □ Parents and caregivers who support their adolescent girls' access to oral PrEP can help their adolescent girls remain HIV negative.
- □ When parents talk to adolescent girls about oral PrEP, it can help those adolescent girls stay safe and healthy.
- □ New methods of PrEP may become available soon.

#### Matching

Please draw a line to match the HIV prevention or treatment medicine on the left with the correct description of the medicine on the right.

<b>ART</b> (antiretroviral therapy)	
<b>PrEP</b> (pre-exposure prophylaxis)	
<b>PEP</b> (post-exposure prophylaxis)	

	Taken by HIV-negative people after exposure to HIV to prevent HIV infection
5)	Used by HIV-positive people to treat HIV
s)	Used by HIV-negative people to prevent HIV acquisition

#### ANSWER KEY FOR PRETEST AND POST-TEST

#### **True or False**

Facts have checkmarks ( $\checkmark$ ) in the box next to the statement.

- □ Oral PrEP protects against pregnancy.
- □ Oral PrEP protects against sexually transmitted infections other than HIV.
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- Everyone using oral PrEP plans to have many sexual partners.
- Parents and caregivers who support their adolescent girls' access to oral PrEP can help their adolescent girls remain HIV negative.
- When parents talk to adolescent girls about oral PrEP, it can help those adolescent girls stay safe and healthy.
- Vew methods of PrEP may become available soon.

#### Matching

Answers are in bold.



#### HANDOUTS

### PrEP, PEP and ART

**Antiretrovirals** are a type of medication that make it harder for HIV to attack the cells in a person's body and spread to other cells. PrEP, PEP and ART use different combinations of antiretrovirals that work in different ways to fight the virus at different stages. PrEP, PEP and ART cannot be swapped — they only work when used as prescribed.

ANTIRETROVIRAL MEDICATION

#### **PrEP** (Pre-Exposure Prophylaxis)

#### WHO IS IT FOR?

People who don't have HIV and want to protect themselves from getting it.

#### HOW DOES IT WORK?

PrEP protects a person from HIV by creating a shield around the cells that HIV tries to attack.

#### WHEN IS IT USED?

During periods in a person's life when they're vulnerable to HIV.

#### HOW EFFECTIVE IS IT?

When PrEP methods are used correctly and consistently, the medication is most effective at preventing HIV. Levels of effectiveness vary by method. PEP (Post-Exposure Prophylaxis)

#### WHO IS IT FOR?

People who are worried they've been exposed to HIV in the past 72 hours.

#### HOW DOES IT WORK?

It stops HIV from spreading to other cells. When HIV can't spread, it dies.

#### WHEN IS IT USED?

PEP must be started within 72 hours of exposure and taken every day for 4 weeks.

#### HOW EFFECTIVE IS IT?

It depends on a lot of things, but if someone starts taking PEP straightaway and they take it every day for 4 weeks, there's a high chance it will prevent them from becoming HIV positive. ART (Antiretroviral Therapy)

WHO IS IT FOR? People who are HIV positive.

#### HOW DOES IT WORK?

ART involves taking a combination of HIV medication (antiretrovirals) that reduces the amount of HIV in a person's body and boosts their immune system.

#### WHEN IS IT USED?

People with HIV should start ART as soon as possible.

#### **HOW EFFECTIVE IS IT?**

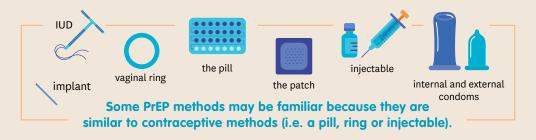
It's different for everyone, but if a person begins ART soon after they get HIV, they have the best chance of living a long and healthy life. It can also stop the virus from being transmitted to others.

#### **Expanding Options to Fit Our Lives**

Just like contraception comes in many different options to meet different people's needs and preferences, more HIV prevention options are also on the way. PrEP methods will continue to be developed to provide people with options so that can make an informed choice for what works best for them.

**Comparing PrEP methods** and condoms: **PrEP Methods Oral PrEP** Ring Injectable Condomo On-demand for sex; placed on the penis (male condom) or Pill taken Vaginal ring replaced Injection given How Þ in the vagina/rectum it's used daily each month every 2 months (female/internal condom) Vaginal/anal area Site Whole body Vaginal area Whole body †ŕ depending on type of sex of action (systemic) (localised) (systemic) (localised) Role of male Woman initiated; Woman initiated; Woman initiated; ð Male partner consent required partner use use can be private use can be private use can be private Over 90%, About 50%, Over 99%, Over 90%. How effective for when used correctly when used correctly when used correctly when used correctly **HIV** prevention (with lubricant) and consistently and consistently and consistently Protection Yes, if used correctly each against STIs NO \* NO \* NO \* and every time one has sex and pregnancy Available in Available in Not vet available: Availability Widely available most countries some countries not yet approved (check local guidelines) (check local guidelines)

PrEP methods should always be used in combination with a condom and a reliable method of contraception if possible. Future MPTs in the form of a pill or ring will be able to protect against HIV and pregnancy.



