

# HIV Partner Counseling and Referral Services

## *Guidance*

December 30, 1998



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service • Centers for Disease Control and Prevention •  
National Center for HIV, STD, and TB Prevention • Divisions of HIV/AIDS Prevention



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# Preface

This guidance is intended to assist state and local health department HIV prevention cooperative agreement grantees and HIV prevention community planning groups in planning, implementing, and evaluating the services provided to persons living with HIV and their sex and needle-sharing partners. External consultants and CDC staff collaborated in the development of this guidance, which is intended to supplement current CDC cooperative agreement guidance for HIV prevention programs. The development process included input based on reviews of the relevant scientific literature, actual program experience, and expert recommendations from within and outside CDC.

This guidance uses new terminology to label the process of reaching and serving sex and needle-sharing partners. As opposed to *contact tracing* and *partner notification*, the term *partner counseling and referral services* (PCRS) is used in this document because it better reflects the type and range of public health services that are recommended for sex and needle-sharing partners. These services are vital to any community's HIV prevention efforts. This guidance should assist in developing programs, planning services, or prioritizing resource allocation for PCRS, and state and local programs supported with CDC funds should adapt it to meet their local policies, needs, and circumstances.

The principles listed on the following pages constitute the basis for PCRS and are applied to issues discussed throughout this document. Principles 1–11 apply to partner counseling and referral services associated with partner services for all sexually transmitted diseases, including HIV. Principles 12–13 apply to partner counseling and referral services associated with HIV in particular.

The reader can refer to Appendix B, “Glossary of Terms Associated with PCRS,” for clarification on how some terms are used in this document. For example, the term ***PCRS provider*** is used to refer to any qualified health care personnel, including physicians, nurses, counselors, or disease intervention specialists, who might be involved in serving HIV-infected clients, their partners, and affected communities. Guidance in this document assumes and strongly recommends that PCRS providers be specifically trained in delivering these services.

For technical assistance or inquiries, PCRS providers should contact their state health department. State health departments should contact their CDC project officers.

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## ***Principles Associated with Providing PCRS for All Sexually Transmitted Diseases, Including HIV***

1. **Voluntary.** PCRS is voluntary on the part of the infected person and his or her partners.
2. **Confidential.** Every part of PCRS is confidential.
3. **Science-Based.** PCRS activities are science-based and require knowledge, skill, and training.
4. **Culturally Appropriate.** PCRS is to be delivered in a nonjudgmental, culturally appropriate, and sensitive manner.
5. **A Component of a Comprehensive Prevention System.** PCRS is one of a number of public health strategies to control and prevent the spread of HIV and STDs. Other strategies include access to clinical services, outreach to and targeted screenings of at-risk populations, behavioral interventions, and educational programs.
6. **Diverse Referral Approaches.** PCRS may be delivered through two basic approaches: provider referral, whereby the PCRS provider locates and informs sex or needle-sharing partners of their exposure, and client referral, whereby the infected person takes responsibility for informing his or her partners. Sometimes a combination of these approaches is used.
7. **Support Services and Referral.** PCRS is delivered in a continuum of care that includes the capacity to refer sex and needle-sharing partners to HIV counseling, testing, and treatment, as well as other services, e.g., STD treatment, family planning, violence prevention, drug treatment, social support, housing.
8. **Analysis and Use of PCRS Data.** PCRS program managers should collect data on services provided and use the data for evaluating and improving program efficiency, effectiveness, and quality.
9. **Counseling and Support for Those Who Choose To Notify Their Own Partners.** Counseling and support for those who choose to notify their own partners is an essential element of PCRS. Such efforts can assist in ultimately reaching more partners and minimizing unintended consequences of notification. Assistance to clients in deciding if, how, to whom, where, and when to disclose their infection can help them avoid stigmatization, discrimination, and other potential negative effects. Working with a client to think through what it means to notify a partner and creating a specific plan to ensure he or she successfully accomplishes the notification is a vital role of the provider.
10. **Client-Centered Counseling.** Providing client-centered counseling for HIV-infected individuals and their partners can reduce behavioral risks for acquiring or transmitting HIV infection. In addition, client-centered counseling will help the provider understand the readiness of the client to notify partners. This will allow the provider to offer services to assist the client in successfully notifying partners without adverse consequence.
11. **Increased Importance as New Technologies Emerge.** As new technologies emerge, such as rapid diagnostic tests, vaccines, behavioral interventions, and even more effective therapies, PCRS will become an increasingly important prevention tool.

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***Principles Associated with Providing PCRS,  
Particularly for HIV***

**12. Ongoing Access to PCRS for HIV-Infected Individuals and Partners.**

PCRS should not be a one-time service. It should be offered as soon as an HIV-infected individual learns his or her serostatus and made available throughout that person's counseling and treatment. If new partners are exposed in the future, PCRS should be made available again. HIV-infected individuals should have the ability to access PCRS whenever needed.

**13. Assistance in Accessing Medical Evaluation and Treatment To Prolong Life.**

Sex and needle-sharing partners might already be HIV-infected but be unaware of or deny their risks. They can be assisted through PCRS in learning their status, and in obtaining earlier medical evaluation and treatment for HIV disease and opportunistic infections. PCRS provides an opportunity for HIV primary prevention interventions for those partners not infected with HIV and an opportunity for secondary prevention for those partners living with HIV.

## ***How To Use This Document***

The standards and guidance in this document describe the core elements that are essential for successful PCRS programs at publicly funded sites. Even though HIV and STD programs share many common goals, policies, and activities, PCRS is designed specifically for HIV prevention programs. It is not intended to replace or modify CDC guidance for partner notification for other STDs.

The two levels of recommendations in this document are **Standards** and **Guidance**:

**Standards.** Specific standards are provided in several sections and are intended to be applied consistently. **Standards must be followed by CDC grantees in virtually all cases where CDC funds are used to support services.** To assist the reader, each standard is set apart from the other text in

***reverse type on a black background.***

In addition, Appendix A is a concise listing of all the PCRS standards in the order discussed in the main part of the document.

**Guidance.** The main text of this document provides overall guidance for PCRS programs. **This guidance *should* be followed in most cases, but can be tailored to fit the individuals and affected communities being served as well as the program needs.** Providers are urged to follow this guidance but have flexibility to modify or adapt based on state or local needs, policies, or circumstances.

Other organizations providing PCRS or other HIV prevention service providers might also find this document a useful guide. CDC recommends that the guidance be shared with providers and consumers of services in local areas. Managers of PCRS programs are urged to work closely with STD prevention, violence prevention, drug treatment, reproductive health, and other state agencies in planning, implementing, and evaluating their program and services.

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## 1.0 PARTNER COUNSELING AND REFERRAL SERVICES FOR HIV PREVENTION

### AN OVERVIEW

#### 1.1. *How HIV PCRS Has Evolved*

Once known as “contact tracing,” outreach activities for finding, diagnosing, and treating partners of persons infected with sexually transmitted diseases (STDs) have long been used by public health workers as a prevention activity. In the 1930s, U.S. Surgeon General Thomas Parran advocated the use of contact tracing to help “prevent new chains of [syphilis] infection” (Parran, 1937). Contact tracing was later expanded to include partners of persons infected with gonorrhea and other STDs, including the human immunodeficiency virus (HIV), and came to be known in the 1980s as “partner notification” (West and Stark, 1997).

In the 1980s, when public health workers were first being confronted with the rapid spread of HIV, the virus that causes acquired immunodeficiency syndrome (AIDS), informing persons of their possible exposure to HIV and offering counseling, testing, and referral services were already recognized as an important disease prevention effort that could help stem the tide of HIV infection. As HIV prevention activities have evolved, so has the terminology for informing the HIV-infected person’s sex and needle-sharing partners of their possible exposure to the virus. Today, the term *HIV partner counseling and referral services (PCRS)* more accurately reflects the range of services available to HIV-infected persons, their partners, and affected communities through this public health activity.

