CSTE Trip Report

CDC HIV/AIDS Public Health Data Uses Project: Pre-Consultation Meeting, June 16, 2003

Jerry Gibson and Gus Birkhead, June 16, 2003

This small "pre-consultation" was held to analyze early drafts of working papers for the above-named Report on Public Health Data Uses which have been in development for about 8 years. The purpose of this Report (to be published in a MMWR R & R) is to provide a set of ethical guidelines for uses of public health surveillance data by states, counties and also by federal agencies. It was first championed by Pat Fleming of CDC/DHAP and Dixie Snyder, and has now been taken over by Pat Sweeney and Alan Nakashima of CDC and Larry Gostin of the Georgetown Center for Public Health Law. In order to make progress after 9/11, the scope of the first set of Guidelines was narrowed to focus on HIV/AIDS data only, but it is intended that this will be eventually extended to all surveillance data. My conclusion from today's meeting is that this process will produce in time a set of Guidelines that state epidemiologists will find it hard to ignore, and that therefore CSTE needs to become more closely and officially involved in the process to assure that the resulting guidelines are appropriate and feasible.

Attendees included all the above-named persons, and two Columbia Univ. School of Public Health professors of ethics (really), Prof. Gostin and Gable from Georgetown School of Law, an attorney from New York City, Cornelius Baker (Director of Whitman-Walker Clinic in DC), Sandy Schwarcz from San Francisco, and Gus Birkhead and myself. CDC had wanted this meeting to be co-sponsored by CSTE, but the CSTE Executive Committee decided in June 2001 to discontinue CSTE's involvement in this process. Now that the guidelines have come closer to final format, CDC/DHAP would like CSTE's involvement once again. It appeared that the primary purpose of this meeting was to gain the review and approval of state and city public health, and of a representative of affected communities, for a first draft of these guidelines.

CSTE member involvement in this process is particularly important because so far these draft documents on ethics of surveillance data use have been written by academic ethicists and attorneys, and they include many (in Jerry Gibson's opinion) seriously inappropriate or unfeasible recommendations which would if implemented make disease surveillance much less efficient and effective. Some of these may be deleted from the next draft of the Guidelines, but some will not be. Examples include:

a) Health departments would be expected to conduct ethical reviews of all their current existing surveillance data collection, data use within and outside the department, disclosure, linkage, etc practices, by independent ethics panels that included substantial representation by "affected communities." In effect, all our current surveillance practices (beginning with HIV/AIDS) would have to be subjected to review by the equivalent of HIV community planning groups, to "enlist the trust and support of affected communities."

b) One recommendation said that: “Even in emergency outbreak situations, where expedited decision-making is necessary, ethical review and community consultation are critically important.”
c) “Secondary data use” would be prohibited without special review with community representation, and such secondary review was not defined

I would like to urge that CSTE become represented officially in this process once again.
Jerry