ISSUES -
Partner
notification

FAX COVER SHEET

CENTERS FOR DISEASE CONTROL AND PREVENTION
DIVISION OF HIV/AIDS PREVENTION
1600 CLIFTON ROAD, N.E
MAILSTOP E-35
ATLANTA, GEORGIA 30333

Pages _____ **including this cover**

To: SANDY THURMAN **Date:** 7-23-98

Fax#: (202) 456-2439 **Tel#:** _____

From: Gary West
Office of Director
Tel#: (404) 639-5200
Fax#: (404) 639-0897

Subject: SPOUSAL/PARTNER NOTIFICATION MATERIALS

Comments: ATTACHED IS A COPY OF THE BRIEFING GARY PREESENTED TO REPRESENTATIVE COBURN AND A COPY OF THE DRAFT GUIDELINES ON HIV PARTNER COUNSELING AND REFERRAL SERVICES. IF I CAN BE OF FURTHER ASSISTANCE, PLEASE CONTACT MY SECRETARY, YULONDA WILLIAMS AT (404) 639-5200.

Briefing of Representative Coburn on HIV Prevention Partner/Spousal Notification Requirements, July 21, 1998

- Public health perspective on partner notification
- Review of CDC/HRSA process for certification
- Summary of actions taken/planned to be taken by States
- Follow-up since certification
- Overview of data available to CDC on State partner notification activities
- Review of the situations in California, New Jersey, and New York State
- Questions and discussion

CDC

Public Health Perspective on HIV Prevention Partner/Spousal Notification

- Spouses and other sex/needle-sharing partners need to be reached, counseled and provided HIV testing and other services.
- Partner/spousal notification is an essential component of a comprehensive program to prevent HIV infection. CDC has required states to establish standards and implement procedures for partner notification since 1988.

CDC

Public Health Perspective on HIV Prevention
Partner/Spousal Notification
(continued)

- Generally HIV-infected persons and their partners readily accept partner notification services and, with appropriate counseling, will not only provide confidential, very sensitive information, but will actively assist in finding and encouraging partners and spouses to receive testing and counseling.

CDC

Public Health Perspective on HIV Prevention
Partner/Spousal Notification
(continued)

- Programs depend on the trust and cooperation of HIV-infected persons to identify and locate sex and needle-sharing partners, including spouses.
- Because HIV is a lifelong infection, potential for exposure to sex or needle-sharing partners exists over the long term and programs need to maintain trusting relationships as they provide counseling and other services to help reduce or eliminate HIV risks.

CDC

Public Health Perspective on HIV Prevention
Partner/Spousal Notification
(continued)

- Partner/spousal notification will be increasingly important as the effectiveness of prevention efforts and antiretroviral therapies and treatment improve.
- Fear or misunderstanding regarding health department policies and practices could lead to HIV-infected persons not coming forward or not revealing confidential information needed to reach partners and spouses.

CDC

Requiring A Good Faith Effort to Notify Spouses of Known HIV-Infected Individuals: *Process for Certification of States*

- CDC and HRSA program and legal staff developed proposed procedures and criteria for certifying state compliance.
- Opportunities were provided for input by state/local health department and community representatives into proposed policies/procedures
- Examples of activities were developed that would constitute a minimal "good faith" effort to notify spouses.
- A packet of instructions was mailed to each state, territory, Puerto Rico, and the District of Columbia.

CDC

Requiring A Good Faith Effort to Notify Spouses of Known HIV-Infected Individuals: *Process for Certification of States*

(continued)

- Each state was required to certify to CDC in writing its intent to comply with the spousal notification requirements. States were also requested to provide a summary of relevant administrative actions taken or other planned activities or legislation.
- Certification submissions were reviewed by CDC staff and also provided to HRSA for their review.
- All states certified compliance prior to the February 1, 1997, due date.

CDC

A Good Faith Effort to Notify Spouses

- Examples of a minimal good faith effort were provided to all states and were used as the basis for review of submissions.
- Examples included:
  - Asking all known HIV-infected persons if they have, or have had, a spouse(s) within the 10-year period prior to diagnosis with HIV infection and informing them that they should notify their spouse(s) of the potential exposure to HIV.
  - Making reasonable efforts to determine if each HIV-infected individual intends to notify his or her spouse or agrees to have a qualified health care provider notify them.

CDC

A Good Faith Effort to Notify Spouses
(continued)

- Examples included: *(continued)*
  - If the HIV-infected individual is unable or unwilling to notify his or her spouse, making available culturally competent services by the provider or the health department to do so.
  - Developing state policies that address situations involving HIV-infected individuals who do not plan to notify their spouses and who refuse health department assistance. CDC suggested that States refer to the recommendations made by ASTHO regarding the "privilege to disclose" in developing policy for such situations.

CDC

A Good Faith Effort to Notify Spouses
(continued)

- Examples included: *(continued)*
  - Implementing reasonable procedures to ensure that spouses receive referrals for HIV testing, other prevention services, and treatment.
  - Establishing agreements between health departments and public and private health care providers to ensure spouses are notified.

CDC

Response by States to Spousal Notification Requirements

- All states certified compliance and were taking action to implement.
- No state opposed the requirements or was in any way resistant to implementation.
- States did request more guidance from CDC on program operations and protocols for spousal notification and partner notification in general.

CDC

Response by States to Spousal Notification Requirements *(continued)*

Summary of actions taken or planned to take based on initial responses of states:

- 32 states reported to CDC that their current procedures provided for spousal notification. All agreed to take reasonable actions to require a good faith effort is made to notify spouses.
- 44 sent communications to private physicians.
- 51 were planning special training initiatives.
- 17 states substantially revised protocols.

CDC

Follow-up Since State Certification of Compliance with Spousal Notification Requirements

- In 1996 CDC began a process for developing comprehensive guidelines for HIV prevention partner notification. Draft guidelines will be mailed to all health departments for comment later this month.

- Beginning in 1997, CDC made compliance with spousal notification requirements a specific condition for HIV prevention cooperative funding of states.

- Several states have begun their own process for developing state-specific guidance on HIV prevention partner notification (including Alaska, California, and

CDC

Follow-up Since State Certification of Compliance with Spousal Notification Requirements

(continued)

- CDC staff published scientific articles on HIV prevention partner notification in the peer-reviewed journals, emphasizing its importance especially as it relates to primary prevention and linkage of HIV-infected persons to antiretroviral treatment.

- Spousal notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences and workshops involving state/local HIV prevention programs and national organizations.

CDC

HIV Prevention Partner Notification/Spousal Notification: *New York State*

- The New York State health department does require a good faith effort to notify spouses as required by CDC and Federal law.
- New York State has reviewed its partner/spousal notification policies and confirms that its programs operate in accordance with national guidelines.
- The State has updated its protocols and training materials and is disseminating materials to promote the availability of partner notification services. Materials explicitly reference spousal notification requirements.

CDC

HIV Prevention Partner Notification/Spousal Notification: *New York State*
(continued)

- 9,174 sex or needle-sharing partners, including spouses, were notified and received HIV testing and counseling during the first two quarters of 1997. 396 (4.31%) were found to be HIV infected.
- Statements quoted in the New York Times on January 25, 1998, by New York City health officials incorrectly represented policies of the State.

CDC

HIV Prevention Partner Notification/Spousal Notification: *California*

- California renamed its program: "Spousal and Partner Notification" to emphasize spousal notification as a primary objective.
- The State revised its program and operational guidance to reflect the priority of spousal notification.
- It incorporated the spousal notification requirements into all State contracts with local health departments and other organizations to ensure statewide compliance.

CDC

HIV Prevention Partner Notification/Spousal Notification: *California* (continued)

- California developed training materials to emphasize the importance of spousal notification. Hundreds of counseling and testing staff will be trained in a statewide ($520,000) effort.

- The State presented to the California Medical Association and the California Conference of Local Health Officers to address implementation of spousal notification requirements in the private sector. The CMA adopted a resolution strongly supporting partner notification by private physicians.

CDC

HIV Prevention Partner Notification/Spousal Notification: *New Jersey*

- New Jersey asserted that administrative actions, policies, and practices have existed since 1988 which require a good faith effort to notify spouses. They have since reported to CDC that they are requiring a good faith effort as required by Federal law.

- State legislation was introduced in November 1996 to formally authorize HIV prevention partner notification, but did not pass.

CDC

HIV Prevention Partner Notification/Spousal Notification: *New Jersey*
(continued)

- 3,788 sex or needle-sharing partners, including spouses, were notified and received HIV testing and counseling during the first two quarters of 1998; 173 (4.56%) were found to be HIV infected. Situations involving HIV-infected persons who refuse to notify, or consent to allow the health department, are extremely rare.

CDC

Partner Counseling and Referral Data

- All States and territories must provide counseling, testing, and partner notification and referral services as a condition of receiving CDC HIV prevention funding.

