

USING DATA TO STRENGTHEN
ART SERVICES:
A USERS' GUIDE ON CORE
INDICATORS, REDUCING LOSS
TO FOLLOW UP, AND
MORTALITY CASE REVIEWS

JUNE 2010



USAID
FROM THE AMERICAN PEOPLE

ASIA

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
APRO	Asia Pacific Regional Office (of FHI)
ART	Antiretroviral therapy
CoC	Continuum of Care
CoD	Cause of death
FHI	Family Health International
HIV	Human Immune Deficiency Virus
IDU	Injecting drug user
OI	Opportunistic infection
MRC	Mortality case review
PITC	Provider initiated testing and counseling
PLHA	People living with HIV/AIDS
QA	Quality assurance
QI	Quality improvement
RDM/A	Regional development mission/Asia
STI	Sexually transmitted infection
TB	Tuberculosis
USAID	United States Agency for International Development
VA	Verbal autopsy
WHO	World Health Organization

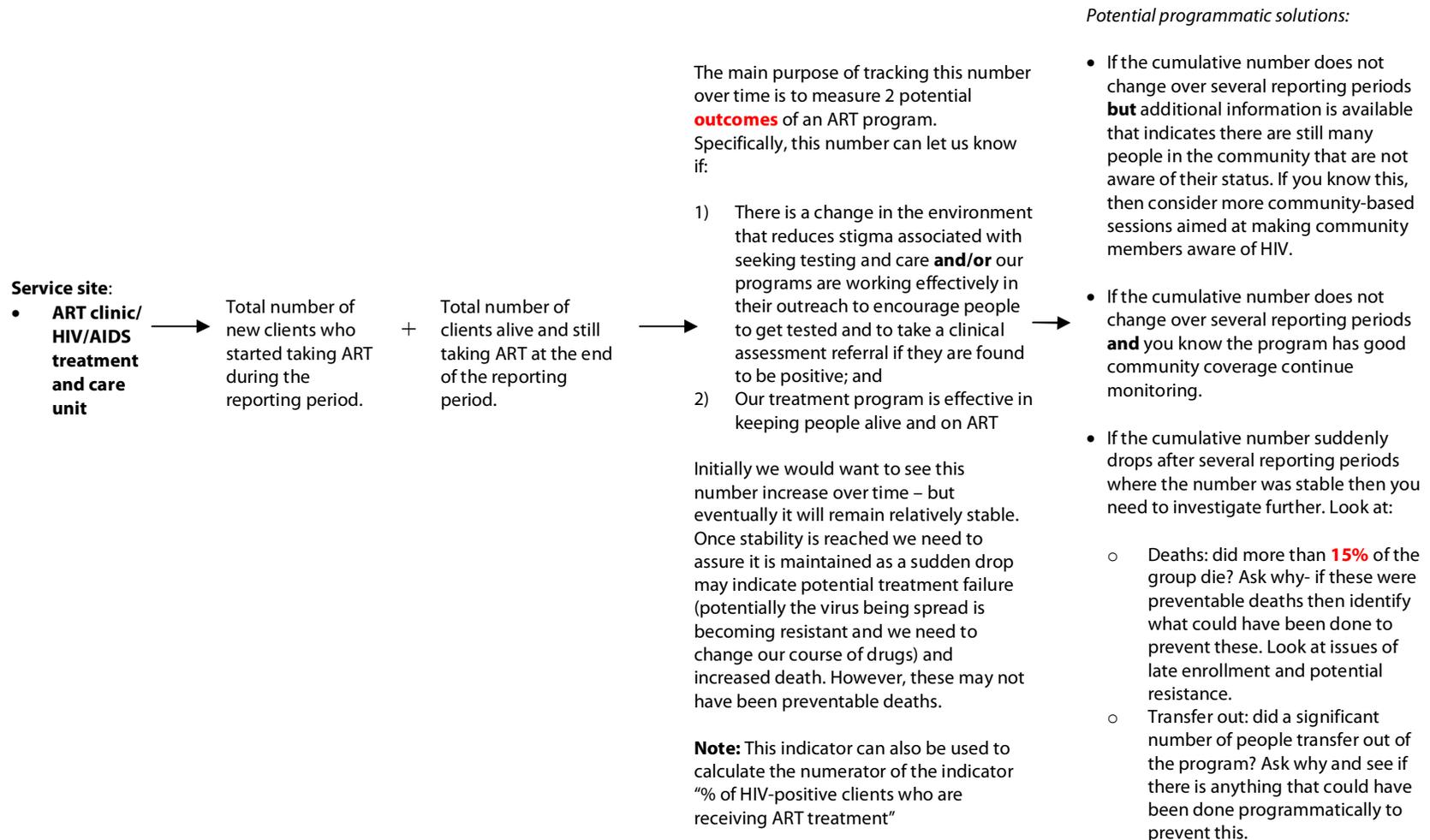
Core indicators for ART programs

The following section includes core indicators that have been built based on routine data that is available within most program databases. These indicators aim to assist in making programmatic decisions which can strengthen the program overall. Two types of indicators are presented: those that can assist in making routine decisions about how well the program is progressing, and evaluation indicators which can be used to assess overall program outcomes and impact.

