

**ACTIVIST**

**TOOLKIT**

**Campaigning for Routine Viral Load Monitoring**



**ITPC**

INTERNATIONAL TREATMENT  
PREPAREDNESS COALITION

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## Acknowledgements

The *Activist Toolkit: Campaigning for Routine Viral Load Monitoring* was developed with the aim of strengthening the capacity of activist groups to be able to demand access to viral load testing and encourage uptake among communities, with the objective of increasing accessibility to, and coverage of viral load testing.

The International Treatment Preparedness Coalition (ITPC) and Médecins Sans Frontières (MSF/Doctors Without Borders) partnered to produce this toolkit, to be used in training workshops in southern and east Africa and other parts of the world.

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### About ITPC:

The International Treatment Preparedness Coalition (ITPC) is a worldwide community activist network, with nine regional networks in Africa, Asia, the Caribbean, Eastern Europe, Latin America, and the Middle East. ITPC is a grassroots movement whose vision is to see a longer, healthier, more productive life for all people living with HIV.

ITPC's mission is to enable communities in need to have access to HIV treatment. Our campaigns for access to HIV treatment focuses on helping to alleviate the challenges PLHIV face when trying to access adequate treatment and monitoring. We aim to alert the world about the desperate need to improve access to HIV treatment.

**For more about Routine Viral Load Testing campaigns, go to:**

**[www.knowyourviralload.org](http://www.knowyourviralload.org)**

**[www.samumsf.org/blog/portfolio-item/viral-load-vl-toolkit/](http://www.samumsf.org/blog/portfolio-item/viral-load-vl-toolkit/)**

**[www.msfacecess.org/undetactable](http://www.msfacecess.org/undetactable)**



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# Abbreviations

<b>AIDS</b>	Acquired Immunodeficiency Syndrome	<b>NNRTIS</b>	Non-Nucleoside Reverse Transcriptase Inhibitors
<b>ARASA</b>	AIDS and Rights Alliance for Southern Africa	<b>NRTI</b>	Nucleoside/Nucleotide Reverse Transcriptase Inhibitors
<b>ART</b>	Antiretroviral Therapy	<b>PEPFAR</b>	United States President's Emergency Plan for AIDS Relief
<b>ARV</b>	Antiretroviral	<b>PI</b>	Protease Inhibitors
<b>CCM</b>	Country Coordinating Mechanism	<b>PLHIV</b>	People living with HIV
<b>DNA</b>	Deoxyribonucleic Acid	<b>POC</b>	Point of Care
<b>DBS</b>	Dried Blood Spot	<b>PREP</b>	Pre-Exposure Prophylaxis
<b>FDC</b>	Fixed Dose Combination	<b>RNA</b>	Ribonucleic Acid
<b>HCV</b>	Hepatitis C Virus	<b>RVLT</b>	Routine Viral Load Testing
<b>HIV</b>	Human Immunodeficiency Virus	<b>STI</b>	Sexually Transmitted Infection
<b>HPV</b>	Human Papillomavirus	<b>TASP</b>	Treatment as Prevention
<b>INSI</b>	Integrase Inhibitor	<b>TB</b>	Tuberculosis
<b>ITPC</b>	International Treatment Preparedness Coalition	<b>VL</b>	Viral Load
<b>MSF</b>	Médicins Sans Frontières/Doctors Without Borders	<b>WHO</b>	World Health Organization
<b>NGO</b>	Nongovernmental Organization	<b>XDR TB</b>	Extensively Drug Resistant TB

# 1 WHY THIS TOOLKIT?

Today, almost 16 million have access to HIV treatment.<sup>1</sup> While many more people need to be reached with life-saving medicines, this is important progress. However, the monitoring (checking if the treatment is working for each person taking ARVs) that goes hand in hand with HIV treatment, through routine viral load testing, is still lagging behind in developing countries.<sup>2</sup>

Routine Viral Load Testing (RVLT) is an essential part of effective HIV treatment: it is the most accurate way of measuring the number of copies of HIV in the body. It has been routinely used in high-income settings for many years.<sup>3</sup>

Although many governments have committed to providing RVLT, it is not routinely offered to people living with HIV (PLHIV) in many parts of the world, especially in Africa, where there is a high burden of HIV. For people who try to access a viral load test, it is frequently not available, or is unaffordable.

In response to this, campaigns to demand that routine viral load testing is made available have been launched, including by the International Treatment Preparedness Coalition (ITPC) and Médecins Sans Frontières (MSF/Doctors Without Borders).

In October 2015, ITPC launched the *Be Healthy, Know your viral load* campaign,<sup>4</sup> in partnership with the AIDS and Rights Alliance for Southern Africa (ARASA). The ongoing campaign aims to inform people living with HIV about the value of viral load testing to mobilize people to demand routine viral load testing and to urge governments to make sure the tests are routinely available, accessible and affordable.

Educational material such as an advocacy leaflet for activists and people living with HIV, an

information sheet for decision-makers, sample letters that can be sent to governments, an information sheet for health facilities and a film have been produced to mobilize people to demand routine viral load testing.<sup>5</sup>

With funding from UNITAID, MSF has been implementing routine viral load, CD4 and early infant diagnosis monitoring in nine southern African countries (Democratic Republic of Congo, Kenya, Lesotho, Malawi, Mozambique, South Africa, Swaziland, Uganda, and Zimbabwe) in 2013.<sup>6</sup>

Along with the provision of viral load services, MSF has been advocating independently, and together with civil society organizations, globally and in-country for routine viral load testing to be made available to all people living with HIV. MSF has documented and published a wealth of materials, resources and tools both for implementers, activists and policy makers.

MSF's *HIV Status: Undetectable* campaign identifies steps that can be taken to improve access to viral load testing in resource-limited settings. These include an educational ARV flipchart for people living with HIV, a toolkit for health care workers, implementers and providers on how viral load testing can be used, a series of reports aimed at addressing the barriers and challenges to scaling up routine viral load testing, and to provide evidence of best practice models in settings where routine viral load testing has successfully been rolled out in low-resource settings. The campaign also includes educational and advocacy materials such as videos, stickers, flipcharts and t-shirt designs.<sup>7</sup>

This Toolkit and the associated trainings form an essential part of these campaigns to demand viral load testing.

# 2 ABOUT THE TOOLKIT

## 2.1 What is the aim of the toolkit?

The aim of the *Activist Toolkit for Routine Viral Load Testing* is to enable and mobilize PLHIV and activists to use science and evidence to persuasively and actively advocate to decision makers and service providers for access to, and availability of, affordable routine viral load testing for PLHIV.

The purpose of this Toolkit is to provide up to date information that provides the knowledge and skills needed to advocate for access to Routine Viral Load Testing (RVLT).

This toolkit aims to inform and show the importance and value of routine viral load testing and to train community activists to passionately advocate about access to viral load testing for PLHIV, including those from key populations.

## 2.2 Who should use the toolkit?

The toolkit is for advocacy champions, activists, civil society, trainers, and organizations that promote access to HIV treatment, including access to routine viral load testing.

## 2.3 What does the toolkit contain?

Each section in the toolkit contains some or all of the following:

- Section objective, summarizing what community activists can achieve by using the section.
- Key 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 for training.
- Training options for how the section can be used within different types of training for community activists.

In all sections, there is:




- Option A, giving a short (1 hour) and information-based option for training, such as through a PowerPoint presentation and discussion.
- Suggested key messages for the topic of the section.
- Useful resources, including links to other useful documents and websites on the topic.

**In some sections, there is also:**

- Option B, giving a longer (approximately 2 hours) and more participatory option for training, such as through group work and activities.

## 2.4 How to use the toolkit

There are colored blocks throughout the document to help you identify specific information that you may need. Look out for these are they are the key pieces of information.

1. **Examples of actions** you or your organization can take are in yellow 
2. **Key messages** are in orange 
3. **Useful resources** are in green 

Use this Toolkit flexibly – in whatever way is most useful to you. For example, use it to develop a 1 to 3 day training workshop: you can use all of the sections or include only some. You can also use it for shorter and less formal initiatives. You can select a few sections, according to the number of participants, their needs and the time available.

Use this *Activist Toolkit* to train activists, advocacy champions, trainers, staff, to plan workshops, in any way possible for advocacy and raising awareness, and in whatever way is most useful to you.

The Toolkit works best if you use it in participatory training. This means the user of the Toolkit (you) should place the participants' needs first and enable them to: share their knowledge, experience and ideas; ask questions and have discussions; build their skills and confidence; and learn by doing, by going through activities and analyzing case studies.

This Toolkit does not give detailed guidance on how to prepare or facilitate participatory training.

# 3 REVIEWING THE SCIENCE OF HIV

## Section Objectives:

For community activists to be able to explain to other PLHIV how HIV works, including: what is HIV, how it is transmitted, how it is diagnosed, how it progresses and how it is treated?

## Training Materials:

PowerPoint presentation 1: Reviewing the Science of HIV

## Training Options:

Option A: (approx. 60 minutes)

1. Explain the objective of the section.
2. Present PowerPoint presentation 1: Reviewing the Science of HIV.
3. Ask the participants to write down on a piece of paper any points from the presentation that were unclear, any issues they are unsure of or need to be explained again or any questions which remain unanswered. Ask participants to write one point or one question per sheet 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 to answer the questions among themselves, then, if necessary, provide additional information yourself.
6. Repeat the process for all the sheets of paper.
7. Ask the participants to summarize the session, by developing key messages about 'What is HIV?' 'How is it monitored?' 'What is the purpose of treating HIV?' Support their ideas by sharing examples of messages (see below).



