

Spring 1998

the Active Voice+

an educational publication for AIDS activists, advocates and people living with HIV

Inside

Health Information Privacy
STD Testing and Treatment

SPECIAL FEATURE MONITORING THE EPIDEMIC

NAPWA, ACLU, and CSTE
on HIV Surveillance

and
An Advocate's Guide to
Unique Identifiers

the ActiveVoice+

The Active Voice+ is an educational publication of the National Association of People with AIDS (NAPWA). NAPWA is 501(c)(3) nonprofit organization which advocates on behalf of all people living with HIV and AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS. Since 1983, NAPWA has served as the collective voice and national consumer education and advocacy resource for all people living with HIV disease in the United States.

Information contained in this publication is for educational purposes only, and does not constitute an endorsement.

Copyright © 1998 NAPWA. Permission to duplicate is granted and encouraged provided the source is acknowledged.

Editor

Mike Shriver
Deputy Executive Director for Policy

Managing Editor

Matthew Doerpinghuas
Associate Executive Director

Contributors

Michael Adams
Jeffrey S. Crowley, M.P.H.
Anna Forbes, MSS
Kris MacDonald
Judy Wasserheit, M.D.

Executive Director

A. Cornelius Baker

world wide web

www.napwa.org

Subscriptions to the Active Voice+ are available free-of-charge. We ask that you please support us so we can continue to support you. Please make a tax-deductible contribution of \$25 or more to support the Active Voice+ and the important work of NAPWA.

Yes, Please send me copies of NAPWA's publications like the Active Voice+.

Enclosed is my gift to support NAPWA's work on behalf of people living with HIV.

Name _____

Organization (if applicable) _____

Address _____

City/State/Zip _____

Phone Number _____

FAX _____

Email _____

How can we better serve you? _____

Protecting

For many years, advocates for people living with HIV have fought at the state and federal levels for comprehensive legislation to protect the privacy of people living with HIV. The push for enactment of federal legislation to protect the privacy of individually identifiable health information was given a stimulus with the enactment of the Health Insurance Portability and Accountability Act of 1996 (signed into law in the summer of 1996). This legislation, commonly known as the Kassebaum/Kennedy Law, received widespread attention because it limited the circumstances under which an insurer can exclude an individual from health insurance coverage based on a pre-existing condition. This law also contained provisions that provide for the electronic (i.e. computer) dissemination of medical records. Because there was no consensus over how far to go in protecting the privacy of an individual's health information, Congress allowed for the electronic dissemination of these records, but did not enact any privacy protections. Instead, Congress called upon the Secretary of Health and Human Services to regulate the electronic transmission of medical records if the Congress had not legislated on this issue in three years (by the summer of 1999). The passage of this law and its authorization for the Secretary to regulate electronic medical records has increased the likelihood that Congress will legislate on this issue.

NAPWA has been advocating for consumer privacy protections in coalition with other partners in the HIV and disability communities through the Consortium for Citizens with Disabilities (CCD). NAPWA and CCD believe that it is very important that Congress enact strong federal legislation to protect the privacy of individually identifiable health information (See sidebar for NAPWA's Principles for the Protection of Health Information Privacy). It is also important to underscore that this legislation must cover all health information, including paper records (the Secretary's regulatory authority would only extend to electronic records).

Broad agreement on federal privacy legislation is likely to hinge on the resolution of three key issues:

A federal law should not replace good state laws

Because states have had to grapple with very complex issues that Congress is unlikely to adequately address, such as standards for involuntary commitment to mental institutions, it is important that federal law should not preempt (or override) more protective state public and mental health laws. Rather, we believe that federal legislation should establish a uniform minimum standard, which still protects the flexibility that states need to respond to regional or local circumstances that may arise. This is especially true for HIV, given that the epidemic is concentrated in a relatively small number of states and among communities that already face a history of discrimination and marginalization within the health care system. Enacting a federal privacy law as a floor,

Principles on the Protection of

The United States has made great strides in improving its understanding of people living with HIV and millions of people are committed to caring for and supporting the more than 650,000 people believed to be living with HIV in the United States. Nonetheless, HIV disease and AIDS remain deeply stigmatizing. The National Association of People with AIDS (NAPWA) believes that individuals must retain the right to control the disclosure of their health status and personal health information.

As Congress and national policy makers grapple with complex issues related to the privacy of health information, NAPWA affirms its support for the following principles:

Federal legislation should statutorily establish an individual's right to privacy with respect to individually identifiable health information, including genetic information. Individuals should retain the ultimate right to decide to whom, and under what circumstances, their individually identifiable health information will be disclosed. Confidentiality protections should extend not only to medical records, but also to all other individually identifiable health information, including genetic test results, clinical research records, mental health therapy notes, etc.

Privacy

by Jeffrey S. Crowley M.P.H.

without pre-empting state law, is also consistent with all other privacy and civil rights legislation enacted by Congress.

Privacy rights and research needs must co-exist NAPWA and the CCD also believe that it is possible to strike a balance between providing individuals with a strong and enforceable privacy right and supporting biomedical and other research. Some pharmaceutical and health care organizations have alleged that the individual privacy protections we seek would put an end to most current biomedical research. People living with HIV greatly depend on research, however, and NAPWA's positions would not stop or inhibit scientific advancement. We advocate, for example, for researchers to have continued access to existing

anonymized databases and tissue banks. We also encourage researchers to seek anonymized clinical information. At the same time, we believe that unrestricted access to individually identifiable health information by all researchers would produce a loophole with great potential for inappropriate use of personal health information.

