Case Studies

Development of a Monitoring Framework for Referral within a Network of HIV/AIDS Service Providers

Final Report Based on Four Case Studies

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Acronyms

AIDS	acquired immune deficiency syndrome
APHIA	AIDS, Population, and Health Integrated Assistance II project
ART	antiretroviral therapy
ARV	antiretroviral
CBO	community-based organization
CCC	comprehensive care centers
CHEW	community health extension worker
CHW	community health worker
CHV	community health volunteer
CiSHAN	Civil Society Coalition on HIV/AIDS in Nigeria
FBO	faith-based organization
FOMWAN	Federation of Muslim Women Association, Nigeria
HIV	human immunodeficiency virus
M&E	monitoring and evaluation
NACC	National AIDS Council (Kenya)
NELA	Network on Ethics, Law/Human Rights, HIV/AIDS Prevention, Support and Care
NECAIN	NELA Consortium AIDS Initiative in Nigeria
NGO	nongovernmetal organization
OVC	orphans and vulnerable children
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLWHA	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission of HIV
SWAAN	Society of Women and AIDS in Africa, Nigeria
VCT	voluntary counseling and treatment
USAID	U.S. Agency for International Development
ZPCT	Zambia Prevention, Care, and Treatment Partnership

Background for Four-Country HIV/AIDS Referral Study

Rationale for Study

The Need for Integrating HIV/AIDS Services — The number and scope of services available for prevention, support, care, and treatment of HIV/AIDS has risen dramatically in the last several years, in great part due to the efforts of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), as well as other global health initiatives, such as the Global Fund to Fight AIDS, Tuberculosis, and Malaria. In this increasingly complex service environment, integrating HIV services among themselves and with other services is important for making those services accessible to clients and their delivery efficient for the health system, and ultimately for improving individual and family outcomes. There has been interest in integrating various HIV services into a seamless continuum (e.g., voluntary counseling and treatment [VCT] with antiretroviral treatment [ART]); in integrating HIV services with other health services (e.g., family planning, tuberculosis services, and antenatal care); and with integrating various HIV services with services outside of the health system (e.g., educational services, social and protection services, etc.). There are many context-specific models for integrating services, but approaches can be grouped into three main categories. That is, services can be integrated by being offered by:

- a single provider capable of providing multiple services;

- different providers at the same site (sometimes referred to as "co-location of services"); or

- different providers at different sites using a referral system.

Referring service	The health or social service making the referral of the client.
Receiving service	The health or social service to which the client is being referred.
Counter-referral	Process by which service provider at receiving service sends client back to referring service with information about services provided there.
Service provider network	The inter-connected group of service providers among whom referrals are made.
Coordinator of care	The person who manages or facilitates care for the client.
Facilitated referral	Referral that includes a set of actions shown to increase adherence.

Figure 1.   **Definitions of key terms used in this report.**

The first category of models gives the client the most seamless access to various services; however, this route to integration is often not practical as it implies the most disruption to current systems of care with consequent concerns about feasibility and cost because of needs to reconfigure infrastructure, personnel profiles, training, and supervision systems. The second and third categories of models are, therefore, considered to be the most feasible to implement over the short term. In fact, the third option (referral among sites) causes the least disruption to current institutional structures and arrangements; however, this option requires a well-functioning referral system. Such systems are lacking in many contexts.

Referral within a Network of Service Providers — Medline, an Internet site (www.medline.com) operated by the medical device manufacturing company Medline Industries, Inc., defines "referral" as "the practice of sending a patient to another program or practitioner for services or advice, which the referring source is not prepared to provide." Another key concept is that of "facilitated referral" (see Figure 2). A recent study by Johns Hopkins University scientists on referral of sick children from the community by community health workers (CHWs) defined facilitated referral as including four or more specific actions to encourage completion of the referral; such actions as various kinds of counseling, linking to transport, accompanying a client, preliminary treatment, referral slips, counter-referrals, monitoring referrals, etc. (Winch, Gilroy, Wolfheim, et al., 2005). It is important to note that these definitions and much of the health services literature on referral assume a one-way referral process, moving clients "up a pyramid" of care, from less specialized primary health care services to more specialized care (Figure 3 shows this traditional conception of referral, which has been used, for instance, to describe referral from a general doctor to a specialist in the formal medical system in the case of needed care for an unusual or complex condition). The pyramid also accurately depicts referral from a community health agent, such as a CHW or traditional birth attendant, to a first-level facility and beyond, for care of severe cases of such relatively common conditions as childhood pneumonia or pregnancy complications.

Many of the lessons learned on referral from the MCH literature using this pyramidal model are relevant to HIV/AIDS. Nevertheless, in the case of comprehensive HIV/AIDS services, this traditional depiction of referral does not adequately capture the complex nature of referrals needed between and among services at various levels of the health system, and even services outside the health system. Such referral systems have been more accurately depicted as a network or web with referral potentially occurring from various parts of the network to various others. Referring and receiving services can be located in the community or a health facility (necessitating facility-to-facility, community-to-facility, facility-to-community, and community-to-community referrals).*

In a traditional pyramidal system, all service providers work for the same government health service; but in a network model, service providers might work for different organizations, with different organizational, service, and personnel profiles, accentuating coordination difficulties. In order to ensure the smooth working of a complex network of service providers, some mechanism for coordination and cohesion of the network itself is necessary. A country's ministry of health, with the help of donors or other nongovernmental agencies, will want to ensure communication flow and decision-making to ensure a coordinated and consistent approach across partners.

There are also considerations of coordination of care and adherence to referral recommendations at the individual client level. Traditionally, with a single service or related set of services, a

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* Intra-facility referrals systems were not examined.

A community health worker (CHW) is performing "facilitated referral" if, at a minimum, she or he performs all actions in Components 1 and 2 listed below, and at least one action in Component 3, in an effort to ensure that sick children requiring care reach the nearest facility.

Component 1. *CHW promotes compliance with referral (both of the following actions):*

- *CHW counsels families about why referral is necessary and promotes compliance with referral.*

- *CHW fills out a referral slip or writes in a referral book and gives it to the child's caregiver.*

Component 2. *Monitoring of referral (all three of the following actions):*

- *CHW records all referred cases in a register.*

- *After examining and treating the child at a health facility, health worker writes a note to the CHW stating the outcome of the referral and explaining the follow-up that the CHW should perform in the home. This is sometimes called "counter-referral".*

- *Both referral and counter-referral are tracked in a health information system, and the outcome of referral is one topic covered in supervisory visits or monthly meetings.*

Component 3. *CHW addresses barriers to referral – geographic and financial access (at least one of the following actions):*

- *CHW inquires about barriers to referral and works with the family to address them.*

- *CHW has access to, or can inform the family about, a source of money at the community level that can provide or lend the family the funds necessary to seek care from a health facility.*

- *CHW has access to, or can inform the family about, a source of emergency transport at the community level.*

- *CHW accompanies the family to the health facility to ensure that they receive immediate care.*

(Source: Winch, Gilroy, Wolfheim et al. , 2005)

Figure 2.　　Definition of facilitated referral by CHWs, in this case for sick children.
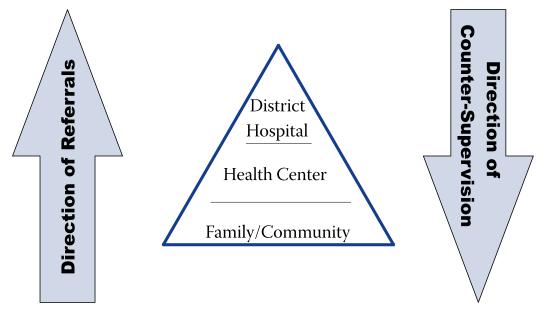
Figure 3.   Levels of care.

CHW or a nurse might be the "coordinator" of care. In the primary care systems of developed countries, there is the concept of a "medical home" (Starfield, 1998). Often, this is a primary care doctor who is aware of the various services needed by the client and to which the client has been referred. It is the keeper of this "medical home" that receives counter-referral information and assesses the need for additional follow-up or referrals. In both developed and less developed country settings, a similar concept of "case management," taken originally from social work, is utilized and later adopted in the health system as "medical case management," often done by nurses for chronic conditions requiring multiple service providers.* The case manager coordinates referrals and manages the client in the totality. The supposed benefits of a medical home and of case management include greater adherence to recommendations for referral because of the personal relationship developed between client and provider, the tailored support the coordinator of care can give, and the follow-up of defaulters. A simplified version of these concepts has been distilled in the concept of "facilitated referral" (see Figure 2). In community-based referral systems, this has been shown to increase rates of referral (Villaume, Ezzat & Gaumer, 2000).

Proposed Criteria for Measuring Success of a Referral Network — A four-country evaluation of integrating family planning and HIV/AIDS services by Family Health International found that, although in all cases there were referral systems in place and service providers reported making referrals, clients reported being referred with much lower frequency than providers reported making them (Family Health International, 2005). Due to poor documentation, it was impossible to determine the reasons for this discrepancy. This highlights two common problems with referral systems and their monitoring: referral systems often do not function as intended and far from optimally; and there is often lack of solid monitoring data to determine if a referral system is functioning as designed. Monitoring and evaluation of referral systems should allow referral system stakeholders to:

- know if their referral system is working; and

- identify well-functioning referral systems in order to provide information to others interested in establishing or improving referral systems.

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* For a brief explanation, see for instance: http://en.wikipedia.org/wiki/Medical_case_management

Not all information relevant for assessing the functioning of a referral system is likely to be captured through monitoring. Depending on the outcome to be studied, an evaluation or special study may be needed, but such studies are done infrequently because of the time and expense involved.* A relatively robust monitoring system based on routinely collected information is, therefore, desirable. A brief literature review was done, including review of articles that do not specifically deal with HIV/AIDS services (see References). In fact, much of the useful referral literature is from the maternal and child health field, especially for sick children and for management of obstetric complications. This review helped to generate the following proposed core set of generic indicators for monitoring referral systems (listed below and in Table 1). These indicators are stated in a general form and would need to be adapted to a context in order to monitor a specific referral system adequately. These indicators are all at the level of what can be called intermediate outcomes (if expressed as fractions). Indicators 1 and 2 can also be expressed as outputs (i.e., counts without denominators):

Indicator 1: Utilization rate for receiving service (# clients attended/# population).

Indicator 2: Referral rate from referring service (# clients referred/# clients seen).

Indicator 3: Referral uptake rate (# referred clients seen at receiving service/# clients referred).

Indicator 4: Counter-referral rate (# clients received back at original referring service with adequate information from receiving service/# clients referred).

Indicator 5: Median delay in completion of referral (median time in days from referral to capture at receiving service).

Indicator 6: Client satisfaction (optional) (# clients satisfied with service/# clients referred).

Client outcomes, such as treatment adherence and coverage with antiretroviral (ARV) drugs, can also be measured. Population impacts, such as morbidity and mortality from disease, can also be measured. While these are critically important and the ultimate aim of any referral system is to contribute to improvement in client outcomes and impacts, their measurement will usually be beyond the scope of a monitoring system and are more in the realm of evaluations or special studies. The one exception may be if a simple measure of client satisfaction with referral is tracked at the original referring service (after counter-referral). Tracking this at the referring service after counter-referral is a simple and practical way to capture the information; however, this will cause a bias as only those clients who were counter-referred will have their satisfaction recorded. Nevertheless, tracking client satisfaction this way may still give programmatically useful information.

These indicators are written as rates, but simple counts can be used instead (i.e., the numerator only). Using counts has serious drawbacks, however, in terms of the ease of use of the indicators for management decision-making. Rates are the more useful forms of the indicators, as rates are much easier to use in setting general targets and making comparisons from one site to another, either within or across projects. For example, it is much more apparent how one referral system is functioning compared to another if we know that 80% of all clients seen by CHWs are referred for VCT, rather than simply knowing the count of the number referred, even if this count is compared to a target set at baseline. Hence, the discussion here on the utility of these suggested core indicators will focus on coverage rates. If only counts are

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* See Swaziland Referral Technical Working Group Team (2008) for an example of an evaluation of referral for HIV/AIDS services in a low-resource setting.

Table 1. Summary of Proposed Core Indicators for Monitoring Referral

Indicator	Numerator	Denominator*	Why Track This? Other Notes	Data Source
1. **Utilization rate for receiving service**	*# clients attended at receiving service*	*Total population in catchment area of receiving servic*	If utilization rate is lower than expected, this may indicate client perception of low quality of care at receiving service or other barrier.	Register at receiving service.
2. **Referral rate from referring service**	*# clients referred out from referring service*	*Total # clients seen for that service*	Indicates if all appropriate clients being referred. Appropriate benchmarks depend on client and service characteristics.	• Register at referring service • Tracking slips
3. **Referral uptake rate**	*# clients who complete referral*	*# clients referred*	A barometer of referral success (if low, should trigger further investigation into barriers: cost, distance, stigma, locus of control, perception of low disease severity).	• Compare registers at receiving and referring services • Tracking slips
4. **Counter-referral success rate**	*# clients who return to referring service with complete counter-referral information*	*# clients referred*	An indicator of health worker compliance with counter-referral	• Register at receiving service • Tracking slip
5. **Median delay in completing referral**	*Median # days from referral to completion*	*(not applicable)*	• In cases where timeliness of referral is essential (e.g., urgent medical problems), this is most useful. • Need referral date to be recorded on referral slip and register • Best to use median as a normal distribution unlikely, making mean less useful.	• Register at receiving service • Tracking slips
6. **Client satisfaction with referral (optional)**	*# clients who state they were satisfied with the referral*	*# clients referred*	• This is the one outcome of referral that is most easily tracked, rather than being deferred to an evaluation • It is most feasible to use a simple general question like "Were you satisfied?" • Most feasibly tracked by recording client satisfaction when counter-referred back to referring service. This will introduce a bias as only those counter-referred can have this information recorded, and those successfully both referred and counter-referred are almost certainly more likely to have had a satisfactory experience.	• Register at referring service • Periodic survey of consecutive clients

Note
 * Simple counts can be used for indicators 1 and 2 (i.e., no denominators), but this will not give as obvious an indication of the functioning of the system.

used, at least we can look for improvement in the trend over time.

Utilization rate for receiving service — Increasing utilization at the receiving service is one of the aims of referral. So, of course, we would look for the utilization rate to rise. If simple counts (without denominators) were used, we would look for a rising trend in this form of the indicator; however, counts are less useful because even for well functioning and improving service utilization, we expect that eventually the level of utilization will level out. When it does, we will want to distinguish between the possibility that we have reached complete coverage of all those in the population who need the service or, alternatively, that this plateau in utilization rate is a reflection of the limitations of the service system (e.g., barriers to care, such as poor geographic accessibility or perceived low quality of care). There is the additional complication that a higher level of utilization may not always be reflective of good practice. For instance, if CHWs simply refer all adults from the community for VCT without regard to their level of risk, this may not be reflective of an optimal use of scarce resources.

Some examples can illustrate the above points. In the traditional pyramidal health system model, a well-functioning referral system should help to rationalize care. That is, simple health problems should be dealt with in simple facilities and more complex problems in more sophisticated facilities. In point of fact, it is often the case that clients bypass first-level facilities because of perceived low quality of care at that level, and "self-refer" themselves to higher levels of care (see, for instance, Akande, 2004). For instance, people may self-refer to a district hospital for treatment with ARV drugs rather than to a nearby health center if they perceive that the quality of care at the hospital is superior to the center (for instance, perhaps there is better drug availability at the hospital). When such a pattern of care-seeking occurs, it is easily discernible in the utilization profile (lower-

level facilities will be relatively under-utilized, and higher-level facilities will be over-utilized). A pre-requisite for this sort of analysis is to have some sense as to reasonable rates of utilization for the levels of facility. For some maternal and child health conditions, this sort of analysis has been done. For instance, in a less developed country setting with typical childhood disease profiles, a rough benchmark used for a reasonable utilization rate for sick-child visits might be that there should be 1.0 annual visits per child under five in the catchment area a first-level health facility. If a higher level of the health system is only meant to have contact with clients through a referral mechanism (i.e., it is not meant to be a first contact point), then benchmarking the target utilization rate for the receiving service simply depends on both the targeted utilization rate at referring facilities and the targeted referral rate (see "referral rate from referring service" section below). For instance, If there should be 1.0 annual sick visits per child under five years of age in the first-level facility catchment and if we take the benchmark that 5% to 10% would probably need referrals (Bossyns, Abache, Abdoulaye et al., 2006), then we should expect 0.005 to 0.01 sick visits per child under age five in the receiving facility's catchment area (presumably for more severe cases of illness). If the rate is much higher than this, it may mean that people are bypassing the first-level facilities; and if much lower, it could be reflective of either low accessibility of these services or an inappropriately low referral rate from first-level facilities. This sort of benchmarking is not as well developed for utilization of HIV services in low resource settings.

