Community ART Group (CAG) Toolkit

Lessons learnt from implementing CAGs in Thyolo, Malawi

Bringing treatment closer to home and empowering patients









Contents

| Glossar | y of terms | 2 |
|---------|---|----|
| Part 1 | Understanding Community ART Groups (CAGs) at a glance | 3 |
| 1. | Why CAGs? | 3 |
| 2. | How CAGs work? | 4 |
| 3. | The benefits of CAGs | 6 |
| 4. | The critical enablers for CAGs | 8 |
| Part 2 | How to implement CAGs? | 9 |
| 1. | Involving networks of people living with HIV | 9 |
| 2. | Defining roles and responsibilities 1 | 0 |
| 3. | Eligibility criteria for CAGs 1 | 1 |
| 4. | Defining systems for referral back to clinic-based care 1 | 2 |
| 5. | The CAG visit schedule 1 | 3 |
| 6. | Preparing healthcare workers 1 | 15 |
| 7. | Promoting CAGs among PLHIV 1 | 5 |
| 8. | Establishing CAGs 1 | 6 |
| 9. | Identifying and supporting CAGs facing challenges1 | 8 |
| 10. | Do CAGS pose challenges to the Malawian ART guidelines? 1 | 8 |
| 11. | Recommendations 1 | 9 |
| 12. | Frequently asked questions? | 20 |
| 13. | List of Annexes | 21 |

Glossary of terms

| ANC ART CAGs | Ante natal clinic Anti-retroviral therapy Community ART Groups | MA NAPHAM | Medical Assistant National Association of People Living with HIV/AIDS |
|--------------------|--|--------------|---|
| CBO | Community Based Organisation | 01 | Opportunistic infection |
| CO | Clinical Officer | PAGs | Prison Antiretroviral Groups |
| COWLHA | Coalition of women living with HIV | PLHIV | People living with HIV |
| | and AIDS | PMTCT | Prevention of Mother to Child |
| DHO | District Health Office | | Transmission |
| HSA | Health Surveillance Assistant | ТВ | Tuberculosis |
| | (community worker) | VHW | Village health worker |
| HCW | Healthcare worker | VL | Viralload |
| HF | Health facility | WHO | World Health Organisation |
| MoH | Ministry of Health | | |

MSF Malawi

Po Box 30353, Chichiri, Blantyre, 3 Office: +265 1 844 409 Email: msfocvb-blantyre-advocacy@brussels.msf.org www.msf/org/malawi

All photos courtesy of Marco Longari/AFP, thanks to Bote Zamadenga and Charles Mumba for their contributions.



Understanding Community ART Groups at a glance

Community ART Groups (CAGs) are a model for ART distribution, whereby groups of PLHIV rotate for clinic visits and drug refills at the clinic while dispensing drugs to their peers in the community and ensuring peer support.

Since 2012 the CAG model has been introduced as a pilot in Thyolo District. To date over 5,000 PLHIV have joined these community ART groups. The pilot has proved extremely successful with excellent adherence and retention rates and minimal defaulter rates as compared to the conventional ART programme outcomes. Additional evidence on viral load outcomes for CAG members and qualitative research with ART providers and patients on the effectiveness of CAG is being documented.

Introducing CAGs in Thyolo district has supported decongestion at health facilities and reinforced peer support for PLHIV at the community level.

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 accessing ART services and retention is required.

There is no 'one size fits all' strategy. There are other strategies that may also reduce the burden for both PLHIV and healthcare workers. These include extending the duration for drug refills and/or accessing a 'fast track service' at the health facility for quick delivery of drugs to stable PLHIV on ART. It is also possible to combine CAGs with other strategies to accommodate for the different needs of PLHIV.

1. WHY CAGs?

Despite the rapid scale up of antiretroviral therapy (ART), People living with HIV (PLHIV) still encounter barriers accessing treatment. Simply getting to the health centre can be very time-consuming, difficult and costly. At the same time health systems, with severe shortages of health staff and over-congested waiting rooms, struggle to provide care to the growing number of PLHIVs receiving life-saving ART treatment.

The Malawi HIV program has made significant gains over the years and by December 2013 the national cohort of ART patients was 459, 261. The adoption of the new WHO guidelines in 2013; moving from an initiation criteria of CD4 count 350 to 500, has increased the number of Malawians receiving antiretroviral treatment. From mid-2016, when universal eligibility criteria for PLHIV comes into effect the numbers on treatment will rise significantly again.

As the scale-up in ART treatment continues towards Malawi's ambitious 90-90-90 target, it will be vital to put alternative mechanisms in place to help deal with the increasing demands being placed on Malawi's health delivery system.

^{1.} See the "suggestions for further reading", in the List of Annexe section

^{2.} Integrated HIV Program report, October-December 2013

4 Malawi Community ART Group (CAG) Toolkit

A number of community oriented service delivery strategies have been piloted in Malawi in order to help relieve the pressure on the health system and improve care and support for PLHIV.