- There is no national database with comprehensive information on Partner Notification/Spousal Notification activities. However, States, Territories and local areas participate in a national data system including more than 2 million tests annually reported from nearly 10,000 publicly funded counseling and testing sites.

CDC

Partner Counseling and Referral Data
(continued)

- While this system does not differentiate spouses from others who are sex or needle-sharing partners, it does list the reason for seeking HIV counseling and testing services including as partner referral or provider referral. It also tends to underestimate the number of persons who are referred by partners.
  - Of the 81,999 tests reported for 1996, 35,260 were referred by their partners, and 46,739 were referred by the health department; more than half were female.
    - 4.0% were HIV seropositive.

CDC

Partner Counseling and Referral Data
(continued)

- In the first two quarters of 1997, 68,556 tests were reported Of these, 29,896 were referred by partners, and 38,660 by the health department; like 1996, more than half were female.
  - 3.6% were HIV seropositive.
  - The 1997 partial year figures, if projected for a 12 month period, will show a significant increase in the number of partners who were referred.
- HIV/AIDS case reports, compiled and reported by state health departments, do not contain information on marital status. Reports are usually abstracted from medical records that do not include this information.

CDC

Spousal Notification Conferences

Spousal notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences, workshops involving state/local HIV prevention programs and national organizations including:

September 1996- April 1997	Numerous teleconferences with State AIDS program directors
October 1996	Scientific consultation on Partner Notification for HIV and other STDs
December 1996- June 1997	Multiple State site visits by CDC

CDC

Spousal Notification Conferences
(continued)

June 1997	External expert consultation to develop principles for CDC guidance for HIV Prevention Counseling and Referral Services
June 1997	National Organization Consultants
October 1997	HIV Satellite Prevention Teleconference reaching 12,000 health care providers nationwide

CDC

Spousal Notification Conferences
(continued)

March 1998	1998 HIV Prevention Summit meeting of 1,100 community planning co-chairs
July 1998	Follow-up assessment of State programs begins

CDC

Achieving an Optimal Partner/Spousal Notification Program in the United States

- States have clearly complied with Federal law requiring that a good faith effort be made to notify spouses of known HIV-infected individuals of their exposure to HIV — These efforts form the basic foundations of a program.

- States are supportive of increased efforts to reach, counsel, test, and refer spouses and other sex/needle-sharing partners at high risk for HIV. Almost all are trying to make this activity a high priority component of their comprehensive efforts to prevent HIV.

CDC

Achieving an Optimal Partner/Spousal Notification Program in the United States

- Achieving an optimal program versus meeting the minimal requirements of current law will require increased counseling and testing services, substantial increases in trained counselors, more access to antiretroviral treatment and other needed services, establishment of new data collection systems, and the resources to cover the costs of such a large, but urgently needed program.

CDC

FAX COVER SHEET

CENTERS FOR DISEASE CONTROL AND PREVENTION
DIVISION OF HIV/AIDS PREVENTION
1600 CLIFTON ROAD, N.E
MAILSTOP E-35
ATLANTA, GEORGIA 30333

Pages _____ **including this cover**

To: SANDY THURMAN **Date:** 7-23-98

Fax#: (202) 456-2439 **Tel#:** _____

From: Gary West
Office of Director
Tel#: (404) 639-5200
Fax#: (404) 639-0897

Subject: SPOUSAL/PARTNER NOTIFICATION MATERIALS

Comments: ATTACHED IS A COPY OF THE BRIEFING GARY PREESENTED TO REPRESENTATIVE COBURN AND A COPY OF THE DRAFT GUIDELINES ON HIV PARTNER COUNSELING AND REFERRAL SERVICES. IF I CAN BE OF FURTHER ASSISTANCE, PLEASE CONTACT MY SECRETARY, YULONDA WILLIAMS AT (404) 639-5200.

HIV PARTNER COUNSELING AND REFERRAL SERVICES

OPERATIONAL GUIDELINES

REVISED July 16, 1998

FOR OFFICIAL REVIEW ONLY – DO NOT DISTRIBUTE!

PREFACE

This operational guidelines document is intended to assist state and local health department HIV prevention cooperative agreement grantees in planning, implementing, and evaluating the services provided to partners of persons infected with HIV. External consultants and CDC staff collaborated in the development of these guidelines, which are intended to supplement current CDC cooperative agreement guidance for HIV prevention programs.

As opposed to *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.

The standards and guidelines contained in this document are all based on reviews of the relevant scientific literature, program experience, and expert opinion. The following principles constitute the basis for PCRS and are applied to issues discussed throughout this document:

PRINCIPLES FOR PROVIDING PCRS

1. **Voluntary, Confidential, and Ongoing Service** PCRS is a voluntary, confidential, and ongoing service for HIV-infected individuals, their sex and needle-sharing partners, and affected communities. Because PCRS, as do all HIV prevention activities, relies on the trust, mutual respect, and willing participation of HIV-infected individuals and their partners, it should never be made mandatory or coercive. Scientific studies have found repeatedly and program experience continually confirms that HIV-infected clients and their partners willingly cooperate. Further, counseling, testing, and referral to other related social or health services should not be made contingent on a client's willingness to disclose partner names. Publicly funded HIV prevention programs must ensure that PCRS is

available to *all HIV-infected individuals and their partners*, regardless of how the individual first learned his or her serostatus (publicly funded testing site, private physician, or home test kit, for example) and regardless of his or her ability to pay for services. PCRS can even be provided at anonymous testing sites and in states not requiring HIV name reporting.

2. **Part of Overall HIV Prevention Program** PCRS is only one component of an overall science-based public health program to prevent HIV infection. Its success is highly dependent on the success of other program components.

3. **Science-Based, Diverse Activity Requiring Skill and Training** PCRS is a science-based prevention activity that must be tailored to meet the individual needs of those being served. A multidisciplined team of professionals, some with backgrounds in medical and social sciences, is required to support effective implementation of PCRS. Each of these professionals must also have training specific to HIV prevention and PCRS activities.

4. **Client-Centered Counseling and Referrals to Other Support Services** Providing client-centered counseling in combination with assistance in accessing other related services can reduce behavioral risks for acquiring or transmitting HIV infection. Involving both the HIV-infected client and his or her partner in services such as couples or group counseling, substance abuse treatment, women's health services, or treatment for other sexually transmitted diseases, can enhance each person's efforts to avoid risky behavior.

5. **Support for Those Who Choose To Notify Their Own Partners** Client-centered counseling and support is an essential element of PCRS. Especially for those who choose to notify their own partners, client-centered counseling can assist in ultimately reaching more partners and minimizing unintended consequences of notification. Assistance for clients in deciding if, how, and when to disclose their HIV-positive status can help them avoid stigmatization, discrimination, and other potential negative effects.

6. **Ongoing Activity for HIV-Infected Individuals and Partners** PCRS is an ongoing activity. It begins as soon as an HIV-infected individual learns his or her serostatus, and it continues throughout that person's counseling and treatment. And, if and when 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.

7. **Provides Assistance with Medical Evaluation and Treatment To Prolong Life** Many HIV-infected persons who are unaware of or deny their risks can be assisted through PCRS in obtaining medical evaluation and treatment for HIV disease and opportunistic infections.

8. **Designed To Meet Community Needs** Acceptance of PCRS can be increased by designing culturally competent, linguistically specific services for HIV-infected persons and their partners. By listening to and understanding the valid concerns of affected communities, unintended consequences can be minimized, response to PCRS can be enhanced, and prevention benefits can be maximized.

9. **Research Support for Other Prevention Efforts** Although PCRS is not a disease surveillance mechanism, data from its activities can be used to enhance other prevention efforts and services. PCRS data can be used in identifying clusters of HIV transmission within social and sexual networks, neighborhoods, or affected communities. Prevention efforts and services can then be better targeted in clinical settings, counseling and testing sites, and communities.

10. **Increased Importance as New Technologies Emerge** As new technologies emerge such as vaccines, behavioral interventions, and even more effective new classes of antiretroviral therapies, PCRS will become an even more important prevention tool.

CONTENTS

HOW TO USE THIS DOCUMENT

This document describes 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, it is designed specifically for HIV prevention programs. It is not intended to replace or modify CDC guidance for partner notification for other STDs. Managers of agencies receiving CDC funds in support of HIV prevention programs are urged to follow the standards and guidelines contained in this document. Other organizations providing PCRS might also find that this document is a useful guide.

Several levels of guidance are provided. ***Standards*** are intended to be applied consistently, so they must be followed by CDC grantees in virtually all cases. To assist the reader, each standard is set apart from the other text in ***boldface italic print***. In addition, Appendix A is a concise listing of all the PCRS standards in the order discussed in the main document.

Guidelines are also discussed throughout this document. Guidelines ***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. In some instances, ***options*** and ***special considerations*** (Eddy, 1996) are discussed. These are intended to reflect the fact that different providers make different choices about how they serve their clients and communities.

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, trained health care personnel including physicians, nurses, counselors, or disease intervention specialists, who might be involved in serving HIV-infected clients, their partners, and the affected communities.

