



WHAT WORKS FOR ME

ACTIVIST TOOLKIT ON DIFFERENTIATED SERVICE DELIVERY

Acknowledgements

The *What Works for Me: Activist Toolkit on Differentiated Service Delivery* was developed with the aim of strengthening community engagement and demand for recipient-centred models of care, specifically differentiated antiretroviral therapy (ART) delivery.

The International Treatment Preparedness Coalition (ITPC) and the AIDS and Rights Alliance for Southern Africa (ARASA) partnered to produce this toolkit, which will be used by community activists, People living with HIV (PLHIV) networks and organizations promoting access to HIV treatment globally. The toolkit was made possible due to the support of the International AIDS Society (IAS).

The Toolkit Project Team included Bactrin Killingo (ITPC), Lynette Mabote (ARASA), Lesley Odendal (ARASA), Anna Grimsrud (IAS) and Kevin Osborne (IAS).

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Note on terminology

This toolkit uses terminology that may be unfamiliar to some users. We used a consultative approach and sought community and partner organization feedback on terminology. We tested out different options during the participatory training workshop in Bangkok, where the toolkit was introduced. These options were reviewed and discussed in plenaries, and final decisions for the document were made after taking all concerned views into account.

The use of acronyms: Each section has an acronym box at the beginning of the section.

People living with HIV (PLHIV): Participants were asked if they felt that this acronym should be replaced with the whole phrase in the document. The consensus was that this was not necessary.

We use **“stable”** and **“unstable”** to refer to specific stages of HIV illness in accordance with the language used by the World Health Organization. We acknowledge that many PLHIV feel that the word “unstable” is potentially stigmatizing, but community feedback suggested that as long as the word is being clearly used in a very specific technical context, it is better to stick to universal language rather than create new terminology upon which we also lack a broad consensus.

We use **“recipients of care”** as much as possible as opposed to “clients” or “patients”.

If we have replaced a term in a direct quote, you will see these brackets to indicate that we have done this [].

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Photo: Ruben Siddiqui/MCSP

SECTION 1.

WHAT YOU NEED TO KNOW ABOUT THIS TOOLKIT

Section 1.1 Background

Section acronyms

ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
ARV	Antiretroviral
DSD	Differentiated service delivery
HIV	Human immunodeficiency virus
IAS	International AIDS Society
ITPC	International Treatment Preparedness Coalition
PLHIV	People living with HIV
SRHR	Sexual and reproductive health and rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

The ambitious Joint United Nations Programme on HIV/AIDS (UNAIDS) 90-90-90 goals¹ are that by 2020, 90% of people living with HIV (PLHIV) will know their status, 90% of people who know their HIV-positive status can access treatment, and 90% of people on treatment have suppressed viral loads. These goals, together with implementation of the World Health Organization (WHO) 2015 recommendation to “treat all HIV-positive individuals on antiretroviral therapy (ART)”, has meant that already overstretched health systems will have to re-examine how ART care is delivered.²

WHO has recommended a “differentiated care approach” to address the current challenges. This approach is based on the core principle of acknowledging diversity and preferences in how PLHIV access HIV-related services. It also accounts for the various contexts within which PLHIV present for care, as well as how they perform on treatment. Differentiated care hinges on the fact that reaching more and more people will require an approach that has the potential to reduce costs and increase efficiencies using already existing resources³ while delivering care “in ways that improve quality of care and life”.⁴ Service delivery models based on features of differentiated care (such as community-based service delivery, task shifting to less highly trained health personnel and decentralization away from primary health centres) can result in increased health system efficiencies yielding improved coverage of ART, levels of adherence and viral suppression.⁵ These are all critical if targets are to be met.

One component of differentiated care is differentiated ART delivery. Findings from a rapid assessment with communities in seven countries in sub-Saharan Africa⁶ showed that awareness and perceptions related to differentiated ART delivery varied widely across countries and key demographics.⁷ While the vast majority of respondents across countries indicated that this was of interest to them and that one or more of the proposed models for differentiated ART delivery would make collecting their antiretrovirals easier, results varied across countries in terms of which existing model would be most suitable.

¹ UNAIDS. 90-90-90: *An ambitious treatment target to help end the AIDS epidemic*. 2014.

² WHO. *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach – 2nd ed*. 2016.

³ The Global Fund to Fight AIDS, Tuberculosis and Malaria. *HIV Information Note*. 2016.

⁴ UNAIDS. *Ending AIDS: Progress towards the 90-90-90 targets*. Global AIDS Update. 2017.

⁵ UNAIDS. *Ending AIDS: Progress towards the 90-90-90 targets*. Global AIDS Update. 2017.

⁶ The International AIDS Society (IAS) supported collaboration between the AIDS and Rights Alliance for Southern Africa (ARASA) and the International Treatment Preparedness Coalition (ITPC) in 2016 to undertake research with communities and PLHIV in order to: (i) understand community perceptions around differentiated models of ART delivery; and (ii) gauge the “readiness” of PLHIV networks and communities to consider differentiated models of ART delivery as part of the treatment continuum.

⁷ ARASA and ITPC. *Differentiated Models of Antiretroviral Therapy (ART) Delivery: Report on The Rapid Assessment Study May - July 2016*. 2016

Recognizing the critical role played by PLHIV in ensuring sustainable, responsive and effective HIV treatment outcomes, the longer-term goal of this work is to galvanize increased community demand for client-centred models of care (and specifically models of differentiated ART delivery) from national governments in Africa. With this in mind, the AIDS and Rights Alliance for Southern Africa (ARASA) and the International Treatment Preparedness Coalition (ITPC) in collaboration with the International AIDS Society (IAS) have embarked on promoting a coordinated and strategic approach to PLHIV community advocacy on this issue; the overall objective is to strengthen the capacity of civil society organizations to advocate nationally and regionally on differentiated models of care and ART delivery. Informative resources and tools, which are developed in a participatory manner, are critical for mobilizing communities, and the aim is that this toolkit is one such resource.

Section 1.2 What is the purpose of the toolkit?

The toolkit is aimed at strengthening PLHIV engagement and demand for client-centred models of care, specifically differentiated ART delivery.

The purpose of this toolkit is to provide up-to-date information, knowledge and skills that are required to advocate for differentiated ART delivery in its different forms.

This toolkit illustrates the value of differentiated ART delivery and of training community activists to passionately advocate about it to PLHIV (including key populations) and policy makers.

Section 1.3 What is not the purpose of the toolkit?

The toolkit is not intended to be used as a comprehensive introductory manual on HIV that would necessarily include a wide range of topics (HIV science, treatment, law and human rights, etc.). There are several useful and detailed toolkits available that already serve this purpose. See: “Read this for more information”.

This toolkit also does not deal with differentiated service delivery across the HIV treatment continuum. However, the intention is that future toolkits on differentiated service delivery (DSD) with relation to testing and treatment initiation will be created and that these will be used as a suite of documents dealing with the broad spectrum of DSD. Finally, the toolkit is not intended to be a guide for participatory training.

Section 1.4 Who should use the toolkit?

The toolkit should be used by community activists, PLHIV networks, trainers, human rights organizations working with PLHIV, and organizations promoting access to HIV treatment.

Section 1.5 How was the toolkit developed?

The toolkit was developed through a consultative process between partner organizations, external reviewers and PLHIV community activists participating in a training workshop. After the creation of the first draft, reviewers’ comments were incorporated as much as possible, bearing in mind the purpose and objectives of the toolkit and in the interests of clarity and optimal length. Since the toolkit is primarily envisaged to be a tool for use by community activists, 23 participants representing six countries at the training workshop spent two sessions reviewing the toolkit with a specific focus on whether concepts were clearly explained and whether the format, language and presentation of content worked for them. The feedback was submitted in writing and was, in large part, included for the next draft. The document was finalized after a further opportunity was given to partners and external reviewers to make final comments. Once the content was finalized, the document was professionally designed to be ready for publication and online dissemination.

Section 1.6 What does the toolkit contain?

Each section in the toolkit contains:

- i. Section objective: This summarizes what community activists can achieve by using the section.
- ii. Useful resources box, including links to other useful documents and websites on the topic.
- iii. Training materials: This is a list of materials (such as PowerPoint presentations or flipcharts) needed for training.
- iv. Training options: These are options for different types of training.
 - Option A:** This is a PowerPoint presentation, which is discussion based and is used to ensure that participants understand the key issues
 - Option B:** Participatory training conducted through group work and activities
 - Option C:** Additional training exercise for a session.
- v. A box with key messages for the topic of the section.
- vi. A box with important terms to understand, highlighting key definitions or terms discussed in the section.

Section 1.7 How to use the toolkit

The toolkit can be used as a part of a comprehensive multi-day training on HIV or as a one-day introduction to DSD and differentiated ART delivery.

As you go through the toolkit, you will see that **key messages, important definitions and useful resources** are highlighted in coloured boxes. In addition, within each section, if we refer to issues that we cannot explore in detail, there will be an accompanying text box entitled, **“Read this for more information”**. Case studies and WHO guidelines are also in distinct boxes.

Read this for more information

For a comprehensive toolkit that supports and trains community activists on issues around HIV and access to treatment, take a look at the **ACT Toolkit 2.0. Advocacy for Community Treatment by the ITPC** (<http://itpcglobal.org/wp-content/uploads/2015/02/ACT-Toolkit-2.0.pdf>).

For a toolkit that focuses specifically on HIV and human rights, take a look at ARASA's **HIV/AIDS and Human Rights Advocacy and Training Resource Manual** (<http://arasa.info/info/training-manuals/>).

For a useful interactive online tool that deals with sexual and reproductive health and rights (SRHR) and HIV, take a look at WHO and the International Planned Parenthood Federation's **SRHR and HIV Linkages Toolkit** (<http://toolkit.srhivlinkages.org>).

For a toolkit on HIV and TB look at ARASA's **6 I's, HIV/TB Communication and Advocacy Toolkit** (http://arasa.info/files/7114/8482/2800/TB_Toolkit_1_Background_19.01.2017.pdf).

For a toolkit on the right to health, look at Fick N, London L & Coomans F. **Toolkit on the Right to Health. Cape Town: Learning Network. 2011.** http://www.publichealth.uct.ac.za/sites/default/files/image_tool/images/8/toolkit_final_version.pdf
Other useful reading includes the Open Society Foundation's **Human rights and HIV/AIDS – Now More than Ever** (https://www.opensocietyfoundations.org/sites/default/files/nmte_20090923_0.pdf).

Useful websites, which contain information about HIV transmission, the latest prevalence data and related information on prevention, treatment, care and support:

- o Avert: <http://www.avert.org/>
- o UNAIDS: www.unaids.org
- o World Health Organization: http://www.who.int/topics/hiv_aids/en/

Photo: by PATH

SECTION 2.

UNDERSTANDING THE HIV TREATMENT CONTINUUM AND LINKING THIS TO DIFFERENTIATED SERVICE DELIVERY

Section acronyms

ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
ARV	Antiretroviral
DSD	Differentiated service delivery
HIV	Human immunodeficiency virus
ITPC	International Treatment Preparedness Coalition
MSF	Médécins Sans Frontières/Doctors Without Borders
PLHIV	People living with HIV
PPT	PowerPoint
WHO	World Health Organization

Section objective

The objective of this section is to ensure that community activists have the necessary information about what the HIV treatment continuum is, common barriers to ART delivery, and why monitoring HIV treatment is important.

Training material

PPT on the treatment continuum
MSF – HIV Status Undetectable, video
ITPC/ARASA – *Be Healthy, Know Your Viral Load* video
Flipchart

Training options⁸

Option A (30 minutes)

1. Explain the objective of the section.
2. Show the MSF HIV Status Undetectable video.
3. Show the ITPC/ARASA Be Healthy, Know your Viral Load video.
4. Facilitate a discussion with participants about why routine viral load testing is needed.

Option B (60 minutes)

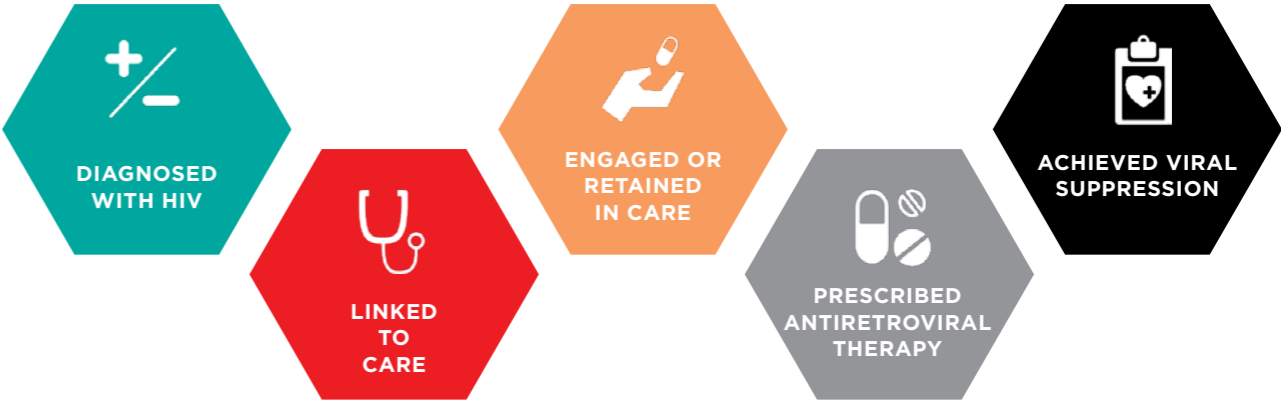
1. Explain the objective of the section.
2. Go through the PPT on the treatment continuum.
3. Divide participants into groups of five or less.
4. Ask groups to brainstorm for 20 minutes about what the continuum might look like in their country/region. Discuss structural and support issues that may affect retention in care and adherence. Discuss key and vulnerable populations.
5. Each group should present five key points.

⁸ Times for these options are estimates based on a room of 20-25 participants.

Useful Resources

FHI 360. *HIV Cascade Framework for Key Populations*. 2015
(<http://www.fhi360.org/sites/default/files/media/documents/linkages-hiv-continuum-framework-oct15.pdf>).
UNAIDS. *Treatment 2015*
(http://www.unaids.org/sites/default/files/media_asset/JC2484_treatment-2015_en_1.pdf).
ITPC. *Activist Toolkit: Campaigning for Routine Viral Load Monitoring*. 2016
(<http://itpcglobal.org/wp-content/uploads/2016/05/ITPC-RVLT-Toolkit-English.pdf>).

Section 2.1 What is the HIV treatment continuum?



(Source: *What is the HIV Care Continuum?* Accessed from www.hiv.gov)

There are various steps that a person living with HIV goes through once they have been diagnosed with HIV. This is known as the continuum of HIV care or the HIV treatment continuum.

The treatment continuum is constituted of a series of steps,⁹ as shown in the following diagram.
The person has counselling and testing, and receives a diagnosis: The HIV care continuum begins with a positive diagnosis of HIV. The only way that a person can be sure of his or her status is to get an HIV test. In order to access the care and treatment needed to stay healthy, a person must know their status.¹⁰

The person is connected to a healthcare provider and monitored: Once a person knows their HIV status, they will be referred to an HIV healthcare provider who can offer treatment and prevention counselling to help them stay as healthy as possible and prevent HIV transmission.

The person receives antiretroviral therapy (ART): Common practice in the past was that people were only put onto ART after their CD4 count reached a certain point. Current WHO guidelines suggest that everyone diagnosed with HIV receives treatment, regardless of their CD4 cell count or viral load. Treatment with ART can help HIV-positive people to live longer, healthier lives, and has been shown to reduce sexual transmission of HIV by 93%.¹¹

The person achieves viral suppression: By taking ART regularly, viral suppression, a very low level of HIV in the blood, can be achieved. This is not a cure, but at a lowered level of virus, people can stay healthy, live an almost normal lifespan, and to a very large extent reduce the chances of passing the virus on to others.¹²

⁹ Centers for Disease Control and Prevention (CDC). *Viral Suppression is Key. Vital Signs*. November 2014.
¹⁰ <https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum>
¹¹ See the HPTN052 Study
(<https://www.hptn.org/news-and-events/press-releases/publication-of-hptn-052-final-results-hiv-treatment-offers-durable>).
¹² CDC. *Viral Suppression is Key. Vital Signs*. November 2014.

WHO guidelines on when to start HIV treatment

In 2015, WHO released new guidelines on when ART should be started. These guidelines support ART initiation in all adults, adolescents and children with HIV at any CD4 cell count or disease stage. WHO recommends that “efforts should be made to reduce the time between diagnosis and ART initiation to improve health outcomes [...] based on an assessment of a person’s readiness”.

(WHO. *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: what’s new*. Policy Brief. 2015)

Important terms to understand

Antiretroviral therapy (ART) is the medication used to treat HIV. The treatment is effective because antiretrovirals (ARVs) control the reproduction of HIV in the body, keeping the amount of virus in the body low, and allowing the body’s immune system to fight infections again.

CD4 cells: These are white blood cells that act as “soldiers” of the immune system, fighting off infections, bacteria and viruses. ART allows these cells to increase again.

Adherence: This involves people taking their medication at the same time every day, and is the most important aspect in determining the success of taking HIV treatment. Adherence prevents the immune system from being weakened and helps avoid the development of drug-resistant forms of the virus.

Viral suppression: When a person has a very low level of HIV in the blood.

Viral load: The amount of HIV in a sample of blood.

Read this for more information

The science of HIV, including testing, diagnosis and treatment:

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).

Module 2 and 3 of the ACT Toolkit 2.0. **Advocacy for Community Treatment by the ITPC** (<http://itpcglobal.org/wp-content/uploads/2015/02/ACT-Toolkit-2.0.pdf>).

What do we mean by lost to follow up?

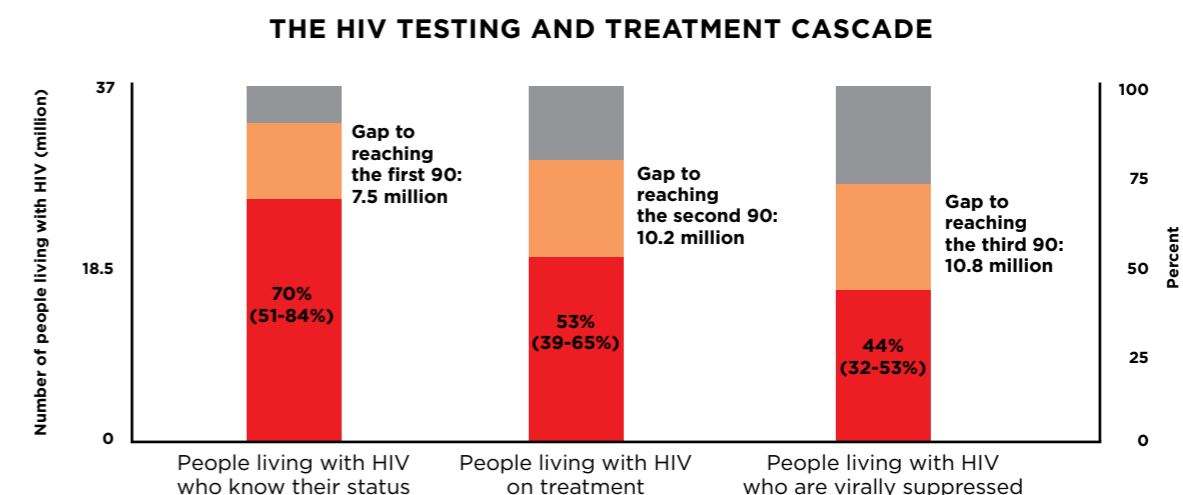


FIGURE 1: KNOWLEDGE OF HIV STATUS, TREATMENT COVERAGE AND VIRAL LOAD SUPPRESSION, GLOBAL, 2016¹³

As the graph shows, there are “gaps” or people being “lost to follow up” out of the HIV care continuum. These gaps are indicators that can illustrate problems in access to services.¹³

What do the “gaps” show us?¹⁴

- Millions of PLHIV have not joined the treatment continuum because they have not been diagnosed with HIV.
- Many people do not continue to access care following their diagnosis because they lack necessary support and proactive interventions.
- Many individuals who test positive for HIV are not effectively linked to care.
- Many who are linked to care do not receive antiretroviral therapy once they are eligible according to WHO criteria.
- Many who start HIV treatment are not retained in care.