Out of a total of 30 health facilities across the Thyolo district, 12 already have CAGs in operation and CAGs are being progressively rolled out across the district. In some facilities over 50% of the ART cohort have joined a CAG.

In other countries, such as in Mozambique and Lesotho, CAGs include non-stable PLHIVs and specific groups such as pregnant women, adolescents, children as well as pre-ART PLHIVs, who benefit from receiving support from fellow CAG members.

2. HOW CAGs WORK

CAGs are self-formed groups of stable PLHIV on ART who take turns attending the health facility to receive a clinical assessment and monitoring tests, whilst collecting drugs for themselves and the other members of their group. The CAG provides a means of accessing ART for the group members and a source of social support. In Thyolo the CAG group consists of six members however in other contexts, such as Mozambique and Zimbabwe, the group can range from 4 up to 12 depending on the geographic location and how far PLHIV have to travel to pick up their drugs.

Depending on the duration of refill available (up to 3 months of drugs), the following steps are repeated:



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

PLHIV meet at the home of a CAG member to report on their health and talk through personal health issues and any challenges they're facing. A pill count is conducted and adherence issues are identified and the information is recorded on the CAG community card. The CAG group leader supports other members with advice on how to avoid missing their doses.

CAG members rotate responsibility to go and collect the drugs on behalf of the group. If a member of the group is particularly unwell and needs a clinical consultation they can be accompanied to the clinic by the CAG representative who is collecting the drugs.



STEP 2: CAG representative reports to the health facility

© Marco Longari/A

The representative presents the CAG community card and reports on the adherence and health of the other CAG members and collects drugs for all group members. While at the clinic the CAG representative receives a clinical consultation, and blood tests as required.

In other countries all the members of a CAG report to the clinic once a year together, for their clinical consultation and viral load monitoring tests.

<image>

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

Marco Longari/AFP

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 BENEFIT OF CAGs

CCAGs support key aspects of effective health system management including:

- Improving patient's access to ART by addressing barriers to accessing health facilities
- Reducing the workload of health staff
- Reducing loss to follow-up
- Improving adherence
- Empowering patients to take more responsibility to manage their own health
- Encouraging peer-to-peer support.

A study on the impact of CAGs in Thyolo found that³:

- Retention in care rates (two years after the introduction of CAGs) was 96.3% for CAG members as compared to 94% for non-CAG patients in the study group (who were also stable patients).
- The introduction of CAGs reduced the number of ART refill visits per person per year amongst the study cohort of 177 patients by 59.3% per person per year.

Indirect benefits of the CAG model include:

- Enhancing patient's knowledge of ART because PLHIV meet regularly in their groups and share experiences
- Bringing community ownership to the ART program
- Supporting the diffusion of information from the health facility back to the community.

The PLHIV perspective

"We meet a day before ART refill. This equips the representative with information concerning our group. The whereabouts, health status and pill count of each member is documented and reported to the health facility during ART refills."

A member of Bvumbwe CAG

"With the coming of CAGs we only go to the clinic for drug refills and clinical consultations twice a year and fellow CAG members contribute towards each other's transport costs. Now, we don't miss our drug refill and clinical consultations appointments."

A member of Tadala CAG, Thyolo

"We don't waste a lot of time at the clinic because we are attended to much earlier than those who are in conventional care."

A member of Nasomba CAG, Mikolongwe Health Centre

 Billaud A, Zamadenga B, Cuenca M, GaroneD, Gerstenhaber R, Triviño L et al. Impact of Community ART Groups on the decongestion of health services: Evidences from a retrospective before-and-after study in Thyolo, Malawi. operational research component one (unpublished). 2013.



"The other 5 members of the CAG stay at home doing their household chores while a representative of the group goes to the clinic for drug refill for us all."

A member of Madalitso CAG, Mikolongwe Health Centre

"Health care workers treat us well because they don't get so tired attending to so many PLHIV."

A member of Matabwala CAG, Bvumbwe Health Centre

"We give each other social support and this helps reduce stigma in our community." A member of Tikondane CAG, Khonjeni Health Centre

The health care worker perspective

"I was one of the staff who complained about the workload due to the introduction of CAGs. After introduction, I actually realised that it reduced my workload: for example I see one patient instead of six. I should admit that the workload is high in the preparatory phase of the CAG model. For instance, during orientation, registration of the new CAG and the first ART refills. Afterwards, CAGs lessen the workload."

Medical Assistant, Mikolongwe Health Centre

"Before CAGs were introduced, sometimes one or two health care workers would see between 200 to 300 PLHIV. It would take the whole day to attend to them."

HSA and CAG focal person at Mangunda Health Centre

"Decongesting the clinic since the introduction of CAGs, allows us to spend more time examining one patient; instead of rushing through many patients just to see them off." Health Centre staff, Bvumbwe Health Centre

"Defaulter and death rates are reduced among PLHIV in CAGs mainly due to social support. Our records show that between May 2012 and November 2014 we had 169 patients default from our regular cohort but no defaulters amongst our CAG member cohort."