Referral rate from referring service — The referral rate for a referring service indicates the percentage of clients attended who were sent on (i.e., referred) to the receiving service. Referral rates can be general (i.e., summing the total of all clients referred for any reason) or specific (i.e., the number of clients referred only for a specific service). Not all clients seen at the referring service may require

specialized services from the receiving service, so in most cases we do not expect the referral rate to be 100%. In fact, in a case where 100% of clients in one service require the services of the receiving service as well, this is an ideal situation for co-location of services or, if possible, even making arrangements so that a single type of health worker can provide both services. The target set for the referral rate at the referring service will depend on local contextual factors as well as the nature of the referral. For instance, using a classic "pyramidal" system of health organization as an example, the original norm for referral of sick children set by the designers of child health programs was that 5% to 10% of children seen at first-level facilities would have severe enough illness that they would need referrals for higher level care (Bossyns et al., 2006). Norms for HIV services, such as VCT, ART, etc., can be set on technical or programmatic grounds — a certain percent of all adults should be referred for VCT given known seroprevalence rates; all those identified with the World Health Organization's stage III or stage IV level of HIV infection (i.e., clinical AIDS) should be on ARTs, etc.

Referral uptake rate — This refers to the percent of clients who were referred that actually complete the referral process. It has been shown that service providers often over-estimate the uptake rate for their referral recommendations, especially when done verbally. Facilitated referral has been shown to increase uptake of referral recommendations. Common barriers to referral that any system must overcome; the most common of these for HIV/AIDS services are stigma/discrimination as well as factors related to cost for care and for transport. Adherence rates of greater than 80% have been considered by some as an acceptable benchmark in maternal and child health services (Villaume et al., 2000) and might be applied to HIV services as well.

Counter-referral rate — The term "counter-referral" refers to the idea that the service provider

at the receiving service sends the client back to the referring service with information about the activities and outcomes that occurred while under the care of the receiving service. Referral systems in many places have traditionally had great difficulty with successful counter-referral. Part of the problem may often be attributable to practical considerations (e.g., overly burdensome methods for the receiving service provider to get information back to the referring provider). Anecdotal reports from many project sites, however, also point to possible attitudinal problems as contributors to low counter-referral success. That is, the receiving service provider is often more highly trained than the referring provider, and consequently may have lower confidence in the diagnostic or treatment capabilities of the referring service provider. This lack of confidence can manifest itself as an attitude among providers at the receiving service in which they say to themselves, "Why bother sending back information to the referring provider?" It would probably be theoretically reasonable to benchmark the counter-referral success at an 80% rate, as with referral adherence. In point of fact, though, many referral systems will have a much lower success rate than this in the absence of concerted intervention to raise the rate.

Median delay in completion of referral — First of all, "median" rather than "mean" is used as a measure of central tendency because it is not a realistic assumption that the distribution will be normal. There is likely to be a group or sub-set of clients that delay referral because of experience with common barriers to referral (e.g., cost, transport, stigma). Another way to construct this indicator is the percent of clients that complete referral in an acceptable time lapse. The "acceptable time lapse" will clearly depend on the level of urgency of the referral. For instance, a service like VCT is less urgent than a referral to initiate ART for a client diagnosed as HIV-positive. The context of the service and the service environment will have to be taken into consideration in setting a benchmark for this indicator.

Client satisfaction with referral — The outcomes of the referral are generally more feasibly included in an evaluation than in the monitoring system. The one exception to this rule may be client satisfaction. There are examples of client satisfaction being included in the monitoring system, based on results from simple periodic surveys of randomly selected or consecutive clients.

Besides being based on routinely collected information and capturing the information needed to construct the relevant proposed key monitoring indicators, an ideal monitoring system for referral within a service network should also have the following characteristics:

- **Data quality assurance:** There are mechanisms to ensure the quality of the data collected.

- **Client confidentiality:** There are functioning mechanisms in place to protect the confidentiality of the client.

- **Low-burden:** The documentation and monitoring system is low-burden for service providers.

- **Data use:** There are mechanisms to facilitate the use of the collected information for improvement of the network and its referral system.

Scope and Methods of Assessment

Scope of the Four Case Studies — To illustrate real-life scenarios for monitoring of referral systems, MEASURE Evaluation examined four country systems. These case studies include:

- notes on the context for referral within a network: strategies employed for integration of care that obviate the need for referrals as well as strategies for strengthening the service network, thereby facilitating referrals;

- examples of monitoring indicators for

referral currently being used that are context-specific examples of the generic indicators listed in Table 1;

- examples of mechanisms for capturing the data elements needed to construct the proposed generic indicators (e.g., referral forms, registers, tracking slips, periodic reports); and

- suggestions for capturing and analyzing referral monitoring information in a way that conforms to ideal characteristics listed above and ensures data quality, client confidentiality, low burden for service providers, and facilitating data use for referral system improvements.

In order to develop the proposed referral system monitoring framework, there was a need to understand better the context in which referrals were being done; what referral strategies were currently being used (i.e., verbal referral, client-held card or form, provider-assisted referral, etc.); what HIV services (i.e., VCT, prevention of mother-to-child transmission of HIV [PMTCT], services to orphans and vulnerable children [OVC], etc.) were being integrated through the referral process with what other services (i.e., family planning, tuberculosis services, palliative care, etc); and at what level the integration/referral occurs (i.e., within facilities, between facilities, community-facility, or community-community). We sought to implement case studies that included referrals between these various HIV and non-HIV services and were services located both within communities and in larger health facilities. The case studies that were performed are shown in Table 2. These examples were selected based on these criteria, as well as such practical considerations as the ability to consult with implementing organizations within the short span of time available for this activity.

Methods Used to Conduct Case Studies — It should be emphasized that these were case studies

Table 2.   Case Studies of HIV/AIDS Referral Systems

	Kenya*	Nigeria	Swaziland†	Zambia
Region	Central and Western provinces	Osun, Edo, Nasarawa, Bornu, Kebbi, Adamawa	National	Kabwe, Samfya, Mkushi Districts
Agency or project	AIDS, Population, and Health Integrated Assistance II project (APHIA)	NELA[??} Consortium	Ministry of Health	Zambia Prevention, Care, and Treatment Partnership (ZPCT)
HIV/AIDS services examined	Concentration on: • CHW (community) referral to testing and treatment services (facility) • Comprehensive care center (facility) referrals to support groups and HBC[??] (community)	Care and prevention	All HIV/AIDS services	All HIV/AIDS services
Methods of study	• Initial offsite interviews • Country visit (interviews with key staff, record reviews, site visits to facilities and community groups)	Off-site interviews and record reviews	• Review of recent referral study • Offsite interview of study author	Off-site interviews and record reviews

Notes

* This study was based on a country visit.

† This study was a pilot of the study methodology and was based on a review and synopsis of a recently performed MEASURE Evaluation   assessment of the national referral system for HIV/AIDS.

and not formal evaluations. The main purpose of this activity was to document the methods used for tracking and analyzing referrals. This was a preliminary investigation, employing exclusively qualitative techniques. Also studied were the network of service providers itself, any other strategies employed for service integration, and the context in which the service provider network is located.

The scope of work for the study was developed in consultation with PEPFAR (see Appendix B). The scope of work included specifics on the services to be investigated and that there be a variety of referral situations investigated that included referrals from facility to facility, community to facility, facility to community, and community to community. A list of potential case studies was developed that covered this range of situations. The number of case studies that could be done was limited to four or five, and the specific cases chosen took into account both their coverage of

the areas of interest, as well as the feasibility of completing the work on a short timeline.

A study protocol was developed by MEASURE Evaluation staff (see Appendix B) who had experience in clinical settings and study of referral systems. The protocol was centered on semi-structured interviews and also included review of background project documents, relevant forms, reports, and, in the case of the country visit, review of completed forms and registers.

The semi-structured interview form (see Appendix B) was developed based on one used by MEASURE Evaluation for an in-depth investigation of referral systems in Swaziland. This interview employs a combination of open-ended questions and closed coding for certain responses, to give information on some topics in a structured manner. It covers domains dealing with general background information on the context and project area, the service provider network and referral system, the monitoring of information on

referrals, and the manner in which the data are collected and analyzed (focusing on the topics of client confidentiality, data collection burden, data quality assurance, and data use).

The draft study protocol, interview form, and basic analysis plan was piloted by applying it to a MEASURE Evaluation staff member with experience in such work. Final adjustments were made, and the ICF Macro institutional review board approved the protocol, consent form, and interview form.

Two of the studies (Nigeria, and Zambia) were done off-site through interviews with project managers and review of the key documents (sent electronically) indicated in the study protocol.

The Kenya case study was done through a six-day country visit. The geographic and topical areas of focus were agreed upon in conjunction with PEPFAR and the USAID Kenya mission staff. Two project areas of the AIDS, Population, and Health Integrated Assistance II (APHIA) project were chosen as positive case examples of functioning referral systems. These were Central Province (run as Nairobi/Central, with Pathfinder International as the lead agency) and Western Province (PATH as lead agency). In both project areas, key project staff were interviewed, including the directors, deputy directors, and staff in charge of operations and monitoring and evaluation. Site visits were made to a range of service providers and project staff (see Table 3).

Table 3. Number of Respondents, by Type, in Kenya Cental and Western Site Visits

Type of Respondent	Central	Western
APHIA project staff	9	11
District health teams	3	1
Facility-based service site staff	6	1
Comunity-based service site staff	2	1

Summary of the Four Case Studies

Detailed accounts of the results of the four case studies are included in the individual reports, found in Appendices A through D. The following are summary descriptions of the results in terms of the tools used, the data collected, and the key characteristics of the monitoring system, all compared to the proposed criteria outlined in the scope-of-work (see Appendix E) and in the introduction.

Monitoring Tools Used (Maps/Directories, Referral Forms, Tracking Slips, Registers)

Maps/Directories — In all but the Swaziland study, there was some form of a map or directory of service providers either in use or under development. This was put together by the network coordination organization. In some of the countries, the directory/map seems not to have been widely distributed to service providers. In the case of Kenya, the service providers among whom referrals occurred tended to know each other quite well and many of those interviewed did not feel that a directory was necessary. In Nigeria this tool was being developed.

Referral Forms — Across the case studies, all forms reviewed recorded the basics of client name, referring provider, provider to whom the client was referred, and reason for referral. Date of referral was not always recorded (the date is necessary for calculating median delay). Forms were also variable in their utility for use in counter-referral. The most feasible for use for counter-referral were forms with several sections — at least one section completed by the referring service and given to the client, and then another section completed by the receiving service and sent back with the client. This method of having separate sections, in turn, brings up two other practical issues:

- Producing forms with multiple sections causes certain complications (more training is needed and also increased costs to produce a form with perforations or other method to separate the multiple sections). This may not be a significant cost for a project; but in terms of longer-term sustainability, it may represent a significant cost for a ministry of health.

- If the receiving service provider sends the client back with the counter-referral portion of the form, then this brings up the question as to what part of the referral record the receiving provider will retain. This is handled in various ways by the receiving provider, typically by either simply repeating the information within the client's record or by making a copy of the form.

Tracking Slips — These were used in Nigeria and Zambia, but not in Kenya or Swaziland. In Kenya, the referral slip was made in duplicate. One copy was used as a tracking slip, eliminating the need for a separate tracking slip.

Registers — The registers examined were generally well-maintained. There was a wide variation in the information recorded in registers. The information necessary for calculating utilization and referral rates was almost universally present. The data least likely to be available for the proposed key indicators were recording of date of referral in the receiving service register (for calculation of median delay) and whether someone completed counter-referral in the referring service register (for calculation of counter-referral success).

Other Forms/Reports — In the cases of Zambia and Kenya, specific formats were used to collect information related to data quality assurance. In the Zambia Prevention, Care, and Treatment Partnership (ZPCT) project in Zambia, information is regularly collected on client satisfaction through a periodic client survey.

Project-Specific Indicators and Referral Characteristics

Table 3 proivdes a summary of project-specific indicators that correspond to proposed key standard referral monitoring indicators. Table 4 summarizes data on the characteristics of the four referral system studied, with respect to several key domains (collection of key data, data quality assurance, probable maintenance of client confidentiality, provider burden, and data use). Complete descriptions of the individual case studies are in Appendices A through D.

Table 3.   Project-Specific Indicators

Indicator	Findings
Utilization rate for receiving service (# clients attended / population)	In all cases except Nigeria, utilization appears to be tracked. Usually, this is done in the form of counts, rather than rates (i.e., no denominators are used).
Referral rate from referring service (# clients referred / # clients seen)	In all cases, referrals appear to be tracked. These data were generally collected as counts.
Referral uptake rate (# referred clients seen at receiving service /# clients referred)	In Nigeria, this was mentioned but no evidence was provided. In both Zambia and Kenya, there was some effort to look into calculating these rates. This should be possible, given the data elements already available in the information systems in both places.
Counter-referral success rate (# clients received back at original referring service with adequate information from receiving service/# clients referred)	Counter-referral was acknowledged to be a problem in all cases but Zambia, but solid data on counter-referral was lacking in several of the cases.
Median delay in completion of referral (median time in days from referral to capture at receiving service)	Zambia had data on this. Kenya and Swaziland did not collect the data in a way that this could be calculated (date of referral not recorded in the receiving institution's register).
Client satisfaction (optional) (# clients satisfied/# clients referred)	Only Zambia collected this on a regular basis. This was collected through the periodic application of a short survey of randomly selected clients.

Table 4.   Case Studies of HIV/AIDS Referral Systems

Characteristic	Criterion	Kenya APHIA	Nigeria NECAIN	Swaziland National	Zambia ZPCT
Recording and reporting of basic data element	Referral rate from referring institution (register records if client referred)	◉	◉	◉	○
	Utilization rate at receiving institution (register records if client referred)	◉	○	◉	◉
	Referral adherence rate (tracking and analysis done)	○	◉	○	○
	Counter-referral adherence rate (tracking and analysis done)	—	○	○	○
	Median delay (dates logged in registers)	—	○	—	◉
Data quality mechanism	Protocols/guidelines exist (PMTCT, VCT, ART)	◉	◉	◉	○
	Provider training on monitoring system	○	○	—	—
	Quality checks on reported data	◉	○	—	—
Client confidentiality	Provider protocols and training include confidentiality	◉	—	—	◉
	If name in register, there are safeguards	○	○	◉	○
	No name in reports	◉	○	◉	◉
Data use for programmatic decision	Reporting done to central authority	◉	—	—	◉
	Analysis done	—	○	—	○
	At least one programmatic decision made based on data	—	○	—	—
Provider burden	Methods of study	*Low*	*Medium*	*Low*	*Low*

Legend

◉   Fulfills criterion

○   Partially fulfills criterion

—   Does not fulfill criterion

Conclusions and Recommendations

Summary of Performance in Capturing Data for Proposed Key Referral Monitoring Indicators

Utilization Rate for Receiving Service and Referral Rate from Referring Service — There were generally adequate data (and of good quality) collected to calculate these indicators. They were generally analyzed as counts. This makes it difficult to make managerial decisions based on this information. The simple expedient of dividing by the denominator of the estimated catchment area population would render these data much more easily understandable and useful.

Referral Uptake Rate, Counter-Referral Success Rate, Median Delay in Completion of Referral, and Client Satisfaction — These are the indicators that would give the clearest sense of whether the referral system is functioning adequately. Unfortunately, it is also a bit more complicated to collect the data elements for these and they are, consequently, less likely to be collected and analyzed. Calculation of referral adherence rates takes some measure of coordination between the data collected in the referring and the receiving services. For instance, the number of referral slips issued in one site and received in another site might be compared. Traditionally, communication between service sites has been problematic, making such information coordination difficult. But currently, with universal mobile telephone communication even in many rural areas, this should be much less difficult.

Median delay and counter-referral success data are not as simple to collect and analyze as utilization or uptake data; but on the other hand, collection of the data elements for these indicators does not need to be overly complicated. For instance, to get median delay in referral, the date of referral as well as the date of service need to be noted in the register and the difference in number of days noted. For the monthly report, the median

would need to be calculated. An easier to report summary indicator for delay would be the percent of cases where the delay was less than some critical value (for instance, the percent of clients initiated on ARTs less than one week after being referred from a VCT center).

Client satisfaction is the least likely indicator of all to be reported. This is much more likely to be analyzed in an evaluation; however, the Zambia case study showed that this can be feasibly analyzed and periodically reported. The key here is to keep the questions on satisfaction simple and easily coded, otherwise the data analysis can become overwhelming. This simple outcome measure can give some sense about the overall functioning of a referral system from the client's perspective.

Summary of Current Performance within Focus Domains for Referral Monitoring

Recording and Reporting of Basic Data Elements — Please see the last section for an analysis of this.

Data Quality Mechanisms — In general, data quality mechanisms were in place (norms and protocols, initial provider training, supervision on the use of the system, and periodic data checks and on-the-job training).

Client Confidentiality Considerations — In general, considerations of client confidentiality were taken into account and managed adequately. The main gaps were that considerations of client confidentiality were not always included in provider training and that client registers were not always secured so that only authorized staff had access.

