

Adherence to ART Practices in Resource- Constrained Settings

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About RPM Plus

RPM Plus works in more than 20 developing and transitional countries to provide technical assistance to strengthen pharmaceutical and health commodity management systems. The program offers technical guidance and assists in strategy development and program implementation both in improving the availability of health commodities—pharmaceuticals, vaccines, supplies, and basic medical equipment—of assured quality for maternal and child health, HIV/AIDS, infectious diseases, and family planning and in promoting the appropriate use of health commodities in the public and private sectors.

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ACRONYMS

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
DAART	Directly Administered Antiretroviral Therapy
DOT	Directly Observed Treatment
HAART	highly active antiretroviral therapy
HIV	human immunodeficiency virus
INRUD	International Network for Rational Use of Drugs
MEMS	Medication Event Monitoring System
MI	motivational interviewing
OI	opportunistic infection
PI	protease inhibitor
PLWHA	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission
RCT	randomized controlled trial
RNA	ribonucleic acid
RPM Plus	Rational Pharmaceutical Management Plus Program
TB	tuberculosis
USD	U.S. dollar
VCT	voluntary counseling and testing

SUMMARY

In 2004, Management Sciences for Health (MSH) Rational Pharmaceutical Management (RPM) Plus carried out a literature review to examine adherence to antiretroviral (ARV) practices among patients and health care providers in both high-income and resource-constrained settings. One of the major observations of this literature review was that there was little or no documentation on the adherence to ART practices among resource-constrained countries.

In February and March 2006, MSH/RPM Plus, in collaboration with the International Network for Rational Use of Drugs (INRUD), conducted a survey on adherence monitoring and promotion practices in antiretroviral therapy (ART) in five East African countries—Ethiopia, Kenya, Rwanda, Tanzania, and Uganda. The survey's objective was to analyze adherence to ART practices in these countries in terms of measuring patient adherence and defaulting, and calculating adherence levels at health facilities and HIV programs. The survey also included a subset of questions that aimed to explore the current and potential interventions used for adherence promotion in ART.

An overview of the findings related to the primary objective is presented elsewhere.¹ This paper presents the findings based on survey participants responses to interventions used for adherence promotion in ART in their specific settings.

In addition to providing a general overview of the interventions used to improve adherence in these settings, survey participants also recommended a number of different interventions to improve adherence in their clinical setting. Some target health service provision, others the patients' socioeconomic or psychological conditions, or improvements to patients monitoring and follow-up. This suggests that health care providers in facilities understand the complexity of factors affecting adherence to ART. The recommendations included a number of interventions that cannot be addressed by the health facility itself, such as food support and provision of transport costs. This suggests that providers and managers at health facilities are willing to cooperate with organizations operating outside the formal health care setting.

A question concerning underlying reasons for less than optimal adherence was not answered by all respondents at the facility level, suggesting that the analysis of adherence problems may be challenging.

¹ Chalker, J. 2007. *The Importance of the Sida-funded Initiative on ARV Adherence in East Africa*. Arlington, VA: Management Sciences for Health/Center for Pharmaceutical Management. PowerPoint slides.

INTRODUCTION

In recent years, the international donor community has invested tremendously in making access to ART a reality for HIV-positive patients living in developing countries. As a result, an increasing number of patients have commenced ART. So far, the success of donor support to ART programs has mainly been measured in the number of patients initiating ART.

However, it is important for HIV treatment programs and the international donor community to emphasize the importance of HIV treatment adherence to achieve positive treatment outcomes. Failure to achieve high levels of patient adherence in ART programs will lead to an increase in the rates of treatment failure and an increase in demand for second-line treatment, which is currently ten times more expensive than first-line treatment.²

Adherence to ART is challenging, because patients need almost perfect adherence of at least 95 percent to keep viral load at undetectable levels as long as possible and to maintain the functionality of the immune system. A recent meta-analysis of adherence levels found that a pooled estimate of only 77 percent of people taking antiretroviral medications in sub-Saharan Africa adhered to the regimen.³ Overall, there are little data on the adherence levels reached at health facilities providing routine ART services.

Patients in developed and developing countries face common barriers to adherence like fear of disclosure, forgetfulness, difficult regimens, high pill burden, suspicions about treatment, concomitant substance abuse, work and family responsibilities, falling asleep, and access to medication. In resource-poor countries, access to medication is further challenged through patient's socioeconomic conditions and the availability of medication.⁴

In 2004, MSH/RPM Plus conducted a literature review⁵ aimed at understanding and highlighting the interventions used in high-income and resource-constrained settings. This review found a number of interventions being carried out successfully primarily in high-income settings. They include interventions which could be classified in the following categories—

- Directly observed therapy also known as DOT (including Modified-DOT and Directly Administered Antiretroviral Therapy [DAART])
- Social support

² Hardon, A., S. Davey, T. Gerrits, et al. 2006. *From Access to Adherence: the Challenges of Antiretroviral Treatment. Studies from Botswana, Tanzania and Uganda*. Geneva: World Health Organization.

³ Mills, E. J., J.B. Nachega, I. Buchan, et al. 2006. Adherence to Antiretroviral Therapy in Sub-Saharan Africa and North America: A Meta-analysis. *Journal of the American Medical Association*; 296: 679–90.

