

# Reaching Closer to Home

Progress implementing community-based and other adherence strategies supporting people on HIV treatment

Experiences from DRC, Lesotho, Malawi, Mozambique, South Africa & Zimbabwe



**MSF Analysis & Advocacy Unit (AAU) Brussels  
with Southern Africa Medical Unit (SAMU)**

Building 20-303 A&B, Waverley Business Park  
Wyecroft Road, Mowbray, Cape Town, South Africa  
Tel: +27 21 448 3101/1058

[www.samumsf.org](http://www.samumsf.org)



## Contents

Abbreviations .....	2
1. Introduction .....	3
2. Factors that enable access and adherence .....	4
3. Community ART delivery .....	5
4. Adapting strategies for different contexts .....	6
5. Description of models and strategies .....	7
5.1 Appointment spacing & fast-track drug refill in Malawi .....	8
5.2 Adherence clubs in South Africa .....	10
5.3 Community ART distribution points in DRC .....	16
5.4 Community ART Groups:	
5.4.1 Mozambique .....	19
5.4.2 Malawi, Zimbabwe and Lesotho .....	23
6. Discussion: Common elements, challenges and concerns for community ART delivery .....	28
7. Conclusion .....	32
References .....	34

Published December 2013  
MSF Analysis & Advocacy Unit (AAU) Brussels  
with Southern Africa Medical Unit (SAMU)

*This document describes progress in implementing community-based models of ART care since the release of the report "Closer to Home" by UNAIDS and MSF in July 2012.*

## Abbreviations

ART	Antiretroviral Therapy	MSF	Médecins Sans Frontières/Doctors Without Borders
CAG	Community ART Group	PLHIV	People living with HIV
CDU	Central Dispensing Unit	PODI	Points de distribution communautaires (Community distribution points)
CHW	Community Health Worker	RIC	Retention in Care
DOH	Department of Health	SMA	Six Month Appointment
FDC	Fixed Dose Combination	TasP	Treatment as Prevention
HRH	Human Resources for Health	VL	Viral Load
HSA	Health Surveillance Assistant	WHO	World Health Organization
HTC	HIV Testing and Counselling		
MOH	Ministry of Health		
MD	Medical Doctor		

## 1. Introduction

Remarkable progress has been achieved in the past decade in increasing access to antiretroviral therapy (ART) in developing countries at the epicentre of the HIV epidemic in sub-Saharan Africa. Ambitious target-setting by the World Health Organization and UNAIDS<sup>1</sup> backed by substantial political rhetoric – often unmatched with sufficient financial support from major donors – has catalysed a global effort to scale up access to ART. At the end of 2012, 9.7 million people were receiving ART in low- and middle-income countries, more than three quarters of whom live in sub-Saharan Africa<sup>2</sup>. In order to maximise the individual and population-level benefits of HIV treatment, it is essential that people on ART are retained in care and properly adhere to the treatment.

The benefits of ART in reducing mortality and morbidity have been convincingly demonstrated. Despite initial concerns about the feasibility of large-scale HIV treatment programmes in resource-limited settings<sup>3</sup>, early reports have shown comparable treatment outcomes to those reported from upper-income countries<sup>4,5</sup>. More recent data suggests that people receiving ART in sub-Saharan Africa can have an almost normal life expectancy<sup>6</sup>. Recent evidence as well as updated WHO ART guidelines show that treating people early with ART reduces HIV transmission<sup>7,8</sup>, which further supports the need to increase and sustain access to ART.



Initiating and maintaining nearly 10 million people on ART in low- and middle-income countries within a decade represents an unmatched achievement in public health history. This scale-up now imposes an immense challenge on health systems, particularly in high-prevalence countries of sub-Saharan Africa where health workers are already scarce<sup>9</sup>. Many people still lack access to regular testing and hence are unaware of their HIV status. Others who are identified as HIV-positive do not yet have access to HIV care and treatment due to programme or financing shortfalls, or leave care prior to the initiation of ART or are later lost to follow-up on ART for a variety of reasons.

Recent systematic reviews have highlighted substantial rates of attrition in HIV services for people who were not successfully linked to care and treatment following diagnosis, and in those on ART who did not yet succeed in integrating the treatment into their daily lives. This underscores the pressing need to improve access and retention through adaptation of service delivery to the reality of people's lives<sup>10,11</sup>. Furthermore, with the introduction of the 2013 WHO Consolidated guidelines recommending a higher initiation threshold (up to a CD4 count of 500 cells/ $\mu$ l) and that all pregnant women, children under five, TB co-infected and sero-discordant couples be started on ART, the number of people eligible for ART is now estimated to have risen to 28.6 million globally<sup>2</sup>.

In health facilities in high HIV prevalence settings, it is becoming clear that further successful scale-up will neither be feasible, nor sustained if it is solely supported by traditional models of healthcare delivery. To overcome these challenges a number of health facility and community-based strategies are being implemented to reduce the burden on health systems and people living with HIV (PLHIV) and to improve retention in care for those on ART. The 2013 WHO Consolidated guidelines recommend that provision of ART can be maintained in the community, but operational guidance is needed for this to happen in practice (8). As national, provincial and district teams address the various challenges, lessons from these innovative patient-oriented models can help shape the next stages of HIV care and treatment scale-up.

## 2. Factors that enable access and retention

There are three distinct phases in the use of ART. The initial phase is **stabilisation** that includes treatment of associated opportunistic infections and management of possible early treatment-related adverse events, sometimes requiring extended clinical services. This is followed by a **stable phase on ART**, where people require minimal clinical follow-up, and then, for some, a third phase in which treatment fails – often with the return of a **weakened immune system**.



In the first phase, patients require support to understand the need for life-long therapy on medicines that can have a range of possible side effects. Beyond this first phase, once their health has stabilized and their immune status has improved, most patients no longer require intensive clinical care and frequent visits to a health facility. With time, however, a proportion of people in the third phase will face adherence challenges and risk developing resistance to treatment, which will require another period of intensive clinical and adherence support.

There is strong evidence of a link between 'user friendliness' of services and retention in care. Long distances to clinic services and associated transport costs, payment of services,

long queuing times and the impact on competing demands, such as a person's need to work and care for the family, have all been associated with poor adherence to treatment and patients leaving care<sup>12,15</sup>.

**Decentralisation of ART services** to community clinics reduces the distance for patients have to travel to access care and also supports retention in care<sup>16,15</sup>. If ART initiation and follow-up care is decentralised from hospitals to health centres, together with a faster, more efficient drug refill system, this can improve retention in care while also decongesting secondary and tertiary level health services<sup>20</sup>. A priority for WHO and UNAIDS now is to decentralise HIV care to primary health centre level<sup>22</sup>. Significant progress on decentralisation of care has been made in some countries, while others continue to lag behind (Mozambique, Democratic Republic of Congo, Central African Republic, Guinea). As health centres are rarely staffed by physicians, decentralisation usually means that patients on ART must be managed principally by nurses and other non-clinicians. **Task shifting** of ART services from physicians to other providers is supported by WHO guidance<sup>23</sup>, allows medical staff to focus on more complicated cases and its safety and efficacy has been demonstrated<sup>8,24</sup>. This has been accompanied in many countries by changes in regulations to permit nurses to initiate and/or continue prescribing ART. Similarly, lay counsellors have played an important role in the provision of HIV testing and ART adherence support in most countries<sup>25,26</sup>. However, they are often not officially recognized by Ministries of Health (MOH) and are financially supported only through international partners.

