



ACT

TOOLKIT

ADVOCACY for
COMMUNITY
TREATMENT

Strengthening Community Responses to HIV Treatment and Prevention

About ITPC

ITPC is a worldwide network of community activists unified by our vision of a longer, healthier, more productive life for all (people living with HIV). ITPC's mission is to enable communities in need to access HIV treatment. As a grassroots movement based primarily in the Global South, ITPC is the community's voice on HIV treatment and is driven, led by, and committed to the human rights of those most impacted by the pandemic. ITPC is a global coalition that includes nine regional networks in Africa, Asia, the Caribbean, Eastern Europe, Latin America, and the Middle East; and over the past decade ITPC has made over 1,000 grants totaling more than \$10 million to community-based organizations of PLHIV in almost 100 countries.

Additional information about ITPC is available at: www.itpcglobal.org

Acknowledgements

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Table of Contents

INTRODUCTION	1
Abbreviations	2
What is the ACT Toolkit?	3
What does the ACT Toolkit contain?	4
How can the ACT Toolkit be used?	5
1. THE SCIENCE OF HIV	9
Section 1.1 What is HIV?	10
Section 1.2 What is HIV treatment?	15
2. TREATMENT INITIATIVES	23
Section 2.1 What is the global guidance on treatment?	24
Section 2.2 What are other important initiatives for HIV treatment?	29
Section 2.3 What are the entry points for advocacy on treatment initiatives?	40
3. HUMAN RIGHTS AND TREATMENT.	45
Section 3.1 What are human rights?	46
Section 3.2 How do human rights relate to access to treatment?	51
Section 3.3 What are the entry points for advocacy on human rights and access to treatment?	56
4. TRADE AND TREATMENT	59
Section 4.1 What is a patent and Intellectual property?	60
Section 4.2 Why does trade matter to HIV treatment?	64
Section 4.3 What is TRIPS?	68
Section 4.4 How can you advocate on trade and access to treatment?	73
5. FINANCING AND TREATMENT	79
Section 5.1 How does funding relate to access to treatment?	80
Section 5.2 What needs to happen to increase funding for treatment?	84
Section 5.3 What are the entry points for advocacy on funding and treatment?	88
6. COMMUNITY ADVOCACY PLANNING.	91
Section 6.1 What is advocacy for community treatment?	92
Section 6.2 What are your opportunities and barriers for advocacy for community treatment?	95
Section 6.3 What are your priorities for advocacy for community treatment?	98

Section 6.4	How do you develop a plan for advocacy for community treatment?	100
Section 6.5	How do you develop messages for advocacy for community treatment?	104
Section 6.6	‘What works’ for community advocacy on common barriers to treatment?	106
ACT CASE STUDIES	107
ACT Case Study 1: Uganda		
	Advocating against human rights abuses of sex workers living with HIV	108
ACT Case Study 2: Ukraine		
	Advocating against barriers to CD4 counts and art for key populations	109
ACT Case Study 3: Cameroon		
	Advocating against negative attitudes of treatment-providers	110
ACT Case Study 4: Vietnam		
	Addressing the ‘evidence gap’ for advocacy on art for key populations.	111
ACT Case Study 5: Kenya		
	Advocating on the lack of appropriate health services for LGBT people	112
ACT Case Study 6: Georgia		
	Advocating for the involvement of people who use drugs in ART services.	113
ACT Case Study 7: Russia		
	Advocating for improved provincial procurement of ARVs	114
ACT Case Study 8: West Africa		
	Advocating against poor quality ART for women living with HIV.	115

Introduction

INTRODUCTION

THE SCIENCE
OF HIV 1

TREATMENT
INITIATIVES 2

HUMAN RIGHTS
AND TREATMENT 3

TRADE AND
TREATMENT 4

FINANCING
AND TREATMENT 5

COMMUNITY
ADVOCACY
PLANNING 6

ACT
CASE
STUDIES

Welcome to the **Introduction** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

The aim of the **Introduction** is to explain what the ACT Toolkit is, what it contains and how it can be used.

Abbreviations

ACT TOOLKIT	Advocacy for Community Treatment Toolkit	MSM	Men Who Have Sex with Men
AFSU-EN	Association des Frères et Soeurs Unis du Cameroun	NGO	Nongovernmental Organization
AIDS	Acquired Immunodeficiency Syndrome	NNRTIS	Non-Nucleoside Reverse Transcriptase Inhibitors
ART	Antiretroviral Therapy	NRTI	Nucleoside/Nucleotide Reverse Transcriptase Inhibitors
ARV	Antiretroviral	MDR TB	Multi Drug-Resistant TB
CCM	Country Coordinating Mechanism	OST	Opioid Substitution Therapy
CTAAP	Community Treatment Access Advocacy Program	PCP	Pneumocystis Pneumonia
DNA	Deoxyribonucleic Acid	PI	Protease Inhibitors
GHRN	Georgian Harm Reduction Network	PPK	Professionals in Pride Kenya
HCV	Hepatitis C Virus	PREP	Pre-Exposure Prophylaxis
HIV	Human Immunodeficiency Virus	RNA	Ribonucleic Acid
HPV	Human Papillomavirus	STI	Sexually Transmitted Infection
IAC	International AIDS Conference	TASP	Treatment as Prevention
IPT	Isoniazid Preventive Therapy	TB	Tuberculosis
ICASA	International Conference on AIDS and STIS in Africa	UHRA	Uganda Harmonized Rights Alliance
ITPC	International Treatment Preparedness Coalition	VNP+	Vietnam Network of People Living with HIV
LGBT	Lesbian, Gay, Bisexual and Transgender	WHO	World Health Organization
		XDR TB	Extensively Drug Resistant TB

What is the ACT Toolkit?

What is the aim of the ACT Toolkit?

The **aim** of the Advocacy for Community Treatment (ACT) toolkit is to support and train community activists to advocate effectively and passionately on access to treatment for people living with HIV, including those from key populations.

Such activists might be part of the **International Treatment Preparedness Coalition (ITPC)** (see box). Or they might be part of a wide range of other types of organizations, networks or campaigns related to HIV treatment throughout the world.

Why is the ACT Toolkit needed?

By December 2012, 9.7 million people living with HIV in low and middle-income countries were receiving life-saving antiretroviral therapy (ART).¹ This is important progress and very welcome. However, it is **not enough**. It represents *just 34%* of the people who are eligible for ART according to guidelines produced by the World Health Organization (WHO) in 2013.²

In reality, access to HIV treatment – for many different community members in many different contexts – is still limited. This is due to a range of **social, political and economic factors**. Examples include the: cost of treatment; quality of treatment; political support for treatment; and where, how and by whom treatment is delivered. These challenges especially affect people from key populations (see box³) who experience inequitable and unacceptably low access to ART.

Community advocacy is crucial to bringing change. Yet community activists often lack the knowledge and skills needed to raise their voices and communicate their needs in the local and national forums where decisions are made. The ACT Toolkit contributes to addressing that gap.

How was the ACT Toolkit developed?

The ACT Toolkit was developed by **partners, staff and consultants** of ITPC with extensive, practical experience of community advocacy on access to treatment. ITPC is grateful to all of the individuals and organizations that contributed. In particular, thanks are given to: Sam Avrett, David Barr, Kajal Bhardwaj, Abraham Siika, Allan Maleche, Sarah Middleton-Lee, David Traynor and Othoman Mellouk.

1 *AIDS 4 Numbers*, UNAIDS, 2013.

2 *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach*, WHO, 2013.

3 *Bridging the Gap: Key Populations*; <http://www.hivgaps.org/key-populations/>

What is ITPC?

ITPC is the world's leading community-based movement of people living with HIV and their supporters who are united in promoting access to treatment. The coalition members include community organizations, local NGOs, researchers and activists with strong expertise in HIV treatment, HIV co-infections, health systems and related issues. ITPC is engaged in treatment advocacy and literacy - ensuring that people living with HIV are at the forefront of actively shaping their own futures and leading productive lives.

Who are key populations?

Key populations include lesbian, gay, bisexual and transgender (LGBT) people, sex workers and people who use drugs. Key populations live among every population in the world. However, national governments often ignore their responsibility to ensure access to health for these people. As a result, they are disproportionately affected by HIV.

Drafts texts were **tested and improved** during training with community activists in four regions: Anglophone Africa, Asia, Eastern Europe and Central Asia, and Latin America. This Toolkit brings together all the lessons and suggestions from those experiences.

The ACT Toolkit has been developed within ITPC's Community Treatment Access Advocacy Program (CTAAP). This forms part of the organization's contribution to *Bridging the Gaps* – a global collaborative program coordinated by AIDS Fonds and supported by the Government of the Netherlands. The program focuses on health and rights for key populations. For further information, please see <http://www.hivgaps.org/>.

What does the ACT Toolkit contain?

PART	SECTIONS
INTRODUCTION	<ul style="list-style-type: none"> What is the ACT Toolkit? What does the ACT Toolkit contain? How can the ACT Toolkit be used?
1 THE SCIENCE OF HIV	<ul style="list-style-type: none"> 1.1 What is HIV? 1.2 What is HIV treatment?
2 TREATMENT INITIATIVES	<ul style="list-style-type: none"> 2.1 What is the global guidance on treatment? 2.2 What are other important initiatives for HIV treatment? 2.3 What are the entry points for advocacy on treatment initiatives?
3 HUMAN RIGHTS AND TREATMENT	<ul style="list-style-type: none"> 3.1 What are human rights? 3.2 How do human rights relate to access to treatment? 3.3 What are the entry points for advocacy on treatment initiatives?
4 TRADE AND TREATMENT	<ul style="list-style-type: none"> 4.1 What is a patent and Intellectual Property? 4.2 Why does trade matter to HIV treatment? 4.3 What is TRIPS? 4.4 How can you advocate on trade and access to treatment?
5 FINANCING AND TREATMENT	<ul style="list-style-type: none"> 5.1 How does funding relate to access to treatment? 5.2 What needs to happen to increase funding for treatment? 5.3 What are the entry points for advocacy on funding and treatment?
6 COMMUNITY ADVOCACY PLANNING	<ul style="list-style-type: none"> 6.1 What is advocacy for community treatment? 6.2 What are your opportunities and barriers for advocacy for community treatment? 6.3 What are your priorities for advocacy for community treatment? 6.4 How do you develop a plan for advocacy for community treatment? 6.5 How do you develop messages for advocacy for community treatment? 6.6 'What works' for community advocacy on common barriers to treatment?

ACT CASE STUDIES	<ol style="list-style-type: none"> 1. Advocating against human rights abuses of sex workers living with HIV, Uganda 2. Advocating against barriers to CD4 counts and ART for key populations, Ukraine 3. Advocating against negative attitudes of treatment-providers, Cameroon 4. Addressing the ‘Evidence Gap’ for advocacy on ART for key populations, Vietnam 5. Advocating on the lack of appropriate health services for LGBT people, Kenya 6. Advocating for the involvement of people who use drugs in ART services, Georgia 7. Advocating for improved provincial procurement of ARVs, Russia 8. Advocating against poor quality ART for women living with HIV, West Africa
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What does each Section contain?

Each Section in the ACT Toolkit contains some or all of:

- **Section objective** summarizing what community trainers can achieve by using the Section.
- **Key information** providing basic information about the subject of the Section, sometimes including examples, illustrations or case studies.
- **Training materials** providing a list of any materials (such as PowerPoint presentations or flipcharts) needed to use the Section for training.
- **Training options** providing options for how the Section can be used within different types of training for community activists.

In all Sections, there is an:

- **Option A** giving a short (60 minutes) and information-based option for training, such as through a PowerPoint presentation and discussion.

In some Sections, there is also:

- **Option B** giving a longer (approx. 120 minutes) and more participatory option for training, such as through group work and activities.
- **Advocacy messages** suggesting some key advocacy messages for the subject.
- **Useful resources** giving links to other useful documents and websites on the subject.

Many of the Sections are supported by a PowerPoint presentation.

How can the ACT Toolkit be used?

Who can use the ACT Toolkit?

The ACT toolkit is designed to be used by **community trainers**. These are people who work closely with community activists, such as people living with HIV and members of key populations. The trainers might be such community members themselves and/or they might work or volunteer with nongovernmental organizations (NGOs), training groups or academic institutions. They should already have basic skills in participatory training.

How can the ACT Toolkit be used?

The ACT Toolkit is designed to be used **flexibly** – in whatever way is most useful to the trainer and community activists. For example, it can be used to develop a 3-5 day training workshop that addresses all of the Parts. It can also be used for shorter and less formal initiatives – with trainers selecting a few of the Parts and Sections according to the number of participants, their needs and the time available.

The ACT Toolkit requires only basic training **equipment** - a laptop and projector, flipcharts and marker pens.

How can the ACT Toolkit support participatory training?

The ACT Toolkit works best if it is part of participatory training. This means training that puts the **participants first** and enables them to: share their own knowledge, experience and ideas; ask questions and have discussions; build their skills and confidence; and 'learn by doing', such as through doing activities and analyzing case studies.

This Toolkit does not give detailed guidance on how to prepare or facilitate participatory training. However, the following suggests 10 'top tips' for trainers to consider:

TEN 'TOP TIPS' FOR FACILITATING A PARTICIPATORY WORKSHOP

1. PREPARE YOURSELF

- 'Do your homework' - reading the ACT Toolkit, researching access to treatment and having discussions about the key issues.
- Prepare each Section - considering the objective, activities and key advocacy messages. Ensure you are familiar with any materials, such as PowerPoint presentations.
- Don't take on something you don't know about (unless you have time to prepare very well). Instead, swap the session with another trainer or identify an external resource person.

2. ADAPT THE TRAINING

- Adapt the content of the training to your community. This might involve considering the context in relation to:
 - The scale of unmet needs for HIV treatment and the key barriers to access.
 - Human rights and stigma, especially for key populations.
 - Stakeholders involved in decision-making on HIV treatment.
 - 'What works' in local HIV advocacy.
 - National policies and laws related to HIV treatment.
 - National and international funding for HIV treatment.
- Make any necessary changes to the content of the training. For example, you might want to: add case studies on access to treatment in your community; refer to national guidelines and protocols in your country; or use different types of media (such as films about treatment by local campaign groups).

3. PREPARE THE PROGRAM

- Develop an outline program to share with the participants – showing what sessions will occur, when and for how long. Base the program on a pace that will encourage hard work, but also take care of the participants (for example with adequate lunch breaks).
- Run through the full program with the participants at the start of the training. Then run through the program at the start of each day or Section – to show the flow of the training.

- If possible, provide the participants with an information pack to support the training. This might include copies of PowerPoint Presentations or national HIV treatment guidelines.

4. PREPARE THE SPACE

- Make the training venue as comfortable and energising as possible. For example, if possible, choose a room with lots of windows (to give natural light) and plenty of space.
- Ensure that the venue is a 'safe space' that, for example, will enable people from key populations to maintain confidentiality.
- Arrange the room in a way that encourages sharing and participation. For example, have a circle of chairs rather than a classroom-style layout.
- Ensure that the equipment (laptop, projector, etc.) is ready and that you know how to work it.

5. USE AVAILABLE EXPERTISE

- Use the expertise that you have among the participants. Recognise that everyone comes with some experience and knowledge of access to HIV treatment.
- Work in partnership and identify external resource people to provide expert input into the training or to facilitate specific Sections. Examples might include representatives of networks of people living with HIV, groups of key populations or the Ministry of Health

6. SET AND ENFORCE GROUND-RULES

- At the start of the training, work with the participants to identify and agree ground rules by which everyone will work. Examples include: keep to time; have mobile phones on silent; do not answer calls during the training; participate openly and honestly; and respect each other's opinions.
- Ask the participants to help you enforce the ground rules throughout the training. For example, if someone is not participating, ask the others to encourage them to do so.
- Respect the ground-rules yourself. For example, if a rule is 'keep to time', finish facilitating your sessions promptly. If you are running late, ask the participants if they would prefer to continue or to re-arrange the program.

7. ENCOURAGE PARTICIPATION

- Do not dominate sessions. Instead, facilitate the involvement of the participants.
- Respect participants' different experiences and perspectives. For example, say: *"Thank you for that important contribution"* or *"It was great to hear your interesting example."*
- If some participants are not participating, consider: using buzz groups (groups of 2-3 participants that provide a 'safe space' and encourage people to talk); or speaking to them in a break to check if there are any problems and encourage them to give input.
- If some participants are being dominant, consider: politely stopping them from making long interventions (for example by saying "Thank you ... and now I'd like to hear about other people's experiences"); speaking to them in a break and encouraging them to keep engaged, but to speak less; or giving them a task to do (for example, being a rapporteur who will report back on the day at the beginning of the next morning).

8. WORK AS A TEAM

- If you are working with other trainers, work as a team – supporting each other and your roles. Ensure that everyone in the team is familiar with the whole program – so that they understand the flow of the training and can 'jump in' if there are emergencies.

- Where possible, co-facilitate sessions – to support each other and provide a variety of styles, inputs and energies.
- Support each other if there are crises. For example, if a session is not going well, ask for suggestions from the other trainers or take a short break.

9. ASK YOUR PARTICIPANTS

- Ask the participants their expectations at the start of the training and regularly re-visit those expectations to ensure you are on track.
- Keep in touch with your participants. For example, have a brief feedback session at the end of each day or each Section - for participants to share their 'highs' and 'lows' and any concerns. Or have informal discussions during the lunch break to check-in on how people are feeling.
- Check throughout the training that your participants have understood key terms and concepts. For example, ask: "Is that clear?" or "Shall I go through that again?"
- Respond to feedback from your participants – either making changes to the program or explaining why you cannot do so.

10. LEARN FROM EXPERIENCE

- Evaluate the training, such as through a form or activity to collect the participants' feedback (for example on the quality of the sessions and the facilitation).
- After the training, carry out a debrief among the trainers to identify lessons learned and what could be done better or differently in the future.

More information about participatory training can be found in a number of other resources. Examples include:

- *A Facilitators' Guide to Participatory Workshops with NGOs/CBOs Responding to HIV/AIDS*, International HIV/AIDS Alliance, December 2003. http://www.aidsalliance.org/includes/Publication/fge1101_Facilitators_guide_eng.pdf
- *100 Ways to Energize Groups: Games to Use in Workshops, Meetings and the Community*, International HIV/AIDS Alliance, December 2003. http://www.aidsalliance.org/includes/Publication/ene0502_Energiser_guide_eng.pdf

1

THE SCIENCE OF HIV

INTRODUCTION

**THE SCIENCE
OF HIV** 1

TREATMENT
INITIATIVES 2

HUMAN RIGHTS
AND TREATMENT 3

TRADE AND
TREATMENT 4

FINANCING
AND TREATMENT 5

COMMUNITY
ADVOCACY
PLANNING 6

ACT
CASE
STUDIES

Welcome to **Part 1: The Science of HIV** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

The aim of Part 1 is to support community activists to have a strong understanding of the ‘basics’ of HIV and treatment – before looking at the current HIV treatment world and community advocacy.

SECTION 1.1. What is HIV?

SECTION OBJECTIVE

To build community activists' understanding of the 'basics' about HIV, including: what it is; how it is transmitted, diagnosed and monitored; how it progresses; and what infections are related to it.

TRAINING MATERIALS

Powerpoint presentation '1.1. What is HIV?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Divide the participants into 'buzz groups' of 2-3 people. Ask them to discuss and write down any questions that they have about 'What is HIV?' These might be things that they do not know or information that is unclear to them.
3. Present Powerpoint presentation '1.1. What is HIV?'
4. Ask the participants if they have any questions about the presentation. Check if you have answered all of the questions that they identified in their 'buzz groups'. If you have not, provide them with further information.
5. Ask the participants to summarize the session by developing advocacy messages about 'What is HIV?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

HIV is still a serious disease. If it is not treated, it causes death.

- Access to key tools - such as CD4 counts and viral load tests - are vital for monitoring HIV effectively and identifying when to start treatment.
- Access to HIV treatment also requires access to treatment for the opportunistic infections and cancers that affect people living with HIV.

USEFUL RESOURCES

- *What is AIDS and HIV?*, (online lesson), AIDSMEDS. http://www.aidsmeds.com/articles/WhatIsAIDS_4994.shtml
- HIV 101 - HIV Information to Help You Understand, (online fact sheet), About.com. <http://aids.about.com/cs/aidsfactsheets/a/hivbasics.htm>
- *HIV in Our Lives: Book of Information Sheets for People Living With HIV, Support Groups and Clinics*, Treatment Action Campaign, 2007. <http://ebookbrowse.net/gdoc.php?id=23475917&url=fc3c9bf333d616c700290cef759e3ecc>
- *HIV/AIDS 101: What is HIV?*, AIDS.gov. <http://aids.gov/hiv-aids-basics/hiv-aids-101/what-is-hiv-aids/>

What is HIV?

The **Human Immunodeficiency Virus (HIV)** is a tiny virus that cannot be seen with the naked eye.

HIV affects a person's immune system. It destroys CD4 cells – white blood cells that fight off infections.

There are two **types of HIV**:

- HIV 1 is the most common. It is found around the world. It has different groups, of which the most common is M. Group M has several sub-types, named A – K.
- HIV 2 is less common. It is most often found in West Africa.

HIV causes **Acquired Immunodeficiency Syndrome (AIDS)**. This is where a person's immune system fails, allowing opportunistic infections and cancers to destroy the body.

How is HIV transmitted?

HIV is transmitted through a person's **body fluids**. Examples include blood, semen, vaginal fluids and breast milk.

HIV can be **transmitted** in different ways. These include:

- A person having unprotected (without using a condom) vaginal or anal sexual intercourse with someone who is living with HIV.
- A mother who is living with HIV passing the virus to her baby during pregnancy, delivery or breastfeeding. This is sometimes referred to as 'vertical transmission', 'mother-to-child transmission' or 'parent-to-child transmission'
- A person sharing a needle, syringe or other injection equipment with a person who is living with HIV.
- A person having a transfusion of blood that is infected with HIV.
- A person having contact with needles, knives and other sharp objects that have blood infected with HIV on them.

There are factors that affect a person's **risk of infection**. This means how likely HIV is to be transmitted to them from someone living with HIV. The factors include:

- The viral load of the person who is living with HIV (i.e. how much of the virus they have in their body).
- The frequency of exposure (i.e. how often the situation that risks transmission occurs).
- The duration of exposure (e.g. how long the situation that risks transmission lasts).
- The condition of their protective barriers (i.e. whether the barriers are strong enough to stop the virus being transmitted through them). Such barriers include skin and mucous linings (such as in the vagina and anus). They can get damaged in different ways. Examples include through:
 - Illness, such as if someone has a sexually transmitted infection (STI) which causes sores on their genitals.
 - Accidents, such as if someone pricks themselves with a needle that has infected blood on it.
 - Behaviors, such as if a man and woman have dry sex - where the natural lubrication of the woman's vagina is reduced and the lining might get ripped.

How is HIV diagnosed?

HIV is usually **diagnosed** through a blood test. This can tell if a person is living with HIV due to the presence of:

- Antibodies that are produced by the body to fight HIV.
- Proteins that are on the surface of the virus.
- Genetic material that related to the virus, such as deoxyribonucleic acid (DNA) or ribonucleic acid (RNA).

There are a number of different **types of HIV tests**. Examples include:

- Antibody test (such as the ELISA, Western blot and rapid test). This is the most common type. It involves identifying if a person's blood sample contains antibodies to HIV.
- Antigen/p24 marker test. This is rarely used. It involves identifying if a person's sample contains protein number 24 of the HIV virus.
- Combined antibody and antigen test. This is not common. It involves identifying if a person's sample contains both antibodies to HIV and protein number 24 of the HIV virus.
- Nucleic acid test (also called RNA PCR test)/viral load test. This is a complex and expensive process that is commonly used for children under the age of 18 months. It is a viral load test that identifies the presence and amount of the HIV virus in a body fluid.

How is HIV monitored?

HIV uses CD4 cells to reproduce – by making more and more copies of itself. As it increases, HIV destroys the CD4 cells - leaving the body vulnerable to infection.

CD4 cells can be used to monitor how strong or weak a person's immune system is. Measuring someone's level of CD4 cells – known as a **CD4 count** - is an indirect way to find out how HIV is affecting them. The lower the count, the weaker the person's immune system - due to a higher level of the virus.

An average CD4 count is about 500 cells/mm³ - meaning that there are 500 CD4 cells per cubic millimeter of blood. Women usually have higher CD4 counts than men.

A CD4 count can be used to help decide when a person needs to start HIV treatment. It, once a person is taking the drugs, gives an indication of how successful the treatment is.

HIV infection can also be monitored through a person's **viral load**. This involves counting how many copies of the virus are present in their blood. The higher the viral load, the more the immune system is in danger of being weakened.

Viral load is reported according to the number of copies of the HIV virus per milliliter of blood:

- A high viral load is over 50,000 copies per ml
- A low viral load is under 10,000 copies per ml
- An undetectable viral load is under 50 copies per ml

A viral load test is generally better than a CD4 count for monitoring HIV treatment. This is because it shows how much HIV is still in the person's blood and, therefore, how effective the treatment is or is not.

How does HIV progress?

If a person is living with HIV, but is not on HIV treatment, their infection will get worse. This is what is called the natural progression of HIV infection – based on ‘staging’ of the disease identified by the World Health Organization (WHO). The natural progression has five recognized **stages**:

The natural progression of HIV infection
<p>Stage 1: Acute (early) phase infection</p> <ul style="list-style-type: none"> ● This is also known as acute retroviral syndrome. ● It usually lasts up to six months. ● The person usually develops a mild illness a few days or few weeks after becoming infected with HIV. They may have one or more of: sore throat; rash; enlarged lymph nodes; headache; malaise; fatigue; fever; poor appetite; vomiting; and muscle pain. ● The person’s viral load goes up dramatically for a few weeks. It then goes down. ● Many scientists believe that this is an important stage at which to take action and achieve better outcomes. It is why there has been attention to people starting HIV treatment earlier after their diagnosis.
<p>Stage 2: Asymptomatic phase</p> <ul style="list-style-type: none"> ● This is also known as chronic HIV infection. ● It can last from a few weeks to many years - averaging eight years. ● The person is generally well, has a high CD4 count and a low viral load.
<p>Stage 3: Early symptomatic phase</p> <ul style="list-style-type: none"> ● During this stage, the person has simple illnesses (such as colds, flu or skin rashes) more often.
<p>Stage 4: AIDS stage</p> <ul style="list-style-type: none"> ● This is marked by the start of the person’s first AIDS defining illness or opportunistic infection. AIDS defining illnesses tend to be very severe infections that are extremely rare in people with normal levels of immunity. Examples include Kaposi Sarcoma and Tuberculosis outside of the lungs. ● The average length of time between the start of the AIDS stage and death is less than two years.
<p>Stage 5: Death</p> <ul style="list-style-type: none"> ● If the person does not receive treatment, HIV infection will lead to their death.

What infections are related to HIV?

Once a person's immune system is weakened by HIV, their body becomes vulnerable to diseases. These include opportunistic infections (that are caused by organisms such as bacteria) and cancers.

Common **opportunistic infections** related to HIV include:

TUBERCULOSIS (TB). This infection:

- Is caused by a bacteria called Mycobacterium Tuberculosis.
- Is transmitted through the air – such as if someone coughs.
- Can affect different parts of a person's body, including their lungs and bones.
- Can be diagnosed in different ways, such as a sputum (spit) test, chest X-ray or skin test.
- Is a chronic curable illness (i.e. it is long-lasting, but can be treated effectively).
- Is treated by giving the person a combination of drugs.
- If it is not treated, leads to death.

HEPATITIS C. This infection:

- Is caused by the Hepatitis C virus (HCV) which infects a person's cells.
- Is transmitted from one person's blood to the other.
- Is common among people who inject drugs.
- Can be diagnosed using an HCV antibody test or HCV viral load test.
- Is a treatable and curable disease.
- Is treated by giving the person a combination of drugs.
- If it is not treated, eventually stops the person's liver from working properly and usually leads to death.

Other common opportunistic infections include: oral thrush; malaria; and fungal pneumonia, also known as Pneumocystis Pneumonia (PCP).

People living with HIV are also much more likely to have some forms of **cancer** than the general public. The most common types related to HIV include:

KAPOSI'S SARCOMA. This cancer:

- Is a type of skin cancer.
- Is several thousand times more common in people living with HIV.
- Is particularly common among people living with HIV who are men who have sex with men.

NON-HODGKIN LYMPHOMA. This cancer:

- Commonly affects a person's brain and lungs.
- Is at least 70 times more common in people living with HIV.

CERVICAL CANCER. This cancer:

- Is associated with Human Papillomavirus (HPV) - an opportunistic infection that is transmitted through sex.
- Is at least five times more common in people living with HIV.
- Is particularly high among people living with HIV who are sex workers – because they are more likely to be exposed to HPV.

SECTION 1.2. What is HIV treatment?

SECTION OBJECTIVE

To build community activists' understanding of the 'basics' of HIV treatment, including: what it is; how it works; when someone should start it; what adherence means; the current options for treatment; treatment for infections related to HIV; treatment as prevention; and treatment as pre-exposure prophylaxis.

TRAINING MATERIALS

- Powerpoint presentation '1.2. What is HIV treatment?'
- Box or bag (to put small pieces of paper in).

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Present Powerpoint presentation '1.2. What is HIV treatment?'
3. Ask the participants to write down on a piece of paper any points from the presentation that were unclear or any questions that were not answered. Ask them to write one point or one question per piece of paper.
4. Ask the participants to put their pieces of paper in a box or a bag.
5. Take one of the pieces of paper out of the box or bag. First ask the participants for their answers, then, if necessary, provide additional information yourself.
6. Repeat the process for the other pieces of paper.
7. Ask the participants to summarize the session by developing advocacy messages about 'What is HIV treatment?'. Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

- HIV treatment is highly effective and critical to any response to HIV. It saves and improves lives of people living with HIV.
- HIV treatment must be part of a 'cascade' of steps that take people from HIV counselling and testing through to having reduced HIV infection. It must also be part of a 'continuum' that also includes HIV prevention, care and support.
- According to global guidance, HIV treatment should now be provided to all adults and adolescents with a CD4 count of over 350 cells/mm³ and under 500 cells/mm³, as well as priority groups such as pregnant women and children living with HIV.

