Adherence Clubs: An Essential Strategy To Care for People Living with HIV

Guidelines for Churches and Christian Ministries

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Abbreviations Used in These Guidelines	
ABC	**A**bstinence; **B**e Faithful; **C**ondoms
ACs	Adherence Clubs
ART	Antiretroviral treatment (HIV treatment)
ARVs	Antiretroviral medicines
4 A's	**A**ttendance; **A**ssessment; **A**dherence; **A**RT
BTC	Back to Clinic
CAGs	Community Adherence Groups
CBOs	Community-based organizations
CCM	Churches and Christian ministries
CHE	Community Health Evangelism
D	Died
DNA	Did Not Attend
DOT	Directly observed treatment
EID	Early infant diagnosis
FBOs	Faith-based organizations
LTFU	Lost to Follow Up
MACs	Medication Adherence Clubs
MSF	Médicins Sans Frontières (also known as Doctors Without Borders)
MSM	Men who have sex with men
NGOs	Non-governmental organizations
NS	No Symptoms
PLWH	People living with HIV
PrEP	Pre-exposure prevention
PWID	People who inject drugs
RART	Returned ART back to clinic
RIC	Remaining in Care
RTC	Refer to Clinic
TB	Tuberculosis
TO	Transferred Out
WHO	World Health Organization
WRG	Will Return to Group

INTRODUCTION

This section covers:
- About These Guidelines
- Summary of Adherence Clubs
- Background on HIV Treatment

About These Guidelines

Purpose of these guidelines

These guidelines are to equip churches and Christian ministries (CCM) to facilitate adherence clubs for people living with HIV (PLWH). A vision and rationale for the clubs is covered, as well as practical guidance to conduct the clubs.

Adherence clubs are an essential strategy to provide supportive care for PLWH to enable them to be stable on lifesaving HIV treatment (called "ART") and stay on it lifelong. The strategy includes delivery of ART medicines to members in club meetings.

How these guidelines are organized

These guidelines cover **5 building blocks** for adherence clubs. 4 of these – **WHO**, **WHAT**, **WHEN**, and **WHERE** – are derived from the International AIDS Society key resource, *Differentiated Care for HIV: A Decision Framework for Antiretroviral Therapy Delivery*. *Life*Rise has added **WHY** as the first building block and the foundation, because we feel CCM are motivated by the vision and rationale to run the clubs.

Our **WHAT** building block includes the **4 A's: Attendance; Assessment; Adherence; and ART**. We designed these 4 A's as an easy way to remember the 4 most important tasks to accomplish in adherence clubs.

Churches and Christian ministries (CCM)

CCM is the full range of Christian organizations, including a local church or group of churches; denominations or networks of churches; parachurch ministries; local and international charities; evangelical fellowships; relief and development agencies; missions organizations; Christian hospitals, clinics, and community health programs; Christian health associations; and Christian FBOs (faith-based organizations), NGOs (non-governmental organizations), and CBOs (community-based organizations).

Important role for CCM

Churches and Christian ministries have an important role to play in providing lifesaving HIV treatment (ART). You can provide the *supportive care* that PLWH need to help them stay in care and on ART lifelong.

HIV treatment is the most critical intervention to care for people living with HIV (PLWH). ART brings healing; it is lifesaving and keeps people from dying of HIV. Once started on ART, PLWH need to stay on it lifelong. Providing ART is a clinical intervention which requires medical staff and infrastructure. Therefore, CCM may feel like there is no role for you to play. However, you can still have a big role to play. You can partner with clinics which are providing ART to provide the *supportive care* that PLWH need to be stable on ART lifelong.

*Life*Rise AIDS Resources believes that the most effective strategy to provide supportive care for people living with HIV is adherence clubs. The most important part of adherence clubs is delivery of ART which has been pre-packed by the clinic pharmacy through the clubs. This delivery brings ART close to home for PLWH in the communities where they live. Community delivery of ART helps PLWH stay on their medicines lifelong.

Churches and Christian ministries are well-placed to run ACs and provide supportive care and deliver ART through them. This is because the clubs are facilitated by lay leaders who do not need medical qualification, and because of CCM's extensive reach and presence in local communities. This document provides guidelines for you to coordinate and facilitate a network of adherence clubs and to partner with clinics for delivery of ART through the clubs.

Use of these guidelines for policies and training

CCM can use these guidelines to develop policies and standard operating procedures for adherence clubs. You can also use them for training.

Summary of Adherence Clubs

Adherence clubs are a special form of support group to care for people living with HIV. Médicins Sans Frontières (MSF) has pioneered the model of adherence clubs. A nice video about the clubs by MSF can be found on YouTube – Join the Club (2). (Version (2) is the longer version.)

The following bullets summarize the standard model used in these *Life*Rise guidelines. Variations are also included in these guidelines.

- Adherence clubs have 20 to 30 members who are stable on HIV treatment.
- Trained facilitators lead the clubs. Facilitators may be community health workers or other lay persons, such as pastors and church volunteers. Group members may also be trained to be facilitators.
- The groups meet monthly in communities in locations central to where members live.
- Meetings are held at the most convenient times to allow members to conduct their everyday activities, such as in the early morning so they can get to work on time.
- ART is delivered pre-packed from the clinic pharmacy directly to members in the adherence club meetings. ART is given for the maximum refill time allowed.
- The members benefit from the fellowship, emotional and psychosocial support, and spiritual care provided through the groups.
- The CCM Coordinator coordinates the entire program of the network of clubs, as well as liaises with the clinic that provides the ART.
- The Clinic Manager who is part of the clinic staff manages the program and liaises with the CCM Coordinator.

Background on HIV Treatment

The HIV virus is extremely harmful to the body. It circulates in the bloodstream and slowly destroys the body's way to fight infection. The good news is that there is lifesaving treatment for HIV. This treatment is called "ART." It is medicines that people take. ART works by killing the HIV virus that is circulating in the bloodstream. Without treatment, PLWH will eventually die. With treatment, PLWH have the hope that they will live long and productive lives and not die from HIV.

Benefits of treatment

- Treatment improves the health of PLWH.
- The body's system to fight infection that HIV degrades can recover with treatment.
- ART is good for the major organs of the body like the brain, heart, lungs, and digestive system.
- People who are stable on ART can live a long life and not die from HIV.
- An added benefit is that people who are stable on treatment do not pass the virus to others.

Good adherence

For ART to work, PLWH need to take every pill every day at the same time of the day and not skip any pills. This is called having good adherence. If people miss pills, the virus may become "resistant" to treatment, and ART may stop working. Good adherence is when people take 95% or more of their medicines.

Retention in care
HIV treatment is initiated and monitored under the care of a clinic. People on treatment need to stay in care and keep all their scheduled visits.

Stable on treatment
The goal of treatment is to get "stable" on ART. This is when people feel better and are no longer getting sicker from HIV. Also, they have good laboratory tests to monitor HIV.

Lifelong treatment
Every person who tests positive (infected) for HIV needs to start ART as soon as possible. The sooner people start, the better. Once they start, they need to become stable on treatment and stay on it lifelong. This is because although HIV treatment is lifesaving, it is not a cure for HIV. ART kills only the virus circulating in the bloodstream. It is not able to kill other HIV virus that hides in places in the body where the treatment cannot reach. If treatment is stopped, the virus returns to the bloodstream in full force. Therefore, treatment must be continued lifelong to contain the virus.

Adherence clubs
Adherence clubs help people living with HIV with all the important aspects of treatment, including having good adherence and retention in care, and becoming stable on ART and staying on it lifelong.

WHY – THE FIRST BUILDING BLOCK

WHY is the first of the 5 building blocks for adherence clubs, and the foundation of your program. This section includes:

- Vision for Adherence Clubs – The ultimate result that CCM are striving for
- Rationale for Adherence Clubs – Reasons to run the clubs

Vision for Adherence Clubs

By building a network of adherence clubs, CCM will see the fulfillment of an inspiring vision:

- People living with HIV will be stable on ART lifelong. They will have improved health and not die from HIV. They will live long, healthy, and productive lives with great hope. They will experience God's healing through ART.
- Members of ACs will be assisted with supportive care all along their journey of living with HIV. You will show Christ's compassion as you care for members holistically to meet their physical, emotional, social, and spiritual needs.
- PLWH and their family members will have an opportunity to come to Christ and grow in their relationship with him. Their lives will be transformed.
- When PLWH no longer die, their children will no longer be left alone as orphans.
- Pregnant women on HIV treatment will protect their own health and will not pass the virus to their babies. They will experience the joy that their infants are born free of the deadly disease of AIDS.
- As a result of the care and kindness you demonstrate through adherence clubs, PLWH will feel valued and have dignity. Stigma in the community will fade away.
- Because PLWH stable on ART do not pass the virus to others, the spread and burden of HIV will be lessened in the communities served by the clubs. As CCM build networks of clubs, HIV can even be eliminated in ever-widening spheres, extending to whole countries. Through adherence clubs, you can be part of something big – to help end the tragedy of AIDS!

Rationale for Adherence Clubs

This section includes reasons why CCM will desire to build a network of adherence clubs in the communities you serve.

Show compassion and care for the sick

Adherence clubs are a way for you to follow Christ's example and fulfill his calling to show compassion and care for the sick. The supportive care you provide will help PLWH stay on the "Care Pathway" for HIV treatment. The Care Pathway has 6 steps, each of which depends on the step before. These 6 steps can be remembered by **6 S's**: **S**tatus; **S**eek; **S**tay; **S**tart; **S**table; **S**ustain:

- Know **S**tatus – People at risk for HIV need to be tested so they know their status.
- **S**eek medical care – After testing positive, people need to seek medical care as soon as possible at a clinic that gives HIV treatment.
- **S**tay in medical care – People need to stay in medical care until they start ART, and for their entire lives.
- **S**tart treatment – People need to start ART as soon as possible.
- Become **S**table on treatment – People need to have good adherence so that they become stable on treatment.
- **S**ustain treatment – People need to sustain treatment lifelong.

Bring holistic healing

You can bring God's healing to PLWH through adherence clubs. Healing is holistic through physical, emotional, social, and spiritual care.

Physically, clubs help strengthen adherence to ART and retention in health care. Emotionally, members can share their struggles and feelings. Pastors and other counselors can be made available to provide emotional and spiritual counseling. Socially, PLWH often feel alone and isolated; adherence clubs help them experience a sense of belonging through the fellowship and peer support of the groups. Participants build lasting friendships with each other.

