

# Community ART Group Toolkit

## How to implement the CAG model

Bringing treatment closer to home and empowering patients



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## Glossary of terms

ART	Antiretroviral therapy	OI	Opportunistic infection
CAGs	Community ART Groups	PLHIV	People living with HIV
HCW	Healthcare worker	VHW	Village health worker
MOH	Ministry of Health	VL	Viral load

More information on other models can be found in the MSF reports "Reaching Closer to Home" and "ART Adherence Club Toolkit - Khayelitsha". Visit [www.samumf.org/resources/toolkit-cag/](http://www.samumf.org/resources/toolkit-cag/)

# Understanding Community ART Groups at a glance

## 1. WHY WE NEED CAGs

Despite the rapid scale-up of antiretroviral therapy (ART), patients still encounter barriers accessing treatment. At the same time health systems struggle to provide care to the growing number of patients on ART.

A number of clinic and/or community based strategies, such as a decentralization of services to health centres and health posts, providing longer drug supplies to patients and drug refills through fast track systems, adherence clubs and community distribution points, have been implemented to reduce the burden on health workers and patients. Community ART Groups (CAGs) are one such strategy for ART distribution, whereby groups of patients rotate for clinic visits and drug refill at the clinic while dispensing drugs to their peers in the community and ensuring peer support.

Different programmatic challenges will require different ART delivery strategies to be put in place. Choosing the most appropriate model will be context-specific and conditioned by a range of factors, including: individual patient barriers, the extent of existing decentralization, HIV prevalence, the capacity of health services, and, in some cases, regulatory or logistical constraints to ART delivery. This toolkit is aimed at implementers who, after assessment of their context, have decided CAGs would be the most suitable model to adopt in their setting. The kit gives practical tools that can be adapted for a specific setting.

*"Many people lost their lives because if someone is too weak to go to the health centre, there's no one to help him. He lives perhaps 45km from the health centre. It's far. And he would go alone to collect the drugs, weakened without anyone to help him..."*

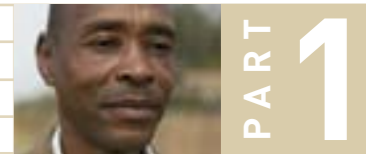
**CAG focal person in Tete, Mozambique<sup>1</sup>**

*"We only visit the health post once a month. Patients are many and they are waiting for us to arrive from early morning. Pressure on us is high."*

**Nurse, Lesotho**

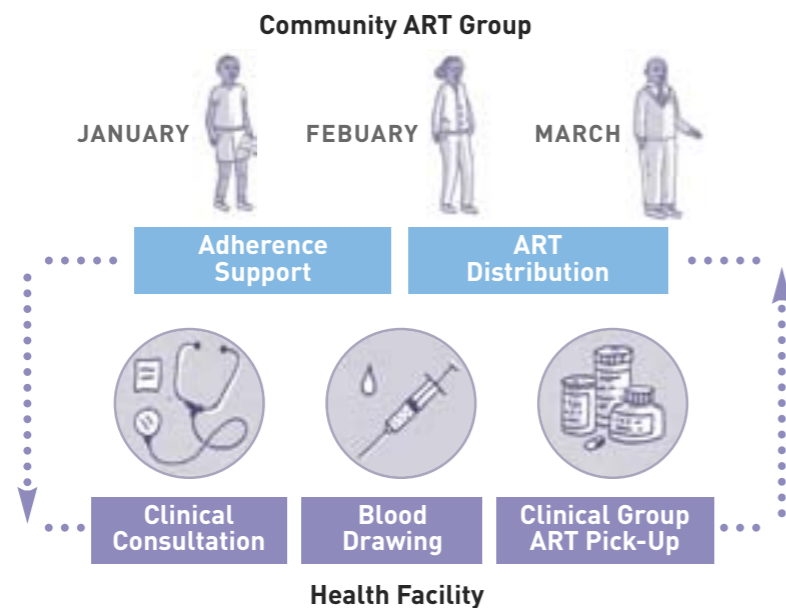


1. Rasschaert F, Telfer B, Lessitala F, Decroo T, Candrinho B, Mbofana F, Martinez D, Mondlane V, Maikere J, Biot M. *The dynamic and impact of the Community-based Antiretroviral distribution model in Tete Province, Mozambique; Findings of a qualitative research.* ICASA 2013, A2429592.



