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# EQUITY AND ACCESS TO ART IN ETHIOPIA: STUDY PROTOCOL

**JUNE 2010**

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The views expressed in this publication do not necessarily reflect the views of the U.S. Agency for International Development or the U.S. Government.



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## **ABBREVIATIONS**

AIDS	acquired immune deficiency syndrome
ART	antiretroviral treatment
FGD	focus group discussion
FHAPCO	Federal HIV/AIDS Prevention and Control Office
HIV	human immunodeficiency virus
NGO	nongovernmental organization
PLHIV	people living with HIV
USAID	United States Agency for International Development

# STUDY OBJECTIVES AND RESEARCH QUESTIONS

## Objectives

The study objectives were to

- Increase knowledge of how Ethiopia's antiretroviral treatment (ART) delivery system impacts different client groups and determine whether ART access is equitable;
- Identify the barriers to equitable access to ART at individual, household, community, and health system levels;
- Identify the factors for lack of adherence to treatment and the reasons patients are lost to follow-up;<sup>1</sup> and
- Provide evidence-based recommendations on how to reduce barriers to accessing ART.

## Research Questions

The key research questions included the following:

- How does ART use vary among population groups (e.g., by gender, age, geographical location, socioeconomic groups, ethnicity, etc.)?
- How have patterns of ART use changed over time? Is the ART scale-up (free ART) benefiting only some types of target groups or improving equity of access?
- What are the individual/household factors that inhibit ART use?
- What are the community/contextual factors that inhibit ART use?
- What are the key facility-related (health system) factors that inhibit ART use? And how do these factors vary by type of health facility?
- What are the barriers to treatment adherence? And how do these barriers work across gender, age, and socioeconomic groups?
- What are the reasons for lost to follow-up from treatment, and how do the reasons compare across gender, age, and socioeconomic groups?

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<sup>1</sup> ART patients' outcomes encompass the following broader categories: patients who (1) are alive and still on treatment, (2) stopped treatment, (3) transferred to another facility, and (4) were lost to follow-up. A patient who misses appointments for one to three months is considered lost to follow-up.

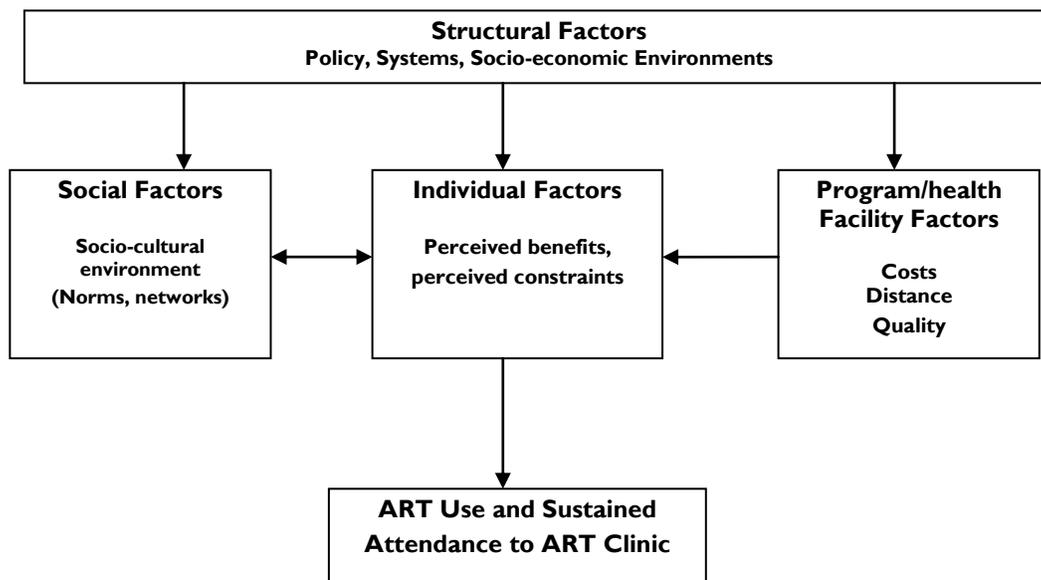
## STUDY METHODOLOGY

The study was predominately based on qualitative methods, including focus group discussions, in-depth interviews, key informant interviews, and document reviews. The authors also performed secondary analysis of data from other HIV prevalence and treatment studies.

### Conceptual Framework

A social-ecological framework was used to understand the factors underpinning ART use at individual, community, programmatic, and structural levels (see Figure 1).<sup>2</sup> The framework builds on existing theories to illustrate possible interactions between contextual and individual determinants and the pathways through which these affect health-seeking behavior. Social-ecological theories situate individuals in a dynamic “social ecology” in which individuals adapt their behavior to their social environment and make decisions based on information, influence, and interactions available through local social networks, relationships, and institutions. At the same time, social structures and processes are shaped by the collective behavior of individuals, which can shift over time.<sup>3</sup> This framework guided the data collection, analysis, and interpretation of findings.

