Community ART Group Toolkit

Kingdom of Lesotho

Taking antiretroviral treatment closer to home
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 decentralization of services to health centres and health posts, providing longer drug supplies to patients and drug refills through fast track systems, have been implemented to reduce the burden on health workers and patients. Community ART Groups (CAGs) are another such strategy for ART distribution, whereby groups of patients rotate for drug refill at the clinic while dispensing drugs to their peers in the community and ensuring peer support.

This toolkit is aimed at Health Care Workers and Community members in Lesotho who have decided to adopt CAGs in their setting. The kit gives practical tools that will be used to implement CAGs in their setting.

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1P A R T

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2. HOW CAGs WORK

CAGs are self-formed groups of HIV positive patients who take turns to collect drugs at the health facility for themselves and the other members of the group, whilst ensuring yearly clinical assessment and monitoring tests. The CAG provides a means of accessing ART for the group members and a source of social support. CAGs can have up to 12 members.

The following steps are repeated when patients are coming for drug refill (according to the duration of the drug supply, ideally every 2 / 3 months):

**STEP 1** CAG meeting in the community before collection of ART by the group representative.
Patients meet at the home of a CAG member or another Community venue to report on their adherence and health and discuss daily issues. The members choose a representative to go and collect drugs for the group at the clinic.

**STEP 2** CAG representative reports to the health facility.
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 another Community venue, where the group representative distributes the drugs to each CAG member and shares any information from the health facility.

There are 2 options to ensure timely clinical consultation and laboratory monitoring for CAG patients:

**Option 1** Routine viral load and yearly clinical consultation for all members on the same day
Routine viral load is the recommended monitoring strategy for patients on ART. CAG patients should all come together once a year for a viral load test and clinical consultation. There will be a need to decide on a medium time between the first due date and the last due date for blood drawing of the individual members to determine when the annual visit will occur. From there, the group would come yearly for blood drawing and clinical consultation and alternate amongst each other to come for refills in the meantime. The group should receive their ART refill on the day they come for clinical consultation and viral load test.

**Option 2** CD4 count every 6 months and yearly clinical consultation for all CAG members on the same day
If patients are monitored through CD4 count, CAG members will come all together every 6 months for their CD4 test (as recommended in the clinical guidelines). On the same day of one of these 2 visits for blood drawing, all CAG members should have their yearly clinical consultation. There will be a need to decide on a medium time between the first due date and the last due date for blood drawing of the individual members to determine when the annual visit will occur. The group should receive their ART refill on the day they come for clinical consultation and/or CD4 test.

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.
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 for those in CAGs. In other settings where CAGs are implemented, the CAG model also works with longer refills – it does not have to be a monthly pick up.

- 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 other settings where CAGs have been successfully implemented these tasks have most commonly been performed by Village Health Workers, lay counsellors or a LENA50 focal person.

- 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 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 and support drug supply. A form should be used at the community level for self-monitoring and a list should be kept at the health facility to keep track of who is in the CAGs. The ART register, as for all patients, will be the tool to monitor retention in care and clinical outcomes. A column could be added in the ART register to mention if the patient is a CAG member (Yes/No).

- Buy-in from the clinic staff. The acceptance of the health staff to use additional mentoring materials can raise issues. It is then utterly important to ensure buy-in from the staff before implementing new tools. A presentation of the additional tasks to be implemented by the clinic staff should mention the advantages of the CAG (reducing workload and decongesting health facilities).

PART 2
How to implement CAGs at health facilities

1. ANALYSIS OF THE SITUATION

Lesotho is a small kingdom situated in the southern part of Africa and is completely surrounded by the territory of the Republic of South Africa. Although small and mountainous, it has a population of approximately 2,171,000 and a GNI per capita of 1,380 USD (2012), with 57% of people estimated to be living on less than USD 1.25/day. Lesotho faces some of the most extreme health challenges in southern Africa, nearly all of which are driven by the country’s devastating HIV and TB epidemics. Lesotho has the third highest HIV prevalence in the world (after Swaziland and Botswana) and is the poorest of the three.

