

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
Centers for Disease Control and Prevention/
Agency for Toxic Substances and Disease Registry**



**Joint Meeting of the
Ethics Subcommittee of the
Advisory Committee to the Director, CDC
and the
CDC Public Health Ethics Committee
April 7, 2009**

Minutes

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**JOINT MEETING OF THE
ETHICS SUBCOMMITTEE OF THE
ADVISORY COMMITTEE TO THE DIRECTOR, CDC
AND THE
CDC PUBLIC HEALTH ETHICS COMMITTEE
April 7, 2009**

Meeting held by Conference Call

Minutes of the Meeting

Welcome, Introductions and Roll Call of Ethics Subcommittee Members

**Bruce Jennings, MA
Chair, Ethics Subcommittee**

- ❑ At 1:00 PM, Mr. Bruce Jennings called the Joint Meeting of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC) and CDC's Public Health Ethics Committee (PHEC) to order. He reviewed the meeting agenda and clarified the meeting purpose: 1) to review changes to the travel restrictions document made in response to comments raised during the February Ethics Subcommittee meeting and 2) to discuss any remaining concerns that either members of the Ethics Subcommittee or PHEC may have with the document. The intent is to submit the document to the Advisory Committee to the Director (ACD) for review at their meeting currently scheduled for April 30.

A list of attendees is included as Appendix 1.

Review and Discussion of Revised Ethics Guidance on Use of Travel Restrictions

Dr. Drue Barrett provided an overview of changes to the document. She noted the following:

- ❑ The background section was modified to clarify that the government may, and in many other contexts does, legitimately restrict freedom when the actions of individuals place others at risk.
- ❑ Reference to tribal and territorial governments was added in addition to referring to state and local health departments.
- ❑ Language was added to clarify why CDC does not communicate directly with individuals and instead leaves this role to state health departments.
- ❑ Language was added to the social justice section to describe CDC's review of cases and procedures for informing affected persons of their right to request a review of their case if they feel they have been placed on travel restrictions in error.

- ❑ The beneficence section was revised to add language about not intentionally causing harm.
- ❑ The maximizing preparedness section was revised to include reference to preparedness requiring that policies be put in place and that training be provided to ensure that personnel are knowledgeable about the policies and understand how the policies are to be implemented. This includes specific training about the importance of ethical considerations in implementing travel restrictions.
- ❑ The legal and technical considerations regarding protecting privacy and the security of individually identifiable data was moved to an appendix.

Mr. Jennings solicited comment on any remaining issues, changes and/or comments.

Discussion Points

Dr. Ben Truman raised a number of questions about harms and benefits of the use of travel restriction tools and suggested that the ethical considerations may be different for adding people to the Do-Not-Board (DNB) list than for removing people from the list. He was also concerned that the ethics document had not provided details about how the decision is made to place someone on the DNB List. It was explained that the ethics document is meant to be included within a larger standard operating procedures (SOP) document that clearly describes the criteria for placing someone on the DNB list. Dr. Truman also raised concerns about health disparities that result in foreign-born and racial and ethnic minorities being more likely to develop tuberculosis and thus more likely to be placed on travel restrictions. He suggested that it would be useful to use routinely collected data to assess the effectiveness of efforts to ensure equity in making DNB-related decisions. The group pointed to the equally important goal of protecting privacy and confidentiality and for not collecting more data than are required to implement the travel restriction tools. The document also points to the need to apply travel restriction tools carefully in order to avoid stigmatizing or blaming individuals or groups. To accomplish this, use of travel restrictions should be based solely on clinical and public health information and never on the individual's financial status or group membership (e.g., ethnicity, race, religion, gender, or citizenship).

Dr. Ronald Bayer requested clarification to a statement in the background section regarding avoiding stigmatizing or blaming individuals or groups, including those individuals who have been non-adherent with public health recommendations. As there is never a moral justification for stigmatizing groups, he suggested that this sentence be reworded to clarify that CDC's goal is to focus on treating individuals with respect and dignity. Dr. Barrett suggested the following new language:

“CDC and its partners deliberately attempt to avoid stigmatizing and blaming individuals and/or groups and instead focus on treating these individuals with respect and dignity, including those who have been non-adherent with public health recommendations.”

All agreed that the statement was sufficient.

