

Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings

FAMILY HEALTH INTERNATIONAL

JANUARY 2005



Acknowledgments

Family Health International (FHI) is proud to present *Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings*. FHI developed this document to help organizations and communities in low-resource settings create effective referral networks to provide comprehensive prevention, care, treatment and support for persons living with HIV/AIDS and their families and caregivers.

Leine Stuart, PhD, ACRN, Judith Harkins, MSN, MPH, and Merywen Wigley, MSc, wrote *Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings* in collaboration with other FHI staff members. Special thanks go to Gloria Sangiwa, MD, Awa Toure, MD, Eric van Praag, MD, Sarah Finocchiaro, MPH, Gretchen Bachman, MBA, and Marie Coughlan, MPH. Their technical expertise and practical guidance were instrumental in developing this document.

To obtain additional information, please contact:

Institute for HIV/AIDS

Family Health International

2101 Wilson Boulevard, Suite 700

Arlington, VA 22201

USA

Tel: +1-703-516-9779

Fax: +1-703-516-9781

E-mail: aidspubs@fhi.org

Table of Contents

Introduction	4
Definition of Key Terms	4
Rationale for Creating Referral Networks	4
Proposed Models of Referral Networks	5
Health facility-based referral network	5
Community-based referral network	7
HIV case management model of referral network	8
Essential Elements of a Referral Network	9
How to Start or Strengthen a Referral Network	13
Convene an initial stakeholders' workshop	13
Conduct a participatory mapping exercise	14
Put systems in place to develop and support the referral network	14
Mobilize the community to use and support the referral network	15
How to Make a Successful Referral	15
Tools to Facilitate the Referral Process	15
Monitoring and Evaluation of Referral Networks	17

Introduction

Meeting the needs of growing numbers of persons living with HIV/AIDS (PLHA), their caregivers and their family members requires the collective effort of many facilities and organizations, both clinic- and community-based. It also requires appropriate policies, supportive social attitudes and community support systems.

Strengthening access to a range of HIV-related services for those in need and promoting communication among service providers requires a formalized referral network of providers. However, little information about how to create these networks and few standardized tools to facilitate effective network functioning are available. This document aims to describe several models of referral networks and to provide tools and instructions that can be adapted to different settings. The document is intended for implementers, stakeholders and service providers at the facility and community levels who need guidance for creating or improving a referral network of HIV/AIDS-related services.

Definition of Key Terms

In the context of HIV, a **referral** is the process by which immediate client needs for comprehensive HIV care and supportive services are assessed and clients are helped to gain access to services, such as setting up appointments or giving directions to facilities. Referral should also include reasonable follow-up efforts to facilitate contact between service providers and to solicit clients' feedback on satisfaction with services.

In this document, many references are made to the different organizations participating in the referral process. The organization that first makes the referral is called the **referring organization**; it is also sometimes called the point of initiation of the referral. The organization to which the client is referred for services is called the **receiving organization**; it is also sometimes called the organization that fulfilled the referral. The organization designated as a central focal point for the referral network is called the **coordinating organization**.

Rationale for Creating Referral Networks

As an overarching goal, the purpose of a referral network is to help PLHA, their caregivers and their family members obtain the highest level of quality of life, to facilitate their active participation in decisions affecting their lives and to promote social acceptance and respect for those living with HIV and those caring for HIV-infected persons.

Persons living with and affected by HIV have a wide range of needs spanning multiple dimensions of life: physical health, psychosocial well-being, human rights, food resources, economic security and spirituality. These needs vary depending on many factors, including the age and gender of the person. Also, over time and with disease progression, the needs of PLHA, their caregivers and their families change.

Rarely can a single facility, agency or community group deliver all of the services to meet these needs. A well-established referral network is vital to meeting the needs of PLHA and maintaining or re-establishing contact with clients and families who need ongoing care and support. As

different organizations provide prevention, care, treatment and support services, a system is required to link these agencies so they can provide HIV-infected and -affected persons with access to needed services across the continuum of care.

The referral system entails a process of coordinating service delivery to ensure that:

- Access to needed services is expedited.
- Confidentiality is maintained.
- Referrals between the organizations in the network can be tracked.
- Referrals and their outcomes are documented.
- A feedback loop informs the organization initiating the referring organization that the requested service has been delivered and has met the needs of the client.
- Gaps in services can be identified and steps taken by organizations in the network to bridge them.

Proposed Models of Referral Networks

There are several models of referral networks for HIV-related services. These models are defined by such factors as setting, scope of services and locus of coordination. Two main models are defined by the type of organization that coordinates the network: health facility-based referral networks and community-based referral networks. Another model is the HIV case management referral network model, in which patients are assigned to a case manager, a professional who helps patients and families define and meet their needs. This model can be either health facility- or community-based.