Disclosure of information must be carefully structured

Another key issue in any federal privacy legislation relates to how we will structure a system for individuals to authorize disclosure of their personal health information. NAPWA supports a two-tier system, wherein the first tier of authorization would include disclosure of information for treatment and payment. In this

tier, a refusal to authorize disclosure for either of these purposes could lead to denial of care. As a result, a first-tier authorization is referred to as a compelled authorization. We believe that this type of authorization is legitimate because the practice of good health care is impossible if a provider is not free to consult with other professionals to make wise judgements regarding appropriate care. We also believe that it is reasonable that if a provider delivers health care, they should have access to enough information to get paid for their services. The second tier of authorization is for disclosures for which refusal to authorize has no impact on the delivery of health care. For example, your pharmacist may ask to disclose your health information to a firm that will call to remind you to renew your prescriptions a few days before they are set to run out. Some patients may choose to receive this service, but if the individual does not want to disclose their information, or is not interested in receiving such a service, there is no requirement that they do so.

Health Information Privacy

Federal legislation should prohibit the use or disclosure of individually identifiable health information absent an individual's informed consent. Health care providers, insurance companies, and others in possession of individually identifiable health information should be prohibited from using or disclosing such information unless authorized by the individual. In addition, any information used or disclosed should be limited to the minimum amount necessary for the use or disclosure. Unauthorized disclosures should be permitted only under exceptional circumstances--for example, if a person's life is endangered, if there is a threat to the public health, or if there is a compelling law enforcement need (as evidenced by a warrant or court order mandating access to a specific individual's records).

Federal legislation should guarantee an individual the right to access his or her own health information and the right to amend such information. Individuals should have the right to access and amend their own medical records so that they can make informed health care decisions and can correct erroneous information in their records.

Federal legislation should establish strong and effective remedies for violations of privacy protections. Remedies should include a private right of action, as well as civil penalties and criminal sanctions, where appropriate.

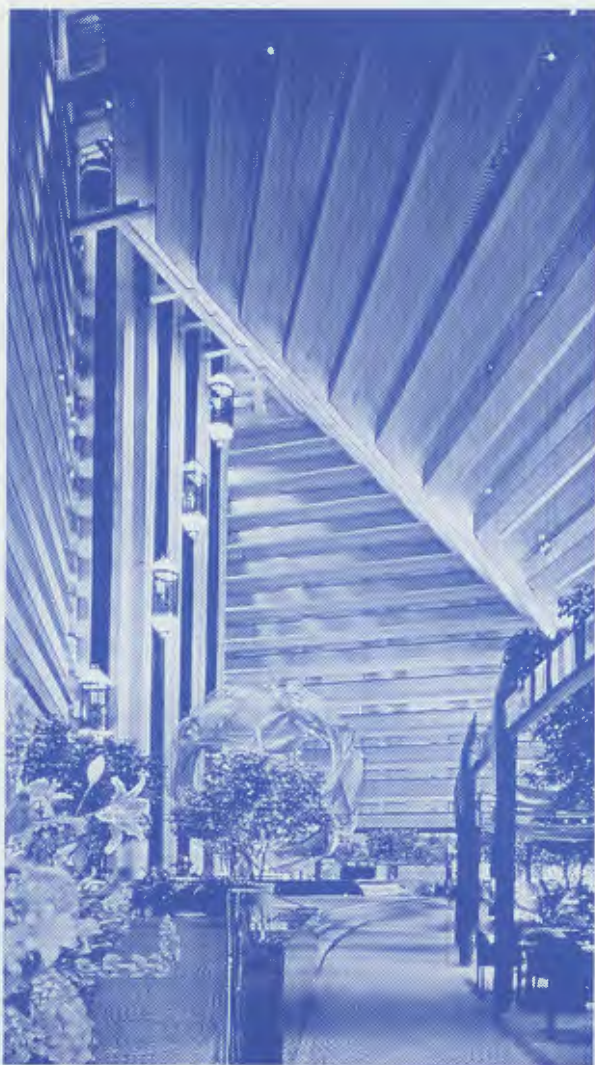
Federal legislation should provide a floor for the protection of individual privacy rights, not a ceiling. Like all other federal civil rights and privacy laws, federal privacy legislation for health information should set the minimum acceptable standard. Federal legislation should not pre-empt any other federal or state law or regulation that is more protective of an individual's right to privacy of or access to individually identifiable health information.

While protecting individual privacy rights, federal legislation should not impede important clinical and medical research. Federal privacy protections should not hinder the conduct of biomedical research and development. For example, researchers should be allowed to continue using existing anonymized patient databases and tissue samples. We believe, however, that "research" should not be defined so broadly as to permit the disclosure of individually identifiable health information for marketing or commercial purposes.

Adopted by NAPWA's Board of Directors in September 1997. Adapted from principles established by the Consortium for Citizens with Disabilities.

The challenge in crafting legislation will be to determine which activities of health plans and others are so critical that they should be included in the first tier authorization, and which activities are most appropriately left in the second tier authorization. NAPWA's position is that we want health plans to be able to appropriately manage care and provide individuals with high quality care. Nonetheless, we believe that the activities falling under the first tier, because a refusal to authorize can lead to denial of care, must be extremely narrow.

At the present time, several Members of Congress have either introduced legislation, or are intending to do so, including Senator James Jeffords, Chairman of the Senate Labor and Human Resources Committee, which has jurisdiction over privacy legislation. As the debate on health information privacy moves forward, it is important that people living with HIV and their advocates share their experiences and concerns with their Members of Congress and urge them to support efforts to enact strong and enforceable legislation to protect the privacy of individually identifiable health information.



Register now!

20th Anniversary
of the
National Lesbian & Gay
Health Conference
and
16th National AIDS/HIV
Forum

in San Francisco!
July 25-July 29, 1998

for more information, contact:

NLGH 1998 Conference
P.O. Box 33022 ■ Washington, DC 20033
202/939-7880 ■ 202/234-1467 (fax)

for hotel reservations, contact:

Connections at 1-800-262-9974

HYATT
REGENCY
SAN FRANCISCO
IN EMBARCADERO CENTER

Monitoring the HIV Epidemic

Editor's Note:

The Centers for Disease Control and Prevention (CDC) has recently announced its intention to promote the expansion of our nation's HIV/AIDS surveillance efforts to include the reporting of HIV infections.