## 2. HOW CAGs WORK

CAGs are self-formed groups of stable patients on ART who take turns attending clinical assessment and monitoring tests at the health facility, whilst collecting drugs for themselves and the other members of the group. The CAG provides a means of accessing ART for the group members and a source of social support.



On a monthly to 3-monthly basis the following 3 steps are repeated:

### STEP 1: CAG meeting in the community before collection of ART by the group representative

CAGs are self-formed groups of stable patients on ART who take turns attending clinical assessment and monitoring tests at the health facility, whilst collecting drugs for themselves and the other members of the group. The CAG provides a means of accessing ART for the group members and a source of social support.

### STEP 2: CAG representative reports to the health facility

The CAG representative reports to the clinic for a clinical consultation and blood tests. The representative reports on the adherence and health of other members to the clinic and collects drugs for all group members.

### STEP 3: CAG meeting after ART collection upon the return of group representative

The group meets on the same day of the ART refill date at the home of a member or an other community venue, where the group representative distributes the drugs to each CAG member.

To date CAGs have been formed from stable patients on ART. The definition of stable has varied between sites and some examples are given in the implementation guide. CAGs are now being piloted to extend to non-stable patients on ART and specific groups such as pregnant women, adolescents and pre-ART patients.

## 3. THE BENEFITS OF CAGs

Community ART groups (CAGs) facilitate access to drugs for **patients** by reducing financial and time costs associated with frequent clinic visits. CAGs encourage peer support at community level, thereby facilitating a social fabric among patients and reducing perceived stigma. They create a stronger engagement of the community in HIV care with patients taking up critical roles in the delivery of ART in their communities. In addition organised patient groups can form an accountability mechanism towards the health system, calling for adequate and quality services.

CAGs reduce the workload of overburdened **healthcare workers** by decreasing the number of patients individually attending the clinics whilst achieving good health outcomes for the patients. The CAG model also fosters patient self-management and independence from the health-service.

### Objectives of CAG model



*“I discovered that we help each other, we love each other and we are working together. As a result, if somebody is not taking his treatment correctly, we are able to assist.”*

**CAG member, in Roma, Lesotho**

### Health outcomes in CAGs

In the Tete district in Mozambique more than 6,000 patients have joined CAGs since 2008. A cohort analysis showed retention<sup>2</sup> in CAGs was 98% at 12 months and the level was maintained up to 92% at 48 months<sup>3</sup>. High retention rates were also achieved in sites where CAGs were newly implemented, ranging from 90% in Malawi (N=299) to 100% in Lesotho (N=108) at a median time in CAGs of 9 and 5 months respectively<sup>4, 5</sup>.

2. Retention figures reported reflect retention in the CAGs and not retention in care for the programme.  
 3. Decroo, T. (2013). *Four year retention and risk factors for mortality among members of community ART groups in Tete, Mozambique*. Unpublished master's thesis for master's degree, Institute of Tropical Medicine, Antwerp, Belgium.  
 4. Billaud A, Coulborn, R, Zamadenga, B, Cuenca, M, Garone, D, Gerstenhaber, R., Trivino Duran, L, Likaka, A, Mbewa, K, Chidakwani, R. *One Stone, Two Targets. Strategies To Improve*

*ART Delivery And Clinical Outcomes Of Stable ART Patients: Lessons Learned From The Implementation Of Community ART Groups In Thyolo District, Malawi*. ICASA 2013, A2401134.  
 5. Baert S, Billaud A, Zamadenga B, Vandendyck M, Dezembre S, Decroo T, Olsson J, Abreu E, Motsamai M, Nyekete O, Bemelmans M, Bygrave H, Biot M. *Implementing Community ART Groups in low resource settings: Lessons learned from Médecins Sans Frontières*. ICASA 2013, A2429514.



### Reducing workload in Malawi

Preliminary data<sup>6</sup> from Thyolo suggests a big reduction in clinic visits for CAG members. When comparing clinic attendance for patients 10 months before and 10 months after they joined CAGs, ART refill visits reduced by 62% for CAG members whilst the number of other visits for acute problems or malaria stayed nearly constant.