Within health facility- or community-based models there can be varying degrees of formalization. For a referral network to work at its best, relationships between service providers are formalized and organizations agree upon procedures, and one organization also takes a leading role as the coordinating organization. Some networks will be highly standardized and organized and will have good documentation procedures; the organizations collaborate on an ongoing basis and communicate regularly, and the network integrates all or most of the eight essential elements described above. In other systems, communication and coordination are ad hoc and based on service demand, and fewer of the essential elements are in place. These variations are described below.

Health facility-based referral network

Example 1:

Staff in the HIV care unit of the health facility coordinate referrals between clients and services provided both within the facility and by community organizations. The client's relationship to the facility begins after a positive HIV diagnosis, or if he or she is a family member of a PLHA. The focal persons for referrals are usually nurses working within the unit where HIV care is provided. In health facilities that have a home-based care (HBC) component, the HBC coordinator may also serve as the focal person.

In discussion with the patient and/or caregivers, and using the directory of services (see Tool 1), the designated focal person determines the patient's needs and initiates a referral to a defined service. The patient receives a written referral form that includes information on the patient, the organization making the referral, the service(s) needed and the organization and person to whom the patient is being referred (see Tool 2). A record of the referral goes into the patient's file (see

Tool 3) and the facility's referral register (see Tool 4). Tracking to obtain information on the outcome of the referral, including the patient's satisfaction with the service(s), usually occurs at the patient's next clinical visit or via direct communication with the receiving organization.

Example 2:

At facilities that are just beginning to refer patients or at those with limited resources, an ad hoc referral network may exist. In such a system, a particular service unit, such as those for prevention of mother-to-child HIV transmission (PMTCT) or voluntary counseling and testing (VCT), assumes the lead in making referrals to clinical and non-clinical service providers in the catchment area after discussions with the patient, caregivers or family members have identified their needs. Linkages between organizations providing services are informal and communication is ad hoc based on immediate need. A staff member of the unit, often a nurse, directs the individual to the provider(s) of the desired service(s); a written referral form may or may not be provided noting those service(s). At the point of initiation, the referral may or may not be documented, based upon the unit's records system. Other than in discussion during the patient's next clinical visit, there is no formal mechanism for following up on a referral to determine if the need has been satisfied. This system functions best when a referral network is in its infancy. As the program matures, this ad hoc system grows to become more formal and incorporate more of the essential elements described earlier.

Example of a Health Facility-based Referral Network

St. Mary's Hospital in Mumias, Kenya, provides HIV prevention, care, treatment and support services through its Comprehensive Care Center (CCC), which includes VCT, PMTCT, home-based care and clinical care (including managing opportunistic infections and other HIV-related conditions, prophylaxis for opportunistic infections, TB management and antiretroviral therapy). Facility-based services also include nutritional support and PLHA group support. The CCC refers clients for other HIV-related services to organizations throughout the Butere Mumias District.

Two facility-based clinicians, a community nurse and a public health technician who are part of the CCC team, manage the referral system in addition to coordinating the hospital's HBC program. They also serve as the focal point for linkages between the health facility-based services and District residents, with community health workers (CHW) from the HBC project functioning as intermediaries.

The referral coordinators have created a Referral Network Guide Sheet (a type of directory of services) that details available services and contact persons. A referral form has also been developed that:

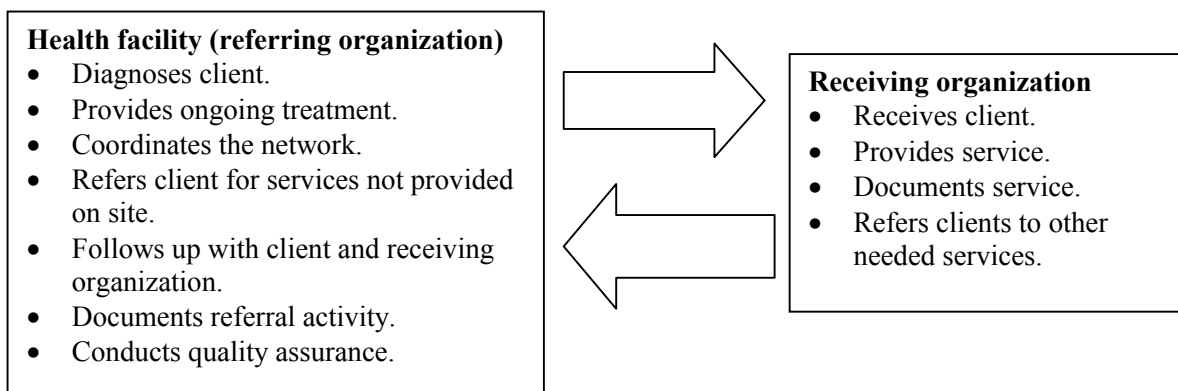
- Directs patients to the needed service
- Provides basic information for the service provider on the patient and reason for the referral.
- Documents the referral.