According to the Demographic Health Survey performed in 2009, 23 percent of adults age 15-49 in Lesotho are infected with HIV. The prevalence of HIV infection is 27 percent for women age 15-49 and 18 percent for men age 15-49, with an estimated 16,000 – 20,000 deaths among this group annually. The scourge has also contributed to the male and female life expectancy of 46 and 50 years respectively. Of those thought to be in need of ART, it is estimated that only 51% are currently accessing it.

The government of Lesotho declared HIV/AIDS a national emergency in 2000 and launched a national response. The government has continued to target significant resources towards combating the pandemic. During the 2009/2010 financial year alone, an estimated USD 108,412,653 was directed towards this fight. While services have scaled up and access improved, the ability to do this has been hampered by chronic understaffing and inadequate infrastructure in the healthcare system. In 2009, there was one physician for every 17,000 people while the nurse to population ratio was 1:2,226. Retention on ART is also a challenge; in rural Lesotho 55.4% were reported to be alive and on treatment at three years on ART, 13.5% had died, and 30.9% were lost to follow-up.

Barriers to accessing ART services and retention have been assessed through group discussions with patients and healthcare workers in Nazareth health centre.

2. DEFINING ELIGIBILITY FOR CAGs

CAGs will be started with stable patients who have been on ART for more than 6 months and have a viral load less than 1000 copies/ml. If routine VL is not available patients with CD4>200 should be eligible for CAGs.

<table>
<thead>
<tr>
<th>CURRENT ELIGIBILITY CRITERIA FOR CAGS</th>
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<tbody>
<tr>
<td>More than 6 months on ART (more than 3 months on current regimen 1st or 2nd line)</td>
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<tr>
<td>Viral load &lt; 1000 copies/ml or CD4 count &gt;200 cells/μL, stable patients with no current evidence of immunological or clinical failure</td>
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<tr>
<td>Any patient on an adult dose of ART</td>
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<td>Pregnant or lactating women if attending for ANC/PNC follow-up at clinic</td>
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<td>No active TB in the intensive phase of the treatment (Patient can join CAG after the intensive phase)</td>
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<tr>
<td>No other active opportunistic infection</td>
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</table>

Active members can get their drug refills through CAGs and come to collect ART for other group members.

Patients who do not or no longer fulfil eligibility criteria can stay in 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. Once the patients fulfill the screening criteria again they can join or rejoin the CAG as an active member.

Dependent members are patients who can get their refills through the CAG, go with the CAG representative to the clinic for clinical follow-up, but cannot go unaccompanied to collect drugs for other members.

This is the case for:
- Patients below 18 years old on a stable (non-weight dependent) adult dose of ART
- People suffering from mental disability.

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.

CAGs are piloted in other settings for non-stable patients, pre-ART patients, children and adolescents. Further data may allow adaptation of eligibility criteria for CAGs once the current model has been successfully implemented.
3. 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 temporary 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 evidence of clinical, immunological failure or virological failure

4. DEFINING THE CAG ANNUAL VISIT SCHEDULE

The visit schedule for CAG members takes into consideration the maximum benefit for patients as well as for healthcare workers, ensuring the minimal clinical follow-up. It is recommended that CAG members attend for a clinical consultation and viral load monitoring once a year.

In case there is no routine viral load, patients will have a yearly clinical consultation and 6 monthly CD4 test or toxicity monitoring. When possible, stable patients should receive 2 to 3 months refill. If the setting does not allow such flexibility, CAG members will receive minimum 1 month of drug refill. Depending on the number of members in the group and the timing in between refills, this model can be adapted.

Option 1: Annual cycle for Routine Viral load and clinical consultation annually all together with 2 months refills

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Option 2: Annual cycle for 6 monthly CD4 and yearly clinical consultation all together with 1 monthly refills

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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.

All patients get their viral load / CD4 test and clinical consultation on the same day. The CAG representative going to the health facility on the next refill date brings back the results to the group.
5. 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 during ART preparation sessions and during the counselling sessions in the first few months on ART, through health promotion in the health facility waiting area, through existing community channels like Village Health Workers, Pitsie (Public Gathering) and Community leaders.