HSA supervisor at Mikolongwe Health Centre.

"Having CAGs means there's more social surveillance on how drugs are distributed. CAGs are introduced into a village under the oversight of the chief so they're checking, and all the members of a CAG group are also checking that the drugs are handed out responsibly. It's a more reliable system for drug disbursement than the guardian ART distribution system."

Clinical officer, Bvumbwe Health Centre

8 Malawi Community ART Group (CAG) Toolkit



Patients waiting at a health facility in Thyolo district

4. THE CRITICAL ENABLERS FOR CAGs

There are a number of critical enablers that need to be considered during the establishment and implementation of CAGS.

- Reliable procurement, pharmacy and supply-chain management are critical for implementing CAGs. It is important that the duration of drug supply is adapted to the PLHIVs' needs, both for those PLHIVs individually attending for their ART refill at the clinic, as well as those in CAGs.
- For CAGs to function well, new key tasks such as responsibility for the training and monitoring of groups need to be clearly assigned to specific cadres.
- Mechanisms to identify problems with other CAG members should be clearly put in place and additionally PLHIV need 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.
- Systematic supervision of the implementation and outcomes of the model should also be a prerequisite of any community-based model.



How to implement CAGs

1. INVOLVING NETWORKS OF PEOPLE LIVING WITH HIV

It is important to involve local networks of people living with HIV in the development and implementation of CAGs. Networks such as: the National Association of People Living with HIV/AIDS (NAPHAM), and the Coalition of Women and Girls Living with HIV and AIDS (COWLHA) and organisations representing key populations.

PLHIV networks 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 and in the national HIV response.



A CAG member conducting a health talk at a facility

2. DEFINING ROLES AND RESPONSIBILITIES

Different cadres 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: Task division grid)

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 health care workers. The strategy does however bring along new tasks that need to be clearly defined and assigned to an existing cadre in the clinic.

A key role that is assigned at each health facility is HSA CAG focal person, they play a vital role in coordinating the support of the CAG dynamic. They fulfil the majority of new tasks that the CAG model has generated such as: the promotion, formation, training and supervision of CAGs.

The CAG team

The team in the Thyolo model is composed of both MSF⁴ and Thyolo district health office staff.

The MOH staff supporting CAGs in Thyolo include: the ART/PMTCT coordinator, and the deputy ART/PMTCT coordinator and at the facility level include: MA/nurse, an HSA CAG focal person and the HSA team.



A CAG member waiting in line at the health facility

^{4.} In the pilot in Thyolo MSF's staff supported the Thyolo District Health Office with an initial briefing to introduce CAGs to the community leader and to the health facility staff; provided support to health staff for the screening and recruitment of the first CAG members, and later with quarterly supervisory visits. If the CAG model is scaled up in other districts these activities can be taken over by the District's ART/ PMTCT Coordinator (or Deputy).



3. ELIGIBILITY CRITERIA FOR CAGs

To be eligible to join CAGs in the Thyolo pilot, PLHIVs must fulfil the following requirements:

- Must have been on ART for 6 months or more
- Viral load < 1,000 copies/ml (in absence of viral load: patients with no current evidence of immunological or clinical failure)
- No active TB or other active opportunistic infection
- Not on second line treatment
- Be above 18 years⁵
- Not pregnant or lactating (CAG members who fall pregnant can remain in the group but will need to attend ANC and exposed baby follow up).

Who can join a CAG and when?

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

However, PLHIVs who do not fulfil eligibility criteria (they may be diagnosed with TB or haven't been on ART for 6 months, or are pregnant) can still join CAGs as a social member. Social members of CAGs form part of the CAG peer network, but they still attend the health facility in person for closer clinical follow-up and drug refills. Once this PLHIV fulfils the eligibility criteria again they can join or re-join the CAG as an active member.

Dependent members are PLHIVs who do not fulfil eligibility criteria 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 or physical disability.

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.

The Thyolo pilot is considering including children, who weigh 25kg or over, who are on a fixed adult dose first-line as co-members.

4. DEFINING SYSTEMS FOR REFERRAL BACK TO CLINIC-BASED CARE

A CAG member can opt to go back to regular (conventional) 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:

- PLHIVs newly diagnosed with tuberculosis or any other serious active opportunistic infection or other co-morbidity
- PLHIVs with a viral load of above 1,000 copies/ml or in absence of VL PLHIVs with evidence of clinical or immunological failure
- Women during pregnancy and subsequent follow-up of the 'HIV-exposed' baby if they are not respecting clinic visits for ANC and the baby.

Viral load testing in 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 PLHIV requiring referral for more intensive clinical and adherence intervention.



