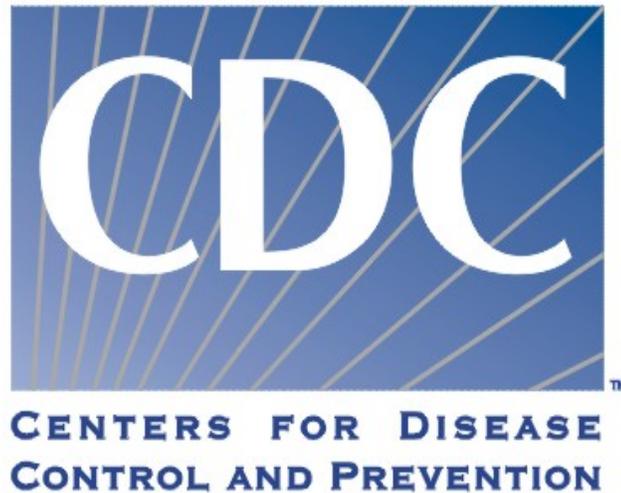


**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Centers for Disease Control and Prevention/  
Agency for Toxic Substances and Disease Registry**



**Joint Meeting of the  
Ethics Subcommittee of the  
Advisory Committee to the Director, CDC  
and the  
CDC Public Health Ethics Committee  
November 13-14, 2008**

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**Executive Summary**

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## Acronyms Used in This Report

ACD	Advisory Committee to the Director
ADL	Advanced Distributed Learning
ASTHO	Association of State and Territorial Health Officials
CDC	Centers for Disease Control and Prevention
DGMQ	Division of Global Migration and Quarantine
DHS	Department of Homeland Security
HBCUs	Historically Black Colleges and Universities
HHS	Department of Health and Human Services
MDR-TB	Multi-drug Resistant Tuberculosis
MMWR	Morbidity and Mortality Weekly Report
NACCHO	National Association of County and City Health Officials
NGO	Non-Governmental Organization
NHANES	National Health and Nutrition Examination Survey
OSHA	Occupational Safety and Health Administration
OWCD	Office for Workforce and Career Development
PHEC	CDC Public Health Ethics Committee
SOP	Standard Operating Procedure

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
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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  
November 13-14, 2008  
Atlanta, Georgia**

**Executive Summary 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 November 13-14, 2008 at CDC's Thomas R. Harkin Global Communications Center, Rooms 254/255, Roybal Campus, in Atlanta, Georgia. Meeting participants are listed in Attachment 1.

**Introductory Remarks and Overview of Meeting Goals**

Thomas Hooyman, PhD, Chair, Ethics Subcommittee, called the meeting to order at 1:05 PM on Thursday, November 13, 2008.

**Information and Discussion:  
Current Members and Priorities of the Advisory Committee to the Director (ACD)**

Bradley A. Perkins, MD, MBA, Chief, Office of Strategy and Innovation, Office of the Director, CDC; Designated Federal Official, Advisory Committee to the Director (ACD), CDC, described recent changes made to the ACD. Based on the priority of modernizing CDC to prepare it for future health challenges, and due to the Internet and other technologies, CDC is shifting from being a "wholesaler" to governmental public health entities to a "retailer" to the public. Further, there was a call for the agency to provide leadership in the larger health system. The CDC renovated the ACD to become consistent with the agency's direction and to solicit help and advice surrounding customer centricity, the "retail" notion, health system leadership, and reinforcing innovation and networks that support innovation.

The ACD members include governmental public health professionals and former state health commissioners. The Committee also includes representation from patient care, health insurance, and academicians from schools of public health as well as from urban planning. Business represented on the ACD, companies such as Target and Wal-Mart, are helping CDC learn how to better talk to customers. The ACD also includes representation from the faith community and the non-governmental organization (NGO) community, as well as the media. He noted that the ACD would benefit from additional input from local health departments. While the ACD is strong, a number of its

members are not public health experts. Therefore, CDC works hard to bring the right topics to the group and to prepare them to make quality decisions. The burden on subcommittees has increased as the need for subject matter expertise has increased. A monthly newsletter called *T3* communicates to the ACD. Every three months, a 90-minute conference call allows for dialogue between the CDC Director, other senior leaders at CDC, and ACD members.

### **Discussion Points**

- The ACD meets two times per year; however, there is flexibility in scheduling ACD meetings. If an urgent matter occurs outside the scheduled meeting structure, the ACD can be convened by phone.
- Several members of the Ethics Subcommittee expressed concern regarding CDC's use of the term "customers." Obligation to citizens is different from obligation to customers. "Customer" is not satisfying for an organization that is committed to creation of public good.
- The group discussed the concept of "choice architecture" and its use to "nudge" consumers toward better choices, rather than limiting customers' liberty and freedom of choice. Wal-Mart's approach to health will be in the vein of choice architecture.
- Issues regarding partnering with particular corporations were discussed. An association with CDC might be seen as an unfair marketing advantage. The CDC Foundation developed ethical guidelines for interactions with business, which CDC generally follows. Companies that are clearly not "good public health citizens" are deemed "off-limits." For other companies, the guidelines encourage analyzing the situation using a set of criteria, including what the project entails, what CDC and the public will get out of it, benefits for the company, and potential risks.
- The Ethics Subcommittee could be helpful in identifying and clarifying underlying issues, or could raise points to consider. Innovative ideas involve complicated ethical issues, especially concerning direct contact with the public. The Subcommittee can think about those issues in advance and help prepare CDC for them.