The more people are aware, the easier it becomes for groups to form. 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 1 provides an example of a health talk to promote CAGs in Seisotho

6. SCREENING AND ESTABLISHING CAGs

The nurse should screen patients 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 (for example the VHW of the area).
- 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. In this case, screening could be done during the training.

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 Counsellors and Village Health Workers will have a key role in bringing interested patients together and to facilitate disclosure within these smaller groups.

Assisting in the establishment of CAGs is an important task to ensure successful implementation of CAG.

Interested and volunteer patients will be advised to form groups up to 12, elect a group focal person and bring their Bukana to their Village Health Workers or Health Centre for documentation in the patient file, creation of a CAG folder and booking for training.

The CAG group focal person is a CAG member who ensures the good functioning of the group and acts as a contact person with the health facility. The CAG focal person is elected by the CAG members.
7. PREPARING HEALTHCARE WORKERS AND VILLAGE HEALTH WORKERS

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

Explanatory sessions will be given to CAG focal persons and the VHW before implementation. A supportive session should be repeated after 6 months to report back, express challenges and find solutions.

The CAG model means a shift in thinking of healthcare workers and patients and therefore implementation needs strong support from the start.

8. TRAINING OF CAGs

Training for new CAGs 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

There are 2 ways to train CAGs:

- All members of the CAGs will receive training at the health facility. On this day, they will also receive their drug refill, to align the yearly visit schedule. This training could also happen at community level.
- Only the CAG group focal persons from each group are invited for a formal training. They are then given the responsibility to inform the other members of their CAG, and bring to the community the first refill for the group.

See:
- Annex 2: Training for CAG members

9. MONITORING OF CAGS

National Monitoring and Evaluation tools will be used for all CAG members as they are for all ART patients.

- At each CAG group representative visit, the Nurse will fill in the Ministry of Health (MoH) individual patient ART card and the patient’s Bukana. The Nurse indicates drug prescription and dispensing of drugs on the CAG Community form for each member.
- Appointment of the next group representative is recorded in the Appointment book.

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

- CAG members’ patient files are gathered in a CAG folder and a folder summary sheet is opened to be able to follow-up the number of members in a CAG.
- Before every refill visit, CAG members fill in the CAG community form. This information is shared by the CAG representative with the healthcare worker at the clinic.
- To follow-up the size of the group, rotation of group representatives and appointments attendance (identify any no-show CAGs) a CAG facility register can be used (not compulsory). It should be filled in by the Counsellor or Nurse when the CAG is formed and updated at every group representative visits.
- The CAG focal point of the Health Facility fills in the quarterly CAG report and transmits information to the CAG Steering Committee of the district composed of representatives from DHMT and partners.

See:
- Annex 3: CAG folder summary sheet
- Annex 4: CAG community form
- Annex 5: CAG facility register (optional)
- Annex 6: CAG quarterly report
10. 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 VL >1000 copies/ml for more than one member
- CAG member deceased or lost to follow-up
- Same representative always presenting for refill (even though some flexibility should be allowed)
- Conflicts or problems within the group dynamic
- CAG community form incorrectly completed

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

See Annex 7: Red flag support visit form

11. INVOLVING LESOTHO NETWORKS OF AIDS SERVICES ORGANISATIONS

It is important to involve civil society in the development and implementation of CAGs. They can play an important role in:

- Binding health facilities and communities, including leadership
- The promotion and formation of CAGs
- Linking CAGs to other initiatives such as income generating activities and treatment literacy
- Strengthening the voice of PLWHIV within communities
12. DEFINING ROLES AND RESPONSIBILITIES

Different staff members will need to be involved in supporting CAGs to ensure optimal functioning. 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 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. The following table suggests who of existing cadres could perform the different tasks.

