



KEY POPULATION ACTIVIST TOOLKIT **PrEP**

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About ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003 by a group of 125 HIV activists from 65 countries at a meeting in Cape Town, South Africa, ITPC actively advocates for treatment access in eight regions across the globe, including Africa, Asia, Latin American and the Caribbean, Eastern Europe, and the Middle East. ITPC believes that the fight for HIV treatment remains one of the most significant global social justice issues.

ITPC embarked on an initiative to develop and implement innovative community-led demand creation solutions for access to and use of oral pre-exposure prophylaxis (PrEP) for HIV by key populations. This initiative included hosting a global think tank meeting, conducting a preliminary desk review of global community perspectives on PrEP, articulating key PrEP messages by key population networks and PrEP experts in a policy brief, and the development of this toolkit.

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INTRODUCTION

This section introduces the PrEP toolkit, what it is about, why it is important, what it contains, and how it can be used.

Key Acronyms

ARV	Antiretroviral	PLHIV	People living with HIV
FTC	Emtricitabine	PWID	People who inject drugs
HTC	HIV testing and counselling	PEP	Post-exposure prophylaxis
HIV	Human immunodeficiency virus	PEPFAR	US President's Emergency Plan for AIDS Relief
INPUD	International Network of People who Inject Drugs	PrEP	Pre-exposure prophylaxis
KP	Key population	STI	Sexually transmitted infection
LGBTI	Lesbian, gay, bisexual, trans and intersex	TDF	Tenofovir
MSM	Men who have sex with men	UN	United Nations
MSMGF	Global Forum on MSM & HIV	UNAIDS	Joint United Nations Programme on HIV and AIDS
NSWP	Global Network of Sex Worker Projects	WHO	World Health Organization

Why a toolkit to promote community-led demand creation solutions for PrEP for key populations?

The rate of new HIV infections among adults globally remains the same, but in some locations and some populations, the rates have risen. It is good news that the annual global number of new HIV infections among adults (15 years+) has remained static at about 1.9 million. However, there has been a troubling rise in new HIV infections among adults in many parts of the world, including many countries in South America, Central and Eastern Europe, the Asia-Pacific region and Africa.¹

Key populations are among the most at risk of HIV infection. This toolkit focuses on preventing HIV among key populations – sex workers², people who inject drugs, transgender people, and gay men and other men who have sex with men. Globally, key populations are 10-24 times more at risk of contracting HIV than adults in the general population.³ In 2015, infections among key populations accounted for 36% of all new infections.

¹ UNAIDS. *Prevention Gap Report*. 2016.

² The UNAIDS Guidance Note on HIV and Sex Work (2012) defines sex workers as female, male and transgender adults and young people who receive money or goods in exchange for sexual services, either regularly or occasionally. Sex work varies between and within countries and communities. Sex work may vary in the degree to which it is more or less “formal” or organized, and in the degree to which it is distinct from other social and sexual relationships and types of sexual economic exchange.

³ UNAIDS. Special analysis, 2016; Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *The Lancet Infectious Diseases*. 13(3): 214-222. March 2013.

Key populations stand to benefit from PrEP services. Based on the findings of clinical PrEP research, the World Health Organization (WHO) recommends that oral PrEP be offered to people who are HIV negative and at increased risk of HIV infection. PrEP is recommended in addition to and in combination with other HIV prevention services, such as condoms, male circumcision, antiretrovirals (ARVs) for people living with HIV (PLHIV) and drug harm reduction services.

PrEP is not yet widely available and barriers to PrEP access are making PrEP uptake unequal. About 100,000 people in 30 countries were estimated to be accessing PrEP in late 2016. Gradually, countries are enabling access to PrEP through research/demonstration projects and pilot programmes. In many countries, individuals can buy PrEP privately. However, many countries still do not have national PrEP programmes and many people may not be able to afford to access PrEP services privately. Also, there are several other barriers to enabling key populations to access PrEP, including widespread lack of awareness about it, stigma and discrimination in healthcare settings, and legal and social environments that are hostile to key populations.

Access to PrEP is a human right to health. People who need PrEP have a right to access it as a human right to health. Governments have a duty to progressively enable access to PrEP for those in need. According to the standards of health rights, PrEP should be progressively made available, affordable and accessible, and be offered in a manner that is appropriate to the needs and responsive to the concerns of the communities to which it is delivered.

Community demand for PrEP is essential for enabling access. Community-led demand efforts, whether PrEP services are widely available or not at all, can influence the success of PrEP programming, including influencing how accessible PrEP services are to the community, whether people actually choose to take PrEP, and whether these services are being offered in a way that is suited to the needs of PrEP users.

What is the aim of this toolkit?

There are three main aims of this toolkit:

- To equip community activists with the knowledge and skills that they need around PrEP, advocacy and community mobilization so that they are able to mobilize their communities to demand PrEP
- To enable community PrEP activists to advocate with their governments and service providers to allow key populations access to PrEP services
- To ensure that these services are provided in a manner that is affordable, appropriate to their needs, and addresses access barriers.

How was the toolkit developed?

Before the toolkit was drafted, ITPC conducted a literature review that included discussions with key population networks and that explored the perspectives of key populations and global key population network organizations on PrEP. Some of the areas it covered were:

- Whether they believe PrEP is or could be beneficial to them
- The concerns that they have about PrEP
- Recommendations that they have for making PrEP accessible to their communities.

The literature review also gave an overview of past and current efforts in PrEP research and implementation at country level, as well as how WHO and other United Nations (UN) agencies recommend that PrEP be rolled out.

The literature review found that those key populations consulted with generally believe PrEP to be beneficial to their communities, but they raised a number of concerns and made several recommendations about how it should be implemented.

The toolkit was also informed by the discussions and information shared at a global think tank meeting that ITPC hosted in Trinidad & Tobago. Participants from several parts of the world represented a variety of audiences, including key population communities, the PrEP research community, treatment activists, WHO, UN agencies and ministries of health. At this meeting, participants shared information on PrEP research and implementation projects, and discussed the variety of considerations in order to make PrEP available to those in need. They also made recommendations about how PrEP should be implemented. Members of this think tank then volunteered to help design the toolkit, offer information for its content and review it.

Is this toolkit for you?

The toolkit is intended for individuals, organizations and networks – particularly those representing key populations – wanting to:

- Learn more about PrEP
- Contribute to preventing the spread of HIV in their communities
- Gain the knowledge and skills that they need to mobilize their communities and advocate with community leaders and decision makers for access to PrEP.

The toolkit was primarily designed to be used by a trainer to train others in a participatory learning environment.

Know your community

Who are most at risk of HIV infection in my community?

Are they accessing PrEP? Why? Why not?

How is the toolkit organized?

The toolkit is divided into four chapters, then one or several sessions, and then smaller units of activities. You can use one or all of the sessions in the chapter, and even only one or several of the activities, depending on your need.

- **INTRODUCTION TO THE CHAPTER** Provides an overview of the whole chapter, why it is important and what it seeks to achieve holistically.
- **SECTIONS** Each chapter is broken down into sections that will take no longer than two hours each to work through. Each section is further broken down into activities. Sometimes different activity options are provided. Each activity is further broken down into steps that the facilitator takes to complete the section. Each session contains the following:
- **OBJECTIVE** Each session has an objective(s) that explains what it seeks to achieve and how the participants can demonstrate their learning.
- **TIME** An estimate is made of time needed for each activity.
- **MATERIALS NEEDED** Reference is made to any additional materials or resources needed, such as a PowerPoint presentation. It should be assumed that general training supplies, such as flipchart paper, markers and tape, as well as pens and notebooks for participants, should always be available. This instruction will not be repeated again in the document.

How is the toolkit to be used?

The toolkit is a participatory learning guide for trainers that help participants learn by DOING – by sharing ideas and experiences, discussing and analysing issues, identifying opportunities, coming up with solutions to problems, and planning next steps.

The toolkit is also designed to facilitate ACTION – to help communities not only learn about PrEP, but also act on that awareness by planning and implementing advocacy activities in their communities. The trainer does not need to use all of the sections. Depending on the aim of the training, the audience and the duration of the training event, the trainer can pick and choose sections or even just activities from different sections to make their own unique training curriculum. The toolkit can also be used as a resource for personal learning.

Tips for training for learning & action

Prepare yourself

- Do your homework. Read the toolkit. Find out more about PrEP research and how it is being implemented with key populations around the world.
- Know your community. Find out more about whether PrEP is available and if key population communities in your area are accessing it.
- Prepare your training session. Things to think about: How much time do you have? Who am I training and how many are they? How comfortable are my participants reading and writing? What language should I use to train and do I need to translate my materials? How literate are they? What training resources do I need (presentations, stationery, PowerPoint projector and electricity)?

Encourage learning, sharing and action

- As you go through the training, encourage your participants to take responsibility for their learning and to ask any questions if they don't understand, no matter what the question is.
- Remind your participants that they have a lot of information that is valuable to the training from their own personal experiences and their knowledge of their community. Encourage them to share it with you and the other participants.
- Since an important end goal is for participants to be able to do things in their community that help improve access to PrEP, keep reminding your participants to think about “what does this mean for my community?” throughout each section.

READ THIS FOR MORE INFORMATION

International HIV/AIDS Alliance. [*A Facilitators' Guide to Participatory Workshops with NGOs/CBOs Responding to HIV/AIDS*](#). December 2003

International HIV/AIDS Alliance. [*Ways to Energize Groups: Games to Use in Workshops, Meetings and the Community*](#). December 2003

1

PREVENTING HIV INFECTION AMONG KEY POPULATIONS

Sections contained in this chapter:

Section 1.1 **Who are key populations in the context of HIV prevention?**

Section 1.2 **Global HIV prevention goals, objectives and interventions with key populations**

READ THIS FOR MORE INFORMATION

International HIV/AIDS Alliance. [Tools Together Now!](#)

UNAIDS. [Prevention Gap Report](#). 2016

[Policy Brief: WHO Expands Recommendation on Oral Pre-exposure Prophylaxis of HIV infection \(PrEP\)](#). 2015

Avert. [What is Pre-Exposure Prophylaxis?](#)

Section 1.1 Who are key populations in the context of HIV prevention?

Session objective

By the end of this session, participants will be able to:

- Describe the two characteristics of key populations
- Identify the specific populations that are often defined as key populations globally, discuss some reasons why they are at a higher risk of HIV infection, and describe some of the laws used against them or to deny them access to services.

Activity options

Activity A: General overview about HIV risk in and legal barriers against key populations

1. Give presentation: Overview: Who are key populations in the context of HIV prevention?
2. Get participants into groups to discuss:
 - Who are the key populations in your community and in what ways are they at a higher risk of HIV infection?
 - Do you know whether there are laws that criminalize them? What are they? How do these laws make it difficult for the key populations in your community to access services?
3. Give an opportunity for feedback.
4. Give participants an opportunity to ask questions and give comments.

Extended Activity B: Focus on specific key populations

After doing Activity A, you can also choose to discuss HIV risk and legal barriers of particular key populations. Use the key population focus information provided in the next section to guide your discussion.

Curriculum

Overview: Who are key populations in the context of HIV prevention?

The changing definition of “key populations”: In 2012, WHO defined “key populations” widely to include three categories:

- People living with HIV
- Most-at-risk populations: men who have sex with men (MSM), transgender people, people who inject drugs (PWID), and sex workers
- “Vulnerable groups”: people who are particularly vulnerable to HIV infection in certain situations, such as adolescents, orphans, people in closed settings (e.g., prisoners), people with disabilities, and migrant and mobile workers.

Over the years, the definition of “key populations” as provided by WHO and the Joint United Nations Programme on HIV and AIDS (UNAIDS) has gotten narrower and more specific. People working in HIV prevention are increasingly focusing their attention on country-level and community-level situations and looking at which populations are most in need. This is called a “**location-population approach**”. Also, the definition shows that people working in the HIV response understand that the issue of HIV is not only about the individual and the choices they make, but that structural and environmental factors, including laws, policies, stigma and discrimination, have a huge effect on the ability of people to take care of their health. In most countries where the HIV epidemic is generalized, the response has focused largely on the general population. According to WHO, even where the HIV epidemic is concentrated among certain key populations, there has been a reluctance to implement adequate interventions to reach those most in need.⁴ The HIV response will not be successful if the needs of key populations are not adequately addressed.

Who are key populations? According to WHO and UNAIDS, key populations are groups who, because of specific higher-risk behaviours, have an increased chance of becoming infected with HIV. They often have legal and social issues that block their access to services and increase risky behaviour.⁵

Key population groups as currently defined by UNAIDS*

- Gay men and other men who have sex with men (MSM)
- Sex workers
- Transgender people
- People who inject drugs (PWID)

(Source: UNAIDS Terminology Guidelines. 2015)

*These are the four main groups, but UNAIDS also recognizes that prisoners and other incarcerated people are vulnerable to HIV and lack access to services.

The two characteristics of key populations are closely linked. Often key populations engage in high-risk behaviour because they run the risk of being “found out”, stigmatized and discriminated against, arrested and even prosecuted because of their criminalized status. Other laws and policies that are hostile to key populations are also often used to deny them access to services and make it very difficult for them to access justice where their rights to health have been denied.

Key population groups often overlap in terms of the behaviours that put them at higher risk for HIV. For example, some sex workers also inject drugs and share syringes, and PWID may have sex without using condoms. In addition, many people from these groups may be incarcerated at some point and face risks related to sexual violence, increased drug use or lack of access to services related to this.

Key populations are defined as such because “their engagement is critical to a successful HIV response everywhere—they are key to the epidemic and key to the response”⁶ and countries should **define the specific populations that are key to their epidemic and response** based on the epidemiological and social context.

⁴ WHO. Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations: 2016 Update. 2016.

⁵ WHO. Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations: 2016 Update. 2016.

⁶ UNAIDS. Terminology Guidelines. 2015.