**Figure 1. The Socio-Ecological Model of Determinants of ART Use**



### Study Sites and Respondents

In preparation for the study, staff from Futures Group visited selected urban and rural areas and health facilities to determine the availability of information, review options for data collection, and gain background for data collection tool development. A consultative meeting with concerned government and nongovernment actors predominantly involved in providing ART was also held to introduce the methodology and ensure buy-in for the study.

<sup>2</sup> Roura, M., J. Busza, A. Wringe, D. Mbata, M. Urassa, and B. Zaba. 2009. “Barriers to Sustaining Antiretroviral Treatment in Kisesa, Tanzania: A Follow-Up Study to Understand Attrition from the Antiretroviral Program.” *AIDS Patient Care STDS* 23(3): 203–210.

<sup>3</sup> Murphy, E. 2005. “Promoting Healthy Behavior.” *Health Bulletin* 2.

The selection of sites and facilities was purposive and not intended to represent all sites/facilities providing ART countrywide. The sites were selected from varying geographic locations to include major urban areas, urban slums, and semi-urban and rural (proximate) areas. In terms of facilities, the study focused on public hospitals and health centers. About 94 percent<sup>4</sup> of ART users access services at public facilities. Criteria for selecting sites included the number of ART users and the geographic areas with the highest concentration of users. In total, the study focused on nine facilities (5 hospitals and 4 health centers) and their surrounding communities (see Table 1). The sites were distributed across three regions known for a high concentration of ART users: Addis Ababa, Amhara, and Oromia.

**Table 1. Study Sites in Ethiopia**

	Region		
	Addis Ababa	Amhara	Oromia
Major urban	Zewditu Hospital	Dessie Hospital	Jimma Hospital
Small town/ Rural	N/A	Shoa Robit Health Center Akesta Hospital	Wolliso Health Center
Urban slum	Arada Health Center Kirkos Health center	N/A	Shashemen Hospital

N/A: Not applicable

## Target Respondents for the Study

To address the various research questions, the study collected information from the following groups:

- Individual community members
- People living with HIV (PLHIV) who are not on ART
- PLHIV who are on ART
- PLHIV who are on pre-ART (chronic care)
- PLHIV who discontinued ART
- Associations of PLHIV, religious groups, and other community groups
- ART service providers

## Focus Group Discussions

Focus group discussions (FGDs) served as the main information resource for (1) understanding the factors influencing ART use and adherence to treatment at individual, household, and community levels; and (2) thereby identifying the barriers to equitable access to ART. The FGDs also revealed insight into individuals' experiences and helped document case stories.

A total of 22 FGDs (10–12 participants per FGD) were held in the nine sites. Separate FGDs were conducted for each category.

<sup>4</sup> Calculation based on the most recent monitoring and evaluation report, 2009 (HAPCO, unpublished). The total number of people currently on ART is 153,741; of these people, only 4,591 are accessing treatment from a private facility and 4,987 from uniformed workers' facilities.

The main target groups included the following:

- General community members
- PLHIV who are not on ART
- PLHIV who are on ART
- PLHIV who are on pre-ART
- PLHIV who discontinued ART

FGD participants were recruited through different contact points. General community members were recruited in close consultation with a Kebele administration after receiving a written permission from higher level administrative offices. PLHIV on ART, those who discontinued ART, and those who did not start on ART were recruited through PLHIV associations and their representatives in the selected sites. The Kebele administration and PLHIV association representatives were oriented on the study's objectives.

The FGD facilitators were from the core research team and were not residents of the study sites. Local experts were not involved in facilitating the FGDs.

FGD guides were prepared and translated to local languages (see Annex 2). All discussions were tape-recorded and later transcribed verbatim by the core research team. Each discussion lasted 1.5–2 hours.

## **In-depth Interviews with Health Workers**

The health worker interviews revealed facility-related barriers to ART use, treatment adherence, and ART provision. They also provided health providers' view of community access to ART and barriers to service uptake. A total of 27 interviews were conducted in all nine sites (about 3 per site). The providers included medical doctors, nurses, pharmacists, and counselors. A semi-structured interview guide was used (see Annex 3).

## **Key Informant Interviews with Community-based Organizations**

To gather additional information on factors influencing access to ART and barriers at the community/contextual level, key informant interviews were conducted with representatives of key community groups, including PLHIV associations, religious groups, *Idirs* (Burial association), women's groups, and local nongovernmental organizations (NGOs) providing care and support services. A total of 63 key informants were interviewed. A semi-structured interview guide was used (see Annex 4).

## **Secondary Data Analysis**

ART service statistics were obtained from the Federal HIV/AIDS Prevention and Control Office (FHAPCO) and health facilities included in the study. A secondary analysis of the characteristics of patients on ART and those lost to follow-up was performed to understand levels of equity in access to treatment in the context of gender, age, socioeconomic, and geographic differentials.