## **Information and Discussion: Possible Future Project: Healthiest Nation Initiative**

### **Overview of Healthiest Nation Initiative**

Casey Chosewood, MD, Chair, CDC Healthiest Nation Coordinating Council; Director, CDC Office of Health and Safety, explained the Healthiest Nation Initiative, which begins with the fact that the United States lags behind the rest of the developed world in nearly all measures of health. Further, many in the United States consider health to be the absence of disease, where "health" should have a broader definition. Most Americans are unhappy with the current healthcare system and feel that it needs fundamental change. That change should reemphasize health instead of just healthcare.

The Healthiest Nation Initiative approaches this issue with an eye to social determinants of health. Behavior change alone is not sufficient to improve health. People cannot change their behavior when their environments make it impossible. Large amounts of money are now focused on disease treatment instead of prevention and health protection before illness begins. The Healthiest Nation Initiative promotes investing more in a robust network of prevention, health promotion, and

preparedness. CDC, the Association of State and Territorial Health Officials (ASTHO), and the National Association of County and City Health Officials (NACCHO) are the founding members of the Alliance for the Healthiest Nation. The Alliance's end goal is to see that the United States is the healthiest nation in a healthier world. The Alliance aspires to be a grassroots movement with members from every sector of society. The Alliance hopes to use targeted interventions, following a policy framework and partnerships, committed to creating a culture where better choices exist and where communities are engaged in creating an atmosphere where health can thrive. Another goal of the Alliance is to engage Americans and leaders in conversations about health, to improve health equity, to include health in all policies, and to leverage innovations. People and organizations that join the Alliance are asked to do three things: 1) talk about health, in addition to healthcare; 2) take at least one action to improve their own personal or family health or an action on behalf of employees in organizations; and 3) share their success and measure their efforts. This way, the Alliance hopes to include enough people and organizations to change the overall context of the conversation and drive health system transformation.

There is great potential in making health the "lens" through which all new legislative efforts at every level are considered. The Alliance must also be multi-sectoral and examine ways to influence areas that have not traditionally included health. Dr. Chosewood described the "Health Protection Game" tool, which allows leaders at every level to experience their potential to transform the United States healthcare system. The game allows for immediate feedback and makes it clear that interventions are needed in ways that may not be immediately obvious. Health equity must be addressed; people must move from disadvantaged to advantaged states, and upstream investments in prevention must be made.

One of CDC's contributions to the effort will be to create appropriate measures of health. Today, morbidity, mortality, and disease measures are the norm. Future measurement strategies will focus on outcomes and determinants and will include the development of an interactive database tool so that specific indices can be built based upon users' specific needs. Corporate and workplace involvement will be important. There is a strong drive to make workplaces healthy, and events in the workplace often transcend to the home.

The Healthiest Nation efforts will remain true to CDC's Health Protection Goals and aligned with the agency's Goal Action Plans. There are also opportunities for the Healthiest Nation Initiative to have impact on CDC's public health research agenda as we move forward.

### **CDC's Social Determinants of Health Activities**

Marilyn Metzler, RN, BA, Social Determinants of Health Analyst, Division of Adult and Community Health, National Center for Health Promotion and Disease Control, CDC, offered a snapshot of CDC activities regarding the strong relationship between the context in which health happens and health outcomes.

Social determinants of health equity include critical resources needed for health and the relationships that determine how these resources are distributed across populations. Pathways described in the literature include limited access to material resources; differential exposure to stressful conditions; limited practical and social support; policies and practices that inhibit opportunity for full engagement in society based on racial/ethnic, gender, or income status; and life course effects at different points in time. For instance, children raised in poverty who are elevated to middle-class in later life do not have the same health outcomes as children not raised in poverty.

Some of CDC's strategic imperatives support a social determinants approach to health. The overarching goal of Healthy People 2010 is to eliminate health disparities. Healthy People 2010 also includes the idea that a multidisciplinary approach is critical to achieve health equity. CDC's Health Protection Goals, the Healthiest Nation Initiative, and health equity workgroups are other ways that the agency is working to address social determinants of health equity. One workgroup's goal is to create an operationalizable definition of health equity for CDC. The current definition is not ideal, but does provide an opportunity to integrate social determinants and health equity into the agency's work.

Since much of the work on social determinants of health occurs outside the traditional public health arena, there are questions about how to integrate it into CDC's public health activities, including technical assistance. CDC is working on developing better measures to understand the relationships between living and working conditions and health including food security, housing security and civic participation. Social determinants are also being incorporated into various Centers' and Divisions' research agendas. Many staff members across CDC are on workgroups and in staff-led initiatives that address social determinants of health. CDC's work in research and translation is beginning to reflect growing awareness of the importance of addressing social determinants in order to achieve health equity.

Despite these successes, there are gaps at CDC that need attention. Little work has been done on policy analysis and guideline development; there is limited research and program activity; and, there is also limited capacity to provide technical assistance and other support to partners that take a social determinants approach. More progress is needed in partnerships, including participatory partnerships with groups that experience health inequities.

### **Discussion:**

- It is important to distinguish between improving health at the population level and illuminating inequalities in health. Population health can be affected without changes in inequalities, or even by creating inequalities. Therefore, in measuring American health at the population level, the goal of eliminating inequities may require different strategies. From an ethical point of view, it is possible to have inequities with a utilitarian approach.
- The idea of social determinants of health is not new, so the group discussed how to take ownership of it and to make this initiative successful.
- The Ethics Subcommittee supported the Healthiest Nation Initiative and was prepared to assist CDC.
- There is a need to define what CDC means by "health inequities," as the differences between "health inequalities" and "health inequities" are not clear. Are all of inequalities equally objectionable, and what are the implications?
- If it is possible to prove that inequality yields bad health, then people might be more willing to combat these sources of bad health, whether in a traditional public health sector or another arena.
- It was suggested that the role of the Ethics Subcommittee could be to help clarify basic ethical concepts and to help CDC find a language that will help the Healthiest Nation Initiative agenda move forward and succeed.

