DEPARTMENT OF HEALTH AND HUMAN SERVICES

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

October 09, 2008
Meeting Held by Conference Call

Record of the Proceedings

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Acronyms Used in This Report

ACD	Advisory Committee to the Director
CBPR	Community-Based Participatory Research
CDC	Centers for Disease Control and Prevention
COI	Conflict of Interest
COTPER	Coordinating Office for Terrorism Preparedness and Emergency Response
DHS	Department of Homeland Security
HHS	Department of Health and Human Services
IRB	Institutional Review Board
MMWR	*Morbidity and Mortality Weekly Report*
PHEC	Public Health Ethics Committee

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Minutes of the Meeting

The Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC) convened a joint meeting of the Ethics Subcommittee of the Advisory Committee to the Director, CDC, and the CDC Public Health Ethics Committee (PHEC). The meeting was held on October 09, 2008 by conference call. Meeting participants are listed in Attachment 1.

Welcome, Introductions, and Roll Call of Ethics Subcommittee Members

Thomas Hooyman, PhD, Chair, Ethics Subcommittee, called the meeting to order at 12:00 p.m. He welcomed those present, thanked everyone for their participation, and led the group in a round of introductions. Prior to beginning the review process, he confirmed that no one on the call had any real or perceived conflicts of interest (COI). The purpose of this conference call was to review and discuss the draft White Paper titled, *Ethical Guidance for Public Health Emergency Preparedness and Response: Highlighting Ethics and Values in a Vital Public Health Service* following the changes made subsequent to the September 25, 2008 conference call. Dr. Hooyman explained that the group should focus on content issues during the call, while any grammatical and typographical issues noted should be emailed to Dr. Jennings or Dr. Arras. He pointed out that if the Ethics Subcommittee could come to consensus about the content of the document and vote to approve it, it could then be finalized for submission to the Advisory Committee to the Director (ACD), which is meeting on October 30, 2008.

Approval of Minutes from September 25, 2008 Ethics Subcommittee Meeting

Dr. Hooyman inquired as to whether there were any revisions to or discussion of the minutes from the September 25, 2008 Ethics Subcommittee meeting. Hearing none, he called for approval:

Motion

Kathy Kinlaw motioned to approve the September 25, 2008 Ethics Subcommittee meeting minutes. Dr. Lo seconded the motion, which carried unanimously.

Review, Discussion, and Vote on Revised White Paper on Public Health Emergency Preparedness and Response

Dr. Hooyman opened the floor for discussion of the White Paper, suggesting that the group focus on the changes made based on the September 25, 2008 conference call.

Discussion Points

- There was agreement that the revisions made to the Executive Summary appeared to be appropriate and acceptable.

- Dr. Arras inquired as to whether the revisions made to the section regarding the distinction between research and public health activities had been addressed to CDC's satisfaction. Dr. Barrett responded that she had received no comments from CDC staff and did not anticipate that the revisions made would cause consternation. She suggested that the new points be added to Figure 10.1 as part of the highlights section. Although she did not know whether Dr. Besser had had an opportunity to review the revised version, Dr. Ellis thought the revisions were suitable and that Dr. Besser would concur.

- Mr. Jennings asked whether the revisions suggested by Dr. Besser during the September 25th meeting pertaining to CDC deployment and the importance of making recommendations in the face of incomplete data and information during a declared emergency were appropriately addressed. Dr. Ellis responded that these issues appeared to have been suitably addressed. Dr. Barrett agreed.

- With regard to the suggestion during the September 25, 2008 meeting concerning potential conflicts between the Commissioned Corps and CDC staff, Dr. Barrett pointed out that there had been discussion about incorporating Footnote 15 on Page 176, which she did not see in the revised draft. Given that this suggestion was originally made by Josephine Malilay, Dr. Barrett indicated that she would request verbiage from Dr. Malilay for this note.

- Given that he had to leave the call early, it was suggested that Dr. Lo offer his comments. Dr. Lo indicated that he was comfortable with the changes that had been made, and that he was primarily interested in knowing whether the issues previously raised by Dr. Gamble had been addressed to her satisfaction. In the effort to draw a line between the perfect document and a very good document that is good enough, given the importance of equity and fairness, if Dr. Gamble's issues / suggestions were satisfactorily addressed, Dr. Lo would feel comfortable moving the document forward. He indicated that he would vote for approval, offering to give Kathy Kinlaw his proxy vote to approve, with the understanding that these issues be addressed. While it was not clear whether offering a proxy vote was permitted, Dr. Barrett indicated that Dr. Lo's statement would be duly noted in the minutes of the meeting. At this time, Dr. Lo departed.