With nation-wide declines in AIDS deaths and AIDS incidence, only tracking AIDS cases is no longer providing us with an accurate snapshot of the current and emerging trends of the HIV epidemic. As a result, the CDC is encouraging the expansion of surveillance efforts to include reporting of HIV infection.

While there is consensus that we need to expand surveillance efforts to include HIV infection reporting, there is NO agreement on the manner in which we should actually collect this data. This expansion could be done by confidential name reporting or by reporting using a unique identifier.

By this summer the CDC will issue to the states and localities a "Best Practices Guidance" This document will suggest the manner in which all states should expand their surveillance efforts to incorporate HIV infection reporting (in addition to the standard AIDS case reporting which happens in every state, territory and locality).

It is important to remember that under our current AIDS case reporting system, which is done using a person's name, the CDC NEVER receives the name of any individual. That name is kept at the state/local level and only demographic and other relevant information is sent to the CDC.

This special section of the Active Voice+ is devoted to the issue of monitoring the HIV epidemic in the US. Below, you will find NAPWA's Policy on Monitoring the HIV Epidemic which was the first position paper on surveillance issued from the national HIV/AIDS organizations and has served as a model for others. Then, we feature articles from the American Civil Liberties Union (ACLU) and the Council of State and Territorial Epidemiologists (CSTE) opposed to and in favor of HIV infection case reporting by name. Finally, we have an incredibly and informative article by Anna Forbes on Unique Identifiers.

NAPWA feels that it is vital that people living with HIV disease and the community-based organizations who provide prevention and care services to people affected and infected with HIV-be as informed as possible so that the decision to expand our nation's surveillance be a balanced and fully informed process in every jurisdiction.

The following criteria define NAPWA's position on the responsible and ethical approach to monitoring the HIV/AIDS epidemic in the United States. Collectively, these fourteen criteria define a comprehensive approach to both our nation's surveillance system and our nation's HIV counseling and testing system, as well as federal public policy and civil rights concerns.

1. Under no circumstance does NAPWA support HIV named reporting, the CDC's promotion of a national standard in support of HIV named reporting or the creation of a federal name-based registry of people living with HIV/AIDS. The CDC should in no way encourage or require states to do HIV named reporting.
2. NAPWA guardedly supports the expansion of our national HIV/AIDS surveillance system to include HIV infection case reporting; however, only using unique or coded identifiers that insure privacy and confidentiality of the individual.
3. The CDC must aggressively promote, expand and improve anonymous HIV testing in the United States. The availability of readily accessible anonymous testing is a necessary condition/prerequisite for any maintenance and/or expansion of HIV surveillance in the United States. CDC must mandate readily accessible anonymous testing in all HIV Prevention Cooperative Agreement jurisdictions as a condition of establishing HIV surveillance tools nationally.
4. CDC-funded research has shown that certain individuals and/or communities will only use anonymous testing sites. Therefore, access to primary care (after testing positive) is predicated upon the availability of anonymous testing.
5. CDC's HIV/AIDS surveillance's primary goal is to collect useful data in a timely fashion to provide an accurate estimate of the prevalence of HIV/AIDS in the United States. Accordingly, HIV/AIDS surveillance has to provide reliable data. As such, while it is a goal of anonymous and confidential counseling and testing to link individuals into services, this is not necessarily either a goal or an outcome of surveillance.
6. The applied uses of reliable, accurate and timely surveillance data include informing: resource allocation; health planning; and evaluation of both programmatic as well as system-wide activities (i.e. access to care, survival/death rates, seroincidence rates, etc.).
7. As a guiding principle, unless a name is uniquely essential for the protection and promotion of an individual's health and well-being or a community's health and well-being, the name of the person whose information is being reported to the state or local health department should not be taken.
8. Surveillance is an adaptive science. As such, surveillance systems should be constantly re-evaluated to determine if the goal of applying surveillance data to meaningful education, programs, planning and resource allocation is happening. If not, these systems should be discontinued.
9. Surveillance systems consist of several different types of activities in addition to case counting (number of individuals living or deceased who have said disease): sentinel studies; incidence and prevalence studies (density of disease and breadth of disease); and even behavioral (risk-taking) surveillance. The more varied the surveillance system, the more relevant the data sets that result.
10. Decisions regarding what type of HIV/AIDS surveillance to implement in a given jurisdiction are best made by each jurisdiction based on resources, community acceptance, confidentiality/privacy protections, the severity of the epidemic, and other local considerations.
11. Data from HIV case reporting must be appropriately disseminated to the community planning bodies within jurisdictions for use in both prevention and care planning.
12. Categorical funding for HIV/AIDS surveillance must be maintained and augmented. However, resources for HIV/AIDS surveillance must not come at the expense of resources for HIV-related research, care and prevention (both primary and secondary) programs.
13. National HIV/AIDS public health policy should reinforce that the data collected under this system must remain decoupled from partner notification and contact tracing processes. These processes' relationship to surveillance must be made only as a component of and only with the explicit concurrence from the jurisdiction's HIV Prevention Community Planning group.
14. Federal law must establish an individual's enforceable right to privacy with respect to individually identifiable health information, and must protect each person from discrimination based on real or perceived health and/or genetic status. Such laws must include strong and enforceable repercussions for those individuals and systems that breach an individual's confidentiality and/or privacy.