WHO DOES WHAT

<table>
<thead>
<tr>
<th>Nurse</th>
<th>Counsellor/VHW</th>
<th>CAG Member</th>
<th>DHMT/CAG focal point</th>
<th>Dispenser/Pharmacist</th>
<th>LENASO focal person, CBOs and NGOs</th>
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</thead>
<tbody>
<tr>
<td>Promotion of CAGs at health facility</td>
<td>Promotion of CAGs at health facility</td>
<td>Promotion of CAGs in the community</td>
<td>Verify data, conduct quality assurance exercises</td>
<td>Dispense ART for all CAG members</td>
<td>Support the establishment of CAGs</td>
</tr>
<tr>
<td>Decide upon eligibility for CAG of individual patients</td>
<td>Support the establishment of CAGs</td>
<td>Attend community CAG meetings</td>
<td>Ensure CAG standards are being maintained</td>
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<tr>
<td>Support the establishment of CAGs</td>
<td>Train CAG members on the use of CAG tools</td>
<td>Go to the health facility for clinical consultation and VL/CD4 test</td>
<td>Analyse and report on CAG outcomes back to the health facility staff</td>
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<tr>
<td>Train CAG members on the use of CAG tools</td>
<td>Follow-up CAG representative at clinic visit on adherence and outcomes of other CAG members</td>
<td>Collect medication for the group</td>
<td>Consult with and report to health authorities</td>
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<tr>
<td>Follow-up CAG representative at clinic visit on adherence and outcomes of other CAG members</td>
<td>Identify CAGs with problems</td>
<td>Report on adherence and health of other CAG members</td>
<td>Training of new staff on the CAG model/Training of trainers.</td>
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<tr>
<td>Identify CAGs with problems</td>
<td>Follow-up of CAGs with problems at health facility/community</td>
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<tr>
<td>Clinical consultations</td>
<td>Collect and enter data into setting-specific ART database</td>
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<tr>
<td>Prescribe ART for all CAG members</td>
<td>Promotion of CAGs in the community</td>
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<tr>
<td>Dispense ART for all CAG members</td>
<td>Collect and enter data into CAG Community Card</td>
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<tr>
<td>Blood collection for CD4/VL/other</td>
<td>Enter data in the CAG summary sheet and the quarterly report</td>
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<tr>
<td>Collect and enter data into ART register and bukanas</td>
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</table>
13. THE CAG FLOW ON ART COLLECTION DAY

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

- The group meets on the same day or on the day before the ART refill date at the home of a CAG member or another community venue (depending on the distance to go to the health facility)
- Each member of the group reports on her/his adherence which is then documented on the CAG community form (pill count) and signs the form.
- Each member is asked simple health screening questions (regarding: TB; pregnancy)
- 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.
- The group representative collects the Bukanas of all members and takes the community form

STEP 2
CAG representative reports to the health facility

- On a rotational basis, a CAG representative reports to the clinic.
- The group representative will be seen by different healthcare workers:
  - With the counselor
    - The representative will:
      - Present the information on the CAG Community form;
      - Report back on the adherence and health of other CAG members;
      - Report on group dynamic.
    - The counselor will:
      - Pull out CAG folder;
      - Red flag a group in need of support;
      - Update the CAG Register (if it is in use at the health facility);
      - Report to the Nurse any problem encountered by a member who needs clinical follow-up.
  - The nurse will:
    - Update the group representative patient file;
    - Review the CAG Community form. Any member requiring additional clinical follow-up should be identified and asked to attend the clinic;
    - Update ART register;
    - Update the Bukanas of the non-present members;
    - Update ART card for all CAG members, writing prescription and dispensing of drugs;
    - Share results of recent blood tests with group representative, so they can be reported back to the CAG members;
    - Do a clinical examination and draw blood for all members when they come together once a year.
  - The group representative will:
    - Collect the drugs at the pharmacy.

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 the CAG group monitoring form to confirm that they have received their drugs.
LIST OF ANNEXES

Tools enabling the smooth implementation of CAGs are available on the SAMU website: www.samumsf.org. You can find, in the following folder, tools specifically adapted for the Lesotho context:

Annex 1: Health promotion for CAGs (in Sesotho)  
Annex 2: Training for CAG members  
Annex 3: CAG folder summary sheet  
Annex 4: CAG Community card (in Sesotho)  
Annex 5: CAG register  
Annex 6: CAG Quarterly report  
Annex 7: CAG red flag visit form

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