It is important to understand that while personal responsibility plays a role, the gaps are often caused by logistical, structural and practical barriers in terms of access to healthcare. Examples are if someone has to go to different places for testing and then treatment, if diagnosis is not immediately followed by linkage to a healthcare provider, or if the proper information is not provided. Individuals who have been newly diagnosed may also delay engaging with treatment services if they are worried about barriers, such as cost and time of transport, lack of confidentiality or distrust of health services.¹⁵

¹³ UNAIDS. *Ending AIDS: Progress towards the 90-90-90 targets*. Global AIDS Update. 2017

¹⁴ UNAIDS. *Treatment 2015* (http://www.unaids.org/sites/default/files/media_asset/JC2484_treatment-2015_en_1.pdf).

¹⁵ <https://www.avert.org/professionals/hiv-programming/treatment/cascade>

Section 2.2 Barriers to accessing ART delivery

As revealed in the treatment continuum graph on page 13, only 53% of all people living with HIV have access to ART. This means that more than 17 million people are not currently accessing treatment.¹⁶

There is a growing body of literature on health system barriers to ART access, which has identified a range of critical factors. These include fears of confidentiality breaches, poor staff attitudes, transport costs, social costs, lack of comfortable hospital facilities to provide ART, fear of stigma and discrimination, shortages and unavailability of ART (especially in low-income settings), and lack of adequate social support.¹⁷

Durable access to ART remains a critical problem for PLHIV in resource-limited settings, and “there is evidence that in addition to limited supply of antiretrovirals (ARVs) and ART in many low-income countries, [PLHIV] often encounter challenges in accessing ARVs and ART services even in contexts where these services are freely available”.¹⁸

Shown on page 15 are responses from one study that illuminated **the way in which these barriers work**.¹⁹

The ARASA/ITPC rapid assessment findings were similar to the findings already mentioned with regard to access barriers to collecting ARVs. The two most major obstacles cited were the high financial costs (especially for travel) and the time costs due to delays at the facilities. A large proportion of respondents described long journeys, the necessity of using several modes of transport, and many hours of waiting at the clinic in long queues every time ARVs were to be collected. It was also apparent that for specific groups, such as younger respondents or single-income households, the break from schedules, such as a day off school or work, was particularly problematic. For example, younger respondents mentioned challenges around missing exams or test days. Other respondents, especially women, who were the only income earners for their household, also mentioned the difficulty of losing a day’s wages. As one respondent from Tanzania explained, “As a single mother with four children who depend on me as the breadwinner, it costs me dearly to come for ARV refilling.”²⁰

¹⁶ UNAIDS. *Fact sheet – Latest statistics on the status of the AIDS epidemic* (<http://www.unaids.org/en/resources/fact-sheet>).

¹⁷ Mills EJ, Nachega JB, Bangsberg DR, Singh S, Rachlis B, et al. (2006) *Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators*. *PLoS Med* 3: e438.

Posse M, Meheus F, van Asten H, van der Ven A, Baltussen R (2008) *Barriers to access to antiretroviral treatment in developing countries: a review*. *Trop Med Int Health* 13: 904-913. 16:738.

See also Hardon AP, Akurut D, Comoro C, Ekezie C, Irunde HF, Gerrits T, Laing R. *Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa*. *AIDS Care*. 2007;19(5):658-65 and Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. *The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS*. *J Gen Intern Med*.2009; 24(10): 1101-8.

¹⁸ Ankamah A, et al. *ART access-related barriers faced by HIV-positive persons linked to care in southern Ghana: a mixed method study*. *BMC Infectious Diseases*. 2016.

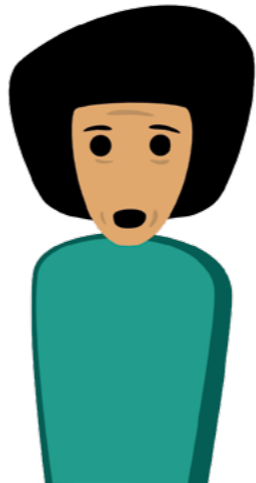
¹⁹ These are not quotes but rather consolidated responses from the Ankamah et al study cited above. The study was done in Ghana among 540 adults receiving ART at four treatment centres.

²⁰ ARASA and ITPC. *Differentiated Models of Antiretroviral Therapy (ART) Delivery: Report on The Rapid Assessment Study May - July 2016*. 2016

Common barriers to accessing and adhering ART

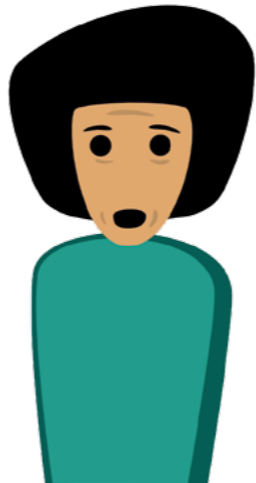
Stigma

Sometimes the medicines cause skin rashes and people ask questions. Being seen at the ART clinic by friends or family is also a big concern. Going to the clinic can be a very stressful experience and sometimes that is why I don't go there.




Time constraints

Time is a big problem. I go to the clinic early and I come back home very late. Too many hours. There is a delay getting our folder. Then there is a delay before we see a doctor and/or counsellor. At the pharmacy where the medicines are given to us, there is another delay. This is a huge problem for me. I worry about the time taken off work - maybe I will be replaced.




Shortage of medicines

The clinic is far away. Sometimes I have gone all the way to the clinic and found that there are only enough medicines for one week. This makes me not want to bother to go to the clinic.




Healthcare worker perspective

Too many people coming for treatment, too few healthcare workers and special days designated for ART delivery mean long delays. When medicines run out, this causes more problems for recipients of care and for us.



Finances

Yes, the costs for ART are small, it is subsidized, but we have to add transport costs and also the cost of missing a day of work. Coming to the clinic frequently means these costs add up. For people who are unemployed especially, these costs become the deterrent.



Section 2.3 Monitoring HIV treatment through viral load testing

Monitoring HIV treatment

There are two main ways of monitoring HIV treatment:

A **viral load test** measures the amount of HIV in a sample of blood. This is the most effective way to learn if HIV treatment is working for someone. Unfortunately, it is not available in many countries.

CD4 testing tells you how strong the immune system is. It gives you a level of how many CD4 (soldier) cells are in the body to fight off germs, bacteria or viruses, and has been the most common way to monitor a person's response to HIV treatment, especially in resource-poor settings.

What is viral load?

For people living with HIV, viral load is the number of copies of the virus, or viral particles, in your blood. To treat HIV, you are given antiretroviral therapy (ART). This is a combination of medicines designed to keep down the level of virus in your blood.

What is a viral load test?

A viral load test tells you if your treatment is working. If you take your medicine as prescribed and you are on the right treatment, it is possible to achieve viral suppression. This means that there are fewer than 50 copies of the virus per millilitre of blood. This is also described as an undetectable level of HIV in your blood. It is very good news because your treatment is working.

A test showing a level above 1,000 copies/ml of blood indicates treatment failure. Either this is because you are not taking your medication correctly the regimen of treatment is no longer working. If the problem is with your treatment, your doctor will prescribe a different regimen.

Why is viral load monitoring important?

??

I keep hearing about viral load testing... what is this?

A viral load test measures the amount of HIV in a sample of blood

Why do I need a viral load test?

This test is the quickest way to see if the virus is multiplying. If you have it once a year, you can monitor if things are going wrong before you get seriously ill.

Okay ... so what is a "good" test result?

A low or "undetectable" viral load result, which means there is less than 1,000 copies of the virus per ml of blood, shows us that the treatment is working. Research has shown that the risk of transmitting HIV to a sexual partner is also greatly reduced if a person has an undetectable viral load.

But why can't I just carry on with the CD4 testing?

Your viral load can be going up for a long time before we see a drop in the CD4 cell count. This means that you have been less well, with a higher viral load, for a longer time before you notice that your treatment is not really working for you.

So, you mean that it helps me identify problems with my treatment before I become ill?

Yes, it means we can catch problems sooner and stop you becoming seriously ill. A rising viral load may be related to adherence, in which case we can give you the additional support you need. Or it may be that you are becoming resistant to the drugs.

It seems like a better way to keep track of how well my treatment is working for me.

Yes, that's right. You have more information and are not dealing with your HIV in the dark. It can also prevent you from having to switch to more complicated treatments due to illness.

It sounds good, but what is the point of all this if it doesn't exist in my area?

Now that you know about it, you can ask for it. Start talking to others about it, and demand that your government provides this so that you are getting the best treatment possible.

WHO guidelines on monitoring HIV treatment

- Once a person has started taking ARV treatment, the first viral load test should be taken at six 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.
- A viral load of less than 1,000 copies/ml is a sign of successful treatment.
- If your viral load is found to be high (above 1,000 copies/ml) through any of these tests, another viral load test should be taken three months later.
- During this time, adherence support should be provided.

(WHO. *What's new in HIV monitoring. Fact sheet.* 2016)

What are the problems with access to routine viral load testing?

Many PLHIV, especially in resource-limited settings, do not have access to viral load monitoring. Research studies have found that even where it is available, it is still being used “mainly in a targeted way to confirm treatment failure, following clinical or immunological failure before switching to second-line ART”.²¹ One survey, conducted by community research teams in 12 African countries, found that while government policy did endorse the WHO guidelines, only three of the 12 countries actually provided routine viral load monitoring.²² The study also found that “viral load tests were only done when knowledgeable PLHIV requested them”.²³ This is a problem since there is a general lack of awareness about the importance of this monitoring tool. For activists, this means working to generate awareness and demand for viral load testing in communities.

Access to viral load testing is limited due to several reasons, which may be dependent on local contextual factors. These include:²⁴

- Viral load tests are often not available in HIV clinics.
- Even where it is available, it is not free in many countries. If people have to pay for their viral load test, it will not be taken since it is unaffordable for many at US\$14-\$85 per test.
- 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 restocking management.
- PLHIV and healthcare providers have low levels of awareness and knowledge about the importance and availability of routine viral load monitoring.

Linking routine viral load testing to DSD

A suppressed viral load is an objective measure of adherence that can support less frequent clinical consultations and ART delivery within the community. In this sense, a suppressed viral load can be seen as an entry point into DSD programmes. This is an important outcome of routine viral load testing.

Key messages

- **HIV treatment** must be part of a continuum of steps that take people from HIV counselling and testing through to having a low viral load. HIV treatment must also be provided as part of a continuum that includes HIV prevention, care and support.
- It is important to **start treatment early**. The World Health Organization now recommends that all PLHIV start ARV treatment as soon as possible at any CD4 count.
- **Adherence** is an important principle in HIV treatment. It means that people must take their treatment at the same or similar time every day and for life. The more adherent a person is, the better their HIV treatment will work.
- An important tool for PLHIV is **access to viral load testing**, which can reveal if a person is failing in their treatment or is having problems with their adherence. This objective measure can be used to support the demand for less frequent clinical consultations and **recipient-centred models of ART delivery**.

Read this for more information

ITPC. *Activist Toolkit: Campaigning for Routine Viral Load Monitoring.* 2016
(<http://itpcglobal.org/wp-content/uploads/2016/05/ITPC-RVLT-Toolkit-English.pdf>).



Photo: Allan Gichigi/MCSP

²¹ International Treatment Preparedness Coalition (ITPC). *Activist Toolkit: Campaigning for Routine Viral Load Monitoring.* 2016.

²² 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.

²³ Ibid.

²⁴ ITPC. *Activist Toolkit: Campaigning for Routine Viral Load Monitoring.* 2016.



Photo: Allan Gichigi/MCSP

SECTION 3.

UNDERSTANDING DIFFERENTIATED SERVICE DELIVERY

Section acronyms

ACs	Adherence clubs
ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
ARVs	Antiretrovirals
CAGs	Community ART groups
CARGs	Community ART refill groups
CDC	Centers for Disease Control and Prevention
CDDPs	Community drug distribution points
CHW	Community health worker
CSW	Commercial sex worker
DSD	Differentiated service delivery
GIPA	Greater involvement of People living with AIDS
HIV	Human immunodeficiency virus
HSAs	Health surveillance assistants
IAS	International AIDS Society
ITPC	International Treatment Preparedness Coalition
MIPA	Meaningful involvement of People living with AIDS
MSF	Médécins Sans Frontières/Doctors Without Borders
PLHIV	People living with HIV
PPT	PowerPoint
PWID	People who inject drugs
RVLT	Routine viral load testing
WHO	World Health Organization
TB	Tuberculosis

Section objective

The objective of this section is to explain to people living with HIV (PLHIV) what differentiated service delivery is and what differentiated ART delivery is. This includes what WHO recommends, main models of differentiated ART delivery, case studies showing how it can be implemented for different groups of people, and a “decision framework” that can be used by programme managers tasked with designing these interventions.

Training material

1. PowerPoint presentation on DSD
2. Any relevant video material
3. Scenario cards to use for a training exercise under the sub-section on building blocks. These cards should introduce characters and lay out brief scenarios relating to challenges around ART pickups/treatment. These cards will include concerns relevant to different groups, including key populations, adolescents and people with co-morbidities.

Training options

Option A: Learning review (30 minutes)

- 1. After going through the PPT presentation, ask participants to work in pairs and write down:
 - a. Key features of what they have learned
 - b. What they think of it
 - c. Potential positive/negative aspects.

Option B: Brainstorming (60 minutes)

- 1. Divide participants into groups.
- 2. Each group should have a flip chart.
- 3. Ask groups to brainstorm around the following questions:
 - a. If I was a programme manager considering differentiated ART delivery, what would I need to consider?
 - b. What variations do I need to be looking at?
- 4. Encourage participants to use their own experience and knowledge to brainstorm around adjustments according to context, the communities that they might be dealing with, and clinical needs.
- 5. Ask each group to present its conclusions.

Option C: Scenario card analysis (60 minutes)

- 1. Divide participants into groups of four (this will depend on size of the group; the exercise can be done in smaller or bigger groups).
- 2. Give each group a set of cards as described under “Training materials”.
- 3. Ask each group to create a grid (who/what/where/when) and fill in what it thinks might work for the particular scenario that it is dealing with.
- 4. Ask each group to present its decisions to the whole group.

Useful resources

The website, www.differentiatedcare.org, is an excellent resource on this topic and provides links to multiple other resources and comprehensive data on the issue.

Kavanagh, M. et al. *Evolving Human Rights and the Science of Antiretroviral Medicine*. *Health and Human Rights Journal*. Issue number 1, volume 17. June 2015 (<https://www.hhrjournal.org/2015/06/evolving-human-rights-and-the-science-of-antiretroviral-medicine/>).

Grimsrud et al. *Reimagining HIV service delivery: the role of differentiated care from prevention to suppression*. *Journal of the International AIDS Society*. 2016, 19:21484 (<https://www.ncbi.nlm.nih.gov/pubmed/27914186>).

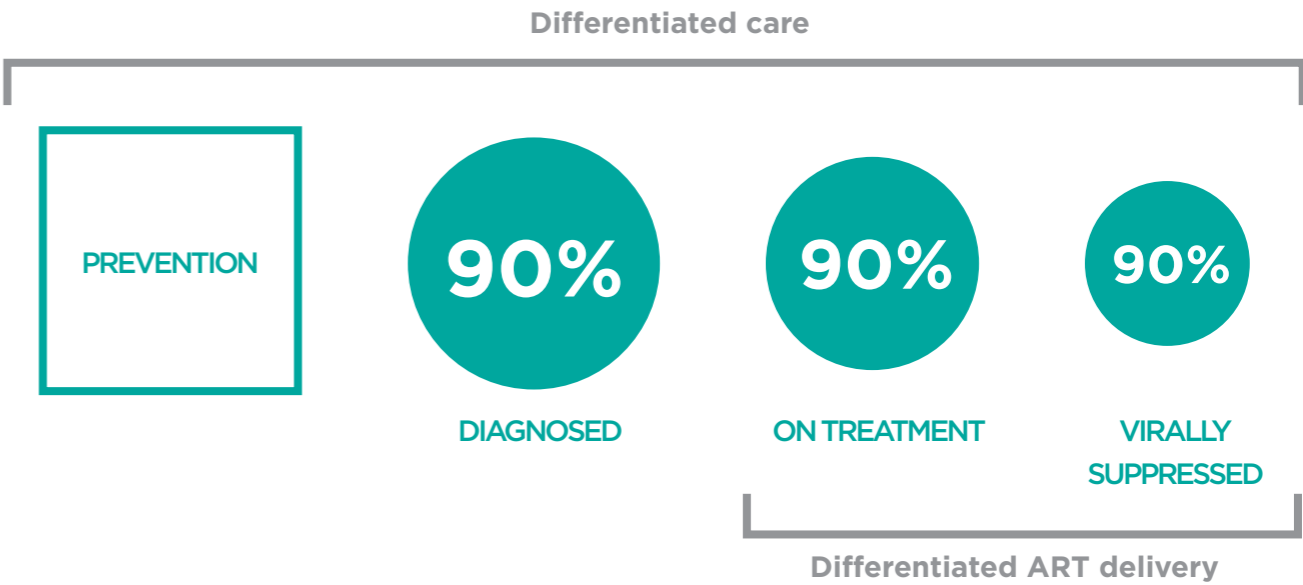
Section 3.1 What is differentiated service delivery (DSD) or differentiated care?

Differentiated service delivery or differentiated care is a recipient of care-centred approach that simplifies and adapts HIV services across the continuum to reflect the preferences and expectations of various groups of PLHIV while reducing unnecessary burdens on the health system.

For example, under this approach, “people who are clinically stable on treatment would have a reduced frequency of clinical visits and medication prescribing allowing health service resources to focus on care for people who are ill and require intensive clinical follow-up”.²⁵

As shown in Figure 2, differentiated care is relevant to and includes models of care across the HIV continuum, from testing of people who don’t know their HIV status to viral suppression of those enrolled in care.

Figure 2: Differentiated care is a concept that is applicable across the HIV care continuum



Differentiated care applies across the HIV care continuum. This Activist Toolkit focuses on differentiated ART delivery.

²⁵ World Health Organization. *Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations*. Geneva: 2017.

Summary of key points from WHO on differentiated care

- We cannot rely on a **“one-size-fits-all”** approach in the face of increasingly diverse sets of patient needs.
- The healthcare system will have to support double the number of recipients of ART who will need to “access ART within a service delivery model that meets their needs and expectations”.
- There is a shift in thinking – from who is eligible and when to start ART to providing high-quality and recipient of care-centred treatment to all PLHIV.
- A “differentiated care framework” can **support** less frequent visits to clinics for stable individuals, **reduce** the burden on healthcare settings, and **improve** care and attention (including enhanced adherence support, viral load testing and potential changes of regimen) for people with more complex conditions.

(Source: WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. 2016)

Differentiated ART delivery

Differentiated ART delivery is **one component of differentiated care** and has received considerable attention at an international policy and national programme implementation level (see Figure 2, page 3). Significant evidence shows high retention and viral suppression rates among PLHIV participating in these ART delivery programmes.²⁶

Differentiated ART delivery addresses a context in which increasing numbers of people in treatment programmes do not require frequent clinical and laboratory monitoring. By recognizing that different groups of PLHIV on treatment may have different needs, retention in care and viral suppression can be improved.

As seen in the following table, WHO identifies four groups of PLHIV with specific needs,²⁷ and these have recently been updated to include new recommendations, such as differentiated service delivery for those individuals with advanced HIV disease.²⁸

PLHIV	Elements of care package
Individuals presenting or returning to care when clinically well. Such individuals may be ART naïve or have interrupted treatment.	Support for adherence and retention in care
Individuals presenting or returning to care with advanced HIV disease. Such individuals may be ART naïve or have interrupted treatment.	A package of interventions, including screening, treatment and/or prophylaxis for major opportunistic infections, rapid ART initiation and intensified adherence support ²⁹
Individuals who are clinically stable on ART	Community ART models and reduced frequency of visits
Individuals receiving an ART regimen that is failing.	Adherence support, viral load testing, switch to second- or third-line treatment

²⁶ UNAIDS and Médecins Sans Frontières. *Community-based antiretroviral therapy delivery*.
²⁷ World Health Organization (WHO). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach – 2nd ed.* 2016.
²⁸ WHO. *Guidelines for managing advanced HIV disease and rapid initiation of antiretroviral therapy*. July 2017.
²⁹ WHO. *Guidelines for managing advanced HIV disease and rapid initiation of antiretroviral therapy*. July 2017.

What does WHO mean by “stable” and how are specific populations included?