USEFUL RESOURCES

- *When Should I Start Treatment and What Should I Take?* (online lesson), AIDSMEDS. http://www.aidsmeds.com/articles/WhenToStart_7512.shtml
- ARVs, (online guide to each type of ARV), i-base. <http://i-base.info/guides/category/arvs>
- *The Use of Antiretrovirals in the Prevention and Treatment of HIV*, (webpage), WHO. <http://www.who.int/hiv/topics/treatment/en/>

- *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach, WHO, June 2013. <http://www.who.int/hiv/pub/guidelines/arv2013/download/en/>*

What is HIV treatment?

HIV treatment saves and improves the quality of life of people living with HIV.

HIV treatment involves using drugs known as antiretrovirals (ARVs). These reduce the reproduction of HIV in a person's body and lower their viral load. This allows the body to re-build its immunity.

Providing ARVs to a person living with HIV is known as antiretroviral therapy (ART).

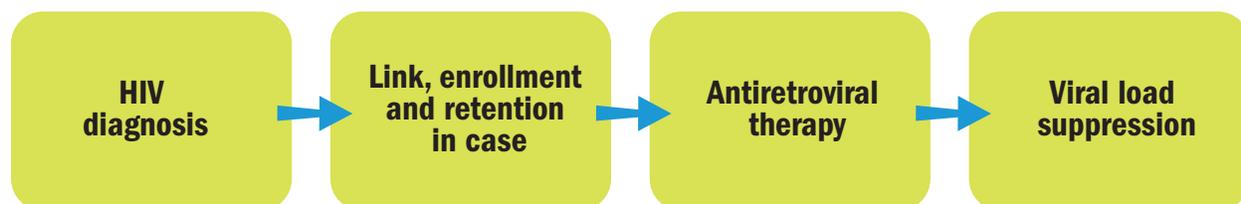
HIV treatment also includes the treatment of opportunistic infections and cancers that affect people living with HIV (see Section 1.1).

HIV treatment requires a 'cascade' or 'continuum'. This involves a series of steps – all of which are vital to achieve a successful result. The cascade begins with a person undergoing HIV counselling and testing (HCT) and receiving a diagnosis. It then goes on until the person's viral load is lowered.

The HIV treatment cascade

ART needs to be part of 'a package' of prevention, care, support and treatment for people living with HIV. This also includes psychological, emotional, nutritional and social support – all of which are vital for HIV treatment to be effective.

HIV TREATMENT CASCADE



How does HIV treatment work?

HIV treatment works by **interfering** with the reproduction of the HIV virus. ARVs slow down the reproduction and allow the body's immune system to get back to normal and fight infection.

Different ARVs have to be taken together. This is referred to as **combination therapy**. It is so that different drugs can target different stages in the life cycle of the virus.

Over the years, important developments have taken place in areas of science related to HIV, such as vaccines and microbicides. However, currently, there is no **cure or vaccine** for HIV. As such, ART – as part of a 'package' of HIV prevention, care, support and treatment - is the most important option available to save the lives of people living with HIV. It is also – as described later in this Section – an increasingly important option for HIV prevention.

When should someone start HIV treatment?

When a person has been diagnosed HIV-positive, they should have a CD4 count. This will identify how far HIV has developed in their body and if they should start HIV treatment.

The World Health Organization (WHO) provides the following global guidance on who should be eligible for HIV treatment (i.e. when different types of people living with HIV should be offered ART):

World Health Organization guidance on when people should start ART

ART should be started in:

Ideally, **all** adult and adolescent people living with HIV who have a CD4 count of **more than 350 cells/mm³ and less than 500 cells/mm³** regardless of their WHO clinical stage. However, priority should be given to those with:

- **Severe or advanced HIV clinical disease (WHO clinical stage 3 or 4);** and
- A CD4 count **less than 350 cells/mm³** .

Adult and adolescent people living with HIV regardless of their WHO clinical stage or CD4 count who:

- Have active **TB** disease.
- Have **HBV** with severe chronic liver disease.
- Are part of a **serodiscordant couple** (with a partner who is HIV-negative).

All **pregnant women** for the duration of pregnancy, delivery and breastfeeding and continuing for life.

All children living with HIV with severe or advanced symptomatic disease (WHO clinical stage 3 or 4) regardless of their age and CD4 count.

Any **child under 18 months** who is thought to have a clinical diagnosis of HIV infection.

All **children under 5 years living with HIV**, regardless of their WHO clinical stage or CD4 count.

All **children above 5 years living with HIV** with a CD4 count **less than 500 cells/mm³**, **regardless** of their WHO clinical stage.

What is adherence to HIV treatment?

Adherence means taking the right drugs, in the right quantity, in the right way and over the right length of time – as recommended, for example, by a doctor or community health worker.

ARVs do not cure HIV. So, a person living with HIV must take drugs for their whole life, without any interruptions.

Adherence to HIV treatment is very important for a person living with HIV. This is because it helps them to:

- Avoid giving the virus a chance to weaken their immune system.
- Improve their health over a longer period of time.

Adherence also helps to avoid the development of an HIV virus that is resistant to the types of ARVs that are currently available.

The **benefits** of being and staying on HIV treatment include that it can:

- Save and improve the quality of life of a person living with HIV.
- Enable families to improve their social and financial situation, for example because a parent living with HIV can go to work.

- Reduce the transmission of HIV from a person living with HIV to their sexual partner (see later in this Section).
- Save and improve the quality of life of a mother living with HIV and also prevent transmitting HIV to her baby.

What are the current options for HIV treatment?

The following provides examples of the types of ARVs that are currently available. It states the type of ARV, describes how it attacks HIV and gives examples of drugs:

TYPES OF ARVS CURRENTLY AVAILABLE

TYPE OF ARV	HOW THE ARV ATTACKS HIV	EXAMPLES OF DRUGS
Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) - also known as nucleoside analogues or nukes	Interferes with an HIV protein called reverse transcriptase which the virus needs to reproduce itself	Zidovudine (AZT,ZDV); Didanosine (ddI); Stavudine (D4t); Lamivudine (3TC); Abacavir (ABC); Emtricitabine (FTC); Tenofovir (TDF); Zalcitabine (ddC)
Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) - also known as non-nucleosides or non-nukes	Stops HIV replicating within cells by interfering with the reverse transcriptase protein	Efavirenz (EFV); Nevirapine (NVP); Delavirdine (DLV); Etravirine (ETR); Rilpivirine
Protease Inhibitors (PIs)	Inhibits protease - another protein involved in the replication of HIV	Lopinavir/Ritonavir (LPV/r); Nelfinavir (NLF); Darunavir (DVR); Atazanavir (ATZ); Indinavir (IDV);
Fusion or Entry Inhibitors	Prevents HIV from binding to or entering the body's immune cells	Enfuvirtide (INN); Maraviroc (MVR)
Integrase Inhibitors	Interferes with the integrase enzyme which HIV needs to insert its genetic material into human cells	Raltegravir (RAL), Dolutegravir (DOL), Elvitegravir (EVG)

Different types of ARVs are combined to form a **drug regimen** for a person living with HIV. This might include at least three drugs from the different types.

When a person become eligible for treatment, the first group of medicines to be used is called the **1st line regimen**. If this set of drugs do not work, a person is then switched to a **2nd line regimen**.

There are also **3rd line regimens**. However, these drugs are usually newer and expensive.

Treatment failure happens when one or more ARVs in a drug regimen do not work (i.e. they cannot stop replication of HIV). Failure can be identified if a person's viral load is increasing, CD4 count is decreasing and/or if clinical symptoms (such as opportunistic infections) return.

The following summarizes global guidance by WHO on the best available 1st and 2nd line regimens for different types of populations living with HIV. The drugs that are in bold type are the first choice combination for the regimen in question:

RECOMMENDED 1ST LINE ARV REGIMENS

POPULATION LIVING WITH HIV	RECOMMENDED REGIMEN
Adults and adolescents (aged 10-19 years)	2 nucleoside reverse-transcriptase inhibitors plus 1 non-nucleoside reverse-transcriptase inhibitor
	TDF + 3TC (or FTC) + EFV as a fixed-dose combination
	or AZT + 3TC + EFV or AZT + 3TC + NVP or TDF + 3TC (or FTC) + NVP
Pregnant and breastfeeding women	TDF + 3TC (or FTC) + EFV as a fixed-dose combination
Children	Under 3 years: ABC or AZT + 3TC + LPV/r or ABC or AZT + 3TC + NVP
	3 years and older: ABC + 3TC + EFV or AZT + 3TC + EFV (or NVP) or TDF + 3TC (or FTC) + EFV (or NVP)

RECOMMENDED 2ND LINE ARV REGIMENS

POPULATION	RECOMMENDED REGIMEN	
Adults and adolescents (aged 10-19 years), including pregnant and breastfeeding women	2 nucleoside reverse-transcriptase inhibitors plus 1 ritonavir-boosted protease inhibitor - Fixed-dose combinations ATV/r and LPV/r	
	If the following 1st line nucleoside reverse-transcriptase inhibitor fails:	Replace it with:
	TDF + 3TC (or FTC)	AZT + 3TC
	AZT or d4T + 3TC	TDF + 3TC (or FTC)
Children	1 boosted Protease Inhibitor - LPV/r plus 2 nucleoside reverse-transcriptase inhibitors	
	Under 3 years: Stay on 1st line regimen and improve adherence	
	3 years and older:	
	If the following 1st line nucleoside reverse-transcriptase inhibitors fails:	Replace it with:
	ABC or TDF + 3TC (or FTC)	AZT + 3TC
	AZT or d4T + 3TC (or FTC)	ABC or TDF + 3TC (or FTC)
If the LPV/r-based regimen fails, replace it with 1 non-nucleoside reverse transcriptase inhibitor - EFV plus 2 nucleoside reverse-transcriptase inhibitors		

What treatment is available for infections related to HIV?

It is also vital that people living with HIV have access to treatment for the infections that they experience. The following focuses on two of the most common opportunistic infections (as described in Section 2.1).

OPPORTUNISTIC INFECTION	RECOMMENDED TREATMENT
Tuberculosis (TB)	<p>Treatment for active TB (people who are sick and infectious) requires a combination of drugs:</p> <ol style="list-style-type: none"> 1. For drug-susceptible TB (i.e. TB that responds to available drugs): <ol style="list-style-type: none"> a. New patients with TB in their lungs should receive: 2 months of Isoniazid, Rifampicin, Pyrazinamide and Ethambutol, followed by 4 months of Isoniazid and Rifampicin (2HRZE/4HR). b. New patients with TB in other parts of their bodies should receive: 2 months of Isoniazid, Rifampicin, Pyrazinamide and Streptomycin, followed by 4 months of Isoniazid and Rifampicin (2HRZS/4HR). c. Those in need of re-treatment should receive: 2 months of Isoniazid, Rifampicin, Pyrazinamide, Ethambutol and Streptomycin, followed by 1 month of Isoniazid, Rifampicin, Pyrazinamide and Ethambutol, followed by 5 months of Isoniazid, Rifampicin and Ethambutol (2HRZES/1HRZE/5HR). 2. For drug-resistant TB: <ol style="list-style-type: none"> a. People with multi drug-resistant TB (MDR TB) (i.e. TB that does not respond to Isoniazid and Rifampicin) require: fluoroquinolones and any of the 2nd line injectables (such as amikacin, kanamycin or capreomycin) – as guided by tests for the person’s sensitivity to the drugs. The treatment takes about 2 years. b. People with extensively drug resistant TB (XDR TB) (i.e. TB that does not respond to isoniazid, rifampicin, fluoroquinolones or any of the 2nd line injectables (amikacin, kanamycin or capreomycin) require: the same treatment as for MDR TB – as guided by tests for the person’s sensitivity to the drugs. The treatment takes up to 2 years.
	<p>Treatment for latent TB (people who are not sick or infectious) requires:</p> <ul style="list-style-type: none"> ● Daily use of Isoniazid Preventive Therapy (IPT) for 6 months – to prevent the TB from becoming active
Hepatitis C	<p>Treatment for HCV requires a combination of drugs:</p> <ul style="list-style-type: none"> ● Interferon plus ribavirin. Also, an HCV protease inhibitor can be added for specific types of HCV. ● Treatment usually lasts 48 weeks.

What is treatment as prevention?

Treatment as prevention (TasP) is a term increasingly used to describe HIV prevention methods that use antiretroviral treatment to decrease the chance of HIV transmission. In 2011, the HIV Prevention Trials Network Study 052 showed that using ART can have strong benefits for HIV prevention. The study found that, if a person living with HIV is taking ART, there can be a huge (96%) reduction in the transmission of HIV to their partners. Also, the person's own viral load can decrease to an almost undetectable level.

With TasP, HIV treatment is used for the benefit of both the person living with HIV and people who are uninfected.

ART reduces the amount of HIV in the person's body – which dramatically reduces the chances of them transmitting HIV to other people.

TasP is seen as important strategy for ending the HIV epidemic. It is a critical part of combination HIV prevention. This means prevention that combines different strategies (such as those that are behavioral, biomedical and structural) and works at different levels (such as individual, relationships, community and societal).

Particular emphasis is given to TasP for particular communities where the impact on HIV prevention might be the greatest. These include serodiscordant couples, pregnant women and members of key populations.

What is pre-exposure prophylaxis?

Pre-exposure prophylaxis (PrEP) involves making a medical intervention *before* someone is exposed to a disease. The aim is to prevent them becoming infected.

PrEP is a method for HIV prevention. It involves people who are HIV-negative taking Truvada (a pill that contains two ARVs) every day to reduce their risk of becoming infected. It could be a way for people who are at very high risk of HIV – such as some members of key populations – to lower that risk.

Research is on-going about the effectiveness of PrEP.

What is post-exposure prophylaxis?

Post-exposure prophylaxis (PEP) is an intervention that uses treatment to reduce the likelihood of HIV infection after possible exposure through, for example, accidental needle pricks, cuts with sharp contaminated objects or sexual intercourse.

Two types of PEP include:

- 1. Occupational PEP** (sometimes called “oPEP”), taken when someone working in a healthcare setting is potentially exposed to material infected with HIV
- 2. Non-occupational PEP** (sometimes called “nPEP”), taken when someone is potentially exposed to HIV outside the workplace (e.g., from sexual assault, during episodes of unprotected sex or needle-sharing injection drug use).

For effective protection, PEP must be started within 72 hours of exposure, before the virus has time to multiply in the body.

PEP consists of a combination of antiretrovirals that are taken for 28 days. Some authorities suggest retesting after 4 weeks and then after 12 weeks. National guidelines should be followed to ensure the preventive effective of treatment.

2

TREATMENT INITIATIVES

INTRODUCTION

THE SCIENCE OF HIV

1

TREATMENT INITIATIVES

2

HUMAN RIGHTS AND TREATMENT

3

TRADE AND TREATMENT

4

FINANCING AND TREATMENT

5

COMMUNITY ADVOCACY PLANNING

6

ACT CASE STUDIES

Welcome to **Part 2: Treatment Initiatives** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

Part 2 focuses on a number of global initiatives (such as frameworks and guidelines) that shape the treatment ‘world’ and influence access to HIV treatment in communities and countries.

Section 2.1 What is the global guidance on treatment?

SECTION OBJECTIVE

To build community activists' understanding of the 2013 ART Guidelines* and why they matter for access to HIV treatment.

(* The Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach, WHO, June 2013)

TRAINING MATERIALS

- PowerPoint presentation '2.1. What is the global guidance on treatment?'
- Copies of *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach*, WHO, June 2013.
- Flipchart and pens.

TRAINING OPTIONS

Option A (approx. 60 minutes)

For this activity, it is helpful to give each participant a copy of the Summary of the 2013 ART Guidelines in advance and to ask them to read it: <http://www.who.int/hiv/pub/guidelines/arv2013/intro/rag/en/>

1. Explain the objective of the Section.
2. Facilitate a group discussion, asking the participants what they know about the 2013 ART Guidelines and how they might affect access to HIV treatment in their communities.
3. Present PowerPoint presentation '2.1. What is the global guidance on treatment?'
4. Compare the participants' discussion and the content of the presentation.
5. For example: *Were there any differences in understanding or opinions about what the guidance says?*
6. Encourage the participants to ask additional questions for clarification.
7. Ask the participants to summarize the session by developing advocacy messages about 'What is the global guidance on treatment?'
8. Support their ideas by sharing examples of messages (see below).

Option B (approx. 120 minutes)

For this activity, it is necessary to give each participant a copy of the 2013 ART Guidelines in advance and to ask them to read it.

1. Explain the objective of the Section.
2. Provide a general introduction to the 2013 ART Guidelines. For example, summarize who produced the guidelines, what they cover and who can use them.
3. Divide the participants into two groups, each with a question to focus on:
 - Group 1:** What do the guidelines recommend about *who* should have access to HIV treatment?
 - Group 2:** What do the guidelines recommend about *how* HIV treatment should be provided?
4. Give the groups about 45 minutes to discuss their question. Encourage them to base the answer to their question on the specific recommendations in the 2013 ART Guidelines.

5. Bring the two groups back together. Ask each group to briefly report back on the answer to their question. Encourage the other participants to make additional points.
6. Facilitate a group discussion on:
 - In the 2013 ART Guidelines, what matters most to communities? For example, which recommendations will make the greatest difference in access to treatment for:
 - People living with HIV (in general)?
 - People living with HIV who are from key populations, such as sex workers, people who use drugs and lesbian, gay, bisexual and transgender (LGBT) people?
7. Support the participants to identify about four priorities in the ART Guidelines from the perspective of communities. Write the priorities on a flipchart.
8. Ask the participants to summarize the session by developing advocacy messages about ‘What is the global guidance on treatment?’ Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. The 2013 ART Guidelines are a vital opportunity to follow ‘good practice’ and achieve *universal access* to HIV treatment for *all* people living with HIV, including those from key populations.
2. The 2013 ART Guidelines emphasize the vital role of *communities* in delivering HIV services and increasing access to treatment. However, that role can only be fulfilled if such groups have access to decision-making and resources.
3. Implementing the 2013 ART Guidelines and achieving universal access is not just about scaling-up ART. It is about the ‘*wrap-around*’ *package* of good quality and comprehensive treatment and support that is needed - such as with attention to the quality of drugs, treatment for co-infections and the availability of 2nd and 3rd line treatment options.

USEFUL RESOURCES

- *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach*, WHO, June 2013. http://apps.who.int/iris/bitstream/10665/85321/1/9789241505727_eng.pdf
- *Summary of New Recommendations of the Consolidated ARV guidelines*, June 2013. <http://www.who.int/hiv/pub/guidelines/arv2013/intro/rag/en/>
- *Summary of the New 2013 Guidelines Recommendations and Key Issues from a Community and Civil Society Perspective*, International HIV/AIDS Alliance, Stop AIDS Now and GNP+, 2013. <http://www.treatmentsciencewriters.com/wp-content/uploads/2013/09/Community-ART-briefing-paper-V7-FINAL.pdf>

Who is responsible for global guidance on health?

Global guidance on health issues and diseases is provided by the World Health Organization (WHO) - a United Nations agency based in Geneva, Switzerland. WHO provides UN member states with access to essential information about health and health care delivery in order to improve health outcomes in their countries. WHO guidance aims to ensure that all people have equitable access to essential healthcare and, in turn, have the highest possible level of health.

WHO is governed by the World Health Assembly (WHA) – the world’s highest body for health policy-making. The Assembly is attended by delegations from 194 member states; approves the WHO work program and budget; and elects WHO’s Director General.

WHO's responsibilities include:

- Providing leadership on global health matters and engaging in partnerships where joint action is needed
- Shaping the health research agenda and stimulating the generation, translation and dissemination of valuable knowledge
- Setting health norms and standards and promoting and monitoring their implementation
- Articulating ethical and evidence-based health policy options
- Providing technical support to countries
- Monitoring and assessing health trends

What does WHO say about HIV treatment?

WHO has produced guidelines on the use of antiretroviral therapy (ART) since 2002. It published its latest version in June 2013 titled *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach*. In the ACT Toolkit, they are referred to as the '2013 ART Guidelines'.

The 2013 ART Guidelines address the use of ARV drugs for HIV treatment and prevention across all age groups and populations, based on the broad continuum of HIV care. They provide:

- Evidence-based clinical recommendations with a focus on settings with limited capacity and resources in the health system
- Guidance on key operational and service delivery issues that need to be addressed to increase access to HIV services
- Programmatic guidance for decision-makers and planners at the national level on adapting, setting priorities for and implementing the clinical and operational recommendations and monitoring their implementation and impact

The 2013 ART Guidelines are for use by all stakeholders involved in HIV treatment. This includes Ministries of Health, health program managers, health workers, people living with HIV and key populations. The 2013 ART Guidelines are very detailed – totaling over 250 pages – but a shorter summary version is also available.

What communities should know about the 2013 ARV Guidelines

HIV testing: The beginning of a successful implementation of these guidelines is scaling up HIV testing that preferably is community driven, so that communities can then demand and access HIV treatment.

When to start ART: The Guidelines recommend immediate initiation of ART for anyone <500. Additional consideration for starting above 500 is made for certain populations – such as sero-discordant couples. *But given limited resources, the guidelines prioritize treating the sickest patients first.* So, everyone <500 should be offered and have access to treatment. But greater priority should be to people <200 or <350 and/or who are symptomatic.

Eliminating toxic regimens: Regimens that are not tolerable due to their harsh side effects should no longer be used. d4T is no longer recommended as a first line regimen because of side effects.

Lifelong treatment for pregnant women: Pregnant women should have the opportunity to access life long HIV treatment under option B+, which ensures prevention of vertical transmission but also their ongoing health.

Treatment beyond just HIV: Fulfilling the 2013 ART Guidelines also requires the management and treatment of co-infections, including Tuberculosis (TB), Hepatitis C and sexually transmitted infections (STIs).

The role of communities in supporting health: There is acknowledgment in the Guidelines that communities are essential in the implementation of the new guidelines through treatment and rights literacy, creating demand for and linking communities to health and interrelated services, reaching those hardest to reach to increase impact, and providing complementary behavioral interventions at healthcare facilities (e.g. through peer education and counselling), among others.

The following provides further examples of WHO's recommendations that are particularly relevant to community activists. It uses the exact text of the 2013 ART Guidelines:

EXAMPLES OF RECOMMENDATIONS IN THE WHO 2013 ART GUIDELINES

SUBJECT	RECOMMENDATIONS
When to start ART in adults and adolescents	<ul style="list-style-type: none"> ● As a priority, ART should be initiated in all individuals with severe or advanced HIV clinical disease (WHO clinical stage 3 or 4) and individuals with CD4 count ≤ 350 cells/mm³. ● ART should be initiated in all individuals with HIV with CD4 count >350 cells/mm³ and ≤ 500 cells/mm³ regardless of WHO clinical stage. ● ART should be initiated in all individuals with HIV regardless of WHO clinical stage or CD4 cell count in the following situations: <ul style="list-style-type: none"> ● Individuals with HIV and active TB disease. ● Individuals co-infected with HIV and HCV with evidence of severe chronic liver disease. ● Partners with HIV in sero-discordant couples should be offered ART to reduce HIV transmission to uninfected partners.
When to start ART in pregnant and breastfeeding women	<ul style="list-style-type: none"> ● All pregnant and breastfeeding women with HIV should initiate triple ARVs (ART), which should be maintained at least for the duration of mother-to-child transmission risk. Women meeting treatment eligibility criteria should continue lifelong ART. ● For programmatic and operational reasons, particularly in generalized epidemics, all pregnant and breastfeeding women with HIV should initiate ART as lifelong treatment. ● In some countries, for women who are not eligible for ART for their own health, consideration can be given to stopping the ARV regimen after the period of mother-to-child transmission risk has ceased.
Community-based testing	<ul style="list-style-type: none"> ● In generalized HIV epidemics, community-based HIV testing and counselling with linkage to prevention, care and treatment services is recommended, in addition to provider-initiated testing and counselling. ● In all HIV epidemic settings, community-based HIV testing and counselling for key populations, with linkage to prevention, care and treatment services is recommended, in addition to provider initiated testing and counselling.
Task shifting	<ul style="list-style-type: none"> ● Trained non-physician clinicians, midwives and nurses can initiate first-line ART. ● Trained non-physician clinicians, midwives and nurses can maintain ART. ● Trained and supervised community health workers can dispense ART between regular clinical visits.

What are important issues about the 2013 ART Guidelines?

The International Treatment Preparedness Coalition (ITPC) welcomed the 2013 ART Guidelines as an important tool to scale-up access to life-saving ART.

However, ITPC is concerned about issues that need to be addressed if the 2013 ART Guidelines are to increase access to treatment for *all* people living with HIV, including those from key populations. These issues are vital for community advocacy.

For example, the Guidelines acknowledge the **vital role of communities** in access to HIV treatment. This includes that communities: do ‘treatment literacy’ work; create demand for treatment services; link communities to health services; reach communities that are ‘hardest to reach’; and provide a range of services that complement ART (such as counselling and peer education). However, in practice, many community organizations lack the opportunities or support to play such a role - because, for example, they are not included in decision-making processes. They also often lack the resources that they need – not only in terms of money, but, for example, technical capacity.

EXAMPLES OF OTHER ISSUES OF CONCERN TO ITPC ARE THAT:

- To successfully implement the 2013 ART Guidelines, **HIV counseling and testing (HCT)** needs to be scaled-up dramatically. This is so that more people know their HIV status and, in turn, more people demand treatment. At the same time, there is a need to protect against forcible or coerced HIV testing.
- Priority should be given to all people living with HIV who have a **CD4 count of under 500 cells/mm³**, not just those with a count of under ≤ 350 cells/mm³.
- Increasing the scale of HIV treatment should not come at the cost of its **quality**. Drugs that are of low quality and have bad side effects should not be used to implement the 2013 ART Guidelines.
- The 2013 ART Guidelines risk placing even more pressure on health and community systems that are already over-stretched. As such, attention must be paid to developing and using ‘smarter’ and more effective ways to **deliver HIV treatment services**. The role of communities to support ‘task shifting’ needs further elaboration.
- As the 2013 ART Guidelines are implemented, the supply of all types of drugs must be improved to cope with the increase in demand. For example, as access to 1st line ARVs is scaled-up, so must access to **2nd and 3rd line drugs**. (See Section 1.2 for further information about 1st and 2nd line drugs). Yet in many contexts, these regimens remain unaffordable and unavailable due to intellectual property regimens and trade agreements.
- Despite the 2013 ART Guidelines, **HIV treatment options for children** under 5 years old are still limited. In settings with limited resources, it will still remain difficult to access child-friendly formulations of drugs. Children in resource-limited settings continue to lack child friendly formulations, including a pediatric ARV fixed-dose combination. Current formulations need to be refrigerated or mixed with clean water before taking. Research and development is urgently needed to get more optimal pediatric regimens produced and then distributed.
- Some populations face specific treatment challenges – such as **key populations and adolescents** – that are not addressed in the Guidelines.

SECTION 2.2

What are other important initiatives for HIV treatment?

SECTION OBJECTIVE

To refresh participants' knowledge on current treatment issues and to build community activists' understanding of key global initiatives and why they matter for access to HIV treatment.

TRAINING MATERIALS

- PowerPoint presentation '2.2. What are other important initiatives for HIV treatment'
- Copies of the Useful Resources.
- Flipchart and pens.

TRAINING OPTIONS

Option A (approx. 60 minutes)

For this activity, it is helpful to give participants copies of resources on the initiatives in advance and ask them to read them.

1. Explain the objective of the Section.
2. Present PowerPoint presentation '2.2. What are other important initiatives for HIV treatment?'
3. Encourage the participants to ask questions about the initiatives addressed in the presentation and to share any experiences of advocacy related to them. Also ask them to add any other global, regional or national initiatives that they know of that are relevant to HIV treatment.
4. Facilitate a discussion about the opportunities and challenges presented by the initiatives in terms of community advocacy on access to HIV treatment. Encourage the participants to focus on issues affecting access for people from key populations, such as sex workers, people who use drugs and lesbian, gay, bisexual and transgender (LGBT) people.
5. Ask the participants to summarize the session by developing advocacy messages about 'What are other important initiatives for HIV treatment?' Support their ideas by sharing examples of messages (see below).

Option B (approx. 120 minutes)

For this activity, it is necessary to give participants copies of resources on the initiatives in advance and to ask them to read them.

1. Explain the objective of the Section.
2. Present Powerpoint presentation '2.2. What are other important initiatives for HIV treatment?'
3. Encourage the participants to ask questions about the initiatives addressed in the presentation. Also ask them to add any other global, regional or national initiatives that they know of that are relevant to HIV treatment.
4. Divide the participants into four groups, with each focused on a different global initiative:

Group 1: Treatment 2015

Group 2: Community Systems Strengthening

Group 3: Investment Framework

Group 4: Treatment 2.0

5. Ask each group to discuss their initiative and identify the opportunities and challenges that it presents for community advocacy on access to HIV treatment.
6. Bring all of the participants back together. Ask Group 1 to present a summary of the opportunities and challenges that they identified. Encourage the other participants to ask questions and make additional points.
7. Repeat the process for Groups 2, 3 and 4.
8. Ask the participants to consider the feedback from Groups 1, 2, 3 and 4. Ask them to pick out the opportunities and challenges that especially affect access to HIV treatment for key populations, such as sex workers, people who use drugs and LGBT people.
9. Ask the participants to summarize the session by developing advocacy messages about ‘What are other important initiatives for HIV treatment?’ Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. The Strategic Investment Framework and Treatment 2015 provide a vital framework for catalyzing the next phase of scaling-up HIV treatment - by promoting innovation and efficiency. It is critical for achieving universal access to HIV treatment, as well as maximizing the prevention benefits of ART.
2. All global treatment initiatives have emphasized that it is not only about what needs to be done (the priority areas of work), but how it needs to be carried out. For example, Treatment 2.0 outlines principles – such as equity and accessibility – that are vital, especially for ensuring access to treatment for key populations.
3. Community mobilization, involvement and systems are fundamental to achieving all key global initiatives related to HIV treatment. They are not ‘optional’.
4. Community involvement and systems not only make programmatic sense – such as for reaching marginalized groups, such as key populations. They are also central to cost-effective, investment approaches to increasing access to HIV treatment.
5. Community organizations and systems do not ‘just happen’ They require funding and other resources to play their full role in increasing access to HIV treatment.