The form is retained by the referral coordinators at the hospital as documentation of the referral.

While several features of this referral system contribute to its operational effectiveness, the following are particularly important:

- This district-wide system forges a close collaboration between health facilities and community members through a clearly defined referral process.
- The referral coordinators are members of the HIV care team at the hospital. They work collaboratively with other team members who recognize their work as an essential component of comprehensive patient care.
- The referral coordinators interact frequently with patients, CHW, hospital staff and staff of other services in the community.

Diagram 1: Client flow in a health facility-based referral network

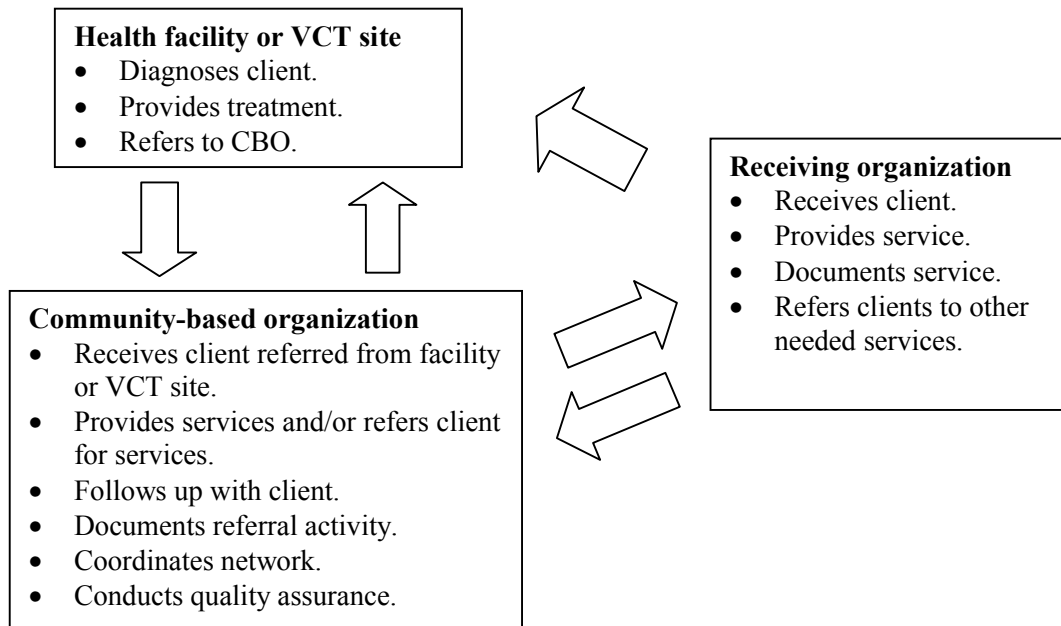


Community-based referral network

While the objectives and processes in this model are very similar to those of the health facility-based referral network, an organization based in the community coordinates the referral system. In this instance, a client who is diagnosed as HIV-positive at a VCT center or health facility is referred to a community-based organization (CBO) that provides other HIV-related services, such as prevention, advocacy, peer education or spiritual support. The CBO assumes referral coordination as an additional function of the organization.

As in the facility-based model, the CBO establishes linkages with health facilities and other organizations providing services to PLHA, their caregivers and their families within a defined geographical area. A staff member of the organization is dedicated to managing the referral network. With input from other organizations in the network, the CBO develops and updates both referral forms and the referral directory. It also schedules regular meetings of the network participants to discuss issues and challenges in operationalizing the referral process. The CBO also conducts quality assurance to ensure that services are meeting the satisfaction of PLHA, their caregivers and their family members and that gaps in services are addressed.