- Stable individuals are specifically determined according to WHO guidelines as those:
- **Who have received ART for at least one year** and have no adverse drug reactions that require regular monitoring,
 - **Who have no current illnesses**
 - Who have **good understanding of lifelong adherence** and evidence of treatment success (i.e., two consecutive viral load measurements below 1,000 copies/ml). **In the absence of viral load monitoring, rising CD4 cell counts or CD4 counts** above 200 cells/mm3, an objective adherence measure can be used to indicate treatment success.
- Pregnant and breastfeeding women:
- Clinically stable on ART when conceiving: already accessing differentiated ART delivery model plus at least 1 VL < 1000 copies/ml in last 3 months and accessing antenatal care.
 - If initiated on ART during pregnancy: an HIV-negative result in her infant with a nucleic acid test (NAT) at six-weeks and evidence of accessing infant follow-up care are additional requirements
- Children:
- Should be at least two years old, taking the same regimen for more than three months and caregivers counselled and oriented on the disclosure process
- Adolescents:
- Access to psychosocial care”

(Source: WHO. *Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations and A decision framework for differentiated anti-retroviral delivery for children, adolescents and pregnant and breastfeeding women*)

It should be noted that there is some flexibility in the way that countries and programmes identify who is “stable” (sometimes less strictly than the official WHO assessment). In Zimbabwe and South Africa, for example, PLHIV are eligible for differentiated ART delivery following their first suppressed viral load 3-6 months after ART initiation.

Although most existing evidence from interventions relates to adult, stable recipients of care, there is growing recognition that groups previously excluded from differentiated ART delivery criteria (such as pregnant women) may also benefit from models of care specifically for clinically stable clients. The most recent guidance on this from WHO states: “Clinically stable children, adolescents and pregnant and breastfeeding women as well as members of key populations (people who inject drugs, sex workers, men who have sex with men, transgender people and people living in prisons and closed settings) can benefit from access to clinically stable client differentiated anti-retroviral therapy (ART) delivery models.”³⁰

The guidance explains that population characteristics should not exclude these groups since differentiated ART delivery can in fact serve to:

- Help keep families together by simplifying access and cost issues
- Improve the access of key populations to HIV treatment services by addressing inequities in service delivery
- Facilitate greater involvement of key population communities in treatment and care.

³⁰ World Health Organization (WHO). *Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations*. 2017.

Consider the example of pregnant and breastfeeding women.

What are the challenges for pregnant and breastfeeding mothers?	How could differentiated ART delivery help?
1. Pregnancy and caring for their infants and other children means increased responsibilities	Women who are clinically stable on ART at conception can choose to get their antiretrovirals through a differentiated ART delivery model (ideally close to their homes). Refill collection could be delinked from maternal, newborn and child healthcare.
2. Antenatal, postnatal, routine health visits for children, which may be provided at different locations and times	Women who are diagnosed during pregnancy and become clinically stable can be enrolled in an ART service that is integrated into maternal, newborn and child health services or that works alongside it.
3. Transitioning between maternal, newborn and child health services and HIV care clinics	If there are existing mobile outreach services providing ART to adults in remote areas, pregnant and breast-feeding women and their infants could also be seen and provided with integrated HIV and maternal, newborn and child healthcare.

(Source: WHO: *Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations*)



Section 3.2 Understanding the Decision Framework for Differentiated ART Delivery

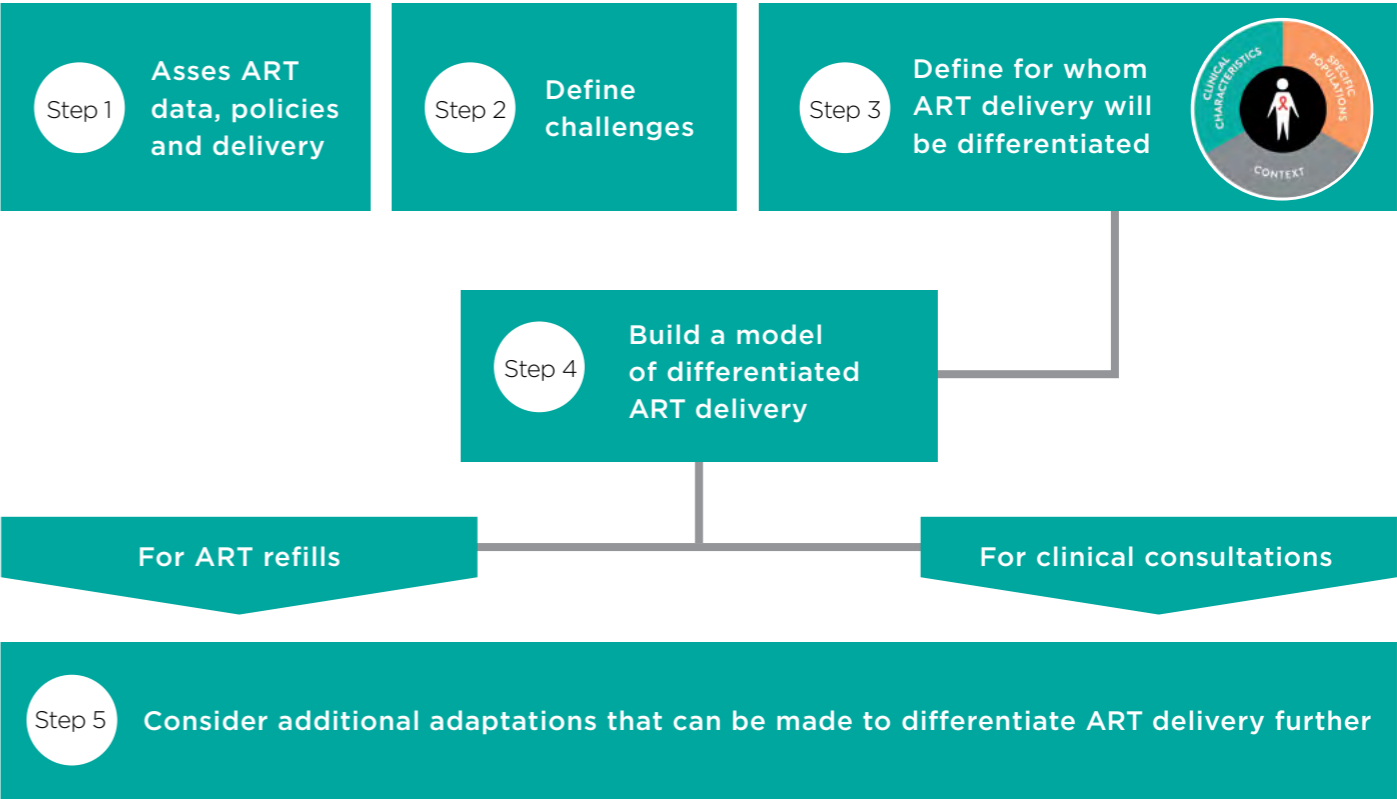
The first Decision Framework focuses on differentiated ART delivery in sub-Saharan Africa.³¹ It provides guidance to support programme managers at individual, national and district levels on how to prioritize which elements of differentiated care for implementation in each setting. The document focuses on **delivery to stable individuals**, according to the WHO definition provided above.³²

Read this for more information

Differentiated care for HIV: A decision framework for antiretroviral therapy delivery and also A decision framework for differentiated antiretroviral delivery for children, adolescents and pregnant and breastfeeding women (www.differentiatedcare.org).

What does the decision framework look like?

The following decision framework diagram shows a five-step approach to differentiated delivery planning. These steps are useful for ministries of health and programme managers, even though they are not the target audience of this toolkit. It is also useful for community activists to see how a basic model of differentiated ART delivery can be formed.



(Source: The International AIDS Society. *Differentiated Care For HIV: A Decision Framework for Antiretroviral Therapy Delivery*. 2016)

³¹ International AIDS Society. *Differentiated Care For HIV: A Decision Framework for Antiretroviral Therapy Delivery*. 2016.

³² As mentioned in the preface on terminology, we have used the terms, “stable” and “unstable”, in accordance with WHO guidelines and to refer to the technical aspect of being stable or unstable on ART.

Section 3.3 Models of differentiated ART delivery

Recent innovations in ART delivery can be categorized into four models. We will describe each of these with accompanying case studies to illustrate how they are being implemented in different places.

Key points for community advocacy

- All recipients of care continue to have clinical consultations as part of their package of care.
- The models are adaptable and flexible. They can work in parallel so that an individual can move between them during the course of their lifetime.
- They can accommodate “up referral”, meaning that individuals who may want or require more intense clinical care are catered for.

CASE STUDY: Chiradzulu, Malawi

In rural Malawi, recipients of care were waiting several hours for ART refills and nurses were faced with lines of 40-50 patients a day. A facility-based individual “fast-track” model was developed for ART refills for recipients of care who fit the eligibility criteria.

Who: Stable individuals on ART are assisted by health surveillance assistants (HSAs); these are paid community health workers who are part of the health system.

What happens: The recipient of care needs to go to clinic only once every six months for clinical assessments and once every three months to collect their ART refills. HSAs provide the quarterly refills and check adherence according to a standardized assessment tool. HSAs also refer recipients of care back to medical staff if problems arise.

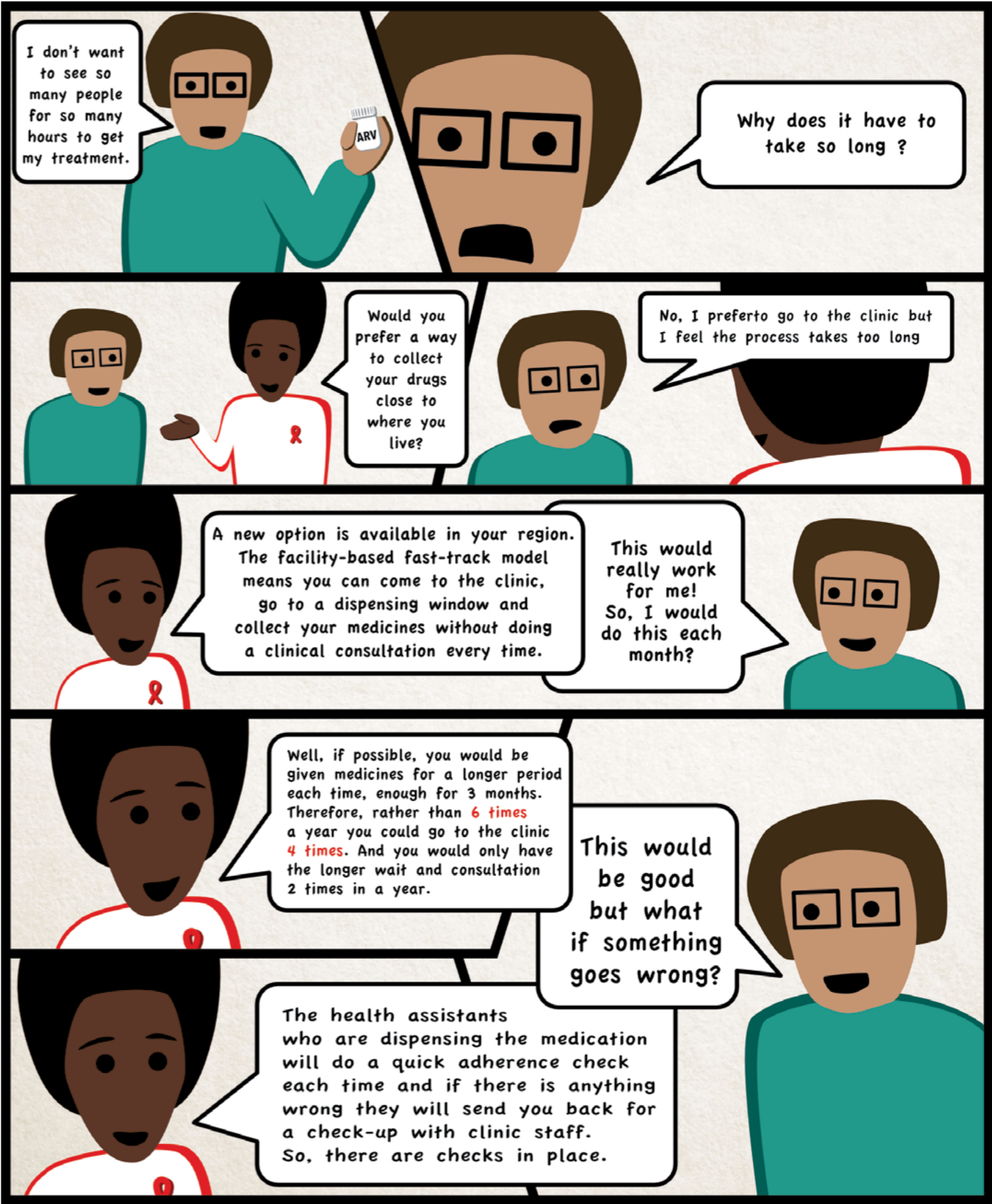
Outcomes: One year into the programme, there was 97% retention for those who had enrolled in this system.

Resource needs: Recruiting of HSAs.

(Source: Prust ML, Banda CK, Nyirenda R, Chimbwandira F, Kalua T, Jahn A, et al. *Multi-month prescriptions, fast track refills, and community ART groups: results of process evaluation in Malawi on using differentiated models of care to achieve national HIV treatment goals.* Journal of International AIDS Society. 2017;20(Suppl 4):21650)

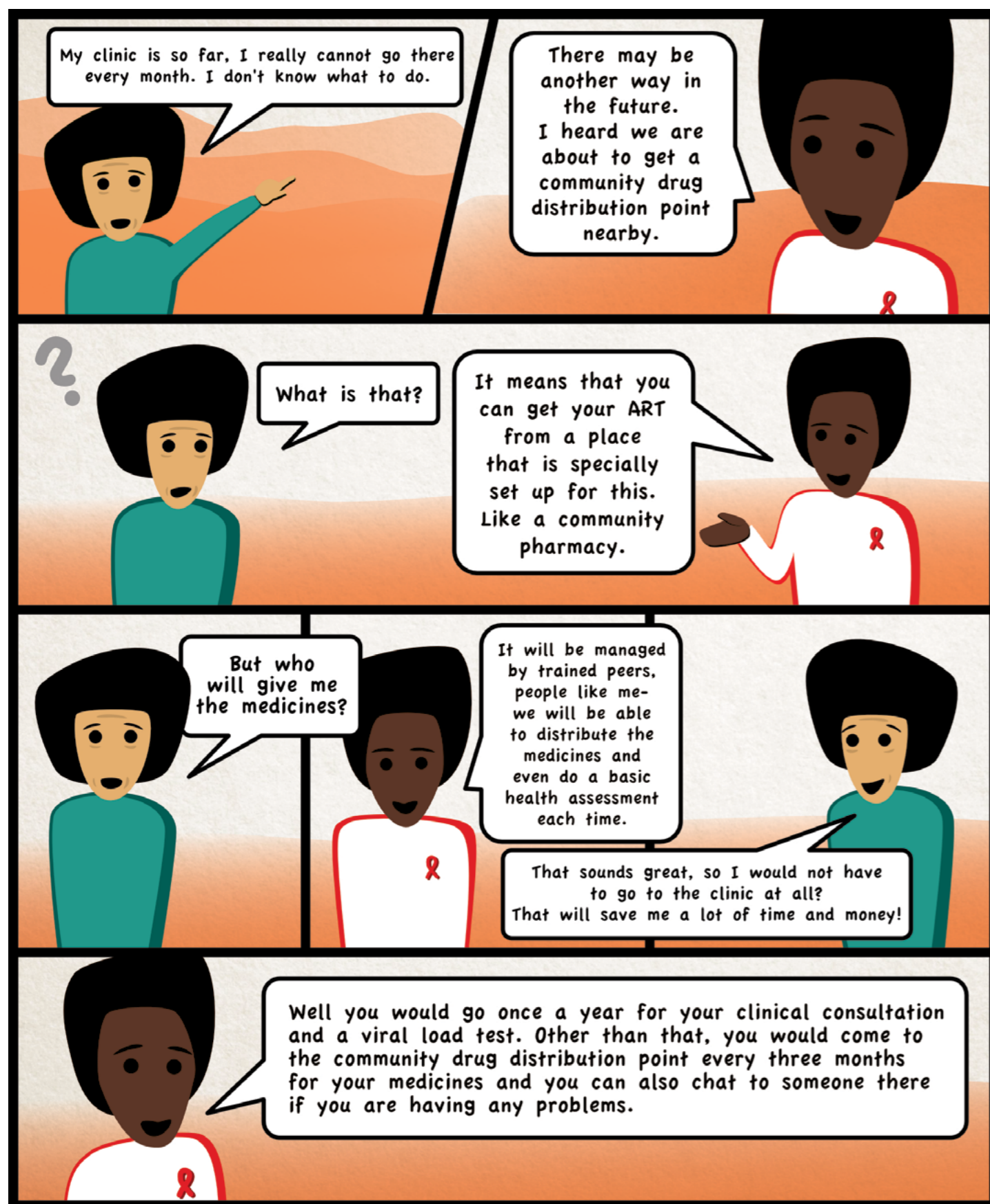
1. Facility-based individual models

ART refill visits are separated from clinical consultations, and recipients of care can proceed directly to a “fast-track window” to get their medication. In this model, they do not need to meet clinical staff.



2. Out-of-facility individual models

These include community drug distribution points (CDDPs) or community ART distribution points at which ART refills can be collected. In this model, ART delivery and even clinical consultations can be provided outside of healthcare facilities. This model might include community private/public pharmacies, outreach methods and home delivery.



CASE STUDY: Kinshasa, DRC

In Kinshasa, in the Democratic Republic of the Congo, PLHIV faced expensive transportation to the few health facilities providing ART in the city. High levels of stigma and discrimination were also deterrents to attending the facilities. Community ART distribution points were piloted here as a collaboration between MSF and local networks of PLHIV.

Who: PLHIV who have been on ART for more than six months and who meet the other eligibility criteria are eligible for participation. The points are managed by PLHIV who have been trained in provision of refills, adherence support and follow-up health assessments.

What happens: Participants come to the distribution point for ART refills every three months. Free HIV testing and counselling is also offered. Peer counsellors trace individuals who do not appear at their scheduled visits through phone calls and local support groups. Referral to clinical care is done by lay workers from networks of PLHIV. Participants also report to the health service annually for clinical consultation and blood tests (for CD4 count testing).

Outcomes: Retention in care was 89% at a 12-month follow up in 2012.

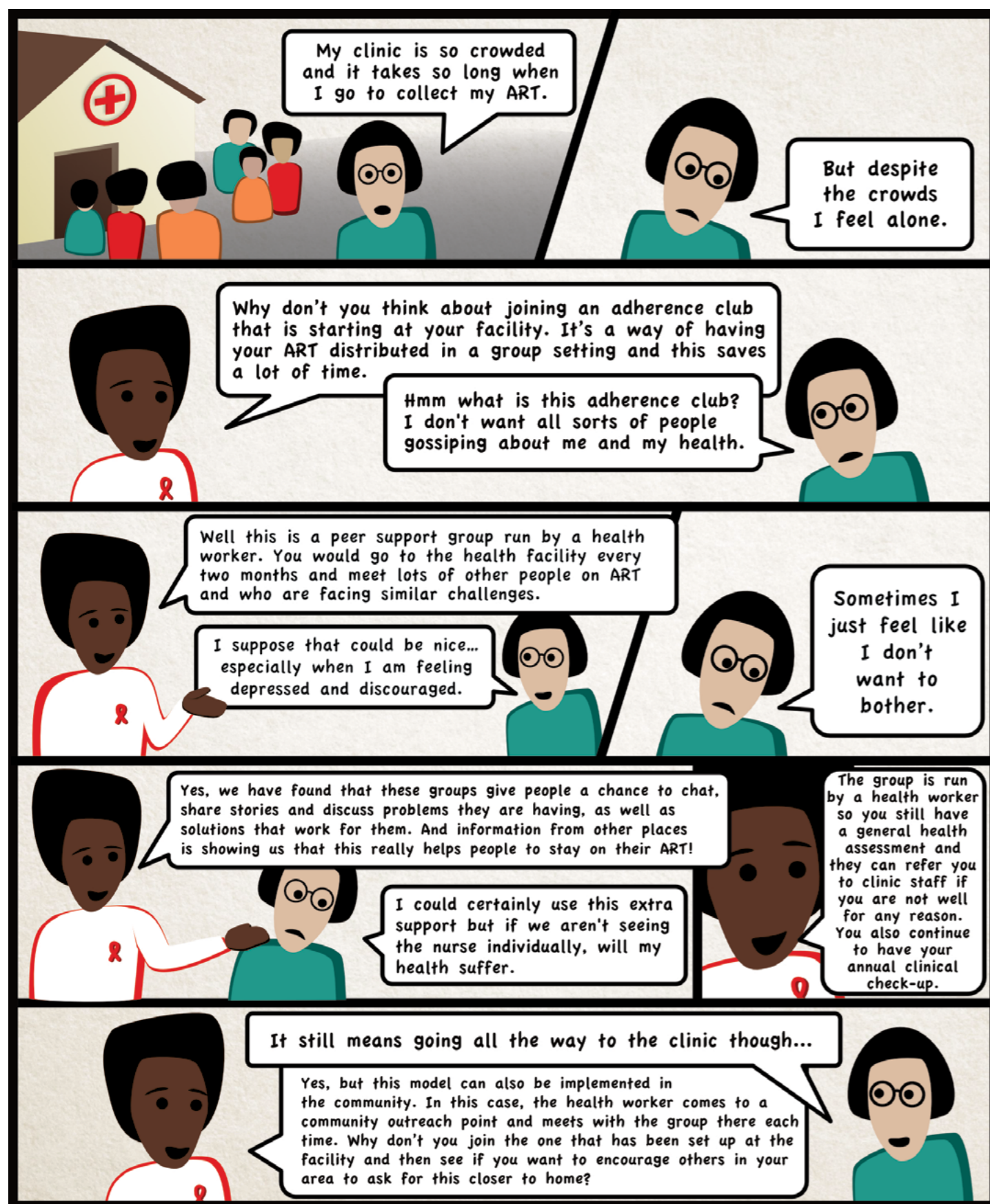
Resources needed: Lay workers for staffing, secure spaces to store medication, and a means of transportation to bring medication from the health facility to the distribution posts.