Adapted by NAPWA's Board of Directors on October 3, 1997

THE ACLU ON HIV SURVEILLANCE AND NAME REPORTING: PROTECTING CIVIL LIBERTIES IS STILL GOOD FOR PUBLIC HEALTH

By Michael Adams

Citing new medical advances that delay the onset of AIDS, some public health officials and commentators have renewed calls for shifting the focus of systematic surveillance to the front end of the epidemic and instituting names-based HIV case reporting. The ACLU recognizes that the case for expanded HIV surveillance may well be stronger at this juncture in the AIDS epidemic. The ACLU also recognizes that individual privacy rights are not absolute, and may have to give way if there is no other means of protecting the public health. Name reporting, however, not only violates individual privacy rights, but also disserves public health efforts to stem the spread of HIV. Because unique identifiers and existing HIV surveillance tools like sentinel studies and prevalence and incidence studies provide viable alternatives, the ACLU opposes name reporting.

Proponents of name reporting argue that new medical treatments require us to alter our approach to surveillance, and that it no longer makes sense to systematically track just AIDS cases, which represent only the last stages of HIV disease. Instead, proponents of name reporting argue that we must track HIV from the point of infection, in order to get an accurate picture of how the epidemic is currently developing.

Name reporting proponents generally make five points. They say name reporting: (1) would provide more accurate epidemiological data; (2) would help better target prevention and public health efforts; (3) would allow for proactive linking of individuals to health care; (4) would permit a more efficient allocation of AIDS funding; and (5) would strengthen partner notification programs.

Proponents of name reporting also argue that opposition to name reporting is no longer justified because public health authorities have a good track record on protecting confidentiality and we now have strong anti-discrimination laws in place.

While these rationales may be persuasive at first blush, they do not withstand closer scrutiny.

First, while the goal of increased HIV surveillance is to bring those with HIV into the public health system and to obtain more accurate epidemiological data, name reporting

will likely have the opposite effect. The most current scientific research strongly suggests that eliminating anonymous HIV testing will discourage individuals from being tested because they fear that their confidentiality will be violated and that they will be subjected to discrimination and social stigma. Name reporting will thus prevent many people from entering into the public health system, will severely damage HIV prevention efforts, and coincidentally will hamper HIV tracking.

Second, name reporting is not essential to effectively monitor the epidemic, target prevention, or allocate AIDS funding. Existing surveillance mechanisms, including sentinel studies and prevalence surveys, help to accomplish these goals. Moreover, the use of unique identifier systems, which assign an alpha-numerical code to each HIV test subject, provide an alternative means of systematic HIV case reporting without using names. While some argue that unique identifiers are not a viable means of HIV surveillance, the Maryland AIDS administration reports that Maryland's unique identifier program is fulfilling that state's surveillance needs. Unique identifier systems do not produce perfect statistics, but if properly implemented they can produce the data we need to fight the AIDS/HIV epidemic.

Third, no form of HIV surveillance will link individuals to health care that does not exist. We are presently unable to provide antiretroviral therapy to everyone seeking HIV treatment, and there is no reason to believe that instituting name reporting will improve on that record. In fact, fourteen of the twenty eight states that currently have name reporting also have AIDS Drug Assistance Programs (aDAP's) that have waiting lists, cut-offs, or other eligibility restrictions that are inconsistent with federal treatment guidelines. The key to linking individuals with HIV to health care is making the care available, and this will be accomplished when there is sufficient funding for care, regardless of what forms of HIV surveillance are in place.

Fourth, partner notification does not require knowing the name of the individual who tests positive for HIV. Partner notification is routinely conducted without advising the notified partner of the identity of the test subject. Partner notification is effectively

accomplished when the identities of partners are disclosed by the test subject and public health authorities have sufficient resources to hire trained staff to trace and notify partners of their possible exposure to HIV. Partner notification inherently relies on the willingness of the test subject to report the names of his or her partners. Coercive public health measures accomplish nothing in this regard.

Finally, legal protections for people with HIV are far weaker than advocates of name reporting think they are. There have been troubling breaches of confidentiality by public health authorities during the AIDS epidemic. Courts are also severely restricting the reach of the Americans with Disabilities Act. One federal appeals court, for instance, has held that the ADA does not offer any protection to HIV-positive individuals who are the victims of discrimination but are asymptomatic. Another federal appellate court has ruled that the ADA does not prohibit insurers from discriminating against people with HIV.

A Word On Anonymous Testing

The ACLU firmly believes that anonymous HIV testing must be available in all states to ensure that nobody is deterred from being tested and individual privacy is protected. Some have suggested that name reporting be adopted, but that anonymous testing be maintained as an option for those who would otherwise refuse to be tested.

This suggestion reveals that we do not need perfect surveillance data, since the use of anonymous testing in a name reporting system means that some cases of HIV infection would not be reported at all. And if we do not need perfect surveillance data, there is no reason to adopt name reporting instead of unique identifiers. Even without a penny of federal funding, Maryland has demonstrated that HIV surveillance can effectively be conducted by using unique identifiers.

While unique identifier systems may not yield perfect surveillance data, if used properly they can yield the data we need while protecting individual privacy.

*Mr. Adams is Staff Counsel at the
ACLU AIDS/HIV Project*

THE COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS ON HIV SURVEILLANCE

A "Q and A" with Kris MacDonald

Why is there a need now to look closely at HIV surveillance?

There have been dramatic changes in the HIV/AIDS epidemic in the past two years with the first declines in AIDS cases and AIDS deaths since the beginning of the epidemic. These declines began prior to the wide spread use of combination anti-retroviral therapy and are likely to accelerate in the future. Because progression from HIV infection to AIDS takes a long time, a median of about 8-10 years prior to availability of effective therapy, AIDS surveillance data have always been somewhat out of date relative to current HIV transmission. However, the recent dramatic slowing of disease progression has let many epidemiologists and others to seriously question the value of relying solely on AIDS to track the epidemic.