USEFUL RESOURCES

- *Treatment 2015*, UNAIDS, 2013. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/JC2484_treatment-2015_en.pdf
- *Community Systems Strengthening Framework: Revised Edition*, the Global Fund to Fight AIDS, Tuberculosis and Malaria, February 2014. www.theglobalfund.org/documents/core/.../Core_CSS_Framework_en/
- *Community Systems Strengthening and Key Populations: A Policy Discussion Paper*; Global Forum on MSM and HIV, 2013. http://www.msngf.org/files/msngf//Publications/CSS_and_Key_Populations_3oct2013.pdf
- *Investing for Results. Results For People: A People-Centered Investment Tool Towards Ending AIDS*, UNAIDS, 2012. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20131130_smart-investments_en.pdf
- *Smart Investments*, UNAIDS, 2013. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20131130_smart-investments_en.pdf
- *Global AIDS Report*, UNAIDS 2013 http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf

HIV treatment – the big picture

While significant gains have occurred over the past ten years to scale-up access to HIV treatment, many people still lack treatment today. The statistics are stark: In 2012, there were 35.3 million people living with HIV globally, and in the same year 1.6 million people died of AIDS.

How many people are eligible for treatment? As of 2013, about 28.6 million people living with HIV (PLHIV) are eligible for ART under the WHO Consolidated ARV Guidelines.

How many are receiving treatment? By the end of 2012, 9.7 million people in low and middle-income countries were on ART –representing 61% of all who were eligible under the 2010 World Health Organization (WHO) HIV treatment guidelines. Antiretroviral coverage among pregnant women living with HIV reached 62% in 2012. It appears that the world might meet its global goal to put 15 million people on treatment by 2015.

Where are the gaps? Some countries have been able to accelerate treatment scale-up while others lag far behind. Treatment gaps also remain for certain populations – for example, only 34% of children aged 0 - 15 who need treatment access it. Unacceptably, there is no data available on treatment coverage for key populations (LGBT, PUD, SW) or adolescents aged 10 – 19. As of 2013, HIV was the second leading cause of death among adolescents worldwide.

Issues with testing and retention in care: In Sub-Saharan Africa, by the end of 2012, only half of PLHIV know their status; a third of PLHIV were receiving ART; and less than a quarter of PLHIV had their viral load suppressed. Even when PLHIV begin treatment, not all remain on treatment – reducing the proportion of people living with HIV who achieve viral suppression and other treatment benefits. There is considerable variation in reported retention rates among countries.

Dwindling international resources for treatment: In 2012, US\$ 18.9 billion were available for HIV programs in low- and middle-income countries – leaving a resource gap of approximately US\$ 3.1 – 5.1 billion. While domestic spending has encouragingly increased for HIV, still in 2012, 51 countries looked to international sources for more than 75% of HIV-related spending.

The following global initiatives were designed to galvanize efforts to increase treatment access for all in need.

Treatment 2.0

Treatment 2.0 was launched in June 2010 as an initiative of the World Health Organization (WHO) and Joint United Nations Program on AIDS (UNAIDS). The *Treatment 2.0 Framework for Action: Catalysing the Next Phase of Treatment, Care and Support* was published in 2011.

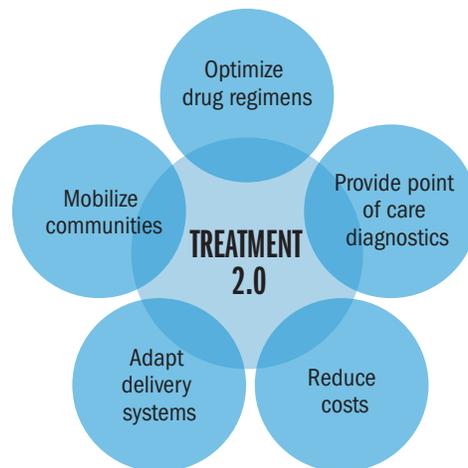
Treatment 2.0 aims to catalyze the next phase of scaling-up HIV treatment by promoting innovation and efficiency. It helps countries to reach and sustain the goal of universal access to HIV treatment and also to make the most of the prevention benefits of ART.

Treatment 2.0 is based on a set of principles:

- Simplification
- Innovation
- Efficiency
- Effectiveness and cost-effectiveness
- Accessibility
- Affordability
- Equity
- Decentralization and integration
- Community involvement

Treatment 2.0 focuses on five priority areas of work. These are illustrated below and also described, with the relevant goals for 2020 (using the exact wording of the Framework):

THE FIVE PRIORITY AREAS OF WORK OF TREATMENT 2.0



PRIORITY AREA	GOAL FOR 2020
Optimize drug regimens	<p>2020 Goal: Effective, affordable, one pill, once daily potent ARV regimens, suitable for most populations with minimal toxicities or drug interactions and high barrier to resistance are available in low and middle income countries (LMICs).</p> <ul style="list-style-type: none"> • Regimens should be easy to use, with little side effects without compromising quality • Regimens should be standard across all populations
Provide point-of-care (POC) and other simplified diagnostic and monitoring tools	<p>2020 Goal: A package of simple, affordable, reliable, quality-assured POC and other simplified diagnostics are available and accessible in LMICs.</p> <ul style="list-style-type: none"> • Diagnostics to initiate and monitor treatment should be simple, efficient and easily accessible to all
Reduce costs	<p>2020 Goal: High-quality HIV prevention, care and treatment programs are available at the lowest possible cost with optimal efficiency to all in need in LMICs.</p> <ul style="list-style-type: none"> • Cost of care should not be a barrier to accessing treatment
Adapt service delivery	<p>2020 Goal: HIV care and treatment programs are decentralized and appropriately integrated with other HIV and non-HIV health services, with increased community engagement in service delivery and improved retention in care.</p> <ul style="list-style-type: none"> • Services should be closer to the people with communities actively involved in the delivery system
Mobilize communities	<p>2020 Goal: People living with HIV and key populations are fully involved in the demand creation, planning, delivery and evaluation of quality-assured, rights-based HIV care and treatment programs in all LMICs.</p> <ul style="list-style-type: none"> • Active and meaningful engagement of PLHIV & key populations in the leadership and service delivery of HIV care

The full involvement of people living with HIV and key populations – and the groups that are by/for them - is central to the success of Treatment 2.0. Among other roles, they are vital to:

- Driving demand for more and better treatment services. This includes by advocating for: fair prices for medicines; better quality services; full access to services, including for key populations; and the rights of people living with HIV.
- Identifying ‘what works’ – for example for treatment optimization – by documenting and learning from the real life experiences of people living with HIV, including those from key populations.
- Decentralizing the delivery of treatment services – bringing them closer to community members and ensuring that they are accessible (practically, financially, socially, etc.).
- Providing the ‘wrap-around’ services that are needed for ARVs to be effective, such as treatment literacy for communities and adherence counselling for people living with HIV.
- Addressing specific ‘bottlenecks’ and inequities in treatment, such as for key populations.
- Promoting practical ways for Treatment 2.0 to be a reality. For example, by using funding opportunities for Community Systems Strengthening through the Global Fund to Fight AIDS Tuberculosis and Malaria (the Global Fund) (see Section 5.1).
- Advocating for ‘nothing about us without us’ and ensuring that the voices of communities, including people living with HIV and key populations, are heard in decision-making on treatment.

However, Treatment 2.0 will require resources –like funding and technical support – for communities to play their full role.

The Treatment 2015 framework

Treatment 2015 was launched by the United Nations Joint Program on AIDS (UNAIDS) in July 2013. It is a framework to accelerate action to meet the target set by the 2011 United Nations Political Declaration on HIV/AIDS – of having 15 million people on antiretroviral therapy (ART) by 2015. It **builds on** the Treatment 2.0 initiative and the 2013 WHO Consolidated ARV Guidelines.

Treatment 2015 calls for intensified efforts in the 30 countries where 9 out of 10 of the people with an unmet need for HIV treatment live:

PRIORITY COUNTRIES FOR TREATMENT 2015

Africa	Angola · Cameroon Central African Republic · Chad · Cote d'Ivoire	Democratic Republic of the Congo · Ethiopia · Ghana · Kenya	Lesotho · Malawi Mozambique Malawi Mozambique · Nigeria ·	South Africa South Sudan · Togo · Uganda · Tanzania · Zambia · Zimbabwe
Asia	China · India · Indonesia · Myanmar · Thailand · Vietnam			
South America	Brazil · Colombia			
Eastern Europe	Russian Federation · Ukraine			

Treatment 2015 addresses three main areas:

1. DEMAND. This focuses on:

- Creating demand for HIV treatment that is led by people living with HIV, as well as key populations, and is sustained by civil society and the international community.
- Having strategic actions to increase the demand for HIV testing and treatment services. This includes:
 - Re-thinking HIV testing by adopting multiple, proactive strategies to encourage people to know their HIV status.
 - Investing in treatment literacy initiatives in communities.
 - Removing barriers to access to HIV treatment.
 - Emphasizing the prevention, as well as treatment, benefits of ART.

2. INVEST. This focuses on:

- Mobilizing sustained investment, giving priority to innovation and using available resources as strategically as possible.
- Having strategic actions to mobilize enough resources to cope with the scale-up of treatment and to enhance the effectiveness and efficiency of spending. This includes that:
 - Domestic and international contributions should increase.
 - Continued efforts should be made to improve the efficiency of HIV treatment programs.
 - Health and community systems should be strengthened.
 - Programmatic innovation to speed up scale-up should be encouraged.
 - The means to manufacture ARVs in Africa should be created.

3. DELIVER. This focuses on:

- Ensuring that health and community systems, infrastructure, laws and policies are in place to deliver treatment to all people living with HIV who are eligible for it.
- Having strategic actions to close gaps in the HIV treatment continuum. This includes:
 - Implementing efficient and innovative delivery models.
 - Taking steps to ensure equitable access to treatment.
 - Promoting accountability through rigorous measurement of outcomes.
 - Forging strategic partnerships that make best use of the unique experience and expertise of diverse stakeholders involved in treatment.

Treatment 2015 is important because it represents a high-level commitment by UNAIDS, its 11 UN agencies (known as co-sponsoring organizations) and other partners. It is also important because it aims to build on existing lessons and tools to provide a 'push' to achieve the 2015 target for treatment.

Community systems strengthening

Community systems strengthening is a term that has evolved over the last several years to encompass how communities (or people affected by a disease/issue) and their organizations (such as community-based organizations) engage in health service-delivery, health-related decision making and other critical health system functions.

The goal of community systems strengthening (CSS) is to develop the roles of key affected populations and communities, community organizations and networks, and public or private sector actors that work in partnership with civil society at community level, in the design, delivery, monitoring and evaluation of services and activities aimed at improving health outcomes.

Community systems strengthening **strategies** often focus on building the capacity of civil society organizations (such as through improved human and material resources), with the aim of enabling communities and community actors to play a full and effective role alongside health and social welfare systems.

Since community organizations and networks engage regularly with affected communities, they are uniquely positioned to react quickly to community needs and emerging health concerns. These organizations can also provide direct services to communities not reached through the traditional national health care sector (such as a peer outreach program for adolescents or people who use drugs). They also advocate for improved programming and policy environments.

Example of CSS in practice: In 2009, the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) introduced the concept of community systems strengthening (CSS) to its funding model. This built on the existing understanding of many agencies about the vital role of communities in action on HIV. However, it aimed to articulate and strengthen that role in a more systematic way. The CSS Framework was updated in 2014.¹ Its goal is to achieve improved health outcomes by developing the role of key populations, communities and community-based organizations in the design, delivery, monitoring and evaluation of services and activities related to prevention, treatment, care and support for HIV, tuberculosis and malaria.

The Global Fund CSS Framework has six core components (CCs) or ‘building blocks’:

- 1. Enabling environments and advocacy** – including community engagement and advocacy for improving the policy, legal, and governance environments and for affecting the social determinants of health.
- 2. Community networks, linkages, partnerships and coordination** – enabling effective activities, service delivery and advocacy, maximizing resources and impacts, and coordinated, collaborative working relationships.
- 3. Resources and capacity building** – including: human resources with appropriate personnel, technical and organizational capacities; financing (including operational and core funding); and material resources (infrastructure, information and essential commodities, including medical and other products and technologies).
- 4. Community activities and service delivery** – accessible to all who need them, evidence-informed and based on community assessments of resources and needs.
- 5. Organizational and leadership strengthening** – including management, accountability and leadership for organizations and community systems.
- 6. Monitoring and evaluation (M&E) and planning** – including M&E systems, situation assessment, evidence-building and research, learning, planning and knowledge management.

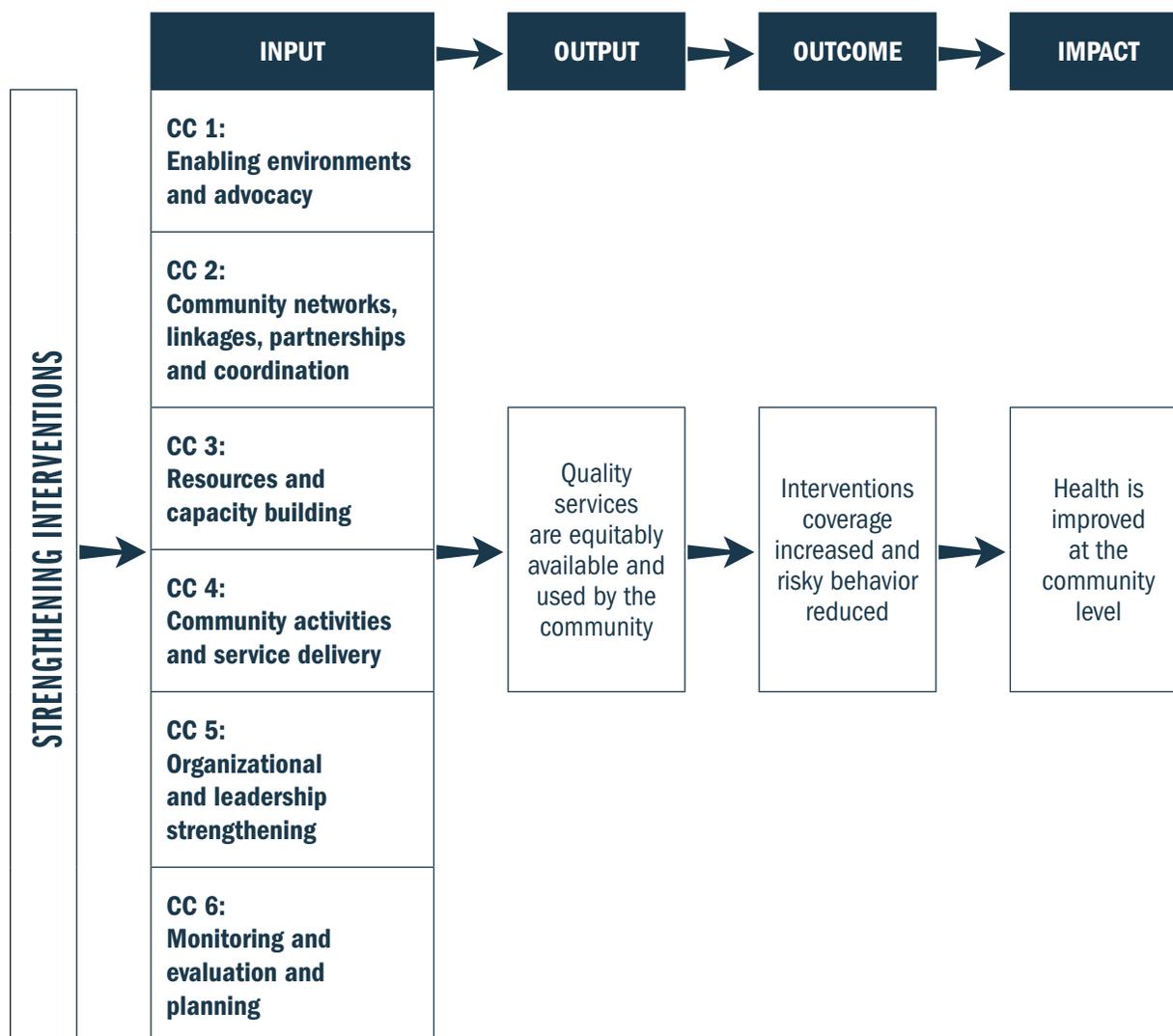
¹ *Community Systems Strengthening Framework: Revised Edition*, The Global Fund to Fight AIDS, Tuberculosis and Malaria, February 2014.

The six CCs (building blocks) add up to ensure increased results for action on HIV:

HOW COMMUNITY SYSTEMS STRENGTHENING IMPROVES RESPONSES TO HEALTH

The CSS Framework can be used by all those who have a role in dealing with health challenges and have an interest in community involvement and action. This includes community actors, governments, donors and partner organizations.

CSS is vital for achieving the HIV treatment initiatives described in this Part 2 of the ACT Toolkit. For example, the task shifting that is required for the 2013 ART Guidelines can only take place if community actors are mobilized and supported.



CSS is also a particularly important opportunity to recognize and strengthen the role of groups, organizations and networks by and for key populations, such as sex workers, people who use drugs and LGBT people. Such groups have often faced particular challenges - such as hostility towards their programs and lack of opportunities to get funding and build their capacity. CSS provides an important 'entry point' for community advocacy on access to HIV treatment. For example, a meeting convened by the International Treatment Preparedness Coalition (ITPC) identified the following activities that community-based organizations are uniquely placed to deliver and which, through advocacy, should receive the resources to do so:

EXAMPLES OF COMMUNITY SYSTEM CONTRIBUTIONS TO EXPANDING HIV TREATMENT²

HIV SERVICES	HIV ADVOCACY
<ul style="list-style-type: none"> ● Support for adherence to HIV treatment ● HIV counselling and testing (HCT) ● HIV treatment literacy ● Linkages to HIV care and support services ● Linkages to harm reduction services for people who use drugs ● Management of a person's health and psycho-social needs following HCT ● Support for disclosure of HIV status ● Delivery of HIV treatment (extending the role of community organizations) ● HIV case management ● Nutritional support for people living with HIV 	<ul style="list-style-type: none"> ● Monitoring and accountability (of health systems, government responses, abuses of human rights, etc.) ● Quality assurance of health services ● Anti-stigma, anti-discrimination and decriminalization efforts (including legal support, law reform and lobbying) ● Policy analysis around access to and development of essential medicines ● Ensuring the meaningful involvement of people living with HIV in policy and program development

The investment framework

The Investment Framework was initially developed by individuals working at different global health agencies and published in the Lancet medical journal in June 2011. The framework was proposed to facilitate more focused and strategic use of scarce resources by concentrating investments strategically and cost-effectively through resourcing in evidence-based interventions suitable for each country's epidemic scenario, while also emphasizing a human rights approach. The framework estimated that its application could avert 12.2 million new infections and 7.4 million AIDS-related deaths between 2011 and 2020.

Since the initial Lancet article the term and concept have been adapted by many normative global health institutions – such as UNAIDS and the Global Fund to Fight AIDS, TB and Malaria. In 2011, UNAIDS published *A New Investment Framework for the Global HIV Response*. In 2012, this was complemented by *Investing for Results, Results for People: A People-Centred Investment Tool towards Ending AIDS*.

What are the basics of the Investment Framework? The framework provides a road map for accelerating progress on the global response to HIV to:

- Maximize the benefits of the HIV response.
- Support more rational resource allocation based on country epidemiology and context.
- Encourage countries to prioritize and implement the most effective programmatic activities.
- Increase efficiency in HIV prevention, treatment, care and support programming.

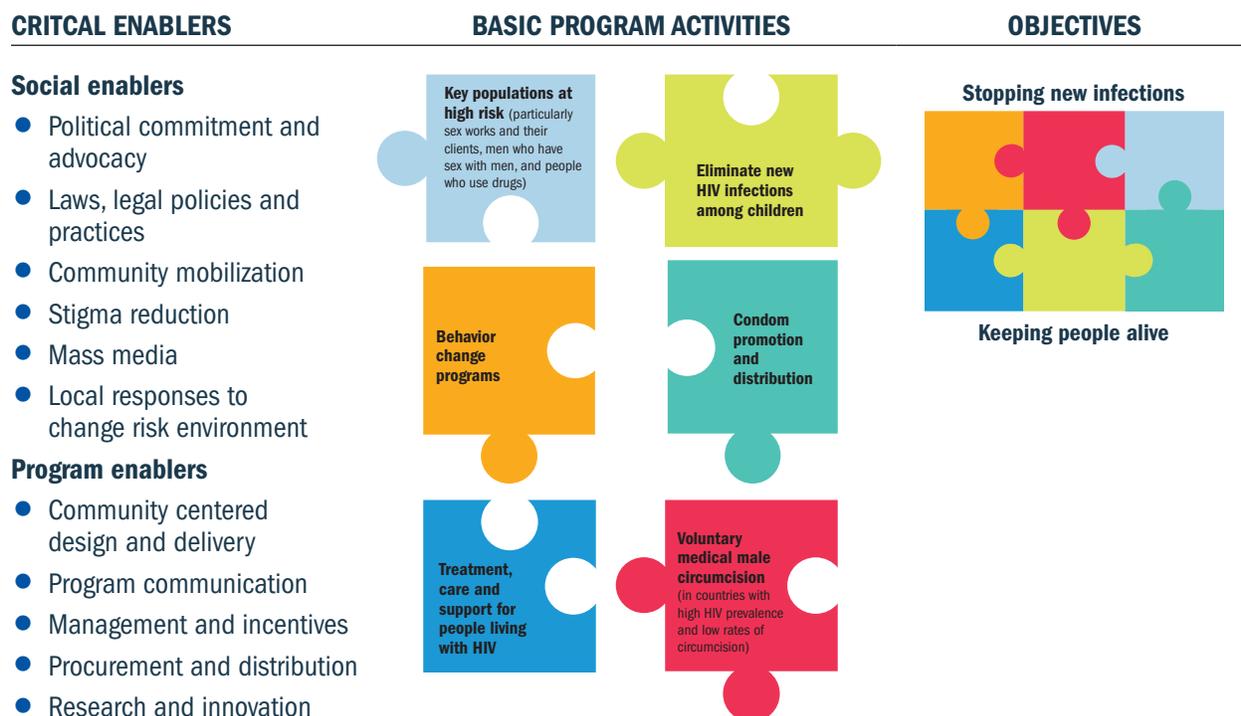
As shown by the graphic below, the Investment Framework focuses on:

- **Scaling up basic program activities** that have a direct effect on HIV risk, transmission, sickness and death and that **should be delivered as a comprehensive package** – such as:

2 Treatment 2.0: The Next Phase of HIV Treatment and Prevention Scale-Up a Community-Based Response, ITPC, 2011.

- Programs on key populations at higher risk (particularly sex workers and their clients, men who have sex with men, and people who inject drugs)
 - Elimination of new infections in children
 - Programs that focus on the reduction of risk of HIV exposure through changing people's behavior and social norms
 - Procurement, distribution and marketing male and female condom programs
 - Treatment, care and support for people living with HIV
 - Voluntary medical male circumcision in countries with high prevalence of HIV and low rates of male circumcision
- **Supporting critical enablers** that are crucial to the success of programs – such as support for human rights based health service delivery. **Social enablers** create environments conducive to rational HIV responses – such as stigma reduction and human rights advocacy, while **program enablers** create demand for programs and improve their performance, such as VCT, treatment literacy, psycho-social support services and adherence support.
- **Synergies with development sectors** – recognizing that HIV programs are not implemented in isolation and should, for example, support a country's wider development objectives and social, legal and health systems. Relevant development sectors include: social protection, education, legal reform, gender equity, poverty reduction and gender-based violence.

THE INVESTMENT FRAMEWORK³



SYNERGIES WITH DEVELOPMENT SECTORS

Social protection, Education, Legal reform, Gender equality, Poverty reduction, Gender-based violence, Health systems (incl. STI treatment, Blood safety, Community systems, and Employer practices.

3 A New Investment Framework for the Global HIV Response, UNAIDS, 2011.

The Investment Framework has informed the development of an Investment Approach and Investment Cases (see below). These are increasingly critical for how countries express their needs and mobilize their resources. For example, they can be used in proposals to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Investment approaches and investment cases⁴

An Investment Approach:

- Makes the best use of investments in action on HIV.
- Focuses on combinations of actions that will make the biggest difference.
- Improves the equity and impact of actions by focusing efforts on the populations and places that need them most.
- Improves the efficiency of HIV prevention, treatment, care and support programs.
- Uses evidence and models to identify priorities and gaps.
- Supports sustainable funding for HIV programs.
- Provides a framework for aligning government and donor funding.

An Investment Case:

- Is a way to make strategic decisions about resource allocation, resource mobilization, service delivery and funding.
- Can be articulated in different ways, based on a country's specific contexts and needs.
- Is a way to show national leadership in the response to HIV.
- Brings together different stakeholders including: Ministries of Finance, Health, Development and Planning; civil society; people living with HIV; and international partners.
- Communicates a joint effort to identify program gaps and bottlenecks and create a roadmap for action.

⁴ Smart Investments, UNAIDS, 2013.

SECTION 2.3

What are the entry points for advocacy on treatment initiatives?

SECTION OBJECTIVE

To build community activists' understanding of the entry points and 'what works' for advocacy on treatment initiatives.

TRAINING MATERIALS

PowerPoint presentation '2.3. What are the entry points for advocacy on treatment initiatives?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Ask the participants to think about the HIV treatment initiatives that have been addressed in Part 2.1, 2.2. Ask them to identify some examples of entry points for advocacy on those initiatives. Explain that an entry point is an opportunity to 'get started.' It might, for example, be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Present PowerPoint presentation '2.3. What are the entry points for advocacy on treatment initiatives?'
4. Ask the participants to share other lessons learned about advocacy on treatment initiatives – based on their own experiences.
5. Summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Explain to the participants what is meant by an entry point for advocacy on treatment initiatives – in terms of an opportunity to 'get started.' For example, an entry point might be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Divide the participants into groups of about 5 people. Ask the participants to identify 1-2 entry points for advocacy on treatment initiatives that relate to their community.
4. Bring all of the participants back together. Ask each group to present their examples of entry points. Encourage the other participants to ask questions and make comments.
5. Ask the participants to think about what type of advocacy they could carry out for the entry points that they have identified. Facilitate a discussion on:
 - *What do we know about 'what works' in advocacy on treatment initiatives?*
6. Encourage the participants to identify the lessons learned from their own experiences. Write their inputs on a flipchart.
7. Summarize what has been discussed and agreed during the session.

What needs to happen to increase access to treatment for all in need?

In order to increase treatment access, there must first be increased **demand** for treatment from people living with HIV, other affected communities and their allies. People living with HIV who do not know their status must be supported to access testing and links to treatment, preferably through community-based initiatives that ensure a rights-based approach.

National strategies need to include and support communities to be involved in all aspects of HIV prevention, treatment and care. Community treatment literacy programs (aimed at improving treatment seeking behavior and adherence as well as promoting the prevention benefits of treatment) must also be recognized and supported by national HIV policies and strategies as well as be adequately funded.

Countries must also immediately adopt the new 2013 ART Guidelines with clear strategies of how to mobilize the necessary resources to meet the new recommendations. The inclusion of civil society/expert patients/community members in national treatment guideline task forces is mandatory to ensure that the adoption and use of the new guidelines is fast tracked.

At the same time, laws and policies that infringe on the right to life and health that deter persons in need of testing and treatment – such as laws that criminalize HIV transmission or exposure, laws that criminalize behavior such as same-sex relations, sex work and drug use – must be eliminated.

At the end of the day, treatment scale-up can only happen with more investment and political will. To help mobilize this, communities can:

1. Champion innovative financing mechanisms.
2. Be the watchdog of budgetary allocation and expenditure of resources to ensure appropriate prioritization and allocation of resources; identify and report misappropriation, diversion, misuse and wastage of resources; and ensure accountability and transparency is always in place in procurement and supply of medicines, equipment and supplies.
3. Demand utilization of TRIPS Flexibilities to minimize costs of medicines and expand access to affordable generic ARVs and other essential medicines, such as HPV treatment.
4. Advocate for more investment in the development of optimal ARV regimens (easy to use, minimal side effects, affordable).
5. Advocate for capacity building for drug manufacturing in Africa, creating new supply chains and less dependency on drug producers elsewhere through developing the local production capacity for pharmaceuticals.

Treatment scale-up also needs efficient and robust treatment delivery systems. To help achieve this, communities can:

1. Be involved in the establishment and management of Primary Treatment Delivery Points so that treatment services can be brought closer to where people live.
2. Focus on training community health workers including PLHIV to be part of a country's task shifting strategy.
3. Be involved in treatment outreach programs, especially for key populations and other groups not often reached by mainstream health services.

What are entry points for advocacy on treatment initiatives?

For community activists, there are many different entry points that can be used for advocacy on treatment initiatives. An entry point is an opportunity to 'get involved,' 'get going' and 'make a difference.' It is an opportunity to start discussions, influence opinions and achieve change.

