



Visions, voices, and priorities*

YOUNG PEOPLE TALK ABOUT PRE-EXPOSURE PROPHYLAXIS (PrEP)

1 **Young people want quality sexual and reproductive health services, from ethical and well-trained health service providers, with services tailored to their needs, rights and desires – especially as young people living with and most affected by HIV.**

PrEP implementation should prioritise availability and accessibility, as well as accurate, clear and comprehensive information on the use of PrEP as part of a HIV prevention package, and on wider issues such as adherence, side effects, possible drug interactions, safer sex including STI and pregnancy prevention. PrEP should not be offered as a stand alone prevention method. Young people should be partners in service design and PrEP preparedness.

2 **Young people want to enjoy their sexual and reproductive rights, including the freedom to love and be loved safely.**

PrEP can present an opportunity for young people to explore their sexuality safely, particularly those who are most vulnerable to acquiring HIV. Benefits of PrEP use could include feeling confident and safe in sexual relationships; this was especially important for sex workers if clients refuse to use a condom. There were concerns around identifying and defining HIV 'risk' and it is important that programming addresses this in an inclusive and non-stigmatising way. **It is critical to HIV reduction that PrEP is not treated as a stand-alone prevention method** – but part of a comprehensive package that should be used in tandem with condoms and other prevention methods, sexual and reproductive health services including family planning, as well as behavioural and structural interventions.

3 **Young people want full access to information and education on HIV and sexual and reproductive health and rights (SRHR), including on sexual orientation and gender identity.**

Prevention and treatment literacy was recognised as an important element of PrEP roll-out and one that young people felt they could play a leading role in (with the proper

technical support and resourcing). They identified a need for the community to be fully aware and sensitised on HIV, risk perception and behavior, adherence, treatment literacy and possible side effects, and that this should be peer-led and driven. Informational needs identified include the need for clarity between pre- and post-exposure prophylaxis, the role of HIV testing in PrEP use, adherence and use with condoms and family planning, efficacy and possible side effects, interactions (such as with methadone for people who use drugs) and co-infections.

4 **Young people seek gender equality and to see an end to gender-based violence, including sexual violence, in all its forms, including because of sexual orientation or gender identity.**

Particular concerns about the impact of PrEP access and uptake on young women and on young people who sell sex were identified, especially the potential for condom use to become more difficult for girls, young women, and young people who sell sex (of all genders) to negotiate. It is essential that community education, advocacy and programming around PrEP take these issues into consideration, and that people planning to use PrEP are made fully aware of its limitations and supported with a full range of SRHR and HIV prevention information and commodities.

5 **Young people, in all their diversity, want to be a meaningful part of the solution, and participate in the decision-making that affects their lives.**

Young people should be involved in advocacy, programme development, community mobilisation and comprehensive education campaigns around PrEP. Young people from key populations should be involved in advocacy and programme design, and represented in policy fora. They should be adequately informed, supported and resourced to do this work (both technically and financially).

* The Link Up Visions, Voices and Priorities consultation created a five-point framework for programming and advocacy designed by and for young people living with and most affected by HIV. This issue brief applies the framework to Adolescent access to HIV care and treatment services. See www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people



Background and introduction

The original *Visions, Voices, and Priorities* report¹ shares the findings of a global consultation carried out by the ATHENA Network and the Global Youth Coalition on HIV and AIDS (GYCA) in partnership with local community-based organisations as part of the Link Up project in 2013. The consultation explored access to and priorities for SRHR for young people living with and most affected by HIV,² through an on-line survey and community dialogues involving over 1,200 young people. Near the end of the Link Up project in 2016, three new areas of focus within the HIV and SRHR spheres were identified for further consultation:

- Access to HIV treatment and care among adolescents living with HIV – with attention to adherence and staying in care
- Attitudes toward and perceptions about pre-exposure prophylaxis (PrEP)
- Attitudes toward and perceived benefits and challenges of self-testing for HIV among different key populations and age groups.