Spiritually, CCM will see the lives of members transformed in Christ. Members have an opportunity to come to Christ, grow in their faith, and be discipled. As one woman who was a member of an adherence group run by MSF commented, "The community ART groups are like a church. We greet each other; we visit each other; we listen to each other; and we feel each other's pain."

Relieve the burden for PLWH

CCM can help PLWH to carry the heavy burden of having a chronic disease. Along a lifelong path of illness, people face many challenges. By coming alongside people on their long journey with HIV, you can help make it easier for them.

The burden for PLWH is that they need to make frequent visits to busy health centers. Transport is expensive; or they may not have transport and have to walk a long distance. The visit to the clinic may take all day. This is time away from home, family, and work. Clients may have to arrange for child care while they are away. The clubs help relieve these burdens because they are held in communities where members live. The clubs take place at convenient times, allowing members to go to work. Clubs help decrease costs of care for members because they are close to home.

At the clinic, clients have long waiting times at each step, even for routine check-ups and medicine refills. When their turn finally comes up, service lasts only for a few minutes. This is not enough time to discuss issues; answer questions; provide education; and meet psychosocial needs. Clubs help relieve these burdens because they can take care of routine care and ART refills. Groups are a means to provide health education and supportive care.

Relieve the burden for clinics

Adherence clubs run by CCM help clinics to care for PLWH. Since all PLWH now need to start treatment as soon as possible after testing positive, clinics are facing an increased burden of care. More clients need care, and need it for their entire lives. Clinics have staff shortages and limited budgets which hinder

their ability to provide care. Staff must take time for stable clients who need only routine care, leaving less time to care for new clients or those who are sicker. Medical providers lack the time to provide the emotional and other holistic care that clients need.

ACs help to relieve the clinic's burden of care. ACs are efficient by caring for people in groups. ACs include "task shifting," decentralized care, and supportive care, all of which are recommended by the World Health Organization (WHO). The clubs are run by lay persons, shifting routine tasks from medical personnel. Clubs provide care for stable patients, reducing the workload for medical staff and allowing them more time to care for sicker, unstable patients. The clubs are run close to home for clients, decentralizing care. CCM have more resources and time than clinics to provide holistic supportive care.

Care through ACs has been shown to be just as good as clinic care, and even better in some ways. More people stay in care; more are stable on ART; fewer people die. ACs improve the quality of health services. Clients are more satisfied with the care. Also, the clubs have been shown to reduce costs and increase cost-effectiveness for both clinics and clients.

Provide differentiated care

"Differentiated care" is streamlined delivery of HIV services and ART to both meet the needs for clients and reduce the burdens of care for clinics. This differentiated care is advocated by UNAIDS and WHO. See the website www.differentiatedcare.org endorsed by all the major international HIV organizations. Differentiated care resources stress how this type of care is urgently needed to help people stay on ART. Models of differentiated care include: group care like adherence clubs; care provided by mobile clinic outreach; providing care through home visits; and fast-track ART refills from drug distribution points.

*Life*Rise likes adherence clubs because we believe they are the best model to meet holistic needs and provide supportive care, as compared to fast-track ART refills. And, the clubs are more efficient than mobile outreach and home visits because care is delivered in groups. Also, ACs are an intervention which churches and Christian ministries can do well.

Prevent HIV

CCM provide compassionate care for people who are already infected and living with HIV through the clubs. You may also help prevent HIV for those who are at risk through the clubs and your engagement with families and communities. One important type of prevention is called "treatment as prevention." This prevention happens when PLWH become stable on ART. Then they do not pass the virus to others. So, by helping AC members with adherence, retention in care, and supportive care so they become stable on ART, you also prevent HIV for others. Through an ever expanding network of adherence clubs in more and more communities run by CCM, the hope of treatment as prevention is that HIV can be eliminated.

A disadvantage of treatment as prevention is that people who are not infected need to depend on others to take their ART medicines. CCM can also promote prevention that people can do for themselves, when they change their own behavior to prevent HIV.

You can promote behavior change to prevent the most common way HIV is passed from person to person, which is through sexual relations. CCM can help prevent this transmission of the virus by promoting God's design for marriage – abstinence until marriage, and faithfulness in marriage. You can encourage people that if they practice God's design, they will experience the greatest joy and fulfillment in marriage. An easy way to remember how to prevent passing HIV through sexual relations is **ABC**:

- **A**bstinence – Abstaining from sex until marriage, or returning to abstinence for the unmarried. Abstinence may also be called "waiting for sex" until marriage, or "saving sex" for marriage.
- **B**e Faithful – Both partners uninfected and faithful to each other
- **C**orrect and **C**onsistent use of **C**ondoms – For couples in which one partner is infected and the other is not; and for those who are not able, ready, or willing to practice **A** and **B.**

C includes both male and female condoms. From a public health view, **A** also includes delaying the age when a person has first sex; **B** also includes decreasing the number of partners. Additional prevention includes male circumcision as an infant or later as an adult.

You can also promote behavior change to prevent the other major way HIV is passed, which is by exposure to infected blood for drug addicts (people who inject drugs (PWID)). This happens when they use syringes and needles used by other addicts to inject illicit drugs. Two interventions help PWID prevent this transmission of HIV: exchange of used syringes and needles for clean ones; and opioid substitution therapy. Opioid substitution is when PWID take pain medicines on a regular schedule which are provided under the supervision of a health center. This controlled schedule helps to decrease the chaos in addicts' lives which comes from obtaining drugs on the street. To help prevent HIV, CCM may inform PWID of these intervention programs. Or, CCM may prefer to promote Christian rehabilitation programs to help people break completely free of addiction, rather than continue the addiction or substitute one addiction for another.

Empower members to care for themselves and others

Adherence clubs help educate members about their HIV disease and ART. The group dynamic of the clubs also helps members to learn from their peers. Members are empowered to play an active role in their own care. They take more responsibility to self-manage their illness. They become advocates for their own health. Members also help care for each other through the groups. .

Provide community-based care

PLWH are best cared for close to their homes in the communities where they live, by health workers who are part of the community. Because churches and Christian ministries have extensive reach and presence in local communities, you are well-placed to provide care. Community workers can get to know people and their needs; they can follow up clients better and provide ongoing care. Local ministries know the community and culture and have acceptance and credibility. You know the assets and resources of your communities which can be mobilized to help care for PLWH.

CCM are well-placed to advocate for community delivery of ART, close to where PLWH live. You can do this advocacy with the clinic that provides the ART, as well as with the local, district, and national health departments and HIV programs.

Through your community engagement, your program will allow you to know and partner with *all* the PLWH in the community, not just those who are attending the adherence clubs. This may include those who have not yet started treatment; those who are not stable on treatment and need adherence support; and those who have failed treatment and need hospice care.

Lessen stigma and discrimination

Churches and Christian ministries can help to lessen the stigma and discrimination of HIV in your communities by coordinating adherence clubs. A special effort like your program for people suffering because of HIV affords them dignity, value, and worth. Your program helps the community to become more accepting of PLWH as friends and neighbors. Stigma fades and compassion grows as CCM pastors and church members engage with people living with HIV, getting to know them one-on-one and hearing their stories. Your program can help PLWH to disclose their status to partners, family members, and others, which also helps acceptance to grow.

Provide expanded services

The priorities of adherence clubs are adherence, retention in care, and community delivery of ART. However, the clubs can have a broader impact through additional activities to serve members in extended meetings or at optional times. CCM can be creative to expand services and opportunities for PLWH. Examples of expanded services are found in the WHAT section of these guidelines.

Mobilize volunteers

Your CCM program of adherence clubs mobilizes Christian volunteers who are altruistically motivated to serve with compassion. Volunteers can help with a myriad of tasks related to ACs, such as facilitating the clubs; providing snacks; transporting members to the meetings or to the clinic for special visits; providing reminders through phone/text/email for meetings; picking up ART from the clinic and returning unclaimed ART; and following up members in the community through home visits.

Mobilize the Christian response to HIV

Through adherence clubs, you can help mobilize the Christian response to HIV in communities. Churches join together to form networks of clubs. Pastors learn about HIV and use their credibility to provide leadership in the community to prevent HIV through God's design for marriage, as well as to care for those who are already infected with the compassion of Christ. Pastors and church volunteers can be engaged to lead as well as assist with the clubs. Serving PLWH shows that CCM are responsive to the needs around you. The clubs are a missional opportunity to reach out beyond the church to serve your community.

Engage in the international response to HIV

Christians can engage in the international response to HIV by coordinating a network of adherence clubs. You can help to fulfill the UNAIDS 90-90-90 strategy. This strategy promotes 3 goals – all people living with HIV need to start on HIV treatment as soon as possible; become stable on treatment; and stay on it lifelong. These 3 goals are steps along the HIV Care Pathway. The 3 goals are:

- 90% of all PLWH get tested so they know their status;
- 90% of these receive ongoing ART (this works out to 81% of all PLWH);
- 90% of these become stable on ART (this works out to 73% of all PLWH).

Lower the burden of HIV in communities to countries

Because PLWH who are stable on HIV treatment do not pass the virus to others, adherence clubs can decrease the spread and burden of HIV in your local area. As you increase the number of clubs and expand your network, you can lessen HIV and even eliminate it in larger regions and your entire country. You can be part of something big – the end of AIDS! This vision to end HIV/AIDS is worthy for Christians to take up the challenge of adherence clubs.

WHO – THE SECOND BUILDING BLOCK

WHO is the second of the 5 building blocks for adherence clubs. This section includes:

- Members
- Facilitators
- CCM Coordinator
- Clinic Manager

Members

Recruiting members

To gather members to form the first adherence club:

- Connect with the clinic from the start of your program – Obtain the list of clients who live in the community you would like to serve.
- Establish groups first before connecting with the clinic – Advertise in the community and around the nearest HIV testing sites for PLWH to contact the club facilitator and attend an introductory meeting. You may want to start regular support groups first. Then, convert the groups to adherence clubs and gain experience before connecting with the clinic.

Number of members

Clubs have 20 to 30 members. In rural areas, they may have fewer members.

Stable on ART

It is best to start clubs with adults who are stable on ART. As clubs become established and you gain experience, you may wish to include: those who have not yet started ART; those who are unstable on ART and in need of enhanced adherence support; those who have stopped ART and need to restart; or those who have failed ART and need hospice care. And, as you gain experience, you may want to start clubs for special groups. Urban areas with higher numbers of PLWH provide opportunity for these clubs.

