DESIGN, IMPLEMENTATION, MONITORING, AND EVALUATION OF CROSS-CULTURAL HIV-RELATED MENTAL HEALTH AND PSYCHOSOCIAL ASSISTANCE PROGRAMS:

A USER'S MANUAL FOR RESEARCHERS AND PROGRAM IMPLEMENTERS

(ADULT VERSION)

MODULE 1:

QUALITATIVE ASSESSMENT

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This version is an expansion and adaptation of that original manual with specific reference to research on psychosocial and mental health problems related to HIV. This adaptation process was implemented by AMHR through Project SEARCH | USAID: Research to Prevention (R2P), funded by the United States Agency for International Development (USAID) through task order # GHH-I¬00-07-00032.

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TABLE OF CONTENTS

ACRONYMS

AIDS	Acquired immunodeficiency syndrome
AMHR	Applied Mental Health Research
ART	Antiretroviral therapy
BA	Behavioral activation
CBI	Components based intervention
CBT	Cognitive Behavior Therapy
CD4	T-helper cell targeted by HIV
CDC	Centers for Disease Control
CPT	Cognitive Processing Therapy
CSA	Child sexual abuse
DHS	Demographic health survey
DIME	Design, implementation, monitoring and evaluation
DRC	Democratic Republic of Congo
EBT	Evidence Based Treatment
FG	Focus Group
FL	Free List
GBV	Gender Based Violence
HIN	Health information network
HIV	Human immunodeficiency virus
IDU	Injecting drug user
IPT	Interpersonal Therapy for Depression
IRB	Institutional Review Board
JHU	Johns Hopkins University
KAP	Knowledge, attitudes and practices
KI	Key Informant
LGBT	Lesbian, gay, bisexual, transgender
LMIC	Low and middle income countries
MEMS	Medication Event Monitoring System
MI	Motivational interviewing
MOH	Ministry of Health
MSM	Men who have sex with men
NGO	Non-governmental organizations
OVC	Orphans and vulnerable children
PE	Prolonged Exposure
PLWHA	People living with HIV/AIDS
POFO	Positive Outcome for Orphans Study
PPS	Probability proportional to size

PRA	Participatory rural appraisal
PTSD	Posttraumatic stress disorder
R2P	Research to Prevention
RCT	Randomized Controlled Trial
REC	Research Ethics Committee
SEARCH	Supporting Evaluation and Research to Combat HIV/AIDS
SES	Social economic status
SMS	Short Message Service
SOW	Scope of Work
SRP	Stress related response
STI	Sexually transmitted infections
SW	Sex worker
USAID	United States Agency for International Development
TFCBT	Trauma Focused Cognitive Behavior Therapy
VCT	Voluntary counseling and testing
VOT	Victims of Torture Program
WHO	World Health Organization

INTRODUCTION TO THE MANUAL

The Manual for Design, Implementation, Monitoring, and Evaluation of Cross-Cultural HIV-Related Mental Health and Psychosocial Assistance Programs: A User's Manual for Researchers and Program Implementers has been written to assist researchers and organizations developing and implementing programs in HIV affected populations to 1) identify and measure the impact and prevalence of mental health and psychosocial problems in the populations they seek to serve; 2) to develop or adapt appropriate interventions to address these problems; and 3) to measure the impact of these interventions. The Manual consists of 6 modules. Collectively, the modules describe a process of program **d**esign, **i**mplementation, **m**onitoring, and **e**valuation (DIME) that has been developed and used by the authors since 2000. The modules may be used in sequence, to follow the life of a project, or as stand-alone units to address a specific project need.

- **Module 1** describes procedures for a qualitative assessment to identify priority problems from the local perspective.
- **Module 2** provides guidance in the development and validity testing of tools to measure these priority problems.
- **Module 3** describes population-based assessments to gauge prevalence and severity of the priority problems using the instrument developed in Module 2.
- **Module 4** describes a process for overall design of a program to address the priority problems, including design of program monitoring and evaluation.
- **Module 5** outlines the selection, adaptation, and implementation of interventions.
- **Module 6** describes procedures for assessing intervention impacts.

Definition Box

Intervention(s): Service(s)/activity(ies) directly benefitting the client

Program: The intervention(s) and all ancillary activities necessary to support the intervention(s): logistics, finance monitoring and evaluation, etc.

LAYOUT OF THE MANUAL

Modules are presented in narrative form, with extensive use of subheadings. With the exception of text boxes, each section and each paragraph is meant to be read sequentially. Additional material that is useful as examples of concepts or expansion on subjects discussed in the text has been included in text boxes. Examples of study materials which may be adapted for use in an actual study are placed separately as appendices.

 This symbol indicates that what follows is a critical requirement or constraint.

INTENDED USERS

This manual is primarily intended for researchers and groups responsible for mental health and psychosocial interventions for HIV affected populations, such as government providers and non-governmental organizations (NGOs).

The methods described in each module are intended to be within the typical budget, resources, and time constraints of organizations that normally focus on implementation rather than data collection. The approach is designed to be used in a limited area among a population with a homogenous language, culture, and similar circumstances. In areas containing populations with a variety of languages, cultures, and environments, the approach described in this manual should be used separately with each group. For this reason, the authors have focused on developing a process that is rapid and relatively inexpensive.

This is meant as a **'**user**'** manual rather than a training manual. It is intended for use in the field by those who have previously received field-based training in its methods (or have similar training experience) and are now leading teams in their own sites. Such persons should either have some prior experience in qualitative and quantitative data collection methods (depending on the module being used) or lead teams with persons who have such experience.

 THIS MANUAL IS NOT APPROPRIATE FOR 'OFF THE SHELF' USE WITHOUT PRIOR ON-THE-GROUND TRAINING OR SIMILAR EXPERIENCE. THOUGH WHAT IS PRESENTED HERE REPRESENTS WHAT THE AUTHORS HAVE FOUND TO WORK WELL TO DATE, FIELD SETTINGS VARY. USERS OF THE METHODS PRESENTED HERE NEED FIELD EXPERIENCE TO INTERPRET AND ADAPT THESE METHODS TO DIFFERENT SITUATIONS.

The authors have found that even with prior experience in data collection, individuals and organizations attempting to use the methods described here for the first time will have many important questions during the process that cannot be addressed in the manual itself. Answering these questions as they arise—and developing the skills required for using the approaches in different settings—is best done in a field-based training situation, with direct instruction in the course of supervised use of this approach among a local population. Even after training, organizations using this approach may want guidance and ad hoc assistance.

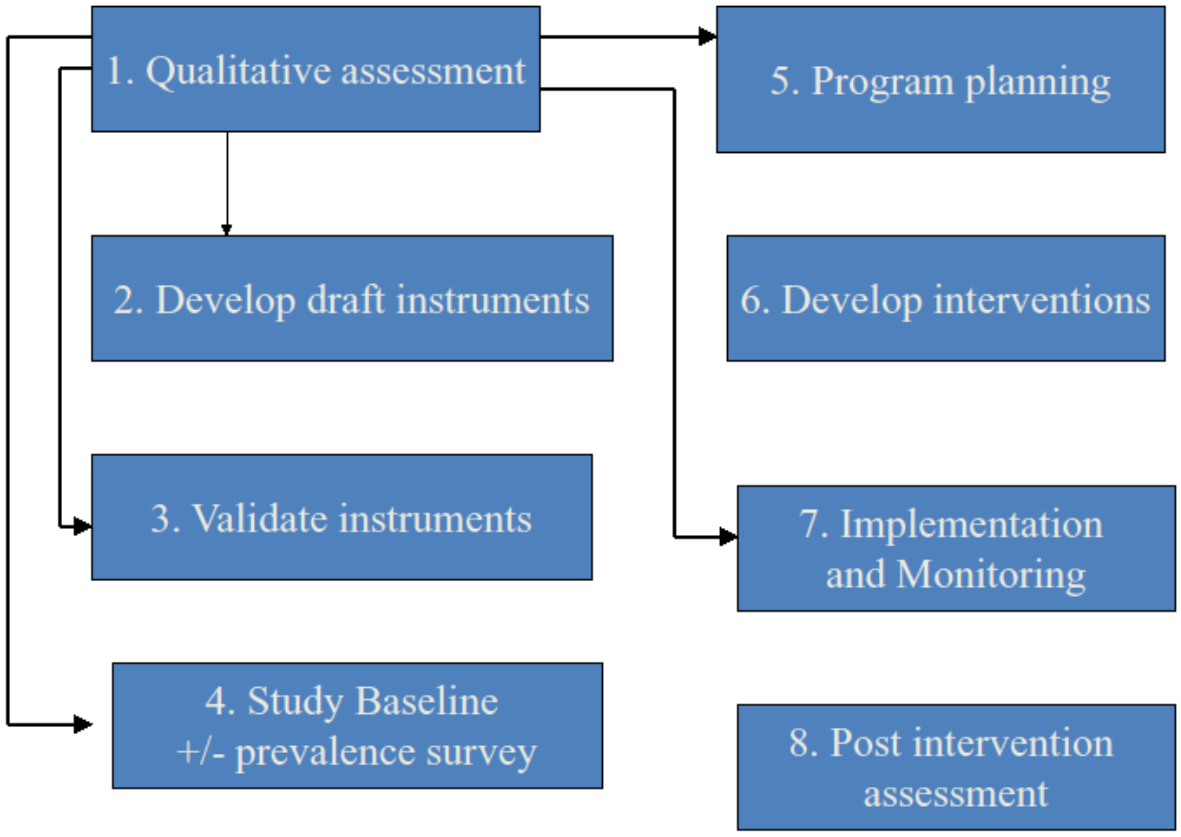
The authors would be pleased to discuss training and technical assistance with any interested organization or individual.

The manual does not contain detailed descriptions of commonly done research activities, such as quantitative interviewing, partly due to the expectation that organizations have persons experienced in these activities and partly because there are many other manuals available that describe these activities. Instead, the manual focuses on research activities or methods that are different from commonly used approaches. For example, Module 1 contains much more information on interviewing than the other modules because the qualitative methods used in Module 1 are less commonly used than quantitative methods.

THE DIME MODEL

The diagram below outlines the steps of the **d**esign, **i**mplementation, **m**onitoring, and **e**valuation (**DIME**) process described in this manual. Qualitative data collection (Module 1) is the first step in the process and the diagram indicates which of the subsequent steps (2-8) are informed by qualitative data. A brief description of each step follows.

Figure 1: Steps of the DIME Process



1. **Qualitative Assessment to identify and describe priority HIV-related mental health and psychosocial problems: (Module 1)**

   Variations in culture and environment affect how people understand the mental health and psychosocial problems related to HIV. By *understand,* we mean how these problems are described, how they are prioritized, their perceived causes, and how people currently cope with them. This information is vital in selecting problems that are important to local people, accurately communicating with them about these problems, and identifying interventions that are likely to be acceptable and feasible for local people and therefore effective and sustainable.

2. **Develop draft instruments to assess priority HIV-related mental health and psychosocial problems: (Module 2)**

   Having decided which problems the program will address, we then draft quantitative assessment instruments to address these problems. These instruments have various uses, depending on the program: conducting community or clinic-based surveys; screening persons for inclusion in a specific intervention program (for programs where not all people will be served); identifying those with severe problems who may need specialized services including referral; and monitoring and evaluating the effectiveness of services by tracking changes in severity and/or prevalence of the problems identified.

   The process of drafting appropriate instruments includes reviewing the published literature for measures that have already been developed for the selected problems and comparing available measures with the qualitative data to select the measure or measures that best match how local people describe the problem. These measures are then adapted to better fit local concepts.