(Source: Bemelmans M, Baert S, Goemaere E, Wilkinson L, Vandendyck M, Cutsem G, et al. Community-supported models of care for people on HIV treatment in sub-Saharan Africa. *Tropical Medicine & International Health*. 2014;19(8):968-77.)



3. Healthcare worker-managed group models/adherence groups

Recipients of care receive their ART refills in a group either within and/or outside of healthcare facilities. These are managed by healthcare workers or a lay healthcare staff member.



CASE STUDY:³³ Cape Town, South Africa

In the Cape Town Metro health district of South Africa, congestion within the clinics, long waiting times and inadequate long-term retention rates were prevalent. Adherence clubs (ACs) for stable adults living with HIV were developed.

Who: In the ART adherence clubs, groups of up to 30 PLHIV meet. The clubs are open to any adult who has been on ART for at least 12 months and who has an undetectable viral load.

What happens: The group meets every two months for up to an hour. Group activities include weight measurements and symptom-based general health assessments. These are recorded by the peer educator or lay counsellor who acts as a club facilitator. This person also brings pre-packaged ARVs to each participant. If someone is reporting symptoms of illness, side-effects or weight loss, they are referred back to the main clinic for assessment. Twice a year, all club members see a nurse – once for blood tests for routine monitoring and two months later for their annual clinical check-up.

Where: Clubs are run in the health facility within the community or at community venues or the homes of members. This means that members may access medication closer to their homes, reducing time spent at the clinic. It also allows more people to join the clubs.

Outcomes: Between 2011, when ACs were first implemented, and 2015, the total ART cohort in the district doubled to nearly 130,000 recipients of care. In an analysis of a representative sample of the adherence club cohort, 95% of recipients of care were retained and 97% were virally suppressed 12 months after AC enrolment.

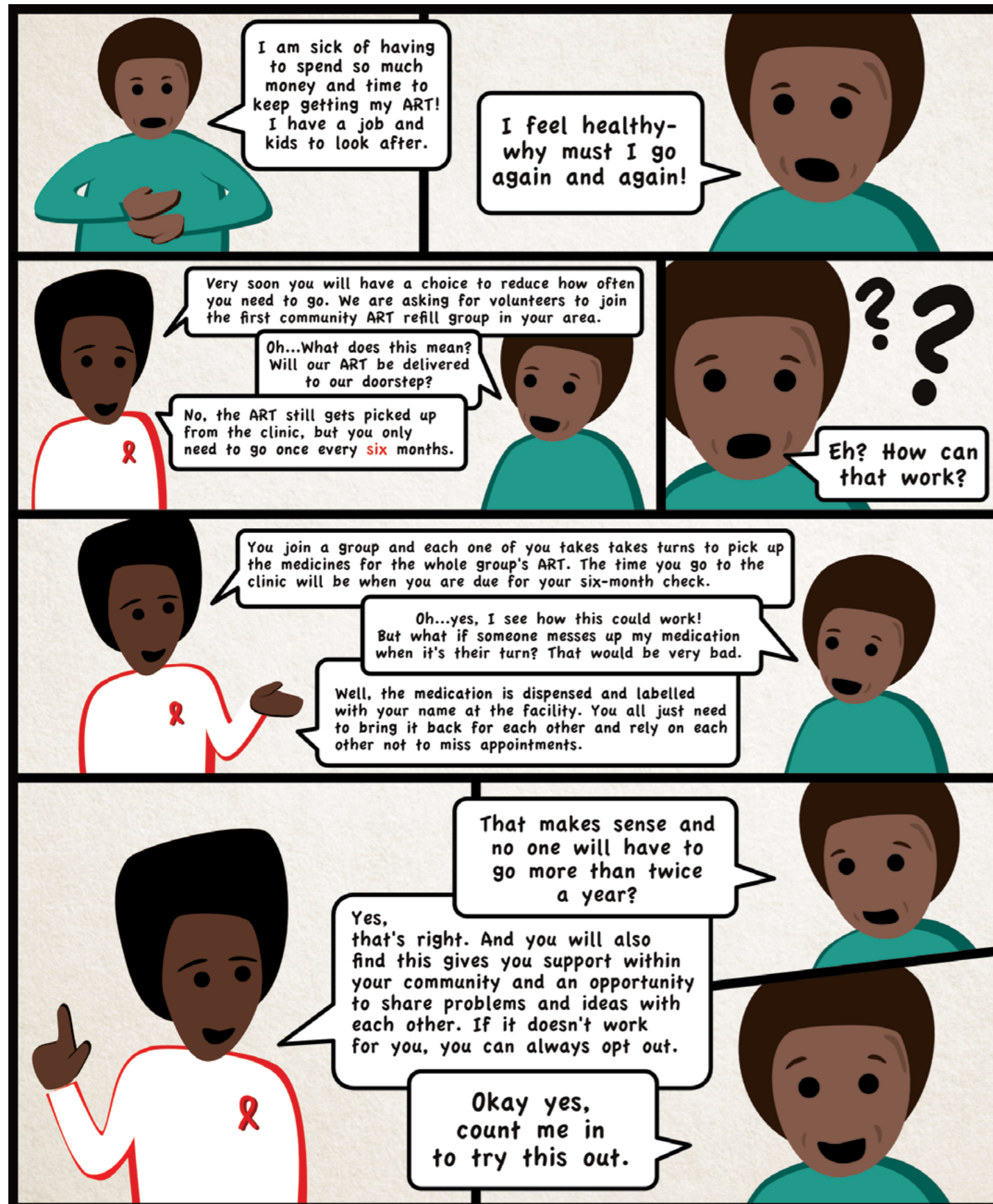
(Source : Tsondai P, Wilkinson L, Grimsrud A, Mdlalo P, Ullauri A, Boule A. *High rates of retention and viral suppression in the scale-up of anti-retroviral therapy adherence clubs in Cape Town, South Africa.* Journal of International AIDS Society. 2017;20(Suppl 4):21649.)



³³ UNAIDS and Médecins Sans Frontières. *Community-Based Antiretroviral Therapy Delivery.* Pg 7-8. 2015.

4. Recipient of care-managed group model

Recipients of care receive their ART refills in self-managed groups. The group usually meets outside of healthcare facilities and works on a roster system sharing pickup and distribution duties. Examples of recipient of care-managed group models are community adherence groups (CAGs) piloted in Mozambique and community ART refill groups (CARGs). Benefits of these groups include increased peer support, reduced time and costs associated with ART refills, and “stronger engagement of the community in HIV care with [recipients of care] taking up critical roles in the delivery of ART in their communities”.³⁴



CASE STUDY: Tete, Mozambique

Who: The pilot programme involved self-formed community ART groups (CAGs) of six stable recipients of care who took turns collecting antiretroviral medication.

What happens: The visits are scheduled so that one member goes every month and the visit fits in with the individual's six-monthly check-up and blood test. They also support each other with adherence and monitor treatment outcomes.

Where: Members organize delivery of the ART to other group members in the community.

Outcome: More than 6,000 recipients of care have joined CAGs in this district since 2008. A cohort analysis showed retention in CAGs was 98% at 12 months, and the level was maintained up to 92% at 48 months.

Resource needs: Proper linkages are needed between a focal point at the health centre and the CAG.

(Source: Rasschaert F, Decroo T, Remartinez D, Telfer B, Lessitala F, Biot M, et al. *Adapting a community-based ART delivery model to the patients' needs: a mixed methods research in Tete, Mozambique*. BMC Public Health. 2014;14(1):364.)

CAGs are a good example of how adaptations to these models can be implemented based on feedback from PLHIV. For example, the Zimbabwe adaptation or CARG (community ART refill group) was changed according to the local context (wherein members had access to three-month refills and yearly clinical consultations) and in line with PLHIV preferences for bigger groups. The groups are made up of between four and 15 recipients of care.³⁵

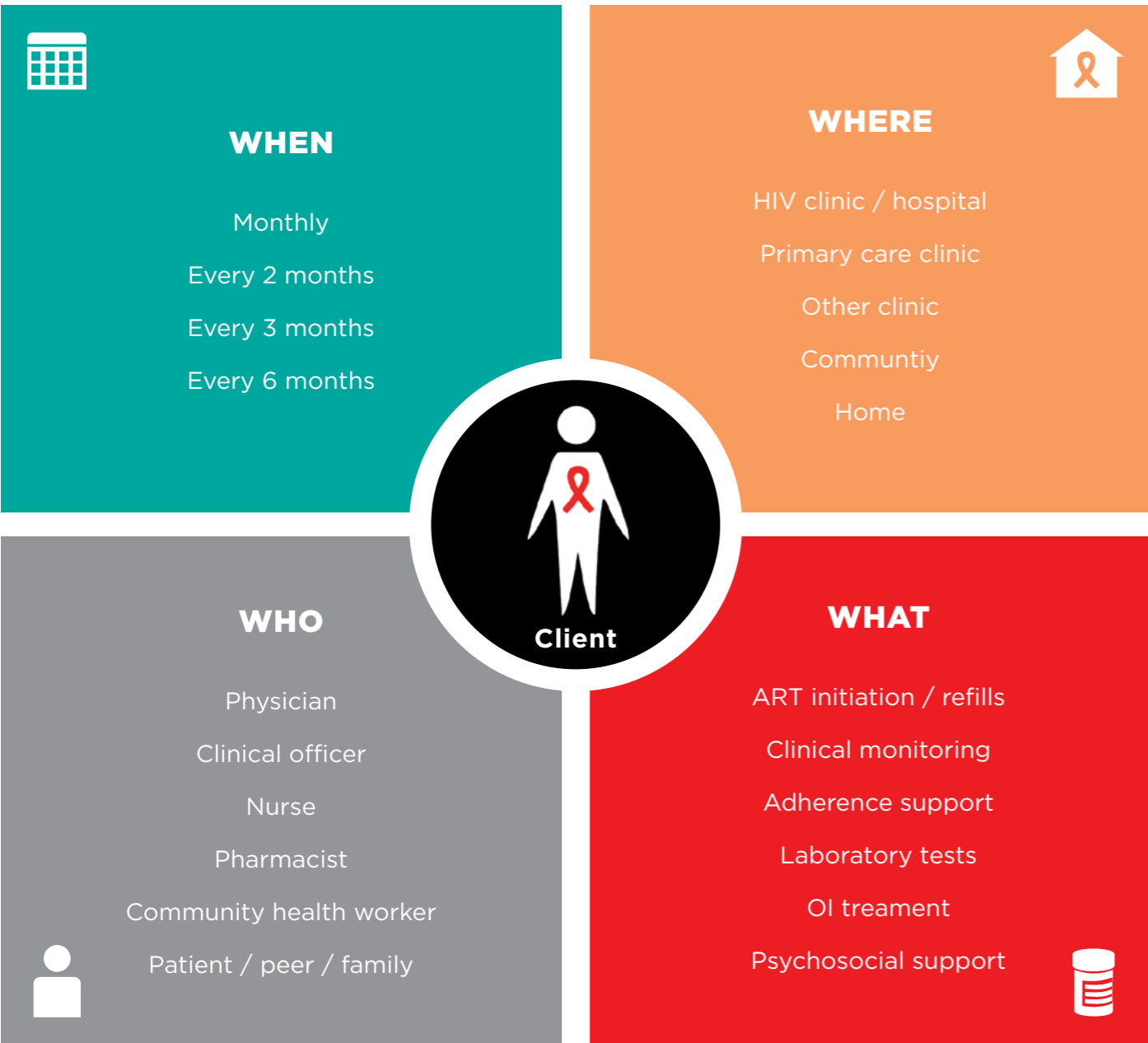
Key messages

- The **“one-size-fits-all”** approach to delivery of HIV treatment and care is not meeting the growing number and diverse needs of PLHIV.
- WHO recommends service delivery based on a **“differentiated care framework”**.
- Differentiated care is a **recipient of care-centred approach**, which reflects the preferences and expectations of various groups of PLHIV, thereby easing the burden of treatment and care on their everyday lives.
- Differentiated care **reduces unnecessary burdens** on the health system and refocuses resources on those most in need.
- There are **four models of differentiated ART delivery** and recipients of care may require different models at different stages in their treatment
- Evidence from implemented programmes has shown **high levels of adherence and retention in care** among PLHIV.
- Community activists should particularly note the **“outcomes”** and **“resource needs”** for each model.

³⁴ Wilkinson L, Harley B, Sharp J, Solomon S, Jacobs S, Cragg C, Kriel E, Peton N, Jennings K, Grimsrud A. *Expansion of the Adherence Club model for stable antiretroviral therapy patients in the Cape Metro, South Africa 2011-2015*. Tropical Medicine & International Health. 2016 Jun 1;21(6):743-9. See also, Médecins Sans Frontières, Southern Africa Medical Unit (MSF-SAMU). *How to implement the CAG model, Bringing treatment closer to home and empowering patients*.

Section 3.4 The building blocks of differentiated ART delivery: Who, Where, When, What

The decision framework lays out the “building blocks” or four main questions that constitute the key components of building a differentiated model of service delivery. In this section of the toolkit, we will look at these questions and see how they encompass the fundamental principles around which differentiated delivery revolves.



i. WHO?

Addressing **who** can distribute and dispense ART is a critical aspect of differentiated ART delivery. According to the WHO guidelines, “the number of available health workers remains inadequate in many settings with a high burden of HIV”.³⁶

Important term to understand: “Task shifting”

This involves reassigning tasks from highly qualified health workers to health workers with shorter training and fewer complementary qualifications or to supervised lay people, including key population members. Although increasing the number of healthcare personnel is also crucial, clinical tasks have to be shared and shifted to ensure that enough health workers are available. Task shifting can increase the effectiveness and efficiency of available personnel, enabling the existing workforce to service more people.

How might this look?

- Trained and supervised community health workers (CHWs) dispensing ART at facilities between regular clinical visits
- Trained and supervised CHWs dispensing ART refills at community pharmacies, outreach centres or even at home
- Trained peer educators facilitating the formation of community-based groups and supporting recipient of care self-management.

WHO recommendations on task shifting and task sharing

- Trained and supervised lay providers can distribute ART to adults, adolescents and children living with HIV.
- 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.

These recommendations have implications at a regulatory level within countries in terms of laws and policies that govern who can dispense and distribute medication. For example, in Kenya, trained lay providers are allowed to distribute ART, but they are not allowed to “dispense” (meaning package the ART for individual patients). This must be done by professional healthcare workers.³⁷

They also have implications at the individual level. The rapid assessment showed that recipients of care had reservations related to reduction in their quality of care, fears that they would become ill again and a lack of trust in potentially new healthcare providers.³⁸ For activists trying to create demand within communities, dealing with these concerns will be particularly important. **The role of lay providers is essential to differentiated service delivery, but ongoing training, awareness raising and supervision are critical, as is proper remuneration for the work.** This was also reiterated by healthcare workers who participated in the research.³⁹

³⁶ World Health Organization (WHO). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach* – 2nd ed. 2016

³⁷ Ministry of Health, National AIDS & STI Control Programme. *Guidelines on use of Antiretroviral Drugs for Treating and Preventing HIV Infection in Kenya 2016*. Nairobi, Kenya: NASCOP. July 2016.

³⁸ ARASA and ITPC. *Differentiated Models of Antiretroviral Therapy (ART) Delivery: Report on The Rapid Assessment Study May - July 2016*.

³⁹ ARASA and ITPC. *Differentiated Models of Antiretroviral Therapy (ART) Delivery: Report on The Rapid Assessment Study May - July 2016*.

Relevance for key populations?

Research shows that “the presence of peer educators, promoters, counsellors and supporters is regarded as essential to engaging with key populations and building trust that encourages uptake of services and retention in care”.⁴⁰ Provision of services by peers using a task-shifting approach could be particularly helpful to key populations who may have experienced stigma and judgmental attitudes from healthcare providers in the past.

ii. WHERE?

Addressing physical access to ART, in terms of **where** it can be delivered is central to differentiated ART delivery. Data shows that access remains challenging for PLHIV in terms of time and money spent travelling to clinics and in terms of stigma that persists within healthcare settings and communities. These challenges continue to hinder retention in care and viral suppression.⁴¹

Important term to understand: “Decentralization of services”

According to the World Health Organization, “the rapid scale-up of ART programmes has posed significant challenges to health systems in high-burden, resource-limited settings”. Decentralizing HIV treatment and care involves shifting ART delivery from central hospitals to primary care sites. According to WHO, decentralization: reduces waiting times; brings HIV services closer to people’s homes; strengthens community engagement by linking community-based interventions with health facilities; and can optimize access to services, care-seeking behaviour and retention in care.

(Source: WHO consolidated guidelines)

How might this look?

- Initiating ART in hospitals, but maintaining it through peripheral health facilities
- Initiating and maintaining ART through peripheral health facilities
- Initiating ART at peripheral health facilities and maintaining at community level through outreach sites, health posts, community civil society organisations and even home delivery.

Relevance for key populations?

“Many communities prefer, are more comfortable with and are more likely to access services outside the formal health sector when they are provided in safe and convenient places where members of key populations are less likely to experience stigma, discrimination, abuse or arrest.”⁴²

For members of key populations, delivery of ART closer to the community and where they live may be undesirable due to stigma-related and disclosure-related concerns. These people may perceive differentiated service delivery as having potentially negative impacts on their care and treatment. In a differentiated delivery framework, programme managers can account for these issues, prioritize areas with high concentrations of key populations and use peer outreach in comfortable settings to reach them. Services can be provided at sites located near places of work, such as sex work and drug use sites.

iii. WHEN?

Important term to understand: “Separation of visits”

“A key principle, linking all models of differentiated ART delivery, is separating ‘refill-only’ visits from visits that require clinical, counselling and/or laboratory assessment.”

The WHO guidelines recommend less frequent clinical visits and less frequent medication pickups for individuals who are stable on ART (every 3-6 months). This includes key populations. Rapidly growing children (0–5 years old) and adolescents will need to be monitored more frequently for treatment dosing/weight changes and adherence support.

(Source: IAS. Decision Framework)

WHO recommendations

3-6 months clinical visits
3-6 month ART refills

How might this look?

- If adequate ART refills are available, a stable recipient of care may not have to attend the clinic again until their next clinical check-up.
- If only 1-3 month supplies are available, intervening visits could be used only for picking up ART at a special fast-track window, thus hugely reducing waiting time at the clinic.
- ART delivery could be community based and visits to the clinic will only be needed for clinical appointments.
- If routine viral load testing (RVLT) is available, clinical visits for recipients of care with suppressed viral loads can be reduced to once a year. This is current practice in South Africa.

Less frequent visits to the clinic each year can significantly reduce the burden of treatment. Recipients of care save time and money both on transport costs and salary lost due to missing days of work. Less frequent visits also reduce the high levels of stress associated with asking for time off work and school or needing to leave family members in need of care for many hours each month.⁴³ Health services also benefit from fewer recipients of care, shorter queues and the opportunity to spend more time with those who need their services more.