Provider Burden — In general, all the referral monitoring systems examined had low provider burden. This confirms the fact that well-designed

referral monitoring systems do not have to take much provider time. On the other hand, in all case studies there appeared to be significant burden in terms of monitoring and evaluation at the level of the staff involved in collating and reporting the data. This also emphasizes the point that the minimum number of data elements and analyses should be done to give an adequate picture of the health of a referral network, in order not to increase the burden on already heavily-taxed monitoring and evaluation staff.

Data Use for Programmatic Decisions — There was very little evidence of the use of the referral data for making programmatic decisions. Of the criteria discussed for referral monitoring, this seemed to be the most problematic. The fact that counts are generally used rather than rates with denominators makes data use more difficult. For instance, one project staff member interviewed was asked if referral seemed to be done more effectively in communities where CHWs were in place. He was unable to answer this question, although he had quite a lot of referral data, but all in the form of counts. It would be much easier to answer this question if the data were in terms of coverage rates. In other words, one might know, for instance, that 20% of adult community members had been referred for VCT in one area and only 5% in another. One might also know the ongoing or cumulative utilization rates for VCT services in various communities. Clearly, risk factor prevalence will vary from one community to another, but if most areas with CHWs have higher VCT referral and utilization rates than those without, then we could feel fairly comfortable in asserting that CHWs were probably making a difference in getting community members tested and counseled.

Proposed Checklist for Assessing Referral Network and Its Monitoring

For a key service needed by clients, the ultimate goal is that clients have timely access to the service (and, therefore, utilize that service appropriately).

The following is a proposed algorithm for deciding if referral is the best option for achieving this goal and, if so, some key considerations for structuring the referral system and its monitoring.

1. First explore if referral is the most appropriate mechanism to attain the goal of making the needed service accessible to clients. Illustrative common alternative mechanisms to increase access are:

    a. *establish a system so that one health worker can provide both services* (this route should be taken with caution as it is more complex than simply training health workers; there must also be adequate logistics, support, and management systems to make this option functional);

    b. *co-locate services in the same facility, if feasible* (an example is the establishment of comprehensive care clinics in Kenya where VCT and ARV drugs are delivered in the same location;

    c. *establish mobile services* (this still technically entails referral, but it eliminates a major barrier to timely referral adherence in many settings — the cost or inconvenience of transport); and

    d. *send a sample rather than the client* (for instance, in the case of CD4 counts or sputum testing for tuberculosis, it may be possible to perform collection of samples in convenient locations and send biological samples to a central laboratory, rather than referring the client to a distant facility).

2. If referral within a network of service providers at distinct locations is felt to be the best option for ensuring that clients have access to both needed services (rather

than co-location of services or training one worker to provide both services), then assess that the building blocks of a good referral system are in place:

    a. *Strong network of service providers* — referral is most successful when done to a health workers at the receiving service who are personally known and trusted by those who are referring.

    b. *Establish/strengthen a mechanism for facilitated referral*, that is:

        i. the client should receive counseling about the need for referral;

        ii. referrals should be written;

        iii. the referring provider should address client barriers to referral in some manner (counseling, finances, transport, and/or accompaniment);

        iv. there should be a counter-referral mechanism;

        v. referrals should be recorded in a register; and

        vi. referrals should be monitored routinely in the health information system.

3. When monitoring referrals, ensure that adequate data are collected to assess if the referral process is working well. There are five key generic indicators to monitor (and optimally one additional parameter):

    a. *utilization rate* for receiving service (is the rate adequate? rising?);

    b. r*eferral rate* of referring service (is proportion appropriate within upper/lower bounds?);

    c. *referral uptake rate* (some authors feel a realistic benchmark is > 80%);

    d. *counter-referral success rate* (probably should also be > 80%; often much lower);

    e. *median delay for referral completion* (suggest using only in the case of urgent referrals); and

    f. (optional) at referring service, collect data on *client satisfaction* with referral.

4. A set of generic documents/forms is needed for a well-functioning referral network and its monitoring. The minimum data elements that they should contain to calculate the proposed key indicators are described in Table 5.

5. In addition to collecting and analyzing data to construct the key indicators, the monitoring system should handle information in a way that follows four key principles:

    a. respects *client confidentiality* (include confidentiality in provider training, data security measures for registers with names, no names in public reports);

    b. is a *low burden* to service providers (forms with minimum necessary information, use of check boxes on forms when possible);

    c. has adequate *data quality* assurance (initial training, spot checks, on-the-job training, periodic review); and

    d. facilitates *data use* for programmatic decision-making (indicators that are rates are better than those that are counts; targets set; mechanisms/forums for partner discussion of results).

Suggested Areas for Further Investigation

This was a preliminary investigation, summarizing four case studies. This investigation could be characterized as documenting referral systems and their monitoring across a variety of situations, in order to give a sense of how such systems were currently functioning. It also acted as an

Table 5.   Forms and Documents Needed for a Well-Functioning Referral Network

Form or Document	Minimum Data Elements Needed to Construct Proposed Key Indicators	
Mapping/Directory of Service Providers	geographic locations of providers contact information of providers hours of operation of providers services provided	
Client-Held Referral Form	name of client name of referring provider date of referral name/location of receiving provider reason for referral (can be checklist)	
Referral Tracking Slip *(may not be necessary)*	If used, should have client name/date/reason for referral *(copy or portion of referral form can be substituted)*	
Register at Referring and Receiving Services *(includes referral information)*	*Referring Service* Name of client Date of service Referred? (+ Reason for referral) Counter-referred?	*Receiving Service* Name of client Date of service Date referred
Summary Reports from Service Providers to Central Autority	*Referring Service* Number of clients seen Number of clients referred (referral rate) Summary of counter-referral rate Possibly, client satisfaction data	*Receiving Service* Number of clients seen (utilization) Summary of referral delay data
Summary Analytical Report of Central Authority	Key indicators, calculated from data elements reported from service provider summary reports.	

opportunity for performing a proof of concept for a more general generic framework that can be used for developing or analyzing monitoring of HIV referral systems across a variety of contexts.

The following are some additional activities that would help round out the activities already done:

- Based on the literature review, facilitated referral has been a successful model in child health programs. Several of the cases had elements of this model, but none seemed to be implementing this model explicitly. However, limited information provided for a Haiti case study (which could not be completed) showed that some form of facilitated referral is being used in Haiti for HIV/AIDS and ANC referral services. Further study of the Haiti approach could be beneficial.

- For the purpose of rounding out the analysis, the addition of a case from another region (i.e., Asia) and an explicit examination of services for most-at-risk populations would be advantageous, as issues of stigma and confidentiality are even more crucially important.

- Zambia appears to have a well-developed referral system and referral monitoring system in place. It would be beneficial to use lessons learned from Zambia and provide a forum for exchange of information about monitoring of referrals between case-studies, to incorporate best practices in the spirit of South-to-South cooperation.

If further investigation is done, we would suggest the following:

- The median referral delay should be dropped as an indicator, as it would be difficult to collect and, for most of the services likely to be studied, immediate adherence to referral is not as critical as it is for referral of acutely ill clients for which this indicator was originally constructed. Additionally, for non-acute services, this indicator is not likely to give further insight into the functioning of the referral system beyond the information provided be the referral adherence rate. If delay time is felt to be important to collect and report, a more feasibly constructed indicator would be to benchmark an acceptable delay time (say, two weeks) and have sites report the percent of referred patients that met this benchmark.

- The client satisfaction rate is clearly the most complex of the remaining indicators. This should clearly be continued to be considered optional.

Appendix A: Kenya APHIA II Central and Western Province Case Study; Community-Facility Referral for Adult Diagnosis and Community-Based Care

Background

This brief case study documents selected aspects of the community-facility referral system and its monitoring for HIV/AIDS services in two of Kenya's eight provinces — Central and Western. It specifically focuses on referral of adults from the community for voluntary counseling and testing (VCT) and referral of HIV-positive adults in first-level health facilities to community-based support and home-based care. The overall system of referrals within the network of providers of preventive, diagnostic, treatment, care, and support services is clearly much more complex than these selected services, but this study focuses on this level of coordination and referral, as this is a level at which referrals often break down, resulting in either delay or failure of clients to access needed care. This is one of several case studies done by MEASURE Evaluation as part of a preliminary study of HIV/AIDS referral systems.

HIV/AIDS Service Providers in Kenya — The Kenya National AIDS Control Council (NACC) reported a national adult seroprevalence rate of 5.1% in 2007, based on sentinel surveillance data. Kenya's response to this generalized epidemic has been comprehensive and multi-faceted. The number of voluntary counseling and testing sites has risen dramatically. Most ART and other treatment services occur in the network of comprehensive care centers (CCCs) established across the country. After initially being established in mainly urban and district centers, the Kenya Minstry of Health extended the CCC network to smaller health centers, raising the availability of ART dramatically, so that now about 39% of those estimated on a nationwide basis to be in need of ART are receiving it.

Community health workers and other community-based volunteers have been key in helping link facility-based services in CCCs with community services. In 2006, the health ministry articulated its new community strategy in an attempt to deploy these community resources better, by adding community health extension workers (CHEWs) to these facilities. CHEWs are mainly responsible for organizing community-based service delivery around various community-level volunteers. This strategy has remained mainly unimplemented, save for some pilot experiences, but some of the pieces are in place in various areas of the country.

APHIA II Project in Central and Western Provinces — The AIDS, Population and Health Integrated Assistance Program (APHIA) II is a USAID Kenya mission-funded effort in all eight of Kenya's provinces, initiated in 2006 and scheduled to end in December 2010. The mission has awarded the contract in each of the provinces separately. In Central Province, the lead agency is Pathfinder International; and in Western Province, the lead agency is PATH. There is latitude to respond to specific needs in the particular context, but in all APHIA II projects the three main results areas are as follows:

> **Result 1:** Improved and expanded HIV/AIDS prevention, care, and treatment.

Result 2: Improved and expanded civil society activities to increase healthy behaviors.

Result 3: Improved and expanded support for people affected by HIV/AIDS.

All APHIA II projects emphasize a comprehensive approach to prevention, care, treatment and support for people infected and affected by HIV/AIDS, including OVC. A network of service providers and community groups is involved in each province. There is an attempt to integrate HIV/AIDS services with other medical services (maternity, tuberculosis, and child health), as well as such non-health services as child protection and education.

Scope of the Case Study — It should be stated at the outset that this brief case study was in no way meant to be an evaluation of either of the APHIA II projects nor a comparison of them. The methodology was exclusively qualitative and the sampling of service providers was purposive, looking for examples where the referral system, as designed, was working well. The responses are the opinions of respondents, backed as much as possible by documentary evidence. As designed, the results of the study describe the optimal functioning of the system for networking/referral and its monitoring as they exist now.

A broad range of referral systems could have been analyzed. As an illustrative list of those that were discussed during site visits, see Table A1.

For the purposes of this case study, there was not enough time or resources to examine the entire network of services within the APHIA II project areas in Central and Western provinces. So a decision was made, in consultation with PEPFAR officials in Washington and the Kenya USAID mission, to focus on community-facility referral. Given that this still encompasses a variety of referral systems, each with distinct providers

of services, systems, and formats, it was decided to focus on referral from the community for counseling and testing and from facilities, referral of newly diagnosed HIV-positivie clients back to the community for support and home-based care.

Table A1.   Illustrative List of Referral Systems, APHIA II Central and Western Provinces

Referring Service	Receiving Service
Counseling and testing	Care and treatment
Community dialogue group/other community group	Counseling and testing
Care and treatment	Tuberculosis diagnosis
Care and treatment in one CCC	Care and treatment in another CCC
Care and treatment	Community support group
Care and treatment	Home-based care
OVC community client (CHW)	Counseling and testing
OVC community client (CHW)	Legal services
Antenatal care	Prevention of mother-to-child transmission of HIV

The Referral Network and Its Monitoring

Community-Facility Network and Referral System — The specific objectives of the pieces of the referral system with which we are concerned in this case study are to identify community members in need of counseling and testing and to refer them. There are various sites to which clients could be referred within Central and Western provinces, but in most areas, it is to the CCCs that people are referred for VCT. Once diagnosed as HIV-positive, a client would then have the severity of his or her disease categorized by stage, by getting a CD4 count, and would be re-referred back to community structures for social support or home-based care, as appropriate.

As the referral system is designed, the client is referred from the community with a standard National AIDS/STD Control Programme (NASCOP) referral form. This slip acts as the signal that a client has been referred. There is apparently not an agreed-upon protocol stating

that such clients should be given preferential consideration at the receiving institution; however, there have been informal agreements made in some facilities with referring community health workers (CHWs) that the client will, in fact, be sent to front of the queue. Several CHWs and project staff interviewed felt that, in the absence of such preferential treatment, there would be a lack of respect for the referring CHW on the part of the client and a feeling that getting a referral was not worth the trouble, since the client could simply self-refer. It was reported that some facility-based health providers did not feel they should give any sort of preferential treatment as they did not want to disrupt their queue system. Many interviewed CHWs stated that they called facility-based health personnel, using their mobile telephones, to let them know that they had referred a client.

In Western Province, CHWs (called community health volunteers or CHVs) organize community members into structured dialogue education groups. After an initial training in group facilitation and adult education, CHVs meet with community members in these groups on a semi-regular basis to go through topics in a standard curriculum. One of the topics covered is HIV/AIDS, emphasizing the importance of knowing one's serostatus. Clients self-identify as potentially being at risk, may discuss with the CHV the need for referral, and this will then trigger a referral to a CCC or other center for VCT. A similar process, but less structured, occurs with CHWs in Central Province. CHWs in both provinces report physically accompanying many of their clients to ensure adherence with referrals. They universally report leaving the question of accompaniment up to the client, but they also feel that if the client does not want to be accompanied, this is likely a sign that they are not serious about adhering to the referral.

After attending to the referred client, facility-based personnel are to send the client back with what has traditionally amounted to a verbal

counter-referral. There has been no space in the traditional NASCOP community referral form for counter-referral information. The form can be used for referral to community-based care like psychosocial support or home-based care.

Description of Monitoring of Referrals — The community-facility referral system uses several standard forms and documents, with some variations among areas in their exact appearance. There also are some novel project-generated forms used, including:

- a mapping or directory of providers in both provinces;

- a standard ministry of health-designed community referral form (copies of the referral forms are usually retained by the referring providers, often in a booklet);

- health ministry-standard registers in both provinces (the projects have generated standard registers for CHWs in both provinces as well; and

- monthly reports that include referral data by facility/community entity and by reason for referral are generated in both provinces.

Directory/map of service providers — In both Central and Western provinces, mapping of key institutions and health providers was done. This information was summarized in different ways. In the case of Central Province, the information was put in tabular form, showing the correspondence between facilities and community service providers in their catchment areas. This table included the types of both facility and community services provided. In Western Province, a geographic information system (GIS) was used to map where facilities were located throughout the province. Community-based services and service providers have not been similarly mapped.

In both Central and Western, it seemed to be

project staff who exclusively made use of these maps and matrices. No community-based or facility-based provider interviewed in either area had these project-generated maps, nor did they have any other kind of mapping or directory of service providers. Both community-based and facility-based providers interviewed did not feel that such a map or directory was necessary, because they were familiar with the service providers to whom they referred.

Referral forms — The NASCOP community referral form has the following information):

- name of the client
- date
- gender
- age
- location from which client was referred
- entity to which the client is being referred
- reason for referral (standard checklist)
- name of referring health agent
- comments section

There is no space in the traditional NASCOP form for counter-referral information once the facility-based staff receive the client. The APHIA II Western staff members had recently modified this form, with health ministry permission, and were disseminating a version of it that allows for counter-referral information to be recorded. The facility-based provider retains a portion for their records and then gives the bottom portion to the client for counter-referral.

Tracking slips — Tracking slips were not utilized. The NASCOP referral form is meant to serve the purpose of a tracking slip. There are variations on the official NASCOP form, as project funds have been used to generate copies and booklets of the forms. In most places observed, a carbon-paperless copy is generated. The client is given one copy to take with him or her to the receiving institution. The other copy stays with the referring provider.

Client registers — Both facility-based and community-based providers utilize registers that, on spot checks, were universally well-maintained, up-to-date, and contained complete information. Community-based providers could and did compute numbers of referrals from these registers. Facility-based providers did not record in their registers who had been referred for care. The most commonly observed method for facility-based providers to track whom they had referred for care was to retain duplicate copies of the referral slips.

Reports and analysis — In both provinces, referral data were reported monthly. These data had mainly been analyzed in the form of counts. In Central, some data were converted to rates. In Western, there was a plan, initiated after a recent assessment, to look at rates of referral as well. Reporting to the central project office was done monthly.

Measures Corresponding to Proposed Key Referral Monitoring Indicators

Referral Rate from Referring Service — This represents the number of clients referred out from a referring service divided by the total number of clients seen for that service.

The following information was being recorded and reported — numbers of clients referred for VCT, ART, prevention of mother-to-child transmission of HIV, ANC, family planning, and other treatment services.

Although counts are reported for key services, the referral rates are generally not calculated, except in the case of referral of home-based care clients for ART in Central Province. Since the numbers of clients referred as well as the number utilizing the referring service are known, all the information necessary for producing referral rates is present, if referral rate information were desired.