- The Subcommittee hoped that they would not drive a wedge between this approach and the movement to create a universal health insurance system in the United States, which will include both acute and long-term care. There was concern about the possibility of limiting choice in healthcare and whether there might be pushback from the public.
- Finding a language of values and concepts that will resonate with the American people will be a challenge.
- Addressing poverty and health inequities reaches beyond humanitarianism: in a pragmatic sense, a global economic system requires consumers in other countries. For example, a low infant mortality rate ensures that babies and young adults live through their lives as consumers.
- While there is overlap between social determinants and inequities, the two terms are not synonymous. For instance, it is possible to use social determinants to improve health without reducing inequities. The public's health would be positively affected in this case. Further, inequities could be reduced without improving the public's health. These are different conceptual goals, with different messaging. Some of the greatest inequities may require large resource investments.
- A key theme in the social determinants literature is the speculation that inequality might generate bad health. The literature supports the idea that the goal of policy should be to reduce inequality.
- Another approach recognizes people's liberty and agency versus their basic circumstances. Focusing on choice architecture from an economic standpoint also addresses the tensions between freedom and the common good.
- Clarification of the appropriate role of government in this effort is needed. Americans are less likely to support mandatory measures, such as motorcycle helmet laws, but Americans are receptive to nudges or incentives to change culture and receptive to positive reasons to create health.
- Conceptual work should acknowledge concerns regarding abusing the power of the state in public health and distinguish those efforts from the Alliance's aims.
- It was noted that the government is the biggest consumer and the biggest provider of healthcare in the country. From this provider-consumer perspective, there is a responsibility for using monies in a responsible fashion.
- Because of the nature of this initiative and of its growth, the Subcommittee discussed creative approaches to the project. Subcommittee members could be "on call" to address questions that may arise.
- It was suggested that the Subcommittee address particular issues concerning implementing the program as well as involvement in larger, conceptual issues.
- Subcommittee members who were interested in participating on a workgroup identified themselves. Dr. Arras, Dr. Bayer, Dr. Kass, and Mr. Jennings indicated their interest, as did Dr. Hooyman. The possibility of splitting into more than one workgroup was discussed. One group could address basic ethical questions of equality, while another could discuss how the CDC should implement what it has already committed to doing.

- It was suggested that personnel running the various Healthiest Nation Initiative activities prepare a short memo for the Subcommittee detailing the ethical issues that concern them and that would benefit from clarification and consultation.
- There is synergy between concern about health and environment both at the family and at the individual levels. Further, while American healthcare costs are calculated at two trillion dollars annually, consumers are also spending one trillion dollars of discretionary funds, upstream of healthcare.
- The group watched a three-minute video produced by the Alliance for the Healthiest Nation.

### **Update and Discussion: Ventilator Distribution Guidance Document**

Ms. Kinlaw gave the group an update on the ventilator distribution guidance document, which grew out of public call for a translation of the broader guidance on ethical issues in pandemic influenza to particular situations, particularly to the distribution of mechanical ventilators in the course of a pandemic. The specific deliverable was a short, concise discussion of the ethical framework for ventilator distribution without including specific priorities. The first part of the document will cover certain important assumptions about the expected course of pandemic influenza. Then, the document will look at proactive planning, including issues of triage and planning. The next part of the document concerns implementation itself. The document will examine ethical issues related to when to terminate the triage process, ethical obligations to consider, how to determine where triage failed to meet its goals, and ensuring that the process is transparent.

The workgroup met by phone in August and October to look at fundamental questions and assumptions in the early part of the document. The fundamental questions include:

- What are the differences between ethical considerations for ventilator use and distribution of other types of resources during a pandemic?
- What are the differences between usual clinical practice and clinical practice in a public health emergency setting?
- What impact would the declaration of a public health emergency have on distribution of ventilators?
- What aspects of the original pandemic influenza ethics guidance might be incorporated into the ventilator document?

The overarching organizational principle in the original pandemic influenza ethics document was to preserve the functioning of society. The workgroup decided that this principle was not appropriate for distribution of ventilators. The goal of ventilator distribution would be to maximize the number of lives saved and, where possible, to decrease morbidity.

Interesting questions arise concerning stockpiling. Unless stockpiling ventilators occurs in sufficient quantity to make allocation decisions minimal, which is unlikely, triage decisions will have to be made. These decisions will include not treating certain individuals, and some patients who do not receive treatment will die. The document requires clear wording regarding this reality. Additionally, the document must address the ethical implications of removing individuals from treatment. In considering these questions, the ventilator document will revisit the original document's statements regarding community engagement and transparency about decision making. The document will also

address ventilator availability and the availability of staff who are trained or cross-trained to provide ventilation and care.

Dr. Robert Levine, Ethics Subcommittee consultant, spoke to the group via phone. He described the two most critical components of ethical clinical practice: professional competence, which includes the competence to do professional work and the willingness to do the work; and the fiduciary obligation, which binds the physician to undiluted loyalty to the well-being and the interests of her or his patients. He suggested that the ventilator allocation decision should be made by a professional physician who has no relationships (professional or otherwise) with the individuals being considered in the triage system.