⁴ Mills, E.J., J.B. Nachega, D.R. Bangsberg, et al. 2006. Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med* 2006 3(11):e438.

⁵ Beith, A., and A. Johnson. 2006. *Interventions to Improve Adherence to Antiretroviral Therapy: A Review of the Evidence*. Submitted to the U.S. Agency for International Development by the Rational Pharmaceutical Management Plus Program. Arlington, VA: Management Sciences for Health.

- Knowledge and counseling
- Financial incentives
- Technological devices
- Additional effective interventions combined elements of each of the categories outlined above, and all these interventions could be replicated in resource-constrained settings

The literature review also highlighted that there were few documented studies on the types of interventions being used to improve adherence to ART in resource-constrained settings. To better understand the current practices in adherence monitoring and to explore adherence interventions used in resource-constrained settings of sub-Saharan Africa, MSH/RPM Plus collaborated with INRUD in conducting an adherence survey in five East African countries.

THE EAST AFRICAN ART ADHERENCE SURVEY

Objective

The primary objective of the survey was to compare current practices in measuring patient adherence to ART and calculating adherence levels and default rates at health facilities and HIV programs. The secondary objective was to explore current and potential interventions being used to promote ART adherence.

This report provides an analysis of interventions that the survey participants indicated are being used at their facilities and recommendation for additional interventions that were suggested to improve adherence to antiretroviral therapy in these settings. The survey aimed at answering the following questions—

- Are ART programs/providers using adherence promotion interventions?
- What kinds of interventions are being used?
- Are the kinds or combinations of interventions associated with the types of facilities or the range of ART services provided?
- Are ART programs/providers planning for new adherence promotion interventions?
- What kinds of interventions health providers suggest to be effective?
- What kind of adherence challenges should be addressed?

Methodology

The survey instruments (questionnaires) were developed by MSH/RPM Plus and INRUD. Two sets of surveys (copies of which are available in Annex 1) were developed—one for the health facilities and one for the programs (systems of care).⁶

The survey was administered between February and March 2006 in the five East African countries—Ethiopia, Kenya, Rwanda, Tanzania, and Uganda—by teams from INRUD and the national AIDS control bodies recruited from the five countries.

Survey administration was carried out in two phases. During Phase I, participants from the programs were interviewed about the current practices of adherence monitoring and promotion in the facilities they support. Program managers and researchers then identified the health facilities to conduct the investigation on adherence monitoring and promotion in practice. During Phase II,

⁶ Organizations or associations providing or supporting ART services may more appropriately be classified as “systems of care.” In this report we use the term program throughout to mean all kinds of systems of care for patients on ART, even when a specific ART program was not defined.

managers of health care facilities and other medical practitioners treating patients who were HIV-positive were interviewed.

A total of 24 programs and 48 health care facilities participated in the survey, responding to a range of questions covering the following topic areas—

- Methods used for measuring and calculating patient adherence*
- Reported adherence rates*
- Definitions of treatment default
- Current interventions used or planned to improve adherence to ART
- Recommendations for additional interventions

An asterisk (*) signifies that the question appeared in the survey for the health care facilities while the rest of the questions appeared in both surveys.

A list of programs and facilities participating in the survey is attached in Annex 2, and an overview is presented in Table 1.

Table1. Overview of the Health Care Systems Related to HIV/AIDS Treatment

	Ethiopia	Kenya	Rwanda	Tanzania	Uganda	Total
Programs that participated in the survey	7	6	1	5	5	24
Earliest program	2003	2001	1999	2004	1991	—
Total health facilities	102	248	84	177	52	663
Facilities that participated in the survey*	10	14	5	10	9	48
Total ART patients						
Adults	22,000	70,035	17,615	38,757	51,332	199,739
Children	2,000	4,500	1,443	3,783	6,106	17,832
Patients treated in survey facilities						
Adults	9,720	22,933	5,375	19,779	22,332	60,039
Children	331	1,618	697	1,667	2,560	6,873

*36 hospitals (13 referral, 12 provincial/district, 4 mission, 3 military/police, 4 private), 4 mission clinics, 5 NGO clinics, 2 health centers, 1 community-based organization

Closed questions were used to investigate measures for adherence promotion applied or planned. Survey participants were asked to choose from a list the interventions that they either currently use or plan to use to promote adherence to ART. Open questions were used to investigate which additional interventions respondents would recommend to improve adherence to ART to appropriately capture all areas of interventions that respondents would suggest.

Facility managers and ART providers were asked—

“If resources were not a problem, what do you think would be some useful intervention approaches to improve ARV adherence rates at your clinic?”

To understand the perceived adherence problems identified by the survey participants, they were asked—

“...what barriers to adherence would the suggested interventions address?”

One precondition for the approach is that managers and ART providers at health care facilities understand the complexity of adherence promotion and are willing to collaborate with patients and stakeholders outside the health facility in their effort to improve adherence to ART.

ANALYSIS OF SURVEY RESPONSES

Interventions to Improve ART Adherence at the Program and Facility Level

The survey questionnaires for both the programs and the health care facilities contained the following list from which survey participants were asked to indicate the interventions they either used or plan to use to improve adherence to ART—

- Patient counseling before starting ARVs
- Repeated counseling after ARVs
- Use of a support/care person
- Systematic monitoring at the clinic
- Social support
- Use of a technological device
- Use of community-based health workers
- Fast-track services at the health care facility
- Use of reminder devices
- Reimbursement of travel expenses
- Additional financial incentives

Survey participants were also asked to indicate additional interventions not on the prepared list that they use or plan to use to improve adherence. Table 2 below provides an overview of interventions to improve adherence to ART that were either used or planned in the programs and health care facilities participating in the survey.