A nurse organizes viral load samples at a health centre



5. THE CAG VISIT SCHEDULE

When defining the visit schedule for CAG members the maximum benefit for PLHIV 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 PLHIV on a particular ART regimen need a clinical consultation for early identification of serious adverse events and OIs?
- How often do stable PLHIV on ART need to have blood drawn for VL?
- What is the maximum number of days of drug refill that can be given to PLHIV?

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

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



A CAG member is checked by a clinical officer at a health facility, threee hours walk away from his village

14 Malawi Community ART Group (CAG) Toolkit

Example of an annual visit schedule from Zimbabwe for a CAG using a three monthly drug supply with an annual clinical visit and blood test. In this model CAG members number up to 12 and visit the clinic in pairs.

| Patient | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|---------|----------|----------|--------|-----------|---------|--------|---------|-------|-----|-----|-----|-----|
| Month | | | | | | | | | | | | |
| 0 | | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 |
| 3 | 0 | 8 | | | | | | | | | | |
| 6 | | | 0 | 0 | | | | | | | | |
| 9 | | | | | 8 | 8 | | | | | | |
| 12 | | 100 | 100 | 100 | 100 | 180 | 100 | 100 | | 100 | 100 | 100 |
| 15 | | | | | | | 8 | 0 | | | | |
| 18 | | | | | | | | | 0 | 0 | | |
| 21 | | | | | | | | | | | 0 | 8 |
| 24 | 1 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 |
| | bloo | d drawir | ng 🗐 d | linical c | onsulta | tion 🖉 | drug re | efill | | | | |

Example of an annual visit schedule from Thyolo for a CAG using a monthly drug supply with twice yearly clinical consultations and blood tests. In this model CAG members number up to 6.



Marco Longari/AFP



6. PREPARING HEALTHCARE WORKERS

Healthcare workers need to understand the functioning of CAGs and the use of its tools. An initial training on CAGs should be organised before implementation of the CAG model in a health facility (see Annex B: Facilitator's manual CAG). For new staff members joining a facility a briefing on the CAG model will be offered by the HSA CAG focal person or MA.

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

7. PROMOTING CAGS AMONG PLHIV

PLHIV 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 (by HSAs or CAG members who are expert clients) and through community channels like drama groups, PLHIV networks, local leaders network and community radios. 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 PLHIV will be the best way to pass on the message.

The main messages to pass on to PLHIV are:

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



Members of a CAG drama group performing at one of the Health Facilities in Thyolo to encourage PLHIVs to form CAGs



8. ESTABLISHING CAGs

When planning to implement the CAG model at a health facility, the local leaders are approached and briefed about the program. This is important because once the chiefs are sensitised they can help in encouraging their community's engagement and in resolving any disputes that may arise among the members.

Some PLHIV hear about CAGs through the PLHIV support groups while others are informed during health talks at the ART clinic.

A medical assistant or nurse should screen PLHIV to assess them based on CAG eligibility criteria, during a clinical visit. There are 2 ways in which screening and establishing groups can be organised:

- Ideally, PLHIV are routinely screened during their regular individual ART refill consultation. Once assessed as stable by the MA/nurse, the PLHIV can choose to join a CAG and be referred to the health facility HSA CAG focal person responsible for coordinating CAG formation. The options for ART refill should also be explained in the ART counselling sessions, when patients have their first viral load blood test.
- Formation of CAGs can also happen before screening. PLHIV can meet at the community level to voluntarily form a CAG and choose the leader of their group. Thereafter, the group members present themselves to the HSA CAG focal person at the ART clinic who gives them an appointment for screening. The group members then come for screening together, if they pass the criteria, their group is registered.

During the first day of ART refill for the new group, all individual health passports for group members are brought to the health facility, all individual drugs are brought to be cross-checked with their health passports, and to harmonise drugs and refill dates. On the subsequent visits, the CAG representative carries their health passports together with the CAG group card for ART refill.

To facilitate support for the good functioning of CAGs a CAG focal of focals, who is an expert client, is identified from amongst 5-10 CAG group leaders within a certain catchment area. This CAG focal of focals conducts regular support visits to groups under their responsibility, assists the CAG group leader with technical issues in regards to the CAG functioning and liaises with the HSA responsible for the catchment area.

Training for CAG members

All CAG members are given orientation on the following topics on the day of registration of the group at the health facility:

- Dynamics of a CAG
- Tools to be used by PLHIV in a CAG
- Roles and responsibilities of each person involved in a CAG
- Symptoms that need referral to the clinic

Additional training for the leaders of new CAG groups can be considered, as well as other trainings which networks of PLHIV may be able to offer.