Diagram 2: Client flow in a community-based referral network



HIV case management model of referral network

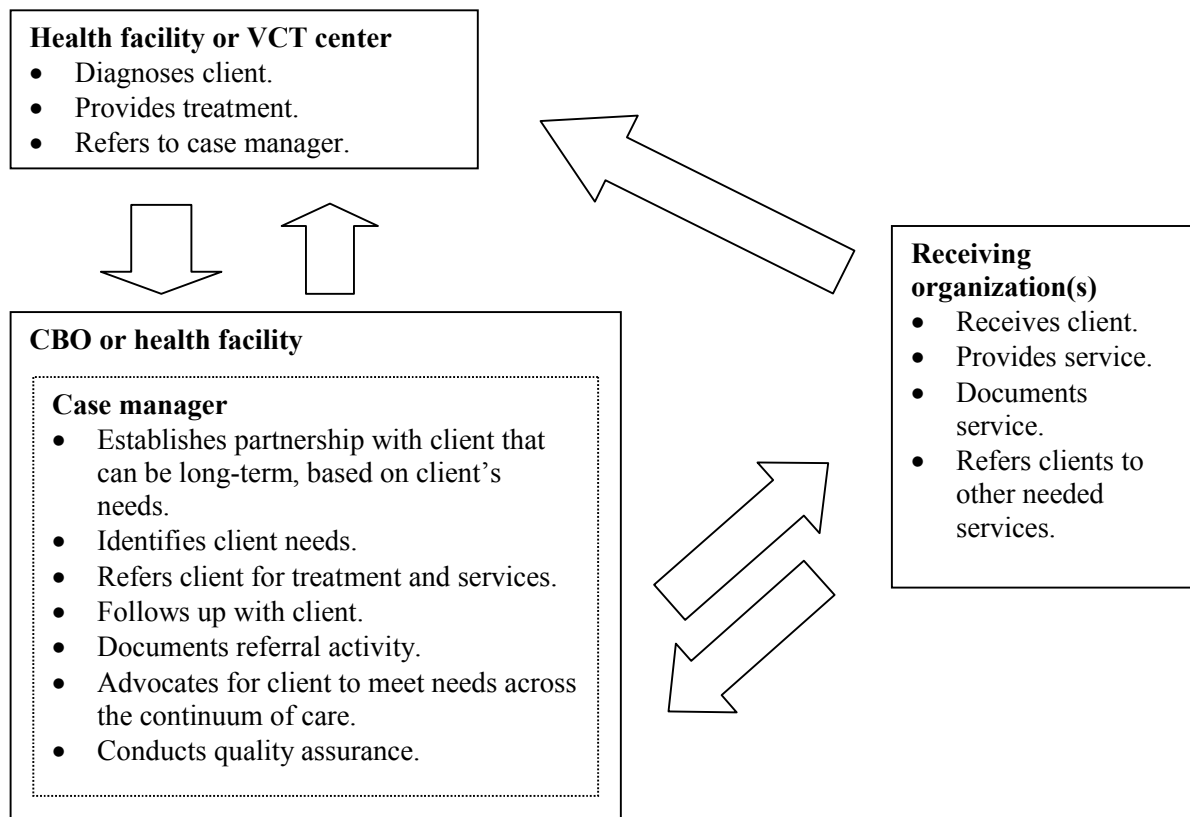
One approach to coordinating care across a system of services and providers to meet the needs of people living with HIV and their caregivers is HIV case management. In this model, PLHA and their caregivers are active participants in defining their needs and seeking options to meet these needs. They work collaboratively with a cadre of case managers who have been trained in the HIV disease process, community care, treatment and support services, and facilitating access to needed care and services. Each case manager has a defined caseload of clients with whom they maintain a consistent, long-term partnership.

An HIV case manager performs the following general functions:

- Identify and conduct outreach to clients.
- Assess the comprehensive needs of the client and caregivers.
- Develop an individual service plan with the client and caregivers.
- Implement the service plan by linking with the service delivery system.
- Monitor service delivery.
- Advocate for clients.
- Continue evaluation of client needs.

The case managers may be employed by either a health facility or CBO that serves as the coordinating organization. Within their system, they use standardized forms and a directory of services. A designated staff member within the case management group coordinates network meetings and directory updates.

