3. PROCESS

SECTION 3.1: QUESTIONNAIRE DESIGN

The process the study team undertook began with the design of three separate questionnaires: community/population, PLHA, and health care provider. The community questionnaire was designed first, and common elements, where appropriate, were integrated into the PLHA and provider questionnaires. The process of development for all three questionnaires was to develop an outline of key domains and issues that should be covered, review existing instruments, and then develop individual questions based on the existing instruments and identified domains. The project team worked collectively on this process. They also ensured that all the proposed stigma indicators were measured and that all AIDS Indicator Survey[3] stigma questions were included in the community survey.

Once a final draft of the English version was complete and agreed upon, it was translated into Kiswahili. The first round of pre-testing of the Kiswahili version was done with the trainees during training. Revisions were made based on their input. This version was then pre-tested. For the community questionnaire, pre-testing was done in Kawe ward, Kinondoni district, Dar-es-Salaam (some distance from our study community), and changes were made accordingly. Once a final version of a questionnaire was ready, a revised English version was produced, based on the final Kiswahili.

SECTION 3.2: SAMPLING

SECTION 3.2.1: COMMUNITY SURVEY IN KIMARA WARD, KINONDONI DISTRICT

Kimara Ward was selected as the site for the community sample for two reasons: to allow comparison with previously collected qualitative data on stigma, and because of a planned community stigma-reduction intervention by Kimara Peer Educators and Training Trust. An important element of testing indicators is examining how they perform over time and around an actual intervention. The hope was that a second phase of funding would allow additional testing of the indicators by conducting a follow-up survey at the end of the community stigma-reduction intervention in Kimara. Therefore, sample size estimates were based on estimating differences between two proportions, with proportion one being the proportion anticipated at the present time (the baseline), and proportion two the proportion one might anticipate in a cross-sectional survey after one year of stigma-reduction activities in the community. The following parameters were used to determine the estimated sample size: power, 80%; confidence level, 95%; ratio of first to second survey, 1:1; possible detectable differences between the two samples, 5%; and estimates of the outcome variable, 20–25%. Based on these parameters, a sample size of 1,134 was calculated.

Probability sampling methods were employed to obtain the study population. In particular, the cluster-sampling technique, with probability proportional to size method, was adopted. The administrative structure was used as the sampling frame. Administratively, a district comprises divisions, wards, streets, balozis[4] (formally 10 cell units), and households. To

---

[3] AIDS Indicator Surveys (AIS) are being conducted by Macro International, with U.S. government funding, in countries participating in the President's Emergency Plan for AIDS Relief.

[4] Balozis are the smallest unit of the government administrative system.

obtain the study population in Kimara ward, the streets in the ward were listed together with the corresponding balozis. All five streets in Kimara ward were included in the study. From the listed 288 balozis, an effective sampling interval of three was applied to obtain the 100 clusters (balozis) required for the study. A cluster was defined as one balozi—a group of approximately 10 households. The number of clusters obtained from one street was proportional to the size of the street (i.e., streets with larger populations contributed more balozis than those with a smaller population).

For each balozi selected, the respective households were listed, and six households were randomly selected. From each selected household, one male and one female aged 16 years or older were randomly selected for participation in the study. To obtain accurate information, an enumerator, working with the research assistants, updated each level in the sampling frame before selection was done.

A total of 1,196 respondents were selected for participation in the study, and 978 participated fully by responding to the administered questionnaire. The remaining 218 could not participate due to the following reasons: non-eligibility (105), could not be found after three strategic visits (82), moved (6), dead (2). The remaining 23 persons declined to participate. The response rate for the community survey was therefore 978/1083 = 90.3%.

SECTION 3.2.2: PEOPLE LIVING WITH HIV/AIDS SURVEY

The questionnaire for PLHA was administered to a purposively selected sample of 218 people living in/around Dar-es-Salaam district. Respondents were recruited into the study via one of several organizations with a membership or clientele of people living with HIV/AIDS: Service Health and Development for People Living Positively with HIV/AIDS, Mbagala Dispensary, Mbagala Kizuiani, and the Magomeni-TAYOPA (Tanzania Young People Living with AIDS) counseling centers.