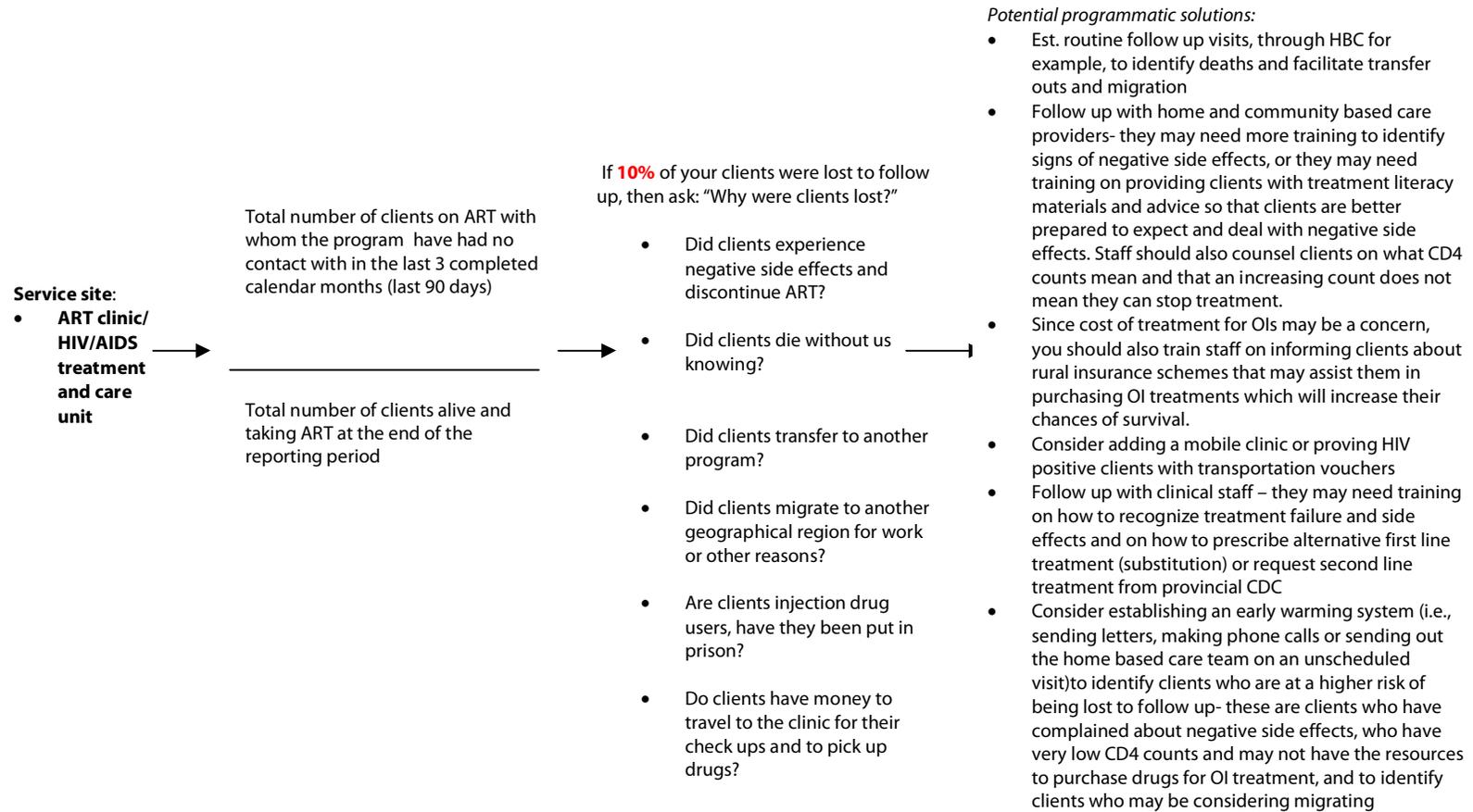
The indicators are presented in the form of “decision trees”, they indicate where data comes from, how to calculate the indicator, how it can be interpreted and finally, some ideas about programmatic options that could be considered to improve the situation.

Program monitoring indicators

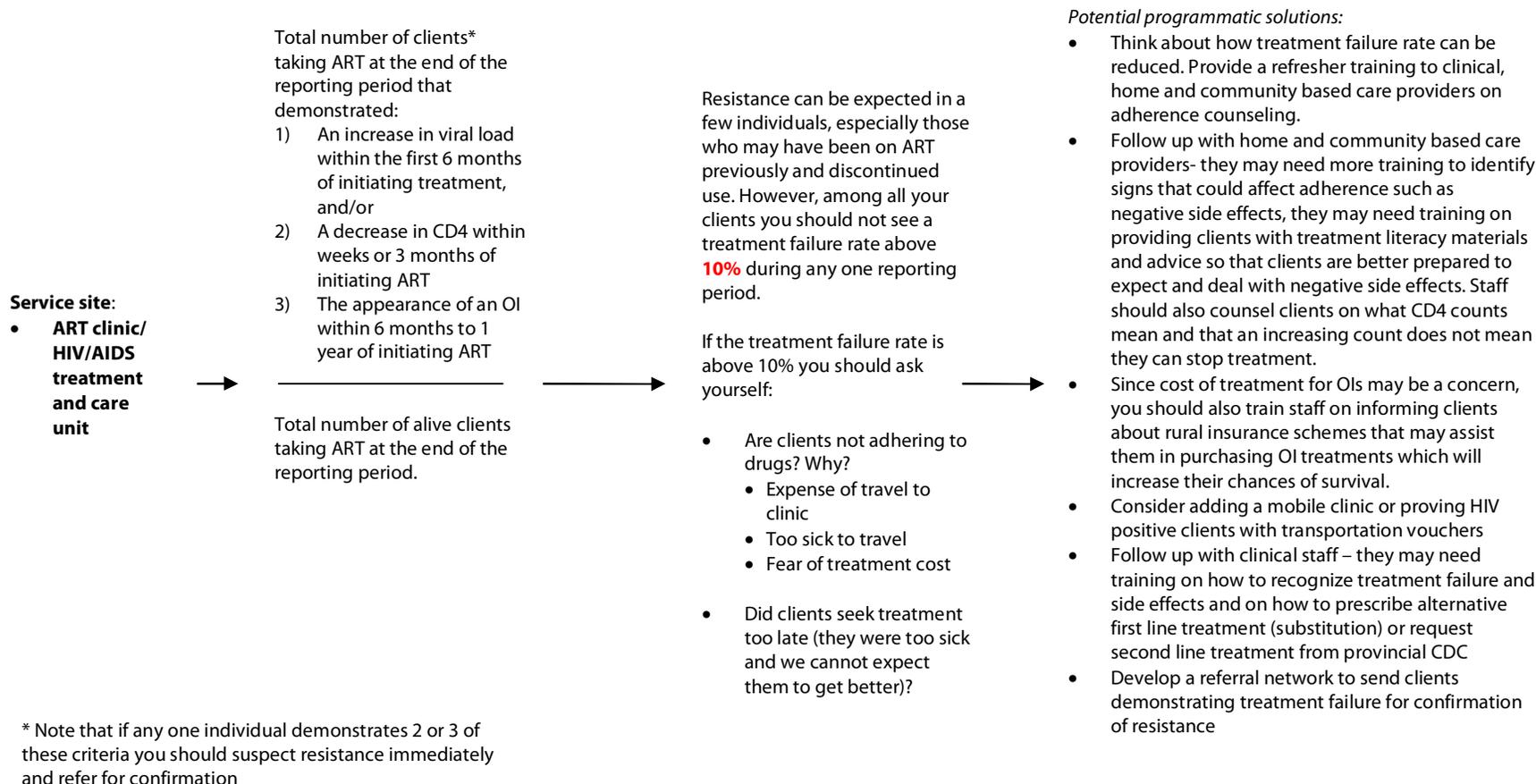
Cumulative number (old and new) of people on ART