#### Answering Your Questions — Oral PrEP

#### Hi! I'm an HIV Prevention Ambassador. Do you have any questions about oral PrEP?



It's a medication that an HIV-negative person can take to protect themselves from HIV.

The word **PrEP** stands for **Pre** (before) **Exposure** (coming into contact with the virus) **Prophylaxis** (medication to prevent an infection from happening).

#### How does it work?

Oral PrEP creates a shield around your blood cells to protect them from HIV. Because HIV cannot infect these blood cells, the virus dies.

#### How effective is it?

If you take it every day, it will build up in your system and become over 90% effective at preventing HIV. Talk to your health care provider to find out how long you need to take it before it will protect you from HIV.

#### Is oral PrEP right for me?

That's your decision. It's your body, so it's your choice! You might consider oral PrEP if you're having sex and you want an additional method to protect yourself from HIV. PrEP methods only need to be used during times in your life when there is a chance you may acquire HIV, and they have pros and cons for different people — so it is important to discuss your HIV prevention plan with your health care provider so that you can make an informed choice.

#### Will oral PrEP protect me from other STIs and pregnancy?

No! Oral PrEP will not prevent other STIs or pregnancy. It's best to use condoms and contraception with oral PrEP.

#### Are there any side effects?

Oral PrEP is just like any other medication. A small number of people experience minor side effects like headaches, weight loss, nausea, vomiting or abdominal pain, but these will likely go away in a few weeks.

#### Can I take oral PrEP if I'm taking other medications?

Yes. Oral PrEP does not interact with most other medications. But let your health care provider know about all the medications you are taking.

#### If I take oral PrEP, does that mean I can't drink or take drugs?

Alcohol and other drugs won't affect oral PrEP. But make sure to keep yourself safe when drinking or using drugs. If you're having sex, make sure to use condoms to protect yourself from other STIs and pregnancy.

#### What do I need to do if I want to take oral PrEP?

The first step is to see a health care provider. They will help you take the next steps.

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#### **Answering Your Questions — Ring**

Hi! I'm an HIV Prevention Ambassador. Do you have any questions about the ring?

#### What is the ring?

It's a flexible silicone ring that contains the ARV dapivirine and provides a way to reduce the risk of HIV infection. The ring is inserted into the vagina and worn for a full month before being replaced. It is designed to be easily inserted and removed by the user.

The ring slowly releases dapivirine into the vagina over the course of the month. Dapivirine works by stopping HIV from making copies of itself in the body. Because HIV cannot replicate in the body, there will not be enough of the virus for you to get HIV.

#### How effective is it?

How does it work?

If you wear the ring continuously and replace it each month, the ring can reduce the chance of getting HIV through vaginal sex by about 50%. The ring must be in place for at least 24 hours to provide maximum protection from HIV, and dapivirine quickly leaves the body after ring removal. Therefore, it is important to use a back-up form of HIV protection, like a condom or abstaining from sex, for the first 24 hours. Keep the ring inserted at all times until it is replaced each month.

#### Is the ring right for me?

It's your body, so it's your choice! You might consider the ring if you are having vaginal sex and want to protect yourself from HIV but cannot get or use daily oral PrEP consistently. It is also a discreet option that no one has to know about! PrEP methods only need to be used during times in your life when there is a chance you may acquire HIV, and they have pros and cons for different people. It is important to discuss your HIV prevention plan with your health care provider to make an informed choice.

#### Will the ring protect me from other STIs and pregnancy?

No! The ring protects against HIV. For protection against other STIs and pregnancy, it's best to use condoms (with water-based lubricant, when possible) and contraception with the ring. The ring can be used with most family planning methods except the contraceptive vaginal ring.

#### Are there any side effects?

Some people experience side effects, such as urinary tract infections, discomfort of the vagina and/or area outside the vagina (vulva), changes in vaginal wetness or odour, increased itching, and pain in the lower part of the belly. These are usually mild and go away after a few days without removing the ring. If you experience vaginal changes while using the ring, it is important to visit your health care provider to make sure these are not symptoms of an STI.

#### Can I use the ring if I am taking other medications, or if I drink or use recreational drugs?

The ring is safe to use with alcohol and drugs. The medication in the ring when released stays local to the vaginal area; the medication does not circulate throughout the body. But make sure to keep yourself safe when drinking or using drugs.

#### Should I take the ring out for sex, bathing or during menses (monthly menstruation/bleeding)?

#### No.

- The ring does not need to be taken out to be cleaned.
- The ring will not affect frequency of menses, length, or amount of bleeding. It is safe to use tampons or a menstrual cup with the ring, and the ring will not block the flow of blood. Menstrual bleeding may change the colour of the ring, but this is ok and will not change the ring's ability to protect from HIV.
- The ring does not affect a women's libido (sex drive). Most women and men do not feel the ring during sex, and some even report that the increased vaginal wetness increases sexual pleasure!

What do I need to do if I want to use the ring?

The first step is to see a health care provider. They will help you take the next steps.