Dr. Lo then addressed the group and emphasized that this ventilator guidance is meant to complement other work that has been done in this area. He further noted that the document is a “work in progress.” The workgroup’s next steps will be to draft sections of the document for the Subcommittee to review at the February meeting.

### **Discussion Points**

- CDC has not specified a deadline for development of the guidance.
- The degree and severity of the triage progress depends on the basic commitment to stockpile. Many local organizations around the country are planning for a pandemic, but have no ventilators at their disposal.
- It was suggested that a document with an overview and assessment of extant guidances might be helpful. There was discussion regarding whether the Subcommittee should provide directed guidance about how ventilator allocation decisions are made and who makes the decisions. They could use models or an evidence base for a systematic approach to making these decisions. The Ethics Subcommittee does not provide specific recommendations or criteria to triage officers, nor does it make policy decisions. Their role is only to make recommendations about ethical considerations for those who are in the position to make policy decisions. The document will not be proscriptive, as other federal “players” are not part of creating the document. It can encourage decision-makers to employ objective models or use examples from models.
- The document will have to address elective procedures. Further, the document will have to consider the context in which decisions are being made.
- Working and planning with Boards of Medicine was recommended as part of the proactive planning.
- An important issue with stockpiling is not just the ventilators, but also the staffing required for operation of the ventilators, including intensive care unit staff, respiratory therapists, and others.
- Reviewing state documents could be informative. Without identifying the state, it could be useful to point out elements that are problematic or practices that are laudable.

**Update:  
ACD Review of the White Paper on Emergency Preparedness and Response**

Dr. Barrett reminded the group that the emergency preparedness and response White Paper was reviewed and enthusiastically accepted by the ACD at their meeting on October 30<sup>th</sup>. Mrs. Berryhill represented the Subcommittee, and Dr. Hooyman provided the ACD with an overview of the document. Two items resulted from the ACD review:

- It was recommended that additional training material be developed in order to make the document more acceptable and useful “on the ground.”
- A shorter or condensed version of the document could be posted on the Internet.

The document will be published in a special supplement of the *Morbidity and Mortality Weekly Report (MMWR)*, which will include the White Paper in its entirety and five focus papers that have been written by non-CDC authors. CDC members of the workgroup are preparing an introductory article. The document will be forwarded from the ACD to Dr. Gerberding, CDC Director, for her approval. It then is sent to the Office of the Secretary of Health and Human Services, which has 30 days to comment on it. Dr. Hooyman, Mr. Jennings, and Dr. Arras expressed an interest in contributing to the development of additional training material. There was discussion about the five focus papers being published with the White Paper. The papers were reviewed by members the Emergency Preparedness and Response Workgroup, and the authors were receptive to revising the papers in response to comments received. While the focus papers are being published with the White Paper, they do not require the same level of CDC approval or CDC endorsement.

### **Public Comment Period**

No public comments were offered during this session.

### **Wrap up and Final Comments**

Dr. Hooyman reminded the group of changes in the next day’s agenda, which would include time in the morning to continue discussion of the Healthiest Nation Initiative.

### **Day Two Call to Order and Unfinished Business**

Dr. Hooyman called the meeting to order at 8:33 AM on November 14, 2008. Dr. Hooyman requested feedback on issues discussed during the June Ethics Subcommittee meeting, including creation of a workgroup to address “partnership issues” and recommendations regarding unlinked anonymous testing for HIV infection in international settings. Dr. Barrett indicated that a workgroup on partnerships was established and a project proposal developed focusing on partnership with vaccine manufacturers for the study of vaccine adverse effects. However, the activity was put on hold because the Immunization Safety Office (the principle CDC program that would need to be involved in the workgroup) was in the middle of a re-organization. The Ethics Subcommittee discussed having a partnership workgroup that would focus on broader partnership issues relating to the Healthiest Nation Initiative, especially how CDC works with non-traditional partners. Regarding the issue of unlinked anonymous testing for HIV in international settings, Dr. Popovic pointed out that since the June

meeting there has been agreement among CDC staff about the need to ensure that people who have been part of testing receive test results. Dr. Hooyman requested that a written statement be provided to update the Ethics Subcommittee on the status of that issue. The group then discussed an action plan regarding the Healthiest Nation Initiative.

## **Discussion Points**

- Dr. Perkins requested that the Ethics Subcommittee create a draft charge regarding Ethics Subcommittee input on the Healthiest Nation Initiative for Mrs. Berryhill to present to the ACD.
- The Healthiest Nation Initiative efforts and goals dovetail with Healthy People 2010 and 2020. Other tools include Presidential initiatives and other activities outside HHS, including other federal agencies, states, communities, and corporations.
- Work needs to be done around the conceptual clarification of health inequality versus health inequity, including the question of whether all health inequalities are equally objectionable and the implications if they are.
- There is a need to define the language that will enable the Healthiest Nation Initiative agenda to succeed.
- Healthiest Nation Initiative efforts should not “drive a wedge” with the movement to create universal health insurance.
- Partnerships are also a component of the Healthiest Nation Initiative that may need ethical advice. It was suggested that a workgroup could elucidate the considerations that policymakers should take into account as they are deciding priorities for the Healthiest Nation Initiative activities. They could also provide suggestions regarding how to balance or “trade off” priorities in certain circumstances. This information might be helpful when considering different partnerships with different organizations in different contexts. A range of concerns could emerge, and a conceptual framework for thinking about partnerships and balancing potential risks and benefits might be helpful.
- The aim of including health in all policies resonated with the group. The Subcommittee could assist with different partnerships outside the traditional public health arena and with ethical guidelines to be considered when health is part of every policy.
- If the Subcommittee articulates ethical considerations for the policy choices in the “health protection game,” then they can share those considerations with every group that plays the game, at every level.
- There was discussion about the Occupational Safety and Health Administration’s (OSHA) involvement in the Alliance. One of the Alliance’s next steps will be to reach out to other federal partners, including OSHA, the Department of Labor, and others.
- Public engagement could make a contribution the Healthiest Nation Initiative. The Subcommittee could deliver a product on an ethical topic pertaining to the Healthiest Nation Initiative that also addresses public engagement.