## Key Messages:

- HIV is a manageable disease if treated with antiretroviral therapy (ART). However, if left untreated, HIV will cause death.
- HIV treatment is highly effective at stopping HIV from multiplying. This reduces the amount of virus in the body and allows for the immune system to recover.
- It is important to start treatment early. The World Health Organization now recommends that all people living with HIV start ARV treatment as soon as possible, at any CD4 count.
- In order to know if a person's ARV treatment is working, it is essential that HIV monitoring, through viral load testing, is done routinely (see Section 4: Monitoring HIV Treatment).

### 3.1 What is HIV?

The Human Immunodeficiency Virus (HIV) is a very small virus that cannot be seen with the naked eye. HIV affects a person's immune system (the system in the body that fights off illnesses). The immune system is made up of CD4 cells, white blood cells that act as the soldiers of the immune system and fight off infections, bacteria and virus. HIV destroys these CD4 cells as it tries to multiply.

When a person living with HIV does not take antiretroviral (ARV) treatment, HIV causes **Acquired Immunodeficiency Syndrome (AIDS)**. This is where a person's immune system fails, allowing opportunistic infections and cancers to destroy the body.

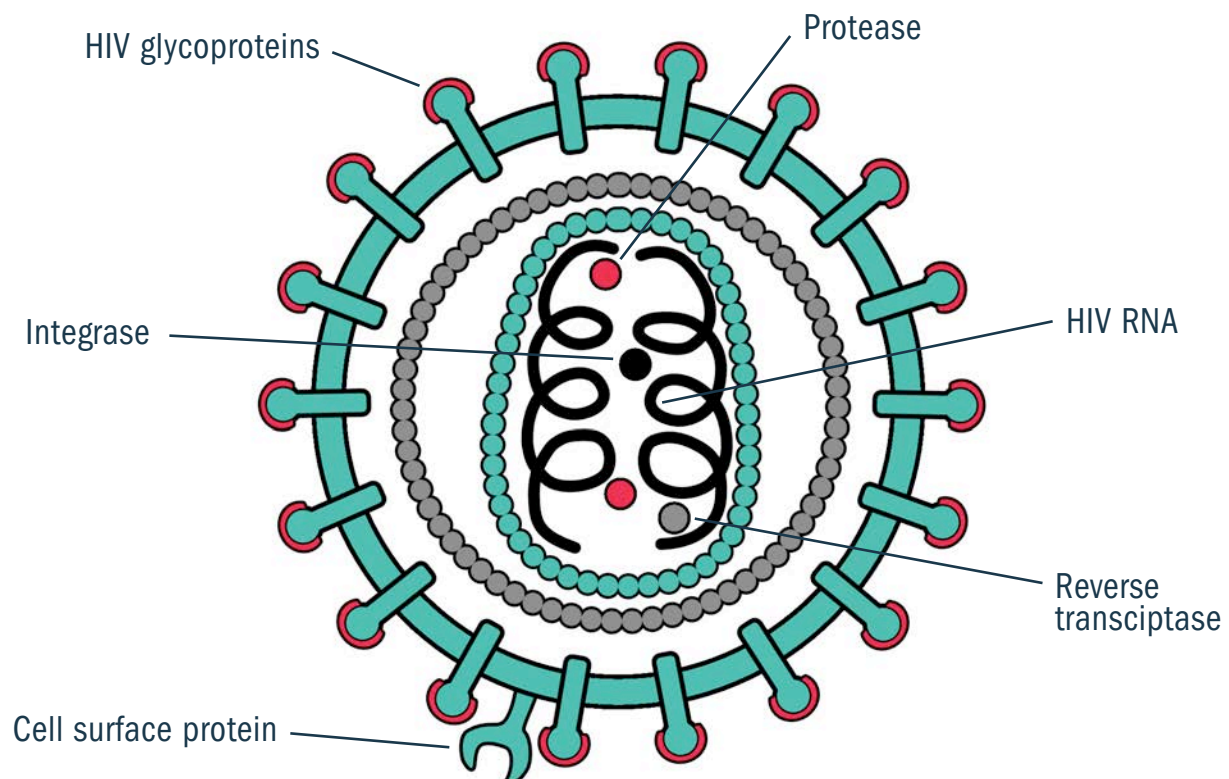


Figure 1: Structure of a HIV cell

## 3.2 How does HIV interact with the body?

When HIV enters the body, HIV infects the first cells. It then takes several hours for the newly infected cells to carry HIV to the lymph nodes, which are packed with CD4 cells.<sup>8</sup> HIV reproduces using the CD4 cell. The virus enters the CD4 cell and uses this cell to make more viruses. During the next few days or weeks, HIV continues to multiply in the CD4 cells found in the lymph nodes and blood, as is illustrated in Figure 2 below.

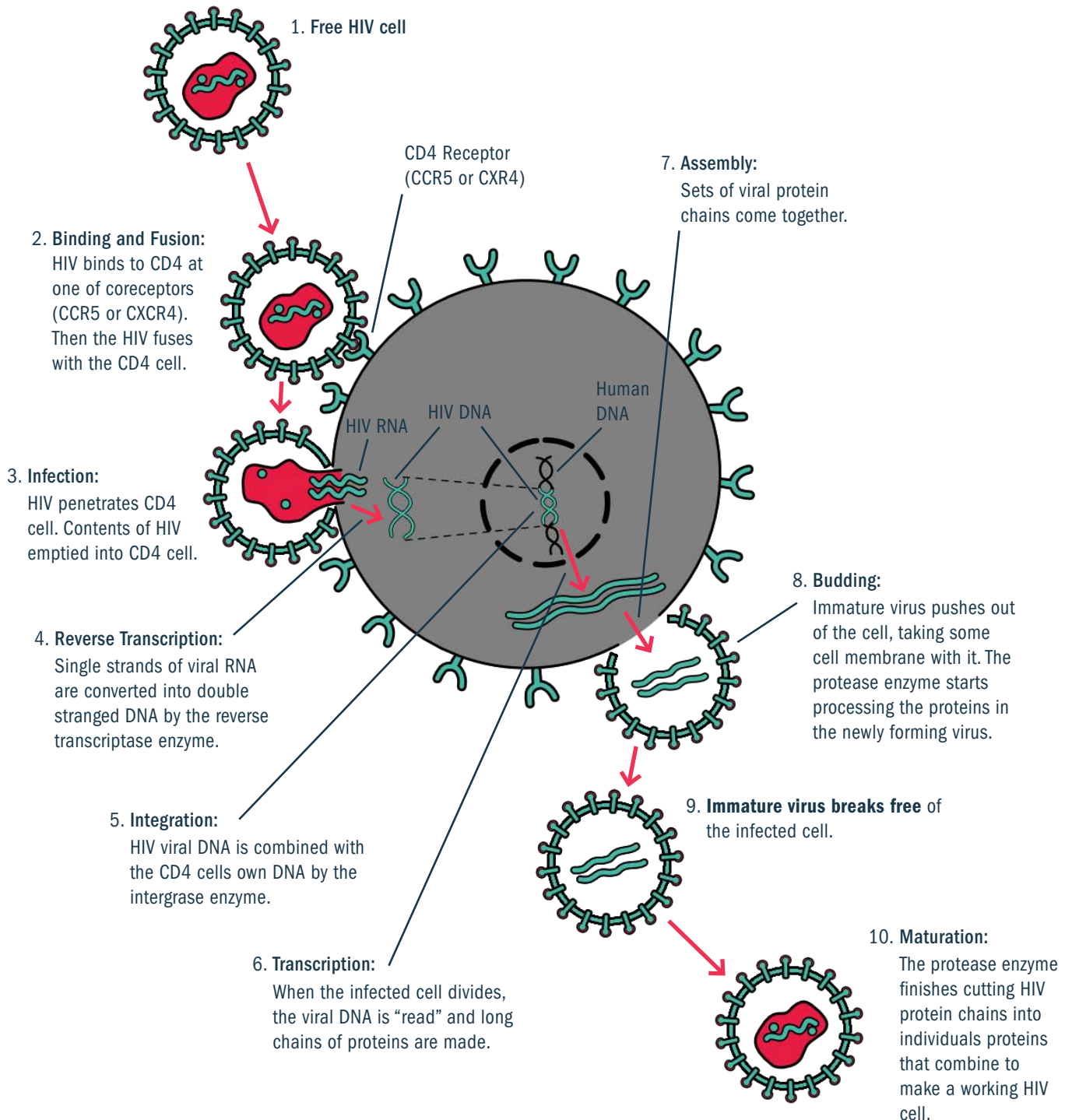


Figure 2: HIV reproduces itself by turning CD4 cells into HIV cells.

Once a person has been infected with HIV, it reproduces more and more HIV in our body, by attacking our CD4 cells and destroying the immune system of the body. If a person then becomes infected by a germ, bacteria or virus, there are not enough CD4 cells (the soldiers of the body) to fight off the infection. This causes a person living with HIV to become ill, as illustrated in the diagram below.

