Council of State and Territorial Epidemiologists
Position Statement

03-EC-01

Committee: **Executive**
Title: **Data Collection for Public Health Surveillance**

Statement of the Problem:
CDC programs ask states and other funded entities to provide them with a wide variety of data, and the quantities of data requested are increasing steadily each year. In some programs, the data requested are individual-level and are collected on a universal basis. Provision of such data is increasingly being made a requirement for funding. A number of forces can be assumed to motivate these trends, for example: CDC's commitment to improve the public's health, scientific curiosity, the need to respond to pressures and questions from Congress and groups advocating for various causes, competition for scarce resources, and increased needs for accountability (e.g., Government Performance and Results Act of 1993). The rapid expansion and dissemination of computer capacities, as well as wide access to web-based communication facilitates these efforts.

The expanding scope and quantity of data shared with CDC by state programs, and the move toward collecting individual-level data raise important issues meriting broad CSTE consideration and focused CSTE input to CDC. The amount of (often highly sensitive) data accumulated on individuals, and the potential for cross-matching otherwise separate databases using non-name identifiers, increase the likelihood of identifying individuals or, at the very least, creating a public perception that this is possible.

The large quantity of federal (and state) resources required to collect and manage these data, the often poor quality of universal data, and the issues related to the validity of using passively collected universal data to address different questions all raise concerns about the cost effectiveness of growing the federal databases. Such concerns will only increase as resources are further constrained.

Accumulation of such a large quantity of data additionally helps to further blur the lines between surveillance, programmatic conduct, and research. It will be useful to broadly identify the issues involved and their implications for state responsibilities, potential federal research, individuals on whom data are collected, and resource allocation that universal data collection entails.

An illustrative example drawn from HIV Prevention programs follows, since it represents one end of the spectrum. Other programs (e.g., Immunization) are also struggling under reporting requirements.

To address important questions raised by Congress, advocates, and others; to study program outcomes; and to guide future activities at the national level, CDC, Division of HIV/AIDS Prevention staff have indicated the agency plans to require submission of non-name-identified individual data on HIV testing and prevention interventions from health departments and community-based organizations. Individual identifiers will be generated for each encounter to allow cross-matching, in order to estimate individuals' service utilization patterns and programmatic outcomes.

These plans raise a number of questions:

- Is the confidentiality of individuals at risk? Individual level service data from areas with small populations or participation can identify individuals even when names are not used (for example, HIV testing data with demographic information plus zip code of residence, participation in multiple services). Over time, considerable information may accumulate on some individuals.
- HIPAA public health exemptions would not pertain to activities not related to surveillance, evaluation or investigation of diseases for protection of the public's health. Will these data be affected?
- Will the effort be cost-effective, given the expected quality of universally-collected data? The infrastructure necessary to support such an endeavor (at provider, state, and CDC levels) is significant and resource-intensive.
- Could more valid data be obtained at lower cost through smaller, focused studies addressing the most important questions and hypotheses?
- The activities to be conducted may be research rather than public health practice at the federal level. Will federal IRB approval be obtained for specific research questions or will data be "mined" at will?
- Will particular subpopulations of individuals, including those likely to be most socially vulnerable, be disproportionately subject to having their personal information included in these databases?
- Will it be possible (even if not planned) to use non-name individual identifiers to cross-match prevention service data with CDC databases such as those for HIV/AIDS, STD, TB, hepatitis B and C, etc.?
- Will participants in prevention interventions be advised that information about them is being shared with and used by CDC?

Potential also exists for members of the public to become concerned about the types and quantity of personal information collected and transferred electronically, even though the data will not be associated with their names. Such concerns may jeopardize participation in prevention interventions or, because health departments may be involved in both areas, be generalized to disease reporting activities.

A fundamental tension exists between surveillance activities by public agencies that permit collecting information without individual consent to enumerate cases, follow trends, and develop hypotheses; and research that does require consent, may not be population-based, and has its goal elucidating new, generalizable results.

Statement of the desired action(s) to be taken:

Broad discussion of this issue among CSTE members, and a subsequent, high-level discussion between CSTE and representatives of CDC leadership, is merited. Clarification is needed of the amount and types of data collected without consent under State public health authority and data collected for research that requires individual patient consent.

CSTE calls upon CDC to fund a "Cold Spring Harbor" retreat with representatives of CDC and CSTE to examine these issues and to publish a white paper that addresses issues such as, but not limited to:

- What is a reasonable expectation for completeness of case ascertainment for passive disease reporting under State public health powers?
- How much individual case data are reasonable to collect on cases reported under State public health powers without patient consent?
- In what circumstances should patient identifiers collected by States be shared with CDC and under what authority?
- Is it appropriate or necessary to try to collect extensive data on every case of reportable disease?

Public Health Impact:
Accumulation of increasing amounts of data from multiple programs, plus the development of (non-name) identified, individual-level databases, and the potential to cross-match these data, may impinge in reality or perception upon individuals' expectations of confidentiality. Such a perception could profoundly and adversely affect states' abilities to monitor and protect the public's health.

It is critical that CDC's capability to conduct disease surveillance at the national level and to support public health activities at state and local levels be sustained and enhanced. It is also critical that studies on which such guidance is based be sound and their results valid, that data systems preserve rather than predetermine the relationships between local, state, and federal partners, and that resources be utilized wisely. CSTE has much to contribute to decisions in this arena.

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