Table 2. Summary of Interventions Used or Planned by Programs and Health Care Facilities

Interventions	Facilities, % N = 48		Programs, % N = 24	
	Use	Plan to	Use	Plan to
Patient counseling before starting ARVs	100	0	100	0
Repeated counseling after ARVs	98	2	100	0
Support person/care partner	77	6	79	5
Systematic monitoring at clinic	67	19	63	0
Social support	44	19	63	11
Use of a device	38	19	21	21
Community-based health workers	30	35	47	42
Fast-track service at health facility	27	6	26	16
Other interventions	23	2	5	0
Reminder phone calls	21	13	16	5
Reimbursement of travel	15	6	16	11
Additional financial incentives	10	2	5	5

Summary of Responses from Program Managers

Twenty-four program managers responded to the questions in the survey that addressed adherence promotion interventions. One program in Kenya did not provide any information on adherence promotion and was excluded from this analysis.

All programs analyzed reported using a number of services and interventions to promote adherence to ART and most of these interventions target HIV patients. The following is a summary of the survey responses from the programs.

Patient Counseling

All the programs reported implementing pre-counseling and continuous counseling for ART.

Support Person

Patients in the programs need to present a support person for ART treatment.

Systematic Monitoring

A majority of the programs also indicate that they use systematic monitoring of patient adherence at clinic level, but investigations at facility level showed that data on adherence levels were rarely available.

Community-Based Health Workers

Twelve of the 19 programs reported using community-based health workers or volunteers while 6 other programs reported plans to introduce community-based services.

Social Support

A form of social support was reportedly already used by 13 programs and planned by three others.

Fast-Track Services

The use of this intervention seems to be less of a priority among program managers. Only one program indicated that it uses this at large clinics by requesting that patients who have been on ART for a long time to make fewer clinic visits and training the nurse to provide fast-track clinical services

Reminder Devices

Pill boxes, diaries, and other devices that can be used by patients as a reminder or for monitoring of adherence were only used by five programs.

Summary of Responses from Health Care Facilities

Forty-eight representatives of health care facilities in the countries participated in the survey and they also responded to the same set of questions addressing interventions to improve adherence to ART as the representatives of the programs.

Responses from the health care facilities in the participating countries indicate that patient counseling is carried out prior to commencing treatment. This intervention was the most widely used form of adherence promotion among all the survey participants from the health care facilities. All but one facility indicated that the patient is repeatedly counseled⁷ when on treatment.

Other interventions were only implemented by some of the facilities assessed. Facilities had not implemented all interventions indicated by the programs that supported the facilities, and reported carrying out additional interventions that were not indicated by the programs. Deviations were found especially for community-based care, systematic monitoring of medication adherence at clinic level, and social support. This may suggest that the facility plays a bigger role in the implementation of adherence promotion interventions than do the programs.

The following is a summary of the interventions to improve adherence that survey participants from the health care facilities reported that they either use or plan to use.

Community-Based Health Care Workers

A third of the facilities which participated in the survey reported using the services of community-based health workers or volunteers to promote adherence; many others have plans of starting such services. Faith-based facilities and facilities receiving support from a nongovernmental organization (NGO) had more often implemented adherence support through community-based health workers and volunteers. The facilities sometimes collaborate with a partner to provide home-based care and to link with the community network. Some other facilities indicated that they planned to introduce this intervention in the future.

Support Person

A number of health care facilities indicated that they use a support person or care partner as a means of improving the patient's level of adherence. At most facilities, HIV patients are requested to identify a support person or treatment partner to observe adherence to ART, while others plan to make this a requirement. This may not mean, however, that patients are denied treatment when they do not have a support person. Very few facilities indicated that they planned to introduce the use of a support or care person in the future.

Social Support

Quite a few health care facilities indicated that social support interventions were being introduced in the near future. Examples of social support interventions that were already being used include the reimbursement of hospital and funeral bills for needy people following a social worker's assessment, peer education schemes and advocacy training, provision of food support especially to patients who are malnourished,⁸ clothing for very sick patients, special counseling, and day trips for children. One facility indicated that it links patients requiring social support with organizations that provide these services.⁹ Additional social support interventions are provided by social workers who conduct home visits and by family members who are educated

⁷ The analysis of the survey does not include an analysis of the content of counseling sessions and how often and how long the sessions last in average.

⁸ Patients with a body mass index (BMI) of less than 17 were considered by survey participants as malnourished.

⁹ Services reportedly provided include assistance with school fees, and food, housing, and orphan support.

in family care. One facility indicated that children are offered special counseling and that clothing is provided to needy patients. None of the facilities' survey participants indicated that patients are provided with direct financial incentives for achieving good adherence rates.

Systematic Monitoring of Patient Adherence at Clinic Level

Many facilities indicated that they systematically monitor medication adherence at the clinic, but a systematic monitoring approach could not be confirmed by the availability of respective data at clinic level. Clinic adherence data are important to assess the need for introducing adherence promotion measures and for the evaluation of the effectiveness of respective interventions and most of the survey participants from the facilities did not have a clear picture of the adherence situation at their clinic.

