



Social Networks Testing

*A Community-Based Strategy
for Identifying Persons with
Undiagnosed HIV Infection*

*Interim Guide for HIV Counseling, Testing,
and Referral Programs*



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OVERVIEW

Background

An estimated 40,000 persons in the United States become infected with HIV every year (1). Of the one million persons living with HIV in the United States, approximately 250,000 are not aware of their infection and their risk for transmitting HIV to others. Of those who are unaware, many are diagnosed late in the course of their infection, after a prolonged asymptomatic period during which further transmission may have occurred. Persons who are diagnosed late in their infection miss a valuable opportunity to start HIV care and are at greater risk for AIDS-related complications (than those diagnosed earlier). Therefore, it is a national priority to identify HIV-infected persons and link them to medical, prevention, and other services as soon as possible after they become infected.

CDC currently funds health departments and community-based organizations (CBOs) to conduct HIV counseling, testing, and referral (CTR) in a variety of settings. These publicly funded sites, which perform approximately two million HIV tests yearly, account for approximately 30 percent of positive tests in the US (2). The prevalence of positive tests in these sites is highly variable, but is often very low (less than 1%), suggesting a need for more efficient targeting strategies that will reach persons not being reached with current strategies.

One strategy for reaching and providing HIV CTR to persons with undiagnosed HIV infection is the use of social networks. Enlisting HIV-positive or high-risk HIV-negative persons (i.e., recruiters) to encourage people in their network (i.e., network associates) to be tested for HIV may provide an efficient and effective route to accessing individuals who are infected, or at very high risk for becoming infected, with HIV and linking them to services [originally developed by Jordan and colleagues (3)]. The social network approach has proven to be a viable recruitment strategy for reaching people beyond current partners.

*In CDC's Social Networks Demonstration Program (2003 – 2005), social network strategies were used to identify people who were unaware of their HIV infection in communities of color. Across nine sites funded for the program, approximately 6% of people tested were newly diagnosed with HIV (4). **This prevalence rate is six times higher than the average of most HIV CTR programs, illustrating the great value of using social networks to reach people at risk for HIV infection.***

Introduction to the Social Networks Strategy for HIV CTR

The use of social networks is a recruitment strategy whereby public health services (e.g., HIV CTR) are disseminated through the community by taking advantage of the social networks of persons who are members of the community. The strategy is based on the concept that individuals are linked together to form large social networks, and that infectious diseases often spread through these networks. The social network approach and ethnographic assessment provide a broader understanding of HIV transmission in the community and the role of all members of the network, whether infected or not, in transmission and its prevention.

Although similar in some ways, the social networks strategy is not partner counseling and referral services (PCRS), partner notification, outreach, health education, or risk education—and it is not intended to replace these services. It is a programmatic, peer-driven, recruitment strategy to reach the highest risk persons who may be infected but unaware of their status. This technique is accomplished by enlisting newly and previously diagnosed HIV-positive and high-risk HIV-negative recruiters on an ongoing basis and providing HIV CTR to people in their networks. This type of strategy facilitates expansion and penetration of testing within networks.

Participating as a recruiter in a social networks testing project gives people living with HIV the chance to help protect others in their community. In addition, if people in their networks are infected, it gives them the opportunity to get medical care and treatment. Most people living with HIV understand the importance of getting tested and can be powerful allies in this type of HIV prevention effort.

Below is an illustration of a network diagram (Figure 1). In this figure, an HIV-positive recruiter (large solid black square) was responsible for the ultimate identification of eight different individuals who were diagnosed with HIV and previously unaware of their infection (big and small black solid circles). Six of these eight individuals were directly identified by the recruiter and are considered to be part of the recruiter’s network; the remaining two were identified by a network associate who later decided to enlist as a recruiter himself (bottom right).

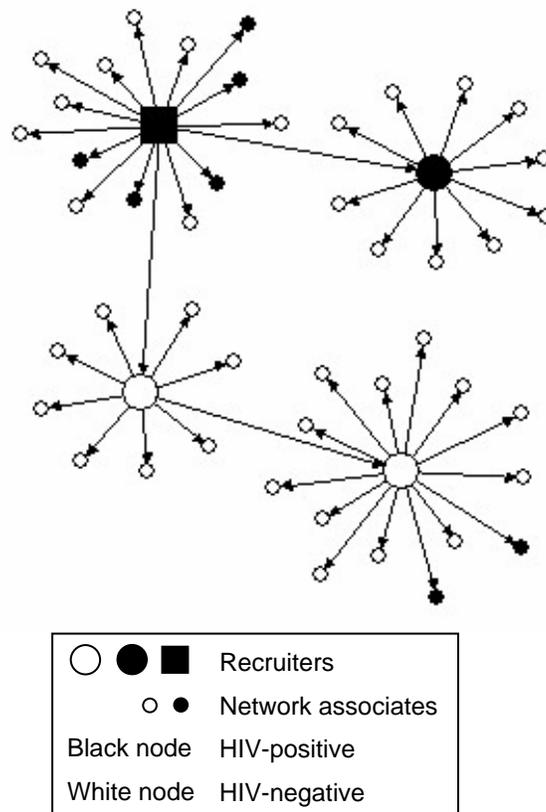


FIGURE 1-Example social network of an HIV-positive recruiter and his network associates

The primary goal of a program using a social network strategy is to identify persons with undiagnosed HIV infection within various networks and link them to medical care and prevention services.

Purpose of this document

This guide is intended to provide an overall description of a social networks strategy to identify persons for HIV CTR and, also, to guide the development of protocols, policies, and procedures for agency's planning to use this strategy. Lessons learned from the field (from sites funded for CDC's Social Networks Demonstration Program) are highlighted throughout this document so that future program managers can learn from past social network experiences.

Thanks

We would like to thank all the staff of the nine CBO sites that took part in the Social Networks Demonstration Program. Because of their hard work, dedication, and valuable input, we are able to disseminate the social networks testing toolkit to CBOs and health departments nationwide. In addition, we would like to acknowledge Wilbert Jordan's seminal research in the area of social networks (3). Without his early work identifying HIV-positive patients in networks, the development of this social networks testing strategy would not have been possible.

—CDC, Division of HIV/AIDS Prevention, Social Networks Team



“Social Networks is all about breaking from the old model of just doing outreach. A main goal of social networking is to prevent HIV. What is put into the community in terms of knowledge and awareness is better than just random testing of people.”

SECTION ONE: PROGRAM PREPARATION AND DESIGN

Part 1: Overview of program phases

There are four major phases to a social networks program. Agencies conducting a social networks testing program to reach persons with undiagnosed HIV infection should model their programs after these phases. These phases are

- Recruiter Enlistment
- Engagement (Orientation, Interview, and Coaching)
- Recruitment of Network Associates
- Counseling, Testing, and Referral (CTR)

Each phase is briefly described below. A flow diagram illustrating all four phases can be found on the next page (Figure 2).

Recruiter Enlistment

In this phase, HIV-positive or HIV-negative high-risk persons from the community who are able and willing to recruit individuals at risk for HIV infection from their social, sexual, or drug-using networks are enlisted into the program. To identify recruiters, agencies approach their HIV-positive clients and identify additional people through the agency's existing counseling and testing, medical, social services, or through HIV prevention programs. On an ongoing basis, program staff will approach and enlist new recruiters who may be able to provide access to additional networks.