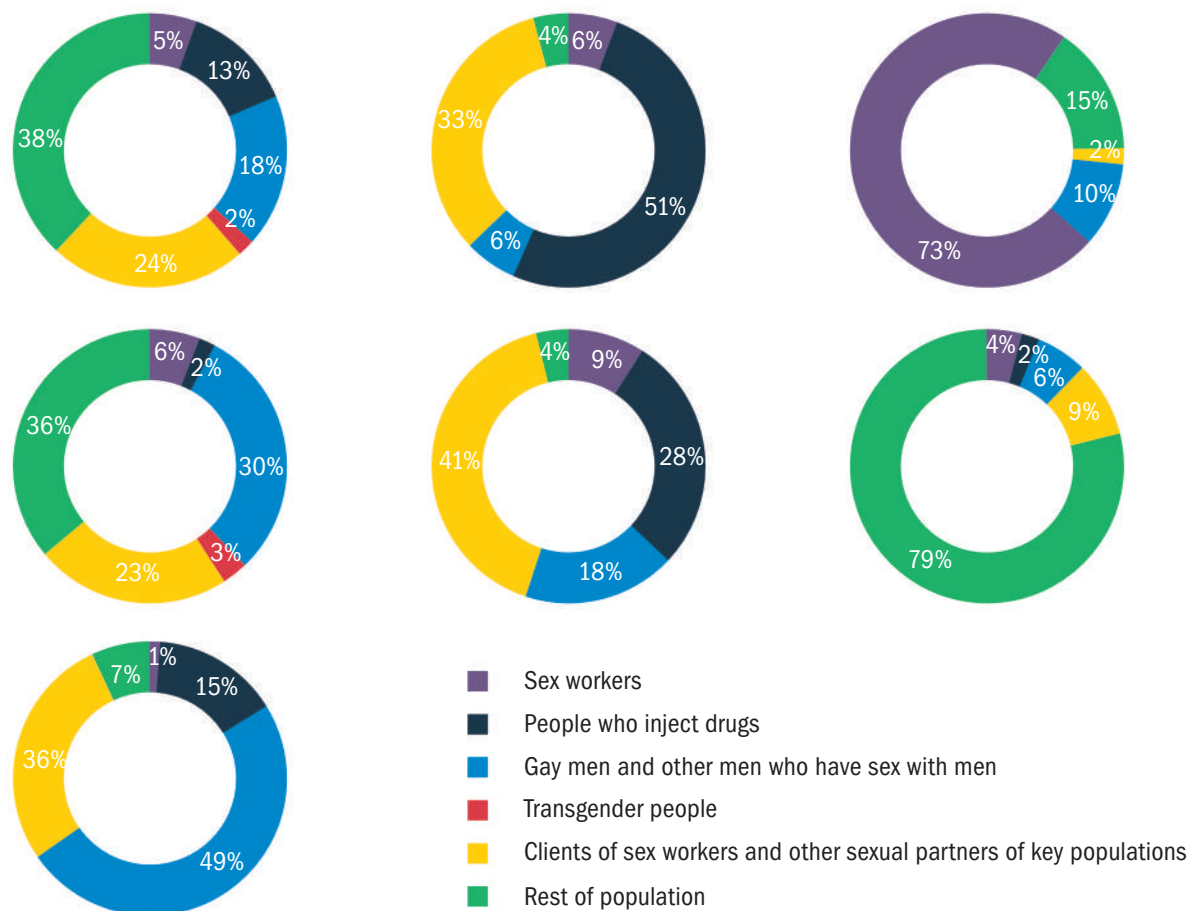
<p>Higher-risk behaviours</p>	<p>Sex workers are often offered more money to have unprotected sex with their clients or their clients may remove the condom during sex.</p> <p>People who inject drugs often share needles and syringes, for example, as a part of social bonding or because they do not have access to new needles.</p> <p>Young women and girls are often unable to negotiate safer sex because of unequal power dynamics with their sexual partners.</p> <p>Gay men and other MSM globally report low levels of consistent condom use.</p>
<p>Punitive laws, policies & hostile environments impeding access</p>	<p>The buying and/or selling of sex is effectively criminalized in many countries through a variety of laws. Police have taken condoms from sex workers, and condoms have been used as evidence in prosecutions. Sex workers also report being stigmatized, denied access to condoms, and having their privacy breached.</p> <p>Homosexuality is criminalized in 71 countries. In 13 countries, homosexuality is punishable by death. The risk of being “found out”, discriminated against or prosecuted makes it hard for MSM to access condoms, treatment of sexually transmitted infections (STIs) and other HIV prevention services.</p> <p>Illicit drug use is criminalized in many countries. Only 57% of countries that have documented illegal drug use have safe needle and syringe exchange programmes. PWID often have to share needles and syringes because they do not have access to clean ones, or because they don’t carry clean ones for fear of being searched by the police.</p> <p>Sex workers are often offered more money to have unprotected sex with their clients or their clients may remove the condom during sex.</p> <p>People who inject drugs often share needles and syringes, for example, as a part of social bonding or because they do not have access to new needles.</p> <p>Young women and girls are often unable to negotiate safer sex because of unequal power dynamics with their sexual partners.</p> <p>Gay men and other MSM globally report low levels of consistent condom use.</p>

New HIV infections among key populations: Key global facts

- Between 40% and 50% of all new infections worldwide occur among key populations and their immediate partners.⁷ In some countries in Asia and Eastern and Central Europe, among them account for 53-62% of all new infections are among key populations.⁸
- Globally, sex workers are 10 times more at risk of HIV infection than the general population. Gay men and other MSM and PWID are 24 times more at risk.
- Transgender people are 49 times more likely to be living with HIV than the general population.

⁷ WHO. Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations: 2016 Update. 2016.
⁸ WHO. Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations: 2016 Update. 2016.

Figure 1. Distribution of new HIV infections among population groups, by region, 2014



Methodological note: Estimated numbers of new HIV infections by key population were compiled from country Spectrum files submitted in 2015 to UNAIDS (2014 data), available modes-of-transmission studies and additional sources of data drawn from GARPR reports. Where data were lacking, regional medians were calculated from available data and applied to countries population.

Source: UNAIDS special analysis, 2016

Key population focus: HIV risk and legal barriers

GAY MEN AND OTHER MEN WHO HAVE SEX WITH MEN

WHAT DO THE NUMBERS SAY?

The rate of new infections among MSM is increasing in most countries, and the HIV prevalence among MSM in urban areas is about 13 times higher than in the general population.

In 2014, gay men and other MSM accounted for 54% of all new HIV infections in Western Europe, 68% in North America, and 30% in Latin America and the Caribbean.⁹

In Jamaica, one in three MSM is living with HIV.¹⁰

⁹ UNAIDS. Prevention Gap Report. 2016.

¹⁰ Jamaica Ministry of Health. Jamaica Country Progress Report. 2014.

Reasons for the high level of risk of HIV infection among MSM include:

- HIV is more easily transmitted through anal intercourse without a condom than vaginal intercourse without a condom
- High number of male partners
- High reporting of inconsistent condom use. In one study, only three of 104 countries studied reported greater than 90% condom use at last sexual intercourse.¹¹
- Between 25% and 54% of MSM globally know their status.¹² This means that many MSM do not know their status and may not be taking the necessary precautions to protect themselves or their sexual partners from infection.
- Alcohol and drug use is common among some communities of MSM. Alcohol and drug use lower sexual inhibitions and make people more likely to have unprotected sex and with more sexual partners, which in turn increases the risk of HIV infection.
- MSM often experience depression as a result of stigma and social isolation, and disconnectedness from health systems, which makes accessing services and adhering to treatment more difficult.¹³

Legal barriers and hostile environments

- As of May 2017, 72 countries criminalized same-sex conduct and, in 13 of them, homosexuality is punishable by the death penalty.
- Additionally, in 21 countries, there are “morality” laws and “homosexual propaganda” laws, which make it against the law for lesbian, gay, bisexual, transgender and intersex (LGBTI) people to publicly express themselves either as individuals or in organizations; it is also illegal to register or operate such an organization.¹⁴ These laws make it difficult for local organizations to promote the health and rights of the LGBTI community.
- MSM often experience stigma, discrimination and violence at the hands of healthcare workers or others if they are known or believed to be gay or having sex with other men.
- As a result of criminalization and hostile environments, MSM and gay men are less likely to access HIV-related healthcare or, when they do, to reveal adequate information about their sexual health that would help them access appropriate services.

¹¹ UNAIDS. Prevention Gap Report. 2016.

¹² UNAIDS. The Gap Report. 2014.

¹³ WHO. Prevention and treatment of HIV and other sexually transmitted infections among men who have sex with men and transgender people. 2011.

¹⁴ ILGA. Sexual Orientation Laws in the World – Criminalisation. 2017.

SEX WORKERS

WHAT DO THE NUMBERS SAY?

Worldwide, the HIV prevalence among sex workers is estimated to be about 12%.¹⁵

Data from 110 countries showed HIV prevalence among sex workers, on average, to be 12 times higher than for the general population. In four countries, it was found to be 50 times higher.¹⁶

In 26 countries that have a medium to high HIV prevalence in the general population, 30.7% of sex workers were HIV positive.¹⁷

Reasons for the high level of risk of HIV infection among sex workers include:

- Sex workers usually have a comparatively higher number of sexual partners and they are not always able to insist on condom use. This may be because clients are unwilling to use condoms, force them not to, or offer more money for unprotected sex.
- Sex workers are inadequately protected by the law, leaving them vulnerable to high levels of violence, assault and rape. HIV transmission is facilitated in situations of forced sex.¹⁸
- Stigma and discrimination faced at healthcare services deter sex workers from seeking out HIV prevention, testing and treatment services.¹⁹

Legal barriers and hostile environments

Sex workers face many different legal barriers that hinder their ability to prevent HIV infection and access other related services. These include the direct criminalization of sex work, as well as the unfair use of general laws linked to public morality, order and security, drugs and public health.

Criminalization of sex work. Criminalization refers to a legal framework that directly makes sex work or activities associated with sex work (such as brothel keeping) a crime.²⁰ The criminal laws are enforced by the police and other law enforcement agencies, and result in the arrest, prosecution and punishment, including imprisonment, of sex workers.

Penalization of sex work. Regardless of whether a country has prostitution laws, many countries indirectly criminalize sex work by using general laws to target and penalize sex workers and others involved in sex work. Extreme violations of sex workers' rights as a result of the unfair interpretation of these laws are often reported, including police harassment, violence and extortion.

“The criminalization of sex work, drug use and same-sex relationships among consenting adults in a large number of countries hinders reaching people at higher risk of HIV infection with the services that have been shown to prevent and treat HIV...”

Source: UNAIDS. The Gap Report. 2016

¹⁵ [Avert. Sex Workers, HIV and AIDS. 2017.](#)

¹⁶ UNAIDS. The Gap Report. 2014.

¹⁷ WHO. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2016.

¹⁸ [Avert. Sex Workers, HIV and AIDS. 2017.](#)

¹⁹ [Avert. Sex Workers, HIV and AIDS. 2017.](#)

²⁰ Global Network of Sex Work Projects (NSWP). Briefing Paper #7: Sex Work and the Law.

SEX WORK, THE LAW AND RISKY BEHAVIOUR

Using condoms as evidence against sex workers. In several countries where sex work is criminalized and/or penalized, sex workers have reported that the police often search them or raid their workplaces and confiscate condoms. These condoms are often then used as evidence against them in court. This makes it difficult for sex workers to carry or use condoms, increasing their risky behaviour.

Sex workers denied condoms in health facilities. Sex workers often report that when they go to get condoms, healthcare workers often limit how many they can take or refuse to give them condoms at all.

Mandatory Condom Use Programmes (100% CUP). These are agreements between public health authorities and the police in which the police agree not to raid brothels that are complying with condom use regulations. This has resulted in giving police more power over sex workers and increasing corrupt police practices, such as the extortion and harassment of sex workers.²¹

Forced STI and HIV testing policies. In some countries, sex workers are forced by law or policy to test for STIs and HIV.

The decriminalization of sex work. Globally, sex worker activists are calling for the full decriminalization of sex work, which is the removal of all legal barriers to sex work.²² Global HIV response leaders, such as WHO and UNAIDS, acknowledge that decriminalizing sex work will dramatically reduce new HIV infections and promote better access to HIV-related services for sex workers living with HIV. Decriminalizing sex work could reduce the rate of new HIV infections by 33-46% over the next 10 years.²³

IMPORTANT TERM TO UNDERSTAND

The **decriminalization** of sex work is not the same as the **legalization** of sex work. The legalization of sex work refers to the regulation of sex work, whereas the decriminalization of sex work is the removal of all legal barriers to sex work.

²¹ Global Network of Sex Work Projects (NSWP) Briefing Paper #7: Sex Work and the Law.

²² HIV and Sex Work Series. 2014 (<http://www.thelancet.com/series/HIV-and-sex-workers>).

²³ Kate Shannon et al. Global Epidemiology of HIV among female sex workers: influence of structural determinants. 2014.

PEOPLE WHO INJECT DRUGS

WHAT DO THE NUMBERS SAY?

PWID are 24 times more at risk of contracting HIV than the general population. On average, one in 10 new HIV infections is caused by the sharing of needles.²⁴

Nevertheless, globally it is estimated that only 90 needles are available per person per year, while the need is about 200 per year.²⁵

Women who inject drugs are at a higher risk of infection than men who inject drugs. In 2013, the global HIV prevalence rate among women who inject drugs was 13% in comparison to 9% among their male counterparts.²⁶

Almost one-third of global HIV infections outside of sub-Saharan Africa are caused by injecting drugs and there is evidence that the size of PWID communities in different parts of Africa is increasing.²⁷

It is estimated that there are 11.7 million people who inject drugs worldwide, and 14% of them are thought to be living with HIV.²⁸

Three countries account for nearly half of all people who inject drugs globally: China, Russia and the United States of America.²⁹

In Eastern Europe and Central Asia, there was a 57% increase in new HIV infections between 2010 and 2015. In 2015, over half of new HIV cases in the region were among PWID.³⁰

Reasons for the high level of risk of HIV infection among PWID include:

- **Sharing of needles:** HIV can be transmitted through the sharing of needles that have HIV-infected blood on them. In some cases, PWID are unaware of safe injecting practices and may share needles as a way to bond with each other, as well as to save costs if they are not offered for free through harm reduction programmes.
- **The coverage of harm reduction services is very low:** 43% of countries with documented injecting drug use do not have needle and syringe exchange programmes in place.

FOR EXAMPLE ...

In the Russian Federation, where the official policy is against providing needle and syringe programmes or opioid substitution therapy services for people who inject drugs, the HIV prevalence among PWID is estimated to be between 18% and 31%. In contrast, in countries in Western and Central Europe, where coverage of these services is high, the numbers of people becoming newly infected with HIV are low.

