New York State AIDS Advisory Council

Findings of the HIV Surveillance Workgroup
April, 1998
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March 26, 1998

Preamble

While changes in the demographics of the HIV epidemic and the development of more effective treatments (that prolong the lives of many people with HIV/AIDS who gain access to these treatments) have brought about a need for changes to HIV surveillance systems, such changes should not happen in a vacuum. HIV surveillance must be a component of a comprehensive program of HIV prevention, education and care. In addition, there must be recognition that HIV infected persons have a personal responsibility not to transmit the virus.

Modifications to HIV surveillance systems must be accompanied by a renewed and expanded commitment to ensure that all New Yorkers are provided with education about the importance of HIV testing and the need for early medical intervention; adequate prevention services including access to clean needles, condoms and other barrier methods; and access to health care and supportive services for all persons living with HIV/AIDS.

I. HIV Surveillance

A. There is a need to better document and monitor the extent of and trends in the HIV epidemic in New York State.

The Workgroup finds that better data are needed to track the HIV epidemic in New York than are available from the current AIDS case reporting system. That system has served the state well for the first 15 years of the epidemic, but a number of factors now make these data inadequate for public health purposes. These factors include the incubation period of an average 10 years between infection and development of AIDS, improved prevention and treatment of opportunistic infections, the availability of comprehensive medical and support services, and most recently, the dramatic effects of combination anti-retroviral therapy, which together have led to delayed progression of HIV infection to AIDS. With slowed progression to AIDS, the AIDS case count becomes a reflection of HIV transmission patterns further and further in the past. Relying on AIDS case data obscures changes that have occurred in the last decade and therefore results in underestimating both the relative and absolute impacts of the epidemic in populations where it has more recently arisen, including injection drug users, minorities, women and adolescents. It also impairs the ability to recognize reoccurrence of the epidemic in populations like MSM and gay youth, in a timely way. These points were driven home by data from other states with HIV reporting, which highlighted the discrepancy between HIV and AIDS cases in adolescents. AIDS case data are thus inadequate to identify and prioritize current prevention and health care needs, to monitor the success of prevention and treatment programs, or to give early warning of the next waves of the epidemic. The declining AIDS case count also gives false reassurance to the public and to legislative bodies that the HIV epidemic is waning, and is likely to make it more difficult to assure adequate levels and equitable distribution of public funding in the future.

The Workgroup adopted the Preamble (new) and I.A. (no revisions) by consensus.
B. HIV data collection is the best way to track the epidemic.

The Workgroup finds that having an accurate and, to the extent possible, unduplicated description of HIV cases is critical for prevention and service planning, resource allocation and public education.

_The Workgroup adopted I.B. (with revisions) by consensus._

II. HIV Counseling and Testing

A. In the era where more effective treatments for HIV are on the market and should be accessible as soon as medically appropriate, both anonymous and confidential HIV counseling and testing must be widely available, accessible and user-friendly.

B. New York State must provide adequate funding for targeted education campaigns that are both linguistically and culturally appropriate to advise at risk populations, physicians, other health care providers and managed care organizations about the benefits of early intervention, HIV counseling and testing and entry into care.

C. The Workgroup has determined that it is imperative to have ready and easy access to anonymous HIV counseling and testing services, regardless of how an HIV surveillance system is implemented. The Workgroup recommends further that the State significantly increase funding for anonymous counseling and testing services.

Anonymous testing provides a mechanism for persons to learn their HIV status without concern for possible reporting to public health agencies. These concerns may arise in some populations, for example, immigrants, regardless of the type of surveillance system adopted. Supplemental epidemiologic studies may be required to ensure that utilization of anonymous test sites does not result in undercounting of selected demographic groups. Continued blinded serosurveys may help serve this purpose.

_The Workgroup adopted the revised HIV Counseling and Testing section in its entirety, by consensus._

III. Legal Protections

A. As with the current AIDS case reporting system, any HIV surveillance system must be supported by strong confidentiality protections limiting disclosure or misuse of HIV-related information, with significant penalties for violations which are strictly enforced.

_The Workgroup vote on III.A. (with revisions) was: 18 in favor; 0 opposed; 0 abstained_
B. Any HIV surveillance system must be supported by strong antidiscrimination protections with significant penalties for violations which are strictly enforced.

*The Workgroup vote on III.B. (no revisions) was: 18 in favor; 0 opposed; 0 abstained*

C. In order to prevent HIV discrimination and to assist persons who have suffered discrimination, funding for public education on HIV discrimination and funding to increase civil rights enforcement by City and State human rights agencies must be significantly expanded.