Although PrEP is not yet available in many countries, its approval and use as a method of HIV prevention is gaining momentum globally. However, gaps remain in the understanding of how different age groups and populations of people most impacted by HIV perceive the benefits and utility of PrEP, and how they would like to see it rolled out in their communities. This dialogue was undertaken in order to explore and understand the knowledge and perceptions of young people living with and most affected by HIV around PrEP access, utilisation and adherence. It was particularly important for us to emphasise that **PrEP cannot be treated as a standalone prevention method, and will only be effective when used holistically with other HIV prevention tools and a comprehensive package of SRH services, including STI and pregnancy prevention/family planning.**

Methodology

Link Up supported five community dialogues in Uganda, Burundi, Ethiopia and Myanmar, involving 63 young people including young women who sell sex (Myanmar, Burundi, Uganda), young people and adolescents living with HIV and adolescent mothers (Uganda), and young men who have sex with men (Myanmar and Burundi). These dialogues were led by and for young people living with and most affected by HIV. The results of the dialogue were validated in a meeting in Yangon, Myanmar in June 2016, and further validated among participants virtually in July 2016. Each community dialogue was facilitated using a discussion guide, which included a set of key questions and background information on PrEP (see box below).



“Me, I’m MSM and a sex worker, so you see I am doubly vulnerable to HIV. PrEP would help me a lot with prevention.”

YOUNG MAN WHO HAS SEX WITH MEN, AND SELLS SEX, BURUNDI

1. *HIV and sexual and reproductive health and rights: visions, voices, and priorities of young people living with and most affected by HIV*. Available at: www.aidsalliance.org/resources/510-report-visions-voices-and-priorities-of-young-people

2. In this case, “most affected” refers to young people at elevated risk of HIV exposure such as young women, young people who sell sex, young people who identify as lesbian, gay, bisexual, or transgender (LGBT), or young men who have sex with men.

ABOUT PrEP

- **What is PrEP?** PrEP, or pre-exposure prophylaxis, is a type of HIV prevention that uses antiretroviral drugs. A person who does not have HIV but does have a higher risk of acquiring it, takes a pill every day, that prevents them from getting HIV.
- **How does it work?** PrEP uses a drug that is also used as HIV treatment. When someone who is HIV-negative takes it, it greatly reduces the chances that they will acquire HIV if they are exposed to it. For PrEP to be effective, it is essential that the person using it has good adherence, taking the drug when they are supposed to. In some trials, participants have found this challenging.
- **Can I access it?** PrEP is not yet available in many countries. But many advocates are calling for it to be made available.
- **Are there any side effects?** There can be some side effects at first (such as nausea and headaches) these generally reduce after a few weeks of use. People who take PrEP should have regular sexual health check-ups, including HIV testing to ensure the medication is working.



“It should be taken because we cannot see HIV, so it is better to prevent it by taking PrEP.”

YOUNG PERSON WHO SELLS SEX, MYANMAR

Key findings from the dialogues

POSITIVE PERCEPTIONS, OPPORTUNITIES AND BENEFITS

Participants' views on whether they would take PrEP were mixed, with some participants indicating that they would take PrEP as a preferable alternative to acquiring HIV and requiring life-long treatment. Others valued PrEP as an effective prevention tool. They described a range of opportunities that PrEP might offer for young people, including increased agency and freedom to young people who are living with HIV and their HIV-negative partners, and to young people who sell sex. On several occasions PrEP was welcomed as a safe alternative to using condoms, further underscoring the need for comprehensive education programming around PrEP and its uses, as well as its potential benefits and risks.

PRIORITY ACCESS TO PrEP

While some participants expressed reservations about the effect PrEP would have on HIV prevention and safer sex practices among the general population (see below), many recognised its value as a critical piece of a comprehensive prevention package for those at elevated risk of HIV exposure, and felt that it should be made available and promoted to HIV-negative partners of people living with HIV, sex workers, people who use drugs and men who have sex with men, among others:

"PrEP improves or promotes the right of sexual satisfaction on the side of the young people living with HIV."

