

1 Title

2 Scaling Up Community ART Groups in Mozambique

3

4

5 SUMMARY

6 The ability of the health sector to respond to the pandemic in SSA has been
7 compromised by severe human resource for health (HRH) shortages. To

8 improve the accessibility and affordability of antiretroviral therapy (ART) the

9 Provincial Directorate of Health and Médecins Sans Frontières piloted a
10 community-based and patient-driven model for HIV care in Tete province,



11 Mozambique, to improve retention on ART. The Community ART Group

12 (CAG) strategy was designed to empower patients to take responsibility for

13 community ART delivery, and to overcome patient reported barriers to

14 monthly drug refills. In this paper we will describe the stepwise implementation

15 and roll out of CAG. The first CAG commenced in 2008, in rural health facility

16 catchment areas, where members of CAG shared transport costs to overcome

17 distances to the ART clinics. In 2009, lessons learnt were exported in Tete

18 province and CAG were launched in semi-urban contexts to decrease time

19 spent in the clinics. In 2011, retention rates as high as 97,5 % convinced a

20 joint task force that included MOH and major partners to pilot the CAG

21 strategy on a national scale. Success of scale up will depend on the between

22 policymakers, donors, health-managers, caregivers, communities, and

23 patients.

24 **Key words:** HIV; antiretroviral therapy, highly active; task shifting; health
 25 services accessibility; patient participation; peer group

26

27

28 **Introduction**

29 Scale-up of antiretroviral therapy (ART) in sub-Saharan Africa (SSA) over the
 30 past decade has been nothing short of spectacular, but it is not enough. Of
 31 the region's 10.5 million people in need of treatment, less than half are on
 32 ART. The pandemic has decimated the ranks of farmers, teachers, doctors,
 33 nurses, young entrepreneurs and the future leaders of many nations, with a
 34 staggering 1.2 million HIV attributable deaths in SSA in 2010 alone.¹ The high
 35 mortality is the result of low treatment coverage and poor retention of patients
 36 initiated on treatment. A recent meta-analysis from over 17 countries in SSA
 37 revealed that patient retention was 70% and 65% at 24 and 36-months
 38 respectively.² All of the world's high HIV prevalence countries are saddled
 39 with severe human resource for health (HRH) shortages. The ability of the
 40 health sector to respond to the pandemic in SSA has been further
 41 compromised by the current provider-centered biomedical model for HIV care.
 42 While such models were designed to provide periodic, time-limited services
 43 such as vaccinations and manage acute diseases such as malaria, they are
 44 ill-equipped to support chronic disease programs and to ensure optimal
 45 patient retention.

46

47 With these perspectives in mind, in 2011, the Mozambique Ministry of Health
 48 began reshaping the traditional model of HIV care through the development of
 49 a patient-centered model inspired by a **Community ART Groups (CAG)** pilot in
 50 Tete province. This community based strategy was designed in 2008 in Tete
 51 province to empower self-managed patient groups to deliver antiretroviral
 52 therapy. In this paper we describe the stepwise implementation of CAG in
 53 Mozambique, and how lessons learnt from an innovative small-scale
 54 intervention were exported to the national level, to become a national strategy.
 55 The data on CAG were obtained through a chart review and routine data-
 56 collection.

57

58 **Background**

59 From 2003 to 2011, 397,671 patients started life-saving ART therapy in
 60 Mozambique and as of December 2011, 273,561 remain active on treatment.³
 61 This marks an exponential increase in access to ART, undoubtedly saving
 62 thousands of lives. However, with national-level studies estimating 12-month
 63 patient attrition at 26%, there are serious concerns about the current health
 64 care model's ability to retain patients on treatment in the long-term.⁴ A study
 65 done in Mozambique documented significant loss to follow-up (LTFU)
 66 observed at each step from HIV testing to treatment - also known as the
 67 leaking cascade. Only 56% of Mozambican patients testing positive enrolled
 68 in HIV care, and only 31% of patients living with HIV/AIDS (PLWHA) eligible
 69 for ART started treatment within 90 days of eligibility.⁵ Studies examining the
 70 principal barriers to accessing ART in Mozambique have identified long