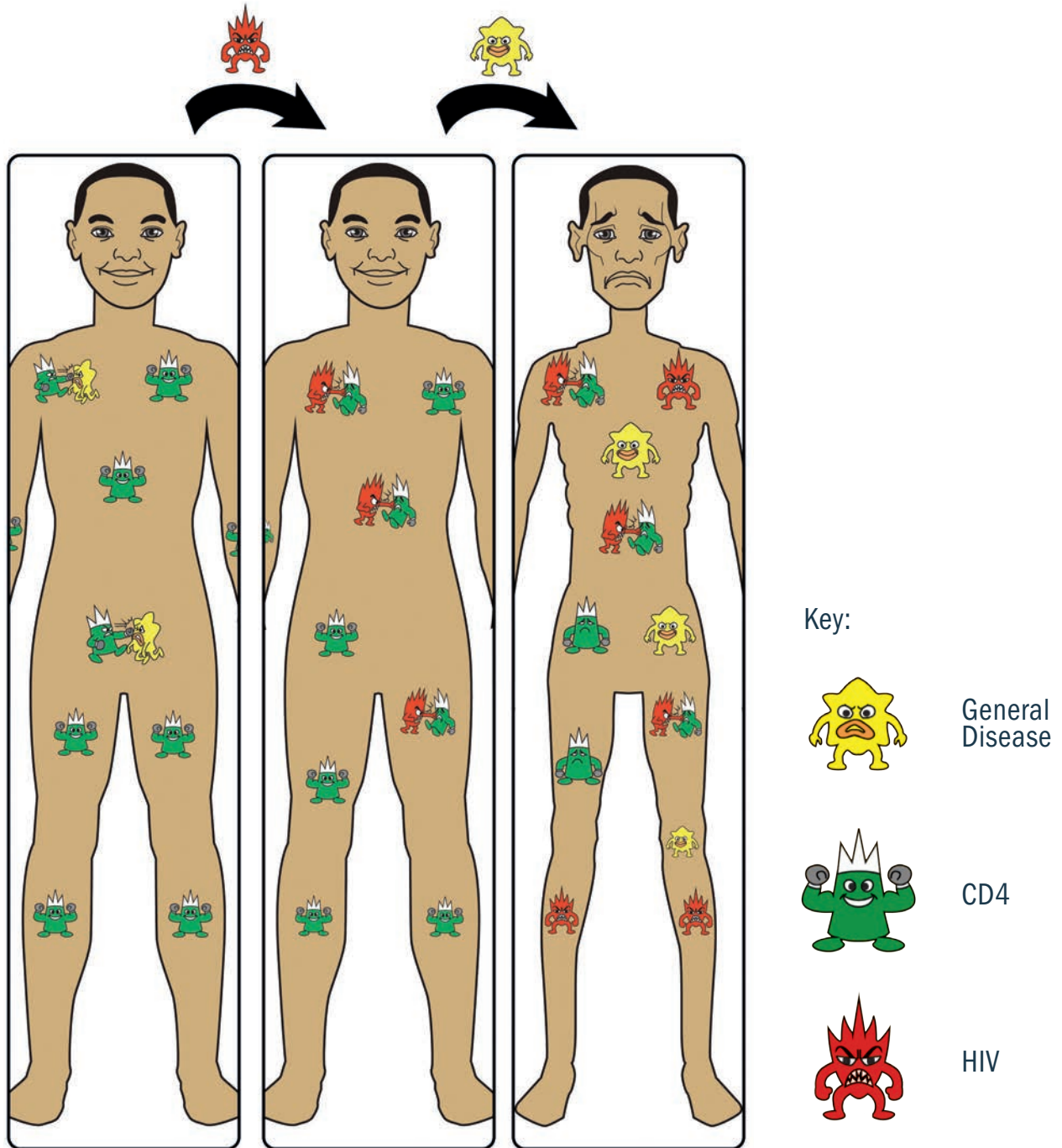


Figure 3: The body's response to HIV infection, without ARV treatment. These diagrams are taken from the MSF ART Toolkit, 2014

### 3.3 What is the purpose of treating HIV?

HIV treatment works by **interfering** with the reproduction of the HIV virus. ARVs are medicines that stop HIV from multiplying. This allows the number of CD4 cells to increase again, making the immune system stronger and able to fight off diseases.<sup>9</sup>

Different ARVs have to be taken together. This is referred to as **combination therapy**. Different drugs can target different stages in the life cycle of the virus. By starting ARVs early, you reduce your chances of becoming sick or damaging your immune system permanently. HIV treatment also includes the treatment of opportunistic infections and cancers, that affect people living with HIV.

Being on treatment also prevents HIV from being transmitted from person to person, because ART reduces the amount of HIV in the person's body. This is known as Treatment as Prevention (TasP). Therefore HIV treatment is used for the benefit of both the person living with HIV and people who are HIV-negative.

Studies have shown that using ART can have strong benefits for HIV prevention: if a person living with HIV is taking ART and has an undetectable viral load, there can be a significant (96%) reduction in the transmission of HIV to their sexual partners.<sup>10</sup>

Particular emphasis is given to this evidence for groups where the impact of HIV prevention may be the greatest. These include serodiscordant couples (when one partner is HIV-negative and the other is HIV-positive), pregnant women and key population groups, such as sex workers and men who have sex with men.

Over the past 30 years, important developments in HIV prevention have taken place. However, currently there is no cure or vaccine for HIV. As such, ART (as part of a 'package' of HIV care, support and treatment) is the most important method to manage and prevent HIV.

### 3.4 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 pregnant woman who is living with HIV, passing the virus to her infant during pregnancy, delivery or breast-feeding. 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 injecting 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. These factors include:<sup>11</sup>

- 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 with a risk of 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.

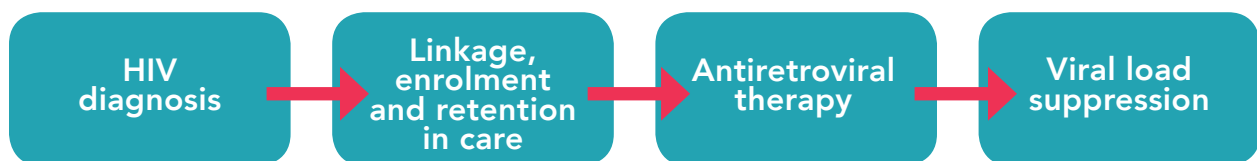
Examples include through:

- 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.

### 3.5 The HIV treatment cascade

The process of being tested for HIV and starting and staying on treatment requires a 'cascade' or 'continuum'. The HIV programme is made up of various steps or stages that a person living with HIV goes through once they have been diagnosed with HIV. This is known as the continuum of HIV care. This is also known as the HIV treatment cascade.<sup>12</sup>

This involves a series of steps—all of which are vital to achieving a successful result. The cascade begins with a person undergoing HIV counselling and testing (HCT), receiving a diagnosis and being put on ART. It then goes on until the person's viral load is lowered.



When people are first diagnosed with HIV, they need to be referred to receive the health care and monitoring they need. Because HIV treatment is life-long, people on ARVs need to stay in the HIV programme, known as retention in care. Once they have started ART, the goal is to reach viral load suppression.

### 3.6 WHO recommendations for treating HIV<sup>13</sup>

The World Health Organization (WHO) recommends that all people living with HIV start antiretroviral treatment as soon as possible, regardless of their CD4 count. Table 1 below provides more details on when adults, adolescents, children and pregnant women should start ART.

Table 1: World Health Organization guidance on when to start ART

World Health Organization guidance on when people should start ART
ART should be started in:
<b>All adults and adolescents (&lt;10 years of age) with HIV regardless of WHO clinical stage and at any CD4 cell count.</b> As a priority, ART should be started among all adults and adolescents with severe or advanced HIV clinical disease (WHO Stage 3 or 4) and adults with a CD4 of <350 cells/mm <sup>3</sup>
Adult and adolescent people living with HIV regardless of their WHO clinical stage or CD4 count who: <ul style="list-style-type: none"><li>• Have active <b>TB</b> disease</li><li>• Have <b>HBV</b> with severe chronic liver disease</li><li>• Are part of a serodiscordant couple (with a partner who is HIV-negative)</li></ul>
All <b>pregnant women</b> for the duration of pregnancy, delivery and breastfeeding and continuing for life <b>All children living with HIV with severe or advanced symptomatic disease</b> (WHO clinical stage 3 or 4), regardless of their age and CD4 count Any <b>child under 18 months</b> who is thought to have a clinical diagnosis of HIV infection <b>All children under 5 years living with HIV</b> , regardless of their WHO clinical stage or Cd4 count <b>All children above 5 years living with HIV</b> with a CD4 count <b>less than 500 cells/mm</b> , <b>regardless</b> of their WHO clinical stage As a priority, ART should be initiated among all children 2 years old or with WHO stage 3 or 4 or CD4 count < 750 cells/mm <sup>3</sup> or CD percentage <25% among children younger than 5 years and CD4 count < 350 cells/mm <sup>3</sup> among children 5 years and older.

## What are the current options for HIV treatment?

When HIV enters the body and begins entering the CD4 cells to make copies of itself, ARV treatment works by stopping different parts of the process, as is illustrated in Figure 4 below.