Special groups include: pregnant and breastfeeding women; families, including HIV-positive children; adolescents; and key and vulnerable populations.

The World Health Organization (WHO) defines stable on ART. Viral load tests measure the copies of the virus in the blood. These copies should be "undetectable" or at low levels on ART. CD4 cells are the special cells in the body that fight infection which HIV destroys. CD4 cell counts should be stable or rising on ART.

WHO defines stable as:

- Received ART for at least one year
- No adverse reactions to ART drugs that require regular monitoring
- No current illnesses
- Good understanding of lifelong adherence
- Evidence of treatment success
    - Two consecutive viral load measurements below 1,000 copies/mL
    - Or, in the absence of viral load monitoring, rising CD4 cell counts or CD4 counts above 200 cells/mm^3

CCM need to know what criteria the clinic they partner with use for a stable client, since a clinic may use different criteria than the WHO criteria. Because clinics are so overburdened, this usually means they have made the criteria less strict. For example, the clinic has lessened the required time for clients to be on ART from one year to 6 months.

Pregnant and breastfeeding women and infants

A pregnant HIV-positive woman can pass the virus to her baby in the womb, during delivery, and through breastfeeding. Infants born with HIV are very sickly. Most die before age 3 if they do not receive lifesaving ART. If a mother is stable on ART, she is much less likely to pass the virus to her infant. Therefore, an HIV-positive woman who becomes pregnant should start ART as soon as possible during pregnancy if she is not already on it. She should continue it lifelong after delivery. ART is important for the woman's own health and to prevent her infant from getting infected.

If a woman who is a member of a club becomes pregnant, it is better for her to stay in her usual club than to switch to a special club. This is allowed by the World Health Organization (WHO). Her continuity of care will suffer if she leaves her regular group to join a special group. This is especially true if she has multiple pregnancies and has to leave her regular group each time. A special club is also likely to meet further from her home than her regular group, so it will be more difficult for her to attend. Therefore, it is best for a woman who becomes pregnant to stay in her regular club. However, if CCM do not feel comfortable to address her special needs and those of her infant in a regular club, then you may want to run separate clubs for pregnant and breastfeeding women.

The special needs of pregnant women and their infants are as follows:

- For the woman:
    - Disclosure of her status and testing of her partner for HIV
    - Staying on ART lifelong after delivery
    - The choice whether to breastfeed or use baby formula, since HIV can be passed from mother to infant in breastmilk
    - Contraception to prevent future pregnancies
- For the infant:
    - ART medicines may be needed for a temporary period after birth to prevent infection
    - Continued risk for infection while breastfeeding
    - HIV testing should be done at as early an age as possible to give a certain result whether the infant is infected. This is called "Early infant diagnosis" (EID). The special tests required for EID may not be readily available in the community.
    - If the infant is infected, he or she needs to start ongoing ART as soon as possible. The adherence support of the club is needed for both mother and infant.

When a woman in the club is pregnant, there will be additional pre- and postnatal visits to the clinic for her, as well as additional pediatric visits for her baby, compared to the usual visits to the clinic for adherence club members. The club can help both mother and infant to keep all their scheduled visits with the clinic.

Family clubs and special needs of children

Families that have more than one person on ART benefit from family clubs. It is helpful for all family members to receive pre-packed ART in the groups, rather than each one having to go to the clinic individually. Family clubs include parents or guardians and their children. Mothers recently delivered and their infants can join a family club. Infected children may include those who have been orphaned – who have lost one or both parents from HIV.

Special needs for children are:

- Disclosure of HIV – Explaining to children about their chronic disease
  - Partial disclosure may start as early as age 3, not yet saying HIV as the name of the disease. The child can be told he or she has a "sleeping germ" kept asleep by special medicines.
  - Full disclosure should take place by age 10, revealing the name of the sleeping germ as HIV.
- ART medicines for young children can be challenging
  - Young children who are growing need more frequent ART dose changes; refills may be given for shorter time periods; and more frequent clinical checks may be needed. Dosage adjustments are less frequent for children age 2 years and older. Clubs may need to help monitor the weights of children on ART if clubs have a scale.
  - Medicines may taste bad and children resist taking them
  - The form of the medicines – Powders may require mixing with pure water; liquids may require refrigeration; large pills may need to be cut in half or crushed; capsules may need to be sprinkled in food
- Children rely on a caregiver who is able to keep the schedule of ART
- Young children need more frequent visits to the clinic for primary health care like immunizations

Adolescents

Adolescents are age 10 to 19. They may be infected with HIV at birth, or later in life from sexual activity or injecting drug use. Adolescents who are HIV-positive have been shown to have lower access to and use of services, adherence to ART, and retention in care. They have more need for psychosocial care. They need assistance to develop life skills. CCM can make a big difference in their lives through adherence clubs.

Adolescents' special needs include:

- They may experience a difficult time after their HIV status is disclosed to them and they begin to understand their disease, how they became infected (if from their mother at birth), and what it means for the rest of their lives
- Having been cared for as a child, they now face the challenge of responsibility for their own care
- Peer pressure and desire to be like other adolescents
- Inconsistent daily routine and forgetfulness to take medicines
- Rebel against a lifestyle in which they must take ART
- May have a difficult time with loss of supportive care as they change from child to adult care in the health system
- Older adolescents need teaching about sexual and reproductive health
- Adolescent girls are considered a vulnerable population (see next section below). They are infected through sexual relations at younger ages than males in their age group; they may carry heavy burdens of caregiving for others who are living with HIV in the household; they suffer from gender inequality.

Key and vulnerable populations

People who are members of key and vulnerable populations are at higher risk of HIV and lack of care. CCM may want to include members of key and vulnerable populations in regular clubs; or, you may wish to start special clubs for them if serving in more densely populated communities and to better meet their needs.

Key populations include sex workers; men who have sex with men (MSM); those who are transgender; people who use alcohol or inject drugs; migrant and mobile workers; and people who are in prison or those who have recently been released.

Vulnerable populations include adolescent girls; orphans; people with disabilities; the homeless; and people with mental health needs.

Special needs of key and vulnerable populations include:
- Stigma and discrimination from medical staff and the community
- Difficulty accessing health services. For example, people with disabilities face physical challenges to visit the clinic.
- Need special services. For example, sex workers need evening services and help with daytime child care.
- Often live transient, disorganized lives which make it difficult to keep the schedule of ART and stay in care. For example, prisoners struggle to stay on ART when released from the structured environment of prison.
- Poor understanding of treatment plans
- More at risk of exploitation
- Rely on caregivers to give them ART

CCM need sensitivity and compassion in caring for these members. You need to understand and assist these members with their special needs. Everyone should be welcome in a group no matter who they are, what they have done, what lifestyle they lead, or where they are in their journey of faith in their lives. Clubs should be a safe haven from stigma and discrimination. Facilitators or other club members may need to accompany some members on visits to the clinic if they cannot go alone.

Members with chronic diseases other than HIV

In some countries, adherence clubs have expanded to "medication adherence clubs" to include treatment for chronic diseases other than HIV, such as high blood pressure or diabetes. For CCM, it is best to limit the clubs only to HIV treatment when starting your program. As CCM gain experience, you may wish to add other chronic diseases if you feel comfortable with the increased requirements.

Some HIV club members may also be on medicines to prevent or treat tuberculosis (TB). The principles of adherence and retention in care which apply to HIV also extend to TB.

Facilitators

Roles

The primary role for facilitators is to serve the clubs:
- Facilitate all activities, including the meetings as well as optional or expanded activities outside the meetings
- Lead club meetings
  - Opening devotions
  - 4 A's, including: recording **A**ttendance; screening members with a basic medical **A**ssessment and referring members for special clinic visits; assessing **A**dherence; delivering **A**RT in the group meeting
  - Emotional support sessions when members share their struggles
  - General health or HIV education sessions
  - Optional spiritual teaching like Bible studies to follow the meeting
- Fill in club registers
- Follow up members who do not attend meetings by phone/text/email or a home visit
- Report how the clubs are doing to the CCM Coordinator

Facilitators may also have a wider role in the community. With their knowledge and experience, they will likely become known in the community as an expert on HIV.

- Promote HIV prevention
- Help people get tested by accompanying them to the testing center and organizing testing outreaches in the community
- Link people who test positive to the nearest clinic which provides ART and accompany them for their initial visits
- Help PLWH to disclose to sexual contacts who are at risk and assist to trace contacts in the community
- Make home visits to provide supportive care to people who have failed treatment and are on hospice

Qualifications for facilitators – lay workers

It is preferred that facilitators be lay rather than clinically trained workers. They do not need medical training or qualifications. They can be community health workers; PLWH or their family members; pastors; and volunteers from the church or community. When initiating your program, it is best to start with facilitators who are outside the groups, who the program knows, and who are of proven character. As the groups become established and you get to know the members, you can draw facilitators from the groups. This is important for sustainability, since members have the highest stake to continue the groups over the long term.

Additional qualifications

In addition to the criteria that the facilitators be lay workers, your program may develop additional criteria. Although the groups should welcome people of all faiths as members of the group, the leaders should be Christians and the groups should be run in a Christian manner. Facilitators should be active in their churches. It is best if facilitators live in the communities where the groups are held, or close in distance. As much as possible, facilitators should be people living with HIV. Other criteria may be set by your program such as age; gender; marital status; and education and literacy levels.

Training

Your program should have initial and ongoing training for facilitators. Facilitators do not need to have any medical training, but they do need a good lay understanding of HIV. You can train extra facilitators who can substitute for others who need to miss a meeting, and to lead new groups as the network expands. Your program should have a curriculum for training. *Life*Rise has developed a training manual, *Supportive Care for People on HIV Treatment*, that is helpful to train facilitators in general HIV. This manual is available from the Global CHE (Community Health Evangelism) Network; or, you may get a copy from our website.

Compensation

If your program has resources, it is beneficial to pay the facilitators stipends or a modest salary. If your program does not have resources, facilitators will need to be volunteers. As your program becomes established, you can draw more and more from group members to become facilitators, since they have the most at stake in keeping the groups going over the long term. The program may use means other than compensation to reward volunteer facilitators. Also, groups may engage in income generation to compensate facilitators.

