Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

THE RYAN WHITE CARE ACT

Implementation of the Spousal Notification Requirement

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EXECUTIVE SUMMARY

PURPOSE

To identify whether States are implementing their approved plans to ensure a good faith effort is made to notify spouses of persons infected with HIV of their possible exposure.

BACKGROUND

Section 8 of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act requires that any State receiving Ryan White Title II funding take administrative or legislative action to require a *good faith effort* be made to notify current and former spouses of known HIV-infected patients of possible exposure. A State that does not comply with this requirement will lose its Title II funding. Title II provides funds to States for health care and support services for those with HIV and AIDS. The total Title II appropriation for FY 1999 was over $709 million.

The requirement for States to make a "good faith effort" does not mandate that all spouses of HIV-positive individuals be notified, but does require States to establish procedures which facilitate faithful attempts to notify all impacted spouses.

States have administered HIV and STD partner notification programs which included spouses for many years. The activities to which States certified were both ongoing efforts and additions to their Partner Counseling and Referral Services programs that were designed to specifically address spousal notification requirements.

Each State provided the Centers for Disease Control and Prevention (CDC) with information on existing or planned legislative and/or administrative actions in order to comply with Section 8 requirements. The CDC approved the certifications of compliance submitted by all 50 States, the District of Columbia and U.S. territories. We reviewed all 51 State certifications in order to gain a firm understanding of the details of this program. However, for the purposes of this study, we assumed that CDC's approval of certifications indicates State activities constitute a good faith effort as required.

We focused on determining whether States were implementing the programs that CDC had certified. To accomplish this goal, we collected documentation and conducted site visits with State public health staff and HIV test site counselors in six States with high prevalence of HIV cases. Additionally, we interviewed and collected documentation from State public health staff in five randomly selected States.

This evaluation was conducted at the request of Congressman Thomas Coburn.

FINDINGS

The 11 Sampled States Have Taken Action on Their Approved Plans

All sampled States have followed up on certified activities, including revising counseling guidelines and contract language, updating training materials, retraining counselors and informing providers about changes due to Section 8 of the Ryan White CARE Act. Some States have initiated additional notification activities not contained in their original certifications.

States Are Responding to Common Barriers

Efforts to notify spouses and partners of persons with HIV are hampered by legislative and administrative barriers, by the structure of State and local governments and by physician, counselor and patient concerns. States have responded to barriers by offering freedom from liability for providers who notify, and by organizing elicitation and notification programs to fit into existing governmental and health care structures. Some States offer training for physicians and counselors, and make efforts to explain the process and benefits of notification to persons newly diagnosed with HIV.

Several States Are Undertaking Promising Notification Efforts

While all sampled States have done what they certified to, several States have taken actions which appear particularly useful or successful. Several States have made efforts regarding provider and counselor training, data utilization and notification that balance informing partners and maintaining confidentiality for index cases.

Data Collection Is Limited and Uneven

Five sampled States collect data on partner notification. However, none of the 11 sampled States collects data specifically on the number of spouses who have been notified of their HIV exposure risk. The six others currently do not collect notification data as part of their programmatic efforts. Three of these States are currently developing or piloting data systems. In at least one State which does not collect data at the statewide level, some counties collect local data on notification.

RECOMMENDATIONS

While States have taken action on their certifications, their efforts do not completely ensure that vulnerable people are always made aware of their possible exposure to HIV. Based on our findings, additional efforts need to be undertaken to ensure maximum notification while ensuring confidentiality and meeting patients' needs.

Continue to Facilitate Understanding of Notification Efforts Through Publicity, Education and Training

The CDC currently engages in public education efforts on a number of HIV-related issues. To increase knowledge for all parties, we recommend that CDC augment its current efforts by facilitating targeted education campaigns and provider trainings.

Establish and continue efforts to publicize notification goals, efforts and benefits. Publicizing information about notification and other Partner Counseling and Referral Services activities can increase awareness and broaden acceptance of the purpose and benefits of informing spouses and partners about their HIV risk. We recommend that CDC establish targeted public affairs efforts for providers, HIV advocacy groups and persons at high risk of contracting HIV. Spouse and partner notification should be addressed at senior levels in the department, and information about State efforts should be conveyed to interested parties in a manner that increases the issue's acceptability.

Facilitate local cooperation and collaboration. We recommend that CDC facilitate local level collaboration between State and local public health departments and private providers. Over 80 percent of HIV tests are conducted in the private sector. Training, technical assistance and other written and oral guidance can help public health departments and private providers understand the process of spouse and partner notification, their roles in the process and the benefits of partner notification.

Share Good Practices, Replicable Efforts

We recommend that CDC facilitate the sharing of information about successful State notification practices, including training, data collection and other efforts which enhance spouse and partner notification outcomes. The CDC should sponsor multi-State meetings on notification issues and efforts, and encourage the spread of promising practices.

Encourage the Establishment of Data Collection Systems

We recommend that CDC encourage the development and use of data collection systems to monitor State spouse and partner elicitation and notification efforts. Information collected provides a snapshot of efforts that are working and those that may need more attention. The agency should facilitate the development of pilot and full-scale data collection programs, identifying successful State data collection efforts and facilitating information sharing between States on notification data collection issues. Data on elicitation and notification can be aggregate information which does not require States to collect and store identifying information on partners or index cases. Due to the substantial costs involved in data collection, the above recommendation is contingent on the availability of funding.

AGENCY COMMENTS

We would like to thank the Centers for Disease Control and Prevention and the Health Resources and Services Administration for commenting on the draft of this report.

The Centers for Disease Control and Prevention suggested some additions and a change to the first recommendation. Based on their comments, some changes and clarifications were made to this report. In particular, at their suggestion we have attached their guidance to State public health officials regarding certification of compliance with the spousal notification requirement. These guidelines provide examples of principles and practices that constitute a "good faith effort" for certification. The full text of their comments is attached.

The Health Resources and Services Administration concurred with our recommendations and had no additional comments.

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INTRODUCTION

PURPOSE

To identify whether States are implementing their approved plans to ensure a good faith effort is made to notify spouses of persons infected with HIV of their possible exposure.

BACKGROUND

The Ryan White CARE Act

In response to the HIV epidemic and its impact on individuals, families, communities, cities and States, Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990. Ryan White programs provide health care and support services to persons with HIV and AIDS who would otherwise not have access to care.

The Ryan White Act, which was re-authorized in 1996 through the year 2000, has four titles:

- Title I: HIV emergency relief grant program for cities
- Title II: HIV care grants to States
- Title III: Early intervention services
- Title IV: Pediatric care and reports and evaluations

Through its HIV/AIDS Bureau, the Health Resources and Services Administration (HRSA) administers the Ryan White program. The HIV/AIDS Bureau conducts programs to benefit low-income, uninsured and under-insured individuals and families affected by HIV/AIDS. Total appropriations for HRSA-funded CARE Act programs is $1.41 billion for fiscal year 1999.