Fast-Track Services for Patients on ART

Few facilities promoted fast-track services for ART patients at the health facility and fewer indicated that they planned to introduce this intervention.

Technological Devices

Some facilities indicated that they use technological devices to promote adherence, but only few indicated which devices were offered to the patients. The most common example of a device used was a pill box. Some devices are provided by the programs that support the facility, while a number of facilities indicated that they planned to introduce them. Since the information that was provided on the use of device was sparse, it was assumed that this intervention was not consistently used.

Reminder Phone Calls

Only two facilities who participated in the survey indicated that they used reminder telephone calls for adherence promotion. Few others had planned to introduce this intervention at their facility. It was difficult to ascertain how frequently such telephone calls are made or planned to be made.

Reimbursement of Travel Expenses

Eight of the health facilities who participated in the survey indicated that they reimburse patients for travel expenses. One facility indicated that the travel expenses are reimbursed through a partner organization. Few facilities indicated that they planned to introduce this intervention in the future.

Additional Financial Incentives

Provision of training on potential income-generating techniques was the only additional form of financial incentives that was indicated by survey participants from the facility. Additional direct financial incentives were rarely provided and no other direct monetary incentives were provided to the patients.

Survey participants indicated a few additional interventions. One of the facilities indicated that they had created a forum held during appointment dates for information sharing and support among patients. Another facility used drama groups and a church choir for adherence promotion. In addition, a post-testing club was planned at one of the facilities.

Several of the survey participants from the facilities indicated that additional training is given to health care providers as a means of improving provider motivation.

Provider Interventions to Improve Adherence to ART at the Program and Facility Level

Fifteen of the 24 surveyed programs indicated that they use interventions to improve provider motivation, while one program indicated plans to introduce this in the future.

Thirty of the 48 respondents from health care facilities indicated that provider motivation is addressed at their facility.

Several survey participants representing the programs indicated that they considered training and discussion forums an incentive for health care providers.

Performance-based financial incentives were provided to health care workers supported by one of the programs and this was confirmed during a visit to the two facilities that are supported by the program. A community-based charity organization involves health care providers setting up targets and this is perceived as an incentive. Additional provider incentives include providing transportation and lunch allowances to field workers, and making loans and savings accounts possible to community health workers. Some programs provide competitive salary packages, money for phone calls, and equipment for home visits like gum boots and raincoats.

In one of the programs where the only incentive that was provided was training, staff motivation was described as low.

Additional provider interventions/incentives include—

- Psychological support
- Occasional one-day workshops
- Mentorship and frequent supportive supervision by mobile teams
- Knowledge building measures like seminars, workshops, continuous training, and the allowances paid for participation and overtime
- Meals at work and retreats

Recommendations for Interventions to Improve Adherence to ART

Survey participants from both the programs and the health care facilities were asked to provide recommendations for interventions to improve adherence in their settings. Fewer of the survey participants from the programs provided recommendations for interventions to improve

adherence than those from the health care facilities. The health care facilities' recommendations are analyzed in this section.

Forty-two of the 48 surveyed health care facilities suggested interventions to improve adherence to ART. Many participants proposed providing social support, making health services better accessible to the patients, and improving health care providers' capacity and motivation.

While most of the health care providers working with patients on ART were able to make suggestions on how to improve adherence in their setting, they found it more difficult to explain the underlying problems that the interventions recommended would ultimately address.

Figure 1 provides a visual analysis of the recommendations for interventions to improve adherence to ART made by survey participants from the health care facility.

