

# Young Women Lead, Evidence, Advocate, Research, Network (LEARN): What does PrEP mean for young women?

Findings from a qualitative, participatory, peer-led study exploring values, views and preferences around pre-exposure prophylaxis with adolescent girls and young women in Kenya and Uganda

ATHENA INITIATIVE, ICWEA, PIPE



Determined

Resilient

Empowered

AIDS-Free

Mentored

Safe





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**Principal Investigators:** Jacqui Stevenson, ATHENA Initiative,  
Uganda: Lillian Mworeko, ICWEA, Kenya: Rahab Mwaniki

**Researchers:** Agneter Adero, Irene Akoth, Juliet Amoli, Patricia Nabwire, Catherine Nakafeero, Joan Nakalema, Teddy Nankumba, Belianne Onyango, Leonidah Wangari

**Report authors:** Jacqui Stevenson, Kristen de Graaf

**Project team:** Jacquelyne Alesi, Tyler Crone, Kristen de Graaf, Ebony Johnson, Valarie Musavi, Hajjarah Nagadya, Dorothy Namutamba, Catherine Nyambura, Beatrice Ogolla, Teresia Otieno, Rachel Yassky

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## Abstract

Adolescent girls and young women (AGYW) are disproportionately affected by HIV, and can face barriers to access, uptake and use of HIV prevention methods. Pre-exposure prophylaxis (PrEP) is a new, effective, individually-controlled HIV prevention tool that could benefit some AGYW. This study used qualitative, participatory, peer-led methods to explore the knowledge, views and preferences of AGYW about PrEP, HIV prevention, and sexual and reproductive health and rights more broadly. In three districts in Uganda and two counties in Kenya, trained young women peer researchers led 10 Community Dialogues with AGYW in their communities. The Community Dialogues each included around 25 AGYW as participants, who shared their views and preferences about PrEP. The dialogues were held in 2018, with the project closing at the end of September 2018.

Findings from the study will help to inform effective PrEP implementation and rollout. The research was conducted as part of a two-year project, Young Women LEARN, funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) as part of the DREAMS Innovation Challenge, managed by JSI Research & Training Institute, Inc. Participants identified challenges for PrEP use including problems taking pills, worries about side effects and inaccessibility of clinics and services. Opportunities of PrEP for AGYW included control over HIV prevention and improvements to relationships. AGYW had limited knowledge about PrEP and in some cases confused it with PEP. Information, outreach and sensitization for and by AGYW is needed. Peer-led support and mobilization, continued PrEP and HIV prevention innovation, agency and rights for AGYW, economic empowerment and comprehensive and accurate information were identified by AGYW as a blueprint to make PrEP work for them.

## Abbreviations

AGYW	adolescent girls and young women
ARV	antiretroviral
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe
LEARN	Lead, Evidence, Advocate, Research, Network
MSM	men who have sex with men
PEP	post-exposure prophylaxis for HIV
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PrEP	pre-exposure prophylaxis for HIV
SRHR	sexual and reproductive health and rights
TASO	The AIDS Support Organization
WHO	World Health Organization



Young Women Lead, Evidence, Advocate, Research, Network (LEARN) was a two-year project funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) as part of the DREAMS Innovation Challenge, managed by JSI Research & Training Institute, Inc. LEARN, led by the ATHENA Initiative and their community partners Personal Initiative for Positive Empowerment (PIPE) and the International Community of Women living with HIV Eastern Africa (ICWEA), aimed to promote an HIV prevention agenda informed by the meaningful participation of adolescent girls and young women (AGYW) in research that affects their lives. The project worked in three districts in Uganda (Mityana, Mubende and Mukono) and two counties in Kenya (Homa Bay and Nairobi).

Global estimates indicate that AGYW account for 60% of new HIV acquisitions among young people.<sup>1</sup> 80% of the world's AGYW living with HIV reside in sub-Saharan Africa.<sup>2</sup> Available sex and age disaggregated HIV incidence and prevalence data from Kenya and Uganda country level HIV epidemic indicators clearly show that AGYW are disproportionately affected.<sup>3</sup> In Kenya for example, acquisition rates among 15-24 year old females are approximately two times higher than in males of the same age group.<sup>4</sup> AGYW in the LEARN implementation counties and districts in Kenya and Uganda face heightened vulnerability to HIV acquisition compared to other population groups, as outlined in the following section of this report. This is driven by gender inequity and gender-related barriers to HIV prevention, including new tools such as PrEP. Addressing this uneven burden is increasingly prioritized in the global HIV response, especially in the context of the "youth bulge" in population demographics, and has prompted a focus on AGYW as a target for

HIV prevention from PEPFAR and the Global Fund to Fight AIDS, Tuberculosis, and Malaria among others.

Pre-exposure prophylaxis, or PrEP, is a prevention tool that is discreet, individually controlled and highly effective, and is increasingly prioritized as an HIV prevention intervention for AGYW. The significant HIV burden faced by AGYW in settings in sub-Saharan Africa requires new approaches to HIV prevention, including the effective implementation of new and innovative prevention tools. Existing prevention options can be challenging for some AGYW to utilize, for example, negotiating condom use can be difficult. Therefore PrEP, as an effective, individually-controlled prevention option, has the potential to provide an accessible alternative means of effectively preventing HIV transmission.

For the rollout and scale-up of PrEP to be effective for AGYW, more needs to be understood from the perspective and experience of AGYW themselves. It is essential to understand the values, views and preferences of AGYW around PrEP to ensure that access is supported effectively, and that barriers and enablers to uptake and use are understood and addressed. An HIV prevention agenda that works for AGYW and is led by and informed by their views, priorities and preferences is vital to overturn the disproportionate impact of HIV on AGYW.

The DREAMS Innovation Challenge aimed to deliver a core package of evidence-informed HIV prevention approaches that addressed the structural drivers of disproportionate HIV acquisition among AGYW. LEARN contributed to this effort by identifying the knowledge and access gaps around new HIV prevention tools for AGYW and identifying and piloting solutions to bridge these gaps.



## Project description

The LEARN project aimed to support effective roll-out and uptake of PrEP among AGYW in Kenya and Uganda, through creating an evidence base to support implementation that is responsive to the needs, rights, priorities and preferences of AGYW in all of their diversity. LEARN involved three distinct but mutually supportive areas of activity: **mobilization, research and advocacy.**

- 1. Peer and community mobilization:** LEARN Ambassadors, supported by Peer Mobilizers, held mobilization activities in their local communities where AGYW were reached with PrEP information and were able to ask questions and share experiences.
- 2. Qualitative research:** the Ambassadors led implementation research, convening Community Dialogues with AGYW in their communities using participatory methodologies to explore knowledge, views and preferences about PrEP.
- 3. Locally owned and informed evidence-based advocacy:** the Ambassadors were supported and mentored to develop advocacy agendas based on the research findings to inform, shape and contribute to the body of knowledge on HIV prevention with a particular focus on PrEP, and to advocate with key stakeholders and decision-makers.

Ten young women were recruited as LEARN Ambassadors and trained in peer research skills to lead community-based implementation research with AGYW in their communities, and nine went on to lead research interventions with AGYW. Taking the form of Community Dialogues, the research intervention involved up to 25 participants, led by two young women (LEARN Ambassadors) and supported by project staff who attended each Dialogue. The dialogues utilized a mix of research methods and information sharing activities to inform participants and gather their views, priorities and preferences for HIV prevention, including new prevention technologies such as PrEP.

In total, 10 Community Dialogues were held, with 247 participants. The study received ethical approval from AMREF in Kenya and TASO in Uganda. The data collected was analyzed and is reported here, and will also be disseminated through conference abstracts and other publications.





AGYW face disproportionate vulnerability to acquiring HIV. Despite only accounting for 11% of the global adult population, AGYW account for 20% of all new HIV acquisitions among adults.<sup>1</sup> This gender imbalance is even more severe in high HIV prevalence geographical areas. Sub-Saharan Africa is home to 80% of the world's AGYW living with HIV.<sup>2</sup> This unequal distribution of HIV transmission has prompted a global focus on adolescents, especially girls, as a target population for HIV prevention. In 2014, PEPFAR set HIV prevention and treatment targets including reducing new infections among AGYW (ages 15-24) within the highest burden geographic areas of 10 sub-Saharan African countries by 40% by the end of 2017.<sup>3</sup> The DREAMS partnership seeks to achieve this goal by targeting the root causes of vulnerability among young women. Among a package of recommended interventions is pre-exposure prophylaxis (PrEP).