An initial sample size of 100 was determined to fall within the minimum required size on which statistical tests could be meaningfully conducted and within the maximum that the study resources could support. However, the majority of the first 100 respondents, recruited from the first organization, were women. Therefore, a second wave of recruitment and data collection was needed, made up of greater numbers of male respondents, to ensure equal numbers of men and women respondents. Data collection resumed 3–4 months later, after the recruiting strategy was modified to enroll more men. At the final tally, 103 women and 115 men participated in the study.

SECTION 3.2.3: HEALTH CARE PROVIDERS SURVEY

A sample of 100 respondents was drawn for the health care providers survey from three locations: Muhimbili National Hospital, Mwananyamala District Hospital, and the Kimara Government Dispensary. A sample size of 100 was determined to fall within the minimum required size on which statistical tests could be meaningfully conducted and within the maximum that the study resources could support.

Muhimbili National Hospital is a referral and teaching hospital. It provides services to patients referred from lower level health facilities from across the country. It has a capacity of 1,000 beds, with 1,254 health care providers of which 105 are doctors (52 medical specialists, 53

medical officers), and 1,149 are nurses (281 registered nurses, 300 enrolled nurses, 568 health attendants).

To select respondents, a list of all health care facility workers was obtained from the administration of Muhimbili National Hospital. Administrative staff was excluded from the sampling frame. The rest of the staff (doctors, nurses, and attendants) were then stratified by cadre, and random samples were drawn from each cadre, using a systematic sampling approach, after working out the sampling interval. Out of the 105 doctors, every other third was sampled. For nurses and attendants (1,717), every 30th was sampled. Out of the 78 persons selected, 44 participated in the study by responding to the questionnaire. Three of the remaining 34 declined to participate; 18 could not be reached after three attempts; and 13 were ineligible (e.g., not clinical staff) despite being listed otherwise.

Mwananyamala Hospital is the Kinondoni District (municipal) hospital with the mandate to deliver and monitor health services for the district, attend referrals from lower level facilities, and refer difficult cases to higher level facilities. Hospital facilities provide outpatient and inpatient services with a capacity of 162 beds, attended by 168 health care providers, including two medical specialists, 16 assistant medical officers, 13 clinical officers, and 136 nurses and clinical service supportive staff.

A list of all doctors/clinical officers, nurses, and attendants (168) was obtained from the administration of Mwananyamala Hospital. All doctors/clinical officers (32) were included in the study. Of the nurses/attendants, every third was selected for participation in the study, for a total of 45 individuals. Out of the 77 selected staff, 42 participated fully by responding to the questionnaire. The remaining 35 were not available due to being on holiday, in training, sick, or off duty.

Kimara dispensary is a government health facility for Kimara ward, providing services for about 70,000 people. It has 16 health care providers (five clinical officers, one nurse officer, two nurse midwives, two public health nurses, four nurse attendants, and two maternal and child health attendants). The dispensary offers outpatient services only, including maternal and child health and antenatal care, as well as family planning. It has a maternity room for uncomplicated deliveries (provided with one delivery bed and one examination bed) and an observation room (two beds; 12-hour observation maximum). For the Kimara Government Dispensary, 14 of 16 employees were available[5] and interviewed as a part of the study.

