

TRIP REPORT: SECOND SMALL CONSULTATION ON THE ETHICAL USES OF PUBLIC HEALTH DATA PROJECT

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Drs Gus Birkhead and Jerry Gibson serve as CSTE representatives on this CDC work group to develop a draft guidance on “ethical uses of public health data.” The Group had its first “small consultation” in May 2003, at which we reviewed a set of several background papers written by academic ethicists at Columbia University’s Center for the History and Ethics of Public Health and at Georgetown University Law School, in order to produce a draft set of brief one-paragraph guideline statements with attached explanations and illustrations. The “small consultation” meeting today reviewed those guideline statements and refined them for writing up as a CDC MMWR Supplement issue similar to the recent Supplement on Evaluation of Public Health Programs.

Attendees included Prof Larry Gostin (facilitator and discussion leader), Prof Ronald Bayer and Amy Fairchild of Columbia School of Public Health, John Barnhart of NASTAD, Drs Andy Vernon, Matt McKenna and Pat Sweeney of CDC/NCHSTP, Dr Kathleen Toomey of GA (representing ASTHO), Sandy Schwartz of San Francisco HIV/AIDS Program, and Drs Birkhead and Gibson representing CSTE. Dr. Patricia Fleming and Michael Isbell (AIDS advocate) are also group members.

The group decided that this Guidance document should deal with all public health data, not only HIV/AIDS, even though that CDC unit has provided the funding and main impetus for this work. The consensus was that the guidance should address only the ethical principles of data uses, and not involve the process by which such guidelines should be implemented in health departments, since that was thought to be too intrusive. A vigorous discussion followed on whether the document should deal with ethical principles of collection of public health data as well as uses of such data after it was collected; this was not resolved.

Such guidelines may serve to assist public health officers as much in preventing demands for inappropriate uses such as testing school teachers for HIV, as for overseeing appropriate uses for disease prevention. In general, the members of the work group are very supportive of the goals of public health disease prevention.

The draft guidelines include statements about systematic ethical oversight of public health data use, the need for data collection to be of high quality, the requirement that all data collection enhance the capacity to reduce morbidity or mortality, need for public consultation and public information on data use, limiting the burdens on vulnerable populations, access of individuals to their own data, and collecting minimum necessary data.