*The Workgroup vote to add III.C. (new) was: 17 in favor; 0 opposed; 1 abstained*

D. Use of information obtained through an HIV surveillance system must be limited to statistical and epidemiological purposes and for planning and resource allocation. Workgroup members voting in opposition felt that HIV surveillance data should be available for broader public health purposes.

*The Workgroup vote on III.D. (revised) was: 15 in favor; 4 opposed; 0 abstained*

The Workgroup finds that the assurance of confidentiality for any data in the possession of the State or City health departments is critical to any surveillance system designed to meet public health goals. The current legal protections and systems to collect and maintain AIDS case data at the State and City health departments' AIDS surveillance units have been adequate to protect from both purposeful or inadvertent release; all reasonable steps are being taken to prevent such release and to date there has never been a breach of any AIDS surveillance data. Any proposed system of HIV reporting should include similar strong protections for data in transit to or in the possession of health department HIV/AIDS surveillance programs. The Workgroup also finds that there is a much greater risk to confidentiality in health care and other settings, such as prisons, through widespread access to medical records, than exists for surveillance data reported to the health department.

The Workgroup finds that, at the state level, while the underlying antidiscrimination provisions in law appear adequate, these provisions are not often utilized. This raises the question of whether the systems to seek recourse from discrimination are adequate. More information about the barriers to accessing antidiscrimination remedies is needed.

The Workgroup also finds that, while State and Federal antidiscrimination provisions appear strong, further information is needed to judge whether these provisions have been effectively used and whether further strengthening may be needed. In particular, there is concern that future actions by the U.S. Supreme Court may weaken the provisions of the Americans With Disabilities Act (ADA) as they apply to persons with HIV. This situation will need to be monitored over time. The Workgroup recommends that an AIDS Advisory Council make a fuller exploration of these issues and develop additional recommendations for State legislation to replace any ADA protections that may be eliminated, if necessary.

IV. Key Elements of an HIV Surveillance System

A. Mechanism of Reporting.

The Workgroup considered whether individual case-based reporting should be implemented.
By a vote of 11 in favor, 3 opposed, and 5 abstained, the Workgroup voted in favor of implementing a system of individual case-based reporting.

The Workgroup considered three possible options for individual case-based reporting:

Position A.1.:

- **Named HIV Reporting**

*The vote on Position A.1. was: 7 in favor; 10 opposed; 1 abstained*

Position A.2.:

- **Unique Identifier HIV Reporting**
  A system of identifying individuals by characteristics such as date of birth, gender, portions of social security number, which when taken together are believed to be unique to that individual.

*The vote on Position A.2. was: 8 in favor; 7 opposed; 4 abstained*

Position A.3.:

- **Delinked Identifier HIV Reporting**
  An identifier that contains a code word and/or numbers that the patient provides, which would be used in all subsequent reporting.

*The vote on Position A.3. was: 11 in favor; 5 opposed; 2 abstained*

The Workgroup devoted an entire session on 2/9/98 to an exploration of the uses of HIV surveillance data, the necessary legal protections, and identifying the advantages and disadvantages of unique identifier and named reporting systems (see Appendix A). The Workgroup strongly recommends the following provisions be in place for any individual case-based reporting system:

- The existing confidentiality protections that apply to AIDS case reporting should be applied in order to prohibit the use of HIV surveillance information in criminal proceedings, and for other than statistical, epidemiological, planning, and resource allocation purposes. However, some Workgroup members felt that HIV surveillance information should be available for broader public health purposes.

- A strong re-affirmation must be made of federal and state antidiscrimination provisions and their applicability to all HIV infected persons.

- HIV cases should be reported to the same governmental entities that currently receive AIDS case reports.

- The State Health Commissioner must ensure that:
  - Anonymous counseling and testing services are accessible statewide for those individuals who prefer this option.
A multi-media educational campaign is conducted advising the public of the benefits of early HIV counseling and testing, and of early clinical intervention for infected persons. The campaign must be designed in a language and culturally appropriate manner.

An educational campaign targeted to health and human service providers, including physicians and managed care organizations, regarding the new HIV surveillance system regardless of the method finally adopted; the importance of encouraging counseling, testing and early health care; methods to address patient concerns regarding testing and reporting; and the availability of the anonymous testing option.