   Drafting includes translation. Terminology suggested by translators often differs from that used by local populations, particularly by poor and uneducated people. Therefore, qualitative data is preferred as the best source for translating key concepts. Employing the words and phrases that local people actually use (as identified in the qualitative data) will improve the clarity of the instruments, thereby improving their acceptability and accuracy. The translators are instructed to utilize the qualitative data to directly translate all signs, symptoms, problems and topics in the instruments that were mentioned by interviewees in the qualitative study using the same words found in the qualitative data. Only where concepts are not mentioned in the qualitative data do the translators themselves choose the appropriate terms.

3. Validate draft instrument(s): (Module 2)

Once translated, the draft instrument(s) must be piloted and tested for ease of use, clarity, acceptance (both by interviewers and interviewees), and accuracy in the field. Accuracy refers to reliability and validity, which in turn refer to whether the instrument gives the same result with repeated use or use by different interviewers (reliability), and whether it measures what it is supposed to measure (validity). Testing involves interviews with members of the target population using the assessment instrument and analyzing the results.

Validity and reliability testing are particularly important with psychosocial and mental health measures, where assessment is based on the interview alone (i.e., there are no laboratory or other tests). A tool that is not accurate can lead to inappropriate inclusion/exclusion of intervention participants and also provide incorrect conclusions about need and program impact.

4. Study baseline +/-prevalence surveys: (Module 3)

Both baseline assessments and prevalence surveys are based on the instruments developed in steps 2 and 3. Baseline assessments refer to interviews done using the instrument in order to establish the eligibility of individuals for participation in an intervention program. Prevalence surveys perform the same function at the population level to measure the percentage and numbers of eligible (i.e., affected) persons in the population as well as giving some indication about the variation in severity of problems at the population level.

5. Overall program planning: (Module 4)

This includes planning the program goals and objectives and the strategy and the type of intervention(s) for achieving these. It also includes the development of process and impact indicators and the overall program work plan.

6. Develop interventions to address the identified HIV-related mental health and psychosocial problems: (Module 5)

The qualitative data on the perceived causes of problems and how those affected cope with the problems are critical to intervention design. Interventions need to address the perceived causes of priority problems (or explain why they do not) in order to make sense and therefore inspire both confidence and cooperation. The more closely interventions can match the ways in which people currently think about and address the

selected problems, the more likely the interventions are to be acceptable to them. Where there are differences, they need to be explained and agreed upon by the local population. For example, using counseling to address a problem that is thought to be caused by poverty will take some explaining.

7. **Implementation and monitoring: (Modules 4 and 5)**

   This refers to the implementation and monitoring of the intervention and the overall program. It includes procedures for iterative changes in the planned activities as needed, according to the monitoring data.

8. **Post intervention assessment: (Module 6)**.

   Upon completion of the intervention, participants are interviewed using qualitative methods to identify potentially important unexpected impacts of the program. They are also re-interviewed using the baseline quantitative instrument, to measure changes in the outcome indicators such as problem severity and function. Where possible, the amount of change is compared with the amount of change experienced by a control group, to determine the true program impact.

MODULE 1:

QUALITATIVE ASSESSMENT

A. INTRODUCTION TO MODULE 1

A.1 PURPOSE OF MODULE 1

This module describes a process for identifying locally relevant HIV-related mental health and psychosocial problems and selecting which problems to address with relevant interventions. Included in the domains of mental health and psychosocial problems are common mental health problems related to HIV (depression, anxiety, and posttraumatic stress disorder); psychosocial problems that are often difficult to assess, such as stigma, socially unacceptable behaviors, and substance use issues; and other related issues such as treatment utilization and adherence and severe mental illness.

Upon completing the methods described in this module, program staff will be able to

1. Understand local perceptions of HIV-related mental health and psychosocial problems including:
   A. Descriptions of the problems themselves
   B. Some indication of their relative importance to local people
   C. Their perceived severity and impact on other areas of life
   D. Their perceived causes
   E. What people currently do to address these problems

2. Understand local perceptions of healthy functioning and wellbeing, including aspects related to living with HIV as well as living with family members, friends, and communities affected by HIV

3. Select the problem(s) to be addressed by an intervention program, based on 1 and 2 as well as other inputs

The approach described in this module has been field-tested in a variety of countries since the original version was first developed in 1998. The approach is intended to be simple, rapid, efficient and suitable for use in low resource environments. It is specifically intended for use in these environments by both implementing organizations and researchers.

A.2 BACKGROUND

A.2.1 BRIEF HISTORY OF THIS APPROACH

The qualitative study methodology described in this module was first developed in 1999 to assist humanitarian organizations with identifying and understanding adult priority health problems from the point of view of a local population. The methodology emerged from the authors' perception that many program failures occur in the design phase and are caused by misunderstandings between implementers and partners about what issues programs will address and what approach they will take. Experience, review of program reports, and conversations with colleagues suggested to the authors that these types of misunderstandings were common and led to frustration on all sides. They also led to programs that were not well appreciated or well understood by recipients who were therefore not willing to support them. Simply increasing the amount of communication between implementers and the population did not effectively address these problems. This was partly because conversations were usually limited to community leaders and prominent people, but mainly because both sides still did not enter or leave the conversation with a good understanding of how the other side viewed the situation. Normal methods of conversation employ too many closed and leading questions based on assumptions that both sides think similarly. Therefore, these methods alone cannot provide a basis for really understanding local problems, priorities, and needs from the local population's point of view. Just as important, implementers often did not realize when their assumptions were wrong and significant misunderstandings occurred.

What was needed was an approach for communicating with both ordinary and knowledgeable local people that was more exploratory than normal conversation and less subject to influence by the interviewer. Such an approach would increase the amount and depth of information provided by local people while reducing the impact of the implementers on what local people say and on how it is understood by the implementer.

The qualitative interviewing methods presented in this module meet these requirements by adhering to the following principles:

- Letting the interviewee lead the conversation
- Using non-leading questions and statements
- Probing for as much information as possible without leading
- Not showing approval or disapproval of what is said
- Treating the interviewee as the expert
- Recording verbatim everything the interviewee says about the topic
- Repeating interviews

When qualitative methods are used correctly, the resulting information reflects the respondent's own thinking absent the influence of the interviewer or researcher. This is different from quantitative interviewing methods, which normally use specific (and usually leading) questions designed by the researchers. Similarly, responses are limited to options also selected by the researchers (e.g., yes/no; none, a little, a lot; 1, 2, 3). Even where possible responses are open-ended, the effect of using a specific question, and of the content of the rest of the questionnaire, affects the answers that are given.

Qualitative interviewing methods can be used alone, such as in Participatory Rural Appraisal,[1] or together with quantitative data gathering methods. In the latter approach, the qualitative/quantitative combination can be done sequentially or concurrently depending on research and program needs. The methods presented in this module adopt the sequential approach, with the qualitative phase informing both the design of the quantitative assessments and the intervention program design itself.

Since 1999, the authors have adapted this approach specifically to inform a wide range of mental health and psychosocial programming. Adaptation has included repeatedly shortening the duration of the study while striving to retain sufficient accuracy and scientific rigor. The version of the qualitative study described here normally requires 12 working days for training, data collection, and basic analysis.

A.3 PURPOSE OF QUALITATIVE ASSESSMENT

A.3.1 INFORMING PROGRAM DECISIONS ON WHICH PROBLEMS TO ADDRESS

Investigation into how local people perceive and prioritize their mental health and psychosocial problems is important in deciding which problem(s) to address, yet this is not commonly done. Instead, this decision is often made by an outside expert(s) based on a review of available literature and their own experiences, both of which are often derived from work with other populations. Those deciding which mental health and psychosocial problems to address tend to focus on the most dramatic or negative experiences of the population and to address problems likely to arise from those experiences, or the problems they expect to be most important based

[1] Participatory Rural Appraisal **(PRA)** is an approach used by non-governmental organizations (NGOs) and other agencies involved in international development. The approach, described in 1983 by Robert Chambers, aims to incorporate the knowledge and opinions of rural people in the planning and management of development projects and programs.

on work with other populations. For example, when working with populations affected by torture and other traumatic experiences, it is commonly assumed that post-traumatic stress disorder (PTSD) is the dominant mental health problem that must be addressed. This is based on many survey studies that have found PTSD to be prevalent in such populations. Similarly, when working with populations living with HIV, depression is often assumed to be the dominant mental health and psychosocial issue because of the substantial research linking HIV-infection with depression. Workers also tend to assume that these problems will be expressed in the same way across populations; that symptoms, causes, and effects will be the same.

Quantitative studies in non-Western cultures have tended to confirm the existence and similarity of the common mental disorders of depression, anxiety, and PTSD across cultures. However, these studies use questionnaires that are based on symptoms found among Western populations. Since questionnaires use closed and/or leading questions, an interviewee need not understand the question (or recognize the symptom) in order to respond. Given the incentive to report problems and potentially receive aid, there is reason to doubt whether the results of such interviews alone form evidence for the local existence of a problem and how it is manifested.

Given these concerns, the qualitative study is intended to provide a more open and less leading approach to investigating the following questions:

1. *Does a suspected problem occur in the population?*
   Implementing organizations and research teams often begin their work with certain assumptions about the types of problems that might exist and be relevant to the HIV-affected populations they are working with. The qualitative methods described in this module will allow these teams to learn from the local population whether these suspected problems really are relevant in the local context, as well as whether there are other problems not initially considered by the teams, which need further investigation.

2. *What does the problem 'look' like locally?*
   The methods described in this module allow the study team to understand the local presentation of HIV-related mental health and psychosocial issues using the terminology and idioms of the target population. This includes HIV-related behavioral problems such as risk taking and/or inappropriate health seeking behaviors and psychosocial problems such as stigma.

3. *Do local people consider it a problem?*

If the 'problem' does occur in the population and is recognized in ways similar to other populations it may not necessarily be considered to be a problem. This is particularly important with mental health issues, where people might recognize the symptoms, but may not think that they are problematic for the people experiencing them. For example, in some communities someone who hears voices may be thought to be in communication with spirits or the dead.

4. *Do they consider the selected problem(s) to be a priority?*
   Populations in need of assistance programs tend to have multiple problems. If a program is seen to be addressing a minor issue, or an issue affecting only a few people, local people may not consider it worthy of support. This distinction is particularly important when addressing problems of people living with HIV, as the local community may not think the target population 'worthy' of services (i.e., if those engaging in HIV-risk behaviors are highly stigmatized). Knowing the degree to which a community prioritizes the selected problems will assist an implementing organization in thinking through how to introduce the program to the community and what type of preparation work and community education may be needed.

Our experience is that all these questions should be investigated, and that the answers will guide the selection, adaptation and introduction of services. The qualitative study described in this module is intended to answer these questions.

A.3.2 INFORMING PROGRAM DESIGN, IMPLEMENTATION, MONITORING, AND EVALUATION

In addition to identifying and describing which problems to address, the qualitative data informs other aspects of the DIME model. Qualitative data collection is the first step in the process and informs subsequent steps, including the development of draft instruments to assess priority HIV-related mental health and psychosocial problems; translating and validating the instruments; and planning interventions. See Figure 1 and its description in the Introduction to the Manual for an overview of the various uses of the qualitative data.

B. METHODOLOGY

B.1 OVERVIEW

Qualitative methods are designed to investigate how local people understand their own situation, with an emphasis on understanding local concepts and language usage. This manual describes a qualitative approach to investigating local topics of particular relevance to the planning, implementation, and evaluation of HIV-related mental health and psychosocial programs. These topics are:

1. Important HIV-related mental health problems affecting local people, including common mental health problems, substance abuse, and severe mental disorders
2. Relevant co-occurring psychosocial issues, such as stigma and health seeking behaviors (i.e., initiation and/or adherence to HIV-treatment) that are associated with HIV-related mental health and psychosocial problems
3. Detailed, in depth information about a selection of the mental health and psychosocial problems and issues that can be addressed by existing, or to-be-developed, services.
4. Local perceptions of important areas of functioning related to daily living.