Monitoring and supervising CAGs

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

- At the registration of a new CAG, the CAG register is filled in (see Annex C), to be able to follow membership and appointments of groups. This form should be filled in by the HSA CAG focal person when the CAG is formed and updated whenever any changes in the CAG outcomes occur such as death or defaulting. 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 leader fills in the CAG Community Card (see Annex D), with information on the members' pill count. The CAG leader also checks in with all group members on any clinical problems they're experiencing and writes them down in the group's CAG book. This information is then taken by the CAG representative back to the clinic and shared with the clinician. If a member is having clinical problems they will be supported by a fellow member to seek medical attention at the health facility.
- At each CAG clinical visit the healthcare worker indicates the prescription of drugs for each member and data from the CAG community card is copied into the Ministry of Health's (MoH) individual patient ART card by the healthcare worker.
- The health facility HSA CAG focal person fills in the CAG facility quarterly report form (see Annex E) and transmits information to the CAG/ART Coordinator.
- Every quarter HSA's conduct quarterly supervisory visits to the CAGs in their respective villages to support and assess the functioning of their groups. Information collected is included in a Quarterly CAG supervision form (see Annex F) that is filled in by the HSA CAG focal person.

Using the ART patient card in Malawi

In Thyolo, the individual standard national ART mastercard is used to register data for individual CAG members. 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 health facility staff, based on data provided by the CAG Community card. Since the beginning of 2015, a new system is being implemented to reduce time spent in pulling out individual cards.

In Thyolo District Hospital (TDH), at the registration stage of a new CAG all the ART cards for a CAG group are filed together and are stored in a separate folder. Feedback by the ART clerks is that this new system is more efficient and saves time. This pilot at TDH should be rolled out across the district in the coming months.

| Ι | | | | | | | | | | | | | | | | | | | | | |
|---|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| Τ | | | | | | | | | | | | | | | | | | | | | |
| T | | | | | | | | | | | | | | | | | | | | | |

9. IDENTIFYING AND SUPPORTING CAGS FACING CHALLENGES

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 consultation with the CAG group representative:

- Missed appointment for drug refill/blood drawing/clinical consultation by one of the group members
- Viral load >1,000 copies/ml for more than one member
- If the same representative is always presenting for refill
- Conflicts or problems within the group dynamic
- CAG group community form incorrectly completed
- CAG member deceased or lost to follow-up

10. DO CAGS POSE CHALLENGES TO THE MALAWIAN ART GUIDELINES?

According to the 2008 Guidelines for the Use of Antiretroviral Therapy in Malawi, three essential prerequisites for the success of ART management are required: "The regular supply of ARV drugs, their appropriate storage and use, and the monitoring of drug security."

So do CAGs pose challenges to the Malawian ART guidelines - if ART drug storage, security and monitoring cannot be guaranteed when drugs are distributed outside the health facility?

No. The implementation of CAGs in no way negates the security, monitoring and supervisory systems. These systems remain intact. The new element that CAGs bring is that, instead of each stable PLHIV, or guardian, going to the clinic every month or two months to collect his or her drugs, PLHIV take turns to collect drugs on behalf of each other.

In CAGs, just as with individual clients who use guardians to collect ARTs on their behalf, there is a risk of drugs being misappropriated. One example would be if a CAG group representative decides to keep the drugs or sell them, rather than delivering them back to his peers. This scenario has not occurred in the three years that CAGs have been operating in Thyolo. Beyond Malawi - in MSF's experience of implementing CAGs in other countries, like Zimbabwe, Mozambique and Lesotho, there has been no documented occurrence of drugs being stolen by any member of a CAG.

The risk of drugs being misappropriated is minimal because of the shared sense of responsibility that exists within a community ART group. Group theory shows that mutual accountability exists in groups that are comprised of between 4 and 10 people. To minimize the risk of drug loss a multi-sectorial approach has been established during the roll out of the CAG model of care in Thyolo. Local, influential leaders at the community level reinforce messages to CAG members that drug disbursement must be managed appropriately. These local leaders are entrusted with a responsibility to check on any possibility of drug misuse in CAGs as part of their role as duty-bearers.

Concerns around storage do not arise in the CAG model because the group representative distributes the drugs to the owners on the same day of collection. PLHIV store the drugs in the same way they were doing before joining the CAGs.



In order to ensure the correct medicines are delivered to the correct CAG member, medicine bottles are labelled at the health facility. During the CAG discussions questions on how to take the treatment are addressed and patients are encouraged to know the names of their own regimens.

Documentation of drug refill also remains the same on the ART mastercards and cohort reporting can still be carried out.

11. RECOMMENDATIONS

Based on MSF's experience of piloting the CAG model in Thyolo since 2012, the following recommendations are proposed to support the successful implementation of community ART groups within the Malawian health system.