⁴⁰ <http://www.differentiatedcare.org/Portals/0/adam/Content/oCtvR-Zf5kqnD-DYmcy-nQ/File/DSD%20Key%20populations%20review.pdf> Differentiated service delivery for key populations – men who have sex with men, sex workers, transgender people, people who inject drugs and prisoners and other people living in closed settings: A background review. 2016.

⁴¹ International AIDS Society. *Differentiated Care For HIV: A Decision Framework for Antiretroviral Therapy Delivery*. 2016.

⁴² <http://www.differentiatedcare.org/Portals/0/adam/Content/oCtvR-Zf5kqnD-DYmcy-nQ/File/DSD%20Key%20populations%20review.pdf> Differentiated service delivery for key populations – men who have sex with men, sex workers, transgender people, people who inject drugs and prisoners and other people living in closed settings: A background review. 2016.

⁴³ ARASA and ITPC. *Differentiated Models of Antiretroviral Therapy (Art) Delivery: Report on The Rapid Assessment Study May - July 2016*.

Relevance for key populations?

Facility-based ART sites could dedicate specific clinic days to specific groups (sex workers, MSM, LGBTI). Flexible hours, weekends or evening service provision could also be of use to key and vulnerable populations, including adolescents, since missing school is reported as a barrier to adherence for them.

iv. WHAT?

This building block refers to **what** services should be offered to a recipient of care. As already mentioned, differentiated delivery is based on the fact that ART refill visits will be split up from clinical visits for stable individuals on ART. Therefore, “it is necessary to define what package of additional services (if any) will accompany these two types of visits”.⁴⁴

How might this look?

- ART refill visits can include counselling, brief symptom screens or group counselling.
- Clinical visits for stable recipients of care should include “management of other co-morbidities, provision of medications or drug refill, counselling and psychosocial support, and laboratory interventions”.
- Psychosocial support is an important component of HIV care and can be provided at ART refill visits, clinical consultations or in addition to these visits. It is also important to note that psychosocial support can come from peers.

Relevance for key populations?

When examining what services should be provided, programme managers should look specifically at the potential to provide integration of services for key populations, including TB services, sexual and reproductive health services, and drug dependence treatment. A differentiated service delivery model could provide integrated services allowing recipients of care to take care of their various health needs at the same time and in the same location.⁴⁵

Section 3.5 Differentiated ART delivery and human rights

This section of the toolkit deals specifically with human rights in relation to differentiated service delivery. Many other documents deal, in detail, with the links between human rights and HIV generally.

Read this for more information

HIV/AIDS and Human Rights Advocacy and Training Resource Manual
(<http://arasa.info/info/training-manuals/>).

Open Society Foundation. Human rights and HIV: Now More than Ever
(<https://www.opensocietyfoundations.org/reports/human-rights-and-hiv-ids-now-more-ever>).

What is a human rights-based approach to HIV?

This approach considers and addresses human rights at all levels and in all processes of action on HIV. The approach:

- Recognizes that protection of human rights is important at all stages of the HIV continuum through prevention, treatment and care and for key and vulnerable populations, as well as those already living with HIV
- Makes human rights a key element of the design, implementation, monitoring and evaluation of policies and programmes⁴⁷
- Is based on principles such as non-discrimination, participation, inclusion, transparency and accountability.

Human rights and the WHO guidelines

Implementation of the guidelines must be accompanied by efforts to promote and protect the human rights of people who need HIV services, including ensuring informed consent, preventing stigma and discrimination in the provision of services, and promoting gender equity.

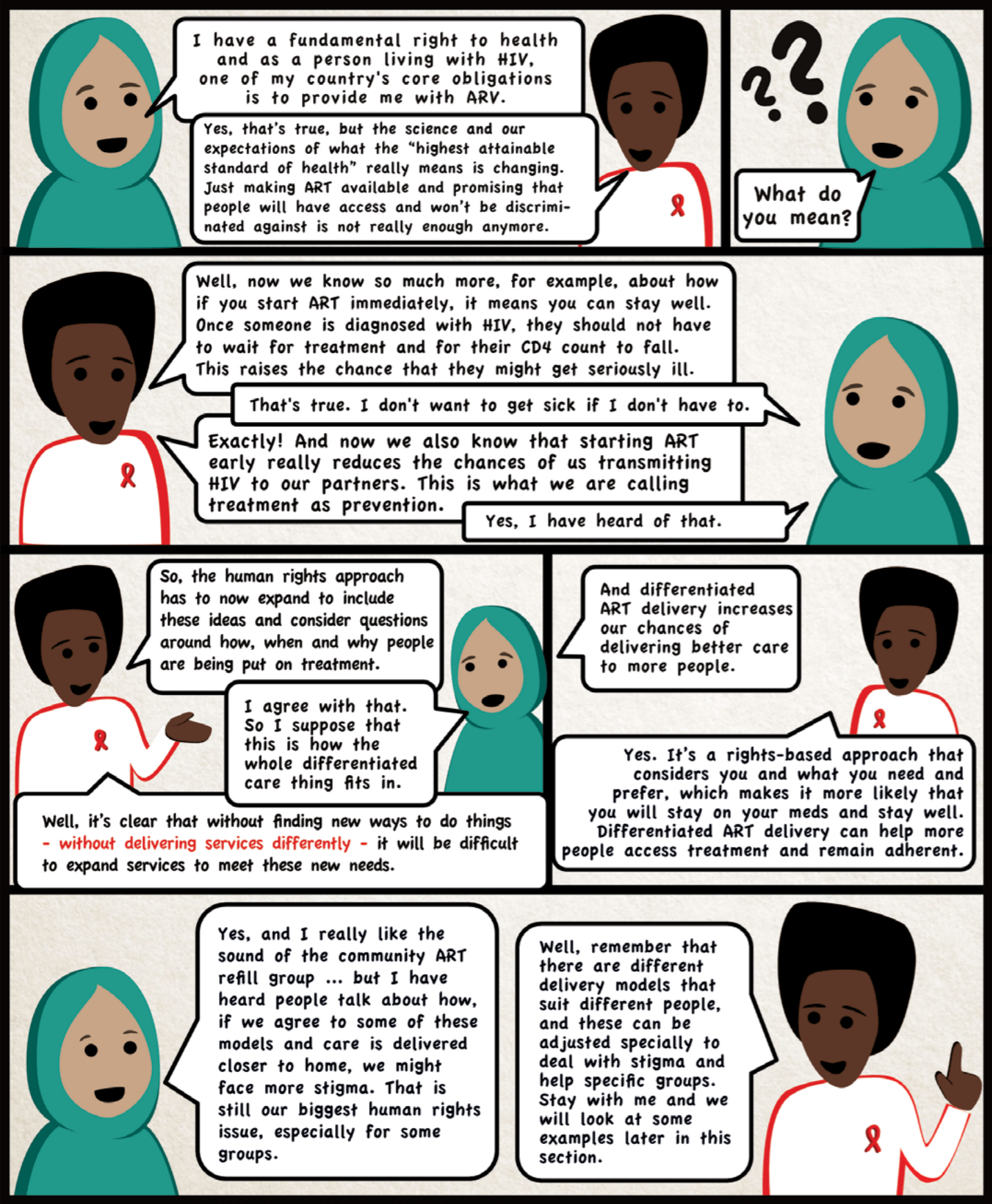
Developing and implementing the guidelines should realize the rights and responsibilities of PLHIV and promote the greater involvement of PLHIV (GIPA) and meaningful involvement of PLHIV (MIPA) principles.

⁴⁴ International AIDS Society. *Differentiated Care For HIV: A Decision Framework for Antiretroviral Therapy Delivery*. 2016.

⁴⁵ Ibid.

⁴⁶ *Differentiated service delivery for key populations – men who have sex with men, sex workers, transgender people, people who inject drugs and prisoners and other people living in closed settings: A background review*. 2016.

⁴⁷ International Treatment Preparedness Coalition (ITPC). *ACT Toolkit 2.0, Advocacy for Community Treatment-Strengthening Community Responses to HIV Treatment and Prevention*. 2016.



What should community activists ask their governments for?

To look at and examine their guidelines, plans and policies: Even if states do not intend to provide early ART, their guidelines must address this issue. The decision to start treatment only after a particular CD4 count is reached now has human rights implications. This is highlighted in lower-income countries, where research shows that many of those diagnosed and sent home because their CD4 count is too high will die before they re-approach health services to access ART.⁴⁹

To provide enough and accurate information: States have a human rights obligation to ensure populations are given adequate information relating to health and prevention benefits of early ART and the fact that an undetectable viral load is a powerful prevention tool. With regard to this, information relating to routine viral load monitoring (Section 2.3) should also be provided to communities and healthcare workers.

Important terms to understand

Access to early ART is the option to start ART immediately upon diagnosis and after an informed voluntary decision. This is now considered a core human rights obligation.

Treatment as prevention (TasP) is a term used to describe HIV prevention methods that use ART to decrease the chance of a person passing on HIV to others.

Evidence supporting TasP: The HIV Prevention Trials Network (HPTN) O52 study was carried out in 1,763 HIV-serodiscordant couples (one person is living with HIV while the other is not) from 13 sites in nine countries. The study showed that starting ART early reduced the overall risk of HIV sexual transmission to uninfected partners by 93%.

Pre-exposure prophylaxis (PrEP) is a way for people at a high risk of HIV to take ARV drugs to reduce the risk of HIV infection. It is a very effective prevention measure when used consistently.

(Source: World Health Organization. *Guidelines on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV*. 2015)

⁴⁸ Kavanagh M, et al. *Evolving Human Rights and the Science of Antiretroviral Medicine*. *Health and Human Rights Journal*. Issue number 1, volume 17. June 2015. Available at <https://www.hhrjournal.org/2015/06/evolving-human-rights-and-the-science-of-antiretroviral-medicine/>

⁴⁹ Ibid.

How can DSD work for underserved groups?

As shown in Section 3.2 (ii) relating to the **building blocks of differentiated ART delivery**, it has the potential to provide solutions for groups that are facing barriers to access in conventional delivery systems.

“With differentiated ART delivery, we would feel ourselves exist, and we would feel less alone.”
(Source: *Rapid Assessment*, male respondent, age 36-50, Morocco)



Differentiated delivery programmes can address regulatory barriers to access

Researchers suggest that implementation of differentiated delivery programmes “affords significant opportunities to confront legal and structural barriers that prevent underserved [recipient of care] groups from accessing services”.⁵⁰

For example, a significant barrier for people who inject drugs (PWID) to access ART services in Pakistan is the prerequisite that an HIV-positive drug user should first be drug free. Can planning and implementation of DSD interventions at a national level address some of these barriers? In a similar way, national programmes have been and will need to continue pushing regulatory barriers relating to who can dispense and distribute ART. These “task-shifting” aspects of DSD are highly relevant for key populations, allowing them to receive HIV-related services from peers and reducing interaction with staff in healthcare facilities. Good examples of DSD for key populations include moonlight outreach programmes for sex workers or those that integrate harm reduction services into ART delivery services for PWID.⁵¹

Key populations and DSD: Commercial sex worker (CSW) community outreach clinic, Nsanje District, Malawi

What: Comprehensive HIV package of care, including ART, post-exposure prophylaxis, emergency contraception, initiation of ART for all sex workers who test positive, condoms and lubricants

Who: Nurses and peer educators

Where: Community outreach clinics in locations where sex workers feel comfortable gathering; HIV testing services are also provided at hotspots

When: Night time

(Source: *Differentiated Service Delivery for Key Populations: A Background Review*. www.differentiatedcare.org)

Differentiated delivery programmes can address social barriers to access

Adolescents living with HIV have specific concerns, as well as clinical and psychological needs that may remain unmet in HIV services that group them with children or adults. They have high levels of anxiety relating to having their status disclosed among their peers, as well as concerns around having to frequently miss school for check-ups and ART refills. They also face barriers at health facilities, “including long wait times, negative health worker attitude and, at times, limited privacy”.⁵² While these barriers are not unique to adolescents, their developmental stage and the changes they are facing mean that they may experience a greater sense of frustration and isolation deterring them from regular attendance. DSD models that **facilitate peer support and youth-friendly clinics that are geared towards adolescent needs** have tremendous potential in terms of reducing the sense of isolation that adolescents may feel and increasing adherence to ART.

Key populations and DSD: TB/HIV Care Association Key Populations Programme, South Africa

What: HIV testing, ART and harm reduction programme, including referral for opioid substitution therapy

Who: Nurse

Where: Community-based outreach and drop-in centres

When: Day and night shifts 5 days a week

(Source: *Differentiated Service Delivery for Key Populations: A Background Review*. www.differentiatedcare.org)

Adolescent teen clubs: Malawi

Who: Adolescents who understand their status are enrolled in Saturday teen clinics known as “teen clubs”. There are separate clubs for younger and older youth (30-70 youth in a club depending on size of cohort at the site). A trained mentor facilitates the club.

When: Every Saturday outside of normal clinic hours

Where: Local health facility

What: Services provided include adherence and psychosocial support. During the club activities, a nurse sees each adolescent individually for their ART refill and clinical review as per a routine clinic visit. Stable adolescents may attend every second or third month and receive 2-3 month ART refills.

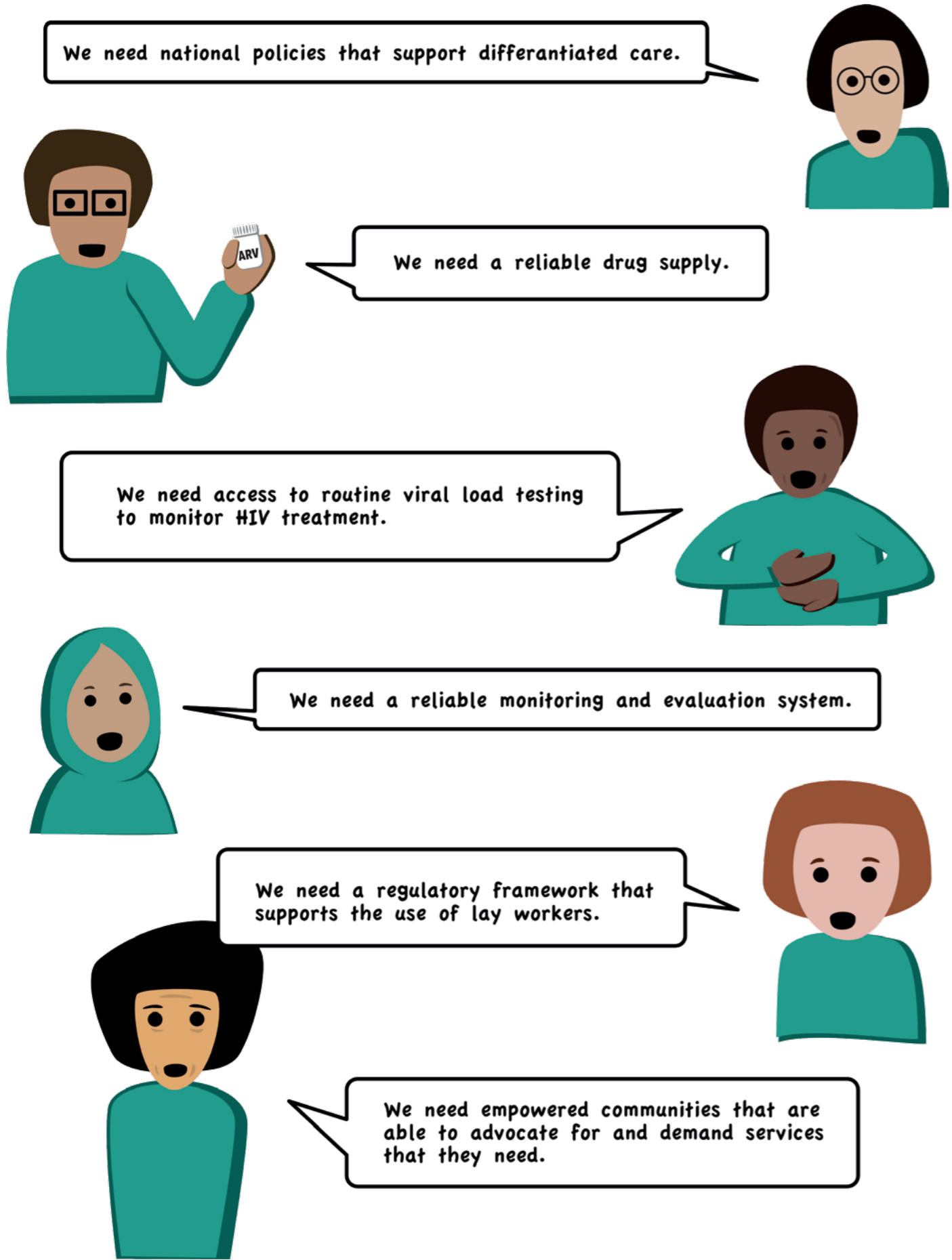
Outcomes: More than 9,000 adolescents have been enrolled in more than 135 clubs to date. High levels of adherence and viral suppression are reported.

(Source: *Differentiated Care for HIV: A decision framework for differentiated antiretroviral delivery for children, adolescents and pregnant and breastfeeding women*. (2017)

⁵⁰ Grimsrud et al. *Reimagining HIV service delivery: the role of differentiated care from prevention to suppression*. Journal of the International AIDS Society. 2016, 19:21484.
⁵¹ *Differentiated service delivery for key populations – men who have sex with men, sex workers, transgender people, people who inject drugs and prisoners and other people living in closed settings: A background review*. 2016.

⁵² *Differentiated service delivery for families – children, adolescents, and pregnant and breastfeeding women: A background review*. 2016. (Prepared for the consultation on HIV differentiated service delivery models for specific populations and settings: Pregnant and breastfeeding women, children, adolescents and key populations. Geneva. 16-18 November 2016)

What do we need for successful implementation of differentiated care in countries?⁵³



⁵³ Grimsrud, et al. *Reimagining HIV service delivery: the role of differentiated care from prevention to suppression*. Journal of the International AIDS Society. 2016, 19:21484.

Key messages

- A human rights-based approach is one that considers and addresses human rights at all levels and in all processes of action on HIV.
- **Treatment as prevention (TasP)** is a term used to describe HIV prevention methods that use ART to decrease the chance of a person passing on HIV to others.
- States have a human rights obligation to ensure populations are given adequate information relating to the health and prevention benefits of early ART and the fact that an undetectable viral load is a powerful prevention tool.
- Differentiated ART delivery has the potential to provide solutions for groups that are facing barriers to access in conventional delivery systems.
- Good examples of DSD for key populations include moonlight outreach programmes for sex workers and those that integrate harm reduction services into ART delivery services for people who use drugs.





Photo: Allan Gichigi/MCSP

SECTION 4.

MAKING AN ADVOCACY PLAN

Section acronyms

ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
ARVs	Antiretrovirals
CDDPs	Community drug distribution points
HIV	Human immunodeficiency virus
HSAs	Health surveillance assistants
IAS	International AIDS Society
ITPC	International Treatment Preparedness Coalition
PLHIV	People living with HIV
PPT	PowerPoint
WHO	World Health Organization
VMMC	Voluntary medical male circumcision

Section objective

The objective is to enable community activists to spread awareness of and raise demand for differentiated ART delivery within communities.

Training material

- PPT presentation on making an advocacy plan
- Flipchart
- Pens and papers
- Handouts of the advocacy cycle.

Training options

Option A: What does advocacy mean to you? (30 minutes)

1. Explain the objective of the session.
2. Ask participants to share their experiences of community advocacy – either an experience that they have been a part of or that they have experienced as a member of “target” audience.
3. Ask them to identify what was successful and what was not in their opinion.

Option B: How can we make an advocacy plan around differentiated ART delivery? (75 minutes)

1. Divide participants into groups.
2. Ask each group to choose a specific population to focus on, such as pregnant and breastfeeding women, adolescents or one of the key population groups.
3. Ask each group to develop an advocacy plan relating to enhancing access for its specific population to differentiated ART delivery services. The plan must include how it will increase demand for these services among these groups. (45 minutes)
4. Each group must then present back to the whole group. (5 minutes each)

Option C: Developing an advocacy message relating to differentiated ART delivery (60 minutes)

1. Divide participants into groups of five.
2. Ask them to come up with two core advocacy messages relating to:
 - “Treat all”
 - Differentiated ART delivery.
3. Ask them to identify how they might adapt delivery of these messages to different target audiences.
4. Ask each group to report back to the whole group.

Useful resources

Module 7 of the ITPC ACT 2.0 *Toolkit for Community Activism*
(<http://itpcglobal.org/wp-content/uploads/2015/02/ACT-Toolkit-2.0.pdf>).