For technical assistance or inquiries, program managers should seek the advice of CDC project officers and consultants.

APPENDIXES

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 and West and Stark, 1997). 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."

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, referral, and partner notification 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 assistance available to HIV-infected persons, their partners, and the affected community.

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 life-long issue for those affected. Furthermore, because society frequently stigmatizes

and sometimes discriminates against HIV-infected persons and their families and friends, the manner in which PCRS is viewed by members of the affected community is extremely important. HIV prevention programs need the affected community's involvement in and understanding of PCRS for the overall prevention efforts to be accepted and effective.

Federal and state legislative mandates in the 1990s, such as the requirement to notify spouses of HIV-infected persons, have also underscored the importance of notifying sex and needle-sharing partners of their possible exposure to HIV. 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). Those public health policies and legislative actions 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 goals of –

1. Providing services to sex and needle-sharing partners of HIV-infected individuals so they can avoid infection or, if already infected, can prevent transmission to others; and

2. Helping partners gain earlier access to individualized counseling, medical evaluation, treatment, and other prevention services.

Through PCRS, persons – some of whom are unsuspecting – are informed of their possible exposure to HIV. Those individuals can then choose to be tested, and if found to be uninfected, they can practice 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. PCRS can also be instrumental in identifying high-risk sexual

and drug-injecting networks (Fenton and Peterman, 1997; West and Stark, 1997). Network research, combined with new methods of virus typing and identification of recently infected persons, will all contribute to a better understanding of HIV transmission and when during the course of infection transmission rates are greater (Fenton and Peterman, 1997). Future prevention interventions can then be more effectively implemented, and the spread of the virus eventually reduced.

1.3 WHAT ARE SOME OF THE CONCERNS ABOUT PCRS?

Using PCRS as a primary prevention activity in publicly funded HIV and STD programs is not without controversy or cost. Fenton and Peterman (1997) explored the financial costs (See also Sections 3.2.2 and 4.5) and the longstanding ethical dilemmas surrounding attempts to identify, locate, and notify partners. Certainly, in addition to the financial costs of staff and other resources necessary for operating a PCRS program, are the personal costs to HIV-infected clients and their partners.

Some ethical issues frequently debated about counseling and testing activities involving partners are confidentiality and intrusions on privacy, potential violence, and financial costs (Fenton and Peterman, 1997). This document is intended to assist PCRS providers in maximizing the benefits to clients and minimizing the potential for negative consequences.

1.4 WHO BENEFITS FROM PCRS?

Clearly, three distinct beneficiaries of PCRS are (1) persons with HIV infection; (2) their partners and contacts; and (3) affected communities (Fenton and Peterman, 1997). Through client-centered counseling, HIV-infected persons can receive education about risky behavior 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 *at al.*, 1996 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, which is particularly helpful 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 risky 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.

Evidence is also accumulating that antiretroviral therapy might reduce, at least at a population level, the infectivity of HIV. A particular concern is that some might misinterpret that antiretroviral therapy now provides a cure for HIV and be less concerned about being safe or exposing others. Therefore, the role of PCRS, earlier diagnosis, and prevention and treatment services might have future prevention benefits in reducing future rates of HIV transmission.

PCRS can also greatly benefits affected communities. Effective PCRS can improve disease surveillance, identify disease networks, increase dissemination of HIV prevention information (Fenton and Peterman, 1997), and assist a comprehensive program in lowering the transmission rate of HIV.

1.5 WHERE AND WHEN SHOULD PCRS BE INITIATED?

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

PCRS should also be made easily accessible to patients of other health care providers such as private care physicians and community clinics.

The HIV-infected client must have a good understanding of PCRS and be willing to participate before activities can begin.

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. But the HIV-infected person is the "gatekeeper" to the partners, so PCRS cannot actually begin until that person understands the benefits for themselves and their partners and is willing to participate voluntarily.

1.6 WHAT ACTIVITIES ARE INVOLVED IN PCRS?

PCRS, as illustrated in Fig. 1, can be thought of as beginning and ending with an individual seeking HIV prevention counseling and testing. A brief overview of the activities associated with PCRS is included in this section, but more detailed discussion is 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 risk of acquiring or transmitting HIV;

2. Developing a plan for reducing or eliminating risky behavior for themselves and their partners; and

3. Realizing their responsibility, if HIV test results are positive, for informing their partners of 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** During the initial counseling and testing session, the provider (might be one of many types of professionals) should explain (1) how HIV testing will be conducted if the client does choose to be tested, and (2) all the available options for PCRS. Once a client's test results are confirmed positive, that person should be provided an opportunity to receive partner counseling and referral services.

- **PCRS Provider and Client Together Formulate a Plan and Set Priorities** The PCRS provider (might or might not be the same as the previous provider) will first need to counsel the client on if, how, and when specific partners should be informed of their risk of exposure. No one's HIV serostatus should be revealed to others. Then, the client and PCRS provider together can decide on a plan for reaching partners. The plan should be one that will result in each partner being (1) informed of possible exposure to HIV; (2) provided accurate information about HIV's transmission and prevention; (3) assisted in accessing counseling, testing, and other support services; and (4) cautioned about revealing serostatus of himself/herself or original client to others. 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 Partner Information for Those the PCRS Provider Will Inform** 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 will attempt to inform.

- **Client and/or Provider Inform Each Partner of Possible Exposure to HIV** The client and /or the PCRS provider inform each sex or needle-sharing partner who can be located of his or her possible exposure to HIV. (Ideally, the partner would always be informed confidentially and 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 Assist Partner in Accessing Counseling, Testing, and Other Support Services** At the core of PCRS is referring the now-informed partner to counseling, testing, and other social and medical services. If on-the-spot testing for HIV and other STDs is not practical, each partner should receive, immediately upon being informed of possible exposure to HIV, a service provider referral list for obtaining client-centered counseling and testing. Some partners will also need immediate referrals for physical 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 the community perceives the value of such efforts to public health. Quality assurance for services provided, routine staff and program evaluations, and network analysis are, therefore, necessary components of PCRS. Ensuring, for example, that strict confidentiality is maintained for all persons involved in PCRS will perpetuate community support and involvement. Each of these is discussed in more detail in Section 6.0, "Ensuring the Quality of PCRS."

2.0 AVAILABILITY OF PCRS

2.1 MAKING SERVICES AVAILABLE TO ALL HIV-INFECTED CLIENTS

Publicly funded programs must make PCRS available to all HIV-infected clients, regardless of how their test results were obtained.

Persons might learn that they are HIV-infected, or might come to suspect that they are, through a variety of sources, including such sources as confidential and anonymous testing sites, private care physicians, or home test kits. Some PCRS providers might require that test results that have come from any other source be confirmed. But, regardless of where and how a person has been tested, PCRS must be made available.

The client who has just been informed of being HIV-infected will, of course, need to have PCRS offered immediately, 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 now has new sex or needle-sharing partners;
- A previously identified HIV-infected client who is now seeking additional STD or family planning services or substance abuse treatment; or
- An HIV-infected sex or needle-sharing partner who has other partners than the original HIV-infected client.

If the person being offered PCRS has not yet been tested for HIV themselves, client-centered counseling techniques can assist them in deciding whether to seek testing and how to reduce their future risk if uninfected with HIV.

HIV prevention program staff should ensure that private physicians in their area are aware that PCRS is available at publicly funded sites and are aware of how to access those services. PCRS providers will need to take a proactive approach to ensure that HIV-infected patients of private physicians are informed about the availability of PCRS at publicly funded sites. Printed information that the physician can distribute and a formal agreement between the PCRS provider and the private physician can better ensure that private-care patients are aware of how to access these services.

2.1.1 Services for Those Persons Tested Anonymously

Anonymous counseling and testing sites must provide PCRS without requiring that the infected client disclose his or her identity.

An HIV-infected client must not be denied PCRS because he or she has been tested anonymously and chooses to remain anonymous. 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 provided counseling on how to enter a confidential system and strongly encouraged to do so. This will assist them in receiving medical care and other services including PCRS. Although collecting information about sexual and drug-injecting networks is more difficult in anonymous settings, an HIV-infected client has a right to maintain anonymity.

2.2 OTHER SERVICE CONSIDERATIONS

2.2.1 Inability To Pay

All HIV-infected clients must be offered PCRS regardless of ability to pay (CDC, 1993).

If fees for services are charged, providers receiving CDC funds should have a mechanism in place to ensure that no HIV-infected client will be denied PCRS if unable to pay. However, CDC encourages all providers to offer this service without charge because of the public health benefits.

2.2.2 Accommodating Requests from Other Health Jurisdictions

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

PCRS providers might sometimes be asked to contact the partner of an HIV-infected person residing in another health jurisdiction. For example, a PCRS provider might request that the staff in a neighboring state health department assist in informing a former spouse of an HIV-infected client. An effort must be made to accommodate that request if it complies with state and local regulations and policies.