The sex, age, education, occupation, religion, marital status, CD4 counts, WHO staging, functional status, and so on, of patients who started on ART during January 2007–August 2009 was extracted from the nine facilities. A facility record extraction form was used (see Annex 5). Facility data clerks ascertained proper transfer of the information from the facility ART intake form and registry book onto the extraction form. The data was computerized using EPI-INFO and analyzed using STATA 10.0.

The quantitative data analyses of individual ART records primarily focused on two issues: (1) descriptive and Univariate analysis of the socio-demographics of patients on ART to examine the extent of equity in

access to ART by sex, age, occupation, education, and marital status; (2) determination of the level of treatment discontinuation and other patients' outcome including mortality and transfer-out. The analysis also looked into socio-demographics and facility-related factors influencing treatment discontinuation. A logistics regression model was employed to examine the predictors of treatment discontinuation.

## Qualitative Data Analysis

Researchers analyzed the qualitative information generated through the FGDs and in-depth interviews through a social-ecological framework adapted to the Ethiopian context to understand the factors underpinning ART use at individual, community, programmatic, and structural levels.<sup>5</sup> The framework builds on existing theories to illustrate possible interactions between contextual and individual determinants and the pathways through which these affect health-seeking behavior.

Analysis was also guided by the study objectives and research questions, and the different data sources were triangulated, as necessary. A content analysis of the FGD transcripts was done to generate concepts, key themes, and patterns, with coding done manually.

## Ethical Considerations

Ethical clearance was sought and obtained from the Ethiopian Public Health Association (EPHA) in Addis Ababa and the Health Media Lab in Washington, D.C. FGD participants were thoroughly oriented on the study objectives and benefits/risks, and informed consent was required prior to participation. The consent form was prepared in English (see Annex 1) and the local language. The FGD facilitators/moderators were oriented and given written instructions on how to maintain the ethical aspect of the study.

The information collected contained no identifiers, such as names, identification numbers, etc., that could be used for tracing purposes after the data collection. All the information and data collected were organized, stored, analyzed, and retrieved guaranteeing confidentiality. The information gathered was kept in locked lockers and rooms and on secure computers. Information was analyzed as group data and not on the individual level. No one outside of the core research team has had or will have access to the information.

## Intended Use of the Findings

Identification of the primary barriers to ART in Ethiopia will allow the government and other actors to design policy solutions for reducing the barriers and will help increase uptake of ART services in the facilities. Recommendations to improve Ethiopia's care and treatment program and increase use of ART were generated based on the data collection findings. The study's results, analysis, and recommendations are detailed in the report titled *Equity and Access to ART in Ethiopia*. For a description of the process in implementing the overall activity, please see *Equity and Access to ART in Ethiopia: Activity Report*.<sup>6</sup>

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<sup>5</sup> Roura, M., J. Busza, A. Wringe, D. Mbata, M. Urassa, and B. Zaba. 2009. "Barriers to Sustaining Antiretroviral Treatment in Kisesa, Tanzania: A Follow-Up Study to Understand Attrition from the Antiretroviral Program." *AIDS Patient Care STDS* 23(3): 203–210.

<sup>6</sup> Both publications are available online at [www.healthpolicyinitiative.com](http://www.healthpolicyinitiative.com).

# **ANNEX I. INFORMED CONSENT FOR FOCUS GROUP PARTICIPATION**

## **Purpose of the Study**

To identify the primary barriers to ART use in Ethiopia, allowing the government and other actors to design policy solutions for reducing these barriers, and to help increase uptake of ART services in the facilities.

## **About the Organizations Conducting the Study and the Study Team**

Futures Group, in collaboration with FHAPCO and the United States Agency for International Development (USAID), is conducting the study. We (names of facilitators) are consultants to Futures Group and are assigned to facilitate the focus group discussion.

## **Explanation of Procedures**

During a focus group discussion, approximately 6–12 persons, guided by a facilitator, talk freely and spontaneously about a certain topic. If you decide to participate in this study, you will join other participants of a similar background in a discussion led by a facilitator (Name of facilitator). A focus group assistant/observer (Name of FGD assistant) will also be present. We will tape the session and make a written copy for later analysis. The facilitator's questions will relate to your opinions about ART service access and barriers faced by people living with HIV in your community. The focus group session will last approximately 1.5–2 hours.

## **Confidentiality**

The information collected will remain confidential. This means that your identity as a participant will not be revealed to people other than the facilitators. Any references to information that would reveal your identity will be removed or disguised prior to preparing any research reports and publications. All research material will be kept in a locked office in Addis Ababa. All audio recordings will be erased upon completing the study.

## **Risks and Discomforts**

We do not anticipate that participation in this study will pose physical or psychological risks beyond what you encounter in everyday life. However, if you are uncomfortable answering a particular question, you are free to refuse to answer the question, and you are free to quit the study at any time.