Briefly, this approach addresses issues 1 and 2 above by gathering lists and descriptions of problems and related issues identified by local people. From these lists of problems and issues, the implementing organization selects which problems they want to learn more about to inform the services they can provide. The selected problems are then investigated in more detail (issue 3). Local perception of functioning (issue 4) is addressed in the same way as issue 1 and 2, by developing lists of tasks and activities that local people report as being important aspects of their regular family and community roles.

The qualitative assessment study is composed of the following steps:

1. Preliminary meetings with community members, leaders and other relevant stakeholders, such as government and implementing organizations
2. Hiring interviewers and supervisors
3. Training qualitative interviewers and supervisors
4. Conducting Free List (FL) interviews
5. Analyzing FL interview data
6. Selecting problems likely to be addressed by future programs
7. Conducting Key Informant (KI) interviews
8. Analyzing KI interview data
9. Conducting Focus Groups (FG)
10. Analyzing FG data

The remainder of this module is a detailed description of each of these steps with examples presented in the appendices. An example work-plan and expected resource needs for implementing the qualitative study are presented in Appendices A and B.

B.2 PRELIMINARY MEETINGS

B.2.1 PARTICIPANTS

Staff from the organization implementing the qualitative assessment should initiate a meeting with recognized community leaders and other relevant local stakeholders. Depending on the focus of the study, the meeting may include a variety of individuals from the community, such as traditional leaders, local government officials, and staff of local NGOs. In communities with relatively high rates of HIV-infection, where the community in general recognizes the problem of HIV and is already motivated to accept community-level programs, these meetings may be open to the general community.

If the purpose of the study is to focus on more select populations, such as those with severe mental illness or highly stigmatized groups such as commercial sex-workers (CSWs), injection drug users (IDUs), etc., thought needs to be given to which members of the community will be open to talking about these groups and who will be relevant in ensuring smooth implementation of the study and collaboration within the community. We have found that contacting local advocacy groups, such as groups of individuals currently living with HIV or groups of former drug users, is an important step in deciding who needs to be informed of the study and in gaining assistance with approaching the relevant stakeholders. The meetings can take place individually or with many participants at one time, depending on participant availability and what is considered feasible and appropriate.

B.2.2 CONTENT AND SEQUENCE

Information presented should avoid specifics whenever possible, to avoid influencing responses or stigmatizing participants.

The meeting(s) should include an outline of the study that covers the following issues:

- Purpose of the study – focused on gaining local information to inform service development and service improvement
- A general description of the type of questions (open ended) that will be asked and the kind of persons/groups of persons likely to be interviewed
- The voluntary nature of participation, and the right of each individual to refuse to participate or to withdraw at any time without consequences
- Confidentiality of the information, and how confidentiality will be maintained

- Any risks and/or benefits to individuals and the community
- An opportunity for leaders and stakeholders to ask questions

After these issues have been presented and discussed by meeting participants, organization staff should:

- Request the consent of leaders and stakeholders to conduct the study in their communities and request their support in mobilizing the community/target population and gaining their cooperation.
- Discuss whether leaders and stakeholders believe a larger, community 'town hall' meeting is warranted. The decision about whether to hold such a meeting depends on whether community leaders feel it is needed and how much of an imposition it would be on community members to attend.

When a community town hall meeting is recommended by the leaders and stakeholders, everyone in the community should be invited. The meeting should take place soon after the meeting with local leaders and stakeholders. The presentation to the community should cover the same points as the meeting with the leaders and stakeholders and include ample time for everyone to ask questions. The meeting should be convened at the time and place most convenient for community members. Leaders should be asked to encourage as many community members as possible to attend. Again, information should be kept general to avoid influencing responses or stigmatizing participants. Also, community members should be told that participation does not entitle them to benefits or special treatment.

In presenting the study and answering questions, both to community leaders and in a town hall meeting, it is important not to provide information that could influence responses. Information should be as general as possible. For example, when possible the study should be described as learning about ‘community problems’ rather than referring to any particular type of problem. Staff should repeatedly emphasize that participation is voluntary and will not favor participants, improve their status, or entitle them to any special benefits. Likewise, those refusing to participate will not be denied any services or benefits that they would otherwise receive in current or subsequent programs.

B.3 HIRING INTERVIEWERS AND SUPERVISORS

This approach relies on many interviewers and several supervisors. These roles may be filled by staff from the implementing organization, outside hires, or a combination of both. Staff is used if there is an interest in building capacity (particularly if future studies are anticipated) and/or in order to save costs. Usually, however, there is not sufficient staff to cover all positions, so interviewers and supervisors are typically a mix of staff and outside hires. It is important to

ensure that the selected interviewers are acceptable to the population being interviewed, particularly when the target population, such as individuals or groups generally stigmatized in their communities, may be mistrustful. For example, in one study we responded to this sensitivity by using former drug users as interviewers to investigate HIV-related behaviors related to current drug use. Though not all of the interviewers were former drug users, all had experience working with that population.

It is useful to engage the leaders and stakeholders from the preliminary meetings (described above) to think through who would be appropriate interviewers, and to consider using them to assist with identifying potential interviewers.

Potential interviewers and supervisors must be informed of the importance of working every day during the study. Once hired, they will be expected to prioritize the study over other work (an issue that often comes up when interviewers come from the implementing organization and are pulled in many different directions). Emergencies and/or unexpected but important events can occur that can oblige those involved to miss a day or more, and under such circumstances, an interviewer can leave briefly and return to the study as soon as possible. In addition, potential interviewers should arrange childcare, as it is inappropriate to have infants and children present in the interview

 **If a person misses any of the class-room training, she/he cannot continue to work on the study regardless of the reason.** This includes the general interviewer training during the first day of the study and the explanation and practice periods for the specific interviewing methods. Without the training she/he cannot be expected to use the interviewing methods correctly.

For a given site, 12 interviewers and three supervisors are needed. The study can be done with ten interviewers but 12 are hired to account for up to two interviewers being absent on any day, or to take the place of those who leave the study for any reason. If the study is to be done in multiple sites that have different characteristics (i.e., urban vs. rural; different languages; etc.), it will be necessary to multiply the number of interviewers and supervisors by the number of different types of sites, in effect conducting separate studies at each site.

B.3.1 INTERVIEWER QUALIFICATIONS

- ✓ Fluent and literate in the language(s) of the local population where the study will be conducted
- ✓ Able to commit to the study timeline (full time for approx. 12 working days)
- ✓ In good health and able to walk long distances if needed
- ✓ Acceptable to the target population (in terms of reputation, where they are from, gender, age, ethnicity)

No previous experience in interviewing is required. In some cases, previous experience raises problems because the methods used here are different from those used in most studies and interviewers might find it difficult to adapt. Typically persons who have completed high school are preferred, although anyone who can speak, read, and write the local language is acceptable. Where there are limitations or restrictions on communications between men and women, selection of the interviewers must reflect the gender of people being interviewed. For example, interviewers should be predominantly women in cases where mostly women or girls are being interviewed and women cannot be interviewed by men.

While the interviewers need to be acceptable to the sample being interviewed, they should not be personally well known by the interviewees. This is because the goal is to have the interviewees provide all the information they can on the topics being studied. If they know the interviewer, they may assume the interviewer already knows some of the problems and/or may not feel comfortable talking about certain issues.

B.3.2 SUPERVISOR QUALIFICATIONS

- ✓ Fluent and literate in language(s) of the local population with whom the study will be conducted
- ✓ Fluent and literate in language of the project/study director (in order to act as a liaison between study director and interviewers where they do not share a common language)
- ✓ Able to commit to the study timeline (full time for approx. 12 working days) plus any additional preparation time
- ✓ In good health and able to walk long distances, where needed
- ✓ Acceptable to local people (in terms of reputation, where they are from, gender, age, ethnicity)

Supervisors provide the link between the study director and the interviewers. Like the interviewers, they need not have interviewing experience although prior experience working on a study of any type is helpful. As they may also conduct some interviews, they share the same qualification requirements as the interviewers and undergo the same training with the

additional stipulation that they are able to communicate verbally with both the interviewers and the study director.

B.3.3 STUDY DIRECTOR QUALIFICATIONS

- ✓ Preferably team leader or manager from the implementation organization that is planning the project, or someone with similar expertise
- ✓ Available to direct pre-study planning and activities and post-study use and sharing of data
- ✓ Available for duration of study itself (full time for approximately 12 working days) plus additional preparation time
- ✓ Can also be the trainer or otherwise speak the same language as the trainer and the supervisors (and interviewers if possible)

B.4 TRAINING INTERVIEWERS AND SUPERVISORS

Trainees are expected to take active roles during training. All interviewers and supervisors receive the same training regardless of previous interviewing or qualitative study experience. This is necessary because the interviewing methods may differ from studies they have previously worked on and because the training builds capacity as a research team, where cooperation among trainees is essential. Based on our experience, interviewers are more likely to adhere to research protocols if they understand why they exist. Hence, a major focus of training is instilling an understanding of fundamental qualitative interviewing principles and their rationale. This focus encourages a commitment to quality interviewing. It also enables the interviewer to appropriately adapt procedures when faced with unexpected problems, and to be confident that any changes she/he makes is correct as long as they are consistent with the basic principles. A second, equally important training focus is the protection of interviewees from harm. Interviewers will be trained to respond appropriately to potential interviewee discomfort and to protect interviewee privacy. Protocols for dealing with both issues are established prior to data collection and included as part of the training.

B.4.1 PRELIMINARY INTERVIEWING TRAINING

Training of Interviewers and Supervisors is divided into two phases. The first phase covers general principles and includes the following topics:

1. An introduction to the study, its purpose, and how it fits in to the wider program and research cycle
2. Principles common to all research, including ethics and human subject issues

3. Principles for working with vulnerable populations (i.e., HIV-positive, highly stigmatized groups, etc.)
4. Principles specific to qualitative methods and a brief overview of the different interviewing methods used in this study
5. The interview process from start to finish, including introduction, consent, interview, and review
6. Procedures for assisting interviewees who become upset or otherwise might be affected by the interviewing process

This training is provided in the classroom over 1-2 days using both didactic and participatory methods.

B.4.2 TRAINING IN SPECIFIC METHODS: FREE LISTING, KEY INFORMANT INTERVIEWS, AND FOCUS GROUPS.

The second phase of training refers to the specific activities that the trainees will perform. These are:

1. Training in Free List (FL) interviewing
2. Training in FL analysis
3. Specific training in (KI) interviewing
4. Training in KI analysis
5. Training in Focus Group (FG) methods, when they are to be done by interviewees rather than the study director

Training during this phase is based on the *just in time* training principle, in which training in an activity occurs immediately prior to the activity itself. By experiencing training in this way, trainees make use of their training at the point where they retain the most information (before they have forgotten material) while reinforcing those lessons through practice to help them retain the information in the future.

In this approach, training in the first specific interviewing method – Free Listing (FL) - is provided after completion of the general interviewer training and immediately before conducting the FL interviews—either the day before the interviews or even the same day. Once the FL interviews are completed, interviewers receive training in how to analyze the FL data and then immediately conduct the analysis. Similarly, Key Informant (KI) interview training is done immediately prior to conducting the KI interviews and training in analysis is completed just prior to analysis. The same procedure is used for Focus Group (FG) interviewing and analysis.

Training in each specific interviewing method uses the following format:

1. Explanation of the interviewing procedure and its rationale according to the basic principles covered in the general training
2. Demonstration by the trainer(s), followed by a critique of the demonstration by the trainers and the class
3. Demonstration by trainees, followed by a critique by the trainers and the class
4. Practice in small groups of interviewers and supervisors with roving observation by the trainer(s)
5. Group discussion about the experience, emphasizing problems and solutions

On interviewing days, when interviews are finished, interviewers and supervisors meet together with the study director/trainer. This meeting is a continuation of the training process, where interviewers and supervisors discuss their experiences, emphasizing problems they encountered and how those problems were addressed. The study director/trainer provides guidance on the appropriateness of their actions, correcting them and providing additional instruction where necessary.