Utilization Rate for Receiving Service — This rate represents the number of clients attended at receiving service divided by total population in the catchment area of the receiving service.

The following information was being recorded and reported:

- number of clients seen for counseling and testing services (numerator only); and

- number of clients seen for home-based care and support service (numerator only).

The numbers of clients seen for receiving services both in the community and in facilities is regularly tracked through community agents (CHWs in Central Province and CHVs in Western Province) and in facilities (in CCCs) where clients are referred for VCT or treatment once diagnosed as HIV-positive.

Referral Adherence Rate — This represents the number of clients who complete referrals divided by the number of clients referred.

Indicators corresponding to this parameter were not being analyzed or reported for any of the services to which clients were referred. Indicators could be calculated for this parameter, especially for community referrals. The number of clients referred is being recorded and reported monthly. Utilization of services at receiving institutions was also being recorded and reported; however, those clients that were referred were not being noted in registers nor being reported out.

Counter-Referral Success Rate — This represents the number of clients received back at the original referring service with adequate information from the receiving service divided by the number of clients referred.

No indicator was being analyzed that corresponded to this parameter. Community-based providers and

project staff were aware that the rate of successful counter-referral was quite low. Partly, this seemed to be due to technical issues with the NASCOP form, as the standard traditional form did not have a place for counter-referral information to be recorded, nor a mechanism to give a piece of the form back to the client to take back to the referring provider. APHIA in Western Province had tried to address this with the new version of the NASCOP form, which had a portion of the form to be torn off and returned by the client to the referring provider. APHIA staff reported that this was not in regular use, and inspection of the completed forms in several facilities confirmed this.

Median Delay in Completion of Referral — This is the median time in days from referral to capture at the receiving service.

An indicator corresponding to this parameter was not being reported or analyzed. In terms of capture of the data elements necessary to analyze and report on this parameter, the date for referral was on the NASCOP form, but was not being recorded in registers (where the date on which the client was received is recorded). Delay time was not reported on standard monthly reporting.

Client Satisfaction Rate — This rate is the number of clients who state they were satisfied with the referral, divided by the total number of clients who were referred.

No data were being collected or recorded in either location on client satisfaction or other outcomes of referral.

Key Considerations for Monitoring this Referral System

Table A2 shows a summary of the monitoring system compared to the key criteria developed from a brief literature review and discussions with PEPFAR officials in Washington. This report previously dealt with a summary of the data

Table A2. Kenya Summary of Characteristics of Monitoring Versus Key Criteria

	Criterion	
Recording and reporting of basic data element	Referral rate from referring institution (register records if client referred)	◉
	Utilization rate at receiving institution (register records if client referred)	◉
	Referral adherence rate (tracking and analysis done)	○
	Counter-referral adherence rate (tracking and analysis done)	—
	Median delay (dates logged in registers)	—
Data quality mechanism	Protocols/guidelines exist (PMTCT, VCT, ART)	◉
	Provider training on monitoring system	○
	Quality checks on reported data	◉
Client confidentiality	Provider protocols and training include confidentiality	◉
	If name in register, there are safeguards	○
	No name in reports	◉
Data use for programmatic decision	Reporting done to central authority	◉
	Analysis done	—
	At least one programmatic decision made based on data	—
Provider burden	Methods of study	*Low*

Legend

◉ Fulfills criterion

○ Partially fulfills criterion

— Does not fulfill criterion

recorded and reported. The narrative sections below describe the other characteristics of the monitoring system summarized in the table (data

quality assurance, ability to maintain client confidentiality, provider burden, and facilitation of data use).

Data Quality Assurance Mechanisms — There were guidelines for the use of the NASCOP referral form. In Western Province, there had been a recent roll-out of a new version of the form, adding space for counter-referral information. This part of the form, however, was not being used regularly by facility-based providers.

Community-based personnel were trained in use of the referral forms as part of their overall training. On the other hand, it was not clear whether facility-based providers received training or follow-up on the use of referral or counter-referral forms.

Project M&E staff regularly visit facility and community-based health providers in the field, monitoring data quality and giving on-the-job training. M&E staff had been trained on MEASURE Evaluation's data quality tools for selected indicators and were using the tools, but not for referral indicators.

Client Confidentiality — Both community-based and facility-based providers interviewed were aware of client confidentiality issues and had received training on this. CHWs in multiple areas reported leaving the ultimate decision about accompaniment up to the client, in order to respect their prerogative to self-refer to another facility.

The client's name was recorded on the referral slip and in registers. Access to registers is theoretically only open to health providers, but security of registers was uncertain in several facilities observed. No names of clients appeared in summary reports.

Burden to Service Providers — All facility and community-based providers interviewed stated that they find the amount of time necessary to

fill out the referral form to be minimal and not burdensome.

Several project staff stated that when counter-referral information is not filled out by facility-based providers, they feel that this is much more likely to occur because of an attitude that this is not a necessary step or valuable exercise, rather than being a burdensome step.

Data Use — The data collected on referrals is all centrally reported to APHIA staff and provincial health authorities. The rates of reporting are impressively high and regularly above 90%, generally close to on-time, and quite complete.

There had been little systematic analysis of the referral data. The data that were reported were counts of service utilization and referral for key services.

In Western Province, there was interest in looking at whether there were differential referral rates for VCT and other facility-based services in facilities whose catchment areas are covered by CHVs and dialogue education groups, compared with facilities not covered by such groups. So there may be the beginning of referral data use for decision-making.

Discussion and Recommendations for Future Evaluation of Referral System

Recommendations are as follows:

- The referral network was well-established, with fairly good coordination among members in both provinces. Service providers were generally well-known to each other, thus facilitating referral. Community providers reported not always being as integrated into the system nor as respected as they would like, so there is room for improvement in terms of the strength of the network.

- The concept of facilitated referral was well-established among CHWs in both provinces. That is, clients were being counseled on referral; given a written form; had referral information monitored; and had barriers to referral addressed. In terms of addressing barriers, the most common method was physical accompaniment of the client. Although the protocols used by CHWs did not specifically tell them that physical accompaniment was necessary, the personal investment that many of them feel in their clients meant that many of them willingly accompanied clients. This concept of facilitated referral could be made more explicit and systematic. Perhaps CHWs with the most success at referral could train others. In addition, facility-based providers could benefit from learning more about and using the techniques of facilitated referral already in wide use at the community level.

- Referral forms were standardized and had adequate data to construct utilization and referral rates; counts were being reported. Referral adherence was not reported. A reasonable approximation of this could feasibly be calculated, even without comparing registers, by comparing the counts of clients referred to the counts of clients received with referral slips at receiving services.

- Counter-referral had been an ongoing problem. This was being addressed. Tracking counter-referral success rates across facilities would facilitate improvement on this parameter. CHWs were already regularly reporting referral numbers monthly. It would be quite feasible to have them report the

number of clients that had returned with counter-referral information completed.

- Other data were not being collected that could be helpful, especially on delay. Dates were on the NASCOP form. This date could be noted in the client register and compared with the date on which service was rendered.

- No data on client satisfaction was being collected. This could be considered.

- Several of the criteria for monitoring were very well met by the referral system monitoring: the data quality assurance mechanisms were exemplary; the system was reported by providers to be low burden; and there had clearly been much attention paid to considerations of client confidentiality.

- The large amount of data collected on referrals seemed generally not to have been used for programmatic decisions. It was clear that the data analysis burden on project staff was considerable. The time for additional analysis is likely minimal. However, some PEPFAR conventions also were not facilitative of data use. For instance, all data on utilization and referrals were in the form of counts and not rates. Counts do not lend themselves to easy comparisons. For instance, if we would like to know if the dialogue education system or network of CHWs is likely to be facilitating referrals, then we would expect there to be higher referral rates from communities with these structures/services than in communities that lack these structures/services. Comparison of counts is not adequate to the task.

Appendix B: NELA Consortium AIDS Initiative in Nigeria Case Study

The Nigeria case study was done offsite through an interview with a project manager and review of the key documents provided in the electronic format.

The following documents and forms were reviewed for this case study:

- Two standard two-way referral forms (for prevention, OVC, and adult basic care programs).

- List of indicators by program area, with information on how they are collected.

- Protocol on referral within the NECAIN project.

- Participants' course evaluations from an M&E workshop.

Background

The Network on Ethics, Law/Human Rights, HIV/AIDS Prevention, Support and Care (NELA), a non-governmental organization with headquarters based in Ibadan, Oyo State, and three other organizations (Society of Women and AIDS in Africa, Nigeria [SWAAN], Federation of Muslim Women Association, Nigeria [FOMWAN], and Civil Society Coalition on HIV/AIDS in Nigeria [CiSHAN] North Central Zone), are part of a broad-based health program in Nigeria called the NELA Consortium AIDS Initiative in Nigeria (NECAIN). Supported by USAID, NECAIN operates in six geopolitical zones of Nigeria, focusing in Osun, Edo, Nasarawa, Bornu, Kebbi, and Adamawa. USAID/PEPFAR fund the NECAIN project Strengthening Civil Society and Faith-Based Organizations Capacity for Effective Responses and HIV/AIDS Service Delivery in Nigeria. The project aims to strengthen the capacity of consortium members to build/strengthen capacity of their local chapters and other NGOs/community-based organizations (CBOs)/faith-based organizations (FBOs) to design, implement, monitor and evaluate and expand service delivery of HIV/AIDS prevention, care and support services for people living with HIV/AIDS and orphans and OVC in their various communities.

The Referral Network and Its Monitoring

Description of Community-Facility Network and Referral System — The NECAIN project focuses on community-based services in three thematic areas (prevention, adult care and support, and OVC) in eight states. The project provides palliative home-based care services, and the clients are referred for other services that the project does not offer. Referrals can occur when clients are visited at home or when they take part in support group meetings at NECAIN project sites. NELA is a formal network in which coordination of services among partners is facilitated and discussed. The project works with multiple organizations (SWAAN, CiSHAN NC and FOMWAN) which also work with 24 CBOs in different communities; the range of multiple organizations includes civil society organizations that have chapters in multiple states. Among the types of organizations collaborating with NECAIN projects are hospitals, health centers,

public health units, a specialized TB clinic, NGOs, and support group. It is estimated that 96 people work for NECAIN project. The partners meet with NELA at the end of the year in Ibadan to review the project and develop workplan for better implementation.

It is unclear how many people reside in the area served by NECAIN project.

As of March 2009, a directory of service providers was being developed with the goal to link service providers that the clients can be referred to after negotiation has been made with the facilities on the compiled list. The steps the NECAIN project has taken in preparing the directory include:

- asking the CBOs working on the project at their various states to link with organizations to which they can refer clients, and which would be willing to render services on free basis or with minimum cost;

- introducing the two-way referral form to such organizations and getting their buy-in;

- obtaining the necessary details of the services such organizations provide; and

- identifying a contact person who will be trained as a caregiver whom the clients can meet at the various identified sites.

The intention is to send a list of service directory details to the project coordinating organization, NELA, and to update it regularly.

In addition to the absence of a directory of service providers, at the time of this desk-review there was no formal written agreement, but rather a verbal agreement between the CBOs and the facilities to which they refer clients. The need for such an agreement is recognized by the

NECAIN project management, primarily for the purpose of enabling receiving organizations to complete and abide by the forms being sent and attended to clients. In the absence of a directory of providers and a formal agreement, in order to find out about the services provided by others that NECAIN project would refer to, enquires are made from such organizations about the services they provide. The NECAIN project encourages networking amongst CBOs working on different thematic areas within the project and outside. Additional information is obtained from media, news, and word of mouth.

Within the NECAIN project, most providers have a trained care giver who ensures that clients receive and accessed services to which they are being referred. The trained care giver/service provider assesses the client's needs and makes a referral to a facility he or she has identified and made arrangements with. There is usually no assigned person to make a referral, since he or she may not be present when a client comes to have her or his services accessed.

Due to a specific nature of care and support services provided by the NECAIN project, clients are referred out for a wide range of services that cannot be provided by NECAIN providers, including prevention of mother-to-child HIV transmission (PMTCT), VCT, family planning, TB diagnosis/treatment, psycho-social and spiritual support, micro finance and financial support, skills acquisition, PLWHA support group and peer counseling, post exposure prophylaxis and treatment, food and nutrition, youth friendly services and sexual prevention, welfare support and education, and pharmacies. Referrals are made from the NECAIN project to various types of facilities, including but not limited to medical providers, specialized clinics (for ART, TB, sexually transmitted infections), NGOs, CBOs, FBOs, outreach/peer educators, and support groups.

Staff members at the NECAIN project use various referral methods and processes, such as issuing a standard referral form, telephone referrals, and escorting clients. Standard referral forms are distributed only among the 24 CBOs working on the NECAIN project, and are not used by receiving organizations outside of the NECAIN project.

As the referral system is designed, once the client's needs are assessed and the decision is made to refer her or him, in the case of using a standard referral form, the client is given the second and third parts of a standard referral form to the service provider to which he or she has been referred. The receiving organization keeps the second part, tears the third part, and gives the torn third part to the client to take back to the referring organization. This torn third part is what actually conforms that a client has accessed services. The first part of the standard referral form is retained at each of the CBOs, to keep track of outgoing clients, and to report the total number of referral services provided during the reporting period. The third part of the standard two-way referral form tracks if client actually accessed services at the receiving organization services. Slips from the first and third part of the referral forms are collated monthly and filed. It is believed that most of the facilities that clients are being referred to have trained care givers; therefore, these trained care givers follow up on collecting the third part of the form.

In health facilities where NECAIN clients are referred, there are patient's/client's registers for the adult care and support program, used to register clients who are already benefiting from the NECAIN project. In other organizations where there are no care givers, the CBOs have a collection box for the slips. There are cases when the clients collect the third part themselves from the facility and take it back to the referring CBOs. Usually, the only way that a receiving organization knows that a client has been referred to them is through the form that she or he provides. For the NECAIN

project to know that a client completed a referral and if further services are needed, there is a slot in the third part of the standard referral form for follow-up services. The care giver/service provider actually follows up based upon the information provided in the third part of the form. Thus, the referral forms have information on outcomes. There is also a register to record information on outcomes.

All outgoing and incoming referrals are documented in separate files for periodic reporting, monthly or beyond; however, documentation to confirm that was not provided.

Providers sometimes ask clients what they think about the referrals, if their needs have been met, and if such concerns as stigma have been addressed. However, there does not appear to be a formal mechanism or forms to conduct client satisfaction surveys. While the referral system is considered feasible and useful, the NECAIN project management recognizes that it sometimes may turn out to be expensive for the client. In the cases where on the third part of the standard referral form there is an identified need to follow up with the other provider, there is no formal consent obtained from the client. Consent could, however, take place in individual cases when the client interacts with the provider directly.

The NECAIN project accepts referrals from various thematic CBOs, all within the NECAIN project (e.g., a client accessing adult care and support services with a child can be referred to an OVC organization, all within the NECAIN project). If a client is referred from a health facility to access services at the NECAIN project, such a client would be given the facility's referral form; however, NECAIN staff had not encountered such cases. As previously mentioned, there is no formal directory of providers. However, NECAIN is familiar with partners working in different thematic areas, and there is interaction with other organizations within the consortium as well as

with other CBOs located within the catchment areas.

Often clients and providers find out about the work that NECAIN project does through posters, handbills, etc. and incoming referrals are usually made for such services as palliative and home-based care, and OVC services.

The standard two-way referral form includes logos of the donor agency and the project logo, and such information as who retains what part of the form, referral date and date when the client is to access such services, client's information, organization making the referral information details, details of the organization the client is being referred to, services the client is being referred for and name and signature of person doing the referral and designation. According to the information provided by the NECAIN project management, the standard referral form is used to refer clients within the consortium. It appears that the two-way referral forms (separate for prevention, OVC, adult basic care programs) are intended to be used for referring from the NECAIN project or between such types of organizations as CBOs, FBOs, and support groups. As indicated by the NECAIN project management, health care providers are likely to use their own referral forms if they were to refer people to CBOs, FBOs, etc.

Clients' identification and referral information from the referral forms is stored with the CBOs at their various sites within the NECAIN project and their information is made available to those working on the NECAIN project, only after client is counseled and their consent sought. Sample client consent form was not provided.

Description of Monitoring of Referrals — It appears that even with an absence of formal agreements between service providers and regular meetings, there are tools that allow for limited monitoring of the community-facility referral system within the NECAIN project.

There are documented protocols or/and guidelines on referrals for the three thematic programs with which NECAIN is primarily involved and for which two-way referral forms have been provided: OVC services; adult care and support; and prevention. The guidelines are specific to NECAIN and local needs, not necessarily health care system in general. While the described referral method is client-centered, there is a recognized need to improve the system by facilitating the client's actual use of services to which they are referred. Protocol on referral has been made available to all organization within the NECAIN project. The following information is included:

- formal definition of referral within NECAIN project;

- detailed explanation on the use of sections of standard referral forms by program area;

- rationale for referrals by program areas; and

- reference to specific indicators, for which the standard referral form is used by program area.