- If the Subcommittee adopts the structure of two workgroups, then the groups should communicate with each other or perhaps have a member in common.
- The group discussed the importance of language in this area. Use of terms such as “redistribution of wealth” may have a negative impact. The notion of “parity” might better resonate with Americans. Instead of talking about “eliminating health inequities,” which sounds negative, the language could focus on giving everyone “health parity” and establishing health as a form of social capital. If health is increased, there will be positive effects throughout society.
- The Subcommittee could be helpful in identifying potential “speed bumps” or “red flags” for the Healthiest Nation Initiative and could serve as a resource for providing input on specific issues.
- After further discussion it was decided that one workgroup would consider issues of social determinants of health, equity, whether all inequalities are equally objectionable, and other discussions, such as the meanings of terms and the ethical implications of approaching differences in health outcomes among different populations. A second workgroup would examine partnership issues relating to the Healthiest Nation Initiative and the issue of priorities for the Initiative. If needed, additional workgroups could be developed to address different topics.
- Subcommittee members self-identified which workgroup they would prefer to be part of, and were asked to identify a few areas in which the Subcommittee could make major contributions. This information would be used to develop a draft charge for presentation to the ACD at their next meeting.

### **Discussion and Vote: Ethical Guidance for Use of Travel Restrictions**

#### **Discussion and Vote: Ethical Guidance for Use of Travel Restrictions**

Through CDC’s Division of Global Migration and Quarantine (DGMQ), the federal government can issue a variety of travel restriction tools to prevent the importation and spread of infectious disease. Many ethical questions arise in this area, particularly those related to the threshold for use of travel restrictions, the types of tools used, the question of fairness, use of the least restrictive means, due process, privacy, and many others. DGMQ is in the process of finalizing the Standard Operating Procedures (SOP) related to issuing travel restrictions.

The Ethics Subcommittee Travel Restrictions Workgroup was charged to:

- Conduct a review of the CDC travel restriction SOP;
- Make recommendations regarding the development of a mechanism for review of ethical issues raised by specific cases of use of travel restrictions;
- Work with the CDC members of the Travel Restrictions Workgroup to draft a written summary of ethical issues identified in the SOP and provide specific recommendations about how to address those ethical issues.

The workgroup has met four times: in January, June, August, and October 2008. They have worked through specific cases to create a process for case review. A number of observations came from the working group:

- ❑ It is important to establish standardized points for consideration when determining to release private information for law enforcement purposes. This information should be made clearly available in a transparent and easily accessible manner, not just through publication in the Federal Register.
- ❑ Points to be considered should be incorporated into the SOP as guidance to field staff.
- ❑ There should be a sense of obligation to work with law enforcement agencies, such as Customs and Border Protection. This collaboration involves the principles of mutual cooperation and reciprocity, but is not an ethical justification for release of information.
- ❑ Rights of United States citizens need to be protected, but obligations to protect non-United States citizens should be considered as well.

Clive Brown, MD, Acting Associate Director for Science, Division of Global Migration and Quarantine, National Center for Preparedness, Detection, and Control of Infectious Diseases, CDC, described a Homeland Security Council after-action review of a high-profile case in 2007 concerning a patient with multi-drug resistant tuberculosis (MDR-TB). The patient traveled outside the country, despite public health recommendations. The Homeland Security Council's report only deals with the response of federal agencies, not the roles of individual states. The report addresses privacy, communication, the use of travel restriction tools, and other issues. A list of 22 corrective actions for various agencies were outlined. Of interest to CDC is Corrective Action Five, which recommends that HHS, in coordination with the Department of Homeland Security (DHS) and the Attorneys General as necessary, should convene a workgroup to examine whether certain diseases that pose imminent and extraordinary public health risks should be subject to compulsory isolation, quarantine, and/or additional restrictive actions. The HHS/DHS workgroup should discuss the practical aspects of implementation of these restrictions, including decisions regarding when to impose them. These actions are usually highly case-dependent and may be less suitable for automatic actions. This charge has implications for the SOP that the DGMQ is drafting, and it raises a number of ethical issues and thus Dr. Brown had requested that the Ethics Subcommittee Travel Restrictions Workgroup provide input on Corrective Action Five.

Ms. Kinlaw directed the group's attention to recommendations generated by the Ethics Subcommittee Travel Restrictions Workgroup regarding Corrective Action Five. The workgroup members agreed that compulsory use of the "do not board" list and other restrictive actions without consideration of certain issues such as disease attributes, information on the patient's risk of transmission, and others, is not consistent with the ethical obligation to use the least restrictive measures in a manner that is proportional to threat. Further, staff will consult with subject matter experts to attempt to identify categories of disease, clinical characteristics, and patient's behavioral attributes that could justify placing him or her on the "do not board" list. If the patient demonstrates compliance with all treatment recommendations, then use of these measures constitutes excessive response to the risk and would unnecessarily threaten the patient's privacy and civil liberties. It is important to balance the resources necessary for implementing these interventions against other public health measures. Consequences to patients of the use of restrictive measures should be examined, and the effectiveness of these interventions on protecting the public itself should be further studied.