For example, an entry point might be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change). More examples of entry points can be seen in the experiences of ITPC partners and other organizations throughout the world:

EXAMPLES OF ENTRY POINTS FOR ADVOCACY ON HIV TREATMENT INITIATIVES

EXAMPLES OF ENTRY POINTS	EXAMPLES OF ADVOCACY ACTIONS
<p>The District AIDS Plan does not recognize or fund the role of community groups in providing HIV counseling and testing (HCT) and mobilizing local people to ‘know your status’ and access treatment.</p> <p>(For example, as called for in the 2013 ART Guidelines)</p>	<ul style="list-style-type: none"> ● Gathering data on how many people community groups have provided HCT to in recent years. In particular, highlighting ‘hard to reach’ groups – such as key populations – that might, otherwise, not access HCT. ● Asking for a meeting with the District Health Director to present the data and advocate for a change to the Plan. ● Working with the District Health Authority to draft new text for the Plan that recognizes – and allocates a budget to – the role of community groups.
<p>The country’s Investment Case – for inclusion in a proposal to the Global Fund – does not use community data about HIV treatment or include community knowledge about ‘what works’, especially in relation to reaching key populations.</p> <p>(For example, as called for in the Investment Framework)</p>	<ul style="list-style-type: none"> ● Gathering examples of community data about HIV treatment and lessons on ‘what works’ for increasing access for key populations. ● Implementing an e-campaign – with community groups throughout the country mobilized to send e-mails to the coordinators of the Investment Case to call for the inclusion of community data. ● Using all relevant contacts – such as the community sector representatives on the Country Coordinating Mechanism – to promote advocacy messages that neglect of community data and lessons is unacceptable and argue for why their inclusion will produce a stronger and more accurate Investment Case.
<p>The country is not investing in the development of high quality ARV regimens - that, for example, have drugs that are easy to use, affordable and have minimal side effects.</p> <p>(For example, as called for in Treatment 2.0)</p>	<ul style="list-style-type: none"> ● Working with other stakeholders – such as the country office of the World Health Organization (WHO) – to raise understanding of the logic and benefits of Treatment 2.0 among the Ministry of Health and Ministry of Finance. ● Preparing case studies of community members living with HIV – to show why a high quality ARV regimen will both improve their quality of life and improve the efficiency of treatment. ● Arranging meetings between people living with HIV, the Ministry of Health and pharmaceutical companies to present the ‘human face’ of why investing in high quality ARV regimens matters.
<p>The Provincial Health Authority supports task shifting (from government clinic staff to community health workers) for providing HIV treatment and supporting adherence. But it will not fund the training of the community health workers.</p> <p>(For example, as called for in relation to Community Systems Strengthening)</p>	<ul style="list-style-type: none"> ● Asking for a meeting with the Director of the Provincial Health Authority and promoting the initiatives (such as the 2013 ART Guidelines and Community Systems Strengthening) that call not only for task shifting, but the funding and support of community systems. ● Developing a proposal for bringing together the Provincial Health Authority and community groups to provide a joint training program for the community health workers – that can be replicated in the future. Where possible, involving people living with HIV – including those from key populations – as trainers.

What works in advocacy on HIV treatment initiatives?

Many lessons have been learned - including by ITPC's partners - about 'what works' in advocacy on HIV treatment initiatives. The following presents examples that apply to different contexts:

'What works' in advocacy on HIV treatment initiatives

- **USING GLOBAL 'PEER PRESSURE'.** For example, using the existence of global initiatives – such as the 2013 ART Guidelines developed by WHO – to advocate to the government on why and how action on access to HIV treatment needs to be increased and improved in your country.
- **IDENTIFYING WHAT CAN AND CANNOT BE CHANGED.** For example, identifying what aspects of treatment initiatives (such as the 2013 ART Guidelines and Treatment 2.0) can or cannot be adapted within your country and, therefore, what aspects are worth advocating on.
- **FOCUSING ON YOUR PRIORITIES.** For example, identifying 2-3 key community issues to advocate on within national consultations on treatment initiatives (which may be complex and address many different areas).
- **DOING YOUR HOMEWORK.** For example, researching the specific process and stages for adapting and rolling-out the latest treatment initiatives in your country – so that you can identify the best entry points for advocacy.
- **SUPPORTING YOUR MESSAGES WITH EVIDENCE.** For example, gathering data and case studies that demonstrate why Treatment 2.0 (with its emphasis on simplification, equity, etc.) will increase access to HIV treatment for 'real life' people living with HIV in your community.
- **'SPEAKING THE LANGUAGE'.** For example, using the language of the Investment Framework - such as 'critical enablers' and 'value for money' - to convince decision-makers (such as in the Ministry of Finance) about why action on issues such as stigma represents a good investment for scaling-up access to treatment.
- **USING EXAMPLES FROM OTHER CONTEXTS.** For example, using an Investment Case from another country - that addresses the treatment needs of key populations and has contributed to a successful proposal to the Global Fund – to advocate for why such a case is needed in your country.

3

HUMAN RIGHTS AND TREATMENT

INTRODUCTION

THE SCIENCE
OF HIV

1

TREATMENT
INITIATIVES

2

**HUMAN RIGHTS
AND TREATMENT**

3

TRADE AND
TREATMENT

4

FINANCING
AND TREATMENT

5

COMMUNITY
ADVOCACY
PLANNING

6

ACT
CASE
STUDIES

Welcome to **Part 3: Human Rights and Treatment** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

Part 3 focuses on human rights and how they affect access to HIV treatment.

SECTION 3.1 What are human rights?

SECTION OBJECTIVE

To build community activists' understanding of what human rights are and why they matter for advocacy for community treatment.

TRAINING MATERIALS

- PowerPoint presentation '3.1 What are human rights?'
- A list of the key international, regional and national agreements and other instruments (such as policies and guidelines) that your country has committed to for human rights (in general) and the right to health (specifically)

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion on:
 - What are human rights?
 - Why do human rights matter?
3. Present PowerPoint presentation '3.1 What are human rights?'
4. Encourage the participants to ask questions about anything in the presentation that is unclear.
5. Facilitate a group discussion on:
 - In our country, what are the international, regional or national agreements and other instruments (such as policies and guidelines) that commit to:
 - Human rights (in general)?
 - The right to health (specifically)?
6. Write lists of the commitments and instruments on a flipchart. If necessary, add to the participants' inputs (based on your own research for this Section).
7. Ask the participants to summarize the session by developing advocacy messages about 'What are human rights?' Support their ideas by sharing examples of messages (see below).

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Divide the participants into small groups of about 5 people. Start by giving each group 10 minutes and asking them to discuss:
 - What are human rights?
3. Give the groups another 10 minutes and ask them to discuss:
 - What types of human rights are there? (An example might be 'the right to life' or 'the right to education')
4. Give the groups a further 10 minutes and ask them to discuss:
 - Who has human rights and who should protect them?

5. Bring all of the participants back together. Go through each of the three questions and ask the groups to share their ideas.
6. Facilitate a discussion on:
 - What do we mean by health?
 - What is the right to health?
7. Write the participants' ideas on a flipchart.
8. Divide the participants into the same small groups of about 5 people. Ask each group to discuss:
 - In our country what are the international, regional or national agreements and other instruments (such as policies and guidelines) that commit to:
 - Human rights (in general)?
 - The right to health (specifically)?
9. Bring all of the participants back together. Ask one of the small groups to present their work. Ask the other participants to share any additional information or ideas that were raised in their own groups.
10. Write a list on a flipchart of the country's agreements and instruments that commit to human rights and the right to health – as identified by the participants. If necessary, add to the participants' inputs (based on your own research for this Section).
11. Ask the participants to summarize the session by developing advocacy messages about 'What are human rights?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

- Human rights – such as to life, equality and non-discrimination - are not 'optional'. They are essential principles and legal guarantees that **all** governments must fulfill for **all** people, including those living with HIV and from key populations.
- Everyone has the right to health. This right is not just about having enough health facilities, services and commodities. It is also about ensuring that they are accessible, available, acceptable and of high quality.
- All governments have made commitments to human rights, including those related to health. They **must** promote and protect those rights, including for people living with HIV and members of key populations.

USEFUL RESOURCES

- *The Universal Declaration of Human Rights*, United Nations, 1948. <http://www.un.org/en/documents/udhr/>
- *The Right to Health*, (website page), World Health Organization, November 2013. <http://www.who.int/mediacentre/factsheets/fs323/en/>
- *Fact Sheet No. 31: The Right to Health*, World Health Organization and Office of the United Nations High Commissioner for Human Rights. http://www.who.int/hhr/activities/Right_to_Health_factsheet31.pdf
- *Chapter 2: HIV, Health and Human Rights in Health and Human Rights Resource Guide*, FXB Centre for Human Rights, Harvard School of Public Health, November 2013. <http://fxb.harvard.edu/health-and-human-rights-resource-guide/>
- *HIV/AIDS & Human Rights in Southern Africa: An Advocacy Resource and Training Manual*, AIDS and Rights Alliance for Southern Africa, 2008. http://www.arasa.info/files/4813/9056/2374/arasa_training_manual_english.pdf

What are human rights?

Human rights are basic **values and principles** that are essential to human dignity. They are also **legal guarantees**.

Human rights are **universal**. This means that they apply equally and to everyone – regardless, for example, of a person's sex, behavior or status. Human rights have other common characteristics. These include that they are:

1. **INHERENT** – meaning that they are not granted by any person or authority because you are born with them.
2. **FUNDAMENTAL** – meaning that, without them, life and dignity would be meaningless.
3. **INALIENABLE** – meaning that they cannot be taken away, given away or denied.
4. **INDIVISIBLE** – meaning that they cannot be divided and are all equally important.
5. **INTERDEPENDENT** – meaning that fulfilling one cannot happen without fulfilling others.

Who has human rights and who should protect them?

With human rights, there are:

- **Rights-holders** – individuals or groups that have the rights.
- **Duty-bearers** – individuals or institutions that are responsible for ensuring that individuals or groups can claim their rights.

The duty-bearers are governments. Their role is to:

- **Respect human rights.** They must not do anything that violates (abuses) the rights and freedoms of individuals or groups.
- **Protect human rights.** They must prevent others from violating the rights and freedoms of individuals or groups.
- **Fulfil human rights.** They must secure possibilities for all its citizens to claim their rights and needs.

What types of human rights are there?

Human rights have been defined in a number of international agreements (also called commitments, conventions, covenants or treaties). These started with the **Universal Declaration of Human Rights** which was agreed by the United Nations in 1948. This listed a broad range of rights, such as:

- The right to equality and dignity
- The right to non-discrimination
- The right to life
- The right to health
- The right to privacy
- The right to marry and found a family
- The right to participation
- The right to education
- The right to freedom from arbitrary arrest or detention

The Declaration emphasized that **all** of these rights apply to all people “*without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status*”. Therefore, the rights apply to people living with HIV and members of key populations.

Since then, countries have made more detailed or specific commitments to:

- **Sets of human rights**, such as through the International Covenant on Economic, Social and Cultural Rights (1966).
- **Types of human rights violations**, such as through the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984).
- **The human rights of particular groups of people**, such as through the Convention on the Rights of the Child (1989) and Convention on the Elimination of All Forms of Discrimination against Women (1979).

How are human rights enforced?

All of the agreements listed above – and many other examples – are legally binding on the States that have committed to them. In turn, such international agreements are often reflected in regional agreements and/or national laws.

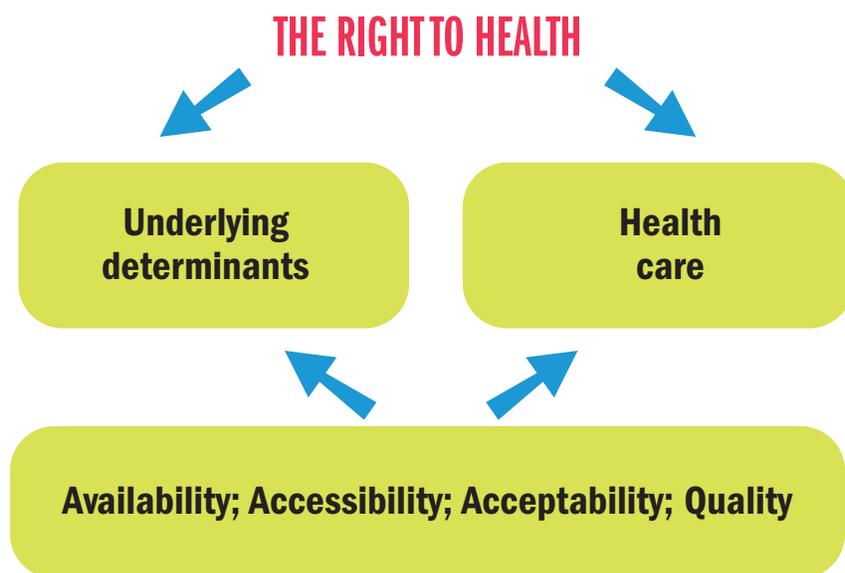
Human rights are also committed to in other types of instruments at the country, district or local level. Examples include guidelines, codes of conduct and sets of principles. These are not legally binding. However, they provide important tools to ‘push’ for action on human rights.

Ultimately, governments are responsible for enforcing human rights. However, many other individuals, institutions and sectors have an important role to play. Examples include the judiciary, the police, parliamentarians, local leaders and community members.

What is the right to health?

The **right to health** was first formally described in the Constitution of the World Health Organization (WHO) in 1946. This defined health as a state of “*complete physical, mental and social well-being*”

In 2000, the idea was further described through a General Comment on the Right to Health by the United Nations Committee on Economic, Social and Cultural Rights. As shown in the diagram below, this emphasizes that the right to health is not only about providing healthcare, but addressing the ‘underlying determinants’ of health. This means the factors – such as education, housing and nutrition – that affect the quality of people’s health.



As also shown in the diagram, the General Comment states that the right to health requires a comprehensive (holistic) approach. This is one that involves attention to four areas:

1. **AVAILABILITY:** Ensuring that there are enough health facilities, services and commodities.
2. **ACCESSIBILITY:** Ensuring that those health facilities, services and commodities are accessible to everyone. This means that they are:
 - Non-discriminatory (people can use them without fear of being treated badly).
 - Physically accessible (people can reach them).
 - Economically accessible (people can afford them).
 - Information accessible (people can get health information in a language and style that they can understand).
3. **ACCEPTABILITY:** Ensuring that all health facilities, services and commodities are respectful of medical ethics, local cultures and issues related to gender and age.
4. **QUALITY:** Ensuring that all health facilities, services and commodities are medically and scientifically good quality.

Importantly, the General Comment also states that, to fulfill someone's right to health, they must have access to:

- Prevention, treatment and control of diseases.
- Essential medicines.
- Maternal, child and reproductive health.
- Health-related education and information.

Participation in health-related decision-making at national and community levels.

By 2014, every State in the world had agreed to at least one international agreement that addresses rights related to health.¹

The right to health is also specifically addressed in a number of regional agreements and national laws. For example, it is recognized in the Constitution of at least 115 countries.

1 *Health and Human Rights*, WHO website; <http://www.who.int/hhr/en/>

Section 3.2 How do human rights relate to access to treatment?

SECTION OBJECTIVE

To build community activists' understanding of how human rights relate to access to treatment for people living with HIV, including those from key populations

TRAINING MATERIALS

- PowerPoint presentation '3.2 How do human rights relate to access to treatment?'
- Brief profiles of 'typical' local people living with HIV, including some from key populations. These should provide key information about the person, such as their sex, age, location and economic situation. They should *not* be real people.

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion on:
 - Why do human rights matter for action on HIV?
3. Present PowerPoint presentation '3.2 How do human rights relate to access to treatment?' Ask the participants if they have any questions about the presentation or additional points to add.
4. Return to the PowerPoint slide that shows the table of human rights and examples of violations in relation to access to HIV treatment.
5. Facilitate a discussion on:
 - In our country, which international or national agreements, policies or laws should protect people living with HIV – including those from key populations - against such violations of their rights in relation to access to treatment?
6. Ask the participants to summarize the session by developing advocacy messages about 'How do human rights relate to access to treatment?' Support their ideas by sharing examples of messages (see below).

Option B (approx. 120 minutes)

For this activity, it is necessary to develop brief profiles of 'typical' local people living with HIV, including some from key populations

1. Explain the objective of the Section.
2. Divide the participants into 'buzz groups' of 3-4 people. Ask each group to discuss:
 - Why do human rights matter for action on HIV?
3. Bring all of the participants back together and facilitate a discussion of the question.
4. Present PowerPoint presentation '3.2. How do human rights relate to access to treatment?' Ask the participants if they have any questions about the presentation or additional points to add.
5. Divide the participants into small groups of about 5 people. Give each group a different profile of a 'typical' local person who is living with HIV.

6. Ask each group to think about their 'typical' person and to discuss the challenges that they might face in relation to access to HIV treatment.
7. Ask each group to identify whether their 'typical' person might experience violations of their human rights in relation to access to treatment. Remind the groups that there are a broad range of human rights, such as the right to life, health, equality and participation.
8. Bring all of the participants back together. Ask one of the groups to present the key points from their discussions. Encourage the other participants to ask questions or make additional points.
9. Facilitate a discussion about:
 - In our country, which international agreements or national policies or laws should protect the rights of people living with HIV to access treatment?
10. Is this protection any different for members of key populations – such as sex workers, people who use drugs and lesbian, gay, bisexual and transgender (LGBT) people – living with HIV?
11. Ask the participants to summarize the session by developing advocacy messages about 'How do human rights relate to access to treatment?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. Human rights and HIV are closely connected. Action on one will not be effective without action on the other.
2. Every day, a wide range of human rights violations prevent people living with HIV from accessing life-saving HIV treatment. The situation is especially severe for people from key populations.
3. Governments have made formal commitments to addressing human rights in responses to HIV. Such commitments are not 'optional'. They must be fulfilled *now* for people living with HIV to access life-saving treatment.

USEFUL RESOURCES

- *The Equity Deficit: Unequal and Unfair Access to HIV Treatment, Care and Support for Key Affected Communities*, Report by the NGO Delegation to the Programme Coordinating Board of UNAIDS, December 2013. http://www.unaids.org/en/media/unaids/contentassets/documents/pcb/2013/pcb33/agendaitems/20131206_PCB-NGO-report.pdf
- *HIV/AIDS & Human Rights in Southern Africa: An Advocacy Resource and Training Manual*, AIDS and Rights Alliance for Southern Africa, 2008. http://www.arasa.info/files/4813/9056/2374/arasa_training_manual_english.pdf
- *HIV and the Law: Risks, Rights & Health*, Global Commission on HIV and the Law, 2012. <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>

Why do human rights matter for action on HIV?

Since the HIV epidemic began over 30 years ago, human rights have been a vital part of the response. The relationship between human rights and HIV is two-way:

- **Poor human rights fuel the spread of HIV and make its impact worse.** For example, if a person lacks rights (such as to non-discrimination), they may be more likely to take risks and become infected with HIV. They may also be less likely to have access to effective antiretroviral therapy (ART).
- **The spread of HIV limits progress on human rights.** For example, HIV epidemics are often accompanied by specific challenges (such as stigmatizing attitudes) that prevent people from fulfilling their everyday human rights.

Over the years, it has become increasingly clear – and widely agreed – that action on HIV will not be effective without action on human rights. This is especially the case for key populations – who often have the biggest needs for HIV prevention, treatment, care and support, but face routine denial and violations of their rights.

What is a human rights-based approach to HIV?

Growing attention has been given to a **human rights-based approach to HIV**. This is one that considers and addresses human rights at *all* levels and in all processes of action on HIV.

The characteristics of a human rights-based approach include that it²:

- Uses human rights as a framework.
- Addresses the impact on human rights of any policy or program.
- Makes human rights a key element of the design, implementation, monitoring and evaluation of policies and programs.

A human rights-based approach can be part of a response at all levels. For example, it can be part of community advocacy work or part of core national policies, such as the National AIDS Strategy.

Human rights are central to all of the current global initiatives on HIV treatment (as summarized in Part 2). For example, the 2013 ART Guidelines, the World Health Organization (WHO) states that:

Human rights and the 2013 ART guidelines

“Global and national commitments require providing HIV treatment and prevention to everyone in need, following the human rights principles of non-discrimination, accountability and participation Key ethical principles of fairness, equity and urgency should also be observed in the process of reviewing and adapting guidelines. The design of effective and equitable policies implies that strategies should focus comprehensively on addressing barriers to access testing, prevention and treatment services, particularly those faced by key populations.”

Action on human rights is seen as a ‘critical enabler’ of investment approaches to HIV (described in Section 2.2). These are ones that focus resources where they will make the biggest difference, as promoted by the United Nations Joint Program on AIDS (UNAIDS) and other agencies. Such approaches – and programs that actively address human rights, including in access to treatment – are increasingly welcomed by donor mechanisms. A key example is the New Funding Model of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

What types of human rights are relevant to access to treatment?

Access to treatment for *all* people living with HIV – including those from key populations – requires the **full range of rights** listed in the Universal Declaration of Human Rights. For example, access not only involves the right to health. It also involves the right to: privacy (such as with ART services that respect people’s confidentiality); non-discrimination (such as with key populations getting the same quality of treatment counselling as others); and participation (such as with people living with HIV able to influence decisions about how treatment is managed and funded).

In practice, however, violations of human rights against people living with HIV are still common. This, in turn, presents a major **barrier to access to treatment**. The chart below focuses on the same rights from the Universal Declaration that were listed in Section 3.1. It provides examples of how those rights are violated in the context of access to treatment for people living with HIV, including those from key populations:

2 Adapted from: HIV/AIDS & Human Rights in Southern Africa: An Advocacy Resource and Training Manual, AIDS and Rights Alliance for Southern Africa, 2008.

HUMAN RIGHT	EXAMPLES OF VIOLATIONS IN RELATION TO HIV TREATMENT
Right to equality and dignity	<ul style="list-style-type: none"> ● People living with HIV have to wait until all other patients have been seen at a clinic before they are given their antiretroviral drugs (ARVs). ● Members of key populations receive poorer quality ART services than other people living with HIV.
Right to non-discrimination	<ul style="list-style-type: none"> ● People living with HIV who seek treatment receive judgmental attitudes by health care providers at ART services. ● Members of key populations, such as people who use drugs, are denied ART because they are presumed to be ‘unreliable patients’.
Right to life	<ul style="list-style-type: none"> ● People living with HIV who are eligible for treatment are denied ART because of stock outs. ● Key populations face multiple, routine barriers to all health care – resulting in those living with HIV not accessing treatment until they are seriously ill and it is too late.
Right to health	<ul style="list-style-type: none"> ● People living with HIV are denied treatment for life-threatening opportunistic infections, such as TB. ● People living with HIV are denied access to affordable, life-saving medicines due to their government’s patent laws or trade agreements.
Right to privacy	<ul style="list-style-type: none"> ● People living with HIV have their confidentiality breached, such as by ART counsellors. ● Young people living with HIV cannot access ART services without permission from their parents.
Right to marry and found a family	<ul style="list-style-type: none"> ● Women living with HIV are forced to be sterilized, rather than being offered a range of HIV prevention and treatment options. ● Women living with HIV are given a minimal package for prevention of mother-to-child transmission (PMTCT) – that only provides them with treatment until after birth.
Right to participation	<ul style="list-style-type: none"> ● People living with HIV are not asked their opinions about the quality and effectiveness of treatment services. ● People living with HIV, including those from key populations, cannot influence decision-making on treatment, such as by district health services.
Right to education	<ul style="list-style-type: none"> ● People living with HIV are not given enough information about treatment to make good decisions about which options to take. ● People living with HIV lack opportunities to ask questions about the side effects of different treatment options.
Right to freedom from arbitrary arrest and detention	<ul style="list-style-type: none"> ● Key populations that are criminalized - such as sex workers - fear recognition and arrest at health facilities and do not access ART services. ● Key populations, such as people who use drugs, experience imprisonment – which stops their access to treatment.

As seen above, some violations relating to access to treatment are due to a lack of action to promote and protect human rights. However, others are due to the use of brutal measures by governments, such as laws that criminalize and punish key populations.

The world of human rights and HIV treatment is constantly changing. For example, new developments – such as treatment as prevention (described in Section 1.2) – raises important and ethical questions about the right to ART for people living with HIV ‘versus’ the right for people who are at risk of HIV, but currently uninfected.

How are human rights addressed in HIV commitments?

As seen in Section 3.1, all countries are committed to at least one international agreement on human rights, including related to health.

Countries have also made specific commitments to address human rights within the response to HIV. For example, the **Political Declaration on HIV and AIDS** – which was agreed by the United Nations in 2011 – specifically addresses human rights, including in relation to access to treatment:

COMMITMENTS TO HUMAN RIGHTS IN THE POLITICAL DECLARATION ON HIV AND AIDS (2011)³

ARTICLE 32. Recognize that access to safe, effective, affordable, good quality medicines and commodities in the context of epidemics such as HIV is fundamental to the full realization of the right of everyone to enjoy the highest attainable standard of physical and mental health.

ARTICLE 38. Reaffirm the commitment to fulfil obligations to promote universal respect for and the observance and protection of all human rights and fundamental freedoms for all in accordance with the Charter, the Universal Declaration of Human Rights and other instruments relating to human rights and international law; and emphasize the importance of cultural, ethical and religious values, the vital role of the family and the community and, in particular, of people living with and affected by HIV, including their families, and the need to take into account the particularities of each country in sustaining national HIV and AIDS responses, reaching all people living with HIV, delivering HIV prevention, treatment, care and support and strengthening health systems, in particular primary health care.

ARTICLE 39. Reaffirm that the full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV epidemic, including in the areas of prevention, treatment, care and support, recognize that addressing stigma and discrimination against people living with, presumed to be living with or affected by HIV, including their families, is also a critical element in combating the global HIV epidemic, and recognize also the need, as appropriate, to strengthen national policies and legislation to address such stigma and discrimination.

Commitments to human rights – including in relation to access to treatment – can also be found in many key national policies on HIV. For example, human rights are often a guiding principle of a country’s National AIDS Strategy. Also, many countries have a Bill of Rights that is enshrined in their Constitution.

Similarly, commitments can be found in important regional policies. For example, the Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infections Diseases (2010) commits members of the Organisation of African Unity to respecting human rights, including of people living with HIV.

Global and national commitments are supported by a growing amount of evidence about why human rights matter and why further action must be taken. For example, the **Global Commission on HIV and the Law** published a ground-breaking report in 2012.⁴ This provides evidence and recommendations about a range of issues related to human rights and access to treatment. Examples include discrimination, criminalization of HIV transmission and intellectual property. The report also has specific sections on the rights of key populations and serves as an important advocacy tool.

3 Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS, United Nations General Assembly, 2011.

4 *HIV and the Law: Risks, Rights & Health, Global Commission on HIV and the Law, 2012.*

Section 3.3

What are the entry points for advocacy on human rights and access to treatment?

SECTION OBJECTIVE

To build community activists' understanding of the entry points and 'what works' for advocacy on human rights and treatment.

TRAINING MATERIALS

- PowerPoint presentation '3.3 What are the entry points for advocacy on human rights and treatment?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Ask the participants to think about the human rights and treatment issues that have been addressed in Part 3.1, 3.2. Ask them to identify some examples of entry points for advocacy. Explain that an entry point is an opportunity to 'get started'. It might, for example, be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Present PowerPoint presentation '3.3 What are the entry points for advocacy on human rights and treatment?'
4. Ask the participants to share other lessons learned about advocacy on human rights and treatment – based on their own experiences.
5. Summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Explain to the participants what is meant by an entry point for advocacy on human rights and treatment – in terms of an opportunity to 'get started'. For example, an entry point might be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Divide the participants into groups of about 5 people. Ask the participants to identify 1-2 entry points for advocacy on human rights and treatment that relate to their community.
4. Bring all of the participants back together. Ask each group to present their examples of entry points. Encourage the other participants to ask questions and make comments.
5. Ask the participants to think about what type of advocacy they could carry out for the entry points that they have identified. Facilitate a discussion on:
 - What do we know about 'what works' in advocacy on human rights and treatment?
6. Encourage the participants to identify the lessons learned from their own experiences. Write their inputs on a flipchart.
7. Summarize what has been discussed and agreed during the session.

What are entry points for advocacy on human rights and treatment?

For community activists, there are many different entry points that can be used for advocacy on human rights and treatment. An entry point is an opportunity to ‘get involved,’ ‘get going’ and ‘make a difference.’ It is an opportunity to start discussions, influence opinions and achieve change.

An entry point might, for example, be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change). Examples of entry points can be seen in the experiences of ITPC partners and other organizations throughout the world:

EXAMPLES OF ENTRY POINTS FOR ADVOCACY ON HUMAN RIGHTS AND TREATMENT

EXAMPLES OF ENTRY POINTS	EXAMPLES OF ADVOCACY ACTIONS
<p>Health workers at a government Health Center are discriminating against people living with HIV – by making them wait until last for their treatment</p> <p>(For example, denying the right to life of people living with HIV)</p>	<ul style="list-style-type: none"> ● Gathering evidence of the discrimination carried out by the health workers against people living with HIV. ● Gathering information about relevant national laws and local policies that state people’s rights to equality, health and life. ● Asking for a meeting between people living with HIV and the manager of the Health Center. Using your evidence and information to advocate for changes to the practices of health workers.
<p>People who use drugs or sex workers – who are criminalized in the country - are refusing to access ART services due to fear of arrest and imprisonment</p> <p>(For example, denying the right to freedom from arbitrary arrest or detention for people living with HIV)</p>	<ul style="list-style-type: none"> ● Gathering evidence of the fears and concerns of the people who use drugs. ● Holding briefings with the local Police Chief and Health Director to explain the problem and how it denies people their right to health. Working together to identify a practical solution - such as the police ‘allowing’ people use drugs to access ART services (despite remaining criminalized). ● Providing feedback to the sex workers and people who use drugs and encouraging them to access ART services and monitor the implementation of the agreement.
<p>Women living with HIV are only offered ART if they take specific action – such as being sterilized or terminating their pregnancy.</p> <p>(For example, denying women the right to marry and found a family)</p>	<ul style="list-style-type: none"> ● Gathering evidence of the scale and nature of the denial of treatment for women living with HIV. ● Partnering with human rights, women’s and HIV organizations to hold a demonstration outside the local government office – highlighting that denying treatment is denying women’s human rights (such as to health, life and to marry and found a family). ● Using the demonstration to get media attention on the issue and, if they are happy to speak publicly, provide a platform for women living with HIV to advocate for their need. ● Taking lawsuits against the government for denying women living with HIV their human rights (such as to health, life and to marry and found a family).

The District Health Authority is carrying out a midterm review of the principles, services and budget for HIV treatment

(For example, presenting an opportunity to use a human rights-based approach)

- Making a formal request to the District Health Authority to have community representatives – including from key populations - involved in the midterm review process.
- Gathering evidence of ‘what’s working’ and ‘what’s not working’ in relation to a human rights-based approach to HIV treatment – including for people living with HIV in the District, including those from key populations.
- Using the evidence to advocate for stronger principles, services and budget allocations to HIV treatment services that, for example, are equitable, confidential and non-discriminatory.

What works in advocacy on human rights and treatment?