Engagement (Orientation, Interview, and Coaching)

After recruiters are enlisted into the program, they are provided with an orientation session that explains the nature of the program and the social network techniques that might be used to approach their associates and discuss HIV testing with them. Next, recruiters are interviewed to elicit information about their network associates. The period of time needed to elicit information from recruiters is typically brief—recruiters may be able to give all of their network information within just a few interviews. Unlike peer outreach workers, recruiters' participation time overall may be relatively short.

Coaching may be required on an ongoing basis throughout the period of the recruiter's participation. Coaching may involve discussion with recruiters on how to approach associates about 1) obtaining HIV CTR, 2) disclosing their own HIV status if they wish to do so, and 3) how to avoid disclosing status if desired.

Recruitment of Network Associates

Next, recruiters will refer individuals for testing who they have identified as being at risk for HIV infection. All individuals should be approached by the recruiter alone, without the provider).

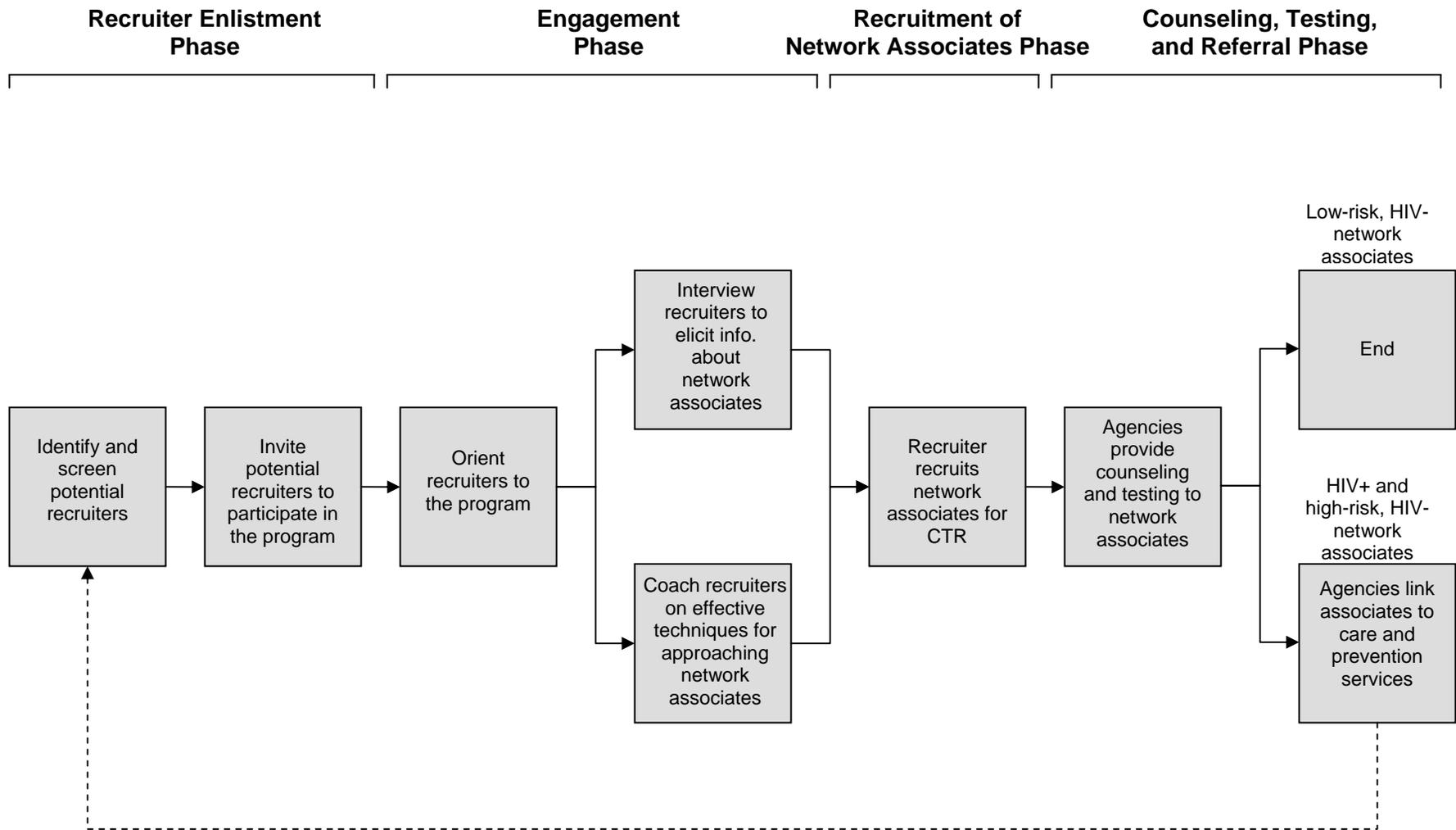


FIGURE 2-Four phases of the Social Networks testing strategy

Counseling, Testing, and Referral (CTR)

The next phase involves providing HIV CTR to the network associates identified through the social networks strategy. Agencies may provide HIV CTR services to network associates in their own facilities (e.g., office, clinic) or they may make services available in areas where network associates live, work, and gather (e.g., testing in a mobile van, a housing program, a park, or cruising area). Agencies should be capable of providing their own CTR services without referring to another agency.

Part 2: Protocol development

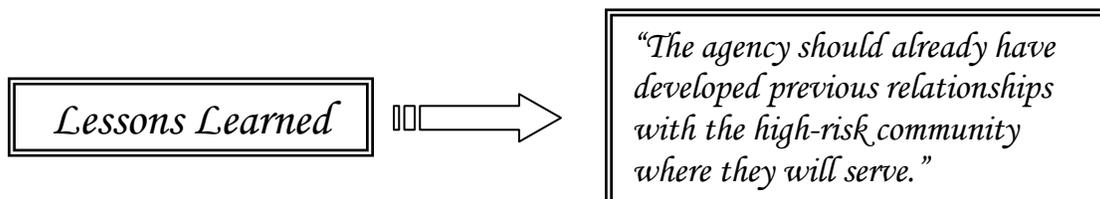
Any agency planning to use the social networks strategy should be able to:

- Define broad goals of the program (e.g., provide HIV CTR to women of color who are at risk for HIV but are not receiving CTR through other strategies)
- Define the target population that the program is trying to reach with CTR (e.g., African American men who have sex with men, ages 18-30, in the Tenderloin district of San Francisco, who have not been tested previously and are not being reached through other CTR strategies)
- Determine significant cultural or social characteristics of the target population
- Develop procedures for planning and initiating the program
- Develop procedures that will be used to enlist recruiters, recruit network associates, provide HIV CTR to network associates, and link network associates to services
- Develop procedures for record keeping and documentation
- Develop procedures for quality assurance
- Develop procedures for obtaining necessary local approvals (e.g., local Health Department regulations)
- Procedures for monitoring and evaluation

Part 3: Planning and initiating the program

Involving the target population

Agencies should involve their target populations (i.e., the population from which recruiters will be enlisted and the population that the program is trying to reach with CTR) in planning, implementing, and evaluating their program. Involvement may be accomplished through various strategies. For example, advisory groups from the target population may be formed to get input on community needs, or information may be gathered through focus groups or interviews.