CCM Coordinator

Roles

If your program has a network of clubs, a CCM Coordinator is needed to coordinate the clubs and liaise with the clinic which is the source of ART. If your program has just a few clubs, one of the club facilitators can play the role of the Coordinator:

- Manages club schedules
- Trains, supervises and mentors facilitators
- Liaises with the Clinic Manager for ART delivery and other clinical needs such as referrals for special visits to the clinic for club members
- Monitors the groups and reports to the clinic
- Assists with issues that arise in the groups

Qualifications

CCM Coordinators can be lay persons just like facilitators. See the criteria above for facilitators. If possible, it is good if the Coordinator has experience as a facilitator. Your program may choose from among the facilitators a Coordinator who has management skills.

Compensation

If possible, the Coordinator should receive compensation from the program, even if the facilitators are volunteers.

Clinic Manager

Roles

The Clinic Manager is part of the clinic staff and works closely with the CCM Coordinator to provide oversight and manage the clubs.

- Responsible for the health of club members
  - Care through clubs must be voluntary for members. Club members who would like to leave the club and return back to clinic care should be allowed to do so at any time. The ultimate responsibility for the health of club members rests with the clinic and the Clinic Manager, not with CCM or the clubs.
- Helps to coordinate club schedules
- Provides clinical oversight of the clubs, including:
  - Works with the clinic pharmacist for scripting of ART refills for club members and delivery of pre-packed ART to members in club meetings
  - Annual laboratory testing for members to prepare for the annual clinic visit
  - Annual clinic visit for members
  - Referrals to the clinic for members with a special health need
- Supervises and mentors the CCM Coordinator
- Reviews CCM monitoring and reporting
- Assists the CCM Coordinator with issues that arise in the groups

Qualifications

The Clinic Manager should have medical training. A nurse who has knowledge of HIV and ART makes a good Clinic Manager. CCM do not need to set other criteria for the Clinic Manager since the clinic assigns this person and is responsible for his or her qualifications.

Compensation

The clinic is responsible for compensating the Clinic Manager.

WHAT – THE THIRD BUILDING BLOCK

WHAT is the third of the 5 building blocks for adherence clubs. This section includes what to do in the clubs and other important considerations for providing services:

- Starting a Club
- The 4 A's – The 4 most important tasks to accomplish in group meetings:
  - Attendance – The First of the 4 A's
  - Assessment – The Second of the 4 A's
  - Adherence – The Third of the 4 A's
  - ART – The Fourth of the 4 A's
- Additional Considerations for Providing Services

Starting a Club

Preliminary planning

Churches and Christian ministries which have caught the vision for adherence clubs and desire to start them need to first understand the HIV need and the services provided in the communities where you wish to start clubs. The following is a list of helpful information:

- Number of PLWH – There is a high need for services when there is a high rate of HIV (percent of people infected), or a large number of people infected like in urban areas.
- Key and vulnerable populations – People who have a high risk for HIV and lack of care:
  - Key populations – Sex workers; men who have sex with men (MSM); those who are transgender; people who use alcohol or inject drugs; migrant and mobile workers; and people who are in prison or those who have recently been released.
  - Vulnerable populations – Adolescent girls; orphans; people with disabilities; the homeless; and people with mental health needs.
- Hot spots – Areas where there is a high risk for HIV spread, including urban areas with a dense population, as well as around bars, clubs, or other places where people go to socialize; brothels; informal settlements; workplaces with large numbers of male workers, like mines, police stations, and military bases; and transit stops along major highways.
- HIV services – What HIV services are being done and what are the gaps in services.
- HIV testing – Ongoing HIV testing or special testing outreaches conducted, and the percent and number of people who test positive.
- ART delivery – How ART is being provided for PLWH in the community, including:
  - Where PLWH go to get their ART and how far away in distance and travel time this is;
  - Number of months ART refills are given for;
  - How often PLWH need to go to the clinic for a check-up, compared to how often they need to go to pick up an ART refill.
- Adherence club policies – Some countries have made adherence clubs part of national HIV strategies. You can use policies to help advocate with the local clinic for community delivery of ART through ACs.
- Adherence clubs being conducted – If any HIV support groups or adherence clubs are already being conducted in your region, you can go and visit the program to learn about the clubs and explore collaboration.
- Church networks – Churches interested in joining together to build a network of adherence clubs.
- Resources – As adherence clubs become established and procedures become routine, clubs can become sustainable. However, additional resources may be needed to start the clubs and expand the network of clubs. CCM can explore what resources may be available like grants to start the clubs.

Starting clubs – when to connect to the clinic

CCM which desire to start adherence clubs may consider when to connect with the clinic that provides ART. You may wish to connect with the closest health center that is providing ART no matter who is running it, such as the government. Or, you may wish to start in an area with a Christian mission hospital or clinic, which may be more open to partnering with CCM.

- Connect with the clinic from the start – Meet with the clinic to inform them that you would like to start adherence clubs and let them guide you to set up your program. Receive a list of clients who have been recruited by the clinic to join clubs. Connecting with the clinic from the start is the best option to achieve the most important goal – to have ART delivered to members in the group meetings.
- Establish groups first before connecting with the clinic – This is the best option if you feel the clinic may not be open to working with your program.
  - First, start regular support groups for PLWH without involving the clinic.
  - Then, when these regular support groups are established, build into the groups the first **3 (three)** of the **4 A's** to convert the support groups to adherence clubs – **A**ttendance; **A**ssessment; and **A**dherence. These **3 A's** will greatly help PLWH even without the **4th (fourth) A**, which is delivery of **A**RT.
  - Then, when the 3 A's have been built into the clubs and you have accomplished a good track record, you can approach the clinic to advocate to start the **4th (fourth) A** – delivery of pre-packed ART in the groups, provided by the clinic.

The 4 A's
Attendance – The First of the 4 A's

The first activity of the group meeting should be 10-minute devotions. Then, the facilitator should go through the 4 A's, starting with Attendance. This is when members' attendance to the meeting is monitored.

Register and member information

Each club should have a register to record the meetings. The register includes monitoring of the 4 A's. It can be kept in a large ledger book. Or, if the facilitator has a laptop computer or tablet, the register can be an Excel spreadsheet. See Appendix A for a sample of the columns in the register, how to fill in the columns, and abbreviations to use.

In addition to the register, facilitators should maintain separate, private files for individual club members. These files should contain contact information for the member. They should be kept confidential to protect the member's HIV status. Facilitators should refer to this contact information whenever connecting with members by phone/text/email and home visit to share information about the club; to remind members to attend meetings; and to follow up when members have missed a meeting.

Contact information in the member's file should include:

- Address and directions to the member's home
- List of household members, and who in the household knows the member's HIV status
- Member's phone/text/email and whether these are private or shared
- Who in the member's family or household the facilitator is permitted to share information with about the member by phone/text/email, or on a home visit

Record Attendance in the register

Attendance for group members is very important and should be noted by the facilitator for each meeting in the club register. Continuing members (called "Remaining in Care" (RIC) members) should be listed for each meeting and attendance checked off in the register. New members should be added to the register. Those who miss meetings should be recorded as DNA (Did Not Attend) in the register. They should be followed up by facilitators and the results of follow up recorded in the register. For those who send a buddy to the meeting, record "Buddy" in the register.

Good attendance important for all members

Attendance at every monthly meeting is very important for all members for club cohesion. For members on ART, attendance is important to document adherence and retention in care.

Members on ART need to understand the club's policies for the number of meetings which they are allowed to miss and still stay in the club. Members who miss more than the allowed meetings will need to return back to clinic care.

Members not on ART may miss meetings while still staying in club care. However, they should be encouraged to attend, since a record of good attendance will help the club to advocate with the clinic for them to start ART and receive it through the club.

If a member is missing meetings for the clubs which are close to home, they are likely to miss more visits to the clinic which is further away. Therefore, you should try as much as possible to keep the member in club care rather than transferring them back to clinic care, even if it means that the facilitator will need to follow up and monitor the member more closely.

Meeting reminders

To help members have good attendance, the facilitator or volunteers from the group can make phone calls or send out text/email reminders a few days prior to the meeting.

Sending a buddy to the meeting

A member who does not attend a routine meeting may send a buddy instead, such as a family member, to report how he or she is doing and pick up ART refills. CCM needs to decide in discussion with the clinic how many times in a row a member who is on ART is allowed to send a buddy to the meeting before the member must return back to clinic care. Médicins Sans Frontières (MSF) recommends a limit of 2 times in a row. Record "Buddy" in the register for those who send a buddy to the meeting.

Members cannot send a buddy to meetings when blood laboratory tests will be done, or to meetings when the annual clinical check-up is done.

Time limit for members to get ART

For members who are on ART who have missed a meeting and have not picked up their ART, this is an *urgent* matter. The longer a member goes without ART, the more the virus may become resistant to the medicines and the medicines may stop working.

CCM can decide in discussion with the clinic how many days members are allowed to go without ART if they do not attend a meeting. Médicins Sans Frontières (MSF) recommends a time limit of 5 days. If members who miss meetings pick up their ART within the 5-day time limit, they may continue on ART and in club care. The member can come to meet the facilitator to pick up ART. Or, the facilitator can make a home visit to the member to bring the ART. If members do not meet the time limit, they must return back to the clinic to re-start ART.

Follow up of members who miss a meeting

Members who miss a meeting should be recorded as DNA (Did Not Attend) in the register. The facilitator should follow up *as soon as possible* to determine why the member missed the meeting. Follow up can first be done by phone/text/email. If this is not successful, the facilitator should make a home visit. The facilitator should continue trying to follow up the member for at least 2 weeks after the meeting before concluding that the member is Lost to Follow Up.

Record the results of follow up in the register as follows:

- Will Return to Group (WRG) – The member will return to the group the next meeting. The member should arrange with the facilitator to get his or her ART.
- Back to Clinic (BTC) – The member has stopped attending the group and will return to clinic care. The facilitator should encourage the member to continue ART and make a visit back to the clinic as soon as possible.
- Transferred Out (TO) – The member has moved from the area. The facilitator can help the member connect with a club or clinic that provides ART in the new area.
- Died (D) – The member has died. The facilitator can help the family with bereavement support.
- Lost to Follow Up (LTFU) – The facilitator is not able to discover what has happened to the member after 2 weeks' of trying. If the member is on ART, the facilitator should report this loss to the CCM Coordinator or to the Clinic Manager as soon as possible for further follow up by the clinic.