Many lessons have been learned - including by ITPC’s partners - about ‘what works’ in advocacy on human rights and treatment. The following presents examples that apply to different contexts:

- **DOING YOUR HOMEWORK.** For example, if you are advocating on the lack of confidentiality in ART services for people living with HIV, it is important to gather evidence – such as documenting examples of where, when and to how many people this has taken place.
- **ADDRESSING BOTH RIGHTS-HOLDERS AND DUTY-BEARERS.** For example, if you are advocating for a new law to protect the rights of all people living with HIV to access treatment, it is vital to also advocate for who should have responsibility for applying it.
- **USING A RANGE OF ACTIVITIES AND MESSAGES.** For example, if you are advocating on the denial of ART to people living with HIV, it may be effective to use direct methods (such as demonstrations) with some targets and indirect methods (such as briefing papers) with others. It might also be effective to use ‘rights’ messages with some stakeholders and ‘public health’ ones with others.
- **USE INTERNATIONAL AND NATIONAL COMMITMENTS.** For example, even where a government criminalizes key populations, arguing that they have to protect the right to life and health of those living with HIV because they have formally committed to do so.
- **USING HUMAN RIGHTS EXPERTISE.** For example, partnering with a legal company or human rights organization to bring knowledge and experience to your advocacy work of how to ‘navigate’ the human rights system and achieve change.
- **PROTECTING PEOPLE’S CONFIDENTIALITY.** For example, while people living with HIV should be supported to participate in all stages of advocacy, they should not be forced to disclose their identity or status during advocacy action.
- **‘PUSHING’ THE LEGAL SYSTEM THROUGH LITIGATION.** For example, ‘testing’ laws and their protection of human rights, such as by taking the government to court for denying access to ART for people living with HIV. This can bring about changes in the legal system, as well as bring important publicity.

4

TRADE AND TREATMENT

INTRODUCTION

THE SCIENCE OF HIV 1

TREATMENT INITIATIVES 2

HUMAN RIGHTS AND TREATMENT 3

TRADE AND TREATMENT 4

FINANCING AND TREATMENT 5

COMMUNITY ADVOCACY PLANNING 6

ACT CASE STUDIES

Welcome to **Part 4: Trade and Treatment** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

Part 4 focuses on trade and how it affects access to HIV treatment.

Section 4.1 What is a patent and intellectual property?

SECTION OBJECTIVE

To build community activists' understanding of what is a patent and Intellectual Property and why they matter for access to HIV treatment.

TRAINING MATERIALS

PowerPoint presentation '4.1 What is a patent and Intellectual Property?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Divide the participants into 'buzz groups' of 2-3 people. Ask each group to discuss:
 - What is Intellectual Property?
 - What is a patent?
3. If the participants do not know what Intellectual Property and patents are, ask them to write down questions that they would like answered about them.
4. Present PowerPoint presentation '4.1 What is a patent and Intellectual Property?' Check-in with the participants about whether the presentation has answered any questions that they wrote down.
5. Ask the participants to share any examples they know of that show how issues relating to patents and Intellectual Property affect access to HIV treatment. Ask them, in particular, to share examples of where advocacy has helped to overcome such barriers.
6. Ask the participants to summarize the session by developing advocacy messages about 'What is a patent and Intellectual Property?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. Patents – such as of HIV drugs - should be for the 'public good'. The people and companies that create inventions have the right to benefit from them, but so do the general public.
2. Generic medicines are vital for ensuring affordable and high quality medicines for all people living with HIV. Patents and other systems should not be a barrier to their benefits.

USEFUL RESOURCES

- MSF Access to Essential Medicines Campaign: <http://www.msfacecess.org/>
- *Untangling the web of antiretroviral price reductions*, MSF, 2013: <http://utw.msfacecess.org/>
- *Access Challenges for HIV Treatment among People Living with HIV and Key Populations in Middle-Income Countries: Policy Brief*, GNP+, NSWPI, INPUD, MSMGF and ITPC, October 2013. http://www.msmsgf.org/files/msmgf/Publications/Access_Challenges_for_HIV_treatment_KAPs.pdf
- Gagnon, M A and Lexchin, J. "The cost of pushing pills: A new estimate of pharmaceutical promotion in expenditures in the United States." *Plos Medicines* (2008), 5(1):29-33

What is intellectual property?

Intellectual Property (IP) refers to work or inventions that are the creation of people's minds. Examples include inventions, songs or a new medicine. The creations are 'property' because they are produced at a cost and have a commercial value.

Intellectual Property Rights (IPRs) are the legal rights of the owner of IP. They are exclusive – meaning that they can only be used by that person. Others cannot use the creation without permission or payment.

There are two types of IPRs: copyright (for creations such as songs and paintings); and industrial property (for creations that have an industrial use). **The IPRs that are most relevant to HIV treatment are patents and trademarks.** IP rights are typically granted by a state's national institutions (e.g. a patent office), are valid only on the national territory and only for a limited period of time. However, some countries have opted into regional patent offices; for example the European Patent Office (EPO) grants patents which can take effect in some or all of the European Patent Convention (EPC) countries.

What is a patent?

A patent can be granted to the creator of a product or a process. It is the right to stop other people from making, using, selling, offering to sell or importing their invention for a limited period of time. **Trade-Related Aspects of Intellectual Property Rights (TRIPS)** rules require countries to protect medicines with patents like they would for any other invention. Patents on medicines can be granted for the product or for the process of production. Under TRIPS, protection through a patent is effective for a period of 20 years but in order to be granted the invention must satisfy certain criteria (known as 'patentability criteria'; please see more information on TRIPS in Section 4.3).

Patents are given by Patent Offices at the national level or regional level by governments and intergovernmental organizations. There is no such thing as a global patent. Each country can decide what criteria it uses for giving and using patents. This means that, for example, a drug that is patented in one country may not be patented in another.

In theory patents are supposed to serve the 'public good.' The reason for granting patents is that they benefit society by encouraging inventors to disclose their research to the public and to give us access to new products or technologies. In exchange, the inventor is rewarded for this disclosure. However, when it comes to health, in practice patents have functioned as monopolies and the abusive exercise of these monopolies has led to reduced competition, higher prices and reduced availability of medicines.

In theory, patents are supposed to protect genuinely new developments but the fact is that in many cases, companies apply for new patents to protect often minor modifications of existing drugs – this is known as "evergreening." Companies might also apply for a new patent when a drug is shown to be effective to treat a different disease than the one the medicine was initially registered for. For example, the first ever medicine to treat HIV, zidovudine (AZT) was originally registered as a treatment for cancer but once it became clear that it would also be effective in HIV treatment, a new patent was registered in the late 1980s even though the drug was developed in the 1960s. It is these kinds of practices that extend indefinitely the patent protection period which allow patents to become a real obstacle to access for medicines for those most in need, creating unsustainable cost burdens in the country of the patent as well as for national governments in other countries due to Free Trade Agreements (which will be discussed later).

Very often, multinational pharmaceutical companies argue that the key barrier to access to medicines is not patents, but the weak health systems in developing countries, as well as lack of infrastructure to produce high quality medicines. But this argument ignores how consumers get medicines in developing countries – not always from public distributors, but using their own money. This may be because medicines are not available through the public sector or even if they are, the public health system might experience stock outs.

Another argument is that strong protection of intellectual property rights is an incentive for research and

development (R&D) for new medicines. In general, patents are most effective at attracting investment in products that have commercial prospects, leaving important gaps where R&D is the most commercially risky. The diseases and conditions that affect people in the world's major markets largely determine where the pharmaceutical industry's investments go. Of the 1,393 new chemical entities developed globally between 1975 and 1999, only 16 were for the treatment of tropical diseases and tuberculosis, which primarily affect people in developing countries. The Global Forum for Health Research notes that only 10 percent of global R&D spending is directed to the health problems that account for 90 percent of the global disease burden—the so-called 10/90 gap.

It is also important to put the profits generated by commercial companies into perspective, noting that much of this profit is used to market drugs in 'profitable markets.' For example, one study from 2008 (highlighted in the Useful Resources section) analyzed the US pharmaceutical market and concluded that companies spend almost twice the amount on marketing than they do on research and development.

In practice, patents can result in a monopoly – as they give all the power to one individual or company. **In the case of HIV drugs and diagnostics, they can lead to less competition, higher prices and reduced availability.**

What is a trademark?

A trademark is a sign (like a word or a symbol) that is used to distinguish the goods or services of one person or company from another's. Often, a company will put a small TM next to the name or symbol that it has trademarked.

The same drug – such as for HIV treatment - can be sold by different companies using different trademarks.

What are the different types of medicines?

There are two different types of medicines:

ORIGINATOR /INNOVATOR/ BRANDED MEDICINE

This medicine has been developed by a company after it has been authorized for marketing world-wide. It has met requirements for efficacy, safety and quality, according to requirements at the time of authorization. It is also known as an 'originator medicine'. It is usually a patented product and has a brand name (although this might vary between countries). A branded medicine is often more expensive than other options.

GENERIC MEDICINE

This medicine is a pharmaceutical product comparable to brand/reference listed drug product in dosage form, strength, route of administration, quality and performance characteristics, and intended use; interchangeable with the originator brand product, manufactured with or without a license from the originator manufacturer. This category includes pharmaceuticals whose patents or other exclusivity rights have expired, pharmaceuticals that have never been patented, and copies of patented pharmaceuticals in countries where the drug is not patented or where a compulsory license has been granted. **These medicines are identical with the innovator product, but cost significantly less.** It is made by a company that does not hold the patent for it. The generic market is highly price competitive because buyers can choose among several sources of chemically identical medicines.

Often we also hear the term 'counterfeit' or 'counterfeit medicines.' It is important to understand what this term means because it is often incorrectly used in the context of generic medicine: **generic medicines have nothing to do with counterfeited ones.**

COUNTERFEITS: WHO defines counterfeit medicines as a pharmaceutical product whose origin and/or identity specifications have been deliberately and **fraudulently** modified, regardless whether it is a pharmaceutical product protected by a patent or whether it concerns a generic drug. This commonly accepted meaning falls within the broader concept of substandard medicines.

Counterfeit medicines may be:

- Products containing the same active ingredients and the same excipients of the original pharmaceutical agent, correctly packaged and labeled, but illegally imported into a country.
- Products containing the same ingredients of the genuine medicine, with genuine packaging, but containing incorrect amounts of ingredients.
- Products that – despite being identical from an external point of view and have genuine packaging – do not contain any active ingredients.
- Products externally similar to original products with genuine packaging, but containing harmful substances instead of the same active ingredients.
- Products with counterfeit packaging and correct amounts of active ingredients.
- Products with counterfeit packaging but with different amounts of active ingredients.
- Products with counterfeit packaging that contains a different active ingredient.
- Products with counterfeit packaging that does not contain active ingredients.

EXAMPLE OF HOW ANTI-COUNTERFEIT LAWS THREATEN ACCESS TO MEDICINE:

In Kenya, an anti-counterfeit law was proposed in 2008. Although the law intended to combat counterfeit drugs, there were significant problems with the legislation, which failed to categorically distinguish between counterfeit and generic drugs. As a result, the legislation would have negatively impacted the importation and production of generic drugs, affecting people living with HIV and others.

To fight the legislation, a civil society coalition, including the International Treatment Preparedness Coalition Eastern Africa, took the Kenyan government to court for drafting ambiguous legislation that made dealing with substandard drugs even more difficult by widening the scope to include generics. The petitioners sought to have the Anti-Counterfeit Act 2008 declared unconstitutional, on the grounds that it infringed on their right to health. In court, a judge ruled in favor of the civil society coalition and against the Kenya Anti-Counterfeit Act 2008. In her ruling, the judge said that the Anti-Counterfeit Act was more concerned with seeking extra-territorial enforcement of Intellectual Property Rights at the expense of access to medicines. The decision in this case was a landmark – it was the first legal challenge in Africa against a new push for anti-counterfeit legislation that is widely expected to also appear in other East African countries.

Section 4.2 Why does trade matter to HIV treatment?

SECTION OBJECTIVE

To build community activists' understanding of why trade matters to access to HIV treatment, the role of the World Trade Organization and the impact of Free Trade Agreements on access to medicines.

TRAINING MATERIALS

- PowerPoint presentation '4.2 Why does trade matter to HIV treatment?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a group discussion on:
 - Why does trade matter to HIV treatment?
3. Encourage the participants to share their experiences – or stories that they have heard – about how issues related trade can make access to HIV treatment better or worse.
4. Present PowerPoint presentation '4.1 Why does trade matter to HIV treatment?'
5. Check if the participants have further points or questions about the subject.
6. Ask the participants to summarize the session by developing advocacy messages about 'Why does trade matter to HIV treatment?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. Issues relating to trade can 'make or break' effective access to HIV treatment, as well as other essential medicines, for community members living with HIV.
2. Trade issues not only affect how much medicines cost. They also affect their quality, availability and accessibility.
3. Fair trade – that is not restricted by agreements and where there is healthy competition – is vital to ensuring access to life-saving HIV drugs and diagnostics.

USEFUL RESOURCES

- World Trade Organization, (website). <http://www.wto.org/>
- *Access Challenges for HIV Treatment among People Living with HIV and Key Populations in Middle-Income Countries: Policy Brief*, GNP+, NSWPI, INPUD, MSMGF and ITPC, October 2013. http://www.msmsgf.org/files/msmgf/Publications/Access_Challenges_for_HIV_treatment_KAPs.pdf
- *The potential impact of Free Trade Agreements (FTAs) on public health*, UNAIDS, 2012: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2349_Issue_Brief_Free-Trade-Agreements_en.pdf

Why does trade matter to HIV treatment?

Trade refers to the buying and selling of goods and services. In this ACT Toolkit, it particularly refers to the buying and selling of:

- HIV-related drugs, such as antiretrovirals (ARVs) and medicines to prevent and treat opportunistic infections and co-infections (e.g. TB, Hepatitis C).
- HIV-related diagnostics, such as HIV tests and equipment for CD4 counts and viral load tests.

Trade matters to HIV treatment because it can affect:

- How much drugs and diagnostics cost.
- The quality of drugs and diagnostics.
- Where and by whom drugs and diagnostics can be made.
- Where and by whom drugs and diagnostics can be sold and distributed.

For HIV treatment to be affordable it has to have the “right cost” – one that countries, health systems and people can afford. National, regional and global markets drive the cost of HIV drugs and diagnostics. These markets are in turn driven by trade. Trade that is fair and ethical is important to ensure access to HIV treatment for all people living with HIV. For example, ideally, markets should not be driven by monopolies – where just one company has control over the market of a particular product, and is therefore able to set a high price. Instead, competition is better – as this can drive down the costs of medicines, while also increasing the quality.

The buying and selling of goods and services should take place in an environment that regulates trade and promotes ‘fair play’. Without regulation, there is the risk of monopolies and other bad practices – which reduce people’s access to essential products, such as medicines.

The impact that market regulations and, in particular, intellectual property regulations can have on access to medicines is easily understood when we look at the incredible price reductions that occurred for ARVs through generic competition from 2003 onward. The cost of the first generation of first line ARVs dropped by 99% which led to a 20-fold increase of people living with HIV being on antiretroviral therapy since 2003.

What is the World Trade Organization?

The **World Trade Organization (WTO)** is an international body. It was set up to regulate trade between countries and to ensure fair trade. It started in 1994 and now has 155 member countries.

The WTO is based on agreements that are signed by all of its members. These legally bind the countries to take actions at the national level to support global trade. The agreements require governments to make changes in their laws and policies relating to trade in goods, services and intellectual property rights (IPRs) (described in the Section 4.1). In terms of intellectual property rights, WTO sets a minimum standard of protection for patents, copyright, trademark and industrial design in an agreement called **TRIPS** which stands for **Agreement on Trade Related Aspects of Intellectual Property Rights** (described in the Section 4.3).

TRIPS is only one trade agreement among many, and all agreements are open to interpretation. In practice, some developed countries choose to interpret agreements in a way that protects their IP rights over the rights of Southern countries to access medicines; these developed countries then use a range of strategies and tactics to enforce WTO Agreements.

For example, the United States of America and the European Union try to avoid multilateral negotiations over intellectual property issues, instead preferring bilateral or regional trade agreements. These enable certain countries to exploit unequal power relationships, link intellectual property with other trade issues, divide developing countries and create norms that can then be imposed on the rest of the world.

What is a Free Trade Agreement?

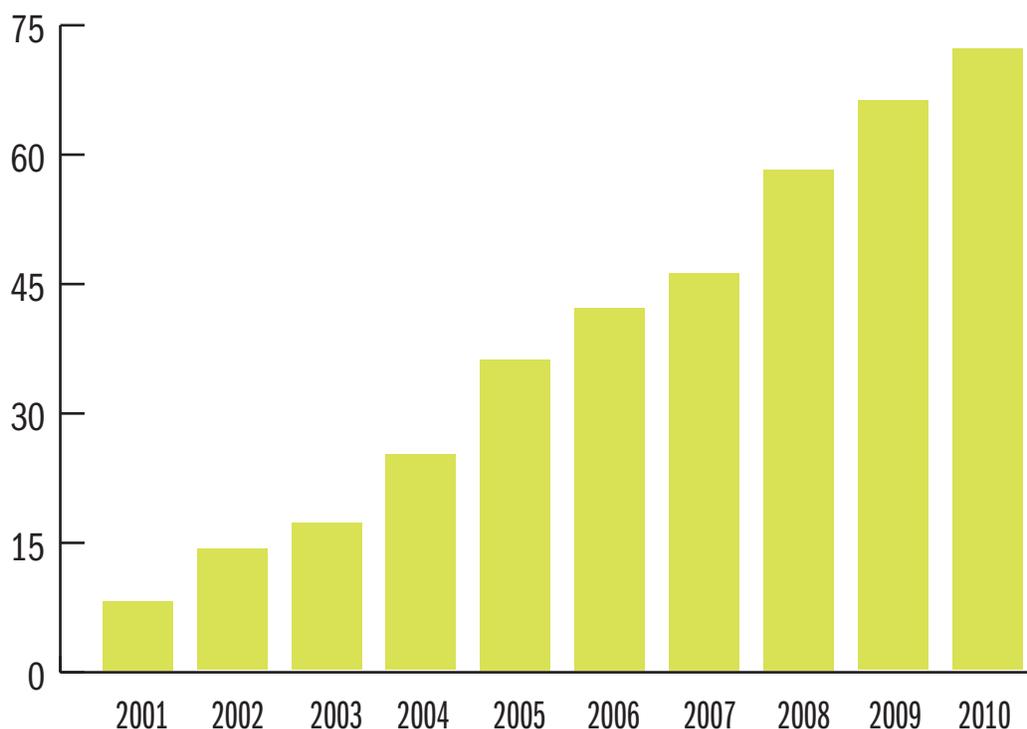
A **Free Trade Agreement (FTA)** can be negotiated between individual countries or blocs of countries in a region. It is an agreement that the countries can trade goods and services between them without tariffs (taxes or duties) or other barriers. Developed governments typically propose FTAs to derive an economic benefit from the cheaper flow of goods between countries as well as to ensure their products (including patented medicines) are profitable in other countries. FTAs can also be known as Regional Trade Agreements (RTAs) or Economic Partnership Agreements (EPAs).

Developed countries sometimes use FTAs to get even greater commitments to ‘free trade’ than those agreed through the WTO. Often, developed countries insert stringent intellectual property regulations into FTAs that are in contradiction to the WTO TRIPS Agreement and threaten to block access to affordable medicines. Meanwhile, developing countries often have less power to resist or control the terms of FTAs, since they may be in need of increased economic revenue or other benefits that the developed countries can provide.

For example, the United States-Jordan Free Trade Agreement, which was fully implemented on January 1, 2010, has had disastrous results for public health. As a result of the FTA, Jordan has witnessed an increase in the price of medicine; over 25% of the Ministry of Health’s budget is now spent on buying medicines, data exclusivity has delayed the introduction of cheaper generic versions of 79% of medicines and higher medicine prices are threatening the financial sustainability of government public health programs.

FREE TRADE, MOUNTING CONSTRAINTS

Number of free-trade agreements with intellectual property clauses, 2001-2010



How Free Trade Agreements undermine access to HIV treatment and other essential medicines*

TRIPS-plus FTAs and EPAS generally

- Include clauses to extend patent terms beyond the twenty-year minimum required by TRIPS
- Limit the use of compulsory licenses
- Require data exclusivity that restricts the use of clinical data by national drug regulatory authorities to approve generic production for a certain time period
- Prevent countries from restricting evergreening or allowing pre-grant oppositions

As a result, countries should:

- Develop/amend national patent laws in order to protect and promote the right to health and guarantee access to affordable essential medicines, by adopting the full range of TRIPS flexibilities including:
 - high patentability criteria – patents should only be granted for real and meaningful innovation and not for evergreening;
 - explicit language allowing for the use of compulsory licenses and parallel imports;
 - the opportunity for the public, generic manufacturers, and civil society to challenge patents through pre- and post-grant patent opposition provisions
- Low and middle-income country governments must reject, from the outset, any provisions in all trade-agreements that in anyway impact affordable access to essential medicines, including TRIPS-plus provisions and investment protection provisions.
- Low and middle-income country governments must guarantee access to safe, effective and affordable generic medicines, including developing manufacturing capacity when possible, by broadly and boldly using the TRIPS flexibilities.

*Excerpted from Zaidi, Sarah, "Access Challenges for HIV Treatment Among People Living with HIV and Key Populations in Middle-Income countries." Read the full list of issues and recommendations at: http://www.msmgf.org/files/msmgf/Publications/Access_Challenges_for_HIV_treatment_KAPs.pdf

Section 4.3 What is TRIPS?

SECTION OBJECTIVE

To build community activists' understanding of what TRIPS is and why it matters to access to HIV treatment.

TRAINING MATERIALS

- PowerPoint presentation '4.3 What is TRIPS?'
- Flipchart and pens

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Ask the participants what they know about:
 - Trade Related Aspects of Intellectual Property Rights (TRIPS)
 - TRIPS Plus
 - TRIPS Flexibilities
3. Ask them to, in particular, share any examples of where situations related to TRIPS have threatened or improved access to treatment for people living with HIV. Write the ideas on a flipchart.
4. Present PowerPoint presentation '4.3 What is TRIPS?' Check if the participants have any further questions.
5. Ask the participants to build on the previous discussion and identify any additional ways in which situations related to TRIPS could threaten or improve access to HIV treatment in their community. Add the ideas to the flipchart.
6. Ask the participants to summarize the session by developing advocacy messages about 'What is TRIPS?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. TRIPS presents a significant threat to access to life-saving treatment for people living with HIV. For example, it can block access to new medicines, promote monopolies and keep prices of medicines unaffordable.
2. The threats are even greater under TRIPS Plus. Practices - such as Patent Term Extension, evergreening and data exclusivity - risk protecting the rights of foreign businesses at the cost of public health.
3. TRIPS Flexibilities present a vital opportunity to focus on what matters most – in terms of access to essential medicines that protect public health and deal with health crises, such as HIV.

USEFUL RESOURCES

- TRIPS and Health: Frequently Asked Questions, (webpage), World Trade Organization. http://www.wto.org/english/tratop_e/trips_e/public_health_faq_e.htm
- *Good Practice Guide: Improving Access to Treatment by Utilizing Public Health Flexibilities in the WTO TRIPS Agreement*, UNDP, 2010. <http://apps.who.int/medicinedocs/documents/s17762en/s17762en.pdf>

- *Access Challenges for HIV Treatment among People Living with HIV and Key Populations in Middle-Income Countries: Policy Brief*, GNP+, NSWP, INPUD, MSMGF and ITPC, October 2013. http://www.msmsgf.org/files/msmsgf/Publications/Access_Challenges_for_HIV_treatment_KAPs.pdf
- *Voluntary licensing practices in the pharmaceutical sector: An acceptable solution to improving access to affordable medicines?* <http://www.i-mak.org/storage/Oxfam%20-%20Voluntary%20Licensing%20Research%20IMAK%20Website.pdf>
- Trends in Compulsory Licensing of Pharmaceuticals Since the Doha Declaration: A Database Analysis: <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001154>

What is TRIPS?

Trade Related Aspects of Intellectual Property Rights (TRIPS) is an agreement under the World Trade Organization (WTO). It outlines minimum standards for many types of regulations for Intellectual Property Rights (IPRs) but leaves space for countries to include in their national laws safeguards to protect public health. TRIPS requires members of the WTO to change their national laws in order to provide protection of IPRs. Countries have to give the same protection to nationals and foreigners. Under TRIPS, the term of a patent is 20 years. TRIPS includes an enforcement mechanism through economic sanctions for countries that fail to comply with the minimum standards for protecting intellectual property rights.

One of the challenges of TRIPS is that, through its high level of protection for IPRs, it can block access to new products, promote monopolies and keep prices high for essential medicines.

Different deadlines for the implementation of TRIPS have been set depending on the level of economic development, financial, administrative and technological constraints to conforming and previous existence of patent on pharmaceutical products:

- 1995 for developed countries
- 2000 for developing countries who grant patents on pharmaceuticals before joining the WTO
- 2005 for developing countries that had not introduced patents for pharmaceuticals before joining the WTO
- 2016 for pharmaceuticals for “least developed countries”

The TRIPS agreement includes a certain number of flexibilities that allow countries to break or work around patents and to balance between monopolies and public health.

What are TRIPS flexibilities?

A **TRIPS Flexibility** is an amendment to the TRIPS Agreement. It allows members of the WTO to avoid patent rights for the sake of better access to essential medicines. It ensures that TRIPS does not prevent countries from taking steps to protect public health and, in particular, deal with health crises.

TRIPS Flexibilities create a supportive environment for WTO members to exercise their right to promote access to medicines for all. Examples of Flexibilities include:

STRICT PATENTABILITY CRITERIA

Member states may set high patentability criteria, denying new patents on new uses, forms, formulations or combinations of known medicines. This prevents “**evergreening**” of patents, where pharmaceutical companies will obtain new patents by making minor changes to the medicine to extend its monopoly period.

TRANSITION PERIOD

Least developed countries are not obliged to grant patents on pharmaceutical products until 2016 and should take advantage of this transition period.

COMPULSORY LICENSING (GOVERNMENT USE)

A compulsory licence is a government order allowing other persons or companies to use, make, sell, offer for sale or import the patented product or process **without** the consent of the patent holder. Under the TRIPS Agreement, countries are free to determine the grounds on which a compulsory license should be issued. Patent holders still have the right to be compensated for the use of their patent rights by competitors and generic producers have to pay royalty on the sales of the generic versions of the medicines made under the compulsory license.

In Africa, for example, Ghana, Eritrea, Zambia, Mozambique and Zimbabwe have issued compulsory licenses for generic ARVs. Some more examples are in the picture below.

COUNTRY & DATE OF ISSUE	TYPE OF LICENSE & NAME OF MEDICINE	IMPACT OF COMPULSORY LICENSE
INDIA March 2012	Compulsory license to locally produce generic sorafenib tosylate to treat kidney cancer and liver cancer	Price set by India's Patent Controller will result in 97% reduction
ECUADOR April 2010	Compulsory license to import and, if necessary, locally produce generic ritonavir	Resulted in a patent holder reducing price of brand medicine by 70%
THAILAND January 2008	Government-use license for import of generic letrozole used to treat breast cancer	Projected aggregate price reduction of 96.8%
BRAZIL May 2007	Compulsory license issued by government to import generic efavirenz	Resulted in a 71.8% price reduction
THAILAND January 2007	Government-use order to import or locally produce generic lopinavir/ritonavir	Projected price reduction of 80.2% expected
INDONESIA October 2004	Government-use order to locally manufacture generic lamivudine, nevirapine	Resulted in price reduction of 53.3%
MALAYSIA November 2003	Government-use order for the production of combination of generic stavudine + didanosine + nevirapine	Resulted in price reduction of 83%

PARALLEL IMPORTATION

Allows countries to import a patented medicine from other countries where it is produced and sold by the patent holder or an authorized party at a lower price than in the domestic market. This can happen without the permission of the intellectual property owner.

EXCEPTIONS TO PATENTS RIGHTS

TRIPS allows states to establish limited exceptions to the exclusive rights of a patent owner, as long as they do not unreasonably prejudice his or her ownership rights. For example, the **Bolar Exception** – an 'early working' exception which allows for research and experimental use of products still under patent. This allows generic versions to promptly enter the market right after the patent expires.

PATENT OPPOSITIONS

Countries may permit any person to oppose patent applications before the patent is granted by filing a case in court (pre-grant opposition). Under certain circumstances, a patent can be challenged after it has been granted by filing a case in court (post-grant opposition). Patent oppositions ensure higher scrutiny of patent applications before and after they are granted to ensure a novel, inventive step.

LIMITS ON DATA PROTECTION

TRIPS does not require countries to grant exclusivity of clinical trials data. This should only be protected from “unfair commercial use.” Registration of a generic medicine is not considered an unfair commercial use.

What are voluntary license mechanisms?

A pharmaceutical company that holds patents on a product can offer on their own accord a license to a third party (usually a generic producer) to produce, market and distribute the patented product. In exchange, the patent holder will usually request a royalty on the net sales made by the licensee. This is also referred to as ‘out-licensing.’ Other types of licenses granted by patent holders to generic companies could be marketing licenses (or distribution agreements), where a company may simply sell the branded version of the product.

However, very often the patent holders impose some restrictions:

- geographical restrictions on where the licensee can sell the product
- restrictions on what price the product may be sold at
- and any other terms or conditions it might insist on

In general, multinational companies negotiate directly with generic companies the terms of voluntary licenses, which are usually kept secret. More recently, the Medicines Patent Pool made efforts to advance the voluntary licenses agenda. The pool aims to act as a central hub for sub-licensing HIV medicines to generic producers with more transparent licenses and from a public health perspective. However, the licenses agreed on so far have the same limits in term of geographical coverage and other issues. The voluntary license process remains voluntary and multinational companies are free to give what they want. The Medicine Patent Pool has no real leverage for negotiation.

In conclusion, voluntary licenses could help in reducing prices when there is no alternative. However, they do not create the real competition needed for progressive price reductions: voluntary licenses replace one monopoly with another monopoly. Voluntary licenses do not guarantee the availability of medicines on the market either. Several voluntary licenses have not yet led to the production of actual medicines and have remained just public announcements. Some multinational companies use them only to prevent governments from using other TRIPs flexibilities (like compulsory licenses) to get patented pharmaceutical products.