(Source: UNAIDS. The Gap Report. 2016)

²⁴ AIDS Alliance. The facts speak for themselves: so why is no-one listening? 2016 (Accessed 15/07/2015).

²⁵ UNAIDS. The Gap Report. 2016.

²⁶ UNAIDS. The Gap Report. 2014.

²⁷ United Nations Office on Drugs and Crime. World Drug Report 2016. 2016.

²⁸ Harm Reduction International. Global State of Harm Reduction. 2016.

²⁹ Harm Reduction International. The Case for a Harm Reduction Decade: Progress, potential and paradigm shifts. 2016.

³⁰ Harm Reduction International. Global State of Harm Reduction. 2016.

- **Even where harm reduction programmes exist, police may target service providers** to crack down on PWID, which discourages them from accessing services.
- **PWID often delay testing for HIV**, creating a higher likelihood of onward transmission.
- **The overlap between drug use and sex work** means that people who inject drugs and also engage in sex work are at an even higher risk of HIV infection. For example, HIV prevalence among sex workers in Central Asia, Afghanistan and Mongolia who inject drugs is 20 times higher than sex workers who don't inject drugs.³¹
- **There is also a wide overlap between drug use and imprisonment.** It is estimated that 56-90% of drug users will be imprisoned at some point in their lives.³² There is high drug use and a high prevalence of HIV in many prisons across the world. Unsafe injecting practices and unprotected sex are common, making HIV infection much more likely. Currently, only eight countries have at least one needle and syringe exchange programme in prison and only 43 have opioid substitution therapy.³³

Legal barriers and hostile environments

Existing laws against injecting drug use make it a crime to possess and use illegal drugs, and often also to carry and distribute syringes and needles for non-medical use. These laws block access to HIV prevention services, discourage PWID from accessing harm reduction and HIV-related services where available, and increase risky forms of drug use that put PWID at greater risk of HIV infection.

TRANSGENDER PEOPLE

WHAT DO THE NUMBERS SAY?

Transgender people are 49 times more likely to be living with HIV.³⁴

It is estimated that 19% of transgender women are living with HIV.³⁵

HIV prevalence among transgender women sex workers is estimated to be about nine times higher than in any other sex worker population.³⁶

Very little is known about transgender males and their risk of HIV infection.

Reasons for the high level of risk of HIV infection among transgender people include:

- There are high rates of unprotected anal sex among transgender women since they often do not feel able to insist on condom use. This increases the risk of HIV transmission.³⁷
- Discrimination, social exclusion and a lack of protective laws for transgender people mean that in many countries, it is very difficult for them to find work. Transgender women often work as sex workers for this reason, increasing their risk of HIV infection.

³¹ Baral S, et al. *HIV among female sex workers in the Central Asian Republics, Afghanistan, and Mongolia: contexts and convergence with drug use.* *Drug Alcohol Dependency* 132(Supplement 1):13-16. 2013.

³² Harm Reduction International. *Global State of Harm Reduction.* 2013.

³³ UNAIDS. *Prevention Gap Report.* 2016

³⁴ UNAIDS. *Prevention Gap Report.* 2016

³⁵ UNAIDS. *Prevention Gap Report.* 2014.

³⁶ UNAIDS. *Prevention Gap Report.* 2014.

³⁷ [Avert. Transgender People, HIV and AIDS.](#)

- Transgender women are less likely to access healthcare services due to the stigma and discriminatory attitudes that they face.
- Transgender female sex workers may not have adequate knowledge about condoms, and many report not using them. In Asia and the Pacific, only 50% of transgender sex workers are aware of HIV and HIV testing, and only 50% reported using condoms consistently with clients and casual partners.³⁸

Legal barriers and hostile environments

- Few countries recognize transgender people or protect their rights. The identity documents of transgender people often reflect their sex at birth.
- Anti-homosexuality laws are often used against transgender people, and many countries have laws that restrict non-traditional gender expression.³⁹
- Often transgender people cannot hide the fact that they are transgender, making it difficult for them to avoid stigma, discrimination and violence.

KEY POINTS TO NOTE

- Key populations are groups who, because of specific higher-risk behaviours, have an increased chance of becoming infected with HIV. These higher-risk behaviours are often linked to the fact that they face stigma, discrimination and criminalization of their profession and preferences, which blocks their access to the services and care that they critically need.
- The main key population groups, as identified by UNAIDS, are gay men and other men who have sex with men, transgender people, sex workers, people who inject drugs, and prisoners.
- The engagement of key populations is recognized as critical to the HIV response everywhere. Countries should define the specific populations that are key to their epidemic and response based on the epidemiological and social context.

³⁸ UNAIDS. Prevention Gap Report. 2016.

³⁹ [Human Rights Watch. Prosecutions for “cross-dressing” undermine privacy and free expression right. 2014.](#)

Section 1.2 Global HIV prevention goals, objectives and interventions with key populations

Session objective

By the end of this session, participants will be able to:

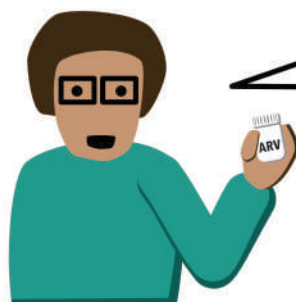
- Briefly state the global HIV prevention goal that must be met by 2020 and the key objectives that relate to HIV prevention among key populations
- Briefly discuss the different recommendations for how new HIV infections are to be prevented among key populations through the provision of targeted and combined HIV prevention services and “critical enablers”.

Activity (60 minutes)

1. Ask, “*What are the ways in which HIV is being prevented among key populations in your community?*”
2. Give participants a chance to share their responses.
3. Give presentation: **Reducing HIV risk among key populations: Global targets, objectives and interventions.** After the presentation, give participants a chance to ask questions.
4. Get participants into key population groups of 2-4 people to each focus on one key population group. Ask groups to discuss, “*In what ways can HIV prevention interventions be combined to help reduce HIV infection among key populations? What would work for you?*”
5. In reporting back, get groups to respond one by one. Ask that groups only give one response at a time to give other groups a chance to share. Continue until all key population groups have been discussed and all responses have been given.

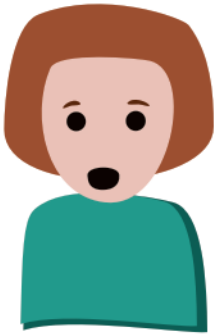
Examples of responses: What would work for you?

MSM



We need easy access to condoms and lubricants, and health workers should be trained so that they provide a high quality of care free from stigma and discrimination.

SEX WORKERS



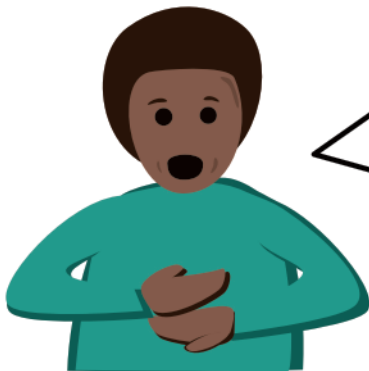
It's important to make sure that sex workers can get as many condoms as they need easily. We want police to stop confiscating our condoms and using them as evidence against us. Sex work must be recognized as work. We also want sex work decriminalized for us all - sex workers, clients, third parties, families, partners and friends. Sex workers must be enabled to access justice where the law has been used unfairly against them.

PEOPLE INJECTING DRUGS



We need harm reduction commodities and services as the main part of HIV prevention, but we also need PrEP and condoms. We need to know that we will not be targeted by police when we seek out services. Policies must ensure that our clean needles and syringes are not confiscated if we are carrying them.

TRANSGENDER



It is challenging to go to healthcare workers who don't understand us. Train them on transgender-specific issues and healthcare, including hormone replacement therapies and other stages of transition. We can't always access services during regular operating hours, so it would help if HIV programmes could be designed according to our life circumstances. We need to know that the healthcare workers we deal with will keep our status and concerns, as well as our records, confidential.

YOUNG PEOPLE



We need to know more so that we can make safe sex decisions, so we need more sex education and empowerment training. We also need fewer laws that stop us accessing medical treatment without guardians, more access to SRH services, and more condoms.

Curriculum

Reducing HIV risk among key populations: Global targets, objectives and interventions

What are we trying to achieve in HIV prevention globally, and how does it relate to HIV prevention among key populations?

The United Nations General Assembly aims to end AIDS by 2030 by implementing a “fast-track” response that sets the milestone for HIV prevention as reduction of new HIV infections to fewer than 500,000 globally by 2020. It has been noted that this goal is unlikely to be met, and one of the reasons is because many populations are being left behind, including key populations.⁴⁰

WHAT MUST BE DONE TO REACH THE GLOBAL HIV PREVENTION GOALS?

According to the UNAIDS Prevention Gap Report of 2016, in order to reach the goal of fewer than 500,000 new HIV infections by 2020, interventions with key populations are necessary. The objectives are to:

- Implement prevention programmes that are evidence informed and human rights based for key populations, including dedicated services and community mobilization and empowerment
- Enable PrEP for population groups at higher risk of HIV infection, including key populations.

How will these global objectives be met?

WHO recommends that a comprehensive package of interventions, referred to as combination HIV prevention, be used to prevent new HIV infections among key populations.⁴¹ This package consists of two interdependent parts:

- The direct provision of healthcare services
- Promoting an enabling environment through critical enablers.

According to WHO, the health sector interventions will be of most use when the enabling environment factors are in place, but this does not mean that countries should delay implementation of services

IMPORTANT TERM TO UNDERSTAND

Combination HIV prevention refers to a combination of behavioural, biomedical and structural approaches to HIV prevention to achieve maximum impact on reducing HIV infection.

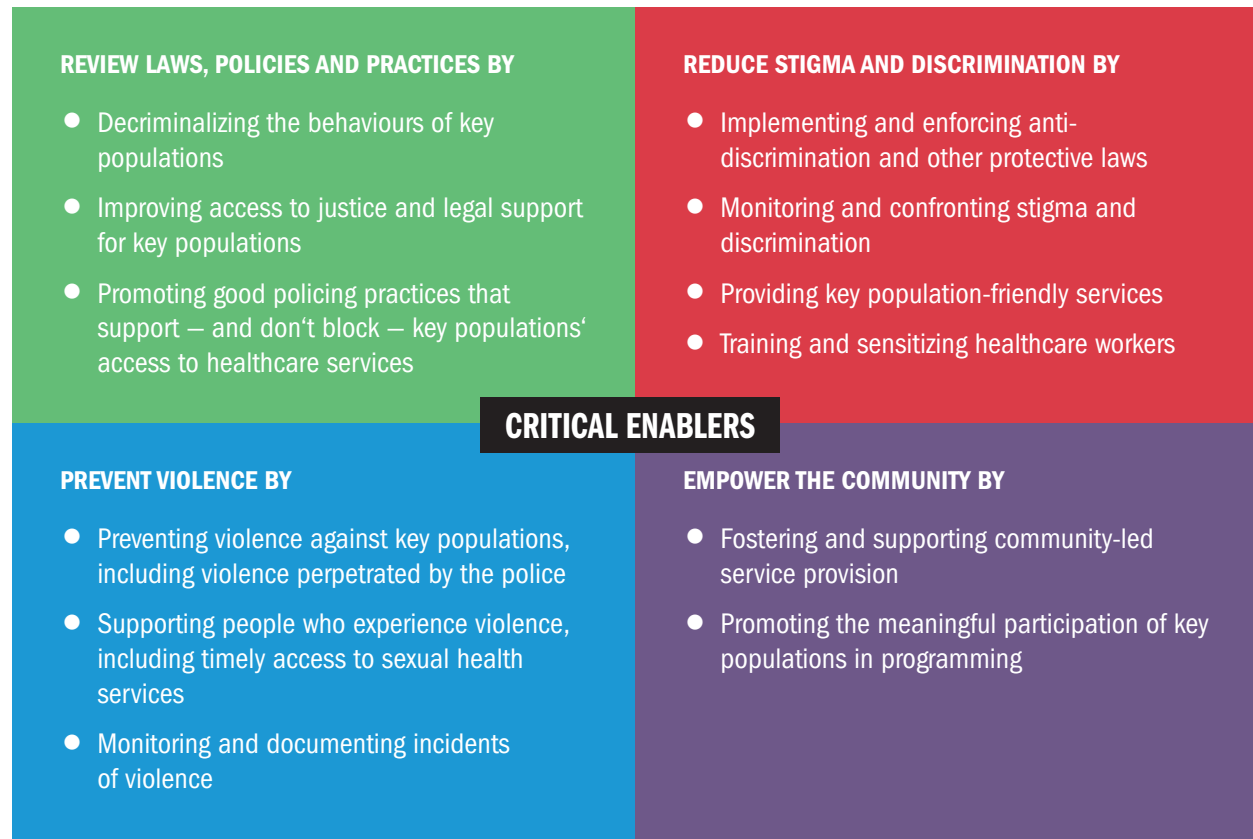
⁴⁰ UNAIDS. Prevention Gap Report. 2016.

⁴¹ WHO. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2016.

1. The Direct Provision of Healthcare Services

- Condoms (both female and male) and lubricants. Increasing availability of free condoms is an important part of promoting HIV prevention for key populations. Also, ensuring that condoms are not used as evidence against key populations is essential.
- Harm reduction for people who inject drugs. This especially entails needle and syringe exchanges and opioid substitution therapy. Despite the inadequate coverage of harm reduction programmes, they remain the priority intervention for HIV prevention among PWID.
- HIV testing and counselling (HTC). Knowing your status is the first step to getting the services that you need, whether HIV negative or positive. However, about 50% of people living with HIV do not know their status. Among key populations, even fewer know their status, due in part to delays in HIV testing and knowledge about HIV. HTC should be routinely offered to all key populations and then they should be linked to other HIV-related prevention, treatment or care services.
- Behavioural interventions. This includes providing information and empowering people in key populations to reduce their high-risk behaviours through individual, group and peer counselling, sharing of information in the media, and in outreach and empowering influential community leaders to communicate to key populations.
- The use of ARVs to prevent HIV infection. ARVs are used in the following ways to prevent HIV infection:
 - Pre-exposure prophylaxis (PrEP). Oral PrEP is the use of ARV drugs by HIV-uninfected people to block the acquisition of HIV before exposure to HIV. WHO recommends that oral PrEP be offered as an additional prevention choice for key populations who are at a higher risk of HIV infection.
 - Post-exposure prophylaxis (PEP). PEP is the use of ARV drugs by HIV-uninfected persons to reduce the likelihood of becoming infected with HIV after exposure to HIV, and should be used within 72 hours of a possible exposure.
 - Starting PLHIV (including among key populations) on ARVs early. ARVs can reduce the viral load of a person living with HIV, which in turn reduces the likelihood of HIV transmission.
- Voluntary medical male circumcision. Voluntary medical male circumcision reduces the risk of female-to-male sexual transmission by about 60%. The programme should also include sexual health education with men, including those from key populations to promote safer sex practices among them.
- Vaginal rings. These are currently on track for global and national regulatory approval.