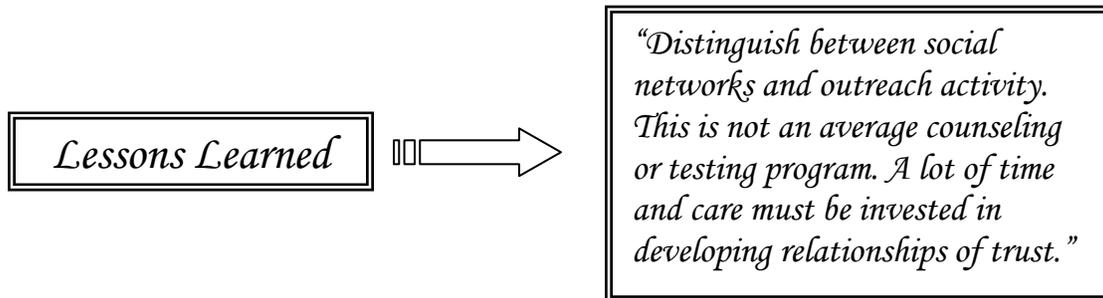


Protocols should clearly describe the procedures planned for obtaining target population input, as well as the type of input that should be sought. The following are examples of input that might be sought:

- Reviewing the draft protocol and suggesting approaches for implementation (e.g., recommendations regarding whether incentives should be used, and if so, what they should be)
- Reviewing progress reports and monitoring and evaluation data and offering suggestions for improving program performance
- Promoting the program within the target population and the community.

Promoting the program

Agencies should develop and implement materials and strategies to publicize and promote the program among their staff and clients. Among staff, it is important to emphasize the importance of this testing strategy on the HIV epidemic. Staff must have a high-level of understanding of the program concepts, and “buy into the project” since they will be enlisting recruiters to participate. Promotions for clients in the community may include displaying posters or distributing written information promoting the program, or making group presentations. An agency may want to create a new name for the program to reflect the community served or the goals of the program.



Any agency planning to use the social networks strategy should clearly describe materials and strategies that will be used to promote the program, including processes by which materials will be developed.

Part 4: Procedures

Core Phases

The social networks strategy includes four core elements or phases: a Recruiter Enlistment phase, an Engagement phase, a Recruitment of Network Associates phase, and a CTR phase.

1. Recruiter Enlistment

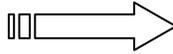
Potential recruiters are identified, screened for eligibility, contacted, and invited to participate in the program.

Note: The term “recruiter” is used exclusively in this manual to refer to individuals who recruit from their networks. However, each agency should use a term that will be accepted by its target population (e.g., peer advocate, health promoter, community advocate), and culturally appropriate.

Any agency planning to use the social networks strategy should:

- Define the population or pool from which potential recruiters will initially be identified. For example, this population might be defined as African American women who are injection drug users and currently enrolled in care services within the agency.

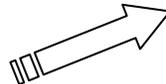
Lessons Learned



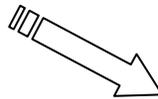
“Beyond identifying specific target groups, consider structuring it based on risks and behaviors. Networks succeeded in identifying positives when they hit on groups that had behavioral connections related to high-risk activities, such as homelessness. IDU. etc.”

- Develop procedures by which potential recruiters will be identified from this population or pool. For example, potential recruiters could be identified by reviewing client records, or by asking case managers or care providers to nominate specific clients.

Lessons Learned



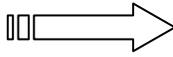
“Know your gatekeeper in the agencies and have continual contact.”



“Go back to being outreach workers and building relationships with providers and remembering those folks with follow-up phone calls. An effective way to identify with recruiters in building relationships with providers is to show how the program is being affected by their work.”

- Develop procedures and criteria (inclusion and exclusion) for screening potential recruiters to determine eligibility for the program. For example, exclusion criteria could include persons who might pose a risk for violence or persons with significant mental illness who might interfere with appropriate participation. These criteria may be modified on the basis of ongoing experience. Input on appropriate criteria should be sought from the program advisory group.
- Develop procedures for identifying additional potential recruiters. HIV-positive and high-risk HIV-negative network associates may be invited to enlist as recruiters.

Lessons Learned



“The high-risk negatives who were prior associates brought in 75% of all the positives, versus the positive recruiters who were prior associates, so I think they have a lot of value in identifying target populations. The high-risk negative people seem to have a larger network than the positives.”

- Develop procedures for contacting potential recruiters (e.g., by telephone, or during a routine visit to the agency).
- Develop procedures for explaining the program to potential recruiters and inviting them to participate. For example, explanations may be given individually or in groups. Explanations should include certain standard information, such as a brief description of the program’s purpose; what participation involves; the role of the recruiter; potential benefits the program might have for recruiters, network associates they recruit for CTR, and the community; and what risks might be involved in participation. Explanations of the program can be provided using a checklist list of key points (e.g., role of recruiters, role of provider, who should be referred for CTR, incentives).
- Develop supporting written or visual materials that will be used to help explain the program to potential recruiters and how these materials will be developed.
- Determine the specific staff members who will perform each of these functions (e.g., HIV counselors, case managers, service providers).

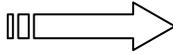
2. Engagement (Orientation, Interview, and Coaching)

Orientation

Persons who accept the invitation to become recruiters will receive a more thorough orientation to the program. Orientation should take place, even when recruiters only participate in the program for a short period of time (which is typical). Due to different circumstances, there may be some variation in how orientation is accomplished. Protocols should clearly describe the following:

- Procedures for how and when new recruiters will be oriented to the program. For example, this may be done individually or in groups.
- The content to be used in the orientations. For example, the content should include an in-depth discussion of the program and its purpose; what constitutes participation; the role of the recruiter; the meaning of the term “network associate;” options for recruiting network associates; and a detailed discussion of potential benefits and risks of the program. The orientation can be conducted using a checklist of key points.

Lessons Learned



“You don’t want to overwhelm the person with information. The initial orientation should be no longer than 30 minutes. But after that, orientation should be ongoing.”

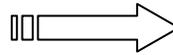
- Supporting written or visual materials that will accompany the orientation and how these materials will be developed.
- Procedures for documenting persons who receive the orientation, understand the program, understand that participation in the program is voluntary, and still elect to participate in the program. Documentation could be accomplished by maintaining a log of persons attending the orientation session or, more formally, by asking each person to sign a consent form indicating her or his desire to participate in the program.
- Specific staff who will conduct the orientation (e.g., HIV counselors, case managers).

Interview

Obtaining network information

Persons who still elect to participate in the program as recruiters after orientation should meet with agency staff for in-depth interviews and discussions about recruiting their network associates for HIV CTR.

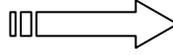
Lessons Learned



“The easier I rolled it out, the better. But when I tried to over-explain about the social networks process, it was too much information.”

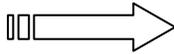
Interviewers should work with the recruiter to elicit names of network associates the recruiter thinks would benefit from HIV CTR (i.e., persons who the recruiter knows and believes may be at high risk for HIV infection). (This program was not designed for anonymous testing since it would be difficult to link recruiters to their network associates without names.) Interviewers may also attempt to elicit information about the nature of the recruiter’s relationship with each network associate (e.g., sex partner, injection drug partner, other social contact). This information would help prioritize which network associates to contact first, as well as allow a better understanding of the dynamics of the network.

Lessons Learned



“Sometimes recruiters would just give first names. But once they saw how we dealt with the first wave of folks, they gave us more information as they became more comfortable.”

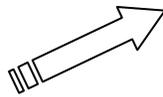
Lessons Learned



“If you’re too client-centered, you don’t get what you need. Ask for what you want; be direct. Don’t beat around the bush to try to get to a question.”