Key enablers of decentralisation are the availability of a heat stable, once-a-day **fixed dose combination** first line ART regimen with minimal side effects and a lower initiation threshold allowing earlier initiation of ART that prevents greater numbers of patients developing complicated opportunistic infections. Additionally the availability of a monitoring test that measures the amount of HIV directly, rather than relying on a marker of immune function (i.e. CD4 count) supports decentralisation. Although monitoring of adherence through HIV viral load testing is the gold standard and annual **viral load testing** is recommended as the monitoring strategy of choice in the 2013 WHO Consolidated guidelines, many resource-limited countries are yet to introduce it.

## 3. Community ART Delivery

WHO and UNAIDS guidelines support increased **community engagement** in the delivery of HIV and ART services in order to improve retention in care<sup>8</sup>. Several pilot programmes are testing the feasibility of separating ART delivery from clinical visits by establishing models of ART delivery at the community level. In these models health centres and hospitals still serve as referral sites when problems arise for patients with more complicated clinical needs.

The relationship between social support and improved adherence to treatment is well established. Systematic reviews have found that ART programmes that provide patient support and education improve adherence to ART<sup>27,28</sup>. Community-based provision of ART helps build patient participation and hence empowerment<sup>29</sup> and can be a cornerstone of further decentralisation of ART service delivery.

The feasibility of providing ART beyond the health facility setting has been demonstrated in several studies<sup>30</sup>. In Uganda, patient survival and virological suppression in a home-based ART delivery model matched outcomes of facility-based ART<sup>31</sup>. In western Kenya, people living with HIV (PLHIV) have been trained and paid to provide follow-up care and delivery of ART to other clinically stable patients living with stable PLHIV in their communities<sup>32</sup>. In Tanzania, a model of ART delivery by community-based volunteers linked to trained medical workers has led to fewer patients being lost to follow-up treatment<sup>33</sup>.

Médecins Sans Frontières/Doctors Without Borders (MSF) has supported HIV/TB programmes in resource-limited settings over the past decade. In collaboration with Ministries of Health, MSF has been an early innovator and implementer of community-based models of ART delivery in sub-Saharan Africa, while documenting their outcomes through operational research.



## 4. Different strategies for different contexts

There is no 'one size fits all' strategy to reduce the burden for both healthcare workers and patients when providing HIV care for an ever-increasing number of people. Choosing the most appropriate model will be context specific and dependent on a range of factors, including:

- Individual patient barriers to retention in care
- Geographical barriers to accessing the health system
- The existing extent of service decentralisation
- Task shifting to lay health worker cadres
- 'Fast tracking' of medication refills
- HIV prevalence
- Commonly used ART regimens (and likelihood of side effects)
- The capacity of health services
- Any regulatory or logistical constraints to ART delivery

Other regular health needs such as family planning, or co-morbidities such as hypertension and diabetes, will also determine which model is most appropriate for a particular setting. In order to ensure that the model is accepted and provides optimal retention in care, decisions should be made in collaboration with PLHIV.

Each model of ART delivery will reach a specific set of objectives. From a **patient perspective**, the main objective of the model is to reduce the financial and time costs associated with frequent clinic visits. Another objective is to encourage peer support at community level, thereby facilitating a social fabric among patients and reducing perceived stigma. These strategies have the potential to enhance community participation with patients taking up crucial roles in the delivery of ART in their communities. Additionally, organised patient groups can represent an accountability mechanism towards the health system, advocating for adequate and quality services and reporting breakdowns in their provision.

From a **health system perspective**, reduction of staff workload and keeping clinical staff focused on clinical problems is a major objective, along with quality of care and improved programme outcomes while fostering patient self-management and a level of independence from health services.

Figure 1. Objectives for models of long-term ART delivery



## 5. Description of models and strategies

A continuum of strategies can be used to optimise long-term ART delivery, ranging from health service-driven to patient-driven options. The overall aim, however, remains to maximise the benefits for both patients and healthcare services.

A number of models of ART delivery in six different countries are described below along a range of health service-driven to patient-driven strategies presented in Table 1.

Table 1. Summary of strategies for alternative models for delivery of long-term ART

		Health Service Driven				Patient Driven	
		Appointment spacing and fast-track drug refill	Adherence Clubs		Community ART Distribution Points (PODI)	Community ART Groups (CAGs)	
Key Objectives			Facility-based clubs	Community-based clubs			
Patient's Perspective	Reduce costs (time + transport)	• Reduction of clinical visits • Less time spent at clinic for drug refill	• Reduction of clinical visits • Less time spent at clinic for drug refill	• Reduction of clinical visits • Reduction of distance for drug refill	• Reduction of clinical visits • Reduction of distance for drug refill	• Reduction of clinical visits • Reduction of distance for drug refill	
	Increase peer support	No	At club in health facility and potentially beyond into community	At club in community and beyond	At distribution point by expert patient	At CAG meeting in community and beyond	
	Enhance community participation	No	Potentially	Potentially	Potentially	Potentially	
Healthcare Service Perspective	Reduce workload • nurse • pharmacist • counsellor/CHW /expert patient	Yes Yes -	Yes No No (facilitation by club)	Yes No No (facilitation by club)	Yes Yes No (distribution and monitoring)	Yes Yes No (formation, training and supervision of CAGs)	
	Maintain / improve health outcomes • adherence • retention	Unknown Yes	Yes Yes	Unknown Unknown	Unknown Yes	Unknown Yes	
	Improve self-management of patients	Individual patient empowerment	Adherence support	Adherence support and tracing	Organisation of services for drug refill, adherence support, tracing and testing	Drug refill, adherence support, tracing, testing	

\* CHW: Community Health Worker

## 5.1 Appointment spacing and fast-track drug refill

### Malawi

Key principles of this strategy are:

- Individual facility-based strategy for stable patients on ART
- Reduction in frequency of clinical consultations in combination with collection of drug supplies for longer periods
- Direct access to ART dispenser for individual drug refill and adherence checks

#### National data and follow-up schedules in Malawi

COUNTRY CONTEXT	
Population	15.3 million, largely in rural areas
HIV adult prevalence	10.6%
Number of PLHIV	1.1 million
<b>ART access</b>	
ART coverage*	74%
% public sector facilities offering ART	98%
Retention in Care (RIC) at 12 months	80%
<b>HRH &amp; Task shifting</b>	
Staffing	2 MD, 50 nurses per 100,000
1st line ART initiation	nurses
HTC & adherence counselling	lay worker/health surveillance assistant, government funded
<b>Clinical monitoring &amp; drug refill (nationally)</b>	
Clinical visit for patient	every 2-3 months
ART drug refill	every 2-3 months
Monitoring	routine viral load at 6 months, then every 24 months, limited availability
<b>Appointment spacing</b>	possible, but depends on sufficient drug availability/reliability of supply system

\* initiation threshold = CD4 count of 350 cells/ $\mu$ l

#### Reducing appointment frequency in Chiradzulu, Malawi

MSF has been supporting HIV and TB activities in Chiradzulu district in Malawi (population 320,000) since 1997, where the adult HIV prevalence is 14.5%. ART was introduced in 2001 and by June 2013, a total of 39,601 patients had been enrolled in HIV care, of which 27,513 were on ART. HIV care has been progressively decentralised from the hospital to 10 health centres in order to support scale-up and improve retention in care.