## **Benefits**

You will have the opportunity to discuss your views on a very important health issue such as HIV/AIDS and on community access to ART. In addition, the study results will further reveal community opinions about barriers to ART use. The final results will be shared with representatives of the government, NGOs, and concerned community groups to help improve access to ART. Ultimately, this will help Ethiopia to improve its care and treatment program and increase the uptake of ART.

## **Freedom to Withdraw Participation**

Participation in this study is voluntary. You are free to withdraw consent and end your participation in this focus group discussion at any time.

## **Remuneration**

You will not receive any payment to participate in the focus group discussion. However, you will be given 30 Eth. Birr (about US\$3) as a reimbursement for expenses incurred as a result of participation, including travel and time lost.

## **Contact Information**

If you have concerns about this study or would like to receive a copy of the study's results, please contact (Name).

**Your signature below shows that you understand the above and agree to participate in this focus group discussion.**

Please print your name \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

## ANNEX 2. FOCUS GROUP DISCUSSION GUIDES

### FGD Guide I—ART Users:

#### I. Decision and Process to Start on ART and Barriers

Topic Focus	Core Questions
Decision and process to start on ART	<p>How did you start on ART? <i>(Probe on: from whom/where did you get the information about ART Where did you seek (treatment) the first time you knew you are HIV positive? How did you decide to take ART? Who assisted you in your decision?)</i></p> <p>What treatments do you know to be available for treating HIV? What is your opinion about these? <i>(Probe on: alternative treatment: holy water, traditional healers.)</i></p>
Barriers to accessing ART	<p>How do you assess the uptake of ART by PLHIV in this community? <i>(Probe on low, medium, high.)</i></p> <p>Which groups of PLHIV are accessing ART in this community and which are not? Why and why not? <i>(Probe on: age, sex, economic status, educational status, marital status, religion, etc.)</i></p> <p>What are the most common reasons for deterring ART use by PLHIV in this community? <i>(Probe on: lack of knowledge, fear of side effects, poverty, lack of support, stigma, etc. – any friends/families not taking ART? Some personal experiences, etc.)</i></p> <p>Have you ever tried to help PLHIV friends/families to start on ART? <i>(Probe on: success stories, failed to convince, why and why not? What are their concerns for not taking ART?)</i></p> <p>What do you think should be done to help more PLHIV taking ART? <i>(Probe on: the role of health facilities, PLHIV associations, NGOs, families, and community, etc.)</i></p>

## 2. Experience with ART and Concerns

Topic Focus	Core Questions
Experience with ART	<p>What is your experience of ART? <i>(Probe on: improved health outcome, adverse effects, pill burden, lack of food, lifestyle issues, adherence, etc.)</i></p> <p>How do you describe your health situation before and after ART?</p> <p>Does your family know about you taking ART? Do your close friends know you are on ART? Why and why not?</p> <p>What support is available for you in the community, in the family, in the workplace? <i>(Probe on: care and support services, discrimination, and stigma.)</i></p> <p>How do you think you are being treated (handled) by the health workers? <i>(Probe on: in relation to adherence: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services, etc.)</i></p> <p>What do you think about the counseling that you receive? <i>(Probe on: especially importance of adherence)</i></p> <p>What do you think could be done to help people like you to adhere more easily to their treatment?</p> <p>Do you know PLHIV on ART that discontinued treatment? <i>(Probe on: why did they discontinue? Economic problem, side effect, stigma, etc. Probe on: for personal experience, holy water as an option for dropouts, etc.)</i></p>
Concerns about taking ART	<p>What do you perceive as the biggest problem regarding taking ART?</p> <p>What do you think could be done to improve this?</p>

## FGD Guide II—Community Members:

### I. Community Perception and Awareness about HIV/AIDS

Topic Focus	Core Questions
Perception and awareness regarding HIV/AIDS	<p>What is the situation of HIV/AIDS in this community? <i>(Probe on: what is the most affected group in terms of gender {male/female}, economic status, marital status {married Vs single}, and age {youths Vs adults}?)</i></p> <p>What mechanisms are in place to help PLHIV in your community?</p>