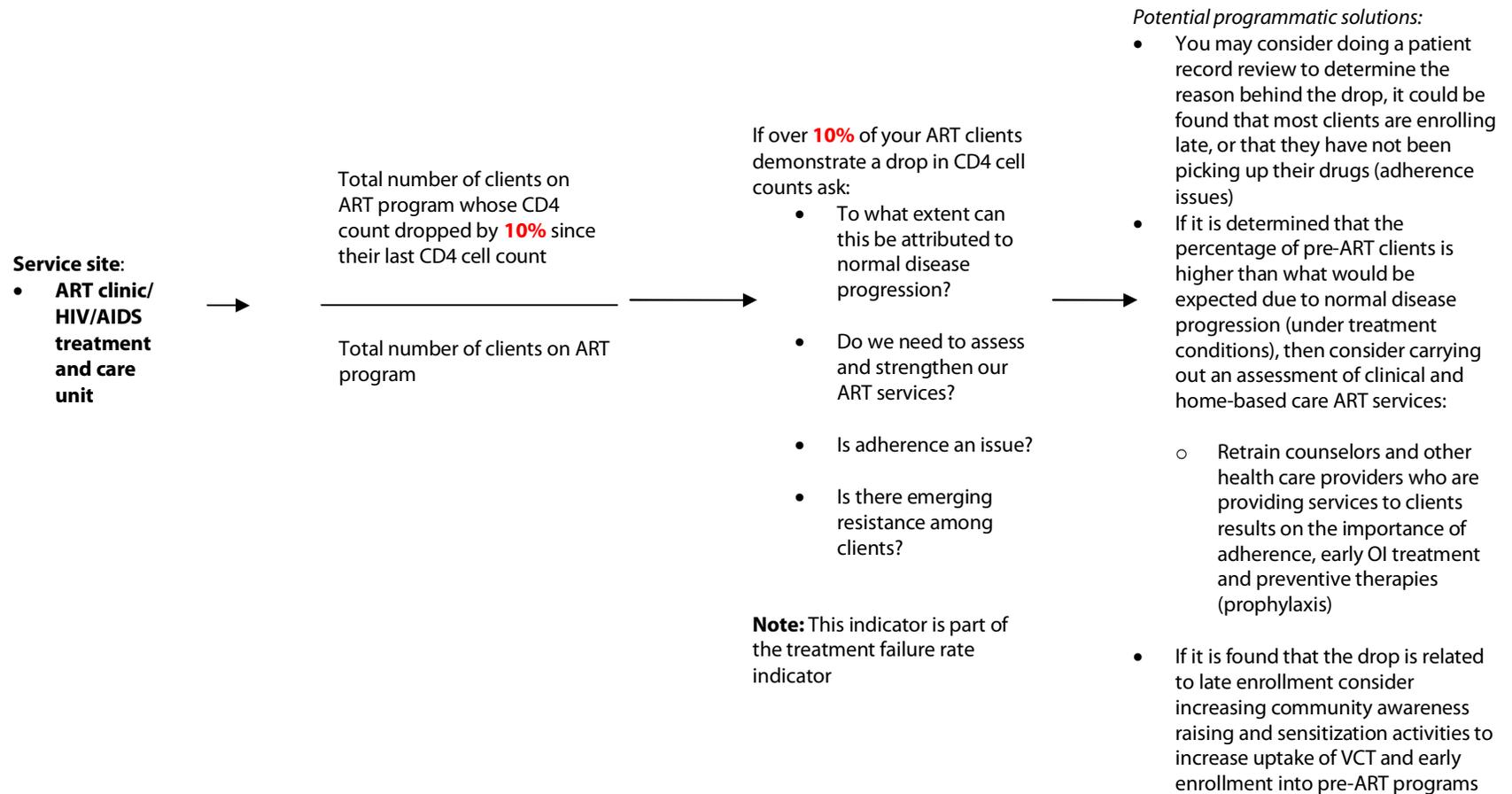
% of clients lost to follow up during last reporting period



% of clients on ART demonstrating potential treatment failure at the end of reporting period



% of clients on ART whose CD4 cell count dropped since last CD4 count



% of clients on ART program whose weight dropped

Service site:

- ART clinic/
HIV/AIDS
treatment
and care
unit



Total number of clients on-
ART program whose weight
dropped by **10%** since their
last clinical visit

—————
Total number of clients on ART
program



If over **10%** of your ART clients demonstrate a drop in weight ask:

- To what extent can this be attributed to normal disease progression?
- Do we need to assess and strengthen our ART services? For example, are nutritional services needed?
- Is adherence an issue?
- Is there emerging resistance among clients?
- Is the client suffering from side effects from treatment?
- Are there other factors about the client that make him or her less likely to adhere to treatment (i.e., are they using drugs and abusing alcohol?)

Note: This indicator can be used if treatment failure is too difficult to measure, it can be used as a proxy for treatment failure.



Potential programmatic solutions:

- You may consider doing a patient record review to determine the reason behind the drop, it could be found that most clients are enrolling late, or that they have not been picking up their drugs (adherence issues)
- If it is determined that the percentage of weight loss among ART clients is higher than what would be expected due to normal disease progression (under treatment conditions), then consider carrying out an assessment of clinical and home-based care ART services:
 - Retrain counselors and other health care providers who are providing services to clients results on the importance of adherence, early OI treatment and preventive therapies (prophylaxis)
- If it is found that the drop is related to late enrollment consider increasing community awareness raising and sensitization activities to increase uptake of VCT and early enrollment into pre-ART programs
- Consider DOT, if possible or feasible. Using partners and families, for example.
- Retraining on adherence counseling

Time between diagnosis and ART initiation

Service site:

- **ART clinic/
HIV/AIDS
treatment
and care
unit**

→ Calculate the time (specify if time is in days or months) between HIV confirmation and initiation of ART treatment

→ This indicator needs to be interpreted with caution.

A long delay between HIV confirmation and initiation of ART could indicate appropriate follow up care- that is, the patient received all OI treatment needed in order to delay initiation of ART.

In order to correctly interpret this indicator other indicators need to also be looked at. Specifically, this indicator should be compared to the average time between initiation of treatment and death. If people die quickly after initiation treatment, this indicates that people came too late. It implies therefore that the time between diagnosis and treatment was too long.

Potential programmatic solutions:

For cases where it is found that time between initiation of ART ad death is short (i.e., within 1-3 months) **and** the time between diagnosis and ART initiation long, then consider the following options.

- Consider implementing the use of rapid tests and/or Elisa results to initiate OI treatment among clients presenting with OIs for testing (for cases tested at the hospital)
- Consider initiating OI treatment as needed once rapid test results are obtained
- Follow up with home and community based care providers- they may need more training to identify early OI treatment that is needed, or they may need training in encouraging health seeking behavior among clients
- Consider doing a routine case review to assure that individual patients are being monitored appropriately and that their needs are being addressed proactively

Note: In some cases there may be little that can be done, a patient may have come for HIV testing when they were already at a late stage of disease. Consideration should be given as to how to encourage people to be tested early.