71 distances to health facilities, transport constraints, food insecurity, low levels
 72 of knowledge around HIV, and lack of access to health facilities as the most
 73 commonly cited reasons for ART discontinuation.⁶ One study conducted in
 74 central Mozambique highlights the challenges health facilities confront in
 75 attending burgeoning patient populations. In this study, high volume ART sites
 76 were found to have greater attrition than lower volume sites and a dose-
 77 response effect was identified associating levels of health facility staff and
 78 patient retention.⁷ As in many countries, these problems have been
 79 addressed in Mozambique through adoption of task-shifting strategies,
 80 including non-physician medical technicians taking over the administration of
 81 ART traditionally handled by medical doctors, thus mitigating the effects of the
 82 HRH shortage.⁸

83

84 These strategies, however, are unlikely to adequately address the challenges
 85 of an ever-growing ART population in a country that has goal of providing
 86 universal access to ART for PLWHA by 2015. It is imperative to develop out-
 87 of-clinic approaches to complement traditional task-shifting schemes. One
 88 such strategy based on a pilot model in the central Mozambique province of
 89 Tete proposes shifting key aspects of care and treatment responsibilities to
 90 Community ART Groups.

91

92 **Stepwise Implementation of CAG**

93 Tete Province has a large geographic area of 100,724 km² and a population
 94 of 2.1 million inhabitants, of which approximately 7.5% are HIV-infected.⁹ With
 95 over 90% of the population living in rural settings and only 32 of 105 official
 96 MOH health facilities offering ART, access to HIV/AIDS care and treatment
 97 services is a major obstacle for ART initiation and long-term retention. After
 98 noticing alarming rates of attrition from the ART program in 2007, health
 99 officials in Tete conducted a bottleneck analysis, which revealed a 21% LTFU
 100 rate among ART initiates who started treatment between May 2002 and
 101 August 2007.¹⁰ Even more alarming was the subsequent finding that over half
 102 of the successfully traced LTFU population had died.¹⁰ Despite significant
 103 investment in training volunteers, liaising with community-based
 104 organizations, and working to improve the quality of facility-based counseling
 105 services, retention of patients remained low.

106 

107 Realizing that a fundamental modification was necessary, the provincial health
 108 team in Tete, supported by Médecins Sans Frontières (MSF), began to look at
 109 ways to address the underlying barriers to patient retention. Drawing on the
 110 robust body of chronic care literature and contemplating the potential
 111 implications and impact of a model designed to empower patients to care for
 112 themselves, the CAG strategy emerged.^{11,12,13} To overcome barriers to
 113 monthly prescription pick-ups, stable patients on ART would be encouraged to
 114 form CAG that would serve as a vehicle for community ARV distribution,
 115 adherence promotion, monitoring and reporting.

116

117 In February 2008, the provincial pilot commenced in rural health facility
 118 catchment areas where ART was not yet available and LTFU rates were high.
 119 Local nurses, volunteers and community leaders were asked to invite known
 120 PLWHA to a community meeting with counselors to explore and document
 121 barriers to HIV service uptake. These discussions revealed three principal
 122 obstacles: 1) distances to health facilities, 2) costs of transport; and 3)
 123 availability of transport options. Noticing that the PLWHA enjoyed the social
 124 nature of the discussions and were, to a large extent, from the same
 125 communities, a suggestion was made to work as a team to overcome the
 126 herence obstacles. PLWHA were asked to invite other known HIV positive
 127 individuals including family members, friends and neighbors to a follow-up
 128 meeting. There, the CAG strategy materialized as PLWHA began forming
 129 groups based principally on members' natural affinity (belonging to the same
 130 social network), and common needs as patients. A maximum of six members
 131 per group were registered on CAG group cards, one copy of which would be
 132 held by the members of the group themselves and the other of which would
 133 remain at the health facility for use by care providers. The CAG agreed to
 134 meet monthly to verify and register member adherence (evaluated via pill-
 135 count) on the group card and to send one representative each month using
 136 pooled resources to the health facility to retrieve ARV prescriptions for all
 137 group members. At the health facility, the representing CAG member would
 138 communicate to the clinician or counselor any important events occurring in
 139 the lives of the other members, have a routine consultation, and receive a
 140 treatment refill for all the group members of his or her CAG. Every six months
 141 groups met locally in the community or at the health facility with the counselor