Pre- and post-test evaluations are conducted regularly around trainings. There was training for the monitoring and evaluation (M&E) program staff for the organizations that work with the NECAIN project on how the project operates, on M&E, where a period was slotted specifically for training on referrals in January 2009, with 27 organizations participating. It was found to be effective, according to NELA. Based on an electronic copy of the participants' course evaluation of the M&E workshop, various M&E topics were covered and found useful, including such relevant aspects as data management processes, data quality, concept of data flow and feedback, indicators and data use, etc. While the topic of referral was not singled out, it appears that

the training on broader M&E concepts, combined with available referral protocols, provided solid background for effective monitoring of the referral system.

To assure the accuracy of recorded information on utilization and referral, verification visits and periodic audits are conducted within the consortium. There is also regular supervision by the program staff from organizations within the NECAIN project. Multiple participating organizations conduct regular supervision with periodic audits of all of their data, however reports generated from such visits are not exclusive to the referral system alone and are confidential. According to the NECAIN project management, improvements have been made to the referral forms based on the information gathered during visits and regular supervision. For instance, originally there was no way to capture follow-up services provided on the referral form.

Provider burden has not been evaluated but, according to NECAIN management, it is likely that compliance with a referral system and reporting are burdensome and time-consuming. Data about referrals, obtained from various parts of the standard referral form, are compiled monthly by the CBOs and quarterly by multiplier organizations in paper form. The reports are entered electronically and sent to the multiplier organizations via e-mail, and printouts are filed.

The M&E officer complies and uses the data. Referral data are discussed by all program staff, concerning services that needed to be rendered, monitored, and evaluated. Data on services that people are referred for are primarily used for budgeting in the year of the project according to the cost of living in the various localities the CBOs are situated in. In management's opinion, the referral records are not really given much thought. Only data on numbers are recorded but it is an in-house document and not reported beyond the organization.

Measures Corresponding to Proposed Key Referral Monitoring Indicators

Referral Rate from Referring Service — This represents the number of clients referred out from a referring service divided by the total number of clients seen for that service.

The main data source for this indicator should be a facility/provider register. Alternatively, the first part of the two-way referral form can be used, as it is retained by a CBO in a separate file. For the denominator, a facility/provider register should be used. A register template was not provided, however it is likely that CBO providers have a record of incoming clients. Additionally, protocol on referral references a home visit register, which, when combined with a record of incoming clients could be used to calculate denominator. Note that based on the standard two-way referral form and the list of indicators provided, the numerator can be calculated per services rendered, according to codes or general categories (indicators 2, 2.1 and 6.1).

Utilization Rate for Receiving Service — This rate represents the number of clients attended at receiving service divided by total population in the catchment area of the receiving service.

The main data source for this indicator should be a facility/provider register. A register template was not provided, however it is likely that CBO providers have a record of incoming clients. Additionally, protocol on referral references a home visit register, which, when combined with a record of incoming clients could be used to calculate numerator. Size of population would be identified from most recent census and population in catchment area would be calculated during mapping exercise.

Referral Adherence Rate — This represents the number of clients who complete referrals divided by the number of clients referred.

The main data source for both numerator and denominator can be the first and third parts of the standard two-way referral form. Numerator can be disaggregated to be service specific based on service codes and according to general categories on provided indicator forms. Additionally, protocol on referral references the home visit register, which can be used for data verification purposes.

Success Rate for Counter-Referral — This represents the number of clients received back at original referring service with adequate information from receiving service divided by the number of clients referred.

The main data sources for this indicator should be a facility/provider register or referral slips. For the numerator, the third part of the referral form can be used, after adjustment is made to include codes for follow-up, consistent with the first two parts of the form. For the denominator, the first part of the standard two-way referral form can be used. Additionally, protocol on referral references the home visit register, which can be used for data verification purposes.

Median Delay in Completion of Referral — This is the median time in days from referral to capture at receiving service.

The main data source for this indicator is the registers at receiving services. A register template was not provided, therefore it was not possible to establish feasibility of collecting data for this indicator. Alternatively, data elements can be obtained from the first part of the standard two-way referral form, retained by the CBO; and the second part, retained by the receiving organization. However, this would require coordination of efforts between referring and receiving organizations, which could be costly and logistically complicated.

Client Satisfaction Rate — This represents the number of clients who state they were satisfied

with the referral divided by the number of clients referred.

Data elements for this indicator would be collected from different sources. As stated by the NECAIN management, client satisfaction surveys are not systematically conducted and no survey template was provided. The third part of the two-way referral form can be adjusted to collect client satisfaction information, to make it a client's responsibility to fill in such information after the form is completed by the receiving organization. The assigned collection boxes currently available in selected organizations would be an ideal tool to ensure confidentially. However, to avoid alteration of information, only a representative from a referring organization or a coordinating person within a consortium should be available to access the box. The data source for the denominator is the first part of the standard referral form.

Key Considerations for Monitoring the Referral System

Table B1 shows a summary of the monitoring system compared to the key criteria developed from a brief literature review and discussions with PEPFAR officials in Washington. The previous section of the report already dealt with a summary of the data recorded and reported. The narrative sections below describe the other characteristics of the monitoring system summarized in the table (data quality assurance, ability to maintain client confidentiality, provider burden, and facilitation of data use).

Data Quality Assurance Mechanisms — It was noted that regular supervision, data verification visits and periodic audits are conducted. According to the management, there is a documentation mechanism for ensuring data quality, however, it is not available to ensure referral data quality within NECAIN consortium. The documents provided were insufficient to establish existence of formal mechanisms of data verification. A home visit register, referenced in the protocol on

Table B1. **Nigeria Summary of Characteristics of Monitoring Versus Key Criteria**

	Criterion	
Recording and reporting of basic data element	Referral rate from referring institution (register records if client referred)	◉ Fulfills
	Utilization rate at receiving institution (register records if client referred)	◯ Partially
	Referral adherence rate (tracking and analysis done)	◉ Fulfills
	Counter-referral adherence rate (tracking and analysis done)	◯ Partially
	Median delay (dates logged in registers)	◯ Partially
Data quality mechanism	Protocols/guidelines exist (PMTCT, VCT, ART)	◉ Fulfills
	Provider training on monitoring system	◯ Partially
	Quality checks on reported data	◯ Partially
Client confidentiality	Provider protocols and training include confidentiality	— Does not fulfill
	If name in register, there are safeguards	◯ Partially
	No name in reports	◯ Partially
Data use for programmatic decision	Reporting done to central authority	— Does not fulfill
	Analysis done	◯ Partially
	At least one programmatic decision made based on data	◯ Partially
Provider burden	Methods of study	*Medium*

Legend

◉ Fulfills criterion

◯ Partially fulfills criterion

— Does not fulfill criterion

referral, could be used to cross-check data against the second part of the standard referral form kept on file at the NECAIN project participating organizations.

Client Confidentiality — Management expressed concerns about the maintenance of confidentiality within the information and referral tracking systems. The main issue raised was related to the location of clients' forms and whether privacy or confidentially are ensured, provided that NECAIN project staff have access to clients records.

The two-way referral form collects patient names and other identifying information. It was stated that client referral forms are individually-based and are normally subjected to the rules of confidentiality as apply at the health institution level, which does not address client confidentially within such organizations in the consortium as NGOs, FBOs, CBOs, or support groups.

The documents provided were insufficient to establish whether any client identifying information was included in any other forms or reports.

Service Provider Burden — From a standpoint of NECAIN management, it is likely that the existing system is burdensome, however no documented evaluation of the degree of burden has been provided.

The referral forms require limited information and coding system facilitates expedited recording.

It was noted that it is a client's responsibility to return the third part of the referral form with information on whether she or he accessed referral services, or that the third part of the form could be dropped into the assigned collection boxes at selected receiving organizations. If a client does not return back to the facility with a report on accessing services, someone has to retrieve those forms from the referral facilities, which could be somewhat burdensome in terms of time and cost. Additionally, it leaves room for receiving organization to alter the feedback form in their favor.

Data Use — It was noted that the NECAIN

project does not report referral data to its donor agency since this was not requested; and reports with referral data are considered an in-house documents, which do not circulate beyond the organization.

Data were used internally primarily for budgeting considerations, and were not shared with all managers and providers. It was recognized that the project would benefit from allowing program managers and providers to receive this information, in addition to an M&E officer.

The provided documents were insufficient to establish whether monthly and quarterly reports have information on which other decisions could be made, beyond budgeting.

Individual organizations use the data, but there is no unitary system for tracking or for reporting referral monitoring data; therefore, no analysis was being done and no programmatic decisions were being made based upon the data.

This system captured significant amounts of information on the client, her or his identified need, whether these needs were met, and associated timelines.

Calculating indicators is mentioned in relation to capturing data on a patient's completion of referral. Provided list of indicators and referral protocols illustrate the existence of several associated indicators by program areas, collected and reported only in numbers.

Discussion and Recommendations for Future Evaluation

Recommendations are as follows:

- After a directory of service providers is compiled, we recommend establishing a formal network or consortium of HIV/AIDS service providers in which coordination of services among partners

is facilitated or discussed, in a particular catchment area. According to NECAIN project management, this would be helpful because it would trace the flow of linkages among organizations.

- An operations manual should be developed for the formally established network.

- Establish a mechanism for selecting a referral focal person within a formally organized network whose responsibility would be to monitor the referral process between partner organizations, and with whom M&E officers/assigned care-givers, who are responsible for managing referrals, would report to.

- Conduct a meeting within a consortium/network and among providers and sign memoranda of understandings. Having formal agreements among services would be helpful as this would make clear the roles and responsibilities and might facilitate standardization of referral mechanisms and forms used.

- Establish a formal mechanism with standard questionnaires to conduct client satisfaction surveys or adjust standard referral forms to collect data on client satisfaction. The third part of the two-way referral form can be adjusted to collect client satisfaction information, so that the client fills in this information after the form is completed by the receiving service. The assigned boxes currently available in selected organizations would be an ideal tool to ensure confidentially. However, to avoid alteration of information, only a representative from a referring organization or a coordinating person within a consortium should have access to the box.

- While it is possible to obtain the median time in days from referral capture through the feedback parts of the standard referral form, there does not appear to be a benchmark against which this would be measured. While this may vary by service, it would be helpful for a client handed a referral form to have a recommended time-frame within which she or he should reach the receiving organization.

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Appendix C: HIV/AIDS Referral System Brief Case Study Pilot for Swaziland National System

Scope and Methods of Assessment

This country brief is a secondary data analysis and desk review. It is a summary based entirely on the work done by MEASURE Evaluation and partners in 2008 to assess the functioning of the referral system for HIV/AIDS services within the Swaziland national service delivery system. This evaluation was comprehensive in scope, assessing facility and community services. The evaluation report was reviewed. A key informant involved in the evaluation responded to an interview script developed for this activity. The draft report was reviewed and edited for accuracy by this key informant.

Description of Swaziland — Its HIV/AIDS Epidemic, Health and Referral Systems*

Description of Country and Context — Swaziland is a bilingual (siSwati and English) landlocked country surrounded by the Republic of South Africa on three sides and Mozambique on its eastern frontier. With a land area of 17,363 km², the country is divided into four regions: Hhohho, Lubombo, Manzini, and Shiselweni. Regions are sub-divided into Tinkhundla (55 in total), each is headed by an Indvuna, who is elected by the constituency. Each Nkhundla is comprised of several chiefdoms, formed by Sigodzi (clusters of homesteads, or communities). About 77% of the population is rural. In 2006, the Swazi population was estimated to be 1.14 million. The median age is 18.5 years and 56% of the population are between the ages 15 and 64 years. Life expectancy at birth is 32.62 years, with an infant mortality rate of 71.85 deaths per 1,000 births. In 2005, the estimated per capita gross domestic product ranged from $1,300 to $5,000, with a real growth rate of 1.8%. In 2006, unemployment was estimated to be at 40%, with 69% of the population living below the poverty line.

HIV and AIDS in Swaziland — The first diagnosis of HIV in the Kingdom of Swaziland was reported in 1986. The first case of AIDS was reported in 1987, and HIV/AIDS was declared a national disaster in Swaziland in 1999. A sentinel surveillance system to monitor the proportion of pregnant women attending ANC clinics infected with HIV has been in place since 1992. More than 90% of pregnant women are reported to make contact with ANC services at least once during pregnancy ANC-based HIV sero-prevalence has risen from between 3.0% and 3.9% in 1992 to 42.6% in 2004. With results of 39.2% in 2006, Swaziland has the highest prevalence rate among pregnant women seeking services at an ANC clinic in the world. While there may now be signs of the epidemic beginning to slow, according to the 2006-07 Swaziland Demographic and Health Survey, the overall HIV prevalence in the country remains high at 26% among adults age 15 to 49.

The Health Care System in Swaziland — The formal health system is divided into primary care (clinics), secondary care (public health units and health centers) and tertiary (hospitals), and includes public, mission, and private facilities. The system is assumed to be highly accessible with 80% of the population residing within 8 km of a health care unit and over 60% able to access a health care unit within an hour. Additionally, the

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* Description is from Swaziland Referral Technical Working Group Team, 2008; sources available in that report.

private health care sector is a major stakeholder. Physicians in private practice or industry account for almost 50% of all physicians; there are two privately run hospitals; and just over 100 care services points are private, nongovernmental organization, or industry clinics. To date, Swaziland lacks a national protocol for referral. In 2006, the design of a formal discharge and planning system was initiated. Referral forms have been developed in the past, but their current use is unknown. It is hoped that this study can now fill some of these knowledge gaps.

Description of Referring and Receiving Services Assessed (Service Type, Location) — The MEASURE Evaluation country assessment on which this summary report is based examined various HIV/AIDS health and social services across multiple supporting organizations in Swaziland. So this example is quite complicated and comprises referrals both from community to facility, facility to community (e.g. ART to psychosocial care), facility to facility (e.g. HIV to TB diagnosis and treatment), and community to community. Even within specific services like VCT, the assessment looked at both referrals into the service (e.g. from traditional healers) and out from this service (e.g. to ART). Clearly, there was great variability of some measures across such a broad range of services. For instance, the proportion of clients referred for ART from another facility-based service was 16%. The proportion of clients reporting referrals from community-based organizations is considerably lower — traditional healers 1%, CHWs 3%, and other community-based providers 2%. This report summarizes aggregate information within this complex network of services. As in most contexts, the main barrier to referral is cost, as seen in Table C1. This list matches well with reasons cited by clients themselves.

Table C1. Barriers to Referral Cited by Providers of Care

Barrier	Percent of Providers Citing this Reason
Cost	71
Perception of poor care	34
Lack of transport	27
Lack of understanding of reason for referral	14
Preference for traditional healers	13

Description of Monitoring System for Referrals

Verbal or Written Referral/Forms Used/ Information Recorded — As shown in Table C2, there are multiple systems used across the various implementing organizations. Referring service providers interviewed reported almost universally use of written referral notes (94% of surveyed referring providers). There was evidence of written referral note use, as well, in 73% of health facilities surveyed, but not as consistent reporting of use of a written referral system. A system of registers is common but not universal (78% had this system). There is evidence of register use in a majority of facilities (61%). These registers take a variety of forms. They can be as simple as tally sheets, a book used exclusively to record referrals, or a general-purpose register with a space or column to record "referral in" or "referral out."

Characteristics of Referral Monitoring System Compared to Key Criteria — Table C3 provides a summary of the referral monitoring system as compared to key criteria.

Recording and reporting of basic data elements — The fact that registers are in place and fairly well utilized means that referral and utilization rates could be calculated if and when data analysis would be done on centrally reported data. Referrals may be written down, but the process of making the referral, notifying the receiving site, and follow-

up with the client did not seem to be happening. In terms of tracking adherence rates for referral and counter-referral, there was no direct data recording that could do this on an individual basis, but this could be imputed and estimated by looking at the number of referrals received versus those made. It would be better if there were some kind of client tracking mechanism in place. On the other hand, no data were being recorded that would allow even an estimate of average or median delay for compliance with referral.

Table C2. Existence and Use of Key Documents/Formats for Monitoring Referral

Form/ Document*	Percent Where Form/ Document Existed	Percent of Interviewed Health Providers Who Could Produce Form When Asked
Client-held referral form	94	73
Register for recording referrals	78	61

* Mapping/directory of providers was available (National HTC/VCT Referral Directory and Guide)

Data quality mechanisms — There appear to be no mechanisms in place to ensure data quality. Data quality checks would be complicated by the fact that there are now multiple systems of collecting the data and no need to report to a single authority.

Patient confidentiality considerations — It appears that there has been no training of health care providers on confidentiality issues in general, nor specifically in regard to the referral system. On the other hand, the data as they are currently collected seem to respect confidentiality, on the whole. Patient names appear on registers, but most of the time these registers are controlled by the clinic manger, limiting access to them. There are no reports on which a client's name can appear.