3.0 DECIDING ON A PCRS PLAN AND SETTING PRIORITIES

3.1 ENCOURAGING CLIENT PARTICIPATION

3.1.1 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.

Providers' environmental settings should be comfortable enough so that clients are encouraged to participate in PCRS without feeling fearful or coerced. Frequent reminders of the voluntary nature of PCRS and of how privacy will be maintained for clients and partners alike will be necessary before some individuals feel secure enough to participate.

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.

How well the provider fosters an atmosphere of trust, respect, and easy 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 the original client but also with each of their partners. This ability to develop trust and rapport will also influence the PCRS provider's effectiveness when working in the community.

3.1.3 Introducing PCRS

All persons entering publicly funded HIV prevention programs must be counseled at the earliest opportunity about PCRS and options for informing sex and needle-sharing partners of possible exposure to HIV.

Using a client-centered counseling approach (CDC, 1994), the health care provider should begin discussing the client's relationships with his or her partners during the client's first visit, and in some cases, even before the decision to be tested has been made. 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.

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 a fear of a violent reaction from a partner or suicidal ideation When the provider demonstrates genuine concern for the overall well-being of the client during discussions about partners, the provider encourages greater client participation in PCRS.

3.2 FORMULATING A PCRS PLAN

The PCRS provider must explain to the HIV-infected client all the options for serving partners and then assist that client in deciding on the best plan to confidentially reach each partner and refer them 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 also Section 3.2.1). (NOTE: The terms ***patient referral*** and ***self referral*** are sometimes used in other literature 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 also Section 3.2.2).

Sometimes a combination of the two approaches is used. With the ***dual-referral*** approach, the PCRS provider and the client are together when one or the other informs the partner of the client's positive HIV serostatus. This approach gives the client the support, and perhaps safety, of having a professional counselor present. The ***contract referral*** approach is similar, but the PCRS provider does the informing only if the client does not notify the partner within a negotiated time period.

The PCRS provider should explain to the client all available options for serving 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 roleplaying, for example, might help the client overcome barriers to participating in PCRS and help them better prepare for their part in those activities.

3.2.1 Taking a Closer Look at the Client Referral Approach

When HIV-infected clients choose to inform their partners themselves, they usually need some assistance to succeed or at least minimize any potential negative consequences. The PCRS

provider should, therefore, be prepared to coach the client on –

1. The best ways to inform each partner;

2. How and where each partner can access HIV prevention counseling and testing;

3. How to deal with the personal impact of disclosing one's HIV status to others; and

4. How to respond to a partner's reactions, including the possibility of personal violence.

Despite the provider's coaching, however, the client's lack of counseling skill and experience might result in unsuccessful or ineffective PCRS. 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.

Two other serious disadvantages of the client-referral approach are –

1. The client forfeits anonymity to partners, increasing the potential for disclosure of serostatus to third parties, subsequent discrimination, or partner repercussion.

2. The client might unintentionally convey incorrect information about HIV transmission, available support services, confidentiality questions, and so forth.

For anonymous test sites, the client-referral approach poses a slightly different problem because some clients give the provider little or no information about partners. The provider might not be able, therefore, to ensure that PCRS has been successful and might not be able to perform any network analysis. One solution, then, is for anonymous test site providers to encourage the client to voluntarily enter a confidential setting for PCRS and/or additional medical follow-up. Here again, an appropriately detailed discussion with the anonymous client of how confidentiality will

be maintained for themselves and their partners can ease the transition of an anonymous client to a confidential setting. That transition will also be eased if the client is 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 be easily transferred to the confidential setting.

At confidential test sites, PCRS providers should make every effort to follow up with each HIV-infected client to assess how well he or she has progressed with PCRS. Whenever possible, careful monitoring of which of the client's partners do actually access counseling and testing services can greatly enhance quality assurance and program evaluation. This will also help assure 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 result in a prompter partner referral to counseling and testing. Also, some clients apparently 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, fewer staff and resources are consumed than with the provider-referral approach, so the financial burden for HIV prevention programs is lessened.

3.2.2 Taking a Closer Look at the Provider-Referral Approach

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 much more easily 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 able to help 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-injecting networks, thus potentially enhancing the overall HIV prevention efforts in the affected community.

One of the disadvantages of the provider-referral approach is 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 affected community leaders (Fenton and Peterman, 1997; West and Stark, 1997). The HIV prevention program incurs substantial expense for staff and resources when the provider is responsible for locating and informing partners. For example, Fenton and Peterman (1997) found that financial costs for provider referral are between $33.00 and $373.00 per partner notified and between $810.00 and $3,205.00 per infected partner notified. This program expense, however, is greatly offset in the long run because PCRS frequently reaches persons who do not suspect having been exposed to HIV. Once informed, they can access prevention counseling and testing, and if HIV-infected, they can enter treatment earlier.

A simple threshold analysis presents the cost effectiveness of PCRS to society. Assuming $154,402 lifetime cost in the United States of a person acquiring HIV infection and eventually dying from HIV-related illness and $3,205.00 cost of PCRS to reach one infected person, PCRS must prevent 1 infection out of 51 recipients of PCRS to be cost effective. Greater effectiveness, such as preventing only 2-3 infections fore every 51 recipients, would convey substantial cost savings to society.

3.2.3 Taking a Closer Look at the Combined Approaches

Two variations on provider and client referral are the dual- and contract-referral approaches, each of which combine the advantages and disadvantages of provider and client referral.

Dual Referral Some HIV-infected clients feel that their partners would be best served by having both the client and the provider present when the partner is informed. The dual-referral approach works well for these clients. The PCRS provider is available to render immediate counseling, answer questions, allay concerns, provide referrals to other services, and in some cases thwart 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. The provider still needs to coach and support the client as with the client-referral approach.

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, three days for example, during which the client will contact and refer the partners. If the client is unable to complete the task within that agreed-upon time, the PCRS provider then has the permission and information necessary to serve the partner. 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 fails to inform the partner before the time limit expires.

When the contract-referral approach is used, the PCRS provider should also negotiate a provision whereby the partner confirms in some way to the provider that he or she has been informed of being at risk. Otherwise, the provider has no way to monitor which partners have been informed or to follow up with other professional services for the partner.

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 also be infected and who is most likely to be located.

The PCRS plan must include prioritizing which sex or needle-sharing partners need to be reached first, based on each client 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 the most likely to be infected already; (2) which partners are the 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 priority be given to notifying current spouses or persons who have been spouses during the past 10 years** [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, such as the following:

- **Number of Partners the Client Has Had** Obviously, if the client has had only one partner during his or her lifetime, that partner is very likely to be infected. When the client has had more than one partner, other factors then have to be considered.

- **History of Negative Test Results** If, for example, the client had a negative HIV test result six months ago, but now the test result is positive, partners within that six-month time period would receive priority.

- **Partners at Continuing Risk** Reaching the client's current, recurring, or recent partners is a high priority because those partners might be at continuing risk of becoming infected with HIV, if not already infected.

- **History of Other STDs** Either the client or partner's history of other STD infections is an important factor. If the client knows, for example, that a previous partner was treated for another STD during a certain time period, that partner is more likely to also be infected with HIV and additionally, more likely to be transmitting HIV to others.

- **Possible Transmission of HIV to Others** The partner who is most likely to transmit HIV to others must receive high priority. For example, if the partner is a pregnant woman, she would need to be reached as soon as possible for counseling, testing, and referral to medical treatment if infected, to avoid transmission to the child. Likewise, the partner who the client knows has multiple other partners needs to be reached as soon as possible to lessen the spread of HIV to others.

- **Transmission of Strains of HIV That Are Resistant to Antiretroviral Therapies**

The PCRS provider and client should begin by noting current or recent partners. 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 and locatability of partners might permit. Some HIV prevention programs routinely attempt to locate and counsel all partners within a defined time period of each partner's exposure. This time period, often 1-2 years, is frequently based on availability of resources. Programs with greater amounts of resources or that decide to give higher priority to PCRS attempt to reach and counsel partners exposed over a longer time period.

Once the provider and client have established the priorities, they can begin discussing the details of each partner's exposure. For those partners the provider will be contacting, exact locating information, plus the dates, types, and frequency of exposure will need to be noted (See also Section 4.2). During this phase, new information about partners might come to light that necessitates adjustments in the priorities previously established.

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 partners, but who are integral to a sexual or drug-injecting network. Although not direct partners of the HIV-infected client, these other persons should be offered HIV prevention counseling and testing, if the resources of the program permit. CDC encourages such efforts to identify and lower risks of HIV and other STDs within social or sexual networks.

3.4.2 "But, I Do Not Want My Partner To Be Contacted!"

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 an HIV-infected client will simply not want his or her partners notified. The client might claim that the partners have already been informed about their risks, or

they might claim that the partner 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. When clients are determined, however, not to disclose partner names, the PCRS provider will probably have to counsel the client as if he or she is choosing the client-referral approach.