2. Promoting an Enabling Environment through “Critical Enablers”



2

PRE-EXPOSURE PROPHYLAXIS (PrEP) – PrEP BASICS AND THE PrEP USER

Sections contained in this chapter:

Section 2.1 **What is PrEP?**

Section 2.2 **Should I take PrEP?**
**Personal risk assessment
and implications for key
populations**

READ THIS FOR MORE INFORMATION

PrEP Watch www.prepwatch.org. This website provides up-to-date information about the science of PrEP, PrEP research and implementation activities and advocacy.

Section 2.1 What is PrEP?

Session objective

By the end of this section, participants should be able to explain what PrEP is and provide some basic facts about how it works in order to prevent HIV infection.

Activity options

1. Ask participants, “By a show of hands, who knows what PrEP is?”
2. Get participants to share what they know about PrEP.
3. Give presentation: What is oral PrEP? The basics
4. Give participants a chance to ask questions.
5. Get participants into pairs and give each pair one of the questions about PrEP listed below (“What is PrEP?”; “How effective is oral PrEP in preventing HIV infection?” etc.) and ask, “Pretend that a community member were to ask you the question you have been assigned (e.g., When must I take PrEP for it to be effective?). Come up with an answer in your own words. What would you say in your local language?”
6. Get pairs to share their answers. Listen carefully for anything that might be unclear or inaccurate in the responses and help participants correct and clarify their responses.

Curriculum

What is oral PrEP? The Basics

What is PrEP?

Pre-exposure prophylaxis (PrEP) is an HIV prevention strategy that uses antiretroviral (ARV) drugs to protect an HIV-negative person from HIV infection.

PrEP stands for **Pre-Exposure Prophylaxis**:

Pre = before

Exposure = coming into contact with HIV

Prophylaxis = treatment to prevent an infection from happening

Thus, people take antiretrovirals (ARVs) when they are at risk of exposure to HIV, in order to lower their risk of infection.

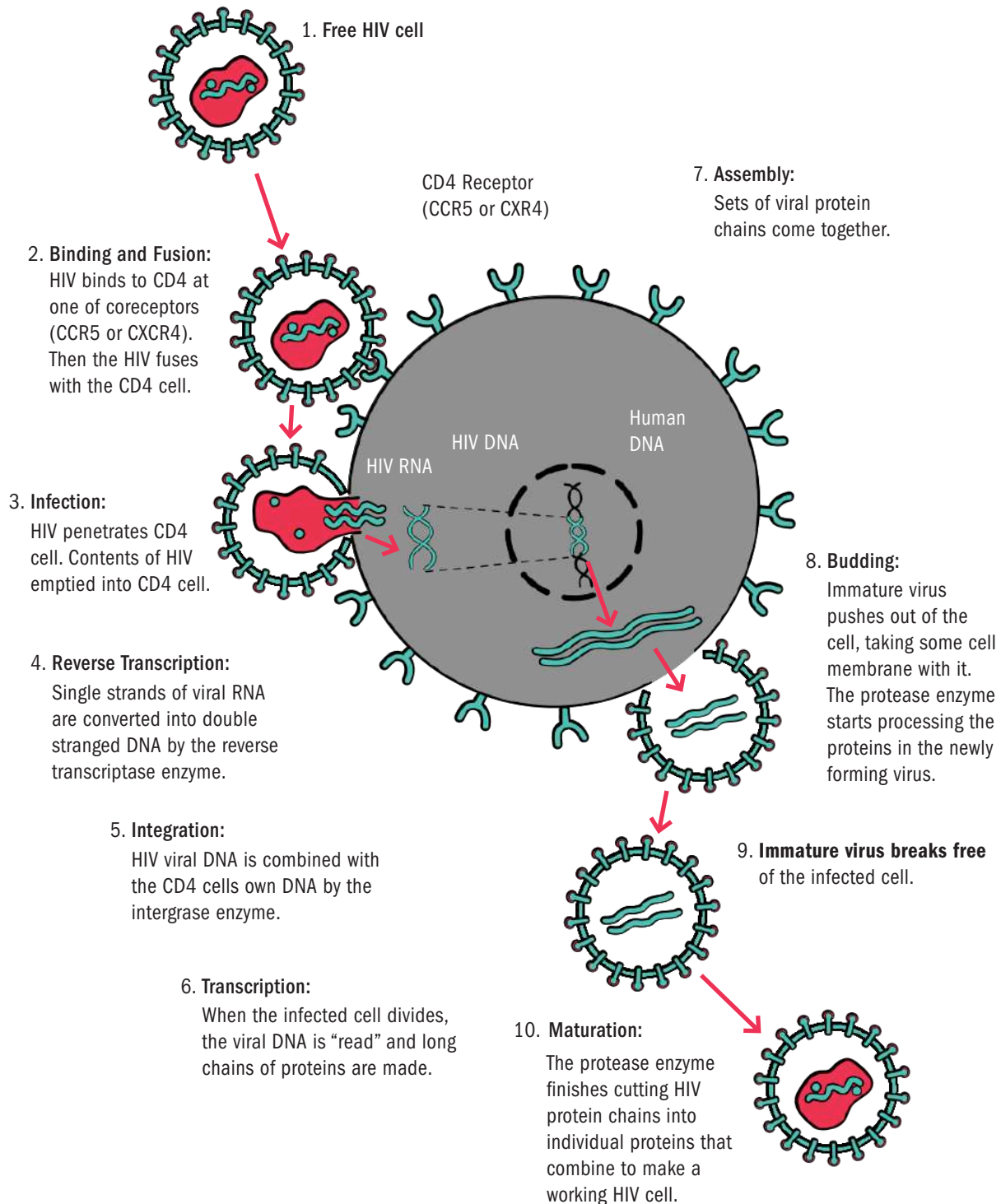
The main ARV used in oral PrEP is tenofovir (TDF) and it can either be taken on its own or as a pill that combines TDF with another ARV called emtricitabine (FTC).

Although PrEP is most commonly used to refer to ARVs in oral tablets (i.e. oral PrEP), other delivery methods are possible. Injectable forms and vaginal rings are currently being researched.

How does PrEP work in the body?

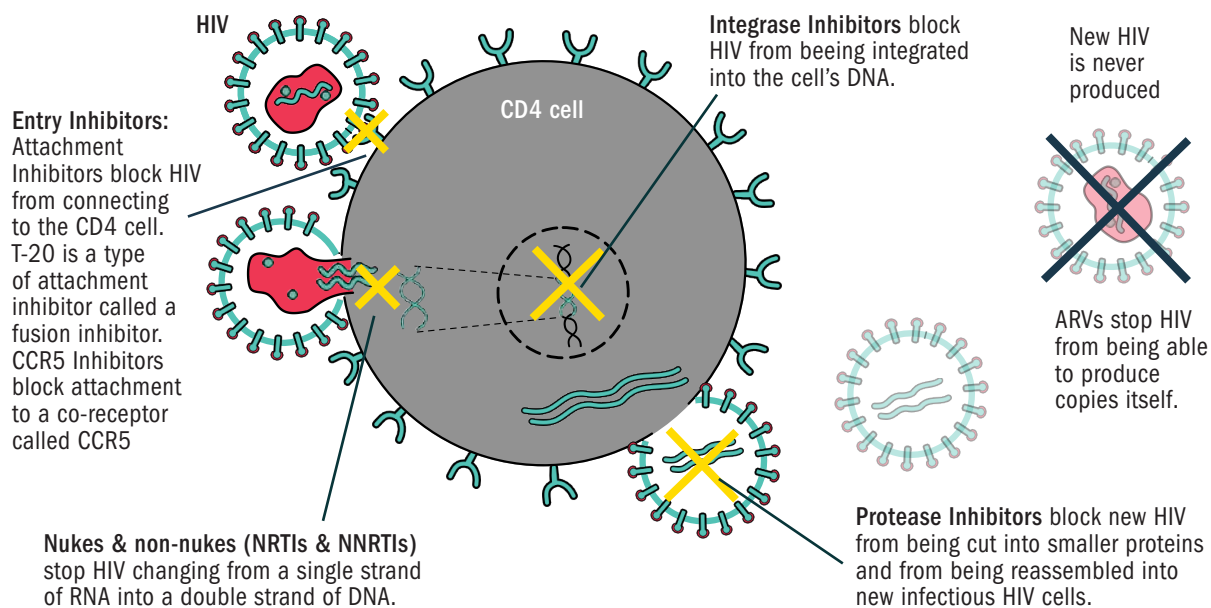
In order to understand how PrEP works in the body, you must first understand how HIV reproduces and how ARVs work in the treatment of HIV. When HIV enters the body, the virus infects CD4 cells and uses these cell to make more copies of itself, as illustrated in Figure 2 below. Without any ARV drugs to stop it, HIV will continue to replicate and establish itself in the body. (This explanation continues on Page 24).

Figure 2. How HIV reproduces itself using a person's CD4 cells



ARVs drugs can stop HIV from replicating, with different ARVs working at different stages of this process, as illustrated in Figure 3 below.

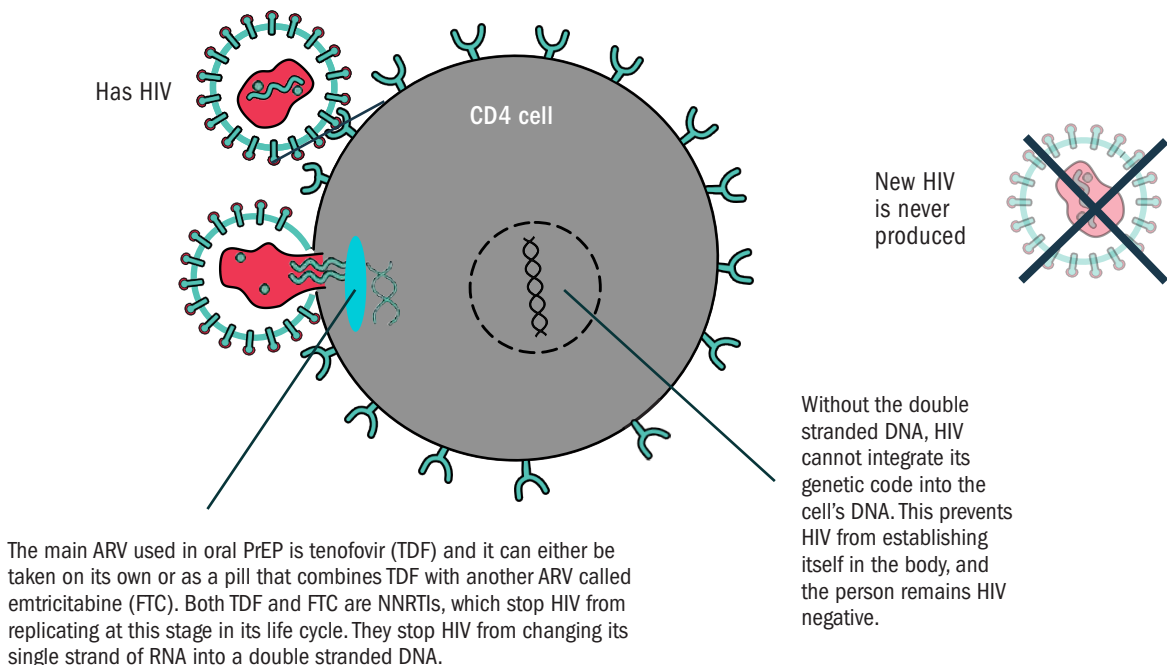
Figure 3: How ARVs work for treatment of HIV



In an HIV-negative person, taking ARV drugs that work at the early stages of the HIV cycle – as done in PrEP – can prevent HIV infection from happening.

The main ARV used in oral PrEP is tenofovir (TDF) and it can either be taken on its own or as a pill that combines TDF with another ARV called emtricitabine (FTC). Both TDF and FTC are NNRTIs, which stop HIV from replicating at an early stage in its life cycle, as shown below in Figure 4. This prevents HIV from establishing itself in the body.

Figure 4: How ARVs (PrEP) work to prevent HIV



With PrEP, an HIV-negative person takes these ARV drugs every day. This builds a high concentration of the ARV drugs in their blood before any exposure to HIV. If or when exposure to HIV occurs (for example, when having sex with an HIV-positive partner), the ARV drugs stop HIV from replicating inside the body's CD4 cells. This prevents HIV from establishing itself in the body, and the person remains HIV negative.

All ARV drugs work the same way whether used for prevention or for treatment. In a person who is already infected with HIV (an HIV-positive person), taking ARV drugs controls the reproduction of HIV in the body through the same mechanism. This keeps the amount of virus in the body low so their immune system stays strong enough to fight off other infections.

How effective is oral PrEP in preventing HIV infection?

When adhered to, PrEP is very effective in preventing HIV infection. Adhering to PrEP is very important for its effectiveness: the higher the adherence to PrEP, the more effective it is in preventing HIV infection. The reverse is also true: the lower the adherence to PrEP, the less effective it is.

When must I take PrEP for it to be effective?

It is recommended that PrEP be taken on a DAILY BASIS, and not be taken only immediately before and/or after sex. Although there is evidence suggesting that in the case of anal sex, PrEP becomes effective after only four pills (4 days), and in vaginal sex, after seven pills (7 days), it is globally recommended that PrEP is taken on a daily basis to avoid confusion. **Daily dosing is recommended for everyone.**

HIV can be transmitted in different ways. In which ways does PrEP prevent HIV infection?