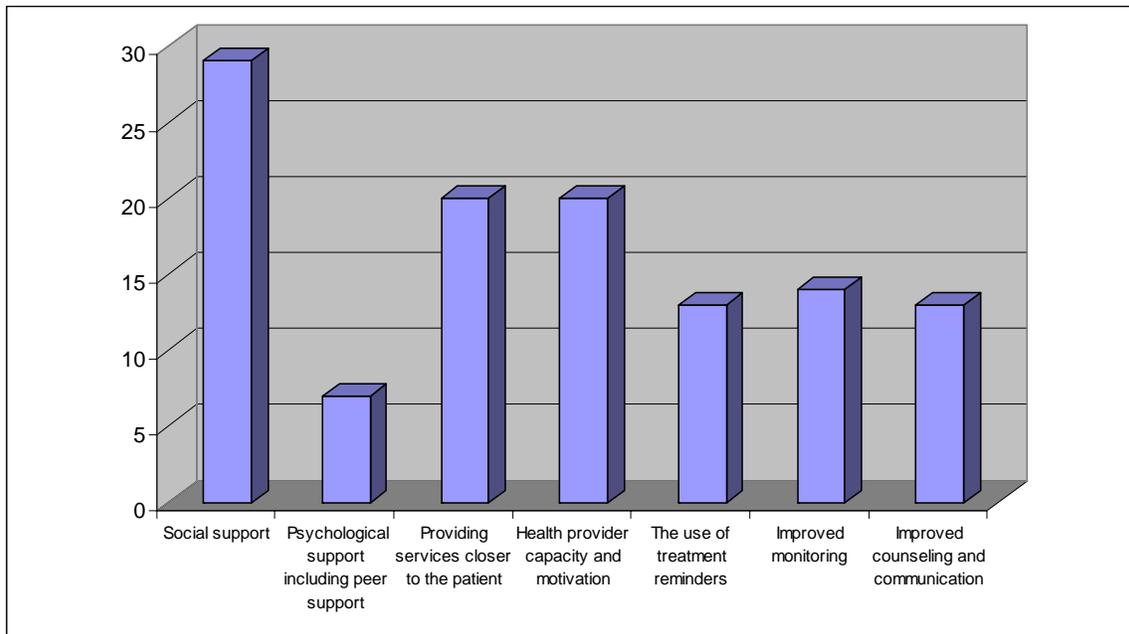


Figure 1. Recommendations for Interventions to Improve Adherence to ART by 48 Facility Survey Participants

Most of the interventions recommended could be summarized in the categories outlined in the survey and the survey participants presented different approaches to address an identified need.

Social Support

Food support and reimbursement of transport costs were frequently suggested by the respondents. Food support was recommended to target poor patients, to be provided to children, or given under specific criteria only. Clothing and shelter was also indicated as required by some patients. Some facilities recommended linking patients at the hospital to the community or community-based organizations so that they can receive the needed support there. One

respondent suggested providing health insurance to the needy patients so that they can access health services.

Psychological Support

Psychological support including peer support was said to help patients disclosing their HIV status to family or friends and for patients to motivate each other. One suggestion was to provide peer support and encourage patients to exchange experiences during clinic visits. An alternative suggestion was to form patient organizations. Other respondents suggested the use of social workers as a means of alleviating patients' worries. Psychological support was only sometimes directly emphasized. Interventions suggested to improve communication may have also sometimes included psychological support to the patient, but was not categorized as such.

Health Care Facility Location

A number of recommendations were made on providing health care services in closer proximity to the patient's residence. Suggestions included decentralization of health care services or the provision of home-based care. Home-based care was recommended in combination with treatment observation. Additional recommendations included making home-based treatment services more attractive to volunteers or community health workers by providing incentives, such as making transportation available to conduct home visits. As an alternative approach, some survey participants suggested an extension of clinic hours and opening at weekends to provide services to more patients.

Health Provider Capacity and Motivation

Health care providers suggested an increase in the number of health care staff and provision of additional training and refresher training. Regular medical supervision was recommended as a way to improve the quality of health care services and to motivate staff.

Use Reminders for Patient Adherence

Adherence aids were suggested by a number of participants with particular emphasis on pill boxes and medication calendars. Timers were recommended by a facility treating pediatric patients. Telephone reminders were recommended.

Improved Adherence Monitoring

Some respondents suggested providing a DOT system at the patients' homes. An evaluation of adherence rates at the clinic and establishing relevant measures to improve adherence was recommended. Facilities could reinforce skills of staff to monitor adherence, conduct pill count, and to improve defaulter tracing. Close monitoring was recommended for after office hours. One respondent suggested using medication event monitoring system caps to improve adherence monitoring.

Improved Patient Counseling and Communication

A number of different approaches were suggested to improve counseling. These included involving domestic partners in counseling and providing spiritual counseling, or providing intensified counseling for specific patients. The use of peer counselors was often recommended. Counseling and written information were recommended to be given in the patient's native language. Some respondents emphasized the need to increase patient literacy to increase

understanding and willingness to adhere to the medicines. One respondent suggested that for patient literacy education to be effective, it must be systematic, routine, and integrated as part of the patient's overall treatment. By having all patients go through literacy education, they would feel that they have "ownership" of their treatment.

In addition to these main categories of responses, facility providers made few additional suggestions—

- An analysis of the major reason for non-adherence before introducing interventions to improve adherence
- Set up a separate room for adherence counseling
- Conduct viral load and resistance testing at the tertiary level
- Improve access and availability of all medicines to ensure reliable and uninterrupted supply of medicines
- Computerize to reduce paper work
- Introduce free laboratory and treatment services
- Ensure that each unit of the Armed Forces has a comprehensive clinic with fully equipped laboratory and pharmacy

CONCLUSION

The survey results illustrate that all the programs and health care facilities that participated in the survey use a variety of adherence interventions that target both patients and health care providers.

Pre-counseling and continuous counseling for ART are most consistently offered to patients by all programs and at all facilities. The implementation of other interventions varies from facility to facility. Their introduction seems not to depend significantly on the program that is supporting the facility. Available human resources, the capacity of health staff, and support from the community and local partners seem to have a greater impact on the implementation of interventions locally.

Since health care facilities rarely monitor adherence levels at ART clinics, it is not possible to analyze the effectiveness of adherence promotion measures. Establishing a simple adherence monitoring system at health facility level is required to detect problems with adherence promotion and develop respective interventions.

HIV treatment programs regard provider motivation such as capacity building measures and financial incentives as an important factor in adherence promotion for ART. Performance-based incentives are rarely used, and were only reported by two programs.

There is no distinction between the interventions provided by public health facilities and other facilities. Differences were more visible in terms of providing social and financial support that were more widely implemented by faith-based and charity organizations, or at facilities receiving substantial support from an NGO.

