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FAX TRANSMITTAL

TO: Daniel Montoya

FAX NUMBER: 202-632-1096

DATE: October 10, 1997

NUMBER OF PAGES: 11 *(not including cover)*

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Daniel,

Ben thought this would be useful for the HIV reporting discussion.

Marcello

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September, 1997

MYTHS AND FACTS ABOUT HIV CASE REPORTING BY NAME VERSUS BY UNIQUE IDENTIFIER

The American Medical Association, the Council of State and Territorial Epidemiologists and the New England Journal of Medicine, among others, have recently started urging all states to adopt name-based reporting of HIV. This policy requires doctors, test sites and labs to report to their state Health Department the names of all individuals who test positive for HIV.

Some people who oppose Mandatory Name Reporting (MNR) of people with HIV believe that HIV case data should be collected using unique identifier codes instead of names. They argue that this enables epidemiologists to track HIV spread and study the epidemic without putting the privacy of people with HIV at risk by entering their names into a permanent state registry.

These are a few of the myths and facts about HIV case reporting by MNR unique identifiers:

MYTH: **If state Health Departments have the names, they can make sure that everybody who tests HIV positive gets into care early and has a chance to take advantage of medical advances in HIV treatment.**

FACT: In 1996 through early 1997, only 25% of Americans with CDC-defined AIDS were on any kind of Protease Inhibitor therapy. The federally funded AIDS Drug Assistance Programs (ADAP) got medication to somewhere between 14% and 28% of all ADAP eligible people in 1996. Even while serving a quarter of the eligible population, ADAP initiatives are going broke. Medicaid is clearly unable to afford triple combination therapy for all the Medicaid recipients with HIV who might benefit from it. How will collecting names get everyone into care when money to pay for the care obviously isn't available?

MYTH: **People with HIV don't have to worry about having their names in a state HIV registry because existing privacy laws protect them from discrimination.**

FACT: On September 11, 1997, Health and Human Services Secretary Donna Shalala recommended to the US Congress that police and other law enforcement officials be given unlimited access on request to all private medical records. If her recommendation is passed into law, it could very well give them legal access to name-based HIV registries. How do we know that this access won't be used by INS (since HIV positivity disqualifies an individual for legal immigration) or by police in states where laws exist that criminalize HIV under various circumstances (such as "willful transmission" laws, sodomy statutes, etc.)?

State privacy laws are only as strong as the legislatures' will to uphold them. States can, and do, change their laws regarding privacy all the time. If a state Health Department has a name-based registry listing people with HIV, it can be forced at any time to open that registry by either legislative mandate or court order.

MYTH: **The fear that HIV name reporting will cause people to avoid getting tested for HIV turns out not to be true.**

FACT: The recently completed MESH (Multi-State Evaluation of Surveillance of HIV) study surveyed HIV positive and negative people in eight states about the attitudes and factors that influenced their HIV testing decisions. Nearly 20% of those surveyed listed fear of name reporting as one reason for avoiding HIV testing. Since 50% of HIV positive Americans don't know they are infected, anything that discourages testing to this extent should be a serious public health concern.

MYTH: **Health Departments need the names so that they can contact people and get the names of their sex and needle sharing partners for partner notification.**

FACT: The MESH study also disproved this. Of the HIV positive people surveyed in the MESH study, those tested at anonymous test sites (where names aren't used) supplied the same number of partner names on average as those tested at confidential test sites (where names are collected). In partner notification, it is the *partners* who are contacted during follow up. Thus, the name of the person testing positive is not needed in order for effective partner notification to be done.

MYTH: **Unique identifier-based reporting systems are uniformly inefficient and inadequate for HIV case reporting.**

FACT: Unique identifier-based HIV case reporting is done in the U.S. by Maryland and Texas and abroad by France and Australia. The Maryland Health Department, to give one example, reports that its system accurately monitors statewide HIV trends and has achieved 96.6% completeness in reporting by state-funded HIV test sites. Completeness rates from other testing sites (hospitals and private physicians) are lower but steadily improving.

It is a mistake, however, to evaluate unique identifiers in general by looking at one or two systems. A wide variety of unique identifier systems are available. They vary widely in efficiency and effectiveness at protecting privacy. Some make it hard to prevent duplication of records, for example, while others ensure a lower duplication rate than is achievable with names. Some unique identifier codes are very easy to

"crack" (decipher to obtain the person's identity) and some are virtually impossible to crack. Each system has to be weighed on its own merits.