Time between ART initiation and death

Service site:

- **ART clinic/
HIV/AIDS
treatment
and care
unit**



Indicate the time (specify if time is in days or months) between ART initiation and death



If individuals die within 1-3 months of initiating treatment, the clinical staff should ask themselves: "Why?"

- Did the patient present too late (at late stage of disease)?
- Was the appropriate care not provided?



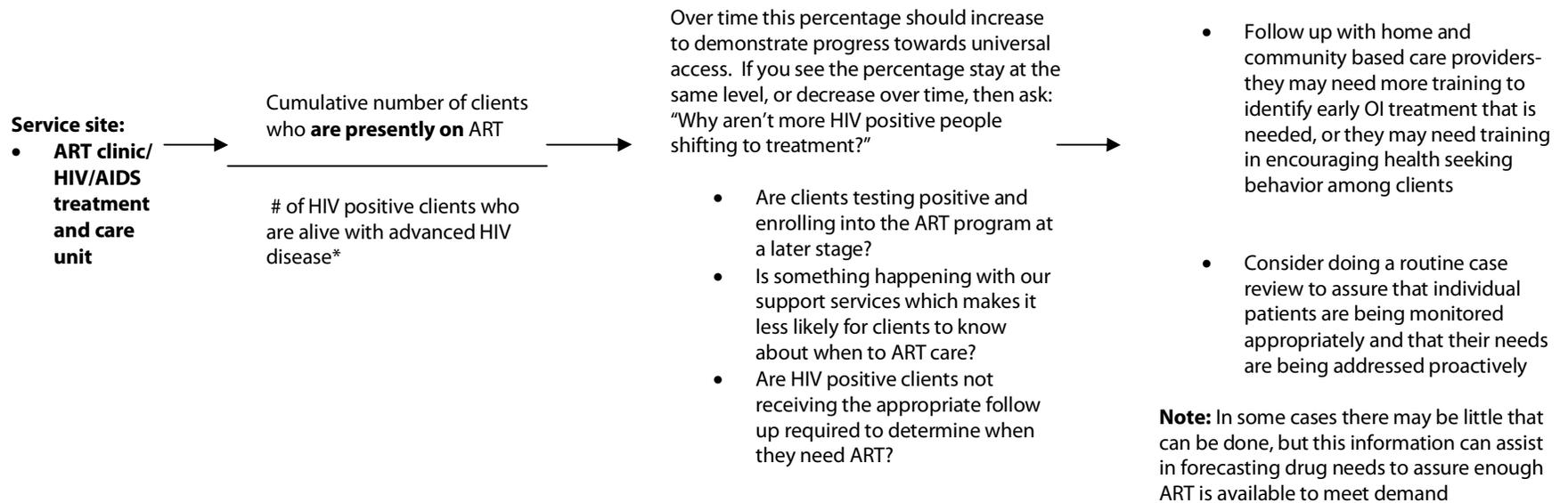
Potential programmatic solutions:

- Consider doing a mortality case review in order to identify what may have been done to prevent death

Note: In some cases there may be little that can be done, a patient may have come for HIV testing when they were already at a late stage of disease. Consideration should be given as to how to encourage people to be tested early.

Program evaluation indicators

% of HIV-positive clients who are receiving ART treatment



* Calculation: multiply the total number of HIV positive people (**not** on ART) by 15%

% of clients who are still prescribed a standard first-line treatment regimen after 6, 12, and 24 months from the initiation of treatment

- Service site:**
- ART clinic/
HIV/AIDS
treatment
and care
unit

Number of clients who are still on treatment and who are still prescribed a standard first-line regimen 6, 12 and 24 months after initiating treatment.

Total number of clients alive and on ART

This indicator can be used to measure the program's success at early detection of treatment failure, and success at improving adherence. Programs with over 80% of clients on second line drugs within a year of beginning treatment will be at risk of not controlling emerging drug resistance. You should aim to keep clients on first line drugs as long as possible if you see over **10%** of clients needing a second line regime this could be an indication of treatment failure and that people are not adhering to drugs. You should ask yourself:

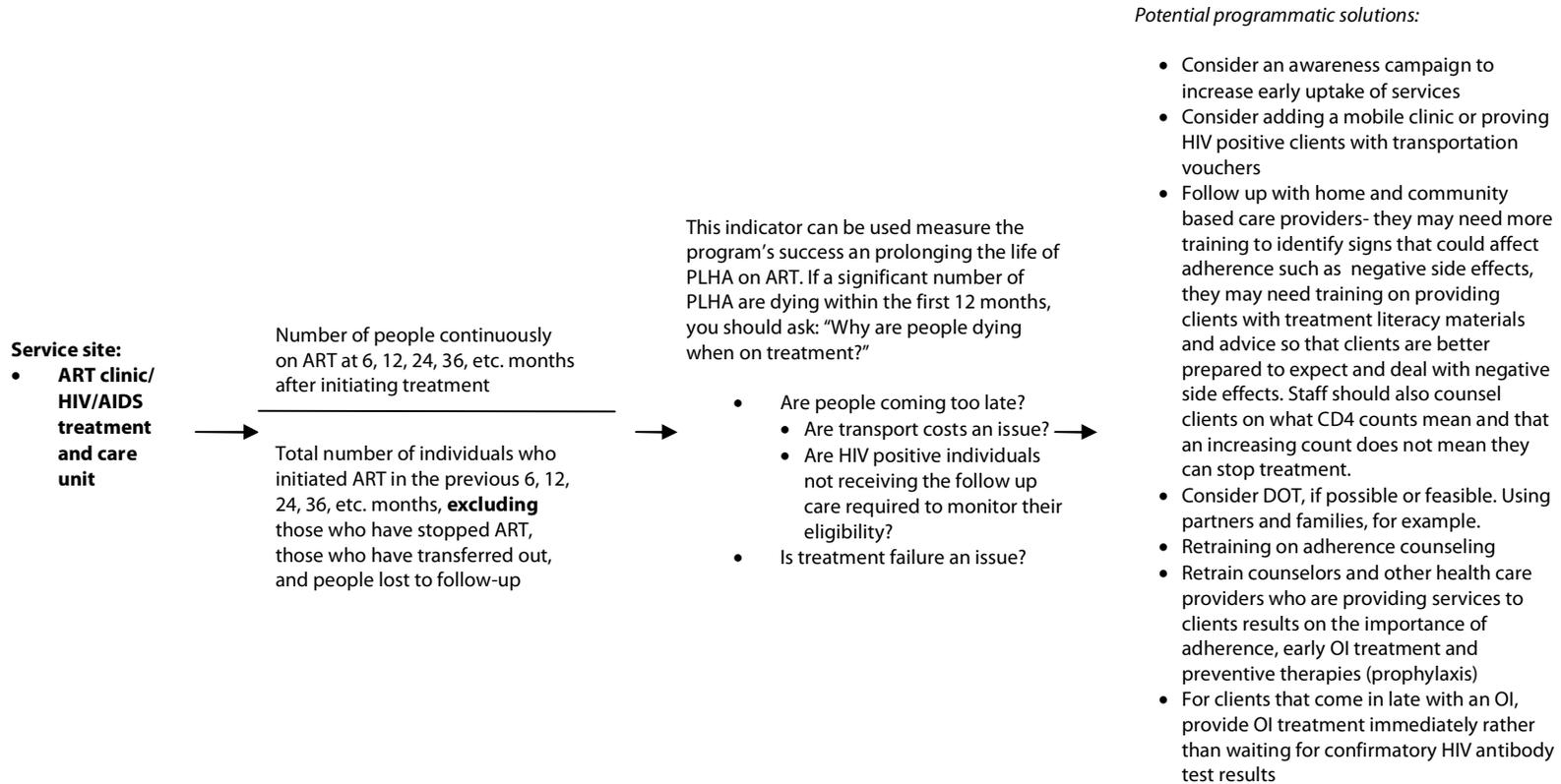
- Are clients not adhering to drugs? Why?
 - Expense of travel to clinic
 - Too sick to travel
 - Fear of treatment cost
- Did clients seek treatment too late (they were too sick and we cannot expect them to get better)?
-