In 2008 a new protocol for appointments was established, whereby stable patients were required to attend the clinic only once every six months for clinical assessments and once every three months to collect antiretroviral drugs. Health Surveillance Assistants (HSAs – paid community health worker cadres which are part of the health system) provide the three-monthly ART refills at health centres and check patient adherence according to a standardised assessment tool. When problems arise, the HSAs refer patients back to the medical staff for clinical consultations. Between January 2008 and mid-2013, 8,566 patients were enrolled in the six-monthly appointment (SMA) programme, representing 20% of active patients on ART. Cumulative retention at one year since enrollment has been 97%, with 2% loss to follow-up and <1% mortality<sup>34</sup>. Despite HSAs performing similar duties at health facility level, dispensing ART is not yet part of their job description due to reluctance to allow lay cadres to handle drugs.

#### Appointment spacing and fast-track drug refill

MALAWI – Chiradzulu model	
• <b>Context:</b>	rural
• <b>Target group:</b>	stable patients on ART
• <b>ART refill:</b>	every 3 months at health facility
• <b>Clinical visit for patient:</b>	every 6 months for clinical consultation and yearly for viral load
• <b>Referral mechanism back to clinic:</b>	by health surveillance assistant and self-referral
• <b>Number of patients:</b>	8,566
• <b>Patients uptake:</b>	20% of active patients on ART
• <b>Retention in care in SMA:</b>	97% at 12 months follow-up
• <b>Resource needs:</b>	health surveillance assistants
• <b>National response:</b>	issues around lay cadre handling drugs

#### Appointment spacing and fast-track in other settings

Other countries have also adopted changes in pharmacy regulation and practice that allows for longer supplies of antiretroviral drugs in combination with fewer appointments, such as South Africa and Zimbabwe. However, drug supply challenges are threatening implementation and constitute a major challenge to adherence and retention in care.

Some MSF-supported sites with access to viral load monitoring such as Malawi, South Africa and Zimbabwe are now moving to a once a year clinical visit with two to three monthly drug refills in between.

## 5.2 Adherence Clubs

### South Africa

Key principles of adherence clubs are:

- Group distribution of drugs provided at health facility or community level for stable patients on ART
- Peer counsellors dispense drugs, measure weight and conduct symptom-based general health assessments
- Peer support provided by counsellor and group at the time of drug distribution

#### National data and follow-up schedules in South Africa

COUNTRY CONTEXT	
<b>Population</b>	50 million
<b>HIV adult prevalence</b>	17.8%
<b>Number of PLHIV</b>	5.3 million
<b>ART access</b>	
ART coverage*	78%
% public sector facilities offering ART	68%
Retention in Care (RIC) at 12 months	67-90%
<b>HRH &amp; Task shifting</b>	
Staffing	8 MD, 408 nurses per 100,000
1st line ART initiation	nurses
HTC and adherence counselling	lay worker accepted and mostly government funded
<b>Clinical monitoring &amp; drug refill (nationally)</b>	
Clinical visit for patient	every 2 months
ART drug refill	every 2 months
Monitoring	routine viral load yearly then every 24 months
<b>Appointment spacing</b>	accepted but not yet widely implemented

\* initiation threshold = CD4 count of 350 cells/ $\mu$ l

#### Facility-based Adherence Clubs in Khayelitsha

ART provision started in 2001 in Khayelitsha, a township of more than 500,000 inhabitants located on the outskirts of Cape Town, which carries one of the highest burdens of both HIV and TB in the country. ART scale-up has been successful with more than 25,000 people initiated by mid-2013.

As the number of patients on ART increased rapidly, the proportion of patients being lost to follow-up also began to rise as clinics became saturated. In response, the model for ART delivery was adapted to relieve pressure on clinics by moving towards a nurse-based, doctor-supported decentralised model of care and by developing out-of-clinic approaches to adherence support for stable patients.

Facility-based ART Adherence Clubs were piloted in the largest ART clinic in November 2007 as a way to decongest facilities by shifting consultations and ART collections for stable patients to clubs organised by peer educators at the clinic. From a patient perspective, the club-based distribution reduces time spent at the clinic, while from the health service perspective this approach reduces the clinic workload.

In the ART Adherence Clubs, groups of up to 30 patients meet every two months for less than an hour. Participation is offered to all adults who have been on ART for at least 12 months and are considered clinically stable with an undetectable viral load. In these groups, essential tasks such as measuring weight and conducting symptom-based general health assessments are provided and recorded by a peer educator and/or lay counsellor who acts as the club facilitator. As legislation requires that only staff with a dispensing license can dispense medication, ARVs are pre-packaged and labelled for each participant and brought to the group by the club facilitator. Any patient reporting symptoms suggesting illness, adverse drug effects or weight loss are referred back into the main clinic for prioritised assessment by a nurse. All club patients see a nurse twice a year; once for blood tests and then two months later for their annual clinical check-up. The club facilitator is also responsible for completion of the club register as the patient files are not drawn other than for annual clinical check-up.



While clubs reduce the workload for clinic clerks and nurses, they increase workload for lay workers facilitating the clubs. The workload for pharmacy staff remains similar in facilities where the clinic pharmacy assistants pack for the clubs<sup>35</sup>. In the Western Cape Province, the workload for the clinic pharmacy staff has been vastly reduced through the use of a Central Dispensing Unit (CDU) system for pre-packing ARVs for club patients. The Department of Health (DOH) has contracted a private pharmaceutical courier company to pre-pack prescriptions for club patients and deliver these to clinic pharmacies.

Over 40 months, 97% of club patients remained in care, compared to 85% of those who qualified for clubs but remained in mainstream clinic-based care. Club participants were also 67% less likely to experience virological rebound, indicating better adherence in clubs compared to mainstream care. Club participation reduced loss to follow-up by two-thirds and almost halved the proportion of people with a detectable viral load, compared with patients who remained in clinic-based care<sup>36</sup>.

A cost-effectiveness study showed the cost per patient year was US\$58 in the ART club model, versus US\$109 in the mainstream model of care. Fewer barriers to ongoing access to care were identified in the adherence club model including shorter waiting times, higher acceptability of services and fewer missed clinic appointments<sup>37</sup>.

In order to run multiple facility-based clubs simultaneously, or due to space constraints at clinics, facility-based clubs in Khayelitsha are also run at community venues very close to the clinic.

This model was replicated by the City of Cape Town and Western Cape health services from 2011, and by June 2013 all 10 Khayelitsha clinics were running 221 facility-based clubs involving 23% of all patients on ART. In total 776 adherence clubs had been implemented across Cape Town amounting to approximately 18,700 patients, or 19% of ART patients in care in the metropolitan area.

### Adherence Clubs: Facility-based and Community-based

SOUTH AFRICA – Khayelitsha model	
• <b>Context:</b>	urban
• <b>Target group:</b>	stable patients on ART
• <b>ART refill:</b>	every 2 months at health facility / community
• <b>Clinical visit for patient:</b>	yearly for viral load and clinical consultation
• <b>Referral mechanism back to clinic:</b>	by lay worker and self-referral
• <b>Number of clubs and patients:</b>	23 clubs / ± 5,900 patients
• <b>Patients uptake:</b>	23% of active patients on ART (including community clubs)
• <b>Retention in care:</b>	97% at 40 months
• <b>Extended functions:</b>	utilising alternative health points to support management and drug supply for community clubs
• <b>Resource needs:</b>	lay workers as facilitators of clubs; resources for club outreach
• <b>National response:</b>	adoption and quick roll out in City of Cape Town and Western Cape Province. National Department of Health provisional endorsement

### Towards community-based adherence clubs in Khayelitsha

Facility-based adherence clubs in Khayelitsha have been a stepping stone towards setting up community-based ART adherence clubs, in order to increase benefits for patients by allowing access to drugs closer to their homes.