As the epidemic changes, the emerging epidemic in new populations, its possible reemergence in existing populations and the changing mix of risk, race, geographic and socioeconomic factors, cannot be tracked without current, accurate, population-based information on HIV infection. Efforts to marshal financial resources need to be supported by such data and are threatened by headlines that proclaim the end of the AIDS epidemic.

We need better data.

What is CSTE's position on HIV surveillance?

CSTE's recommendation is to expand the current national scope of the AIDS surveillance system to include reporting of HIV infections.

What does CSTE mean by a "national" HIV surveillance system?

By a "national" surveillance system we mean a system where CDC recommends standard surveillance methodologies, definitions, confidentiality guidelines, analytic framework, technical support and funding, but where CDC allows each state to implement its own system based on state law, regulation and program guidelines.

It is important to remember that no identifying information on AIDS cases, and by this we are talking about names, is ever sent from states to CDC. In other words, CDC NEVER receives the names of people with AIDS, and in an

expanded surveillance system, the CDC would still not ever receive the names of people with HIV infection.

What is CSTE's position on named HIV reporting?

CSTE recommends named HIV reporting. However, CSTE holds that this decision is nested within a comprehensive framework. CSTE's support of named HIV infection reporting, as part of a comprehensive package, includes strong support for confidentiality protections and the availability of data for local planning groups. CSTE believes that continued availability of anonymous testing is not incompatible with named reporting. In addition, linkage (or not) of HIV surveillance to partner notification efforts is a local decision, and not a requirement of a named reporting system.

Why wouldn't a system of reporting via a unique identifier be adequate?

In CSTE's judgement, unique identifier systems are not adequate for three reasons:

You can't get a reasonably accurate case count. Current experience with unique identifiers based on social security number, age, sex, and date of birth in Maryland and Texas show that only 60% to 70% of reported cases have a complete identifier. Completeness of reporting (based on comparison to known reported AIDS cases during the same time period) was only about 50% in Maryland and only 26% in Texas, therefore, it is likely that significant under reporting would occur with a unique identifier system. This has very important and critical implications for funding issues and for assessing effectiveness of prevention programs. We believe that a unique identifier system simply will not provide an accurate enough assessment of the HIV disease burden in the community to be reliable;

There are likely to be significant biases in who is reported. Any system that relies on social security number will likely not count people who do not have a number. This will likely result in a significant bias against reporting cases in immigrants, illegal aliens, adolescents, minorities, etc., exactly the population where the epidemic is having an increasing impact. Without good information, resources will likely not be made available to

serve these populations and may actually promote a "head-in-the-sand" approach to dealing with HIV in these groups. At the very least, this could have a detrimental effect on AIDS prevention in these communities; and

Confidentiality is a major concern at the health care provider site. In order to get accurate information on race, ethnicity, and risk factors any surveillance system has to be able to go back to the reporting physician and collect data that might have been missing in the first report. In Maryland, this requires each health care site to maintain a log of the name of persons with HIV infection who they have reported and their unique identifier so they can go back to the medical record. It seems that many physicians are not keeping such logs and therefore there is no way to collect accurate information. Also, if the provider is keeping the log, this raises two problems. First is the burden placed on the provider to keep such a "list" updated. This could deter providers from reporting cases at all and further lead to decreases in overall case reporting. An even greater risk is the potential for breaches in confidentiality from this approach, since "lists" of name will be scattered among various providers throughout the community.

Won't named reporting deter people from being tested?

CDC has commissioned researchers at the University of California, San Francisco to conduct the first comprehensive study designed to address this issue. Interviews were conducted in eight states of persons at risk recruited in community settings. Preliminary data indicate that many people are unaware of whether or not there is HIV reporting in their state. Only 2% indicated that concerns about reporting was the primary reason they had not sought HIV testing. (Editor's note: As of time of print, these data have not been published).

What about confidentiality?

Confidentiality is key, and the record of state health departments protecting AIDS data (and where applicable HIV data protection) is strong. Unauthorized confidentiality breaches are much more likely to occur in medical care settings.

continued on page 10

An Activist's Guide to Unique Identifiers

By Anna Forbes, MSS

In its recent position paper "Monitoring of the HIV Epidemic," NAPWA expresses guarded support for HIV case reporting "only using unique or coded identifiers that insure privacy and confidentiality of the individual."

So what are these unique identifiers people are talking about? How do they work? Since just about any code can be cracked, why should I trust them to protect my privacy?

These are the very legitimate questions I'll try to address in this article.

Unique identifiers (UIs) are nothing new. We use them every day in the form of telephone numbers, zip codes, credit card numbers, product serial numbers, etc. Any number or letter-number code that has a one-to-one correspondence to a given person, thing or location is a UI. Your telephone number, for example, only rings in your house. When people call you, they don't have to be concerned that the phone will ring in someone else's house (assuming that they dial correctly) because your phone number corresponds with your phone on a one-to-one basis.

For HIV case reporting, we need a UI that has a couple of other important characteristics. Specifically, it needs to use common data elements, be reproducible and have a low duplication rate.

**Aaaaaghhh.....techno-speak!!!
What does all that mean?**

Relax. Remember, you are the people who taught yourselves how drugs work (and don't work) in the body. This is nowhere near as difficult as that.

DATA ELEMENTS are the chunks of information that UIs are made out of. Maryland has a UI system for HIV case reporting, for example, in which the data elements are the last four numbers of a person's Social Security number plus his/her birth date and codes indicating race and gender. The testing provider arranges these data elements in a specific way to produce a twelve-digit UI code. The code gets attached to the person's blood sample before it goes to the lab for HIV testing.

Now, we have public data elements and private data elements. Public data elements are pieces of information about you that show up in public records all the time, such as birthdate, race, gender, Social Security number, etc. Every

time you turn around, someone is requiring you to list that information on a form and then entering it from the form into a database. The information pieces that shows up at the Department of Motor Vehicles, birth and death registries, Social Security registries, etc. are public data elements.