Table C3. Swaziland Summary of Characteristics of Monitoring Versus Key Criteria

Criterion		
Recording and reporting of basic data element	Referral rate from referring institution (register records if client referred)	◎
	Utilization rate at receiving institution (register records if client referred)	◎
	Referral adherence rate (tracking and analysis done)	○
	Counter-referral adherence rate (tracking and analysis done)	○
	Median delay (dates logged in registers)	—
Data quality mechanism	Protocols/guidelines exist (PMTCT, VCT, ART)	◎
	Provider training on monitoring system	—
	Quality checks on reported data	—
Client confidentiality	Provider protocols and training include confidentiality	—
	If name in register, there are safeguards	◎
	No name in reports	◎
Data use for programmatic decision	Reporting done to central authority	—
	Analysis done	—
	At least one programmatic decision made based on data	—
Provider burden	Methods of study	*Low*

Legend

◎ Fulfills criterion

○ Partially fulfills criterion

— Does not fulfill criterion

Provider burden — There is no systematic norm or protocol. On the other hand, the illustrative sample of forms contains only forms that are one

page long. They do require open-ended responses, rather than check boxes, so the time required to fill them out is more than minimal, but still is likely to be low.

Data use for programmatic decisions. Individual organizations might use the data themselves, but there is no unitary system for tracking nor for reporting referral monitoring data; therefore, no analysis was being done and no programmatic decisions were made based upon the data.

Conclusions

Strengths and Challenges in Referral System and Its Monitoring — Strengths include the following:

- Recording of basic information, while not complete, was probably sufficient to give a sense of utilization and referral patterns and trends, if analyzed.

- The conditions to respect client confidentiality seemed to be in place in terms of forms and registers.

With regard to challenges, many of the challenges stem from only having a system that adequately tracks the initiation of the referral, and not the follow-up or counter-referral; specifically:

- community-based groups not sufficiently tied in to regional planning network;

- directory of service providers not sufficiently well-disseminated;

- inadequate training on existing forms;

- monitoring counter-referrals and client outcomes were made difficult by the fact that the feedback portion of the forms were often left blank;

- tracking adherence rates with referral and counter-referral could only be approximated in monitoring and calculation of median delays would not be possible at all, as documentation system seems to be structured by the implementing partners; and

- reporting and analysis of referral data was not being done.

Further Questions — Further questions concerning the referral system and its monitoring including the following:

- It was not clear the extent to which confidentiality issues for referrals were covered in any health provider trainings on HIV/AIDS topics.

- What is the range of information recorded in registers on client-held referral forms? Do the forms or registers of any partners record dates of referral (data element needed to track median delay)?

Appendix D: Zambia Prevention, Care, and Treatment Partnership Case Study

The Zambia case study was done offsite through interviews with project managers and review of the key documents (sent electronically) indicated in the study protocol. Documents listed in the inventory were submitted for desk review. These include manuals, forms, and notes from meetings.

Background

As part of a broad-based health program in Zambia, through a cooperative agreement with Family Health International, USAID is supporting the Zambia Ministry of Health (MoH) and the National AIDS Council (NAC) in strengthening and expanding HIV and AIDS services in five of Zambia's nine provinces, through the Zambia Prevention, Care and Treatment Partnership (ZPCT), which ran from 2004 to 2009 (ZPCT was a cooperative agreement between Family Health International and the USAID, through the U.S. President's Emergency Plan for AIDS Relief). ZPCT assisted the MoH to implement its policies in program planning, implementation, and monitoring by providing support to provincial health offices and district health management teams and at the health facilities. Through successful partnership with the Government of the Republic of Zambia (GRZ) and with nongovernmental organizations (NGOs), local communities, and workers at healthcare facilities, ZPCT strengthens GRZ programs in order to provide HIV clinical services. ZPCT works with the existing MoH policies and guidelines to ensure that the existing systems and structures are accessed and strengthened for the benefit of the clients. In addition to health facilities, among many community-level service providers that address the many needs of people living with HIV/AIDS (PLHA) are the district health offices (DHOs), the district AIDS task forces (DATFs), faith-based organizations, and local and international NGOs, including ZPCT. ZPCT-supported health facilities accept clients and referrals from the communities for VCT, PMTCT, clinical care, and ART services. Once accepted and initiated on treatment, clients are referred out to additional community HIV care and support services such as nutrition, home based care, etc. ZPCT was supporting 212 MoH facilities and seven Churches Health Association of Zambia Mission facilities, with a total of over 400 providers in 35 districts in the five ZPCT supported provinces.

The Referral Network and Its Monitoring

Description of Facility-Community Network and Referral System — While the emphasis of ZPCT is on supporting health facilities, community outreach to bring clients in for services is a big part of the project, which aims to facilitate comprehensive HIV/AIDS care. ZPCT has been working with the provincial health offices (PHOs), DHOs, DATFs, and a range of other partners in Central, Copperbelt, Luapula, Northern and North Western provinces to establish or strengthen district-wide referral networks in ZPCT-supported districts. The goal of these referral networks is to increase access of comprehensive HIV care and support services and to facilitate the systematic and formal linking of HIV/AIDS related services to ensure that clients receive the available services.

In order to initiate referral network in a particular district, ZPCT provincial teams met with the

DHOs and DATFs to introduce the concept of the network and obtain buy-in to facilitate the mapping exercise to be conducted in that district. This was done through visiting the different service providers to establish the different services provided, type of tools they use to refer client, location of the services, contact persons and numbers, hours of operations, and if they charge for their services. This information was used to develop the directory of services for each district. From 2006 to 2009, 34 of the 35 ZPCT districts had been involved in conducting institutional mapping.

A referral coordinating unit would then be selected through a participatory process by network members; the coordinating unit was responsible for convening meetings, coordinating activities, mobilizing resources, and providing technical assistance to new members. Usually, as the next step after mapping exercise and selecting a coordinating unit, a memorandum of understanding would be signed between the referral network coordinating unit and network member organizations. The memorandum of understanding typically stipulates the roles and responsibilities for the referral network member organizations and referral coordinating unit.

Interactions of referring and receiving organizations within a network would be done through regular meetings; the network participants/members may meet once every month or every quarter depending on what the members have agreed within the network. At the meetings, issues of common interest relating to the welfare of PLHA are discussed, including but not limited to the following — client needs in a catchment area, resource mobilization, technical assistance to network members, monitoring of referral, coordination of activities, and updating and disseminating information about services. ZPCT and the network members in each district contributed to logistics for regular monthly or quarterly meetings, such as stationery, printing,

meeting venues, and refreshments. This type of professional interaction has been found to be helpful in increasing client's access to services, especially in resolving issues of feedback and updating members on new services introduced or dropped from service providers in the directory of services.

Minutes for the quarterly meeting of the Kabwe District HIV/AIDS Related Services Referral Network, dated January 2007, illustrates how useful and beneficial these meetings are. With 37 members of the network and five visitors present, such matters as particular cases of client dissatisfaction with network operations, monitoring observations, and logistics were discussed. Responsible persons were assigned to follow-up on every matter brought up at the meeting, and it appears that their reports on outcome were a mandatory part of the meetings. The network members also discussed successes and challenges, and ways forward. Based on the visitors' remarks, Kabwe district referral network was the best in the country, and was recommended as an example for exchange visits with other districts.

In order to facilitate the above described activities, ZPCT supported the development and dissemination of standardized tools to refer and monitor the movement of clients between ZPCT supported health facilities and other CBOs, NGOs, faith-based organizations, support groups and traditional healers, who provide HIV-related support services and community assistance within referral networks. Health workers and some members of the referral network partner organizations have been trained in the use of these referral documentation and tools:

- a directory of services with contact details of all organizations providing HIV-related services for PLHA and their families within a district;

- a referral operations manual, developed by

all network members to define principles and processes that guide its functioning;

- district specific protocols or/and guidelines on making referrals, which are relatively standard between districts;

- incoming and outgoing referral register, managed by a referral focal point person at each health facility or organization in the network; and

- the initial standard referral forms, printed and distributed to its network members by the coordinating unit. As a contribution to the network, the members will in turn start printing more copies required during the performance of their services to refer clients.

ZPCT's contribution focuses on referral activities at the health facilities it supports, where a referral focal point person is responsible for identifying, processing, monitoring, and documenting referrals in each organization. Due to the primarily medical and clinical nature of services provided at ZPCT-supported health facilities, clients are usually referred out for a wide range of other services, such as financial, material and food support, social and legal services, spiritual support, support for domestic violence victims, orphan care and support, microfinance, etc. to NGOs, faith-based organizations, support groups, government social welfare and community development departments. On the receiving side, ZPCT-supported facilities receive referrals primarily for medical and clinical HIV/AIDS related services, specifically from NGOs, community-based care, faith-based organizations, support groups, and traditional healers.

Depending on the service provider at the facility or organization, the referral focal point person could be anyone — a doctor, nurse, support group member, peer educator, data clerk, or lay

counselor. At the client's visit, the referral focal point person at each ZPCT supported facility identifies and discusses client's needs and, if necessary starts a referral process, with a client's consent, after outlining available health and social service options available and help clients choose the most suitable in terms of distance, cost, culture, language, gender, sexual orientation and age. After discussing shared confidentiality and obtaining the client's consent, the referring officer will document the client in the referral register and on the tracking form before issuing a standard referral form/slip. In the event that services are provided within the same building, the client may be accompanied to the respective department.

The client will be entered in the referral register and given a referral slip by the referring organization. The register keeps track of all the referrals made and received and are kept in a secure permanent and accessible place within the facility to protect client's confidentiality. All referrals are tracked from the point of initiation to the point of delivery and back with the referral tracking form. The person initiating the referral completes the referral slip (part A), which includes the following information: date and time of referral, referral/registration/VCT/ART number, client's name, date of birth and sex, name, address and phone number of the organization/facility initiating referral, name of the referral focal point person at the organization where the client is being referred, list of services provided by the referring organization, space is provided to write additional notes regarding the client's needs, name of the referring officer, designation and signature.

This referral slip would be given to the client to take to the receiving organization that will provide feedback on the services rendered to the referred client. To follow up with the other provider, the referring person would get consent from a client through a signed client consent form at the time of referral. The feedback slips are either given to

the client to take back to the referring organization or collected by the referral focal point person at referring organization or the district referral officer designated at the coordinating unit.

The person who initiated the referral or any other team member attending to the client shall follow up with the client at the next visit, if necessary, or with the receiving organization, and the information should be recorded on the client referral tracking form. If the client received referral services, Part B of the referral slip should be completed by the person who rendered services at the receiving organization and will provide the essential information regarding services rendered and follow-up needed. This information must be transcribed on the client referral tracking form and then into the referral register services (available upon request).

The standard referral form helps the provider at receiving organization to know that a client has been referred to them. The written feedback on the client referral form provides evidence that the client accessed the desired services, and whether or not there were problems. The receiving organization shall report to the referring organization on the services delivered to the client and give the feedback slip to the client or make other arrangements with the referring organization on how to send feed back if giving the slips to the clients will not be effective. The information collected from written feedback slips is entered in the client referral tracking form (Kabwe referral forms and Samfya operations manual appendixes services are listed at the end of this appendix).

In the event of further services not provided at a health facility, the receiving organization will be required to refer back the client to the original facility.

Description of Monitoring of Referrals — Issues of feedback are regularly discussed in the referral meetings. In some cases, if there is delay in receiving the written feedback on the client

referral form, the referral focal point person will follow-up with the colleagues at the receiving organization to check on the status of the clients they referred to access the services. Additionally, client satisfaction surveys are conducted with randomly selected clients to get feedback on the services received from both the referring and receiving organization. These surveys are conducted to determine access and satisfaction with the provided services. The district referral officer redistributes the referral feedback slips during the network meetings or during the bi-weekly monitoring visits to the respective network member organizations. Alternatively, the referral feedback slips may be distributed at the network member organization depending on the transport/resources within a particular district.

ZPCT had established a referral network database, which was being used by referral network members to input their referral activity reports at Kabwe DHO offices in Kabwe district. Each referral network member compiled monthly reports that were submitted to the coordinating unit. The coordinating unit prepared quarterly reports, which were submitted to the provincial referral officer, who in turn shared this information with program team and service providers. The process of refining the district referral network database to be able to generate reports automatically was underway.

The referral systems in Kabwe and Samfya districts used several standard forms and documents, with slight variations among them. There also were some novel project-generated forms used, including:

- a mapping/directory of providers

- a standard referral form

- standard registers

- monthly, quarterly, and annual reports with referral information

Directory/map of service providers — In all three districts (Kabwe, Samfya, and Mkushi) mapping of key institutions and health providers was done. This information was summarized in a directory of the network members, but presented in slightly different ways.

In the case of Kabwe district, the information was put in list form, without numbering, showing the name of the facility, its contact information, types of services provided with associated fees, and operating hours.

The directory of service providers for Samfya district included two parts. Part A had information arranged in a tabular form, with all the same information as in Kabwe district, with additional information on linkages and partnerships, such as funding and service partners. Part B had a table of services and a corresponding list of organizations.

The directory of services for Mkushi District also has a list of providers, in alphabetical order, similar to Kabwe district, excluding information on associated fees for services.

The Samfya district directory of services appeared to be more user-friendly, primarily due to having information presented in two ways, to facilitate use of such information and lower burden on the referring provider. It should be noted that the operations manuals for Kabwe and Samfya districts, and Mkushi District memorandum of understanding, have sections devoted to maintenance of the directory, and updates. Moreover, Samfya's district manual included a data collection and update form for directory of HIV/AIDS related services.

Referral forms — Both Kabwe and Samfya district referral forms (part A) have the following information:

- detailed instructions for referring, and receiving organizations
- separate section with register number,

ART number, and referral number

- client name
- date
- time
- gender
- date of birth
- name, address, and phone of the agency from which client was referred
- name, address and phone of the agency to which the client is being referred
- name of referring contact person/ referral focal point person (RFPP)
- services provided by referring department/organization
- reason for referral (standard codes)
- additional notes section
- designation of referring officer/RFPP
- signature of referring officer/RFPP

Kabwe District form also included a field entitled "sensitization activity."

The second part of referral feedback form can be used to track counter-referral rates; however, this can be done only if clients return the form to the original referring institution, and after this information is combined with other tools. If the second part of feedback form is matched with the client tracking form and then with the outgoing referral register, counter referrals can be tracked.

Client referral tracking forms — These forms were provided for Kabwe and Samfya districts, and contained similar information to referral forms and cross-referenced with the register, and were designed to remain in the client's file.

Client Registers. Both districts provided register templates. While Kabwe District providers had separate incoming and outgoing referral registers,

Samfya District only has one referral register.

Reports and analysis — Monthly, quarterly, and annual report templates included referral data from providers, with counts of referrals made, follow-up referrals made, referral services completed, and number of team members trained in referral networks. Additionally, there were sections to provide information on activities accomplished in reference to referrals and time frame, challenges and constraints, lessons learned, and recommendations. According to the completed report of community youth mobilizations in Kabwe District, these data would mainly be analyzed in the form of counts.

ZPCT has supported the establishment of a referral network database that was being used by the coordinating unit Kabwe DHO to input referral activity reports from network members. ZPCT was in the process of refining the referral network database to be able to generate reports. Based on the information provided, it was unclear in what format reports are generated, and whether numbers would be converted to percentages with associated denominators.

Data quality assurance survey — Samfya District network had a template for conducting a quality assurance survey of providers, primarily by the coordinating unit officer. Through multiple choice questions, the survey evaluates such issues as documentation accuracy and completeness, reporting accuracy and timelines, and prompts the evaluator to fill in the minimum requirements checklist on availability of a referral focus person, their attendance at meetings, presence of directory of services, and availability of a feedback loop.

Client satisfaction survey. — Both districts use similar templates for conducting client satisfaction surveys with a wide range of questions, and space provided for comments.

Measures Corresponding to Proposed Key Referral Monitoring Indicators

Referral Rate From Referring Service — This is determined by taking the number of clients referred out from referring service and dividing that by the total number of clients seen for that service. Registers of outgoing referrals and client record form templates can be used for the numerator. For the denominator, a facility/provider register should be used, for which a template was not provided. For the ZPCT partners programs that provide clinical services, assumptions can be made that standard medical registers would be available. It appeared feasible to collect data for the denominator, although that was not being done.

Utilization Rate for Receiving Service — This rate is obtained by dividing the number of clients attended at receiving service by the total population in catchment area of receiving service. A facility or provider register template was not provided, so it was not feasible to collect data for this indicator. Size of population would be identified from most recent census and population in catchment area.

Referral Adherence Rate — This rate is calcuated by dividing the number of clients who complete referral by the number of clients referred. Number of clients referred out should come from a referral register; number of referred clients at the intended receiving institution should come from an incoming referral register and/or collected slips from client referral forms which clients bring with them. Samfya District referral register, unlike Kabwe, does not distinguish between incoming and outgoing referrals.

Alternatively, within a network, facility registers can have additional columns to indicate whether client came as per referral and from which facility. That would be facilitated by having codes for all the providers within a network.

For service specific referral rate, service codes were not standardized among districts, which make it difficult to compare codes within a network.

Success Rate for Counter-Referral — This rate is determined by taking the number of clients received back at original referring service with adequate information from receiving service and dividing that by the number of clients referred.