### 2. Community Awareness and Perception about ART

Topic Focus	Core Questions
Community awareness about ART	<p>What treatment options are available for PLHIV in this community? <i>(Probe on: ART, holy water, traditional healers, etc.)</i></p> <p>What do you know about ART? <i>(Probe on: what is ART? What are the benefits, side-effects, rumors, realities, etc?)</i></p> <p>Do you know where people can obtain ART in this area? <i>(Probe on: paid services, free access, facilities—government, private, accessibility, direct and indirect costs)</i></p> <p>How do you assess the uptake of ART by PLHIV in this community? <i>(Probe on: low, medium, high.)</i></p> <p>Which groups of PLHIV are accessing ART in this community and why? <i>(Probe on: age, sex, economic status, educational status, marital status, religion, etc.)</i></p> <p>Which groups of PLHIV are <b>NOT</b> accessing ART in this community and why? <i>(Probe on: age, sex, economic status, educational status, marital status, etc.)</i></p>
Community perception about ART and PLHIV on ART	<p>How does your community view people who are taking ART? <i>(Probe on: stigma, discrimination, supportive attitude, negative attitude, etc.)</i></p> <p>Do PLHIV on ART in this community openly discuss their treatment? Why and why not?</p> <p>Do people taking ART face any socioeconomic and other problems because of taking ART? <i>(Probe on: poverty, hunger, transport problems, lack of support, etc.)</i></p>
Community perception about existing program activities on ART	<p>What activities take place at the moment in your community to help PLHIV access ART? <i>(Probe on: awareness programs, health facilities, NGOs, home-based care givers, etc.)</i></p> <p>What <i>should</i> be done to ensure that PLHIV access ART in this community? <i>(Probe on: the role of government, NGOs, facilities, religious groups, community, community groups, health facilities, etc.)</i></p>

## FGD Guide III—ART Discontinuers and Lost to Follow-up:

### I. Decision and Process to Start on ART and Barriers

Topic Focus	Core Questions
Decision and process to start on ART	<p>How did you start on ART? <i>(Probe on: From whom/where did you get the information about ART? Where did you seek (treatment) the first time you knew you are HIV positive? How did you decide to take ART? Who assisted you in your decision?)</i></p> <p>What treatments do you know to be available for treating HIV? What is your opinion about these? <i>(Probe on: alternative treatments; holy water, traditional healers.)</i></p>

### 2. Experience with ART and Concerns

Topic Focus	Core Questions
Experience with ART	<p>What is your experience of ART? <i>(Probe on: improved health outcome, adverse effects, pill burden, lack of food, lifestyle issues, adherence, etc.)</i></p> <p>How do you describe your health situation before and after ART?</p> <p>Does your family know about you taking ART? Do your close friends know you are on ART? Why and why not?</p> <p>What support is available for you in the community, in the family, in the workplace? <i>(Probe on: care and support services, discrimination, stigma.)</i></p> <p>How do you think you are being treated (handled) by the health workers? <i>(Probe on: in relation to adherence: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services, etc.)</i></p> <p>What do you think about the counseling that you receive? <i>(Probe on: especially importance of adherence)</i></p>
Reasons for discontinuing ART and treatment options	<p>Why did you discontinue ART?</p> <p>What did you do after discontinuation? <i>(Probe on: treatment options.)</i></p> <p>How do you compare your health situation before and after discontinuation?</p> <p>Do you want to restart on treatment?</p> <p>What do you want to see happening for you to restart ART?</p> <p>What do you think could be done to help people like you to continuously use ART and properly adhere to treatment?</p>

## FGD Guide IV—PLHIV Not on ART:

### I. Awareness and Perception about ART

Topic Focus	Core Questions
Awareness about ART	<p>What treatment options are available for PLHIV in this community? <i>(Probe on: ART, holy water, traditional healers, etc..)</i></p> <p>What do you know about ART? <i>(Probe on: What is ART? What are the benefits, side-effects, rumors, realities, etc?)</i></p> <p>Do you know where people can obtain ART in this area? <i>(Probe on: paid services, free access, facilities—government, private, accessibility, direct and indirect costs.)</i></p> <p>Do you know or do you have friends/families who are currently taking ART? <i>(Probe on: how did they start ART? Did they talk to you about it? Did they advise you to take ART?)</i></p> <p>Have you ever been advised/encouraged by a health worker/social worker/people providing care and support services/association of PLHIV to start on ART? <i>(Probe on: Why didn't you start ART?)</i></p>
Attitude toward ART	<p>What is your opinion about ART as a treatment for HIV/AIDS? <i>(Probe on: How does it differ from other treatment options? Also probe on: opinion about other treatment options: holy water, etc.)</i></p> <p>How do you compare yourself with the other PLHIV taking ART? <i>(Probe on: in relation to age, sex, education, employment status, poverty, etc.)</i></p> <p>Do you think it is a wise decision to take ART for PLHIV like you? Why and why not?</p> <p>How do you compare yourself with the other PLHIV taking ART in relation to health and well-being? <i>(Probe on: Do you think they have benefited from ART?)</i></p> <p>Do you see yourself deprived of ART? Why and why not?</p>
Individual and social influences/barriers	<p>How does your community view people who are taking ART? <i>(Probe on: stigma, discrimination, supportive attitude, negative attitude, etc.)</i></p> <p>Do people taking ART face any socioeconomic and other problems because of taking ART? <i>(Probe on: poverty, hunger, transport problems, lack of support, etc.)</i></p> <p>What are the main reasons for you not taking ART? <i>(Probe on: stigma, do not think it is beneficial, discrimination, fear of side effect, do not know where to go, lack of family supportive, poverty, transport problems, etc.)</i></p> <p>What do you think would be the reaction of your family/friends if you start taking ART? Why and why not? <i>(Probe on: separately for family and friends perceived reaction.)</i></p>