### **Discussion Points**

- Another widely-used concept used in restrictive health measures is to minimize the adverse consequences that a restricted person will experience while achieving a public health goal. There was discussion regarding including an explicit statement about making provisions for adequate care for the patient's disease.

- The group debated a better definition of “compliance with all treatment recommendations.” The document must be clear regarding whether the treatment recommendations specify that the patient poses a hazard to others and should not travel.
- The Subcommittee recommendations might include a bullet about the need for clear communication with the involved individual regarding expectations, protective measures, and the possible consequences associated with not following the measures.
- Because of discomfort with the terms “compliance” and “behavioral attributes,” the following wording was suggested: “if the patient has cooperated with all treatment recommendations.” In addition, language regarding “minimizing adverse consequences” was added to the opening paragraph.

### Motion

Dr. Lo motioned to accept the recommendation with the changes suggested. Dr. Kass seconded the motion, which carried unanimously with no recusals or abstentions. The recommendation will be forwarded to the ACD for review at their next meeting.

### **Information and Discussion: CDC/Tuskegee Public Health Ethics Fellowship**

Ms. Jill Rickman presented an overview of the CDC/Tuskegee Public Health Ethics Fellowship, which came into being in May of 2007, on the tenth anniversary of President Bill Clinton’s formal apology for the United States Public Health Service’s study of syphilis in Tuskegee, Alabama. The Fellowship kickoff was held in November 2007. Key leaders from CDC and Tuskegee University met to lay out a framework for the Fellowship. The Fellowship is intended to integrate public health ethics into the infrastructure and daily decision-making of public health. There are two components to the Fellowship: a Faculty Fellowship and a Student Fellowship. The two-year Faculty Fellowship will be housed in Atlanta and will be competency-based. Fellows are asked to complete a scholarly activity and/or research, which could include writing a journal article or presenting at an accredited conference. The inaugural Faculty Fellow, Dr. Leonard Ortmann, will assist in developing the student component of the Fellowship. Subsequent Faculty Fellows will serve as mentors for the student fellows.

The Fellowship’s mission statement is “To develop professional expertise in addressing ethical issues that impact the practice of public health, with special focus on addressing the concerns of underserved communities.” The Fellowship goals are to:

- Promote the study and application of public health ethics;
- Engage underserved communities to spread knowledge of public health principles;
- Partner with state and local health departments to engage underserved communities;
- Share the knowledge gained through the Fellowship with other historically black colleges and universities (HBCUs); and
- Strengthen and expand the public health ethics curriculum and training opportunities among participating institutions.

A key component of the design process was a discussion of how to partner with state and local entities and universities. The Fellowship brand includes the cornerstones of public health, philosophy, education, and law.

The expectations for the Faculty Fellow are to:

- Be a leader in the Tuskegee University National Center for Bioethics in Research and Healthcare, or in other departments within the university;
- Share knowledge gained through the Fellowship back at the university;
- Help create the Student Fellowship, including the competencies, curriculum, and calendar.

The Fellowship timeline began in 2008 with planning. The project is currently in its second phase, in which it is open to Tuskegee University. Phase Three will begin in 2014, when the program opens to other HCBUs. Finally, Phase Four in 2024 will open the program to other universities.

Ms. Rickman then explained the recruitment and selection process for Fellows. The eligibility requirements for the Faculty Fellow stipulate that the Fellow shall be a senior-level professor at Tuskegee University with expertise in ethics or bioethics and an interest in public health. Fellowship activities include applied, or “on the job” experience, and didactic, or training, activities.

The next steps for the Fellowship development are to:

- Finalize the competencies for the Faculty Fellowship;
- Finalize the Steering Committee;
- Create the Student Fellowship, including competencies; and
- Recruitment and selection of the Student Fellow.

Dr. Ortmann then addressed the group. He expressed his excitement to be at CDC, noting that he was honored and humbled by the opportunity. He commented on the sense of mission, camaraderie, and idealism at CDC. He observed that the time is critical for public health ethics discussion. Since beginning the Fellowship, Dr. Ortmann has been shadowing Dr. Barrett and learning about the various CDC public health ethics projects. He has also met with various programs to learn about their interest in specific public health ethics project collaborations. When he returns to Tuskegee, he will help his home institution implement public health initiatives. In the future, he hopes to institute a Master’s of Public Health program at Tuskegee.

### **Discussion Points**

- The idea for the Fellowship was a result of discussions between CDC staff and Tuskegee University. As part of the Presidential apology, CDC worked with the National Institutes of Health and other agencies to establish follow-up activities. One of their larger initiatives was to establish an Ethics Center at Tuskegee University. While CDC was funding work at Tuskegee, it was thought that more could be done to foster relationships between Tuskegee University and CDC staff. Therefore, the Fellowship was designed to engage Tuskegee University on a more personal basis.
- Providing ongoing funding for the Fellowship is part of the planning discussions. It was clarified that the Student Fellowship will take place in the summer.
- Mentoring in the Fellowship is largely informal and collegial, and there has been a great deal of give-and-take between the Fellow and CDC staff. The Fellow will be helpful in addressing internal capacity to address public health ethics issues, including consultations and activities that are

needed on an urgent basis.