B. Special Considerations for Named HIV Reporting

In addition to the above provisions, the Workgroup recommends the following provisions should a name-based reporting system be adopted:

- Any named reporting system should include a provision that requires the deletion of names from the system, through an encryption process, after a reasonable time period has elapsed to conduct look-back investigations for the purpose of ensuring complete reporting and high quality data. The system should clarify that the intent of this provision is to limit the length of time that a name-based registry is maintained to decrease the potential for breaches of confidentiality and the use of this information for other than public health purposes.

- That the State Health Commissioner be charged with responsibility for developing a protocol to implement the encryption process, including the period of time a name would be maintained in the system.

The Workgroup vote on Section B was: 14 in favor; 1 opposed; 2 abstained

C. Special Considerations for Unique Identifier Reporting

In addition to the above provisions, the Workgroup recommends the following provisions should a unique identifier reporting system be adopted:

- Unique identifiers that do not involve social security numbers should be explored because many New Yorkers at risk for HIV may not have social security numbers and requiring social security numbers may deter immigrants and others from testing, and/or result in an undercount of these groups.

- To improve data completeness and quality, unique identifiers should be developed that meet the following criteria:
  
  - Should be unique (no one else has the same number);
  
  - Reproducible (any health care provider assigning the number would come up with the same number);
  
  - It should be easy to code so health providers can understand it and will take the time to do it;
- It should be universal (everyone would have the basic elements to construct the identifier);

- It should contain elements that are contained in other data bases (e.g., death certificates, hospital discharges) for purposes of matching, and should permit reporting, either electronically or manually by physicians and labs.

- Unique identifier reporting should be accompanied by zip code and risk factor information to minimize the need for look-back investigations.

- Reporting entities should be provided with adequate time and resources to implement a UI reporting system.

- The State should conduct a comprehensive program to educate health care providers about protection of HIV reporting logs to be maintained by each provider for purposes of look-back investigations and should conduct periodic monitoring of provider sites to ensure that the confidentiality of logs is protected.

D. Special Consideration for Delinked HIV Reporting

In addition to the above provisions, the Workgroup recommends the following provisions should a delinked unique identifier system be adopted:

- Any delinked HIV case reporting system must include steps to ensure that no information regarding the identity of the person tested and for whom a delinked identifier is assigned is maintained in any file or database except by explicit consent of the individual;

- The State Health Commissioner is charged with developing a system that permits each person seeking testing to have input in the development of their delinked unique identifier so that it can be easily remembered;

- Any delinked HIV reporting system must include public education and training for service providers on how to encourage persons being tested to remember their unique identifier and to use it each time they get tested;

- The State Health Commissioner is charged with conducting studies to estimate the rates of duplicated results and to use the surveys to adjust the reported estimates of HIV seroprevalence; and

- The State Health Commissioner is charged with expanding cohort and anonymous seroprevalence surveys to collect detailed information on the profile of HIV infection in New York communities.

V. HIV Surveillance and Partner Notification

A. The role of partner notification in HIV prevention.

- Partner notification must continue to be a voluntary process without coercion or criminal penalties for failure to disclose partners.
Partner notification discussion and assistance is the standard of care and should be universally available to persons with HIV from the time of diagnosis throughout the course of their infection, in every health and human service setting.

Partner notification by appropriately trained staff, has the potential to be an effective primary and secondary prevention strategy as one component of a comprehensive program of HIV prevention.

Partner notification must continue to be conducted in a manner that does not disclose the identity of the infected individual to others.

The Workgroup finds that partner notification is a useful strategy 1) to reinforce prevention messages; 2) to detect and refer for care partners with early HIV infection; and 3) to provide and refer for risk reduction education and other services partners at risk who are HIV negative. Information provided through partner notification can provide life-saving information to individuals who are not otherwise aware of their risk for HIV. However, the working group also finds that partner notification should only be employed as one component of a comprehensive program of HIV prevention, not as a stand alone program. Partner notification should only be conducted by professionally trained staff who are trained in sensitive and non-coercive interview techniques and behavioral risk reduction techniques, and are fully knowledgeable about and can refer clients and partners for a full range of health care and support services. Counselors should be trained and sensitive about possible client issues regarding the potential for domestic violence relating to HIV disclosure. Offering partner notification assistance does not require the name of the index patient to be known to offer services. (For example, partner notification services are currently offered to all persons testing HIV positive in anonymous testing programs.)