What is the Doha Declaration?

The Doha Declaration is a joint agreement endorsed by all WTO countries that gives countries the right to take wide-ranging actions to protect the health of their citizens. The 2001 WTO Doha Declaration states: “The TRIPS Agreement does not and should not prevent Members from taking measures to protect public health. ... [W]e affirm that the Agreement can and should be interpreted and implemented in a manner supportive of WTO Members’ right to protect public health and, in particular, to promote access to medicines for all.”

The Doha Declaration reaffirmed countries’ right to use TRIPS flexibilities to overcome patent barriers in order to increase access to medicines, including specifying that the grounds for issuing a compulsory license are unlimited and can apply to any disease or public health situation (for example, emergencies as well as chronic health issues).

What is TRIPS-Plus?

“TRIPS-Plus provisions” refer to those measures related to intellectual property that go far beyond what governments are required to do under TRIPS. This includes efforts to extend patent periods beyond the twenty-year TRIPS minimum, limit compulsory licensing in ways not required by TRIPS, limit exceptions that facilitate the prompt introduction of generics, and grant clinical data needed for registration of medicines during a period of exclusivity.

Many developing countries have been forced to include such provisions in their national laws after signing a Free Trade Agreement. However, some did so voluntarily because of a lack of expertise when drafting their national laws or as a result of technical assistance provided by developed countries.

Examples of TRIPS-plus measures include:

- Expansion of the patentability criteria (second use, new formulation, etc.)
- Exclusion of patent pre-grant opposition
- Restrictions of grounds for patent revocation
- Extension of the term of patent protection
- Data exclusivity for data submitted to regulatory authorities
- Limitations on compulsory licenses
- Limitations or interdictions on parallel import
- Linkage between patent status and market approval

Two TRIPS-plus measures are of particular interest:

EVERGREENING

Refers to a variety of legal and business strategies by which technology producers with patents over products that are about to expire retain royalties from them, by either taking out new patents (for example over associated delivery systems or new pharmaceutical mixtures) for longer periods of time than would normally be permissible under the law or by buying out or frustrating competitors.

Used to refer to the myriad of ways in which pharmaceutical patent owners use the law and related regulatory processes to extend their high rent-earning IP rights particularly over highly profitable (either in total sales volume or price per unit) “blockbuster” drugs

DATA EXCLUSIVITY

This refers to a different type of monopoly on medicines separate from patents. Data exclusivity refers to the period during which the data of the original marketing authorization holder relating to (pre-) clinical testing is protected. A country’s drug regulator will be prohibited from registering an effective generic medicine as long as the exclusivity over the clinical trial data submitted by a pharmaceutical company lasts – this can be up to 10 years.

Section 4.4

How can you advocate on trade and access to treatment?

SECTION OBJECTIVE

To build community activists' understanding of the entry points and 'what works' for advocacy on trade and access to treatment.

TRAINING MATERIALS

- PowerPoint presentation '4.4 How can you advocate on trade and access to treatment?'
- Flipchart and pens

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Ask the participants to think about the information on trade and HIV treatment that has been addressed in Section 4.1-4.3. Ask them to identify some examples of entry points for advocacy. Explain that an entry point is an opportunity to 'get started'. It might, for example, be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Present PowerPoint presentation '4.4 How can you advocate on trade and access to treatment?'
4. Ask the participants to share other lessons learned about advocacy on trade and access to treatment based on their own experiences.
5. Summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Explain to the participants what is meant by an entry point for advocacy on trade and HIV treatment – in terms of an opportunity to 'get started'. For example, an entry point might be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Divide the participants into groups of about 5 people. Ask the participants to identify 1-2 entry points for advocacy on trade and access to treatment that relate to their community.
4. Bring all of the participants back together. Ask each group to present their examples of entry points. Encourage the other participants to ask questions and make comments.
5. Ask the participants to think about what type of advocacy they could carry out for the entry points that they have identified. Facilitate a discussion on:
 - *What do we know about 'what works' in advocacy on trade and access to treatment?*
6. Encourage the participants to identify the lessons learned from their own experiences. Write their inputs on a flipchart.
7. Summarize what has been discussed and agreed during the session.

USEFUL RESOURCES

- Patentoppositions.org; and “Success story: The Case of TDF in Brazil” http://patentoppositions.org/case_studies/4f106d0504a7f92f5b000003
- *Global Commission on HIV and the Law, Chapter 6*, UNDP <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>
- *Don't Trade Our Lives Away*, (website) <https://dontradeourlivesaway.wordpress.com/>

How can you advocate around trade issues and HIV treatment?

For community activists, there are many different opportunities to get involved on trade and access to treatment and make a difference. Advocacy is about starting discussions, influencing opinions and achieving change.

While advocacy on trade might sound like a complicated concept, there are many “entry points” for advocacy that provide the opportunity to get involved, such as a process (that provides an opportunity to influence decision-making) or a crisis (that provides a chance to achieve urgent change). Examples of advocacy opportunities can be seen in the experiences of ITPC partners and other organizations throughout the world:

EXAMPLES ON HOW TO ADVOCATE ON TRADE AND ACCESS TO TREATMENT

ADVOCACY OPPORTUNITIES	EXAMPLES OF ADVOCACY ACTIONS
<p>Call for law reform for better inclusion of TRIPS flexibilities in your national law</p>	<ul style="list-style-type: none"> ● Analyze your national intellectual property law and highlight all provisions that could undermine the use of TRIPS flexibilities ● Assess the impact of such provisions on access to medicines ● Draft amendments to integrate safeguards ● Meet with legislators and parliamentarians to explain your position and why it's in their interest to support law reform ● Mobilize communities and the media to build support
<p>Develop a “post license strategy” if your country has been excluded from a voluntary license</p>	<ul style="list-style-type: none"> ● Issue a press statement ● Push your Ministry of Health to protest against such exclusion ● Analyze if there are potential sources of generic supply or local capacity for production ● Call on your government to issue a compulsory license or call for amendment of the voluntary license to include your country ● Mobilize communities, engage with the media and build support

<p>Call on your government to issue a compulsory license (CL)</p>	<ul style="list-style-type: none"> ● Make the case for why a CL is urgently needed in your country through research and personal stories of people who would be affected by the CL ● Rally public opinion to your side through media outreach, demonstrations and other advocacy actions. ● Seek the support of legal experts and experts in other countries who helped achieve CLs to ensure your government feels comfortable proceeding ● Rally decision-makers to your side through targeted lobbying meetings and, if they are elected officials, through pressure from their constituents through public rallies, petitions and so on
<p>Oppose an abusive patent</p>	<ul style="list-style-type: none"> ● Do research and analysis to identify abusive patents or applications that hinder generic competition ● Build arguments for a case to oppose the abusive patent ● Communicate with the patent office to explain why a patent should not be granted ● File an opposition according to your national legislation ● Mobilize communities and gain media coverage to build support
<p>Influence your government as it debates entering a Free Trade Agreement (FTA)</p>	<ul style="list-style-type: none"> ● Analyze the impact the FTA would have on medicines in your country. ● Publicize your analysis so others can be informed ● Rally public opinion to your side through media outreach, demonstrations and other advocacy actions ● Rally decision-makers to your side through targeted lobbying meetings and, if they are elected officials, through pressure from their constituents through public rallies, petitions and so on

The Global Commission on HIV and the Law issued recommendations on what needs to change with regards to trade and IP to ensure the right to health is protected. You can also advocate for their recommendations, which included:

- High-income countries, including donors such as the United States, European Union, the European Free Trade association countries (Iceland, Liechtenstein, Norway and Switzerland) and Japan must immediately stop pressuring low- and middle-income countries to adopt or implement TRIPS-plus measures in trade agreements that impede access to life-saving treatment.
- All countries must immediately adopt and observe a global moratorium on the inclusion of any intellectual property provisions in any international treaty that would limit the ability of countries to retain policy options to reduce the cost of HIV-related treatment.
- High-income countries must stop seeking to impose more stringent TRIPS-plus intellectual property obligations on developing country governments. High-income countries must also desist from retaliating against countries that resist adopting such TRIPS-plus measures so that they may achieve better access to treatment.
- Individual countries may find it difficult to act in the face of political pressure; they

should, to the extent possible, incorporate and use TRIPs flexibilities, consistent with safeguards in their own national laws.

- Low- and middle-income countries must not be subject to political and legal pressure aimed at preventing them from using TRIPs flexibilities to ensure that infants, children and adolescents living with HIV have equal access to HIV diagnosis and age-appropriate treatment as adults.
- WTO members must indefinitely extend the exemption for IDCs from the application of TRIPs provisions in the case of pharmaceutical products. The UN and its member states must mobilize adequate resources to support IDCs to retain this policy latitude.
- TRIPs has failed to encourage and reward the kind of innovation that makes more effective pharmaceutical products available to the poor, including for neglected diseases. Countries must therefore develop, agree and invest in new systems that genuinely serve this purpose, prioritizing the most promising approaches including a new pharmaceutical R&D treaty and the promotion of open source discovery.

To read the full report: <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>

What works in advocacy on trade and access to treatment?

Many lessons have been learned - including by ITPC's partners - about 'what works' in advocacy on trade and access to HIV treatment. The following presents examples that apply to different contexts:

EXAMPLE 1:

OPPOSING A FREE TRADE AGREEMENT BETWEEN THE U.S. AND SOUTHERN AFRICA

In early 2000, the U.S. engaged in parallel free trade negotiations with various developing countries and regional trading blocs. Among these were South Africa and its Southern African Customs Union (SACU) partners, commonly referred to as the BNLS countries (Botswana, Namibia, Lesotho and Swaziland). Shortly after the negotiations started, civil society groups began organizing against the potential free trade agreement. For people opposing the FTA, the main concern was that certain elements proposed by the U.S. for inclusion would be detrimental to the developmental aspirations of the SACU countries, while also putting public health, food security and service delivery in the region at risk.

For example, the U.S. sought extensive intellectual property rights in the agreement, which would have constrained the region's ability to provide medical care to its people. Eventually, the negotiators failed to reach a consensus on many of the contested issues, and the talks collapsed. In the end, civil society groups and activists were successful in averting an FTA that could have had disastrous consequences for the Southern African region.

EXAMPLE 2:

SUPPORTING THE GOVERNMENT OF THAILAND TO ISSUE COMPULSORY LICENSES

In 2004, 500,000 people were reported to be living with HIV in Thailand, and some were beginning to develop resistance to the available first-line treatment regimens. Second-line treatment at the time was unaffordable at \$2,200 per person. The Thai government estimated that if it distributed second-line ARV therapy to people who could not afford it 8,000 lives per year would be saved. As a result, between October and January 2007, the Thai government used lawful flexibility under the TRIPs Agreement to issue compulsory licenses for four drugs, including Abbott's ARV Kaletra. There was a backlash towards the Thai government from Abbott, other pharmaceutical companies and the U.S. government, but even Abbott's investors denounced the backlash as unethical. For more information, please see: www.uaem.org/cms/assests/uploads/2013/03/uaemconference2008-compulsory-licensing

EXAMPLE 3:**ITPC SOUTH ASIA RALLIES AGAINST A POTENTIALLY HARMFUL FREE TRADE AGREEMENT BETWEEN INDIA AND THE EUROPEAN UNION**

In 2007, the European Union began secret talks with India on a potential FTA. When the Delhi Network of People Living with HIV (DNP+), ITPC South Asia and others learned of the talks, they began asking questions on the terms of the FTA and were rebuffed. As a result, they began forming a coalition of diverse civil society groups that would be affected by the FTA – including groups focused on health, agriculture, environment and trade unions – and began organizing public protests. As a result of their first protest in March 2009, they were granted a meeting with Indian government negotiators. As talks continued, the coalition has kept up public pressure through additional protests (some of which resulted in police abuse and detention), media actions and letters to public officials. Activists also publicly presented Carla Bruni, the wife of the then French President Nicolas Sarkozy and an ambassador for the Global Fund to Fight AIDS, TB & Malaria with 5 ml of blood to symbolize the deaths that would occur under an FTA that protects IP over people's health. The protests spread outside India to other parts of Asia, Africa and Latin America – regions that would be affected if India was no longer able to produce generic drugs and export them. Increasingly, the Indian government began making public statements indicating that it would not trade away IP rights.

EXAMPLE 4 :**OPPOSING A QUESTIONABLE PATENT IN BRAZIL**

In Brazil, the drug tenofovir disoproxil fumarate (TDF) is widely used as part of first and second-line HIV treatment regimens. However, this was not always the case. In 1998, the pharmaceutical company Gilead filed a patent application for TDF in Brazil, and while the patent was under examination by the Brazilian Patent Office, the lack of competition in Brazil allowed Gilead in 2003 to charge US\$3,300 per person per year (ppy). In 2006, a coalition of non-governmental organizations (NGOs) known as the *Working Group on Intellectual Property from the Brazilian Network for the Integration of Peoples (GTPI/REBRIP)* utilized a pre-grant opposition to prevent the patent from being granted and encourage competition to reduce the drug's price. In August 2008, the patent office in Brazil rejected the patent application on TDF on the grounds that it lacked inventiveness. The Brazilian government has since announced the start of local production of TDF through a partnership between public and private manufacturers in Brazil. Gilead is still appealing its patent application [number PI9811045], in the Brazilian courts. To read more, please access the full case study at: http://patentoppositions.org/case_studies/4f106d0504a7f92f5b000003

'What works' in advocacy on trade and access to HIV treatment

- **FOCUSING ON WHAT YOU CAN HELP CHANGE.** Depending on your skills, focus your advocacy on areas where you have the ability to affect change. For example, if you identify that in your country, some aspects of trade and treatment are difficult and take a long time to change (such as patent law), you may decide to focus instead on advocating for a compulsory license.
- **KNOWING WHO TO TARGET.** Identify who makes and influences decisions on trade in your country and target them with your advocacy. These may be stakeholders – such as the Ministry of Trade – that are not your usual targets for HIV advocacy.
- **SHOWING THE 'HUMAN FACE'.** For example, developing case studies that tell the story of real people living with HIV and how trade-related issues have affected their access to treatment.
- **FORMING ADVOCACY COALITIONS.** For example, joining forces with other organizations – such as ones focused on different aspects of health and development – to do joint campaigning on harmful aspects of trade, such as the impact TRIPS-Plus would have on people's health.
- **ACCESSING EXPERTISE.** You don't have to go it alone! There are many people and organizations working on these issues who can assist you. For example, you could call on free legal expertise to confirm that your advocacy 'asks' about patents and HIV treatment are accurate and possible within your country's legal and policy system.

5

FINANCING AND TREATMENT

INTRODUCTION

THE SCIENCE
OF HIV

1

TREATMENT
INITIATIVES

2

HUMAN RIGHTS
AND TREATMENT

3

TRADE AND
TREATMENT

4

**FINANCING AND
TREATMENT**

5

COMMUNITY
ADVOCACY
PLANNING

6

ACT
CASE
STUDIES

Welcome to **Part 5: Financing and Treatment** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

Part 5 focuses on funding and how it affects access to HIV treatment.

SECTION 5.1 How does funding relate to access to treatment?

SECTION OBJECTIVE

To build community activists' understanding of how funding relates to access to treatment for people living with HIV.

TRAINING MATERIALS

- PowerPoint presentation '5.1. How does funding relate to access to treatment?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion on:
 - Why does it 'make sense' to fund HIV treatment?
 - Who could and should fund HIV treatment in our country?
3. Present PowerPoint presentation '5.1 How does funding relate to access to treatment?' Ask the participants if they have any questions or comments.
4. Ask the participants to summarize the session by developing advocacy messages about 'How does funding relate to access to treatment?' Support their ideas by sharing examples of messages (see below).

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Divide the participants into small groups. Ask each group to discuss why it 'makes sense' to fund HIV treatment. Ask them to develop 2-3 advocacy messages that they could use to convince advocacy targets, such as the Ministry of Finance or an international donor.
3. Bring the participants back together. Ask each group to share one of their advocacy messages. Encourage the other participants to provide feedback.
4. Present PowerPoint presentation '5.1 How does funding relate to access to treatment?' Ask the participants if they have any questions or comments.
5. Facilitate a discussion on:
 - What are the sources of funding for HIV treatment in our country?
 - What is the current status of each of those sources? (For example: How much support do they currently provide? Is their funding increasing or decreasing? Are there specific challenges?)
6. Ask the participants to summarize the session by developing advocacy messages about 'How does funding relate to access to treatment?' Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. Funding HIV treatment is a cost-effective way to prevent illness, death and further infections. Increasing investment now will save money in the future.

2. US \$22 billion is needed per year for governments to achieve their commitment to providing universal access to HIV prevention, treatment, care and support.
3. All stakeholders – including national governments, international donors and community members – have a vital role in providing and/or advocating for increased funding for HIV treatment.

USEFUL RESOURCES

- *Financing the Response to AIDS in Low and Middle-Income Countries: International Assistance from Donor Governments in 2012*, UNAIDS and Kaiser Family Foundation, September 2013. <http://kff.org/global-health-policy/report/financing-the-response-to-aids-in-low/>
- *Closing the Resource Gap*, UNAIDS. <http://www.unaids.org/en/targetsandcommitments/closingresourcegap/>
- *Sustaining the Global HIV Response: Innovative Financing Options*, amfAR, March 2014. <http://www.amfar.org/innovative-financing-options/>

Why does funding matter for action on HIV treatment?

Worldwide, about 35 million people are living with HIV.¹ According to the 2013 ART Guidelines (see Section 2.1), 29 million of those people should be provided with antiretroviral therapy (ART).

In practice, however, only about 10 million people have started HIV treatment. Also, only about a quarter of those benefit from treatment to the point of having a suppressed viral load (as explained in Section ##).

There is a gap. An additional 19 million people living with HIV in low and middle-income countries could benefit from ART.

Funding is vital for closing that gap.

Why does it make sense to fund HIV treatment?

There are many reasons why it makes good sense to fund HIV treatment. These include that:

1. HIV TREATMENT IS AN EFFECTIVE WAY TO PREVENT ILLNESS, DEATH AND FURTHER INFECTIONS

For most people, HIV treatment is relatively simple, effective and safe. For people living with HIV who are taking treatment and achieving viral suppression, their expected life span is now near normal.²

By reducing the virus that is circulating within a setting or a population, scaled-up ART helps to reduce the number of new HIV infections. During 1995 – 2012, ART averted 6.6 million AIDS-related deaths throughout the world, including 5.5 million deaths in low and middle-income countries.

Scaling-up HIV treatment to the 29 million people who need it is a fundamental part of a strategy to end the HIV pandemic.

2. EXPANDING HIV TREATMENT IS A COST-EFFECTIVE STRATEGY AGAINST POVERTY

In today's global economy, wealth and development depends on more than natural resources (such as oil or land) and infrastructure (such as roads or buildings). Economic development depends on people and, specifically, on healthy, skilled and productive people. Studies in countries as diverse as Mexico and Singapore have shown a link between improved health and economic growth.

1 World Health Organisation. http://www.who.int/gho/hiv/epidemic_status/cases_all/en/

2 Hogg RS, Althoff KN, Samji H, et al. *Increases in Life Expectancy among Treated HIV-Positive Individuals in the United States and Canada, 2000-2007*. Poster, IAS 2013.

What level of funding is needed?

The Joint United Nations Program on AIDS (UNAIDS) estimates that the cost of achieving universal access to HIV prevention, treatment, care and support will be approximately US \$22 billion per year through 2015.^{3,4}

UNAIDS estimates that, in 2012, global HIV funding available from all sources — domestic public and private spending, donor governments' bilateral assistance, multilateral organizations and private philanthropic groups — totaled US \$18.9 billion. Of this, \$9.9 billion was spent on treatment and care. Therefore, the total resources available in 2012 were well below what is needed to achieve universal access.

The cost of antiretroviral (ARV) drugs has been reduced drastically over the past 8 years. First-line regimens now cost an average of approximately \$100 per patient per year in developing countries. Even costs for second-line regimens are being reduced — with some costing as little as \$300 a year. However, overall, second-line regimens remain too expensive for many countries.

To achieve universal access, funding also needs to be used effectively and efficiently. Every year, more and more people are being reached with each amount of funding that is raised for HIV treatment. This is because programs are scaling-up and gaining experience. After the initial cost of establishing HIV treatment programs, governments and community organizations are able to enroll and support additional people with increasing efficiency and effectiveness.

Who pays for the response to HIV?

Many different entities provide funding for HIV care, treatment, prevention and support.

Of the estimated \$18.9 billion spent in 2012, \$10 billion (53% of the total spent in low and middle-income countries) came from domestic in-country resources (i.e., spending by individuals, communities and their governments). This mirrors the overall pattern of funding for all health programs. For example, in sub-Saharan Africa, more than two-thirds of general health spending comes from domestic sources.⁵

Additional HIV funding comes from donor governments, which in 2012 contributed \$7.8 billion. Private foundations contributed approximately \$640 million.

Overall, funding for HIV has been relatively flat for the past three years.

In reality, people living with HIV carry the biggest financial burden of all.

In Africa and elsewhere, people living with HIV and their families and communities spend a large amount on healthcare — spending from their income, savings or borrowed funds. Researchers suggest that this spending accounts for 15–45% of total national spending on HIV-related treatment and care. This means that people living with HIV — and their families and communities — are likely to be the single largest 'funder' of HIV-related health care in many countries.

Payments for HIV-related treatment and healthcare can be a leading cause of financial catastrophe and impoverishment for people living with HIV. It can force people to choose between borrowing money to stay healthy or waiting, eventually getting sick and needing more intensive healthcare.

To ease the burden on individuals and communities, governments have a responsibility to provide accessible and affordable healthcare. Because HIV treatment can prevent serious illness and reduce the risk of HIV transmission, there are also important public health, ethical and financial reasons for governments to ensure easy access to HIV treatment.

3 Vassall A et al. Financing Essential HIV Services: A New Economic Agenda. *PLoS Med* 10(12). 2013.

4 Schwartländer B, Stover J, Hallett T, Atun R, Avila C, et al. (2011) Towards an Improved Investment Approach for an Effective Response to HIV/AIDS. *Lancet* 377: 2031–2041.

5 UNAIDS. *Together We Will End AIDS*. Geneva. 2012.

Private health insurance is another way to ease the burden of healthcare costs for individuals and households. Health insurance is a mechanism that collects and pools funding and then finances health services. As such, national schemes have a potential to generate resources for HIV services, redistribute resources from rich to poor and help people avoid catastrophic spending. Private and pre-paid health insurance is widely used in Europe, North America, Latin America and in countries such as Namibia, South Africa and Thailand. However, it is only now expanding to many countries in Africa and Asia.^{6,7} In African countries – such as Rwanda - where national health insurance schemes are being introduced, these efforts are associated with considerable improvements in the use of health care services.⁸

SECTION 5.2

What needs to happen to increase funding for treatment?

SECTION OBJECTIVE

To build community activists' understanding about what needs to happen and by which stakeholders to increase funding for HIV treatment.

TRAINING MATERIALS

- PowerPoint presentation '5.2 What needs to happen to increase funding for treatment?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion on:
 - What needs to happen to increase funding for HIV treatment? For example, what kind of steps need to be taken by:
 - Local and national governments?
 - International donors?
 - Private sector donors?
3. Present the PowerPoint presentation '5.2 What needs to happen to increase funding for treatment?' Encourage the participants to ask questions and make comments.
4. Ask the participants to summarize the session by developing advocacy messages about 'What needs to happen to increase funding for treatment?' Support their ideas by sharing examples of messages (see below).

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion about:

6 amfAR. *Sustaining the Global HIV Response: Innovative Financing Options*. March 2014.

7 Vassall A et al. *Financing Essential HIV Services: A New Economic Agenda*. *PLoS Med* 10(12). 2013.

8 Spaan E, Mathijssen J, Tromp N, McBain F, ten Have A, Baltussen R. *The Impact of Health Insurance in Asia and Africa: A Systematic Review*. *Bull World Health Organ*.2012;90:685-692.

- What needs to be done to increase funding for treatment? For example, what kind of steps need to be taken by:
 - Local and national governments?
 - International donors?
 - Private sector donors?
- 3. Present PowerPoint Presentation ‘5.2 What needs to happen to increase funding for treatment?’ to add to the points raised by the participants in the discussion.
- 4. Divide the participants into four groups. Ask each group to focus on a different type of funder for HIV treatment:
 - **Group 1:** Local government
 - **Group 2:** National government
 - **Group 3:** International donors
 - **Group 4:** Private sector

Ask each group to:

 - Discuss the current opportunities and challenges for mobilizing funding for HIV treatment from their funder.
 - Identify actions that community activists could take to advocate for greater funding for HIV treatment from their donor.
- 5. Bring all of the participants back together. Ask each group to present its work. Encourage the other participants to ask questions and make comments.
- 6. Ask the participants to summarize the session by developing advocacy messages about ‘What needs to happen to increase funding for treatment?’ Support their ideas by sharing examples of messages (see below).

ADVOCACY MESSAGES

1. The current level of funding for HIV treatment is too low. It is not enough to achieve universal access to HIV prevention, care, support and treatment and bring an end to AIDS.
2. Funding for HIV treatment must be increased at all levels:
 - National and local governments must step-up their funding
 - All wealthy country governments must contribute their fair share
 - The private sector must continue its crucial role

USEFUL RESOURCES

- *Financing the Response to AIDS in Low and Middle-Income Countries: International Assistance from Donor Governments in 2012*, UNAIDS and Kaiser Family Foundation, September 2013. <http://kff.org/global-health-policy/report/financing-the-response-to-aids-in-low/>

What needs to happen to increase funding for HIV treatment?

To increase funding for HIV treatment, action is needed at three levels:

1. National and local governments must step-up their funding
2. All wealthy country governments must contribute their fair share of HIV funding
3. The private sector must continue a crucial role in HIV funding

Each of these are described below:

1. NATIONAL AND LOCAL GOVERNMENTS MUST STEP-UP THEIR HIV FUNDING

A total of 135 countries include the right to health – or a commitment to health – in their national constitution. Of those, 95 state that people have the right to access health facilities, goods and services and 111 mandate the right to equal treatment or freedom from discrimination.⁹

Those national governments have a constitutional and legal obligation to fulfill the right to health and to protect their populations from illness.

The International Monetary Fund (IMF) has set a benchmark level of 15% of Gross Development Product (GDP) for low-income countries to invest in health. To date, however, progress has been limited. For example, in Africa, only 9 countries have met this target (Lesotho, Liberia, Madagascar, Malawi, Rwanda, Swaziland, Togo, and Zambia). Several countries with large HIV epidemics - including Botswana, Kenya, South Africa, Namibia, and Zimbabwe - have not met the target.¹⁰

International donors are increasingly looking to national governments to match investments in health programs. For example, for HIV spending:

- The President's Emergency Plan for AIDS Relief (PEPFAR) now requires cost-sharing assurances of 25% from governments.
- The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) now requires governments to provide 5-60% counterpart financing, depending on the country's income.

Studies on governments spending in some African countries - such as Kenya, Rwanda and Zambia - show that government spending for HIV still accounts for less than 25% of the total and needs to be increased.¹¹

2. ALL WEALTHY COUNTRY GOVERNMENTS MUST CONTRIBUTE THEIR FAIR SHARE OF HIV FUNDING

International resources for HIV – spending by donor governments, multilateral organizations and the private sector – totaled an estimated US\$8.9 billion in 2012. This was 47% of total spending on HIV programs.

More than 20 high-income countries have the potential to contribute to the global response to HIV. These include the United States (US) and Canada, the countries of Western Europe, Japan, Australia and New Zealand. They also include wealthy or emerging economies such as Brazil, China, India, Mexico, Russia, South Korea and Saudi Arabia.

However, in the last few years, only five countries accounted for most (approximately 80%) of the total donor support for HIV. In 2012, the USA was the largest donor – providing US\$5 billion, which accounted for nearly two-thirds of all donor government assistance for HIV. The United Kingdom (UK) was the second largest donor (10.2%), followed by France (4.8%), Germany (3.7%), and Japan (2.7%).¹²

9 Pehudoff, S. K., R. O. Laing, and H. V. Hogerzeil. 2010. Access to Essential Medicines in National Constitutions. *Bulletin of the World Health Organization* 88(11):800.

10 Vassall A et al. *Financing Essential HIV Services: A New Economic Agenda. PLoS Med* 10(12). 2013.

11 Muchiri S et al. HIV/AIDS Expenditures in Sub-Saharan Africa: Observations from Kenya, Rwanda and Zambia. July 2013.

12 UNAIDS and Kaiser Family Foundation. Financing the Response to AIDS in Low- and Middle-Income Countries: International Assistance from Donor Governments in 2012. September 2013. At <http://kff.org/global-health-policy/report/financing-the-response-to-aids-in-low/>

Most international assistance for HIV - nearly \$6 billion (or 76%) - is provided bilaterally. This means that it comes from high-income countries to low- and middle-income countries in the form of international development aid. The USA and UK are the largest funders of direct bilateral aid.

The remaining international government assistance for HIV is provided through the multilateral mechanisms of the Global Fund and UNITAID. In 2012, the Global Fund received \$1.7 billion in contributions from governments and UNITAID received \$135 million. Four donor governments provided a majority of their funding through the Global Fund and UNITAID: Canada (65%), the European Commission (70%), France (85%) and Japan (90%).¹³

As a result of a United Nations resolution in 1970, most of the wealthiest countries in the world have agreed to spend a target of 0.7% (\$7 for every \$1,000) of their Gross National Income (GNI) on international development aid. However, few countries have ever met this target, with the exception of Denmark, Luxembourg, the Netherlands, Norway and Sweden.

For international assistance for HIV programs, only seven countries spend more than 20 cents for every \$1,000 of their GNI: Denmark, Ireland, the Netherlands, Norway, Sweden, the UK and the USA.¹⁴ The largest economies that are not meeting this threshold are Australia, Canada, France, Germany, Italy and Spain. High-income country governments have not significantly increased international funding for HIV since 2008.