Topic Focus	Core Questions
Self-efficacy	<p>Do you think you will use ART at any time in the future? Why and why not? <i>(Probe on: What condition should be fulfilled for you to start on ART?)</i></p> <p>What do you perceive as the biggest problem/barrier for you to start taking ART?</p> <p>What do you think could be done to improve this?</p>
Existing program activities on ART	<p>What activities take place at the moment in your community to help PLHIV access ART? <i>(Probe on: awareness programs, health facilities, NGOs, home-based care givers, associations of PLHIV, etc.)</i></p> <p>What should be done to ensure that PLHIV access ART in this community? <i>(Probe on: the role of government, NGOs, facilities, associations of PLHIV, religious groups, community, community groups, health facilities, etc.)</i></p>

## FGD Guide V—PLHIV on pre-ART:

### I. Awareness and Perception about ART

Topic Focus	Core Questions
Awareness about ART	<p>What treatments do you know to be available for treating HIV? What is your opinion about these? (Probe on: alternative treatments: holy water, traditional healers.)</p> <p>What do you know about ART? (Probe on: What is ART? What are the benefits, side-effects, rumors, realities, etc?)</p> <p>Do you know or do you have friends/families who are currently taking ART? (Probe on: How did they start ART? Did they talk to you about it? Did they advise you to take ART?)</p>
Experience with pre-ART	<p>How did you enroll into the pre-ART? (Probe on: From whom/where did you get the information about the program? Where did you seek (treatment) the first time you knew you were HIV positive? How did you decide to start on the pre-ART? Who assisted you in your decision?)</p> <p>What is your experience of the pre-ART? (Probe on: type of services, for how long, follow-up period, counseling, its benefits, etc.)</p> <p>Does your family know about you being on the pre-ART program? Do your close friends know you are on the pre-ART program? Why and why not?</p> <p>What support is available for you in the community, in the family, in the workplace? (Probe on: care and support services, discrimination, stigma.)</p> <p>How do you think you are being treated (handled) by the health workers while on pre-ART? (Probe on: in relation to privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services, etc.)</p> <p>What do you think about the counseling that you receive as part of the pre-ART follow up?</p> <p>Do you know PLHIV that were on pre-ART and later on transferred to the ART program and <u>started on ART</u>? (Probe on: describe their age, sex, educational status, marital status, etc.)</p> <p>Do you know PLHIV that were on pre-ART but later on declined to start on ART despite being advised by health workers to start on ART? (Probe on: Why did they decline? Economic problem, stigma, fear of side effect, etc? Probe on: for personal experience, holy water as an option for this?)</p>
Attitude toward ART	<p>What is your opinion about ART as a treatment for HIV/AIDS? (Probe on: How does it differ from other treatment options? Also probe on: opinion about other treatment options: holy water, etc.)</p> <p>Do you think it is a wise decision to take ART for PLHIV like you? Why and why not?</p>

Topic Focus	Core Questions
Individual and social influences/barriers	<p>How does your community view people who are taking ART? <i>(Probe on: stigma, discrimination, supportive attitude, negative attitude, etc.)</i></p> <p>Do people taking ART face any socioeconomic and other problems because of taking ART? <i>(Probe on: poverty, hunger, transport problems, lack of support, etc.)</i></p> <p>What do you think would be the reaction of your family/friends if you start taking ART? Why and why not? <i>(Probe on: separately for family and friends perceived reaction.)</i></p>
Self-efficacy	<p>Do you think you will use ART at any time in the future? Why and why not? <i>(Probe on: What condition should be fulfilled for you to start on ART? How determined are you?)</i></p> <p>What do you perceive as the biggest problem/barrier for you to start taking ART?</p> <p>What do you think could be done to improve this?</p>
Opinion on the program pre-ART activities	<p>How do you assess the effectiveness of the pre-ART program in transferring ART eligible patients to the service? <i>(Probe on: patient volume, follow-up activities, patient handling practices, whether there is a delay between eligibility and actual initiation of ART, counseling efforts to encourage ART use, etc.)</i></p> <p>What <i>should</i> be done to ensure that those PLHIV on pre-ART are successfully transferred to the ART service when eligible for treatment?</p>

## FGD Participant's Basic Information

FGD Session Code \_\_\_\_\_ Moderator \_\_\_\_\_ Rappporter \_\_\_\_\_

### Area Identifier:

Tape Code # \_\_\_\_\_ (transfer the tape label (code) onto this form.)  
 Region \_\_\_\_\_ Zone \_\_\_\_\_ Woreda \_\_\_\_\_  
 Residence: 1. Urban, name of town \_\_\_\_\_ 2. Rural, name of Kebele \_\_\_\_\_  
 Specific location \_\_\_\_\_  
 Target Facility \_\_\_\_\_