- First, establish a strong CAG team at the District Health Office level with a lead focal person who is allocated enough time to focus on the CAG program. Ensure the DHO CAG team has sufficient access to transport, allowances, communication tools and stationary (CAG group card, CAG register, CAG supervision tools).
- Prioritize sites to launch CAG activities where there are large ART cohorts or that are in remote locations.
- The CAG model requires a shift in thinking of healthcare workers and PLHIV, and the introduction of CAGs to a health facility needs strong support from the start. Ensure the engagement of the DHO CAG team each time the CAG program is launched at a health facility and involve all the health facility staff in information dissemination on CAGs. Local staff will need support from the DHO CAG team with the first recruitment of CAG members and to ensure the program is running smoothly.
- Ensure clear responsibility for the management of the CAG group is assigned to a full-time staff member at the health facility (either an ART provider, ART clerk or HSA).
- Establish a CAG Stakeholder Technical Working Group at each health facility to meet quarterly to oversee and assess the functioning of the CAGs in their catchment area. The working group members to include the person in charge at the facility, the CAG focal person and representatives from stakeholders such as NAPHAM.
- From the beginning work with PLHIV networks such as NAPHAM when recruiting new CAG members.
- Provide regular supervision of CAGs in the community by an HSA (the DHO CAG/ART team to provide additional supervisory support in the beginning).
- Introduce three monthly refills for all CAG groups, to align with the Malawian government's ART refill program. The model is flexible and can be adapted and simplified. When defining the visit schedule for CAG members the maximum benefit for PLHIV as well as for healthcare workers needs to be taken into account, whilst ensuring the minimal clinical follow-up.
- Introduce a system whereby all members of a CAG attend the clinic together for clinical visits and viral load testing. Grouping visits of CAG members together will support oversight of the CAG group dynamic and reinforce the importance of VL monitoring.

- Given that stable patients including CAG members will receive clinical check-ups at the health facility at spaced out intervals, it is important to ensure that their clinical status is assessed by medically trained personnel.
- Introduce a system of grouping CAG members' ART cards together to ease processing at the health facility level (this needs to be done for the paper based and EMR systems).
- Eligibility criteria for CAG membership to be broadened to include PLHIV whose VL is more than 1,000 copies/ml; and for PLHIV who have been on second line treatment for 6 months or more; pregnant and lactating women (who are attending for ANC follow-up at clinic); and children (as co-members) who are on a fixed dose adult first line regimen. Close clinical follow up and enhanced adherence counseling of cohorts with detectable viral load will be vital.
- Introduce CAGs in prison settings. MSF has supported the introduction of CAGs (called Prison Antiretroviral Groups: PAGs) into two prisons⁶ in Malawi since late 2014. Prisoners within the PAG take it in turns to collect ARTs for their group (10-15 people) every month and come as a group for their clinical follow-up every 3 months.

12. FREQUENTLY ASKED QUESTIONS

1. Are discordant couples included in a CAG?

The partner who is on ARVs is included in a CAG but the HIV negative partner can join as a social member.

2. Are mothers and their children accepted in CAGs?

Mothers are but the children are not however, the Thyolo pilot is considering to include children, who weigh 25kg or over, who are on a fixed adult dose first-line as co-members.

3. What is the cost to introduce the CAG model of care at a given health facility?

It is not an expensive model to introduce. Approximately, MK 300,000 is needed to kick start CAGs at a site. The resources are required to cover the cost of briefing local leaders, health facility staff, and CAG group leaders. Other activities are conducted by the existing health facility staff.

4. How are side effects monitored among CAG members?

The CAG members are briefed on the basic signs and symptoms for side effects and TB, and when the group meets if symptons are observed, then a member is advised to go to the health facility.

5. Who selects the group members for a CAG?

The groups are self-formed; information about the CAG model is communicated via health talks at the health facility level and in the community by the chiefs or at NAPHAM support group meetings. Interested clients seek out their potential fellow members themselves, because they know each other. As a new group, they will go to the health facility together, for registration and screening, to ascertain if they meet the criteria to form a CAG. Additional support from the HSA in introducing interested patients to each other to form a CAG can facilitate CAG formation.

.....

6. In Chichiri and Maula Prisons



6. Why are only stable clients on ART targeted to join CAGs when we know that clients who are pre ART are the cohort with the most defaulters?

In other countries CAGs have eligibility criteria, that includes pre-ART patients, (Mozambique and Lesotho) so broadening the eligibility criteria in Malawi is feasible, subject to the approval of the MOH.

7. Can work-based CAGs be created?

MSF has not yet explored this option in Thyolo, but the advantage for an employer of facilitating a CAG based in the workplace means that fewer employees will need to go to the health facility to collect their drugs regularly.

8. What about CAG groups targeting teenagers?

The principle of brining teenagers together for drug refill and adherence support is effective, but is preferably done in counsellor/peer educator led groups.