MSF piloted fully decentralised community clubs in May 2012 with clubs meeting in patients' homes or at community venues. The lay club facilitator collects the pre-packed treatment at the health facility and walks to the nearby home or community venue for the two-monthly club visit. Community clubs also make use of the CDU system with direct delivery to a health point where one is available. Clinical follow-up, eligibility criteria and referral mechanisms are the same as for facility-based clubs. Stable patients are recruited at the facility by geographical area. Group size is limited to 15 patients for clubs meeting in patients' homes and up to 30 members for community venues. Club venues are selected by the members themselves.

In support of the community-based clubs, Wellness Hubs have been piloted since April 2013. These are permanent health points situated in the community offering access to basic screening services (such as TB, HIV, point-of-care CD4 testing, diabetes, hypertension, pregnancy testing, and provision of family planning). Wellness Hubs also offer focused linkage to PMTCT, pre-ART and ART care at the main clinic as well as support for its community clubs. Club support includes management of local community clubs and acting as the pre-packed ART delivery and collection site. Peer educators collect drugs and club registers for the community club session at the Wellness Hub. Club patients undergo their annual blood specimen collection visit at the Wellness Hub – and if they remain well, only attend the health facility annually for a clinical consultation by a nurse.

Community-based clubs require paid lay workers to facilitate them and may require resources to move between the health facility and health points in the community depending on where lay workers reside and drug delivery options. As of July 2013, there were 10 community clubs in Khayelitsha.



### Facility-based clubs paving the way for Community ART groups in KwaZulu-Natal

Together with the Department of Health, MSF started an innovative treatment as prevention project (TasP) in the Mbongolwane district in the KwaZulu-Natal (KZN) province in 2011. The decentralisation of services and ART initiation by nurses enabled the scale-up of the number of patients being initiated on ART, which rapidly increased the size of the cohort. The project will pilot the expansion of ART initiation criteria in 2014 (CD4 threshold of up to 500 cells/ $\mu$ l and PMTCT option B+\*), which will further increase the burden on health facilities in the district. A community model of care has been designed to cope with the expected increase in workload, while removing barriers for patients such as distance travelled to and time spent at the clinic.



From 2012 onwards, facility-based adherence clubs were implemented in KZN with the same clinical follow-up and referral mechanisms as Khayelitsha's facility-based clubs. Eligibility criteria have been widened whereby patients with only one recent undetectable viral load result can also join the club as well as pregnant/lactating women, or patients with chronic conditions. The rationale for this is to allow patients at high risk of sub-optimal adherence and treatment defaulting to benefit from easier access to drugs and peer support. By June 2013, 794 patients had joined 30 clubs, representing 14% of active patients on ART. Retention in care in clubs is 91% after one year follow-up. Apart from saving time at the clinic, the facility-based clubs allow members to meet other HIV-positive patients in a neutral clinic setting, especially in a rural environment where a high level of stigma prevails.

Time spent at the clinic, an important barrier for patients, is addressed through facility clubs but distance to health facilities remains an important hurdle for patients in rural areas of KZN. To ensure proximity for drug refill, Community ART Groups (CAGs) have also been implemented as of April 2013 in rural settings (see p19 for further descriptions of the CAG model). Drug refill by patients themselves (instead of lay workers as in community clubs) was preferred for this vast area, as the number of community health workers would not be sufficient to cover the area. Patients are recruited from facility-based adherence clubs, since they have had the opportunity to meet other peers through the club. The choice of model lies with the patients whereby facility-based clubs can thus be the preferred option for some, and a good step-up to CAGs for other patients. Three months after start of the pilot in two health centres, 10 CAGs had been formed, representing 47 patients, or 2% of active patients on ART. Lay counsellors and village health workers play an important role in establishing training and supervision of CAGs.

The provincial health authorities are in favour of a further roll out of the model where both facility-based clubs and CAGs would be implemented.

\* PMTCT Option B+ stands for life-long ART provision for HIV-positive pregnant women

### Adherence Clubs (Facility-based) and Community ART groups

SOUTH AFRICA – KwaZulu-Natal model	
• <b>Context:</b>	mainly rural with some urban areas
• <b>Target group:</b>	stable patients on ART including pregnant/lactating women and patients with other chronic conditions
• <b>ART refill:</b>	every 2 months in club or CAG
• <b>Clinical visit for patient:</b>	yearly for viral load and clinical consultation
• <b>Referral mechanism back to clinic:</b>	by lay worker and self-referral
• <b>Number of patients:</b>	804 patients in 107 clubs/CAGs
• <b>Patients uptake:</b>	14% of active patients on ART
• <b>Retention in care in clubs:</b>	91%
• <b>Resource needs:</b>	lay workers as facilitators of clubs; or to help formation, training and supervision of CAGs
• <b>National response:</b>	interest in roll out of clubs and CAGs in KZN province





## 5.3 Community ART Distribution Points (PODI)

### DRC

Key principles of community ART distribution points are:

- Individual distribution of drugs provided in the community for stable patients on ART
- Members of network of PLHIV dispense drugs, measure weight and conduct symptom-based general health assessments
- Peer support provided by expert patient at time of drug distribution

#### National data and follow-up schedules in Democratic Republic of the Congo (DRC)

COUNTRY CONTEXT	
Population HIV adult prevalence Number of PLHIV	69.5 million 1.1% 480,000
ART access ART coverage* % public sector facilities offering ART Retention in Care (RIC) at 12 months	26% estimated at 6.6% (573/8650) 78% (based on selected sample in Kinshasa)
HRH & Task shifting Staffing 1st line ART initiation HTC and adherence counselling	9 MD per 100,000 and 1 nurse per 1,000 nurses lay worker accepted but not recognised, and donor funded
Clinical monitoring & drug refill (nationally) Clinical visit for patient ART drug refill Monitoring	every 4 months for patients >1 year on ART every 2 months CD4 count every 6 months
Appointment spacing	accepted but not widely implemented

\* initiation threshold = CD4 count of 350 cells/ $\mu$ l

*It remains a huge challenge to obtain reliable country wide data in DRC. Prevalence estimates have been reviewed recently, based on survey data collected in 2007 and Spectrum-modelling. This revised prevalence estimate led to halving the expected number of people in need of ARV in 2013. Mid 2014 a new estimate is expected, taking into account data from the planned Demographic Health Survey. Similarly, a revision of the number of patients on treatment is ongoing end 2013. This in turn will likely lead to reduced figures of people on treatment. All this makes coverage estimates highly volatile and the increase from 12% in 2011 to 26% in 2012 should not lead to an interpretation of a positive evolution of treatment access in DRC.*

Since 2002 MSF has supported the provision of ART services in Kinshasa, a megapolis with approximately 10 million inhabitants. Early identification of patients eligible for treatment has been hampered by a general lack of access to health services, a shortage of HIV diagnostic tests and limited availability of CD4 testing, and by the requirement for patients to pay for most elements of care in public and private health facilities. Many of the patients at MSF-supported clinics only enter care with advanced HIV illness, with complications reminiscent of the pre-ART era. Patients pay high transport costs to access care in the few health facilities providing ART in the city, while being at a high risk of exposure to stigma and discrimination.

ART was initially provided by MSF at the Centre Hospitalier de Kabinda but by 2005 the hospital had reached its capacity, with more than 1,500 patients on ART and another 1,300 in pre-ART care. To try to decongest the hospital, a process of down-referral began in mid-2005, with stable patients referred to health centres. However, this referral was insufficient to cope with the overwhelming number of patients to the extent that new enrolment into care had to be closed. Enrolment restarted in 2009 once those patients on the pre-ART waiting list had been initiated on ART.