ANNEX 1. QUESTIONNAIRES USED FOR THE SURVEY

FACILITY QUESTIONNAIRE

Antiretroviral Treatment Health Facility Adherence Survey

Name of interviewer:

Date:

Location:

Name of clinic or health facility:

Name of respondent:

Face to Face or Telephone:

If telephone what is the number_____

1. Which of the following describes the nature of your position? (Check all that apply)

- Person in charge of HIV/AIDS services
- Physician treating HIV patients
- Other health provider caring for HIV patients
- Other please describe_____

2. Which of the following best describes the nature of your health facility? (Check one)

- National/referral hospital
- Provincial/district hospital
- Other public health facility, please describe: _____
- Charity/mission/religious/NGO hospital
- Other charity/mission/religious/NGO health facility, please describe:.
- Private hospital
- Military facility
- Other private health facility, please describe: _____
- Community-based organization
- Workplace program
- Other (please describe): _____

Description (interview HIV health facility manager)

3. Which HIV-related services does your facility provide? (Check all that apply)

- ARV treatment for adults
- ARV treatment for children
- Voluntary counseling and testing (VCT)
- Prevention of mother-to-child transmission (PMTCT)
- Prophylactic co-trimoxazole for HIV-infected patients
- Prophylactic isoniazid for HIV-infected patients
- Home-based care
- Other (please describe): _____

4. Which of the following lab tests does your facility routinely conduct? (Check all that apply)

- Viral load
- CD4 counts
- Lymphocyte counts
- Other (please describe):

5. When did you start supplying ARVs to your patients?

6. How many adults are currently being treated with ARVs in this clinic?

7. How many children are currently being treated with ARVs in this clinic?

Policies Regarding Antiretroviral Therapy

For Patients already established on ARVs

8. For which period of time are ARVs usually dispensed for outpatients already established on ARVs?
(Check one)

- Daily
- Weekly
- One to three weeks
- One month
- One to three months
- More than three months
- Not known

9. Who is allowed to collect ARVs for the established patient? (Check all that apply)

- Patient
- Registered support person/care partner
- Any family member
- Community health worker
- Other, please describe: _____
- Not known

Clinical Data and ARV Adherence Monitoring

10. How frequently are the following data available in the records for each clinic visit of ARV patients at this clinic (either medical records or dispensing records stored at the clinic)? (*Interviewer should obtain copy of medical record and dispensing record if available*)

Type of data	Always	Usually	Sometimes	Never
Dosing schedule for ARV medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Names of other medications being taken by patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reported side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient self-report of recent adherence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provider's written findings from patient medication calendar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pill counts of medicine in patient's possession	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provider subjective assessment of recent patient adherence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of pills of ARV dispensed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Expected days' supply of ARVs dispensed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Date of next scheduled clinic visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For each visit, how close actual visit was to scheduled visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether patient referred for adherence counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether patient received adherence counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reported reasons for non-adherence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other data that could be used for monitoring: Please describe:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Individual Patient Level Adherence to ART

11. How is an individual patient's adherence to ART monitored in this health facility? (Check all that apply) [*Interviewer should obtain copies of the forms used*]

Adherence measure	By clinic staff	By pharmacy staff	Not used
Patient self report	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient medication calendar (checked at the facility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pill count	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinicians subjective judgment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient complying with regular appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Directly observed treatment at health facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Directly observed treatment at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Electronic pill bottle (for example: MEMS cap)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Do you calculate a numerical rate of adherence to ARVs for an individual patient from the patient-level monitoring data? [Collect examples of forms used]

- Yes, please give example of the calculation _____
- No If no, please go to Q. 14

13. What rate of adherence to ARVs does the facility consider to be satisfactory for an individual patient? _____

Clinic or Health Facility Level Adherence to ARVs

14. Do you monitor rates of adherence to ARVs at the health facility level (that is, adherence rates averaged across multiple patients)?

- Yes
- No

If you don't monitor adherence at facility/program level, what are reasons for not doing so?

If no, please go to Q. 19

15. What source of data is used to calculate this ARV adherence rate at the health facility? (Check all that apply)

- Records from individual patients' routine adherence monitoring
- Special survey conducted to monitor adherence
- Not known

16. How do you calculate the ARV adherence rate at the health facility? (Give formula) [Collect examples of forms used]

17. What is the most recent rate of ARV adherence at the health facility?

Adherence level: _____ Date reported (month, year): _____

18. What rate of ARV adherence does the clinic consider to be satisfactory at the health facility? _____

Defaulter Monitoring

19. Are patients given scheduled appointments for their next attendance?

- Yes
- No

20. Do you have a formal system in place to monitor whether patients receiving ARVs attend scheduled appointments?

- Yes
 No

If yes, please describe how this is done:

If no, please go to Q. 25

21. If a patient does not attend, do you have a way of knowing if they are ill, have died or have dropped out?

- Yes
 No

If yes, please describe how this is done and how it is recorded:

22. At what point is a patient considered an ART program dropout or defaulter?

- After failing to attend for a certain length of time, specify how long ____
 After missing a certain number of scheduled appointments, specify how many _____
 Patients are never counted as dropouts or defaulters
 Other, please describe: _____

23. Do you calculate an overall rate of program dropout?

- Yes, please give current dropout rate: _____
 No

24. Do you include patients receiving ARVs who do not attend clinic appointments in the calculation of ARV adherence rates at the health facility level?