If the recruiter is not comfortable providing names, the interviewer will, at a minimum, ask for the first name, or initials, of the network associates she or he intends to attempt to recruit. Interviewers might also ask recruiters to identify perceived “leaders” in the network, who might themselves be enlisted as recruiters.

Lessons Learned



“There is a big difference between educating people and eliciting information from them. People need interviewing skills. There should be training around motivational interviewing techniques.”



“While it’s good to target populations, we must be fluid in following the networks and going where those trends lead us.”

Developing plans for recruitment

After identifying individual network associates, the interviewer should help the recruiter understand how to recruit these network associates for HIV CTR. The basic strategy for contacting individual network associates is for the recruiter to approach the individual alone, make personal contact with the network associate, and then refer or accompany them to HIV CTR.

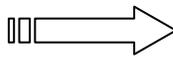
Any agency planning to use the social networks strategy should be able to describe:

- Approaches and strategies that will be offered to recruiters for recruiting network associates.
- The interview format to be used for interviewing recruiters about their network associates.
- How interviewers will work with recruiters to develop plans for attempting to recruit network associates for HIV CTR.
- Supporting written or visual materials that will be used for interviewing.
- Procedures for documenting information obtained during interviews.
- Specific staff who will conduct the interviews (e.g., HIV prevention counselors, case managers).

Coaching

The interviewer should coach the recruiter on how best to approach network associates to recruit for HIV CTR. Coaching should include: 1) personal safety, 2) approaches for raising the topic of HIV CTR with network associates, 3) issues to consider with regard to disclosing their serostatus, 4) approaches for disclosing their own HIV serostatus to network associates, should they choose to do so, 5) approaches to raising the topic of CTR to network associates without revealing their own serostatus, should they prefer not to disclose, 6) how to respond to network associates' questions about HIV transmission risks, available support services, confidentiality protections, or other issues, 7) how to respond to network associates' reactions, including the possibility of an angry or violent response, and 8) how and where each network associate can receive HIV CTR. Coaching should include role-plays.

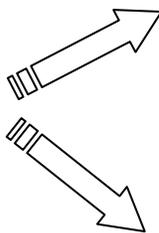
Lessons Learned



“Engage in role playing or show videos of an appropriate coaching session. Having examples of seeing someone do it effectively would be helpful.”

The intent of coaching is for recruiters to get comfortable with recommending HIV CTR to persons they know or are acquainted with well enough to believe they are at high risk for HIV. Recruiters may know or be acquainted with some network associates through shared network venues (e.g., if they hang out in the same locations). However, the emphasis of this activity is on social connections. It is not the intent of this activity for recruiters to approach venues that are not part of their own social networks and conduct “outreach” to persons with whom they have no social connection.

Lessons Learned



“Focus on the importance of being client-centered. Give a sense of ownership so recruiters feel they are a part of something. Look at the volunteer as an expert resource and a guide.”

“Reiterate that this is not a job and we are not their employer.”

Once the recruiter has been satisfactorily coached, he/she should be provided CTR referral cards that can be given to network associates when they are contacted. Referral cards should contain information such as CTR site location and recruiter ID #. Color coded cards may be used to distinguish network associates from other clients (e.g., if the associate loses the card, they may still remember the color of the card, allowing the associate to be linked to the recruiter).

Any agency planning to use the social networks strategy should develop:

- Methods that will be used, including topics to be covered
- Supporting written or visual materials that will be used
- Staff who will perform different tasks in the program (e.g., HIV prevention counselors, case managers)

Follow-up with recruiters

The interviewer should arrange a follow-up plan with the recruiter. Follow-up may be accomplished in person or by telephone. This will allow the interviewer to assess how the recruiter's efforts are progressing. If the recruiter has not been successful in recruiting network associates for testing, the interviewer should work with the recruiter to develop strategies to overcome obstacles to successful recruitment. This will also provide an opportunity to elicit additional network associates.

Lessons Learned →

"In follow-up, it's important to go back to whom they identified previously. Did they encounter the person and he refused? Or was it that the network associate is too caught up in his lifestyle? We had recruiters who were told off by a network associate. It's important to encourage them for the job they did, even if referrals weren't successful."

Any agency planning to use the social networks strategy should clearly describe procedures for following up with recruiters after the interview.

3. Recruitment of Network Associates

After they have been interviewed and a recruitment plan has been developed, recruiters should begin contacting their network associates to recommend HIV CTR. The recruiter will attempt to locate her or his network associates to recommend HIV CTR. The recruiter will then either offer to accompany the associate to testing (CTR agency or mobile van testing site) or provide, to his associates, a CTR referral card that includes information on how to access the program's CTR services.

Follow-up of network associates

Some network associates who are referred to the program's CTR services may not report for CTR. The program may include provisions for coaching recruiters to follow up with any network associates who are referred, but do not report for, CTR.

4. Counseling, Testing, and Referral Phase

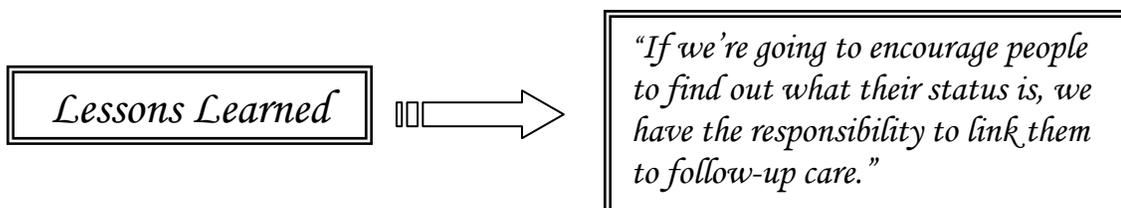
Network associates who accept recommendations for HIV CTR may receive CTR in the field (e.g., in mobile van) or be accompanied by the recruiter or referred to the program CTR site. Agencies should comply with all health department requirements regarding HIV counseling, testing, and referral services.

Newly diagnosed HIV-positive persons, previously diagnosed HIV-positive persons, and persons at high risk for acquiring HIV are useful for referring other high-risk persons from the network. Therefore, providers should consider these individuals as potential recruiters and assess whether they meet the criteria for a recruiter. If criteria are met, providers should invite them to participate in the program. Enlisting such individuals will facilitate additional testing within the network. Newly diagnosed individuals may not initially be interested in serving as a recruiter but, given some time, they may become interested once they have adjusted to their serostatus.

Including high-risk HIV-negative persons as recruiters may make it less likely that other recruiters' serostatus will be assumed, which may lead to a decreased likelihood of stigmatizing. There may be some variation in how CTR should be conducted, depending on local requirements.