## 4. THE CHALLENGES OF CAGs

There are a number of challenges to be faced in the establishment of CAGs. These challenges need an adapted response to maximise their potential benefit.

- Reliable **procurement, pharmacy and supply-chain management** are critical for implementing CAGs. Supply-chain weaknesses can lead to ART stock-outs and such weaknesses must be critically monitored and reported. It is important that the duration of drug supply is adapted to the patient's needs, both for those patients attending for their ART refill at the clinic as well as in those in CAGs.
- For CAGs to function well, new key tasks such as formation, training and monitoring of groups need to be clearly assigned to a specific cadre. In the pilot projects these tasks have most commonly been performed by **community health workers, lay counsellors or expert patients**. These positions are often not a recognized occupational cadre within the Ministry of Health (MoH) and are often not remunerated, a factor that risks interruption of services.
- Self-management critically depends on rapid self-referral to health professionals if a CAG member's health deteriorates. A **minimal level of clinical oversight** should be guaranteed through direct contact with a professional health professional responsible for ART care. Mechanisms to identify problems with other CAG members should be clearly in place and additionally patients are to be educated on the potential signs and symptoms of tuberculosis (TB), common Opportunistic Infections (OI), to monitor weight loss and to be alert for specific ART related toxicities, any of which would require them to present back to the health services.
- **Simplified monitoring systems** with a minimum set of indicators are needed to ensure quality is maintained and to support drug supply. Systematic supervision of the implementation and outcomes of the model should also be a prerequisite of any community-based model.

6. Personal communication, MSF Thyolo project, October 2013.

## How to implement CAGs at health facilities

### 1. ANALYSING THE SITUATION

In order to decide whether CAGs may be a potential strategy for ART delivery in a specific setting a careful analysis of the barriers to access ART services and retention is required. These barriers can be assessed through group discussions with patients and healthcare workers at the health facility, in combination with an analysis of strengths and weaknesses of the healthcare services.

There is no 'one size fits all' strategy; other strategies that may also reduce the burden for both patients and healthcare workers include extending the duration which drug refills last and/or accessing a 'fast track service' at the health facility for quick delivery of drugs to stable patients on ART.

It is also possible to combine CAGs with other strategies to accommodate for the different needs of your patients.

### Consulting patients in Lesotho

Patients identified transport costs or long walking distances to the clinic as an important barrier to accessing HIV care. Wasting time, while waiting in queues at the health facility, was another burden for this rural population who needed to tend to their cattle and fields. Patients proposed longer-lasting drug refills and further decentralisation of HIV care as ways to address these barriers. They were positive about the CAG model and suggested this could reduce stigma in the community as peers would support one another. They also saw it as an opportunity to start income generating projects within their group.



### Stigma in KwaZulu-Natal, South Africa

Healthcare workers in KwaZulu-Natal identified stigma as a barrier to implement CAGs, fearing that patients would not want to gather with their peers for fear of HIV disclosure. Discussions with patients revealed that they were indeed afraid of disclosing their status in the community, but would be happy to meet other HIV-positive peers to share their concerns. Because many patients said they did not have an existing network of peers, counsellors are gathering patients at the health facility for fast group drug refills to ensure patients can get in touch with other HIV positive people in their community to form CAGs.







## 1. ANALYSING THE SITUATION continued ...

**Implementing CAGs in Maputo, Mozambique**

Since the roll-out of CAGs in 2011 in urban Maputo, 15% of patients on ART had formed a group by June 2013. The main benefits for patients to join CAGs are linked to reduced time spent at the clinic. The uptake of CAGs in Maputo remains lower than in rural settings such as in Tete province where 50% of patients have joined CAGs. While reasons for these differences are being analysed, it appears that the fast track strategy answers most patients' needs for faster access to longer lasting drug refills while avoiding risks linked to disclosing their status to other patients.

**Combining strategies in Zimbabwe**

The majority of patients in the Gutu district have access to 3-monthly ART refills without a clinical consultation at a health centre close to their home. Distance and time spent at the clinic is not a barrier for these patients. CAGs have only been implemented for patients living in remote sites where the distance to the clinic has affected their ability to adhere.

