

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL
AND PREVENTION (CDC)**

**Joint Meeting of the Ethics Subcommittee of the
Advisory Committee to the Director (ACD) of CDC
and the CDC Public Health Ethics Committee**



**Summary Report
January 4, 2011
via Conference Call**

Table of Contents

DEPARTMENT OF HEALTH AND HUMAN SERVICES CENTERS FOR DISEASE CONTROL.....	1
AND PREVENTION (CDC)	1
Joint Meeting of the Ethics Subcommittee of the Advisory Committee to the Director (ACD) of CDC.....	1
and the CDC Public Health Ethics Committee	1
Summary Report	1
January 4, 2011	1
Acronyms	3
Introductory Remarks and Overview of Meeting Goals	4
Review of ACD Charge and Overview of Discussion of Ethics Subcommittee Activities during the October 2010 ACD Meeting	4
Public Comment.....	12
Meeting Wrap-Up / Review of Action Items.....	12
Certification.....	13
Participant Roster	14

Acronyms

ACD	Advisory Committee to the Director
CDC	Centers for Disease Control and Prevention
DFO	Designated Federal Official
FACA	Federal Advisory Committee Act
PHEC	Public Health Ethics Committee
SMEs	Subject Matter Experts

Introductory Remarks and Overview of Meeting Goals

Robert Hood, PhD, Ethics Subcommittee Chair Florida Department of Health

At 2:03 PM on Tuesday, January 4, 2011, Robert Hood, PhD, Chair, Ethics Subcommittee, called the meeting to order. He confirmed that there was a quorum of at least seven Ethics Subcommittee members on the call. (Shortly following the call to order, all Ethics Subcommittee members were present on the line.)

Dr. Hood welcomed members of the Ethics Subcommittee and members of CDC's internal Public Health Ethics Committee (PHEC). He asked if there were any declarations of conflicts of interest from members of the Ethics Subcommittee. Hearing none, he asked the conference call participants to introduce themselves.

Dr. Ronald Bayer (Columbia University, Ethics Subcommittee member) noted the large number of participants on the telephone. He was concerned that discussing broad issues with so many people, many of whom have never met, via telephone was not the optimal approach.

Dr. Hood replied that most of the Ethics Subcommittee's work is conducted in workgroups. During this meeting, they would discuss how the Subcommittee should handle the charge posed by the Advisory Committee to the Director (ACD) in their October 2010 meeting and then identify members to form a workgroup to address the charge.

Dr. Drue Barrett, CDC, Designated Federal Official, Ethics Subcommittee, added that the Ethics Subcommittee follows Federal Advisory Committee Act (FACA) rules, so all meetings are open to the public. The telephone participants were members of PHEC, which holds joint meetings with the Ethics Subcommittee. Other invited participants included CDC subject matter experts (SMEs) and CDC leaders in non-communicable diseases. The meeting was being conducted by conference call due to the need to organize this call quickly in advance of their in-person meeting scheduled for February 2011.

Review of ACD Charge and Overview of Discussion of Ethics Subcommittee Activities during the October 2010 ACD Meeting

Robert Hood, PhD, Ethics Subcommittee Chair Florida Department of Health

Dr. Hood presented a summary of the Ethics Subcommittee activities at the October 2010 meeting of the ACD. During that meeting, Dr. Hood reported on the Ethics Subcommittee's work, including preliminary results and future goals regarding their outreach efforts to state health officials in different regions. He also reported on the distribution and dissemination of the ventilator document.

During discussion of the Ethics Subcommittee activities, Dr. Eduardo Sanchez, ACD Chair, commented that some of the Ethics Subcommittee areas of interest also "spill over" into broader issues, specifically to non-communicable diseases. Further, questions about individual

responsibility versus societal or public policy issues emerged in discussions of preparedness. Dr. Sanchez felt that state health agencies are often asked to follow evidence that is politically unpopular, and he suggested that an ethics mechanism for assessing these issues might be beneficial.

One ACD member noted that communicable diseases are bankrupting different economies, and there was discussion about CDC's role in non-communicable disease prevention. Another ACD member commented that there should be consideration of the roles of consumers in ethics, not just at the level of programmatic engagement. There was also conversation regarding the ethical dimensions of work that is done by not-for-profit organizations. Much discussion focused on the ethical issues related to non-communicable diseases, and several examples were given. The group mentioned topics such as childhood obesity, childhood poverty, and other areas in which relationships between social determinants of health and non-communicable diseases, as well as communicable diseases, are clearly identified.