13. LIST OF ANNEXES

| Annex A: | CAG task division grid 22 |
|----------|---------------------------------------|
| Annex B: | Facilitator's manual CAG23 |
| Annex C: | CAG register 23 |
| Annex D: | CAG group card24 |
| Annex E: | CAG facility quarterly report form 25 |
| Annex F: | Quarterly CAG supervision form27 |
| Annex G: | New CAG site assessment form |
| | |

Suggestions for further reading:

http://www.msf.org/sites/msf.org/files/community_models_msf_unaids_joined_report_eng.pdf
http://samumsf.org/priority-dossiers-for-field-projects/
http://samumsf.org/download/bemelmans-comm-supported-models-2014-tmih-pdf/
http://samumsf.org/download/baert-comm-moc-orday-2014-final-voiceover-ppt/
http://samumsf.org/download/bmc-public-health-14-raesschaert-adapting-a-community-based-artdelivery-model-to-patient-needs-in-tete-pdf/
http://samumsf.org/download/geelhoed-utilisation-mcg-by-cag-members-2013-pdf/
http://samumsf.org/download/decroo-cag-4-year-outcomes-2014-tmih-pdf/
http://samumsf.org/download/decroo-distribution-arv-through-patient-groups-jaids-2011-pdf/
http://samumsf.org/download/cag-toolkit-light-pdf/
http://samumsf.org/download/art-adherence-club-report-and-toolkit-khayelitsha/
http://samumsf.org/download/luque-fernandez-effectivenes-patient-adherence-groups-plosone-2013-pdf/
http://samumsf.org/download/luque-fernandez-effectivenes-patient-adherence-groups-plosone-2013-pdf/
http://samumsf.org/download/wilkinson-art-adherence-clubs-sahivsoc-2013-pdf/

Annex A

CAG TASK DIVISION GRID

| CADRE | TASK |
|--|--|
| Nurse/clinician (MA, CO or MD) | Clinical consultation of CAG representative Decide upon the eligibility for an individual PLHIV to join a CAG Prescribe ART for all CAG members Follow-up CAG representative during the clinic visit on adherence and clinical outcomes for other CAG members |
| HSA | Dispense* ART to CAG representative (if not done by nurse or clinician) Blood collection for CD4/VL/other Collect and enter data into health facility-specific ART database/ updating ART master cards and ART register Promotion of CAGs at health facility Identify CAGs facing challenges Conduct quarterly supervisory visits to CAGs in their village |
| Health Facility CAG focal person | Training of new staff members on CAG model Promotion of CAGs at health facility Support the establishment of CAGs Analyse and report on CAG outcomes back to health facility staff (CAG facility quarterly report form) Consult with and report to health authorities Continuous quality improvement of CAG model |
| CAG Focal of focals | Conduct regular support visits to groups under their responsibility Assist the CAG group leader with technical issues in regards to the CAG functioning Liaise with the HSA responsible for the village |
| CAG group leader | Fill out the CAG group card Support & counsel CAG group members |
| PLHIV support group leaders, CAG members, expert clients | • Promotion of CAGs in the community |
| The ART/PMTCT coordinator or deputy ART/PMTCT coordinator | Organise regular meetings with team members in the CAG program Analyse and evaluate CAG data Supervise health workers on biannual basis on CAG activities Organise initial trainings and briefings to health centre staff, HSAs, HIMS staff CAG focal point and expert clients Conduct home visits with individual members if the needs arises Report to the DHO and HIV/ART technical working group Ensure follow-up of patients with negative outcomes Continuous quality improvement of the CAG program and organise possible roll-out of CAGs after pilot |

 As per the Recommendations and guidelines for the management of task shifting to health surveillance assistants in Malawi, 2014 p 34 task shifting to HSAs the provision of ART - adults and children over 25 kg.

CAG FACILITATOR'S MANUAL



Annex C

Sample page of CAG register

| | | | | | | | 1 | | | | | | |
|-----|------------|------|-----|-----|-------------|-----------------------|-----------------------------------|---------------------------|--------------------------------------|-------------------------------|---|------------------------------|---|
| No. | ART No. | Name | M/F | Age | Name of CAG | Group (CAG) No. | Date the pat joined the CAG | ART initiation date | Adverse ART outcome (which) | Date of adverse outcome | Returned to conventional care / moved to another CAG / other | Date of changed status | Reason for change (write not known OR reason) |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |

Annex D

Community ART group (CAG) card

| these questions: 1. Is the member: Adherent? Coughing? Pregnant? 2. Partners/childree Note: Record probl | Having d Having s en of the memb | | Thytolo District Health Office |
|--|--|-----------------|---------------------------------------|
| neter necold probe | | | |
| Members ART No. | Outcome | Date of Outcome | Health facility: |
| Members ART No. | Outcome | • | Health facility: Group (CAG) Name: |
| Members ART No. | Outcome | Date of Outcome | |
| Aembers ART No. | Outcome | Date of Outcome | Group (CAG) Name: |
| Members ART No. | Outcome | Date of Outcome | Group (CAG) Name: Village: |