## 2. INVOLVING NETWORKS OF PEOPLE LIVING WITH HIV

It is important to involve local networks of people living with HIV (PLHIV) in the development and implementation of CAGs. They can play an important role in:

- the promotion and formation of CAGs
- linking CAGs to other initiatives such as income generating activities and treatment literacy
- strengthening the voice of PLHIV within communities

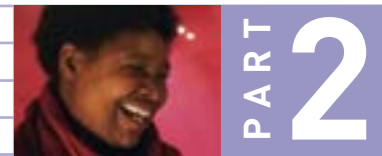
**Local networks of people living with HIV Thyolo, Malawi**

In Thyolo, about 20-30% of patients make up part of a Napham (National Association for people living with HIV and AIDS Malawi) support group. Initial promotion of CAGs has been done through support group leaders to facilitate rapid formation of CAGs. After a one-year pilot program, 85% of CAG members were recruited from Napham support groups, while CAGs were progressively being formed from non-support group members<sup>8</sup>. The collaboration with Napham for CAGs is an opportunity to connect more patients to local networks of PLHIV and at the same time relieve some of the tasks related to formation and follow-up of CAGs.

**CAGs forming networks in Maputo, Mozambique**

In Maputo, different CAGs spontaneously started meeting in the community after having met at the health facility. They organise themselves for drug refills in bigger groups, discuss further on daily life issues and are interested to look for income-generating projects together. They also wish to play a role in speaking out about the needs of PLHIV.





### 3. DEFINING ROLES AND RESPONSIBILITIES

Different staff members will need to be involved in supporting CAGs to ensure optimal functioning. The following factors need to be assessed:

- What staff and community lay workers are available?
- What tasks can be shifted to a lower cadre?
- Who can perform which task? (See Annex A for list of tasks)

CAGs do not need extra staff or a new cadre as the aim of CAGs is to reduce the workload of clinical and drug refill visits for HCWs. The strategy does however bring along new tasks such as the promotion, formation, training and supervision of CAGs which are vital to ensure their proper functioning. These tasks need to be clearly defined and assigned to an existing cadre in the clinic.

#### Task shifting challenges in Tete, Mozambique

In the pilot CAG programme in Tete, lay counsellors play a vital role in supporting the CAG dynamic. They fulfil the majority of new tasks that CAGs brought along such as promotion, formation, training and supervision of CAGs. Lay counsellors are not recognised or funded as a formal health cadre by the Ministry of Health which undermines the model. However other sites where CAGs were piloted have tried to bypass this pitfall by assigning the new tasks to MoH recognised cadres such as nurses and village health workers.



### WHO DOES WHAT

#### Nurse

- Decide upon eligibility for CAG of individual patients
- Support the establishment of CAGs
- Train CAG members on the use of CAG tools.
- Follow-up CAG representative at clinic visit on adherence and outcomes of other CAG members.
- Identify CAGs with problems.
- Clinical consultation of CAG representative.
- Prescribe ART for all CAG members.
- Blood collection for CD4/VL/other
- Dispense ART for all CAG members
- Promotion of CAGs at health facility



#### Counsellor/VHW

- Support the establishment of CAGs
- Train CAG members on the use of CAG tools.
- Follow-up of CAGs with problems at health facility/ community
- Promotion of CAGs at health facility
- Promotion of CAGs in the community



#### Phlebotomist

- Blood collection for CD4/VL/other



#### Dispenser

- Dispense ART for all CAG members



#### CAG Member

- Promotion of CAGs in the community



#### Support Group Leaders

- Support the establishment of CAGs
- Promotion of CAGs in the community



#### Data Clerk

- Collect and enter data into setting-specific ART database



#### Data Manager

- Verify data, conduct quality assurance exercises



#### Health Facility Coordinator

- Ensure CAG team is in place.
- Ensure CAG standards are being carried out.
- Training of new staff members on CAG model.
- Analyse and report on CAG outcomes back to health facility staff.
- Continuous quality improvement of CAG model.
- Consult with and report to health authorities.





#### 4. DEFINING ELIGIBILITY FOR CAGs

CAGs have been started with stable patients on ART, although variations between sites exist in the definition of stability. Currently MSF is piloting CAGs for non-stable patients such as those not yet eligible for ART (i.e. pre-ART), children and adolescents, pregnant women and patients on second line treatment, showing options for further adaptation of eligibility criteria for CAGs. The following criteria will need to be further adapted to the local context.