Community Toolbox, Developing a plan for advocacy
(<http://ctb.ku.edu/en/table-of-contents/advocacy/advocacy-principles/advocacy-plan/main>).

International Council of AIDS Services Organisations and International HIV/AIDS Alliance. *Measuring Up – A Guide for Learners: HIV-Related Advocacy Evaluation Training for Civil Society Organisations*. 2010
(<http://www.icaso.org/publications/2011/Measuring-up-learners-30.09.10.pdf>).

Please also look at www.differentiatedcare.org for extensive resources that are useful for advocacy, including global guidance, national policies and operational plans relating to differentiated care and summaries of available evidence from programme interventions.

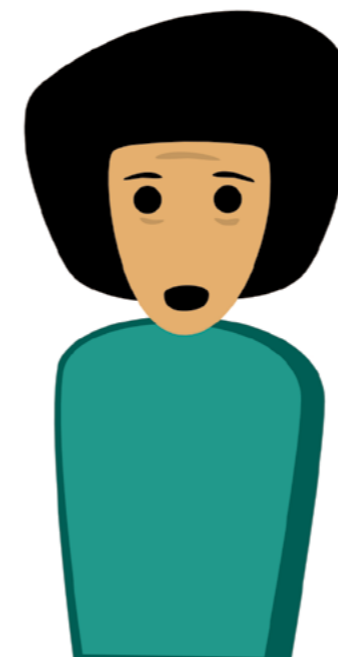
Section 4.1 What are communities saying about differentiated ART delivery?

This section highlights some key findings from the rapid assessment to assist and inform advocacy within communities.⁵⁴ Among 266 respondents (221 PLHIV and 45 healthcare workers) surveyed across the seven countries, several key trends were highlighted:

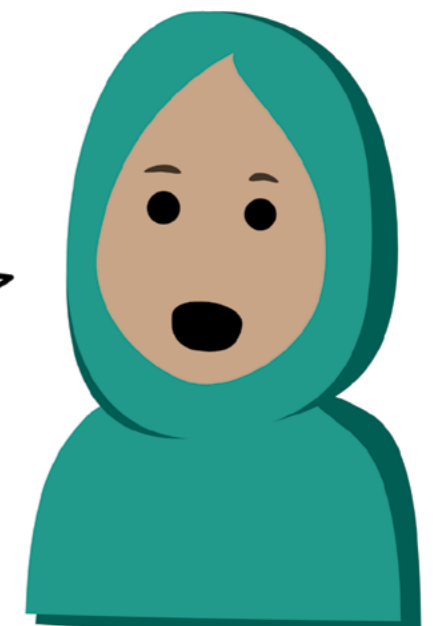
- Only 18 % of all PLHIV interviewed had heard of differentiated models of delivering ART.
- Most respondents said that one or more of the proposed models for differentiated ART delivery would make collecting their ARVs easier.
- The most popular options were community drug distribution points (CDDPs) and a fast-track window within the clinic.
- The most positive perceived impact was the potential of saving time and saving money, specifically on transport.
- Regarding potential negative impacts, the primary concern among respondents was that delivery of their ARVs closer to home would lead to exposure of their status and consequent stigma and discrimination.

⁵⁴ ARASA and ITPC. *Differentiated Models of Antiretroviral Therapy (ART) Delivery: Report on the Rapid Assessment Study May - July 2016*.

- Healthcare worker respondents expressed concern that groups such as adolescents and key populations would be particularly concerned about doing anything that might expose their status to their friends or broader community.
- They also stated that any roll out of differentiated ART delivery models would need to be accompanied by comprehensive training for healthcare workers and the implementation of treatment literacy programmes to educate communities about differentiated ART.
- An additional online survey, still ongoing, is finding that these trends are persisting.⁵⁵



“The first (fast track) would be the best for me because it allows us to safeguard the secret of our disease, which is very important to avoid the discrimination that can be subject in our environment, and for the safeguarding of these secrets, only the doctor is able to do it better than anyone else ...” (Online survey: Female respondent, age 35-49)



“Most of us would not like other people to know their health status. AIDS is still perceived as a shameful disease. If people, especially my friends, know I am a victim, they might abandon me.” (Girl, age 15-20, Tanzania coastal district)

⁵⁵ An online survey conducted by ARASA and ITPC on community perceptions related to differentiated ART delivery has been posted on global list servers since May 2017.

Section 4.2 What does advocating for differentiated service delivery mean?

Empowered and informed PLHIV communities will need to demand differentiated ART delivery as part of their right to access the best possible treatment and care. To demand this, they must know about it, understand it, and be able to assess the impact it will have on their lives and treatment. In this section, we will examine how advocacy to create this sort of demand might be carried out.

Characteristics of successful advocacy

- Based on evidence** so that it responds to the real needs of community members, especially PLHIV. In this context, community responses to surveys on differentiated ART delivery, as well as to implemented programmes, should be carefully reviewed
- 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.

(Source: ITPC RVLT Toolkit: Creating an Advocacy Plan)



Section 4.3 Creating an advocacy plan

Although there is no one absolute way to create a plan and conduct advocacy, a helpful approach is to create an advocacy cycle. An advocacy cycle can guide activists through different planning steps.⁵⁶ This diagram shows the five stages of the cycle from research to evaluation of impact.

Let us briefly look at what these steps involve:



⁵⁶ The cycle on page 53 is adapted from ITPC's *Advocacy for Community Treatment (ACT)* Toolkit 2.0 to make it specifically relevant to differentiated ART delivery

Step 1: Identify the issues, gaps, problems and barriers by conducting baseline research

This step is about identifying the extent of the problem and familiarizing yourself with all the issues therein.

What questions might be useful in the context of differentiated ART delivery?

- What do my country's ARV guidelines say about differentiated service delivery? Are they in line with the WHO recommendations?
- Are there any existing interventions using models of differentiated delivery in my country?
- Are there existing interventions into which ART delivery could be integrated, for example, postnatal and infant health services for women?
- Does data, research or community feedback exist on any running programmes?
- What are the specific population groups in the areas we are targeting? (Examples are key population groups or adolescents)
- Are any specific communities/regions more likely to be targeted for these interventions?

You can also conduct your own research through community monitoring (when members of a community conduct research themselves about an issue). Here are some questions you could ask PLHIV communities at health facilities or in existing community networks or peer groups:

- What are the challenges you face in terms of ART collection?
- Would you be interested in splitting ART collection from clinical check-ups?
- Do you think any models of differentiated ART delivery sound useful to you? (Describe them.)
- What do you think the positive and negative aspects of differentiated ART delivery might be?

Collecting the necessary information: Where do I go and who do I talk to?

You can refer to **documents, reports and news** and a lot of information will be available online. This toolkit has already referred to many useful websites. Particularly relevant and easy to use with a great deal of consolidated information about differentiated care is: www.differentiatedcare.org.

Talk to the **health ministry and public health facilities** to find out what guidelines on differentiated ART delivery are in place, what the regulatory environment is, what policies exist, etc. Many of these can also be found online.

Contact **DSD research and implementation partners** in your country, for example, MSF and UNAIDS. **Community-based HIV service providers** in your area will be able to share useful information on number of people accessing services, bottlenecks in these services, and who could most benefit from differentiated ART delivery.

Key advocacy point: Opportunities and barriers



Step 2: Set priorities

Set priorities so that you can work most effectively, make the best use of your resources and achieve the most impact. Realize that you will not be able to do everything at once.

Try to identify the clearest and strongest priorities using specific criteria. Useful questions to ask yourself include:⁵⁷

- Will the PLHIV communities in this area benefit from differentiated ART delivery?
- How can we bring the greatest benefit to PLHIV?
- Would advocacy for specific models of delivery or specific populations be most useful in this area?
- Which barriers and opportunities are the most significant for work on differentiated delivery at this point?
- Will advocacy work for this issue?

⁵⁷ These are adapted from ITPC's Advocacy for Community Treatment (ACT) Toolkit 2.0 and are made specifically relevant to differentiated ART delivery.

Step 3: Make a plan

This involves setting out what you want to achieve and how you will do it. The following chart is a useful way to outline a plan and provides examples relevant to differentiated ART delivery. The examples are adapted from advocacy plans created at a think tank workshop with community activists on differentiated care.⁵⁸

Potential goal: All PLHIV living within one province will have access to a “fast-track” facility, as well as a community distribution facility, so that they may choose the way that best suits them to collect their ARVs separately from clinical checks.

Objectives	Activities	When?	Targets	Partners	Resources
This is a short-term goal that contributes to achieving your long-term goal	These are the advocacy actions that you will take to achieve your objective	This is the time period when the advocacy actions will take place	These are the people, organizations or institutions that you will target to help us bring about the change that we want	These are our supporters who you will work with to carry out your advocacy	These are the resources (such as people, time, money and skills) needed to do your advocacy
Improve knowledge about different models of differentiated ART delivery within PLHIV communities and increase demand for these services	Conduct outreach, dialogues and focus group discussions at community level. Conduct workshops for community healthcare workers	Once a week for 6 months	PLHIV community living within a specific area and going to specific clinics. Community-based healthcare workers, networks and peer groups. Care and treatment centres and support groups	Partner organizations within regional and local PLHIV networks, key population groups, doctors and healthcare workers	Vehicle/ money for transport Information communication and Education materials on DSD

Step 4: Take action

This involves putting your advocacy plan into action. This could involve strategies such as lobbying parliamentarians, holding demonstrations or working with the media. It could also, as mentioned, involve focusing on raising awareness among PLHIV communities.

⁵⁸ The chart is adapted from ITPC’s Advocacy for Community Treatment (ACT) Toolkit 2.0 and made specifically relevant to differentiated ART delivery.

Step 5: Evaluate your work

During this stage, you need to ask yourself 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?
- What were the lessons learned?

Section 4.4 Developing an advocacy message

A clear and concise message is very important. Advocacy messages are used to summarize what community activists are asking for and communicate it to their target audience. They can be used in speeches, briefing papers, interviews and also within meetings and on social media. If advocates are working in a coalition, it is important that all members agree to the message.

Advocacy messages should be:⁵⁹

- Short** can be said in less than 20 seconds
- Focused** be clearly related to the advocacy priority
- Simple** use straightforward language and avoiding jargon
- Targeted** be appropriate and relevant to the advocacy audience
- Powerful** convince stakeholders about why the issue matters and why they must take action
- Agreed** be supported by all those who need to use it.

When you are drafting an advocacy message, think about:

The “ask”: A brief statement of what the advocacy is aimed at changing.

The reason for the “ask”: What’s the point?

What is at stake: What will happen (or not happen) if changes do not take place?

Action to be taken: What should target audiences do in order to effect or support the proposed change?
Also think about the audience and how key messages may need to be delivered depending on who you are speaking to.

(Source: Adapted from: UN Women. <http://www.endvawnow.org/en/articles/1238-key-elements-of-the-campaign-message.html>)

⁵⁹ International Treatment Preparedness Coalition (ITPC). Activist Toolkit: Campaigning for Routine Viral Load Monitoring. 2016.

Section 4.5 Demand creation case study

CASE STUDY: Kenya - Using evidence to create demand for voluntary medical male circumcision (VMMC)

Context:	<p>Generating demand for VMMC is a key component of HIV prevention in 14 priority countries with high HIV prevalence in eastern and southern Africa. It is estimated that “if 80% of males aged 15 to 49 years in these priority countries were circumcised within 5 years, and if coverage levels were maintained thereafter, 3.4 million HIV infections could be prevented over 15 years”. By the end of 2014, an estimated 8.5 million men had undergone VMMC for HIV prevention in these priority countries, but demand among men at highest risk for HIV infection remains a barrier to optimizing the programme’s impact.</p> <p>The Kenya VMMC programme provides a good example of how programmes should use evidence to inform their demand-side response. It has achieved about 70% VMMC coverage, against its target of 80%. First, formative research identified a number of individual, interpersonal, cultural and structural barriers to circumcision. The programme developed interventions to address each of these barriers.</p>
Cultural:	<p>The Luo tribe was traditionally non-circumcising, unlike other tribes. Therefore, traditional barriers to uptake were addressed, but working with the traditional leaders and building an enabling environment for the programme through them.</p>
Individual:	<p>Community mobilizers were used for a large, sustained, incentivised outreach campaign. Journalist training and radio shows ensured a positive “noise” in the environment.</p> <p>The programme is now focusing on interventions to reach the hardest-to-reach men (those over 25 years old and employed). One barrier to VMMC uptake among this subgroup is financial concerns, specifically lost wages from taking time off for surgery. Therefore, an incentive-based demand-creation strategy was evaluated. The study found that small amounts of fixed compensation in the form of food vouchers were effective in removing structural barriers for men who had already committed to getting circumcised. The national programme is currently exploring scaling up this intervention.</p>

(Source: *Toward a Systematic Approach to Generating Demand for Voluntary Medical Male Circumcision: Insights and Results from Field Studies*)

This research was part of a study analysing current demand generation interventions for VMMC by reviewing the available literature and reporting on field visits to programmes in seven priority countries. The study identified certain helpful practices, which are interesting to look at in the broader context of community advocacy and demand creation.

Good practice tips for community advocacy identified during this research

- Tailor messages carefully to the audience. Find the most appropriate message for the group you are talking to and consider the stage they are at with regard to intentions and motivations.
- Reach out to traditional leaders. Tribal and religious leaders can change an existing norm, give reassurance and lend authority to a programme.
- Use mobilizers. Interpersonal communication can address individual concerns.
- Target women as an audience for messaging and use them as change agents if this is relevant.
- Appeal to reasons/motivations beyond just the very obvious. What are the longer-term benefits of the action?
- Package the actions with other interventions if you can.
- Use new technologies. Messaging delivered via the Internet, social media and mobile phones should be part of the mix, along with traditional media.
- Partner and collaborate with people.
- Use multi-media forms of communication (theatre/film/radio) if you can.

(Adapted from *Toward a Systematic Approach to Generating Demand for Voluntary Medical Male Circumcision: Insights and Results from Field Studies*)

Read this for more information

Please take a look at Module 8 of the ITPC’s *Advocacy for Community Treatment (ACT) Toolkit 2.0*, which provides several detailed real-world examples of advocacy for community treatment (<http://itpcglobal.org/wp-content/uploads/2015/02/ACT-Toolkit-2.0.pdf>).



WHAT WORKS FOR US

SECTION 5.

YOUTH-LED ADVOCACY ON DSD

Section acronyms

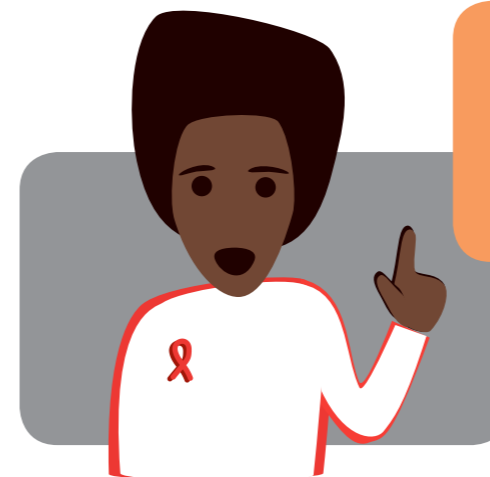
ART	Antiretroviral therapy
ARV	Antiretroviral
CIPHER	Collaborative Initiative for Paediatric HIV Education and Research
DSD	Differentiated service delivery
HIV	Human immunodeficiency virus
IAS	International AIDS Society
ITPC	International Treatment Preparedness Coalition
MSM	Men who have sex with men
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
IAS	International AIDS Society
YPLHIV	Young people living with HIV
PWID	People who inject drugs
RVLT	Routine viral load testing
SRHR	Sexual and reproductive health and rights
TG	Transgender
WHO	World Health Organization
YKP	Young people from key populations

Section 5.1 FOR YOUTH, BY YOUTH: WHY THIS CHAPTER?

Section objective

The objective is to understand why interventions must renew their focus on young people living with HIV (YPLHIV) and to make clear the unique challenges faced by individuals at this stage of life.

Young people living with HIV: What are the facts?



“Reaching YPLHIV with better information, improved services and innovative approaches that can address our specific health needs is of paramount importance. Available evidence shows that we are still not having our needs met by current services and that, globally, compared to adults, we have worse access to and coverage of ART, higher follow-up loss rates and poorer adherence to treatment.”¹

WHO defines “adolescents” as individuals in the 10-19 years age group and “youth” as the 15-24 year age group. The term “young people” covers the age range 10-24 years.

¹ IAS, CIPHER and WHO. Research for an Aids Free Generation: A Global Research Agenda for Adolescents Living With HIV.

What do the numbers tell us? (UNAIDS, 2016)

An estimated 1.8 million adolescents (aged 10-19) globally are living with HIV. 90% of these are in sub-Saharan Africa.

In Asia, young people from key populations make up 95% of young people diagnosed with HIV. (www.avert.org)

37% of new infections are among young people aged 15-24, 22% among young women, and 15% among young men.

New infections among 15-19 year olds have declined, but more slowly than children under 15 years of age.

Adolescents and young people living with HIV are the only age group where mortality from AIDS-related conditions has not decreased.

“Youth Bulge”: In 2050, it is estimated that there will be 450 million young people, due in large part to the “youth bulge”. On a positive note, this implies more children growing up and surviving into adolescence, but on the other hand, it also means more young people are at risk of HIV.

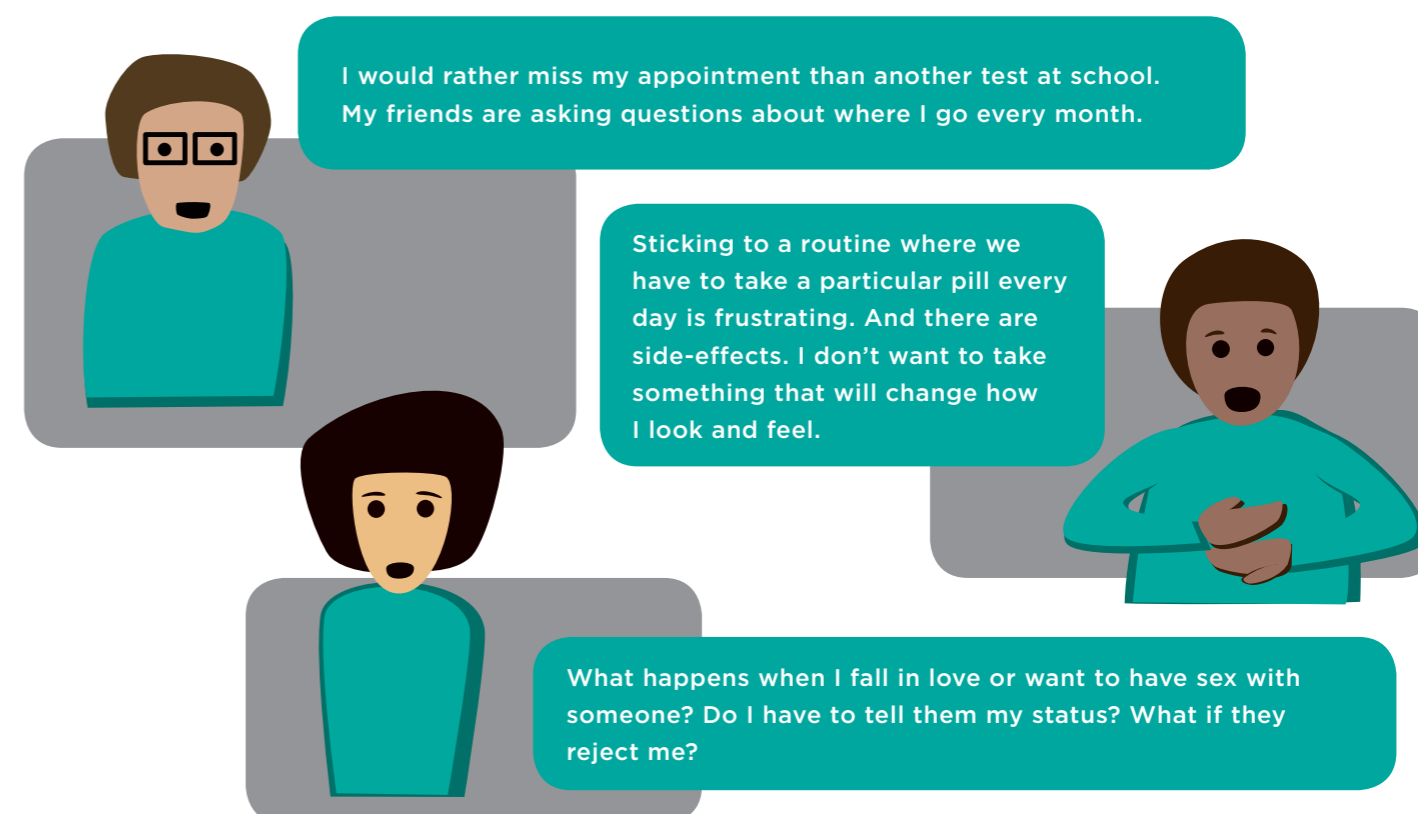
“So, looking at the numbers, we need to ask, why is the rate of new infections among young people (aged 10-24) still so high and what is getting in the way of our needs being met? Keep reading to understand more and to see what we can do about it. A reminder, whilst some guidance in this chapter is specifically for adolescents ((10-19 years old), most of the chapter is relevant for the overlapping age group of YPLHIV.”