### Epidemiology data

Strategies aimed at reducing HIV acquisition require an understanding of the epidemiologic context of the HIV

epidemic. Estimates by geographic location differ greatly with uneven distribution of HIV due to complexities surrounding social, structural, and economic environments. Certain locations and populations are more vulnerable than others.<sup>4</sup> While the figures summarized in the table below are an important starting point, it is crucial to understand that national level data often mask local variations and substantial heterogeneity exists in countries in terms of where and in whom HIV acquisitions take place. For example, in Kenya, the geographic regions of Homa Bay and Kisumu experience >15% HIV prevalence (hyper-endemic) compared to Mandera where the HIV prevalence among the general population is 1-4.9%.<sup>5</sup>

Available sex and age disaggregated HIV incidence and prevalence data on adolescents are limited.<sup>6</sup> However the available Kenya and Uganda country level HIV epidemic indicators clearly show that AGYW are disproportionately affected. In Kenya, infection rates among 15-24 years old females are approximately two times higher than in males of the same age group.<sup>7</sup> Uganda experiences a similar HIV epidemic picture where AGYW experienced

**TABLE 1: COUNTRY LEVEL HIV EPIDEMIC INDICATORS**

Indicators	Uganda (2013)	Kenya (2013)
People living with HIV	1,600,000 (1,500,000-1,700,000)	1 600 000 (1,500,000-1,700,000)
AIDS-related deaths	63,000 (56,000-71,000)	58 000 (49,000-72,000)
HIV prevalence (adults aged 15-49)	7.4% (7.0-8.0%)	6.0% (5.6-6.6%)
HIV incidence (adults aged 15-49)	0.80% (0.70-0.92%)	0.44% (0.34-0.56%)
HIV prevalence among young women (15-24 years)	4.2% (3.7-5.0%)	2.8% (2.4-3.4%)
HIV prevalence among young men (15-24 years)	2.4% (1.7-3.3%)	1.7% (1.3-2.3%)
New infections among young women (15-24 years)	29,000 (35,000-35,000)	19,000 (15,000-25,000)
New infections among young men (15-24 years)	17,000 (12,000-21,000)	10,000 (7,500-14,000)

Sources: UNAIDS 2013 HIV estimates; Uganda Global AIDS Response Progress Report, 2013; Kenya AIDS Indicator Survey (2007 and 2012).

Kenya	HIV prevalence of general population	New HIV acquisition (0–14 years)	New HIV acquisition (15+ years)	Population of girls (15–24)
Homa Bay	25.7%	2,724	12,279	238,746
Nairobi	8.0%	316	3,098	219,152

Kenya HIV Estimates 2014; Kenya Population Census 2015 Projections

new HIV acquisition rates significantly higher compared to their male peers (29,000 and 17,000 respectively).

The HIV prevalence among AGYW in the central Uganda district, which covers Mubende, Mukono, and Mityana, is 5.1%.<sup>8</sup> Distinct district level HIV estimates for AGYW are unavailable.

### Knowledge and behavior data

Although not sufficient to change behavior and reduce risk on its own, a basic understanding of HIV and how it spreads is a necessary component of prevention. Comprehensive knowledge is an indicator that measures how much young people know about transmission and prevention of HIV. Comprehensive knowledge includes knowing that condoms and monogamy prevent HIV transmission, that a healthy person can have HIV, and rejects the two most common local misconceptions about HIV transmission.<sup>9</sup>

Demographic and Health Surveys (DHS) are nationally-representative household surveys that provide data for a wide range of indicators including HIV and AIDS knowledge, attitudes, and behavior. Participants are asked if it is possible to reduce the risk of HIV acquisition through the following prevention methods: consistent condom use during sexual intercourse,

limiting the number of sexual partners or staying faithful to one partner, and sexual abstinence. The last DHS in Kenya was in 2014 and in 2011 in Uganda.

The table below summarizes the most recent Kenya and Uganda DHS and shows that knowledge about condom use and limiting sexual partners as methods of avoiding HIV transmission is generally high and widespread. Seventy-seven percent of young women and 86 percent of young men aged 15–24 years know that the risk of HIV acquisition can be reduced by using condoms. In both countries, knowledge of HIV prevention methods is consistently higher among men compared to women in each knowledge area. This pattern is consistent in most affected regions globally. These disparities are linked to gender, education, household health, and place of residence.<sup>6</sup>

Comprehensive knowledge about HIV prevention is defined in the DHS as knowing that consistent use of condoms during sexual intercourse and having just one HIV negative faithful partner can reduce the chance of HIV acquisition, knowing that a healthy-looking person can have HIV, knowing that HIV cannot be transmitted by mosquito bites, and knowing that HIV cannot be acquired by sharing food with a person who has AIDS.

	Kenya		Uganda	
	Women (15–24 years)	Men (15–24 years)	Women (15–24 years)	Men (15–24 years)
Using condoms	77.4%	86.1%	79.0%	83.9%
Limiting sexual intercourse to one uninfected partner	89.3%	92.0%	87.3%	90.9%
Using condoms and limiting sexual intercourse to one uninfected partner	72.8%	82.0%	73.6	79.1%
Total number	11,555	4,666	3,677	872

Kenya DHS 2014; Uganda DHS 2011



Data from the Kenya DHS survey of 2014 found that comprehensive knowledge about HIV prevention among young people aged 15-24 years was 64 percent.

In 2014 in Uganda, the percentage of young men and women aged 15-24 years who correctly identify ways of preventing transmission of HIV and who reject major misconceptions about HIV transmission was 38.5 percent. Disaggregating the data by sex revealed that young women's comprehensive knowledge was significantly less: 42.3 percent of young men and 35.7 percent of young women had comprehensive knowledge of HIV prevention.

### Pre-exposure prophylaxis

PrEP is the daily use of antiretroviral HIV medicines (ARVs) by an HIV negative individual to prevent the acquisition of HIV. When taken consistently, data show that PrEP has reduced HIV acquisition by up to 92% in people who are at high risk.<sup>10</sup> In 2014, the WHO produced guidance recommending PrEP for persons at substantial risk of HIV infection including offering PrEP to men who have sex with men (MSM) and the HIV negative partner in serodiscordant couples.<sup>11</sup> As a result, high and middle income countries are starting to prioritize its use in the MSM population.<sup>12</sup> In 2015, the WHO amended their original briefing on PrEP to expand upon the recommendations from serodiscordant couples and MSM to an all-encompassing "people at substantial risk". This risk is defined as places where incidence of HIV is high (>3 per 100 person-years) in the absence of PrEP. In these settings classified as having "high" HIV incidence among young women aged 15 to 24 years, PrEP should be offered for voluntary uptake.<sup>13</sup>

In May 2017, the National AIDS & STI Control Program (NAS COP) published the *PrEP Implementation Framework* to provide guidance on the rollout of PrEP in Kenya.<sup>14</sup> In Uganda, the Ministry of Health published guidelines in 2016 that recommend PrEP be offered to HIV-negative people at substantial risk of acquiring HIV infection, with over 17 public healthcare facilities now providing PrEP as of September 2018.<sup>15</sup>

A growing body of high-quality evidence supports that PrEP is an effective intervention for HIV prevention. Globally, there are numerous ongoing and planned PrEP demonstration and implementation studies, including of different formulations for PrEP delivery such as injectables. Of these, around twelve include adolescent girls and young women. Results for these are yet to be published.<sup>16</sup> Key evidence show that PrEP: is effective when taken consistently, has an exceptional safety profile, the risk of drug resistance is low, it can be used with hormonal contraception and during pregnancy, and is acceptable among the populations studied.<sup>17</sup>

A number of studies have been conducted to specifically assess PrEP efficacy amongst women. The evidence base is somewhat mixed, due to low levels of adherence among women participants in some studies, which highlights that supporting adherence is key to ensuring effectiveness. In order for AGYW to benefit from PrEP, more evidence is needed to understand knowledge and perceptions of PrEP amongst AGYW, concerns and potential barriers to access and/or adherence, and factors that may influence successful implementation, take-up and adherence in practice.<sup>18</sup> Five randomized trials provide the best available evidence for use of PrEP for AGYW in a Kenya/Uganda setting. The following trials explored the efficacy of daily oral PrEP to prevent HIV acquisition in several high risk populations of sexually active women:

- FEM-PrEP<sup>19</sup>
- VOICE trial<sup>20</sup>
- Partners PrEP<sup>21</sup>
- TDF2 Study<sup>22</sup>
- ADAPT<sup>23</sup>
- PlusPills<sup>24</sup>

There is enough evidence to show that PrEP does work for women however as with any prevention tool, it won't be right for everyone and adherence is a major consideration for AGYW.<sup>18</sup>



## RESEARCH QUESTION & OBJECTIVES

The goal of this study was to explore the views and preferences of AGYW about PrEP, in order to inform effective implementation and rollout, including assessing barriers and enablers.

Research question: What does pre-exposure prophylaxis mean for adolescent girls and young women?

The objectives were to:

1. Understand and generate evidence about the knowledge, views and preferences of AGYW on PrEP.
2. Inform AGYW about PrEP, HIV prevention and sexual and reproductive health and rights (SRHR).
3. Assess knowledge, skills and confidence of AGYW before and after the Community Dialogues, on the topics listed above, to evaluate the impact of the Community Dialogues.





## Study design

This qualitative implementation research study used peer-led and participatory methodologies. Participants were AGYW aged between 15 and 24, with parental consent sought and obtained for all participants aged under 18 years old. Participant inclusion criteria included residence in the LEARN district/county in which the Community Dialogue was held. All participants were provided with information about participating prior to registering, and were provided with a participant information sheet and asked to complete a consent form at registration on the day of the Community Dialogue. Participants were informed that they were free to withdraw at any time, before or during the Community Dialogue. Participants completed a demographics questionnaire and a pre- and post-questionnaire. They were also provided with a photo release form and asked to sign only if they wished their photo to appear in LEARN reports and other publications.