##### Who can join a CAG and when:

Current criteria	Future criteria
More than 6 months on ART	At first viral load < 1,000 copies/ml (if earlier than 6 months on ART)
More than 3 months on current regimen (according to local regimen)	-
CD4 count >350 cells/uL	Viral load <1,000 copies/ml In absence of viral load: Stable patients with no current evidence of immunological or clinical failure
No active TB or other active opportunistic infection	HIV-TB co infected patients if attending for TB drug refill at clinic
Not on second line treatment	-
Not pregnant	Pregnant or lactating women if attending for ANC/PNC follow-up at clinic
Age cut-off varying from above 15 years to above 18 years	Any child on a stable (non-weight dependant) adult dose of ART

Patients fulfilling a set of eligibility criteria can join CAG as an **active member**, meaning they can get their drug refills through CAGs and rotate for clinic visits.

Patients who do not or no longer fulfil eligibility criteria can join CAGs as a **social member**. They form part of the CAG peer network, but attend the health facility in person for closer clinical follow-up and drug refills. Once this patient fulfils the screening criteria again they can join or rejoin the CAG as an active member.

**Dependent members** are patients who do not fulfil but go with the CAG representative to the clinic for clinical follow-up and drug refills as they cannot go unaccompanied. This is the case for children who no longer need dose-changes or people suffering from mental disability.

Experience shows that establishing CAGs for specific types of patients, such as patients on second line treatment or pregnant women, is complex due to geographical distance, or the limited peer network of people who recently discovered they are HIV positive. There are different options to include other patient types in CAGs:

- First, create a dynamic with CAGs consisting of stable patients on ART, which can form a core group. At a later stage eligibility criteria for CAGs can be extended so that other patients can join the existing CAG in their area.
- Allow wider eligibility criteria from the start with clear procedures for referral back to the health facility for closer monitoring.

When fulfilling the eligibility criteria, the final choice to join a CAG will lie with the patient. Due to issues related to disclosure, patients cannot be forced to step into a community-based model of care.

##### Linking newly-HIV tested patients to CAGs in Changara, Mozambique

Community counsellors link up with CAGs to offer HIV testing and point-of-care (POC) CD4 testing to CAG family members or other people in their community. People who test HIV positive can establish a link with the existing CAG; eligible patients go to the health centre for ART initiation and join the CAG temporarily as a social member. Pre-ART patients who join can get their monthly Cotrimoxazole (CTX) refill through CAG members and get their CD4 count done when it is their turn to pick up drugs for the group.



##### Children in CAGs

An age cut-off is often used to determine who can join as an active CAG member, varying from between 15 to 18 years. More sites are now moving towards using a weight cut-off point according to ART regimen for children to become dependent members of CAGs. In Zimbabwe, children also need to have their HIV status fully disclosed to them before becoming a dependent CAG member.





## 5. DEFINING SYSTEMS FOR REFERRAL BACK TO CLINIC-BASED CARE

A CAG member can opt to go back to regular ART care within the health facility at any moment.

Some CAG members will have to go back to regular care for closer clinical follow-up and drug refills. This will be the case for:

- Patients newly diagnosed with tuberculosis or any other serious active opportunistic infection or other co-morbidity
- Patients with a viral load above 1,000 copies/ml – or in absence of VL, patients with evidence of clinical or immunological failure.
- Women during pregnancy and subsequent follow-up of the 'HIV-exposed' baby.

Once patients again fit the CAG criteria, they can rejoin their regular CAG as active members.



### Why viral load testing is important in CAGs

Viral load can – where available - play an important role for the management of CAGs:

- Viral load can be used to demonstrate virological suppression to motivate for early and routine referral into CAGs.
- Viral load can be used as a monitoring tool for those already in CAGs as it clearly identifies patients requiring referral for more intensive clinical and adherence interventions.

## 6. DEFINING THE CAG ANNUAL VISIT SCHEDULE

When defining the visit schedule for CAG members the maximum benefit for patients as well as for healthcare workers needs to be taken into account, whilst ensuring the minimal clinical follow-up.