For instance, one of the CDC Director's "Winnable Battles" is tobacco. There is significant evidence for prevention in that area. One ACD member wondered at what point prevention becomes a moral imperative. Dr. Sanchez remarked on the controversy that exists about some topics in non-communicable diseases; however, many prevention activities, such as road guardrails, are not controversial today. He wondered whether reframing these discussions might be useful. Dr. Tom Frieden, CDC Director, commented that some people feel that actions taken at the government level undermine personal responsibility. Other people believe that the government has the responsibility to ensure that the healthy choice is the easiest, or the default, choice.

In this context, Dr. Sanchez suggested that the Ethics Subcommittee might be charged with assessing the ethical dimensions of non-communicable diseases in a preliminary fashion. A motion was made by the ACD that carried unanimously to charge to the Ethics Subcommittee with the following:

"Provide a preliminary overview to the ACD on ethical issues related to non-communicable disease prevention and control and an ethics framework to guide future CDC programs, activities, and initiatives."

Dr. Hood emphasized that the ACD seeks a preliminary overview. Therefore, he felt that they should keep their product brief and that they should respond quickly to the charge. He was excited about the charge and its direction, but agreed with Dr. Bayer's concerns regarding the broad and complex nature of the issues. Further, the kinds of questions and moral dimensions that apply to the various issues in the charge from the ACD will likely vary somewhat, which complicates their work. Non-communicable diseases include a large range of issues, from injury prevention to newborn screenings, and more issues which may or may not pose certain ethical issues.

He suggested that they address which kinds of ethical issues and questions a workgroup should consider, and which questions would meet CDC's needs and represent the field. One way to approach the rationale for public health ethics is to consider the avoidance of harm, or protecting the public from harm. Whether that rationale extends to non-communicable diseases raises an interesting question. Additionally, Dr. Hood wondered about different ways of thinking about the rationale for public health interventions, such as the amelioration of inequality and assurance of justice.

Dr. Barrett added that in their discussions during this call, the aim was to identify how the Ethics Subcommittee will tackle the charge given to them by the ACD and who should be involved in working on this task. The outcome would be to provide a relatively short overview to the ACD at their upcoming meeting on April 28, 2011. Generally, they are given approximately 20 minutes on the meeting agenda, and she suggested a short PowerPoint presentation, perhaps with a short document to accompany it.

Discussion Points

- Dr. Bayer commented that the issues outlined in the charge are not new. They were discussed even before the term “public health ethics” was coined. He found it interesting that the charge could potential cover a broad range of issues, from social behavior-related morbidity and mortality to environmental health, occupational health, and injury prevention. These areas raise different sets of ethical issues. For instance, questions of paternalism hardly ever arise within discussions of the duty to protect. Issues of paternalism almost always arise in areas of modifying social behavior. All of these areas are politically charged, as they have to do with the role of the state, intrusion, and autonomy. A vast proportion of public health issues are touched on by this charge.
- Dr. Hood agreed. He pointed the group’s attention to the list of the CDC Director’s “Winnable Battles,” which may be a way for the workgroup to focus its efforts within the broad range of the charge.
- Dr. Norman Daniels (Harvard University, Ethics Subcommittee member) agreed with Dr. Bayer regarding the breadth of the ACD’s request. He felt that the “Winnable Battles” may help to narrow their focus, but not in a systematic way that characterizes the differences among the issues. If they are aiming toward presenting an overview to the ACD, the enormous scope still needs to be limited. He felt that while using the “Winnable Battles” as a focus was not arbitrary because they are important, many other issues could also be listed as winnable battles. Clarifying what makes a battle winnable versus not winnable is also an interesting question.
- Dr. Barrett clarified that the “Winnable Battles” were identified by CDC’s Director as important focus areas for CDC’s public health work. In order to make the Subcommittee’s output of most practical use to Dr. Frieden, it is important to focus on the “Winnable Battles.” Four of the six named issues apply to their charge: obesity, physical activity, nutrition, and food safety; preventing teen pregnancy; reducing death and disease caused by tobacco use; and reducing motor vehicle injuries.
- Dr. Nancy Kass (Johns Hopkins University, Ethics Subcommittee member) was less troubled by the notion of using the CDC’s “Winnable Battles” to focus their response to the ACD request. They can focus on the four relevant areas as they outline key ethics issues and questions around prevention strategies for non-communicable diseases. In doing so, they can make clear that the ethics issues are not unique to the four selected areas. She felt that using the CDC terminology of “battles” carried with it a number of empirical assumptions, but she supported the idea of employing a general framework for key ethical considerations in examining different strategies related to prevention for the four areas of interest.