Private data elements, on the other hand, are pieces of information that don't show up in public databases. They're also called "keys". The private word, initials or set of numbers you use to access your account when you go to an automatic teller machine is a good example of a key. You control it. Even if somebody steals your bankcard, he or she can't get into your account without your private key. More about these later.

When you select common data elements to use in a UI system, you're looking for pieces of information that everyone has, that don't change over time and that people don't mind giving at HIV test sites. This can be trickier than it sounds. Maryland chose to use last four digits of the Social Security number, for example, not realizing the extent to which people either didn't know their Social Security number, didn't have one or didn't want to give it out. In retrospect, the Maryland folks believe that their system (which works well, overall) might work even better if they hadn't selected this particular data elements.

Having a REPRODUCIBLE UI is important because, without it, people tested more than once will be assigned a different UI each time they are tested. This results in undetectable duplications -- people listed in the HIV registry more than once -- which throws off the accurate epidemiological picture we are trying to obtain of how many people are living with HIV and in what populations. This is also why random or sequential numbers don't work. They can be used to count the number of tests done but can't count the number of individuals tested with any accuracy.

LOW DUPLICATION RATE means that is very unlikely that two people will be assigned the same UI. Duplication can't be eliminated entirely (even name reporting has some duplication) but it can be reduced by using a good UI system. SOUNDEX (frequently used as a UI system even though it's not technically a UI) has a duplication rate of approximately ten to twenty percent --- too high by most people's standards.

By contrast, the Unique Record Number System (designed by HRSA, the federal entity that administers the Ryan White Care Act) has a duplication rate of only .02% - .04% -- an acceptable rate in most people's books. The duplication rate you get depends on the data elements you select and the rules you establish (also called the algorithm) for creating the UI.

This sounds really complicated. Do UIs actually work? Is anyone using them?

YES! They are being used successfully in a number of settings to protect health-related information (not to mention being used constantly in the banking/business side of life). Maryland is already using them for HIV case reporting and Massachusetts has announced its intention to pilot a UI for its HIV surveillance. However, Texas was not happy with the performance of its UI and is considering adopting name reporting. They are considering this mainly because their system is desperately underfunded and because they've had a low level of "buy-in" by providers and local health departments.

Maryland's UI system is also underfunded. But both the Health Department and the consumer/advocacy communities view it as a success. It enables the Health Department to collect and track information without causing testing avoidance or putting the privacy of people living with HIV at risk. Maryland is already using the information it has collected through the UI system to make funding allocation decisions and plan targeted prevention and care programs.

UI-based (as opposed to name-based) HIV case reporting systems are also in place in Australia, Denmark, Belgium and the United Kingdom. And beyond HIV, states also using UIs to protect people's privacy in all kinds of sensitive, health-related situations.

New York state, for example, uses a UI in place of the woman's name on "fetal death certificates" (documentation of miscarriages and abortions). In Massachusetts, the state Health Department uses UIs on the records of people receiving state-funded mental health care. Pennsylvania, similarly, uses UIs in place of names to aggregate information about people receiving services through the state Office of Drug and Alcohol Programs. So there's nothing new or unusual about the idea of using UIs to track health care information.

But can't UIs be cracked? Why should I trust them?

Imagine a big, long line. Put "absolute privacy" on the **right end** of the line and "no privacy at all" on the **left end**. All UI systems fall somewhere along that line, between the two extremes. Put Social Security numbers on the left end next to "no privacy at all" because, as we all know, if you have a Social Security number, then practically everybody has it on file. It's a UI but it's not one that guarantees any privacy.

Near the right end you can put UIs that combine a key (private data element) with the public data elements discussed above. UIs made entirely of public data elements fall along the middle of the line.

Computerized encryption systems give you somewhat more security than manual ones because more complex algorithms are harder to crack manually than simple ones. Since a computer can whiz through the process of encrypting (mixing up) the information, it can handle really fancy algorithms that have lots of steps in the same amount of time as it takes a human to carry out a simple algorithm. This means that a computer encrypted UI is less likely to be cracked by someone who is just trying to do it casually (a curious "browser" who somehow gets obtains a list of UIs). Even computer encrypted UIs, however, can be cracked by someone with a computer and access to the UI algorithm.

People tend to assume that computer encrypted UI systems are too expensive, too difficult and would require every HIV testing provider to have a computer on site. But what if you used a centralized, call-activated computer that providers accessed via touch-tone phone? The provider could call up the computer and punch in the necessary data elements using the dialing buttons. The computer at the other end could crunch up the data and read back the UI. How hard is that?

OK, I get that. But what are those UIs all the way on the right about?

They're the ones that are more secure because they include a key (private data element). Here's how they work.

Imagine that you're trying to crack a UI system (Mission Impossible music rises in the background). No matter how good the encryption, any system that uses only public data elements can be cracked. You just need three things:

- 1) A computer;
- 2) A secondary data base that has all the necessary data elements in it; and
- 3) A copy of the algorithm used to produce the UIs.

Your secondary database could be Social Security records, a drivers license registry or anything that shows the data elements required for that particular UI system. You process the secondary database through the algorithm to produce a UIs for each of the names on the secondary database. Then you just cross-match those UIs against the original list of UIs you're trying to crack. Every time you find a match, you've identified a person on the original list of UIs. This is called "cracking by cross matching".

Now (take a deep breath, we're almost out of the technical part), what if the UI system you're trying to crack is one that scrambles a key in along with the public data elements? Remember the key is a private word or number that won't show up in a public record's database. If it's a keyed system, you might as well take off the black ski mask because you won't be able to generate the second set of UIs. The public records database can't provide all the data elements you need to produce the UI because it doesn't include the keys. Incorporating a private key selected or controlled by the consumer effectively jams any effort to crack the UI system by cross matching.