B.4.3 ROLE OF THE INTERVIEWER

Interviewers are key to the quality and depth of the qualitative study. The tasks of the interviewer are to:

- Obtain informed consent prior to each interview (where this is required)
- Maintain interviewee confidentiality
- Identify appropriate persons to interview, with assistance from the supervisor
- Conduct interviews according to the principles of qualitative interviewing, emphasizing politeness and respect for interviewees
- Create an accurate and legible record of exactly what was said in the interviews
- Deal with any problems that arise in accordance with their training, including reporting to the supervisor how each interview went, noting the demeanor of the interviewees (particularly any distress) and any problems
- Meet with the supervisor daily or more frequently as directed

B.4.4 ROLE OF THE SUPERVISOR

Interviewers are assisted by supervisors who usually oversee two pairs of interviewers. The tasks of the supervisors are to:

- Manage logistics and ensure interviewees have access to appropriate interviewees
- Meet with the interviewers to review the interview experience. This is done after the first interview using each method and after any difficult interviews. Otherwise it is

done at the end of each day where supervisors and interviewers review all the day's interviews. Review involves:
    - The supervisor discussing the interview process including what went well, any problems, and what the interviewers did to address them
    - Review the complete interview text to identify weaknesses in interviewing methods (leading or closed-questions) and offer guidance for improvement
- Troubleshoot and otherwise assist with any problems the interviewers may have
- Act as a liaison between the interviewers and the project/study director through meetings and other means of communications as needed
- Act in an interviewer's stead when required, such as during her/his temporary absence

B.5 THE INTERVIEWING PROCESS

This section describes aspects of the interviewing process common to both the FL and the KI interviews. Each interview consists of a series of steps emphasizing ethical conduct (informing each interviewee about the interview purpose, conducting organization, and her/his rights in regard to the interview process); encouraging the interviewee to participate; and maximizing the amount of information recorded and its accuracy. The steps are explained and practiced during the interview training and summarized in the *Qualitative Interview Guide*, a document given to each interviewer. Interviewers take this guide into each interview to remind them of interviewing steps and their order. An example FL interview guide is provided in Appendix H.

An important part of the interview is the consent process, which consists of an explanation of the study provided to the interviewee prior to asking them whether they agree to be interviewed. Different types of consent may be necessary depending on who is involved with the study and the way the data will be used. If the results will be used not only to inform the current program but also be published (such as in a scientific journal), a formal consent process (often including signatures of the interviewee and/or a proxy) may be necessary. If the data from the study will be used only to inform local programming, interviewee consent is still necessary, but the format of that consent may be simplified and may not require signatures[2] (see Appendix C for an example of a formal verbal consent and Appendix D for an example of a

[2] The decision for what type of consent is needed should be made in collaboration with the trainers and implementers of the study.

verbal recruitment and information form). Regardless of the type of consent, ethical principles of research and data collection require that the explanation include the following information:

- Which organizations are conducting the study
- What the purpose of the study is and how the results will be used
- How the interviewee was selected to be interviewed
- What the nature of participation in the interview is and the estimated duration
- An explanation of the interviewee's right to refuse to participate or answer any questions, or withdraw at any time, without any adverse consequences
- Assurance of privacy and confidentiality so that the information provided cannot be linked back to the interviewee and only people involved in the study will see the interview text
- Instructions on how to contact those in charge of the study with any questions or concerns

☆TIP: Using written records and working in pairs

Why not make audio recordings of the interviews?
We do not recommend using recording devices in this qualitative process for the following reasons:

1) Lack of familiarity with audio recording can inhibit interviewee's free expression
2) It takes many hours to transcribe a single interview
3) If the tape is heard by others the interviewee's voice might be recognized, violating confidentiality

Why do interviewers work in pairs?

- To enhance fidelity to the methods: We have found that interviewers are more likely to stick to the qualitative interviewing protocols in the presence of a colleague (normally we try to pair interviewers who don't know each other, to decrease the likelihood that they will feel comfortable in violating the protocols in each other's presence)
- Having one interviewer focus on asking the questions allows for better flow of the interview and fewer stops and starts.
- Having one interviewer focus on writing down the questions and responses allows for more complete text.
- To improve accuracy: Having two people monitoring for mistakes also makes it more likely that mistakes will be identified and corrected.

Overall, generating a final record that reflects the input of both the interviewer and the recorder should result in more accurate and complete data than if a single interviewer had to assume both roles.

Interviewers work in pairs, with all interviews conducted and recorded (in writing) in the local language. For each interview, one interviewer asks the questions while the other is responsible for recording what is said. This includes writing down not only what the interviewee says but also what the interviewer says. The latter is done to monitor the quality of the interview. If the recorder identifies a problem during the interview (such as insufficient probing or a leading question), she/he can raise this point during the interview (if appropriate) or after it is over, as part of the review to troubleshoot and suggest improvements. These roles are not absolute:

during the interview the main interviewer may also take notes as reminders of points to be revisited, and the recorder can ask questions for clarification. Interviewers can alternate between interviewing and recording during different interviews or each can assume one role permanently.

After the interview is completed, the interviewer and the recorder review their written notes together and combine them into a single record. Both must agree on the accuracy of the final interview text. **This should be done as soon as possible after completing the interview.** If it cannot be done immediately after the interview, then it should be done later that same day (i.e., during the review period with the supervisor).

Interviews are normally limited to, at most, one hour in duration, so as not to burden either the interviewee or the interviewers. If the interview cannot be completed in an hour, then both the interviewee and interviewer should take a break and continue later in the day, or end the interview and make a plan to continue on a subsequent day. The former option is more likely for interviews that are normally conducted just once with the interviewee (such as FL interviews) whereas the latter option is more appropriate for KI interviews where the same informant may be interviewed multiple times.

B.5.1 CONTENT OF THE INTERVIEW

The interviews generally contain two sections. Section 1 gathers basic information about the interviewee such as the name of the village or community, age and gender. The specific type of information collected may vary depending on the type of population. If the study will be conducted among a population living with and affected by HIV, for example, HIV-status may be a necessary demographic question and therefore it would be appropriate to ask about HIV status. The study director, implementing organization, and any other members of the research team should work together to determine what information is relevant Basic information gathered in the FL interviews is used to track the types of interviewees in the sample (see B.6.1 Free List Interviewees). For the KI interviews, the job or role of the interviewee in the community (i.e., community leader, minister, health worker) will be recorded. **No identifying information, such as name and address, will be collected or recorded on any of the interview forms to maintain confidentiality.**

The second section is the interview data – the text of the interview itself. The interviewee is asked to respond to questions by providing information about other people in the community (or other people like herself/himself or people that she/he knows about) and NOT about the interviewee herself/himself. While it is expected that the interviewee will include personal issues or may talk in terms of "I," recording is limited to those issues that the interviewee

believes or knows also apply to others. Interviewers are trained to identify when the interviewee may be talking about her/his unique problems or experiences. If interviewers think this is the case, they are directed to ask the interviewee whether her/his comments refer only to herself/himself or to other people as well. And if the interviewee reports that the comments are also true for others, s/he is allowed to continue and the comments are recorded. If the interviewee reports that the comments reflect only personal experience and/or they are not known to be problems to others as well, the interviewer reminds the interviewee that the answers sought should be relevant to others, regardless if they are true for the interviewee. If it happens that the interviewee talks about her/his own problems, the recorder does not record these comments (or strikes them out if they are already written).

This approach is different from other types of interviews which ask interviewees to refer to their own experiences. The rationales for this approach are:

- In a rapid qualitative study like this one, it is important to be as efficient as possible. Keeping the focus on issues affecting multiple persons allows for the identification of issues most likely to affect many people.
- Information bias resulting from choosing non-representative convenience samples may be reduced by having people draw on more knowledge than simply that of their own experiences.
- Keeping the focus on people other than the interviewee protects the interviewee's privacy.
- The experience of the authors is that keeping the focus on people other than the interviewee makes it more likely that the interviewee will talk about things that are thought to be shameful, illegal, or otherwise unacceptable. This is an important concern in studies of HIV-related mental health and psychosocial issues. When HIV-infection itself is stigmatized, it can be difficult to get people to talk about their own problems; if the interviewees don't have to talk about their own HIV-infection or their own problems, they may allow themselves to be more open about the problems they know about. In addition, when seeking information about socially unacceptable behaviors, including sexual behaviors such as men having sex with men (MSM), prostitution, and/or drug abuse, asking people to report on problems and behaviors other than their own avoids self-incrimination and thus may result in more information.
- Theoretically, this type of interview is a more appropriate basis for triangulation of data (see Box 2. below) than interviews that ask only about the interviewee. One might argue that asking ten (for example) people about the community they live in is

akin to asking the same question ten times, whereas asking the same ten people about themselves is actually asking about ten different topics.

- By focusing on the population perspective during this qualitative study and on the individual experience during the subsequent quantitative studies (described in later modules), both perspectives are explored using the appropriate method for each.

Definition Box

Triangulation: Triangulation is an approach often used in qualitative studies to ensure the accuracy of study results by looking for agreement in the data collected by multiple interviewers using multiple methods and multiple informants. Using the qualitative assessment process described in this module, we apply triangulation by exploring responses to the same question with different interviewers and interviewees using different interview methods. If the data generated from the different interviews results in similar conclusions, then this information is more likely to be accurate.

B.6 FREE LIST INTERVIEWS

The FL interviews consist of a series of questions (usually 4-6) asked in a way that will generate responses in the form of a list. As the first qualitative data gathering method used in this study, the purpose of the FL interview is to provide two sets of data.

The first set of data represents an overview of all the problems and issues affecting the population that could form the target(s) of intervention(s) and services. The problems included on this list do not all have to be related to mental health, but often there are some issues listed that include mental health and psychosocial related concerns. This overview of problems will be used by the study team and service providers to narrow the focus for the subsequent interviews based on the identified HIV-related mental health and psychosocial issues important to the population that may be amenable to interventions.

The second set of data is composed of lists of the important daily tasks and activities adults regularly do to care for themselves and their families and participate in the community. Unlike the previous problems and issues data, this information is not used to make planning decisions. Instead it is used to develop quantitative instruments that assess functioning, which can then be used as tools to track the impact of interventions and services.

Compared with other types of qualitative interviewing, FL interviews are highly structured. For each FL, there is a single pre-established question asked by all interviewers to each FL interviewee, and a structured data collection form to be completed. In these ways the FL process is a relatively easy qualitative method, leaving less discretion to the interviewer. These

limitations make FL interviewing an ideal first method for new qualitative interviewers. The standardized questions and structure of the interview allow the interviewer to focus on using simple probes (the most difficult skill for interviewers to master) and on accurately recording responses, reducing concern about leading. The method itself is also well suited as a first step in a qualitative study in terms of the data collected. Emphasis is on identifying as many potentially important topics that could serve as targets for intervention as possible. From this overview, those topics of greatest interest can be selected for more detailed investigation using other methods.

B.6.1 FREE LIST INTERVIEWEES

FL interviewees are a *convenience sample* representing the various types of people who will ultimately be served by the program (i.e., the target population). They are not randomly chosen but rather consist of any persons who meet the study selection criteria, who are available during the study period, and who are willing to talk with the interviewers.

There are 2 types of selection criteria used in choosing individuals for the sample: (1) criteria that define the target population and therefore must be the same for everyone (examples might include being an adult, living in a certain region, being of a certain ethnic group, or being HIV-positive); and (2) criteria that vary within the target population and may affect interviewee responses. The latter might include gender, place of residence, income, or education level. Interviewees are selected using both types of criteria so that the entire sample (i.e., all the interviewees) are from the target population and also reflect the range of important variables within that population. (See Box 3 below titled *Selecting a Convenience Sample for FL interviews*.)