What are our needs?

Adolescence is a transitional stage between childhood and adulthood and a time of extreme social, physical and emotional development and change. As adolescents, we all face challenges related to changes in our bodies, increasing independence, development of our sexuality, peer pressure and exploration of new experiences and ideas.

Throughout adolescence and beyond, as YPLHIV, we face additional challenges that include accessing treatment and care, following a regime of lifelong medication, dealing with issues around disclosure to family, peers and potential sexual partners, worrying about the future and facing stigma and discrimination.²

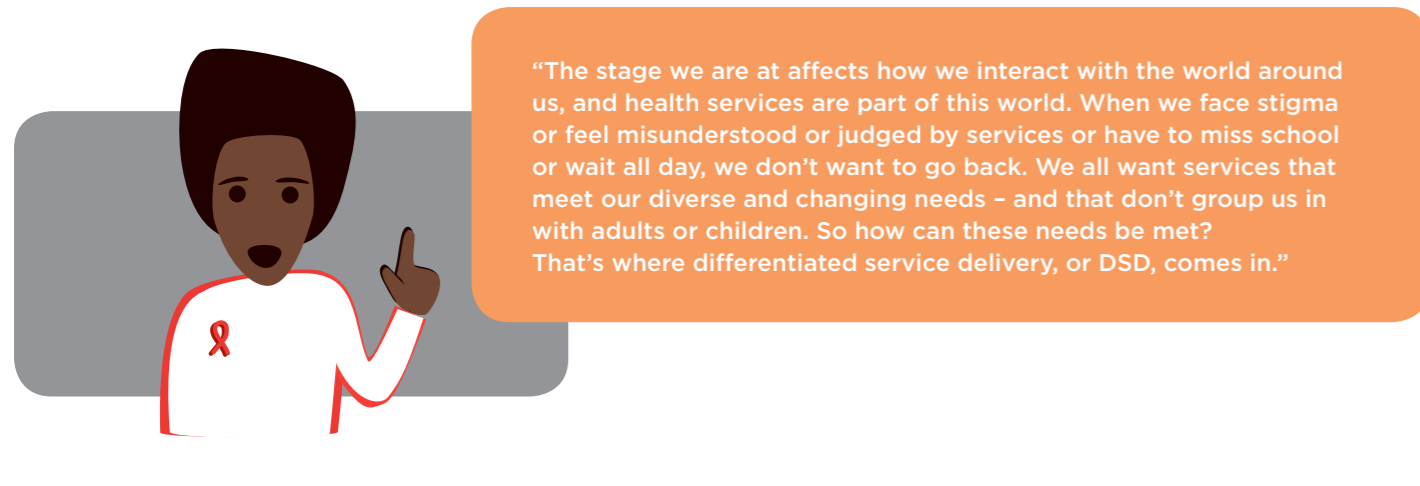


This phase of life also tends to be accompanied by an increase in risk-taking behaviour, which may involve pushing boundaries established by authority figures and trying things that could be harmful. Many scientists now suggest that this might be a normal and, indeed, necessary part of growing up and preparing for adulthood.³ However, this tendency has an effect on the way we think about health, how we look after ourselves and our perception of risk when it comes to non-adherence to treatment regimens.

YPLHIV are a diverse group and come from many backgrounds and walks of life. We may have been born with HIV or we may have acquired it through our lives. We may be in school or college, employed, looking after siblings, living in poverty or wealthy, using drugs, selling sex, pregnant, married or unmarried. The challenges we face will be experienced and navigated differently depending on some of these factors.

² Paediatric Adolescent Treatment Africa (PATA). *One-Stop Adolescent Shop Delivering Adolescent-Friendly Sexual and Reproductive Health, HIV And TB Services*. Promising Practices Series. December 2015.

³ Karaman, Neslihan Güney and Cok, Figen. *Adolescent risk-taking: comparison between adolescents' and adults' opinion*. *Paideia (Ribeirão Preto)* [online]. 2007, vol.17.



So, what is differentiated service delivery?

Differentiated service delivery (DSD) is a way of simplifying and adapting delivery of HIV services in a way that works for each person.

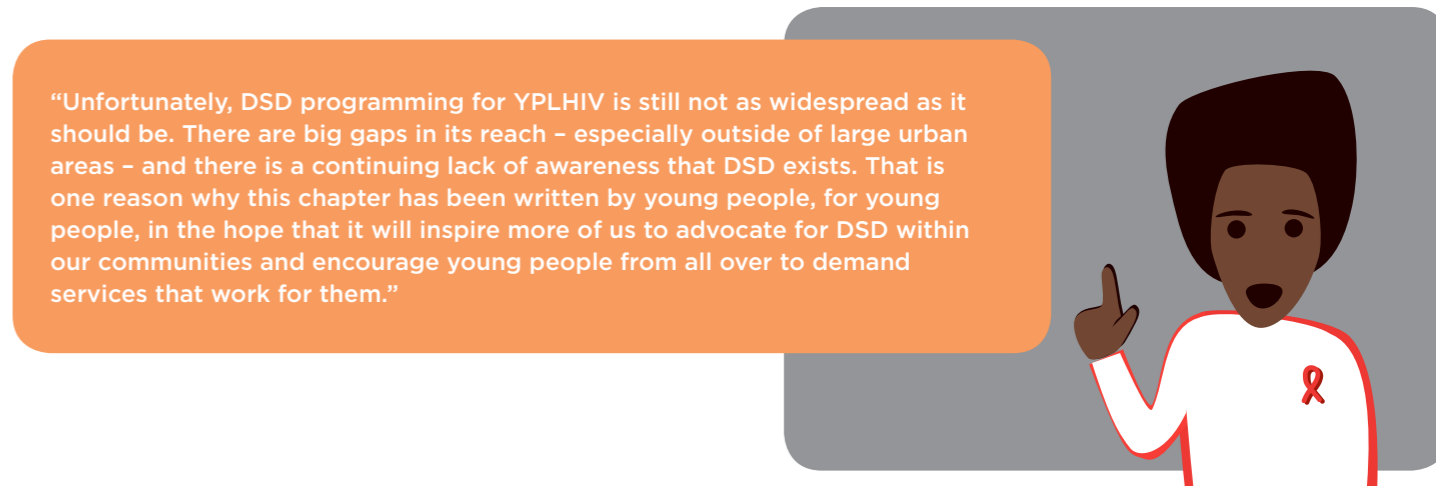
DSD works across the spectrum of HIV-related care and treatment. This means that the approach works for:

- The testing and diagnosis phase (having the test and finding out our status)
- The treatment phase (starting treatment and taking our meds regularly)
- The retention phase (staying on our treatment and keeping the virus suppressed).

Because DSD is not based on an idea of “one size fits all”, it can fill some of the gaps that exist in current programmes. It can also lessen the load on the health system because it allows for new and more efficient ways of doing things. For example, if trained peers can deliver ART, it leaves clinical staff free to deal with more serious cases – that’s just one example.

ADOLESCENTS are a unique group with needs different from those of children and adults. **DIFFERENTIATED SERVICE DELIVERY (DSD)** is a way of providing support and services that put their needs, expectations and preferences first. **DSD MODELS** have the capacity to deliver HIV services in a way that meets the unique emotional, social and medical needs of YPLHIV. **THE WORLD HEALTH ORGANIZATION (WHO)** says a large body of evidence is now showing that differentiated ART delivery provides a significant opportunity to improve treatment.

“DSD really works for young people. It makes it much easier for them to access services, much more quickly and from people who actually understand them and know what they are going through.”
(Tshepo, Youth advocate, South Africa)



Useful resources to read and watch

UNAIDS. *Global HIV & AIDS statistics – 2018 fact sheet* (<http://www.unaids.org/en/resources/fact-sheet>)

UNAIDS. *Ending the AIDS epidemic for adolescents, with adolescents* (http://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf)

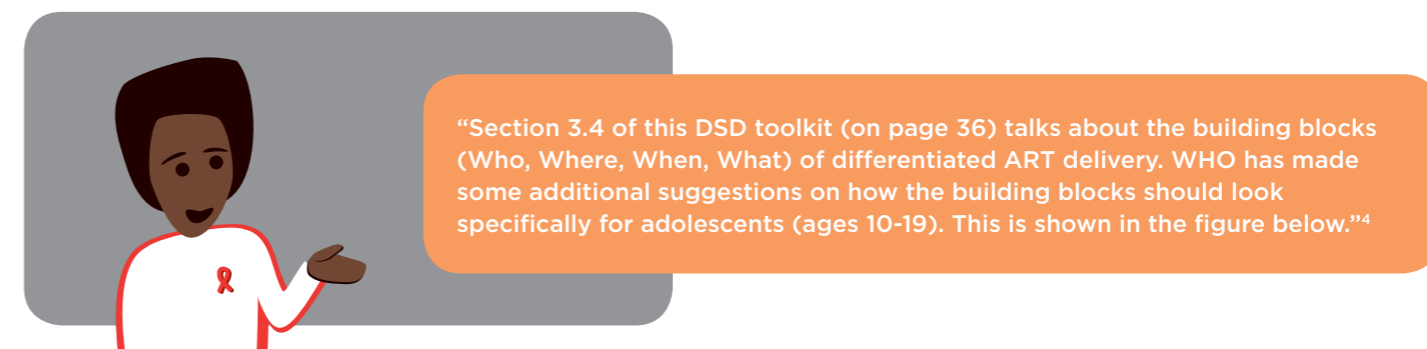
International HIV/AIDS Alliance. *Adolescent HIV programming. Ready- Here we come!* (https://www.childrenandaids.org/sites/default/files/2017-10/Adolescent%20HIV%20Programming_1.pdf)

Section 5.2 WHAT DOES DSD LOOK LIKE FOR YOUNG PEOPLE LIVING WITH HIV?

Section objective

The objective is to understand the technical aspects of DSD, who can benefit from it and how YPLHIV would like to receive their care.

The building blocks of DSD for adolescents and young people: What does WHO say?



⁴International AIDS Society, United Nations Children’s Fund and World Health Organization. *Providing Differentiated Delivery to Children and Adolescents*.

When

We should have access to longer ART refills (3-6 months) and we only need to go for a full clinical consultation every six months.

Where

We can collect ART refills at community venues or at group meetings, which don't have to be held at the facility.

What WHO says

Who

Non-medical staff can provide us our ART refills, as well as other support, and this could include caregivers or even our peers.

What

Psychological and adherence support must be included for us.

The building blocks of DSD for YPLHIV: What do young people say?

"In order to learn from and boost our peers' voices, five of us Youth Advocates have done some research amongst YPLHIV in five countries. We talked to **393 YPLHIV** about their experiences, needs and expectations, and they told us how they wanted to receive their HIV care and how this would look for them."⁵



When

If we are stable and on treatment, we want to see clinicians less often, like every 6 months.

If we have just been diagnosed or are experiencing clinical complications, we prefer more frequent clinical monitoring and peer support.

We want operating hours outside of school time.

Where

We need places that are easily accessible and located close to schools and homes.

It would be good if HIV clinics were not easily identifiable as HIV-only services because many of us fear that our friends, family and community may find out about our status accidentally.

What young people say

Who

We want to receive our care from both clinicians and peers through peer mentoring in group models.

We appreciate services from peers with the same status as us. This is more comfortable for us than working with HIV-negative peers.

What

We don't want everything separate -combine HIV care with other things, including services for sexual and reproductive health.

We would like more access to counselling and support, including from communities and peers.

"We are doing research within the facilities and seeing that DSD works with diverse groups of young people, but we need to have more consultations with vulnerable groups of adolescents to understand the different priorities that they have.

(Source: Research undertaken by youth champions in Malawi, Zimbabwe, South Africa, Kenya and Tanzania. Cited in International Aids Society Policy Brief Series: *Young Lives, New Solutions*)



"Below is an example of how DSD works in practice. In Section 3.3 (page 28) of the toolkit, we described the four main models of DSD. Below is an example of how one of these models works for young people."

Healthcare worker-managed group model: South Africa's youth clubs, Cape Town

Who: Lay healthcare workers manage groups of up to 20 young people (ages 12-25 years) and groups are divided into older and younger as their needs are different. A nurse provides support for clinical aspects.

What: ART refills, symptom checks, viral load monitoring and SRHR services are provided. Interactive activity sessions and discussions also help with adherence and create peer networks for sharing and support.

When: Every month for the first six months and then every two months at the clinic.

Where: Primary care clinic with a separate area for young people.

A **viral load test** measures the amount of HIV in a sample of blood. This is the most effective way to learn if HIV treatment is working for someone. This is an important tool because it shows if a person is failing in their treatment or is having problems with their adherence. As we can see from the WHO guidance, a low viral load can be used to support YPLHIV's demands for DSD.

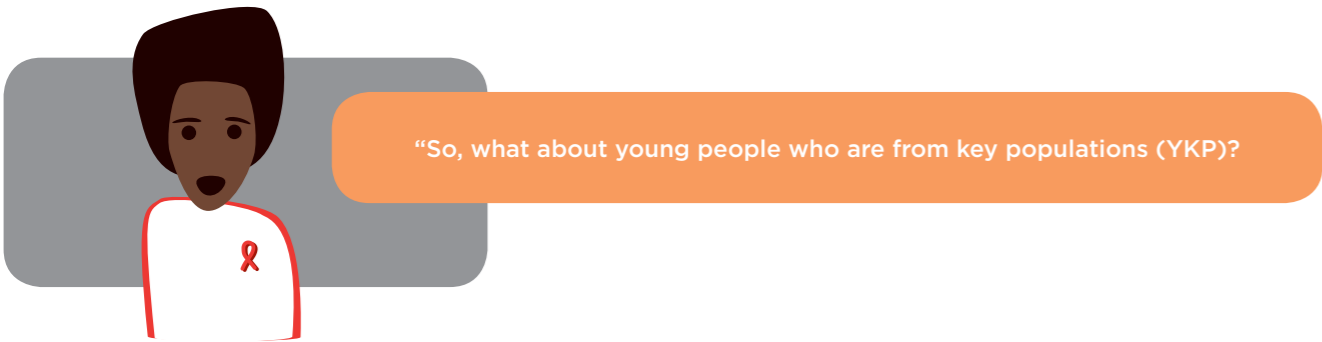
For a lot more information on this and on why we should demand routine viral load monitoring, please see: **Section 2.3 of the toolkit. Also take a look at: ITPC. Activist Toolkit: Campaigning for Routine Viral Load Monitoring. 2016** (<http://itpcglobal.org/resources/community-demand-creation-model-routine-viral-load-testing>)

⁵ International Aids Society Policy Brief Series: *Young Lives, New Solutions*.

Who can benefit from DSD models?

According to WHO, DSD models are suggested for adolescents who are “clinically stable”, which means those:⁶

- Who have received ART for at least one year **and have no adverse drug reactions that require regular monitoring**
- Who have no current illnesses
- **Who have** good understanding of lifelong adherence **and evidence of treatment success (i.e., two consecutive viral load measurements below 1,000 copies/ml)**
- **Who have access to psychosocial support.**



Young people from key populations include:⁷

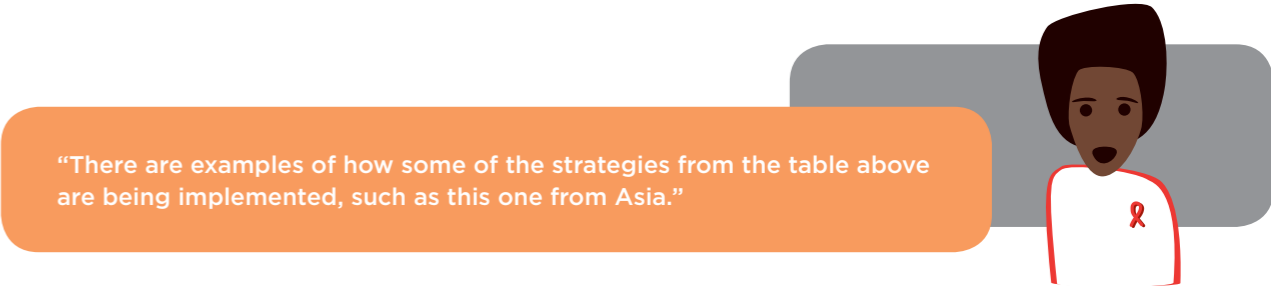
- Young people who sell sex
- Young men who have sex with men (MSM)
- Young transgender persons
- Young people who inject drugs

However, it is important to note that other groups also have different needs, such as pregnant young people or those living with disabilities. YKP face greater obstacles in terms of access to HIV-related care and treatment than other YPLHIV.⁸

These obstacles may include:

- Being alienated from family and friends
- Challenges in terms of access to education, housing or healthcare
- Fear of discrimination and legal consequences in environments where certain behaviours are criminalized
- Stigma and discrimination in healthcare settings
- Ignorance within health systems about gender variance
- Lack of understanding and knowledge of their rights
- Not identifying as being from a group at risk and therefore not seeking care.

WHAT DO YOUNG PEOPLE FROM KEY POPULATIONS NEED? ⁹	CAN DSD HELP?	HOW?
Integrated HIV and SRHR services, as well as those that focus on specific social, emotional, physical and legal needs faced by specific groups	Yes	A DSD approach can involve adding services for YKP to existing youth-friendly services.
Prioritizing building of trust with young stigmatized groups	Yes	Reach out through peers, including those from key populations themselves, who can approach marginalized groups with user-friendly information.
Community-based services using peer outreach and support	Yes	Reach out through peers who can accompany adolescents from key populations to access services delivered in “hotspots” where specific groups gather or work.
Easy access and safe impartial settings	Yes	Delivery through existing key population-focused community-based organizations.
Use of social media to promote services	Yes	Use apps and sites that YKP can access confidentially to get information and treatment.



In Chiang Mai, Thailand, Save the Children is running a programme that focuses on HIV prevention outreach among YKP, specifically young MSM and young transgender people.¹⁰

- HIV outreach is conducted through mobile apps with project staff promoting Mplus Chat, which is used to establish relationships.
- Outreach workers meet in person in safe areas that are frequented by these young people, such as bars and clubs. Tablets are used to make communication easier.
- The tablet is used to show the project website, to provide content for discussion and to record contact details for later follow up. After initial contact is established, online platforms are used to provide information on HIV prevention, treatment, care and support.
- Young people are offered accompanied referrals to free HIV testing, treatment and care services.
- Online counselling services since young MSM and transgender people sometimes prefer to have more privacy.

⁶ World Health Organization (WHO). *Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations*. 2017.

⁷ Asia Pacific IATT on Young Key Populations (<https://iatt-ykp.org/about-young-key-populations/>).

⁸ WHO: *Adolescent HIV Testing, Counselling and Care: Key Populations*. (http://apps.who.int/adolescent/hiv-testing-treatment/page/key_populations).

⁹ Ibid.

¹⁰ WHO. *Serving the needs of key populations: Case examples of innovation and good practice in HIV prevention, diagnosis, treatment and care*. 2017 (https://samumsf.org/sites/default/files/2018-02/case_examples_key_populations_WHO.pdf).