Of necessity, PCRS for HIV differs from partner services for other STDs because the “epidemiological, biological, and clinical characteristics of HIV are different” (West and

Stark, 1997). Despite recent advances in treatment, we do not yet have a cure for AIDS, so HIV remains a lifelong issue for those infected. Furthermore, because society frequently stigmatizes and sometimes discriminates against HIV-infected persons and their families and friends, the affected communities may be concerned about the potential negative impact of PCRS. HIV prevention programs need affected communities to be involved in and understand PCRS for the overall prevention efforts to be accepted and effective.

Federal and state legislative mandates in the 1990s have underscored the importance of notifying sex and needle-sharing partners of their possible exposure to HIV. Recent examples include the federal requirement to notify spouses of HIV-infected persons (Public Law 104-146, Section 8[a] of the Ryan White CARE Reauthorization Act of 1996) and state legislation to require health departments to offer HIV partner notification services to newly reported HIV-infected persons (National Council of State Legislators, 1998). Legal and ethical concepts such as the rights of individuals to know their risk of infection, to learn their HIV status anonymously or confidentially, and to be protected against discrimination if HIV-infected, will continue to drive public health policies and legislative action on HIV PCRS (West and Stark, 1997). Public health policies and legislative actions related to the above concepts will determine, at least in part, how PCRS is conducted.

#### 1.2 *What Are the Goals of PCRS?*

PCRS is a prevention activity with the following goals:

1. Providing services to HIV-infected persons and their sex and needle-sharing partners so they can avoid infection or, if already infected, can prevent transmission to others.
2. Helping partners gain earlier access to individualized counseling, HIV testing,



medical evaluation, treatment, and other prevention services.

Through PCRS, persons – many of whom are unsuspecting of their risk – are informed of their exposure or possible exposure to HIV. Notified partners can choose whether to be tested, and if not tested or if found to be uninfected, can receive counseling about practicing safer behaviors to avoid future exposure to HIV. If, however, they are found to be infected, they can seek early medical treatment and practice behaviors that help prevent transmission of HIV to others and reduce the risk of becoming infected with other STDs.

PCRS can be instrumental in identifying sexual and drug-injecting networks at high risk for transmission of HIV or other sexually transmitted diseases (Fenton and Peterman, 1997; West and Stark, 1997). These networks are made up of individuals who share social relationships involving sex or drug use. Such networks can be identified and described at least partly through information obtained by PCRS activities (West and Stark, 1997). Future prevention interventions can then be more effectively directed, and the HIV risks within the network(s) potentially reduced. Network research, combined with new methods of virus typing and identification of recently infected persons (Janssen, *et al.*, 1998), will contribute to a greater understanding of HIV transmission (Fenton and Peterman, 1997).

### **1.3 Is PCRS Cost-effective?**

Some have raised concerns about the high potential cost of PCRS and have questioned on these grounds whether or not it should be supported. In fact, although the relative investment per person reached might be greater than other public health activities, PCRS is likely to be highly cost-effective. A simple threshold analysis illustrates the probable cost-effectiveness of PCRS to society.

Assuming an estimated current \$154,402 lifetime cost in the United States of a person acquiring HIV infection and eventually dying from HIV-related illness (Holtgrave and Pinkerton, 1997) and a conservatively estimated average \$3,205 cost of PCRS to reach one infected person (Toomey *et al.*, 1998), PCRS must prevent 1 infection out of every 51 HIV-infected partners reached through PCRS to be cost-effective. As PCRS links HIV-infected partners to client-centered counseling and other interventions proven or likely to be effective, this appears to be a threshold relatively easy to achieve by programs. Greater effectiveness, such as preventing only 2–3 infections for every 51 HIV-infected partners reached through PCRS, would convey substantial cost savings to society.

### **1.4 Who Benefits from PCRS?**

Clearly, three distinct beneficiaries of PCRS are (1) persons with HIV infection; (2) their spouses and other sex and/or needle-sharing partners; and (3) affected communities (Fenton and Peterman, 1997). Through a client-centered approach, HIV-infected persons can receive counseling about their risk behavior and be offered a range of choices and support in informing their partners of the possibilities of exposure to HIV (CDC, 1994). Studies have shown that a client-centered counseling approach can result in behavior change, thereby decreasing the likelihood of HIV transmission to others (Kamb *et al.*, 1998 and Fenton and Peterman, 1997). HIV-infected persons can also benefit from referrals to other social and medical services, such as couples counseling, prevention case management, and antiretroviral therapy.

For the partners of HIV-infected persons, one basic benefit comes from being informed that they are at risk. This will be particularly helpful information for those who do not even suspect that they might have been exposed. Once informed, the partner can decide to access available HIV prevention counseling

and testing services. If not infected with HIV, partners can be assisted in changing their risk behavior, thus reducing the likelihood of acquiring the virus. Or, if already HIV-infected, the partner's prognosis can be improved through earlier diagnosis and treatment.

The role of PCRS, earlier diagnosis, and prevention and treatment services might have prevention benefits at the community level in reducing future rates of HIV transmission.

Evidence is accumulating that antiretroviral therapy reduces the amount of HIV in genital secretions and fluids and thus might reduce the infectivity of HIV (Gupta P, *et al.*, 1997; Vernazza PL, *et al.*, 1997; Vernazza PL, *et al.*, 1997; Musicco M, *et al.*, 1994). However, concern may be well justified that some might misinterpret antiretroviral therapy as a cure for HIV and thus be less concerned about adopting safe behaviors or exposing others (Kalichman SC, *et al.*, 1998; Kelly JA, *et al.*, 1998; Remien RH, *et al.*, 1998; Remien RH, *et al.*, 1998). Efforts to link HIV-infected persons to treatment must also continue to emphasize safe behavior during the course of treatment. Effective PCRS also can improve disease surveillance, identify social sexual networks at high risk that can then be targeted for prevention (Fenton and Peterman, 1997), and potentially assist a comprehensive program in lowering the transmission rate of HIV. In addition, PCRS can benefit service providers in the community by increasing their access to individuals in need of their services, especially people who would not come to them on their own.

### **1.5 What Activities Are Involved in PCRS?**

PCRS should be introduced at the point an individual seeks HIV prevention counseling and testing. A brief overview of the activities associated with PCRS is included in this section, but more detailed discussions are provided throughout the remainder of this document.

- ◆ **Person Seeks HIV Prevention Counseling and Testing.** PCRS begins when persons seek, either through private care providers or publicly funded programs, HIV prevention counseling and testing. As they enter services, they should be assisted first, ideally through client-centered counseling techniques, in –

1. assessing their risks of acquiring or transmitting HIV, and
2. negotiating a realistic and incremental plan for reducing risk.

During the initial counseling and testing session, the provider should also explain (1) how HIV testing will be conducted if the client does choose to be tested, and (2) all the available options for PCRS. The provider must assist clients in understanding their responsibility, if their HIV test results are positive, for ensuring that their partners are informed of their possible exposure, and referring those partners to HIV prevention counseling, testing, and other support services (CDC, 1994).