- Dr. Bayer commented that one of their challenges would be to locate the ethical issues raised by the specific questions in a way that conveys that the ethical questions are not unique to them and in a brief timeframe. The presentation will need to include a discussion of the difference between conditions in which the only way to address the issue is by dealing with social inequalities, and conditions in which addressing the issue may produce new social inequalities, such as in smoking. He hoped that since the scope of topics is broad, they would not produce a framework that is thin or shallow.
- In considering the questions, Dr. Daniels felt that emphasizing continuity with other aspects of health was not a good strategy. A distinct set of harms is associated with communicable diseases as opposed to non-communicable diseases, namely transmission from individuals to individuals. At the same time, there are micro-environments to consider, such as people who set poor examples for children by smoking or making bad nutritional choices. These issues suggest that interpersonal interactions facilitate the transmission of non-communicable diseases across individuals. The specific mechanism of infectious agent, in this case, is not the distinctive way to characterize where a state's role lies. Similarly, the issue of paternalism should be addressed. It speaks to the issue of personal responsibility, and Dr. Daniels felt that a public health role requires that people accept some notion of responsibility for health. The question is: What comes with that notion? He described a certain kind of accountability for anyone who plays a certain role in producing a condition. He suggested focusing on answering some of the features of responsibility that would interfere with an acceptable state role in protecting public health.
- Dr. Kass interpreted the question to ask: To what extent the government can intervene in ways alter choices, thereby making the healthy choice the easy choice? It is also important to address the related question of when the government has the duty to deny choice altogether by requiring the healthy choice. She offered the example of guardrails. There is no available alternate road that does not have guardrails that individuals may choose. There are similar decisions in which the healthy choice is the only choice, and they should think through the considerations inherent to situations in which the government essentially mandates a healthy choice. What conditions are at play when the healthy choice is the easy choice, and what conditions are at play when it is inappropriate to manipulate the situation to such a degree as to deeply influence choice?
- Dr. Bayer commented on the notions of "nudging" and "libertarian paternalism." He turned to the issue of mandating motorcycle helmets. There was a time when almost every state mandated helmets. Currently, half of the states do not mandate helmets. This shift shows that many battles are not winnable. It also indicates the relationship between conceptions of the appropriate role of the state. The distinctions of informing people, versus guiding them, versus nudging them, versus requiring them, regarding certain topics could be useful.
- Ms. Sara Rosenbaum (George Washington University Medical Center, ACD Representative to the Ethics Subcommittee) noted that the issues are complicated because CDC generally has limited regulatory power. The agency does have spending clause powers, which could be considered "nudges." Traveling down the spectrum described by Dr. Bayer presents challenges to CDC both because of its inherent authority and because of self-imposed limits on its powers.