Note: This indicator should be reported for those on treatment after 6, 12 and 24 months.

Potential programmatic solutions:

- Think about how treatment failure rate can be reduced. Provide a refresher training to clinical, home and community based care providers on adherence counseling.
- Follow up with home and community based care providers- they may need more training to identify signs that could affect adherence such as negative side effects, they may need training on providing clients with treatment literacy materials and advice so that clients are better prepared to expect and deal with negative side effects. Staff should also counsel clients on what CD4 counts mean and that an increasing count does not mean they can stop treatment.
- Since cost of treatment for OIs may be a concern, you should also train staff on informing clients about rural insurance schemes that may assist them in purchasing OI treatments which will increase their chances of survival.
- Consider adding a mobile clinic or providing HIV positive clients with transportation vouchers
- Follow up with clinical staff – they may need training on how to recognize treatment failure and side effects and on how to prescribe alternative first line treatment (substitution) or request second line treatment from provincial CDC
- Develop a referral network to send clients demonstrating treatment failure for confirmation of resistance

% of clients alive and known to be on treatment at 6, 12, 24, 36 months after initiation of treatment



Standard Operating Procedures (SOPs) for reducing loss to follow up among PLHA

Objectives

- 1) To establish a clinical system to prevent loss to follow up of the ART recipients

Target: Each patient should not miss more than two doses per month (in accordance with national guidelines)

- 2) To set up adherence support activities in communities with Home Based Care (HBC) teams

Implementers

Within different setting, different parties will be involved in assuring that patients continue treatment, plan for treatment continuation if they are migrating, and seek care in the case of negative side effects. Addressing such issues can contribute towards reducing loss to follow up. Two main settings where loss to follow up activities can be carried out have been identified, these include the clinical and the home/community settings.

Within the clinical setting:

- The nurse at the ART clinic has overall responsibility for tracking and following up patients at risk of being lost to follow up.
- A doctor may become involved if there are many patients
- Additional hired or volunteer staff (such as PLHA or local organization staff) can be considered in order to reduce the work load. In some cases the program may consider having one staff (volunteer or paid) sitting within the clinic at all times to provide additional adherence counseling support to patients; this person or persons could come from local organizations providing services to PLHA within the clinical and community settings.

Within homes and communities:

- Community care providers, such as members of HBC teams, local organizations, or village leaders and/or doctors who have agreed to follow up patients, who have been trained on ART adherence issues (including confidentiality) and counseling
- Family members who have been trained on adherence issues and counseling

Procedures

Different procedures for reducing loss to follow up will be implemented at the clinical sites and within the communities and homes.

At clinical level:

- 1) Registration of the first visit:
 - Assure patient that confidentiality will be maintained

- Complete all registration forms and confirm that correct information about name and address is provided:
 - o Ask for ID number (or establish a new one)
 - o Get mobile/ home phone number and call the number while patient is present to confirm it is correct
 - o Obtain address
 - Start OI prophylaxis or treatment immediately for a period of time
 - o If TB is indicated, refer for treatment
 - Assess adherence during OI prophylaxis/ treatment and use this as an indication of future adherence to ART
 - Introduce the patients to HBC care providers (if applicable)
 - Provide counseling to patients in order to encourage them to allow HBC team or village focal person to follow up with them in the home
- 2) Pre-ART education and counseling sessions:
- Provide education to patient (and their care givers, if present) on the importance of treatment adherence, potential side effects, and resources to consult if patient has any questions or side effects
 - Introduce the use of pill boxes, calendars, treatment plans or other adherence tools being used
 - Involve family members or other care giver selected by the patient in education sessions
 - Train family members or other care giver selected by the patient on adherence support
 - Monitor patient adherence to appointments using past OI adherence records, and appointment records

Preventing loss to follow up among ART patients in Lu Zhai People's Hospital

All patients are categorized into 3 groups based on adherence to ART. This adherence is assessed by the nurse who works in the ART clinic and who is responsible for counseling patients. Computer software in the database alerts staff of upcoming appointments, and provides patient contact information. The first group is called three days prior to clinical appointment and called once every day until the appointment day; the second group is called two days prior (and also on the day of the appointment), and the third group is called one day prior to their appointment (as this group has demonstrated the best adherence by not missing appointments in the past). If a patient misses an appointment, the clinical team calls them on the day of the missed appointment to follow up.

Each patient is linked to a focal person (working in township hospital, village doctor, or village leader) within their village. If the ART clinic cannot reach a patient, they contact the focal person living in the same village and ask them to follow up. Patients are aware of the person to whom they are assigned, and as part of initiating ART the clinic connects patients to the focal person.

Since initiating ART treatment in May, 2006, Lu Zhai People's Hospital has recorded 2 patients as lost to follow up (0.5% of all people on ART); it is known that these two patients migrated to another province.