By late 2010, MSF, working with a local network of people living with HIV (Réseau National des Organisations des Assises Communautaires), established community ART distribution points in Kinshasa, free of charge, bringing drug delivery closer to patients' homes. These distribution points are managed by PLHIV who are trained to provide ART refills, adherence support and follow-up of basic parameters and alert signs. Patients who have been on ART for more than six months, have no active opportunistic infections (OI) and a CD4 count above 350 cells/ $\mu$ l are considered stable and eligible for participation in these PODI's. Patients attend the distribution point every three months for drug refill and report to the health service annually for clinical consultation and blood drawing for CD4 count testing. Referral to clinical care is done by the lay workers of the network of PLHIV, while patients not showing up for their visits are traced by the peer counsellors by phone or through the network of local support groups. In addition, the distribution points offer free HIV testing and counselling at community level, where people are referred for testing by other community members.

As of July 2013, 2,162 patients had been down-referred from the facility-based HIV treatment centre to one of the three community ART distribution points – representing 43% of active patients on ART. A cohort analysis shows that over 89% of patients were retained after 12 months post-transfer to the distribution points<sup>38</sup>. Initial analyses of a limited number of patients have found that the average cost in human resources expenditure per patient is a lot lower at community distribution points than at the clinic. A linked qualitative survey of patient perspectives found that transport costs are about three times higher for patients receiving care at the hospital compared with those receiving care at the community distribution points. Patients at the community ART distribution points spend an average of 12 minutes collecting ART refills – seven times less than patients receiving ART at the hospital (85 minutes)<sup>39</sup>.

Community distribution points require lay workers for staffing, adapted secure spaces to store the drugs, plus transport for drugs from the health facility to the distribution posts.

The MOH has recognised the distribution points as one of the good practices for community-based access to ART in their recent national strategic plan.

### Community ART distribution points (PODI)

DRC – Kinshasa model	
• <b>Context:</b>	urban
• <b>Target group:</b>	stable patients on ART
• <b>ART refill:</b>	every 3 months at community distribution point
• <b>Clinical visit for patient:</b>	yearly for CD4 and clinical consultation
• <b>Referral mechanism back to clinic:</b>	by lay worker or self-referral
• <b>Number of patients:</b>	2,162
• <b>Patients uptake:</b>	43% of active patients on ART
• <b>Retention in care in SMA:</b>	89% at 12 months follow-up (2012)
• <b>Extended functions:</b>	tracing by lay workers and support groups, HIV testing at distribution points
• <b>Resource needs:</b>	lay workers, accommodation, transport and storage of drugs
• <b>National response:</b>	recognition as good practice



## 5.4 Community ART Groups (CAGs)

### 5.4.1 Mozambique

Key principles of Community ART Groups are:

- Self-formed groups of stable patients on ART from the same geographic location/community
- Group members take turns for collection of ARVs, clinical consultation and blood drawing at the clinic
- Community-based delivery of drugs by group members, adherence support and treatment outcomes monitoring by group members

MSF has developed a toolkit to enable those interested to replicate and adapt the Community ART Group model. The toolkit, *“Community ART Group Toolkit: how to implement the CAG model”* (2013) explains the model, how to set up adapt it according to local conditions as well as providing practical tools and sharing MSF’s experiences of implementing the model in several countries. The CAG Toolkit is available at: [www.samumsf.org/resources/toolkit-cag](http://www.samumsf.org/resources/toolkit-cag)

### Mozambique

#### National data and follow-up schedules in Mozambique

COUNTRY CONTEXT	
<b>Population</b>	25 million, largely in rural areas
<b>HIV adult prevalence</b>	11.5%
<b>Number of PLHIV</b>	1.4 million
<b>ART access</b>	
ART coverage*	47%
% public sector facilities offering ART	22%
Retention in Care (RIC) at 12 months	74%
<b>HRH &amp; Task shifting</b>	
Staffing	5.2 MD, 25 nurses per 100,000
1st line ART initiation	majority of nurse-levels allowed
HTC and adherence counselling	lay worker allowed, not recognised and donor funded
<b>Clinical monitoring &amp; drug refill (nationally)</b>	
Clinical visit for patient	monthly
ART drug refill	monthly
Monitoring	triggered limited availability
<b>Appointment spacing</b>	accepted but not yet widely implemented

\* initiation threshold = CD4 count of 350 cells/ $\mu$ l

### Community ART Groups in rural Mozambique - Tete

By the end of 2012, close to 300,000 patients had been initiated on ART in Mozambique. However, at least one quarter of those patients were lost to follow-up after 12 months<sup>40</sup>. In 2008, this high attrition figure, combined with increasing numbers of patients required to travel to a health facility every month to collect drugs and the limited number of clinics still providing ART, prompted the government, with support from MSF, to launch a pilot programme of community-based ART distribution and adherence monitoring in Tete Province<sup>41</sup>.

In this programme, self-formed groups of six stable patients on ART were established. Patients are deemed stable after a minimum of six months on ART without side effects or OIs and with a CD4 count above 200 cells/ $\mu$ l. They take turns to collect ARVs every month for group members while visiting clinics for their six-monthly appointments and blood drawing for CD4 count testing. Patients organise drug delivery to their group members in the community, and adherence support and monitoring of treatment outcomes is done by group members. In case of problems, patients present themselves at the clinic or are referred by other CAG members<sup>42</sup>.

The CAG pilot has undergone a quantitative, qualitative and costing evaluation. CAGs were gradually established over 20 health facilities in seven districts of Tete province since April 2008. Approximately half of all eligible patients stable on ART are part of the groups. As of September 2013, 95.1% of the 8,181 patients enrolled in a CAG remained in care, though 7.6% were either transferred out to another facility (292) or went back to individual care (333). 4% had died and 0.35% had been lost to follow-up. Results from the qualitative study highlight the high level of acceptance of the model among patients and the critical role the counsellor plays to ensure establishing, training and supervising patient groups<sup>43</sup>. Preliminary analysis of the costing study reveals patient benefits including reduced travel time and expenses, and less time spent away from their work and home activities.

MSF has further refined the model for specific key populations, such as children and adolescents. Children are included as “dependent members” in CAGs, meaning that they join the CAG representative on the trips to the clinic to receive their monthly clinical visit and drug refill. As of March 2012, 312 children below the age of 15 were part of 225 different CAGs, representing 6% of all CAG members. Retention among children in CAGs was 94%<sup>44</sup>.

With the objective to improve testing and linkage to care through CAGs, a pilot programme involving community counsellors was set up in Changara district in 2012. CAG members who became paid community counsellors offer HIV testing to family members of CAG participants or other people in their community and refer them for CD4 testing to the nearest clinic. People who test HIV positive can establish links with the existing CAG. ART eligible patients go to the health centre for treatment initiation and join the CAG temporarily as social members. Once they are stable on ART, they join the CAG as full members and get drug refills with the group. Patients ineligible for ART can also join CAGs as social

members alongside stable patients on ART, or join pre-ART CAGs. By September 2013, 3,168 people were tested, with 273 (8.6%) testing positive, 115 (42%) of whom were eligible for ART and from these, 102 (89%) started ART.

The model is being further adapted to benefit pregnant women and commercial sex workers.

Following this early success, the Ministry of Health recommended in July 2011 that CAGs be incorporated into the national HIV care strategy and launched a national CAG pilot programme<sup>42</sup>.