Dr. Nancy Kass addressed an issue in the beneficence section, noting that there was a brief discussion regarding how individuals on travel restrictions might be financially harmed through loss of employment. The document states how CDC will try to intervene to mitigate the impact of harms, such as assisting with having visas extended and airlines fees deferred, none of

which have to do with employment. As it is not clear how CDC could intervene if use of travel restrictions result in loss of employment, reference to “loss of employment” should be removed. All agreed to the removal of reference to “loss of employment.”

Dr. Kass also suggested adding another paragraph to the end of the beneficence section to indicate how the development of the SOP document exemplifies a commitment to beneficence. That is, having the guidelines is a way to ensure that travel restriction tools are implemented fairly and in a manner than minimizes harms. Language should also be added about CDC’s obligation to provide training on the use of the SOP and to provide support to staff on addressing ethical issues that may arise in the implementation of the travel restriction tools. Dr. Vanessa Northington Gamble suggested that the language be added at the beginning of the document and not just under the beneficence section.

Mr. Jennings raised a concern about language in the beneficence section regarding not intentionally harming individuals. He stressed that the committee must be careful in making strong statements that might contradict the early part of the document. Because the Subcommittee begins framing the issue in the document as an issue of the ethically justified restriction of liberty for the sake of preventing harm to others, perhaps the sentence “in the interest of pursuing the public’s health, one must not intentionally harm any individual,” was too strong a statement and should be deleted.

Dr. Kass suggested the following statement:

“In the interest of pursuing the public’s health, one must avoid the deliberate infliction of harm to others. There are times, however, when through fulfilling the goal of preserving the public’s health, we sometimes cause burdens and at times harms to others. In the process, however, we must minimize these harms to the extent possible.”

There was agreement on accepting Dr. Kass’ recommended revision.

Dr. Gamble suggested that it should be made clear that this document was not meant to be an exhaustive list of all ethical considerations. All agreed that the background section should be modified to indicate that the document addressed “some” of the ethical consideration pertinent to use of travel restrictions.

Dr. Gamble also raised a concern about the reference to communications being culturally and linguistically appropriate. She suggested that more information should be included about how to achieve culturally and linguistically appropriate communications, such as referring to the National Standards on Culturally and Linguistically Appropriate Services (CLAS Mandates).

As there were no additional comments, Mr. Jennings called for a motion regarding approving the document pending revisions discussed during the meeting.

Motion

A motion was made to approve the document subject to the suggestions made. The motion carried unanimously.

Public Comment Period

No public comments were made during this meeting.

Wrap-Up and Final Comments

Dr. Barrett reviewed the changes that will be made to the document. Dr. Kass agreed to e-mail suggested revisions for the beneficence section to Dr. Barrett.

Dr. Robert Hood, Co-Chair of the Ethics Subcommittee, thanked everyone for their comments and noted that the next meeting was scheduled to take place June 17-18, 2009.

With no further business posed or comments raised, the meeting was adjourned at 2:10 PM.

Certification

I hereby certify that to the best of my knowledge, the foregoing Minutes of the April 7, 2009 Ethics Subcommittee Meeting are accurate and complete.

Date

Bruce Jennings, MA
Chair, Ethics Subcommittee

Attachment 1: List of Attendees

Ethics Subcommittee, Advisory Committee to the Director

Ronald Bayer, Columbia University
Vivian Berryhill, ACD Representative, National Coalition of Pastors' Spouses
Vanessa Northington Gamble, George Washington University
Robert Hood, Co-Chair, Florida Department of Health
Bruce Jennings, Chair, Center for Humans and Nature
Nancy Kass, John Hopkins University
Leslie Wolf, Georgia State University

Centers for Disease Control and Prevention

Francisco Alvarado-Ramy
Jessica Apps
Rachel Avechen
Drue Barrett (Designated Federal Officer, Ethics Subcommittee)
Karen Bouye
Clive Brown
Nicole Cohen
Laurie Dieterich
Jan Devier
Dave Dotson
Tonji Durant
Karen Gavin
Neelam D. Ghiya
Gail Horlick
Gloria Krahn
Annie Latimer
Ashley Marrone
Leonard Ortmann
Lauretta Pinckney
Scott Santibanez
Ben Truman

Members of the Public

None