Dr. Ortmann is particularly interested in the Healthiest Nation Initiative and pointed out that the Initiative could create a different notion of ethics and bioethics, by advocating an “ethics of prevention.” The “ethics of care” is based on vulnerabilities and emotional connectedness; in keeping with the uniqueness of the public health perspective, an ethics of protection and prevention could be appropriate for the Healthiest Nation Initiative activities.

- Fellowship news and knowledge will be shared with other HBCUs at the annual meeting of the HBCU Faculty Development Network and the Black Scholars’ Conference.
- It was suggested that the CDC institute a K grant award program (i.e., awards that support career development) in order to have a significant impact on schools of public health and contribute to the future development of the public health workforce.

### **Information and Discussion: Web-Based Course on Public Health Ethics**

Daniel McDonald, PhD, Lead, Public Health Training Team, Office of Workforce and Career Development (OWCD), CDC, explained that the Public Health Training Team is responsible for providing public health-related training to CDC employees. He described the development of an online course in public health ethics to be widely accessible to CDC staff, contractors, and partners. In June 2008, HHS implemented a learning management system that allows online training to be available through the Internet. The new system’s online format allows for training to be open to non-government employees. The public health ethics course is also an OWCD case study for advanced distributive learning (ADL).

Dr. McDonald described the considerations behind the public health ethics course design. They wanted to make sure the course was in manageable pieces and utilized case studies. There are opportunities for test-takers to practice different algorithms to reinforce learning. The program goal is to increase awareness of ethics in the practice of public health, to increase the capacity to recognize potential ethical issues, and to increase understanding of the steps taken at CDC on how to address ethical issues. The course is being developed and documented so that it will be expandable and modifiable over time. They can also devote some resources to more advanced public health ethics training at CDC, but it is difficult to provide advanced training when new employees still need basic awareness. In conclusion, Dr. McDonald gave the group a tour of the course prototype and invited feedback from the members of the Ethics Subcommittee.

#### **Discussion Points**

- A group of contractors is working on this project. The PHEC Education Subcommittee has also been reviewing the content.
- It is important to be clear about the target audience and purpose of the course. Additionally, there should be a follow-up plan to build on the momentum from this initial exposure to public health ethics.

- This course is a means to broadly reach all CDC staff. It is not geared to a certain level of staff. They also hope that the course will be useful for other stakeholders, such as state and local health departments.
- It was noted that making online learning exciting and engaging is challenging. This course can be ambitious and set the standards for public health online education. Concern was expressed about educational design of the course. Dr. McDonald pointed out that as part of the ADL assessment, an independent contractor will evaluate the product and how it works within the learning management system. The next rendition of the learning management system will allow for associations between courses and communities.
- The course is “case-based” in that its purpose is to lay out principles and concepts and then use cases as examples of those concepts.
- It was suggested that the course should allow a platform for Web 2.0 and greater interactivity. However, Dr. McDonald pointed out that the content of the course does not have to be on the Web: another delivery method, such as a compact disc, could be used. There could be benefit to delivering the course in other ways, given possible connectivity issues in other countries.
- Subcommittee members Dr. Hood, Dr. Kass, and Ms. Kinlaw indicated interest in reviewing the course content.

### **Information and Discussion: Survey About the Code of Public Health Ethics**

Dr. Barrett received a request from the Public Health Leadership Society, which developed the Code of Public Health Ethics. They are interested in doing a survey to examine CDC leaders' knowledge and use of the Code of Public Health Ethics. They have approached ASTHO, NACCHO, and CDC to determine whether they would be willing to administer the survey to senior leadership. There is interest in the survey at the highest levels of CDC. It could present an opportunity to bring ethics issues to several hundred CDC leaders and to raise awareness about public health ethics. In a related matter, PHEC has discussed endorsing the Code of Public Health Ethics. This survey affords an opportunity to learn from those who have adopted a code, including how adopting the code affects their activities. PHEC has been engaged in discussion with the developers of the Code regarding the difference between “endorsing” the code and “adopting” the Code. The Code was meant to be aspirational rather than as a guide for specific behaviors. The principles in the Code are important for public health, and it is up to each agency to develop how to implement the principles in their activities. An endorsement is an acknowledgement that the principles are important to aspire toward. Adopting the Code would include an implementation plan.

#### **Discussion Points**

- CDC is considering what the agency would be doing differently if the Code were adopted. PHEC's next step will be to communicate with agencies that have adopted Code to learn from their experiences.
- One meeting participant pointed out that only endorsing the Code may seem hypocritical. Because of CDC's stature, though, the agency's position will carry force. Some may see the Code as aspirational, while others who look up to CDC may interpret the principles more strongly. The

goal of using the Code as a vehicle for raising awareness is valid, but is this particular code the right one for CDC? It does not include elements that should be included in a code of ethics for the world's premiere public health agency. It is important to understand whether the code is binding, and the extent to which it guides behavior.

### Public Comment Period

No public comments were offered during this session.

### Procedural Issues and Meeting Wrap Up

Dr. Hooyman presented action items and next steps for the Ethics Subcommittee:

- Healthiest Nation Initiative: The Subcommittee agreed to form two groups: the programmatic and conceptual group. Each will identify two or three areas of focus.
- Ventilator Allocation Guidance Document: The workgroup will continue development of the document and provide an initial draft for review at the Subcommittee's February 2009 meeting.
- Partnerships Workgroup: The discussion of partnerships and possible workgroup described in the June 2008 meeting minutes will be folded into discussion of the Healthiest Nation Initiative.
- Unlinked Anonymous Testing for HIV: CDC will provide the Ethics Subcommittee with a brief written description of how this issue, addressed by the Subcommittee in June 2008, was resolved.
- Travel Restrictions: Recommendations from the workgroup were reviewed and approved. The recommendations will be forwarded to the ACD for their review and approval. The workgroup will also continue to review the SOP on ethical issues associated with travel restrictions.
- Web-based Public Health Ethics Course: Dr. Nancy Kass, Ms. Kathy Kinlaw, and Dr. Robert Hood agreed to provide comments on the course's content.
- Survey of Public Health Code of Ethics and Endorsement of the Code: CDC staff will conduct further study on this issue.