The research encounter was a Community Dialogue, led by LEARN Ambassadors, with support from both the co-Principal Investigators (remotely) and in-person support and supervision by the project partners, PIPE in Kenya and ICWEA in Uganda. A staff member from PIPE or ICWEA was present at each Community Dialogue, to provide support and supervision, and to ensure the safety and wellbeing of the participants and LEARN Ambassadors.

## Recruitment

Participants were recruited by LEARN Ambassadors with support from staff at PIPE and ICWEA. Snowball techniques were used, building on existing networks and past participants in other LEARN activities as community mobilization activities had been implemented over a number of months before recruitment began for the research. Partner organizations and DREAMS Innovation

Challenge grantees were also requested to support recruitment, linking AGYW involved in their services to take part in Community Dialogues. This included Mildmay, MUWRP, MOD and UYDEL in Mityana and Mubende and SIKYOMU, CCAYEF, Youth Education, UYDEL, ISORE, CHAIN and Child Link in Mukono.

Recruitment criteria included that participants were adolescent girls and young women aged between 15 and 24, and living in the area of the research site. AGYW living with HIV were able to participate. AGYW who were using or had used PrEP were able to participate, but no participant identified themselves as such during the Community Dialogues.

The Community Dialogues were supported by local officials, support which was critical to their success and which we acknowledge with gratitude. In Uganda, a research launch event was held in each district, and stakeholders committed to support the study: *“As Mukono district, we will give the necessary support to ICWEA as we have done to other institutions to see that the research is a success”*, Musenero Samalie, Secretary for Health Mukono district.

## Data collection

The Community Dialogue methodology has been developed and refined by ATHENA over a number of research projects, including a global review of barriers to women’s access to HIV treatment supported by UN Women, and a consultation on sexual and reproductive rights amongst young people conducted as part of the Link Up five-country project promoting HIV and SRHR integration, in which ATHENA was a global policy partner.

The approach and topic guide used in this study was initially developed by ATHENA and partners for the Link Up study, and so has been piloted and

implemented previously. These dialogues were led by and for young people living with and most affected by HIV. Each Community Dialogue was facilitated using a discussion guide, which included a set of key questions and background information on PrEP.<sup>25</sup>

Under LEARN, the discussion guide utilized in the Link Up study was reviewed, updated and expanded by the Principal Investigator, to focus specifically on AGYW and to incorporate broader questions and themes around HIV prevention and SRHR. The resulting *LEARN Community Dialogue Facilitator Guide* defines a 5-hour/1 day program, including information sharing, focus group discussion and participatory activities. It includes guidance on facilitating and documenting and a step-by-step guide to leading the Community Dialogue and gathering data.

This guide was subsequently piloted with LEARN Ambassadors, during a five-day residential training in Nairobi in May 2017, led by the Principal Investigator, which covered core research skills (e.g. ethics, safety, recruitment, data quality, reporting, facilitation). This included a participatory review of the guide and accompanying tools, to ensure understanding, and elicited feedback on adaptations, including language, to ensure accessibility. The Ambassadors also practiced using the guide, as facilitators and documenters, to support their confidence in using it effectively.

Subsequently, the research design and tools were further refined by the Principal Investigators, a Global Reference Group convened to support the LEARN project, country partners and the LEARN Ambassadors. This aimed to ensure they reflected the discussions from the workshop and were user-friendly and adequate for the proposed study, designed to gather quality data that provides insights into the knowledge, needs and preferences of AGYW in regard to PrEP and other HIV prevention tools. Further revision was made in the process of securing ethical approval.

Data was collected through ten Community Dialogues held from January to August 2018. Two dialogues were conducted in each research site, Mityana, Mubende and Mukono in Uganda, and Homa Bay and Nairobi in Kenya.

## OVERVIEW OF THE COMMUNITY DIALOGUES

- Each Community Dialogue lasted five hours
- Facilitated and documented/co-facilitated by two LEARN Ambassadors
- Project staff present to support
- Participants given participant information sheet and provide informed consent (parental consent also required if under 18)
- All participants complete a demographics questionnaire
- LEARN Ambassador introduces the Community Dialogue and participants agree ground rules
- Participants complete pre-questionnaire, with questions on knowledge about PrEP and HIV prevention, and rating knowledge and confidence on different issues.
- Introduction to PrEP: Ambassador shares information about PrEP
- Discussion session 1: exploring knowledge, views and preferences on PrEP
- Introduction to SRHR, family planning/contraception and sexual health
- Word association game 'sexual health'
- Discussion session 2: force field analysis of barriers and enablers for AGYW in their community to access information and make choices about HIV prevention and sexual and reproductive health
- Discussion session 3: group discussion on solutions to barriers identified
- Summary and closing
- Participants complete post-questionnaires, to assess impact on knowledge and self-evaluated confidence after the Community Dialogue

## Study limitations

As a peer-led study, the Community Dialogues were led by young women with limited prior experience of conducting research. To ameliorate potential limitations due to this relative inexperience, the LEARN Ambassadors were trained in core research skills, over a five-day residential training, led by the Principal Investigator, which covered ethics, safety, recruitment, data quality, reporting, facilitation and other skills. Practical activities and role play was included to explore and practice key skills including active listening and asking open and probing questions. Ongoing support and training was provided by the country partners, who were also present at each Community Dialogue and provide supervision and support. Additionally, the training addressed researcher bias, which is a potential issue for all researchers, including peer researchers. The training included skills-based activities and role play on key topics including hearing and documenting all views and opinions, recognizing and addressing bias and capturing all data that was shared. LEARN Ambassadors worked in pairs to facilitate and document the Community Dialogues to further address this.

As a qualitative study, the number of participants was small and not designed to be representative of the population of AGYW in each county or district. Efforts were made to ensure diverse recruitment across age, key population group and life experiences, so that a diversity of viewpoints was included, but further research would be required to extrapolate population level findings for sub-groups. In validating this research, stakeholders identified that it would be of interest to explore the views of pregnant participants as PrEP is safe to use during pregnancy and pregnancy is associated with higher risk of HIV acquisition. Although there were a number of pregnant participants, the Community Dialogues did not explore views on PrEP use during pregnancy, and at the time data was collected, PrEP was not offered to pregnant women in Uganda, which influenced the discussion on this topic. Further research is needed and would be valuable to explore issues around PrEP and pregnancy further.

The analysis presented draws out the themes and issues that emerged from the AGYW's discussions during the Community Dialogues, combined for the study as a whole. Limited time and resources prevented an analysis by research site, and that is a limitation of this report.

## Analysis

All participants were assigned a participant number at registration on the day of the Community Dialogue, which was used in documentation, for demographics forms and pre- and post-intervention questionnaires. These were gathered and stored separately from participant consent forms on which names were present. Flipcharts were photographed and typed up, and included in reports.

The Community Dialogues were audio recorded (and participants informed of this and asked for express consent). Each Dialogue was facilitated by one LEARN Ambassador, while a second acted as documenter, taking detailed notes throughout the Dialogue. Notes were taken using a shared template, including their own reflections, direct quotes and vignettes and summaries of discussions.

This handwritten report, supplemented with flipchart notes and other materials from the Community Dialogue, were used along with the audio recording to create a complete, typed report. This report was produced by staff at PIPE and ICWEA who had attended and supervised the dialogues.

These reports were then submitted to the Principal Investigator at ATHENA, who combined the data from all ten dialogues and led the analysis. An initial review and close read identified topics and themes, which were then used to re-analyse the data and determine themes and sub-themes. This thematic analysis was validated with the LEARN Ambassadors in two workshops, in Nairobi and Kampala, where findings were shared and discussed to ensure they resonated with the researchers who collected the data. In addition, a draft report was presented to stakeholders in two LEARN research symposiums held in September 2018 in Nairobi and Kampala, and feedback incorporated into this final report. Review and feedback was also provided by members of the LEARN Global Reference Group: Charles Brown, Resty Nalwanga and Luisa Orza.

## Translation

The Community Dialogues were conducted in local languages where this was most appropriate for the participants (Swahili in Kenya and Luganda in Uganda). The informed consent form, participant information sheet and other tools were translated by experienced, professional translators, coordinated by country partners PIPE and ICWEA and led by staff



fluent in both English and the language of translation, and approved through the IRB process. The Dialogues were led and supported by Ambassadors and staff able to work comfortably in the language being used, and data gathered in that language, and translated subsequently for reporting. Final data for analysis was all in English, and analysed and reported in English.

## Ethics

Formal ethical approval for the study was secured in both Kenya and Uganda. The study team gave significant consideration to ethical concerns implied by the study, and undertook appropriate steps to address and mitigate these. Informed consent was sought and secured from all participants in the study, including parental consent (requiring signed consent forms) for participants aged under 18.



Ten Community Dialogues were held in total, two in each LEARN implementation site of Mityana, Mubende, Mukono in Uganda and Homa Bay and Nairobi in Kenya. The following demographics combine participants in the two dialogues held in each county/district.

**Homa Bay:** 50 participants, 25 aged 15-19 and 25 aged 20-24. 12 were married (4 aged 15-19, 8 aged 20-24). Six were currently pregnant (all aged 20-24) and 13 were mothers (4 aged 15-19, and 9 aged 20-24). One identified as bisexual. Four were living with a disability, and one was living with HIV. One identified as a sex worker and four as having exchanged sex for something. The majority, 20 had reached secondary education, 10 tertiary education, and 6 primary education.