- Dr. Bayer agreed, noting that many of these issues fall under the domain of state health department regulations and authority. Dr. Bernard Lo (University of California, San Francisco, Ethics Subcommittee member) commented on the emphasis in the background materials on evidence-based interventions. He felt it would be useful to reflect on what is different about the non-communicable conditions, and the different challenges that might arise in conducting evidence-based interventions. He also raised the issue of entities that have a vested interest in selling products that may not foster public health, such as soft drink manufacturers and the tobacco industry. Unlike infectious diseases, in which it is difficult to imagine a powerful social entity that is in the business of making products that spread infectious diseases, there are different economic issues at play in non-communicable diseases. Various issues and potential ways that these entities could be threatened by evidence-based interventions should be considered.
- Dr. Hood summarized the themes that had emerged in the discussion thus far and requested that the group consider whether these were the main issues to examine, and whether additional issues should be added to the list:
 - Topics of harms, the continuity of harms distinctions, and making distinctions about different kinds of non-communicable diseases as opposed to infectious diseases and other non-communicable diseases
 - Issues of personal responsibility
 - Profound questions about the role of the state
 - Potential difficulty in collecting evidence about non-communicable diseases
- Dr. Janet Collins (Deputy Director for Programs, CDC) added some ethical issues that she and her colleagues encounter. The issue of resource allocation is significant. They often do not have enough resources to stretch to the full need. The interface of disparities and health and how to allocate resources is not unique to non-communicable diseases, but is an important issue. Additionally, the protection of children emerges as an issue. Different age stages and the notion of personal responsibility, and how those issues interface with populations that, for various reasons, may not have the freedom of choice or maturity to make decisions, are also important considerations.
- Dr. Ursula Bauer (Director, National Center for Chronic Disease Prevention and Health Promotion, CDC) described economic issues related to the control of non-communicable diseases. These issues are a key aspect of what separates non-communicable diseases from some communicable diseases. The notion of the government's role in protecting the population, and where the protection role ends in terms of protecting the population from aggressive or predatory marketing and promotion of products that cause these diseases, is important to consider. These questions are critical in tobacco use and poor nutrition, but the arguments do not necessarily apply to other issues, such as teen pregnancy. There are implications in this issue for the market system.

- Dr. Daniels agreed that some distinct issues fit some of the different “Winnable Battles.” The issue of the market versus the state, and who is responsible for addressing a certain set of diseases that are perhaps promoted by market activity, raises special questions about the state that are different from the questions raised with regard to teen pregnancy, although there may be some overlap. It may be useful for them to sort out some of the various issues about the role of the state as it pertains to the different “Winnable Battles.”
- Dr. Bayer noted that the ethical issue of aggressive marketing and promotion is uniquely American in character, due to the unique position of the First Amendment and how advertising is protected as a form of speech. The history of efforts to regulate tobacco advertising within a frame of protecting children is an indication of the necessity of locating a set of issues in a unique time and place.
- Dr. Vikas Kapil (Chief Medical Officer and Associate Director for Science, National Center for Environmental Health/Agency for Toxic Substance and Disease Registry, CDC) said that environmental issues present unique concerns. Often, they are dealing with exposures and circumstances that are not within the control of the individual, so risks are viewed in a different way and the perception of the degree of risk is altered. Additionally, the health outcomes and impacts from environmental exposures are remote and insidious compared to other chronic disease and injury impacts, which may often have readily apparent impacts.
- Ms. Rosenbaum commented on news regarding the new Congress that is about to be sworn in. Remarks from the new House of Representatives members indicate that they view funding to carry out the new food safety law as having low priority, as they do not view the small incidence of exposure as justification for the national investment. Perspectives such as these will have to be considered as they create an ethical framework, not only in terms of the value of intervention, but also by what measures society should prioritize interventions.
- Dr. Hood said that there could be some continuity across communicable and non-communicable diseases in the areas of prioritization and resource allocation. Interventions to address non-communicable diseases are different in kind. Some interventions focus on changing behavior, such as interventions aimed at obesity or diabetes. Other interventions focus on “design,” such as auto safety in which seatbelts and passive restraints are included in cars, or in the design of roadways and lighting. These interventions are very different from those that ask a person to change his behavior. Arguably, the “design” interventions are constructed so that in the absence of behavior change, the harms that result from an error are reduced. Further, in hospital infections, the interventions focus on engineering processes and how systems, organizations, and processes work. Different interventions raise different ethical questions and suggest that different people may be morally responsible.
- Dr. Bayer commented that the “design” type interventions, such as highway design, are similar to some public health approaches to preventing disease in that they involve a modification of the environment. There are overlaps in the different approaches. Certain infectious disease strategies involve the relationship between person-to-person contact, which is a behavioral issue, and other strategies for infectious disease or environmental issues have to do with social structures beyond individuals. The same seems to be true of non-communicable diseases.