A few procedural issues were then discussed.

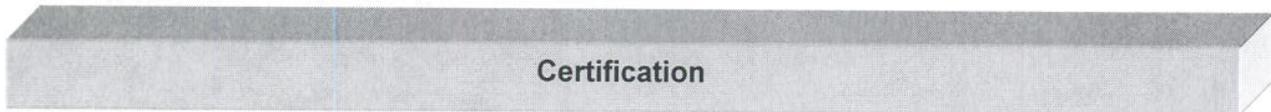
### **Discussion Points**

- There was discussion regarding a relative drop in attendance of CDC staff at the Ethics Subcommittee (i.e., members of the internal CDC public health ethics committee – PHEC). Scheduling is a major problem. There is interest at their monthly meetings and other events and activities. When the Ethics Subcommittee works on particular projects, PHEC members and other

CDC staff are involved are in attendance at the meeting. Also, requests for internal public health ethics consultations have increased.

- It was suggested that the Ethics Subcommittee meeting agenda be adjusted so that one day is devoted to key ethical challenges facing the agency. The Subcommittee could hear specific topics that the CDC wants to address and on which CDC needs feedback and advice. This interactive approach may persuade CDC staff to attend the meetings. The external and internal committee could meet together for these topics. Further, they could focus on practical, ongoing decisions that could be better informed by an ethical inquiry. Focusing on process-oriented issues may not tap the Subcommittee members' abilities and stimulated debate as much as a focus on practical and policy issues could.
- Regarding meeting structure, it was noted that oral presentations may not be the most efficient way to disseminate information. Some of the information currently being presented during the meetings could be disseminated to Subcommittee members for their review prior to the meeting allowing more time for discussion during the meeting. Subcommittee members were asked to notify Dr. Barrett about their preference for receiving "read ahead" materials electronically or in hard copy.

*With no further business posed, the meeting was adjourned by Dr. Hooyman at 2:04 PM.*



**Certification**

I hereby certify that to the best of my knowledge, the foregoing Minutes of the November 13-14, 2008 Ethics Subcommittee meeting are accurate and complete.

Feb. 10, 2009

Date

Drue H Barrett

Drue H. Barrett, PhD; Designated Federal Official, Ethics Subcommittee, Advisory Committee to the Director

## Attachment 1: List of Attendees

### **Day One: November 13, 2008**

#### **Ethics Subcommittee, Advisory Committee to the Director**

Arras, John, University of Virginia (on phone)  
Bayer, Ronald, Columbia University  
Berryhill, Vivian, (ACD Member), National Coalition of Pastors' Spouses  
Hooyman, Thomas, (Chair), Regis University  
Hood, Robert, Florida Department of Health  
Jennings, Bruce, Center for Humans and Nature (on phone)  
Kass, Nancy, John Hopkins University  
Kinlaw, Kathy, Emory University  
Lo, Bernard, University of California, San Francisco  
Wolf, Leslie, Georgia State University's College of Law

#### **Centers for Disease Control and Prevention**

Barrett, Drue (Designated Federal Officer, Ethics Subcommittee)  
Beltrami, Elise  
Bloom, Fred  
Brown, Clive  
Campbell, Scott  
Carnes, Linda  
Chosewood, Casey  
Dixon, Richard  
Durant, Tonji  
Garza, Roberto  
Ghiya, Neelam  
Giordano, Sara  
Harrison, Kathleen McDavid  
Leinhos, Mary  
Lollar, Don  
Metzler, Marilyn  
Murphy, Fred  
Ortmann, Leonard  
Perkins, Bradley  
Popovic, Tanja  
Santibanez, Scott  
Semaan, Salaam  
Snider, Dixie  
Spadaro, Antonia  
Stephens, James

#### **Members of the Public**

Levine, Robert, Yale University, Ethics Subcommittee Consultant

**Day Two: November 14, 2008**

**Ethics Subcommittee, Advisory Committee to the Director**

Arras, John, University of Virginia (on phone)  
Bayer, Ronald, Columbia University  
Berryhill, Vivian, (ACD Member), National Coalition of Pastors' Spouses  
Hooyman, Thomas, (Chair), Regis University  
Hood, Robert, Florida Department of Health  
Kass, Nancy, John Hopkins University  
Kinlaw, Kathy, Emory University  
Lo, Bernard, University of California, San Francisco  
Wolf, Leslie, Georgia State University's College of Law

**Centers for Disease Control and Prevention**

Barrett, Drue (Designated Federal Officer, Ethics Subcommittee)  
Bernier, Roger  
Brown, Clive  
Campbell, Scott  
Chosewood, Casey  
Devier, Jan  
Dixon, Richard  
Garza, Roberto  
Ghiya, Neelam  
Giordano, Sara  
Horlick, Gail  
Marrone, Ashley  
McDonald, Daniel  
Murphy, Fred  
Ortmann, Leonard  
Popovic, Tanja  
Rickman, Jill  
Santibanez, Scott  
Semaan, Salaam  
Snider, Dixie

**Members of the Public**

None