# that's easy to find Keep your pills in a place

spot, away from small children and in a dry area. Make sure you pick a safe



# 2 Use a daily pill box

the pill you need to take each day. This can help you keep track of

Se / M / Tu /W /Th /F/Sa

# Keep a back-up supply with you

keep it in your backpack or handbag. That way, to keep them dry and safe! one at work, school, or if you travel. Make sure you'll have them with you if you need to take Put some pills into a makeup bag or purse and



#### you brush your teeth time each day, like when Take the pill at the same 4 Take the pill as part of your daily routine

or at bedtime.



before swallowing. bending your head forward taking a sip of water and Try placing it on your tongue,



# 6 Set an alarm on your phone or use a pill reminder app

health care provider. keep notes about things you want to tell your get your refills. You can also use the app to a free pill app to remind you take your pills and Set a repeating alarm on your phone or download





your pill today Don't forget

# support group with friends Join or start an oral PrEP

so you can support each other. Some use social media or virtual chat groups. support groups meet in person, others Connect with other girls and young women You're not the only one using oral PrEP.







# Keep appointments with your health care provider

if you're having trouble taking the pill every day them. Your health care provider can also help care provider about how to reduce or manage If you're having side effects, talk to your health

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# **Fips for Using the PrEP Ring**

#### Set a reminder ring each month. to replace the 9:28 85

- Reminders could be on your phone, diary, or a note in a place you look
- Set reminders to request more rings things you want to tell your health use your phone to keep notes about from your provider. You can also each day, like on a mirror.

care provider.



# It is always good to have a back-Keep back-up rings.

provider to see if you can receive Check with your health care comes out without you noticing. out in an unhygienic place or up supply in case the ring comes more than one ring at a time.



#### care provider. your own. It is easy! And if you inserting and removing Get comfortable with health care provider. Practice on when you are not near your falls out or has to be replaced this yourself in case the ring learn to feel confident in doing can do it on your own. have questions, ask your health to insert and remove. You can The ring is designed to be easy the ring so that you



#### support group with Join or start a ring You're not the only one friends.

using the ring. Connect or virtual chat groups others use social media groups meet in person. other. Some support can support each young women so you with other girls and



ω

Store your back-up children and animals. place away from rings in a dry, coo

privacy. It's best to store unused rings in their original foil their rings in a small change purse or toiletry bag for more and not in direct sun. Some women like to hide or carry small children and animals. The location should be dry packaging unopened, to keep them clean. Make sure you choose a safe, private spot, away from

# Only remove the ring if you are replacing it.

your health care provider for support If you are having discomfort while using the ring, contact insert but firm enough to 'hug' the vagina to stay in place. up into the vagina. The ring is flexible enough to easily discomfort, use your fingers to adjust it or push it further you if it is not in place in your vagina. If the ring is causing bathing or menses or to clean. The ring cannot protect Remember, the ring does not have to be removed for sex.

Use your fingers to adjust it



Always have clean hands when inserting harmful bacteria. If the ring falls out in

anything in the vagina to avoid introducing

a clean place such a bed or underwear,

and removing the ring.

Use clean hands when inserting

unused ring with others. Everyone should see their health care provider to get their own rings Never share your used or

00

toilet/latrine, replace it with a new ring.

ring has been somewhere dirty, such as a rinse with water before reinserting. If the

#### **SCRIPT FOR ACTIVITY 3**

Woman 1: It's so good to see you! It's been so long!

- Woman 2: I know! It is wonderful to see you! And oh my, your daughter is looking so grown!
- Woman 1: Yours too. It's nice for them to go and be together and for us to catch up.
- Woman 2: Tell me. How are things going for you all?
- **Woman 1:** We are well. My daughter is doing well in school and her scores on the latest exams were very good. We are so pleased, and we think she will be able to go to the local university next year.
- **Woman 2:** That is great! My daughter has her exams next year, but for now she is really involved in a girls' group and has become a leader there. She has come home with such interesting information.
- **Woman 1:** I always knew she would be a leader! What kind of information is she sharing with you?
- **Woman 2:** Well, she has been talking a lot about how girls can stay healthy and about preventing pregnancy. You know one of her friends fell pregnant last year, so this has been on her mind a lot.

Woman 1: Are you talking about Nancy?

Woman 2: Yes! Exactly.

- **Woman 1:** It is such a shame! Nancy was only 15 when she fell pregnant. I know her parents. They were so sad and angry when she could not keep attending school. And Nancy was so very smart. Or at least she seemed smart before she put herself in that situation.
- Woman 2: I'm sure she did not get into such a situation alone and I don't think we should place blame so quickly. I would hate for our words to harm her further when she is already going through so much. My daughter and I have been talking about how girls find themselves in situations like Nancy's. In my daughter's group, they talk a lot about how important it is to know ways to prevent pregnancy and HIV, that they should know of methods like condoms. I wonder if Nancy knew how to protect herself from pregnancy or had ways to do so. The clinic near her house is known for turning away girls who ask for condoms. Being smart can't help if you don't have access to information or services.
- **Woman 1:** OK, I see your point. All of this just makes me think about how scary this world is for our children! But do you think it is a good idea for them to be so informed about condoms? Aren't we telling them to go and have sex? And if the man doesn't want to use a condom or forces sex, what can our girls do?
- **Woman 2:** I know what you mean! I see things on the news, I hear things from my friends, and I worry so much for my daughter. But I must tell you, I think it's good for them to know more ways to protect themselves, other than abstinence. And like you said, they should know ways that don't depend on men always wearing condoms.