142 and the clinician. During these meetings, experiences, difficulties and practical
 143 solutions were shared, and counselors and nurses educated CAG on issues
 144 such as the importance of unscheduled consultations whenever a member
 145 became ill. In this way, the strategy created a feedback loop between the
 146 provider and the community, assuring ownership by the communities, and
 147 creating an opportunity for the health provider to empower CAG members and
 148 guide the process of community participation. Once the first CAG were
 149 established, newly initiating ART patients began presenting themselves to
 150 CAG focal points in communities expressing their desire to become members.
 151 In this rural and poor context the advantages of social support outweighed the
 152 application of clinical inclusion criteria. PLWHA often joined CAG having not
 153 yet completed six months on ART and with CD4 counts below 200 cells per
 154 μL .



155

156 Drawing on this first CAG experience, health officials in Tete subsequently
 157 extended the option to participate to patients living in semi-urban communities
 158 in closer proximity to major ART sites. While this demographic did not
 159 experience the same adherence barriers as their rural counterparts (transport
 160 costs and long distances to health facilities), CAG was a means of reducing
 161 time spent at health facilities and the stigma tied to frequent clinic visits.
 162 Health officials implemented CAG in major ART sites using a process similar
 163 to that employed in the rural context: lay counselors met with patients to
 164 understand perceived barriers to ART follow-up and subsequently proposed
 165 CAG as a means to facilitating long-term adherence to treatment. In semi-
 166 urban communities access was less problematic than in rural communities,

167 and clinical inclusion criteria were applied. Participation in CAG was offered to
168 clinically stable patients. Interested candidates were screened to ensure they
169 were more than six months on ART, had a CD4 count more than 200 cells per
170 μL , and without active opportunistic infection. Each group was registered on a
171 CAG group card similar to one that had been successfully employed in the
172 rural context.

173

174 To assure consistency and proper monitoring, a mobile team composed of
175 provincial CAG program managers consistent of a senior counselor and a
176 senior clinician visited each health facility implementing CAG on a monthly
177 basis, providing technical support as needed. Provincial health partners also
178 met regularly to review and discuss obstacles and achievements as well as to
179 fine-tune implementation details such as inclusion criteria, data collection and
180 monitoring tools.

181

182 To document this innovative strategy a chart review was conducted as part of
183 a retrospective cohort study. Of the 1301 patients enrolled in 291 CAG
184 between February 2008 and May 2010, 1269 (97.5%) were remaining in care,
185 30 (2.3%) had died, and 2 (0.2%) were lost to follow-up. Median follow-up
186 time within a group was 13 months. The chart review confirmed that all
187 patients that had died or that had abandoned treatment had been reported by
188 the CAG members. The results of this retrospective cohort study and a
189 description of the CAG monitoring tools were published elsewhere.¹⁴ By the
190 end of June 2012, the number of members enrolled in CAG increased

191 substantially. These early results have been sustained over time, with 4700
 192 (96%) of 4895 members still in care by June 2012 (routine project data) LTFU
 193 rates remained low, as CAG members knew each other's whereabouts and
 194 reported deaths and adherence challenges to health staff as they occurred.
 195 The CAG dynamic is illustrated in Figure 1.

196

197 **Figure 1**  **Link between the members of a Community ART Group and the**
 198 **health facility.**

199

200 This simple patient-driven and community embedded ART care model had
 201 profound benefits for the patients and the health system. First, health workers
 202 reported **reduced work burden resulting from CAG members sending**
 203 **representatives to retrieve pharmacy prescriptions**  **behalf of other group**
 204 **members. Second, both health workers and patients reported the**
 205 **improvement in the quality of patient/provider relationships.**  **ird, CAG**
 206 **members' timely and accurate reporting on patient outcomes and adherence**
 207 **challenges led to the availability of more accurate information for use in**
 208 **program planning, management and indicator reporting. Deaths that occurred**
 209 **in the community didn't pass unnoticed, and were reported by fellow CAG**
 210 **members to the clinic staff. As a result of the proportion of patients with**
 211 **unknown treatment outcome among CAG members was less than 1%.**
 212 **Communication between the provider and the patients in CAG was further**
 213 **enhanced through the CAG group card that recorded disease screening**
 214 **results performed by group members and submitted each month to the**

215 clinician seeing the monthly CAG representative. This effectively created an
216 early warning system for disease identification and referral.