- Dr. Pamela Sankar (University of Pennsylvania, Ethic Subcommittee member) said that the range of issues that present themselves in non-communicable diseases is broader than those raised in communicable diseases. They can consider the issues on a range of “specificity versus diffuseness.” With tobacco or motor vehicles, a broad framework might be appropriate, including various social structures. A specific set of interventions can also effectively address the issues. For obesity or teen pregnancy, on the other hand, the issues cannot be addressed without embracing a broader social framework. The difference between limiting access to cigarettes and trying to encourage people not to overeat is vast, and they require different sets of ethical considerations.
- Ms. Rosenbaum commented that over time, policymakers and the public came to accept the notion of tobacco regulation. Similar breakthroughs have not occurred in other areas. Tobacco is unique for a number of reasons, but understanding how society’s past experiences with behavioral interventions came to be more than just behavioral is a place for focus. It will be difficult to convince policymakers that these areas are appropriate for policy.
- Dr. Sankar said that the cause-and-effect relationship between cigarette smoking and lung cancer is more pronounced than in some other non-communicable diseases, and it still took some time for the public to accept the relationship. She agreed that obesity is a significant problem and wondered whether in 30 years, as people who are obese now start to become very sick and die, it may be easier to convince people that these areas are important for policy.
- Ms. Rosenbaum expressed hope that they could speed up the learning process so that many lives would not be lost.
- Dr. Bayer volunteered to participate in the Ethics Subcommittee’s work on these issues. He felt that thinking about the various kinds of interventions in terms of how efficacy is judged would address the evidence issue. The relationship between how effective something is and how it involves intrusions on autonomy or liberty, and how these interventions affect questions of social justice and equity, may be a useful way to frame a simple set of questions that anyone considering policy in one of these domains should take into account. Questions of using market forces to nudge behaviors as opposed to persuasion and education present a set of ethical challenges as well.
- Dr. Harold Jaffe (Associate Director for Science, CDC) explained that in pushing the “Winnable Battles” agenda forward, Dr. Frieden hopes to learn about ethical problems or traps that they could fall into unwittingly. In particular, are there traps related to disparities? For instance, if cigarettes are made unaffordable and if there are taxes on sugary drinks, will that discourage their consumption and will these measures have differential effects on individuals depending upon their income?
- Dr. Kass agreed that the question should be considered conceptually and ask whether it is appropriate to tax people in ways that could have disproportionate impact. She emphasized, however, that the analysis should address the fact that the federal government subsidizes some areas that are unhealthy. Individuals are being given economic incentive to drink sodas, so “the playing field is not level.”

- Dr. Sankar warned them against framing their comments around potential ethical traps in pushing an agenda regarding non-communicable diseases. She hoped that the Subcommittee's product would help CDC answer these questions, but it would be more useful to develop a broad foundation and conceptual framework for understanding the ethical issues involved in containing or preventing non-communicable diseases.
- Dr. Hood pointed out that the day's discussion would end in a vote pertaining to whether the Ethics Subcommittee should create a workgroup to address the charge from the ACD. He also hoped to set a direction for that workgroup. The workgroup's suggested product was a presentation of about 20 minutes, perhaps with a written handout. He noted that the ACD members are extremely thoughtful, but not all of them may have expertise in the technical jargon of bioethics. With that in mind, they should communicate their points in a manner that does not presuppose a background in ethics. He then asked for volunteers to participate in the workgroup. The workgroup must include at least two Ethics Subcommittee members and could be augmented with CDC subject matter experts. The following Ethics Subcommittee members expressed interest in participating: Ronald Bayer, Norman Daniels, Nancy Kass, and Bernard Lo.
- Dr. Barrett said that she would send an email to assess the interest of members of the internal CDC Public Health Ethics Committee. At the Ethics Subcommittee meeting on February 17-18, participants would have an additional opportunity to provide input, with the goal of having the product ready at the beginning of April to provide it to ACD members in advance of their meeting.
- Dr. Leonard Ortmann (Public Health Ethicist, Office of the Associate Director for Science, CDC) suggested creating a table to help organize the work. The vertical column could list the "Winnable Battles." The top of the table could list overlapping issues. The table could indicate which of the overlapping issues apply to each battle, and a column at the end could list unique issues for each. This grid could help them divide the workgroup into smaller groups to consider each area.
- Dr. Lo returned to the question of the kind of product that would be most useful to the CDC Director and the ACD. A 20-minute presentation is not long. If they address four ethical pitfalls and the question of whether disparities set limits on public policy, that content will take more than 20 minutes to present. He was concerned about trying to take on more than they could handle by the April deadline and about the possibility of not responding to the nature of the request.
- Dr. Hood and Ms. Rosenbaum agreed and noted that the ACD asked for a "preliminary overview." With that in mind, if the ACD finds the preliminary overview to be compelling, they may ask for additional information or guidance.
- Dr. Barrett said that their next step would be to gather input from internal CDC staff who wish to participate on the workgroup and then to schedule a conference call of workgroup members to hone their focus. Clearly, the scope should be limited due to the short amount of time available before the ACD meeting and due to the presumably short time allocated to the topic on the ACD agenda. She would clarify with the Executive Secretary for the ACD how much time they would have.