Section 8 of the Ryan White CARE Act

Section 8 of the Ryan White reauthorization requires that any State receiving Ryan White Title II funding take administrative or legislative action to require a good faith effort be made to notify current and former spouses of known HIV-infected patients of possible exposure. A State that does not comply with Section 8 of the 1996 reauthorization of the Ryan White Act will lose its Title II funding. The requirement for States to make a "good faith effort" does not mandate that all spouses of HIV-positive individuals be notified, but does require States to establish procedures which facilitate faithful attempts to notify all impacted spouses.

While HRSA-administered Ryan White Title II funding is at risk for States which fail to comply with Section 8 of the Act, spousal notification falls under the purview of the Centers for Disease Control and Prevention (CDC). The CDC directly funds HIV/AIDS prevention activities through the agency's HIV Prevention Projects. These programs assist public health departments (1) to reduce or prevent the transmission of HIV by reducing or preventing behaviors or practices that place persons at risk for HIV infection; and (2) to reduce associated morbidity and mortality of HIV-infected persons by increasing access to early medical intervention. This funding is the primary source of HIV prevention funding for all State health departments and six city health departments.

Officials at HRSA have noted that States that fail to comply with Section 8 requirements will lose their Title II funding, despite the fact that CDC administers partner notification and other HIV prevention activities. Just as different Federal agencies administer Ryan White and HIV prevention programs, the agency administering Ryan White Title II funds at the State level is often different from the one conducting HIV and AIDS partner notification. Thus, the State agency responsible for funding health care and social services for persons with HIV may be forced to respond to a loss of funds without having any authority to fix the problem which caused the loss. A State that does not make a good faith effort to notify spouses and partners loses funds earmarked for HIV health and ancillary care services not money directed for prevention.

CDC Approval Process

In December 1996, CDC asked States and Territories to certify that they were taking legislative and/or administrative steps to ensure compliance with Section 8 of the Ryan White CARE Act (P.L. 104-146). The "CDC Guidance to State Public Health Officials Regarding Certifications of Compliance With Public Law 104-146" describing what constitutes a good faith effort accompanied the CDC request for State certification information. This document is included in Appendix B of this report. All States responded in January and February 1997. Each State provided CDC with information on existing or planned legislative and/or administrative actions. The CDC reviewed the documents and approved those found to be acceptable. The CDC worked with States whose certifications did not appear to meet compliance standards in order to develop compliance plans which would ensure a good faith effort. In letters sent on February 13, 1997, CDC acknowledged State certifications.

In our analysis of the steps States have taken to fulfill promises made in the certifications, we assumed that CDC's approval of certifications indicated State activities constituted a good faith effort as required.

All States: Certifications

The CDC has approved the certifications of compliance with P.L. 104-146 submitted by all 50 States, the District of Columbia, and U.S. Territories. The certifications indicated

what laws and policies each State currently had in place or intended to implement. Certifications cited existing State law, recently passed legislation and planned legislative changes as well as current policy, planned policy changes and current or planned attempts to publicize laws and policies.

Thirty State certifications made reference to current law or planned legislation which addressed spousal notification requirements. Forty-six States described policies and guidelines which were in place or which the State planned to implement. In addition, 20 States specifically described language regarding spousal notification which was already required for contracts and memoranda of understanding or which they intended to insert into such agreements.

Partner Notification in Context

States have administered Partner Counseling and Referral Services (PCRS) programs for many years. While these efforts include notification of spouses and other partners, they are not limited to such activities. The activities to which States certified were both ongoing efforts and additions to their PCRS programs which were designed to specifically address spousal notification requirements.[1]

In December 1998, CDC's National Center for HIV, STD and TB Prevention published a revised "HIV Partner Counseling and Referral Services" guidance document. The guidance provides information on availability of PCRS, advises programs developing a PCRS plan gives direction on locating and notifying partners, collecting and analyzing PCRS data and ensuring the quality of PCRS. While previous to this guidance States had their own guidelines and program rules for spouse and partner notification, many States run their programs and update their procedures using CDC's ongoing guidance.

Health departments and other organizations which provide PCRS to their clients offer services based on a number of core PCRS principles. As CDC indicates in their 1998 guidance document, PCRS must be voluntary, confidential and culturally sensitive. A PCRS program is one component of a comprehensive HIV prevention system, and is based on client-centered counseling which makes use of multiple support services and diverse referral options.

While this report focuses on two aspects of PCRS (elicitation of partner names and notification of those partners of their possible exposure to HIV), these elements are understood to be part of a comprehensive PCRS program. As CDC stresses in their guidance, counseling is the key to successful efforts to reduce HIV transmission and improve the health of currently infected persons.

[1]Also see Appendix B for examples of "good faith effort" principles and practices that CDC provided to State public health officials.

Eliciting names of spouses, sex partners and intravenous drug needle-sharing partners often takes place during post-test counseling, or at a session held shortly after diagnosis. Notification is generally, though not exclusively, carried out by State or local public health employees. It is always conducted in person and never involves identification of the index case to notified partners or other individuals. Elicitation may be performed by the same person who notifies spouses or partners, but this is not always the case.

Defining Index Cases and Partners

In the elicitation and notification process that is started when an individual tests positive for HIV, State public health staff often refer to the person tested as an "index case." This designation helps define the individual as someone who has tested positive for HIV and who is asked to name spouses and partners at the start of the notification process.

Many States' certifications do not specifically define partners, though many define "spouse" by referring to language used in Section 8 of the Ryan White CARE Act. States which do explicitly define partners in their certifications include spouses, non-spouse sex partners and individuals with whom persons share intravenous drugs and needles.

Notification of Spouses

None of the States in our sample or in the larger group of States and Territories which certified to the CDC runs a notification program which only notifies spouses about possible HIV exposure, but does not notify other sex or needle-sharing partners. Even States which made legislative and/or policy changes in order to comply with Section 8 of the Ryan White CARE Act already ran previously existing partner notification programs. To ensure compliance, States made changes to law and/or policy with regard to *spousal* notification specifically. Several States added language to their partner notification policies to specifically address Section 8 requirements.

This evaluation was conducted at the request of Congressman Thomas Coburn.

METHODOLOGY

We examined approved certifications from the 50 States and the District of Columbia. We reviewed the administrative and legislative actions each State had taken or planned to take to ensure compliance with Section 8 of the Ryan White CARE Act. We conducted on-site interviews with six higher prevalence HIV States (California, the District of Columbia, Florida, Illinois, New Jersey and New York). The site visits included discussions with State staff responsible for spouse and partner notification activities and with individuals directly involved in HIV counseling and testing at the local level. In addition, we conducted telephone interviews with State staff responsible for spouse and partner notification activities in five randomly selected States (Kansas, Missouri, North Carolina, Washington and West Virginia).