MYTH: **Unique identifier systems are too expensive.**

FACT: HIV case reporting costs money to implement, whether names or unique identifiers are used. Maryland and Texas set up their systems after receiving one-time CDC grants of $600,000, allocated to evaluate the systems over three years. Both states report that the difficulty of mounting a unique identifier system was exacerbated by the total lack of state funding. Maryland estimates that it now takes about $100,000 per year to keep its unique identifier system functioning.

By comparison, New York's Health Department spends twice that amount on name-based reporting of low CD4 test results. To follow up on approximately 2000 low CD4 reports per month, New York had to add four FTE's (two research specialists and two public health representatives) to its HIV/AIDS surveillance staff as well as a 1/4 FTE for ongoing computer system maintenance and improvement. These staffing costs can be assumed to total $200,000 or more.

MYTH: **Since most of the states have Mandatory Name Reporting, the rest of the states might as well go along with it.**

FACT: 30 states already have some form of MNR for people with HIV. All but two of these, however, are not high incidence states. The CDC estimates that 75% of all US residents with HIV are living in the high incidence states and territories that *don't* yet require HIV case reporting by name. These are California, Georgia, Illinois, Maryland, New York, Pennsylvania, Puerto Rico and Texas.

Whether these places adopt MNR or not will depend on the level of resistance to it generated by the consumer, civil rights and activist communities. A number of national organizations including the National Association of People with AIDS (NAPWA), the National Minority AIDS Council and the National Lesbian and Gay Health Association are already on record as opposing MNR for HIV.

July, 1997

A Brief Overview of the Unique Identifier System Used by the Maryland Department of Health and Mental Hygiene for HIV and CD Reporting

Why Was It Created?

Maryland's unique identifier (UI) system was created following passage of House Bill 375 in 1993. Three years in a row (1992, 93 and 94), mandatory name-based HIV reporting legislation had been introduced in Maryland's General Assembly and defeated as a result of vigorous community opposition to it. So this UI system was developed in an atmosphere of strong community insistence on UI-based, rather than name-based, reporting.

What Criteria Were Used in Creating It?

Maryland assigns a UI to each person being tested for HIV infection or CD4 count. Since the UI is regenerated (created in the same way each time with the same results), individuals receive the same UI code every time they get tested, regardless of provider (whether in a physician's office, hospital or community test site).

The Department established the following criteria in preparation for creating this UI system. They decided that it had to:

- be simple to generate (i.e. does not require access to a computer, does not take more than 90 seconds per code to generate, does not require staff to make subjective determinations)

- have data elements that are immutable (don't change over time)

- be generated from factual information (data elements) provided by the client

- have a duplication rate no greater than 2% (less than 2 chances in 100 that one person will be assigned two different codes and, thus, counted twice)

- not be easily "cracked" (not permit easy identification of the individual to whom a code was assigned)

- not depend on an individual's ability to recall and accurately report a previously assigned code

What Are the Department's Objectives for the System?

The Department sees the UI system as enabling them to accomplish two main objectives:

1) monitoring trends in HIV infection throughout the state accurately and

2) enabling the Department to conduct case identification as needed of individuals with symptomatic HIV infection and AIDS.

What Are the UI Components?

Maryland's UI is a 12-digit number consisting, from left to right, of:

Last four digits of client's Social Security number

Client's Date of Birth (in the form MMDDYY)

Client's race/ethnicity (using the same coding scheme as appears on the CDC's HIV/AIDS Care Reporting Form)

Client's gender (also as coded on the CDC's Reporting Form)

So, for example, an African-American man born on February 4, 1952 and with a Social Security number of 678-01-1234 gets a UI of 123402045221

Does Everyone Have to Use UI's?

All providers of HIV and CD4 testing are required to assign UI's to test recipients and to report HIV positive and low CD4 test results to the Maryland Health Department by UI. Labs are also required to report these test results by UI. The only people exempted from these reporting requirements are:

- blood, tissue and semen donors
- people known to reside outside of Maryland
- those receiving testing at Health Department designated anonymous test sites
- people participating in IRB-approved research in which specimens are blinded

and/or in research not primarily intended to provide medical treatment to participants

- people participating in research approved by an IRB located outside of Maryland

How Much Did Conversion To It Cost and How Was It Funded?