**Nairobi:** 50 participants, 19 aged 15-19, 30 aged 20-24, 1 did not state. 8 were married (all aged 20-24). Four were pregnant (2 aged 15-19, 2 aged 20-24) and 15 were mothers (1 aged 15-19, 14 aged 20-24). One identified as lesbian. One identified as a person who

uses or has used drugs. One identified as a sex worker and three as having exchanged sex for something. One was homeless. 30 had completed secondary education, 11 tertiary education and 6 primary education.

**Mityana:** 53 participants, 11 aged 15-19 and 41 aged 20-24 (1 not stated). 18 were married (10 aged 15-19, 8 aged 20-24). Four were currently pregnant (1 aged 15-19, 3 aged 20-24) and 26 were mothers (3 aged 15-19, 33 aged 20-24). Two were living with a disability, and one was living with HIV. One identified as a person who uses or has used drugs. One identified as a sex worker and 17 as having exchanged sex for something (5 aged 15-19, 12 aged 20-24). Five identified as someone who had an abortion. Two were homeless. The majority, 37 had reached secondary education, 10 tertiary education, and 4 primary education.

**Mubende:** 47 participants, of whom 34 completed the demographics questionnaire. Of those who responded, 5 were aged 15-19 and 34 aged 20-24 (1 not stated). 16 were married, 1 pregnant, and 24 were mothers (all aged 20-24). One identified as living with a disability. Two identified as a person who uses or has used drugs. One had exchanged sex for something. Four had previously had an abortion. Three were homeless. The majority, 27 had reached secondary education, 7 tertiary education, and 3 primary education.

**Mukono:** 47 participants, 15 aged 15-19 and 32 aged 20-24. 8 were married (2 aged 15-19, 6 aged 20-24). One woman, aged 15-19, was pregnant, and 10 were mothers (5 aged 15-19, 5 aged 20-24). One identified as lesbian. One was living with HIV. One had used or injected drugs. Five identified as a sex worker (1 aged 15-19, 4 aged 20-24) and 8 had exchanged sex for something (1 aged 15-19, 7 aged 20-24). Six had previously had an abortion (2 aged 15-19, 4 aged 20-24). One was homeless. The majority, 32 had reached secondary education, 9 tertiary education, and 4 primary education.

The following are the themes that emerged from the qualitative data collected in the Community Dialogues, from activities including facilitated focus group discussion and small group work. As qualitative data, it is not presented with numbers and percentages, but instead reflects the views and opinions shared by participants in the Community Dialogues.

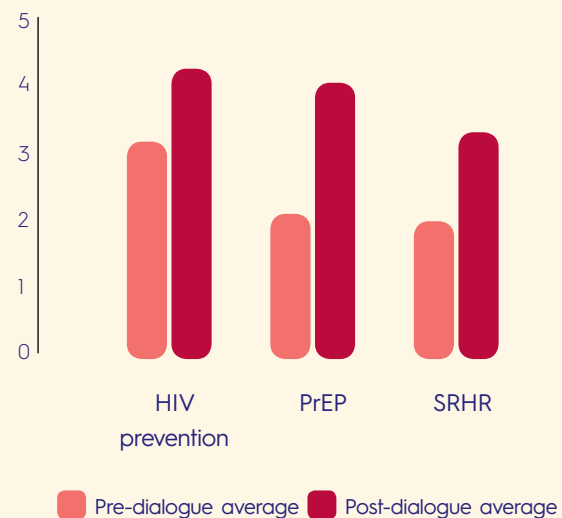


Snapshots from each site based on pre- and post-Community Dialogue questionnaires demonstrate the impact of the Community Dialogues on participants.

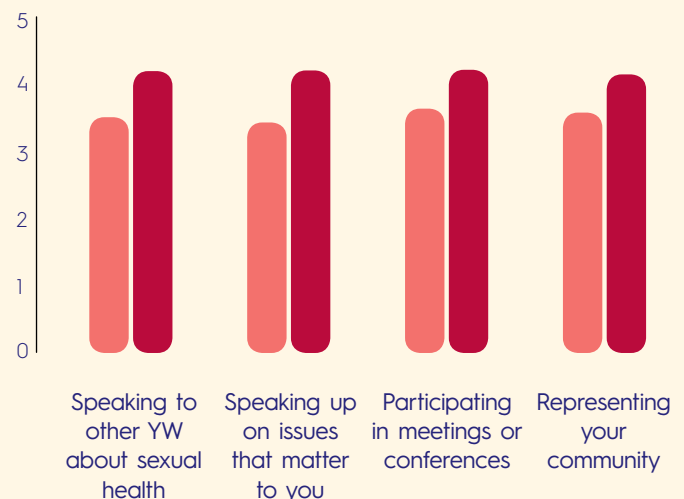
## What we LEARNed in Homa Bay

- 74% of AGYW had heard of PrEP before the Community Dialogue, 24% had not.
- Most, 34%, thought PrEP was best described as 'a pill taken after unprotected sex to prevent HIV'.
- 32% knew it was 'a pill taken every day to prevent HIV'.
- 52% said they knew someone who had used PrEP, 38% did not.
- After the Community Dialogue, participants were more likely to correctly identify effective methods to prevent unwanted pregnancy.
- 76% of AGYW answered 'yes' to the question 'Do you feel you have enough information about sexual health?' after the Community Dialogue, compared to 32% before.
- 84% said they had enough information about HIV prevention after the Community Dialogue, compared to 50% before.

Participants were asked to rate how knowledgeable they were on three topics, on a scale from 1 (not at all) to 5 (extremely)



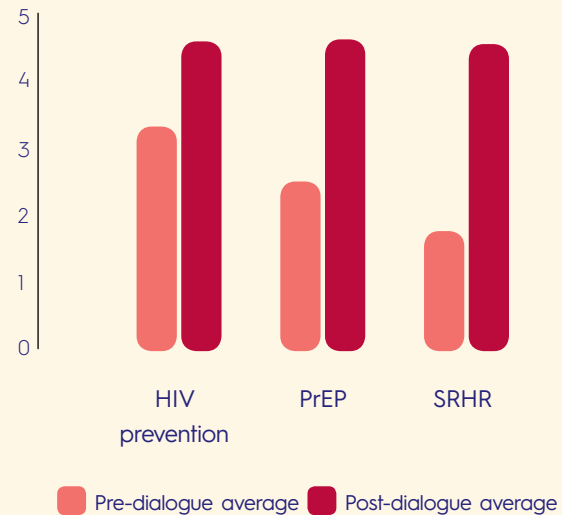
Participants were also asked to rate how confident they felt in different activities, from 1 (not at all) to 5 (very)



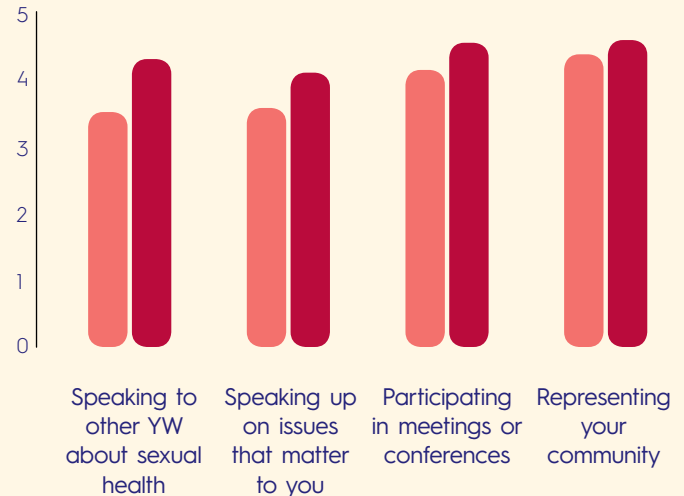
## What we LEARNed in Nairobi

- 74% of AGYW had heard of PrEP before the Community Dialogue, 26% had not.
- Most, 44%, thought PrEP was best described as 'a pill taken after unprotected sex to prevent HIV'.
- 38% knew it was 'a pill taken every day to prevent HIV'.
- 36% said they knew someone who had used PrEP, 64% did not.
- 38% were currently using a contraceptive method, 54% were not. These answers were slightly different after the Community Dialogue compared to before, suggesting that after receiving more information participants changed their response.
- 84% of AGYW said they had enough information about sexual health after the Community Dialogue, compared to 44% before.
- 88% said they had enough information about HIV prevention after the Community Dialogue, compared to 44% before.
- 86% said they had enough information about contraception after, compared to 50% before.