In each of the 11 States where we conducted on-site or telephone interviews, we discussed the State's current spouse and partner notification policies and laws. We also asked each State about the planned actions in their certifications to identify whether the State had taken action on these items. We collected documents regarding States' implementation of spousal notification programs.

We conducted our review in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

FINDINGS

The 11 sampled States have taken action on their approved plans

All 11 States certified to planned activities

Each State certification describes existing and planned administrative policies.[2] Six of the 11 States cite laws that specifically refer to the notification of spouses of persons diagnosed with HIV. Certifications in six States outline where language regarding spousal notification was inserted into contracts and memoranda of understanding; seven States' certifications describe current or planned attempts to publicize notification rules and policies.

All sampled States have followed up on planned activities, including revising counseling and testing guidelines and contract language, updating training materials, retraining counselors and informing public and private providers about changes due to Section 8 of the Ryan White CARE Act.

Eliciting spouse and partner names from index cases

State or local health department employees are specifically employed to elicit names in seven sampled States. In these States, staff eliciting spouse and partner names may either be stationed at the counseling site or may contact the original patient using information provided by the physician or counselor. The latter is generally employed when a private provider has conducted an HIV test for a patient. Although elicitation is often performed by State or local public health staff in these seven States, it is the sole responsibility of the public health department in only one of them.

In four States, names are primarily elicited by physicians and HIV counselors at the time an individual's diagnosis is discussed. An HIV counselor may be employed by the State, local health department or a private agency.

[2]For further information on the activities States describe in their applications, see Table 1: "State Spousal Notification Efforts - Actions Described in Certifications" in Appendix C.

Notification duties and State partner notification staff

State or local health department staff have primary responsibility for notifying spouses and partners in all 11 sampled States. In over half the sampled States, physicians and HIV counseling staff may notify spouses and partners, although they do not usually have primary responsibility for this activity. In one State, the attending physician is responsible for ensuring that notification occurs, whether or not he performs this activity. In another State, providers are encouraged but not required to elicit names and notify spouses. This State's certification notes that State law frees them from liability whether they choose to notify or not.

The role of counseling in the elicitation and notification process

Respondents at the State and local level indicated that good counseling is the key to eliciting partner names and successfully educating partners about their risk and steps they can take whether or not they test positive for HIV. Counseling activities for both the HIV-positive individual and his or her partners are extremely important. Thorough counseling outlines the client's risk and facilitates the development of strategies to prevent further transmission of HIV. As CDC indicates, counseling takes substantial time, effort, training and resources. These investments are worthwhile, because clients who understands their risks and the possible danger they pose to others are more likely to fully participate in partner notification activities. State respondents indicated that counseling sites with more developed programs and better trained staff are more successful at eliciting partner names from their HIV-positive clients.

Spouses and notification without patient consent

Due to confidentiality laws, five States in our sample require patient consent for a provider to notify a spouse. In one State, a physician may personally notify a spouse only with patient consent, but can facilitate notification without consent. If a physician knows the identity of his HIV-positive patient's spouse, that physician is required to give the spouse's name to State staff responsible for notification. For non-spouse partners, patient cooperation with elicitation and notification is required.

While confidentiality laws restrict some State notification efforts, 8 of the 11 sampled States allow providers to notify spouses without the index case's permission if the provider knows the spouse's identity. Public health staff or the notifying physician are generally required to contact the index case and try to gain their consent before proceeding with notification.

Steps beyond certifications

In discussions with States about compliance with their spousal notification activities, respondents in four States described actions they have initiated since receiving approval of their certifications. One State is currently implementing a more formal notification process than the one for which it was certified. The old process relied on counselors and physicians to send spouse and partner names to the notification assistance staff, while the new process gives this staff more authority to initiate notification discussions with providers. The new process also puts more responsibility on counselors and physicians to elicit names or to initiate the elicitation/notification process through the State or local notification office.

One State, which already required providers to elicit names in post-test interviews, established an active surveillance program. Nurses hired by the State visit providers who have sent in names of new positives. They discuss spouse and partner name elicitation as well as appropriate patient care and available services with physicians. Providers document notification discussions in their case notes, and nurses encourage physicians to discuss notification with patients on an ongoing basis. The program is being expanded with nurses providing ongoing follow-up with physicians.

State public health staff in another State not only notify spouses and partners of potential exposure, but also offer to perform an HIV test for notified spouses and partners in their residence. This facilitates the elicitation of a second round of partners from an original index case. State notification staff have been very successful at eliciting names from the field cases they post-test counsel, increasing the number of potentially impacted individuals who can be notified.

Another State is currently piloting a counselor training program and data collection system. Using several of its larger counties as test sites, the State is training HIV counselors and local notification staff. This improves participants' ability to perform effective elicitation and notification as well as increasing their knowledge about HIV treatment and available services.

The State's AIDS office, in conjunction with the sexually transmitted disease control program's training center, provides the training to local public health departments. In addition to running a training program, the State helps localities to develop goals and objectives based on State expectations. After staff at publicly funded sites are trained, private providers and counselors may access the free training as well. Once providers, counselors and notification staff in the pilot counties have been trained, the program will be expanded to the rest of the State.

States are responding to common barriers[3]

Legislative and administrative issues

State laws limit who may be informed of an individual's HIV status and how such notification can occur. Several States have patient confidentiality laws which restrict the ability of providers or others with information about infected individuals to inform partners of potential exposure to HIV. Even when notification is not restricted for spouses, States require that confidentiality be upheld for the index client. Other States' administrative rules or policies disallow partner notification without patient consent.

Despite rules that limit notification without patient consent, the majority of sampled States do allow providers to notify known spouses of their potential HIV exposure. Eight States in our sample provide freedom from liability for providers who notify spouses of persons with HIV that they may have been exposed. The majority of these States allow notification of all partners; only two States grant freedom from liability for spousal notifications only. The rules surrounding such notifications vary among States, but providers are generally required to discuss notification with the patient and attempt to convince the individual to participate in the process before taking action to notify a spouse. Some States limit notification without patient consent to cases in which the provider knows the spouse's identity.

One way that States have tried to address the dual concerns of patient confidentiality and public health protection is to involve newly diagnosed individuals in the notification process. Some States that allow spousal notification without patient consent require counselors and providers to first try to gain patient consent before proceeding. If a tested individual still refuses to cooperate, providers in at least one State must inform the person that they will notify. The patient's wishes regarding whether the provider or State public health staff will conduct the notification must also be followed. In another State, patient consent is necessary for the physician to notify a spouse, but consent is not required for the physician to provide the spouse's name to the public health department.