No state dollars have been allocated to either the creation or the implementation of this system. The only federal dollars allocated to it were in the form of a 1993 CDC Cooperative Agreement to evaluate the system, once functional. Prior to implementation, the Maryland Register (Vol. 21, Issue 3, 2/4/94) reported the estimated economic impact to state and local agencies of establishing the new system as $167,750.

By way of comparison, it must be noted that there are also costs inherent in implementation of name-based reporting. New York State AIDS Institute administrators reported in 1996, for example, that when New York adopted name-based reporting of low CD4 test results, they had to make staffing allocations equivalent to two full time program research specialists and two full time public health representatives – just to work on CD4 follow up. This was in addition to the intensive research design work that went into creating their system for name-based reporting which consumed approximately ½ FTE (in high level research design) for a period of at least six months and now requires about 1/4 FTE for system maintenance and improvement.

How Well Does Maryland's System Work?

Dr. Liza Solomon of the Department's AIDS Administration office reports that the UI system, now in Year 3, must be viewed as still immature (as was name-based AIDS Surveillance in its third year of existence, circa 1985).

The greatest area of difficulty is still in getting all provider to report all UI's completely and accurately. She notes, however, that they have achieved 96.6% completeness in reporting by state-funded counseling and testing site over a two year implementation period. She attributes this to the fact that the Department recruits, trains and funds staff at these sites and, thus, is better able to achieve high levels of compliance from them.

Compliance by hospitals and private providers has not been as high but is steadily improving. The overall rate of missing UI components dropped from 35% to 16% in all categories but one between Year One of implementation and Year Three. The overall number of incomplete UI's also dropped by half between Years One and Three.

There is still an 23% missing data rate in the category of Social Security number. Dr. Solomon observes that, "in retrospect, states contemplating a UI system may want to re-think use of the Social Security number, although it does help with linking with other data bases."

Does This UI System Link with Other Data Bases?

It links completely with the HARS AIDS Reporting System, the HIV Counseling and Testing Sites Data Base (Maryland's CTS reporting form includes the UI), death certificates, the ADAP data base and other special investigational data bases. It does not link, however, with Maryland's TB registry and the Hospital Discharge Summaries; ICD9 coding nets.

What Is the Advocacy and Consumer Communities Response to the UI System?

The PWA/HIV Coalition of Baltimore, AIDS Action Baltimore, the Baltimore-based AIDS Research Information Center (ARIC) and the AIDS Legislative Committee agree than name-based reporting scares people away from HIV testing and early intervention services. Says ARIC Executive Director Lee-Angel Hardy, "The only way we're going to get the dollars we need, especially in a Republican Administration, is with the numbers, the data." He adds that Maryland's unique identifier reporting system was created because advocates recognized this but were unwilling to tolerate the dangers posed by name-based reporting.

"It was a very arduous compromise between the advocates and the governor," says Michele Douglas of the AIDS Legislative Committee (in reference to then-Governor Schaefer). "But in the long run, the UI system balances the stated needs of both groups." Douglas added that system allays consumer concerns about case reporting and that, as far as they can tell, effectively prevents the testing and care avoidance that are demonstrably associated with name-based reporting.

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BRIEF OVERVIEW OF SOME UNIQUE IDENTIFIER SYSTEM ALTERNATIVES

The following are some of the Unique Identifier (UI) systems now in use for HIV/AIDS and other forms of health reporting. This is a very preliminary list presented for discussion purposes only and should not be viewed as an exhaustive compilation of all the options.

Least Protective of Privacy

Names are a relatively unique identifier. Everybody has one although duplicates certainly exist. They are not private.

Social Security Number: This was created to be a UI solely for use by the Social Security Administration. Now it is in use everywhere and, thus, offers almost no privacy.

More Protective of Privacy

HRSA's Unique Record Number System for CARE Act services reporting:
Created in 1992 by Mathematica for the federal government. Code comprised of the following data elements:

- First name
- Last name
- Date of Birth
- Gender

Code is created by services provider.

Maryland's Unique Identifier System:
Created by the state of Maryland for HIV case reporting. Code is comprised of the following data elements:

- Last four digits of Social Security Number
- Date of Birth
- Race/ethnicity
- Gender

Code is created by HIV testing provider and reported to state by labs for all HIV positive test results.

