Attachment 13

Data Release Guidelines of the Council of State and Territorial Epidemiologists for the National Public Health Surveillance System

1**Data Release Guidelines of**
the Council of State and Territorial Epidemiologists for
the National Public Health Surveillance System
June 1996

Introduction

A fundamental premise in effective public health practice is that surveillance data should be useful for the control and prevention of disease and disability while at the same protecting confidentiality. Rapid developments in telecommunications and computerization have greatly enhanced our abilities to compile and share data. However, policies concerning data sharing have lagged behind the technological advancements. In 1985, CDC and CSTE jointly negotiated a policy for the release of data from CDC's notifiable disease surveillance system to facilitate its use for public health, while preserving the confidentiality of the data. New issues call for the reexamination of this policy.

- Since 1991, all 50 states, two cities, and four United States Territories have transmitted National Notifiable Diseases Surveillance System data through the *National Electronic Telecommunications System for Surveillance* (NETSS). NETSS allows the collection of line-listed data, whereas prior to 1991, only aggregate case counts were reported by most states.

- While AIDS, TB, and STDs are included in the list of nationally notifiable conditions, data on these conditions are reported separately by state programs with responsibility for these diseases to the respective CDC program. AIDS cases are reported directly to the AIDS Surveillance Program, while STDs and TB are reported both to the responsible CDC program and to EPO through NETSS (which sometimes leads to differences in case counts). A revised data release policy exclusively for AIDS was approved by the CSTE Executive Committee in 1995.

- EPO receives many requests for NETSS data, and the requestors often ask for demographic and/or county-level data. A policy is needed so that these requests may be handled in a consistent manner that will protect confidentiality and ease the burden on both EPO and the states.

Attachment 13

The following is a policy for the dissemination of data maintained by CDC for the diseases and conditions of the National Public Health Surveillance System other than AIDS. The proposal permits CDC to provide a public use data set that consists of a line listing (including selected demographics) for state and national data and tabulated frequencies by county (without demographic information).

CSTE Policy for Release of NPHSS data (other than HIV/AIDS)
June 1996

I.   **To be made available as a public use data set:**

A   *line-listed* data file of all cases reported to CDC through the National Telecommunications System for Surveillance (NETSS) [final data only] or directly to other programs or parts of CDC that collect NPHSS data:

- The variables in the line-listing may include disease/condition; year; event month; age grouped as <1 yr, 1-4 yrs, and by 5 year intervals thereafter; sex; race; ethnicity; state; and (as available) occupation and status on country of origin.

- *County or any geographic unit smaller than state* is excluded.

- New York City (encompassing a 5 county area) and Washington, D.C. report directly to NETSS and should be handled as if they were states.

- If the total number of cases in a state in a year for a given disease/condition is ≤3, then race, ethnicity, occupation, and status on country of origin (but no other variable) would be suppressed for all cases in that state in that year.

II. **To be made available to the public as summary or aggregate count files:**

The following data would be made available depending on the date that reporting began for the disease/condition:

- Total counts of a particular disease/condition by state by month by year.

- Total counts of a particular disease/condition by county by year (but not month).

III. All public use data sets will be updated annually when final data are available. Since the data may vary in the variables reported and in completeness by state and by disease/condition, CDC should provide suitable documentation to ensure that users understand the limitations of the surveillance data.

IV. **Use of NPHSS data by CDC programs:**

Original case reports, including detailed, line-listed NPHSS data and extended case records, may be shared among and used by CDC programs. Internal CDC policies and procedures should be established and enforced to ensure that CDC programs or legal agents of CDC do not subsequently release the case reports and extended records or the detailed, line-listed NPHSS data to other users outside CDC in a format inconsistent with this policy. The data must <u>not</u> be published in a form showing frequencies or cross-tabulations with more detailed information than could be obtained from the public use data sets (section I and II above).

V. **Data requests from agencies, institutions, or persons outside CDC, including other federal agencies:**

There will be <u>no</u> release of data in formats other than those described in I. and II. above, unless the format is more restrictive than described in I and II. Any agency, institution, or person (including other federal agencies) seeking from CDC more detailed data than available in the public use data sets will be directed by CDC to each state.

IV. **Release of NPHSS data to the Epidemiology Branch of the Indian Health Service:**

Original case reports, including detailed, line-listed NPHSS data and extended case records, may be released to the Epidemiology Branch of the Indian Health Service. Internal policies and procedures should be established and enforced to ensure that the Epidemiology Branch of the Indian Health Service does not subsequently release the case reports and extended records or the detailed, line-listed NPHSS data to users outside the Program, including Tribal Nations, in a format inconsistent with this policy. The data must <u>not</u> be

published in a form showing frequencies or cross-tabulations
with more detailed information than could be obtained from
the public use data sets (section I and II above).