For the numerator, neither Kabwe nor Samfya districts' incoming referral registers provided information on whether clients had been counter-referred back to institutions or if these were walk-in clients. Referral feedback form and client tracking form can be used as well, if adjusted. For the denominator, an outgoing referral register should be used.

Median Delay in Completion of Referral — This rate is the median time, in days, from referral to capture at receiving service. Data elements can be obtained from client referral forms and referral feedback forms and facility outgoing referral register, provided by both Kabwe and Samfya districts. The only way that a referring organization would know if a client reaches receiving organization is through feedback slips, brought back either by the client or sent back by the receiving organization. While it is possible to obtain median time in days from referral capture through feedback slips, there does not appear to be a benchmark against which it would be measured. While this may vary by service, it would be helpful for a client who is handed a referral form to have a recommended time-frame within which she or he should reach the receiving organization.

Client Satisfaction Rate — This rate is the number of clients who state they were satisfied with the referral, divided by the total number of clients who were referred.

Both Kabwe and Samfya districts provided templates of client satisfaction surveys, which should be used to collect data for numerator. For

denominator, data from outgoing referral register should be used. Both Kabwe and Samfya districts provided templates.

Key Considerations for Monitoring this Referral System

Table D1 shows a summary of the monitoring system compared to the key criteria developed from a brief literature review and discussions with PEPFAR officials in Washington. The previous section of the report already dealt with a summary of the data recorded and reported. The narrative sections below describe the other characteristics of the monitoring system summarized in the table (data quality assurance, ability to maintain client confidentiality, provider burden, and facilitation of data use).

Data Quality Assurance Mechanisms — There did not appear to be documented mechanisms in place to ensure data quality within networks.

While it is in a mandate on network coordinating unit and an assigned district referral officer to control data quality (Kabwe district), no described mechanisms are presented for data quality checks between facilities and within a network.

At Kabwe and Samfya districts, the stub method provides an opportunity to determine in a documented way if the client reached the receiving organization — matching up the tickets with the stubs regularly between facilities or at the network meetings. The referral focal point can easily determine whether a client saw a provider at the receiving organization.

The Kabwe District operations manual had a section on monitoring referral activities as one of the functions of the coordinating organization with the following components: client satisfaction survey, reviewing monthly reports from network member organizations, and conducting periodic field visits. Minutes from the Kabwe District referral network quarterly meetings confirmed

that these activities were conducted, and feedback was discussed among network members.

Table D3. Zambia Summary of Fulfillment Criteria

	Criterion	
Recording and reporting of basic data element	Referral rate from referring institution (register records if client referred)	○
	Utilization rate at receiving institution (register records if client referred)	◉
	Referral adherence rate (tracking and analysis done)	○
	Counter-referral adherence rate (tracking and analysis done)	○
	Median delay (dates logged in registers)	◉
Data quality mechanism	Protocols/guidelines exist (PMTCT, VCT, ART)	○
	Provider training on monitoring system	—
	Quality checks on reported data	—
Client confidentiality	Provider protocols and training include confidentiality	◉
	If name in register, there are safeguards	○
	No name in reports	◉
Data use for programmatic decision	Reporting done to central authority	◉
	Analysis done	○
	At least one programmatic decision made based on data	—
Provider burden	Methods of study	*Low*

Legend

◉ Fulfills criterion

○ Partially fulfills criterion

— Does not fulfill criterion

Potecting Client Confidentiality — It was stated that the training of health care providers on confidentiality issues had been conducted; and client consent forms were well developed and standardized across districts. While client names appeared on registers, most of the time these registers were controlled by the clinic manager, limiting access to them. There were no template reports on which a client's name would appear.

Information on the Samfya and Kabwe districts' client referral form and feedback stubs provided limited confidentiality — client's name, address, phone, and information about services provided were listed on these stubs.

The Kabwe and Samfya districts' network operations manuals mandate that all network member organizations shall maintain confidentiality at all times, following a client's consent form.

The small district communities in close relationships between service providers and community members are likely to put confidentiality at risk (Kabwe and Samfya districts' client consent forms).

Is the System a Low Burden to Providers? — While the described referral system appears well-functioning and not burdensome for health providers at ZPCT-supported facilities from a standpoint of ZPCT management, no documented evaluation of the degree of burden was provided.

The forms require limited information and coding system facilitates expedited recording. Hospital providers do not have to fill out additional forms and can consult the register and client referral forms.

The Kabwe district network operations manual, in section 2.4.6 (page 14), outlines that it is a client's responsibility to return the feedback slip. If a client does not return back to the facility with

a feedback form, someone has to follow up and retrieve those forms from facilities where clients are referred, which could be somewhat burdensome in terms of time and cost. Additionally, it leaves room for the receiving organization to tweak the feedback form in its favor.

Facilitating Data Used — Aside from the monthly matching of tickets and stubs, it was not clear how the feedback looped within a network at the district level, and if the information was informing the district program.

Reports were reviewed by the district referral officer at the coordinating unit, which could be the DHO or DATF, and during the network meetings by all network members before submission to the provincial referral officer. It was unclear how feedback on the reports from the officer finds its way down the line, back to the district level.

Monthly/quarterly template reports did not appear to be standardized among networks, which would make it challenging for he provincial referral officer to analyze them and calculate standard indicators.

Individual organizations might use the data themselves, but there was no unitary system for tracking or reporting referral monitoring data; therefore, no analysis was done and no programmatic decisions were made based upon the data.

Samfya District's monthly/quarterly reports templates had sections to document activities accomplished, challenges/constraints, lessons learned, and recommendations. However, no copy of the monthly/quarterly report was provided to see examples of action points and follow-up activities, except the minutes from the Kabwe network meeting.

This system, as it was set up, captured a significant amount of information on the client, her or his identified needs, and whether these needs were met and associated timelines.

While it has been stated that indicators, targets, and mechanisms for gathering data were agreed upon before implementing network, no evidence was provided on the existence of indicators and targets.

Discussion and Recommendations

The following are recommendations based on the above findings:

- ZPCT management would like to have regular client satisfaction surveys, and establish database in all the ZPCT-supported sites.

- Sample report forms have sections to record practically all data elements necessary for calculating indicators once reports are submitted to the coordinating unit. However, there was no identified space for these indicators to be calculated and utilized at the district level.

- Monthly/quarterly report forms between networks should be standardized; , and should be separated into outgoing/incoming referrals, similar to how this is done in Kabwe District.

- Include median delay as a standard indicator in reports. Establish benchmarks for delays in referrals. It would be helpful for clients who receive referral forms to be given a recommended time-frame for reaching the receiving organization.

- ZPCT is collaborating with the MoH and U.S. government partners in the design and implementation of the SmartCare ART patient-tracking system, to be used in all MoH ART sites. SmartCare, a computerized system with

a paper backup, can capture patient characteristics and simplify follow-up and referral.

- Based on a comment during the desk review, it became clear that while referral methods have proved effective based on the feedback received from the network members in the different ZPCT-supported districts, there was still room for improvement of the functionality of the network.

Documents and Forms Reviewed

Documents or forms reviewed for this case study included the following from the Kabwe District HIV/AIDS Related Services Referral Network:

- quarterly meeting minutes
- operation manual
- directory of services
- outgoing referral register template
- incoming referral register template
- client referral tracking form template
- monthly/quarterly/annual report forms, incoming referrals templates
- monthly/quarterly/annual report forms, outgoing referrals templates
- completed monthly/quarterly/annual report forms
- client referral form template
- quality assurance survey template
- client consent form

Also reviewed, from the Samfya District HIV/AIDS Related Services Referral Network, were the following:

- directory of services, and organizations providing HIV/AIDS-related services
- referral network manual

- referral register template
- client referral form template
- quality assurance survey template
- monthly report form template
- quarterly report form template
- annual report form template
- client consent form
- data collection and update form for directory of HIV/AIDS related services

Reviewed materials from the Mkushi District HIV/AIDS Related Services Referral Network were the following:

- Mkushi referral network memorandum of understanding between Mkushi District Health Office and member organizations
- the Mkushi District directory of services

Appendix E: Study Tools

Scope of Work Memorandum

SOW: Development of a Preliminary Model for Monitoring HIV Referral Systems

Background and rationale

Integrating HIV services with other services (clinical and community-based) is important to making service delivery more efficient for the health system and more accessible for clients and ultimately to improving individual and family outcomes. Interest in integrating services has centered on integrating clinical services – HIV clinical services with other clinical services such as family planning (FP) or tuberculosis (TB). The client bases for these two services are similar, and they both lie within the purview of the health system. Integration of HIV clinical services with services that traditionally outside of the health system (e.g., educational services, social services, community-based services, etc…) has also been of interest because of the multi-sectoral approach that has been taken in addressing HIV prevention and mitigation. There are many context-specific models for integrating services, but approaches can be grouped into three main categories.   That is, services can be integrated by being
- Offered by a single provider trained in both services
- Offered in the same facility by different providers using a functioning referral system
- Offered by providers in different facilities or sites using a functioning referral system

The first category of models for integrating services implies the most disruption to current systems of care with concerns about feasibility and cost, centering on needs to reconfigure personnel profiles, training and supervision systems, and infrastructure. The referral system models of the second and third categories are considered to be the most feasible models for integration of HIV services. In order for the client to benefit from the various services, there needs to be a well-functioning referral system.

A four-country evaluation of FP/HIV integration by FHI found that although in all cases there were referral systems in place and service providers reported making referrals, clients reported being referred with much lower frequency than providers. Due to poor documentation it was impossible to find out the reasons for discrepancies. This highlights two problems with monitoring of referral systems: (1) patients' perceptions likely to cause them not to seek referred care and (2) the lack of instruments in the referral system that would facilitate its monitoring.

Monitoring and evaluation of referral systems would allow referral system stakeholders to:
- know if their referral system is working and
- identify well-functioning referral systems in order to provide information to others interested in establishing referral systems

Depending on the outcome, a monitoring or an evaluation approach needs to be taken. Evaluations of referral systems have taken place and provide invaluable information, but such studies can only be done periodically because of the time and expense involved.[*] A monitoring system based on routinely collected information is, therefore, needed to determine whether or not a referral system is functioning as expected. Besides being based on routinely collected information, the system must
- Capture the information that is needed to construct the monitoring indicators,
- Ensure the quality of that information
- Protect the confidentiality of the patient
- Be of low-burden to service providers

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[*] Swaziland Referral Technical WorkingGroup Team, "Linkages and Referrals within AIDS Care and Treatment National Service Delivery Systems, Swaziland." September 2008. **Final Report Based on Four Case Studies** | **59**

- Facilitate the use of the information for improvement of the referral system

The purpose of this activity is to propose a monitoring framework for referral systems that includes indicators for monitoring, mechanisms (such as referral tools and registers) to capture the information, and systems to ensure the quality of the information and facilitate its use. In order to develop this monitoring framework, there is a need to understand what referral strategies are currently being used (i.e., verbal referral, client-held card, provider-assisted referral, etc.), what HIV services (i.e., VCT, PMTCT, OVC, etc.) are being integrated through the referral process with what other services (i.e., FP, TB, palliative care, education, etc), and at what level the integration occurs (i.e., within facilities, between facilities, community-facility, and/or community-community).

Proposed Activities

A. MEASURE Evaluation will work with the M&E Technical Working group (TWG) and relevant program TWGs to develop a list of five country-level referral systems to examine. It is hoped that these case systems will cut across different geographic regions, different HIV program areas in which PEPFAR operates (e.g., VCT, treatment, PMTCT, minimum package of services for MARPs, OVC, palliative care, etc.) and different referral types:*
    - Facility-facility
    - Community-facility
    - Facility-community
    - Community-community

B. MEASURE Evaluation will simultaneously refine the qualitative/descriptive information to be collected, core monitoring indicators for referral systems, and data collection instruments. From MEASURE Evaluation's previous work on and knowledge of the area, the following are the core indicators that a referral monitoring system should have :
    a. **Referral rate** from referring institution, including reason-specific and service-specific rates (# and % clients referred))
    b. **Utilization rate** at receiving institution (# clients seen and # per 100,000 population)
    c. **Referral adherence rate** (# clients referred / # referred clients seen at receiving institution)
    d. **Counter-referral success rate** (# clients counter-referred / # clients referred)
    e. **Median delay** (median time lapse from referral to capture at receiving institution)

C. MEASURE Evaluation will do a brief literature review to confirm and refine the "core monitoring indicators" for referral systems outlined in B.

D. MEASURE Evaluation will conduct e-mail and phone interviews with relevant program and country staff to collect basic information on the five selected referral system.

E. MEASURE will then visit one or two promising programs to observe the operations of the referral and monitoring systems first-hand.

In interviewing and visiting programs, MEASURE Evaluation will collect information to address the following points:
- Describe the basic characteristics of the referral system
- Describe the basic characteristics of the monitoring system for referrals (if monitoring is done)

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* Intra-facility referrals systems will not be examined.

- Evaluate the referral system to determine if the mechanism of referral and the monitoring system have the following desirable characteristics for tracking key outcomes:
  - ✓ Information elements are recorded and reported that are necessary for construction of the key indicators outlined in section B above
  - ✓ Data quality mechanisms in place
  - ✓ Patient confidentiality mechanisms in place where appropriate (e.g. MARPs)
  - ✓ Provider burden low
  - ✓ Data used for programmatic decisions
- Evaluate the counter-referral system (if it exists), appropriate data and indicators

Country Matrix

	PMTCT→ OVC/Palliative Care	HIV VCT→ Care & Treatment	HIV VCT→ FP
Facility-facility		Haiti, Swaziland	Kenya
Community-facility		Nigeria	
Facility-community	Zambia		
Community-community		Cambodia	

Deliverables

The following products will be delivered by March 24, 2009:
1) Descriptions of no more than five referral systems and their monitoring
   - ✓ If there is currently no or inadequate monitoring, comments on the changes needed to rectify this
   - ✓ Key barriers and facilitators to monitoring desired indicators
2) Proposed framework for monitoring referral systems and its set up.* The proposed monitoring system will address the following issues:
   - ✓ Minimum proposed set of data elements and indicators
   - ✓ Suggested referral, documentation, and reporting mechanisms
   - ✓ System considerations to ensure data quality and client confidentiality
   - ✓ Suggested tools (e.g., client held referral cards, registers, reporting formats, etc.)
   - ✓ Suggested uses of monitoring information

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* Given the end date of this activity, this model would be preliminary and will need to be reviewed by implementing organizations involved in referral systems.

Interview Protocol for Referral Monitoring Systems Interview/Desk Review

<u>Background and consent</u>
The MEASURE-Evaluation project has been asked by the United States Agency for International Development to conduct a study on referral systems for HIV/AIDS. I would like to ask you some questions about the clients you see, where they are referred from and/or where you refer them to. I would also like to look at documents you use for referral like forms and registers. I am only interested in summary information from these and not individual client names. This information will help MEASURE-Evaluation to make recommendations to USAID about how to improve the tracking of referral systems. It is not an evaluation of your program. Your organization's future funding under this program will not be affected by the answers you give to these questions. This interview usually takes 60 minutes to complete. You and your organization's name will be kept confidential. The only ones who will have access to it will be MEASURE-Evaluation staff involved in the study, so that they can verify data should questions arise in the future. Any identifiers, including your name, position, and the name of your organization, will not be linked to your responses in any reports. Participation in this survey is voluntary and you can choose not to answer any individual question or all of the questions. You can stop the interview at any time. Choosing to not answer questions or stopping the interview will not affect the USAID funding of any current or future project. However, we hope that you will participate in this interview since you have valuable insight into these programs. At this time, do you want to ask me anything about the survey? Would you like to participate in this interview?
RESPONDENT AGREES TO BE INTERVIEWED   YES / NO

<u>People to interview</u>
- <u>For desk review</u>, the main person to interview is the Chief of Party and/or knowledgeable staff member that COP designates.
- <u>For desk review</u>, if possible, confirm information or fill in any gaps by supplementing the main interview with interviews with one interview with a knowledgeable service providers at referring institution and provider at receiving institution.
- <u>For country visits</u>, will additionally do site visits of a convenience sample of referring and receiving facilities/providers, interviewing:
    - Staff at District Health Office
    - Senior medical officers and/or managers
    - Service providers

<u>Prior to Interview</u>
1. Send interview questions ahead of interview with covering letter asking for any documents, data and resources that may be helpful to be identified where possible prior to interview
2. After recording project and respondent's identifying information, ask for signature of consent (or note verbal consent if a telephone interview)
3. Inform interviewee that a transcript will be provided for clarification and amendment after the interview

<u>During Interview</u>
1. Re-confirm permission to record, confidentiality and transcript to be provided.