217

218 At the community level, a cycle of information sharing was created with
219 PLWHA accessing information through the CAG social network and
220 transmitting knowledge and support to other peers over time. Throughout the
221 provincial pilot, CAG also proved effective as a community-based mechanism
222 for providing mutual psychosocial support and shared information on HIV care
223 and self-management. This, in turn, strengthened the perceived value of
224 health services while simultaneously reinforcing the primary objective of CAG
225 - improved ART patient retention. The sharing of information at the community
226 level not only proved beneficial for patients already initiated on ART but also
227 for patients with unknown HIV serostatus. Frequently, CAG members,
228 recognizing possible HIV symptoms among their peers, encouraged and even
229 referred individuals to local health facilities for HIV testing and care.

230

231 Based on the successes of the CAG model in the province of Tete, in 2011
232 the Mozambican MOH began investigating how the strategy could be adapted
233 for use at the national level. A task force composed of MOH officials and
234 selected partner organizations drafted a national strategy, implementation
235 protocol and monitoring tools to guide the expansion of CAG for the national
236 pilot. In addition, a workshop was hosted in Tete City to present the CAG
237 model to clinical and community-based partners active in other provinces and

238 to provide national health authorities the opportunity to observe the model in
239 the field and interact with patient members.

240

241 Since mid-2011, the start of the national pilot phase, CAG were implemented
242 in 30 health facilities throughout Mozambique. Careful selection of pilot
243 facilities ensured participation of three ART sites of various patient volume
244 stratifications in each of ten provinces excluding the province of Tete. Pilot
245 health facilities were selected for each of three patient volume stratifications in
246 each province. The volume stratification included one site with >1000 ART
247 patients, one with between 500-1000 ART patients, and one with < 500
248 patients. All health facilities were selected based on the following inclusion
249 criteria: Availability of TB services, pre-ART and ART services for at least 6
250 months, at least one nurse and one doctor on site, and access to CD4 testing
251 (either on-site or off-site). The evaluation of the national pilot will focus on
252 three key areas: (1) patient outcomes (alive and on therapy, LTFU, transferred
253 out, stopped); (2) health facility workload (number of registered ART patients
254 seeking services before and after CAG implementation); (3) cost implications
255 of the CAG. In addition the CAG experience for patients and healthcare
256 workers will be evaluated through qualitative interviews and focus-group
257 sessions.¹⁵

258

259 At the end of 2011, three mobile teams, each composed of health managers,
260 lay counselors and CAG members visited all of the health facilities
261 participating in the national pilot to support the implementing health facilities.

262 Questions at both the provincial and health facility level related to the
 263 objectives of CAG, mode of implementation, and use of monitoring tools with
 264 practical solutions proposed by the mobile team members. The team
 265 interacted with the direct implementers and the patients in the waiting area of
 266 each health facility. Health facility results, successes and difficulties were
 267 shared at a national workshop led by the Mozambique MOH and attended by
 268 implementing partners and the members of the mobile teams. As such, a
 269 formal feedback loop was created to analyze and direct the national CAG roll
 270 out. The CAG development and implementation process is illustrated in Figure
 271 2.

272

273 **Figure 2.** Timeline of the launch of Community ART Groups in Mozambique.

274

275 Discussion

276 As high burden countries tackle the enormity of the HIV pandemic, institutions
 277 responsible for treating HIV-infected patients in those countries must adapt
 278 and respond to the structural constraints inherent to weak public health
 279 systems as well as the daily realities faced by poor people living with
 280 HIV/AIDS. Innovative approaches for models of ART care need to be
 281 designed with the reality of sub-Saharan Africa in mind. This includes
 282 adaptations to conform to the context of limited resources, diverse cultural
 283 factors and social integrity, as well as application of adherence  promoters
 284 such as increased understanding of the importance of adherence, increased
 285 sense of self-worth, reminder tools, and community and peer support.^{11,16,17,18}

286 To optimally leverage all available resources, increased attention must be
 287 given to initiatives that partner with patients and established patient
 288 communities. This process involves standardization and simplification of
 289 treatment protocols and elimination of strategies not specifically focused on
 290 reaching the primary objective of initiating and maintaining patients on ART.
 291 Successful implementation of these programs could result in a substantial
 292 portion of the ART management workload being shifted to patients and
 293 communities, allowing the medical staff to focus on clinical case management,
 294 training, and supervision.^{12,19}