Voluntary attendance

Attendance at the clubs should always be voluntary. Members can decide to return back to clinic care whenever they wish to without undue pressure to stay in the club. The facilitator may try to gain feedback why the member has stopped coming, so as to improve the group, while not pressuring the member to return.

Monthly attendance reports

The Facilitator should provide a monthly attendance report to the CCM Coordinator. The CCM Coordinator tallies the monthly attendance of all the groups in the network and submits this to the Clinic Manager.

Monthly attendance includes the number of:

- Members Remaining in Care from the month before (RIC)
- Plus New members added to the club (New)
- Minus members who have left the club, noting their status:
  - Back to Clinic (BTC)
  - Transferred Out (TO)
  - Died (D)
  - Lost to Follow Up (LTFU)

The 4 A's
Assessment – The Second of the 4 A's

After having devotions first in the club meeting; then taking Attendance and recording it in the register; the next step is the second of the 4 A's – Assessment. This is when the facilitator goes through a brief list of conditions to see if any members need to be referred to the clinic for a special visit.

Doing the assessment

Assessment is very basic and does not require medical training. It is fine for lay facilitators to do the assessment. The facilitator goes through the list with the entire group, not with each member individually.

Screening list of conditions

The list is to screen for an acute or severe illness; significant side effects of ART; worsening of HIV or development of AIDS (the end stage of HIV); signs of tuberculosis (TB); or newly pregnant. You are screening for members who are experiencing one of the conditions in a ***new*** way, or much ***worse***, since the last meeting.

List of conditions to screen for:

- Fever
- Severe headache
- Severe skin rash
- Nausea or vomiting which are preventing members from taking their pills
- Diarrhea for more than 2 weeks
- Weight loss
- Weakness
- Swelling of glands in the neck, armpits, or groin
- Cough with bloody sputum
- Pregnant

Record Assessment in the register

If the club member has no conditions that need referral to the clinic, record NS (No Symptoms) in the register. If you refer the member to the clinic, fill in RTC (Refer to Clinic) and a brief reason for the referral in the register.

Referrals to the clinic

If any member is experiencing a condition on the screening list, the facilitator should refer the member to the clinic (RTC). The facilitator can be especially concerned about members who: are not yet on ART; are in the first few months of starting ART; do not have good adherence to ART; or are not stable on ART.

The facilitator can try not to refer members to the clinic frequently for continuing or minor conditions. However, if the facilitator has a doubt, it is best to be more careful and refer. Members who are worried about their health and request frequent referrals to the clinic may not be well-suited to the club, and may need to return back to clinic care.

Taking weights

If your program has resources, it is good to provide a scale for each club to weigh members at each meeting. Weigh each member and record the results in the register. Compare the weight at the current meeting to weights taken at the prior 2 meetings which are recorded back in the register. Refer members who have a progressive weight loss of 10% or more who are not trying to diet and lose weight.

The 4 A's
Adherence – The Third of the 4 A's

After having devotions first in the club meeting; then taking Attendance; then doing an Assessment; the next step is to do the third of the 4 A's – Adherence. This is when members' adherence to ART is determined.

95% adherence required

For ART to keep working, club members need good adherence. They need to take every pill every day at the same time of the day. They must take 95% or more of their doses. In group meetings, facilitators need to challenge members to achieve this level of adherence. This needs to be balanced with understanding and open discussion of the barriers to adherence that members face. Members who consistently fall short in adherence need extra help from the facilitator, such as daily reminders and individual counseling. Your program can work with the clinic to determine when these members need to return back to clinic care.

Record Adherence in the register

The facilitator leads the members together as a group to each assess his or her own individual adherence to ART. The facilitator should record adherence as "Good" or "Poor" in the register for each member for each meeting. Adherence can be determined by the number of missed doses on a calendar; or by pill counts (see sections below).

Good adherence is when members take 95% or more of their ART doses. When members take ***one dose per day***, this means:

- Monthly ART refills – Members miss 1 dose or less
- Bi-monthly refills – Members miss 3 doses or less
- Quarterly refills – Members miss 4 doses or less

When members take ***2 doses per day***, double the number of missed doses allowed.

Poor adherence is when members take less than 95% of their doses. This means they miss more doses than allowed as above for Good adherence.

Using calendars to assess adherence

The easiest way for members to record adherence is for them to check off when they take a dose on a calendar. Then, they bring this calendar to the group meeting to assess their own adherence. This helps members become self-empowered to manage their own care.

The program can help members by providing blank calendars. The calendars should most likely be small, so members can keep them confidential. If your program has resources, you can have calendars printed. Or, you can provide blank, 3 inch by 5 inch index cards for members to make up their own calendars at club meetings for future months.

Index cards that you create for calendars can have 7 columns, one column for each day of the week, starting with Sunday and ending with Saturday. The cards can have 5 rows, one row for each week of the month. Fill in the month at the top of the card. Fill in a small date number in the upper right hand corner of each block for the date of the month. Both sides of the card can be used for 2 months. For each dose taken, the member fills in an X in the date block. Blocks without an X show missed doses.

Using pill counts to assess adherence

Another way to assess adherence is to do pill counts. This is a more complicated and it is better to keep a calendar, as above. Pill counts are when members bring their pill bottles to the meeting. They count pills remaining in the bottle to compare the number of pills they *should have taken* with the number they have *actually taken*. Especially, pill counts are more challenging when meetings are held monthly but refills are bi-monthly or quarterly. If you need to do pill counts, the calculation is as follows:

- A – Count the number of pills given in the pill bottle to start out the refill.
- B – Count the number of pills that should have been taken from the date the member started the refill to the current date.
- C – Subtract A minus B for the number of pills that should be left in the pill bottle.
- D – Count the number of pills that are actually left in the pill bottle.
- E – Subtract D minus C for the ***number of pills missed***.
- F – Divide E by B and multiply by 100 for the ***percent of pills missed***.
- G – Subtract 100 minus F for the ***percent adherence***.
- Levels of adherence for G:
  - Good – 95% or more
  - Poor – less than 95%

Pill boxes and other assist devices

If your program has resources, you can provide assist devices to help members with adherence. One device is a pill box. Pill boxes have spaces marked with the 7 days of the week to fill with pills. Each space has a tightly fitting lid. At the beginning of each week, the member fills up all 7 spaces with each day's pills to take. Each day, the member opens the next space to take that day's pills. At the end of the week, all the spaces should be empty and ready to be filled for the next week. Spaces that still have pills in them are missed doses.

The program can also help provide other assistive devices to remind members to take their pills such as alarms. In addition, facilitators or volunteers from the group can send daily text/email reminders to members.

Enhanced adherence support

Facilitators can provide enhanced adherence support for members who consistently have poor adherence. This involves working with a member individually to assess the adherence barriers that he or she is experiencing and to design strategies to address these barriers. Strategies may include one-on-one adherence counseling and education sessions to augment the group sessions; daily phone calls or text/email reminders to take ART; and home visits. It may also mean that the facilitator and member arrange a brief daily meeting in which the facilitator watches the member take his or her ART dose and helps to record the dose on a calendar. This is called "directly observed treatment (DOT)."

The 4 A's
ART – The Fourth of the 4 A's

After first having devotions in the club meeting; then taking Attendance; then doing an Assessment; then determining Adherence; the next step in the meeting is to do the fourth of the 4 A's – ART. This is when ART which is pre-packed by the clinic is distributed to members in the group meeting.

Distributing pre-packed ART

The clinic pharmacy pre-packs the ART for each member who is taking it a few days prior to the group meeting. The packs are then delivered to the facilitator by the clinic, or picked up by the facilitator from the clinic. The packs are then distributed by the facilitator to members in the group meeting. Each pack should have the member's name clearly written on it. It is easy to distribute the ART by matching the name on the pack to the member.

The World Health Organization (WHO) recommends that lay facilitators distribute ART through adherence clubs. CCM facilitators do not need medical training to distribute the ART packs. Distributing the ART should not make facilitators feel anxious. Clubs are not prescribing or dispensing medicines. Clubs are just distributing the medicines as a go-between the clinic and the members. They are just "passing the medicines through." The responsibility that members receive the correct medicines rests fully with the clinic.

Record ART in the register

The facilitator should mark an "X" in the register for each member (or buddy) who receives ART. The facilitator can also ask if any members have been started by the clinic on a new ART regimen and note this on the register as well. Members can inform the facilitator whenever the clinic changes their regimen.

Single source of ART per club

Each club should have a single source of ART for all the members in the same club. The club should not have members who receive their ART from different clinics, because this is too difficult for the CCM coordinator and the group facilitator to coordinate. If the network of clubs is larger, the CCM Coordinator may need to coordinate with several different ART sources. In a large program, each individual club should still have single source of ART.

Maximum time for refills

ART should be given for the maximum time allowed for refills in the country HIV program. In the past, this has been monthly. However, programs have moved to longer refill times, such as bi-monthly, quarterly, or 4-monthly. Even though the refill times may be longer than one month, it is best that the groups still meet monthly for support for adherence and retention in care; ongoing education; peer support and group cohesion; and emotional and spiritual care.

Alignment of refill dates

The clinic pharmacy should align the refill dates for all the members in the same club to match the meeting date. This may mean less or more ART medicines that the usual refill time for the first time ART is distributed in a new group; or for the first time ART is distributed for a new member who is joining the group.

Sufficient ART medicines

Meetings should be scheduled in advance and the clinic informed. This is important to ensure that sufficient ART is included in the pre-packs to cover the number of days between the meetings, so that members do not run out of medicines prior to the meeting.

If possible, the clinic should include additional pills to cover the time limit your program has for picking up ART if a member misses a meeting. If this time limit is 5 days, an extra 5 days of pills should be given by the clinic in the pre-packs as a buffer. A member who has extra pills should take the oldest, leftover pills first before starting the new pills in the refill.

The clinic pharmacy must have a good management system for ART supply. If the clubs are experiencing repeated stock-outs of ART with drugs not being available, or available in shorter supply than the usual refill, then the club system is not working to distribute ART. Members need to return back to clinic care for ART refills. The pharmacy needs to improve the ART supply chain before distribution through the clubs can be restarted.

Checking ART regimens

Facilitators and members can understand how the names of ART medicines work. This is so that they can check the pre-packed ART. Also, members can know what medicines they are taking when they are away from the group.