Advocacy is needed in all high-income countries to convince politicians and voters that international aid is needed. It is important to emphasize that:

- International aid is a small expenditure compared to overall national budgets. Yet, a spending level for HIV of 20 cents for every \$1,000 of GNI would help ensure universal access to HIV treatment and help to end the global HIV epidemic.
- Among the many crises facing the planet - including political instability and environmental disasters - health and infectious diseases (such as HIV) remain a priority.
- Many countries - particularly in Latin America and the Caribbean, Eastern Europe and the Middle East, but also across Africa and Asia - have growing economies and are, therefore, rising into 'middle-income' status. However, due to inequality within those countries, millions of people still live in extreme poverty and desperately need international assistance.

Advocacy is also needed to create new dedicated tax revenues and private investment opportunities for international health, particularly to benefit the Global Fund, UNITAID and the Global Alliance for Vaccines and Immunizations (GAVI). GAVI already raises \$3.7 billion each year from a financing program at the World Bank called the International Finance Facility for Immunization (IFFIm). UNITAID raises \$580 million from an airline ticket tax. Since 2010, HIV advocates have been working in collaboration with many others to get the US and the European Union to adopt a Financial Transaction Tax (FTT or 'Robin Hood Tax') to raise as much as \$400 billion per year for international aid.

3. THE PRIVATE SECTOR MUST CONTINUE A CRUCIAL ROLE IN HIV FUNDING

International funding from the private sector in high-income countries is another important source of support for HIV programs. In 2012, individuals and corporations contributed a total of \$509 million to international HIV programs, largely through foundations, faith-based organizations and international NGOs.

The US is the country with the largest number of private sector grant-makers and the largest total amount

13 UNAIDS and Kaiser Family Foundation. Financing the Response to AIDS in Low- and Middle-Income Countries: International Assistance from Donor Governments in 2012. September 2013. At <http://kff.org/global-health-policy/report/financing-the-response-to-aids-in-low/>

14 UNAIDS and Kaiser Family Foundation. Financing the Response to AIDS in Low- and Middle-Income Countries: International Assistance from Donor Governments in 2012. September 2013. At <http://kff.org/global-health-policy/report/financing-the-response-to-aids-in-low/>

of investment. In 2012, 209 funders gave \$467 million to HIV programs. Of this amount, \$150 million was directed internationally to HIV programs not in the US.

In 2012, the Bill and Melinda Gates Foundation was the largest US-based funder of international HIV programs, investing \$47 million. After that, the M•A•C AIDS Fund, Ford Foundation, Open Society Foundation (OSF), ITPC and the American Jewish World Service (AJWS) were the five largest non-pharmaceutical grant-maker, investing \$31 million. Meanwhile, AbbVie, ViiV, Johnson & Johnson, Merck and Bristol-Myers Squibb were the five largest pharmaceutical grant-makers, investing \$39 million.

Also in 2012, in Europe, a total of 38 private sector grant-makers invested approximately \$100 million in international HIV programs and HIV programs outside of Western and Central Europe. The largest European grant-makers were AIDS Fonds Netherlands, Children's Investment Fund Foundation (CIFF), Elton John AIDS Foundation (EJAF), Foundation la Caixa, Monument Trust, Sidaction, ViiV and Wellcome Trust.

Section 5.3

What are the entry points for advocacy on funding and treatment?

SECTION OBJECTIVE

To build community activists' understanding of the entry points and 'what works' for advocacy on funding and treatment.

TRAINING MATERIALS

- PowerPoint presentation '5.3 What are the entry points for advocacy on funding and treatment?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Ask the participants to think about the funding and treatment issues that have been addressed in Section 5.1-5.2. Ask them to identify some examples of entry points for advocacy. Explain that an entry point is an opportunity to 'get started.' It might, for example, be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).
3. Present PowerPoint presentation '5.3 What are the entry points for advocacy on funding and treatment?'
4. Ask the participants to share other lessons learned about advocacy on funding and treatment – based on their own experiences.
5. Summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Explain to the participants what is meant by an entry point for advocacy on funding and treatment – in terms of an opportunity to 'get started.' For example, an entry point might be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change).

3. Divide the participants into groups of about 5 people. Ask the participants to identify 1-2 entry points for advocacy on funding and treatment that relate to their community.
4. Bring all of the participants back together. Ask each group to present their examples of entry points. Encourage the other participants to ask questions and make comments.
5. Ask the participants to think about what type of advocacy they could carry out for the entry points that they have identified. Facilitate a discussion on:
 - What do we know about ‘what works’ in advocacy on funding and treatment?
6. Encourage the participants to identify the lessons learned from their own experiences. Write their inputs on a flipchart.
7. Summarize what has been discussed and agreed during the session.

What are entry points for advocacy on funding and treatment?

For community activists, there are many different entry points that can be used for advocacy on funding and treatment. An entry point is an opportunity to ‘get involved’, ‘get going’ and ‘make a difference.’ It is an opportunity to start discussions, influence opinions and achieve change.

An entry point might, for example, be a process (that provides an opportunity to influence decision-making) or a crisis (that provides an opportunity to achieve urgent change). Examples of entry points can be seen in the experiences of ITPC partners and other organizations throughout the world:

EXAMPLES OF ENTRY POINTS FOR ADVOCACY ON FUNDING AND TREATMENT

EXAMPLES OF ENTRY POINTS	EXAMPLES OF ADVOCACY ACTIONS
The national government has not met the Abuja Declaration target of allocating 15% of its national budget to health.	<ul style="list-style-type: none"> ● Documenting the experiences of similar countries that have met the 15% target and using them as the basis for advocacy materials. ● Disseminating case studies that show what difference meeting the 15% target could make to treatment for people living with HIV. ● Collaborating with other health organizations to present a petition to the government, urging it to meet its 15% target.
The District Health Authority has merged its HIV budget and health budget – making it impossible to assess what funding is allocated to treatment.	<ul style="list-style-type: none"> ● Facilitating a meeting between the District Health Authority and people living with HIV – to explain why transparent budgeting is important. ● Advocating to the Director of the District Health Authority to provide an annual breakdown of how the health budget is allocated, including to HIV.
The national government refuses to go beyond the minimum amount of domestic funding required to receive an HIV grant from the Global Fund.	<ul style="list-style-type: none"> ● Presenting the government with examples of other countries (with similar economies) that have increased their national contributions to Global Fund programs. ● Facilitating meetings between the Country Coordinating Mechanism and people living with HIV to identify how and when to encourage the government to increase its domestic funding. ● Sharing examples of innovative financing – to encourage the government to identify creative ways in which it could raise further funds for HIV programs.

<p>An international donor is going to stop direct funding for HIV work in your country as it is classified as a “middle-income country”.</p>	<ul style="list-style-type: none"> ● Advocating to the donor about why funding for HIV is still needed in a middle-income country, such as for treatment for people living with HIV who are from marginalized groups and would, otherwise, be neglected. ● Advocating to the donor to maintain or increase its support to multilateral funding mechanisms (such as the Global Fund).
<p>The District Health Authority provides ARVs for free, but does not pay for other services related to treatment, such as CD4 counts.</p>	<ul style="list-style-type: none"> ● Compiling a breakdown of the average annual costs for a community member living with HIV – to show the level of ‘extra’ costs involved. ● Holding meetings with the District Health Authority to advocate for full funding of all treatment-related services and commodities. ● Partnering with national networks of people living with HIV to advocate for ‘treatment funding’ to always include the full package of services and commodities that are needed.

What works in advocacy on funding and treatment?

Many lessons have been learned - including by ITPC’s partners - about ‘what works’ in advocacy on funding and treatment. The following presents examples that apply to different contexts:

‘What works’ in advocacy on funding and treatment

- **DOING YOUR HOMEWORK.** For example, researching - and being able to speak confidently about - how funding for treatment has changed and/or reduced in recent years in comparison to the needs of people living with HIV.
- **SHOWING THE ‘HUMAN FACE’.** For example, translating what reduced funding for treatment means to the health and quality of life of real people living with HIV.
- **PROVIDING FINANCIAL EVIDENCE.** For example, gathering data from community groups about why their areas of work – such as treatment programs for key populations – are cost-efficient and a good investment of resources.
- **EMPHASIZING DOMESTIC AS WELL AS INTERNATIONAL FUNDING.** For example, advocating to local or national governments to fund treatment as well as advocating to international donors to maintain or increase their investments.
- **‘TALKING THE TALK’ OF FUNDING.** For example, talking about the funding of treatment in terms of ‘investment’ and ‘value for money’ – as emphasized in key approaches to HIV supported by donors, such as the Investment Framework (see Section 5.1).
- **ENCOURAGING FLEXIBLE AND INNOVATIVE FUNDING.** For example, not always ‘demanding more money,’ but advocating for how funding for treatment could come from a wider range of sources or how it could be used more efficiently.
- **PARTNERING WITH FUNDING ALLIES.** For example, identifying the stakeholders that make decisions about funding for treatment and identifying partners that can help you to get their attention and influence their thinking.
- **BUILDING SKILLS AND INVOLVEMENT IN BUDGET TRACKING.** For example, becoming familiar with how processes for national budgeting on health work and identifying when and how the process can be influenced.

6 COMMUNITY ADVOCACY PLANNING

INTRODUCTION

THE SCIENCE OF HIV 1

TREATMENT INITIATIVES 2

HUMAN RIGHTS AND TREATMENT 3

TRADE AND TREATMENT 4

FINANCING AND TREATMENT 5

COMMUNITY ADVOCACY PLANNING 6

ACT CASE STUDIES

Welcome to **Part 6: Community Advocacy Planning** of the Advocacy for Community Treatment (ACT) Toolkit of the International Treatment Preparedness Coalition (ITPC).

The aim of **Part 6** is to support community activists to build on the previous Parts of the ACT Toolkit – by ‘translating’ the HIV treatment world to their specific context, identifying their priorities and developing a community advocacy plan.

Section 6.1 What is advocacy for community treatment?

SECTION OBJECTIVE

To build community activists' understanding of what is meant by advocacy for community treatment and how it benefits people living with HIV, including those from key populations.

TRAINING MATERIALS

- PowerPoint presentation '6.1 What is advocacy for community treatment?'
- Flipcharts and pens

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a brief group discussion on:
 - What does 'advocacy for community treatment' mean?
3. Present PowerPoint presentation '6.1 What is advocacy for community treatment?' As you get to each question, ask the participants if anything is unclear or if they have anything to add.
4. Facilitate a group discussion about the participant's own experiences of doing community advocacy for treatment or similar issues. Ask them to share examples of their work and to identify the factors that did - or did not - make them successful. Write the 'success factors' on a flipchart.
5. Ask the participants to summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Facilitate a group discussion on:
 - What does 'advocacy for community treatment' mean?
3. Put sheets of flipchart paper on the wall in three different places in the room. Write one question on top of each sheet:
 - What type of *activities* does advocacy for community treatment involve?
 - What type of *stakeholders* does advocacy for community treatment target?
 - What type of *benefits* does advocacy for community treatment bring?
4. Give the participants marker pens. Ask them to move around the three places in the room and to write their ideas underneath each question.
5. Bring all of the participants back together. Go through the answers that they have written to the three questions.
6. Divide the participants into small groups of about 5 people. Ask the members of each group to share their real life examples of successful community advocacy on treatment or similar issues. Ask them to think about what factors contributed to the success of the work.
7. Bring all of the participants back together. Ask them to briefly summarize what they discussed in their groups and to share the factors that contributed to the success of their community advocacy work.

8. Write the 'success factors' on a flipchart – to provide a checklist that the participants can use to support their work.
9. Summarize what has been discussed and agreed during the session.

USEFUL RESOURCES

- *Advocacy in Action*, International HIV/AIDS Alliance, 2003. <http://www.aidsalliance.org/publicationsdetails.aspx?id=142>
- *Measuring Up - A Guide for Learners: HIV-Related Advocacy Evaluation Training for Civil Society Organisations*, International Council of AIDS Services Organisations and International HIV/AIDS Alliance, 2010. <http://www.icaso.org/publications/2011/Measuring-up-learners-30.09.10.pdf>
- *Speaking Out: Toolkit for MSM-Led HIV/AIDS Advocacy*, Global Forum on MSM and HIV, May 2011. http://www.msmsgf.org/files/msmgf/Advocacy/speakingout_global_web.pdf

What does 'advocacy for community treatment' mean?

Advocacy by communities has been key to action on HIV throughout the world. In particular, advocacy by **people living with HIV** – including those from key populations - has brought dramatic changes and improvements in antiretroviral therapy (ART).

There is no one agreed definition of **community advocacy**. However, in general, it involves:

- Community members coming together and taking action.
- Identifying priority issues that affect access to treatment for people living with HIV.
- Identifying what change is needed for those issues, such as in policies, laws and services.
- Partnering with other individuals and groups that have similar concerns.
- Targeting individuals, groups and institutions that can influence change.
- Achieving results that make a difference to the people most affected by the issues.

Community advocacy is about caring for an issue deeply enough to stand up and say that something needs to change. In practice, almost all community activists do some type of advocacy work - even if they don't use the word 'advocacy'!

What type of activities does advocacy for community treatment involve?

Community advocacy can take many forms – for example, depending on the needs of the community and the political and financial context. It can involve a wide range of different types of activities. Examples include:

- **PARTICIPATING IN DECISION-MAKING FORUMS.** Examples include Community Advisory Boards, District Planning Communities, Country Coordinating Mechanisms or National AIDS Councils.
- **LOBBYING.** Examples include holding meetings with parliamentarians or the District AIDS Director.
- **USING ADVOCACY MATERIALS.** Examples include developing a position paper on an issue and distributing it to selected decision-makers.
- **USING CAMPAIGNING METHODS.** Examples include handing petitions (signed by community members) to decision-makers or carrying out public rallies.
- **WORKING THROUGH THE MEDIA.** Examples include writing a press release, doing a media interview or writing a blog for social media.

What type of stakeholders does advocacy for community treatment target?

Advocacy for community treatment can involve action at many **different levels**, from community to district, national, regional and global.

It can also focus on a wide range of **different targets** – individuals or organizations that can make a difference to the issue and influence the change that is needed. Examples include:

- Community leaders and decision-makers
- Community health services
- Local government departments
- Religious institutions
- Members of Parliament
- National government Ministers, Ministries or Departments
- Law-making agencies, such as the judiciary
- Donor organisations
- Law-enforcement agencies, such as the police
- Businesses, including pharmaceutical companies
- International nongovernmental organisations (NGOs)
- Trade unions
- United Nations agencies

What type of benefits does advocacy for community treatment bring?

Advocacy for community treatment can bring important **changes**. Depending on the context – and on factors such as the time and resources available – the changes might be small or large. However, they all add up to benefits for those who need access to treatment – namely, people living with HIV, including those from key populations.

Some of the many **benefits** that advocacy for community treatment can bring include:

- Lowering the **cost** of antiretrovirals (ARVs) and medicines for opportunistic infections, such as by advocating for cheaper prices from pharmaceutical companies.
- Ensuring appropriate **funding** for ART, such as by advocating for adequate resources for HIV treatment in the District Health Strategy.
- Increasing the **quality** of ART, such as by advocating on the dangerous side effects of low quality drugs.
- Ensuring greater **availability** of ART, such as by advocating for treatment to be integrated with sexual and reproductive health services.
- Ensuring greater **access** to treatment for key populations, such as by advocating for the removal of policies that discriminate against them.
- Ensuring **non-stigmatizing** ART services, such as by advocating for training on human rights for local health workers.

What are the characteristics of successful advocacy for community treatment?

The experiences of ITPC and its partners around the world show that there are factors that contribute to successful advocacy for community treatment. Examples of these ‘success factors’ include advocacy work that is:

- **BASED ON EVIDENCE** – so that it responds to the real needs of community members, especially people living with HIV and key populations.
- **OWNED AND RUN BY COMMUNITY ACTIVISTS** – so that they feel committed to and in control of the work.
- **CARRIED OUT BY A GROUP OF ACTIVISTS** – so that the work is not over-dependent on one or two individuals.
- **WELL-PLANNED** – so that it is strategic and makes the best use of the resources available, especially where those resources are very limited.
- **FOCUSED** – so that it all adds up to concrete changes, even if they are small.
- **REALISTIC** – so that it focuses on changes that are actually possible within the local context and with the resources that are available.
- **CREATIVE** – so that it suits community advocacy and makes the best use of local ideas.

Section 6.2

What are your opportunities and barriers for advocacy for community treatment?

SECTION OBJECTIVE

To support community activists to ‘translate’ the treatment world to their specific context and to analyze their opportunities and barriers for advocacy for community treatment.

TRAINING MATERIALS

- PowerPoint presentation ‘6.2 What are your opportunities and barriers for advocacy for community treatment?’
- Flipchart and pens

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Present PowerPoint presentation ‘6.2 What are your opportunities and barriers for advocacy for community treatment?’ Stop the presentation on the last slide – showing the chart of opportunities and barriers.
3. Facilitate a discussion to fill in the chart - either by typing text into the PowerPoint slide or drawing the chart on flipcharts on the wall. Go through each of the four areas addressed in Parts 2-5 of the ACT Toolkit and ask the participants to identify the opportunities and barriers.
4. Summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Divide the participants into four groups. Give each group one of the areas addressed in the previous Parts of the ACT Toolkit:
 - Treatment initiatives
 - Human rights and treatment
 - Trade and treatment
 - Financing and treatment
3. Ask each group to recall the 'headlines' for their area (i.e. what key issues it addressed and why it matters for access to treatment).
4. Ask each group to draw the following chart on a flipchart:

Part	Opportunities	Barriers
-------------	----------------------	-----------------

5. Ask each group to write their Part in the first column.
6. Then ask each group to discuss the key 'opportunities' and 'barriers' that their area presents for access to HIV treatment in their community. Explain that:
 - An opportunity is a time or set of circumstances that makes it possible to achieve positive change. It is a 'chance,' 'entry point,' 'right time' or 'good moment.'
 - A barrier is something that makes it difficult or impossible to achieve positive change. It might also make the current situation worse. It is an 'obstacle,' 'obstruction,' 'bottleneck' or 'blockage.'
7. Ask each group to write their opportunities and barriers in the second and third columns of their chart.
8. Bring all of the groups back together. Ask each group to provide feedback on their work – first sharing the 'headlines' from their area, then their chart of opportunities and barriers.
9. Place the four charts together on the wall – as a giant chart of opportunities and barriers. Facilitate a discussion about the giant chart. For example, ask the participants:
 - What does it show us about the number of opportunities versus the number of barriers?
 - What does it tell us about which areas have the largest number and/or more significant opportunities or challenges?
10. Ask the participants to summarize what has been discussed and agreed during the session.

USEFUL RESOURCES

- *The Equity Deficit: Unequal and Unfair Access to HIV Treatment, Care and Support for Key Affected Communities*, Report by the NGO Delegation, 33rd Meeting of the UNAIDS Programme Coordinating Body, December 2013. http://www.unaids.org/en/media/unaids/contentassets/documents/pcb/2013/pcb33/agendaitems/20131206_PCB-NGO-report.pdf
- *It Takes a Village: Empowering Communities to Fight HIV*, USAID, July/August 2013. <http://www.usaid.gov/news-information/frontlines/economic-growth/it-takes-village-empowering-communities-fight-hiv>
- *Policy Brief: Access Challenges For HIV Treatment Among People Living with HIV and Key Populations in Middle-Income Countries*, Global Network of People Living with HIV, Global Network of Sex Work Project, International Network of People Who Use Drugs, Global Forum on MSM and HIV and ITPC, October 2013. http://www.msngf.org/files/msngf//Publications/Access_Challenges_for_HIV_treatment_KAPs.pdf

How do you ‘translate’ the treatment world to your own context?

Parts 2-5 of the ACT Toolkit focused on four of the key areas that make up today’s ‘treatment world’:

1. Treatment initiatives
2. Trade and treatment
3. Human rights and treatment
4. Financing and treatment

Each of these areas is complex. It involves many different issues, levels and stakeholders.

For advocacy for community treatment, it is important to understand what each of these areas - and the ‘treatment world’ as a whole - means for you and your community. For example: Are all of the areas important? Are any of the areas in crisis? Which of the areas are open to change? Which areas make the biggest difference to the lives of people living with HIV, including those from key populations?

What are the major opportunities and barriers for advocacy for community treatment in your context?

An **opportunity** is a time or set of circumstances that makes it possible to achieve positive change. It is a ‘chance’, ‘entry point’, ‘right time’ or ‘good moment’.

A **barrier** is something that makes it difficult or impossible to achieve positive change. It might also make the current situation worse. It is an ‘obstacle’, ‘obstruction’, ‘bottleneck’ or ‘blockage’.

In any context, communities – including people living with HIV and key populations – face different opportunities and barriers for access to HIV treatment. These might depend on factors such as: the stage of the HIV epidemic; the level of resources available; the human rights situation; and the political environment.

One way to start translating the ‘treatment world’ to your context is to identify your community’s major opportunities and barriers for access to treatment. This can be done by using a simple chart, such as:

OPPORTUNITIES AND CHALLENGES IN THE 'TREATMENT WORLD'

	OPPORTUNITIES	BARRIERS
Treatment initiatives		
Trade and treatment		
Human rights and treatment		
Funding and treatment		

Section 6.3

What are your priorities for advocacy for community treatment?

SECTION OBJECTIVE

To enable community activists to identify clear and strong priorities for their advocacy for community treatment.

TRAINING MATERIALS

- PowerPoint presentation '6.3 What are your priorities for advocacy for community treatment?'

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Present PowerPoint presentation '6.3 What are your priorities for advocacy for community treatment?' When you have finished, keep showing the final slide – that provides a checklist for identifying priorities. Ask the participants if they have anything to add to the checklist.
3. Ask the participants to consider everything that they discussed in Section 6.2 and to re-cap on the opportunities and barriers that they identified. Ask them to identify the 'top' opportunities or barriers that stand out for them – as the most important ones that make the biggest difference to access to treatment in their community.
4. Support the participants to use the checklist that was included in the presentation to consider the 'top' opportunities and barriers that they have identified and select a priority for their advocacy for community treatment.
5. Ask the participants to confirm their decision by clearly and simply stating:
 - Their priority issue for advocacy for community treatment
 - Their rationale (i.e. why it is the priority)
6. Ask the participants to summarize what has been covered and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion about:
 - Why is it important to identify priorities for advocacy for community treatment?
3. Divide the participants into small groups of about 5 people. Ask each small group to develop a checklist of criteria for identifying priorities for advocacy for community treatment. Explain that a checklist has criteria (key questions) to support the selection of the clearest and strongest priorities possible.
4. Bring all of the participants back together. Ask each small group to share its ideas for a checklist. Use the different ideas to develop a joint checklist. Write the checklist on a flipchart
5. Ask the participants to consider everything that they discussed in Section 6.2 and to re-cap on the opportunities and barriers that they identified. Ask them to develop a short-list of issues for advocacy – in terms of those that ‘stand out’ as the most important and likely to make the greatest difference in their community.
6. Ask the participants to use the joint checklist to analyze their shortlist and identify a priority for advocacy for community treatment.
7. Ask the participants to confirm their decision by clearly and simply stating:
 - Their priority issue for advocacy for community treatment
 - Their rationale (i.e. why it is the priority)
8. Ask the participants to summarize what has been covered and agreed during the session.

USEFUL RESOURCES

- *Advocacy in Action*, International HIV/AIDS Alliance, 2003. <http://www.aidsalliance.org/publicationsdetails.aspx?id=142>
- *Measuring Up - A Guide for Learners: HIV-related Advocacy Evaluation Training for Civil Society Organisations*, International Council of AIDS Services Organisations and International HIV/AIDS Alliance, 2010. <http://www.icaso.org/publications/2011/Measuring-up-learners-30.09.10.pdf>

Why do we need priorities for advocacy for community treatment?

Communities often face many different types and levels of opportunities and barriers in accessing treatment, especially for key populations. However, they can rarely address all of them at once. Instead, it is important to set priorities.

Having priorities enables community activists to work strategically and make the biggest difference. It also enables them to make the best use of their resources (including their energy, skills and funding).

How do you select priorities for advocacy for community treatment?

One way to set priorities is to develop a checklist. This has criteria (key questions) to support the selection of the clearest and strongest priorities possible. The following shares an example:

CHECKLIST FOR SELECTING ADVOCACY FOR COMMUNITY TREATMENT PRIORITIES

CRITERIA (KEY QUESTION)	✓	✗
Will the issue bring positive benefits to people living with HIV?		
Is the issue clear ? (For example, will we be able to easily explain it to people?)		
Can the issue be solved through advocacy ?		
Do we have ideas about who could bring change to the issue?		
Do we have ideas of what could be done to make a difference to the issue?		
Do we have the right resources (such as expertise) to advocate on the issue?		
Are we the right people to advocate on the issue? (For example, will our work be respected or should we, instead, support the advocacy of other stakeholders?)		

Section 6.4

How do you develop a plan for advocacy for community treatment?

SECTION OBJECTIVE

To build community activists' skills in developing a plan for advocacy for community treatment.

TRAINING MATERIALS

- PowerPoint presentation '6.4 How do you develop an advocacy for community treatment plan?'
- Handout of the advocacy cycle
- Handout of the advocacy planning chart
- Flipchart and pens

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Facilitate a brief group discussion on:
 - Why does planning for advocacy for community treatment matter?
3. Present PowerPoint presentation '6.4 How do you develop an advocacy for community treatment plan?' After you have completed it, return to the slide of the advocacy planning chart.
4. Remind the participants of the advocacy priority that they identified in Section 6.3.

5. Go through each part of the advocacy planning chart and ask the participants to complete it. Remind them of the need to ensure that everything in the chart:
 - Contributes towards their advocacy priority (and will make a difference for people living with HIV)
 - Is appropriate for advocacy work
 - Is feasible (for example, considering their resources)
6. Complete the advocacy planning chart – either by typing the information into the PowerPoint slide or drawing the chart on a flipchart.
7. When the advocacy planning chart is complete, ask the participants to review it. For example, ask them:
 - Is this plan something that we want to and will achieve?
 - Will this advocacy work bring an important change to people living with HIV in our community?
8. Ask the participants to summarize what has been covered and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Facilitate a group discussion about:
 - Why does planning for advocacy for community treatment matter?
3. Encourage the participants to briefly share their lessons learned about the importance of planning other types of action on HIV.
4. Divide the participants into small groups of about 5 people. Give each participant a handout of the advocacy cycle. Ask each group to look at the cycle and discuss what each step might involve.
5. Bring all of the groups back together. Go through the advocacy cycle, asking the participants to share what their groups discussed about each step.
6. Present PowerPoint presentation '6.4 How do you develop an advocacy for community treatment plan?' to support the information provided by the participants. Check if the participants have any further questions or issues to clarify about the advocacy cycle.
7. Divide the participants into the same small groups as before. Give each participant a handout of the advocacy planning chart. Ask each group to look at the chart and discuss what each part might involve.
8. Bring all of the participants back together.
9. Remind the participants of the advocacy priority that they identified in Section 6.3.
10. Go through each part of the advocacy planning chart and ask the participants to complete it. Remind them of the need to ensure that everything in the chart:
 - Contributes towards their advocacy priority (and will make a difference for people living with HIV)
 - Is appropriate for advocacy work
 - Is feasible (for example, considering their resources)
11. When the advocacy planning chart is complete, ask the participants to review it. For example, ask them:
 - Is this plan something that we want to and will achieve?
 - Will this advocacy work bring an important change to people living with HIV in our community?
12. Ask the participants to summarize what has been covered and agreed during the session.

USEFUL RESOURCES

- *Advocacy in Action*, International HIV/AIDS Alliance, 2003. <http://www.aidsalliance.org/publicationsdetails.aspx?id=142>
- *Measuring Up - A Guide for Learners: HIV-related Advocacy Evaluation Training for Civil Society Organisations*, International Council of AIDS Services Organisations and International HIV/AIDS Alliance, 2010. <http://www.icaso.org/publications/2011/Measuring-up-learners-30.09.10.pdf>

Why does planning for advocacy on community treatment matter?

As with all action on HIV, it is important to plan advocacy work. This is because, if your work is planned carefully, it is more likely to:

- Be carried out **efficiently** (for example, without wasting time and effort)
- Make the best use of your **resources** (such as your funding)
- Achieve its **goal** – because your activities, targets, etc., will be specifically selected to meet your objectives

What does an advocacy cycle look like?

There is no one agreed way to develop an advocacy plan. Where possible, activists should use planning frameworks that they already know, for example from doing program and project work.

One way to think about this type of work is as an advocacy cycle. As shown below, this takes you through five planning steps:



STEP 1: IDENTIFY THE OPPORTUNITIES AND CHALLENGES. This involves exploring questions such as: What are the specific opportunities and barriers? What are the causes? What are the effects? Identifying the opportunities and barriers for access to treatment was addressed in Section 6.2.

STEP 2: SELECT A PRIORITY. This involves exploring questions such as: Which opportunities and barriers matter most? Which are we best placed to advocate on? How can we bring the greatest benefit to people living with HIV? Priority setting was addressed in Section 6.3.

STEP 3: MAKE A PLAN. This involves setting out what we want to achieve and how we will do it. This can be done using an advocacy planning chart:

GOAL: THIS IS THE LONG-TERM RESULT THAT WE WANT TO ACHIEVE

For example: 'Sex workers living with HIV have full and equal access to ART at local government clinics'

OBJECTIVE	ACTIVITIES	WHEN	TARGETS	PARTNERS	RESOURCES
<p>This is a short-term target that contributes to achieving our goal. It reflects the end result of our activities.</p> <p>FOR EXAMPLE: <i>'Clinic managers understand and support the rights of sex workers living with HIV'</i></p>	<p>These are the advocacy actions that we will take to achieve your objective</p> <p>FOR EXAMPLE: <i>'Hold meeting with clinic managers to present case studies and advocate for the rights of sex workers living with HIV'</i></p>	<p>This is when we will take our advocacy actions</p> <p>FOR EXAMPLE: <i>'June'</i></p>	<p>These are the people, organizations or institutions that we will target to bring about the change that we want</p> <p>FOR EXAMPLE: <i>'Clinic managers'</i></p>	<p>These are our supporters who we will collaborate with to carry out our advocacy</p> <p>FOR EXAMPLE: <i>'Sex workers' support group'</i></p>	<p>These are the resources (such as people, money and skills) that we have or need to do our advocacy</p> <p>FOR EXAMPLE: <i>'2-3 case studies of sex workers being denied ART and the negative impact on their lives'</i></p>

STEP 4: TAKE ACTION. This involves putting our advocacy plan into action. As described in Section 6.4 it might involve strategies such as lobbying parliamentarians, holding demonstrations or working with the media.