- Dr. Gamble responded that her issues and suggestions focused largely on Section 6 pertaining to vulnerable populations, as well as other sections in which vulnerability distinctions should be made (e.g., communications). She agreed to develop appropriate examples to help flesh out the areas which concerned her, which she planned to forward to Dr. Arras and Mr. Jennings. She raised the following concerns:

    → An overarching concern is that the examples given in Section 6 focus primarily on physical and mental disabilities. More details regarding other groups who are indeed vulnerable are needed. For example, some research indicates that approximately 50,000 individuals did not have English as a first language in the Gulf during Hurricanes Katrina and Rita.

    → Add the word "linguistics" in lists of vulnerabilities throughout the document.

    → The communications section does not include information about the importance of communicating information in various languages and in different types of communication media. For example, in the Gulf during Hurricanes Katrina and Rita, some of the people whose lives were the most disrupted were the Vietnamese fisherman for whom there were no materials in their language (e.g., warnings, et cetera). They were not included in the planning.

    → The discussion about community assets and people who might need help in particular situations is key, but it does not appear until Page 70. This should be moved forward.

    → There is discussion regarding taking advantage of public health and public safety systems; however, these systems may be broken during a disaster and / or prior to a disaster. Thus, people cannot take advantage of these systems. Dr. Gamble will forward information to Dr. Arras and Mr. Jennings from the Kaiser Family Foundation that addresses these issues to help flesh this out further.

    → The definition of "vulnerability" is very good; however, Dr. Gamble objected to the term "native intelligence." In addition, examples need to be included that are not simply physical and disability-related.

    → Dr. Gamble pointed out that the terms "intrinsic" and "extrinsic" vulnerabilities are problematic and that further distinctions might be made regarding the different types of vulnerabilities. Make it clearer that vulnerabilities are often overlooked by public health or emergency planners and that those vulnerabilities are not simply limited to physical and mental disabilities.

    → Dr. Gamble raised the question as to whether it was the goal of PHEPR to build or sustain or build resilient communities. She requested that the document be modified to clarify that this means to sustain resilient communities where they exist and build them where they are lacking.

- → Throughout the document, there is discussion about relationships, but in terms of work in community-based participatory research (CBPR), this is about building effective and trustworthy relationships early on. This should be included somewhere in the document. In the Executive Summary and later, there is discussion about communications going up and down. Dr. Arras noted that this could be addressed by expanding the last sentence to read, "Much of this depends upon forging the proper relationship, lines of communication, and effective and trustworthy partnerships."

- → The section on key factors in addressing special needs should have more diverse case studies. In the beginning of this section, there is discussion about physical, emotional, social, cultural, and geographic needs and that people may be particularly susceptible to infectious diseases. Dr. Gamble pointed out that the document did not sufficiently describe how someone's social and cultural vulnerability might cause them to be more vulnerable to infectious disease. Mr. Jennings noted that it is well-established that poverty, poor diet, and other issues compromise people's immune systems making them more vulnerable to infectious disease. Dr. Gamble thought this point should be further developed, with this argument more clearly laid out. She recommended using examples here regarding Vietnamese fisherman and migrant workers. Dr. Gamble referred to work by Regina Benjamin.

- → Additional language should be added to clarify how a registry would work in terms of communication, particularly in an area in which public health infrastructure may be disrupted or broken or where trust has not been developed or has been broken. It was not clear how this would be operationalized. Dr. Gamble suggested that perhaps public health departments work with institutions and organizations that have developed trustworthy relationships with specific vulnerable populations. A structural response that perhaps would parallel a registry would be churches which would be able to identify community members with vulnerabilities (e.g., shut-ins). Some churches have parish nurses. Some people may not be willing to go to a government run shelter, but would trust their church or other faith-based, grassroots, community organizations. Some of these groups do work with the public health infrastructure. Vivian Berryhill will check their database as well, and suggested the National Coalition of Pastors' Spouses as a resource. Dr. Hooyman suggested clarifying the point about registries to read, "Establish a system where individuals who have special needs and vulnerabilities can voluntarily register and work with community partners." Mr. Jennings pointed out that one way to handle this would be to add, "in cooperation with neighborhood and community groups, such as clinics, local physicians, senior centers, independent living centers, churches, local chapters of groups . . . " Dr. Hood liked the focus on systems and resilience in this section and added that many states have special needs shelters that include a registry process, many of which are based in churches as well as the health department. Dr. Gamble thought this could be used as an example along with the use of the term "trusted neighborhood and community groups." Kathy Kinlaw noted that the term "registry" may be part of the problem and perhaps "check-in" would be a better term, and suggested considering using the language, "voluntarily register or otherwise identify themselves through trusted community

organizations to local public health officials." Dr. Gamble suggested including language to address the importance of education and outreach with respect to registries to help people understand the significance.