The Workgroup finds that partner notification is a process that requires the voluntary cooperation and trust of the individual client. Carrying out partner notification in a coercive manner or with the threat of penalty for non-cooperation will ultimately prove counterproductive to public health efforts: First, coercive measures will likely elicit false or incomplete partner information that will waste partner notification program resources. Second, since HIV infection and infectivity are lifelong, coercive measures will likely impair the future cooperation of the individual in protecting and notifying future partners, leading to increased HIV transmission. The Workgroup opposes the criminalization of the refusal of an individual to participate in either a mandatory or a voluntary partner notification system, or to provide inaccurate information or a false name. Finally, knowledge in the community that partner notification activities are coercive will likely deter individuals from seeking HIV testing. There is consensus that coercive approaches should not be used and that failure to disclose partners or accept notification assistance services should not be subject to criminal penalties or implied denial of access to services.

Offering partner notification services to persons newly diagnosed with HIV and periodically throughout health care and support service contacts should be considered a standard of medical and supportive care and should be universally available for persons with HIV. Unlike the situation with other sexually transmitted diseases (STDs), HIV partner notification does not offer an opportunity to cure or abort infection in exposed partners, nor should it be a one time activity at time of initial diagnosis, but a service to be offered throughout care. Doctors, nurses and other health care providers and community support services personnel alike should incorporate and encourage discussion of issues of partner notification into their routine interactions with clients and assist or refer clients for partner notification services when needed.
Note: By a vote of 12 in favor, 6 opposed, 1 abstained, the Workgroup also expressed opposition to proposals that would make engaging in safer sex activities without prior disclosure of HIV positive status a crime. Some members of the Workgroup noted that this topic was outside of the charge to the Workgroup and had not been fully discussed.

B. The relationship between HIV surveillance and HIV partner notification.

Workgroup members reached two opposing positions on this issue:

Position B.1.:

- No direct link is needed between an HIV surveillance system and HIV partner notification. Every physician or other individual providing HIV counseling must be required to notify the person testing positive about the availability of partner notification services. Adequate funding should be provided to ensure that partner notification services are available to all persons who test positive.

The Workgroup vote on Position B.1. was: 13 in favor; 5 opposed; 0 abstained

Position B.2.:

- HIV surveillance information should be linked to HIV partner notification to assure that it is offered and accessible to all persons newly diagnosed with HIV.

The Workgroup vote on Position B.2. was: 6 in favor; 13 opposed; 0 abstained

Two options should be considered in implementing Position B.2.:

(a) offer of partner notification assistance by Department of Health staff directly to all individuals testing HIV positive;

(b) offer of partner notification assistance by Department of Health staff through the health care providers of all persons testing HIV positive.

Under this proposal, partner notification could be offered universally for persons newly diagnosed and reported with HIV through contact with the physician of record, regardless of the type of HIV reporting system adopted. The physician would be contacted by a Department of Health public health representative and could accept or decline the offer of partner notification assistance on behalf of the patient. In declining services on behalf of the patient, the physician could be asked to certify that partner notification services were already being provided. If the physician is not providing partner notification assistance to the patient, patient contact information should be provided to public health officials to directly offer partner notification assistance to the patient.
C. Current PHL provisions for notification of partners against the wishes of the person.

- The Workgroup agreed that physicians and other health care and support service providers should make every effort to ensure that spouses and other partners known to be at-risk are notified by the patient or by the provider with the concurrence of the patient.

*By a vote of 11 in favor, 4 opposed and 0 abstained, the Workgroup voted to retain this bullet in the document*

In the case where notification with patient concurrence is not possible and the physician believes that notification is necessary, the Workgroup reached two opposing views:

**Position C.1.**

- Current law provides an adequate mechanism for physicians and public health officials to conduct direct partner notification against the wishes of the patient under certain circumstances, and the law appropriately places the decision in the hands of physicians.

*The Workgroup vote on Position C.1. was: 9 in favor; 4 opposed; 0 abstained*

**Position C.2.**

- Every person is entitled to all information necessary to make personal decisions regarding behavior that might place him/her at risk of HIV. Mechanisms for direct physician notification of partners allowable in current law are not implemented consistently by physicians and therefore, public health officials need to assure that notification is offered and be directly or indirectly involved with every patient to offer partner notification assistance.