Oral PrEP can prevent the transmission of HIV in anal sex and vaginal sex, as well as in injecting drug use.

Does it mean that I no longer need to use condoms? Get clean needles & syringes? Take the pill?

No it doesn't! PrEP is only one way to protect yourself against HIV infection. It will not prevent pregnancy and other STIs or infections transmitted through injecting drug use. You must continue to use other prevention tools available: the pill, condoms, clean needles and syringes. And men should still get circumcised.

Are there other ways to prevent HIV infection if I am at risk?

Oral PrEP containing Tenofovir is currently the only recommended PrEP HIV tool. Other PrEP tools are still being studied and have not been approved for use. These include a vaginal ring containing the ARV dapivirine, long-acting injectables and vaginal topical gels.

How safe is PrEP?

Oral PrEP is safe! One in 10 users reports a few minor side-effects associated with taking PrEP. These include nausea, abdominal cramps and headache; these usually last for no longer than a month. One in 200 may have creatinine elevation (related to kidney functioning), but this is reversible when PrEP is stopped.⁴²

The other serious side-effect is related to demineralization of bone density. It is important to have a medical screening done before starting PrEP and to get regular medical health check-ups when taking PrEP to prevent the occurrence of these serious side-effects.

Since PrEP uses the same ARVs used for HIV treatment, is there a risk of developing drug resistance?

For people who take PrEP and do not acquire HIV, there is no possibility whatsoever of having drug-resistant HIV

Can I have PrEP on demand?

Research on PrEP on demand is ongoing. There is not yet a WHO recommendation on this due to lack of current evidence.

I'm also taking the pill. What is the interaction between the drugs?

PrEP has not been shown to affect the effectiveness of oral contraception. You can take the pill and PrEP together and both will be effective. There is also no evidence yet to show negative interactions between injectable contraceptives and PrEP.

I am a transgender person and am taking hormonal therapy. Will PrEP be safe and effective still and will it affect my therapy?

WHO has stated in its guidance that gender-affirming hormones are processed in the body by the liver, whereas PrEP medicines are processed in the kidneys.⁴³ Interferences between sex hormones and ART have not been observed.

⁴² World Health Organization. WHO Implementation tool for pre-exposure prophylaxis (PrEP) of HIV infection. Module 1: Clinical. Geneva: 2017

⁴³ World Health Organization. WHO Implementation tool for pre-exposure prophylaxis (PrEP) of HIV infection. Module 2: Community educators and advocates. Geneva: 2017.

If I start taking PrEP, must I take it forever?

PrEP is not meant to be a life-long treatment and is only recommended for when you are in a situation that puts you at a high risk of being infected with HIV. This is sometimes called “seasons or situations of risk”.

What if I want to stop PrEP?

It is your choice to stop taking PrEP if you want to. However, it is not recommended that PrEP be stopped abruptly. It is a good idea to speak to your PrEP provider for advice and risk assessment before you stop PrEP and, if possible, discuss it with current partner(s) and get tested for HIV and other infections together. PrEP should be continued for 48 hours (2 doses) after the most recent risk.⁴⁴ PrEP can be restarted whenever needed.

I want to take PrEP. Where can I get it?

It depends on where you live. Unfortunately, currently PrEP is not available everywhere in the world. Where it is available, it can often be obtained by participating in PrEP implementation projects. Governments are also slowly making it available through government health facilities, and some private health practitioners may also be able to offer it to you. However, even where it is available, it may not be easily accessible to key populations for a variety of reasons. This is the discussion we are going to have in the next chapter – barriers and how we can promote access to PrEP by key populations in situations where it is both available and not.

KEY POINTS TO NOTE

- Oral PrEP of HIV is the use of ARV drugs taken by people who are not infected with HIV to reduce their risk of HIV acquisition.
- PrEP is for anyone at a heightened risk of infection, and not just particular people.
- PrEP can be highly effective with high adherence (taking the medication at the same time every day).
- Daily dosing is recommended for everyone.
- PrEP is safe.
- PrEP is not a replacement for other prevention tools.

⁴⁴<http://i-base.info/guides/prep/can-i-stop-prep-completely>

Section 2.2 Should I take PrEP? Personal risk assessment and implications for key populations

Session objective

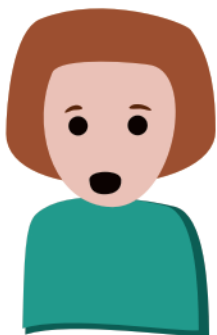
By the end of this section, participants should be able to:

- Identify and discuss the five key personal considerations that a person should make before taking PrEP
- Discuss possible situations key populations might experience that may put them at a heightened risk of HIV infection
- Explain what is meant by “seasons and situations of risk” and discuss some possible implications of using personal risk assessment – and not identity – as central to the decision to enrol on PrEP.

ACTIVITY OPTIONS

1. Ask participants to get into pairs and discuss: *Based on what you have learnt about PrEP, what do you think are some of the personal considerations a person should make before taking PrEP?* (10 minutes)
2. Get some responses, and then give the presentation, **Personal considerations when deciding whether to take PrEP.** (10 minutes)
3. Give participants a chance to comment and ask questions. (20 minutes)
4. Divide participants into groups, each focusing on a specific key population, by asking them to “vote with their feet.” Ask them to brainstorm for 15 minutes on: *“What are some of the high-risk situations that each key population might experience that might be a good reason to consider taking PrEP?”* Get each group to report back. (30 minutes)

SEX WORKERS



When I am with clients who refuse to use condoms or condom use is difficult due to pressure from brothel managers; sometimes it is really difficult to access condoms because of police confiscation; I have found myself at higher risk with sexual partners because of gender-based violence; my partner is HIV positive and we want to be extra safe.

MSM



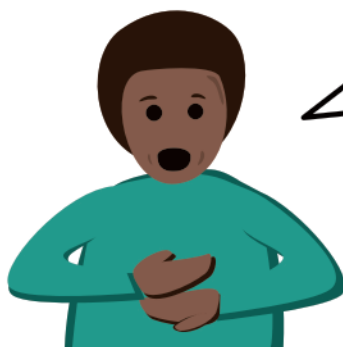
When I want to be extra careful because I am aware of the high HIV prevalence in my community; there are phases when I have multiple sexual partners; my partner is HIV positive and we want to be extra safe; I am an anally receptive partner.

PEOPLE WHO INJECT DRUGS



When taking drugs and there is a possibility of needle sharing or unprotected sex involved; my sexual partner is HIV positive and we want to be extra careful; when I am consummating a new relationship and my partner is HIV positive or does not know their status.

TRANSGENDER PEOPLE



When I want to be extra careful because I am aware of the high HIV prevalence in my community; When I am with clients who refuse to use condoms or condom use is difficult; when I am consummating a new relationship and my partner is HIV positive or does not know their status.

5. Plenary discussion: Process this activity further by discussing a few questions. The questions and potential answers follow.⁴⁵ (30 minutes)

Q What are some of the implications of using the assessment of personal risk – and not a particular identity – in promoting it in key population communities? If PrEP is going to be a successful intervention, what is going to have to happen?

Potential responses

There are many situations of high HIV infection risk that are as a result of being a key population, but there are also many others that are not. An example is having an HIV-positive partner and wanting to have a baby.

It is unfair and likely inaccurate to make assumptions about people's lives and sexual risk. We might think that key populations act a certain way or another and, in some cases, this might be true, but it's not something you can generalize about.

The implications about using the assessment of personal risk to take PrEP, and promoting it in key population communities, are that:

- Key populations need to be empowered, including being equipped with knowledge related to HIV and how it is transmitted, how PrEP can help prevent HIV, how to assess risk and how to access PrEP.
- PrEP providers must be well informed about the diversity of risks that people experience, and not target people simply because they are a member of a key population.
- In order to access and use PrEP effectively, PrEP users and providers will need to work together. The quality of the relationship between them is critical, and must be based on mutual respect, confidentiality and non-judgement.

Q Other than just preventing HIV infection, what do you think could be some of the additional benefits to key populations in accessing PrEP?

Potential responses

- PrEP may give users greater power and control over their sexual health and their ability to protect themselves against HIV infection, especially where safer sex practices are difficult to maintain.
 - It may enable HIV discordant couples to be more comfortable in their sexual relationship.
 - PrEP can bring people into the medical system who otherwise wouldn't access it. PrEP could bring people in for HIV testing and refer HIV-positive people to treatment
6. Ask the group to divide up into random groups (4-5 per group) and use flipcharts and markers to each come up with three creative key messages that would help promote PrEP among key populations and help providers to deliver PrEP services more effectively. (60 minutes)

⁴⁵ Please note that these answers are not meant to be prescriptive. They are simply ideas that could trigger discussion if needed. They also reflect some of the discussions that were held during the development of this toolkit.

Curriculum

Personal considerations when deciding whether to take PrEP

PrEP is a treatment that you take during times in your life when you are at a heightened risk of contracting HIV. It is possible for you to cycle on and off of PrEP, in consultation with your PrEP provider and depending on an assessment of your HIV infection risk level. This has been described by PrEP researchers as the “seasons and situations of risk”, and refers to the fact that PrEP is not targeted towards particular people because of who they are, but rather that it targets particular high-risk behaviours.

The decision to start taking PrEP and for how long is a personal choice. There are several things to consider before you start:

- Do I have HIV? Get tested before starting PrEP, and regularly afterwards.
- Am I eligible for PrEP? PrEP should not be given to anyone who is HIV positive or does not know their status. In addition, it is not recommended for people who are already being treated for hepatitis B since stopping PrEP can cause a worsening of those symptoms.
- Am I at a high risk of HIV infection? Assess your personal risk of infection with the help of a healthcare worker.
- Do I have pre-existing kidney or bone problems?
- Will I be able to go for regular check-ups to monitor my health, for example for HIV and STI testing and renal and bone density testing?

KEY POINTS TO NOTE

- Oral PrEP of HIV is the use of ARV drugs taken by people who are not infected with HIV to reduce their risk of HIV acquisition.
- PrEP is for anyone at a heightened risk of infection, and not just particular people.
- PrEP can be highly effective with high adherence (taking the medication at the same time every day).
- Daily dosing is recommended for everyone.
- PrEP is safe.
- PrEP is not a replacement for other prevention tools.

3

PrEP ACCESS, BARRIERS & ADVOCACY MESSAGES

Sections contained in this chapter:

Section 3.1 **What does “access” mean?**

Section 3.2 **What are the barriers to PrEP access?**

READ THIS FOR MORE INFORMATION

International Treatment Preparedness Coalition. ACT Toolkit 2.0: Advocacy for Community Treatment. 2016.

International HIV/AIDS Alliance. REAct User Guide. Interactive PDF. 2015

USEFUL WEBSITES

Global Forum on MSM and HIV: www.msngf.org

The Global Network of Sex Work Projects: www.nswp.org

The International Network of People who Inject Drugs (INPUD): www.inpud.net

Section 3.1 What does “access” mean?

Session objective

By the end of this activity, participants will be able to explain the elements that make PrEP accessible.

ACTIVITY OPTIONS

Activity A: (30 minutes)

1. Get participants into pairs and ask them to brainstorm about, “What goes into making PrEP accessible to the people who need it?” Responses should be written on cards.
2. Get a few volunteers to come up to the front and cluster the cards into categories or themes.
3. In a plenary, review the different clusters of answers.

Potential responses:

- People need to know about it and how it can help them.
 - People need to understand what behaviours put them at risk.
 - People need to feel safe to access it.
 - It must be available in their countries.
 - It must be affordable.
 - The government should make it available.
4. Present, **Understanding access**.
 5. Give participants a chance to ask questions and make comments.
 6. Ask some questions and let the group brainstorm in a plenary. Make sure that someone is taking notes on a flipchart:
 - Let’s pretend that your government has approved PrEP for use in your country. What are some other factors that will influence whether PrEP is actually available to communities?
 - What are some reasons why acceptability of PrEP is important to its success? What would happen if people did not accept PrEP?
 - What does it mean for PrEP to be delivered “appropriately”? Are there any other rights that you think are important, especially for key populations?
 - How can communities influence access to PrEP?

Activity B: Role plays (90 minutes)

After completing Activity A, you can also facilitate further exploration of what “appropriateness” looks like in practice using a role play exercise done in groups.

1. Get participants into groups of 4-5 people and assign a different key population to each. Ask some groups to give a role play of about three minutes each showing appropriate PrEP service delivery; ask other groups to role play inappropriate PrEP service delivery in a clinic setting.
2. Give participants enough time to develop and practice their role play.

TRAINING TIPS

Consider giving participants a gentle reminder to be aware that this is a sensitive activity showing stigma, discrimination and abusive behaviours that many key populations face in reality. In role playing and in watching them, remind them to be respectful and considerate of one another’s feelings.

As a facilitator, be aware that role playing often results in people playing to stereotypes. You will need to point this out if it occurs.

3. Give participants a chance to present their role plays, and ask the other participants to pay close attention. After each role play, ask the group to consider the following:
 - What were some appropriate/inappropriate ways that the services were delivered?
 - How did the way the service was delivered affect the person’s ability to access PrEP?
 - How much does appropriateness affect a person’s decision to take PrEP or to access it when needed? What about staying on PrEP?
 - Do you think appropriateness of how the services are delivered will have an effect on the acceptability by communities? Why, or why not?
 - What kinds of laws or policies could help ensure that services are delivered in a way that is respectful and supportive of the needs of PrEP users? Give some examples

Curriculum

Understanding access

Global PrEP targets: What are we trying to achieve, and how?

The United States was the first country to approve PrEP for use in 2012. France began to offer PrEP in its national healthcare system in 2016. South Africa was the first sub-Saharan country to issue full regulatory approval of PrEP, followed by Kenya. Canada and Australia have also approved PrEP. There is a growing list of countries approving PrEP for use, participating in implementation research projects, including it in their national programmes, or starting smaller-scale pilot projects.

PrEP global target

Reach 3 million people at higher risk of HIV infection by 2020.