Participants were asked to rate how knowledgeable they were on three topics, on a scale from 1 (not at all) to 5 (extremely)



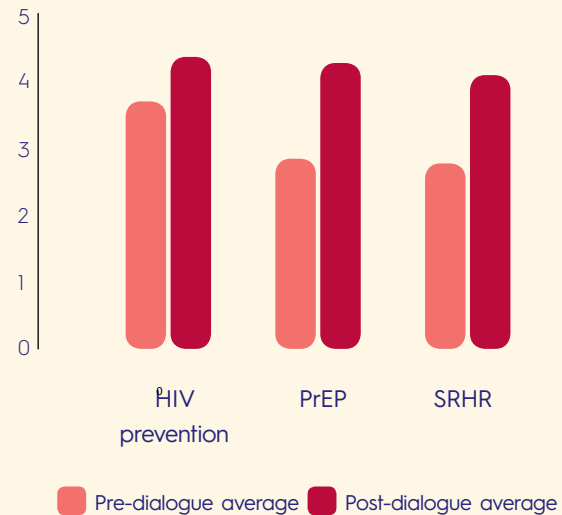
Participants were also asked to rate how confident they felt in different activities, from 1 (not at all) to 5 (very)



## What we LEARNed in Mityana

- 74% of AGYW had heard of PrEP before the Community Dialogue, 23% had not.
- Most, 40%, thought PrEP was best described as 'a pill taken after unprotected sex to prevent HIV'.
- 28% knew it was 'a pill taken every day to prevent HIV'.
- 23% said they knew someone who had used PrEP, 74% did not.
- 68% were currently using a contraceptive method, 28% were not.
- 93% AGYW said they had enough information about sexual health after the Community Dialogue, compared to 51% before.
- 57% said they had enough information about HIV prevention after the Community Dialogue, compared to 76% before, the number saying they did not have enough information reduced from 19% to 4%, and fewer respondents completed this question in the post-questionnaire.
- 76% said they had enough information about contraception after, compared to 45% before.

### Participants were asked to rate how knowledgeable they were on three topics, on a scale from 1 (not at all) to 5 (extremely)



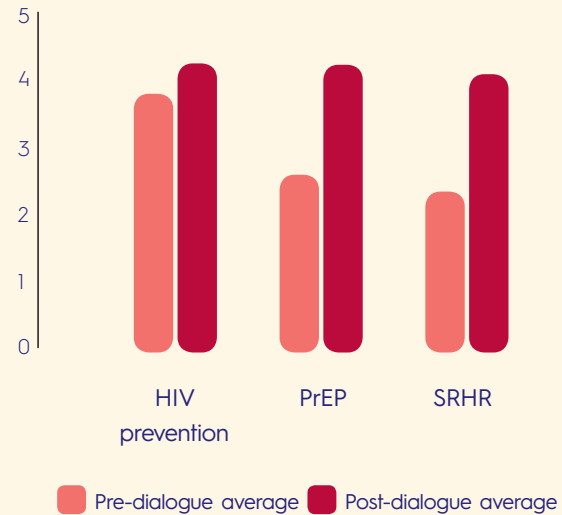
### Participants were also asked to rate how confident they felt in different activities, from 1 (not at all) to 5 (very)



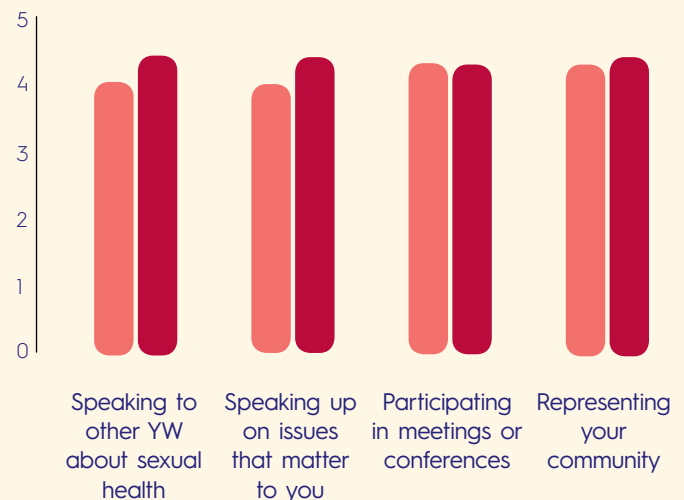
## What we LEARNed in Mubende

- 78% of AGYW had heard of PrEP before the Community Dialogue, only 11% had not.
- Most, 54%, thought PrEP was best described as 'a pill taken after unprotected sex to prevent HIV'.
- 20% knew it was 'a pill taken every day to prevent HIV'.
- 46% said they knew someone who had used PrEP, 48% did not.
- Knowledge of effective contraceptives was generally good.
- 91% AGYW said they had enough information about sexual health after the Community Dialogue, compared to 52% before.
- 87% said they had enough information about HIV prevention after the Community Dialogue, compared to 80% before.
- 87% said they had enough information about contraception after, compared to 67% before.

Participants were asked to rate how knowledgeable they were on three topics, on a scale from 1 (not at all) to 5 (extremely)



Participants were also asked to rate how confident they felt in different activities, from 1 (not at all) to 5 (very)





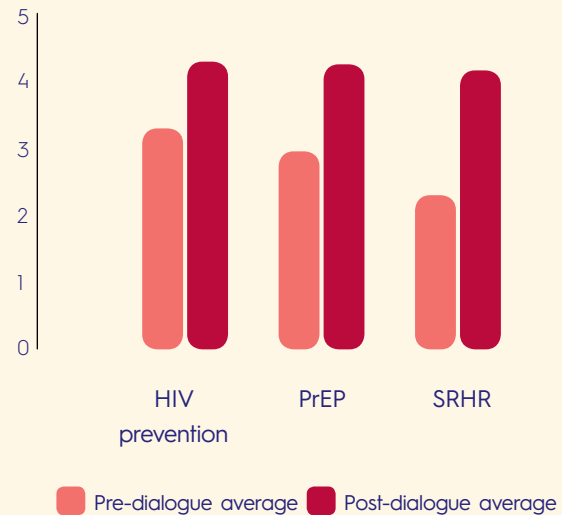
## What we LEARNed in Mukono

- 83% AGYW had heard of PrEP before the Community Dialogue, 17% had not.
- 40% thought PrEP was best described as 'a pill taken after unprotected sex to prevent HIV'.
- Most, 22, knew it was 'a pill taken every day to prevent HIV'.
- 47% said they knew someone who had used PrEP, 60% did not.
- More were able to correctly identify effective contraceptive methods after the Community Dialogue than before it.
- 85% AGYW said they had enough information about sexual health after the Community Dialogue, compared to 51% before.
- 96% said they had enough information about HIV prevention after the Community Dialogue, compared to 81% before.
- 92% said they had enough information about contraception after, compared to 60% before.

## Discussion

In total, 240 adolescent girls and young women who participated in Community Dialogues completed pre- and post-questionnaires. 191 (80%) of these AGYW had heard of PrEP before taking part in the Community Dialogues, but 104 (43%) of them thought it was a pill taken after unprotected sex to prevent HIV transmission. Only 80 (33%) knew it was a pill

Participants were asked to rate how knowledgeable they were on three topics, on a scale from 1 (not at all) to 5 (extremely)



Participants were also asked to rate how confident they felt in different activities, from 1 (not at all) to 5 (very)



taken every day. This confusion between post-exposure prophylaxis (PEP) and PrEP has been identified in previous research led by ATHENA with AGYW<sup>26</sup> and indicates the need for increased awareness-raising and information resources for AGYW. All knowledge and confidence measures improved in the post-dialogue assessment indicating the suitability and impact of the Community Dialogue as a method.



## Understanding of PrEP

Participants were asked to share their understanding of what PrEP is, at the outset of the Community Dialogue. Many had detailed, accurate knowledge about PrEP including how and when it is used. However, many other participants had some confusion and misinformation demonstrating the need for more information and education about PrEP for AGYW. Many confused PrEP with PEP, describing it as something given to women who have been raped, which came up frequently, and to be taken within 72 hours after exposure. Others confused PrEP with contraception, including emergency contraception.

## Views on taking PrEP

Asked if they would take PrEP themselves, AGYW expressed a range of views. Many said that they would take PrEP if they were at sufficient risk of acquiring HIV. Participants assessed potential risk for HIV acquisition based on having multiple partners or partners whose HIV status they did not know. Involvement in sex work or transactional sex were also identified as risks these AGYW considered might apply to them, now or in the future, and lead them to use PrEP. Protection and the value of prevention were highlighted, as were comparisons with other prevention tools such as contraceptives, seen to be equivalent to using PrEP.

*"If PrEP is made available, then people will be protected. Family planning has been made available and yet it only protects against unwanted pregnancies not HIV so making PrEP available would mean people are protected against HIV and unwanted pregnancies."* **24 YEAR OLD PARTICIPANT IN SECOND MUBENDE DIALOGUE**

*"Prevention is better than cure. I can really opt to take PrEP to prevent myself from HIV infection."* **22 YEAR OLD PARTICIPANT IN FIRST HOMA BAY DIALOGUE**

The importance of choice and agency was highlighted. As one participant stressed, she would take PrEP but only if she was not coerced to do so. Trust was a dominant theme that emerged in participants' contributions. Many talked about having boyfriends and husbands who might or did have other partners, the HIV status of whom they did not know. Being unable to trust their partner or the other partners they had, led many AGYW to see PrEP as something they would consider. Similarly, not knowing the HIV status of their partner or a partner being unwilling to test for HIV were identified as reasons to consider taking PrEP. Knowing your own HIV status and that of your partner was seen as a reason not to take PrEP.