2. Don't forget to PROBE and ask for detailed descriptions (i.e. …') Note that all the questions are open-ended questions, even if there are coded categories on the left side. In this intensive interview the emphasis is on obtaining narratives or accounts in the person's own terms. The purpose of probes is to enable the person being interviewed to be as informative as possible in their responses. The interview guide will serve as a primary reference, but the investigator is free to ask additional questions based on the responses heard using probes.
3. Throughout interview take notes. Is space reserved for responses is not enough, use additional blank pages and record answers with appropriate question number.
4. Identify any action to be followed up.
5. Request permissions to follow up issues by telephone/face to face/e-mail
6. Review the document check list (see below)

After Interview
1. Write up contextual interview notes.
2. Identify action points
3. Write letter of thanks to interviewee and ask for confirmation of promised materials+ any extra information needed.
4. Check and edit transcript
5. Send transcript to interviewee and ask to confirm/amend accordingly. Request any additional information at this point.
6. Arrange to follow up with telephone/face to face meeting where necessary
7. A few minutes after the interview find a quiet spot and jot down your thoughts about the interview:
   - Summary of key informant comments
   - Methodological difficulties or successes
   - Personal emotional experience and any emotions you noticed in the informant

Documents to request
Prior, during the interview, or shortly afterwards, in a follow-up, request that the following documents, or copies of such documents, are made available to you (if available):
   - program/project description
   - Mapping report of organizations providing HIV services in catchment area
   - copy of the formal agreement between referring and receiving institutions
   - agenda and/or minutes from a referral network meeting
   - documents from training of providers on referral protocol
   - examples of referral forms or tools used by a project
   - referral guidelines with clinical algorithms
   - record of counter-referrals
   - retained copies of referral slips
   - client tracking forms
   - referral registers
   - referring unit record system
   - report with compiled/analyzed referral data (e.g., any calculation of utilization, referral rate, referral compliance rate, etc.)

- report on evaluation of referral system

Data elements to look for in client-held referral/counter-referral form and register
- client name
- Information on where client referred to: name of provider/organization, address/phone, hours
- other client identifying information for client (ID, address)
- date referred
- condition/diagnosis
- reason for referral
- information that patient was received at the receiving institution
- date of patient being received at the receiving institution
- date of counter referral back to original institution (if applicable)

REFERRAL MONITORING SYSTEMS:
INTERVIEW GUIDE for program managers and health providers
PROJECT/PROGRAM IDENTIFICATION
NAME OF PROJECT/PROGRAM_____ LOCATION (country and sub-national area if relevant)_____ ORGANIZATION TYPE: 1 Government 2 Non-governmental organization 3 Private for profit 4 Faith based organization/Mission 5 Other _____

RESPONDENT / INTERVIEWER INFORMATION	
RESPONDENT NAME _____ POSITION _____ CONTACT INFORMATION:	INTERVIEW DATE: __ __/__ __/__ __ __ _ MM DD YYYY INTERVIEWER: _____
INTERVIEW GUIDE DESCRIPTION	

This Interview Guide is designed to collect information from project managers on the areas of interest to PEPFAR. It also contains a background section (Section1) and a final section in which the respondent can give his/her recommendations (Section 5):

Section 1:   Background characteristics of project/program

Section 2:   Description of the basic characteristics of referral system

Section 3:   Description of the basic characteristics of monitoring/tracking system for referrals (if monitoring is done)
1. Are data elements recorded and reported that are necessary for construction of key indicators (i.e., utilization rate at receiving institution, referral rate from referring institution, referral success rate, counter-referral success rate, and average delay in referral completion)?

Section 4:   Assessment for desirable characteristics of referral system and its monitoring system:
- ✓ Data quality assurance mechanism in place?
- ✓ Patient confidentiality mechanisms in place where appropriate?
- ✓ Provider burden low?
- ✓ Referral monitoring data used for programmatic decisions?

Section 5:   Respondent recommendations

SECTION 1 – BACKGROUND CHARACTERISTICS OF PROJECT/PROGRAM		
#	QUESTION	RESPONSE
The MEASURE-Evaluation project has been asked by the United States Agency for International Development to conduct a study on referral systems for HIV/AIDS. I would like to ask you some questions about the clients you see, where they are referred from and/or where you refer them to. This interview usually takes 60 minutes to complete. I would also like to look at documents you use for referral like forms and registers. I am only interested in summary information from these and not individual client names. This information will help MEASURE-Evaluation to make recommendations to USAID about how to improve the tracking of referral systems which may indirectly benefit your project. But this is not an evaluation of your program. Your organization's future funding under this program will not be affected by the answers you give to these questions. The only risk to you might be any consequences related to others finding out the answers you gave to these questions. However, this risk is minimal as you and your organization's name will be kept confidential. The only ones who will have access to it will be MEASURE-Evaluation staff involved in the study, so that they can verify data should questions arise in the future. Any identifiers, including your name, position, and the name of your organization, will not be linked to your responses in any reports. Participation in this survey is voluntary and you can choose not to answer any individual question or all of the questions. You can stop the interview at any time. Choosing to not answer questions or stopping the interview will not affect the USAID funding of any current or future project. However, we hope that you will participate in this interview since you have valuable insight into these programs. We may want to contact you again in the next several days to confirm information. If you have any questions later, you can contact the leader of this activity: Jim Ricca, MD, MPH, james.g.ricca@macrointernational.com +301-572-0317. Would you like to participate in this interview? If face-to-face: Have them sign and leave a copy of this form with them). RESPONDENT AGREES TO BE INTERVIEWED? YES / NO Signature _____		
1.1	What types of services does this program provide? 1. PMTCT 2. VCT / CT 3. Anti-retroviral therapy 4. Treatment of Opportunistic infections 5. Family Planning 6. STI treatment 7. TB diagnosis/treatment 8. Palliative care 9. Home-based care services 10. Nutrition support services 11. OTHER : _____ PLEASE DESCRIBE	
1.2	Is the emphasis of your project facility-based or community-based or both? 1. Facility-based only 2. Community- based only 3. Both	

SECTION 1 – BACKGROUND CHARACTERISTICS OF PROJECT/PROGRAM		
#	QUESTION	RESPONSE
1.3	Do you know the approximate number of people living in the area(s) served by your project? If so, can please tell me how many?	
1.4	How many people work in your project? How many people work with your project partners? IF YOU ARE UNSURE, PLEASE GIVE AN ESTIMATE	
1.5	Does this project work with other providers? PLEASE DESCRIBE IN DETAIL	
1.6	How many service providers does your project work with?	
1.7	What types of health or other social service providers does your project work with? 1- Hospitals 2-Health Centre 3-Public Health Unit 4-Clinics 5-Specialized VCT Clinic 6-Specialized ART Clinic 7-Specialized TB Clinic 8-Specialized STI Clinic 9-NGO 10-Community-based care 11-Faith-based organization 12-Outreach/peer educator 13- Support group 14-Traditional healer 15- Pharmacy 16. OTHER : _____ PLEASE DESCRIBE	

	SECTION 2 – CHARACTERISTICS OF REFERRAL SYSTEM	
#	**QUESTION**	**RESPONSE**
Now I would like to ask you a few questions specifically about the referral system, both referrals to your organization and referrals from your organization, if relevant.		
2.1	Does your project use a referral system to accept patients and/or link patients to other services? 1-Accept patients 2-Refer patients out 3-Both PLEASE DESCRIBE	
2.2	Has a directory of service providers been developed? If so, please describe when and how this was developed and please provide a copy of the directory.	
2.3	Is there a formal agreement between referring and receiving institutions? If yes, please describe the agreement (What is covered, when signed) IF SO, May I see an agreement or its copy?	
	PROBE: IF THERE IS NO FORMAL AGREEMENT between services, do you think that this is something that would be helpful? If so, how or why would it be helpful?	
2.4	Is there a network or consortium in which coordination of services among partners is facilitated or discussed? IF SO, please describe. IF NOT, do you think that this is something that would be helpful? If so, how or why would it be helpful? skip to Section 3.	

2.5	Which types of health or other social service or community based organizations participate in this network? 1-MOH 2-AIDS Coordinating Committee 3- Public Health Unit 4- Hospitals 5-Health Centres 6-Public Health Units 7-Clinics 8-Specialized VCT Clinic 9-Specialized ART Clinic 10-Specialized TB Clinic 11-Specialized STI Clinic 12-NGO 13-Community-based care 14-Faith-based organizations 15-Outreach/peer educators 16- Support groups 17-Traditional healers PLEASE DESCRIBE	
2.6	How often do network participants meet? How do referring and receiving providers or organizations interact? What types of issues are discussed? Is this type of professional interaction helpful in increasing client's access to services? ASK FOR AGENDA AND MINUTES OF LAST MEETING.	

SECTION 3 – CHARACTERISTICS OF MONITORING/TRACKING SYSTEM		
#	QUESTION	RESPONSE
Now I would like to ask you some questions about how your organization tracks outgoing and incoming referrals, as well as counter-referrals.		
3A – REFERRALS MADE BY THE PROJECT/PROGRAM AND COUNTER-REFERRALS		
Now I would like to ask you about referrals MADE BY your organization to others.		
3.1	Please describe how you know about the services that are provided by other providers that your project refers to?	
3.2	Please describe who identifies and assesses client needs and makes a referral? 1-Referring doctor 2-Nurse 3-Case manager 4-Project officer 5-Support group member 6-Peer educator OTHER_____ PLEASE DESCRIBE	
3.3	What are the services for which your project refers clients elsewhere? 1-PMTCT 2-VCT 3-Palliative care 4-Anti-retroviral therapy 5-Home-based care services 6-Family Planning 7-Nutrition support services 8-Medical follow-up 9-STIs care 10-TB diagnosis/treatment 11.OTHER: _____	

3.4	To where do you usually send referrals to? 1- Hospitals 2-Health Centre 3-Public Health Unit 4-Clinics 5-Specialized VCT Clinic 6-Specialized ART Clinic 7-Specialized TB Clinic 8-Specialized STI Clinic 9-NGO 10-Community-based care 11-Faith-based organization 12-Outreach/peer educator 13- Support group 14-Traditional healer 15- Pharmacy 16. OTHER: _____	
3.5	Please describe the method(s) and the process that are usually used to refer clients? 1- Telling them where to go 2- Issuing standard referral form 3- Blank paper to write referral information 4- Telephone referral 5- Escorting client 6. OTHER:_____ PLEASE DESCRIBE	
3.6	Is there a record keeping system to keep track of <u>outgoing</u> clients? If so, describe in detail? 1- Patient register Individual medical record 2-Retain copies of referral slips 3- Facility/Referring unit record system/register 6. OTHER: PLEASE DESCRIBE IF YES, ASK TO get a copy	
3.7	IF NO COPY IS AVAILABLE, Describe what information is recorded in the system?	

3.8	IF STANDARD REFERRAL SLIPS MENTIONED IN 3.6, ASK (otherwise, skip to 3.9): How is supply of forms monitored?	
3.9	How does the provider at receiving organization know that a patient has been referred to them?	
3.10	Hoes does your project know that a patient completed the referral? Is there a system to follow up with a patient on referral? If so, please explain how?	
3.11	Is there a system in place to measure and record a time lapse between when referral was made and when a client reached the receiving provider? IF SO, can you please show me the record. Has average delay been ever calculated by your project?	
3.12	Who usually follows up with a patient on referral? Describe: 1-Referring doctor 2-Nurse 3-Public health technician 4-Case manager 5-Project officer 6-Social worker 7-Counselor 8-Administrator 9.OTHER: _____	
3.13	Are patients ever referred back to this facility/group for follow-up? If so, explain.	

3.14	Are the cases that are referred back to you documented? If so, please describe? May I see a record?	
3.15	Has your project calculated a counter referral rate?	
3.16	Is there a system to record referral outcome for the patients that were referred out? If so, please explain in detail	
3.17	Do providers regularly ask clients what they think about the referral? Was it what they wanted? Did it address their concerns such as stigma? Is it feasible – cost, transport, hours?	
3.18	Does the provider get permission from the client to follow up with the other provider? How is this done? Is there a formal release of information?	

	3B – ACCEPTANCE OF REFERRALS TO THE PROJECT/PROGRAM	
3.19	Do you accept referrals from other organizations? IF NOT, skip to section 4.	
3.20	Please describe how other providers know about the services that are provided by your organization?	
3.21	What are the services for which clients are <u>referred to your project</u> from elsewhere? 1-PMTCT 2-VCT 3-Palliative care 4-Anti-retroviral therapy 5-Home-based care services 6-Family Planning 7-Nutrition support services 8-Medical follow-up 9-STIs care 10-TB diagnosis/treatment 11 OTHER_____ PLEASE DESCRIBE	
3.22	From where do you usually receive referrals? 1- Hospitals 2-Health Centre 3-Public Health Unit 4-Clinics 5-Specialized VCT Clinic 6-Specialized ART Clinic 7-Specialized TB Clinic 8-Specialized STI Clinic 9-NGO 10-Community-based care 11-Faith-based organization 12-Outreach/peer educator 13- Support group 14-Traditional healer 15- Pharmacy 16. OTHER:_____	

3.23	Please describe the method(s) and mechanisms that are used with clients referred to you? 1-Telling them where to go 2-Issuing a standard referral form 3-Using a piece of paper to write referral information 4-Making a telephone referral 5-Escorting them 6. OTHER_____	
3.24	Please describe what information the referred client usually has: a -name of the referring provider, including provider's location, address, phone number b - name of this project, including location, address, phone number c - information about the type of service given to the client at the original provider d - date of referral e – diagnosis f – instruction on how to follow-up with referring institution OTHER_____ PLEASE DESCRIBE	
3.25	What do you think about this referral method(s)? Is it /are they effective, why or why not? How would you improve? PLEASE DESCRIBE	
3.26	Is there a system to inform a referring service provider that a client has complied with referral? If so, can you please describe this system. 1- Verbal 2- Section of referral form filled out and sent back 3- Separate counter-referral form 4- Blank slip of paper 5- OTHER_____ PLEASE DESCRIBE	

SECTION 4 – ASSESSMENT FOR DESIRABLE CHARACTERISTICS OF REFERRAL AND MONITORING SYSTEMS		
#	QUESTION	RESPONSE
4A – DATA QUALITY ASSURANCE		
4.1	Are there documented protocols or/and guidelines on referrals? If so, for which services: 1-PMTCT 2-VCT 3-Palliative care 4-Anti-retroviral therapy 5-Home-based care services 6-Family Planning 7-Nutrition support services 8-Medical follow-up 9-STIs care 10-TB diagnosis/treatment 11.OTHER: _____	
4.2	IF REFERAL GUIDELINES EXIST: Are they project specific, adapted to the health system in (COUNTRY) or international? Please describe.	
4.3	Has there been training of providers on protocol for referral? If so, please describe the training: Who conducted it? When it occurred? How many providers were trained? Was it effective? Has there been follow up/refresher training? Do you have any documentation that you can show to me?	
4.4	Is there any mechanism to assure the accuracy of recorded information on utilization and referral? IF NO, SKIP TO 4.7	

4.5	Can you describe the process of assuring quality of the data gathered on referrals 1. Regular supervision 2. Periodic audits 3. Other mechanism DESCRIBE IN DETAIL	
4.6	Have any improvements been made based on the information gathered on assuring the quality of referral information? If so, please describe.	
4B – PROVIDER BURDEN OF MONITORING SYSTEM		
4.7	How much health provider time is taken by documenting, reporting and analyzing referrals? Do you feel that this is burdensome?	
4C – DATA USE		
4.8	Does anyone analyze referral data? If so, how often are data compiled and in what form? Who compiles and uses these data? For what purpose(es)? Can you give us any examples of decisions made based on this data? IF NO DATA ARE ANALYZED, can you describe why not?	
4.9	Has your project calculated a referral rate and/or referral compliance rate? IF SO, How often? Where is it recorded and reported to?	

4.10	Are referral data reported to anyone in your organization or elsewhere? If so, describe the people who receive this information (program managers, providers, etc). How often do they receive it? What information in particular do they receive? Can you show me an example of report where compiled data feed into?	
4.11	If program managers and providers are not receiving this information do you think it would helpful if they did?	
4.12	Are the data on referral ever discussed (how often, by whom)? If so, what is the content of these discussions (e.g., were any programmatic or clinical changes made based on these discussions)?	
4.13	Has the referral system ever been evaluated? If so, how many times? When was the last time? Can you send me the last evaluation report?	
4D – CLIENT CONFIDENTIALITY		
4.12	Is the name of client or other identifying information recorded in registers for referral?	
4.13	Is the name of client or other identifying information recorded in any reports about referral? If so, What other information, besides name is recorded?	
4.14	Are there any considerations made to ensure client confidentiality? If so, please describe?	
4.15	Do you have any concerns about the maintenance of confidentiality within the information and/or referral tracking systems? If so, what? What could be done to improve maintenance of confidentiality?	

SECTION 5 – RESPONDENT RECOMMENDATIONS		
#	QUESTION	RESPONSE
I have a few final questions. We are interested to know whether you have any recommendations on how the referral system and its monitoring can be improved.		
5.1	Do you have any recommendations on how the referral system could be improved? If so, could you please tell me?	
5.2	Do you have any recommendations on how the monitoring of referrals could be improved? If so, could you please tell me?	
5.3	Do you have any other comments that you would like to make that we have not already covered?	
Thank you very much for your time and cooperation in answering these questions. If we should need some additional information for this study, may we contact you again? YES NO Do you have questions about this study that you would like to ask me?		

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