- ◆ **Client Tests Positive and Chooses To Participate in PCRS.** Once a client's test results are confirmed positive, that person should be provided the earliest appropriate opportunity to receive partner counseling and referral services. Reactions to learning one is infected with HIV vary, and personal circumstances differ among individuals. PCRS providers need to recognize and accommodate those clients who need other issues resolved before being ready to participate in PCRS. This might mean, for some individuals, scheduling a follow-up appointment to discuss PCRS issues more thoroughly.
- ◆ **PCRS Provider and Client Together Formulate a Plan and Set Priorities.** The PCRS provider (who might not be the counseling and testing provider) counsels the client on if, how, and when

specific partners should be informed of their risk of exposure. The provider should present partner referral options (Section 3.2). Then, the client and PCRS provider together can develop a plan for reaching partners that uses one or more of the referral options. The plan should be one that will result in each partner being (1) informed of possible exposure to HIV; (2) provided with accurate information about HIV transmission and prevention; (3) informed of benefits of knowing one's serostatus; (4) assisted in accessing counseling, testing, and other support services; and (5) cautioned about the possible negative consequences of revealing their own or others' serostatus to anyone else. As the individualized plan is developed, the PCRS provider and client prioritize which partners should be reached first (Section 3.0 provides a discussion of how priorities are set).

- ♦ **HIV-Infected Client Voluntarily Discloses Information About Partners.** The HIV-infected client is encouraged to voluntarily and confidentially disclose the identifying, locating, and exposure information for each sex or needle-sharing partner that the PCRS provider or the client will attempt to inform.
- ♦ **Client and/or Provider Informs Each Partner of Possible Exposure to HIV.** The client and/or the PCRS provider informs each sex or needle-sharing partner who can be located of his or her possible exposure to HIV. Ideally, the partner is always informed confidentially face-to-face, but this cannot necessarily be ensured when the client chooses to inform the partner without the provider's assistance.
- ♦ **Client and/or Provider Assists Partner in Accessing Counseling, Testing, and Other Support Services.** At the core of PCRS is referring the now-informed partner to counseling, testing, and needed

social and medical services. If on-the-spot counseling and/or testing for HIV and other STDs is not practical or not desired at this time, each partner should receive, immediately upon being informed of possible exposure to HIV, a specific referral for obtaining client-centered counseling and testing. Some partners will also need immediate referrals for medical evaluation, substance abuse treatment, mental health, or other support services to enhance or sustain risk-reducing behaviors.

How each PCRS activity is conducted might have a direct impact on how communities perceive the value of such efforts to themselves and to public health. Quality assurance for services provided, routine staff and program evaluations, and network analysis are, therefore, necessary components of PCRS. For example, ensuring that strict confidentiality is maintained for all persons involved in PCRS will encourage community support and involvement. (See Sections 4.3, 4.5, and 6.2)

## 2.0 AVAILABILITY OF PCRS

### 2.1 Making Services Available to All HIV-infected Persons

*All CDC-funded HIV prevention counseling and testing sites, both confidential and anonymous, must make PCRS available to all HIV-infected persons.*

People can learn that they are HIV-infected through a variety of sources, including confidential and anonymous testing sites, private care physicians, or home collection kits. However, regardless of where and how persons have been tested, PCRS must be made easily accessible to all HIV-infected persons.

For example, an HIV-infected person who has been tested by a private provider might seek services from a CDC-funded provider.

Although verified evidence of HIV infection should always be presented to the PCRS provider before partners are contacted, PCRS must be made available to the HIV-infected person.

The client who has just been informed of being HIV-infected will, of course, need to have PCRS offered at the earliest appropriate time, but the PCRS provider will encounter many others to whom services should be offered. For example, those persons could include a previously identified HIV-infected –

- ◆ client who in the past was not offered PCRS;
- ◆ sex or needle-sharing partner who the PCRS provider learns is continuing to have unprotected sex and who has partners other than the original HIV-infected client;
- ◆ client who now has new sex or needle-sharing partners;
- ◆ client who is now seeking additional STD or family planning services or substance abuse treatment; or
- ◆ client who in the past refused or only partially participated in PCRS but has now decided to participate fully.

Health department HIV prevention program staff should ensure that health care and prevention providers in the community and HIV-infected persons in the area are aware that PCRS is available at publicly funded sites and are aware of how to access those services. Furthermore, health departments can expand access to PCRS by developing agreements with private providers. These agreements could specify that the private providers will deliver PCRS to their HIV-infected clients. In such situations, these providers should be given

relevant information, training, and support to successfully deliver the services.

### 2.1.1 Services for Those Persons Tested Anonymously

***CDC-funded programs must provide access to PCRS for persons testing anonymously without requiring that the infected client disclose his or her identity.***

Opportunities to access PCRS must be provided to HIV-infected clients who have been tested anonymously and choose to remain anonymous. Program experience has indicated that PCRS can be conducted in an anonymous setting (Hoffman, *et al.*, 1995). CDC requires that, unless prohibited by state law or regulation, grantees must provide reasonable opportunities for anonymous testing. Clients who test HIV-positive in anonymous settings must be counseled on how to enter a confidential system and be strongly encouraged to do so. This will assist them in receiving medical care and other services, including PCRS.

Recent reports show that persons who enter anonymous HIV testing programs do so earlier in their HIV infection and are more likely to begin medical care while still comparatively well (Bindman *et al.*, 1998; Nakashima *et al.*, 1998). CDC currently recommends that persons initially testing positive for HIV in an anonymous setting be counseled and informed about how to enter a confidential medical care system.

### 2.1.2 Inability To Pay

CDC-funded PCRS programs must provide access to PCRS regardless of clients' or partners' ability to pay (CDC, 1993).

## 2.2 Accommodating Requests from Other Health Jurisdictions

**Requests for PCRS from other health jurisdictions must be accommodated whenever practical.**

PCRS providers might sometimes be asked to contact the partner of an HIV-infected person residing in another health jurisdiction. Such contacts with other jurisdictions is the role of the state

health department. For example, a PCRS provider might request that the staff in a neighboring state health department assist in locating and informing a previous partner or former spouse of an HIV-infected client. A **reasonable** effort must be made to accommodate that request if it complies with state and local regulations and policies, and confidentiality is maintained.

## 3.0 DECIDING ON A PCRS PLAN AND SETTING PRIORITIES

### 3.1 Encouraging Client Participation

#### 3.1.1 Fully Informing and Reassuring Clients

**PCRS providers must ensure that clients are aware that all information disclosed by them will be kept strictly confidential and that participation is always voluntary.**

The PCRS provider should explain the purpose and process of PCRS before PCRS activities can begin. The HIV-infected person serves as the “gate-keeper” to his or her partners. Program experience indicates that once a person understands the benefits both to themselves and their partners, they willingly participate in PCRS. Therefore,

ensuring that the HIV-infected person fully understands the PCRS process and its benefits is important.

Providers should create an environment that is private, confidential, and comfortable enough so that clients are encouraged to participate in PCRS without feeling fearful or coerced. Reminders of the voluntary nature of PCRS and explanations of how privacy will be maintained for clients and partners alike will be necessary before some individuals feel secure enough to participate.

Each interaction a counseling and testing or health care provider has with an HIV-infected client is a potential opportunity to discuss the importance of informing that person’s sex or needle-sharing partners of their possible exposure to HIV. Prevention counseling, prevention case management, and medical follow-up sessions while clients are in treatment, all provide opportunities to stress the importance of getting partners involved in PCRS. Community-level interventions provide other opportunities to reach out to partners.

#### 3.1.2 Developing an Atmosphere of Trust

**To foster an atmosphere of trust, PCRS providers must treat all HIV-infected clients and their partners with respect.**

The success of the PCRS process hinges on the trust and cooperation of the persons infected with HIV and their partners. How well the provider fosters an atmosphere of trust, respect, and rapport with the HIV-infected individual will have a significant impact on PCRS. Client-centered counseling techniques (CDC, 1994) are highly recommended for developing this relationship, not only with original clients but also with their partners. The ability to develop trust and rapport will also enhance the PCRS provider’s effectiveness when working in the community.