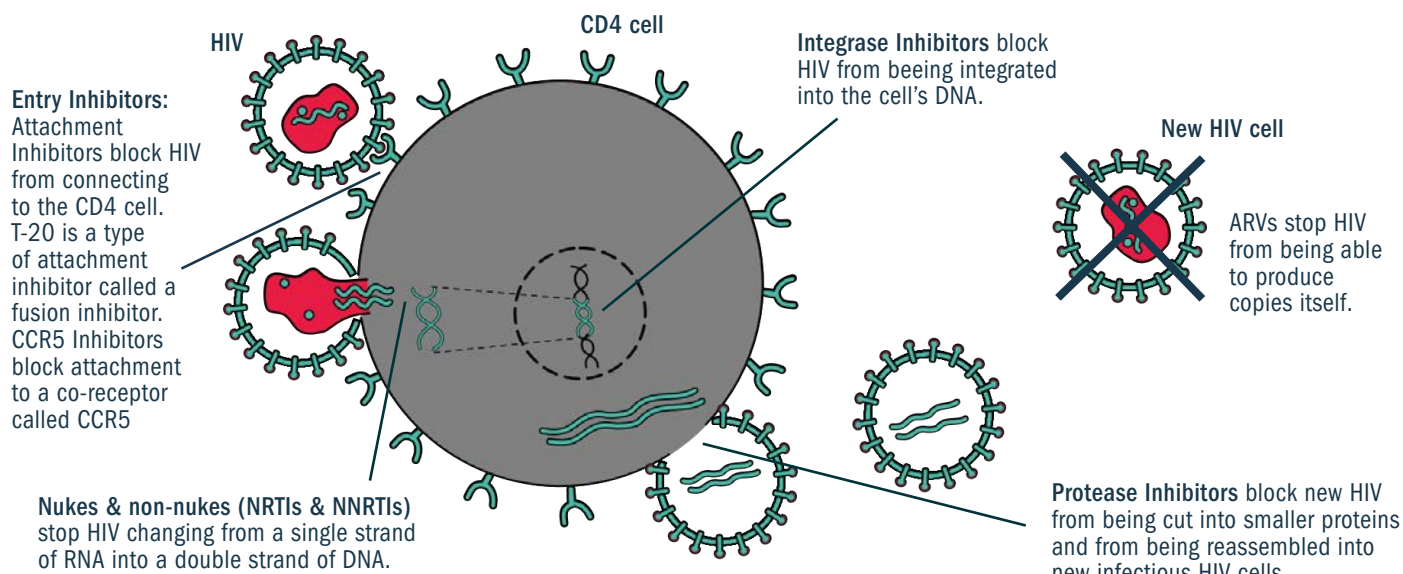


Table 2 below provides examples of the types of ARVs that are currently available, how it stops HIV from multiplying and gives examples of the drugs:<sup>14</sup>

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)
Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)	Stops HIV replicating within cells by interfering with the reverse transcriptase protein	Efavirenz (EFV); Nevirapine (NVP); Delavirdine (DLV); Etravirine (ETR)
Protease Inhibitors (PIs)	Block new HIV from being cut into smaller proteins and from being reassembled into new infectious HIV cells.	Lopinavir/Ritonavir (LPV/r); Nelfinavir (NLF); Darunavir (DVR)
Fusion or Entry Inhibitors	Prevents HIV from binding to or entering the body's immune cells	Enfuvirtide (INN); Maraviroc (MVR)
Integrase Inhibitors (INSTI)	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 usually includes at least three drugs from the different types, called combination therapy. When a person becomes eligible for treatment, the first group of ARVs that people take is called the **first-line regimen**.

**Recommended 1st line ARV regimens for adults and adolescents:**



The preferred option (see Table 3 below) is usually: TDF + 3TC/FTC + EFV. In a few cases, due to medical contraindications, one of these drugs may be substituted with the alternate option, but this is rare.

The following tables summarize global guidance by WHO on the best available first- and second-line regimens for adults, adolescents and children living with HIV.

Table 3: WHO-recommended first-line ARV regimens: <sup>15</sup>

\*XTC = 3TC or FTC

For adults and adolescents (10-19 years)	Recommended regimen
Preferred Option	TDF + XTC + EFV <sub>600</sub>
Alternate Options	AZT + 3TC + EFV <sub>600</sub> AZT + 3TC + NVP TDF + XTC + NVP TDF + XTC + DTG (New) TDF + XTC + EFV <sub>400</sub> (New)
First-line therapy for children less than 3 years of age	
Preferred Option	ABC or AZT + 3TC + LPV/r
Alternate Option	ABC or AZT + 3TC + NVP
First-line therapy for children 3 years to less than 10 years <35kg	
Preferred Option	ABC + 3TC + EFV
Alternate Options	ABC + 3TC + NVP AZT + 3TC + EFV AZT + 3TC + NVP TDF + XTC + EFV TDF + XTC + NVP



## Recommended 2nd line ARV regimens:

Second-line therapy:



Table 4: Recommended second-line ARV regimens<sup>16</sup>

Second-line therapy for adults	ARV regimen (Fixed-Dose Combinations are preferable)
Preferred Options	<p>2 NRTI + ATV/r or LPV/r (heat stable FDCs of boosted PIs are the preferred approach).</p> <p>The following sequence of 2nd line NRTI backbone options is recommended:</p> <ul style="list-style-type: none"> <li>· If in 1st-line, failure was with TDF + XTC, use AZT + 3TC</li> <li>· If in 1st-line, failure was with AZT + 3TC, use TDF + XTC</li> </ul>
First-line therapy for children less than 3 years of age	No change is recommended unless there is advanced clinical disease progress or lack of adherence specifically due to poor palatability of LPV/r
Second-line therapy for children 3 years to less than 10 years <35kg	
Preferred Options	<p>AZT + 3TC + EFV if ABC/AZT + 3TC + LPV/r was the first-line regimen</p> <p>ABC or TDF (only for children older than 2years) + 3TC + EFV if AZT +3TC +LPV/r was the first line option</p>
Alternate Options	<p>AZT + 3TC + LPV/r</p> <p>ABC or TDF + XTC + LPC/r</p>

In the next section we will examine why it is so important to check (monitor) if your ARV treatment is working. This is done through Routine Viral Load Testing.

## Useful Resources:

1. *MSF's ART Flipchart*. December 2014. Available for download here: [https://www.dropbox.com/sh/lkgjyfhb6035wef/AABDyji-NZWLYI7b-Myxfbjfa/Annex%207\\_Patient%20education%20tools/MSF%20ARV%20Flipchart%20Dec2014.pdf?dl=0](https://www.dropbox.com/sh/lkgjyfhb6035wef/AABDyji-NZWLYI7b-Myxfbjfa/Annex%207_Patient%20education%20tools/MSF%20ARV%20Flipchart%20Dec2014.pdf?dl=0)
2. NAM/Aidsmap.com *The Basics*. A collection of illustrated leaflets providing the basic facts about a variety of topics related to HIV, including treatment. <http://www.aidsmap.com/thebasics> (available for download in 7 languages)
3. *HIV 101 - HIV Information to Help You Understand*, (online fact sheet), About.com. <http://aids.about.com/cs/aidsfactsheets/a/hivbasics.htm>
4. ARVs, (online guide to each type of ARV), i-base. <http://i-base.info/guides/category/arvs>
5. *The Use of Antiretrovirals in the Prevention and Treatment of HIV*, World Health Organization. <http://www.who.int/hiv/topics/treatment/en/>

# 4 MONITORING HIV TREATMENT (VIRAL LOAD TESTING)

## Section Objectives:

The objective of the section is to be able to explain to people living with HIV how they can tell if their HIV treatment is working (called monitoring), including: why viral load testing is important, what the World Health Organization recommends about viral load testing and the current situation regarding access to routine viral load testing.

## Training Materials:

Powerpoint presentation 2: Monitoring HIV treatment

## Training Options:

Option A (approx. 120 minutes)

1. Explain the objective of the Section.
2. Present Powerpoint presentation 2: Monitoring HIV treatment
3. Ask the participants to divide into pairs and to discuss the key points of what they have learnt about monitoring HIV treatment, including: 1. What is the best way to monitor HIV treatment?  
2. How often a person's viral load should be tested.
4. Ask the participants to summarize the session by developing advocacy messages about the importance of monitoring HIV treatment

## Key Messages:

- The goal of taking ARV treatment is to have a suppressed (undetectable) viral load. An undetectable viral load is when there are so few copies of HIV in your blood, that it cannot be detected by the viral load test.
- Once you have started treatment, it is important to check (monitor) if your ARV treatment is working.
- The best way to monitor your ARV treatment is to take a viral load test routinely.
- Adhering to HIV treatment, by taking your ARVs every day at the same time, is key to ensuring that the treatment works.

## 4.1 Why do we take HIV treatment?

The aim of taking ARV treatment is to stop HIV from reproducing and making more copies of the virus in your body. This will decrease your viral load, until it is suppressed. **The goal of taking ARV treatment is to have an undetectable (suppressed) viral load.** This means that your ARV treatment is working. Taking ARVs is the best way to reach viral load suppression.<sup>17</sup>

There are other reasons why we should take ARV treatment, including that it optimizes your quality of life, it maximizes the capacity for the immune system to recover (known as immune reconstitution), optimizes overall clinical outcomes and minimizes the long term effects of a high viral load on your body.

## 4.2 How can we tell if HIV treatment is working?

Once you have started HIV treatment, you will need to continue taking treatment daily for the rest of your life. It is important to check (monitor) if your HIV treatment is working for you.

### 1. CD4 testing:

A CD4 cell count tells you how strong the immune system is, by giving you a level of how many CD4 (soldier) cells are in the body to fight off germs, bacteria or viruses. A healthy CD4 range is between 600 and 1500 cells/mm<sup>3</sup>. A diseased range is between 0 and 500 cells/mm<sup>3</sup>.

CD4 testing has been the most common way to monitor how well a person is responding to ARV treatment, especially in resource-poor settings. However, a CD4 count test is a measurement of people's CD4 white blood cell count, which **does not paint an accurate enough picture of how a person is responding to ARV treatment.** CD4 testing should only be used to monitor HIV treatment if there is absolutely no viral load testing available.

### 2. Viral load testing:

The **best** way to tell if your ARV treatment is working for you is to have a regular viral load test, which **measures the amount of HIV in a sample of blood.** It is used routinely in developed countries, but in many resource-limited countries, it is not available due to cost and other barriers.

## 4.3 What do viral load test results mean?<sup>18</sup>

The viral load result is usually reported as the number of HIV particles (copies) per milliliter of blood (copies/ml). The test is telling us how many copies of the virus can be found in a very small amount of your blood.

The aim of taking ARV treatment is to have a low or undetectable viral load. This means that HIV has stopped making more copies of itself in your body because of the effectiveness of ARV.