*The Workgroup vote on Position C.2. was: 5 in favor; 9 opposed; 2 abstained*

PHL Article 27-F allows for notification of partners against the wishes of the person under certain limited circumstances. The director of the state PNAP program indicated that it was rare for physicians to request program assistance for such notifications. No data exists on the number of such notifications that physicians may undertake on their own. Some working group members felt that the current law provides an adequate mechanism to conduct such notifications and that the law appropriately places the decision in the hands of the physician. However, other members felt that physicians were reluctant to use this mechanism because of concerns including ethical objections, time constraints, expense involved, and liability. Some Workgroup members expressed concern that although the law states that physicians “acting in good faith and without malice” are not subject to liability, the law states that notifications must be “in compliance with” the Article. Consequently, any activity by the physician in variance with the law, no matter how minor or unintentional, could technically expose him/her to criminal and civil penalties. Nevertheless, there was agreement that physicians and other health care and support service providers should make every effort to ensure that spouses and other partners known to be at-risk be notified with the concurrence of the patient. Public health officials should also take steps to ensure that physicians’ roles and responsibilities with regard to partner notification are clarified.
Appendix A

Responses to Questions Addressed at the 2/9/98 HIV Surveillance Workgroup Meeting

1. What are the most important uses of information/data collected through an HIV surveillance system?

   A. To have a more complete picture of the HIV epidemic in New York State now and in the future

      - Report current number of cases of HIV infection ("prevalence") (with minimal duplication)
      - Report number of newly diagnosed cases of HIV infection ("incidence") (with minimal duplication)
      - Estimate prevalence
      - Project number of future cases
      - Identify disease stage at time of diagnosis
      - Identify cases with unusual modes of transmission (contaminated blood products, iatrogenic transmission)
      - Monitor incidence and prevalence by geographic region, age, race/ethnicity, gender, risk (subpopulations) now and over time

   B. To determine the need for, design, implement and evaluate HIV prevention and health care programs

      - Target public education/information campaigns
      - Target primary and secondary prevention efforts
      - Evaluate effectiveness of HIV prevention programs/campaigns targeted at different subpopulations
      - Evaluate extent of early intervention including counseling, testing and linkage/access to services and care by subpopulation by disease stage
      - Determine effectiveness of health care services (track progression from HIV to AIDS)

   C. To maximize resource opportunities and allocations

      - Document need based on identified cases
      - Target resources based on trends in the epidemic
      - Obtain equitable share of federal funding
2. What legal protections must be in place for any HIV surveillance system?

A. Antidiscrimination prohibitions and adequate access to mechanisms for recourse
B. Strong confidentiality protections for individuals seeking testing
C. Specification of restrictions on use of surveillance data

Some Workgroup members expressed concern about lack of legal protections relating to redisclosure of HIV test results by third parties and requested that this issue be explored more fully.

3. Identify all of the advantages and disadvantages of an HIV surveillance system using unique identifiers.

A. Advantages:

- Improves maintenance of individual privacy/confidentiality
- Ensures fewer deterrents to testing
- Creates greater community support for surveillance
- Minimizes duplication inherent in name reporting
- Limits misuse of the information by government, insurance companies, schools, others
- Improves completeness of reporting/better data to track the epidemic

B. Disadvantages:

- Unique identifier systems may still deter people from getting tested or into care
- Limits ability to conduct follow-back for additional information to validate case, eliminate duplication, obtain risk information, determine clinical stage
- Prohibits match with death registry, eliminating ability to monitor survival rates and AIDS Registry eliminating ability to track progression to AIDS
- Creates potential for confidentiality breaches at care sites where logs linking UIs and names would be maintained
- Creates need for development of a new UI system as systems tried in other states (Maryland and Texas) unlikely to work in NYS
- Eliminates some populations from being reported (e.g., if social security number is part of the UI, those without social security numbers are not counted); likely to result in undercounting of immigrants, minorities, women, adolescents, drug users.
- Relies heavily on ability of reporting entity to accurately construct and record UI
- Eliminates the reporting of risk information if follow-back is not possible
- Includes reliance on physician compliance which is unlikely, based on other reporting experience
- Requires reporting entities to construct new systems of reporting and therefore is more costly than a named reporting system which would build on the current AIDS reporting system.