### Community ART Groups (CAGs)

Mozambique – Tete model	
• <b>Context:</b>	rural district
• <b>Target group:</b>	stable patients on ART, pre-ART, children/adolescents, pregnant women
• <b>ART refill:</b>	monthly in CAG
• <b>Clinical visit for patient:</b>	every 6 months for combined drug refill, clinical check-up, blood drawing for CD4 testing
• <b>Referral mechanism back to clinic:</b>	self referral or other CAG members
• <b>Number of groups and patients:</b>	2,023 groups, 8,181 patients (Sept 2013)
• <b>Patients uptake:</b>	~50% of those eligible
• <b>Retention in care in SMA:</b>	95.1% after 20 months follow up in CAG
• <b>Extended functions:</b>	testing by community counsellors through CAGs
• <b>Resource needs:</b>	linkage between CAG and Health Centre (counsellor) critical
• <b>National response to pilot:</b>	CAGs as national strategy

### Community ART Groups in urban Mozambique - Maputo

In urban Maputo, CAGs have been implemented since 2011 to reduce the number of visits to the clinic and increase peer support among patients. CAG members take turns for monthly clinic visits to receive drug refills, and attend every six months as a group for their clinical consultations and blood tests. Patients can also opt for appointment spacing, meaning they can individually pick up drugs every month directly from the pharmacy and attend six-monthly clinical consultations (‘fast-track’).

Since the start of the CAG roll out, 18.9% of patients on ART had formed 620 groups. Uptake of CAGs in Maputo remains lower than in rural settings, due to the diminished return on benefit of CAGs in an urban setting where the advantage of reduced visits to a close-by health facility may not outweigh the risks linked to disclosure of their status to other patients.

At the patients’ initiative, some CAGs (two to six patients) have amalgamated into bigger groups with an average of 16 members per CAG during 2013. Apart from easier dispensing of drugs, they wanted to increase their peer network and are willing to take assertive roles in advocacy in their community.



## Community ART Groups (CAGs)

Mozambique – Maputo model	
• <b>Context:</b>	urban
• <b>Target group:</b>	stable patients on ART
• <b>ART refill:</b>	monthly in CAG and fast track clinic
• <b>Clinical visit for patient:</b>	every 6 months for combined drug refill, clinical check-up, CD4 blood drawing
• <b>Referral mechanism back to clinic:</b>	self referral or other CAG members
• <b>Number of groups and patients:</b>	620 groups, 2,093 patients (mid 2013)
• <b>Patients uptake:</b>	18.9%
• <b>Retention in care in SMA:</b>	95.5%
• <b>Extended functions:</b>	advocacy in community through peer networks
• <b>Resource needs:</b>	linkage between CAG and Health Centre (counsellor) is critical



## 5.4.2 Malawi, Zimbabwe and Lesotho

Based on initial promising outcomes of CAGs in Tete, Mozambique, MSF and several Ministries of Health have begun piloting the use of CAGs in other countries (Malawi, Lesotho, South Africa and Zimbabwe), adapting the model to suit each specific context<sup>45</sup>.

### Malawi

Since 2003, ART services have been decentralised to all public health centers in the rural district of Thyolo in Malawi, with the support of MSF. Following the implementation of option B+ in 2011 and associated rapid expansion of the number of facilities initiating ART from 14 to 27, the level of ART access has changed radically in Thyolo. With more patients on ARVs, more patients spent an increasing amount of time at the health facility, waiting in queues. In 2012, the MOH implemented CAGs to reduce healthcare workers' increased workloads and to allow patients to play an active role in their own health-care. Eligibility criteria and referral mechanisms of the Tete model were implemented, with protocols being adapted in 2013. CAG representatives now attend every second month for drug refills, and receive clinical consultations annually, plus viral load tests once every two years, while to be considered stable, patients now need to have a viral load of below 1,000 copies/ml.

As of October 2013, 1,537 patients on ART had established more than 250 CAGs at four health facilities. An analysis of outcomes of 299 patients showed 92% were retained in CAGs with a median time of 14.9 months in CAGs. Close partnership with existing social support networks facilitated formation while follow-up of CAGs and the critical role of establishing, training and supervising CAGs is fulfilled by the existing community health worker cadre<sup>46</sup>. Preliminary results of a review of patient-held health records, comparing clinic visits ten months before and ten months after inclusion in CAGs, showed a reduction of 62% in ART refills and 49.6% in all clinic visits of CAG members between the pre- and post-



CAG enrollment period. This means a decrease of on average of 4.3 visits per patient per year – mainly related to a decreasing number of ART refill visits. Despite patients visiting the health facility less frequently, the study showed that healthcare seeking behavior did not substantially change after patients were enrolled in CAGs. This suggests that patients will still consult clinicians when they need it for non-HIV-related reasons, such as malaria or acute problems.

The MOH in Thyolo is now considering including other patient groups in CAGs, such as pregnant women, pre-ART and unstable patients, while expanding the programme to other sites in the district. MSF and other partners wish to further develop the model for potential wider implementation in Malawi.

Malawi – Thyolo model	
• <b>Context:</b>	rural district
• <b>Target group:</b>	stable patients on ART
• <b>ART refill:</b>	every 2 months in CAG
• <b>Clinical visit for patient:</b>	every 6 months for combined drug refill, clinical check-up, blood drawing (viral load)
• <b>Referral mechanism back to clinic:</b>	self referral or other CAG members
• <b>Number of groups and patients:</b>	>250 CAGs and 1,537 patients
• <b>Patients uptake:</b>	between 16-27% in 4 pilot sites
• <b>Retention in care in SMA:</b>	92% at 15 months follow-up in CAG
• <b>Resource needs:</b>	health surveillance assistants for formation, training and supervision
• <b>National response:</b>	interest in piloting elsewhere



## Zimbabwe

In Gutu district in rural Zimbabwe (population 203,533, HIV prevalence 14%), ART services have been decentralised to 28 of the 30 primary care centres, so that patients are now able to access care within a range of 5-10km from their homes. Stable patients on ART have access to three monthly ART refills with a single annual clinical consultation. The pilot CAG projects during 2013 only targeted patients from hard-to-reach sites, who struggle with treatment adherence due to distance and difficult road conditions.

Establishing CAGs in Gutu is being done alongside an existing community-based non-governmental organization (NGO) supporting HIV-related activities. Eligibility to join CAGs is based on viral load results and a patient's time on treatment. Routine viral load monitoring and a longer time between ARV refills make it possible for CAG members to attend annual clinical appointments and viral load testing. Drug supplies for the group are collected every three months by two group members – thereby further reducing transport costs and time away from work or home. Primary care counsellors and local support group leaders play a vital role in forming, training and supervising the CAGs. As of September 2013, two months after the start of the pilot programme in two health centres, 21 CAGs had been created with 110 patients, all of whom were still remaining in care in the CAGs.