Diagram 3: Client flow in an HIV case management referral network

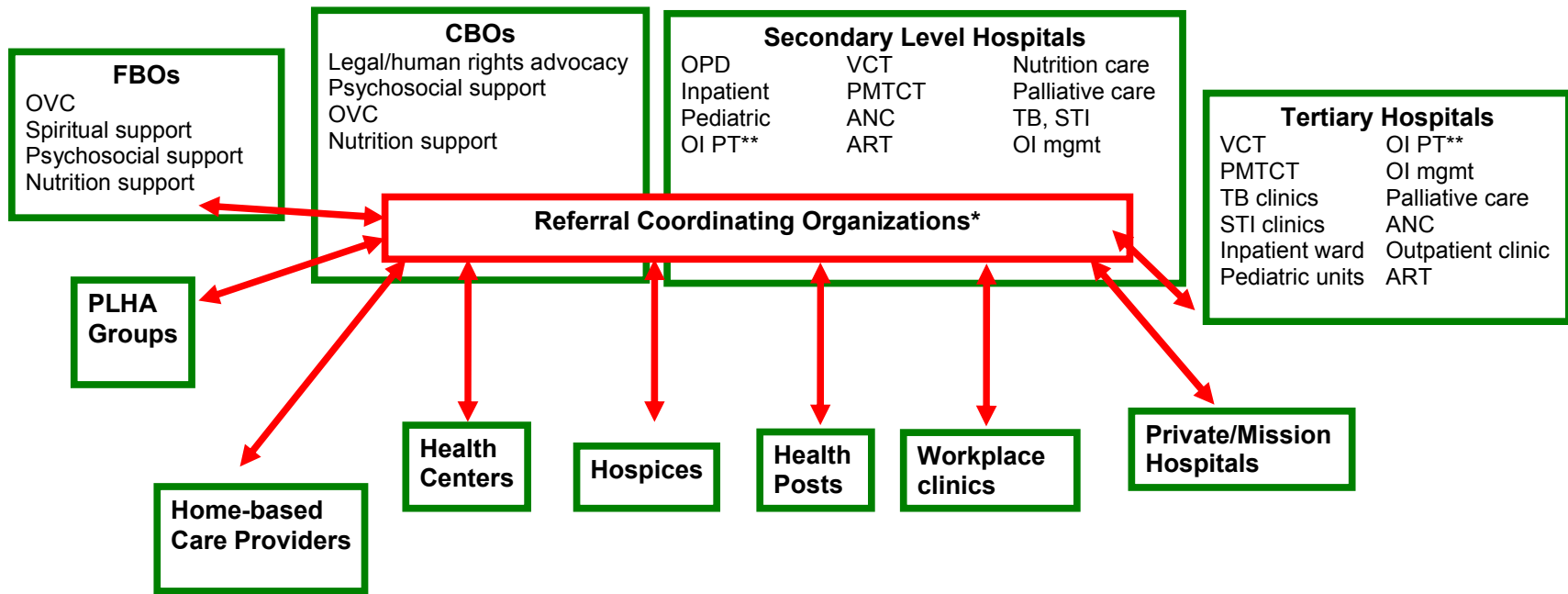


Essential Elements of a Referral Network

Regardless of the model used, there are certain essential elements that need to be in place to optimize the referral system's operational effectiveness and outcomes for PLHA, their caregivers and their family members. The essential elements are:

- a. *A group of organizations that, in the aggregate, provide comprehensive services to meet the needs of PLHA, their caregivers and their families within a defined geographic area.* The needs of PLHA and their caregivers span the continuum of care, encompassing the medical/nursing, psychosocial, economic, legal and spiritual domains. To effectively address these needs, the network must include as broad a range of services and organizations as possible. Diagram 4 shows the full range of services that could be included. While many communities will not have all of these services in place, that should not stop them from initiating a referral network. Service gaps can be addressed as the network matures.
 - Resolving access issues is essential to service uptake, and barriers to access should be removed so that clients can have their needs met.
 - Organizations in the network can both refer patients to other services and receive patients being referred from other services. In other words, the referrals go in both directions among organizations in the network.
 - Diagram 4 shows how the referral network includes health facilities at all levels (tertiary hospitals, secondary hospitals, health centers and health posts) and a range of organizations providing HIV/AIDS-related services in the community.

Diagram 4: Referral network for prevention, clinical care, treatment and support



*Coordinating organization can be a health facility or CBO

**PT=prophylactic treatment

b. *A unit or organization that coordinates and oversees the whole referral network.*

- A specific organization or unit in the network serves as the locus of responsibility for the network and its performance (in addition to its regular duties). This coordinating function is performed by a health facility, preferably a unit within the facility that is dedicated to this function, or a community-based organization. This focal point is called the coordinating organization or unit.
- The primary functions of the coordinating organization/unit include convening regular meetings of providers, working with providers to address gaps and other inefficiencies in the system, updating the directory, providing standardized tools and forms, and performing quality assurance for the referral system.
- At the coordinating organization/unit, there is a specific person designated to fulfill the tasks listed above.

c. *Periodic meetings of network providers.*

- Regular meetings of organizations in the network provide a venue for ongoing communication, exchange of information about the referral process, discussion of challenges and gaps in service, and updating the service network directory. The coordinating organization/unit convenes these meetings.
- The regular meetings promote collaboration and commitment to the referral process as an essential component of HIV service delivery.

d. *Designated referral person(s) at each organization.*

- This designated person has responsibility for processing referrals efficiently and expeditiously. S/he is also responsible for managing core referral activities, such as tracking and documenting referrals and attending network meetings.
- Referring clients specifically to this designated person helps clients gain access to needed services.
- This designated person could be a nurse, counselor, social worker or other type of staff member.

e. *A directory of services and organizations within a defined catchment area.*

Services to include in the network

The referral network should ideally include organizations in a defined geographical area that are providing the following services needed by PLHA, their caregivers and their families:

1. Adherence counseling
2. Antiretroviral therapy
3. Child care
4. Clinical care
5. Education/schooling
6. Family planning
7. Financial support
8. HIV counseling and testing
9. Home-based care
10. Legal support
11. Material support
12. Mental health services
13. Microfinance
14. Nutrition counseling
15. OB/GYN services
16. Peer counseling
17. Post-exposure prophylaxis (PEP)
18. Pharmacy
19. PLHA support
20. PMTCT services
21. Post-test clubs
22. Prevention services
23. Psychosocial support
24. Social services
25. Spiritual support
26. STI services
27. Substance abuse management
28. Support for domestic violence victims
29. Treatment support
30. TB services
31. Youth support groups
32. Other _____