### 3.1.3 Introducing PCRS

***Persons entering CDC-funded HIV prevention counseling and testing programs must be counseled at the earliest opportunity about PCRS and options for informing sex and needle-sharing partners of possible exposure to HIV.***

During the first visit, the health care provider, using a client-centered approach (CDC, 1994), should begin discussions with the client on the risks to his or her partners. This visit

would typically be for HIV counseling and testing. When clients choose to be tested and the results are positive, then the provider must offer, at the earliest appropriate opportunity, to assist in formulating an individualized PCRS plan. That plan is always based on the personal circumstances of the HIV-infected client and each of his or her partners.

When the provider demonstrates genuine concern for the overall well-being of clients and their partners during discussions about PCRS, the provider encourages greater client participation. Clients' reactions vary significantly to learning that their HIV test results are positive; therefore, the provider must gauge the appropriate point at which to initiate the discussion about the PCRS plan. In fact, other critical issues might need to be resolved first. For example, the client might express suicidal ideation or a fear of a violent reaction from a partner. Because potentially violent situations might be encountered, collaboration between the PCRS program and the appropriate state or local violence prevention programs is important. Such collaboration will help in developing plans and protocols for such situations and provide opportunities for the PCRS provider to learn about relevant services.

### 3.2 Formulating a PCRS Plan

***The PCRS provider must explain to the HIV-infected client the options for serving partners and then assist that client in deciding on the best plan for reaching each partner confidentially and referring him or her to counseling, testing, and other support services.***

HIV prevention programs use two basic approaches for reaching partners (West and Stark, 1997). In this document, the term *client referral* is used when HIV-infected individuals choose

to inform their partners themselves and refer those partners to counseling and testing (see Section 3.2.1). (NOTE: The terms *patient referral* and *self-referral* are sometimes used instead of *client referral*.) The term *provider referral* is used in this document when the PCRS provider, with the consent of the HIV-infected client, takes the responsibility for contacting the partners and referring them to counseling, testing, and other support services (see Section 3.2.2).

Sometimes a combination of the two approaches is used. With the *dual-referral* approach, the HIV-infected client informs the partner of his/her serostatus in the presence of the PCRS provider. By having a professional counselor present, this approach supports the client and reduces other potential risks. In such situations the PCRS provider must not reveal the client's serostatus to the partners without prior informed consent. With the *contract-referral* approach, the PCRS provider does the informing only if the client does not notify the partner within a negotiated time period (see Section 3.2.3).

The PCRS provider should explain to clients all available options for reaching their partners, including the advantages and disadvantages of each approach. Then, together they

can formulate a plan that can result in each partner being confidentially informed and encouraged to access counseling and testing or other social or medical services. Some HIV-infected individuals will be reluctant to participate in PCRS. Client-centered counseling techniques and reassurances of confidentiality can encourage better participation. Resolving problems through role-playing, for example, might help clients overcome barriers to participating in PCRS and help them better prepare for their part in those activities. No matter which approach is chosen, the PCRS provider should ensure the partners are actually informed of the exposure.

### 3.2.1 Taking a Closer Look at Client Referral

When HIV-infected clients choose to inform their partners themselves, they usually need some assistance to succeed. Although the majority of clients do not experience negative consequences when notifying partners, the PCRS provider can help the client minimize any potentially negative consequences. The provider should, therefore, be prepared to assess the situation and ability of the HIV-infected client to make successful notification and referrals. Based on this information, clients might need to be coached on:

1. the best ways to inform each partner;
2. how to deal with the psychological and social impact of disclosing one's HIV status to others;
3. how to respond to a partner's reactions, including the possibility of personal violence directed toward the client or others; and
4. how and where each partner can access HIV prevention counseling and testing.

Despite the provider's coaching, however, the client's lack of counseling skills and experience might result in unsuccessful or ineffective PCRS. Another disadvantage of the client-referral approach is that the client might

unintentionally convey incorrect information about HIV transmission, available support services, confidentiality protections, or other issues. The client also forfeits anonymity to partners, increasing the potential for disclosure of serostatus to third parties, subsequent discrimination, or partner repercussion. The findings of Landis *et al.* (1992) clearly indicate that fewer partners are actually informed of their possible exposure to HIV when the client-referral approach is used. However, because PCRS is a voluntary process, clients should be able to choose this approach. The PCRS program needs reasonable systems for monitoring whether partners are actually reached (see "Contract Referral" in Section 3.2.3). Also, more support to the client in notifying their partners will enhance the effectiveness of notifying partners.

For anonymous test sites, the client-referral approach poses a slightly different problem because some clients might be less likely to give the provider information about partners. Under these circumstances the provider will be less likely to determine whether PCRS has been successful. Although PCRS can be provided to anonymous clients, CDC currently recommends providers encourage the client to voluntarily enter a confidential setting for PCRS and additional medical follow-up. Here again, an appropriately detailed discussion with anonymous clients of how confidentiality will be maintained for themselves and their partners can ease the transition of anonymous clients to a confidential setting. That transition will also be eased if clients are not required to take another HIV test. If the anonymous and confidential test sites are at separate facilities, reciprocal agreements between the two might be necessary so that the client's confirmed positive test result can easily be transferred to the confidential setting.

At confidential test sites, PCRS providers should make every reasonable effort to follow up with each HIV-infected client to assess how

well he or she has progressed with PCRS. Whenever feasible, careful and confidential monitoring of which of the client's partners actually do access counseling and testing services can greatly enhance quality assurance and program evaluation. This also will help ensure that partners have actually been reached.

Despite its drawbacks, client referral is the approach frequently chosen, and it can have some advantages. Because the client is usually more familiar with the identity and location of the partner, this approach can allow some partners to be referred for counseling and testing more promptly. Also, some clients choose this approach because they feel the best way to preserve a current relationship is by informing the partner themselves rather than having a third party – the provider – do it. Finally, when client referral is conducted successfully, fewer staff are used and fewer resources are consumed than with the provider-referral approach, so the financial burden for HIV prevention programs is reduced.

### 3.2.2 Taking a Closer Look at Provider Referral

When the client chooses provider referral, the provider will also need to assess the situation regarding each partner, including the best ways to inform them, how to locate and contact them, suggestions on how to approach them, how to predict the psychosocial impact of their learning their HIV serostatus, and how to respond to partners' reactions. Research indicates that provider referral is more effective in serving partners than client referral (Landis *et al.*, 1992). The following are some of the advantages of using the provider-referral approach:

1. The PCRS provider is able to readily verify that partners have been confidentially informed and have received client-centered counseling and testing services.
2. The PCRS provider can better ensure the HIV-infected client's anonymity since no information about the client is disclosed to his or her partners.
3. A well-trained PCRS provider is better able to defuse the partner's potential anger and blame reactions as well as accurately and more comprehensively respond to the partner's questions and concerns.
4. Provider referral better facilitates learning about sexual and drug-injection networks, thus potentially enhancing overall HIV prevention efforts in affected communities.
5. In many cases, the PCRS provider can deliver on-site HIV testing to the partner.

Among the disadvantages of the provider-referral approach is the fact that PCRS providers are not always able to readily locate and identify the partners. Because the provider is less familiar with how to reach the partners, actually locating them to discuss their possible exposure to HIV can be more difficult. The provider-referral approach also entails substantial financial costs and causes some ethical concerns among leaders of affected communities (Fenton and Peterman, 1997; West and Stark, 1997). For example, Fenton and Peterman (1997) found that financial costs for provider referral are between \$33 and \$373 per partner notified and between \$810 and \$3,205 per infected partner notified. This program expense, however, is greatly offset in the long run because PCRS frequently reaches persons who do not suspect they have been exposed to HIV and is likely cost-effective (see Section 1.3). Once informed, they can access prevention counseling and testing, and if HIV-infected, they can enter treatment earlier. It is important to note that some infected people who choose provider referral might still notify some partners about their serostatus and will thus need relevant counseling.



### 3.2.3 Taking a Closer Look at Combined Referral Approaches

Two variations on provider and client referral are the dual- and contract-referral approaches. Potentially, combinations of these approaches can enhance the advantages of both approaches for the client while reducing the disadvantages.