## National data and follow-up schedules in Zimbabwe

COUNTRY CONTEXT	
<b>Population</b>	12.6 million
<b>HIV adult prevalence</b>	15%
<b>Number of PLHIV</b>	1.2 million
<b>ART access</b>	
ART coverage*	86%
% public sector facilities offering ART	64.5%
Retention in Care (RIC) at 12 months	78%
<b>HRH &amp; Task shifting</b>	
Staffing	16 MD, 72 nurses per/100,000 population
1st line ART initiation	nurses possible
HTC and adherence counselling	Primary Care Counsellors accepted, donor funded
<b>Clinical monitoring &amp; drug refill (nationally)</b>	
Clinical visit for patient	every 2 months
ART drug refill	every 2-3 months
Monitoring	targeted viral load testing with limited access, want to move to routine and 6 monthly CD4 testing
<b>Appointment spacing</b>	possible, but depends on sufficient drug availability/reliability of supply system

\* initiation threshold = CD4 count of 350 cells/ $\mu$ l

Zimbabwe – Gutu district model	
• <b>Context:</b>	rural district
• <b>Target group:</b>	stable patients on ART in hard to reach sites only
• <b>ART refill:</b>	every 3 months
• <b>Clinical visit for patient:</b>	yearly for combined drug refill, clinical check-up, blood drawing (viral load)
• <b>Referral mechanism back to clinic:</b>	by nurse, self referral or other CAG members
• <b>Number of groups and patients:</b>	21 CAGs and 110 patients
• <b>Patients uptake:</b>	22%
• <b>Resource needs:</b>	primary care counsellor and clinic nurse
• <b>National response:</b>	acceptance of pilot

## Lesotho

### National data and follow-up schedules in Lesotho

COUNTRY CONTEXT	
<b>Population:</b>	2 million
<b>HIV adult prevalence:</b>	23%
<b>Number of PLHIV:</b>	350,000
<b>ART access</b>	
ART coverage*:	51%
% public sector facilities offering ART:	94%
Retention in Care (RIC) at 12 months:	71%
<b>HRH &amp; Task shifting</b>	
Staffing:	4.5 MD, 56 nurses per 100,000 population
1st line ART initiation:	nurses
HTC and adherence counselling:	lay worker accepted but not recognised and donor funded
<b>Clinical monitoring &amp; drug refill (nationally)</b>	
Clinical visit for patient:	monthly
ART drug refill:	monthly
Monitoring:	triggered viral load, limited availability and CD4 test every 6 months
<b>Appointment spacing</b>	accepted but not yet widely implemented

\* initiation threshold = CD4 count of 350 cells/ $\mu$ l

MSF started its project in the rural catchment areas of Roma and Semonkong in 201 in the Maseru district, which is home to over 130,000 people. While supporting HIV care in nine health centres and one hospital, MSF further prepared seven health posts (outreach sites of the health centre) for ART initiation and follow-up in order to reduce geographical barriers for patients.

To further reduce the burden of patients travelling great distances, MSF in collaborated with the Lesotho Network of AIDS Services Organization (LENASO) and the MOH, in piloting CAGs in November 2012 in one health centre and four attached health posts. Stable patients in regular clinic care attend monthly for drug refills and six-monthly for clinical visits and blood drawing for CD4 count testing. CAGs were formed using the eligibility criteria, follow-up and referral mechanisms similar to those used in the Tete CAGs.

By June 2013, a total of 108 members had established 21 CAGs at the piloting health centre, representing approximately 9% of active patients on ART – all of whom were retained in care after a median follow-up time of five months. Uptake of CAGs in health posts was much higher: 42% compared to 4% in the health centre (45). High numbers of patients flocking to the monthly health posts and well-established social ties are the likely explanation of the rapid uptake of CAGs by patients attending health posts.

The existing village health worker cadre performs key functions in establishing, monitoring and supervising the groups, thus broadening their scope of activities. Nurses at the health facility identify problems within CAGs, such as CAG members missing appointments, which triggers further support by the respective village health worker.

The MOH and other international NGOs have expressed interest in rolling out CAGs to other sites, once MSF's one-year evaluation of the CAGs is complete.

Lesotho - Roma model	
• <b>Context:</b>	rural
• <b>Target group:</b>	stable patients on ART
• <b>ART refill:</b>	monthly at CAG
• <b>Clinical visit for patient:</b>	every 6 months for combined drug refill, clinical check and blood drawing
• <b>Referral mechanism:</b>	self-referral or by other CAG members
• <b>Number of groups and patients:</b>	21 CAGs and 108 patients
• <b>Patients uptake:</b>	9%
• <b>Retention in care in SMA:</b>	100% at 5 months follow-up in CAG
• <b>Resource needs:</b>	Lay workers at facility as well as community as facilitators of CAGs
• <b>National response:</b>	Interest to roll out to other sites

## 6. Discussion: Common elements, challenges and concerns for community ART Delivery

A variety of innovative, community-based models that provide care and treatment to an increasing number of PLHIV have been implemented in a range of settings and populations in mostly southern Africa. While the choice and implementation of each model has been adapted specifically to each context, they all share several key elements, challenges and risks.

### Minimum requirements and enabling factors

Several factors are required as a foundation to enable adequate functioning and roll-out of community-based models.

#### Sufficient and flexible drug supply

Procurement, pharmacy management and supply chain management to peripheral sites are critical for implementing community-based models. Supply chain weaknesses can lead to ART stock outs and these weaknesses must be critically monitored and reported proactively. It is important that the duration of drug supply can be adapted to the patients' needs and frequency of refills reduced to a minimum to decrease burden on patients and health systems. Many of the models described will require a change in policies and maintaining supply chain integrity to permit ART dispensing of more than a month's supply. This is currently allowed in most countries but due to insufficient volumes in drug supply or delays or shortage in funding, it is often not implemented.

In Khayelitsha, due to restrictions around non-pharmacy staff dispensing drugs, a public-private partnership model is used, in which a private logistics company pre-packs the drugs.

The recent switch in most countries to a first-line ART regimen - tenofovir (TDF), lamivudine (3TC) and efavirenz (EFV) - provided as a fixed-dose combination (FDC) for all adults is a real advantage in terms of simplifying logistics and follow-up within the dynamics of a community model.

#### New tasks and recognition of lay cadres

Most programmes described in this report have lay counsellors, community health workers or expert patients involved in new key tasks that support these community models in establishing, training, monitoring and facilitating the groups. However they also assume 'task shifted' activities such as measuring weight and doing symptom-based general health assessments. Not only do these cadres further reduce the workload of professional healthcare workers, they also increase the acceptance of the service to the patient as these lay staff usually come from the same area and socio-cultural background as the groups. The increased need for such lay staff is currently offset in many countries by limitations by health authorities in prescription and dispensing regulations. Given the precedents for such lay dispensing in other areas of healthcare – such as the model of community case management of malaria<sup>47</sup> as well as the 2013 WHO Consolidated guidelines recommending that trained and supervised community health workers dispense ART between regular clinic visits<sup>8</sup> – such restrictions should be lifted. Non-formalised health workers are often not a recognised cadre, nor are they well supervised or

remunerated, which can risk service interruption. A major stumbling block for Ministries of Health is the incapacity to include a new cadre in their wage bill envelope, while existing cadres already face difficulties with remuneration and retention packages.

Generally, Ministries of Health have a weak negotiating position against Ministries of Finance. They often fail to obtain budgets to match human resource for health (HRH) plans based on needs. Budget limits or wage bill caps, determine levels of expenditure for remuneration packages and numbers of health workers on the payroll. In Lesotho, for example, due to reduction in donor funding and lack of absorption into the health system, almost half the lay counsellors (256), critical in the scale up of HIV care and supporting adherence, stopped working between 2011 and 2012.

#### Access to quality clinical management

Self-managing care is dependent on rapid referral to health professionals if the patient's health deteriorates. There is general consensus to attend a minimum level of clinical and biological monitoring through direct contact between patients and the relevant healthcare professional every 6-12 months. A patient's contact with a lay cadre health worker, or the group representative along with a healthcare worker, offers another opportunity to trigger referral to clinical care. In addition, patients are educated to identify potential signs and symptoms such as TB, other common OIs, significant weight loss or ARV-specific toxicity. They also develop the capacity to resolve problems within the group, such as peers not adhering.