ART is not just one drug but a combination of drugs. Members are usually taking at least 3 different medicines. 2 or more medicines may be combined into one pill. The pills are usually taken once or twice a day. The usual ART regimen is 2 pills taken once a day.

Each medicine has 2 names: the *generic* name is the chemical ingredients; the *brand* name is assigned by the drug manufacturer to market the drug. The generic name should be the same in all countries. The brand names may differ from country to country. The generic names of ART medicines are commonly abbreviated as 3 letters. The following chart shows commonly used ART medicines and the abbreviations. This list changes as new drugs start being used and older drugs are discontinued.

ART Medicines	
Abbreviation	**Generic Drug Name**
3TC	lamivudine
ABC	abacavir
ATV	atazanavir
AZT	zidovudine
DRV	darunavir
DTG	dolutegravir
EFV	efavirenz
FTC	emtricitabine
LPV	lopinavir
NVP	nevirapine
RAL	raltegravir
RTV	ritonavir
TDF	tenofovir

As much as possible, facilitators and members can check that the pre-packed ART are the correct medicines when the ART is distributed. Facilitators are not responsible for the correct labeling and makeup of the packs. The clinic is responsible for this. However, checking by facilitators and members is helpful as an extra safeguard.

In addition to checking the pre-packs, members can know what HIV medicines they are taking, so they are empowered to self-manage their own care. Clubs can help teach the members their ART regimens. Members who are not literate need extra help. Clubs can help members have a list of their medicines to carry with them at all times. Members can inform facilitators when the clinic changes their regimens.

In addition to knowing their ART medicines, members can also know whether they are on first-line, second-line, or third-line treatment. Clinics usually start PLWH on ART with first-line medicines. These are most readily available, easiest to take, and have the least side effects. If people do not have good adherence to first-line medicines, the virus may become resistant to the treatment, and people will need to move to second- and third-line medicines.

Delivery of ART from clinic

The clinic can deliver the ART packs to the facilitator a few days prior to the meeting. This is best since the clinic is likely to have more resources for transport costs. However, if your program has resources, the facilitator can arrange with the clinic to pick up the medicine packs at the pharmacy a few days prior to the meeting.

Unclaimed ART

If the time limit has been exceeded for a club member who misses a meeting to pick up ART or send a buddy to pick it up, facilitators will be left with unclaimed ART. Your program should have a policy on how unclaimed ART is returned to the clinic. The clinic can come to pick it up. Or, facilitators can transport it back to the clinic. When ART is returned back to the clinic, record this in the register as RART (Returned ART).

Storage of ART

Proper storage of ART by the facilitator is needed for the few days prior to the group meeting, as well as for a few days after the meeting for unclaimed ART. ART should be stored in a protected place. As much as possible, this place should be clean; dry; cool; dark away from bright sunlight; safe from pests; locked and secure; and private and confidential. Most ART liquids for children do not need to be refrigerated, or only after a few months, so they are okay for the time it takes for distribution through the clubs.

Annual clinical check

Members should have an annual medical check-up with the clinic to assess how they are doing on ART. Some clinics may require this more often than annually. Your program can work with the clinic to schedule the annual check-up for the group members. An efficient way is for clinic personnel to travel annually to a group meeting and check all the members on the same day. Or, your program can transport all the members as a group to the clinic by bus, and the clinic can see them all on the same day. Or, the program can assist with transport for each member to visit the clinic individually. Members may not send a buddy to the annual check-up.

Laboratory testing and results

Lab tests to monitor ART can be done at a group meeting one month before the annual clinical check-up is scheduled. These lab tests can be dried blood spots done for each member. It is best if clinic staff come to the meeting to do the blood spots. This helps to ensure that proper precautions are taken for handling blood to protect people who are HIV-negative. An alternative is that the clinic can teach facilitators and members how to do the blood spots at the meeting, which can then be transported to the clinic. Blood spots should be carefully labeled with the member's name and clinic identification number.

The usual lab tests to monitor PLWH who are on ART, or waiting to start ART, are viral loads and CD4 counts. Viral load tests measure the copies of the virus circulating in the blood. People who are not yet on ART may have millions of copies of HIV in their blood. People who are stable on ART have viral loads which are "undetectable" (no virus copies are found in the blood) or at low levels (only a few virus copies are found).

CD4 cells are the special blood cells that protect the body from infection. HIV destroys these cells. ART helps to raise the number of CD4 cells so PLWH are no longer at risk for infections. People who are stable on ART have CD4 counts which are rising or stable at a high level.

Groups can help members understand the lab tests and know their results for self-management. Members can self-report their latest test results, or their latest status on ART as stable or unstable, for recording in the club register. Or, the clinic may report members' test results to the club for recording in the register. Reports of lab tests or stable status may not be accurate if they are self-reports, and they should not be a criteria to stay in the club. Members can be referred back to the clinic if they show a trend toward increasing viral loads or decreasing CD4 counts.

Pre-exposure prevention (PrEP)

Pre-exposure prevention (called "PrEP") is when ART medicines are taken *before* the exposure happens to prevent HIV. People who are HIV-negative but who are at high risk may take PrEP to prevent infection if it is available from the clinic. For example, for a couple in which one partner is infected and the other partner is not infected, the uninfected partner may take PrEP to prevent infection. PrEP is usually 1 or 2 ART drugs, compared to 3 drugs for full ART treatment.

Clubs may include people who are on PrEP because they need good adherence and retention in care, the same as people who are on full ART treatment. PrEP which is pre-packed by the clinic can be distributed at the group meeting in the same way as the full ART.

Tuberculosis (TB) medicines

Club members who are taking medicines to prevent or treat TB, along with ART medicines, need good adherence and retention in care, the same as people who are on ART only. TB medicines which are pre-packed by the clinic can be distributed at the group meeting in the same way as ART.

Additional medicines

Additional medicines that members take for which adherence is important may be included in the pre-packs from the clinic, including: cotrimoxazole refills (medicines to prevent infections for adults and children); medicines for chronic disease like high blood pressure; and contraceptive pills.

Additional Considerations for Providing Services

Naming the groups

Although groups may use the Adherence Clubs (ACs) model, they may wish to call their groups by a different name. Different names for the groups appear in the information literature. *Life*Rise likes an alternative name for the groups – TASC groups. TASC stands for "Treatment Adherence and Supportive Care." We like this because it includes supportive care in the group's purpose. And, it is a word play on "task" groups, which are groups specially formed to achieve an important task.

Groups have also been called "Community Adherence Groups or Clubs" (CAGs or CACs); "Community ART Refill Groups" (CARGs); and "Medication Adherence Clubs" (MACs). Groups may also be called simply "support groups."

Group members may also wish to name their groups individually, like "Hope" or "Grace" group.

Order and timing of what to do in the group meetings

The order and timing of what to do in the regular group meetings is as follows:

- First – Devotions – This can take no longer than 10 minutes. Devotions should be Christian, uplifting, and positive. Devotions can be led by the facilitator. Or members can take turns leading devotions.
- Second – Go through the 4 A's – This can take no longer than 35 minutes. Take Attendance; then do an Assessment; then determine Adherence; then distribute pre-packed ART.
- Members are free to leave after the 4 A's if they need to go to work or fulfill other obligations.
- Third – Emotional support session or health education session – Do one or the other but not both in the same day, rotating from month to month. These sessions can take no longer than 15 to 30 minutes. This means that the entire meeting lasts one hour, or one hour and 15 minutes.
- Fourth – Optional spiritual care session – The meeting officially ends after the emotional support or health education session and members are free to leave. An optional Bible study or spiritual teaching lasting no longer than 30 minutes can be done after the official end of the meeting for those who wish

to stay. Or, a time entirely separate from the meetings can be arranged for the spiritual activity for those who wish to attend.

For family clubs, activities for children during the meetings may include crafts, games, watching videos, or sports. Adolescents may need life skills teaching.

Peer support

As much as possible, allow members to interact with each other for group activities. Divide up the large group into smaller groups so members can share with and learn from each other. This helps members to care for and support each other.

Emotional support session

After having devotions and going through the 4 A's, meetings can include an emotional support session, rotating with a health education session from meeting to meeting. The emotional support session is what makes the group a "support group." This is a time when members can share their feelings and struggles of everyday life. Members gain strength and encouragement from sharing with their peers. Smaller groups of 5 or 6 people are best for this session, so large groups will need to divide up.

Guidelines for conducting the emotional support session are in Appendix B. The guidelines include a handout for facilitators and members to understand how the session is conducted. Each group can read the handout guidelines aloud before starting the session.

It is very important in the session that members share only their own feelings and emotions about their own struggles and what has helped. They should use "I" and "me" language to share feelings and what has helped them. They should avoid using "you" language that can sound like they are telling other members how they should feel, and like they are giving advice to other members what actions they should do to help themselves.

- Each member uses "I" and "me" language – for example, "I feel . . ." and "This is what helped me . . ."
- Members should avoid "you" language – for example, "You feel . . ." and "This is what you should do . . ."

Health education session

Groups can rotate a health education session with an emotional support session from meeting to meeting. The education session can be on general health, HIV, or other helpful topic. Your program can develop lessons that the facilitators or members can use to do the teaching; or the group may invite a guest speaker; or videos can be used. Médicins Sans Frontières (MSF) and other organizations may have some lessons available for clubs to use.

Spiritual care

Although your program is run in a Christian manner, members of all faiths, or those who do not profess any faith, should be welcome in the groups. Basic services should be available to all, while spiritual care activities and opportunities to learn more about Christ are optional. Members should not be required to participate in spiritual care activities, or forced in any way to accept Christ, in order to receive services.

Spiritual care activities may be scheduled as an extension of the regular group meetings, or at a time entirely separate. Activities may include Bible studies, Christian education, church services, prayer, worship, and other growth and discipleship activities. As small groups, adherence clubs are beneficial for discipleship. This is because members can interact with the group leader and with each other to share what is going on in their lives and discuss spiritual concepts, which they are not able to do in a church service.

Pastoral care

In addition to spiritual care group activities, your program may arrange for volunteer pastors to be available to members for individual pastoral care and counseling. The CCM program can actively seek the involvement of additional local churches and pastors in the communities served by the adherence clubs to increase opportunity for spiritual care.

Attitudes

Program staff and volunteers should cultivate good attitudes towards PLWH to help them to stay in care and not cause them more emotional pain than they already have in their lives. Members should also be encouraged to show these attitudes towards each other.