**Dual Referral.** Some HIV-infected clients feel that they and their partners would be best served by having both the client and the provider present when the partner is informed. The dual-referral approach can work well for these clients. The dual approach allows the client to receive direct support in the notification process. The PCRS provider is available to render immediate counseling, answer questions, address concerns, provide referrals to other services, and in some cases potentially minimize partner repercussions. Being present also enables the provider to know which partners have in fact been served, and to some extent, learn about sexual and drug-injecting networks. Whether the client or provider will take the lead in informing the partner should be worked out in advance of the notification.

The provider still needs to coach and support the client as with the client-referral approach. The provider and the HIV-infected client need to consider, in particular, the partner's possible concerns about having his or her relationship with the client revealed to the provider. By considering this issue in advance, the client and the provider can anticipate the partner's possible reactions and discuss how to respond appropriately.

**Contract Referral.** The other variation on provider and client referral, the contract-referral approach, might require more negotiation skill on the PCRS provider's part. In the contract-referral approach, the provider and client decide on a time frame during which the client will contact and refer the partners. If the client is unable to complete the task within

that agreed-upon time period, the PCRS provider then has the permission and information necessary to serve the partner. The provider must also have agreement with the client about how to confirm that partners were notified and what follow-up is required for situations where the client does not make the notification. Negotiation skill and a relationship of trust are needed so that the provider will have the identifying and locating information immediately available if the client does not inform the partner before the time limit expires.

When the contract-referral approach is used, the PCRS provider should also negotiate a provision with the client whereby the partner confirms in some way (e.g., telephone call, appointment for services) to the provider that he or she has been informed of being at risk. Otherwise, the provider may have difficulty knowing which partners have been informed and whether or not provider referral or some other assistance is now needed.

### 3.3 Setting Priorities for Reaching Partners

***The PCRS provider and HIV-infected client must prioritize reaching partners based on who is most likely to transmit infection to others and who is most likely to become infected.***

The PCRS plan must include prioritizing which sex or needle-sharing partners need to be reached first, based on each client's and partner's circumstances. Ideally, all partners should be reached, but limited program resources usually dictate that priorities have to be set. Priorities are determined by deciding (1) which partners are most likely to be already infected and to transmit infection to others; (2) which partners are most likely to become infected; and (3) which partners can be located. Priority is also affected by federal and state laws. For example, **federal legislation requires that a**

good-faith effort be made to notify “any individual who is the marriage partner of an HIV-infected patient, or who has been the marriage partner of that patient at any time within the 10-year period prior to the diagnosis of HIV infection.” (Public Law 104-146, Section 8[a] of the Ryan White CARE Reauthorization Act of 1996.)

A number of factors influence how the PCRS provider and client decide which partners need to be reached first. Obviously, if the client has had only one partner during his or her lifetime, that partner is likely to be infected. When the client has had more than one partner, other factors then have to be considered, such as the following:

- ◆ **Possible Transmission of HIV to Others.** The partner who is most likely to transmit HIV to others must receive highest priority. A partner who is a pregnant woman should be reached as soon as possible for counseling, testing, and referral to medical treatment if infected, to avoid perinatal transmission. Likewise, the partner who the client knows has multiple other sex and needle-sharing partners needs to be reached as soon as possible to reduce the potential for transmission of HIV to others.
- ◆ **Partners of a Recently Infected Client.** If, for example, the client had a negative HIV test result 6 months ago, but now the test result is positive, partners within that 6-month time period or in the potential “window period” that preceded the negative test would receive priority. These partners are more likely to have acquired or been exposed to HIV than any of the client’s partners during the period before the client’s HIV negative test. Other evidence of a recently infected person might be indicated by the exposure history of the client, e.g., client with a history of negative test results, findings from less sensitive EIA or serologic

testing algorithm for recent HIV seroconversion, or other evidence of recent infection.

- ◆ **Likelihood of the Partner Being Unaware of Exposure to HIV.** Some individuals are less likely than others to suspect a risk for HIV infection or to understand what being “at risk” means. For example, many heterosexual women might be less aware of their HIV risk and therefore less likely to access counseling, testing, or other prevention services without PCRS.
- ◆ **Partners at Continued Risk.** Reaching the client’s current, recurring, or recent partners is a high priority because those partners might be at continued risk of becoming infected with HIV, if not already infected.
- ◆ **History of Other STDs.** Either the client’s or partner’s history of other STD infections is an important factor in setting priorities. For example, if a partner was treated for another STD, that partner is more likely to also be infected with HIV and, additionally, more likely to transmit HIV to others. If the HIV-infected client has a recent history of other STD infection, then his or her sex partners are more likely to have been HIV-infected, especially those exposed during the STD infection (Wasserheit, 1992).
- ◆ **Transmission of Strains of HIV That Are Resistant to Antiretroviral Therapies.** If information or evidence exists that the client is infected with a strain of HIV resistant to antiretroviral therapies, partners of this client would have high priority for PCRS services.

The PCRS provider and client should begin by noting current or recent partners and the details of their exposure. Next, working back in time, they should consider any other partners who need to be contacted. By briefly

noting the circumstances for each partner and then moving quickly on to the next one, the provider will be better able to stimulate the client's memory. Then, together, they can determine the priorities for reaching as many partners as program resources might permit. Because determining when a client was actually infected or the circumstances associated with individual partners is often difficult or impossible, some HIV prevention programs routinely attempt to locate and counsel all partners from a defined time period. This time period, often 1-2 years, frequently is based on availability of resources for PCRS. Programs with greater amounts of resources, those with lower morbidity, or those that give higher priority to PCRS frequently attempt to reach and counsel partners exposed over a longer time period.

Once the provider and client have established which partners are to be reached, they can begin discussing a plan for reaching these partners. For those partners the provider will be contacting, exact locating information, plus the dates, types, and frequency of exposure should be noted (See Section 4.2). During this phase, new information about partners might come to light that necessitates adjustments in the priorities previously established.

In addition to the factors listed previously, the PCRS provider must also consider federal legislation and relevant state laws that require a *good-faith effort* be made in notifying current spouses or persons who have been spouses of a known HIV-infected person during the 10 years prior to the client's diagnosis of HIV infection. Both the program policies of PCRS and the efforts of individual providers contribute to the required good-faith effort.

PCRS providers can satisfy the requirement of a good-faith effort by (1) asking all HIV-infected clients if they have a current or past marriage partner(s), (2) notifying these part-

ners of their possible exposure to HIV, except in situations when, in the judgment of public health officials, there has been no sexual exposure of a spouse to the known HIV-infected individual during the relevant time frame; (3) referring them to appropriate prevention services; and (4) documenting these efforts. Programs need to have or develop policies to guide providers in situations in which the HIV-infected client does not give consent and will not allow the provider to notify his or her current or past marriage partner(s).

### **3.4 Considering Other Options and Special Circumstances**

#### **3.4.1 Other Persons Who Might Need To Be Contacted**

While the PCRS plan is being developed and priorities are being set for reaching partners, the provider should take special note of any other persons being mentioned who might be at risk. For example, during interviews or counseling sessions, the HIV-infected client might discuss other persons who are not sex partners but are involved in a sexual or drug-injection network with high risks of HIV transmission. Another example is children or newborns who might have been exposed perinatally or through breast-feeding. Although not direct sex or needle-sharing partners of the HIV-infected client, these other persons should be offered HIV prevention counseling and testing, if resources and program policies permit. General information obtained through PCRS, not just a person's name, can be used to identify high-risk places and venues where PCRS programs can provide outreach services. CDC encourages such efforts to identify and lower risks of HIV and other STDs within sexual or drug-injection networks and is interested in working with state and local health authorities to develop methods and more detailed guidance on network identification, analysis, and intervention.