The following questions help in defining the yearly schedule:

- How often do stable patients on a particular ART regimen need a clinical consultation for early identification of serious adverse events and OIs?
- How often do stable patients on ART need to have blood drawn for CD4/VL or toxicity monitoring?
- What is the maximum number of days of drug refill that can be given to patients?

The frequency of clinical visits can further define the number of patients needed to form a CAG. The size of a group influences its dynamic and experience shows that groups comprising 4 to 10 patients are ideal to ensure the objective of peer support while maintaining an individual responsibility of each member for the group.

At the initial phase of CAG formation drug refills, blood drawing and clinic visits will need to be aligned for all CAG members of the same group. It is useful to call all CAG members for the first health centre visit together to ensure this alignment and to train members on how to use the CAG tools.

Patients who are not feeling well can report to the health facility at any time outside of these fixed appointment dates.

### CAG annual visit schedule – Zimbabwe

In Zimbabwe, patients have access to 3-monthly drug supplies and need an annual viral load test and clinical consultation. CAGs can have a minimum of 6 and a maximum of 12 members. For practical reasons and to ensure accountability for drug refills, patients go in pairs to pick up the drugs. Patients with a viral load >1,000 copies/ml are traced and asked to attend a clinical visit and enhanced adherence counselling, whilst others with viral load <1,000 copies/ml receive their results through the group representative at the next refill date. The average number of visits to the clinic for each CAG member in a 12 member CAG, is now 4 visits in 24 months versus 9 visits if they were in individual fast-track follow-up.



Patient	1	2	3	4	5	6	7	8	9	10	11	12
Month												
0	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊
3	💊	💊										
6			💊	💊								
9					💊	💊						
12	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊
15							💊	💊				
18									💊	💊		
21											💊	💊
24	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊	🩸📄💊
	🩸 blood drawing    📄 clinical consultation    💊 drug refill											



6. DEFINING THE CAG ANNUAL VISIT SCHEDULE *continued ...*



**CAG annual visit schedule in Lesotho**

In Lesotho, drug refills are monthly, while patients need to attend clinic twice a year for CD4 count testing and clinical consultation. Patients form groups of maximum 6 patients. CAG members get their clinical consultation and blood drawn when they attend for drug refill at the health facility. At the next refill date, the following group representative brings back the CD4 results of the previous test. The average number of clinic visits is now 2 instead of 12 a year when there are 6 members in a CAG.



Patient	1	2	3	4	5	6
Month						
0						
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						

blood drawing clinical consultation drug refill

7. PREPARING HEALTHCARE WORKERS

Healthcare workers need to understand the functioning of CAGs and the use of its tools. This training should be ensured before implementation and should be offered regularly to new staff members.

The CAG model means a shift in thinking of healthcare workers and patients and therefore implementation needs strong support at the start. CAGs can be piloted in selected sites, whereby at a later stage the experienced CAG teams can support roll-out in other sites.

*Annex B: Training manual for HCW and CAG members, Malawi*

8. PROMOTING CAGs AMONG PATIENTS

Patients need to know that a CAG system exists and that they can voluntarily join. This can be done by spreading the message in the health facility waiting area, through existing community channels like support groups or village health workers and during clinical consultations. The more people are aware, the easier it becomes for groups to form spontaneously and present at the clinic. Once the model is well known by a few, word-of-mouth promotion by patients will be the best way to pass on the message.

The main messages to pass on to patients are:

- how the CAG model works
- who is eligible to join a CAG
- who to address when they are interested in forming a CAG

*Annex C: CAG leaflet Malawi*





## 9. SCREENING AND ESTABLISHING CAGs

A healthcare worker should screen patients to assess them based on eligibility criteria for the CAGs during a clinical visit. There are 2 ways in which screening and establishing groups can be organised:

- Ideally, patients are routinely screened during their regular individual ART refill consultation. Once assessed as stable by the healthcare worker, the patient can choose to join a CAG and be referred to the lay worker coordinating CAG formation.
- Formation of CAGs can also happen before screening. Patients step forward as interested and once the minimal number of people required for a functioning group is formed they present to the healthcare worker for screening to ensure they are clinically ready for active CAG membership.

While the latter option is often used for the start-up of CAGs, routine screening is the preferred option in the long term to ensure patients are proactively linked to CAGs in a simple way.