4. What steps could be taken to overcome the disadvantages?

A. Development of the Unique Identifier System

- Clearly identify the goals of the UI HIV surveillance system. Determine what information is essential to collect through the HIV surveillance system and what can be collected from other sources; design the UI system to collect just the information needed. This system will provide the information most needed while protecting individuals' confidentiality.
- Identify areas where technical assistance is needed
- Involve PWAs in the development and implementation of the system
- Develop a delinked identifier that contains a code word and/or numbers that the patient provides, and therefore could not be linked to the individual.
- Determine and evaluate implementation costs of the UI system
- Consider ways to protect identifying information at care sites to facilitate the ability to conduct follow-back
- Conduct evaluation of the UI system to make sure it's working (use sampling methodology)
- Construct the system to allow the collection of risk information
- Encourage community support by eliminating the ability to conduct follow-back
- Use encryption technology to protect individuals' identifying information
- Provide reporting entities with adequate time and resources to implement any new UI system.
- Permit reporting entities (laboratories and physicians) to report either electronically or on paper.
B. Development of the Unique Identifier Code

- Create a UI that is unique, reproducible, easy to code, able to be assigned to everyone
- Include clients in the construction of the UI; allow clients to create own UI

C. Uses of Surveillance Data

- Limit the use of surveillance data to research for the purpose of tracking the epidemic and monitoring trends
- Use the UI solely for case reporting with no link to name or social security number

D. Legal Protections

- Ensure aggressive enforcement of, and strengthen anti-discrimination and confidentiality laws
- Pass laws that prohibit the use of HIV surveillance information for partner notification or in criminal proceedings

E. Education

- Conduct public education campaign to make people aware of their rights and avenues for recourse
- Conduct language and culture appropriate community education about what the UI system is and what UIs represent
- Conduct extensive physician education campaigns to encourage cooperation and use of the system

F. Services

- Ensure access to health care services
- Ensure that any UI system minimizes deterrents to testing

5. Identify all of the advantages and disadvantages of an HIV surveillance system using names

A. Advantages:

- Eliminates need to create new system if design builds on existing AIDS case reporting
-Minimizes cost of implementation/operation by using existing system
-Decreases chances of confidentiality breaches by using AIDS case
reporting model where historically breaches have not occurred (AIDS case
reports have not been linked to partner notification or criminal justice
settings and are immune to release by court order)
-Decreases chances of confidentiality breaches by having a centralized
system through the State health department with many confidentiality
protections as compared to a decentralized system with fewer protections
and more places/opportunities for breaches to occur
-Holds the greatest potential for accuracy in a reporting system
-Facilitates linking to AIDS case reporting, death certificate and other
registries
-Includes the ability to conduct follow-back for risk, clinical stage,
subpopulation and missing information; identification of duplication
-Promotes greater accuracy of reporting which may result in more equitable
distribution of resources
-Increases ability to target resources and primary and secondary prevention
efforts appropriately

B. Disadvantages:

-Serves as a deterrence to testing, including anonymous testing particularly
among immigrants, minorities
-Creates potential for confidentiality breaches by having a list with names
-Creates potential for misuse of the information by government, insurance
companies, employers and others
-Lacks broad community support
-Creates potential for use of this information for partner notification and/or
by criminal justice system
-Creates lists that could exist for many years with HIV infected people
living longer
-Increases chances of missing significant parts of the population with
potential for increase in people seeking anonymous testing
-Creates potential for inaccurate count due to people using
pseudonyms/changing names

6. What steps could be taken to overcome the disadvantages of an HIV
surveillance system using names?

A. Development of an HIV Surveillance System Using Names

-Move incrementally from a UI system to a name reporting system
-Keep names for a limited period of time
-Use encryption methodologies to code names to better protect confidentiality
B. HIV Counseling and Testing

- Increase the number of anonymous counseling and testing sites; make sites more accessible, clean and comfortable
- Aggressively promote HIV counseling and testing, with community based providers having a large role in this promotion

C. Uses of Surveillance Data

- Limit the use of surveillance data for public health purposes only
- Limit the use of surveillance data for the purpose of tracking the epidemic and monitoring trends
- Forbid use of surveillance data for criminal justice purposes

D. Legal Protections

- Encompass the same protections that currently exist for AIDS reporting, where there have been no breaches or use of data for other than surveillance purposes
- Ensure aggressive enforcement of, and strengthen anti-discrimination and confidentiality laws
- Pass laws that prohibit the use of HIV surveillance information for partner notification or in criminal proceedings

E. Services

- Ensure access to health care services

7. What changes, if any, are needed to make HIV counseling and testing (both anonymous and confidential) easily accessible?

- Increase the number of testing sites
- Make sites more clean and comfortable for clients
- Expand hours that counseling and testing is available
- Ensure language and culturally appropriate services are available
- Conduct extensive education and outreach campaigns about the benefits and availability of HIV counseling and testing and testing options, targeted to the public, physicians and other health care providers, and managed care organizations