Woman 1: Like what?

- Woman 2: I am thinking about family planning methods like birth control pills and about HIV prevention like oral PrEP. You and I both know about family planning, but do you know about oral PrEP? I didn't until my daughter told me, and then I read about it myself. Oral PrEP is a pill that one can take to prevent them from getting HIV. So if something happens, if a condom isn't used, my daughter would still be protected from HIV.
- **Woman 1:** But do you really want your daughter to have access to such things? If there are no consequences for her actions, aren't you worried she will begin to have many sexual partners?
- **Woman 2:** Well, I trust my daughter to think about her actions and to remember the lessons and values we've shared with her. But I also don't want one action to end up with a lifetime of consequences. Think about some of the things we did when we were younger.

#### BREAK FOR FIRST DISCUSSION

- **Woman 1:** What are you talking about? Things we did!?!? Like what!?! I never even had boyfriends. You know that!
- **Woman 2:** I am not talking about boyfriends. Remember the time you decided to swim across the lake that was near our village? You managed to make it across, but we all thought you were going to drown and none of us could get to you to help. You told me later that you were scared and unsure if you could make it.
- Woman 1: Oh! I think about that day a lot! It could have been awful.
- **Woman 2:** I know! You were smart, but you still did this thing that could have carried very serious consequences. Almost all of us do such things at sometimes in our lives. Wouldn't it have been better to have a life preserver with you? A way to make sure that this one tiny decision didn't end badly?
- **Woman 1:** I do think about that day a lot and how lucky I was to make it across. I don't know what made me decide to try. Maybe I just didn't think it all the way through. It still makes me shiver!
- Woman 2: Exactly! And I know that you had no boyfriends, but you got married at 18. You hope that your daughter will go to university at 17. Are you sure she will have no boyfriends during all the time she studies? Depending on what she studies, she could be in school for another five years! Wouldn't it be better for her to know about some "life preservers" in case she comes to a time when she could benefit from them? That is how I think of PrEP.
- Woman 1: And your husband, what does he say?
- **Woman 2:** Well, his dream is to have our daughter join him in his business. When I first talked to him about what our daughter was learning about PrEP and contraception and how it could help alleviate some of our worries for her, he was worried about what other people would think.
- Woman 1: Exactly! People could say that she is promiscuous!
- **Woman 2:** Yes, but we would know that she is just being smart and staying healthy. And now he sees both PrEP and contraception as ways she could protect herself and shape her own future. For both of us, what other people think isn't so important as our daughter's health or her ability to live her own dreams, and maybe even be her father's business partner. Plus, how would anyone else know what medication she takes if we are not telling others?

Woman 1: But truly, if your neighbours find out, what would you do?

- **Woman 2:** People will always find something to talk about! But I know myself and my intentions. I will share that PrEP is to keep my daughter healthy, which is what every parent wants for their children. We taught her to use mosquito nets, to wash her hands, to get vaccinated... PrEP is one more thing that can protect her health.
- Woman 1: So, is your daughter using PrEP now?
- **Woman 2:** Not yet. But she asked if I would go to the clinic with her in a few weeks, so that we could both ask the doctor some questions about it. My daughter is very informed, but I want to hear directly from an expert. So, we will go and hear what there is to know, and then my daughter will decide if it's something that she wants to use now or just know about for later.
- **Woman 1:** That is a good point. If you don't learn about it before you need it, when you do need it, it could be too late to use it... just like a life preserver.
- **Woman 2:** Exactly. Which could be a good reason to talk to your daughter before she goes to university. Or even before she goes back to boarding school.
- **Woman 1:** Uf! But how do I even bring this up? Your daughter brought the information to you instead of you having to tell her.
- **Woman 2:** Well, I can tell you the name of the clinic and you all could go together to hear about the options. Then your daughter knows that she has your support if she wants to use PrEP or contraception or both now or in the future.
- **Woman 1:** It would be nice to worry about one less thing in this world where so much seems to be on our children's shoulders.
- Woman 2: It's very true. Taking one worry off of them and off of ourselves is very welcome.

BREAK FOR SECOND DISCUSSION

#### **IMAGES FOR ACTIVITY 5**

#### Negative communication image 1



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#### Positive communication image 1



Negative communication image 2





Supplementary content for family strengthening programmes that support youth sexual and reproductive health

#### Positive communication image 2



#### **IMAGES FOR ACTIVITY 6**

Image 5



A father wants his daughter to be protected from HIV, but when he tries to bring it up, his own mother says that this will bring shame on the family because neighbours will assume the girl is promiscuous.



The young woman's father tells his mother that he would rather his daughter be healthy, and let people say what they will, than his daughter's health be unprotected and the neighbors be happy.



A health care provider tells a 16-year-old adolescent girl that it is not appropriate for her to use PrEP. The provider shames the girl for having sex. 69



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 come back for regular medical care. The parents ask what can be done so that this doesn't happen to other adolescents.