### 3.4.2 “But, I Do Not Want My Partner To Be Contacted!”

***CDC-funded PCRS providers must review with the HIV-infected client in appropriate detail the legal and ethical reasons for informing sex and needle-sharing partners of their possible exposure to HIV.***

Unfortunately, in some cases HIV-infected clients initially will simply not want their partners notified. For example, they might fear loss of anonymity, the breakup of a relationship, or other adverse consequences. Clients might say that partners have already been informed about

their risks or that partners would not be interested in counseling, testing, or other support services. Providers can encourage a client’s participation by explaining that the partner benefits by knowing his or her HIV status and being able to seek immediate treatment if infected. Also, if infected, the partner can avoid transmitting the virus to others. However, when a client is determined not to disclose partner names, the PCRS provider should counsel the client as if he or she has chosen the client-referral approach.

Sometimes a client might not want his or her partner notified because of fear of a violent reaction from the partner. It is not uncommon for persons receiving public health services to report having experienced violence in their lives (Maher, 1998). Therefore, providers should be aware of the potential for partner violence and should be prepared to make appropriate referrals. If the provider has indication of a potentially violent situation for the client or others, the provider must make an assessment prior to notifying the partner and seek expert consultation before proceeding. States have varying legal requirements about reporting situations such as those involving violence or child abuse. The PCRS program must comply with relevant state laws and local regulations.

In some cases, the provider knows of a partner at risk even though the client has not identified that partner. Whether or not a legal “duty to warn” such partners (or identified partners that the client did not want notified [see Appendix B]) exists is best determined by reviewing applicable state laws or regulations, especially regarding spousal notification. All states must have a policy established to guide health department staff in situations in which an HIV-infected client indicates he or she does not plan to notify known partners and will not provide the information necessary for the health department staff to make the notification.

The Association of State and Territorial Health Officials recommends in its 1988 *Guide to Public Health Practice: HIV Partner Notification Strategies* that a health care provider may invoke his or her “privilege to disclose” (see Appendix B) when that provider knows of an identifiable at-risk partner who has not been named by the HIV-infected person. State and local HIV prevention program managers should consider the ASTHO recommendations and their own relevant laws when developing policies and procedures.

### 3.4.3 PCRS for Needle-sharing Partners

Sharing of needles, syringes, and other paraphernalia used for injection drug use (e.g., illicit drugs, steroids) carries high risk for transmission of HIV. Throughout this document, the importance of providing partner counseling and referral services to HIV-infected clients with needle-sharing partners is emphasized. CDC recognizes that some HIV prevention programs have relatively limited experience in working with needle-sharing partners and that special issues exist relating to clients disclosing information about such partners, reaching such partners, deciding which prevention interventions should be provided, and referring them for needed services.

Some state and local HIV prevention programs have already gained considerable experience in reaching and serving needle-sharing partners and report that such services are feasible and likely to be effective. For example, Levy and Fox (1998) reported that injection drug users infected with HIV want to notify their sex and needle-sharing partners and are willing to participate in the PCRS process. Information provided by HIV-infected clients who are injection drug users may help HIV prevention program managers gain insight into the extent and types of prevention service needs of injection drug users and how best to deliver and target such services.

CDC will provide expanded guidance on PCRS for needle-sharing partners in future versions of this guidance.

## 4.0 LOCATING AND NOTIFYING PARTNERS

### 4.1 Preparing the PCRS Provider

***Program managers and supervisors must ensure that each PCRS provider has the appropriate training and skills to effectively serve HIV-infected clients and their partners.***

In large part, the manner in which PCRS is provided to and perceived by the affected communities determines how successful HIV

prevention programs will be (see Section 4.5). Therefore, program managers and supervisors should ensure that PCRS staff –

- ◆ are skilled and competent in providing PCRS;
- ◆ are culturally competent and demonstrate respect for the community to be served;
- ◆ are knowledgeable about HIV infection, transmission, and treatment;

- ◆ are knowledgeable in local, state, and federal laws regarding HIV and other relevant issues of providing health care, especially the right to privacy and confidentiality;
- ◆ receive updated information and periodic retraining as appropriate;
- ◆ have standards, objectives, and specific guidelines for performance;
- ◆ are appropriately supervised and given written and oral feedback about their performance on a regular basis; and
- ◆ have appropriate problem-solving skills to deal with situations that might be encountered in a field setting, e.g., personal safety, violence to others.

In addition to receiving formal training, such as CDC's training course on PCRS, an inexperienced PCRS provider should complete an internship by being teamed with a more experienced provider for a period of time before conducting PCRS alone (see Section 6.1). Another way to enhance a provider's performance is through routine peer review of selected cases.

Providers of successful PCRS programs regularly go outside the clinic or office setting to reach partners. The inexperienced provider will need training in deciding when to deliver PCRS outside the office or clinic and when to postpone PCRS. Benefits of delivering PCRS in a partner's home might include providing the partner with a familiar environment and helping the provider better understand the personal circumstances of that partner.

Whether or not to do PCRS outside the clinic or office, or whether it is best postponed until an adverse situation can be resolved, must be decided on a case-by-case basis. In addition, training in avoiding confrontations, diffusing anger, and mediating disputes will better prepare any provider for handling potentially violent situations.

## 4.2 Setting Activities in Motion

**Locating and notifying activities must begin promptly once the PCRS plan has been formulated and the priorities set for reaching partners.**

For those partners the provider will be contacting, the first step the provider should take is to verify the identifying and locating information

given by the HIV-infected client. Locating and notifying partners should begin as soon as possible after the provider and HIV-infected client have decided on the best approach to use for each partner and priorities have been set for reaching partners. If the client will be informing partners, the client should be well-coached on how to do so and should be provided opportunities to obtain additional counseling, assistance, or other support during the process.

## 4.3 Maintaining Confidentiality

**While conducting PCRS activities in the community, providers must continue to maintain confidentiality for all HIV-infected clients and their partners.**

Confidentiality for all persons involved in PCRS must continue to be maintained. All attempts to make contact with a sex or needle-sharing partner should be confidential. This is often difficult because other community

members might ask the purpose of the provider's visit and why he or she is attempting to make contact. Nevertheless, providers should not, for example, reveal to others why they are trying to find a particular person. Likewise, providers should never leave a note or message that mentions HIV exposure as the reason for attempting to make contact. In addition, no other information should be revealed that might lead to others learning the reason for the contact or that might otherwise

lead to disclosure of sensitive information or to a breach of confidentiality. As each partner is located, he or she should be informed privately and face-to-face, if at all possible. However, if the person refuses to meet with the provider, informing a partner by telephone might become necessary. In such situations, only limited information should be provided to the partner, and the goal still should be to arrange a face-to-face meeting if at all possible. Informing a partner by telephone should only be done as determined by state and local jurisdictions and after every step has been taken to ensure that the correct person has been located, is on the telephone, and others are not listening. Further attempts should be made to arrange a meeting in person.

The original HIV-infected client will sometimes inquire about the results of the PCRS provider's activities regarding his or her partners. The provider, when requested, can reveal whether a particular partner has been informed of his or her exposure to HIV, but must not reveal any confidential information about that partner, including whether the partner decided to be tested or whether he or she is HIV-infected.

Of equal importance is not revealing any identifying information about the original client to the partner, including the person's sex, name or physical description, or time, type, or frequency of exposure. Although the PCRS provider will need to document the results of his or her activities in a thorough, concise, and timely manner, confidentiality must still be maintained for all persons involved. Information that identifies partners should be kept locked in a secure location. Client and partner information, other than the official record (as determined by state practice), should be destroyed when current PCRS activities are concluded.