- Show the grace, love, and compassion of Christ
- Empathize with people, hearing their stories, feeling their pain, and imagining what it is like to walk in their shoes
- Show respect for people, value them, and afford them dignity and worth
- Encourage others
- Be non-judgmental
- Come alongside group members wherever they are on their spiritual journey in life and help them to draw strength from faith
- Focus on a member's relationship with God, not on their actions or behavior
- Be future oriented, not concerned with people's past and how they got infected, but helping them live positively, looking forward with hope

Signing a group covenant

We suggest that the facilitator have every new member sign a Group Covenant when they join the club. This is a simple document but helps to reinforce the most important commitments that members are making. See Appendix C for a sample Group Covenant.

Your program can determine how strongly to "enforce" the Group Covenant. You can develop a policy of progressive enforcement, moving from more to less allowance. Facilitators can first provide warnings. After an agreed number of warnings, some remedial action may be required. As a last resort, a member will need to leave the club and return back to clinic care. Your program should make every effort to keep members in the group, especially for clubs that meet far from the clinic, allowing as much grace as possible when members break a commitment.

Privacy and confidentiality

Privacy and confidentiality for groups and their members is critical and must be stressed at every meeting. PLWH may question involvement in a group because of fear of exposure of their HIV status. A breach of confidentiality can result in stigma and discrimination, abuse, violence, or other harm towards PLWH, as well as a cycle of destructive gossip in the community. Members who compromise the confidentiality of other members may need to return back to clinic care.

As a participant in a group, PLWH fear that their HIV status will be revealed to people whom they have not chosen to inform, including partners, parents, children, and other family and household members, as well as pastors, church and community members. Group members should be regularly admonished not to share another member's HIV status with someone outside the group. It is for PLWH alone to share their status. Facilitators should take care to maintain confidentiality of a member's HIV status when connecting with the member by phone/text/email or a home visit.

Members should not share what is said or what has happened in the group with anyone outside the group. The important requirement to remember is: "What is said or what happens in the group, stays in the group."

Some PLWH who do not wish to be part of an adherence club in their own community may be willing to attend one held at the health center or in a neighboring community, if one is available. Clubs should try to have as private a place as possible to meet in the community. Facilitators can still help care for PLWH individually in the community who identify themselves but who do not wish to participate in the group.

Conflict in the groups

Conflicts between members can affect group cohesion. The facilitator can encourage members who have conflicts to first work these out between them. If they are not able to resolve the conflict, the facilitator can act as mediator. Or, a local pastor may be asked to mediate. If the conflict cannot be resolved, then one or both members may need to leave the group and return back to clinic care.

Clinic responsibility for club members

CCM who are running a network of adherence clubs are being very helpful to clinics. The clinic must always continue to take the full responsibility for the health of club members as their patients. The clinic should not use an active program of clubs run by CCM as a way to escape responsibility for their patients.

Transitions in providing services

Members may need extra supportive care from clubs when they go through important changes in receiving services from the clinic. These are times when members require different health services on a schedule other than the usual. Clubs need to be aware of members' special needs during these transitions, and help them to stay in clinic and club care.

Transitions include when:

- A woman becomes pregnant and she transitions from regular adult care to maternity care – This transition continues after delivery until she stops breastfeeding; and until her infant has a definitive HIV test to determine whether he or she is infected. Then there is another transition back to regular adult care for the woman, and to pediatric, child care for the infant.
- A child transitions to adolescent care
- An adolescent transitions to adult care
- A club member fails ART and transitions to hospice care

It is best for continuity of care for club members to stay in their same clubs during these transitions. However, some programs with high numbers of people may have special clubs at these transitions. For example, there may be clubs just for pregnant and breastfeeding women; or teen clubs for adolescents.

Failure of treatment and need for hospice care

Groups may include PLWH who have failed ART. The virus has become resistant to all the ART medicines that are available at the clinic, and ART no longer works. This may occur when a member has had poor adherence. Or, it may occur when a member has caught a virus strain when first infected that is already resistant. The member has moved from first- to second- to third-line ART. Laboratory tests are not good. He or she stops all ART medicines and gets weaker and sicker as the disease takes its natural course and progresses to AIDS, which is the end stage of HIV. In addition to ART failure, a member can develop an additional terminal illness, like cancer.

These developments are very troubling for the member and he or she will need a lot of compassion from the group. In time, the member will need hospice care. Group members can help to care for and visit their fellow member to provide support and comfort. When the member dies, the club can help family members with bereavement support and the funeral.

Smaller, member-led groups

Another model for groups pioneered by MSF other than Adherence Clubs is Community ART Groups (CAGs). These groups have fewer members – 6 to 12 members. They are used in rural areas where the number of PLWH is lower. Because groups are more remote, they are more self-formed, -led, and -managed by members than adherence clubs. Members rotate leading the meetings. Activities in group meetings include going through the 4 A's. Members take turns to visit the clinic, meet with the Clinic Manager to report how the members are doing, and pick up pre-packed ART for themselves and the other group members. Members may each contribute funds to pay for the transport to the clinic.

*Life*Rise feels that adherence clubs are a better model than CAGs to care for PLWH because they are more structured. ACs allow CCM more opportunity to assist the members and to provide greater supportive care. However, your program may find that a mixture of the two models works best.

Provide expanded services

The main goals of adherence clubs are to improve adherence and retention in care through the 4 A's, community delivery of ART, and supportive care. However, the clubs can have a broader impact through additional activities that can take place in extended meetings or at optional times. CCM can be creative to expand services for PLWH as they see needs arise. Examples are the following:

- HIV and general health education
- Spiritual care activities
- Clubs joining together to share resources, such as health teachings; child care to allow members to work; transport services
- Clubs joining together for social outings; special events such as retreats, rallies, and camps
- Self-help groups and other income generation projects
- Group projects like communal gardens; fish ponds; raising chickens, goats, pigs, or livestock
- Assisting group members with life crises, such as an acute illness; food emergency; become homeless; loss of a job; death of a caregiver
- Assisting members with basic needs, including clean water; hygiene; food and nutrition; clothing; stable housing; job training; and education assistance
- Prevention education in the community
- Outreaches to test people for HIV and linkage of those who test positive to the nearest clinic which provides ART to start it as soon as possible
- Assistance to members to disclose their HIV status to others; help with tracing contacts who are at risk
- Activism in the community for the needs of PLWH
- Expansion of clubs to include adherence to other chronic disease medicines, such as for high blood pressure; diabetes
- Preventive or primary care health services through the clubs, such as immunizations; distribution of bed nets to prevent malaria; contraception; de-worming

Costs of running the clubs

Costs of running the clubs can be limited as much as possible to ensure sustainability (see the following section, Sustainability).

Costs may include:

- Training of Facilitators – Stipends for trainers; transport for trainers and trainees; meals; accommodation; training materials
- Salary or stipends for the CCM Coordinator
- Stipends for Facilitators
- Transport
  - Facilitator to attend monthly club meetings
  - Pick up ART from the clinic before the meetings; and return unclaimed ART back to the clinic after the meetings
  - Club members to attend meetings, especially for those who live a far distance away
  - Annual clinical check-ups or laboratory testing – Transport of clinic staff to the group meeting; or transport the entire group to the clinic
  - Attend meetings between Facilitators and the CCM Coordinator; between the CCM Coordinator and the Clinic Manager
- Facilitator follow up of members in the community by phone/text/email, or home visits
- Snacks for meetings
- Materials for meetings
  - Ledger books for the meeting register
  - Folders for individual member files
  - Whiteboard or newsprint; markers; easel; masking tape
  - Calendars to mark ART doses; or blank index cards, pens, and rulers to make calendars; pill boxes; alarms
  - Scale to weigh club members
  - Copies of handouts
  - Bibles; devotionals
- Costs for expanded services and activities beyond the club meetings

Sustainability of the groups

Groups should become as self-sustainable as possible to ensure their long-term continuation. CCM can train and use church volunteers and PLWH and their family members to lead and serve. It is best if facilitators serve as volunteers from the start; however, small stipends may be needed as your program and groups are starting up. As the groups become established, your program can draw facilitators from group members who are willing to serve as volunteers. Paid facilitators can move on to start new groups.

Also for group start-up, it may be a good idea to provide snacks during the meeting and a small amount of transport assistance to attend the meeting. These are incentives for members to attend. Adolescents and other members of key and vulnerable populations may especially need these incentives. As the groups become established and the meetings are held in the communities where members live, these incentives can be discontinued. Members can rotate providing snacks for the meeting.

The clubs are run in partnership with clinics, which should help with resources since the clubs save effort and help lessen costs for the clinic. For example, clinic staff can transport the ART to the group facilitator in time for the monthly meeting, and return after the meeting to pick up unclaimed ART. Clinic staff can travel to the group for annual clinical check-ups or laboratory testing.

Members can contribute to the costs of running the groups, since they have a big stake. The groups may engage in income generation to help individual members, the groups, and the entire CCM program. Your program can become a registered charity and raise funds.

The longer the clubs operate, the more sustainable they can become as procedures become routine. However, additional resources may be needed to start new clubs and expand the network of clubs.

WHEN – THE FOURTH BUILDING BLOCK

WHEN is the fourth of the 5 building blocks for adherence clubs. This section covers when club meetings are held.

Monthly meetings

Clubs meet monthly so as to foster adherence and retention in care, supportive care, and group cohesion. This is even if the refill time for ART is longer than one month, such as bi-monthly or quarterly.

As the club becomes established, members may wish to extend the time between meetings beyond one month to the refill time for ART. Your program can monitor how effective this is for adherence and retention in care and supportive care. The club can still have optional monthly activities like meeting for an emotional support session or a spiritual care activity, even if the time between official meetings is extended.

If the meetings are monthly but the ART refill time is longer than one month, there may be some club members who want to attend only the meetings when ART is distributed. Your program may allow this for members who are stable on ART and more independent, especially those who live a far distance away.

Schedule of club meetings

Club meetings should be held monthly as close to the same date of the month as possible. Scheduling the same *day* of the week, such as “the second Tuesday of the month,” may be better than the same *date* of the month. This is because the day of the week will vary for the same date from month to month. Meetings should be scheduled for at least 6 months’ in advance. Your program Clinic Manager, pharmacist, CCM Coordinator, Facilitators, and members should all be kept informed of the group schedules.

Sufficient ART needs to be prescribed by the clinic pharmacy to cover the time between refills, as well as to cover the 5-day time limit or other grace period allowed by your program for a member who misses a meeting to pick up ART.