Any agency planning to use the social networks strategy should determine:

- Whether CTR will be offered in the field and, if so, how and under what circumstances
- Specific staff that will conduct the CTR
- Whether anonymous testing will be offered and, if so, how and under what circumstances
- Procedures for CTR using routine or rapid testing
- Other services that will be available to clients, either directly from the agency or through referral (e.g., medical evaluation; additional HIV risk reduction interventions; STD screening, diagnosis, and treatment; substance abuse treatment; mental health treatment; and social services)
- Procedures for making referrals, assisting clients with getting to referrals, and confirming that referred clients acted on the referrals and received, or are receiving, services as a result of the referral



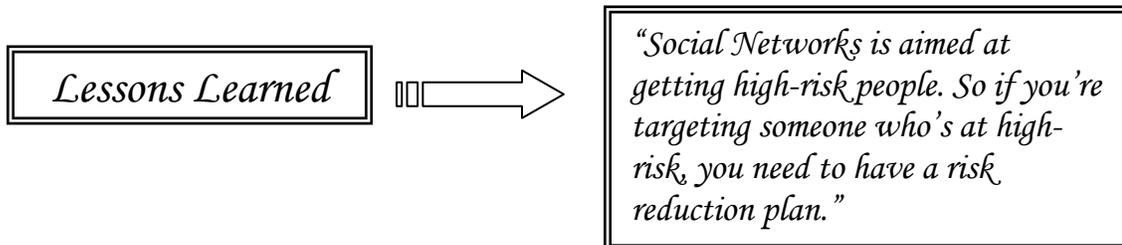
For network associates who test positive, the agency should:

- Provide post-test counseling
- Provide, or refer for, medical evaluation and management
- Assess HIV behavioral risks and provide, or refer for, appropriate HIV risk reduction interventions

- Provide, or refer for, other appropriate services (e.g., STD screening, diagnosis, and treatment; hepatitis screening and vaccination; substance abuse treatment; mental health services; and social services, such as assistance with food, housing, employment, or finances)
- Provide, or refer for, PCRS (following all applicable health department guidelines, protocols, procedures, and performance standards)
- Conduct follow-up with clients to determine if they acted on referrals and received relevant services
- Consider enlisting them as recruiters

For network associates who test negative, the agency should:

- Assess the need for follow-up testing
- Assess HIV behavioral risks and refer for appropriate HIV prevention interventions and follow-up testing
- Refer for other relevant services and access potential candidates to be enlisted as recruiters
- Consider enlisting them as recruiters (if high-risk)

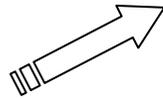


Part 5: Incentives

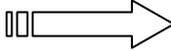
Programs may provide incentives (e.g., certificates of appreciation or certificates of participation in the program, movie passes, transportation passes or tokens, phone cards, meal certificates) to encourage recruiters to refer their network associates for HIV CTR. Cash incentives are not recommended. Use of incentives must always be carefully considered because of the possibility that they may be, or be viewed as, coercive.

Incentives could be provided on a one-time or periodic basis to encourage potential recruiters to participate in the program. An incentive could also be provided to recruiters for every network associate they successfully recruit for HIV CTR. However, the latter approach should be closely monitored because it may lead to recruitment of many “network associates” who are not truly at risk for HIV. Programs may also provide incentives to network associates to encourage them to participate in CTR or to encourage them to return for test results.

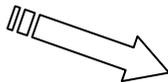
Lessons Learned



“If you offer incentives, have them ready.”



“Be conscious about how you spend your money on incentives. Know your population. Don’t provide phone cards if people don’t use them.”



“The message that we relay is that we’re thanking them for coming back for their results and thanking them for their time. We need to relay the message that we’re not buying anyone.”

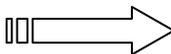
Protocols should indicate whether or not incentives will be used, and if so, what they will be, how they will be obtained, and when and under what conditions they will be provided.

Part 6: Privacy and confidentiality

Ensuring client privacy and confidentiality are standards of care that are critical to the success of this program. Confidential information includes any material that identifies or can readily be associated with the identity of a person and is directly related to his/her HIV status, risk behavior, and/or health care (whether oral or recorded in any form or medium).

Minimum professional standards for any agency handling confidential information should include providing employees with appropriate information regarding confidential guidelines and legal regulations. Agencies should develop and maintain procedures to protect the privacy and confidentiality of all clients, including ensuring the security of all client records.

Lessons Learned



“Filling out documentation in front of people so they can see what you’re doing is important. Also, when you go into a locked filing cabinet, people can see that the information is secure.”

Any agency planning to use the social networks strategy should describe procedures for protecting the privacy and confidentiality of clients and ensuring the security of all client

records. These procedures must comply with the information security requirements in the local area. In addition, procedures should include, but not be limited to, the following:

- All staff with access to confidential information should sign a confidentiality statement acknowledging the legal requirements not to disclose HIV information.
- All services, whether in the office or clinic or in the field should be provided in spaces that maintain the client's privacy.
- Efforts to contact and communicate with clients, network associates, partners, and spouses should be carried out in a manner that preserves the confidentiality and privacy of all involved.
- Client records should be kept in a locked office or file room when not being used to provide services.
- Access to client records should be limited to designated staff in the organization.
- When records are being used outside of the room designated for file storage, they should not be left visible or accessible to unauthorized persons.
- Databases containing electronic client records should be password-protected and should never be left open and visible on unattended computers.
- Computers with access to electronic client records should be kept in locked offices.
- Client information should not be released to other persons, agencies, or organizations without written informed consent from the client (or her or his legally designated representative).
- Policies and procedures regarding release of client information to other persons, agencies, or organizations must comply with all applicable requirements related to the Health Information Portability Privacy Act (HIPAA).

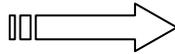
Part 7: Potential risks for recruiters

Recruiters may feel they are being intrusive when approaching network associates about HIV testing. In some instances, recruiters may encounter persons who become angry when asked about HIV. Recruiters may also feel uncomfortable if discussion leads to questions about their own HIV status. Disclosure of serostatus can potentially have adverse consequences for HIV-infected persons (e.g., stigmatization, rejection by others, employment discrimination).

Any agency planning to use the social networks strategy should define anticipated potential risks and procedures for minimizing these risks. Following are some examples of such procedures.

- Orientation and coaching of recruiters should emphasize that they should not approach people with whom they are not comfortable and should terminate any encounters during which they feel uncomfortable or threatened.
- Recruiters should be advised that they do not need to reveal their own HIV status or history in order to discuss HIV risk in a general way.
- At each follow-up encounter, staff should ask recruiters if they have been subject to negative reactions or violence associated with participation in the program. Agencies should have procedures for obtaining expert consultation regarding domestic or partner violence and complying with all applicable reporting requirements.
- Agencies should have procedures for expeditiously addressing potential psychological consequences of learning one is HIV-positive.

Lessons Learned



“Consider ethical issues around relationships between recruiters and associates. Sometimes there is unprotected sex between recruiters and associates. Recruiters need support in dealing with those issues.”

Part 8: Informed consent

Agencies may want to consider obtaining informed consent when enlisting recruiters into their programs. Also, because there may be local requirements related to informed consent for this type of service, agencies should discuss this issue with their respective health departments. If agencies decide to include informed consent for participation in the program, they should ensure that their process is in accordance with all applicable local and state requirements.

In general, forms used for informed consent should be written at no higher than an eighth-grade reading level and should include certain standardized information, such as the following:

- Brief description of the purpose of the program, who is conducting the program, what participation in the program involves, and what their role will be
- Brief description of any reasonably foreseeable risks or discomforts to the participant (i.e., recruiter)
- Brief description of potential benefits the program may have for the participant, those they recruit for CTR (i.e., network associates), and the community
- Statement regarding the extent to which confidentiality of records identifying the participant will be maintained
- Explanation of whom to contact for answers to questions about the program and whom to contact in the event issues arise with recruiting network associates
- Statement that participation in the program is voluntary, that not participating will have no effect on the client receiving other available services, and that the client can decide to discontinue participation at any time without any loss of benefits to which she or he would otherwise be entitled

Informed consent is also required for HIV CTR, although there are options for accomplishing this. Informed consent procedures for HIV CTR should be in accordance with local and state requirements and CDC guidelines. Informed consent procedures and forms should be reviewed and approved by the appropriate health department prior to use.