State or local areas should establish PCRS record-keeping policies and procedures, and

client and partner information should be maintained in accordance with these policies. Many public health programs have developed policies and procedures to safeguard sensitive client or partner information. One example can be found in CDC's *Guidelines for HIV/AIDS Surveillance*, Appendix C, Security and Confidentiality (as revised October 1998). In developing their policies, PCRS managers can choose to review and adapt the policies and procedures in this document or those of other public health programs.

#### 4.4 Helping Partners Access Services

***As each partner is informed of possible exposure to HIV, the PCRS provider must be prepared to assist that person with immediate counseling and referrals for more intensive counseling as well as testing and other support services.***

The PCRS provider must be well prepared to handle the initial reactions of the person who is being informed of possible exposure to HIV. That person will undoubtedly need immediate counseling, followed by referral to additional HIV prevention counseling. The provider must be prepared

to answer the questions and concerns of each partner without revealing any identifying information about the original HIV-infected client.

As described earlier, referring partners to needed prevention, treatment, and other relevant services is a goal of PCRS. Testing is a very important issue to persons who have just learned of possible exposure. The provider must be prepared to, at a minimum, refer them to counseling and testing services. For many years, providers have taken blood specimens of those who consent at the time of notification, which requires specialized training. With the

current availability of oral fluid and urine collection kits, and rapid testing systems, program managers are encouraged to consider providing on-the-spot collection of specimens for HIV testing as each partner is informed. If the partner has previously been tested, and those results were negative, the PCRS provider should stress the need to follow up with another test if exposure history indicates it is warranted.

However, many partners will need referrals for other kinds of social and medical support services beyond counseling and testing. The PCRS provider should already have agreements in place and an up-to-date resource guide so that immediate referrals can be made to services such as substance abuse treatment, family planning assistance, other STD treatment, domestic violence prevention, mental health counseling, or housing assistance (CDC, 1993). Having agreements in place for collaboration between PCRS providers and referral sources will help ensure that those services can be successfully accessed. PCRS providers should then follow up with each partner contacted to ensure that test results and other referral services have in fact been received. If providers in another health jurisdiction have been asked to contact a partner, health departments should follow up with that provider to determine that services have been received.

#### 4.5 Addressing Community Concerns

The potential exists for PCRS to have a negative impact on HIV-infected individuals, their partners, or affected communities (Rothenberg and Paskey, 1995; West and Stark, 1997). Some community leaders view these kinds of activities with suspicion and are apprehensive about such issues as –

- ♦ whether disclosure of partner names is done voluntarily;
- ♦ possible denial of health care or other services if the HIV-infected client refuses

to reveal partner names or otherwise refuses to cooperate with the provider;

- ◆ unintended effects on personal relationships, such as partnership breakup or violence;
- ◆ potential for invasion of privacy or loss of confidentiality for HIV-infected clients and their partners; and
- ◆ possible discrimination if confidential information held by government agencies is ever released, either accidentally or by law.

Although PCRS providers cannot always resolve these issues, they can strive to build relationships of trust between themselves and those they serve, including the leaders of affected communities. Working with HIV prevention community planning groups and others when determining and evaluating priorities, policies, and procedures for PCRS will help increase community support and acceptance. PCRS providers should be prepared, whenever an opportunity arises, to address legitimate concerns and dispel misconceptions about policies and practices (West and Stark, 1997).

## 5.0 COLLECTING, ANALYZING, AND USING PCRS DATA

### 5.1 Why Collect Program Data?

PCRS data must be collected and used (1) to assess the behavioral risks for sex and needle-sharing partners of HIV-infected persons; (2) to evaluate the effectiveness of the PCRS program as part of the overall HIV prevention effort; and (3) to improve how other HIV prevention activities, interventions, and services are implemented.

Accurate and consistent data collection is a critical component for evaluating how effective the PCRS program is, as well as how well it enhances the overall HIV prevention inter-

vention (CDC, 1994). Moreover, PCRS data enable providers to better focus prevention efforts on those persons most at risk. When the data reveal information about networks of people who are having sex or injecting drugs, the dynamics of HIV transmission can be better analyzed (Fenton and Peterman, 1997), and more intensive prevention and education efforts can be applied for specific high-risk groups (West and Stark, 1997). To do all this, however, the collected data must be relevant to behavioral risks, HIV/AIDS prevalence, and the demographics of affected communities. With accurate and consistent data, the staff of health departments and community-based organizations and members of HIV prevention community planning groups can establish an effective mix of prevention strategies.

### 5.2 What Data Should Be Collected?

***CDC-funded PCRS providers must collect data that help answer key questions about how well the PCRS program is functioning, the extent and quality of services being provided, the degree to which clients and their partners accept and are satisfied with services, and how PCRS and other prevention services can be enhanced.***

***CDC-funded PCRS providers must use standardized data collection tools throughout the program that maintain the privacy or confidentiality of the original HIV-infected client and his or her partners.***

Any data collection tool used in a PCRS program should be designed so that certain core information can be ascertained, including answers to the following:

- ◆ What proportion of HIV-infected clients is offered PCRS?



- ♦ What are the reasons those clients either reject or accept PCRS?
- ♦ What is the range of PCRS services (e.g., client referral, provider referral, combinations of referral approaches) offered to and accepted by each client?
- ♦ How many sex or needle-sharing partners are identified?
- ♦ What is the percentage of partners actually reached through PCRS, and how many of those partners are HIV-infected? Of those partners who are HIV-infected, how many are being informed of their infection for the first time?
- ♦ What are the demographics (e.g., marital status, age, sex, race/ethnicity) of the clients and partners actually served?
- ♦ How many partners are offered referral services? How many receive these services? In what time frame do they receive referral services?

And, perhaps most importantly, PCRS program managers should routinely assess what all of this information means in regard to how well PCRS is working for HIV-infected clients, their partners, and the community at large. Are clients served well? Are partners gaining access to services that might not be otherwise available? Are communities becoming more supportive of public health efforts? Does evidence exist that risks are being reduced? Are other prevention program services better targeted to communities in need?

The HIV prevention program managers in each health jurisdiction should decide how best to collect, analyze, and use PCRS data. This should be done in a manner that is consistent with the policies and procedures that they have developed to safeguard the security of the data and the confidentiality of the client or partner (see Section 4.3). Those managers should keep in mind that misconceptions about the collection and use of HIV data, in addition to a general mistrust of publicly

funded agencies, are two of the biggest barriers to HIV prevention efforts in affected communities. CDC plans to work with state and local HIV prevention and STD prevention and treatment programs to develop proposals for standardizing the collection and analysis of PCRS data.

## 6.0 ENSURING THE QUALITY OF PCRS

***PCRS providers must be well trained to provide effective PCRS services.***

### 6.1 Training

Of all the resources necessary for the successful operation of PCRS programs, training is perhaps the most critical (Fenton and Peterman, 1997). Each individual PCRS provider must receive initial basic training plus periodic updates on how to conduct PCRS (including its scientific rationale), provide client-centered counseling, protect individuals' rights to privacy, use scientific information in prioritizing partners, administer HIV tests when appropriate, and defuse potentially violent situations involving clients, partners or staff (see Section 4.1). PCRS providers also need to understand laws regarding confidentiality of medical records.

### 6.2 Quality Assurance and Evaluation

***CDC-funded PCRS programs must have a quality assurance plan.***

Quality assurance for PCRS programs entails ensuring that appropriate and standardized methods are used for –

***CDC-funded PCRS programs must evaluate their services.***

1. counseling HIV-infected clients regarding the notification of their partners;
2. developing a PCRS plan with HIV-infected clients;

3. prioritizing which partners are to be reached;
4. locating and informing those partners of their possible exposure to HIV;
5. providing immediate counseling and testing services to informed partners and/or referring them to other service providers; and
6. collecting, analyzing, using, and storing PCRS data.