For studies of community-wide issues, members of the general community might be chosen simply by going door to door. When the target population is a distinct part of the wider community, then non-community based methods will be used to find interviewees. For highly stigmatized and/or hard to reach groups (for example those with HIV, drug users, people living on the streets, sex-workers) it may be necessary to use a snowball sampling approach: identifying individuals who are part of the target population and asking them to refer the interviewers to others like them. Interviewees might also be recruited from specific sites, such as health centers or HIV treatment clinics. When using site recruitment recruiters must be careful to choose interviewees representing the variety of experience and breadth of the study population. Whether this is an issue depends on the topic of the study. For example, if the topic is the needs of persons receiving treatment then limiting recruitment to clinics would be acceptable. If the topic is treatment behavior of those with HIV then recruiting solely from clinics will bias the results by limiting interviews to people who are already accessing treatment.

However, in the latter case the clinic may still be a good starting point for recruitment. Those recruited at a clinic may be able to guide the interviewers to others they know who are not currently attending the clinic, which would allow access to a wider range of responses and experiences. For a more detailed discussion on sampling methods, please see Module 3: Population Measurement.

BOX 3: SELECTING A SAMPLE FOR FREE LISTING

The tables below show 2 examples of how to plan a sample selection to achieve a range of interviewees for the free listing interviews, based on Maximum Variation Sampling (Lincoln and Guba, 1985). The process can be adapted from the general community-based sampling described here, to more focused sampling of specific target populations, by changing the variables in the different boxes.

Cells A-C refer to the neighborhoods in these communities— in this example there happen to be 3 neighborhoods in both communities.

Community Alpha

Male						Female					
Older			Younger			Older			Younger		
A1	B1	C1	A2	B2	C2	A3	B3	C3	A4	B4	C4

Community Beta

Male												Female											
Older						Younger						Older						Younger					
Low SES			High SES			Low SES			High SES			Low SES			High SES			Low SES			High SES		
A1	B1	C1	A2	B2	C2	A3	B3	C3	A4	B4	C4	A5	B5	C5	A6	B6	C6	A7	B7	C7	A8	B8	C8

The implementing organization has decided that gender and age are relevant demographic variables that may distinguish the types of responses obtained in both communities.

In community Alpha the implementing organization has either decided that there is no significant variation in socio-economic status (SES) in the community, or that the organization is interested in only one level of SES (usually the lower SES). Therefore, to achieve a total of 40 interviewees, they will allocate 3-4 interviewees to each neighborhood category at the bottom row of the table.

In community Beta, the organization has decided that there is significant SES variation and that they wish to include the range of variation among their interviewees. Therefore, given a total of 40 interviewees, 1-2 interviewees will be allocated to each of the cells on the bottom row of the table. In this example, it may be worthwhile to increase the number of interviewees to ensure that enough of each type is represented.

Note that each row represents a separate Varying Criterion. As in this example, when adapting this table the number or rows will vary according to the number of Varying Criteria. For each row, the more similar the numbers in each cell, the more equally representative the sample is for that Varying Criterion.

Targeted recruitment methods are also needed for study of HIV-associated severe mental illness because these are not common. Therefore, interviewing general community members may not generate useful information because few will know individuals with these problems. In such cases the interviewees will often say that they do not know much about the topic, and/or the briefness of their responses will make this clear. There is a danger, however, that some unknowledgeable interviewees will have a lot to say and appear knowledgeable, though their responses may simply reflect an outsider's perspective on the problem. When the implementing organization and research team are specifically interested in HIV-related severe mental illness, it may be useful to identify stakeholders who work with individuals and families affected by severe mental Illness and begin the investigation with them. The same approach is used for investigation of any uncommon issue.

B.6.2 FREE LISTS TO ELICIT HIV RELATED MENTAL HEALTH AND PSYCHOSOCIAL PROBLEMS

Each FL begins with the interviewer asking a single primary question designed to elicit multiple responses. The FL data then consist of all the respondent's answers to that question. In this study, the FL interview begins with a primary question about problems:

'What are all the problems that affect the [target population]?'

The resulting data is then recorded in the form of lists of problems, from which we identify the priority HIV-related mental health and psychosocial problems. Depending on the target population, the primary question can designate a particular gender or other defining factor. For example, instead of 'people' the question could refer to males or females, to individuals living with or affected by HIV, or to very specific target populations like sex workers, people injecting drugs, etc.

Sometimes a more detailed FL question may be used to reflect a specific focus of the study, such as psychosocial issues such as stigma, health seeking behaviors related to treatment initiation and/or adherence, or HIV-related risk behaviors. The box below, titled *Selection of Free List Primary Questions*, reviews how additional questions may be generated in a case such as this.

FL question(s) are translated into the local language during the FL training, when interviewers and supervisors agree on the most appropriate translation.

During the interview, the interviewer introduces each FL using the translated question(s). Once the FL primary question is asked, the different responses (i.e., problems) are recorded using the exact language of the interviewee (i.e., no summaries, paraphrasing, or translation). Recording is done on a specialized form (see Appendix E) that contains 2 columns. Responses to the primary question (i.e., the problems) are recorded in the left column. The interviewee is repeatedly probed for as many responses as possible until the interviewee indicates that s/he can think of no more. The interviewee is then asked for a brief description of each problem. This description is recorded in the right column, which includes space for a description opposite each problem in the left column. This sheet purposely has only a few lines to record the description. Interviewers are instructed to ask for one or two sentences only. If the interviewee provides more than this (which frequently happens) the interviewer does not attempt to summarize the interviewee's comments. Instead, the interviewer asks the interviewee to summarize her/his own comments and records this summary.

After the list is complete, the interviewer and recorder review the list of problems and their descriptions, looking for problems potentially relevant to the topic of the study. For example, if the focus is on mental health problems, potential mental health problems are generally defined as any problem relating to thinking, feelings, relationships, and behaviors. If the focus is on stigma, then factors associated with social disapproval and/or differing from social or cultural norms are selected. If the focus is HIV-related risk behaviors or HIV-related health seeking behaviors, then mention of the behaviors or issues related to these behaviors will be highlighted by the interviewers.

For each problem relevant to the study the interviewee is asked who is considered knowledgeable about it and/or who, if anyone, local people consult when they have this problem. The interviewer asks about local people who are part of the community, not outsiders who visit the community or are living there temporarily. Any persons who have outside training in dealing with these types of problems (i.e., nurses and doctors with formal medical training) are excluded, since they tend to understand the problems on the basis of their training and not as community members. The interviewer records in their notebook the name, role, and contact information of any people who meet these criteria. These persons will be approached at a later date for the KI Interviews (described below).

B.6.3 FUNCTION FREE LIST

After completing the *problem* FL interviews additional FLs are generated with the same interviewee during the same interview. Each additional FL focuses on a different area of *function*. Unlike problem data, the information is not used in program planning but to develop function assessment instruments to assess program impact (see box below).

The primary questions for each of the *function* FLs are:
1. What are the activities that men/women do frequently to care for themselves?
2. What are the activities that men/women do frequently to care for their family?
3. What are the activities that men/women do frequently to contribute to their community?

As with the *problem* FL, primary questions with the minimum number of concepts are used. Here the major concepts are 'activities', 'caring', 'contributing to', 'frequently', 'self', 'family', and 'community'. Specifying self, family, and community is important to covering the full range of adult responsibilities with respect to self and others.

Note that in contrast to the primary problems questions, these *function* FL questions do not ask the interviewee to refer only to a specific target population (e.g., adults infected with HIV) but to men/women generally. This is because the intent of the final instrument will be to assess how well program recipients have been able to take up the various functions expected within their society. Sometimes, the program focus may be the ability to perform tasks within a subgroup or under particular circumstances. For example, the authors have developed instruments that focused on the functioning of street children rather than on children in general. In this case, the primary question referred to activities that 'street children' do rather than children in general. Similarly, the *function* FLs might refer to population subcategories such as 'drug users' or 'sex workers' or other groups of interest with respect to prevention and treatment of HIV.

As with the *problem* FL questions, interviewers and supervisors translate each of these questions during the training period. Once translated, the FL interviewing process is otherwise the same as for the problem FL interviewing process, with probing to maximize the number of responses, requesting a brief description of each activity, and recording all information verbatim. As with the *problem* FL, the interview results are recorded on a special form. This form is identical to that in Appendix E, except that the title of the FL form, and of the 1st column, refers to 'Tasks and Activities' rather than 'Problems'. Note that KIs (described below) are not solicited from the *function* FL interviews and data.

Why study function?

Unlike the problem data, the Free List function data are not used in planning the intervention. Instead, the data are used to develop function indicators and instruments as measures of both need and program impact. Improving function is an important impact of most humanitarian and development programming. One could argue that there are only two development rationales for health programs –to reduce mortality and/or increase functioning. Much of the distress that individuals feel as the result of mental and physical health issues, poverty, disasters, and challenges come from their inability to meet their responsibilities as children, parents, spouses, family members and members of society. Including measures of how well people can fulfill these roles is an important aspect of assessing both need and program impact.

The specific tasks and activities that constitute these roles vary between cultures and contexts. We recognize that while standard function instruments exist, most were developed for Western highly resourced populations. They do not describe how tasks and their priorities vary across populations or by gender. Therefore we use qualitative methods to discover those specific tasks and activities that are important for local people to do.

B.7 ANALYSIS OF FREE LIST DATA

The goal of the FL analysis is to consolidate all the data into a single list of responses for each FL question including the number of different interviewees reporting each response.

Analysis is done as soon as possible after the FL interviews are completed (usually the next day). The research team (study director, supervisors and interviewers) convenes at the training site. All the FL interviewees are given an identification number. The analysis is conducted on the original data and not on a translated version.

There are two approaches to reviewing and analyzing the FL data, depending on which is most convenient given for the local team. In the first approach, pairs of interviewers first consolidate all of their own interviews and then all of the interviewers come together to create master consolidated lists for each FL question. In the second approach, pairs (or groups) of interviewers review all FL interviews for a specific question. For example, one group of interviewers collects all the problem FLs and consolidates them, another group collects all of the *function* FLs and consolidates them. Using the second approach, if there were 5 FLs generated for each interview, then there should be 5 analysis teams to consolidate them all. In reality, if some of the free list topics tend to have fewer responses then one team could consolidate more than one topic thereby requiring fewer teams.

Regardless of the approach taken, the analysis begins with the interviewers listing out all the different responses (problems or tasks/activities) from the forms they have in the local language with the interviewee ID number listed next to each response. When multiple interviewees report the same problem, then all the relevant id numbers are listed next to that

response. The result will be one list for each FL question of the different problems (or tasks) and the ID numbers of different interviewees who mentioned each problem. Where two or more interviewees clearly refer to the same concept but the wording is different, the review team selects and records the wording that they feel is the most accurate and the most likely to be understood by a member of the target population. For example, if a study were being conducted in English and one interviewee referred to 'not enough to eat' and another referred to 'insufficient food' an analysis team might choose the first one as being a clearer description. The selected wording is therefore used to record the concept along with the interviewee ID numbers for the two interviewees that reported it. If the same interviewee mentions the same problem (or function/task) in different ways, the most accurate language is chosen in the same way. However, the interviewee's ID number is only reported once. As the team works through the interviews, they will continually come across new items that mean the same thing as items they have already recorded on the summary sheet. If they feel that the wording on the summary sheet is better, they will simply add the id number of the interviewee that gave that response. However, if they feel the new wording is better than that in the summary sheet, they will not only add the ID number, but also replace the summary sheet wording with the new wording. It is important that this entire process is done in the local language. In this way, decisions on what to combine are based on the original language and are not dependent on the accuracy of translation.

In cases where the team cannot agree on whether items from two or more interviewees are referring to the same thing, they consult with the supervisors and the study director about whether or no they should be combined. If the team and supervisors cannot agree then the items are recorded separately. Note that the decision is based on whether multiple items really refer to the same concept or not in the local language. It is not enough that they refer to the same category of problem or of function.