SECTION 3.3: DATA COLLECTION
Training of the data collection team was conducted at the premises of Kimara Peer Educators and Health Promoters Trust Fund, Kimara Ward, Kinondoni District, Dar-es-Salaam. The research team involved 13 interviewers (four males and nine females). Training lasted for two weeks and covered the following topics: (1) understanding HIV-related stigma based on the results of the multi-country research study, (2) the study objectives, (3) the research instrument, (4) data collection procedures, and (5) data editing and consistency checks in the questionnaire. Participants studied the questionnaire section by section and question-by-question, referring to the interviewers manual as needed. Brainstorming, paired group

---

[5]Two providers were absent during interviews: one was away at a training course, and one was sick.

discussions, and role-playing were used to facilitate understanding of the concepts of HIV stigma and discrimination and of the questions employed in the research instruments. Both the data manager and the data entry clerks participated in the training to gain an understanding of the data collection instruments, which facilitated the data entry process.

A pilot test took place over two days during the second week of training. Two "streets" (mitaa) of Kawe ward in Kinondoni district were selected for this exercise. A pilot area far from Kimara was selected to avoid contamination with the study area. Interviewers randomly selected one male and one female present at the time each household was visited.

When the full study was mounted, arrangements were made to ensure that the randomly selected individuals were visited and interviewed. To facilitate this activity, members of the research team were allocated to the local administrator, who led them through the selected households. Upon selection of the study participants, interviews were conducted in private after informed consent was obtained. Informed consent was obtained orally and confirmed in writing by the interviewer. If the selected respondent was not available at the time, appointments (callbacks) were scheduled for future strategic visits. A person was declared "nonrespondent" if he/she could not be found after three strategic visits.

SECTION 3.4: DATA MANAGEMENT

Questionnaires were checked for errors, consistencies, and gaps in the field by the field supervisor. The questionnaires were also edited in the office by the office data editor/ manager before data entry. Three data entry screens were developed (to correspond with the field questionnaires), using Epi Info Version 6.04. Before data entry, each questionnaire was given a unique ID to facilitate data cleaning later in the process. Each dataset was entered twice by two data entry clerks, checked for errors and inconsistencies, cleaned, and validated. Coding of open-ended questions and merging of files (e.g., questionnaire sections originally entered separately or data from the two waves of PLHA data collection) was executed after data was exported from Epi Info to SPSS.

SECTION 3.5: ORGANIZATION OF FINDINGS

The findings section is organized first by the population surveyed (community members, health care providers, and PLHA) and then by key stigma domains appropriate for the particular population. For each domain, we present existing and new indicators that were tested, questions asked to collect data relevant to the indicator, and basic frequencies for those questions. We then present further analysis of individual items, indexes, or scales, focused on reliability and validity testing, where appropriate. Each section closes with our recommendations for indicators and associated data collection questions/items for that particular domain, based on this population. These are made based on the results of the analysis and taking into consideration programmatic relevance and importance.

Conclusions and specific guidance for measuring the recommended indicators (e.g., as single indicators, scales, or indices) are summarized in table format in the conclusion section that follows. We provide recommendations for indicators at two levels (*Essential* and *Expanded*) to accommodate the varying needs, interests, and resources of different organizations for data collection. The first level comprises what we term *Essential-level indicators*—the minimum set of indicators recommended for each domain. We then provide a set of

recommendations for *Expanded-level indicators* for those wishing to collect more comprehensive stigma evaluation data. A revised set of questionnaires that reflect lessons learned about which survey questions worked well and which did not can be found in Appendix C.

These recommendations are the first step in a process of indicator testing and validating that must include studies at additional sites. This is a working document describing the initial findings from this first field test and aimed at generating feedback, discussion, and a basis on which to move forward in further developing, refining, and testing HIV-stigma indicators.

4. COMMUNITY/POPULATION

As described in the Background section, a random sample survey was conducted among 978 respondents in Kimara Ward, Kindononi district, Tanzania. Table 1 presents the background socio-demographic characteristics of the sample.

Table 1. Background Characteristics of Community Sample	
Background characteristics	**Percent**
Sex	
Female	53.3
Male	46.7
Age	
15–24	27.1
25–34	28.1
35–44	22.5
>44	27.1
Education	
No formal	7.5
Primary	58.7
Post-primary	25.5
University	8.4