In some cases, the provider already knows of a partner at risk even though the client has not identified that partner. Whether or not a legal "duty to warn" (See Appendix B) exists for PCRS providers is best determined by applicable state laws or regulations, especially regarding spousal notification. All states should have a policy established to guide health department staff in situations where 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 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 (ASTHO, 1988; West and Stark, 1997). State and local HIV prevention program managers should consider the ASTHO recommendations and their own relevant laws when developing policies and procedures.

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.

The manner in which PCRS is perceived by the affected community determines, in large part, how successful HIV prevention programs will be (See Section 4.5). Therefore, program managers and supervisors should ensure that PCRS providers –

- Have appropriate and culturally competent counseling skills;
- 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 regarding the right to privacy and confidentiality;
- Receive updated information and periodic retraining as appropriate; and
- Are appropriately supervised and given written and oral feedback about their performance on a regular basis.

In addition to formal training, 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 also Section 6.1). Routine peer review of selected cases is another way to enhance a provider's performance.

In reaching some partners, the provider sometimes goes outside the clinic or office setting. Providing PCRS in a client's home, for example, sometimes comforts the client and helps the provider better understand the personal circumstances of the client and partner. However, 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 making this decision, the provider must consider such factors as safety issues or a possible adverse outcome on those PCRS is intended to serve (Fenton and Peterman, 1997). The inexperienced provider will need training in deciding when to provide PCRS outside the office or clinic. In addition, training in avoiding confrontations, diffusing anger, and meditating 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.

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 which partners to attempt to reach first. By this point, the client should be well-coached on how to best inform those partners he or she will be informing.

For those partners the provider will be contacting outside the clinic or office setting, the first step the provider should take is to verify the identifying and locating information provided by the

HIV-infected client. Standard resources such as city directories should be available for the PCRS provider to verify as much information as possible before attempting to make the first contact.

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.

As the PCRS provider works in the community serving partners, confidentiality for all persons involved must continue to be maintained. Ideally, attempts to make contact with a sex or needle-sharing partner should be confidential. This is often not possible as other community members might ask the purpose of the provider's visit and why he or she is attempting to make contact.. The provider should not, for example, reveal to others why he or she is trying to find a particular person. Likewise, any note or message left for a partner should not say HIV exposure is the reason the provider is 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 break of confidentiality.

As each partner is located, he or she should be informed privately and face-to-face, if at all possible. Informing a partner by telephone might become necessary if the person refuses to meet with the provider, for example. This should only be done, however, after every step has been taken to ensure that the correct person has been located, is on the telephone, and others are not listening.

The original HIV-infected client will sometimes inquire about the results of the PCRS provider's

activities regarding the 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 they are HIV-infected. Of equal importance is not revealing any identifying information about the original client to the partner, including the person's 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. Personally identifying information regarding partners should be kept locked up in a secure location. Client and partner information, other than the official record, should be destroyed when PCRS activities are concluded.

4.4 GOING BEYOND MERELY INFORMING PARTNERS

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.

Testing for HIV is another very important issue to the person who has just learned of possible exposure, so the provider must be prepared to, at a minimum, refer them to 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 collection kits, and rapid testing systems, program managers might want 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 a another test at a public health facility.

Beyond counseling and testing services, however, many partners will need referrals for other kinds of social and medical support services. The PCRS provider should already have formal agreements in place and an up-to-date resource guide so that immediate referrals can be made to other services such as substance abuse treatment, family planning assistance, other STD treatment, or housing assistance (CDC, 1993). Having formal agreements in place for collaboration between PCRS providers and referral sources will 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, follow up with that provider should be conducted to determine the outcome.

4.5 ADDRESSING COMMUNITY CONCERNS

The potential exists for partner notification activities to have a negative impact on HIV-infected individuals, their partners, or the affected community (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 other health care services if the HIV-infected client refuses to reveal partner names or cooperate with other coercive practices by providers;

- 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. PCRS providers should be prepared, whenever an opportunity arises, to correct misconceptions about policies and practices and to address legitimate concerns about confidentiality (West and Stark, 1997).

5.0 COLLECTING, ANALYZING, AND USING PCRS DATA

5.1 WHY COLLECT PROGRAM DATA?

PCRS data are collected and used (1) to assess the scientific and behavior 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 directed.

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 intervention (CDC, 1994). Moreover, PCRS data enable providers to better focus prevention efforts on those persons most at risk. When the data include information about sexual and drug-injecting networks, 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 scientific and behavioral risk, HIV/AIDS prevalence, and demographics of the affected community. With accurate and consistent data, the staff of health departments, community-based organizations, and community planning groups can establish an effective mix of prevention strategies.

5.2 WHAT DATA SHOULD BE COLLECTED?

PCRS providers must collect data that answer key questions about how well the PCRS program is functioning, the extent and quality of services actually 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.

PCRS providers must use a standardized data collection tool throughout the program that does not violate the privacy or confidentiality of the original HIV-infected client nor 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 the answers to the following:

- What is the proportion of HIV-infected clients who are offered PCRS?
- What is the range of services offered to and accepted by each client?
- What are the reasons those clients either reject or accept PCRS?
- What is the percentage of partners actually reached through PCRS and how many of those partners are HIV-infected?
- What are the demographics (age, sex, race/ethnicity, risk behaviors, and so forth) of the clients and partners actually served?

692 And, perhaps most importantly,

693 • What does all of this information mean in regard to how well PCRS is working for HIV-
694 infected clients, their partners, and the community at large?

695 To obtain PCRS data that are readily collectable, relevant, and usable, the data collection tool can
696 be designed to include some or all of the following information:

697 • Which program or service sites are providing PCRS?

698 • What are the demographic characteristics of the HIV-infected clients?

699 • When are services provided (dates, for example)?

700 • What are the demographic characteristics of the partners?

701 • What is the relationship between client and partner (sex or drug-injecting, for example)?

702 • How is one relationship between a client and partner connected to any other relationship?

703 • What services are chosen by the clients? By the partners?

704 And,

705 • How do clients and partners rate the services they receive?

706 The HIV prevention program managers in each health jurisdiction will have to decide how best
707 to collect, analyze, and use PCRS data. Those managers should keep in mind, however, that
708 misconceptions about the collection and use of HIV data in addition to a general mistrust of

709 publicly funded agencies are two of the biggest barriers in affected communities to HIV
710 prevention efforts.

711 # 6.0 ENSURING THE QUALITY OF PCRS

712 ## 6.1 EVALUATING PCRS

Resources necessary for providing quality PCRS include adequate staff, facilities, supervision, and training, with each of these evaluated on an ongoing basis.

713 Quality assurance for PCRS program entails ensuring that appropriate and standardized
714 methods are used for –

715 1. Counseling HIV-infected clients regarding the notification of their partners;

716 2. Developing a PCRS plan;

717 3. Prioritizing the order in which attempts to reach partners will be made;

718 4. Locating and informing those partners of their possible exposure to HIV;

719 5. Providing immediate counseling and testing services to informed partners and/or referring
720 them to other service providers; and

721 6. Collecting, analyzing, using, and storing PCRS data.

Of all the resources necessary for the successful operation of PCRS programs, however, training is perhaps the most critical (Fenton and Peterman, 1997). At a minimum, each individual PCRS provider must receive initial basic training plus periodic retraining in –

1. Conducting each facet of PCRS;

2. Client-centered counseling techniques;

3. Protecting individuals' rights to privacy and the laws regarding confidentiality of medical records;

4. Understanding and using scientific information about HIV prevention;

5. Defusing potentially violent situations involving clients, partners, or staff;

6. Stress management;

7. Administering HIV tests, if appropriate; and

8. Career development issues.

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.

The overall program should also be frequently evaluated to determine the quality of effort and the possible impact PCRS has had on the affected community's HIV prevention efforts (Fenton and Peterman, 1997). Program evaluations should include a comprehensive assessment of all confidentiality procedures that includes, at a minimum, record keeping.

6.2 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, documentation on the latest scientific findings about HIV is available through the CDC National AIDS Clearinghouse (toll-free, 800-458-5231).

REFERENCES

Association of State and Territorial Health Officials (ASTHO). *Guide to Public Health Practice: HIV Partner Notification Strategies*. Public Health Foundation: Washington, D.C., 1988.

Centers for Disease Control and Prevention. *HIV Counseling, Testing, and Referral: Standards and Guidelines*, Atlanta, Georgia, May 1994.

Centers for Disease Control and Prevention. "Technical Guidance on HIV Counseling." *Morbidity and Mortality Weekly Report; Recommendations and Reports*, Vol. 42, No. RR-2, January 15, 1993, pp. 8-17.

Centers for Disease Control and Prevention. *HIV Prevention Case Management: Guidance*. Atlanta, Georgia, September 1997.

Eddy, David M. "Designing a Practice Policy: Standards, Guidelines, and Options." *Clinical Decision Making; From Theory to Practice: A Collection of Essays from JAMA*. BOSTON: Jones and Bartlett Publishers, 1996, pp. 57-62.