Fitting notification into State structure

States' partner elicitation and notification programs are often shaped by States' HIV prevalence and the structure of their State and local governments. In one State with high HIV prevalence, HIV prevention staff decided that the most effective strategy was to place notification activities within the context of ongoing service provision. Rather than develop a parallel infrastructure, the State developed an elicitation and notification program structured around existing service providers and testing sites. State staff indicated that they wanted notification to fit into a larger system of care. They wanted

[3]Also see Table 2: "Barriers to Spousal Notification and State Solutions" in Appendix C.

people to see notification as a service rather than a burden. In addition, with such a large number of HIV-positive individuals, public health staff determined that the cost of a program not tied to existing structures would have been prohibitive.

Several sampled States have large areas with low HIV prevalence. Some of these States have decided that it is not economical for disease intervention staff to be stationed in every public testing site throughout the State. In two States, higher prevalence areas are staffed by State-funded staff, who are called in when needed to counsel individuals in other areas. Counselors at HIV test sites are also trained to elicit spouse and partner names. These counselors, as well as private physicians, are able to counsel individuals about the value of notifying partners.

In several States, the counties have a fair amount of autonomy regarding the administration of their health and social services. This county orientation can impede State attempts to use one program structure that runs identically in every locality. One State's notification program was developed as a framework within which each county can develop program details that fit the locality. To accommodate the county independence, the State allows each county to design its own notification program, but offers training to local HIV counselors and notification staff. Training includes information on what elicitation should entail as well as how to conduct notification and what notifiers should know about HIV treatment and available services.

Physicians and elicitation

While many people seek HIV testing from public health clinics, CDC estimates that over 80 percent of HIV tests are conducted in the private sector - by private providers using private laboratories. With a large percentage of HIV tests conducted by private providers such as physicians, barriers to physician participation in HIV spouse and partner notification can have a large impact on the success of a state notification program.

Physicians may fail to elicit partner names from their HIV-positive patients for several reasons. Physicians vary in their ability and motivation to ask patients about their partners; many private physicians do not have the time or inclination to elicit names. Many physicians test only a few patients a year and are not practiced in HIV counseling and name elicitation.

Respondents indicated that physicians may not see a role for themselves in HIV partner notification in part because they are used to the sexually transmitted disease (STD) notification model. Public health officers conducting STD elicitation and notification do not rely heavily on participation by private physicians. There is no established working relationship between the two groups, and physicians may not understand that their role is different with regard to HIV notification than it is with STDs.

Several States in our sample encourage physician participation by following up with providers who test individuals for HIV. Two States ask providers to return forms indicating their elicitation efforts. Another State employs nurses who conduct follow-up work with physicians reporting HIV cases.

Most States offer HIV counseling training to both private and public counseling and testing staff, and many make completion of a training program mandatory for anyone providing HIV counseling and testing. Although this may not ensure participation, it encourages it by increasing providers' notification-related knowledge and skill base.

Counselors and elicitation

Many HIV counselors are hesitant to push patients to engage in partner elicitation, as they do not want to alienate the patients. Many counselors are primarily concerned that an individual diagnosed with HIV seek needed services. They may not want to broach topics which may impact the patient's willingness to return for services. In addition, some providers may not entirely understand the partner notification process. They can not pass on correct information about confidentiality, voluntary notification and other issues if they are not clear about what is required or allowed in their State.

Many of our respondents at the State and local level indicated that the keys to successful partner elicitation are training and a "corporate culture" in which partner notification is valued. Counselors, physicians and those managing test facilities must recognize the importance of partner notification and understand the central role elicitation plays in that process. Public health staff in one State indicated that variance in testing sites' success at convincing individuals to supply partner names was based in part on the motivation provided by site managers. They suggested that while all counselors received the same State-sponsored trainings, some managers stressed elicitation more than others and created an organization-wide sense that elicitation is important and achievable.

Respondents from another State noted that counselors' skills, as well as their relationships with the communities they serve, are key to successful notification efforts. A skilled counselor who establishes a rapport with a client and clearly explains the benefits of notification can greatly improve the affected individual's willingness to reveal behaviors and names to an individual the client has just met.

Notifiers

All 11 States appear to do a good job with the actual notification of partners and spouses. Each State we interviewed has motivated, well trained notification staff. They have few problems locating and notifying the individuals on whom they receive information. Many States rely on HIV notification staff who have previously worked in sexually transmitted disease (STD) units. These individuals transfer their knowledge and many of their protocols from the STD field to HIV notification.

Patients

HIV spouse and partner notification can usually only proceed with the patient's consent and cooperation. Even an accommodating individual may not be able or willing to discuss partners when he is digesting the news of his HIV status. In addition, patients may lack information about partners from longer time periods. The tested individual may not have good information about an ex-spouse or partner he or she has not seen in years. Other patients may refuse to identify spouses due to domestic violence concerns.

A number of States have addressed patient cooperation issues by clearly identifying notification as a voluntary process. Several States make efforts to market spouse and partner notification as a service rather than an imposition. Most States require post-test counseling to include a discussion of the benefits of notification, a description of the process and an explanation of available services and participation options.

Several States are undertaking promising notification efforts

While all sampled States have taken action on the activities to which they certified, several States have taken actions which appear particularly useful or successful. In particular, several States have made efforts regarding provider and counselor training, data utilization and notification which balance informing partners and maintaining confidentiality for index cases.

Training

Respondents in several States indicated that training is a key to successful elicitation and notification efforts. While all State notification programs require their staff to be trained, some States take the additional step of requiring all HIV counselors involved in elicitation and notification to undergo State sponsored training in this area. One State which requires training for all HIV counselors indicates that this allows the State partner notification program to ensure that all counselors learn why notification is beneficial, how the process works and how to perform their part of the process.

Another State ensures participation by private providers through its program of active surveillance. Public health staff visit providers who report cases of HIV. They discuss notification and other HIV related issues. During these meetings providers are encouraged to participate in notification activities. Active surveillance visits can serve a dual purpose, training private providers to participate in spouse and partner notification and improving relationships between public health staff and private medical providers. Working together, the two parties can better understand the issues each one faces and help one another with the elicitation and notification process.

Utilizing data

Of the five States that currently collect information on partner notification activities, two States stand out in terms of the data they collect and the way they use it. These States collect a large amount of information about their notification efforts, including the number of index cases interviewed, the number of partners elicited and the results of partner notification efforts. This information is aggregate data intended to assess trends rather than track individual cases. The data helps partner notification staff monitor their success and determine areas in need of improvement.

These States take the additional step of monitoring the results of notification efforts in terms of whether notified partners agree to have an HIV test, whether partners have been tested in the past and the results of previous and new tests. The data collected is aggregated to help State notification programs assess whether a broad approach to partner notification is effective in identifying new cases of HIV. A high percentage of notified partners identified as "never previously tested" or "previous negative test, new positive test" would suggest that notification efforts are successfully locating previously unidentified cases of HIV. If many notified partners test negative for HIV, this could suggest that the public health department may want to further target its HIV identification efforts.