Given all this, you'd think that people committed to privacy would automatically want to use keyed UI systems for HIV case reporting. BUT... because they can't be cracked by cross matching, they also can't be used to cross-match HIV data against other, relevant databases such as:

- The AIDS registry (to prevent having a lot of people listed twice, once on the HIV list and again on the AIDS registry);
- The national death registry (to make sure that people who have died are removed from the HIV registry so that it's current); and even
- The ADAP records (to find out what proportion of people with HIV in your state are in the state's ADAP program).

In both Maryland and Texas, the process described above is exactly how they determine how many of the people in the HIV registry are also in the AIDS registry, the ADAP registry, etc. They produce UIs for everyone in those registries and then cross match those UIs against the HIV registry. But if states use a keyed UI system for HIV reporting, they won't be able to generate UIs for that second database because they'll be missing one of the necessary data elements.

How important is that?

Only you and your state can decide.

What I recommend to states seriously considering this issue is that you form a Working Group that includes people with

HIV/AIDS, Health Department personnel, HIV counseling and testing providers and one or more UI experts to serve as technical advisors. Selecting a UI system is like buying a car -- you have to consider and discuss the advantages and disadvantages of a lot of models before choosing what you need and can afford.

The Working Group needs to ask itself these questions:

- 1) **What data elements don't change over time and are supplied without objection?**
- 2) **What's the highest level of confidentiality we can agree on?**

Is the state insisting that our UI system has to be one that can be cross-matched against other data bases? Can we come up with a way to get the ancillary information we need while using a keyed UI system for HIV case reporting? Can we agree to "grandparent it in" (i.e. start assigning keyed UIs to everyone with HIV/AIDS with the understanding that, eventually, the AIDS registry and ADAP registries will be made up entirely of people with keyed UIs so we can cross-match at least those registries against the HIV list)?

- 3) **What's the highest level of confidentiality we can afford?**

Adopting any kind of HIV case reporting system is going to cost money. Maryland is spending about \$100,000 per year to process 7500 UI reports of HIV infection. New York State, in comparison, is spending at least \$200,000 per year solely to support the five additional staff they had to add to 14,400 name-based reports of CD4 counts below 200. The two systems are comparable in cost.

- 4) **Is the system we're considering user-friendly enough that providers will comply when required to use it?**

This is a tough set of questions and the Working Group may have to sweat to hammer out an acceptable compromise. Like all good compromise, it will probably make both sides a little unhappy.

You may not get as much privacy protection as you want and the Health Department will have to cope with a system that, let's face it, isn't going to be as easy for them to use as name reporting would be.

Remember that my recommendation is that the UI expert(s) should be there as a technical advisor only. The Working Group should think carefully about the first three questions before

continued on page 10

Unique IDs

continued from page 9

addressing the fourth. Technology should serve people; people shouldn't have to conform to the technology. Once you figure out what you want, it's the UI expert's job to find or create a system that meets your requirements and that is user-friendly enough for providers. Don't let yourself get bulldozed into a system that doesn't work for you.

Above all, don't let anyone tell you that implementing an UI-based HIV case reporting system in your state is impossible. Would you look at a Volkswagen Beetle, decide it's too small, look at a Mercedes, decide it's too expensive and, on that basis, decide that you don't really want a car? Heck, no! You'd just keep shopping!

Finding the right UI system and getting your state to use it may be a labor intensive advocacy process but think about it. Isn't your privacy worth it?

ACKNOWLEDGMENT: With sincere thanks to Walter Cuirle, who taught me practically everything I know on this subject.

CSTE Position

continued from page 7

Regardless of their unblemished track record, all reporting jurisdictions should be sure they have adequate protections against and penalties for unauthorized release of data regardless of the type of HIV reporting in a jurisdiction.

The authorized release of the name of an individual living with HIV disease can occur NOW (i.e. through a court order) can occur now of names of persons with HIV in Medicaid and ADAP programs and other administrative databases accessible by state governments. If this is an issue, it should be addressed regardless of HIV named reporting.

Partner notification?

This topic warrants a newsletter issue of its own. CSTE's position is that linking HIV surveillance to partner notification is a local call. "Mandatory" partner notification is a misnomer because PN requires the cooperation of the individual. One can never know whether a complete and accurate list of partners has been given.

Who or What is CSTE?

CSTE, the Council of State and Territorial Epidemiologists, is a professional organization

of over 400 epidemiologists who work primarily in state health departments around the country. CSTE was founded in 1952 and, among other things, is the group designated by ASTHO, the state health commissioners' association, to advise CDC on what diseases should be under public health surveillance. CSTE members do not typically hold Policy (big "P") making positions, but are career professionals whose expertise is in the science of epidemiology.

CSTE makes recommendations through position statements passed at its annual meeting and by letters to national policy makers. In addition to its position on HIV surveillance, CSTE is on record in favor of syringe exchange and decriminalization of the sale and possession of syringes. CSTE also has two staff members in its national office who have assisted HIV community planning groups around the country develop and interpret their epidemiologic profiles. CSTE is on record in favor of increased prevention funding and in opposition to proposed legislation such as the Coburn bill.

Mrs. McDonald is the lead HIV Consultant to CSTE and at the Minnesota Department of Health.

POSSESS THE POWER OF ADVOCACY!

Feeling run down? Got the Blues? Does it ever seem like your life is just passing you by? Do you ever think to yourself, "I want more out of my life?"

Well, my friend, we've got the sure-fire cure for what ails you...

Don't just sit there! Advocate!

That's right. You, too, can be a successful Grassroots Advocate. You, too, can take charge of your government, your life, your destiny! You can be a winner every day of your life!

Amaze your friends and family. Be the first one at the office to know what's new on Capitol Hill. Learn how to get what **YOU WANT WHEN YOU WANT IT!**

Possess the power of advocacy **TODAY!**

Yes! I want to be a Winner!