Protocols should clearly describe procedures for obtaining informed consent for HIV CTR. If the agency plans to ask recruiters for informed consent for participation in the program, the protocol should also clearly describe procedures for doing this.

Part 9: Collaborations

Health departments

Agencies should coordinate program activities with their respective health department HIV/AIDS programs. This includes complying with: 1) all health department requirements regarding HIV counseling, testing, and referral, 2) HIV/AIDS reporting, 3) partner counseling and referral services, 4) and other program activities.

Prior to initiating services, agencies should meet with health department representatives to review their implementation plans and policies and procedures to ensure they meet all relevant requirements. Examples of other topics that agencies might address with their respective health departments include training, coaching, or mentoring that might be available to program staff through the health department.

Agreements for collaboration between the agency and the health department should be documented by memoranda of agreement.

Other collaborators

Agencies may plan to provide some services in their program (e.g., evaluation) through subcontractors or other collaborators. Such arrangements should be formalized and documented by written contracts or memoranda of agreement, which should clearly delineate the parties' respective roles and responsibilities.

Any agency planning to use the social networks strategy should clearly define all formal collaborations including, at a minimum, the following:

- Name of the collaborating person, organization, or agency
- Services to be provided by the collaborating person, organization, or agency
- Respective roles and responsibilities of all parties involved in the collaboration
- Copies of all subcontracts and memoranda of agreement

SECTION TWO: RECORD KEEPING AND DOCUMENTATION

Agencies planning to use the social networks testing strategy should develop systems and procedures for maintaining appropriate records and documentation for this program. Examples include, but are not limited to, the following:

- Program descriptions (including flow diagrams), and any modifications
- Protocols, policies, and procedures, and any modifications
- Records for each recruiter, including demographic data and interview information
- Records for each network associate, including demographic data and outcome information (e.g., whether reached and tested, whether test results received, whether referrals completed)
- Site forms, and any modifications, including reasons.
- Local approvals (e.g., program review panel)
- Progress reports
- Technical assistance and training assessments and plans
- Subcontracts and memoranda of agreement
- Training curricula used

SECTION THREE: QUALITY ASSURANCE

Part 1: Policies, operational procedures, and protocols

Agencies planning to use the social networks testing strategy should develop and implement quality assurance, training, and technical assistance procedures. Agencies should develop and maintain written policies, operational procedures and protocols for all activities performed in their social networks programs including the following:

- Ensuring accessibility of services
- Ensuring appropriateness and acceptability of services to client needs
- Ensuring appropriateness of services and materials to clients' culture, language, sex, sexual orientation, and age
- Ensuring staff adherence to program guidelines and performance standards
- Providing all program services including
 - Orienting, interviewing, and coaching recruiters
 - Supporting and following-up on recruiters
 - Locating and contacting network associates and recruiting them for HIV CTR
 - Conducting HIV prevention (risk reduction) counseling
 - Conducting HIV testing, including obtaining informed consent for testing
 - Assessing client needs and successfully referring clients for appropriate services
- Ensuring staff adherence to written protocols for provision of service to individual clients
- Ensuring staff performance and proficiency
- Supervising staff
- Ensuring safety in the field
- Using appropriate recordkeeping procedures
- Protecting client privacy and confidentiality
- Providing data management, including data collection and entry, transmission, analysis, and security
- Conducting HIV counseling, testing, and referral, including collection, handling, and storage of specimens and ensuring laboratory safety
- Assessing staff training needs and providing training
- Assessing program technical assistance needs and acquiring technical assistance
- Monitoring and evaluating the program
- Collaborating with health departments and other relevant agencies and organizations

Policies and procedures should be kept up-to-date and easily accessible to program staff. Program staff should be trained and periodically re-trained on all policies and procedures relevant to their work.

Part 2: Regulatory compliance

Agencies should ensure and document that their activities are in compliance with all applicable federal, state, and local laws and regulations. For example, if you are planning to use rapid HIV testing, then you should 1) obtain a Certificate of Waiver under the Clinical Laboratory Improvement Amendment (CLIA), or 2) establish a relationship with a laboratory to operate

under the laboratory’s CLIA certificate. Also necessary is evidence of compliance with CLIA requirements and relevant state and local regulations applicable to waived HIV testing in the settings proposed for the program.

Agencies should ensure that all staff are appropriately credentialed for the functions they will be performing (e.g., state credentialing for HIV CTR, if required). Protocols should describe how agencies will ensure and document that their activities are in compliance with applicable laws and regulations and that all staff are appropriately credentialed.

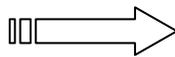
Agencies should be aware of, and comply with, any state or local requirements related to the Health Information Portability Privacy Act. Protocols should clearly describe such requirements and how they will be addressed.

Part 3: Training

With regard to staff training, agencies should:

- Develop and implement plans to ensure all staff are fully oriented to the program’s purpose and goals
- Train staff in all policies, procedures, and protocols relevant to them

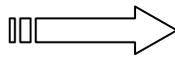
Lessons Learned



“Provide a guidance tool for coaching individuals and motivational tools that people can go to when they need personal motivation for themselves or for staff. Staff training should not just focus on how to do the program, but on how to do it with belief and motivation.”

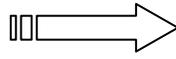
- Conduct initial assessment of individual and collective staff training needs (e.g., interviewing, outreach, CTR, rapid testing) and develop and implement plans for providing or obtaining appropriate training
- Conduct periodic reassessment of training needs
- Develop cross-training where possible such that recruiter and network associate needs can be met by a variety of staff members

Lessons Learned



“Having dedicated staff members is an excellent idea but the danger is that many CBOs have a high turnover rate, so when a “dedicated” person leaves, the network falls off. Cross-train when possible, and find backup or support in the event of turnover, which can be crippling to a social network.”

Lessons Learned



“Even with cross-training, titles can be complicated and create barriers. For instance, a recruiter came in but the worker wasn’t there, resulting in a missed opportunity because it was considered someone else’s role.”

- Review training plans with health department to ensure that training is in accordance with state and local requirements
- Determine how training needs will be assessed
- Determine how training plans will be developed
- Determine how training will be provided or obtained (e.g., local/state health department).

Part 4: Technical assistance

Any agency planning to use the social networks strategy should:

- Conduct initial assessment of technical assistance needed to support program activities and develop and implement plans for obtaining appropriate assistance
- Conduct periodic reassessment of technical assistance needs and develop and implement appropriate technical assistance plans
- Review technical assistance plans with health department to ensure adherence to state and local requirements

Protocols should describe how technical assistance needs will be assessed, technical assistance plans developed, and technical assistance obtained (e.g., local/state health department).

SECTION FOUR: MONITORING AND EVALUATION

Part 1: General approach to program monitoring and evaluation

Agencies should develop and implement plans to monitor and evaluate implementation of the program and to determine if objectives are being met and if services are effective. Agencies should support adequate experienced staff (or consultants) for conducting program monitoring and evaluation, including data collection, management, analysis, interpretation, application, and reporting.

Agencies should use monitoring and evaluation data on an ongoing basis to adjust program activities for maximum effectiveness. Agencies should also collaborate with other contractors in data analysis and dissemination of program findings.

The monitoring and evaluation plans should be based on logic models and flow diagrams describing the program. Logic models and flow diagrams should be used to identify quantitative and qualitative questions that need to be addressed through monitoring and evaluation.