One of the two States that collects a lot of notification data also gathers information on the success of elicitation efforts. Elicitation is primarily performed by counselors at HIV testing sites, and some sites receive State grants for their testing efforts. The State monitors the success of counselors at each site in eliciting partner names from persons newly diagnosed with HIV. Each site that receives State funding is required to maintain a 1.0 partner index, meaning that on average, each site must elicit at least one partner name from each interviewed patient. Collecting this information allows the State partner notification program to assess which sites are successful at partner elicitation. The State program can help less successful sites perform better by offering or mandating retraining sessions for counselors and suggesting that lagging sites emulate practices utilized by the more successful sites.

Balancing public health and confidentiality concerns

While some States use their HIV name reporting system to initiate spouse and partner notification efforts, partner notification can be conducted without linking it to a State surveillance program. In one sampled State, the public health department conducts a strong HIV spouse and partner notification program not connected to surveillance efforts. This State appears to have success notifying spouses and partners of their possible exposure to HIV by developed a program that balances the public health need to notify partners of possible exposure and the concern that confidentiality is assured for index cases. Although the State employs name reporting of HIV, the partner notification program is administered separately from the name reporting program. The separation allows notification staff to assure index clients that any information they provide about partners can not be linked back to them. Partner names and locating information are separated from patient information by testing site staff and given to the State health department staff responsible for notification. The notification field staff never learn the names of the individuals who provided the partner names, so they are not able to pass those names along even if they wanted to.

Data collection is limited and uneven

Although public health notification staff have a sense of their success at elicitation and notification, States often do not collect data in this area. None of the sampled States collects information on whether elicited partners are spouses or ex-spouses of index patients. Demographic information linking contacts to the index cases who name them is not collected in many States. One reason data on a partner's relationship to an index case is not collected is that this information could jeopardize confidentiality for the index case.

One sampled State collects information on how many notified individuals are currently married, but their confidential notification system does not allow them to link partners and index cases. Partner information is collected at the HIV test site and transferred to the partner notification field staff without any information about the index case. If an individual is recorded as the spouse of the index case who named him, the index case's identity can be readily discerned.

Five of the 11 sampled States collect data on partner notification.[4] Although each State collects somewhat different information, most of these States monitor the number of referred cases which result in a notification discussion, the number which result in spouse/partner elicitation, total contacts elicited and average contact index. Two States also collect information on the disposition of the notified case, including whether the

[4]For information on what types of data States collect, see Table 3: "Data Collection in the 11 Sampled States" in Appendix C.

partner or spouse had been previously tested and whether notification led them to get tested. The six other States in our sample currently do not collect data on spouse and partner notification as part of their programmatic efforts. Three of these six States are currently developing or piloting data systems. In at least one of the States which does not currently collect data at the statewide level, some counties do collect local information on notification activities.

RECOMMENDATIONS

States have been conducting spouse and partner HIV notification as part of PCRS and other counseling programs for many years; some programs were established in the mid 1980s. The planned and ongoing efforts States described in their 1997 certifications to CDC stemmed from States' larger public health mission to protect both HIV-infected persons and their partners. The certified activities were actions the States planned on implementing, and we found that the States in our sample have taken action on their certified activities.

This does not mean that spousal and partner notification has achieved its goal of ensuring that vulnerable people are always made aware of their possible exposure to HIV. Based on our findings, additional efforts need to be undertaken to ensure maximum notification while ensuring confidentiality.

As States have primary responsibility for public health issues and private physicians have primary responsibility for testing and initiating the notification process, we make the following recommendations to CDC:

Continue to facilitate understanding of notification efforts through publicity, education and training

The goals of partner notification are prevention of HIV transmission and improvement of HIV-infected persons' access to care. For partner notification to work, it requires participation by all parties - counselors, physicians, patients. This is most likely to occur when participants are educated about the process and benefits of partner notification. The benefits for providers, counselors, HIV-positive individuals and their partners should be stressed.

The CDC currently engages in public education efforts on a number of HIV-related issues. To increase knowledge on all sides, we recommend that CDC augment its current efforts by facilitating targeted education campaigns and provider training opportunities.

Establish and continue efforts to publicize notification goals, efforts and benefits

Misconceptions about spouse and partner notification are often due to lack of information. Providing information on notification and other elements of PCRS can increase awareness about the intent and benefits of informing spouses and partners about their HIV risk. Increased knowledge is key to clearing up the misconceptions, fears and mistrust that hamper participation by providers and patients.

Information about notification efforts and processes should be tailored to specific audiences. Specifically, physicians and other providers should be educated about their role in eliciting partner names and notifying affected persons. Providers need information about what spouse and partner notification entails, how it occurs in the provider's State, what its benefits are and the ways in which providers can participate.

Educational efforts should also be aimed at organizations which represent and advocate for persons affected by HIV and AIDS. As these organizations communicate with the HIV/AIDS community and with subgroups within the larger affected population, increasing knowledge at the organizational level can improve individuals' understanding of notification efforts and willingness to participate in the process.

For information on spouse and partner notification to be heard and accepted by the population at large, it must come from individuals who command respect by a given population. The message's acceptance will hinge on the speaker's legitimacy with the listeners. In addition, efforts to publicize this information must be targeted, the message clear. A message that is simple, easy to comprehend and explained by a trusted speaker has the best chance of convincing individuals to participate in spouse and partner notification for HIV.

In order to publicize the process and benefits of spouse and partner notification, we recommend that CDC establish targeted public affairs efforts. Spouse and partner notification should be addressed at senior levels in the department, and information about State efforts should be conveyed to interested and affected parties in a manner that increases the issue's acceptability. Programs should complement CDC and other efforts currently underway.

The CDC currently funds State efforts to increase individuals' knowledge of their HIV status. Much of the funds go to health departments to support the development of new and innovative early identification strategies to reach high risk populations and create linkages with care. Special emphasis is placed on projects that target minority populations, including women and adolescents. Funded activities may include coalition building, product development, outreach activities, and evaluation of effective interventions.

The funds are also used to promote risk reduction interventions to help those uninfected to stay that way, and to encourage those infected to practice safe behaviors to prevent the spread to others. The Secretary's Emergency Fund for HIV/AIDS funds such projects.

Facilitate local cooperation and collaboration

Respondents at the national, State and local levels indicated that cooperation between State health departments, private groups and individuals is necessary for a successful notification program. Cooperative efforts require good working relationships.

Unfortunately, several respondents indicated that private and public health professionals in many States do not have strong relationships. Efforts to strengthen these relationships and improve knowledge can greatly improve outcomes for elicitation and notification efforts.

We recommend that CDC facilitate local level collaboration between State and local public health and private providers through State medical societies, nurse practitioner groups and other provider groups. The CDC can encourage State and local public health agencies to facilitate this process by continuing to offer guidance and training to public health departments. Private providers should be encouraged to participate in trainings and other information sharing efforts. This is especially important as at least 80 percent of HIV tests are conducted in the private sector, yet these providers are often not linked to the State or local notification systems. Trainings, technical assistance and other written and oral guidance can help public health departments and private providers understand the process of spouse and partner notification, their roles in the process and the benefits of spouse and partner notification. Such efforts can also encourage public health and private providers to work together to improve their relationships in ways which smooth the process of notification.