UNAIDS recommendations to reach the global PrEP targets and scale up PrEP to reach those who need it:

- Get regulatory approval: Get as many countries as possible to approve TDF/FTC for use as PrEP (i.e., get regulatory approval) and to buy PrEP from manufacturers at the best possible prices to improve access.
- Establish PrEP national policies and programmes: Get countries to draft national guidelines on PrEP and provide PrEP through national programmes.
- Acquire donor funding through PEPFAR and the Global Fund.
- Educate people in need: Raise awareness among populations at higher risk of HIV.
- Advocate for PrEP access: Advocate for PrEP access in collaboration with the priority populations (including key populations).
- Integrate PrEP in HIV programmes: Integrate PrEP into existing combination prevention programmes

<p>What does “access to PrEP” involve?</p>	<p>Access to quality healthcare is a human right. It includes the right of members of key populations to appropriate quality healthcare without discrimination. Healthcare providers and institutions must serve people from key populations based on the principles of medical ethics and the right to health.⁴⁶ Health services should be accessible to key populations. This guidance can be effective only when services are acceptable, high quality and widely implemented. Poor quality and restricted access to services will limit the individual benefit and public health impact of the recommendations.</p> <p>Source: WHO. <i>Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations</i>. 2016</p>
<p>What health rights do PrEP users have?</p>	<p>The right to choose to take PrEP. Nobody should be forced to take PrEP. PrEP is a personal decision. In the case of young people, the right to not having parental consent regulations restrict access to services is also relevant here.</p> <p>The right to having one’s medical information kept private. Key populations often have their health information unfairly disclosed as a way to discriminate against them, or it is used as evidence against them in a prosecution.</p> <p>The right to be treated fairly and free from discrimination in all settings</p> <p>The right to dignity. PrEP users should not be stigmatized or treated as less than human.</p> <p>The right to protection of the law and to be recognized by the law. For example, laws, policies and practice that are used against key populations must be removed and replaced with supportive and protective laws. Having one’s transgender identity recognized relates to these rights, as well.</p> <p>The right to access other health services that will further strengthen people’s ability to protect themselves from HIV transmission and also promote their general wellbeing and health.</p>

⁴⁶World Health Organization. *Effectiveness of interventions to address HIV in prisons*. Geneva: 2007

PrEP services should be **AVAILABLE** in-country if they are to be accessed

PrEP must be available in their communities if people are to be able to get it. PrEP is not widely available in all countries. A lot of things go into making it available, including governments making it legal for PrEP to be provided in their countries. This is followed by the development of national PrEP policies and guidelines and the setting up of funding mechanisms and an implementation model for rolling out services. Communities can really influence whether PrEP is available in their countries through advocacy actions that demand it.

Governments have a central role to play in ensuring that PrEP is available and affordable by doing the following:

- Approving PrEP drugs (TDF and TDF/FTC) for use to prevent HIV infection (regulatory approval)
- Negotiating good prices for PrEP drugs (original and generic drugs) with drug manufacturers, usually using international laws and agreements
- Securing funding from donors, such as PEPFAR and the Global Fund
- Developing a national PrEP policy that will guide its implementation in-country
- Including PrEP in national strategic and operational plans, and ensuring that there are adequate resources and funds put towards PrEP programmes
- Conducting operational research to explore the best ways to implement PrEP programming before rolling it out fully
- Scale up of PrEP. Governments then provide PrEP across the country at a large scale.

IMPORTANT TERMS TO UNDERSTAND

ORIGINAL DRUGS are the very first unique drug formulations. They are the original brand. Usually, original drug formulations are protected by intellectual property laws, which prohibit any one else from copying them.

GENERIC DRUGS are exact copies of the original and are usually manufactured by other drug companies. Generic drugs cannot be made and sold until they have legal permission to do so. Generics are usually cheaper than the original drug formulations, but not always.(including key populations).

PrEP services must be **ACCEPTABLE** to key populations

Acceptability of services relies on the user knowing that the service exists, perceiving that it is beneficial to them and being willing to take the necessary steps to access it. **How acceptable PrEP will be to key populations will depend a lot on whether the PrEP programme is appropriately designed to meet their needs in terms of confronting barriers to access.**

“Acceptability” of PrEP is a factor influencing access to it is. This is not just about whether the science of PrEP is accepted or believed, but also about whether the programme itself and implications surrounding it are acceptable. The question is: Has the PrEP programme been designed in such a way as to also confront and address the laws, policies (importantly, the criminalization of key populations) and harmful societal and institutional practices (like health worker stigma or police harassment) that marginalize key populations so that they are able to access PrEP without fear of harm? Both science and programming must be acceptable.

So what does this mean?

- Key populations have to be engaged in and have an input into the decisions relating to how the programme is designed and services are delivered from the start, and remain involved throughout its implementation. Questions to ask here are:
- Do key population communities know enough about PrEP, and do they believe it will benefit them? Have the PrEP users and community (in this case, of key populations) been sufficiently prepared and equipped to take up services?
- Have they been engaged in the PrEP implementation plans and policies? The involvement of and engagement with key populations in decisions that affect them is a critical step to ensuring access and sustained uptake of services. It is also important to recognize that while key populations may face similar barriers, they also face different ones, which participatory research processes must account for.

Acceptability of services is a key aspect of effectiveness. Interventions to reduce the burden of HIV among people from key populations must be respectful, acceptable, appropriate and affordable to recipients in order to enlist their participation and ensure their retention in care. Services for members of key populations often employ appropriate models of service delivery, but lack expertise in HIV. Conversely, people from key populations may not find specialized HIV services acceptable. There is a need to build service capacity on both fronts. Consultation with organizations of people from key populations and including peer workers in service delivery are effective ways to work towards this goal.⁴⁷ Mechanisms for regular and ongoing feedback from beneficiaries to service providers will help inform and improve the acceptability of services to key populations.

(Source: WHO. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2016)

PrEP MUST BE AFFORDABLE

If people who need PrEP are to get it, they must be able to afford it, and PrEP can potentially be costly. Often key populations live in conditions of poverty that make it difficult for them to pay even the smallest amount of money. It is the responsibility of governments to make PrEP affordable, ideally free of charge, through the government health system. In order to make PrEP as affordable as possible, governments need to negotiate with drug manufacturers to bring the price of PrEP drugs down as much as possible or they must secure donations from funders.

On the other hand, they need to make sure that they implement PrEP as efficiently as possible and do not waste money on unnecessary things, without compromising the effectiveness of their programmes. The affordability of PrEP will influence how it is implemented, and may end up not being accessible to those who need it the most. If provided to the right populations, PrEP can avert new HIV infections and subsequent lifetime treatment costs.

Affordability of drugs relies on whether original or generic drugs are being used, how the drug is being procured, and how it is being distributed in-country.

PrEP SERVICES AND THE SURROUNDING ENVIRONMENT MUST BE APPROPRIATE

The “appropriateness” aspect of access relates to how the service is being delivered and whether the surrounding environment is supportive enough to enable or facilitate access. In this way, it relates to both the health sector interventions and the critical enablers that facilitate uptake.

⁴⁷ [World Health Organization. Implementing comprehensive HIV/STI programmes with sex workers. Geneva: 2013](#)

Appropriateness of the surrounding environment. Does the environment surrounding the individual support and enable access, or hinder it? The surrounding environment includes the **PrEP user's family life and intimate relationships, their work life and communal life**. Stigma, discrimination and violence perpetrated by community members, employers and even family members isolate key populations and make them more vulnerable and less likely to seek out healthcare services. On the other hand, environments that help promote health-seeking behaviours are usually those in which key populations are organized around their issues and have strong community-led and key population-led organizations to support them and often deliver health services to them.

As explained in Section 1, the broader environment, made up of policies, laws and institutional practices, also impacts on the daily life of the individual and may drive key populations further away from healthcare services.

Access to justice is a major priority for people from key populations due to high rates of contact with law enforcement services and the current illegality of their behaviours in many countries. Access to justice includes freedom from arbitrary arrest and detention, the right to a fair trial, freedom from torture and cruel, inhuman and degrading treatment, and the right, including in prisons and other closed settings, to the highest attainable standard of health.⁴⁸ The protection of human rights, including the rights to employment, housing and healthcare, for people from key populations requires collaboration between healthcare and law enforcement agencies, including those that manage prisons and other closed institutions. Detainment in closed settings should not impede the right to maintain dignity and health.⁴⁹

Source: WHO. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2016

Appropriateness of service delivery. Is the manner in which the services are being delivered appropriate? Some key questions to examine here would be:

- Do they respect the health rights of those using it, for example, by ensuring that services users' rights to confidentiality are being respected?
- Are the services being offered at locations where key populations are present and where they feel safe?
- Are the services appropriately responsive to the needs and context of the key populations, including ensuring that service providers know enough to meet their needs and respect their rights?

A WAY FORWARD: SERVICE DELIVERY IN COMMUNITIES

Community-based approaches to service delivery can increase accessibility and acceptability for key populations. This involves taking the services to users, rather than expecting them to always come to a health facility. Outreach, mobile services, drop-in centres and venue-based approaches are useful for reaching those with limited access to, or who are underserved by, formal health facilities. These approaches help connect users to services. Community-based programmes can also refer to programmes that are led and delivered by members of the key population community who are trained to deliver services.

Adapted from WHO's Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2016

⁴⁸ [United Nations General Assembly. International Covenant on Economic, Social and Cultural Rights, International Covenant on Civil and Political Rights and Optional Protocol to the International Covenant on Civil and Political Rights. A/RES/21/2200. New York: 1966.](#)

⁴⁹ [World Health Organization. Effectiveness of interventions to address HIV in prisons. Geneva: 2007.](#)

Section 3.2 What does “access” mean?

Session objective

By the end of this section, participants will be able to describe some of the barriers that key populations in their communities face when accessing PrEP or other health services, and be able to discuss a few of the concerns that have been documented in the literature.

ACTIVITY OPTIONS

Activity A: Exploring barriers to PrEP access (90 minutes)

1. In pairs, get participants to brainstorm responses to the following question on the wall, “Think about your community and think about the factors that we have just discussed. What are the gaps to accessing PrEP, or that you think might be gaps in the future based on your knowledge about access to healthcare services by key populations in general?” The responses should be written down on cards.
2. Once there are several cards up on the wall, get a few volunteers to organize the responses into the four Access A's (Availability, Affordability, and Acceptability, Appropriateness). Don't worry too much if they can't decide if a response fits into one category or another: there is a lot of overlap, for example, many issues relating to appropriateness also have to do with acceptability, and so on. This is just one way of helping the participants organize their ideas. Feel free to organize the responses in another way if this is better. The point really is to get them to think about all of the issues that they experience with regards to PrEP access.
3. Then divide participants into smaller groups and assign one category of issues to each group. Ask them to answer,
 - Explain these issues in more detail. How is this a barrier to access?
 - How big an issue is this? Prioritize the issues from largest to smallest, and discuss why you organized them as such.
 - How can each barrier be resolved? Who do you think is involved in resolving it? What can you do as a community to resolve it?
4. Have each group present its analysis of the barriers to access, explaining why it prioritized the issues the way it did, and give a brief set of recommendations for how the barriers should be resolved.
5. Finish by giving a short presentation, PrEP and PrEP access: Documented barriers, challenges and concerns and allow for questions and comments.

Extended Activity B: Sharing personal testimonials (60 minutes)

After conducting Activity A, and especially if you are working with key population participants, you could consider giving participants an opportunity to share their personal testimonials or the stories of others in their communities that describe the barriers to accessing PrEP services. Since PrEP may not be widely available, the story could also be about barriers relating to accessing other health services that are similar to PrEP to show what can be expected to happen with PrEP. This helps personalize the issues and drive home the reality of PrEP programming from the point of view of a PrEP user.

You can do this activity in small groups, or you could conduct it in a plenary, depending on how comfortable you feel the groups are with each other. Make sure before doing this activity that you are familiar with facilitating sensitive topics such as these. Also, invite people to only share what they are comfortable sharing.

CURRICULUM

PrEP AND PrEP ACCESS: Documented barriers, challenges and concerns

Background: To inform the development of this toolkit, ITPC conducted a literature review and interviewed global key population support networks to find out more about how key populations feel about PrEP, and also to explore current PrEP efforts taking place around the world, mostly PrEP demonstration and implementation projects. The barriers discussed here are taken from the literature review and interviews.

Individuals interviewed from key populations and who are primary contributors to the following section of the toolkit on **barriers, concerns and challenges** are from the following networks:

The Network of Sex Worker Projects (NSWP): NSWP is an organization that connects regional networks advocating for the rights of female, male and transgender sex workers. It is a membership organization with 240 registered members in 72 countries and is committed to amplifying the voices of sex workers both in the global North and South.

Global Forum on MSM & HIV (MSMGF): MSMGF is an expanding network of advocates and other experts in sexual health, LGBTI/human rights, research and policy, working to ensure an effective response to HIV among gay men and other men who have sex with men. They are directly linked with more than 120 community-based organizations across 62 countries.

The International Network of People who Use Drugs (INPUD): INPUD is a global peer-based organization that seeks to promote the health and defend the rights of people who use drugs. INPUD will expose and challenge stigma, discrimination and the criminalization of people who use drugs and its impact on the drug-using community's health and rights. INPUD will achieve this through processes of empowerment and advocacy at the international level while supporting empowerment and advocacy at community, national and regional levels.

Community feedback and concerns relating to the 4 A's

ACCEPTABILITY

1. Levels of PrEP knowledge and awareness are still very low. The starting point to even consider if PrEP will be wanted or accepted is if communities know about PrEP and how it can benefit them. Consultations with key populations globally have shown that awareness about PrEP is still very low, even in countries where PrEP projects are being conducted.
2. While the efficacy and safety of PrEP is generally accepted, key populations still express concerns about the biomedical aspects of PrEP. These include:
 - Can PrEP be taken with hormonal therapies? Transgender communities have concerns related to the interaction between PrEP drugs and hormonal therapies often used by transgender people.
 - Is PrEP really effective in protecting against HIV transmission through injecting drug use? There has, to date, been only one completed PrEP trial conducted with people who inject drugs. Although organizations supporting people who inject drugs do not doubt that PrEP is effective in preventing sexual transmission of HIV, they question whether the single study that was done is enough to show that PrEP protects against HIV through injecting drug use.

3. Key populations, through their support networks, feel that they are not always fully engaged and involved in PrEP programme and policy decisions. Global guidelines clearly support the engagement and meaningful participation of key populations in the designing of health programmes. Also, key population support networks strongly believe that their involvement is important so that PrEP programmes meet the needs and circumstances of their communities. At implementation level, community organizations led by and supporting key populations (KPs) are often the critical link between individuals in need and services, and can really help promote the acceptability of PrEP among communities. However, these groups often feel left out of the PrEP spaces where decisions are made.