→ In the section dealing with communication plans, Dr. Gamble pointed to the need for "linguistically appropriate" plans. Dr. Hooyman raised questions about the use of the term. Dr. Hood noted that in public health, the term "health literacy" would more likely be used. Public health thinks a lot about messaging in ways that are effective and meet the needs of diverse communities. He suggested a sentence such as, "Public health officials should develop communication plans." Dr. Gamble responded that the term "culturally and linguistically appropriate" come direct from the CLAS Standards (National Standards for Culturally and Linguistically Appropriate Services). Another member of the Ethics Subcommittee added that this is the language of the DHHS Department of Minority Health.

- Dr. Hood pointed out that often, one of the reasons people refuse to leave their home is because they do not want to leave their pets. People need to know their pets will be safe as well. There is a paragraph that begins, "It is important to stress that special needs and vulnerabilities do not come from the conditions usually thought of as disabilities." Perhaps this is a place to locate the point that special needs and vulnerabilities are not limited to physical and emotional dependency on others. For some people who are socially isolated, their pet is their closest companion. With respect to an inquiry regarding whether it would be beneficial to include Florida, for example, as a resource, Dr. Hood responded that he preferred the general level rather than pointing to specific states or agencies. Mr. Jennings noted that the bibliography includes numerous references which readers can seek out as additional resources, including information from Florida.

- Dr. Barrett will forward a list of typographical revisions to Dr. Arras and Mr. Jennings.

- With regard to the title of the White Paper, an inquiry was posed concerning whether the word "guidance" carried special meaning in the public health arena and perhaps should be changed. Dr. Barrett responded that to her knowledge, the use of the word has not caused anyone any consternation. Dr. Ellis agreed, pointing out that the document provides a rich review of the literature and highlights key gaps in areas that need more thought and attention.

- In response to two graduate students on the call and Dr. Gamble's inquiry regarding whether she could share information about the document in order to further develop the examples she would be submitting to Dr. Arras and Mr. Jennings, Dr. Barrett indicated that this is a public document. However, she stressed that the document is considered draft until it is approved by the CDC ACD. The approved version will be published in its entirety in a special supplement of the *Morbidity and Mortality Weekly Report* (*MMWR*) along with five focus papers in early spring of 2009. In the interim, Dr. Barrett requested that anyone interested in receiving a copy send her an email at dhb1@cdc.gov.

Motion

Dr. Gamble motioned to approve the White Paper titled, *Ethical Guidance for Public Health Emergency Preparedness and Response: Highlighting Ethics and Values in a Vital Public Health Service* based on the discussion, giving Dr. Arras and Mr. Jennings the authority to make the changes suggested. Dr. Hood seconded the motion, which carried unanimously.

Public Comment

No public comments were offered.

Wrap Up, Adjournment, and Certification

In conclusion, Dr. Arras and Mr. Jennings agreed to make the proposed revisions by COB October 14, 2008.

Motion

A motion was made and seconded to adjourn the meeting. With no further business posed, Dr. Hooyman officially adjourned the meeting at 1:30 p.m.

11/6/08
Date

I hereby certify that to the best of my knowledge, the foregoing minutes of the October 09, 2008 Ethics Subcommittee meeting are accurate and complete.

Thomas Hooyman, PhD, Chair
Ethics Subcommittee, Advisory Committee to the Director

Attachment 1: List of Attendees

Public Health Ethics Committee (All by Telephone)

John Arras, PhD
Vivian Berryhill
Vanessa Northington Gamble, MD, PHD
Thomas Hooyman, PhD
Robert Hood, PhD
Bruce Jennings, MA
Kathy Kinlaw, MDiv
Bernard Lo, MD (first 30 minutes of the call)

Centers for Disease Control and Prevention

In Person
Drue H. Barrett , Designated Federal Officer, Ethics Subcommittee, ACD
Neelam D. Ghiya
Marinda Logan
Leonard Ortmann

By Telephone
Amanda Cadore
Scott Campbell
Richard Dixon
Barbara Ellis (OD/COTPER)
Kathleen McDuffie

Members of the Public (All by Telephone)

Katie Brewer (American Nurses Association)
Camille Jackson (George Washington University)
Holly Mercaum (George Washington University)