Share good practices, replicable efforts

While each State has unique issues which stem from governmental structure, program needs, affected population and State laws, some public health practices can be successfully utilized in multiple locales with only small variations. We recommend that CDC facilitate the sharing of information about successful State notification practices, including training, data collection and other efforts which enhance spouse and partner notification outcomes. The CDC should sponsor multi-State meetings on notification issues and efforts, and encourage the spread of promising practices. As this is an area in which CDC has experience, current conferences and meetings can be utilized for information sharing purposes.

Encourage the establishment of data collection systems

Data can be a useful part of a State's spouse and partner notification program. Information collected on elicitation and notification efforts provide a snapshot of what efforts are working and which areas may need more attention. Data can encourage HIV counselors, private providers and public health staff who are successful at eliciting and notifying spouses and partners. It can also be used to provide benchmarks against which struggling providers and programs can measure themselves.

There may be reasons why a successful notification program may elicit and notify few partners. Some newly identified HIV cases may elicit few contacts because the individual may have had a limited number of partners. Similarly, notification efforts are affected by the quality of elicited information, which is impacted by the time period between an individual's last contact with a partner and the date they are asked for information. Memory is fallible, and people move, change names and die.

The fallibility of data aside, data collection can help recognize successful efforts, encourage providers, counselors and others involved with notification, and help identify areas for improvement in elicitation and notification.

We recommend that CDC encourage the development and use of data collection systems for spouse and partner elicitation and notification. The agency should facilitate the development of pilot and full-scale data collection programs by informing States of key data elements and collection procedures, by identifying successful State data collection efforts and by facilitating information sharing between States on notification data collection issues.

Although some States do conduct their notification programs in conjunction with their HIV surveillance efforts, data collection does not require the collection and storage of partner names or identifying information. Most States which collect elicitation and notification data aggregate their information in order to get a sense of trends and successes. Analysis of this data does not call for personal information on index cases or partners, as indicated by the work of one State which completely separates its HIV surveillance data from its elicitation and notification information.

Comments on implementation costs

The OIG recognizes that our recommendations have costs to States and the Federal government. The publicity and trainings we recommend require State and local partner notification staff to be hired and trained and private providers to be trained and included in public program efforts. Successful public awareness programs will increase costs associated both with locating, counseling and interviewing HIV-infected persons and their

partners and with program administration. Successful campaigns will encourage more providers to refer patients to participate in partner notification efforts. Additionally, instituting data collection programs could significantly increase costs to local, State and Federal governments.

We are uncertain of the cost of fully implementing the recommendations we have made. Few cost estimates exist on partner notification. In 1997, CDC estimated that fully implementing partner notification services using existing notification guidelines would require an additional national outlay of at least $20-30 million. This amount does not include the cost of establishing State data collection systems or conducting targeted public awareness campaigns. Additionally, CDC notes that resources to perform a comprehensive PCRS program are inadequate to meet current needs. The CDC estimates that the cost of implementing OIG's above recommendations would require an outlay which is two to three times current resources.

The OIG recognizes the substantial costs involved in the development and use of data collection systems and the implementation of public awareness campaigns. Our recommendations are contingent on the availability of funding for such efforts.

AGENCY COMMENTS

We would like to thank the Centers for Disease Control and Prevention and the Health Resources and Services Administration for commenting on the draft of this report.

The Centers for Disease Control and Prevention suggested some additions and a change to the first recommendation. Based on their comments, some changes and clarifications were made to this report. In particular, at their suggestion we have attached their guidance to State public health officials regarding certification of compliance with the spousal notification requirement. These guidelines provide examples of principles and practices that constitute a "good faith effort" for certification. The full text of their comments is attached.

The Health Resources and Services Administration concurred with our recommendations and had no additional comments.

APPENDIX A

Centers for Disease Control and Prevention Comments on the Draft Report

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control
and Prevention (CDC)

Memorandum

Date JUL 26 1999

From Acting Director, Office of Program Support

Subject CDC Comments on the Office of Evaluation and Inspection, Draft Report, "The Ryan White CARE Act: Implementation of the Spousal Notification Requirement" (OEI-05-98-00391)

To June Gibbs Brown
Inspector General

Thank you for the opportunity to review the draft report. In general, the report accurately describes the steps taken by CDC to certify states' implementation of spousal notification procedures required by the Ryan White CARE Reauthorization Act of 1996. It shows that CDC followed the law and used reasonable procedures. It also frames the statute's spousal notification requirements in the larger context of states' ongoing partner notification efforts. Below for your consideration are additional comments on the report.

1. CDC Approval Process: The draft report makes reference to the guidance document that CDC sent the states prior to the certification process, but does not provide the text of CDC's statement of minimal public health principles and practices that constitute a "good faith" spousal notification effort. There has been much confusion and some misunderstanding on the good faith concept, but this CDC statement has held up well and remains a key concept in the process. A copy of these principles should, at the minimum, be attached or appended to the final report. The OIG has previously been provided with a copy of these principles.

2. The words, *elicitation* and *notification,* used in describing what was called partner notification are too limited. Although they are important component of the service, now more properly referred to as Partner Counseling and Referral Services (PCRS), the concept that workers merely elicit names and then perform notification services is short sighted. The counseling activities are extremely important to a complete understanding of the client's risk and to develop a client-centered strategy to prevent further transmission of HIV. Counseling has to come first and takes time, effort, training and resources. Counseling is of immeasurable value in understanding how the infection was acquired, identifying others who might be at risk, and imparting information for understanding and minimizing risky behaviors. A client who understands his/her risks, and the potential dangers they pose to others, is much more likely to participate fully in referring others for counseling and testing. Likewise, the section of the report that describes notification efforts fails to address the related prevention outcomes. In cases where the partner has not become infected, such notification often has a beneficial prevention effect that reduces future risk practices and involves the couple in informational counseling and education.

APPENDIX A

Centers for Disease Control and Prevention Comments on the Draft Report

3. Comments on Implementation Costs: The draft report does not adequately address the cost of a comprehensive PCRS program, and does not seriously mention cost until page 22. The additional costs noted there, however, are two or three times the amount current resources. Resources to perform PCRS are inadequate to meet current needs; increasing notification, examination and counseling standards for partners will require larger expenditures to improve the quantity and quality of those services.