- 3) ART adherence counseling by nurse, pharmacist, or PLHA peer educator:
 - Provide ART adherence counseling based on national standard on a monthly basis initially and subsequently every three months
 - Develop a simple treatment plan with the patient and include their family member or selected care giver, if possible
- 4) Preparing for the next follow-up visit:
 - Out-patient staff make a clinical appointment plan that outlines what appointments are expected during coming weeks and months
 - Prepare patients' records a week before their appointment
 - Call patients or send an SMS sent a few days prior to their appointment to confirm and remind them.
- 5) On appointment day
 - If patient does not come to appointment, call their home or mobile phone number to remind them to come in for their follow up and to pick up drugs
- 6) In a week after missed appointment date
 - Call the patient at their home or mobile phone numbers for three consecutive days
 - If contact is not made, call any focal person that is available to follow up with the patient, these can be HBC teams, village leaders or doctors, for example.
- 7) If a patient comes in after several unsuccessful attempts were made to contact him or her (they come two to three weeks late, for example), then identify why the patient did not come. Provide additional education or counseling to patient to promote adherence and reduce likelihood of resistance.
- 8) After 3 consecutive months of no contact from patient, consider him or her lost to follow up.

At home and community level:

- 1) HBC team and clinical staff meets monthly to discuss patient issues:
 - Individual cases related to adherence, negative side effects, logistical problems, etc.
 - HBC team and clinical staff provide patient feedback regarding quality of clinical and/or home based care services, if any
 - HBC team and clinical staff share information about problematic cases and develop a plan of action, if needed
- 2) HBC providers visit patients at homes at least once a month for stable patients and more frequently for those patients who are considered to be very ill. HBC team splits patients and each team has a list of patients who agreed to be followed up at homes and for

whom the team is responsible. Services provided to decrease likelihood of loss to follow up include:

- Assessment of side effects and help in solving issues or in comforting patients
- Carrying out pill counts and comparing this to the treatment schedule to assess adherence
- Encouraging and reminding patients to keep all appointments
- Making referrals to clinical services if needed
- Providing additional support for transportation, if necessary, and depending on resources available by the HBC program

Pre-conditions for HBC provision:

- All HBC providers should be trained on adherence support
- As part of the HBC team, recruit ART experienced PLHA as a HBC providers; they can work effectively on ART adherence support.

Other resources:

"My staying healthy handbook" from Cambodia

This is a handbook that links clinical and community-based services for PLHA. At the clinical level, staff complete basic follow up information on each patient including CD4 count (if done during a visit), weight, and any issues discussed or needing follow up; this is done each time the patients come. Within the community or home, patients, family members and HBC providers can use this handbook to follow the treatment progress, note appointments and follow up on or note any key issues regarding treatment. The booklet is designed to be kept by the patient, and provides educational messages regarding treatment, care, and adherence.

Standard Operating Procedures (SOPs) for Mortality Case Review for PLHA

Objectives

- 1) To provide MRC standard operating procedure to be utilized in the clinical setting
- 2) To identify potential causes of mortality among patients on treatment (ART and OIs) and propose interventions to prevent them

Implementers

MRC are carried out by the clinical ART team which includes:

- 1) ART clinic doctor
- 2) ART clinic nurse
- 3) HIV ward in-patient doctor
- 4) HIV ward in-patient nurse
- 5) HIV counselor
- 6) Staff responsible for dispensing ART and OI drugs
- 7) If possible, external medical consultant from provincial or national level

Frequency of review

The MRC should be carried out during a special meeting of the ART team **once a quarter**. During this meeting all records of PLHA that have expired during the previous quarter should be reviewed, along with any verbal autopsy forms that have been completed.

Preparation for the review

- A. A nurse from the ART team compiles all patient files where the clinical records indicate "death" or "loss to follow up" as the cause of termination.
- B. Generate a list indicating all causes of death indicated on the clinical records, these can be:
 - a) AIDS-related illness
 - b) Accidental death (traffic accidents, illicit drug overdose, suicide, etc.)
 - c) Non AIDS-related illness
- C. If a patient is lost to follow up and it is later found out that s/he died at home, the nurse should try to contact family members (or other care givers such as HBC team members, village leaders or doctors) in order to carry out a verbal autopsy (see **Annex A**). This will allow the ART team to make a decision about the cause of death.

According to some national guidelines there can be four or more forms in ART clinics. You should look for forms that contain the following information, these are the basis for the entire MRC:

- 1) Patient basic condition: this can usually be found on a registration form for patients who are found to be eligible and are referred to the ART clinic.

- 2) Follow up form: any form that documents all follow up visits of patients on ART
- 3) Treatment termination form: documents when a patient dies, is lost to follow up, or transfers out of the program
- 4) Change of treatment regimen form: this form is used to indicate when patients have changed/substituted their treatment regimen

Review process

A) ART team meeting

The ART team meets and reviews, on a quarterly basis, all patient forms looking for specific indicators.

Indicators to look at in a *Patient Basic Condition form*:

- a) Age: Patients who are older may experience faster progression
- b) Drug sharing: there may be a few cases where couples are both positive, but only one of them is on treatment (the other may not yet be eligible). It may be important to determine if partners are positive, and whether or not they were on treatment. If they were not, then the team should investigate whether or not the patient shared his or her drugs with their partner.
- c) Time between HIV status confirmation and treatment start date: Calculate the lag time between confirmed diagnosis and ART start up; this may indicate inadequate follow up of HIV positive patients.
- d) Time between treatment start day and death: When compared to the time between HIV status confirmation and treatment start date ("c", above) these indicators can serve to identify cases where diagnosis was made too late and little could have been done to prevent death.
- e) Number of past treatment regimens, including past treatment for OIs: this could indicate issues related to patient adherence to treatment. The team should review notes made during the initiation of ART or OI treatment in order to identify whether or not this was an issue. If adherence was an issue treatment failure could be considered.
- f) Use of alternative medicines such as Chinese traditional medicines and/or steroids: Knowing that the patient was using alternative medicines may indicate that there were possible drug interactions and side effects. In some cases patients may have stopped taking ART once they began taking traditional medicines. Steroid use over time could also lead to serious side effect such as internal bleeding.
- g) Weight: Severe weight loss at the beginning of treatment can be used as an indicator that the patient may have come when they were already terminally ill (late stage) and little could have been done.
- h) Symptoms: Make a list of the various symptoms the patient demonstrated during their last clinical follow up, or noted on the verbal autopsy form. Note any OIs and determine their severity as these could have contributed to death.

Lab results: Review patient record to identify any underlying liver or renal malfunctions. Look for anemia and consider the CD4 cell count, if low, this may be an indication that the patient came at late stage.