## 1. A low or undetectable viral load result:

A viral load of less than 1000 copies per ml, is a low viral load. An undetectable viral load usually means that there is a lower number of HIV in your blood than what can be detected by the viral load test used.

An undetectable viral load does not mean that you have no HIV in your blood: it only means that there is so little HIV in your blood, that the current tests we have cannot detect it. This means that your HIV is not multiplying in your body and that your ARV treatment is working.

## 2. A high viral load result:

A high viral load is any result above 1000 copies per milliliter. A high viral load result means that HIV is multiplying, even though you are taking your treatment.

This could mean that you are facing some problems to take your treatment correctly every day (non-adherence). This has been found to be the most common reason for a detectable viral load. You and your health care provider or peer supporter can address your adherence problems early, which should bring your viral load down to low or undetectable.<sup>19</sup>

In a few cases, you could be taking your ARV medication correctly (being adherent), but you have become resistant to your treatment. This means that the HIV has learnt how to multiply in your body, even when you are taking your treatment correctly, as illustrated in figure 5 below.

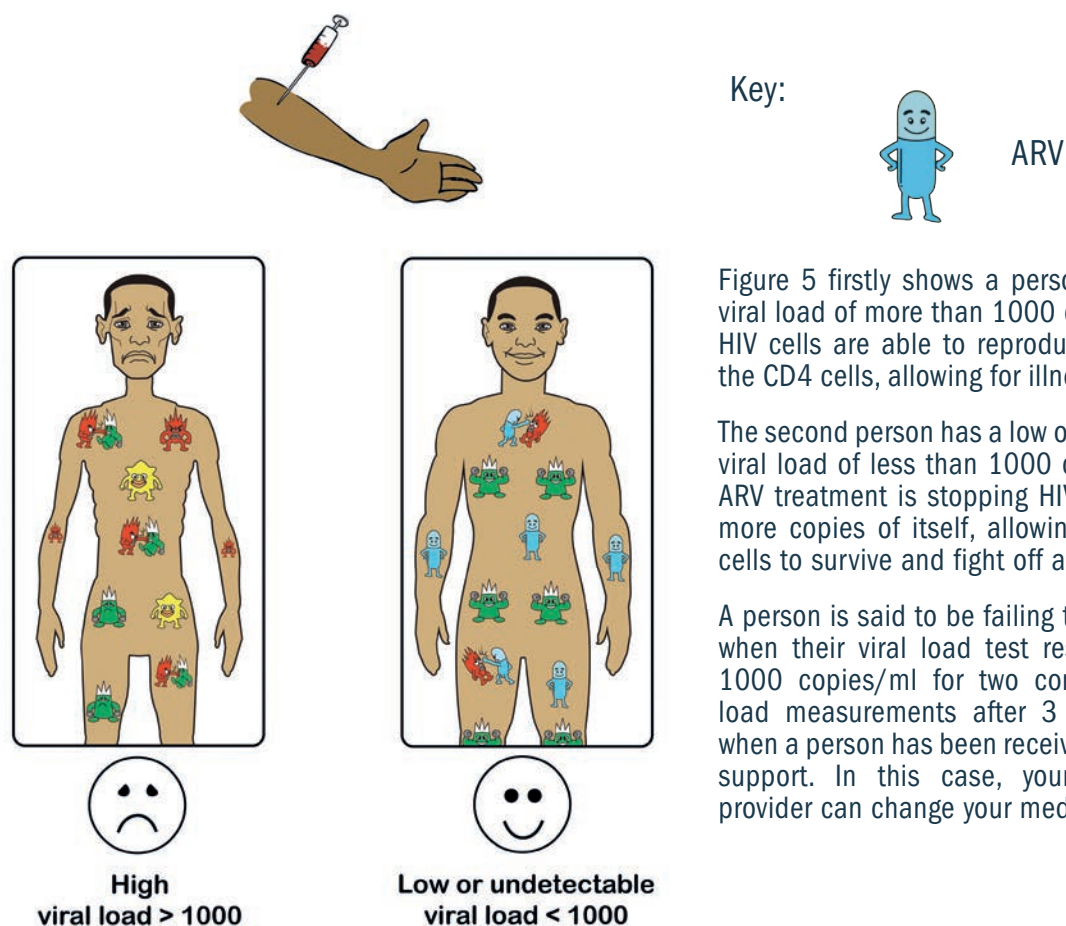


Figure 5 firstly shows a person with a high viral load of more than 1000 copies/ml. The HIV cells are able to reproduce and kill off the CD4 cells, allowing for illnesses to occur.

The second person has a low or undetectable viral load of less than 1000 copies/ml. The ARV treatment is stopping HIV from making more copies of itself, allowing for the CD4 cells to survive and fight off any illnesses.

A person is said to be failing their treatment when their viral load test results is above 1000 copies/ml for two consecutive viral load measurements after 3 months, even when a person has been receiving adherence support. In this case, your health care provider can change your medication.

Figure 5: High and low/undetectable viral load. These figures are taken from the MSF ART Toolkit, 2014

## 4.4 WHO recommendations for monitoring HIV treatment<sup>20</sup>

Guidelines for ART management issued by the World Health Organization (WHO) have recognized the importance of viral load monitoring; and in 2013, routine viral load testing was more strongly recommended as the monitoring strategy for ART than ever before. The 2015 guidelines recommendations are summarised below:

- Once a person has started taking ARV treatment, the first viral load test should be taken at 6 months and then again at 12 months.
- Every person should receive a viral load once a year as part of the routine follow up of HIV-positive people on ART.
- WHO defined a viral load of less than 1000 copies/ml as indicative (a sign) of successful treatment.
- If your viral load is found to be high (above 1000 copies/ml) through any of these tests, another viral load test should be taken 3 months later.
- During this time, adherence support should be provided.

## 4.5 Adherence

For ARV treatment to work, it is very important that people take their medication every day, at the same time, as prescribed by their health care provider. This is called adherence, which is the most important factor that determines the success of taking HIV treatment.

In HIV treatment, people usually take a combination of three anti-HIV medications (which are often combined into one tablet/pill) as described in Section 3. Adherence to an HIV regimen gives HIV medicines the chance to do their job: to prevent HIV from multiplying and destroying the immune system.

ARVs should be taken every day as close to the same time as possible. Poor adherence occurs when we often take our pills too late, when we forget to take a dose, when we do not take all our pills or when we stop taking our treatment. Poor adherence can also be caused by health systems issues, such as no ARVs being regularly available at your clinic or you not being treated well by health care providers.

If you do not take your ARVs every day at a chosen time, you will not have enough ARVs in your body to stop HIV from multiplying, which will reduce the number of CD4 cells to fight off infections in your body. If the level of ARVs in your body is too low, HIV is able to transform itself (mutate) and will start multiplying again. This means that the HIV has become resistant to the ARVs you are taken,<sup>21</sup> as illustrated in Figure 6.

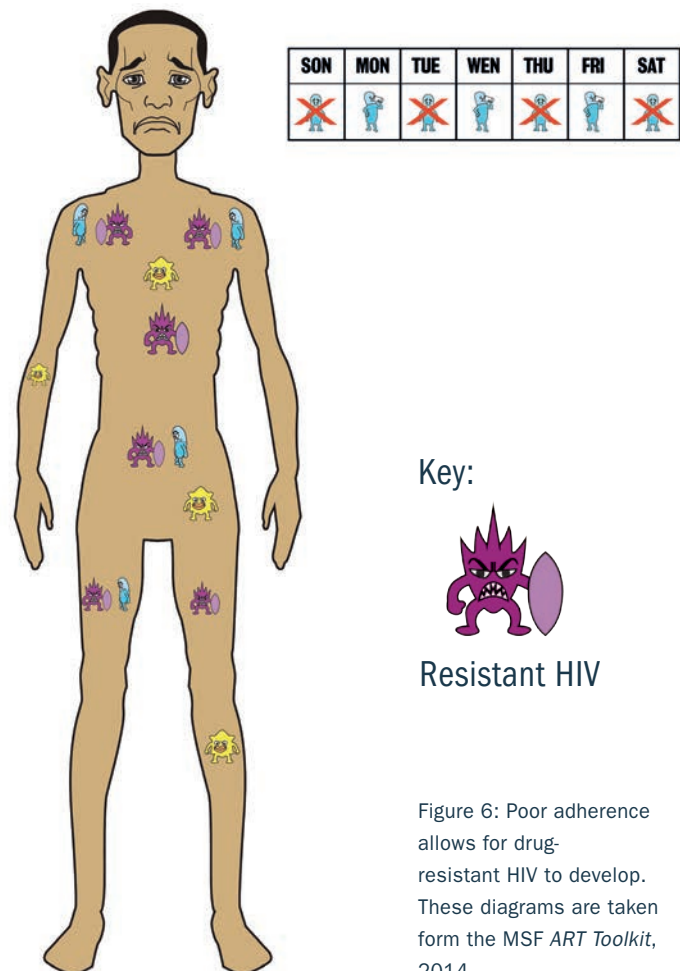


Figure 6: Poor adherence allows for drug-resistant HIV to develop. These diagrams are taken from the MSF ART Toolkit, 2014

## 4.6 Why is viral load testing important?

Viral load monitoring is important for monitoring how well ARV treatment is working. It is the earliest indicator for showing that the virus is reproducing. Only after the viral load has been increasing for some time does this lead to a drop in the CD4 cell count.<sup>22</sup>As such, viral load is the preferred monitoring strategy for patients on ARV over CD4 cell count.

1. A high viral load result can be an indication (sign) that the person may be having difficulties with their treatment adherence. This allows an opportunity for adherence support. Providing additional adherence support to people with high viral load often leads to viral suppression, according to data from MSF sites in South Africa.
2. Viral load testing also helps to identify people who are indeed failing their treatment and need to be switched to another set of medicines.