Access to PrEP was a key determinant of potential uptake. If drug supply was constant with no stock-outs, and PrEP available in clinics that were accessible, participants felt they would be more likely to use it.

That PrEP is used only during period of risk, and is not a life-long treatment, like antiretroviral for HIV would be, was seen as a benefit and a reason to use PrEP.

Many participants also said they would not consider taking PrEP. Some felt that condoms were preferable as they also prevented pregnancy and sexually transmitted infections. For others, dislike of taking tablets or concern about taking tablets every day was a barrier. Some said they would consider PrEP if it was in an injectable form but would not consider a daily pill.

The impact of PrEP on behavior was also a concern, with some participants highlighting concerns about potential ‘immorality’ as a result of taking it, an increase in sexual partners or change in sexual behaviors.

Side effects were a major reason given by participants for not considering PrEP use. Participants described side effects they were concerned about or had heard were associated with PrEP as including reduced libido, hallucinations, dizziness, and weakness.

### Views on who should use PrEP

Asked if PrEP should be offered to anyone in particular, participants identified specific groups or experiences including sex workers, people in sero-discordant relationships, people with multiple partners, people who had a partner who was unfaithful or had other partners, people who did not know the HIV status of their partner(s), anyone at substantial risk of acquiring HIV and people at risk of rape. Some felt all AGYW should be offered PrEP due to their increased risk of HIV acquisition, while others suggested only those aged over 18 should have access to avoid encouraging sexual activity by under-18s.

### Potential impact of PrEP use on condom and contraceptive use

Reduced condom use and potential increase in acquisition of sexually transmitted infections (STIs) and in unintended pregnancies, has been described as a risk of increased PrEP uptake. Participants in the Community Dialogues were asked for their views on how PrEP might impact on use of condoms and contraceptives. There was good understanding by this stage of the Community Dialogue that PrEP only prevented HIV, not other STIs or pregnancy, but many voiced concern that without adequate information and support other AGYW may not know this, so would stop using condoms and/or hormonal contraceptives, increasing their risks. This was also associated with a sense that HIV was the main priority for prevention for many AGYW, so if PrEP was used to address this, other things would lose focus. However, others felt pregnancy was a bigger concern so PrEP would not reduce contraceptive use.

*“PrEP is good but it will take away use of other methods. People are going to focus on preventing HIV only and leave out focus on other conditions like pregnancy and STIs” 24 YEAR OLD PARTICIPANT IN SECOND MITYANA DIALOGUE*

That PrEP use involves regular HIV and STI testing was seen as a reason to stop using condoms by one participant. Some highlighted that if male partners were using PrEP they may refuse to use condoms, as pregnancy was not their major concern.

Side effects, and the challenges of taking two pills every day, were also highlighted as potential barriers to contraceptive use while on PrEP.

*“Chances of getting pregnant is high because taking PrEP and contraceptive pills at the same time will be difficult.” 24 YEAR OLD PARTICIPANT IN SECOND NAIROBI DIALOGUE*

### Benefits of PrEP for adolescent girls and young women

Community Dialogue participants were asked to share their views on what the benefits and opportunities of PrEP are for AGYW. A range of potential benefits were identified, including the ability to stay HIV negative and prevent HIV acquisition, while still having the opportunity to conceive, or to have sexual relationships (including transactional relationships), have multiple partners, or do sex work.

Comprehensive, accurate information about HIV prevention including PrEP, and access to testing, were seen as benefits of taking up PrEP.

PrEP use could contribute to reduced infection rates for AGYW, helping individual AGYW to stay in school, reduce worry and promote self-acceptance.

Where PrEP could be accessed was described as determining potential benefits of PrEP for AGYW. Suggestions for where PrEP should be made available included safe spaces used by AGYW, accessible hospitals and clinics, family planning services, facilities at village level, pharmacies, outreach sites in schools and public areas and government facilities. Accessibility, confidentiality and friendly services were the priority to ensure AGYW could benefit from PrEP.

### Benefits of PrEP for people living with HIV

We asked participants in the Community Dialogues to reflect on what benefits PrEP might offer for people living with HIV. Many noted that, of course, PrEP itself is not to be taken by people living with HIV, but that PrEP use by the partners of people living with HIV would offer



benefits to them. Primarily, participants cited the ability for people living with HIV to have relationships or sex with people who are HIV negative without having to worry about HIV transmission, and reducing discrimination from current or potential partners. Benefits for couples where one partner is living with HIV and the other is not were also felt to include reduction in gender-based violence, and the ability to conceive without the risk of HIV transmission to the negative partner. One participant suggested that both partners taking a pill every day would help provide moral support for the partner living with HIV.

### PrEP accessibility and payment

We were interested to understand the views of AGYW on whether PrEP should be made available for free or should be paid for by users. Participants overwhelmingly felt PrEP should be made available without charge, as many AGYW who might benefit are living in poverty and would not be able to pay if that was required. Equity of access was prioritized, as was equity with other prevention tools and antiretroviral treatment that are made available at no cost.

*“No, because both PrEP and condom act as preventative measures, the same way condom is given for free, PrEP [should] also be free always.”* **18 YEAR OLD PARTICIPANT IN FIRST HOMA BAY DIALOGUE**

Some did feel that requiring payment would be a positive thing as people would value PrEP more and reduce waste.

*“People should pay for PrEP because if the AGYW know that PrEP is free, they won’t care for their lives”* **21 YEAR OLD PARTICIPANT IN FIRST MITYANA DIALOGUE**

### Challenges of PrEP use for AGYW

Participants shared a number of concerns and potential challenges about PrEP use for adolescent girls and young women. This included peer pressure and discrimination, with concerns that partners, family and the wider community might make judgments or assumptions about the sexual behaviors of AGYW using PrEP leading to discrimination and pressure

to stop PrEP use. There was also worry that people seeing AGYW using PrEP pills would assume they were in fact living with HIV and taking treatment, leading to HIV stigma which would influence PrEP use.

*“Because the drug and the tins are similar to those of PLHIV, people in communities may think that they are taking ARVs if they do not know that it is for HIV prevention”* **24 YEAR OLD PARTICIPANT IN SECOND MUBENDE DIALOGUE**

Clinics could also introduce challenges, including stigma from community members seeing AGYW go to clinics, and barriers within or associated with clinics themselves including judgmental attitudes from healthcare providers and accessibility issues including transport and opening hours.

Practical challenges associated with PrEP use were frequently described. Many AGYW described fears of taking or swallowing pills, and felt the pills were too large. Injectable PrEP was felt to be more accessible and usable and was a priority for many AGYW. The range of options of contraceptive tools was valued and achieving the same variety for PrEP was felt to be a goal.

Side effects were also a dominant theme. Participants described a long list of side effects they had heard about or were worried would be caused by PrEP. The Community Dialogue offered an important learning opportunity where these concerns could be addressed by the LEARN Ambassadors who were able to correct misconceptions. The range of concerns indicates the urgent need to include information on side effects in PrEP sensitization materials and campaigns. Side effects cited by participants as things they worried might be associated with PrEP or had heard were associated with PrEP included: weight gain, impact on appetite, long-term damage or impact on health, nausea, nightmares, hallucinations, morning flu, dizziness, vomiting, stomach ache, headache, weakness, blood pressure problems. Participants felt that if side effects were well-managed and AGYW were informed and supported, they should not prevent PrEP use. Support included managing side effects, but also potentially explaining them, as one participant noted that vomiting may lead people to think the AGYW is pregnant, and that would be challenging to manage.

The impact of PrEP on relationships was also discussed by some participants. While it was felt there were potential benefits, as described above, there were also concerns that PrEP use may lead to an increase in partners having other partners if they felt they could do so without risk of acquiring HIV. It was felt that PrEP could affect trust in relationships, and also that if a partner discovered the AGYW was using PrEP it may lead to conflict in the relationship especially if they assume the PrEP use is because the AGYW has other sexual partners.

### Involving AGYW in PrEP roll-out and implementation

Participants felt that AGYW should be involved in the process of PrEP roll-out and implementation, in particular in offering peer leadership, mobilization and involvement. PrEP users as role models was one opportunity identified. Having AGYW lead activities, as in the LEARN model, was described as positive as peers were more likely and able to benefit from and understand information from peers.

*“Even us who have got this information we need to go to the villages and inform people about PrEP since we have sensitized. I came here knowing PEP and was confusing it so we need to support people with this information using different avenues so as to reduce on HIV infection rates.”* **23 YEAR OLD PARTICIPANT IN SECOND MUBENDE DIALOGUE**

Involvement in awareness creation, social and other media campaigns, peer-to-peer learning models, leading trainings, dialogues in communities with community leaders, and outreach activities, were also suggested as positive opportunities.

Research, decision-making, policy formulation and advocacy forums were also highlighted as priorities for involvement of AGYW.

*“AGYW should be involved in decision-making especially on issues that are affecting us.”* **19 YEAR OLD PARTICIPANT IN FIRST HOMA BAY DIALOGUE**

### Barriers and enablers to choices and information about HIV prevention and SRH

The LEARN Ambassadors facilitating the Community Dialogue invited participants to work in small groups to



complete a force field analysis\* of the things that make it easier or make it harder for AGYW in their community to access information and make choices about HIV prevention and sexual and reproductive health (SRH). A table showing barriers and enablers that were identified is shown on the next page of this report.