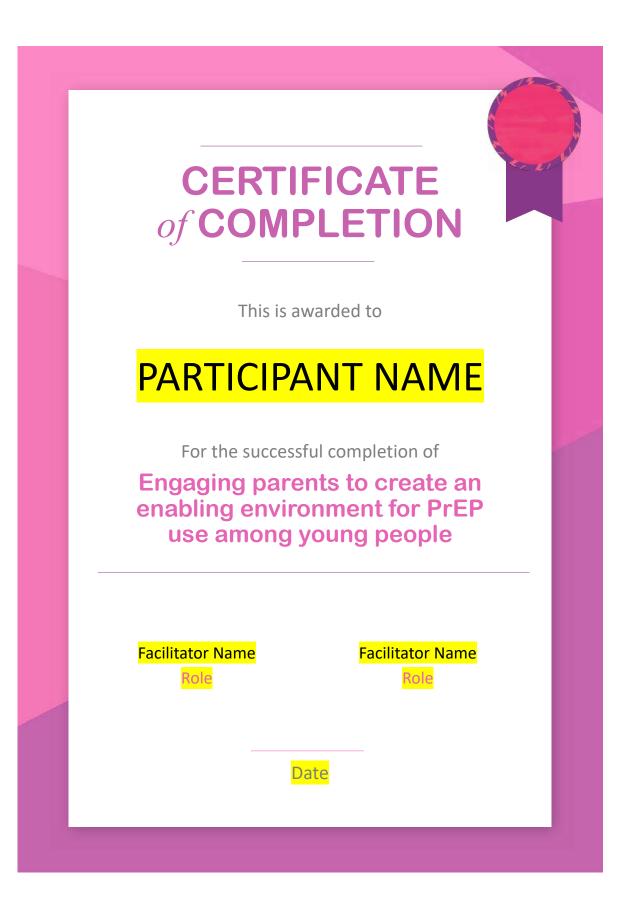
A mother's sister-in-law shames the woman for allowing her daughter to use PrEP, saying that she will become infertile. (Her husband sees this occur and wants to correct her and defend his family's choices.)

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The father supports his wife to share a pamphlet on PrEP with his sister. It explains how PrEP works and clarifies that it does not impact the ability to have children.

## CERTIFICATE



# Literature review on parents' role in AGYW's PrEP use

Parents can be an important part of AGYW's PrEP use. This is particularly true when young women live with their parents (Scorgie, 2021). While 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 (Scorgie, 2021; Camlin, 2020). Young women's reasons for telling parents about their PrEP use include wanting to ask their parents for permission, generally in keeping with social norms related to respect for elders, and wanting to disclose their PrEP use to explain trips to the clinic or the presence of PrEP products in the home (Scorgie, 2021). In some locations, parental consent is required for PrEP use by individuals younger than 18 (Taggart, 2019).

When parents do not understand what PrEP is, they may reject PrEP because they believe it is an HIV treatment or that it would lead to HIV acquisition (Scorgie, 2021; Giovenco, 2021). Yet, many parents are interested in and supportive of PrEP for their children once they understand what it is (Kidman, 2020; Hill, 2020). Parents of AGYW PrEP users reported feelings of relief that their daughter were protected and pride that their children were grown up enough to make such good decisions (Scorgie, 2021). Some AGYW reported feeling happy that they could alleviate their parents' fears about their daughters' health by disclosing their PrEP use. In many places — especially those with a high HIV prevalence — parental acceptance of PrEP was the rule and not the exception (Maykyao, 2018; Scorgie, 2021). However, parents in each setting will have different opinions (Koay, 2021; Scorgie, 2021). In some settings, parents raised concerns that their daughters would be perceived as promiscuous because they used PrEP, but most were still willing to support PrEP use (Makyao, 2018). The parents most likely to support AGYW PrEP use are those who knew that their daughters were sexually active or those who were living with HIV themselves (Scorgie, 2021).

Young women who tell their parents about their PrEP use report that this disclosure can be a positive and meaningful experience (Giovenco, 2021). It can also be supportive logistically; for example, young women who have disclosed PrEP use to their parents report relying on parents for reminders to take oral PrEP. Mothers versus fathers may use different support strategies. Mothers were more likely to note that they would create a supportive environment for their daughters' PrEP use — for example, by ensuring a good diet — while fathers expressed shame and embarrassment related to talking to their daughters to health centres (Makyao, 2018). When parents are not told about PrEP use, AGYW report that adherence is more difficult and they need to go to lengths to hide their PrEP. Many AGYW who felt they could not disclose their PrEP use shared struggles with taking oral PrEP or discontinuing use (Scorgie, 2021).

If parents do accept or support their daughter's PrEP use, it is important that they have the skills to vocalise this support (Scorgie, 2021). Young women decide whom to tell, or not tell, based in part on perceptions of acceptance. They may also ask a trusted parent or other adult to help them disclose their PrEP use to additional family members, if necessary. 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 (Giovenco, 2021).