Viral load monitoring can identify these problems much sooner than CD4 testing. It is better to not wait for the body to reveal problems with the immune system or to show clinical signs of treatment failure. This misses an ideal moment to provide additional adherence counselling or where necessary, to change to second-line treatment.

Viral load testing avoids people having a high viral load over a long period and can prevent people from switching to more expensive and complicated regimens when it is not necessary. It also prevents illness and potential transmission of HIV.

Table 5: The benefits of viral load testing

<b>The benefits of viral load testing:<sup>23</sup></b>	
For people living with HIV	<p>Knowing if my treatment is working.</p> <p>Receiving adherence support to reach an undetectable viral load, if necessary.</p> <p>Switching to a different ARV regimen early, before I get sick, if I have drug-resistance.</p>
For treatment providers	<p>Viral load testing means I can know if the treatment a person is taking is not working. I can then provide additional adherence support or switch their treatment, when necessary.</p>
For programme managers	<p>Better information about treatment adherence and health outcomes across the programme. Assists in identifying areas that need more attention.</p>
For policy-makers and national governments	<p>Monitoring of community-wide progress towards viral suppressions.</p> <p>Assists in identifying areas that need more attention.</p> <p>Allows for a decrease in unnecessary spending on incorrectly switching regimens.</p>
For donors	<p>Can reduce global HIV incidence by reducing viral transmission within communities.</p> <p>Allows for a decrease on unnecessary spending on incorrectly switching regimens.</p>

Furthermore, implementation of routine viral load testing will be essential to achieve the UNAIDS 90-90-90 targets: 90% of people living with HIV should know their status, 90% who know their status should be on ART, 90% of those on ART should be virologically suppressed. In order for these targets to be reached, routine viral load testing will be essential.

## 4.7 HIV viral sample preparation and laboratory testing

Samples for viral load testing collected from patients, can be sent from health facilities to the laboratory as whole blood or as a Dried Plasma Spot (DBS). DBS samples have less strict requirements for transport and storage unlike whole blood samples and are the preferred sample types with the scale up viral load testing. Nonetheless, only a handful of machines in the laboratory can accurately provide viral load results from DBS samples.

Currently, viral load testing is still largely conducted in central laboratories with sophisticated equipment and highly trained technicians. There are different techniques and machines available for measuring viral load. Most of the laboratory machines calculate viral load based on the Polymerase Chain Reaction (PCR) technique; which quantifies HIV by amplifying the target nucleic acid. It is the most used viral load test technique.

Complexity and costs of reagents and machines have been barriers for scaling up viral load testing in developing countries. The turn-around-time (TAT) for a viral load result varies with: laboratories, availability of reagents, testing backlog and

equipment function, among other factors. However, experience from MSF-supported laboratories has shown a TAT of between 7 days to 14 days, depending on setting.

Viral load test blood samples are sent to a centralized laboratory that send the results back to the health-facility. This can cause delays in getting results and can cause patients being lost in the HIV treatment cascade, because they need to return to the health facility on a different day to receive their viral load results.

There is a global move to demand the development and implementation of a viral load test that can be used and analyzed in health facilities, in a decentralized manner. This is called point-of-care (PoC) viral load testing.

New viral load point-of-care diagnostics have been developed and some are under development. They hold the potential to simplify ARV treatment monitoring as they bring viral load testing closer to the patients which could accelerate clinical decision making. These PoC machines are less expensive, are smaller and less complicated to use.<sup>24</sup>

According to the **WHO ASSURED** criteria, point-of-care testing should be:

- A:** Affordable
- S:** Sensitive (giving a positive result when the result is truly positive)
- S:** Specific (giving a positive result when the result is truly positive)
- U:** User-friendly
- R:** Rapid and robust (must provide the results as soon as possible)
- E:** Equipment-free
- D:** Deliverable to those intended

Examples include:



a. GeneXpert HIV viral load testing



b. SAMBA PoC for viral load testing

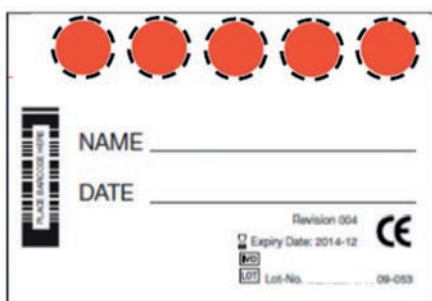


c. ALERE PoC Tool

## What procedures are followed to administer a viral load test?

1. Trained medical staff draw blood from a vein with a syringe and use the following technique:

- a) **Dried Blood Spot (DBS) sample:** blood collected using a syringe can be directly applied gently to fill each of the 5-circles of the DBS card as shown in the figure below. Care must be taken to make sure the circles do not touch each other when blood is being applied. The DBS card should be left to dry for 4 hours and the samples can be kept at room temperature for 1-2 weeks, or for longer at lower temperatures, before being sent to the laboratory.
- b) **Whole blood and or plasma samples:** blood collected through a syringe should immediately be put into anti-coagulated tubes for preservation. The samples should reach the laboratory within 6 hours of collection, if kept at room temperature, or the sample can be separated into plasma (only in health facilities with small laboratories that can centrifuge the blood), which can be stored for up to 5 days at 4 degrees Celsius.<sup>25</sup>



DBS sample for HIV viral load enumeration



Anti-coagulated blood sample for HIV viral load enumeration

## 4.8 Access issues to routine viral load testing

Unfortunately, despite the 2013 World Health Organization recommendations of viral load as the preferred ARV monitoring tool, it is still not routinely available to many HIV-positive people, especially in low and middle-income countries. MSF and ITPC and partners have been conducting surveys to assess the extent to which routine viral load testing is available in resource-limited settings.

MSF conducted an analysis of survey data on access to viral load testing across 47 MSF projects in 15 resource-limited countries. Only 61% of the projects had some access to viral load, but this was used mainly in a targeted way to confirm treatment failure, following clinical or immunological failure before switching to second-line ART. Another 2012 internal review of MSF data from 12 countries found that only 2% of patients had ever received a viral load test result.<sup>26</sup>

ITPC and ARASA also conducted a survey of 12 African countries by community research teams.<sup>27</sup> Eight of the countries reported the existence of a government policy of the WHO guidelines regarding routine viral load testing. However, the survey found that only three countries actually provided routine viral load monitoring. The survey also found that people were asked to pay for viral load testing in eight of the countries.

The survey also found that in the majority of cases, viral load tests were only done when knowledgeable people living with HIV requested them. This is problematic as very few people know about the importance of viral load testing and may be requesting them. This finding is the basis for providing knowledge through various treatment education forums to strengthen communities to demand for access to routine viral load testing.<sup>28</sup>



## 4.9 Why do people not have access to viral load testing?<sup>29</sup>

There are many reasons why people do not have access to routine viral load testing. These reasons are different from place to place and will depend on the contextual factors.

- Viral load tests are often not available in HIV clinics.
- The high price of a viral load test (at US\$14-US\$85 per test) is unaffordable to most people who need it.
- The equipment for monitoring viral load is expensive and requires infrastructure, electricity and experienced laboratory technicians.
- The consumables, like reagents and other products, needed to carry out the tests, often run out because of poor planning and re-stocking management.
- There is a low level of awareness among health providers and people living with HIV, about the importance and availability of routine viral load monitoring.

It is important to know and understand why routine viral load testing is not available in your country, based on the context-specific issues. Mapping out these reasons will help inform the advocacy priorities you take on in your viral load campaigns.

In the next section we will be discussing how to advocate for viral load testing to be made available routinely.

### Useful Resources:

- ITPC's *Be Healthy, Know your viral load* campaign [www.knowyourviralload.org](http://www.knowyourviralload.org)
- MSF ART *Flipchart* [https://www.dropbox.com/sh/lkgjyfhb6035wef/AACt0WZNt3k8dE8Js\\_-lgpa/Annex%207\\_Patient%20education%20tools?dl=0](https://www.dropbox.com/sh/lkgjyfhb6035wef/AACt0WZNt3k8dE8Js_-lgpa/Annex%207_Patient%20education%20tools?dl=0)
- MSF *Viral Load Toolkit*: <http://www.msfacecess.org/content/undetectable-how-viral-load-monitoring-can-improve-hiv-treatment-developing-countries>
- *Treatment Training for Advocates*: Chapter 2. I-base. Available here: <http://i-base.info/ttfa/section-2/>

# 5 ADVOCATING FOR ROUTINE VIRAL LOAD TESTING

## Section Objectives:

The aim of this section is to learn how to demand Routine Viral Load Testing in your community, through advocacy. This section will examine the advocacy cycle, discuss entry points for advocacy, share existing advocacy resources and provide you with an opportunity to develop your own advocacy plan for access to routine viral load testing.

## Training Materials:

PowerPoint presentation 3: Advocating for Routine Viral Load Testing

## Training Options:

Option A (approx. 90 minutes)

1. Explain the objective of the section.
2. Show the MSF *HIV Status: Undetectable* video
3. Show the ITPC *Be Healthy, Know your viral load* video.
4. Facilitate a discussion with participants about why routine viral load testing is needed.
5. Present PowerPoint presentation 3: Advocating for Routine Viral Load Testing.
6. Breakaway sessions: Divide participants into groups according to their organizations, country or region. Ask each group to develop an Advocacy Plan (30 minutes) and to present back to the group (5 minutes each).

Option B (approx. 120 minutes)

1. Explain the objective of the Section.
2. Show the MSF *HIV Status: Undetectable* video.
3. Show the ITPC *Be Healthy, Know your viral load* video.
4. Facilitate a discussion with participants about why routine viral load testing is needed.
5. Present PowerPoint presentation 3: Advocating for Routine Viral Load Testing.