Some patients do know other peers on ART, but others do not, or they do not know enough patients to form a CAG. In most cases the lay worker will have a key role in bringing interested patients together and to facilitate disclosure within these smaller groups. Experience shows that assisting in the establishment of CAGs is an important task to ensure successful implementation of CAG and should be assigned clearly to a specific healthcare or lay worker.

CAGs will elect a CAG focal person. This is a CAG member who leads the group and acts as a contact person with the health facility and is elected by the CAG members.



### Establishing and screening CAGs in KwaZulu-Natal, South Africa

Some patients already attend clubs (group drug refills at the clinic) where they meet others potentially interested in setting up CAGs. Other patients are informed about CAGs through the community outreach activities. Patients interested in CAGs fill in a CAG application form with relevant names of patients and indicating a contact person. They hand over this form to the clinic nurse, who will screen each patient's file according to the eligibility criteria. The contact person is then called by the nurse and information is passed on as to who is potentially eligible to join CAGs and when the next CAG training date is for members to attend. The contact person will in turn inform other candidate CAG members. At the planned training day, patients receive their individual consultation for the nurse to take the final decision on eligibility for CAGs.

### Role of counsellors in establishing CAGs in Tete, Mozambique

"To be able to form a CAG, we rely very much on the counsellors. The day I told the counsellor I was interested in becoming a CAG member, he asked me different questions about where I live and if I knew other patients on ART from my area. He asked me to come back in a week and on that day I got to know other people from my area that also wanted form a CAG. That's how I got to know my other CAG members and we formed a group." **CAG member, Tete**



## 10. TRAINING CAG MEMBERS

Training for new CAG members needs to be organised and cover the following topics:

- Dynamics of a CAG
- Tools to be used by patients in a CAG.
- Roles and responsibilities of each person involved in a CAG
- Events and symptoms that need referral to the clinic

In some settings all CAG members are trained, whilst in other places only CAG representatives are invited for a formal training. The representative is then given the responsibility to inform the other members of their CAG.

*Annex B: Training manual for HCW and CAG members, Malawi*







## 11. THE CAG PROCESS FLOW ON ART COLLECTION DAY

### STEP 1

#### CAG meeting in the community before ART collection by the group representative

- The group meets on the day before or the same day as the ART refill date at the home of a CAG member or another community venue
- Each member of the group reports on her/his adherence which is then documented on the CAG group monitoring form (pill count). Each group member signs the form in the presence of the group's representative
- Each member is asked simple health screening questions (regarding for example: TB screening; weight loss; diarrhoea for more than 2 weeks; severe headache; specific symptoms related to ART side effects, such as ankle swelling, puffiness of the face, breathlessness; and family planning needs)
- The group discusses day-to-day issues of living with HIV and supports one another as needed
- The group chooses a person that will represent the others at the health facility and may opt to all contribute financially for transport. Anyone who is feeling unwell can join the group representative to attend a consultation at the health facility.



### STEP 2

#### CAG representative reports to the health facility with the CAG form

- On a rotational basis, a CAG representative reports to the clinic. Depending on the annual visit schedule and the organisation at the health facility, the representative may need to be seen by different healthcare workers. Experience shows that the greater the number of healthcare workers the patient needs to see, the greater the chance that the CAG representative will miss out on some of the steps. It is thus important to keep the movement between different services at the health facility to a minimum
- During the consultation the representative will: report back on the adherence and health of other CAG members; present the information on the CAG refill form; collect drugs; and according to the context, get a clinical consultation and have their blood drawn



- Through review of the CAG refill form and in discussion with the representative, the clinician should ensure that all group members are progressing well. Relevant documentation should be made in each CAG member's clinic-based ART card as usual. Any member requiring additional clinical follow-up should be identified and asked to attend the clinic.
- The prescription and dispensing of drugs should be written on the CAG refill form along with the results of recent blood tests so they can be reported back to the CAG members.

### STEP 3

#### CAG meeting after ART collection upon the return of group representative

- The group meets on the same day of the ART refill date at the home of a member or another community venue
- The representative distributes drugs to each patient, and when necessary (according to staff at the health centre) requests a group member to go to the health facility for a special consultation
- Patients sign CAG group monitoring form to confirm that they have received their drugs.