In response to the literature, this module informs parents about PrEP and addresses common misconceptions. It normalises supporting PrEP use and stresses that PrEP use can alleviate some of both parents' and daughters' concerns about young women's health. Finally, it helps parents vocalise their acceptance of PrEP to both their daughters and to others who may misunderstand and/or stigmatise PrEP use.

# Findings from field dialogues on how to introduce PrEP to parents

As part of the CHOICE collaboration, LVCT Health in Kenya and PZAT in Zimbabwe — both of which implement AGYW PrEP programming — held field dialogues to gather input from stakeholders involved in PrEP and/or family strengthening activities as part of DREAMS programming. As outlined in Table 1, the stakeholders were: facilitators implementing family strengthening activities under AGYW programmes<sup>2</sup> (20); parents of AGYW participating in family strengthening programmes through DREAMS (46); and AGYW who were (29) and were not (34) using PrEP. The AGYW not using PrEP were eligible to use PrEP.

In total, there were two group dialogues and four individual interviews with facilitators, six group dialogues with AGYW using PrEP, and four group dialogues with AGYW not using PrEP. Results of these discussions, presented below, were gathered to inform the content and design of this module and are not intended to represent generalisable knowledge.

	<b>RESPONDENT TYPE</b>			
	Programme facilitators	Parents	AGYW using PrEP	AGYW eligible but not using PrEP
COUNTRY				
Zimbabwe	4	29	16	17
Kenya	16	17	13	17
PROGRAMME IN USE				
Families Matter!	20	46	N/A	N/A
Sinovuyo	0	0	N/A	N/A
AGE				
15-24	Not reported	0	29	34
25-44	Not reported	18	N/A	N/A
45-64	Not reported	19	N/A	N/A
65+	Not reported	9	N/A	N/A
SEX				
Male	9	21	N/A	N/A
Female	11	25	29	34

#### **Discussion participant demographics**

<sup>1</sup> The DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe) Partnership is an ambitious publicprivate partnership implemented by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and private sector partners — the Bill & Melinda Gates Foundation, Gilead Sciences, Girl Effect, Johnson & Johnson, and ViiV Healthcare — to reduce rates of HIV among adolescent girls and young women in the highest HIV burden countries. DREAMS is implemented across 15 countries: Botswana, Côte d'Ivoire, Eswatini, Haiti, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe.

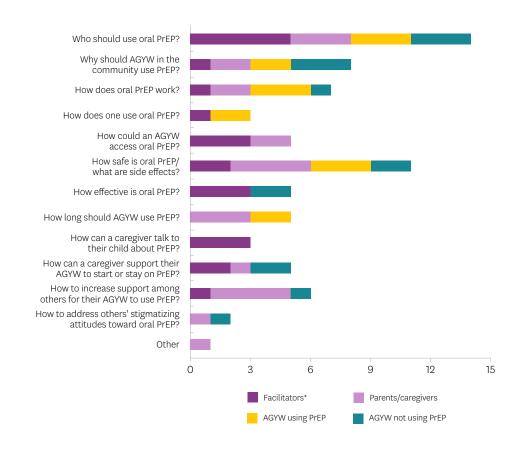
<sup>2</sup> This module can be added to any family strengthening programme that meets the criteria described under "Using this module", including the Families Matter! programme and Sinovuyo Teen, which are commonly used in DREAMS programming.

## CURRENT AND DESIRED KNOWLEDGE AND SKILLS RELATED TO PREP

To inform the module, it was important to understand existing knowledge on PrEP among parents so that it could be built upon and any misconceptions could be countered. Knowledge about PrEP among parents varied from very little to quite high. One group of parents confused PEP and PrEP, but at least one person in each parent dialogue group knew that PrEP is used to prevent HIV acquisition; in some cases, the majority of the group had heard of PrEP and understood its purpose. It was also important to understand what would make parents feel comfortable talking to their daughters about PrEP. Parents felt that communication skills, coupled with a close and open relationship with their child, would most positively affect discussions about PrEP.

To determine the specific content presented in the module, all participants were asked to identify the knowledge most important for parents to have about PrEP and the skills they most needed to discuss PrEP with AGYW. Figure 1 captures the opinions of each group regarding priority topics. The unit for each type of respondent is "dialogue group", except for dialogues with facilitators in Zimbabwe, where each facilitator completed an individual interview. (Responses were similar across countries and are presented in combination.) In Zimbabwe, respondents worked together as a dialogue group to select their top three answers. In Kenya, each participant selected as many of the answer choices as they wished, and analysts identified the three choices with the most votes. (In case of a tie, more than three priorities could come from one group.)

The options that dialogue participants chose from are listed in Figure 1. There were no major differences between countries.



#### Figure 1. Priority topics for inclusion in PrEP session for parents

\*Facilitator data reflects individual interviews in Zimbabwe and group discussions in Kenya

The table below goes into more details on the findings from this ranking activity, incorporating answers from open-ended questions on necessary knowledge and skills. The table then describes how these findings were used to inform the module.