Indicators to look at in a *Treatment Follow-up form*:

- a) Was all patient follow-up carried out in a timely manner and complete (i.e., in line with national guidelines for follow up care)? This indicator indicates whether the patients had regular follow up or not
If follow up was not regular, there is the possibility that low adherence and subsequent resistance were the cause of death. Alternatively, it could also point to a weakness in the program as it did not successfully follow up patients.
- b) Are there any indications of side effects? Review all side effects noted through the course of disease, if severe these could point to adherence issues.
- c) Weight: If the patient failed to gain weight during the course of treatment (approximately 10% less than at the initiation of treatment), this may be a sign of treatment failure.
- d) How many doses were missed per month? Use this indicator together with Treatment Follow up form item "a" to interpret adherence to treatment
- e) Lab results: Look for any indications of liver or renal toxicity. Viral load and CD4 count should also be looked at over time- did the patient demonstrate and increases in viral load or decreases in CD4 counts towards the end of life, if so treatment failure or low adherence can be considered.

Indicators to consider in a *Treatment Termination form*:

- a) Cause of Death: focus on AIDS-related deaths. However, non-AIDS-related deaths might show underlying diseases such as liver disease and renal failure exacerbated by ARVs toxicity
- b) Reason for Stopping Treatment: In many cases this indicator may be left blank. This indicator is very important and in any follow up form: some information on side effects, follow-up and adherence can be obtained but that form does not have indicators on drug interaction and treatment failure. These two indicators will be recorded only at termination of treatment. If information is missing, this can be followed up through HBC teams and calls to caregivers.

Indicators to consider in a *Change of Treatment Regimen form*:

- a) Old and new regimens: Determine if the patient had changed regimen prior to death, this may indicate treatment failure.
- b) Reason for changing ART regimen: review any notes related to why the treatment regime was modified or completely changed. Serious side-effects

could be the cause of death, as well as an indication that adherence may have been an issue.

- c) Time between patient stopping first line drugs and initiating a modified or completely new regime. If the time between these treatments was long, resistance may have developed resulting in treatment failure.

B) Complete the following table

Based on the team review of the patient forms, core information can be summarized into the table below to facilitate determining the cause of death. This summary form should be attached to the report summary, explained in the following section.

Summary table on cause of death

Patient No.	Date of death (dd/mm/yy)	Age/ Sex	WHO clinical stage	CD4 at initiation/ at death	Time between diagnosis and ART initiation	Time between ART initiation and death	Clinical patient summary/ART regimen	Probable cause of death	Clinical recommendations (for clinical management)

Notes:

Patient No.: Patient Registration Number

Date of death: enter this date in the format dd/mm/yy; for cases where the exact date of death is not known, indicate an estimated date about when death occurred.

Age/Sex: Enter the patient's age at time of death, in years indicate whether they were male (M) or female (F).

WHO clinical stage: Indicate the clinical stage a time of death in accordance with WHO guidance.

CD4 at initiation/ at death: Indicate the CD 4 count at the initiation of ART and at the last visit prior to death.

Time between diagnosis and ART initiation: Indicate the time (specify if time is in days or months) between HIV confirmation and initiation of ART treatment.

Time between ART initiation and death: Indicate the time (specify if time is in days or months) between ART initiation and death.

Clinical patient summary and ART regimen: In this section indicate key information related to major signs and symptoms which have been identified during the record review. Summarize key lab results before death and note the ART regimen the patient was on at the time of death.

Cause of death: In this box indicate the ART team's consensus on definite/ probable cause of death for the patient.

Clinical recommendations (for clinical management): In this column note any recommendations on clinical management that could have delayed death.

Examples:

Patient No.	Date of death (dd/mm/yy)	Age/ Sex	WHO clinical stage	CD4 at initiation/ at death	Time between diagnosis and ART initiation	Time between ART initiation and death	Clinical patient summary/ART regimen	Probable cause of death	Clinical recommendations (for clinical management)
	20/04/07	40/M	4	40/ 45	2 weeks	<2 weeks	Very thin; anemic. GI bleeding; Hb dropping to 5. Transfused 6 pints. Post Tx Hb 11.5. F/u Hb 10. On ATT. Died after d/c from PTB Died at home ARVs:d4T/3TC/NVP 31/3/07	Malnutrition and PTB	Late initiation
	06/07 (estimated)	20/M	3	50/ 21		2 months	Hb 4 at baseline. Transfused, admitted, started ART. No f/u Hb available. D/c. Seen 1 mo later for f/u. Unknown cause of death Died at home ARVs: d4T/3TC/NVP 16/4/07	Unknown	Implement verbal autopsy

C) Report on MRC process, including recommendations for program improvement

Based on findings from the MRC, the ART team should summarize findings and consensus reached on cause of death (CoD) in the above table. In addition, the team should complete the report outlined below which asks the team to consider what changes will be made to the program as a result of the MRC process. This is a quality improvement (QI) exercise and the team should include the main areas where improvements can and should be made and roles and responsibilities should also be indicated. Progress can be followed up during the next MRC.

Quarterly Mortality Case Review (MRC) summary report and recommendations

Period covered by MCR: (dd/mm/yy) _____/_____/_____

Summary findings:

1. Cumulative number of adults alive and on ART, up to the end of this quarter: _____
2. Total number of deaths this quarter: Male: _____ Female: _____
3. Total number of patients that died this quarter.
Within 1-3 months of initiating treatment: _____
Within 4-6 months of initiating treatment: _____
Within 7-12 months of initiating treatment: _____
Over (>) 12 months of initiating treatment: _____

Summarize the causes of death for those patients that were reviewed:

Example:

- Wasting: 3 cases
- TB: 6 cases
- Unknown: 2 cases
- Hepatic failure: 1 case

Summarize important clinical findings: In this section, summarize key clinical management issues identified during the review process regarding gaps in clinical treatment.

Example:

- Delayed diagnosis of TB because of initial sputum smear was negative
- High mortality in the first month because patients came too late

Summarize key clinical management recommendations based on the review:

In this section, make realistic recommendation, including assigning roles and responsibilities, regarding how to improve clinical treatment.

Example:

- Improve diagnosis of sputum smear negative TB: Dr Smith, by August 2010
- Promote early HIV testing and counseling among IDUs and implement PITC (Provider Initiated Testing and Counseling of HIV): Dr. Joseph, by September 2010

Names of review team members:.....

Date:.....

*****Attach the summary table to this report*****

Quality improvement (QI) plan

Each quarter, the analysis of core indicators combined with the loss to follow-up and MCR results should be discussed among provincial and county partners. These discussions should be used to present findings and to brainstorm with a wider range of partners on possible ways that programs can be strengthened. The ART team should present their report for MRC as well as present key data including loss to follow up rates and core indicators (see core indicators for ART treatment programs)

Some common programmatic options that can improve the quality of services:

- Shorten the time from diagnosis to initiation of treatment,
- Initiate OI treatment prior to confirmation of positive status
- Provide symptomatic and supportive services such as nutritional services and re-hydration
- Provide prompt diagnosis and treatment of serious OIs such as TB, PCP, Cryptococcosis, Penicilloles
- Consider approaches for maintaining adherence to ART
- Address problems of side-effects and drug-interactions
- On the job training of ART team regarding specific issues, advance/ new skills

Program improvement:

- Promote early VCT uptake among high risk populations
- Implement PITC
- Ensure access to OI diagnosis and treatment
- Link facilities to home-based care services to maintain adherence and reduce loss to follow-up
- Set up a tracing system for ART clients who may be at risk of becoming lost to follow up or who may exhibit negative symptoms that could indicate an opportunity to reduce preventable deaths

Additional improvement options are presented in the core indicator decision trees that are part of this package.