### Type of FGD Participants:

Participant's code	Sex	Age	Education	Occupation
P1				
P2				
P3				
P4				
P5				
P6				
P7				
P8				
P9				
P10				
P11				
P12				

### Short Introductory Remarks:

- Introduce FGD moderators, rapporters, and participants
- Thank participants for agreeing to participate
- Explain the purpose of the study and this discussion, reassure participants about confidentiality, and agree on the rules

## ANNEX 3. IN-DEPTH HEALTH CARE WORKER INTERVIEW GUIDE

### Area Identifier:

Region_____ Zone_____ Woreda_____
Residence: 1. Urban, name of town_____ 2. Rural, name of Kebele_____
Specific location_____
Type of Facility: Hospital [ ] Health center [ ] Other, specify_____
Name of Facility_____

Note: respondents to this questionnaire include medical directors, medical doctors, nurses, pharmacists, and counselors working on ART.

### Short Introductory Remarks:

- Thank the respondent for agreeing to participate
- Explain the purpose of the study and this in-depth interview and reassure the respondent about confidentiality

### I. Respondent identifier

1.1. Respondent category: Mark [  ]

- Medical Director [ ]  
Medical Doctor [ ]  
Nurse [ ]  
Pharmacist [ ]  
Counselor [ ] Other, specify\_\_\_\_\_ [ ]

1.2. Specialization\_\_\_\_\_

1.3. How long have you been doing this job in this facility?  
[ ] Months (*convert it to months*)

1.4. Sex of respondent  
Male [ ] Female [ ]

### 2. ART access, use, and barriers

2.1. How does this community view those people who are taking ART? (*Probe on: stigma, discrimination, supportive attitude, negative attitude, etc.*)

2.2. Which groups of PLHIV are accessing ART in this facility and why? (*Probe on: age, sex, economic status, educational status, marital status, religion, etc.*)

2.3. We would like to get your views on the following:

- a) How would you compare the number of patients on ART in this facility by their gender? Please elaborate. (*Probe on: possible explanation.*)

- b) How would you compare the number of patients on ART in this facility by their educational level? Please elaborate. (*Probe on: possible explanation.*)
- c) How would you compare the number of patients on ART in this facility by their marital status? Please elaborate. (*Probe on: possible explanation.*)
- d) How would you compare the number of patients on ART in this facility by their economic status? Please elaborate. (*Probe on: possible explanation.*)

2.4. What strategies have been in place to enroll new patients on ART by this facility? (*Probe on: the link with the pre-ART program, partnership with community programs, with association of PLHIV, with holy water sites/religious groups, etc.*)

2.5. What are the main challenges you face in enrolling new patients on ART?

2.6. How do you compare the number of patients currently on ART in this facility with the target? (*Probe on: What should be to enroll more patients on ART? What activities are underway, if there is any, etc?*)

### **3. Treatment adherence, continuous ART use, and lost to follow-up**

3.1. How do you think your patients do, generally speaking, in terms of adherence to ART? (*Probe on: Do your patients keep their appointments? Why and why not?*)

3.2. Which groups of patients in this facility are more or less likely to adhere to ART? (*Probe on: age, sex, economic status, educational status, marital status, religion, etc.*)

3.3. We would like to get your views on the following:

- a) How would you compare adherence between women and men? Please elaborate. (*Probe on: possible explanation.*)
- b) How would you compare adherence between older patients and younger patients? Please elaborate. (*Probe on: possible explanation.*)
- c) How does a patient's educational level affect adherence? Please elaborate. (*Probe on: possible explanation.*)
- d) How does a patient's marital status affect adherence? Please elaborate. (*Probe on: possible explanation.*)
- e) How does patient's economic status affect adherence? Please elaborate. (*Probe on: possible explanation.*)
- f) How do you think the distance to the health facility affects adherence? Please elaborate. (*Probe on: possible explanation.*)
- g) Does duration of treatment affect adherence? Please elaborate. (*Probe for possible explanation.*)
- h) Does treatment side effects affect adherence? Please elaborate. (*Probe for possible explanation.*)
- i) Does patients' knowledge about ART affect adherence? Please elaborate. (*Probe for possible explanation.*)
- j) Does patients' disclosure HIV status to families affect adherence? Please elaborate. (*Probe for possible explanation.*)
- k) Does patients' disclosure of his/her taking ART to families/friends affect adherence? Please elaborate. (*Probe on: possible explanation.*)

3.4. Do you have a standard practice at this facility to support your patients to adhere to their treatment? If yes, is it documented? Can we see it? In what way is it used?

3.5. What are the main challenges you face in supporting your patients to adhere to ART (especially for longer term users)?