- Yes
 No

If yes, please describe how rates are calculated for these patients: _____

25. Are there systems in place at this clinic for following-up with ARV patients who do not appear for an appointment?

- Yes, please describe: When a patient misses an appointment, a home visit is planned.
 No

Interventions to Promote Adherence

26. Which interventions do you currently use or plan to use at this clinic to promote patient adherence to ART? (Check all that apply)

Type of Intervention	Already in use	Plan to use
Patient counseling before starting ARVs	<input type="checkbox"/>	<input type="checkbox"/>
Repeated counseling after starting ARVs	<input type="checkbox"/>	<input type="checkbox"/>
Community-based health workers or volunteers	<input type="checkbox"/>	<input type="checkbox"/>
Require support person/care partner to observe treatment	<input type="checkbox"/>	<input type="checkbox"/>
Social support (e.g., home visits, food support, day care) **	<input type="checkbox"/>	<input type="checkbox"/>
Systematic monitoring of medication adherence at the clinic	<input type="checkbox"/>	<input type="checkbox"/>
Fast track service at health facility	<input type="checkbox"/>	<input type="checkbox"/>
Use device to promote adherence (e.g. diary, pill box, memory cap) **	<input type="checkbox"/>	<input type="checkbox"/>
Reminder phone calls **	<input type="checkbox"/>	<input type="checkbox"/>
Compensation for travel expenses to health facility	<input type="checkbox"/>	<input type="checkbox"/>
Other financial incentives **	<input type="checkbox"/>	<input type="checkbox"/>
Other intervention **	<input type="checkbox"/>	<input type="checkbox"/>

** Please describe any interventions of this type. Home visits are currently conducted by social workers or nurses at the facility level.

27. Do you use any interventions to improve the health provider’s motivation to promote better patient adherence?

- Yes, please describe: _____
 No

28. Have you carried out any evaluation of your intervention approaches to improve adherence to ARVs at this clinic? [*Obtain copy of any relevant reports*]

- Yes
 No

If yes, please describe evaluation and results: _____

29. If resources were not a problem, what do you think would be some useful intervention approaches to improve ARV adherence rates at your clinic?

[Ask also why suggested interventions are expected to improve adherence, which problem would they address.]

PROGRAM QUESTIONNAIRE

Antiretroviral Treatment Program Adherence Survey

Name of interviewer:

Date:

Name of program:

Location:

Name of respondent:

1. Which of the following describes the nature of your position? (Check all that apply)

- Program coordinator
- ARV clinic manager
- Physician treating HIV patients
- Other health provider caring for HIV patients

Program Description

2. Which of the following best describes the nature of your organization?

- National HIV/AIDS program
- Other unit within MoH, please describe: _____
- Local health authority
- Charity/mission/religious organization
- Other NGO
- Private medical program
- Employer-based medical program
- Community-based organization
- Other, please describe: _____

3. Which HIV-related services does your program provide? (Check all that apply)

- ARV therapy for adults
- ARV therapy for children
- Voluntary counseling and testing (VCT)
- PMTCT
- Prophylactic co-trimoxazole for HIV-infected patients
- Prophylactic isoniazid for HIV-infected patients
- Home-based care
- Other, please describe:

4. Which of the following lab tests does your program routinely conduct? (Check all that apply)

- Viral load
- CD4 counts
- Lymphocyte counts
- Other (please describe):

5. When did you start supplying ARVs to your patients?
6. How many clinics or health facilities do you have providing ARVs?
7. How many adults are currently being treated with ARVs in this program?
8. How many children are currently being treated with ARVs in this program?

Adherence Monitoring

9. Do you monitor rates of adherence to ARVs at the patient level ?
 - Yes (It is only an appreciation of adherence on ARVs for each patient, no rate is calculated)
 - No If no, please go to Q. 12

10. How is adherence to ARVs monitored in this program? (Check all that apply) *(Interviewer should obtain copies of the forms used)*

Adherence measure	By clinic staff	By pharmacy staff	Not used
Patient self report	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient medication calendar (checked at the facility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pill count	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinicians judgment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient complying with regular appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Directly observed treatment at health facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Directly observed treatment at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Electronic pill bottle (for example: MEMS cap)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(one project)

11. Is adherence to ARVs in this program monitored the same in each health facility?
 - Yes
 - No

If no please describe the reasons why they are different and the constraints involved

12. Do you monitor rates of adherence to ARVs at the program level (that is, adherence rates averaged across multiple patients)?

- Yes
 No

If you don't monitor adherence at facility/program level, what are reasons for not doing so?

If no, please go to Q. 17

13. What source of data used to calculate this ARV adherence rate at the program level? (Check all that apply)

- Records from individual patients' routine adherence monitoring
 Special survey conducted to monitor adherence
 Not known

14. How do you calculate the ARV adherence rate at the program level? (Give formula) [*Collect examples of forms used*]

15. What is the most recent rate of ARV adherence at the program level?

Adherence level: _____ Date reported (month, year): _____

16. What rate of ARV adherence does the program consider to be satisfactory at the program level?

Defaulter Monitoring

17. Are patients given scheduled appointments for their next attendance?

- Yes
 No

If no, please go to Q. 23

18. Do you have a formal system in place to monitor whether patients receiving ARVs attend scheduled appointments?

- Yes
 No

If yes, please describe how this is done: Card with scheduled appointments, names of patients written in a book on the date of the appointment.