YOUNG MAN LIVING WITH HIV, 17, UGANDA

PERCEIVED CHALLENGES AND BARRIERS

By far the most frequently cited challenge expressed among participants was the concern that access to PrEP would have a negative impact on condom use for the prevention of HIV, unwanted pregnancy and other sexually transmitted infections (STIs). In particular they were concerned that it would become more difficult for young women and girls to negotiate condom use. For some participants, this was linked to a sense of young people in particular lacking the skills or access to information to make fully informed choices. Responses also reflected a concern that young people might be more afraid of HIV than pregnancy, choosing to protect themselves from one over both. Some suggested that educational information would be necessary to avoid these challenges.

"There will be a large decrease in the use of condoms because people are afraid of getting AIDS, not to get pregnant."

YOUNG WOMAN WHO SELLS SEX, BURUNDI

"When people start taking PrEP it will be like giving a free pass/a go ahead for youth to have unprotected sex because PrEP will be making them feel secure and not minding about other STIs."

ADOLESCENT WOMAN WHO SELLS SEX, UGANDA

Participants also identified a range of challenges that might come alongside using PrEP, in particular concerns around stigma, side effects, how PrEP would integrate into the lives and lifestyles of young people, and the impact it might have on romantic relationships.

The potential to forego condom use and rely on the protection afforded by PrEP was also mentioned as a perceived benefit. PrEP education campaigns are needed to fully inform users on the need for PrEP to be used as part of an integrated HIV/SRHR regime and not as a standalone prevention tool.

HIV-RELATED STIGMA AND DISCRIMINATION

One participant suggested that using PrEP could expose them to stigma if they were seen using it, while others expressed stigmatising sentiments themselves – unwilling to use PrEP because they felt doing so meant that they were 'like' people who had HIV, or willing to have sex with an HIV-positive person. However, other participants saw that PrEP could have a positive effect on HIV-related stigma.

"[PrEP] could change the way people see people living with HIV, and that could reduce discrimination. People will see that it's not the end of the world having HIV."

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI



"Personally I think it will help HIV-positive people because

we can see couples where there is one person who is infected without risk of infecting his partner with the PrEP."

YOUNG WOMAN WHO SELLS SEX, BURUNDI



"I am seeing a free generation from HIV where there is no

HIV transmission because people are taking treatment PrEP. It creates confidence among partners, this is if my boyfriend is positive living and I am taking PrEP."

YOUNG WOMAN LIVING WITH HIV, 14, UGANDA



"During [my] stay in high school many girls used to get pregnant.

Guys often say they don't like condoms as it decreases the pleasure and when a girl says to use one and keeps on insisting, she was regarded as backward and not cool. The only leverage girls had was HIV, and with PrEP the little ground girls had would be lost."

YOUNG PERSON, ETHIOPIA



"PrEP pill is known as ARVs when people take it others might think that you're HIV-positive hence stigmatising you."

ADOLESCENT WOMAN WHO SELLS SEX, UGANDA



"If I take PrEP, then I am believing and becoming okay

to engage in an intercourse with an HIV-positive individual"

YOUNG PERSON, ETHIOPIA



“Young people are restless. They go around a lot like in vacations, school trips, clubbing and what not ... at such time, taking PrEP is probably going to be the last thing on their mind. The problem lies in trusting the young people be reminded to take it daily. We have seen cases where young people often neglect from taking mandatory medicines let alone an optional one like PrEP”

YOUNG PERSON, ETHIOPIA



“I would like to be the source for PrEP I want to be able to deliver PrEP to my fellow youths the same way I do on condoms.”

YOUNG TRANSGENDER PERSON LIVING WITH HIV, 18, UGANDA



“The challenges I see, is access to PrEP because it is not everyone who can access these medicines.”

YOUNG WOMAN WHO SELLS SEX, BURUNDI



“I think it is the parents who are going to be an obstacle because if she hears that her child wants to take the PrEP, parent will oppose because she will think that the young wants unprotected sex and more in Burundi sexuality is a taboo subject.”