Written job descriptions, including minimum performance criteria, and comprehensive procedures for delivering quality PCRS should be developed and copies made available to all personnel. Also, supervisors should directly observe a new PCRS provider until confident that the provider is proficient in serving clients and their partners. Then, through periodic supervisor observation, peer review of selected cases, and “customer” satisfaction surveys, each PCRS provider should be given constructive oral and written feedback.

PCRS programs should include policies relevant to situations in which an HIV-infected

person knowingly exposes others to HIV. These policies must comply with relevant state or local laws.

The overall program should also be regularly evaluated to determine the quality of effort and the success in reaching the PCRS goals (Fenton and Peterman, 1997) (see Section 1.2). Program evaluations should include a comprehensive assessment of all confidentiality procedures that includes, at a minimum, record-keeping.

### **6.3 How Can CDC Help?**

Many types of technical assistance are available for designing, managing, or evaluating PCRS through CDC’s project officers, program consultants, and network of HIV prevention partners. In addition, training is provided through CDC and its contractors that is designed to enhance PCRS providers’ skills regardless of their level of experience. Finally, information on the latest scientific findings about HIV is available through the CDC National Prevention Information Network (toll-free, 800-458-5231).

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## APPENDIX A

### PCRS PROGRAMMATIC STANDARDS

All PCRS programmatic standards are listed here, followed by a reference to the section of this document where a discussion of that standard and other related guidance can be found.

- ◆ All CDC-funded HIV prevention counseling and testing sites, both confidential and anonymous, must make PCRS available to all HIV-infected persons. (Section 2.1)
- ◆ CDC-funded programs must provide access to PCRS for persons testing anonymously without requiring that the infected client disclose his or her identity. (Section 2.1)
- ◆ Requests for PCRS from other health jurisdictions must be accommodated whenever practical. (Section 2.2)
- ◆ PCRS providers must ensure that clients are aware that all information disclosed by them will be kept strictly confidential and that participation is always voluntary. (Section 3.1)
- ◆ To foster an atmosphere of trust, PCRS providers must treat all HIV-infected clients and their partners with respect. (Section 3.1)
- ◆ Persons entering CDC-funded HIV prevention counseling and testing programs must be counseled at the earliest opportunity about PCRS and options for informing sex and needle-sharing partners of possible exposure to HIV. (Section 3.1)
- ◆ The PCRS provider must explain to the HIV-infected client the options for serving partners and then assist that client in deciding on the best plan for reaching each partner confidentially and referring him or her to counseling, testing, and other support services. (Section 3.2)
- ◆ The PCRS provider and HIV-infected client must prioritize reaching partners based on who is most likely to transmit infection to others and who is most likely to become infected. (Section 3.3)
- ◆ CDC-funded PCRS providers must review with the HIV-infected client in appropriate detail the legal and ethical reasons for informing sex and needle-sharing partners of their possible exposure to HIV. (Section 3.4)
- ◆ Program managers and supervisors must ensure that each PCRS provider has the appropriate training and skills to effectively serve HIV-infected clients and their partners. (Section 4.1)
- ◆ Locating and notifying activities must begin promptly once the PCRS plan has been formulated and the priorities set for reaching partners. (Section 4.2)
- ◆ While conducting PCRS activities in the community, providers must continue to maintain confidentiality for all HIV-infected clients and their partners. (Section 4.3)
- ◆ As each partner is informed of possible exposure to HIV, the PCRS provider must be prepared to assist that person with immediate counseling and referrals for more intensive counseling as well as testing and other support services. (Section 4.4)
- ◆ CDC-funded PCRS providers must collect data that help answer key questions about how well the PCRS program is functioning, the extent and quality of services being provided, the degree to which clients and their partners accept and are satisfied with services, and how PCRS and other prevention services can be enhanced. (Section 5.2)

**PCRS PROGRAMMATIC STANDARDS** *(Continued)*

- ◆ CDC-funded PCRS providers must use standardized data collection tools throughout the program that maintain the privacy or confidentiality of the original HIV-infected client and his or her partners. (Section 5.2)
- ◆ PCRS providers must be well trained to provide effective PCRS services. (Section 6.1)
- ◆ CDC-funded PCRS programs must have a quality assurance plan. (Section 6.2)
- ◆ CDC-funded PCRS programs must evaluate their services. (Section 6.2)

## APPENDIX B

### GLOSSARY OF TERMS ASSOCIATED WITH PCRS

<b>Client-Centered Prevention Counseling</b>	Counseling conducted in an interactive manner that is responsive to the individual's needs. This approach requires an understanding of the unique circumstances of the client – behaviors, culture, knowledge, and social and economic status.
<b>Client Referral Approach</b>	A PCRS approach whereby the HIV-infected client informs his or her partners of their possible exposure to HIV and refers them to counseling, testing, and other support services.
<b>Confidential</b>	Requirement that all personally identifying records be kept secure in a locked file and that no information be released to anyone without signed authorization from the client.
<b>Contract Referral Approach</b>	A PCRS approach whereby, if the HIV-infected client is unable to inform a partner within an agreed-upon time, the provider has the permission and information necessary to do so.
<b>Dual Referral Approach</b>	A PCRS approach whereby the HIV-infected client and the provider inform the partner together.
<b>Duty To Warn</b>	A legal concept indicating that a health care provider who learns that an HIV-infected client is likely to transmit the virus to another identifiable person must take steps to warn that person; state laws determine what actually constitutes a “duty to warn.”
<b>Partner</b>	A person who shares sex or drug-injection needles with another.
<b>PCRS</b>	Partner counseling and referral services.
<b>PCRS Provider</b>	A wide variety of qualified, trained health care professionals including physicians, nurses, counselors, disease intervention specialists, and others.
<b>Prevention Counseling</b>	Guiding a client's understanding of his or her perception of risk for becoming infected with HIV and developing a plan for reducing that risk for themselves and their partners.
<b>Privilege To Disclose</b>	Guidance for a PCRS provider who knows the identity of a partner at risk for HIV, whom the infected client is unable or unwilling to inform; usually guided by state laws.
<b>Provider Referral Approach</b>	A PCRS approach whereby, with the permission of the HIV-infected client, the provider informs the partner and refers him or her to counseling, testing, and other support services.

**GLOSSARY OF TERMS ASSOCIATED WITH PCRS *(Continued)***

**Spouse**

A legal marriage partner as defined by state law (for purposes of the requirements of the Ryan White CARE Act).

**Window Period**

Period of time in between initial infection of HIV and development of a positive antibody test for HIV. The window period can last anywhere from about 2 weeks to (rarely) a year, although antibodies will usually be detected within 3 to 6 months.



## ACKNOWLEDGMENTS

The following Centers for Disease Control and Prevention staff made substantial contributions in the preparation of this document:

**Dave Brownell, M.P.H.**

Division of HIV/AIDS Prevention

**Steven J. Davis**

Division of HIV/AIDS Prevention

**Susan DeLisle, A.R.N.P., M.P.H.**

Division of STD Prevention

**Linda Elsner**

Division of HIV/AIDS Prevention

**John H. Glover**

Division of STD Prevention

**Robert Janssen, M.D.**

Division of HIV/AIDS Prevention

**Robert Kohmescher, M.S.**

Division of HIV/AIDS Prevention

**Kellie E. Lartigue**

Division of HIV/AIDS Prevention

**Jill K. Leslie**

Division of HIV/AIDS Prevention

**Beth A. Macke, Ph.D.**

Division of STD Prevention

**Julie E. Maher, Ph.D.**

Division of HIV/AIDS Prevention

**C. Kay Smith-Akin, M.Ed.**

Division of HIV/AIDS Prevention

**Steven Stewart, M.S.**

Division of HIV/AIDS Prevention

**Gary R. West, M.P.A.**

Division of HIV/AIDS Prevention

**Linda Wright-DeAgüero, Ph.D.**

Division of HIV/AIDS Prevention