- A directory provides an inventory of services available within a geographical area, including the name of the organization, the type of service provided, the referral contact person(s) and the location of the service (see Tool 1).
- A directory of services facilitates referrals by making it easy to get information on available services in the geographic area.
- A directory needs to be constantly updated to ensure that information on service providers is current and accurate, new providers are included and providers no longer offering a service are deleted.
- The directory is managed by the coordinating organization (see point #2 above). Each organization in the network provides new information for directory updates to the coordinating organization. These updates can be distributed to all organizations in the network at the periodic network meetings (see point #3 above).

f. A standardized referral form.

- A referral form—either a card or piece of paper—that is standardized throughout the network ensures that the same essential information is provided whenever a referral is initiated and that this information is received by the organization fulfilling the referral (see Tool 2).
- The minimum information required on the referral form includes:
 - The date of the referral request.
 - The type of service needed.
 - The name of the client.
 - The name and contact information of the organization initiating the referral request (referring organization).
 - The name and contact information of the organization to which the referral request is directed (receiving organization).
 - The names of the designated contact persons at both organizations.
- A referral form is given to the patient, caregiver or family member to direct this person to the service needed. It introduces the person being referred to the organization fulfilling the referral and identifies the organization and person initiating the request. It also indicates which services the client needs.
- Ideally, after the services are completed and the referral is fulfilled, the referring organization follows up with both the client and the receiving organization. If this is not feasible, then the client returns the form to the referring organization. This feedback loop is important for documenting referrals and evaluating the system.

g. A feedback loop to track referrals.

- A system to track a referral from point of initiation to point of delivery and, as a feedback loop, from point of service delivery back to point of initiation is needed to ensure that the client used the service(s) needed.
- Written feedback provides evidence that the referral process was completed and the service was delivered, and it can note whether there were problems. Using the original referral request (such as the referral form in point #6 above), documenting the status of service delivery and other pertinent information and returning the form to the site of referral initiation is one method of feedback documentation.
- The effectiveness of a referral system is determined by the individuals being referred, so it is essential to determine if a client is satisfied with the service received and whether her or his need was met. One method of getting this information is for the

site that made the referral to contact the client directly for feedback, if the client agrees.

- This component of a referral system presents many challenges requiring deliberate, consistent action by:
 - Referring organizations, which must take the initiative to follow up with clients about the services for which they were referred.
 - Receiving organizations, which must take the initiative to report on service delivery to the organization initiating the referral.

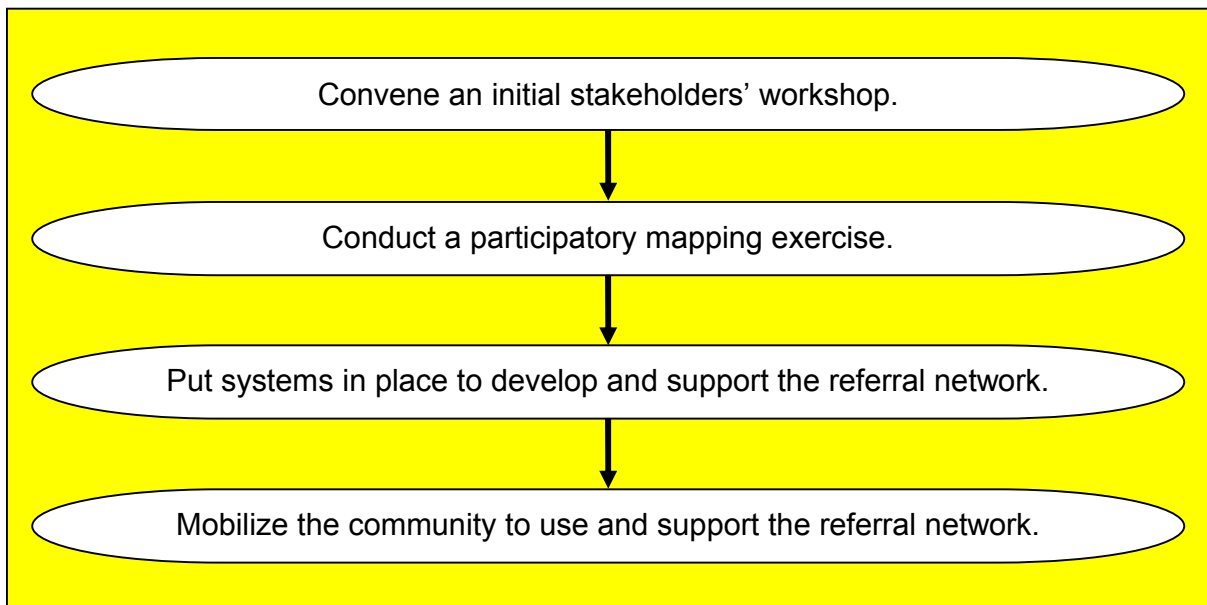
h. Documentation of referral.