295

296 ART care delivery models embedded in the community reduce geographic
 297 barriers to medication refill and service utilization. Community-based ART
 298 care models have the potential to improve accessibility and affordability of
 299 treatment, and to result in a significant decrease in patient volume at already
 300 overburdened health facilities.²⁰ Furthermore, such models allow clinical staff
 301 to dedicate their time to symptomatic patients, ART initiations, and patients
 302 with non-HIV-related illnesses. In Uganda and Kenya community-based ART
 303 care provided by lay staff proved to be as effective as health facility-based
 304 care as measured by retention and response to treatment. Additionally clinic
 305 visits were reduced from an estimated 50% to 75%.^{21,22,23} A study in Uganda
 306 found that community-based ART was associated with multiple positive social
 307 outcomes such as emotional support and relationship strengthening, and did
 308 not increase the stigma in the community.²⁴ This is consistent with other
 309 studies that have recognized community support as a determinant for
 310 improved treatment response and reduction of stigma.^{17,25,26}

311

312 The community-based ART model in Mozambique differed from the care
313 models in Uganda and Kenya. In Uganda and Kenya the community ART
314 provider functioned as an extension of the health facility provider but within
315 the community. In Mozambique, PLWHA organized themselves in a social
316 network of small community support groups, and performed critical functions
317 such as ARV distribution, outcome reporting, referral, and adherence support,
318 motivated by health and psychosocial benefits, without any financial incentive.

319

320 The proportion of CAG members LTFU were lower than reported in the
321 literature.² However, the eligibility criteria that requires patients to be clinically
322 stable and to have been on ART for 6 months before being able to join the
323 program limit the comparison due to survivorship bias. Moreover, the data
324 presented are program data and as such are subject to a number of
325 limitations common to observational studies that threaten the validity and
326 generalizability of the findings.¹⁴ While the low rate of attrition in this program
327 suggests that the approach described herein has clear potential in supporting
328 long-term ART management, questions remain regarding the impact of the
329 CAG model in urban settings, how CAG members interact socially, and the
330 impact of stigma on CAG-uptake in communities. A rigorous quantitative,
331 qualitative and costing evaluation of the pilot will attempt to answer some of
332 these questions. Adaptations of the CAG model are planned to reach
333 particularly vulnerable groups, such as pre-ART patients, children, pregnant
334 woman and patients being treated for tuberculosis.

335

336 Another concern is that the link between the community and the clinics was
337 assured by counselors, remunerated by MSF. Counselors played an important
338 role in the development of CAG, as they catalyzed the enrolment of patients in
339 CAG and voiced the needs of the patients. A solution will need to be found for
340 the dependency of the professional category of counselors, which has not yet
341 been established in Mozambique.

342

343 The Government of Mozambique decided to scale-up nationwide the field
344 experience of Community-Based ART and a national protocol was developed.
345 Interested in the potential of the strategy, The governments of Malawi,
346 Zimbabwe, Swaziland, Lesotho and South-Africa have sent delegations to
347 visit Tete, and plan to adapt the CAG model to their context. In Tete, CASG
348 were implemented as a response to local challenges. Can the strategy that
349 was successful in Tete be applied to other social, cultural and political
350 contexts, inside and outside of Mozambique? Considering that the process of
351 implementation is as important as the evidence on which new protocols are
352 built, Paine and Peters proposed to look at the health system as a complex
353 adaptive system when scaling up effective and efficient health interventions.²⁷
354 Health systems are compromised of many interacting components and actors,
355 such as policymakers, managers, regulators, researchers, caregivers,
356 communities, and patients. Diverse socio-cultural and political factors,
357 changing evidence, characteristics of delivery systems, characteristics of the
358 users, and implementation capacity determine the complexity of the scale up
359 of health interventions in developing countries. The scale-up of CASG is

360 expected to be a non-linear process, marked by uncertainties, and
 361 unexpected events. The cycle of planning, implementation, monitoring, and
 362 evaluation may result in new insights. And, to assure a successful roll out of
 363 this innovative model of community ARV-delivery through patient networks,
 364 PLWHA need to be involved continuously during implementation, as
 365 community participation for HIV care can only be successful when driven and
 366 owned by the patients and the communities.²⁸

367

368 A sequence of events has catapulted a patient-driven community delivery
 369 ART care model from a small-scale intervention in central Mozambique to a
 370 national strategy being supported by the MOH and their partners. Neighboring
 371 countries are exploring how to implement CAG and adapt it to their
 372 environments. However, success of scale up and expansion of CAG will
 373 depend on the collaboration and interaction between policymakers, donors,
 374 health managers, caregivers, communities, and patients.