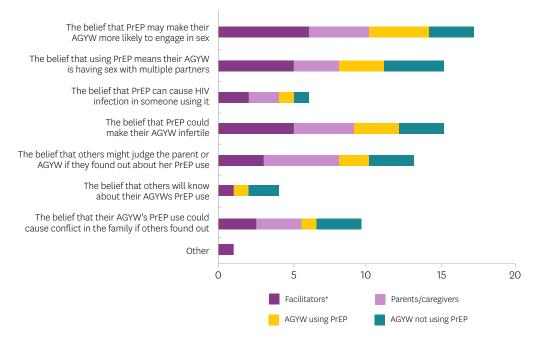
#### INCORPORATING PRIORITY KNOWLEDGE AND SKILLS INTO THE MODULE

Findings	Impact on the module	
Regarding knowledge, most respondents across all respondent types felt that parents should have knowledge on who can use PrEP, why someone would decide to use PrEP, and its safety and side effects.	This information is the focus of <b>activities 1 and 2</b> in the module, with opportunities to apply and reiterate this knowledge in <b>activities 3, 5, and 6.</b> If parents have remaining questions after <b>Activity 1,</b> they can be addressed by experts during the guest speaker activity ( <b>Activity 2</b> ).	
Regarding skills, most respondents reported that parents should have the ability to support their child to start or stay on PrEP and to increase others' support of AGYW's PrEP use.	<b>Activities 3, 5, and 6</b> focus on building skills to have conversations about PrEP with one's children and skills to encourage others' support of PrEP.	
One group of parents in Kenya requested advocacy training to help them raise awareness and support within their community for AGYW to use PrEP, stating that people need to know that PrEP use is not only for individuals engaging in sex work and that PrEP is needed by AGYW to stay healthy, similar to family planning.	Activity 3 describes PrEP as similar to family planning in terms of its utility in AGYW's lives. Activity 6 addresses raising support for PrEP in the broader community, including by countering stereotypes about who may decide to use PrEP.	
Not all AGYW felt comfortable telling their parents about PrEP use, but the majority of AGYW felt that disclosing was important and helpful to their PrEP initiation and effective use because:	The activities reiterate that PrEP use is ultimately an adolescent girl or young woman's decision but that parents can have a role to play. We share the specific opportunities for support described by AGYW in <b>Activity 5</b> and encourage parents to think about how they could engage in some of these supportive	
1) it would be hard to hide their PrEP use,	activities.	
2) parents could provide emotional support,		
and		
3) parents could provide them with reminders and help them manage side effects, including via nutritional support		

## **CONCERNS ABOUT AGYW'S PREP USE**

Following the same process described above, participants were asked to reflect on concerns that parents may have about potential content. This information was important to collect so that any major concerns could be addressed directly and clearly in the activities. Figure 2 describes their responses. Again, there were no major differences between countries.

#### Figure 2. Parents' concerns about their AGYW using PrEP



\* Facilitator data reflects individual interviews in Zimbabwe and group discussions in Kenya

Findings about concerns, some of which are specific to PrEP and others that span AGYW's sexual and reproductive health more broadly, and ways in which those concerns informed the module are summarised in the table below.

#### INCORPORATING PARENTS' CONCERNS ABOUT PrEP USE INTO THE MODULE

Findings	Impact on the module
All respondent types shared that they believed parents would be concerned that PrEP use either signifies that an adolescent girl or young woman has multiple sexual partners or that PrEP use will make her more likely to have sex. Related concerns about AGYW engaging in sexual behaviours that carry an additional risk of HIV transmission because they felt that PrEP would protect them were shared in the qualitative responses of all respondent types. Among AGYW who said they did not plan to tell their parents about their PrEP use (either current or future), the most commonly reported reason was that their parents would not accept that they were having sex. These AGYW feared that parents would believe they were "promiscuous".	The introduction directly counters this concern and includes a citation for a study refuting AGYW's "risk compensation", the idea that someone will engage in new behaviours if they are more protected. We do not include a myth versus fact sorting exercise, because activities to sort myth from fact have been shown to reinforce misinformation (Pluviano, 2017). Instead, we provide access to a medical expert (Activity 2) so that parents can ask about risk compensation if it is a concern, and we directly reference and address this concern in Activity 3.
The belief that parents would be concerned about infertility was also common across respondent types.	Participants can ask a health care provider about this concern in <b>Activity 2</b> and have the chance to challenge this misinformation in <b>Activity 6</b> . In <b>Activity 4</b> , a scenario shared as an example of the group work assignment explains how PrEP can actually make conception easier instead of more difficult.
The concern that parents may believe that PrEP can cause HIV infection was not one of the most commonly mentioned issues but was raised by all groups. In addition, in response to qualitative questions, concerns were raised about PrEP being confused for ART.	Literature further fleshes out this concern by noting that it may be connected to misperceptions that PrEP is taken by individuals living with HIV. To clearly describe PrEP within in the context of other HIV prevention methods, <b>Activity 1</b> provides a space to contrast PrEP with ARVs as well as other methods. In addition, <b>Activity 2</b> includes the opportunity for a provider to answer any questions and address any misinformation.