- At both ends of the referral (referring organization and receiving organization), a written record of the referral is needed to document outcomes.
- Both the site initiating the referral and the site fulfilling the referral are responsible for documenting their respective roles in the referral process.
- A standardized referral register (see Tool 4) is one way to document referrals.

How to Start or Strengthen a Referral Network

Starting a new referral network or strengthening an existing one is a multi-step process involving many players and stakeholders. The main steps are described below.

Diagram 5: Steps to start or strengthen a referral network



Convene an initial stakeholders' workshop

- The first step in creating or strengthening a referral network is to identify and bring together the various stakeholders to initiate a community dialogue, seek input on creating a formal referral network and generating “buy-in” for the activity.

- Stakeholders to invite include PLHA support group representatives, district (government) health staff, key staff from health facilities at all levels (from tertiary to community level), social welfare office representatives, local NGOs and CBOs, and faith-based organizations.

Conduct a participatory mapping exercise

- The point of a mapping exercise is to generate a list of all organizations and facilities providing HIV-related services within the geographic area that might be included in the referral network.
- The mapping should identify key entry points (that is, how a client gets into the referral network), potential barriers to access and how the network will be linked to existing comprehensive care and support services in health facilities and community-based organizations.
- The mapping exercise should identify community resources, including the traditional authority structures that can be tapped to strengthen and expand the referral network.
- PLHA will be an excellent resource in this activity and should play an active role.
- As part of the process, a directory of services can be created showing all clinical and social service agencies and NGOs that might assist HIV-positive clients and their families in the catchment area.

Put systems in place to develop and support the referral network

- Identify and train an organization to serve as the coordinating organization. This can be either a health facility or a CBO (see #2 under “Essential Elements”).
- Identify and train key contacts within each organization in the network.
- Determine the roles and responsibilities of each organization within the referral system, including potentially developing a Memorandum of Understanding between organizations.
- Hold sensitization meetings with stakeholders and staff of participating organizations to achieve consensus on operating principles, such as ensuring that all referrals are honored.
- Supervisors in the network’s organizations should ensure that staff understand the referral network and how it works and support staff at all levels (clinic- or community-based) in providing referrals as necessary.
- Establish agreed-upon guidelines to address the issue of confidentiality within the referral network. There should be a discussion about confidentiality, stigma and the potential for “shared confidentiality”¹ and what that means to the community.
- Outline an appropriate mechanism for referral, including referral forms and registers to document the process for the referrals and follow-up.
- Create and distribute standardized forms, tools and procedures and train all organizations in the network to use them.
- Encourage and help providers at all levels to nurture personal contacts within the network to facilitate referrals and follow-up.
- Monitor the network’s activities and use findings to improve the system.

¹Clients’ HIV test results must be kept confidential. However, there are circumstances when other professionals, such as counselors and health and social service staff at organizations where the client is being referred, might also need to know the person’s HIV status in order to provide appropriate care. This shared confidentiality is encouraged. Shared confidentiality also refers to confidentiality that is shared with others at the discretion of the person who will be tested. These might include family members, loved ones, health and social service providers, caregivers and trusted friends.

Mobilize the community to use and support the referral network

- Collaborate with PLHA, their families and their caregivers to develop a referral network that will respond to their needs and engage them in its implementation.
- Undertake intensive community mobilization and promotional and public awareness activities to build demand for services.
- Seek the support of church and education leaders, medical providers and policymakers to use their influence to increase community support for the referral network.

How to Make a Successful Referral

- Work with clients to decide what their immediate referral needs are.
- Outline the health and social service options available and help the client choose the most suitable in terms of distance, cost, culture, language, gender, sexual orientation and age.
- In consultation with the client, assess which factors may make it difficult for the client to complete the referral (e.g., lack of transportation or child care, work schedule, cost, stigma) and try to address them.
- Discuss shared confidentiality with clients and support them as they decided with whom they want to share their HIV status.
- Make a note of the referral in the client's file. Ensure follow-up and monitor the referral process.
- Document the referral in the organization's referral register.
- Give the client a list of other available services with addresses, telephone numbers and hours of operation.
- Ask the client to give feedback on the quality of services to which he or she is referred.