Part 2: Program monitoring

Monitoring refers to the simple description, counting, and tracking of processes or events, without in-depth analysis or comparisons. Monitoring will answer the questions *What? Where? When? and How much or how many?* but not *Is it effective?* or *Why is it effective?* Thus, monitoring will be important for assessing if something is being done and if it is being done as intended, if it is being done where and when intended, and if it is being done as much as intended. In particular, monitoring will be useful for assessing adherence to and changes in policies, procedures, and protocols and progress toward achieving objectives. Domains that should be addressed by monitoring include 1) program implementation and management, 2) processes, 3) program performance, 4) achievement of goals and objectives, and 5) resource requirements (i.e., staffing and cost).

Monitoring program implementation and management

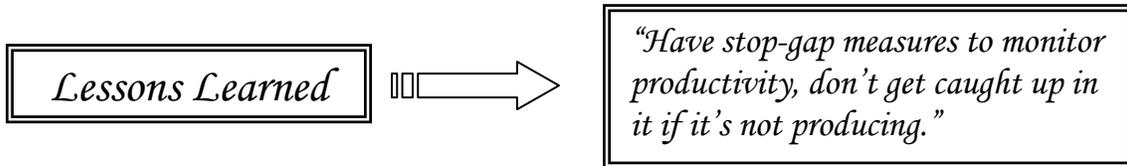
Monitoring implementation and management of the program (e.g., hiring staff, purchasing equipment, developing policies and procedures) will ensure that critical operational issues are being addressed and that program implementation is on schedule, and will provide a better understanding of what is needed to develop a social networks program.

Protocols should include plans for implementing the program, as well as implementing objectives (e.g., “By [date], all program staff will be hired and in place.”) and time lines.

Monitoring processes

The program monitoring plan should identify key processes and describe how the agency initially plans to accomplish them. The plan also should include barriers encountered, how the barriers were addressed, and lessons learned (e.g., What was their initial plan for enlisting recruiters to participate in the program? Were there any problems or barriers? Were the methods

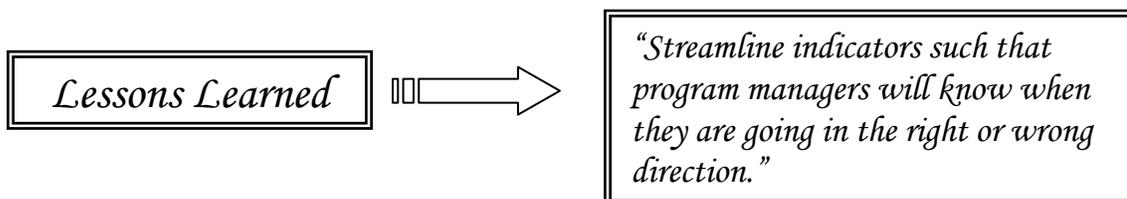
for enlisting recruiters changed to address problems or barriers? If so, in what way were they changed?). Monitoring will be done using qualitative data, which may come from the contractor's original site protocols, interviews with staff, debriefing notes of outreach and program coordinator staff, weekly reports of activities incorporated in quarterly reports, and interviews with staff.



Monitoring program performance

The program monitoring plan should quantitatively measure the performance of each key step or procedure, including, at a minimum, the following:

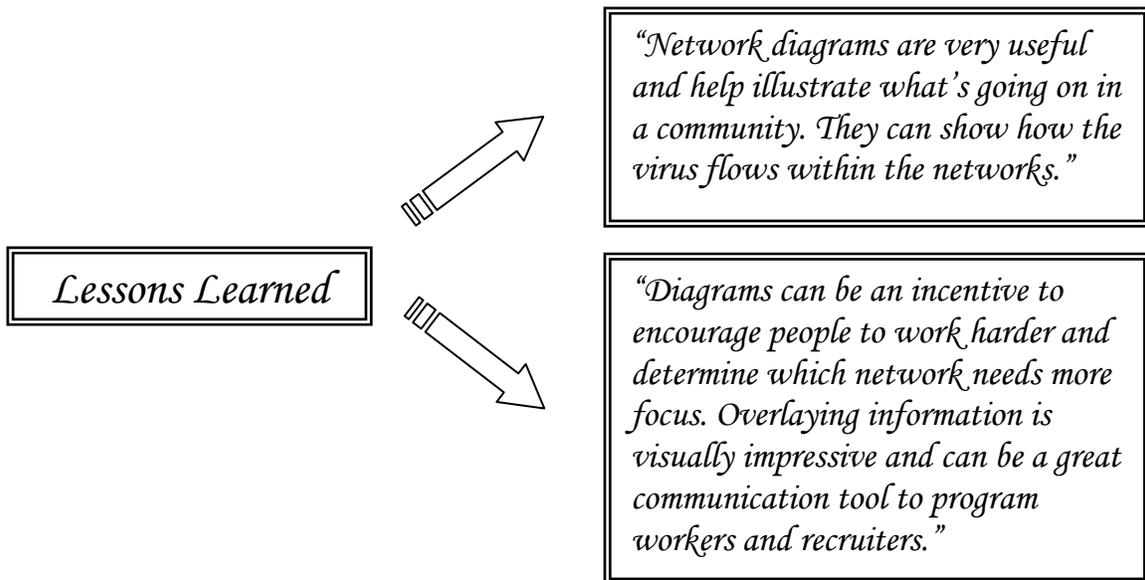
- Number of HIV-infected persons invited to serve as a recruiter
- Number of HIV-infected persons who agree to serve as a recruiter
- Demographics of recruiters
- Number of network associates identified by each recruiter
- Number of network associates located and offered CTR services
- Demographics of located network associates
- HIV risk characteristics and HIV testing histories of network associates
- Number of network associates who receive CTR services
- Number of network associates who test HIV-positive and were previously undiagnosed
- Number of network associates who test HIV-positive and were previously diagnosed
- Number of network associates testing positive who receive test results
- Number of network associates who test negative
- Number of network associates testing negative who receive test results
- Number of network associates testing positive who are successfully referred for medical evaluation, treatment, and prevention services
- Number of high-risk network associates testing negative who are successfully referred for prevention services



A useful way to illustrate the networks being targeted by your program, and to monitor program success, is to periodically create a network diagram that visually represents all the individuals who have been identified and/or tested to date. Network diagrams can help program managers determine which networks are more productive than others (i.e., which networks lead to a greater number of undiagnosed HIV-positive individuals but require fewer people be tested). These diagrams are also useful tools to show outreach workers and other staff in the field how well the

testing strategy is working within various networks. On the next page is an example of a network diagram for a site that enlisted 15 recruiters in its program (Figure 3). Which networks are worth pursuing in the future (e.g., network of recruiter #2-1) and which networks may not be worth continued efforts (e.g., network of recruiter #2-277) can quickly be seen.

Network diagrams also help identify *indirect network associates* (people who want to get tested because they learned of the program through a network associate). Indirect network associates may also be invited to be recruiters if they meet eligibility criteria.