Participants were asked to share their suggestions and priorities for how the barriers they identified could be overcome, to ensure AGYW could access information, services and support and make and enact their own choices. Changes identified included more information and services to be provided in rural areas, increased media and social media campaigns, support and interventions for parents and guardians to be informed about the rights of AGYW, economic empowerment initiatives, investment in peer-to-peer learning and mentoring models, ensuring services are friendly, accessible and comprehensive.

## Discussion

Success in implementing PrEP is dependent on fulfilling all the stages in a complex process, which has been defined by Nunn et al as a continuum of nine steps:<sup>27</sup>

1. Identifying individuals at highest risk for contracting HIV
2. Increasing HIV risk awareness among those individuals
3. Enhancing PrEP awareness
4. Facilitating PrEP access
5. Linking to PrEP care
6. Prescribing PrEP
7. Initiating PrEP
8. Adhering to PrEP
9. Retaining individuals in PrEP care.

The LEARN research study aimed to explore knowledge, views and preferences of AGYW about PrEP in order to inform stages 3 through 9, while the mobilization and outreach activities as well as the Community Dialogues undertaken in the project supported stages 2 and 3.

In order for PrEP implementation and roll-out to work effectively for AGYW, investment, attention and

commitment is needed to ensure that accurate, comprehensive information about PrEP is made available to AGYW in all their diversity. Peer-led approaches, including peers using PrEP as role models, are valued highly by AGYW and felt to be more effective and accessible. Recognizing access barriers, information should be made available in different settings and through media and social media campaigns. AGYW demonstrated some knowledge of factors which increased vulnerability to HIV acquisition and their own level of risk, but more support is needed to provide counselling and guidance in accessible, non-judgmental settings to facilitate greater risk awareness.

There is a potential for stigma associated with PrEP use, and this may represent a barrier to uptake or retention in PrEP care. Knowing others who are using PrEP and being able to discuss concerns is critical to support adherence and ongoing PrEP use. Creating community-level awareness and acceptance of PrEP is also key, as outlined by Cowan et al: "raising community awareness using messages that resonate with young women to improve knowledge and establish norms around PrEP use and maximize its acceptability will be critical."<sup>28</sup>

The Population Council provides a conceptual framework of PrEP introduction for AGYW, a complex diagram indicating the range of factors that are relevant. In the framework, a range of contextual factors, players and relationships that can affect AGYW's health seeking behaviors and their PrEP uptake and use are depicted. Young women are positioned at the center and shown in the context of their partners, peers, family, health providers, social values/community contact and broader scientific knowledge about PrEP. These contextual factors can influence and interact with the choices AGYW make or are able to make. Broader community knowledge, young women's access to education, information and social support and their own HIV risk perceptions can significantly influence informed choice, uptake and use of PrEP.<sup>29</sup>

As PrEP implementation continues to scale up, further research is needed to understand the view, priorities and preferences of AGYW in specific local contexts.

\* Force field analysis is a group work activity in which participants are asked to consider a particular issue and discuss the things that make it harder or easier, coming up with specific barriers or enablers. It provides a framework to consider and explore the forces affecting an individual's behavior and actions in relation to the issue being explored.

## Barriers and enablers identified by AGYW in the Community Dialogues

BARRIERS	ENABLERS
<ul style="list-style-type: none"> <li>➤ Limited information and lack of knowledge about HIV prevention and SRH</li> <li>➤ Peer influence and peer pressure</li> <li>➤ Myths and misconceptions from peers and the community</li> <li>➤ Lack of healthcare personnel to do outreach e.g. in rural areas</li> <li>➤ Parents/guardians restricting information and access to services</li> <li>➤ Religious rules about contraceptive use</li> <li>➤ Poor communication in homes and with family</li> <li>➤ Poverty and lack of income for basic needs including food and transport</li> <li>➤ Increased risk of transactional sex due to poverty</li> <li>➤ Lack of respect for the rights of AGYW</li> <li>➤ Language barriers in health facilities</li> <li>➤ Male partners preventing AGYW attending meetings or services</li> <li>➤ Limited services in rural areas</li> <li>➤ Lack of confidence and fear about accessing services or information</li> <li>➤ Parental concerns or lack of information</li> <li>➤ Organizations that give inaccurate information</li> <li>➤ Fear about accessing services or finding out HIV status</li> <li>➤ Judgmental attitudes or unfriendly treatment from healthcare providers</li> <li>➤ Lack of confidentiality in services</li> <li>➤ Traditional and religious beliefs including spiritual healing and witchcraft</li> <li>➤ Lack of agency and decision-making</li> <li>➤ Limited respect for peer mentors</li> <li>➤ Inaccessible health services</li> <li>➤ Limited access to phones and social media to access information</li> <li>➤ Illiteracy or language barriers</li> <li>➤ Discrimination</li> <li>➤ Lack of assertiveness among AGYW</li> <li>➤ Practical barriers like limited time</li> <li>➤ Lack of knowledge about PrEP</li> </ul>	<ul style="list-style-type: none"> <li>➤ Community outreach</li> <li>➤ Peer education</li> <li>➤ School-based mobilization, peer education and sensitization activities</li> <li>➤ Media adverts and campaigns</li> <li>➤ Involving community and faith leaders and churches</li> <li>➤ Talks at health facilities</li> <li>➤ User friendly language for information and outreach</li> <li>➤ Community outreach e.g. posters</li> <li>➤ Counselors available at health facilities</li> <li>➤ Community mobilization and sensitization about HIV prevention.</li> <li>➤ Sharing information through radios and other communication channels</li> <li>➤ Accessible facilities providing HIV prevention information and services</li> <li>➤ Safe spaces for AGYW</li> <li>➤ Economic empowerment activities</li> <li>➤ Peer facilitators and mentors</li> <li>➤ Projects like DREAMS</li> <li>➤ Counselling, advice and information</li> <li>➤ Social media engagement</li> <li>➤ Friendship networks that provide positive support and accurate information</li> <li>➤ Parents who speak about SRH and HIV to their children</li> <li>➤ Condom distribution</li> <li>➤ Peer-to-peer learning</li> <li>➤ Open, friendly and non-judgmental healthcare workers</li> <li>➤ Youth friendly services</li> <li>➤ Role models</li> <li>➤ Parental guidance</li> <li>➤ Capacity building forums</li> <li>➤ Flyers, seminars and workshops on PrEP and family planning</li> <li>➤ Self-acceptance</li> <li>➤ Accessible and affordable services</li> <li>➤ PrEP outreach by AGYW</li> <li>➤ Accessible and available PrEP</li> </ul>

Additional research that includes individual interviews, and other participants such as partners, parents and healthcare workers, would also be of value.

Participants in this study frequently cited concerns about PrEP in pill form, and preferences for other implementation methods, especially injectables. This echoes earlier findings, from the VOICE-D qualitative follow up study with VOICE trial participants, explored their PrEP product formulation preferences.<sup>30</sup> 81% of 68 participants expressed a preference for products in the 'injectable, implant and vaginal ring' category. Important product attributes defined by participants

included duration of activity, ease of use and route of administration amongst others. These preferences show that oral PrEP is not enough and efforts must continue to broaden the range HIV prevention options.

Understanding how potential users of PrEP perceive PrEP can inform effective service design and delivery<sup>31</sup> and leads to improvements in retention in care. For AGYW in Mityana, Mubende and Mukono in Uganda, and Homa Bay and Nairobi in Kenya, perceptions include worry about side effects and how PrEP users will be perceived, and a context of limited access to choice, agency, information and services that make PrEP inaccessible.





Based on the views, priorities and preferences shared by adolescent girls and young women in the LEARN Community Dialogues, five clear recommendations emerge. Implementing these recommendations will support effective PrEP implementation and roll-out across all nine stages of the PrEP care continuum outlined in the previous section. This has implications for community sensitization, demand creation, service delivery, and policy and program development.

1. **Fulfilling and supporting the agency, choice and rights of all adolescent girls and young women is imperative.** Interventions that sensitize partners, parents and healthcare providers to recognize the rights of AGYW and to uphold their choice and agency are vital to overcome barriers that AGYW face to accessing PrEP and HIV prevention even where they recognize and want to address their vulnerability of HIV acquisition.
2. **Comprehensive, accurate and up-to-date information about PrEP is critically important.** AGYW want to learn about PrEP and be involved in discussions, and there is significant unmet need for accessible information and services that speaks to the lives and experiences of AGYW.
3. **Action is needed to remove barriers to services including healthcare provider attitudes, inaccessible services and poverty.** Improvements and investments in youth friendly services, and in making information and services available in all settings, is needed. Economic empowerment initiatives are sought and valued by AGYW who recognize poverty as a key barrier to protecting their sexual and reproductive health and preventing HIV acquisition.
4. **Peer-led information, sensitization, mobilization and support are valued and effective.** AGYW want to learn about, discuss and share experiences of PrEP with their peers, who are best placed to understand their point of view and share information that is accessible and understandable. AGYW who are using PrEP acting as role models would be effective.
5. **Research to develop new HIV prevention tools and options must continue.** PrEP as an oral pill is not appropriate or accessible for all AGYW, who describe dislike or fear of taking pills and concerns about taking multiple pills, if using PrEP alongside contraceptive pills. Injectable options were the preference of many AGYW taking part in Community Dialogues. PrEP packaging was also a source of concern, due to potential to be misidentified as HIV treatment.