375

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 377 which was critically reviewed and improved by all the co-authors. All the co-
 378 authors have seen and approved the final version.

379

391

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394 **Ethical approval:** Not required.

395

396 **Legend figure 1: Link between the members of a Community ART Group**
 397 **and the health facility.**

398 Community ART Groups (CAG) consist of a maximum of 6 members.

399 Interested patients can join voluntarily and agree to meet monthly to verify

400 member adherence (evaluated via pill-count), update a group card, and send

401 one representative each month to the health facility to pick up ART for all

402 group members. At the health facility, the representing CAG member would

403 communicate to the clinician or counselor any important events occurring in

404 the lives of the other members, have a routine consultation, and receive a

405 treatment refill for all the group members of his or her CAG. When back in the

community the representative will distribute the ART. During the next months the other members will conduct the trip to the health facility.

Legend figure 2: Timeline of the launch of Community ART Groups in Mozambique.

Community ART Groups (CAG) commenced in 2008 as a small-scale initiative in rural communities to overcome barriers related to distances and transport. In 2009 this patient driven dynamic was adapted to the context of semi-urban areas, where patients joined CAG to spend less time in the queue of the clinics. Retention rates as high as 97,5% after a median time of 13 months in CAG convinced the Ministry of Health of Mozambique to pilot this innovative patient-centered treatment strategy on national scale from 2011 onwards. To assure that this innovative strategy was well understood, all stakeholders including policymakers, managers, regulators, researchers, caregivers, communities, and patients met during a workshop. While a national protocol informed all provincial health teams, a mobile team consisting of health professionals and CAG representatives visited all the provinces and gave support based on their experiences.

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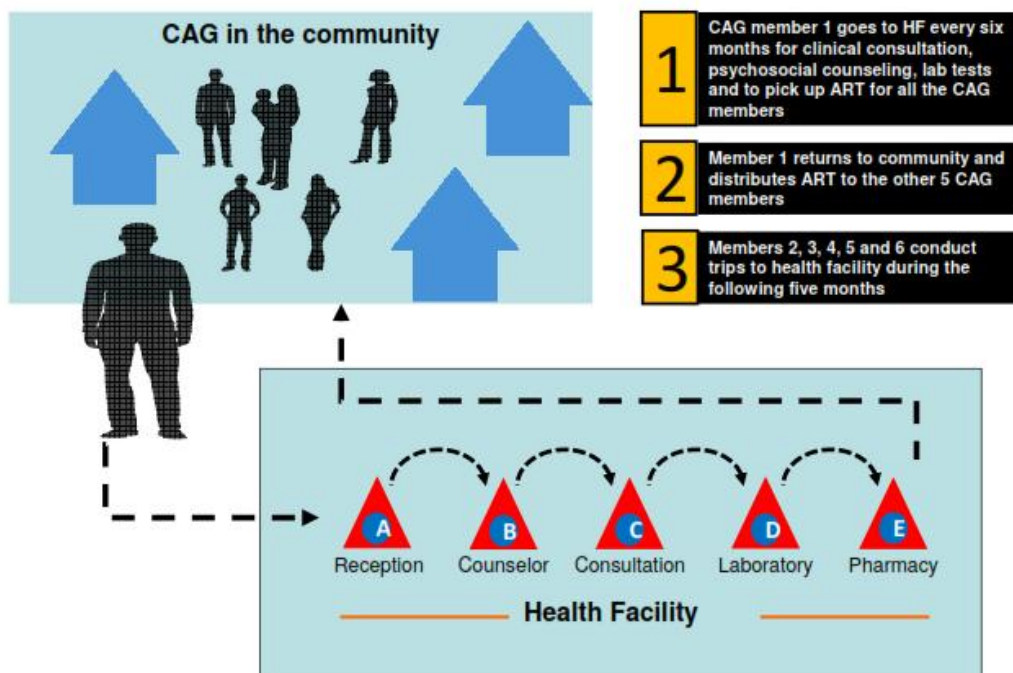
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Figure 1 Link between the members of a Community ART Group (CAG) and the health facility.