### **4. Challenges in ART service provision**

4.1. What are the main challenges you and your colleagues face more generally in your work? (*Probe on: workload, stress, incentive, staff turn over, burnout, etc.*)

4.2. Have these challenges changed in any way since you started here? If so how?

4.3. Is any special support made available to staff engaged in ART at this facility?

4.4. Is there anything you would like to see done differently in this facility in relation to the provision of ART? If yes, what?

## ANNEX 4. KEY INFORMANTS INTERVIEW GUIDE

### For Use with Community-Based Organizations:

#### Area Identifier:

Region _____ Zone _____ Woreda _____
Residence: 1. Urban, name of town _____ 2. Rural, name of Kebele _____
Specific location _____

Note: Respondents to this questionnaire include representatives from PLHIV associations, religious groups, *Idirs*, women's groups, and local NGOs working on HIV/AIDS care and support.

#### Short Introductory Remarks:

- Thank the respondent for agreeing to participate
- Explain the purpose of the study and this in-depth interview and reassure the respondent about confidentiality

#### I. Respondent identifier

1.1. Respondent category: Mark [  ]

Medical Director [  ]

Medical Doctor [  ]

Nurse [  ]

Pharmacist [  ]

Counselor [  ] Other, specify \_\_\_\_\_ [  ]

1.2. Organization \_\_\_\_\_

1.3. Responsibility \_\_\_\_\_

1.4. How long have you been doing this job in this facility?

[  ] Months (*convert it to months*)

1.5. Sex of respondent: Male [  ] Female [  ]

1.6. Age [  ]

#### 2. Perception and awareness about HIV/AIDS

2.1. What is the situation of HIV/AIDS in this community? (*Probe on what is the most affected group in terms of gender {male/female}, economic status, marital status [married Vs single], and age [youths Vs adults]*)?

2.2. What mechanisms are in place to help PLHIV in your community?

#### 3. Community awareness and perception about ART

3.1. What treatment options are available for PLHIV in this community? (*Probe on: ART, holy water, traditional healers, etc.*)

3.2. How do you assess the use of ART by PLHIV in this community?

3.3. Do you think most people with HIV/AIDS are using ART in this community? Why and why not?

- 3.4. How do you assess ART use by gender?
- 3.5. How do you assess ART use by age?
- 3.6. How does your community view people who are taking ART? (*Probe on: stigma, discrimination, supportive attitude, negative attitude, etc.*)
- 3.7. Do PLHIV on ART in this community openly discuss about their treatment? Why and why not?
- 3.8. Do people taking ART face any problem because of taking ART? (*Probe on: poverty, hunger, transport problems, lack of support, etc.*)
- 3.9. What activities take place at the moment in your community to help PLHIV access ART? (*Probe on: awareness programs, health facilities, NGOs, home-based care givers, etc.*)
- 3.10. What is your organization doing to improve PLHIV use of ART? Any example?
- 3.11. What should be done to ensure that PLWHAs access ART in this community? (*Probe on: the role of government, NGOs, facilities, religious groups, community, community groups, health facilities, etc.*)

## ANNEX 5. ART PATIENTS' RECORD EXTRACTION FORM

### I. Study Site/Facility Identification

Region \_\_\_\_\_ Zone \_\_\_\_\_ Woreda \_\_\_\_\_ Kebele \_\_\_\_\_. If urban, town name \_\_\_\_\_

Type of Facility: Hospital [ ] Health center [ ] Other, specify \_\_\_\_\_

Facility owner: Government [ ] Private [ ] Other, specify \_\_\_\_\_ Year start of ART service \_\_\_\_\_

### 2. ART Patients' Socio-Demographics

Q1 Serial	Q2 Today's date (record extraction date)	Q3 Patient's permanent residence Woreda/ Kebele	Q4 Sex 1=male 2=female	Q5 Age at start of ART	Q6 Marital status 1=married 2=divorced/ separated 3=widowed 4=never married	Q7 Education 1=Illiterate 2=read/write 3=grade 1-6 4=grade 7-8 5=grade 9-12 6=College Dip 7=College Degree	Q8 Religion 1=Orthodox 2=Muslim 3=Protestant 4=others	Q9 Occupation 1=employed 2=self- employed 3=unemployed 4=Student 5=other__	Q10 Income (per month)

### 3. ART Patients' Clinical, Biological Information, and Current Status

Q1 Serial	Q11 Year confirmed HIV status	Q12 Date start of ART	Q13 Weight at start of ART	Q14 Functional status at start of ART 1=Working 2=bedridden 3=Ambulatory	Q15 WHO stage at start of ART	Q16 CD4 at start of ART	Q17 Patient's current status 1=still in follow up 2=drop (3 or more months) 3=lost (<3 months) 4=Dead 5=Stop	Q18 If drop, lost, or dead Record date of patient 1 <sup>st</sup> registered as drop, lost or dead



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