Once all the FL interviews have been reviewed and the consolidated list is complete each team reviews the list to see if any of the responses should be further combined. As before, items are combined only if there is consensus that they express the same concept. Finally, the lists are re-organized in order of decreasing frequency of number of interviewees who mentioned each item by counting up the total of different ID numbers reported for each item. The relative frequency of items is used as an indicator of relative importance or prioritization in that items mentioned more frequently are considered to be more important than items mentioned infrequently. Given that this is a small convenience sample, we do not attempt to attach any more detailed interpretation to the numbers than this. The complete analysis process usually takes 1-2 days.

Appendix F is an example of a completed FL interview form and Appendix G is an example of a consolidated FL analysis. Both were originally completed in the local language and have been translated here by way of illustration.

B.8 SELECTING PRIORITY ISSUES FOR FURTHER EXPLORATION

The summary problem lists resulting from the FL analysis usually contains more problems of interest than can be addressed by a single program, and more than can be explored in detail in a brief qualitative study. Therefore, a choice is made at this stage in the study regarding which problems to investigate in detail. Constraints in both the study duration[3] and in a programs' ability to address multiple problems normally restrict the investigation to no more than 4 problems. These are chosen based on the following criteria:

- Priority is given to problems mentioned frequently and which appear to be severe in terms of their impact, as suggested by the problem names and brief descriptions.
- Problems that are not already well understood or otherwise need further exploration in order to appropriately plan interventions. Since the KI interviews provide in-depth information on the selected problems, those that are already well understood in the local context are not a priority for further investigation. Note that this does not mean that these topics will not be addressed in the program.
- Problems that are most likely to be addressed using available resources. This includes consideration of whether interventions exist that are known to be effective and whether those interventions are feasible locally. (See Module 5 for brief descriptions of different possible mental health interventions).

The process of selecting which problems to investigate further is also influenced by the preferences and background of the service organization partner(s) and their funder. For example, they may have experience developing treatment programs to deal with specific mental health problems such as depression, anxiety or PTSD, or to deal with mental health and related issues connected with HIV-treatment utilization. Or they may be focused on developing prevention programs to reduce high-risk behaviors associated with HIV infection, such as drug use or sex work. Or possibly, they may be interested in developing community-based

[3] Our experience is that service organizations find it difficult to conduct studies longer than 2 weeks.

programming on stigma reduction. It is important for the implementing partner to keep in mind their own service and program goals while deciding which problems to explore.

The decision about which problems to focus on is normally done at a meeting of the implementing organization staff and members of the study team including the director and the supervisors. The decision should be done by consensus, but if that is not possible, the implementing organization staff has the final say.

B.9 KEY INFORMANT INTERVIEWS

The purpose of the KI interviews is to gather in-depth information about the problems selected from the FL interview data. In-depth information includes

- Further descriptions of the problems, including other symptoms, problems and behaviors that may be associated with the selected problems, and local terminology that describes them;
- Information on the local perceptions of causes and effects of the selected problems and information on current practices to deal with the problems (i.e., coping, help seeking behavior).

Training in the KI interviewing method is done after the priority problems are selected from the FL data and prior to the KI interviews themselves. Interviewers and supervisors practice open-ended interviewing with equal emphasis on asking non-leading questions, using various means of probing, and verbatim recording. As with the FL interviews, KI interviewers work in pairs, one as the interviewer and the other as the observer/recorder. After the interview is completed the interviewer and the recorder together review their written notes and combine them into a single interview. Both must agree on the final interview text accuracy. This should be done immediately after the interview, when the interview is still fresh in the mind of both interviewers. Unlike the FL interviews which use formatted data collection sheets, the record of the KI interviews are usually done in an exercise book or on a writing pad. The interviews are recorded in pencil on lined paper with text written on every second line in order to make it easier to change or insert notes during the interview and later when consolidating notes.

The KI interview process is similar to that used in the FL interviews in terms of what happens before and after the main interview (see interview guide in Appendix I). The main difference is in the KI process itself, which is much less structured than the FL interview process. For the KI interviews, the interviewer begins with a pre-defined ‘grand tour’ question developed during the training based on the priority problems selected from the FL data. These introductory questions ask the interviewee to share what they know about the selected problem. One introductory question is developed for each priority problem being investigated, with

interviewers asking that question and probing on that problem before proceeding to the next question/problem.

Following the introductory question, the interviewer interjects only to probe for more information on the topic of interest or to guide the interviewee back if they diverge from the topic. KI interviews serve to complement FL interviews. Whereas FL interviews aim to solicit a small amount of information on a broad range of topics, KI interviews are intended to gather detailed information about a few select topics. For this reason, the interviews are conducted with persons who are believed to be very knowledgeable about the topics of interest (hence, 'Key' Informants). The expectation is that such persons can talk at length about the topic and will need little guidance to do so. In fact, most KIs will be interviewed at least twice, with some interviewed three or four times, because a single one hour interview is usually not enough time to obtain and record all that they know about the topics.

B.9.1 KEY INFORMANT INTERVIEWEES

The initial KI interviewees are selected from the local persons identified by FL interviewees as being knowledgeable about the problems selected from the FL data. Those asked to be KIs can include persons infected with or otherwise affected by HIV (depending on the study population), someone an affected person may rely on when she/he has any of the selected problems, or someone who for other reasons are well connected to the study population. It is important that the KIs are nominated by members of the target population, with priority given to persons who are mentioned by multiple FL interviewees. KIs are local people who are part of the community in which the target population lives and works, not outsiders who visit the community or are living there temporarily. Any persons who have outside training in dealing with these types of problems (such as medical doctors, nurses, or social workers) are usually excluded since they tend to think about these problems on the basis of their training and not as community members.[4]

Using the contact information collected during the FL interviews, the interviewer locates the KI and requests an interview. In cases when select FL interviewees appear particularly knowledgeable about the topics of interest, they may be invited to be interviewed as KIs. At the end of each interview, the interviewer asks the KI if there are other persons who are knowledgeable about the topic. If so, the interviewer records their contact information and

[4] The perspective of these persons is important but it is more appropriately obtained outside the qualitative study.

these persons can also be interviewed as KIs. This process of snowball sampling can be particularly helpful when the FL interviews do not generate sufficient appropriate KI options. KIs named by community members in other contexts (such as during a meeting with community leaders or during an informal discussion with community members) can also be used. Typically, 15-20 KIs are interviewed, each on multiple occasions. Unlike the FL interviewees, there is no formal attempt to get variety in terms of ages, gender, or geographical distribution of interviewees. However, if there is a choice, it is usually desirable to attempt variety, such as including community leaders, healers, representatives of both genders, and people from different areas.

B.9.2 DATA COLLECTION

After the same preliminary steps of introduction and explanation as in the FL interview, the interviewer begins the data collection process by introducing one of problems selected from the FLs and stating that other people in the community mentioned that the interviewee would be a good person to ask about that problem. The interviewer than asks the KI to tell what they know about the problem (see the example of the Key Informant Interviewing Guide in Appendix I). The recorder focuses on recording everything the interviewer says and everything that the KI says about the topic. **Do not summarize or translate.** This can be difficult work and often the interviewee will talk more quickly than the recorder can record. If that happens the recorder should feel free to ask the interviewee to slow down or to pause until the recorder can catch up, explaining that "what the interviewee says is important to us and we want to make sure we get it all down." The interviewer also takes notes in order to remind him/herself of points that s/he may want to come back to and probe on later.

KI interviews focus on the following aspects of each problem:

- Nature (e.g., what are the characteristics/symptoms or signs/how it is recognized)
- Perceived Causes
- Effects on those with the problem and on others close to them
- What people currently do about it
- What should be done about it (if resources were available)

Interviewers are trained to remain silent while the interviewee is talking about any of these issues and to simply listen and take notes. If the interviewee begins to talk about unrelated topics, the interviewer politely leads them back to one of the above topics through the use of appropriate probing. As in the FL interview, the interviewer avoids introducing new concepts but instead probes in a non-leading way, usually by reminding the interviewee of something they had previously said and asking them for more information (for example, reminding them

about a cause they had mentioned and asking them to talk more about that cause or about other causes). Interviewers are trained to probe repeatedly on the same topic, and to do so until the interviewee states that they have no more to say about the topic. In this way, the interviews normally produce a lot of information, and two or three one-hour interviews may be required to record all the information an interviewee has to provide. Subsequent interviews are each conducted on separate days to avoid exhausting the involved parties and to give the interviewee time to reflect and think of further information between interviews.

After each interview is completed (and before doing another interview) both the interviewer and recorder review their notes from the interview. At this stage they reconcile and combine their notes and add any material that they remember from the interview that is not yet recorded[5] and clarify anything that is not clear. It is important that this is done soon after the interview, as memory fades quickly. The result should be a final set of complete and clear interview notes that records what both the interviewee and the interviewer said.[6]

At the end of each day, the interviewers go through the full text of each of the day's interviews with the supervisor. The supervisor and interviewers discuss the experience, any problems that may have arisen, and how the interviewers handled them. To facilitate this review the interview notes contain not only what the interviewee said but also the interviewer. The supervisor reads through the interview text and identifies any problems or mistakes, including inadequate probing or leading. If inadequate probing is identified, the supervisor points out to the interviewers where they have missed an area of interest, or where they probed but did not probe enough. The supervisor then works with the interviewers to plan how to probe on these topics at the next interview. If interviewers have led the respondent in any way this is pointed out in order to avoid similar mistakes in the future. This review process is vital to the success of the study. On the one hand, the interviewers learn best by going through the interview with the supervisor and seeing where they can improve. On the other hand, the supervisor and interviewers are able to plan the follow-up interviews and ensure that the interviewers revisit

[5] If during the review and consolidation of notes the interviewers remember information that was not recorded, it is best to add text in parentheses ( ) since it may be difficult for the interviewer and recorder to recognize whether they are summarizing what the interviewee said or if they are remembering the interviewee's EXACT words. Using ( ) allows the information to be included while acknowledging that the exact wording may not be correct.

[6] Interviewers may decide to rewrite their notes completely, however this is time consuming. Alternatives are to use a computer to type the interview as it occurs (if appropriate and the recorder has the typing skills), or to use a notebook and write in pencil on every second line. This makes it easier (and quicker) to make changes and additions while not rewriting the original notes.

gaps in the information that was collected, thereby greatly improving the quality and amount of data collected.

B.9.3 ANALYSIS OF KEY INFORMANT INTERVIEWS

Prior to the analysis, separate piles or folders are created, each one consisting of all the interviews for a particular KI (i.e., if there are 16 KIs there will be 16 piles). The interview sheets in each KI pile are stapled together. If they are put in a folder, they must be stapled to the folder. Each pile is given a numeric code to identify the KI. If there are 16 piles/KIs then the piles might be coded 1-16.

Interviewers are divided up into teams. The number of teams is equal to the number of problems (usually 2-4) that were explored in the study and each team focuses on a different problem. Each team creates a summary sheet (or computer file) for their problem with subheadings according to the areas of interest explored in the interviews:

- Nature of the problem (e.g., what are the characteristics/symptoms or signs/how it is recognized)
- Perceived causes
- Effects on the person with the problem and on others close to them
- What people currently do about it
- What should be done about it (if resources were available)

The rest of the analysis process is similar to the FL analysis. As with the FLs, the analysis is done using the original interviews rather than translations. Each team picks up one of the interview piles and proceeds to read through the first interview, looking for mention of their problem topic. Whenever they find a mention, they record what was said under the relevant subheading, using the exact wording of the interviewee. The complete interview text, including second and possibly third interviews with the same interviewee is reviewed in this way. If the KI subsequently (in the same interview or a later interview) mentions the same fact using different wording and the team feels that this new wording is more easily understood they erase the original wording and substitute the new wording.