6. Breakaway sessions: Divide participants into groups according to their organizations, country or region. Ask each group to develop an Advocacy Plan (30 minutes) and to present back to the group (5 minutes each).
7. Allow for discussion at the end of each presentation where groups can provide feedback on each other's Advocacy Plans.
8. Ask the participants to summarize the session by developing advocacy messages about the importance of monitoring HIV treatment.

## Key Messages:

- Understanding your current situation before starting an advocacy intervention is key to identifying the barriers that exist and will help prioritize what to address first.
- Demand routine viral load testing. It is your right to know if your ARV treatment is working.
- By investing in routine viral load testing now, overall costs can be reduced as less people are unnecessarily switched to more expensive second-line treatment. Costs could also be reduced if viral load testing completely replaced CD4 testing.
- Working in partnership with organizations that have similar goals to your organization, can be an effective way of increasing impact and sharing tasks.
- If the evidence shows that a specific model of care can work in one place, you can advocate for it to be implemented in another part of the world, where the context is similar.
- Using personal stories about the impact of an advocacy issue can be effective to illustrate to decision-makers why it is important to address the issue.

## 5.1 What does advocating for viral load testing mean?

Advocacy by communities, by people living with HIV in particular, has been key to improving access to HIV care throughout the world and has brought dramatic changes and improvements in antiretroviral therapy. Just as activists and communities fought for their right to access the best medicines for their HIV, we now have the opportunity to demand for routine viral load testing to be made available to all.

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'.<sup>30</sup>

### Characteristics of successful advocacy:<sup>31</sup>

The experiences of ITPC and its partners around the world show that there are factors that can 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.
- **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.

## 5.2 Creating an Advocacy Plan

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.

There is no one agreed way to develop an advocacy plan. Where possible, activists should use planning frameworks that they already know, 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:

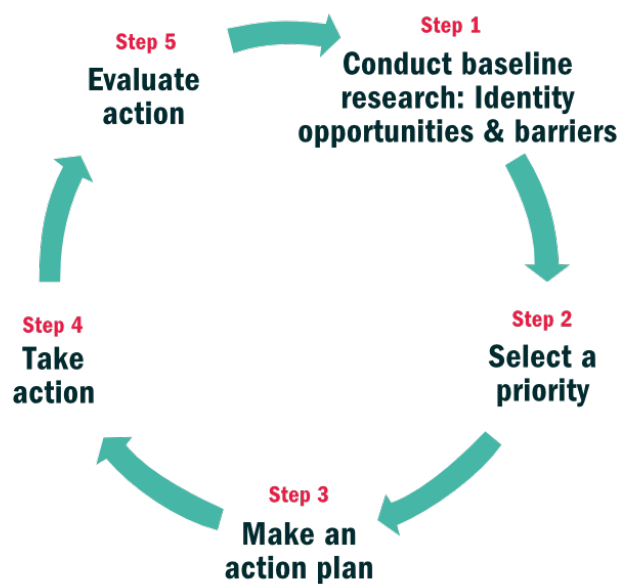


Figure 7: Steps in the Advocacy Cycle

## Step 1: Conduct Baseline Research

Before any advocacy work begins, you need to know the extent of the problem. You could research documents and reports, but these often do not give a true reflection of what is happening, or may not contain specific information about your area. For example, you could ask questions, such as:

- What does my country's ARV guidelines say about making routine viral load testing available? Do our guidelines meet the recommendations made by the World Health Organization?
- Is viral load testing offered free of charge or is there a cost involved to the person living with HIV?
- Have people living with HIV in my community/country been able to access a viral load test, if they request one? Is viral load testing **routinely** done by health care providers?
- Is there a stable supply of viral load tests available?
- Is the laboratory infrastructure required to provide viral load test results available?

Community monitoring is another way that you could use to research what the current state of access to viral load testing is in your community. Community monitoring is when members of a community conduct research themselves about an issue. It can involve asking other community members about their experience of accessing a service.

Below is a list of questions you could ask people living with HIV at a health service:

1. Do you know what a viral load test is? Do you know what it measures?
2. Have you ever been offered a viral load test by your health care provider?
3. Have you ever taken a viral load test?
4. How often is your viral load tested?
5. Have you ever had a problem accessing viral load testing?

Getting the answers to the above questions will give you an idea of whether viral load testing is available in your community, if it is done routinely, if there are any supply issues and if people living with HIV are well-informed about routine viral load testing.

Once you know the extent of the problem, you can identify opportunities and barriers for change. This involves asking questions such as: What are the specific opportunities and barriers to advocating for routine viral load testing? What are the causes of routine viral load monitoring not being available?

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.' An opportunity to advocate for routine viral load testing, for example, could be when the World Health Organization announces guidelines that recommend routine viral load testing or when a new scientific article shows the benefits of routine viral load testing.

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.'

Your opportunities and barriers 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.

List all your potential opportunities and barriers for advocating for routine viral load testing.

## Challenges for scaling up routine viral load testing:

In order to be able to advocate for viral load testing to be made available to all people living with HIV, we need to understand why routine viral load testing is essential and we also need to understand the challenges for scaling up RVL. This will help inform the Advocacy Plan we decide to implement.

1. Viral load testing can be expensive for governments. However, it is important to note that by investing in routine viral load testing now, longer-term costs can be reduced as less people are unnecessarily switched to more expensive second-line treatment. Costs could also be reduced if viral load testing completely replaced CD4 testing.
2. The infrastructure required to conduct viral load testing is complex, such as laboratory equipment and trained staff to analyze results. A point-of-care viral load test (which requires no electricity, operates via fingerprick whole blood, requires no refrigeration, is battery operated, requires simple training, can be operated by a community health worker, is less expensive than compared to laboratory-based tests) is necessary.
3. Health care providers are not always motivated to follow protocols and there may be lack of human resources to provide the test and to do the counselling.
4. Many people living with HIV and health care providers do not know of the importance of viral load testing for monitoring HIV treatment. Many still believe that CD4 testing is the best way to monitor if HIV treatment is working.

### Case Study: Thylo Community ART Groups (CAGs) and education about viral load testing

In order for more people to access and demand viral load testing, they need to understand the importance of monitoring HIV treatment. Community education can lead to a change in health policy as more people demand a specific service, as illustrated in the example of the Thylo Community ART Groups.

From 2012 to 2015, MSF collaborated with Thyolo District Health office to pilot a community model for ART distribution called Community ART Groups (CAGs). CAGs are self-formed groups of stable PLHIVs who are on ART, who take turns attending the health facility to receive a clinical assessment and monitoring tests, while collecting drugs for themselves and the other members of the CAG.

The main objective of the CAG model of care is to reduce the workload of the existing health providers in the health facilities, reduce the number of visits to the health facility by PLHIVs and to improve long-term retention in care, by reducing access barriers and enhancing the role of the ART client in the management of their HIV.

CAGs help to improve PLHIV's access to ART by addressing barriers to accessing health facilities such as long distance, transport costs and spending long hours at the health facility. CAGs also reduce the workload for health workers.

One of the requirements for one to join a CAG is to have a viral load of less 1000 copies/ml of blood. This means that before one joins a CAG, he or she must get his or her viral load tested. This means that people living with HIV have to be provided with treatment literacy about the importance of viral load testing in order to join the CAGs.

## 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?

For any advocacy issue, you will be faced with many different types and levels of opportunities and barriers in accessing treatment. However, you will rarely be able to address all of them at once. Instead, it is important to set priorities. Having clearly set priorities enable community activists to work strategically and make the biggest difference. It also enables you to make the best use of your resources (including your energy, skills and funding).

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, as shared in the example below:

Criteria	✓	✗
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 ideas of what could be done to make a difference to 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?)		

## 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, as illustrated below:<sup>32</sup>

Objectives	Activities	When	Targets	Partners	Resources
This is a short-term target that contributes to achieving our goal. It reflects the end result of our activities.	These are the advocacy actions that we will take to achieve your objective.	These are the advocacy actions that we will take to achieve your objective.	These are the people, organizations or institutions that we will target to bring about the change that we want.	These are our supporters who we will collaborate with to carry out our advocacy.	These are the resources (such as people, money and skills) that we have or need to do our advocacy.

## Step 4: Take action.

This involves putting our advocacy plan into action. This might involve strategies such as lobbying parliamentarians, holding demonstrations or working with the media.

Advocacy for HIV treatment monitoring involves:<sup>33</sup>

- Community members coming together and taking action.
- Identifying priority issues that affect access to routine viral load monitoring for people living with HIV.
- Identifying what change is needed for those issues, such as in policies, funding, infrastructure 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 for viral load testing can take many forms, depending on the needs of the community and the political and financial context. It can involve a wide range of different types of activities, including:<sup>34</sup>

- **Using campaigning methods:** handing petitions (signed by community members) to decision-makers, carrying out public rallies or a demonstration
- **Raising awareness:** through peer-to-peer education, workshops, training sessions and treatment literacy.
- **Lobbying:** such as holding meetings with decision-makers and influencing people who can bring about change.
- **Working through the media:** such as writing a press release, doing a media interview, using social media to relay your message.
- **Participating in decision-making forums:** Representing the views of your community at meetings where decisions are made such as Community Advisory Boards, District Planning Communities, Country Coordinating Mechanisms or National AIDS Councils.
- **Monitoring access:** conducting community led monitoring surveys to assess if people have access to services and/or their human rights.