Scheduling of meetings includes the annual meeting when laboratory testing is done, as well as the annual meeting when clinical check-ups are done.

Convenient times

Meeting times can be discussed with the members to decide the most convenient time which works best for the majority of the members, as well as for the facilitator and for your program. The time of the meeting should allow members to attend to daily activities. For example, meetings may be held in the early morning, or in the evening, or on weekends (Saturday or Sunday), to allow members to go to work or tend to their farms.

Special considerations include:

- Members should be allowed to leave the meeting after devotions and the 4 A's if they need to get to work
- School-aged children and adolescents – Meetings should be after school, or on school holidays or weekends
- Members of key populations – Meetings may need to be in the late evening

WHERE – THE FIFTH BUILDING BLOCK

WHERE is the fifth of the 5 building blocks for adherence clubs. This section covers where the clubs meet.

Meeting in the community close to home

A priority for adherence clubs is for them to meet in communities which are close to where the members live. This is to facilitate community delivery of ART, which helps members to adhere to and become stable on ART and stay in care. When starting the club, make a map of where members live and choose as central a location as possible. If there is more than one place where the club can meet, rotate the meeting place from month to month.

Private

Places where the clubs meet should be as private as possible to help PLWH maintain confidentiality. This can be a secluded place with a back entrance. Or, it can be a public place where many people are coming and going for their daily business, such as libraries, community centers, or markets.

Churches may be a good choice, since they are used frequently for other group meetings. This is if the church is open to ministering to PLWH and confidentiality can be maintained.

Groups can meet in private homes if they are large enough.

Health center

Groups can meet in the health center which is the source of the ART. However this may be distant from where members live and therefore does not provide community delivery of ART. Or, groups may meet in a local clinic which provides primary health care in the community but which is not the source of the ART for group members.

Sustainability

It is best for your program if the place where clubs meet is free of charge.

APPENDICES

Appendix A – Meeting Register

Appendix A gives guidelines for keeping the club register in the meetings. The register should be prepared ahead of the meeting, and then filled in for each meeting. The following table gives a list of columns for the register and what to fill in for each column. This is a suggested list which your program can alter for your own use.

Meeting Register

Fill in the first row at the top of the register above the column heading row:

- **Date of Meeting**
- **Type of Meeting** – Regular; Clinical Check; or Lab Test

Column Heading	Options to Fill In	Description of Options to Fill In
Name	Personal and family name	Member's full name
New	Contact	Change in contact information or ART regimen, or new member to the club starting this meeting
	ART	
	Member	
Attendance	X	Attended
	Buddy	Member sent a buddy
	DNA	Did Not Attend
Assessment	NS	No Symptoms and stable
	RTC and brief reason	Refer to Clinic – Refer to clinic for a special visit. Fill in a brief reason for the referral. For example, new illness; weight loss; TB symptoms; pregnancy.
Weight	Weight	Fill in weight if the club has a scale and can weigh members. Compare to previous 2 weights in the register and Refer to Clinic for 10% or more weight loss.
Adherence	Good	Good adherence is when members take 95% or more of their ART doses. For *once per day dosing*, this means: • Monthly ART refills – Members miss 1 dose or less • Bi-monthly refills – Members miss 3 doses or less • Quarterly refills – Members miss 4 doses or less
	Poor	Poor adherence is when members take less than 95% of their doses. This means they miss more doses than allowed as above for Good adherence.

ART	X	Given to member or to buddy at the meeting
	X on Follow up	Given to member on follow up for DNA
	RART	Returned ART – ART was not given to the member and was returned back to clinic
New Lab Test Results	CD4	If the member can self-report a new CD4 laboratory test, fill in the result and date
	VL	If the member can self-report a new viral load laboratory test, fill in the result and date
Did Not Attend (DNA) Follow Up Date	Date	Date when the member who Did Not Attend a meeting is followed up
DNA Follow Up Type	PH	Follow up by Phone
	TX/EM	Follow up by Text/Email
	HV	Follow up by Home Visit
DNA Follow Up Results	WRG	Will Return to Group – Member will return to the group the next meeting
	BTC	Back to Clinic – Member has stopped attending the group and returned back to clinic care
	TO	Transferred Out – Member has moved from the area
	D	Died – Member has died
	LTFU	Lost to Follow Up – Unable to follow up member; unknown status

Appendix B – Emotional Support Session

One of the important activities to conduct during adherence club meetings is an emotional support session. This is a time when members may share their feelings and emotions and care for each other emotionally and spiritually. This session helps to make an adherence club a "support group." Groups set aside a specific time for this session, which is usually 15 to 30 minutes.

Instructions for conducting an emotional support session

- Members divide up into smaller groups of 5 or 6 people.
- The small group chooses one member who acts as the facilitator for the session. Members rotate this role. In addition to guiding the session, facilitators can join in the sharing.
- Members share briefly in the group for up to 3 minutes to allow others an opportunity to share as well.
- To start the session, the facilitator first goes over with group members the guidelines in the handout which follows, **Guidelines for Facilitators to Conduct an Emotional Support Session in an Adherence Club Meeting**. This handout is on a separate page so you can print it out.
- After going over the guidelines, the facilitator begins the time of sharing by asking, "Who would like to share first today?"
- The first member who has something he or she is struggling with shares feelings and emotions. He or she may also share what has helped.
- After the first member shares, the facilitator asks "Who else can relate to that who would like to share?"
- Then, a second member who can relate to what the first member shared may share his or her own feelings and what has helped.
- This process continues until the cycle plays out when no other member relates to the feelings shared by the first member.
- There is a brief silence while members pause. The facilitator steps in and says, "Can anyone else relate to that? If not, who would like to share different feelings and start a new cycle?"

- Another member may now start a new cycle. Other members who can relate share in turn and the process continues.
- It is very important that members share only their own feelings and emotions about their own struggles and what has helped. They should use "I" and "me" language to share feelings and what has helped them. They should avoid using "you" language that can sound like they are telling other members how they should feel, and like they are giving advice to other members what actions they should do to help themselves.
  - Each member uses "I" and "me" language – for example, "I feel . . ." and "This is what helped me . . ."
  - Members should avoid "you" language – for example, "You feel . . ." and "This is what you should do . . ."

Example of an emotional support session – role play

The following role play is borrowed from the *Life*Rise training manual, *Supportive Care for People on HIV Treatment.* The role play shows the process of sharing in an emotional support session.

Role play of an emotional support session in an adherence club meeting

5 members are participating (abbreviated ACM (Adherence Club Member) and numbered 1 through 5 in the script).

Facilitator	Who would like to share first today?
ACM1	I would like to share. I have been feeling very anxious lately. I am worried about my HIV treatment. My doctor does not think the medicines are working and he says I need to switch my pills to a different kind. He has to check if they are available. I worry what will happen if the new medicines are not available.
Facilitator	Who else can relate to that who would like to share?
ACM2	(Brief pause) I can relate. I also have been feeling anxious. I have been worried since I got pregnant that my baby will get HIV even though I am on ART. My husband is worried as well. What has helped me is to remember the Bible verse Philippians 4:6 about not being anxious but instead giving my requests to God in prayer with thanksgiving, and the peace of God will come. Every time I get anxious, I try to pray. I picture myself leaving my fears at the foot of the cross and walking away, giving them to the Lord.
ACM3	(Brief pause) I can relate as well. I am anxious about my future. What is in store for me as I get older? I feel well on ART now but what if I get sick? I do not have anyone to take care of me. I have been trying to trust God, believing that He will take care of me.
Facilitator	(Long pause – facilitator waits out the pause until it seems that no other members desire to share about feeling anxious.) Can anyone else relate to that? If not, who would like to share different feelings and start a new cycle?
ACM4	I would like to share different feelings. I have been feeling angry and betrayed lately. I am mad at my wife for giving me this HIV. I feel like leaving her sometimes.
Facilitator	(Brief pause) Who else can relate to that who would like to share?
ACM5	I can relate to that. I felt the same way towards my husband when I tested HIV positive. I asked him to go for marriage counseling with the pastor. He refused to go. So I went on my own and the counseling really helped me.

Guidelines for Facilitators
To Conduct an Emotional Support Session in an Adherence Club Meeting

Facilitator reads the following guidelines at the start of the emotional support session:

- Members will share briefly for up to 3 minutes only to allow others an opportunity to share as well.
- To begin the time of sharing, I (the facilitator) will ask, "Who would like to share first today?"
- The first member who has something he or she is struggling with shares feelings and emotions. He or she may also share what has helped.
- After the first member shares, I (the facilitator) will ask, "Who else can relate to that who would like to share?"
- Then, a second member who can relate to what the first member shared may share his or her own feelings and what has helped.
- This process continues until the cycle plays out when no other member relates to the feelings shared by the first member.
- We will wait a brief time while members pause. Then, I (the facilitator) will step in and say, "Can anyone else relate to that? If not, who would like to share different feelings and start a new cycle?"
- Another member may now start a new cycle. Other members who can relate share in turn and the process continues.
- It is very important that members share only their own feelings and emotions about their own struggles and what has helped. They should avoid telling others how they should feel and giving advice what they should do to help themselves.
    - Each member uses "I" and "me" language – for example, "I feel . . ." and "This is what helped me . . ."
    - Members should avoid "you" language – for example, "You feel . . ." and "This is what you should do . . ."

Appendix C – Group Covenant

This section includes a sample covenant for members to sign when they join the group. You can adapt this covenant to your own program. It is best to keep the covenant as simple as possible. You can give the member the original copy of the covenant, and keep a copy on file with your program.

Group Covenant

I, _____ (Fill in name of member) commit to the following as a member of the adherence club in my community _____ (Fill in name and location of community).

- Attend and participate in meetings
- Make every effort to have good adherence to my HIV treatment, taking all my medicines
- Show respect and kindness towards group facilitators and members
- Follow the "Golden Rule" – "Treat others as I would like to be treated"
- Strive to be at peace with others without conflict
- Help to care for and support other members
- Not share a member's HIV status with anyone outside the group. Only the member may share his or her own status with others; it is not for me to share.
- Keep what is said or what happens in the group confidential from anyone outside the group. I accept the requirement, "What is said or what happens in the group, stays in the group."
- Be on time to meetings
- Turn off my cell phone during meetings

_____
Print Name of Member

_____ _____
Signature of Member Date

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