Useful resources to read and watch

Section 3.3 of DSD toolkit *What Works for Me*

International HIV/AIDS Alliance. *Link Up: Key resources* – SRHR, HIV and young people (<https://www.aidsalliance.org/resources/835-link-up-key-resources>)

Video: *Be Healthy – Know your viral load* (https://www.youtube.com/watch?v=OVR72_IPyGo)

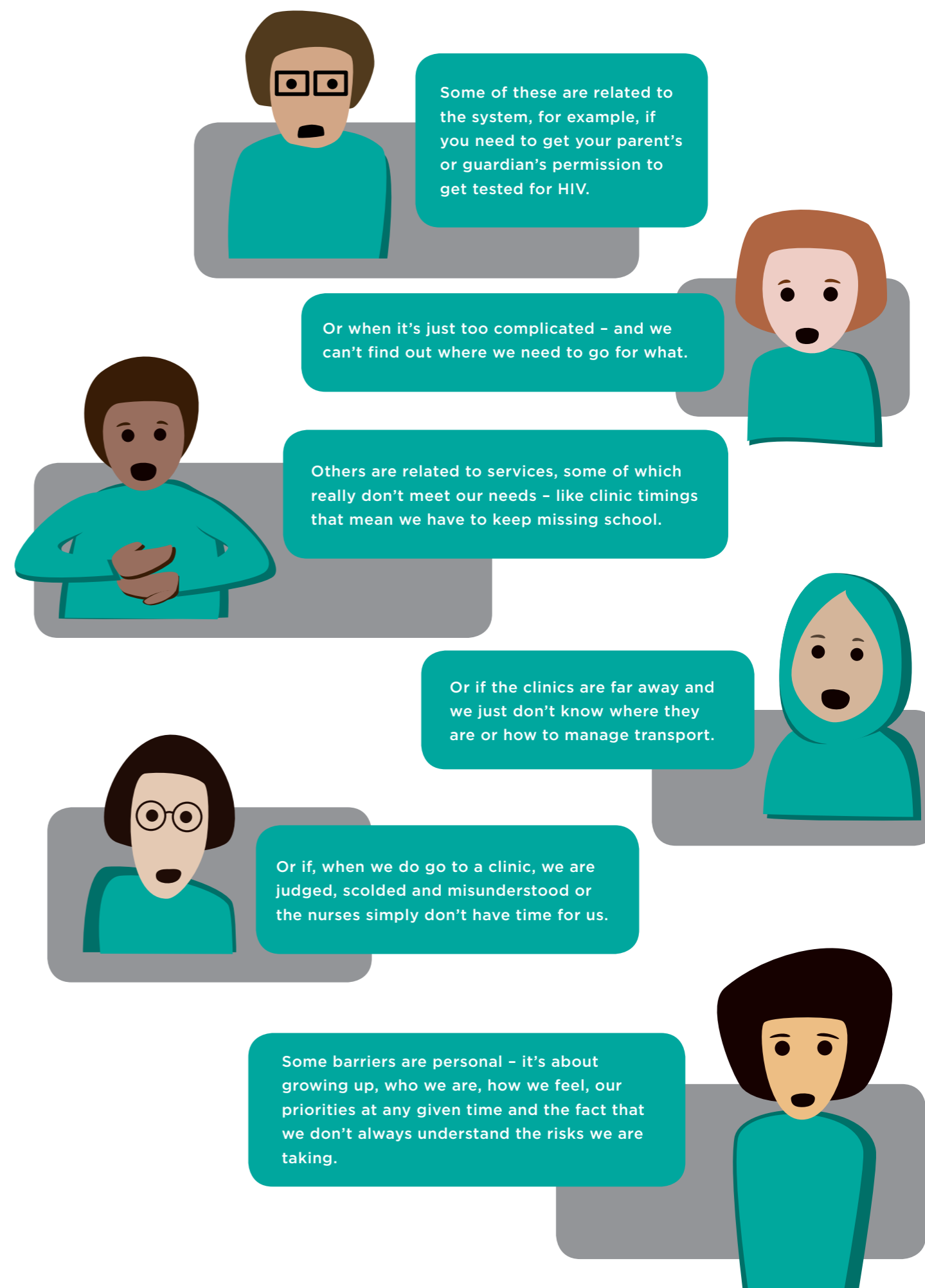
Video: IAS Youth Voices: *What is Differentiated Care?* (<https://www.iasociety.org/HIV-Programmes/Campaigns/Youth-Voices/Multimedia>)

Section 5.3 OVERCOMING BARRIERS: IMPLEMENTING DSD MODELS FOR ADOLESCENTS AND YOUNG PEOPLE

Section objective

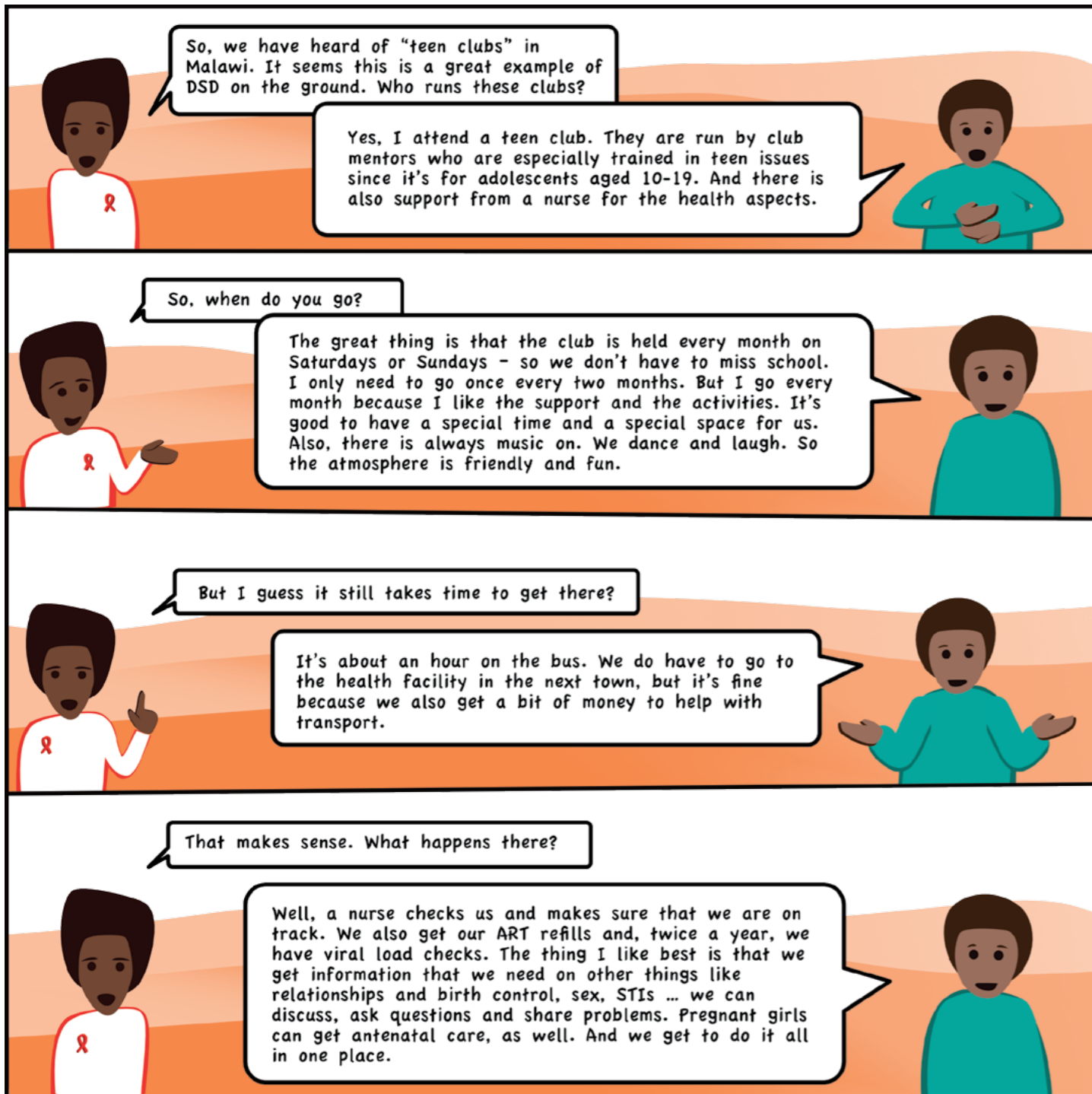
The objective is to highlight barriers to accessing HIV services and to effective DSD implementation, as well as examples of how these difficulties are being overcome by young people.

What barriers do we face in accessing HIV services?



How can DSD address these barriers?

“DSD can address these barriers by delivering services differently – the building blocks shown previously (Who, Where, When, What) can be adapted to reflect our needs and address the barriers that we face. Let’s meet Teleza, who will give us an example of how this is being done in Malawi.”



Useful resources to read and watch

<http://www.differentiatedcare.org/Models/TeenClub>

Namusoke from Kampala. DSD for Adolescents https://www.youtube.com/watch?v=gOVbHb7_8s

<https://www.msh.org/resources/teen-clubs-help-retain-adolescents-in-hiv-care-and-treatment>

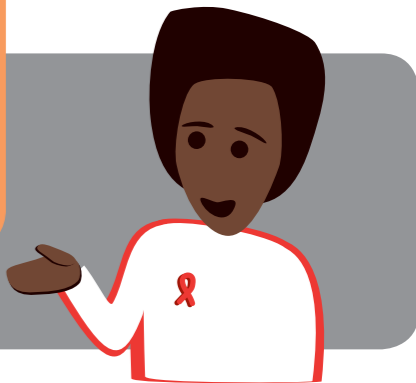
A DSD model for young people must include:

- Options for how support is given
- Clear information on what is available
- Safe and confidential peer counselling support groups run by peers who are also HIV positive
- Adolescent days/times at facilities, and information and sharing sessions at a clinical level
- Multi-month ART prescriptions
- Comprehensive services, including information and counselling on SRHR, harm reduction, drug use, PMTCT
- Convenient hours for young people
- New and innovative approaches to share information and support participation and adherence using social networks like WhatsApp, Twitter and Facebook.

“I have been working as a youth facilitator for youth clubs that are running for YPLHIV. We prepare the medication for our club members. They come straight to the club room when they get to the clinic. They have a health screening and then those who are adhering just take their meds and go home after the club meeting. They don’t have to stand in lines or anything. In our programme, YPLHIV services are provided mostly by other young people, who are trained and understand young people’s problems.”
(Tumie, Youth champion, South Africa)

What are the barriers to implementing DSD models?

“**When fully implemented**, DSD can address many of these. However, we also need to understand some of the obstacles to delivering DSD for YPLHIV in our countries. Feedback from healthcare workers, ministry officials and youth activists from all over the world at a meeting in New York suggests that there are some significant barriers at the local level to putting DSD into place for YPLHIV.¹¹ Below are some ideas of how to overcome these barriers from Youth Advocates working in different countries.”¹²



¹¹ https://cquin.icap.columbia.edu/wp-content/uploads/2018/02/ALHIV-Meeting-Report_Final.pdf.

¹² Interviews with Youth Advocates in October 2018.

BEST PRACTICE: Zvandiri programme, Africaid, Zimbabwe

A key feature of this DSD programme is the community adolescent treatment supporters (CATS), trained HIV-positive young people who provide support to children, adolescent and young people living with HIV.

Advocacy point: CATS are integrated within the health facilities supervised by the Ministry of Health and therefore their role is recognized and supported. CATS work **between clinics and the community**, encouraging and supporting YPLHIV to access the services they need. Clinical staff and social workers refer YPLHIV to the CATS for necessary peer support and follow up.

- CATS do community outreach going door to door linking YPLHIV to HIV-related services and providing advice and support on adherence issues.
- CATS, supervised by clinical staff, also work within the health facilities at clinic-based Zvandiri centres, which are safe spaces to link YPLHIV to clinical and social services, including SRHR services, mental health and socio-economic services, as well as PMTCT services for pregnant individuals.
- CATS run monthly community support groups with planned activities that develop skills and awareness, promote adherence and improve sexual and reproductive health. These groups also provide a chance for YPLHIV to meet others in a similar situation, make friends and share troubles.
- As of September 2017, a team of 860 CATS were actively providing adherence support for more than 45,000 HIV-positive children, adolescents and young people in Zimbabwe.

For more information on this programme, see:

Video: Zvandiri - Peer to Peer Support with HIV Positive Adolescents (https://www.youtube.com/watch?v=zlFCl4_Up2s)

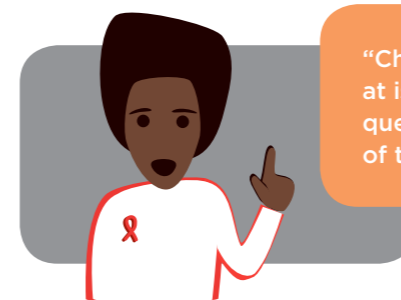
International HIV/AIDS Alliance: Supporting children, adolescents and young people living with HIV to start and stay on HIV treatment – Zvandiri Case Study (<https://www.aidsalliance.org/resources/1022-supporting-children-adolescents-and-young-people-living-with-hiv-to-start-and-stay-on-hiv-treatment>)

YPLHIV are an essential part of leading advocacy around improved HIV-related services that meet our diverse and specific needs. Youth activists are working within communities, inside clinical facilities and outside in different spaces as advocates, facilitators and peer educators. Our work includes going door to door within communities to speak to young people about the services that our local facilities are offering, hosting meetings, handling referrals within clinics, providing counselling and support at adolescent groups and meetings and following up with peers to make sure that they are not lost to follow up.

“At the facility, we do one-on-one adherence counselling and provide support, helping young people address their obstacles. We do home visits to see what support they have at home. And we do peer-to-peer engagement. My main work, though, is helping young people and service providers have a dialogue, creating links between them. This is an important part of helping adolescents access DSD services. One of the other ways we help them access DSD is home visits, where we are able to tell young people about the diverse services that are available in their facilities and in their community. We are also able to provide some of these services. So, if they cannot reach the facility, they know that a peer supporter is close by and can be reached for counselling and support.”

(Phakamani, Youth Champion, Zimbabwe)

So how do we do advocacy?



“Chapter 4 of this toolkit has information on how to conduct advocacy and looks at issues like how to make an advocacy plan, what is an advocacy cycle, suggested questions for baseline research on DSD and other useful information. However, some of the basics from the chapter are adapted in the picture below.”

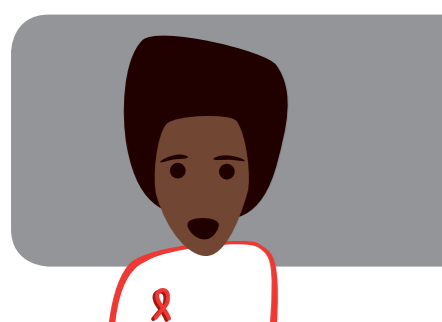


Section 5.4 YOUTH-LED ADVOCACY ON DSD

Section objective

The objective is to help and empower youth activists to advocate and demand DSD.

What do we have to do?



“As Youth Advocates, we have many tasks. We have to:

- Examine and understand the challenges and barriers so that we know what to address and what to ask our governments for.
- Do the research so that we know what our peers want and need.
- Spread awareness within our communities about what is available and what we can ask for.
- Find ways to raise community demand – so that adolescents and young people are gathering and raising their voice and asking for what they need.”

“I advocate on differentiated care amongst YPLHIV. I do demand creation sessions online and in and out of schools and these are effective because YPLHIV are getting the information they need about all the types of services (ARV collection, SRH, nutrition, economic) that they can access in one place.”

(Gladwell, Youth Champion, Kenya)

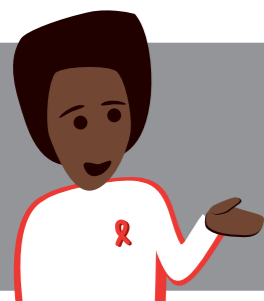
How can we measure the impact of our advocacy?

It's important for us to examine whether what we are doing is working. Below is a simple checklist of questions that we can use to help us decide if the goal of increasing demand for and provision of DSD services is being met.”



Some questions you can ask:

- Do more YPLHIV in your area know what DSD is?
- Do more local community health workers know what DSD is?
- Are options available for YPLHIV, for example, fast track at the clinic/community group closer to home?
- Can YPLHIV get ART refills for longer periods of time, at least two months?
- Can YPLHIV get ART refills from a community-based group, from trained peers?
- If peer-facilitated community groups exist, are more people approaching and accessing the services?
- During clinical checks, do the nurses and doctors show increased understanding of young people's needs and issues?
- Can YPLHIV go for a check-up and ART refills and also access other relevant services at the same time and place?



“Depending on the tools and tactics that you are using within your advocacy, you might measure things differently. For example, if you are using social media to spread awareness, you might be looking at how many people are looking at and liking your informative posts. However, simple questions like the ones above or any that make sense in your community context are useful to see if practical changes are happening on the ground.”

Useful resources to read and watch

Chapter 4 of the DSD Toolkit. *What Works for Me!*

IAS. *The Young HIV Advocates' Cookbook*

(https://www.iasociety.org/Web/WebContent/File/IAS_Young_HIV_Advocates_Cookbook.pdf)

IAS Youth Voices videos

(<https://www.iasociety.org/HIV-Programmes/Campaigns/Youth-Voices/Multimedia>)

Module 7 of the ITPC ACT 2.0 Advocacy for Community Treatment

(<http://itpcglobal.org/wp-content/uploads/2015/02/ACT-Toolkit-2.0.pdf>)

Community Toolbox. *Developing a Plan for Advocacy*

(<http://ctb.ku.edu/en/table-of-contents/advocacy/advocacy-principles/advocacy-plan/main>)

What do we need?

“It's not easy being a Youth Advocate and getting our voices heard where the decisions are being made – at national and regional levels, and also within our local communities. Read on to see what Youth Advocates in different countries have to say about what they need to support their work as they advocate for DSD.”



The following are some important areas of support:

- Technical: support on knowledge around issues, guidelines and protocols, participation in forums with diverse stakeholders, training on skills and management
- Financial: support of running of campaigns, gathering supporters, transport, materials for campaigning
- Emotional: including assistance with resilience, trauma and security threats when operating in unstable political environments
- Political: supporting linkages between national- and district-level implementation.

“Youth advocacy is not known. We need buy-in from the Department of Health (DOH). This is the support we need, recognition so that the health centres know what we are doing and then allowing us to do our work with adolescents in the facilities. I have to tell the clinic staff, ‘This is what I am supposed to do.’ It’s much easier for us when the DOH buys in because they are the ones who are heard.”

(Tumie, Youth Champion, South Africa)

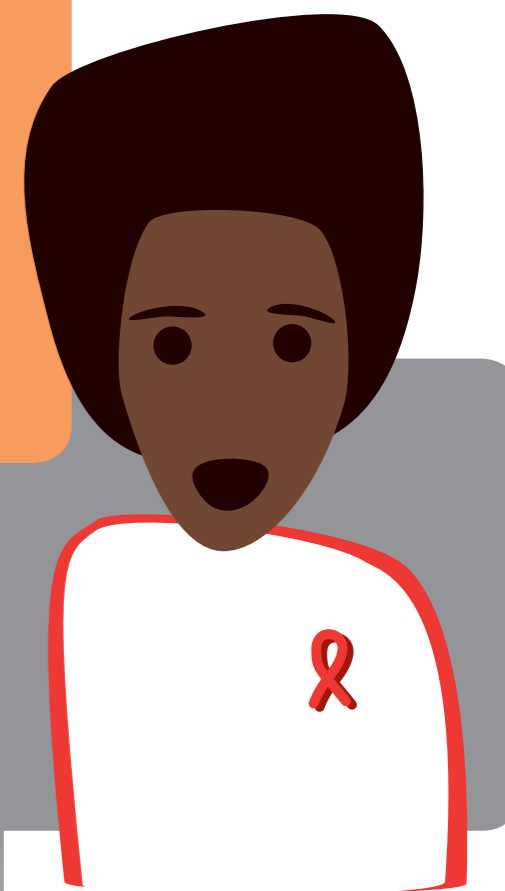
“We need more financial resources so that we can meet with key stakeholders, like community healthcare workers on the ground, and run big campaigns to raise awareness in rural areas. Policies about DSD are on the books, but there is a gap between national policy and things happening at the local community level. The message doesn’t go to those people who can actually make the changes.”

(Tanaka, Youth Champion, Malawi)

“When you’re an activist or an advocate, there are times when things are just not working out. But we still keep on going and still keep on trying. You need to keep going to help other young people. But that’s where emotion comes in - we need some ways to get support. You can be the shepherd, but the shepherd also needs help.”

(Kelvin, Youth Advocate, Zimbabwe)

“The important thing to remember is that, as YPLHIV, we understand the needs of our peers better than anyone else. If we aren’t involved, programmes and services won’t meet our needs. If we stay informed and continue to demand services and information that works for our community, our peers will be encouraged to do the same. Don’t stop learning, don’t stop talking and don’t stop demanding what works for you.”





ARASA
AIDS & Rights
Alliance
for Southern Africa



ITPC
INTERNATIONAL TREATMENT
PREPAREDNESS COALITION