Fenton, Kevin A. and Peterman, Thomas A. "HIV Partner Notification: Taking a New Look." *AIDS*, Vol. 11, No. 13, November 1, 1997, pp. 1535-1546.

Kamb, M. *et al.* "A Multi-Center, Randomized Controlled Trail Evaluating HIV Prevention Counseling, Project Respect: Preliminary Results." (Abstract TH.C.4380). *Abstracts of the Eleventh International Conference on AIDS*, Vol. 2, p. 315.

Landis, S. E. *et al.* "Results of a Randomized Trial of Partner Notification in Cases of HIV Infections in North Carolina." *New England Journal of Medicine*, Vol. 326, No. 2, January 9, 1992, pp. 101–106.

Levy, Judith A. and Fox, Susan E. "The Outreach-Assisted Model of Partner Notification with IDUs." *Public Health Reports*, Vol. 113, Supplement 1, June 1998, pp. 160-169.

Parran, Thomas. *Shadows on the Land.* New York: Waverly Press, 1937.

West, Gary R. and Stark, Kathleen A. "Partner Notification for HIV Prevention: A Critical Reexamination." *AIDS Education and Prevention: HIV Counseling and Testing*. Vol. 9, Supplement B, June 1997, pp. 68–78.

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 guidelines can be found.

- All publicly funded HIV prevention counseling and testing sites, both confidential and anonymous, must make PCRS available to all clients. (Section 1.5)

- The HIV-infected client must have a good understanding of PCRS and be willing to participate before activities can begin. (Section 1.5)

- Publicly funded programs must make PCRS available to all HIV-infected clients, regardless of how their test results were obtained. (Section 2.1)

- Anonymous counseling and testing sites must provide PCRS without requiring that the infected client disclose his or her identity. (Section 2.1)

- All HIV-infected clients must be offered PCRS regardless of ability to pay (CDC, 1993). (Section 2.2)

- Requests for PCRS from other health jurisdictions must be accommodated whenever practicable. (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)

- All persons entering publicly funded HIV prevention 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 review with the HIV-infected client all the options for serving partners and then assist that client in deciding on the best plan to confidentially reach each partner and refer them 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 also be infected and who is most likely to be located. (Section 3.3)

- PCRS providers must explain to 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)

- PCRS data are collected and used (1) to assess the scientific and 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 directed. (Section 5.1)

- PCRS providers must use a standardized data collection tool throughout the program that does not violate the privacy or confidentiality of the original HIV-infected client nor his or her partners. (Section 5.2)

- Resources necessary for providing quality PCRS include adequate staff, facilities, supervision, and training, with each of these evaluated on an ongoing basis. (Section 6.1)

APPENDIX B

GLOSSARY OF TERMS ASSOCIATED WITH PCRS

This operational guidelines document uses the following concepts and terminology:

Client-Centered Prevention Counseling — 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.

Client-Referral Approach — 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.

Confidential — 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.

Contract-Referral Approach — 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.

Dual-Referral Approach — A PCRS approach whereby the HIV-infected client and the provider inform the partner together.

Duty To Warn	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."
Partner	A person who shares sex or drug-injection needles with another.
PCRS	Partner counseling and referral services.
PCRS Provider	A wide variety of qualified, trained health care professionals including physicians, nurses, counselors, disease intervention specialists, and others.
Prevention Counseling	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.
Privilege To Disclose	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.

Provider-Referral Approach

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.

Spouse

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

ACKNOWLEDGMENTS

[This section to be updated with appropriate names or deleted]

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

Steven J. Davis
Division of HIV/AIDS Prevention

John H. Glover
Division of STD Prevention

Robert Kohmescher, M.S.
Division of HIV/AIDS Prevention

Kellie E. Lartigue, M.A.
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

Thomas A. Peterman, M.D., M.S.
Division of HIV/AIDS Prevention

C. Kay Smith-Akin, M.Ed.
Division of HIV/AIDS Prevention

Gary R. West, M.P.A.
Deputy Director
Division of HIV/AIDS Prevention

Linda Wright-Deaguero, Ph.D.
Division of HIV/AIDS Prevention

Testimony on Hearing for HR 4431 (DRAFT)

I am Dr. Helene Gayle, Director of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention. Thank you for the opportunity to testify today about issues related to HIV prevention partner counseling and referral services in the context of H.R. 4431, the HIV Partner Protection Act. I'm especially happy to be here because it's an opportunity for me to share with you CDC's updated guidance on HIV partner counseling and referral services -- which has just been released for public comment.

However, before we focus on partner counseling and referral services, let me briefly describe the major goal of HIV prevention in this country and the sound public health approaches that we think are needed to achieve this goal. Our goal is to prevent HIV infection by reducing behaviors likely to transmit the virus and assisting individuals at risk or already infected in gaining access to prevention services, medical care, and other needed services. This ambitious goal can be achieved only by using a comprehensive strategy. Elements of this strategy must include monitoring the epidemic; informing the public regarding risk and modes of transmission; conducting health education and risk-reduction activities, including school-based education efforts for youth; promoting and implementing HIV prevention counseling and testing; providing referrals for medical treatment as well as prevention and social services; and promoting and implementing STD screening and treatment. An essential component of HIV counseling and testing is reaching out to and counseling sex and needle-sharing partners of persons identified as HIV positive. These partners are often unaware that they have been exposed to HIV and some may already be infected. All must have access to counseling, testing, and other prevention or

treatment services. Each of these elements contributes to preventing the spread of HIV. Together, they become a powerful prevention strategy. No single activity, by itself, will achieve the overall goal of preventing new HIV infections.

I will briefly describe CDC's current recommendations for partner counseling and referral services, or PCRS, and our current requirements for programs providing these services. The goals of PCRS are, first, to provide services to sex and needle-sharing partners of HIV-infected individuals so they can avoid infection or, if already infected, can prevent transmission of HIV to others; second, to help HIV-infected partners gain earlier access to counseling, medical evaluation, and other prevention, treatment, and support services. CDC has required States to establish standards and implement procedures for PCRS since 1988, when it was referred to as "partner notification."

PCRS is a process that begins when people receive HIV prevention counseling and testing and is carried out by different health professionals in a wide range of counseling and testing settings. If a person tests positive, the PCRS provider and client together formulate a plan for reaching any sex or needle-sharing partners. The plan should be one that will result in each partner's being informed of possible exposure to HIV and provided with accurate information and counseling about HIV transmission and prevention. Next, the HIV-infected client voluntarily discloses identifying information about partners, and the client and/or the provider informs each partner of possible exposure to HIV. The next step is really the core of PCRS practice: assisting the partner in accessing additional counseling, testing, medical care, and other support services. Throughout this process, the confidentiality of the infected person's identity and that of their partners must be preserved.

The ability to successfully identify the exposed individual is directly dependent on establishing trust with the infected person. This is a critical point that has always been a cornerstone of partner services for HIV and all other STDs. The PCRS process, by its nature, is a voluntary one on the part of the client. A client who tests positive for HIV or any other STDs cannot be mandated to reveal names of partners. In the wake of receiving an HIV-positive test result, clients may fear discrimination, abuse, or domestic violence; they may fear the loss of a job, health insurance, housing, or the loss of important personal relationships. The success of the PCRS process absolutely hinges on the trust and cooperation of the person living with HIV, their partners, and their communities. We know that people will cooperate if they believe that their confidentiality will be protected; otherwise they may avoid the system altogether. The way to maximize the public health benefit is to have a valuable service -- one with skilled counselors fully supported by adequate resources -- that people perceive as beneficial and easy-to-use.

Partner counseling and referral services related to HIV infection have evolved from similar services, known as "contact tracing," that were begun in this country in the 1930s as a method of preventing the spread of syphilis. This prevention effort was called contact tracing because public health workers would, and still do, conduct analyses to determine which sex partners were most likely to be infected and then make confidential efforts to locate them and provide treatment. Contact tracing services later expanded to include partners of persons infected with gonorrhea and other sexually transmitted diseases, including HIV, and came to be known as "partner notification" in the 1980s. Today, the term "HIV partner counseling and referral services" more accurately reflects the range of services available to HIV-infected persons, their partners, and affected communities through this essential public health activity.

But of necessity, PCRS for HIV differs from partner services for other STDs. The primary difference is that, despite recent advances in treatment, we do not yet have a cure for AIDS, so HIV, unlike syphilis and gonorrhea, remains a life-long issue for those affected. For HIV-infected persons, PCRS needs to be continuously available. The process begins as soon as an HIV-infected person learns their serostatus, and it continues throughout that person's counseling and treatment. If new partners are exposed in the future, PCRS is again utilized. Also, because society frequently stigmatizes and sometimes discriminates against HIV-infected persons and their families and friends, counseling and support must be provided for clients who choose to notify their own partners. For exposed partners who test positive for HIV, PCRS provides assistance in reducing risks posed to others and accessing medical evaluation, treatment, and other prevention and support services to prolong life. As new prevention tools emerge, such as vaccines, better behavioral interventions, and more effective antiretroviral therapies, PCRS will almost certainly become an even more important prevention tool.