- Dr. Daniels asked about the discretionary powers of the workgroup in terms of whether the group would have the option to narrow or broaden the scope of the project.
- Dr. Barrett answered that in creating the workgroup, the Ethics Subcommittee gives the task to the workgroup to manage as they see fit based on the day's discussion. The workgroup will bring their work to the Ethics Subcommittee in February, and there will be time to make refinements to the presentation before the ACD meeting in April.

Motion

A motion was made and seconded to form a workgroup to address the charge presented by the ACD to the Ethics Subcommittee. The workgroup would create a preliminary framing of the issues, perhaps touching on potential pitfalls and traps as well as disparity issues. The motion carried unanimously. The following Ethics Subcommittee members expressed interest in serving on the workgroup: Ronald Bayer, Norman Daniels, Nancy Kass, and Bernard Lo.

Public Comment

No public comments were offered during this teleconference.

Meeting Wrap-Up / Review of Action Items

Dr. Hood said that the Ethics Subcommittee would see the workgroup's output at its face-to-face meeting in February. At that time, the Subcommittee would have the opportunity to offer advice and commentary. The final presentation would be ready at the beginning of April.

Dr. Barrett indicated that she would contact members of the workgroup to schedule a conference call. She thanked Dr. Hood and all those present on the teleconference.

With no further business posed or questions / comments raised, the meeting was officially adjourned at 3:26 PM.

Certification

I hereby certify that to the best of my knowledge, the foregoing minutes of the January 4, 2011 Ethics Subcommittee meeting are accurate and complete.

February 28, 2011

Date

Robert Hood, PhD

Ethics Subcommittee Chair

Participant Roster

Ethics Subcommittee, Advisory Committee to the Director

Ronald Bayer, Columbia University
Ruth Gaare Bernheim, University of Virginia
LaVera Marguerite Crawley, Stanford University
Norman Daniels, Harvard University
Robert Hood, Chair, Florida Department of Health
Nancy Kass, Johns Hopkins University
Bernard Lo, University of California, San Francisco
Sara Rosenbaum, ACD Representative, George Washington University Medical Center
Jennifer Prah Ruger, Yale University
Pamela Sankar, University of Pennsylvania
Marion C. Wheeler, ACD Representative, Strategic Consultant
Leslie Wolf, Georgia State University

Centers for Disease Control and Prevention

Karen Angel
Mick Ballesteros
Drue Barrett (Designated Federal Officer, Ethics Subcommittee)
Ursula Bauer
Barbara Bowman
Kata Chillag
Janet Collins
Catina Conner
Shanna Cox
Sandra DeShields
Barbara Ellis
Debralee Esbitt
Lindsay Feldman
Deborah Galuska
Neelam D. Ghiya
Gail Horlick
Sonja Hutchins
Robin Ikeda
John Iskander
Harold Jaffe
Vikas Kapil
Dolly Katz
Rachel Kaufmann
Mim Kelly
Lisa M. Lee
John Lehnherr
Bryan Lindsey
Aun Lor
Josephine Malilay
Mike Mizelle
Julie Orta

Leonard Ortmann
John Piacentino
Tanja Popovic
Joan Redmond Leonard
Cheri Rice
Lisa Richardson
Stevenson Richardson
Renee Ross
Scott Santibanez
Salaam Semaan
Ruth Shults
Tom Simon
Alexandria Stewart
Patricia Sweeney
Cheryll Thomas
Denise Traicoff
Lee Warner