AVAILABILITY AND AFFORDABILITY

1. **PrEP is currently not available in many countries.** In many places, it is available only through private doctors, and PrEP users have to pay for the drugs and the service out of their own pockets. Some people are unable to pay even the smallest amount. PrEP must ideally be available free of charge from government facilities.
2. **There is a concern that the potentially high cost of PrEP may have implications on funding to enable PrEP access to the least resourced and most vulnerable groups.** MSM groups in particular have said that it is possible that because of the high cost of PrEP, PrEP programmes may choose to target the highest-risk populations (e.g., low-income MSM). However, they explain that these populations may also be the least likely to afford PrEP or to pay for health insurance coverage to access PrEP. This, they say, will have implications for country-level and multinational donors who will have to ensure access to the people who need it most.
3. **There are ethics to consider in providing TDF/FTC for PrEP where it is not widely available for treatment.** It is well documented that there are significant gaps in the provision of key prevention and treatment services overall. Key population groups have raised a related concern that it would not be ethical to make PrEP drugs available to HIV-negative people in countries where people living with HIV are not able to access those same drugs (TDF/FTC) to treat HIV.

APPROPRIATENESS

To get to PrEP, key populations often have to deal with hostile service delivery amid criminalized and discriminatory legal and policy environments. The research revealed that **the most concerning area of access to PrEP for key populations** is whether the services are being delivered in an enabling and supportive environment.

1. Key populations are concerned about hostile legal and policy environments

There is now wide acknowledgement in global policy and by key population support networks that stigma, discrimination, gender inequalities and criminalization block their access to and uptake of sexual and reproductive healthcare services. UNAIDS mentions in the Prevention Gap Report that “PrEP empowers individuals with limited personal prevention options to discreetly take control of their own HIV risk”. This could be seen to respond to the lived realities of many individuals, men and women, who, as a result of hostile legal and social environments, are often unable to negotiate safer sex, or experience sexual violence that puts them at risk of HIV infection.

However, key population groups emphasize that **PrEP programming should not** overlook the need to confront and address – as a priority and as fundamental to the HIV response – **the underlying legal barriers and other structural blocks** that put individuals in positions of vulnerability to begin with.

PrEP should not compete with other programmes for funding and attention. Most key population groups are also concerned that the introduction of PrEP may divert attention away from other programmes. They emphasize that PrEP should be implemented **in addition to other prevention interventions**, as is recommended by global guidance.

Condoms as evidence against sex workers – maybe PrEP as evidence against key populations, too?

It is known that the possession of condoms has been used as evidence in court cases against sex workers, and that police have confiscated needles and syringes from people who inject drugs. Key populations have reported that they fear that PrEP medications might be used against them in the same way.

FOR EXAMPLE ...

PrEP before harm reduction programming? Harm reduction programming has been described as the central HIV prevention programme for PWID, but it is still critically limited. PWID question the appropriateness of introducing PrEP when harm reduction strategies, which have been proven to work and are desperately needed, are still denied to the vast majority of injecting drug users globally, primarily on the basis of legal prohibitions against drug use. There is a strong feeling that the introduction of PrEP is premature unless harm reduction programming is sufficiently scaled up to meet the demand. WHO and UNAIDS have emphasized in global guidance that PrEP should be implemented alongside harm reduction programming, but what is actually done at country level could be a different situation.

PrEP before decriminalization of sex work? The NSWP has come out strongly to say that it believes that unless sex work is decriminalized, PrEP programming is premature. Community-led, participatory research is needed to better understand the structural barriers faced by sex workers in accessing health services within their country of residence.

2. Key populations are concerned about hostile healthcare settings

Key populations fear having their human rights violated by healthcare workers when accessing PrEP services. Key population support networks have voiced concerns about introducing PrEP in already hostile healthcare settings where, in the absence of adequate access to justice for key populations, their rights have been violated. These violations include having their medical information disclosed unfairly, being forced to take medications, and being denied condoms. Pressure to implement PrEP at country level may lead to similar human rights violations extending into PrEP programmes.

Sex workers are concerned that PrEP could undermine condom use in sex work settings. Although PrEP implementation projects have reported that their studies have not shown a significant change in condom use, sex worker networks fear that in real-life scenarios, clients who know that a sex worker is taking PrEP may demand unprotected sex or offer more money in exchange for it. They have also expressed concern that employers of sex workers may encourage or coerce sex workers not to use condoms with clients. They are concerned that this will severely disempower sex workers from being able to negotiate safer sex and may lead them to internalize risk compensation. Based on these concerns, some sex workers have said that they would be willing to take PrEP in their personal lives, but would not be able to take it with their clients' or employers' knowledge.

SEX WORKERS' CONCERNS

"The police often search me when I am working and take my condoms away. I am worried that they will do the same with my PrEP pills."

"I would consider using PrEP with my boyfriend, but I wouldn't want to use it with my clients, because otherwise they may insist on unprotected sex."

"If the police find me with PrEP drugs, they might arrest me and try and use them against me as evidence of my sex work."

CONCERNS OF GAY MEN AND OTHER MSM

"In order to get PrEP, I am going to have to tell the nurse that I am gay/MSM. I am afraid to do that because they will stigmatize me and might even refuse to give me PrEP."

"If the nurse finds out that I am gay, she might tell the authorities and I will be arrested and might face prosecution."

CONCERNS OF TRANSGENDER PEOPLE

"When I go to a clinic, it is not always easy to hide that I am transgender. I can't be open with them about being transgender. If I tell them, they might stigmatize me, and refuse to give me services, including PrEP."

CONCERNS OF PEOPLE WHO INJECT DRUGS

"I can't go to the clinic because the police know that people who inject drugs go there to get help. They might arrest me."

"What I want are clean needles and syringes, and to have access to opioid substitution therapy, but these are not available. What is the point of taking PrEP if I am still at risk of being infected with other conditions, like hepatitis C?"

KEY POINTS TO NOTE

- Key populations face many common barriers when accessing PrEP that relate to its **affordability, availability, acceptability and appropriateness** in how it is delivered.
- Although governments are increasingly working toward getting PrEP in their countries, **it is not available in all countries** yet. Nor is it always affordable if it is available.
- **Punitive laws, policies and practices** are a very serious barrier to key populations trying to access services, including PrEP.
- **Knowledge levels** about PrEP are still very low.
- Generally, key populations who understand PrEP believe the science. But the science must translate into **well-designed programmes that respond to the needs of key populations** and respect, protect and fulfil their rights.

4

GETTING PrEP TO KEY POPULATIONS: COMMUNITY-LED DEMAND FOR PrEP

Sections contained in this chapter:

Section 4.1 **What is community-led demand creation for PrEP and why is it important?**

Section 4.2 **Creating community-led advocacy plans to demand access to PrEP**

Section 4.3 **Developing key advocacy messages for promoting key population access to PrEP access to PrEP**

READ THIS FOR MORE INFORMATION

A really useful tool to support community based advocacy is the [ACT Toolkit 2.0: Advocacy for Community Treatment, International Treatment Preparedness Coalition, 2016.](#)

A tool that can be used to document rights related barriers to accessing health services is the [REAct User Guide, Interactive PDF. International HIV/AIDS Alliance, 2015](#)

Section 4.1 What is community-led demand creation for PrEP and why is it important?

Session objective

By the end of this session, participants will be able to explain what community-led demand creation for PrEP is, why it is important, and some of the advocacy actions that communities can engage in to demand access to PrEP.

ACTIVITY OPTIONS

Activity A: (30 minutes)

1. Rotational brainstorm: Put four flipcharts around the room, each with one of the headings listed under “Flipchart titles”. Then get participants into four groups and give each group a few markers. Ask them to rotate around the room filling in responses to each of the questions.

Flipchart titles:

- Flipchart 1: Why is it important for key populations to demand PrEP?
 - Flipchart 2: What are some of the things that communities can demand when it comes to PrEP?
 - Flipchart 3: What are some of the things that communities can do to promote community demand for and access to PrEP in their communities?
 - Flipchart 4: What do communities need in order to promote community demand for and access to PrEP in their communities?
2. After each group has had a chance to add their responses to each of the flipcharts, bring the flipchart papers to the front and go through each in turn, giving time for additional comments and discussion.
 3. Then present: **Community-demand creation for PrEP: Why it is important, and what communities can do to promote PrEP access.**

CURRICULUM

Community-demand creation for PrEP: Why it is important, and what communities can do to promote PrEP access

Community demand for PrEP is essential for enabling access. In countries where PrEP services are readily available, communities in need have to be aware of them, value their benefits and seek them out. In countries where PrEP services are yet to be made readily accessible, community demand for them and involvement in how they are offered is critical to enabling access and sustained uptake.

Community-led demand efforts can influence:

- How accessible PrEP services are to the community
- Whether people actually choose to enrol
- Whether these services are being offered in a way that is suited to the needs of PrEP users.

Communities can demand that PrEP services be made available, affordable and appropriate and that their concerns about the safety and effectiveness of PrEP be answered and responded to. Communities have a right to demand that PrEP services are provided in a manner that responds to their needs and that don't put them in harm's way, especially ensuring that key populations are not stigmatized, discriminated against, harassed or arrested as a result of their accessing PrEP services.

What can activists do to promote community demand for access to PrEP?

- Take an active part in educating their community members about PrEP and how it can benefit them.
- Get community members who are using PrEP to educate and share their experiences with others.
- Engage their community leaders on PrEP, getting their support to represent their interests at higher levels of governance, including in district-level and national-level policy and programming development.
- Involve the media to bring attention to the issue.
- Use social networking tools to bring awareness to the issues, encourage discussion and mobilize support.
- Demand access to PrEP from their healthcare facilities.
- Demand “a place at the table” where local and national decisions about HIV programming, funding and policies are made.

In order for communities to successfully promote demand for and access to PrEP, communities will need:

- **To mobilize support from influential others.** In many communities, there are existing community-led groups that work on HIV issues with key populations. It will be important to mobilize and engage these groups to support their cause. In communities where such groups don't exist, forming a community group of interested and committed people, especially from key populations themselves, is critical.
- **To educate themselves and their communities.** Communities need to know as much as they can about PrEP. Communities can educate their members about PrEP and what it can offer those most in need. Researching PrEP and finding out more from organizations and groups working on PrEP is important. Knowledge about how to do advocacy work effectively will be important, as well. Demand creation for PrEP starts with knowledge about PrEP.
- **To mobilize support from influential others.** Identifying and engaging the support of influential people in the community and at higher district and national level who support – or have the potential to support – key population health issues will be important if a greater impact is to be made. Networking with as many individuals who might have different kinds of influence (social, cultural, political and otherwise) as possible is strategic. Getting support from the media and using social networking tools to promote visibility of the issues will also have a great impact.
- **To find resources to support their efforts.** For a sustained effort, community-led advocacy needs knowledgeable people, a space where communities can meet and organize themselves, money for transport,

Section 4.2 Creating community-led advocacy plans to demand access to PrEP

Session objective

By the end of this session, participants will be able to explain what community-led advocacy is, why it is important, and the steps and elements that go into successful advocacy plans.

ACTIVITY (60 MINUTES)

1. Ask, “What is community-led advocacy?”
2. Present: Community-led advocacy to promote demand for and access to PrEP.
3. Get participants into groups of 3-4 and give each a handout of the advocacy cycle. Ask each group to develop a draft advocacy plan to share with the group.
4. Get participants to share their plans.

CURRICULUM

What is community-led advocacy and why is it important?

There are very many different communities, and we will explain what “community” and “community-led” means for the purposes of this toolkit, that is, promoting demand for and access to PrEP.

Key characteristics of this community are that:

- They are people with a shared interest in seeing that PrEP is made accessible to key populations.
- There is a geographical area in which they want PrEP to be made accessible.
- They are themselves members of key populations, or involve the input and meaningful participation of key populations as the group for whom PrEP access is being promoted.
- They want to bring about a change, that is, encourage more people to demand PrEP in the geographical area they are targeting. They want to make sure that the way in which PrEP is operationalized in their countries responds to the needs of key populations and confronts the barriers that hinder or could potentially hinder access to PrEP.
- The community itself takes charge of bringing about the change. Its members coordinate and lead the change. They may involve others from outside their community, but the decisions that are taken and the visibility of the issues are focused in the community.

Important terms to understand

- **Community:** Any number of people who have a shared interest, who typically live and/or work in a particular country (or district, town or even village), and who are interested in seeing that PrEP is made available for those who are at a substantial risk of HIV infection.
- **Community-led advocacy** is when community members themselves have a shared interest in bringing about a specific change in their community and for their community, and work together and with others to bring it about.
- **Advocacy:** Actions geared towards bringing about a change.