Texas' Unique Identifier System:

Created by Texas for HIV case reporting. Code is comprised of the following:

- Last four digits of Social Security Number
- Date of Birth
- Race/ethnicity
- Gender

Data elements are sent by testing providers to the state Health Department which then creates the UI codes.

New York system for recording woman's identify on Fetal Death Certificates:

Created by New York in 1992. Codes are comprised of the following data elements:

- First name
- Last name at birth ("maiden" name)
- date of birth
- gender
- last four digits of Social Security Number

Most protective of privacy

Any system that incorporates a private data element into the mix of data elements used to produce a UI is more protective of privacy than one using entirely public record data elements. Two such systems have been created in connection with HIV reporting.

Client Key System:

Created in Philadelphia in 1992 and field tested in 10 CARE Act funded services sites in Pennsylvania in 1992-93.

Code comprised of the following data elements:

- Name
- Date of Birth
- Gender
- Key word or phrase selected by client

Code is created by services provider.

DoubleLock System:

Hypothetical system invented in Philadelphia. Not yet implemented or field tested.

Code comprised of the following data elements:

- Name
- Date of Birth
- Gender
- Standardized measurement of ratio of hand size

Code would be created by services provider.

July, 1997

A Very Preliminary Overview of the Unique Identifier Systems Used by the Australian and French Governments for HIV/AIDS Case Reporting

Please note that I am still seeking additional information about both these systems. The following is provided just to give you an initial idea of how these systems are constructed.

Australia

Australia's National Centre in HIV Epidemiology and Clinical Research has been maintaining an AIDS Registry since AIDS first appeared in Australia in 1982. Nationally standardized HIV reporting procedures (prospective and retrospective) were initiated in 1989 with the establishment of a National HIV Database, also maintained by the Centre (located in Sydney, New South Wales).

Provider and lab-based reporting of positive HIV test results is required by law in all of Australia's states and territories. Some states used name-based HIV reporting prior to 1989 when a unique identifier system was established as part of the national reporting standard. No names or addresses are now used in connection with national HIV case surveillance.

Using back projection and other statistical techniques, statisticians calculated that 12,000 - 16,000 people were infected with HIV in Australia by the end of 1990. The number of individuals reported to the National HIV Database at the end of 1990 was approximately 14,000 – the midpoint of the back-projected range.[1] This suggests that the impact duplicate reporting on the Database, while still problematic, may be limited. By the end of 1992, the National HIV Database contained over 16,000 diagnoses of HIV infection in Australia

Kaldor et al. reported in 1993 that "the date of first HIV diagnosis was reported in the registry for 83% of the people diagnosed with AIDS between 1 January 1991 and 31 December 1991."[2] This suggests that the HIV Database, within two years of its creation, was already capturing a very high percentage of the HIV infected individuals who would later be reported with AIDS.

Doctors and labs reporting HIV infection in Australia are required to report the following data:

state or territory of diagnosis
case identifying number
date of birth
sex
postcode of residence of the person being reported
date of specimen collection that resulted in diagnosis with HIV
source of exposure to HIV

France

In France, AIDS cases are reported to the national HIV/AIDS Surveillance Unit of the Reseau National de Sante Publique by unique identifier code. This code is comprised of the following data elements:

date of birth (YY/MM/DD)
first name initial
last name initial
geographic department of the case (this is a 3 digit code, similar to zip code)
an additional digit is added to distinguish between possible duplicates

There is now some discussion of adopting national HIV case reporting in France. If this is done, the same identifying code will be used for HIV case reporting as is now used for AIDS case reporting.[3]

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1. McDonald AM, Crofts N, Blumer CE at al. The patters of diagnosed HIV infection in Australia, 1984-1992. *AIDS* 1994. 8:518.

2. Kaldor J, McDonald AM, Blumer CE et al. The acquired immunodeficiency syndrome in Australia: incidence 1982-91. *The Medical Journal of Australia* 1993. *158:11*.

3. All of this information was kindly provided by Francoise Hamers, MD, MPH, of the WHO-EC Collaborating Center on AIDS, Saint Maurice, France, via personal correspondence with the author, June 24, 1997. Additional information is being sought directly from the Reseau National de Sante Publique.