4. RECOMMENDATIONS: The suggestion to stage a public information campaign needs refining. While CDC wants to increase the number of persons who know their HIV serostatus, programs publicizing PCRS for the general public run the real risk of crowding counseling and testing sites with legions of the "worried well." This clogs the system for persons who are truly at high risk, consumes precious resources, and results in a degradation of the entire scope of PCRS services. Information on counseling and partner notification services should be targeted to segments of the population who are much more likely to encounter these programs. In general, the most cost-effective opportunity to expound the value of these services occurs when a partner is being notified of his/her exposure, or when a positive client is offered PCRS during his/her counseling service. A friendly, well-trained health worker can tailor the message to fit the location, urgency and circumstances of clients and/or their partners.

Please contact Carolyn Russell, Director, Management Analysis and Services Office, (404) 639-0440, if you should have any questions regarding these comments.

James D. Seligman

APPENDIX B

CDC Guidance to State Public Health Officials Regarding Certifications of Compliance with Public Law 104-146

Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA)

Examples of Principles and Practices Regarding HIV Spousal Notification that Constitute a Good Faith Effort

SUMMARY: On May 20, 1996, the Ryan White CARE Reauthorization Act was signed into law (P.L. 104-146). Section 8(a) requires that States take "administrative or legislative action to require that a good faith effort be made to notify a spouse of a known HIV-infected patient that such spouse may have been exposed to the human immunodeficiency virus and should seek testing." Under this section, States that fail to take administrative or legislative action will be ineligible to receive grant funds under Part B of the Ryan White CARE Act administered by HRSA.

Currently, CDC requires all health department recipients of HIV prevention funding to "establish standards and implement procedures for partner notification consistent with State/local needs, priorities, and resource availability."

States must certify to CDC that they have taken the administrative or legislative actions necessary to require a good faith effort to ensure that spouses of known HIV-infected individuals are notified of their possible exposure to HIV and referred for testing.

All identifying information regarding HIV-infected patients and spouses must be kept confidential. No personally identifying information shall be disclosed unless required by State law or political subdivision, or unless the individual provides written, voluntary informed consent. Anonymous HIV testing does not preclude effective partner or spousal notification. Unless prohibited by State law or regulation, reasonable opportunities to receive HIV-antibody counseling and testing services anonymously should continue to be offered. Anonymous testing services may encourage some persons at risk of HIV, who might otherwise be reluctant to be tested, to seek testing.

The following are examples of public health principles and practices that constitute a "good faith" spousal notification effort by States. States should review these examples, but are not limited to them in considering which policies, systems, or actions will be appropriate for their jurisdictions.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

1. Individuals reported to the State on or after April 1, 1997, as diagnosed with AIDS (or HIV infection in States requiring HIV-infection reporting by law or regulation), if not already determined by the reporting health care provider, each such individual shall be a) asked if they have, or have had, a spouse (defined by this law as "any individual who is the marriage partner of an HIV-infected patient, or who has been the marriage partner of that patient at any time within the 10-year period prior to diagnosis of HIV infection"), and b) informed that he or she should notify their spouse, or former spouse(s), of the potential exposure to HIV.

2. Reasonable efforts must be made to determine if each HIV-infected individual intends to notify his or her spouse of their possible exposure to HIV or agrees to have a qualified health care provider notify them. In situations where the HIV-infected individual reports that he or she intends to notify the spouse, culturally competent counseling and educational services on the following issues should be available--how to make the notification, how to preserve confidentiality of both the individual and the spouse, how HIV infection and transmission can be prevented, and how the spouse can access testing, other prevention services, and treatment. If the HIV-infected individual is unable or unwilling to notify his or her spouse, culturally competent services should be available from the provider or the health department to do so. Unless covered by existing law, policy, or regulation, States should develop policies that address situations involving HIV-infected individuals who do not plan to notify their spouses and who refuse health department assistance. In developing these laws, policies, or regulations, States should consider guidance contained in *Guide to Public Health Practice: HIV Partner Notification Strategies* (Association of State and Territorial Health Officials, et. al., 1988). Notification is not necessary in situations where, in the judgement of public health officials, there has been no sexual exposure of a spouse to a known HIV-infected individual during the relevant time frame.

3. Reasonable procedures to ensure that notified spouses receive referrals for HIV testing, other prevention services, and treatment should be implemented.

4. Health departments that document spousal notification policies and practices of public and private health care providers reporting AIDS and HIV that meet State requirements or establish agreements with them for this purpose need not directly contact every HIV-infected individual reported by such providers for purposes of spousal notification.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 1: State Spousal Notification Efforts - Actions Described in Certifications[5]

Action Description	Action Type	State/States
ALLOW NOTIFICATION This includes: freedom from liability for notification and active responsibility to make a good faith effort to notify or facilitate notification.	Legislative	AL AZ CT DE GA HI ID IL IN IA KS KY LA ME MD MI MS MO NH NY OH RI SC TN UT VA WI WY
	Administrative	AL AK AZ AR CA CO DE DC FL IN MA MN MT NE NV NH NJ NM NY NC ND OK OR PA SD TX VT WA WV
REQUIRE OR OFFER COUNSELING ON NOTIFICATION Most, if not all, States appear to do this to some degree, but not all States codify this in law. Other States have policies regarding notification counseling, but not all have noted these policies in their certifications.	Legislative	AL FL MD MS NY VA
	Administrative	AL AK AR CO CT DE DC GA HI IL IN IA KS MA MI MN MO MT NV NH NJ NM OH OK OR SD TN TX UT VT WA WV WI
OUTLINE PROVIDER AND PUBLIC HEALTH STAFF PARTICIPATION Some States put an affirmative duty on the public health department, private physicians or the person performing post-test counseling to carry out notification.	Legislative	AL AK CT ID MD MI MS NV NH NC SC WY
	Administrative	AZ CO DE DC FL HI IN IA KS KY LA ME MA MN MT NV NH NJ NM NC ND OH OK SD TX UT VT VA WY WI

[5]This table is based on information provided to the CDC by States. Some State certifications contained attachments which were not available to OIG during our analysis. Any information contained in such an attachment may be missing from the information provided in this table.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 1: State Spousal Notification Efforts - Actions Described in Certifications, continued

Action Description	Action Type	State/States
REPORT HIV CASES FOR PUBLIC HEALTH PARTNER NOTIFICATION FOLLOW UP	Legislative	AK MS MO NY[6]
	Administrative	CO[7] CT IA MN NH OK SC SD WV[8] WI
REQUIRE VERIFICATION OF A NOTIFICATION PERFORMED BY AN INDEX CASE	Legislative	OK
	Administrative	AL CO MN TN WV WI
ENSURE CONFIDENTIALITY	Legislative	CA CT NY VA
	Administrative	CO DE DC ID LA MA MT NJ NM NC OH OK SD TN TX WY
UTILIZE CDC GUIDELINES, FORMS	Administrative	AL AK AR ID NH
REVISE NOTIFICATION LAWS, POLICIES, GUIDELINES TO ADDRESS SPOUSAL REQUIREMENTS	Legislative	MD
	Administrative	AK AZ CA[9] CO DE FL IA KS KY NE LA MA MI MO MT NV NH NM NY ND OR PA RI SC TX UT WA WV WI WY

[6]This is part of the new law under implementation in New York.