YOUNG WOMAN WHO SELLS SEX, BURUNDI

SIDE EFFECTS AND ADHERENCE

Adherence challenges, including side effects, mirror those often associated with taking ARVs. A few participants also felt that these challenges were greater for people taking medications when they themselves were not ill.

“PrEP leads to side effects like headache, nausea like ARVs which is a challenge.”

YOUNG WOMEN AND MEN LIVING WITH HIV, UGANDA

“If someone has to take both contraceptives and PrEP, the number of pills will be increased.”

YOUNG MAN WHO HAS SEX WITH MEN, MYANMAR

One participant also pointed out the importance of risk perception in relation to adherence:

“There are some who will accept [PrEP] and some who will not. I think that young MSM and sex workers will accept taking PrEP for prevention, but other young people who only have occasional sexual relationships are not going to adhere, especially with the side effects that can scare young people.”

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI

While not explicitly stated in the dialogues, implications for more attention to be dedicated to defining and assessing individual risk in relation to HIV acquisition and determining PrEP use that considers the cost, burden and potential health risks of adhering to medication regime in low prevalence contexts.

Some have raised concerns that PrEP use might lead to further opportunities for drug resistant strains of HIV to develop. Drug resistance that develops while a person is on PrEP would limit treatment options for those who subsequently become infected with a drug-resistant strain. Instances might be rare but data on PrEP and drug resistance is scant.

PrEP ADVOCACY AND IMPLEMENTATION

Participants identified a role for young people in advocacy and roll-out of PrEP in their countries and communities. In low prevalence countries, such as Bangladesh, PrEP is unlikely to be widely available, however, it is still important for young SRHR and HIV champions to be aware of the role of PrEP as an HIV prevention tool, and to have a voice in the global discourse around PrEP.

“Young people should be involved in planning how PrEP will be implemented ... because they are better informed about their needs and strategies to use.”

YOUNG WOMAN WHO DOES SEX WORK, BURUNDI

“I want to advocate for free access of PrEP without pay such that it becomes affordable and available for the low income earners and youths who are school-going but sexually active.”

YOUNG MAN LIVING WITH HIV, 18, UGANDA

“Youth should be involved in sharing information to educate other young people about the existence of PrEP treatment and where they can get it.”

YOUNG MAN WHO HAS SEX WITH MEN, BURUNDI

LIMITED AVAILABILITY AND BARRIERS TO ACCESS

Currently PrEP is available in only 20 countries, and is yet to be introduced in any of the FDG settings. Access to ARVs for people living with HIV and general access to SRHR services continues to be barrier for young people. Participants theorised how access barriers could follow PrEP launches in their countries.

“It can be a problem, just like when ART cannot be sufficiently supplied.”

YOUNG MAN WHO HAS SEX WITH MEN, MYANMAR

LINKUP

Link Up has improved the sexual and reproductive health and rights (SRHR) of almost 940,000 young people affected by HIV across five countries in Africa and Asia. The project is being implemented by a consortium of partners led by the International HIV/AIDS Alliance. For more information visit: www.aidsalliance.org/linkup

Special thanks to our country partners who led the dialogues: **Bangladesh:** Rokonol Rabbi (GYCA) and Moly Farhana (ATHENA Network). **Burundi:** Cédric Nininahazwe and Mona Ndayizeye (HUMURE). **Ethiopia:** Yoadan Workneh Shiferaw and Akllilu Guulay (Talent Youth Association); Hanna Hagos (Nikat Charitable Association). **Myanmar:** Chan Aye San, Ei Mon Kyaw, Moe Kyaw and Myo Thet Oo, (Myanmar Youth Stars). **Uganda:** Allen Kyendikuwa, Mariam Nassaka and Charles Bwire (Uganda Youth Coalition on Adolescent SRHR and HIV (CYSRA-Uganda)); Brian Ssensalire, Stanley Nsubuga and Resty Nalwanga, (Uganda Network of Young People Living With HIV (UNYPAL)). Photo © International HIV/AIDS Alliance