States, territories, and local areas contribute to a national data system maintained by CDC that includes information on more than two million HIV tests reported annually from nearly 10,000 publicly funded counseling and testing sites. While this system does not differentiate spouses from others who are sex or needle-sharing partners, it does record the reasons for seeking HIV counseling and testing services, including referrals by partners and health departments. In 1996, 81,999 tests were conducted for people who were referred from a variety of health care delivery settings; of these, 35,260 (43 percent) were referred by their partners, and 46,739 (57 percent) were referred by the health department. More than half of all the people referred were female. Many of these persons did not realize they might have been exposed to HIV and thus did

not consider themselves at risk for infection until they received the referral. Nationally in 1996, 4 percent of these referred partners tested HIV seropositive, and in some areas up to 15 to 20 percent were HIV positive. This represents a much higher rate than the national average of 1.5 percent who tested HIV positive at publicly funded test sites that year. These data underscore the importance of the PCRS process in reaching high-risk populations and providing individuals with the critical linkage to appropriate prevention and treatment services. The data also illustrate the degree of success PCRS has already demonstrated.

Concerning the effectiveness of PCRS, we know that, in general, HIV-infected persons and their partners readily accept PCRS and, with appropriate counseling, will not only provide confidential and very sensitive information, but will actively assist in finding and encouraging partners and spouses to receive counseling and testing. Also, when located, sex partners are generally receptive to confidential notification by the client or the health department and will usually seek HIV testing. Another indication of the efficacy of PCRS is the fact that many people at high risk for infection are linked by this process to prevention services that have been proven to be effective.

Notwithstanding these benefits to public health, it is also important to note the practical limitations of PCRS. Frequently it is difficult or impossible to determine exactly when a person became infected with HIV and when specific sex or needle-sharing partners were exposed to the virus. During the potentially long period during which the virus could have been transmitted, the HIV-infected person may have had many partners. In addition, the HIV-infected person may not be able to identify all partners or know how to reach others who are known. Because of the long time periods involved, often it is difficult for the client or health department to locate all the

partners, especially those exposed years earlier. Also, while many HIV-infected persons willingly participate in PCRS, fear or misunderstanding of health department policies and practices may keep some HIV-infected persons from coming forward or revealing information needed to reach partners and spouses. A climate of trust, confidentiality, and understanding is essential; without it, this highly effective and targeted intervention is jeopardized. Another limitation is the lack of human and financial resources in the public health arena necessary to carry out this important prevention activity.

Let me now describe some of the numerous ways that CDC has been working to further strengthen and enhance PCRS activities. As a result of the reauthorization of the Ryan White legislation, each State is required to certify to CDC in writing the State's intent to comply with the spousal notification requirements contained in the legislation. Programmatic and legal staff of CDC and the Health Resources and Services Administration have developed procedures and criteria for certifying each State's compliance with Ryan White CARE Act requirements that mandate that States make a good faith effort to notify spouses of known HIV-infected individuals. All States certified compliance by February 1997 and have taken action to implement spousal notification. No State opposed the requirements.

In addition to the specific activities related to spousal notification, CDC also provides technical assistance and guidance to help States achieve optimal performance in their PCRS programs. Spousal and partner notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences, and workshops involving State and local HIV prevention programs and national organizations. CDC has published scientific articles on HIV prevention partner notification in peer-reviewed journals, emphasizing its importance, especially

as it relates to primary prevention and linkage of HIV-infected persons to treatment. CDC has delivered training on PCRS through a satellite video conference and at national conferences, and training is currently being conducted at State and local health departments for staff who implement PCRS programs.

As I mentioned at the beginning, CDC, with input from a wide range of public health and professional partners, also has developed comprehensive guidelines for HIV PCRS and recently mailed the draft to all State health departments for comment. The HIV Partner Protection Act of 1998 and this new PCRS Guidance do share important goals of notifying partners, including spouses, who may have been exposed to HIV and linking them to appropriate prevention and medical services. CDC believes that the new PCRS Guidance improves and refines current practices and elevates partner counseling and referral services to a higher standard of public health practice and a greater degree of potential effectiveness. We will receive comments on the Guidance and will then finalize and implement it.

Let me now briefly address some other issues related to the HIV Partner Protection Act. The Act departs from the CDC Guidelines and science-based public health practice by mandating reporting of all HIV-positive tests, by client name, without any provision to support the continuation of anonymous testing. The resulting effect will be to discourage and drastically reduce anonymous testing opportunities. Anonymous testing has been strongly encouraged by CDC Guidelines and is integral to public health practice because it has been proven to bring people for testing earlier in the course of infection and also bring in people who might never access such services or who might access them only when symptoms of disease develop. CDC currently recommends that people who test positive in anonymous settings be linked with medical

care so they can receive life-prolonging clinical services. It is also through this medical delivery system that clients develop the trusting relationships that facilitate the identification of exposed partners not revealed with the initial inquiry. In States that require name reporting, the names of clients who tested positive anonymously are reported to State health departments at the point of interacting with medical care providers.

In addition, we are concerned that directive legislation may inadvertently constrain the application of sound public health activities that require greater flexibility. For example, studies have shown that clients might not want their partners notified because they fear a violent reaction from the partner. Domestic violence is a well-documented reality in the lives of many newly diagnosed individuals, especially women. Providers must be sensitive to the threat of violence and other issues of concern to the client. PCRS providers should have the flexibility to make an assessment prior to notifying the partner and seek expert consultation before proceeding with notification. Legislative mandates could decrease the flexibility that public health staff require to apply sound judgment in complicated situations, as are frequently encountered when providing PCRS, especially those situations involving the potential for interpersonal violence. Passage of this or other legislation that might reduce this flexibility could prevent clients who fear such violence from seeking counseling and testing for HIV.

What then are our recommendations? We would like to have the opportunity to implement the new PCRS Guidance and then evaluate its outcomes and impact. CDC will provide technical assistance to State and local programs to build the service delivery capacity of PCRS programs and will continually assess PCRS practice across the country as programs are further developed and strengthened. Knowing the subcommittee's interest and concern, we

would be happy to provide a progress report six months from the date the Guidance is finalized.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection systems.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.

would be happy to provide a progress report six months from the date the Guidance is finalized.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection systems.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.

would be happy to provide a progress report six months from the date the Guidance is finalized.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection systems.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.

would be happy to provide a progress report six months from the date the Guidance is finalized.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection systems.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.

would be happy to provide a progress report six months from the date the Guidance is finalized.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection systems.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.

Testimony on Hearing for HR 4431 (DRAFT)

I am Dr. Helene Gayle, Director of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention. Thank you for the opportunity to testify today about issues related to HIV prevention partner counseling and referral services in the context of H.R. 4431, the HIV Partner Protection Act. I'm especially happy to be here because it's an opportunity for me to share with you CDC's updated guidance on HIV partner counseling and referral services -- which has just been released for public comment.

However, before we focus on partner counseling and referral services, let me briefly describe the major goal of HIV prevention in this country and the sound public health approaches that we think are needed to achieve this goal. Our goal is to prevent HIV infection by reducing behaviors likely to transmit the virus and assisting individuals at risk or already infected in gaining access to prevention services, medical care, and other needed services. This ambitious goal can be achieved only by using a comprehensive strategy. Elements of this strategy must include monitoring the epidemic; informing the public regarding risk and modes of transmission; conducting health education and risk-reduction activities, including school-based education efforts for youth; promoting and implementing HIV prevention counseling and testing; providing referrals for medical treatment as well as prevention and social services; and promoting and implementing STD screening and treatment. An essential component of HIV counseling and testing is reaching out to and counseling sex and needle-sharing partners of persons identified as HIV positive. These partners are often unaware that they have been exposed to HIV and some may already be infected. All must have access to counseling, testing, and other prevention or

treatment services. Each of these elements contributes to preventing the spread of HIV. Together, they become a powerful prevention strategy. No single activity, by itself, will achieve the overall goal of preventing new HIV infections.

I will briefly describe CDC's current recommendations for partner counseling and referral services, or PCRS, and our current requirements for programs providing these services. The goals of PCRS are, first, to provide services to sex and needle-sharing partners of HIV-infected individuals so they can avoid infection or, if already infected, can prevent transmission of HIV to others; second, to help HIV-infected partners gain earlier access to counseling, medical evaluation, and other prevention, treatment, and support services. CDC has required States to establish standards and implement procedures for PCRS since 1988, when it was referred to as "partner notification."