Findings	Impact on the module
All respondents also reported the concerns that others might judge a parent or young woman if her PrEP use were discovered and that AGYW's PrEP use could cause conflict in the family. Interestingly, these were reported as concerns more often by AGYW who were not using PrEP compared to those who were. In addition, facilitators believed that the potential for increased engagement in sex would be parents' biggest concern, and this was of concern to parents. However, parents' biggest concern was what others may think about their AGYW's PrEP use.	Activity 3 helps parents think about which concerns they have, why they have these concerns, and how these concerns can be addressed. Parents can then go on to use their skills to counter judgmental attitudes in Activity 6. Activity 2 also gives them the chance to ask an HIV Prevention Ambassador about her experiences with PrEP stigma and how it can be addressed. The activity that focuses on helping parents cope with and address others stigmatising attitudes (Activity 6) is one of those recommended for inclusion regardless of time constraints.
All groups of AGYW said that parent support would be important if available, but one group of AGYW not using PrEP mentioned it was culturally unacceptable even for mothers to discuss SRH with their daughters.	The base curriculum, to which activities on PrEP can be added, must include content on parents' role in their children's SRH. In addition, the PrEP activities describe parents who talk to their children about SRH as part of larger conversations regarding goals and dreams for their daughters ( <b>activities 3 and 4</b> ).
In some of the Zimbabwe parent groups, fathers stated that it was inappropriate/ taboo for fathers to discuss sex with daughters, but other groups including fathers did not mention this opinion. Fathers were also more likely to disapprove of their daughters' PrEP use than mothers were. (The fathers in Zimbabwe were older than the mothers, which may also have influenced the gap between their perspectives; <b>the mean age for male caregivers was 58 vs.</b> <b>46 for female caregivers.</b> ) In Kenya, the parent groups were mixed sex and fathers' versus mothers' opinions did not seem to differ widely but may have influenced one another. However, one mixed sex group in Kenya said fathers could talk to their sons about PrEP/SRH, implying that men would not be comfortable talking to their daughters about it. All dialogue groups with mothers alone shared that it is possible for women to discuss PrEP with their daughters, with or without the knowledge or involvement of fathers.	The sessions acknowledge that women are more likely than men to talk to their daughters about PrEP, but they also challenge the idea that fathers do not have a role to play. In <b>Activity 3</b> , both a father and a mother are seen supporting their daughter's PrEP use, and <b>Activity 5</b> provides opportunities to improve both male and female caregivers' support to AGYW who may benefit from PrEP. <b>Activity 6</b> includes two scenarios that ask participants to think about fathers' involvement in a daughter's PrEP use. Finally, facilitator notes during the activities give the implementers flexibility and opportunities to add more roles for fathers, depending on the make-up of the parent groups.

## **ADVICE ON MODULE IMPLEMENTATION**

Finally, facilitators were asked for their advice on facilitation and implementation, their recommendations, and how these recommendations informed the module, are presented below.

## INCORPORATING RECOMMENDATIONS ON IMPLEMENTATION AND FACILITATION INTO THE MODULE

Findings	Impact on the module
Facilitators in both countries reported that PrEP- focused content should not exceed three hours and could be as short as one hour. In Kenya, facilitators were concerned that any content that made the parent intervention longer could increase participant fatigue.	The activities in this module are designed to be implemented within three hours. During field testing, facilitators who were able to extend implementation time reported that it can take up to four hours if parents have extensive questions or are completely new to PrEP. The "Using this module" section includes instructions on how to cut that time based on participants' existing knowledge and needs. All activities are highly interactive, which should help to alleviate participant fatigue.
Facilitators suggested that the module include role-plays, visual aids/IEC materials, or audio.	The session includes role-plays, visual aids, print-outs, and theatre. To avoid situations in which resource constraints would limit the use of the session, it does not included recorded audio.
One group of facilitators in Kenya suggested adding content only to family strengthening programmes for the parents of adolescents old enough to be eligible for PrEP use according to local guidelines. For example, Families Matter Program 1 is for 9–14-year-olds, a group too young to be eligible for PrEP in most settings.	The "Using this module" section includes guidance on how to use this module with parents whose children are too young to be eligible to use PrEP. The activities, and particularly <b>Activity 3</b> , also address the importance of knowing about PrEP before its needed, in order for its protective potential to be greatest.
Facilitators did not have strong opinions on when in the base curriculum to insert content on PrEP. All favoured its inclusion after content on sexual health but before the completion of the training.	In "Using this module", we discuss where to place the session on PrEP. We suggest placing it late in the family strengthening intervention or after its completion.
Some facilitators felt that it would be logical to spread new PrEP content across existing sessions; however, many strongly felt that this approach could be confusing for facilitators and participants. The majority of those interviewed suggested creating one session that focuses on PrEP.	To ensure this module can be used with a number of base curricula, and not just one, the module presents a single session, with no instructions on how to distribute it across several existing sessions. However, the content in this module can be divided into multiple sessions if that best fits the needs of parents and/or the programme context.
One group of parents in Kenya felt strongly that adolescent boys and young men should not be left out and that the module for parents should include content on young men's PrEP use.	While this module was originally designed for AGYW and the literature review and group dialogues focused on AGYW, the module content can also be used for adolescent boys and young men. The "Using this module" section includes adaptations to facilitate this approach.

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