STEP 5: EVALUATE YOUR WORK. This involves exploring questions such as: How effective has our advocacy been? What are the results? What did and did not work? Should anything have been done differently?

Section 6.5

How do you develop messages for advocacy for community treatment?

SECTION OBJECTIVE

To build community activists' skills in developing strong and clear messages to support their priorities for advocacy for community treatment.

TRAINING MATERIALS

- PowerPoint presentation '6.5 How do you develop messages for advocacy for community treatment?'
- Flipchart and pens

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Present PowerPoint presentation '6.5. How do you develop messages for advocacy for community treatment?' When you have finished, keep showing the last slide – that lists the characteristics of a good advocacy message.
3. Remind the participants of the advocacy priority that they identified (see Section 6.3) and the advocacy plan that they developed, including their targets (see Section 6.4).
4. Support the participants to use the characteristics of a good advocacy message to develop messages to support their advocacy priorities.
5. Write the advocacy messages on a flipchart. Give the participants feedback on ways that they could strengthen their messages.
6. Summarize what has been discussed and agreed during the session.

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Facilitate a discussion on:
 - What is an advocacy message and how can it be used?
3. Ask the participants to suggest the characteristics of a good advocacy message. Write their ideas on a flipchart.
4. Remind the participants of the advocacy priorities that they have identified (see Section 6.3) and the advocacy plan that they have developed, especially their targets (see Section 6.4).
5. Divide the participants into small groups of about 5 people. Ask each group to use the characteristics that they identified to develop a message for their advocacy priority.
6. Bring all of the participants back together. Ask each group to present their advocacy message. Support the participants to decide which of the messages is the clearest and strongest.

7. Ask for two participants to volunteer to take part in a role-play. Ask the first volunteer to play the part of a community activist (i.e. themselves). Ask the second volunteer to play the advocacy target (i.e. the person or organization that was identified in the advocacy planning chart in Section 6.4).
8. Facilitate a role-play of a scenario where the community activist uses their advocacy message during a meeting with the advocacy target.
9. Ask the other participants to give feedback to the volunteers, such as on how the advocacy message could have been used more effectively.
10. Repeat the role-play with other pairs of volunteers and with different types of advocacy targets.
11. Summarize what has been discussed and agreed during the session.

USEFUL RESOURCES

- *Advocacy in Action*, International HIV/AIDS Alliance, 2003. <http://www.aidsalliance.org/publicationsdetails.aspx?id=142>

What is an advocacy message?

Messages are an important tool for advocacy work. They summarize what community activists are asking for and communicate it to their target audience.

Advocacy messages can be used in a number of different ways. These include in briefing papers, media interviews, speeches, blogs and meetings with decision-makers.

What makes a good advocacy message?

The characteristics of a good message for advocacy for community treatment include that it is:

- **SHORT** – being able to be said in under 20 seconds
- **FOCUSED** – being clearly related to the advocacy priority
- **SIMPLE** – using straightforward language and avoiding jargon
- **TARGETED** – being appropriate and relevant to the advocacy audience
- **POWERFUL** – convincing stakeholders about why the issue matters and why they must take action
- **AGREED** – being supported by all those who need to use it

Section 6.6

‘What works’ for community advocacy on common barriers to treatment?

SECTION OBJECTIVE

To build community activists’ understanding of ‘what works’ and ‘what doesn’t work’ – by sharing real life case studies of advocacy for community treatment.

TRAINING MATERIALS

- Part 6: ACT case studies of the ACT Toolkit

TRAINING OPTIONS

Option A (approx. 60 minutes)

1. Explain the objective of the Section.
2. Ask the participants to re-cap on the priority that they have identified for their advocacy for community treatment (see Section 6.3) and the plan that they have made (see Section 6.4).
3. Ask the participants to identify which of the following case studies might give them the most useful ideas for implementing their advocacy plan:

ACT CASE STUDY 1: *Advocating against human rights abuses of sex workers living with HIV, Uganda*

ACT CASE STUDY 2: *Advocating against barriers to CD4 counts and ART for key populations, Ukraine*

ACT CASE STUDY 3: *Advocating against negative attitudes of treatment-providers, Cameroon*

ACT CASE STUDY 4: *Addressing the ‘Evidence Gap’ for advocacy on ART for key populations, Vietnam*

ACT CASE STUDY 5: *Advocating on the lack of appropriate health services for LGBT people, Kenya*

ACT CASE STUDY 6: *Advocating for the involvement of people who use drugs in ART services, Georgia*

ACT CASE STUDY 7: *Advocating for improved provincial procurement of ARVs, Russia*

ACT CASE STUDY 8: *Advocating Against poor quality ART for women living with HIV, West Africa*

4. Give each participant a copy of the case study that they have selected. Give them time to read the case study.
5. Facilitate a discussion to identify:
 - What are the key lessons from the case study – such as about ‘what worked’ and ‘what didn’t work’ in the advocacy for community treatment?
 - How could those lessons be adapted to our context and our own advocacy for community treatment?
6. If you have time, repeat the process for other case studies.
7. Summarize what has been discussed and agreed during the session.

ACT Case Studies

INTRODUCTION

THE SCIENCE
OF HIV 1

TREATMENT
INITIATIVES 2

HUMAN RIGHTS
AND TREATMENT 3

TRADE AND
TREATMENT 4

FINANCING
AND TREATMENT 5

COMMUNITY
ADVOCACY
PLANNING 6

**ACT
CASE STUDIES**

Welcome to **ACT Case Studies**.

The aim of the **Case Studies** is to provide real world examples of advocacy for community treatment from a range of ITPC partners working in different contexts and countries.



ACT CASE STUDY 1: UGANDA

Advocating against human rights abuses of sex workers living with HIV

What is the context?

In Uganda, HIV prevalence is estimated at 7.2%.¹ In 2012, 403,089 people living with HIV were provided with antiretroviral therapy (ART) – less than a third of the estimated 1.4 million who are now eligible under the 2013 ART Guidelines.² There is little data on the specific situation for members of key populations. However, HIV prevalence among female sex workers is estimated to be significantly higher (at 33%, according to one study)³, while their access to ART is believed to be significantly lower.

What is the organization?

The Uganda Harmonized Rights Alliance (UHRA) is a coalition of human rights organizations that support sex worker activism.

What was the barrier to treatment?

Sex workers living with HIV were experiencing a number of practical and legal barriers to access to treatment. These included that they could not freely pick up their antiretroviral drugs (ARVs) at clinics (due to the stigma of being sex workers); access clinics during opening times (due to their work hours); or take their ARVs while in police cells (following frequent arrests).

What were the advocacy actions and messages?

UHRA's advocacy actions included:

- Advocating at a national level for policies to promote and protect the human rights of sex workers. This included attention to the right to health, non-discrimination and a safe working environment (free from arrest, abuse and violence).
- Carrying out public demonstrations, with banners stating that sex workers have equal rights to other Ugandans.

- Carrying out meetings with health care providers and officials to call for changes to the systems of clinics – such as with longer opening hours and with other people allowed to pick up ARVs on behalf of sex workers.
- Holding a protest whenever a sex worker was arrested and negotiating with the police for her release, so that she could take her ARVs.

The advocacy work was based on messages that: 'sex workers are Ugandans'; and 'sex workers living with HIV have the right to treatment'.

What were the advocacy results and lessons?

The results of UHRA's advocacy included sex workers living with HIV being released from police cells (and being able to take their ARVs) and the agreement of a system whereby people can collect ARVs from clinics on behalf of sex workers.

UHRA's lessons included that:

- A country's Constitution – combined with international laws – can provide a strong tool for advocacy if, for example, it states that everyone has the right to health.
- It is best to try 'advocacy through talking' before taking other action. For example, UHRA found that sometimes, when they did demonstrations, their members were themselves arrested and beaten.
- Working through one advocacy target can enable you to reach another. For example, by working with the media (such as informing newspapers and radio stations when a sex worker was arrested), UHRA achieved action by police – which did not want their stations to be a focus of attention and, therefore, released the women.

1 Uganda, UNAIDS, 2012. <http://www.unaids.org/en/regionscountries/countries/uganda/>

2 UNAIDS Global Report 2013, UNAIDS, 2013.

3 Country Progress Report 2012, Uganda AIDS Commission, April 2012.



ACT CASE STUDY 2: UKRAINE

Advocating against barriers to CD4 counts and ART for key populations

What is the context?

In Ukraine, HIV prevalence in adults is estimated at 0.9%.⁴ In 2011, 31% of new infections were associated with injection drug use.⁵ In 2012, 38,082 people living with HIV were provided with antiretroviral therapy (ART). This was just 39% of those eligible under the 2010 ART Guidelines and an even smaller proportion of the 220,000 now estimated to be eligible under the 2013 ART Guidelines.

What is the organization?

Kirovograd is a regional department of the All-Ukrainian League LEGALIFE. It aims to provide access to timely CD4 testing and treatment for people living with HIV who are prisoners, people who use drugs, sex workers or from remote areas/small towns.

What was the barrier to treatment?

LEGALIFE was concerned about a group of related issues. Firstly, people living with HIV were unable to access ART if they could not register a place of residency, such as due to being homeless. Secondly, those with a place of residence experienced interruptions to their treatment – and resistance to ARVs – if they had to travel to another area and were not permitted to use local ART services. This affected groups such as migrant sex workers. Finally, in some locations – especially small towns and detention centres – there was poor access to equipment for CD4 testing. This was especially due to the lack of mobile testing equipment – with, despite having manufacturers in the country, production held up due to protocols not being approved. As a result of all these barriers, there were increases in mortality among people living with HIV.

What were the advocacy actions and messages?

LEGALIFE took a range of advocacy actions to address the different issues. These included:

- Gathering evidence, including by analysing legislation related to access to ART for people living with HIV who chose to move away from their registered place of residency. Also sending letters of enquiry to AIDS

Centres about cases of interruptions to treatment for people experiencing challenges related to registration/residency.

- Mobilizing the government and community organizations to be interested in the issue of mobile CD4 testing. Activities included carrying out: a speech to the Ukrainian Community Advisory Board; meetings with civil society leaders, including the All-Ukrainian Network of People Living with HIV; and a roundtable with representatives of communities, government medical services and laboratories.
- Advocating to Alere and Partec - the companies producing mobile CD4 equipment – to lower the price of supplies.
- Holding a national conference – involving United Nations agencies, the Ministry of Health, NGOs (from Ukraine and Russia), AIDS Centres, sex workers and organisations of people living with HIV – on sex work and HIV, with attention to the issue of migration and access to/continuity of ART.

The advocacy work was based on message such as: ‘quality diagnosis = early treatment’; and ‘life depends on timely diagnosis’.

What were the advocacy results and lessons?

The results of the advocacy included an agreed way forward for distributing mobile CD4 equipment and an agreement with the manufacturers on the possibility of lower prices for supplies. The results also included better options for people living with HIV regardless of their place of registration and residency.

The lessons included that:

- It is important to mobilize all relevant stakeholders for your cause – especially for a subject such as CD4 testing which stakeholders may not immediately see as a vital part of HIV treatment.
- Before carrying out public events – such as roundtables – with different stakeholders, it is vital to understand the interests of each one and, in some cases, conduct individual meetings beforehand.

⁴ Unless stated otherwise, all data in this section from: UNAIDS Global Report 2013, UNAIDS, 2013.

⁵ *Ukraine Harmonized AIDS Response Progress Report: Reporting Period: January 2010 – December 2011*, endorsed by National Council to Fight Tuberculosis and HIV-infection/AIDS, 2012.



ACT CASE STUDY 3: CAMEROON

Advocating against negative attitudes of treatment-providers

What is the context?

In Cameroon, HIV prevalence is estimated at 4.3%, with some 600,000 people living with HIV.⁶ In 2012, 117,791 people were receiving antiretroviral therapy (ART). This represents less than a quarter of those now eligible for ART according to the World Health Organization (WHO) 2013 Guidelines.

What is the organization?

Association des Frères et Soeurs Unis - Extrême Nord (AFSU-EN) is based in Maroua in the Farth North region. It is a network of activists that works with over 15 community based organizations of people living with HIV, including women and young people. AFSU-EN is supported by the International Treatment Preparedness Coalition (ITPC) Central Africa.

What was the barrier to treatment?

AFSU-EN identified that the negative attitudes of some health workers at a Treatment Centre were a major barrier to access to ART for the community. The staff had poor attitudes to their work, such as arriving late and being absent. They also had very negative attitudes to people living with HIV, such as insulting and discriminating against them. Some were also involved in the illegal sale of antiretroviral drugs (ARVs). As a result of these problems, some people living with HIV were discouraged from going to the Treatment Center and stopped their ART. Also, some that continued to go to the Centre did not receive their drugs on time.

What were the advocacy actions and messages?

Over a period of fifteen months (August 2012 – October 2013), AFSU-EN's advocacy actions included:

- Holding focus group discussions with community members, facilitated by ITPC Central Africa. These aimed to better understand and gather evidence about the issues faced by people living with HIV.
- Writing a letter from the community (and supported by ITPC Central Africa) to the health authority. This complained about the attitudes and behavior of the health workers and outlined the impact on the health and well-being of people living with HIV.

- Holding a meeting between the community and the management of the Treatment Centre, including the health workers that had shown negative attitudes. During this, community members denounced the workers' attitudes and their harmful impact on the lives of people living with HIV.
- Getting legal support for the community from a lawyer. The lawyer helped the community to prepare a dossier (a report containing strong evidence). This led to the Director of the Treatment Centre suspending two health workers who had demonstrated negative attitudes.

In its letter, meeting and dossier, AFSU-EN used advocacy messages stating that: 'the mistreatment of patients living with HIV is a flagrant violation of human rights'; 'the sale of ARVs is illegal. It is also unacceptable'; and 'access to high quality and sustained treatment, care and support for people living with HIV is critical not only to individuals, but to public health'.

What were the advocacy results and lessons?

After its advocacy action, AFSU-EN found that:

- Health workers at the Treatment Centre became more attentive to the needs of people living with HIV.
- Access to treatment improved for people living with HIV – due to an end to the illegal sale of ARVs.
- People living with HIV became more motivated to go to the Treatment Centre, to get their drugs and to receive medical follow-up.

AFSU-EN's lessons included that:

- Before starting advocacy, it is crucial to ensure that community members are concerned about the issue; committed to the advocacy; and involved in every step, including gathering evidence.
- For high quality advocacy, your information must be genuine and accurate. At the start, AFSU-EN found that some of its information was false. However, through double-checking, it accessed the correct data.
- Involving an expert at the right time can make a vital contribution to successful advocacy. For AFSU-EN, working with a lawyer enabled them to take the formal action that was needed to achieve change.

⁶ All data in this section from: *UNAIDS Global Report 2013, UNAIDS, 2013.*



ACT CASE STUDY 4: VIETNAM

Addressing the 'Evidence Gap' for advocacy on ART for key populations

What is the context?

In Vietnam, HIV prevalence is estimated at 0.4% among the general public, but much higher among key populations, such as sex workers (2.7%), people who use drugs (11.6%) and men who have sex with men (16.7%).⁷ In 2012, 68,883 people living with HIV were provided antiretroviral therapy (ART). This represented 58% of those eligible under the 2010 ART Guidelines and a much smaller proportion of those eligible under the 2013 ART Guidelines. A study of the 'treatment cascade' found that many individuals are lost at various stages in the HIV treatment continuum – reducing the number of people living with HIV who achieve viral suppression and other benefits from ART.

What is the organization?

The Vietnam Network of People Living with HIV (VNP+) is an organization run by and for people living with HIV. It fights stigma and discriminations and advocates for the rights of HIV-positive people (such as to treatment, care and support), including those from key populations.

What was the barrier to treatment?

Stigma and discrimination was presenting an immense barrier to ART for people living with HIV. Fear of disclosing their HIV status was thought to be the top reason why such community members were not accessing treatment. However, there was a lack of evidence to prove it to decision-makers.

What were the advocacy actions and messages?

The advocacy actions of VNP+ included:

- Implementing the People Living with HIV Stigma Index in 2012 – to gather concrete data on the situation for people living with HIV and provide evidence about the impact of stigma and discrimination. People living with HIV were involved throughout the process.
- Using the findings of the Stigma Index to inform a pilot program of the Treatment 2.0 Framework, supported by the United Nations Joint Program on AIDS (UNAIDS) and World Health Organization (WHO).
- Sharing the findings of the Stigma Index with the government – resulting in the Ministry of Health using

them during presentations at the National AIDS Conference.

Since 2013, developing and running a treatment literacy program for groups of people who use drugs, sex workers and men who have sex with men. The program is run by people living with HIV and involves monthly meetings of the groups to share information, especially about the vital importance of people living with HIV accessing treatment and staying healthy.

Carrying out further research to identify the opportunities and barriers to access to treatment, care and support for people living with HIV.

The advocacy work used messages such as: 'AIDS can be treated'; and 'no one needs to die of HIV, but they are dying from stigma and discrimination'.

What were the advocacy results and lessons?

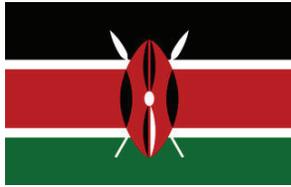
The results of VNP+'s work included that:

- 450 people were informed about HCV/HIV co-infection, ARV treatment adherence and other health services related to HIV
- 180 clients were successfully referred to additional health services, including HCV treatment, VCT services and STI treatment.

The lessons learned of VNP+ included that:

- Concrete data and evidence provides vital foundations for successful advocacy work – as it increases the power of your messages to decision-makers.
- Advocacy on access to treatment needs to be accompanied by work within communities, such as with treatment literacy and peer education among people living with HIV to encourage them to overcome their own fears and to access treatment.

⁷ All data in this section from: *UNAIDS Global Report 2013*, UNAIDS, 2013.



ACT CASE STUDY 5: KENYA

Advocating on the lack of appropriate health services for LGBT people

What is the context?

In Kenya, HIV prevalence among adults is estimated at 6.1%, but estimated to be much higher among key populations – such as 18.2% among men who have sex with other men.⁸ In 2012, 548,588 people living with HIV were provided with antiretroviral therapy (ART) – less than half of the 1.3 million people who are now projected to be eligible according to the 2013 ART Guidelines.

In Kenya, homosexuality is criminalized, with imprisonment of up to 14 years for those convicted. There is evidence that men who have sex with men do not seek health services – such as for sexually transmitted infections – due to fear and stigma.

What is the organization?

Professionals in Pride Kenya (PPK) support the lesbian, gay, bisexual and transgender (LGBT) community, including those living with HIV.

What was the barrier to treatment?

There were no ‘LGBT-friendly’ health services in most clinics in Kenya, including the capital Nairobi. For example, few doctors or nurses had any understanding of the specific health issues affecting men who have sex with men, such as anal infections. In addition, LGBT people faced criminalization – so, for example, those living with HIV would feel unable to discuss their needs honestly, for fear of disclosing their sexuality or sexual orientation.

What were the advocacy actions and messages?

PPK’s advocacy activities included:

- Holding meetings with government officials, including the Kenya National AIDS and STI Control Program. During these, PPK shared their concerns about the dangers that their community members are exposed to without LGBT-specific health facilities. They highlighted the needs of those living with HIV – for ART and also for commodities (such as condoms and lubricants) for HIV prevention.
- Holding demonstrations to build awareness among the public of the existence of LGBT people and to demand their rights as Kenyans.

- Building partnerships with stakeholders prepared to support the LGBT community. For example, some pastors publicly supported in PPK during radio interviews.

The advocacy work focused on messages such as: ‘gay rights = human rights’; and ‘no judgment based on my sexual orientation’.

What were the advocacy results and lessons?

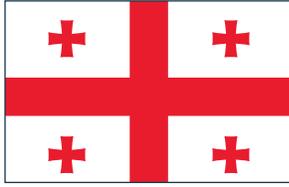
The results of PPK’s advocacy include that:

- LGBT people can now go on the media and talk about their issues without fear of arrest.
- Other civil society organization have increased their understanding of LGBT issues and joined PPK in their fight for rights.

PPK’s lessons include that:

- It is important to base advocacy on evidence and existing, supportive resources. For example, PPK used relevant sections of the national Constitution, HIV Bills, HIV policies and quotes from the President and Minister of Health.
- It is vital to get the media interested in your case and ‘on your side’. If there is a lot of publicity, it is hard for your advocacy targets to make the wrong decisions – because everyone is watching.
- As well as targeting decision-makers, it is important to educate the general public about your issue. This creates understanding and – even if not everyone agrees with you – enables you to build the scale and influence your support.

⁸ All data in this section from: *UNAIDS Global Report 2013*, *UNAIDS*, 2013; or *The Kenya AIDS Epidemic: Update 2011*, *Office of the President: National AIDS Control Council*, 2012.



ACT CASE STUDY 6: GEORGIA

Advocating for the involvement of people who use drugs in ART services

What is the context?

In Georgia, HIV prevalence in adults is estimated at 0.3%.⁹ Prevalence is much higher among key populations, such as people who use drugs (estimated at 3.9%) and men who have sex with men (estimated at 6.4%).¹⁰ In 2012, 1,598 people living with HIV were provided with antiretroviral therapy (ART). This was just 71% of those eligible under the 2010 ART Guidelines, but only about a quarter of the 6,000 now estimated to be eligible under the 2013 ART Guidelines.

What is the organization?

The Georgian Harm Reduction Network (GHRN) is a national network of 26 organizations from across the country. It is based in the capital (Tbilisi) and supports people who use drugs.

What was the barrier to treatment?

Georgia has a program supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria that provides the treatment component of services related to ART, opioid substitution therapy (OST), Tuberculosis (TB) and co-infection of HIV and HCV. However, major barriers still exist that prevent people who use drugs from accessing such treatment. These include that such community members are criminalized and experience stigma from both the public and health workers. Also, people who use drugs have not been involved in the design, planning and implementation of the services – so feel little ownership of them or ability to influence them.

What were the advocacy actions and messages?

GHRN's advocacy activities included:

- Carrying out advocacy campaigns – such as on access to treatment for HIV, HCV and OST – with the involvement of people who use drugs and people living with HIV.

- Bringing community members together with decision-makers. For example, GHRN supported people living with HIV, people who use drugs and lesbian, gay, bisexual and transgender (LGBT) people to become members of the Country Coordinating Mechanism and its oversight committee. This was done through transparent election processes coordinated by the community sector.

The advocacy work was based on messages such as that: 'ART = health can be bought' (to promote government funding of ART); and 'health is not a luxury' (to draw attention to the impact of HCV).

What were the advocacy results and lessons?

The results of GHRN's advocacy included that:

- People who use drugs and people living with HIV experience increased access to treatment services and quality of life – such as through the launch of a state program to address HCV and reduced price of drugs to treat the disease.
- Representatives of the community sector are able to influence national decisions about policies and programs that affect them – through membership of the CCM.

GHRN's lessons include that community involvement is essential to advocacy – as it gives issues a 'human face' to your issues and makes targets more like to support them.

⁹ Unless stated otherwise, all data in this section from: *UNAIDS Global Report 2013, UNAIDS, 2013.*

¹⁰ *Georgia: Country Progress Report: Reporting Period January 2010 – December 2011, Georgia.*



ACT CASE STUDY 7: RUSSIAN FEDERATION

Advocating for improved provincial procurement of ARVs

What is the context?

In contrast to many other countries, the HIV situation in the Russian Federation is getting worse, rather than better – with increased numbers of new infections each year. According to unofficial data,¹¹ there are now an estimated 1.2 million people living with HIV – only 157,000 of whom receive antiretroviral therapy (ART). According to UNAIDS, a projected 820,000 people living with HIV are now eligible for treatment under the 2013 ART Guidelines.¹² Access to ART is known to be especially challenging for people who use drugs.

What is the organization?

The International Treatment Preparedness Coalition in Eastern Europe and Central Asia (ITPCru) was established in 2005. It is an initiative of people who are united by common ideas. Its objectives are to ensure: universal, adequate and equitable access to HIV care, treatment and prevention for all people living with and at risk of HIV; and their greater input in decision-making that affects their lives.

What was the barrier to treatment?

ITPCru was concerned that people living with HIV – including people who use drugs – faced frequent stock-outs of antiretroviral drugs (ARVs). This came to a head in 2013 with the decentralization of ARV procurement, with each of the country's 83 provinces given responsibility for organizing its own program.

What were the advocacy actions and messages?

ITPCru's advocacy actions included:

- Training and supporting a team of 15 local activists to analyze about 2,000 tenders for ARVs in the 83 provinces. The work was based on a simple methodology for monitoring electronic tenders and analyzing the relevant data, such as on the prices of drugs. The problems identified included the: late announcement of tenders; exorbitantly high prices of ARVs; purchase of single pills instead of fixed-dose combinations; and the cancellation of tenders due to there being no bids.
- Publishing the activists' results, including a report¹³ that combines information on stock-outs (and their impact) with an analysis of the federal government procurement of ARVs.

When activists identified a problem about tendering in a province, carrying out advocacy activities such as street rallies, press conferences and round tables – all with good media coverage. These were supported by a database of advocacy tools, including samples of advocacy letters and press releases and instructions for organizing street actions. In total, over 100 activities were conducted.

The advocacy work was based on messages such as: 'treatment is needed for all people living with HIV'; and 'access to high quality ART is not optional – it is the human right of all people living with HIV'.

What were the advocacy results and lessons?

The results of ITPCru's advocacy included the successful analysis of approximately 20,00 tenders for ARV medicines in 83 provinces in Russia. This monitoring led to the development of advocacy tools, including sample letters, press-releases, and instructions for organizing street actions, that can be used in addressing late tender announcements and the annulment of tenders due to the absence of bids.

The lessons learned included that:

- Practical tools – such as a methodology for analyzing tenders – are key to scaling-up advocacy as they can be used by different people in different locations, adding up to a large-scale initiative. They also, however, benefit from re-adjustment. For example, while very useful for individual contexts, ITPCru's methodology did not serve to identify systemic stock-outs of ARVs as a result of decentralization.
- The media is a vital 'ally' for advocacy. For example, ITPCru gained media coverage for many of its activities – which served to mobilize stakeholders and also document the work. Many examples can be seen on YouTube, such as from: July 2013 <http://www.youtube.com/watch?v=Ey4MPLwdYAs>; April 2013 <https://www.youtube.com/watch?v=6WQwqwatch?v=6WQsxSAWZTI>
- To be effective, advocacy objectives must constantly be updated. For example, ITPCru's work now also includes advocacy for the inclusion of community activists in local tender committees – an opportunity that arose from a new law on procurement that started at the end of January 2014.

¹¹ All data in this section from: www.aif.ru/health/life/38768

¹² *UNAIDS Global Report 2013*, UNAIDS, 2013.

¹³ *To Treat or Not to Treat? Report Based on the Results of Community Research*, ITPCru, EVA, Simona+ and CF Candle, 2012. http://www.itpcru.org/netcat_files/10/196/To_treat_or_not_to_treat_0.pdf



ACT CASE STUDY 8: WEST AFRICA

Advocating against poor quality ART for women living with HIV

What is the context?

In West and Central Africa, some 79% of people living with HIV who are eligible for antiretroviral therapy (ART) do not receive it.¹⁴ In the region, some progress has been made on the Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive¹⁵ (the Global Plan). However, two thirds of pregnant women living with HIV still do not receive ART for their own health.¹⁶

What is the organization?

The International Treatment Preparedness Coalition (ITPC) West Africa is a regional network of treatment activists based in Abidjan, Côte d'Ivoire. It works with communities of people living with HIV – including those from key populations – as well as all other stakeholders involved in the response to HIV.

What was the barrier to treatment?

In 2011, single-dose Névirapine was being prescribed to pregnant women living with HIV in five countries in West Africa. The drug prevents the vertical transmission of HIV from a mother to her baby. However, using it alone is not as effective as triple therapy and has great potential to result in resistance. The Global Plan recommends that single-dose Névirapine is rapidly phased out, and replaced by triple therapy as suggested in option B+.

What were the advocacy actions and messages?

ITPC West Africa launched a campaign to put an end to use of single-dose Névirapine and make African countries provide high quality ART to pregnant women living with HIV. The campaign included:

- Distributing postcards during the International Conference on AIDS and STIs in Africa (ICASA) in Addis Ababa, Ethiopia, in 2011. The postcards were signed by over 2,000 people and handed to the Chairperson of the African Union through the Social Affairs Commissioner.
- Distributing postcards during the International AIDS Conference (IAC) in Washington DC, United States of America, in 2012.
- After the IAC, seeking an appointment with the representative of the Africa Union in Cote d'Ivoire to discuss the problem of single-dose Névirapine in the region.

The campaign focused on messages such as: 'Africa: Say no to single-dose Névirapine'; and 'full ART for HIV-positive women'.

What were the advocacy results and lessons?

As a result of the advocacy:

- Many people, including women living with HIV gathered at the booth gained knowledge about PMTCT issues. As a result, they were able to share this knowledge when they returned to their communities.
- Important stakeholders at the African Union were sensitized to PMTCT issues after they were inundated with 1,500 postcards demanding the AU prioritize PMTCT."

The lessons included that:

- Regional and international events (such as AIDS conferences) provide important advocacy opportunities – as they give access to both advocates (for example, to sign campaign postcards) and targets (such as policy-makers).
- International policy initiatives – such as the Global Plan – provide important advocacy tools to put pressure on regional decisions-makers about why they must make changes to policies related to HIV treatment.

14 Based on the number of people receiving ART in December 2012 compared to the estimated number eligible for ART according to the WHO Guidelines in 2013. Access to antiretroviral Therapy in Africa: Status Report on Progress Towards the 2015 Targets, UNAIDS, 2013.

15 The Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive: 2011-2015, UNAIDS, 2011.

16 2013 Progress Report On The Global Plan: Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive, UNAIDS, November 2013.



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