Annex D: CAG Video Tete

#### Priority of consultation for CAG members

In Tete, Mozambique, CAG group representatives did not have to queue in lines for consultation and drug refill like other patients. They were assisted more swiftly and this added benefit of participation in CAGs further reduced their time spent at the clinic. Patients who had opted to stay in regular individual care, however, perceived it as creating inequity. Strategies that reduce time spent at the clinic should be beneficial for patients in CAGs as well as patients in individual care in order to be fair.



## 12. MONITORING OF CAGs

A number of standard tools need to be implemented to allow for monitoring and evaluation of the CAGs:

- At registration of a new CAG, the **CAG register** is filled in (see Annex E), to be able to follow membership and appointments of groups. This form should be filled in by the lay worker or nurse when the CAG is formed and updated whenever any changes in CAG composition occur. Appointment dates are marked on this register to plan the CAG visits and to identify any defaulting CAGs or CAG members. Some health centres may also prefer to use the standard clinic appointment diary for the latter.
- Before every refill visit, CAG members fill in the **CAG group monitoring form** (see Annex F). This information is shared by the CAG representative with the healthcare worker at the clinic.
- At each CAG clinical visit the healthcare worker indicates the prescription of drugs for each member and data from the CAG group monitoring card is copied into the **Ministry of Health (MoH) individual patient's ART cards** by the healthcare worker.
- The healthcare worker fills in the **quarterly CAG report** and transmits information to the health facility manager. (see annex G)

National M&E tools should be used as much as possible, to reduce extra workload for healthcare workers.

A standard set of **indicators** is suggested in the quarterly report (see annex G), referring to the cumulative cohort in CAGs. Additionally a separate cohort monitoring of outcomes by time on treatment should be performed at least once per year.

*Annex E: CAG register*

*Annex F: CAG group monitoring form Zimbabwe*

*Annex G: CAG quarterly report form*

### Using the ART card in Zimbabwe

In Gutu, the individual standard national ART card is used to register data of individual CAG members. Health staff chose not to make up a new CAG monitoring tool for use at the health facility to avoid extra workload for the healthcare workers, to avoid possible data loss and to stay aligned with the MoH monitoring and evaluation system. At registration of a CAG, all individual ART cards of the members are put together in one folder. When the CAG representative comes for drug refill, the folder is taken out and the individual ART cards of each CAG member is filled in by the nurse, based on data provided by the CAG group monitoring form.

## 13. IDENTIFYING AND SUPPORTING CAGs WITH PROBLEMS

CAGs that are not functioning well should receive closer scrutiny and support. The following criteria can be used to **identify** the need for additional support, and can be assessed during the consultation with the CAG group representative:

- Missed appointment for drug refill/blood drawing/clinical consultation by one of the group members
- CD4 drop of more than 30% or viral load >1,000 copies/ml for more than one member
- Same representative always presenting for refill
- Conflicts or problems within the group dynamic
- CAG group monitoring form incorrectly completed
- CAG member deceased or lost to follow-up

**Support** can be given by immediately solving problems with the group representative during the consultation. If needed, the CAG can be gathered at the health centre where they pick up their drugs or be visited in the community by the healthcare workers for support as needed.

Village health workers or lay counsellors may play an important role in supporting poorly functioning CAGs in the community, but they will need the means to fulfil this task.

### Supervision in Angonia, Mozambique

During the pilot phase in Angonia a number of CAGs were visited on a 3-monthly basis to ensure quality within these CAGs. This intensive supervision was seen as neither feasible nor necessary in the long run. Only CAGs facing difficulties that cannot be solved with the group representative during the consultation are now asked to report individually or as a group at the health facility or are visited in the community.



*Annex H: Red flag supervision form for village health worker, Lesotho*

### LIST OF ANNEXES

Tools enabling the smooth implementation of CAGs are available at: <http://samumsf.org/resources/toolkit-cag/>  
These tools are merely examples and require further adaptation to the specific context where they will be used.

*Annex A: CAG task division grid*

*Annex E: CAG register, generic*

*Annex B: Training manual for HCW and CAG members, Malawi*

*Annex F: CAG group monitoring form Zimbabwe*

*Annex C: CAG leaflet Malawi*

*Annex G: CAG quarterly report form Malawi*

*Annex D: Video CAG Tete*

*Annex H: CAG supervision form for VHW, Lesotho*