If no, please go to Q. 24

19. If a patient does not attend, do you have a way of knowing if they are ill, have died or have dropped out?

- Yes
- No

If yes, please describe how this is done and how it is recorded:

20. At what point is a non-attending patient considered an ARV program dropout or defaulter?

- After failing to attend for a certain length of time, specify how long ____
- After missing a certain number of scheduled appointments, specify how many _____
- Patients are never counted as dropouts or defaulters
- Other, please describe: _____

21. Do you calculate an overall rate of program dropout?

- Yes, please give current dropout rate: _____
- No

Please describe how the rate is calculated _____

22. Do you include patients receiving ARVs who do not attend scheduled clinic appointments in the calculation of ARV adherence rates at program level?

- Yes
- No

If yes, please describe how rates are calculated for these patients: _____

23. Are there systems in place for following-up with ARV patients who do not attend scheduled appointment?

- Yes, All clinics: please describe:
- Yes, some clinics: please describe: _____
- No
- Don't know

Interventions to Promote Adherence

24. Which interventions do you currently use or plan to use at this clinic to promote patient adherence to ARVs? (Check all that apply)

Type of Intervention

	Already in use	Plan to use
Patient counseling before starting ARVs	<input type="checkbox"/>	<input type="checkbox"/>
Repeated counseling after starting ARVs	<input type="checkbox"/>	<input type="checkbox"/>
Community-based health workers or volunteers	<input type="checkbox"/>	<input type="checkbox"/>
Require support person/care partner to observe treatment	<input type="checkbox"/>	<input type="checkbox"/>

Type of Intervention

**Already
in use**

**Plan
to use**

- Social support (e.g., home visits, food support, day care) **
- Systematic monitoring of medication adherence at the clinic
- Fast track service at health facility
- Use device to promote adherence (e.g. diary, pill box, memory cap) **
- Reminder telephone calls **
- Compensation for travel expenses to health facility
- Other financial incentives **
- Other intervention **

<input type="checkbox"/>	<input type="checkbox"/>

** Please describe any interventions of this type:

25. Do you use any interventions to improve the health provider's motivation to promote better patient adherence?

- Yes, please describe:
- No

26. Have you carried out any evaluation of your intervention approaches to improve adherence to ARVs at this clinic? [*Obtain copy of any relevant reports*]

- Yes
- No

If yes, please describe evaluation and results: _____

27. If resources were not a problem, what do you think would be some useful intervention approaches to improve ARV adherence rates?

28. Which underlying problem or barrier to adherence would these interventions deal with?

ANNEX 2. PROGRAMS AND FACILITIES WHICH PARTICIPATED IN THE SURVEY

List of Facilities by Country

ETHIOPIA

1. Betezatha Hospital
2. St. Paul's Hospital
3. Tikur Anbessa Children's
4. Tikur Anbessa Adult's
5. Zewditu Memorial Hospital
6. Menelik II Hospital
7. Hayat Hospital
8. ALERT Hospital
9. Police Hospital
10. Yekatit 12 Hospital

KENYA

11. Ampath/Chulaimbo
12. Ampath Eldoret
13. AIC Kijabe Hospital
14. Kibera Clinic
15. Mbagathi Dist Hospital
16. Busia District Hospital
17. Holy Family Nangina
18. Nyeri PGH
19. Maragua District Hospital
20. Amurt Clinic
21. Armed Forces Memorial Hospital
22. Kenyatta National Hospital
23. Lea Toto Program
24. Nazareth Mission Hospital

RWANDA

25. Centre Hospitalier Universitaire de Kigali (CHUK)
26. Kabgayi Hospital
27. Kicukiro Clinic
28. Kimironko Clinic
29. Treatment and Research AIDS Centre (TRAC) clinic

TANZANIA

30. Makuti
31. PASADA
32. Aga Khan Hospital
33. Amana
34. Kilimanjaro Christian Medical Center
35. Lugalo
36. Mawenzi
37. Muhimbili National Hospital
38. Mwananyamala
39. Temeke

UGANDA

40. Mulago ISS Clinic
41. Naguru HC ISS Clinic
42. Joint Clinical Research Centre (JCRC) Iganga Hospital
43. The AIDS Support Organization (TASO) Gulu Centre
44. TASO Mulago
45. Makerere University Hospital
46. Gulu Hospital ART Clinic
47. IDI Adult Clinic Mulago

List of Programs by Country

ETHIOPIA

1. Addis Ababa City Administration Health Bureau (Global Fund)
2. Sr Helen Adugna
3. ENAHPA/CCF Canada
4. MSH/RPM Plus
5. Police
6. Private organization
7. Private organization

KENYA

8. CMMB/CRC
9. Médecins Sans Frontières (MSF)-B
10. MSF-S
11. PEPFAR USAID
12. NASCOP
13. Academic Model for the Prevention and Treatment of HIV (AMPATH)

RWANDA

14. TRAC

TANZANIA

15. National AIDS Control Program
16. AIDS Relief
17. Columbia University
18. MUCHS-Dar es Salaam City—Harvard (MDH)
19. EGPAF

UGANDA

20. JCRC
21. ACP
22. Infectious Diseases Institute
23. MJAP
24. TASO ART