*“The really exciting and innovative thing about the LEARN Project is that we young women are the ones leading it. Developing the research tools, supporting the analysis and from that, we will be developing advocacy strategies and communication messages to take out to adolescent girls and young women in our communities using language they can understand.”* **LEARN AMBASSADOR, UGANDA**

The best way to reach young women to understand their needs, desires, and preferences for HIV prevention, including roll-out and implementation of PrEP, is through the people who understand them better than anyone else - other young women like themselves. The LEARN Ambassadors have demonstrated their unique ability to reach their peers with knowledge about PrEP and

engaged AGYW about HIV prevention, PrEP and SRHR by going into their communities and talking to their peers. The LEARN research model was effective in reaching and engaging AGYW in all their diversity as research participants, yielding critical insights into the views, knowledge and preferences of AGYW about PrEP.

PrEP has the potential to significantly reduce the disproportionate burden of HIV acquisition among AGYW in Sub-Saharan Africa. Achieving this potential depends on effective implementation and roll-out that recognizes and addresses the barriers AGYW face in accessing information, understanding their potential vulnerability to HIV acquisition, and in uptake, adherence and retention to PrEP. The recommendations that emerged from the LEARN research study offer a critical blueprint to achieving this.





## References

- UNAIDS (2016), *Global Aids Update*.
- UNAIDS (2014), *The Gap Report*.
- CDC (2017), *HIV Risk and Prevention: PrEP*. <http://www.cdc.gov/hiv/risk/prep/>
- Global Fund (2017), *Technical brief: adolescent girls and young women in high-HIV burden settings*. [https://www.theglobalfund.org/media/4576/core\\_adolescentgirlsandyoungwomen\\_technicalbrief\\_en.pdf](https://www.theglobalfund.org/media/4576/core_adolescentgirlsandyoungwomen_technicalbrief_en.pdf)
- UNAIDS (2014), *Kenya HIV epidemic profile*. <http://www.unaids.org/en/regionscountries/countries/kenya>
- Idele, Priscilla et al. "Epidemiology of HIV and AIDS Among Adolescents". *JAIDS Journal of Acquired Immune Deficiency Syndromes* 66 (2014): S144-S153.
- Kenya AIDS Indicator Survey (2007 & 2012). <http://www.prb.org/pdf09/kaiskenyadatasheet.pdf>, [http://www.unaids.org/sites/default/files/country/documents/KEN\\_narrative\\_report\\_2014.pdf](http://www.unaids.org/sites/default/files/country/documents/KEN_narrative_report_2014.pdf)
- Uganda AIDS Indicator Survey (2011). <https://dhsprogram.com/pubs/pdf/AIS10/AIS10.pdf>
- National AIDS Control Council (2015), *Kenya's Fast-track Plan To End HIV and AIDS Among Adolescents and Young People*. Retrieved from <http://www.lvcthealth.org/online-library?format=raw&task=download&fid=55>
- PEPFAR, USAID (2014), LQAS in 60 districts under USAID. [http://www.unaids.org/sites/default/files/country/documents/UGA\\_narrative\\_report\\_2015.pdf](http://www.unaids.org/sites/default/files/country/documents/UGA_narrative_report_2015.pdf)
- WHO. Guidance on oral pre-exposure prophylaxis (PrEP) for serodiscordant couples, men and transgender women who have sex with men at high risk of HIV. 2012. Available from: [http://www.who.int/hiv/pub/guidance\\_prep/en/](http://www.who.int/hiv/pub/guidance_prep/en/)
- Baggaley, Rachel et al. "Beyond The 90-90-90: Refocusing HIV Prevention as Part of the Global HIV Response". *Journal of the International AIDS Society* 19:1 (2016).
- WHO (2015), WHO expands recommendation on oral pre-exposure prophylaxis of HIV infection (PrEP). [http://apps.who.int/iris/bitstream/10665/197906/1/WHO\\_HIV\\_2015.48\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/197906/1/WHO_HIV_2015.48_eng.pdf?ua=1)
- NASCOP (2017), *Framework for the Implementation of Pre-Exposure Prophylaxis of HIV in Kenya*. Retrieved from: [https://www.prepwatch.org/wp-content/uploads/2017/05/Kenya\\_PrEP\\_Implementation\\_Framework-1.pdf](https://www.prepwatch.org/wp-content/uploads/2017/05/Kenya_PrEP_Implementation_Framework-1.pdf)
- Ministry of Health, Uganda (2016), *Consolidated Guidelines for Prevention and Treatment of HIV in Uganda*. Retrieved from: [https://www.prepwatch.org/wp-content/uploads/2017/08/consolidated\\_guidelines\\_hiv\\_prevention\\_uganda.pdf](https://www.prepwatch.org/wp-content/uploads/2017/08/consolidated_guidelines_hiv_prevention_uganda.pdf)
- AVAC, PrEP Watch (2017). <http://www.prepwatch.org/>
- WHO (2015), Policy brief on oral pre-exposure prophylaxis of HIV infection. <http://www.who.int/hiv/pub/prep/policy-brief-prep-2015/en/>
- ATHENA Initiative (2017), *A Review of the Pre-Exposure Prophylaxis (PrEP) Research and Evidence Landscape in Kenya and Uganda for adolescent girls and young women*. <http://www.athenanetwork.org/assets/files/LEARN/ATHENA%20Initiative,%20review%20of%20PrEP%20and%20AGYW,%20LEARN%20project%202017.pdf>
- Van Damme, L., Corneli, A., Ahmed, K., Agot, K., Lombaard, J., & Kapiga, S., et al. (2012). Preexposure Prophylaxis for HIV Infection among African Women. *The New England Journal Of Medicine*, (367), 411-422. <http://dx.doi.org/10.1056/NEJMoal202614>
- Thomson, K., Baeten, J., Mugo, N., Bekker, L., Celum, C. & Heffron, R. (2016). "Tenofvir-based oral PrEP prevents HIV infection among women". *Current Opinion in HIV and AIDS*, 11(1), pp.18-26.
- Baeten JM, Donnell D, Ndase P, Mugo NR, Campbell JD, Wangisi J, et al. "Antiretroviral prophylaxis for HIV prevention in heterosexual men and women". *New England J Med*. 2012 Aug 2;367(5):399-410.
- Thigpen MC, Kebaabetswe PM, Paxton LA, Smith DK, Rose CE, Segolodi TM, et al. "Antiretroviral preexposure prophylaxis for heterosexual HIV transmission in Botswana". *New England J Med*. 2012 Aug 2;367(5):423-34.
- Bekker LG, Hughes JP, Amico KR, Roux S, Hendrix C, Anderson PL, et al. (2015). HPTN 067/ADAPT Cape Town: a comparison of daily and nondaily PrEP dosing in African women.
- Gill, K. (presenter), Dietrich, J., Pidwell, T., Kayamba, F., Bennie, T., & Myer, L. et al. (2017). Pluspills: an open label, safety and feasibility study of oral pre-exposure prophylaxis (PrEP) in 15-19 year old adolescents in two sites in South Africa. In 9th International AIDS Society Conference on HIV Science. Paris, France. Retrieved from <https://www.youtube.com/watch?v=MlhjTsqpN0&feature=youtu.be>



**30 LEARN: What does PrEP mean for young women?**

25. ATHENA, GYCA, International HIV/AIDS Alliance. [http://www.athenanetwork.org/assets/files/Link%20Up/Link-Up-com%20dialogue\\_prep-FINAL.pdf](http://www.athenanetwork.org/assets/files/Link%20Up/Link-Up-com%20dialogue_prep-FINAL.pdf)
26. ATHENA, #WhatWomenWant, *HIV prevention that works for adolescent girls and young women*. [http://www.athenanetwork.org/assets/files/WhatWomenWant/ATHENA%20WhatWomenWant\\_AGYW%20powering%20HIV%20prevention\\_2017.pdf](http://www.athenanetwork.org/assets/files/WhatWomenWant/ATHENA%20WhatWomenWant_AGYW%20powering%20HIV%20prevention_2017.pdf)
27. Nunn, A. S., Lauren Brinkley-Rubinstein, Catherine E Oldenburg, et al. 2017. Defining the HIV pre-exposure prophylaxis care continuum. *AIDS*. 2017 Mar 13; 31(5): 731-734.
28. Cowan, F.M. et al, "PrEP implementation research in Africa: what is new?" *Journal of International AIDS Society* 2016; 19(7Suppl 6)
29. Population Council (2016), Building evidence to guide PrEP introduction for adolescent girls and young women.
30. Luecke EH, Cheng H, Woeber K, et al. Stated product formulation preferences for HIV pre-exposure prophylaxis among women in the VOICE-D (MTN-003D) study. *Journal of the International AIDS Society*. 2016;19(1):20875. doi:10.7448/IAS.19.1.20875.
31. Koechlin, F.M., Fonner, V.A., Dalglish, S.L. et al. *AIDS Behav* (2017) 21: 1325. <https://doi.org/10.1007/s10461-016-1627-z>.





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RESEARCH, NETWORK

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