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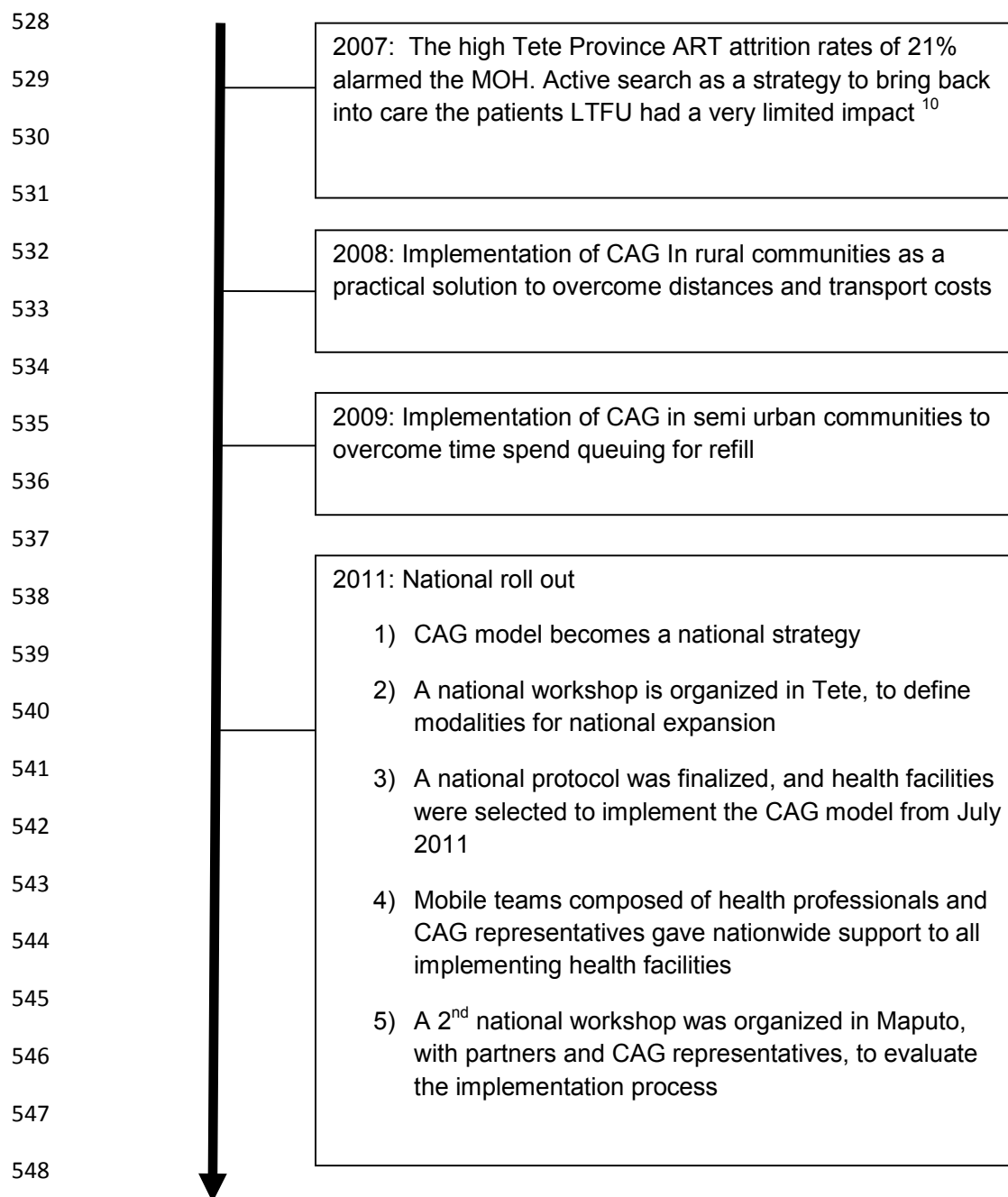
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527 **Figure 2.** Timeline of the launch of Community ART Groups in Mozambique 



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550 CAG: Community ART Group; LTFU: lost to follow up; MOH: Ministry of Health

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