This process continues with each new interview pile. Next to the record of each statement, the team keeps a record of which KIs mentioned that information. The team continues to replace the wording used to describe each concept if they come across a new and superior way of saying it in subsequent piles.

Figure 2. Example of Key Informant Summary Sheet

Problem – "Continuing to suffer from past events"

Symptoms	**Key Informants**
Reliving events	2, 6, 12, 3, 7
Body pain	2, 6, 13, 5
Restlessness	6, 5, 9
Head hurts, very emotional	9
Cause	**Key Informants**
Have no work	2, 3, 13, 1
Sense of lack of justice	13, 4, 10

The table above is an example of what a summary sheet/computer file might look like while still being completed by an analysis team. The table depicts analysis of the problem of '*continuing to suffer from past events* ' and the team has so far reviewed the interview piles for KIs 2, 6, 5, 12, 3, 7, 13, 9, 1, 4, and 10. The table shows the progress they have made for two of the subheadings – Nature of the Problem (Symptoms) and Cause. So far, KIs 2, 6, 12, 3, and 7 have mentioned '*reliving events'* as a symptom of '*continuing to suffer from past events*.' The local terminology for '*reliving events*' will be whichever description of this concept they have found so far that they feel is most easily understood by local people. This decision is subjective and arrived at by group consensus, considering factors like how many interviewees used that terminology (more commonly used terms are preferred) and how easily understood it is considered to be.

One way we have found to keep track of which team has reviewed which interview pile is to have a team sign the folder (or the top page of the pile) when they have finished reviewing to keep track of those they have reviewed. Once all the teams have completed their reviews of all the piles/interviews, each team reviews the summary sheets or computer files to determine if there are items that they feel are saying the same thing. If so, they select the best phrasing, erase the phrase not selected, and add the tally of those interviewees from the erased phrase

to those of the selected phrase. In doing so they are careful not to add the same informant twice. For example, if KIs 2, 5, 7, and 10 said the selected phrase, and 4, 5, 7, and 11 said the phrase to be removed, then the total tally would be 6 KIs who expressed that concept, not 8.

The final result is a summary sheet or computer file for each problem, with statements listed under each of the five subheadings – *Nature of problem, Perceived Causes, Effects, What people do,* and *What should be done* – and the ID numbers of the KIs who made each statement or its equivalent. The latter can be replaced by a count of the number of KIs. A translation of part of a summary sheet for one question asked in a study of HIV-related discrimination is provided in Appendix K.

B.10 FOCUS GROUPS

FGs are used in this qualitative assessment process to build on the *function* FL data collected identifying the tasks and activities that constitute normal functioning and well-being. The FGs are usually conducted after the FL interviews are completed and analyzed and are used to confirm the data from the FL as well as generate new data on function.

Function FGs typically take place while the interviewers are conducting the KI interviews. They can be led by the study director, a supervisor or by a pair of interviewers, depending on availability. As with the other interviewing methods, two people are required to implement the FG discussions – one to primarily engage with the group while the other focuses on recording responses.

B.10.1 FOCUS GROUP PARTICIPANTS

For studies in which the target population includes both genders, at least two FGs are held – one for men and one for women. If there is time, more FGs can be held to better reflect variation by age, location, or other relevant factors. Within FGs participants should represent the same criteria used to select FL interviewees. FG participants should not be FL interviewees, in order to improve triangulation of the results. Interviewees can be recruited through various channels, including suggestions from community leaders, organizations, or FL interviewees.

FGs should range in size from 8-15 persons. Fewer may result in more limited results and more might result in groups where not everyone has an opportunity to speak.

B.10.2 FOCUS GROUP IMPLEMENTATION

FGs can be held inside buildings or outside, as long as it is easy to hear the participants. They should be held in a private location if possible. The non-controversial and non-personal nature of the discussion means that the meetings may be held in less private surroundings if it is necessary, however, and if those in the group do not mind.

The dynamics of FGs (and of group methods in general) are different from those of individual interviews. The facilitator must encourage the whole group but she/he must also notice who is shy or saying little and try to encourage them and create space for them to speak while (politely) preventing a few people from dominating the conversation. As with the FL and the KI interviews, the facilitator uses probing to encourage comments in a non-leading way. Sessions usually last up to one hour. During that time it can be difficult for the recorder to keep up with the group. As with the other interviews, the recorder does not hesitate to ask people to slow down or to pause while she/he catches up.

The introductory steps for the FGs are similar to those of the FL and KI interviews (See Focus Group interview guide – Appendix J). At the end of the session, the recorder and interviewer quickly read through the notes to make sure that everything is clear, and they ask for clarifications before the group is dismissed. As with the other interview records, they then review the notes to create a final record of the group meeting.

Two different processes can be used to initiate the FG discussion. One option is to have the main interviewer (or Facilitator) asks the same primary questions as were used for the *function* FLs. Using this option, the interviewer would ask the first function question and then ask all the FG participants to share the tasks and activities they thought were relevant. Once all the responses to the first function question were generated, the interviewer would move on to the second function question, followed by the third.

A second option is to start the FG discussion by presenting the results of the FL function questions analysis. The *function* FLs were analyzed in the same way as the *problem* FLs, with the result being lists of tasks and activities in order of frequency reported. For the FG discussions, the interviewer presents the 6-10 most frequently reported tasks for each of the three function questions and asks the FG participants to 1) identify any important tasks not on the list and add them to the list, and 2) prioritize the tasks by those that are considered most important for the most number of people.

The goal for either approach is to expand on the FL function data to more fully explore aspects of healthy functioning in the target population and identify tasks and activities that many men

and women are expected to regularly do to care for themselves, their families, and their communities.

B.10.3 ANALYSIS OF FOCUS GROUP DATA

There is no formal analysis of the FG data. Once the facilitator and recorder have generated a final record of each group meeting, these records are set aside with the *function* FLs, to be used at a future time for quantitative instrument development. A description of that process is described in Module 2, which covers the development of the function section of quantitative instruments using a template consisting of tasks activities that were frequently mentioned in the *function* FLs and also mentioned in the FGs. The language used to describe the items is the wording agreed upon by the FL interviewers during the FL analysis and in the FGs.

B.11 SPECIAL CONSIDERATION OF COMPLEX CONTEXTS AND POPULATIONS

Situations may arise when the qualitative study process needs to be adapted. This can occur because of context (for example, multiple language groups or multiple contexts) or population (for example, a highly stigmatized or hard to reach population like IDUs).

In the first instance, given that the results of the qualitative data inform not only program development but also the development of quantitative assessment tools for each language and context, the full qualitative study (i.e., 20-40 interviews and accompanying KI interviews) needs to be done in each language or geographic area separately.

In cases where the intention is to work with hard to reach and/or highly stigmatized groups, planning and special care must be taken to ensure that the participants are appropriately identified and kept safe. It is always important to work with local staff who know the target population, but when working with special populations it is often necessary to have representatives of the target population involved with the planning and, if possible, with the actual implementation of the study. For example, the target population for a study of barriers to ART usage in central Kazakhstan was intravenous drug users. To access this population, the authors of the study worked with a local advocacy group made up of former drug users, many of whom were themselves HIV-positive. By including them in the planning and study implementation, the authors were able to gain access to the target population and gain their trust for the interviews.

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APPENDIX A: EXAMPLE WORKPLAN

PRIOR TO COMMENCING QUALITATIVE STUDY

- Local staff creates a list of all target communities in the study area and the approximate populations of the target groups (i.e., people living with HIV, people affected by HIV, etc.).
- In the weeks before the data collection, local staff meets with local authorities and describes the study to gain tentative approval. They may also hold a 'town hall' meeting with leaders and as many people as possible from the community, to explain the study.
- Local staff identifies and when necessary, hires interviewers and supervisors for the qualitative study based on the qualifications described in the manual.

QUALITATIVE STUDY SCHEDULE:

A typical schedule of working days is described in the table below. It may be adapted as needed. This schedule **assumes** that the distance from the training site to the community in question is less than one hour, and that both training and data collection in the community can occur in the same day. When the training site and communities are farther apart, it will be necessary to take into consideration travel time and whether interviewers and supervisors will need to spend the night (or several nights) at the site of the interviews and then return to the training site for analysis and further training.

Day*	Activities
1	Welcome interviewers/supervisors and provide didactic training for at training site.
2	Didactic training on qualitative interviewing techniques and FL.
3	Free Listing interviews in the community. Supervisor and interviewer review of interviews at training site.
4	FL interviews in the community. Supervisor and interviewer review of interviews at training site.
5	Group analysis of FL data at the training site; Meet to decide questions to explore in KI interviews.
6	Conduct KI interview training at training site; 1st KI interviews in the community.
7	Continue KI interviews.
8	Continue KI interviews; Conduct FGs at a time and place convenient for the group members.
9	Continue KI interviews; Conduct FGs.
10	Complete KI interviews.
11	Analysis of KI data at the training site.
12	Analysis of KI data at the training site.

* NOTE: The study is presented as 12 working days. The expectation is that there will be at least one 1-day break in the middle (i.e., working two 6-day weeks).

APPENDIX B: RESOURCE LIST

TIME

Preparation for the qualitative study usually requires one month prior to the study on a part-time basis. Activities completed during this preparation period include:

- Meeting with community leaders and community members
- Preparing logistics
- Arranging personnel

Actual implementation of the qualitative study—including personnel training, conducting interviews, and completing analyses—takes about 12 working days (See typical time schedule in Appendix A)

PERSONNEL

- Study director for four weeks, including approximately two and a half weeks implementing the study
- Logistics staff to address logistic and personnel issues
- 2-3 translators for training, supervision, and translation of data
- Three supervisors for 12 working days
- 12 interviewers for 12 working days

Study Director Qualifications

- ✓ Preferably team leader or manager for the provider, or someone with similar experience.
- ✓ Available to direct pre-study planning and activities and post study use and sharing of data
- ✓ Available for duration of study itself (12 working days)
- ✓ Can also be the trainer or otherwise speaks the same language as the trainer and supervisors (and interviewers if possible)

Supervisor Qualifications

- ✓ NGO or Ministry of Health (MOH) MOH local staff or students (e.g., nursing students)
- ✓ At least a high school education (Preferred = college level education and good knowledge of English)
- ✓ Available for duration of study
- ✓ Ability to read and write in the local language
- ✓ Willing and able to ride a motorbike, if available

- ✓ Good knowledge of the language of the trainer(s), study director, and interviewers

Interviewer Qualifications

- ✓ NGO or MOH local staff or students (e.g., nursing students)
- ✓ Available for duration of study (12 working days)
- ✓ Ability to read and write in the local language
- ✓ Willing and able to ride a motorbike, if available
- ✓ Capable of walking long distances
- ✓ Understand they will be overseen by supervisors

TRANSPORT

The project director and all staff will meet at the training site at the beginning of each day before proceeding to the study site. Daily transport between the training and study site for all workers (interviewers and supervisors) is required throughout all phases of the project.

TRAINING AND OFFICE MATERIALS

Training for all modules should take place at a combined training and office site that is quiet, secure and has adequate electricity. The site should be exclusively used by the team throughout the project and should be able to be locked at night.

Site Requirements

- ✓ Large enough to seat all study personnel
- ✓ Quiet
- ✓ Available power (electric or generator)
- ✓ Available exclusively for use by the team throughout the project (24-hour access)
- ✓ Able to be locked at night

Equipment

- ✓ Blackboard/whiteboard/easel and chalk/marker pens
- ✓ Computer
- ✓ PowerPoint projector
- ✓ Printer and spare toner cartridge (on site or easily accessible)
- ✓ 1 ream of paper

INTERVIEWER MATERIALS

Each interviewer and supervisor should have the following:

- ✓ Exercise book
- ✓ Two pencils, eraser and sharpener
- ✓ Waterproof carrying bag
- ✓ Daily portable lunch (or per diem and options for purchasing lunch)
- ✓ Sufficient copies of FL and consent forms (if the latter are used)
- ✓ Cell phones or other method of communication with study director and supervisors

APPENDIX C: EXAMPLE OF FORMAL CONSENT FORM

VERBAL CONSENT FORM FOR RESEARCH STUDY

Instructions for the Interviewer

The following sections printed in italics are to be read to the subject prior to the interview. If the subject then agrees to participate, you must sign on the line marked 'Witness to Consent Procedures' at the end of this form. Also mark the date on the appropriate line.