Back view of a group card

Front view of a group card

| fear: | Date: | / | / | / | / | / | / | / | / | / | / | / | / |
|------------------|------------|------------|------------|------------|------------|------------|------------|------------|------------|------------|------------|------------|------------|
| ART#/Members Nam | ne/Regimen | Pills left |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| /ear: | Date: | / | / | / | / | / | / | / | / | / | / | / | / |
| RT#/Members Nam | ie/Regimen | Pills left |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |

Inside the CAG group card

Annex E

Community ART Group – Facility Quarterly Report Form

| Name of the Health facility: | Compiled by: |
|--|-------------------|
| Q/year: | Date: |
| Variable | Figure/percentage |
| New CAGs (groups) registered in the quarter | |
| New CAG members registered in the quarter | |
| CAGs(groups) dissolved/disintegrated in the quarter | |
| Cumulative CAGs (groups) registered at the Health Facility | |
| Cumulative CAG members at the Health Facility | |
| Cumulative alive CAG members at the health Facility | |
| Percentage of alive CAG member out of the total alive ART c of the Health facility | ohort % |
| Viral Load: | |
| Number of VL test taken | |
| Out of VL taken, number VL > 1000 copies/mls | |
| Number attended EAC: | |
| Number referred for 2nd line: | |
| Outcomes: | |
| • Died | |
| Defaulters | |
| Transfer Out | |
| Returned to conventional Care (RCC) | |
| | 1 |

Observations/Comments:

Annex F

QUARTERLY CAG SUPERVISION FORM

To be used by CAG Supervisor

| CAG Name/Village/TA: | | | | | |
|----------------------|-----------------|--------|------|------|--|
| | CAG Name/Villad | ae/TA: | | | |

CAG FUNCTIONING

| Meetings | | Pill count | | Drug collection | | | |
|---|--------------|-----------------------|--|---|-----------------|--|--|
| Before refills Y / N | | Same pill count Y / N | | Member refused to collect drugs during his/her turn | | | |
| After refills | Y / N | lf no, why? | | If yes, who and why? | | | |
| If no, why? | | - | | | | | |
| Did the group miss | review date? | | | Y / N | How many times? | | |
| Did the representative communicate wrong review date? | | | | | | | |
| Were all members taken baseline VL? | | | | | | | |

If no, how many remaining and why?

| Any r | relationship problem in the group? | Y / N | |
|-------|------------------------------------|-------|--|
| | If yes, state it and wayforward: | - | |

Any problem representatives face at the health facility? Y / N

If yes, explain:

GROUP CARD

| Is the meeting date indicated correctly on the group card? | Y/N |
|--|-----|
| Pills left indicated correctly on the group card? | Y/N |
| Are the assessment questions asked during every meeting? | Y/N |

If not, why?

| Is the group card in a plastic pouch and clean? | Y / N | |
|---|-------|--|
| GENERAL | | |
| Any other problem in the group? | Y/N | |

Any other problem in the group?

If yes, explain:

| Were | e there issues discussed with members or group? | Y / N | |
|------|---|-------|--|
| | If yes, explain: | | |

| Any | other activity the group is doing apart from ART refills? | Y / N | |
|-----|---|-------|--|
| | If yes, explain: | | |

If yes, explain:

Annex G

NEW CAG SITE ASSESSMENT

Name of the Health facility

| 1. | Human Resources in Health | |
|----|---|--|
| | How many health workers and with which Cadre? | |
| | Clinicians: | |
| | Nurses: | |
| | HSAs: | |
| | Hospital attendants: | |
| | Ground workers: | |
| | Security Guards: | |
| | Other: | |
| | How many are active in HIV care cascade? | |
| | How many HSA trained for ARV? | |
| | How many HAS/Hospital attendants trained in Viral Load sample collection? | |
| | Total number of Staff? | |
| 2. | Health Centre organization | |
| | Specific day for ART refill? | |
| | • Specific day for new initiations? | |
| 3. | Pharmacy: | |
| | How is it organized? | |
| | How much stock out of ARVs? | |
| | CPT: | |
| | Condoms: | |
| 4. | ART register: | |
| | • Quality of the register? | |
| | How many patients are alive on ART? | |
| | • Where are people coming from? | |
| 5. | Patient flow for ART patients? | |
| 6. | Clinicians, Nurses and HSAs: do they agree to start CAGs in the HC? | |
| 7. | Number of villages in the catchment area? | |
| | Other Local leaders. CBO, ADC, VDC etc.: | |
| 8. | Other | |



The Community ART Group (CAG)



STEP 1: IN THE COMMUNITY

Before ART drug refill, CAG members meet to report on their pill count, discuss their health & adherence issues and select a representative to go to the health facility.



STEP 3: BACK IN THE COMMUNITY

The CAG representative distributes the drugs, sets next appointment dates and reports back on any issues from the health facility. CAG works in 3 steps



All photos: Marco Longari

MSF Malawi

Po Box 30353, Chichiri, Blantyre, 3 Office: +265 1 844 409 Email: msfocvb-blantyre-advocacy@brussels.msf.org

www.msf/org/malawi