[7]Verification is performed if the HIV-positive individual agrees to participate in notification and wants to notify their spouse/partner on their own.

[8]Follow-up occurs for persons tested in the private sector. Persons tested in the public sector automatically receive notification counseling.

[9]The State encourages local programs to change the language in their guidelines, policies, etc. to address spousal notification issues.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 1: State Spousal Notification Efforts - Actions Described in Certifications, continued

Action Description	Action Type	State/States
DISCUSS SPOUSES AND PARTNERS These State certifications specifically indicate that HIV counseling includes discussion of both individuals' partners and spouses and notification issues generally.[10]	Administrative	AL AK AR CO CT DE DC FL HI IL IN IA KS KY LA ME MA MI MN MS MO MT NE NV NH NJ NM ND OH OK OR SD TN TX VA WA WV WI
AMEND CONTRACTS AND MEMORANDAS OF UNDERSTANDING (MOUS)	Administrative	AL AK AZ CA CO CT DC FL HI ID IL IN KS LA MA MO MT NE NV NH NM ND OH OR PA TX UT WV WI
PUBLICIZE RULES, LAWS, POLICIES	Administrative	AL AK AZ AR CA CO CT DE DC FL HI IL IN KS KY LA ME MD MI MN MS MT NE NV NH NM NY ND OH OR PA TX UT WV WI
REVISE TRAINING AND TRAINING MATERIALS	Administrative	AK AZ CA IN KY MA NV NM NY RI TX WA

[10]Although State programs generally require or encourage this in their counseling guidelines, not all States mentioned it in their certifications.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 2: Barriers to Spousal Notification and State Solutions

Issue	Description	State Solutions
Legislative and Administrative Barriers	State laws (including patient confidentiality laws) limit who may be informed of a person's HIV status and how such notification can occur. Most States require that the identity of the index case not be revealed through HIV notification. Some States' administrative rules or policies disallow partner notification without patient consent.	Address both patient confidentiality concerns and public health protection by involving newly diagnosed individuals in the notification process. Require counselors and providers to first try to gain patient consent before proceeding with notification without patient consent. If a tested individual refuses to cooperate, the provider must inform the person that they will notify. The patient's wishes regarding whether the provider or State public health staff will conduct the notification must also be followed.
Fitting Notification into State Structure	States' partner elicitation and notification programs are often shaped by States' HIV prevalence and the structure of their State and local governments. Designing a program without taking local issues, strengths and weaknesses into account will hinder program success.	States with high HIV prevalence: Structure the notification program around existing service providers and testing sites. With many HIV-positive individuals, the cost of a program not tied to existing structures may otherwise be prohibitive. States with low HIV prevalence: Augment efforts by State-funded staff with private HIV test site counselors trained to elicit names. County autonomy: Develop a framework notification program within which each county can develop program details to fit the locality. Each county designs its notification program; the State can offer training to local HIV counselors and notification staff.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 2: Barriers to Spousal Notification and State Solutions, continued

Issue	Description	State Solutions
Physicians and Elicitation	The Hippocratic oath orders physicians to "tell no secret" obtained through the therapeutic relationship. Physicians vary in their ability and motivation to ask patients about their partners; many private physicians do not have the time or inclination to elicit names. Many physicians test only a few patients a year and are not practiced in HIV counseling and name elicitation.	Encourage physician participation by following up with providers who test individuals for HIV. Ask providers to return forms indicating their elicitation efforts. State-hired nurses who conduct follow-up work with physicians reporting HIV cases. Offer HIV counseling training to private and public counseling and testing staff. Make completion of a training program mandatory for anyone providing HIV counseling and testing. Encourage participation in the notification process by increasing providers' notification-related knowledge and skill base.
Counselors and Elicitation	Many HIV counselors are hesitant to push patients to elicit partners, as they do not want to alienate the patient. Many counselors do not want to broach topics which may impact the patient's willingness to return for services. Some providers may not entirely understand the partner notification process.	Stress counselor training and a "corporate culture" in which partner notification is understood and valued. Counselors, physicians and those managing test facilities must recognize the importance of partner notification and understand the central role elicitation plays in that process. Counselors' skills and the relationships they establish with the community are key to successful notification efforts. A skilled counselor establishes a rapport with a client and clearly explains the benefits of notification. This can greatly improve the affected individual's willingness to reveal behaviors and names to an individual the client has just met.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 2: Barriers to Spousal Notification and State Solutions, continued

Issue	Description	State Solutions
Patients	HIV notification can usually only proceed with the client's consent and cooperation. A client may not be able or willing to discuss partners while digesting HIV test results. Patients may lack information about partners from longer time periods or may refuse to identify spouses due to domestic violence concerns.	Clearly identify notification as a voluntary process. Market spouse and partner notification as a service rather than an imposition. Require post-test counseling to include a discussion of the benefits of notification, a description of the process and an explanation of available services and participation options.

APPENDIX C

Spouse and Partner Notification Activities: State Level Data

Table 3: Data Collection in the 11 Sampled States

Type of Data Collected	States
Number of newly identified index cases eligible for post-test interview	FL MO NJ NC
Number of index cases which result in a notification discussion	FL MO NJ NY NC
Number of index cases which result in spouse or partner elicitation*	FL NJ NC
Number of contact notifications that were spousal notifications	NJ
Number of index cases interviewed within specific time frames	FL NC
Average contact index (average number of contacts elicited per interview)	MO NJ NC
Total number of contacts elicited from all interviews	FL MO NJ NC
Number of elicited partners who were notified within a certain time period	FL NJ NC
Number of elicited partners who were not contacted or notified	FL NJ NC
Disposition of HIV test administered to a notified spouse or partner	FL NJ

Notes:
*This category differs from the previous one in that Missouri and New York monitor whether a notification discussion occurred, not whether contacts were elicited. It can be assumed that if contacts were elicited, a discussion occurred. Thus, some States listed as tracking information in this category are also listed as tracking information in the "Number of cases which result in a notification discussion" category.

Florida - Cases are tracked by "closed" cases only. Cases which do not result in an interview are sorted by reason for lack of interview - "refused interview", "unable to locate" and "other". The State also notes how many contacts are "new" partners. Of the new partners, the interview activity report records how many have had a previous negative HIV test, how many have not been tested and how many refused to be tested.

Missouri - A "new" case is one which has not been previously reported to the State. All newly reported HIV cases are interviewed, unless a physician specifically indicates that the patient should not be contacted. The interview consists of spouse and partner elicitation and referral to HIV care services.

North Carolina - Monthly Epidemiologic Case Reports also track the number of cases which do not result in an elicitation interview and the number of cases with no contacts named. All the information is tracked for HIV cases and AIDS cases. The data is also broken out by gender of the index case.