#### Involvement of community stakeholders

Chronic care requires a rethinking of traditional primary healthcare models. Patients, peers and communities should play a more significant role. As a minimum, community stakeholders should be consulted in planning and implementing community-based models. Community models have the potential to stimulate stronger demand of accountability from the health system, such as through a 'watchdog' to monitor drug stock outs or other break-downs in quality of patient care. Linking with other civil society groups who operate at regional or national levels is therefore desirable to boost information flow between peripheral and central levels. The current trend of reduced funding from international partners for these networks is worrying. In order for civil society to link strongly with 'grass roots' community groups and question the system, they need sufficient resources, ideally from an independent source.

#### Adherence monitoring through routine HIV viral load testing

Stable patients who are on ART may be at risk of treatment failure despite a lack of clinical symptoms. Routine annual viral load testing provides confidence that a patient, despite infrequent interaction with the health facility, is adherent to treatment. If the person's HIV viral load is 'undetectable', he/she can continue using the same regimen within the same ART delivery system. Conversely, a detectable viral load is an early warning of poor adherence and/or treatment failure, which in turn should lead to referral for enhanced adherence support and clinical assessment for ART treatment failure. In addition, viral load testing is a game-changer and allows for simplified eligibility criteria (e.g. to join a CAG) and reduced clinical follow-up. Although it should not be a pre-condition for developing a community model, access to viral load monitoring is an important enabler.

### Monitoring and evaluation

Monitoring and evaluation (M&E) are essential parts of implementation of any community model. The challenge is to have information follow the patient, i.e. in hospital, health centre as well as community. Tools have been developed to assist with M&E during the pilot phase of these programmes but these should be further simplified and adapted. Where possible these should be combined or integrated with existing MoH tools. In addition to paper-based systems or simple electronic tools that are currently in use, there is growing interest in the potential contribution that mHealth (the use of mobile devices to support healthcare delivery) could make in sharing information between laboratory or clinic-based interventions and community groups and/or individuals. Further operational research is needed to determine the potential benefits and optimal use of mHealth in delivery of ART services.

### Are we reaching our objectives around long-term ART delivery?

A set of objectives for the various models have been set out in the beginning of this document, while the extent to which they have been achieved is variable for each of these goals.

### Who is benefiting from these models?

Innovations that reduce costs for patients and the work burden for the health service have been mostly focused on stable patients on ART. Unfortunately, patients with sub-optimal adherence or requiring intensive clinical follow-up have mostly been excluded from these strategies, even though they may be in high need of community-based adherence support and easy access to drug refills.

Stable patients are usually defined as being on ART for at least six months, having a viral load result of less than 1,000 copies/ml, and clinically stable without active opportunistic infection. With the latest



WHO guidelines recommending earlier ART initiation at CD4 counts up to 500 cells/ $\mu$ l, it might be possible to offer community-based care earlier to those on ART for less than six months. This because those being initiated on ART will tend to be less sick and require less intensive early clinical supervision and therefore can do well in community-based models. In order to deal with an increase of patients following expanded eligibility criteria and the roll out of PMTCT B+, further differential management is needed to decongest the health services of people without needs for clinical care.

Pilot programmes are needed that look at linking groups that possibly need more intensive clinical follow-up (adolescents, children, pregnant women, etc) to existing community groups.

### Reducing the burden for patients and offering a choice

Cost savings have been reported for patients accessing community-based strategies, such as those receiving care at community distribution points in Kinshasa and at adherence clubs in Khayelitsha. Trends in patients' preferences for certain models are becoming increasingly apparent. Where the burden of distance to the clinic is high, e.g. in rural areas, CAGs or community clubs seems to be preferred above facility-based adherence clubs. The latter might be preferred in urban settings where less time at the clinic is desired and where the local social fabric might be weaker. Appointment spacing and fast-track drug refill is highly accepted in all contexts and therefore should be offered in combination with another community-based strategy.

Although there are several advantages to community-based models, a substantial number of patients may still choose to stay in regular care for different reasons. They may not wish to disclose their HIV status to the local community in order to avoid the risk of stigma, they may prefer to see a health professional on a regular basis, or they may see less benefit in the social fabric of their community. Participation in a community model of ART delivery is therefore always voluntary and providing a range of options will make it possible for patients to choose the model that best suits their needs and preferences.

### Reducing the burden for healthcare workers

While the reduction in workload for professional health staff is a clear advantage, it is important to take into account the new additional tasks related to community models such as facilitation, establishing training and supervision of such patient dynamics. Additional resources may be needed in terms of (lay) counsellors, CHWs or other lay workers to perform these functions. Although current evidence suggests a substantial reduction in workload at clinics and in particular for clinical staff, it is essential that sufficient resources are allocated to ensure these key supporting tasks.

### Peer support and community participation

The extent to which patient groups engage in mutual support is context-specific and dependent on the pre-existence of social networks, the number of patients in a group, the level of stigma, and the capacities of lay workers to facilitate group dynamics. The quality of the local social network will in itself determine to what extent community participation will be enhancing outcomes. Links with other civil society groups who operate at regional or national levels seem crucial to ensure a watchdog role for these newly-emerged community groups.



## 7. Conclusion

In many countries, HIV care has evolved from being a service delivered by specialised HIV clinics to one that is delivered in primary health centres. The time has come to bring treatment even closer to people via clinic outreach and community-based models. These developments are aimed at responding to the ever-increasing number of people on ART in health services strained by resource limitations. In high HIV prevalence settings in particular, but elsewhere too, application of these strategies can critically improve survival and adherence and reduce transmission. In western and central Africa, ART coverage is the lowest on the continent, and therefore improved adherence strategies are urgently needed, however, in these contexts, innovative community models are applied least<sup>48</sup>.

The programmes outlined in this document present several options, from health service-driven to patient-driven strategies, that enhance patient adherence and retention in care for those on long-term ART. The choice of model will very much depend on the context. Ideally, models are designed and adapted according to the daily lives of people and their cultural and economic environments.

Key objectives of these models are two-fold. From a patient perspective, these include reducing costs, establishing peer support and increasing community participation in order to support adherence. From a health system perspective, objectives include a reduction of workload whilst improving health outcomes and encouraging patients' autonomy.

High levels of adherence and retention in care have been reported in several models. Promising progress is being made to scale up HIV testing and linkage to care through community models. National programmes are also being based on the pilot models, with the Western Cape Provincial authorities in South Africa and the Mozambican authorities adopting adherence clubs and community ART groups



respectively. However, some Ministries of Health remain cautious, with concerns about maintaining adequate oversight of community activities, supervision of lay cadres so as to preserve quality of care, and security of ARV drug stocks to prevent loss due to pilferage.

There are certain risks when expanding from and adding another layer to the health services, therefore adequate support must be ensured. Flexibility and stability of drug supply are essential, and a solid monitoring system should be in place. Lay workers must receive sufficient support, both in terms of supervision as well as remuneration and recognition for any cadres spending a significant part of their time on these tasks.

The models' success depends on sufficient and reliable support and resources. In contexts with weak health systems, adding an extra layer may increase the burden, and drugs and human resources might fail to reach the community. Realistic planning and flexible adaptations are crucial, otherwise the shortcomings of the health system will be carried over into community care. In that case, alternatives should be explored.

While these models mainly target stable adults on ART, health systems must also ensure that appropriate services, including community-based services, are available for patients with special needs. These include those facing the most difficulty in adhering, and specific groups such as adolescents, children, pregnant women, commercial sex workers and migrants.

All of the alternative models of care described come with an attached cost, but with an ever-increasing number of patients needing lifelong ART, do we have a choice? Community-based and other innovative adherence strategies will provide cost savings over traditional facility-based models of care. Looking to the future, beyond CAGs and adherence clubs, there will be a need for even more radical simplification of ART delivery within the community.

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