Purpose of the Study

You are being asked to be part of a research study. We want to find out about the problems affecting people in this community and about the tasks and activities that people normally do. By learning about the problems and normal activities of local people [organization you are working for] hopes to design better programs to assist local people. This research is being done by [organization you are working for]. We would like to invite you to participate.

Procedures

To obtain this information we are talking to people who live here and know about the situation of local people. This is why we selected you to participate. If you agree to be in this study I will ask you some questions about the problems affecting local people and the things that local people do.

Risks and Discomfort

Each interview will take about 30-60 minutes. It is possible that you may not like some questions or that some questions may upset you. You may refuse to answer these questions, or any questions, if you wish. You may stop the interview at any time.

Benefits

This information will help [your organization] to provide better programs to improve the health of the people in this area. However, there may be no direct benefit to you personally.

Confidentiality

During the interview I will write down the information you tell me. This is the information we will use for our study. The record of this information will not include anything which can be used to identify you. I will also record your name and address, but this will be stored separately from the record, and will be locked in the project director's office. The project director will have the key. Only the research team will be able to see this information. Nothing that you tell us will be

shared with anyone outside the research team. We will not allow anyone else to find out who gave a particular answer unless we think that you or someone else might be in danger. In that case, we cannot keep that information private and we will take steps to make sure that all people involved are kept safe. Every effort will be made to protect the confidentiality of this information as far as is legally possible.

Voluntariness

It is your decision whether or not to be in this study. You can stop being in this study at any time. This will not affect any assistance you get from (your organization) or any other organization.

Whom to Contact

If you have any questions now please ask me. If you have any questions after I leave, you can ask [insert name of project director]. He/she is in charge of the study and can be contacted through the [your organization] office in _____, telephone _____. In the future if you have any questions about the study, you should ask (local contact for your organization). He/she and the other researchers will tell you if they learn anything new that they think will affect you.

Do you have any questions?

Do you agree to participate in this study? **Yes** (PROCEED) **No** (STOP)

_____ _____

Signature of Interviewee Date

[I have explained this research study to the subject.]

_____ _____

Interviewer or other witness to consent. Date

(to be signed only if subject has verbally consented).

_____

Signature of Investigator

APPENDIX D: EXAMPLE OF VERBAL RECRUITMENT AND INFORMATION PROCESS

FREE LIST RECRUITMENT AND INTRODUCTION PROCESS FOR FREE LIST INTERVIEWS OF PREGNANT WOMEN AT A PRENATAL CLINIC

Hello, my name is: _____ and I am working with the _____(Names of collaborating Organizations). We are doing a study to understand more about the problems and situation, including how women cope with their problems, of pregnant women like you. Over the next several days, we are inviting women who get services here to participate in an interview where we will not be asking you questions about yourself or any other particular woman. Instead we will ask you questions about pregnant women. Can you tell me how old you are? We are inviting women who are over age 18 to participate.

The interview will take up to one hour and we can do it while you are waiting for your appointment or afterwards, whichever is more convenient for you. To make it more comfortable, we will do the interview in one of the small rooms here at the clinic. If you don't want to participate, that is fine, it will not affect any assistance you receive from this clinic or any other doctor or organization. If you agree to be interviewed you can stop the interview at any time or you can refuse to answer any questions. Your opinions are very important to us. We will use what you share with us to make programs for the women better but right now you will not receive anything for helping us.

Are you interested in participating?

If no, say thank you and go to next woman in clinic.

If yes, invite the woman into one of the small rooms and continue with the rest of the introduction process

Thank you for agreeing to answer our questions. I am going to ask you some questions to understand the situation about women like you. I will not record your name or other information that can be used to identify you other than your age and how many children you have. We will record what you say in the interview because what you say is important to us. This record will be kept confidential. Only we interviewers and our research team will see it.

We will make some notes about what you tell us, but your name will not be recorded or shared with other people so whatever you tell us will be protected and you can tell us what you think and know.

There is a small possibility that some of the questions we ask may make you feel upset. If that happens we can continue on with other questions or stop the conversation. You don't have to

tell us anything you don't want to share or feel comfortable sharing. If you want to talk with one of the investigators anytime after this interview, I can provide you with their information. The local collaborator who is working with us is _____ (Phone number: _____). Is it ok for us to begin now? Thank you for agreeing to help us.

APPENDIX E: EXAMPLE FREE LIST RECORDING FORM

FREE LIST RECORDING FORM: PROBLEMS

Site_____ Age____ Gender__ Interviewer_____ Date_____

PROBLEMS	**DESCRIPTIONS**
1	
2	
3	
4	
5	
6.	
7.	
8.	

APPENDIX F: EXAMPLE FREE LIST *PROBLEM* RECORDING FORM RESULTS

EXAMPLE OF FREE LIST RECORD FROM ZAMBIA (2001)

Compound: ZAMTAN Age: 29 Gender: F Interviewer: D. Phiri ***Date:*** *23/08/01*

	Primary Question	***Short description***
1.	*Few companies*	*Many companies are in town and many people cannot reach town.*
2.	*Water*	*The boreholes are starting to dry up* *There is queuing* *Some go to the stream*
3.	*Feeding*	*We can't get money to buy food* *Only one meal around 12.00 or 20.00 hours* *Can't find money and food*
4.	*I have a dumb child – a concern*	*I want him to go to school* *He won't find some one to support him*
5.	*Poor standard of living*	*We would want to have enough food*
6.	*Many men not working*	*Need to work so that they reduce beer-drinking* *There should be some companies established*
7.	*Women looking after homes*	*There are men who do nothing* *Women are the ones going to look for relish*

APPENDIX G: EXAMPLE OF FREE LIST RESULTS SUMMARY FORM

STUDY OF BARRIERS TO ART TREATMENT AMONG INJECTION DRUG USERS IN CENTRAL KAZAKHSTAN

Reasons People Have Difficulty Taking ART Regularly	**N**
Failure to follow the regimen	13
It is all rubbish – this treatment does not help	8
They are concerned that their relatives and neighbors will find out about the disease	7
Illegal drugs use	6
Poor nutrition	5
Alcohol dependence	5
Adverse effects (diarrhea, nausea, dysphagia)	4
Adverse effects – pain in the right upper quadrant	3
Family problems	3
Poor condition/health	3
Not having a HAART drug at the right time	3
They don't use the opportunity	3
Incompatibility of treatments for TB and HIV	2
They are afraid of misunderstanding (*from others*)	2
They don't want to be healthy	2
Fear of having to take the tablets for the rest of one's life	2
Lack of information	2
Lack of money	2
Unemployment	2
They just don't want to (*take the pills)*	2
In the bout of heavy drinking they don't remember to take the pills	2
They do not believe in this therapy	2

NOTE: ID numbers replaced by the number of interviewees giving each response. Only responses given by more than 1 interviewee are included.

APPENDIX H: EXAMPLE OF FREE LIST INTERVIEW GUIDE

1. Greet person.

2. Introduce self and indicate the organization(s) you are working for.

3. Explain the study either using formal consent process or recruitment/information form.

4. If person agrees to interview, find a private location (if not already in one).

5. Fill in information on recording form about date and site of interview, relevant demographic information.

6. Ask the *problem* FL question(s).

    a. One interviewer asks the questions while the other interviewer records the responses on the problem FL recording form in the first column. Probe until the interviewee says they cannot think of any more problems. Then ask for a short description of each problem and record this short description in the second column.

7. Conduct *function* FL interviews.

    a. For each function FL, probe until the interviewee says they cannot think of any more items. Then ask for a short description of each response and record this short description in the second column

8. Review the *problem* FLs for problems related to the topic of this study (mental and psychosocial problems).

    a. Ask if the person can recommend community members who are knowledgeable about these problems.

9. Both interviewers read through the recording form with the interviewee still present. If anything is not clear ask for clarification and correct your notes as necessary.

10. Ask if interviewee has anything to add. Add to the interview notes as needed.

11. Ask if you can return if necessary (Record when and where you can return on the back of the recording form).

12. Thank person and leave.

APPENDIX I: EXAMPLE OF A KEY INFORMANT INTERVIEW GUIDE

1. Greet person.
2. Introduce self and indicate the organization(s) you are working for.
3. Explain the study either using formal consent process or recruitment/information form.
4. If person agrees to interview, find a private location (if not already in one). In your exercise book/writing pad fill in information about date and site of interview, age and gender of interviewee, name of interviewers.
5. Begin KI interview:

   We previously interviewed people in this area and they told us about '___' *(the selected problem from the FL results)****. Some people also told us that you would be a good person to talk to about this problem. We would like you to tell us everything you can about this problem.***

   One interviewer asks the questions while the other interviewer records the responses in the exercise book/writing pad. Record everything that is asked by the interviewer (including probes), and everything that is said by the interviewee about the topic.
6. At end of the interview, both interviewers read through the recording form with the interviewee still present. If anything is not clear, ask for clarification and correct the notes as necessary.
7. Ask if the interviewee can recommend others who are knowledgeable about this topic. If so, record their contact information.
8. Ask if interviewee has anything to add. Add to the interview notes as needed.
9. Ask if you can return if necessary (Record when and where on the back of the recording form).
10. Thank person and leave.

APPENDIX J: EXAMPLE OF A FOCUS GROUP INTERVIEW GUIDE

1. Greet all participants.
2. Introduce self and indicate organization(s) you are working for.
3. Explain the study either using formal consent process or recruitment/information form.
4. If anyone does not agree to participate, invite him/her to leave. For the remaining persons find a private location (if not already in one).
5. In the exercise book/writing pad fill in information about date and site of interview, name of interviewers, number of interviewees and their ages and gender.
6. Begin FG discussion:

   We previously interviewed people in this area and they told us about the types of activities that men and women normally do. We would like to learn more about this by talking with you as well. Can you tell us about all the activities and tasks that men/women[7] do?

   One interviewer asks the questions while the other interviewer records the responses. Record everything that is said by the interviewer (including probes), and everything that is said by the FG members about the topic.
7. At the end of the discussion, the recorder should review the notes while the group is still present. If anything is not clear, ask for clarification and correct the notes as necessary.
8. Ask if any participants have anything to add. Add additions to the interview notes as needed.
9. Thank the group and leave.

[7] FGs are normally composed of only men or women. As with the function free lists, only ask men about men and women about women.

APPENDIX K: EXAMPLE OF A KEY INFORMANT INTERVIEW ANALYSIS FOR ONE PROBLEM

GENERAL KNOWLEDGE AND BELIEFS ABOUT A.R.T. (N=24)

Number	
9	The medications are very toxic and put a lot of strain on your body
7	Those people who refused taking medicine consider that this is a kind of experiment
7	These medications block the access of the virus to CD-4 cells that are responsible for the immune system, giving the opportunity for CD-4 cells to develop
6	People need to be sure, but we are told that no one knows what will happen when you take the pills. That's why people feel bad and people stop taking the pills.
4	ART slows down the development of the virus
3	That these pills are bad, people die because of them, feel ill, they blame the pills on bad qualities
3	(Pills) should be taken for the rest of life
3	These medications are incompatible with other medicines; with alcohol
2	While taking therapy the regimen of nutrition should be followed
2	Taking this medication you cannot infect another person
2	These pills are a kind of trap: people worry they will run out of pills, because you feel worse without pills, and where will people find them if the government stop funding them?
2	Maybe people consider that they are healthy, that's why they stop taking (pills), people don't consider themselves to be sick