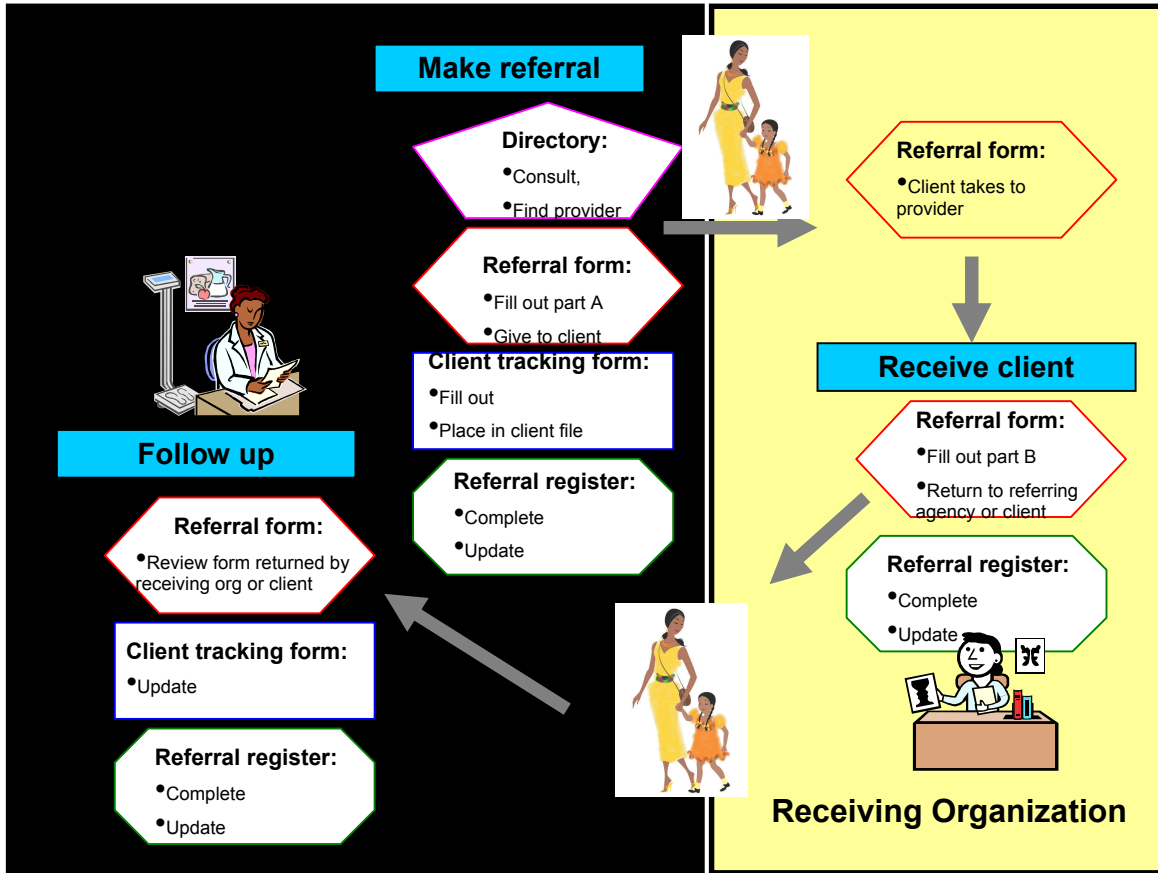
Tools to Facilitate the Referral Process

In the companion document, "Tools for Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings," different forms and tools are discussed, such as a directory of services, referral forms and referral registers. Having such tools standardized and available to organizations in the referral network is critical to maintaining accuracy, efficiency and consistency.

These sample tools can be adapted for different settings. Each tool is accompanied by instructions that describe how the tool is designed to be used. The tools presented include:

- Directory of services (and data collection and update form).
- Referral form.
- Client tracking form.
- Referral register.

Diagram 6: The referral process and corresponding forms



Monitoring and Evaluation of Referral Networks

Referral networks are an integral component of providing truly comprehensive care to PLHA, their families and their caregivers. Monitoring and evaluation (M&E) activities provide essential information for assessing the extent to which the network is achieving its intended objectives and client needs are met. Evaluating the referral networks provides feedback for quality assurance and for informing the planning, design and implementation of future services. Some illustrative indicators for monitoring and evaluating referral networks are as follows:

- Total number of referrals made.
- Number of follow-up referrals made.
- Number of referrals made to which services (i.e., legal, nutrition, spiritual).
- Number or percent of referral services completed.
- Number or percent of clients who report their needs were met.
- Number or percent of clients who report satisfaction with referral process.

The coordinating organization/unit is responsible for conducting quality assurance of the activities performed by the referral network. One proposed strategy to monitor quality of services is a quarterly review of the referral register maintained by each service provider within the network to identify missing information, incomplete service delivery and other service and documentation problems. Findings from the review are discussed with the service providers, and organizations participating in the network meet monthly to share findings and develop solutions to cross-cutting issues.