PCRS is a process that begins when people receive HIV prevention counseling and testing and is carried out by different health professionals in a wide range of counseling and testing settings. If a person tests positive, the PCRS provider and client together formulate a plan for reaching any sex or needle-sharing partners. The plan should be one that will result in each partner's being informed of possible exposure to HIV and provided with accurate information and counseling about HIV transmission and prevention. Next, the HIV-infected client voluntarily discloses identifying information about partners, and the client and/or the provider informs each partner of possible exposure to HIV. The next step is really the core of PCRS practice: assisting the partner in accessing additional counseling, testing, medical care, and other support services. Throughout this process, the confidentiality of the infected person's identity and that of their partners must be preserved.

The ability to successfully identify the exposed individual is directly dependent on establishing trust with the infected person. This is a critical point that has always been a cornerstone of partner services for HIV and all other STDs. The PCRS process, by its nature, is a voluntary one on the part of the client. A client who tests positive for HIV or any other STDs cannot be mandated to reveal names of partners. In the wake of receiving an HIV-positive test result, clients may fear discrimination, abuse, or domestic violence; they may fear the loss of a job, health insurance, housing, or the loss of important personal relationships. The success of the PCRS process absolutely hinges on the trust and cooperation of the person living with HIV, their partners, and their communities. We know that people will cooperate if they believe that their confidentiality will be protected; otherwise they may avoid the system altogether. The way to maximize the public health benefit is to have a valuable service -- one with skilled counselors fully supported by adequate resources -- that people perceive as beneficial and easy-to-use.

Partner counseling and referral services related to HIV infection have evolved from similar services, known as "contact tracing," that were begun in this country in the 1930s as a method of preventing the spread of syphilis. This prevention effort was called contact tracing because public health workers would, and still do, conduct analyses to determine which sex partners were most likely to be infected and then make confidential efforts to locate them and provide treatment. Contact tracing services later expanded to include partners of persons infected with gonorrhea and other sexually transmitted diseases, including HIV, and came to be known as "partner notification" in the 1980s. Today, the term "HIV partner counseling and referral services" more accurately reflects the range of services available to HIV-infected persons, their partners, and affected communities through this essential public health activity.

But of necessity, PCRS for HIV differs from partner services for other STDs. The primary difference is that, despite recent advances in treatment, we do not yet have a cure for AIDS, so HIV, unlike syphilis and gonorrhea, remains a life-long issue for those affected. For HIV-infected persons, PCRS needs to be continuously available. The process begins as soon as an HIV-infected person learns their serostatus, and it continues throughout that person's counseling and treatment. (~~If new partners are exposed in the future,~~ too close to cumulation) PCRS is again utilized. Also, because society frequently stigmatizes and sometimes discriminates against HIV-infected persons and their families and friends, counseling and support must be provided for clients who choose to notify their own partners. For exposed partners who test positive for HIV, PCRS provides assistance in reducing risks posed to others and accessing medical evaluation, treatment, and other prevention and support services to prolong life. As new prevention tools emerge, such as vaccines, better behavioral interventions, and more effective antiretroviral therapies, PCRS will almost certainly become an even more important prevention tool.

States, territories, and local areas contribute to a national data system maintained by CDC that includes information on more than two million HIV tests reported annually from nearly 10,000 publicly funded counseling and testing sites. While this system does not differentiate spouses from others who are sex or needle-sharing partners, it does record the reasons for seeking HIV counseling and testing services, including referrals by partners and health departments. In 1996, 81,999 tests were conducted for people who were referred (for PCRS) from a variety of health care delivery settings; of these, 35,260 (43 percent) were referred by their partners, and 46,739 (57 percent) were referred by the health department. More than half of all the people referred were female. Many of these persons did not realize they might have been exposed to HIV and thus did

not consider themselves at risk for infection until they received the referral. Nationally in 1996, 4 percent of these referred partners tested HIV seropositive, and in some areas up to 15 to 20 percent were HIV positive. This represents a much higher rate than the national average of 1.5 percent who tested HIV positive at publicly funded test sites that year. These data underscore the importance of the PCRS process in reaching high-risk populations and providing individuals with the critical linkage to appropriate prevention and treatment services. The data also illustrate the degree of success PCRS has already demonstrated.

Concerning the effectiveness of PCRS, we know that, in general, HIV-infected persons and their partners readily accept PCRS and, with appropriate counseling, will not only provide confidential and very sensitive information, but will actively assist in finding and encouraging partners and spouses to receive counseling and testing. Also, when located, sex partners are generally receptive to confidential notification by the client or the health department and will usually seek HIV testing. Another indication of the efficacy of PCRS is the fact that many people at high risk for infection are linked by this process to prevention services that have been proven to be effective.

Notwithstanding these benefits to public health, it is also important to note the practical limitations of PCRS. Frequently it is difficult or impossible to determine exactly when a person became infected with HIV and when specific sex or needle-sharing partners were exposed to the virus. During the potentially long period during which the virus could have been transmitted, the HIV-infected person may have had many partners. In addition, the HIV-infected person may not be able to identify all partners or know how to reach others who are known. Because of the long time periods involved, often it is difficult for the client or health department to locate all the

partners, especially those exposed years earlier. Also, while many HIV-infected persons willingly participate in PCRS, fear or misunderstanding of health department policies and practices may keep some HIV-infected persons from coming forward or revealing information needed to reach partners and spouses. A climate of trust, confidentiality, and understanding is essential; without it, this highly effective and targeted intervention is jeopardized. Another limitation is the lack of human and financial resources in the public health arena necessary to carry out this important prevention activity.

Let me now describe some of the numerous ways that CDC has been working to further strengthen and enhance PCRS activities. As a result of the reauthorization of the Ryan White legislation, each State is required to certify to CDC in writing the State's intent to comply with the spousal notification requirements contained in the legislation. Programmatic and legal staff of CDC and the Health Resources and Services Administration have developed procedures and criteria for certifying each State's compliance with Ryan White CARE Act requirements that mandate that States make a good faith effort to notify spouses of known HIV-infected individuals. All States certified compliance by February 1997 and have taken action to implement spousal notification. No State opposed the requirements.

In addition to the specific activities related to spousal notification, CDC also provides technical assistance and guidance to help States achieve optimal performance in their PCRS programs. Spousal and partner notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences, and workshops involving State and local HIV prevention programs and national organizations. CDC has published scientific articles on HIV prevention partner notification in peer-reviewed journals, emphasizing its importance, especially

as it relates to primary prevention and linkage of HIV-infected persons to treatment. CDC has delivered training on PCRS through a satellite video conference and at national conferences, and training is currently being conducted at State and local health departments for staff who implement PCRS programs.

As I mentioned at the beginning, CDC, with input from a wide range of public health and professional partners, also has developed comprehensive guidelines for HIV PCRS and recently mailed the draft to all State health departments for comment. The HIV Partner Protection Act of 1998 and this new PCRS Guidance do share important goals of notifying partners, including spouses, who may have been exposed to HIV and linking them to appropriate prevention and medical services. CDC believes that the new PCRS Guidance improves and refines current practices and elevates partner counseling and referral services to a higher standard of public health practice and a greater degree of potential effectiveness. We will receive comments on the Guidance and will then finalize and implement it.

Let me now briefly address some other issues related to the HIV Partner Protection Act. The Act departs from the CDC Guidelines and science-based public health practice by mandating reporting of all HIV-positive tests, by client name, without any provision to support the continuation of anonymous testing. The resulting effect will be to discourage and drastically reduce anonymous testing opportunities. Anonymous testing has been strongly encouraged by CDC Guidelines and is integral to public health practice because it has been proven to bring people for testing earlier in the course of infection and also bring in people who might never access such services or who might access them only when symptoms of disease develop. CDC currently recommends that people who test positive in anonymous settings be linked with medical

care so they can receive life-prolonging clinical services. It is also through this medical delivery system that clients develop the trusting relationships that facilitate the identification of exposed partners not revealed with the initial inquiry. In States that require name reporting, the names of clients who tested positive anonymously are reported to State health departments at the point of interacting with medical care providers.

In addition, we are concerned that directive legislation may inadvertently constrain the application of sound public health activities that require greater flexibility. For example, studies have shown that clients ~~might not want~~ may fear having their partners notified because they ~~fear~~ have reason to anticipate a violent reaction from the partner. Domestic violence is a well-documented reality in the lives of many newly diagnosed individuals, especially women. Providers must be sensitive to the threat of violence and other issues of concern to the client. PCRS providers should have the flexibility to make an assessment prior to notifying the partner and seek expert consultation before proceeding with notification. Legislative mandates could decrease the flexibility that public health staff require to apply sound judgment in complicated situations, as are frequently encountered when providing PCRS, especially those situations involving the potential for interpersonal violence. Passage of this or other legislation that might reduce this flexibility could prevent clients who fear such violence from seeking counseling and testing for HIV.

What then are our recommendations? We would like to have the opportunity to implement the new PCRS Guidance and then evaluate its outcomes and impact. CDC will provide technical assistance to State and local programs to build the service delivery capacity of PCRS programs and will continually assess PCRS practice across the country as programs are further developed and strengthened. Knowing the subcommittee's interest and concern, we

would be happy to provide a progress report six months from the date the Guidance is finalized.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection systems.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.