Communities must lead their own advocacy because:

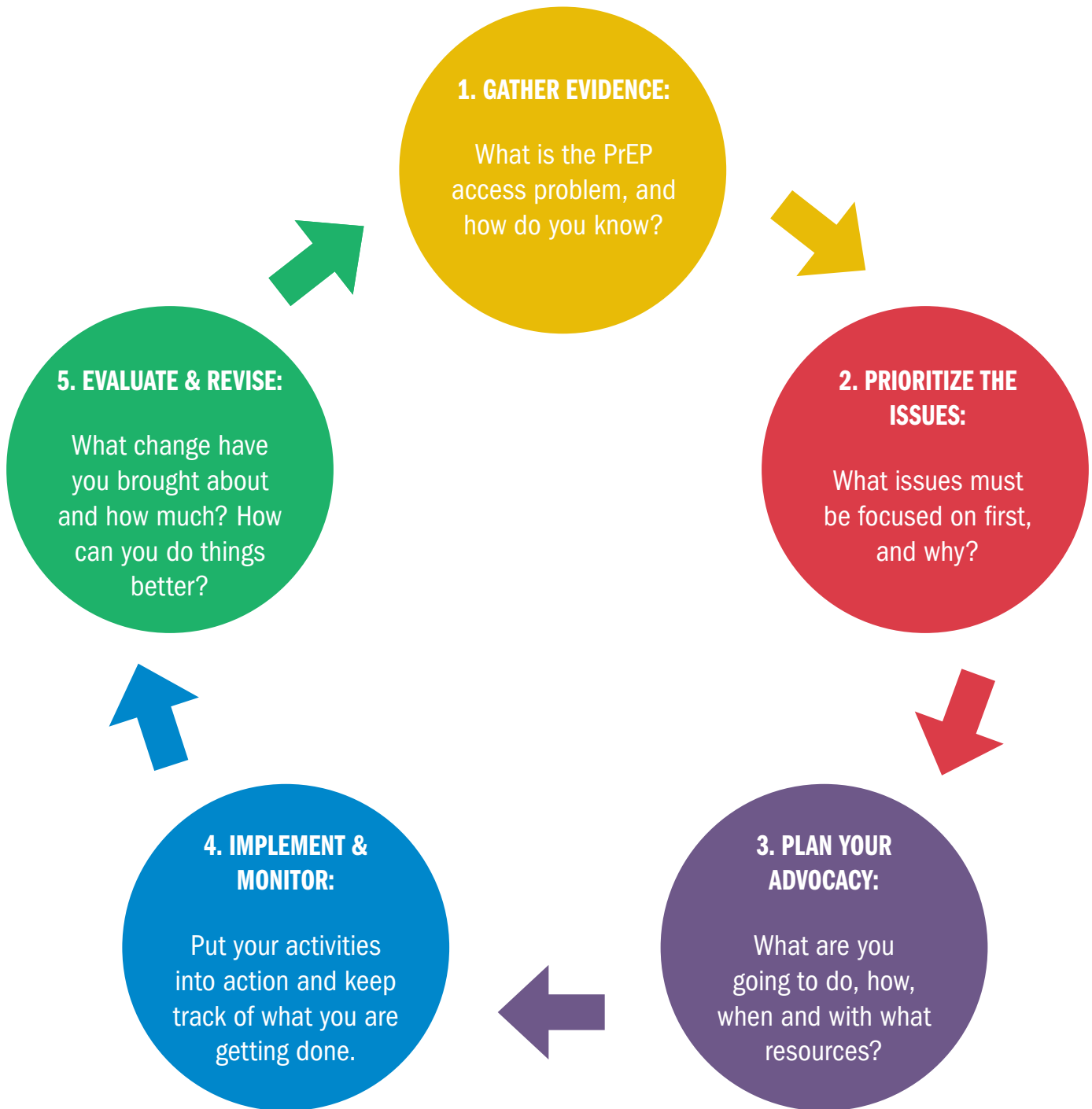
1. Communities know themselves better than anyone else, and are thus best placed to guide programmes that are intended for them. They have intimate knowledge about themselves that outsiders might overlook, and so their input into programmes is important for their success.
2. Communities have a right to influence decisions that are made on their behalf.
3. Community ownership and acceptance of programmes is critical if community members are going to use them. If communities have not fully accepted a programme, it is not likely to succeed.
4. Advocacy done by others from outside the community but on behalf of it often does not hold the same legitimacy with people in positions of authority.

What are the characteristics of successful community advocacy?

- **Evidence based.** Advocacy efforts should be based on the evidence about what key populations want and need.
- **Community led.** Any action that is taken really must be informed by key populations themselves.
- **Necessity.** There must be a real need that has to be addressed, and that need has to be clearly stated or articulated. Identifying what exactly must change, and being able to show it, is an important step.
- **Well planned.** Advocacy must be planned so that it makes the best use of the resources available, especially where those resources are limited.
- **Focused.** This is so that it makes (or recommends) concrete changes, even if they are small.
- **Realistic.** This is so that it focuses on changes that are actually possible within the local context and with the resources that are available.
- **Commitment.** Doing advocacy work takes time and a lot of effort. Being committed and having other activists working with you is really important if you are going to see your efforts through.
- **Capacity.** There are many ways to do advocacy and many different activities, strategies and tools. Capacitating yourself as much as you can with advocacy skills will help you do successful advocacy.
- **Creative.** Keep an open mind and try out new and inventive strategies.

The Advocacy Cycle

The following advocacy cycle has been adapted from the one that ITPC often uses in its advocacy training guides.⁵⁰ Here it has been made to focus specifically on PrEP access.



⁵⁰ ITPC's Advocacy for Community Treatment (ACT) Toolkit 2.0. Available for download at: <http://itpcglobal.org/resources/advocacy-community-treatment-toolkit/>

1. GATHER EVIDENCE: What is the PrEP access problem, and how do you know?

Before you can bring about change, there must be something worth changing. Gathering evidence that shows what the problem, issue or challenge is the first step. It's not enough to say that there is a problem; you must have the evidence or proof to show it.

What do you need to know and how do you go about finding it?

Here you are trying to identify what the problems, gaps, concerns and challenges that key populations face in accessing PrEP. And you want to find out the whole body of the problem, that is: What is the problem itself? What is the problem caused by? What effects does the problem have?

Using the 4 A's access may be helpful to guide you to come up with your research questions:

<p>Is PrEP AVAILABLE in my community?</p>	<p>Has it been registered to be used as PrEP? If not for PrEP, is TDF+FTC registered for treatment? Does my country have any plans to implement PrEP? Why or why not? If yes, is PrEP really available and are people accessing it? Where? How many people and whom?</p>
<p>Is PrEP ACCEPTABLE to my community?</p>	<p>Does my community know about PrEP? What are their perspectives on it? Do they see PrEP as beneficial to them, and why, or why not? Who do they think might benefit the most from PrEP, and how do we get them interested in PrEP? What are their concerns with PrEP?</p>
<p>Is PrEP AFFORDABLE for my community?</p>	<p>How much does PrEP cost the PrEP user? Is the cost of PrEP affordable to key populations? If the cost of PrEP is high, why is this so? If PrEP were affordable, would people take it? Why, or why not?</p>
<p>Is PrEP APPROPRIATE to my community?</p>	<p>What are the punitive/protective laws, policies and practices that affect key population communities' access to HIV services (including PrEP)?</p> <hr/> <p>How is PrEP being operationalized in implementation? Are affected communities being engaged and meaningfully involved in PrEP policies, plans and implementation? Is there stigma and discrimination in healthcare settings against KPs?</p>

Where can I get information?

Depending on what information you are looking for, you can gather it from different places, including:

- From talking to key populations themselves about PrEP (e.g., to find out if they know about it and what they think about it)
- Approaching ministry/department of health, health facilities (to find out if your government is implementing or planning to implement PrEP, the regulatory environment, any policies, etc.)
- Speaking to PrEP research and implementation partners. Your country may have a few, and they could really be a useful resource and support for your advocacy efforts
- Gathering information from community-based HIV service providers in your area
- Going online. There are many websites that share useful information about PrEP.

Ensure that your information is reliable and accurate. This means that the information that you gather should really be a true reflection of what you say it is and can be verified if someone were to check.

What do I do with the information after I have gathered it?

After you have evidence, you have to put it all together in a way that makes sense. A helpful and easy way to do this is to think of your information as a story. Use the information you have to tell a story that includes all of the different pieces of information.

EXAMPLE

Even though PrEP is available, sex workers are not accessing it because many of them don't know about it. They don't know about PrEP because they don't usually go to the clinics where it is being offered, and they only visit sex worker-led service providers who give them condoms and other prevention tools.

Connecting the information together into a clear story is the first step.

2. PRIORITIZE THE ISSUES: What issues must be focused on first, and why?

Now you have found out a lot about the issues, concerns and challenges that key populations face in accessing PrEP. You can't do everything, at least not at once, so you must prioritize what to focus on first. Certain questions can guide your decision:

- How big an issue is it? For example, how many people are affected by this issue?
- How big would the impact be if this issue were resolved?
- How pervasive is the issue? In other words, how many other issues does it affect, or cause?
- How immediate is it? Is it an emergency?
- How much of an influence do you think you can make if you tackled this issue?
- How long will it take you to address the issue?
- How much money and other resources will you need to properly address this issue?

Prioritizing your issues also helps you and your team organize yourself and also helps you better communicate what should be done to others. The number of priorities you choose will depend on many things, including your time, resources and level of effort.

3. PLAN YOUR ADVOCACY: What are you going to do, how, when and with what resources?

Now is the time to strategize and plan. Make sure that this step is not done by one person, but by everyone who is involved. It is the backbone of your advocacy. Having the buy-in of all community activists is important. For every step, make sure that your goals, objectives and activities are specific and targeted, that they can be measured, that they are realistic, and that they are time bound.

Define a long-term goal: What exactly do you want to achieve overall?

EXAMPLE

Transgender women are able to access PrEP free of charge from government facilities and community-based organizations free of stigma, discrimination or police harassment

This goal clearly articulates:

- Who stands to benefit (transgender women)
- What they stand to benefit from (free PrEP)
- From whom they receive the benefit (government health facilities and community-led organizations)
- How they are to benefit (free of stigma, discrimination and harassment).

The long-term goal also helps shed light on the problems being addressed, and is positive and forward thinking (promoting access) (affordability, stigma, etc.).

PLAN your shorter-term objectives, activities and other elements

Areas to plan	EXPLANATION	EXAMPLE
Objectives	<i>This is a short-term goal that contributes to achieving your long-term goal</i>	Sex workers in X community know about PrEP and how it can benefit them
Activities	<i>These are the advocacy actions that you will take to achieve your objective</i>	Conduct outreach to brothels and with street-based sex workers, as well as those working through venues like hairdressers
When?	<i>This is the time period when the advocacy actions will take place</i>	Once a week for 6 months
Targets	<i>These are the people, organizations or institutions that you will target to help us bring about the change that we want</i>	Sex workers
Partners	<i>These are our supporters who you will work with to carry out your advocacy</i>	Sex worker peer educators
Resources	<i>These are the resources (such as people, time, money and skills) needed to do your advocacy</i>	Vehicle/ money for transport Information, Education, Communication (IEC) PrEP materials
Risks/ opportunities	<i>These are some risks or opportunities that may arise in doing this activity. Often these issues must also be planned into your advocacy</i>	Police harassment and confiscation of PrEP educational materials

4. IMPLEMENT AND MONITOR

Put your activities into action and keep track of what you are getting done. There are different ways to monitor your plan, some easier than others. It depends on the activity. For example, if you are doing education outreach with sex workers, you could monitor:

- How many different sex workers you are talking to
- How many sex workers you are talking to more than once
- How many fliers you are handing out
- How many hours you are spending working
- How much fuel you are using
- Which locations you are visiting and how often.

What you monitor should relate back to what you are trying to achieve. Keep it simple. Make sure that it makes sense to you and that you are monitoring information in a consistent way so that you can count up all of your efforts over time, and use this information to evaluate your efforts and your impact.

5. EVALUATE & REVISE: What change have you brought about and how much change (results)? How can you do things better?

Depending on the duration of your action, you should sit back every so often and look at what you have done and what impact you have made. This might mean that you have to go out and gather more information to find out. You could also get other people to do it for you so that the information is not biased. Put your activities into action and keep track of what you are getting done. There are different ways to monitor your plan, some easier than others. It depends on the activity. For example, if you are doing education outreach with sex workers, you could monitor:

Section 4.3 Developing key advocacy messages for promoting key population access to PrEP

Session objective

By the end of this activity, participants should be able to discuss some key advocacy messages that respond to the barriers to PrEP access by key populations.

ACTIVITY (90 MINUTES)

1. Get participants into small groups of 4-5 and give each group four flip chart papers.
2. Ask them to write one of the following headings on each of the papers: STOP, START, STRENGTHEN, CONTINUE.
3. On each of the flipchart papers, write at least 2-3 strong advocacy messages about what needs to be stopped, started, strengthened or continued in order to reduce HIV risk and promote access to HIV prevention services for key populations.
4. In each message, think about WHO is responsible, WHO is involved, WHAT should be done, HOW and WHY.

STOP: What must be STOPPED? Who must stop it, how and why?

START: What must be STARTED? Who must start or lead it, how and why?

STRENGTHEN: What must be STRENGTHENED? Who must strengthen it, how and why?

CONTINUE: What must be CONTINUED? Who must continue it, how and why?

5. Give the following example to demonstrate the activity if necessary:

Descriptors	Who is involved, who is to make sure it happens, how must it be done, and why?
STOP	<p>STOP DISCRIMINATION OF KPs IN HEALTHCARE SETTINGS:</p> <p>Ministries of health are responsible for ensuring that KPs are not discriminated against in healthcare settings by conducting stigma and discrimination training with healthcare workers and enabling policies that prohibit discrimination on the basis of sex work, gender/sexual identity or sexuality.</p> <p>As long as KPs do not feel safe in healthcare settings, they will be reluctant to seek out services.</p>
START	<p>PROVIDE HARM REDUCTION SERVICES:</p> <p>Governments must commit to and invest in providing harm reduction services to people who inject drugs.</p> <p>Harm reduction programming has been shown to reduce risk of HIV and other infections, and is indispensable to HIV prevention strategies in countries with documented injecting drug use</p>
STRENGTHEN	<p>SUPPORT COMMUNITY-LED SERVICE PROVIDERS:</p> <p>Governments must strengthen support to community-led service providers to enable them to scale up their services to KPs.</p> <p>KPs will more likely seek out services from providers they feel safe with.</p>
CONTINUE	<p>PROVIDE EVIDENCE THAT PROMOTES ADEQUATE AND APPROPRIATE HIV SERVICE PROVISION TO KPs:</p> <p>Global agencies and governments should continue to monitor the HIV epidemic among KPs and to find new ways of addressing their challenges to HIV prevention service access.</p> <p>The more evidence KPs have that reveals their needs and that shows what works, the better.</p>

6. Encourage participants to be as clear as possible about each aspect of their message: what exactly they want, who must be involved or lead the change, how they believe the change should be implemented, and why the change is necessary. For each aspect (Stop -> Continue), encourage participants to come up with at least two really solid advocacy messages/recommendationss.
7. Give participants time to discuss and write down their advocacy messages.
8. Give each group an opportunity to present its advocacy messages.
9. Consolidate and revise advocacy messages. There will likely be variations of the same advocacy message and it would be useful to consolidate similar messages into single, strong messages. Get participants to organize themselves into groups again, and get each group to revise each key message by taking the best parts of each of the variations.
10. Get each group to present its consolidated advocacy messages, and seek feedback in a plenary. Make each advocacy message visible on a wall for the rest of the workshop.

NOTES



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