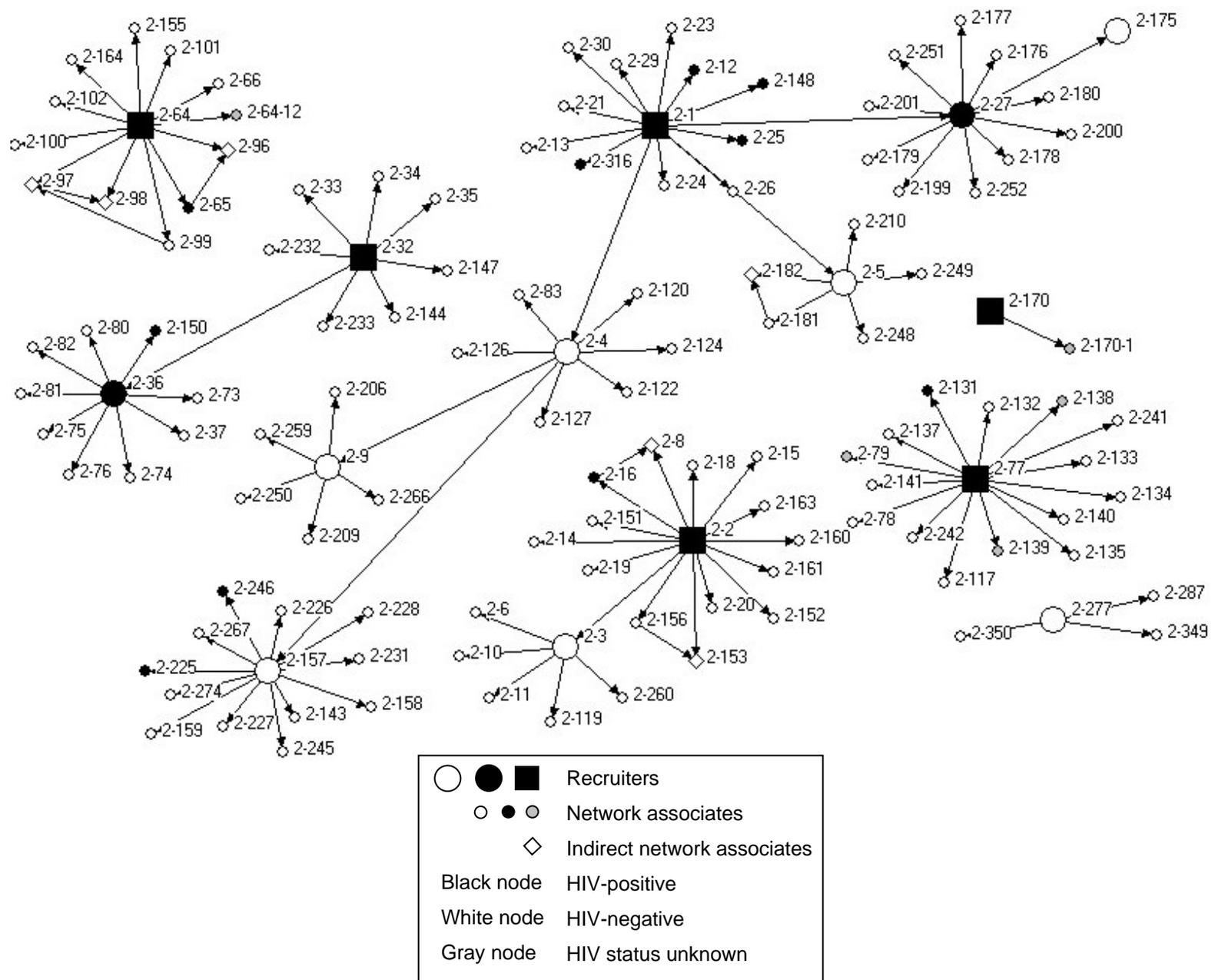


FIGURE 3-Example network diagram for a site (15 total recruiters)

Monitoring achievement of goals and objectives

Monitoring the achievement of program goals and objectives is critical for knowing which elements of the program need to be modified or improved. Agency goals and process and outcome objectives should serve as the framework if progress reports are submitted to stakeholders.

1. Goals

The program monitoring and evaluation plans should include the agency's broad goals for its program (e.g., *Increase the number of HIV-infected African American men who have sex with men, 18-30 years of age, in the Tenderloin district of San Francisco, who are aware of their infection*).

2. Process objectives

The monitoring and evaluation plans should include process objectives for the program (e.g., *By [date], [number] recruiters will have been enlisted to participate in the program*). These process objectives should be based on the key steps or procedures identified in the implementation plan.

3. Outcome objectives

The primary outcomes for this program should be: a) HIV-positive persons not previously aware of their infection will be identified and linked to medical, prevention, and other services; and b) HIV-negative persons at high risk for becoming infected with HIV will be identified and linked to prevention and other services.

Monitoring and evaluation plans should include at a minimum the following outcome objectives:

- Number and percentage of persons tested who were HIV-positive and previously unaware of their infection
- Number and percentage of newly identified HIV-positive persons who were successfully linked to appropriate services
- Number of high-risk HIV-negative persons who were identified
- Number and percentage of high-risk HIV-negative persons identified who were successfully linked to appropriate services

Monitoring resource requirements (costs and personnel)

Agencies should track and document costs and staffing requirements (e.g., number of personnel, skills and expertise) needed to implement their program. This will provide information about resource requirements to other organizations interested in implementing similar programs.

Progress reports

Progress reports should include both quantitative data and qualitative information regarding implementation of the program and lessons learned, such as facilitators and barriers to the program and how barriers were addressed. Progress report procedures will include the following:

- Progress report format, to be structured around the stated goals and implementation, process, and outcome objectives
- Standard format data reports for assessing program performance

Part 3: Program evaluation

“Evaluation” refers to in-depth analysis and comparisons to answer questions such as *Is it effective? Why is it effective?* or *Is one approach more effective than another?* Evaluation is important for determining how to make something work better. Evaluation should involve use of multiple data types (e.g., quantitative, qualitative, cost), and will use multiple analytic methods.

The following are examples of possible analytic methods that could be used for evaluation:

- Plot program outcomes against program changes or key events (e.g., staff changes, procedural changes, training event, technical assistance received, HIV counseling and testing promotional campaign in area)
- Analyze the network quantitatively, or map the network graphically, to identify possible recruiters or gaps in networks being reached and determine which networks were the most productive
- Evaluate cost-utility or cost-effectiveness

Part 4: Data management

Data collection and entry

Data should be collected by staff from a variety of sources (e.g., client record reviews, recruiter interviews, network associate interviews, HIV CTR sessions, and program staff interviews) using logs, data collection forms, and other methods. Some data should be collected in an aggregate format, and other data will be collected at the individual level, depending on the intended purpose.

Data may be collected on paper forms, and then entered into databases, or may be entered directly into databases using desktop or handheld computers. In some instances, data may be collected using audio-computer assisted self interview (A-CASI). Validity checks will be incorporated into data entry processes, and procedures for data cleaning will be developed, to optimize data quality. Data collection and entry systems will be designed to use alpha-numeric identification schemes that will protect the confidentiality of clients, but also allow files to be updated.

Data security

Agencies should develop and maintain procedures to protect all client-related data collected for monitoring and evaluation purposes. These procedures must comply with the information security requirements included in the contract solicitation. In addition, the procedures should include the following:

- Data collected should be limited to that necessary for program monitoring and evaluation.
- Personal identifiers should be included with such data only as necessary for program operations, monitoring, and evaluation. Alpha-numeric identification schemes should be used whenever possible. Personal identifiers should be removed from data prior to transmission.
- Hardcopy data should be kept in locked file cabinets in locked offices.
- Electronic data should be password-protected. Computers containing, or with access to, such data will be kept in locked offices and will be accessible only to authorized program staff.
- Data should be recorded and reported in accordance with existing guidelines and regulations.

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