Sign me up on the winning team!

Name _____

Address _____

City _____ State _____ Zip code _____

Phone _____ FAX _____

Email _____

"I used to get angry. Now I get exactly what I need!"

What would you pay for this? Don't answer yet, because, in addition, you get all the great benefits of being a member of the winning team. You get:

- Updates on hot federal legislation as it happens and info on what YOU can do to effect positive outcomes!
- A quarterly newsletter filled with the latest on HIV/AIDS policy, treatment, and prevention info!
- Training and assistance on developing successful advocacy strategies!
- Technical assistance to non-profit groups on policy development and political advocacy!
- Advance notice of important conferences and training opportunities!
- And much more!



What are you waiting for?
Join the winning team **TODAY!**
Send **NO MONEY.**
Just fill out the information below and
send it back to us. **Hurry!**

Jean-Michel Breville is the Associate Director for Policy at NAPWA and the writer for this humorous piece.

The Role of STD Testing & Treatment in HIV Prevention

By Dr. Judy Wasserheit, Director, Division of STD Prevention and Control, Centers for Disease Control and Prevention (CDC)

There is compelling evidence that testing and treatment of sexually transmitted diseases (STDs) can be an effective tool in preventing the spread of HIV. Consequently, HIV programs should develop strong linkages with STD testing and treatment programs. This is especially important for programs targeting sexually active young women, who represent one of the fastest growing populations with AIDS.

The risk of HIV transmission is increased in the presence of STDs that cause genital ulcers such as with syphilis, herpes, or chancroid as well as other STDs (e.g., chlamydia, gonorrhea, or trichomoniasis). Frequently these STDs have no symptoms, especially in women.

What is the link between HIV and other STDs?

In the United States, the spread of HIV infection among women through sexual transmission has followed in the footsteps of other STD epidemics. For example, the geographic distribution of heterosexual HIV transmission in the South closely parallels that of syphilis. Most of the health districts with the highest rates of syphilis and gonorrhea are concentrated in the South, where HIV prevalence among childbearing women also is highest.

Individuals who are infected with STDs are three to five times more likely than non-infected individuals to acquire HIV if exposed to the virus through sexual contact. In addition, if an HIV-infected individual also is infected with another STD, that person is three to five times more likely than other HIV-infected persons to transmit HIV through sexual contact (Wasserheit, 1992).

Is there biological evidence that STDs facilitate HIV infection?

There is substantial biological evidence demonstrating that the presence of other STDs increases the likelihood of both acquiring and transmitting HIV:

Increased susceptibility. In women who are infected with other STDs, cervical secretions contain an increased number of the types of cells that are targeted by HIV (e.g., CD4+ cells). Researchers believe that an increased number of these cells probably increase a woman's likelihood of becoming infected if she is exposed to HIV; and

Increased infectiousness. Studies have shown that when HIV-infected individuals are also infected with other STDs, they are more likely to transmit HIV to their sexual partners. In studies conducted in Africa, individuals who were infected with both gonorrhea and HIV were more than twice as likely to have HIV genetic material detectable in their genital secretions than were those who were infected only with HIV. Moreover, the average concentration of HIV genetic material in semen is dramatically higher in men who are infected with both gonorrhea and HIV than in men infected only with HIV.

How can STD treatment slow the spread of HIV infection?

New evidence from intervention studies indicates that detecting and treating STDs can substantially reduce HIV transmission at the individual and community levels:

STD treatment reduces an individual's ability to transmit HIV. As stated earlier, studies have shown that treating STDs in HIV-infected individuals decreases both the amount of HIV they shed and how often they shed the virus; and

STD treatment reduces the spread of HIV infection in communities. A landmark community-level, randomized trial in a rural area of Tanzania demonstrated a 42 percent decrease in new, heterosexually transmitted HIV infections in communities with improved treatment of people with symptomatic STDs, as compared to communities with minimal STD services, where incidence remained about the

same (Grosskurth et al., 1995). An ongoing randomized trial in Uganda is exploring alternative approaches, including treatment of STDs that do not have symptoms, to further examine the impact of STD treatment on HIV prevention.

What does this mean for HIV prevention programs?

Strong STD prevention, testing, and treatment can play a vital role in comprehensive programs to prevent sexual transmission of HIV. Furthermore, STD trends can offer important insights into where the HIV epidemic may grow, making STD surveillance data helpful in forecasting where HIV rates are likely to increase. Better linkages are needed between HIV and STD prevention efforts nationwide in order to control both epidemics.

To address these issues, comprehensive HIV prevention programs may develop linkages with STD programs to incorporate:

- Community-based efforts to improve STD care-seeking behavior;
- Quality on-site STD detection and treatment services at a variety of settings for HIV-infected persons, other persons at risk for HIV or other STDs and their partners;
- Improved STD treatment for sex partners of infected persons; and
- Expanded STD surveillance systems.

References

Grosskurth H. et al. 1995. "Impact of improved treatment of sexually transmitted diseases on HIV infection in rural Tanzania: randomized controlled trial." In: *The Lancet*, 346:530-36.

Institute of Medicine. *The Hidden Epidemic: Confronting Sexually Transmitted Diseases*. 1996. Washington, DC: National Academy Press.

Wasserheit JN. 1992. "Epidemiologic synergy: interrelationships between human immunodeficiency virus infection and other sexually transmitted diseases." *Sexually Transmitted Diseases* 9:61-77.

For more information, you can call:
CDC National AIDS Hotline 1-800-342-AIDS
CDC National STD Hotline 1-800-227-8922

AIDS **Victory** 1988

H **IS** **NOT** **HOPE**
VICTORY

202-898-0414
NAPWA

Call J-M Breuelle

May 3-5, 1998
Washington, DC

1413 K Street, NW
Washington, DC 20005-3442