Verbal autopsy (VA) form

When ART patients are lost to follow-up and later found to have died at home or somewhere outside of the hospital, a verbal autopsy is needed to determine probable cause of death. This tool includes a questionnaire which is applied to the caregiver(s) of the patient before s/he died; the purpose is to collect enough information from the care giver so that the clinical ART team can determine probable or possible cause of death. If a death certificate with cause of death is available, then this should be considered together with these verbal autopsy questionnaires in order to make a better determination.

In a *Treatment Termination form*, there are usually three categories given for cause of death:

- a) AIDS-related illness
- b) Accidental death (traffic accidents, illicit drug overdose, suicide, etc.)
- c) Non AIDS-related illness

These can be modified to include: non-health related death, and health related death (HIV and non-HIV related) in order to facilitate the data collection process.

When a patient dies outside of the facility, VA can be used to try to differentiate accident and non AIDS-related illnesses. Non AIDS-related illnesses should be clarified in order to assure that they are not the result of toxicity to the treatment regime.

Interviews should be carried out between 1-3 months following death in order to avoid recall bias. Participation is voluntary and there may be cases where the caregiver(s) refuse to discuss the death, in such cases the VA cannot be carried out.

Verbal autopsy interview form

Instructions for use: This form is to be used for PLHA deaths that did not occur within a facility. It aims to provide information that can help the ART team make a decision about the probably/most likely cause of death. The information can help identify places where the clinical team may have been able to prevent death, and therefore this information is important for improving service quality.

The questions asked in this form are sensitive and interviewers must be aware that many people may have difficulty in discussing the death of a patient. The interviewer should be clear that this information will be used to improve service quality, and acknowledge that it is difficult to talk about death. Participation is voluntary; if a respondent refuses after trying to contact them 2-3 times the interviewer should inform the ART team that follow up is not possible.

Section I: Background	
Note to interviewer: Some of this information may be available in the clinical record, however the interviewer should confirm all of this information with the respondent. Prior to the interview as much information as possible should be completed based on the clinical record, this will make the interview process shorter. Do not forget however, that this information should be confirmed by the respondent.	
Name of ART site:	_____
Patient registration number:	_____
Date of death (dd/mm/yy):	____/____/____
Age at death:	_____
Sex:	<input type="checkbox"/> Male <input type="checkbox"/> Female
Respondent name (optional):	_____
Relationship to patient:	_____
Place of death (check one):	<input type="checkbox"/> At home
	<input type="checkbox"/> On the way to hospital/clinic
	<input type="checkbox"/> Other (please specify):
Is a death certificate available?	
If yes, ask: what cause of death is indicated?	

Section II: Cause of death according to respondent	
<input type="checkbox"/> Non-health related <input type="checkbox"/> Accident (please explain briefly): <hr/> <hr/> <hr/> <input type="checkbox"/> Suicide <input type="checkbox"/> Illicit drug overdose (eg., heroin) <input type="checkbox"/> Homicide (murdered) <input type="checkbox"/> Other (please specify): <hr/> <hr/> <hr/> ⇒ Thank respondent and end interview	<input type="checkbox"/> Non AIDS- related, but health related: <input type="checkbox"/> Heart attack <input type="checkbox"/> Stroke <input type="checkbox"/> High blood pressure <input type="checkbox"/> Other (explain briefly): <hr/> <hr/> <hr/> ⇒ Thank respondent and end interview
<input type="checkbox"/> AIDS- related illnesses (please continue to next section)	
<p>Read to respondent: We would like to better understand why (<i>use patient name</i>) died. In order to do this, I will need to ask you about some of the symptoms that (<i>use patient name</i>) may have experienced in the week (7 days) prior to dying. To the best of your memory, did (<i>use patient name</i>) have:</p>	
<p>Instructions to interviewer: check all boxes that apply</p>	
<input type="checkbox"/> Coughing with blood	<input type="checkbox"/> Abdominal pain
<input type="checkbox"/> Dry cough	<input type="checkbox"/> Diarrhea
<input type="checkbox"/> Difficulty breathing	<input type="checkbox"/> Bloody diarrhea
<input type="checkbox"/> Pain or tightness in the chest	<input type="checkbox"/> Bloody stool (not diarrhea)
<input type="checkbox"/> Pain in the mouth or throat	<input type="checkbox"/> Severe headache
<input type="checkbox"/> Pain when swallowing	<input type="checkbox"/> Stiff and painful neck
<input type="checkbox"/> Loss of appetite	<input type="checkbox"/> Blurred vision
<input type="checkbox"/> Vomit blood	<input type="checkbox"/> Convulsions/seizures
<input type="checkbox"/> Fatigue	<input type="checkbox"/> Unconsciousness
<input type="checkbox"/> Muscle weakness	<input type="checkbox"/> No urine
<input type="checkbox"/> High fever	<input type="checkbox"/> Appear yellow in the skin and/or eyes (jaundice)
<input type="checkbox"/> Chills	<input type="checkbox"/> Wasting (lost weight rapidly)
<input type="checkbox"/> Could not eat	<input type="checkbox"/> Paralysis (including facial palsy)
<input type="checkbox"/> Other symptoms mentioned by respondent (please specify): <hr/>	

Did the patient stop medication (ART and/or OI treatment)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
If yes, ask when:	_____
If yes, ask exactly what medications were stopped:	_____
If yes, ask why:	_____ _____ _____
<p>Read to respondent: I would now like to ask you about the events prior to (<i>use patient's name</i>) death. In the few days (i.e., 1-2 days) prior to death can you recall anything that was different about (<i>use patient's name</i>)? Can you please share with me anything that stands out in terms of symptoms, mental state or anything that you recall as being different?</p>	

Read to respondent: This is the end of the interview. I would like to thank you for the time you have taken to answer these difficult questions. The clinical team and I appreciate that you have participated; it will help us to make our services better and of high quality for everyone in the community.

Interviewer name: _____

Interview date (dd/mm/yy): ____/____/____

Instructions to interviewer: return the completed form to the ART team so that they can use this information to make a decision related to probable cause of death.