## Case study: Influencing the PEPFAR COP<sup>35</sup>

One crucial way that civil society organizations can advocate for routine viral load monitoring to be made available, is by influencing key donors who fund HIV programmes. The United State's President's Emergency Plan for AIDS Relief (PEPFAR) is a key donor that funds routine viral load monitoring in resource-limited settings.

In the majority of countries where they work, the PEPFAR program completes an annual Country Operational Plan (COP) that describes national PEPFAR targets, goals, implementing partners and budgets. According to their own policies, PEPFAR must engage with civil society when reviewing their COP. There are many ways that civil society can influence COPs, such as:

- Writing to and/or requesting a meeting with the PEPFAR Coordinator, and heads of relevant agencies in your country.
- Ask to review the targets in the draft COP. Look to see what the targets related to routine viral load testing in your country are.
- Craft a clear, specific set of recommendations about what PEPFAR should commit to fund: targets, funding levels, etc. Provide any evidence you can. The most effective recommendations will be very specific and will tackle what PEPFAR does or could fund and provides ideas about what should change.
- Lobby national decision-makers to enact policy through national strategic plans or commitments that can be used to leverage more ambitious routine viral load testing targets.
- Share questions and advice with other advocates working on similar campaigns.

### 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?

## Case Study: Creating demand for routine viral load testing

An example of the implementation of an advocacy plan is the launch of ITPC's *Be Healthy, Know your viral load* campaign which took place in Lusaka, Zambia in October 2015.

### What is the context?

By as early as 2013, the World Health Organization had recommended that routine viral load testing be used to monitor HIV treatment. It is the gold standard (the best method) for checking if a person's ARV treatment is working in resource-rich countries, but is unavailable in many resource-poor settings. This is because of the cost of routine viral load testing and the infrastructure and human resources needed to set up a system for delivering routine viral load testing to all people living with HIV.

### What was the barrier to HIV treatment?

A survey by ITPC and ARASA also found that in the majority of cases, viral load tests were only done when knowledgeable people living with HIV requested them. This is problematic as very few people know about the importance of viral load testing and may be requesting them. This finding is the basis for providing knowledge through various treatment education forums to encourage communities to demand viral load testing.

### What were the advocacy actions?

- ITPC conducted the survey as a way of gathering information on the lack of RVLT in 12 countries in Africa. The information gathered from this survey formed the basis of all the advocacy actions.
- To increase the demand for viral load testing, ITPC made a short film about the personal impact of viral load testing on the daily lives of two people living with HIV.
- A website was developed with information about viral load testing for people living with HIV about the importance of routine viral load testing and to encourage people to demand viral load testing to know if their treatment is working. This included a template letter that could be sent to decision-makers, demanding that routine viral load testing be made available to all people living with HIV.
- An information leaflet for people living with HIV and decision-makers was developed, outlining the benefits of viral load testing for people living HIV and the HIV response.
- In October 2015, a march was held in Lusaka, Zambia, to mark the launch of the campaign, as a pan-African campaign for improving access to RVLT.

### What were the advocacy results?

As a direct result of the *Be Healthy, Know your viral load* campaign launch held in Lusaka and subsequent meetings with the Treatment Advocacy and Literacy Campaign (TALC), the Zambian Ministry of Health issued a directive to all ART facilities, instructing the immediate uptake of viral load testing. In support of the anticipated increase in viral load testing, the Ministry has committed to procuring viral load testing machines for all provinces (outside of the sole machine currently in use in a private laboratory in Lusaka). As of March 2016, several clinics have already reported the scale up of routine viral load testing.

### Lessons include that:

- Conducting baseline research (sometimes know as a situational analysis) is useful to inform your advocacy campaign.
- Sharing personal stories about the effect of viral load testing helps other people living with HIV relate to the issues and can motivate them to take action.
- Developing targeted advocacy tools that people can adapt and use throughout the campaign gives partners tools to begin using as soon as they are ready to embark on the campaign.

## 5.3 Developing an Advocacy Message:<sup>36</sup>

Advocacy 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 being used in your briefing papers, media interviews, speeches, blogs and meetings with decision-makers.

### Advocacy messages should be:

**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

## Useful Resources:

- Video: *HIV Status: Undetectable*. A film by MSF. Available here: <http://www.msf.org/article/video-hiv-status-undetectable>
- Video: *Be Healthy, Know your viral load*. A film by ARASA and ITPC. Available here: [https://www.youtube.com/watch?time\\_continue=2&v=vCEkfff\\_EOY](https://www.youtube.com/watch?time_continue=2&v=vCEkfff_EOY)
- Resources from the *Be Healthy, Know your viral load* campaign. Available here: <http://www.knowyourviralload.org/language/en/resources/>
- *Advocacy in Action*, International HIV/AIDS Alliance, 2003. <http://www.aidsalliance.org/publicationsdetails.aspx?id=142>
- *MSF Viral Load Toolkit*: <http://www.msfaccess.org/content/undetectable-how-viral-load-monitoring-can-improve-hiv-treatment-developing-countries>
- *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>

# 6 REFERENCES

1. UNAIDS. AIDS by the Numbers 2015. 2015. Available at [http://www.unaids.org/sites/default/files/media\\_asset/AIDS\\_by\\_the\\_numbers\\_2015\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/AIDS_by_the_numbers_2015_en.pdf)
2. International Treatment Preparedness Coalition (ITPC) and the AIDS and Rights Alliance for Southern Africa (ARASA). Routine for you, but not for me: A Sobering Review of Access to Routine Viral Load Monitoring in 12 Countries in Africa. 2015. Available at <http://itpcglobal.org/routine-for-you-but-not-for-me/>
3. Ibid.
4. International Treatment Preparedness Coalition (ITPC) and the AIDS and Rights Alliance for Southern Africa (ARASA). Be Healthy, Know your Viral Load Campaign. Available at [www.knowyourviralload.org](http://www.knowyourviralload.org)
5. Ibid
6. Médecins Sans Frontières. HIV Status? Undetectable Campaign. Available at [www.msfacecess.org/undetectable](http://www.msfacecess.org/undetectable)
7. Ibid.
8. Médecins Sans Frontières. ART Flipchart. December 2014. Available at: [https://www.dropbox.com/sh/lkgjyfhb6035wef/AABDyii-NZWLYI7b-Myxfbjfa/Annex%207\\_Patient%20education%20tools/MSF%20ARV%20Flipchart%20Dec2014.pdf?dl=0](https://www.dropbox.com/sh/lkgjyfhb6035wef/AABDyii-NZWLYI7b-Myxfbjfa/Annex%207_Patient%20education%20tools/MSF%20ARV%20Flipchart%20Dec2014.pdf?dl=0)
9. International Treatment Preparedness Coalition (ITPC). Advocacy for Community Treatment (ACT) Toolkit. 2015. Available at: <http://itpcglobal.org/act-toolkit-launches-in-english-french-russian-and-spanish/>
10. Ibid.
11. i-base. Treatment Training Manual, Section 2. Updated 2016. Available at: <http://i-base.info/ttfa/section-2/>
12. International Treatment Preparedness Coalition (ITPC). Advocacy for Community Treatment (ACT) Toolkit. 2015.
13. World Health Organization (WHO). 2013 Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. 2013. Available at: <http://www.who.int/hiv/pub/guidelines/arv2013/en/>
14. International Treatment Preparedness Coalition (ITPC). Advocacy for Community Treatment (ACT) Toolkit. 2015.
15. World Health Organization (WHO). 2013 Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. 2013. Available at: <http://www.who.int/hiv/pub/guidelines/arv2013/en/>
16. Ibid
17. Médecins Sans Frontières. ART Flipchart. December 2014.

18. World Health Organization (WHO). 2013 Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. 2013. Available at: <http://www.who.int/hiv/pub/guidelines/arv2013/en/>
19. Médecins Sans Frontières. ART Flipchart. December 2014.
20. Ibid
21. Médecins Sans Frontières. Issue Brief: HIV status? Undetectable, Four essential interventions to improve HIV treatment, save lives and reduce transmission. 2013. Available at: <http://www.msfaccess.org/content/issue-brief-hiv-status-undetectable>
22. Ibid.
23. i-base. Treatment Training Manual, Section 2. Updated 2016.
24. Médecins Sans Frontières. ART Flipchart. December 2014.
25. Médecins Sans Frontières South African Medical Unit (SAMU). Viral Load Testing Toolkit. Available at: <http://samumsf.org/blog/portfolio-item/viral-load-vl-toolkit/>
26. Médecins Sans Frontières. How viral load testing can improve HIV treatment in developing countries. 2012. Available at: <http://www.msfaccess.org/content/undetectable-how-viral-load-monitoring-can-improve-hiv-treatment-developing-countries>
27. International Treatment Preparedness Coalition (ITPC) and the AIDS and Rights Alliance for Southern Africa (ARASA). Routine for you, but not for me: A Sobering Review of Access to Routine Viral Load Monitoring in 12 Countries in Africa. 2015.
28. Ibid
29. International Treatment Preparedness Coalition (ITPC) and the AIDS and Rights Alliance for Southern Africa (ARASA). Advocacy Leaflet for Decision-Makers. 2015. Available at: [www.knowyourviralload.org/wp-content/uploads/2015/10/Decision-Makers\\_Flyer\\_FINAL1.pdf](http://www.knowyourviralload.org/wp-content/uploads/2015/10/Decision-Makers_Flyer_FINAL1.pdf)
30. International Treatment Preparedness Coalition (ITPC). Advocacy for Community Treatment (ACT) Toolkit. 2015.
31. Ibid
32. Ibid
33. Ibid
34. Ibid
35. Influencing PEPFAR COPS: An Advocate's guide. AVAC. March 2013
36. International Treatment Preparedness Coalition (ITPC). Advocacy for Community Treatment (ACT) Toolkit. 2015.







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